



# *ADULT IN-PERSON SURVEY*

*Maine Report 2017-18*



<b>What is NCI?</b> .....	<b>1</b>
<b>What is the NCI Adult In-Person Survey?</b> .....	<b>1</b>
<b>What topics are covered by the survey?</b> .....	<b>2</b>
<b>How were people selected to participate?</b> .....	<b>3</b>
<b>Proxy Respondents</b> .....	<b>3</b>
<b>Data Analysis</b> .....	<b>3</b>
<b>Weighting</b> .....	<b>4</b>
<b>Significance Testing</b> .....	<b>4</b>
<b>Limitations of Data</b> .....	<b>5</b>
<b>What is contained in this report?</b> .....	<b>5</b>
<b>Demographics</b> .....	<b>6</b>
Table 1. Age .....	7
Table 2. Age Group .....	7
Table 3. Gender .....	7
Table 4. Marital Status .....	7
Table 5. Race and Ethnicity .....	7
Table 6. Race and Ethnicity (Continued) .....	8
Table 7. Residential Designation .....	8
Table 8. Type of Residence - ICF/IID, Nursing Facilities or Other Specialized Institutional Settings .....	8
Table 9. Type of Residence - Group Residential Setting .....	8
Table 10. Type of Residence - Other Home Settings .....	9
Table 11. Length of Time at Current Residence .....	9
Table 12. Person's Residence Owned or Controlled by Provider Agency .....	9
Table 13. Person Is Named on the Lease .....	9
Table 14. Person Owns Home .....	10
Table 15. Has ID Diagnosis .....	10
Table 16. Level of ID (if the Person Has an ID Diagnosis) .....	10
Table 17. Mood, Anxiety, Behavior, Psychotic, and Other Mental Illness .....	10
Table 18. Other Disabilities .....	10
Table 19. Other Disabilities (Continued) .....	11
Table 20. Health Conditions .....	11
Table 21. Health Conditions (Continued) .....	11
Table 22. Preferred Means of Communication .....	11
Table 23. Primary Language .....	12
Table 24. Mobility .....	12

Table 25. Behavioral Support Need .....	12
Table 26. Level of Guardianship.....	13
Table 27. Guardian’s Relationship to Person.....	13
<b>Choice and Decision-Making.....</b>	<b>14</b>
Charts for Choice and Decision-Making .....	15
Chart 1. Chose or had some input in choosing where they live (if not living in the family home; proxy respondents were allowed for this question) .....	16
Chart 2. Chose or had some input in choosing their housemates or chose to live alone (if not living in the family home; proxy respondents were allowed for this question) .....	16
Chart 3. Chose or had input in choosing paid community job (proxy respondents were allowed for this question)* .....	16
Chart 4. Chose or had some input in choosing day program or workshop (proxy respondents were allowed for this question) ° .....	16
Chart 5. Chose staff or were aware they could request to change staff (proxy respondents were allowed for this question) .....	17
Chart 6. Decides or has input in deciding daily schedule (proxy respondents were allowed for this question).....	17
Chart 7. Decides or has input in deciding how to spend free time (proxy respondents were allowed for this question).....	17
Chart 8. Chooses or has input in choosing what to buy, or has set limits on what to buy with their spending money (proxy respondents were allowed for this question) .....	17
Chart 9. Can change case manager/service coordinator if wants to (proxy respondents were allowed for this question) .....	18
Tables for Choice and Decision-Making .....	19
Table 28. Choice and Decision-Making.....	20
<b>Work .....</b>	<b>21</b>
Charts for Work.....	22
Chart 10. Has a paid job in the community (information may have been obtained through state records) ° .....	23
Chart 11. Type of paid community job (information may have been obtained through state records) ° * .....	23
Chart 12. Average number of biweekly hours by type of community job (information may have been obtained through state records) ° * .....	23
Chart 13. Average biweekly hourly wage by type of community job (information may have been obtained through state records) ° * .....	23
Chart 14. Length of employment in current paid community job (in months; information may have been obtained through state records) ° * .....	24
Chart 15. Receives paid time off (for example, paid vacation and/or sick time) from paid community job (information may have been obtained through state records) ° * .....	24
Chart 16. Four most common job industries of those with a paid community job (information may have been obtained through state records) ° ∞ .....	24
Chart 17. Does not have paid community job, and would like a job in the community ° .....	24
Chart 18. Has community employment as a goal in their service plan (information may have been obtained through state records) ° .....	25
Chart 19. Takes classes, training or does something to get a job or do better at current job .....	25
Chart 20. Attends a day program or workshop .....	25
Chart 21. Volunteers .....	25
Tables for Work.....	26
Table 29. Has paid community job .....	27
Table 30. Type of paid community job .....	27
Table 31. Hours and wages by type of paid community job.....	28
Table 32. Length of employment at current job, in months.....	28

Table 33. Receives paid time off at paid community job (information may have been obtained through state records) .....	28
Table 34. Most common types of jobs among those with a paid community job (information may have been obtained through state records).....	29
Table 35. Employment goals and other daily activities .....	29
<b>Self-Determination .....</b>	<b>30</b>
Charts for Self-Determination .....	31
Chart 22. Uses a self-directed supports option (information may have been obtained through state records).....	32
Chart 23. People who make decisions or have input in making decisions for how budget for services is used (proxy respondents were allowed for this question) .....	32
Chart 24. Hires or manages staff (proxy respondents were allowed for this question).....	32
Chart 25. Can make changes to individual budget/services if needed (proxy respondents were allowed for this question).....	32
Chart 26. Has enough help deciding how to use their individual budget/services (proxy respondents were allowed for this question) .....	33
Chart 27. Gets information about how much money is left in budget/services (proxy respondents were allowed for this question) .....	33
Chart 28. Information about budget/services is easy to understand (proxy respondents were allowed for this question).....	33
Chart 29. Frequency with which the person gets information about budget/services (proxy respondents were allowed for this question).....	33
Tables for Self-Determination .....	34
Table 36. Uses self-directed services option .....	35
Table 37. People who make decisions or have input in making decisions for how budget for services is used .....	35
Table 38. Self-Direction.....	36
Table 39. Frequency of information about how much money is left in budget/services, among those who receive information.....	36
<b>Community Inclusion, Participation and Leisure.....</b>	<b>37</b>
Charts for Community Inclusion, Participation and Leisure .....	38
Chart 30. Went out shopping at least once in the past month (proxy respondents were allowed for this question) .....	39
Chart 31. Went out on errands at least once in the past month (proxy respondents were allowed for this question).....	39
Chart 32. Went out for entertainment at least once in the past month (proxy respondents were allowed for this question) .....	39
Chart 33. Went out to eat at least once in the past month (proxy respondents were allowed for this question).....	39
Chart 34. Went out to religious service or spiritual practice at least once in the past month (proxy respondents were allowed for this question).....	40
Chart 35. Participated as a member in community group (proxy respondents were allowed for this question).....	40
Chart 36. Went on vacation in the past year (proxy respondents were allowed for this question) .....	40
Chart 37. Able to go out and do the things s/he like to do in the community .....	40
Chart 38. Able to go out and do the things s/he like to do in the community as often as they want .....	41
Chart 39. Has enough things to do when at home .....	41
Tables for Community Inclusion, Participation, and Leisure .....	42
Table 40. Community Inclusion, Participation, and Leisure .....	43
<b>Relationships .....</b>	<b>44</b>
Charts for Relationships .....	45
Chart 40. Has friends who are not staff or family members .....	46
Chart 41. Has best friend (may be staff or family).....	46

Chart 42. Wants more help to meet or keep in contact with friends.....	46
Chart 43. Has friends (may be staff or family) and can see them when s/he wants.....	46
Chart 44. Reasons cannot see friends if often unable to ∞ ^ .....	47
Chart 45. Has other ways of talking, chatting, or communicating with friends when cannot see them .....	47
Chart 46. Can see and communicate with their family when they want (if not living with family) .....	47
Chart 47. Often feels lonely ^ .....	47
Chart 48. Can go on a date or is married or living with partner .....	48
Tables for Relationships.....	49
Table 41. Friendships .....	50
Table 42. Reasons cannot see friends if often unable to ^ .....	50
Table 43. Relationships .....	51
<b>Satisfaction.....</b>	<b>52</b>
Charts for Satisfaction.....	53
Chart 49. Likes home or where s/he lives.....	54
Chart 50. Wants to live somewhere else ^ .....	54
Chart 51. Has a paid job in the community and likes job* .....	54
Chart 52. Has a paid job in the community and wants to work somewhere else * ^ .....	54
Chart 53. Attends a day program or workshop and wants to go more, less, or the same amount of time.....	55
Chart 54. Services and supports help the person live a good life.....	55
Tables for Satisfaction.....	56
Table 44. Satisfaction at home and with paid community job .....	57
Table 45. Amount of time wants to spend at day program or workshop s/he attends .....	57
Table 46. Services and supports help person live a good life .....	57
<b>Service Coordination.....</b>	<b>58</b>
Charts for Service Coordination .....	59
Chart 55. Has met case manager .....	60
Chart 56. Case manager asks person what s/he wants .....	60
Chart 57. Able to contact case manager when s/he wants .....	60
Chart 58. Staff come and leave when they are supposed to.....	60
Chart 59. Took part in last service planning meeting, or had the opportunity but chose not to.....	61
Chart 60. Understood what was talked about at last service planning meeting.....	61
Chart 61. Last service planning meeting included people who person wanted to be there.....	61
Chart 62. Person was able to choose services they get as part of service plan .....	61
Tables for Service Coordination .....	62
Table 47. Service Coordination .....	63
<b>Access .....</b>	<b>64</b>
Charts for Access.....	65

Chart 63. Has a way to get places s/he needs to go .....	66
Chart 64. Able to get places when s/hewants to do something outside of home .....	66
Chart 65. Staff have right training to meet person’s needs (proxy respondents who were not staff were allowed for this question) .....	66
Chart 66. Additional services needed (proxy respondents were allowed for this question) ∞ .....	66
Chart 67. Additional services needed—continued (proxy respondents were allowed for this question) ∞ .....	67
Chart 68. Additional services needed—continued (proxy respondents were allowed for this question) ∞ .....	67
Tables for Access .....	68
Table 48. Transportation and staff training .....	69
Table 49. Additional services needed .....	70
<b>Health .....</b>	<b>71</b>
Charts for Health .....	72
Chart 69. Has a primary care doctor or practitioner (information may have been obtained through state records)* .....	73
Chart 70. In poor health (proxy respondents were allowed for this question) ~ .....	73
Chart 71. Had a complete physical exam in the past year (information may have been obtained through state records)* .....	73
Chart 72. Had a dental exam in the past year (information may have been obtained through state records)* .....	73
Chart 73. Had an eye exam in the past year (information may have been obtained through state records)* .....	74
Chart 74. Had a hearing test in the past five years (information may have been obtained through state records) * .....	74
Chart 75. Had a Pap test in the past three years (women 21 and older; information may have been obtained through state records)* .....	74
Chart 76. Had a mammogram test in the past two years (women 40 and older; information may have been obtained through state records).....	74
Chart 77. Last colorectal cancer screening (people 50 and older; information may have been obtained through state records) ∞ .....	75
Chart 78. Had a flu vaccine in the past year (information may have been obtained through state records)* .....	75
Tables for Health .....	76
Table 50. Regular and preventive screenings .....	77
Table 51. Last colorectal cancer screening, people age 50 and older .....	78
Table 52. Had a flu vaccine in the past year .....	78
<b>Medications.....</b>	<b>79</b>
Charts for Medications.....	80
Chart 79. Takes at least one medication for mood, anxiety, psychotic disorder and/or behavioral challenge (information may have been obtained through state records) * ~° .....	81
Chart 80. Takes medication for mood, anxiety, and/or psychotic disorders (information may have been obtained through state records) * ~° .....	81
Chart 81. Takes medication for behavior challenges (information may have been obtained through state records) * ~° .....	81
Chart 82. Number of medications taken for at least one of the following: mood disorders, anxiety, or psychotic disorders (information may have been obtained through state records) *° .....	81
Chart 83. Number of medications taken for behavior challenges (information may have been obtained through state records) *° .....	82
Chart 84. Has a behavior plan (information may have been obtained through state records) * ~° .....	82
Chart 85. Takes medication for behavior challenges and has a behavior plan (information may have been obtained through state records).....	82
Tables for Medication .....	83
Table 53. Takes medication .....	84

Table 54. Number of medications taken .....	84
Table 55. Behavior plan and medication .....	84
<b>Wellness.....</b>	<b>85</b>
Charts for Wellness .....	86
Chart 86. Exercises or does physical activity at least once a week at least 10 minutes at a time (proxy respondents were allowed for this question).....	87
Chart 87. Exercises or does physical activity at least 3 times per week that makes the muscles in arms, legs, back, and/or chest work hard (proxy respondents were allowed for this question) ° .....	87
Chart 88. Body Mass Index (BMI) category (information may have been obtained through state records)* .....	87
Chart 89. Uses tobacco products (information may have been obtained through state records) * ° .....	87
Tables for Wellness .....	88
Table 56. Exercise.....	89
Table 57. Body Mass Index (BMI) category (information may have been obtained through state records) * .....	89
Table 58. Uses tobacco products * ° .....	89
<b>Rights and Respect.....</b>	<b>90</b>
Charts for Rights and Respect .....	91
Chart 90. Has a key to the home (proxy respondents were allowed for this question).....	92
Chart 91. People (who do not live in the home) let the person know before entering home .....	92
Chart 92. Can lock bedroom (proxy respondents were allowed for this question) .....	92
Chart 93. People let person know before entering person's bedroom.....	92
Chart 94. Others read mail or email without asking ° .....	93
Chart 95. Can use phone and internet when s/he wants .....	93
Chart 96. Can be alone with friends or visitors at home .....	93
Chart 97. There are rules about having friends or visitors at home °° .....	93
Chart 98. Has a place to be alone in the home.....	94
Chart 99. Staff treat person with respect .....	94
Chart 100. Has attended a self-advocacy group, meeting, conference or event or had the opportunity and chose not to (proxy respondents were allowed for this question) .....	94
Chart 101. Has voted in local, state, or federal election, or had the opportunity and chose not to (proxy respondents were allowed for this question).....	94
Tables for Rights and Respect .....	95
Table 59. Rights and Respect .....	96
<b>Safety.....</b>	<b>97</b>
Charts for Safety.....	98
Chart 102. There is at least one place where the person feels afraid or scared (in home, day program, work, walking in the community, in transport, or other place) ° .....	99
Chart 103. Has someone to go to for help if they ever feel scared .....	99
Tables for Safety.....	100
Table 60. Safety.....	101





## What is NCI?

The National Core Indicators™ (NCI™) program is a voluntary effort by state developmental disability agencies to track their performance using a standardized set of consumer and family/guardian surveys with nationally validated measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

NCI has developed more than 100 standard performance measures (or ‘indicators’) that states use to assess the outcomes of services for individuals and families, including outcomes in the areas of employment, rights, service planning, community inclusion, choice, health, and safety. In 2017-18 a total of 45 states, the District of Columbia and 22 sub-state entities participated in NCI. Not all states participate in the Adult In-Person Survey every year. Thirty-five (35) states and the District of Columbia administered the Adult In-Person Survey in 2017-18 and submitted valid samples for analysis.<sup>1</sup> Together, they collected survey responses and information from a total of 25,671 individuals.

## What is the NCI Adult In-Person Survey?

The NCI Adult In-Person Survey is a face-to-face meeting conducted with a person who is receiving services from the state; it is used to gather data on approximately 60 consumer outcomes, and it is regularly refined and tested to ensure that it is valid and reliable. Surveyors meet with individuals to ask questions about where they live and work, the kinds of choices they make, the activities they participate in within their communities, their relationships with friends and family, and their health and well-being.

Information contained in this report come from three distinct survey sections:

1. **Background Information.** This section consists of questions about demographics, residence, health, employment status, and services and supports. Data is generally collected from state records, case managers, or a combination of both.
2. **Section I.** This section attempts to determine the individual’s level of satisfaction and opinions. It may only be completed through a direct meeting with the individual.
3. **Section II.** This section contains questions that are answered by a direct meeting with the individual when possible. If the person is unable to respond, a proxy who knows the person well may be used. Case managers or service coordinators are not allowed to respond to these questions on the individual’s behalf.

---

<sup>1</sup> States that participated in the Adult In-Person Survey were: Alabama (AL), Arizona (AZ), Arkansas (AR), California (CA), Colorado (CO), Connecticut (CT), Delaware (DE), District of Columbia (DC), Florida (FL), Georgia (GA), Illinois (IL), Indiana (IN), Kansas (KS), Kentucky (KY), Louisiana (LA), Maine (ME), Massachusetts (MA), Michigan (MI), Minnesota (MN), Missouri (MO), North Carolina (NC), Nebraska (NE), Nevada (NV), New York (NY), Ohio (OH), Oklahoma (OK), Oregon (OR), Pennsylvania (PA), Rhode Island (RI), South Carolina (SC), Tennessee (TN), Utah (UT), Vermont (VT), Virginia (VA), Wisconsin (WI), and Wyoming (WY).

## What topics are covered by the survey?

The National Core Indicators are organized by “domains” or topics. These domains are further broken down into sub-domains, each of which has a statement that indicates the concerns being measured. Each sub-domain includes one or more “indicators” of how the state performs in this area. The following table lists the domains, sub-domains, and concern statements addressed by the NCI Adult In-Person Survey indicators.

### Individual Outcomes Domain

<b>Sub-domain</b>	<b>Concern Statement</b>
<b>Work</b>	<i>People have support to find and maintain community integrated employment.</i>
<b>Community Inclusion, Participation and Leisure</b>	<i>People have support to participate in everyday community activities.</i>
<b>Choice and Decision-Making</b>	<i>People make choices about their lives and are actively engaged in planning their services and supports.</i>
<b>Self Determination</b>	<i>People have authority and are supported to direct and manage their own services.</i>
<b>Relationships</b>	<i>People have friends and relationships.</i>
<b>Satisfaction</b>	<i>People are satisfied with the services and supports they receive.</i>

### Health Welfare and Rights Domain

<b>Sub-domain</b>	<b>Concern Statement</b>
<b>Safety</b>	<i>People are safe from abuse, neglect, and injury.</i>
<b>Health</b>	<i>People secure needed health services.</i>
<b>Medications</b>	<i>Medications are managed effectively and appropriately.</i>
<b>Wellness</b>	<i>People are supported to maintain healthy habits.</i>
<b>Respect/Rights</b>	<i>People receive the same respect and protections as others in the community.</i>

### System Performance Domain

<b>Sub-domain</b>	<b>Concern Statement</b>
<b>Service Coordination</b>	<i>Service coordinators are accessible, responsive, and support the person's participation in service planning.</i>
<b>Access</b>	<i>Publicly funded services are readily available to individuals who need and qualify for them.</i>

## How were people selected to participate?

Each state is instructed to attempt to complete a minimum of 400 surveys with a random sample of individuals age 18 or older who are receiving at least one publicly funded service besides case management. A sample size of 400 allows valid comparisons to be made across states with a 95% confidence level and a +/- 5% margin of error. States that do not complete a sample that reaches the 95% confidence level and 5% margin of error (based on the size of the total sample frame) are not included in NCI reporting. Both the confidence level (95%) and margin of error (5%) used are widely accepted for reviewing results, regardless of population size. Most states draw a sample greater than 400 to account for refusals and inaccurate contact information. For more information on sampling, please see Appendix C of the national report, accessible at [nationalcoreindicators.org/resources/reports/](http://nationalcoreindicators.org/resources/reports/).

## Proxy Respondents

Proxy responses are allowed only for Section II (Community Inclusion, Choices, selected Respect/Rights items, and Access to Needed Services), which is based on objective measures. Proxy respondents are used only when the individual receiving services cannot complete the survey or chooses to have a proxy respondent. Only people who know the individual well—such as family, friends, or staff—are acceptable respondents. To avoid conflict of interest, service coordinators are not allowed to provide proxy responses for individuals on their caseloads.

## Data Analysis

All individuals selected in the survey sample are given an opportunity to participate in a face-to-face meeting. There are no prescreening procedures. Exclusion of responses occurs at the time of data analysis by HSRI, based on the criteria described below. There is no threshold number of answers to be given for a survey to be considered complete.

Surveys are excluded from analysis of questions occurring in Section I if:

1. The surveyor indicated that the individual receiving supports did not respond validly to questions in Section I.
2. All questions in Section I were missing or marked 'not applicable' or 'don't know'.

Surveys are excluded from analysis of questions occurring in Section II if:

1. The individual receiving supports was marked as the respondent to all questions in Section II but Section I was deemed invalid (for one of the reasons above).
2. No questions were answered in Section II.

Individual questions left blank or marked 'not applicable' are not included in analysis. For outcome data 'don't know' responses were excluded from analysis. For all items shown, states receive an 'n/a' designation in table presentations for a survey item if fewer than 20 people responded; however, their data are included in the NCI Average.

## Weighting

Prior to 2016-17, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). Beginning last year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states’ systems. The NCI averages contained in this report are “weighted” means. Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average—that is, the state’s contribution to the NCI average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.<sup>2</sup>

When a state’s sampling strategy is to identify and interview survey participants using simple random sampling or proportional stratified random sampling, each completed survey in the state gets assigned the same weight. When a state’s sampling strategy departs markedly from simple random or proportional, it may be necessary for completed surveys in the state to be assigned different weights based on which sampling strata they correspond to. For example, if a state intentionally oversampled one or more of its sub-populations or geographical regions to be disproportionately represented in the survey sample, it may be necessary to develop and apply different weights for surveys completed in those sub-populations or regions. The procedure for calculating weights for a state is similar to calculating national weights but uses the number of completed surveys and service population sizes in each stratum (i.e., sub-population or region) separately. In the calculation of the NCI average, this type of weight was applied to the results from California, based on disproportionate sampling from regional centers (for more information see State Sample procedures in Appendix C of the national report, located here: <https://www.nationalcoreindicators.org/resources/reports/>).

## Significance Testing

For individual outcomes, each state’s percentage was compared to the weighted NCI average (described above), and the differences between the two were tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state’s result depends in part on the size of the state’s sample: the larger the sample, the more likely it is that even a small difference will be found *statistically* significant.

The t-test analyses established whether the state’s percentage was:

1. Higher than the NCI average, and the difference was statistically significant (denoted in the report with an up arrow ▲);
2. Within the average range (i.e., not statistically different from the NCI Average); or
3. Lower than the NCI average, and the difference was statistically significant (denoted in the report with a down arrow ▼).

Statistical significance was determined at the  $p \leq .01$  level.<sup>3</sup> Demographics data and data on services received were not tested for statistically significant differences.

<sup>2</sup> For more information on weighting, see the Methodology section of the National Adult In-Person Survey Report.

<sup>3</sup> For more information on significance testing, see the Methodology section of the National Adult In-Person Survey Report.

## Limitations of Data

The NCI Adult In-Person Survey tool is not intended to be used for monitoring individuals or providers; instead, it assesses system-wide performance. The NCI Average should not be interpreted as necessarily defining “acceptable” levels of performance or satisfaction. Instead, it describes average levels of performance or satisfaction across the states. It is up to public managers, policy-makers, and other stakeholders to decide what is an acceptable or unacceptable result (i.e., scale score or percentage of individuals achieving the indicated outcome).

**IMPORTANT NOTE ON ANALYSIS.** In examining the results included in this report, we found questions for which 25% or more of an individual state’s sample were marked “don’t know” or were missing data. Results denoted with an asterisk (\*) indicate that there were states in which this occurred. To see individual break-outs of which states reported 25% or more “don’t know” or missing for a particular question, see the National Report (<http://www.nationalcoreindicators.org/resources/reports/>).

The quantity of missing data can be a result of several factors. We do not know whether the data are missing systematically or randomly. For example, for a specific state, are the data missing across the board for those in a specific waiver? If so, the resulting data are not representative of the entire sample or population. We advise caution when examining data that are indicated as having high rates of missing or “don’t know” responses.

Also critical to note is that differences by state in requirements for eligibility for DD services may also be reflected in differences in the NCI data.

## What is contained in this report?

This report illustrates the 2017-18 NCI Adult In-Person Survey demographic and outcome results from Maine (ME) compared to the NCI Average. All results are shown first in charts and then in table form, and arrow symbols (▲ and ▼) are used to indicate areas where the state average was statistically higher or lower than the NCI Average. **Please note: items without the ▲ or ▼ arrow symbols indicate that the state was within the NCI Average range.** For most items, the total number of respondents (N) from the state and across NCI states is displayed in charts and tables. Results from states with fewer than 20 responses are not displayed; however, the data are included in the NCI Average. All state and national data results for this survey can be found online at <http://www.nationalcoreindicators.org/resources/reports/>.

## Demographics

*This section presents descriptive information of individuals surveyed.*

### **Important Note on Missing Data:**

For several states, survey items in the Background Information section had a large amount of missing data or data recorded as “don’t know.” Items that include states results for which 25% or more of their sample were missing data (or reported as “don’t know”) are indicated with an asterisk (\*) next to NCI Average.

We advise caution when examining data that are indicated as having high rates of “missing” or “don’t know” responses as we don’t know whether the data are missing systematically or randomly. Please note that the NCI average reflects the average of data that were reported to HSRI and may not be reflective of the service population across the country.

Table 1. Age

	Mean	Min	Max	Standard Deviation	Median	N
ME	42	21	74	15	38	398
NCI	42	18	95	16	39	25,562

Table 2. Age Group

	18-22	23-34	35-54	55-74	75+	Unknown	N
ME	4%	37%	38%	21%	0%	0%	399
NCI	9%	31%	34%	23%	2%	1%	25,671

Table 3. Gender

	Male	Female	Other	N
ME	54%	46%	0%	397
NCI	59%	41%	0%	25,568

Table 4. Marital Status

*Includes data from states with 25% or more missing or “don’t know” data.*

	Single, Never Married	Married	Single, Married in the Past	Don't Know	N
ME	95%	1%	4%	0%	399
NCI	94%	2%	2%	2%	25,459

Table 5. Race and Ethnicity

	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White
ME	1%	1%	1%	0%	95%
NCI	1%	2%	16%	0%	67%

Table 6. Race and Ethnicity (Continued)

	Hispanic or Latino	Other	Two or More	Don't Know	N
ME	1%	0%	1%	1%	397
NCI	10%	1%	1%	1%	25,553

Table 7. Residential Designation

Information based on residential designation defined by the USDA: <http://www.ers.usda.gov/data-products/rural-urbancommuting-area-codes.aspx>. Includes data from states with 25% or more missing or “don’t know” data.

	Metropolitan	Micropolitan	Rural	Small Town	N
ME	51%	19%	16%	15%	398
NCI	80%	12%	6%	3%	24,168

Table 8. Type of Residence - ICF/IID, Nursing Facilities or Other Specialized Institutional Settings

Includes data from states with 25% or more missing or “don’t know” data.

	ICF/IID, 4-6 Residents with Disabilities	ICF/IID, 7-15 Residents with Disabilities	ICF/IID, 16 or More Residents with Disabilities	Nursing Facility	Other Specialized Institutional Facility	N
ME	0%	0%	0%	0%	1%	391
NCI	2%	1%	1%	0%	0%	25,488

Table 9. Type of Residence - Group Residential Setting

Includes data from states with 25% or more missing or “don’t know” data.

	Group Living Setting, 2-3 People With Disabilities	Group Living Setting, 4-6 People With Disabilities	Group Living Setting, 7-15 People With Disabilities	N
ME	29%	12%	2%	391
NCI	8%	18%	5%	25,488



Table 10. Type of Residence - Other Home Settings

*Includes data from states with 25% or more missing or “don’t know” data.*

	Own Home or Apartment	Parent or Relative's Home	Foster Care or Host Home (2 or More People With a Disability)	Foster Care, Host Home, or Shared Living (1 Person With a Disability)	Homeless	Other	Don't Know	N
ME	20%	19%	3%	14%	0%	0%	0%	391
NCI	18%	39%	3%	2%	0%	1%	1%	25,488

Table 11. Length of Time at Current Residence

*Includes data from states with 25% or more missing or “don’t know” data.*

	Less Than 1 Year	1-3 Years	3-5 Years	Over 5 Years	Don't Know	N
ME	12%	27%	13%	46%	2%	393
NCI	9%	18%	8%	60%	4%	25,303

Table 12. Person's Residence Owned or Controlled by Provider Agency

*Includes data from states with 25% or more missing or “don’t know” data.*

	Yes	No	Don't Know	N
ME	60%	38%	2%	394
NCI	36%	58%	5%	24,901

Table 13. Person Is Named on the Lease

*OR and WI data were not available in state records and therefore are not included in NCI average.*

	Named on Lease or Deed	Named on Other Legally Enforceable Rental Agreement	No	Don't Know	N
ME	16%	9%	63%	11%	394
NCI	18%	4%	68%	10%	22,404

Table 14. Person Owns Home

Includes data from states with 25% or more missing or “don’t know” data.

	Yes	No	Don't Know	N
ME	1%	98%	1%	393
NCI	2%	96%	2%	23,992

Table 15. Has ID Diagnosis

	Yes	No	Don't Know	N
ME	95%	4%	1%	399
NCI	90%	9%	1%	25,465

Table 16. Level of ID (if the Person Has an ID Diagnosis)

	Mild	Moderate	Severe	Profound	Unspecified	Unknown	N
ME	51%	31%	9%	6%	3%	1%	380
NCI	41%	29%	13%	8%	7%	1%	22,674

Table 17. Mood, Anxiety, Behavior, Psychotic, and Other Mental Illness

Categories are not mutually exclusive and N may differ by category; therefore, N is not shown. Includes data from states with 25% or more missing or “don’t know” data.

	Mood Disorder	Anxiety Disorder	Behavior Challenges	Psychotic Disorder	Other Mental Illness or Psychiatric Diagnosis
ME	38%	43%	31%	10%	13%
NCI	30%	27%	28%	11%	12%

Table 18. Other Disabilities

Categories are not mutually exclusive and N may differ by category; therefore, N is not shown. Includes data from states with 25% or more missing or “don’t know” data.

	Autism Spectrum Disorder	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency	Down Syndrome
ME	24%	10%	5%	21%	1%	11%
NCI	20%	15%	5%	26%	2%	9%

Table 19. Other Disabilities (Continued)

Categories are not mutually exclusive and N may differ by category; therefore, N is not shown. Includes data from states with 25% or more missing or “don’t know” data.

	Prader-Willi	Fetal Alcohol Syndrome	Limited or No Vision	Severe or Profound Hearing Loss	Other Disabilities, Not Listed	No Other Disabilities
ME	1%	1%	8%	8%	20%	7%
NCI	1%	1%	10%	6%	17%	8%

Table 20. Health Conditions

Categories are not mutually exclusive and N may differ by category; therefore, N is not shown. Includes data from states with 25% or more missing or “don’t know” data.

	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
ME	8%	12%	4%	16%	13%
NCI	7%	11%	2%	20%	18%

Table 21. Health Conditions (Continued)

Categories are not mutually exclusive and N may differ by category; therefore, N is not shown. Includes data from states with 25% or more missing or “don’t know” data.

