

# Adult Consumer Survey

*Illinois Report 2016-17*



# Contents

- What is NCI? ..... 1
- What is the NCI Adult Consumer Survey?..... 1
- What topics are covered by the survey? ..... 1
- How were people selected to participate?..... 3
- Proxy Respondents ..... 3
- Data Analysis..... 3
- Weighting..... 4
- Significance Testing..... 4
- Limitations of Data..... 5
- What is contained in this report? ..... 5
- Demographics ..... 6
  - Table 1. Age..... 7
  - Table 2. Age Group..... 7
  - Table 3. Gender ..... 7
  - Table 4. Marital Status\* ..... 7
  - Table 5A. Race and Ethnicity..... 8
  - Table 5B. Race and Ethnicity (continued) ..... 8
  - Table 6. Residential Designation <sup>v</sup> \*..... 8
  - Table 7. Type of Residence (Institutional Setting) ..... 8
  - Table 8. Type of Residence (Group Residential Setting)..... 8
  - Table 9. Type of Residence (Other Home Settings) ..... 9
  - Table 10. Length of Time at Current Residence\* ..... 9
  - Table 11. Residence is Owned or Controlled by Provider Agency\* ..... 9
  - Table 12. Person is Named on Lease\* ..... 9
  - Table 13. Person Owns Home\* ..... 9

Table 14. Person Has ID Diagnosis ..... 10

Table 15. Level of ID (If Person Has ID Diagnosis)..... 10

Table 16. Psychiatric Diagnoses: Mood, Anxiety, Behavior, Psychotic, and Other Mental Illness∞..... 10

Table 17A. Other Diagnoses: Other Disabilities∞..... 10

Table 17B. Other Diagnoses: Other Disabilities (continued) ∞ ..... 10

Table 18A. Health Conditions ∞ ..... 11

Table 18B. Health Conditions (continued) ∞ ..... 11

Table 19. Preferred Means of Communication..... 11

Table 20. Primary Language ..... 11

Table 21. Mobility ..... 11

Table 22. Level of Behavioral Support Needed..... 12

Table 23. Level of Guardianship..... 12

Table 24. Guardian’s Relationship to Person \* ..... 12

Choice and Decision-Making..... 13

Charts for Choice and Decision-Making..... 14

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) ..... 15

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)..... 15

Chart 3. Chose or had some help in choosing where they work (proxy respondents were allowed for this question) ..... 15

Chart 4. Chose or had some input in choosing where they go during the day (proxy respondents were allowed for this question)..... 15

Chart 5. Chose staff or were aware they could request to change staff (proxy respondents were allowed for this question) ..... 16

Chart 6. Decides or has help deciding their daily schedule (proxy respondents were allowed for this question) ..... 16

Chart 7. Chooses or has help deciding how to spend free time (proxy respondents were allowed for this question) ..... 16

Chart 8. Chooses or has help choosing what to buy, or has set limits on what to buy with their spending money (proxy respondents were allowed for this question) ..... 16

Chart 9. Can change case manager/service coordinator if wants to (proxy respondents were allowed for this question) ..... 17

Tables for Choice and Decision-Making..... 18

Table 25. Choice and Decision-Making ..... 19

Work..... 20

Charts for Work..... 21

Chart 10. Has a paid job in the community (information may have been obtained through state records) ..... 22

Chart 11. Type of paid community job (information may have been obtained through state records) ~ ..... 22

Chart 12. Average number of biweekly hours by type of community job (information may have been obtained through state records) ..... 22

Chart 13. Average biweekly gross wages by type of community job (information may have been obtained through state records) ..... 22

Chart 14. Average biweekly hourly wage by type of community job (information may have been obtained through state records) ..... 23

Chart 15. Length of employment in current paid community job (in months; information may have been obtained through state records) ..... 23

Chart 16. Receives paid time off (for example, paid vacation and/or sick time) from paid community job (information may have been obtained through state records) ..... 23

Chart 17. Four most common job industries of those with a paid community job (information may have been obtained through state records) ∞ ..... 23

Chart 18. Does not have paid community job, and would like a job in the community ..... 24

Chart 19. Has community employment as a goal in their service plan (information may have been obtained through state records) ..... 24

Chart 20. Takes classes, training or does something to get a job or do better at current job ..... 24

Chart 21. Attends a day program or workshop ..... 24

Chart 22. Volunteers ..... 25

Tables for Work..... 26

Table 26. Has paid community job (*information may have been obtained through state records*)\* ..... 27

Table 27. Type of paid community job (*information may have been obtained through state records*)..... 27

Table 28. Hours and wages by type of paid community job..... 27

Table 29. Length of employment at current job, in months (*information may have been obtained through state records*)\* ..... 27

Table 30. Receives paid time off (for example, paid vacation and/or sick time) at paid community job (*information may have been obtained through state records*) ..... 28

Table 31. Most common types of jobs among those with a paid community job (*information may have been obtained through state records*) ∞ ..... 28

Table 32. Employment goals and other daily activities ..... 28

Self-Determination..... 29

Charts for Self-Determination..... 30

- Chart 23. Uses a self-directed supports option (information may have been obtained through state records) ..... 31
- Chart 24. People who make decisions or have input in making decisions for how budget for services is used (proxy respondents were allowed for this question) ..... 31
- Chart 25. Hires or manages staff (proxy respondents were allowed for this question)..... 31
- Chart 26. Can make changes to individual budget/services if needed (proxy respondents were allowed for this question) ..... 31
- Chart 27. Has enough help deciding how to use their individual budget/services (proxy respondents were allowed for this question) ..... 32
- Chart 28. Gets information about how much money is left in budget/services (proxy respondents were allowed for this question)..... 32
- Chart 29. Information about budget/services is easy to understand (proxy respondents were allowed for this question) ..... 32
- Chart 30. Frequency gets information about budget/services (proxy respondents were allowed for this question) <sup>a</sup> ..... 32

Tables for Self-Determination..... 33

- Table 33. Uses self-directed services option (*information may have been obtained through state records*)..... 34
- Table 34. People who make decisions about how to use budget/services (*proxy respondents were allowed for this question*) ..... 34
- Table 35. Self-direction ..... 34
- Table 36. Frequency gets information about how much money is left in budget/services, among those who receive information (*proxy respondents were allowed for this question*)..... 34

Community Inclusion, Participation and Leisure ..... 35

Charts for Community Inclusion, Participation and Leisure ..... 36

- Chart 31. Went out shopping at least once in the past month (proxy respondents were allowed for this question)..... 37
- Chart 32. Went out on errands at least once in the past month (proxy respondents were allowed for this question)..... 37
- Chart 33. Went out for entertainment at least once in the past month (proxy respondents were allowed for this question) ..... 37
- Chart 34. Went out to eat at least once in the past month (proxy respondents were allowed for this question)..... 37
- Chart 35. Went out to religious service or spiritual practice at least once in the past month (proxy respondents were allowed for this question)..... 38
- Chart 36. Participated as a member in community group (proxy respondents were allowed for this question)..... 38
- Chart 37. Went on vacation in the past year (proxy respondents were allowed for this question) ..... 38
- Chart 38. Able to go out and do the things likes to do in the community..... 38
- Chart 39. Able to go out and do the things likes to do in the community as often as wants to ..... 39

Chart 40. Has enough things to do when at home ..... 39

Tables for Community Inclusion, Participation, and Leisure ..... 40

    Table 37. Community Inclusion, Participation, and Leisure..... 41

Relationships..... 42

Charts for Relationships..... 43

    Chart 41. Has friends who are not staff or family members ..... 44

    Chart 42. Has best friend (may be staff or family) (This was a new question in 2016-17; item was used in tools prior to 2015-16.)..... 44

    Chart 43. Wants help to meet or keep in contact with friends ..... 44

    Chart 44. Has friends (may be staff or family) and can see them when wants ..... 44

    Chart 45. Reasons cannot see friends if sometimes or often unable to ± ∞ ..... 45

    Chart 46. Has other ways of talking, chatting, or communicating with friends when cannot see them ..... 45

    Chart 47. Can see and communicate with their family when they want (if not living with family) ± ..... 45

    Chart 48. Often feels lonely ˇ ..... 45

    Chart 49. Can go on a date or is married or living with partner ..... 46

Tables for Relationships ..... 47

    Table 38. Friendships ..... 48

    Table 39. Reasons cannot see friends if sometimes or often unable to ± ∞ ..... 48

    Table 40. Relationships ..... 49

Satisfaction..... 50

Charts for Satisfaction..... 51

    Chart 50. Likes home or where lives ..... 52

    Chart 51. Wants to live somewhere else ˇ ..... 52

    Chart 52. Has a paid job in the community and likes job ..... 52

    Chart 53. Has a paid job in the community and wants to work somewhere else ˇˇ ..... 52

    Chart 54. Attends a day program or workshop and wants to go more, less, or the same amount of time º ..... 53

    Chart 55. Services and supports help person live a good life ..... 53

Tables for Satisfaction ..... 54

Table 41. Satisfaction at home and with paid community job ..... 55

Table 42. Amount of time wants to spend at day program or workshop s/he attends ..... 55

Table 43. Services and supports help person live a good life ..... 55

Service Coordination..... 56

Charts for Service Coordination ..... 57

Chart 56. Has met case manager/service coordinator ..... 58

Chart 57. Case manager/service coordinator asks person what s/he wants ..... 58

Chart 58. Able to contact case manager/service coordinator when wants ..... 58

Chart 59. Took part in last service planning meeting, or had the opportunity but chose not to ..... 58

Chart 60. Understood what was talked about at last service planning meeting..... 59

Chart 61. Last service planning meeting included people respondent wanted to be there ..... 59

Chart 62. Person was able to choose services they get as part of service plan..... 59

Chart 63. Staff come and leave when they are supposed to ..... 59

Tables for Service Coordination ..... 60

Table 44. Service Coordination ..... 61

Access..... 62

Charts for Access..... 63

Chart 64. Has a way to get places needs to go ..... 64

Chart 65. Able to get places when wants to do something outside of home..... 64

Chart 66. Staff have right training to meet person’s needs (proxy respondents who were not staff were allowed for this question) ± ..... 64

Chart 67. Additional services needed (proxy respondents were allowed for this question) ∞ ..... 64

Chart 68. Additional services needed, continued (proxy respondents were allowed for this question) ∞ ..... 65

Chart 69. Additional services needed, continued (proxy respondents were allowed for this question) ∞ ..... 65

Tables for Access..... 66

Table 45. Transportation and staff training ..... 67

Table 46. Additional services needed ∞ (proxy respondents were allowed for this question) ..... 68

Health..... 69

Charts for Health ..... 70

- Chart 70. Has a primary care doctor or practitioner (information may have been obtained through state records) ..... 71
- Chart 71. In poor health (proxy respondents were allowed for this question) <sup>~</sup> ..... 71
- Chart 72. Had a complete physical exam in the past year (information may have been obtained through state records) ..... 71
- Chart 73. Had a dental exam in the past year (information may have been obtained through state records) ..... 71
- Chart 74. Had an eye exam in the past year (information may have been obtained through state records)..... 72
- Chart 75. Had a hearing test in the past five years (information may have been obtained through state records) ..... 72
- Chart 76. Had a Pap test in the past three years (women 21 and older; information may have been obtained through state records) <sup>±</sup> ..... 72
- Chart 77. Had a mammogram test in the past two years (women 40 and older; information may have been obtained through state records)..... 72
- Chart 78. Last colorectal cancer screening (people 50 and older; information may have been obtained through state records) <sup>° ∞</sup> ..... 73
- Chart 79. Had a flu vaccine in the past year (information may have been obtained through state records) ..... 73

Tables for Health ..... 74

- Table 47. Regular and preventive screenings ..... 75
- Table 48. Last colorectal cancer screening, people age 50 and older (*information may have been obtained through state records*) <sup>° ∞</sup>..... 76
- Table 49. Had a flu vaccine in the past year (*information may have been obtained through state records*)<sup>\*</sup> ..... 76

Medications ..... 77

Charts for Medications..... 78

- Chart 80. Takes at least one medication for mood, anxiety, psychotic disorder and/or behavioral challenge (information may have been obtained through state records) ..... 79
- Chart 81. Takes medication for mood, anxiety, and/or psychotic disorders (information may have been obtained through state records) ..... 79
- Chart 82. Takes medication for behavior challenges (information may have been obtained through state records) ..... 79
- Chart 83. 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)..... 79
- Chart 84. Number of medications taken for behavior challenges (information may have been obtained through state records) ..... 80
- Chart 85. Has a behavior plan (information may have been obtained through state records) ..... 80
- Chart 86. Takes medication for behavior challenges and has a behavior plan (information may have been obtained through state records)..... 80

Tables for Medication ..... 81



Table 50. Takes medication..... 82

Table 51. Number of medications taken..... 82

Table 52. Behavior plan and medication ..... 82

Wellness ..... 83

Charts for Wellness ..... 84

Chart 87. Exercises or does physical activity at least 3 times per week (proxy respondents were allowed for this question) ..... 85

Chart 88. Body Mass Index (BMI) category (information may have been obtained through state records) ..... 85

Chart 89. Uses tobacco products (information may have been obtained through state records) ~ ..... 85

Tables for Wellness ..... 86

Table 53. Exercises or does physical activity at least 3 times per week (proxy respondents were allowed for this question) ..... 87

Table 54. Body Mass Index (BMI) category (*information may have been obtained through state records*) \* ..... 87

Table 55. Uses tobacco products (*information may have been obtained through state records*) ~ \* ..... 87

Rights and Respect..... 88

Charts for Rights and Respect ..... 89

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

Chart 91. People (who do not live in the home) let person know before entering home ..... 90

Chart 92. Can lock bedroom (proxy respondents were allowed for this question)..... 90

Chart 93. People let person know before entering person’s bedroom ..... 90

Chart 94. Others read mail or email without asking ~ ..... 91

Chart 95. Can use phone and internet when wants ..... 91

Chart 96. Can be alone with friends or visitors at home ..... 91

Chart 97. There are rules about having friends or visitors at home ° ~ ..... 91

Chart 98. Has a place to be alone in the home ..... 92

Chart 99. Staff treat person with respect ..... 92

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)..... 92

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)..... 92

Tables for Rights and Respect ..... 93

    Table 56. Rights and Respect ..... 94

Safety ..... 95

Charts for Safety..... 96

    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) ~ ..... 97

    Chart 103. Has someone to go to for help if they ever feel scared ..... 97

Tables for Safety..... 98

    Table 57. Safety..... 99

## 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 2016-17 a total of 45 states, the District of Columbia and 22 sub-state entities participated in NCI. Not all states participate in the Adult Consumer Survey every year.

## What is the NCI Adult Consumer Survey?

The NCI Adult Consumer 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. Interviewers 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.

## 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 tables on the following page lists the domains, sub-domains, and concern statements addressed by the NCI Adult Consumer Survey indicators.

**Individual Outcomes Domain**

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

**Health Welfare and Rights Domain**

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

**System Performance Domain**

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

## 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, Respect/Rights, 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 n/a 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

In previous years, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). This year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states’ systems. Beginning this year, 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>1</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. In some cases, 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 is similar 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 Texas, based on disproportionate sampling from DD Agency Programs (for more information see State Sample procedures in Appendix C of National Adult Consumer Survey located here:

<https://www.nationalcoreindicators.org/resources/reports/>.

## Significance Testing

Starting this survey cycle (2016-17), statistical significance is shown in this state report. The 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>2</sup> Demographics data and data on services received were not tested for statistically significant differences.

<sup>1</sup> For more information on weighting, see the Methodology section of the National Adult Consumer Survey Report.

<sup>2</sup> For more information on significance testing, see the Methodology section of the National Adult Consumer Survey Report.

## Limitations of Data

The NCI Adult Consumer 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. Please note that the NCI average reflects the average of data that were reported to NCI and may not be reflective of the service population across the country.

## What is contained in this report?

This report illustrates the 2016-17 NCI Adult Consumer Survey demographic and outcome results from Illinois (IL) 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. States with fewer than 20 responses to a question were excluded from analysis for that question. 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 (\*).

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. 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
IL	42	19	80	14	39	375
NCI	42	18	105	16	40	21,382

**Table 2. Age Group**

	18-22	23-34	35-54	55-74	75+	Unknown	N
IL	3%	37%	37%	21%	1%	1%	379
NCI	8%	31%	35%	22%	2%	1%	21,548

**Table 3. Gender**

	Male	Female	Other	N
IL	55%	45%	0%	376
NCI	58%	42%	0%	21,408

**Table 4. Marital Status\***

	Single, Never Married	Married	Single, Married in the Past	Don't Know	N
IL	96%	2%	2%	0%	377
NCI	94%	2%	2%	2%	21,190

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

**Table 5A. Race and Ethnicity**

	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White
IL	0%	2%	24%	0%	63%
NCI	1%	1%	16%	0%	72%

**Table 5B. Race and Ethnicity (continued)**

	Hispanic or Latino	Other	Two or More	Don't Know	N
IL	7%	0%	4%	0%	378
NCI	6%	1%	1%	1%	21,385

**Table 6. Residential Designation ~ \***

	Metropolitan	Micropolitan	Rural	Small Town	N
IL	82%	10%	1%	7%	362
NCI	74%	15%	4%	8%	20,202

**Table 7. Type of Residence (Institutional Setting)**

	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
IL	0%	0%	0%	0%	1%	378
NCI	2%	2%	2%	1%	0%	21,385

**Table 8. Type of Residence (Group Residential Setting)**

	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
IL	4%	23%	15%	378
NCI	8%	18%	5%	21,385

~Information based on residential designation defined by the USDA: <http://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes.aspx>

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

**Table 9. Type of Residence (Other Home Settings)**

	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
IL	11%	44%	1%	1%	0%	0%	0%	378
NCI	17%	39%	3%	2%	0%	1%	1%	21,385

**Table 10. Length of Time at Current Residence\***

	Less Than 1 Year	1-3 Years	3-5 Years	Over 5 Years	Don't Know	N
IL	8%	16%	13%	59%	5%	376
NCI	9%	15%	11%	59%	5%	21,065

**Table 11. Residence is Owned or Controlled by Provider Agency\***

	Yes	No	Don't Know	N
IL	43%	54%	3%	373
NCI	33%	49%	18%	21,133

**Table 12. Person is Named on Lease\***

	Named on Lease or Deed	Named on Other Legally Enforceable Rental Agreement	No	Don't Know	N
IL	11%	1%	78%	10%	376
NCI	14%	3%	67%	16%	21,040

**Table 13. Person Owns Home\***

	Yes	No	Don't Know	N
IL	2%	93%	5%	375
NCI	2%	90%	8%	21,045

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

**Table 14. Person Has ID Diagnosis**

	Yes	No	Don't Know	N
IL	97%	3%	0%	376
NCI	94%	5%	1%	21,366

**Table 15. Level of ID (If Person Has ID Diagnosis)**

	Mild	Moderate	Severe	Profound	Unspecified	Unknown	N
IL	45%	28%	15%	11%	1%	0%	364
NCI	39%	28%	13%	9%	10%	1%	20,149

**Table 16. Psychiatric Diagnoses: Mood, Anxiety, Behavior, Psychotic, and Other Mental Illness∞**

	Mood Disorder	Anxiety Disorder	Behavior Challenges	Psychotic Disorder	Other Mental Illness or Psychiatric Diagnosis
IL	30%	21%	24%	12%	8%
NCI	27%	23%	28%	11%	12%

**Table 17A. Other Diagnoses: Other Disabilities∞**

	Autism Spectrum Disorder	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
IL	18%	13%	3%	23%	1%
NCI	18%	15%	4%	26%	1%

**Table 17B. Other Diagnoses: Other Disabilities (continued) ∞**

	Down Syndrome	Prader-Willi	Fetal Alcohol Syndrome	Limited or No Vision	Severe or Profound Hearing Loss	Other Disabilities, Not Listed	No Other Disabilities
IL	9%	1%	1%	5%	5%	21%	6%
NCI	10%	1%	1%	10%	6%	19%	6%

∞Categories are not mutually exclusive, and N may differ by category; therefore, N is not shown

**Table 18A. Health Conditions ∞**

	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
IL	5%	8%	2%	15%	10%
NCI	7%	11%	3%	20%	17%

**Table 18B. Health Conditions (continued) ∞**

	Dysphagia	Pressure Ulcers	Alzheimer's	Oral Health or Dental Problems	Sleep Apnea	Other Health Conditions
IL	4%	0%	2%	1%	5%	38%
NCI	7%	2%	3%	6%	7%	36%

**Table 19. Preferred Means of Communication**

	Spoken	Gestures	Sign Language	Communication Device	Other	Don't Know	N
IL	82%	14%	3%	1%	1%	0%	377
NCI	78%	15%	2%	1%	2%	1%	21,376

**Table 20. Primary Language**

	English	Other	N
IL	97%	3%	372
NCI	97%	3%	21,186

**Table 21. Mobility**

	Moves Self Without Aids	Moves Self With Aids or Uses Wheelchair Independently	Non-Ambulatory	Don't Know	N
IL	83%	12%	4%	0%	375
NCI	77%	15%	8%	0%	21,233

∞Categories are not mutually exclusive, and N may differ by category; therefore, N is not shown

**Table 22. Level of Behavioral Support Needed**

	None	Some	Extensive	Don't Know	N
IL	80%	15%	4%	1%	372
NCI	75%	18%	5%	3%	21,222
IL	62%	33%	5%	1%	372
NCI	62%	27%	7%	3%	21,239
IL	71%	25%	4%	1%	370
NCI	72%	19%	6%	3%	21,202

**Table 23. Level of Guardianship**

	None	Limited Guardianship	Full Guardian	Has Guardian, but Unable to Distinguish Level	Don't Know	N
IL	29%	5%	66%	1%	0%	377
NCI	44%	6%	35%	12%	3%	21,396

**Table 24. Guardian’s Relationship to Person \***

	Family	Friend	Employee of State or Guardianship Agency	Other	Don't Know	N
IL	85%	2%	9%	2%	2%	265
NCI	74%	2%	13%	3%	9%	11,948

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

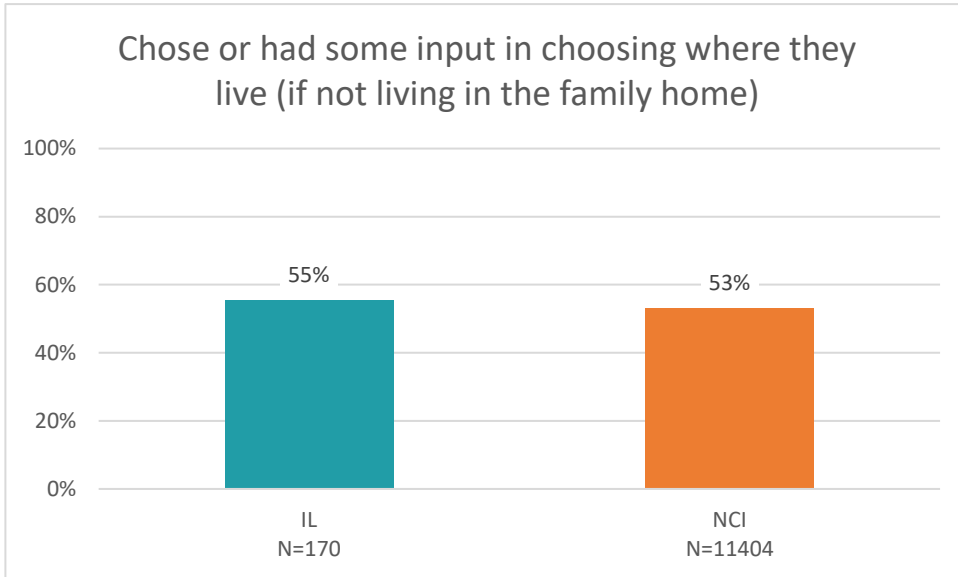
## *Choice and Decision-Making*

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

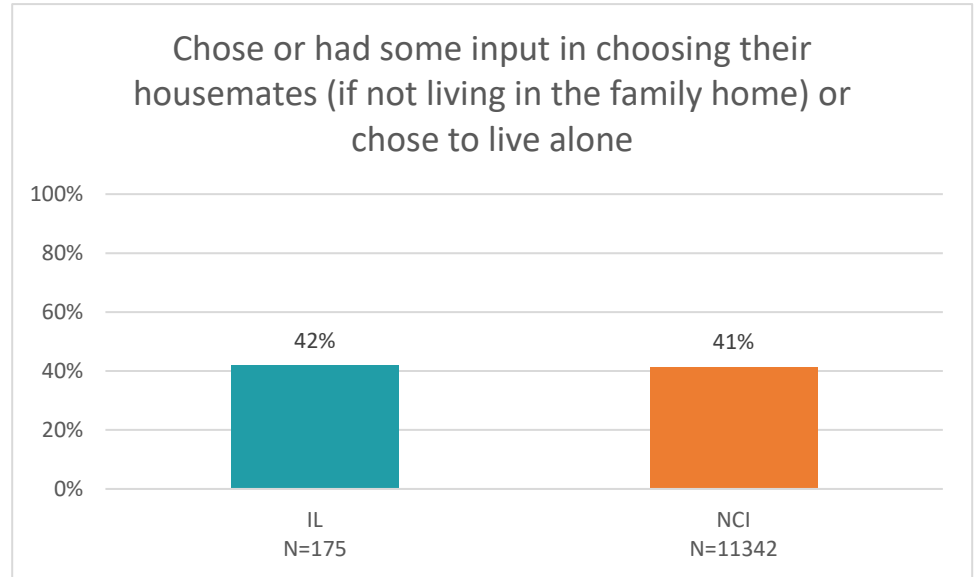
*Charts for Choice and Decision-Making*



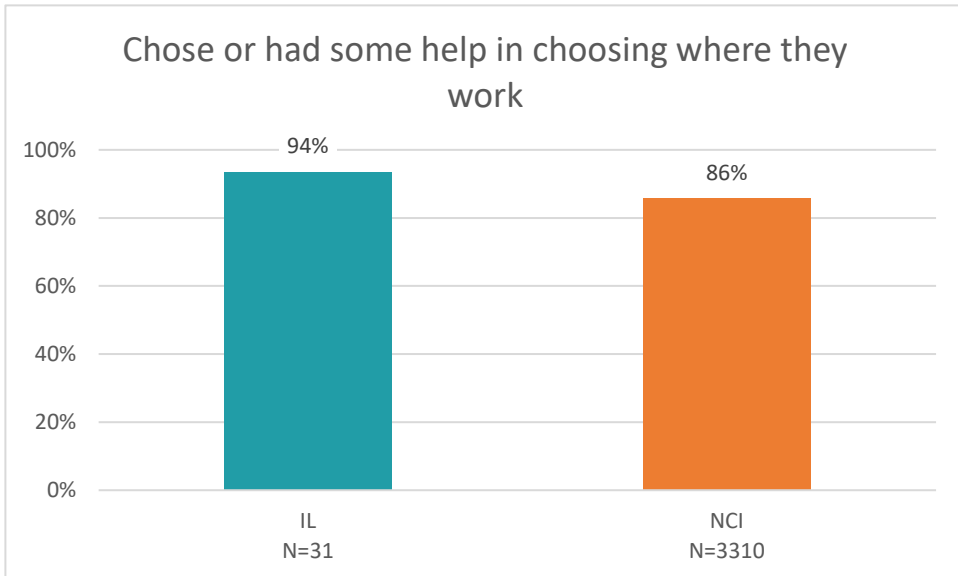
[Chart 1.](#) Chose or had some input in choosing where they live (if not living in the family home; proxy respondents were allowed for this question)



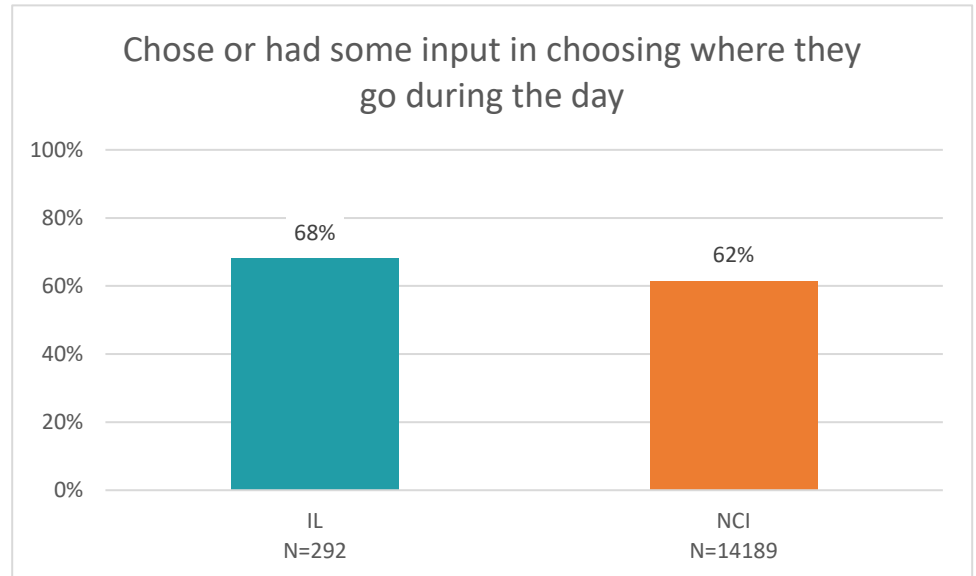
[Chart 2.](#) Chose or had some input in choosing their housemates or chose to live alone (if not living in the family home; proxy respondents were allowed for this question)



