Minnesota Community Services Input Study Report

Minnesota Department of Human Services, June 2013

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This study and its insights were made possible by the many individuals who gave generously of their time.

This study would not have taken place without the Minnesota Legislature's genuine interest in hearing directly from people with disabilities, people with mental illness, older persons, and their families and caregivers. This support helped ensure that we heard directly about people's quality of life, and experiences with and hopes for long-term services and supports in Minnesota.

The understanding and wisdom about how Minnesota's systems are structured from the Department of Human Services was invaluable. Alex Bartolic, Jean Wood, Jennifer Strei and Kari Benson, and others in the Department of Human Services provided guidance throughout this study.

A network of people, including County staff, service providers and key leaders, ensured that people with a wide variety of perspectives in every region of the state were represented in the study. They helped us make phone calls, got notices out to their communities, gave us invaluable advice and shared their own insights. Without them, the stories that informed this study would not have been heard.

Most importantly, over 400 individuals shared deeply personal stories. They took time away from their own lives to participate in focus groups, complete surveys and be interviewed. They told us about their hopes and goals, anxieties and frustrations.

About the Minnesota Department of Human Services

The Minnesota Department of Human Services (DHS) helps people meet their basic needs by providing or administering health care coverage, economic assistance and a variety of services for children, people with disabilities and older adults. In 2013, the Commissioner of the Department of Human Services released a Framework for the Future. This framework specifically outlines goals to keep people healthy in their homes and communities. The framework also prioritizes innovation in care delivery, equity through decreased disparities, and integrity. DHS's Continuing Care Administration strives to improve the dignity, health, and independence of Minnesotans in its annual administration and supervision of $3.5 billion in state and federal funds, which serve over 350,000 individuals. The goal of the DHS Chemical and Mental Health Services Administration is to ensure that the mental and chemical health system of care develops a welcoming, accessible and comprehensive process for service delivery and supports the principle of a "no wrong door" approach to accessing services for co-occurring disorders of addiction and mental illness.

About the Improve Group

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

Introduction

The Improve Group conducted the Community Service Input Project (CSI) under contract with the Minnesota Department of Human Services. The study augments the information gathered through the Gaps Analysis Surveys to Minnesota's counties. The Community Service Input Project fills a critical information gap by gathering insights about long-term services[1] and supports directly from people with disabilities, people with mental illness, older people, and their families and informal caregivers. This information is important because:

➜ There is an increasing proportion of Minnesotans who have a disability, mental illness or chronic condition. More than 20% of Minnesotans have a disability,[2] 5% of Minnesotans have a serious mental illness,[3] and 13% of Minnesotans are aged 65 or over.[4] A 2009 study estimates that 31% of households have at least one person who has served as a caregiver.

➜ Systems to provide Minnesotans with long-term services and supports are complex, rely on a mix of public, private and family resources, and represent a very big investment. While a variety of private and public sources are used for long-term service and support needs for people with disabilities, people with mental illness, and older people, billions of dollars are spent annually to support their health and well-being.

➜ A number of data sources already exist that describe the services and systems that help people with disabilities, people with mental illness, older people, and their families and informal caregivers. However, there is a lack of information that describes the desires and hopes of people, how services are meeting their needs, and where service and system improvements are required.

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[1] The term "long-term services and supports", or LTSS, can be used interchangeably with the term long-term care, or LTC. Both refer to on-going supports that an individual needs due to a chronic condition. These services can be delivered in the home, in another community setting or in an institutional setting.

The term "home and community-based services", or HCBS, refers to long-term services and supports that are delivered specifically in homes or other community-based services, not in institutional settings. Home and community-based services are a subset of long-term services and supports.

Over time, the phrase "long-term care" has become strongly associated with nursing facility services, even though it has a wider meaning. In order to emphasize that these on-going support services can be delivered in both institutional and community settings, this report will use the term "long-term services and supports".

[2] From the Center for Disease Control's 2011 Behavior Risk Surveillance System survey. Data can be found at http://www.cdc.gov/brfss/data_tools.htm.

[3] The Substance Abuse and Mental Health Services Administration, National Survey on Drug Use and Health. Data can be found at http://www.samhsa.gov/data/2k12/NSDUH110/sr110-adult-mental-illness.htm.

[4] From the U.S. Census Population Estimates Study. Data can be found at http://quickfacts.census.gov/qfd/states/27000.html.

[5] From the National Alliance for Caregiving report, Caregiving in the U.S. 2009, available at http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf.

In addressing the information gap, the Community Services Input Project took an interactive, creative approach that valued the experiences of people, put respondents at ease, and gathered stories to share directly with leaders and policy makers. The study focused on **obtaining insights that are representative of the state as a whole** and **using methods that are a good match for each population**.

About Minnesotans who need long-term services and supports

In 2011, 67,903 Minnesotans, or about 1.3% of the state's population, were enrolled in home and community-based services waiver programs managed by the Department of Human Services Continuing Care Administration. These programs provide funding to eligible people to enable them to access long-term services and supports. About half of these Minnesotans were people over the age of 65 and about half were people with disabilities, including people with mental illness and developmental and physical disabilities. Some people are eligible for these programs but are on a waiting list. For example, 1,381 eligible people are on a waiting list for the Community Alternatives for Disabled Individuals (CADI) waiver, and 2,235 eligible people are on a waiting list for the Developmental Disabilities (DD) waiver. This population represents a portion of Minnesotans who need long-term services and supports.

Minnesotans who need long-term services and supports are served within a wide variety of systems. The Department of Human Services Continuing Care Administration serves one subset of Minnesotans who use long-term supports and services - those funded by Medical Assistance. This report was designed to represent perspectives from a much broader group – that is – all Minnesotans who need long-term services and supports. Nevertheless, findings from this report have implications for the Continuing Care Administration and the Chemical and Mental Health Administration in particular about the programs they manage. This report also has implications for local, state, and federal officials and decision makers; each group has a role in reducing service gaps across Minnesota.

Legislative intent. DHS contracted with the Improve Group to conduct this study in order to fully respond to the Legislature's intent in Minn. Stat. §144A.351 to seek community input regarding the status of the full range of long-term services and supports for older persons, individuals with disabilities, and individuals served by the mental health systems.

Additional Background Information: Jensen Settlement Agreement. In July 2009, three former residents of the Minnesota Extended Treatment Options (METO) program, and their parents, brought a class action lawsuit against the State of Minnesota and the Minnesota Department of Human Services in the United States District Court, District of Minnesota, on behalf of residents of METO who were subjected to the use of restraints and seclusion in alleged violation of the United States Constitution and other federal and state laws. In June 2011, the Plaintiffs, on behalf of the class, and the State reached a comprehensive class action Settlement Agreement, which was approved by court on December 5, 2011.

A component of the Settlement Agreement requires the State and department to develop and implement a comprehensive Olmstead plan that uses measurable goals to increase the number of people with disabilities receiving services that best

meet their needs in the most integrated setting and is consistent and in accord with the U. S. Supreme Court's decision in Olmstead v. L.C., 527U.S.582 (1999). In January 2013, Governor Dayton, by Executive Order, created the Olmstead Sub-Cabinet and directed the development and implementation of the Minnesota Olmstead Plan. The information collected in this report will greatly assist the Sub-Cabinet in this work.

Using this study. This study can be used by many people, all of whom have a role to play in eliminating service gaps. Policy makers can use the stories described in the study to identify top priorities for strengthening and streamlining systems. State agencies can provide financial incentives, such as funding pilot programs, and identify areas to help people better navigate their systems. Local agencies can use these stories to understand where they should be refining and developing new service options. Providers can use the study to propose creative new service ideas that meet people's needs. People with disabilities, people with mental illness, older people, and their families and caregivers can use this study to support their own stories, explain why they are important, and advocate for improved systems. Anyone interested in this topic area can become involved with organizations that serve people with disabilities, people with mental illness, or older people. For example, interested stakeholders can seek out opportunities to sit on various stakeholder groups, committees, and councils to ensure that these perspectives are brought forward. Local agencies, service providers, or concerned individuals can use the data presented here to apply for grant funds to close service gaps using innovative approaches.

Methodology

Review of Existing Research and Literature

Two related research studies conducted by the Minnesota Department of Human Services were reviewed to examine trends in service availability over time, and in specific populations. These included the 2003 to 2009 Long-Term Care Gaps Analysis Study and the 2013 Initial Needs Determination Study for Disability Waiver Residential and Support Services. DHS administers biennial Gaps Analysis Surveys with Counties. The Gaps Analysis Study examines a topic similar to this research. The key difference is in the Gaps Analysis study, areas of need were identified primarily by county staff. In the current study, gaps were identified through input by people receiving or needing support: people with disabilities, people with mental illness, older people, their families and informal caregivers, as well as advocates and experts in the field, county and tribal leaders.

Additional relevant literature was reviewed including: The Promise of Olmstead, Recommendations of the Olmstead Planning Committee; various related court documents and public comments received by DHS; the Biennial Report on Long-term Services and Supports for People with Disabilities, January 2013; The Mental Health Legislative Network 2013 Report; State of Minnesota, Reform 2020, Pathways to Independence Report; The State Advisory Council on Mental Health, and the Governor's Subcommittee on Children's Mental Health 2012 Annual Report to the Governor and Legislature.

Finally, a number of articles were reviewed to inform project planning and tool development. Information

contained in these articles helped to inform the use of best practices in developing and conducting focus groups and ethical evaluations with persons who are older, persons who have a disability, or persons who have mental illness and may be vulnerable. Another goal of this review was to assure that project personnel and focus group facilitators had a foundation of knowledge of culturally appropriate research for current programs and services, and also current information on issues related to long-term services and supports.

Minnesota Department of Human Services Waiver Review

For this study, secondary analysis of the Home and Community-Based Waiver survey data was conducted. Since 2005, the Department of Human Services has administered one to two reviews of home and community-based services programs in each of Minnesota's 87 counties. The reviews are an opportunity for DHS to monitor compliance with program requirements, learn about and disseminate best practices in program administration, and receive feedback about DHS supports and resources. As part of the first waiver review cycle (2005 to 2012), lead agency staff knowledgeable about the services provided through the HCBS Waiver Programs were surveyed about the availability of long-term services and supports in their area. Surveys were conducted between 2006 and 2012 in advance of a site visit to their lead agency. A total of 1,315 case managers were surveyed. In the second round of waiver reviews (2012-2013), providers offering home and community based services in 33 counties were also surveyed. Data on providers' impressions of service gaps is also presented in the current study.

Input from People with Disabilities, People with Mental Illness, Caregivers, and Older Adults

In-depth data was collected through structured, interactive focus groups held in 16 communities across Minnesota. Focus groups were held with three primary groups including persons with disabilities and/or mental illness, older persons, and informal caregivers. Communities were selected through a collaborative effort by the Improve Group and DHS. Communities were selected to represent diversity in terms of geographic locations and density of services. Focus group participants were recruited on a voluntary basis through a variety of means including local contacts and newspaper ads. Community members needed to be at least 18 years of age to participate in a focus group; care was taken to recruit parents and caregivers of children with mental health conditions and disabilities in order to ensure data about their needs and preferences would be gathered. While most focus groups were held directly in the communities selected, groups

were also held at two large conferences that draw attendees from across Minnesota. One conference was for primarily people who have developmental disabilities, and one was for parents and caregivers of children with mental health conditions. Participants were asked to pre-register for the focus group by phone when possible. The recruitment process focused on people who had not had prior opportunities to give feedback on services, and who would normally face barriers to participation. All eligible participants were offered an incentive, a light meal, and supports such as transportation, to help them attend the focus group.

The registration process included a series of questions to determine eligibility, establish consent, and to subsequently route them to the appropriate focus group to attend in their community. Focus group participants were offered an incentive of $35 cash or a $35 gift card to Wal-Mart. Although participants were encouraged to pre-register, same-day registration was allowed if space was available. Instead of going through the formal screening process, the same-day participants underwent a brief screening with the facilitator to confirm eligibility for the group. Focus groups were held in various settings in communities with close attention paid to selecting a neutral, convenient, and accessible location. The number of participants in the focus groups ranged from 2 to 14, with 260 individuals taking part in the process altogether.

A standard focus group format was used for all populations and each group included a trained facilitator. In most communities, an assistant attended the group to help with registration and note-taking. Prior to beginning the 90-minute focus group, participants were offered a light meal and given background information about the project.

Everyone participating was asked to give verbal consent to indicate they had been informed of how the information from the focus group would be used. All participants gave verbal consent to audio record the discussion. The focus groups used an interactive image-based exercise – Image Grouping – in which participants were instructed to rate different areas of their life, or the life of the person they care for, by placing the life domain stickers on a scale from "good" to "bad." Participants were given a choice of three stickers with different images for each domain area: community membership; health and wellness; independence; relationships; and employment, volunteerism, and school. Participants were instructed to choose one or more stickers per domain area to place on their scale. This activity was used to inform a more traditional question-and-response discussion led by the facilitator. Focus group participants were asked to share their experiences with receiving or accessing long-term supports or services. The same process was used in every focus group allowing for cross-site comparisons.

Input from County Personnel

Twelve group interviews were held with county government staff to learn more about the types of services and supports available in their community, as well as any gaps that exist in their county or region. Interviewees in each community were identified through contacts provided by DHS. These individuals primarily included managers from disability services, adult and children's mental health, aging services, public health, or collaborative community partner agencies such as a local Area Agency on Aging when the manager felt this partner could best speak to a specific population's current needs. The goal was to solicit feedback from

county staff from a variety of areas of expertise. The interviews were typically held on-site in each community, but some were also completed by phone due to scheduling difficulties. The number of participants in the interviews ranged from two to six.

Each interview was facilitated by an Improve Group staff member with the assistance of a note-taker, when available. Interviewees in each community were asked a standard set of questions about the availability of services and supports as well as service development in their communities. More individualized interaction with staff allowed the facilitator to gather insights and perspectives from respondents through follow-up questions and discussion prompted by the standard interview protocol.

Input from Tribal Leaders and Providers

Two group interviews were held with elected and appointed officials and service providers in the Mille Lacs Band of Ojibwe tribal community. Leading up to the community visit, staff from the Improve Group held phone meetings with the Directors of Community Support Services, and Tribal Health Services, and others. The goal of these conversations was to share insights, plan the visit, and determine the best ways to get input that was helpful to the Tribe while also informing the larger study. Within the Mille Lacs Band of Ojibwe tribal community, health and community services leaders felt it was important to seek input from elected and appointed officials, and also health and community services providers. Facilitators from the Improve Group, accompanied by the Tribal Director of Community Support Services, conducted input

sessions for these two groups that combined aspects of an interview and a focus group. Seven providers and three tribal leaders were interviewed. A meal was provided to these two groups, giving providers and leaders a chance to commune together. The Commissioner of Health was interviewed separately due to a scheduling conflict that prevented him from participating in the interview with tribal leaders.

