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Health care needs assessment: White Earth Nation members and other American Indians in the Twin Cities

Minnesota Department of Health Report to the Minnesota Legislature 2012

February 2012

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Executive Summary

Background

The 2011 Minnesota Legislature called for a needs assessment for a health clinic or other health care needs of the White Earth Tribe in the Twin Cities metropolitan area. The Minnesota Department of Health contracted with the Amherst H. Wilder Foundation to prepare the needs assessment. The project included background research, interviews and focus groups with White Earth members and other American Indians in the Twin cities and with other key informants.

Findings

About 26,000 American Indians live in the seven-county Twin Cities area, including 3,500 White Earth Nation members. This population has steadily grown over the past 50 years.

This population's overall health status is significantly worse than the general population. Diabetes, alcoholism, mental illness and suicide, cancer, heart and other chronic diseases, and tobacco-related health problems are much more prevalent among American Indians.

This study identified the following unmet health care needs and service use patterns for American Indians in the Twin Cities. Few differences emerged between the health care needs of White Earth members and other American Indians in the Twin Cities.

- Poverty, affordability, lack of knowledge about nutrition, and barriers to exercise and physical activity contribute to the poor health in the American Indian population.
- Lack of adequate insurance and lack of affordable, accessible specialty services contributed to these outcomes.
- Dental care and eye glasses are often not covered by public insurance (or they are commonly understood to be uncovered services).
- A large proportion of the community is publicly insured.
- Culturally responsive and trusted mental health and chemical dependency services are lacking, and serious transportation challenges reduce access to care.
- American Indians are less likely than other racial/ethnic groups to have a regular primary care provider, and they are more likely to use hospitals and emergency rooms to meet their health care needs.
- About one in five use some form of traditional medicine or spiritual healing.
- Twin Cities American Indians find the health care system to be fragmented and confusing, and they are frustrated trying to navigate eligibility and insurance requirements.

- Many American Indians also struggle with knowing where to go for which services, and communicating with their providers.
- Twin Cities American Indians often have low trust in their health care providers, many of whom lack familiarity with traditional healing practices.
- Many American Indians experience outright racism and discrimination, and some believe they receive substandard services because of their race or because of their insurance status.

Recommendations

The findings suggest significant health care needs among White Earth Nation members and other American Indians in the Twin Cities. To address these needs, providers and community members expressed a strong desire to focus on the needs of all American Indians and to take a holistic approach.

Scope

• Pursue an approach that addresses the health needs of the entire American Indian population in the Twin Cities, rather than focusing on a tribe by tribe approach, in order to eliminate fragmentation, achieve economies of scale, and improve effectiveness.

Ultimate Vision

- Explore methods to overcoming the reimbursement and policy barriers to creating the community's ultimate vision and preferred solution: one center that provides wellness activities, primary care, specialty services, social support (especially for elders) and child care, and traditional healing, in a welcoming and culturally responsive environment. Begin intensive, detailed planning for this comprehensive center as soon as possible.
- Increase partnerships and collaboration between existing community providers, Tribes, Indian Health Service (IHS) and state government to better improve the health and wellness of Minnesota's American Indian community.

Access to Primary Care and Specialty Care

- If pursuit of the ultimate vision is not possible in the near term, do not create another isolated and under-resourced primary care clinic; begin to improve existing clinics' collaboration as recommended below whether or not a new comprehensive urban American Indian health center develops.
- Improve access to specialty care. Provide existing clinics and patients with more support and access to specialty care services, or consider other approaches to improving specialty care access.
- Increase collaboration and partnerships between clinics with significant American Indian case loads and local health systems.
- Integrate and enhance care coordination services with existing primary care clinics.

Health Care Coordination and Navigation

- Increase the number of American Indian health care navigators or community health workers available to help American Indians navigate the system.
- Identify individuals with significant health needs and offer them additional culturally-informed care coordination services.
- Raise awareness of health care homes and encourage American Indians to enroll in those health care home clinics that have a culturally appropriate environment.

Prevention and Wellness

- Improve availability of opportunities for physical activity and exercise through existing programs and resources.
- Increase access to healthy foods, especially fresh produce.
- Increase educational activities related to preparing fresh foods.
- Take a systemic approach to improving nutrition by improving community and family food choices and include an emphasis on healthy traditional foods (wild rice, fish, etc.). Focus on family and community education with programs and events such as community feasts that feature nutritional food.
- Focus on engaging young adults and young parents in preventive self-care and encourage the idea of routinely maintaining health through periodic clinic visits and the development of life-long healthy habits.

Increased Outreach and Access for Diabetes, Mental Health, and Substance Abuse

- Use evidence-based practices to deliver information and improve care for diabetes, mental illness, and substance abuse.
- Identify providers interested and able to provide culturally competent care. Then provide this list to the community, perhaps in conjunction with a Web portal that would allow for provider reviews and community feedback.
- Create and implement a long-term plan to recruit and train more American Indian providers.
- Draft a plan for raising awareness among Twin Cities American Indians about prevalence, prevention, and treatment of diabetes, mental health, and substance abuse issues

Transportation

• Improve the current transportation system so that it can better provide elders with extensive shuttle services to all health care appointments, inner-city patients who might need specialty care in the suburbs, and emergency transportation services to American Indians who are disabled, homeless, severely mentally ill or chronic alcoholics.

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Health Information Technology Solutions and Future Research

- Integrate electronic health records among providers who provide care to American Indians, particularly regarding labs and screenings, medication lists and compliance, hospitalizations, discharge plans and basic data.
- Improve the sharing of information among providers caring for American Indian patients.
- Improve data collection for tribal affiliation to better understand health care usage patterns and tribal needs.

Ultimately, to be effective, any mode of health care service delivery must bridge communication gaps and build trust. The results of this study must be considered in the context of broader social and political issues, including historical traumas, tribal enrollment and eligibility for services, and distrust of the system. Further input from the American Indian community is needed on all of these proposed solutions.

Background

During the first special session of the Minnesota Legislature in 2011, funding was appropriated from the general fund for "a needs assessment for a health clinic or other health care needs of the White Earth Tribe in the Twin Cities metropolitan area" (S.L. 2011, 1st Special Session, Ch. 9, Sec. 4, Subd. 3). Based on anecdotal reports of unmet health care needs among this population, White Earth Nation lobbied the Minnesota Legislature to appropriate funds for this study.

In December 2011, Wilder Research was contracted by the Minnesota Department of Health (MDH) to conduct this needs assessment. MDH and White Earth Nation expanded the scope of the study to include other American Indians in the Twin Cities. Therefore, the target population for this study is: White Earth Nation members and other American Indians who live in and/or seek health care services in the seven-county Twin Cities metropolitan area. The following research questions are addressed by this study:

- How many members of the target population live on a Minnesota Native Reservation, in particular White Earth, and how many live in the Twin Cities? What are the migration patterns between the reservation(s) and the Twin Cities?
- What is the overall health status of the target population? What are the health care service use patterns of the target population? How many receive their health care services at tribal and/or IHS facilities?
- What are the critical cultural issues that should be considered when developing a new clinic and/or service(s) for the target population?
- What are the unmet health care needs among the target population? What are the challenges to accessing appropriate services?
- Is there a need for a new comprehensive primary care clinic for White Earth Nation members or descendants or other Tribal Populations in the Twin Cities area? What other health care services are needed by this population?

Social and Political Context

The results of this study must be considered in the context of several broader issues, such as historical traumas, unique Indian health services, national health care reform, and the need for a population-wide solution. First, American Indian people have experienced significant traumas related to the invasion of their homeland and their forced removal to reservations. Those historic events resulted in drastic lifestyle changes and behavior patterns in American Indian communities that are reflected in current health and social issues. This topic that is beyond the scope of this study, but is worthy of mention, since many study participants reflected on it when asked about their health care needs. Any proposed solutions should take into consideration the past experiences American Indians have had with health care services and institutions.

"The health system needs to address historical trauma and health issues in the Native American community. I don't discuss historical trauma I face because people tell me I make it up, or am not believed, or people just don't want to hear it." – an elder

"The residue of the way the U.S. government and Indian relations happened...It may be five generations, which is not that long a time for something like that to be erased from the cultural memory. Being an Indian carries with it enormous baggage. Every Indian knows they are the descendant of a survivor...There is the self-image of Indian people. Then there is current Indian life which, for most, is poverty." – a health care provider

Second, American Indians are eligible for certain services because of their unique status in relation to the federal government. This eligibility is often tied to tribal enrollment, but many providers and even tribal members are unclear about eligibility requirements or the availability of these services. The American health care system is already complex, and American Indians confront an additional level of complexity due to due to the sovereign status of American Indian Tribes. The responsibilities and capacity of the federal Indian Health Service is another complicating factor. See Appendix C for more background information about health care coverage among the target population, including information about Indian Health Service (IHS), and American Indian access to other state and federal health care programs.

Third, the U.S. Federal Affordable Care Act (ACA) provides specific provisions which have the potential to improve health care coverage and health care service availability for American Indians. For example, the ACA makes permanent the Indian Health Care Improvement Act (IHCIA), which provides funding for health care for American Indians through Indian Health Service (IHS). ACA also expands federal authority to fund new and ongoing mental health and home and community based services (HCBS), demonstration programs to address critical healthcare workforce shortages, patient travel costs, and urban health programs for American Indians. See Appendix D for more information about how health care reform may impact access to care among the target population.

Finally, there was a consensus among many health care providers that this study should focus on the entire American Indian population of the Twin Cities rather than the White Earth Nation specifically.

Methods

Several approaches were used to gather information about the target population to address the research questions. First, information was gathered from existing health-related research studies and population-based data sources, including the following:

- The U.S. Census Bureau for the most current population-based estimates, and American Community Survey to describe demographic characteristics such as age, gender, migration, income, disability status, and health care coverage (see references).
- The Minnesota Chippewa Tribe's (MCT) enrollment list, for White Earth members living in the Twin Cities, provided to Wilder by MCT in January 2012.
- A study of health disparities and barriers to health care utilization that was conducted by the University of Minnesota School of Public Health for the Minnesota Department of Human Services, which includes information from a statistically representative sample of American Indian adults and children who are enrolled in one of Minnesota's public health insurance

programs: Medicaid, Medical Assistance, MinnesotaCare, or General Assistance Medical Care. (Wilder Research was contracted by the University of Minnesota to conduct this survey.) See Appendix A for detailed tables from this data set. The data reported here were provided directly to Wilder Research from the University of Minnesota after receiving permission from the Minnesota Department of Human Services. The publicly available report was used to obtain comparison data from all racial/ethnic groups (Minnesota Department of Human Services, 2009).

- Indian Health Service's Government Performance and Results Act (GPRA) data. This data source contains measures of IHS performance from the standpoint of both the Office of Management and Budget (OMB) and Congress. It includes detailed health measures and indicators for chronic disease that are predictors of overall health status. These measures are reported annually. See Appendix B for detailed tables from this data set. These data were provided directly to Wilder Research from IHS on request.
- The Survey of the Health of Adults, the Population and the Environment (SHAPE) is a survey conducted with adult residents of Hennepin County every four years. SHAPE asks residents about their health status, behaviors, health care utilization, and social and environmental factors that influence their health. The 2002 survey oversampled communities of color, allowing the data to be reported by six major racial/ethnic groups including American Indians (the subsequent surveys in 2006 and 2010 did not provide this tabulation). Data from this study were obtained through publicly available sources (Hennepin County Community Health Department, Bloomington Division of Public Health, 2003).
- Information about the American Indian population and other racial/ethnic groups that is publicly available from the Minnesota Department of Health's Center for Health Statistics (Minnesota Department of Health, Center for Health Statistics, 2009).

Second, researchers interviewed 21 health care providers and others familiar with the health status and health care needs of the target population. The majority are leaders of healthcare organizations that provide direct services to American Indians or work on the behalf of American Indians. Two key informants focus specifically on health care for White Earth Nation members. The key informants were asked about the target population's health status and health care utilization, availability of health care services, challenges or barriers to accessing available services, gaps in available services, and recommendations or opportunities for expanding or enhancing existing services. See Appendix E for more information about the informants and the complete interview script.

Third, 69 White Earth Nation members and 45 other American Indians were asked about their health care needs and preferences during 10 listening sessions held in January and February 2012. Wilder Research collaborated with individuals and organizations that had strong connections to the American Indian community in the Twin Cities. In some cases, staff of these organizations co-facilitated and took notes.

The research team divided the listening sessions into four homogenous target demographics: elders, families with children, older adults, and young adults. Participants were asked four broad thematic questions that allowed Wilder Research to

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- identify a list of places and people that participants visit to stay healthy;
- assess the barriers and challenges that make it difficult for participants to be healthy, and
- develop recommendations that are responsive to the experiences of members of the American Indian community.

Participants also completed a post-survey that identified their age, tribal affiliation, health insurance status and provider, primary and secondary residences, and people or places where they access health and wellness care. All participants were given the option to receive a summary report of the findings. See Appendix F for more information about participants and host organizations, as well as for the listening session protocol and post-survey.

Limitations of this study

This study has two important limitations. First, it was completed in a short timeframe that limited follow-up in order to validate the findings and recommendations. Additional efforts are recommended to inform study participants and the American Indian community about the key findings and recommendations, after the report is released to the Legislature.

The second major limitation of this study is its over-emphasis on the subset of American Indians who live in the inner cities and who are poor and on public insurance or uninsured. The over-emphasis on this sub-group happened for three reasons.

- It was assumed that this sub-group has more significant unmet health care needs, so it was agreed a priori to focus more heavily on this sub-group.
- Community members who participated in this study were recruited through community-based organizations in Minneapolis and Saint Paul, and these organizations serve mainly inner city residents.
- One rich source of data that was used for this study, the 2008 health disparities study from the Minnesota Department of Human Services, included only those American Indians who are publicly insured.

The 2008 disparities study addressed many of the research questions included in this needs assessment, but unfortunately, no corollary data sets exist for American Indians who are uninsured or those who have private, employer- or union-based insurance. The main caution when interpreting the findings is that they do not thoroughly reflect the circumstances of suburban American Indians with middle- or upper-incomes and private insurance. Because the U.S. Census does, in fact, show a high rate of uninsured American Indians in suburban Hennepin and Ramsey counties (more details in Health Insurance Coverage section below), a more thorough investigation of the health care needs of this sub-group of American Indians may be warranted.

In each of the following sections of this report, information was obtained using a variety of methods and from multiple data sources, as described above. In many cases, information is only

available about one sub-group (e.g., American Indians in the Twin Cities who are enrolled in one of Minnesota's public health insurance programs) that may not be available for other groups or the entire target population. In other cases, information is only available for sub-groups that include some members of the target population as well as other American Indians outside of the target population (e.g., enrolled White Earth members who used Indian Health Service during the most recent reporting period, who may be mostly from the reservation and some from the Twin Cities). In most cases, quantitative and qualitative information can be triangulated to indicate a clear pattern, trend, or theme in terms of the health care needs of the target population.

Defining the Target Population

The target population for this study is White Earth Nation members and other American Indians who live in and/or seek health care services in the Twin Cities metropolitan area. This study defines the Twin Cities metropolitan area as the seven counties of Anoka, Carver, Dakota, Hennepin, Ramsey, Scott, and Washington.

About 3,563 White Earth Nation members live in the seven-county Twin Cities metropolitan area, according to Minnesota Chippewa Tribe's list of enrollees by current/last known address, as of January 2012.

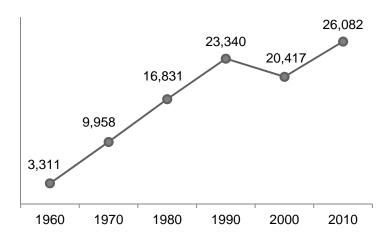
1. Enrolled White Earth Nation members living in the Twin Cities

	Number	Percent
Cities of Minneapolis and Saint Paul	1,675	47%
Suburban Twin Cities (all but Minneapolis and Saint Paul)	1,888	53%
Total	3,563	100%

Source(s): Minnesota Chippewa Tribe (January 2012).

White Earth Nation members represent about 14 percent of the American Indians living in the Twin Cities. According to the U.S. Census Bureau, 26,082 American Indians live in the Twin Cities (as of 2010). Except for the period 1990-2000, the size of the American Indian population in the Twin Cities has grown steadily since 1960. American Indians make up about 1 percent of the total population in the Twin Cities (Minnesota Compass, 2012).

2. American Indian population in the Twin Cities, 1960 – 2010

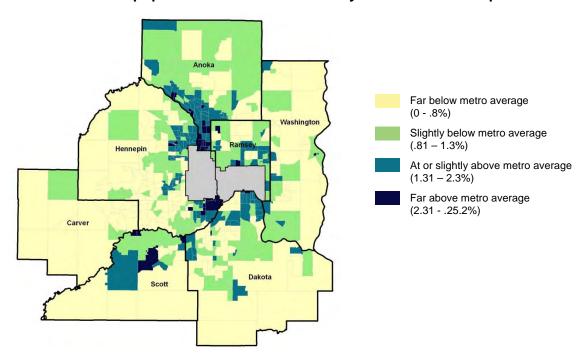


Source(s): 2000 and earlier: U.S. Census Bureau, Decennial Census. 2010: U.S. Census Bureau, Population Estimates (as of April 1, 2011).

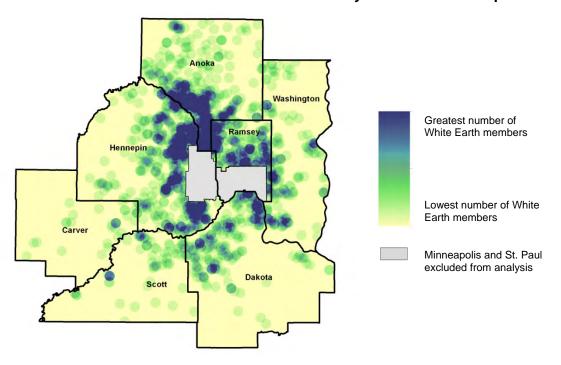
Note(s): Prior to 2000, the Decennial Census allowed individuals to select only one race, with the result that some multiracial people may have been counted only as white. In 2010, the Census Bureau's Population Estimates program reclassified individuals in the "some other race" category into one of the five standard race categories. In most counties, this change results in the number of American Indians being slightly larger than it would otherwise have been.

