NORC at the University of Chicago

FINAL REPORT
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HCBS Evaluation of the Assessment process for Racial/Ethnic Disparities (HEARD) Phase II:

Qualitative Evaluation of the Initial HCBS Assessment Process

Presented by:
NORC at the University of Chicago

Presented to:
Minnesota Department of Human Services

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Table of Abbreviations

Abbreviation	Definition
CAB	Community Advisory Board
CBO	Community-Based Organization
CFSS	Community First Services and Supports
CIL	Center for Independent Living
DHS	Minnesota Department of Human Services
HCBS	Home- and Community-Based Services
HEARD	HCBS Evaluation of the Assessment process for Racial/Ethnic Disparities
LTSS	Long-Term Services and Supports
NORC	NORC at the University of Chicago
PCA	Personal Care Assistant
SME	Subject Matter Expert
SMRT	State Medical Review Team

Executive Summary

Home and community-based services (HCBS) fill a critical need in the continuum of person-centered care. However, there are racial and ethnic disparities in HCBS use. Funded by the Minnesota Department of Human Services (DHS), NORC at the University of Chicago (NORC) conducted an evaluation of the initial HCBS assessment process to understand how people learn about and seek out an assessment, facilitators and barriers they may encounter, and opportunities to improve the process to serve Minnesotans more equitably. A community advisory board (CAB) of HCBS recipients, family members and loved ones of HCBS recipients, and providers, an advisory group of subject matter experts (SMEs) from DHS, and community partners co-designed the evaluation using participatory methods to ensure assumptions and approaches were culturally responsive and utilized an equity lens.

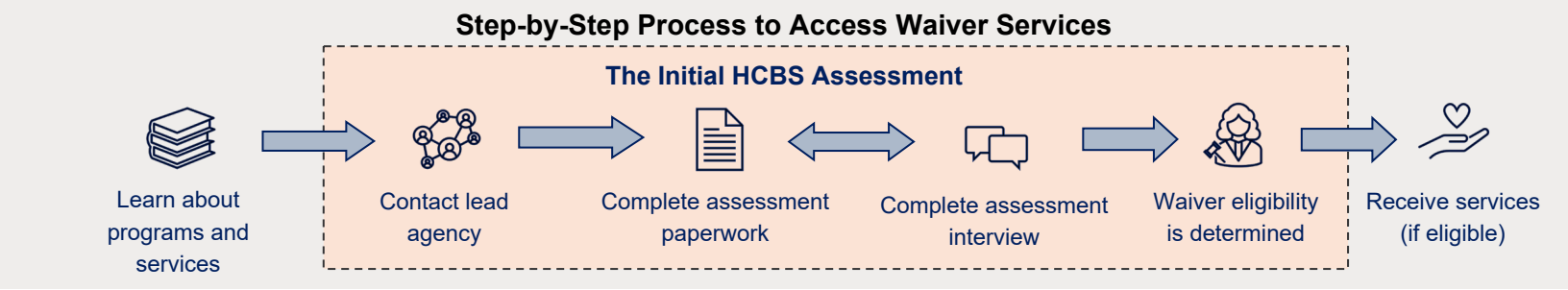
The evaluation consisted of:

- 14 semi-structured individual and group interviews with 38 lead agency staff across 13 lead agencies (August to October 2023), and
- 10 semi-structured one-on-one interviews with Latinx, Somali, Hmong, and U.S.-born Black Minnesotans (December 2023 to April 2024).

This report summarizes findings of the experiences of Somali, Latinx, Hmong, and U.S.-born Black Minnesotans as they learn about, seek, and navigate the initial assessment process to HCBS and the perspectives of the lead agencies that conduct the assessments.

Key Findings

Evaluation findings highlighted barriers and facilitators to the initial HCBS assessment process and suggestions for improvement. We group findings into three core steps in the process, as defined below.



Findings Related to Step I: Learning About Available HCBS

Understanding what HCBS may be available for a community member/their loved one is a crucial step in deciding to apply and reaching out to lead agencies to schedule an initial assessment.

- Gaps in accessible, community-facing information, and education about HCBS persist, which hinder community members from accessing the initial assessment.
- Community members currently rely on word-of-mouth and other informal sources to learn about HCBS, but more accessible information and partnerships with CBOs could increase awareness of service offerings.

Findings Related to Step II: Navigating the HCBS Assessment Process and Receiving a Determination of Eligibility

Navigating the HCBS assessment process encompasses initial interactions with lead agencies, completing required paperwork, and scheduling and conducting the initial assessment interview.

- Complex documentation requirements, high administrative burden, and system fragmentation (particularly the distinct but concurrently required disability certification and financial eligibility determination processes) leads to confusion and results in delayed or foregone HCBS. This is particularly challenging for individuals with limited English proficiency and other priority populations who face language barriers and lack of additional supports.
- Stigma and distrust may lead community members to hesitate to share their level of need, preventing them and their family member/loved one from receiving the appropriate HCBS. Community members noted the need for cultural sensitivity throughout the process to reduce distrust and stigma.
- Lack of materials in plain language exacerbate barriers for people with limited English proficiency, people with mental illness and/or cognitive issues, and people who are deaf and/or blind. Individuals may rely on family members and loved ones for translation support, which can result in inaccurate interpretation.
- Social drivers of health like lack of transportation and unstable housing also exacerbated access to the initial HCBS assessment.
- Case managers, building rapport, and timely communication resulted in more positive experiences with the assessment process.
- Demand, acuity, and complexity of community need has increased since the COVID-19 public health emergency, leading to staff burnout, delays, and less individualized attention for each community member.

Findings Related to Step III: Accessing Services Once Eligible

After a community member receives notice that they are eligible for HCBS, they may still face challenges accessing necessary services.

- HCBS workforce shortages limits access to and quality of services that community members receive. There is also a lack of providers that reflect the demographic makeup of the populations they serve. Satisfaction with HCBS received was also variable among community members, with some community members expressing persistent unmet needs.

Discussion and Recommendations

Lead agencies, community members, and CAB members identified and recommended several potential areas for improvement, including changes to lead agency processes and policies to facilitate timelier HCBS determinations and improve equity. DHS established how they will consider or implement these policy recommendations and the timeline for each.

Timeframe	Recommendation
Short-term	• Increase materials for learning about HCBS • Increase cultural competency training for lead agency staff • Standardize terminology and assessment documents • Increase availability of non-English documents • Include more plain language assessment documents • Promote early engagement of lead agencies in policy and process changes related to the initial assessment
Medium-term	• Extend the 20-day mandate • Increase access to and visibility of in-person assessment options • Engage CBOs in helping community members learn about HCBS • Introduce lead agency caseload management • Expand the HCBS provider workforce
Long-term	• Provide follow-up materials to community members after critical steps of the assessment process • Re-evaluate outdated HCBS eligibility thresholds

Conclusion

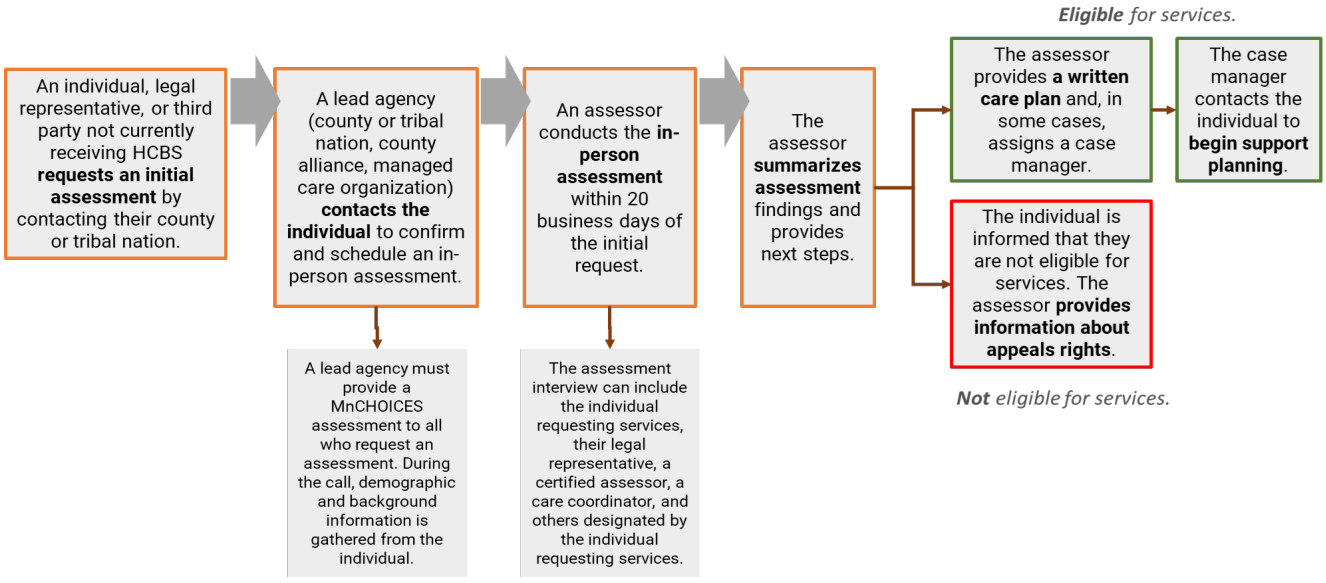
Individuals, particularly those with limited English proficiency and other priority populations, experience challenges with complex requirements, fragmentation, and lack of culturally responsive practices during the initial HCBS assessment process. In addition, lead agencies are grappling with increased demand and acuity and limited staff capacity. Use of case managers, timely communication, working with community partners, and using culturally responsive approaches can create more positive and equitable experiences for individuals with the initial assessment process. Process changes, like caseload management, expanding the HCBS workforce, and re-evaluating policies around asset thresholds and the 20-day mandate, could facilitate timelier HCBS eligibility determinations.

Introduction

This report summarizes findings from a qualitative evaluation of the experiences of Somali, Latinx, Hmong, and U.S.-born Black Minnesotans as they learn about, seek, and navigate the initial assessment process for home and community-based services (HCBS) and the lead agencies that serve them. In 2019, the Minnesota Department of Human Services (DHS) began a mixed methods evaluation, the HCBS Evaluation of the Assessment process for Racial and Ethnic Disparities (HEARD), to analyze access to and utilization of HCBS in Minnesota by race and ethnicity. Phase I (2019-2021) of the evaluation identified racial and ethnic disparities in HCBS program participation, screening, and use of HCBS, and acute care utilization.[1] Minnesota DHS contracted with NORC at the University of Chicago (NORC) to conduct Phase II of HEARD (2022-2024), a follow-on study to qualitatively assess the experiences of specific racial and ethnic populations with the initial HCBS assessment process.

The initial HCBS assessment process (see **Exhibit 1**) spans the moment an individual learns about HCBS and contacts their lead agency to when they receive an eligibility determination for services. A lead agency is a county, tribal nation, county alliance, or managed care organization (MCO) that administers the HCBS assessment. DHS selected the initial assessment as the "touchpoint" of focus for this evaluation because it serves as a near-universal entry point to services. Better understanding community members' experiences navigating that assessment process can provide critical context and concrete examples of the systemic barriers to access reported across the HCBS continuum in HEARD Phase I. NORC worked with DHS, a community advisory board (CAB), an advisory group of DHS subject matter experts (SMEs), and community partners that include centers for independent living (CILs) and community-based organizations (CBOs) to design and conduct the Phase II study.

Exhibit 1: Minnesota Initial HCBS Assessment Process[2,3]



Background

HCBS fill a critical need in the continuum of person-centered care. HCBS allow individuals to receive long-term services and supports (LTSS) in their community, honoring individual preferences to remain in their home or other community setting instead of in nursing facilities or other institutional settings.[4] However, there are racial and ethnic disparities in HCBS use when comparing HCBS recipients to the state's overall population in 2023 (see **Exhibit 2**).[5,6] In particular, Black or African American, Asian or Pacific Islander, and American Indian or Alaska Native populations use of waiver services is disproportionate compared to their makeup of the state's population.[7] By contrast, Hispanic or Latino populations made up only 3.2% of HCBS recipients despite representing 6.5% of Minnesota's total population.[8,9]

Exhibit 2: Racial and Ethnic Disparities in HCBS Usage in Minnesota, 2023

Racial and Ethnic Identity	% of State's Population in 2023*	% of State's HCBS Usage in 2023±
American Indian or Alaska Native	1.4%	2.3%
Asian or Pacific Islander	5.6%	8.4%
Black or African American	7.9%	20.4%
Hispanic or Latino	6.5%	3.2%
White	76.9%	57.0%

* LTSS demographic dashboard. Minnesota Department of Human Services. Updated on September 11, 2023. https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/public-planning-performance-reporting/performance-reports/demographic-dashboard/.
± QuickFacts Minnesota. United States Census Bureau. https://www.census.gov/quickfacts/MN.

Despite their overrepresentation among the HCBS population, American Indian or Alaska Native, Asian or Pacific Islander, and Black or African American populations face limitations in HCBS access, such as cultural bias during assessments, reluctance to having outsiders come into the home, and stigma surrounding care for mental health and intellectual/developmental disabilities (IDD).[10,11,12] Multilevel factors influence HCBS access and utilization. At the structural and systems level, a lack of cultural inclusiveness and humility in LTSS and medical services could limit the use of HCBS. Stigma and historical mistrust may prevent people from seeking services at the community and individual levels.[13] Limited knowledge of available services and differences in eligibility by income, disability status, and level of functional impairment may also hinder access to HCBS within and across populations.[14,15,16,17]

Phase II of HEARD aims to understand the barriers and facilitators that may drive these observed disparities in access to and use of HCBS by race and ethnicity and put forth recommendations to address these disparities.

Methods

NORC conducted a qualitative evaluation of the initial HCBS assessment process that consisted of interviews with lead agencies and community members. The purpose of the evaluation was twofold: to 1) understand the experiences of Somali, Latinx, Hmong, and U.S.-born Black persons undergoing the initial HCBS assessment, and 2) identify recommendations to support the development of state-level short- and long-term policy solutions.

Community engagement is essential to the relevance of evaluation questions, participant recruitment and retention, construction of culturally responsive and valid measurement instruments, and contextualization of findings.[18] NORC worked with Minnesota DHS, a CAB, an SME advisory group, and community partners to co-design and carry out culturally responsive and participatory evaluation approach with an equity lens. NORC met with these groups several times throughout the course of this evaluation and engaged with them on an ad hoc basis as needed. During each meeting, we co-designed and requested input into evaluation approaches and assumptions, provided evaluation updates, shared evaluation challenges and discussed potential solutions, presented emerging findings, and solicited thoughts and feedback about these findings. Findings from these meetings are integrated into our report. A detailed summary of NORC's approach to assembling and engaging with these groups is available in **Appendix 1**.

Community-engaged Approach to HEARD

- **CAB:** HCBS recipients, family members/loved ones of HCBS recipients, and providers form a CAB that informed evaluation design, data collection approach, data analysis and interpretation, and dissemination of findings. We held four CAB meetings from March 2023 to June 2024 and provided updates and opportunities to provide additional feedback on study design, materials, and findings in between scheduled meetings. CAB members provided feedback during synchronous meetings, through email and text, and through 1:1 calls with members of the study team.
- **DHS SME Advisory Group:** A group of DHS SMEs advised on the evaluation design and data collection approach, reviewed evaluation materials, and provided expertise in LTSS, HCBS, racial and ethnic disparities, community engagement, and the HCBS assessment process. We held six DHS SME Advisory Group meetings from January 2023 to June 2024.
- **Community Partners:** CBOs that serve the populations of focus or engage with HCBS recipients informed the evaluation design, reviewed evaluation materials, and recruited community interviews and interview participants for the community member interviews as well as CAB members. We held eight meetings with community partners between January 2023 and April 2024.

