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Assessing Needs, Gaps, and Barriers

Nebraska Integrated HIV Prevention and Care Plan 2017-2021

REGION	Midwest
PLAN TYPE	Integrated state-only prevention and care plan
JURISDICTIONS	State of Nebraska
HIV PREVALENCE	Low

Nebraska's needs, gaps, and barriers section is broken out by type of assessment activity: community town hall meetings; Ryan White HIV/AIDS Program provider surveys; and Ryan White HIV/AIDS Program client surveys. All information presented is broken out and emphasized by region and because a majority of the state is rural, the regional town halls presented strong evidence for the jurisdiction's needs, gaps and barriers. Strengths include a thorough examination and feedback around issues that relate to difficult political/legislative structures in the state as well as insufficient funding to provide comprehensive prevention and care services. The information provided in this section is supported by relevant data and needs assessments/survey findings.

SELECTION CRITERIA: ASSESSING NEEDS, GAPS, AND BARRIERS

Exemplary Assessing Needs, Gaps, and Barriers sections met the following criteria (based on the Integrated HIV Prevention and Care Plan Guidance):

- ☑ Includes description of the process used to identify HIV prevention and service needs of those at risk and PLWH
- ☑ Demonstrates engagement of those at risk and PLWH in planning
- ☑ Clear and robust description of service needs
- ☑ Clear and robust description of service gaps
- ☑ Clear and robust description of barriers (social, policy, health department, program, service provider, and client barriers).

Additional exemplary plan sections are available online:
www.targetHIV.org/exemplary-integrated-plans

Part D: Assessing Needs, Gaps, and Barriers

Addressing Needs, Gaps, and Barriers

Subpart 1: Community "Town Hall" Meetings

Description of Procedures

The assessment included the planning and implementation of one statewide stakeholder meeting, followed by six regional meetings. NDHHS contracted a team from the University of Nebraska at Omaha, led by Dr. Jason D. Coleman, to coordinate and conduct this process. The meetings used a focus group, "town hall" format conducive to the elicitation of needs across stakeholder groups. Stakeholders included, but were not limited to, HIV-related prevention, care, and treatment providers; persons living with HIV; representatives of local, state, and federal entities that support HIV-related services; persons at higher risk of HIV infection (e.g., men who have sex with men, racial minorities); and other parties.

Statewide Stakeholder Meeting

A statewide stakeholder meeting was held in Lincoln, Nebraska in October 2015 at the Cornhusker Hotel. The meeting lasted approximately 6 hours, with 41 individuals attending the meeting. The purpose of this meeting was to engage stakeholders to identify HIV-related prevention, service, and treatment needs at the state level.

Regional Meetings

Regional meetings used a "town hall" format and lasted approximately 90 minutes each. Meeting locations for each city were identified following the October HIV Statewide Stakeholder meeting. Cities were chosen based on urban and rural population hubs, in addition to places with CTR and case management services. Regional meetings occurred during April and May 2016. One additional meeting was implemented at the May 2016 Community Planning and Nebraska HIV CARE and Prevention Consortium (NHCPC) meeting. Regional meetings were held in public locations, including libraries, colleges, and health departments.

Locations included:

1. Scottsbluff
2. Kearney
3. Lincoln
4. Sioux City
5. Norfolk
6. Omaha
7. NHCPC

The UNO team led recruitment for the regional meetings and utilized NDHHS and other sexual health organizations to help assist recruiting participants. Recruitment was conducted by the UNO team with the assistance of staff from the NDHHS staff and local organizations. Recruitment flyers were distributed in paper format and via social media. When possible, local media organizations were also asked to promote meetings in each location. Case managers were asked to invite their clients and other consumers.

The regional meetings were facilitated using a semi-structured format; i.e., when discussion led to salient topics or ideas not included in the original regional meeting guide, the facilitator followed the lead of the participants. During each regional meeting, data was recorded in written or audio format. At the conclusion of all regional meetings, all recordings were transcribed, and data were analyzed by the UNO team using qualitative data analysis methods.

Focus groups were facilitated using a semi-structured format; i.e., when discussion led to salient topics or ideas not included in the original focus group guide, the facilitator followed the lead of the participants.

Regional Meetings Participants

A total of 56 participants attend the regional meetings. Participants represented 11 Nebraska towns/cities (Scottsbluff, Harrisburg, Gering, Columbus, Lincoln, Omaha, Grand Island, Hastings, Norfolk, Bennet, Kearney) or 7 Nebraska counties (Scottsbluff, Banner, Platte, Lancaster, Douglas, Hall, Madison). Most participants reported being Caucasian (n=44, 78.6%). Other participants identified as African American or Black (n=5; 8.9%), Hispanic (n=3; 5.3%), Asian (n=2; 3.5%), Mixed (1; 1.9%), and American Indian (n=1; 1.9%). 6 participants reported an ethnicity of Latino or Hispanic. The age range was 21 to 65 years, and the mean age of participants was 45.1 years. Thirty participants were women (54.7%), 24 were men (43.6%), one participant was transgender (1.8%), and one participant was genderqueer (1.8%). A total of 9 participants (16.1%) who attended the town hall meetings reported living with HIV.

Data Analysis Plan

The guiding analytical strategy included using a qualitative, community based participatory-research (CBPR) approach to data analysis and interpretation. Each focus group was audio recorded and transcribed verbatim. Transcripts were then loaded into QSR NVivo qualitative data management and analysis software for detailed coding. Codes were based on the areas of interest from the Statewide Coordinated Statement of Needs town hall meeting guide. After coding, the project team reviewed the codes and transcripts to ensure accurate interpretation of the data. Notes from post-focus group project team meetings were also reviewed to ensure accurate interpretation of the data.

Outcomes

Outcomes are grouped by the previously identified themes of importance for the Statewide Coordinated Statement of Needs town hall meetings: HIV Service Barriers, HIV Service Gaps, and HIV Service Needs. Within each theme, data was synthesized to determine salient and key sub themes across the 7 town hall meetings. Outcomes are reported at the aggregate level.

HIV Service Barriers

Participants in the regional meetings discussed service barriers related to HIV prevention and care. HIV-related barriers were defined as obstacles to HIV prevention in the community. HIV-related service barriers were identified across multiple domains that included: social and structural, service providers, program, legislative or policy, and client.

Social and Structural

Regional meeting participants discussed social and structural barriers, which included stigma, fear, being ostracized, and cultural practices and perspectives.

Stigma

Participants most frequently discussed stigma towards HIV prevention and care in terms of denial—the perception that HIV is not an issue that impacts people in Nebraska. Many participants shared that Nebraska residents believe that contracting HIV is nearly impossible, especially in rural Nebraska, or that HIV does not exist at all in Nebraska.

One participant stated, "It's [HIV] just something that they heard about and happens in big cities I guess. It's not so much a concern here in rural Nebraska." Another participant added, "I've heard people say that there's not HIV or AIDS in the Panhandle [Western Nebraska]. They think we don't have that here." Denial creates a context of "not my problem" for many, which facilitates HIV-related stigma.

Some participants also shared the belief that HIV exclusively affects gay men. One described the perception around HIV only occurring in among gay men by stating, "Well, we're not them [gay men]. We're not going to get it.'"

Some participants noted that the younger generation is not concerned with contracting HIV because of medical and treatment advances. Further, participants discussed that HIV is not often discussed among younger people. One reflected that, "there will be people saying HIV is on its way out… Everybody says that they can treat it and it's no big deal." Another participant shared his clinical experience with youth: "We have gotten a few of the younger clients that they just don't realize what it is. It's kind of like any other infectious disease. Give me a pill and I will be okay. It's not that kind of a thing; it's more difficult."

Participants in several regional meetings specifically discussed HIV-related stigma among members of racial minority populations. Participants noted that "those communities [racial minority]… are very small so the stigma is just so much higher." Further, participants believed that HIV-related stigma among minority populations directly contributed to a lack of service seeking, which further led to a decreased likelihood of having a controlled or undetectable viral load.

Other participants believed HIV-related stigma among some primary care providers was a major barrier for minorities seeking HIV prevention and treatment. One participant stated, "We have even have had some experiences where we have purchased insurance for undocumented individuals, but they [providers] still do not want to provide care because they do not think it is fair that they [PLWHA] have insurance." Another participant followed that comment by stating minorities were, "…in absolute fear of the medical system."

