

**Minnesota Behavioral Health Home Planning  
and Community Engagement**

***Final Report***

**By the Minnesota Department of Human Services**

**In partnership with National Alliance on Mental Illness (NAMI) Minnesota**

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## **PURPOSE**

The Chemical and Mental Health Division and Health Care Administration of the Minnesota Department of Human Services (DHS) are working together to design a Behavioral Health Home (BHH) model that will operate under a “whole person” philosophy and assure access to and coordinated delivery of primary care and behavioral health services for adults and children with serious mental illness.

DHS is developing a framework that will require a standard of integrated care that encompasses mental, chemical, and physical health conditions, and considers the influence of multiple conditions, social factors, social function, and consumer preferences to personalize assessment, treatments and goals of care. DHS believes that more integrated care, regardless of setting, contributes to improved health and decreases the risk of adverse outcomes, including hospital admissions. DHS is starting with the population with serious mental illness because of the known barriers of health care access, high co-occurrence of chronic health conditions, and early mortality. DHS may build on this framework to serve other complex populations in the future.

In planning Behavioral Health Homes, DHS contracted with the National Alliance on Mental Illness (NAMI) Minnesota to gain input from people with mental illnesses across the state to help shape policy. Through participation in focus groups, Medicaid recipients from a very wide range of communities provided feedback on topics that will inform the BHH program that is being planned for them. Focus group questions concentrated on such topics as:

- Access to and experience with physical and mental health care
- Care transition experiences
- Methods of obtaining health information
- Experience with and opinions about the facets of integrated care
- Ways in which individual, cultural, spiritual, and gender values have been and should be incorporated into the care process

This report includes detailed analysis of data from participant input and recommendations for integration within BHH policy.

## **METHODOLOGY**

Focus group questions were developed in accordance with the BHH Input and Engagement contract. Sample questions were presented to the BHH Advisory Group for input. Questions were modified and piloted. Cultural community experts and leaders were consulted for input into modifying questions for cultural relevance, language, and approach.

The focus group questions and questionnaire were piloted twice to parents of children and adult children in focus groups conducted at NAMI in St. Paul. Modifications to the order of questions, clarification of language, elimination of repetitive questions, and selected prompts were based on the pilot evaluations.

Participants were asked 18 questions and given a six-question questionnaire to answer at the end of the focus group session. Questions sought input in the area of health promotion, medical and mental health care experience, care coordination and management, and care transition. Questions specifically addressed participants' experiences with physical, mental, and transitional health care, barriers encountered receiving care, cultural/spiritual/physical health needs and practices, the extent to which these practices were incorporated in their care experience, preferences for receiving health information, and perceptions of and opinions on how health care delivery and their health could be improved. The questionnaire (see Appendix A) asked participants to rate their likelihood of participating in specific aspects of the program.

Individual or phone interviews and a computer survey were available to people as an alternative to participating in a focus group. While both individual and phone interview options were used, online surveys were not due to higher-than-anticipated focus group participation.

Focus groups targeted people enrolled in Minnesota health care programs or who have similar characteristics and live with a mental illness, chronic illness, or both. Focus groups were conducted in African-American, Hispanic/Latino, American Indian, Russian, Hmong, lesbian-gay-bisexual-transgender, and criminal justice communities, and reached parents of minor children, transition-age youth, adults, families of adults, and older adults. Focus groups were also conducted in specific low-population areas in northeast, northwest, central, west, southeast, and southwest communities in greater Minnesota, as well as the Twin Cities metropolitan area (see Appendix B). Each focus group took one hour and forty-five minutes to complete. Most focus groups were recorded and supplemented by observer notes. Most metropolitan area participants received a \$20 Target gift card. Participants for whom Target or Walmart are not easily accessible received \$25 VISA gift cards.

A total of 30 focus groups and 14 in-person or phone interviews were conducted from September 2014 to February 2015. Forty groups were originally scheduled. Ten were rescheduled, seven due to a lack of attendance and three due to inclement weather.

A variety of outreach strategies were used to reach target communities, including:

- Contact with clinics, mental health providers, residential treatment centers, peer support networks, county case managers, clubs, and support agencies
- Promotion of focus groups in agency and NAMI affiliates' news and e-newsletters
- Flyers posted in community and health centers
- Collaboration with community workers, support group leaders, and health and mental health workers in cultural communities

In several communities, NAMI trainings were traded for access to established groups. Networking with agencies that serve cultural communities and in culturally focused meetings and forums drew additional participants in cultural communities. Community leaders were consulted and relied upon to promote focus groups. Having a presence and being available to

answer questions and explain the purpose and importance of participation in focus groups were also important in the recruitment process.

All targeted communities were surveyed except the African/Somali community. Despite multiple attempts, outreach to the African/Somali community was unsuccessful.

## **ANALYSIS OF FOCUS GROUP FINDINGS**

The findings presented here are based on information and opinions gathered from all input. Findings from all focus groups and individual interviews are organized according to the major group targeted and, where appropriate, further organized by subgroup. Not all participants answered all questions, nor were all questions relevant to each participant's experience. Data reflects responses to a particular question, not number of participants.

### **Overarching Focus Group Themes**

Qualitative data analysis revealed overarching themes across focus group types. Within each of the major themes, a number of subthemes were identified. Subthemes will be addressed within the analysis of each group's findings. The major themes were:

1. Provider relationship and trust
2. Short appointment times
3. Access as a barrier to care
4. Education and information
5. System barriers
6. Lack of provider wellness and recovery perspective, and system wellness and recovery model and structure
7. Stereotyping and negative experiences with care

#### ***Provider relationship and trust***

Trust and relationship with the provider were the most prevalent themes that emerged in all focus groups. Participants identified having a relationship with their provider as a very important precursor to developing trust. With a trusting relationship, participants felt more comfortable talking to the provider about sensitive issues, expressing preferences, and being honest with their provider. With a trusting relationship, participants had an increased perception of provider credibility that resulted in improved medication and care plan adherence, a positive sense of well-being, and improved hope for recovery.

Across all cultural groups, participants described provider cultural or racially similarity as a factor that contributes to their positive experiences with care. Cultural and racial similarity also facilitated relationship and trust with providers. People for whom English was not their primary language stressed the importance of having a provider who speaks their language. Having interpreters who speak the language was met with mixed opinions. Interpreters who only interpreted and were brought into the exam room once the respondent was placed there and who did not interact beyond interpreting were generally appreciated but not valued, whereas interpreters who met with participants while waiting for the provider, who talked to them, asked questions about their family, remembered their situation at the next visit, asked about needed resources, and had ready information were very much valued. Participants with the latter experience also had a more positive perception of their care, expressed a higher degree of trust and confidence in their provider, and expressed a greater degree of wellness and health even when experiencing serious chronic illness such as stage IV cancer with co-occurring mental illnesses.

### ***Appointment times***

In all focus groups, participants cited limited appointment times as a barrier to care. They felt limited quality time with their provider impeded their ability to receive effective care and address their needs. Lacking adequate time with a patient, providers are limited to asking about symptomology and medication side effects, and cannot ask questions that would help to better understand the participant's needs.

### ***Access***

Across many focus groups, participants reported challenges accessing mental health appointments. Participants report that due to limited availability of appointments, wait times for an appointment are often three or more months; in some areas, wait times for an appointment with a mental health provider have been as long as a year.



### ***Education and information***

Participants in most focus groups discussed the difficulty of accessing credible information to learn about their illness. Parents expressed frustration with provider unavailability to discuss their child's illness and the consequences of the illness, especially during a crisis. Parents described frustration and anger at having to search for information to help them understand what is happening with their child when they are stressed and afraid during their child's mental health crisis. People for whom English is not their first language also identified difficulty in communicating with providers about their care.

A strong educational component that allows time for participants to talk to providers about illness, diet and exercise and to learn wellness skills is desired.

### ***System barriers***

Across most focus groups, participants reported experiencing poor care coordination and care management. Care coordination often had to be initiated and even managed by participants. While some providers had access to patient records within a system, participants were unsure if providers actually read the records and talked with other providers and supporters. Other system barriers cited were frequent changes of providers, lack of consistent transition planning and supports, and spotty continuity of care after hospitalization.

### ***Lack of wellness and recovery resources***

Participants in most focus groups reported limited availability of wellness and recovery resources, limited education and information to aid in recovery and wellness, and limited access to tools to aid in achieving wellness and recovery.

### ***Stereotyping and negative experiences with care***

Across most focus groups, participants reported negative experiences with care in which they felt stereotyped, disrespected, not listened to, or dismissed by providers. Participants also discussed a

range of experiences in which they were either refused care, provided substandard or not helpful care, or subject to unwarranted police intervention.

## **RECOMMENDATIONS FOR INTEGRATION WITHIN BHH POLICY**

Analysis of the focus group findings reveals that it would not be feasible to take a one-size-fits-all approach in structuring the Behavioral Health Home model to meet the needs of participants. BHH clinics will need to know their patient population to maximize the benefits of this focus group information.

### **Agency Recommendations**

**1. Include peer-based supports and services:** Participants recommended developing peer-based supports and services to provide opportunities for:

- Peer-to-peer support
- Facilitating medical and mental health system navigation and helping new users get acclimated to medical and mental health systems and services
- Providing wellness, recovery and social support
- Making available needed information about illness, reputable web sites to search for information about specific illnesses, and social supports

**2. Enhance direct care:** Recommendations for improving provider care and provider-patient relationship and trust span a range of quality, access, cultural competence, and recovery areas.

- Increase appointment times for the first two to three visits to allow providers an opportunity to get to know their patients and their preferences, to talk with them about their diagnosis, and to allow patients to have their questions answered.
- Formalize health, wellness, and recovery approaches and activities that are reinforced during appointments.
- Incorporate “health partners” and wellness coaches in care structure and plan.
- Foster a wellness approach rather than one focused on illness or medication management. This approach speaks to what people can do to achieve wellness and cope while living with their illnesses.

- Adopt a policy of including patients’ natural supports (family, friends, or others) in their care, transition, and discharge planning. Such planning should ask *who* they want to include, not *if* someone should be included.
- Make available annual or biannual pharmacy appointments for medication monitoring/checks.

**3. Enhance supports for parents with mental illnesses:** Provide enhanced supports and resources when parents are in crisis, including assistance with placing children while in crisis or hospitalized.

**4. Improve systems:** Participants recommended four key systemic changes.

- Develop a system of care for mental illnesses that are not yet a crisis but are unmanageable by the individual or family member.
- Institute a step-down system for people when no mental health treatment slots are available in which clients would be screened and referred to an alternative system of care (i.e. recovery coaches) until an appointment is available.
- Mental health education and training for primary care providers and emergency room staff.
- Ensure forms and computer systems allow patients to self-identify their preferred name and gender pronoun.

### **Clinician and Clinical Staff Recommendations**

Focus group participants recommended two changes in the training of clinicians and clinical staff:

1. Train providers in cultural competency, particularly in dealing with youth, young adults, and GLBT health.
2. Train providers to:
  - Better understand mental health
  - Develop a recovery mindset and model
  - Better manage mental health medication
  - Better handle crisis management

- Accurately understand the requirements of the federal Health Insurance Portability and Accountability Act, in particular, the actual versus perceived limitations of privacy that pertain to inclusion of a patient's family, friends, and others involved in their care

## **FOCUS GROUP FINDINGS**

### **Adults**

Eleven adult focus groups were conducted in the metro area and throughout the state. Subgroups represented in the adult focus groups included:

- Greater Minnesota communities:
  - Bemidji
  - Brainerd
  - Winona
  - Fond Du Lac Reservation
  - Hoffman
  - Worthington
- Adult homeless
- African-American, criminal justice (3 groups)
- Twin Cities metropolitan area

### ***Medical health experience***

Focus group participants were varied in their perceptions of health and wellness. General themes encompassed self-actualization, access and resilience. Self-actualization ranged from having peace of mind to being able to cope, having fewer or no mental health symptoms, being able to enjoy life, or feeling happy. Access responses included having access to and using needed physical and mental health care and resources, and resilience included having a positive attitude, feeling satisfied or contented, being fit, engaging in exercise or activities, and having good nutrition. Having a stable lifestyle and attaining basic needs such as housing were other frequently identified components of health and wellness. A small set of participants also described health and wellness as managing physical and mental health symptoms or associated disability.

### ***Medical health care experience***

Participants connected to their primary health care provider in a number of ways. Connecting by default constituted the majority of responses; this included taking whomever had an opening when needed, being referred by Medical Assistance or Medicare, seeing whomever was available at a hospital or clinic or whomever accepted Medical Assistance, connecting to a provider as a result of a hospitalization, and, in the case of most participants living in greater Minnesota, connecting to whomever replaced a provider who left or retired. Providers who were family doctors and those recommended by a family member or friend were the next most frequent responses, followed by self-choice. Family doctors were typically doctors retained from birth or who were referred by a family member, friend, or agency. Very few participants said they shopped around and chose a specific provider.

Generally, participants who reported having a “family doctor” also reported having a good relationship, level of trust, and belief or perception of provider credibility. They also indicated they felt more comfortable telling their provider about sensitive issues, and reported having a greater likelihood of following or trying to follow a care plan. The most common source of referrals were mothers. Throughout this and most focus groups, mothers were prominently identified as the bridge to medical care, and provided medical advice, recommendations and referrals.