The DHS Institutional Review Board (IRB) reviewed and approved the methodology and approach for this study as well as all interview guides and supplemental shared materials. The review occurred in

three phases, first for the overall methodology and approach (approved on May 3, 2023), second for an increase in interviewee compensation and minor changes to interview guides (approved on November 7, 2023), and third for expanded recruitment efforts (approved on March 7, 2024).

Evaluation Questions

NORC worked with DHS, the CAB, and the SME advisory group to develop and refine the evaluation questions for this study (see **Exhibit 3**).

Exhibit 3: Evaluation Questions

Evaluation Question	Community Interviews	Lead Agency Interviews
How do people come to learn about HCBS?	✓	✓
What are the individual, structural, and systemic barriers and facilitators to learning about HCBS?	✓	✓
What are the individual, structural, and systemic barriers and facilitators to receiving an initial HCBS assessment?	✓	✓
What works and what does not work about the initial HCBS assessment process?	✓	✓
What additional supports would benefit people going through/ supporting someone who's going through the initial HCBS assessment process?	✓	✓
How do intersectional identities (e.g., race, ethnicity, gender, socioeconomic status, age, disability) influence experiences with the initial HCBS assessment?	✓	

Data Collection

The evaluation consisted of two data collection streams: 1) semi-structured individual and group interviews with lead agency staff (August to October 2023), and 2) semi-structured one-on-one interviews with community members (December 2023 to April 2024).

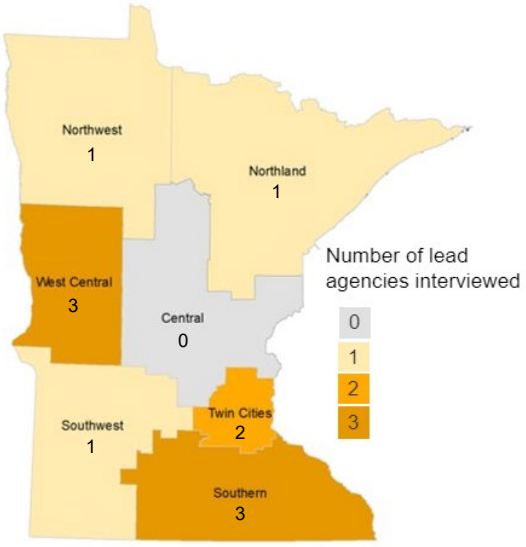
Lead Agency Interviews

NORC conducted 14 sixty-minute, semi-structured, virtual individual and group interviews with 38 lead agency staff across 13 lead agencies. The purpose of these interviews was to learn about lead agency experiences implementing the initial HCBS assessment.

Sampling. NORC worked with DHS, the CAB, and the SME Advisory Group to establish a sample of lead agencies, out of the available 87 non-tribal lead agencies, to prioritize for outreach. The prioritization process considered organization type (i.e., county, county alliance, MCO), Minnesota region, urbanicity and rurality, whether the lead agency is a beta tester for the new MnCHOICES assessment tool,[1] and county diversity to ensure a diverse set of lead agencies from across the state. The lead agency interviews included a mix of urban and rural, and small and large lead agencies.

NORC used the LTSS demographic and performance measures dashboards to assess diversity among populations served by lead agencies.[19,20] NORC also used school-based language tracking data called "2022-23 Primary Home Language Totals" to determine county-level representation of language.[21] Beyond these characteristics, NORC aimed to select a sample that was as random as possible.

Exhibit 4: Regional Distribution of Lead Agency Interviews*



*This exhibit does not include MCOs

In addition, we included a range of positions and levels of staff at selected lead agencies. This included staff working on the central intake call line, assessors, program managers, and agency staff in financial or administrative roles. Interviews included up to five staff members to hear from multiple perspectives within the same agency. NORC's sample of lead agencies and their breakdown by characteristics is available in **Exhibit 4** and **Appendix 2**.

Outreach and Recruitment. DHS consulted with the Minnesota county-state workgroup about the process for outreach to and recruitment of lead agencies. First, DHS notified all lead agencies in NORC's proposed sample of the study ahead of time so that they could anticipate NORC's outreach. Next, DHS worked with the Minnesota county-state workgroup to identify and provide NORC with up-to-date points of contact and contact information for each lead agency sampled. NORC then sent an outreach email to each lead agency to invite them to participate in an interview, providing background on the project and the goals of the evaluation. For all lead agencies, NORC focused their initial outreach on lead agency administrative personnel but asked these administrative personnel who they recommended from within their agency to participate in our interview, allowing them to nominate themselves if appropriate. NORC followed up with each agency up to three times before deeming them unresponsive to interview requests. After the second outreach attempt, DHS conducted a third follow-

[1] MnCHOICES is the name of Minnesota's assessment and support planning tool that is used my lead agencies during the initial assessment process. MnCHOICES underwent a revision in 2023 that aims to better support certified assessors and facilitate a more person-centered initial assessment process. Lead agencies who are testing the revised tool before it is widely rolled out are called beta testers (Update on launch of MnCHOICES revision project).

up with lead agencies. NORC reached out to 16 lead agencies and conducted interviews with 13, resulting in an 81% response rate.

Protocol Development. Working with DHS, the CAB, and the SME Advisory Group, NORC developed a semi-structured interview guide focused on assessing structural and systemic barriers and facilitators to the initial HCBS assessment, how agencies share information about HCBS, and suggestions for policy-level change. Questions focused on the experience, policies, and supports lead agencies offer and did not ask lead agencies to speculate or speak on behalf of people that moved through their processes. The guide also includes specific questions directed toward MCOs and MnCHOICES Revision beta testers. NORC shared the guide with DHS, the CAB, and the SME Advisory Group for review and feedback and made edits based on feedback received; a final guide is available in **Appendix 3**.

Scheduling and Convening. NORC used Calendly, a secure, 508-compliant scheduling web-based application, to schedule the 60-minute interviews with lead agencies. Calendly allowed for lead agency staff to view and select any available 60-minute time slot, reschedule or cancel their interview, and receive automated reminder notifications. All interviews occurred virtually via Zoom. A NORC senior staff member facilitate each call. NORC recorded interviews for transcription and note-taking purposes only, with participant consent.

Semi-Structured Interviews with Community Members

NORC and community interviewers (see "Recruitment and Training of Community Interviewers" section below) conducted 13 thirty-minute, semi-structured interviews with Latinx, Somali, Hmong, and U.S.-born Black Minnesotans, of which 10 were eligible for analysis.[2] The purpose of interviews were to better understand the experiences of populations of focus with the initial HCBS assessment process. Available interview languages were English, Spanish, Somali, and Hmong. Interviews occurred via Zoom or phone.

Sampling. NORC employed a multi-modal approach, drawing on publicly available data and expert feedback from the CAB and SME

Demographics of Interview Participants

Of the 10 eligible interviewees,

- 4 identified as Somali, 4 identified as U.S.-born Black, 1 identified as Latinx, and 1 identified as Hmong.
- 4 occurred in a language other than English
- 7 were over the age of 40
- 6 identified as female
- 7 identified as living in an urban area
- 7 had applied for HCBS services for themselves and a family member or someone they support, and 3 applied for HCBS services for a family member or someone they support.

[2] NORC excluded three interviews from analysis as during the conversation it became clear that the community members involved in those interviews were not eligible for the study based on study criteria.

Advisory Group to narrow down the populations of focus for the evaluation and design a purposive or convenience sampling approach.

Publicly available data on HCBS use. NORC relied on several publicly available data sources to understand the demographic makeup of various racial and ethnic populations in the state and among HCBS and LTSS users. NORC found that:

- Black Minnesotans comprise 7% of the state's population. In addition, 5.6% of the Minnesotan population identify as Hispanic or Latino, 5.2% as Asian, 2.6% as two or more races, and 1.4% as American Indian.[22] About 8% of Minnesotans are immigrants, mainly comprised of Mexican, Somali, Indian, Hmong, Ethiopian, Chinese, Vietnamese, and Korean immigrants.[23] These groups are overrepresented among Minnesotans who use HCBS.
- Of the population of Minnesotans receiving LTSS, 11% reported speaking a language other than English at home, with Somali and Hmong as the most widely reported languages. Russian, Karen, and Spanish are also top languages that Minnesotans who receive LTSS report speaking.[24]

Based on these activities, NORC and DHS identified four populations of focus for this evaluation: Somali, Latinx, Hmong, and U.S.-born Black populations.

CAB and SME Advisory Group Input. NORC presented four potential populations of focus to DHS, the CAB, and the SME Advisory Group. In meetings, CAB members expressed that Somali, Tribal Nations and communities, and U.S.-born Black populations should be populations of focus as these populations have historically been underrepresented in research. When NORC asked about potentially missing populations of focus, CAB members specifically noted that the study should not expand to additional groups, including Minnesotans that speak Oromo nor Karen, as the addition would decrease the number of interviews that would be conducted for each population of focus.

Given the feedback, NORC and DHS confirmed the four populations of focus for this evaluation: Somali, Latinx, Hmong, and U.S.-born Black populations. The populations of focus determined the languages for the study: English, Spanish, Somali, and Hmong.

Further, CAB members noted that there is a lack of education about accessing waiver services and fewer plain language materials provided to Tribal Nations and communities, underscoring the need to include Tribal Nations and communities as a population of focus. The SME Advisory Group noted that NORC should include Tribal Nations and communities that span lead agency status, geographies, and rurality. CAB members also provided feedback that specific Tribes of focus should include Ojibwe, Chippewa, Leech Lake, and Dakota tribes. NORC and DHS are conducting listening sessions and interviews with Tribal Nations and communities through a separate process and results will be available in a second report in the fall of 2024.

Outreach and Recruitment. NORC worked with DHS, the CAB, and the SME Advisory Group to develop participant recruitment materials and establish a culturally and linguistically appropriate outreach and recruitment approach. Recruitment materials included a participant recruitment flyer, a

project information form that partners could use to share information about the study to their networks, and sample email outreach language that partners could use (**Appendices 4-6**). We developed all recruitment materials in plain language and at an appropriate reading level (e.g., 5th -6th grade), used nontechnical/non-academic language, and avoided use of stigmatizing language when describing the evaluation participants.[25,26,27,28,29]

In total, NORC conducted outreach to 53 community partners using email outreach methods and one-on-one calls with partners. NORC worked in collaboration with DHS, the CAB, and the SME Advisory Group to identify and review a list of potential community partners in the state. NORC worked closely with eight organizations to recruit community members for the study. We provided these with a $500 honorarium for recruiting community participants. In addition to working with community partners, the study also used a snowball technique where, at the conclusion of each interview, interviewers asked participants to suggest additional participants for this study.

Due to the small population this study tried to recruit participants from and limitations on sharing recruitment materials on social media (see "Interviewee Criteria and Recruitment Methods" section below), recruitment barriers limited the number of people who participated in this study despite the significant amount of outreach to community partners. This study was able to complete 10 out of 30 planned interviews.

Protocol Development. NORC worked with DHS, the CAB, and the SME Advisory Group to develop a semi-structured interview guide about experiences with the initial HCBS assessment process, with a focus on factors influencing seeking HCBS at multiple levels of influence as structural inequity and systemic barriers are a confluence of interpersonal, organizational, community, and societal factors.[30] Key domains included: the process of learning about HCBS availability; how individuals reach out for an initial assessment and who conducts that assessment; experiences with the initial assessment process; challenges and facilitators with accessing the assessment; and challenges and barriers with receiving services.

NORC developed two discussion guides for community members—one for individuals who sought services on their own behalf and one for individuals who sought services on behalf of a family member or loved one (see **Appendices 7 and 8** for guides).

NORC worked with a certified translation vendor to translate the semi-structured interview guide and recruitment materials to Spanish, Somali, and Hmong. CAB members and community interviewers (see "Recruitment and Training of Community Interviewers" section below) also reviewed the translations for accuracy and accessibility.

Recruitment and Training of Community Interviewers. Trusted community members were critical to gain cooperation for participation in this evaluation. NORC worked with community partners to identify community members to serve as interviewers for this study. NORC worked with community partners to recruit five interviewers, ensuring at least one interviewer for each language. Of the five interviewers, two were bilingual in English and Somali, two were bilingual in English and Hmong, and

one was bilingual in English and Spanish. Community interviewers received $25 per hour for time spent training, onboarding, and conducting interviews. All interviewers completed CIRTification training, in accordance with NORC IRB requirements.[3]

Interviewee Criteria and Recruitment Methods

Eligibility Criteria. NORC determined eligibility criteria in concordance with feedback from community partners and DHS SMEs. Final criteria included that participants must:

- be 18 years or older.
- currently live in Minnesota.
- have recently applied for waiver services or helped someone apply for waiver services. Where possible, NORC also engaged with community members that are not currently accessing services but have attempted to or could be eligible for services, or community members who have experienced barriers to the HCBS assessment process.
- identify with one or more of the priority populations.
- comfortably speak English, Spanish, Somali, and/or Hmong.

NORC used a screener to determine eligibility for the study. Recruitment materials guided individuals to an online screener that asked for demographic information (i.e., race/ethnicity, age, sexual orientation, disability status, etc.), whether they contacted someone for an HCBS assessment, when they underwent an initial HCBS assessment, and information about where they are in the assessment process. The screener was available in all four languages; a copy is available in **Appendix 9**.

Online Fraud. The utilization of a combination of IP addresses, Qualtrics RelevantID, phone numbers, time zones, open-end responses, and interviewer checks helped determine the validity of survey screener responses and identify and subsequently screen out fraudulent or botted responses. Should a response satisfy all but one check, NORC conducted additional scrutiny of responses, including additional email or phone follow-up, to determine validity. During initial outreach, some community partners shared recruitment materials to social media, resulting hundreds of fraudulent responses received from outside the United States. This led the team to ask community partners to not share recruitment materials through public-facing social media, only closed groups (e.g., Facebook groups). The detailed fraud detection steps NORC undertook are available in **Appendix 10**.

Scheduling and Convening. Once NORC determined a respondent was legitimate and eligible, we facilitated the scheduling of their interview via Calendly. NORC then conducted all one-on-one interviews virtually via Zoom. If participants granted consent, community interviewers recorded all

[3] The University of Illinois Center for Clinical and Translational Science developed the CIRTification training program to provide a program tailored to the roles and experiences of community research partners. For more information, see: https://ccts.uic.edu/resources/cirtification/.

interviews to enable transcription of English-language interviews. For interviews with interviewees who did not provide their consent to record the interview, interviewers took detailed notes for each interview question and shared them with NORC. NORC provided all interviewees with a $125 electronic gift card as compensation for their time.

NORC worked with Minnesota DHS to compile a list of local and culturally specific resources to share with participants who expressed unmet need, distress, or would like more information about HCBS or the initial assessment process (**Appendix 11**). NORC shared these resources with community interviewers and trained interviews on how to report cases of emotional distress, unmet need, and/or endangerment if they arose.

Analysis

NORC employed both thematic analysis and participatory analysis and sensemaking to extract themes and contextualize findings.

Thematic Analysis. NORC used thematic analysis to analyze all interview data in NVivo 14, a qualitative analytic software. Using a deductive and inductive approach to analysis, we developed a codebook based on the evaluation questions and updated the codebook based on themes that emerged from the transcripts. Our evaluation questions also informed codebook development and definitions. Project staff coded the interviews: staff independently cross-coded an initial interview transcript and then met to discuss emergent themes, coding divergence, and needed codebook refinements.

