



National Core Indicators

Aging and Disability Adult Consumer Survey

2016-2017 Minnesota Results





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# **Preface**

The Minnesota Department of Human Services (MN DHS) helps provide long-term services and supports (LTSS) to Minnesotans with disabilities. Together with our partners, the MN DHS works to create a Minnesota where people with disabilities lead fulfilling, community lives of their own design. Our goal is to make it easier for people to live, work, and enjoy life in ways that are most meaningful to them.

The NCI-AD is one way that MN DHS measures quality and uses the results to improve services and supports. The NCI-AD survey was developed by the National Association of States United for Aging and Disabilities (NASUAD) and the Human Services Research Institute (HSRI) as a validated tool to assess states' publicly funded LTSS. The NCI-AD is how DHS hears directly from people about how well their services and supports help them to live, work, and engage in their community.

#### The NCI-AD results are used to:

- report on the quality of life and experiences of people served;
- · inform improvements to current services based on reported needs and preferences; and
- support efforts to develop new services and initiatives.

Minnesota is proud to participate once again in this year's NCI-AD. Hearing directly from people is invaluable to making meaningful improvements to the LTSS system.

Alex Bartolic, Director, Disability Service Division Minnesota Department of Human Services





DEPARTMENT OF HUMAN SERVICES

Human Services Research Institute (HSRI) 2336 Massachusetts Avenue Cambridge, MA 02140 National Association of States United for Aging and Disabilities (NASUAD) 1201 15th St. NW, Ste. 350 Washington, DC 20005 Minnesota Department of Human Services (DHS) 540 Cedar Street Saint Paul, MN 55101

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# List of Abbreviations Used in This Report

BI - Brain Injury Waiver

BI-NB – Neurobehavioral Hospital level of care criteria for the BI Waiver

BI-NF – Nursing Facility level of care criteria for the BI Waiver

CAC – Community Alternative Care Waiver

CADI – Community Access for Disability Inclusion Waiver

CDCS – Consumer Directed Community Supports

DHS – Department of Human Services

HC – State Plan Funded Home Care program

HCBS – Home and Community-Based Services

HSRI - Human Services Research Institute

LTC – Long Term Care

LTSS – Long Term Services and Supports

MA – Medical Assistance

N - Number of respondents

NASUAD - National Association of States United for Aging and Disabilities

NCI-AD – National Core Indicators for Aging and Disabilities

PACE – Program of All-Inclusive Care for the Elderly

QAM – Quality Assurance Monitor

SMRT – State Medical Review Team

VR – Vital Research

# Contents

What Is NCI-AD?	
NCI-AD Survey	2
NCI-AD in Minnesota	
Sample	
Survey Process	6
Stakeholders	ε
Organization of Results	ξ
Limitations of Data	<u>C</u>
Results	10
Community Participation	10
Choice and Decision Making	11
Relationships	12
Satisfaction	13
Service Coordination	14
Care Coordination	16
Access	17
Safety	19
Health Care	20
Wellness	21
Medications	22
Rights and Respect	23
Self-Direction of Care	24
Work	25
Everyday Living	26
Affordability	27
Planning for future	28

Control	29
Appendix A: Rules for Recoding and Collapsing Responses	30
Appendix B: Un-Collapsed Data	36
Demographic Tables	36
Community Participation—un-collapsed	40
Choice and Decision Making—un-collapsed	41
Relationships—un-collapsed	42
Satisfaction—un-collapsed	43
Service Coordination—un-collapsed	45
Care Coordination—un-collapsed	48
Access—un-collapsed	49
Safety—un-collapsed	53
Health Care—un-collapsed	55
Wellness—un-collapsed	
Medications—un-collapsed	59
Rights and Respect—un-collapsed	59
Self-Direction of Care—un-collapsed	61
Work—un-collapsed	62
Everyday Living—un-collapsed	63
Affordability—un-collapsed	64
Planning for the Future—un-collapsed	64
Control—un-collapsed	
Appendix C: Minnesota's State-Specific Questions	
Appendix D: Overview Table—All NCI AD Domains and Indicators	67

### What Is NCI-AD?

The National Core Indicators for Aging and Disabilities™ (NCI-AD™) are standard measures used across participating states to assess the quality of life and outcomes of seniors and adults with physical disabilities—including traumatic or acquired brain injury—who are accessing publicly funded services through Medicaid, the Older Americans Act, the Program of All-Inclusive Care for the Elderly (PACE), skilled nursing facilities/nursing homes, and/or state-funded programs. The effort is coordinated by the National Association of States United for Aging and Disabilities (NASUAD)—the membership organization for state Aging, Disability, and Medicaid directors—and the Human Services Research Institute (HSRI). Data for the project are gathered through a yearly in-person Adult Consumer Survey administered by state Aging, Disability, and Medicaid Agencies (or a state agency-contracted vendor) to a sample of at least 400 individuals in each participating state. NCI-AD data measure the performance of states' long-term services and supports (LTSS) systems and help state agencies with quality improvement initiatives, strategic planning, and legislative and funding prioritization. The project officially launched in mid-2015 with 13 participating states: Colorado, Delaware, Georgia, Indiana, Kansas, Maine, Minnesota, Mississippi, New Jersey, North Carolina, Ohio, Tennessee, and Texas.

Currently, the project is in its third year of data collection. The data presented in this report were collected during the project's second year of implementation (2016-2017). For more on the development and history of NCI-AD, refer to the <u>National Core</u> <u>Indicators Aging and Disability Adult Consumer Survey: 2015-2016 National Results</u> report, available on the NCI-AD website at <u>www.NCI-AD.org</u>.

### **NCI-AD Survey**

#### **Survey Overview**

The NCI-AD Adult Consumer Survey is designed to measure outcomes across 18 broad domains and key areas of concern. These 18 domains are comprised of approximately 50 core indicators. Indicators are the standard measures used across states to assess the outcomes of services provided to individuals, including employment, respect and rights, service coordination, care coordination, choice, and health and safety. An example of an indicator for Service Coordination is: "Proportion of people who receive the services that they need."

While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the Access indicator that measures "Proportion of people who get needed equipment, assistive devices" is measured by several survey questions that ask about the person's need for various equipment and devices.

#### **Survey Organization**

The NCI-AD Adult Consumer Survey consists of a pre-survey form, a background information section, the in-person interview questions, and an interviewer feedback form. An additional Proxy Version of the survey is available for surveys conducted only with a proxy respondent. Each is described below.

**Pre-Survey Information:** This form has questions that help the interviewer prepare for the meeting. Pre-Survey data are not received by the NCI-AD project team, are not analyzed, and thus are not included in this report. The Pre-Survey form is for interviewer use only.

**Background Information:** This section consists of questions about the consumer's demographics, residence, and services and supports. Data are generally collected from state records, case managers, or a combination of both. When information is not

available or is incomplete, the interviewer is responsible for collecting the missing Background Information items at the end of the interview.

**In-person Consumer Survey:** This section includes all questions that compose the full in-person interview. The survey is organized into thematic sub-sections with related questions grouped together (e.g., questions about employment are in the same section; questions about the home are in a separate section, etc.). The in-person section is completed one-on-one with the person receiving services, whenever possible. The respondent may ask for assistance answering certain questions through the help of a proxy respondent (e.g., family member or close friend) if needed. While the full in-person survey includes both subjective and objective questions, the proxy may only assist with answering a pre-determined subset of more objective items.

**Proxy Version:** This version of the survey is used when the person receiving services is unable to complete *any* of the survey or has asked a proxy to complete the survey on their behalf. This version includes only the pre-determined subset of more objective survey questions that may be answered by a proxy respondent. Questions in the proxy version are rephrased to reflect that they about the individual receiving services and not the proxy respondent.

**Interviewer Feedback Form:** This form is completed by the surveyor after the interview is finished to record information such as length and place of the meeting, respondent's ability to answer the questions, if others were present during the interview, any problematic questions encountered, and general feedback for the NCI-AD project team.

#### **NCI-AD** in Minnesota

The Minnesota Department of Human Services (DHS), in partnership with NASUAD and HSRI, implemented the 2016-2017 NCI-AD Adult Consumer Survey in Minnesota. DHS contracted with Vital Research Inc. to independently evaluate Minnesota's publicly funded LTSS. Results will be used to support Minnesota's efforts to strengthen LTSS policy, inform quality assurance activities, and improve the quality of life and outcomes of people with disabilities. To measure and track results over time, Minnesota will participate in the NCI-AD on a yearly basis.

### Sample

The total number of NCI-AD Adult Consumer Surveys completed in Minnesota and included for analysis in 2016-2017 was 403 (Total N=403). The four program populations included in the survey sample are detailed below.

