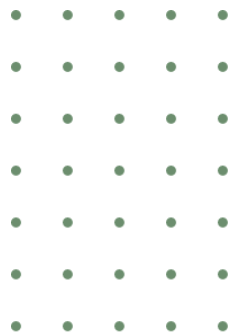


# National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)



**National Report 2022-23**

**Adult Family Survey (AFS)**





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## List of Acronyms Used in This Report

AFS	Adult Family Survey
CMS	Centers for Medicare & Medicaid Services
HCBS	Home and Community-Based Services
HSRI	Human Services Research Institute
IDD	Intellectual and developmental disabilities
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NCI	National Core Indicators

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## Executive Summary

The National Core Indicators®-Intellectual and Developmental Disabilities (NCI-IDD) are standard measures used across states to assess the outcomes of services provided to individuals with intellectual/developmental disabilities and their families. Indicators address key areas of concern such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that result from NCI-IDD surveys are often used to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Many states also share the data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction.

The National Core Indicators (NCI) Adult Family Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who lives in the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Adult Family Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI-IDD during the 2022-23 data collection cycle, 10 states submitted a valid sample of Adult Family Survey data: Delaware (DE), District of Columbia (DC), Georgia (GA), Louisiana (LA), Maryland (MD), Missouri (MO), North Dakota (ND), New Jersey (NJ), Oklahoma (OK), and Pennsylvania (PA). This Final Report provides a summary of results based on data submitted by June 30, 2023.

# Results

## Presentation of the Data

In addition to basic demographic questions and questions on services received, the survey contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes.

- Each question is constructed so the respondent selects from either four possible responses (“always”, “usually”, “sometimes”, “seldom/never”) or two responses (“yes” or “no”). Respondents also have the option to indicate that they don’t know the answer to a question or that the question is not applicable.
- Demographic results are shown in table form with states listed alphabetically. Outcomes are shown first with a chart depicting the NCI-IDD Average. The charts are followed by accessible tables showing state outcomes and the NCI-IDD Average listed in descending order, grouped by level of significance.
- Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI-IDD Average range, their ‘always’ or ‘yes’ response was not statistically different from the NCI-IDD Average.
- States with 20 or fewer respondents to a question are not included in tables; however, their data **are** included in the NCI-IDD Average.
- **Note on Significance:** Statistical significance depends on both the amount by which a state differs from the average for a given item and the state’s sample size for that item. So, there may be instances where State A’s difference from the average is larger than State B’s, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.
- **Note on NCI-IDD Averages:** The NCI-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the states’ sample sizes. Prior to 2016-17, NCI-IDD averages were calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.
- **Note on language used in this report:** “You” and “Respondent” refers to the person (usually a parent or guardian) filling out the survey. “Family Member” refers to the person receiving services whom the respondent is answering questions about in this survey.
- **Note on responses:** All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

## Demographics

**Note on responses:** All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

**Note on responses:** Some pages in this section are in landscape orientation because some table headers cannot be displayed in full in portrait orientation

## **Family Member**

This section provides demographic information about the family member receiving services.

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics

Table 1. More Than One Person Living in the Home Has IDD

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State (names abbreviated)	Yes	No	N
DE	13%	87%	166
DC	17%	83%	163
GA	14%	86%	441
LA	14%	86%	1,191
MD	12%	88%	715
MO	13%	87%	256
ND	11%	89%	121
NJ	10%	90%	730
OK	8%	92%	354
PA	13%	87%	642
<b>Weighted NCI-IDD Average</b>	<b>12%</b>	<b>88%</b>	<b>4,779</b>

Table 2. Family Member’s Residential Designation

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State (names abbreviated)	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
DE	69%	31%	160
DC	99%	1%	146
GA	55%	45%	425
LA	54%	46%	1,189
MD	70%	30%	720
MO	60%	40%	260
ND	82%	18%	128
NJ	74%	26%	720
OK	65%	35%	353
PA	58%	42%	637
<b>Weighted NCI-IDD Average</b>	<b>64%</b>	<b>36%</b>	<b>4,738</b>



Table 3. Family Member's Age

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State (names abbreviated)	Age	N
DE	32.9	169
DC	39.3	150
GA	43.6	441
LA	36.4	1,261
MD	31.4	755
MO	33.9	263
ND	29.1	130
NJ	32.8	703
OK	38.3	358
PA	41.8	670
<b>Weighted NCI-IDD Average</b>	<b>37.6</b>	<b>4,900</b>

Table 4. Family Member's Gender

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State (names abbreviated)	Male	Female	Other	N
DE	64%	36%	0%	163
DC	61%	39%	0%	160
GA	61%	39%	0%	455
LA	56%	44%	0%	1,215
MD	61%	39%	0%	683
MO	55%	45%	0%	256
ND	55%	45%	0%	127
NJ	67%	33%	0%	704
OK	53%	47%	0%	361
PA	56%	44%	0%	664
<b>Weighted NCI-IDD Average</b>	<b>59%</b>	<b>40%</b>	<b>0%</b>	<b>4,788</b>

Table 5. Family Member’s Race/Ethnicity

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer not to say
DE	4%	3%	25%	1%	63%	6%	2%	4%
DC	2%	3%	87%	2%	5%	4%	1%	1%
GA	1%	2%	42%	0%	53%	2%	1%	2%
LA	3%	1%	30%	0%	65%	3%	1%	2%
MD	1%	8%	26%	0%	60%	5%	1%	4%
MO	2%	2%	7%	0%	90%	3%	0%	1%
ND	5%	1%	3%	0%	86%	3%	2%	3%
NJ	1%	8%	11%	0%	72%	8%	1%	5%
OK	16%	3%	10%	0%	76%	5%	1%	1%
PA	1%	1%	13%	0%	82%	3%	1%	2%
<b>Weighted NCI-IDD Average</b>	2%	4%	19%	0%	72%	4%	1%	3%

Table 6a. Family Member’s Conditions

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Intellectual disability	Mood illness or psychiatric diagnosis	Autism spectrum disorder	Cerebral palsy
DE	76%	21%	49%	10%
DC	70%	13%	33%	20%
GA	75%	24%	31%	22%
LA	59%	27%	33%	17%
MD	70%	22%	46%	15%
MO	62%	26%	40%	20%
ND	68%	17%	35%	23%
NJ	65%	25%	51%	17%
OK	76%	18%	22%	27%
PA	82%	23%	28%	14%
<b>Weighted NCI-IDD Average</b>	72%	24%	37%	17%

Table 6b. Family Member's Conditions (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Limited or no vision	Hearing loss (severe or profound)	Brain injury	Seizure or neurological disorder
DE	5%	4%	3%	14%
DC	10%	4%	5%	17%
GA	11%	6%	10%	37%
LA	10%	6%	9%	31%
MD	8%	4%	6%	22%
MO	7%	6%	10%	34%
ND	9%	6%	5%	32%
NJ	8%	3%	7%	27%
OK	12%	11%	14%	34%
PA	10%	8%	7%	23%
<b>Weighted NCI-IDD Average</b>	9%	6%	8%	27%

Table 6c. Family Member's Conditions (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Chemical dependency	Down syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
DE	1%	15%	1%	1%	18%
DC	1%	11%	0%	2%	12%
GA	0%	11%	0%	2%	14%
LA	0%	13%	0%	1%	23%
MD	0%	14%	0%	1%	17%
MO	0%	19%	0%	0%	17%
ND	0%	18%	0%	0%	19%
NJ	0%	12%	1%	1%	18%
OK	0%	20%	1%	1%	20%
PA	0%	18%	0%	0%	16%
<b>Weighted NCI-IDD Average</b>	0%	15%	0%	1%	17%

Table 7a. Family Member’s Health Conditions

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Cardiovascular Disease	Diabetes	Cancer	High blood pressure	High cholesterol
DE	4%	13%	2%	24%	23%
DC	9%	21%	3%	35%	30%
GA	7%	24%	5%	49%	39%
LA	13%	17%	5%	36%	33%
MD	11%	12%	4%	17%	23%
MO	14%	12%	3%	21%	21%
ND	10%	4%	6%	16%	9%
NJ	9%	11%	5%	18%	33%
OK	11%	16%	5%	29%	23%
PA	12%	20%	4%	31%	34%
<b>Weighted NCI-IDD Average</b>	11%	17%	4%	29%	32%

Table 7b. Family Member's Health Conditions (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Dysphagia	Pressure ulcers	Alzheimer's disease or dementia	Oral health problems	Sleep apnea
DE	3%	1%	2%	9%	25%
DC	1%	0%	1%	4%	13%
GA	11%	2%	3%	12%	18%
LA	10%	3%	1%	12%	16%
MD	9%	2%	1%	6%	19%
MO	15%	1%	2%	21%	24%
ND	17%	6%	0%	12%	22%
NJ	11%	1%	1%	8%	17%
OK	14%	1%	1%	16%	25%
PA	8%	1%	2%	10%	15%
<b>Weighted NCI-IDD Average</b>	10%	1%	2%	11%	17%



Table 7c. Family Member’s Health Conditions (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Asthma	Other pulmonary diagnosis (e.g., COPD, bronchitis, emphysema)	Chronic kidney disease	Long-term health problems associated with COVID-19 (also known as Long COVID)	Other
DE	16%	1%	1%	0%	32%
DC	24%	2%	3%	2%	21%
GA	13%	6%	5%	1%	15%
LA	14%	8%	5%	1%	25%
MD	17%	5%	3%	1%	36%
MO	14%	4%	4%	1%	28%
ND	17%	3%	7%	1%	28%
NJ	17%	6%	6%	2%	34%
OK	16%	5%	5%	2%	22%
PA	11%	4%	5%	1%	23%
<b>Weighted NCI-IDD Average</b>	14%	5%	5%	1%	26%

**Table 8. Family Member’s Preferred Means of Communication**

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
DE	87%	8%	0%	2%	2%	162
DC	80%	12%	1%	1%	7%	162
GA	73%	18%	1%	1%	6%	449
LA	79%	14%	1%	1%	5%	1,241
MD	78%	13%	2%	3%	4%	742
MO	76%	16%	0%	3%	4%	244
ND	72%	17%	1%	2%	8%	127
NJ	79%	11%	0%	3%	7%	745
OK	73%	20%	3%	1%	4%	357
PA	82%	11%	2%	1%	3%	664
<b>Weighted NCI-IDD Average</b>	79%	13%	1%	2%	5%	4,893

Table 9. Family Member's Preferred Language

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State (names abbreviated)	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
DE	99%	1%	0%	0%	0%	0%	0%	164
DC	96%	2%	0%	0%	0%	1%	1%	164
GA	97%	0%	0%	0%	0%	2%	2%	448
LA	98%	0%	0%	0%	0%	1%	1%	1,246
MD	97%	1%	0%	0%	0%	1%	2%	743
MO	98%	0%	0%	0%	0%	0%	2%	257
ND	97%	0%	0%	0%	0%	2%	1%	126
NJ	95%	1%	0%	0%	0%	0%	3%	743
OK	95%	1%	0%	0%	1%	1%	2%	355
PA	96%	1%	0%	0%	0%	1%	1%	658
<b>Weighted NCI-IDD Average</b>	96%	1%	0%	0%	0%	1%	2%	4,904

Table Note: "Chinese" includes Mandarin, Cantonese, and Hokkien; "Tagalog" includes Filipino.

Table 10. Family Member Has Legal Court Appointed Guardian or Conservator

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State (names abbreviated)	No guardianship	Limited guardianship	Full guardianship	Has guardianship but level unknown	N
DE	38%	14%	44%	4%	160
DC	36%	14%	40%	10%	155
GA	32%	16%	47%	6%	415
LA	34%	14%	45%	8%	1,133
MD	55%	8%	33%	4%	691
MO	21%	7%	71%	2%	252
ND	4%	13%	81%	2%	125
NJ	21%	6%	70%	2%	732
OK	17%	9%	70%	4%	352
PA	47%	9%	37%	6%	611
<b>Weighted NCI-IDD Average</b>	<b>35%</b>	<b>10%</b>	<b>50%</b>	<b>5%</b>	<b>4,626</b>

Table 11. Guardian or Conservator Relationship to Family Member

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State (names abbreviated)	Family	Friend	Employee of state or guardianship agency	Other	N
DE	99%	0%	0%	1%	94
DC	89%	0%	2%	9%	90
GA	93%	1%	0%	5%	233
LA	93%	1%	0%	6%	676
MD	95%	0%	0%	4%	306
MO	98%	0%	0%	2%	194
ND	97%	0%	1%	2%	117
NJ	98%	0%	0%	2%	568
OK	96%	0%	0%	3%	275
PA	95%	0%	0%	4%	288
<b>Weighted NCI-IDD Average</b>	96%	0%	0%	4%	2,841

Table 12a. Family Member’s Highest Level of Education

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State (names abbreviated)	Did not complete high school – Not currently in school	Currently enrolled in high school	High school certificate (NOT a high school diploma or GED)	N
DE	7%	0%	61%	165
DC	22%	0%	40%	157
GA	21%	0%	47%	435
LA	21%	2%	46%	1,221
MD	8%	2%	59%	732
MO	12%	1%	28%	250
ND	2%	9%	35%	110
NJ	13%	1%	26%	723
OK	12%	2%	26%	357
PA	17%	3%	19%	629
<b>Weighted NCI-IDD Average</b>	<b>15%</b>	<b>2%</b>	<b>32%</b>	<b>4,779</b>

Table 12b. Family Member’s Highest Level of Education (continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State (names abbreviated)	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
DE	20%	2%	5%	5%	165
DC	21%	8%	5%	3%	157
GA	28%	1%	0%	2%	435
LA	19%	3%	5%	5%	1,221
MD	16%	3%	5%	6%	732
MO	50%	1%	5%	4%	250
ND	46%	1%	4%	3%	110
NJ	43%	4%	5%	9%	723
OK	52%	3%	1%	3%	357
PA	54%	3%	2%	3%	629
<b>Weighted NCI-IDD Average</b>	40%	3%	4%	5%	4,779

Table 13. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State (names abbreviated)	No support needed; no issues with managing behavior	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
DE	70%	27%	2%	162
DC	63%	24%	12%	161
GA	52%	31%	17%	440
LA	51%	32%	16%	1,222
MD	57%	25%	18%	715
MO	52%	31%	18%	251
ND	53%	37%	10%	123
NJ	50%	31%	18%	724
OK	61%	25%	13%	357
PA	63%	26%	10%	647
<b>Weighted NCI-IDD Average</b>	56%	29%	15%	4,802



Table 14. Family Member’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State (names abbreviated)	No support needed; no issues with personal care activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed	N
DE	41%	41%	18%	165
DC	37%	40%	23%	161
GA	24%	34%	42%	440
LA	20%	38%	42%	1,240
MD	24%	38%	38%	734
MO	20%	37%	42%	259
ND	15%	43%	43%	129
NJ	16%	36%	48%	736
OK	20%	35%	45%	359
PA	31%	39%	30%	656
<b>Weighted NCI-IDD Average</b>	24%	37%	39%	4,879

Table 15. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State (names abbreviated)	No support needed (no issues with other daily activities)	Some support needed; requires only occasional assistance or monitoring	Extensive support needed	N
DE	7%	27%	66%	166
DC	8%	27%	65%	161
GA	4%	18%	78%	442
LA	6%	19%	75%	1,228
MD	2%	19%	79%	739
MO	2%	14%	84%	261
ND	2%	18%	80%	128
NJ	2%	16%	81%	740
OK	2%	16%	81%	356
PA	5%	21%	74%	652
<b>Weighted NCI-IDD Average</b>	<b>4%</b>	<b>19%</b>	<b>77%</b>	<b>4,873</b>

## **Respondents**

This section provides information about the survey respondent.

Table 16. Language Usually Spoken at Home

State (names abbreviated)	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
DE	99%	1%	0%	0%	0%	0%	1%	164
DC	95%	2%	0%	0%	0%	1%	2%	162
GA	99%	0%	0%	0%	0%	0%	1%	452
LA	99%	0%	0%	0%	0%	0%	0%	1,248
MD	95%	2%	0%	0%	0%	0%	2%	723
MO	99%	0%	0%	0%	0%	0%	0%	261
ND	99%	0%	0%	0%	0%	1%	0%	124
NJ	95%	2%	0%	0%	0%	0%	2%	734
OK	97%	2%	0%	0%	1%	1%	0%	355
PA	97%	2%	0%	0%	0%	1%	1%	660
<b>Weighted NCI-IDD Average</b>	97%	1%	0%	0%	0%	0%	1%	4,883

Table Note: "Chinese" includes Mandarin, Cantonese, and Hokkien. "Tagalog" includes Filipino.

Table 17. Respondent's Age

State (names abbreviated)	18 - 34	35 - 54	55 - 74	75 or older	N
DE	1%	19%	74%	6%	166
DC	4%	23%	57%	15%	162
GA	2%	10%	67%	21%	449
LA	3%	23%	60%	14%	1,256
MD	3%	19%	72%	6%	741
MO	2%	25%	63%	11%	263
ND	5%	31%	58%	6%	129
NJ	2%	12%	77%	10%	745
OK	1%	16%	63%	20%	357
PA	2%	15%	65%	18%	657
<b>Weighted NCI-IDD Average</b>	2%	16%	68%	14%	4,925

Table 18. Respondent's Health

State (names abbreviated)	Excellent	Very good	Good	Fair	Poor	N
DE	12%	39%	37%	10%	1%	164
DC	12%	34%	41%	12%	1%	164
GA	7%	27%	43%	22%	2%	446
LA	9%	33%	37%	18%	3%	1,256
MD	14%	38%	36%	11%	1%	741
MO	13%	33%	39%	13%	2%	261
ND	16%	40%	35%	8%	1%	129
NJ	14%	37%	34%	13%	1%	741
OK	11%	29%	42%	17%	1%	359
PA	9%	32%	42%	16%	1%	658
<b>Weighted NCI-IDD Average</b>	<b>11%</b>	<b>33%</b>	<b>39%</b>	<b>15%</b>	<b>2%</b>	<b>4,919</b>

Table 19. Respondent's Relationship to Family Member

State (names abbreviated)	Parent (biological, adoptive, or foster)	Sibling	Spouse	Grandparent	Other	N
DE	88%	5%	1%	4%	2%	167
DC	75%	12%	1%	6%	7%	163
GA	77%	14%	0%	2%	6%	450
LA	83%	7%	1%	4%	5%	1,257
MD	94%	4%	0%	0%	1%	743
MO	92%	6%	0%	1%	2%	259
ND	98%	2%	0%	1%	0%	128
NJ	93%	5%	0%	1%	1%	745
OK	86%	6%	0%	3%	5%	360
PA	81%	16%	0%	1%	2%	666
<b>Weighted NCI-IDD Average</b>	86%	10%	0%	1%	3%	4,938

Table 20. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services

State (names abbreviated)	No	Yes, respondent does	Yes, another family member does	N
DE	90%	6%	4%	164
DC	58%	34%	10%	161
GA	88%	6%	7%	449
LA	64%	20%	18%	1,228
MD	65%	25%	13%	738
MO	73%	12%	15%	260
ND	86%	2%	12%	129
NJ	40%	37%	27%	738
OK	46%	39%	17%	357
PA	68%	20%	15%	656
<b>Weighted NCI-IDD Average</b>	63%	23%	17%	4,880

Table Note: Data combined from “select all that apply” questions and therefore might sum over 100%.



Table 21. Number of Adults in Household (Not Including Family Member Receiving Supports)

State (names abbreviated)	One	Two	Three	Four or more	N
DE	4%	20%	52%	24%	163
DC	19%	43%	28%	10%	159
GA	10%	37%	43%	10%	446
LA	11%	32%	45%	12%	1,240
MD	4%	22%	52%	23%	737
MO	5%	30%	50%	15%	261
ND	9%	25%	53%	14%	129
NJ	4%	20%	50%	26%	738
OK	8%	32%	51%	9%	360
PA	4%	32%	47%	17%	657
<b>Weighted NCI-IDD Average</b>	<b>6%</b>	<b>28%</b>	<b>48%</b>	<b>18%</b>	<b>4,890</b>

Table 22. Number of Children (Under 18 Years Old) in Household

State (names abbreviated)	One	Two	Three	Four or more	None	N
DE	7%	2%	1%	0%	90%	166
DC	8%	3%	1%	1%	88%	160
GA	5%	1%	1%	0%	94%	450
LA	7%	3%	1%	0%	89%	1,250
MD	7%	3%	1%	0%	89%	740
MO	5%	3%	1%	1%	90%	263
ND	9%	3%	1%	2%	86%	125
NJ	5%	1%	0%	0%	94%	739
OK	4%	1%	1%	1%	93%	359
PA	4%	3%	0%	0%	93%	659
<b>Weighted NCI-IDD Average</b>	<b>5%</b>	<b>2%</b>	<b>1%</b>	<b>0%</b>	<b>92%</b>	<b>4,911</b>

Table 23. Respondent’s Highest Level of Education

State (names abbreviated)	No high school diploma or GED	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
DE	3%	21%	4%	19%	52%	159
DC	10%	34%	4%	22%	30%	162
GA	9%	32%	10%	18%	31%	447
LA	9%	31%	8%	19%	32%	1,239
MD	1%	13%	2%	20%	63%	723
MO	5%	22%	6%	20%	47%	251
ND	1%	14%	11%	16%	58%	127
NJ	2%	15%	4%	18%	61%	728
OK	4%	26%	6%	25%	39%	359
PA	6%	39%	8%	18%	29%	661
<b>Weighted NCI-IDD Average</b>	5%	27%	7%	19%	43%	4,856

Table 24. Total Taxable Household Income of Wage Earners Last Year

Please note: Respondents did not respond if they were a public guardian/administrator, or if they represent a financial institution or guardianship agency. Does not include state/federal benefits such as SSI, SSDI etc.

State (names abbreviated)	No earned income	Up to \$15,000	\$15,001–\$25,000	\$25,001–\$50,000	\$50,001–\$75,000	Over \$75,000	Prefer not to say	N
DE	7%	2%	5%	14%	15%	27%	29%	163
DC	17%	10%	7%	18%	6%	13%	28%	162
GA	20%	7%	12%	16%	8%	11%	26%	437
LA	15%	8%	12%	16%	10%	14%	24%	1,208
MD	5%	1%	4%	12%	15%	37%	26%	725
MO	9%	5%	9%	24%	16%	20%	16%	255
ND	8%	3%	6%	13%	18%	39%	13%	126
NJ	4%	3%	5%	11%	14%	36%	28%	732
OK	7%	11%	10%	17%	17%	16%	21%	349
PA	14%	6%	9%	16%	11%	17%	26%	643
<b>Weighted NCI-IDD Average</b>	11%	5%	8%	15%	12%	23%	25%	4,800

## **Services and Supports Received**

This section provides information about the services and supports received by the family from the state IDD agency.

Table 25a. Services and Supports Received from IDD Agency

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Financial support	In home support	Out-of-home respite care	Day or employment supports
DE	6%	4%	17%	73%
DC	11%	69%	33%	47%
GA	18%	37%	20%	54%
LA	13%	61%	16%	23%
MD	13%	43%	21%	55%
MO	20%	43%	25%	50%
ND	9%	55%	41%	62%
NJ	22%	34%	17%	62%
OK	15%	45%	10%	34%
PA	14%	38%	23%	48%
<b>Weighted NCI-IDD Average</b>	16%	40%	20%	51%

Table 25b. Services and Supports Received from IDD Agency (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Transportation	Mental or behavioral health care or other treatments or therapies	Self-direction or fiscal intermediary services
DE	67%	28%	25%
DC	66%	36%	34%
GA	61%	28%	42%
LA	45%	24%	37%
MD	57%	30%	41%
MO	57%	32%	47%
ND	57%	32%	40%
NJ	62%	35%	64%
OK	46%	21%	38%
PA	59%	27%	44%
<b>Weighted NCI-IDD Average</b>	<b>58%</b>	<b>29%</b>	<b>47%</b>

Table 26. Additional Services and Supports Received (not from the IDD Agency)

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Social Security (SSI or SSB)	Services or supports from other agencies or organizations
DE	87%	33%
DC	89%	26%
GA	97%	22%
LA	94%	22%
MD	93%	34%
MO	95%	37%
ND	90%	54%
NJ	94%	28%
OK	97%	20%
PA	94%	40%
<b>Weighted NCI-IDD Average</b>	<b>94%</b>	<b>32%</b>



## Main Survey Results

Note on Significance: Statistical significance depends on both the amount by which a state differs from the average for a given item and the state's sample size for that item. There may be instances where State A's difference from the average is larger than State B's, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.

## Information and Planning

Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state developmental disabilities system.

**Note: Significance is based on “Always” or “Yes” response.**

“**You**” and “**Respondent**” refers to the person (usually a parent or guardian) filling out the survey.

“**Family Member**” refers to the person receiving services whom the respondent is answering questions about in this survey.

## Do you get enough information to take part in planning services for your family member?

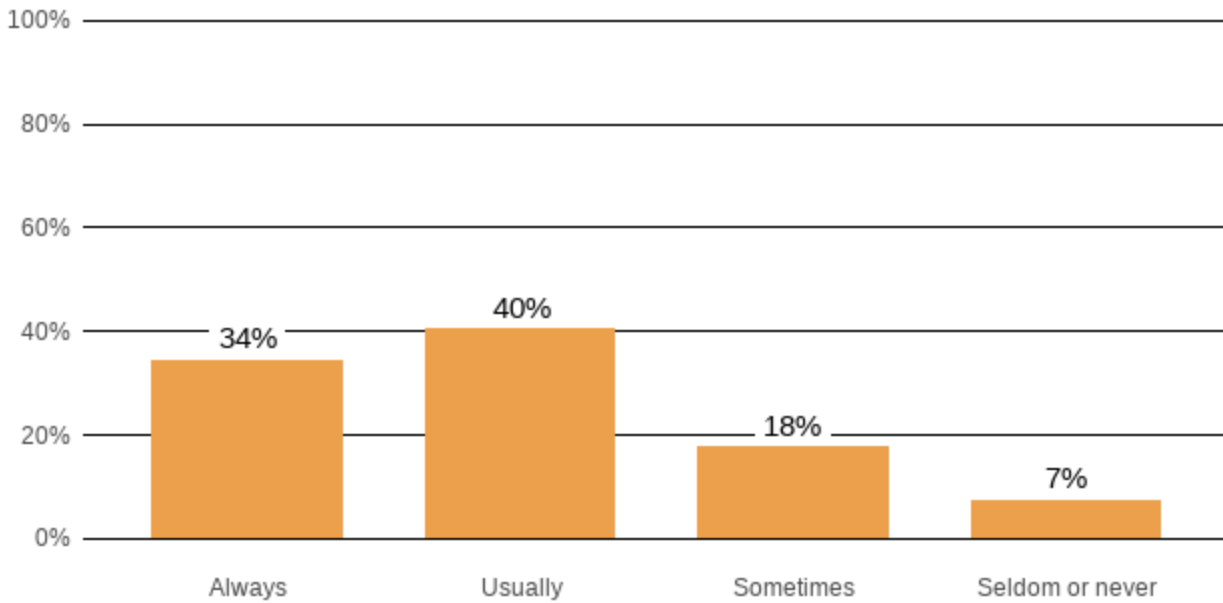


Table 27. Do you get enough information to take part in planning services for your family member?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	46%	30%	20%	4%	158
LA ↑	41%	36%	17%	6%	1,132
ND	39%	41%	16%	4%	128
PA	39%	39%	15%	8%	594
OK	36%	42%	15%	7%	344
<b>Weighted NCI-IDD Average</b>	<b>34%</b>	<b>40%</b>	<b>18%</b>	<b>7%</b>	<b>4,569</b>
GA	34%	39%	17%	10%	381
MO	32%	45%	17%	7%	246
MD	30%	43%	20%	7%	705
DE	29%	34%	27%	11%	161
NJ ↓	29%	43%	22%	7%	720

## Is the information you get about services and supports easy to understand?

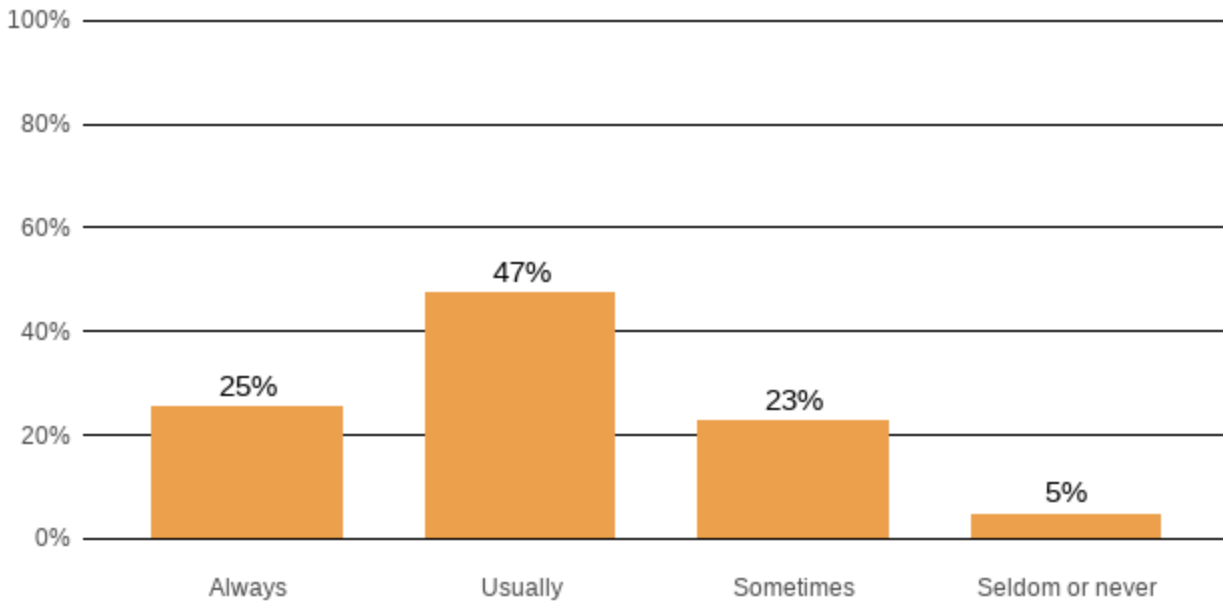


Table 28. Is the information you get about services and supports easy to understand?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	41%	41%	17%	1%	151
LA ↑	34%	45%	18%	4%	1,167
ND	30%	52%	14%	5%	128
OK	29%	48%	18%	5%	337
MO	29%	48%	18%	4%	250
GA	28%	43%	24%	5%	395
PA	26%	49%	22%	3%	616
DE	25%	44%	26%	4%	161
<b>Weighted NCI-IDD Average</b>	<b>25%</b>	<b>47%</b>	<b>23%</b>	<b>5%</b>	<b>4,646</b>
NJ ↓	20%	47%	26%	6%	724
MD ↓	19%	49%	25%	7%	717