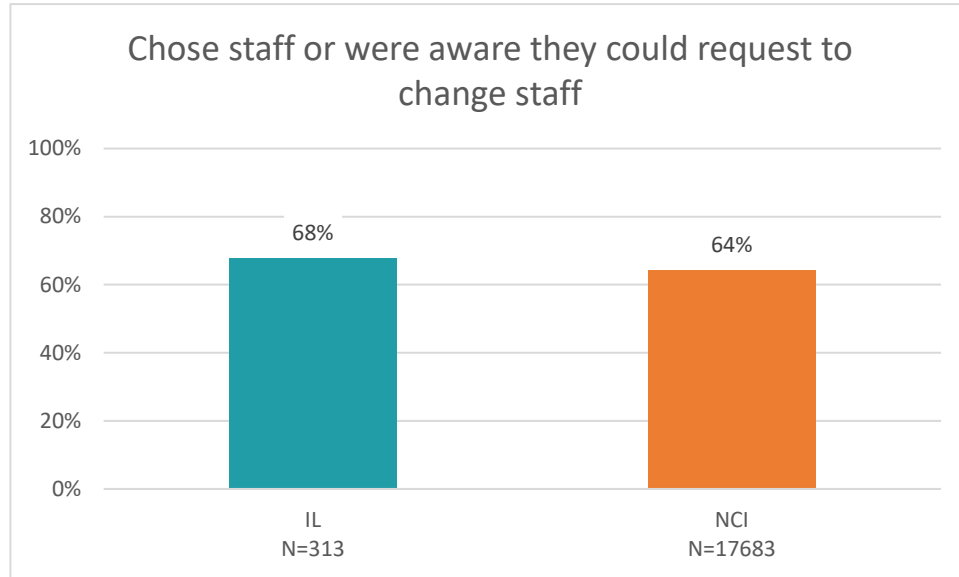
[Chart 3.](#) Chose or had some help in choosing where they work (proxy respondents were allowed for this question)



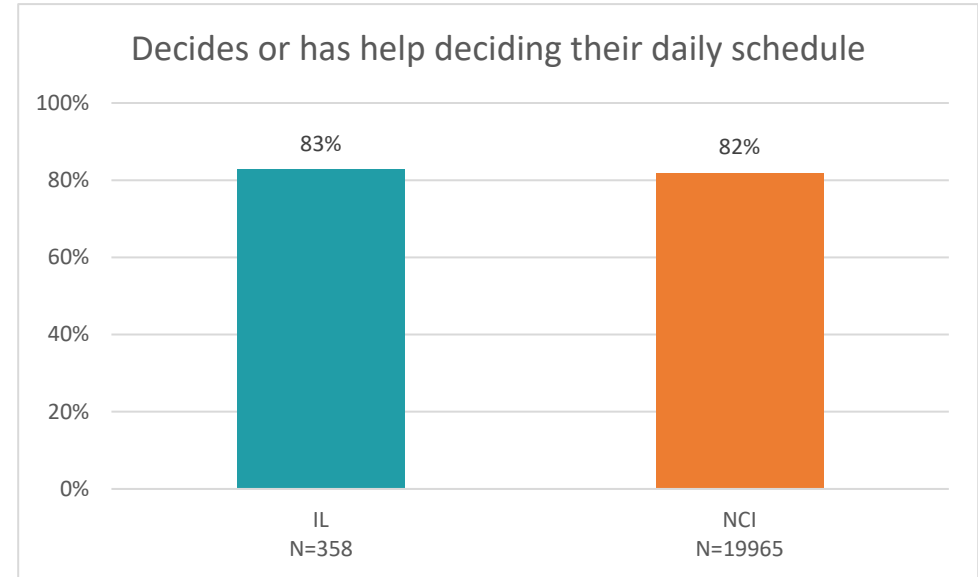
[Chart 4.](#) Chose or had some input in choosing where they go during the day (proxy respondents were allowed for this question)



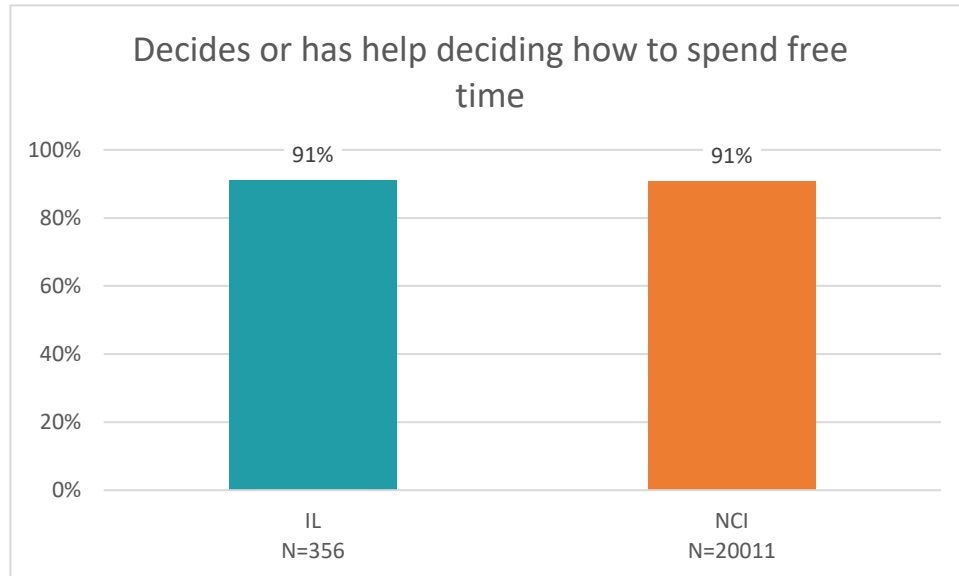
[Chart 5.](#) Chose staff or were aware they could request to change staff (proxy respondents were allowed for this question)



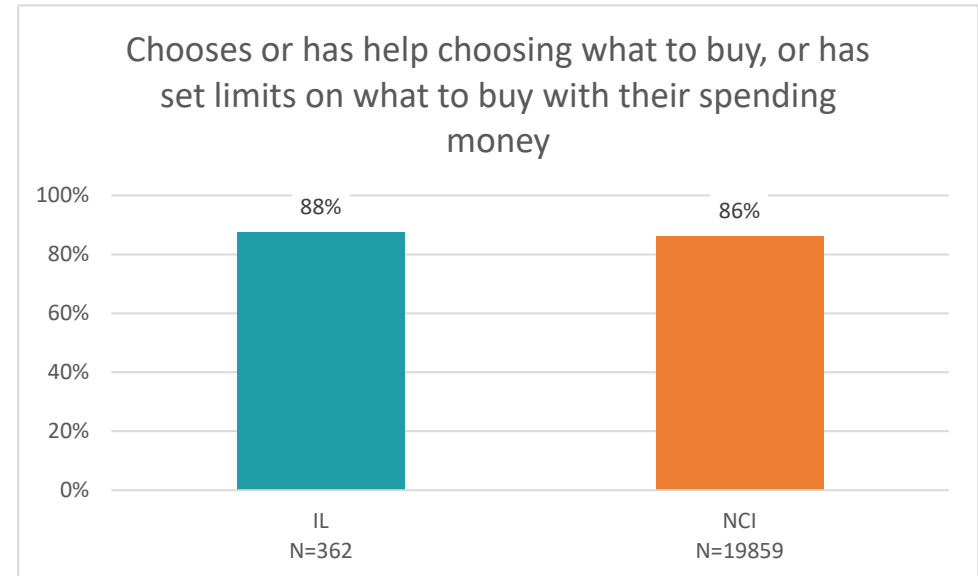
[Chart 6.](#) Decides or has help deciding their daily schedule (proxy respondents were allowed for this question)



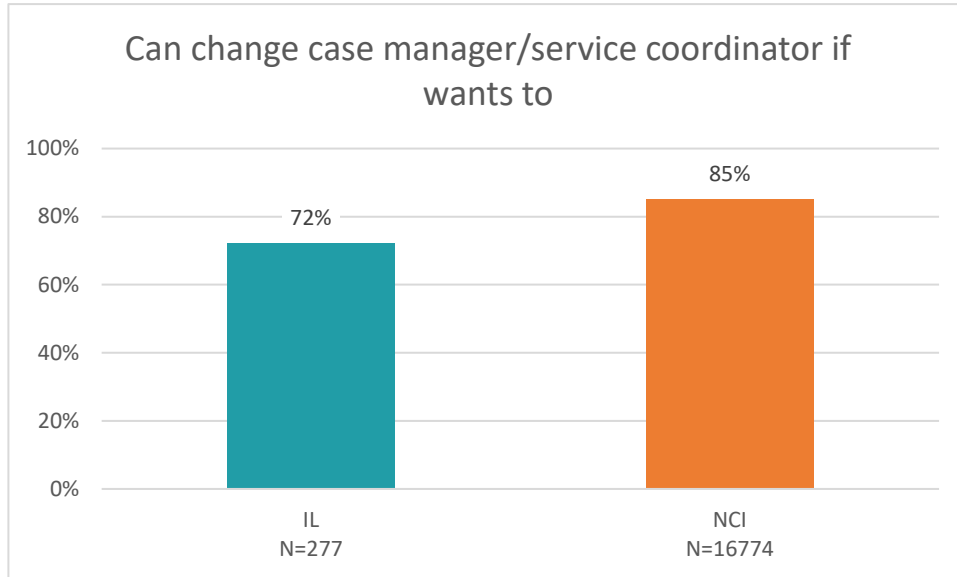
[Chart 7.](#) Chooses or has help deciding how to spend free time (proxy respondents were allowed for this question)



[Chart 8.](#) Chooses or has help 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 25. 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>	IL	55%	170
	NCI	53%	11,404
Chose or had some input in choosing their housemates <i>or chose to live alone (if not living in the family home; proxy respondents were allowed for this question)</i>	IL	42%	175
	NCI	41%	11,342
Chose or had some help in choosing where they work <i>(proxy respondents were allowed for this question)</i>	IL	94%	31
	NCI	86%	3,310
Chose or had some input in choosing where they go during the day <i>(proxy respondents were allowed for this question)</i>	IL	68%	292
	NCI	62%	14,189
Chose staff or were aware they could request to change staff <i>(proxy respondents were allowed for this question)</i>	IL	68%	313
	NCI	64%	17,683
Decides or has help deciding their daily schedule <i>(proxy respondents were allowed for this question)</i>	IL	83%	358
	NCI	82%	19,965
Decides or has help deciding how to spend free time <i>(proxy respondents were allowed for this question)</i>	IL	91%	356
	NCI	91%	20,011
Chooses or has help 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>	IL	88%	362
	NCI	86%	19,859
Can change case manager/service coordinator if wants to <i>(proxy respondents were allowed for this question)</i>	IL	72%	277
	NCI	85%	16,774

## Work

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

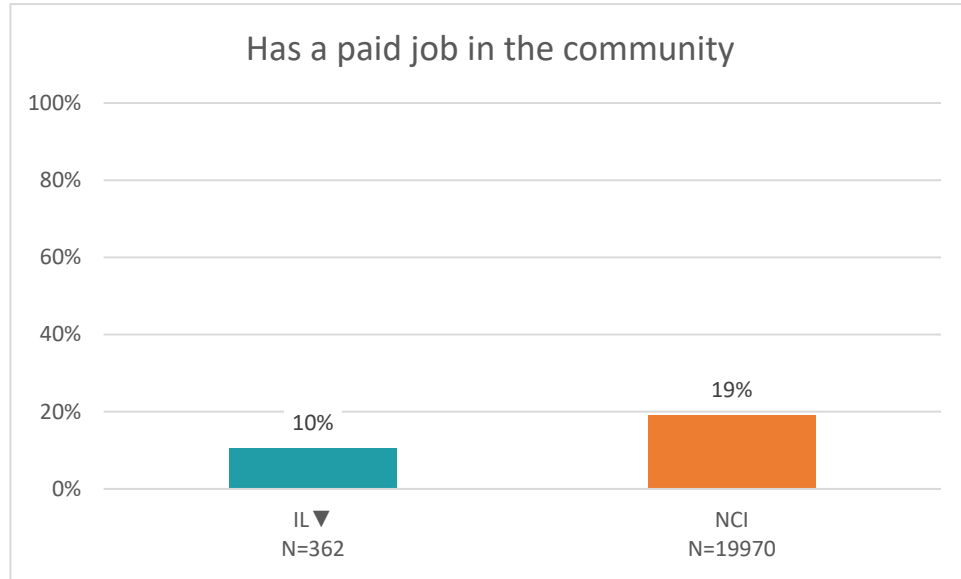
### **NCI reports on three types of community jobs:**

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; and
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.

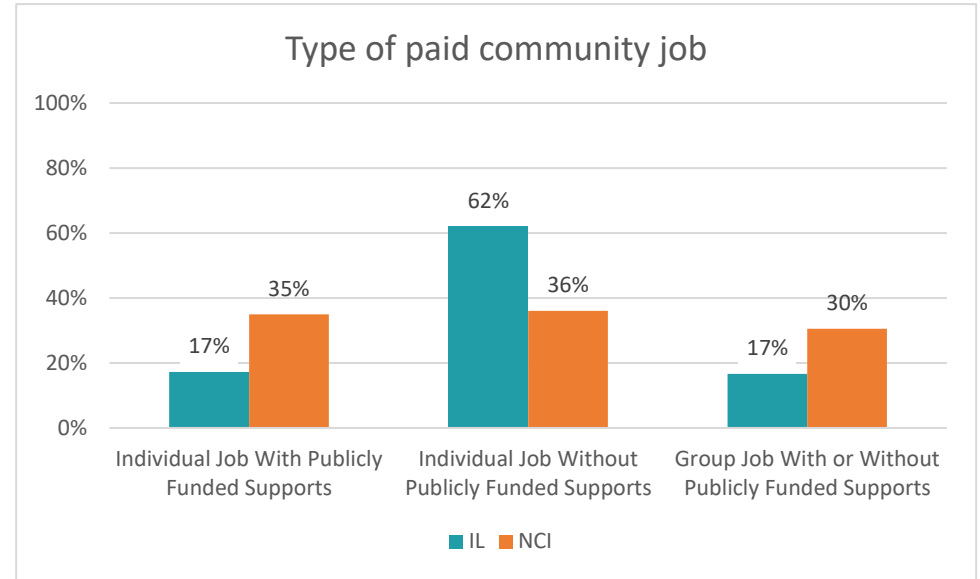
For several states, survey items pertaining to paid community employment had a large amount of missing data or data recorded as “don’t know.” Items that include states results for which 25% or more of their sample were missing data (or reported as “don’t know”) are indicated with an asterisk (\*).

*Charts for Work*

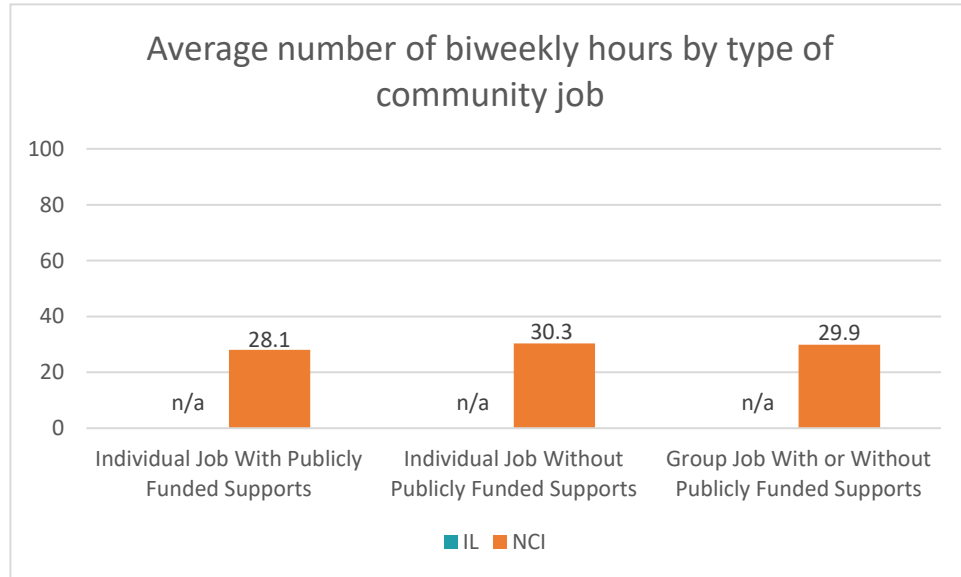
**Chart 10.** Has a paid job in the community (information may have been obtained through state records)



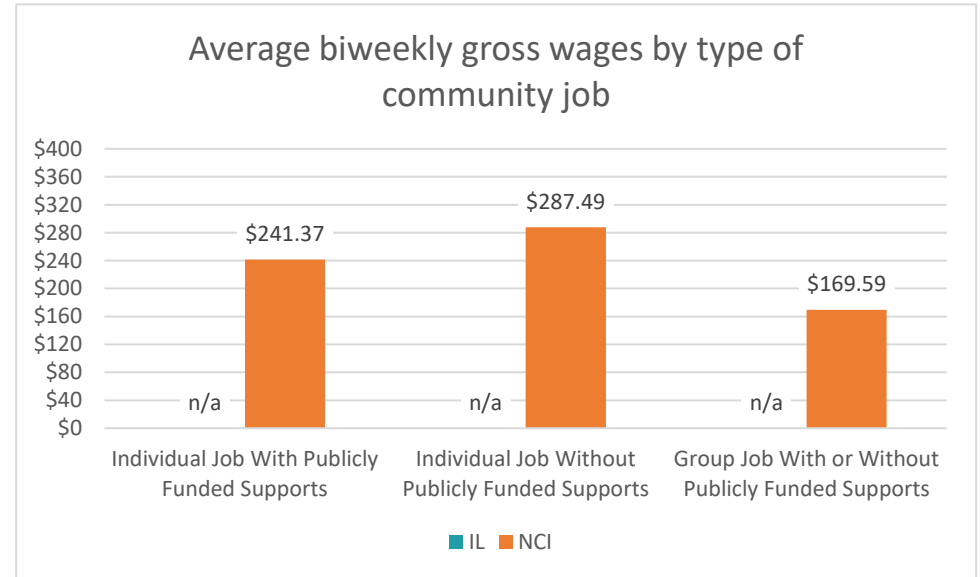
**Chart 11.** Type of paid community job (information may have been obtained through state records)



**Chart 12.** Average number of biweekly hours by type of community job (information may have been obtained through state records)



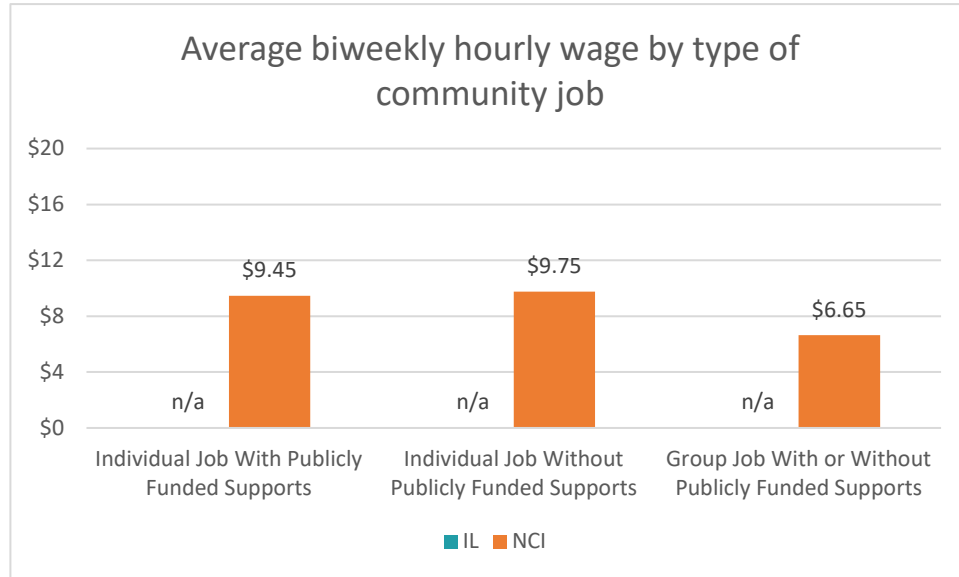
**Chart 13.** Average biweekly gross wages by type of community job (information may have been obtained through state records)



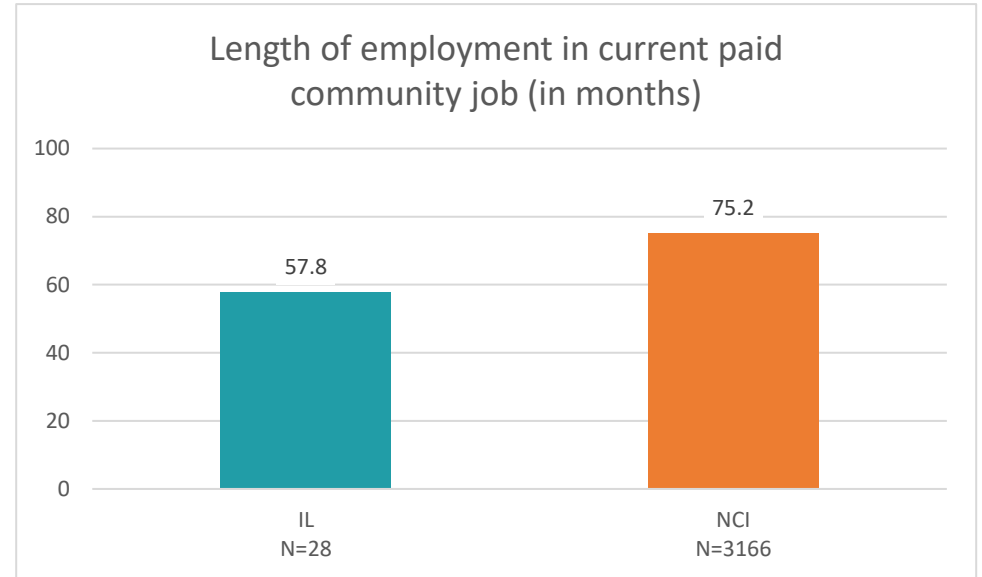
\*N's are not shown as they vary by type of paid community employment



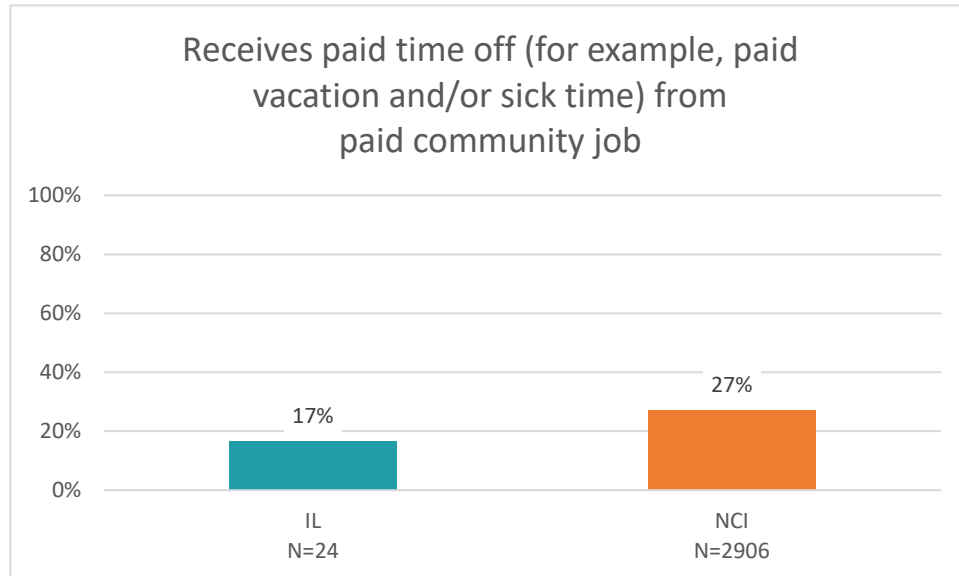
[Chart 14.](#) Average biweekly hourly wage by type of community job (information may have been obtained through state records)



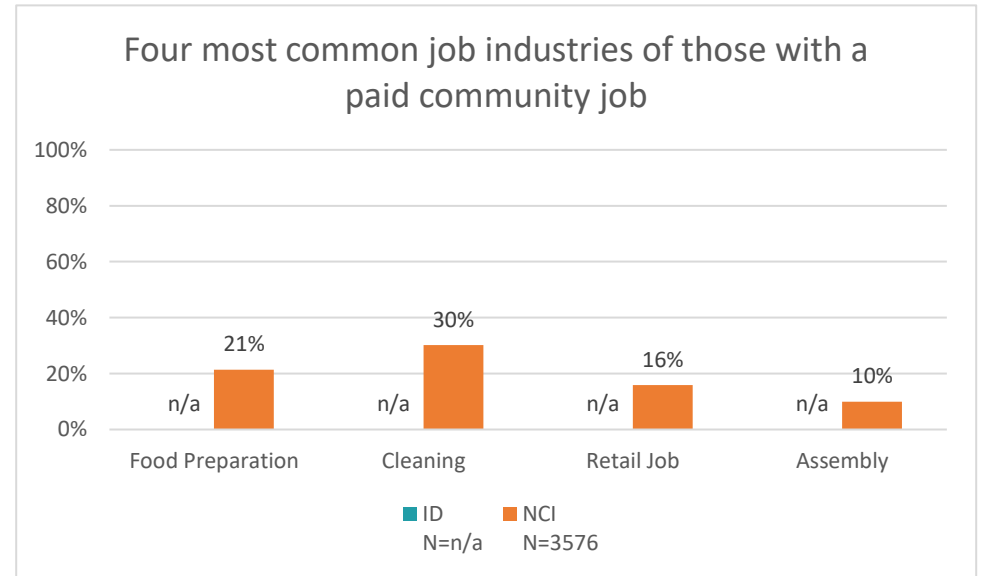
[Chart 15.](#) Length of employment in current paid community job (in months; information may have been obtained through state records)



[Chart 16.](#) Receives paid time off (for example, paid vacation and/or sick time) from paid community job (information may have been obtained through state records)

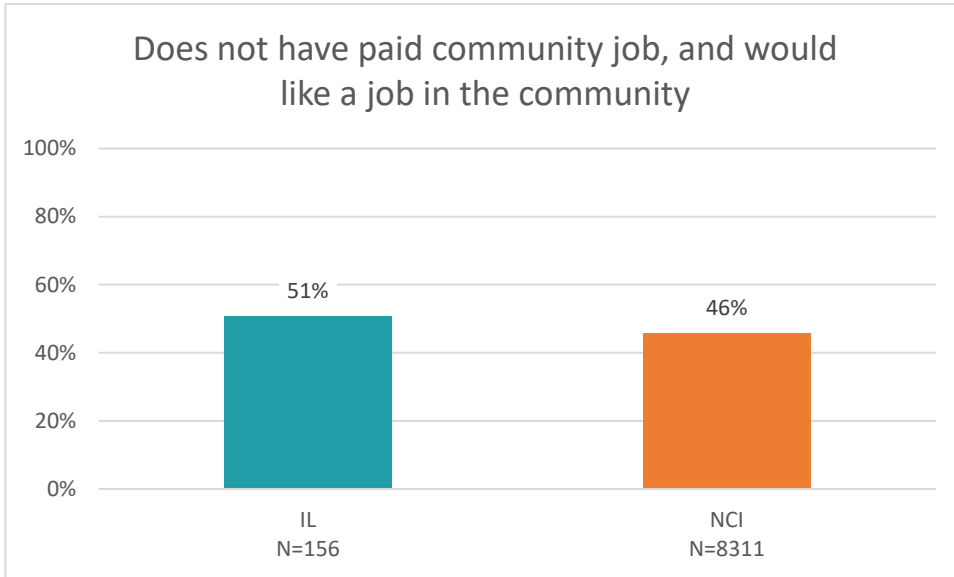


[Chart 17.](#) Four most common job industries of those with a paid community job (information may have been obtained through state records) ∞