A significant proportion of the American Indian population in the Twin Cities lives in South Minneapolis – especially in five zip codes: 55404, 55406, 55407, 55418, and 55421. The distribution of White Earth Nation members follows a very similar pattern to the distribution of all American Indians in the Twin Cities. However, it appears that White Earth Nation members may be less likely to live in the West Side and West Seventh neighborhoods of Saint Paul and Near North in Minneapolis.

3a. American Indian population in the seven-county Twin Cities metropolitan

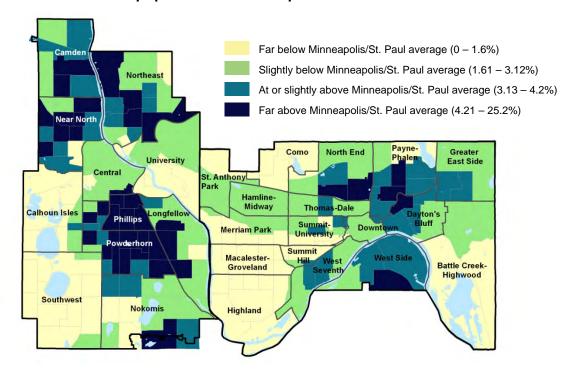


3b. White Earth Nation members in the seven-county Twin Cities metropolitan area

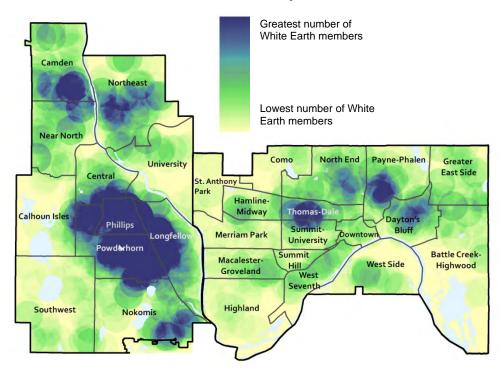


Source(s): 3a: U.S. Census Bureau, 2010 (as of April 1, 2011), and 3b: Minnesota Chippewa Tribe (January 2012).

4a. American Indian population in Minneapolis and Saint Paul



4b. White Earth Nation members in Minneapolis and Saint Paul



Source(s): 3a: U.S. Census Bureau, 2010 (as of April 1, 2011), and 3b: Minnesota Chippewa Tribe (January 2012).

Demographic Characteristics

The latest information available from the U.S. Census Bureau shows a relatively static distribution of age and sex across the region for American Indians. There are significant differences in socioeconomic status, however. For example, nearly half of the American Indian persons residing in Minneapolis and St. Paul are in living in poverty (under 100% of the federal poverty threshold in 2010), compared with one-quarter of the total population in the same area. This pattern is also present in the suburban areas of Hennepin and Ramsey counties, where the poverty rate for American Indians is almost three times that of the total population (29% vs. 10%). These differences are less dramatic in Anoka, Carver, Dakota, Scott, and Washington counties – where 13 percent of American Indians are at or below poverty compared with 7 percent of the overall population.

5. Age and gender of American Indians¹ by region

	Minneapolis and Saint Paul cities	Suburban Hennepin and Ramsey counties	Anoka, Carver, Dakota, Scott, and Washington counties
Males	45%	50%	36%
Females	56%	50%	64%
Under 18 years	42%	28%	37%
18 – 24	14%	7%	15%
25 – 34	9%	11%	9%
35 - 54	25%	40%	24%
55 – 64	7%	9%	14%
65 years old +	4%	6%	2%

6. Poverty status of American Indians¹ by region

	Minneapolis and Saint Paul cities		Suburban Hennepin and Ramsey counties		Anoka, Carver, Dakota, Scott, and Washington counties	
	American Indian	Total Population	American Indian	Total Population	American Indian	Total Population
Under 50% of poverty threshold	26%	15%	21%	5%	8%	3%
51-100%	23%	12%	8%	5%	5%	4%
101-200%	30%	18%	22%	13%	42%	11%
Over 200%	22%	55%	50%	77%	45%	81%

Source(s): U.S. Census Bureau, Decennial Census; Integrated Public Use Microdata Series from the U.S. Census Bureau, American Community Survey.

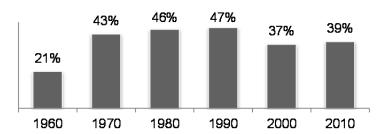
Note(s): 1 American Indian in this table was defined using a bivariate indicator of whether a person's race or races include "American Indian or Alaska Native."

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Migration Between the Twin Cities and the Reservation

Since the 2000 Census, nearly 4 out of 10 American Indians in Minnesota live in the Twin Cities. The proportion grew steadily from 1960 through 1990, but between 1990 and 2000 it decreased by about 10 percent.

7. Proportion of all American Indians in Minnesota who live in the Twin Cities, 1960 – 2010



Source(s): 2000 and earlier: U.S. Census Bureau, Decennial Census. 2010: U.S. Census Bureau, Population Estimates (as of April 1, 2011).

Note(s): 1 Prior to 2000, the Decennial Census allowed individuals to select only one race, with the result that some multiracial people may have been counted only as white. In 2010, the Census Bureau's Population Estimates program reclassified individuals in the "some other race" category into one of the five standard race categories. In most counties, this change results in the number of American Indians being slightly larger than it would otherwise have been.

Because tribal affiliation is not specifically defined in the Decennial Census, it was not possible to determine if the migration pattern for White Earth Nation members parallels the pattern for all American Indians in Minnesota. But there is not any reason to believe that the city-reservation migration pattern for White Earth Nation members significantly differs from the overall population of American Indians in Minnesota.

There is some degree of migration between the Twin Cities and the reservation for the purposes of seeking health care services. The main reasons cited included lack of coverage or inadequate coverage and the desire to seek care from a trusted and more culturally responsive provider. Conversely, need for specialty care and a desire for more confidentiality were cited as reasons why American Indians from the reservation may seek care in the Twin Cities.

However, providers had different impressions about how frequently American Indians travel back and forth for health care.

About one-third of the providers who were interviewed for this study said migration for health care reasons occurs frequently.

"I think there is a lot of going back and forth seeking service from the tribal health service. I think a lot of it is due to that there are a lot of people uninsured or underinsured. And then the whole cultural piece of people wanting to go back to their reservation, seeing the clinics there as being more available to them and more responsive to their cultural needs.." – a health care provider

Another third of providers said that some American Indians in the Twin Cities may travel back and forth between the reservation and the Twin Cities for health care reasons, but that this probably does not occur very often.

"I think it [migration back to the reservation for health care reasons] used to be more frequent than it is today. Even seven or eight years ago, you used to be able to go home [to the reservation], be seen at the clinic, and get your medicine. But now the reservations have set up residency requirements, so you have to be on the reservation for a period of time before you can be seen in the clinic." – a health care provider

Some providers noted that funerals, pow-wows, holidays, and family celebrations might be other reasons that people travel between the reservation and the Twin Cities, and that sometimes people just happen to need health care while they are traveling.

"My general perception is that people come and go a fair amount, because of things like funerals, other family reasons, kids going to live with someone. I don't remember anyone ever saying they just came here for their health care or to get to a clinic." – a health care provider

The topic of traveling back and forth between the reservation and the Twin Cities specifically for health care reasons came up in almost all of the listening sessions (in some cases prompted by the facilitator). Inability to pay for care or even for co-pays, coupled with eligibility for free services through IHS on the reservation, forces some of the listening session participants to travel to their home reservation to receive needed care. Most of the listening session participants who did travel from the Twin Cities back to their home reservation for care specifically mentioned being able to get lower-cost or free eye glasses. However, many listening session participants also noted that it is not practical, especially if you do not have a car, to go to White Earth for health care. (It is about a four and a half hour drive from the Twin Cities to White Earth.)

"In the Cities, even if you have a pretty decent income, it is hard to make ends meet and pay for your co-pay or deductible. For these reasons, sometimes, we're forced to go to the reservation to seek these services." – a listening session participant

In terms of the impact of migration on their ability to provide high quality care, the providers who were interviewed for this study feel that treatment for chronic conditions particularly suffers.

"Continuity and medication and follow up can get lost in that whole thing. Or puts a big burden on providers who are very conscientious to track down everything." – a health care provider

Health Status

Overall health status of the target population, including White Earth Nation members and other American Indians in the Twin Cities, is significantly worse than the general population, according to . the combination of secondary data sources, qualitative data gathered for this study, and anecdotal information.

Self-Reported Health Status

Health status was measured by asking people to self-report their health on a scale that includes the response options: excellent, very good, good, fair, and poor.

8. Self-reported overall health status of various groups

	American Indians in Hennepin County ^a (N=221)	Adult American Indians in the Twin Cities who are publicly insured ^b (N=194)	Child American Indians in the Twin Cities who are publicly insured ^b (N=155)	Hennepin County residents of all races ^a (N=9,917)	Minnesotans of all races who are publicly insured ^b (N=4,588)	Adults of all races in Minnesota ^c (N=1,987)
Health is good, very good, or excellent	71%	64%	98%	91%	84%	89%
Health is fair or poor	30%	36%	2%	9%	15%	11%

^a Source: Hennepin County, 2003.

^b Source: Minnesota Department of Human Services, 2009; and additional analyses conducted by the University of Minnesota School of Public Health for this study.

^c Source: BRFSS, 2010.

These results show that American Indians are more likely to perceive their own health as fair or poor compared with how the general population rates its health. American Indians in Hennepin County, and in particular American Indians in the Twin Cities who are publicly insured, are about three times as likely as people of all races to say their own health is fair or poor.

American Indians in Hennepin County also report a higher number of days in which their health is not good compared with people of all races.

9. Self-reported number of days health is not good

	Minnea	apolis	Hennepin County		
	American Indian All races		American Indian	All races	
In the past month, physical health not good for 14 or more days. **	14%	8%	20%	7%	
In the past month, the average number of unhealthy physical health days.	4.4 days	2.9	5.8 days	2.5	

Source(s): Hennepin County Community Health Department and Bloomington Division of Public Health. SHAPE 2002: Racial and Ethnic Data Book, Survey of the Health of Adults, the Population and the Environment. Minneapolis, Minnesota, March 2003.

Note(s): "Indicates a statistically significant difference between American Indians and All races.

Health Indicators

Another indicator of overall health status is mortality rate. There are significant disparities between American Indians and whites in mortality rates at every age level. The death rate for American Indians is two and a half to three and a half times greater than the death rate for whites in age groups under 65 years old. The disparity in the 25 to 44 year old group is especially pronounced (Minnesota Department of Health, 2009).

Another way of describing health disparities is looking at Years of Potential Life Lost (YPLL), which measures premature mortality, defined as the total sum of years of life lost annually to persons who suffered early deaths before age 65. The YPLL rate for American Indians is nearly twice that of whites. Furthermore, all other racial/ethnic groups experienced declines over 9 percent in YPLL rates from the early 1990s to the mid-2000s, whereas for American Indians the change was only -0.5 percent (Minnesota Department of Health, 2009).

Finally, the U.S. Census Bureau measures several health status indicators that are particularly relevant for older adults. These include measures of cognitive difficulty, ambulation, independent living, self-care, and vision or hearing problems. Across most of these measures, American Indians are more likely to experience problems compared with the total population. It is particularly notable that American Indians in suburban Hennepin and Ramsey counties are at least twice as likely to experience these problems compared with the total population in the same geographic area.

10. Selected health status indicators of American Indians¹ by region

	Cities of Minneapolis Suburban Hennepir and Saint Paul and Ramsey countie		•	Dakota,	Carver, Scott, and on counties	
Percent who have problems with	American Indian	Total Population	American Indian	Total Population	American Indian	Total Population
Cognitive difficulty ²	9%	7%	8%	4%	8%	4%
Ambulatory ³	7%	6%	11%	4%	4%	3%
Independent living ⁴	4%	5%	12%	4%	5%	3%
Self-care ⁵	3%	3%	8%	2%	3%	2%
Vision or hearing ⁶	3%	4%	10%	4%	3%	3%

Source(s): Integrated Public Use Microdata Series from the U.S. Census Bureau, American Community Survey.

Note(s): 1 American Indian in this table was defined using a bivariate indicator of whether a person's race or races include "American Indian or Alaska Native."

- ² Cognitive difficulties include learning, remembering, concentrating, or making decisions because of a physical, mental, or emotional condition.
- ³ A condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying.
- ⁴ Any physical, mental, or emotional condition lasting six months or more that makes it difficult or impossible to perform basic activities outside the home alone. This does not include temporary health problems, such as broken bones or pregnancies.
- ⁵ Any physical or mental health condition that has lasted at least 6 months and makes it difficult for them to take care of their own personal needs, such as bathing, dressing, or getting around inside the home. This does not include temporary health conditions, such as broken bones or pregnancies.
- ⁶ A long-lasting condition of blindness, deafness, or a severe vision or hearing impairment. "Long-lasting" is not defined in the questionnaire.

Health Insurance Coverage

American Indians are less likely to have health insurance compared with the overall population of the Twin Cities, according to the U.S. Census Bureau, American Indians living in suburban Hennepin and Ramsey counties have a particularly high uninsured rate.

11. Health insurance coverage of American Indians¹ by region, 2010

	Cities of Minneapolis and Saint Paul		Suburban Hennepin and Ramsey counties		Anoka, Dakota, Carver, Scott, and Washington counties	
	American Indian	Total Population	American Indian	Total Population	American Indian	Total Population
Any kind of health insurance	83%	86%	69%	92%	89%	93%
Public health insurance	61%	33%	41%	25%	36%	20%
Medicaid	57%	24%	36%	12%	31%	10%
Private insurance	35%	61%	38%	80%	59%	83%
Employment- or union-based	32%	52%	31%	67%	53%	73%
Indian Health Services	23%	1%	7%	<1%	4%	<1%
Insurance purchased directly	11%	12%	7%	16%	9%	13%
Medicare	7%	11%	6%	15%	4%	11%
Veterans Administration	1%	2%	1%	2%	2%	2%
No health insurance	17%	14%	31%	8%	11%	7%

Source(s): Integrated Public Use Microdata Series from the U.S. Census Bureau, American Community Survey.

Note(s): ¹ American Indian in this table was defined using a bivariate indicator of whether a person's race or races include "American Indian or Alaska Native."

Public Verses Private Coverage

American Indians are nearly twice as likely as the total population to have public health insurance and are also significantly more likely to have Medicaid. American Indians are also far more likely to have insurance through Indian Health Services (IHS) compared with the total population. Conversely, American Indians are less likely than the total population to have individually-purchased private insurance or employer- or union-based insurance. American Indians are also less likely to have Medicare.

Data are not available specifically for White Earth Nation members to address the questions of whether or not they are insured and, if so, what type of insurance they have. However, there is no reason to believe that the overall rate of being insured, nor the type of insurance held, is different for White Earth Nation members compared with the overall population of American Indians in the Twin Cities.

Effects of Being Uninsured

Lack of insurance and being under-insured among the target population often results in not getting needed health care. The issue of not having a primary care provider because of lack of insurance appears to be particularly prevalent among young adults in the American Indian community.

"[Facilitator: Where do you go to stay healthy?] I don't go anywhere because I don't have health insurance." – a young adult

"I take care of myself. I don't want to pay. If I have something broken, I go to the hospital." – a young adult

"I apply at [local clinic] for sliding-scale-fee and also for the [local pharmacy] to apply for MinnesotaCare, and I never pass that. That makes it hard. According to poverty guidelines, I don't qualify. People who live above their guidelines still struggle like me, so I must go without insurance. They keep accepting me at [clinic] so I will keep going there. If I don't have a co-pay, I can keep my appointments..." – an elder

"One of the things we do in our case management program is to work with our clients... [so they can get] state reimbursement of the premium for health care insurance. But people have to make sure they fill [the paperwork] out and get them in. I think they have access [to primary care]. If you can stay on top of things and maneuver the system, then you have access. If you are on public funds, there are forms to fill out every month, or you get cut off and have to start out all over again... People living in shelters or with other people or unemployed – that creates some challenges for people..." – a health care provider

In 2002, one-quarter (25%) of American Indians in Hennepin County who said they needed medical care were not able to receive the care they needed. When asked about the main reason they did not get or delayed getting needed care, half (48%) cited a lack of insurance and/or cost of the services (compared with 28% of adults of all races who were unable to get needed care) (Hennepin County Community Health Department, Bloomington Division of Public Health, 2003).

Nearly half of adult American Indians in the Twin Cities who are enrolled in one of Minnesota's public health insurance programs, and nearly one-quarter of parents of American Indian children, said they are worried that their insurance will not cover needed care. Many of these individuals also indicated that they are not sure if they have been dropped from their public health insurance. See Figure A3 in Appendix A.

A couple of providers specifically described how the high uninsured rate impacts their organizations financially.

"Probably one of the largest things that overshadows everything is the socio-economic things. Our uninsured rate is about 40 percent. We do a lot of uncompensated care – providing medicines, primary care, screenings, a glucometer, dietician, etc. We do bill for it, but we don't necessarily collect for it. It is nearly \$1 million yearly of uncompensated care that we provide." – a health care provider

Cost of services is a huge barrier for those who are uninsured and those with inadequate insurance. American Indians in the Twin Cities who are on public health insurance reported significant barriers in the areas of cost of care. About half of those adults and about one-quarter of parents of those children were worried they would have to pay more for care than they could afford, or that they will be asked to pay more than they were told to expect. Nearly 4 out of 10 of those adults were also concerned that their prescription medications would cost too much. See Figure A13 in Appendix A.

Lack of coverage among the target population can only be understood within the broader socioeconomic context that American Indians are more likely to be uninsured because they are more likely to be poor. Nearly one-third (30%) of American Indians in the metropolitan area were living below the poverty line in 2012 compared with just 7 percent of white residents (Minnesota Compass, 2012).

Several health care providers and many community members who participated in this study suggested that socioeconomic factors, and related insurance coverage issues, are the most pressing health care challenges facing this community.

"Insurance [is the community's biggest need]. I had an emergency a few weeks ago. I went to one clinic and because I didn't have insurance they wouldn't take me. I had to call around to find someplace to take me and when I got there and I had to pay \$90 up front." – a listening session participant

Health and Wellness Activities

There is a lack of health and wellness activities in the American Indian community in the Twin Cities related to this population's generally worse health outcomes and poorer health status. Nutrition and obesity were the most frequently mentioned wellness issues. Lack of exercise is also commonly noted as a health concern for American Indians.