Community Alternative Care Waiver (CAC): This program provides home and community-based services necessary as an alternative to institutionalization that promote the optimal health, independence, safety and integration of a person who is chronically ill or medically fragile and who would otherwise require the level of care provided in a hospital. To be eligible for the CAC waiver, a person must be eligible for Medical Assistance, certified disabled by Social Security or the State Medical Review Team (SMRT), under age 65 at the time of opening to the waiver, determined by the case manager/service coordinator to meet the hospital level of care criteria, certified by the primary physician to meet the level of care provided in a hospital, and has an assessed need for supports and services over and above those available through the MA State Plan. Some services covered include: case management/service coordination, chore services, Consumer Directed Community Supports (CDCS), and family adult day services. Eight people (N=8) from this program were included for analysis.

**Community Access for Disability Inclusion Waiver (CADI)**: The CADI waiver program provides home and community-based services necessary as an alternative to institutionalization that promote the optimal health, independence, safety and integration of a person who would otherwise require the level of care provided in a nursing facility. To be eligible for the CADI waiver, a person must be eligible for Medical Assistance, certified disabled by Social Security or the State

Medical Review Team (SMRT), under age 65 at the time of opening to the waiver, determined by the case manager/service coordinator to need nursing facility level of care, and has an assessed need for supports and services over and above those available through the MA State plan. Some services covered include: case management/service coordination, chore services, Consumer Directed Community Supports (CDCS), and family adult day services. Three hundred and fifty-two people (N=352) from this program were included for analysis.

State Plan Funded Home Care (HC): The HC program provides medical and health-related services and assistance with day-to-day activities to people in their home. It can be used to provide short-term care for people moving from a hospital or nursing home back to their home, or it can also be used to provide continuing care to people with ongoing needs. Home care services are available to people who are eligible for Medical Assistance or MinnesotaCare Expanded, who have needs that are medically necessary and physician ordered and provided according to a written service plan. Services include equipment and supplies, home care nursing, home health aide, personal care assistance, skilled nursing visits, occupational therapy, physical therapy, respiratory therapy, and speech therapy. Fifteen people (N=15) from this program were included for analysis.

Brain Injury (BI): The Brain Injury waiver program provides home and community-based services necessary as an alternative to institutionalization that promote the optimal health, independence, safety and integration of a person and who would otherwise require the level of care provided in a specialized nursing facility or neurobehavioral hospital. To be eligible for the BI Waiver, a person must be eligible for Medical Assistance, certified disabled by Social Security or the State Medical Review Team (SMRT), under age 65 at the time of opening to the waiver, determined by the case manager/service coordinator to meet one of the following level of care criteria: Nursing Facility (BI-NF), Neurobehavioral Hospital (BI-NB). Also, they must have a completed BI Waiver Assessment and Eligibility Determination and be diagnosed with one of the documented diagnoses of brain injury or related neurological condition that resulted in significant cognitive and behavioral impairment. Some of the services covered include: 24-hour emergency assistance, adult day services, residential care services, respite, prevocational services, structured day program, case management/service coordination and supported employment services. Twenty-eight people (N=28) from this program were included for analysis.

Because of the small numbers of people interviewed in three of the four programs, only Minnesota's overall state averages are calculated and reported. Using all completed surveys, the margin of error for the state as a whole is approximately 5% (at 95% Confidence Level). Readers should be aware that for some survey items, the actual number of valid responses may be smaller than the total number of completed surveys. This is explained in more detail in "Organization of Results" section below.

### **Survey Process**

DHS contracted with Vital Research (VR), a national survey group, to hire and manage local survey interviewers to conduct the NCI-AD.

#### **Interviewer Training**

The interviewers attended a three-day training. The training consisted both of classroom-style teachings as well as hands-on and group activities provided by HSRI. It covered a large number of topics with the goal that each interviewer would feel confident and ready to begin data collection as soon as training was complete. Additional trainings were conducted with HSRI via webinar and in-person with an experienced VR interviewer and trainer.

#### **Survey Invitation**

Individuals sampled received a letter and brochure from DHS to explain they may receive a call from VR inviting them to participate in the survey. Interviewers reached out to consumers and/or guardians over the phone to explain the project and, if they agreed to participate, to schedule an appointment to conduct the interview at the consumer and/or guardian's convenience. During this call, interviewers obtained verbal consent from the consumer and/or guardian prior to scheduling an appointment.

#### **Quality Assurance**

Quality assurance standards were ensured across all field activities through in-person monitoring, verification calls, and data validation.

#### In-person monitoring

A Quality Assurance Monitor (QAM) was selected and trained to observe interviewers and provide feedback. The QAM observed returning interviewers during one interview and new interviewers during two interviews. During these visits, the QAM observed the interviewers conducting surveys and assessed the interviewers' adherence to VR quality standards. The QAM also followed along with the interview and entered survey data for interrater comparison. Overall agreement between the QAM data and interviewer survey data was 94.72%. During the interview, the QAM completed an interview observation checklist, which was used to evaluate the interviewers on a set of behaviors: interview environment navigation, professionalism and rapport, interviewing skills, and procedural/technical skills. The QAM tallied the scores the interviewers received on the set of behaviors, which then created an overall skills rate score. If any interviewer scored lower than 80% overall, the QAM would call VR to discuss.

#### Verification calls

VR conducted verification calls for approximately 5% of all completed interviews to confirm interview completion and to ask the service participant about his/her experience with the interviewer.

#### Data validation

VR implemented methods to reduce data entry errors, improve data quality/accuracy, and validate data once received. Data collection software was programmed to support data validation and minimize data entry errors.

- Survey logic was programmed to generate the NCI-AD question skip patterns.
- Answers were required for all survey questions.

- Double-entry of the interview ID was required at the beginning of each survey to reduce entry and matching errors.
- A tracking database was developed with queries to flag and check for potential data issues.
- Interview start and end times were tracked to verify appropriate interview lengths.

#### MN-specific questions

Minnesota elected to add three state-specific questions to the main NCI-AD in-person survey.

#### Stakeholders

Stakeholder engagement was a core component of planning and implementing the NCI-AD survey. The stakeholder groups that were part of this ongoing process include the HCBS Partners Panel, State Quality Council, Managed Care Organizations, Area Agencies on Aging, and cultural communities. In addition, the results of the survey are used in reports and performance measures communicated with the MN Legislature, Olmstead Committee, and the general public.

### **Organization of Results**

The following section of the report presents findings from Minnesota's 2016-17 NCI-AD data collection cycle. Results are grouped by domain. For each item, collapsed data are shown, as well as the number of people that responded to that item. For rules on collapsing response options, please refer to Appendix A.

The Ns (number of respondents for the item) are the number of valid responses to that survey item. That number may be smaller than the total number of completed surveys for several reasons:

Certain questions in the survey could only be asked of the service recipient; proxy respondents were not allowed to answer
those questions. As the number of completed surveys includes both the full in-person surveys and the proxy surveys, these
questions were only asked in the full in-person survey and thus have a smaller number of respondents.

- Only valid responses were included in both denominator and numerator. The Ns also represent the number of valid responses only. Unclear, refused and, unless otherwise stated, "don't know" responses were excluded.
- The survey contains several skip logic patterns. This means that depending on the response to a previous survey item, a question may or may not be asked, as appropriate. When a question is skipped due to skip logic, that survey case does not contribute to the calculations for the item and does not contribute to the N.

Un-collapsed data showing all categories of responses for each item are shown in Appendix B.

Minnesota's state-specific questions that the state chose to add to the main NCI-AD in-person survey are show in Appendix C.

#### Limitations of Data

This report contains survey results related to the quality and impact of LTSS in Minnesota. However, the report does not include benchmarks for acceptable or unacceptable levels of performance for the state. Rather, it is up to stakeholders to assess the information contained in this report and draw conclusions. This report is intended to be one mechanism for state leaders and community stakeholders to assess the current state of Minnesota's LTSS system and identify areas that are working well and areas that could use improvement. It is up to public managers, policy-makers, and other stakeholders to decide whether a particular finding suggests that intervention or further investigation are necessary. Furthermore, by aligning NCI-AD measures with specific state and federal initiatives, Minnesota can more accurately demonstrate the areas in which transformation is evident and continue to promote quality efforts, while also recognizing limitations and ongoing challenges.

Extreme caution should be exercised when interpreting results where the item sample size is small. Valid item Ns for each item are shown throughout. Any time the sample size is smaller than 20, the N is also asterisked. It is advised that in these cases the data are treated as suggestive and informational only, and not used for drawing firm conclusions.

## Results

# **Community Participation**

People are able to participate in preferred activities outside of home when and with whom they want.

There is one Community Participation indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who are able to participate in preferred activities outside of home when and with whom they want.

There are three survey items within this domain. Un-collapsed data are shown in Appendix B.

The following are the collapsed results for Minnesota:

- 49% are as active in the community as they would like to be (N=360)
- 20% have tried to leave the house to go somewhere in the past week and have not been able to go (N=365)

Note: These are both new variables.