	Dysphagia	Pressure Ulcers	Alzheimer's	Oral Health or Dental Problems	Sleep Apnea	Other Health Conditions
ME	7%	2%	3%	7%	9%	25%
NCI	7%	2%	3%	6%	6%	35%

Table 22. Preferred Means of Communication

	Spoken	Gestures	Sign Language	Communication Device	Other	Don't Know	N
ME	87%	9%	2%	1%	3%	0%	396
NCI	78%	17%	1%	1%	2%	0%	25,455

Table 23. Primary Language

	English	Other	N
ME	97%	3%	393
NCI	94%	6%	25,357

Table 24. Mobility

	Moves Self Without Aids	Moves Self With Aids or Uses Wheelchair Independently	Non-Ambulatory	Don't Know	N
ME	83%	13%	4%	1%	396
NCI	77%	13%	9%	0%	25,471

Table 25. Behavioral Support Need

		None	Some	Extensive	Don't Know	N
Support Needed to Manage Self-Injurious Behavior	ME	76%	19%	4%	2%	396
	NCI	78%	16%	5%	1%	25,399
Support Needed to Manage Disruptive Behavior*	ME	62%	30%	8%	1%	395
	NCI	61%	28%	9%	1%	25,414
Support Needed to Manage Destructive Behavior*	ME	73%	20%	6%	1%	394
	NCI	73%	20%	5%	2%	25,365

\*Includes data from states with 25% or more missing or “don’t know” data.

Table 26. Level of Guardianship

	None	Limited Guardianship	Full Guardian	Has Guardian, But Unable to Distinguish Level	Don't Know	N
ME	26%	4%	68%	2%	0%	396
NCI	54%	9%	28%	6%	2%	25,499

Table 27. Guardian's Relationship to Person

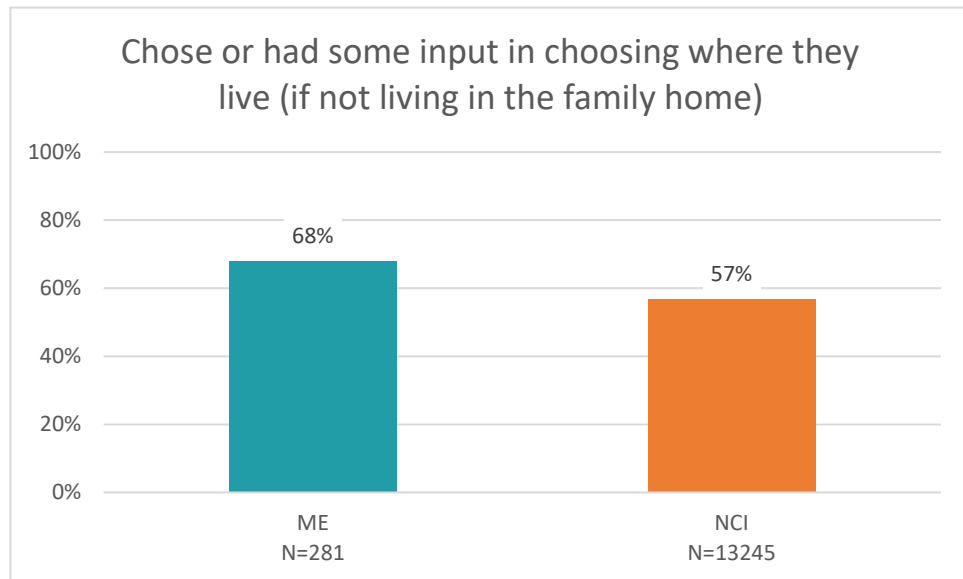
	Family	Friend	Public Guardian or Public Administrator	Financial Institution	Nonprofit Guardianship Agency	For-profit Guardianship Agency	Other	Don't Know	N
ME	62%	4%	31%	0%	0%	0%	1%	2%	290
NCI	72%	3%	10%	0%	2%	0%	1%	12%	10,617

## *Choice and Decision-Making*

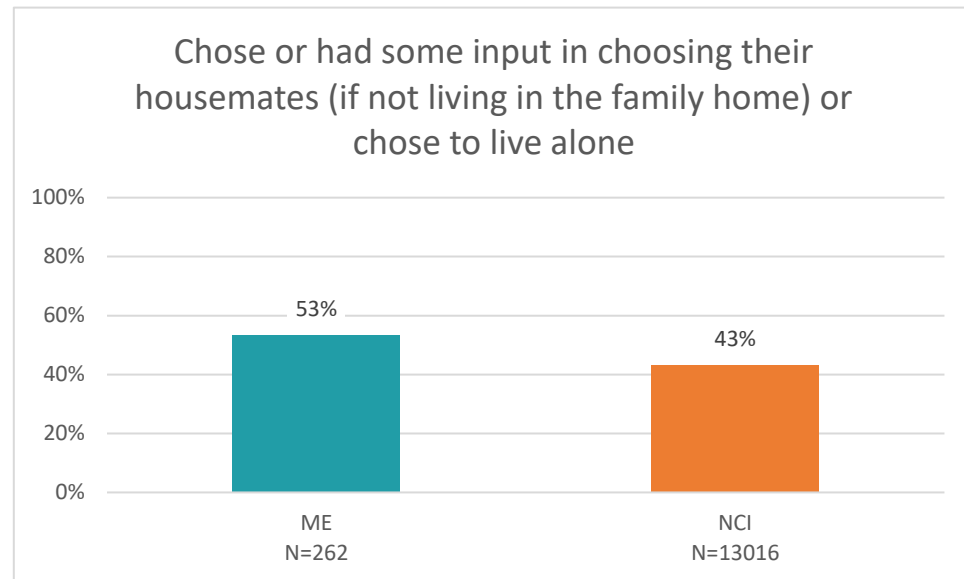
*People make choices about their lives and are actively engaged in planning their services and supports.*

*Charts for Choice and Decision-Making*

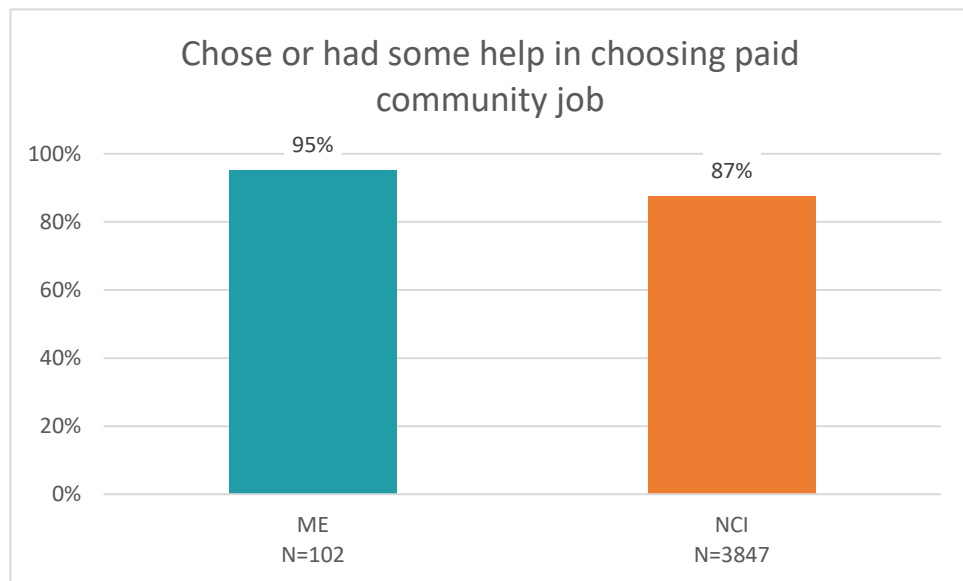
[Chart 1.](#) Chose or had some input in choosing where they live (if not living in the family home; proxy respondents were allowed for this question)



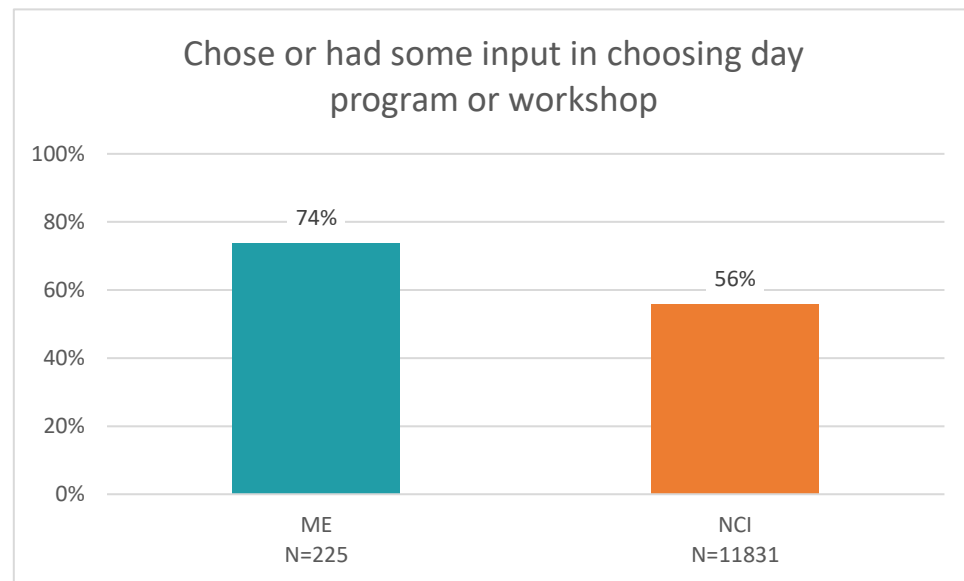
[Chart 2.](#) Chose or had some input in choosing their housemates or chose to live alone (if not living in the family home; proxy respondents were allowed for this question)



[Chart 3.](#) Chose or had input in choosing paid community job (proxy respondents were allowed for this question)\*



[Chart 4.](#) Chose or had some input in choosing day program or workshop (proxy respondents were allowed for this question) ²

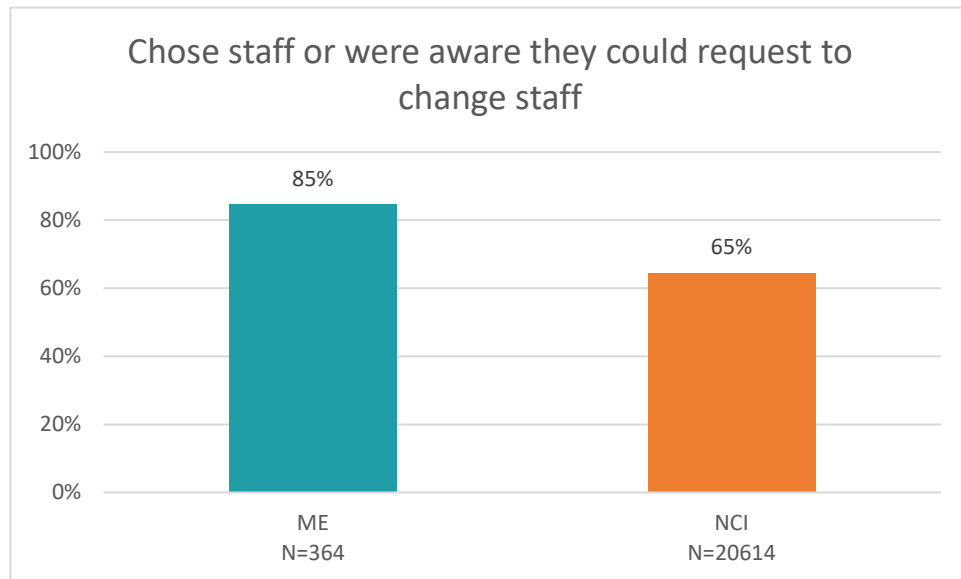


\* Note on OR and WI data: OR and WI data on type of community employment captured “no” and “don’t know” responses together (NCI states typically collect this information separately); therefore, their data are not comparable to other states and are not included in the NCI Average.

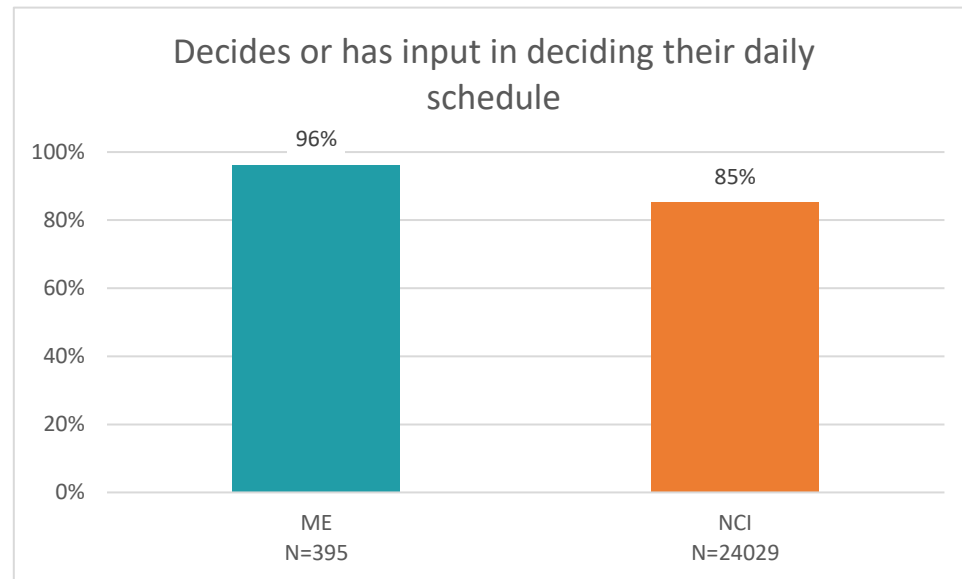
² Analysis of this question changed from previous years; now based on those determined in the Background Information to attend an unpaid community activity, unpaid paid facility activity, or paid facility activity



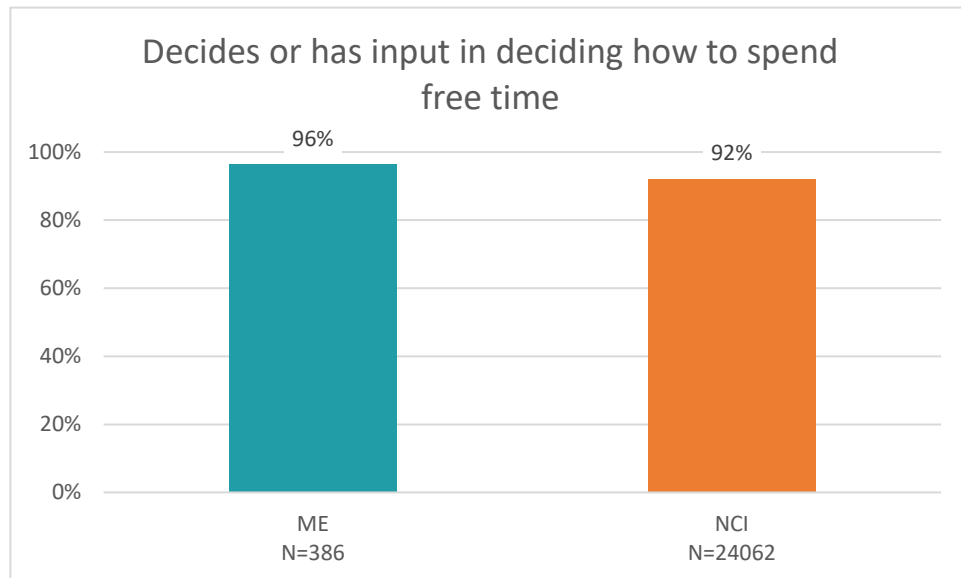
[Chart 5.](#) Chose staff or were aware they could request to change staff (proxy respondents were allowed for this question)



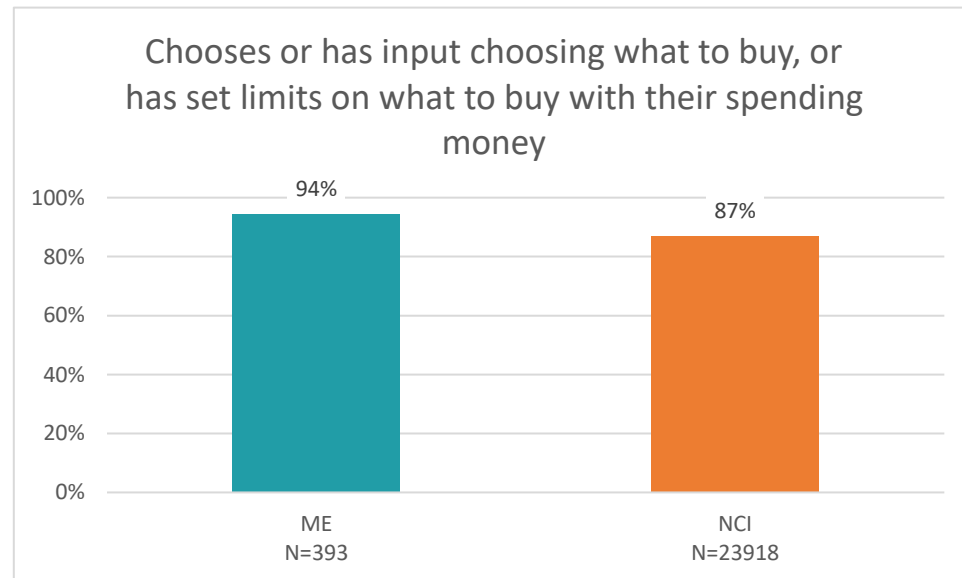
[Chart 6.](#) Decides or has input in deciding daily schedule (proxy respondents were allowed for this question)



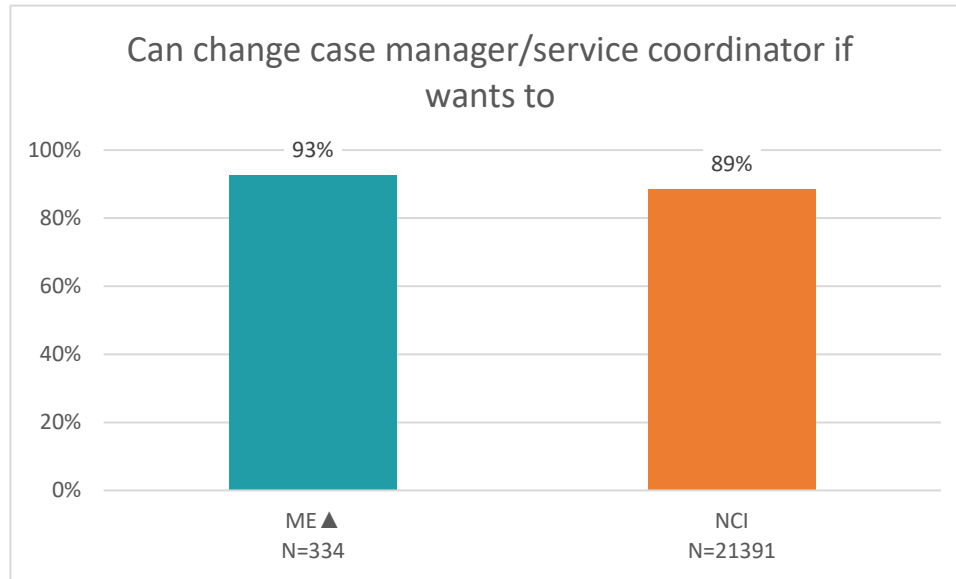
[Chart 7.](#) Decides or has input in deciding how to spend free time (proxy respondents were allowed for this question)



[Chart 8.](#) Chooses or has input in choosing what to buy, or has set limits on what to buy with their spending money (proxy respondents were allowed for this question)



[Chart 9](#). Can change case manager/service coordinator if wants to (proxy respondents were allowed for this question)



*Tables for Choice and Decision-Making*

Table 28. Choice and Decision-Making

		Yes	N
Chose or had some input in choosing where they live ( <i>if not living in the family home; proxy respondents were allowed for this question</i> )	ME	68%	281
	NCI	57%	13,245
Chose or had some input in choosing their housemates or chose to live alone ( <i>if not living in the family home; proxy respondents were allowed for this question</i> )	ME	53%	262
	NCI	43%	13,016
Chose or has input in choosing paid community job ( <i>proxy respondents were allowed for this question</i> )*	ME	95%	102
	NCI	87%	3,847
Chose or had some input in choosing day program or workshop ( <i>proxy respondents were allowed for this question</i> ) <sup>o</sup>	ME	74%	225
	NCI	56%	11,831
Chose staff or were aware they could request to change staff ( <i>proxy respondents were allowed for this question</i> )	ME	85%	364
	NCI	65%	20,614
Decides or has input in deciding their daily schedule ( <i>proxy respondents were allowed for this question</i> )	ME	96%	395
	NCI	85%	24,029
Decides or has input in deciding how to spend free time ( <i>proxy respondents were allowed for this question</i> )	ME	96%	386
	NCI	92%	24,062
Chooses or has input in choosing what to buy, or has set limits on what to buy with their spending money ( <i>proxy respondents were allowed for this question</i> )	ME	94%	393
	NCI	87%	23,918
Can change case manager/service coordinator if wants to ( <i>proxy respondents were allowed for this question</i> )	ME ▲	93%	334
	NCI	89%	21,391

\* Note on OR and WI data: OR and WI data on type of community employment captured “no” and “don’t know” responses together (NCI states typically collect this information separately); therefore, their data are not comparable to other states and are not included in the NCI Average.

<sup>o</sup> Analysis of this question changed from previous years; now based on those determined in the Background Information to attend an unpaid community activity, unpaid paid facility activity, or paid facility activity

## Work

*People have support to find and maintain community integrated employment.*

NCI reports on four types of community jobs:

1. Individual job without publicly funded supports—an individual job in which the person does not receive state or other funded supports;
2. Individual job with publicly funded supports—an individual job in which the person receives state or other funded supports;
3. Group-supported—a job that takes part in an integrated setting but is done with a group of individuals with disabilities (e.g., work crew). Group-supported jobs may or may not receive publicly funded supports; and
4. **New in 2017-18:** Community job in a business that primarily hires people with disabilities—a job where the employees with disabilities interact with the non-disabled population; this job is not in a traditional sheltered workshop and is NOT an enclave.

Note on OR and WI data: OR and WI data on type of community employment captured “no” and “don’t know” responses together (NCI states typically collect this information separately); therefore, their data are not comparable to other states and are not included in the employment tables that look at paid community job participation. Available data are reported in Appendix D of the national report.

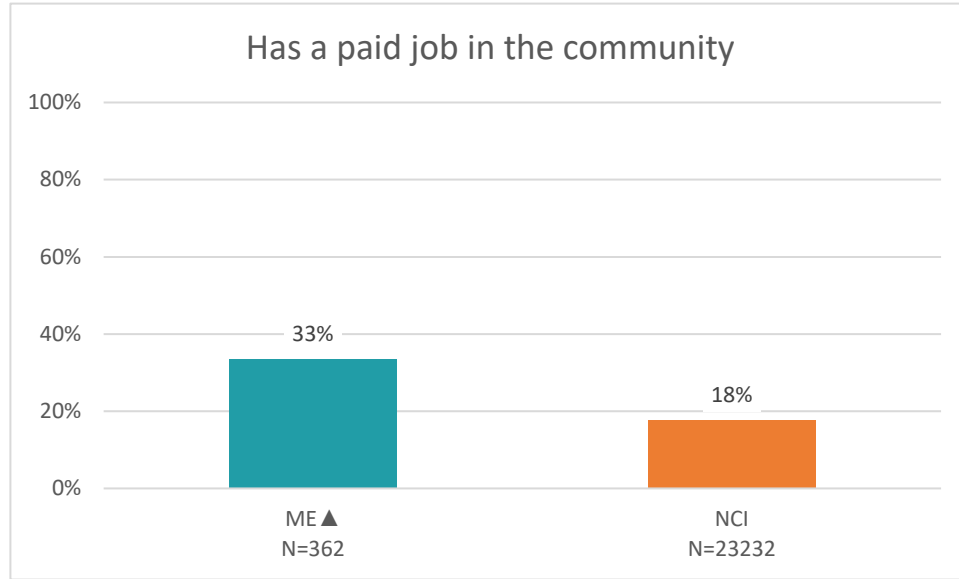
### **Important Note on Missing Data**

For several states, survey items in the Background Information section, including information on employment, had a large amount of missing data or data recorded as “don’t know.” Items that include states results for which 25% or more of their sample were missing data (or reported as “don’t know”) are indicated with an asterisk (\*) next to NCI Average.

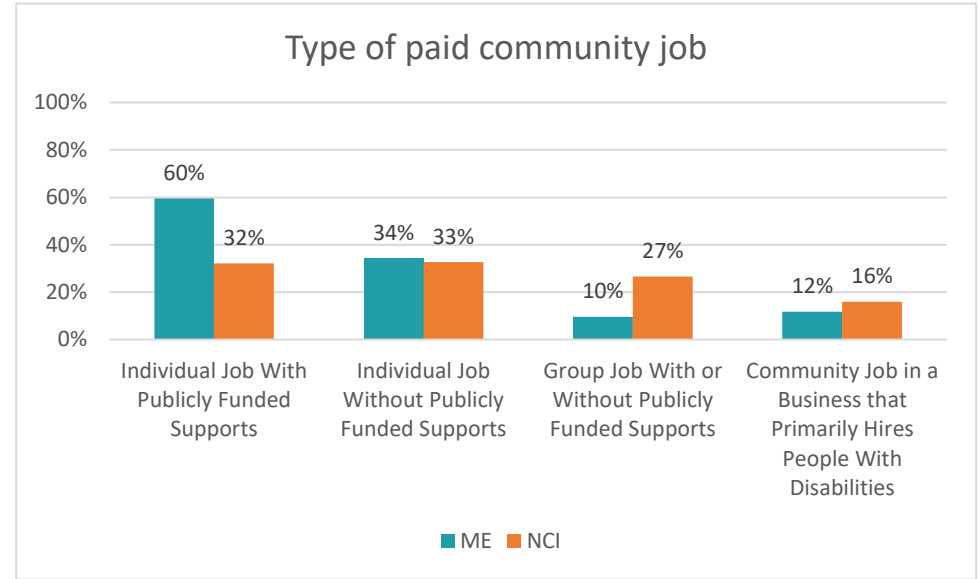
We advise caution when examining data that are indicated as having high rates of “missing” or “don’t know” responses as we don’t know whether the data are missing systematically or randomly. Please note that the NCI average reflects the average of data that were reported to HSRI and may not be reflective of the service population across the country.

*Charts for Work*

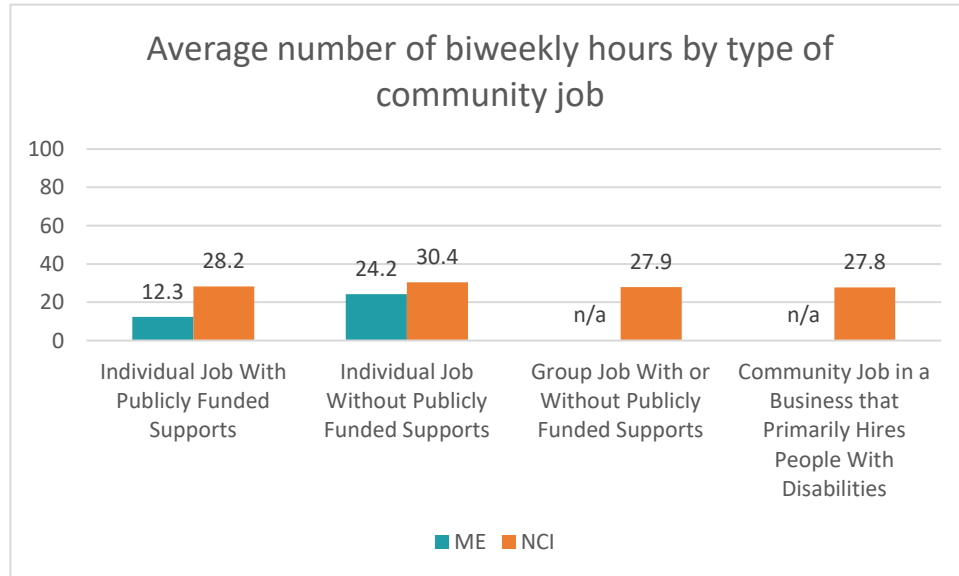
**Chart 10.** Has a paid job in the community (information may have been obtained through state records) <sup>o</sup>



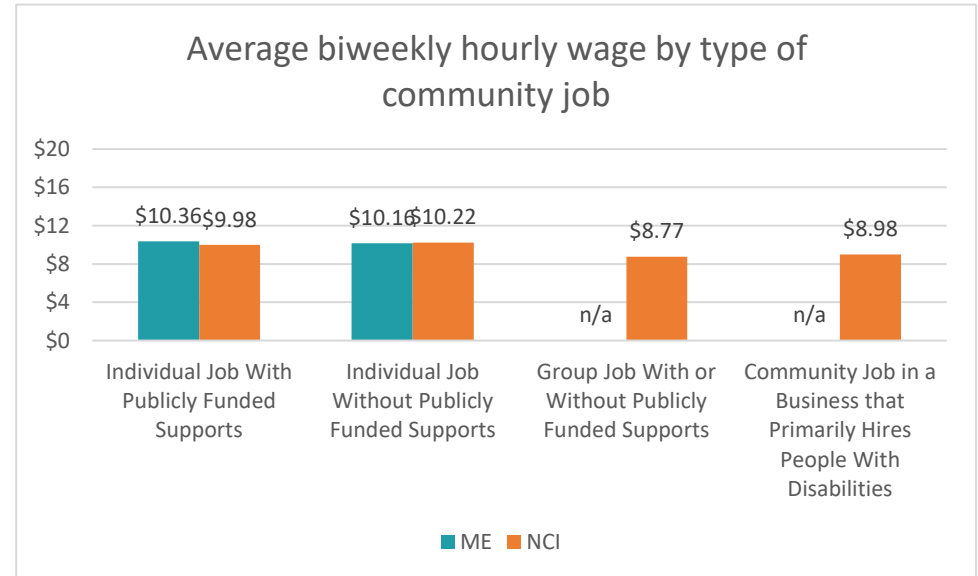
**Chart 11.** Type of paid community job (information may have been obtained through state records) <sup>o</sup> \*



**Chart 12.** Average number of biweekly hours by type of community job (information may have been obtained through state records) <sup>o</sup> \*



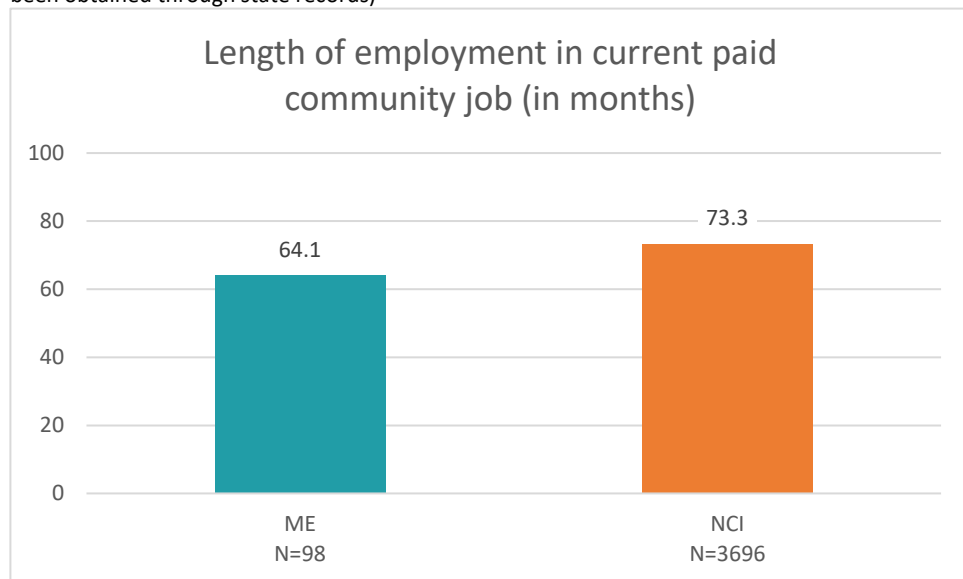
**Chart 13.** Average biweekly hourly wage by type of community job (information may have been obtained through state records) <sup>o</sup> \*



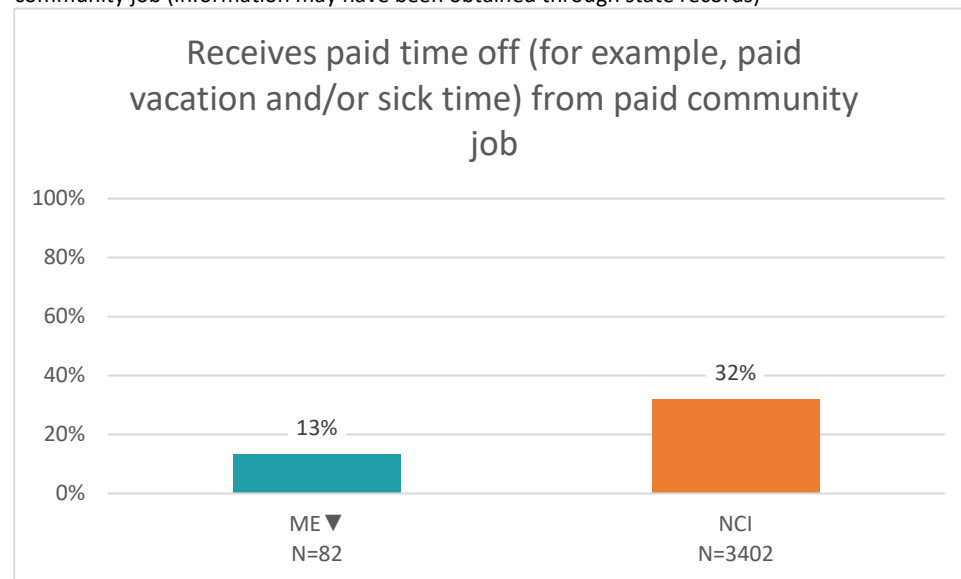
<sup>o</sup> Employment categories changed in 2017-18; therefore, results should not be compared to previous years.