American Indian community members who participated in this study clearly recognized a need for more individual and community attention to nutrition and physical activity. Many community members acknowledged a need to eat better or get more exercise, but most also talked about the barriers they face in actually doing these things. The cost of healthy food is the most significant barrier in the community with regard to nutrition. Many participants also noted the relative convenience of fast food compared with healthy food, both in terms of lifestyle (busy schedules, not wanting to cook, etc.) and in terms of geographic proximity in their neighborhoods.

"Regular food verses organic is very expensive. Prices are astronomical. Cost gets in the way of us eating healthy." – a listening session participant

"When you try to stay healthy and you are too lazy to cook it is easy to stop at a fast food place, because they are all around here." – a young adult

"I want to blame my parents, too. We had to eat whatever was for dinner or not eat, and we had to finish what we were given, because they said there were starving kids in Africa. All of our get-togethers were food based. If I got a good report card we got to go to Pizza Hut, so I have carried that into my adult life." – a young adult

"People talk about eating healthy, but you eat what is on sale. That is what determines how you eat, not some chart that tells you what is best for you." – an elder

"It takes a lot of money to get healthy. Gym memberships are crazy! Everyone wants to promote a healthy lifestyle but it is impossible to obtain." – a young adult

A few participants noted the lack of knowledge of how to prepare healthy foods. A frequent desire expressed by community members and providers is to have access to and learn how to prepare traditional foods as a way of adopting a more healthful diet for themselves, their families, and their community. Many participants also talked about the importance of including the family and opportunities for combining socializing and exercise.

"[People also eat too much] fry bread. But people on the reservation are pushing for us to eat what our ancestors ate, like fish, meats, wild rice." – elders listening session

"Classes, maybe a fitness center, working with a physical trainer. A lot of them could never afford it. If they had access to things like that, it would improve their health greatly, and once you improve the health of a couple of people in the family, it kind of goes through the family." — a health care provider

"Again, the preventive health care services could be much more available. Like weight, and getting diabetes. We have always been weighing people. Homeless people we see have too high a body mass index. I don't see many programs, other than diabetes programs, that are dealing with this, and those are actually too late." – a health care provider

"I think lifestyle is going to have to be big – eating, diet, nutrition. If they could go back to eating Native food – berries, dried berries, Native meat rather than processed meat." – a health care provider

It is important to consider how to create incentives for healthy behavior and disincentives for unhealthy behavior among the target population. It appears that existing programs have not done this well. One provider noted that many of the American Indians served by their organization request rides (transportation assistance) to places that are easily within walking distance, adding how this behavior pattern contributes to long-term health problems.

"I give rides all the time to the clinics and the pharmacy, but they are only a few blocks away. We have bikes to rent out, but that never really took off. I can't get anyone to go to the new fitness center. We even had to drive them to the grand opening. The fitness center is only about four or five blocks away. We have [a local American Indian school], which is only about 3 blocks away, and people want rides there, too." – a health care provider

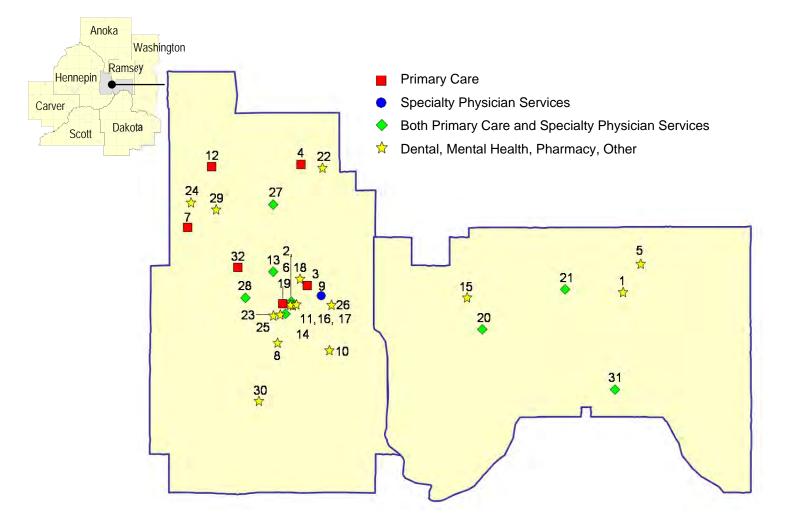
A few of the American Indian community members who participated in this study talked about the need for people in their community to take more initiative regarding their own health and the health of their families. Some participants discussed this in general as something all people should do, and others talked about barriers such as untreated mental health issues, poverty, and lifestyle, that prevent American Indians in particular from being more proactive about their health.

"Self-education is needed for all of the types of health. You need to know how to be physically, spiritually, and mentally healthy. It is not just something that happens by chance." – an elder

Health Care Services Available to American Indians in the Twin Cities

A list of all of the Federally Qualified Healthcare Centers (FQHCs) in the Twin Cities is included in Appendix G. These clinics and other Community Health Clinics are also shown in the map in Figure 12. In addition, other health care services that were mentioned by listening session participants and/or health care providers who were interviewed as a part of this study were also added to this map and to the list in Appendix G. This list is not an exhaustive list of all health care providers that serve American Indians in the Twin Cities. Rather, it is a list of the providers that are most likely to serve the members of the American Indian population in the Twin Cities who have the greatest unmet health care needs. It is important to note that only one of these 30 providers fell outside of the cities of Minneapolis and Saint Paul.

12. Federally Qualified Healthcare Centers (FQHC) in the Twin Cities



Health Care Service Use Patterns and Needs

No one data source is available that can address the questions about health care service usage patterns for the target population. However, information from a variety of sources all points to the fact that American Indians have differences in health care service usage compared with the general population.

For example, American Indians are less likely than other racial/ethnic groups in Hennepin County to have a regular doctor or provider they always see for their primary care needs. In addition, it appears that American Indians are more likely than the general population to use hospitals and emergency rooms to meet their health care needs. See Figure 13.

No data are available that specifically show health care service usage patterns for White Earth Nation members in the Twin Cities, although we have no reason to believe this population would have a significantly different pattern than American Indians in general.

13. Use of various types of health care settings, 2002

When the same side of the same side of the same	Minnea	polis	Hennepin County	
When you are sick or need advice about your health, which one of the following places do you usually go?	American Indian	All races	American Indian	All races
Doctor's office clinic/public health clinic/community health center	54%	81%	64%	85%
Hospital outpatient department	21%	3%	17%	2%
Hospital emergency room	9%	3%	7%	2%
Urgent care center	3%	5%	3%	7%
Some other kind of place	9%	4%	7%	3%
No usual place	4%	4%	3%	3%

Source(s): Hennepin County, March 2003.

Note(s): Figures in italics should be interpreted with caution due to high confidence intervals in weighted survey data.

Of American Indians who are publicly insured, adults were most likely to report using a doctor's office or clinic (64%), an Indian Health Center (11%), or an outpatient clinic in a hospital (6%). These publicly insured American Indians in the Twin Cities are somewhat less likely than all American Indians in Hennepin County to use a hospital emergency room. See Figure A4 in Appendix A.

Preventive and Primary Care

Most American Indians in the Twin Cities value primary care from a medical doctor as well as other types of health and wellness activities, to keep them healthy. Nearly 9 out of 10 parents of American Indian children in the Twin Cities on public insurance and three-quarters of adult American Indians in the Twin Cities on public insurance said visiting a doctor for a regular check-up or exam is "very important" in keeping them/their child from getting sick (see Figure A14 in Appendix A). Participants in most of the listening sessions mentioned things like "going to the doctor for a check-up" when asked about what keeps them healthy.

"I keep my family healthy by making sure my kids are up to date with preventative medicine and immunizations." – a listening session participant

Overall, it appears that American Indians in the Twin Cities report receiving regular physical exams at a rate similar to other racial/ethnic groups. In 2002, about 6 out of 10 American Indian adults in Hennepin County reported having a complete physical exam within the past year, which was similar to the rate for whites and Asians. Hispanics had slightly lower rates and African Americans/blacks had slightly higher rates (Hennepin County Community Health Department & Bloomington Division of Public Health, 2003).

American Indians in the Twin Cities who are enrolled in public insurance are *more* likely than the overall population of American Indians in Hennepin County to be receiving regular primary care. About 8 out of 10 American Indians (both adults and children) in the Twin Cities who are enrolled in one of Minnesota's public health insurance programs said they had been to see a doctor or clinic for regular or routine care within the past year. See Figure A5 in Appendix A.

However, health care providers and community members very frequently noted the less than ideal circumstances within which primary care is provided. Many of the American Indian community members who participated in this study talked about long wait times once they arrived at their primary care clinic, as well as being sent to other sites for X-rays and other basic tests. And one provider who was interviewed for this study indicated that lack of access to primary care is a problem for American Indians who need specialty care, specifically because certain specialty care providers often require a referral from a primary care provider.

"There are limits on both ends, tribal and Twin Cities, in being able to provide preventative services. People are going to most often go when they are sick. There is not enough effort, on any part, to provide preventive services. It is not just the hospitals and clinics, but the whole system. That is true not just for the reservation, but also for health care in the Twin Cities, where we could move upstream to prevent some of these catastrophic illnesses that people are experiencing." – a health care provider

"X-rays are 'specialty care' in the clinics intended for Natives. I could understand if we needed specialty heart or lung care, but X-rays? Come on. Being shuttled from one health care location to the next is not ideal for someone who is sick." – a listening session participant

Traditional Healers and Healing Practices

Traditional healing practices and traditional medicine are an important component of health for many American Indians in the Twin Cities. Visiting a spiritual healer is "very important" to about 2 out of 10 publicly insured American Indian adults and 1 out of 10 parents of publicly insured American Indian children. And visiting an alternative or complementary health care provider is "very important" to about 1 out of 10 of these adults and parents. See Figure A14 in Appendix A.

Many American Indians in the Twin Cities already use some form of traditional medicine or spiritual healing. American Indians in Hennepin County are far more likely to have seen a traditional or spiritual healer about their health in the past year than any other race/ethnic group in the county (about 20% vs. 4% of all adults – a statistically significant difference) (Hennepin County Community Health Department & Bloomington Division of Public Health, 2003).

Many of the American Indian community members who participated in this study expressed a desire for more access to traditional healers and traditional medicine (as well as the desire to eat more traditional foods as a way of improving the healthfulness of their diets, which is discussed in another section). Several also described the important role traditional healing plays in maintaining their health currently.

"We need more spiritual leaders. There are zero, none, opportunities for spiritual things in our life. It is such an important part of our lives, but we need to travel to do things like sweating and traditional things." – an elder

"I go to church and see a spiritual healer. They do a ceremony for me and make me feel better." – a listening session participant

"Traditional medicine is healthier, because you aren't taking all those drugs and supplements and vitamins, just using natural stuff." – a listening session participant

"We should have a medicine man on site [in the community]. I don't have a car, so I can't get to White Earth to see a medicine man." – a listening session participant

Dental Care

Access to dental care is a gap among the target population, primarily due to lack of insurance coverage for dental care and/or lack of awareness of eligibility/coverage for dental services. Indian Health Services (IHS) reports that slightly fewer than 4 out of 10 White Earth Nation members who received IHS services had a documented dental visit during their most recent reporting timeframe. This is slightly better than the rate of 3 out of 10 Bemidji Area IHS patients who had a documented dental visit in the past year (IHS, 2012). By contrast, 8 out of 10 Minnesota adults self-reported visiting a dentist in the past year (BRFSS, 2010). See Figure B2 in Appendix B.

Several listening session participants described situations in which they or their family members were expected to undergo dental procedures without pain medication. In one case the pain medication was in some cases unavailable at the clinic, and in other cases it was not covered by their insurance. Other community members were concerned about the quality of the dental care they received. There was widespread agreement among community members, especially those who are on public insurance, that they do not currently have access to the full array of dental services they need.

"[Talking about two local primary care clinics] The quality of their service is horrible... Both are under-resourced and don't always have all of the services. I once went to the dental clinic, and they ran out of Novocain. They gave me some cheap stuff to numb my mouth but it didn't work. It kicked in hours later when I got home." – an elder

"I go to [local clinic] for my dentures. They made the wrong size dentures and they wouldn't even fit in my mouth. They told me that I couldn't get another one for 7 years. They messed up, and that's not my fault. I don't have any teeth now, see? (laughs) What I really need is a cheap dentist to fix my mouth." – an elder

Among the publicly insured American Indians in the Twin Cities just under half of adults and 65 percent of children had been to the dentist in the past year (see Figure A5 in Appendix A). Of those who had received dental care within the past year, 27 percent of children and 41 percent of adults said it was either a "big problem" or "small problem" for them to get dental care. Of the children who did <u>not</u> receive dental care in the past year, by far the most common reason given by parents was that their child did not need to see a dentist (67%).

Other common reasons given by parents include: no time/inconvenient (11%), no dentist would accept the child as a patient (7%), and no appointments were available when they were able to go (5%).

Of the adults who did not receive dental care in the past year, the most common reasons given were that they did not need to see a dentist (22%) and no dentist would accept them as a patient (22%). Other common reasons given by these adults include: no appointments were available when they were able to go (14%), they could not afford it/no insurance (12%), no time/inconvenient (11%), and they did not know their Minnesota Health Care Program insurance included dental coverage (10%) (special analysis of 2008 health disparities study data conducted by University of Minnesota School of Public Health, January 2012).

Eye Care and Eye Glasses

Eye care, and in particular being able to get eye glasses, came up as an issue for some American Indian community members. This issue was especially salient to elders. It appears that going to Indian Health Service (IHS) to get eye glasses is one of the main reasons why American Indians from the Twin Cities may seek health care on the reservation instead of closer to home. Many community members mistakenly believe that public insurance and Medicare do not cover glasses. In fact, the 2011 Benefit sets for Medicaid and MinnesotaCare cover basic eyeglasses. In 2011, MinnesotaCare has a \$25 copay for some groups but not for all groups; children do not have copays for glasses. Medicare is more mixed with some managed care plans covering glasses. Fee-for-service Medicare does not cover glasses.

"The top priorities [to address health care needs in the community] are dental and glasses. One of the clinics has dental care but it is not sufficient. Glasses are a major problem and many of us need to go back to White Earth to simply get glasses. It needs to be understood that there is a relationship between diabetes and eyesight. Add age onto diabetes and people can barely even see. This is probably one of our greatest needs as elder Native people." – an elder

Prescription Medications

Affordable prescription medications is an issue in the community, as is the widespread use of and concern with the use of prescription pain medications for recreational purposes. Some providers, and several community members, perceive that American Indians are discriminated against specifically with regard to prescription pain medications.

"They will go out of their way to tell you they won't give you narcotics." – a young adult

There is one tribally-based pharmacy that operates in the Twin Cities, and was mentioned in every one of the listening sessions as a resource for community members. Several of the health care providers who were interviewed for this study also noted the benefits of having this resource in the community. On the other hand, some providers noted the disadvantage of American Indians who are not tribally enrolled not being able to use this pharmacy.

Specific Health Concerns and Specialty Care Needs

A variety of data sources indicate that there are specific health issues and problems that are much more prevalent among American Indians in the Twin Cities than in the general population. In particular, diabetes, mental health, chemical dependency, cancer, chronic diseases, prenatal care, tobacco use and tobacco-related health problems, and accidental injury and death are areas in which the largest gaps in care are observed.

All of the primary care providers who participated in an interview for this study and several of the other key informants also noted the need for specialty care in the community.

"Specialty care is an area that is difficult to fill. We don't get Contract Health Service (CHS) dollars, which the reservations or IHS has access to. If I were to send you to a specialist, you would be responsible for that [paying the medical bills]. We have been finding ways to do it, though. [A local hospital] will see our patients and will find another mechanism to bill them at a later date, or find other ways to do things." – a health care provider

"I am in clinic tomorrow. I have four or five openings tomorrow. But if I see patients who are uninsured and who need cardiac care, if there are no specialists accepting uninsured patients, we have a problem. I know the constraints of my practice. I would say that specialty care is where the problem is." – a health care provider

"I would say gastroenterology, cancer screening. Cardiology. Third would be radiological services. The theme is that a lot is procedure-based. If you don't have insurance, there are no procedures being done for you." – a health care provider

"I think everybody would agree on the specialty stuff [as a need in the community]. The psychiatry and the fitness stuff. It is obvious needs, as opposed to duplication of things that already exist." – a health care provider

"Very often, specialty care is in the suburbs. You can't just easily get on a bus. And then they [specialists] are carrying a full load and can't see you when you need to be seen. They will put you on a list for months down the road." – a key informant

Diabetes

Although diabetes rates are not available for the target population in comparison to the general population, it is clear from both anecdotal information and diabetes-related mortality rates that **American Indians in the Twin Cities are significantly and disproportionately affected by diabetes**. The age-adjusted mortality rate per 100,000 is 87.9 for American Indians, compared with 51.0 for African Americans, 30.4 for Hispanics, 21.0 for whites, and 19.0 for Asians (Minnesota Department of Health, 2009).

American Indians in the Twin Cities cited diabetes as the most critical health concern confronting the community. of Most of the interviewed providers also said diabetes as a critical

health concern for this population. In addition, several providers noted obesity and poor nutrition as upstream solutions that need more attention in this community.

"I think they really need to do something with health care because it is terrible. We have people every day getting diagnosed with diabetes, even as young as 10 or 11 years old." – a health care provider

Data from Indian Health Services (IHS) indicates that White Earth Nation members are more likely than all Bemidji Area IHS patients to be assessed for diabetes-related health concerns. Overall, about three-quarters of diabetic White Earth members who were served by IHS during the last reporting period were assessed for LDL cholesterol and nephropathy (diabetes-related kidney complications), and just over half were assessed for retinopathy (diabetes-related eye complications). See Figure B1 in Appendix B. It is not clear why the diabetes-related assessments are more common for White Earth Nation members.

Mental Health

Mental health is a major concern among American Indians in the Twin Cities. When asked to rate their emotional health, only 6 out of 10 American Indian adults in the Twin Cities on public insurance said their emotional health is "good," "very good," or "excellent." By contrast, 9 out of 10 parents of American Indian children in the Twin Cities on public insurance said their child's emotional health is "good," "very good," or "excellent". See Figure A6 in Appendix A.