Input from Key Stakeholders

Phone interviews were conducted with 24 key stakeholders from a variety of organizations and backgrounds. Of those interviewed, 33% represent consumer, family and advocacy organizations, 29% service provider collaboratives, 17% government advisory groups and councils, 13% government division, 4% regional development organizations, and 4% health plans. Key stakeholders were identified through a variety of sources including contacts provided by DHS, professional contacts through Improve Group staff, and an internet search of leaders in the field. A total of 39 key stakeholders were contacted for a phone interview. Of these, 24 participated, 5 declined to participate and 10 did not respond to several contact attempts. Phone interviews were 30 to 60 minutes in length and conducted by an Improve Group staff member.

Online Survey

This study used a website[6] as a data collection strategy to reach people across the state. The website included a link to a 10-minute survey with questions focusing on the availability of services in each respondent's community. The survey was also available for download on the website and could be completed and mailed to the Improve Group.

[6] www.mnservicestory.com

Additionally, Improve Group staff provided assistance with completing the survey at a local conference for persons with developmental disabilities in order to receive input from this population. In total, the online survey had 110 total respondents. Of these, 29% identified as having a disability, 23% as parents and caregivers, 7% persons who are older, 6% as parents and caregivers who also have a disability themselves, 25% other (friend, community member, employee, et cetera), and 9% did not specify their role. A little over half of the responses (54%) came from outstate Minnesota; 10% of which came from St. Louis County. A little under half (47%) of responses came from the 7 county metro area; 24% of which came from Hennepin County.

Input from Health Plan Care Coordinators

An online focus group was held with care coordinators who work with persons with disabilities of all ages as well as older adults who need services and supports. In order to ensure their perspective on relevant study questions was gathered, the Improve Group worked with DHS staff to gather a pool of eligible care coordinators from around Minnesota who represented health plans and county-based purchasing entities that serve older people on the Elderly Waiver through Minnesota Senior Health Options (a Medicare-Medicaid integrated product). A total of 23 care coordinators participated in a one-hour, online, chat-based focus group and shared feedback about current gaps in services, barriers to serving clients, and what they feel most needs to change.

Cultural and Ability Considerations

For the entire length of the project, from the drafting of the proposal to the drafting of this report, the

researchers have operated under the following principle: in order to treat all people with respect we must be sensitive to individual needs and respect differences, without judgment. This study was also guided by the understanding that relationships are important to helping people feel comfortable and share stories about sensitive topics.

This study aimed to include people and groups whose voices are not often heard. In the process of selecting which Minnesota communities to visit, many communities and locations were chosen specifically because of their diversity. For example, early in the project a focus group was scheduled at a North Minneapolis location that typically draws diverse participants to its events. Later, a focus group for older people was held at a Hmong Community Center.

Focus group invitations were translated into Hmong, Somali and Spanish, made available in large print, and distributed broadly. Work was done preemptively to have ready access to language interpreters, including American Sign Language. A language line service was available to researchers, to accommodate all people who called to register, no matter what language they spoke.

The focus group Image Grouping activity and protocol were designed to be understandable across cultural and language barriers, and accessible to people with disabilities. Images were specifically chosen to depict people of different races, included people of a wide range of ages, and some with obvious or implied disabilities. Materials were converted to large-print and Braille for participants with visual impairments.

Analysis

The Community Services Input Project was designed to collect data using primarily qualitative methods. The qualitative data were analyzed using a multi-step process that follows the constant comparison/grounded theory model. First, data were prepared by organizing items in an Excel spreadsheet as responses to the key evaluation questions. Next, all of the data were reviewed and organized into themes. Once all of the data were assigned to one or more theme(s), quantitative data were analyzed and assigned to themes where it supported or supplemented the qualitative data. Quantitative data were gathered from a variety of sources including the Image Grouping activity in focus groups, web survey, and polls in the care coordinator focus group. The data were used to support and verify findings from the qualitative analysis.

FINDINGS

Characteristics of Minnesotans who need long-term services and supports

In focus groups, participants who needed long-term services and supports or cared for someone who did were asked to rate their satisfaction with several different areas of their lives, consistent with the DHS focus on the CHOICE domains for a meaningful life. These areas include: community membership; wellness; safety; independence; relationships; and employment and school. In follow-up discussions, participants were asked to describe how these areas of their lives affected and were affected by their access to long-term services and supports. The effects of employment, volunteerism, and school were highly connected to life satisfaction in the four other domains discussed during the focus groups. Therefore, the points made in reference to these ideas are incorporated into the four sections that follow and are not presented as a stand-alone piece.

Community membership

The community membership domain represents the individual's experience with feeling part of the community and being able to participate in it. Feelings of community connection were typically described in terms of where one lived, the activities available and utilized, and access to government assistance. Caregivers, people with disabilities, people with mental illness, and older people expressed their desire to be engaged with the community and feel accepted and welcomed. Individuals offered examples of activities they enjoy doing, all of which they associated with being part of the community: sewing circles, book clubs, swimming, volunteering, church, movies, and meals. Some people with disabilities and some people with mental illness said that a challenge in engaging with the community is the stigma attached to people like them; as a result, they do not feel comfortable getting out and participating in the community. Caregivers of children also shared their desire for their child or children to be able to interact with their peers and be included in community activities.

Community membership was also associated with participating in particular community groups or social circles. For people with disabilities, people with mental illness, and older people, interacting with their peers or others with shared experiences provides a much needed support circle in which to relate issues. These groups also provide an opportunity to share knowledge about accessing services and resources.

Wellness

The wellness domain captured perceptions around access to healthy foods and opportunities to participate in physical activity. Individuals in the focus groups shared that they want to be healthy, but access to the necessary resources to maintain a healthy lifestyle varied. Some individuals spoke about being able to access healthy foods on their own or through food assistance programs. Older people in particular highlighted the accessibility of quality food assistance programs or food shelves to get healthy foods. However, this same group as well as people with disabilities and caregivers across the state cited the high cost of healthy foods as being a barrier to their food access.

Likewise, people expressed that they valued being able to participate in regular exercise. Participants discussed various exercises and activities they enjoyed such as walking, swimming, biking, and even being out volunteering. Similar to accessing healthy foods, several participants said that they were unable to afford a membership at an exercise facility and that their health insurance would not pay for fitness center memberships. Others felt they had different barriers such as lack of motivation or not having someone with whom to exercise.

Safety

Concerns about safety were raised in a few communities. While most focus group participants felt safe in their communities and living situations, participants from each of the different groups who live in Duluth specifically highlighted drug and crime problems in the downtown area. Some participants did not have enough money to live in safer neighborhoods. People said that they were scared and did not feel safe walking around, decreasing both social and mobility opportunities. While this was a major theme among the urban community of Duluth, similar concerns with drugs and crime were also mentioned in the tribe community of Mille Lacs.

Independence

Independence means being able to choose where to live, make decisions about supports and services, and having resources like transportation to remain mobile in the community. Although many people who receive long-term support felt that they were satisfied with their independence, they likewise had additional goals and ideas for how things could be better. Participants often related their independence to their current housing situation; owning a home and living alone were important for independence.

While participants mentioned that moving from a group home setting to independent living or from apartments to home ownership would add to their sense of independence, there are some barriers and trade-offs to becoming more independent. In many cases, focus group participants shared that they valued the feeling of community and social opportunities organized by group homes, assisted living facilities, and other congregate settings. As an older person noted, it is "good to have people like [a program counselor] that brings people together." In addition, participants feel safe and are able to receive needed services and supports in this setting. Conversely, while this environment is more restrictive, participants noted that improving independence meant having the financial resources to pay for the services they would need to live and function on their own. Compounding the issue, alternative living opportunities to support people who are able to live more independently while also maintaining safety and social connections do not always exist in certain communities.

In addition, older people and people with disabilities were often most concerned about their mobility and the impact of transportation on their independence. Participants reported facing several barriers to being able to get around within the community, most of which were related to transportation. Caregivers also reported limitations to their independence as a result of their role in caring for someone with long-term service and support needs. They expressed a sense of loss of their personhood by having to sacrifice so many aspects of their own life to take care of their family member.

Relationships

Relationships are a key area of importance for people needing long-term services and supports and include connections to important people like family, friends, neighbors, coworkers, or community members. During discussions of what is going well in their lives, people with disabilities, older people, and caregivers alike spoke of building and maintaining relationships. Close relationships, love, and belonging were tied together in discussions with people with disabilities, people with mental illness, older people, and caregivers. Participants shared that positive relationships contributed to a better quality of life. Notably, a number of people discussed their good relationships as something they were proud of in the context of doing things they enjoy. Family members were often cited as the most important relationships for people who need long-term services and supports. Other groups that provide valued relationships are those in networks associated with hobbies, faith, employment, and volunteering. For example, people with disabilities, people with mental illness, and older people said that volunteer and employment opportunities became places to socialize and meet new people. One person's co-workers became "like a family."

Positive relationships with others have also enabled people to operate more independently. Family members and friends also advocate on behalf of their loved ones and provide informal supports like checking in on them, running small errands, or cooking on their behalf. In other situations, some people learn about available services through their relationships. One person with a disability shared, "if it wasn't for friends, I wouldn't know about a lot of the services [available to me]."

Despite most focus group participants feeling that their relationships were going okay or great, some participants talked about challenges with forming and maintaining relationships. People spoke of being lonely and having a hard time generating friendships or relationships with people with whom they could regularly converse. In particular, older people who faced barriers to leaving their homes felt more isolated. Caregivers spoke of the lack of appropriate activities available for their children that could allow them more interaction with others their age. In some cases, children with a disability or mental health condition did not have an accepting environment in which to make friends. In others, youth needed a drug and alcohol-free space to promote good behaviors and alleviate the pressure of the caregiver to keep watch. One caregiver described her relationships as both strong but limiting; as an older female caring for grandchildren, it was difficult to provide the care and watchful eye needed for youth who are easily exposed to negative behaviors in the community.

Employment and Volunteering

A common thread across all communities was participants' desires to have meaningful employment or volunteer in some capacity in the community. It was revealed that participants' ability to be employed or volunteer often depends on the availability of services, supports, and opportunities in the community for individuals to work or volunteer. Employment and volunteering were linked to an individual's feeling of financial independence and self-worth; as one person with disabilities said about employment, "It has also fostered growth in myself." Participants who worked or volunteered reported feeling productive and liked that they were contributing to the community. Another person spoke about working and volunteering, "I just want to work in the community for something to do."

Current status of service strengths, gaps and opportunities

Through focus groups, interviews, and surveys, community members and key stakeholders across Minnesota shared their experiences with service availability in their areas. Communities were grouped by type: urban, "hub" communities in greater Minnesota that have a larger concentration of services, rural communities, and tribal communities. This enabled the researchers to examine differences in service availability by type of location. Additionally, differences were examined in responses by group – people with disabilities, children with mental health conditions, adults living with mental illnesses, older people, and caregivers. Overall, few service surpluses were noted. People shared that the level of services available were either just the right

amount, or not enough to meet the needs in their community. Focus group, interview and survey data were analyzed to identify the most commonly reported service gaps, which included transportation, employment, housing, respite care, mental health services, and services to help people maintain their homes, such as chore and homemaking services.

Service gap: Transportation

Craig's Story: Craig is a young man with a disability from Southern Minnesota. He recently finished high school and has started community college. He currently lives with his parents and his biggest challenge is transportation. *"I only have one bus route to get to and from home, and sometimes I miss the bus that is only on the hour. I have some money to get a car but being on social security you have to be looking for jobs if you have a car. That isn't feasible to me in my life because of where I'm at right now. I'm worried that they'd take away my social security. I'm caught in between needing a car and fear of losing benefits if I get one."* Craig is likely going to need continued help transitioning into adulthood; it is not clear that he knows what is available, or is ready to ask for help.

In every community outside of the urban centers, a shortage of affordable and reliable transportation options was identified as a problem. In particular, people in rural and tribal communities reported that transportation was the area they most wanted to improve. Older people across the state reported that transportation is the most important factor in being able to live independently and participate more fully in the community. People with disabilities and caregivers also rated transportation as one of the top five factors in being able to live independently.

Focus group participants shared that transportation is a key issue that greatly affects the quality of their lives. Many people with disabilities, older people, and people with mental illness do not drive because of their lack of ability or income level and therefore rely on public transportation services or transportation provided by friends or family. Older people in particular mentioned that without transportation, they are unable to get to appointments and experience isolation. Many have moved into a larger town nearby specifically because they have not been able to access transportation close to their homes; older people reported great sadness in having to leave their homes due to a lack of nearby transportation.

Only 26% of case managers surveyed report that there are enough transportation services to meet the needs of their communities.

Source: DHS Waiver Review
Case Manager Survey, 2006 - 2012

Several modes of transportation were identified by the people with whom we spoke, including walking, public transit, cabs, specialized transportation, and private transportation such as owning a vehicle or having access to rides from family, friends, and volunteers. Whether for medical appointments, errands such as grocery shopping, or social activities – people with disabilities, older people, their caregivers, and county staff reported that having access to affordable and reliable transportation that is easily accessible greatly supports independence.

Focus group participants who reported that they were able to live independently attributed this, in part, to their available transportation options.

Public transportation is much more readily available in urban areas as compared to rural locations. For participants in urban areas, the majority utilized public transit and public specialized transit, such as Metro Mobility, as their primary method of transportation. However, some people with disabilities and especially older people, shared that the bus stops and warming stations are not always fully accessible, particularly in inclement weather. Additionally, many participants with disabilities expressed that they spend many hours each week

commuting when they would prefer to spend that time working.