Some participants who connected to default medical providers came to consider the provider their primary or family provider. Providers were often embraced as an individual’s primary doctor after offering assistance or connecting the participant to needed resources, taking time to listen, talk, ask questions, or get to know the individual, or by openly discussing how they will help. Providing information about how others dealt with the same problem in addition to facts about the illness and building rapport were other reasons participants decided to retain a provider. One participant described what influenced his decision to establish a primary doctor this way:

“I went to the same clinic but saw different doctors each time until the first time I saw my doctor. When he saw me, he said to me, ‘I’m going to be your doctor.’ I have been seeing him ever since.”

Most participants see their physical health provider for chronic illness. Diabetes and neuropathy were the leading chronic conditions, followed by arthritis and a variety of other chronic illnesses. Other reasons to see a physical health provider were for general/preventative health, medication management, hypertension, and mental health.

Participants in greater Minnesota cited a lack of providers due to high turnover rates and the retirement of current providers, as well as a shortage of medical providers within a reasonable distance. These participants were more likely than metropolitan area participants to have physical health physicians who managed their medications and mental health needs.

Most participants either go to the emergency room or call/ visit their doctor when they are sick. Emergency room use was related to a lack of insurance, a lack of education, or the occurrence of a medical or mental health crisis. High levels of emergency room use were noted among the adult homeless population and were reported as being due to factors related to an inability to meet basic needs, coupled with the lack of facilities, insurance and the resulting inability to access health care or resources to manage or prevent illnesses. Three participants in the adult homeless focus group reported having had no medical insurance for 7, 10, and 20 years, and described being prevented from making appointments due to their lack of insurance.

A barrier specifically noted in the African-American focus groups was a lack of knowledge about how to access and appropriately use the health care system. One participant described her previous history of frequent emergency room use and lack of education about the medical system this way: “I used to be an emergency room freak. I used to go to the ER and urgent care every time me or my kids were sick. One time I went (and) a nurse took me aside and told me I didn’t

have to bring the kids in for everything. She educated me about what to do first. Then I started calling the nurse line. I almost never use the ER now.”

Respondents reported using a variety of practices when sick. Significant numbers use meditation, yoga, Reiki, and prayer or spiritual practices when sick, while others use exercise and vitamins or supplements. Epsom salts baths, teas, and home remedies were also frequently used self-care strategies.

Mental health was participants’ most significant health care problem. Pain management and diabetes had equal representation as the second most important health care problem. Remaining responses were highly individualized and ranged from lack of mental health facilities and doctors, a theme prominent in outstate Minnesota, to arthritis and a range of chronic illnesses such as chronic bronchitis, liver and kidney issues, and hypertension. Physical conditions identified as participants’ most important health care condition were not representative of their most severe health conditions or co-occurring disorders. Severe health conditions were revealed later in the context of answering subsequent focus group questions.

Barriers to care were highly individualized and showed general patterns clustered by region and care system. Several barriers were consistently identified across most groups and prompted participants to elaborate how access to care was made more difficult and sometimes impossible. These barriers included:

1. Homelessness
2. Lack of dentists who accept Medical Assistance
3. Lack of mental health services and providers
4. Long delays for mental health appointments
5. Feeling like providers do not listen
6. Difficulty accessing care for medical issues when medical issues are attributed to mental health
7. Stereotyping and negative experiences with care

8. Transportation
9. Difficulty with insurance when filling prescriptions for psychiatric medication
10. Provider reluctance or refusal to provide pain management

Participants' most frequently cited barriers to receiving care for their most important health problem were homelessness, negative patient/provider interactions (providers who do not listen or take symptoms seriously, do not treat or have time to treat presenting problems, or do not believe the patient), long wait times and a lack of providers, lack of monitoring of medications, medication interactions, and cost and availability of medications and treatments.

In greater Minnesota focus groups, the existence of a mental illness was frequently cited as a barrier to receiving physical health care. One respondent shared his experience while seeking care in the emergency room for a broken shoulder. Upon seeing mental illness documented in the respondent's medical record, the ER provider instructed the participant he would have to submit to a toxicology screen. The participant was told he would not be seen unless he submitted to it. When he refused, ER staff refused to see him and called the police. The police sent him to the "psych ward" instead. Five other participants in the same focus group reported having the same experience. "Physical health problems are not heard when I go to the ER," explains one participant. "You get immediately sent to the psych ward."

Another participant described using the care system inappropriately and experiencing great difficulty finding help to figure out what he needed to do; "The ER doesn't educate about how to find a primary doctor."

Still another described the challenge of accessing care without insurance: "If you don't have insurance, they just fix you up enough to get you out the door, but they don't solve the problem."

Homelessness and finding housing were the most frequently reported barriers to care. Participants experiencing homelessness described the difficulty of trying to follow multiple

aspects of care and health while homeless. Challenges included trouble obtaining insurance for care, receiving appropriate treatment, and having the basics needed to achieve health. One participant describes the challenges he has faced and continues to face in his attempt to get health insurance. He explains that he completed the insurance paperwork, but because he does not have a permanent address to receive correspondence from Medical Assistance, he has not been able to actually obtain insurance. Another participant shared his difficulty getting services that take into account his life and socioeconomic situation: “The doctor referred me to (a provider in) Plymouth after my heart attack. I told him I couldn’t get to Plymouth. He didn’t provide a different referral.”

Another person in the same group reported receiving inadequate care when he goes to the emergency room: “Doctors don’t listen, and that’s a barrier to health care.” Eight other participants reported having the same experience.

Trouble finding a dentist who accepts Medical Assistance was a prominent barrier identified in several groups. Participants cited the unaffordability of dental care, while others reported that certain psychotropic medications cause expensive dental problems and lead them to question whether they could continue using the medication.

Highlighted in almost all groups, most notably in greater Minnesota, were the barriers experienced due to lack of mental health services, a perception that doctors do not listen, the failure of providers to treat medical issues because they attribute physical symptoms to mental illness, the availability of and access to a provider, and long delays to see a provider. Participants in the northeast area, for example, report that the wait for an appointment with a psychiatrist or therapist has sometimes been as long as a year, whereas other greater Minnesota participants reported they typically experience delays of three to three and a half months when seeking mental health appointments.

Transportation and childcare issues are significant barriers to care in some regions. Southeast participants reported that they have a transportation service for medical and mental health

appointments, but the level of service is inadequate. Many participants reported needing transportation assistance due to the revocation of their driver's license; this, combined with low socioeconomic status, the likelihood that supportive family members may not be able to provide transportation because of their own license revocation, and distance from the nearest hospital or clinic, leaves few transportation options. The need for child care providers and the paucity of child care providers and services to care for children when parents have medical appointments are significant ongoing barriers. The problem of adequate child care is worse when school is out for the summer or holiday break. Infant care is very limited, so even if participants have money and resources to afford childcare, they may still not have childcare options.

A concern central to all greater Minnesota groups is that after waiting for months to see a provider, if they do not “click” with the provider, they will again have to wait for months to see a different provider. Some groups reported their community has only a single provider who is available on a limited basis, requiring them to drive long distances to see a different provider. Availability of a single provider also creates problems if the participant and provider are incompatible or the provider does not offer a needed therapy.

Outstate participants regularly experience delays filling prescriptions for mental health medications because the pharmacy in their area either does not carry the medication or does not have enough of it to fill the prescription.

To get care for their most important physical health care problem, participants said they need:

- Medical providers to take more time with their patients
- Sensitive, knowledgeable providers who care, take them seriously, and listen to them
- Providers who have the ability to take care of multiple problems in one visit
- Affordable care and medications

To better meet their physical health needs, participants said they need:

- Housing
- Providers who do not assume all of their medical symptoms are due to mental illness
- A place to work out and get exercise
- Access to pain medications for people with a history of chemical abuse
- A health partner-someone to help achieve wellness and recovery, who can help acclimate participants to the medical and mental health system and advocate for participants when needed

Homeless participants felt that having showers available would help them to meet their physical health needs.

Among participants who reported emergency room use, more than half reported using the emergency room for mental health problems. Of these, three-quarters used the emergency room for a mental health crisis, a small number were escorted to the ER by police; some reported that they attempted to access psychiatric help through the emergency room but were turned away. Sickness or injury and chronic illness accounted for the rest of emergency room visits.

### ***Mental health care experience***

Participants in adult focus groups reported the majority of their connections to mental health providers occurred by default; through the provider being the only doctor available or the only provider accepting Medical Assistance, as a result of accessing a walk-in clinic, because of a commitment or court order, or because a previous provider left. To a much lesser degree, participants were connected to a mental health provider through an agency, self-referral, or the recommendation of a friend or family member.

Slightly less than half of participants see their provider for medication management; the remainders see providers for general mental health, therapy, just to check in, or when a crisis occurs. A few participants seek care for alcohol abuse and to gain coping skills.

Participant strategies for handling mental health symptoms provide insight into preferred and commonly used coping/calming strategies, the role and importance of community supports and supporters, and the range of other coping techniques. When experiencing mental health symptoms, participants most frequently call, text, or visit their provider. Talking to family or friends and using yoga, meditation, or mindfulness techniques are the next most used strategies. Exercise, sleeping, and calling crisis teams are about equal in their use, followed by marijuana use, smoking, and employing Wellness Recovery Action Plan (WRAP) strategies.

When asked, participants generally knew what was needed to better meet their mental health care needs. Identified needs include advocates to help individuals navigate the mental health and insurance systems, as well as advocates to help the entire family.

All groups voiced a need to have more time with providers to develop a relationship so they would feel more comfortable sharing personal or sensitive information with their provider. African-American groups addressed race and trust issues in their responses. There was general consensus in the three criminal justice groups that having a provider of the same race was important for developing a connection and trust. A provider showing that he or she cared and was “there for” the participant was a prerequisite to establishing a trusting relationship irrespective of provider racial similarity. In discussing trust African American criminal justice group participants discussed the process by which information is entrusted to providers. Very little information is initially shared with a provider. Additional information or more personal or sacred information is not shared unless a provider has acted in a way that shows his trustworthiness. Passing the test of trustworthiness, showing a willingness to help nonjudgmentally and a willingness to explain illness, treatment information and options are generally required before many African American participants to feel comfortable to trust or share more personal information. An African-American participant described how he determined how much he would trust a provider: “(I) told him a small amount to see if he would help out. If he had helped, I would have told him more.” Testing to determine if a provider is genuine and committed to helping versus “just being there for a paycheck” was a method most

African-American participants used when initiating a relationship with a mental health provider. If a provider was not of the same race, genuineness was a factor in determining if the participant would continue seeking services from that provider.

Barriers to care fell equally into five categories:

- Overextended providers
- Unavailability of appointments within a reasonable amount of time
- Discomfort with or distrust of provider
- Lack of insurance and resulting inability to get treatment
- Crisis line issues

Crisis line issues arose when participants called a mobile crisis unit and needed to speak to a provider rather than a volunteer. Participants report that while they were told a mental health provider would call within one hour; this was not always their experience. Providers called back from one hour to days later, and sometimes not at all. Problems arose when the provider called back but the participant did not answer. When no one answered, the police were then called.

### ***Care coordination/management***

Half of participants had providers who developed a care plan with their input and half did not. The providers who used participant input employed different approaches to solicit it. Participants considered jointly developing a care plan or combining provider and participant goals during care planning to be very respectful approaches. Examples participants gave of helpful and validating approaches included inviting a participant's grandmother to come to his appointment to offer her input, asking the participant what makes them feel good, incorporating WRAP strategies, and providing a treatment plan packet.

A majority of participants said their providers talk with other providers or supporters involved in their care; they did not know, however, the frequency of such contact. Half as many participants reported that their providers do not talk with other providers and supporters. Half of these

participants reported that although they signed a release allowing providers and supporters to talk, coordination and collaboration did not occur.

A very high percentage of participants have been asked if they wanted or have received assistance in making appointments. Few reported being offered or asked if they needed assistance to follow their medical plan. A small but still significant number of participants' providers consider their important cultural and spiritual practices by doing such things as asking about spirituality, referring them to cultural parenting classes, and encouraging their attendance at and providing transportation to monthly sobriety feasts. One respondent described how her provider included her spiritual practices in his approach to her care: "My doctor asks if I have been going to church. If I say no, he asks if there is anything keeping me from doing that." The relationship between the participant and her provider, where the provider got to know what was important to her and understood the significance of her missing church, was the type of relationship participants preferred to have with a provider.

The first and most used source of information for participants was the Internet (Google, MyChart, and Webmd.com were cited specifically). Other sources of information included handouts provided after an appointment, information from family or friends (usually a mother), medical records, and, for a few people, talking with their provider. While the latter was one of the least used resources, obtaining information from a provider was the most preferred method of receiving information. The importance of getting information directly from a provider was stressed by one participant: "I didn't understand my diagnosis, and my mental health provider wasn't giving me any answers, so I looked it up by myself. Now I have a doctor who helps me understand. I am comfortable with what he is telling me. Now I understand my diagnosis and what I need to do for my wellness."