Suicide can often be attributed to untreated mental health problems. American Indians have a suicide rate of 22.4 per 100,000. That is more than twice as high as whites and nearly four times as high as African Americans, Asians, and Hispanics (Minnesota Department of Health, 2009).

"That [untreated and stigmatized mental illness] is why we have so many suicides in the younger communities. But no one really wants to talk about anything." – an elder

Many of the community members who participated in this study described serious, untreated, or under-treated mental health conditions in themselves and their family and friends. Many of these participants indicated a need for more mental health services specifically for the community.

"More support groups for people that have lived through abuse and neglect. More sharing from other Native people. Sometimes I think 'am I the only one with these experiences?..." – an elder

"Mental health is our biggest problem and it is not recognized. No one wants to deal with it..." – a staff member from an organization that hosted a listening session

"There is so much pain, psychological pain, in the Indian community, in so many areas. I believe highly in this whole area of mental health issues – foster homes, rejection, racism, addiction, battering, spousal abuse, everything – we've got it. It is all related to mental health. We are medicating ourselves, running around trying to have relationships, trying to raise families. But we don't know how. Our elders still have some values, but they have been broken down. Even some of our healthy families have some issues. Selfesteem. Who is an Indian, who is not an Indian – blood quantum. People too light and don't feel Indian enough – people not liking them, because they are not dark enough. And on top of all that, we live in a very racist white society." – a health care provider

"We do as much as we can. We do psychiatry, for example, through a consultant that comes in to see our patients [at a local primary care clinic], both adult and child. The wait to see a psychiatrist was so incredibly long. I was seeing children sent home from school as being disruptive, with the school saying they needed an assessment for ADD. They needed more thorough screening than I could do. A referral would have taken a 12 month wait. We found a psychiatrist who would work partnering with us to see our patients. We do not get the funding to do a lot of what we wish we could do." – a health care provider

"Psychiatry is a very rare thing in the Cities for *everyone*, not only Native Americans. Mental health services are so scarce. Family practice physicians are forced to do so much medicating. Psychiatrists and psychiatric nurses are such a huge gap affecting the whole city. Especially those providers who are familiar with chemical dependency issues, who can work in those systems, too." – a health care provider

"Mental health services [are the most needed health care services in the community]. (Interviewer: Why?) There is not a lot of it, even for the general population. And there is great reluctance in the Indian population to get mental health services." – a key informant

"You need a good support system. Mental health is a big issue in the Indian community and we need to take care of that. A support system helps, and you need to keep yourself busy and active." – an elder

Most of the providers and American Indian community members who participated in this study feel that there is a large gap in the community for culturally responsive, trusted mental health care providers. The cost of co-pays for regular mental health treatment is also prohibitive for some community members.

Use of mental health care services (through primary care and mental health service providers) is limited in the community relative to self-reported mental and emotional problems. Of American Indians in the Twin Cities enrolled in a public health insurance program, one-third (33%) of adults and 15 percent of children reported seeing a psychiatrist, psychologist, social worker, psychiatric nurse, counselor, or other doctor in the past year for an emotional or mental health problem. See Figure A5 in Appendix A.

During the most recent reporting period, 7 out of 10 White Earth Nation members who receive health care services from Indian Health Services (IHS) were screened for depression. This compared to less than half of all Bemidji Area IHS patients who received depression screening during the same time period (IHS, 2012). See Figure B4 in Appendix B.

There is significant stigma in the American Indian community associated with mental health problems, and with seeking professional help for these problems. Publicly insured American Indians were asked how comfortable they would feel in seeking care for emotional problems. Nearly 18 percent said they would "probably not go" or "definitely not go" for professional help for emotional problems. In addition, one-quarter of adults (24%) said they would be "very embarrassed" or "somewhat embarrassed" if their friends knew they were getting help for an emotional problem (University of Minnesota School of Public Health, 2012).

The issue of stigma associated with mental illness and receiving services for mental health issues was raised in every listening session that was held as a part of this study. In one of the elders' listening sessions, an extensive discussion occurred about how younger people in the American Indian community do not want to talk about mental health. One elder described how she had to convince her son to address her grandson's mental health issues, and how her son wanted to believe and continue to treat the grandson as if he only had a learning disability (which is, apparently, not as stigmatized in the community, at least according to this one person's story).

Several providers and many of the community members who participated in listening sessions talked specifically about the need for a trusted, confidential source for mental health services. The provider is preferably a Native person or at least culturally responsive and familiar with traditional worldviews, and is *not* an active member of the local American Indian community (because they do not want to see their therapist at the powwow).

"As far as mental health, there are a lot of people who do not want to talk about it because the community is too close and they don't want their business to be talked about in the community, and I don't blame them. It is hard to find trust as far as mental health [providers]." – an elder

"A lot of people don't do them because of the stigma that comes with going to a group. Most people would try to work it out themselves, rather than talk to others." – a young adult

Chemical Dependency and Related Health Concerns

Next to diabetes, chemical dependency and alcoholism are the biggest health concerns in the American Indian community in the Twin Cities. American Indians in Minnesota have an age-adjusted mortality rate for cirrhosis of 37.6 per 100,000, which is six to nine times higher than any other racial/ethnic group in Minnesota (Minnesota Department of Health, 2009).

Many of the American Indian community members who participated in this study talked about sobriety as an important facet of health. They also characterized addiction and chemical dependency as a barrier to health and overall stability.

"[Facilitator: How do you keep yourself and your family healthy?] I live a sober lifestyle that does not involve drinking or drugging." – a listening session participant

The providers and community members who participated in this study noted a lack of culturally appropriate chemical dependency treatment. One provider said that the only culturally appropriate treatment programs are "up north."

"There are a lot of [chemical dependency and mental health] treatment programs, but they [American Indians] have a hard time in programs that are not Native specific, where they tend to sit back and isolate and be watching. They don't feel part of it. I don't think that is intentional..." — a health care provider

"I think chemical dependency treatment that is really available and culturally sensitive [is needed in the community], particularly for pregnant and parenting women, so they could have their children nearby. There could be more done about chemical health and treatment in particular for women and for everyone in general. There never seems to be enough..." – a health care provider

There is also a shortage of providers who can do substance abuse (Rule 25) assessments in the community, and a need for community-based after-care and well-being programming for youth and adults who are coming out of treatment.

"When you come back [from treatment] you are right back to the same environment where you were doing the drugs and alcohol, and the same bad people." – an elder

Cancer

Cancer disproportionately affects American Indians. In Minnesota, American Indian males have the highest rate of all racial/ethnic groups for cancers of the lung and bronchus and colon. Compared with other racial/ethnic groups, American Indian females have higher rates of cervical cancer and lung and bronchus (Minnesota Department of Health, 2009). Six providers who were interviewed for this study specifically mentioned cancer as the most significant health challenge facing American Indians in the Twin Cities.

White Earth Nation members may be screened less frequently than the general population for cancer. White Earth Nation members who receive health care services from Indian Health Services (IHS) are significantly less likely than the general adult population of Minnesota to receive basic cancer screenings such as cervical/pap, mammography, and colorectal cancer(see Figure B4 in Appendix B). Several providers who were interviewed for this study also noted poor access among the target population to these cancer screenings.

Both cancer screenings and follow-up diagnostic testing are problematic. Of those patients who are screened positive, the diagnostic testing can be a problem due to poor insurance coverage for diagnostic testing at specialists, travel costs, and poor coordination with specialty physician providers. This makes it a difficult to screen patients fully since the likelihood of follow-up and follow-through on a positive screen is low.

"You live in the Twin Cities, with all kinds of specialty centers, but you do not have access to them. (Interviewer: What are the greatest needs for specialty care?) The areas of cancer screening. Colon cancer is one of the greatest things we encounter. I would also love to have an endocrinologist for our diabetes care." – a health care provider

Chronic Health Conditions

In Minnesota, American Indians are more likely to die of chronic diseases than other racial/ethnic groups. The age-adjusted mortality rate from heart disease for American Indians - 221.4 per 100,000 - is nearly double the rate for whites and African Americans and more than three times as high as the rate for Asians and Hispanics. American Indians are also more likely to die of nephritis (kidney disease) than any other racial/ethnic group. And finally, American Indians are more likely than any other racial group except African Americans to die from a stroke (Minnesota Department of Health, 2009).

Six out of 10 White Earth Nation members who receive health care services from Indian Health Services (IHS) received comprehensive cardiovascular disease screening. This compared to only 4 out of 10 Bemidji Area IHS patients who received this type of screening (IHS, 2012). See Figure B4 in Appendix B.

Heart disease was mentioned as a major health concern for American Indians in the Twin Cities by eight providers. One provider specifically mentioned a need among the Twin Cities American Indian population for anti-coagulation/blood thinning therapy, and two providers also noted the high incidence of stroke in the American Indian population.

"I had a man who showed the need for cardiac care but was uninsured, and I could not send him to a specialist, but to the ER. He needed the specialty, but he had no access through insurance.... Heart disease is a very common condition in our community. It is a lot around diabetes. A lot of people smoke in the community... So specialty care around cardiac disease and screening for heart disease [is a need in the community]." – a health care provider

Prenatal Care and Infant Mortality

Health disparities start early for American Indians in Minnesota. American Indian women are seven times more likely than white women (16% versus 2.3%) to receive inadequate care or no care during their pregnancies. Further, the American Indian infant mortality rate is more than double that of the white population (9.3 per 1,000 live births vs. 4.4), despite an overall steep decline over at least the past 20 years (Minnesota Department of Health, 2009).

Nine out of 10 White Earth Nation members who are pregnant patients of Indian Health Service (IHS) were screened for prenatal HIV. This rate of screening for prenatal HIV is significantly higher than the rate for all Bemidji Area IHS patients, about two-thirds of whom received prenatal HIV screening (see Figure B4 in Appendix B). IHS also reports that about 7 out of 10 IHS patients who are females of child bearing age and enrolled White Earth Nation members received alcohol screening for the purposes of Fetal Alcohol Syndrome (FAS) prevention. White

Earth Nation members are screened at a higher rate than all Bemidji Area IHS patients -- about half of all Bemidji Area IHS patients receive FAS screening (IHS, 2012). See Figure B4 in Appendix B. It is unclear what the reason is for the higher rate of screening among White Earth Nation members.

When asked about the most pressing health care needs of American Indians in the Twin Cities, several providers who were interviewed as a part of this study mentioned topics related to prenatal care, infant mortality, and fetal alcohol syndrome. When asked about the specific subgroups within the target population that are especially in need of specific services, one provider talked about teenage females and reproductive health.

"We want the community to help us develop better ways to help them deal with a planned pregnancy, do prenatal care, and have a good delivery, and have good post-partum care, for a good life in the first five years of life. The American Indian population has a high infant mortality ratio." – a health care provider

"Fetal alcohol syndrome is rarely diagnosed, not talked about, but it is certainly happening... children growing up with adverse experiences do much poorer." – a health care provider

Tobacco Use, Cessation, and Tobacco-Related Health Concerns

Tobacco use rates are not available for the target population. However, **compared to other ethnic/racial groups, American Indians misuse tobacco earlier, at higher rates, and with more severe health consequences.** About half of Indian men and 40 percent of women in this area report current cigarette smoking (Centers for Disease Control and Prevention, n.d.). American Indians in Minnesota also have disproportionately higher rates of health problems associated with tobacco use. In Minnesota, four of the five leading causes of death among American Indians are related to tobacco use: cancer, coronary heart disease, diabetes, and chronic lung disease (University of Minnesota School of Public Health, n.d.).

Indian Health Service (IHS) reported that nearly one-third of White Earth Nation members who received care at an IHS facility and who are current tobacco users received tobacco cessation counseling during their most recent reporting period, which is similar to the rate of cessation services provided to all Bemidji Area IHS patients (IHS, 2012).

About half of the health care providers who participated in interviews as a part of this study noted that tobacco cessation services are unavailable to American Indians in the Twin Cities. In the community listening sessions, very few participants said that tobacco use was a problem in response to the questions about their biggest health care needs. However, there were several respondents who said that they "didn't like people smoking" around them and that "secondhand smoke can be a barrier" for being healthy. Another respondent mentioned that he had to get his teeth removed because he had mouth cancer from use of chewing tobacco; he tried to stop but continues to chew tobacco.

Accidental Injury or Death

According to the Minnesota Department of Health (2009), American Indians are 2.3 to 3.9 times more likely than people of other races to die from unintentional injuries. Several of the health care providers who were interviewed for this study also noted the high rates of premature mortality due to accidents among American Indians.

One of the providers we interviewed mentioned sexual violence as a major health concern among the target population. Indian Health Services (IHS) reports that two-thirds of their female patients between the ages of 15 and 40 were screened for domestic violence or intimate partner violence during their most recent reporting period. White Earth Nation members are screened for domestic violence at a higher rate than all Bemidji Area IHS patients, about half of whom receive this type of screening (IHS, 2012). It is unclear what the reason is for the higher rate of screening among White Earth Nation members.

In the listening sessions, several participants mentioned family and friends who have died as a result of an accident or homicide.

Experiences With Health Care

Overall Experience

Most American Indian adults in the Twin Cities who are on public health insurance (86%) who were surveyed for the 2008 health disparities study rated their overall health care as "good," "very good," or "excellent," whereas only 14 percent said it was "fair" or "poor." Nearly all parents of American Indian children who are on public insurance (97%) rated their child's overall health care as "good," "very good," or "excellent." However, during the listening sessions and key informant interviews, an overall pattern of negative health care experiences emerges. The cause of the inconsistency is not known.

"When I go, I wait when I get there. I wait in the room for an hour, then I see the doctor for 5 minutes." – an elder

"HMOs are 5 minutes a patient and they just want to keep pushing people through. It's all about the money." - a young adult

"I'm tired, so I want them to follow their mission statement and have compassion." – a listening session participant

Many of the providers who were interviewed for this study also pointed to a need for broad systems change to improve access to care. These providers suggested that real systems change is about more than insurance coverage and timely appointments.

"What needs to be changed is the system – improving access, and perceived access. People need to see that these places *are* for them – that they do have access, that they are welcome, that they will provide quality care for them." – a health care provider

"I got some of the best training in the world. I know what will make people healthier, and what they need to treat or manage disease, but if they can't go [to see needed specialists], it is very frustrating, as a professional. I did all this training to help people, to get people healthier, but there are so many roadblocks that prevent me from doing this." – a health care provider

General concern about the practices of their health care providers is prevalent among American Indians in the Twin Cities. Nearly half (45%) of American Indian adults in the Twin Cities who are enrolled in one of Minnesota's public health insurance program have concerns about their usual health care provider's practices. (This includes those study participants who said their provider only does a "fair" or "poor" job of explaining things in a way they can understand, and/or those who said their provider only "sometimes" or "never" finds out what their concerns are, spends enough time with them to address their concerns, and/or treats them as a partner in making health care decisions.) See Figure A9 in Appendix A. This is compared with one-third (32%) of white adults who are enrolled in public health insurance in Minnesota who had concerns about their provider's health care practices (Minnesota Department of Human Services, 2009).

Finding Out About Health Care Services and Programs

When asked how American Indians in the Twin Cities find out about the health care services available to them, most of the providers who were interviewed for this study mentioned word-of-mouth, standard marketing materials such as ads in community newspapers or fliers, and the organization's website or social networking sites. Community events are also a common place where providers make people aware of their services.

In addition, many providers noted that their organization receives referrals from other providers in the community. In fact, a majority of the providers who were interviewed discussed the use of extensive referral networks among Twin Cities providers that serve American Indians to try to provide adequate care for patients, since these organizations individually have limited resources and services.

"All of the Native organizations [make American Indians aware of available services in the community]. Even our competitors...will send people to us." – a health care provider

"I think there is a really tight network of providers that focus on American Indian people. Everybody knows about the [names three providers]. The community is really tight. It is really established and really tight." – a health care provider

Fragmented and Confusing System

American Indians in the Twin Cities experience the health care system as fragmented and confusing. Many of the community members who participated in a listening session as a part of this study described their frustration with having to navigate the system including eligibility and insurance requirements, where to go for which services, and communicating their needs and understanding the instructions given by their providers.

"The other part of it [specialty care] is that it is kind of piece meal a little bit. And it is inconsistent. A lot of these programs to provide things like chemical dependency services, etc., depend on money from the government or grant dollars. That limits or affects access, too, because they have to go to a lot of places to get all these services rather than being able to go to just one place for the services." – a health care provider

"It took them like 5 years to find out I had [condition] until I got physically sick from it. I get tired of going to all the different specialists. It's a constant circle..." – a young adult

It appears that some members of the target population **struggle to maintain continuity with providers, including primary care and specialty care providers.** This may be due to unstable insurance coverage, cost issues and outstanding medical bills, and problems with "flags" on their record for missing appointments.

"We have some patients that use multiple community health centers. This is also very hard to track, because IT systems don't talk to one another in the state." – a health care provider

"That circle of referrals. If you do miss some appointments and then you can't go to your specialists from the referral, and you have to start all over again." – a young adult

"I would like to have a relationship with a doctor. I don't have that. I have been going to the same hospital for years and I have to keep having different doctors." - a young adult

Lack of Trust for Health Care Providers and Systems

Lack of trust for health care providers is another common theme among American Indians in the Twin Cities. One-quarter (23%) of American Indian adults in the Twin Cities with public health insurance said doctors are not trustworthy. About 4 out of 10 public insured American Indian adults said they are afraid their health care provider might not do enough to find out what is making them sick or find an illness they have. About 3 out of 10 said they are afraid their provider might not do anything to make them feel better or that what their provider does might actually make them feel worse. These concerns are slightly less common among parents of American Indian children in the Twin Cities who are on public insurance (see Figure A11 in Appendix A). They were much less likely to experience these concerns if their provider was also American Indian (see Figure A12 in Appendix A).

Providers and community members also noted low levels of trust as an issue that **results in a lack of preventive care**.

"People [American Indians] are in distrust of the medical profession. They may not go until they are very ill." – a health care provider

"I go to [local clinic], but I only go when I have to. I don't trust anyone. I keep to myself. Right now I can't see out my glasses. I have to make an appointment for glasses; it has been 3 years..." – an elder

Many of the American Indian community members who participated in this study described their experiences with a health care system that they **perceive to be purely profit-based and not actually designed to address real people's health care needs in an effective or holistic way**.