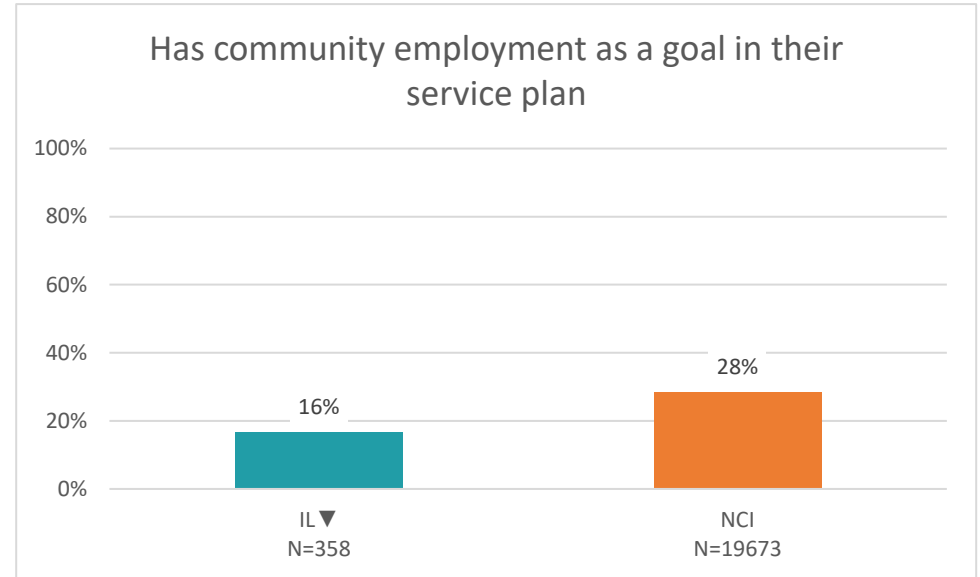


∞Categories are not mutually exclusive

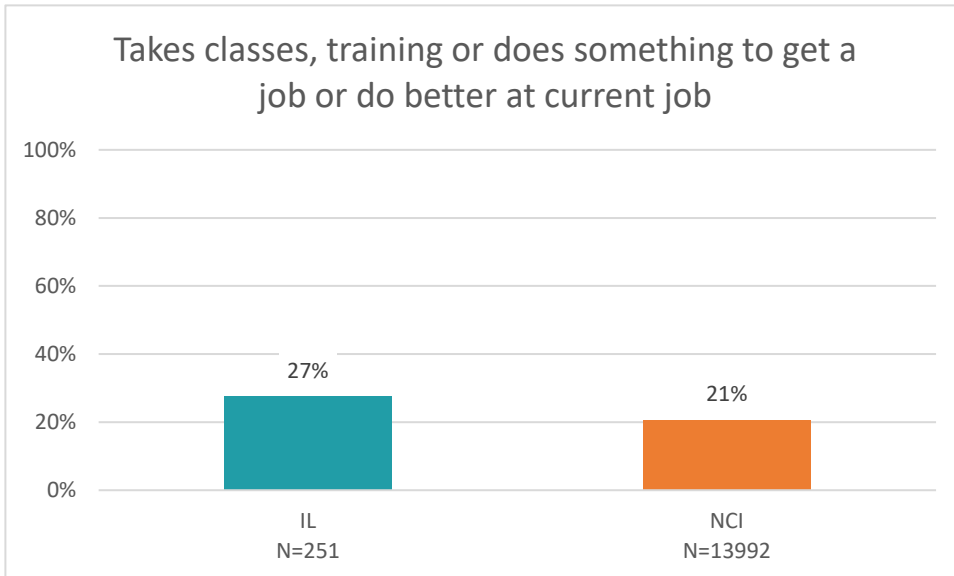
[Chart 18.](#) Does not have paid community job, and would like a job in the community



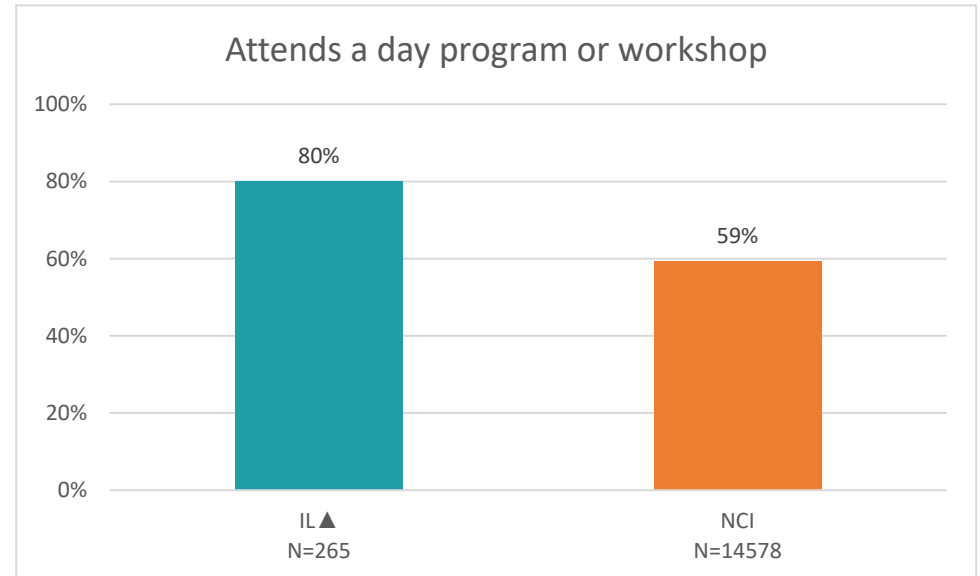
[Chart 19.](#) Has community employment as a goal in their service plan (information may have been obtained through state records)



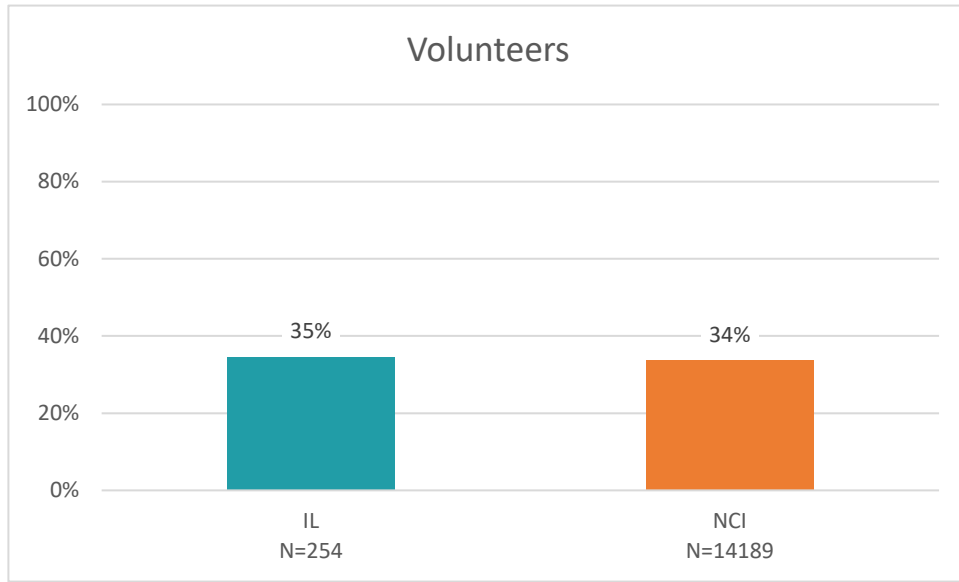
[Chart 20.](#) Takes classes, training or does something to get a job or do better at current job



[Chart 21.](#) Attends a day program or workshop



[Chart 22.](#) Volunteers



*Tables for Work*

**Table 26. Has paid community job (information may have been obtained through state records) \***

	Yes	N
IL ▼	10%	362
NCI	19%	19,970

**Table 27. Type of paid community job (information may have been obtained through state records)**

	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
IL	17%	62%	29	17%	36
NCI	35%	36%	3,353	30%	3,566

**Table 28. Hours and wages by type of paid community job**

		Individual Job With Publicly Funded Supports	Individual Job Without Publicly Funded Supports	Group Job With or Without Publicly Funded Supports
Average number of biweekly hours by type of community job (information may have been obtained through state records) *	IL	n/a	n/a	n/a
	NCI	28.1	30.3	29.9
Average biweekly gross wages by type of community job (information may have been obtained through state records) *	IL	n/a	n/a	n/a
	NCI	\$241.37	\$287.49	\$169.59
Average biweekly hourly wage by type of community job (information may have been obtained through state records) *	IL	n/a	n/a	n/a
	NCI	\$9.45	\$9.75	\$6.65

**Table 29. Length of employment at current job, in months (information may have been obtained through state records) \***

	Average Months	N
IL	57.8	28
NCI	75.2	3,166

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

**Table 30. Receives paid time off (for example, paid vacation and/or sick time) at paid community job  
(information may have been obtained through state records) \***

	Yes	N
IL	17%	24
NCI	27%	2,906

**Table 31. Most common types of jobs among those with a paid community job  
(information may have been obtained through state records) ∞**

	Food Preparation	Cleaning	Retail Job	Assembly	N
IL	27%	19%	16%	8%	37
NCI	21%	30%	16%	10%	3,576

**Table 32. Employment goals and other daily activities**

		Yes	N
Does not have paid community job, and would like a job in the community	IL	51%	156
	NCI	46%	8,311
Has community employment as a goal in their service plan (information may have been obtained through state records) *	IL ▼	16%	358
	NCI	28%	19,673
Takes classes, training or does something to get a job or do better at current job	IL	27%	251
	NCI	21%	13,992
Attends a day program or workshop	IL ▲	80%	265
	NCI	59%	14,578
Volunteers	IL	35%	254
	NCI	34%	14,189

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

∞Categories are not mutually exclusive

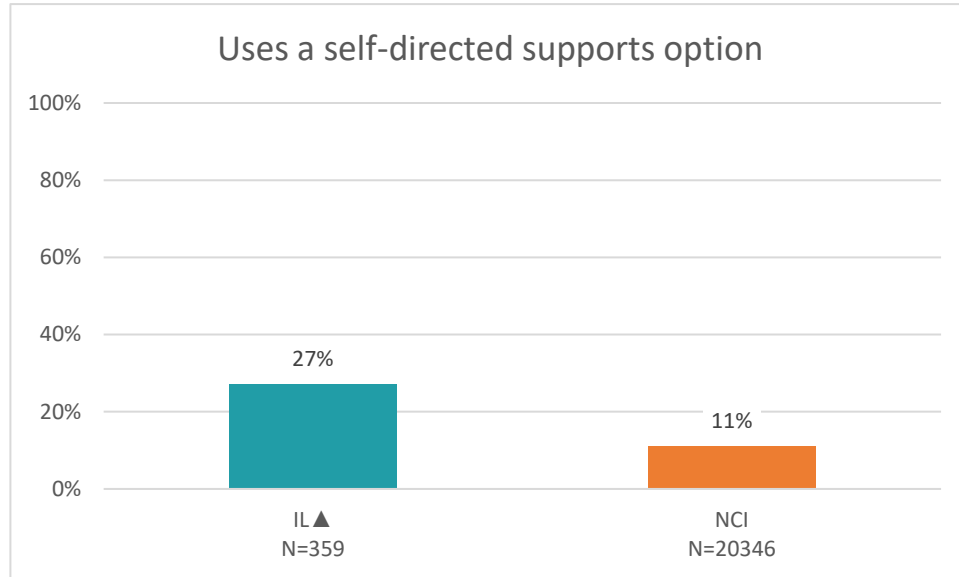
## *Self-Determination*

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

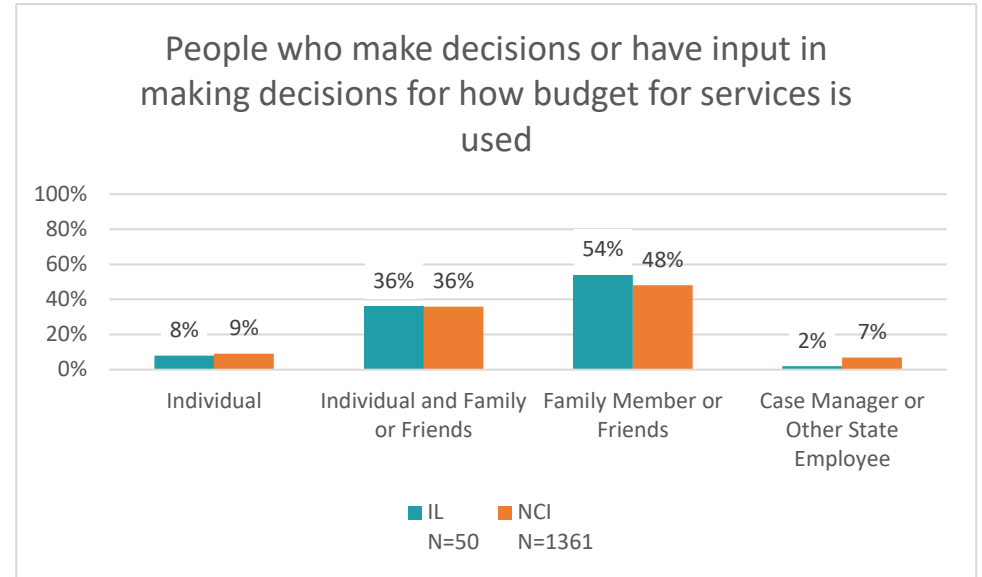
*Charts for Self-Determination*



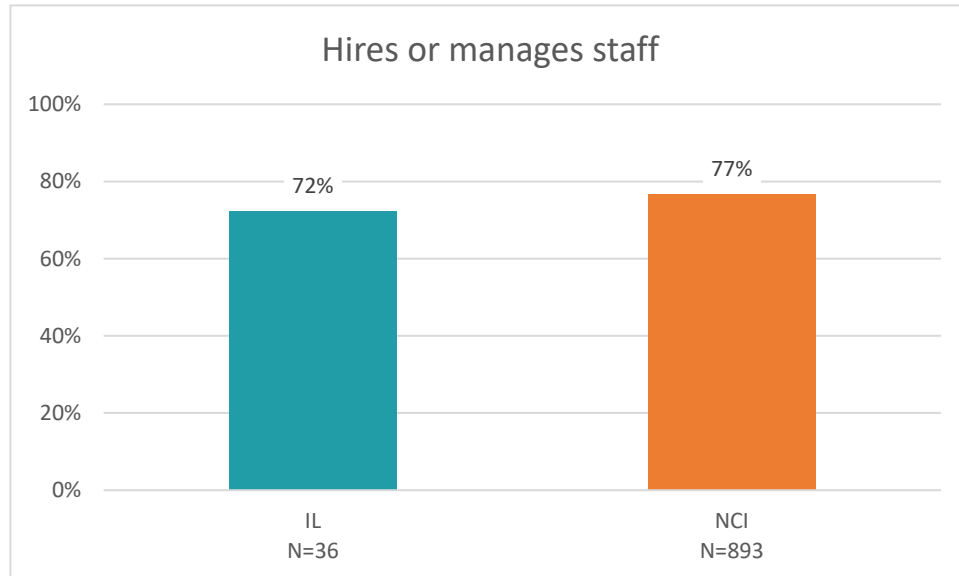
[Chart 23.](#) Uses a self-directed supports option (information may have been obtained through state records)



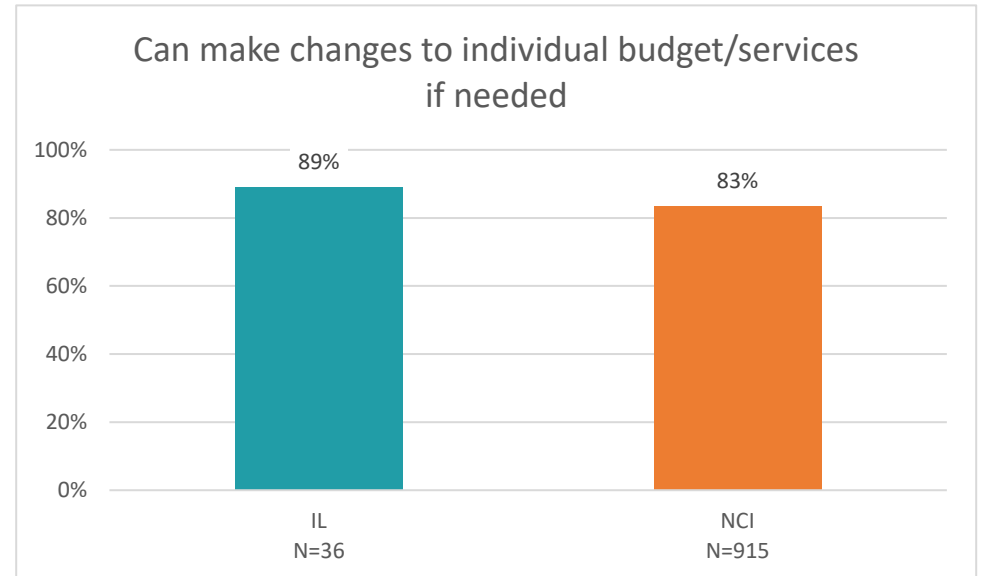
[Chart 24.](#) People who make decisions or have input in making decisions for how budget for services is used (proxy respondents were allowed for this question)



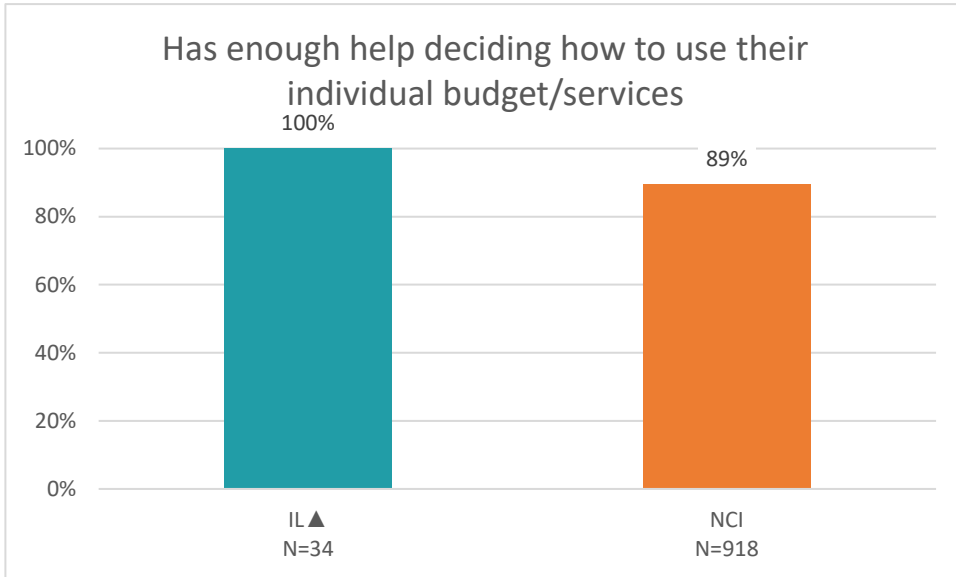
[Chart 25.](#) Hires or manages staff (proxy respondents were allowed for this question)



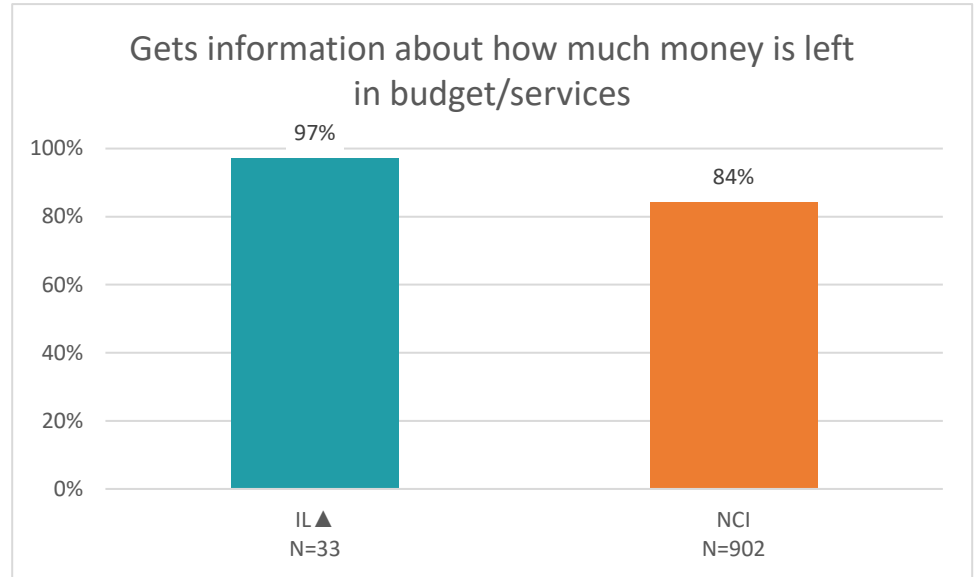
[Chart 26.](#) Can make changes to individual budget/services if needed (proxy respondents were allowed for this question)



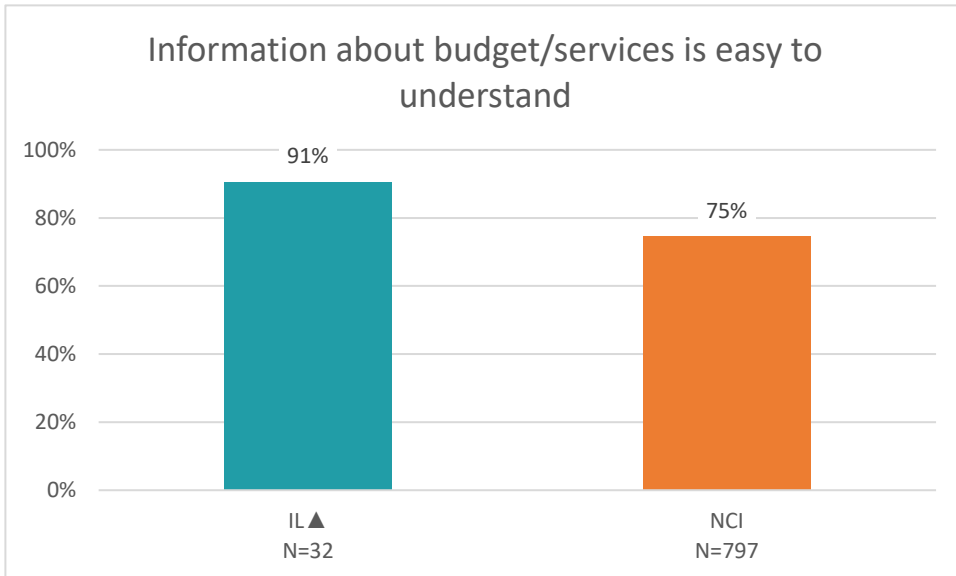
[Chart 27.](#) Has enough help deciding how to use their individual budget/services (proxy respondents were allowed for this question)



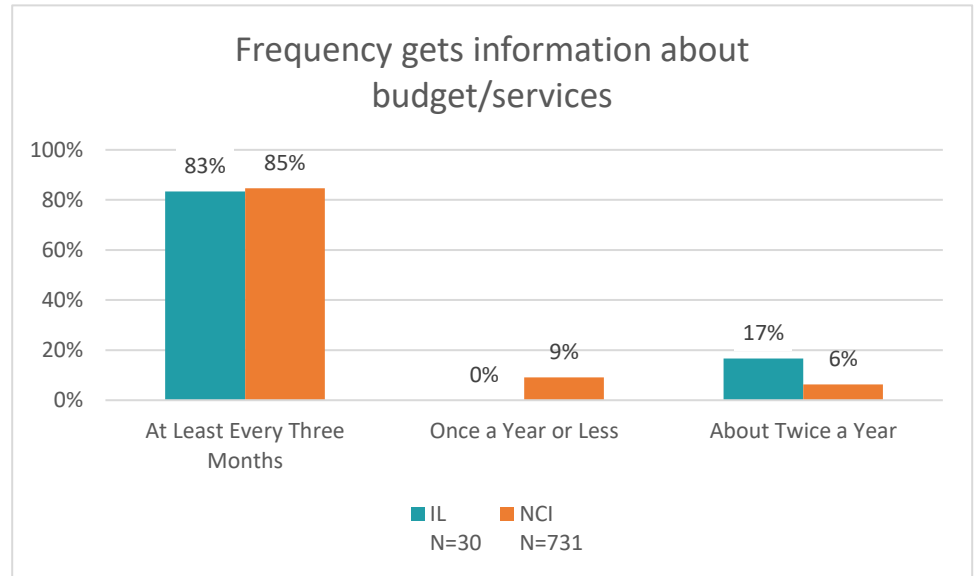
[Chart 28.](#) Gets information about how much money is left in budget/services (proxy respondents were allowed for this question)



[Chart 29.](#) Information about budget/services is easy to understand (proxy respondents were allowed for this question)



[Chart 30.](#) Frequency gets information about budget/services (proxy respondents were allowed for this question) <sup>o</sup>



<sup>o</sup>New question in 2016-17

*Tables for Self-Determination*

**Table 33. Uses self-directed services option (information may have been obtained through state records)**

	Yes	N
IL ▲	27%	359
NCI	11%	20,346

**Table 34. People who make decisions about how to use budget/services (proxy respondents were allowed for this question)**

	Individual	Individual and Family or Friends	Family Member or Friends	Case Manager or Other State Employee	N
IL	8%	36%	54%	2%	50
NCI	9%	36%	48%	7%	1,361

**Table 35. Self-direction**

		Yes	N
Hires or manages staff (proxy respondents were allowed for this question)	IL	72%	36
	NCI	77%	893
Can make changes to individual budget/services if needed (proxy respondents were allowed for this question)	IL	89%	36
	NCI	83%	915
Has enough help deciding how to use their individual budget/services (proxy respondents were allowed for this question)	IL ▲	100%	34
	NCI	89%	918
Gets information about how much money is left in budget/services (proxy respondents were allowed for this question)	IL ▲	97%	33
	NCI	84%	902
Information about budget/services is easy to understand (proxy respondents were allowed for this question)	IL ▲	91%	32
	NCI	75%	797

**Table 36. Frequency gets information about how much money is left in budget/services, among those who receive information (proxy respondents were allowed for this question)**

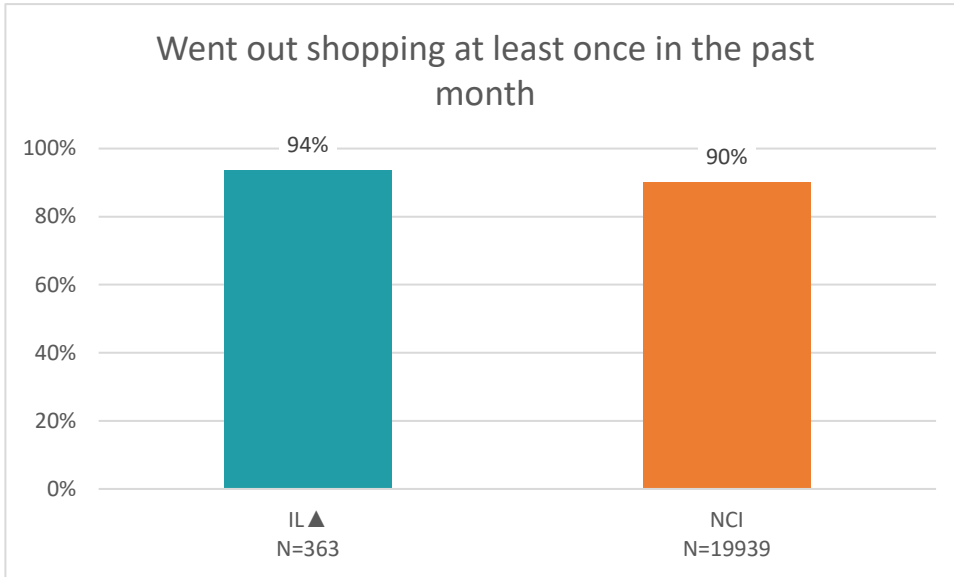
	At Least Every Three Months	Once a Year or Less	About Twice a Year	N
IL	83%	0%	17%	30
NCI	85%	9%	6%	731

## *Community Inclusion, Participation and Leisure*

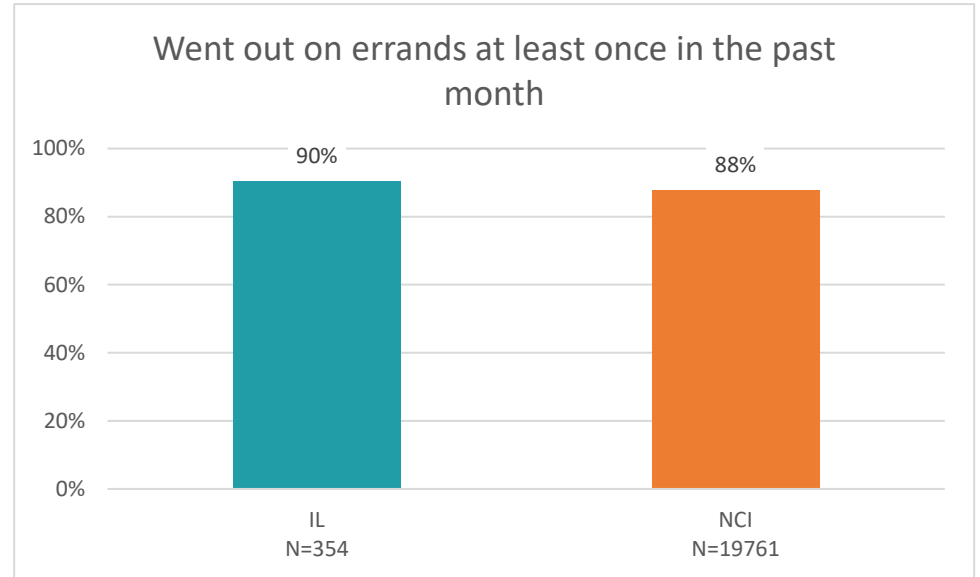
*People have support to participate in everyday community activities.*