Responses pertaining to how providers' help participants understand and live with their conditions varied, with none predominating. Participants cited offering assistance to get needed supplies and referrals, providing assistance to get needed appointments, and encouraging

volunteer work (which was also mentioned as a strategy when experiencing mental health symptoms).

Most participants in adult focus groups had no response to the question of how providers help them stay healthy. Participants felt providers did not necessarily help them stay healthy as much as they helped them manage their medications. Based on the discussion generated by this question, participants felt their providers do not generally address health, wellness or recovery beyond recommending they eat well and exercise. Wellness Recovery Action Plans (WRAP) and Adult Rehabilitative Mental Health Service (ARMHS) workers were identified as having a wellness and recovery perspective; however, many participants do not receive these services. Respondents who answered this question felt providers help them stay healthy by giving referrals, helping them stay healthy enough to be able to work, by listening, giving advice and helping with problems when they arise.

Participants discussed changes they would make to the current system if they had the ability to do so. Emphasis fell heavily on providers and the medical system. Participants recommended changing the amount of time for appointments to allow providers to take more time to diagnose, be more personable, have the time to treat patients with compassion and dignity, be able to better communicate to patients about their condition, and provide needed maintenance, prevention and recovery care.

A theme for provider changes unique to outstate Minnesota groups was the need to increase the knowledge base of providers so that individuals can access medical treatment for medical issues despite having mental illnesses. Training for emergency room staff was recommended so that when individuals whose medical records reflect that they live with mental illness present for treatment, they will not be stereotyped, judged and sent to jail.

System changes included making the medical and mental health system more user friendly, taking action to ensure a more caring health system, relying less on medication and

hospitalization, including other types of treatments such as massage and meditation, and making earlier and more efficient diagnoses and referrals to support services. In an area of the state where people living with mental illnesses have had difficulty with police, one participant recommended developing a system in which a record of psychiatric medications would be used to alert the police that the person lives with a mental illness.

### ***Care transition***

Participants report not being consistently included in their transition planning. Those who were involved reported a widely differing degree of involvement. Some were involved to the degree that they wanted to be, whereas others were more involved than they either wished to be or were able to be. Still others said that they were asked their preferences but those preferences were not respected.

Ways in which participants were involved included receiving a questionnaire asking their preferences, being asked about a health directive, and providers making suggestions and recommendations and discussing options.

Participants expressed a variety of ways in which they wished their involvement in their care transition had been different, including:

- Being consulted even if they are very ill
- Not being handcuffed
- Having the situation handled without involving police
- Being treated with respect by staff
- Being asked if they were comfortable
- Being listened to
- Being told the available options

Components of care transition that participants found helpful included:

- Wrap-around services and open-door policies

- Coordination and check-in with a social worker
- Knowing where they were going (e.g., taking a “field trip” to see where they would be going decreased their fear)
- Stabilization
- Education
- Being informed what was going to happen
- Being taught social skills
- Receiving three months of after-care and checkups

The most difficult parts of the transition included:

- Not getting help to access services or find providers
- Inconsistent care after hospitalization
- Not enough support for mental or physical health after transition
- Needing medication after hospitalization but having no provider and no money to buy it
- Being asked preferences but not given a choice
- Anxiety about and fear of the unknown
- Feeling disrespected

Recommendations participants made for improving the transition experience included:

- Having a follow-up call or check-in visit the week after hospitalization (most often recommended improvement)
- Developing a list of who to call if experiencing problems during transition.
- More family support
- Support to care for children during a crisis

Participant narratives provided a much broader context for understanding their health and mental health experiences, challenges, values, and needs. In the course of responding to focus group questions, participants in criminal justice and metropolitan area focus groups described multiple,

often extreme, early, and ongoing traumas. They described early experiences of neglect, drug-addicted parents, multiple bouts of homelessness and food insecurity, of being abused, being fed cocaine as a child, witnessing violence and experiencing the death of a sibling.

Participants also revealed co-occurring mental illnesses and substance use disorders; however, few identified mental illness or chemical abuse as their most important health care problem. While many participants in the criminal justice group described their prison experience as “traumatizing” and an experience that exacerbated their mental illness, a subset of these also described receiving benefit from the structured prison environment.

A prominent theme throughout was the influence of females (mother, sisters, girlfriends, ex-girlfriends) in making medical care decisions, obtaining medical care, providing medical information, and obtaining insurance. Women also held a prominent role in advising on the course of care when the participants were experiencing mental health problems. Asking or encouraging users of the BHH system could be an opportunity to involve influential females and others in care and recovery and lead to better adherence and health for individuals.

Participants in the criminal justice groups also cited a lack of exposure to and knowledge of health, mental health, and well care systems, along with high marijuana use for mental and physical illnesses.

“Coming out of the penitentiary,” one participant recalled, “no one ever taught or told me about health care. (I) was given books to choose from (about health care options) without anyone checking to see if I could read. There is no health care in the inside (penitentiary), so there is no chance of getting well care on the outside. (I) came out and got no guidance about health care. When I was released out into society, society doesn’t understand the complication of coming from a controlled environment where you are told what to do. You may not have had a family so you may be without knowledge about the system.”

Another participant observed, “You may be from a second generation where you were never taught. You need to have people tell you about medical programs and what you need to do and what is the benefit. It’s hard to figure out how to get a doctor, hard to have one without knowing (that), and doing what you need to do to get one is hard for someone coming from someplace where you don’t have knowledge and haven’t been responsible for making decisions about yourself.” Experiences like those described by these respondent highlight the need to have systems that effectively identify and respond to users with limited English proficiency or who are illiterate or have comprehension or other issues that present as a barrier to appropriately using care services and medication.

Trust, relationship with provider, and actions that show the provider cares about the individual were the strongest themes throughout most focus groups statewide. In criminal justice groups, most participants reported not trusting the doctor or mental health provider. Lack of trust and relationship with providers accounted for reluctance to go to the doctor, failure to honestly or completely disclose medical, mental or chemical health problems, and delaying or forgoing needed treatment.

Participants in most focus groups reported receiving poor care in the emergency room. Participants in the homeless, criminal justice, and American Indian groups described care in the emergency room as just enough treatment to get them out of the door with a recommendation to go see their family doctor. One participant elaborated that he does not have a family doctor and he needed but was not given instructions on how to obtain one.

When describing his distrust of providers, a participant in a group of seven African-American and one Native American men commented: “(I) don’t trust providers; they help you but they have another plan to kill you off.” Seven of the eight participants in this group indicated agreement with this statement.

While survey questions asked about barriers to obtaining health care for the most important medical problem, participants often also included barriers to achieving health. Discussions of diabetes in the homeless population focused on the role diet plays in being healthy. The homeless focus group had a significant number of diabetics who described their life as being in and out of facilities. One respondent described the challenges he experienced trying to manage his diabetes while staying in a homeless shelter: “Facilities load you up with carbs. This contributes to my diabetes. (This) facility has 80% diabetics, and it has two pop machines. The most expensive thing in the pop machine is the water. Cheapest thing in (another) machine is donuts. To monitor my diabetes, I need to be in my own environment so that I can feed myself.”

Among the strategies for better health that participants reported following were keeping a list of symptoms to take to doctor visits and monitoring blood pressure by having it checked at a local fire station rather than going to a doctor for that.

#### ***Recommendations from the adult focus groups***

- Take more time to diagnose; set a standard amount of time that providers must spend with a patient before making a diagnosis.
- Change provider practice to focus on asking “What have you been through?” instead of “How do you feel?”
- Include peer support specialists in the medical model.
- During the transition from prison to society, assign a social worker to help introduce the individual into the medical and mental health system; provide the individual with information on how to get a provider, how to make appointment, and what to do when ill; and offer help with meeting housing, food, and other needs.
- In greater Minnesota, provide mental health and sensitivity training for police and emergency room staff and incorporate culturally competent standards of care.
- Survey emergency room patients about their experience with the emergency room staff.
- Increase appointment times.

- Provide access to a clinical pharmacist once or twice a year to check for medication interactions.
- Ensure all patients are told their diagnosis. Allow time for patients to talk with their provider, a community health worker, or an education specialist about their diagnosis, health and wellness. Provide for people who are unable to read or may have memory or comprehension problems.
- Develop and maintain a robust list of social resources.
- Institute a wellness and recovery model of care.
- Ensure that visits with providers include information about wellness, health, and recovery in addition to medication management.
- Maintain a list of credible web sites on illnesses, health and wellness, and medical conditions.

## **OLDER ADULTS**

### ***Health and wellness***

Perceptions of wellness for most participants in the older adult focus group centered on being able to be happy, communicating with others, staying physically and mentally healthy, and doing the best that can be done despite having physical or mental health problems. Hmong elders could not articulate a specific idea of wellness. When asked their perception of wellness, most focused on not being well, with some saying they felt too sick to have an idea of wellness, and one person noted, “Well or not well, still the same.”

### ***Health care experience***

How people in the older adults group were connected to their doctor was defined by their specific subgroup. For example, most veterans report connecting to their doctor by default; they saw whomever they were assigned to by the Veterans Administration—whereas most of the Hmong elders saw whoever was available when they scheduled their appointment or presented at the clinic or hospital. Hmong elders assigned to a provider by default did not consider the physician or relate to them as a primary or family physician. Connecting to a physician was very

different for Russian elders. Responses show Russian participants were connected to a physician equally by self-referral, agency referral, and physician referral. Referral by an agency or physician for the purposes of this document are typically considered default referrals, that is, participants typically did not chose the provider and ended up with whomever was available, had an opening, or was chosen by someone other than themselves. For Russian participants, all types of referral sources identified involved a thoughtful directed connection, and included consideration of the participant's culture, language and desires as well as needs. Agency referrals were primarily made by the Jewish Family Services, the agency housing case managers and social and community support programs serving Russian elders. Participants choosing their own provider based their choice on provider cultural similarity and ability of the provider to speak their language. Referrals to non-Russian providers were usually a provider with a known history of doing well with Russian patients.

Latino and Chicano elders also report a high degree of self-initiated connection to their providers. Elders typically asked others in the community for recommendations about a provider, hospital or clinic under consideration. Self-initiated appointments, and using the services and social worker at Centro Cultural Chicano were methods most often used to locate and choose a provider. Centro Cultural Chicano, like the Jewish Family Services, was identified as a significant resource for mental health, social, and community support.

Despite similarities in the amount of time that Russian and Hmong elders have resided in the United States, there existed a great disparity in Hmong elders level of assimilation and understanding of American culture and systems and in their ability to navigate the medical and mental health system as compared to Russian elders. Hmong elders in this focus group session were profoundly without knowledge of the medical and mental health system, and had few helpful avenues by which to obtain this information. Russian elders were very well informed about care systems and insurance, and where to get help with questions about each. When discussing how they connected to their medical provider, one Hmong woman recounted, "I don't know (how I was connected to my provider). They just gave me one. I don't know how to choose

a provider.” Five other participants expressed agreement with this statement. A phrase that was heard many times in this group when discussing access to a working with providers translates to “I am not worthy, I am stupid.” The Hmong interpreter explains this is how participants report they feel when interacting with medical providers and systems.

Older adult participants report seeing their provider most often for chronic illness management, followed by general health and wellness, and sickness or pain. Only one person in this session reported seeing their physical health doctor for mental health.

Vitamins, supplements, and home remedies are the first course of action when older adults were sick. The next most frequent option was to a medical provider or system (by calling a doctor, 911, urgent care, or a nurse line) followed by use of traditional providers and practices.

Most Hmong elders prefer to take traditional herbal medications when ill but do not know where to find them. Instead, they seek prescriptions from a medical provider for medical problems. Seeking to feel better, some Hmong elders also discussed a desire to perform or participate in traditional rituals such as the spirit-calling ritual, but have been unable to do so. The ritual requires participation of the whole family and their children are too busy to take part.

Russian participants explained that integrative medicine is popular in their culture. Integrative medicine takes account of the whole person, including all aspects of lifestyle, by emphasizing the therapeutic relationship and making use of all appropriate therapies, both conventional and alternative. Many used integrative medicine, activities, classes, exercise, and water activities when they were not feeling well. They also used traditional herbs, but participants reported difficulty finding some desired traditional medicines. Some veterans reported experiencing the body, mind, and spirit approach promoted at the Veterans Administration. This approach is also a component of integrative medicine.

Participants cited their most important health care problem as chronic illness, in which blood pressure accounted for about a third of the responses followed by mental health and the effects of aging which were reported equally. Three Latino /Chicano elders voiced that maintaining wellness was their most important health care problem; “balanced meals balanced with exercise” or weight maintenance was their concern.

Though not identified as the most important health care problem by any Hmong elders, all discussed concern about life-impacting memory loss and forgetfulness.

Veterans reported experiencing no barriers when seeking care for their most important health care problems. Russian and Latino and Chicano elders reported experiencing few barriers. Needing a dentist and difficulty finding dentists who accept Medical Assistance and obtaining an insurance card were the only barriers identified.