Specialized transit was identified as a valuable resource, but also as having significant limitations in scheduling, service area, and cost. This was clearly demonstrated during the recruitment and registration process for this study. Many participants in urban areas who were excited to participate and contribute to a focus group had to make considerable efforts to secure transportation to participate – either through submitting a request through specialized transit over a week ahead of time to ensure a ride, seeing if a friend or family member could drive them, or utilizing a cab service. It was essential that this project was

Percent of Counties Reporting Gaps in Transportation is Rising

Across four Gaps Analysis surveys conducted for the older adult population, transportation was consistently the most frequently cited gap by participating counties. The percentage of counties overall citing this gap grew from 42% in 2003 to 66% in 2009. Agencies participating in the Gaps Analysis survey shared that the rising gap in transportation is related to the elimination of reimbursement for non-load miles.
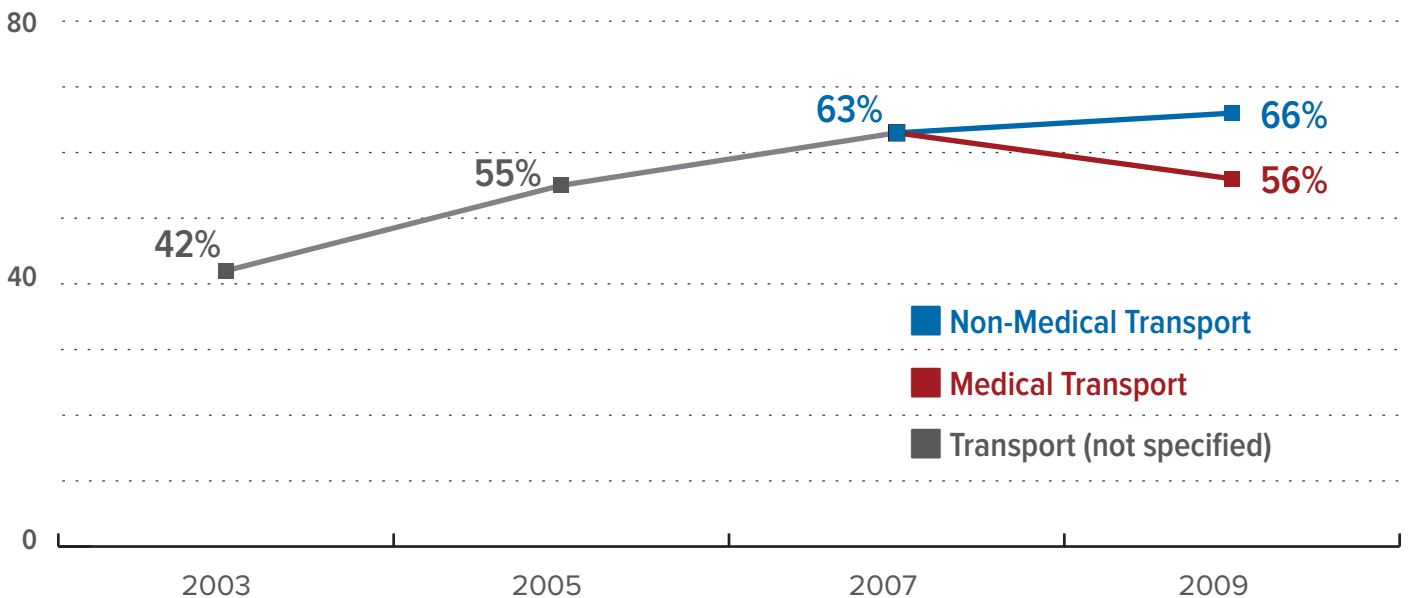
Source: 2009 County Long-Term Care Gaps Analysis Survey

able to provide financial support and reimbursement for these services to ensure transportation would not be a barrier to participation, as it certainly would have been for many older people and persons with disabilities otherwise.

While some hub and rural communities have public transportation options, most of these services have significant limitations. For example, most public transportation options are only open during standard business hours and then close down by 4:00 P.M. on weekdays; often times services do not run at all on the weekends. These hours limit work opportunities as people have a way of getting to work but do not have a way home at the end of the day. Additionally, attending late afternoon medical appointments is not an option for someone relying on public transportation in many rural communities. People who would otherwise be able to attend a community event over the weekend or during the evenings are unable to do so as public transportation does not operate during those hours.

Where specialized transit is offered, many participants experienced barriers which make it a limited option. In the Twin Cities, where the services are more readily available, the high cost is a barrier for many participants who are struggling financially. In the Duluth area, specialized transit availability was felt to be inadequate; there are such limited spaces available that participants with disabilities told us that often, even when they called a week in advance at 8:00 A.M. when the office first opens, they have been unable to secure a ride because so many other people were calling as well.

Outstate public transportation often has limited routes that do not reach every place people with disabilities, people with mental illness, and older

people would like to go. In particular, several participants discussed how limited transportation options impact where and when they can work or volunteer. In some small communities, focus group participants explained that they need to have four or more additional people along for the ride in order to be able to utilize the available transportation services. In very remote areas, there are no public transportation options at all. In some places, taxi services are an option, but they are too expensive for most community members to use on a regular basis.

Many participants with access to private transportation spoke of the large financial burden of maintaining a private vehicle. Some people shared that they have a driver's license but are unable to use their vehicle because of the high cost of insurance. Others have medical conditions that prevent them from driving periodically, which makes it challenging to hold a regular job. Many participants spoke of relying on a friend or family member for private transportation, and going without transportation when their usual rides were unavailable and they had no other options. Asking others for rides felt

burdensome to many participants and older people in particular experienced decreased feelings of independence. The older adults we spoke with do not want to have to rely on their adult children for transportation for errands, volunteering, and social engagements. As a result, many people we heard from only utilize rides for medical appointments and forgo opportunities for community engagement; they very much want to participate, but they simply lack accessible transportation that allows them to do so independently.

Service gap: Employment

Tracy's Story: **Tracy is in her forties and lives in the Twin Cities. She has chronic health problems and is visually impaired. Tracy rates her independence as high and has a supportive family. She has received services through State Services for the Blind. Three years ago she lost her job due to layoffs, and has been seeking employment. As a person with a disability, she finds it extremely challenging.** *"There are so many other people looking for work with a visual impairment people aren't willing to give you a chance."* **She shared about her experience with discrimination when she was called for an interview, "They were excited to interview me, once I got there she saw my cane...they did not even interview me...I went home and cried." Tracy said in addition to needing help locating potential jobs, she needs emotional support and an advocate to help with these challenges. More than anything, she wants a chance to work again and to not be seen as just her disability. "If you can't find a job, you can't have self-worth. Give people a chance to do their best. We want to be independent like anyone else. Just give us an opportunity."**

Employment was rated as the top priority area that participants want to improve in both urban and "hub" locations. Additionally, it was in the top five areas that participants wanted to improve in rural and tribal communities. As a whole, participants in urban communities and people with disabilities and people with mental illness across the state felt employment is the most important factor in being able to live independently and participate more fully in the community. Caregivers of people with disabilities and people with mental illness also felt very strongly that employment opportunities and supports need to improve.

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Only 40% of case managers reported that their counties have adequate employment support and prevocational services available.

Source: DHS Waiver Review
Case Manager Survey, 2006 - 2012

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Overall, many participants expressed a deep desire for meaningful employment and volunteer opportunities. However, 30% of focus group participants shared that employment or volunteering was going poorly in their lives. This finding was most pronounced in rural and hub communities, as well as with people with disabilities and people with mental illness. Participants reported experiencing multiple barriers to employment, including discrimination. This was especially true for people with disabilities or mental illness. Some participants felt like they had a strike against them when seeking employment because employers show reluctance to make accommodations for their disability, even when they

are required to do so by law. Systemic barriers that prevent some people who receive government aid from working were also frequently mentioned; these participants need supportive services but fear they would lose these if they exceed even modest income levels. Transportation was also frequently cited as a barrier to employment; in fact, participants who said employment, volunteering, and school were going well for them frequently shared that reliable and affordable transportation was available to them.

In an online survey of community members and stakeholders, 52% reported that their communities do not have enough **supported employment services** and 60% responded that their communities lack help with **finding and keeping a job**.

Source: Community Services Input Study
Web Survey, 2013

County staff reported that communities are aware of the need to develop more employment options; however, they also described multiple barriers to employment. Many employment opportunities currently available for people with disabilities are center-based day programs; there is a shortage of community based programs, jobs, and market rate positions available, especially in non-urban areas. Sufficient supportive employment options are also lacking, especially for the transition age population and people with mental illness. The jobs available are not always tailored to fit a person's strengths, needs, and interests. Staff reported that there is not

sufficient funding to sustain ongoing supports like job coaching and supervision, which was described as being especially lacking in rural areas. Where coaching, supervision, and training opportunities do exist for people with disabilities, focus group participants explained that they are mostly targeted at adolescents and those with specific disabilities; older adults and some people with disabilities feel that there are not as many opportunities available for them.

Young people have unique challenges of their own when it comes to employment. As one advocate articulated, young people with disabilities are different than the previous generation in that they have been raised to believe they have a right to be included. They have been completely integrated in school and expect to be able to access their communities as independently as possible. When they leave school and hope to work, maintain relationships, and participate in their communities, they find it difficult to get from place to place and gain the support they need.

23% of providers surveyed reported that community-based employment was a **top service gap** in their community. This was true for urban, rural and "hub" communities.

Source: DHS Waiver Review Provider Survey, 2012–2013

County staff shared that it is important to provide transition-aged young adults with opportunities to work in the community. Many young adults with disabilities have skills for working that are unable

to be used at center-based employment facilities. Sometimes young adults with disabilities miss opportunities for community-based employment as the employment providers do not have the staff to coach young people as employees. In the case of one focus group participant, her son's school offered transition services to prepare him for the workforce, but she felt that they were so oversimplified that they would not have real-world applicability.

Service gap: Housing

Sarah's Story: **Sarah is a young woman with severe and persistent mental illness who lives in a hub city in Southern Minnesota. She spoke quite a bit about things that are going well in her life, including work and relationships. She began volunteering at a local advocacy organization for people with mental illness and she shares how it has helped her.** *"It has helped me through when my symptoms get really bad. The people I get to meet – they're struggling the same as I am. I can feel so isolated otherwise. I use my voice to speak for anyone who feels they can't. And I can do that because of opportunities I've had in my life."* **She also recently got married. Sarah's husband has mental illness too, but does not qualify for services. He is unable to work and her benefits must support both of them. In order to continue to qualify for the services that allow her to function, her income must stay low.** *"We have to live in an area where I don't feel safe but I don't have a choice. There needs to be more communication about services that are available to help."*

Insufficient affordable housing[7] has been well-documented as a significant issue throughout Minnesota. A study published in 2012 found that 94% of Minnesota's 87 counties lack enough affordable rental housing for extremely low-income residents, which includes many people who need long-term services and supports. In 2010, approximately half of renters and more than a quarter of owners paid more than they could afford for their homes, according to HUD affordability guidelines.[8] Additionally, within the Twin Cities seven county metropolitan area, 15% of affordable housing has been developed in Minneapolis and St. Paul in the past 17 years, and 25% within the developed suburbs.[9] In general, these often are areas with the greatest concentration of services and supports for people with disabilities, mental illness, and older adults.

This statistical evidence for the affordable housing deficit in Minnesota supports what we heard from focus group participants. A lack of affordable, quality housing options was reported by all of the populations we reached through the study - people with disabilities, people with mental illness and older adults. Many people from across the state shared that they could not afford some of the housing options available to them and there is a particular shortage of housing in places where there is convenient access to services. Multiple focus group participants reported long waiting lists for HUD-subsidized housing in their regions, as well.

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[7] Policymakers and advocates generally consider housing "affordable" when a household pays no more than 30% of its total income for housing costs (rent or mortgage payment, insurance, taxes, and utilities).

[8] Minnesota Housing Partnership, Facts and Stats. http://mhponline.org/publications/reports-and-research/county-profiles/320/320-2012

[9] http://www.minnpost.com/cityscape/2011/12/twin-cities-communities-falling-far-behind-affordable-housing

While a need for better quality housing options was identified across rural and urban settings, there are some unique challenges in each setting. Urban residents and older adult focus group participants in particular, shared concerns about high crime rates in the public housing neighborhoods. Additionally, some participants expressed problems with bug infestations that can be particularly difficult for people with disabilities and older adults, as they may exacerbate existing health issues. Rural communities were seen as having too few options and a lack of availability for housing, especially housing for older people.

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53% of case managers reported that their counties provide enough **independent living skills services** to match demand.

Source: DHS Waiver Review
Case Manager Survey, 2006 – 2011

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Many participants expressed a desire to live in a housing situation that allows them to be as independent as possible. Participants shared a need for choices in housing and supports, where people can live self-sufficiently with the right amounts and kinds of support. Older adults are looking to access assisted or maintenance-free housing where the physical demand for upkeep and maintenance is not required. People living with serious mental illness need affordable housing options where they can receive some minimal supports. Young people with disabilities who are looking to leave their parents'

homes could do well living in an apartment, possibly with a roommate, and with supports for a few hours each week. That level of service and support is not currently available in every community; instead, family members see that their loved ones have the choice between remaining at home or moving into a congregate setting. Findings from this current study align with the 2013 Foster Care Needs Determination Report which surveyed 64 counties and tribes from across the state. The Foster Care Needs Determination Report shows that congregate, corporate foster care is the most available and widely used housing model in Minnesota, while services to support people in their own homes require more development in most regions. Additionally, the study's survey results revealed that independent living skills and training are the most-needed support service in order to move people out of foster care and into their own homes.

County staff reported the need for housing for transition age young adults and in particular, the need for more apartment-style housing with services and monitoring which would appeal to these individuals. County staff also reported additional challenges in finding housing for people with a criminal background, especially people convicted of sex offenses and felonies. It is also always a challenge to find housing to serve people with high behavioral or mental health needs. They often mentioned Minnesota's moratorium on developing corporate foster care homes as a barrier to finding appropriate housing for young adults.
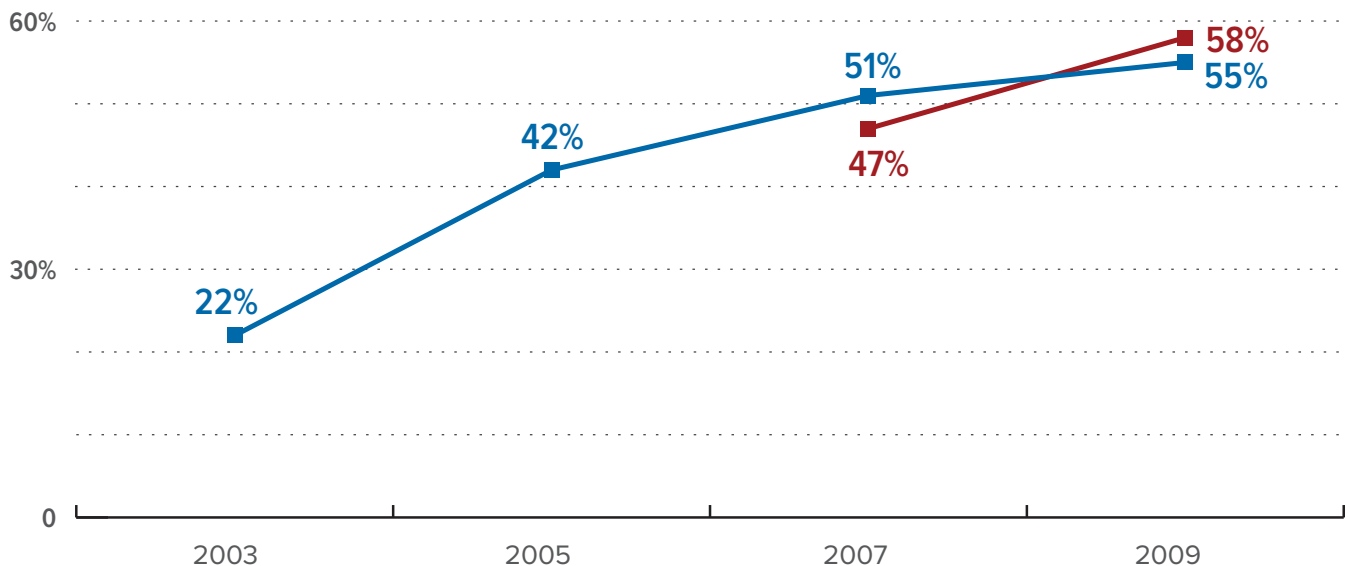
Service gap: Respite care

Kathy's Story: Kathy lives in the Twin Cities. She has two children who both have multiple disabilities and mental illness. Her children are Hannah, who is 12; and Aubrey, age 5. Kathy feels Hannah is currently doing well after a recent medication change, but she is very concerned about Aubrey, who requires a high level of services including hospitalizations and in-patient treatment. One of the biggest barriers Kathy sees is that TEFRA is unaffordable for them and their current insurance will not cover many services that her children need, including a PCA for Aubrey or respite services for their family. As a result, Aubrey is not able to participate as independently in activities and the community. Kathy relies on friends when they are available, since leaving the house with Aubrey can be very challenging at times. *"We're trying to get on a waiting list for respite care. The agency won't call us back because they are so backlogged from the government shutdown. We need a break. It's sad when an emergency hospitalization [for Aubrey] is our vacation."*

Caring for a person with a disability, a person with mental illness, or an older adult with chronic health conditions is a commitment that can take a physical and emotional toll on the caregiver. Many participants and county staff reported a need for more respite care, out-of-home respite services, and respite care providers with more skills, for caregivers.