*Charts for Community Inclusion, Participation and Leisure*

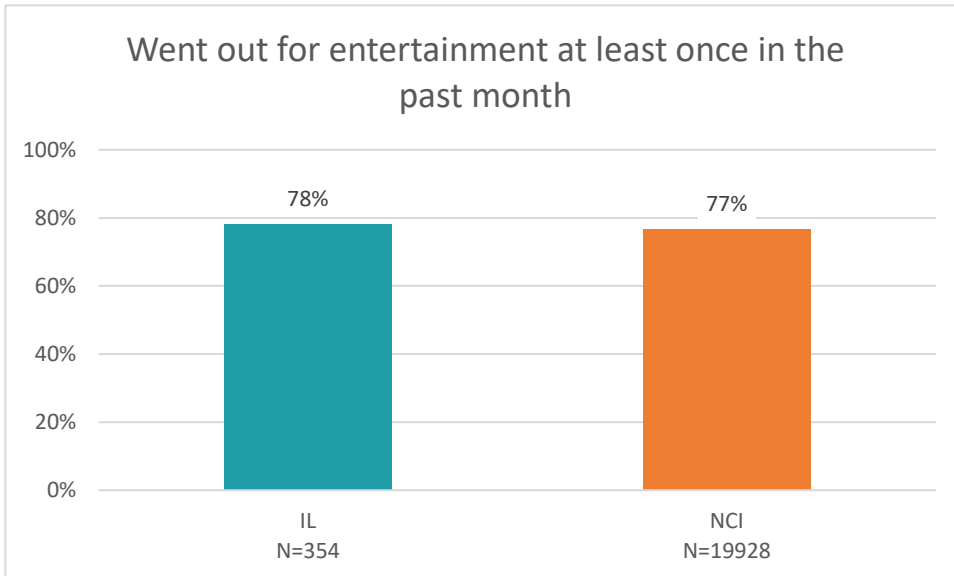
[Chart 31.](#) Went out shopping at least once in the past month (proxy respondents were allowed for this question)



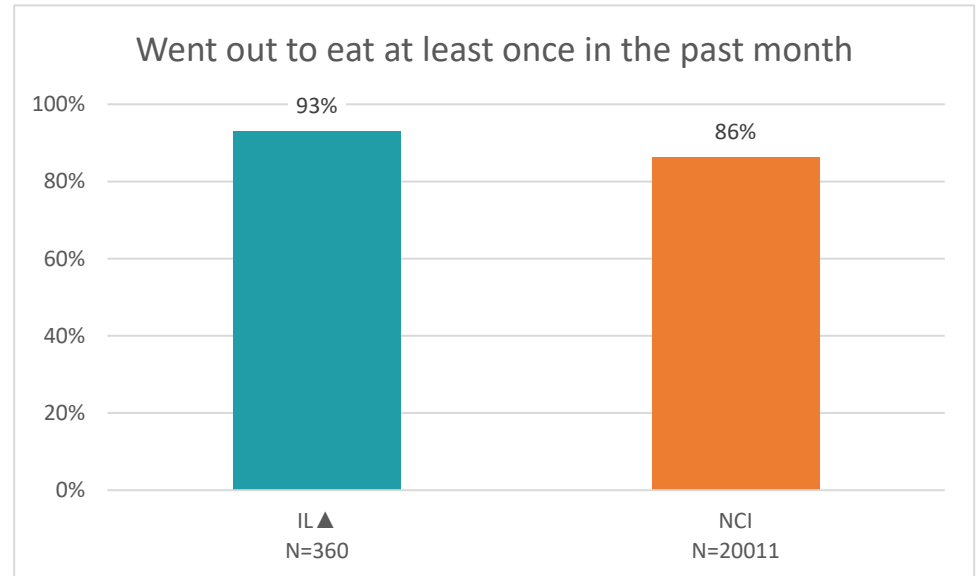
[Chart 32.](#) Went out on errands at least once in the past month (proxy respondents were allowed for this question)



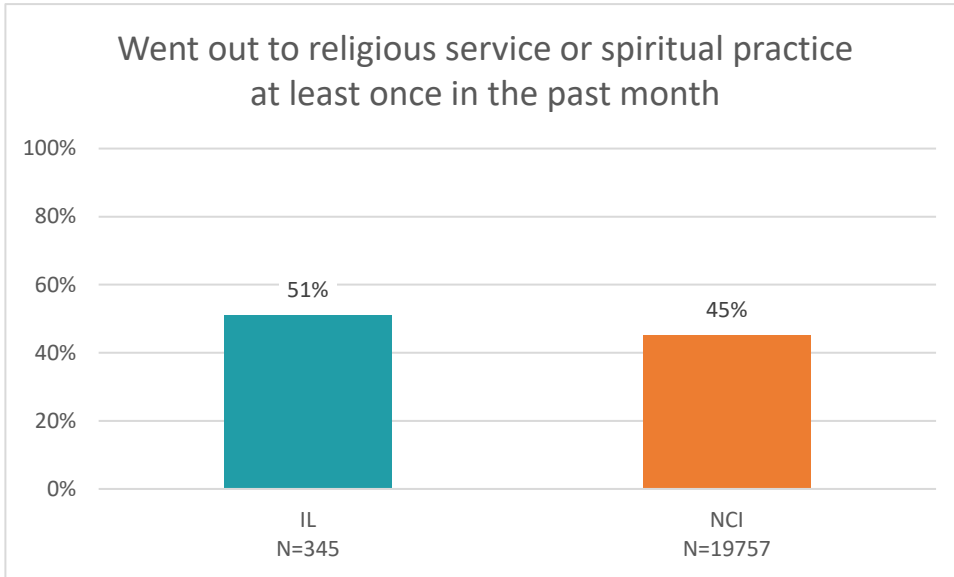
[Chart 33.](#) Went out for entertainment at least once in the past month (proxy respondents were allowed for this question)



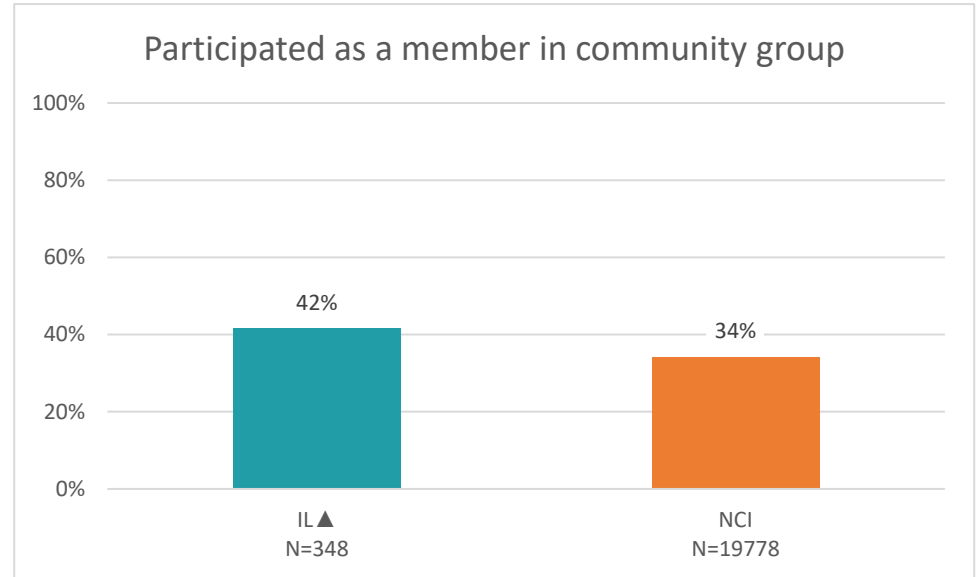
[Chart 34.](#) Went out to eat at least once in the past month (proxy respondents were allowed for this question)



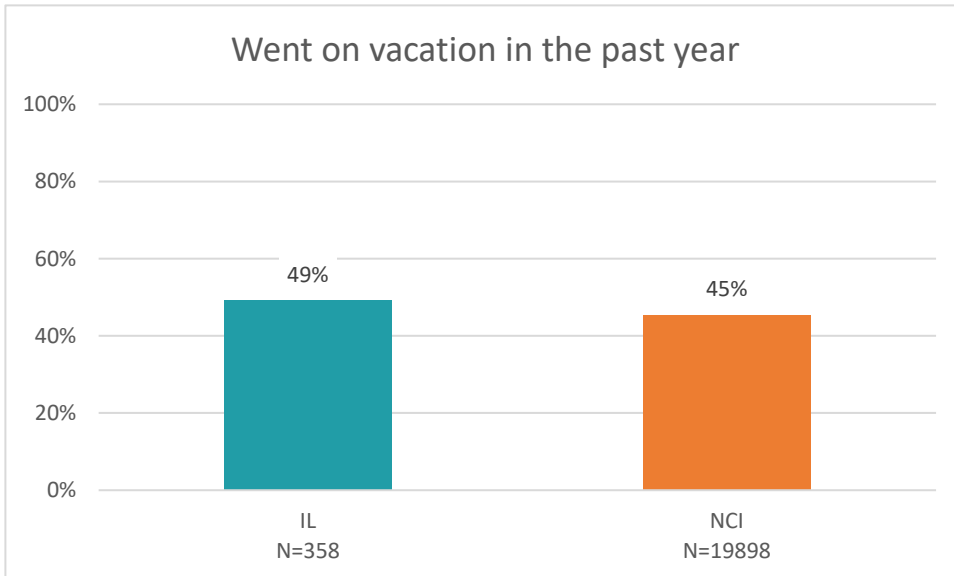
[Chart 35.](#) Went out to religious service or spiritual practice at least once in the past month (proxy respondents were allowed for this question)



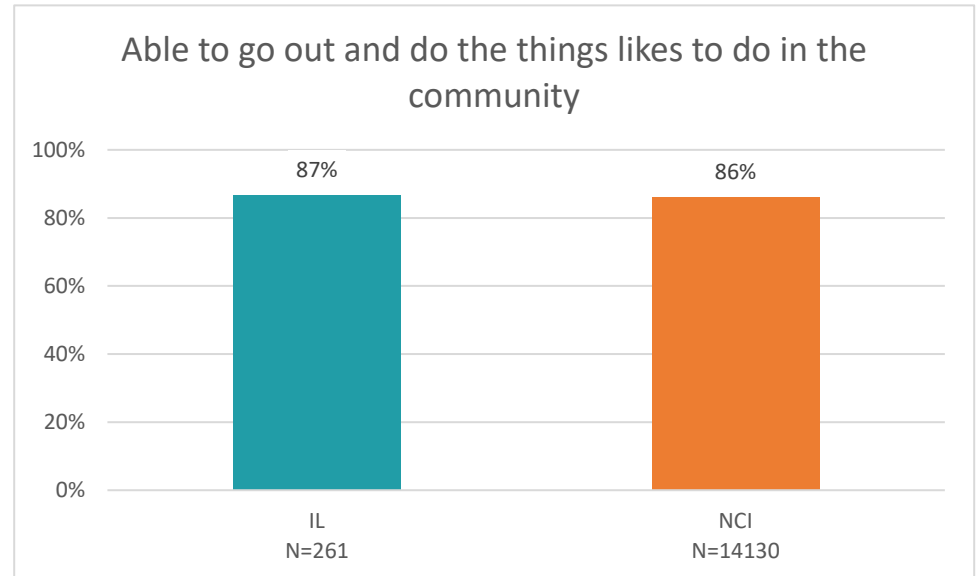
[Chart 36.](#) Participated as a member in community group (proxy respondents were allowed for this question)



[Chart 37.](#) Went on vacation in the past year (proxy respondents were allowed for this question)

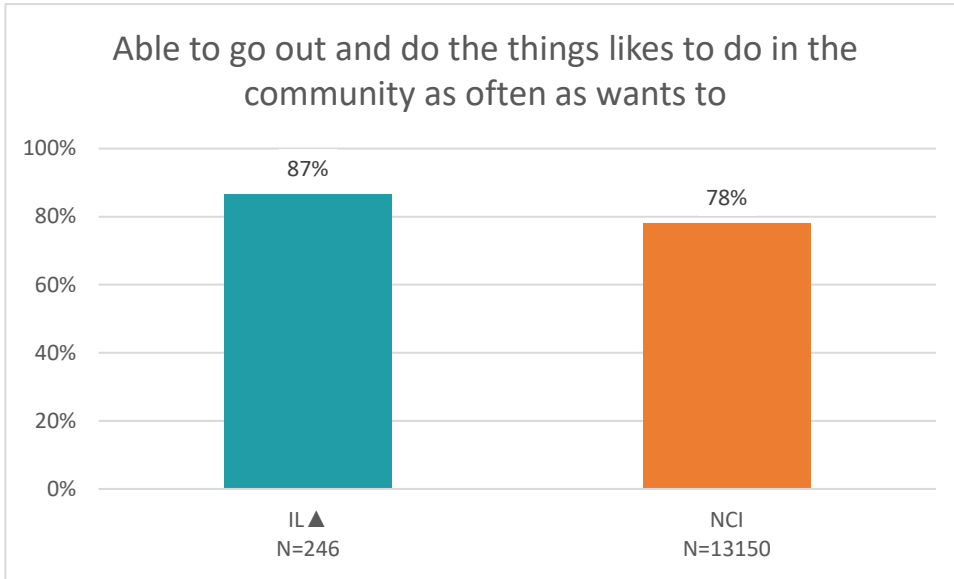


[Chart 38.](#) Able to go out and do the things likes to do in the community

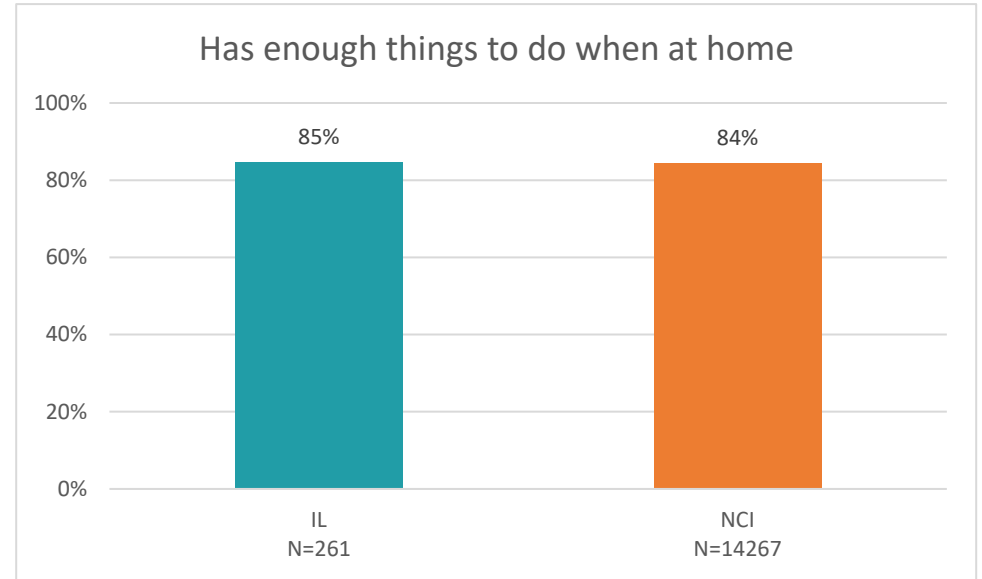




[Chart 39.](#) Able to go out and do the things likes to do in the community as often as wants to



[Chart 40.](#) Has enough things to do when at home



*Tables for Community Inclusion, Participation, and Leisure*

**Table 37. Community Inclusion, Participation, and Leisure**

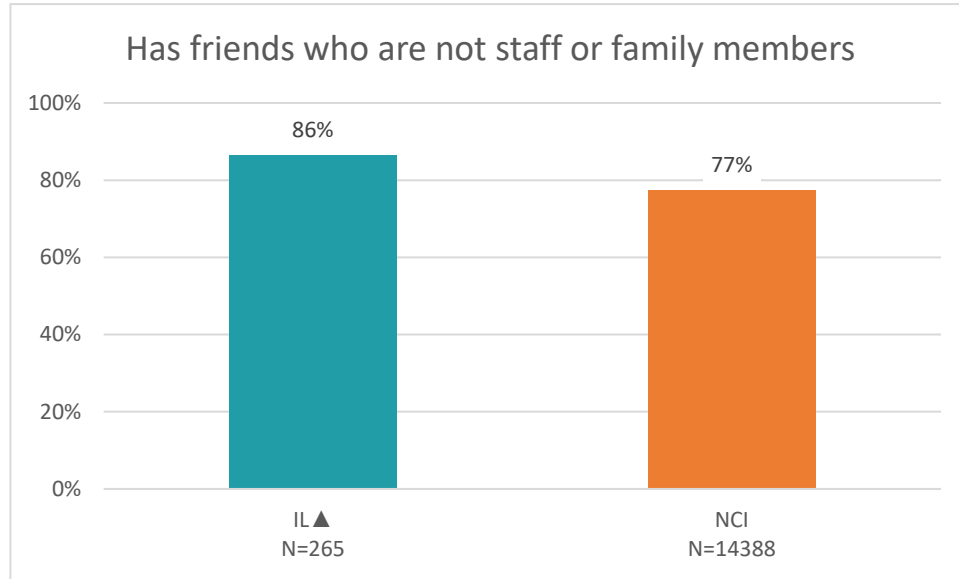
		Yes	N
Went out shopping at least once in the past month <i>(proxy respondents were allowed for this question)</i>	IL▲	94%	363
	NCI	90%	19,939
Went out on errands at least once in the past month <i>(proxy respondents were allowed for this question)</i>	IL	90%	354
	NCI	88%	19,761
Went out for entertainment at least once in the past month <i>(proxy respondents were allowed for this question)</i>	IL	78%	354
	NCI	77%	19,928
Went out to eat at least once in the past month <i>(proxy respondents were allowed for this question)</i>	IL▲	93%	360
	NCI	86%	20,011
Went out to religious service or spiritual practice at least once in the past month <i>(proxy respondents were allowed for this question)</i>	IL	51%	345
	NCI	45%	19,757
Participated as a member in community group <i>(proxy respondents were allowed for this question)</i>	IL▲	42%	348
	NCI	34%	19,778
Went on vacation in the past year <i>(proxy respondents were allowed for this question)</i>	IL	49%	358
	NCI	45%	19,898
Able to go out and do the things likes to do in the community	IL	87%	261
	NCI	86%	14,130
Able to go out and do the things likes to do in the community as often as wants to	IL▲	87%	246
	NCI	78%	13,150
Has enough things to do when at home	IL	85%	261
	NCI	84%	14,267

## *Relationships*

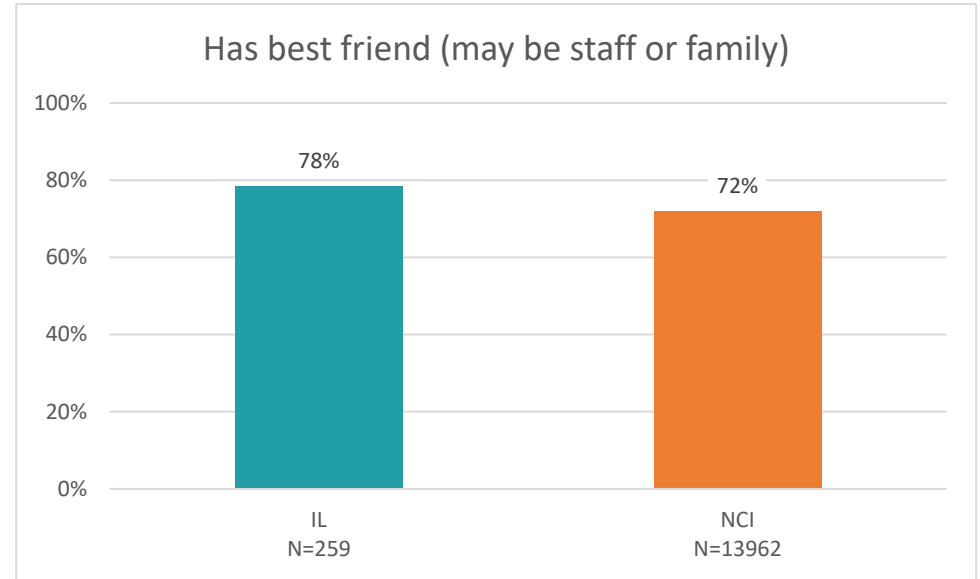
*People have friends and relationships.*

*Charts for Relationships*

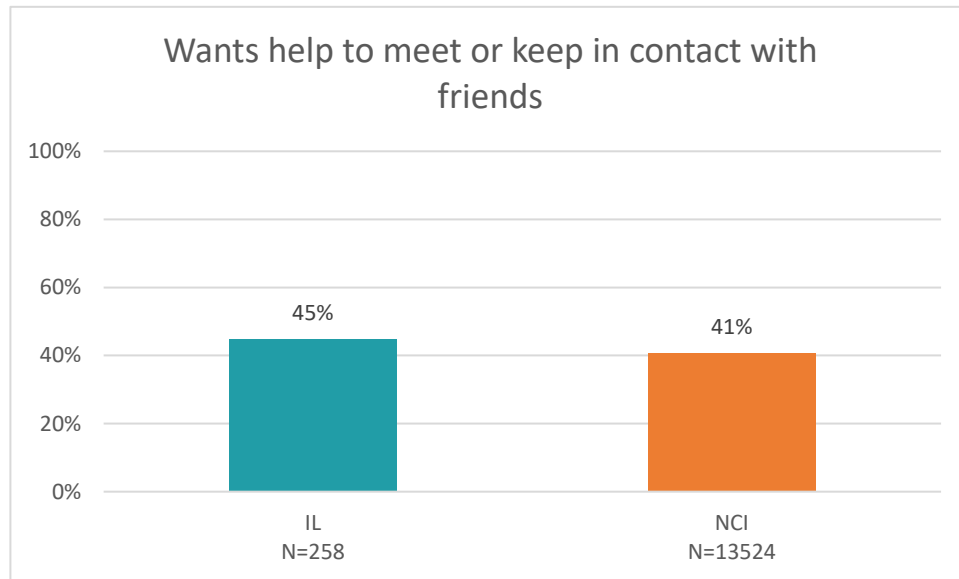
[Chart 41.](#) Has friends who are not staff or family members



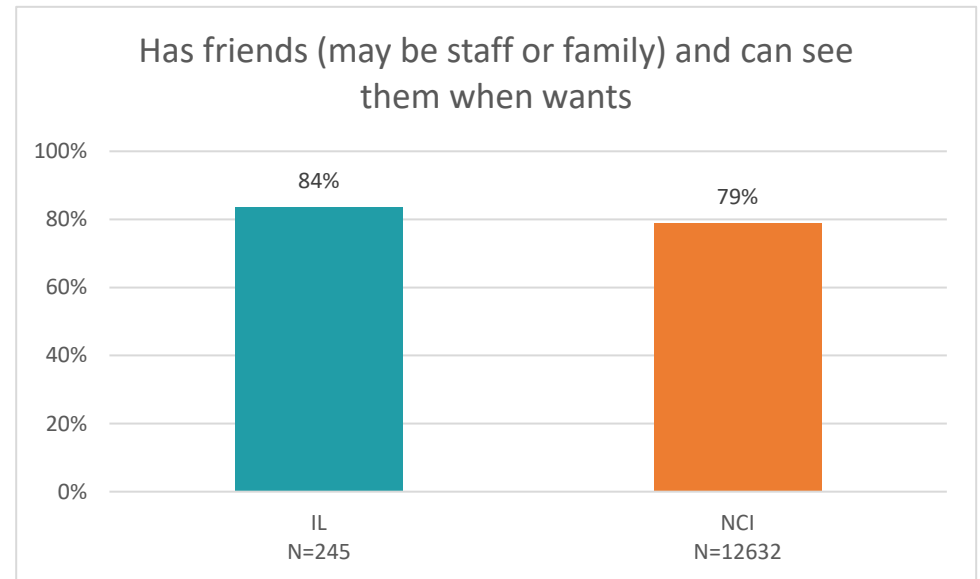
[Chart 42.](#) Has best friend (may be staff or family)  
(This was a new question in 2016-17; item was used in tools prior to 2015-16.)



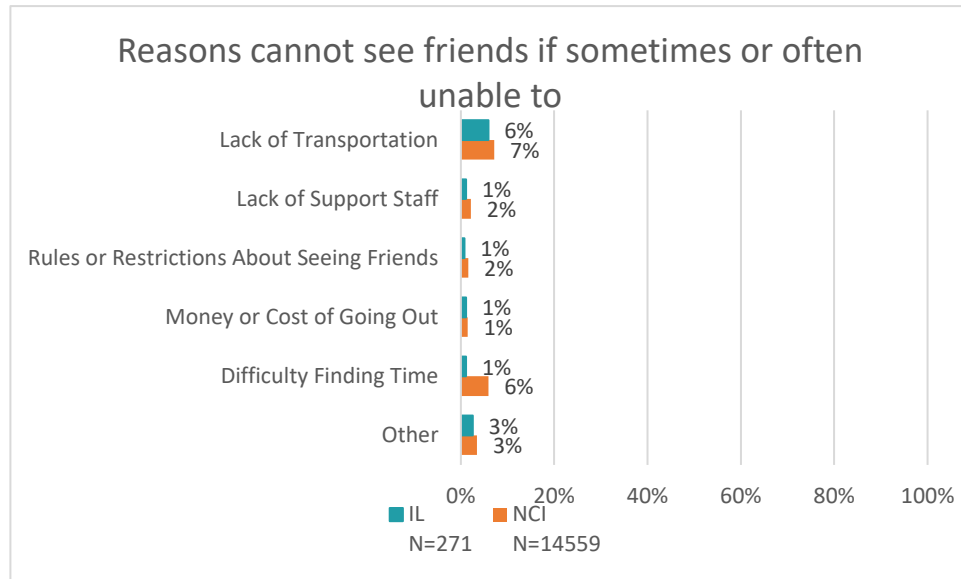
[Chart 43.](#) Wants help to meet or keep in contact with friends



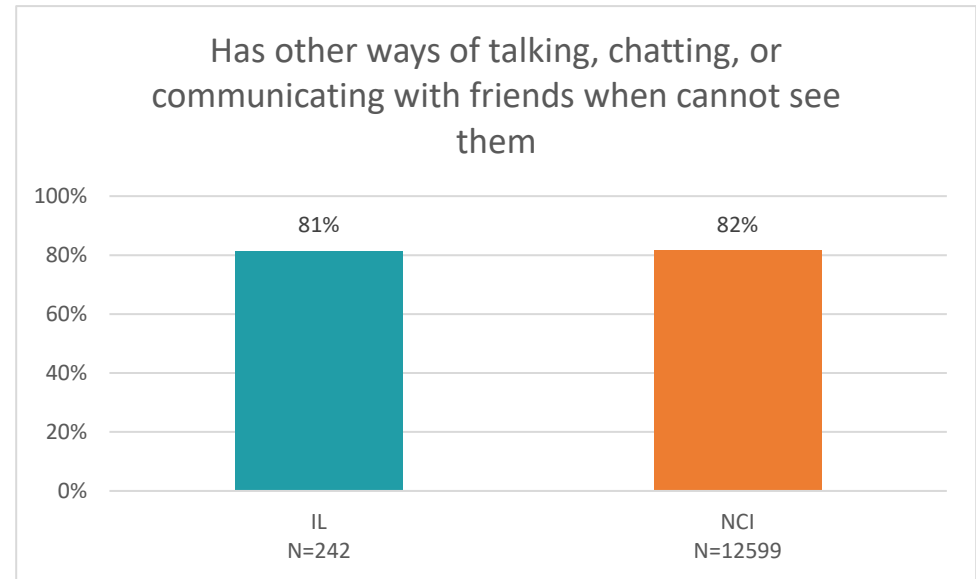
[Chart 44.](#) Has friends (may be staff or family) and can see them when wants



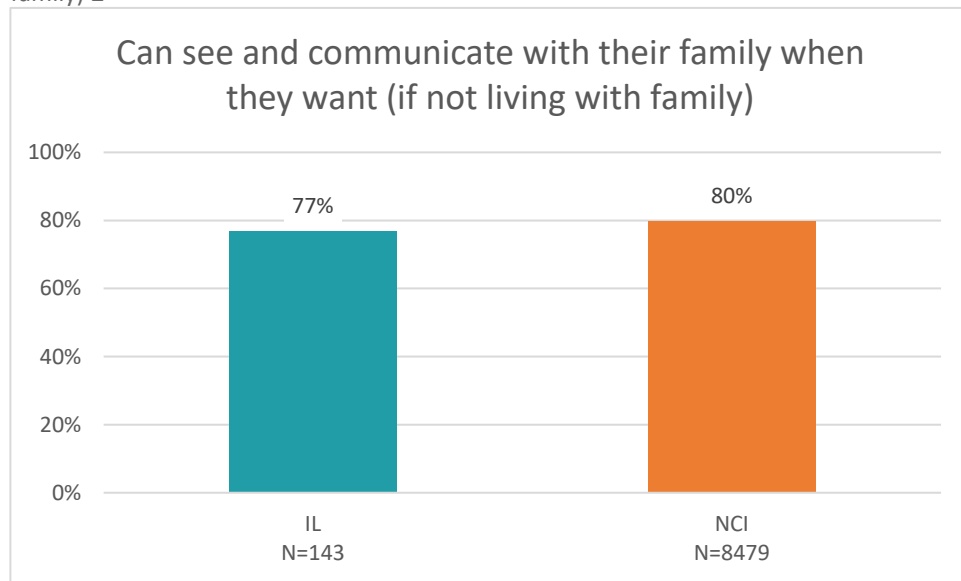
[Chart 45.](#) Reasons cannot see friends if sometimes or often unable to ± ∞