\*Includes data from states with 25% or more missing or "don't know" data.

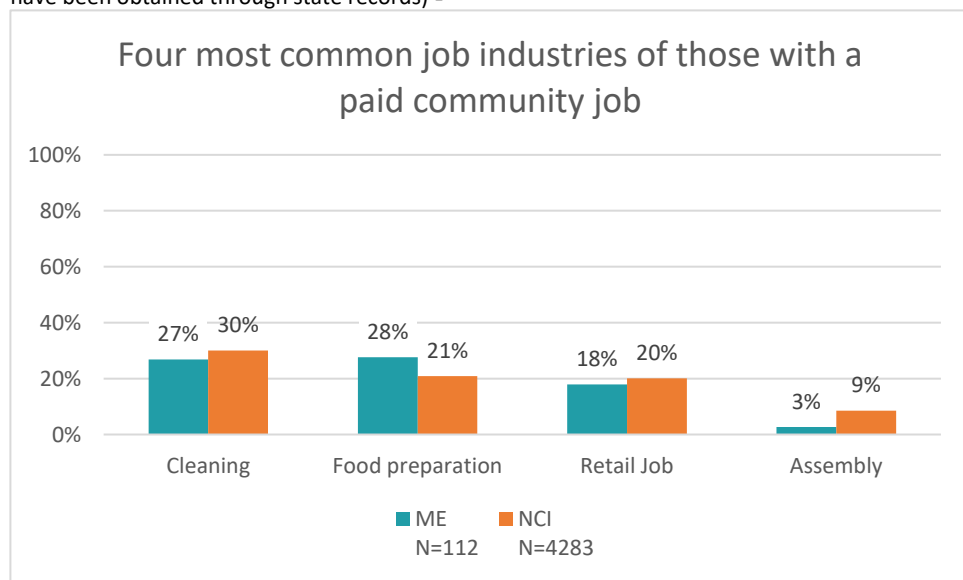
**Chart 14.** Length of employment in current paid community job (in months; information may have been obtained through state records) <sup>Ⓐ</sup> \*



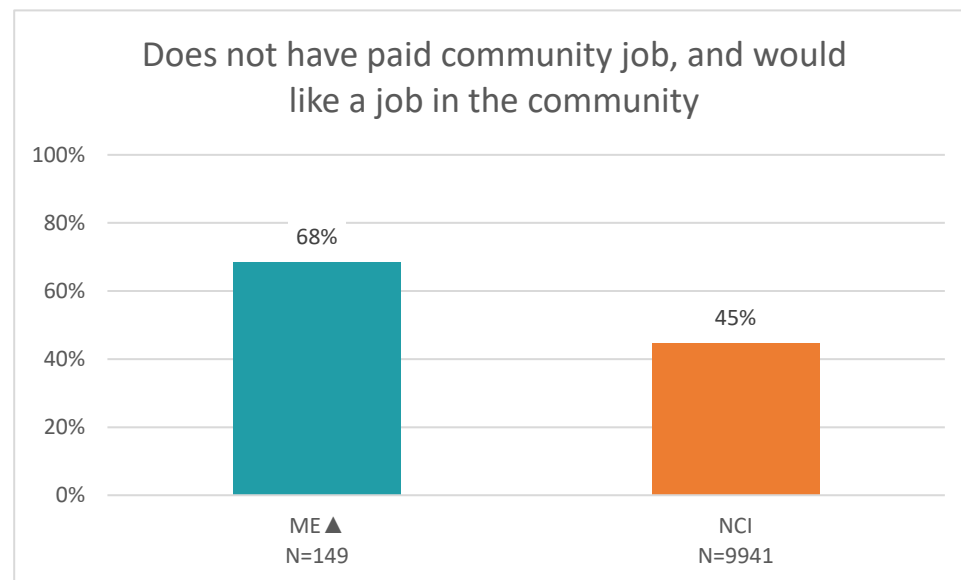
**Chart 15.** Receives paid time off (for example, paid vacation and/or sick time) from paid community job (information may have been obtained through state records) <sup>Ⓐ</sup> \*



**Chart 16.** Four most common job industries of those with a paid community job (information may have been obtained through state records) <sup>Ⓐ</sup> ∞



**Chart 17.** Does not have paid community job, and would like a job in the community <sup>Ⓐ</sup>



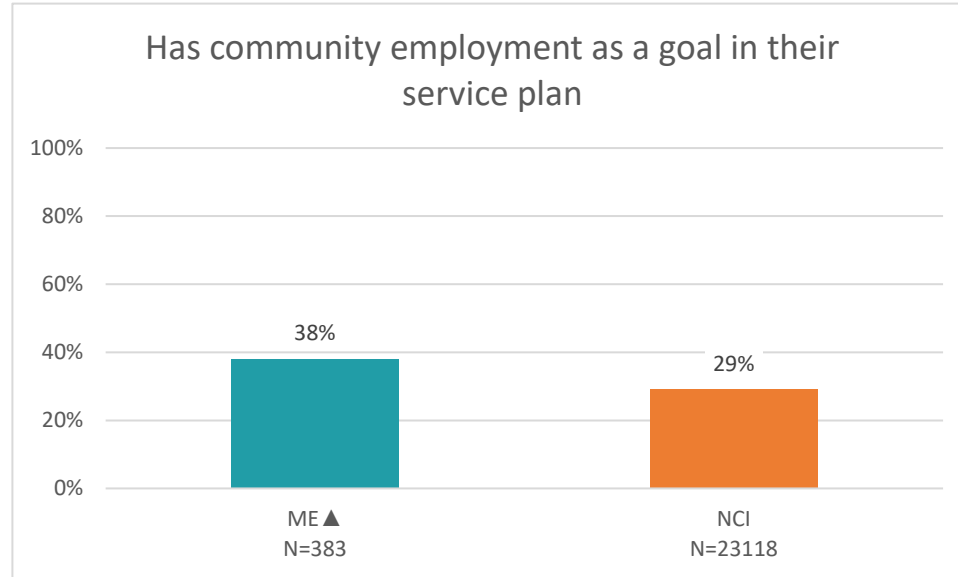
<sup>Ⓐ</sup> Employment categories changed in 2017-18; therefore, results should not be compared to previous years.

∞ Categories are not mutually exclusive

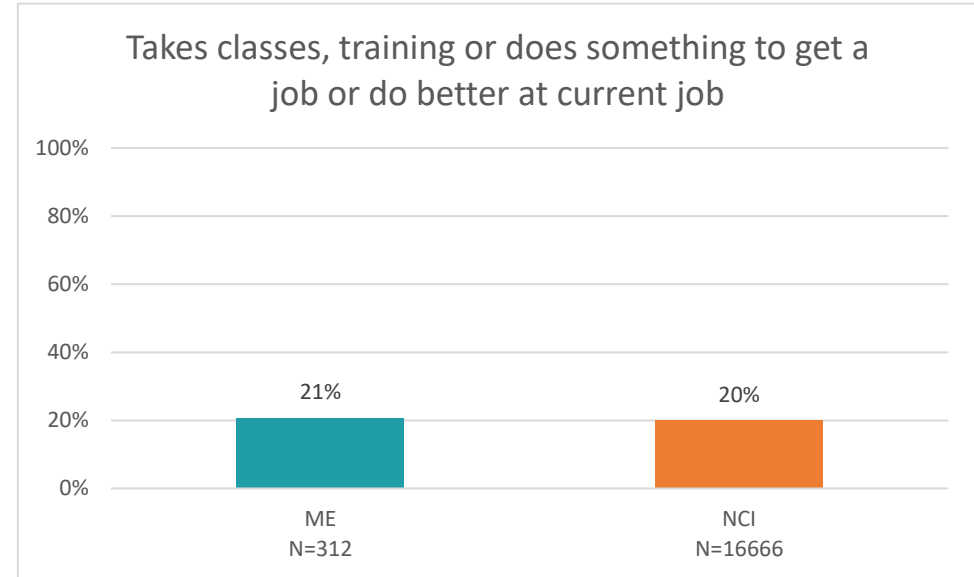
\*Includes data from states with 25% or more missing or "don't know" data.



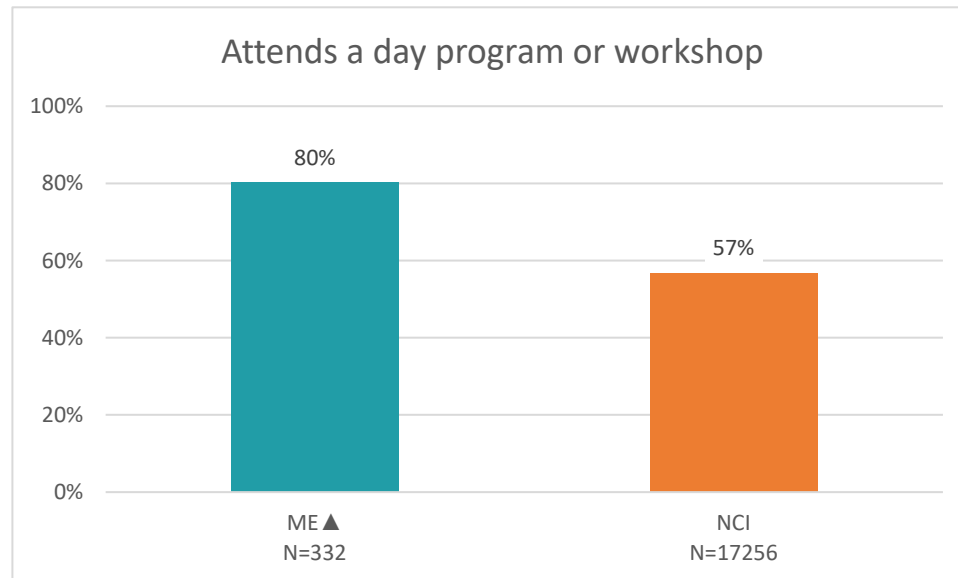
[Chart 18](#). Has community employment as a goal in their service plan (information may have been obtained through state records) <sup>9</sup>



[Chart 19](#). Takes classes, training or does something to get a job or do better at current job



[Chart 20](#). Attends a day program or workshop



[Chart 21](#). Volunteers



<sup>9</sup> Employment categories changed in 2017-18; therefore, results should not be compared to previous years.

*Tables for Work*

**Table 29. Has paid community job**

*Employment categories changed in 2017-18; therefore, results should not be compared to previous years. Information may have been obtained through state records.*

	Yes	N
ME ▲	33%	362
NCI	18%	23,232

**Table 30. Type of paid community job**

*Employment categories changed in 2017-18; therefore, results should not be compared to previous years. Information may have been obtained through state records. Includes data from states with 25% or more missing or “don’t know” data.*

	Individual Job With Publicly Funded Supports	Individual Job Without Publicly Funded Supports	Individual Job N	Group Job With or Without Publicly Funded Supports	Group Job N	Community Job in a Business that Primarily Hires People With Disabilities	Community Job N
ME	60%	34%	99	10%	104	12%	102
NCI	32%	33%	3,887	27%	4,150	16%	4,097

Table 31. Hours and wages by type of paid community job

Employment categories changed in 2017-18; therefore, results should not be compared to previous years. Information may have been obtained through state records. Includes data from states with 25% or more missing or “don’t know” data.

		Individual Job With Publicly Funded Supports	Individual Job Without Publicly Funded Supports	Group Job With or Without Publicly Funded Supports	Community Job in a Business that Primarily Hires People With Disabilities
Average number of biweekly hours by type of community job (information may have been obtained through state records)*	ME	12.3	24.2	n/a	n/a
	NCI	28.2	30.4	27.9	27.8
Average biweekly hourly wage by type of community job (information may have been obtained through state records)*	ME	\$10.36	\$10.16	n/a	n/a
	NCI	\$9.98	\$10.22	\$8.77	\$8.98

Table 32. Length of employment at current job, in months

Employment categories changed in 2017-18; therefore, results should not be compared to previous years. Information may have been obtained through state records. Includes data from states with 25% or more missing or “don’t know” data.

	Average Months	N
ME	64.1	98
NCI	73.3	3,696

Table 33. Receives paid time off at paid community job (information may have been obtained through state records)

Employment categories changed in 2017-18; therefore, results should not be compared to previous years. Information may have been obtained through state records. Includes data from states with 25% or more missing or “don’t know” data.

	Yes	N
ME ▼	13%	82
NCI	32%	3,402

Table 34. Most common types of jobs among those with a paid community job (information may have been obtained through state records)

Employment categories changed in 2017-18; therefore, results should not be compared to previous years. Information may have been obtained through state records.

	Cleaning	Retail Job	Food preparation	Assembly	N
ME	27%	28%	18%	3%	112
NCI	30%	21%	20%	9%	4,283

Table 35. Employment goals and other daily activities

		Yes	N
Does not have paid community job, and would like a job in the community <sup>a</sup>	ME ▲	68%	149
	NCI	45%	9,941
Has community employment as a goal in their service plan ( <i>information may have been obtained through state records</i> )	ME ▲	38%	383
	NCI	29%	23,118
Takes classes, training or does something to get a job or do better at current job	ME	21%	312
	NCI	20%	16,666
Attends a day program or workshop	ME ▲	80%	332
	NCI	57%	17,256
Volunteers	ME ▲	47%	309
	NCI	31%	16,815

<sup>a</sup> Employment categories changed in 2017-18; therefore, results should not be compared to previous years. Categories are not mutually exclusive.

## *Self-Determination*

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

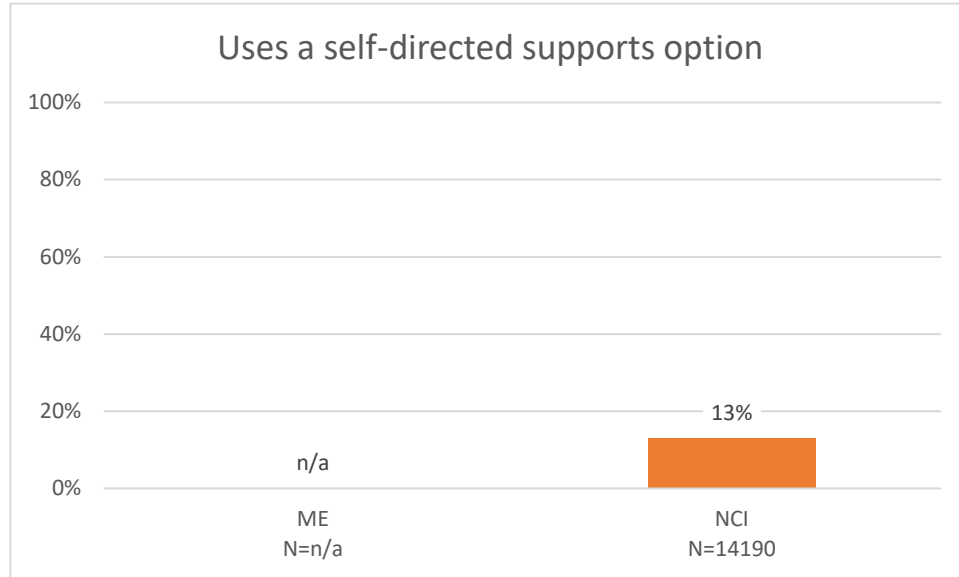
Due to low response rates to questions in this section within states, and because data may not be missing randomly, no significance testing was conducted on self-determination items.

**Note on change to survey:**

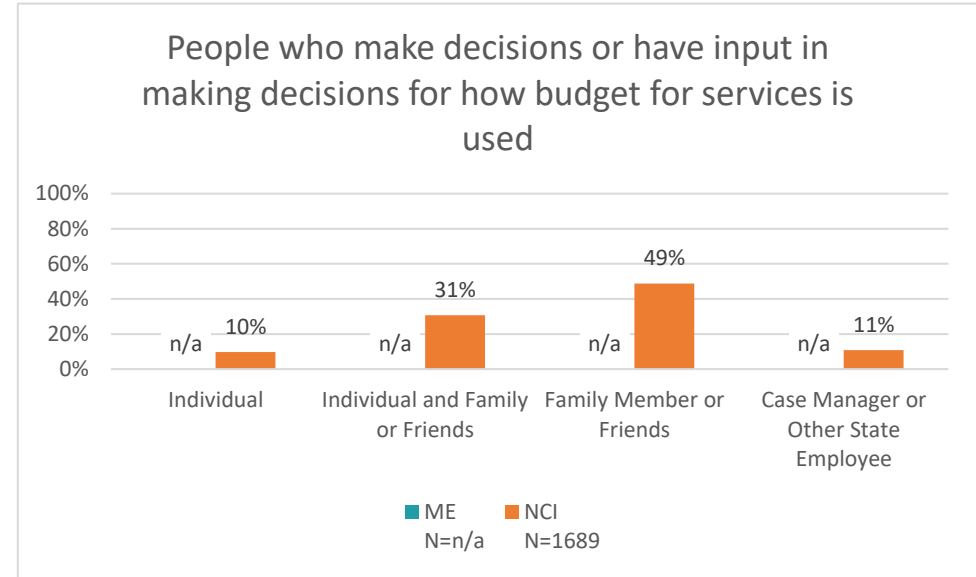
This section attempts to assess the self-direction experience, about which a proxy may be able to provide personal insight. Therefore, questions in this section may have been asked of the individual and/or proxy. Note on WI data: For 20 participants in WI's IRIS, WI collected items in the Self Direction module over the phone. Results should be viewed with caution as this is not standard NCI protocol.

*Charts for Self-Determination*

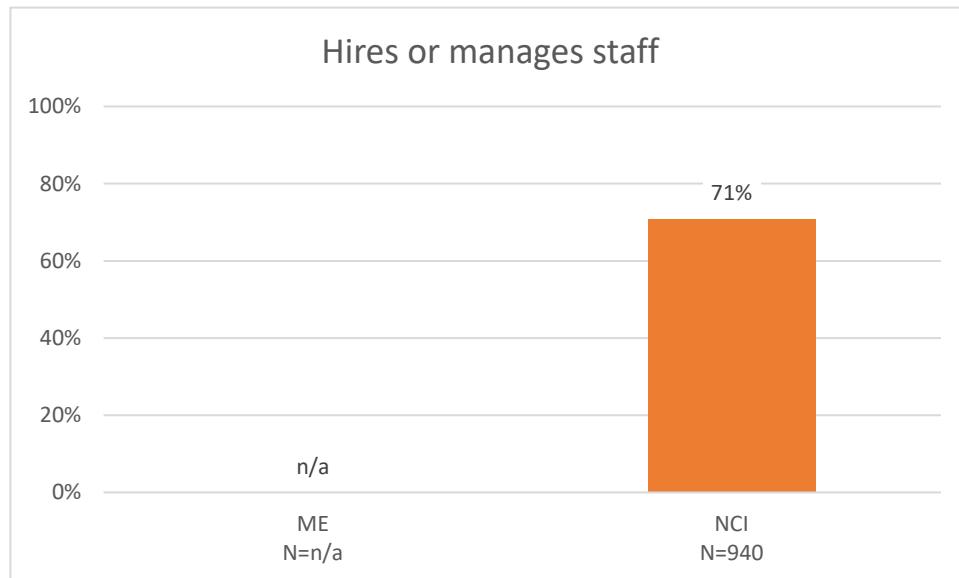
**Chart 22.** Uses a self-directed supports option (information may have been obtained through state records)



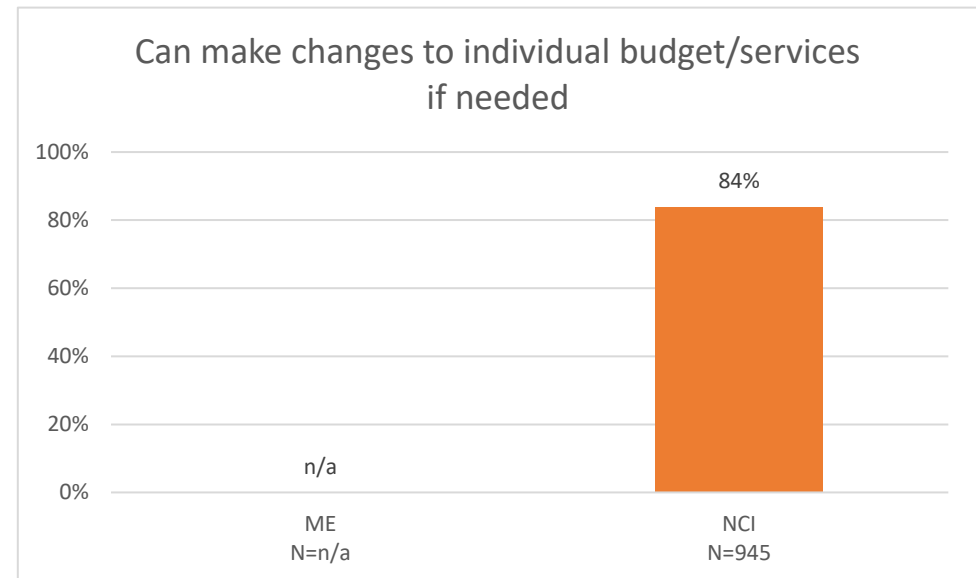
**Chart 23.** People who make decisions or have input in making decisions for how budget for services is used (proxy respondents were allowed for this question)



**Chart 24.** Hires or manages staff (proxy respondents were allowed for this question)

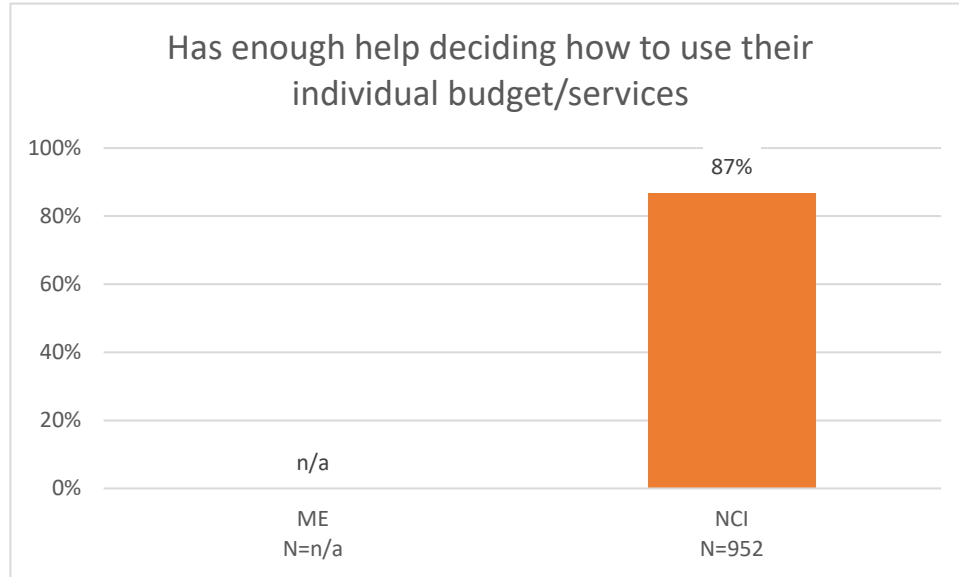


**Chart 25.** Can make changes to individual budget/services if needed (proxy respondents were allowed for this question)

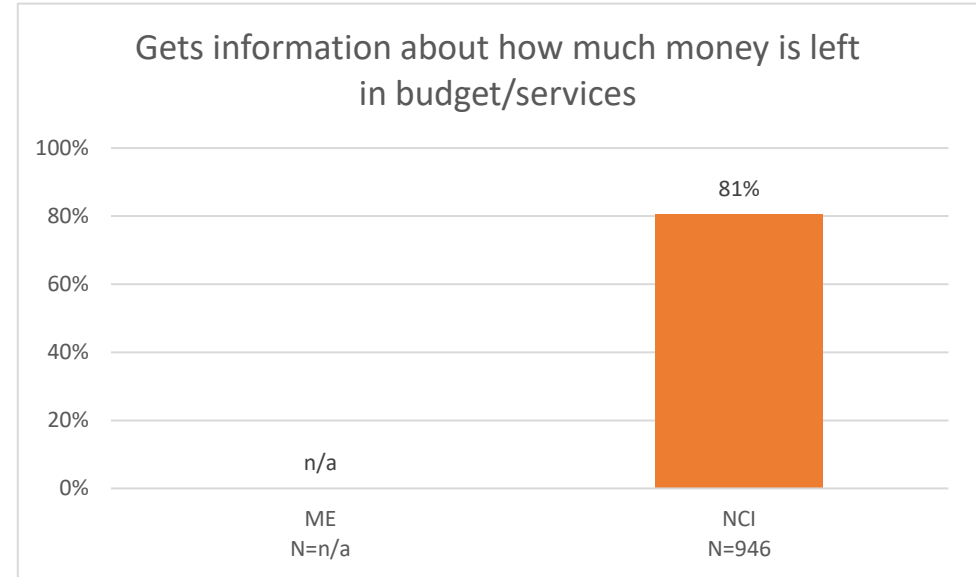




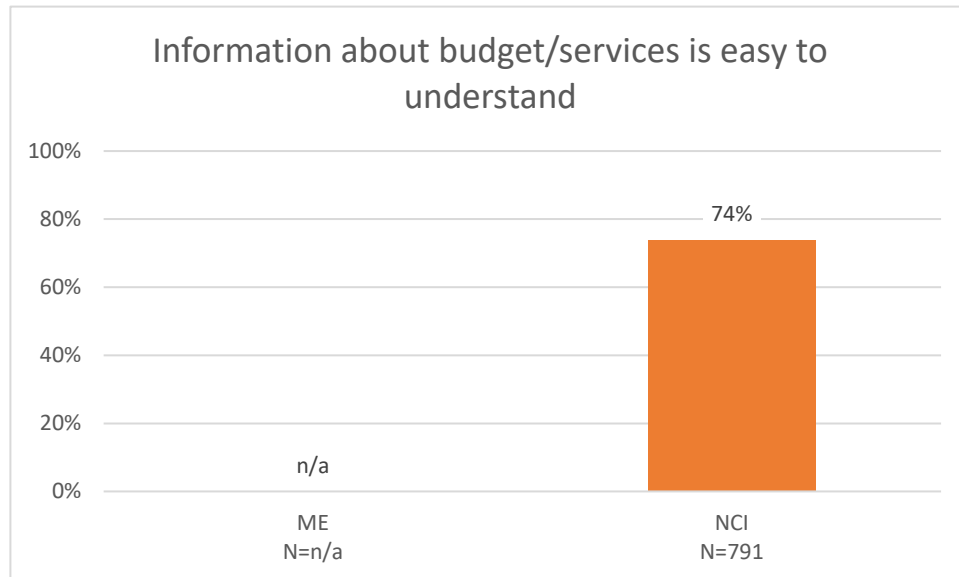
**Chart 26.** Has enough help deciding how to use their individual budget/services (proxy respondents were allowed for this question)



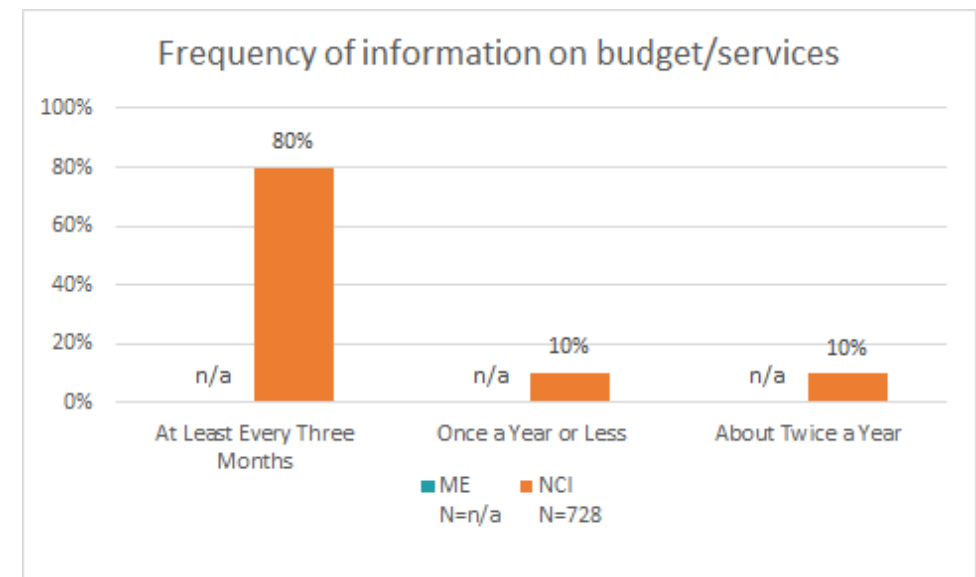
**Chart 27.** Gets information about how much money is left in budget/services (proxy respondents were allowed for this question)



**Chart 28.** Information about budget/services is easy to understand (proxy respondents were allowed for this question)



**Chart 29.** Frequency with which the person gets information about budget/services (proxy respondents were allowed for this question)



*Tables for Self-Determination*

Table 36. Uses self-directed services option

*Information may have been obtained through state records.*

	Yes	N
ME	n/a	n/a
NCI	13%	14190

Table 37. People who make decisions or have input in making decisions for how budget for services is used