"The reality is the biggest issue is funding. We sit and listen to the government, and they have the worst health system they talk about reducing it more. I have Medicare and they cover very little. The doctors and hospitals want to collect more, and they come after you. They will throw you in jail for some ridiculous sum of money..." – an elder

Other participants also conveyed a general perception that western medicine always recommends pills or surgery and that these types of treatments typically do not cure the problem and/or may not be warranted.

"I went to see the local medicine man. Some people like his ways, and some don't. He gave me medicine for my heart. My doctors wanted me to get a double bypass in a couple weeks, and that was years ago. I brought him [the medicine man] coffee and tobacco and he gave me some medicine. It didn't cure the problem but it has been a lot better." – an elder

Lack of Cultural Responsiveness

Many existing providers of health care services lack of cultural responsiveness to American Indians in the Twin Cities. In particular, several providers who were interviewed as a part of this study mentioned that lack of knowledge and use of traditional healing practices among existing providers of health care for American Indians in the Twin Cities is a barrier to them receiving primary care. In addition, other providers commented on the specific health care needs of American Indians that are currently going unmet.

"One [barrier specific to American Indians] is getting that culturally based or culturally specific treatment, where they have someone who understands them and gets through to them in more of a culturally respectful way." – a health care provider

"I think having people that respect and understand cultural values is a big thing. That is probably true for other cultural groups as well. If you have people who don't understand or respect those things, that is a barrier." – a health care provider

About 10 to 15 percent of publicly insured American Indian adults reported problems getting needed health care because doctors do not understand their culture, speak their language, or respect their religion. And 13 percent said the place they go for health care is not welcoming. Parents of American Indian children who are on public insurance were slightly less likely than adults enrollees to report these problems with getting needed health care for their child (see Figure A8 in Appendix A).

Some American Indian patients are frustrated because they feel that two of the local clinics were created especially for them, and they do not feel welcome there, nor do they feel that their community is given priority for care. Some community members express resentment toward the immigrant communities that also use these clinics.

"They [providers] are not as culturally aware, so they do not make appropriate efforts. For example, [a local provider of care] came to me and a committee I called together, saying Indians were leaving without ever being seen or admitted... What we found was that they also serve a large Somali population, and there was a lot of heavy gang stuff going on between Somali and Native Americans. Because there were so many Somalis, the Indians would leave." – a health care provider

"The clinics with Native names attached to them are serving more non-Natives than Natives." – a listening session participant

Several of the providers we interviewed also specifically noted a need for culturally responsive care and support in accessing care, in particular to bridge a gap in communication styles between providers and American Indian community members.

"I think the challenges are the total misunderstanding and miscommunication that most people don't get. You really think that they understand what you are saying, but they don't understand a thing that has been said. You can't really work on your issue, because you don't have the right information. And it happens on both sides. Maybe have some paraphrasing of what is said, having someone there to hear what was said. I don't think it has to do with education level. Most people say it is because they are not educated. I am saying there is a cultural difference on how information is taken in and processed, and that is on all levels." – a health care provider

"I think again services that are pretty behavioral slanted. You have to behave a certain way to get service. Like counseling, where you have to talk about things. Indian people may just want to get a prescription, not talk. Things that require you to be more social, have more social interaction [can be difficult for American Indians to access] – counseling for anxiety, for example. That is what I see." – a health care provider

"And then, at the end of life, a good number of Indian people want to have a ceremony. But in a hospital you cannot light anything. A friend of mine said his bed had to be facing west, and his hospital did it. He was very pleased with that. But nine times out of ten, that wouldn't have happened. So, the barrier of culture." – a key informant

"Surgeons. You may need surgery for any number of things. They come in and out. The family never seems to know what they are going to do, the chances for recovery, and what the procedures are. They are so specialized, thinking of parts, not the whole person. That is so contrary to Indian medicine that that stands out." – a key informant

Discrimination

American Indians in the Twin Cities experience or perceive outright discrimination when seeking health care. About one-quarter (24%) of parents of American Indian children in the Twin Cities on public insurance and 38 percent of adult American Indians in the Twin Cities on public insurance said they are treated unfairly because of their race, ethnicity, or nationality. When asked specifically if they had been discriminated against during the past year because of their race or skin color, 12 percent of adults and 4 percent of parents of children said yes (special analysis of 2008 health disparities study data conducted by University of Minnesota School of Public Health, January 2012).

Incidents of outright racism and discrimination were discussed at every listening session that was held as a part of this study. Participants mentioned being accused of being drunk, being preemptively denied narcotics/pain medications, being made to wait for long periods, and being provided substandard services.

"The first thing they ask you is 'how much have you had to drink?' I thought they asked everybody, but it's not just us. I watched one time and they asked a black person, but didn't ask any white people." – a listening session participant

- "If you and a white person come in with the same thing, the white person will be long gone before you even get seen." a listening session participant
- "A lot of it is that we get stereotyped. If your bone isn't protruding out your arm they [doctors/clinics] don't care." a young adult
- "I see people being disrespected at clinics. It is a negative healing environment. You feel disrespected, and it is hard to get healthy in that setting." a young adult

Several providers also mentioned racism and discrimination as a barrier in meeting the health care needs of the target population.

- "They see different treatment, being treated differently...because they are Indian. That is what they are telling me. We survey our clients and ask why they don't go to places like emergency rooms, hospitals, clinics for health care, and they tell us discrimination. Poverty should get you into health care, but it doesn't... Once they hit the Cities, Indian Health Service doesn't cover them." a health care provider
- "And there is racism. We are treated with more racism than other racial groups. I think this happens more often than we care to admit." a health care provider
- "Because the way they are treated, they often times choose to not seek health care unless absolutely necessary, or if it is a crisis of sorts. Unfortunately, they will use the ER much more often than a regular clinic, because it is uncomfortable to go to places where they don't treat them well." a health care provider
- "Another reason they don't go [for primary care] is that the experience of Indian people going to doctors and dentists has been extremely off-putting, being talked to as though they are inferior or not intelligent enough to understand things.." a health care provider

Discrimination can be based on insurance status as well as race. Twenty percent of publicly insured American Indian adults and 6 percent of parents of publicly insured American Indian children said they had experienced discrimination during the past year because of their enrollment in public insurance (requested analysis of 2008 health disparities study data conducted by University of Minnesota School of Public Health, January 2012).

One of the providers who was interviewed for this study and several of the community members who participated in a listening session also described personal experiences in which they or their relatives were not given adequate care because of their public insurance. In several of these cases, the participants claimed that permanent disability or death resulted from the inadequate care.

"In the last year we had a medical crisis with my nephew and our barrier is insurance and money. They treat you differently on MA and won't run all the tests they should." – a listening session participant

American Indian Patients Prefer American Indian Providers

The experience of American Indians receiving care from another American Indian person is generally more positive than the experience of American Indians who receive care from a non-American Indian provider. Of those on public health insurance, 19 percent of the parents of American Indian children and 30 percent of the American Indian adults reported that the doctor or provider they usually see is of their same race/ethnicity. Those who reported having an American Indian provider were significantly more likely than those who reported having a provider of another race/ethnicity to say the provider explained things in a way they could understand, spent enough time with them to address their concerns, and treated them as a partner in making health care decisions (see Figure A10 in Appendix A).

It is also important to note that American Indians who had a provider of their same race were less likely than American Indians who had a provider of a different race/ethnicity to express concerns about their provider's practices.

Listening session participants wished that there were more medical school programs that pipelined American Indian health providers into clinics aimed for American clinics. Other participants noted that there is distrust between American Indians and the medical community who is predominantly white.

"I want to be served by people who look like me. I don't want an India [from South Asia] or a white person serving me. Our people have a historically negative relationship with the medical community and it makes many of us nervous." – a listening session participant

Other Challenges to Accessing Health Care Services

Clearly, significant and widespread barriers prevent members of the target population from accessing health care services. In 2002, approximately 69 percent of American Indians residing in Hennepin County said that they needed medical care sometime in the past year; however, one-quarter (25%) of those respondents said they had delayed or not gotten the care they needed (twice the rate of all adults, 13%; Hennepin County, 2003). Similarly, among the group of American Indians who live in the Twin Cities and are publicly insured, 16 percent of adults and 4 percent of parents of children reported a time during the past year where they or their child needed but went without medical care. Further, 34 percent of those adults and 7 percent of those parents of children reported delaying needed care for themselves or their child (requested analysis of 2008 health disparities study data conducted by University of Minnesota School of Public Health, January 2012).

Accessibility and Capacity of Providers Who Serve American Indians in the Twin Cities

Many members of the target population struggle to get health care appointments with their primary care providers and with needed specialists. When asked if they experience problems with getting an appointment for their child as soon as they need one, more than 4 out of 10 parents of American Indian children in the Twin Cities who are on public health insurance said this is a problem for them. More than one-third of American Indian adult public insurance enrollees also indicated this is a problem. More than one-quarter of adults and parents of children also said it is a problem for them to get an appointment with the doctor they want to see. And finally, about 2 out of 10 adults said the clinic is not open when they can go (see Figure A7 in Appendix A).

Several listening session participants mentioned that they have been "flagged" in the system at the clinic for missing too many or coming too late to too many appointments. At that time, they can only receive walk-in services.

"I missed too many appointments and got flagged. I tried to call in so I could be on the list of walk-ins, but then I end up sitting there for 6 hours waiting. After that happened a few times, I just started to go to the emergency room whenever I had a health care need." – an elder

In some cases, it appears that the providers who serve the community are at capacity (i.e., unable to take new patients) and/or that they lack the resources (e.g., equipment, staff, facilities) to provide needed care. Of the health care providers who were interviewed for this study, most of whom are "safety net" providers who mostly serve those who are publicly insured or uninsured, about half said their organization is currently at capacity in terms of number of patients they are serving, and the other half said their organization could accept more patients.

One of these providers who is already at capacity said his clinic is unable to take more patients because of the limited facility space, and two providers specifically mentioned being under-

staffed. Another provider mentioned having waiting lists for almost all of the services. Several providers indicated their most pressing capacity challenge is limited availability of providers who can complete substance abuse and Rule 25 assessments (which determine eligibility for public funding for substance abuse treatment and identify the most appropriate treatment options). Other shortages included clinicians to provide mental health care, nephrology (renal care), endocrinology (diabetes care), and oncology (cancer care). Providers who offer dental care also noted being at full capacity.

Most providers indicated wait times for well-child visits and other routine care to be within a few weeks, which is in accordance with the State of Minnesota standards. Several providers indicated that generally they have a lot of room to add patients and would eagerly do so in order to increase staff hours and staff.

In terms of waiting times for appointments, many of the providers who were interviewed described having same-day accessible services for urgent needs including acute illness and/or pain. Some of these providers also noted their capacity to handle walk-in patients. However, some of the providers and many of the American Indian community members who participated in this study also noted that same-day appointments may not be as convenient as they are intended to be.

"You can't get in. You have to call at 10:00 to get a same-day appointment. I have brought people in who waited the whole day and had to come back the next day [and this has happened at several local providers]. And some just give up and go untreated. They have symptoms, but they don't even go to the doctor." - a health care provider

"The clinics in the neighborhood just tell me to call tomorrow to get on the walk-in list. I can do that for a day or two, but then it is difficult to be on the walk-in list for any longer and not being able to get the appointment. I just quit calling and quit going to the clinic." - a young adult

Transportation

Not having access to transportation may be the biggest challenge outside of the health care system itself (i.e., not including the cost of care and health insurance coverage) to accessing health care for the target population. Transportation is a problem for half of the American Indian adults in the Twin Cities on public insurance programs and a quarter of the parents of American Indian children in the Twin Cities who are on public insurance programs (see Figure A13 in Appendix A).

When asked to name the most significant barriers for American Indians in accessing primary care services in the Twin Cities, by far the most common response given by health care providers who were interviewed for this study was transportation. Several providers noted that their organization or other organizations already provide transportation, but that it is not enough to meet the need of the population.

"We have a transportation service here. And also the tribe has a transportation department as well. It is always booked and doesn't meet the needs of all patients." - a health care provider

American Indian community members who participated in this study, particularly elders and single young adults, also identified transportation as a barrier to them getting needed health care.

"Transportation, our local Native clinics do not have a lot of internal capacity. We get referred all over the place! [Names two local hospitals], suburbs, and more." – an elder

"Transportation—you can't get to where you need to go, to get the services and help that you need." – a listening session participant

"More funding for transportation, for gas money, someone to drive, and pay them to stay and not take off when I have to wait in the waiting room for a long time." – an elder

It is not clear the extent to which public transportation is used by the study participants, although it is likely that in some cases the cost of a bus ride may be prohibitive. Also, several of the elders who participated in focus groups talked about being too disabled or too ill to take public transportation to their health care appointments.

Lack of Information

It appears that many members of the American Indian community in the Twin Cities lack the information they need to make informed health care decisions and lifestyle choices that will reduce their chance of developing chronic diseases. When asked about the specific things that make it hard for them to get needed health care, American Indians in the Twin Cities who are on public health insurance reported significant barriers in the areas of lack of information. For example, nearly half of those adults and more than a third of parents of those children said they did not know what services their Minnesota health care program covered (see Figure A13 in Appendix A).

Several providers who were interviewed for this study also mentioned lack of awareness of programs for which they are eligible. Many of the American Indian community members who participated in this study also talked about not being eligible for various services based on tribal enrollment, county of residence, and type of health insurance. It is clear that in some cases community members' frustration is due to the actual requirements for various programs being very complex and in other cases the confusion appears to be related to misinformation in the community about who can use which services.

"The patient has to be educated enough to know to ask the questions, what questions to ask." - a health care provider

"I think there is a great misunderstanding that, if you are an Indian person that you are supposed to go to [names two clinics]. You don't know you can actually go somewhere else. They don't realize that there are other services available to them." – a health care provider

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"[My biggest barrier to staying healthy is not] being able to use pharmacy [because I] live outside the community. [Local pharmacy] is for only people who live in the county, but I can't afford the medicines either. They are so expensive. If [pharmacy] is for Natives, then it should be for all Natives. I think the requirements are tough." – an elder

Conflicting Family or Work Responsibilities

Keeping their jobs and taking care of their children are priorities that often create barriers for American Indian adults in the Twin Cities in getting their own health care needs met. Thirty percent of American Indian adults in the Twin Cities who are on public insurance and a quarter of parents of American Indian children in the Twin Cities who are on public insurance said work or family responsibilities cause problems for them in getting needed health care. One-quarter of the parents of those children also said that getting child care for their other children is a problem for them when taking one child to the doctor (see Figure A13 in Appendix A.)

Some of the community members and providers who participated in this study talked about how difficult family relationships can create barriers for them in accessing health care.

First participant: "I take care of my mom. It is hard because I have to take care of my little sister too. My mom is falling apart because she is having all these surgeries. I have to be there for both of them."

"It is easier to deal with what is right in front of you [rather than focus on your own preventive care]. You have to have your kids healthy to keep them in school so you can work or do what you need to do." – a listening session participant

Summary of Issues to Consider

This study finds critical unmet health care needs among White Earth Nation members and other American Indians in the Twin Cities. In addition, these findings reiterate the severe health disparities facing American Indians in the Twin Cities and Minnesota as a whole. These disparities cut across multiple domains from prevention and wellness, to prenatal care, to health screenings, to accidental death and suicide, to heath disease, cancer, and diabetes. There are also significant community-specific issues and unmet needs in the areas of mental health care and substance abuse assessment, treatment, and aftercare.

It is important to note that **almost no differences were observed between the health care needs of White Earth Nation members compared with other American Indians in the Twin Cities**. Furthermore, both providers and community members want to focus on the needs of all American Indians rather than to emphasize needs or develop services that target the members of one tribe only.

This study suggests that **one of the primary reasons why the health care needs of American**Indians in the Twin Cities go unmet is because of lack of insurance or inadequate insurance coverage. American Indians are much more likely than the general population to be uninsured –

which can be due to extreme poverty and homelessness, or because their income is *too high* to qualify for public programs, but not high enough to purchase private market insurance and not offered through their employer(s). For those who are publicly insured, their insurance coverage is spotty and arduous to maintain. There is a perception that having public insurance is also likely to result in diminished access to quality care, or not having true access to the full range of treatment options for a specific condition. The community members and providers who participated in the study cited lack of insurance and cost as one of the main reasons for using emergency medical services instead of preventive medicine and ongoing care for chronic conditions.

Addressing gaps in insurance is a systems change issue that must be tackled at the state and federal levels. White Earth Nation, other Tribes, organizations that serve American Indians, and the Minnesota Department of Health should continue to address this problem at both the systems level (health care coverage policy) and the individual level (assertive and ongoing outreach to enroll people in services for which they are eligible and need).

Further, this study found many instances (more common than not) of bad experiences and mistrust of the health care system among American Indians in the Twin Cities. Mistrust of the system could possibly be attributed, at least in part, to historical trauma, lack of cultural responsiveness among providers and inability to create a welcoming environment – and outright racism and discrimination. Bad health care experiences are also associated with long wait times at walk-in clinics (which are heavily utilized), limited time with providers, communication barriers and lack of understanding on the part of the patient and the provider, and a lack of effort among providers to really understand and address the patient's concerns. Patients and providers alike are also frustrated that under-resourced community clinics must send patients to other sites (nearby hospitals, usually) for basic services such as X-rays.

It is clear that many American Indian community members and their health care providers struggle to understand the complex eligibility requirements and coverage limitations for all of the public and private health care programs. The American Indian community has an added layer of complexity due to their status with regard to the federal government and the Indian Health Service (IHS) system. If they are tribally enrolled, American Indians are eligible for IHS, but most IHS funded services are provided only on the reservation. Therefore, some American Indians in the Twin Cities travel back and forth between their home reservation and the Twin Cities for the purposes of receiving health care, and in particular eye glasses. A couple of the providers in the Twin Cities also require tribal enrollment for service eligibility, possibly because IHS funds these services.

Another major need identified by this study is for preventive care and upstream solutions.