Participatory Analysis and Sensemaking. Throughout the study, NORC worked with the CAB to discuss and validate key themes and interpretation of evaluation findings emerging from the thematic analyses. During the third CAB meeting, NORC hosted a 'data party' to discuss and interpret preliminary findings from lead agency interviews. During the fourth CAB meeting, NORC hosted an analogous 'data party' to discuss preliminary findings from community member interviews. Data parties serve as a key opportunity for community engagement in the evaluation process, which both strengthens the evaluation analysis and empowers CAB members to inform data-driven suggestions to improve the initial HCBS assessment process.[31,32,33,34]

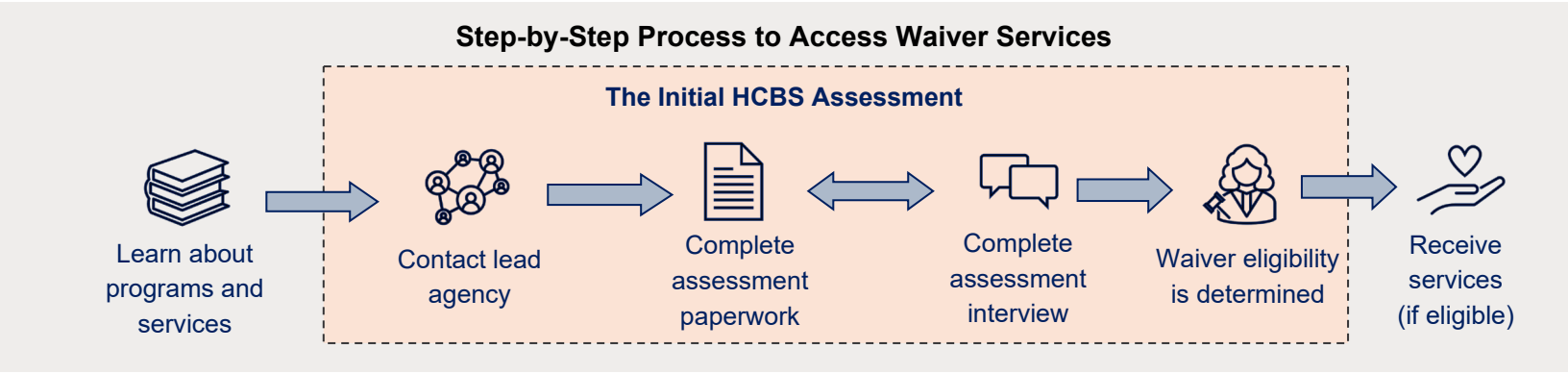
NORC also engaged the SME Advisory Group throughout the study to similarly discuss and validate key themes and interpretation of findings. Similar to the CAB meetings, NORC held "data parties" with the SME Advisory Group. During the third SME Advisory Group meeting, NORC discussed preliminary findings from lead agency interviews. During the fourth SME Advisory Group meeting, NORC discussed preliminary findings from community member interviews. Data parties provided an opportunity for SMEs to discuss policy recommendations based on findings. In total, NORC met with the advisory group six times over the course of the study.

Evaluation Strengths and Limitations

Because DHS sought to understand the experiences of U.S.-born Black, Latinx, Somali, and Hmong community members with the initial HCBS assessment process, we chose qualitative methods as our primary mechanism for data gathering. Using qualitative methods allowed NORC to develop a nuanced understanding of a complex process within the context in which it operates, from the perspectives of those directly involved in and affected by it. Such methods are best suited to understand the context underlying given phenomena we hope to better understand, such as the barriers and challenges an individual or group of individuals may experience in applying for and seeking services. It also provides context to complex topics or issues that do not have easily measurable impact and access to populations that are often overlooked in the research process. That said, findings from qualitative evaluation studies such as the work presented in this report are not generalizable beyond the place, population, and time in which the study took place. Instead, they offer in-depth knowledge and perspectives about the specific program, event, policy, or intervention.

Key Findings

This section presents barriers and facilitators experienced as well as suggestions on improving the initial assessment process as expressed by community members, lead agencies, and the CAB. We group findings into the three core steps in the process, as defined below.



Findings Related to Step I: Learning About Available HCBS

Understanding what HCBS may be available for themselves or a loved one is a crucial step in deciding to apply to HCBS and reaching out to lead agencies to schedule an initial assessment. This section explores challenges and suggestions that community members, lead agencies, and the CAB expressed related to learning about HCBS.

Lack of sufficient, accessible information about HCBS preclude community members from accessing the initial assessment.

There is insufficient accessible, community-facing information and education about HCBS. Several community members explained that the state should provide standardized, community-facing outreach and education materials to lead agencies that agencies can distribute to organizations that work directly with community members, such as CBOs and schools. In addition, community members noted that there is not enough information about HCBS specific services that address mental health needs for children. Among the information that is available, many community members mentioned that materials are complex and difficult to understand. Further, the CAB highlighted that Tribal Nations and communities do not receive as much informational material about HCBS as counties, and that not having materials in plain language exacerbates access barriers.

> **"Right now, I have to know what to ask for and learn on my own."**
>
> - Community Member

Individuals rely on word-of-mouth and other informal sources to learn about HCBS

Individuals rely on informal sources such as word-of-mouth and parent support groups to receive information about HCBS and the initial assessment process. Familial and community networks served as a foundation for individuals to learn about HCBS. Community members described hearing about HCBS through conversations with family members, neighbors, and teachers. Some also noted that they initially heard about HCBS through healthcare professionals such as primary care providers, nurses, and social workers (both through formal referrals and informal conversations). Several community members articulated learning about HCBS through a parent group, with one mentioning that their parent group was critical to overcoming a lack of knowledge and that they *"found out together what services are available."* Lead agencies also underscored that information about HCBS commonly spread through word-of-mouth, explaining that the individuals they served learned about HCBS through conversations with church groups and health-related CBOs.

Several lead agencies noted that the individuals they served learned about HCBS through lead agency or county and statewide resources. These include the mn.gov website, Senior LinkAge Line and Disability Hub. Only one community member mentioned using state- or agency-level online resources to learn about HCBS. Lead agencies also described community events such as fairs, school-based meetings, health expositions, and wellness clinics as avenues for community members to learn about HCBS. Several lead agencies also mentioned direct referrals to lead agencies from hospitals, mental health providers, primary care physicians, school nurses, and other healthcare personnel as how some community members may have been introduced to learning about HCBS.

More accessible information and partnerships with CBOs can help individuals learn about HCBS.

Community members shared a desire for more accessible and easier to understand information about HCBS and the initial assessment process. Community members articulated difficulties around finding accessible and understandable information about HCBS, who is eligible to access services, how to apply, the duration of the assessment process, and who to contact if they have questions. Thus, they noted a need for plain language materials and multiple touchpoints across the community. CAB members furthered that plain language materials and accessible information about HCBS should come from lead agencies, as opposed to informal information sharing networks such as parent groups. Lead agencies noted that language barriers and a lack of non-English materials currently available exacerbated the lack of accessible information.

Community members also highlighted the importance of CBOs in serving a key role in educating individuals about HCBS. Community members suggested that lead agencies working with CBOs to further HCBS understanding may augment efforts to bolster education and awareness about HCBS. Community members articulated existing relationships with CBOs, such as the Somali Parents Autism Network (SPAN), and how these CBOs improved their access to and experience with the initial assessment process by providing assistance and explanations. A CAB member articulated that CBOs may be able to alleviate challenges around learning about and initiating the HCBS assessment process by oneself. Lead agencies also noted that CBO partnerships as a valuable source of increasing awareness of HCBS.

> **"I feel like a lot of people in our community don't know these services are out here to help them…[or] they feel like they don't qualify for them. But you won't qualify until you know [about the waiver]."**
>
> - Community Member

> **"How could it be the case that a parent support group is more effective at spreading the work about HCBS than lead agencies?"**
>
> - CAB Member

Findings Related to Step II: Navigating the HCBS Assessment Process and Receiving a Determination of Eligibility

Navigating the HCBS assessment process encompasses initial interactions with lead agencies, completing required paperwork, and scheduling and conducting the initial assessment interview. This section explores challenges and suggestions that community members, lead agencies, and the CAB expressed related to navigating the HCBS assessment process.

Paperwork Complexity and Fragmentation

Community members and lead agencies described challenges with complex requirements and paperwork and nonresponsive lead agencies that resulted in delayed or foregone HCBS. Having case

managers, building rapport with applicants, and timely communication helped HCBS applicants have more positive experiences with the process.

The complexity of required paperwork and high administrative burden of the process leads to confusion and delayed or foregone HCBS.

> ***"We called the county and asked for an assessment of needs. We just got bounced around from person to person."***
>
> **Being transferred across various lead agency staff led to confusion about next steps in the process**
>
> A.V., a 34-year-old Hmong woman from the Twin cities helped her stepmom apply for HCBS in the fall of 2023. As they started, she had a few questions about what the process would look like. She called her lead agency but got transferred across staff until she got in contact with the lead social worker who was able to answer her questions. After a lot of back and forth, lead agency staff informed her that her stepmom needed to take an IQ test. The test was eventually scheduled for four months out.

Community members expressed that they were often confused about how to navigate the initial assessment process and what they needed. Community members noted that the initial assessment process consist of lots of fragmented communication around what steps and diagnostic requirements are necessary to move the process forward. Community members reported that they faced confusion around several aspects of the initial assessment process, including: not knowing who to call if they had questions, what the next steps are, what information they needed for each step of the process, whether they can complete steps simultaneously or concurrently, what the lead agency is responsible for doing versus what the individual needs to do, and what services community members are eligible for.

Community members described the initial assessment process as complex and administratively challenging. Community members described the amount of paperwork required during the initial assessment process as *"insurmountable,"* adding friction to completing the process. This experience was especially salient for individuals with limited English proficiency. Community members described the process as *"draining"* and *"stressful."* Many community members explained that learning about different programs and services and staying on top of paperwork requires a lot of time and energy. One community member noted that the process was so frustrating for her loved ones that she is not sure whether they will choose to finish their assessment to receive services altogether.

"The [lead agency] losing my paperwork was a big deal…It took a long time to get a call back. I left a few messages…I couldn't get answers about how long things would take."

Administrative challenges with paperwork led to delays in receiving HCBS

S., a 50-year-old Black woman in Duluth, was supporting her 19-year-old daughter through the initial assessment process in the summer of 2023. After submitting the initial paperwork, they did not hear back from the lead agency for three months. She wanted to make sure that the lead agency had all the information they needed, so they followed-up. In doing so, they learned that the agency lost their paperwork, and that they would have to re-submit it in full. This caused delays in getting their daughter the HCBS that she needed.

Confusion and the complexity of the paperwork often resulted in individuals waiting a long time to get a response or not getting a response at all about next steps in the process. Community members reported delays ranging from six-to-eight weeks to up to two years to fully hear back from lead agencies about next steps. In addition to long response times, some individuals noted they, at times, received no response at all from lead agencies. Two individuals reported experiences where the lead agency told them their paperwork was lost, requiring them to restart their initial assessment process. Community members furthered that they may have to restart the process entirely if they miss one requirement, which can be *"really discouraging."* One community member highlighted their frustration and shared that they felt as if *"Somalis and immigrants don't get justice and feel discrimination by not getting the services and support information on time."*

Fragmentation within the initial assessment process delays or hinders an assessment of eligibility.

The financial and services eligibility determinations processes are lengthy and fragmented. The assessment process involves multiple lead agency staff and teams. For example, to be eligible for HCBS, community members must first be deemed as certified disabled (as determined by the state medical review team [SMRT]) as well as be financial eligible. Both disability certification and financial eligibility determination processes are separate from the initial HCBS assessment, adding to fragmentation and delays during the initial assessment process for community members without one or both eligibility standards.[35,36]

> **"I contacted my son's caseworker, and I gave [him] the diagnosis of my son. I asked him what supports and services he can connect [us to]. Then we got no answer for six months. Then after we waited for two years, we filled out the application."**
>
> - Community Member

> **"We had lot of barriers when we contacted the agencies. They always said we will call you. [There were] lots of delays and a lack of knowledge and not knowing who to call were the biggest challenges and they were not making it easy for us."**
>
> - Community Member

The various steps and eligibility determinations required for HCBS lead to significant delays and drop offs throughout the process. There is no *"one-stop shop"* for HCBS eligibility determinations. The need for disability, financial, and HCBS need determinations results in community members feeling that they are being bounced around from one person to the next, making the process *"cumbersome"* and fragmented. Lead agencies reported that community members experience process fatigue and even drop-off when the process is delayed, choosing not to receive HCBS altogether. One CAB member shared that their experience with financial eligibility determination included multiple financial workers that never got back to them. CAB members noted that staff turnover and shortages, during and after the COVID-19 public health emergency, led to community member applicants losing continuity with staff as they were forced to cycle through multiple social workers, financial workers, and assessors.

> **"If a person is not certified disabled, we refer them to the State medical review team. They take about three-to-four months to get the person either approved or not certified. It takes so long that people are just waiting and waiting. The assessment expires, and they have to go through the whole process again in order to get services."**
>
> - Lead Agency Leader

Stigma and distrust hinder accurate assessments of eligibility.

"They're going to take my kids away."

Fear and distrust hindered conversations about community members' level of need

A.V., a 34-year-old woman in the Twin Cities, supported her parents through the initial assessment process. Her parents came to the United States because of war, and the trauma of the war is still fresh in their mind. Growing up, they could not tell their teachers or doctors about the struggles they were experiencing at home for fear that they were going to be separated from their families. Her dad continues to struggle with this trauma: he is still elusive when it comes to sharing details about how his kids, who need HCBS. He did not want the county worker to know that his kids have accidents and that they mostly communicate without words. Without feeling comfortable to fully share his kids' levels of need, unmet need may persist even after the initial assessment process.

Community members expressed stigma that made them hesitant to share their level of need, preventing them and their family member or loved ones from receiving the appropriate level of HCBS. Community members specifically reported stigma around receiving services for mental health needs, receiving help with sensitive tasks such as toileting, and parents receiving support with caring for their children. As a result, some community members reported experiences where they and/or their loved ones were reluctant to disclose their level of need, which could impact their eligibility determination. Community members also expressed a general feeling of distrust in sharing sensitive and/or private information with a government entity. This distrust was around providing financial information, disclosing information concerning disability status, answering questions about their identity, and concerns around losing one's agency if deemed eligible for HCBS. One CAB member added that this distrust may be exacerbated for Tribal Nations and communities, for whom distrust toward

government agencies may be a trauma response. Another CAB member added that stigma and distrust may be compounded by language in HCBS forms if individuals deem questions as feeling threatening due to phrasing around requirements for honesty and proof. One lead agency shared concerns that distrust and fear of the assessment process may be particularly hindering immigrant applicants.

A few community members also described feeling like they were judged or treated differently because of their culture or because they did not speak English. Community members described variable experiences with lead agency staff, with some noting that staff did not seem to fully understand their needs or were unhelpful in answering their questions. A few of these community members attributed these negative interactions to cultural insensitivity given they were from another country, or they did not speak English well. One community member specifically noted that the level of support her loved one received during the assessment process reflected the negative interactions with staff.

> **"It's different when you can't conversate in English. In my process, it felt very friendly. And then in my [stepmom's] process, it felt very standoffish. My assumption is because she couldn't speak English, and because she couldn't understand paperwork…They just didn't feel like really helping her because they presumed that she couldn't really help herself."**
>
> - Community member

Case managers, building rapport, and timely communication resulted in individuals having more positive experiences with the assessment process.

"I relied on [the case manager] from the beginning until the end, and with any questions that I had. He helped me with different referrals that I needed with my uncle."

Having a case manager helped community members feel supported in navigating the process

J., a 46-year-old woman in West Duluth, is a healthcare worker who helped her uncle apply for HCBS. Once she started the process, she realized that she did not know enough about the initial HCBS assessment process on her own. She received a case manager that helped her and her uncle from beginning to end. Throughout the entire process, the case manager answered any questions she and her uncle had and helped with different referrals and paperwork needed. In addition, she shared that after the HCBS application process, the case manager left the door open for her uncle to make sure he had someone to call and to make sure he was receiving the services he needed. Her uncle ended up receiving the HCBS PCA he needed as well as meals on wheels services and reliable transportation services to all medical appointments.