Fear or Shame

In every regional town hall meeting, participants discussed fears and situations that induced shame, and ultimately, prevented individuals from seeking screenings, receiving treatment, or staying in care.

The most frequently discussed fears were in regards to PLWHA disclosing their status to family, friends, or medical providers. One participant noted, "There is still so much fear about not knowing what to do or where to go. Fear of disclosure to my family. We've had people lay in the hospital and die [from HIV] who said, 'No, don't contact my family.'" Participants also noted that due to the small community sizes

across Nebraska, including Omaha, “people won’t go into their primary care provider to do screenings or talk to their primary care provider [about HIV].” Even if individuals have been living with HIV for years, participants noted that they “…are still hesitant to walk into the infectious disease doctor office [because] they might see someone they know;” may “…not feel safe;” or trust the confidentiality of the doctors because, “in the past… there is a problem with confidentially at times."

These fear-based barriers are amplified in rural communities. One participant reflected that “if they [local doctor] find out about that personal information about me, they will stop coming to my business or they won’t want to support me with what I do in the community because they will know too much about me.” A case manager noted that his client “…just quit a job recently because news of his diagnosis was spread throughout [the workplace] and he was ostracized.” Individuals also discussed fear as being a reason for the limited number of PLWHA who serve as community speakers. A participant noted, “In my heart, I wish that people who are HIV positive could speak out. I think that if somebody knew that they knew somebody that was HIV positive, it would break down a lot of barriers.”

Participants also discussed individuals who receive PrEP are being shamed by providers or other community members. One participant noted that, “providers think that if people are using it [PrEP], it is clearly that they are… making bad choices.” Multiple participants agreed with this statement and added that the use of PrEP leads to “slut shaming.”

Cultural Perspectives or Practices

Regional meeting participants discussed four main barriers that were attributed to Nebraska’s cultural perspectives or practices:

1. The political and religious landscape towards sexual health and HIV;
2. Lack of education and awareness of sexual health and HIV;
3. Increase in social media use; and
4. Inadequate resources for minorities living in Nebraska with HIV.

Participants discussed the impact that Nebraska’s political and religious perspectives have on sexual health and HIV. Participants described Nebraska as being “…abstinence only in public” and that they were “afraid to talk about it [sexual health or HIV] because young people may hear it.” Multiple participants believed that Nebraska’s traditional religious views prevented HIV testing and treatment, which one characterized: “I am wondering if there is a reluctance to engage in HIV treatment or prevention because of their religious views about sex?” Other participants believed that HIV prevention was not practiced in smaller communities due to cultural practices, stating, “I think cultural norms that you talk about in the smaller communities, it is seen as some of that thing that we shouldn’t do it [HIV prevention] here.” Another participant state, “We can’t even talk about sex ed in general…. so when you want to talk about HIV, it gets even worse.”

Limited exposure to HIV education or awareness was another barrier for HIV prevention and treatment. Participants believed that HIV education or awareness was not widespread throughout the State of Nebraska due to the perception that HIV is not a concern for educators or Nebraska residents. One participant stated, “There is a lack of awareness that HIV is still a concern. So, a lot of times people put it on the back burner and forget that it really exists… I worked with teachers recently that are not concerned at all.” Another participant stated, “They don’t think about it. They don’t think they’re at risk

so they don't even think about testing because they don't think they're behavior puts them at risk." Going further in regards to HIV not being taught thoroughly in the Nebraska education system, one other participant stated, "When talking to my nursing students, I ask them what they got in high school, and it is still so little. We're 30 years into this illness, and they still don't really know the basics [about HIV] coming into nursing school, and that's really sad."

Social media dating/hook up applications throughout Nebraska, like Grindr, were also discussed as rapidly growing facilitators of the HIV epidemic in Nebraska. One participant stated, "I do think it is increasing the potential for HIV in Nebraska with the increase of social media, especially in these smaller areas." Similarly, another participant described how social media impacts the spread of HIV in rural Nebraska when he noted, "The social media has opened up so many doors to these smaller areas to be able to go somewhere, meet up with somebody, and go home that night without anybody in town knowing about it… so you're going to somewhere, bringing something back to your town and spreading it as you go."

Some providers and educators raised the concerns about the inability to provide HIV prevention messages on social media applications that are intended for dating or sex seeking. One participant stated, "The web masters do not, at least on Grindr are not interested in having us on there [HIV prevention messages]." Continuing this conversation, another participant noted about his experience trying to advertise HIV prevention messages on similar social media applications when he reflected: "They'll sue you to then end of the earth if you put your stuff on there, even if you pay them… It's a tough sell… So I think that a huge barrier for us is the access to the social media and being able to advertise on social media."

Other participants discussed the intersection of Nebraska's limited resources for minorities and cultural beliefs within different minority groups being barriers for HIV treatment and retention in care. One participant stated, "Even internally, in our state, in our large division, we do not have anyone with the background and can't reach out to people [minorities]." Another stated that, "I think it is cultural too. Especially with the Sudanese and Somalians. They have beliefs that if they are feeling well, they should stop taking the meds [antiretrovirals] because you are doing ok."

Service Providers:

Regional meeting participants noted the following barriers when asked about HIV service providers:

1. Not qualified to work with PLWHA;
2. Limited locations of infectious disease doctors;
3. Retirement of devoted staff working in HIV prevention and care; and
4. Language barriers with minorities.

Not qualified to work with PLWHA

In multiple regional meetings, participants reflected that a large majority of primary care providers in Nebraska do not receive adequate education and training about HIV, which makes Nebraska primary care providers less experienced and skilled to implement evidence-based HIV services to patients. One participant stated, "I think a little bit of the education that providers get, doesn't really put them in a place where they are skilled to do sexual histories and talking with patients [about HIV]." Similarly, another participant noted, "Coming from an educational perspective, I don't know that the people that

we want to be the [HIV] providers are getting enough information about it in their training." Specifically, in regards to primary care providers working with PLWHA, one participant stated, "We don't have a lot of primary care providers that are experienced with working with HIV positive patients or HIV." Another participant questioned the education that is provided in Nebraska medical schools when they said, "Along those same lines, just educating our medical school… Are they teaching about those things [HIV]?"

Further, even if providers are educated around HIV and new treatment options like PrEP, their clinics often reach maximum capacity due to the limited number of providers who prescribe or offer PrEP services. One participant stated, "There are few doctors in town or ID doctors or doctors willing to prescribe PrEP… as soon as people know someone prescribed PrEP, that person instantly has a flood of new patients." Another participant echoed that statement, by noting that, "They [providers] are not taking new patients. They are completely full."

Outside of primary care providers, participants discussed that there are limited providers in different supportive health sectors, like dental, eye, and mental health who are educated in HIV, or who will treat PLWHA. One participant stated, "Specifically with the Ryan White Part C funding—that is a great concern. Central Nebraska… has two dentists that are Ryan White-Part C. Eye is the same, we have one in Kearney and one in Grand Island… same with mental health." Similarly, another participant stated, "Another barrier that a lot of consumers face is that there are very few providers that will provide dental services to the consumers that we work with." A participant who self-disclosed that he is living with HIV, reflecting on consumer experiences with dental and eye care, stated, "Then the concern is always how other care like dentist and eye doctors and finding somebody who is a little knowledgeable about the issues of being positive. That they have to watch for things in the eyes. In general, that is a huge concern."

Limited locations of infectious disease doctors or HIV specialists

The limited number and locations of infectious disease doctors and HIV specialists around Nebraska was considered a barrier for HIV prevention, care, and treatment. Multiple participants discussed the need for infectious disease doctors to be more accessible and available throughout Nebraska. One participant stated, "It would be nice to have more infectious disease doctors in Western Nebraska." Another participant noted, "I find it very interesting that we have NAP here in Kearney, but the closest infectious disease doctor is an hour away." Conversely, if individuals are able to receive HIV services from an infectious disease doctor, the client may not receive the level of care that an HIV specialist provides. One participant reflected on past conversations with clients who are living with HIV and stated, "There is a big difference between infectious disease doctor and HIV specialist. Most people would like to have an HIV specialist. Someone who understood them, understood their care… they feel the infectious disease doctor is not interested in them."