*Information may have been obtained through state records.*

	Individual	Individual and Family or Friends	Family Member or Friends	Case Manager or Other State Employee	N
ME	n/a	n/a	n/a	n/a	n/a
NCI	10%	31%	49%	11%	1689

Table 38. Self-Direction

		Yes	N
Hires or manages staff ( <i>proxy respondents were allowed for this question</i> )	ME	n/a	n/a
	NCI	71%	940
Can make changes to individual budget/services if needed ( <i>proxy respondents were allowed for this question</i> )	ME	n/a	n/a
	NCI	84%	945
Has enough help deciding how to use their individual budget/services ( <i>proxy respondents were allowed for this question</i> )	ME	n/a	n/a
	NCI	87%	952
Gets information about how much money is left in budget/services ( <i>proxy respondents were allowed for this question</i> )	ME	n/a	n/a
	NCI	81%	946
Information about budget/services is easy to understand ( <i>proxy respondents were allowed for this question</i> )	ME	n/a	n/a
	NCI	74%	791

Table 39. Frequency of information about how much money is left in budget/services, among those who receive information

*Information may have been obtained through state records.*

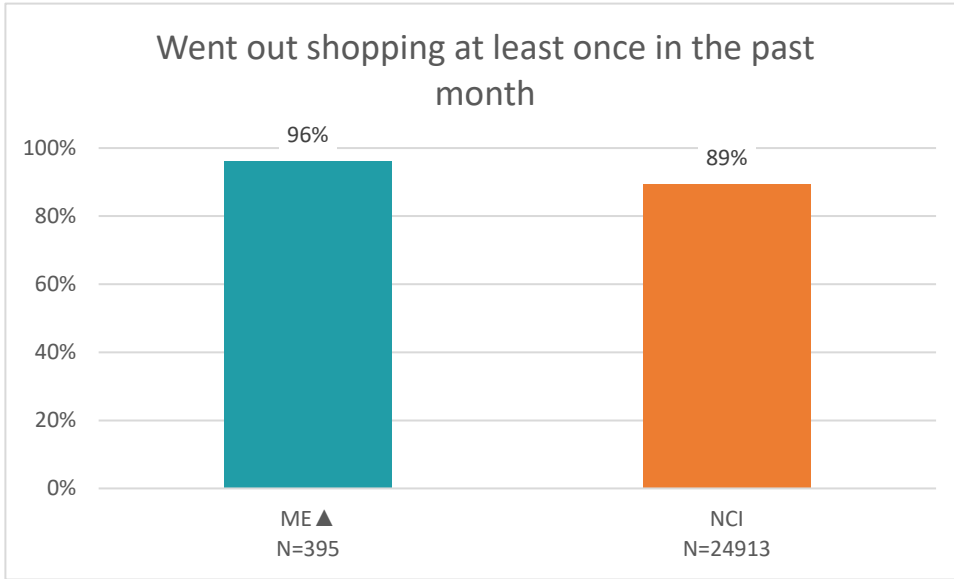
	At Least Every Three Months	Once a Year or Less	About Twice a Year	N
ME	n/a	n/a	n/a	n/a
NCI	80%	10%	10%	728

## *Community Inclusion, Participation and Leisure*

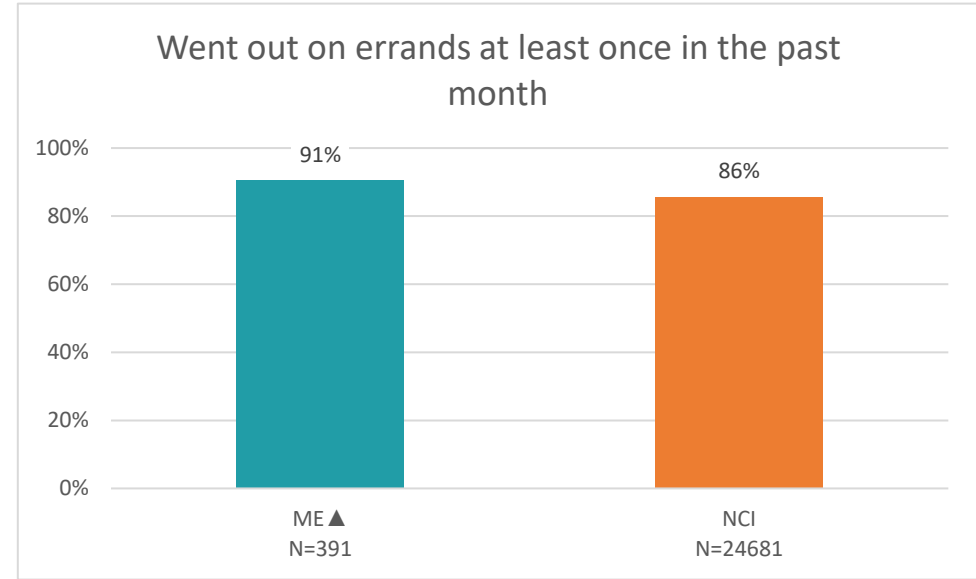
*People have support to participate in everyday community activities.*

*Charts for Community Inclusion, Participation and Leisure*

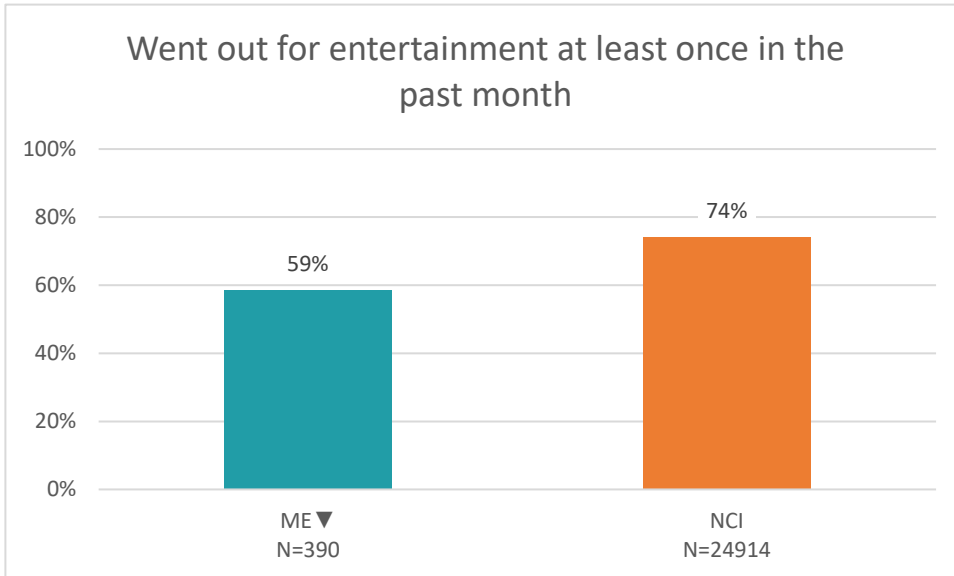
[Chart 30.](#) Went out shopping at least once in the past month (proxy respondents were allowed for this question)



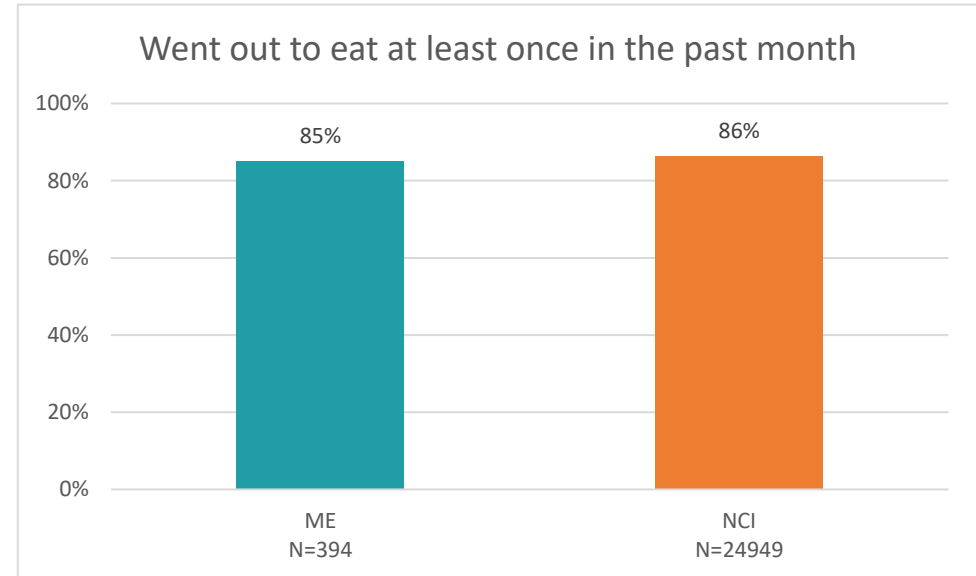
[Chart 31.](#) Went out on errands at least once in the past month (proxy respondents were allowed for this question)



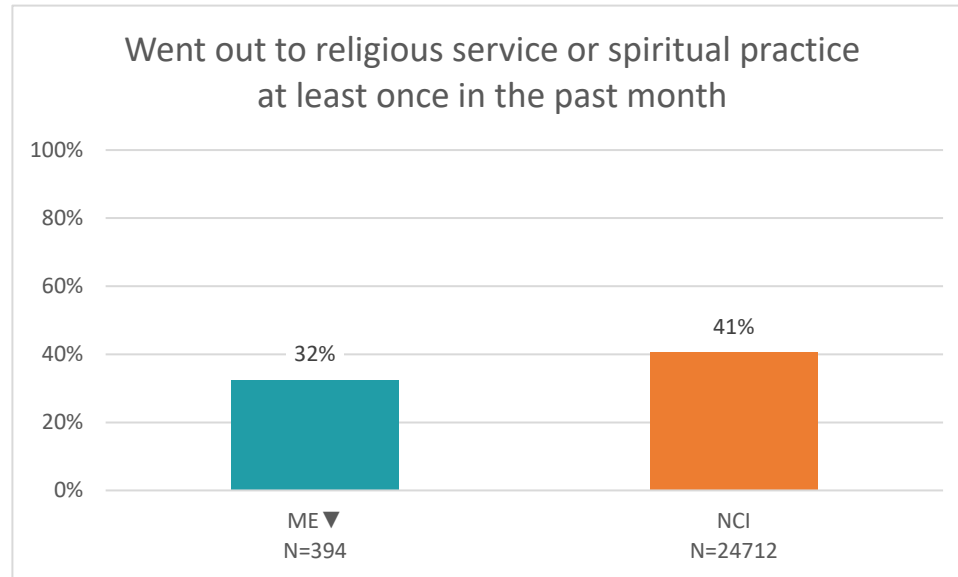
[Chart 32.](#) Went out for entertainment at least once in the past month (proxy respondents were allowed for this question)



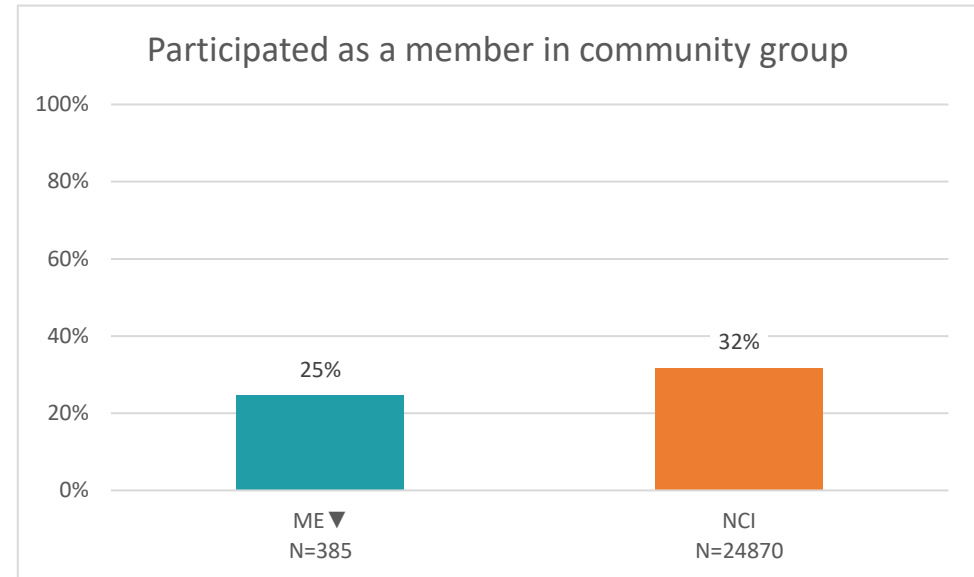
[Chart 33.](#) Went out to eat at least once in the past month (proxy respondents were allowed for this question)



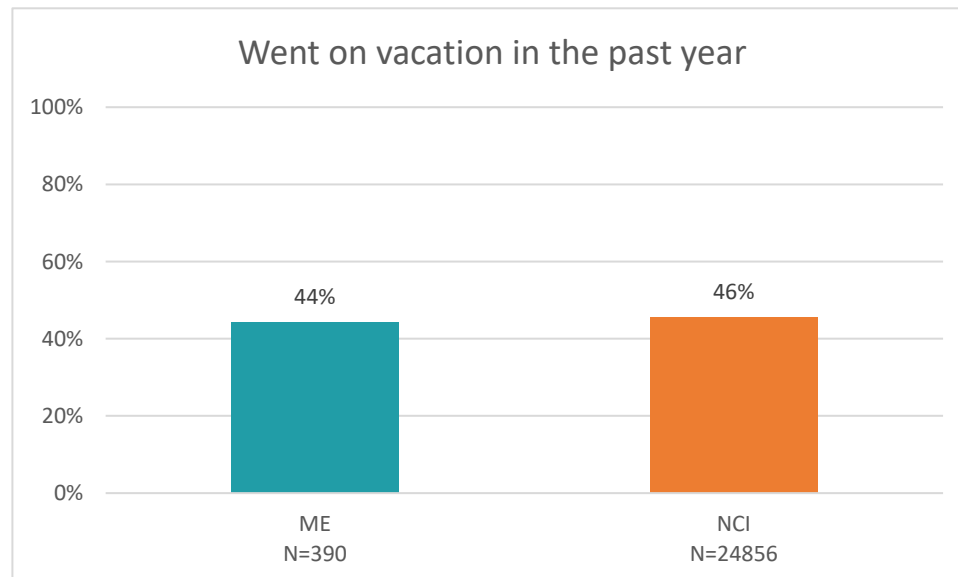
[Chart 34.](#) Went out to religious service or spiritual practice at least once in the past month (proxy respondents were allowed for this question)



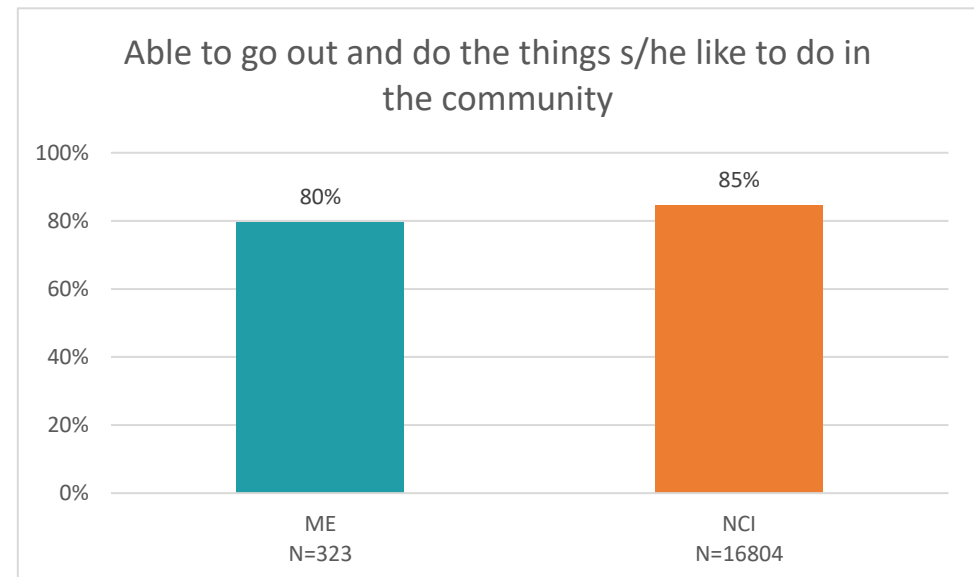
[Chart 35.](#) Participated as a member in community group (proxy respondents were allowed for this question)



[Chart 36.](#) Went on vacation in the past year (proxy respondents were allowed for this question)

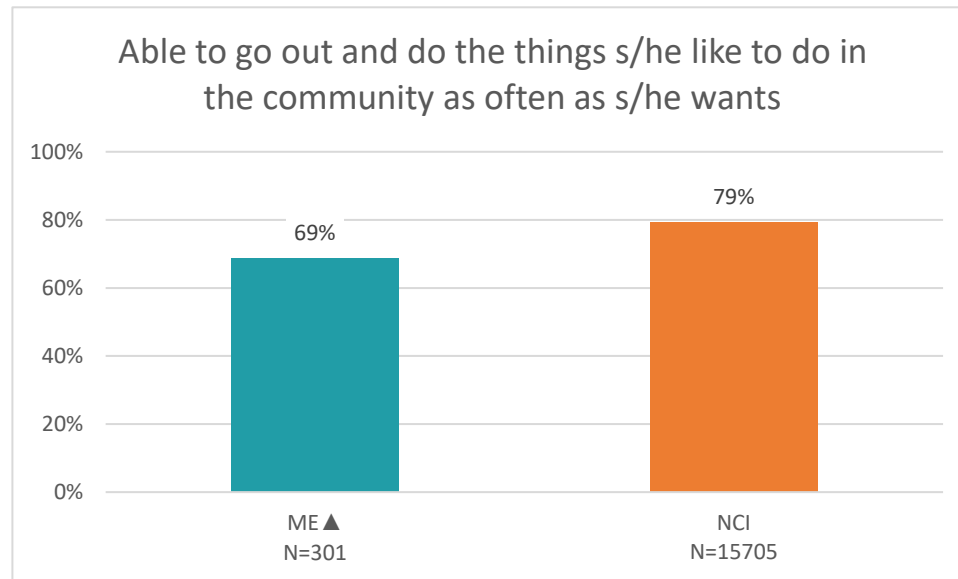


[Chart 37.](#) Able to go out and do the things s/he like to do in the community

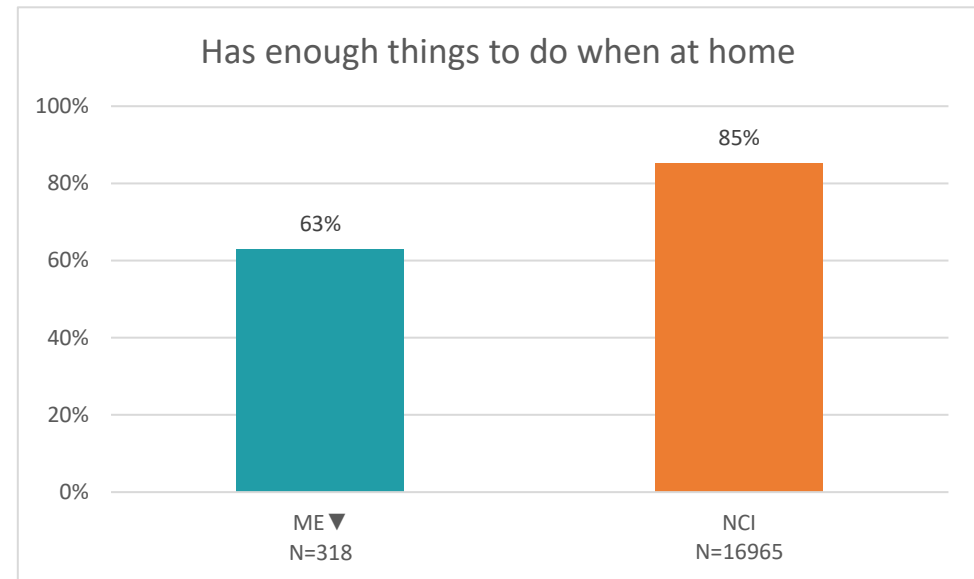




[Chart 38](#). Able to go out and do the things s/he like to do in the community as often as they want



[Chart 39](#). Has enough things to do when at home



*Tables for Community Inclusion, Participation, and Leisure*

Table 40. Community Inclusion, Participation, and Leisure

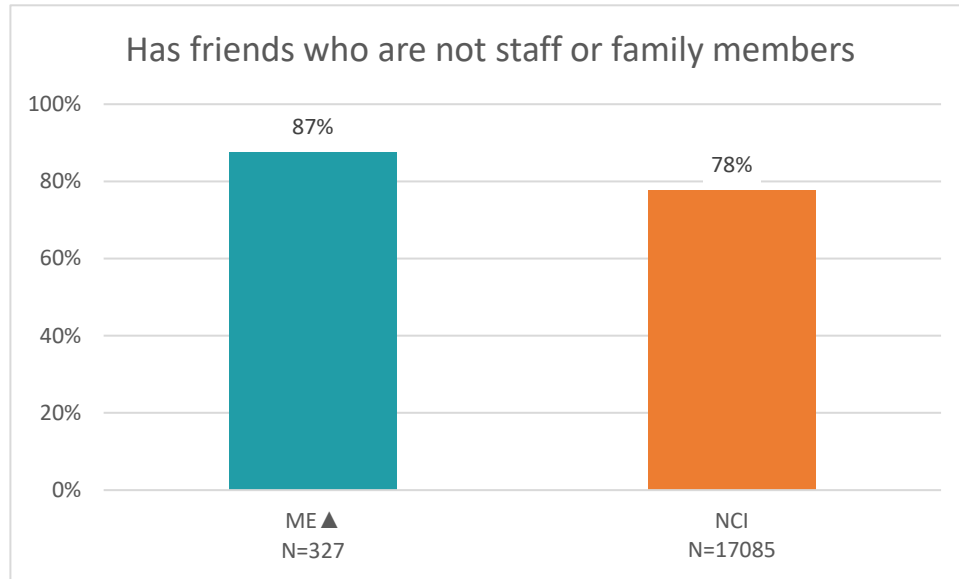
		Yes	N
Went out shopping at least once in the past month ( <i>proxy respondents were allowed for this question</i> )	ME ▲	96%	395
	NCI	89%	24,913
Went out on errands at least once in the past month ( <i>proxy respondents were allowed for this question</i> )	ME ▲	91%	391
	NCI	86%	24,681
Went out for entertainment at least once in the past month ( <i>proxy respondents were allowed for this question</i> )	ME ▼	59%	390
	NCI	74%	24,914
Went out to eat at least once in the past month ( <i>proxy respondents were allowed for this question</i> )	ME	85%	394
	NCI	86%	24,949
Went out to religious service or spiritual practice at least once in the past month ( <i>proxy respondents were allowed for this question</i> )	ME ▼	32%	394
	NCI	41%	24,712
Participated as a member in community group ( <i>proxy respondents were allowed for this question</i> )	ME ▼	25%	385
	NCI	32%	24,870
Went on vacation in the past year ( <i>proxy respondents were allowed for this question</i> )	ME	44%	390
	NCI	46%	24,856
Able to go out and do the things s/he like to do in the community	ME	80%	323
	NCI	85%	16,804
Able to go out and do the things s/he like to do in the community as often as s/he wants	ME ▲	69%	301
	NCI	79%	15,705
Has enough things to do when at home	ME ▼	63%	318
	NCI	85%	16,965

## *Relationships*

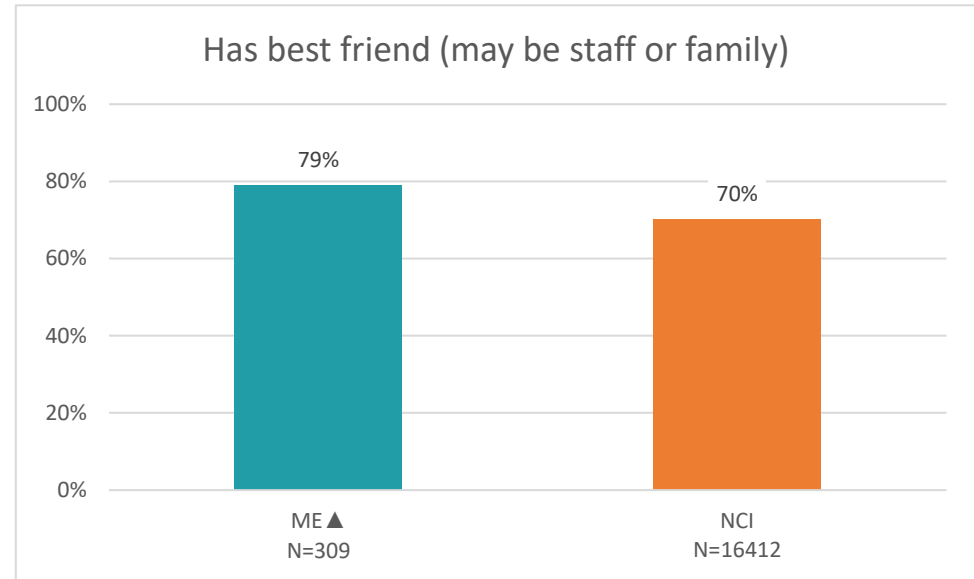
*People have friends and relationships.*

*Charts for Relationships*

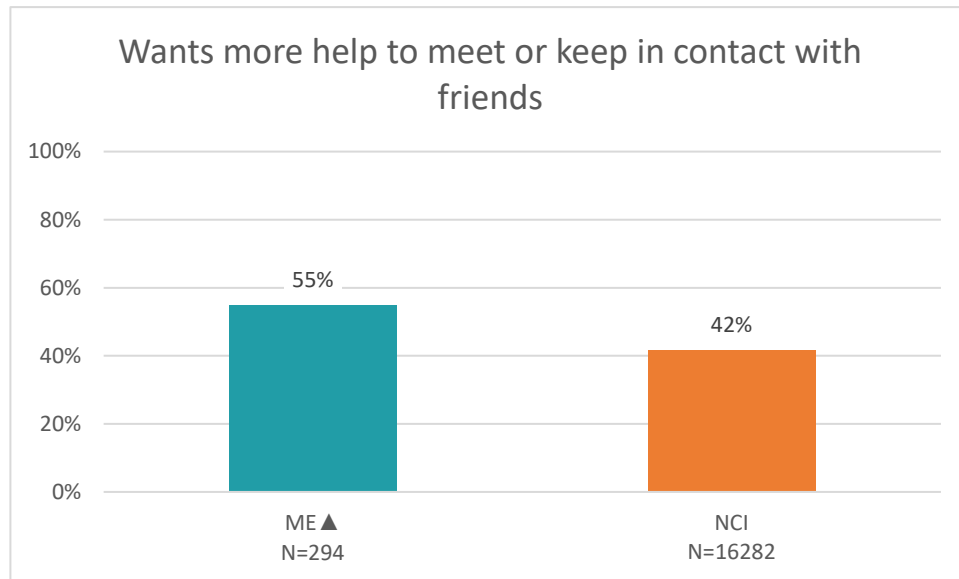
[Chart 40.](#) Has friends who are not staff or family members



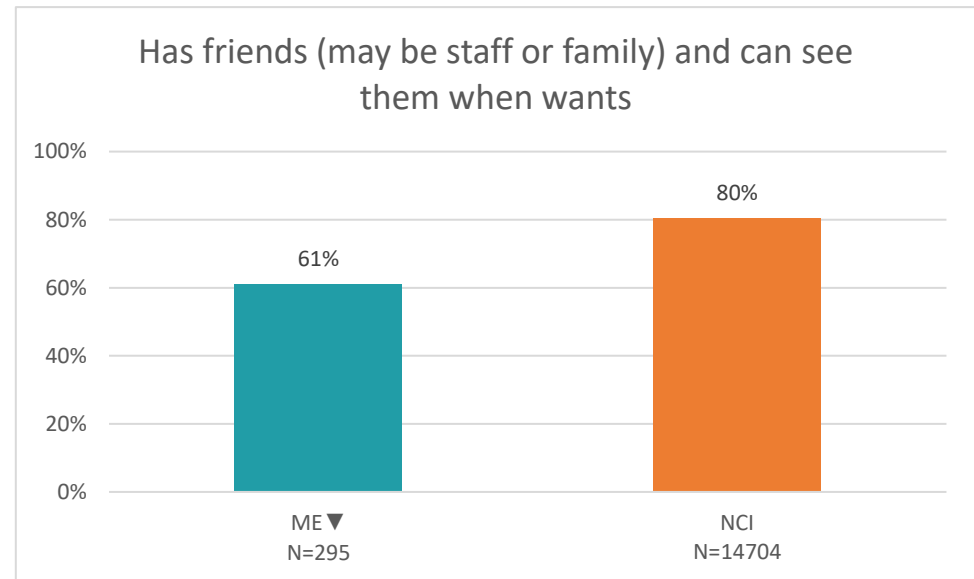
[Chart 41.](#) Has best friend (may be staff or family)



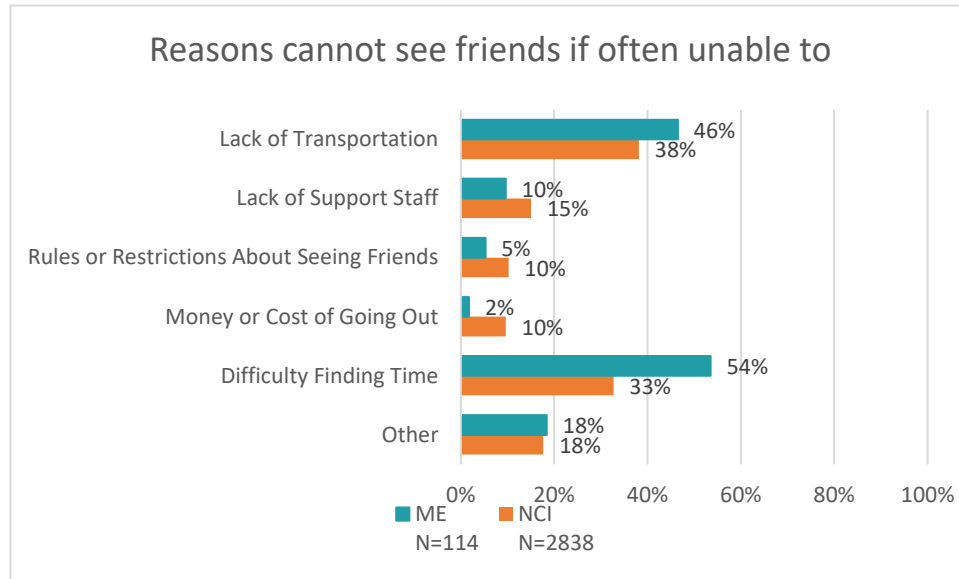
[Chart 42.](#) Wants more help to meet or keep in contact with friends