# Choice and Decision Making

People are involved in making decisions about their everyday lives and with whom they spend their time.

There is one Choice and Decision-Making indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who are involved in making decisions about their everyday lives including where they live, what they do during the day, the staff that supports them and with whom they spend time

There are four survey items within this domain. Un-collapsed data are shown in Appendix B.

- 53% can choose their roommate if they want (if in group setting; \*N=19—very small number of responses)
- 85% can get up and go to bed at the time they want (N=371)
- 74% can eat their meals when they want (N=370)
- 76% may furnish or decorate their room if they want (if in a group setting; N=120)

# Relationships

People have friends and relationships and do not feel lonely.

There is one Relationship indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who are able to see or talk to their friends and families when they want to.

There are two survey items within this domain. Un-collapsed data are shown in Appendix B.

The following is the collapsed result for Minnesota:

• 85% can always or almost always see or talk to friends and family when they want to (if there are friends and family who do not live with person; N=336)

#### Satisfaction

People are satisfied with their everyday lives – where they live, who works with them, and what they do during the day.

There are three Satisfaction indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people who are satisfied with where they live.
- 2. Proportion of people who are satisfied with what they do during the day.
- 3. Proportion of people who are satisfied with staff who work with them.

There are seven survey items within the Satisfaction domain. Un-collapsed data are shown in Appendix B.

- **76%** like where they are living (N=376)
- 44% would prefer to live somewhere else (N=371)
- **59%** always like how they usually spend their time during the day ("sometimes" and "always" responses were combined; N=369)
- 34% feel that paid support staff change too often (proxies allowed; N=263)
- 77% feel that paid support staff do things the way they want them done (N=282)

#### **Service Coordination**

Service coordinators are accessible, responsive, and support the person's participation in service planning and the person receives needed services.

There are ten Service Coordination indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people who know who to call with a complaint, concern, or question about their services
- 2. Proportion of people whose case manager talks to them about any needs that are not being met
- 3. Proportion of people who can get in contact with their case manager when they need to
- 4. Proportion of people who receive the services that they need
- 5. Proportion of people finding out about services from service agencies
- 6. Proportion of people who want help planning for future need for services
- 7. Proportion of people who have an emergency plan in place
- 8. Proportion of people whose support workers come when they are supposed to
- 9. Proportion of people who use a relative as their support person
- 10. Proportion of people who have a backup plan if their support person doesn't show up

There are 12 survey items within this domain. Un-collapsed data are shown in Appendix B.

- 76% know whom to contact if they want to make changes to their services (N=385)
- **78%** can reach their case manager/care coordinator when they need to (if they know they have a case manager/care coordinator; N=359)
- 84% report that their paid support staff show up and leave when they are supposed to (N=280)
- **72**% have an emergency plan in place (N=359)

- 44% want help planning for their future need for services (N=346)
- 62% feel their services meet all their needs and goals (N=385)
- 60% report that their case manager/care coordinator talked to them about services that might help with unmet needs and goals (if they have a case manager and have unmet needs and goals; N=121)
- 31% report that a family member (unpaid or paid) is the person who helps them most often (N=378)
- 50% have a family member (unpaid or paid) who provides additional assistance (N=260)
- 66% have a backup plan in case their paid support people do not show up (this is a new variable; N=262)

#### **Care Coordination**

Individuals are provided appropriate coordination of care.

There are three Care Coordination indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people discharged from the hospital or LTC facility who felt comfortable going home.
- 2. Proportion of people making a transition from hospital or LTC facility who had adequate follow-up.
- 3. Proportion of people who know how to manage their chronic conditions.

There are five survey items that correspond to the Care Coordination domain. Un-collapsed data are shown in Appendix B.

- 34% have stayed overnight in a hospital or rehabilitation facility (and were discharged to go home) in the past year (N=391)
- 78% report having felt comfortable and supported enough to go home after being discharged from a hospital or rehabilitation facility (in the past year; N=126)
- 83% report that someone followed up with them after discharge from a hospital or rehabilitation facility (in the past year: N=120)
- 76% report having one or more chronic conditions (N=396)
- 84% report knowing how to manage their chronic condition(s) (N=297)

#### Access

Publicly funded services are readily available to individuals who need and qualify for them.

There are three Access indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people who have adequate transportation.
- 2. Proportion of people who get needed equipment, assistive devices (wheelchairs, grab bars, home modifications, etc.)
- 3. Proportion of people who have access to information about services in their preferred language.

There are five survey items that correspond to the Access domain. Un-collapsed data are shown in Appendix B.

- 78% have transportation when they want to do things outside their home (N=379)
- 95% have transportation to get to medical appointments (N=391)
- 84% receive information about their services in the language they prefer (if non-English; N=75)
- 9% need new grab bars in the bathroom or elsewhere in the home (N=396)
- 8% need an upgrade to grab bars in the bathroom or elsewhere in the home (N=396)
- 7% need new bathroom modifications other than grab bars (N=391)
- 9% need an upgrade to bathroom modifications other than grab bars (N=391)
- 12% need a new specialized bed (N=394)
- **12%** need an upgrade to a specialized bed (N=394)
- 6% need a new ramp or stair lift in or outside the home (N=394)
- 3% need an upgrade to a ramp or stair lift in or outside the home (N=394)
- 6% need a new remote monitoring system (N=386)
- **0**% need an upgrade to a remote monitoring system (N=386)

- 13% need a new emergency response system (N=394)
- 5% need an upgrade to an emergency response system (N=394)
- 6% need other new home modifications (N=372)
- 2% need an upgrade to other home modifications (N=372)
- **2**% need a new walker (N=397)
- 8% need an upgrade to a walker (N=397)
- **10%** need a scooter (N=394)
- 5% need an upgrade to a scooter (N=394)
- **3%** need a new cane (N=397)
- 5% need an upgrade to a cane (N=397)
- 3% need a new wheelchair (N=398)
- 13% need an upgrade to a wheelchair (N=398)
- 5% need new hearing aids (N=393)
- 4% need an upgrade to hearing aids (N=393)
- 4% need new glasses (N=395)
- 25% need an upgrade to glasses (N=395)
- 2% need a new communication device (N=396)
- 1% need an upgrade to a communication device (N=396)
- 4% need other new assistive devices (N=387)
- 4% need an upgrade to other assistive devices (N=387)

## Safety

### People feel safe from abuse, neglect, and injury.

There are five Safety indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people who feel safe at home.
- 2. Proportion of people who feel safe around their staff/ caregiver.
- 3. Proportion of people who feel that their belongings are safe.
- 4. Proportion of people whose fear of falling is managed.
- 5. Proportion of people who are able to get to safety quickly in case of an emergency.

There are seven survey items that correspond to the Safety domain. Un-collapsed data are shown in Appendix B.

- 95% feel safe at home (N=370)
- 94% feel safe around their paid support staff (N=285)
- 24% have worried about the security of their personal belongings at some point in the last 12 months (N=376)
- 10% report that their money was taken or used without their permission (N=367)
- 54% have concerns about falling or being unstable (or about whom there are concerns; N=393)
- 74% report that someone has talked or worked with them to reduce the risk of falling or being unstable (if there were concerns; N=208)
- 84% can get to safety quickly in case of an emergency like a fire or natural disaster (N=354)

#### **Health Care**

#### People secure needed health services.

There are four Health Care indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people who have been to the ER in the past 12 months.
- 2. Proportion of people who have had needed health screenings and vaccinations in a timely manner (e.g., vision, hearing, dental, etc.)
- 3. Proportion of people who can get an appointment with their doctor when they need to.
- 4. Proportion of people who have access to mental health services when they need them.

There are four survey items that correspond to the Health Care domain. Un-collapsed data are shown in Appendix B.

The following are the collapsed results for Minnesota. The first three items below were restructured for this data collection cycle.

- 46% have gone to the emergency room for any reason in the past year (N=386)
- 29% had visited the ER in the past year due to falling or losing balance (N=178)
- 6% had visited the ER in the past year due to tooth or mouth pain (N=178)
- 85% can get an appointment to see their primary care doctor when they need to (N=389)
- 78% have talked to someone about feeling sad or depressed in the past 12 months (if feeling sad or depressed; N=219)
- 83% had a physical exam or a wellness visit in the past year (N=383)
- 36% had a hearing exam in the past year (N=380)
- 69% had a vision exam in the past year (N=386)
- 72% had a flu shot in the past year (N=375)
- 63% had a routine dental visit in the past year (N=388)
- **85%** had a cholesterol screening in the past five years (N=349)

#### Wellness

#### People are supported to maintain health.

There are seven Wellness indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people in poor health.
- 2. Proportion of people with unaddressed memory concerns.
- 3. Proportion of people with poor hearing.
- 4. Proportion of people with poor vision.
- 5. Proportion of people who have a chronic psychiatric or mental health diagnosis.
- 6. Proportion of people who often feel sad or depressed.
- 7. Proportion of people who have a chronic condition.