Hmong elders seeking care for their most important health care problem cited systemic barriers compounded by lack of knowledge, inability to speak English, and lack of an advocate or established person to provide assistance. Systemic barriers included long delays for interpreters, no connection to a primary doctor, and lack of knowledge to enable them to establish care with a primary doctor. Existing barriers were compounded by language barriers and an overall poor understanding of what to do. Having no one with which to confirm proper steps and medical information, and receiving pamphlets written in English contributes to Hmong elders’ confusion frustration and fear. Most Hmong elders report that they do not speak English well and do not read English or Hmong, and are accustomed to receiving information orally. Providers and interpreters have very limited time and are not available to explain information in the manner that would be most helpful for them. Most Hmong elders described a medical and mental health system that has many unknowns and much confusion for them, with no real pathway to help. These barriers highlight the importance and necessity of having an alternative system or means of providing information for this population.

Having a provider who speaks Hmong, getting information to help find a provider and the right kind of provider for their symptoms (specialist), and connecting to a primary doctor who is stable would make it easier for Hmong elders to access care. Problems experienced by Hmong elders using American doctors include excluding family members from accompanying them when during appointments thus inhibiting family members' ability to help the elder understand and ask questions. A sentiment of many Hmong elders is that they do not know what to ask and wish their children would be allowed to help when they see their doctor. Only an interpreter is allowed in the room, but many are unsure if the interpreter's translation is accurate. Seven Hmong elders agreed that they preferred to have their family member accompany them in the exam room and would like providers to ask if they wish to have someone accompany them in the exam room for support.

Other suggestions that would make accessing care easier include the use of options other than medications; such as imagery and exercise, and offering classes in topics such as pain management, yoga, and massage therapy. While not a commonly voiced sentiment, some participants felt that immigrants were subject to different treatment by their doctors because of their immigrant status and recommended equal treatment.

Blood pressure, heart problems, and serious injury and illness were the main reasons for emergency room use. Only one person reported using the emergency room for mental health, and the majority of Latino and Chicano elders reported that they have never been to the emergency room.

### ***Mental health care experience***

Most participants connected to their mental health care provider through a referral from their doctor. Trusted agencies such as the Jewish Family Services and Centro Cultural Chicano were also instrumental in connecting Russian and Chicano and Latino participants to mental health providers. The number of people who connected to a mental health provider in ways other than through the medical doctor or agency was very low; one person self-referred, and one was

referred by a family member or friend. In contrast, all Hmong elders agreed that they want and need someone to talk to, but no one has gone yet. They indicated they had been thinking about it. When asked what would make them not afraid to go, one elder replied, “I would like to go and talk (with a mental health provider) until I am happy, instead of go, get medication, and come back home.” This question spurred a discussion about the many fears experienced by Hmong elders. They are afraid of what will happen if they go to a provider—will they be hospitalized, will they be given medication? The discussion revealed that most are not medication averse. Their reluctance and fear stem from not being educated about what medications will do to or for them, and not knowing medication precautions and side effects. As mentioned earlier, most Hmong elders reported experiencing forgetfulness and confusion. They have observed that medication makes people they know forgetful and are afraid they will be given the same medication and be more forgetful. An elder who recounted her experience seeing a psychiatrist who gave her medication stated that when she brought the medication home, her daughter-in-law told her not to use it, saying “it will make you lose your mind, be forgetful, and make you dumber.” She did take the medication and her sadness got worse, so she stopped taking it. She reported that she has stopped seeing the doctor.

When feeling mental health symptoms, elders in this group reported:

- Using alternative or coping strategies such as massage therapy; mind, body, and spirit exercises; imagery; deep breathing; yoga; meditation; physical exercise; oxygen therapy; and a light box.
- Calling or seeing a mental health provider
- Talking to community support staff
- Using adult day care

The most frequently used strategies to deal with mental health symptoms were self-initiated. Participants who have been taught coping or symptom management skills use them and reported the strategies do help when experiencing mental health symptoms.

Adult day care was a valued and helpful resource for health, wellness and happiness, as well as a supportive resource for older adults experiencing illness or mental health symptoms.

Participants cited three things that would help them better meet their mental health needs:

- Allow family members to accompany them and ask questions when they see a provider
- Allow more time with all providers
- Have someone to talk to who comes to their home, such as a volunteer or a professional

### ***Care coordination/management***

Russian and Latino/ Chicano participants reported very positive experiences with physical and mental health care. They also reported an increased sense of health and wellness, and hopefulness. Despite their myriad and often severe physical and mental illnesses, they appeared happy, hopeful, and energetic. Their responses to the question of how their input is included in development of their care plan provide insight into provider actions that contribute to a positive experience, perception of wellness and health, and a sense of hopefulness. Providers included their input by:

- “Asking a lot of questions and I notice they use our information because then they ask me if it’s better or worse or how is it working.”
- “One time the doctor told me to do it, and told me, ‘If you don’t feel good, call me in 24 hours.’”
- “The doctor changes medicines for me. It looks like he used what I told him to prescribe new medicine, so I feel important.”
- The provider “calls me about what I’m doing these days.”
- “The psychiatrist always asks me about my family.”
- “She allows me time to talk. When I’m finished, she’s finished.”

Hmong participants who have Hmong primary providers enumerated the ways in which their doctor includes their input:

- “The doctor tells me the most important things in an honest way.”
- “The Hmong doctor tells me everything very well.”
- “He listened when I told him the medication was making me sick.”
- “[The doctor] Tells me what I need to do to take care of myself and stay healthy, and what to expect.”

Hmong elders who didn't have Hmong primary providers did not feel their providers included their input. This was not exclusively due to failure of providers to ask; some elders voiced that fear and uncertainty prevented them from offering their input.

Care is regularly coordinated between doctor, psychiatrist, and social worker at Centro Cultural Chicano. Sometimes the medical or mental health provider initiates contact with the social worker or case manager to have them organize resources, and sometimes the social worker initiates contact with the doctor or psychiatrist.

When asked about care coordination, Hmong elders again reported that family members have been prohibited from participating in appointments. No other care coordination was reported. Care coordination for veterans was accomplished through electronic records accessible to providers throughout the VA system (these records, however, are not available to providers outside of the VA system). No other form of coordination in the Veterans Administration system was acknowledged.

Future appointments are automatically scheduled during appointments in the V.A. system. Social workers or case managers at Jewish Family Services and Centro Cultural Chicano schedule or help schedule appointments.

Most participants' providers do not include their important cultural and spiritual practices in care planning. Those who do, do so by asking if there are cultural issues that the participant wants to address, and providers ask about race and ethnicity.

### ***Health promotion***

Most participants find information about their condition online. Online resources cited included MyChart, My HealthyVet (the Veterans Administration online portal), and Google. Aside from looking up information online, participants ask their provider or the nurse at the adult day care for information about their condition. Most participants preferred to get information about their condition from their provider, with several identifying the internet as the best format to receive information. One Hmong participant explained the difficulties of getting information, saying that family members know where to get information but are too busy to help, so she just listens to what the doctor says. Another explained that because she cannot read or write Hmong or English, "I often need a family member (child) to also ask and confirm things." One Hmong respondent said they would call 911 if they wanted information. Hmong elders' preferred format to receive information is to receive information verbally from a native speaker and to have family members given the information as well.

Participants who feel their providers have done a good job helping them understand and live with the condition they live with identified the following qualities of the relationship:

- The doctor takes the time to talk to them.
- The primary physician is very accessible.
- The doctor calls by the next day with test results.
- The doctor visits them when they are in the hospital.

If one thing about their medical or mental health care could be changed, Hmong participants would have available providers who speak their language, and a stable (primary) provider. Other elders would have medical providers refrain from asking about mental health when it is not pertinent.

**Care transition**

All of the transitional care experiences for the older adult focus groups involved a medical hospitalization. Most participants with transitional care expressed being involved in the transition planning process. Positive transition planning experiences were characterized by the inclusion of the participant and their support person in the planning and discharge process, receiving needed information and supplies before leaving the hospital, having family members read pamphlets and communicate information to the patient, and having follow-up visits scheduled before leaving the hospital. Also helpful was having the social worker coordinate care with the hospital. Transportation inconveniences were the only identified negative aspects.

**Other insights**

Older adult focus groups provided insight into systems, services, supports and support networks that work well and contribute to older adults' positive experiences in the care system. Knowing information about care levels supports, and system modifications that resulted in a more positive experience for older adults can be used as opportunities for the Behavioral Health Home system to better meet the needs of its enrollees.

Discussions that were not captured by focus group questions but were relevant to participant experience, level of satisfaction, and perceived sense of wellness centered on comprehensive community supports used, specifically involvement with adult day care programs and Wellness Recovery Action Plan strategies, and willingness of providers to spend time to talk with individuals and ask questions about their life and family.

**VETERANS**

Veterans who participated in the older adult focus group overall expressed a high level of satisfaction with the care they receive for both mental and physical health. Most expressed satisfaction with their care providers. Veterans' discussion of care satisfaction focused on system and community outreach competencies of the Veterans Administration.

The VA medical and mental health system is a closed system that has incorporated aspects of the proposed Behavioral Health Homes model. Commonalities include shared electronic records and formalized care coordination and management. The VA's electronic records system allows information to be available to all providers within the Veterans Administration system countrywide. The electronic system also has provisions for patients to communicate with their providers via secure e-mail. A particular strength of the VA's system is the ability to provide same day test results. Test result turnaround time is usually a couple of hours; several focus group participants reported having lab tests at 9 a.m. and receiving the results by noon the same day. Same-day turnaround was also reported when medical supplies such as oxygen were needed.

Veteran participants identified three components that contribute to their overall satisfaction with the service they receive:

1. The ability to Skype with providers as a means to keep in touch more frequently
2. Access to a clinical pharmacist every six months to review all medications, look for interactions, and ensure medications are being taken properly
3. The generation of automatic appointments based on diagnosis (e.g., newly diagnosed diabetics would automatically receive dietary and foot care appointments)

The Veterans Administration's mental health wellness plan was known and readily articulated by most participants. The wellness plan is structured so that participants meet monthly with a social worker and quarterly with a mental health provider. In addition to regular meetings with a social worker and provider, vets who live alone receive a survey that asks mental health questions to ascertain how well they are doing. Mental health staff follows up with veterans and provides services based on their survey responses.

Socialization opportunities are provided through the St Cloud Veterans Administration's Adult Day Care Program. The adult day care has daily activities to provide "a reason to get up and get dressed every day, and have something to do." In addition to providing activities, the program

has a monthly weight and medication check to quickly catch problems related to diet and to ensure participants have and are taking their medications as prescribed. The adult day care program assigns vets a person to contact if medication problems arise. Other strengths of the St Cloud Veterans Administration include an effective system of comprehensive in-home and practical services. In the words of a veteran who utilizes the adult day care program “the Veterans Administration is a lifesaver thanks to the adult day care.”

Participants recognized the VA for the way in which they integrate mental health in practice. One participant, describing how her mental health information was integrated in the medical care she received described needing to have her CPAP mask checked by the respiratory therapist. On seeing posttraumatic stress disorder in the participant’s records, the respiratory therapist commented, “I see you have PTSD. Is anything we do in respiratory therapy going to be bothersome for you in terms of masks or even touching you? Is it going to be a problem for you?”

### ***Provider strengths***

Overall, five provider and system strengths were reported by older adult participants:

1. Feeling connected: feeling listened to, cared for, and feeling that they have been heard
2. Cultural competence: providers with a shared cultural background and language or, in the absence of shared cultural background or language, exhibited competence working with people in the culture
3. Provider willingness to help participants get their needs met
4. Time and location flexibility: a willingness to meet the participant outside of the traditional care setting
5. A partnership between patient and provider in the healing or recovery process

### ***System strengths***

1. Appointment flexibility
2. Effective care coordination and relationships with case managers and social workers
3. Same-day test results

4. Availability of ethnically similar providers
5. Availability of culturally competent ethnically dissimilar providers
6. Well-developed community and social supports

## **FAMILY MEMBERS: PARENTS OF CHILDREN AND PARENTS OF ADULT CHILDREN**

Focus groups with family members were held in the following areas:

- Bemidji (Northwest)
- Duluth (Northeast)
- Hutchinson (Western)
- Rochester (Southeast)
- Worthington (Southwest)
- Metropolitan area transgender
- Metropolitan area (two pilots)

### ***Health promotion***

Parents' perceptions of health and wellness for their family member identified self-actualization as a marker of health and wellness where their family member had the ability to function, to be independent, to be engaged in the world and live within societal norms, to be happy, and to be physically and mentally healthy with an active lifestyle. An important concept of health and wellness among parents of transgender children and youth was an ability to present as they are and to feel good about how their body looks and feels.

### ***Medical health care experience***

Participants connected to a physical health provider most often by maintaining an already established connection to a family doctor or by a default connection (a connection not of their choosing). Default connections typically occurred due to random assignment by a health plan, connection by seeing whoever was available or seeing the closest or only available doctor in the area. Agency referrals and connection to a medical provider as a result of a hospitalization were the next most prevalent method of connection.

Most see their medical provider for general wellness care or sickness. In descending order of prevalence, chronic illness and mental health were the other reasons participants saw their providers.

