Health Disparities Project:

Social risk factors that limit wellness, and potential mitigating supports

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The Improve Group

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Executive summary

In order to assist in developing a methodology for healthcare payment rates that takes into account disparities in health, the Minnesota Department of Human Services (DHS) has commissioned a study to gather community input on social risk factors that make it difficult to stay healthy, and ways in which these barriers could be addressed. Fifty-one semi-structured interviews with stakeholders (37 community members, 7 social service organization staff, and 7 physicians) highlighted the following social risk factors and potential supports as especially important.

Social Risk Factors

Income and tangible resources

- 1) Housing instability and homelessness
- 2) Insufficient access to healthful foods
- 3) Insufficient access to childcare
- 4) Transportation challenges
- 5) Low educational attainment

Mental and behavioral health challenges

6) Challenges accessing mental and behavioral healthcare

Culture, language, and immigration status

- 7) Non-fluency in English language
- Differences in cultural understanding and not fully trusting providers
- 9) Immigration status

Potential Mitigating Supports

- 1) Strengths-based approaches and team-based care
- 2) Prevention
- 3) Collaboration between communities and the healthcare system
- 4) Tests or wellness education in the home or neighborhood
- 5) Free groceries at the clinic or pharmacy
- 6) More clinic staff with language and culture knowledge
- 7) Help getting mental and/or behavioral healthcare
- 8) Help getting childcare while at the doctor
- 9) Clinic being open evenings and/or weekends

Introduction

Project purpose

The purpose of this project is to obtain community input on social risk factors that make it difficult for individuals who have experienced or are currently experiencing homelessness, poverty, and/or immigration to stay healthy, and ways in which medical providers, the healthcare system, and communities can help mitigate these risk factors. The Minnesota Department of Human Services (DHS) will use this community input when developing a methodology for healthcare payment rates that takes into account disparities in health, and costs associated with helping those with the greatest health disparities achieve the same health and quality outcomes that are achieved for other patients and populations.

About DHS

The Minnesota Department of Human Services (DHS) works with counties, tribes, nonprofits, and other service providers to assist Minnesota residents, including seniors, people with disabilities, children, and others, with meeting their basic needs. DHS is largely involved with setting policies and directing payments for services delivered.¹

About The Improve Group

The Improve Group conducts rigorous studies to help organizations make the most of information, navigate complexity, and ensure their investments of time and money lead to meaningful, sustained impact. The Improve Group is based in St. Paul, Minnesota, and provides research, evaluation, and strategic planning services to organizations locally, nationwide, and internationally.

Study questions

This study is guided by three primary questions relating to the focus populations of people who have experienced or are experiencing homelessness, poverty, and/or immigration:

¹ <u>http://mn.gov/dhs/general-public/about-dhs/what-we-do/index.jsp</u>

- 1) What factors make it difficult for people to meet their healthcare needs (such as being healthy, finding a provider, obtaining needed services, managing health conditions)?
- 2) What factors help or make it easier for people to meet their healthcare needs (such as being healthy, finding a provider, obtaining needed services, managing health conditions)?
- 3) Would clinics providing additional services be a substantial value to target populations?

Secondary questions considered within the analysis of this study are:

- 4) Do interviewees mention any difficulties associated with race/ethnicity or country of origin?
- 5) Are there any social risk factors currently under examination by DHS for the purpose of care reimbursement determination (see Appendix B) that do not appear to be a major consideration for study participants?
- 6) Are there any social risk factors that pose major challenges for study participants that are not currently under consideration by DHS?

Methodology

Gathering preliminary insights

We began the study by having preliminary 15-minute phone conversations with seven physicians serving the primary population groups for this study (individuals who have experienced or are experiencing homelessness, poverty, and/or immigration). Physicians provided insight into common barriers faced, ways in which clinics and/or communities may help to mitigate those barriers, and ways in which serving the study's target populations can incur additional costs for clinics. The information provided through these conversations helped shape development of interview protocols, including a question asking whether ten potential services recommended by providers would be beneficial for patients (see Appendices E and F).

One of the providers consulted works in a rural area in northern Minnesota, and provided insights into challenges experienced by the low-income rural populations with whom he works, as well as some ways to potentially address these challenges in a rural setting.

Outreach to community organization partners

We conducted outreach to organizations in the Twin Cities (Minneapolis and St. Paul) metropolitan area that serve the study's target populations, and formed partnerships with eight organizations that were able to facilitate interviews with community members/clients, staff, or both.² We reached out to organizations providing a range of primary services (homelessness services, immigrant services, and general social services) in order to obtain a balance of participants between the study's three primary population focus areas. Study partners are represented in Table 1.

Services provided at partner organizations	# Staff interviews	# Client interviews	Low income clients served	Homeless clients served	Immigrant clients served
General social services	1	5	Х	X	
General social services	1	0	Х		Х
General social services	0	5	Х		
Homelessness services	0	6	Х	Х	
Homelessness services	1	5	Х	Х	
Immigrant services	1	6			Х
Immigrant services	2	9	Х		Х
Transitional housing and general social					
services	1	0	Х	Х	
Totals	7	37	7	4	3

Table 1: Organizations' services and the populations served varied.

Sampling and study participants

We used convenience sampling in this study: each partner organization linking us with clients notified community members with whom it works of the opportunity to participate in the study, and arranged for a number of interested individuals to participate in interviews at the organization's facility. Time limitations of the study precluded purposeful sampling to gain participation from proportionate

² Project scope limitations prevented us from partnering with organizations outside of the metro area. However, insights into rural factors were provided by a medical provider interview, as noted above.

numbers of individuals from demographic subgroups; rather, we interviewed interested individuals who were available.

Study limitations also constrained the community member and organization staff participants to English speaking individuals. This latter limitation prevented us from gaining direct insights into barriers faced by patients with limited English proficiency; however, we were able to gather second-hand insights on this topic as participants relayed experiences of friends and family members with limited English proficiency.

For the purpose of this study, homelessness was defined as "a person is living in a place not meant for human habitation, in emergency shelter, or in transitional housing." Table 2 describes demographic characteristics of the 37 community members interviewed.

Partner organization staff who were interviewed were individuals who work closely with populations served. Staff interviewees held roles of program director or manager (2 interviewees), case manager (4 interviewees), and executive director (1 interviewee).

Characteristic		n	%
Age	18 – 25	11	30%
	26 – 35	14	38%
	36 – 45	2	5%
	46 – 55	3	8%
	56 – 65	4	11%
	66+	3	8%
Sex	Female	22	59%
	Male	15	41%
Family monthly	Up to 50% Federal Poverty		
income ³	Guidelines (FPG)	11	30%
	51% - 133% FPG	17	46%
	134%-165% FPG	4	11%
	165% FPG	2	5%
	over 165% FPG	1	3%
	Chose to not disclose	2	5%
Race / Ethnicity	African	12	32%
	African American	13	35%
	American Indian or Alaska Native	1	3%

Table 2: Community member participant demographics, N=37

³ Before taxes, adjusted for number of people in family, see income table in Appendix A.

Characteristic		n	%
	Asian	3	8%
	Hispanic or Latino	2	5%
	White	6	16%
Highest level of education	Elementary, junior high, or some high school	5	14%
	High school Diploma or GED	12	32%
	Some college courses completed	10	27%
	Trade school, technical, or		
	community college degree	1	3%
	4-year degree or higher	9	24%
Country or territory of origin	Cameroon	1	3%
	China	1	3%
	Ghana	1	3%
	Guinea	2	5%
	Kenya	1	3%
	Liberia	2	5%
	Mexico	1	3%
	Nepal	1	3%
	Nigeria	1	3%
	Puerto Rico	1	3%
	Sierra Leone	2	5%
	Somalia	2	5%
	U.S.	21	57%
Current city of			
residence	Brooklyn Park	2	5%
	Champlin	1	3%
	Minneapolis	21	57%
	Minnetonka	1	3%
	New Hope	1	3%
	Richfield	1	3%
	St. Louis Park	1	3%
	St. Paul	7	19%
	Chose to not disclose	2	5%
Currently homeless or living in transitional			
housing	Yes	16	43%
	No	21	57%
Experienced homelessness or transitional housing in last 5			
years	Yes	21	57%
2	No	16	43%

Data Collection

Data was collected through 37 twenty-minute semi-structured interviews with community member participants. These interviews were conducted in-person, and held on-site at the partnering community organizations. Additionally, 7 thirty-minute semi-structured interviews with staff members from partnering community organizations were conducted, either by phone or on-site.⁴ Typed notes were taken in all interviews, and most interviews were audio recorded (unless the participant requested otherwise). Verbal informed consent was obtained for all interviews (see Appendices C and D for consent documents).

A \$25 Visa gift card was provided as incentive for community member participants. No incentive was provided for participants who were staff members of community organization participants, or to medical providers who were interviewed.

Analysis

Interview data was analyzed by theme using qualitative data analysis software Dedoose. It is important to note that this study's sample is small, is a convenience sample, and is primarily metro-based. Therefore, findings from this study may be used to provide important insights into community members' experiences, but should not be used to make generalizations to larger populations.

Reporting

The findings of this study are reported in two primary sections: social risk factors that inhibit meeting healthcare needs, and supports that may help mitigate these risk factors, as suggested by study participants. For each section of the report, a brief discussion is presented, followed by a sample of paraphrased comments from participant interviews. Scope limitations of the study precluded transcribing direct quotes from audio recordings; however, the paraphrased comments are taken from typed interview notes and reflect the points made by participants as closely as possible. Brief demographic identifiers of the speaker are provided after each

⁴ One of the staff interviews was 15 minutes in duration, rather than 30 minutes.

paraphrased comment, with the exception of medical providers, who are all physicians.

Institutional Review Board (IRB)

The DHS IRB approved this study, including consent forms, protocols, and procedures.

Findings

Study participants discussed a wide range of factors that both impeded and supported overall wellness and benefitting from healthcare services. Part I of this report presents the social risk factors noted by study participants that were most frequently discussed. Also included are risk factors that, according to medical providers who contributed to the study, potentially have a major impact despite not being widely discussed within this particular study's small sample. For each risk factor, a brief discussion is presented, followed by paraphrased participant comments that illustrate the discussion. A short section that compares and contrasts the social risk factors currently under examination by DHS for the purpose of care reimbursement determination (see Appendix B) with those social risk factors discussed by study participants concludes Part I.

Part II of the report presents a number of supports that participants felt have the potential to help mitigate the challenges discussed in Part I. These may be supports that could be provided by healthcare clinics, or more broadly by communities.