The significant lack of prevention of chronic conditions such as diabetes and heart disease is an expensive problem for the American Indian community, the State of Minnesota, the federal government and Indian Health Services (IHS), and all taxpayers. Better support and linkages to access preventive, routine care is needed to address the issue of high use of emergency medical services for routine, ambulatory-sensitive conditions. A focus is also warranted on incenting healthy behavior and providing viable alternatives to the use of emergency medical services to treat chronic problems.

In particular, there is high need as well as demand for better access to healthy food and physical activity. The American Indian community in the Twin Cities and health care providers who serve this community describe a lack of access (financial and geographic) to healthy foods, an overabundance of unhealthy food (particularly fast food) in their communities. Many participants described lifestyles and a contemporary culture that support unhealthy eating and limited physical activity. Community members and providers strongly support the reintegration of traditional Native foods into the community's diet. Education is needed about how to prepare these foods in healthy ways. Better local, affordable access to traditional Native foods as well as fresh produce is also needed. Finally, there is a strong indication that an individualized approach to nutrition and exercise is not aligned with the community's perspective. Rather, nutrition and exercise should be integrated into family and community activities and programs to achieve better acceptance.

Lack of transportation was cited by health care providers and community members as a huge barrier to accessing services. Although some providers offer transportation to assist their patients, the available assistance is not adequately resourced or reliable enough to support the community's need. Elders have especially high need for more transportation assistance.

Traditional medicine people for American Indians in the Twin Cities are also in short supply. Many study participants expressed a desire to use more traditional methods for wellness and healing, but not having access to these services. In addition, many other community members talked about the importance of traditional medicine in keeping them and their families healthy. Several participants specifically noted the lack of a traditional healer to serve White Earth Nation members in the Twin Cities, although it was noted that other tribes do have access to traditional healers in the Twin Cities. Many of the providers who were interviewed for this study indicated a need to incorporate more traditional healing and traditional American Indian community practices for engagement into primary health care practices.

Some providers and community members also suggested that there need to be more American Indian providers in general to serve the community.

With these issues in mind, and assuming that the broader social problems of poverty and health care systems change will not be solved in the near future (as the result of this study or any other current efforts), the following recommendations are offered.

Recommendations

It is recommended that a more holistic approach to wellness and support for health promotion activities be used to address the striking health needs of American Indians in the Twin Cities.

Scope

• Pursue an approach that addresses the health needs of the entire American Indian population in the Twin Cities, rather than focusing on a tribe by tribe approach, in order to eliminate fragmentation, achieve economies of scale, and improve effectiveness.

Ultimate Vision

- Explore methods to overcoming the reimbursement and policy barriers to creating the community's ultimate vision and preferred solution: one center that provides wellness activities, primary care, specialty services, social support (especially for elders) and child care, and traditional healing, in a welcoming and culturally responsive environment. Begin intensive, detailed planning for this comprehensive center as soon as possible.
- Increase partnerships and collaboration between existing community providers, Tribes, Indian Health Service (IHS) and state government to better improve the health and wellness of Minnesota's American Indian community.

"It is long overdue for our people to sit down and get some comprehensive planning, and harness the organizations to get behind one concept and one building, so services can be improved system-wide." – a health care provider

Discussion

The White Earth and broader American Indian community's preferred solution to meet its health care needs is one center that would provide wellness activities, primary care, specialty services, social support (especially for elders) and child care, and traditional healing, in a welcoming and culturally responsive environment.

"I think we need one big clinic that combines everything. How can we be referred to go to five different places for things as simple as X-rays? It could be like the VA. They have everything there from medical to mental to specialty..." – an elder

"We recommended that they have a place culturally sensitive to Native Americans, with pictures and staffing that provides them with a place where they could feel welcome. The older people may still have language issues. Some may be speaking their language. And even if they don't still speak their language, their thinking process may still think that way, so they still may not understand." – a health care provider

"I think it has to be a place people feel comfortable going to - that it is their clinic, their providers, their counselor. That it is the investment made by the tribal government, the federal government, the state government into the health of the tribal community. People get health care from a lot of sources, but they like seeing someone who saw their grandmother, their parents, their relatives. Someone who shows them respect. People are there because they are scared, they need some explanation, they need someone to listen to them." – a health care provider

"I would like there to be a community center for elders, where we can socialize and receive our care. We have a different set of circumstances than younger people. We need to be together because we are the strength of our community." – an elder

First participant: "[The community needs] a place that has everything in one building that is free to everyone regardless of income qualification. A free place clinic where anyone can come to." Next participant: "Have a 24 hour daycare for families for parents that need it." Next participant: "The place should be a non-profit." Next participant: "The place should also have traditional medicine for the community and we should practice traditional medicine because there are so many good practices." - families with children, listening session discussion

"[I want a] clinic for Indian people funded by the Indian tribe. Dental, eye, chemical health, Rule 25, transportation, health care support groups, X-ray machines; sometimes not all the machines are available [at the existing clinics] and they must refer you out. The clinic I want will have all equipment to meet medical needs so you don't need to be referred out. Clinic will treat all patients with respect." – an elder

"[I want a] 'minute clinic'. I have to work and I have kids so I can't always drag them all with me." – a parent

"There should be a unified delivery system, where providers of health and social services are all under one roof, working out of one building, to help their clients out of some of the confusion that arises because American Indians access services in so many places. Planning for all American Indians and not just one tribe would be a good way to go about that. There should be more cooperation between service providers." – a health care provider

"I think a wellness center would be huge, and could do the most for improving health. Ways for that center to expand and give more ways for people to improve their nutrition and their exercise. And making more regular opportunity for mammograms, diabetes eye exams, colposcopy exams." – a health care provider

Careful planning is essential to pursue this ambitious goal successfully. Creative thinking about structure, revenue sources and coordination will be required to turn this vision into a reality, because current reimbursement methods do not readily facilitate this kind of a health care facility. In addition, extensive partnership among the existing community providers, including the two Federally Qualified Healthcare Centers (FQHCs) in the Twin Cities with similar visions, Tribes, Indian Health Service (IHS), the State of Minnesota, and the American Indian community will be needed to actualize this vision.

Fortunately, the input received from health care providers that serve the American Indian population in the Twin Cities is one of overwhelming support and desire for more collaboration and partnership.

"I can't over-emphasize that there is a willingness to work together. I can't say it enough. If this is something that is funded, that people truly listen to needs rather than using a needs assessment for gain. This community has been overlooked far too long. It is exciting to have a tribe demonstrate interest in this community. There is definitely interest in partnering to further the health of the people we both have interest in." – a health care provider

"Most of the FQHCs are partnering on a number of things. Southside particularly, when we know someone is doing something that would be valuable to our patients, we partner with them. We work with [names other community-based organizations]. To expand on that would be a very good thing to do." – a health care provider

"Ten of the FQHCs in the Twin Cities are involved to get people involved in health care homes for their patients. It is not just for Native people. It is going to be implemented in the next several months. It is not just the place you go when you are sick, but the place to go." – a health care provider

"The urban offices of the tribes are doing very well at teaching their members and letting them know what is available. I think that is an asset." - a health care provider

Only one of the providers interviewed for this study is a dental care provider. This respondent suggested that dental care should also be better integrated with primary care clinics to improve access for the target population.

One provider made the specific suggestion that White Earth Nation should consider partnering with a large health system to provide its specialty services or to create a satellite specialty clinic for its members.

A community member suggested that the local tribally-based pharmacy should partner with the Tribe's IHS to provide eye glasses to tribal members living in the Twin Cities. According to his plan, a tribal member could bring the prescription from the optometrist to the pharmacy and the pharmacy could be the place where the frames are selected. The pharmacy would then send the prescription and frames up to IHS at the reservation to insert the lenses. When the frames and lenses are done, the reservation or IHS could mail the glasses directly to the tribal member.

These partnership ideas, and more, will need to be capitalized upon to make the vision of a comprehensive center a reality.

Access to Primary Care and Specialty Care

• If pursuit of the ultimate vision is not possible in the near term, do not create another isolated and under-resourced primary care clinic; begin to improve existing clinics' collaboration as recommended below whether or not a new comprehensive urban American Indian health center develops.

- Improve access to specialty care. Provide existing clinics and patients with more support and access to specialty care services, or consider other approaches to improving specialty care access.
- Increase collaboration and partnerships between clinics with significant American Indian case loads and local health systems.
- Integrate and enhance care coordination services with existing primary care clinics.

Discussion

The results of this study indicate that many of the American Indians in the central cities of Minneapolis and Saint Paul have adequate access to primary care clinics. However, there is a broad sentiment that these small, community-based primary care clinics are not meeting the community's needs for various reasons described in this report. Therefore, creating another isolated and under-resourced primary care clinic is not recommended.

"I think primary care would be impossible to get support for, to drop money down for something that is already there. When resources are so tight, with services getting cut back, I don't see how anybody could justify duplication." – a health care provider

"We have more than enough clinics in the Phillips neighborhood. To bring another clinic in is nuts. [Names four local clinics.] More than enough primary care clinics in the Phillips neighborhood. But should we be working together as a group to solve the issues White Earth is concerned about? Yes." – a health care provider

"Collaboration. We don't have to reinvent wheels already invented. We just need to look as one unified community to the needs of the people we serve. Working collaboratively rather than thinking you can improve on something that already exists." – a health care provider

"I don't think it is a good idea to have a system based on just one tribal enrollment. You create conflict among tribal members when you single out one tribe to plan for. And you encourage the kind of separate thinking about planning and providing services that will, I think, devalue the opportunities that may be there to provide quality care." – a health care provider

However, American Indians in the Twin Cities do need better access to specialty care services. This can be accomplished by providing more resources so the local primary care clinics can bring in specialists. In addition, the navigator and health care coordinator functions described below could be used to improve access to the specialty care services available through the many health systems that operate in the Twin Cities.

"I had a vision, when this White Earth study came up, as why not have a White Earth center for specialty care to provide that for people who live here. We would send people to them, probably [two local clinics]. That is a distinct need, I think, rather than another clinic providing primary care within this community." – a health care provider

"Enhancing or making available specialty services is an opportunity that is unique. There are no other tribes in the U.S. who have invested in the urban health needs. Often tribes are very specific to the reservations they exist on. Their health services are on tribal lands. It is unique to have White Earth interested in providing services in the Twin Cities. The one exception is [name of tribal pharmacy]. It would be unique to have specialty providers available to our clinics to send to where they can get services that are culturally specific." – a health care provider

Health Care Coordination and Navigation

- Increase the number of American Indian health care navigators or community health workers available to help American Indians navigate the system.
- Identify individuals with significant health needs and offer them additional culturally-informed care coordination services.
- Raise awareness of health care homes and encourage American Indians to enroll in those health care home clinics that have a culturally appropriate environment.

"Something else [that would be] helpful is an advocacy program to talk to people. Someone to have a voice for those of us who can't explain ourselves or to explain paperwork and everything." – an elder

Discussion

Mistrust and trepidation are widespread among the American Indian community toward health care in general. This reaction to health care systems and providers can be attributed to a wide variety of factors including historical trauma, lack of cultural competence, discrimination, lack of insurance and broader financial issues, lack of appropriate primary care and screenings, delay of care until the problem is severe, etc.

Two specific types of services are recommended for consideration to address these problems. First, the community would benefit from American Indian "health care navigators" or "community health workers" who can help them understand and navigate the health care system to get their needs met. Second, individuals in the community with significant health needs, especially elders, young adults on their own, and the homeless, should be offered more culturally-informed coordination services, such as care coordinators from the American Indian community that are employed within or meaningfully linked to health care home (HCH) settings.

"We need to step forward and start contacting those medical organizations, checking with the client and giving them information on what kinds of services they can access in that system, [whereas now] the expectations on them coming into the system accessing services. A lot of medical organizations are so busy that a lot of that information doesn't get shared until they actually come in. So maybe [access would be improved by providing] a health liaison or case manager." – a health care provider

"They [health care providers] need to be more willing to try things, try new ways to provide health care services. For homeless people, they tried sending doctors into the field. Why not have roaming health care people out there at the [Minneapolis] Indian Center? Why not have them come to existing services where they could see them? That is a way to connect to people and to provide the ability to better understand them where they live. It also would show a commitment." – a health care provider

These services specifically are ones that White Earth Nation, another Tribe, or a local community-based organization could implement to the community's great benefit regardless of what happens with the other recommendations.

Prevention and Wellness

- Improve availability of opportunities for physical activity and exercise through existing programs and resources.
- Increase access to healthy foods, especially fresh produce.
- Increase educational activities related to preparing fresh foods.
- Take a systemic approach to improving nutrition by improving community and family food choices. Focus on family and community education with programs and events such as community feasts that feature nutritional food.
- Focus on engaging young adults and young parents in preventive self-care and encourage the idea of routinely maintaining health through annual clinic visits and the development of life-long healthy habits.

Discussion

The American Indian community in the Twin Cities has suffered from a lack of effective wellness and prevention strategies. High rates of diabetes, cancer, and heart disease are endemic. The community has expressed its desire for better access to healthy food, especially fresh produce and traditional foods. Education is also needed about how to prepare healthy foods, as well as possibly how to budget and find the best deals on healthy foods.

Providing better access to opportunities for physical activity is also needed in this community. The cost of gym memberships is one barrier. Busy schedules and lack of motivation are other common reasons cited for low physical activity. Existing programs, such as Running Wolf, are small, underfunded and over-subscribed within the Twin Cities American Indian Community.

All community wellness initiatives, whether nutrition and/or physical activity focused, should be designed and implemented with community member input and should incorporate a family or community focus instead of an individual focus. For example, community feasts to promote nutrition could integrate healthier meals, education about where to get healthy food and eligibility for food assistance programs, demonstrations about healthy food preparation and group classes on family meal planning. An exercise program could incorporate snowshoeing

with guided tours of local historic sites that hold meaning for the American Indian community or tours that incorporate learning Native languages and terminology for places and things.

In addition, more should be done to encourage and support American Indians in the Twin Cities in getting preventive and primary care. This effort should focus on young adults, who tend to not seek preventive care, and on parents of young children, who tend to get their children their well-child visits and immunizations but may neglect their own preventive care needs. An increased emphasis on primary care and prevention should also be directed to children, who can learn about and establish healthy habits early in life to prevent later health problems. One provider specifically suggested creating better incentives for people to participate in preventive care.

"For that one population, the young adults, under-utilizing us, it is health maintenance, to maintain yourself like you do your car. The parents are good about bringing their kids in and doing the well-child stuff. The obstetric patients, again it is the young adults that fall short on that – and that is education, to get in and get care as soon as you think you are pregnant. You would have to start that in high school, so you already know that, when you are a young adult – that wellness is a way of life, not something you worry about after you get sick." – a health care provider

"Preventive care that is being planned. Preventive services, rather than waiting until they are at that place where there is no return. That might start with the younger population." – a health care provider

Increased Outreach and Access for Diabetes, Mental Health, and Substance Abuse

- Use evidence-based practices to deliver information about and improve care for diabetes, mental health care, and substance abuse.
- Identify providers interested and able to provide culturally competent care. Then provide this list to the community, perhaps in conjunction with a Web portal that would allow for provider reviews and community feedback.
- Create and implement a long-term plan to recruit and train more American Indian providers.
- Draft a plan for raising awareness about prevalence, prevention, and treatment of these health issues.

Discussion

When asked about possible solutions to improve access to health care for American Indians, several providers and community members noted a general need for more education about what services are available.

"The clinics targeting American Indians could do better in outreach education. There could be more done to implement school based programs and extend better... education to families and children." – a health care provider

"I think all of these services and providers need to do a better job of reaching people. There are many people who do not know where to get help. There needs to be better information sharing. If the community does not know about services, then they can't use them. There are lots of things out there, more than I thought there were, but still not enough of everything. [Received a chorus of "Yes!" from other participants]" – an elder

This study finds especially high need for outreach and information in the areas of diabetes prevention and care, mental health care, and substance abuse assessment, treatment, and aftercare. A two-pronged approach is recommended to address these and other health issues that are of pressing concern. And as with all of the recommendations in this report, further input from the American Indian community is needed to determine the best way to address the needs identified here. The following are initial suggestions that need further input and involvement from the community.

The first prong of the recommended approach is to conduct a scan of the Twin Cities to identify and catalog all providers who offer the needed services. Providers should be initially assessed for their current ability and/or interest in receiving training to become culturally competent providers for American Indians. In areas where gaps are still present even after the scan, additional training should be offered to providers who offer the needed services and who express interest but who are not currently culturally responsive. In addition, unified community effort should be made to recruit and retain more qualified providers of these services within the health systems that serve the American Indian community in the Twin Cities. Finally, a listing of the identified providers should be made available to community members and local service providers. (A website that allowed community members to post their ratings, like Angie's list, might be interesting, too.)

A stronger emphasis on long range planning and a targeted strategy for workforce development, recruitment, and retention of American Indian health care providers is also warranted. This emphasis could include the Minnesota Area Health Care Education Centers (AHECs) as well as the health professions schools in universities and colleges across Minnesota.

The second prong of the recommended approach includes a community outreach and education campaign, which should be completed after the initial scan from prong one is completed. The best strategies to increase community awareness of and attention to the issues of diabetes, mental illness, and substance abuse are not known.

Much more dialog with the community is required to understand the specifics of how to proceed. The end goal of these campaigns should be two-fold: increase the community's awareness of the problem and how to prevent and treat it, and increase the community's awareness of and access to culturally responsive providers.

"Mental health services [are the most challenging type of health care services to get support for]. There is not a lot of it, even for the general population. And there is great reluctance in the Indian population to get mental health services." – a health care provider

With regard to the specific place(s) where mental health services should be provided, several comments by providers who participated in this study indicate that the stigma associated with

receiving mental health care is so strong in the American Indian community that care should be taken to separate these services (and even the providers of these services) from the rest of the community.

Transportation

• Improve the current transportation system so that it can better provide elders with extensive shuttle services to all health care appointments, inner-city patients who might need specialty care in the suburbs, and emergency transportation services to American Indians who are disabled, homeless, severely mentally ill or chronic alcoholics.

Discussion

Transportation services are needed, in particular for three main situations. First, elders need transportation for all health care visits and services, even to the neighborhood primary care clinics. Second, community members from the inner city need transportation to specialty care, which is often located in the suburbs. And finally, people who are disabled, homeless, severely mentally ill or chronic alcoholics, and those who are having a health crisis, may need transportation to urgent care or the emergency room.