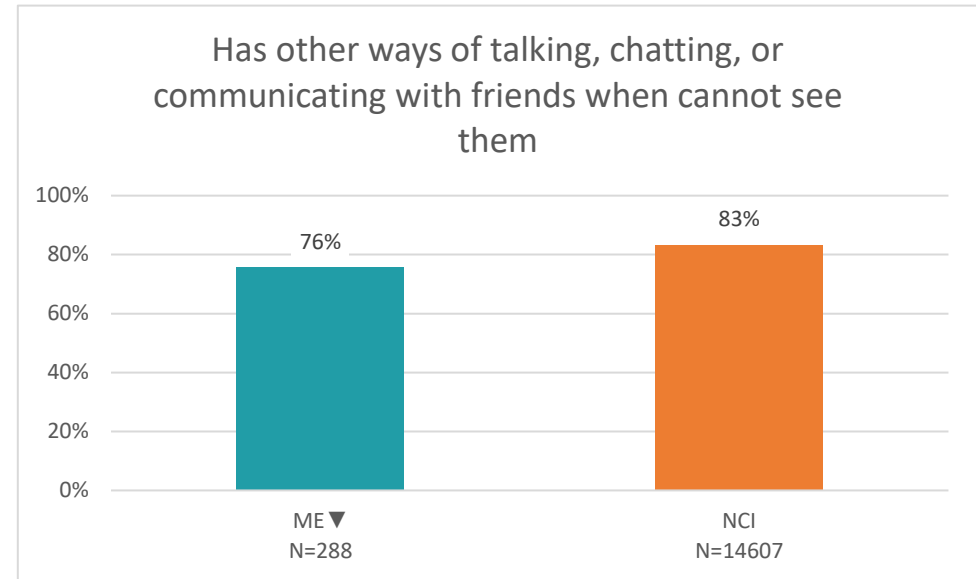
[Chart 43.](#) Has friends (may be staff or family) and can see them when s/he wants



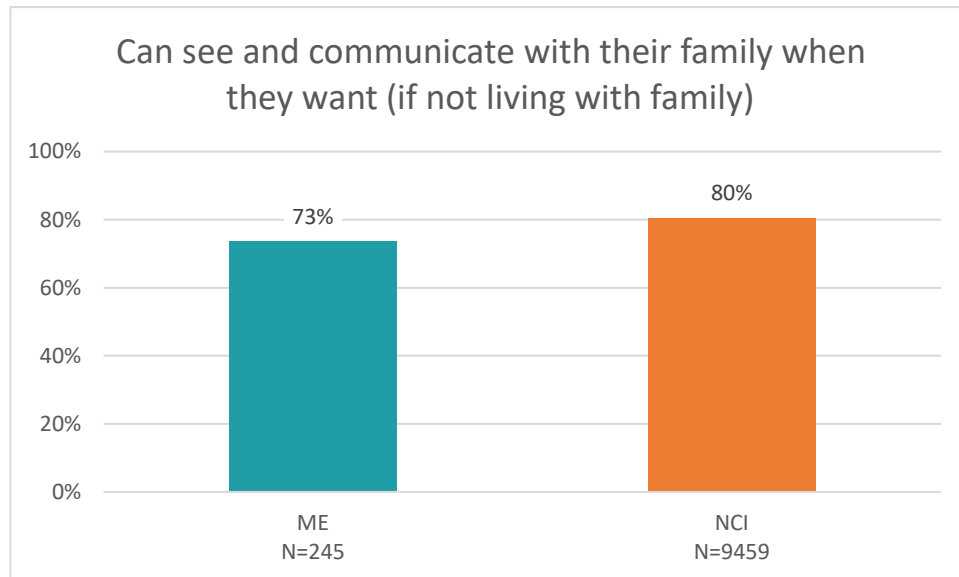
[Chart 44.](#) Reasons cannot see friends if often unable to ∞ ~



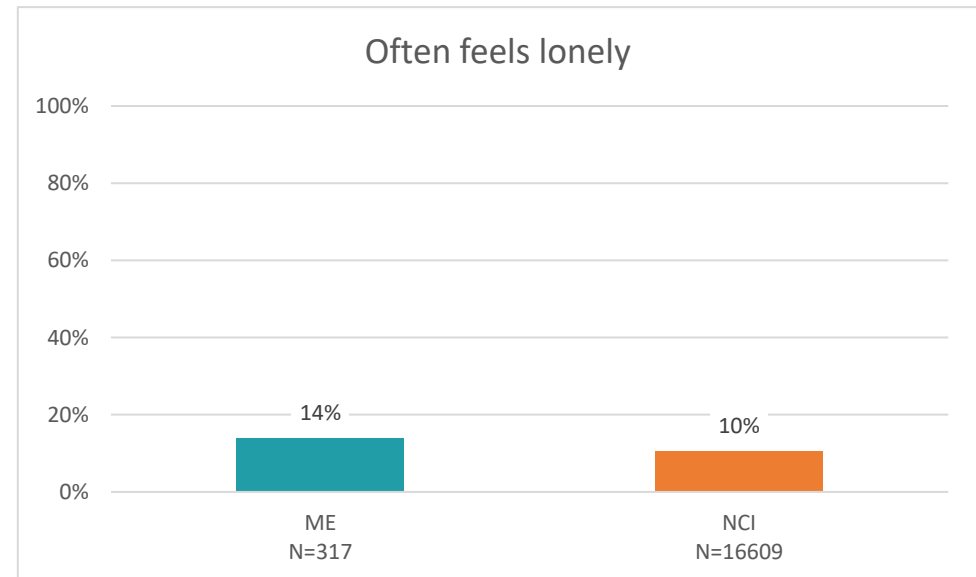
[Chart 45.](#) Has other ways of talking, chatting, or communicating with friends when cannot see them



[Chart 46.](#) Can see and communicate with their family when they want (if not living with family)



[Chart 47.](#) Often feels lonely ^

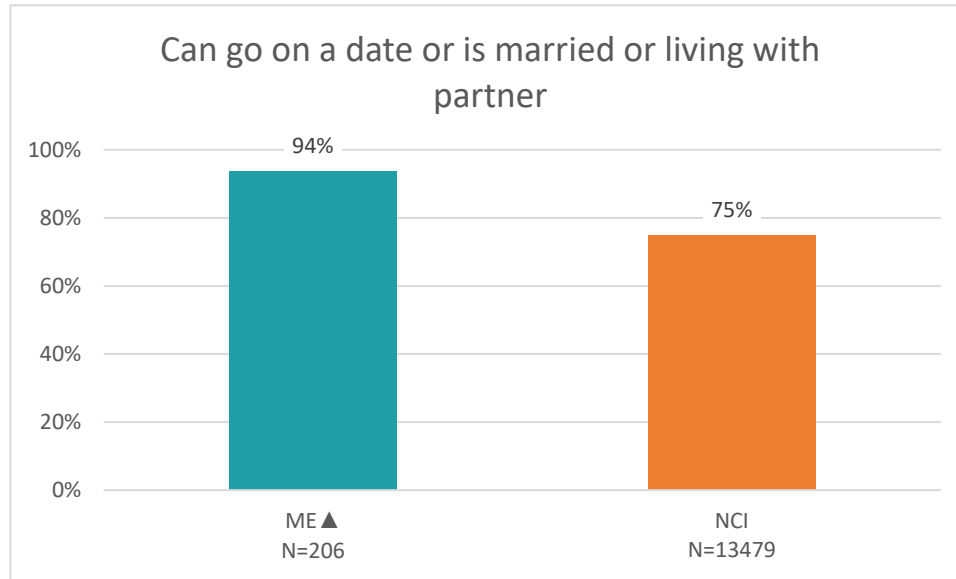


∞ Categories are not mutually exclusive.

~ In 2017-18 only includes people who reported that they could not see their friends when they wanted.

^ A lower percentage indicates that fewer people reported they often feel lonely.

[Chart 48](#). Can go on a date or is married or living with partner





*Tables for Relationships*

Table 41. Friendships

		Yes	N
Has friends who are not staff or family members	ME ▲	87%	327
	NCI	78%	17,085
Has best friend <i>(may be staff or family)</i>	ME ▲	79%	309
	NCI	70%	16,412
Wants more help to meet or keep in contact with friends	ME ▲	55%	294
	NCI	42%	16,282
Has friends (may be staff or family) and can see them when s/he wants	ME ▼	61%	295
	NCI	80%	14,704

Table 42. Reasons cannot see friends if often unable to <sup>~</sup>

*Categories are not mutually exclusive; in 2017-18 only includes people who reported that they could not see their friends when they wanted.*

			N
Lack of Transportation	ME	46%	114
	NCI	38%	2,838
Lack of Support Staff	ME	10%	114
	NCI	15%	2,838
Rules or Restrictions About Seeing Friends	ME	5%	114
	NCI	10%	2,838
Money or Cost of Going Out	ME	2%	114
	NCI	10%	2,838
Difficulty Finding Time	ME	54%	114
	NCI	33%	2,838
Other	ME	18%	114
	NCI	18%	2,838

<sup>~</sup> *In 2017-18 only people who reported that they could not see their friends when wanted were included in this table*

Table 43. Relationships

		Yes	N
Has other ways of talking, chatting, or communicating with friends when cannot see them	ME ▼	76%	288
	NCI	83%	14,607
Can see and communicate with their family when they want ( <i>if not living with family</i> )	ME	73%	245
	NCI	80%	9,459
Often feels lonely <sup>^</sup>	ME	14%	317
	NCI	10%	16,609
Can go on a date or is married or living with partner	ME ▲	94%	206
	NCI	75%	13,479

<sup>^</sup> A lower percentage indicates that fewer people reported they often feel lonely.

## *Satisfaction*

*People are satisfied with the services and supports they received.*

*Charts for Satisfaction*

Chart 49. Likes home or where s/he lives

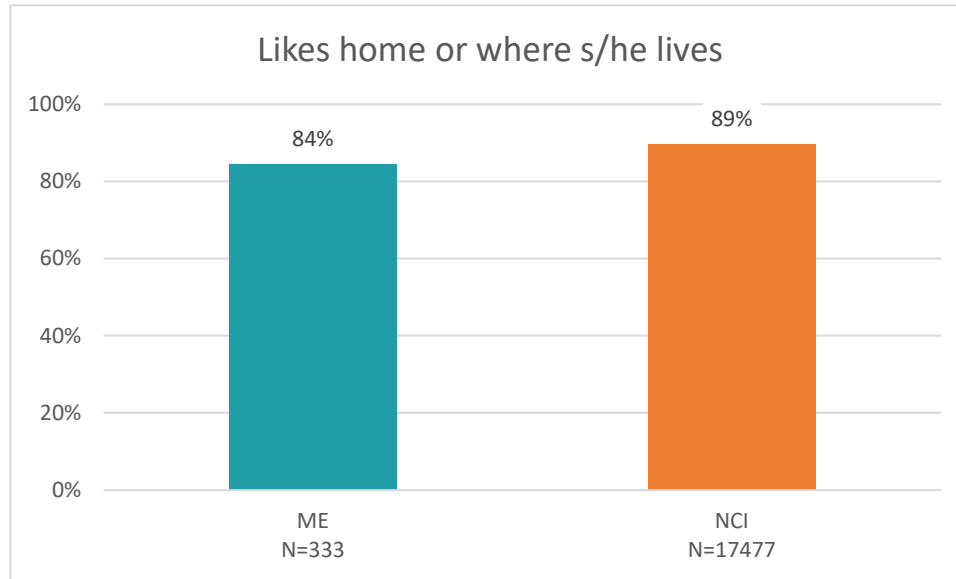


Chart 50. Wants to live somewhere else<sup>~</sup>

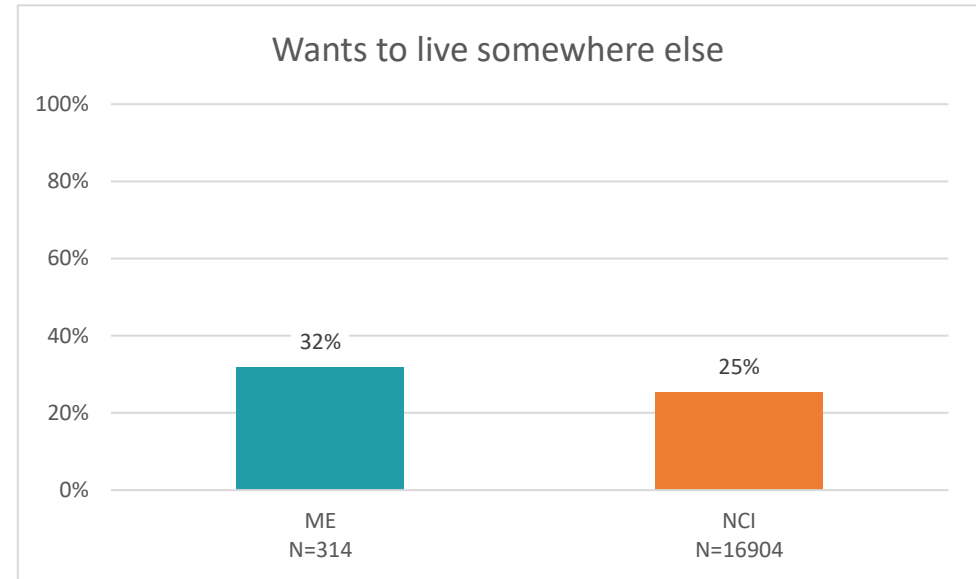


Chart 51. Has a paid job in the community and likes job\*

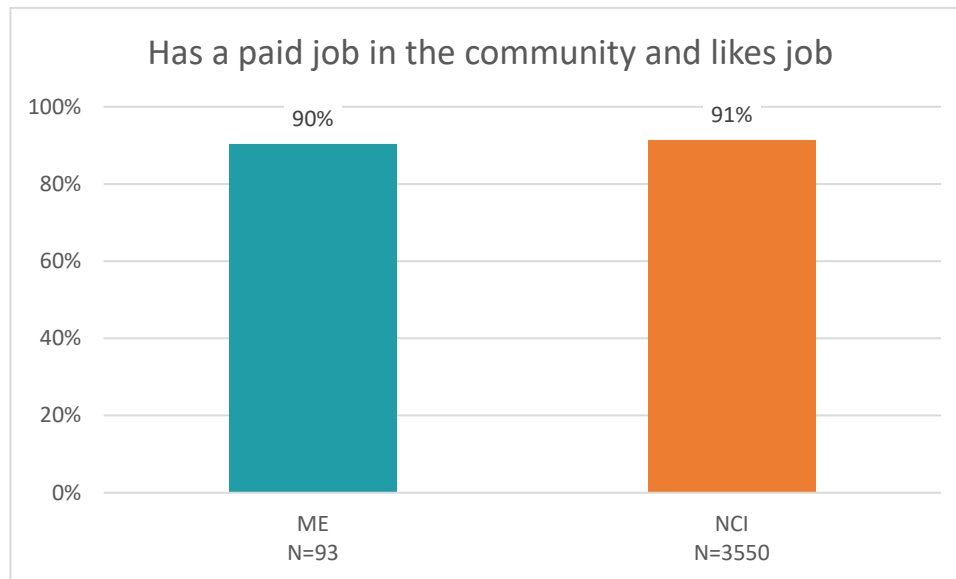
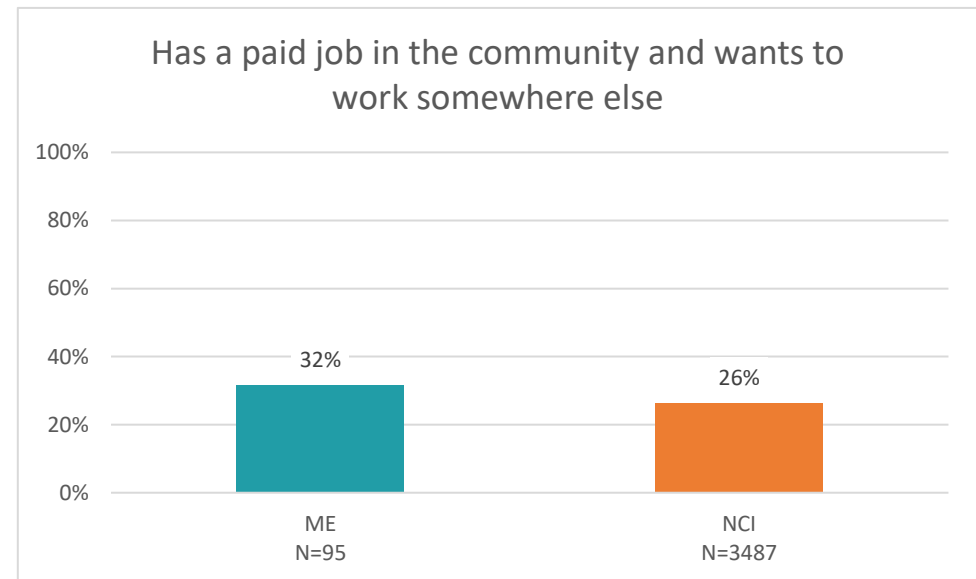


Chart 52. Has a paid job in the community and wants to work somewhere else \*<sup>~</sup>

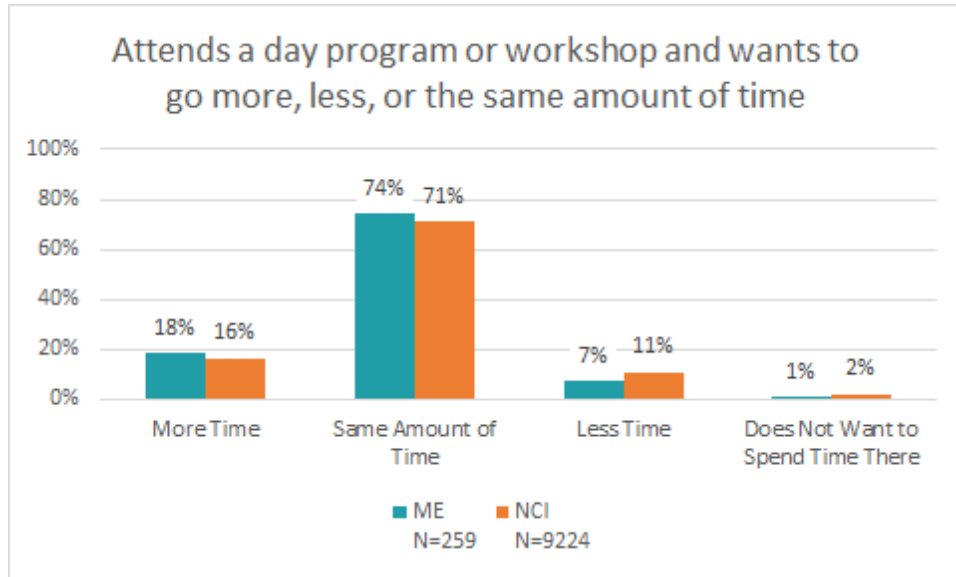


<sup>~</sup>A lower percentage indicates that fewer people reported they want to live somewhere else.

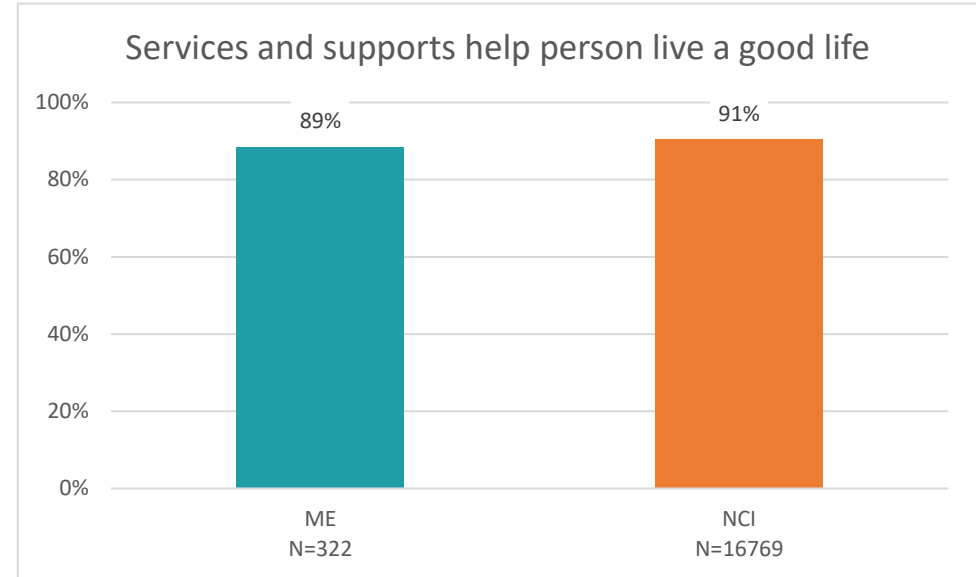
\*OR and WI data on type of community employment captured “no” and “don’t know” responses together (NCI states typically collect this information separately); therefore, their data are not comparable to other states and are not included in the employment tables that look at paid community job participation.

<sup>^^</sup>A lower percentage indicates that fewer people reported they want to work somewhere else.

[Chart 53](#). Attends a day program or workshop and wants to go more, less, or the same amount of time



[Chart 54](#). Services and supports help the person live a good life



*Tables for Satisfaction*



Table 44. Satisfaction at home and with paid community job

		Yes	N
Likes home or where s/he lives	ME	84%	333
	NCI	89%	17,477
Wants to live somewhere else <sup>~</sup>	ME	32%	314
	NCI	25%	16,904
Has a paid job in the community and likes job*	ME	90%	93
	NCI	91%	3,550
Has a paid job in the community and wants to work somewhere else* <sup>^^</sup>	ME	32%	95
	NCI	26%	3,487

Table 45. Amount of time wants to spend at day program or workshop s/he attends

	Does Not Want to Spend Time There	More Time	Same Amount of Time	Less Time	N
ME	1%	18%	74%	7%	259
NCI	2%	16%	71%	11%	9,224

Table 46. Services and supports help person live a good life

	Yes	N
ME	89%	322
NCI	91%	16,769

<sup>~</sup>A lower percentage indicates that fewer people reported they want to live somewhere else.

\*OR and WI data on type of community employment captured “no” and “don’t know” responses together (NCI states typically collect this information separately); therefore, their data are not comparable to other states and are not included in the employment tables that look at paid community job participation.

<sup>^^</sup>A lower percentage indicates that fewer people reported they want to work somewhere else.

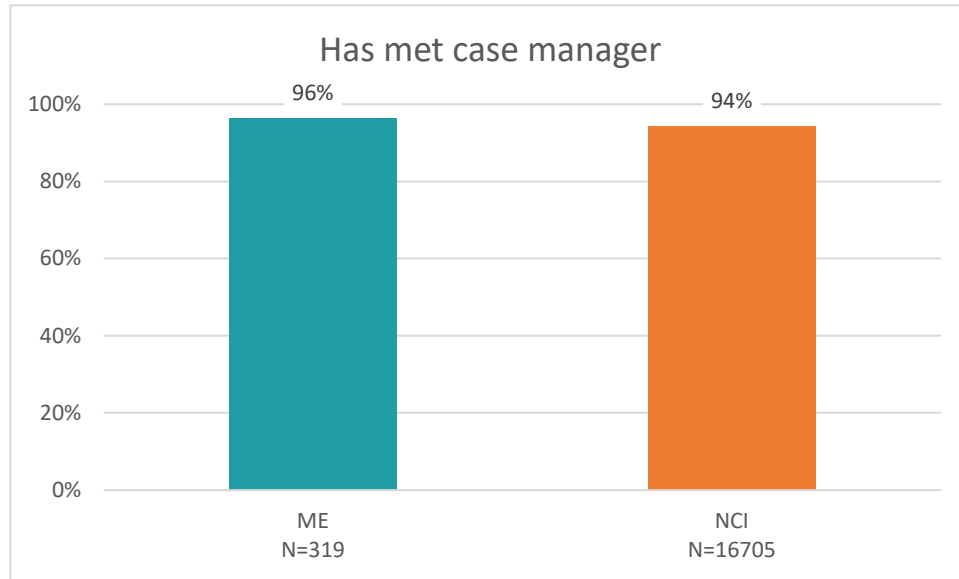
## *Service Coordination*

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

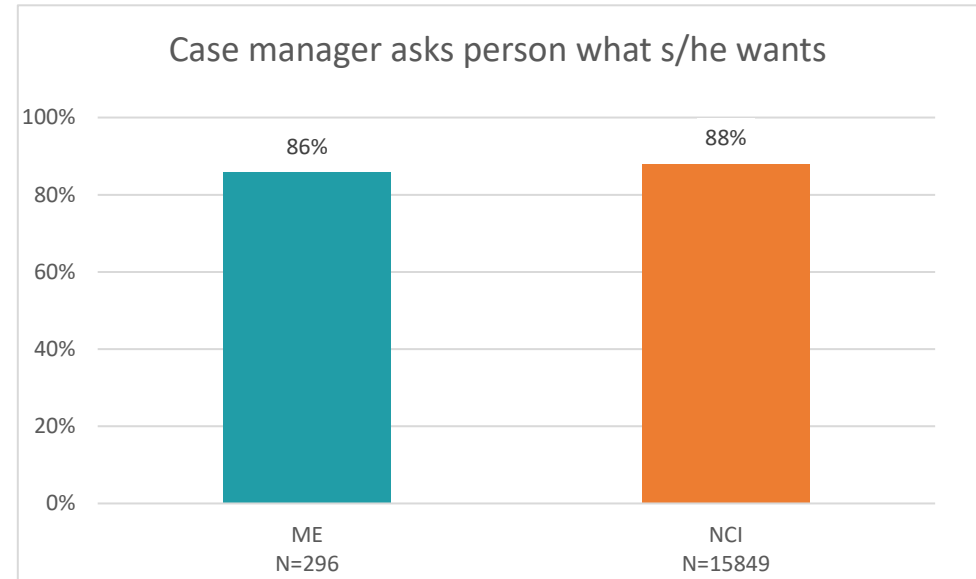
**Note on terminology:** Please note, this report uses the term “case managers,” but state terminology may vary and may include “service coordinator,” “care coordinator,” or other terms. Similarly, NCI uses the term “service plan” whereas state terminology may vary and may include “individual service plan” (ISP) or “individual program plan” (IPP). Surveyors are instructed to use the appropriate state terminology during surveys.

*Charts for Service Coordination*

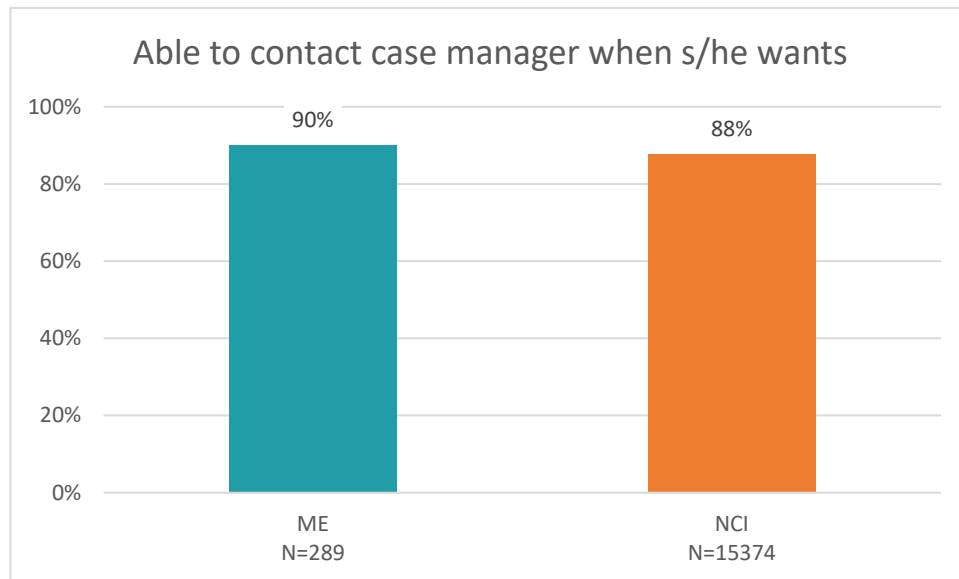
[Chart 55.](#) Has met case manager



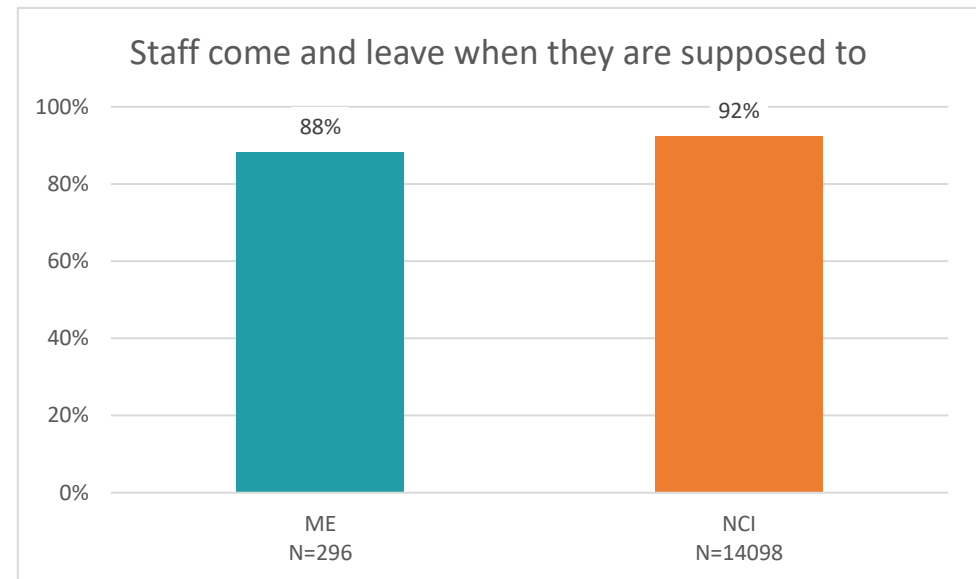
[Chart 56.](#) Case manager asks person what s/he wants



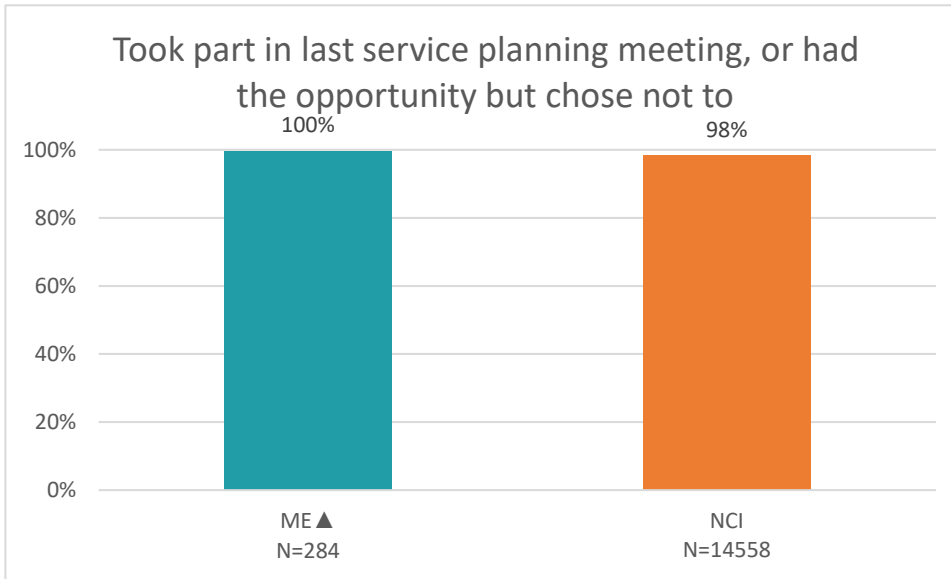
[Chart 57.](#) Able to contact case manager when s/he wants