Part I: Social risk factors impeding health and wellness

The social risk factors discussed by study participants are complex and may intersect or overlap with one another in multiple ways, but for the purposes of this report, I am grouping social risk factors into the primary categories of factors related to income and tangible resources; to mental and behavioral health challenges; to culture, language, and immigration status; and to demographic considerations. The social risk factors discussed in this report are:

Income and tangible resources

- 1) Housing instability and homelessness
- 2) Insufficient access to healthful foods
- 3) Insufficient access to childcare
- 4) Transportation challenges
- 5) Low educational attainment
- 6) Low family income: other effects

Mental and behavioral health challenges

7) Challenges accessing mental and behavioral healthcare

8) Domestic and relationship violence and sex work

Culture, language, and immigration status

- 9) Non-fluency in English language
- 10) Differences in cultural understanding and not fully trusting providers
- 11) Immigration status
- 12) Preferred treatment outside of the Western medical model

Demographic considerations

- 13) Rural challenges
- 14) Challenges specific to race or ethnicity

Social risk factors related to income and tangible resources 1) Housing instability and homelessness

Housing instability and homelessness can take various forms, including moving frequently, staying temporarily with friends or relatives, living in limited term transitional housing, staying in homeless shelters, and living in a car or on the streets.⁵ Many study participants experiencing housing instability and homelessness associated their experiences with low incomes and high housing costs, and personal histories that limit housing options such as having incarceration or eviction records. Partner organization staff observed that these factors can lead to living in neighborhoods having high levels of violence, as well as in poorly maintained housing, which can pose health risks when containing molds, pests, and rodents.⁶ Other effects of housing instability on health described by study participants can include losing Medical Assistance (MA) coverage due to moving from one county to another and not receiving MA paperwork due to frequently changing addresses. Further effects of housing instability and homelessness on health are reflected in the paraphrased participant and stakeholder comments below, with the following themes:

• Chaos of homelessness can impede medical treatment and care,

⁵ <u>http://www.partnering-for-change.org/what-is-housing-instability/</u> <u>http://www.endhomelessness.org/library/entry/changes-in-the-hud-definition-of-</u> <u>homeless</u>

⁶ <u>http://www.cdc.gov/nceh/publications/books/housing/cha04.htm</u> <u>http://www.cdc.gov/nceh/publications/books/housing/cha05.htm</u>

- Exposure to violence through living on the streets or in neighborhoods with high levels of violence can cause physical injury and stress,
- Unaffordable housing can prevent spending funds on medical care,
- Incarceration records can limit available housing options (perhaps limiting individuals to more expensive and less desirable housing), and
- Securing housing is often prioritized over seeking healthcare.

Community members say:

Chaos of homelessness

I don't have housing now. Slept at Salvation housing once, another place once. Been homeless 4-5 months, it's not that short of a time, but I'm still new to it and spin around a lot: trying to find places to sleep, not having enough sleep, or to eat. It takes a lot to survive while homeless, more effort than living in a house. (female, white, 18-25 years old)

Violence

I try to hide at night. I have PTSD so I can't be around all the people at shelters, people like to steal my things and I get into fights so I don't like shelters. I have frostbite on my fingers. I got jumped in the projects and they beat me with a U-lock and chain, but I can't go to the Emergency Room because the people who jumped me would shoot me (because they'd assume I told who beat me). If the ER didn't ask me who did it and try to solve a crime, if they would just treat me, then that would help. (male, American Indian, 26-35 years old)

If you go to school during the day and have to work during the night; there's bad people out there at night. I'd take the bus which dropped me three blocks from my house, and this guy came and ran after me yelling "give me money," I got scared of being raped so ran to a house I don't even know and hid in the yard and he looked around and couldn't find me and he went back. I was scared. (female, African, 18-25 years old)

Unaffordable housing impedes medical treatments and care

We live in a mobile home park and the rent is going up every year. It's almost \$700. So sometimes when I feel sick I would rather just suck it up and move on, because that's money that can go for paying rent or bills. (female, Latina, 26-35 years old)

I'm living in a boarding lodge. Been temporary, lived there 23 years. My meds have been stolen a few times, I'm trying to see if I

can talk to someone to help me find a better place to live in a better neighborhood, this has torn me and my family apart. Lot of stealing. The place I live now costs me almost \$900 a month. (male, white, 56-65 years old)

Other housing barriers

Having a felony makes it harder to find housing and work. (male, Latino, 26-35)

The section 8 lists are too long, we've been on the waiting list in Dakota County since 2008. (female, white, 66 or older)

Community organization staff say:

Healthcare less urgent than other issues

Many clients are dealing with specific issues that are more urgent than health, like getting housing. If you tell them 'you need to make an appointment for health,' they tell you 'no, first thing is I need is a place to sleep.' Much of the time health is not a priority because of other crises. (Case Manager, general social services)

When you're homeless you think minute to minute, you don't think about getting healthcare—it's your last concern. In transitional housing, they're focusing on employment, and education. (Case Manager, general social services)

Unaffordable housing

Affordable housing is a big problem. Sometimes refugee assistance runs out before SSI kicks in, then there's a gap in income and housing is too expensive. They end up in neighborhoods that are unsafe, or the housing is unkempt, dirty, or they have unresponsive landlords. It's the lowest end of the market. (Case Manager, immigration services)

Medical providers say:

Chaos of homelessness (including traumatic brain injury) impedes

medical treatment and care

Impaired functioning due to life chaos of homelessness affects all aspects of making and keeping appointments and following treatment plans. People experiencing homelessness often don't have phones.

Without stable housing, medications can be stolen, it's hard to do special treatments because they're on the streets all day, and you can't expect patients to carry items like medications or treatment equipment with them. Occurrence of traumatic brain injury (TBI) is high among homeless populations and causes memory loss and inability to manage daily activities, such as following treatment plans and remembering appointments.

Additional costs for treating this population

Higher no-show rates for homeless populations leads to unreimbursed time and staff/facility resources.

2) Insufficient access to healthful foods

Numerous respondents listed healthful foods, including fresh produce and non-processed foods, as something they needed for their and their families' health. Benefits of a healthful diet listed by participants were overall disease prevention and more energy. A number of respondents indicated that they did not have enough money to buy healthful foods, and that they more often bought highly processed and snack foods, despite their poor nutritional value, because that was all they could afford. Participant comments are listed below, all under the umbrella theme of not being able to afford healthful foods needed for primary prevention. This barrier was discussed by members of all three participant groups: those who have experienced poverty, homelessness, and immigration.

Community members say:

Healthy food is expensive. You go to McDonald's and get a salad for \$5-6 when you can get a cheeseburger for \$1. In grocery stores, fruits and vegetables are more expensive than chips and cookies. I try to buy as much healthy food as I can, but for the most part, we eat more junk food than heath food. With our family history, this can lead to high cholesterol, high blood pressure, diabetes, and obesity. (female, white, 26-35 years old)

There are food shelves, however, I tried one of them and a lot of the foods you don't actually—like I said, we can't actually go to the doctor much, so I try to feed my family healthy as much as possible, so we won't have to go to the doctor. Prevention is better. But the food shelves don't have anything healthy. And you can't really say "I won't eat this," because it's free. So there is free food, but it's the bad food that is the one that's available for you. If there was more access to free or affordable food that was healthy, that would be helpful. (female, Latina, 26-35 years old)

Availability of health foods. It's a problem with foods that are not natural or organic-processed foods. Healthy foods are not available at a good price. We have challenges getting good food for our family. Grocery store prices here are 75 cents more than in other communities. (female, African American, 26-35 years old)

I have not enough access to good foods. I work at (a major retailer) in the produce department, so Fridays they give us a couple oranges, part of the donation, even though I work there, apples, some stuff that they're not able to sell because it has spots or things, but I can eat it. I just thought of myself, need to take care of myself and eat better food. If I don't eat right maybe I'll get sick. If that happened to me I wouldn't be able to work, my family wouldn't get money. (female, African, 18-25 years old)

Community organization staff say:

In low-income families, produce goes by the wayside. (Case Manager, immigrant services)

3) Insufficient access to childcare

The need for childcare was discussed by a number of community members. Barriers to obtaining childcare mentioned by participants include not meeting requirements for subsidized childcare (such as not receiving child support from a non-custodial parent), long waiting lists, and prohibitive cost. Impacts of not having childcare listed by participants include limiting access to job opportunities needed to increase income, and reducing benefit from medical appointments: parents who stated that they bring their child to their own doctor's appointments reported not being able to fully concentrate on their doctors' instructions, and a staff member suggested that parents can feel inhibited from giving their doctors information that they did not want their children to hear. Participants from all three target population groups expressed the need for childcare.

Community members say:

Me and my baby's father are not together, he has to be on child support for me to get my childcare covered, and I don't know where to find my baby's father to get him on child support, so I can't get back on childcare. (female, African American, 18-25 years old)

If I had childcare I'd have a job. I've missed out on job opportunities: last week I had an interview at [local senior assisted living center] for serving food, but didn't have anyone to keep my child. I couldn't make it to the interview. (female, African American, 18-25 years old)

4) Transportation challenges

Challenges in transportation is another barrier that participants from all three target population groups described as affecting their ability to access healthcare, as well as other areas of life such as employment and education. Like the challenges discussed above, a primary cause of transportation barriers is insufficient income, according to community members and organization staff. Major themes in transportation challenges reported by study participants include:

- Not knowing that health insurance carriers provide transportation to appointments,
- Lack of money for bus fare,
- Unfamiliarity with bus routes,
- Sensitivity to high levels of cigarette smoking at bus stops, and
- Difficulty bringing young children on the bus, especially when it requires waiting for the bus in extremely cold weather.

An organization staff member observes that for her clients who own cars, challenges include not being able to afford child car seats, and having mechanically unsound cars that are prone to breaking down.

Community members say:

Challenges with bus riding: weather, cigarette smoke, routes

We ride the bus. Now that it's snowing and my baby's not in day care, I drag him with me, it's tough. (female, African American, 18-25 years old)

I'm allergic to people to smoke, so waiting for the bus was very hard for me. I smell smoke and I can't breathe. (female, African, 18-25 years old)

I use only the bus, but I don't know where the busses go. When you say 36th and Hennepin, I don't know where that is. Geographical locations are challenging. Payment for the bus is sometimes a challenge. (male, American Indian, 26-35 years old)

Challenges with medical transportation

I didn't find out that I could use medical transportation till end of last year. I knew it was there but thought was just for elderly and disabled people. In the winter it was too cold to get on the bus. (female, African American, 26-35 years old)

Now I'm driving, but when I was new this county, I wanted to go to the doctor but couldn't because of transportation. With my

insurance they said you have transportation and they send you a van to go to the doctor. I tried once but they didn't come, that time I needed a doctor but had to cancel. (female, African, 26-35 years old)

Challenges in ride coordination impede treatment

My daughter had once a week physical therapy, we have two other children, so it's hard to have to be going to pick up one and then pick up the other one to go to physical therapy, because if I didn't pick them both up, we'd have to find someone to pick the other one up while I was in therapy. I know that some PCAs do that but I'm not sure exactly how that works. If we had transportation help it would be a big help because then she'd still be getting physical therapy rather than having that on hold. (female, Latina, 26-35 years old)

Community organization staff say:

Limited income poses challenges: bus fare and safe autos

Transportation can be an issue for some people with limited income. For a first time appointment, we'll drive them there and sit with them. But for some people the bus fare is too much (\$2.75 each way). When we have bus tokens we'll provide them, but we don't always have them. If they go downtown to HCMC they'll walk, but if you're not feeling well you don't want to walk to the ER. (Case Manager, general social services)

It's a safety issue, some don't have car seats, and it's also a legal issue. Having the money to get car seats. Many have unsafe vehicles, and they can get stuck on highways, or anywhere, and they would be there with their kids. (Program Director, transitional housing and general social service)

Medical providers say:

Insurance subsidized transportation to appointments is difficult for people who sleep in a different place every night because you have to schedule the ride three days in advance.