## Do you get information about services and supports in your preferred language?

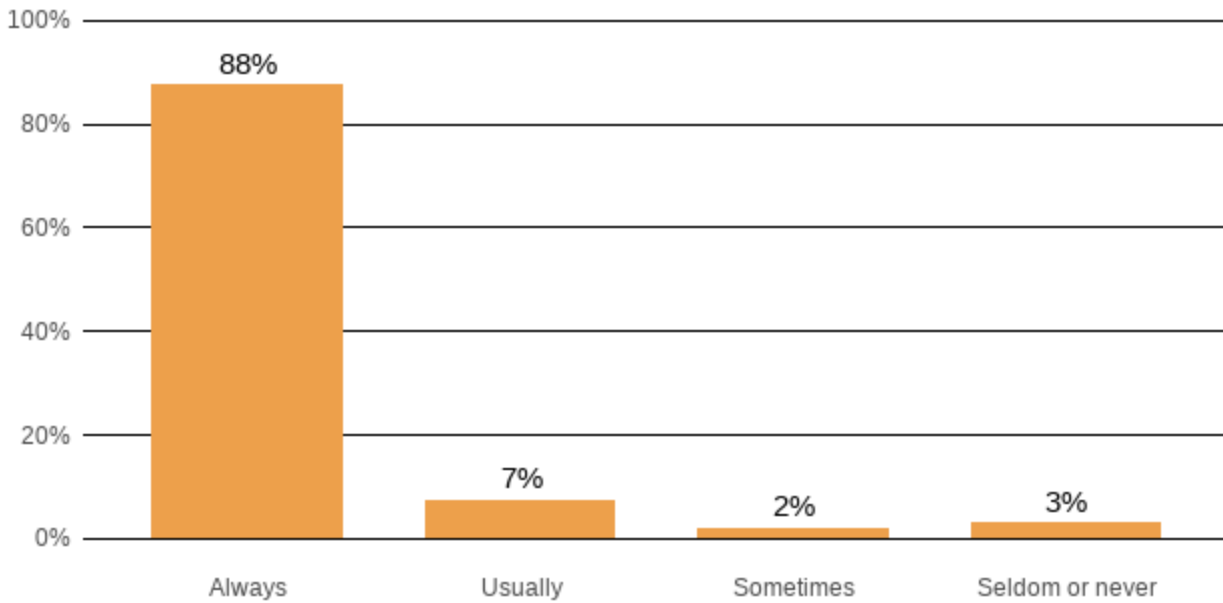


Table 29. Do you get information about services and supports in your preferred language?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
ND ↑	96%	2%	1%	1%	128
DE	90%	7%	1%	2%	159
MO	90%	7%	2%	2%	256
PA	89%	6%	3%	3%	632
MD	88%	6%	2%	3%	732
LA	88%	8%	1%	2%	1,202
OK	88%	7%	2%	3%	344
<b>Weighted NCI-IDD Average</b>	<b>88%</b>	<b>7%</b>	<b>2%</b>	<b>3%</b>	<b>4,759</b>
NJ	87%	8%	2%	3%	729
GA	83%	10%	1%	6%	419
DC	82%	10%	4%	4%	158

## Does the case manager/service coordinator listen to your family's choices and opinions?

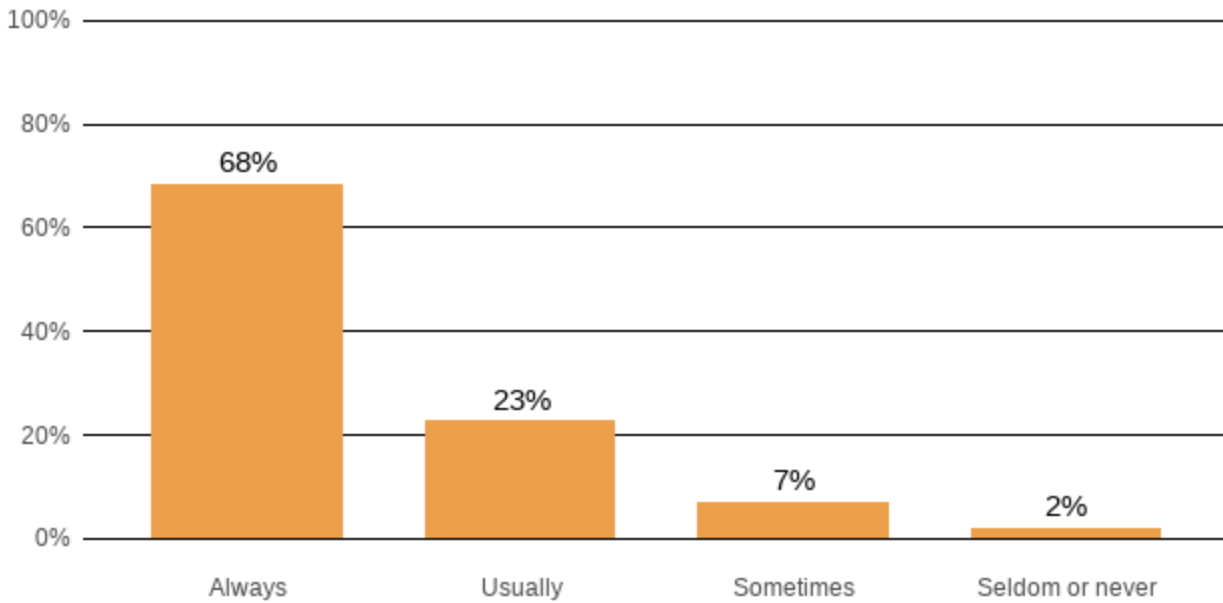


Table 30. Does the case manager/service coordinator listen to your family's choices and opinions?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	78%	15%	6%	1%	156
NJ ↑	74%	20%	5%	1%	716
PA	70%	21%	7%	2%	623
LA	69%	24%	5%	2%	1,176
<b>Weighted NCI-IDD Average</b>	<b>68%</b>	<b>23%</b>	<b>7%</b>	<b>2%</b>	<b>4,672</b>
MO	67%	24%	7%	2%	246
OK	66%	25%	7%	3%	354
MD	65%	25%	7%	3%	716
DE	59%	29%	8%	4%	158
GA ↓	57%	28%	10%	4%	404
ND ↓	56%	34%	7%	2%	123

## Do you have enough information about other public services for which your family is eligible?

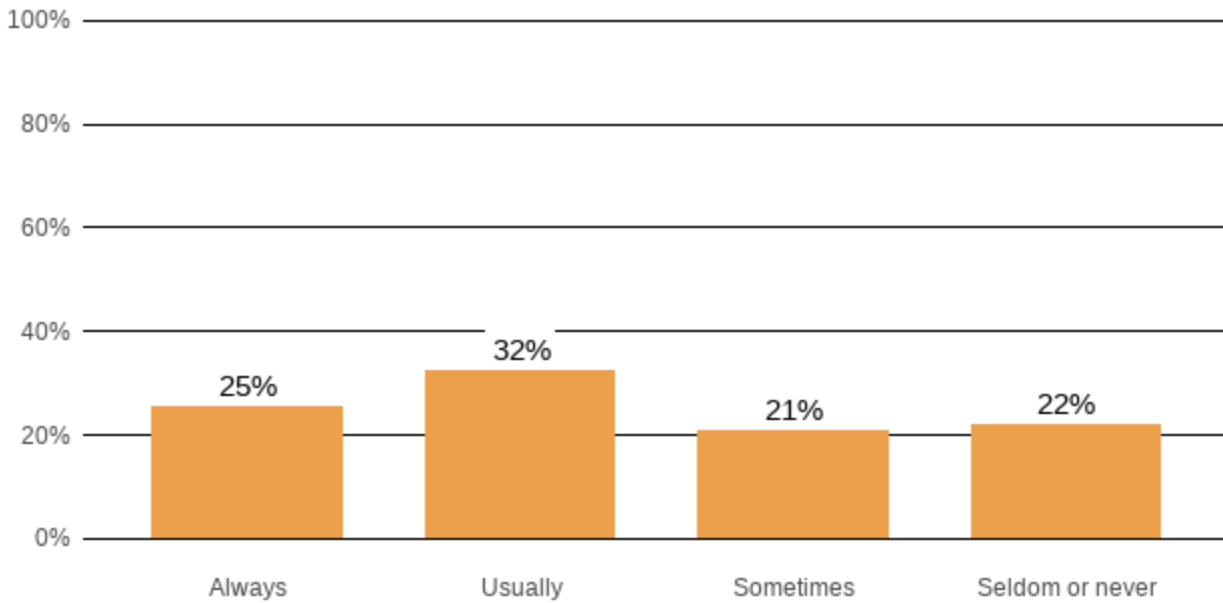


Table 31. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	44%	24%	15%	17%	143
PA ↑	31%	34%	19%	17%	509
OK	27%	34%	18%	21%	302
LA	27%	30%	19%	24%	987
MO	25%	34%	17%	23%	220
ND	25%	32%	25%	18%	110
<b>Weighted NCI-IDD Average</b>	<b>25%</b>	<b>32%</b>	<b>21%</b>	<b>22%</b>	<b>4,026</b>
GA	22%	26%	21%	31%	339
DE	21%	29%	25%	25%	140
NJ ↓	21%	35%	23%	22%	653
MD ↓	21%	31%	26%	23%	623

**Do you need help planning for your family member's future in any of the following areas?**

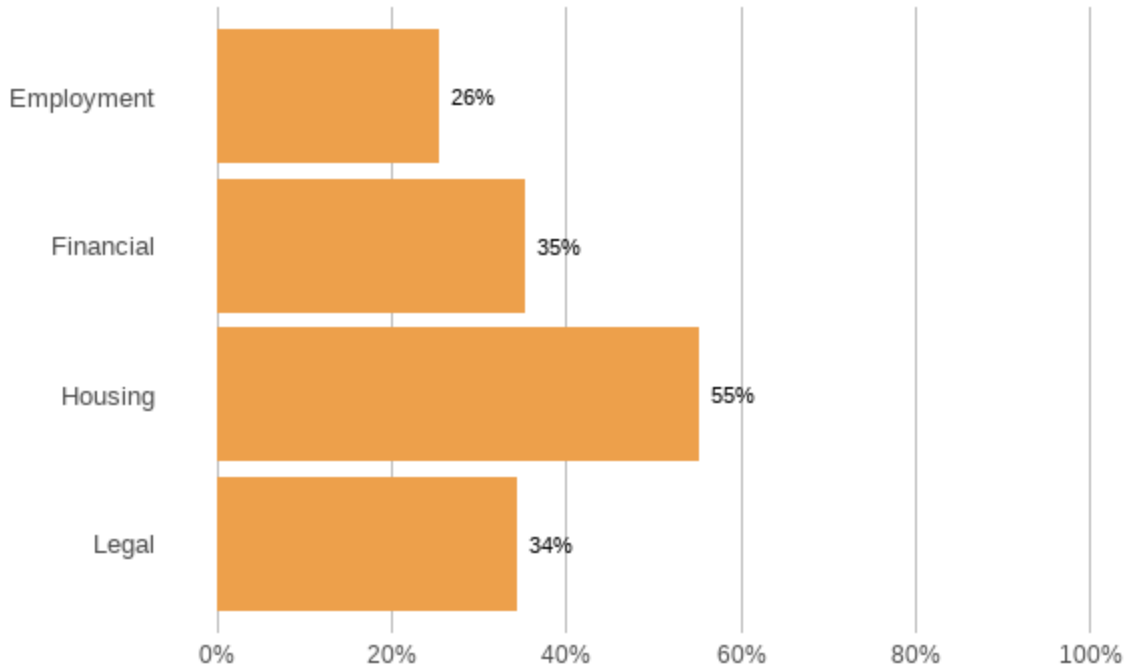


Table 32a. Do you need help planning for your family member's future in any of the following areas?

Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Employment	Financial	Housing	Legal
DE	31%	37%	57%	38%
DC	29%	27%	48%	25%
GA	15%	30%	49%	36%
LA	19%	30%	37%	34%
MD	39%	46%	60%	44%
MO	21%	31%	54%	38%
ND	42%	59%	64%	32%
NJ	31%	41%	69%	35%
OK	24%	22%	42%	25%
PA	21%	31%	49%	30%
<b>Weighted NCI-IDD Average</b>	<b>26%</b>	<b>35%</b>	<b>55%</b>	<b>34%</b>



**Do you need help planning for your family member's future in any of the following areas? (continued)**

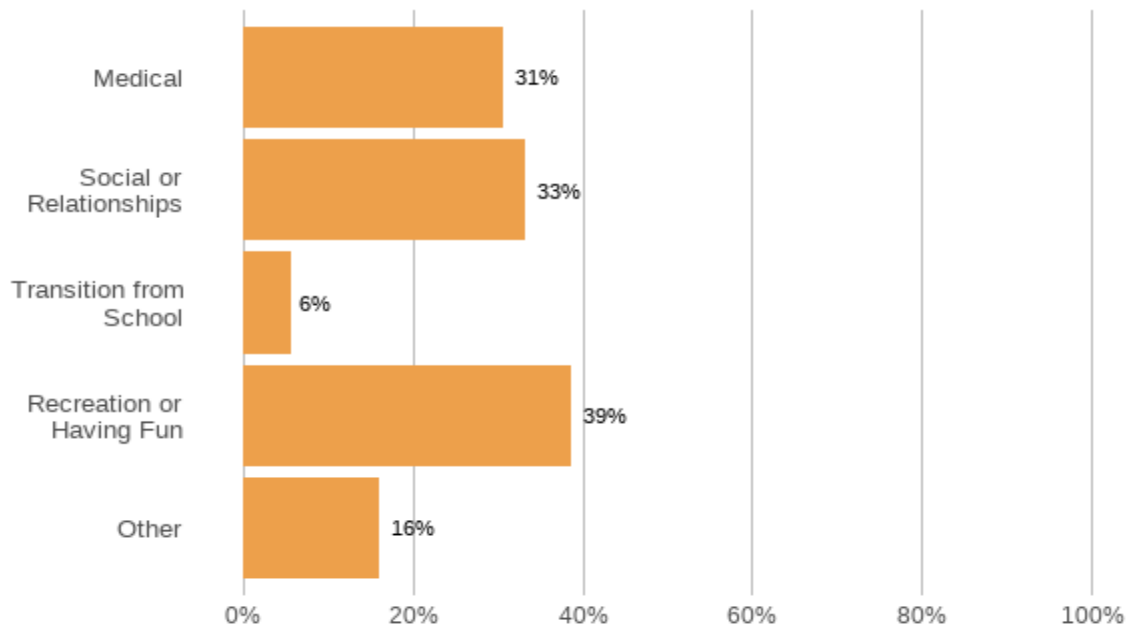


Table 32b. Do you need help planning for your family member's future in any of the following areas? (continued)

Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Medical	Social or Relationships	Transition from School	Recreation or Having Fun	Other
DE	32%	42%	5%	40%	12%
DC	20%	27%	5%	44%	12%
GA	31%	28%	4%	34%	15%
LA	29%	27%	8%	33%	25%
MD	35%	41%	7%	41%	12%
MO	28%	31%	6%	34%	16%
ND	38%	43%	25%	48%	16%
NJ	36%	38%	5%	45%	11%
OK	25%	23%	6%	33%	21%
PA	25%	30%	5%	37%	20%
<b>Weighted NCI-IDD Average</b>	<b>31%</b>	<b>33%</b>	<b>6%</b>	<b>39%</b>	<b>16%</b>

## Has your family learned about alternatives to guardianship?

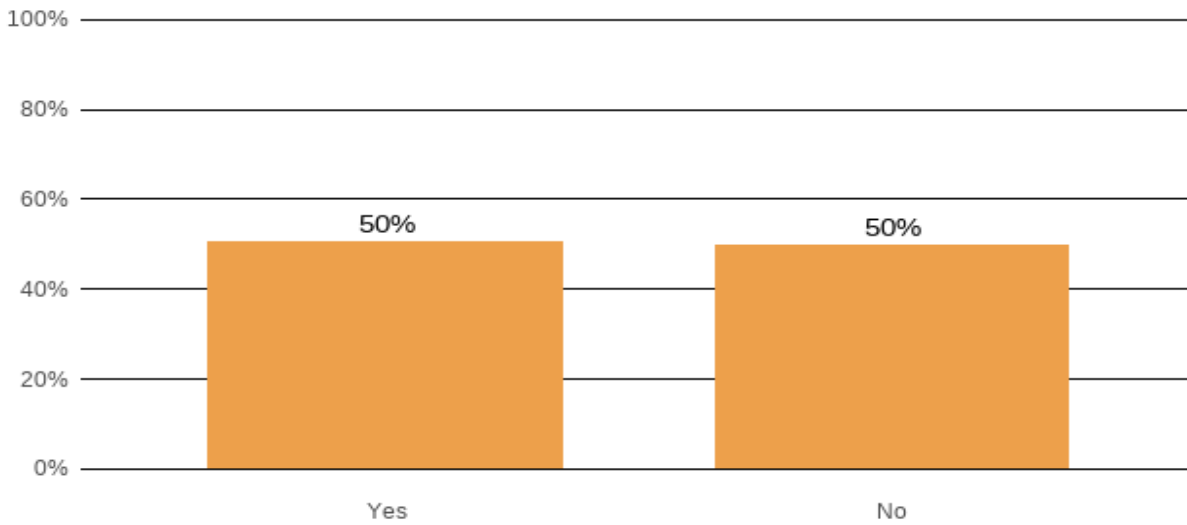


Table 33. Has your family learned about alternatives to guardianship?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
ND ↑	68%	32%	114
PA ↑	56%	44%	526
DC	61%	39%	140
OK	52%	48%	301
<b>Weighted NCI-IDD Average</b>	<b>50%</b>	<b>50%</b>	<b>4,108</b>
MO	50%	50%	228
LA	49%	51%	981
DE	49%	51%	150
MD	48%	52%	655
GA	48%	52%	357
NJ ↓	45%	55%	656

Alternatives to guardianship let a family member make more decisions for themselves, with or without the help of others. This might include: **Supported Decision Making (SDM)**, allows a person with a disability to make their own decisions with the help of people they trust. **Other decision-making supports** like health-care proxies, advance directives, powers of attorney, notarized statements, representation agreements, etc.

## Does your family member have a service plan?

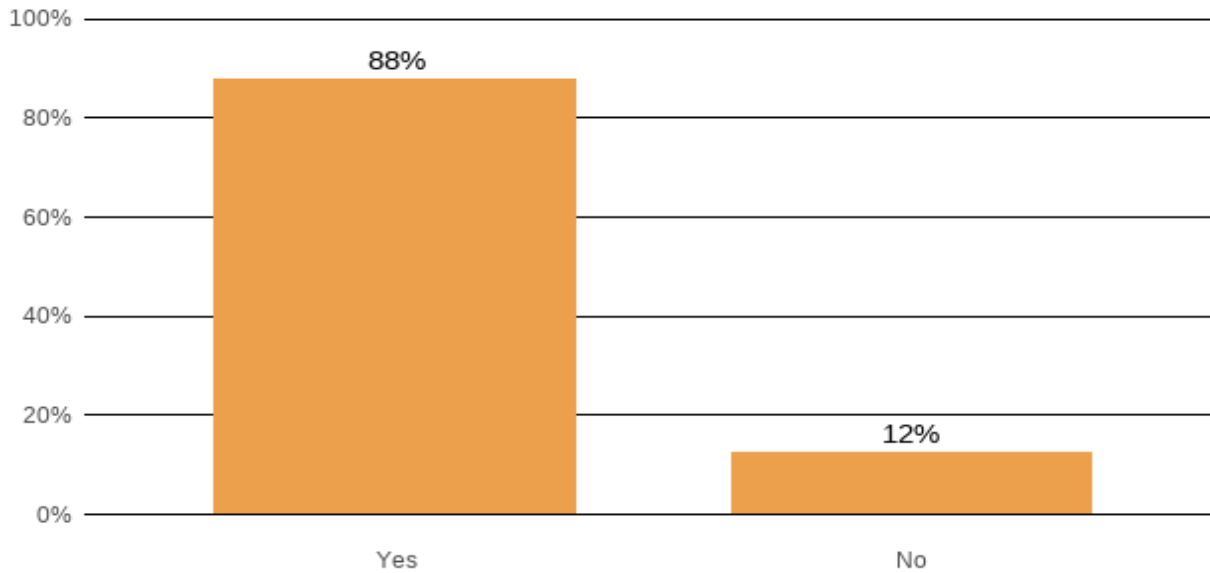


Table 34. Does your family member have a service plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
PA ↑	95%	5%	615
MO	91%	9%	240
OK	91%	9%	341
DC	91%	9%	152
NJ	90%	10%	658
MD	90%	10%	645
<b>Weighted NCI-IDD Average</b>	<b>88%</b>	<b>12%</b>	<b>4,323</b>
LA ↓	81%	19%	1,080
ND ↓	77%	23%	107
GA ↓	64%	36%	357
DE ↓	63%	38%	128

Please note: Data for this question are reported by the respondent based on their understanding of their family member's services and supports.

## Does the plan include all the services and supports your family member needs?

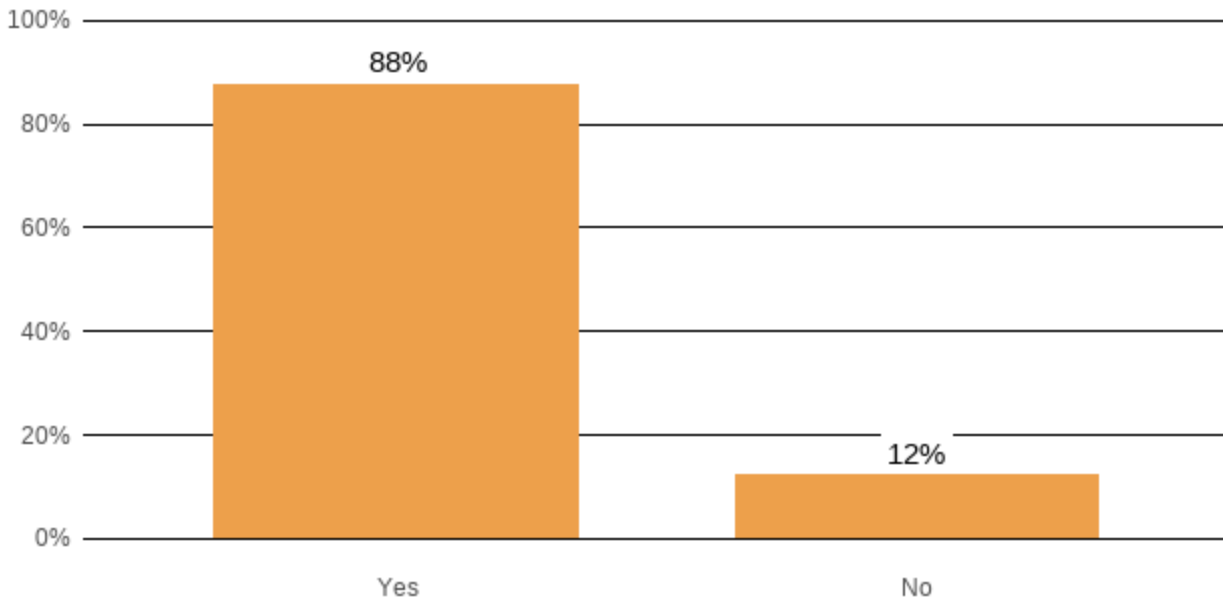


Table 35. Does the plan include all the services and supports your family member needs?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
DC ↑	94%	6%	126
LA ↑	93%	7%	747
PA ↑	93%	7%	508
ND	91%	9%	75
<b>Weighted NCI-IDD Average</b>	<b>88%</b>	<b>12%</b>	<b>3,226</b>
OK	86%	14%	276
MO	86%	15%	200
NJ	84%	16%	525
GA	82%	18%	194
DE	78%	22%	69
MD ↓	81%	19%	506

**Did you or someone else in your family (besides your family member with a disability) help make the plan?**

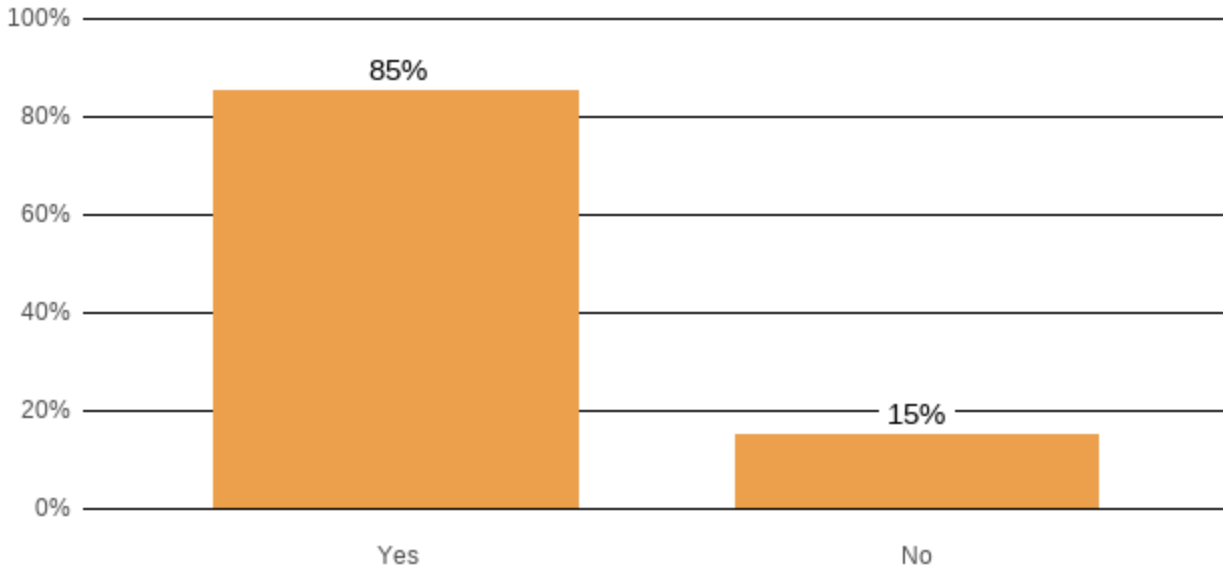


Table 36. Did you or someone else in your family (besides your family member with a disability) help make the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
ND ↑	94%	6%	80
MD ↑	90%	10%	562
MO	90%	10%	214
OK	88%	12%	302
DE	88%	12%	75
NJ	87%	13%	574
<b>Weighted NCI-IDD Average</b>	<b>85%</b>	<b>15%</b>	<b>3,532</b>
GA	84%	16%	219
PA	82%	18%	545
DC	76%	24%	134
LA ↓	81%	19%	827

## Did your family member help make the plan?

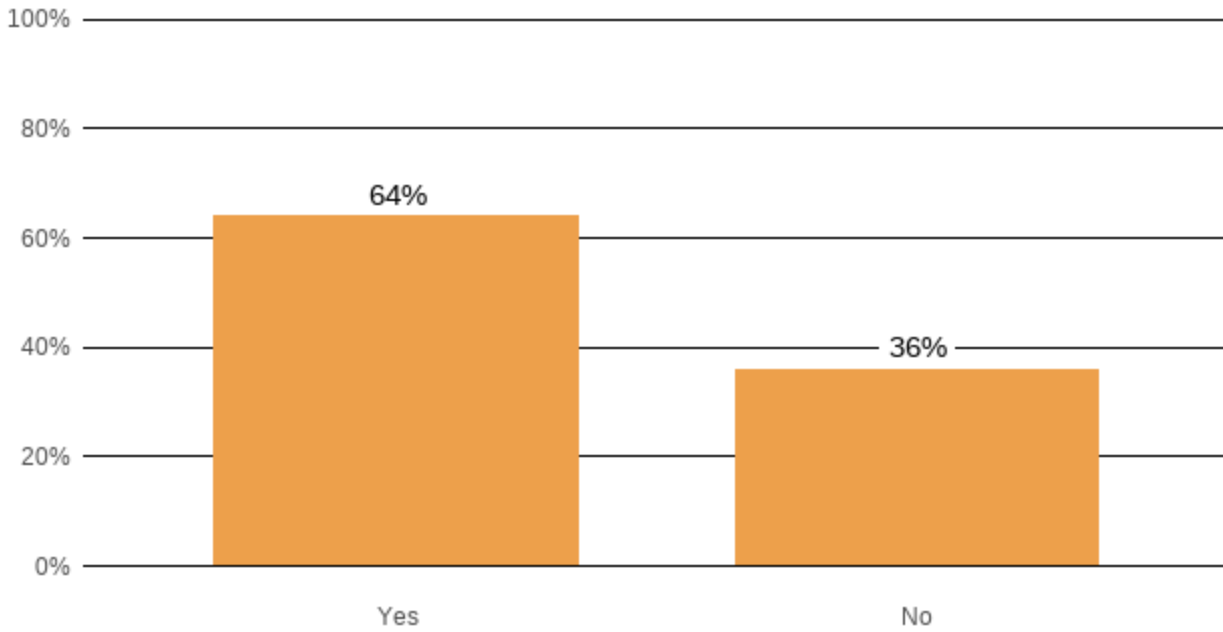


Table 37. Did your family member help make the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
MD ↑	76%	24%	558
MO	67%	33%	211
DE	67%	33%	75
DC	66%	34%	134
ND	65%	35%	78
<b>Weighted NCI-IDD Average</b>	<b>64%</b>	<b>36%</b>	<b>3,506</b>
PA	64%	36%	537
GA	62%	38%	213
OK	61%	39%	302
NJ	61%	39%	577
LA	60%	40%	821