Retirement of devoted staff working in HIV prevention and care

Regional meeting participants discussed the future retirement of devoted infectious disease doctors, case managers, or other individuals as being a barrier for HIV prevention, treatment, and care. One participant expressed her immediate concern about retirement when she stated, "One of the barriers is that in a 5, 6, 7 year period probably most of the folks who have most active with the HIV agency and IDS program in Western Nebraska will retire." Another participant noted that he knew infectious

disease doctors who were going to retire this year and stated that, "Replacing ID docs is not easy… it gets tough… not a lot of people from out of state that want, or have the background are going to move to Western or Central Nebraska….What's going to happen when some of these ID docs start retiring? That's going to be huge!"

Language barriers with minorities

Participants also discussed the limited number of medical interpreters and influx of minorities in Nebraska who do not speak English as their primary language as barriers for HIV provider services. One participant noted, "The refugee population is just skyrocketing in Central Nebraska. Many different languages that NAP [Nebraska AIDS Project] is working with now." Another participant stated, "Huge disparity. So many providers will get some support staff to do the interpreting, instead of medical interpreters [trained], and we deal with barriers then."

Client

Regional meeting participants noted the following barriers for clients receiving HIV services:

1. Transportation (expense, time, distance);
2. Inability to navigate the system;
3. Lack of awareness about HIV resources;
4. Substance use and mental health issues; and
5. The cost of co-pays with insurance or no insurance for HIV treatment.

Transportation (expense, time, distance)

The expense, time, and distance that clients have to travel to HIV treatment appointments was one of the most frequent barriers that regional meeting participants discussed. Multiple participants noted that clients have to drive upwards of 45 to 60 miles to reach their nearest HIV testing or treatment center. One participant stated, "I have a number of people who call me, who might be 60 miles from Kearney and looking for a testing site that is close to them that offer similar services like NAP... they may not be comfortable going to a local doctor." Another participant discussed the frequent appointments clients must attend as contributing transportation barriers when they noted, "The consumer's appointments are in this group, this group, or that group, instead of the combination from general care and the interlinking of care. So they have to take more trips, which creates more problems – time, travel, cost and the whole works." When describing his personal experience and experiences of other HIV positive individuals in regards to transportation, one participated stated, "For folks without a car, it is a nightmare. It really is."

Inability to navigate the system

Regional meeting participants discussed that clients often have a difficult time navigating through the health care system, which creates barriers for clients accessing HIV services. One participant stated, "The health care system for anybody new, and just finding out what has happened to them is overwhelming in itself and then now trying to navigate and go through the system… that is a huge barrier." Another participant noted, "The system can be so complex that I've got clients I've worked with for 16 years who can't tell you the difference between Ryan White, Part B, ADAP." A case manager

believed that clients had to be in contact with NAP if they would be successful in navigating through the system when he stated, "I think once you get outside of the Omaha/ Lincoln area… It's imperative to be in contact with the NAP office because you have the barrier of distance and timeliness… If you can find us [NAP], if you can get into the system, it's great. There's a multitude of things we [NAP] can do in each of those areas, but it is making sure you are able to find that system because you might be 200 miles from the office."

Lack of awareness about HIV resources

Participants throughout the regional meetings believed that clients were unaware about HIV resources, as well as misinformed about the cost of HIV. One participant, when reflecting through clients perspectives, noted, "People are like it is too expensive; I can't afford it… There is just a lot of misinformed information out there about what it is, how it works, and sort of like, not like enough people talking [about HIV]." Another participant stated, "We start to see people in the rural area say that it is going to cost too much. I do not want to do this." Participants also were concerned that clients are simply not aware that HIV services exist in Nebraska. One participant stated, "As far as Kearney, most people don't know that Nebraska AIDS Project exists." Another participant concluded that clients lack the, "Awareness of the fact that service is here and that early intervention is key… I don't think anybody should be entering care in late stage anymore, but we still see it."

Substance use and mental health issues

Mental health and substance use were also discussed as contributing barriers for clients not seeking or sustaining HIV services. A participant stated that, "Depression has a huge impact for consumers getting lost to care." Another participant, discussing why participants get lost to care noted that it was due to, "Substance and mental health issues or just lack of support systems." One participant also brought up the limited locations for social support groups, specifically for young person living with HIV. The participant stated, "They [young PLWHA] want to talk about other interests, than just HIV. They don't want to go to a meeting in that area because the people in that area are older and they are young… so they end up driving 2 to 3 hours to Omaha or Lincoln groups and not going as much as they want or stop going."

Cost of co-pays with insurance or no insurance for HIV treatment

Several participants in the regional meetings also discussed the impact of clients either not having insurance or clients having to cover the co-payment costs as barriers for receiving HIV services. One participant stated, "If you don't have insurance, you essentially don't have access at all." Another participant, reflecting on the cost of co-payments stated, "To try and come up and pay for the co-pay and then the mental health part of becoming positive. It is kind of a shock. Because it's just something else that can really burden someone that does not need this mental anxiety to help lower, say their counts, because stress can really relate to HIV."

Program

Program-related barriers to HIV services in Nebraska identified by regional meeting participants included:

1. Limited funding;
2. Staff capacity; and

3. The distance it takes case managers travel in Central and Western Nebraska to access clients.

Limited funding

Regional meeting participants discussed that one of the largest barriers that HIV service organizations faced was the scarcity of funding for prevention, education, and advocacy, both in local communities and state-wide. A participant passionately said, "These programs at CAPWN and NAP have given so much of their own funding to these programs, they can't do it anymore. All of their budgets have been cut so dramatically that they just can't give anymore." Other participants were angered and questioned the current distribution of HIV program funding, which is not disseminated to locations across the entire state. One participant, referring to funding not reaching all locations equally, stated, "Woah, there is the wall of Nebraska." Another participant noted, "But a lot of our resources for prevention end up in Omaha because of the way some organizations are structured and their resources do not always make their way to Lincoln or other locations."

Staff capacity

Due to budget cuts and limited funding, regional meeting participants believed that current HIV organizations were at staff capacity. One participant stated, "The problem is there is no funding for them to do the work they do every day… If we had that funding to be able to give them what they need, to be able to expand the programs, and to do the outreach—do the programs the way they are intended to be ran—it would be phenomenal!" Multiple other participants firmly stated that an increase in case mangers was needed. A participant reflected on the current job requirements for a NAP case manager: "One of NAP's case managers is supposed to be a part-time case manager and a part-time fundraising, education, outreach person. Well at this point, that position's caseload is pretty close to 30, so they can't do the prevention, education, and the outreach the way he needs to do it because of the caseloads that they have. So they can't abandon the clients to prevent. And they can't prevent without more staff." Another participant believed, "one of the other barriers is that we used to be able to fund community health educators to go out and educate the community. Now there is no longer funding for the specific education piece, so we are lacking in the education around HIV."

Participants also were concerned that their limited funding supports costly language services. Due to the limited presence of medical transcribers throughout Nebraska, a participant stated, "We deal with barriers for accessing pharmaceutical assistance for them [non-English speakers]. The case managers become the entity that calls in their meds every month or they are calling NAP and NAP has to utilize language support services, which is expensive."

Traveling Distance

Several regional meeting participants also discussed the distance that HIV service providers had to drive to reach all of their clients. A participant, reflecting on the territory where her clients live, stated, "We have them scattered throughout all 11 counties and trying to see all of those people and meet all of their needs that is very difficult. The miles we have to put on trying to meet the needs of everyone in the Panhandle; it's very difficult to do that." Similarly, another participant also said, "I just have one more barrier… throughout the Panhandle, the vast area we have to travel to provide services or for those seeking services."

Legislative or Policy

Regional meeting participants discussed four main legislative or policy barriers:

1. Cost of care for PLWHA who do not meet income thresholds for public assistance;
2. Medicaid expansion;
3. Comprehensive sex education; and
4. Support for PLWHA who relocate to Nebraska.