5) Low educational attainment

Low educational attainment links with income in multiple ways: having a low income makes it more difficult to obtain education and other forms of job training due to tuition fees, and as at least one participant pointed out, because time spent in school, training, and studying cannot be used earning money. Simultaneously, low educational attainment can, in some cases, limit job and career options to primarily lower-paying positions that often do not provide benefits such as health insurance and paid time off to go to doctor appointments.⁷

Low educational attainment, especially when combined with factors such as shortage of access to computers and internet service, low computer literacy, and/or limited English proficiency can pose a major barrier to obtaining and understanding information on how the healthcare and health insurance systems work, and where and how to access health and social service resources. These problems are compounded by challenges described by staff participants: the high complexity of applying for and using health insurance, as well as the "legalese" in which health insurance information, whether applications or eligibility letters from the county, are often written.

Some native English speaking community members also reported difficulty in understanding doctors' explanations during appointments due to use of technical medical terminology and complex explanations (a challenge that is compounded when patients have limited English proficiency, as discussed below). One respondent suggested that nurses are often easier to understand than are doctors.

According to study participants, a major problem for immigrants and refugees who come to the U.S. with college and graduate degrees from other countries is that their degrees often do not hold the same weight in the U.S., and they must either repeat their educations at U.S. institutions or take work in occupations in which they are significantly under-employed. Community members report that this type of under-employment can lead to depression, lower family income, lower social status, and family stress.

Community members say:

Understanding communications with medical providers

The communication piece has breakdowns, a lot of time when I talk to a nurse rather than a doctor, I understand more. Nurses break it down better, like a softer touch. Words that are used that I may not know what they mean. Almost in a sense, I want a breakdown of

⁷ Interview respondents did not specifically mention the challenges in this first paragraph unless otherwise noted, but it seems likely that these linkages between education and health may apply.

what they're talking about. (female, African American, 26-35 years old)

Repeating post-secondary education, or being under-employed

Here in the U.S. your diploma is not American standard, so you need to go back to school to be integrated. When you come here at age 40, you need to go back and learn the whole basics. If you have a family it becomes frustrating, depressing. In terms of employment, you come & don't have the technical experiences. The type of job you get, I know a surgeon now doing delivery. They told him has to go back to schools. We know this guy was in the field. I understand in America they're afraid of lawsuits, but we need a system to allow folks to transfer education and experience to the American context. (male, African, 46-55 years old)

Community organization staff say:

Understanding medical communications: verbal and written

Doctors sometimes don't talk in laymen's terms. (Case Manager, homelessness services)

Another challenge is not understanding the medical releases, which are not written at a level that some families could understand. Medical releases and other information should be changed to an 8th grade comprehension level. We explain to families what the releases mean, but often times only after they're signed. (Program Director, transitional housing and general social service)

6) Low family income: other effects

Having a low family income impacts health and healthcare access in additional ways, as well, such as having fewer choices or no choice of health coverage program.⁸ Some participants also described that having a low family income meant having limited means to pay for appointment copays and medications, and having limited funds for food beyond SNAP (Supplemental Nutrition Assistance Program) support.

Individuals and families with the lowest incomes may be eligible to receive Medical Assistance (MA).⁹ Although a large number of participants expressed deep appreciation and gratitude for having MA and the medical benefits it provides, a large number of participants

programs/programs-and-services/medical-assistance.jsp ,

⁸ <u>https://www.mnsure.org/individual-family/cost/finanacial-assistance.jsp</u>⁹ http://mn.gov/dhs/people-we-serve/adults/health-care/health-care-

https://www.mnsure.org/individual-family/cost/finanacial-assistance.jsp

also noted a range of bureaucratic challenges associated with receiving MA.

One experience with MA commonly noted among participants was going to a medical appointment, or to pick up a medication from the pharmacy, and learning that one's MA coverage had been dropped, often resulting in the patient not receiving the care or medication due to not being able to pay out-of-pocket. Conversely, one participant described going to the hospital and being unsure how she would pay for the visit, only to be told that she not only had MA coverage, but had had MA for the prior three years, unbeknownst to her. She expressed deep appreciation for having the coverage, and also that she would have handled her healthcare differently had she known she had insurance.

A related bureaucratic challenge described with MA is receiving recertification paperwork that is dated after the given deadline to recertify, and thus, losing coverage. Other commonly reported experiences were long waits to receive the medical benefits card; and learning that one's MA coverage had been switched from one insurance provider to another, and not understanding why, or how benefits may be different with the new provider.

An additional difficulty with MA described by multiple community participants is that various dental procedures, such as root canals or crowns, are not covered by MA. These participants expressed that since they could not pay for the dental work out-of-pocket, the only option available to them (covered by MA) is the extreme solution of full tooth extraction.

Overall, participants expressed being extremely grateful for the support that MA provides, but also hopeful that bureaucratic challenges of the system that impede receiving care will be reduced in the future. Notably, participants who received help in applying for coverage from MNsure navigators reported a far better experience and fewer challenges in getting started with MA than those who did not.

Community members say:

Limited income for medications, copays, and food

I don't have enough money for medications or copays, even with MA coverage. (male, white, 56-65 years old)

Sometimes I do have the copay for my medicine, but I can't always afford it. I'm pregnant now and if I don't have my prenatal vitamins, it will have a negative effect on my baby and me. (female, African American, 18-25 years old)

SNAP doesn't last all month, at the end of the month, we need to pay in additional. Sometimes there's not enough food for my family. (female, African American, 18-25 years old)

Experiences with a lapse in Medical Assistance (MA):

I couldn't get my medications because my MA lapsed and I couldn't afford to pay out-of-pocket. I moved and didn't get the packet to reapply. It was hard to get through to them and find out where to go. I was on hold on the phone forever. It took days to get a hold of them. I was supposed to do it (reapply) online, then they suggested to go to a navigator. It was super helpful going to a navigator. I'm back on MA now. (female, African, 26-35 years old)

I was uninsured for 5 months. It was a challenge to get my meds because I didn't have the money right away. I was on MA, then was dropped. I went to the doctor and they said you're not covered, so I couldn't go back to the doctor. (male, African American, 26-35 years old)

It was difficult to get MA. The first time I applied for MA it took 2-3 months to get it, but it was a while longer before I got my card. Then I had it and they cut me and my kids off, I don't know why. I was only on MA a couple months, and they said I needed a renewal, so I did my renewal but went to get my birth control and my MA was inactive. (female, African American, 18-25 years old)

I was assigned to Medica, but I broke my hand in November and between October and November I was cut off without being notified. So I ended up in the hospital and got a medical bill. I played sports as a kid and broke a lot of bones so ended up getting used to self-treating. So now I need to pay but don't fully understand what I need to do. (male, African American, 26-35 years old)

Confusion about insurance and Medical Assistance (MA):

I've gotten insurance coverage through the state, what's happened a couple times is I got Health Partners, then got a letter saying you're now with Medica, I don't know if I didn't get the letter about changing plans or what—don't understand how that happened. (female, African American, 26-35 years old)

Right now my insurance is through MNsure, I think it's MA. At first it was hard for me to access the website or figure out how to do my healthcare, I just finished college a few years ago so learning what type of plans were best suited for me, how do I figure out the healthcare terminology, what do deductibles mean, my parents are immigrants and don't know a lot about the healthcare system so they don't know the technicalities of the language and legalese so I'm also trying to figure out what they need. Also I've been getting mail that seems like it's coming later than it should be. At one point I was suddenly switched to a different provider but I don't know why. More transparency would be nice. (female, Asian, 18-25 years old)

I didn't even know I had health coverage until recently. I went to the Emergency Room and had a prescription, I was like, "how does it cost," to say I'll not be able to pay for it, and they were like "oh you have health insurance. We just entered the name and the number popped up." I said, "do I? I never knew." I thought my clinic was covering everything but I had insurance. For three years I've been here, and I just realized I had health insurance. I was immediately taken care of health-wise when I came here, but just the fact of knowing I had insurance, when you think about it, you're like "nope I can't afford it or I can't think about it because I don't have insurance." You don't think about anything else. (female, African, 26-35 years old)

Community organization staff say:

Limited income for medications, copays, and food

Some of our people are working off of \$147 for the month after paying rent. (Case Manager, general social services)

Complexity of the healthcare system is a challenge

The complexity of the system is big factor in accessing healthcare. Filling out an application for insurance is very complex. People don't have a clue about how to do that. Americans educated in English have a hard time. It's hard to even find a phone number of who to talk with to change your address. The system is too large and complex to maneuver. (Case Manager, immigrant services)

Challenges with MA: lapse in coverage

We have lots of transient populations coming from one county to another to us, who maybe don't have a firm mailing address, for Medical they have redetermination paperwork, so we see lapses in medical due to not receiving paperwork. Suddenly their medical is dropped, and it affects them and their children, we see lots of lapses in coverage. Sometimes they don't know until they go to the doctor. (Program Director, transitional housing and general social service)

Sometimes the county will cut off their benefits, the mail from the county is often sent out late so they're required to do a recertification. One person I know got her letter that she needed to

recertify but it was dated after the time she was supposed to go to get recertified, so she went to get her prescription for her and her child and her insurance had lapsed. Now she has to wait for the county and it could take 30 days. (Case Manager, general social services)

Challenges with MA: not having medical card

Sometimes with MA, medical cards are not mailed out in a timely manner, so people must wait longer for them, or go to county. One woman went down to the county to see about getting her medical card because she had applied and was approved, and at the county office they made her reapply, so she had to start all over. These are systematic things that are preventing people from getting care. (Case Manager, general social services)

Often they don't have an actual insurance card because they had to leave it where they lived previously, maybe their abuser lives there. Then they have the issue of places that require the actual insurance card in order to receive services. (Program Director, transitional housing and general social service)

Medical providers say:

Health impacts of not having sufficient income for food

I had a patient who said she didn't take her antidepressants because I told her to take them with food, and so she doesn't take them because she doesn't have any food in her house. It was a medication for which absorption is improved when taken with food, but it's not that it doesn't work at all when taken on an empty stomach. I didn't realize that my words would have had that impact.