There are ten survey items that correspond to the Wellness domain. Un-collapsed data are shown in Appendix B.

- 19% describe their overall health as poor (N=393)
- 29% report that their health is much better or somewhat better than 12 months ago (N=390)
- 42% report forgetting things more often during the past 12 months (N=378)
- **65**% have discussed forgetting things more often with a doctor or a nurse (or someone else discussed with a doctor/nurse on their behalf; N=157)
- 48% describe themselves as having a chronic psychiatric or mental health diagnosis (new variable; N=385)
- 60% feel sad or depressed at least sometimes or often (N=366)
- **76**% have a chronic condition (N=396)
- 9% describe their hearing as poor (taking into account hearing aids, if any; new variable; N=396)
- 17% describe their vision as poor (taking into account glasses or contacts, if any; new variable; N=397)
- 90% describe themselves as having a physical disability (new variable; N=357)

#### Medications

Medications are managed effectively and appropriately.

There are two Medication indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people taking medications that help them feel less sad/depressed.
- 2. Proportion of people who know what their medications are for.

There are two survey items that correspond to the Medication domain. Un-collapsed data are shown in Appendix B.

- 58% take medications that help them feel less sad or depressed (N=379)
- 86% understand what their prescription medications are for (if they take any; N=384)

## Rights and Respect

People receive the same respect and protections as others in the community.

There are two Rights and Respect indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people whose basic rights are respected by others.
- 2. Proportion of people whose staff/workers/caregivers treat them with respect.

There are eight survey items that correspond to the Rights and Respect domain. Un-collapsed data are shown in Appendix B.

The following are the collapsed results for Minnesota. The first item was asked of all individuals; remaining items were asked only of individuals in group settings.

#### All individuals:

• 87% feel their paid support staff treat them with respect (N=285)

#### Individuals in **group settings**:

- 75% report that others ask their permission before entering their home/room (N=123)
- 59% can lock the doors of their room if they want to (N=116)
- 81% feel they have enough privacy in their home (N=121)
- 78% can have visitors at any time (N=118)
- 87% can use the phone privately whenever they want to (N=117)
- 77% have access to food at all times of the day (N=118)
- 11% report that their mail or email is read without asking them first (N=105)

#### Self-Direction of Care

People have authority and are supported to direct and manage their own services.

There are two Self-Direction of Care indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people self-directing.
- 2. Proportion of people who can choose or change the kind of services they receive and who provides them.

There are four survey items that correspond to the Self-Direction of Care domain. Proportion of people self-directing is derived from state administrative records. Un-collapsed data are shown in Appendix B.

- 5% are participating in a self-directed supports option (as defined by Minnesota; data come from state administrative records; N=403)
- 72% can choose or change the kinds of services they get (new variable; N=330)
- 66% can choose or change how often and when they get services (new variable; N=329)
- 75% can change their paid support staff (new variable; N=267)

#### Work

People have support to find and maintain community integrated employment if they want it.

There are five Work indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people who have a paid job.
- 2. Proportion of people who would like a job.
- 3. Proportion of people who have had job search assistance.
- 4. Proportion of people who volunteer.
- 5. Proportion of people who would like to volunteer.

There are five survey items that correspond to the Work domain. Un-collapsed data are shown in Appendix B.

- **15%** have a paying job in the community (N=397)
- 41% would like a job (if not currently employed; N=315)
- 50% report that someone has talked to them about job options (if wanted a job; N=123)
- **15%** do volunteer work (N=393)
- 41% would like to do volunteer work (if not currently volunteering; new variable; N=306)

### **Everyday Living**

#### People have enough supports for everyday living.

There are two Everyday Living indicators measured by the NCI-AD Adult Consumer Survey:

- 1. Proportion of people who have adequate support to perform activities of daily living (bathing, toileting, taking meds, etc.) and instrumental activities of daily living (cleaning, laundry, etc.)
- 2. Proportion of people who have access to healthy foods.

There are five survey items that correspond to the Everyday Living domain. Un-collapsed data are shown in Appendix B.

- 95% generally need a lot or some assistance with everyday activities things like preparing meals, housework, shopping, or taking their medications (N=401)
- 79% always get enough assistance with everyday activities (if assistance is needed; N=378)
- 81% generally need a lot or some assistance for self-care things like bathing, dressing, going to the bathroom, eating, or moving around their home (N=398)
- 80% always get enough assistance with self-care (if assistance is needed; N=317)
- 82% have access to healthy foods like fruits and vegetables when they want them (N=387)

# Affordability

People have enough available resources.

There is one Affordability indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who have ever had to cut back on food because of money.

There is one survey item that corresponds to the Affordability domain. Un-collapsed data are shown in Appendix B.

The following is the collapsed result for Minnesota:

• 12% have ever had to skip a meal due to financial worries (N=391)

# Planning for future

People have support to plan and make decision about the future.

There is one Planning for Future indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who want help planning for future need for services.

There is one survey item that corresponds to the Planning for Future domain. Un-collapsed data are shown in Appendix B.

The following is the collapsed result for Minnesota:

• 44% want help planning for their future need for services (N=346)

# Control

#### People feel in control of their lives.

There is one Control indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who feel in control of their lives.

There is one survey item that corresponds to the Control domain.

Un-collapsed data are shown in Appendix B. Appendix B also presents a ranking of what was most important to people surveyed.

The following is the collapsed result for Minnesota:

• 11% never feel in control of their life (N=368)

# Appendix A: Rules for Recoding and Collapsing Responses

The tables below detail the collapsing and recoding logic for items that were measured using anything other than a "Yes/No" binary response. Unless otherwise stated, "don't know" and "unclear/refused" responses are excluded from both numerator and denominator.

#### **Community Participation**

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who are as active in the community as they would like to be	Collapse "No" and "Sometimes"

#### **Choice and Decision Making**

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who get up and go to bed at the time they want	Collapse "Some days, sometimes" and "No, never"
Proportion of people who can eat their meals when they want	Collapse "Some days, sometimes" and "No, never"
Proportion of people who are able to decide how to furnish and decorate their room (if in group setting)	Collapse "In most ways" and "Only in some ways, or not at all"

#### Relationships

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who can always or almost always see or talk to friends and family when they want to (if there are friends and family who do not live with person)	Collapse "Most of the time, usually, or some family and/or friends" and "No, or rarely"

# Satisfaction

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who like where they are living	Collapse "In-between, most of the time" and "No"
Proportion of people who would prefer to live somewhere else	Collapse "Yes" and "Maybe"
Proportion of people who like how they usually spend their time during the day	Collapse "Some days, sometimes" and "No, never"
Proportion of people whose paid support staff change too often	Collapse "Yes" and "Some, or sometimes"
Proportion of people whose paid support staff do things the way they want them done	Collapse "Some, or usually" and "No, never or rarely"

# **Service Coordination**

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who know whom to contact if they want to make changes to their services	Collapse "Not sure, maybe" and "No"
Proportion of people who can reach their case manager/ care coordinator when they need to (if they know they have a case manager/ care coordinator)	Collapse "Most of the time, usually" and "No, or only sometimes"
Proportion of people whose paid support staff show up and leave when they are supposed to	Collapse "Some, or usually" and "No, never or rarely"
Proportion of people whose services meet all their needs and goals	Collapse "No, not at all, needs or goals are not met" and "Some needs and goals"
Proportion of people whose family member (unpaid or paid) is the person who helps them most often	Collapse "Paid family member or spouse/partner" and "Unpaid family member or spouse/partner"

Outcome Variable	Recoding/Collapsing Logic
Proportion of people whose family member (unpaid or paid) provides additional assistance	Add percentages for "Paid family member or spouse/partner" and "Unpaid family member or spouse/partner"

# **Care Coordination**

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who reported feeling comfortable and supported enough to go home after being discharged from a hospital or rehab facility (if occurred in the past year)	Collapse "No" and "In-between"
Proportion of people who reported they know how to manage their chronic conditions	Collapse "No" and "In-between, or some conditions"

# Access

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who have transportation when they want to do things outside of their home	Collapse "No" and "Sometimes"
Proportion of people who have transportation to get to medical appointments when they need to	Collapse "No" and "Sometimes"
Proportion of people who receive information about their services in the language they prefer (if non-English)	Collapse "No" and "Some information"

# Safety

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who have concerns about falling or being unstable (or about whom there are concerns)	Collapse "Yes, often" and "Sometimes"

# **Health Care**

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who can get an appointment to see their primary care doctor when they need to	Collapse "Usually" and "No, rarely"