"It definitely has to do with transportation. Getting there, if you are referred to a specialist. If you are in poverty or on the edge - it is a big challenge, the geography." - a key informant

Health Information Technology Solutions and Future Research

- Integrate electronic health records among providers who provide care to American Indians, particularly regarding labs and screenings, medication lists and compliance, hospitalizations, discharge plans and basic data.
- Improve the sharing of information among providers caring for American Indian patients.
- Improve data collection for tribal affiliation to better understand health care usage patterns and tribal needs.

Discussion

The integration of a minimum data set of pertinent patient data via Health Information Exchanges (HIE) may contribute to safer and more coordinated care as well as improved monitoring of chronic conditions among the target population. Types of data which would be especially useful include lab and screening results, current medication lists and pharmacy fills, recent emergency room and hospitalization data, universal discharge plans, and basic data to facilitate the coordination and transition of care across multiple health care settings. Some providers who were interviewed for this study noted the challenge of not having access to information across organizations as a barrier to providing the best care possible. Many of the providers who were interviewed expressed a desire for more sharing of information and

resources to improve the overall access to and quality of care American Indians receive in the Twin Cities.

"It could get down to the IT connection, that if we can become aware of patients using ERs, we can connect into them. Community mental health centers may have patients not getting their medical care needs being met." – a health care provider

"If the tribes got together and had their own health hub, and could get that information distributed to the tribes, as a point of contact for you when you get to the Cities. That could then also draw attention to all the specialty needs when you get to a clinic." - a health care provider

"Communication between the programs. Maybe more of a team medical concept. Collaborating between organizations or institutions for the benefit of the client. Doing medical services around the client, and the client not just going into the siloed services to get one thing done, and then another to get another thing done. Hopefully, with electronic records and sharing, that would be taken care of better in the future." – a health care provider

When asked specifically about the needs of White Earth Nation members compared with other American Indians in the Twin Cities, providers said:

"There is not enough data available, especially broken out by tribe. I was thinking about this as I was thinking about the project you are doing. There just isn't a lot of data available, particularly broken out for American Indians and specifically for particular tribes. We just don't have the data." – a health care provider

"Access to care would be different [for White Earth Nation members vs. other American Indians] on the reservation. (Interviewer: How about once they are in the Twin Cities?) That is hard to say, because there isn't any kind of data available for that. There is a real need to improve on the data." – a health care provider

Going forward, agencies such as the Minnesota Department of Health, local public health agencies, and the Centers for Disease Control and Prevention, should track tribal affiliation/enrollment of American Indians to facilitate future tribal-based health care needs assessments and related research and increase ability to identify tribal-specific needs.

Appendix

Acknowledgements

References

Appendix A: 2008 Health Disparities Study tables

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Appendix A: 2008 Health Disparities Study Tables

One of the secondary data sources for this study is the 2008 health disparities study, which was conducted on behalf of the Minnesota Department of Human Services. This study included adults and children who were randomly selected from all American Indian enrollees in one of Minnesota's public health insurance programs: Medicaid, Medical Assistance (MA), MinnesotaCare, or General Assistance Medical Care (GAMC); and who live in the Twin Cities seven-county metropolitan area.

The 155 children included in the study represent a population of 8,185 American Indian children who lived in the Twin Cities and were receiving public health insurance at the time of the study. The 194 adults included in the study represent a population of 13,085 American Indian adults who lived in the Twin Cities and were receiving public health insurance at the time of the study. The data were weighted to correct for unequal selection probabilities and post-stratified to represent the population (i.e., the sample universe of non-institutionalized enrollees as of March 31, 2008).

Caution should be used when generalizing the results from this sub-group to the entire target population, because public health insurance enrollees are by definition lower-income than the general population and therefore also have poorer health status than the general population. On the other hand, because American Indians are far more likely than the general population to be receiving public health insurance benefits, and overall a large proportion of all American Indians in the Twin Cities are insured publicly, particular attention to this sub-group is warranted.

Health Status

More information about the health status of these study participants is provided in Figures A1 and A2. Overall, American Indian public health insurance program enrollees have significantly poorer health status than white public health insurance program enrollees (Minnesota Department of Human Services, 2009).

A1. In general, would you say that your health is... (Q20)

	Percent of Adults (N=193)	Percent of Children (N=154)
Above or about average	72%	94%
Below average	28%	6%

A2. Are you limited in any way in activities because of physical, mental, or emotional problems? (Q21)

	Percent of Adults (N=194)	Percent of Children (N=153)
Yes	48%	16%
No	52%	84%

Health Insurance Coverage

Figure A3 illustrates the problems related to insurance coverage experienced by American Indians in the Twin Cities who are enrolled in one of Minnesota's public health insurance programs.

A3. Percent of respondents who said this is either a "big problem" or a "small problem" for them in getting needed health care (Q8)

	Percent of Adults (N=194)	Percent of Children (N=154)
Worried insurance won't cover needed care (8k)	46%	22%
Not sure if they have been dropped from MHCP (8p)	41%	32%

Health Care Service Use Patterns

Figures A4 and A5 illustrate the health care service use patterns of American Indians in the Twin Cities who are enrolled in one of Minnesota's public health insurance programs.

A4. Which of the following places best describes where you usually go for your health care? (Q9)

	Percent of Adults (N=196)	Percent of Children (N=155)
A doctor's office or clinic	64%	68%
An emergency room	3%	2%
An urgent care center	3%	2%
A hospital	<1%	1%
An outpatient clinic in a hospital	6%	10%
A community health center	1%	<1%
An Indian health center	11%	8%
Other		

A5. Types of health care received in past year (Q3, 2, 7, 6)

Within the past year	Percent of Adults (N=187-195)	Percent of Children (N=151-154)
Been to a doctor or clinic for regular or routine care	82%	79%
Been to a doctor or clinic for illness or injury	71%	80%
Been to the dentist	48%	65%
Been to a health care provider for emotional or mental health problem	33%	15%

Specific Health Concerns and Specialty Care Needs

Figure A6 illustrates the specific health concerns among American Indians in the Twin Cities who are enrolled in one of Minnesota's public health insurance programs.

A6. Overall, how would you rate your emotional health? (Q24)

	Percent of Adults (N=189)	Percent of Children (N=154)
Excellent/Very good/Good	59%	91%
Fair/Poor	41%	9%

Experiences with health care

Figures A7 – A12 illustrate the health care-related experiences of American Indians in the Twin Cities who are enrolled in one of Minnesota's public health insurance programs.

A7. Access to care: Percent of respondents who said this is either a "big problem" or a "small problem" for them in getting needed health care (Q8)

	Percent of Adults (N=194-195)	Percent of Children (N=155)
Getting an appointment as soon as needed (8c)	35%	43%
Getting an appointment with the doctor they want to see (8j)	29%	26%
Clinic isn't open when they can go (8g)	20%	14%

A8. Cultural responsiveness: Percent of respondents who said this is either a "big problem" or a "small problem" for them in getting needed health care (Q8)

	Percent of Adults (N=193-195)	Percent of Children (N=154-155)
Doctors are not trustworthy (8m)	23%	14%
Doctors don't understand their culture (8e)	15%	9%
Doctors don't speak their language (8b)	14%	12%
Place they go for health care is not welcoming (8o)	13%	10%
Doctors don't respect their religious beliefs (8h)	8%	2%

A9. Thinking about the place you usually go for health care, how often does your doctor or other health care provider... (Q10a-d)

	Percent of Adults (N=188-194)	Percent of Children (N=153-154)
Rate how well your usual doctor/provider explains thin	ngs in a way you can unde	erstand
Fair/Poor	17%	9%
Excellent/Very good/Good	83%	91%
Really find out what your concerns are		
Never/Sometimes	28%	17%
Usually/Always	72%	83%
Spend enough time with you to address your health of	oncerns	
Never/Sometimes	26%	14%
Usually/Always	74%	86%
Treat you as a partner in making health care decision	S	
Never/Sometimes	35%	17%
Usually/Always	65%	83%
Concerns about provider's practices (if any of the abo	ove are indicated as proble	ms)
Yes	45%	28%
No	55%	72%

A10. Cross-tabs: American Indian provider vs. providers of other races (Q10a, c, d X Q11)

	,	American Indian provider		r of other thnicity
	Percent of Adults (N=29-30)	Percent of Children (N=29)	Percent of Adults (N=147-150)	Percent of Children (N=116-117)
Rate how well your usual doctor/provide	r explains things in a	way you can ı	understand*	
Fair/Poor	2%	3%	20%	10%
Excellent/Very good/Good	98%	97%	80%	90%
Spend enough time with you to address	your health concerns	**		
Never/Sometimes	6%	18%	32%	13%
Usually/Always	94%	82%	68%	87%
Treat you as a partner in making health	care decisions***			
Never/Sometimes	9%	8%	39%	19%
Usually/Always	91%	92%	61%	81%

^{*} There is a statistically significant differences between adults who had a doctor of the same race and those who had a doctor of a different race (χ^2 =124.7139, p<0.001). The difference for children is not statistically significant.

^{**} There is a statistically significant differences between adults who had a doctor of the same race and those who had a doctor of a different race (χ^2 =161.0523, p<0.01). The difference for children is not statistically significant.

^{***} There is a statistically significant differences between adults who had a doctor of the same race and those who had a doctor of a different race (χ^2 =176.9743, p<0.01). The difference for children is not statistically significant.

A11. Trust in the doctor or health care provider they usually see (Q12)

	Percent of Adults who "somewhat disagree" or "strongly disagree" (N=192)	Percent of Children who "somewhat disagree" or "strongly disagree" (N=152)
I trust that my doctor or other health care provider has my best interests in mind when making health care decisions	11%	4%
	Percent of Adults who "somewhat agree" or "strongly agree" (N=190-192)	Percent of Children who "somewhat agree" or "strongly agree" (N=151-153)
I am afraid that my provider might not do enough to find out what is really making me sick	41%	25%
I am afraid that the health care I receive might actually make me feel worse	28%	12%
I am afraid that my provider might tell me that I have an illness I really don't have	20%	12%
I am afraid that my provider might not find an illness I do have	42%	25%
I am afraid my provider might not do enough to help me feel better	33%	18%

A12. Cross-tabs: American Indian provider vs. providers of other races (Q12a-f X Q11)

	American Indian provider		Provider of other race/ethnicity	
	Percent of Adults for whom this is a problem (N=55)	Percent of Children for whom this is a problem (N=28)	Percent of Adults for whom this is a problem (N=128)	Percent of Children for whom this is a problem (N=119)
I trust that my doctor or other health care provider has my best interests in mind when making health care decisions*		3%	18%	4%
I am afraid that my provider might not do enough to find out what is really making me sick	26%	15%	50%	28%
I am afraid that the health care I receive might actually make me feel worse	20%	12%	30%	12%
I am afraid that my provider might tell me that I have an illness I really don't have**	6%	8%	29%	12%
I am afraid that my provider might not find an illness I do have***	21%	18%	51%	26%
I am afraid my provider might not do enough to help me feel better	23%	9%	42%	21%

^{*} There is a statistically significant differences between adults who had a doctor of the same race and those who had a doctor of a different race (χ^2 =128.9174, p<0.05). The difference for children is not statistically significant.

^{**} There is a statistically significant differences between adults who had a doctor of the same race and those who had a doctor of a different race (χ²=141.5979, p<0.01). The difference for children is not statistically significant.

^{***} There is a statistically significant differences between adults who had a doctor of the same race and those who had a doctor of a different race (χ^2 =177.3245, p<0.05). The difference for children is not statistically significant.

Challenges To Accessing Health Care Services

Figure A13 illustrates the challenges to accessing health care services experienced by American Indians in the Twin Cities who are enrolled in one of Minnesota's public health insurance programs.

A13. Percent of respondents who said this is either a "big problem" or a "small problem" for them in getting needed health care (Q8)

	Percent of Adults (N=192-196)	Percent of Children (N=154-155)
Information		
Don't know what services their MHCP plan covers (8q)	46%	35%
Knowing where to go for help with health care questions (8r)	41%	20%
Knowing where to go (8d)	18%	13%
Cost		
Worried they will have to pay more for care than they can afford (8s)	55%	29%
Worried they will have to pay more for care than they expect (8I)	45%	22%
Worried that prescription will cost too much (8n)	38%	18%
Other things that make getting to the doctor more dif	fficult	
Transportation (8a)	49%	27%
Work or family responsibilities (8f)	30%	25%
Finding someone to take care of your (other) children (8i)	17%	23%

Health Care Preferences of the Target Population

Figure A14 illustrates the health care preferences of American Indians in the Twin Cities who are enrolled in one of Minnesota's public health insurance programs.

A14. Percent of respondents who said the following are "very important" in keeping them from getting sick (Q16a-d)

	Percent of Adults (N=181-192)	Percent of Children (N=148-153)
Visiting a spiritual healer or shaman	19%	12%
Visiting a chiropractor	25%	6%
Visiting an alternative or complementary health care provider such as an acupuncturist or herbalist	12%	8%
Visiting the doctor for a regular check-up or exam	75%	88%

Appendix B: 2010 IHS Data from GPRA Tables

Indian Health Service (IHS) Government Performance and Results Act (GPRA) data provides information about White Earth Nation members who received services from any IHS facility in 2010. For comparison purposes, data is also provided for all American Indians who received IHS services in the region served by the Bemidji Area Office. (The Bemidji Area Office of IHS provides health care and funding to support health services for American Indians and Alaska Natives residing in five states with tribal facilities in Minnesota, Wisconsin, Michigan, and Indiana; and urban centers in Minnesota, Wisconsin, Michigan, and Illinois. The total population served by the Bemidji Area IHS exceeds 90,000 individual patients. In 2010, 13 IHS or Tribal facilities in the Bemidji Area reported GPRA measures. Forty percent of the IHS user population was represented in 2010, the lowest representation among all 12 IHS areas.)

Also for comparison purposes, when available, data for all Minnesota adults (of all races) is reported using data from the Centers for Disease Control and Prevention's Behavioral Risk Factors Surveillance System (BRFSS).

B1. Diabetic measures

Diabetes measures ^a	White Earth enrolled members (GPRA 2010)	Bemidji Area members (GPRA 2010)
Poor glycemic control	22%	15%
Ideal glycemic control	28%	31%
Controlled blood pressure (<130/80)	42%	37%
LDL (Cholesterol) assessedb	76%	65%
Nephropathy assessedc	77%	54%
Retinopathy examd	54%	46%

^a Not available from BRFSS

B2. Dental measures

Dental measures	White Earth	Bemidji Area	Minnesota
	enrolled members	members	adults
	(GPRA 2010)	(GPRA 2010)	(BRFSS)
Dental: general access	38%	29%ª	79% ^b

^a Patients with a documented dental visit during the reporting period

b Low-density lipoprotein (bad cholesterol)

^c Potential diabetic complication of kidney damage

^d Potential diabetic complication of the eyes

^b Adults who visited a dental clinic in past year for any reason

B3. Immunizations

Immunizations	White Earth enrolled members (GPRA 2010)	Bemidji Area members (GPRA 2010)	Minnesota adults and children(BRFSS); MDH Child Immunization report
Influenza 65+	74%	67%	72%
Pneumovax 65+	94%	81%	70%
Childhood immunization	77%	77% ^a	58% ^b

^a Includes 4DTaP, 1MMR, 3HiB, 1HepB, 1Varicella series

B4. Prevention

Prevention	White Earth enrolled members (GPRA 2010)	Bemidji Area members (GPRA 2010)	Minnesota adults (BRFSS)
Cervical (Pap) screening	58%	54% ^a	88% ^b
Mammography screening	49%	46% ^c	83% ^d
Colorectal cancer screening	45%	38% ^e	72% ^f
Tobacco cessation (current tobacco users who have received tobacco cessation counseling during the report period) Alcohol screening (FAS prevention) (female patients 15-44 screened for alcohol use,	31%	29%	Not available
or who have alcohol related diagnosis) DV/IPV screening (female patients age 15 – 40 screened for domestic violence/intimate partner violence)	71% 66%	51% 54%	Not available Not available
Depression screening (among patients 18+)	70%	45%	Not available
CVD-Comprehensive screening ⁹	60%	39%	Not available
Prenatal HIV screening	90%	68%	Not available
Childhood Weight Control	Not available	38% ^h	23% ⁱ

^a Female patients 21-64 with pap screening in past 3 years

b includes 4+DTaP, 3+ IPV, 1+ MMR, Completed HiB, 3+ HepB, 1+Varicella, Completed Prevnar

b Women 18+ with pap screening in past 3 years

^c Female patients 52-64 with mammogram in 2 years

^d Women age 50+with mammogram in past 2 years

e Patients 51-80 who have received any colorectal cancer screening in past year

f Adults 50+ who have ever had colonoscopy or sigmoidoscopy only

^g Assessment includes BP, LDL, Tobacco use, BMI, and lifestyle counseling

h Patients 2-5 years of age with BMI at or above 95th percentile

Children age 10-17 at or above 95th percentile OR 85-95th percentile

Appendix C: Background Information on Health Care Coverage for American Indians in Minnesota

"The U.S. government has a trust responsibility based on treaty obligations and federal statutes to provide health care to members of federally recognized tribes" (Kaiser Family Foundation, 2004). Indian Health Service (IHS) operates within the U.S. Department of Health and Human Services. Most IHS facilities are located on Indian Reservations, but IHS also provides funding to 33 urban Indian health care programs nationally. Although over half of the American Indian population in the U.S. lives in urban areas, only about 1 percent of IHS's annual operating budget of \$2.8 billion is spent in urban areas.

However, eligibility for IHS services is determined based on tribal enrollment, and based on federal law. Therefore, some of the American Indian people in the Twin Cities are not eligible for IHS services, even if they are geographically accessible. (It is unknown what proportion of American Indians in the Twin Cities are tribally enrolled.) American Indians who are not tribally enrolled are subject to the same health care coverage options as the general population.

Finally, it is clear from many comments made by health care providers who participated in this study that eligibility for various programs or services is confusing, particularly with the added layer of complexity of IHS services and eligibility.

"Once they hit the Cities, Indian Health Service doesn't cover them."

"MinnesotaCare doesn't require co-pays or premiums for American Indians".