Percent of Counties Reporting Gaps in Respite Care is Rising

Over the six years that the Gaps Analysis survey was conducted for the older adult population, respite care saw the largest increase of reported gaps, with **58% of counties reporting gaps in out-of-home respite,** and **55% reporting gaps in in-home respite by 2009**. In both cases, low reimbursement rates were tied to low availability. For out -of-home respite, bed availability was often cited as being limited, while in-home respite was especially limited for extended periods, overnights, and during weekends.

Source: 2009 County Long-Term Care Gaps Analysis Survey

Additionally, respite care is needed for many groups of people, including people caring for older family members and for those with mental illness. Caregivers use respite service as a time to get groceries, to attend a religious service, to volunteer, and to participate in other activities that give their lives meaning and purpose. Caregivers reported that when they are rested and have time to recharge, they are better able to meet their loved ones' needs.

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67% of respondents in an online survey of community members and stakeholders reported that their communities do not have enough **respite care services.**

Source: Community Services Input Study
Web Survey, 2013

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Only **19%** of case managers reported having adequate respite services available in their county. This is the second-least available service reported in surveys from across the state.

Source: DHS Waiver Review
Case Manager Survey, 2006 – 2012

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Focus group participants from all parts of the state shared that respite care services are especially needed for overnight care and on the weekends.

Some adults and children that need long-term supports have sleep disturbances; caring for them overnight results in sleep deprivation for the caregivers. Despite the great need for these particular services, providers at these times are rarely available.

Service gap: Mental Health Services

Greg's Story: Greg lives in a small town within a hub county. He was able to receive his regularly needed services as scheduled, but discussed what happened when special circumstances arose. "They didn't have a shrink, a psychiatrist in town here. I was going through a crisis at the time and they're telling me, 'Oh, you've got to wait a couple months'. That's when I said, 'the heck with that... I need to talk with someone now.' Greg was able to get himself to a slightly larger town about thirty miles away from home. He enjoyed the services that he received and started to continue services at that center. Unfortunately, he soon found out that his insurance wouldn't pay for the mileage needed to travel to his new provider, but would only pay for travel within his hometown. He was unable to afford the sixty-mile round-trip to get the services that he prefers, and could not receive those services closer to home. "[I]f the situation comes up again, where am I?"

The lack of mental health services is a major issue for rural and hub communities. Participants expressed frustrations about the limited access they have to both psychiatrists and psychologists. In some situations there are no mental health services available at all. In other situations, there may be one psychiatrist that a participant has access to while there are no psychologists or support groups within their geographic area. Other concerns are

not only about the limited number of psychiatrists and psychologists, but the difficulty in accessing someone to prescribe the necessary medication within a reasonable timeframe. County staff described a particular lack of specialist services for people on the autism spectrum including a lack of children's mental health supports such as behavioral health aides and therapeutic foster care. Participants from rural communities shared that they would like to see more education and awareness services for family members and loved ones of those affected with mental illnesses.

For parents of children with disabilities or mental health conditions, the lack of mental health and behavior support services were the biggest barriers to living the life they wanted to live. Parents of children with disabilities and children with mental health conditions in our focus groups were overwhelmed, sad, exhausted and frustrated. There were many examples shared of significant struggles due to not having enough mental health providers available. Especially in rural areas, it is particularly

difficult to recruit psychologists and psychiatrists, which has led to this service deficit. In areas without crisis services some people are forced to rely on police assistance when children need hospital services. Too often, if hospitals decide to admit the child, there are no beds available. Children can be taken to hospitals far from homes, sometimes even across state lines.

Many people make significant sacrifices in order to raise their children and access services, an emotional situation with great financial cost. One woman described how a lack of reliable, high-quality services led her to decide to stay home with her young child with autism, quitting her job and throwing the family into poverty. Although the family is eligible for in-home services, none of the providers have had the skills to deal with the child's behavioral and communication challenges. The stress and hopelessness of this caregiver, and many others, was palpable in the focus groups.

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Only 19% of case managers surveyed as a part of the DHS waiver program review reported that their counties have adequate **behavioral program services** to meet the mental health needs in their counties.

Source: DHS Waiver Review
Case Manager Survey, 2006 – 2012

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In addition to many regions not having enough mental health services, there is not enough adequate supportive, affordable housing for people with mental illness; accordingly, people are often times placed in regional treatment facilities, costly hospitals and crisis units. When people with mental illness have a legal incident, they often spend extended periods of time in jail and detention facilities or are released into homelessness because there is no appropriate combination of housing and services available. County personnel who were interviewed are especially challenged in trying to find housing for people with a disability or mental illness and who are convicted felons and/or convicted sex offenders. Without housing it is very difficult to get other supports or employment in place.

Participants from the rural communities in particular also shared their concern for the lack of crisis services. Considering that there is already a problem with the limited access to psychologists and psychiatrists, people with mental illnesses could be at a greater risk for experiencing a crisis. County staff shared that because crisis beds for children or adults with mental illness are unavailable; the only options to safely manage some situations require arrests or hospitalizations.

Service gap: Services to help people maintain their own homes

Bob's Story: Bob is an older gentleman living with his wife of 61 years, Marilyn. They are involved in their community and are happy that their children and grandchildren live within a few hours of them. They own a large beautiful home outside of a hub city in Northern Minnesota. Having grown up and stayed in the area his whole life, Bob reminisces about how much he loved maintaining his lawn

while his wife kept up the house. *"Up here...we were raised to be very independent. Therefore, we want to do things for ourselves as long as possible."* Now, with heart problems and multiple health concerns, he says it is too hard to maintain their home. Bob feels they have limited choice in their area; he notes that there are few housekeeping and chore service providers around, and their availability is limited with only about an hour to spend on their house. With such a big place, this is well under what they need. As a result, he and his wife are considering selling their house and moving somewhere with services. Yet Bob has a hard time reconciling the loss of independence and downsizing that would occur. *"You've got a large house and now move into a [senior housing] cracker box of 600 feet...No, it don't work. Therefore, what we live in is just slowly deteriorating. We're staying here until it just falls down."*

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54% of respondents in an online survey of community members and stakeholders reported that their communities do not have enough **chores services**.

Source: Source: Community Services Input Study Web Survey, 2013

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In focus groups, many older adults indicated a greater need for services to maintain their home, including chore services, major repairs, and homemaking. In particular, widowed older adults who used to rely on their spouse for these tasks expressed frustration at their own inability to do these things themselves. Other older adults shared

that they would love to do their own chores and home maintenance, however they simply cannot physically do it anymore. Part of the issue is the limitations from their aging bodies, and part of it is also the lack of skills and financial resources for larger home repair projects. Older people are often times unaware that there may be chore services available to them.

In focus groups, some younger individuals with disabilities expressed a similar need as well.

County staff across the state shared that there is a shortage of services to keep people in their own homes, such as chore, homemaking, home delivered meals, personal care attendants (PCAs), home

health aides, and skilled nurse visits. In some areas, there is one provider who offers these services. If a participant has a conflict with their provider, there may be no one left in the community to offer this service; counties spoke of this being a particular issue for participants with mental illness. Another concern is that providers may not serve rural, remote locations due to the relatively low reimbursement rates for these services and the fact that mileage and travel time is not reimbursed.

Counties Reporting a Service Gap in Chore Services is Rising

In the four Gaps Analysis Surveys conducted for the older adult population, chore services were either rated as the second or third most persistent gap by counties. County officials explained that this gap was directly tied to the low reimbursement rate for these services and therefore limits the incentive to develop service programs.
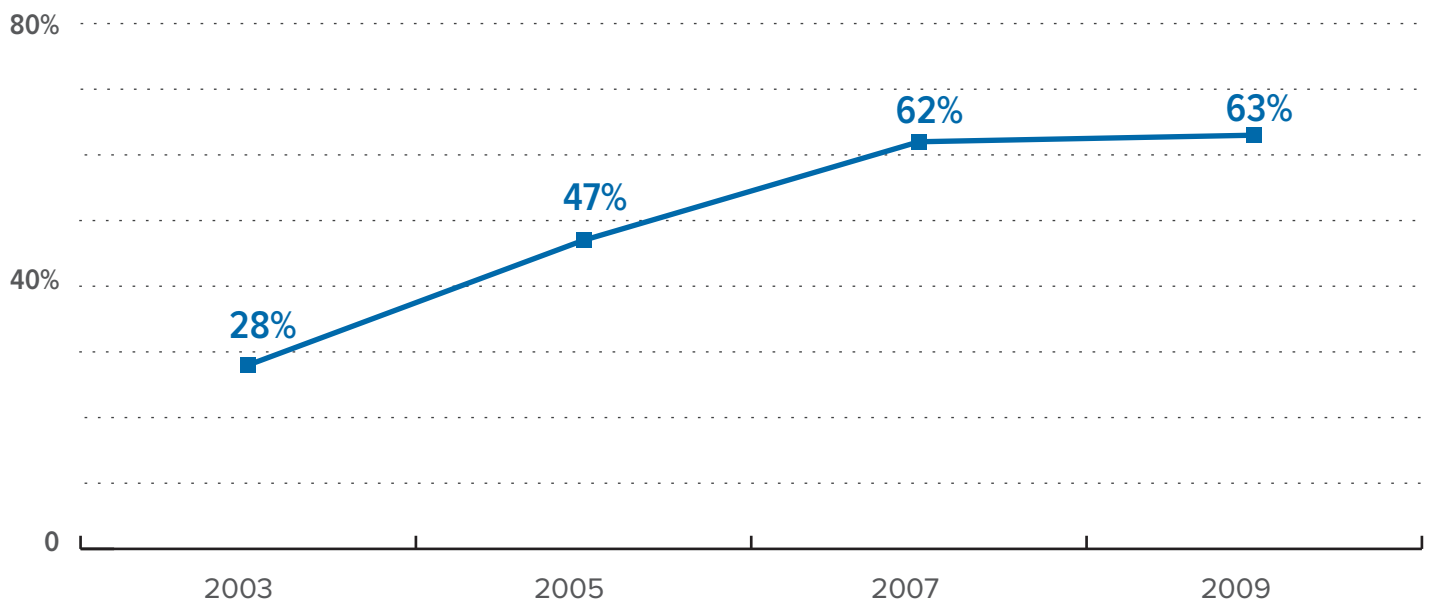
Source: 2009 County Long-Term Care Gaps Analysis Survey

Key Finding: Unless they are in a well-resourced community, people have difficulty getting the service they need in the community of their choice.

There are many communities in the state in which people are not getting their needs met. Rural communities are particularly under-resourced. Most frequently, people cited transportation, home-based services, and specialized services as being unavailable in the communities within which they want to live. A significant service gap that was cited in focus groups across the state involved services that could "check-in" with individuals in their own homes. Older people, people with disabilities, and caregivers alike shared examples where PCA or assisted living services were more intense than necessary, but where the individual was unable to live alone unassisted. County staff and other key interviewees attributed these gaps to the lack of density; when only a few people need a service, it is hard to make the economic model work for providers to offer the service.

A woman in Western Minnesota is preparing to return home to her husband and the grandson they are raising after a grand mal seizure and mental illness episode led to admission to a residential facility. The episode caused her to lose her job and driver's license. She does not know how she will be able to get the supports she needs upon return to her rural home, and she is worried about the financial and emotional challenges her husband is now facing. The future looks uncertain and frightening to her.

Key Finding: People are unable to get the support they need as their needs change, leading to earlier use of more restrictive services.

People reported that while people and their needs change, services and supports do not. Many people described a disconnect between health care and social services that makes this particularly challenging. Consider, for example:

- Many older adults described recovering in a nursing facility after being hospitalized from an illness or injury. As their health improves and they are ready to move back home, they do not get the supportive services they need to make a full recovery. Their illness recurs as they try to manage daily household responsibilities, and they end up back in the hospital or nursing facility.

- As young people with disabilities or a mental illness grow up and are ready to assume more independence, they have difficulty finding living situations that are supportive but not restrictive. Many need to piece together a few different services – such as employment support and independent living support – but have difficulty finding ones that are affordable, can be coordinated with each other, and that recognize that they will learn and have different needs as they master some aspects of independent life.

- For people with mental illness, there was widely held frustration with the fact that there is no flexibility to receive supportive services for a short time when needed to re-stabilize mental health. Frequently 90-day residential placements are used; while using residential services, people can lose their housing, employment, and longer term, less-intensive services. When their placement ends, there is an abrupt end to services, and they return to a much different setting without the housing and employment in place from before their residential placement. This can lead to recurrences of mental health needs.

In every population across the state, people expressed that better attention to transition and long-term health and well-being would benefit those in need of services and their caregivers, and would be more efficient for the broader system. With a more flexible set of available services, people could avoid disruptive, restrictive, disheartening events.
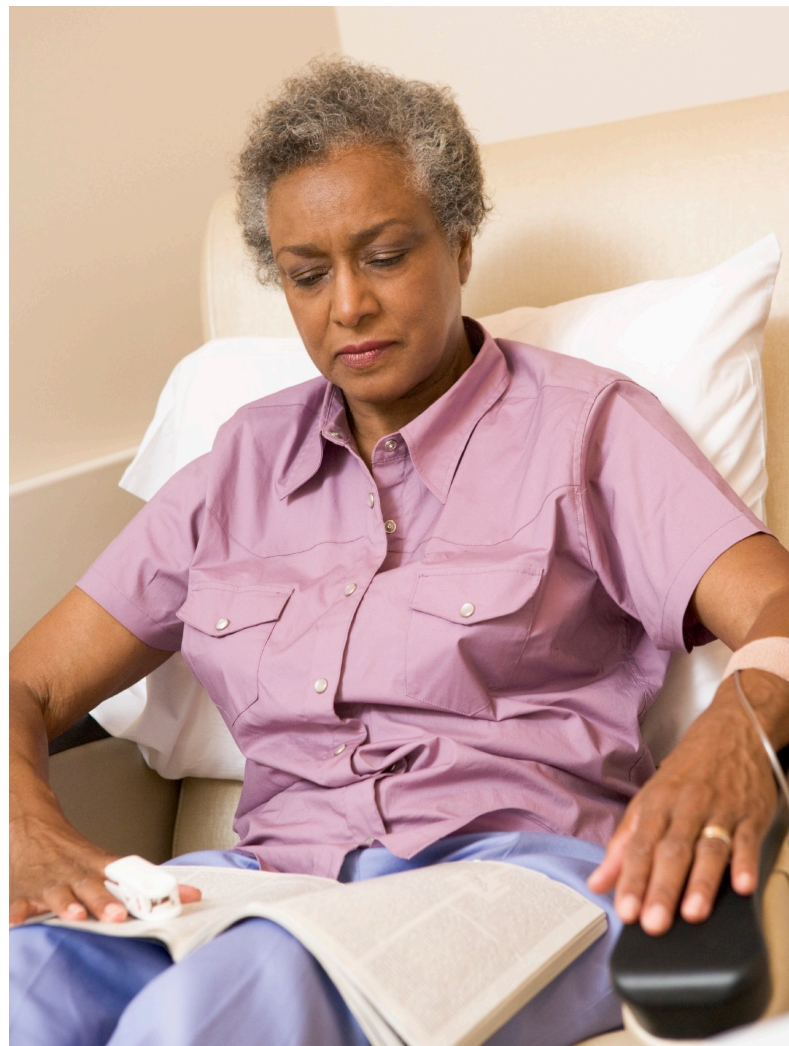
FACTORS THAT HINDER ACCESS TO SERVICES

When experts, advocates, and county personnel were asked about the factors that hinder access to services, they described interferences that fall within two broader categories: those caused by inefficiencies within the service system, and those that are caused by the policies which make services available. Within these two categories, several subthemes emerged under each and in most cases the subthemes paralleled what was discussed in focus groups.