### Do you feel like your family had enough say or input in making the plan?

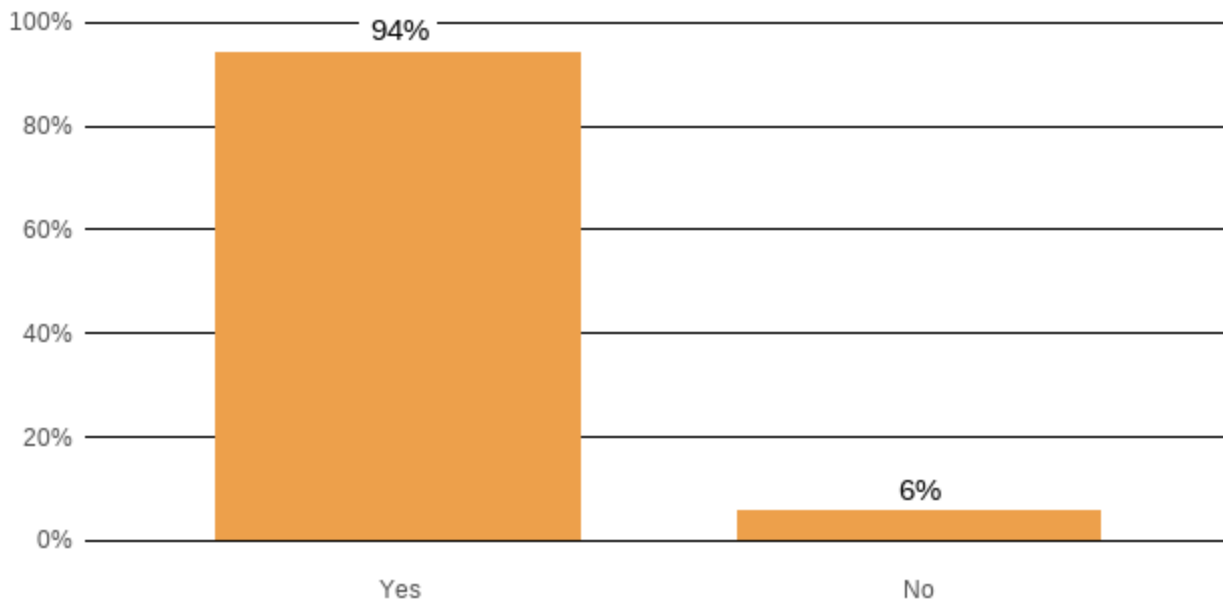


Table 38. Do you feel like your family had enough say or input in making the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
PA	96%	4%	521
MO	96%	4%	201
OK	95%	5%	289
<b>Weighted NCI-IDD Average</b>	<b>94%</b>	<b>6%</b>	<b>3,356</b>
MD	94%	6%	532
LA	94%	6%	788
NJ	93%	7%	550
ND	93%	7%	76
DE	93%	7%	73
DC	90%	10%	126
GA ↓	88%	13%	200

### Did your family member leave school services and begin adult services during the past 12 months?

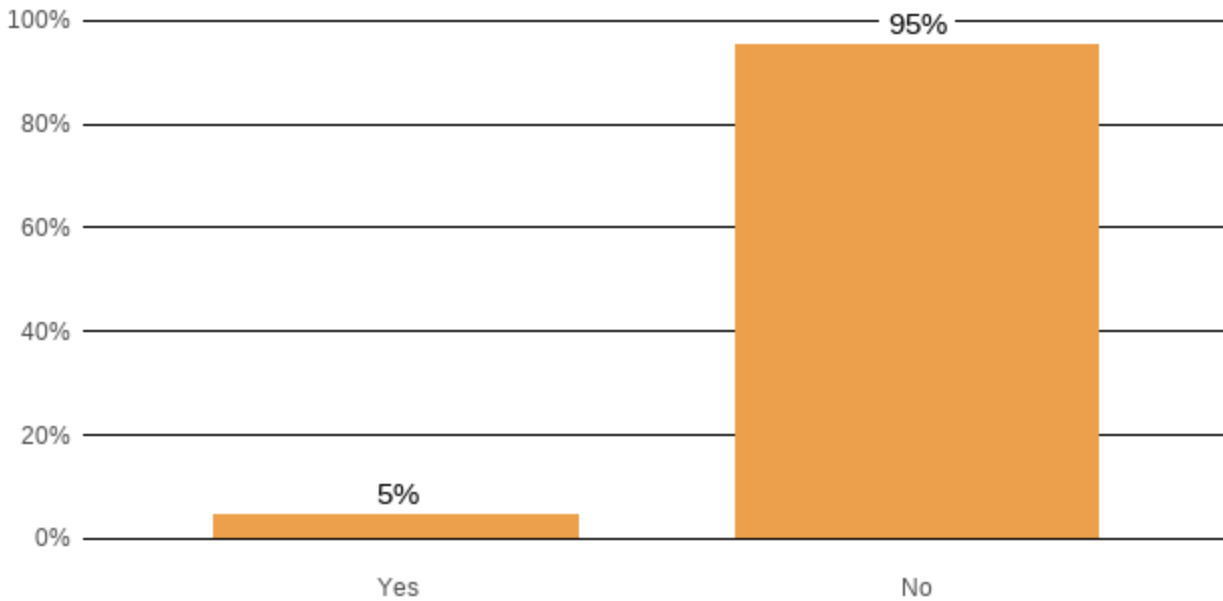


Table 39. Did your family member leave school services and begin adult services during the past 12 months?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
DC ↑	12%	88%	152
ND	11%	89%	121
DE	7%	93%	164
NJ	6%	94%	699
LA	5%	95%	1,163
PA	5%	95%	618
<b>Weighted NCI-IDD Average</b>	<b>5%</b>	<b>95%</b>	<b>3,693</b>
OK	4%	96%	351
GA ↓	0%	100%	410

The following states had a low count of responses (N<20) and were not shown: MD, MO



**If your family member left school services during the past 12 months, did they have a transition plan?**

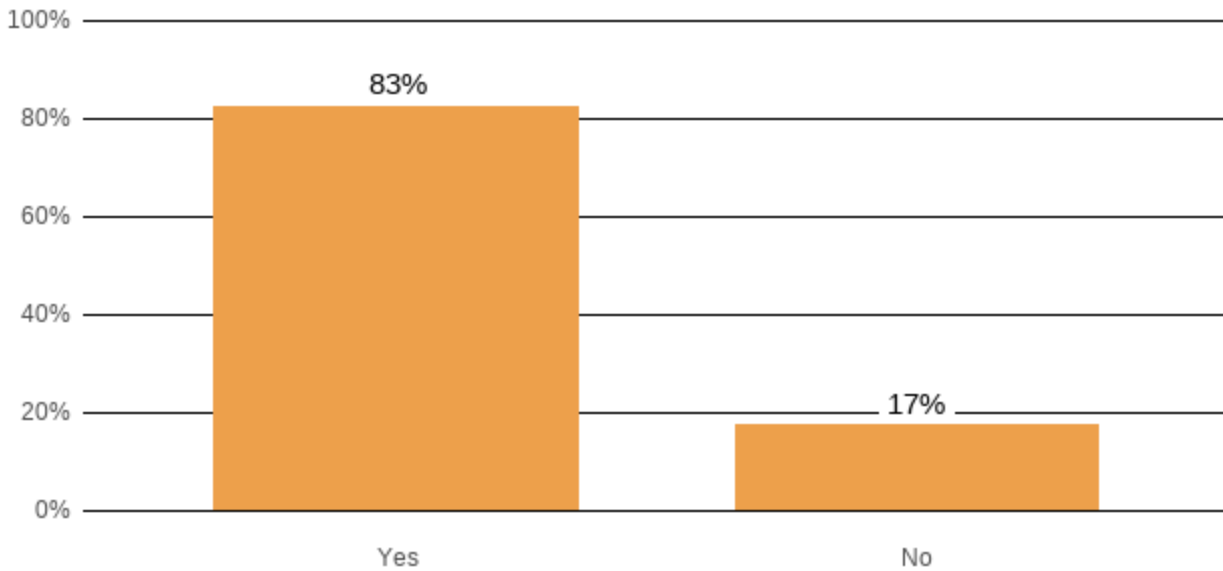


Table 40. If your family member left school services during the past 12 months, did they have a transition plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
PA ↑	100%	0%	21
<b>Weighted NCI-IDD Average</b>	<b>83%</b>	<b>17%</b>	<b>158</b>
NJ	76%	24%	34
LA	70%	30%	46

The following states had a low count of responses (N<20) and were not shown: DE, ND, MD, DC, OK, MO

**If your family member had a transition plan, did the plan include getting or continuing work in a community job?**

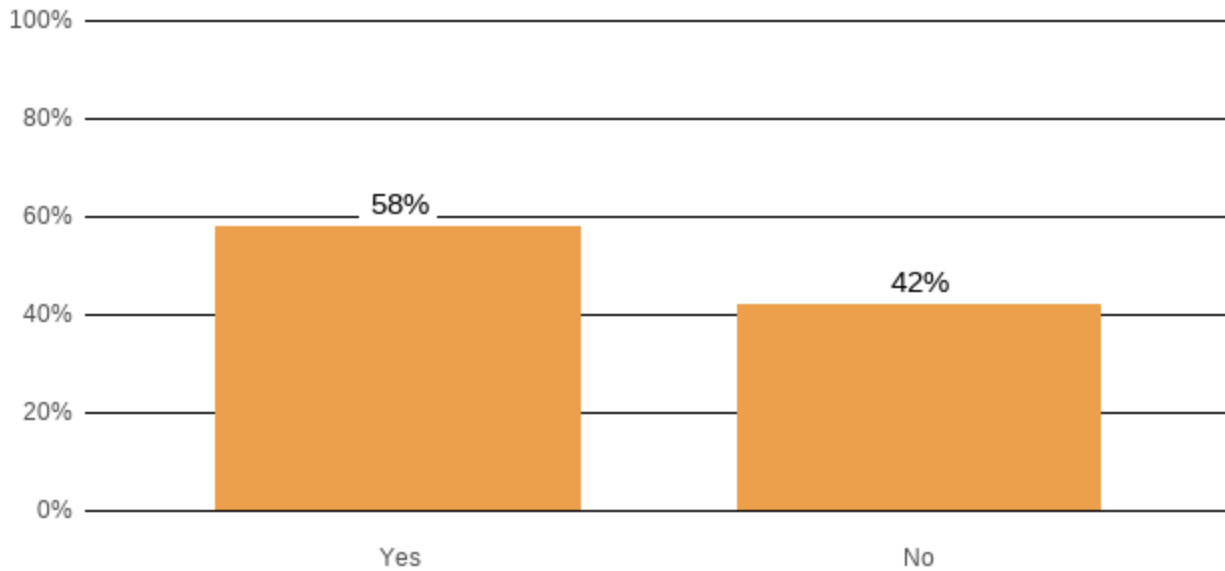


Table 41. If your family member had a transition plan, did the plan include getting or continuing work in a community job?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
<b>Weighted NCI-IDD Average</b>	58%	42%	108
<b>LA</b>	48%	52%	29
<b>NJ</b>	40%	60%	25

The following states had a low count of responses (N<20) and were not shown: DE, MO, OK, PA, DC, ND, MD

## **Access and Delivery of Services and Supports**

Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state developmental disabilities system.

**Note: Significance is based on “Always” or “Yes” response.**

**“You”** and **“Respondent”** refers to the person (usually a parent or guardian) filling out the survey.

**“Family Member”** refers to the person receiving services whom the respondent is answering questions about in this survey.

## Does your family member get all the services listed in the plan?

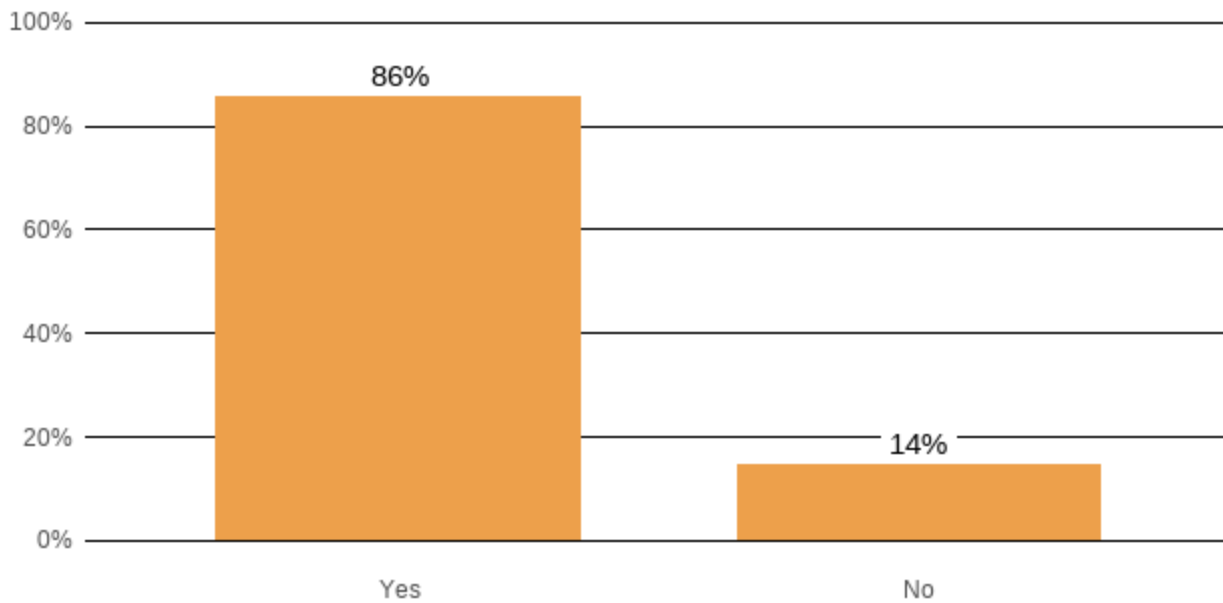


Table 42. Does your family member get all the services listed in the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
OK ↑	91%	9%	284
NJ ↑	90%	10%	546
LA ↑	90%	10%	743
DC	88%	12%	126
PA	86%	14%	520
ND	86%	14%	77
<b>Weighted NCI-IDD Average</b>	<b>86%</b>	<b>14%</b>	<b>3,280</b>
MO	83%	17%	205
GA	78%	22%	194
MD ↓	75%	25%	522
DE ↓	70%	30%	63

## Does your family get the supports and services it needs?

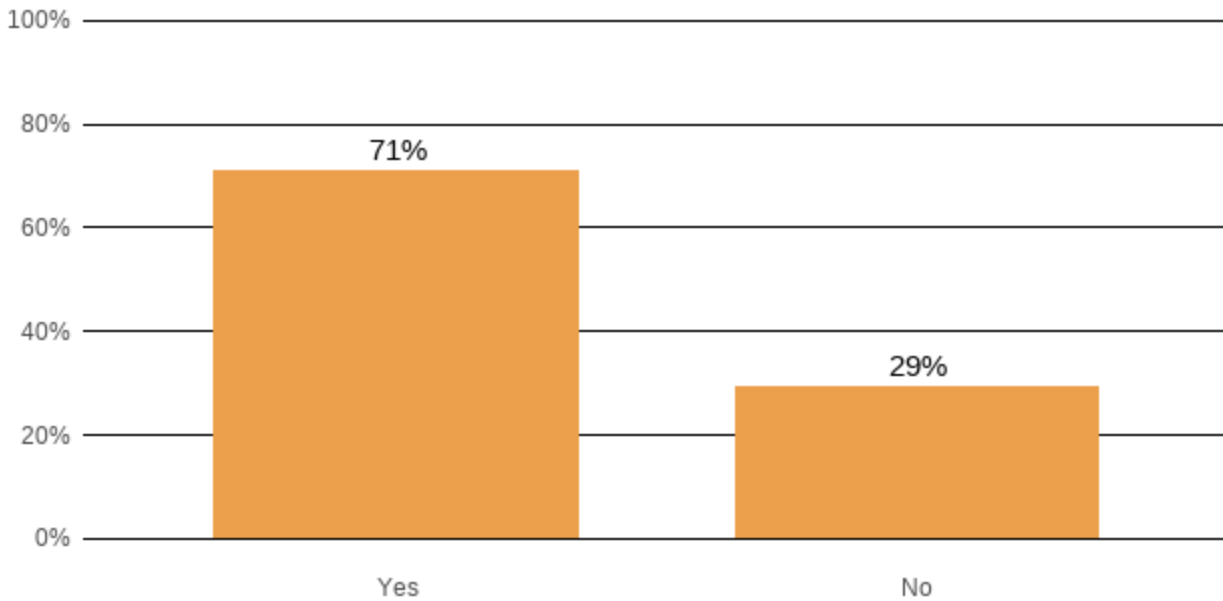


Table 43. Does your family get the supports and services it needs?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
DC ↑	90%	10%	143
LA ↑	78%	22%	1,039
OK	76%	24%	301
PA	74%	26%	563
<b>Weighted NCI-IDD Average</b>	<b>71%</b>	<b>29%</b>	<b>4,086</b>
MO	70%	30%	197
MD	68%	32%	615
DE	67%	33%	136
GA	66%	34%	357
NJ	66%	34%	615
ND	63%	38%	120

**If your family does not get the support and services needed, what additional services does your family need?**

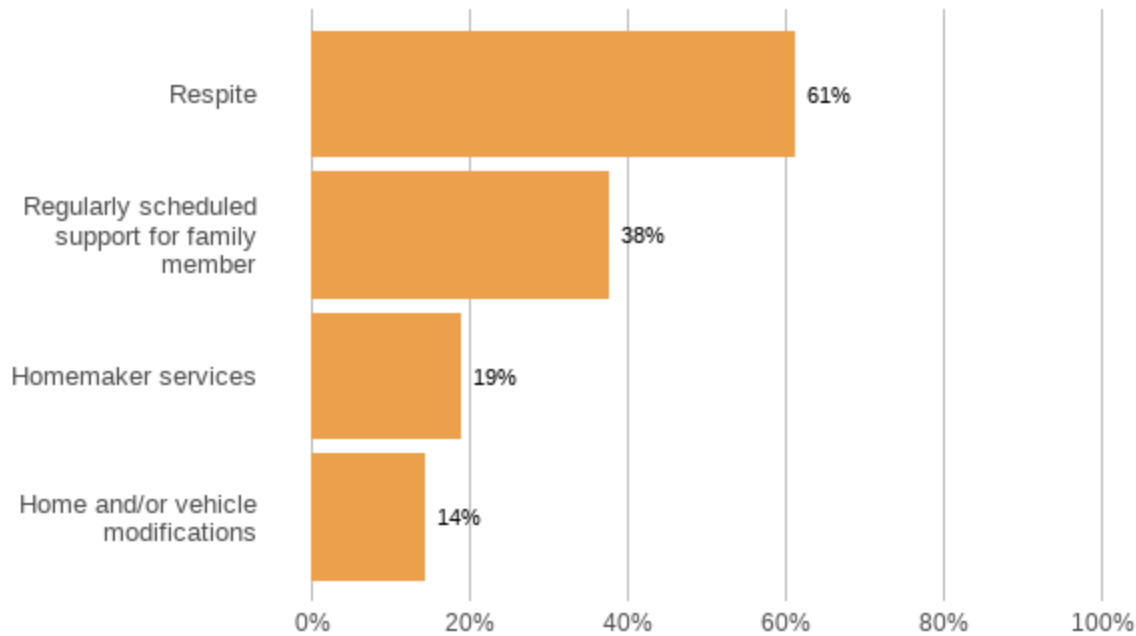


Table 44a. If your family does not get the support and services needed, what additional services does your family need?

Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Respite	Regularly scheduled support for family member	Homemaker services	Home and/or vehicle modifications
DE	60%	37%	23%	16%
GA	68%	46%	14%	17%
LA	55%	42%	14%	21%
MD	66%	46%	23%	15%
MO	61%	47%	14%	8%
ND	70%	52%	9%	16%
NJ	70%	37%	22%	14%
OK	59%	28%	20%	20%
PA	49%	30%	19%	13%
<b>Weighted NCI-IDD Average</b>	<b>61%</b>	<b>38%</b>	<b>19%</b>	<b>14%</b>

The following states had a low count of responses (N<20) and were not shown: DC

**If your family does not get the support and services needed, what additional services does your family need?**

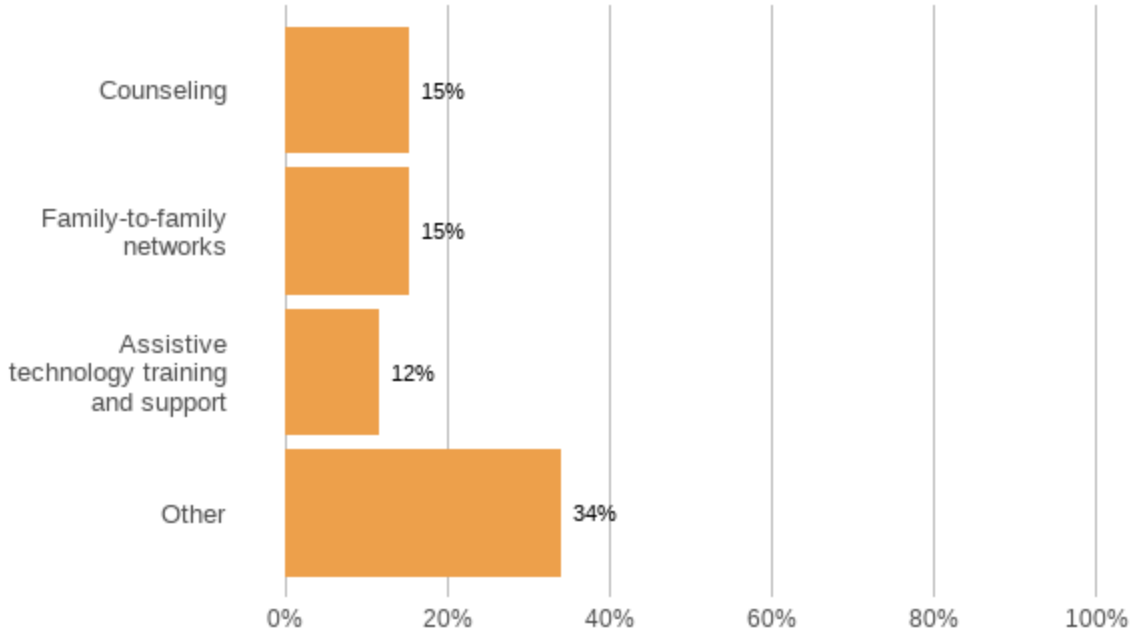


Table 44b. If your family does not get the support and services needed, what additional services does your family need? (continued)

Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Counseling	Family-to-family networks	Assistive technology training and support	Other
DE	14%	14%	9%	42%
GA	8%	8%	12%	21%
LA	17%	10%	9%	28%
MD	19%	22%	16%	32%
MO	19%	14%	12%	24%
ND	11%	14%	11%	41%
NJ	18%	24%	12%	34%
OK	10%	11%	13%	28%
PA	14%	9%	10%	43%
<b>Weighted NCI-IDD Average</b>	<b>15%</b>	<b>15%</b>	<b>12%</b>	<b>34%</b>

The following states had a low count of responses (N<20) and were not shown: DC

## Do services and supports change when your family's needs change?

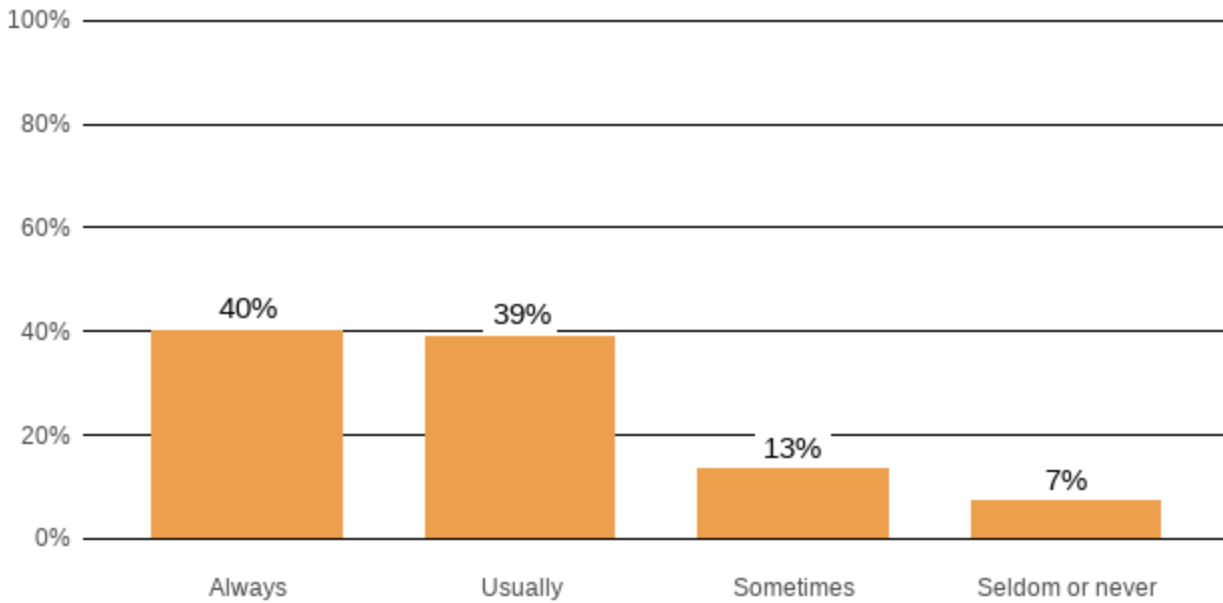


Table 45. Do services and supports change when your family's needs change?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
LA ↑	48%	33%	12%	7%	914
DC	50%	33%	13%	5%	135
PA	43%	39%	12%	5%	489
NJ	42%	39%	12%	7%	504
OK	42%	40%	12%	6%	243
<b>Weighted NCI-IDD Average</b>	<b>40%</b>	<b>39%</b>	<b>13%</b>	<b>7%</b>	<b>3,513</b>
MO	37%	42%	15%	7%	194
GA	34%	38%	17%	11%	289
ND	32%	40%	16%	12%	116
MD ↓	31%	43%	16%	10%	532
DE ↓	19%	45%	20%	16%	97



## Does your family member have enough supports to work or volunteer in the community?

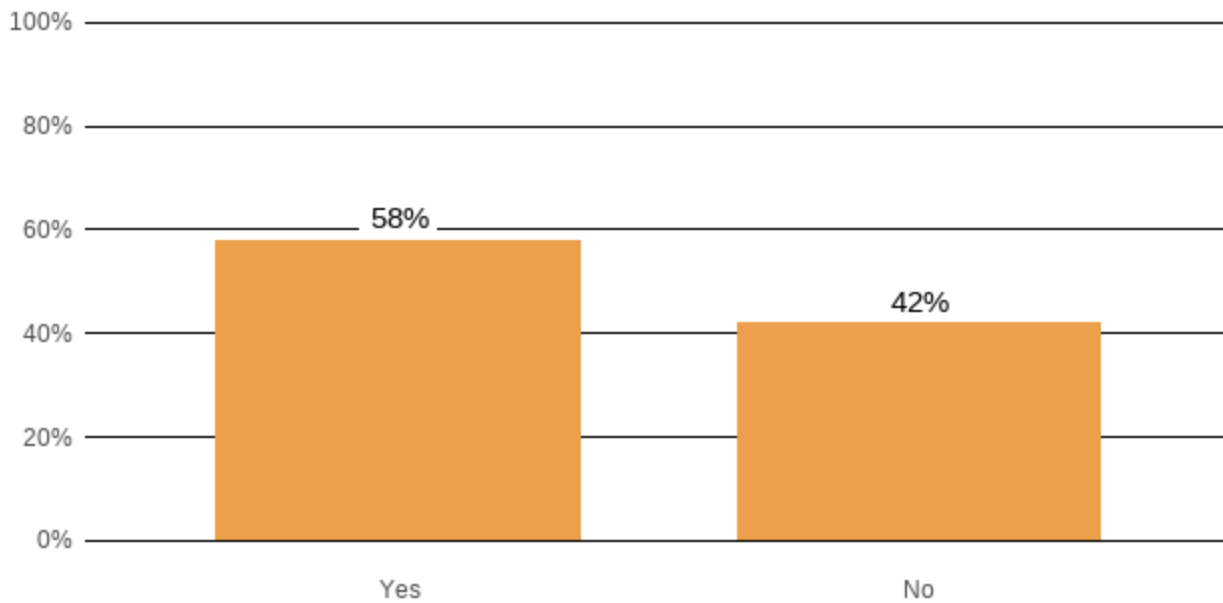


Table 46. Does your family member have enough supports to work or volunteer in the community?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
PA ↑	69%	31%	413
OK ↑	67%	33%	237
DE	65%	35%	131
DC	62%	38%	113
MD	58%	42%	551
<b>Weighted NCI-IDD Average</b>	<b>58%</b>	<b>42%</b>	<b>3,219</b>
ND	57%	43%	98
MO	56%	44%	179
LA ↓	52%	48%	744
NJ ↓	49%	51%	495
GA ↓	47%	53%	258