Cost of care for PLWHA who do not meet income thresholds for public assistance

Regional meeting participants discussed the auxiliary service expenses associated with HIV as a detrimental burden for clients seeking and sustaining HIV services, particularly for those PLWHA living above the threshold for public support, yet who cannot afford services. One participant stated, "There are no resources currently in our area to assist people with the cost of doctor's visits, initial consultation, the lab work they need to have, and we then refer them to specialist. But as soon as they get the first bill for $1000 or more, they're freaking out and calling me going, 'I can't afford this. How can I afford this?'" Other participants perceived the system as being a cost burden for individuals who do not receive assistance. One participant, expressing his frustrations with this legislative barrier, reflected: "We are discouraging them from getting a job and insurance. If they don't have a job, they don't have insurance, we're like, 'Don't worry. We'll pay for it.' But, if you have a job and you're working on whatever you need to do for your family or whatever, we want you to pay. Then we want you pay for your deductible and your out of pockets. To me that makes no sense." Another participant also noted, "Most insurance lacks dental and eye care."

Medicaid Expansion

The State of Nebraska opted not to expand Medicaid, which is a contributing barrier for those living with HIV. One participant stated, "I think we need Medicaid expansion to have better access to health care so people can get in care, get tested, and then have access to PrEP if they need it through Medicaid." Another participant, when discussing why more people are not seeking or sustaining HIV treatment, noted, "A lot of people need Medicaid expansion." Similarly, another participant said, "If Medicaid could be expanded, we really need that."

Comprehensive sex education

Regional meeting participants also discussed the lack of uniformity of school guidelines in Nebraska for providing comprehensive sex education or sexual health education. One participant stated, "Even if it is comprehensive, each school has it own way of teaching it. Each teacher puts [his or her] own spin or who knows what actually gets instructed." Another participant, when discussing why Nebraska did not conduct more HIV education and prevention in schools, noted, "I think the political climate has a lot to do with keeping people from instructing it."

Support for PLWHA who relocate to Nebraska

Some participants noted that the federal regulations which dictate funding based on newly diagnosed individuals within a jurisdiction negatively affects Nebraska due to people who have been diagnosed in other jurisdictions moving into the state. One participant stated, "The new population that we see moving here are typically not diagnosed here. A lot of them were diagnosed either prior to coming to

the US or right after entry into the US. Again, we're not seeing those dollars." A PLWHA who recently moved to Nebraska from California, noted, "I want to make sure that the money that San Francisco is getting is coming back here to Nebraska... I think that it is important because the amount of money that is spent on me through Nebraska is now from Nebraska pocket's not from California's." Similarly, a participant stated, "Sadly, the diagnosis state is the state that receives the finances."

HIV Service Gaps

Regional meeting participants discussed service gaps related to HIV services. HIV service gaps were included discussions about how HIV prevention, care, and treatment services fall short in the community. HIV service gaps were expressed across three areas: HIV prevention, HIV care, and HIV support services.

HIV Prevention Gaps

HIV prevention gaps included:

1. Funding limitations;
2. Education, communication, and partnerships among health sectors; and
3. Limited education and awareness about PrEP.

Funding Limitations for Prevention

According to the regional meeting participants, the limited funding that is available for HIV prevention efforts greatly determines that amount and type of prevention activities that are facilitated throughout Nebraska. One participant stated, "As far as funding for outreach and education, it is limited to testing and screening so we don't do a good job."

Similarly, some participants believed Nebraska does not provide enough education or awareness about HIV to all health sectors and residents of Nebraska. One participant stated, "We see a few activities throughout Nebraska on HIV Awareness Day, but nothing really after that." Another participant, when reflecting on prevention efforts in rural Nebraska, noted, "On a scale of 1-10 in rural areas it is about half a point. I don't think it quite makes it up to one."

Due to the limited funding and current HIV organizations nearing or at staff workload capacity, one participant noted, "I would say the prevention efforts have dropped off as a result of it being the responsibility of the agencies and entities that already have a ton of other responsibilities." Another participant responded by saying, "As far as funding for outreach and education, it is limited testing and screening so we don't do a good job." One participant, when discussing the difference between past and current prevention efforts in Nebraska, stated, "We used to have radio and TV advertisements, but I don't hear or see them anymore." Another participant, commenting in this same discussion, stated that, "HIV educational speakers are less likely to occur at different civic organizations and schools."

Education, Communication, and Partnerships among Different Health Sectors

Regional meeting participants identified a gap in HIV prevention in regard to the education that providers in different health sectors receive and the communication that occurs between providers, as well as communication between providers and patients. One participant stated, "There is not enough education for mental health and substance use professionals [about HIV]." Along with the lack of

education about HIV in other health sectors, another participant discussed that HIV education and access to testing is not being completed in substance abuse centers and programs, when he noted, "The substance abuse programs provided HIV education and access to testing and that used to be very well done in this area with the mental health centers and a few of the other specialty programs and the detox centers, however… in the last couple years, it has sort of fallen off as not a priority to them and we're short on man power to go and do it… so it's kind of a mutual falling away."

Other participants were concerned that communication about HIV testing was not being facilitated by primary care providers adequately and the lack of partnerships between organizations created a gap for HIV prevention efforts. One participant noted, "I don't know if doctors or providers are not doing good screenings or just the stigma of HIV. I think that's one reason we still have it [HIV transmission] is because folks aren't knowing until they're very, very sick and they're infectious and possibly infecting other folks. The cycle continues." Another participant, when discussing partnerships between HIV organizations and other health sectors, stated, "I do not think there is any conscious effort group wise." Similarly, a participant also noted, "We have the NAs [Narcotics Anonymous], the CMAs [Crystal Meth Anonymous], there are those kinds of groups, but we do not even partner with them that I know of. I do not hear anyone partnering with those groups or offering some testing options."

Awareness and Education about PrEP

Regional meeting participants discussed awareness and education about PrEP among both Nebraska residents and providers as a gap that currently existed in HIV prevention across the state. One participant, when discussing the education level about PrEP stated, "That is a very uneducated topic in Central Nebraska." A participant also reflected: "PrEP is new coming, FDA approved it in 2012, but as you see like everything here [in Nebraska] it takes time to slowly spread out to the more rural parts of the country and I think also on perspective wise, helping people understand what it is and how it works."

Other participants believed that access to PrEP was a gap, even if patients and providers were educated and understood how to implement PrEP, it may not accessible in pharmacies or due to not having insurance. One participant stated, "I think access to PrEP is a gap." Another participant, discussing access to PrEP being a gap, noted, "I think we can write prescriptions for it and do the medical care around it, but we are not going to stock it in our pharmacy." A participant, discussing Nebraska residents, stated, "They're hearing about and hearing this is option and this is available, however if you don't have insurance you don't have access to it."

HIV Care Gaps

Participants highlighted multiple service gaps related to HIV care in Nebraska. These gaps characterized how HIV care and treatment fall short. Regional meeting participants believed that the limited number of HIV medical specialists and HIV services across Nebraska was the primary gap in HIV care across Nebraska, as well as an incongruence among providers for patients. One participant, when reflecting about the need for holistic needs of a client, stated, "He [client] wanted to make sure he was going to something where'd he could eat lunch and talk about dentist and dental [care] and not just a mental health support group." Another participant continued by noting, "The need to get all services connected… Our hope at some point is that we have a primary care doctor who is dealing with everything instead of it being a doctor in Omaha and doctor over here, doctor over there." Similarly,

one other participant stated, “Not everybody that comes in to test is from this area…I am not familiar with who to connect them with in their home community.”

Even if patients are receiving care from an infectious disease doctor, participants believed they did not have adequate options for determining who cared for them and feared the worst if they lost their provider. One participant, reflecting on his own personal experience, stated, “You ain’t finding nobody else who knows you even if you don’t like your ID doc. You won’t probably leave if things are a little shaky because you can’t trust the next guy is even going to care of you as much as this person. Consumers are extremely worried about losing the providers that have been there from the get-go for them.”

HIV Support Service Gaps

HIV support service gaps reported by participants included limited social and mental health support systems and transportation.