# Wellness

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who describe their overall health as poor	Collapse "Excellent", "Very good", "Good" and "Fair"
Proportion of people whose who reported their health has gotten much better or somewhat better compared to 12 months ago	Collapse "Much better" and "Somewhat better"; Collapse "Much worse", "Somewhat worse" and "About the same"
Proportion of people who feel sad or depressed at least sometimes or often	Collapse "Often" and "Sometimes"; Collapse "Not often" and "Never, or almost never"
Proportion of people who describe their hearing as poor (taking into account hearing aids, if any)	Collapse "Very good" and "Fair"
Proportion of people who describe their vision as poor (taking into account glasses or contacts, if any)	Collapse "Very good" and "Fair"

# **Medications**

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who understand why they take their prescription medications and what they are for (if take or are supposed to take prescription medications)	Collapse "No" and "In-between, or some medications"

# **Rights and Respect**

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who feel that their paid support staff treat them with respect	Collapse "No, never or rarely" and "Some, or usually"
Proportion of people who get asked permission before people enter their home/room (if in group setting)	Collapse "Sometimes, rarely or never" and "Usually, but not always"
Proportion of people who have enough privacy in their home (if in group setting)	Collapse "Sometimes, rarely or never" and "Usually, but not always"
Proportion of people who can use the phone privately whenever they want to (if in group setting)	Collapse "No, never or rarely" and "Usually"

# **Self-Direction of Care**

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who can choose or change what kind of services they get	Collapse "No" and "Sometimes, or some services"
Proportion of people who can choose or change how often and when they get services	Collapse "No" and "Sometimes, or some services"
Proportion of people who can change their paid support staff	Collapse "No" and "Sometimes, or some services"

# Work

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who would like a job (if not currently employed)	Collapse "Yes" and "Maybe, not sure"

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who would like to do volunteer work (if does not currently volunteer)	Collapse "Yes" and "Maybe, not sure"

# **Everyday Living**

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who generally need a lot or some assistance with everyday activities (Things like preparing meals, housework, shopping or taking their medications)	Collapse "A lot" and "Some"
Proportion of people who generally need a lot or some assistance with self-care (Things like bathing, dressing, going to the bathroom, eating, or moving around their home)	Collapse "A lot" and "Some"
Proportion of people who have access to healthy foods like fruits and vegetables when they want them	Collapse "No, never" and "Sometimes"

# Affordability

Outcome Variable	Recoding/Collapsing Logic
Proportion of people who ever have to skip a meal due to financial worries	Collapse "Yes, often" and "Sometimes"

# Control

Outcome Variable	Recoding/Collapsing Logic	
Proportion of people who never feel in control of their life	Collapse "Yes, almost always, always" and "Inbetween, sometimes"	

# Appendix B: Un-Collapsed Data

# Demographic Tables

Table 1. Average age (reported for those under 90 years of age)

	Average Age	N
MN	50.7	403

Table 2. Proportion of individuals 90 years of age and over

	Under 90	90 and Over	N
MN	100%	0%	403

Table 3. Gender: proportion female

	Male	Female	Other	Don't Know	N
MN	44%	56%	0%	0%	403

Table 4. Race and ethnicity

	American Indian or Alaska Native	Asian	Black or African- American	Pacific Islander	White	Hispanic or Latino	Other	Don't know	N
MN	3%	5%	21%	0%	68%	1%	0%	3%	403

Table 5. Marital status

	Single, Never Married	Married or Has Domestic Partner	Separated or Divorced	Widowed	Don't Know	N
MN	34%	49%	14%	2%	0%	403

#### **Table 6. Primary language**

	English	Spanish	Other	Don't know	N
MN	92%	0%	7%	1%	403

#### Table 7. Preferred means of communication

	Spoken	Sign Language or Finger Spelling	Communication Aid or Device		Don't Know	N
MN	96%	1%	1%	2%	0%	400

Table 8. Type of residential area

	Metropolitan	Micropolitan	Rural	Small town	Unknown	N
MN	78%	10%	5%	7%	0%	403

Note: Residential area categories are created using zip codes and corresponding RUCA codes: Metropolitan - Metropolitan area core, high commuting low commuting; Micropolitan - Micropolitan area core, high commuting; Small town - Small town core, high commuting; Rural

Table 9. Type of residence

	Own or Family Home	·	Assisted Living Facility, Residential Care Facility	Facility, Nursing Home	Homeless, Temporary Shelter		Don't Know	N
MN	65%	27%	7%	1%	0%	0%	0%	400

Table 10. Who the person lives with

	Alone	Spouse or Partner	Other Family	Friend(s)	Live-in PCA	Others (not family, friend, or PCA)	N
MN	29%	20%	19%	19%	0%	31%	403

Table 11. Proportion of people whose address changed in the past 6 months

	No	Yes	N
MN	91%	8%	400

Table 12. Where the person moved from (if address changed in the past 6 months)

	Own or Family Home	Group Home, Adult Family Home, Foster, Host Home		Nursing Facility, Nursing Home	· ·	Other	Don't Know	N
MN	61%	18%	6%	3%	6%	6%	0%	33

Table 13. Proportion of people with diagnosis of Physical Disability

	No	Yes	Don't Know	N
MN	0%	100%	0%	403

Table 14. Proportion of people with diagnosis of Alzheimer's or other dementia

	No	Yes	Don't Know	N
MN	90%	10%	0%	403

Table 15. Proportion of people with diagnosis of Traumatic or Acquired Brain Injury

	No	Yes	Don't Know	N
MN	81%	19%	0%	403

Table 16. Proportion of people with diagnosis of Intellectual or Developmental Disability

	No	Yes	Don't Know	N
MN	96%	4%	0%	403

Table 17. Level of mobility

	Non-ambulatory	Moves Self with Wheelchair	Moves Self with Other Aids	Moves Self Without Aids	Don't know	N
MN	27%	32%	24%	17%	0%	403

# Table 18. History of frequent falls

	No	Yes	Don't Know	N
MN	68%	30%	2%	400

# **Table 19. Receives Medicare**

	No	Yes	N
MN	38%	62%	403

# Community Participation—un-collapsed

# Table 20. Proportion of people who are as active in the community as they would like to be

	No	Sometimes	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	37%	12%	47%	3%	2%	377

# Table 21a. Reasons that people are not as active in the community as they would like to be

	Cost or Money	Transportation	Accessibility or Lack of Equipment		Not Enough Support	N
MN	24%	28%	11%	65%	13%	183

# Table 21b. Reasons that people are not as active in the community as they would like to be (continued)

	Feeling Unwelcome in Community		No Community Activities Outside of Home	Information,		Don't Know	Unclear/ Refused/ No Response	N
MN	4%	10%	8%	14%	10%	1%	2%	183

### Table 22. Proportion of people who have tried to leave the house to go somewhere in the past week and have not been able to

	No	Yes	Don't Know	Unclear/Refused/No Response	N
MN	78%	19%	2%	1%	377

# Choice and Decision Making—un-collapsed

Table 23. Proportion of people who are able to choose their roommate (if in group setting)

	No	Yes	Don't Know	Unclear/Refused/No Response	N
MN	41%	45%	9%	5%	22

#### Table 24. Proportion of people who get up and go to bed at the time when they want

	No, Never	Some Days, Sometimes	Yes, Always, Or Almost Always		Unclear/Refused/ No Response	
MN	6%	8%	84%	0%	1%	377

#### Table 25. Proportion of people who can eat their meals when they want

		No, Never	Some Days, Sometimes		N/A –Unable to Eat Due to Medical Condition	Don't Know	Unclear/Refused/ No Response	N
N	ΛN	14%	12%	74%	0%	0%	1%	374

### Table 26. Proportion of people who are able to decide how to furnish and decorate their room (if in group setting)

	No	In-between, Able to Decide Some Ways		Don't Know	Unclear/Refused/ No Response	N
MN	1%	22%	73%	3%	1%	125

# Relationships—un-collapsed

Table 27. Proportion of people who can always or almost always see or talk to friends and family when they want to

	No, or Only Sometimes		Chooses Not to	Don't Know	Unclear/Refused/ No Response	N
MN	4%	11%	84%	0%	1%	350

# Table 28. Reasons people cannot always see friends/family

	Availability of Transportation	,	Staffing or Personal Assistance Unavailable		Someone Prevents Them or There are Restrictions		Unclear/ Refused/ No Response	N
MN	48%	25%	2%	19%	4%	23%	4%	52

# Satisfaction—un-collapsed

Table 29. Proportion of people who like where they are living

	No	In-between, Most of the Time	Yes	Don't Know	Unclear/Refused /No Response	N
MN	10%	13%	75%	0%	1%	401

Table 30a. Reasons for not liking where people live

	Accessibility	Neighborhood	Feels Unsafe in Home	Home or Building Needs Repairs or Upkeep	Does Not Feel Like Home	N
MN	11%	11%	4%	22%	23%	94