System Barriers

Complexity of the system and its service provision process

Connie's Story: **Connie uses Consumer Directed Community Supports to direct her own services and supports through the waiver. She also participates in Medical Assistance for Employed Persons with Disabilities (MAEPD), which supports people with disabilities who work. Her eligibility is reviewed twice each year. For many years she had the same case manager in the county, and everything went smoothly. He understood her unique financial situation as a substitute teacher, that she makes money during school year, and does not make any money in summer. Her case manager was familiar with this situation and provided support as needed; everything ran very smoothly. Recently, Connie was assigned a new case manager and had a very different experience during this transition. Twice she was told that the county lost her paperwork.**

She described, *"It is a nightmare. It would sit in the supervisor's pile for so many days and you get wiped off the slate and lose services. Who needs that when you are already depressed and feeling powerless?"* **She worked with her new case manager to try to get her services restored. This case manager did not understand that weekly deposits into her bank account were the funding to pay for her services.** *"I get very frustrated. It did not matter who I talked to until I find the 'magical' person who has my file. It has been really, really exhausting."*

Commonly, key informants who were interviewed spoke of access problems caused by bureaucratic barriers and unintended consequences from the system design. Many process-related hurdles for accessing services were discussed; for example, several interviewees mentioned the amount of paperwork and bureaucracy as a major challenge in allowing them to serve participants efficiently. In focus groups held with people with disabilities, people with mental illness, older people, and caregivers, the same themes were echoed; participants expressed feeling exhausted by the amount of paperwork, or from filling out the same forms multiple times, or turning in completed forms and then not hearing back from service providers for months. In particular, participants receiving mental health services and benefits, where eligibility requirements are especially strict, shared that difficulties in staying on top of their paperwork and maintaining the necessary eligibility requirements can often become stressful barriers, and create situations where participants "fell through the cracks." Overall, the amount of "red tape" has led to frustration and confusion between service providers and participants.

A specific example of where care providers experience particular bureaucratic frustration was discussed as being when they first begin working with DHS. Due to current requirements it can take up to eight weeks for a new provider or employee to get a provider number from DHS. Once the new provider or new employee gets their provider number from DHS, if they are serving a participant on a managed care program, they must get yet another, different provider number from the health plan. This can delay the start of services, and makes it hard to match up providers with clients.

Complexities in understanding which program or provider covers which specific services make it challenging for service recipients to navigate the system and make decisions for themselves. For example, because managed care health plans have control over which providers they contract with, a provider may be covered on one health plan but not another. Each managed care health plan has its own contracts with providers, so when a participant switches health plans they may inadvertently be making a change in service providers. Unfortunately this can result in a beloved PCA no longer being able to serve the person because the new health plan does not contract with that particular PCA's agency, for example. Key informants spoke of other access problems due to managed care regulations, especially in border towns, where many Minnesotans travel across state lines to receive services. Some respondents shared that there is not enough monitoring or oversight of health plans' offerings from DHS.

County staff reported that these system complexities create barriers to providing the most integrated services because the system itself is increasingly more difficult for families to navigate in order to

> We at one time had a waivered slot for [our daughter], and we let it go. They always said that if you aren't using all the services, that it won't be as much money, that your fee will go down, or that they would reimburse you. But that wasn't true- yeah right. Never. We went from age 8 to 18 without services It was too much of a hassle. I think that is a huge issue.
>
> - Caregiver

receive their needed services. As one key informant expressed, "Figuring out the language on who is eligible can be difficult for families to understand." Advocates assert that it should be up to the individual person to decide what "most integrated services" means to him or her, and that with fewer complexities and a more easily navigable process, individuals would be able to make more informed decisions regarding their own care. The complexity of the system is further compounded by the second system barrier discussed by key informants: individuals lacking information about available resources.

Lack of knowledge about resources

During focus groups held with people with disabilities, people with mental illnesses, older people, and caregivers, participants consistently cited simply not knowing about which resources were available to them as being a major barrier to accessing services. On nearly every broad topic – from employment and volunteering, to housing,

transportation, and community involvement – participants from across the state said they would like more information about what is available and who is eligible. We observed participants exchanging information with each other when focus group members said that they had not been able to figure out a specific policy or service. This is due to a significant challenge participants reported: that they are unable to access clear, trustworthy information in any specific location.

Focus group participants described the DHS website as confusing and designed for practitioners or policy makers, not the general public. They want information to be presented in a way – either by DHS or by another party – that helps them understand which services are available, the eligibility requirements, and any new or best practices or innovative services. They suggested separating information based on the needs of specific individuals, such as having separate sections for people with mental illness, for example.

The lack of knowledge about resources was not limited to people using DHS services; interviews with key informants revealed that, at times, service providers are also unclear about service availability, service requirements and standards, and where to go for clear and dependable information. The challenges facing the service providers are bolstered by another major system barrier, which was the siloing of information across various departments at the county, state, and federal levels.

Lack of Communication across departments

There were many comments about the need to better facilitate work between departments, both at DHS and at the county level, and between state agencies in order to serve people more effectively and efficiently. Key informants talked specifically about how different counties read and interpret state regulations differently, which can lead to imposing more burdens on service recipients, for example. Additionally, one key informant explained that there is limited collaboration between service providers because "each service is afraid to incorporate or partner with another service. Nobody wants to lose their clientele… We are all a piece to the puzzle and everybody's piece is going to work in the puzzle in a different way." The lack of communication between DHS departments and state agencies makes a holistic approach to services especially challenging, as services are segmented between providers.

Transition Services

Barb's Story: **Barb is the parent of an 18 year old son with Down syndrome. They live in a hub community in Northern Minnesota. Barb has learned how to be a strong advocate for her son. While many things are going well, Barb worries about inclusivity and integration in the community as her son transitions into adulthood. The current job opportunities available for people with developmental disabilities in her community are mainly separate, sheltered workshops.** *"I think that the challenge is because we don't have options. Those places, I'm glad they're there, don't get me wrong, but ... they stay with the same types of activities. If you're eighteen and you go to the [work center] and you have the next forty or fifty years and nothing changes, that's not a quality of life in my view. All people can be employed and there's a plethora of opportunities, we just have to open our minds to it. We have to get better at authentic inclusion and not just because it feels good, but because it's the right thing to do."*

Many participants with disabilities shared their frustrations around transitioning to adulthood. As a person with a disability ages, they may "phase-out" of certain services that they were previously eligible for. For example, a child who was diagnosed with a disability and qualified for certain services may no longer have those services available to them once he or she reaches adulthood.

Focus group participants shared that it seems unfair that age defines a person's disability. Participants expressed their frustration with the hardship of staying on top of paperwork during the transition to adulthood, and that even one slip-up may lead to a temporary discontinuation of services. These transitions and changes frustrate people with disabilities and their caregivers because they occur in not only one, but in many systems (for example, in schools, medical services, and insurance eligibility), and the transitions become very disruptive to the lives of individuals and their families. Caregivers reported that their loved ones may be at greater risk for a crisis situation during these tenuous transition periods.

County staff shared that a good transition from school to employment depends largely on the school and their ability to prepare for the transition. Many schools struggle with transitioning students out of their programs, which ends up delaying the start of services beyond school once they need them. Parents and caregivers of transition-age children are often unaware of the services available to them. For example, several focus group participants spoke of their desire to attend post-secondary education, but caregivers and people with disabilities alike shared a lack of knowledge of what services are available to support young adults in this way.

Lack of investment in professional development and training for service providers

Focus group participants shared concerns about providers, such as PCAs, being under-paid and under-trained leading to poor quality and scarcity of services. In caregiver focus groups, participants cited being eligible for respite or PCA services, and truly needing them, but not using the services because the PCAs that were available to them were not skilled enough. Caregivers shared they felt that the skillsets of the PCAs were not high enough to meet the specific needs of their child or family members, and would prefer to provide the care themselves rather than utilize the under-qualified

PCA services. Furthermore, many parents reported that the only time they get a break from the difficult work of parenting their child is when their child is hospitalized. Low pay and insufficient training was also cited as leading to a high turnover rate for respite caregivers and PCAs, which adds additional challenges to participants, as staff turnover is destabilizing to the person receiving the service and their families.

Policy Barriers

Income limits keep people poor

Across focus groups with people with disabilities, people with mental illness, older people, and caregivers, participants commonly expressed frustration with the income limits for service availability, and how these policies impact multiple other areas of their lives. Essentially, focus groups participants described their experiences as "being kept poor". They recalled being forced to take lower paying jobs or work less or not at all in order to meet the eligibility requirements for the services they depend on; a dichotomy often arose between maintaining eligibility for services and pursuing employment opportunities.

Unfortunately, limiting employment also limits many of the other benefits that come from working, such as feelings of self-worth, additional feelings of independence, or having extra spending money to afford the products that they prefer. Limiting financial resources impacts other areas that are important to the well-being of participants; for example, multiple focus group members reported that because fresh produce and healthy foods are more expensive than less-healthy options, the income limits make healthy food unaffordable. While this was a problem

for many focus group participants, it was particularly problematic for people facing health problems like diabetes, food allergies, and those who hold strong environmental and justice values that they are not able to honor. Caregivers expressed that they are unable to afford low-cost support to help them maintain their own health, such as paying a friend or neighbor to come help provide short term relief. This forces them into using costlier services that are funded through their programs.

Focus group participants also explained that financial eligibility criteria were increasingly complicated to navigate. This was noted as being especially true because the limitations do not apply solely to income; rather, assets are included as well. This complicated things for one caregiver, who described the situation for her adult son and his girlfriend, both of whom receive medical assistance and disability insurance. She explained that they would like to save money for a house and lead a "normal" life, however, they believe they are not able to accumulate any assets or they would lose eligibility. Another focus group participant with a car needs to maintain her disability status in order to receive her services, but this makes her car insurance unaffordable, even though she has had no driving incidents. Her mobility, employment and education options are severely limited as a result. The income limits extend to multiple aspects of the lives of people receiving care, and frustration was expressed in focus groups held across the state.

Mismatch in funding and types of available services to meet needs

Focus group participants and key informant interviewees alike noted several specific cases where the services that are currently available do

not meet the needs of the participants. Overall, the services most commonly mentioned as being too limited or offered in the wrong way were mental health, housing, transportation and dental services. According to interviewees, too often the wrong things are funded and supported, which prevents the expansion and implementation of things that work.

A specific example of a service limitation due to funding that came up both in key informant interviews and focus groups was with in-home services. In this set of services, which includes homemaker and chore providers, PCAs and respite workers, the services themselves are funded, but transportation for the provider is not. The high cost of getting staff around makes it inefficient to provide in-home services in rural communities and, combined with the low-pay of these positions discussed previously, limits the quality of the workforce willing to take on the positions. Having these services available is often what allows people to stay independent and in their own homes; however, when transportation limits the service availability, people's ability to stay in their homes is limited as well.

A mismatch between what is available and what is needed can lead people to use more costly, intensive services than what is actually needed. Many people with mental illnesses and disabilities reported that they need occasional assistance and training to help change behaviors and remain independent. Because there is a lack of readily available behavioral support services, a small challenge can balloon into a much bigger problem, leading to institutionalization or residential placement. Early and more intentional intervention could have other long-lasting, positive benefits, too. For example, a few parents shared their heartache that their child had never been invited to a birthday party. They felt that with some behavioral support, their children would have been more included in their early years, leading to better chances of a full, rich life as they get older.

Living independently in adulthood is another example where services do not match actual needs. For example, people reported that they feel compelled to move into a residential placement, such as a group home or assisted living, because they cannot find the right mix of services to help them live independently. Supported housing options are very limited; people said that they need things like independent living skills training (such as how to cook meals or care for their home), homemaker and chore support, and companion care in order to stay in their own home. Both caregivers and people with disabilities said that if services were more flexible and if more affordable housing was available, they could live more independently and get the services they need in their choice of home. The need for these flexible services was stronger outside of metro areas, where choices were more limited.

RECOMMENDATIONS

The following recommendations are based on the insights of interviewees and focus group participants who are most impacted by the programs and systems being examined. The recommendations focus on presenting actionable strategies and opportunities to the three primary entities that influence the nature of long-term services and supports: State Government, lead agencies, and service providers.

Strengthen working relationships between the State, Counties and provider groups to find creative solutions to fill service gaps

It is important to note that in order to address the recommendations, these entities cannot work in isolation. A common theme identified by interviewees and focus group participants is that breaking down silos between the State Government, lead agencies, and service agencies aids in the creation of a better continuum of care. Increased collaboration and communication are crucial to accomplishing the types of improvements most desired by those receiving long-term services and supports across Minnesota. The need for collaboration is not limited to the most widespread challenges like transportation and employment; meeting the needs of a small number of people with extremely high needs also requires a combination of efforts, resources, and sharing of information across departments and agencies at the state and county levels.

While the recommendations provide general suggestions and serve as a guide for future planning, they rely heavily on the ability of each entity to recognize and understand their role in providing solutions to address the challenges facing those who receive, or want to access, long-term service and supports. The recommendations leave room for the lead agencies and service providers, in particular, to develop creative and innovative solutions to best fit the specific characteristics of their communities. Developing creative ways to increase access to and expand services that allow people to live more independently has the potential to improve efficiency and reduce costs associated with more restrictive settings.

However, lead agencies often do not have the resources (for example, time and funding) to work on service development in critical areas of need, and service providers may have little financial incentive to change existing service models. The State Government's role includes clearly communicating expectations for the types and models of services to be developed, and to provide incentive to do so. There is an inherent risk taken on by lead agencies and service providers by piloting creative programs and solutions that could result in unintended consequences for recipients of services; working cooperatively helps to maintain a safety net while working with the unknowns of new services like technology or alternative housing settings.