More than a quarter of participants reported that when sick, their family member used vitamins, supplements, or calming strategies such as meditation or yoga. Another quarter called or visited their doctor. Calling “mom” to help figure out what should be done was also among the most prevalent responses. One parent differentiated between what her child does when she is sick and is not doing well mentally from when she is sick and is doing well mentally. When she is not doing well mentally, the participant said of her daughter, she “loses her skills so she has to call me. She doesn’t take care of herself when she is mentally unwell.”

Family members’ most important health care problems were almost exclusively mental health problems. Substance use and chronic illnesses were also mentioned, as well as lack of access to a physician and care team.

Barriers experienced while attempting to access care for their most important health care problem were overwhelmingly related to challenges in accessing a provider. Access issues included lack of appropriate providers, long delays for appointments to see mental health providers, issues with the treatment either not being available in the respondent’s area or not being available in the respondent’s network, and, for a number of participants, frequently changing doctors and places where their family member is hospitalized. One parent described her child’s challenges with access: “You can’t get service because you don’t have a diagnosis; you can’t get a diagnosis because you haven’t been hospitalized two times; and you can’t get hospitalized because there is no place to hospitalize (my family member.) We have to travel to Duluth or North Dakota for mental health services.”

Parents of transgender children report having great difficulty finding a provider who is knowledgeable and willing to provide their children with school or preoperative physicals and other general care needs.

The next most prevalent barrier was getting providers to respond to, take seriously, or believe reported symptoms and needed treatment. One parent described her experience with a provider who attributed her daughter's behaviors to "just being a teenager" rather than recognizing the behaviors as a symptom of her daughter's mental illness. Parents consistently reported that when they were caring for their children over the age of 18, they were not listened to or their input was not sought or consistently considered when provided. Health Insurance Portability and Accountability Act (HIPAA) restrictions were cited as the main reason for the lack of communication or failure to communicate with family members or hear their input about their child in crisis who lacked insight. Several reported that even with a signed release of information, their child's provider would not communicate information about their child, their treatment, when they would be released or where they would be released to.

Other noteworthy barriers cited were the county's use of juvenile detention to house individuals needing mental health treatment in the absence of short-term mental health treatment facilities, and the lack of treatment or options to deal with an emerging crisis. Quite a few parents discussed the stress to their child and their family of having to wait for their family member to reach full crisis before being able to access care, and expressed anger at having to lie so that their child would be taken seriously even at that point. They further described having their child released from the hospital when they were not well or stable enough to be released, and, as their child's support system, not receiving instruction on what to do or look out for after their release.

Additional training for physical and mental health providers so that they are not afraid to treat people experiencing both medical and mental health problems would greatly benefit people in some areas outside of the metropolitan area where there are few providers, and where patients are required to travel distances to find providers willing or able to help them. One participant

describer her daughter's challenges receiving care, "My daughter had a spot on her brain. Behavioral health wouldn't touch her because of the brain issue, and physical health wouldn't touch her because of her mental health issue."

Participants identified a need for more providers, providers who care, improved care coordination, general provider education, and education in gender and gender identity to better meet their family member's physical health needs.

Most said family members use the emergency room for mental health problems or when a provider cannot be accessed. Others said the emergency room was used for detoxification, accidents, and medication overdose.

### ***Mental health care***

Connection to a mental health provider most commonly occurred as a result of a hospitalization, according to participants. Suicidality and suicide attempts were the most reported reasons for hospitalization that initiated a connection to a mental health provider. Primary care providers and family or friends were the second most frequently mentioned referral sources. Parents of transgender children and youth predominantly use referral from other families with transgender children to find transgender-friendly doctors, therapists and clinics. This group had fewer default and agency referrals, likely due to parental involvement. One person reported school-based services made the connection to a mental health provider.

Participants reported that their children experiencing mental health symptoms were more likely to use learned coping techniques and calming strategies such as lavender calming sprays, walking, and beading to handle symptom exacerbations. Alternative therapies such as yoga, meditation, acupuncture and chiropractic care, and vitamin and supplement use were used almost equally with coping and calming strategies.

For symptom escalation parents reported using de-escalation techniques learned in family counseling. Police assistance was used for family members lacking insight into their illness or when efforts to convince the family member to seek mental health assistance failed. Suicide attempts or ideation were the main reason for emergency room use. One parent reported success using a weighted blanket for escalating symptoms; another used a de-escalation room in the house reserved for when the family member's symptoms became violent. Several parents reported their child used maladaptive calming/coping strategies such as smoking and self-harm when experiencing symptoms or symptom escalation.

Participants discussed changes needed to better meet mental health crisis needs, pointing out the need for longer appointment times, the availability of more appointments, more providers (to reduce the delays in accessing an appointment), and better follow-up and connection to services after hospitalization. In addition to problems with limited appointment times and long wait lists to see a provider, parents identified a number of problems associated with getting appropriate care for their family member relative to hospitalization. Participants expressed frustration with how difficult it is to get their family member hospitalized when symptoms were unmanageable by the individual and the parents. If the hospitalized child was over the age of 18, the hospital often did not coordinate care with parents, even when a release was signed. Parents voiced concern that their family members were increasingly being released from the hospital before they were well enough to care for themselves or before they were fully stabilized. If the family member was released before they were stable, and if the family member was included in the transition planning before being stable enough to absorb the plan, problems resulted and soon led to an additional hospitalization.

HIPAA restrictions and short appointment times topped the list of barriers to receiving mental health care. One parent reported, "Communication (with mental health providers) is very poor once your child is over 18. Confidentiality works against cooperation."

Providers included input from individuals and parents in a number of ways, according to participants. One parent described her experience with a provider who used a very positive and effective approach: The “doctor approached us as a family unit. We were never kept out of the loop. Once a month, the mental health provider would see us (parents) and our son’s siblings to see how the family relates to my son.”

Asking how they feel about something, inviting input from parents about their child’s care plan, working with the family member to achieve medication adherence, merging the provider’s expectations with those of the child and the parents, and educating parents and their child about alternatives were other ways parents felt providers included their input. Most parents, however, report their input was not solicited or accepted, or that there was no care plan in which to be involved. HIPAA privacy was cited as the basis under which parents were excluded from participating in care planning for their child.

Another parent cited a helpful approach by a provider working with a transgender child, saying the provider “provided a framework around what’s happening, provided a roadmap of what is happening and what to expect.”

### ***Care coordination/management***

Several parents were aware that their child’s providers met every six or 12 months to discuss their child’s case, and several parents were aware that their child’s psychiatrist talked with their child’s pediatrician, however, more often parents reported that providers did not talk with each other. Some parents initiated communication between providers by asking for notes from each visit and taking the notes to the child’s other providers. Other communication occurred with social workers who sometimes talked about care goals, and by the availability of electronic records for providers located within a care system (although parents did not know if communication had actually or if records were just available if providers chose to look at them.)

Overall providers did well in asking if help was needed to make future appointments. Providers often ensured follow-up appointments were scheduled at the end of an appointment. Individuals with known care plans received assistance making appointments and following through on care plans from other community support agencies or workers such as Adult Rehabilitative Mental Health Services (ARMHS) workers and social workers.

For most participants, cultural or spiritual practices were not included in their child's care planning. Two participants did identify one culturally specific agency that did ask and include their child's cultural and spiritual practices in care planning.

### ***Health promotion***

Parents wanting information about their child's condition or other health-related information most often used the Internet. In descending order of frequency, parents talked to other parents, sought information from books, and talked to providers to get needed information. Most preferred to receive information from their child's provider and would prefer to have time scheduled with the provider to allow time to think about what they want to say and ask. Information from the Internet was also cited as a prominent preference with the proviso that they are directed to a reputable web site to get needed information.

Participants reported a number of ways that providers helped individuals understand and live with their condition. Some gave direct information about a particular problem, such as suggestions to help with a sleep problem, whereas others talked about and reinforced things such as healthy eating. One respondent's child's provider gave her information about relapse prevention and psychoeducation, and another facilitated connection to services at the hospital. A parent whose child was referred for Wellness Recovery Action Planning expressed how helpful the training has been for her child.

Participants identified the following changes needed in the current medical and mental health system:

- Loosen the HIPAA restrictions to allow for more involvement of parents and collaboration with providers in the care of their children over 18.
- Provide urgent care for mental health symptoms before symptoms become a crisis.
- Educate parents about a child's illness when the illness first appears.
- Offer longer appointment times.
- Provide greater access to appointments to eliminate delays getting in to see a provider
- In outstate areas, have a provider available at night and on the weekends.

***Care transition: Parent involvement***

Participants reported having the following experiences during their child's care transition:

- The doctor told parents what is normally done.
- They were allowed to visit their child.
- They were allowed to bring a pastor to visit their child.
- They were more involved than they wanted to be. In looking for outpatient resources, they were given ideas but had to make the appointments and figure out what works.
- They were not involved but wanted to be.

Parents cited several difficulties in care transition:

- Hospitalizations are too short
- Inadequate or nonexistent services after discharge or transition, at a time when the individual was not yet able to care for themselves
- No coordination of care or collaboration by multiple providers
- Inpatient locations that are long distances from parents and home
- Isolation
- Privacy issues when the child becomes an adult
- No discharge planning
- Having to push and advocate to get information and services

- Not knowing what is going on and having to figure it out by themselves; no assistance in navigating the system
- Restricted visiting hours; difficulty getting to the hospital during visiting hours to visit their child
- Transition planning that assumes the person is well enough to participate
- Being expected to make sure the child is getting information and understands the situation
- No education to help a family member understand what the diagnosis means or what to do

Parents cited several care transition aspects that they found helpful, including:

- Having a care manager/case manager
- Early intervention programs
- Providers identifying triggers and recommending approaches for working with the child to the child's school
- Providers checking the child for other illnesses
- Providers writing reports that helped their child gain access to services.
- Educational pamphlets

Suggestions to improve experiences in care transition:

- Have one central hub where everybody puts all their information
- Allow parents to be more involved
- Have all doctors, therapists, and pharmacies communicate and work together
- Have providers talk to parents about medications and side effects
- Consistently provide post-discharge information
- Ensure parents and/or individual receives a follow-up phone call after hospitalization
- Increase personal care

- Educate people when they are able to absorb information

### ***Transgender-specific recommendations***

Parents of transgender youth recommendations specific to the care of transgender individuals:

- Train all hospital and clinic staff in transgender care and require a specific level of competency.
- Ensure care managers are knowledgeable about transgender-friendly treatment, specialists, and resources.
- Ensure that the mental health community has the information needed to serve the transgender community.
- Change the rules in in-patient psychiatric wards regarding shaving and the use of makeup for transgender youth. The ability to shave and wear makeup is a mental health issue.
- Provide support groups so transgender youth have a sense of community.
- Hire transgender staff.
- Train pediatricians in transgender health so that they have the information needed to serve transgender children and youth.
- Develop protocols for transgender youth pertaining to puberty and hormone blocker therapy.
- Expand the binary gender pronouns offered on forms and in computer systems to allow for self-identification of preferred gender and preferred name if different than the birth name.
- Provide transgender health education to front-line crisis workers, including emergency room staff, crisis teams, psychiatric hospitalization staff, and residential providers.

## **TRANSITION-AGED YOUTH**

Transition-aged youth's perception of health and wellness encompassed health beliefs and behaviors that health care providers would commend. Among their most reported health and wellness beliefs are eating nutritious food, exercising, staying hydrated, getting enough sleep,

and in general having a healthy lifestyle by taking care of their body and staying free of stress. A small number of responses also described health and wellness as managing physical and mental health symptoms or associated disability. The remaining responses referred to resilience and self-actualization concepts in roughly equal proportions.

### ***Medical health care experience***

Most youth connected to a health care provider by default (lack of choice). They sought care at the nearest clinic, saw whoever was available, or saw whoever their health insurance directed them to. About one third of youth connected to a provider through a recommendation from their mother or other female relative. A few transition-aged youth identified a service provider as their connection to a health care provider.

Most youth did not report seeing a provider for physical health care. Of those who did see a physical health provider, most saw them for physicals and check-ups. One youth reported seeing a medical doctor for a chronic condition and mental health medication.

Youth who are willing to use providers for physical health concerns stress that provider credibility is maintained by providing not only medication, but also by giving consistent explanations about a medication and its purpose. These participants indicated that they welcome advice from a provider on how to stay healthy. Among those willing to use providers for physical health, some indicated a willingness to discuss mental health with physical health providers, but many said they believe it is not realistic to get mental health information from a physical health provider.

Physical health was identified as the most important health care problem for metropolitan area, and outstate youth. The responses categorized as physical health conditions are highly individualized, with the most prevalent physical health issues identified as pain or pain management and obesity. Other examples ranged from a medical problem with a specific body

part to pregnancy to accidents and/or injury. A minority of responses referenced a mental health condition.

As was the case with adult focus group participants, physical health conditions named by transition-aged youth when asked about their most important health care concern paled in comparison to health conditions disclosed in later discussion.

Barriers for youth are as prevalent as barriers for their adult counterparts; however, their age, inexperience, and a pervasive perception among many that mental health symptomology in youth is little more than a phase compound youth's ability to access or receive help to access needed health care. Illustrating the challenges of being a young person with symptoms needing care, one person described how her mental health problems were not taken seriously: "I have had symptoms since sixth grade, but no one referred me for professional help or meds for many years. The school knew but didn't refer me for help."