Table 30b. Reasons for not liking where people live (continued)

	Layout or Size of Home or Building	Problems With Neighbors, Residents, Housemates, or Roommates		Insufficient Amount or Type of Staff		
MN	11%	23%	12%	3%	13%	94

Table 30c. Reasons for not liking where people live (continued)

	Wants More Privacy		From Community		Don't Know	Unclear/Refused/ No Response	
MN	10%	4%	11%	19%	2%	4%	94

Table 31. Proportion of people who would prefer to live somewhere else

		No	Maybe	Yes	Unclear/Refused /No Response	N
M	N	55%	8%	34%	3%	401

# Table 32a. Where people would prefer to live (if would prefer to live somewhere else)

	Different Own Home	,		Group Home, Adult Family Home, Shared Living	
MN	63%	11%	8%	5%	169

#### Table 32b. Where people would prefer to live (if would prefer to live somewhere else, continued)

	Nursing Facility	Other	Don't Know	Unclear/Refused /No Response	
MN	0%	9%	4%	1%	169

# Table 33. Proportion of people who like how they usually spend their time during the day

	No, Never	Some Days, Sometimes	Yes, Always, or Almost Always		Unclear/Refused/ No Response	N
MN	9%	32%	58%	1%	1%	377

#### Table 34. Proportion of people whose paid support staff change too often

	No	Some or Sometimes	Yes	Paid Support Person(s) Are Live-in		Unclear/Refused /No Response	N
MN	60%	16%	15%	6%	1%	1%	286

# Table 35. Proportion of people whose paid support staff do things the way they want them done

	No, Never or Rarely	Some, or Usually	Yes, All Paid Support Workers, Always or Almost Always	Don't Know	Unclear/Refused/ No Response	
MN	3%	20%	76%	1%	0%	286

# Service Coordination—un-collapsed

Table 36. Proportion of people who know whom to contact if they want to make changes to their services

	No	Maybe, Not Sure	Yes	Unclear/Refused /No Response	N
MN	13%	10%	73%	3%	397

# Table 37. Proportion of people who can reach their case manager/care coordinator when they need to (if know they have case manager/care coordinator)

		No, or Only Sometimes	Most of the Time, Usually	Yes, Always	Don't Know	Unclear/Refused/ No Response	N
IV	1N	8%	14%	76%	1%	1%	366

#### Table 38. Proportion of people whose paid support staff show up and leave when they are supposed to

		No, Never or Rarely	Some, or Usually	Yes, All Paid Support Workers, Always, Or Almost Always	Are Live-In	Don't Know	Unclear/Refused/ No Response	N
ı	MN	2%	13%	79%	5%	1%	0%	297

# Table 39. Proportion of people who have an emergency plan in place

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	26%	64%	8%	2%	399

### Table 40. Proportion of people who want help planning for their future need for services

	No	Yes	Don't Know	Unclear/Refused /No Response	
MN	52%	40%	7%	1%	377

Table 41. Proportion of people whose services meet all their needs and goals

	No, Not At All, Needs Or Goals Are Not Met	Goals	Yes, Completely, All Needs And Goals		Unclear/Refused/ No Response	N
MN	8%	28%	60%	3%	0%	397

Table 42a. Additional services that may help if not all needs and goals are met

	Personal Care Assistance, Personal Care Services	Chore Services	Healthcare Home Services, Home Health	Home Delivered Meals	N
MN	32%	29%	14%	9%	145

Table 42b. Additional services that may help if not all needs and goals are met (continued)

	Adult Day Services	Transportation	Respite or Family Caregiver Support		Mental Health Care	N
MN	18%	34%	8%	12%	7%	145

Table 42c. Additional services that may help if not all needs and goals are met (continued)

		Dental Care	Housing Assistance	J. J.	Hospice	Funeral Planning	Other	N
N	ΛN	18%	21%	9%	1%	2%	23%	145

Table 43. Proportion of people whose case manager/care coordinator talked to them about services that might help with unmet needs and goals (if have case manager and have unmet needs and goals)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	37%	56%	5%	2%	130

Table 44a. How people first find out about the services available to them

	Friend	Family	Area Agency on Aging, Aging and Disability Resource Center	Independent	Agency	Case Manager, Care Coordinator	
MN	9%	18%	7%	1%	23%	33%	347

# Table 44b. How people first find out about the services available to them (continued)

	Doctor	Other Provider	Other	N
MN	14%	16%	5%	347

#### Table 45a. Who helps them most often

	Paid Support Worker Who Is Not a Friend Or Relative	•	Paid Friend	Unpaid Family Member Or Spouse or Partner	
MN	66%	17%	1%	14%	380

# Table 45b. Who helps them most often (continued)

	Unpaid Friend Or Volunteer		Don't Know	Unclear/Refused/ No Response	N
MN	2%	0%	0%	1%	380

# Table 46. Who else helps

	Paid Support Worker Who Is Not a Friend Or Relative	Member, Spouse or		Unpaid Family Member, Spouse or Partner	Or Volunteer	Other	No One Else Provides Support	N
MN	30%	9%	1%	43%	15%	2%	20%	374

# Care Coordination—un-collapsed

Table 47. Proportion of people who stayed overnight in a hospital or rehabilitation facility (and were discharged to go home) in past year

	Yes	No	Don't Know	Unclear/Refused /No Response	
MN	65%	34%	2%	0%	398

Table 48. Proportion of people who reported feeling comfortable and supported enough to go home after being discharged from a hospital or rehabilitation facility (if occurred in the past year)

	No	In-between	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	12%	9%	73%	2%	4%	134

Table 49. Proportion of people who reported someone followed up with them after discharge from a hospital or rehabilitation facility (if occurred in the past year)

		No	Yes	Did Not Need Or Want Follow-Up Care		Unclear/Refused/ No Response	
N	ΛN	15%	75%	4%	4%	2%	134

Table 50. Proportion of people who reported having one or more chronic condition(s)

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	24%	76%	1%	0%	398

Table 51. Proportion of people who reported know how to manage their chronic condition(s)

	No	In-between	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	4%	13%	82%	1%	1%	302

# Access—un-collapsed

Table 52. Proportion of people who have transportation when they want to do things outside of their home

	No	Sometimes	Yes	Does Not Want to	Don't Know	Unclear/Refused /No Response	
MN	10%	11%	74%	3%	1%	1%	398

# Table 53. Proportion of people who have transportation to get to medical appointments when they need to

	No	Sometimes	Yes	Doesn't Go to Medical Appointments		Unclear/Refused /No Response	
MN	2%	3%	93%	0%	1%	1%	398

#### Table 54. Proportion of people who receive information about their services in the language they prefer (if non-English)

	No	Some Information	Yes, All Information	Don't Know	Unclear/Refused /No Response	N
MN	8%	8%	83%	1%	0%	76

#### Table 55. Proportion of people who need grab bars in the bathroom or elsewhere in home

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused /No Response	
MN	24%	59%	8%	9%	1%	0%	399

#### Table 56. Proportion of people who need bathroom modifications (other than grab bars)

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused /No Response	
MN	32%	51%	9%	7%	1%	1%	399

Table 57. Proportion of people who need a specialized bed

	Does Not Need	Has One, And Doesn't Need Upgrade	Has One, But Needs Upgrade		Don't Know	Unclear/Refused /No Response	
MN	48%	26%	12%	12%	1%	0%	399

# Table 58. Proportion of people who need a ramp or stair lift in or outside the home

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused /No Response	
MN	58%	32%	3%	6%	1%	0%	399

# Table 59. Proportion of people who need a remote monitoring system

	Does Not Need	Has One, And Doesn't Need Upgrade			Don't Know	Unclear/Refused /No Response	
MN	84%	7%	0%	6%	3%	1%	399

# Table 60. Proportion of people who need an emergency response system

	Does Not Need	Has One, And Doesn't Need Upgrade	· · · · · · · · · · · · · · · · · · ·		Don't Know	Unclear/Refused /No Response	
MN	48%	33%	5%	13%	1%	0%	399

# Table 61. Proportion of people who need other home modifications

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused /No Response	
MN	77%	9%	2%	6%	5%	2%	399

Table 62. Proportion of people who need a walker

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused /No Response	
MN	53%	36%	8%	2%	0%	0%	398

# Table 63. Proportion of people who need a scooter

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused /No Response	
MN	74%	10%	5%	10%	1%	0%	398

# Table 64. Proportion of people who need a cane

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused /No Response	
MI	61%	32%	5%	3%	0%	0%	398

# Table 65. Proportion of people who need a wheelchair

	Does Not Need	Has One, And Doesn't Need Upgrade	· · · · · · · · · · · · · · · · · · ·		Don't Know	Unclear/Refused /No Response	
MN	45%	39%	13%	3%	0%	0%	398