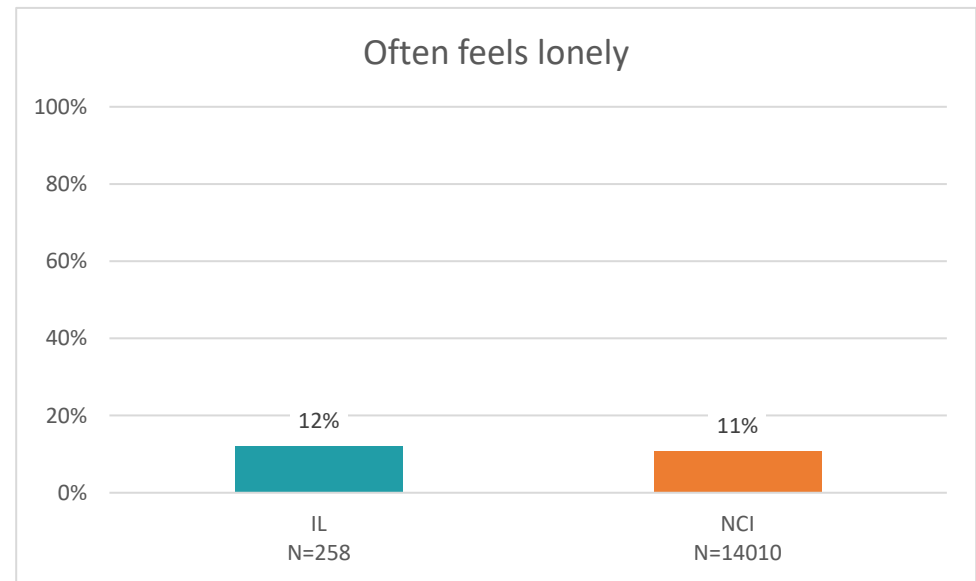
[Chart 46.](#) Has other ways of talking, chatting, or communicating with friends when cannot see them



[Chart 47.](#) Can see and communicate with their family when they want (if not living with family) ±



[Chart 48.](#) Often feels lonely ~

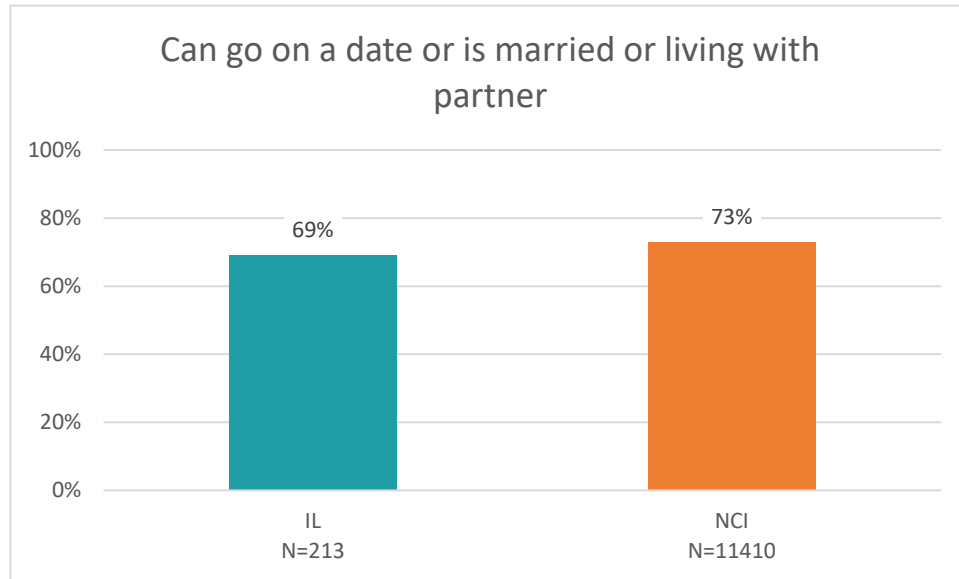


∞ Categories are not mutually exclusive

± Analysis of this question changed from previous years (this may affect overall score and result in a lower N than in previous years)

~ A lower average indicates a lower percentage of people report often feeling lonely

[Chart 49.](#) Can go on a date or is married or living with partner





*Tables for Relationships*

**Table 38. Friendships**

		Yes	N
Has friends who are not staff or family members	IL▲	86%	265
	NCI	77%	14,388
Has best friend <i>(may be staff or family)</i> <sup>9</sup>	IL	78%	259
	NCI	72%	13,962
Wants help to meet or keep in contact with friends	IL	45%	258
	NCI	41%	13,524
Has friends (may be staff or family) and can see them when wants	IL	84%	245
	NCI	79%	12,632

**Table 39. Reasons cannot see friends if sometimes or often unable to <sup>±</sup> <sup>∞</sup>**

			N
Lack of Transportation	IL	6%	271
	NCI	7%	14,559
Lack of Support Staff	IL	1%	271
	NCI	2%	14,559
Rules or Restrictions About Seeing Friends	IL	1%	271
	NCI	2%	14,559
Money or Cost of Going Out	IL	1%	271
	NCI	1%	14,559
Difficulty Finding Time	IL	1%	271
	NCI	6%	14,559
Other	IL	3%	271
	NCI	3%	14,559

<sup>9</sup>New question in 2016-17 (item was used in tools prior to 2015-16)

<sup>±</sup>Analysis of this question changed from previous years (this may affect overall score and result in a lower N than in previous years)

<sup>∞</sup>Categories are not mutually exclusive

**Table 40. Relationships**

		Yes	N
Has other ways of talking, chatting, or communicating with friends when cannot see them	IL	81%	242
	NCI	82%	12,599
Can see and communicate with their family when they want ( <i>if not living with family</i> ) ±	IL	77%	143
	NCI	80%	8,479
Often feels lonely ~	IL	12%	258
	NCI	11%	14,010
Can go on a date or is married or living with partner	IL	69%	213
	NCI	73%	11,410

±Analysis of this question changed from previous years (this may affect overall score and result in a lower N than in previous years)

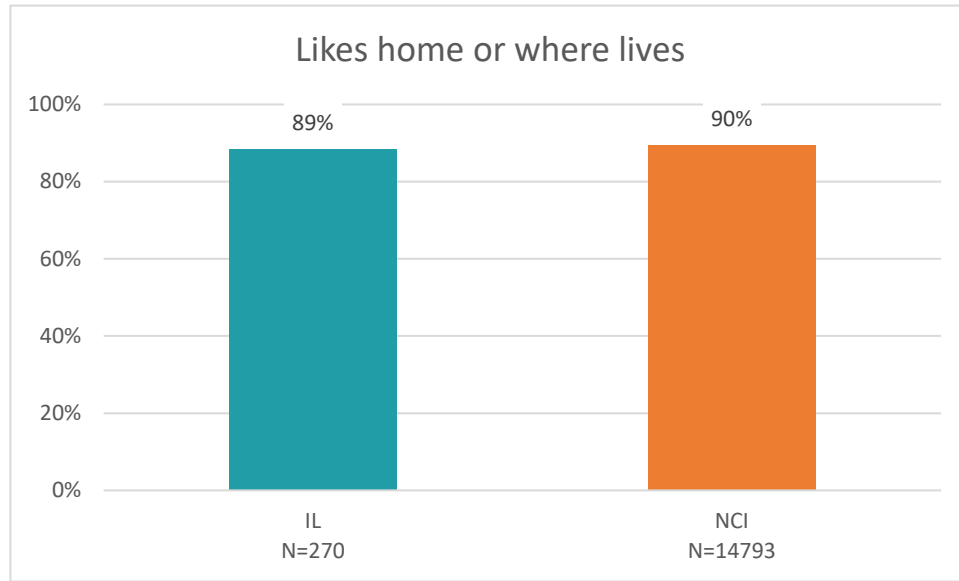
~A lower average indicates a lower percentage of people report often feeling lonely

## *Satisfaction*

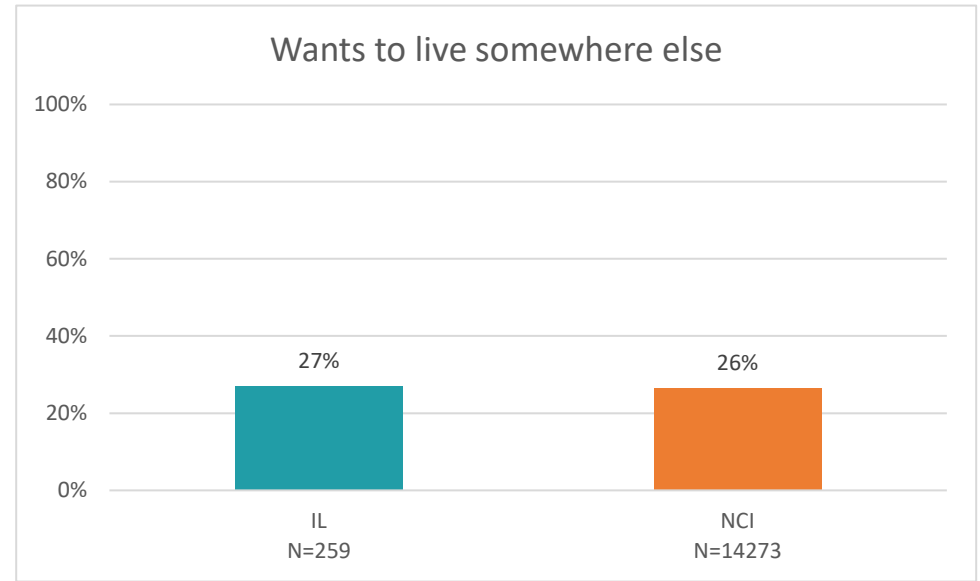
*People are satisfied with the services and supports they receive.*

*Charts for Satisfaction*

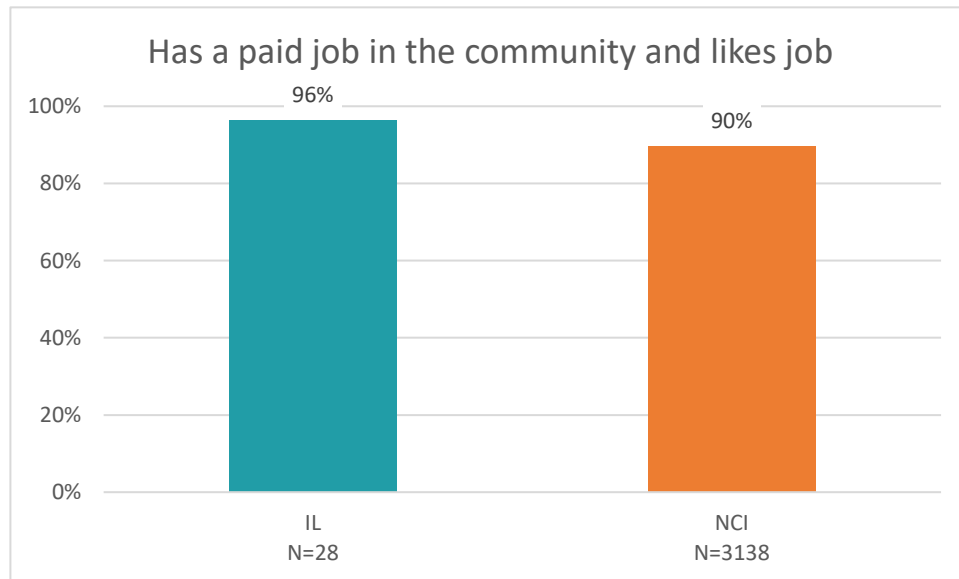
[Chart 50.](#) Likes home or where lives



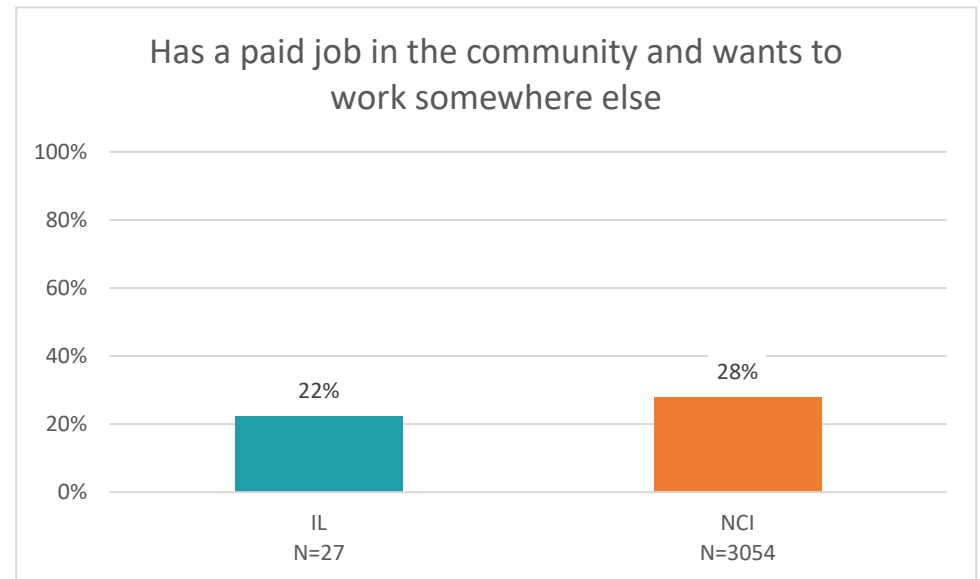
[Chart 51.](#) Wants to live somewhere else<sup>~</sup>



[Chart 52.](#) Has a paid job in the community and likes job



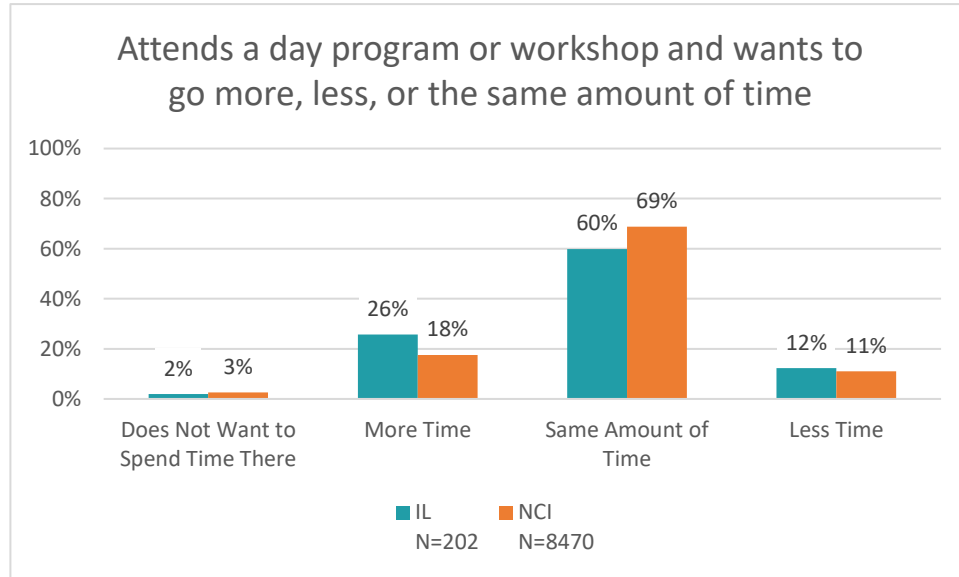
[Chart 53.](#) Has a paid job in the community and wants to work somewhere else<sup>~</sup>



<sup>~</sup>A lower average indicates a lower percentage of people report wanting to live somewhere else

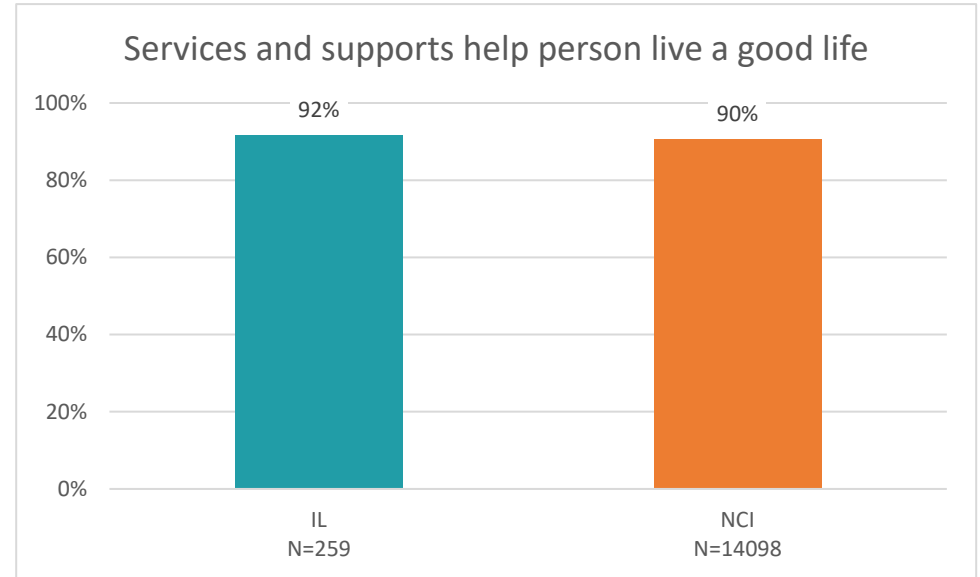
<sup>^^</sup>A lower average indicates a lower percentage of people report wanting to work somewhere else

[Chart 54.](#) Attends a day program or workshop and wants to go more, less, or the same amount of time <sup>a</sup>



<sup>a</sup>Question changed from previous years

[Chart 55.](#) Services and supports help person live a good life



*Tables for Satisfaction*



**Table 41. Satisfaction at home and with paid community job**

		Yes	N
Likes home or where lives	IL	89%	270
	NCI	90%	14,793
Wants to live somewhere else <sup>~</sup>	IL	27%	259
	NCI	26%	14,273
Has a paid job in the community and likes job	IL	96%	28
	NCI	90%	3,138
Has a paid job in the community and wants to work somewhere else <sup>~</sup>	IL	22%	27
	NCI	28%	3,054

**Table 42. Amount of time wants to spend at day program or workshop s/he attends <sup>Ⓢ</sup>**

	Does Not Want to Spend Time There	More Time	Same Amount of Time	Less Time	N
IL	2%	26%	60%	12%	202
NCI	3%	18%	69%	11%	8,470

**Table 43. Services and supports help person live a good life**

	Yes	N
IL	92%	259
NCI	90%	14,098

<sup>~</sup>A lower average indicates a lower percentage of people report wanting to be somewhere else

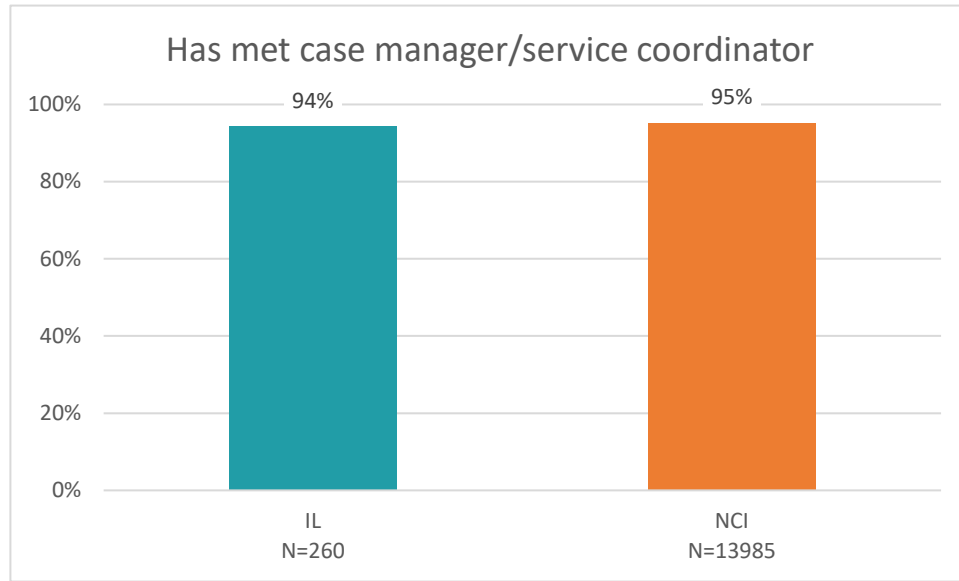
<sup>Ⓢ</sup>Question changed from previous years

## *Service Coordination*

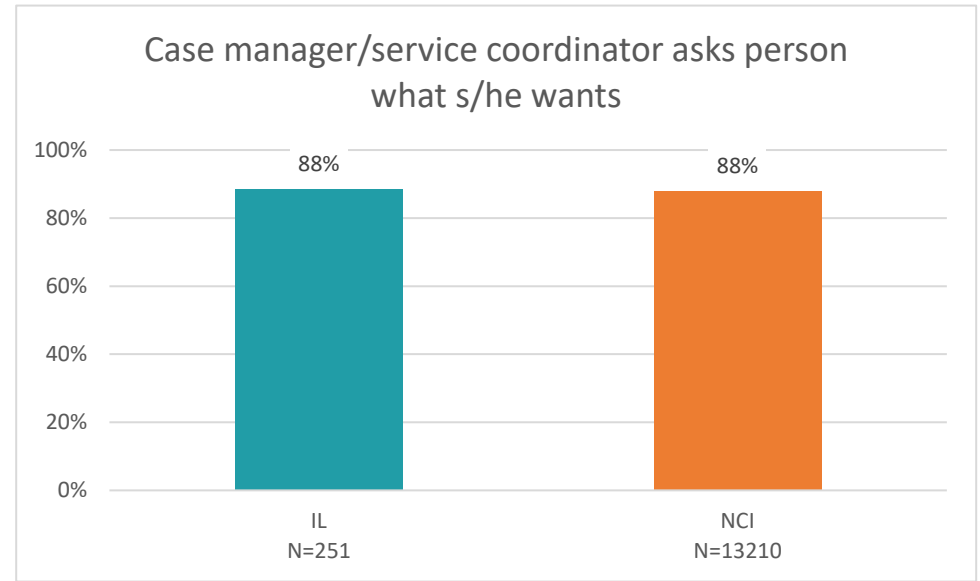
*Service coordinators are accessible, responsive, and support the person's participation in service planning.*

*Charts for Service Coordination*

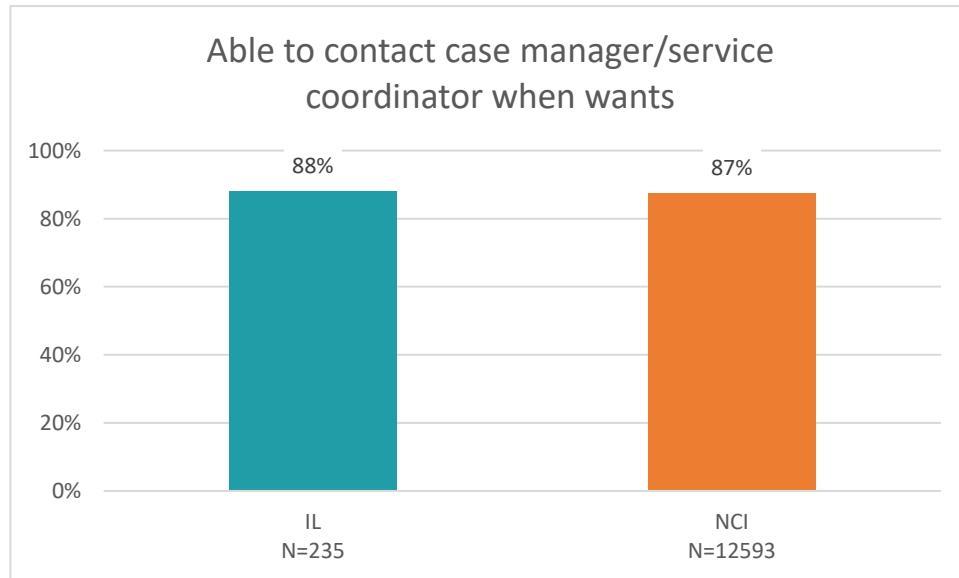
[Chart 56.](#) Has met case manager/service coordinator



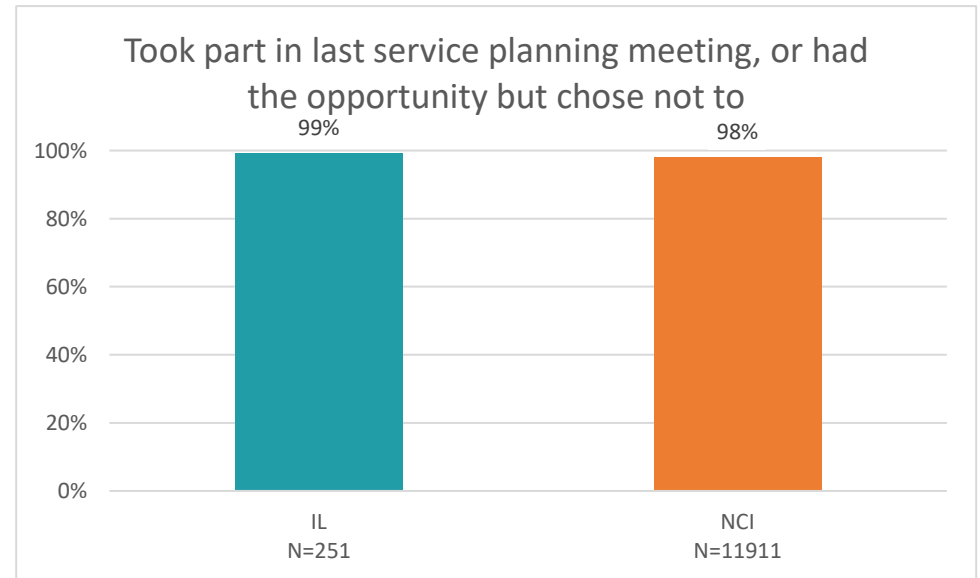
[Chart 57.](#) Case manager/service coordinator asks person what s/he wants



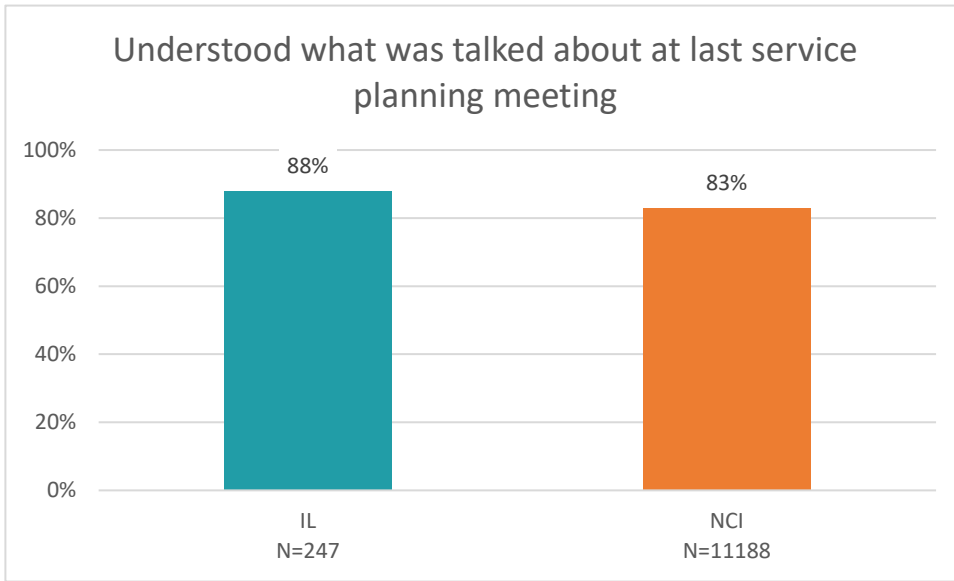
[Chart 58.](#) Able to contact case manager/service coordinator when wants



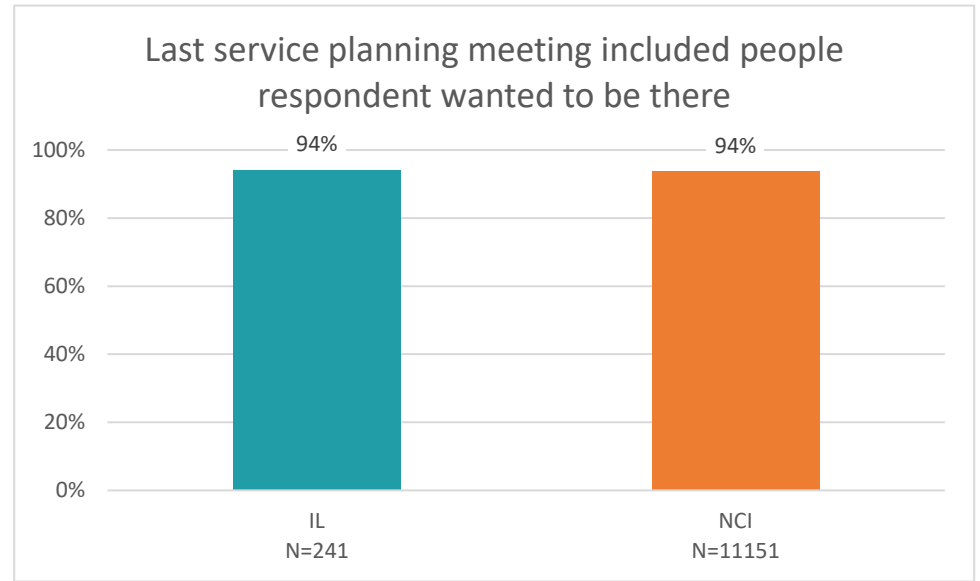
[Chart 59.](#) Took part in last service planning meeting, or had the opportunity but chose not to