Long delays in accessing appointments, lack of providers, especially in the outstate areas, and impatience with wait times experienced at appointments discourage youth from accessing care. This was especially the case among marginalized transition-age youth (those experiencing homelessness and/or those with justice involvement).

Easier and faster communication with providers, including school counselors, would make getting care easier, as would having access to a web site that would help connect youth to specialists. Several youth commented about having to do the research on their own and this being difficult, especially when dealing with their own mental illnesses.

Youth reported needing more programs that are affordable to better meet their physical health needs. One young woman recovering from an eating disorder would like more options and access to proper nutrition and exercise to aid in her recovery. Access to "faster help" or an easier way to get help would also facilitate getting needed care. Unfamiliarity with the health care

system and lack of knowledge about how to best navigate the system play a role in the experiences of youth who have difficulties in the care system. One young woman states, “I never had to manage health care needs before. There’s a lot of stuff that kids who grow up in a difficult lifestyle, we don’t know how to do these things. We just live day to day basically.” She recommended that clinics and hospitals have staff to “teach individuals how to manage their health care and how to navigate the health care system.”

The majority of transition-aged youth reported emergency room use for physical conditions such as injury, accidents, and illness. Other uses included when they were unwilling to wait for an appointment or perceived that going to the emergency room would result in receiving help faster than going to a clinic. A small number of youth reported going to the emergency room as a result of a suicide attempt or other mental health issue.

### ***Mental health experience***

Participants reported connecting to mental health service providers primarily through agency referrals either through a court mandate, law enforcement officers, or parole officers. The high numbers of agency referrals are likely a result of the sources from which transition-age youth were recruited. Metropolitan area recruitments sites drew youth who were homeless or involved with the juvenile justice system, a majority of whom were mandated by the court to a juvenile supervision program.

Despite having a connection to a mental health provider, metropolitan area youth did not report using mental health providers or services in response to the question asking what they see a provider for. Responses from outstate participants indicated that mental health services are accessed primarily for medication management, either alone or in combination with other mental health services. This disparity in access behaviors may be rooted in the fact that metropolitan youth were predominantly youth of color, who, according to research, are less likely to receive needed mental health care. When involved in the criminal justice system due to mental health related behaviors youth of color are less likely to be referred to the mental health system and

more likely to be referred to the justice system. By contrast, outstate youth were recruited from youth treatment and support agencies and were already connected to care.

Noticeable differences in symptom management strategies were seen between metropolitan area and outstate youth. These included increased use of drugs and/or self-injurious behavior for symptom management in the metropolitan area groups. The drugs of choice were marijuana and alcohol, which during focus groups were reported with either bravado or distorted views about their benefits. Outstate youth reported more instances of using professional or therapeutic services.

The top symptom management responses of participants in descending order were:

- Coping strategies: self-calming, yoga, deep breathing
- Activities: reading, dancing, playing games
- Alternative healers, exercise, drugs, and professional or therapeutic services

Increased knowledge, insight into what is needed, and help understanding their diagnosis is needed by youth to better meet their health care needs. As one young participant explains, “(providers) need to do more than tell you what needs to happen. They need to tell you how to do it.” Discussion of mental health needs among all transition-aged youth highlighted youth’s lack of knowledge of medical and mental health systems, inability to identify from who and where to get helpful information, and many levels of misinformation resulting from witnessing the misuse of medical systems by parents and other guardians. Youth described witnessing their parent’s drug-seeking behavior in the emergency room and being forced to participate in a parent’s drug-seeking behaviors.

Barriers to care for youth include too few providers, long waits at appointments, expense of care and medications, distance to a provider, and not being taken seriously.

### ***Care coordination/management***

Most providers include youth's input in care planning, according to participants. Most youth felt positive about how input was solicited. Providers checked and asked about preferences, worked with youth directly while developing the treatment plan, and asked if the care received was what was needed. Conversely, one respondent discussed situations in which she was not listened to and discussed her resolve to make the provider listen to her input.

Participants were equally split between those who said providers collaborated with other providers and supporters and those who said they did not. Several of the youth's providers were part of a system in which records could be accessed electronically or exchanged, but youth were unsure if the providers actually talked with each other or read the records. One young woman recounted the challenges she faced coordinating her care: "I have to call and coordinate all my providers. I have to go to the doctor and get him to print out all the records and take them to the new provider. This is frustrating. I have school, and this is a big undertaking."

In general, youth felt providers did well helping them schedule appointments and follow care plans. Several youth found getting a printed summary of the visit to be helpful in following their care plan. Not all youth were involved in their care planning. One participant discussed her providers' failure to work with her in the way she needed in order to follow through on her care plan. She states: "They give you a destination, but they don't tell you how to get there."

Most youth did not discuss or expect incorporation of their important spiritual practices in care planning. Most youth did not talk with their provider about their spirituality or feel they needed to. One participant did note that his provider asked him about his values.

### ***Health promotion***

Most youth desiring information about their health condition were equally likely to ask their provider or search for information online. Several would ask a family member, friend, or other trusted support person. Youth participants' top preference for receiving health and wellness

information was to receive information from their provider with the proviso that they take the time to explain the information. Other preferences include receiving information in a class or by demonstration.

Responses to how providers help them understand and live with their conditions centered around the provider showing interest in the youth, forging a relationship, and providing information in a manner that is honest and does not give false hope. Getting to know the individual, showing interest in how they are doing, having a willingness to look for what is causing the problem rather than just treating the problem, and providing detail about what is needed or what would be best in an honest way were specific approaches appreciated by this group. Providing information and resources, and taking time to explain a condition, treatment, or medication were other ways providers help them understand and live with conditions.

A small number of youth participants said their provider does not help them understand and live with their condition. They reported that their provider does not provide information and pointed out that the provider does not provide information about wellness unless they specifically ask, and in general information is not provided unless the doctor is concerned about something.

Care and service coordination were the major changes youth participants would make to the current system of care. To improve care coordination, they recommended that all doctors be in the same location and have a system of communication. In a discussion about the benefits of improved care coordination, one young man expressed: “I wish that I could have just one person who would know everything about my health care case and be able to answer my questions. That would help me to take care of myself.” Other suggestions for change include having providers who care and let the patient know that they are “there” for them.

Overall, youth participants had negative perceptions of their care transition experience. Whether or not individuals participated in a transition plan, most recounted having to pursue providers to get information about options other than the one presented. Almost all shouldered

the burden of finding resources and figuring out the next steps. “I gave input on where I could stay once I was out of the hospital,” said one participant. “It wasn’t clear. They only talked about only one option.” Another reported: “I had to talk them into telling me other options.” And yet another said, “They didn’t plan transition, I did. I had to take steps to find things.”

Aspects of transition that were most difficult were being required to do the planning themselves. One person had difficulty because he didn’t understand why he was transitioning.

Most helpful in the transition experience was receiving a list of providers to go to after hospitalization, being encouraged to sign a release of information form to give to providers, and the availability of stepped care.

Receiving more options, input, help from providers, communication from providers, and choice would have improved the transition experience.

### **Other insights**

Focus groups with transition-aged youth provided useful insight into their preferences and expectations in their interactions with providers and care systems, and provided insight into factors that influence youth’s perspectives on the care they receive, their patterns of use, and factors that affect how and when care is accessed or avoided.

Transition-aged youth reported being more likely to handle illness by employing self-strategies such as yoga, meditation, using vitamins and supplements, using alternative providers and practices, and toughing it out. When youth experience physical or mental health symptoms, they are more likely to use home remedies and alternative or practical strategies before using medical interventions such as going to the emergency room or urgent care. They reported seeking medical interventions only after attempts to handle the illness themselves failed or when they were extremely ill.

A number of provider and systemic challenges influence youth's interaction with and use of care systems. Short or limited appointment times, feeling like providers do not listen, and medical and mental health providers who offer medication as the sole treatment option are the systemic and provider challenges that most profoundly affect them.

Among youth who use providers for physical health, some expressed a desire and/or willingness to discuss mental health. Since youth's use of primary care is primarily limited to visits for well care, fewer opportunities exist for primary care providers to initiate or participate in youth's mental health care. Youth participants who did engage a mental health provider reported that the experience generally failed to meet their expectations and need and, in some cases, discouraged future engagement with mental health services.

By far the most discussed and concerning issue for youth accessing mental health services was the limited amount of time providers spent with them in assessment before making a diagnosis. Statements such as "How can a provider assess me when they have only talked to me for 15 minutes?" were a common thread throughout most youth focus group sessions.

Provider credibility is important to most youth. Credibility is not automatic in this group. Youth look for provider actions that prove credibility, which include taking time to talk, sharing information about themselves, actively listening, asking questions about the whole person instead of focusing on the illness, giving consistent explanations about illness, relying less on the hierarchical doctor /patient relationship, and giving consistent explanations of a medication or a medication's purpose. For many participants, offering treatment of a problem through means other than medication, such as yoga, teas or home remedies, increased provider credibility. Credibility helped youth feel more comfortable when seeing a provider and somewhat more confident about provider recommendations or recommendations. A provider who arrived at prescribing medications after trying other strategies and options rather than starting with prescribing medications fostered trust, increased confidence in prescribed treatment plans and increased medication adherence, according to participants. Conversely, failing to approach the

management and treatment of illness in ways important to youth often resulted in spotty adherence, impeded trust, and, for some, resulted in discontinuance of services.

Providers working with youth accessing the new Behavioral Health Home model will do well to understand the opinions, perceptions and preferences expressed by youth in focus group sessions. In summary;

Youth expressed interest and desire to actively pursue wellness. Youth expressed a strong preference to work with providers to achieve wellness as opposed to managing illness when they are not well. Many lack the knowledge to know what to do for wellness and providers lack the time to help them. Youth prefer to be educated by providers, asked for their input, have their input respected and included if possible, and youth prefer to be prescribed practical strategies to employ when working toward wellness or experiencing mental and physical health problems. One young woman, describing the way in which she preferred her provider interact with her, said she would find her provider much more credible if he gave practical strategies to follow such as writing her a prescription for 10 hours of sleep as opposed to writing a prescription for a pill. Many youth expressed that they welcome advice from their provider about how to stay healthy.

**Behavioral Health Homes**  
**September 1, 2014 – February 28, 2015**

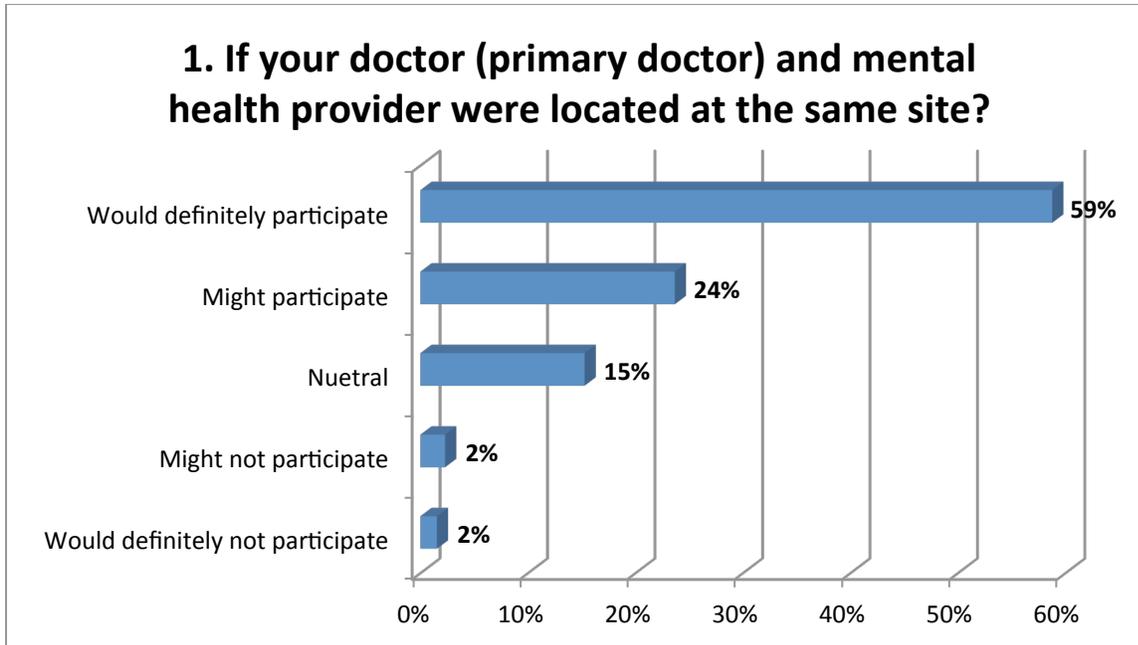
Participants were given a six question questionnaire to complete after each focus group section. The intent of the questionnaire was to have participants rate their likelihood of participating in a model that offered the proposed components of a Behavioral Health home.

Very likely to participate and likely to participate responses were consistent through all questions, with would definitely participate responses averaging 60% and might participate averaging 19%. 1% of respondents would definitely not participate, and might not participate responses averaged 2.8%. On average, 16% were neutral.