Community members who had access to a case manager, or someone in a similar role, reported more positive outcomes during the intake process. While not all community members described receiving a case manager from their lead agency, those who did receive one noted case managers helped them feel supported during the process, understand their next steps, and feel like their needs were met. One community member mentioned having a temporary county caseworker help streamline the assessment process; the caseworker was able to help ease the stress of figuring out what type of HCBS best fit their family's needs. Community members noted that having a single person to talk to about the process, such as a case manager, helped them overcome the complexity, length, and fragmentation of the initial assessment process.

> **"We end up having the most success when case managers just dig in and work side by side with the person who's receiving HCBS. So maybe making a phone call with them or going through paperwork with them or meeting with them in-person."**
>
> - Lead Agency Leader

Several lead agencies highlighted the importance of case management for specific populations including older adults, individuals with mental health needs, and individuals with limited English proficiency. Lead agencies similarly described that having case managers that built rapport with applicants increased engagement and helped applicants navigate the assessment process. According to one lead agency, in addition to counterbalancing the complexity of the assessment process, case managers provided timely communication and assistance that helped applicants feel more comfortable during the assessment process. A few lead agencies highlighted the importance of looping in case managers for applicants over the age of 55 and individuals with mental health needs as they explained that repeated interactions for these community members are especially helpful in keeping them on track during the assessment process. One lead agency with more than 50 case managers on staff articulated benefits of matching a case manager to someone from the same culture or who speaks the same language as the applicant where possible.

Building rapport can lead to more positive experiences with the initial assessment process. Community members noted that, when available, positive relationships with lead agency staff throughout every step of the process helped them avoid *"messing up the process"* or "*getting lost and confused."* One individual shared appreciation of a staff member helping them fix their application. CAB members echoed this sentiment. One shared that respect and efforts to build rapport can help overcome preexisting high levels of distrust and stigma. Another CAB member believed that all people need is one person in the process to show respect and willingness to help for them to realize that they can work through the complicated initial HCBS assessment process. One lead agency shared that building rapport was especially impactful for HCBS applicants struggling with mental health. Two rural lead agencies and the CAB highlighted that building rapport supports applicants' engagement during the assessment process. One of these rural lead agencies mentioned that they may have easier time building rapport because their smaller size allows

> **"[There is] high distrust among families but also a [critical] need for services… Families need and want help but sometimes need someone to help them overcome the initial distrust."**
>
> - CAB Member

them to take the time to get to know their applicants and centralize the assessment process. The other articulated the importance of taking the time to handhold applicants through the process.

Lead agencies highlighted the importance of timely communication and being responsive in helping individuals feel supported during the process. Several lead agencies mentioned the importance of returning calls and emails as soon as possible, if not within 24 hours. These lead agencies noted that responsiveness was critical to building rapport and helped applicants avoid feeling like they are "*sitting in limbo and not knowing or having a sense of where things are."* One lead agency that has a live call desk during business hours noted that applicants have shown gratitude towards their intake phone line and shared that *"people are grateful that someone is answering directly."*

Limited Lead Agency Staff Capacity

Demand, acuity, and complexity of community need has increased since the COVID-19 public health emergency, leading to staff burnout. Some lead agencies mentioned a specific increase in the needs of young applicants and specifically among children with behavioral health needs. Thus, lead agency staff face higher and more complex caseloads, leading to burnout. This increased caseload also results in delays during the assessment process and less individualized attention for each community member, as the same or fewer number of staff must respond to greater community need.

Lead agencies face workforce constraints, leading to delays in administering the initial HCBS assessment. Lead agencies explained that workforce constraints may be due to poor compensation and increased burden on lead agency and HCBS providers following the COVID-19 public health emergency. Lead agencies specifically noted that the 20-day mandate, which states that a lead agency must complete an in-person assessment no later than 20 calendar days from the date that the person requests it is challenging to meet given shortages among staff.[37] Lead agencies explained that, while it is important to quickly assess community members, this mandate does not acknowledge workforce constraints.

Lead agencies and CAB members noted that caseload management, increased state involvement and support in recruitment of case managers, and re-evaluation of the 20-day mandate can help lead agencies overcome workforce challenges and limited agency staff capacity.

- **Introduce caseload management**. Workforce challenges may hinder the timeliness of the initial assessment and ultimate receipt of HCBS. As such, lead agencies explained that introducing caseload caps could help manage staff workloads and community demand, decreasing burden on individual staff and improving service quality.

> **"Caps on caseloads would be great, or assessments… [current caseloads are] a huge complication for us... a lot of times we just feel like we're triaging."**
>
> - Lead Agency Leader

- **Increase state support for recruitment of case managers.** Community members, the CAB, and lead agencies expressed a need for more case managers on lead agency staff teams to help guide community members through the initial assessment process. This person could be a "one-stop-shop" for questions throughout the process, and help break down complex aspects of the process, such as terminology, service offerings, and next steps.

> **"It would be nice for them to have, [case managers] like they do for health insurance to help folks move through. Sometimes it's just like you don't even know where to begin."**
>
> - Lead Agency Leader

- **Re-evaluate the 20-day mandate.** To address challenges relating to the 20-day mandate, during the 2024 legislative session, the Minnesota legislature amended the 20-calendar day period to 20 working days between the date that a community member requests an assessment and the date by which a lead agency must start the assessment. This change was effective immediately.[38]

Lack of Culturally Sensitive and Culturally Tailored Approaches

Individuals with limited English proficiency more acutely experience challenges with complex and administratively burden framework due to language barriers and a lack of additional supports. Cultural sensitivity is imperative for reducing distrust and stigma that individuals may feel toward receiving HCBS. Enhancing the quality and accessibility of communications and documents can help ease some of these challenges for individuals with language and literacy barriers. Lead agencies and community members suggested that community partnerships, training on culturally responsive care, and addressing applicants' social needs as ways to improve cultural sensitivity throughout the process and expand access to HCBS for all Minnesotans.

Language and literacy barriers led to frustration and inequitable experiences during the initial assessment process.

Inconsistent terminology and limited availability of materials in plain language makes the assessment process difficult to understand. Community members and lead agencies noted that some questions that were part of the required paperwork, such as in the application forms, were difficult to understand. Others mentioned that there was a lack of clear and simple instructions regarding the assessment process overall. The CAB mentioned confusion around the inconsistent use of terminology and acronyms in state materials and in paperwork. The CAB reported that this leads to confusion when asking about specific services, since

> **"There is a lack of plain language, but there is also just an insufficient amount of clear and complete language/instructions. When we receive instructions about continuing qualifications for a waiver, the instructions were both incomplete and unclear. No dates/deadlines were given, it was unclear where to send the information, and unclear what exactly was needed to be sent."**
>
> - CAB Member

lead agencies may not recognize what a community member is referring to simply because they use different terminologies or acronyms. For example, while the state refers to the initial assessment process as *"the initial HCBS assessment,"* community members may refer to this process as "*the waiver intake."* Lead agencies also explained that the lack of materials in plain language exacerbated barriers for people with limited English proficiency, people with mental illness and/or cognitive issues, and people who are deaf and/or blind.

A lack of interpretation services results in individuals relying on family members and loved ones for this support. Some community members noted they were not aware of or offered interpretation services. Instead, these community members may rely on family members and loved ones to serve as interpreters during the process. Lead agencies explained that a lack of translated materials and staff interpreters added to barriers for community members with limited English proficiency. Further, lead agencies noted that even if a community member prefers that a family member/loved one help interpret conversations instead of a staff interpreter, it may result in inaccurate interpretation given the complex and niche terminology used during the assessment process.

> **"Family members call back in saying, 'we did the assessment, can we redo it because my family member did not understand the questions?' And this is especially [true] for people whose first language is not English."**
>
> - Lead Agency Leader

Lack of additional supports and flexible approaches to accommodate needs exacerbated barriers to accessing HCBS

Community members explained that many cultures prefer in-person interactions instead of phone calls, creating barriers when communicating with lead agencies over-the-phone. Some steps of the initial assessment process, such as inquiring about HCBS or scheduling an assessment interview, happen over the phone. However, community members noted that they prefer in-person communication. Phone communications cause frustrations for those without reliable cell service, making it difficult for lead agencies to reach out to community members and vice versa. One CAB member added that, in her experience, many members of Tribal Nations and communities regularly change their phone numbers, creating barriers in following-up with them. Another CAB member highlighted that community members, especially those with limited proficiency in English, may struggle to understand someone over the phone.

> **"It's not easy for folks to pick up the phone and call and ask for these needs. It's so much easier to meet in-person."**
>
> - Community Member

Unmet social needs hindered access the initial assessment. Lead agencies, community members, and the CAB described how other barriers such as lack of transportation or unstable housing exacerbated access barriers to the initial HCBS assessment. For example, rural lead agencies reported long travel times and limited transportation options as barriers for their staff getting to applicants to conduct initial assessment interviews. In addition, one CAB member mentioned that many members

and communities are transient due to housing instability. Therefore, they may not receive mail from lead agencies as agencies may not have community members' most updated address, which may lead to community members losing track of services they should be receiving and, thus, having to start the initial assessment process over.

Increasing access to agency staff in-person can provide an additional access point for members who prefer in-person interactions. Community members explained that offering in-person support as well as increasing visibility of in-person options could mitigate challenges faced by those with unreliable cell service or who face difficulty leaving their homes. One community member shared their belief that "getting answers right away in-person is so much better than 'I'll call you next week,' and the phone could be off next week." CAB members echoed this sentiment highlighting the importance of providing options so that community members can pick what is best for them. One CAB member highlighted that meeting in-person outside their home was best for them, while another CAB member highlighted that meeting in-person at their home was critical for their assessment.

Cultural responsiveness throughout the initial HCBS assessment process can help lead agency staff understand and address community members' needs.

"Having that language interpreter helped a lot during the assessment process."

Bilingual lead agency staff made the initial assessment process easier

M., a 20-year-old Argentinian woman in the Twin Cities, helped her friend apply for HCBS in October of 2023. She often helped interpret for her friend who only speaks Spanish. Throughout the initial assessment process, she and her friend were still provided an interpreter. She shared that having an official Spanish interpreter there particularly helped convey specific words she forgot how to say in Spanish, helped translate specific and technical questions, and overall made the application process easier. Her friend ended up receiving the services she needed, and M. noted that the HCBS she receives help her out a lot.

Having culturally responsive staff and processes enable greater access to and navigation success of the initial HCBS assessment process. Offering interpretation services helped ease the experience for community members with limited English proficiency. One lead agency mentioned that matching staff to the culture and/or language of the applicant and tailoring parts of the process to meet the cultural norms of the applicant leads to a better assessment experience for both the applicant as well as lead agency staff. Several lead agencies noted using Language Line, an over-the-phone interpretation service, as a solution to offer live interpretation services when in-person interpretation services were not available.[39]

> **"A chunk of the population that we serve is Indigenous. We try to make sure that we ask about it so that we can be culturally appropriate and sensitive and try to see if there's ways to bring their culture into the services that they're receiving."**
>
> - Lead Agency Leader

Collaboration with external organizations, particularly CBOs, improves access, care coordination, and cultural responsiveness. Lead agencies shared that partnerships with CBOs, neighboring counties, Tribal Nations and communities, and MCOs create positive networks of support for individuals receiving services. Several lead agencies highlighted that partnerships with CBOs can enhance the cultural responsiveness of the initial assessment process. One lead agency shared that they perform cultural competency trainings for their staff in collaboration with local CBOs, including CBOs that serve Hmong populations and individuals in Lower Sioux community. Another lead agency shared that through working with a CBO that serves the Somali community as well as Somali community leaders to update their assessment process to be more culturally appropriate for Somali applicants; for example, because of this partnership, they improved clarity around marital status in their paperwork to include both legal marriages via licensure as well as traditional/faith-based marriages. Several lead agencies articulated that collaboration with neighboring counties, Tribal Nations and communities, and MCOs improves not only care coordination and the provider and referral network, but also improves the standardization of the implementation of the initial assessment. One lead agency shared that *their "region tries to get together to collaborate on MnCHOICES and [their] initial intake process to try to make it as consistent as possible."*

Enhancing the quality and accessibility (e.g., through translated materials and plain language) of documents and communications can make the initial assessment process clearer. The CAB, lead agencies, and community members expressed a need for more culturally responsive and plain language documents to make the initial assessment process clearer. Specific suggestions include:

- **Standardize terminology and materials across lead agencies.** Lead agencies and the CAB noted that descriptions of the HCBS process is inconsistent throughout the state, and CAB members noted that when the state makes any changes, adoption of these changes varies across lead agencies. Consequently, the state ends up pulling back on the change, adding to the confusion. Both lead agencies and the CAB explained that increased standardization and consistency in terminology across the state in all documents and processes related to the initial assessment could help mitigate confusion felt by both lead agency staff and community members. Lead agencies noted that standardized outreach and informational materials about the initial assessment from the state could facilitate the process.

> **"We have our own descriptions about what the waivers are like because the State's brochures don't tell you anything really; they basically tell you to talk to your county."**
>
> - Lead Agency Leader

- **Increase availability of translated documents.** CAB members explained that more materials and documents translated into languages other than English and available across all steps of the initial HCBS assessment process could improve access to HCBS for community members with limited English proficiency. One lead agency mentioned that they are reliant on DHS for the translation of HCBS documents and materials into languages other than English. Several lead agencies noted already having their printed materials available in other languages.

- **Use more plain language in HCBS materials.** CAB members noted that a simple, one-page, step-by-step guide that includes high-level descriptions on each step of the initial assessment process and an estimate of how long each step of the process should take would be helpful. They also described a need for materials to have simpler language to ease understanding for individuals with limited English proficiency and limited literacy.
- **Include more interpreters as part of lead agency teams.** Lead agency explained that staff interpreters who are familiar with the unique terminology and initial assessment processes can more accurately interpret conversations and facilitate the process for community members with limited English proficiency. Furthermore, interpreters can also help overcome English and non-English literacy barriers.

Increasing access opportunities to HCBS for Minnesotans who are undocumented could improve overall wellbeing for this population. Lead agencies mentioned that Minnesotans who are undocumented and who need waiver services can only rely on emergency medical assistance to access services. Many Minnesotans who are awaiting legal citizenship, especially those who may have limited English proficiency, may avoid applying or asking for needed services out of fear of jeopardizing their applications for citizenship. While resolving this gap will require creative solutions, lack of access and options for Minnesotans who are undocumented inequitably leaves out access to HCBS for immigrant communities.

Providing trainings for lead agency staff on care coordination and assessment implementation best practices, person-centered care, and cultural competency could improve experiences around the initial assessment. One lead agency leader shared, *"DHS has fallen short on their training opportunities…there's no training on coordination…it seems like there's still a set of expectations and things that DHS is assuming that we're doing."* CAB members echoed that a centralized source of training for lead agencies would help ensure that all individuals receive the same and equitable HCBS assessment process across the state. One CAB member shared that standardized trainings and resources for lead agencies could also be beneficial for CBOs either directly from DHS or indirectly from lead agencies.

Process changes could facilitate timelier HCBS eligibility determinations.

Lead agencies suggested that changes to the way the initial assessment is implemented could improve the assessment process for both agencies and community members, and lead to timelier receipt of HCBS. Specific process changes suggested include:

- **Re-evaluate outdated asset thresholds**. The CAB and lead agencies noted that the current asset and income eligibility thresholds are outdated and do not account for the increase in cost of living since it was first established. Re-evaluating this threshold could increase access to HCBS.

> **"The asset limit just seems so out of date compared to what we should expect. If we want people to also reach some level of self-sufficiency and help keep them in the community, to allow them only to retain $3,000...it's like we're providing them services, but also really limiting them in their own resources."**
>
> - Lead Agency Leader

- **Engage lead agencies early in conversations around process improvements or changes.** Lead agencies mentioned that it would be helpful to be looped in as early as possible to any systemic, policy, technology, or tool changes that the state is planning to ensure smoother implementation of such changes.
- **Make the MnCHOICES Revision shorter and more person-centered.** MnCHOICES beta testers explained that a shorter, more person-centered assessment would facilitate the assessment process and provide timelier HCBS.