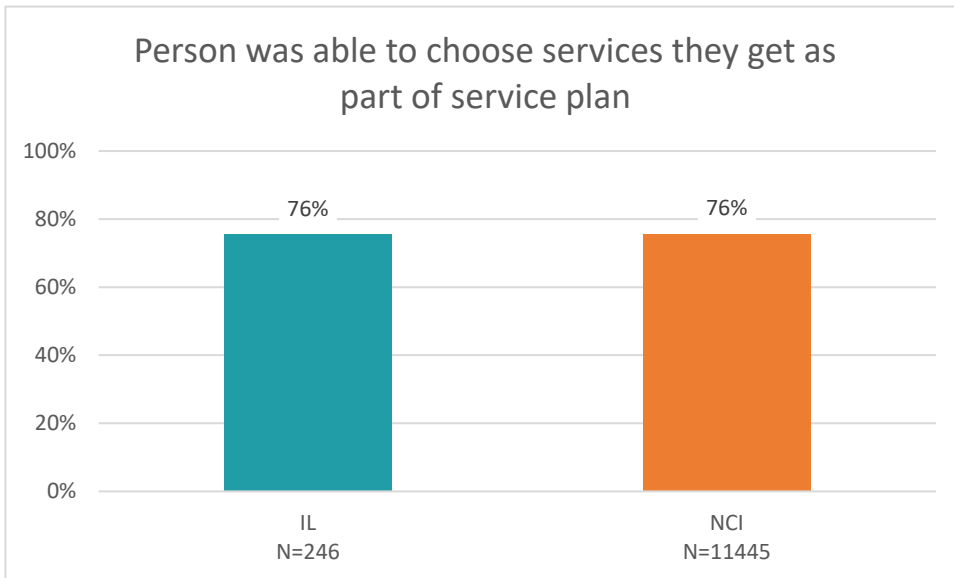
[Chart 60.](#) Understood what was talked about at last service planning meeting



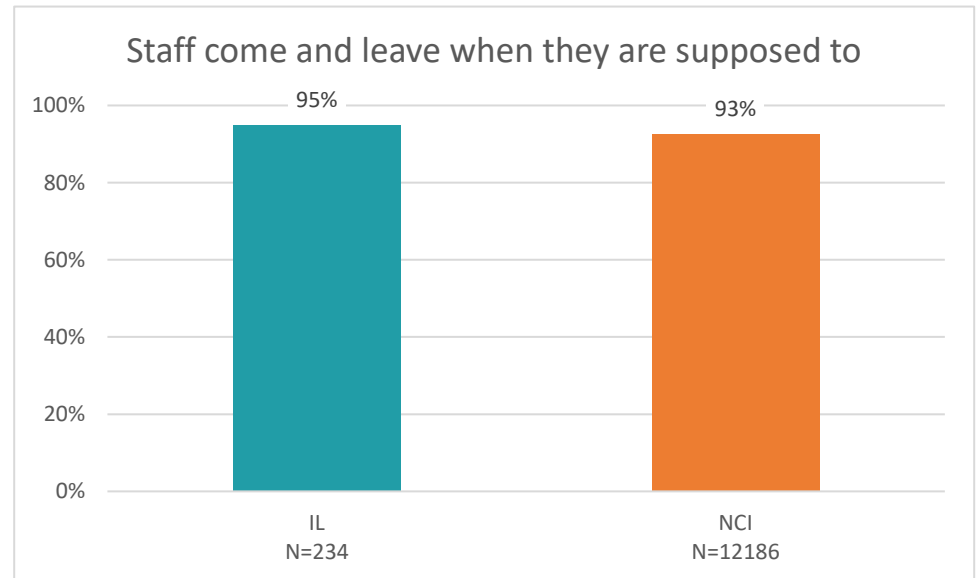
[Chart 61.](#) Last service planning meeting included people respondent wanted to be there



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



[Chart 63.](#) Staff come and leave when they are supposed to



*Tables for Service Coordination*

**Table 44. Service Coordination**

		Yes	N
Has met case manager/service coordinator	IL	94%	260
	NCI	95%	13,985
Case manager/service coordinator asks person what s/he wants	IL	88%	251
	NCI	88%	13,210
Able to contact case manager/service coordinator when wants	IL	88%	235
	NCI	87%	12,593
Took part in last service planning meeting, or had the opportunity but chose not to	IL	99%	251
	NCI	98%	11,911
Understood what was talked about at last service planning meeting	IL	88%	247
	NCI	83%	11,188
Last service planning meeting included people respondent wanted to be there	IL	94%	241
	NCI	94%	11,151
Person was able to choose services they get as part of service plan	IL	76%	246
	NCI	76%	11,445
Staff come and leave when they are supposed to	IL	95%	234
	NCI	93%	12,186

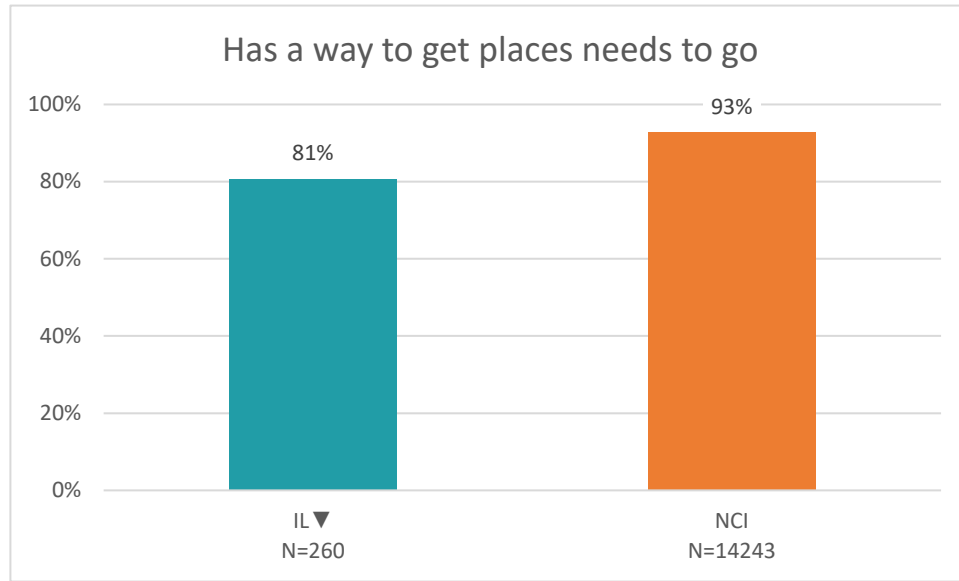
## Access

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

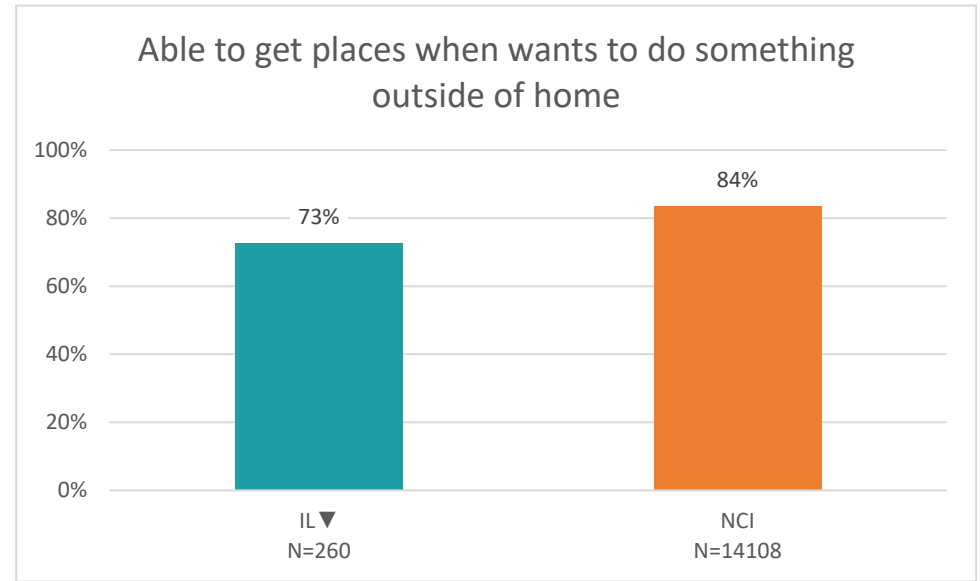


*Charts for Access*

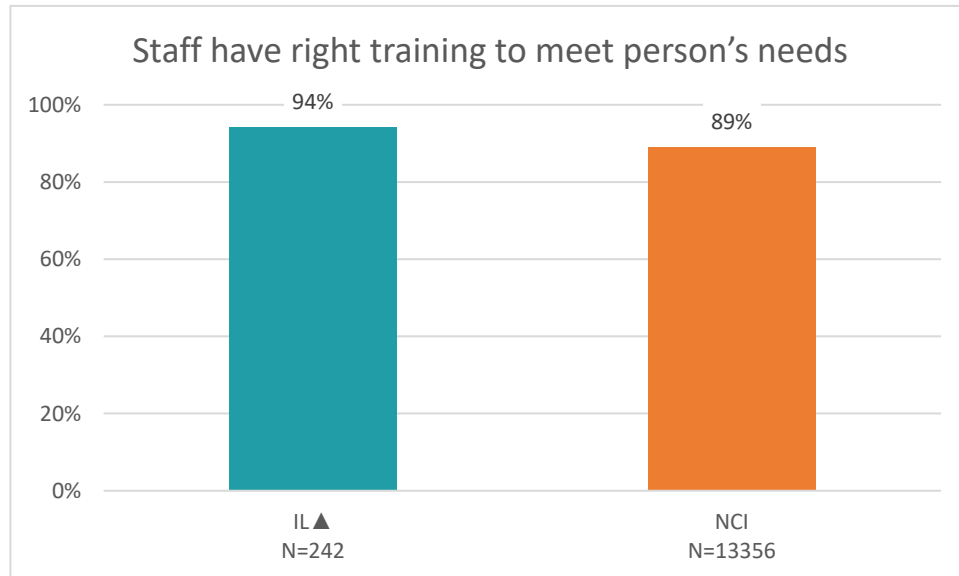
[Chart 64.](#) Has a way to get places needs to go



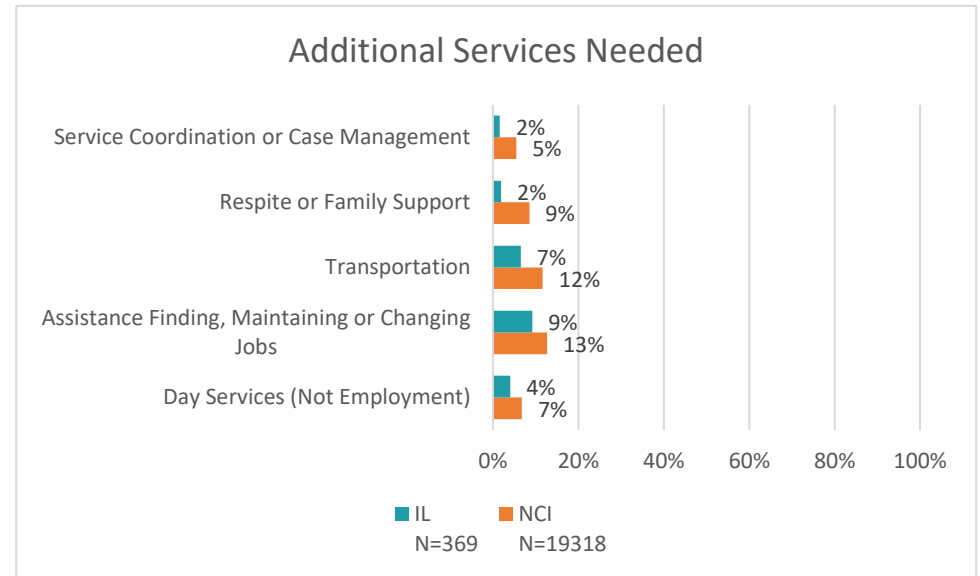
[Chart 65.](#) Able to get places when wants to do something outside of home



[Chart 66.](#) Staff have right training to meet person’s needs (proxy respondents who were not staff were allowed for this question) ±



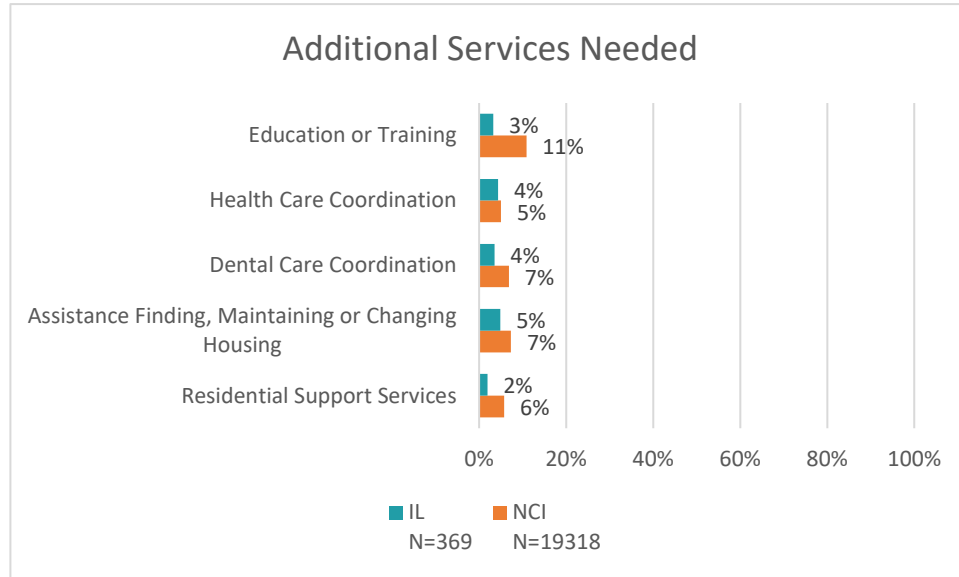
[Chart 67.](#) Additional services needed (proxy respondents were allowed for this question) ∞



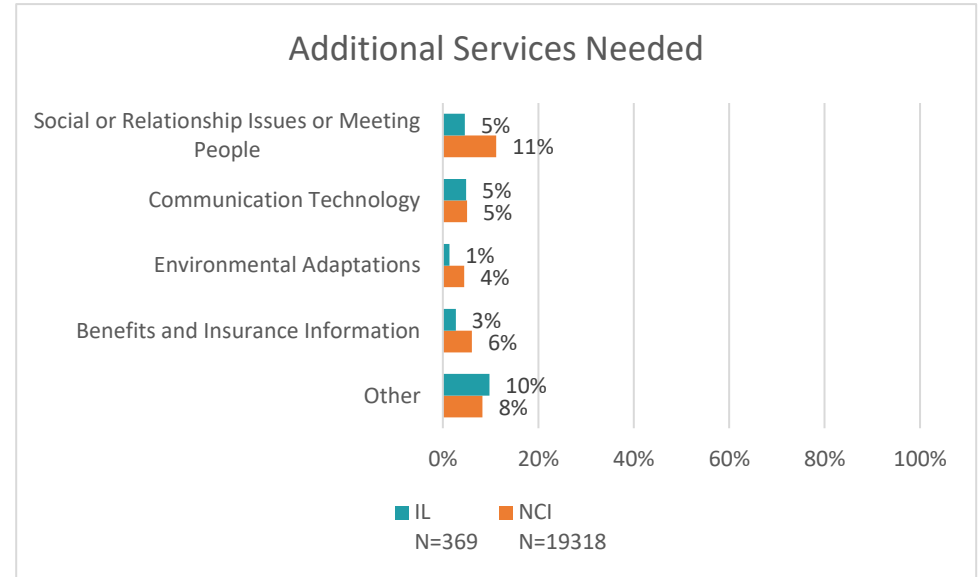
±Analysis for this question changed from previous years (this may affect overall score and result in a lower N than in previous years)

∞Categories are not mutually exclusive

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



[Chart 69.](#) Additional services needed, continued (proxy respondents were allowed for this question) ∞



∞Categories are not mutually exclusive

*Tables for Access*

**Table 45. Transportation and staff training**

		Yes	N
Has a way to get places needs to go	IL ▼	81%	260
	NCI	93%	14,243
Able to get places when wants to do something outside of home	IL ▼	73%	260
	NCI	84%	14,108
Staff have right training to meet person’s needs ( <i>proxy respondents who were not staff were allowed for this question</i> ) ±	IL ▲	94%	242
	NCI	89%	13,356

±Analysis for this question changed from previous years (this may affect overall score and result in a lower N than in previous years)

**Table 46. Additional services needed ∞ (proxy respondents were allowed for this question)**

Service		
Service Coordination or Case Management	IL	2%
	NCI	5%
Respite or Family Support	IL	2%
	NCI	9%
Transportation	IL	7%
	NCI	12%
Assistance Finding, Maintaining or Changing Jobs	IL	9%
	NCI	13%
Day Services (Not Employment)	IL	4%
	NCI	7%
Education or Training	IL	3%
	NCI	11%
Health Care Coordination	IL	4%
	NCI	5%
Dental Care Coordination	IL	4%
	NCI	7%
Assistance Finding, Maintaining or Changing Housing	IL	5%
	NCI	7%
Residential Support Services	IL	2%
	NCI	6%
Social or Relationship Issues or Meeting People	IL	5%
	NCI	11%
Communication Technology	IL	5%
	NCI	5%
Environmental Adaptations	IL	1%
	NCI	4%
Benefits and Insurance Information	IL	3%
	NCI	6%
Other	IL	10%
	NCI	8%
N	IL	369
	NCI	19,318

∞Categories are not mutually exclusive

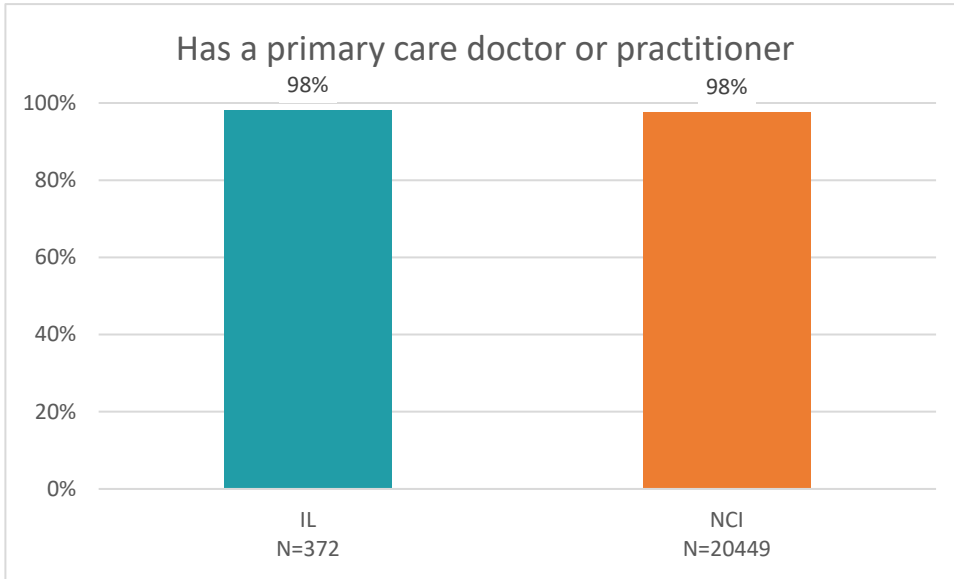
## Health

*People secure needed health services.*

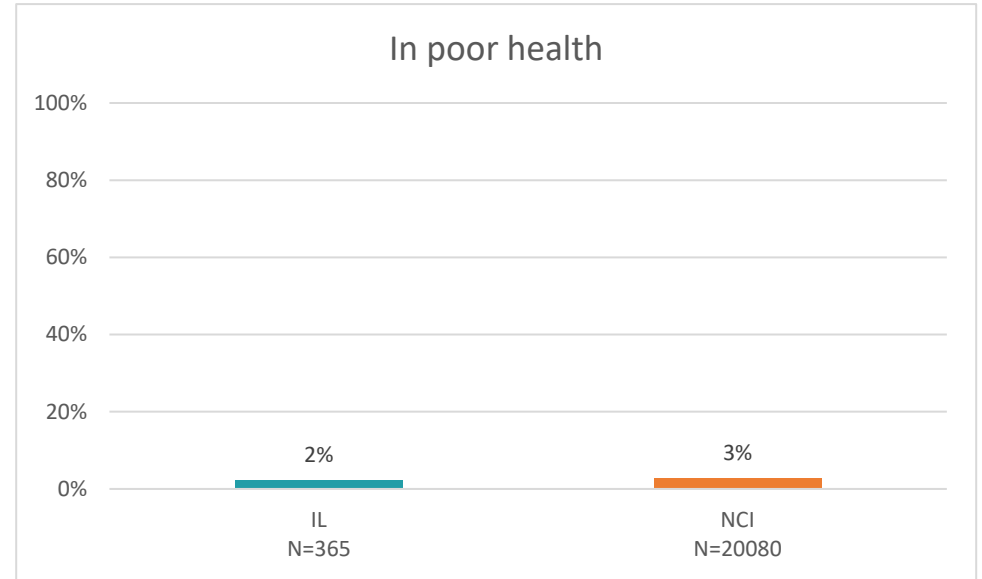
*Charts for Health*



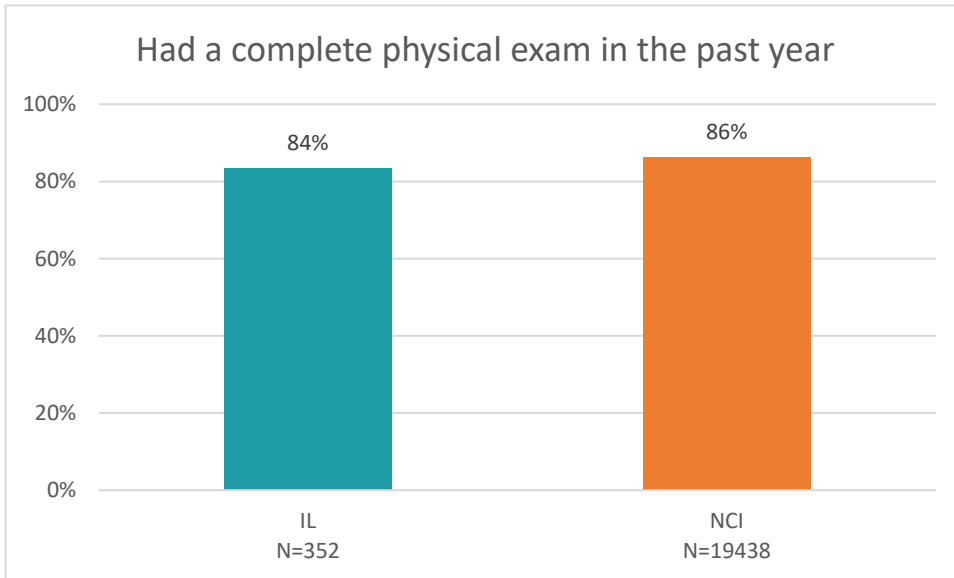
[Chart 70.](#) Has a primary care doctor or practitioner (information may have been obtained through state records)



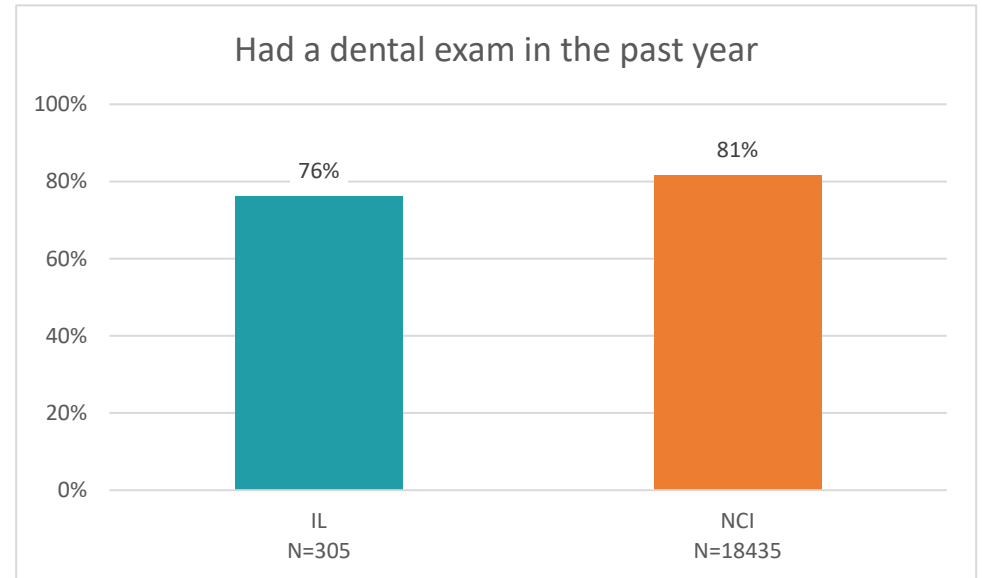
[Chart 71.](#) In poor health (proxy respondents were allowed for this question) ^



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

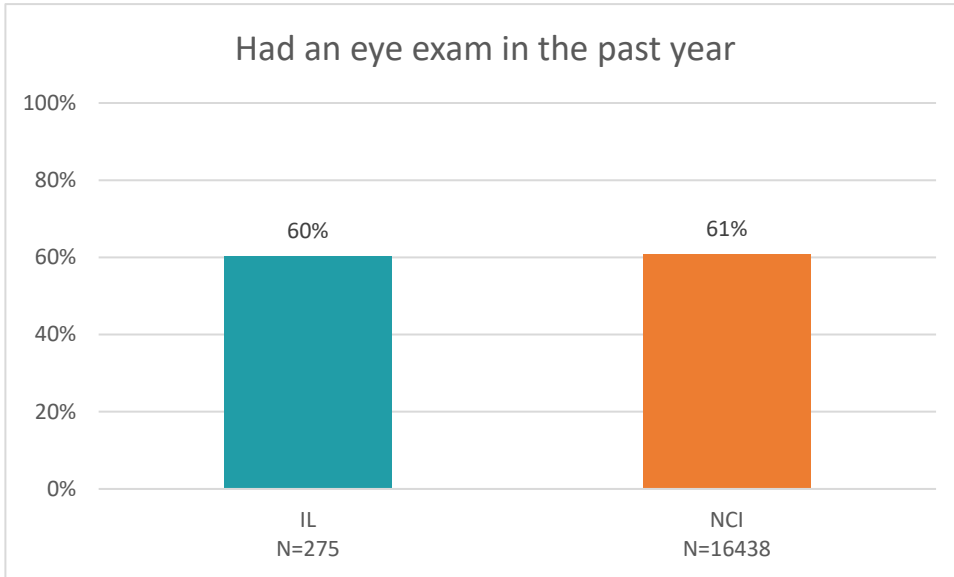


[Chart 73.](#) Had a dental exam in the past year (information may have been obtained through state records)

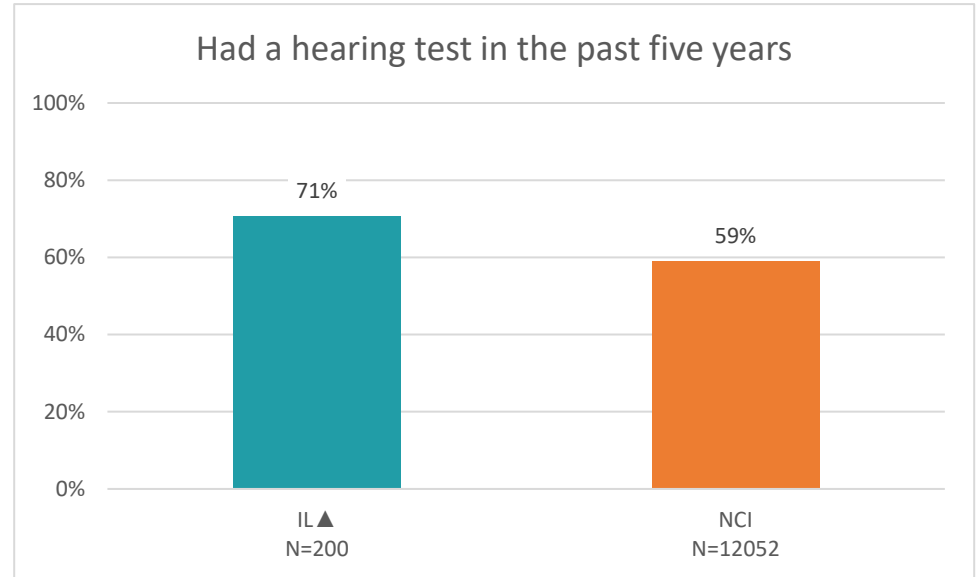


^ A lower average indicates a lower percentage of people reported being in poor health