## Does your family member have the special equipment or accommodations they need?

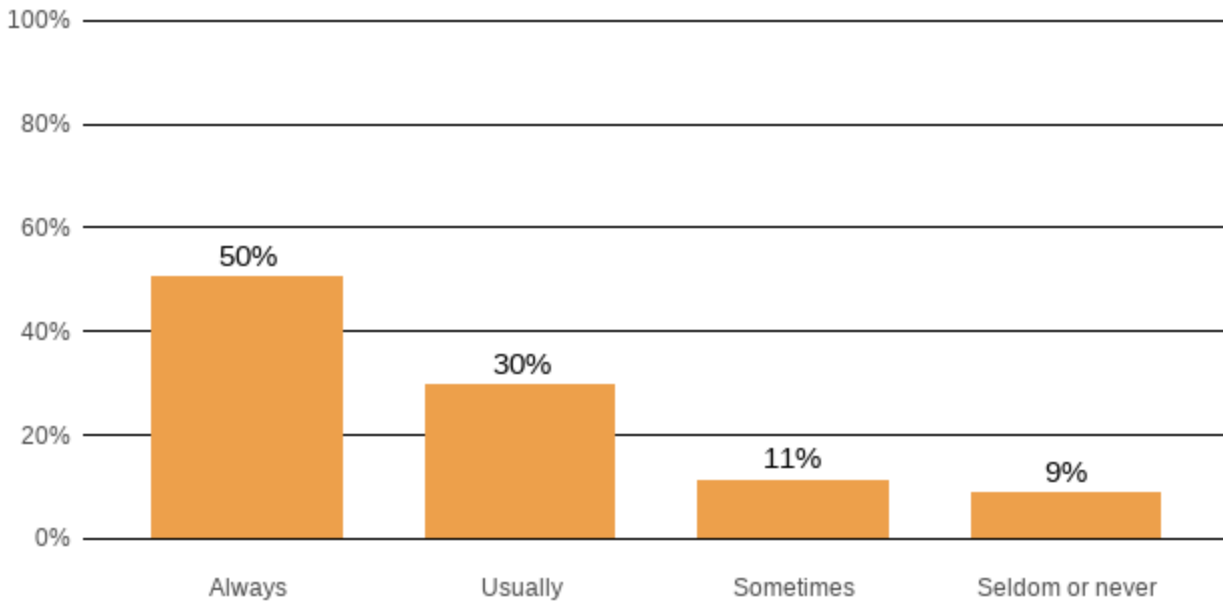


Table 47. Does your family member have the special equipment or accommodations they need?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
LA ↑	58%	26%	11%	5%	617
DC	64%	14%	17%	6%	66
PA	54%	26%	9%	11%	254
ND	53%	23%	12%	12%	74
OK	52%	29%	13%	6%	180
NJ	51%	29%	11%	10%	263
<b>Weighted NCI-IDD Average</b>	<b>50%</b>	<b>30%</b>	<b>11%</b>	<b>9%</b>	<b>2,137</b>
DE	47%	37%	12%	5%	43
GA	44%	36%	13%	7%	218
MO	43%	39%	13%	5%	128
MD	43%	30%	16%	11%	294

## If you need respite services, how often are you able to get them when needed?

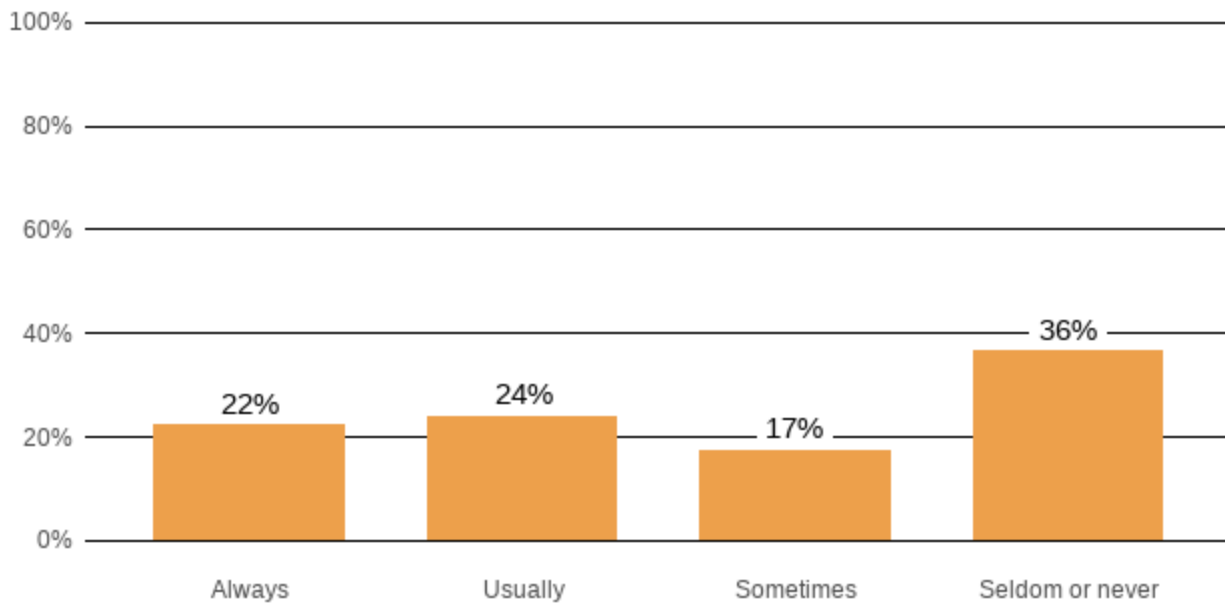


Table 48. If you need respite services, how often are you able to get them when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	57%	25%	8%	10%	114
LA ↑	30%	24%	14%	31%	661
PA	28%	26%	18%	29%	312
<b>Weighted NCI-IDD Average</b>	<b>22%</b>	<b>24%</b>	<b>17%</b>	<b>36%</b>	<b>2,610</b>
GA	22%	22%	13%	43%	268
DE	19%	29%	17%	36%	84
MO	18%	25%	22%	36%	151
OK	18%	21%	15%	46%	169
NJ ↓	16%	21%	18%	45%	357
MD ↓	15%	25%	21%	39%	380
ND ↓	12%	39%	31%	18%	114

**If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?**

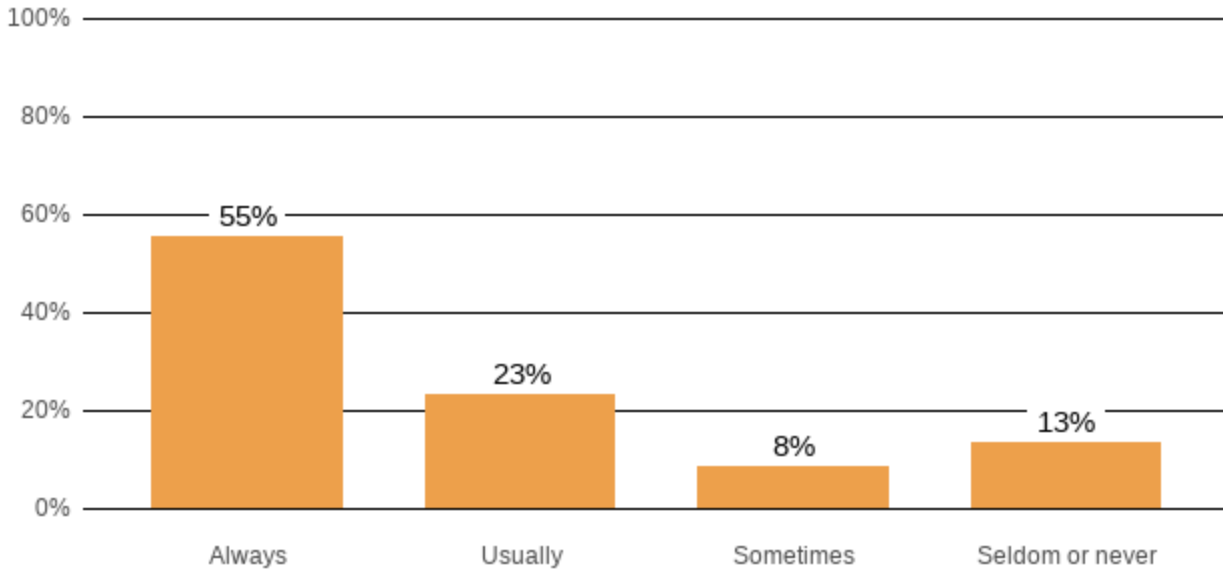


Table 49. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA ↑	69%	15%	5%	11%	135
DE	61%	24%	9%	6%	33
MO	60%	26%	4%	10%	78
OK	57%	23%	7%	14%	44
LA	56%	25%	8%	10%	283
<b>Weighted NCI-IDD Average</b>	<b>55%</b>	<b>23%</b>	<b>8%</b>	<b>13%</b>	<b>1,200</b>
MD	51%	27%	8%	14%	191
GA	50%	23%	7%	20%	123
ND	45%	35%	14%	7%	103
DC	43%	26%	7%	25%	61
NJ ↓	42%	29%	15%	13%	149

## Are you or your family member able to contact their support workers when you want?

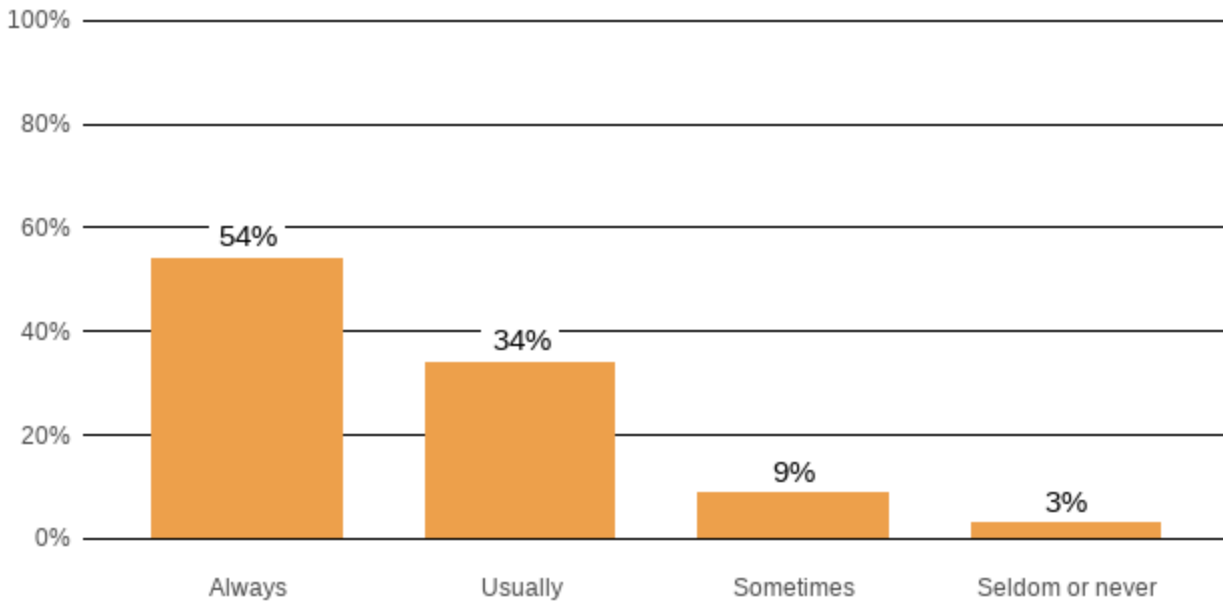


Table 50. Are you or your family member able to contact their support workers when you want?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
LA ↑	63%	27%	7%	2%	1,076
PA ↑	60%	31%	8%	2%	616
DC	64%	26%	8%	3%	148
<b>Weighted NCI-IDD Average</b>	<b>54%</b>	<b>34%</b>	<b>9%</b>	<b>3%</b>	<b>4,235</b>
NJ	53%	36%	7%	3%	603
OK	48%	37%	11%	3%	314
MD ↓	48%	36%	12%	3%	607
GA ↓	47%	37%	11%	5%	387
MO ↓	45%	41%	10%	4%	223
ND ↓	38%	40%	16%	7%	122
DE ↓	37%	41%	14%	7%	139

**Are you or your family member able to contact their case manager or service coordinator when you want?**

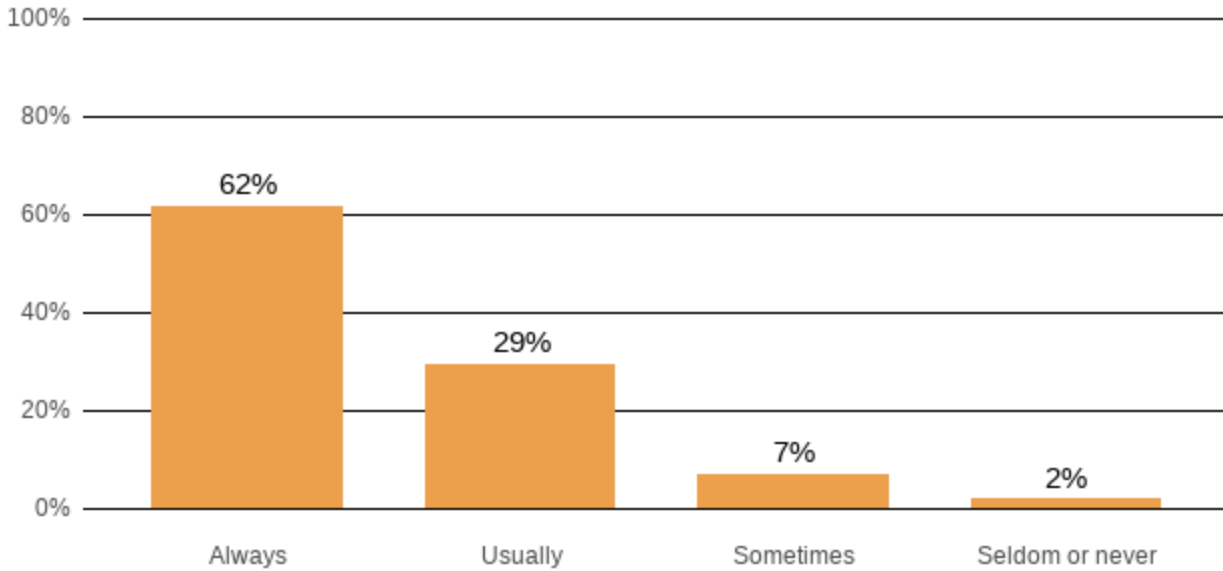


Table 51. Are you or your family member able to contact their case manager or service coordinator when you want?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>NJ</b> ↑	67%	27%	5%	1%	700
<b>DC</b>	71%	20%	9%	1%	163
<b>PA</b>	65%	27%	6%	2%	631
<b>LA</b>	65%	28%	6%	1%	1,163
<b>Weighted NCI-IDD Average</b>	62%	29%	7%	2%	4,652
<b>OK</b>	56%	32%	9%	2%	358
<b>MO</b>	56%	34%	8%	2%	236
<b>MD</b> ↓	57%	33%	8%	2%	701
<b>GA</b> ↓	52%	34%	10%	4%	411
<b>ND</b> ↓	50%	39%	9%	2%	126
<b>DE</b> ↓	50%	37%	11%	2%	163

## Do service providers for your family member work together to provide support?

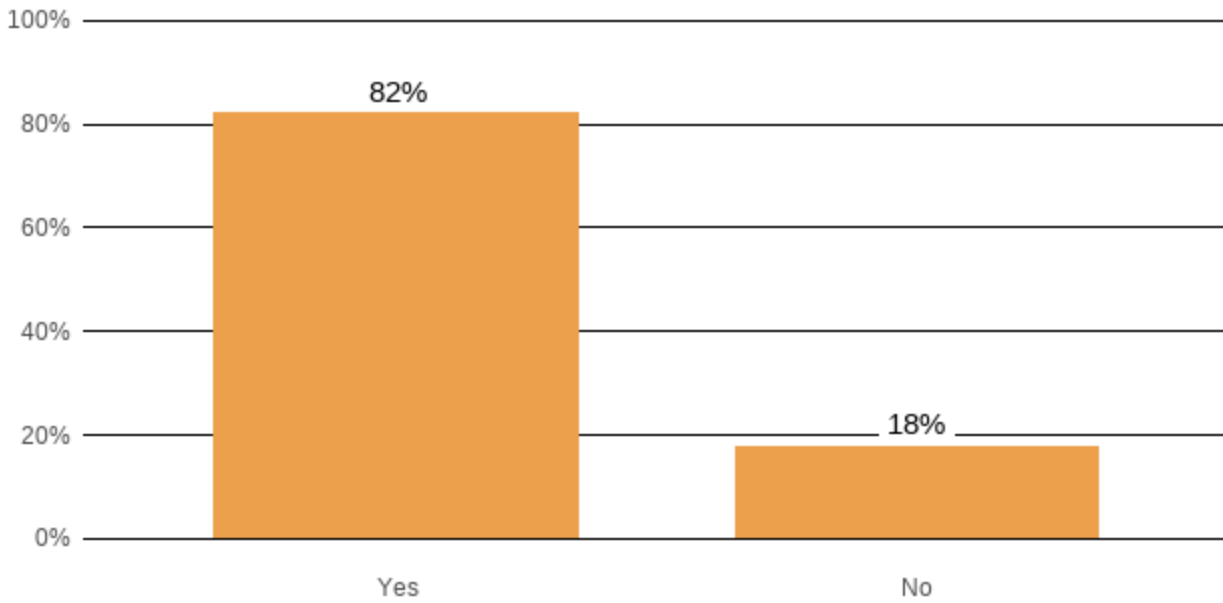


Table 52. Do service providers for your family member work together to provide support?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
PA ↑	88%	12%	361
LA ↑	87%	13%	622
OK	86%	14%	169
DC	85%	15%	115
<b>Weighted NCI-IDD Average</b>	<b>82%</b>	<b>18%</b>	<b>2,547</b>
MD	81%	19%	394
NJ	79%	21%	366
ND	79%	21%	84
MO	77%	23%	125
GA ↓	73%	27%	227
DE ↓	68%	32%	84

## Are services delivered in a way that is respectful of your family's culture?

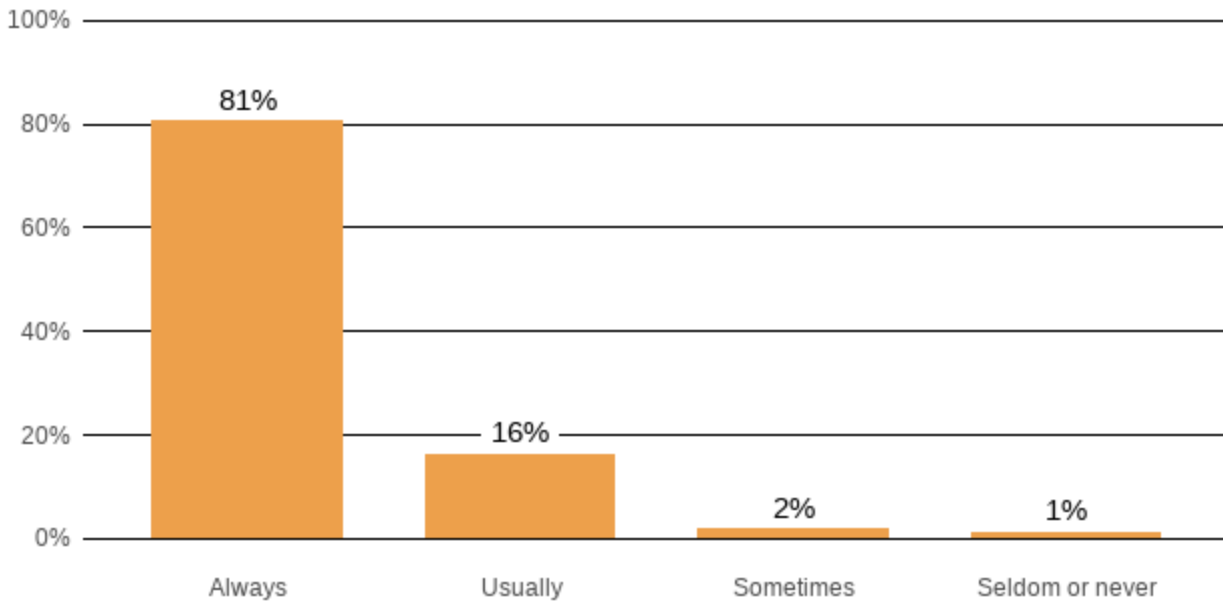


Table 53. Are services delivered in a way that is respectful of your family's culture?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
NJ	84%	14%	2%	0%	636
ND	83%	14%	2%	1%	125
MO	83%	16%	0%	0%	232
PA	83%	14%	2%	1%	597
OK	82%	15%	2%	1%	323
LA	81%	16%	1%	2%	1,106
<b>Weighted NCI-IDD Average</b>	<b>81%</b>	<b>16%</b>	<b>2%</b>	<b>1%</b>	<b>4,345</b>
DC	80%	16%	4%	0%	156
DE	76%	19%	1%	4%	139
MD ↓	76%	20%	3%	2%	654
GA ↓	71%	24%	3%	3%	377



## Does your family member use technology in their everyday life to help them do things on their own?

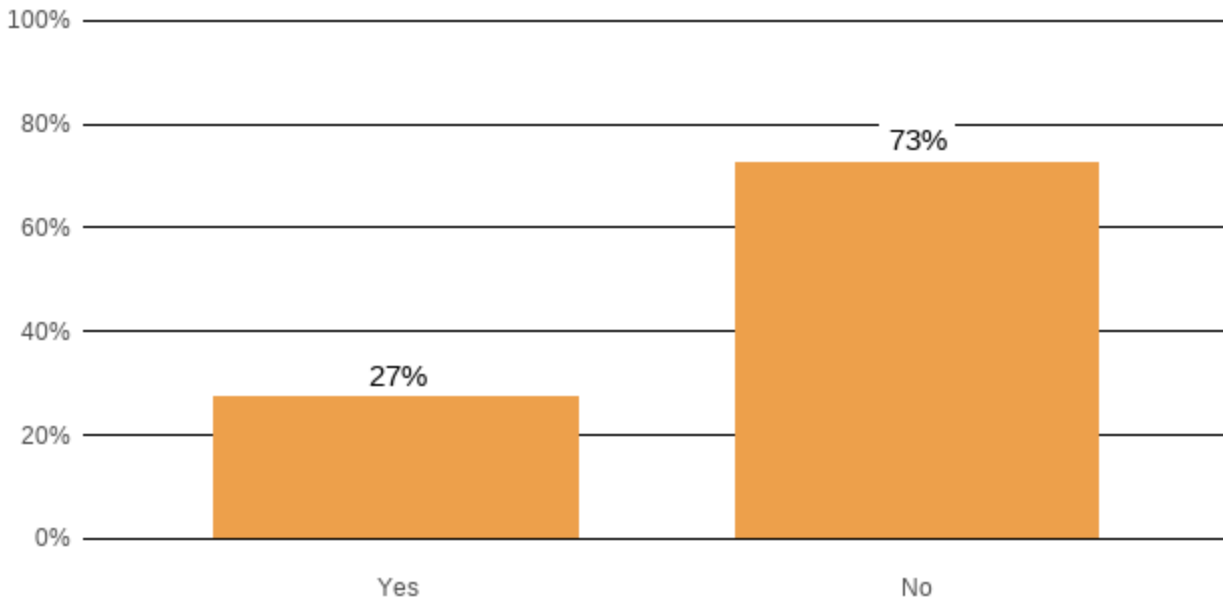


Table 54. Does your family member use technology in their everyday life to help them do things on their own?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
NJ ↑	38%	62%	674
MD ↑	35%	65%	680
DE	31%	69%	162
DC	29%	71%	157
ND	28%	72%	127
OK	28%	72%	354
LA	28%	72%	1,194
<b>Weighted NCI-IDD Average</b>	<b>27%</b>	<b>73%</b>	<b>4,668</b>
MO	25%	75%	252
PA ↓	22%	78%	637
GA ↓	16%	84%	431

**Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?**

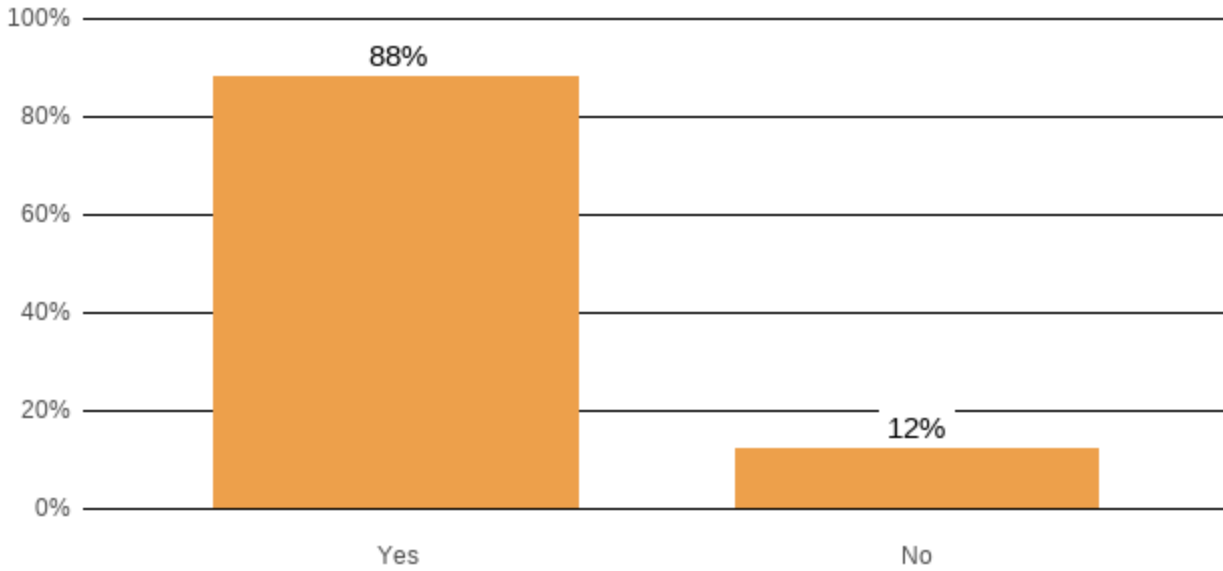


Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
ND ↑	96%	4%	127
MD ↑	95%	5%	700
NJ ↑	95%	5%	687
DE	90%	10%	166
MO	90%	10%	250
<b>Weighted NCI-IDD Average</b>	<b>88%</b>	<b>12%</b>	<b>4,757</b>
LA	86%	14%	1,214
PA	85%	15%	653
DC	85%	15%	160
OK ↓	82%	18%	360
GA ↓	79%	21%	440

## How well does the internet work in your home?

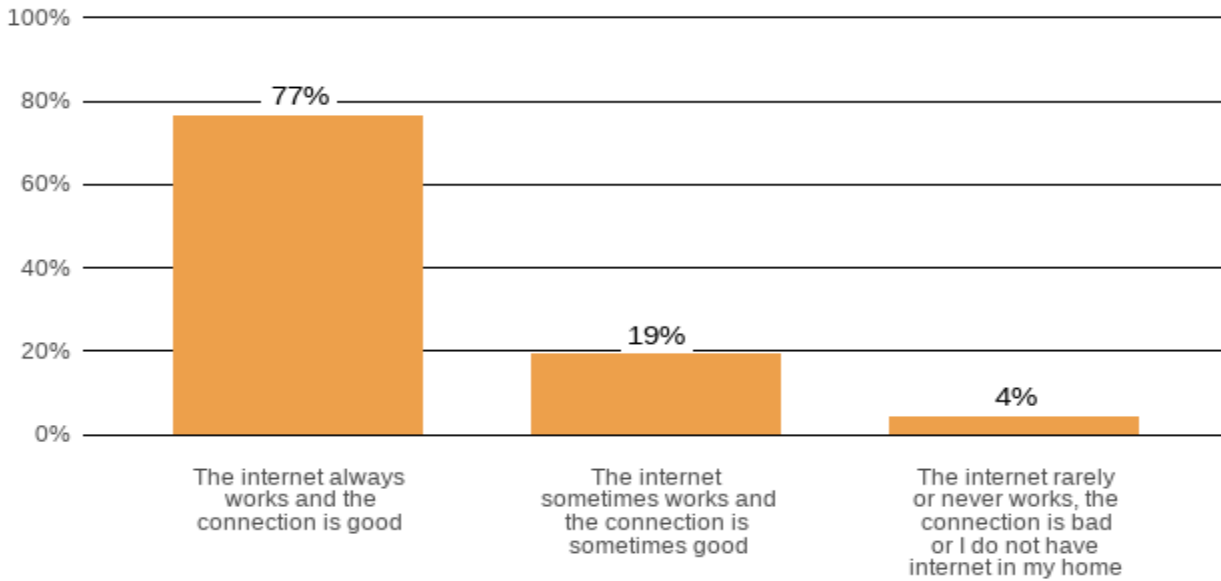


Table 56. How well does the internet work in your home?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	The internet always works and the connection is good	The internet sometimes works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
DE ↑	85%	14%	1%	166
NJ ↑	85%	15%	1%	688
MD ↑	83%	16%	1%	704
ND	84%	16%	0%	127
DC	78%	17%	5%	153
<b>Weighted NCI-IDD Average</b>	<b>77%</b>	<b>19%</b>	<b>4%</b>	<b>4,674</b>
PA	76%	18%	7%	631
MO	73%	24%	4%	250
OK	72%	22%	6%	342
LA ↓	67%	25%	8%	1,196
GA ↓	66%	29%	6%	417

## Workforce

There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.

**Note: Significance is based on “Always” or “Yes” response.**

“**You**” and “**Respondent**” refers to the person (usually a parent or guardian) filling out the survey.

“**Family Member**” refers to the person receiving services whom the respondent is answering questions about in this survey.