Social risk factors related to mental and behavioral health

7) Challenges accessing mental and behavioral healthcare

A few participants described individual and group-level stress and trauma as a source of mental health challenges. When discussing treatment for mental health issues, participants listed challenges as:

- Their insurance not covering treatment (or not knowing that their insurance covers treatment),
- Not knowing whether they have insurance and not knowing how to access treatment without insurance,
- Losing motivation to obtain treatment due to long wait times for an appointment, and
- The most frequently discussed barrier was stigma around mental health issues. This stigma was described as a problem for both

immigrant, and to a lesser but still notable extent, Americanborn populations.

Barriers to behavioral health and substance abuse treatment were listed as:

- Lack of short- and long-term childcare is a barrier to in-patient and out-patient treatment for single parents.
- High levels of bureaucracy around rule 25 assessment for subsidized treatment were noted by a medical provider as a barrier for homeless populations. The small number of community members in this study who received rule 25 assessment did not note barriers in doing so, but that does not negate this factor as a barrier for others.

Effects of mental and behavioral health challenges on other areas of wellness, including accessing housing and healthcare, noted by medical providers were:

- If someone completes substance abuse treatment and returns to a negative environment, such as a homeless shelter, it's easy to relapse.
- Impaired functioning due to intoxication and life chaos affects all aspects of making and keeping appointments and following treatment plans.

Community members say:

Individual and group-level stress and trauma leading to mental health challenges

Yeah, I have memory loss, but not from being hit on the head. I've gone through so much, I forget stuff. It changes your attitude. (female, white, 18-25 years old)

I'm not healthy, there has been a lot of contribution to that. Ebola came, I lost my loved ones, 37 people I lost in my closer family; if you count my extended family, I've lost more than 50 people. That's stress on me. My son is in Arizona, he has a brain injury. He was in a coma, but had no insurance or documentation. However, to apply for surgery, I brought him here to start over. I've gone to school, I want to improve my life, but I'm not healthy because I'm thinking too much. I have bad dreams. Calling Africa, it makes my life miserable. Thank god I'm in America, a great country, if that could be any other country for my son he'd be dead. Thank god.

They gave me insurance, approved him for other help. I'm grateful for this unique country. (male, African, 36-45 years old)

New immigrants feel too much stress because of their situation. (female, African, 26-35 years old)

Insurance challenges as a barrier to mental health treatment

I haven't talk to a doctor to do tests for diagnosis for depression but have had depression my whole life. I don't know about benefits from the county or how to get access to the insurance. I've gotten papers in the mail asking me to choose and I've picked Medica for MA, then got switched over to Health Partners as primary and Medica as secondary, but they got my birthday wrong so it didn't work and it got all messed up and I couldn't control it. It was a super hard process. I don't know if have insurance now. (female, white, 18-25 years old)

Mental health stigma: perceptions of community members

We need more translators for mental health, my dad had depression, don't know if he still has it. We don't talk about this. (female, Asian, 18-25 years old)

I'm not seeing anyone now for mental health, it would be beneficial, but I don't think it's covered by my insurance, I don't know how to set that up. I know nothing about that. Wish it were a more open conversation on how to get help. There's a lot of stigma, it's harder to talk about it: this is the most open I've talked about it. What would make easier? It's a hard question. Accessible resources, more open conversations about it, forums where you get to talk about it, or can see others talking about it. (female, Asian, 18-25 years old)

People from Africa won't talk about mental health issues. The cultural piece is key. Providers are not culturally sensitive enough. We need dialogues to break the stigmas. (female, African, 18-25 years old)

Community organization staff say:

Wait times for treatment as a barrier

Mental and chemical health treatment can have long waiting lists. If someone decides they want help for mental health and we call and can't get an appointment for one to two months, then they fall fast, or they say forget it, it's not worth it, and then they reroute. (Program Director, transitional housing and general social service)

A family is here 3.5 years on average, and it sometimes takes 1-2 years to get someone in the place where they want to try to meet with a therapist. And if they get to that point and have a bad experience, or their medical has lapsed, it's disheartening and they

can give up. (Program Director, transitional housing and general social service)

Mental health stigma: perceptions of organization staff

Different cultures handle trauma and mental health differently, maybe immigrants don't understand that in American culture there's help for trauma and they don't have to feel ashamed. There's still stigma for mental health in the U.S., but there's an even greater stigma in other countries. In some other countries, the stigma is at about the same level you'd see if you stepped back in time 50 years in the U.S. We explain that it's okay to seek help, but the stigma is still there. We're working on helping people understand that mental health problems can get better. Maybe they're not aware that there can be improvement and they think that they have to live with it, think that it can't be improved or changed. We're letting them know that it can improve. (Case Manager, immigration services)

There's a lot of stigma around mental health, and we've been working hard with our families on trying to normalize that. We start from a stress management standpoint, then go on to other mental health issues. We treat it like any other health issue. A lot of new moms come in with post-partum issues, but many haven't heard of post-partum depression so we need to educate them on that. We come from wrap-around of educating all families around pregnancy and depression, then about trauma because many of our families come from trauma situations. (Program Director, transitional housing and general social service)

Lack of childcare is a barrier to treatment

Childcare for treatment is important. For inpatient care, it means they're separated from their child and they're a single parent, so if they don't have a relative or someone to take their child while they're in treatment, they can't do it. Even for outpatient treatment, they need a place that can offer childcare, and the majority don't. (Program Director, transitional housing and general social service)

8) Domestic and relationship violence and sex work

Another social risk factor related to mental and behavioral health that was mentioned briefly by organization staff in the multiple contexts of cultural stigma and wellness education is that of domestic and relationship violence. Providers also noted the importance of this risk factor, and associated both relationship violence as well as sex work with the risk factors of homelessness and chemical dependency.

Community organization staff say:

Domestic violence is an issue. We do partner with organizations, in pockets of the population stigma is high for them, safety across the board an issue. (Program Director, transitional housing and general social service)

Social risk factors: culture, language, and immigration

9) Non-fluency in English language

Participants noted numerous challenges experienced by patients who do not have English fluency. One challenge discussed was that patients struggle to learn what services are available, how to apply for them, and how to access them. Challenges with interpreters were also mentioned: patients sometimes do not have interpreters, have negative experiences with interpreters, or have fears of having negative experiences with interpreters. A third issue raised is that when patients have limited English literacy, they are dependent on others for every step, including making appointments, arranging transportation, and handling payment or insurance.

Community members say:

We need more translators. When my parents go to the doctor they have a hard time articulating in English. My mom would tell me her leg hurts but she'd point to her foot. So she doesn't have the needed vocabulary to talk with the doctor. Like the differences between twinges or aches, or pins and needles. We don't get an interpreter when my parents go to the doctor, my sister and I go, but still there are nuances. (female, Asian, 18-25 years old)

Community organization staff say:

Difficulty understanding and accessing services

Language will be the first thing. They have no way of navigating through the internet, getting written information, or to understand what they need to do as far as health. (Program Manager, immigration services)

Difficulty with interpreters

Our clients are sometimes afraid of interpreters from their same culture. They're afraid the interpreter will talk to people in their community about what they said, afraid of a breach of confidentiality. We explain to them that the interpreter can't break confidentiality. (Case Manager, immigration services) Some clinics have well-trained, specialist interpreters, that's helpful. But we find there are some interpreters who are acting unethically and taking advantage of clients and of the medical system. They develop relationships with clients, then make redundant appointments for clients at multiple clinics, some of them out-of-network. Then the client receives a bill, the insurance will not cover the appointment because it is out-of-network, and the client does not understand because s/he doesn't know the language. (Program Manager, immigration services)

Minnesota is lucky in that there's a good system for interpretation. But sometimes interpreters don't show up at the appointment, that's a barrier and it happens enough that it can be a problem. Clinics' in-house interpreters usually show up, but outside interpreters don't show sometimes. (Case Manager, immigration services)

Medical providers say:

Additional costs clinics incur to serve this population:

It requires more staff resources when patients have language barriers and less independence.

10) Differences in cultural understanding, not trusting providers

Participants described a lack of trust of providers and differences in cultural understanding for multiple demographic groups participating in the study. Immigrant participants told stories of other immigrants they knew who developed fears of providers due to lack of information or misunderstandings. Additionally, an organization staff member currently working with the five study participants who were lowincome, American-born, African American young parents in transitional housing described that most of the people she works with do not trust providers out of fear that they will be treated poorly because they are on MA and have low incomes. This staff member attributes this lack of trust to clients' choice to not have consistent primary care providers, and go to the Emergency Room instead. Not having a primary care provider, or not having consistency of seeing the same provider over multiple visits, was described by staff members as having the potential to lead to providers not knowing patients' health and medication histories, and not being able to provide the best care.

Community members say:

Fear of providers due to lack of information or misunderstandings

My community is largely illiterate, so when we go to the doctor, they ask a lot of questions like what's your religion and ethnicity, so we wonder "why are they asking me these questions." The providers don't explain to the patients that there could be a link to health. I know an elderly woman, and the doctor asked for her religion and ethnicity, and she said why are you asking, and then she didn't tell anything at all to the doctor, not even about her health or why she was at the doctor. She was afraid that because she was Muslim, the doctor would have an issue with her because of what's going on now with politics and Islam. They're afraid. In Somalia there is a high level of autism among children, and people believe autism comes from shots the doctor gives, so some parents don't get vaccinations because they're afraid that the doctors add something to the injections that gives children autism. (female, African, 26-35 years old)

It's important for a patient to always have someone they trust with them when going to the doctor. My wife's great aunt was here, she's 78 yrs old, the first time she went to the doctor, they told her they did some tests and said she still has ovaries that she doesn't need. It wasn't put to her quite right. So they gave her the option to have them taken out, and she was offended. Now, even when she's in pain, she won't go to the doctor because she's afraid they'll take her ovaries. If someone had explained it to her better, she wouldn't now be too scared to go in for anything. (male, African, 46-55)

Community organization staff say:

Fear of providers leads to not having a consistent provider

One of the biggest barriers I see is people don't have primary care doctors. I think it's a cultural thing. Most people I've worked with in the past 18 years, they don't trust doctors. They think they'll be treated poorly because they're on MA. They think they'll be used as guinea pigs for something. Even if they're given antibiotics, some people think it's something else. They would rather see someone quickly, know that at the ER the appointment will be quick, and the doctor at the ER is used to working with poor people so they are less likely to be treated poorly. They also have resistance to getting mental healthcare because of a lack of trust. They won't see a therapist because they think the therapist will give them meds, even though I explain that a therapist is not a psychiatrist. (Case Manager, general social services)

Families go to different clinics or to the ER for standard visits. I wonder if there's a better way to track for consistency of care through electronic medical records. (Program Director, transitional housing and general social service)

11) Immigration status

One additional social risk factor discussed by a small number of study participants is immigration status. Specific barriers directly linked to immigration status were not widely discussed by participants in this particular study. However, ways in which participants did note associations between immigration status and health are high levels of stress often experienced by immigrants and refugees, varying levels of access to subsidized insurance depending on immigration status, and generalized fear of obtaining services when having an undocumented status.