Participants who chose option #1 or #2, would definitely not participate or might not participate, were asked to state their reason why. While a number of respondents did write-in a response, most responses did not relate to their decision relative to participation. Most responses were comments based on the respondents need or personal opinion or experience. One comment voiced in various focus groups was the concern that Behavioral Health Homes would be a closed system so that if someone did not “click” with a BHH provider they would be left without options for care.

## Behavioral Health Homes

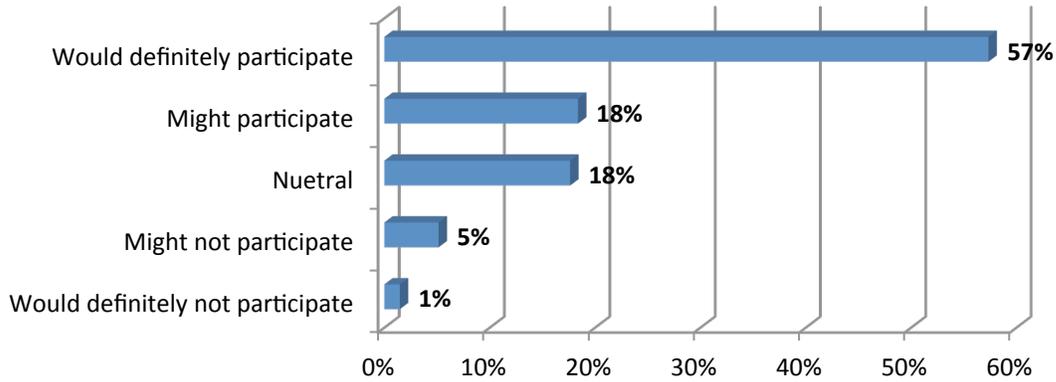
September 1, 2014 – February 28, 2015



If #1 or #2 was chosen, please state why:

- Already do!
- Cause it would make life easier
- Cause they can work together to benefit me!!
- Here
- I don't want to
- I feel as if mental health provider should not be in an enclosed building.
- Mine are
- They already are
- Yes
- Yes all

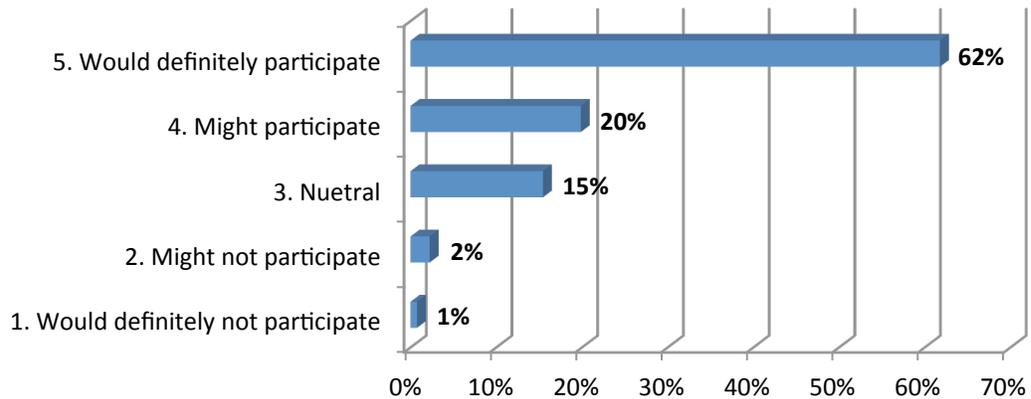
## 2. Your primary doctor and mental health providers talk to each other to plan your care (even if they are not in the same location.)



If #1 or #2 was chosen, please state why:

- Cause what if I don't want one of them to know
- Here
- Hope they start communicating.
- I don't want
- I would like them to come up with a way to find help for future reference.
- Mine do
- My primary care physician is not trained in psychology.
- Rather not have my mental health provider talking about my state of mind.
- Same as above
- The prognosis had better agree with me and the conclusion needs to meet with my approval.
- This bridges the gap between services and needs.

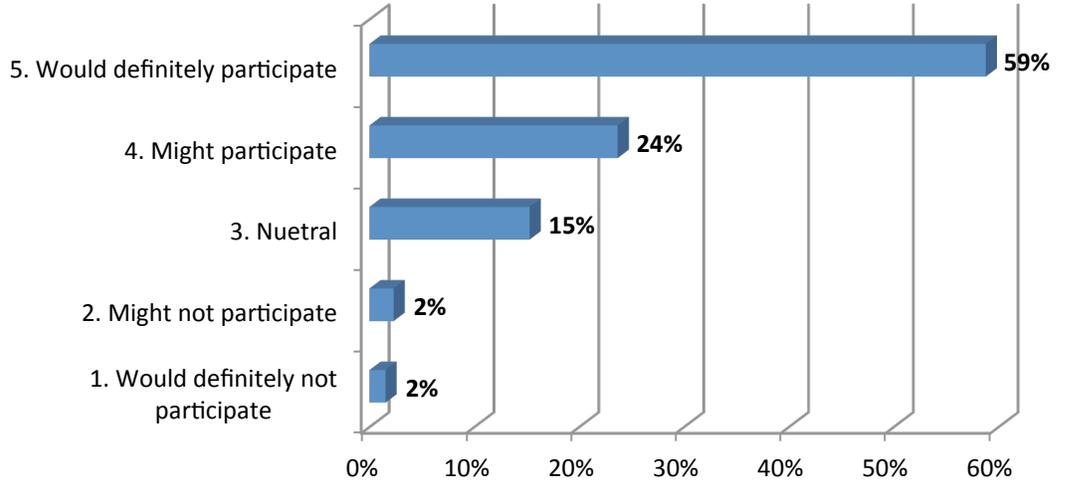
### 3. Your medical provider and mental health providers develop one care plan that includes information from both providers.



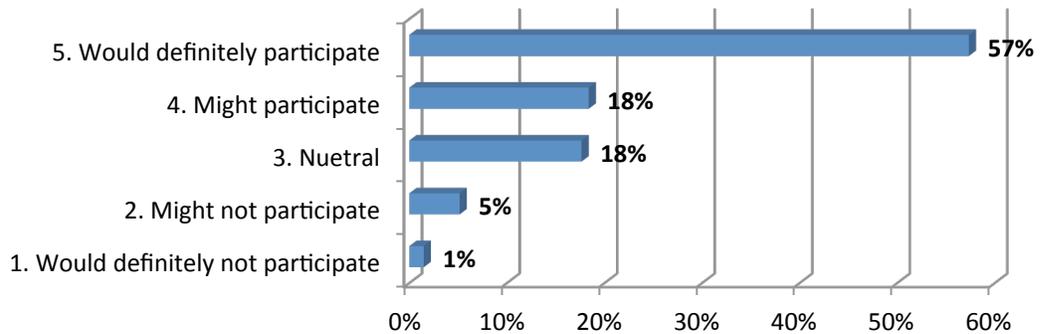
If #1 or #2 was chosen, please state why:

- Hope they start
- It most likely would help out a lot

### 1. If your doctor (primary doctor) and mental health provider were located at the same site?



### 2. Your primary doctor and mental health providers talk to each other to plan your care (even if they are not in the same location.)



By agreement by patient in writing or a waiver.

Hope it starts

I think they do

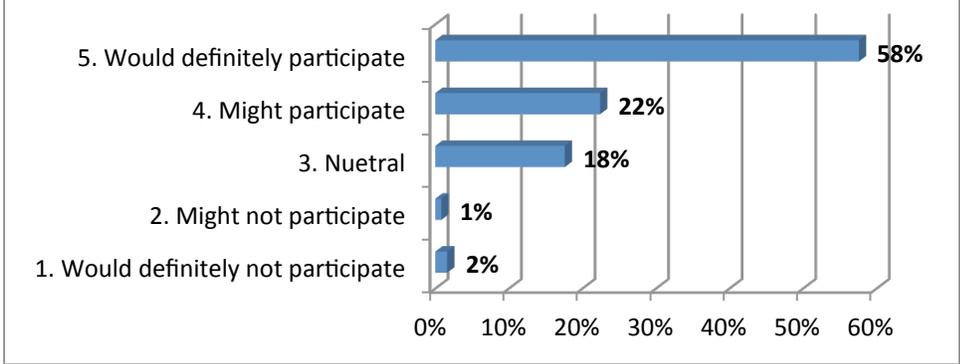
I would like for them to learn about my past medical/mental history.

Sometimes medical care is effected negatively because of mental health diagnosis.

Well because I need different opinion on my mental health.

Yes

#### 4. Your medical and mental health providers share your medical records to coordinate your care.



By agreement by patient in writing or a waiver.

Hope it starts

I think they do

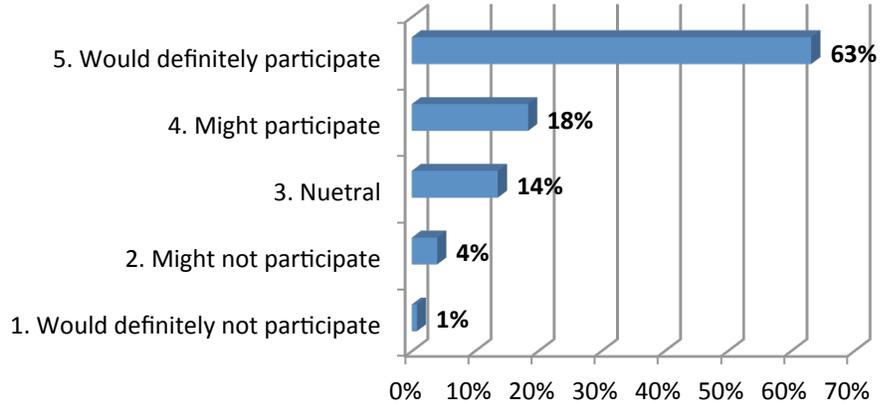
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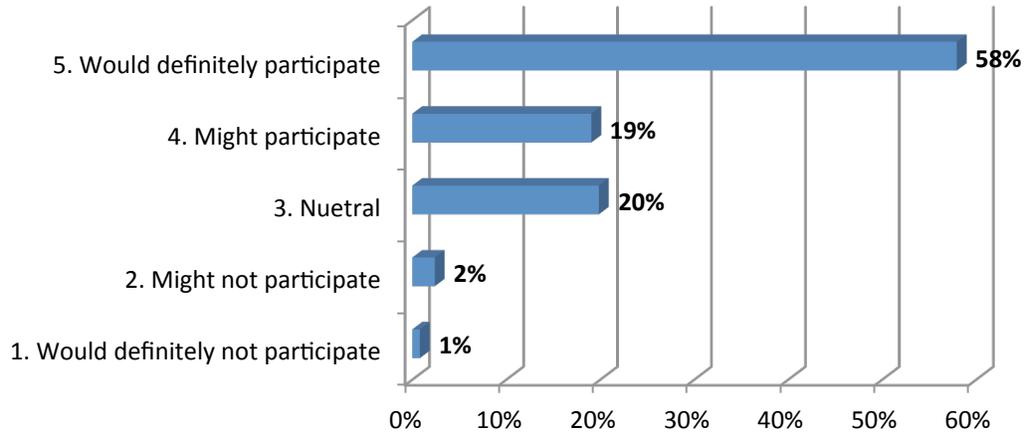
Well because I need different opinion on my mental health.

Yes

**5. Doctors and providers teach you about your conditions with a focus on what you need to do to stay healthy.**



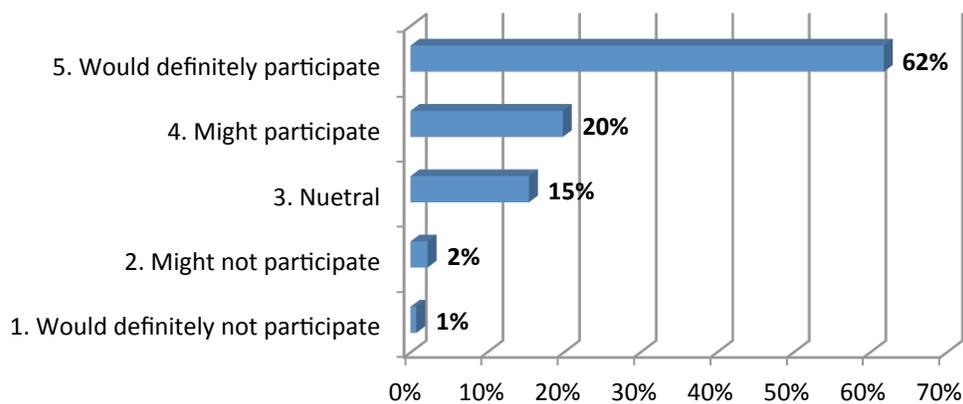
**6. One person who helps arrange appointments when needed and who could accompany you to appointments to help ask questions or help understand the providers care plan.**







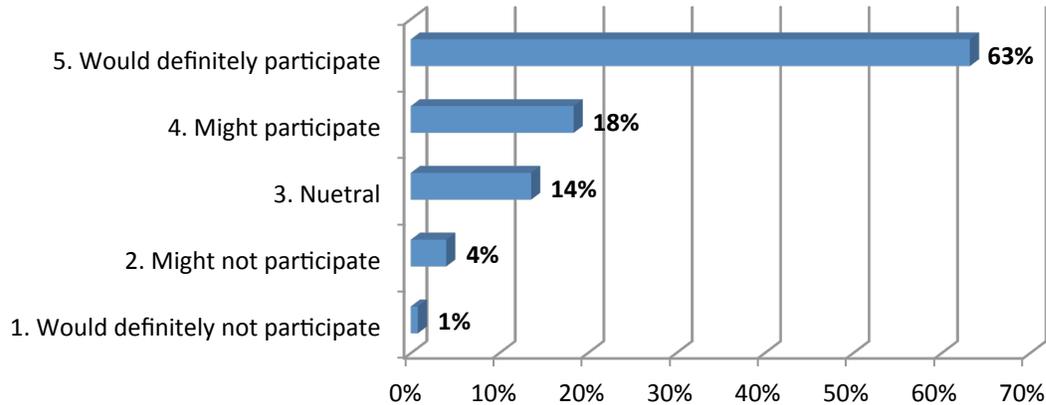
#### 4. Your medical provider and mental health providers develop one care plan that includes information from both providers.