Increase transportation availability to people with disabilities and older adults

Transportation is a critical service which enables people with disabilities and older adults to live an independent life of their choosing. Participants articulated that having reliable and consistent transportation options allowed them to feel more independent, participate in activities they enjoy, provide respite for their caregiver, and stay healthy.

As many of these individuals did not have a vehicle, they relied on family and friends to provide rides, a potentially burdensome request that does not sufficiently address their long-term needs. No matter the community type, this study found that public transportation options were limited. Longer evening and weekend transportation hours would extend the flexibility of accessing needed services. Transportation in and around rural communities and to residences not on a bus line would further enable people with long-term service and support needs to take action and pursue the lives they envision for themselves.

Many programs exist at the state, regional and local levels that fund transportation services for older adults, people with disabilities and people with mental illnesses. The delivery of transportation services is a partnership across and between these entities and requires a significant amount of coordination to make the best use of existing resources. The following recommendations highlight priority areas for this work that were identified through this study.

→ **State Government should continue to work with lead agencies and service providers to find ways to help older adults and those with disabilities to arrange affordable and accessible transportation for non-medical purposes,** such as social outings, employment, volunteering, and errands. This is especially needed in rural and hub communities. One solution could involve giving service providers incentives to develop or expand transportation services. This could be accomplished by increasing funding partnerships from State Government to local communities for pilot programs aimed at increasing transportation for these populations. For example, regularly

scheduled transportation, such as a shuttle, would be appropriate in most cases and help people maintain a sense of independence and increase involvement in the community, thereby decreasing isolation. Existing successful models such as this one and others that rely on strong coordination of existing transportation resources should be disseminated to other communities around the state.

→ **Lead agencies should work to ensure there are adequate transportation options available.** Lead agencies should focus their efforts on coordinating volunteer transportation programs or other flexible community transportation options. Lead agencies often have the resources and capacity to develop and coordinate a county-based program. They are also able to identify specific transportation gaps, communicate the needs of participants to service providers, and partner with service providers to create alternative transportation options.

→ **All community partners should work together to increase the availability of transportation through increased coordination of existing resources.** For example, local partners should work to expand transportation routes and hours of availability wherever possible to allow older adults and people with disabilities to live more inclusively and independently. This change would have the most impact in rural areas, hub communities, and Duluth. People would benefit from additional routes and hours, even if they are offered on a limited basis (e.g., services available 1 to 2 nights per week.) When developing or enhancing transportation services, agencies should also focus on adding shelters and lighting, clearing snow and ice more quickly, and accessibility to increase safety and access.

Efforts should be made to develop and expand employment and volunteer services and address discrimination that people with long-term services and supports needs face.

Many focus group participants expressed a deep desire for meaningful employment and volunteer opportunities. Employment and volunteering are seen as much more than a source of income; for many participants, working and volunteering are key to experiencing greater independence, increased community participation, and decreased isolation, and are a way to share skills and talents with the community. Working or volunteering also led to personal benefits among some people with disabilities by increasing their social skills. This type of interaction with others then decreased other support service needs like social coaches or personal assistants. In many cases, the earnings from these jobs go towards supplementing the expensive services that they need. Furthermore, this type of engagement in the community is not just about the participants themselves, but also about educating others on the strengths and limitations of those with disabilities and/or mental illness. The integration of people who need long-term services and supports into mainstream societal interactions fosters greater awareness and may diminish the existing stigmas and discrimination attached to these groups. Removing barriers to employment and volunteering for people with disabilities, people with mental illness, and people who are older is critical to ensuring that all Minnesotans are able to be productive and contributing members of society.

> If you can't find a job, you can't have self-worth. Give people a chance to do their best. We want to be independent like anyone else. Just give us an opportunity.
>
> - Participant with a disability

→ **State Government should work to communicate the value of authentic and meaningful employment and volunteering opportunities for older adults, people with disabilities, and people with mental illness to lead agencies and service providers.** The current model for employment is shifting away from the traditional day training and habilitation, or sheltered workshop, models in favor of a more individualized model of matching people's strengths and interests with appropriate employment and volunteer opportunities in the community. The State Government not only plays a key role in education, but also in providing resources to assist local governments and service providers in developing the types of services and opportunities which support the changing model.

→ **Lead agencies should actively work with service providers and local businesses to develop more full and part-time employment opportunities for people with disabilities or mental illness, especially in small towns and hub communities.** This includes creating a broader and more flexible range of services to support people with disabilities or mental illness in obtaining and keeping a job (for example, job coaching). As part of their efforts, lead agencies should inform potential employers about the

benefits of employing persons with disabilities and mental illness, and explain the supports that are available to assist them. Working closely with local businesses and providing guidance and resources may incent employers to take a chance and create flexible, supportive employment opportunities. It is particularly important to focus on working with providers to develop employment supports for the emerging transition age population (ages 16 to 21). This includes recognizing that the ongoing need for support is often about help with the soft skills, including positive behavioral supports, in addition to technical skills.

→ **Lead agencies can also act as a clearinghouse of volunteering opportunities and provide support for volunteer coordination** to make it easier for organizations to welcome and utilize volunteers to make meaningful contributions. Many schools, government agencies, and non-profits have volunteering opportunities available but need assistance with management and coordination. These efforts can build on the success of the Lieutenant Governor's Senior One Stop Shop that offers older adults one number to call to connect with volunteer opportunities in their local communities.

→ **The State Government, lead agencies, and service providers all play a part in finding ways to address prevailing attitudes that older adults, people with mental illness, and people with disabilities face.** There is a need to acknowledge and communicate the negative effects of the view of these people as "less than full citizens" and the segregation that, for many, began in school. Creating more awareness and education about these topics as well as the ongoing presence of these populations in the community

through employment and volunteering has the potential to mitigate stereotyping and discrimination they often experience.

Reduce barriers to self-directed choice in services, and find practical ways to include people in their service planning process

Focus group participants, interviewees, and other respondents commented overwhelmingly on the desire for self-directed, person-centered services. Threaded throughout the focus groups was the sense of empowerment and success that comes with making decisions about funding and services to best meet one's own needs when options were available. They would like to see these as the rule rather than the exception. However service gaps and rigid policy or program requirements often leave individuals with limited or no choices in services and providers. Many people who would like to direct their own services face barriers in doing so as some creative solutions to accomplish this goal may include using services not covered in the current funding structure. People experienced limitations with current consumer-directed programs that prevent them from engaging their support system to provide services.   Additional financial and service efficiencies could be realized by allowing people who need long-term services and supports or their caregivers more flexibility in using their budget

→ **The State Government should continue its work to increase the person-centeredness of the long-term services and supports system,** thereby satisfying the strong desire for autonomy expressed by participants and advocates. This includes closely examining the infrastructure at the state and county level including leadership and management structures, work processes,

underlying data systems, and measurement of results. In addition to recognizing gaps in services and access, understanding how these systems impact the ways in which older adults, people with mental illness, and people with disabilities are served can help the State better design initiatives and interventions to minimize or remove barriers to self-directed care and choice in services. MNChoices will be a tool available as part of the person-centered planning process.

→ **The State Government should look for opportunities to increase person-centered planning that could result in cost-savings while improving effectiveness.** This could be accomplished through occasional case studies or the establishment of a regular feedback loop. Some examples of questions that could be beneficial to answer include "Why can't family support be combined with PCA services?" and "Why can't locks be purchased as a one-time purchase?" Develop a continuum of person-centered planning; begin with informal supports requiring no public funds, with options to bring in formal supports as needed to supplement.

→ **Lead agencies should also consider strategies for communicating the expectation and priority of allowing people to live in their own home to providers and other agencies.** In addition, it is important for lead agencies to provide suggestions for how providers and other agencies can support this goal through informal supports or lower cost services. For example, support providers in using person-centered, flexible approaches to service delivery. This will allow people to continue to leverage informal supports and remain in their homes.

→ **Lead agencies should focus on taking specific steps to shift from a provider-driven system to one focused on offering real choices to people with disabilities.** They should consider ways to gather participant input more regularly and develop ways to incorporate this feedback into their plan of care. This may include using a personal futures planning process, a more person-centered approach than the traditional individual plan. One idea shared was the use of a "micro-board," a small group of people in key relationships with a vulnerable service recipient who assist with decisions about services and how funds are spent.

Enhance systems to communicate about resources available and to help people navigate the complexity of programs.

Programs that help connect people with long-term services and supports are extremely complex. Difficulty in accessing information and failure to communicate effectively at multiple levels makes it challenging for people to connect people with the services they need. While case managers fill that role for many people with disabilities, people with mental illness and older adults, this is not universally true. Participants and their caregivers also spoke of a need to help navigate program requirements and keep on top of the program changes that impact their services. Resources that are currently available including the DHS website and many of DHS' written resources are difficult to understand and navigate for people with disabilities, mental illness, older adults, and their families. Additionally, many focus group participants were unaware of services that were available to them. Efforts in this area should, in part, build on the success realized thus far by the Senior LinkAge Line® and Disability Linkage Line, which

were mentioned positively by interviewees and focus group participants in this study.

→ **The State Government should enhance the way information is made available to the public to make it more intuitive and user-friendly.** Strategies to accomplish this include simplifying and streamlining language wherever possible and creating easily accessed tools to guide people through the process of obtaining and maintaining long-term services and supports (for example, policies, lists of services available, checklists).

→ **The State Government should also focus on creating clear pathways to web-based resources and phone support, especially for people with mental illness.** For people with mental illness in particular, this may mean having a distinct mental illness section on the DHS website as well as on county human services websites. The state plays a role in developing this content, and standardizing the information so counties are able to share consistent and accurate information via their websites. It could also include having a separate phone number for a mental illness linkage line, even if it still leads to the Disability Linkage Line.

→ **Lead agencies need to work with service providers and other community organizations to create awareness about available supports and services and also provide more assistance to individuals seeking services.** Currently the most integrated settings are available for those who are knowledgeable, savvy, and have the resources to do so; others require additional, individualized assistance to access needed services. For example, many caregivers need family supports in order to maintain the

independence of the person they care for, but often don't know where to start. Strategies should focus on finding ways to help connect caregivers, older adults, people with disabilities, and people with mental illness with existing services. For counties and managed care organizations, this may mean adding more case management services, but the additional cost taken on should be considered an investment as it is likely to pay off by allowing more people to live inclusively in their communities and avoid more costly placements and services. In addition, more people who otherwise would not be reached can be made aware of preventative services to help them to stay in their own home longer.

Increase resources devoted to services that are both cost-effective and support the independence of people with long-term service and support needs.

Interviewees and focus group participants alike spoke positively of in-home services and supports as being the most flexible and effective ways to help people live independently. Most of the services mentioned that help keep people independent are also less restrictive and more affordable than residential placement. However, many of these types of services that help people remain independent in their own homes and communities are not available due to low reimbursement rates or financial eligibility requirements. The allowance of some smaller, less intensive preventative services, could delay the need for more restrictive, disruptive, and costly services down the road.

→ **Lead agencies should continue to work with service providers to develop options for affordable, accessible housing.** Supported independent living skills programs should be expanded and made available across housing settings. These types of alternative housing arrangements give people with disabilities and mental illness who need minimal supports the option of living in their own place. It is important to increase the availability of these types of housing settings and programs as the emerging transition-age population with disabilities will be looking to move out of their parents' homes. These young adults may want to live in an apartment, possibly with a roommate or two, in the same manner as their non-disabled peers. The addition of more affordable housing options could allow people currently residing in group homes or other residential housing situations to move into a more independent setting.

→ **State and lead agencies should continue to work with service providers to increase the availability of in-home services for all populations and income levels.** Increasing the rate caps for in-home services, including chore, homemaking, home delivered meals, personal care attendants (PCAs), and home health aides, would promote the independence and lifestyle that people who need long-term services and supports seek while also offering a greater variety of choices. Reimbursing respite care providers at a higher rate, for both in-home and out-of-home services; and providing more training would help attract and retain a more highly skilled workforce.

Additionally, increased availability of in-home services, including respite care, can prevent the need for costlier services and out-of-home placement.

→ **In terms of eligibility for services, develop pathways for intervening when the needs are still small.** These should be strength-based, person-centered and self-directed. For people with mental illness, this might include behavioral supports or learning independent living skills to help maintain current housing or employment. For people with disabilities and older adults, these options include chore, homemaker services, home delivered meals, and senior companion services. People with disabilities or older adults could get some basic services more immediately, and in some cases, at lower rates through personal connections.

APPENDIX A: DATA COLLECTION INSTRUMENTS

Focus Group Protocol for Participants

Pre-Focus Group Activities

- Registration

- Food

- Ice-breaker question — "What sign of spring are you most looking forward to?"

- Give an introduction and explanation of what a focus group is and things the facilitator might do to make sure all voices are heard and a respectful climate is maintained. Share norms you have posted. Introduce the note taker.

Introduction

Hi, my name is [moderator's name]. I am a [title] for The Improve Group, a private research group from Saint Paul, which has been contracted by the Minnesota Department of Human Services (DHS) to conduct the Long-Term Services and Supports Community Input Project. Though this project, we are seeking input from community members with disabilities, people with mental illness, people over age 65, as well as caregivers, parents, and families. We want to hear about your experiences and needs with long-term services and supports. The questions we have for you today are:

- What services and supports do you need the most?

- Are you able to choose the long term services and supports that meet your needs and preferences, including being served near your family or loved ones and in the setting you choose?

- What challenges have you faced in accessing long term services and supports and mental health services?

The legislature requested this information and has provided funding for this project. We are hosting focus groups like this one in 18 different communities around Minnesota. We are also gathering information through interviews with advocacy and provider organizations, government advisory councils, and an online discussion board and survey.

Consent Language

The information you share with me today will help us gain valuable insights about the status of long term services and supports and mental health services in your community. The information you share is important and will help inform our report to the legislature. It will be used to look at what services need to be developed or other changes would help people get the right service at the right time. However, we cannot predict what changes will be made as a result of this process.

Attending this focus group today is completely voluntary. You don't need to answer any questions you don't want to or share any personal information unless you choose to. If you decide you want to leave you are free to do so without giving any reason. You will not lose any benefits and participating today has no effect on any current services you're receiving.

We have confidentiality and data privacy practices in place to protect the information you share. All of the comments today will be summarized in our report so individual comments cannot be identified. We'd like to tape the focus group to help with our analysis and make sure we don't miss anything important. Only myself and other Improve Group staff working on the project will have access to the tape, and it will be destroyed after the project is completed. Is everyone comfortable with me taping the focus group? [if anyone not comfortable, do not tape]

If you have any additional questions concerning this evaluation or your participation, please feel free to contact me or DHS staff at any time. [Have business cards/contact info accessible].

Do you have any questions before we begin?

Our focus group will last about an hour – we will be done by [time].

Focus Group Questions

Image Grouping Activity

Directions for Activity

We are going to do an activity to reflect on different areas of life that are important to many people, such as your health, relationships, independence, community membership, and employment/volunteering/school.