## Do support workers come and go when they are supposed to?

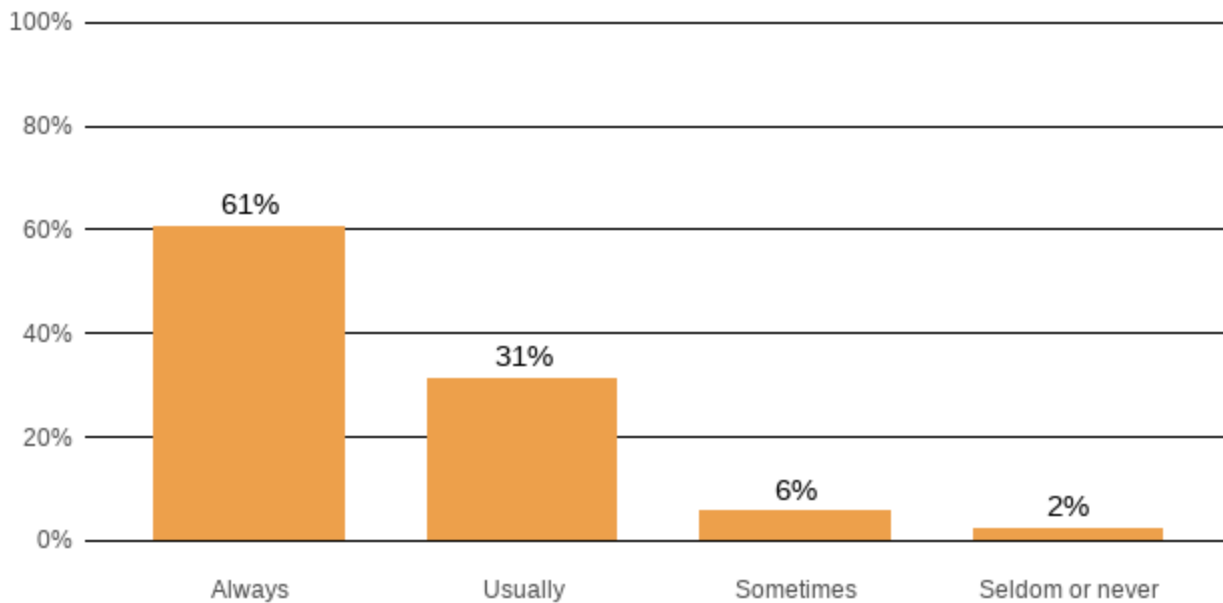


Table 57. Do support workers come and go when they are supposed to?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA ↑	67%	28%	4%	2%	577
LA	65%	27%	5%	3%	992
NJ	63%	30%	5%	1%	546
DC	61%	27%	10%	1%	148
<b>Weighted NCI-IDD Average</b>	<b>61%</b>	<b>31%</b>	<b>6%</b>	<b>2%</b>	<b>3,827</b>
OK	60%	29%	7%	4%	273
MO	56%	37%	5%	2%	198
GA ↓	50%	36%	10%	4%	315
MD ↓	48%	41%	7%	4%	555
DE ↓	44%	37%	9%	10%	102
ND ↓	44%	44%	6%	7%	121

## Do support workers speak to you in a way you understand?

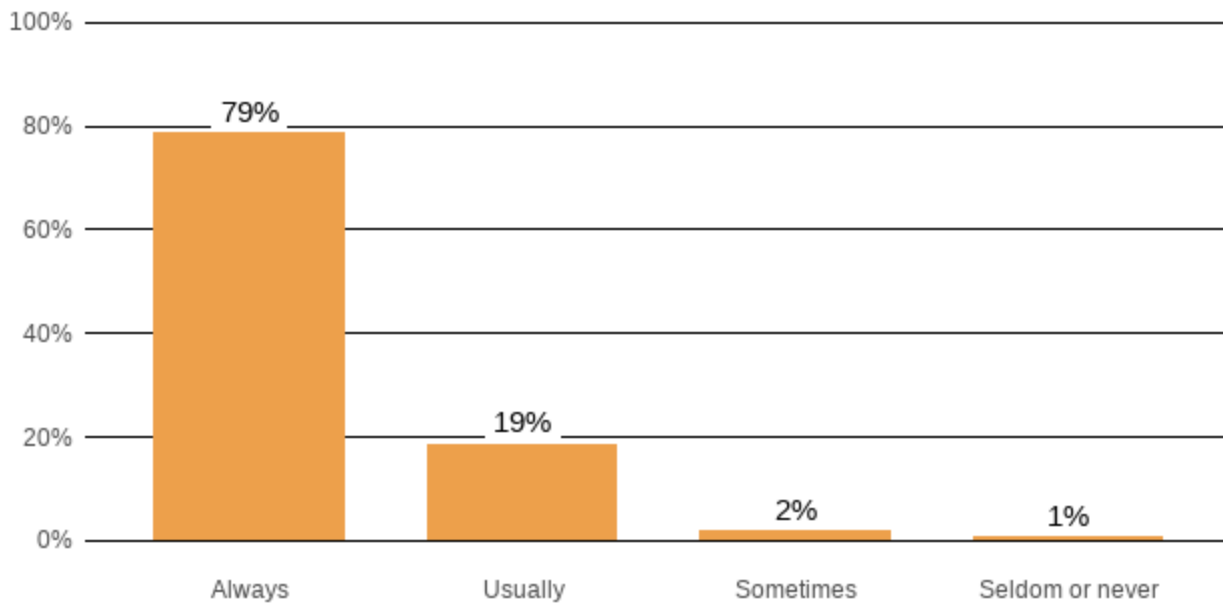


Table 58. Do support workers speak to you in a way you understand?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA	82%	17%	1%	0%	595
LA	82%	16%	2%	1%	1,061
NJ	81%	17%	2%	0%	563
<b>Weighted NCI-IDD Average</b>	<b>79%</b>	<b>19%</b>	<b>2%</b>	<b>1%</b>	<b>4,106</b>
DC	78%	16%	4%	1%	153
MO	78%	21%	1%	0%	209
ND	77%	22%	0%	2%	125
OK	76%	20%	3%	1%	296
DE	71%	25%	3%	1%	135
GA ↓	72%	23%	3%	2%	378
MD ↓	72%	21%	5%	2%	591

**If your family member does not communicate verbally, are there support workers who can communicate with them?**

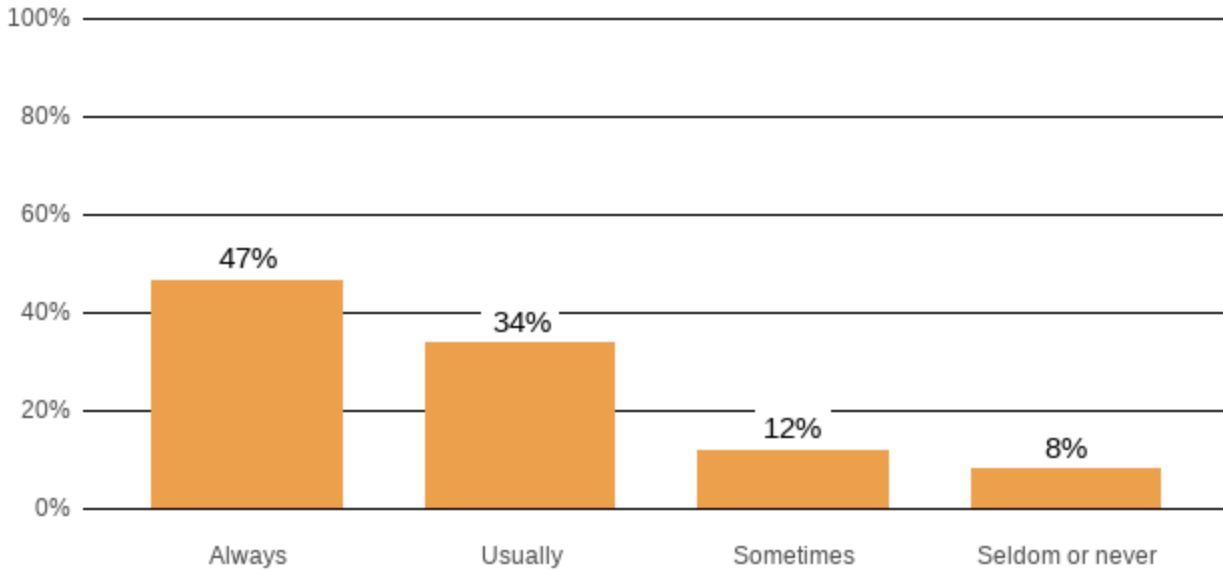


Table 59. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	61%	28%	9%	1%	85
LA ↑	56%	29%	8%	6%	495
PA	51%	30%	11%	8%	249
NJ	49%	31%	11%	9%	246
<b>Weighted NCI-IDD Average</b>	<b>47%</b>	<b>34%</b>	<b>12%</b>	<b>8%</b>	<b>1,912</b>
OK	42%	32%	19%	7%	150
GA	39%	41%	12%	8%	198
MO	39%	35%	16%	10%	110
ND	32%	44%	20%	3%	59
MD ↓	38%	42%	14%	7%	285
DE ↓	23%	49%	14%	14%	35

## Do support workers have the right information and skills to meet your family's needs?

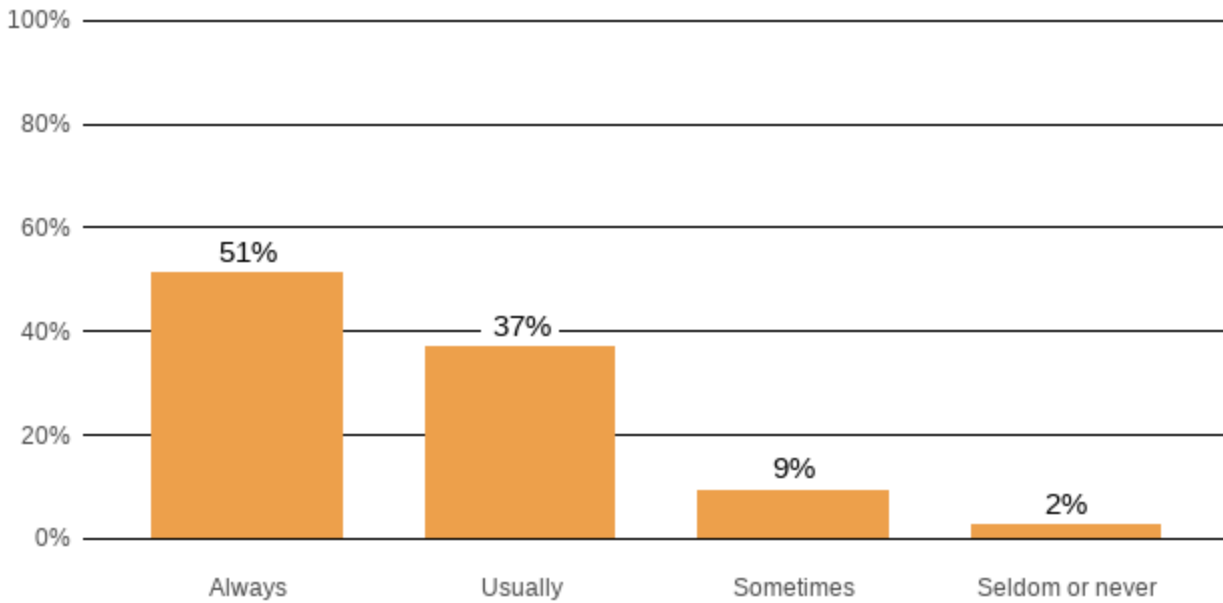


Table 60. Do support workers have the right information and skills to meet your family's needs?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	64%	26%	9%	1%	148
LA ↑	61%	30%	6%	2%	1,014
PA ↑	57%	34%	8%	2%	580
OK	54%	35%	6%	5%	283
<b>Weighted NCI-IDD Average</b>	<b>51%</b>	<b>37%</b>	<b>9%</b>	<b>2%</b>	<b>3,961</b>
GA	48%	40%	9%	3%	350
ND	48%	37%	13%	2%	124
NJ	47%	39%	12%	2%	554
MO	45%	43%	10%	2%	207
MD ↓	39%	44%	13%	5%	576
DE ↓	38%	41%	14%	7%	125



**Do your family member's support workers change too often? Is there too much "turnover" of support workers?**

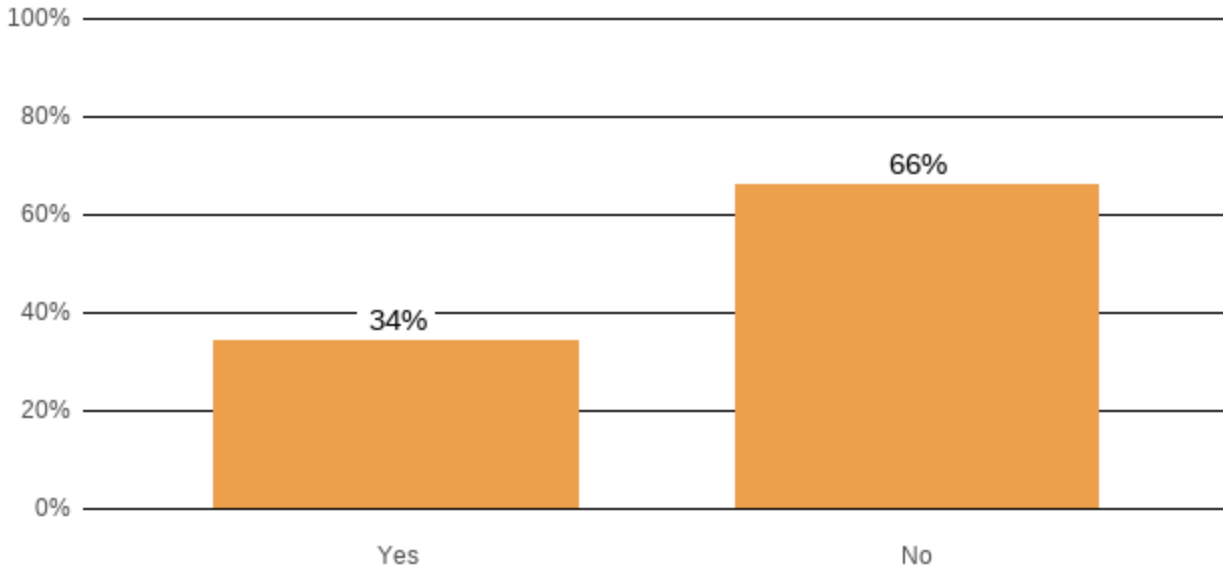


Table 61. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
DE ↑	58%	42%	118
ND ↑	47%	53%	116
MD ↑	45%	55%	537
GA	39%	61%	325
MO	35%	65%	192
<b>Weighted NCI-IDD Average</b>	<b>34%</b>	<b>66%</b>	<b>3,733</b>
PA	33%	67%	558
NJ	30%	70%	516
LA ↓	27%	73%	965
OK ↓	25%	75%	262
DC ↓	14%	86%	144

## Is there always a staff person available to support your family member when support is needed?

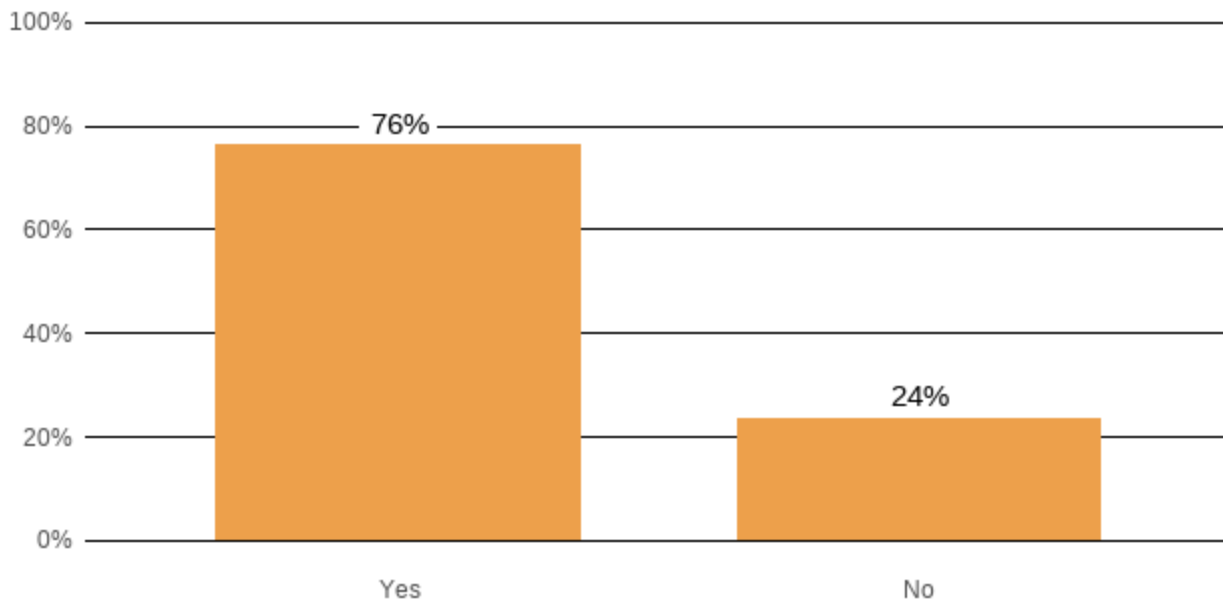


Table 62. Is there always a staff person available to support your family member when support is needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
DC ↑	90%	10%	146
LA ↑	81%	19%	996
PA	80%	20%	529
OK	78%	22%	254
<b>Weighted NCI-IDD Average</b>	<b>76%</b>	<b>24%</b>	<b>3,758</b>
NJ	76%	24%	520
MO	72%	28%	190
GA	72%	28%	344
DE	69%	31%	109
MD ↓	68%	32%	551
ND ↓	52%	48%	119

## **Choice, Decision Making and Control**

Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.

**Note: Significance is based on “Always” or “Yes” response.**

**“You”** and **“Respondent”** refers to the person (usually a parent or guardian) filling out the survey.

**“Family Member”** refers to the person receiving services whom the respondent is answering questions about in this survey.

**Can someone in your family choose or change the agency that provides your family member's services?**

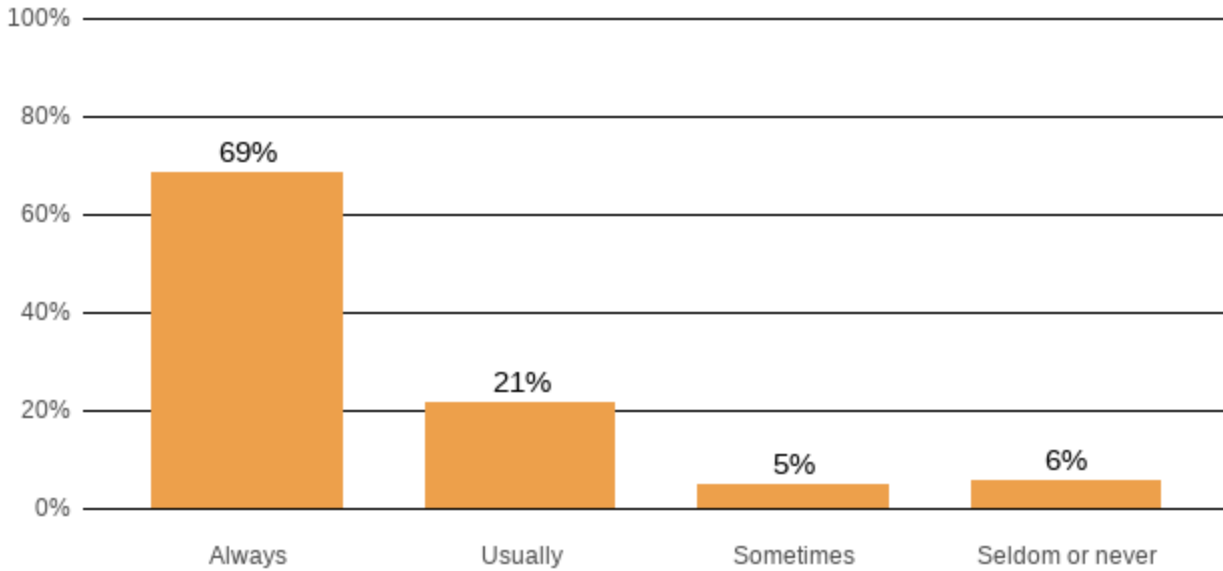


Table 63. Can your family choose or change the agency that provides your family member’s services?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
LA ↑	76%	18%	2%	4%	957
DC	73%	13%	5%	8%	134
OK	72%	19%	4%	4%	250
ND	71%	21%	2%	6%	97
PA	70%	21%	5%	5%	438
NJ	69%	20%	5%	6%	513
<b>Weighted NCI-IDD Average</b>	<b>69%</b>	<b>21%</b>	<b>5%</b>	<b>6%</b>	<b>3,408</b>
MD	67%	22%	6%	5%	504
MO	63%	21%	5%	11%	157
GA	62%	28%	5%	6%	266
DE ↓	54%	33%	7%	7%	92

## Can someone in your family choose or change your family member's support workers?

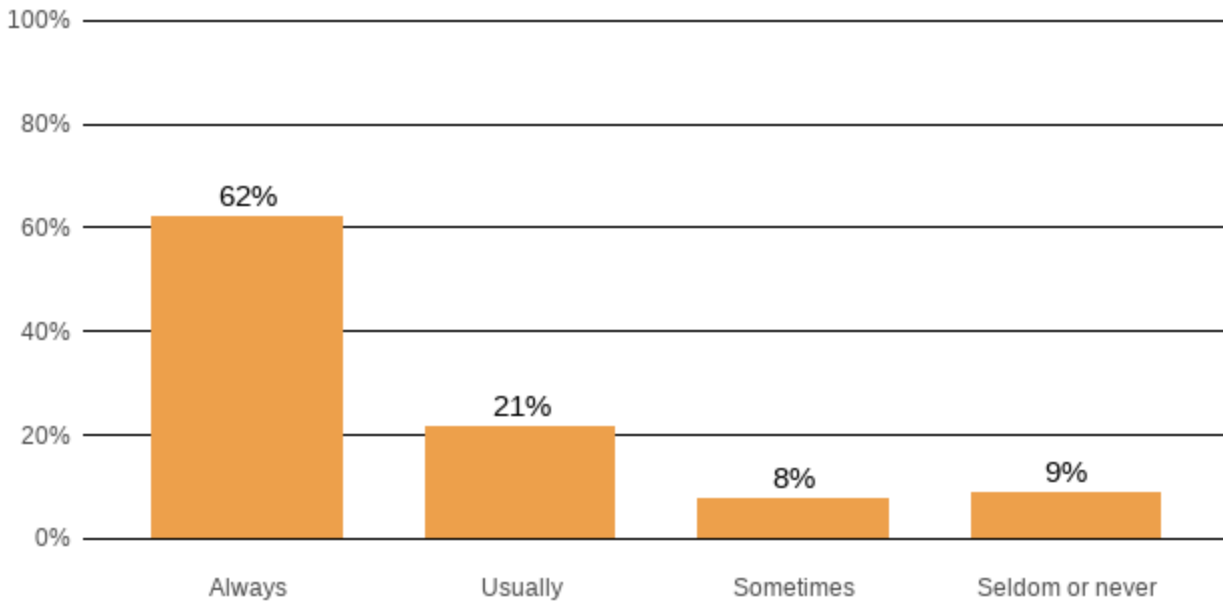


Table 64. Can your family choose or change your family member's support workers?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
LA ↑	72%	17%	5%	6%	921
DC	69%	17%	7%	7%	121
OK	69%	16%	6%	8%	231
PA	64%	21%	6%	9%	434
<b>Weighted NCI-IDD Average</b>	<b>62%</b>	<b>21%</b>	<b>8%</b>	<b>9%</b>	<b>3,200</b>
NJ	61%	24%	9%	7%	435
GA	59%	20%	8%	13%	248
MD	57%	24%	10%	8%	482
MO	56%	22%	8%	14%	148
ND	53%	22%	15%	10%	109
DE ↓	39%	27%	15%	18%	71

## Can someone in your family directly manage support staff?

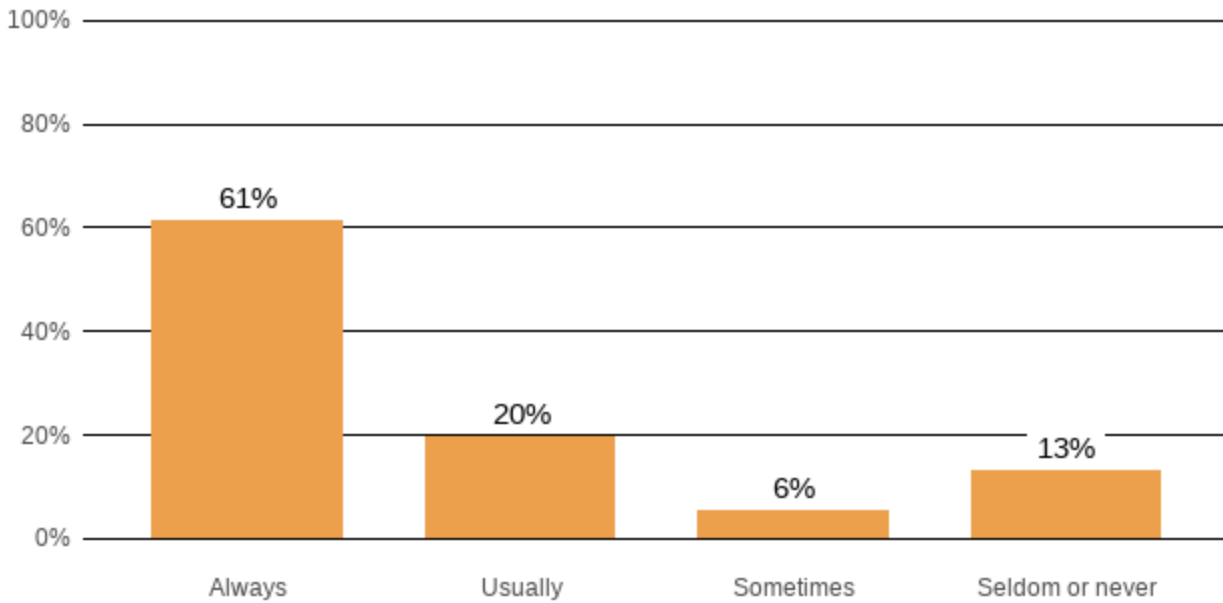


Table 65. Can someone in your family directly manage support staff?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
LA ↑	70%	17%	5%	9%	835
OK	66%	21%	5%	8%	212
MO	65%	18%	3%	13%	157
NJ	65%	21%	5%	9%	399
<b>Weighted NCI-IDD Average</b>	<b>61%</b>	<b>20%</b>	<b>6%</b>	<b>13%</b>	<b>2,958</b>
GA	60%	18%	5%	16%	225
PA	60%	20%	5%	15%	416
DC	59%	25%	6%	9%	111
MD	56%	19%	11%	14%	437
ND ↓	42%	17%	13%	28%	102
DE ↓	30%	28%	6%	36%	64

**Did you, your family member, or someone else  
in your family choose your family member's case  
manager/service coordinator?**

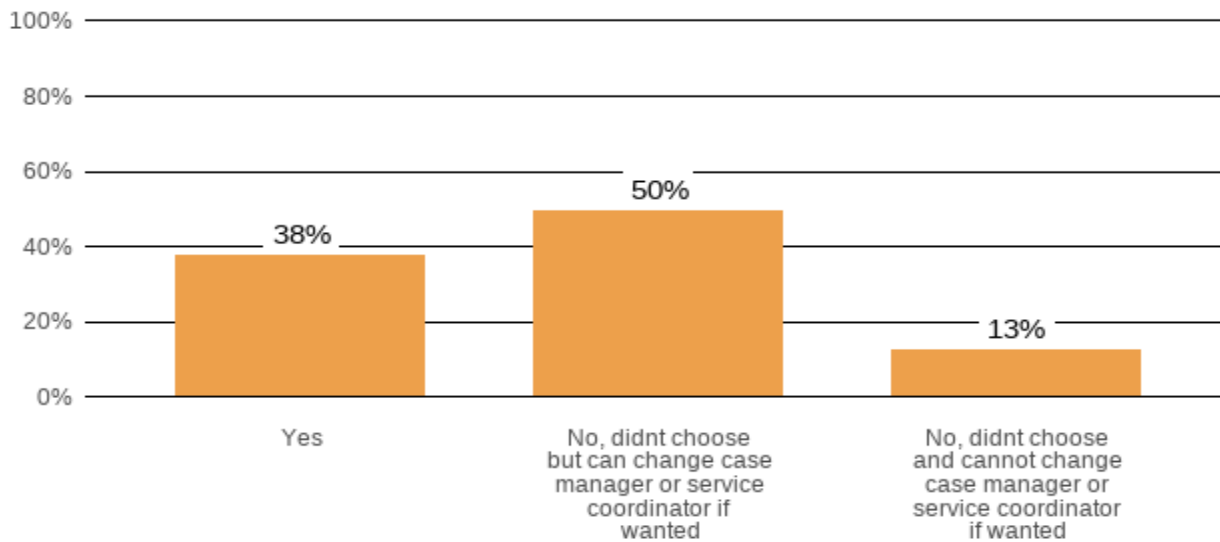


Table 66. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No, didn't choose but can change case manager or service coordinator if wanted	No, didn't choose and cannot change case manager or service coordinator if wanted	N
LA ↑	60%	33%	7%	1,017
NJ ↑	57%	35%	8%	603
ND	46%	38%	16%	95
<b>Weighted NCI-IDD Average</b>	<b>38%</b>	<b>50%</b>	<b>13%</b>	<b>3,941</b>
DC	36%	57%	7%	146
MD	34%	51%	15%	613
PA ↓	31%	60%	8%	533
MO ↓	24%	49%	27%	191
GA ↓	19%	56%	25%	320
OK ↓	14%	65%	21%	296
DE ↓	13%	59%	28%	127

## Community Connections

Family members receiving services and supports from the state Developmental Disabilities system are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.

**Note: Significance is based on “Always” or “Yes” response.**

**“You”** and **“Respondent”** refers to the person (usually a parent or guardian) filling out the survey.

**“Family Member”** refers to the person receiving services whom the respondent is answering questions about in this survey.