Limited Social and Mental Health Support Systems

Regional meeting participants discussed the gap in social groups and mental health services that existed throughout Nebraska. Multiple participants discussed the limited opportunities for social support engagements for PLWHA, their families, and their friends. One participant stated, “As far as mental health goes, there are not mental health support groups in my opinion.” Another participant noted, “We do not have support groups like we used to.” Similarly, another participant said, “One thing I am concerned about is support for people and their families that are HIV positive—just social, emotional stuff.” A participant also believed that social workers in Nebraska communities did not receive adequate HIV training or education when they stated, “We have social workers in every gamut. Throughout our community… anyone working in social services arena should have some sort of education. You should have on a variety of things. It is something [HIV] that is not ever really mentioned.”

Transportation

Transportation was also discussed a gap for clients being able to access HIV services by regional meeting participants. Participants discussed the limited amount of public transportation or transportation assistance to reach services that are needed, but not located within their community. One participant, when reflecting on Central and Western Nebraska, stated, “We do not have access to really anything. There is no public transportation in those areas.” Another participant, when discussing transportation as a gap, noted, “I think that transportation to that true specialist care that cares about unique patients… is limited in general… the geography makes it a challenge.”

HIV Service Needs

Regional meeting participants believed that a variety of HIV prevention and care services were needed to improve HIV services throughout Nebraska. HIV service needs were defined as resources that would improve HIV prevention, treatment and care services in Nebraska. Primarily, participants discussed needs around HIV prevention and HIV care.

HIV Prevention

HIV prevention needs discussed by regional meeting participants included:

1. Increased condom distribution and HIV testing;
2. Greater HIV awareness and education throughout all health sectors in Nebraska;
3. Statewide coordinated efforts between substance use, mental health, and HIV/STI providers;
4. Unified statewide HIV prevention message; and
5. Utilizing social media for HIV prevention.

Participants expressed that residents of Nebraska would benefit from increased HIV and STI education and prevention efforts throughout the state. Prevention efforts named included both structural strategies (e.g. condom distribution and testing) and awareness and education activities.

Increased Condom Distribution and HIV Testing

In every regional meeting, participants discussed the need to increase in the number of locations that offer condom distribution and HIV testing throughout Nebraska. Multiple participants stated that condoms or HIV testing were needed at more public locations, other than just at health departments. One participant stated, "I think if condoms were more available at places… and not just at health departments… condoms just need to be around at more places. Even just more free condom spaces." Other participants discussed specific locations for HIV testing or condoms to be facilitated that included: Boys and Girls State, Prisons, Rotary Clubs, Alternative Schools, Youth Rehabilitation Centers, YMCA, YWCA, and Churches. One participant, when reflecting on what he believed was needed for new locations to be successful at implementing HIV testing, stated, "I just think that rapid testing is super important for people… people come in they want their test results immediately… not by a letter in the mail, phone call. So easy testing, affordable testing, confidential testing, is important!"

In addition to needing more public HIV testing and condom locations, multiple participants also described the need for in-home testing due to the stigma in Nebraska that exists around HIV. One participant stated, "I think that if you're dealing with a population that wants to [get tested], but they don't. Especially in smaller communities where they know folks and they don't want to go where everybody goes. Then the in home testing is a great way." Another participant, when asked why in-home testing would be beneficial for a state like Nebraska, noted, "It just takes away that step of having to go somewhere and dealing with who's going to see you and having to say, 'Can I have an HIV test?' Then you also have the risk of your doctor saying, 'We don't really do that here' or 'You need to go to the Health Department.'"

Greater HIV Awareness and Education

Regional meeting participants frequently discussed that Nebraska would benefit from an increase in HIV awareness and education campaigns throughout all health sectors in Nebraska. One participant, when discussing Nebraska HIV prevention needs stated, "Spreading awareness but also encouraging that broader education standpoint of knowing your risks and not being afraid of talking to someone about it. Whether it is a publication, a poster, or something on their wall. Maybe they won't get tested in their provider's office because they don't feel comfortable doing it there but if they see a sign that says here is a list of places I can go get tested." Another participant, noted, "I think before we can have a voice in prevention, we have to educate first." Participants were worried about HIV prevention education

occurring more frequently in the future, as numerous participants stated that they did not receive adequate HIV prevention funding and current, passionate HIV staff workers are on the verge of retirement with no replacements in sight. One participant stated, "We don't get that funding. It's a real challenge and is needed." Another participant, specifically discussing Central and Western Nebraska noted, "Most of us in this room are aging now… what we need are a new group of folks with commitment and passion." One other participant contributed a solution to the Central and Western Nebraska HIV future employment needs when she reflected: "Maybe the next generation one of the things we need is training for that next generation. Not just training for providers but for that next frontline."

Participants throughout the regional meetings also believed that one of the missing prevention pieces was statewide comprehensive sexual health education. One participant stated, "I would say if we can find a bridge that can close a gap from the political side so that we can have a universal form of educating people, it would probably decrease the amount of time we spend treating gonorrhea, chlamydia, syphilis, and also HIV." Multiple other participants discussed their fear of Nebraska youth not viewing HIV as a concern anymore with the recent advancements in HIV medication, and thus, needed education around HIV. One participant stated, "It goes back to that someone needs to have the education at the youth level… it is not a big deal to a lot of youth anymore." Similarly, another participant noted that the youth needed, "general awareness… what their risk are… and more open conversations."

Regional meeting participants also believed that Nebraska communities, residents, and providers needed increased PrEP awareness and education. One participant stated, "Well I think everyone needs to be educated more about PrEP. Every single community member needs to know more about it [PrEP], so they can help tell people." Multiple other participants were concerned that providers in Nebraska did not have adequate education around PrEP or PEP and therefore were less likely to implement these treatment options to patients. One participant stated, "You need to get in the information out there that it [PrEP and PEP] exists. For PEP, you need to let them [providers] know it is intended for emergencies." The same participant continued by discussing the type of education that providers may need towards PrEP and PEP treatment when they stated, "I think you would also have to work on the social dimensions… correcting the misperceptions about the long term use… a lot of myth busting, like around if it is bad for someone to take and a lot of myth busting around the shame and compensation." Similarly, another participant noted, "I have been looking at and trying to follow or at least get the information on PrEP. We need to get providers on board with this PrEP."

Statewide Coordinated Efforts between Substance Use, Mental Health, and HIV/STIs.

Regional meeting participants were highly concerned that Nebraska did not coordinate efforts adequately between substance use, mental health, and HIV/STIs providers. One participant stated, "We need a better collaboration between substance abuse and mental health providers." Another participant, discussing her perception in regards to the current collaborative efforts throughout different health sectors in Nebraska, noted, "Our mental health and substance abuse, HIV prevention/AIDS, don't collaborate very well together. That includes Medicaid too." Likewise, another participant discussed the dichotomy of HIV services related to intravenous drug users and stated, "We do not partner with the treatment providers very well." Several other participants believed funding was needed to help expand the collaboration between HIV and different health sectors. One participant

noted, “We need funding and expanding that comes under specialty care like neurology, psychiatry, mental health, ophthalmology.”

Other participants believed that new HIV prevention services needed to be extended and partnered with HIV services outside of Omaha and Lincoln. One participant stated, “What we need then is for programs in the Omaha and Lincoln as they are developing and innovation is occurring to think of us [Central and Western Nebraska organizations]. Another participant perceived that there was a loss of connection between different HIV service organizations that are available throughout the state for HIV efforts when they noted, “Here is this overall thing that we should know about HIV or AIDS, but then there is no connection, like here are the services that are available.”

Unified statewide HIV prevention message

Regional meeting participants described the necessity for a unified statewide HIV prevention message. One participant stated, “We do not have a statewide message and I think that is something that we could work on. We have talked about it and everyone should be saying the same thing. No matter how it is funded, it should all be one statewide message.” Similarly, another participant noted, “I think a unified message is definitely missing.”

Participants also discussed more specific messaging strategies that they believed were needed to include in the statewide message. One participant stated, “It needs to be the right message. Concerted, coordinated, uniformed implementation strategy and message.” Other participants believed that HIV sub-messages specific to certain populations were also needed. A participant noted, “I wonder if there just needs to be a multi-pronged approach where maybe we have one overall message, but then we have sub-messages and sub-target populations.” Likewise, another participant stated, “It’s the balance between finding a message, but also from the feedback we’ve heard, having relatable messengers specific to populations.”