"We have contract health services within IHS, where a member lives in the contract health delivery area, the five counties touching the reservation. If you live outside the five counties, you are not eligible for contract health services. Contract health services pays for all medical needs. But if you live outside that five county area, you would not be eligible for that."

"Shakopee sees people who live in Scott County, so they can go there. They provide free care to any Indians that live in Scott County."

"There are a lot of perception issues. It is common knowledge that Native Americans have a lot of health disparities. It is also commonly thought that Native people have wonderful health service available. And it is thought that Indian people have a lot of money, due to gaming. There is that perception out there that they must be getting something. IHS is only funded at 50% of need in the Bemidji area in MN."

For more information about IHS, see:

http://www.ihs.gov or http://en.wikipedia.org/wiki/Indian_Health_Service

For more information about health care coverage and access to care for American Indians, see:

"American Indians and Alaska Natives: Health Coverage and Access to Care," The Henry J. Kaiser Family Foundation, February 2004, Menlo Park, CA.

Appendix D: Background Information on Health Care Reform and the Impact on the Target Population

For more information on the Affordable Care Act (ACA) Provisions for American Indians see:

Heisler, E. J., & Walke, R. (2010). *Indian Health Care Improvement Act: Provisions in the Patient Protection and Affordable Care Act (P.L. 111-148)*. Washington, DC: Congressional Research Service.

Indian Health Service. (2011). *The Indian Health Care Improvement Reauthorization and Extension Act S. 1790 as reported and included in H.R. 3590.* Retrieved from http://www.ihs.gov/PublicAffairs/DirCorner/2011_Letters/07-05-2011%20Enclosure.pdf

U.S. Department of Health and Human Services. (2011). Fact sheet: How does the Affordable Care Act impact American Indians and Alaska Natives? Retrieved from http://www.healthcare.gov/news/factsheets/2011/03/americanindianhealth03212011a.html

For more information on Minnesota's 2008 Health Care Reform, including the provisions for the establishment of Health Information Exchanges (HIE), e-Prescribing (ERx) and Electronic Health Records (EHRs) which structure the methods of data sharing across provider settings, see:

Minnesota Department of Health. (2011). *Electronic prescribing guidance: Understanding the e-prescribing mandate*. Retrieved from http://www.health.state.mn.us/e-health/eprescribing/erx032011guidance.pdf

Minnesota Department of Health, & Minnesota e-Health Initiative Advisory Committee. (2008). Appendix B: Minnesota's 2015 interoperable EHR mandate: Impacting all providers and care delivery settings. In Author, *A prescription for meeting Minnesota's 2015 Interoperable Electronic Health Record Mandate: A statewide implementation plan*. Retrieved from http://www.health.state.mn.us/e-health/hitimp/appendixb.pdf

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Appendix E: Key informant interview script

Minnesota Department of Health White Earth Nation Community Health Assessment Key Informant Interview

Introduction:

Hello, may I please speak with [informant].

My name is [interviewer name] and I am calling from Wilder Research in Saint Paul. We're calling you because you have been identified as someone who knows about health care needs and/or health care services currently available to White Earth Nation members and other American Indians who get their health care in the Twin Cities.

We are calling to see if you would be willing to participate in a phone interview as a part of a community health assessment that we are conducting for the Minnesota Department of Health. This study was requested by the Minnesota Legislature in 2011. White Earth Nation lobbied the legislature to appropriate funds for this study, as the Tribal leadership recognizes there may be significant unmet health care needs among this population. The results of the study will be used to inform the Minnesota Legislature, the Minnesota Department of Health, White Earth Nation, and other stakeholders about the unmet health care needs for this population. This study will also produce recommendations for potential new facilities or services that are most needed, along with a feasibility and cost analysis for the proposed facilities and services.

This interview will take about an hour, depending on how much you have to say and how many different topic areas you have knowledge about and can speak to. Is now a good time to do the interview?

IF NO – When would be a better time to complete the interview? (AS NEEDED: We're wrapping up the interviewing for this study by the end of January, so we'd like to set up a time before then.)

IF YES – Great! Just so you know, everything you tell me in this interview is confidential. The results of your interview and survey will be combined with the responses from other individuals we are interviewing and will be used by Wilder Research and the Minnesota Department of Health to make recommendations in a report to the Minnesota Legislature, which will be completed by March 2012.

Message Script

Hello, I am calling from Wilder Research in Saint Paul. You have been identified as someone who knows something about the health care needs or health care services available to White Earth Nation members and other American Indians in the Twin Cities, and we would like to interview you as a part of a community health needs assessment we are conducting for the Minnesota Department of Health, White Earth Nation, and the Minnesota Legislature. Please call Ron Mortenson at 651-280-2686 to schedule an appointment to do the interview. Thank you!

Background of informant

- 1. First, please tell me about your role in the organization.
 - a. What are your responsibilities?
 - b. How long have you worked there?
- 2. Tell me about your agency.
 - a. What populations does your agency serve? (Specifically White Earth Nation members? Other American Indians?)
 - b. What services does your agency provide?
 - c. What geographic area do you serve? (IF AGENCY SERVES A LERGER AREA THAN TWIN CITIES, ASK: What proportion all your services are provided in the Twin Cities 7county metro area?)
 - d. How long has your agency provided services?
 - e. How many patients/clients is your organization currently serving?
 - Is your organization currently at capacity in terms of the number of patients/clients you can serve?
 - IF CURRENTLY NOT AT CAPACITY: What are the reasons why your organization is not currently serving clients at full capacity? How many more clients/patients could you accept at the current time to reach your full capacity?
 - What is the average length of time between when a client calls for an appointment and when they can get in?

Health status and health care utilization of American Indians in Twin Cities

- 3. Thinking about American Indians who live and/or get their health care in the Twin Cities, in your experience, what are the most significant health challenges facing this population? [PROBE: Any specific needs for families with children? What about young adults? Single adults? Elders?]
- 4. This study is focusing in particular on White Earth Nation members who get health care in the Twin Cities. Have you observed any specific health care needs for White Earth members (including those listed in the previous question and any others)?
- 5. We are interested in gathering some information about the health care-related mobility of White Earth Nation members as well as other American Indians living in the Twin Cities. In your experience, how frequently do American Indians who are living in the Twin Cities seek health care on their home reservation or elsewhere?
 - What about the reverse American Indians who live on Minnesota Reservations who seek their health care in the Twin Cities?
 - What are some of the reasons why White Earth Nation members might seek health care in a different place from where they live? Are these reasons the same for other American Indians who are not White Earth members? (IF REASONS ARE NOT THE SAME: How do White Earth Nation members differ? And why?)
 - What is the impact of that mobility on your organization's ability to provide high quality health care to this population? What is the impact on other organizations?
 - How does your organization keep track of patients/clients who are moving back and forth between the reservation and the Twin Cities?

Availability of health care services in Twin Cities

- 6. Generally, do you feel American Indians living in the Twin Cities have adequate access to primary health care services? Why or why not?
 - IF NOT ALREADY ANSWERED: Does your organization provide primary care services?
 - What other organizations in the Twin Cities are you aware of that target American Indians for primary care services?
- 7. Do you feel American Indians living in the Twin Cities have adequate access to specialty services? Please describe. [PROBE: mental or behavioral health, chemical dependency, diabetes, asthma, cancer, maternity care, geriatric care, etc.]
 - IF NOT ALREADY ANSWERED: Does your organization provide any specialty services? Which services?
 - What other organizations in the Twin Cities are you aware of that target American Indians for these specialty care services?
- 8. Does access to health services differ for members of different tribes (i.e., White Earth members versus others)? If yes, how does it vary?
- 9. How do American Indians living in the Twin Cities become aware of the health care service options available to them? In general, do you think most American Indians in the Twin Cities are aware of the health care options available to them?
 - How do your clients find out about or know about your services?
 - From what other organizations or agencies does your organization receive referrals?
- 10. In your experience, are available health services generally culturally responsive in serving the American Indian population? Why do you see it that way?

Challenges/barriers to accessing available services

- 11. What do you see as the top two or three barriers American Indians face in accessing primary care services in the Twin Cities? [PROBE: Any specific barriers for families with children? What about young adults? Single adults? Elders?]
- 12. What do you see as the top two or three barriers to accessing available specialty care services in the Twin Cities?
 - Which specialty services are most challenging to access, and why?
- 13. Are there any challenges that are unique to the American Indian population, that other population groups may not experience? (e.g., challenges with IHS covered services, tribal enrollment, etc.)
- 14. Are certain sub-groups within the American Indian community more or less likely to use health care services than others?
 - Which groups, and why?
- 15. How could barriers/challenges better be addressed to ensure the community is able to access what services are available?

Gaps in available services

- 16. What needed health care services are lacking or largely unavailable to American Indians living in the Twin Cities? Why?
- 17. Thinking in particular about White Earth nation members, are there any services that are especially challenging for this population?

Recommendations/opportunities for expanding/enhancing existing services

- 18. In your opinion, what are the top two or three ways health care services can be improved for the American Indian population living in the Twin Cities? (PROBE: this may include improving access to existing services, improving existing services, and/or adding new services that do not currently exist in the community)
- 19. What should be done to increase the utilization of existing services among American Indians?
- 20. What suggestions, if any, do you have regarding opportunities for medical partnerships among existing organizations (yours or others) that should be explored?
- 21. What are the **critical** cultural issues that should be considered when developing new clinics/services for American Indians?
- 22. In your opinion, what types of health services for American Indians in the Twin Cities are most likely to be supported at the local and/or state level? At the tribal level? Why?
- 23. Which types of health services would be the most challenging to get support for? Why?

Services and costs

As part of this assessment, after we have completed this first step of information gathering to determine which types of services are needed in the community, we are planning to develop some preliminary costs associated with the types of service enhancement/expansion. Would you, or someone else from your organization, be willing to talk with us again in a few weeks about some potential start-up and maintenance costs for different services? [Get NAME and CONTACT INFO for relevant person, and specifically name which type(s) of services they can speak to]

Other key informants

Are there any other individuals who know a lot about the health care needs and preferences of White earth nation member sand other American Indians in the Twin Cities that we should consider interviewing for this project? This would include people who provide health care to this population and/or people who are very familiar with the health care needs and preferences of this population. If so, what is their role/title? What additional information do you feel they could provide? Name:

Phone number:

Email:

Those are all the questions we have at this time. Do you have any questions or comments for us? Thank you for your time!

Appendix F: Focus Group Participant Characteristics, Focus Group Questions, and Post-Survey

F1. About focus group participants (114 participants)

Tribal Affiliation	
White Earth	61%
Other reservation	35%
Not identified	4%
Age group	
Elders	39%
Families with children	38%
Adults without children	23%
Primary residence	
Minneapolis	68%
Saint Paul	20%
Suburbs (Twin Cities 7-county metro)	12%
Secondary residence	
Only have a primary residence	90%
Minneapolis	5%
Saint Paul	2%
Suburbs (Twin Cities 7-county metro)	0%
Reservation community	3%
Location of receiving health care	
Twin Cities only	88%
Twin Cities + White Earth	5%
Twin Cities + Other reservation	7%
Insurance status	
Public insurance	74%
Private insurance	14%
Uninsured	12%

F2. Focus groups host and target demographic

		Target demographic					
Host organizations	Location	Elders	Families with children	Young adults (age 18-31 without children)	Older adults (age 32-50 without children)		
American Indian Family Center	Saint Paul (Eastside)		X	X			
Cultural Wellness Center	Minneapolis (Phillips)		X				
Minneapolis American Indian Center	Minneapolis (Phillips)	X	X				
Omniciye Program	Minneapolis (Phillips – Little Earth)	X	Х	X	X		
White Earth Urban Office	Minneapolis (Phillips)	X					

Circles Protocol White Earth Nation Health Assessment

Welcome

- 1. Host organization welcome
- 2. Background info
- 3. Purpose: The purpose of the listening circle is to learn about the health care needs and preferences of White Earth Nation members and other American Indian people who seek and/or receive care in the Twin Cities. We are trying to identify any unmet health care needs in the community as well as important considerations related to culturally appropriate services.
- 4. Describe purpose of note taker and recorder (to use as back-up in case we miss anything in the notes we want to record your thoughts accurately) and ask everyone's permission to turn it on.
- 5. Everyone has been given a piece of paper to take notes. On the back side is a quick survey (please do not fill out until the end). You will turn in this paper to receive your \$20 incentive.

Introductory question. Please tell me your name and how you keep yourself and your family healthy? [Looking to define health – mental, physical, spiritual, psychological, chemical]

Please tell me where or who you turn to when you have health or wellness needs.

[Current access - Looking for **NAMES** of <u>clinics</u>, <u>organizations</u>, <u>institutions</u>, <u>individuals</u>] [Why do people go there?]

[MIGRATION PATTERN (IF IT SURFACES): To what extent do you or others from your family travel to the reservation for health care services? If this happens, what are the reasons why you would seek health care in a place other than where you live?]

Please tell me what makes it challenging to be healthy.

[Barriers - Why can't you get that help? – Is it cultural barriers, accessibility, discrimination, etc.] [To what extent aren't the clinics meeting your needs?]

[Wait time, being "flagged"]

[Looking for distinction between primary care and specialty care needs]

Imagine you have the power to create a health or wellness resource for you, your family, or your community. Please tell me that health or wellness resource would be and why.

[What health or wellness resource isn't available that you think should be?]

[Specialty need? Types of services?]

[Culturally responsive? Provider who is American Indian?]

[Care coordinator?]

Survey and Incentives

a) You will turn in the piece of paper with the survey on the back side. <Note taker> will check the survey for completeness and give you another form. You need to sign this form. If you are interested in receiving a copy of the report, you will provide your contact information. The <host organization> will also be sent copies of the report. The summary report should be ready sometime this spring.

Focus group post survey

Please tell me how you keep yourself and your family healthy? [What is your definition of health?]					
[What is your definition of houter.]					
					
Please tell me where or who you turn to when you have health or wellness needs. [NAMES of clinics, organizations, institutions, individuals]					
Please tell me what makes it challenging to be healthy. [What barriers exist? What needs are not being met?]					
Imagine you have the power to create a health or wellness resource for you, your family, or your community. Please tell me what that health or wellness resource would be and why.					

TO RECEIVE YOUR \$20 INCENTIVE, YOU WILL NEED TO FILL OUT THE SHORT QUESTIONAIRRE ON THE OTHER SIDE \rightarrow

SHORT QUESTIONAIRRE

Age : (years)	Gender:	
Tribal affiliation (Whit	te Earth/Red Lake/etc.):	
Location of primary r	residence (Neighborhood/Ci	ty):
Location of secondar	ry residence (if applicable) (Neighborhood/City):
Your health insurance 1. No insurance 2. Public insurance, su 3. Private insurance		IA), MinnesotaCare, General Assistance
If you are currently ir	nsured, who is your health	insurance provider:
 Twin Cities area White Earth Reserva Other Reservation. 		in the following locations (circle all that apply):

Where do you usually go for your health care needs? (Respond to every question)

(What about/Do you use)	Yes	No
a. A doctor's office or clinic	ρ^1	ρ^2
b. An emergency room	ρ^1	$ ho^2$
c. An urgent care center	ρ^1	ρ^2
d. A hospital	ρ^1	ρ^2
e. An Indian health center	ρ^1	ρ^2
f. A mental health provider	ρ^1	ρ^2
g. A spiritual or traditional healer or herbalist	ρ^1	ρ^2
h. Elders	ρ^1	ρ^2
 i. A place of worship or sacred space such as a church, mosque, synagogue, or sweat lodge 	ρ^1	$ ho^2$
j. A fitness center	ρ^1	ρ^2
k. A pharmacy	ρ^1	ρ^2
I. Support groups	ρ^1	$ ho^2$
m. Your support network of family and friends	ρ^1	ρ^2
n. A social worker or home visitor	ρ^1	ρ^2
o. Someone or something else? (Please specify:	- -) ρ ¹	$ ho^2$

Appendix G: List of FQHCs and Other Safety Net Providers that Serve American Indians in the Twin Cities

Key	Organization Name	Primary Care	Specialty Physician Services	Dental	Mental Health	Pharmacy	Other	HRSA Grant Type	Mentioned by study participants
1	American Indian Family Center				х		Х		Х
2	American Indian Community Development Corportation (Kola & Anishinabe Wakiagun)	х	х		х		х		х
3	Cedar Riverside People's Center	Х		Х	х	Х	Х	CHC	
4	Central Avenue Clinic	Х			х		Х	CHC	
5	Community Dental Care			Х					Х
6	Community-University Health Care Center, University of Minnesota	х	х		х		х	CHC	x
7	DBA Northpoint Health and Wellness	х		х	х	х	х	CHC	
8	Division of Indian Work						х		Х
9	Fairview Recovery Services		Х				Х		Х
10	Family Dental of South Minneapolis			Х					
11	First Nations Recovery Center						Х		Х
12	Fremont Clinic	х			х		х	CHC	
13	Hennepin County Public Health Clinic	Х	Х			х	х	CHC, HCH	х
14	Indian Health Board of Minneapolis	Х	Х	х	х		х	CHC	х
15	Juel Fairbanks						х		Х
16	Mashkiki Wakiagun					х			Х
17	Minneapolis American Indian Center						х		х
18	Minnesota Indian Women's Resource Center				х		х		х
19	Native American Community Clinic	х		х	х			CHC	х
20	Open Cities Health Center	х	Х	х	х	х	х	CHC	
21	Open Cities North End Clinic	х	х	х	х	х	х	CHC	

Key	Organization Name	Primary Care	Specialty Physician Services	Dental	Mental Health	Pharmacy	Other	HRSA Grant Type	Mentioned by study participants
22	Overcomers Outreach Ministries						х		х
23	PCHS Teen Age Medical Services						Х	CHC	
24	Plymouth Christian Youth Center						Х	CHC	
25	Running Wolf Fitness Center						Х		Х
26	Seward Co-op						Х	CHC	
27	Sheridan Women and Children's Clinic	х	Х					CHC	
28	Universal Medical Services - AXIS Medical Center	х	Х				Х		
29	Upper Midwest American Indian Center						Х		х
30	Southside Vision Care						х	CHC	
31	Westside Community Health Services, Inc.	х	х	Х	х	х	х	CHC	
32	YouthLink	х						CHC, HCH	
Not on map; in Wash. Co.	St. Croix Family Medical Clinic	х			х		х	CHC	