# Table 66. Proportion of people who need hearing aids

	Does Not Need	Has One, And Doesn't Need Upgrade	·		Don't Know	Unclear/Refused /No Response	
MN	82%	8%	4%	5%	1%	0%	398

Table 67. Proportion of people who need glasses

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused/ No Response	N
MN	21%	49%	25%	4%	1%	0%	398

# Table 68. Proportion of people who need a communication device

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused/ No Response	N
MN	93%	4%	1%	2%	0%	0%	398

# Table 69. Proportion of people who need other assistive devices

	Does Not Need	Has One, And Doesn't Need Upgrade	Needs Upgrade		Don't Know	Unclear/Refused /No Response	
MN	74%	16%	4%	4%	3%	0%	398

# Safety—un-collapsed

Table 70. Proportion of people who feel safe at home

	Rarely or Never	Always or Most of the Time		Unclear/Refused/ No Response	N
MN	5%	93%	1%	1%	377

# Table 71. Proportion of people who feel safe around their paid support staff

	No, Not Always or Not All Paid Support Workers	Yes, All Paid Support Workers, Always		Unclear/Refused/ No Response	N
MN	6%	93%	0%	0%	286

#### Table 72. Proportion of people who are ever worried for the security of their personal belongings

	No, Never	Yes, At Least Sometimes		Unclear/Refused/ No Response	N
MN	76%	24%	0%	0%	377

#### Table 73. Proportion of people whose money was taken or used without their permission in the last 12 months

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	88%	9%	2%	1%	377

# Table 74. Proportion of people who have concerns about falling or being unstable (or about whom there are concerns)

	No	Sometimes	Yes, Often	Don't Know	Unclear/Refused/ No Response	N
MN	45%	18%	36%	1%	1%	398

Table 75. Proportion of people with whom somebody talked to or worked with to reduce risk of falling or being unstable (if there are such concerns)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	25%	72%	2%	0%	214

# Table 76. Proportion of people who are able to get to safety quickly in case of an emergency like a fire or a natural disaster

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	14%	74%	9%	2%	399

# Health Care—un-collapsed

Table 77. Proportion of people who have gone to the emergency room for any reason in the past year

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	52%	45%	3%	0%	398

Table 78. Proportion of people whose one or more visit to the ER in the past year was due to falling or losing balance (if went to ER in past year)

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	70%	29%	1%	0%	179

Table 79. Proportion of people whose one or more visit to the ER in the past year was due to tooth or mouth pain (if went to ER in the past year)

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	94%	6%	1%	0%	179

Table 80. Proportion of people who can get an appointment to see their primary care doctor when they need to

	No, Rarely	Usually	Yes, Always	Does Not Have a Primary Care Doctor		Unclear/Refused/ No Response	N
MN	3%	12%	83%	1%	1%	0%	398

Table 81. Proportion of people who have talked to someone about feeling sad and depressed during the past 12 months (if feeling sad and depressed)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	22%	77%	0%	0%	221

Table 82. Proportion of people who have had a physical exam or wellness visit in the past year

	No	Yes	N/A (e.g., Not Recommended)		Unclear/Refused/ No Response	N
MN	17%	79%	1%	3%	0%	398

#### Table 83. Proportion of people who have had a hearing exam in the past year

	No	Yes	N/A (e.g., Not Recommended)	Don't Know	Unclear/Refused/ No Response	N
MN	61%	34%	1%	4%	0%	398

#### Table 84. Proportion of people who have had a vision exam in the past year

	No	Yes	N/A (e.g., Not Recommended)	Don't Know	Unclear/Refused/ No Response	N
MN	30%	67%	1%	2%	0%	398

# Table 85. Proportion of people who have had a flu shot in the past year

	No	Yes	N/A (e.g., Not Recommended)	Don't Know	Unclear/Refused/ No Response	N
MN	26%	68%	2%	4%	0%	398

#### Table 86. Proportion of people who have had a routine dental visit in the past year

	No	Yes	N/A (e.g., Not Recommended)		Unclear/Refused/ No Response	N
MN	36%	61%	1%	2%	1%	398

### Table 87. Proportion of people who have had a cholesterol screening in the past five years

	No	Yes	N/A (e.g., Not Recommended)		Unclear/Refused/ No Response	N
MN	13%	75%	2%	10%	0%	398

# Wellness—un-collapsed

Table 88. Proportion of people who describe their overall health as poor, fair, good, very good, or excellent

	Poor	Fair	Good	Very Good	Excellent	Don't Know	Unclear/Refused/ No Response	N
MN	19%	29%	29%	15%	6%	1%	1%	398

Table 89. Proportion of people who reported their health has gotten much better, somewhat better, stayed about the same, got somewhat worse, or got much worse compared to 12 months ago

	Much Worse	Somewhat Worse	About the Same	Somewhat Better	Much Better	Don't Know	Unclear/Refused/ No Response	N
MN	6%	19%	45%	18%	11%	2%	1%	398

Table 90. Proportion of people who reported they forget things more often than before during the past 12 months

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	55%	40%	4%	1%	398

Table 91. Proportion of people who have discussed (or somebody else discussed) their forgetting things with a doctor or a nurse (if forget things more often during the past 12 months)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	35%	65%	0%	1%	158

Table 92. Proportion of people who describe themselves as having a chronic psychiatric or mental health diagnosis

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	50%	47%	2%	1%	398

Table 93. Frequency with which people who feel sad or depressed

	Never or Almost Never		Sometimes	Often	Don't Know	Unclear/Refused/ No Response	N
MN	18%	20%	37%	21%	1%	2%	377

# Table 94. Proportion of people with chronic conditions

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	24%	76%	1%	0%	398

#### Table 95. Proportion of people who describe their hearing as poor, fair and very good (taking into account hearing aids, if any)

		Poor	Fair	Very Good	Don't Know	Unclear/Refused/ No Response	N
N	ΛN	9%	21%	70%	1%	1%	398

# Table 96. Proportion of people who describe their vision as poor, fair and very good (taking into account glasses or contacts, if any)

	Poor	Fair	Very Good	Don't Know	Unclear/Refused/ No Response	N
MN	17%	31%	52%	0%	0%	398

#### Table 97. Proportion of people who describe themselves as having a physical disability

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	10%	85%	4%	2%	378

# Medications—un-collapsed

Table 98. Proportion of people who take medications that help them feel less sad or depressed

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	40%	55%	3%	2%	398

Table 99. Proportion of people who understand why they take their prescription medications and what they are for (if take or are supposed to take prescription medications)

	No	In-between, Or Some Medications		Does Not Take Prescription Medications		Unclear/Refused /No Response	N
MN	7%	7%	83%	3%	1%	1%	398

# Rights and Respect—un-collapsed

Table 100. Proportion of people who feel that their paid support staff treat them with respect

	No, Never Or Rarely	· · · · · · · · · · · · · · · · · · ·	Yes, All Paid Support Workers, Always Or Almost Always		Unclear/Refused/ No Response	N
MN	2%	11%	87%	0%	0%	286

Table 101. Proportion of people who report that others ask permission before entering their home/room (if in group setting)

	Sometimes, Rarely, Or Never	Usually, But Not Always	Yes, Always	Don't Know	Unclear/Refused/ No Response	N
MN	10%	14%	74%	1%	1%	125

Table 102. Proportion of people who are able to lock the doors to their room if they want to (if in group setting)

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	38%	54%	6%	1%	125

#### Table 103. Proportion of people who have enough privacy in their home (if in group setting)

	Sometimes, Rarely, Or Never	Usually, But Not Always	Yes, Always	Don't Know	Unclear/Refused/ No Response	N
MN	8%	10%	78%	2%	2%	125

#### Table 104. Proportion of people who are able to have visitors come at any time (if in group setting)

	No, Visitors Allowed Only Certain Times	Yes, Visitors Can Come Any Time	Don't Know	Unclear/Refused/ No Response	N
MN	21%	76%	2%	1%	121

# Table 105. Proportion of people who can use the phone privately whenever they want to (if in group setting)

	No, Never Or Rarely Can Use Privately Or There Are Restrictions	Privately	Yes, Can Use Privately Anytime, Either Independently Or With Assistance		Unclear/Refused/ No Response	
MN	3%	9%	84%	2%	2%	122

# Table 106. Proportion of people who have access to food at all times of the day (if in group setting)

	No	Yes	N/A –Unable to Eat Due to Medical Condition		Unclear/Refused/ No Response	N
MN	22%	73%	2%	2%	1%	125

#### Table 107. Proportion of people whose mail or email is read without asking them first (if in group setting)

	No, People Never Read Mail Or Email Without Permission	Yes, People Read Mail Or Email Without Permission		Unclear/Refused/ No Response	N
MN	78%	10%	8%	4%	120

# Self-Direction of Care—un-collapsed

Table 108. Proportion of people who are participating in a self-directed supports option (as defined by their State—data for this indicator come directly from State administrative records)