If #1 or #2 was chosen, please state why:

- By agreement by patient in writing or a waiver.
- Hope it starts
- I think they do
- I would like for them to learn about my past medical/mental history.
- Sometimes medical care is affected negatively because of mental health diagnosis.
- Well because I need different opinion on my mental health.
- Yes

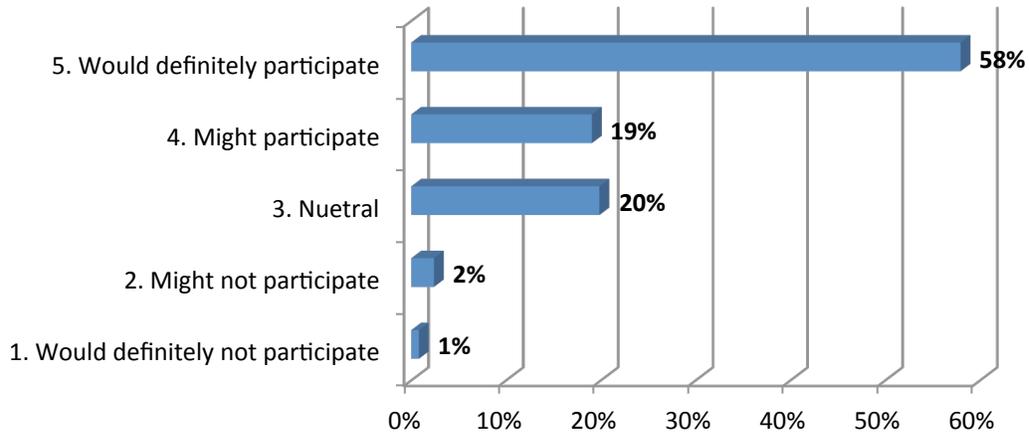
## 5. Doctors and providers teach you about your conditions with a focus on what you need to do to stay healthy.



If #1 or #2 was chosen, please state why:

- Already occurring.
- Because a healthy body accelerates a strong mind
- Depends on the approach and how comfortable they felt talking about the diagnosis.
- Dr. HAS NEVER TALKED TO ME
- Good but doing it too much
- I know my needs but find it hard to carry through. Thinking about getting an ARMS worker again to help with goals.
- I must learn myself. It's not their duty, but mine if it's my condition.
- I would agree if it was agreeable.
- No need for it. I'll just ask what it is I need to know.
- Point person or ombudsperson
- They already do
- Yes

**6. One person who helps arrange appointments when needed and who could accompany you to appointments to help ask questions or help understand the providers care plan.**



If #1 or #2 was chosen, please state why:

- Because I would like to figure out lifesaving plans for the better.
- Being done now.
- Don't need this.
- I'm fairly private outside my providers.
- It would help to keep me more stable.
- Sometimes
- Yes

## BEHAVIORAL HEALTH HOME FOCUS GROUP QUESTIONS

Thank you for agreeing to participate in this focus group. Answers about your experiences receiving medical and mental health care, and your opinions about how your experiences and health could be improved will be used in summary to develop a model for Health Homes. The Health Home model integrates physical and mental health care, and community and social services to improve patients' experience and care so that people with chronic illnesses and mental health problems can have better care, better access to care and achieve better health.

### Clarification:

**Health care** includes the medical services provided by your primary doctor or doctors; an adult medicine doctor, specialists (doctors that help with things like heart problems or kidney problems), Physician Assistant (P.A.) or Nurse Practitioner. Urgent care and emergency room care are also included.

**Medical provider** refers to your doctor, adult medicine or internal medicine doctor, specialists, Physician Assistant or Nurse Practitioner.

**Mental Health care** includes professional counseling, therapy, mental health treatments, substance use treatment.

**Mental Health provider** includes, Psychologists, Psychiatrists, Therapists, Psychiatric Nurse Practitioners, family doctor that handles your mental health needs, Social Worker, Physician's Assistant that handles mental health needs.

### Health Promotion:

1. What is wellness or health to you? (Prompt: what would it look or feel like for you?)

### Healthcare Experience Medical:

2. How did you find the health care provider (primary care Dr.) that you use now?
  - a. What do you usually see this provider for?
3. When you are sick and need medical care, what do you do? (Prompt: call the nurse line, urgent care, doctor's visit, ER visit, home remedies, other.)

- a) What other providers or practices do you use when you are sick? (Prompt supplements, vitamins, Epsom salts baths, homeopathy, traditional healer, etc.)
- 4. What do you consider to be your most important health care problem?
  - a) What barriers have you experienced trying to get care for this problem?
- 5. What do you think could be done to make it easier for you to get care for this health care problem?
- 6. What do you feel is needed to better meet your physical health needs?
- 7. What are the most common reasons that you have used the emergency room?

**Healthcare Experience Mental Health:**

- 8. How did you get connected to the mental health care provider that you use now? (Prompt: therapist, psychologist, psychiatrist, psychiatric nurse practitioner)
  - b) What do you usually see this provider for? (Prompt: medication, therapy, other)
- 9. When you are feeling anxious, depressed or are experiencing other mental health symptoms, what do you do? (Prompt: call crisis line, mental health provider, medical provider, home remedies, traditional healers.)
  - a) What other providers or practices do you use when you experience these symptoms? (Prompt: supplements, homeopathy, medicine man, healer, other.)
- 10. What do you feel is needed to better meet your mental health needs?
  - a) What barriers have you experienced trying to receive this care?

**Care Coordination/Care Management:**

- 11. How have your providers included your input when developing a care plan for your physical and mental health needs?
- 12. How frequently does your doctor or mental health care provider talk with your case manager, psychologist, psychiatrist, home health nurse or other professionals or supporters about your health care goals and needs?
- 13. Have you been asked if you needed help to be able to make future appointments and follow the medical plan before you left appointments?
- 14. How do your providers include your important cultural/spiritual practices in care planning?
  - a) How do your providers show respect and consideration for your gender and sexuality?

**Health Promotion**

15. If you wanted information about your health condition, or if you just wanted to see what you could do to feel better, what would you do?
  - b) What would be the best format for you to receive the health information?  
(Prompt: books, health providers, internet, friends, family)
16. If you could change one thing about your medical and mental health care experience (apart from whether you got better or not) that could help you take better care of yourself and that could help you have better health, what would it be?
17. How do your providers help you to understand and live with the condition(s) that you have?
  - c) What other ways do your providers help you stay healthy? (Prompt: what kinds of things do they say or do?)

### **Care Transition**

When thinking about experiences where you were transferred from one care setting to another, or between levels within one setting,

- a) How were you involved in planning the transition? How did you wish to be involved in this process?
- b) What were the most difficult parts of these experiences for you?
- c) What were the most helpful parts of these experiences for you?
- d) What would have made these experiences better for you?

Have I missed anything?

## BEHAVIORAL HEALTH HOME QUESTIONNAIRE

On a scale of 1 to 5 where 1 is **definitely would not** participate and 5 **definitely would** participate, rate how likely you would be to participate in a health plan that offered the following services:

**As of today, if your health plan offered a plan where:**

1. Your doctor (primary doctor) and mental health provider were located at the same site?

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Would definitely not participate	Might not participate	Neutral	Might participate	Would definitely participate

If #1 or #2 was chosen, please state why \_\_\_\_\_

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2. Your primary doctor and mental health providers talk to each other to plan your care (even if they are not in the same location.)

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Would definitely not participate	Might not participate	Neutral	Might participate	Would definitely participate

If #1 or #2 was chosen, please state why \_\_\_\_\_

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3. Your medical provider and mental health providers develop one care plan that includes information from both providers.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Would definitely not participate	Might not participate	Neutral	Might participate	Would definitely participate

If #1 or #2 was chosen, please state

why\_\_\_\_\_

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4. Your medical and mental health providers share your medical records to coordinate your care.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Would definitely not participate	Might not participate	Neutral	Might participate	Would definitely participate

If #1 or #2 was chosen, please state

why\_\_\_\_\_

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5. Doctors and providers teach you about your conditions with a focus on what you need to do to stay healthy.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Would definitely not participate	Might not participate	Neutral	Might participate	Would definitely participate

If #1 or #2 was chosen, please state

why\_\_\_\_\_

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6. One person who helps arrange appointments when needed and who could accompany you to appointments to help ask questions or help understand the providers care plan.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
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Would definitely  
not participate

Might not  
participate

neutral

Might participate

Would definitely  
participate

If #1 or #2 was chosen, please state

why \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Focus Group Sessions**

**Appendix B**

<b>Adult Participants<sup>1</sup></b>				
<u>Subgroup</u>	<u>Location</u>	<u>Site</u>	<u>Date</u>	<u>Participants</u>
American Indian	Fon du Lac	Fon du Lac Reservation	01/08/15	6
Metro area	Minneapolis	Phyllis Wheatley Community Center	10/27/14	3
Criminal Justice	Minneapolis	Phyllis Wheatley Community Center	10/14/14	4
Criminal Justice	Minneapolis	Phyllis Wheatley Community Center	10/15/14	4
Criminal Justice	Minneapolis	Ujamaa	10/24/14	8
Homeless	Minneapolis	St. Stephens	10/19/14	22
Outstate - Central	Brainerd	1st Lutheran	10/14/14	16
Outstate - Northwest	Bemidji	Hope House	10/06/14	8
Outstate - Southeast	Winona	Connection Support Group	11/03/14	35
Outstate - Southwest	Worthington	Southwest Mental Health	10/28/14	7
Outstate - Western	Hoffman	Hoffman Community Center	12/10/14	10
<b>Subtotal</b>				<b>123</b>
<b>Older Adults<sup>1,2</sup></b>				
<u>Subgroup</u>	<u>Location</u>	<u>Site</u>	<u>Date</u>	<u>Participants</u>
Hmong Speaking	Minneapolis	Park Avenue Elder Center	12/16/14	11
Spanish Speaking	Minneapolis	Centro Cultural Center	11/18/14	22
Russian Speaking	Minneapolis	Jewish Family Center	12/09/14	8
Veterans	St. Cloud	St. Cloud Library	11/18/14	6
<b>Subtotal</b>				<b>47</b>
<b>Transition-Age Youth<sup>3</sup></b>				
<u>Subgroup</u>	<u>Location</u>	<u>Site</u>	<u>Date</u>	<u>Participants</u>
American Indian, Homeless	St. Paul	Ain Dah Yung	10/20/14	5
Homeless	Minneapolis	The Link	10/24/14	14 <sup>4</sup>
Spanish speaking	Minneapolis	Aqui Para Ti	10/26/14	2
Outstate-Central	Brainerd	Northern Pines Youth Act	10/14/14	8
Outstate-Northeast	Duluth	Amberwing	11/06/14	3
<b>Subtotal</b>				<b>32</b>
<b>Family Members</b>				
<u>Subgroup</u>	<u>Location</u>	<u>Site</u>	<u>Date</u>	<u>Participants</u>
Pilot 1	St Paul	NAMI Minnesota	09/04/14	4
Pilot 2	St Paul	NAMI Minnesota	09/04/14	6
GLBT-Trans	Minneapolis	Quatrefoil Library	02/19/15	8 <sup>5</sup>
Outstate-Northeast	Duluth	Amberwing	11/06/14	2
Outstate-Northwest	Bemidji	Hope House	10/06/14	5
Outstate-Southeast	Rochester		01/15/15	7 <sup>6</sup>
Outstate-Southwest	Worthington	SW Mental Health	10/28/14	7
Outstate-Western	Hutchinson	Hutchinson Library	01/13/15	1
<b>Subtotal</b>				<b>40</b>

<sup>1</sup> Adult participants range in age from twenty-two to sixty.

<sup>2</sup> Older Adult refers to participants over the age of sixty.

<sup>3</sup> Transition-Age Youth range in age from sixteen to twenty-one.

<sup>4</sup> Compiled from two separate focus groups.

<sup>5</sup> Compiled from one focus group with 6 members and two telephone interviews with one participant in each.

<sup>6</sup> Compiled from seven telephone interviews with 1 participant each.

TOTAL	242
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