Community members say:

New immigrants feel too much stress because of their situation, some may be admitted to the hospital. I went to the Emergency Room three times because of stress. (female, African, 26-35 years old)

It's pretty difficult to get insurance. I'm here through the DREAM Act. We don't qualify for state insurance. That's really hard because insurance is expensive. I don't have access to doctors or meds if I need them. If I get really sick, I go to a community clinic. (female, Latina, 26-35 years old)

Medical providers say:

Undocumented immigrants may hesitate to even to make appointments because of fear of having their names registered.

12) Preferred treatment is outside of the Western medical model

An additional social risk factor discussed by a small number of participants is having a preferred treatment that does not fit within the Western medical model. One community member who emigrated from China prefers medical treatment using traditional Chinese medicine, primarily herbs, and at times, acupuncture as a supplement to herbs. Her challenge in accessing her preferred treatment is that it is not covered by her medical insurance. Another community member described a similar situation, in that her parents, originally from Vietnam, are uncomfortable taking pills, and prefer traditional massage and acupuncture, which have limited coverage through their insurance.

Community members say:

Last year I feel very tired, now I have a lot of energy, last year my lips were pale, before seeing the doctor, I needed to nap after lunch every day, I was dizzy, had headaches, was vomiting. In a whole day I could do only one or two things, shop, then I was tired. Just eat and sleep. So in my life I couldn't do enough. This Chinese doctor cured me, but the insurance doesn't cover that. Acupuncture is \$70 per week, herbs are \$100-200. Acupuncture is too expensive for me, so I take only herbs. (female, Asian, 26-35 years old)

There's a cultural difference in our understanding of health, my parents do a massage thing to get rid of, well, what they call bad heat, so instead of taking medicine they do a massage: they like to avoid pills. Dad was seeing an acupuncturist for a while for pain, but he could only see an acupuncturist four times a year cause that's all the insurance would cover, but it's better to see them continuously and keep getting help from that. (female, Asian, 18-25 years old)

Community organization staff say:

People have different cultural views about diseases and how to go about treating them. Many go to traditional and spiritual healing first: you have someone who has a mental health challenge, you tell them they need to get treated, and they say no, they will go to the imam or the sheikh to have them recite the Holy Qur'an, or to have the evil eye removed. (Program Manager, immigration services)

Medical providers say:

Non-Western medical model barriers to treatment

Some culture groups not socialized within the Western medical model don't understand the concept of ongoing treatment for chronic conditions, such as high blood pressure or diabetes. They will follow their treatment for a limited period of time, and then stop.

Additional costs for treating this population

Some culture groups conceptualize health and medicine in ways completely different from the Western medical model, so appointments must include time not only for translating language, but also for teaching new concepts about the body, health, and treatment.

Social risk factors related to demographic considerations

13) Rural challenges

As noted above, this project's scope did not enable us to interview community members and organization staff outside the Twin Cities metropolitan area. However, we did discuss social risk factors and mitigating supports with one provider in a rural area of northern Minnesota. The primary challenges that this provider discussed are:

- Many patients have very low incomes and need financial supports
- Many patients travel long distances to reach a clinic or hospital, and therefore, tend to bundle many services into a single appointment, as opposed to going to multiple appointments to receive one service per appointment. This poses a major challenge for clinics in terms of reimbursement. Medicare and Medicaid provide reimbursement per visit (rather than per service provided); therefore, rural clinics may have especially long appointments to provide multiple services to patients, but only receive reimbursement that compensates a single, shorter visit.
- Many patients have insufficient access to transportation to reach appointments: many rural areas do not have public transportation, and low-income patients may not have reliable automobiles or gas money to drive a long distance to the clinic or hospital.

14) Challenges specific to race or ethnicity

Very few participant comments addressed race or ethnicity in itself as a direct social risk factor; most of the risk factors related to race or ethnicity are more likely to be the indirect result of structural racism, and not specifically mentioned by participants. However, two community members did specifically link race and ethnicity to challenges. One Latina participant discussed feeling discriminated against by other Latinas or Latinos with higher levels of education. One Somali participant stated her perception that some social service workers do not treat Somali women well.

Community members say:

I actually speak both languages so that is not an issue, but I think that many times when people have lived in the United States long enough, when they have a higher education they might think of themselves like they are better than the ones just getting here. But you can get discriminated even from people who are from your own race. I think if the people who are getting all that education would understand that that's a good thing, but it doesn't mean necessarily that you need to lose values and understanding the culture of other people. (female, Latina, 26-35 years old)

I've seen it first-hand where nobody really cares what you say, and you're made to feel really stupid. Culture-wise, too, and I've had a lot of workers sit down with me, a lot, just like the one who was mean to me and taking advantage of me, and there's ones who don't like Somali women cause they've always looked down on how you wear your skirts, you know, everyone's human, and the workers have shared that with me – oh you're such a great personbut then are biased toward other people because of that reason. (female, African, 26-35 years old)

Social risk factor comparison: DHS and community

One of the aims of this study is to compare and contrast the social risk factors currently under examination by DHS for the purpose of care reimbursement determination (see Appendix B) with those social risk factors discussed by study participants. This comparison and contrast is presented below: most, but not all, social risk factors discussed by study participants are also under examination by DHS. It should be kept in mind that this study's sample is small and not representative of the state of Minnesota; therefore, no conclusions can be made from this study about individual risk factors having low importance based on their absence in the following list, or by not having been noted by study participants.

Social risk factors noted by study participants but not by DHS

- Insufficient access to healthful foods
- Unaffordable housing
- Incarceration or eviction records posing a barrier to housing
- Insufficient access to childcare
- Overall transportation challenges (DHS lists transportation as "family lacks vehicle")

- Mental and behavioral health challenges and stigma (DHS lists these factors in terms of diminished parental functioning, but not for non-parents)
- Domestic and relationship violence, and sex work
- Lack of trust between patients and providers, for both immigrant and non-immigrant patients
- Desired treatment does not fit within the Western medical model

Social risk factors noted by DHS but not by study participants

- Neighborhood poverty (aside from issues of violence and unmaintained housing, few participants in this study discussed neighborhood poverty)
- Four or more children in the household
- Parental chemical dependency (some participants discussed chemical dependency, but not in reference to being parents)
- Parental mental illness (same as chemical dependency above)
- Child protection involvement
- Rural/urban (this study provides some limited information)
- Race/ethnicity (this study provides some limited information)

Part II: Supports and mitigating factors

Study participants offered many ideas for ways in which the above discussed social risk factors could be mitigated by the healthcare system and/or communities. In some cases, community members forwarded ideas of what they thought would help, and in other instances, they described existing supports that they are using that help them cope with the challenges that they face. Organization staff discussed current approaches to helping clients address challenges, as well as new ideas. These suggestions are discussed in support numbers 1 through 5 below.

Finally, medical providers suggested a number of services that they believe could help mitigate barriers to health, which we included in our interview protocols, asking community members and organization staff their opinion on each suggested service (see Appendices E and F). These services suggested by providers are discussed as support numbers 6 through 12 below. Although the individual supports that would be helpful varied from one community member to the next based on individual needs, overall, all of the provider-suggested

services were described as having the potential to make a large improvement in the health of at least some study participants. Because this study's sample is small and unrepresentative, no conclusions should be made about a given support's lack of importance based on small level of need among participants of this study. The order in which the provider-suggested supports is presented below represents the overall level of participant need for the service, with the most needed services presented first.

1) Collaboration between communities and the healthcare system

One of the most frequently discussed ideas around mitigating barriers to health and wellness was increasing collaboration between communities and the healthcare system. This could take various forms, including:

- Increasing wellness education, activities, and events in communities (see support number 6 below for more on this topic),
- Building relationships between providers/healthcare representatives and communities, and
- Increasing participation of community groups and members in policy discourse and decision-making.

Some participants active in African immigrant community groups suggested that the best way to inform community members of services and resources available, as well as provide brief, basic health education, is to send a healthcare representative—such as a provider or community health worker—to community events such as community meetings, community centers, or even weddings or funerals. Although the idea of sending a health worker to make announcements at a wedding may sound surprisingly non-normative in an American cultural context, study participants identifying as African immigrants made this suggestion. They explained that their communities are far less likely to learn of available health resources through more traditional communication media such as the internet or advertisements (especially when primarily in English), and that it, in fact, would be considered neither rude nor unusual for brief (3-5 minute) community-benefit service announcements to be made at an event like a wedding. They described that additional benefits of doing so would be reaching a large number of individuals in the community

(who would then likely further spread the information through wordof-mouth), and having a medical representative come in-person to give a brief announcement would help build trust and positive relations between the community and the healthcare system.

Community members say:

Visibility and trust in the community through attending events or meetings

Our community has tons of events, if there are providers available to be there, community leaders can inform them when they have a large gathering, like weddings, christenings, or funerals. They may see this as inappropriate, but we would not find that offensive. When we have a community gathering, after the program, we go back and inform the people of community announcements: Mr. A is having a wedding in March, Mrs. B's daughter is having a wedding in April, and there is someone here to talk about smoking cessation. It goes by word-of-mouth. We have texting, yes, but this makes a bigger impact. If people have questions, they ask. It takes 3-5 minutes. All of the African communities have monthly meetings, community events they all go to for one reason or another through the year, more so in spring or summer. To set this up, look for community leaders or community members who can spread the messages. Go to a house warming party, talk for 2 minutes. It's easier to get a large number of people, and they'll give you their time because it's allocated already. If you call them 5 min later, they'll be busy. (male, African, 46-55 years old)

We need communication and trust between community leaders, the state, the clinics, and DHS: if there's no trust, nothing will work. DHS and clinics can work more directly with community leaders, such as to regular community events, like a monthly community meeting or gathering for a community event. To build trust. (male, African, 46-55 years old)

We want providers to be more visible in our communities. However that is doable is up to them; I understand their constraints. We had a community gathering, Allina came and checked blood pressure and gave information to a lot of people that I know they made use of. I work in the healthcare field and check my own blood pressure, but a lot of people don't. People will trust in word-of-mouth information from someone in their own community. If community leaders are first educated about it, and they pass on the message to other people, it will work better. We have a large number in community who can't read or write, and who will rely on word-ofmouth. So first is visibility in the community, and second is engaging community leaders so they know what the whole thing is about and can explain it to the people. (male, African, 46-55 years old) Need to strengthen relationships: people are more comfortable going to people they know. In any gathering, people from clinics can go to the community to give information, or to community organizations that people already trust. Give short talks on education or information on services and how to access them, or to do simple tests. Spread awareness. If you go to the clinic you already know where to go. Trust is built through word of mouth, bring news through people who people already trust and rely on. (male, African, 36-45 years old)