Utilizing social media in HIV prevention

In every regional meeting, participants described the need for HIV prevention messages to be disseminated through social media. Participants believed that social media was the most effective outlet for reaching and connecting with different populations throughout the state. One participant, describing the reach of social media, stated, “That is what the young people are into. With Facebook you can hit a large group. And you can show them locations for testing in their local area.” Another participant noted, “We need a better strategy, or a strategy, using modern technology that is something that people relate to and how they get their messages now.” Other participants believed that HIV prevention messages utilizing social media would be more visible and resonate with Nebraska residents. One participant stated, “There’s so much leverage you might have in social networking that you’re not going to get anywhere else. Just the massive amount of people by one click that you can impact.” Similarly, another participant discussed the importance of social media in Nebraska when he noted, “I don’t think that it’s something that people talk about [HIV prevention]. It is something that is pushed aside… more social media… I don’t want to say constant reminders, but kind of.”

HIV Care

Regional meeting participants described several important HIV care needs, including:

1. Increased HIV staff capacity;

2. HIV education for consumers and providers; and
3. Easy access to services.

Increased HIV staff capacity: case managers and HIV specialists

Participants frequently discussed needing more HIV case managers and HIV specialists throughout Nebraska, especially in Central and Western Nebraska. One participant stated, "I think support for the AIDS project and to have case managers… Kearney needs an additional case manager it sounds like." Another participant discussed the benefits of having an adequate amount of case managers when she noted, "It's nice to have someone… follow up on medication adherence and things like that." One other participant, discussed her concerns about committed case managers and other HIV staff reaching retirement age in Western Nebraska and what solutions were needed to remedy the situation, noted, "The point being, trying to figure out some sort of secession… how do we engage other folks in our clinic, in our networks, who are going to start cross training and going to be able to take over some of this work. The point being, there is a real committed group of folks here, it's what makes us strong, and it's also one of the biggest weakness in terms of care."

Specific to the accessibility and number of HIV specialists in Nebraska, several participants discussed Nebraska residents needing more options or locations of HIV specialists throughout Nebraska. One participant stated, "There is a dearth of providers, so you can't be picky and chose. But in Omaha, there is possibilities." Another participant, when reflecting through his own experiences navigating through the system, discussed what HIV consumers needed in Nebraska when he noted, "To make sure that people know where to get care and that there is choices on where they can go for care… Choices in services matter. If there is only one person who does it, or even two people who do it… that would be a serious barrier." Similarly, another participant stated, "There is just one infectious disease doctor around here, I know there was a doctor from Omaha going to Columbus."

HIV education for consumers and providers

Regional meeting participants believed HIV consumers were in need of increased HIV education opportunities, in order for them to navigate through the system more effectively. One participant noted, "We need people to help navigate the systems. It is so difficult to try to figure out where they need to go, what they need to do and what paperwork they need to fill out and what hoop they need to jump through." Similarly, a participant stated, "A huge barrier is the lack of dumbing down the system for people who really need it." Another participant, discussing the difficulty for HIV consumers to understand and utilize insurance correctly, noted, "You can give them [HIV consumers] insurance and give them a Blue Cross Blue Shield card… but it will not do them a whirl of good if they do not know how to use insurance… One of the biggest things is meeting people where they are at [in the system] and to fill in those gaps." One solution that participants believed would benefit consumers would be the creation of HIV community support groups. One participant noted, "If we could have community or advisory groups that is made up of consumers… people would be able to find out where others go, where they go for treatment, what does it cost; it's just a good way of networking, too."

Regional meeting participants also believed that Nebraska would benefit from creating and facilitating training opportunities for all providers who may work with HIV consumers. One participant stated, "We need to incorporate more into training of at least healthcare people... social work, education, or case

management… but definitely in healthcare... nursing doesn't get that much exposure [HIV] in general." Likewise, another participant proposed a solution for increasing provider trainings in Western Nebraska when she noted, "If we had something at the hospital or regional conference for medical providers, nurses, and dieticians, at maybe the Civic Center and bring in some speakers maybe a day or day and half meeting. Most people come from Chadron and towards from Wyoming and talk about the progress we've made and it wouldn't take much money to do that. If we could get that on an annual or semiannual or even two-year basis we could get that education out there. You know you have new doctors and new nurses out there."

Easy access to services

Regional meeting participants, outside of Omaha and Lincoln, commonly mentioned that statewide transportation services were needed in order for HIV consumers to access and sustain in HIV treatment or care more easily. One participant stated that Nebraska needed to, "identify statewide transportation providers." Similarly, another participant noted, "We cannot lose our transportation service moneys, because we have so many people traveling… If we don't keep ahold of that… they just can't afford to travel." Other participants believed that centralizing locations of different health sectors would reduce several barriers that often occur in HIV consumers. One participant reflected, "Having everything right here will definitely make things a whole lot easier for people, because if they could have all of their care in one place instead of working with 5 doctors... a central location… would eliminate the issue of traveling and having to take a day off of work just to go to a five-minute appointment."

Other participants believed that providing or paying for transportation from Western Nebraska communities to access services in Lincoln or Omaha was not the most conservative way to utilize the already limited resources. Instead, several participants discussed alternative ways to access services that are closer for providers and patients. One participant noted, "We're so much closer to Denver than we are to Omaha. I don't know if we look at regional efforts… but it makes more sense to use the AIDS Patient Training Center out of Denver. It's half the distance to come and half the time than Omaha." Similarly, another participant, when discussing closer places to access HIV treatment or care services, stated, "There's population base and bigger population bases in Cheyenne, Rapid City, Casper, Denver, and Fort Collins, all of those are closer than Omaha or Lincoln. So if there's ways for us to make more natural use of those maybe we should."

Summary

Stigma permeates the environment surrounding HIV in Nebraska, which contributes to continued challenges for the engagement of people in the HIV prevention, treatment, and care systems. Continued challenges are the determination to not expand Medicaid and resistance to the adoption of comprehensive sexuality education curricula in schools across the Nebraska. Salient cultural and religious beliefs further stigmatize behaviors that may lead to HIV transmission or people who are living with HIV, which foster an environment of testing avoidance, fear of disclosure, and shame.

More HIV awareness and education are needed throughout the state, particularly in areas outside of Omaha. Lack of knowledge about HIV is not uncommon in Nebraska, and this lack of knowledge likely drives stigma and policy development that is not supportive of HIV prevention, treatment, or care. Traditional educational approaches, along with structural approaches like condom distribution, must be strengthened. New challenges, particularly in the area of social media and biomedical prevention,

present new opportunities for new strategies for addressing HIV. Support must be provided for staff to learn to use new media. Most medical providers in Nebraska will not prescribe PrEP, so there is a great need for provider education.

For people living with HIV, challenges in navigating the treatment and care system continue to be a reality. For many, access to medical or other services is difficult due to the geographic distance from providers or case managers. Transportation remains a barrier to care for many. The lack of providers creates additional challenges for consistent care, particularly in Western Nebraska. The aging and forthcoming retirements of current providers is a concern that must be acknowledged. The rapid influx of immigrants who bring diverse cultural practices and languages is a growing concern for service provision.

Needs exist across all ecological domains in Nebraska. Systems and organizations would benefit from strengthening services, expanding access, and focusing on services coordination. Communities would benefit from increased, culturally appropriate engagement by well-trained staff. People living with HIV and their support networks would benefit from increased psychosocial support, easier access to care, and better knowledge of support services. A unified, strategic approach that includes intervention at all ecological levels will ultimately address HIV-related stigma, which is among the greatest challenges to HIV prevention, treatment, and care.

Subpart 2: Ryan White Provider Surveys

Description of Procedures

A survey instrument was developed based on a review of provider surveys from states in the region. Providers advised staff that electronic administration was the preferred method. The survey was uploaded into the online platform, and the survey link was disseminated to providers in January, 2016. The survey remained available to providers for one month.

Results

The current findings reflect results of the 2016 Ryan White Statewide Coordinated Statement of Need (SCSN) provider survey to assess the needs of Ryan White providers in Nebraska. Providers representing various organizations responded to the survey. Significant heterogeneity was found in the number of years their organizations have provided HIV/AIDS-related services (range: 1 to 30 years) and the number of clients/patients served each month (10 to 1000+). The majority of respondents were medical providers providing care at a health clinic.