Perspectives on MNCHOICES

Lead agencies reported that the revised MnCHOICES tool is a step toward a more person-centered assessment, but assessment challenges persist. Beta testers of the revised MnCHOICES tool explain that while the tool frames questions using person-centered language, the tool is still challenging to use. For example, the tool does not include all reporting requirements for MCOs (whose reporting requirements are different than that of county or Tribal Nation lead agencies), making the assessment process lengthier for MCO case managers. Additionally, MnCHOICES includes a lot of workarounds and additional processes that fall upon case managers to consider, leading to greater assessment burden on case managers. Therefore, lead agencies suggested that the revised tool should become more streamlined and use more plain language before it is fully deployed across the state.

Findings Related to Step III: Accessing Services Once Eligible

After a community member receives notice that they are eligible for HCBS, they may still face challenges accessing necessary services. Lead agencies indicated that access to services may vary based on workforce capacity across different geographies, leading to persistent unmet needs.

HCBS workforce shortages limits access to and quality of services that community members receive

Workforce challenges hinder individuals' ability to access services once they have been deemed eligible for HCBS. Lead agencies reported provider shortages among PCAs, home health aides, adult day care staff, specialty care, crisis respite, and mental health professionals. Further, lead agencies across the state reported that there is a lack of providers that reflect the demographic makeup of the populations they serve.

Satisfaction with HCBS received was also variable among community members. While some community members expressed that the services that they or their loved one/family member receive meets their needs, others expressed persistent unmet needs. For example, one community member explained that while her parents are eligible for services, they must now pick a financial management service company, which is an additional burden. Another community member explained that while her daughter's needs are met by HCBS, she still does so much for her daughter because, *"she is my daughter and I know her best."*

Expanding the HCBS workforce can help fill the gap between community need and availability of services

Community members, the CAB, and lead agencies noted that providing additional supports to the HCBS workforce can help the HCBS workforce better meet community need. These supports include:

- **Expanding the HCBS workforce**. Lead agencies noted that state support for a more robust workforce, including more home health workers, PCAs, and mental health professionals could improve access to HCBS. Further, increased reimbursement and rate increases that are directly provided to the HCBS workforce could improve staff recruitment and retention. One lead agency leader posited about the current low wages of home health workers, *"why would you, as a worker, go be responsible for these vulnerable children or adults? You're taking on all that liability for 10, 11, 12 bucks an hour. Minnesota will provide a $2 increase to this rate. The provide takes it and they don't necessarily pass it off to the staff."*
- **Implementing Community First Supports and Services (CFSS).** CFSS is a Minnesota healthcare program that offers flexible options to tailor care delivery to individual community members. CFSS expands options for family members to serve as a community member's support worker. In turn, this program could fill existing gaps in the HCBS workforce, as indicated by the CAB's feedback. DHS will begin implementing CFSS across Minnesota on October 1, 2024.[40] CAB members explained that paying family members to provide PCA services could be an opportunity to fill existing gaps in the HCBS workforce, especially in rural areas, and could facilitate the receipt of HCBS for community members who may not feel comfortable receiving care from a HCBS provider that they do not know.

Discussion and Recommendations

Lead agencies, community members, and CAB members identified and recommended several potential areas for improvement, including changes to lead agency processes and policies to facilitate timelier HCBS determinations and improve equity.

Recommendations

Findings from the study informed the following policy recommendations to improve people's experience as they work to access waiver programs. Based on these recommendations, DHS established how the organizations will use these policy recommendations and the timeline for each (i.e., Policy Impacts).

Short-term: DHS can implement the recommendation with minor policy changes or incorporate into current work.

Medium-term: Recommendation requires larger policy change, systems change and/or approval by the MN Legislature.

Long-term: Recommendation requires programmatic change or federal approval.

Process Changes

- **Early Engagement of Lead Agencies:** Involve agencies in systemic, policy, technology, or tool changes that the state is planning as early as possible could improve the implementation of such changes.

Policy Impact

DHS will share this recommendation to help better plan how Lead Agencies are involved with workgroups, meeting, and other forums.

- **Extend the 20-day mandate:** Address workforce bandwidth concerns reported by lead agencies in attempting to meet the 20-day mandate (i.e., the requirement that Lead Agency staff complete an in-person assessment no later than 20 calendar days from the date that the person requests it) to a longer period.

Policy Impact

DHS will share the impact of the 20-day mandate on workforce bandwidth and explore other policies that impact workforce bandwidth. Solutioning will balance the need to support lead agency bandwidth, timely access to programs and services, and meeting federal Centers for Medicare and Medicaid Services requirements.

Note: Minnesota passed legislation during the 2024 legislative session that extends the time lead agencies have to complete the initial assessment from 20 calendar days to 20 business days. This change was effective immediately. During the same legislative session, the state also passed legislation that extends the time an assessment is valid to from 60 to 365 days. This change will take effect on July 1, 2025.

Equity Considerations

- **Re-evaluate outdated thresholds:** Consider revising the current asset and income eligibility threshold, which is outdated and does not account for the increase in cost of living since it was first established.

Policy Impact

DHS will share recommendation with the federal Centers for Medicaid and Medicare Services (CMS) as they set financial eligibility thresholds for Medical Assistance. DHS currently administers two programs that support people with financial eligibility above Medical Assistance thresholds, the Alternative Care waiver and the Essential Community Supports Program.

- **Increase access to initial assessment options:** Offer opportunities for new and visibility of existing in-person support as people navigate the assessment process. Offering multi-modal assessment options may mitigate some challenges faced by those with unreliable cell service or those who face difficulty leaving their homes, as well as those who may prefer in-person.

Policy Impact

DHS will share the need for increased in-person support with lead agencies and DHS programs that work to build capacity within community organizations to support older adults and people with disabilities.

Improvement of Materials Used During the Initial Assessment Process

- **Standardize terminology and materials provided by the state:** Align terminology across documents and processes related to the initial assessment to help mitigate confusion felt by both lead agency staff and community members.

Policy Impact

DHS will share the need for terminology alignment with Lead Agencies and teams that develop materials, forms, and DHS website content.

- **Increase availability of non-English documents:** Make more non-English documents available across all steps of the initial assessment process, to expand access to and understandability of service offerings for non- or limited English speakers.

Policy Impact

DHS will share this recommendation with teams that are currently working to increase the number of languages to which documents are translated.

- **Include more plain language:** Develop a short step-by-step guide that includes high-level descriptions on each step of the initial assessment process and an estimate of how long each step of the process should take would be beneficial to HCBS applicants.

Policy Impact

DHS will share this recommendation with teams currently working to develop and translate plain language guides for people who are trying to access waiver services.

Increased Education about HCBS

- **Increase information for learning about HCBS:** Expand or otherwise enhance the accessibility and understandability of information about HCBS services, including who is eligible and how to access them.

Policy Impact

DHS will share this recommendation with the teams working on creating information in plain language and developing information resources for people.

- **Improve community members' understanding of the initial assessment process:** Provide upfront information about the duration of the intake process and who to contact with questions.

Policy Impact

DHS will share this recommendation with teams working on creating information resources for people, lead agencies, the Senior Linkage Line, and Disability Hub MN.

- **Provide follow-up materials:** Offer links or hard copies of written materials following each step of the initial assessment, to increase accessibility for people with mental health and/or cognitive issues, for those who are deaf and/or blind, and for those without access to printing.

Policy Impact

DHS will share this recommendation with lead agencies and the teams that are working to develop the HCBS Person Portal and on the MnCHOICES assessment.

- **Engage relevant community-based organizations:** Educate relevant CBOs, such as the Somali Parents Autism Network, on the current process and available resource materials.

Policy Impact

DHS will share this recommendation with teams and grant programs that work to build community capacity to support older adults and people with disabilities.

Support for Lead Agency and HCBS Workforce

- **Introduce caseload management:** Introduce caseload caps to better manage staff workloads, decrease burden, and improving service quality.

Policy Impact

Medium-term: DHS will share this recommendation with the teams, including directors of the Legislative Relations and County Relations teams, who are developing legislature proposals to engage with community partners and lead agencies on best practices for establishing benchmarks on caseload caps.

Note: DHS noted that caseload caps are at the lead agency's discretion because they differ from one lead agency to the next due to the complexity and acuity of the individual's needs and the level of coordination they require from staff.

- **Expand the HCBS workforce:** Consider ways to expand the capacity of the HCBS workforce (i.e., home health workers, PCAs, case managers, mental health professionals), such as offering greater reimbursement, rate increases, and incentives for bilingual lead agency staff to mitigate workforce and access challenges. Additionally consider ways to increase payment through CDCS for family members who serve as PCAs.

Policy Impact

DHS will share this recommendation with teams who are working to conduct a new analysis on case management rates of lead agencies and case management agencies. DHS will monitor CFSS' impact on allowing people to pay family members to provide care.

Note: Starting on October 1, 2024, DHS will implement CFSS, which will provide greater flexible options for people to remain independent in their homes and communities. This includes allowing a person's spouse or the parent of a minor to serve as their support worker.

- **Increase training for lead agency staff:** Expand trainings for staff on care coordination and assessment implementation best practices, person-centered care, and cultural competency to help improve community members' experiences around the initial assessment.

Policy Impact

DHS will share this recommendation with teams that develop trainings for Lead Agency case managers/care coordinators.

Opportunities for Further Research

Findings from this study highlight opportunities for additional research to better understand disparities in HCBS for underserved populations. These additional evaluation opportunities include:

- Develop and provide targeted dissemination (1-pagers, presentations, etc.) for DHS policy teams, community partners, and community members (i.e., CBOs, subcommunities) on specific topics or recommendations related to study findings and policy recommendations. Engage "end users" of public-facing products (i.e., individuals from U.S.-born Black, Latinx, Somali and Hmong communities and service providers) to co-design and cognitively test dissemination products to ensure materials are understandable, actionable, and culturally relevant.
- Conduct new and complementary research investigating the experience of individuals from U.S.-born Black, Latinx, Somali, and Hmong communities after they are deemed eligible for HCBS (including the barriers, challenges, and facilitating factors individuals report as they seek out, wait for and ultimately receive HCBS). This research could consider how and the extent to which individuals from these communities:
    - are connected to and ultimately receive the HCBS they are assessed as in need of (as documented in service planning data); and
    - Feel the services they are "planned for," connected to and ultimately receive reflect their needs and preferences, and are accessible.

Conclusion

This study employed community-engaged research methods to conduct a qualitative evaluation of the experiences of Somali, Latinx, Hmong, and U.S.-born Black Minnesotans as they learn about, seek, and navigate the initial HCBS assessment process and the perspectives of the lead agencies that administer the assessment.

Community members, lead agencies, and the study's CAB reported several key barriers in the current assessment process. Complex requirements, burdensome paperwork, and fragmentation result in

delayed or foregone HCBS. Individuals with limited English proficiency experience additional challenges with stigma, distrust, and lack of accessibility such as lack of plain language and translated materials and interpretation services. Demand, acuity, and complexity of community need has increased since the COVID-19 public health emergency, leading to staff burnout, delays, and less individualized attention for each community member. HCBS workforce shortages also limits access to and quality of services for individuals that are deemed eligible. Community members and lead agencies described the importance of case managers, building rapport, timely communication, working with community partners, and using culturally responsive approaches can create more positive and equitable experiences for individuals with the initial assessment process. Other process changes, like caseload management, expanding the HCBS workforce, and re-evaluating policies around asset thresholds and the 20-day mandate, could facilitate timelier HCBS eligibility determinations.

In response to needs, the state has already passed legislation during the 2024 legislative session that extends the time lead agencies have to complete the initial assessment and extends the time an assessment. In addition, DHS will implement CFSS, which will provide greater flexible options for people to remain independent in their homes and communities. DHS will share recommendations with additional partners (e.g., lead agencies, CMS) to further improve access to HCBS and the equity of the process.

Appendices

Appendix 1: Summary of NORC's Approach Selecting and Engaging Community Partners

NORC established partnerships with the Minnesota Home Care Association, Access North Center for Independent Living of Northeastern Minnesota, Metropolitan Center for Independent Living, and Southeast Minnesota Center for Independent Living. These partners have broad access our populations of focus and worked with NORC to weigh in on the evaluation design and conduct outreach to community member interviewers and interviewees.

NORC also worked with DHS to develop a list of CBOs throughout the state based on their service population, service area, and rurality. NORC worked with these CBOs in two ways. First, CBOs supported this evaluation by distributing recruitment materials throughout their networks and providing feedback on study materials. In total, NORC conducted outreach to 49 CBOs. To establish a partnership with these organizations, we invited them to an introductory meeting with the study team, where we introduced the study, explained their role, and answered any questions. Follow-up communications took place through email, where we answered ad-hoc questions and checked-in on recruitment activities.

NORC's outreach approach included multiple rounds of outreach. The first round of outreach included CBOs that both provide HCBS-related services and specifically serve one or more of the populations of focus. The second round of outreach included CBOs that may not work directly to support HCBS or whose missions may not be tied to HCBS, and that may not specifically serve the populations of focus. These organizations include YMCAs, religious groups, advocacy organizations, schools, home health agencies, local municipalities, and area agencies of aging.

Throughout the outreach process, NORC engaged with CAB members and CILs, wherein partnerships were already established, to conduct outreach within their networks to community-based organizations who could be potential partners. CAB members and CILs connected us with several CBOs across the state.

NORC provided an honorarium of $500 to all CILs and CBOs who participated in evaluation activities.

Appendix 2: Lead Agency Sample and Characteristics of Selected Lead Agencies

Characteristic	Number of Lead Agencies
Total	13
Organization Type	
Alliance	2
County	9
MCO	2
Tribe	2
Rurality	
Metro	6
Rural	4
NA	3
MN Region	
North Central	0
Northeast	1
Northwest	0
Central	1
Central East	1
Central West	2
Central South	1
South Central	1
Southeast	3
Southwest	1
NA	2
Beta Tester	
Yes	3
No	10

Appendix 3: Lead Agency Interview Protocol

Hello, my name is [*interviewer name*]. Thank you very much for your time today. I am working with NORC, a nonprofit research group. NORC is funded by the Minnesota Department of Human Services to conduct an evaluation of existing racial and ethnic disparities with the initial home and community-based services (HCBS) assessment process. Throughout our discussion I will simply refer to home and community-based services as HCBS. The purpose of the evaluation is to better understand the barriers and strengths to how people who are not currently receiving state plan or waiver services learn about waiver and state plan HCBS, ask for HCBS, and navigate the process to access HCBS.

Our team has worked closely with the Minnesota Department of Human Services and a community advisory board of HCBS recipients, community members, family members/people who supports a person receiving HCBS, and providers to refine our evaluation goals and questions.

A few things before we get started:

- The interview will take around 60 minutes.
- We are interested in hearing about your experiences working with people who are navigating the process to access HCBS. There are no right or wrong answers. It is also okay for you to decide not to answer or skip a question for any reason. It is also okay to stop the interview at any point.
- We are conducting multiple interviews with lead agencies across the state. We will develop a high-level summary and report based on what we hear from everyone we interview. We will not include your name or any other identifying information in our report, even if we include a quote.
- We would like to audio record this conversation, strictly for note-taking purposes. The notes and recording will be stored on NORC's secure server and will only be used by our project staff. Neither your name nor any other identifying information about you will be shared with anyone outside of the project team.

Is it okay if I audio record this conversation?

[If no, do not proceed with the interview]

Introduction

1. Please briefly describe your agency and your role within your agency.
    a. How would you describe the demographic composition of the community your agency supports? *Prompt*: We do not need specific percentages, but just to get a general sense of your community.
    b. In addition to your role, what roles in your lead agency, if any, are a part of the initial HCBS assessment process?