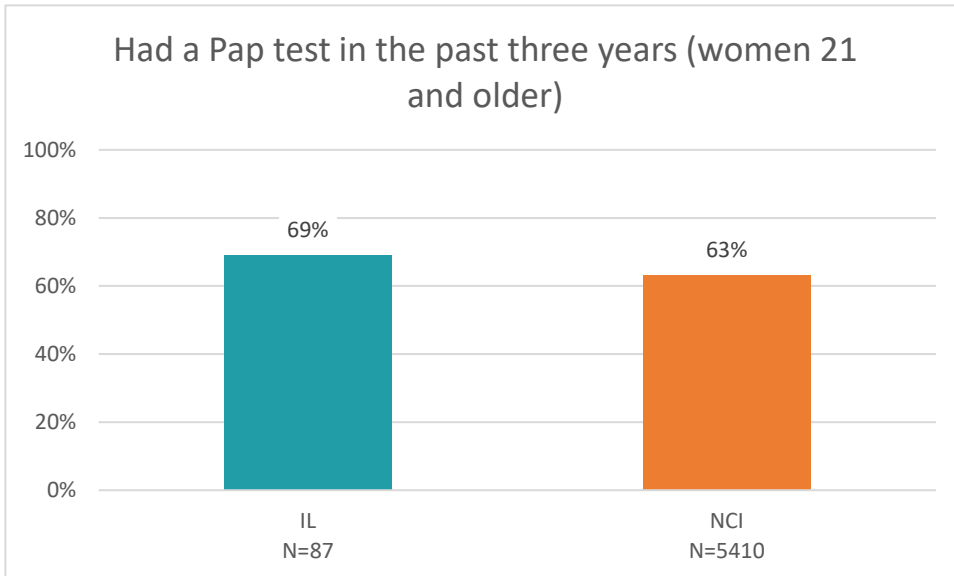
[Chart 74.](#) Had an eye exam in the past year (information may have been obtained through state records)



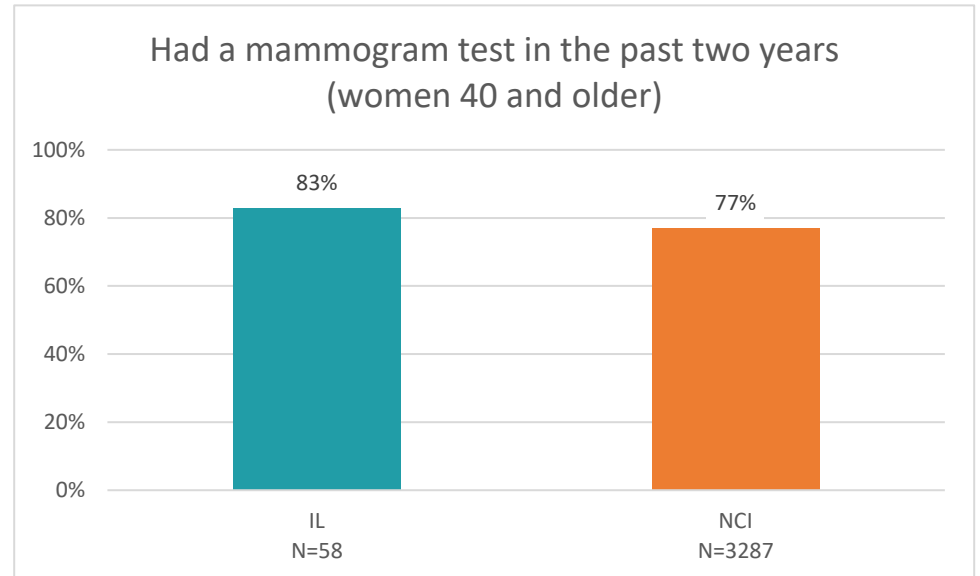
[Chart 75.](#) Had a hearing test in the past five years (information may have been obtained through state records)



[Chart 76.](#) Had a Pap test in the past three years (women 21 and older; information may have been obtained through state records) ±

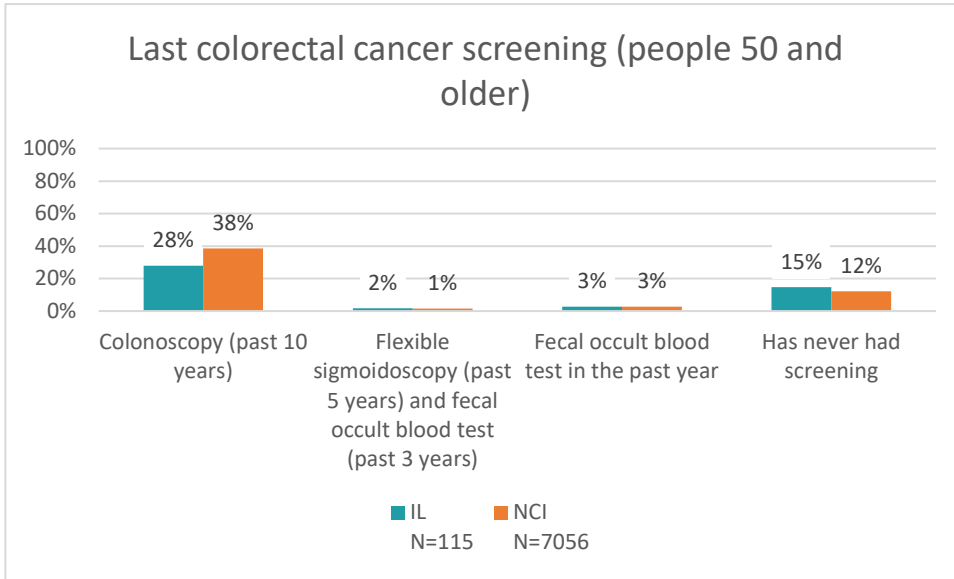


[Chart 77.](#) Had a mammogram test in the past two years (women 40 and older; information may have been obtained through state records)

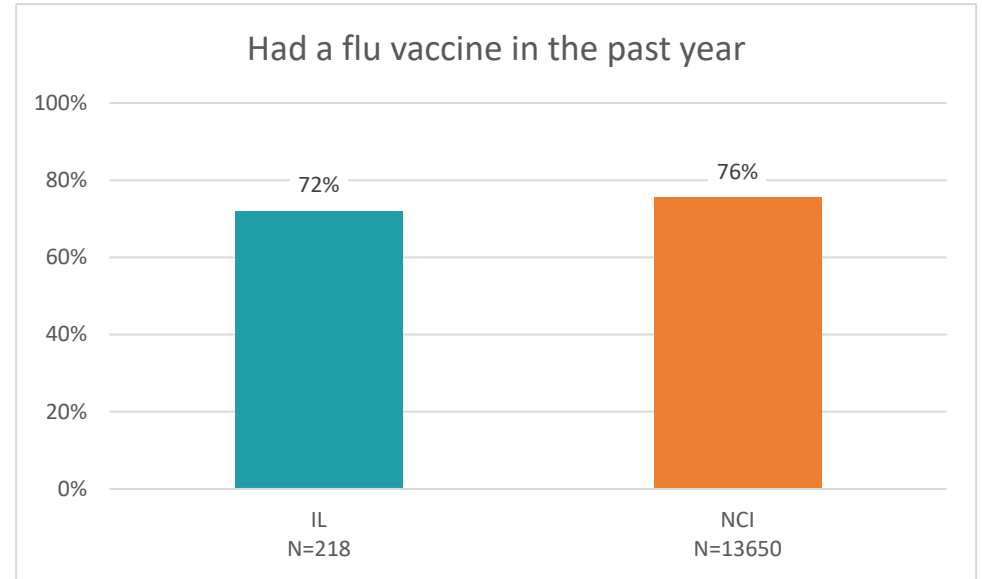


±Analysis for this question changed from previous years (this may affect overall score and result in a lower N than in previous years)

[Chart 78.](#) Last colorectal cancer screening (people 50 and older; information may have been obtained through state records) <sup>Ⓐ</sup> ∞



[Chart 79.](#) Had a flu vaccine in the past year (information may have been obtained through state records)



<sup>Ⓐ</sup>Question changed from previous years

∞Categories are not mutually exclusive

*Tables for Health*

**Table 47. Regular and preventive screenings**

		Yes	N
Has a primary care doctor or practitioner <i>(information may have been obtained through state records)</i> *	IL	98%	372
	NCI	98%	20,449
In poor health <i>(proxy respondents were allowed for this question)</i> ^	IL	2%	365
	NCI	3%	20,080
Had a complete physical exam in the past year <i>(information may have been obtained through state records)</i> *	IL	84%	352
	NCI	86%	19,438
Had a dental exam in the past year <i>(information may have been obtained through state records)</i> *	IL	76%	305
	NCI	81%	18,435
Had an eye exam in the past year <i>(information may have been obtained through state records)</i> *	IL	60%	275
	NCI	61%	16,438
Had a hearing test in the past five years <i>(information may have been obtained through state records)</i> *	IL▲	71%	200
	NCI	59%	12,052
Had a Pap test in the past three years <i>(women 21 and older; information may have been obtained through state records)</i> ± *	IL	69%	87
	NCI	63%	5,410
Had a mammogram test in the past two years <i>(women 40 and older; information may have been obtained through state records)</i>	IL	83%	58
	NCI	77%	3,287

\*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

±Analysis for this question changed from previous years (this may affect overall score and result in a lower N than in previous years)

**Table 48. Last colorectal cancer screening, people age 50 and older**  
*(information may have been obtained through state records) <sup>9</sup> ∞*

	Colonoscopy in the Past 10 Years	Flexible Sigmoidoscopy in the past 5 years, and Fecal Occult Blood Test in the Past 3 Years	Fecal Occult Blood Test in the Past Year	Has Never Had Screening	N
IL	28%	2%	3%	15%	115
NCI	38%	1%	3%	12%	7,056

**Table 49. Had a flu vaccine in the past year**  
*(information may have been obtained through state records) \**

	Yes	N
IL	72%	218
NCI	76%	13,650

<sup>9</sup>Question changed from previous years

∞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%)

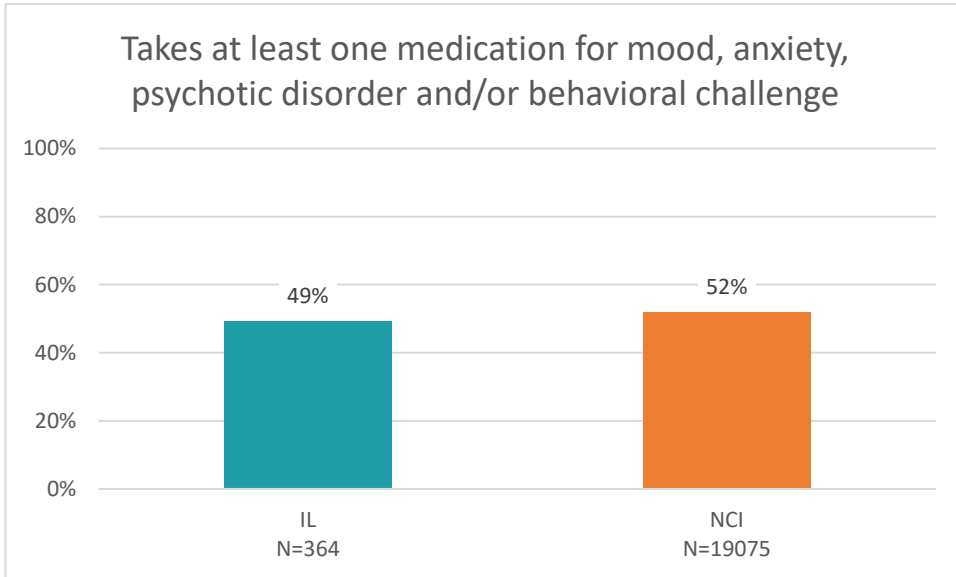
## *Medications*

*Medications are managed effectively and appropriately.*

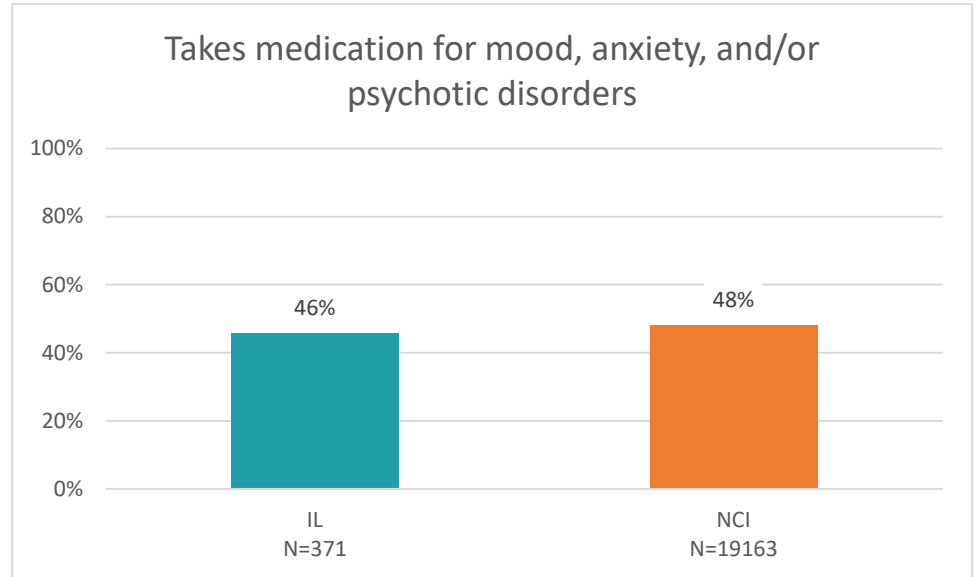
*Charts for Medications*



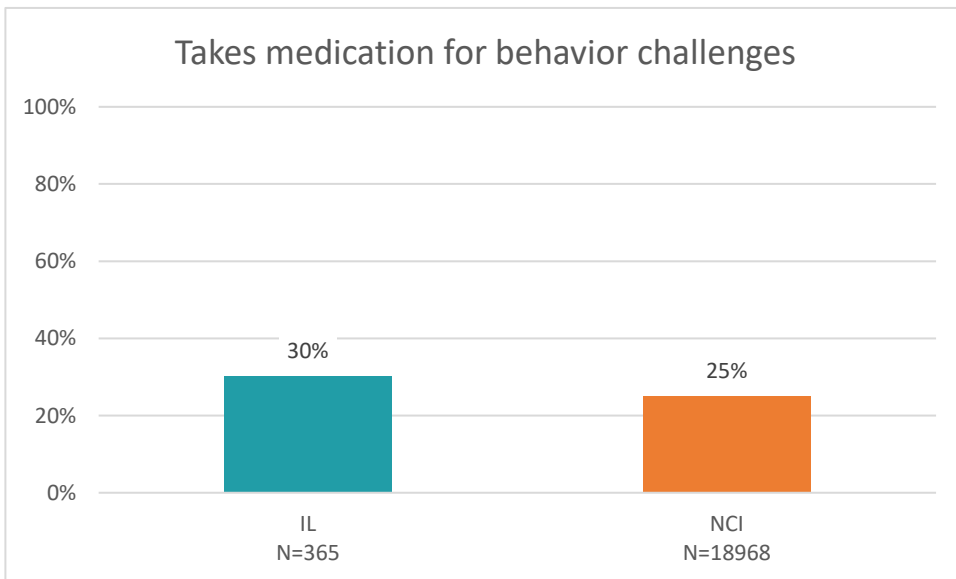
**Chart 80.** Takes at least one medication for mood, anxiety, psychotic disorder and/or behavioral challenge (information may have been obtained through state records)



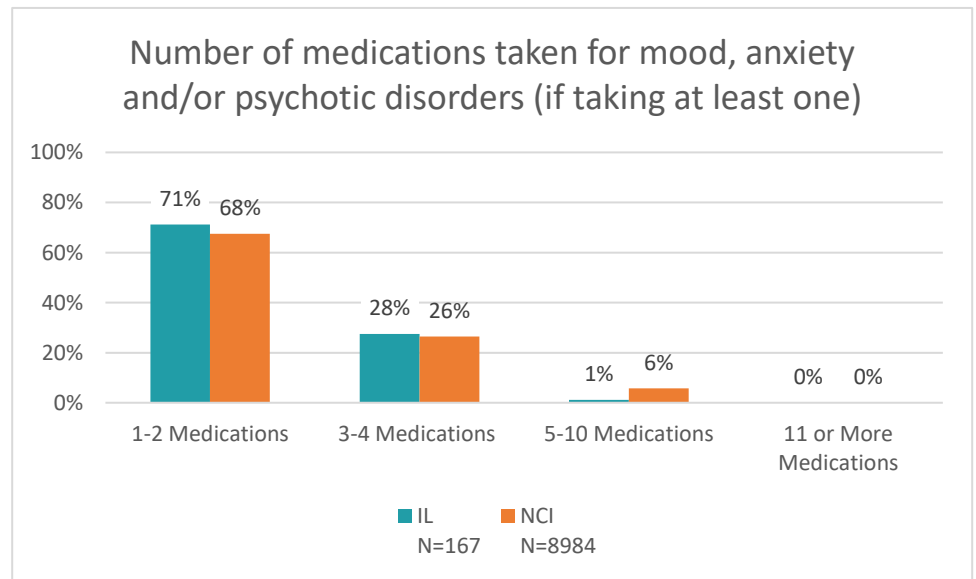
**Chart 81.** Takes medication for mood, anxiety, and/or psychotic disorders (information may have been obtained through state records)



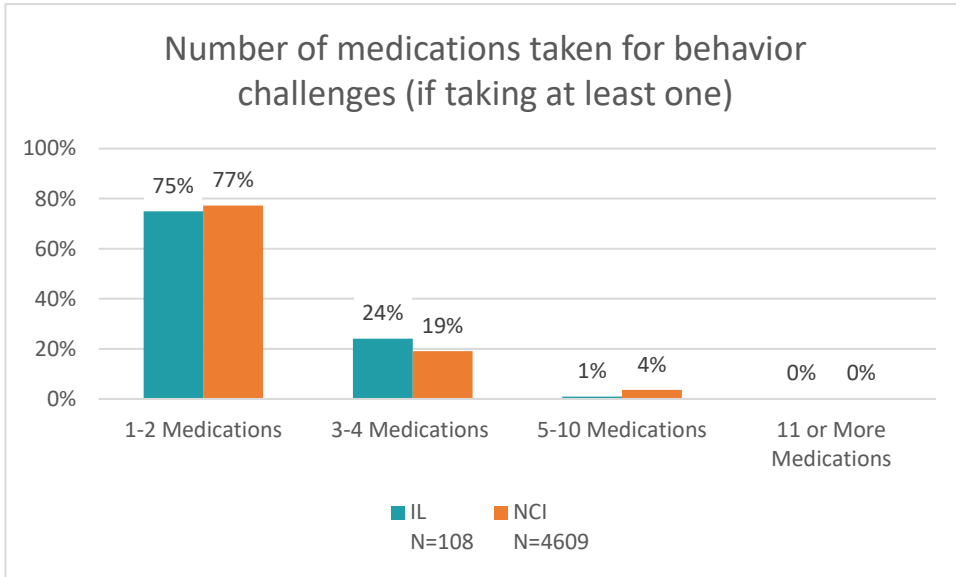
**Chart 82.** Takes medication for behavior challenges (information may have been obtained through state records)



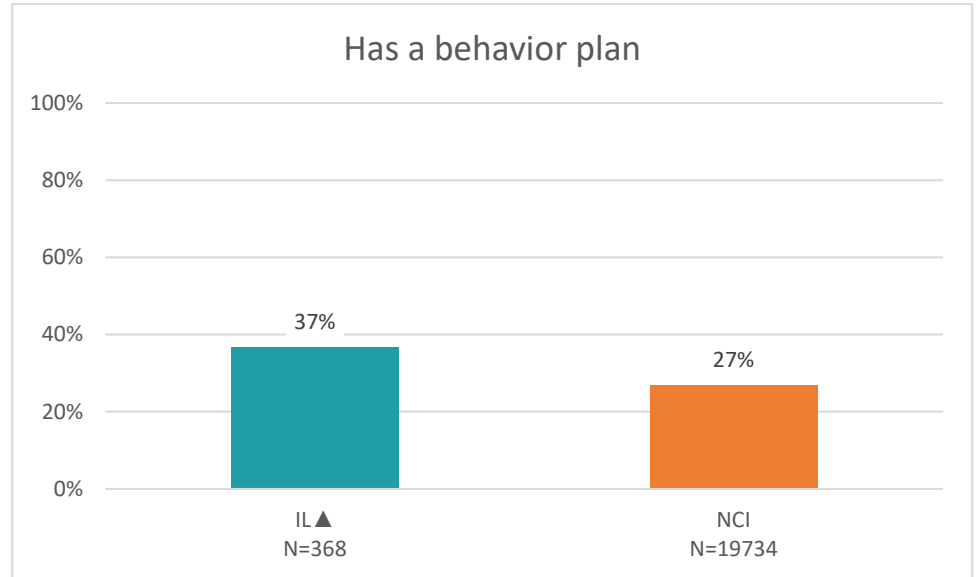
**Chart 83.** Number of medications taken for at least one of the following: mood disorders, anxiety, or psychotic disorders (information may have been obtained through state records)



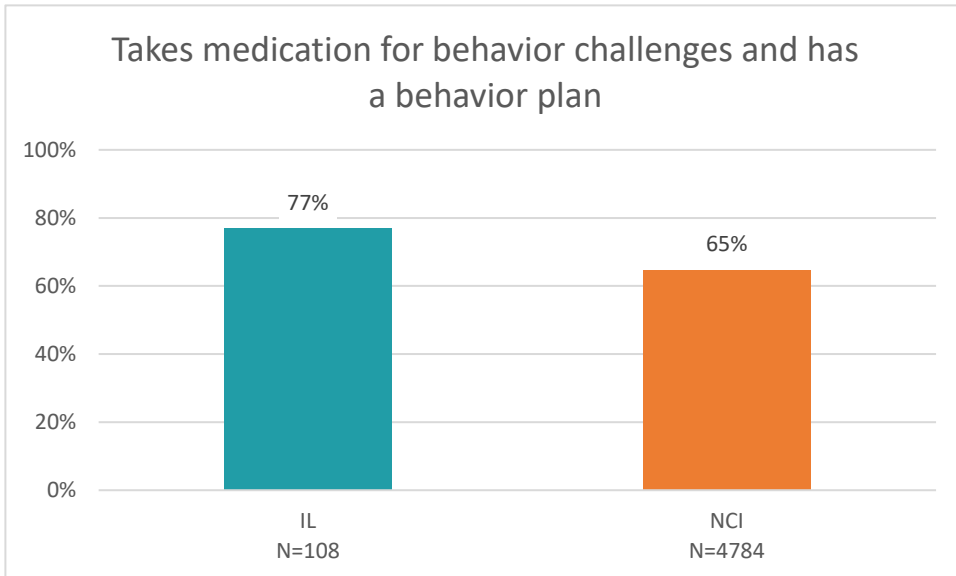
**Chart 84.** Number of medications taken for behavior challenges (information may have been obtained through state records)



**Chart 85.** Has a behavior plan (information may have been obtained through state records)



**Chart 86.** Takes medication for behavior challenges and has a behavior plan (information may have been obtained through state records)



*Tables for Medication*

**Table 50. 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> )	IL	49%	364
	NCI	52%	19,075
Takes medication for mood, anxiety, and/or psychotic disorders ( <i>information may have been obtained through state records</i> ) *	IL	46%	371
	NCI	48%	19,163
Takes medication for behavior challenges ( <i>information may have been obtained through state records</i> ) *	IL	30%	365
	NCI	25%	18,968

**Table 51. 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> ) *	IL	71%	28%	1%	0%	167
	NCI	68%	26%	6%	0%	8,984
Number of medications taken for behavior challenges ( <i>information may have been obtained through state records</i> )	IL	75%	24%	1%	0%	108
	NCI	77%	19%	4%	0%	4,609

**Table 52. Behavior plan and medication**

		Yes	N
Has a behavior plan ( <i>information may have been obtained through state records</i> ) *	IL▲	37%	368
	NCI	27%	19,734
Takes medication for behavior challenges and has a behavior plan ( <i>information may have been obtained through state records</i> )	IL	77%	108
	NCI	65%	4,784

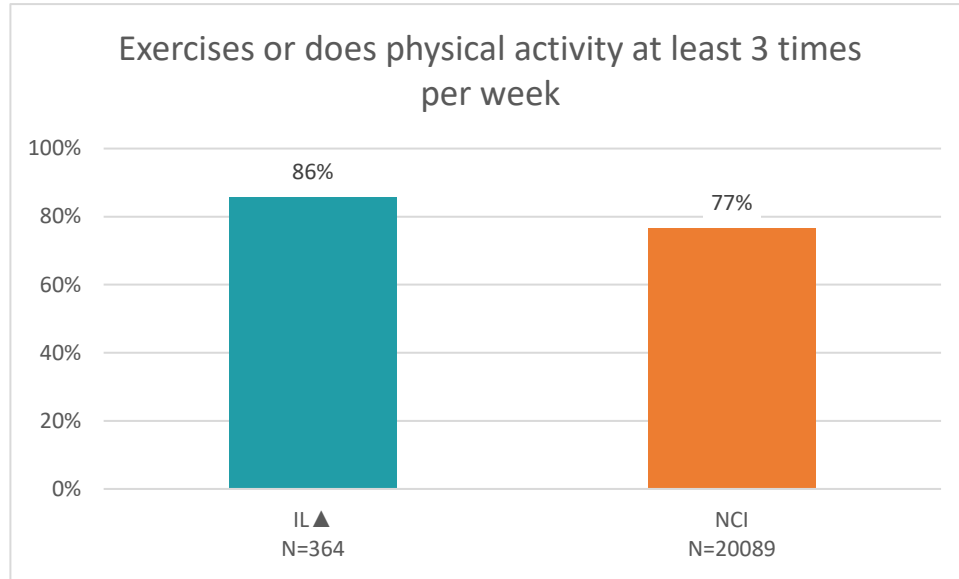
\*Includes data from a state or states that had a large number of “don’t knows” and missing data (at least 25%)

## Wellness

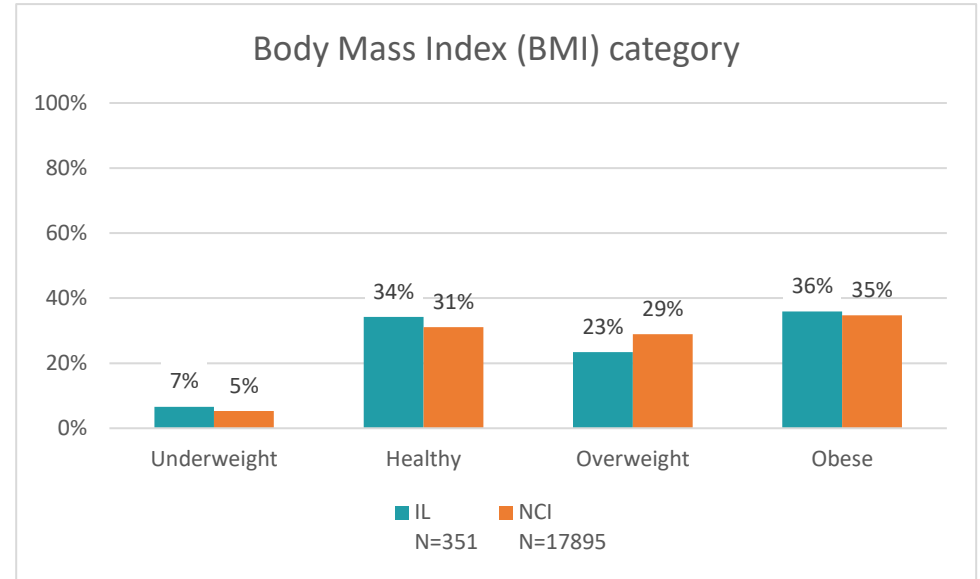
*People are supported to maintain healthy habits.*