We will be creating a picture of how these areas of your life are going right now, then following up with some discussion questions.

No two people are alike and we are interested in each of your individual experiences. There are no right or wrong answers.

We have several picture stickers for you to choose from for each area. For each life area, we'd like you to choose at least one sticker, but feel free to choose more than one if you'd like to.

We will go through each picture sticker individually and explain what it means. At that time, we ask that each of you individually put the image on your large piece of paper indicating how you feel this area is going right now in your life. The line on the page represents a scale, or continuum. Areas of your life you feel are going great should be placed towards the top. Areas of your life you feel are going badly should be placed at the very bottom. Areas of your life you feel are going ok should be placed near the middle. There are no right or wrong answers; we want you to be honest about your own experiences. Feel free to ask us questions as you are going through this activity. Again, just make sure you think about your own life right now as you complete the activity

Let's get started!

Notetaker - hand out images and scales. They are in order – ask participants to just look at/take out one sheet at a time

Community Membership

1. These images (holding them up for the group) represent [**Community membership**]. **This includes things like [feeling included as a part of the community and able to participate as you choose]. Please pick at least one of these images and place it on the scale indicating how you feel it is going for you.**

Health, Wellness, and Safety

2. These images (holding them up for the group) represent [**Health, wellness, and safety**]. **This includes things like [having access to healthy food and opportunities to exercise, having good health care, feeling safe in your community, and feeling you have support for your mental and emotional health]. Please pick at least one of these images and place it on the scale indicating how you feel it is going for you.**

Independence

1. These images (holding them up for the group) represent [Independence]. For some people, this includes things like [being able to choose where to live and choose services and supports that are right you. It also includes things like having the transportation you need, being able to go places when you choose, and being able to do things you want to do when you decide.] Please pick at least one of these images and place it on the scale indicating how you feel it is going for you.

Relationships

3. These images (holding them up for the group) represent [**Relationships**]. **This includes things like [feeling you have a connection to other important people in your life. This could be family, friends, neighbors, co-worker, other community members, or anyone else who is important in your life]. Please pick at least one of these images and place it on the scale indicating how you feel it is going for you.**

Employment, volunteering, and school

4. These images (holding them up for the group) represent [**Employment, Volunteering, and School**]. **This includes things like [being able to receive the supports and services you need to work or pursue educational opportunities in order to live independently]. Please pick at least one of these images and place it on the scale indicating how you feel it is going for you.**

Now that you all have you pictures placed on your paper, circle the **top 3** pictures that you would most like to change or get better in your life. You may have more than three areas but we'd like you to pick the three you feel **most strongly you'd like to change or get better right now in your life.**

[Give time for participants to circle pictures]

Great, now let's talk a little bit about where you put the pictures and why you circled the pictures that you did.

1. What areas of your life (pictures) are going well/are the best right now (top of the paper)?

    a. Why are these areas so great?

    b. What helps make these areas good?

2. Right now, what areas of your life do you most want to change or get better (circled pictures)?

    a. What challenges are there to these getting better?

    b. What needs to change for these areas to improve?[prompt] Are there services or supports you need to help improve these areas of your life?

    c. Imagine what your life would be like if all of these pictures were at the top of the page – you feeling that all of these areas of life are going great. How would your life be different than it is today? What would your life look like?

    d. What needs to change in order for you to live the life you want?

3. Are you able to choose the right services and supports for you?

    a. For example, choice in:

        i. Providers available, who respect your values and culture, can choose provider you want.

        ii. Are able to live where you want to live (both location – St. Paul for example, and setting – home of their own for example).

        iii. Have you been offered help to help in getting work/someone supporting you in employment.

4. Are you able to receive support near your family or where you choose?

5. What challenges have you faced in accessing long term services and supports and mental health services?

Thank you for taking the time to talk with me today. If you want to give additional feedback or share something anonymously, there is information available about how to participate in our online discussion board and survey. If you have any questions or additional comments, feel free to contact me by phone or email [leave business card].

Focus Group Protocol for Caregivers, Parents and Families

Pre-Focus Group Activities

- Registration

- Food

- Ice-breaker question – "What sign of spring are you most looking forward to?"

- Give an introduction and explanation of what a focus group is and things the facilitator might do to make sure all voices are heard and a respectful climate is maintained. Share norms you have posted. Introduce the note taker.

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Hi, my name is [moderator's name]. I am a [title] for The Improve Group, a private research group from Saint Paul, which has been contracted by the Minnesota Department of Human Services (DHS) to conduct the Long-Term Services and Supports Community Input Project. Though this project, we are seeking input from community members with disabilities, people over age 65, as well as caregivers, parents, and families. We want to hear about your experiences and needs with long-term services and supports. The questions we have for you today are:

- What services and supports does the person you support need the most?

- Is the person you support able to choose the right long term services to meet their needs and preferences, including being served near family or loved ones and in the setting they choose?

- What challenges has the person you support faced in accessing long term services and supports and mental health services?

The legislature requested this information and has provided funding for this project. We are hosting focus groups like this one in 18 different communities around Minnesota. We are also gathering information through interviews with advocacy and provider organizations, government advisory councils, and an online discussion board and survey.

Consent Language

The information you share with me today will help us gain valuable insights about the status of long term services and supports and mental health services in your community. The information you share is important and will help inform our report to the legislature. It will be used to look at what services need to be developed or other changes would help people get the right service at the right time. However, we cannot predict what changes will be made as a result of this process.

Attending this focus group today is completely voluntary. You don't need to answer any questions you don't want to or share any personal information unless you choose to. If you decide you want to leave you are free to do so without giving any reason. You will not lose any benefits and participating today has no effect on any current services you're receiving.

We have confidentiality and data privacy practices in place to protect the information you share. All of the comments today will be summarized in our report so individual comments cannot be identified. We'd like to tape the focus group to help with our analysis and make sure we don't miss anything important. Only myself and other Improve Group staff working on the project will have access to the tape, and it will be destroyed after the project is completed. Is everyone comfortable with me taping the focus group? [if anyone not comfortable, do not tape]

If you have any additional questions concerning this evaluation or your participation, please feel free to contact me or DHS staff at any time. [Have business cards/contact info accessible].

Do you have any questions before we begin?

Our focus group will last about an hour – we will be done by [time].

Focus Group Questions

Image Grouping Activity

Directions for Activity

We are going to do an activity to reflect on different areas of life that are important to many people, such as health, relationships, independence, community membership, and employment/ volunteering/school.

We will be creating a picture of how these areas are going right now in the life of the person you are supporting, then following up with some discussion questions.

No two people are alike and we are interested in each of your individual experiences. There are no right or wrong answers.

We have several picture stickers for you to choose from for each area. For each life area, we'd like you to choose at least one sticker, but feel free to choose more than one if you'd like to.

We will go through each picture sticker individually and explain what it means. At that time, we ask that each of you individually put the image on your large piece of paper indicating how you feel this area is going **right now** in the life of the person you are supporting. The line on the page represents a scale, or continuum. Areas of their life you feel are going great should be placed towards the top. Areas of their life you feel are going badly should be placed at the very bottom. Areas of their life you feel are going ok should be placed near the middle. There are no right or wrong answers; we want you to be honest about your own experiences. Feel free to ask us questions as you are going through this activity. Again, just make sure you think about the life of the person you are supporting right now as you complete the activity

Let's get started!

Notetaker - hand out images and scales. They are in order – ask participants to just look at/take out one sheet at a time

Community Membership

1. These images (holding them up for the group) represent [**Community membership**]. This includes things like [**feeling included as a part of the community and able to participate as you choose**]. Please pick at least one of these images and place it on the scale indicating how you feel it is going for the person you support.

Health, Wellness, and Safety

2. These images (holding them up for the group) represent [**Health, wellness, and safety**]. This includes things like [**having access to healthy food and opportunities to exercise, having good health care, feeling safe in your community, and feeling you have support for your mental and emotional health**]. Please pick at least one of these images and place it on the scale indicating how you feel it is going for the person you support.

Independence

3. These images (holding them up for the group) represent [**Independence**]. For some people, this includes things like [**being able to choose where to live and choose services and supports that are right you. It also includes things like having the transportation you need, being able to go places when you choose, and being able to do things you want to do when you decide.**] Please pick at least one of these images and place it on the scale indicating how you feel it is going for the person you support.

Relationships

4. These images (holding them up for the group) represent [**Relationships**]. This includes things like [**feeling you have a connection to other important people in your life. This could be family, friends, neighbors, co-worker, other community members, or anyone else who is important in your life**]. Please pick at least one of these images and place it on the scale indicating how you feel it is going for the person you support.

Employment, volunteering, and school

5. These images (holding them up for the group) represent [**Employment, Volunteering, and School**]. This includes things like [**being able to receive the supports and services you need to work or pursue educational opportunities in order to live independently**]. Please pick at least one of these images and place it on the scale indicating how you feel it is going for the person you support.

Now that you all have you pictures placed on your paper, circle the **top 3** pictures that you would most like to change or get better in the life of the person you are supporting. There may be more than three areas but we'd like you to pick the three you feel **most strongly you'd like to change or get better right now in the life of the person you are supporting.**

[Give time for participants to circle pictures]

Great, now let's talk a little bit about where you put the pictures and why you circled the pictures that you did.

6. What areas of their life (pictures) are going well/are the best right now (top of the paper)?

   a. Why are these areas so great?

   b. What helps make these areas good?

7. Right now, what areas of their life do you most want to change or get better (circled pictures)?

   a. What challenges are there to these getting better?

   b. What needs to change for these areas to improve?[prompt] Are there services or supports they *(and you/your family)* need to help improve these areas of their life?

   c. Imagine what their life would be like if all of these pictures were at the top of the page –feeling that all of these areas of life are going great. How would their life *(and yours/your family's)* be different than it is today? What would their *(and your life/your family's life)* look like?

   d. What needs to change in order for the person you are supporting to live the life they want?

Additional Questions

8. Is the person you support able to choose the right services and supports to meet their needs and preferences?

   a. For example, Choice in :

      i. Providers available, who respect their values and culture, can choose provider they want.

      ii. Are able to live where you want to live (both location – St. Paul for example, and setting – home of their own for example).

      iii. Opportunities for school, work or volunteering

9. Are they able to receive support near their family or where they choose?

10. What challenges have they faced in accessing long term services and supports and mental health services? (Awkward b/c it is the parent accessing the services for the child. Adjust as you see fit.)

11. How do you take care of yourself while supporting someone else?

    a. What have you found to be helpful?

    b. What resources are needed in order to ensure you are able to take care of your own needs?

Thank you for taking the time to talk with me today. If you want to give additional feedback or share something anonymously, there is information available about how to participate in our online discussion board and survey. If you have any questions or additional comments, feel free to contact me by phone or email [leave business card].

GREAT!

BAD

Image Grouping

Community Membership

Health and Wellness

Community Membership

Health and Wellness

Community Membership

Health and Wellness

Image Grouping

Relationships

Employment, volunteering, school

Relationships

Employment, volunteering, school

Relationships

Employment, volunteering, school

Image Grouping

Independence

Independence

Independence

Interview Protocol for County and Tribal Staff

Introduction

Hi, my name is [moderator's name]. I work with The Improve Group, a private research group from Saint Paul, which has been contracted by the Minnesota Department of Human Services (DHS) to conduct the Long-Term Services and Supports Community Input Project.

We shared some information with you when scheduling, and here is a handout about the project. What questions do you have about the project?

Consent Language

The information you share with me today will help us gain valuable insights about the status of long-term services and supports and mental health services in your community.

This interview will take about **90 minutes.**

Your participation is voluntary; you can decline to answer any questions or stop taking part at any time without giving any reason, without penalty. The input you provide is important, and will be taken into account, but we cannot predict what, if any changes will happen, as a result.

We have confidentiality and data privacy practices in place to protect the information you share. All of the comments you share today will be summarized when reporting and individual comments will not be identified.

Participating in the interview and responding to the questions I ask means you consent to participate in the evaluation. If you have any additional questions concerning this evaluation or your participation, please feel free to contact me or DHS staff at any time. [contact info on handout].

Do you have any questions?

NOTE: these questions refer to all people who need services, whether they have a physical or developmental disability, mental illness or are aging.

Interview Questions

1. Name one service area that you think your community does exceptionally well. Why is this so great in your community?

2. Next, I would like to talk about a few different areas in people's lives and the degree to which these areas are being addressed by current services.

For each area, I would like you to let me know if for individuals in your community: all of their needs are being met, some of their needs are being met, none of their needs are being met, or if you are unsure of the degree their needs are being met. Then, we will discuss why you gave each area the rating you did.

    a.   Community participation, inclusion or integration in the community

    b.   Health and well-being, including physical and emotional and mental health

    c.   Living an independent, satisfying life with choice and control

    d.   Social relationships

    e.   Employment, volunteering, and school

Prompts for each area:

- In what ways are needs being met in this area?
- What could be done to improve needs being met in this area?

3. Based on data that has already been gathered through the gaps analysis and by the Waiver Review project, service gaps existing in your community have been identified as [list identified gaps]. What would you want to draw our attention to in terms of the gaps or surpluses in your community?

Prompts*:*

- Are these the service gaps you see existing in your community?
- Have the gaps in services changed?
- Are there gaps that you see in your community that are missing from the list?
- What do feel are the most important services gaps that need to be addressed?

    a.   Looking at this list of identified gaps in services, what are some of the reasons these gaps exist in your community?

4. Next, I would like to talk about what **helps or hinders** access to services, particularly those services that are the least restrictive or most integrated and which **factors are the most important to ensure availability** of these services.

a. What are the challenges that your population faces in accessing services?

b. To what extent are the least restrictive or most integrated services available to the people who want them? What factors prevent people from receiving services in their preferred, least-restrictive settings and communities?

c. What are the barriers to providing those services? Have new barriers or opportunities emerged?

d. Are complementary services or packages of services needed in order to increase use of less restrictive or more integrated services (For example, chore and shopping, or employment support and housing with services)?

e. As people's needs change, what helps or hinders them from getting services in your community? Are there different ways in which these same needs could be met? (I.e., different mixes of services, different types of providers, self-directed services)

5. What would have to happen or change in order for more people to get their needs met in their community and avoid nursing home care and rehospitalization?

6. Many things influence the type, quality and number of services that are available. If you could change one thing, what would it be?

7. Are there any other insights you would like to share with me about the availability of people's choice in long-term services and supports in your community or about the challenges people face in accessing long-term care and mental health services?

Thank you for taking the time to talk with me today. If you have any questions or additional comments, feel free to contact me by phone or email [contact info is on the handout].

Interview Protocol for Service Providers, Advocacy Organizations, Regional Support & Development Organizations, and Legislators

Introduction

Hi, my name is [moderator's name]. I work with The Improve Group, a private research group from Saint Paul, which has been contracted by the Minnesota Department of Human Services (DHS) to conduct the Long-Term Services and Supports Community Input Project.

We shared some information with you when scheduling, and sent information about the project. What questions do you have about the project?

Consent Language

The information you share with me today will help us gain valuable insights about the status of long-term services and supports and mental health services in your community.