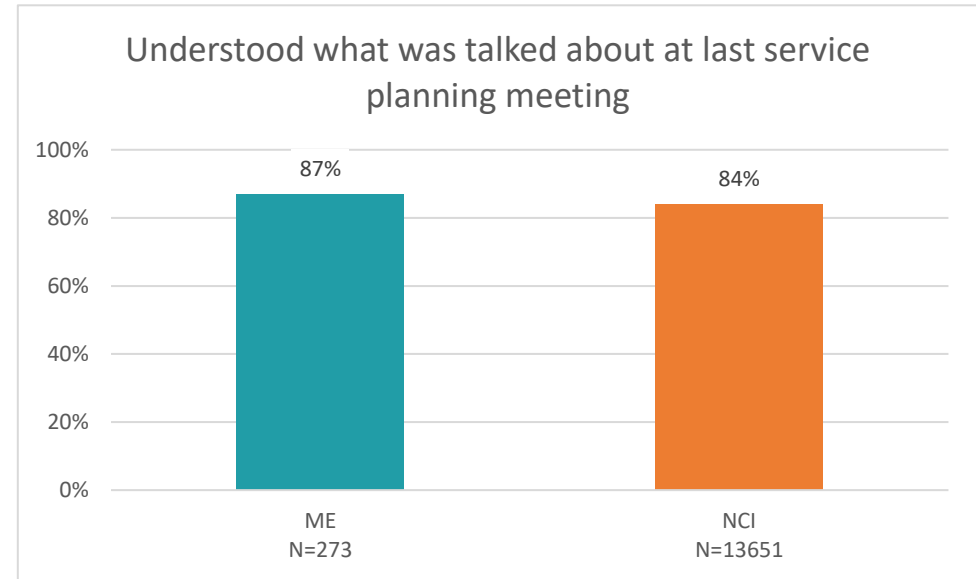
[Chart 58.](#) Staff come and leave when they are supposed to



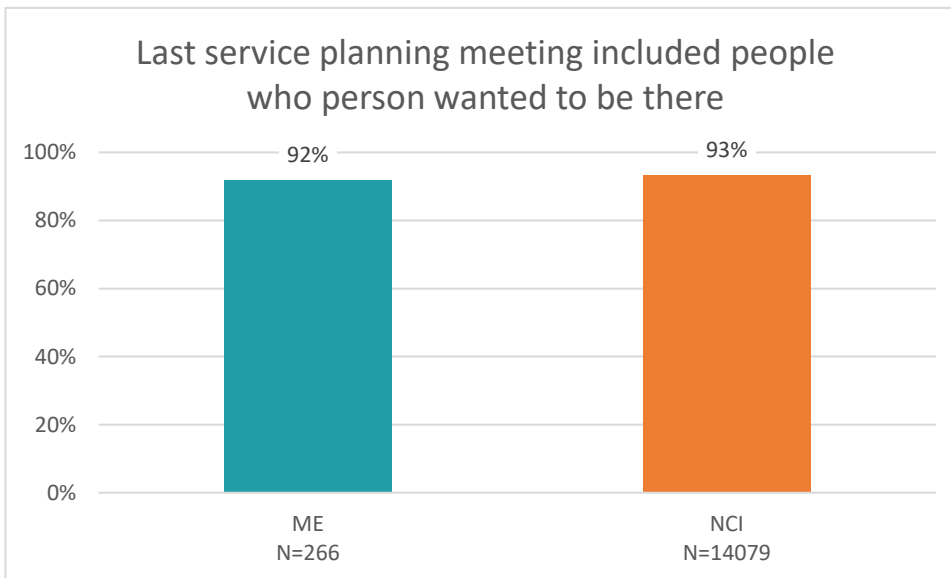
[Chart 59.](#) Took part in last service planning meeting, or had the opportunity but chose not to



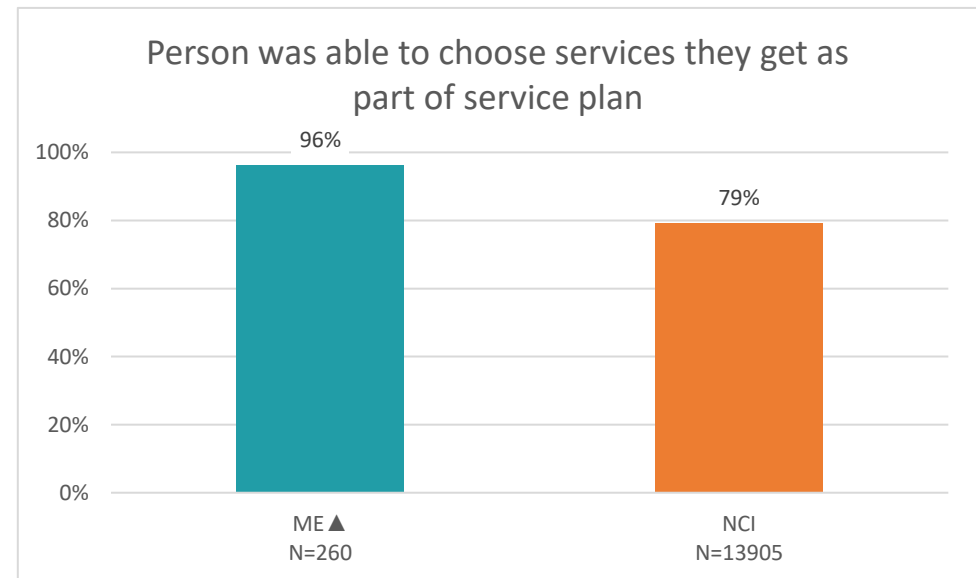
[Chart 60.](#) Understood what was talked about at last service planning meeting



[Chart 61.](#) Last service planning meeting included people who person wanted to be there



[Chart 62.](#) Person was able to choose services they get as part of service plan



*Tables for Service Coordination*

Table 47. Service Coordination

		Yes	N
Has met case manager	ME	96%	319
	NCI	94%	16,705
Case manager asks person what s/he wants	ME	86%	296
	NCI	88%	15,849
Able to contact case manager when s/he wants	ME	90%	289
	NCI	88%	15,374
Staff come and leave when they are supposed to	ME	88%	296
	NCI	92%	14,098
Took part in last service planning meeting, or had the opportunity but chose not to	ME▲	100%	284
	NCI	98%	14,558
Understood what was talked about at last service planning meeting	ME	87%	273
	NCI	84%	13,651
Last service planning meeting included people respondent wanted to be there	ME	92%	266
	NCI	93%	14,079
Person was able to choose services they get as part of service plan	ME▲	96%	260
	NCI	79%	13,905

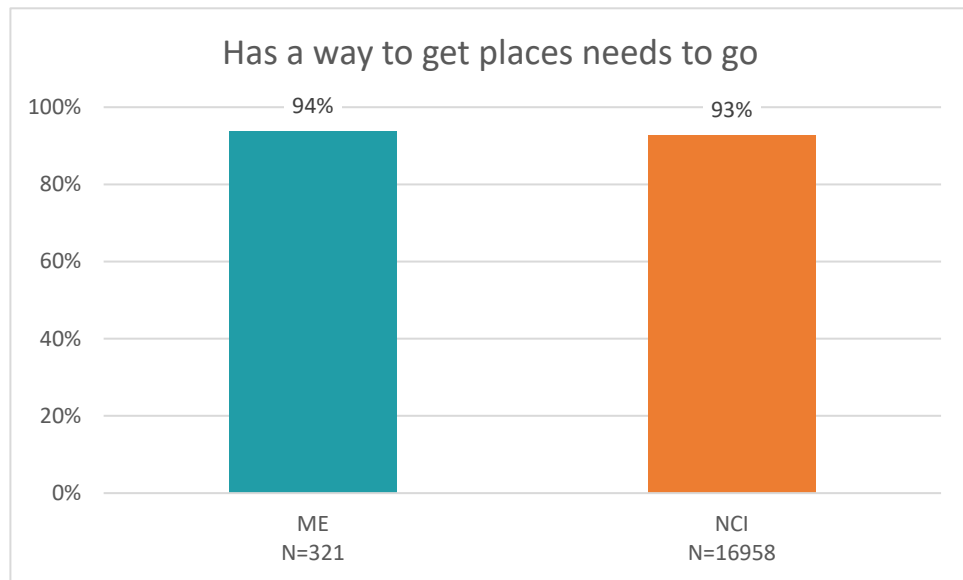
## Access

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

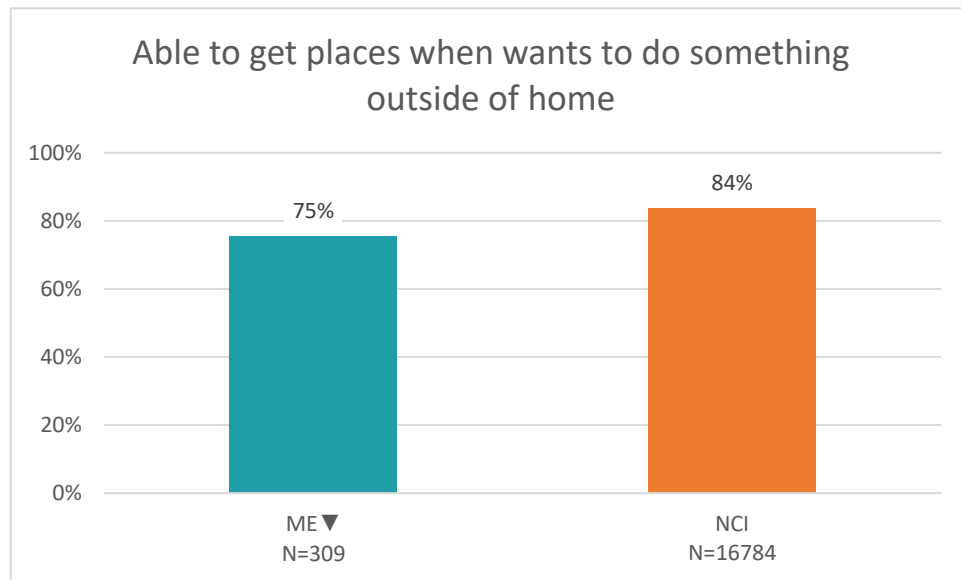


*Charts for Access*

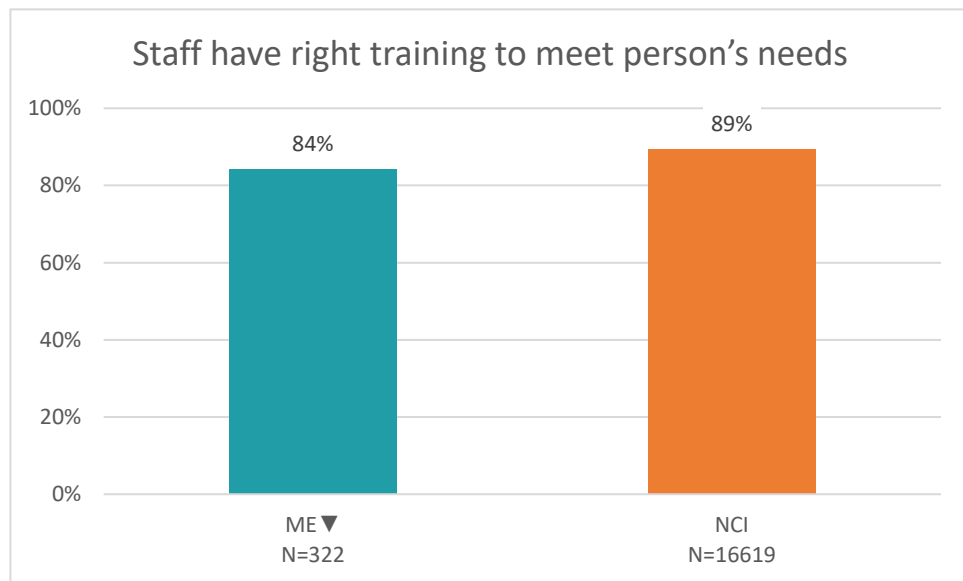
[Chart 63](#). Has a way to get places s/he needs to go



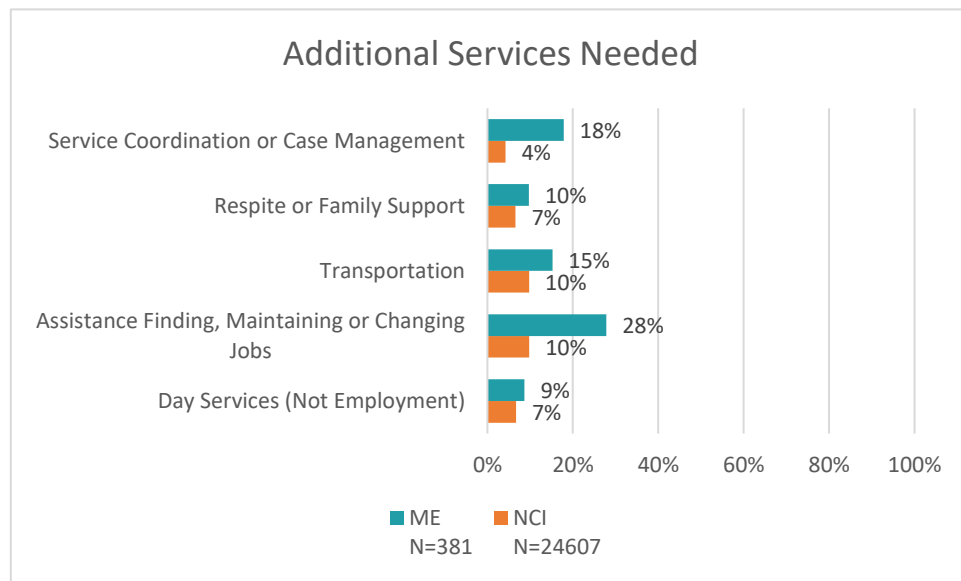
[Chart 64](#). Able to get places when s/he wants to do something outside of home



[Chart 65](#). Staff have right training to meet person’s needs (proxy respondents who were not staff were allowed for this question)

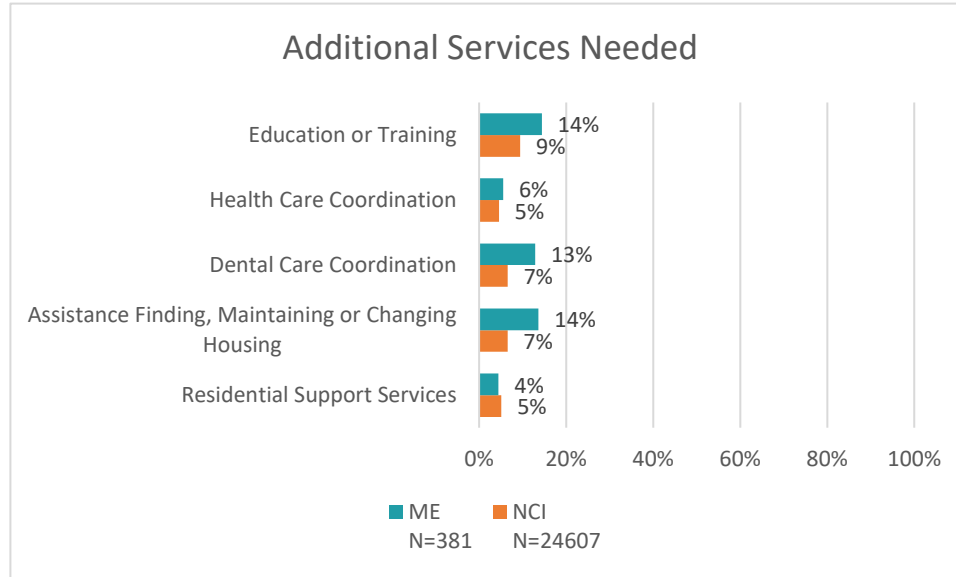


[Chart 66](#). Additional services needed (proxy respondents were allowed for this question) ∞



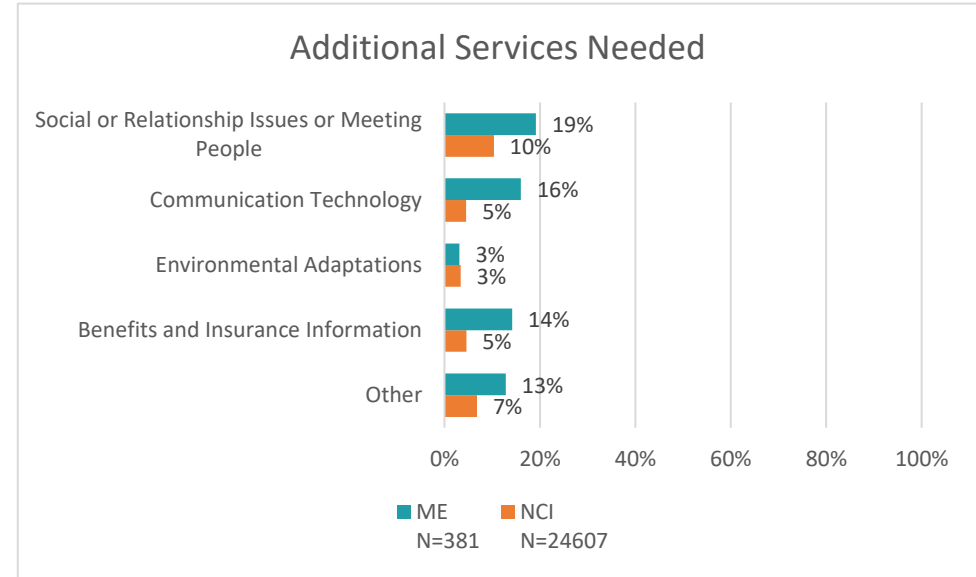
∞ Categories are not mutually exclusive

[Chart 67](#). Additional services needed—continued (proxy respondents were allowed for this question) ∞



∞ Categories are not mutually exclusive

[Chart 68](#). Additional services needed—continued (proxy respondents were allowed for this question) ∞



*Tables for Access*

Table 48. Transportation and staff training

		Yes	N
Has a way to get places s/he needs to go	ME	94%	321
	NCI	93%	16,958
Able to get places when s/he wants to do something outside of home	ME ▼	75%	309
	NCI	84%	16,784
Staff have right training to meet person's needs ( <i>proxy respondents who were not staff were allowed for this question</i> )	ME ▼	84%	322
	NCI	89%	16,619

Table 49. Additional services needed

Categories are not mutually exclusive; proxy respondents were allowed for this question.

Service		
Service Coordination or Case Management	ME	18%
	NCI	4%
Respite or Family Support	ME	10%
	NCI	7%
Transportation	ME	15%
	NCI	10%
Assistance Finding, Maintaining or Changing Jobs	ME	28%
	NCI	10%
Day Services (Not Employment)	ME	9%
	NCI	7%
Education or Training	ME	14%
	NCI	9%
Health Care Coordination	ME	6%
	NCI	5%
Dental Care Coordination	ME	13%
	NCI	7%
Assistance Finding, Maintaining or Changing Housing	ME	14%
	NCI	7%
Residential Support Services	ME	4%
	NCI	5%
Social or Relationship Issues or Meeting People	ME	19%
	NCI	10%
Communication Technology	ME	16%
	NCI	5%
Environmental Adaptations	ME	3%
	NCI	3%
Benefits and Insurance Information	ME	14%
	NCI	5%
Other	ME	13%
	NCI	7%
N	ME	381
	NCI	24,607

## Health

*People secure needed health services.*

### **Important Note on Missing Data**

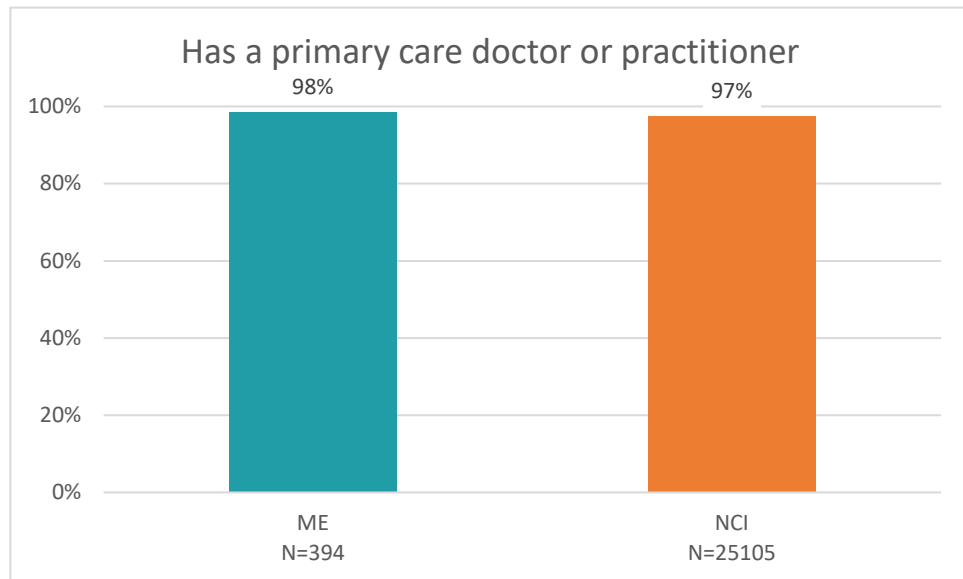
For several states, survey items in the Background Information section, including information on Health, had a large amount of missing data or data recorded as “don’t know.” Items that include states results for which 25% or more of their sample were missing data (or reported as “don’t know”) are indicated with an asterisk (\*) next to NCI Average.

We advise caution when examining data that are indicated as having high rates of “missing” or “don’t know” responses as we don’t know whether the data are missing systematically or randomly. Please note that the NCI average reflects the average of data that were reported to HSRI and may not be reflective of the service population across the country.

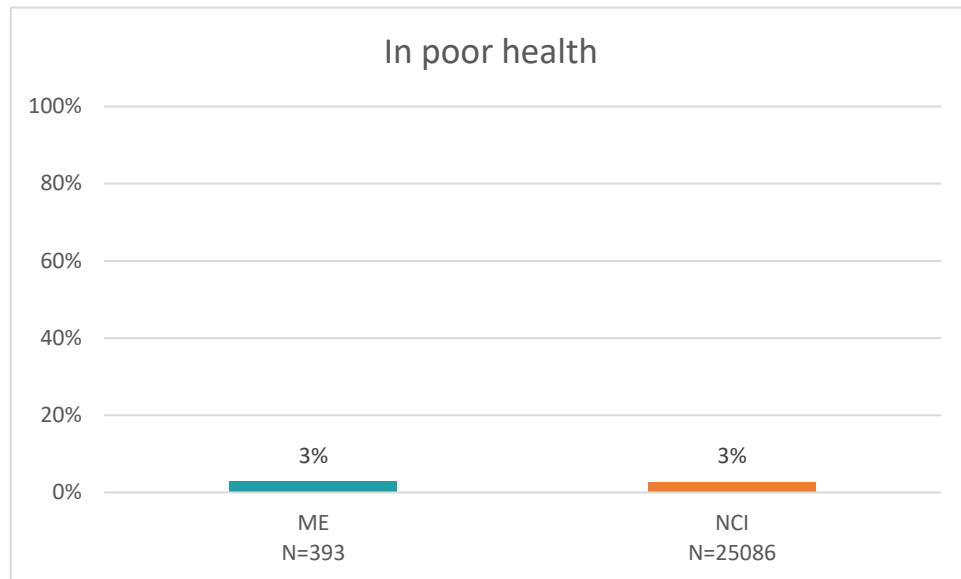
*Charts for Health*



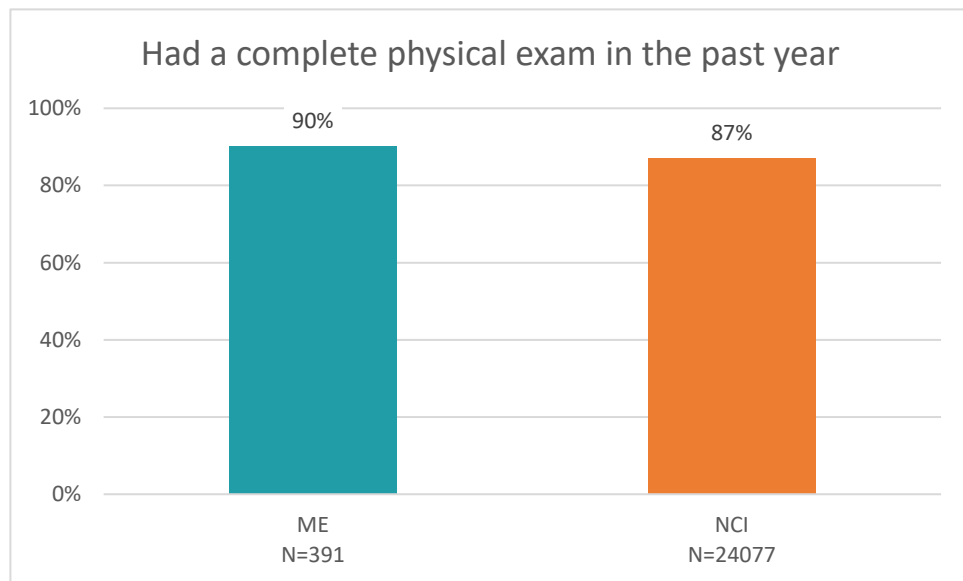
[Chart 69](#). Has a primary care doctor or practitioner (information may have been obtained through state records)\*



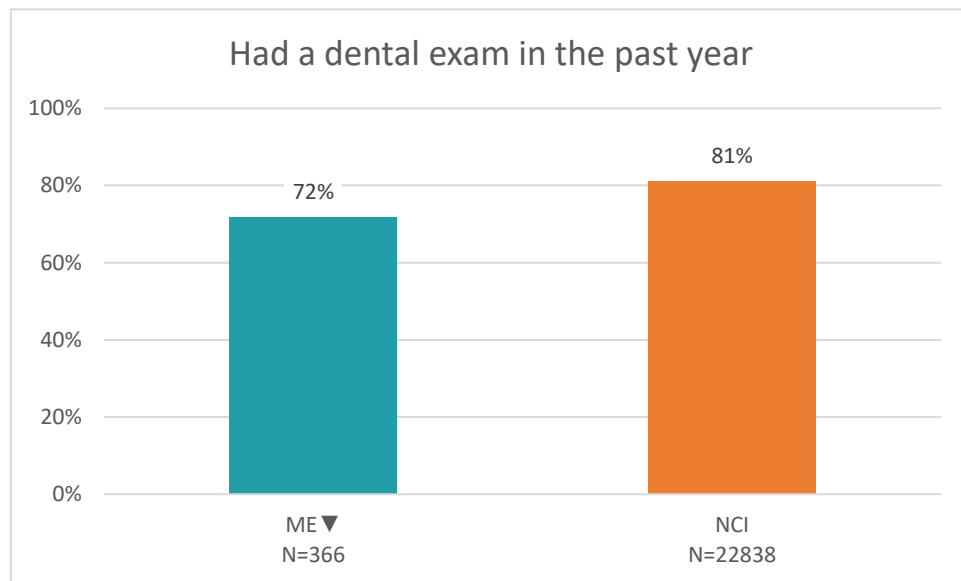
[Chart 70](#). In poor health (proxy respondents were allowed for this question) ^



[Chart 71](#). Had a complete physical exam in the past year (information may have been obtained through state records)\*



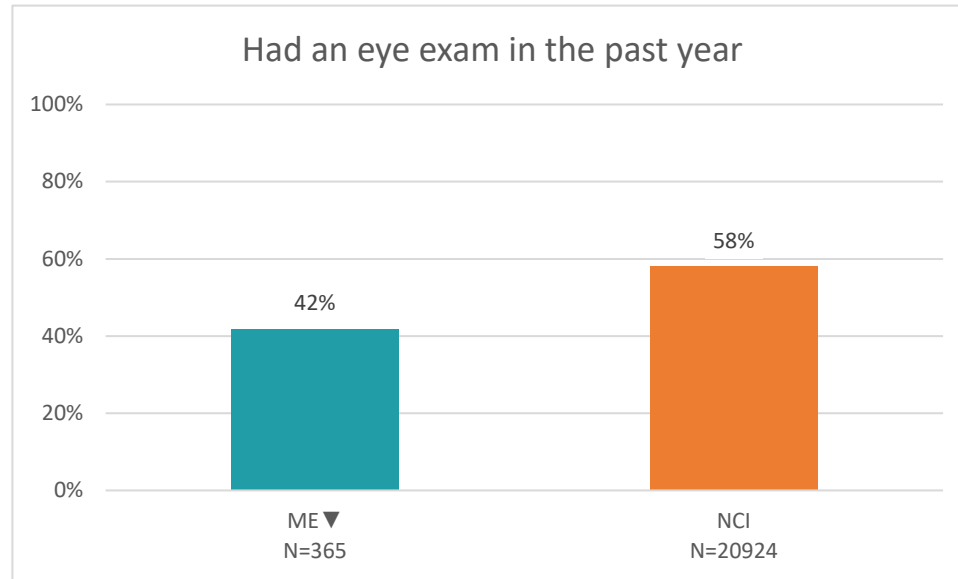
[Chart 72](#). Had a dental exam in the past year (information may have been obtained through state records)\*



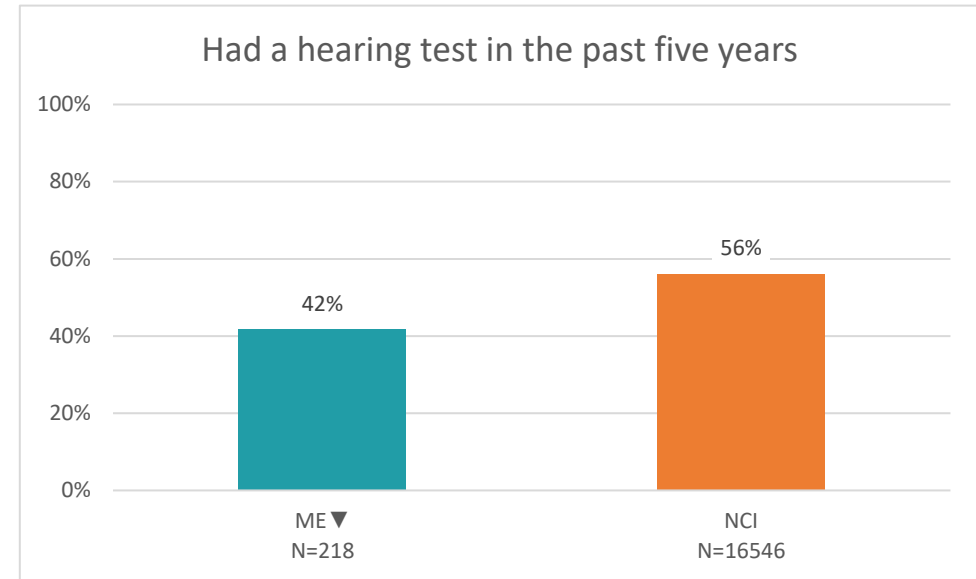
\*Includes data from a state or states that had a large number of "don't knows" and missing data (at least 25%).

^A lower average indicates a lower percentage of people reported being in poor health.