Half of the (n=12) providers indicated their organization works with specific populations (i.e., race/ethnicity, gender, age groups, special needs, etc.). Listed below are the specific populations:

- MSM (4)
- People of color (3)
- Newly diagnosed
- Transgender women
- People living with HIV (3)
- Refugees (2)
- IDU
- Women

Table 52 Provides a summary of providers by type. Table 53 provides a description of the agencies by type, and Table 54 provides an overview of most frequently provided services.

Table 52: Providers by type, Nebraska, 2016

Practitioner Level (check all that apply)	n
Medical Provider (physician, nurse, etc.)	12
Part C Provider	3
AETC Provider	2
Member of a Federally Recognized Indian Tribe	0
Case Manager	8
Consumer of Ryan White Services (Client)	0
Other Provider	1
Advisory Board Member, Non-Service Provider (NHCPC)	2
Health Department Staff	0
Other	3

Table 53: Agency description, Nebraska, 2016

Agency Description (Choose one response only)	% (n)
AIDS Service Organization	25.0% (6)
Health Clinic	45.8% (11)
Hospital	12.5% (3)
Community-Based Organization (not AIDS specific)	4.2% (1)
Multi-Service Agency, including HIV/AIDS services	8.3% (2)
Treatment Facility	4.2% (1)
Dentist	0
Other	0

Table 54: Most frequently provided services, Nebraska, 2016

Most often provided services*	n
Medical care	17
Dental care	3
Case management	17
Substance abuse	3
Counseling/mental health	5
Food distribution/nutrition	5
Access (e.g. child care, transportation)	9
House	5
Benefits/financial assistance	11
Family services (e.g. respite care, kinship care, legal assistance)	0
Other	1

**Check all that apply, no percent calculated*

A little over one third (n=8) providers indicated their organization had training in trauma informed care. The majority (n=18, 78.3%) were interested in opportunities for training/cross-training with other HIV provider organizations or forming an HIV Care Collaborations Team, however, three respondents were "not sure" and two responded "no".

Providers ranked 18 services 1 to 18 in the order of importance necessary to support consumers in the state of Nebraska (1 is highest, 18 least high). Provider rankings varied considerably, therefore the top 5 services are presented below with the percent of providers who chose the service in their top 5 most important services.

1. Access to care (n=15, 71%)
2. ADAP (n=13, 62%)
3. Insurance health premiums (n=10, 53%)
4. Prescription costs (n=9, 45%)
5. Mental health (n=7, 35%) and Housing (n=7, 35%)

Several of the providers (n=13, 65%) indicated there are needs not currently being met by the RW Part B and C programs in Nebraska. Listed below are the specific unmet needs:

- Clients do not qualify for certain medications (2)
- Actual transportation services (3)
- Access to Case Manager services
- Pet services/ animal care
- Client education opportunities
- Translators
- Car repairs
- Primary care for diabetes and other reoccurring issues
- Substance abuse treatment
- Housing assistance
- Coverage for medical appointments for preventative care
- Furniture assistance
- Dental coverage
- Hormone Replacement Therapy coverage
- HIV testing
- High deductibles/ Co-pay assistance for those using employer's insurance (3)
- Hepatitis C treatment coverage
- More comprehensive care

The following barriers to care come to the provider's mind for persons living with HIV/AIDS?

- Substance use (3)
- Stigma (6)
- Unemployment
- Homelessness/ Housing (2)
- Mental health issues (2)
- Transportation/Distance (4)
- Child care
- Financial barriers
- Telecommunications
- Language
- Limited providers (2)
- Fears of treatment
- Poor primary health care access
- Limited insurance coverage
- Inefficiency of mail order pharmacies

A few providers (n=3, 14.3%) indicated there is not an effective process in place linking care for HIV+ individuals. Listed below are suggestions on how to improve this process:

- Linkage between testing sites/ state EPI program and care providers
- Have Ryan White applications at testing sites

- Referral to doctors at testing sites
- Trained counselors to give results to clients
- Better communication between UNMC and NAP
- More referrals made to NAP
- More supportive services
- Better linkage between UNMC and patients outside of their care, especially for those outside of Omaha across the state
- More training
- More collaboration
- Resource Development

Providers were asked to rank methods of implementing Early Identification of Individuals with HIV/AIDS (EIIHA):

1. Peer outreach
2. Minority outreach
3. Intensive case management
4. Other
5. Contractual agreement

"Other" was specified as:

- Comprehensive sexual health education reform in public schools
- Education in non-traditional settings in order to reach high risk populations
- I don't have an answer
- Internet/website interface

Two providers indicated effective collaboration and coordination of care does not exist between the RW Part B, Part C and other HIV-related service providers in Nebraska? Listed below are suggestions on how to improve:

- Stream-lined process and tiered like Iowa
- Better communication (3)
- Periodic visits

Providers rated the effectiveness of components of the Ryan White program. Overall, 45% of providers rated the education provided to case managers on new issues as "good," "effective," or "very effective," while 40% rated the program as "fair," or "poor." Thirty percent of providers were unsure.

Thirty percent of providers believed that the program did a "good" or "effective" job of educating or ensuring that education was provided to consumers about RW program services. Forty percent rated this service as "fair" or "poor," and 30% percent were unsure.

Forty-five percent of providers indicated that the Ryan White program does a "good," "effective," or "very effective" job in dealing with the gap coverage in rural areas, while 20% believed that the program

did a “fair” job. Forty percent were unsure. Table 55 provides a summary of provider perceptions of program services.

Table 55: Program effectiveness, Nebraska, 2016

	Very Effective	Effective	Good	Fair	Poor	Not sure
How effectively is the NE RW program educating or ensuring that education is provided to case managers on new issues related to case management and consumer care and treatment?	5.0% (1)	20.0% (4)	20.0% (4)	25.0 % (5)	15.0% (3)	30.0% (6)
How well is the Nebraska Ryan White educating or ensuring that education is provided to consumers of RW services?	0	15.0% (3)	15.0% (3)	25.0% (5)	15.0% (3)	30.0% (6)
How effectively is the Nebraska Ryan White Program dealing with gap coverage in rural areas?	5.0% (1)	20.0% (4)	15.0% (3)	20.0% (4)	0	40.0% (8)

Additional feedback

- ADAP/ RW service mostly used for medication access and medical bill coverage
- There is apathy among those living with HIV in Nebraska making it difficult to get people to participate in education and advocacy
- Happy with the support their clients currently receive
- NAP case manager educates clients
- Always room for improvement

Subpart 3: Ryan White Client Surveys

Description of Procedures

Client surveys were developed after a review of surveys used by other states in the region. The final survey was provided to case managers from the Nebraska AIDS Project and the University of Nebraska Medical Center for distribution to clients. A total of 245 surveys were mailed to case managers for distribution, along with self-addressed, stamped envelopes for survey submission. An electronic version of the survey was also created. The survey was available in both English and Spanish. Surveys were completed between January and February, 2016.

Results

The current findings reflect results of the 2016 Ryan White Statewide Coordinated Statement of Need (SCSN) survey to assess the needs of Ryan White clients in Nebraska.

Socio-Demographic Characteristics

A total of 107 individuals completed the client survey. Majority of participants identified their sex as male (n=80, 75.5%) and 24.5% as female. No participants identified as transgender. Age of participants ranged from 24 to 87 years with a median age of 52 years. Over half (55 of 93) of the zip codes in NE were represented. Participants were racially and ethnically diverse with 55% (n=59) identifying as White/European American, 13% (n=14) Black/African American, 21.5% (n=23) Latino/Hispanic, and 10.3% as Native American, African refugee, multiracial, or other. Participants identified as heterosexual (n=44, 45.8%), homosexual (45, 46.9%), and bisexual (n=7, 7.3%). Approximately 10% of participants, however, did not respond to the question on sexual orientation. The vast majority of participants (n=94, 91.3%) reported an annual income of $30,000 or less and about half were unemployed (n=52, 49%). In addition, table 56 provides additional information about issues that may impact clients.