Community organization staff say:

Look at how decisions are made, how voices of marginalized communities are positioned, finding solutions with communities rather than for communities. In the broader picture, for health outcomes to be equitable, you need to make sure that those most affected are part of policy decision-making, design, implantation, and evaluation. There are health issues, but most important is engagement. Let the community decide what is important in terms of health issues. How do you prioritize what kind of services are provided and how did you come up with that list, was it driven by community needs? Going into neighborhoods and homes? Community health workers should reflect the community. They know the communities, have a higher stake in the process. (Executive Director, immigration services)

It's important to have a partnership with the people who provide services: MNsure, more clinics, information about accessing healthcare, more people coming and engaging the community. It's also important that we use the institutions they have like radios stations and TV channels broadcasting in Somali, Oromo, and Amharic. If those channels are mainly used, it could reach a lot of people. Also reaching out to mosques, churches, be able to engage community in those areas. Nonprofits already there will be holding different health fairs, reaching out to communities. Clinics should have a community liaison to engage communities. In the past we've had clinics approach us to bring services to the community. Sometimes clinics would come to us and say they want to do shots, we provide access to our community, give fliers, recruit people and they come. We have an annual health fair, have been doing it for the last 7-8 years where we invite 30-35 health providers each year, provide outdoor and indoor space where providers are able to educate people about services and provide immunization, etc. blood sugar, cholesterol. If that can be increased that would be help communities. We've not had colonoscopy screening in our community, that's a disparity. Clinics should not wait for clients to come to clinic, they should go out into communities. (Program Manager, immigration services)

Medical providers say:

We need better communication among entities (healthcare, social services, government agencies, community organizations, schools) about needs and solutions in order to arrive at solutions that would work for each unique community.

2) Prevention

When community members spoke about what was going well with their and their families' health, they often spoke of the importance of eating a nutritious diet, getting exercise, and managing stress. When asked what they need in this area, participants listed access to healthful foods, and more wellness education on topics like nutrition, cooking, grocery shopping, and other health topics.

Community members say:

I work out when can and try to eat what's good. Try to stay active, try to eat less sugar and starch, and eventually want to quit smoking. (male, Latino, 26-35 years old)

Medically, we are where we should be. We do try to limit the times we go to the hospital. For regular check-ups, we focus on preventative. I try to keep us ahead of the game. We do a little holistic immune system upkeep, vitamin D, cod liver oil, vitamin E, Echinacea tea, We're a little ahead of the game. (female, African American, 26-35 years old)

I'm working on reducing stress: trying out relaxing tapes, doing self-care, doodling, taking care of myself physically. That's helping. (female, Asian, 18-25 years old)

We can't actually go to the doctor much, so I try to feed my family healthy as much as possible, so we won't have to go to the doctor. Prevention is better. (female, Latina, 26-35 years old)

3) Strengths-based approaches and team-based care

Several community members, as well as one staff member and one provider, spoke about the importance of a number of individual helping factors that I am grouping together under the umbrella of strengthsbased approaches and team-based care. Factors that community members described as helping them have better results in meeting their healthcare needs can be categorized by the following themes:

- The person (provider, administrator, etc.) really listens to me
- My provider takes into consideration my knowledge of my own health

- Being positive
- Providers working as a team

Factors that organization staff described as important are:

• Find solutions *with* the community rather than *for* the community (quoted above) (executive director, immigration service)

Factors that one provider emphasized are:

- Resiliency approach
- Making the patient the driver of the decisions
- Team-based approach to care

Community members say:

It helps when someone really listens to me, considers my knowledge

They listened. They listened to you, they found you, they didn't dismiss you. They knew there was a way to get a hold of the person, they made sure you were in the right department, talking to the right person. Sent an email with you while you're sitting there, just waiting for a response to say that person got it, instead of just taking your information and then you call back and you're like "hey it's been these months, I need my stuff by this time, who can I talk to and what can I do?" Just help out—don't dismiss the person, and don't be judgmental or make us feel like crap, because we already are feeling like crap for relying on social services, you know? And just because you've heard the story a million times, does not mean that person doesn't really need the help. (female, African, 26-35 years old)

Good doctors, who actually listen to you and what you have to say, that you know what your health is and how you can help. It's not easy. There's a lot of doctors who won't listen: I know what works best for me because I've been on mental health drugs since childhood. They want to make me do the runaround trying different drugs when I can tell them what works. (female, white, 18-25 years old)

Being positive

Doctors will do anything to help but you need to be willing to give them what they need so they can do their job. So I need to take the time to gather my thoughts, so that I go in with a clear head. Sometimes I go in thinking negatively, which gives negative results. I need to give enough time to gather thoughts and go in with positive thinking. (male, African American, 26-35 years old) In the shelter we had help and resources, you only make things hard when you think bad about being in the situation you're in. (female, African American, 18-25 years old)

Things are really hard, especially because I'm a single mom, thank God this country is helpful so I'm trying to improve myself. If I'm stressed, I drink enough water and eat and go to bed, when I get up I'm good. Don't take it so personal, it will come and go away, there's a way to solve it. (female, African, 18-25 years old)

Providers work as a team

The doctor I see now at the mental health clinic, I'm sure she's well-qualified, but it doesn't seem it's her top priority. She was dismissive, I'd like a doctor who's more empathetic. I'm trying to switch from one drug to another, by my doctor hasn't been in contact with my counselor: I need my providers to communicate and work as a team because I'm not getting my meds fixed because they don't communicate. That's frustrating. (male, American Indian, 26-35 years old)

Medical providers say:

Resiliency, empowerment, listening, and team-based care

The most important innovation in health is resiliency. I use motivational interviewing as a tool as a provider, it's the way I talk. It's all about making the patient the driver of the decisions. They need to know you're listening. Clinics need more teams, working in teams. We were the ones going to testify to state legislature on that model. When you look at health equity and at resiliency, you need to look at patient strength and inspire them. Don't look only at negative diagnoses, also look at the good things. It's all about trust and open communication, and listening, it's easy to do it. We need to train other sectors to do the same when working with vulnerable populations.

4) Traumatic brain injury (TBI) testing

One medical provider who specializes in serving populations experiencing homelessness described what he termed a "hidden epidemic": traumatic brain injury (TBI). He explained that TBI can occur with injury to the head, such as from falling, or being hit on the head, and can cause chronic problems with memory loss, affecting the ability to attend to healthcare as well as other life tasks. This physician explained that individuals with TBI are eligible for supports and services. Therefore, he calls for more comprehensive testing for traumatic brain injury, and more awareness-raising among physicians of the prevalence of TBI and the importance of testing.

Medical providers say:

Even if they could have held down a job and apartment if they got sober, if they have a brain injury, they lose the ability to remember things, to take pills on time, to manage daily activities, leading to an inability to execute a life plan.

5) Supports for rural communities

Although this project's scope precluded speaking with community members living in rural areas, the rural-based physician with whom we spoke itemized some supports that have the potential to improve healthcare in rural communities.

- Provide more phone-based case management between appointments. Because people in many rural communities must drive a long distance to reach a clinic, patients often have longer-duration visits and receive more services per visit, but visit the clinic less frequently. Offering phone help from a nurse between visits can help ensure patients have support around correctly following treatment plans, and nurses can identify barriers faced by patients and offer advice.
- Any level of transportation assistance that can be provided is helpful, including home visits for simple tests.

6) Tests or wellness education in the home or neighborhood

One of the supports suggested by providers that was most frequently desired among community members is having simple tests, such as blood pressure, or wellness education in the home or neighborhood. Many participants specified interest in neighborhood or community classes in nutrition, cooking, and/or how to grocery shop on a budget to maximize healthful foods and minimize unhealthy snack foods. Almost all of the community members who noted this service as helpful stated that it would potentially make a large improvement in their and their families' health. Organization staff also addressed the benefits of community-based wellness services. These types of services would intersect with the first support discussed above, collaboration between communities and the healthcare system.

Community members say:

I don't have good healthy eating habits and that's something I want help in. A lot of the foods I eat make me feel lazy sometimes, I

probably have low energy because of my diet. (male, African American, 18-25 years old)

Recipes and cooking healthy foods in new ways in free monthly neighborhood classes. Zone in on one vegetable per month: sweet potato burritos, sweet potato fries. I'm not the only person who'd benefit or even be interested in something like that. (female, African American, 26-35 years old)

7) Free groceries at the clinic or pharmacy

One of the physicians with whom we spoke noted that her clinic's pharmacy has a program in which they distribute "food as medicine," in which patients may pick up at the pharmacy a bag of groceries per week. Community members were strongly in favor of not only having more supports available for free groceries, but especially, for free or low-cost nutritious foods. The vast majority of individuals who said free groceries would be helpful stated that it would potentially make a large improvement in their and their families' health.

Community members say:

Yes! More healthy things like grapes and strawberries, not Ho Hos and cheap things. (male, American Indian, 26-35 years old)

If this were available I'd maybe get more food, fresh fruit. If I want to buy fruit from my pocket that's expensive. (female, African, 18-25 years old)

For that week period at the end of the month (when my SNAP is gone) when I go without food, that'd make a large, large difference for me. (female, African American, 18-25 years old)

Community organization staff say:

We have students in our job training program who can't concentrate because they're hungry. (Case Manager, immigrant services)

Medical providers say:

The pharmacy has a brochure that discusses food as medicine. Nothing is more important to being healthy than having food!

8) More clinic staff with language and culture knowledge

Another of the supports recommended by providers that was strongly desired among community members was having more clinic staff that speak the patients' languages and understands the patients' cultures. This support was most strongly desired by participants for whom English was not their primary language, but many other participants noted the importance for others not fluent in English. Most participants who felt this support would be beneficial for them indicated that it would make a large improvement on their and their families' health. Community members pointed to benefits including increased trust and improved communication leading to better health outcomes.

Community members say:

It would create a more trusting relationship, staff would be more empathetic to the culture, and my parents could articulate what's wrong: my mom has been having vision problems and I can't figure out what the issue is because she can't describe it in English. (female, Asian, 18-25 years old)

They'll understand you more, because sometimes when I talk people don't understand my accent. (female, African, 26-35 years old)

That would be really important for everyone. A lot of people say "thank God I can speak English." But it's important culture-wise, too. (female, African, 26-35 years old)

Community organization staff say:

A lot of health diagnosis is lost in translation. It's not just language, but also cultural, you need the whole context and most diagnoses are detached from the context. There's a need for deeper, more attentive engagement: what are cultural barriers to health solutions, diet, how you see it and how you frame it. It's a whole ecosystem, the clinical and psycho-social parts are disconnected. (Executive Director, immigrant services)

That would make a large improvement. It would help to lower stigma and expand the reach regardless of your background. (Program Director, transitional housing and general social service)

Medical providers say:

Immigrants and refugees often have limited English literacy, and are dependent on others to make and reschedule appointments, arrange transportation, and communicate with providers and the pharmacy.