Sharing Information about HCBS

2. How does your agency share information with the community about state plan and waiver HCBS and the process needed to access state plan and waiver HCBS?
3. To what extent does your agency take steps to make information about HCBS available in culturally and linguistically appropriate formats based on the demographic composition of the community you serve?
    a. *Prompts, if needed:* For example, materials are available in other languages and formats, images are reflective of local communities.
    b. What works well in this process?
    c. What challenges do you face in this process?

The Process to Access HCBS

4. What works well about the process to access HCBS (from when people first learn about HCBS to eligibility determination and program enrollment)?
    a. What does not work well?
5. To what extent does your agency provide person-centered, culturally and linguistically appropriate services, including reasonable accommodations when appropriate, for individuals during the process to access HCBS?
    a. What works well?
    b. What are some challenges?
    c. What do you wish you or your agency could offer or change?
6. If a person meets level of care, how do you determine if that person should use State Plan Home Care only, HCBS waiver, or other services?

Impact of the Initial Process to Access HCBS

7. What are points in the process or aspects of the process where you see people commonly have challenges or drop off?
    a. *Prompts, if needed:* What about (if applicable)…
        i. Needing to interact with different staff at different stages of the assessment process?
        ii. The wait time to receive a MnCHOICES assessment?
        iii. Understanding what paperwork is needed or gathering the correct paperwork?
        iv. Understanding the process in general?
    b. What effective ways or strategies have you used to overcome challenges? For example, having staff that help individuals navigate the process.
    c. What do you wish you or your agency could offer or change?
8. What common feedback have you received about the initial process to access HCBS?
    d. *Prompts, if needed:* For example: People who speak English as their second language, US-born Black populations, Somali populations, Hmong populations, Latinx populations, undocumented populations?
    e. What initiatives has your agency implemented to better support or connect with BIPOC communities? What has worked or not worked?
    f. What would you change to make the process more equitable? A better experience for BIPOC and American Indian communities?

[MnCHOICES BETA TESTERS] MnCHOICES

9. Has the implementation of MnCHOICES impacted the process to access HCBS?
    a. [If Yes] How has MnCHOICES impacted the process? *Prompts, has there been a positive impact or a negative impact? Have barriers been lifted or are there new barriers? Are any of these impacts specific to US-born Black populations, Somali populations, Hmong populations, Latinx populations, people who speak English as their second language, or undocumented populations?*

Structural Barriers

10. What policies or statutes at the state or organizational level create structural barriers to people smoothly moving through the process to access HCBS?
    a. How would you like to see the state better support you or your agency?

Wrap-up Questions

11. What are your recommendations for improving the process to access HCBS?
12. Is there anything else you'd like to discuss about the process we haven't asked about?

Closing

Thank you for your time!

Appendix 4: Community Member Recruitment Flyer

GET A $125 GIFT CARD FOR TALKING TO US ABOUT YOUR EXPERIENCE APPLYING FOR WAIVER SERVICES

We are looking to learn more about your experiences applying for Minnesota home and community-based waiver services, also known as HCBS.

ARE YOU ELIGIBLE?

- 18 years or older.
- Currently live in Minnesota.
- Have reached out, or helped someone reach out, to a county, call center, or other agency to request waiver services in the past year.
- Can comfortably speak English, Spanish, Hmong, or Somali.

HOW LONG AND WHERE IS THE INTERVIEW?

Participate in a 30-minute Zoom or phone interview and get a $125 gift card.

WHO ARE WE?

This study is funded by the Minnesota Department of Human Services (DHS) and carried out by NORC at the University of Chicago.

WANT TO PARTICIPATE? CLICK THIS LINK, OR SCAN THIS QR CODE!

CONTACT US IF YOU HAVE ANY QUESTIONS.

(612) 293-7807

MN_HCBSEvaluation@norc.org

NORC at the University of Chicago

DEPARTMENT OF HUMAN SERVICES

Appendix 5: Project Information Form

Title of Project: Minnesota Home and Community-based Services (HCBS) Evaluation of the Assessment Process for Racial/Ethnic Disparities (HEARD)

- **Who are we?** NORC at the University of Chicago (NORC) is leading this study. NORC is a non-profit research group. Our team is working with the Minnesota Department of Human Services (DHS). We are also working with a group of people in the community and providers to design the study. Doing so helps us do this work "with" the community and not "for" or "to" the community.
- **What is HEARD study?** The goal of this study to understand Black, Indigenous, and other people of color's experiences when applying for home and community-based waiver services. These are also known as HCBS or waiver services. This can include things like job supports, home health aides, or home care nursing. At the end of this study, NORC will develop a report. The report will include key themes from these interviews. We will share the report with Minnesota DHS. We will also share what we find with people who participate in the study and other community members.
- **Why are we here talking to you today?** The purpose of the interview is to learn about your experiences when applying for waiver services. This includes challenges, supports, barriers, and anything else you would like to share.
- **Why should I participate?** Your participation is important to our study. What we learn during this study will help Minnesota DHS make changes to the process of applying for waiver services. These changes will address disparities in access to services.
- **What happens during the interview?** An interviewer will lead the conversation. With your consent, we would like to record your interview. We will use the audio-recording for notes. NORC will destroy the notes and recording when the project is finished. You will receive an electronic $125 gift card for participating in this study. Gifts cards can be sent to you by email or text.
- **Confidentiality:** NORC will keep your participation in this interview confidential. We will NOT include your name or other information that can identify you in summaries or reports we develop. We will also NOT share your name with Minnesota DHS.
- **Voluntary participation:** Your participation in this interview is voluntary. Your participation in this study will not affect your application for waiver services in any way. It will not affect your receipt of waiver services in any way. We have scheduled this discussion to last 30 minutes. But if you need or want to stop for any reason, that is okay. There are no right or wrong answers. We are only interested in hearing your perspective. It is okay for you not to answer or skip a question.
- **Right to ask questions:** Please contact Jared Sawyer (sawyer-jared@norc.org) and Simran Chugani (chugani-simran@norc.org) with questions, complaints, or concerns about this study. If you have any questions or concerns about your rights as a participant, please contact the NORC Institutional Review Board (IRB) Manager toll-free at (866) 309-0542 or by e-mail irb@norc.org.

Appendix 6: Community Member Recruitment Email

Hello,

I am writing on behalf of the NORC at the University of Chicago (NORC) research team that is conducting the MN Home and Community-Based Services (HCBS) Evaluation of the Assessment process for Racial/Ethnic Disparities (HEARD) project.

HEARD is a multi-year study led by the Minnesota Department of Human Services (DHS). HEARD looks at differences in access to and use of HCBS in Minnesota by race and ethnicity. Findings from the study will inform policy changes to address disparities in HCBS. As part of this study, the research team is looking to interview community members who receive HCBS and/or who are a family member/loved one of someone who receives HCBS. The team would like to talk to you about your experiences with the waiver intake process.

The research team is looking for people who are:

- 18 years or older.
- Currently live in Minnesota.
- Have reached out, or helped someone reach out, to a county, call center, or other agency to request waiver services in the past year.
- Can comfortably speak English, Spanish, Hmong, or Somali.

The interview will last 30 minutes, and you will receive $125 for your time.

Additional information is included in the flyer attached. Please make sure to scan the QR code on the flyer or use this link to complete the initial survey (survey link: https://norc.az1.qualtrics.com/jfe/form/SV_5pT0qSIm9IWlcqi). The research team will use this survey to reach out to you.

If you have any questions, please contact the research team at MN_HCBSEvaluation@norc.org.

Thank you,

Appendix 7: HCBS Recipient Interview Protocol

Hello, my name is [*NAME*]. Thank you very much for your time today. I am working with NORC, a nonprofit research group. This study is funded by the Minnesota Department of Human Services.

Our study is to understand people's experiences when applying for home and community-based services, or HCBS. These are often called "waiver services," because many people receive HCBS through the state's waiver programs. Some people receive HCBS through other state programs. For this study, we will use the term "waiver services." We are referring to all HCBS. This can include things like job supports, home health aides, or home care nursing. This can also include personal care assistance or consumer-directed community supports. Our team worked closely with a group of community members to develop study goals and questions.

A few things before we get started:

- The interview will take around 30 minutes. After the interview, we will send you a $125 electronic gift card for your participation.
- The risks to participating in this study are minimal. However, some questions might make you uncomfortable. We want to assure you that there are no right or wrong answers. We are only interested in hearing about your experiences. You are free to skip or not answer any questions for any reason. You can stop at any time.
- We plan to interview many community members for this study. We will develop a summary of major takeaways and report based on what we hear from everyone we interview.
    - We will share this report with the Minnesota Department of Human Services. We will not include your name or any other identifying information in our report, even if we include a quote. Findings from this study will help the Minnesota Department of Human Services make changes to the process of applying for waiver services to address disparities in access to services.
    - We will also share a summary of findings back to you and other community members.
- I have resources I can share with you if have additional questions about waiver services. I will also share a project information form that has contact information for our team, the Minnesota Department of Human Services, and our Institutional Review Board. Your participation in this study will not affect your application for waiver services in any way. It will not affect your receipt of waiver services in any way.
- We would like to audio record this conversation. This recording is only for note-taking purposes. The notes and recording will be stored on NORC's secure server. They will only be used by our study team. The recording will be destroyed once the study is complete. Neither your name nor any other information that can be used to identify you will be shared with anyone outside of the project team.
- However, if you share with me or other study staff any experiences of abuse, neglect, or exploitation, we may be legally required to report this to the Minnesota Department of Human Services. This study does not ask you any questions about abuse, neglect, or exploitation.

Do you agree to participate in this study? *[Get participant's oral consent for participation]*

[*If yes, continue*]

[*If no*] Thank you for your time today.

Is it okay if I audio record this conversation?

[If yes, ***start the recording****]*

[If no] Thank you for letting us know. We will not record this conversation. We will just take notes.

Do you have any questions for me before we begin?

Learning about Waiver Services

The following questions are to understand how you learned about waiver services.

1. How did you first learn about waiver services?
    a. Who or what helped you get the information you needed about waiver services?
        i. *[Prompts, if needed]:* For example, a case manager, other disability-related service providers, state resources.
    b. What barriers did you face in getting the information you need about waiver services?
        i. *[Prompts, if needed]:* For example, lack of information in your primary language, difficulty getting information that you could understand, difficulty finding information about what services you might be eligible for.
2. What influenced your decision to apply for waiver services?

Applying for Waiver Services

The following questions are about the process of applying for waiver services. That is, the experience of first calling your county or other agency to request waiver services.

3. Please describe your experience with starting the application process to receive waiver services.
    a. When was the last time you applied for waiver services?
        i. Have you tried to apply for waiver services multiple times? If so, how many times?
    b. How did you go about starting the application process?
        i. *[Prompt, if needed]* Who did you call or contact to start the process?
            1. *[Prompt, if needed]* Did you start the application process for yourself?
                a. [*If so*], how easy or difficult was it to do so?
        ii. *[Prompt, if needed]* Did someone refer you to a lead agency (a county, managed care organization, a tribal nation) to start the application process?
            2. *[If so]* Who provided this referral? For example, a community worker? A provider? Multiple people?

c. What or who helped you when starting the application process?
    i. *[Prompt, if needed]:* For example, case manager, other disability related service providers.
d. What difficulties did you experience with trying to apply for waiver services?
    i. *[Prompt, if needed]*: For example, issues arranging the intake? Language barriers? Compiling needed paperwork to demonstrate eligibility?
    ii. To what extent did you experience delays throughout the process?
        1. *[Prompt, if needed]:* Were the delays with scheduling the intake? In receiving a final decision about your eligibility?
        2. Did you already have medical assistance (MA)/disability certification prior to starting this process?
            a. *[If not]* How did that affect your experience?

4. What was the role of the person(s) you spoke to during this application process?
    a. [*Prompt, if needed*]: For example, a social services coordinator? A financial worker? Someone on the intake call line? An assessor? Multiple people?
    b. To what extent did the person(s) you talked to during this process take time to understand your values, interests, and goals?
    c. To what extent did the person(s) you talked to during this process explain things to you in a way you could understand?
    d. To what extent did the person(s) you talked to during this process answer all your questions or refer you to someone who could answer your questions?
    e. To what extent did the person(s) you talked to during this process help you navigate the different systems, departments, or paperwork needed to complete your application?
        i. [*Prompt, if needed]*: did the lead agency offer to explain things to you verbally? Translate documents into plain language?

For the interviewer: [If individual did not go through the waiver intake process (e.g., they started the application process but never received an assessment interview or intake stage), skip to the Effects of the Waiver Process section.]

Assessment Interview/Waiver Intake Process

The following questions are about the interview that people get so that Medicaid decides whether or not you are eligible for waiver services. This is sometimes referred to as the initial assessment interview or the waiver intake process.

5. Please describe your experience with completing the assessment interview or waiver intake process.
    a. How easy or difficult was the assessment interview or waiver intake process for you?
        i. *[Prompts, if needed]* What supports or accommodations did you receive during the assessment interview or waiver intake process (i.e., interpreter, case manager)?

3. How easy or difficult was it to request and receive these supports or accommodations?

ii. *[Prompts, if needed]* What challenges or barriers did you experience during the assessment interview or waiver intake process?

4. *[Prompts, if needed]:* For example, language barriers, physical inaccessibility, the time it took to complete the intake process.

b. To what extent did the person(s) who conducted your assessment interview or intake:
   i. …take time to understand your needs and goals?
   ii. …explain things to you in a way you could understand?
   iii. …answer all your questions or refer you to someone who could answer your questions?

c. To what extent did you understand the next steps in the process?

d. Based on your experience, what would make this process better?

Effects of the Waiver Process

6. What were the results of your assessment interview or waiver intake? That is, were you eligible or ineligible for waiver services?
   a. To what extent did the results of your assessment interview or waiver intake:
      i. match your need for waiver services?
   b. To what extent did the results of your assessment interview or waiver intake: get you the service(s) you need(ed)?
   c. [*If eligible*] To what extent do you currently receive waiver services?
   d. *[If not eligible]:* Do you have support needs that were or are unmet? If so, please describe.
      i. *[Prompts, if needed]* How do you meet your service needs without waiver services? For example, do you instead rely on family/friends for unpaid support? Did you look elsewhere for support services?
7. How has this process of applying for waiver services affected your overall health and wellbeing?
   a. *[Prompts, if needed]* To what extent did these challenges cause you stress or other negative effects?

Closing

8. What do you wish you had known before starting this process?
   a. What do you want the Minnesota Department of Human Services or agency that you communicated with to know about this process?

9. Based on your experience, what additional supports would benefit people when:
   a. learning about waivers?
   b. applying for waivers?
   c. completing the assessment interview or waiver intake process?

10. Do you have any final thoughts to share with me before we end?

Interviewer to end recording.

Incentive Payment

You will receive an electronic $125 gift card for your participation in this study. We can send you your gift card via email or text.

- Which type of gift card would you prefer: Walmart, Target, or Amazon?
- Would you prefer to receive the gift card via email or text?
- Please provide your [*email address or cell phone number*] where you would like to receive your gift card.
    - *[If needed, ask participant to spell out the email]*
    - Is this the same contact information you would like us to use to send you the project information form?
        - *[If no]* What [*email address/cell phone number*] would you like me to use to send you this information?

Referrals

- Is there anyone you know that has applied for waiver services or helped someone apply that would be interested in being part of this study?
    - *[If yes]* Would you please provide their name and contact information (e.g., phone number or email of the person(s) you think would be interested in participating in the study) so that we can reach out to them to be part of this study?
    - *[If they do not want to share the contact information]* You can have your friend instead call 612-293-7807 or email MN_HCBSEvaluation@norc.org.