Table 56: Issues that may impact clients, Nebraska, 2016

Item	Yes	No	Don't know
In the past 12 months, have you not seen the doctor because of the cost	11.4% (12)	87.6% (92)	1.0% (1)
In the past year, have you not taken medications because of the cost?	10.5% (11)	89.5% (94)	0
Have you spent time in prison/jail since you were diagnosed with HIV/AIDS?	19.6% (21)	80.4% (86)	0
During the past 12 months have you been homeless at any point?	6.7% (7)	93.3% (8)	0
During the past 12 months did you stay with friends or family because you didn't have your own place?	24.3% (26)	75.7% (81)	0
During the past 12 months did you use HOPWA funding to help pay mortgage, rent or other housing?	15.1% (16)	80.2% (85)	4.7% (5)

Health

Participants reported living with HIV for approximately 15 years on average with a range of 1 to 34 years and 36.2% (n=38) had ever been diagnosed with AIDS. The majority of participants rated both their current health and mental health as at least "good". Medicaid and Ryan White Services were utilized

the most frequently for healthcare coverage. Tables 57 through 59 provide additional details about the health status, coverage, and exposure history of clients.

Table 57: Self-reported health status, Ryan White clients, Nebraska, 2016

	Excellent	Very good	Good	Fair	Poor	Very Poor
How do you rate your current health status?	17.1% (18)	26.7% (28)	24.8% (26)	25.7% (27)	2.9% (3)	2.9% (3)
How do you rate your current mental health status?	13.3% (14)	23.8% (25)	28.6% (30)	27.6% (29)	5.7% (6)	1.0% (1)

Table 58: Types of health care coverage, Ryan White clients, Nebraska, 2016

	Medicaid	Medicare	COBRA	Private	Self	VA Benefits	Ryan White	None	Don't know
What kind of healthcare coverage do you have?*	49	14	2	26	2	1	48	1	2

**Check all that apply, no percent calculated*

Table 59: HIV exposure, Ryan White clients, Nebraska, 2016

How do you think that you were first exposed to HIV?	% (n)
Having Sex With Men	61.3% (65)
Having Sex with Women	11.3% (2)
Occupational Exposure	0
Sharing Needles or Works	4.7% (5)
Born with HIV	0
Blood Products/Transfusion	3.8% (4)
Don't Know/Not Sure	14.2% (15)

Provider/Case Manager Satisfaction

Participants were asked several questions regarding their satisfaction with healthcare providers and case managers. The majority of participants were very satisfied with the care they received. Tables 60 and 61 provide survey responses regarding satisfaction with providers and case managers.

Table 60: Perceptions of case manager experience and knowledge

	Excellent	Very good	Good	Unsure/ Neutral	Fair	Poor	Very poor	N/A
How do you rate your overall experience with your case manager?	62.1% (64)	17.5% (18)	13.6% (14)	4.9% (5)	1.9% (2)	0	0	3.7% (4)
How would you rate your healthcare provider's knowledge of HIV/AIDS?	65.7% (69)	20.0% (21)	8.6% (9)	2.9% (3)	1.9% (2)	1.0% (1)	0	1.9% (2)

Table 61: Perceptions of case manager services, Ryan White clients

	Strongly agree	Agree	Somewhat agree	Unsure/ Neutral	Somewhat disagree	Disagree	Strongly disagree	N/A
I feel that my case manager respects me.	69.8% (74)	30.2% (26)	0.9% (1)	4.7% (5)	0	0	0	0.9% (1)
I feel that my case manager listens to and hears me/my concerns.	69.8% (74)	21.7% (23)	3.8% (4)	4.7% (5)	0	0	0	0.9% (1)
I feel that my case manager values my time.	71.2% (74)	21.2% (22)	2.9% (3)	4.8% (5)	0	0	0	1.9% (2)
My case manager clearly explains the services I am and am not eligible for.	57.3% (59)	30.1% (31)	2.9% (3)	9.7% (10)	0	0	0	1.9% (2)
I feel that I can tell my case manager when I am not happy with the services I receive.	60.4% (64)	27.4% (29)	2.8% (3)	7.5% (8)	0.9% (1)	0.9% (1)	0	0.9% (1)
When I need referrals to another doctor or service, my case manager helps me.	57.4% (54)	26.6% (25)	3.2% (3)	9.6% (9)	2.1% (2)	1.1% (1)	0	10.3% (11)

Services

On average, participants reported driving approximately 49 miles or an hour to their healthcare provider. Miles ranged from 0 to 230 and minutes ranged from 1 to 300. Tables 62 and 63 show the Ryan White services needed and accessed by survey participants in the past year. Case management and ADAP (medications) were reported as the most frequently needed and utilized services.

Table 62: Services needed, Ryan White clients, Nebraska, 2016

Which of the 12 services available to NE Ryan White clients have you needed in the past 12 months?*	**n**
Transportation	42
Mental health	15
ADAP (medications)	62
Dental services	44
Housing	24
Health insurance premiums	40
Emergency assistance (i.e., utilities, food, etc.)	31
Laboratory services	38
Translation/interpretation	6
Nutrition education	15
Support group	18
Case management	62

**Check all that apply, no percent calculated*

Table 63: Services used, Ryan White clients, Nebraska, 2016

Which of the 12 services available to NE Ryan White have you used in the past 12 months?	**n**
Transportation	35
Mental health	11
ADAP (medications)	63
Dental services	37
Housing	17
Health insurance premiums	40
Emergency assistance (i.e., utilities, food, etc.)	23
Laboratory services	39
Translation/interpretation	6
Nutrition education	13
Support group	20
Case management	59

**Check all that apply, no percent calculated*

Participants identified medical services received NOT through Ryan White. A total of 53 responses were obtained with podiatry/foot care followed by optometry/eye care as the most common medical services received outside of Ryan White eligible care.

- Podiatrist/foot care (n=11, 21% of responses)
- Optometry/Eye care (n=7, 13% of responses)
- Dermatologist/Skin Specialist (n=5, 9.4% of responses)
- Chiropractor/ Physical therapy (n=5, 9.4% of responses)
- Therapist/ Psychiatrist/Mental health care (n=4, 9.4% of the responses)
- Dental (n=3, 5.6% of responses)

Part E: Data: Access, Sources, and Systems

Data Sources, Policies, and Availability

The main sources of data for the epidemiologic profile are surveillance data. For HIV/AIDS incidence and prevalence, the main source of data is the HIV/AIDS surveillance data eHARS (Enhanced HIV/AIDS Reporting System) which is used to collect, manage and report Nebraska's HIV/AIDS cases surveillance data to CDC. Data in eHARS includes demographic, risk factor, illness history and laboratory data. These data are used to track the incidence and prevalence of HIV in Nebraska. The demographic information combined with the laboratory data are used to create the care continuum.

The Nebraska Department of Health and Human Services' STD program uses STD MIS to report STD morbidity to the Centers for Disease Control and Prevention (CDC). The database is also used to capture disease investigator efforts and assist in investigations. These reports are intended as a reference document for policymakers, program managers, health planners, researchers, and others who are concerned with the public health implications of these diseases.

The Nebraska Ryan White Program is required to collect data on all consumers accessing funded programs. Demographic and income data are collected at intake, at each service visit, and at the mandatory six-month and annual recertification period. All data is reported to the Nebraska Ryan White Program and subsequently the Health Services and Resource Administration (HRSA) annually through the Ryan White Services Report. The Nebraska Department of Health and Human Services utilizes Provide for the Ryan White Part B program.

Provide Case Management Software system was purchased in 2001 to allow the Ryan White Part B and later the Housing Opportunities for Persons with AIDS programs to collect and report client-specific data to the U.S. Department of Health and Human Services' Health Resources and Services Administration and HUD and the U.S. Department of Housing and Urban Development. The system is also used to track services and cost of services provided to clients. Client service plans and progress in reaching client goals are also entered into system.

HIV Prevention utilizes EvaluationWeb to collect data surrounding the activities of HIV counseling and testing. Data collected ranges from demographics, patient risk factors, agency activities, and co-infections. The purpose of EvaluationWeb is to provide data to better monitor and strengthen HIV prevention activities. Data are collected on forms that accompany the EvaluationWeb system and collected by agencies performing HIV Prevention funded and non-HIV Prevention funded HIV testing.