This interview will take about 30 minutes.

Your participation is voluntary; you can decline to answer any questions or stop taking part at any time without giving any reason, without penalty. The input you provide is important, and will be taken into account, but we cannot predict what, if any changes will happen, as a result.

We have confidentiality and data privacy practices in place to protect the information you share. All of the comments you share today will be summarized when reporting and individual comments will not be identified.

Participating in the interview and responding to the questions I ask means you consent to participate in the evaluation. If you have any additional questions concerning this evaluation or your participation, please feel free to contact me or DHS staff at any time. [Contact information on project description]

Do you have any questions?

NOTE: these questions refer to all people who need services, whether they have a physical or developmental disability, mental illness or are aging.

We have three main questions that we'll want to get to [that are highlighted below]. We also have some follow-up questions if we have time.

Interview Questions

1. First, could you briefly tell me about the service you provide?

   a. Who do you serve? / Who are your constituents?

2. Next, I would like to talk about what **helps or hinders access to services**, particularly those services that are the least restrictive or most integrated and which **factors are the most important to ensure availability** of these services.

   a. What are the challenges individuals face in accessing services?

   b. Which services are most difficult to access?

   c. What are the barriers to providing the least restrictive/most integrated services?

   d. To what extent are least restrictive/most integrated services available to the people who want them?

   e. What has changed related to providing services in recent years? Have new barriers or opportunities emerged?

   f. Are complementary services/packages of services needed in order to increase use of less restrictive/more integrated services (idea: chore and shopping)

   g. What needs are being met by current service mixes?

   h. As people's needs change, what helps or hinders you from serving them? Are there different ways in which these same needs could be met? (I.e., different mixes of services, different types of providers, self-directed services)

3. What would have to happen or change in order for more people to get their needs met in their community and avoid nursing home care?

4. Many things influence the type, quality and number of services that are available. If you could change one thing, what would it be?

5. What services gaps exist?

   a. Why do these service gaps exist in your community?

   b. What factors are barriers to these services being provided?

6. Do you serve multiple communities? If so, what variations have you noticed in different communities?

7. Next, I would like to talk about a few different areas in people's lives and the degree to which these areas are being addressed by current services?

For each area, I would like you to let me know if for individuals in your community: all of their needs are being met, some of their needs are being met, none of their needs are being met, or if you are unsure of the degree their needs are being met. Then, we will discuss why you gave each area the rating you did.

   a. Community participation, inclusion or integration in the community

   b. Health and well-being, including physical and emotional and mental health

   c. Living an independent, satisfying life with choice and control

   d. Social relationships

   e. Employment, volunteering, and school

Prompts for each area:

   • Any barriers to these domains? Are any better addressed than others? In what ways?

   • In what ways are needs being met in this area?

   • What could be done to improve?

8. Are there any other insights you would like to share with me about availability of people's choice in long-term services and supports in your community or about the challenges people face in accessing long-term services and supports and mental health services?

Thank you for taking the time to talk with me today. If you have any questions or additional comments, feel free to contact me by phone or email [on the project description].

INSTRUCTIONS: If you prefer to complete the survey on paper, please fill it out and either have someone enter the information for you are www.mnservicestory.com, or mail to The Improve Group (address provided at the end of the survey)

1. Which county do you live in?

_____

2. Do you identify as any of these descriptions? (Please check all that apply)

- o   Person with a disability
- o   Person with a developmental disability
- o   Person with a mental illness
- o   Person over the age of 65 that needs services or supports
- o   Parent or caregiver of a child with a disability or mental illness
- o   Caregiver or family member of anyone who needs services and supports to live the life they want
- o   County, city, school district or Tribal employee
- o   Service provider of long-term services and supports
- o   Advocate for people that need long-term services and supports
- o   Policy maker or leader
- o   Something else (please describe):

3. For community members with disabilities and people who are older, how well are these areas of life being addressed by current services and supports? Caregivers and family members of children with disabilities also answer this section. (For family members the word "Community" represents the family unit.)

Put an X in the for the response that best represents your opinion

	All of my community's needs are met	Some of my community's needs are met	None of my community's needs are met	Not sure or cannot rate
Community membership - feeling included as a part of the community and able to participate as desired				
Health, wellness, and safety – access to healthy food and exercise opportunities, health care, feel safe in community, support for mental and emotional health				
Independence – choice of where to live and ability to choose services and supports that are right for the individual				
Relationships – a connection to other people: family, friends, neighbors, co-worker, other community members				
Employment, volunteering, and school – able to receive the needed supports and services to work or pursue educational opportunities in order to live independently				

4. Please tell us how well needs in your community are met for the following types of services. If you aren't sure, that's fine.

Put an X in the for the response that best represents your opinion

Services to help people live independently

We have services that...	are more than enough to meet the needs in our community	are just the right amount to meet the needs in our community	are not enough to meet the needs in our community	Not sure or cannot rate
Assisted technology and home modifications				
Chore and homemaker				
PCA				
Home delivered meals				
Transportation				
Help finding and keeping a job				

Services to help people stay physically and emotionally healthy

We have services that...	are more than enough to meet the needs in our community	are just the right amount to meet the needs in our community	are not enough to meet the needs in our community	Not sure or cannot rate
Behavioral services				
Home health aide or visiting nurses				
Therapy (OT, PT, mental health)				
Supports to prevent hospitalization				

Services that offer people the right type of place to live

We have services that…	are more than enough to meet the needs in our community	are just the right amount to meet the needs in our community	are not enough to meet the needs in our community	Not sure or cannot rate
Assisted Living				
Foster Care				
Supportive Housing				

Services that build a network of support

We have services that…	are more than enough to meet the needs in our community	are just the right amount to meet the needs in our community	are not enough to meet the needs in our community	Not sure or cannot rate
Caregiver training and support				
Respite care				
Family support				
Groups and therapies to help maintain balance				

Services that help people live a meaningful life

We have services that...	are more than enough to meet the needs in our community	are just the right amount to meet the needs in our community	are not enough to meet the needs in our community	Not sure or cannot rate
Structured day programs or adult day care				
Personal support/ companion services				
Supported employment				

5. What factors prevent people from receiving services in their preferred, least-restrictive settings and communities? _____

_____

_____

_____

_____

6. What would have to happen or change in order for more people to enjoy meaningful, independent lives? _____

_____

_____

_____

_____

Thank you for completing the survey!

Please enter answers on www.mnservicestory.com online or mail to:

The Improve Group
Attn: Community Services Input

700 Raymond Ave, Suite 140

St. Paul, MN 55114

APPENDIX B: PARTICIPATING COMMUNITIES
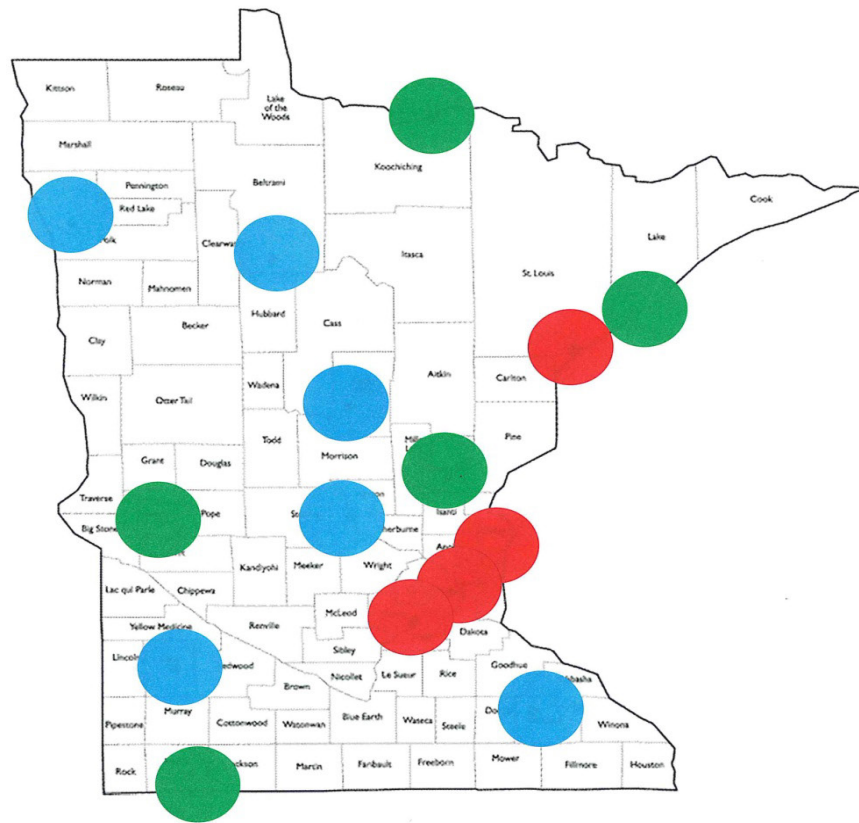
Red dots indicate sites in urban communities.

Green dots indicate sites in rural communities.

Blue dots indicate sites in communities considered a regional "hub" of services.

List of Communities Visited

Minneapolis (participants drawing from Hennepin and Ramsey Counties); April 2 and May 6

Shakopee (participants drawing from Carver and Scott Counties); April 22

Forest Lake (participants drawing from Anoka and Washington Counties); March 27-28

Rochester (Olmsted County); March 25-26

St. Cloud (Stearns County); April 2-3

Marshall (Lyon County); April 18-19

Mora (Kanabec County); April 16

Morris (Stevens County); May 2

Worthington (Nobles County); April 18-19

Brainerd (Crow Wing County); April 8

Duluth (St. Louis County); April 29

Bemidji (Beltrami County); May 1

Crookston (Polk County); April 11

Two Harbors (Lake County); April 29-30

International Falls (Koochiching County)); April 16

Mille Lacs Band of Ojibwe; May 21-22

MN Self Advocacy Conference (Statewide); April 26

Appendix C: Statute

2012 Minnesota Statutes

144A.351 BALANCING LONG-TERM CARE SERVICES AND SUPPORTS: REPORT REQUIRED.

The commissioners of health and human services, with the cooperation of counties and in consultation with stakeholders, including persons who need or are using long-term care services and supports, lead agencies, regional entities, senior, disability, and mental health organization representatives, service providers, and community members shall prepare a report to the legislature by August 15, 2013, and biennially thereafter, regarding the status of the full range of long-term care services and supports for the elderly and children and adults with disabilities and mental illnesses in Minnesota. The report shall address:

(1) demographics and need for long-term care services and supports in Minnesota;

(2) summary of county and regional reports on long-term care gaps, surpluses, imbalances, and corrective action plans;

(3) status of long-term care services and related mental health services, housing options, and supports by county and region including:

(i) changes in availability of the range of long-term care services and housing options;

(ii) access problems, including access to the least restrictive and most integrated services and settings, regarding long-term care services; and

(iii) comparative measures of long-term care services availability, including serving people in their home areas near family, and changes over time; and

(4) recommendations regarding goals for the future of long-term care services and supports, policy and fiscal changes, and resource development and transition needs.

Appendix D: Bibliography of Comparative Reports and Research

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Appendix E: Service Definitions

SERVICE	DEFINITION
Assisted technology	Devices or equipment or a combination of both that improve the ability of a person to: • Communicate in the community • Control or access their environment • Perform activities of daily living
Behavioral services	Service to increase positive behavior and decrease or eliminate severe, challenging behavior.
Caregiver training and education	Training and education to a parent or primary caregiver when the parent or primary caregiver is not employed to provide supervision and care to the person.
Chore	Support or assistance to a person or their primary caregiver to maintain a clean, sanitary and safe home.
Family training and counseling	Services provided for the person and/or the family as identified in the individual plan of care.
Foster Care	Individual waiver services provided to persons living in a home licensed as foster care. Foster care services are individualized and based on the individual needs of the person and service rates must be determined accordingly.
Homemaker	General household activities provided by a trained homemaker when the person (i.e., the person, family member or primary caregiver) who is regularly responsible for these activities is unable to manage the household activities or is temporarily absent.
Home delivered meals	Nutritionally balanced meals delivered to the person's place of residence.

Home health aide or visiting nurses	Provides medically oriented task(s) to maintain health or to facilitate treatment of an illness or injury provided in a person's place of residence.
Home modifications	Improving or maintaining the independent living environment of an older person. It includes modifications to accommodate mobility impairments and to improve energy efficiency of the home
Personal Care Attendant	Providing personal assistance, stand-by assistance, supervision or cues for persons having difficulties with one or more activities of daily living.
Personal support/companion services	Non-medical care, supervision and assistance provided in the home of the person or in the community to achieve increased independence, productivity and inclusion in the community.
Respite care	Short-term care services provided due to the absence or need for relief of the family member(s) or primary caregiver normally providing the care.
Structured day programs or adult day care	Service designed for persons who may benefit from continued rehabilitation and community integration directed at the development and maintenance of community living skills.
Supported employment	Services for persons for whom competitive employment at or above the minimum wage is unlikely, and who, because of their disabilities, needs intensive ongoing support to perform in a work setting. The person receiving services must be in a paid employment situation.
Transportation	Transportation necessary to gain access to community services, resources and activities.

APPENDIX F: INFOGRAPHIC

Infographic is presented on the following page.

WHAT ARE LONG-TERM SERVICES AND SUPPORTS?

Long-term services and supports (LTSS) are ongoing supports that an individual needs due to a chronic condition. With these supports people live productive, fulfilling lives. These services can be delivered in homes, around our communities or in institutions.

Who needs these services?

Minnesotans aged 0 to 100+ use long-term services and supports. This includes people with disabilities (over 20%), people with mental illness (5%), and older people (13%).

1 in 3

Households have at least one person who is or has been a caregiver.

Many people are unable to live the lives they want because services are not available.

TRANSPORTATION
Without transportation, people are unable to get to appointments and suffer isolation.

NO SERVICE

EMPLOYMENT
Poor accommodations and limited options make long-term employment difficult
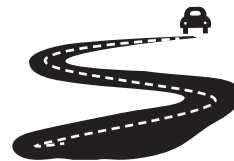
NO HELP WANTED

RESPITE CARE
Families need respite when caregiving becomes overwhelming, but services are rarely available.

MENTAL HEALTH PROVIDERS
Limited resources force people to move far away to get help or go without treatment

HOUSING
Quality housing options are lacking in both rural and urban settings, with unique challenges in each setting.
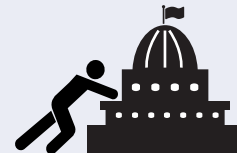
SYSTEMIC BARRIERS
Complex programs and difficult to navigate systems can frustrate people leaving them with more questions than answers.*

POLICY BARRIERS
Participants are frustrated by the limits and harm caused by some policies *

When services and supports match their needs, people can live the lives they want.

These changes could make the biggest difference in participants quality of life

EDUCATION
about existing resources to help people navigate the system

FLEXIBILITY
to choose services that work best for each individual

FUNDING
at the Local, State or Federal level for "high impact" services

*FOR MORE INFORMATION ON THIS STUDY, PLEASE SEE MINNESOTA'S COMMUNITY SERVICES INPUT STUDY REPORT, JUNE 2013.