Request for Additional Help or Resources

If a participant requested additional help during the interview, provide the following information:

- *Offer the **Minnesota Disability Hub** at 800-333-2466 if the participant:*
    - *feels that they have unmet needs,*
    - *would like to learn more about waiver services and other community resources, or*
    - *has questions such as 'who is my case manager?'*
- *If the participant is an older adult and needs additional help, offer the **Senior LinkAge Line** at 800-333-2433.*
- *If the participants needs safe, anonymous, confidential, and free mental health peer support, offer the following: 855-WARMLINE or text 'support' to 85511.*

Also remind the participant that this information is available in the project information form.

Emotional Distress

If a participant is experiencing emotional distress due to topics brought up during the interview, provide the following information and share the MN warmline flyer via email:

- *Share that if they are looking for support and need to talk that the **Minnesota Warmline** is a safe, anonymous, confidential, and free call line answered by a team of professionally trained Certified Peer Specialists who have firsthand experience living with a mental health*

condition. The Warmline can be reached by calling 855-WARMLINE or texting "support" to 85511

Report of Abuse, Neglect or Exploitation

If a participant has expressed or if you suspect that the participant is experiencing abuse, neglect, maltreatment, or exploitation, it is mandatory to report this.

- *After the interview call MAARC (1-844-880-1574) and make a report about the participant's suspected abuse, neglect, maltreatment, or exploitation. You may be required to share personal identifying information about the participant such as name and contact information during this report. This is the only instance in which it is okay to share these.*

Sign Off

Do you have any final questions for me before I let you go?

Thank you for your time!

Appendix 8: Family Member/Loved One of HCBS Recipient Interview Protocol

Hello, my name is [*NAME*]. Thank you very much for your time today. I am working with NORC, a nonprofit research group. This study is funded by the Minnesota Department of Human Services.

Our study is to understand people's experiences when applying for home and community-based services, or HCBS. These are often called "waiver services," because many people receive HCBS through the state's waiver programs. Some people receive HCBS through other state programs. For this study, we will use the term "waiver services." We are referring to all HCBS. This can include things like job supports, home health aides, or home care nursing. This can also include personal care assistance or consumer-directed community supports. Our team worked closely with a group of community members to develop study goals and questions.

A few things before we get started:

- The interview will take around 30 minutes. After the interview, we will send you a $125 electronic gift card for your participation.
- The risks to participating in this study are minimal. However, some questions might make you uncomfortable. We want to assure you that there are no right or wrong answers. We are only interested in hearing about your experiences. You are free to skip or not answer any questions for any reason. You can stop at any time.
- We plan to interview many community members for this study. We will develop a summary of major takeaways and report based on what we hear from everyone we interview.
    - We will share this report with the Minnesota Department of Human Services. We will not include your name or any other identifying information in our report, even if we include a quote. Findings from this study will help the Minnesota Department of Human Services make changes to the process of applying for waiver services to address disparities in access to services.
    - We will also share a summary of findings back to you and other community members.
- I have resources I can share with you if have additional questions about waiver services. I will also share a project information form that has contact information for our team, the Minnesota Department of Human Services, and our Institutional Review Board. Your participation in this study will not affect your application for waiver services in any way. It will not affect your receipt of waiver services in any way.
- We would like to audio record this conversation. This recording is only for note-taking purposes. The notes and recording will be stored on NORC's secure server. They will only be used by our study team. The recording will be destroyed once the study is complete. Neither your name nor any other information that can be used to identify you will be shared with anyone outside of the project team.

- However, if you share with me or other study staff any experiences of abuse, neglect, or exploitation, we may be legally required to report this to the Minnesota Department of Human Services. This study does not ask you any questions about abuse, neglect, or exploitation.

Do you agree to participate in this study?

[*If yes, continue*]

[*If no*] Thank you for your time today.

Is it okay if I audio record this conversation?

*[If yes, **start the recording**]*

[If no] Thank you for letting us know. We will not record this conversation. We will just take notes.

Do you have any questions for me before we begin?

Learning about Waiver Services

The following questions are to understand how you learned about waiver services.

1. What is your relationship to the person that you supported during the waiver intake process?
2. How did you and the person you support first learn about waiver services?
    a. Who or what helped you or the person you support get the information you needed about waiver services?
        i. *[Prompts, if needed]:* For example, a case manager, other disability-related service providers, state resources.
    b. What barriers did the person you support face in getting the information they needed about waiver services?
        i. *[Prompts, if needed]:* For example, lack of information in your primary language, difficulty getting information that you could understand, difficulty finding information about what services you might be eligible for.
3. What influenced the person that you support's decision to apply for waiver services?

Applying for Waiver Services

The following questions are about the process of applying for waiver services. That is, the experience of first calling your county or other agency to request waiver services.

4. Please describe your experiencing helping or the person that you support's experience with starting the application process to receive waiver services.
    a. When was the last time the person you support applied for waiver services?
        i. Have they tried to apply for waiver services multiple times? If so, how many times?

b. How did you or the person you support go about starting the application process?
    i. *[Prompt, if needed]* Who did you or they call or contact to start the process?
        1. *[Prompt, if needed]* Did you or they start the application process for themselves?
            a. [*If so*], how easy or difficult was it to do so?
    ii. *[Prompt, if needed]* Did someone refer you or the person that you support to a lead agency (a county, managed care organization, a tribal nation) to start the application process?
        1. *[If so]* Who provided this referral? For example, a community worker? A provider? Multiple people?
c. What or who helped you or the person you support when starting the application process?
    i. *[Prompt, if needed]:* For example, case manager, other disability related service providers.
d. What difficulties did you or the person you support experience with trying to apply for waiver services?
    i. *[Prompt, if needed]*: For example, issues arranging the intake? Language barriers? Compiling needed paperwork to demonstrate eligibility?
    ii. To what extent did you/they experience delays throughout the process?
        1. *[Prompt, if needed]:* Were the delays with scheduling the intake? In receiving a final decision about your eligibility?
        2. Did they already have medical assistance (MA)/disability certification prior to starting this process?
            a. *[If not]* How did that affect their experience?

5. What was the role of the person that you or the person you support spoke to during this application process?
    a. [*Prompt, if needed*]: For example, a social services coordinator? A financial worker? Someone on the intake call line? An assessor?
    b. To what extent did the person(s) you/they talked to during this process take time to understand their values, interests, and goals?
    c. To what extent did the person(s) you/they talked to during this process explain things to them in a way they could understand?
    d. To what extent did the person(s) you/they talked to during this process answer all their questions or refer them to someone who could answer their questions?
    e. To what extent did the person(s) you/they talked to during this process help them navigate the different systems, departments, or paperwork needed to complete their application?
        i. [*Prompt, if needed]*: did the lead agency offer to explain things to you verbally? Translate documents into plain language?

For the interviewer: [If the person that the individual supports did not go through the assessment or waiver intake process (e.g., they started the application process but never received an assessment interview or intake stage), skip to the Effects of the Waiver Process section.]

Assessment Interview/Waiver Intake Process

The following questions are about the interview that people get so that Medicaid decides whether or not you are eligible for waiver services. This is sometimes referred to as the initial assessment interview or the waiver intake process.

6. Please describe the person you support's experience with completing the assessment interview or waiver intake process, or your experience participating in the intake process.
    a. How easy or difficult was the assessment interview or waiver intake process ?
        i. *[Prompts, if needed]* What supports or accommodations did the person you support receive during the assessment interview or waiver intake process (i.e., interpreter, case manager)?
            1. How easy or difficult was it to request and receive these supports or accommodations?
        ii. *[Prompts, if needed]* What challenges or barriers did you or they experience during the assessment interview or waiver intake process?
            1. *[Prompts, if needed]:* For example, language barriers, physical inaccessibility, the time it took to complete the intake process.
    b. To what extent did the person(s) who conducted the person that you support's assessment interview or intake:
        i. …take time to understand their needs and goals?
        ii. …explain things to them in a way you and they could understand?
        iii. …answer all your/their questions or refer you/them to someone who could answer their questions?
    c. To what extent did you/the person that you support understand the next steps in the process?
    d. Based on the person that you support's experience, what would make this process better?

Effects of the Waiver Process

7. What were the results of the person that you support's assessment interview or wavier intake? That is, were they eligible or ineligible for waiver services?
    a. To what extent did the results of their assessment interview or waiver intake:
        i. Match their need for waiver services?
        ii. Get them the services(s) they need(ed)?
    b. [*If eligible*] To what extent do they currently receive wavier services?
    c. *[If not eligible]:* Do they have support needs that were or are unmet? If so, please describe.
        i. *[Prompts, if needed]* How do they meet their service needs without waiver services? For example, do they instead rely on family/friends for unpaid support? Did they look elsewhere for support services?
8. How has this process of applying for waiver services affected the person you support's overall health and wellbeing?

a. *[Prompts, if needed]* To what extent did these challenges cause them stress or other negative effects?

Closing

9. What do you wish you had known before starting this process?
    a. What do you want the Minnesota Department of Human Services or agency that you communicated with to know about this process?

10. Based on your experience, what additional supports would benefit people when:
    a. learning about waivers?
    b. applying for waivers?
    c. completing the assessment interview or waiver intake process?

11. Do you have any final thoughts to share with me before we end?

Interviewer to end recording

Incentive Payment

You will receive an electronic $125 gift card for your participation in this study. We can send you your gift card via email or text.

- Which type of gift card would you prefer: Walmart, Target, or Amazon?
- Would you prefer to receive the gift card via email or text?
- Please provide your [*email address or cell phone number*] where you would like to receive your gift card.
    - *[If needed, ask participant to spell out the email]*
    - Is this the same contact information you would like us to use to send you the project information form?
        - *[If no]* What [*email address/cell phone number*] would you like me to use to send you this information?

Referrals

- Is there anyone you know that has applied for waiver services or helped someone apply that would be interested in being part of this study?
    - *[If yes]* Would you please provide their name and contact information (e.g., phone number or email of the person(s) you think would be interested in participating in the study) so that we can reach out to them to be part of this study?
    - *[If they do not want to share the contact information]* You can have your friend instead call 612-293-7807 or email MN_HCBSEvaluation@norc.org.

Request for Additional Help or Resources

If a participant requested additional help during the interview, provide the following information:

- *Offer the **Minnesota Disability Hub** at 800-333-2466 if the participant:*
  - *feels that they have unmet needs,*
  - *would like to learn more about waiver services and other community resources, or*
  - *has questions such as 'who is my case manager?'*
- *If the participant is an older adult and needs additional help, offer the **Senior LinkAge Line** at 800-333-2433.*
- *If the participants needs safe, anonymous, confidential, and free mental health peer support, offer the following: 855-WARMLINE or text 'support' to 85511.*

Also remind the participant that this information is available in the project information form.

Emotional Distress

If a participant is experiencing emotional distress due to topics brought up during the interview, provide the following information and share the MN warmline flyer via email:

- *Share that if they are looking for support and need to talk that the **Minnesota Warmline** is a safe, anonymous, confidential, and free call line answered by a team of professionally trained Certified Peer Specialists who have firsthand experience living with a mental health condition. The Warmline can be reached by calling 855-WARMLINE or texting "support" to 85511*

Report of Abuse, Neglect or Exploitation

If a participant has expressed or if you suspect that the participant is experiencing abuse, neglect, maltreatment, or exploitation, it is mandatory to report this.

- *After the interview call MAARC (1-844-880-1574) and make a report about the participant's suspected abuse, neglect, maltreatment, or exploitation. You may be required to share personal identifying information about the participant such as name and contact information during this report. This is the only instance in which it is okay to share these.*

Sign Off

Do you have any final questions for me before I let you go?

Thank you for your time!

Appendix 9: Community Member Screener

The Minnesota Home and Community-based Services Evaluation of the Assessment process for Racial/Ethnic Disparities (HEARD) Study

Thank you for your interest in this study.

This study is to understand people's experiences when applying for home and community-based waiver services. These are also known as HCBS or waiver services. This can include things like job supports, home health aides, and home care nursing. NORC leads this study for the Minnesota Department of Human Services. NORC is a nonprofit research group. Findings from this study will help Minnesota Department of Human Services make changes to the process of applying for waiver services. These changes will address disparities in access to services. Our team worked closely with a group of community members to develop study goals and questions.

Please answer the questions below to see if you qualify to participate in this study. If you do, we will invite you to schedule an interview. Interviews will be 30 minutes. Interviews will be via Zoom or via phone. Spots are limited. People who complete the 30-minute interview will receive a $125 electronic gift card as a thank you for your time.

Eligibility Screener

1) Are you comfortable conversing in one of the following languages: English, Hmong, Somali, or Spanish? [Required]

   - Yes
   - No *[Terminate]*

2) Do you live in Minnesota?
   - Yes
   - No *[Terminate if no]*

3) What ZIP Code do you live in?

4) Do you live in a rural area?
   - Yes
   - No

5) How old are you? [*Required*]
   - *[Terminate if <18 years old]*

6) Do you identify as a person with a disability?
   - Yes
   - No
   - Prefer not to answer

7) [*If 6 = Yes*] Please describe your disability or disabilities. [*open-ended*]

8) Have you ever applied for waiver services (e.g., job supports, home health aides, and home care nursing)?
   - Yes
   - No
   - Prefer not to answer

9) [*IF 8 = Yes*] Do you currently receive waiver services?
   - Yes
   - No
   - Prefer not to answer

10) [*IF 8 = Yes*] When did you start the process of applying for waiver services? That is, when you reached out to your county, call center, or other agency to request waiver services.
   - Within the last year
   - Over a year ago

11) Are you a family member or do you support someone who has applied for waiver services (e.g., job supports, home health aides, and home care nursing)?
   - Yes
   - No
   - Prefer not to answer

12) [*IF 11 = Yes*] Do they currently receive waiver services?
   - Yes
   - No
   - Prefer not to answer

13) *[IF 11 = Yes]* When did they last start their application for waiver services? That is, when they reached out to their county, call center, or other agency to request waiver services.
- Within the last year
- Over a year ago

14) What racial or ethnic identities best describe you? Please select all that apply to you.
- American Indian
- Alaska Native
- Asian
- Black, African American, or African Heritage.
- Hispanic, Latino, or Spanish Origin [any]
- Native Hawaiian or Pacific Islander
- Middle Eastern
- North African
- White or European American
- Other, please describe
- Prefer not to answer

15) [If 14 = American Indian] Please describe your tribal affiliation and/or ethnic group. Select all that apply.
- Bois Forte Band of Chippewa
- Fond Du Lac Reservation
- Gichi-Onigaming/Grand Portage Band of Lake Superior Chippewa
- Leech Lake Brand of Ojibwe
- Lower Sioux Indian Community
- Millie Lacs Band of Ojibwe
- Prairie Island Indian Community
- Red Lake Band of Chippewa Indians
- Shakopee Mdewakanton Sioux (Dakota) Community
- Upper Sioux Community
- White Earth Reservation
- Other

16) [If 14 = Alaska Native] Please describe your tribal affiliation and/or ethnic group. Select all that apply.

- Athabascan
- Eyak
- Haida
- Tlingit
- Tsimshian
- Inuit
- Aleut/Unangan
- Other

17) [If 14 = Asian] Please describe your nationality or county of origin. Select all that apply.
- Hmong [core for Hmong or English speaking]
- Indian
- Chinese
- Vietnamese
- Korean
- Other

18) [If 14 = Black, African American, or African Heritage] Please describe your nationality or county of origin. Select all that apply.
- African American
- Somali
- European
- Mexican
- Liberian
- Other

19) [If 14 = Hispanic, Latino, or Spanish Origin] Please describe your nationality or county of origin. Select all that apply.
- Mexican or Mexican American
- Spanish
- Puerto Rican
- Salvadoran
- Ecuadoran
- Other

20) [If 14 = Native Hawaiian or Pacific Islander] Please describe your nationality or county of origin. Select all that apply.
- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Tongan
- Fijian
- Other

21) [If 14 = Middle Eastern] Please describe your nationality or county of origin. Select all that apply.
- Iranian
- Lebanese
- Israeli
- Other

22) [If 14 = North African] Please describe your nationality or county of origin. Select all that apply.
- Sudanese
- Moroccan
- Egyptian
- Other

23) [If 14 = White or European American] Please describe your nationality or county of origin. Select all that apply.
- German
- Norwegian
- Irish
- Swedish
- English
- Other

24) Were you born in the United States?
- Yes
- No [Terminate for US Born Black – If English speaking only, and selected Black, if No here then terminate. If Somali and/or English speaking, and selected Black if No here then not terminate]

25) What is your current gender identity? Please select all that apply to you.