Additional costs for serving this population:

It requires more staff resources when patients have language barriers and less independence.

9) Help getting mental and/or behavioral healthcare

As discussed in Part I of this report on social risk factors, there are numerous challenges to obtaining mental healthcare, including high levels of stigma. Community members and organization staff were strongly in favor of having additional supports for mental and/or behavioral healthcare. Almost all participants indicating that such care would be useful noted that it would potentially lead to a large improvement in their and their families' health.

Community members say:

We did therapy for my son, family resources would provide more benefit in the black community because some people don't know much about mental health resources. (female, African American, 26-35 years old)

If I had help getting mental healthcare, I could go to the right specialist, and get the therapy I need instead of getting stuck in a rut. (female, African, 26-35 years old)

Community organization staff say:

This would make a large positive impact, if provided. We're working on trying to provide more here as well. It's an untapped need. Making mental and behavioral healthcare accessible is trickier than other services because our culture still has a bit of a stigma, I'm pretty sure most of our students' cultures have a bigger negative stigma. In trying to reduce the stigma, we've started using the term stress management more than mental health. It's so easy to talk about stress, there is no stigma at all connected to the word stress. It's helping. We're pretty sure that all of our clients have experienced trauma to some degree. (Case Manager, immigrant services)

10) Help getting childcare while at the doctor

Numerous community members across population groups, as well as organization staff, expressed that help getting childcare while at the doctor, as well as help meeting childcare needs in general, would make a large positive impact on health. Participants described that when parents have childcare during their own doctor appointments, they are better able to concentrate on what the doctor is telling them about their own health and treatment, and they don't have to worry about their child overhearing details they need to tell their doctor that they don't want their child to hear.

Community members say:

It would help a lot. My son wouldn't have to be with me, he could play with other kids. I could take care of my business and know that he was safe. I could sit and focus and talk to the doctor. (female, African American, 18-25 years old)

I could pay more attention to what the doctor was saying. (female, African American, 18-25 years old)

Community organization staff say:

It would be great if more family friendly clinics could offer drop-in childcare for parents so they could see their doctors without their child there. They would be better able to listen and ask questions they want to ask: the child will potentially understand and sometimes the parent will want confidentiality. (Program Director, transitional housing and general social service)

11) Clinic being open evenings and/or weekends

Many participants noted that having more clinics open on evenings and/or weekends would be helpful. Although a large number of individuals who noted that this would be helpful stated it would make a large positive impact on their and their families' health, a few participants also stated that this would make a medium or a small positive impact on their health. Among those wishing for more evening and/or weekend open hours for clinics, some participants cited having to work during regular business hours and not receiving paid time off in order to go to an appointment. Others did not specifically cite working business hours, but indicated that additional open clinic hours would provide more flexibility on possible appointment days and times. Some mentioned that if illness or injury happened after regular hours, they could go to a clinic rather than the hospital.

Community members say:

Weekends would help because during the week I'm at work and wouldn't be able to make it. I don't work on weekends, and I don't get paid time off work to go to the doctor. (male, African American, 18-25 years old)

I could go after work, or on Saturday or Sunday. (female, African, 18-25 years old)

Community organization staff say:

It would increase access to health services, because some people are working two jobs. Some problems get worse before they are diagnosed. (Executive Director, immigration services)

12) Additional helpful supports

The remaining four supports recommended by providers were favored by a number of participants, but not to the same extent as the first six supports discussed in detail above (supports 6 through 11).

- Transportation help was desired by a number of participants, in the form of bus passes or tokens, and/or expanded medical transportation that would take patients to non-medical social services. However, many participants expressed that they already receive help paying for bus rides, and/or that they currently use medical transportation for appointments. In some cases, participants indicated that they were not certain of what transportation their medical coverage provided, which suggests a potential need for better informing patients on this topic.
- More phone help from a nurse between appointments was also noted by many participants as a potentially helpful service. However, comments about the value of this service were most often stated in terms of vague appreciation for the service if the need were to arise. Some participants mentioned that nurse help lines are currently available to them. Based on the provider comments discussed above regarding increasing phone-based case management services between appointments for rural patients, this support may have the potential to be very beneficial for rural communities, and for people receiving ongoing treatment for chronic conditions.
- Help getting medications when needed was, similarly, a support that participants noted as having potentially high value for their health. Some participants indicated that having lower cost or free medications would be appreciated, and some noted that they have trouble affording medications even with health coverage. For patients without health coverage or for whom their prescriptions are not covered, this service would make a large positive impact on their health. Other participants stated that with their coverage, their prescriptions were affordable.

• Help getting legal services at the clinic was a support that some participants noted would improve their and their families' health. One medical provider discussed potential situations in which legal services would be required to document a change in status that would make a patient eligible for healthcare coverage. This provider elaborated that in such cases, these legal services could be cost prohibitive for patients, and making them available and affordable at the clinic could facilitate these patients receiving healthcare. However, most of the community members in this study discussed this support in more general terms, such that it would be good to have accessible legal services, if needed.

Conclusion

Social risk factors, as complex and often intersecting phenomena, can substantially impede wellness and the ability to benefit from healthcare services and treatments, increasing the effects of health disparities. This study provides community members' and other stakeholders' insights into important social risk factors affecting individuals experiencing poverty, homelessness, and/or immigration, and ideas for how the healthcare system and communities can work toward addressing these challenges. Important social risk factors fall under umbrella categories of income and tangible resources; mental and behavioral health challenges; and culture, language and immigration status. Important supports include strengths-based approaches and team-based care, prevention, and collaboration between communities and the healthcare system.

Appendix A: Family income and federal poverty guidelines (FPG)

Which best describes your family's monthly income before taxes?

Number of people in your family who live with you	50% FPG	51% - 133% FPG	134%-165% FPG	165% FPG	over 165% FPG
1	Less than \$490	\$491-\$1304	\$1305-\$1619	\$1,619	over \$1619
2	Less than \$ 664	\$665-\$1765	\$1766-\$2191	\$2,191	over \$2191
3	Less than \$837	\$838-2226	\$2227-\$2763	\$2,763	over \$2763
4	Less than \$ 1010	\$1010-\$2687	\$2688-\$3335	\$3,335	over \$3335
5	Less than \$ 1,184	\$1184-\$3148	\$3149-\$3907	\$3,907	over \$3907
6	Less than \$ 1,357	\$1357-\$3609	\$3610-\$4479	\$4,479	over \$4479
7	Less than \$ 1,530	\$1530-\$4090	\$4091-\$5051	\$5,051	over \$5051
8	Less than \$ 1,704	\$1704-\$4531	\$4532-\$5623	\$5,623	over \$5623
	Eligible for:	Eligible for:	Eligible for:	Eligible for:	
Medical	MA	МА	MA	MinnesotaCare or health care subsidy	May be eligible for MinnesotaCare or health care subsidy
SNAP	SNAP	SNAP	SNAP	SNAP	

Appendix B: DHS examination of social risk factors

The following social risk factors are currently under examination by DHS for the purpose of care reimbursement determination.

Social Risk Factors that may make it more difficult to get healthcare, and manage one's health

Income and tangible resources

- Family poverty
- Neighborhood poverty
- Homelessness
- Family lacks vehicle
- Low educational attainment

Family structure

- Single parent family (children only)
- Four or more children in household (children only)
- Child in household is medically complex

Language and Immigration

- Patient's immigration status
- Parent's immigration status (children only)
- Language other than English spoken most of the time

Diminished parental functioning (children only)

- Parental chemical dependency
- Parental mental illness
- Child protection involvement

Demographic characteristics

- Rural/urban
- Race/ethnicity

Appendix C: Community member informed consent

What it means to participate in the DHS Health Disparities Project

This document is to be read verbally to client participants, with verbal consent.

Thank you for volunteering to have an interview for the DHS Health Disparities Project. I will tell you about the project—please ask as many questions as you like.

Purpose of the Study

The purpose of this study is to help the Minnesota Department of Human Services, or DHS, learn more about challenges that people have in staying healthy. Your choice to participate in this interview will play a part in helping people figure out how to make it easier for everyone to get the healthcare they need and want. Your input is really important and we thank you for your time and help!

Procedures

If you decide to take part in this study, we will talk right now for about 20 minutes about any challenges you might have in staying healthy and meeting your healthcare needs. We'll also talk about what services and support might make it easier to meet those needs. You can share with me whatever information you like, and you don't have to share information if you don't want to. I may ask you follow up questions based on what you tell me, but if you don't want to answer a question, just say so. I will type notes while we talk, and if it is okay with you, I'd also like to audio record our conversation in case I miss anything in my note taking. The Improve Group interviewers, such as myself, will be the only people with access to this recording. We will destroy it and all other such recordings by August 2017.

Explanation of Risks & Protecting Your Privacy

Sometimes when people talk about challenges they're having, they can feel frustrated or upset. If you think talking about challenges you're having in meeting your healthcare needs might make you upset, you can decide to not have the interview. If you decide to have the interview and you get upset during the interview, we can end the interview at any time. Just let me know if you want to end the interview early. The only places we have your name is on the sign-up sheet for the interview, and that will be shredded later today. We'll ask for your signature to show you received the \$25 Visa gift card to thank you for your time and help. We'll shred the signature page for the gift card in August (2016). We will not collect any other information that could identify you. We will not connect any of the information you tell us in this interview with your name or identify you in any other way. We will share the challenges and ideas you tell us about in a report for DHS that will be publically available, but no one will know that those challenges or ideas came from you.

Costs and Payment

There is no cost to you for participating in this project. You will receive a \$25 Visa gift card for taking the time and effort to have this interview.

Voluntary Participation

You do not have to have the interview if you don't want to. If you decide to not have the interview, that's just fine and it will not affect the services you receive in any way. If you want to stop the interview before we end, just let me know.

Questions

Do you have any questions about the project or interview?

Consent

Would you like to have the interview?

Is it okay if I audio record our conversation?

Project Contacts

Here is my business card. You can contact me by phone or email if you have any questions later. Here is the text of everything I just read, and this sheet includes the names of the main researcher, as well as a member of the DHS Institutional Review Board (research ethics board).