	No	Yes	Don't Know	N
MN	96%	4%	0%	403

#### Table 109. Proportion of people who can choose or change what kind of services they get

	No	Sometimes, Or Some Services	Yes, All Services	Don't Know	Unclear/Refused/ No Response	N
MN	7%	17%	60%	14%	3%	397

#### Table 110. Proportion of people who can choose or change how often and when they get services

	No	Sometimes, Or Some Services	Yes, All Services	Don't Know	Unclear/Refused/ No Response	N
MN	12%	16%	54%	14%	4%	397

#### Table 111. Proportion of people who can change their paid support staff

	No	Sometimes, Or Some Services	·	Don't Know	Unclear/Refused/ No Response	N
MN	12%	11%	67%	9%	1%	297

# Work—un-collapsed

Table 112. Proportion of people who have a paying job in the community, either full-time or part-time

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	85%	15%	0%	0%	398

# Table 113. Proportion of people who would like a job (if not currently employed)

	No	Maybe, Not Sure	Yes	Unclear/Refused/ No Response	
MN	58%	14%	27%	1%	319

#### Table 114. Proportion of people who reported that someone has talked to them about job options (if wanted a job)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	48%	47%	4%	2%	130

#### Table 115. Proportion of people who do volunteer work

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	84%	15%	1%	0%	398

## Table 116. Proportion of people who would like to do volunteer work (if not currently volunteering)

	No	Maybe, Not Sure	Yes	Unclear/Refused/ No Response	
MI	58%	19%	21%	2%	313

# Everyday Living—un-collapsed

#### Table 117. Proportion of people who generally need a lot or some assistance with everyday activities

	None	Some	A Lot	Don't Know	Unclear/Refused/ No Response	N
MN	5%	41%	54%	0%	0%	401

# Table 118. Proportion of people who always get enough assistance with everyday activities when they need it (if need any assistance)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
MN	21%	78%	0%	1%	381

#### Table 119. Proportion of people who generally need a lot or some assistance for self-care

	None	Some	A Lot	Don't Know	Unclear/Refused/ No Response	N
MN	19%	39%	42%	0%	0%	400

#### Table 120. Proportion of people who always get enough assistance with self-care when they need it

	No	Yes	Don't Know	Unclear/Refused/ No Response	
MN	20%	79%	1%	1%	323

## Table 121. Proportion of people who have access to healthy foods like fruits and vegetables when they want them

	No, Never	Sometimes	Yes, Often	N/A –Unable to Eat Due to Medical Condition		Unclear/Refused /No Response	
MN	5%	13%	81%	0%	1%	2%	395

# Affordability—un-collapsed

Table 122. Proportion of people who ever have to skip a meal due to financial worries

	No, Never	Sometimes	·	N/A –Unable to Eat Due to Medical Condition		Unclear/Refused /No Response	
MN	87%	8%	3%	0%	1%	0%	395

# Planning for the Future—un-collapsed

Table 123. Proportion of people who want help planning for their future need for services

	No	Yes	Don't Know	Unclear/Refused /No Response	
MN	52%	40%	7%	1%	377

# Control—un-collapsed

Table 124. Proportion of people who feel in control of their life

	No	In-between	Yes	Don't Know	Unclear/Refused /No Response	N
MN	11%	24%	63%	1%	2%	377

Table 125. Ranking of how important people reported health was to them right now (out of health, safety, being independent, being engaged with community and friends, and maintaining assets/avoiding poverty)

	1 - Health Most Important	2	3	4	5 - Health Least Important	N
MN	53%	25%	14%	6%	2%	352

Table 126. Ranking of how important people reported safety was to them right now (out of health, safety, being independent, being engaged with community and friends, and maintaining assets/avoiding poverty)

		1 - Safety Most Important	2	3	4	5 - Safety Least Important	N
М	N	9%	27%	32%	22%	11%	352

Table 127. Ranking of how important people reported being independent was to them right now (out of health, safety, being independent, being engaged with community and friends, and maintaining assets/avoiding poverty)

	1 – Being Independent Most Important		3	4	5 - Being Independent Least Important	N
MN	22%	28%	28%	16%	7%	352

Table 128. Ranking of how important people reported being engaged with community and friends was to them right now (out of health, safety, being independent, being engaged with community and friends, and maintaining assets/avoiding poverty)

	1 – Engaged with Community Most Important		3	4	5- Engaged with Community Least Important	
MN	10%	11%	12%	27%	39%	352

Table 129. Ranking of how important people reported maintaining assets/avoiding poverty was to them right now (out of health, safety, being independent, being engaged with community and friends, and maintaining assets/avoiding poverty)

	1 – Maintaining Assets/Avoiding Poverty Most Important		3	4	5 - Maintaining Assets/Avoiding Poverty Least Important	
MN	6%	9%	14%	30%	41%	352

# Appendix C: Minnesota's State-Specific Questions

# Minnesota-Specific Questions

Table 130. Proportion of people who have a physical disability according to his/her proxy (MN-1)

	No	Yes	Don't Know	Unclear/Refused /No Response	
MN	5%	91%	5%	0%	22

#### Table 131. Proportion of people who would recommend their paid caregivers to someone else (MN-2)

	No	Some Staff	Yes, All Staff, Always or Almost Always		Unclear/Refused /No Response	
MN	4%	16%	77%	2%	1%	286

# Table 132. Proportion of people who report that their paid caregivers are better than expected, about the same as expected or worse than expected (MN-3)

	Worse Than Expected		Better Than Expected	Don't Know	Unclear/Refused/ No Response	N
MN	5%	48%	43%	3%	1%	286

# Appendix D: Overview Table—All NCI AD Domains and Indicators

Proportion of people who are able to participate in preferred activities outside of home when and with whom they want

#### **Choice and Decision Making**

Proportion of people who are involved in making decisions about their everyday lives including where they live, what they do during the day, the staff that supports them and with whom they spend time

#### Relationships

Proportion of people who are able to see or talk to their friends and families when they want to

#### Satisfaction

Proportion of people who are satisfied with where they live

Proportion of people who are satisfied with what they do during the day

Proportion of people who are satisfied with staff who work with them

#### **Service Coordination**

Proportion of people who know who to call with a complaint, concern, or question about their services

Proportion of people whose CM talks to them about any needs that are not being met

Proportion of people who can get in contact with their CM when they need to

Proportion of people who receive the services that they need

Proportion of people finding out about services from service agencies

Proportion of people who want help planning for future need for services

Proportion of people who have an emergency plan in place

Proportion of people whose support workers come when they are supposed to

Proportion of people who use a relative as their support person

Proportion of people who have a backup plan if their support person doesn't show up

#### **Care Coordination**

Proportion of people discharged from the hospital or LTC facility who felt comfortable going home

Proportion of people making a transition from hospital or LTC facility who had adequate follow-up

Proportion of people who know how to manage their chronic conditions

Access	
	Proportion of people who have adequate transportation
	Proportion of people who get needed equipment, assistive devices (wheelchairs, grab bars, home modifications, etc.)
	Proportion of people who have access to information about services in their preferred language
Safety	Troportion of people who have access to information about services in their preferred language
	Proportion of people who feel safe at home
	Proportion of people who feel safe around their staff/ caregiver
	Proportion of people who feel that their belongings are safe
	Proportion of people whose fear of falling is managed
	Proportion of people who are able to get to safety quickly in case of an emergency
Health Care	
	Proportion of people who have been to the ER in the past 12 months
	Proportion of people who have had needed health screenings and vaccinations in a timely manner (e.g., vision, hearing, dental, etc.)
	Proportion of people who can get an appointment their doctor when they need to
	Proportion of people who have access to mental health services when they need them
Wellness	
	Proportion of people in poor health
	Proportion of people with unaddressed memory concerns
	Proportion of people with poor hearing
	Proportion of people with poor vision
	Proportion of people who have a chronic psychiatric or mental health diagnosis
	Proportion of people who often feel sad or depressed
	Proportion of people who have a chronic condition
Medica	tions
	Proportion of people taking medications that help them feel less sad/depressed
	Proportion of people who know what their medications are for
Rights and Respect	
	Proportion of people whose basic rights are respected by others
	Proportion of people whose staff/worker/caregiver treat them with respect

#### **Self-Direction of Care**

Proportion of people self-directing

Proportion of people who can choose or change the kind of services they receive and who provides them

#### Work

Proportion of people who have a paid job

#### **Everyday Living**

Proportion of people who have adequate support to perform activities of daily living (bathing, toileting, taking meds, etc.) and IADLs (cleaning, laundry, etc.)

Proportion of people who have access to healthy foods

#### **Affordability**

Proportion of people who have ever had to cut back on food because of money

#### Planning for future

Proportion of people who want help planning for future need for services

#### Control

Proportion of people who feel in control of their lives