- Female/ woman/ girl
- Male/ man/ boy
- Transgender male/ man/ boy
- Transgender female/ woman/ girl
- Nonbinary, genderqueer, Two-Spirit, or not only female or male
- Another gender. Please specify __
- Don't know
- Prefer not to answer

26) Do you think of yourself as: Please select all that apply to you:

- Lesbian or gay
- Straight or heterosexual (that is, not gay or lesbian)
- Bisexual
- Queer
- Pansexual
- Something else. Please specify: ____
- Don't know
- Prefer not to answer

[If eligible]
Congratulations, you are eligible for our study! We would like to learn a little more about you before we schedule an interview. The following questions will take less than 5 minutes to complete.

We would like to collect some contact information for the interview. We will only use this information to schedule an interview with you.

27) First Name:

28) In which of the following languages do you want to take the interview? [*Select all that apply*]

- English
- Hmong
- Somali
- Spanish

29) What mode should we use to contact you during the interview?

- Email:

   i. If email: please enter your email address: _____
- Phone:
   i. If phone, please enter your phone number: _____
- Text: _____
   i. If text, please enter your phone number: _____

30) How would you like to participate in this interview?
- Via Zoom
- Via another arrangement
   i. *If yes*: Someone from our team will contact you to schedule this interview and discuss an alternative arrangement.

31) [If 30 = Via Zoom] Please describe any phone or Zoom accommodations or support you may need to participate in this interview (e.g., closed captioning, sign language interpretation): __

Thank you! You can schedule your interview directly here: [insert Calendly link]

Once scheduled, you will receive an email or text notification from Calendly confirming the time and date of your 30-minute interview.

If you would prefer to speak to a member of our team directly for scheduling your interview, please call and leave a message in your preferred language at 612-293-7807 or email *MN_HCBSEvaluation@norc.org* with your preferred dates, times, and language.

This is the end of the survey. Thank you for taking the time to share this information with us.

[If terminate]
We are sorry, but you are not eligible to participate in our study. Thank you for your time!
[Terminate if 8 = No AND 11 = No]
[Terminate if 8 = YES but 10 = Over a year ago AND 101 = YES but 13 = Over a year ago]

Appendix 10: Fraud Detection Protocol

Purpose:

Protocol to screen for bots and fraudulent responses among Qualtrics survey screener responses. Noting that fraudulent responses for this study appear to be prompted from a combination of compensated study, large compensation ($125), and publicly accessible social media posts made about the study and survey screener.

Protocol:

To determine the validity of survey screener responses, we utilized a combination of IP addresses, Qualtrics RelevantID, phone numbers, time zones, open-end responses, and interviewer checks. Should a response satisfy all but one check, the team would conduct additional scrutiny of responses, including additional email or phone follow-up, to determine validity.

- *IP Address Geographic Check:* As study eligibility is limited to those living within Minnesota, we screened IPs for their location. We used sites such as https://www.infobyip.com/ to identify geographic location. As a note, IP may not show exact location of the respondent, therefore we screened for any IP within or adjacent to the state of Minnesota rather than IP matches to respondent-reported Zip Code.
- *IP Address Validity Check:* It is possible for a respondent to have an IP geographically in Minnesota while not being physically present in Minnesota. The easiest way to do this would be through the utilization of a VPN within Minnesota. While identification is not 100% accurate, we used sites such as https://ip.teoh.io/vpn-detection to potentially detect VPNs and identify suspicious IP addresses.
- *Qualtrics RelevantID Check:* Qualtrics RelevantID is an effective detector of fraudulent survey responses. Once enabled in Qualtrics, every survey respondent receives an auto-generated RelevantID score. RelevantID scores under 30 were passing, per Qualtrics guidelines. However, we identified both false positive and false negative flags for RelevantID and believe RelevantID should only be used in tandem with other validity checks.
- *Phone Number Geographic Check:* Not all respondents provided phone numbers. For respondents who did, we assessed if the area code was in Minnesota. While not a requirement for participation nor a certification of residence in Minnesota, positive identification of a Minnesota area code would indicate a potential valid response. We used phone number geographic check in tandem with other validity checks.
- *Phone Number Validity Check:* It is possible for a respondent to have a Minnesota area code without being physically present in Minnesota. The easiest way to do this would be through the utilization of a VOIP or a non-cell specific number such as one obtained through google voice. While identification is not 100% accurate, we used sites such as https://www.numlookup.com/ to potentially detect VOIPs and identify suspicious phone numbers.

- *Time Zone Check:* As study eligibility is limited to Minnesota, which has a central time zone, we included java script code within our Qualtrics survey to identify user time zone. While it is feasible for a respondent to not be within Minnesota's time zone due to a multitude of legitimate reasons, we excluded time zones such as West Africa Standard Time. The Qualtrics java script code we utilized to capture user time zone was: jQuery("#"+this. questionId).hide(); jQuery("#"+this.questionId+" .InputText").val(new Date().toString()); this.clickNextButton();
- *Open-end Response Check:* As a final check for survey responses, we added a few additional open-ended survey responses to the screener. We included questions about geography to verify those living in Minnesota, HCBS that one may not be able to answer without experience in the study topic, and how they heard about the study. We used reviewer discretion to assess if open-ended responses were legitimate. For responses that felt robotic or odd, we used online AI content checkers to detect for AI-generated responses.
- *Interviewer Check:* While the above checks are necessary to identify potentially fraudulent respondents, they are insufficient to identify all fraudulent respondents. We provided our interviewers with agency over cancellation at the start of interviews should they believe an interviewee is unable to provide valid answers and may be a fraudulent respondent.

Appendix 11: Resources Shared with Participants if they Expressed Unmet Need or Distress during Interviews

If you need…	Organization Name	Brief Description	Contact Information
Support for mental health or feelings of emotional distress	Minnesota Warmline	The Minnesota Warmline provides people with mental health support before they reach a point of crisis. The Minnesota Warmline is safe, anonymous, confidential, and free.	Phone: 855-WARMLINE Text: "support" to 85511
Help learning more about HCBS waiver services and other community resources	Minnesota Disability Hub	Disability Hub MN is a free statewide resource. It helps people learn more about HCBS waiver services. It helps people learn about other community resources as well. It answers questions such as, "who is my case manager."	Phone: 800-322-2466 Chat online at DisabilityHubMN.org
Help learning more about HCBS waiver services as an older adult	Senior LinkAge Line	Senior LinkAge Line is a free resource for older adults. Senior LinkAge Line helps people learn more about HCBS waiver services. It helps people learn about other community resources as well. It answers questions such as, "who is my case manager."	Phone: 800-333-2433 Email: senior.linkage@state.mn.us
Support with health resources as a Hmong, or Southeast Asian immigrant or refugee	Hmong American Partnership (HAP)	HAP is a group that serves Minnesota's Hmong community. They serve Southeast Asian, and other immigrant and refugee communities as well. HAP offers a range of services. These include disease self-management programs, mental health resources, and help with health care access.	Phone: 651-495-1557 Email: askHAP@hmong.org
Support with health resources as a Latinx/Latine immigrant	Copal	Copal is a group that aims to support Latin American families. Copal offers navigators to help with health care access and legal assistance.	Phone: 612-249-8736 Email: info@CopalMN.org
	discapacitados abriéndose caminos (d.a.c.)	d.a.c. is a group that provides services and supports to families who have children with disabilities. d.a.c. serves Latinx/Latine families, including immigrants.	Phone: 651-293-1748 Email: centro@dacmn.org
Support with health resources as a Somali or other immigrant or refugee	Somali Community Resettlement Services (SCRS)	SCRS is a group that offers support to immigrant and refugee communities. SCRS offers a range of services. This includes assisting with health care access and legal protection.	Phone: 612-353-8360 Email: info@SomalCRS.org

If you need…	Organization Name	Brief Description	Contact Information
Support with health resources as an East African refugee	African Immigrants Community Services (AICS)	AICS is a group that offers support to East African refugees that are in the Twin Cities area. AICS helps people navigate health insurance. They provide a range of other services and supports as well.	Phone: 612-871-9481 Email: info@aicsMN.org

References

[1] Comparison of Racial and Ethnic Groups in their Level of Care Screenings and Use of Home and Community-Based Services (HCBS) in the Minnesota Medicaid Population. Prepared for the Minnesota Department of Human Services. March 26, 2021.

[2] Assessment applicability and timelines. Minnesota Department of Human Services. Updated July 18, 2023. https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs-291132

[3] The HCBS Waivers, MnCHOICES, and Housing. Minnesota Department of Human Services. 2021. https://mn.hb101.org/documents/2021%20MnCHOICES-%20Disability%20Waivers%20101.pdf

[4] Home- and Community-Based Services. CMS. Updated on September 6, 2023. https://www.cms.gov/outreach-and-education/american-indian-alaska-native/aian/ltss-ta-center/info/hcbs

[5] LTSS demographic dashboard. Minnesota Department of Human Services. Updated on September 11, 2023. https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/public-planning-performance-reporting/performance-reports/demographic-dashboard/

[6] QuickFacts Minnesota. United States Census Bureau. https://www.census.gov/quickfacts/MN

[7] Comparison of Racial and Ethnic Groups in their Level of Care Screenings and Use of Home and Community-Based Services (HCBS) in the Minnesota Medicaid Population. Prepared for the Minnesota Department of Human Services. March 26, 2021.

[8] LTSS demographic dashboard. Minnesota Department of Human Services. Updated on September 11, 2023. https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/public-planning-performance-reporting/performance-reports/demographic-dashboard/

[9] QuickFacts Minnesota. United States Census Bureau. https://www.census.gov/quickfacts/MN

[10] Determining Medicaid Nursing Home Eligibility: A Survey of State Level of Care Assessment, Community Living Exchange Collaborative. Rutgers Health Center for State Health Policy. March 2008. https://www.cshp.rutgers.edu/publications/determining-medicaid-nursing-home-eligibility-a-survey-of-state-level-of-care-assessment-community-living-exchange-collaborative

[11] Unmet needs for home and community- based services among frail older Americans and their caregivers. Journal of Aging and Health. November 2010. doi: 10.1177/0898264310387132

[12] Comparison of Racial and Ethnic Groups in their Level of Care Screenings and Use of Home and Community-Based Services (HCBS) in the Minnesota Medicaid Population. Prepared for the Minnesota Department of Human Services. March 26, 2021.

[13] Comparison of Racial and Ethnic Groups in their Level of Care Screenings and Use of Home and Community-Based Services (HCBS) in the Minnesota Medicaid Population. Prepared for the Minnesota Department of Human Services. March 26, 2021.

[14] Unmet needs for home and community- based services among frail older Americans and their caregivers. Journal of Aging and Health. November 2010. doi: 10.1177/0898264310387132

[15] Interstate Variation and Progress Toward Balance in Use of and Expenditure for Long-Term Services and Supports in 2009. ASPE. March 17, 2014. https://aspe.hhs.gov/reports/interstate-variation-progress-toward-balance-use-expenditure-long-term-services-supports-2009-1

[16] Medicaid Long Term Services and Supports Annual Expenditures Report, Federal Fiscal Years 2017 and 2018. CMS. January 7, 2021. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures-2017-2018.pdf

[17] Final Outcome Evaluation of the Balancing Incentive Program. ASPE. February 11, 2019. https://aspe.hhs.gov/reports/final-outcome-evaluation-balancing-incentive-program-0

[18] The Community-Engaged Research Framework. NORC at the University of Chicago. May 2024. https://www.norc.org/research/library/community-engaged-research-framework.html.

[19] LTSS demographic dashboard. Minnesota Department of Human Services. Updated on September 11, 2023. https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/public-planning-performance-reporting/performance-reports/demographic-dashboard/

[20] LTSS performance measures dashboard. Minnesota Department of Human Services Updated September 11, 2023. https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/public-planning-performance-reporting/performance-reports/performance-measures-dashboard/

[21] 2022-23 Primary Home Language Totals. Minnesota Department of Education. https://education.mn.gov/mdeprod/groups/educ/documents/basic/cm9k/mdcw/~edisp/prod070853.xlsx

[22] QuickFacts Minnesota. United States Census Bureau. https://www.census.gov/quickfacts/MN

[23] All Minnesotans by immigrant group. Minnesota Compass. https://www.mncompass.org/topics/demographics/immigration

[24] LTSS demographic dashboard. Minnesota Department of Human Services. Updated on September 11, 2023. https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/public-planning-performance-reporting/performance-reports/demographic-dashboard/

[25] Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals. The Joint Commission. 2010. https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/health-equity/aroadmapforhospitalsfinalversion727pdf.pdf?db=web&hash=AC3AC4BED1D973713C2CA6B2E5ACD01B&hash=AC3AC4BED1D973713C2CA6B2E5ACD01B

[26] AHRQ Health Literacy Universal Precautions Toolkit (2nd edition). AHRQ. January 2015. https://www.ahrq.gov/sites/default/files/publications/files/healthlittoolkit2_4.pdf

[27] Evaluation of Literacy Level of Patient Education Pages in Health-related Journals. Journal of Community Health. June 2005. doi: 10.1007/s10900-004-1959-x

[28] Finding the Hidden Participant: Solutions for Recruiting Hidden, Hard-to-Reach, and Vulnerable Populations. International Journal of Qualitative Methods. December 2015. doi: 10.1177/1609406915621420

[29] Reaching the hard-to-reach: a systemic review of strategies for improving health and medical research with socially disadvantaged groups. BMC Medical Research Methodology. March 25, 2014. doi: 10.1186/1471-2288-14-42

[30] Advancing Health Equity in Minnesota: Report to the Legislature. Minnesota Department of Health. February 2014. https://www.health.state.mn.us/communities/equity/reports/ahe_leg_report_020114.pdf

[31] The Data Party: Involving Stakeholders in Meaningful Data Analysis. The Journal of Extension. February 1, 2013. doi: 10.34068/joe.51.01.03

[32] Engage Stakeholders in Program Evaluation: Throw Them a Party! The Journal of Extension. August 1, 2019. doi: 10.34068/joe.57.04.15

[33] Data Parties I Have Known: Lessons Learned and Best Practices for Success. The Journal of Extension. August 1, 2018. doi: 10.34068/joe.56.04.09

[34] A guide to incorporating a racial and ethnic equity perspective throughout the research process. Child Trends. October 3, 2019. https://www.childtrends.org/publications/a-guide-to-incorporating-a-racial-and-ethnic-equity-perspective-throughout-the-research-process

[35] State Medical Review Team (SMRT): Overview. Disability Hub MN. https://disabilityhubmn.org/top-topics/other/state-medical-review-team-smrt/

[36] Medical Assistance (MA) coverage for home and community based services through a waiver program. Minnesota Department of Human Services. Updated June 4, 2024. https://mn.gov/dhs/people-we-serve/adults/health-care/health-care-programs/programs-and-services/ma-waiver-programs.jsp

[37] Assessment applicability and timelines. Minnesota Department of Human Services. Updated July 7, 2023. https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs-291132

[38] Minnesota Session Laws – 2024, Regular Session. Minnesota Legislature, Office of the Revisor of Statutes. May 24, 2024. https://www.revisor.mn.gov/laws/2024/0/125/laws.1.15.0#laws.1.15.0

[39] About Language Line. Language Line. https://www.languageline.com/company

[40] Community First Services and Supports. Minnesota Department of Human Services. Updated June 13, 2024. https://mn.gov/dhs/people-we-serve/people-with-disabilities/services/home-community/programs-and-services/cfss.jsp