*Charts for Wellness*

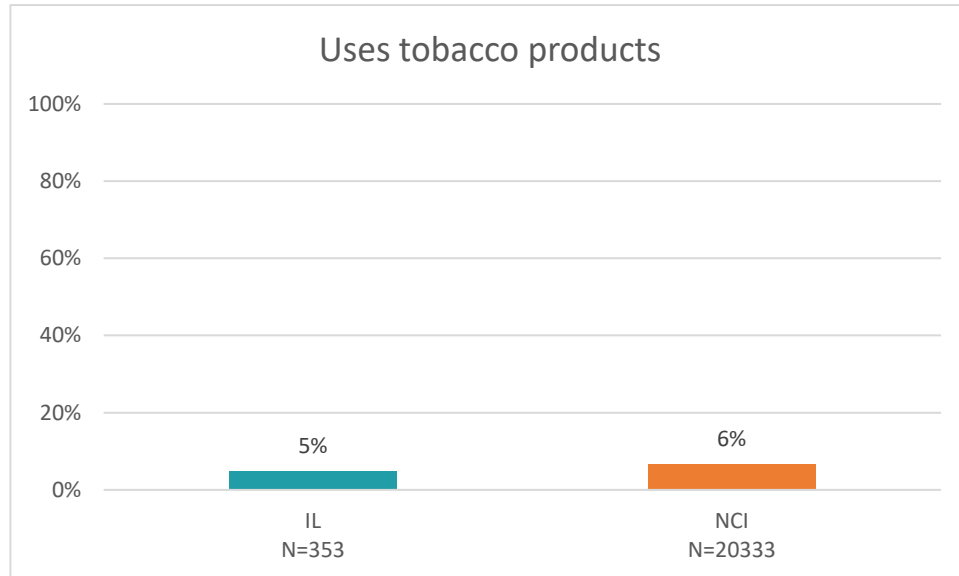
[Chart 87.](#) Exercises or does physical activity at least 3 times per week (proxy respondents were allowed for this question)



[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)



~ A lower average indicates a lower percentage of people use tobacco products

*Tables for Wellness*



**Table 53. Exercises or does physical activity at least 3 times per week (proxy respondents were allowed for this question)**

	Yes	N
IL ▲	86%	364
NCI	77%	20,089

**Table 54. Body Mass Index (BMI) category  
(information may have been obtained through state records) \***

	Underweight	Healthy	Overweight	Obese	N
IL	7%	34%	23%	36%	351
NCI	5%	31%	29%	35%	17,895

**Table 55. Uses tobacco products  
(information may have been obtained through state records) ˇ \***

	Yes	N
IL	5%	353
NCI	6%	20,333

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

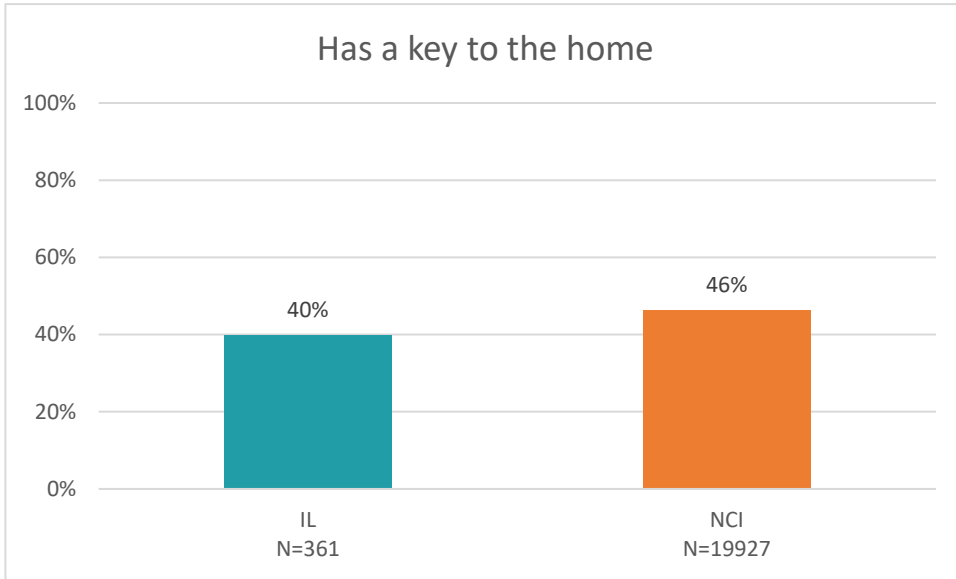
ˇA lower average indicates a lower percentage of people use tobacco products

## *Rights and Respect*

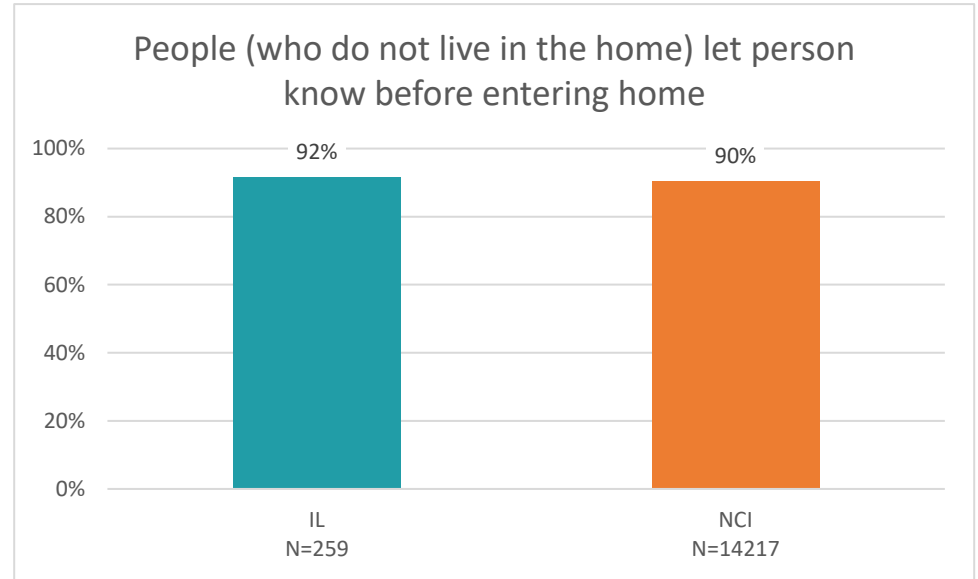
*People receive the same respect and protections as others in the community.*

*Charts for Rights and Respect*

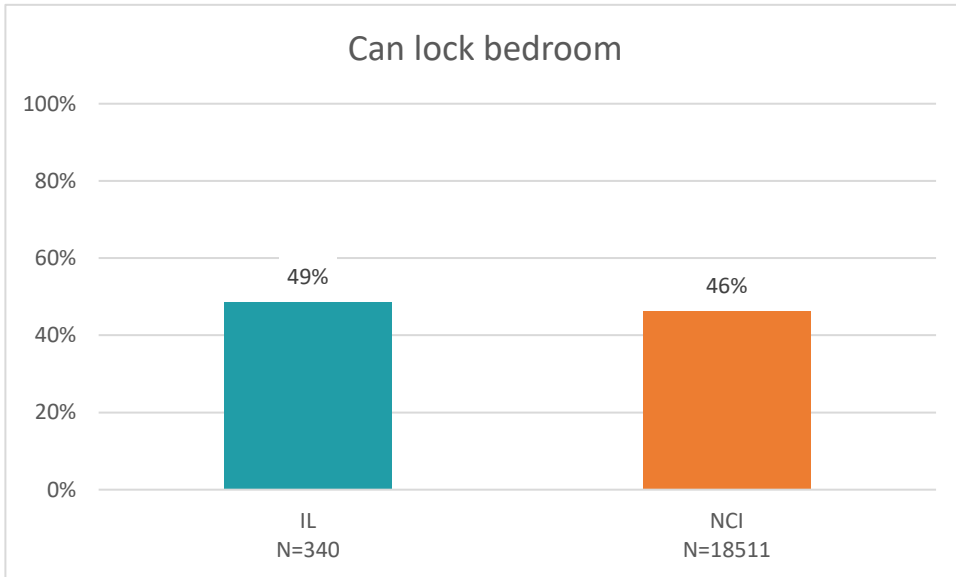
[Chart 90.](#) Has a key to the home (proxy respondents were allowed for this question) <sup>o</sup>



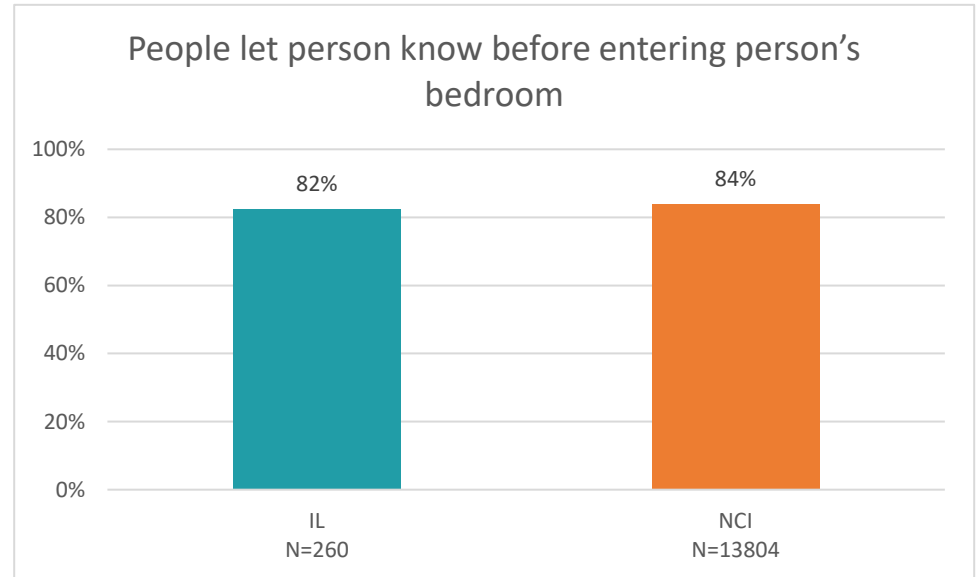
[Chart 91.](#) People (who do not live in the home) let person know before entering home



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

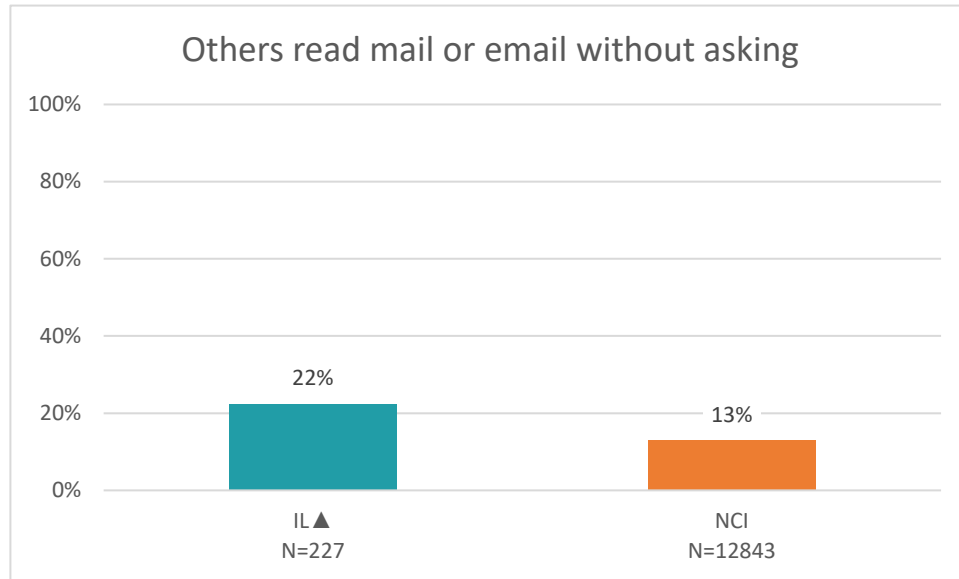


[Chart 93.](#) People let person know before entering person's bedroom

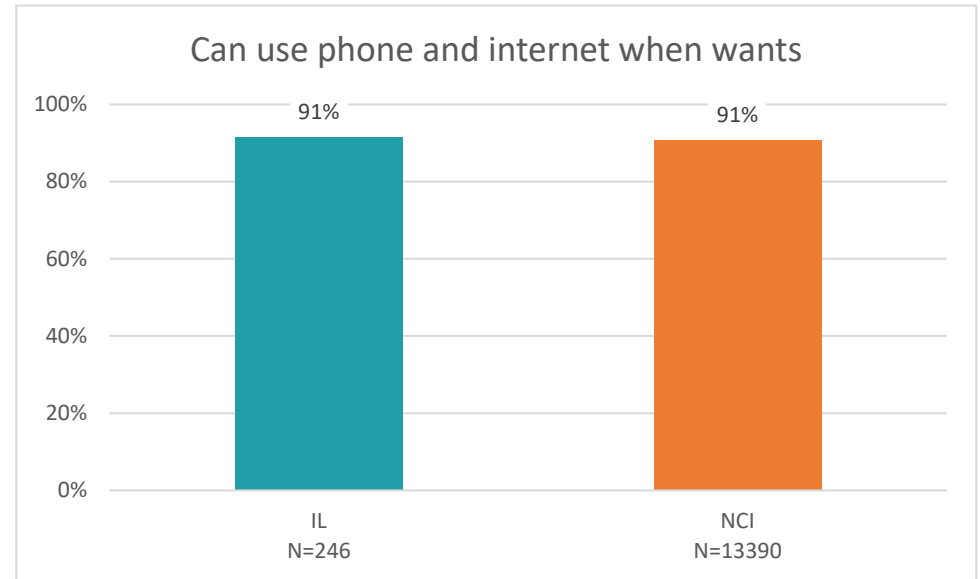


<sup>o</sup> Question changed from previous years

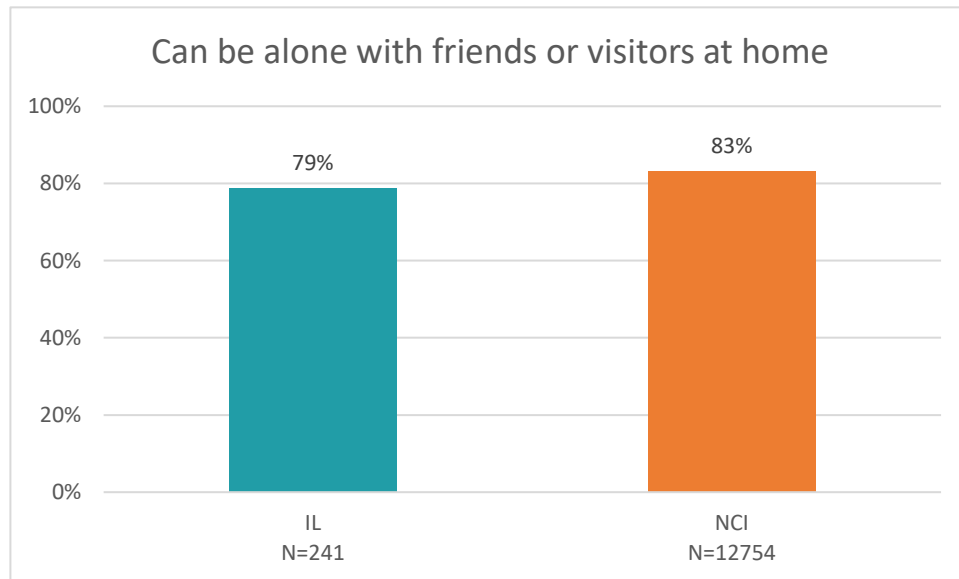
[Chart 94.](#) Others read mail or email without asking ~



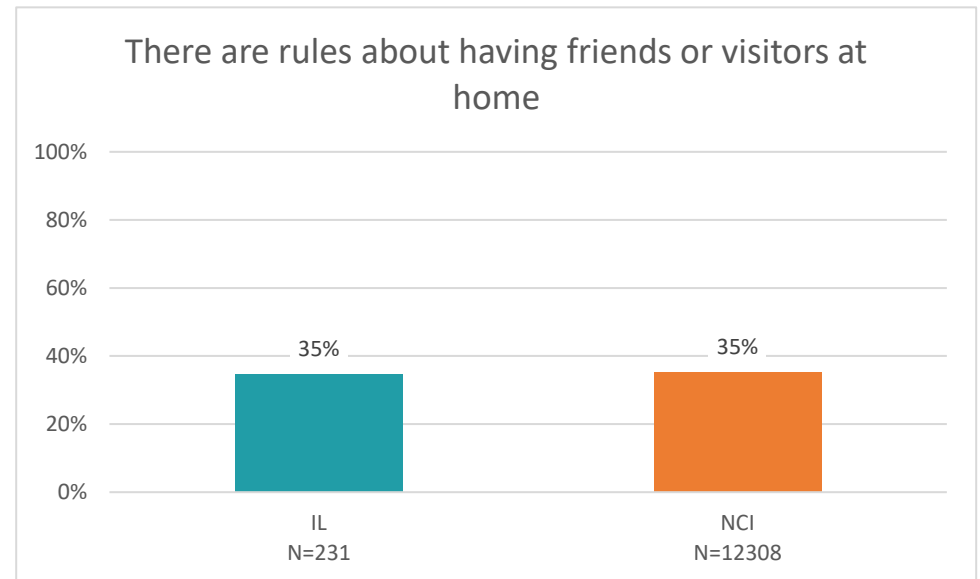
[Chart 95.](#) Can use phone and internet when wants



[Chart 96.](#) Can be alone with friends or visitors at home



[Chart 97.](#) There are rules about having friends or visitors at home ° ~^

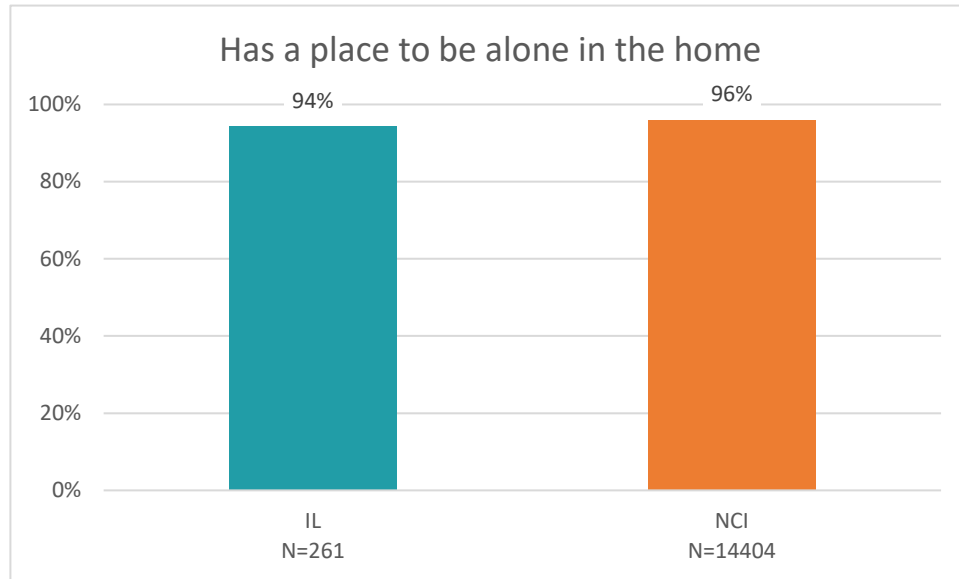


~A lower average indicates a lower percentage of people report others open mail or email without asking

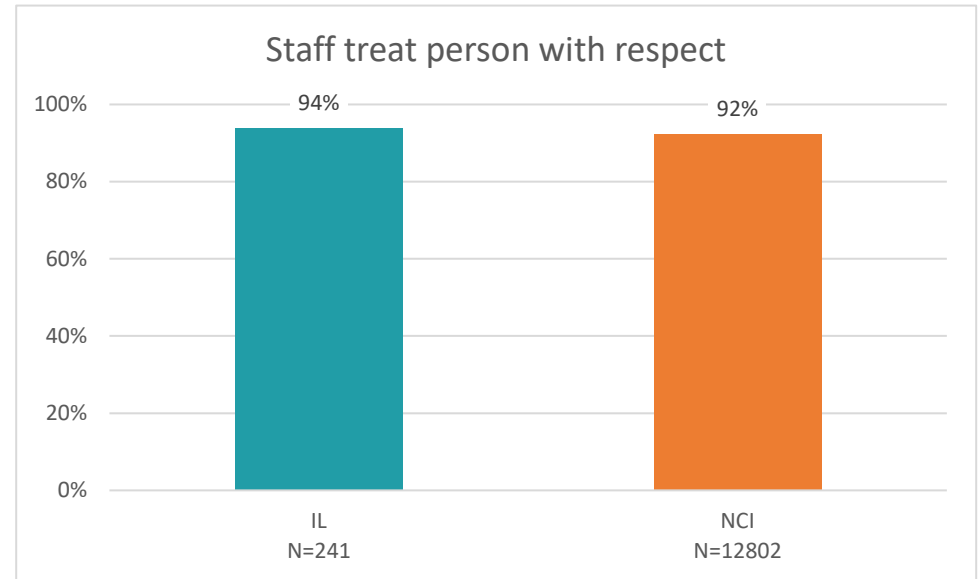
°Question changed from previous years

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

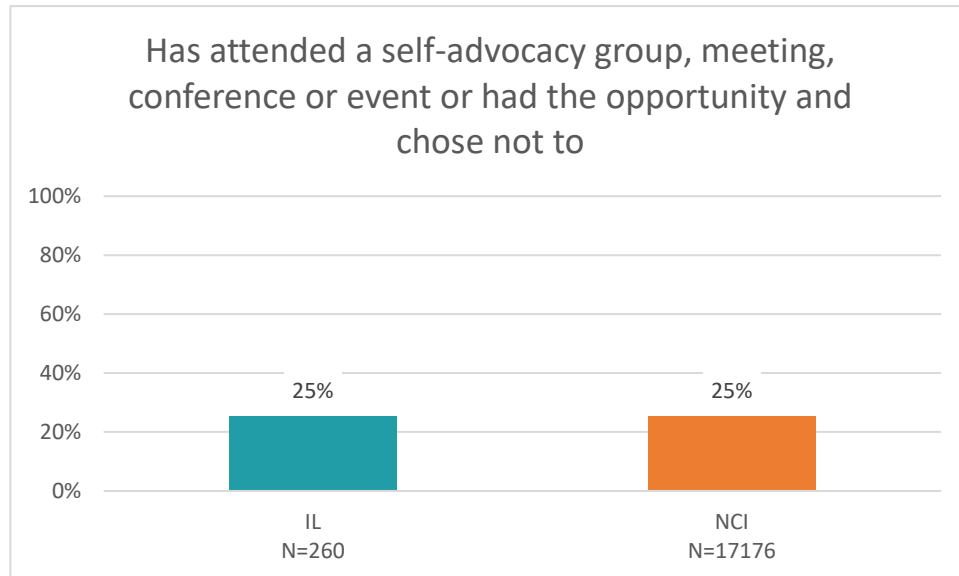
[Chart 98.](#) Has a place to be alone in the home



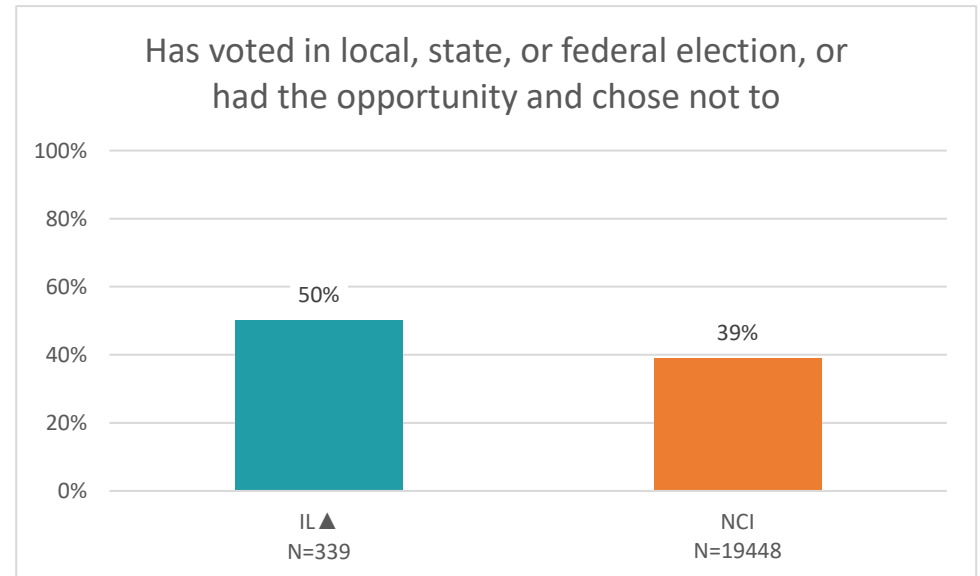
[Chart 99.](#) Staff treat person with respect



[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 56. Rights and Respect**

		Yes	N
Has a key to the home <i>(proxy respondents were allowed for this question)</i> <sup>Ⓐ</sup>	IL	40%	361
	NCI	46%	19,927
People (who do not live in the home) let person know before entering home	IL	92%	259
	NCI	90%	14,217
Can lock bedroom <i>(proxy respondents were allowed for this question)</i>	IL	49%	340
	NCI	46%	18,511
People let person know before entering person’s bedroom	IL	82%	260
	NCI	84%	13,804
Others read mail or email without asking <sup>~</sup>	IL ▲	22%	227
	NCI	13%	12,843
Can use phone and internet when wants	IL	91%	246
	NCI	91%	13,390
Can be alone with friends or visitors at home	IL	79%	241
	NCI	83%	12,754
There are rules about having friends or visitors at home <sup>Ⓐ</sup> <sup>^^</sup>	IL	35%	231
	NCI	35%	12,308
Has a place to be alone in the home	IL	94%	261
	NCI	96%	14,404
Staff treat person with respect	IL	94%	241
	NCI	92%	12,802
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>	IL	25%	260
	NCI	25%	17,176
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>	IL ▲	50%	339
	NCI	39%	19,448

<sup>Ⓐ</sup>Question changed from previous years

<sup>~</sup>A lower average indicates a lower percentage of people report others open mail or email without asking

<sup>^^</sup>A lower average indicates a lower percentage of people report rules about having friends or visitors at home



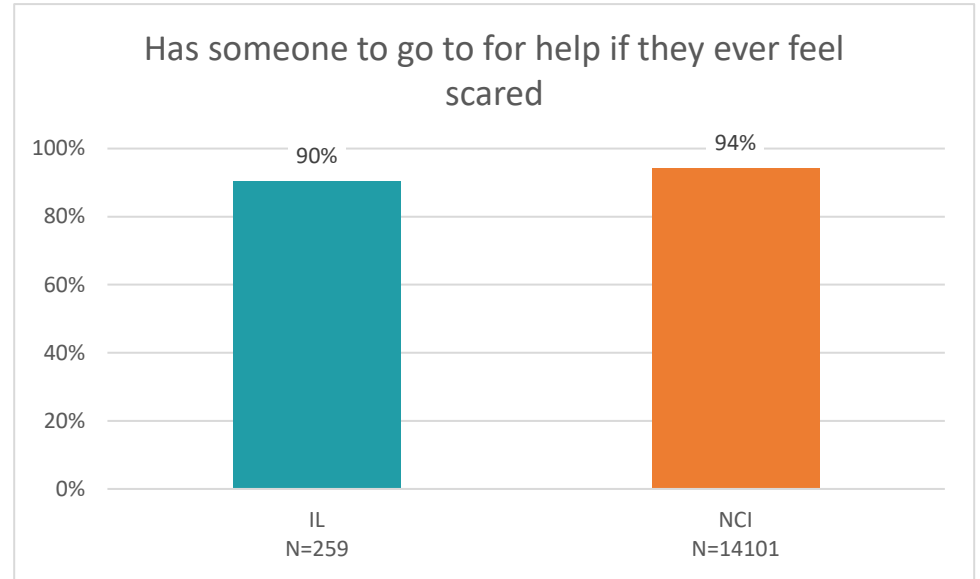
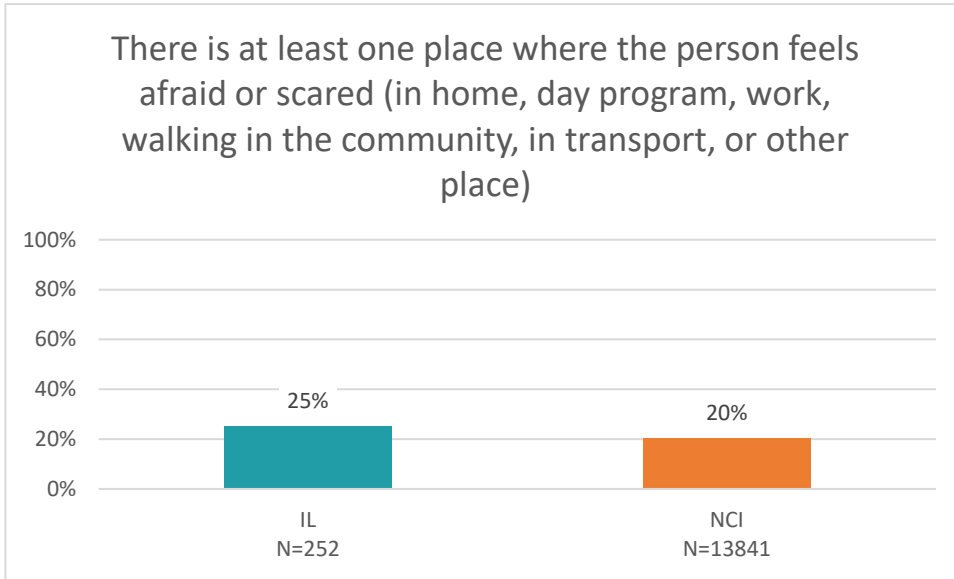
## Safety

*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 57. 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> ) ~	IL	25%	252
	NCI	20%	13,841
Has someone to go to for help if they ever feel scared	IL	90%	259
	NCI	94%	14,101

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