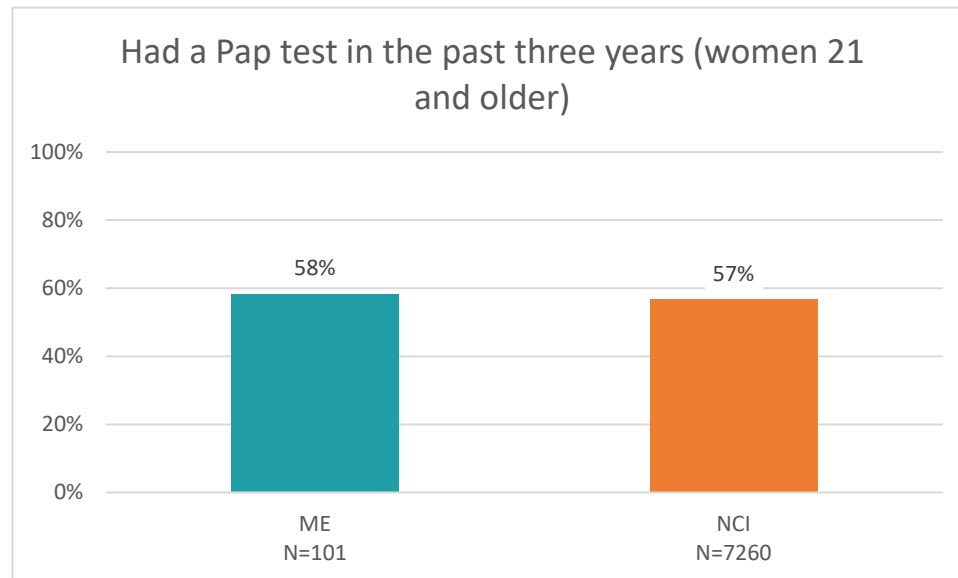
[Chart 73](#). Had an eye exam in the past year (information may have been obtained through state records)\*



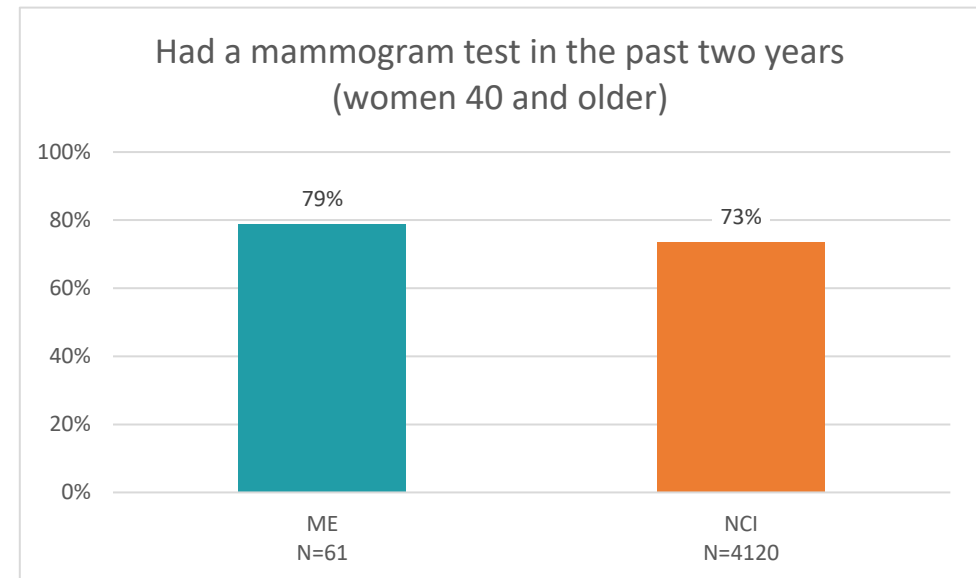
[Chart 74](#). Had a hearing test in the past five years (information may have been obtained through state records) \*



[Chart 75](#). Had a Pap test in the past three years (women 21 and older; information may have been obtained through state records)\*

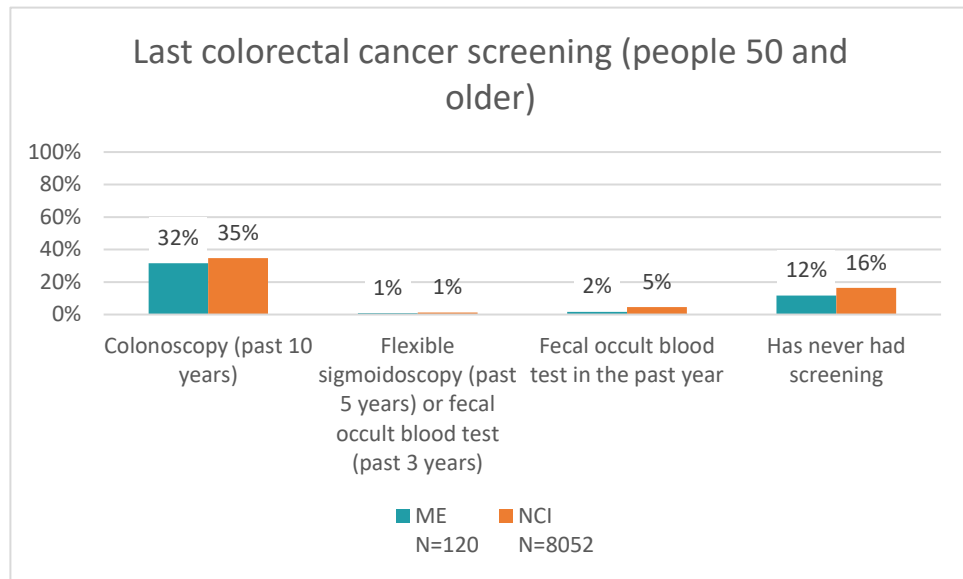


[Chart 76](#). Had a mammogram test in the past two years (women 40 and older; information may have been obtained through state records)

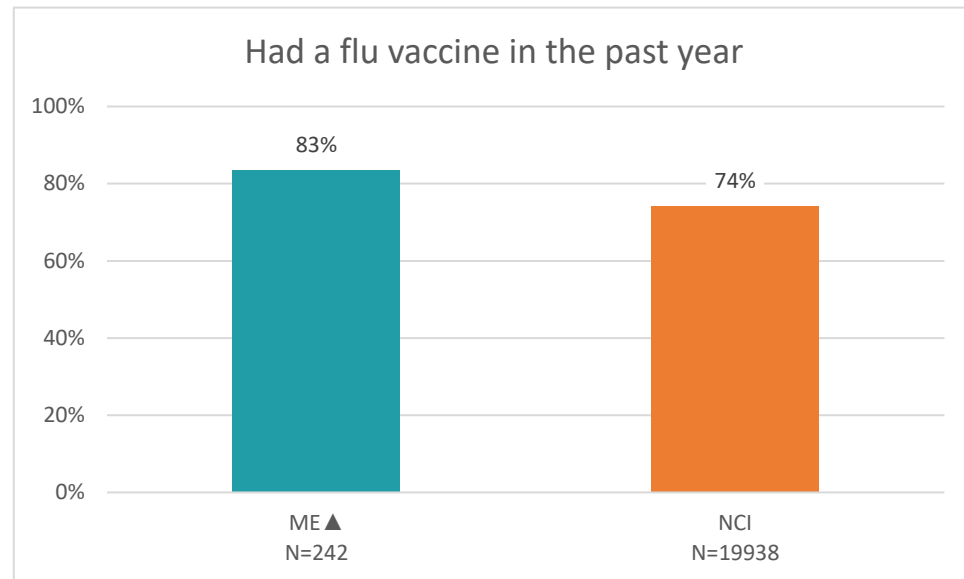


\*Includes data from a state or states that had a large number of “don’t knows” and missing data (at least 25%).

[Chart 77](#). Last colorectal cancer screening (people 50 and older; information may have been obtained through state records) ∞



[Chart 78](#). Had a flu vaccine in the past year (information may have been obtained through state records)\*



∞Categories are not mutually exclusive.

\*Includes data from a state or states that had a large number of “don’t knows” and missing data (at least 25%).

*Tables for Health*

Table 50. Regular and preventive screenings

		Yes	N
Has a primary care doctor or practitioner <i>(information may have been obtained through state records)</i> *	ME	98%	394
	NCI	97%	25,105
In poor health <i>(proxy respondents were allowed for this question)</i> ^	ME	3%	393
	NCI	3%	25,086
Had a complete physical exam in the past year <i>(information may have been obtained through state records)</i> *	ME	90%	391
	NCI	87%	24,077
Had a dental exam in the past year <i>(information may have been obtained through state records)</i> *	ME ▼	72%	366
	NCI	81%	22,838
Had an eye exam in the past year <i>(information may have been obtained through state records)</i> *	ME ▼	42%	365
	NCI	58%	20,924
Had a hearing test in the past five years <i>(information may have been obtained through state records)</i> *	ME ▼	42%	218
	NCI	56%	16,546
Had a Pap test in the past three years <i>(women 21 and older; information may have been obtained through state records)</i> *	ME	58%	101
	NCI	57%	7,260
Had a mammogram test in the past two years <i>(women 40 and older; information may have been obtained through state records)</i>	ME	79%	61
	NCI	73%	4,120

\*Includes data from a state or states that had a large number of “don’t knows” and missing data (at least 25%).

^A lower average indicates a lower percentage of people reported being in poor health.

Table 51. Last colorectal cancer screening, people age 50 and older

Categories are not mutually exclusive; information may have been obtained through state records.

	Colonoscopy in the Past 10 Years	Flexible Sigmoidoscopy in the past 5 years, or Fecal Occult Blood Test in the Past 3 Years	Fecal Occult Blood Test in the Past Year	Has Never Had Screening	N
ME	32%	1%	2%	12%	120
NCI	35%	1%	5%	16%	8,052

Table 52. Had a flu vaccine in the past year

Includes data from a state or states that had a large number of “don’t knows” and missing data (at least 25%).

	Yes	N
ME ▲	83%	242
NCI	74%	19,938

## Medications

*Medications are managed effectively and appropriately.*

### **Important Note on Missing Data**

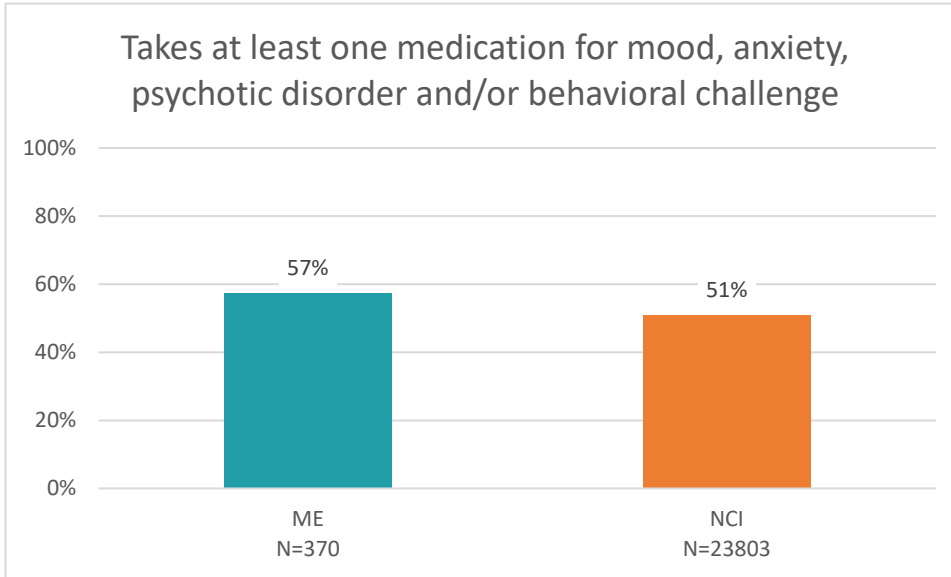
For several states, survey items in the Background Information section, including information on Medications, had a large amount of missing data or data recorded as “don’t know.” Items that include states results for which 25% or more of their sample were missing data (or reported as “don’t know”) are indicated with an asterisk (\*) next to NCI Average.

We advise caution when examining data that are indicated as having high rates of “missing” or “don’t know” responses as we don’t know whether the data are missing systematically or randomly. Please note that the NCI average reflects the average of data that were reported to HSRI and may not be reflective of the service population across the country.

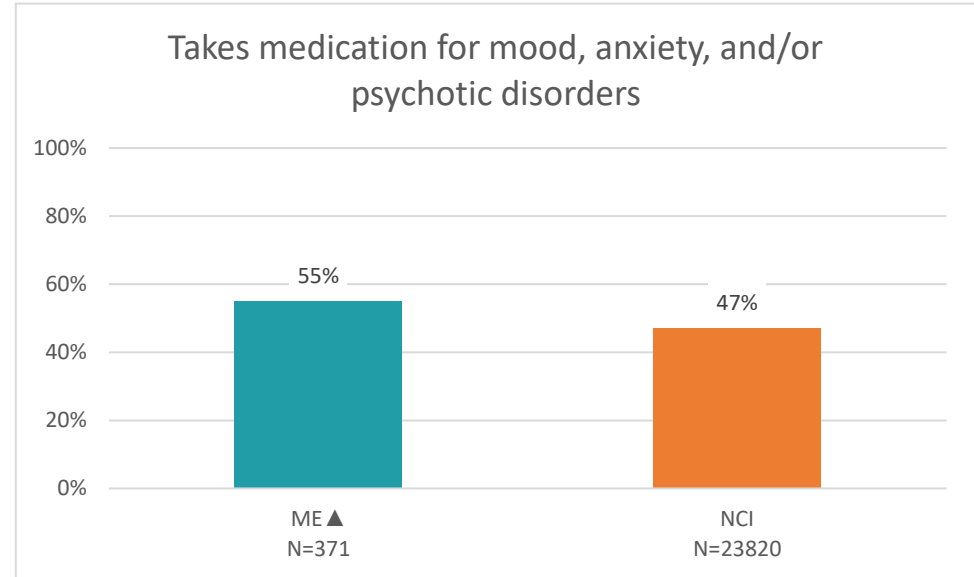
*Charts for Medications*



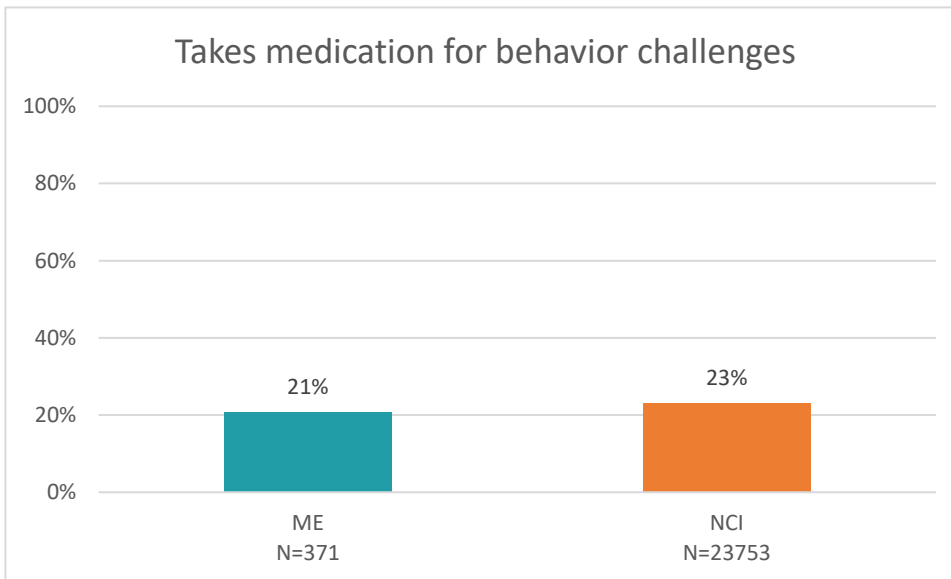
**Chart 79.** Takes at least one medication for mood, anxiety, psychotic disorder and/or behavioral challenge (information may have been obtained through state records) \* ^ °



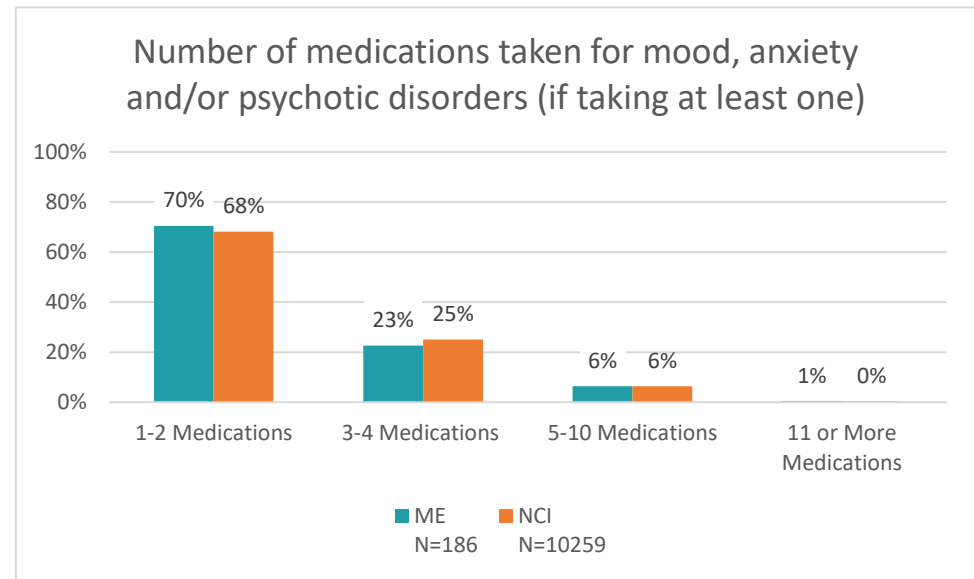
**Chart 80.** Takes medication for mood, anxiety, and/or psychotic disorders (information may have been obtained through state records) \* ^ °



**Chart 81.** Takes medication for behavior challenges (information may have been obtained through state records) \* ^ °



**Chart 82.** Number of medications taken for at least one of the following: mood disorders, anxiety, or psychotic disorders (information may have been obtained through state records) \* ^ °

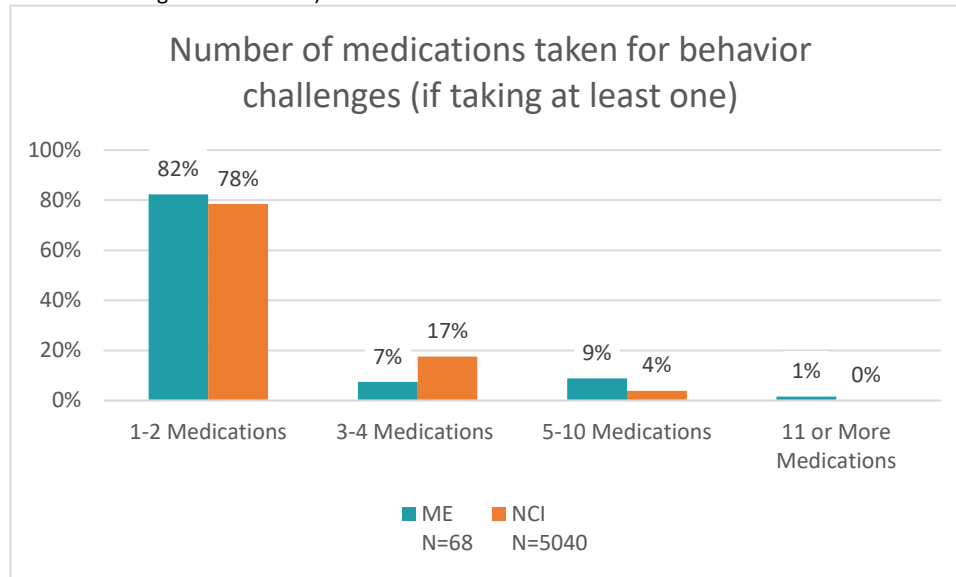


\*Includes data from a state or states that had a large number of “don’t knows” and missing data (at least 25%).

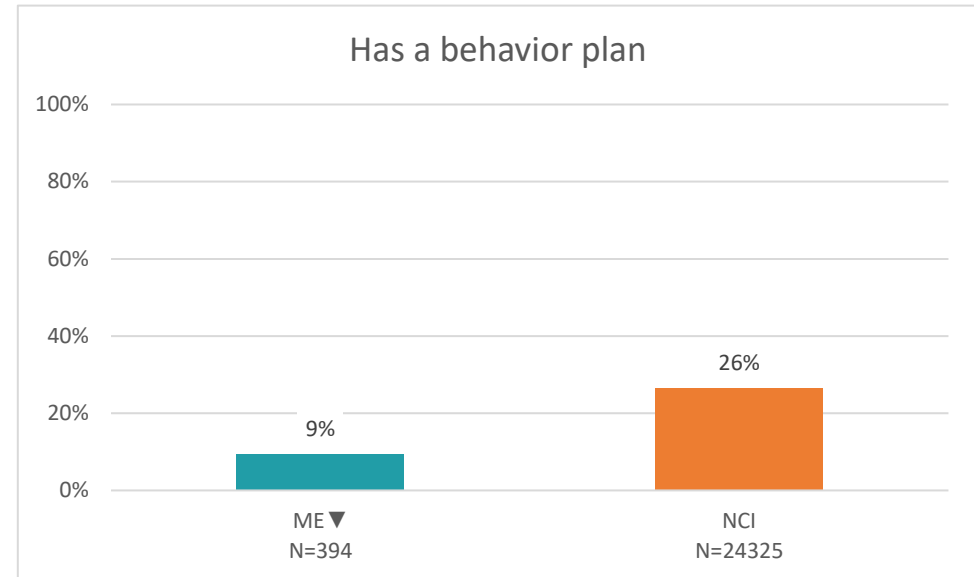
^A lower percentage indicates fewer people were reported to be taking medication.

°OR data were not available in records; therefore, OR is not included in the NCI Average.

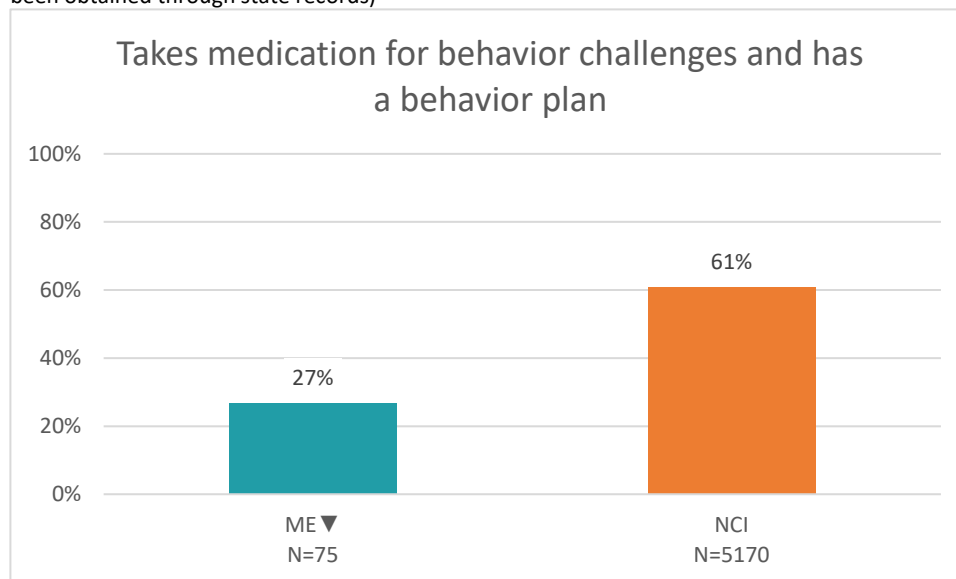
**Chart 83.** Number of medications taken for behavior challenges (information may have been obtained through state records) \*°



**Chart 84.** Has a behavior plan (information may have been obtained through state records) \* ^^



**Chart 85.** Takes medication for behavior challenges and has a behavior plan (information may have been obtained through state records)



\*Includes data from a state or states that had a large number of “don’t knows” and missing data (at least 25%).

^^A lower percentage indicates fewer people were reported to have a behavior plan.

° OR data were not available in records; therefore, OR is not included in the NCI Average.

*Tables for Medication*

Table 53. Takes medication

		Yes	N
Takes at least one medication for mood, anxiety, psychotic disorder and/or behavioral challenge ( <i>information may have been obtained through state records</i> )* °	ME	57%	370
	NCI	51%	23,803
Takes medication for mood, anxiety, and/or psychotic disorders ( <i>information may have been obtained through state records</i> ) * °	ME ▲	55%	371
	NCI	47%	23,820
Takes medication for behavior challenges ( <i>information may have been obtained through state records</i> )°	ME	21%	371
	NCI	23%	23,753

Table 54. Number of medications taken

		1-2 Medications	3-4 Medications	5-10 Medications	11 or More Medications	N
Number of medications taken for at least one of the following: mood disorders, anxiety, or psychotic disorders ( <i>information may have been obtained through state records</i> ) *°	ME	70%	23%	6%	1%	186
	NCI	68%	25%	6%	0%	10,259
Number of medications taken for behavior challenges ( <i>information may have been obtained through state records</i> )*	ME	82%	7%	9%	1%	68
	NCI	78%	17%	4%	0%	5,040

Table 55. Behavior plan and medication

		Yes	N
Has a behavior plan ( <i>information may have been obtained through state records</i> ) * °	ME ▼	9%	394
	NCI	26%	24,325
Takes medication for behavior challenges and has a behavior plan ( <i>information may have been obtained through state records</i> )	ME ▼	27%	75
	NCI	61%	5,170

\*Includes data from a state or states that had a large number of “don’t knows” and missing data (at least 25%).

°A lower percentage indicates fewer people were reported to be taking medication.

°OR data were not available in records; therefore, OR is not included in NCI Average.

°°A lower percentage indicates fewer people were reported to have a behavior plan.

## Wellness

*People are supported to maintain healthy habits.*

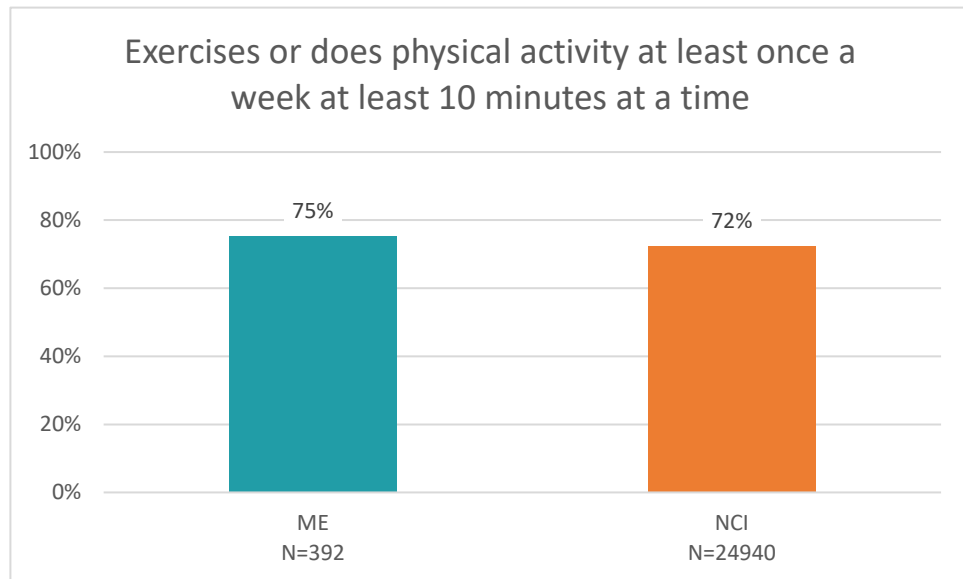
### **Important Note on Missing Data**

For several states, survey items in the Background Information section, including information on Wellness, had a large amount of missing data or data recorded as “don’t know.” Items that include states results for which 25% or more of their sample were missing data (or reported as “don’t know”) are indicated with an asterisk (\*) next to NCI Average.

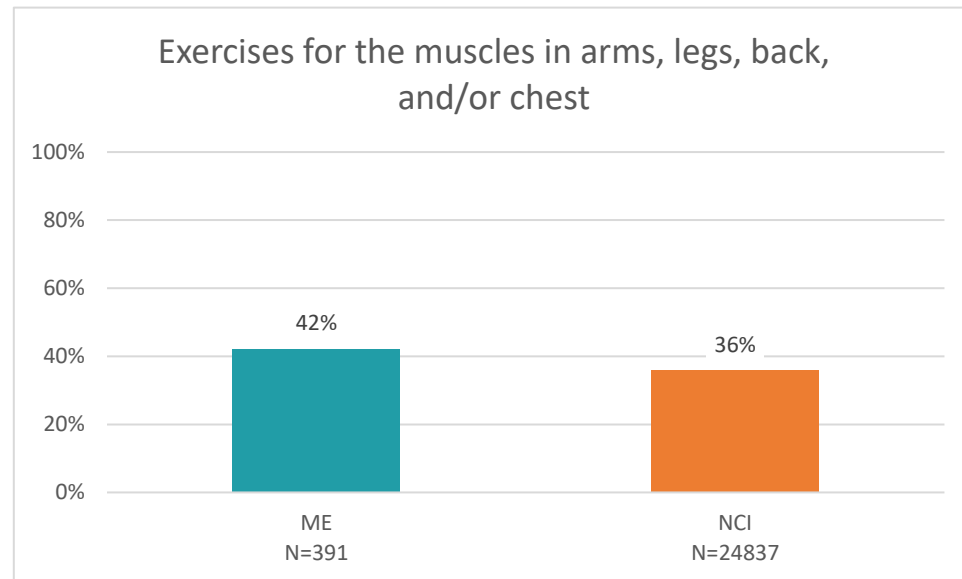
We advise caution when examining data that are indicated as having high rates of “missing” or “don’t know” responses as we don’t know whether the data are missing systematically or randomly. Please note that the NCI average reflects the average of data that were reported to HSRI and may not be reflective of the service population across the country.

*Charts for Wellness*

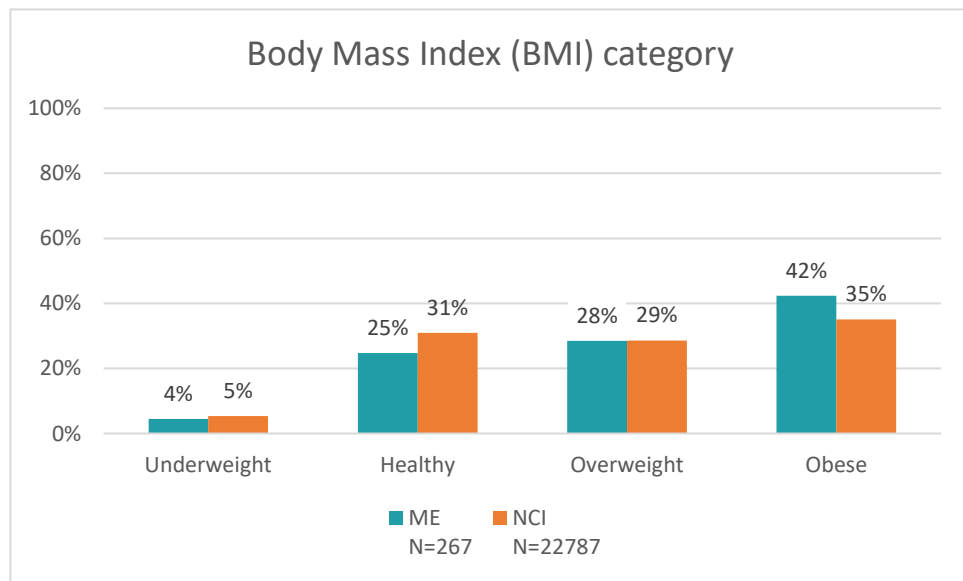
[Chart 86.](#) Exercises or does physical activity at least once a week at least 10 minutes at a time (proxy respondents were allowed for this question)



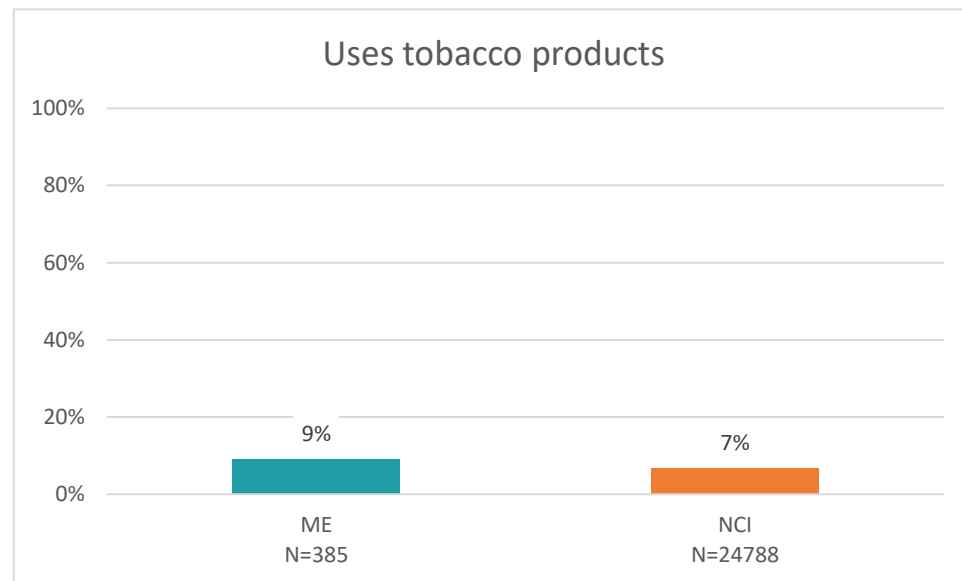
[Chart 87.](#) Exercises or does physical activity at least 3 times per week that makes the muscles in arms, legs, back, and/or chest work hard (proxy respondents were allowed for this question) <sup>9</sup>



[Chart 88.](#) Body Mass Index (BMI) category (information may have been obtained through state records)\*



[Chart 89.](#) Uses tobacco products (information may have been obtained through state records) \* <sup>~</sup>



<sup>9</sup>New question in 2017-18.