## Does your family member do things in the community?

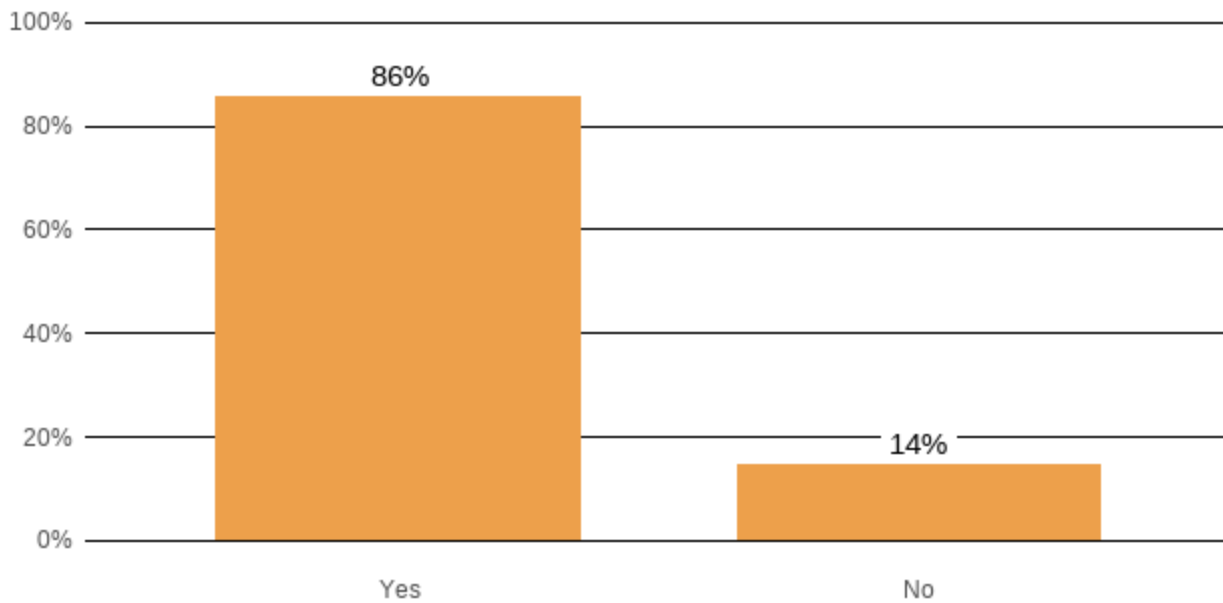


Table 67. Does your family member do things in the community?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
ND ↑	93%	7%	126
DC	91%	9%	159
OK	88%	12%	361
DE	88%	12%	162
MD	88%	12%	673
PA	87%	13%	652
<b>Weighted NCI-IDD Average</b>	<b>86%</b>	<b>14%</b>	<b>4,708</b>
MO	85%	15%	249
LA	85%	15%	1,233
NJ	84%	16%	658
GA ↓	80%	20%	435

### For your family member, what makes it hard to do things in the community?

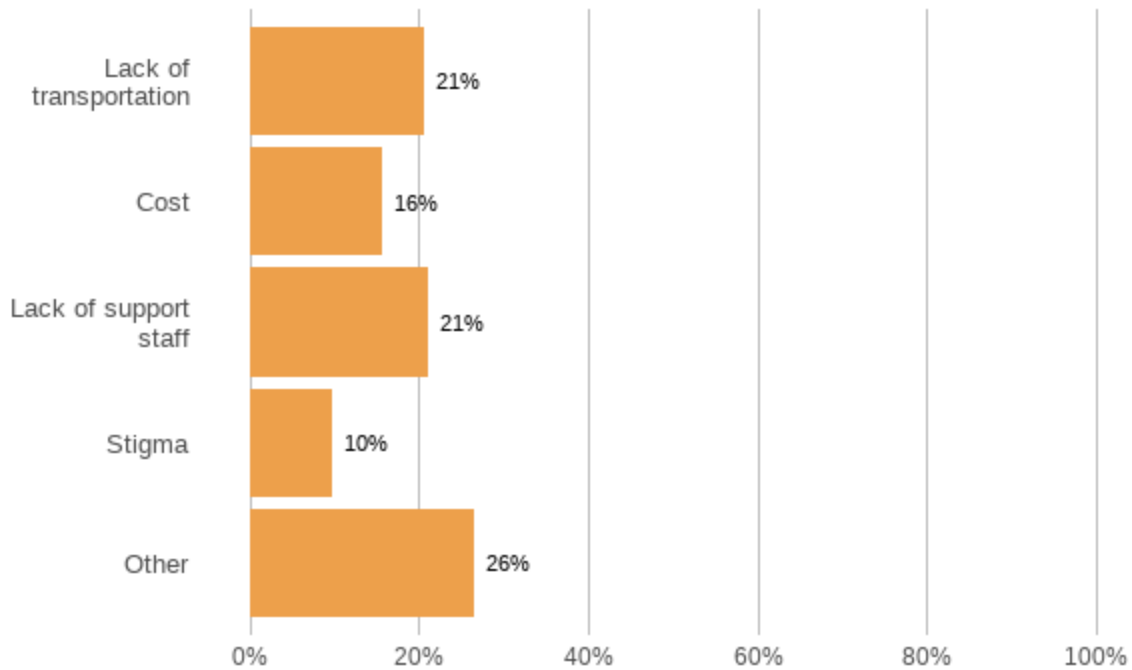


Table 68. For your family member, what makes it hard to do things in the community?

Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Lack of transportation	Cost	Lack of support staff	Stigma	Other
DE	21%	14%	21%	6%	26%
DC	13%	19%	7%	6%	9%
GA	15%	15%	18%	10%	19%
LA	12%	16%	12%	9%	26%
MD	23%	16%	29%	12%	27%
MO	22%	19%	26%	13%	31%
ND	21%	12%	44%	7%	30%
NJ	30%	17%	26%	11%	30%
OK	11%	11%	12%	9%	26%
PA	19%	15%	19%	8%	27%
<b>Weighted NCI-IDD Average</b>	<b>21%</b>	<b>16%</b>	<b>21%</b>	<b>10%</b>	<b>26%</b>

## Does your family member have friends other than paid support workers or family?

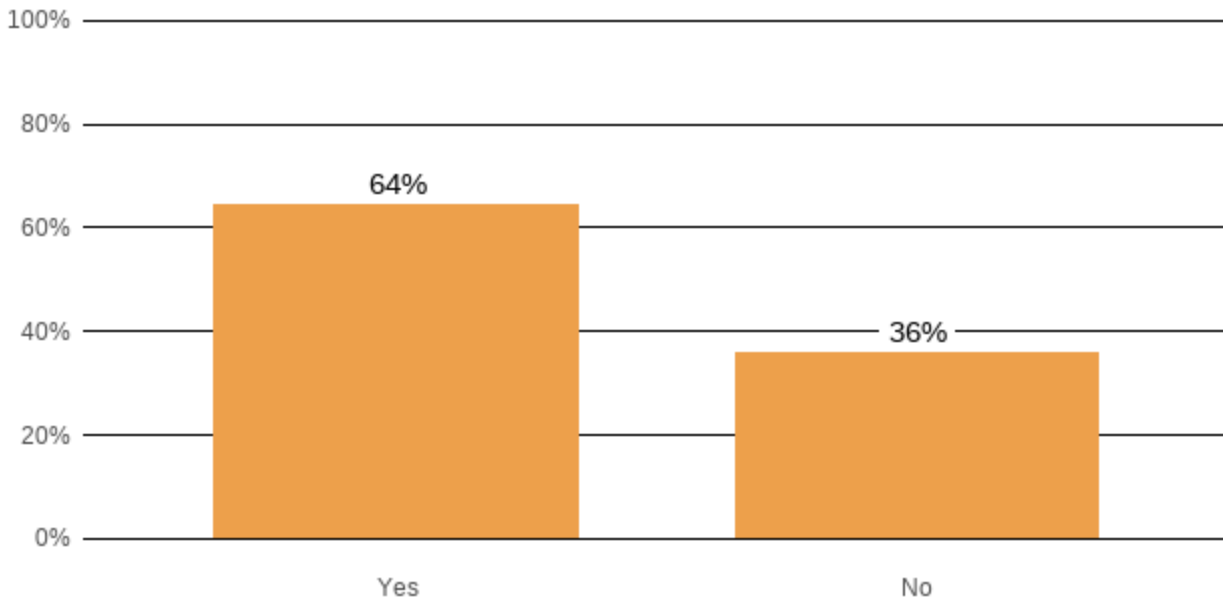


Table 69. Does your family member have friends other than paid support workers or family?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
OK ↑	77%	23%	355
DC	69%	31%	152
ND	68%	32%	129
GA	67%	33%	430
PA	67%	33%	628
MO	67%	33%	246
LA	65%	35%	1,205
DE	65%	35%	161
<b>Weighted NCI-IDD Average</b>	<b>64%</b>	<b>36%</b>	<b>4,632</b>
NJ ↓	58%	42%	664
MD ↓	57%	43%	662

**In your community, are there resources that your family can use that are not provided by the I/DD agency?**

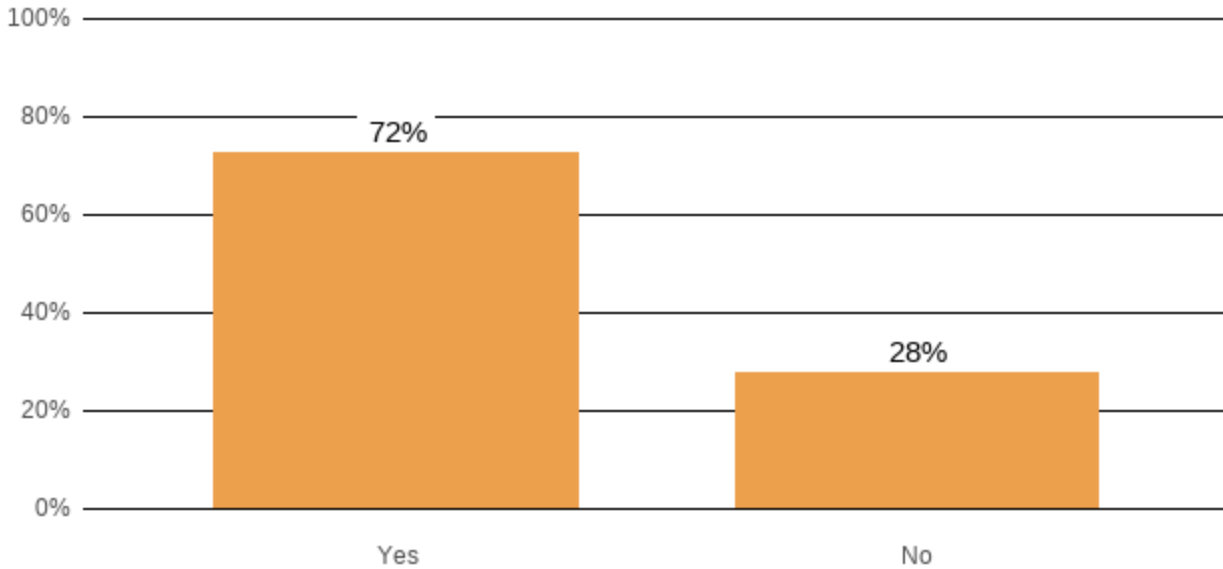


Table 70. In your community, are there resources that your family can use that are not provided by the I/DD agency? (for example, recreational programs, community housing, library programs, religious groups, etc)?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
DE	77%	23%	116
DC	77%	23%	132
ND	76%	24%	98
MO	75%	25%	185
MD	75%	25%	505
PA	75%	25%	438
<b>Weighted NCI-IDD Average</b>	<b>72%</b>	<b>28%</b>	<b>3,455</b>
GA	71%	29%	315
NJ	70%	30%	500
OK	69%	31%	267
LA	68%	32%	899

## Does your family take part in any family-to-family networks in your community?

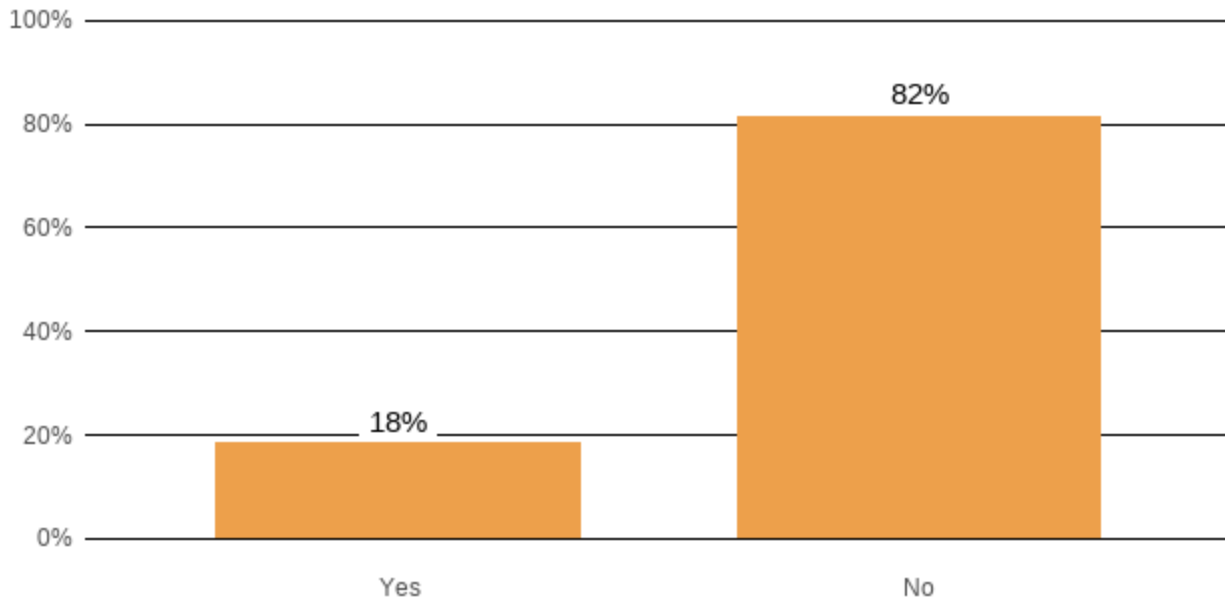


Table 71. Does your family take part in any family-to-family networks in your community?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
DC ↑	36%	64%	138
LA ↑	25%	75%	994
GA	21%	79%	373
OK	19%	81%	294
NJ	19%	81%	590
MD	19%	81%	585
ND	18%	82%	114
<b>Weighted NCI-IDD Average</b>	<b>18%</b>	<b>82%</b>	<b>3,964</b>
DE	18%	82%	148
PA	16%	84%	519
MO	14%	86%	209

## Health, Welfare, and Safety

Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state developmental disabilities system.

**Note: Significance is based on “Always” or “Yes” response.**

“**You**” and “**Respondent**” refers to the person (usually a parent or guardian) filling out the survey.

“**Family Member**” refers to the person receiving services whom the respondent is answering questions about in this survey.

### Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

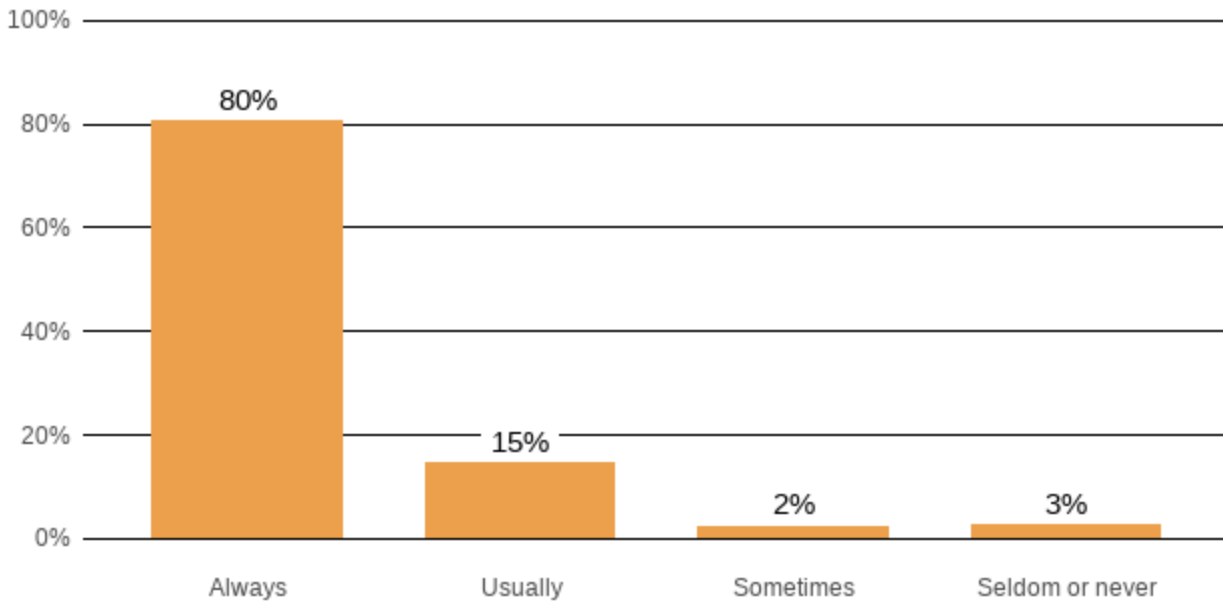


Table 72. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC	82%	15%	3%	1%	156
OK	81%	16%	1%	2%	360
PA	81%	14%	2%	3%	639
MO	81%	14%	3%	2%	249
NJ	81%	14%	3%	2%	676
LA	81%	15%	2%	3%	1,240
<b>Weighted NCI-IDD Average</b>	<b>80%</b>	<b>15%</b>	<b>2%</b>	<b>3%</b>	<b>4,722</b>
MD	80%	16%	2%	1%	674
GA	77%	16%	3%	4%	434
DE	77%	16%	3%	4%	166
ND	73%	17%	5%	5%	128

### Does your family member's primary care doctor understand your family member's needs related to their disability?

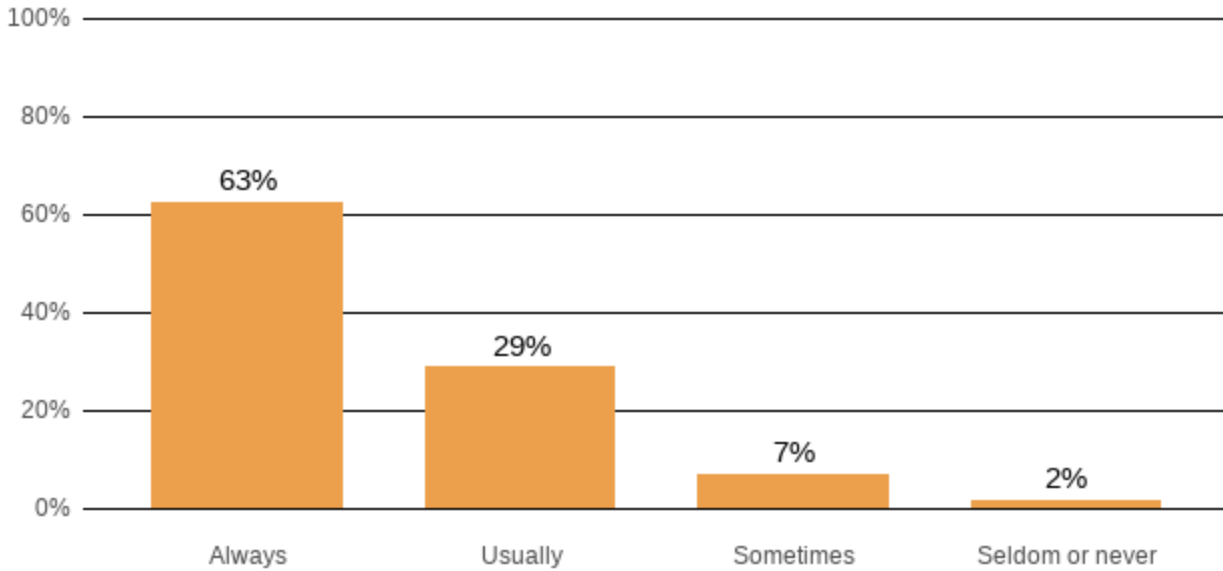


Table 73. Does your family member's primary care doctor understand your family member's needs related to their disability?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	79%	16%	5%	0%	155
LA ↑	71%	22%	5%	1%	1,227
DE	69%	22%	8%	1%	162
PA	63%	28%	7%	2%	646
<b>Weighted NCI-IDD Average</b>	<b>63%</b>	<b>29%</b>	<b>7%</b>	<b>2%</b>	<b>4,688</b>
MD	62%	30%	7%	1%	674
OK	61%	30%	7%	2%	360
NJ	61%	30%	8%	2%	669
GA	59%	31%	7%	3%	433
MO	57%	33%	8%	2%	235
ND ↓	48%	43%	9%	1%	127



## Can your family member go to the dentist when needed?

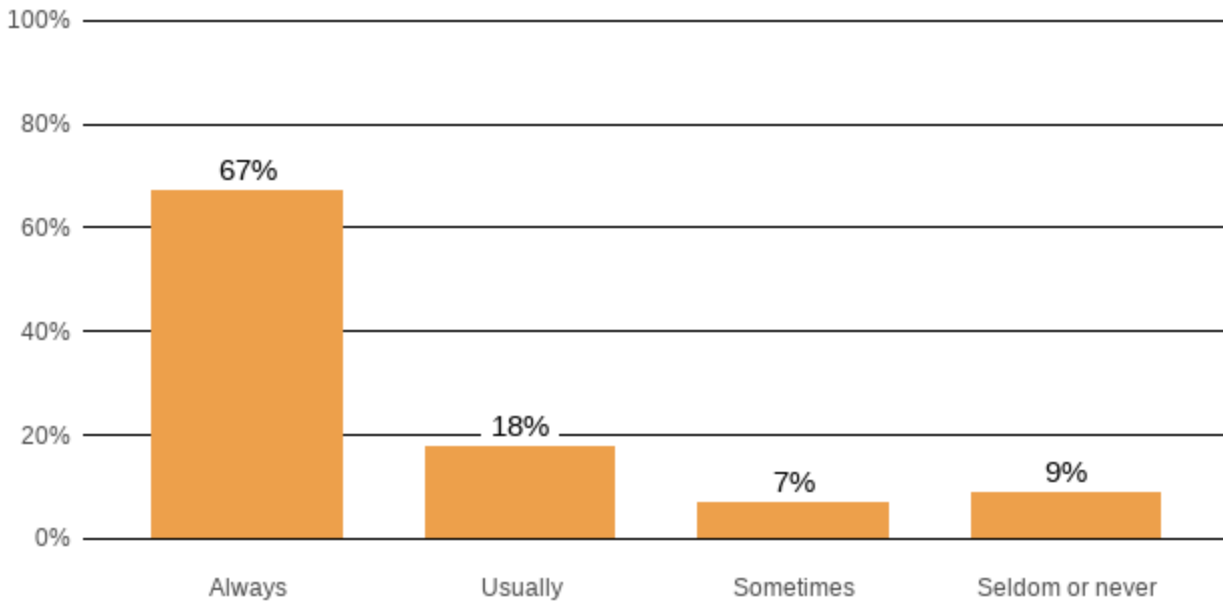


Table 74. Can your family member go to the dentist when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>NJ</b> ↑	72%	16%	5%	7%	673
<b>DC</b>	74%	19%	6%	1%	156
<b>MD</b>	71%	17%	7%	6%	676
<b>DE</b>	70%	13%	9%	8%	164
<b>PA</b>	69%	17%	6%	8%	641
<b>Weighted NCI-IDD Average</b>	67%	18%	7%	9%	4,675
<b>LA</b>	66%	17%	7%	10%	1,215
<b>ND</b>	64%	11%	9%	16%	126
<b>OK</b>	64%	22%	5%	9%	358
<b>GA</b> ↓	57%	19%	10%	14%	430
<b>MO</b> ↓	56%	22%	11%	11%	236

## Does your family member's dentist understand your family member's needs related to their disability?

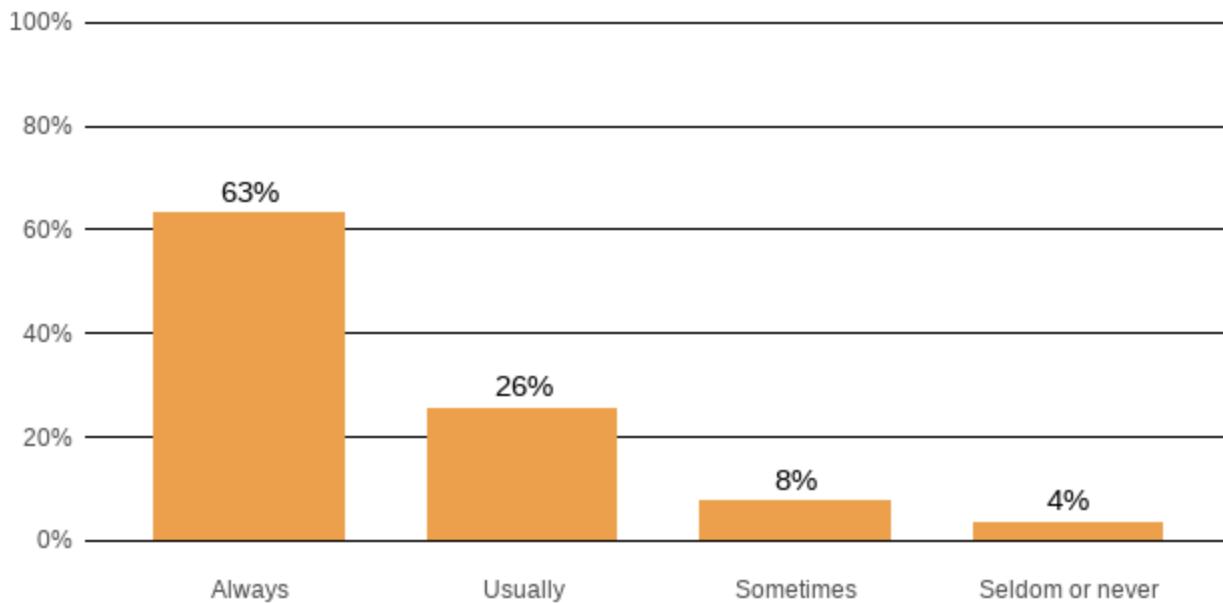


Table 75. Does your family member's dentist understand your family member's needs related to their disability?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	74%	17%	7%	1%	149
ND	66%	22%	6%	6%	109
LA	65%	25%	6%	4%	1,051
MD	65%	25%	8%	3%	627
OK	64%	27%	6%	3%	323
DE	64%	26%	6%	3%	145
NJ	64%	25%	9%	3%	635
<b>Weighted NCI-IDD Average</b>	<b>63%</b>	<b>26%</b>	<b>8%</b>	<b>4%</b>	<b>4,169</b>
PA	63%	27%	7%	3%	566
GA	62%	24%	8%	6%	362
MO	54%	29%	11%	5%	202

### If your family member takes prescription medications, do you know what they're for?

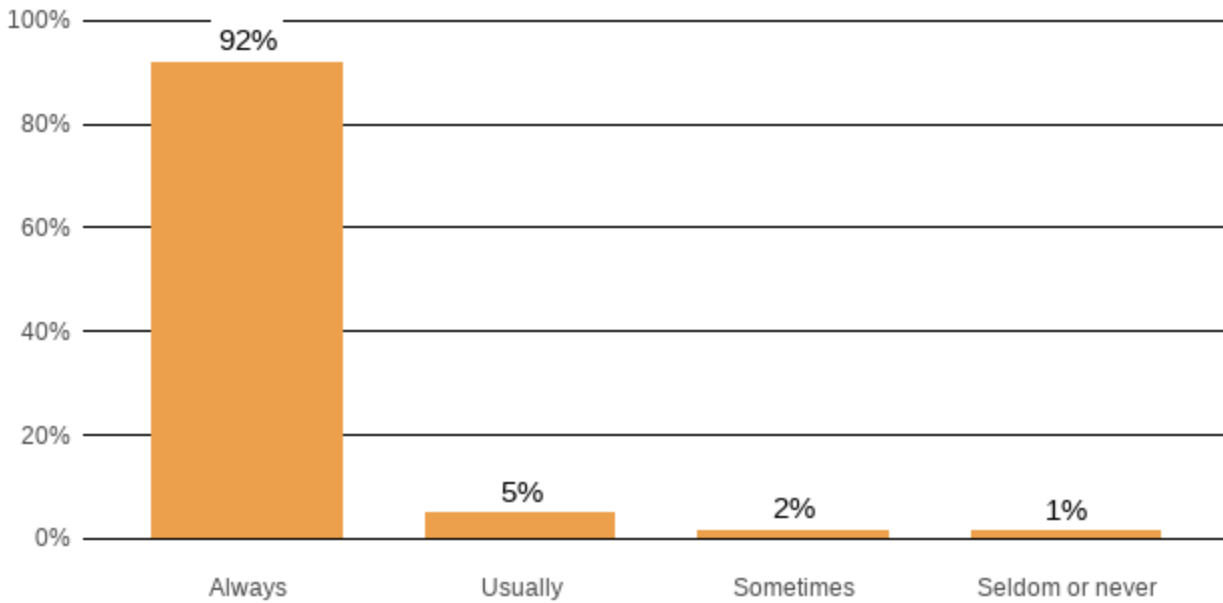


Table 76. If your family member takes prescription medications, do you know what they're for?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
ND	96%	2%	0%	2%	109
DC	95%	5%	0%	0%	129
OK	94%	3%	2%	1%	327
MD	94%	4%	1%	1%	551
NJ	93%	3%	2%	2%	564
<b>Weighted NCI-IDD Average</b>	<b>92%</b>	<b>5%</b>	<b>2%</b>	<b>1%</b>	<b>4,165</b>
MO	92%	6%	1%	2%	233
PA	92%	5%	2%	1%	578
LA	90%	7%	2%	1%	1,127
GA	90%	8%	1%	1%	413
DE	90%	3%	4%	4%	134

**Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications?**

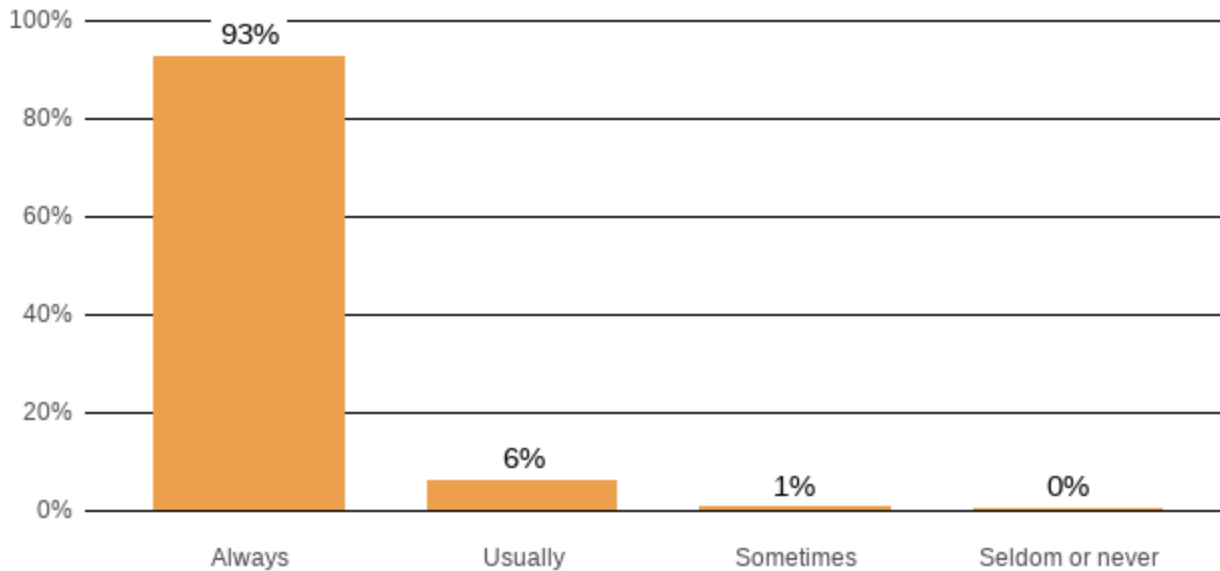


Table 77. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
ND ↑	97%	3%	0%	0%	109
OK	95%	4%	1%	1%	328
DE	95%	5%	1%	0%	131
NJ	94%	5%	1%	0%	568
PA	93%	6%	1%	0%	573
<b>Weighted NCI-IDD Average</b>	<b>93%</b>	<b>6%</b>	<b>1%</b>	<b>0%</b>	<b>4,172</b>
MD	92%	6%	1%	1%	560
MO	92%	6%	1%	1%	233
LA	91%	7%	1%	1%	1,128
GA	90%	9%	1%	1%	414
DC	90%	8%	2%	0%	128

**Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)**

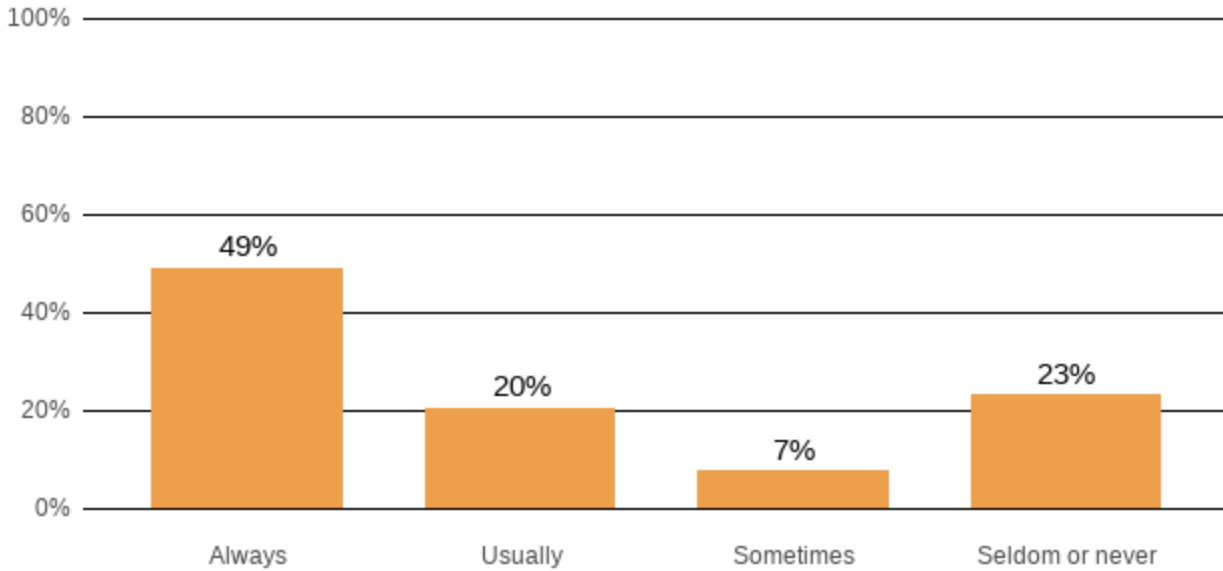


Table 78. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC	60%	15%	6%	20%	124
PA	54%	19%	6%	20%	467
MD	53%	19%	8%	21%	487
LA	51%	20%	6%	23%	906
DE	49%	20%	12%	19%	116
OK	49%	21%	4%	26%	228
<b>Weighted NCI-IDD Average</b>	<b>49%</b>	<b>20%</b>	<b>7%</b>	<b>23%</b>	<b>3,375</b>
MO	47%	21%	9%	23%	173
NJ	43%	22%	8%	27%	478
ND	40%	29%	13%	19%	80
GA ↓	41%	23%	10%	26%	316

**If your family member uses mental health services,  
does the mental health professional understand  
your family member's needs related to their  
disability?**

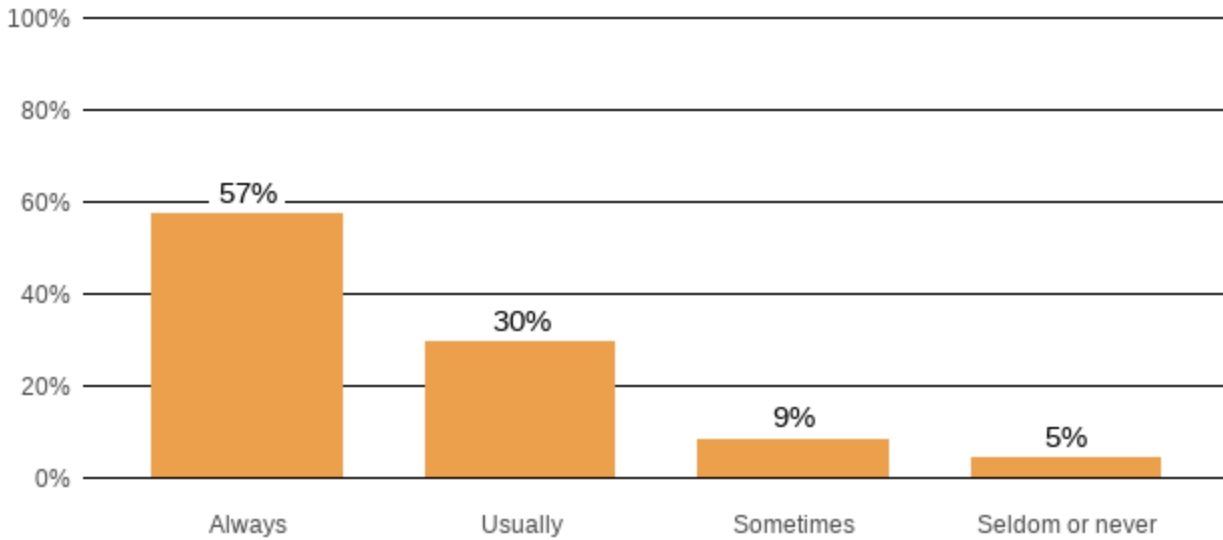


Table 79. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	73%	19%	7%	1%	89
LA ↑	66%	25%	7%	3%	627
OK	63%	24%	9%	4%	131
PA	58%	30%	7%	4%	328
DE	58%	26%	12%	4%	74
<b>Weighted NCI-IDD Average</b>	<b>57%</b>	<b>30%</b>	<b>9%</b>	<b>5%</b>	<b>2,307</b>
MO	56%	29%	9%	6%	114
NJ	56%	29%	10%	5%	319
MD	54%	30%	9%	7%	320
GA	53%	35%	8%	4%	251
ND ↓	39%	44%	15%	2%	54

**If you asked for crisis or emergency services during the past 12 months, were services provided when needed?**

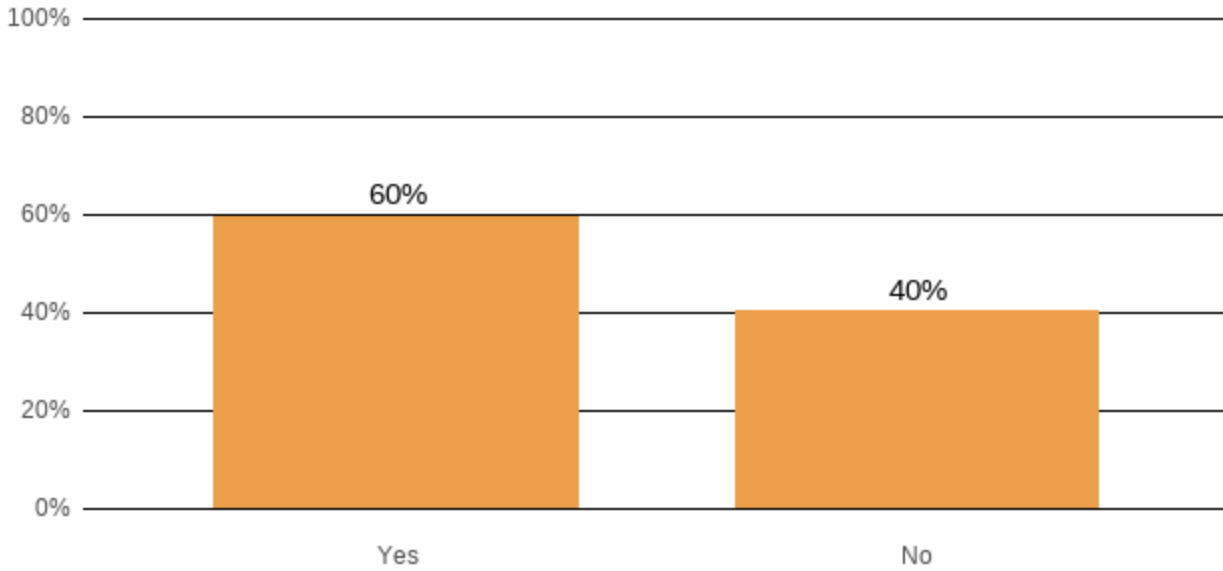


Table 80. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
OK	73%	27%	55
PA	65%	35%	115
LA	65%	35%	304
GA	63%	37%	91
<b>Weighted NCI-IDD Average</b>	<b>60%</b>	<b>40%</b>	<b>918</b>
ND	59%	41%	27
NJ	57%	43%	114
DC	47%	53%	45
DE	45%	55%	22
MO	42%	58%	43
MD ↓	45%	55%	102

**Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?**

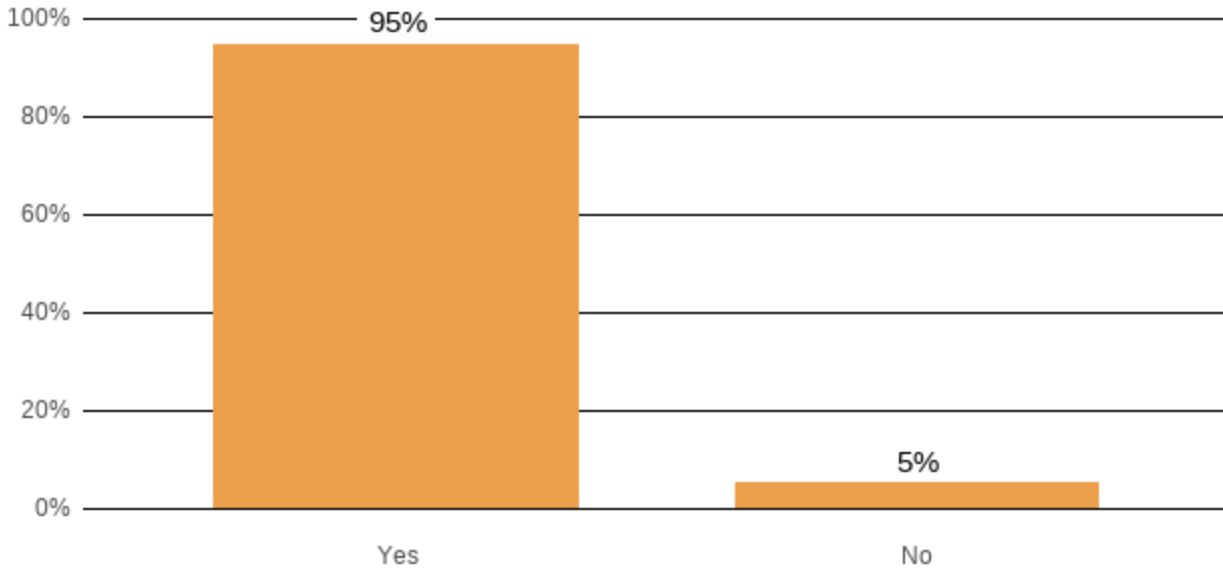


Table 81. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
LA ↑	97%	3%	1,185
PA	97%	3%	601
OK	97%	3%	344
<b>Weighted NCI-IDD Average</b>	<b>95%</b>	<b>5%</b>	<b>4,431</b>
ND	95%	5%	115
DC	95%	5%	153
GA	95%	5%	401
MO	93%	7%	236
NJ	93%	7%	622
DE	93%	7%	153
MD	92%	8%	621



**Have you talked about how to handle emergencies  
with your family member's case manager/service  
coordinator?**

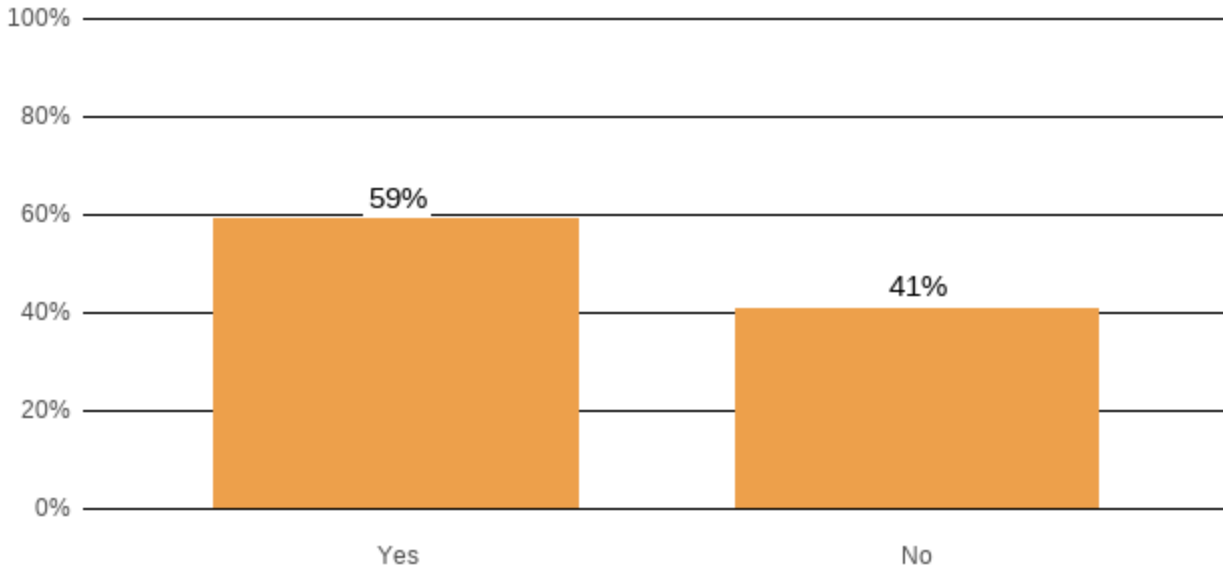


Table 82. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member’s case manager/service coordinator?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
LA ↑	89%	11%	1,208
ND ↑	73%	27%	121
DC ↑	69%	31%	157
OK	65%	35%	345
<b>Weighted NCI-IDD Average</b>	<b>59%</b>	<b>41%</b>	<b>4,503</b>
PA	58%	42%	600
NJ	57%	43%	644
MO	55%	45%	244
MD ↓	52%	48%	632
GA ↓	51%	49%	402
DE ↓	39%	61%	150

## Do you know how to file a complaint or grievance about provider agencies or staff?

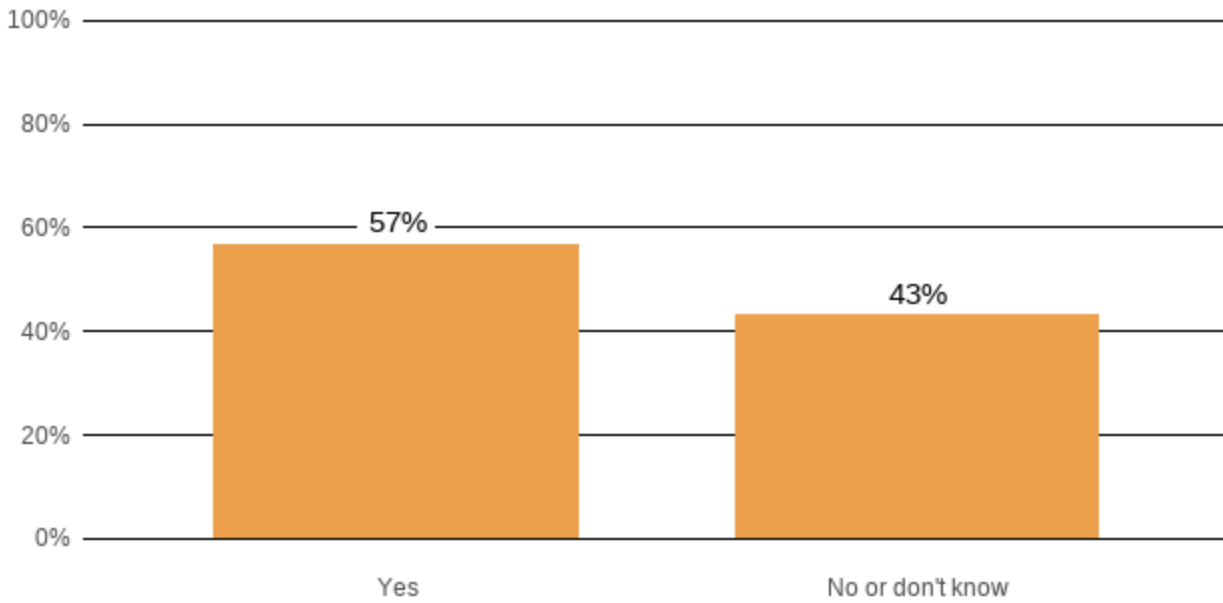


Table 83. Do you know how to file a complaint or grievance about provider agencies or staff?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No or don't know	N
OK ↑	76%	24%	358
DC ↑	75%	25%	162
LA ↑	71%	29%	1,220
PA ↑	69%	31%	653
ND	64%	36%	127
<b>Weighted NCI-IDD Average</b>	<b>57%</b>	<b>43%</b>	<b>4,722</b>
MO	52%	48%	256
GA ↓	48%	52%	440
MD ↓	43%	57%	674
NJ ↓	43%	57%	670
DE ↓	30%	70%	162

**If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?**

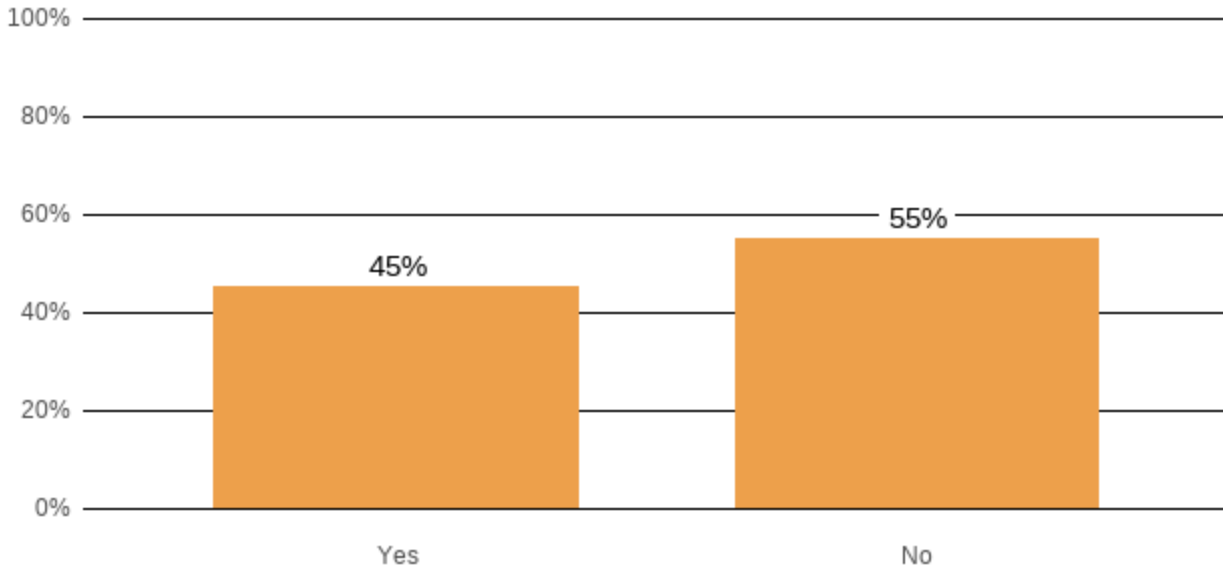


Table 84. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
LA	58%	42%	95
PA	51%	49%	49
GA	49%	51%	45
<b>Weighted NCI-IDD Average</b>	<b>45%</b>	<b>55%</b>	<b>340</b>
DC	41%	59%	32
MD	32%	68%	38
NJ	28%	72%	29

The following states had a low count of responses (N<20) and were not shown: MO, ND, OK, DE

## Do you know how to report abuse or neglect related to your family member?

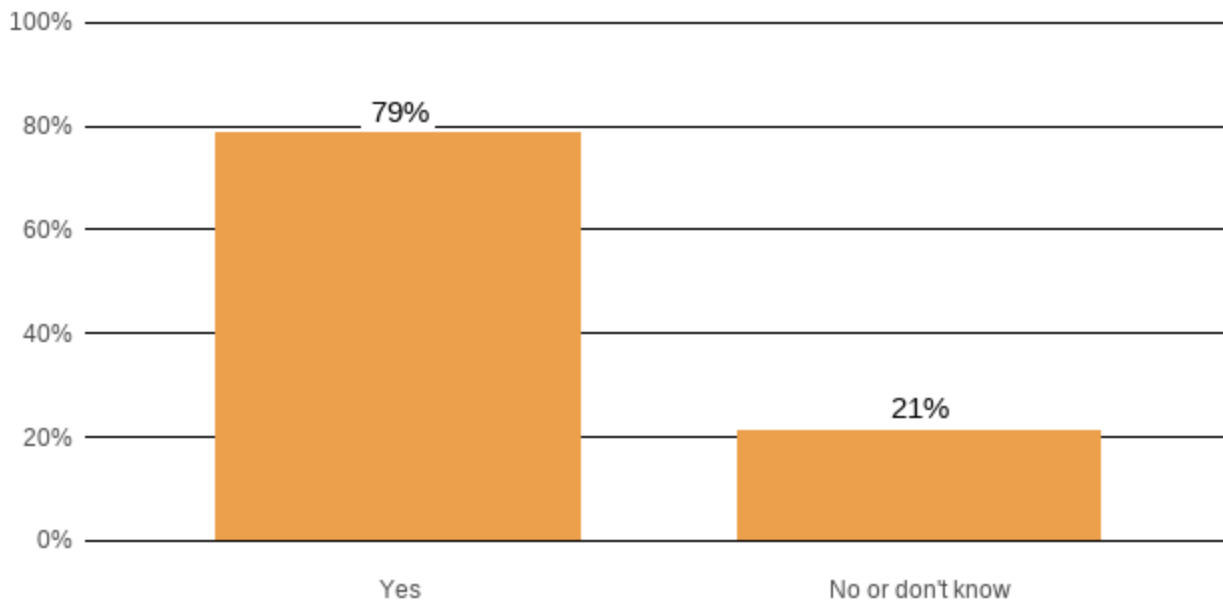


Table 85. Do you know how to report abuse or neglect related to your family member?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No or don't know	N
<b>OK</b> ↑	90%	10%	360
<b>DC</b> ↑	89%	11%	161
<b>PA</b> ↑	86%	14%	651
<b>LA</b> ↑	85%	15%	1,226
<b>MO</b>	82%	18%	255
<b>ND</b>	82%	18%	127
<b>Weighted NCI-IDD Average</b>	79%	21%	4,731
<b>GA</b>	76%	24%	438
<b>NJ</b> ↓	70%	30%	672
<b>DE</b> ↓	66%	34%	162
<b>MD</b> ↓	65%	35%	679

**Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?**

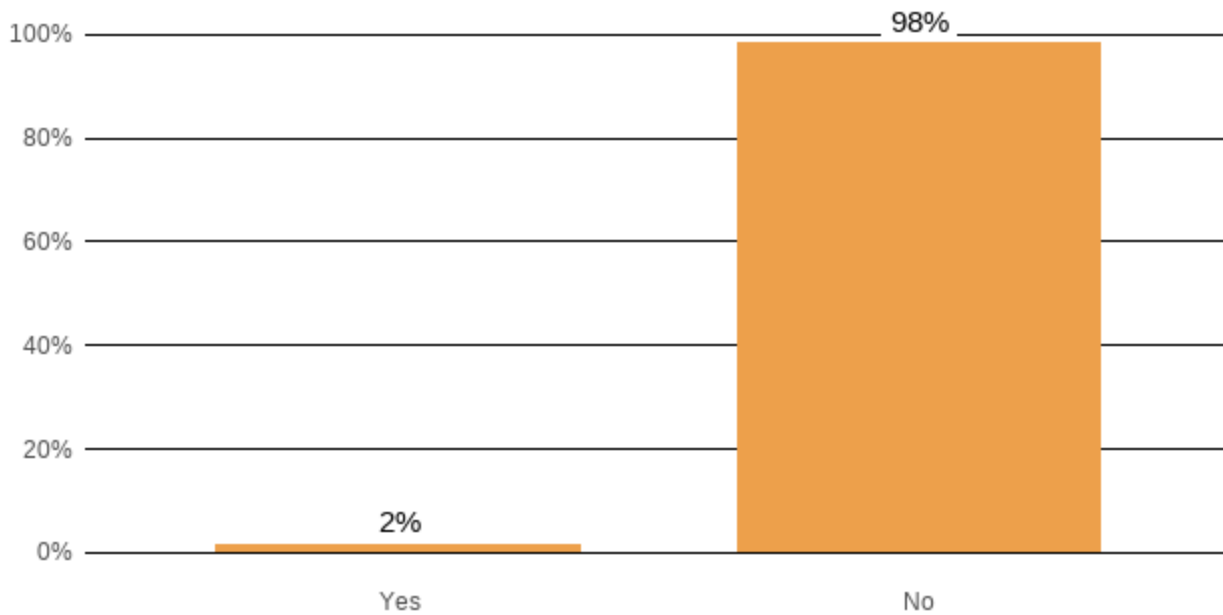


Table 86. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
ND	6%	94%	124
PA	3%	97%	646
<b>Weighted NCI-IDD Average</b>	<b>2%</b>	<b>98%</b>	<b>4,637</b>
MD	2%	98%	660
DC	1%	99%	157
MO	1%	99%	252
OK	1%	99%	355
LA	1%	99%	1,193
DE	1%	99%	163
GA ↓	0%	100%	432
NJ ↓	0%	100%	655

**If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?**

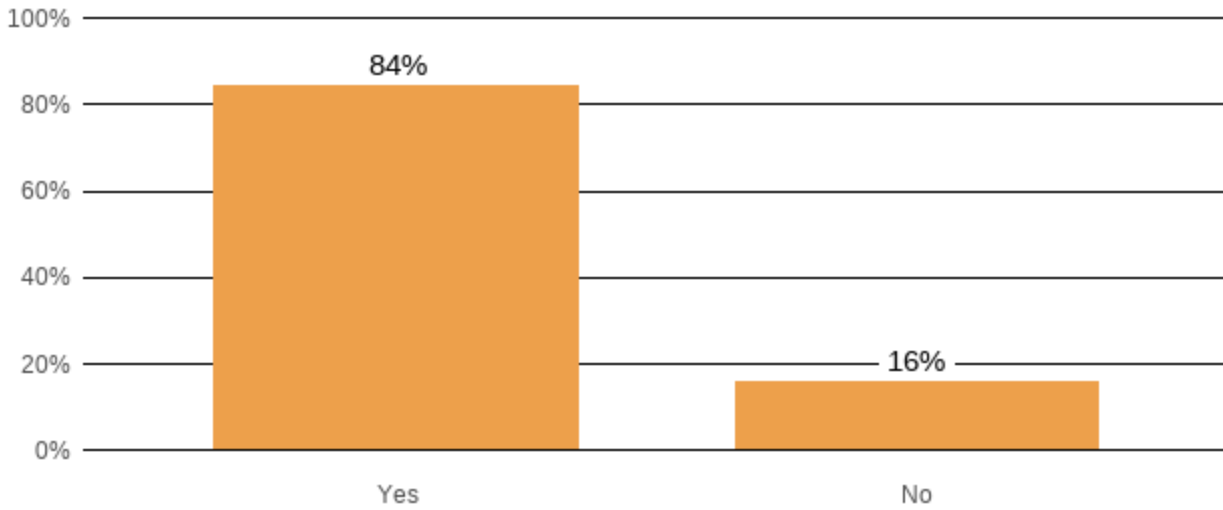


Table 87. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
<b>Weighted NCI-IDD Average</b>	84%	16%	38

The following states had a low count of responses (N<20) and were not shown: DC, DE, GA, MO, OK, PA, MD, ND, LA, NJ

## Family Satisfaction

Services and supports lead to better lives for people with disabilities and their families.

**Note: Significance is based on “Always” or “Yes” response.**

**“You”** and **“Respondent”** refers to the person (usually a parent or guardian) filling out the survey.

**“Family Member”** refers to the person receiving services whom the respondent is answering questions about in this survey.