DHS Health Disparities Project Contacts

Principal Investigator: Stacy Johnson Research and Evaluation Director The Improve Group stacyj@theimprovegroup.com 651-315-8923

For questions about your rights as a person in the study, you may call DHS Institutional Review Board member Sarah Myott, at 651-431-4913 or email her at sarah.m.myott@state.mn.us. The IRB is a group of people who make sure before a study begins and during the study that your rights are protected.

Appendix D: Organization staff informed consent

Staff Interview Introduction (Verbal Informed Consent)

Thank you for agreeing to have an interview for the DHS Health Disparities Project. We appreciate your time and input!

Purpose of the Study

The purpose of this project is to help the Minnesota Department of Human Services, or DHS, learn more about social risk factors that make it more difficult for people who have experienced or are experiencing homelessness, poverty, or immigration to stay healthy, and the ways medical providers can help to address these barriers.

Procedures

This interview should take about 30 minutes, and will gather your insights about what barriers these populations face in staying healthy, and what may mitigate the barriers. I will type notes while we talk, and if it is okay with you, I'd also like to audio record our conversation so that if I miss anything in my note taking I can check the recording. The Improve Group interviewers, such as myself, will be the only people with access to the audio recording and notes. The audio recording and notes will not be shared with DHS or anyone outside of The Improve Group. We will destroy all recordings and notes by August 2017.

Explanation of Risks & Protecting Your Privacy

We will analyze all the data we receive in aggregate and will reflect comments of organization staff in the report anonymously. It may be clear from your comments what populations you work with, but we will not name in the report which organizations we conducted interviews with. There may be other staff members here at your organization who know you had an interview with us for this project, and there is a chance they may be able to recognize your comments if they read the report. We will only retain your name with your interview data in case we need to contact you with a follow-up question about something you say in the interview. Is it okay if I contact you later with a follow-up question? We will destroy all interview notes and project data in August 2017.

Voluntary Participation

This interview is voluntary, and if you change your mind about participating, you can withdraw from the project at any time, including during the interview, by letting me know during the interview or contacting me later by email or phone.

Questions

Do you have any questions about the project or interview?

Consent

Is it okay if I audio record our conversation in case I miss anything in my note taking?

Project Contacts

Here is my business card and the text of what I just read, which includes the names and contact information for the lead researcher (email the information if phone interview). Feel free to contact me or a study manager if you have any questions later.

DHS Health Disparities Project Contacts

Principal Investigator: Stacy Johnson Rassel Research and Evaluation Director The Improve Group <u>stacyj@theimprovegroup.com</u> 651-315-8923

For questions about your rights as a person in the study, you may call DHS Institutional Review Board member Sarah Myott, at 651-431-4913 or email her at <u>sarah.m.myott@state.mn.us</u>. The IRB is a group of people who make sure before a study begins and during the study that your rights are protected.

Appendix E: Community member interview protocol

DHS Health Disparities Project

Semi-Structured Interview Protocol

Client interviews

I. Read Clients' Informed Consent, obtain verbal consent

See informed consent document

II. Situating clients' overall views on healthcare:

- 1. In a few words, how would you describe your overall health?
 - a. (definition if needed: health = physical and mental health)
 - b. (Prompt if needed: very poor, poor, good, very good, etc.)
- 2. People have different goals about health. Which statement best describes your feelings about taking care of your health?
 - a. I don't pay attention to my health or try to take care of my health.
 - b. I do what I can to take care of my health when other things don't get in the way.
 - c. I do everything I can to take care of my health.
 - d. Other? (Please describe)

II. Healthcare needs:

- 3. What do [or would] you need to take care of your health?
 - a. Prompt if needed: Do you have any health conditions that need things like a special diet, or medicines, or that you need to see a doctor or other professional for?
 - a. (If need further prompts: For example, having conditions like diabetes, asthma, high blood pressure, depression, bipolar disorder, or other conditions may mean you'd need a special diet, medicine, or to see a doctor.)
 - b. Prompt if have no health conditions: Do you have any health goals, like eating better or exercising, that you want to do to take care of your health?
 - c. Are there any other things that you need to take care of your health, or to stay healthy?
- 4. How easy or hard is it for you to get [those things you just described]? (Prompt for each need they listed in previous question.)

III. Barriers:

- What are things that make it [use their word from last question (i.e., hard)] to get access to [each need they listed]? (Repeat for each need.)
 - a. If needed, elicit whether there are barriers in any of the following areas: limited income, insurance or paying for services, housing (if homeless, where do you stay and effects on meds, treatments, appointments, etc.), transportation, family or other close relationships (incl. abuse, child protection), sex work, language, different perceptions of health and healthcare, immigration status, chemical dependency (ease of quitting, best support for quitting), head injury, mental illness, physical illness, disability, and/or arrest or incarceration, access to healthy food, safe places to walk or exercise. Mitigating Factors:
- 6. What would make it easier to get access to [each need they listed]? (Repeat for each need.)
 - a. If needed, remind them of their earlier answers: You said that you need X to take care of Y. What would make it easier to get X?
 - b. If needed, provide further prompts such as:
 - i. In a perfect world, what resources would be available to help you be healthy?
 - ii. In a perfect world, how would your community help you be healthy?
 - iii. In a perfect world, how would your family and friends help with staying healthy?
- 7. If clinics could add additional services to help you address some of the barriers you've discussed, would that be helpful to you?
 - a. What services would help you address your health needs? (prompt if needed: assistance with enrolling in public programs, etc.)
 - b. What would be different if you had those services?
 - c. How much do you think this service could improve your health?
 - i. No improvement
 - ii. Small amount of improvement
 - iii. Medium amount of improvement, or
 - iv. A lot of improvement
- 8. Would any of the following services be helpful to you, if your clinic could provide them? (show list of following services):
 - Your clinic being open evenings or weekends

- More phone help from a nurse between appointments
- More staff in your clinic who speak your language and understand your culture
- Transportation help (what would that look like, how long in advance would you need to schedule your ride, etc.)
- Help getting medications when you need them
- Help getting mental healthcare
- Help getting free groceries
- Help getting childcare while you are at the doctor
- Help getting legal services
- Simple tests or wellness education in your home and/or neighborhood

Ask the following for each service above that the client notes as helpful:

- a. What would be different if you had those services?
- b. How much could this service improve your health?
 - i. No improvement
 - ii. Small amount of improvement
 - iii. Medium amount of improvement, or
 - iv. A lot of improvement

VI. Demographics:

Now I'm going to ask you a few specific questions about yourself. We can skip any of these questions if you would rather not answer.

- 9. (Show below age ranges on sheet of paper). Which age range describes your age?
 - a. 18 25 years old
 - b. 26 35
 - c. 36 45
 - d. 46 55
 - e. 56 65
 - f. 66 or older
- 10. (Only ask if unable to determine) What is your gender?
 - a. Man
 - b. Woman
 - c. Other
- 11. (Show below on sheet of paper). Which of these describe your background? Indicate all that apply.
 - a. African

- b. African American
- c. American Indian or Alaska Native
- d. Asian
- e. Hispanic or Latino
- f. Middle Eastern
- g. Pacific Islander or Native Hawaiian
- h. White
- i. Other (please specify)_____
- 12. (Show below on sheet of paper). What is the highest level of education you have completed?
 - a. No formal education
 - b. Elementary, junior high, or some high school
 - c. High school Diploma or GED
 - d. Some college courses completed
 - e. Trade school, technical, or community college degree
 - f. 4-year degree or higher
- 13. Have you moved to the U.S. from another country?
 - a. If yes, which country?
- 14. What language do you speak at home most of the time?
- 15. In what city do you currently live?
- 16. Have you experienced homelessness in the last five years? By homeless we mean that a person is living in a place not meant for human habitation, in emergency shelter, or in transitional housing.
 - a. Yes
 - b. NO
- 17. If yes to Q16: Are you currently homeless?
 - a. Yes
 - b. NO
- 18. How many people live in your household?
- 19. Approximately, what is your [household] monthly income before taxes?

(Consult HSS Poverty Guideline table. If the respondent chooses any of the first 3 income ranges for their family size, ask the following questions) 20. It looks like you meet the income guidelines for Medical Assistance. Are you currently enrolled in MA, or another public healthcare program?

a. Yes

b. NO

If no: Would you like information on how to enroll? It looks like you meet the income guidelines for SNAP, also referred to as Food Stamps. Do you currently receive SNAP?

- a. Yes
- b. NO

If no: Would you like information on how to enroll?

Interviewer question. Did the respondent:

- a. Have no problem understanding and communicating during the survey?
- b. Have some problem understanding and communicating during the survey?
- c. Have a lot of problems understanding and communicating during the survey?

Appendix F: Organization staff interview protocol

DHS Health Disparities Project

Semi-Structured Interview Protocol

Social service organization staff interviews

Organization type (housing shelter, immigrant services organization, etc.):

Is there a particular population your organization focuses on or serves most often (racial/ethnic group, age group, urban/rural, etc.):

Interviewee name: _____

Interviewee contact information (if needed for follow-up question):

Read Staff Interview Introduction (Verbal Informed Consent)

- 1. What is your professional role (job title, primary duties)?
- 2. Can you tell me about the populations you work with, and what types of barriers they have in staying healthy and meeting their healthcare needs?
 - a. Prompt if needed: Are your clients experiencing homelessness, poverty, and/or immigration?
 - b. Prompt for details for each barrier mentioned
 - c. If needed, elicit whether there are barriers in any of the following areas: limited income, insurance or paying for services, housing (if homeless, where stay and effect on meds, treatments, appointments, etc.), transportation, family or other close relationships (incl. abuse, child protection), sex work, language, different perceptions of health and healthcare, immigration status, chemical dependency (ease of quitting, best support for quitting), head injury, mental illness, physical illness, disability, and/or arrest or incarceration.
- 3. What are the best ways to address the barriers the populations you serve face in staying healthy and meeting their healthcare needs?
- 4. If clinics could add additional services to help clients address some of the barriers you've discussed, would that be helpful to clients?
 - a. What services would help clients address their health needs? (prompt if needed: language interpretation, referral for services, etc.)

- b. What would be different if clients had those services?
- c. How much would having those services help clients? (probe for whether would have substantial value)
- 5. Would any of the following services be helpful to your clients, if their clinic could provide them? (show list of following services):
 - The clinic being open evenings or weekends
 - More phone help from a nurse between appointments
 - More staff in the clinic who speak your clients' languages and understand their cultures
 - Transportation help (what would that look like, how long in advance would they need to schedule their ride, etc.)
 - Help getting medications when they need them
 - Help getting mental healthcare
 - Help getting free groceries
 - Help getting childcare while they are at the doctor
 - Help getting legal services
 - Simple tests or wellness education in their home and/or neighborhood

Ask the following for each service above that is noted as helpful:

- I. What would be different if your clients had those services?
- II. How much do you think this service could improve your clients' health?
 - a. No improvement
 - b. Minor improvement
 - c. Moderate improvement, or
 - d. Major improvement