\*Includes data from a state or states that had a large number of "don't knows" and missing data (at least 25%).

<sup>~</sup> A lower average indicates a lower percentage of people use tobacco products.

*Tables for Wellness*



Table 56. Exercise

		Yes	N
Exercises or does physical activity at least once a week at least 10 minutes at a time (proxy respondents were allowed for this question)	ME	75%	392
	NCI	72%	24,940
Exercises for the muscles in arms, legs, back, and/or chest (proxy respondents were allowed for this question) <sup>e</sup>	ME	42%	391
	NCI	36%	24,837

Table 57. Body Mass Index (BMI) category (information may have been obtained through state records) \*

	Underweight	Healthy	Overweight	Obese	N
ME	4%	25%	28%	42%	267
NCI	5%	31%	29%	35%	22,787

Table 58. Uses tobacco products \* ^

	Yes	N
ME	9%	385
NCI	7%	24,788

<sup>e</sup>New question in 2017-18.

\*Includes data from a state or states that had a large number of “don’t knows” and missing data (at least 25%).

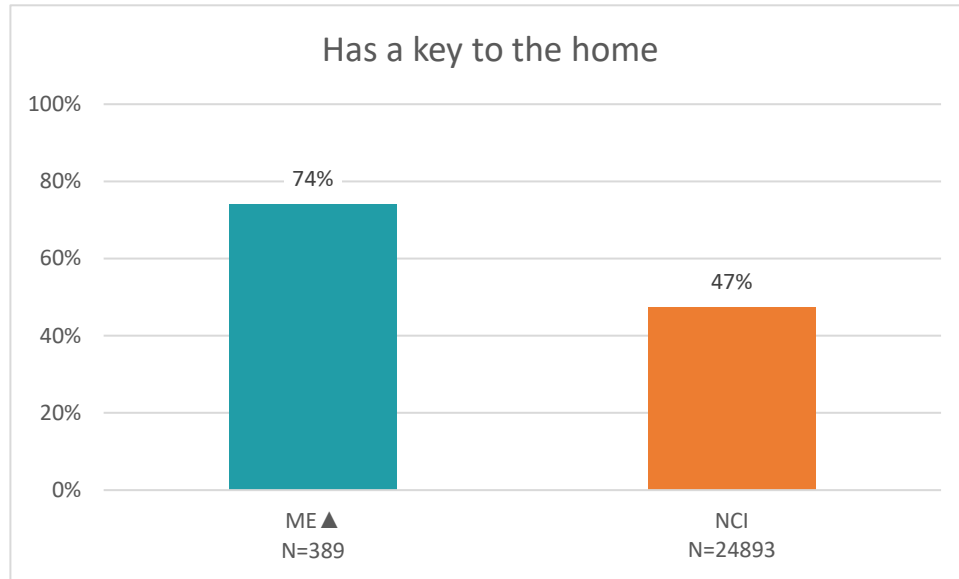
^ A lower average indicates a lower percentage of people use tobacco products.

## *Rights and Respect*

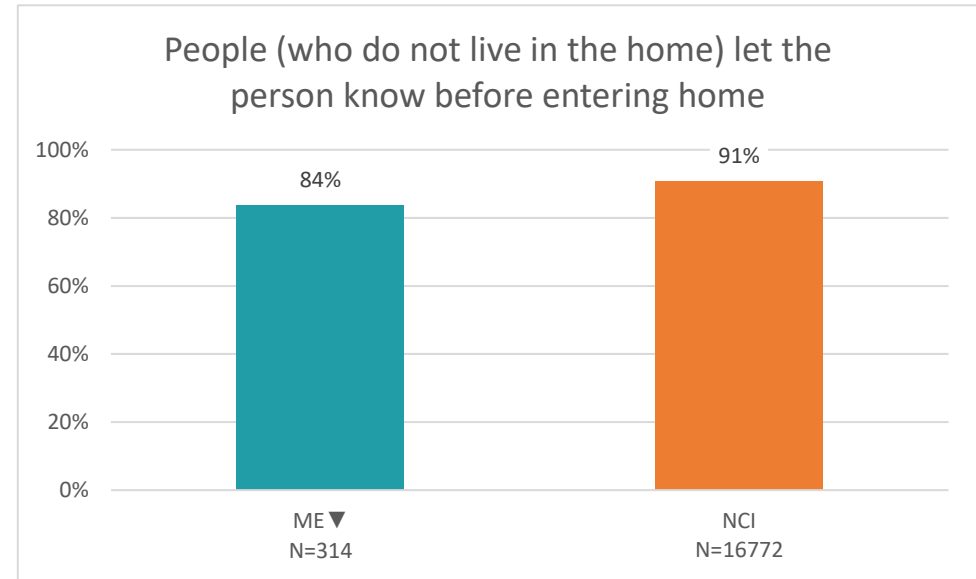
*People receive the same respect and protections as others in the community.*

*Charts for Rights and Respect*

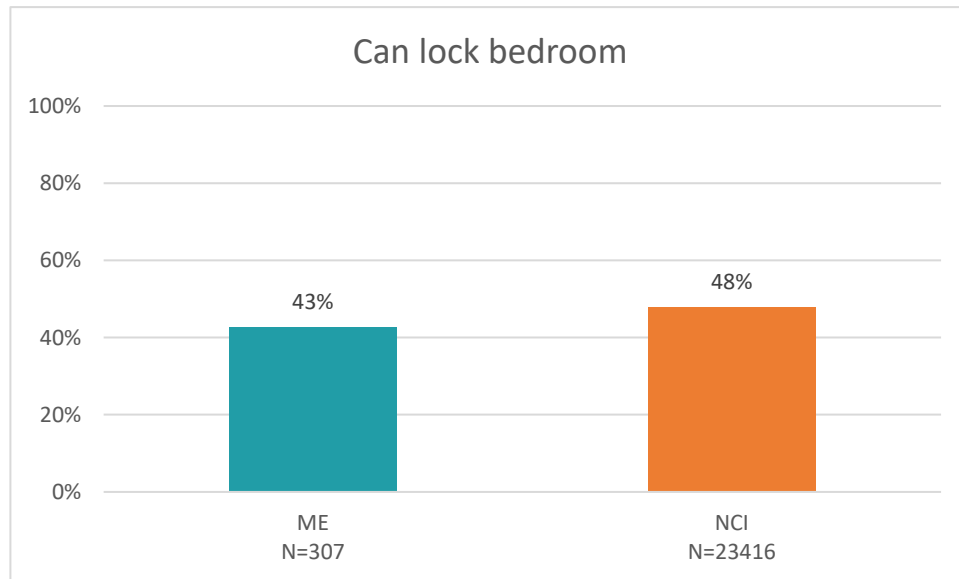
[Chart 90](#). Has a key to the home (proxy respondents were allowed for this question)



[Chart 91](#). People (who do not live in the home) let the person know before entering home



[Chart 92](#). Can lock bedroom (proxy respondents were allowed for this question)



[Chart 93](#). People let person know before entering person's bedroom

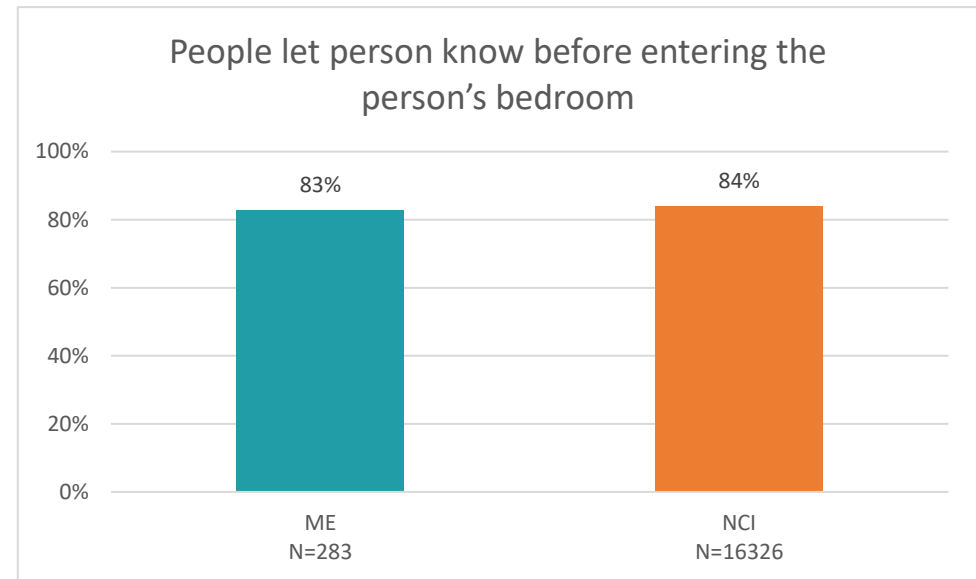


Chart 94. Others read mail or email without asking ~

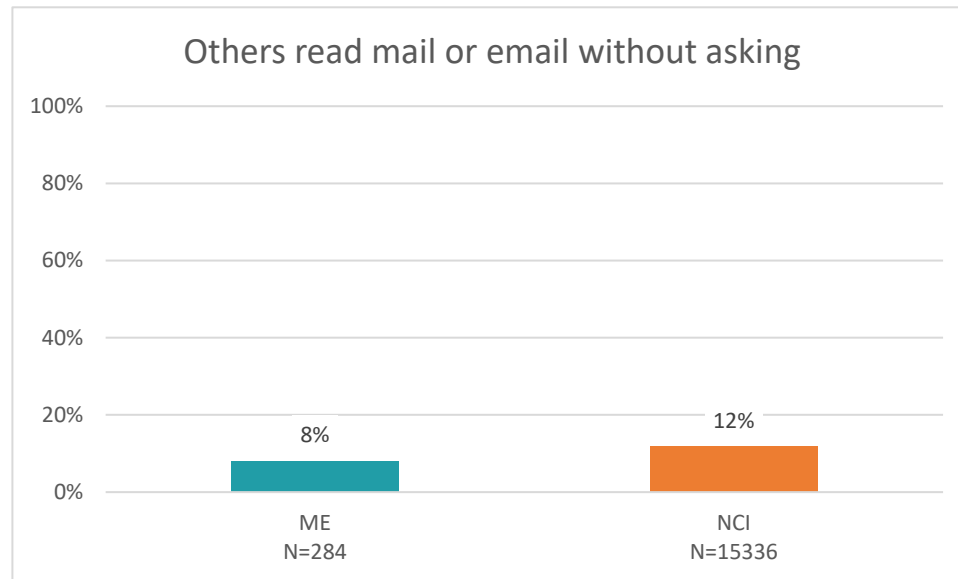


Chart 95. Can use phone and internet when s/he wants

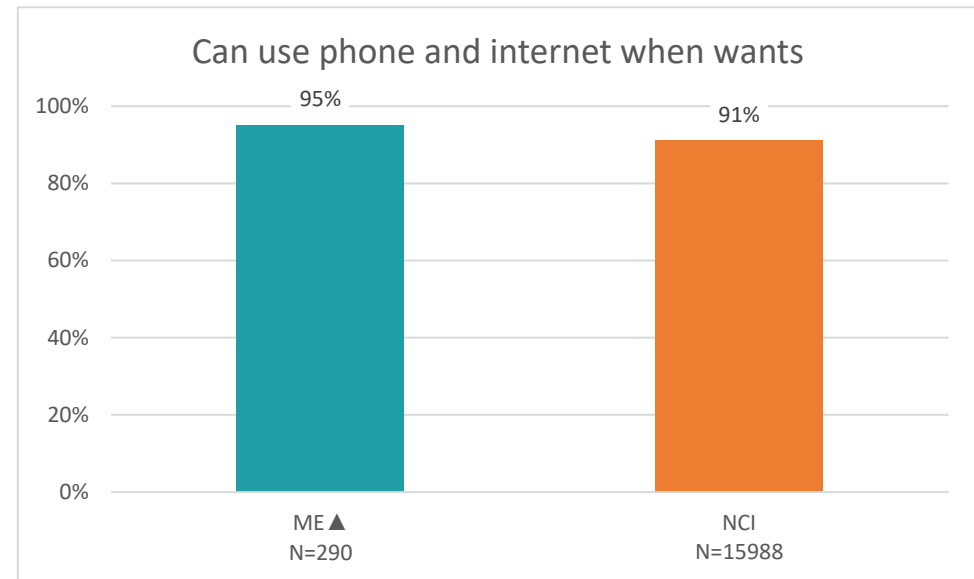


Chart 96. Can be alone with friends or visitors at home

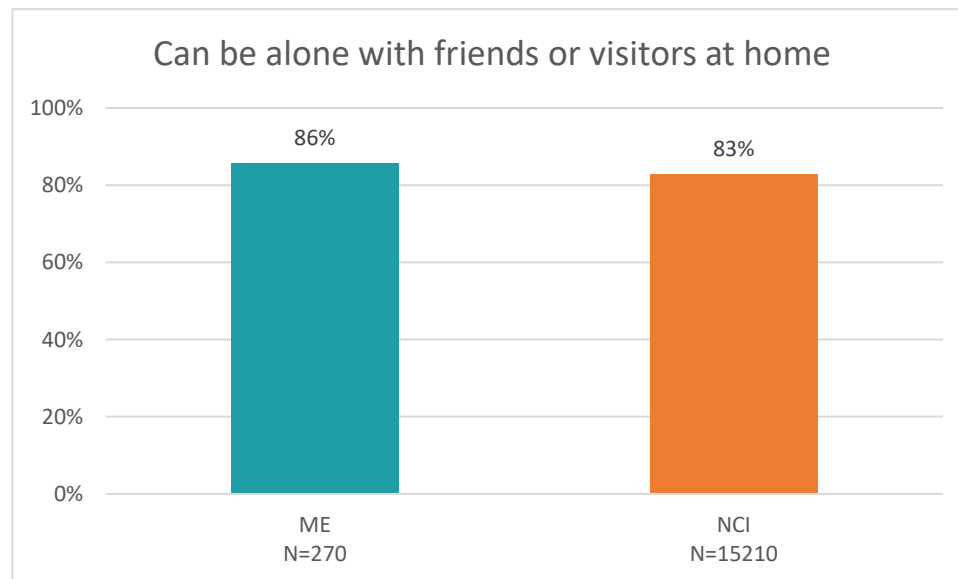
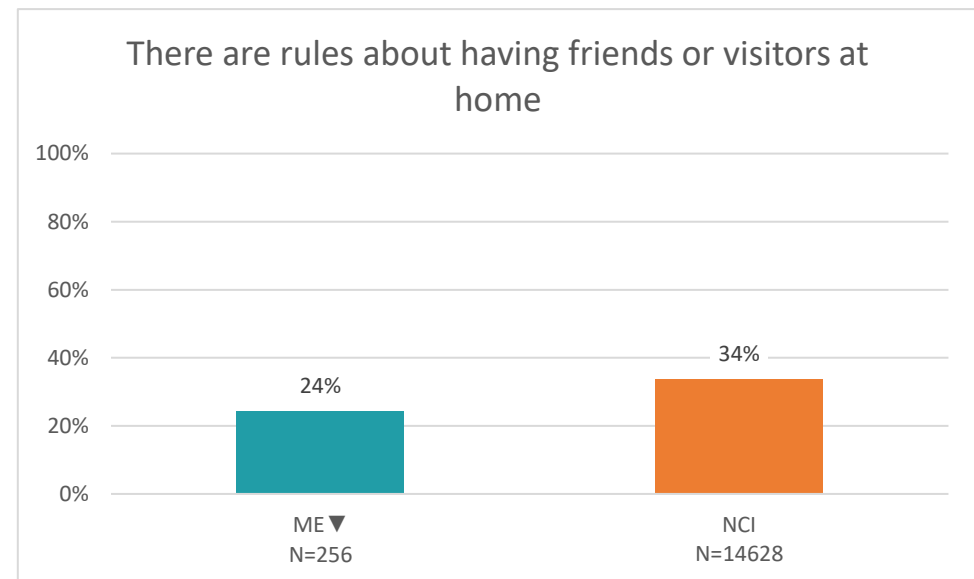


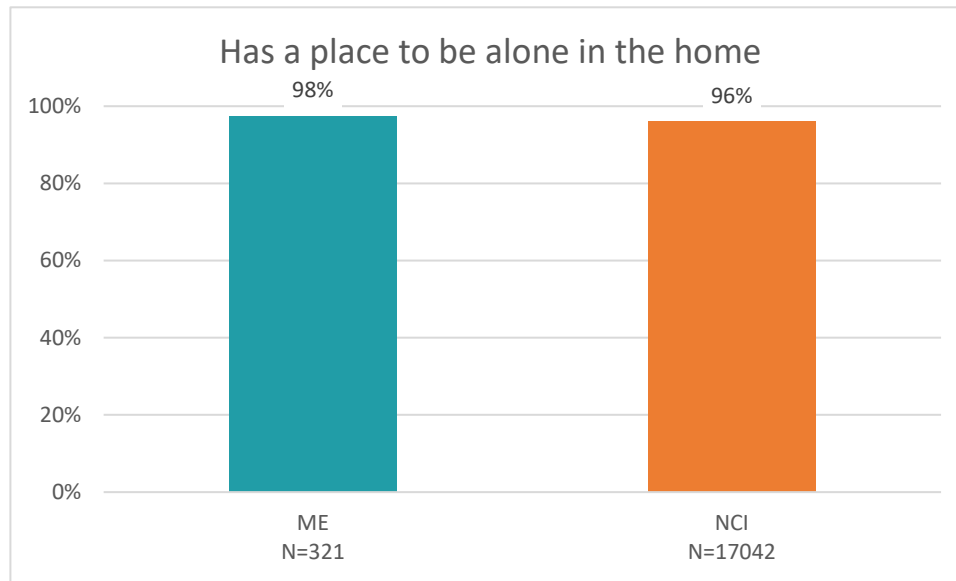
Chart 97. There are rules about having friends or visitors at home ~



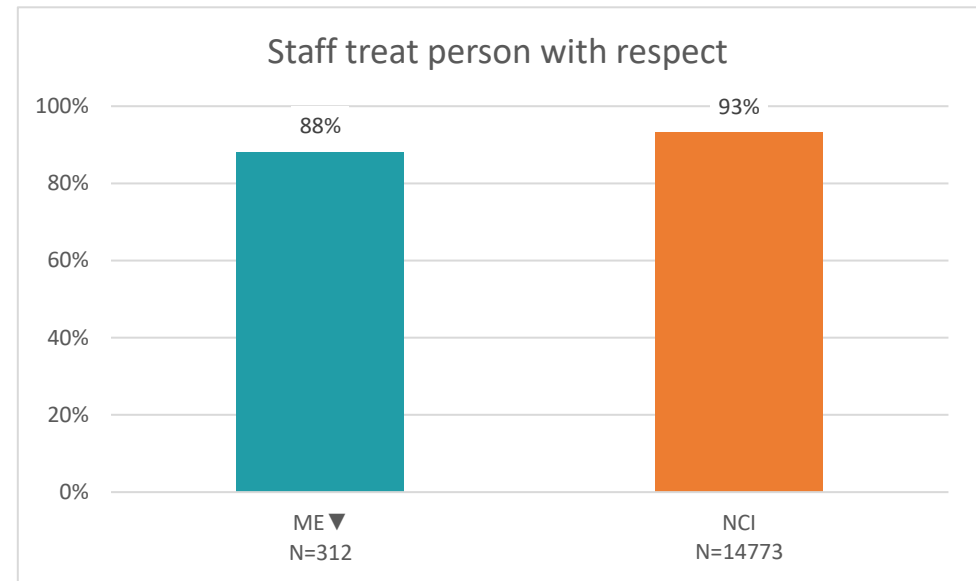
~A lower average indicates a lower percentage of people report others open mail or email without asking.

~A lower average indicates a lower percentage of people report rules about having friends or visitors at home.

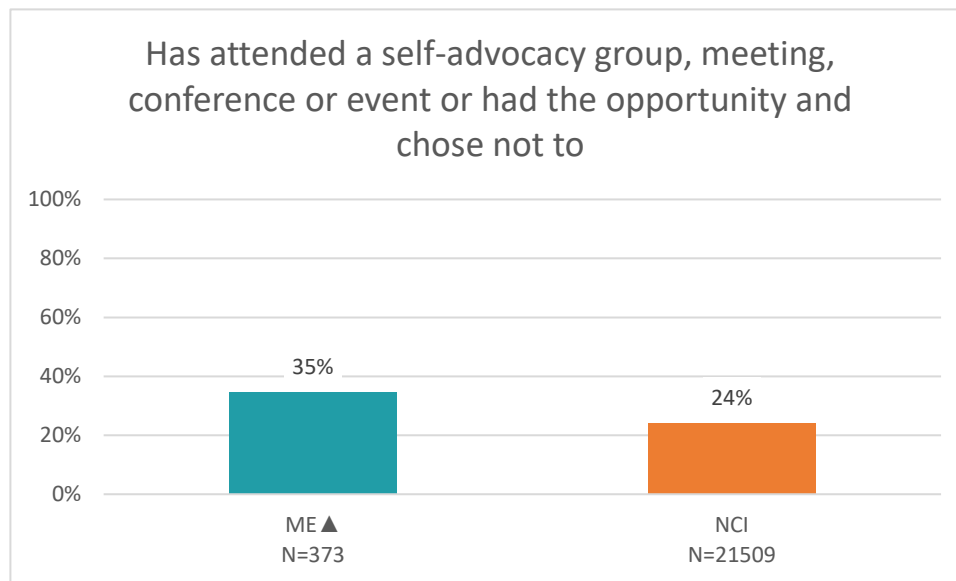
[Chart 98.](#) Has a place to be alone in the home



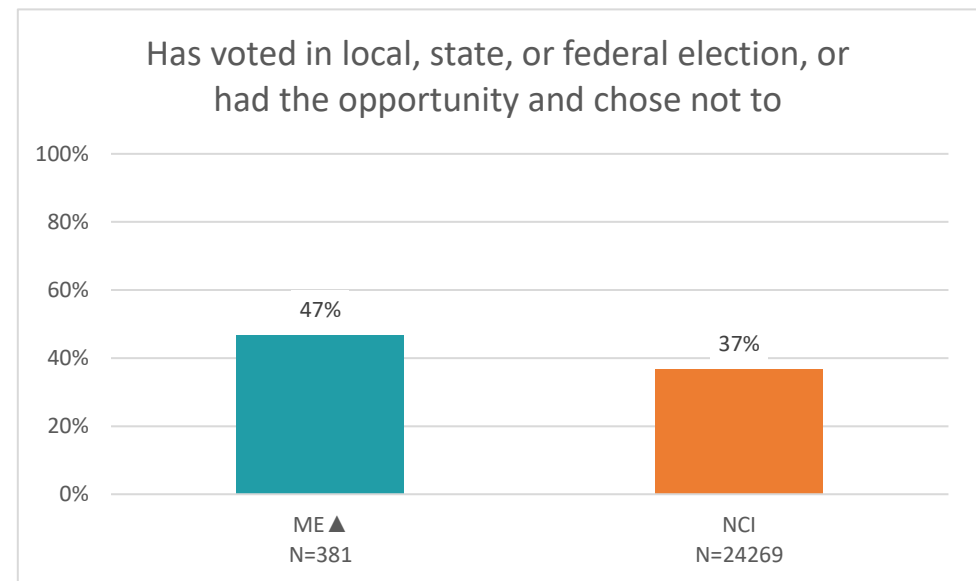
[Chart 99.](#) Staff treat person with respect



[Chart 100.](#) Has attended a self-advocacy group, meeting, conference or event or had the opportunity and chose not to (proxy respondents were allowed for this question)



[Chart 101.](#) Has voted in local, state, or federal election, or had the opportunity and chose not to (proxy respondents were allowed for this question)



*Tables for Rights and Respect*

Table 59. Rights and Respect

		Yes	N
Has a key to the home <i>(proxy respondents were allowed for this question)</i>	ME▲	74%	389
	NCI	47%	24,893
People (who do not live in the home) let the person know before entering home	ME▼	84%	314
	NCI	91%	16,772
Can lock bedroom <i>(proxy respondents were allowed for this question)</i>	ME	43%	307
	NCI	48%	23,416
People let the person know before entering person's bedroom	ME	83%	283
	NCI	84%	16,326
Others read mail or email without asking ~	ME	8%	284
	NCI	12%	15,336
Can use phone and internet when s/he wants	ME▲	95%	290
	NCI	91%	15,988
Can be alone with friends or visitors at home	ME	86%	270
	NCI	83%	15,210
There are rules about having friends or visitors at home ~^	ME▼	24%	256
	NCI	34%	14,628
Has a place to be alone in the home	ME	98%	321
	NCI	96%	17,042
Staff treat person with respect	ME▼	88%	312
	NCI	93%	14,773
Has attended a self-advocacy group, meeting, conference or event or had the opportunity and chose not to <i>(proxy respondents were allowed for this question)</i>	ME▲	35%	373
	NCI	24%	21,509
Has voted in local, state, or federal election, or had the opportunity and chose not to <i>(proxy respondents were allowed for this question)</i>	ME▲	47%	381
	NCI	37%	24,269

~A lower average indicates a lower percentage of people report others open mail or email without asking.

~^A lower average indicates a lower percentage of people report rules about having friends or visitors at home.

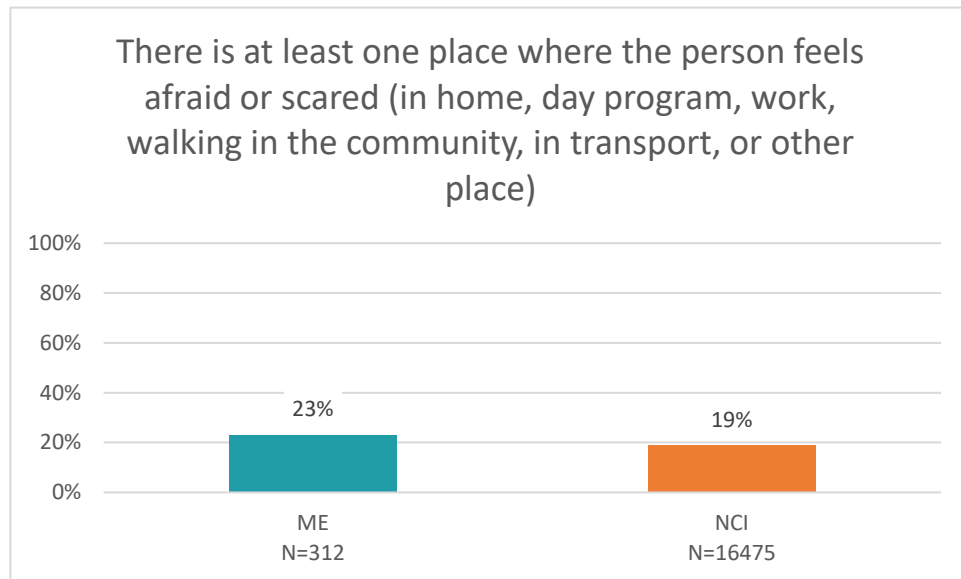


## *Safety*

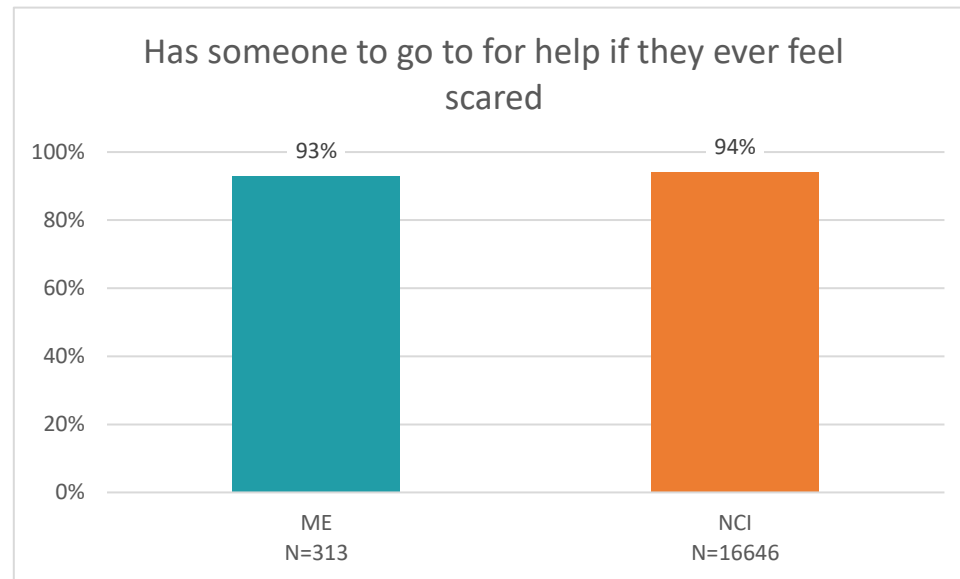
*People are safe from abuse, neglect, and injury.*

*Charts for Safety*

[Chart 102](#). There is at least one place where the person feels afraid or scared (in home, day program, work, walking in the community, in transport, or other place) ~



[Chart 103](#). Has someone to go to for help if they ever feel scared



~A lower percentage indicates a lower proportion of people indicating that there is a place they feel afraid.

*Tables for Safety*

Table 60. Safety

		Yes	N
There is at least one place where the person feels afraid or scared ( <i>in home, day program, work, walking in the community, in transport, or other place</i> ) ~	ME	23%	312
	NCI	19%	16,475
Has someone to go to for help if they ever feel scared	ME	93%	313
	NCI	94%	16,646

~A lower percentage indicates a lower proportion of people indicating that there is a place they feel afraid.