**Overall, are you satisfied with the services and supports your family member currently receives?**

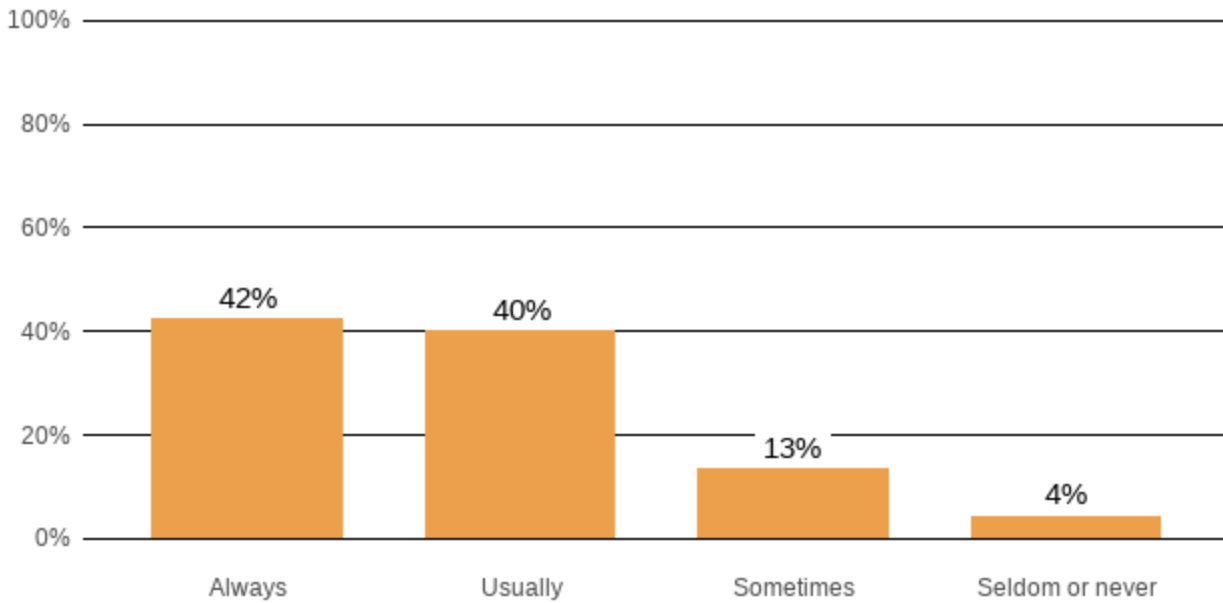


Table 88. Overall, are you satisfied with the services and supports your family member currently receives?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
DC ↑	63%	28%	8%	1%	158
LA ↑	53%	34%	9%	3%	1,207
PA	47%	37%	11%	4%	649
OK	43%	42%	11%	4%	359
<b>Weighted NCI-IDD Average</b>	<b>42%</b>	<b>40%</b>	<b>13%</b>	<b>4%</b>	<b>4,690</b>
GA	39%	40%	15%	6%	427
NJ	38%	43%	15%	4%	678
MO	37%	46%	14%	2%	254
ND	33%	41%	19%	7%	124
MD ↓	31%	46%	17%	6%	671
DE ↓	29%	39%	25%	7%	163



**Do you feel that services and supports have made a positive difference in the life of your family member?**

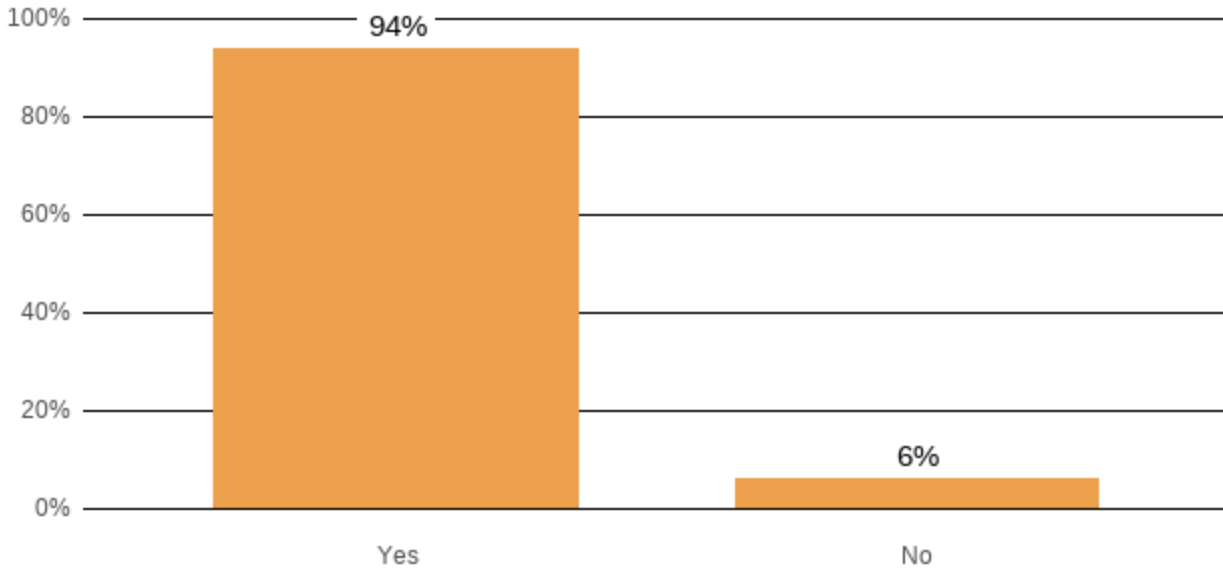


Table 89. Do you feel that services and supports have made a positive difference in the life of your family member?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
MO	96%	4%	247
OK	96%	4%	341
NJ	95%	5%	641
PA	95%	5%	612
ND	95%	5%	121
DC	95%	5%	154
<b>Weighted NCI-IDD Average</b>	<b>94%</b>	<b>6%</b>	<b>4,429</b>
LA	94%	6%	1,145
MD	92%	8%	623
GA ↓	89%	11%	397
DE ↓	84%	16%	148

### Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

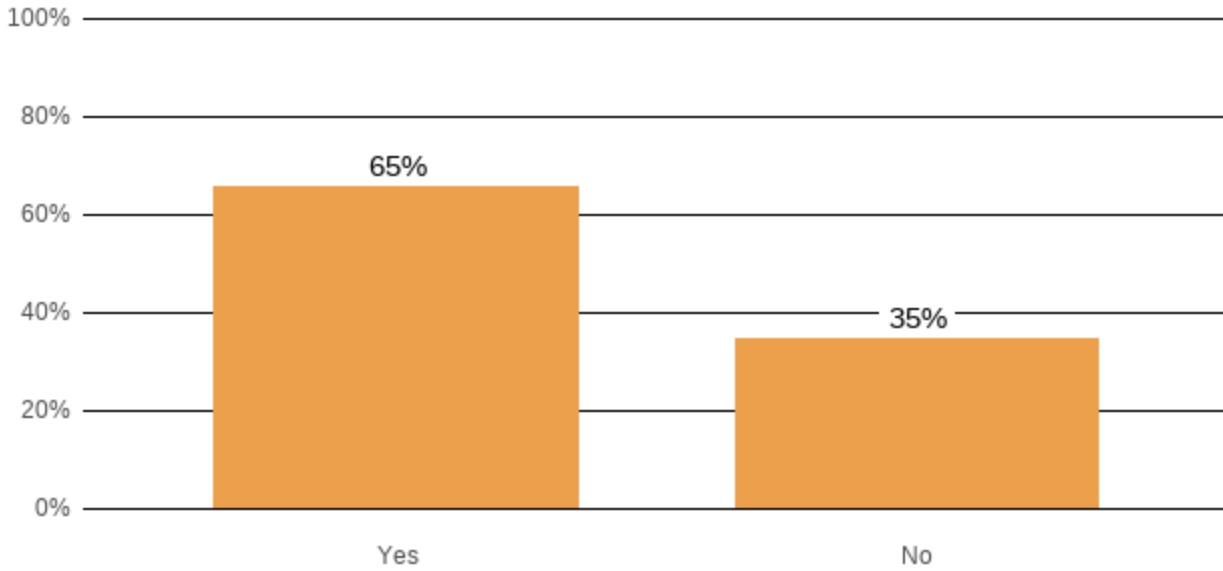


Table 90. Have services and supports reduced your family’s out-of-pocket expenses for your family member’s care?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
NJ ↑	78%	22%	637
OK ↑	75%	25%	321
MO ↑	73%	27%	232
MD	70%	30%	593
<b>Weighted NCI-IDD Average</b>	<b>65%</b>	<b>35%</b>	<b>4,159</b>
LA	65%	35%	1,067
ND	61%	39%	112
GA	60%	40%	373
DE	56%	44%	139
PA ↓	55%	45%	546
DC ↓	53%	47%	139

**Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?**

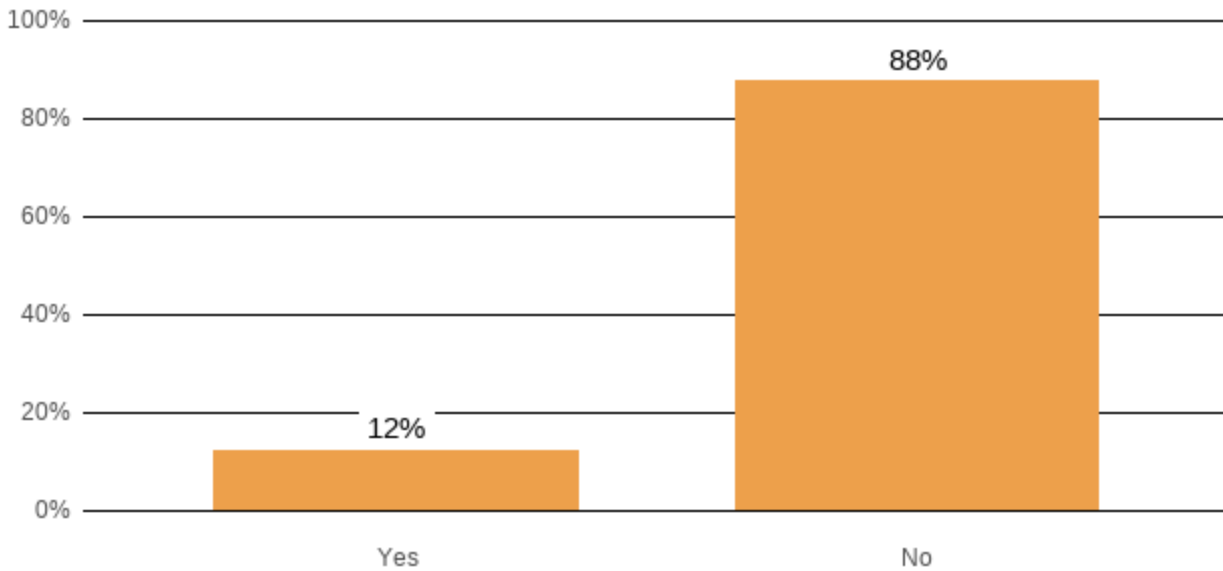


Table 91. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
ND ↑	24%	76%	117
MD ↑	16%	84%	640
DE	16%	84%	155
PA	14%	86%	599
MO	14%	86%	240
GA	13%	87%	401
DC	12%	88%	153
<b>Weighted NCI-IDD Average</b>	<b>12%</b>	<b>88%</b>	<b>4,352</b>
OK	9%	91%	343
LA ↓	9%	91%	1,056
NJ ↓	8%	92%	648

**If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?**

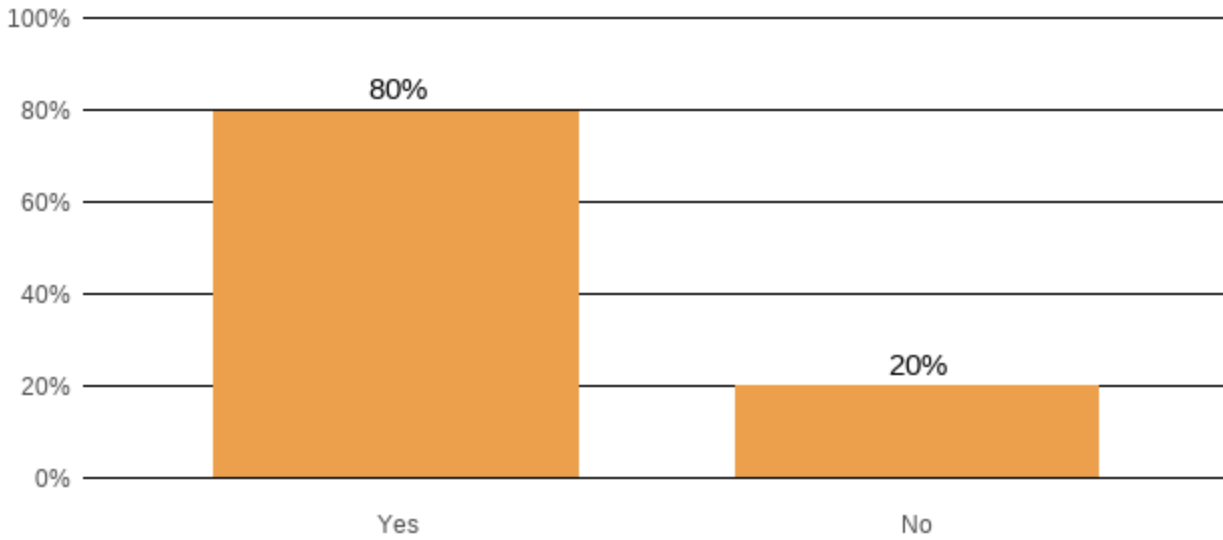


Table 92. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
MO	91%	9%	32
ND	85%	15%	26
NJ	82%	18%	49
MD	80%	20%	92
<b>Weighted NCI-IDD Average</b>	<b>80%</b>	<b>20%</b>	<b>461</b>
GA	80%	20%	44
PA	78%	22%	78
LA	77%	23%	75
DE	71%	29%	21
OK	69%	31%	26
<b>The following states had a low count of responses (N&lt;20) and were not shown: DC</b>			

**Have the services or supports that your family member received been increased in the past 12 months?**

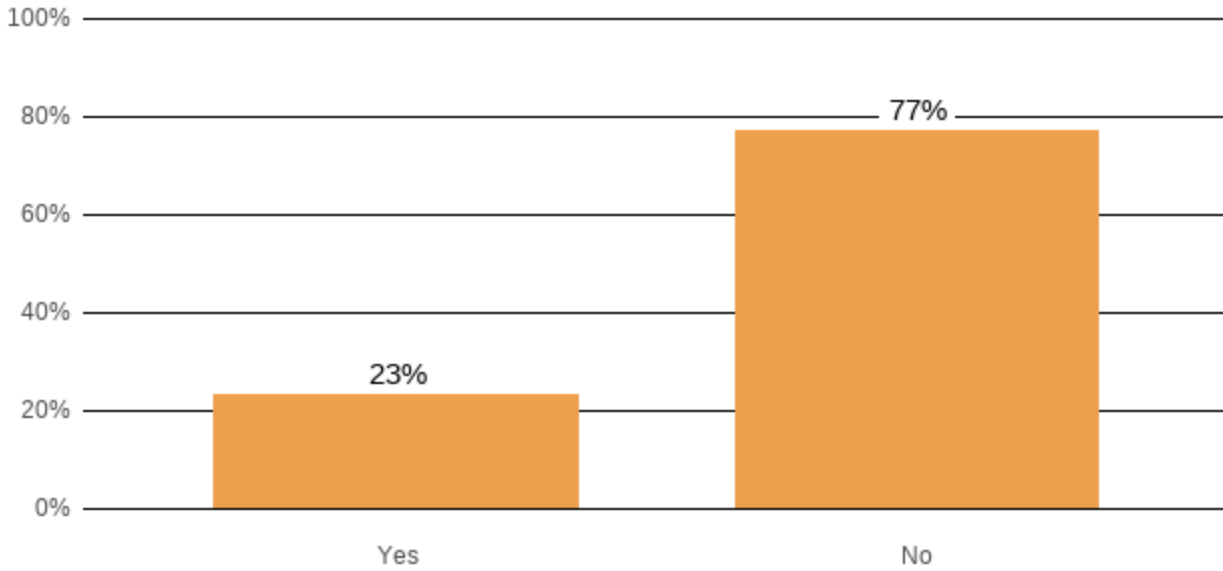


Table 93. Have the services or supports that your family member received been increased in the past 12 months?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
MD ↑	30%	70%	608
MO	29%	71%	235
NJ	25%	75%	611
DC	23%	77%	149
<b>Weighted NCI-IDD Average</b>	<b>23%</b>	<b>77%</b>	<b>4,155</b>
PA	23%	77%	563
OK	22%	78%	317
GA	20%	80%	363
DE	16%	84%	148
LA ↓	15%	85%	1,042
ND ↓	12%	88%	119

## Are services and supports helping your family member to live a good life?

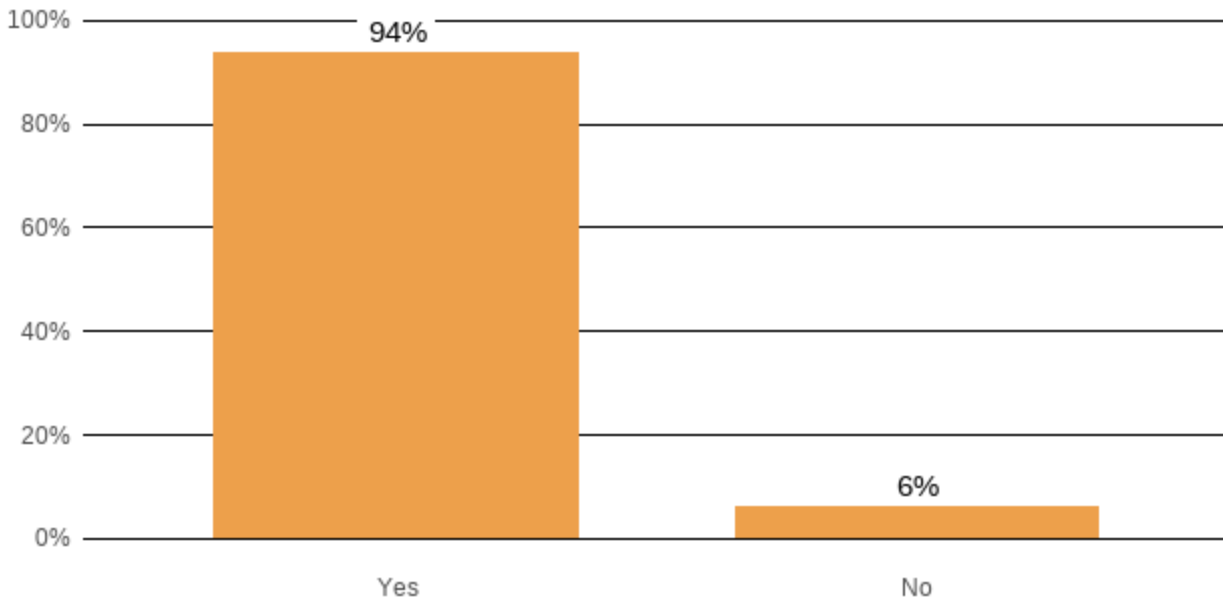


Table 94. Are services and supports helping your family member to live a good life?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
PA ↑	96%	4%	579
OK	95%	5%	333
MO	95%	5%	242
ND	95%	5%	117
NJ	94%	6%	617
<b>Weighted NCI-IDD Average</b>	<b>94%</b>	<b>6%</b>	<b>4,256</b>
DC	93%	7%	153
LA	92%	8%	1,081
MD	92%	8%	612
GA	90%	10%	383
DE ↓	82%	18%	139

## **NCI-IDD History and Activities**

*This section briefly describes the history of the National Core Indicators and NCI-IDD surveys.*

## Overview of National Core Indicators

In December 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI), launched the Core Indicators Project (CIP). The aim of the project was to support state developmental disabilities authorities in the development and implementation of performance and outcome indicators—and related data collection strategies—so that they could measure service delivery system performance. This effort, now called National Core Indicators (NCI), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI-IDD facilitates pooled knowledge, expertise, and resources among the states.

In 1997, 15 states convened to discuss the scope and content of a potential performance measurement framework. Directors and staff from these 15 states worked to identify the major domains and sub-domains of performance, indicators, measures, and data sources. The original 61 indicators, developed through a consensus process, were intended to provide a system-level “snapshot” of how well each state was performing. The states were guided by a set of criteria that was designed to select indicators that were:

1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of disability or residential setting

During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states volunteered to pilot test the indicators. Eight additional states served on the Steering Committee.

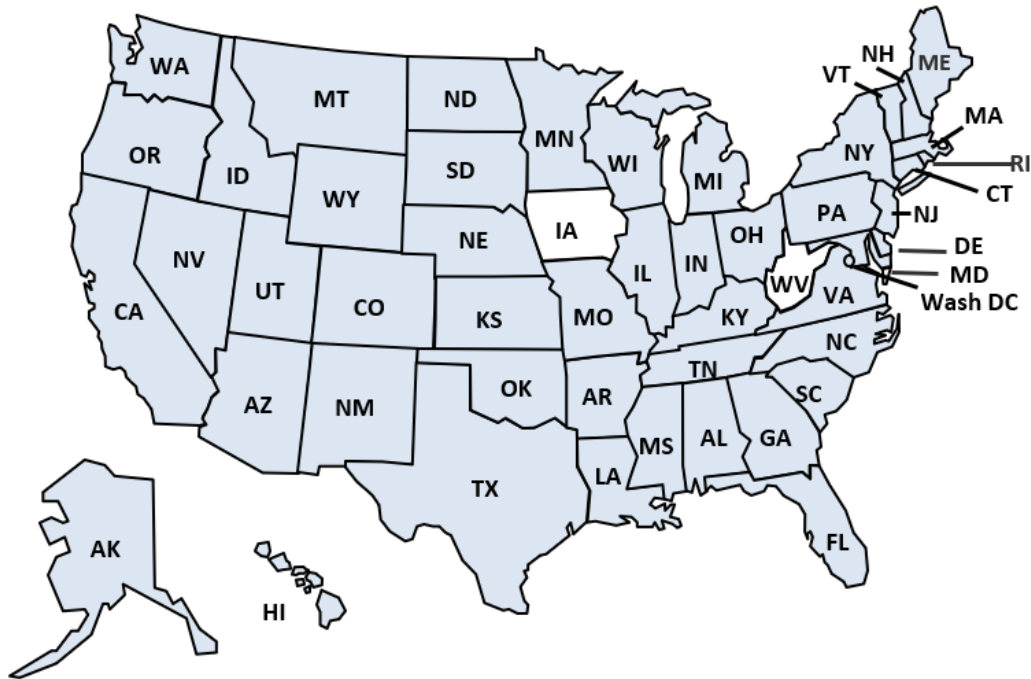
Since the initial field test, NCI-IDD has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI-IDD continues to develop and refine the indicators and expand state participation. For more information about NCI-IDD states, technical reports, and other resources please visit the NCI-IDD website at <https://idd.nationalcoreindicators.org/>.

## State Participation

State participation is entirely voluntary. As of the 2022-23 data collection cycle, the participating states are highlighted on the map below. Not all states participate in all surveys each year.



**Figure 1. NCI-IDD State Participation 2022-23**



## The Core Indicators

The Core Indicators are the standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern, including employment, respect/rights, service planning, community inclusion, choice, and health and safety. An example of a Core Indicator would be, “The proportion of people who have a paid job in the community.” To see the entire list of Core Indicators, please visit the Indicators page on the NCI-IDD website at <https://idd.nationalcoreindicators.org/how-it-works/>.

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

The current set of performance indicators includes approximately 100 consumer, family, system, and health and safety outcomes—outcomes that are important to understanding the overall health of public developmental disabilities agencies. Indicators are organized across four broad domains: Individual Outcomes; Health, Welfare, and Rights; Family Experience; and System Performance. Each domain is broken down into sub-domains, as shown in the following table. Four data sources are used to assess outcomes: the In-Person Survey, three Family Surveys, and State of the Workforce in IDD survey.

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI-IDD initiative is a dynamic effort that allows for measures to be added, dropped, or changed to reflect current and future priorities of participating states.

The data collection tools used to gather indicator data are regularly refined and tested to ensure they remain valid, reliable, and applicable to current issues within the field. Details on the design and testing of this tool are provided in the next section of this report.

## Sub-Domains and Concern Statements

The following table lists the sub-domains under the “Family Outcomes” domain.

### Family Survey Sub-Domains and Concern Statements

Sub-Domain	Value Statement
Information and Planning	Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state Developmental disabilities system.
Choice and Decision Making	Families and their family members receiving services and supports from the state Developmental disabilities system are involved in making choices about supports, services, and providers.
Access & Support Delivery	Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state Developmental disabilities system.
Workforce (New in 2021-22)	There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.
Community Connections	Family members receiving services and supports from the state Developmental disabilities system are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.
Health, Welfare, and Safety (New in 2021-22)	Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state Developmental disabilities system.
Family Satisfaction	Services and supports lead to better lives for people with disabilities and their families.

## How NCI-IDD Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI-IDD as a data source for supplemental performance measures in their home and community-based services (HCBS) waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

For more information on how to use these data for quality improvement, please see this handbook: [Using National Core Indicators for Quality Improvement Initiatives](#).

## Caution and Limitations

This report does not provide benchmarks for acceptable or unacceptable levels of performance. Rather, it is up to each state to decide whether its score or percentage is an acceptable performance level. States that fall into the “below average” tier on any scale or indicator are not necessarily underperforming; instead, this placement indicates only that the state’s scale score or indicator percentage is significantly lower than the average of all states—where “significantly” means “not due to chance.” The results tables throughout this report display states’ scores relative to one another and show which states tend to have similar results. Notably, the difference between a “below average” state and the average across the other states may be very small, and it is up to public managers, policy-makers, and other stakeholders to decide whether a state’s result relative to the Weighted NCI-IDD Average suggests that changes or further investigation are necessary.

Moreover, the Weighted NCI-IDD Average should not be interpreted as defining “acceptable” levels of performance or satisfaction. Instead, it represents a multi-state “norm” that describes average levels of performance or satisfaction across the participating states. In some instances, there are few significant differences among states; this denotes that the majority of states are performing similarly. Instances in which several states’ results are especially high (considerably above the average level) indicate the levels of performance or satisfaction achieved in those states might define a level of performance that may serve as a guidepost for other states.

Data from previous years are not presented in this report. Comparisons of results from year to year should be made with caution: even slight changes in wording or response options of certain questions may affect comparability of results from one year to the next; the mix of participating states differs slightly each year and may affect the Weighted NCI-IDD Averages; and states draw new samples each year rather than following the same group of individuals.

## **Methodology**

This section describes the protocol used by states to select families to participate in the survey, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by NCI-IDD staff to aggregate and analyze the data.

## Sampling & Administration

States were asked to administer the Adult Family Survey by selecting a random sample of at least 1,000 families who:

1. Had an adult individual (aged 18 or over) with an intellectual or developmental disability living in the home; and
2. The adult individual with an intellectual or developmental disability living in the home received at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys.

A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%. Please see “Response Rates” for information on total surveys mailed and received by states as well as each state’s margin of error.

## Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI-IDD reports, we use “Weighted NCI-IDD Average” to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the Weighted NCI-IDD Average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). The approach has since been enhanced to consider the relative numbers of people receiving services through participating states’ systems. The Weighted NCI-IDD Averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the sample sizes.

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 Weighted NCI-IDD Average—that is, the state’s contribution to the Weighted NCI-IDD 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.

## Significance Testing

For each of the items in the report, each state's percentage was compared to the weighted Weighted NCI-IDD 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. A statistically significant difference for a state with a large sample size, in and by itself, does not necessarily mean there is a *practically* significant difference. The inclusion of effect sizes allows us to present “meaningfully significant” results, which take the magnitude or size of the differences into account.

The state percentages in this report are categorized into one of three classes:

1. **Significantly above the Weighted NCI-IDD Average**, where the difference between the state's percentage and the weighted Weighted NCI-IDD Average: a) was in favor of the state, b) was statistically significant (i.e.,  $p < .01$ ), **and** c) met the effect size criterion (i.e., Cohen's  $d > 0.2$ , see below for details);
2. **Within the Weighted NCI-IDD Average range**, where the difference between the state's percentage and the weighted Weighted NCI-IDD Average was: a) not statistically significant (i.e.,  $p \geq .01$ ), **or** b) did not meet the effect size criterion (i.e., Cohen's  $d \leq 0.2$ );  
or
3. **Significantly below the Weighted NCI-IDD Average**, where the difference between the state's percentage and the weighted Weighted NCI-IDD Average: a) was in favor of the Weighted NCI-IDD Average, b) was statistically significant (i.e.,  $p < .01$ ), **and** c) met the effect size criterion (i.e., Cohen's  $d > 0.2$ ).

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the Weighted NCI-IDD Average, within the range of the Weighted NCI-IDD Average, and significantly below the Weighted NCI-IDD Average.

### Technical Details

The comparisons were done through one sample t-tests using the weighted Weighted NCI-IDD Average as the benchmark. A conservative cut-off point (alpha) of  $p < .01$  was used to detect statistically significant differences. Effect sizes are calculated using the formula: *Cohen's d* =  $\frac{2t}{\sqrt{df}}$ . A cutoff point of Cohen's  $d = 0.2$  was chosen for the effect size to be considered “meaningfully significant,” following the standard interpretation offered by Cohen (1988) that Cohen's  $d$  of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

## Data Entry and Analysis

Each state entered its survey responses into the Online Data Entry Survey Application (ODESA). All raw data files were reviewed for completeness, invalid responses were eliminated, and quality checks were performed. The data files were then cleaned and merged to create the national dataset.

Data were considered invalid, and therefore excluded, based on the following two criteria:

1. The respondent indicated the individual with an intellectual or developmental disability receiving services lived outside of the family home.
2. Demographic information was entered into the file but no survey questions were answered.

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the Weighted NCI-IDD Average. The Weighted NCI-IDD Average is a weighted average. Please see the section "Weighting" for more details. Statistical significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

## Response Rates

During 2022-23, 10 states administered the Adult Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The following table shows the number of individuals receiving services who were eligible to be drawn into the sample ("total population"), the number of surveys each state sent, complete surveys, response rates, margins of error, and survey submission modes.

## Adult Family Survey: State Response Rates

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
DC	639	639	166	26.0%	7.0%	46%	54%
DE	1089	500	169	33.8%	6.9%	67%	33%
GA	7373	1700	457	26.9%	4.2%	100%	0%
LA	5182	5182	1262	24.4%	2.5%	87%	13%
MD	6102	6375	755	11.8%	3.3%	1%	99%
MO	3775	1500	263	17.5%	5.5%	87%	13%
ND	378	378	130	34.4%	8.2%	86%	14%
NJ	14340	14340	761	5.3%	3.3%	0%	100%
OK	2095	2092	365	17.4%	4.7%	100%	0%
PA	19494	2000	670	33.5%	3.5%	100%	0%
<b>Total</b>	<b>60467</b>	<b>34706</b>	<b>4988</b>	<b>14.4%</b>	<b>1.3%</b>	<b>63%</b>	<b>37%</b>

*Please note: The family surveys are mail surveys or completed online by respondents who choose to take part in the survey. As such, the final sample is a sample of convenience and cannot be considered representative of the entire service population in the state.*