

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



National Report 2023-24

Adult Family Survey (AFS)





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of
Developmental Disabilities Services

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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 Indicator

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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 2023-24 data collection cycle, 13 states submitted a valid sample of Adult Family Survey data: Arizona (AZ), California (CA), District of Columbia (DC), Georgia (GA), Indiana (IN), Maryland (MD), Missouri (MO), Montana (MT), New Jersey (NJ), New Hampshire (NH), Oklahoma (OK), Pennsylvania (PA), and Virginia (VA). This Final Report provides results based on data submitted by June 30, 2024.

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.
- **State names have been abbreviated throughout the report.**
- **Note on responses:** All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.
- “N” demonstrates the number of valid responses for each question. “N” can vary between questions. The N does not include missing responses, “don’t know” responses or “not applicable” responses. For information on the total sample from each state, see Figure 3.

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.

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	Yes	No	N
AZ	15%	85%	209
CA	17%	83%	13593
DC	12%	88%	131
GA	14%	86%	467
IN	16%	84%	343
MD	12%	88%	600
MO	16%	84%	257
MT	8%	92%	195
NJ	8%	92%	444
NH	9%	91%	541
OK	12%	88%	398
PA	15%	85%	639
VA	13%	87%	210
Weighted NCI-IDD Average	15%	85%	18027

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	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
AZ	83%	17%	204
CA	90%	10%	13115
DC	100%	0%	124
GA	57%	43%	454
IN	59%	41%	347
MD	75%	25%	595
MO	64%	36%	257
MT	59%	41%	206
NJ	79%	21%	447
NH	52%	48%	528
OK	71%	29%	390
PA	59%	41%	628
VA	70%	30%	198
Weighted NCI-IDD Average	79%	21%	17493

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	Age	N
AZ	33.2	201
CA	33.5	14126
DC	39.4	141
GA	47.7	466
IN	34.0	347
MD	33.5	64
MO	34.1	264
MT	35.4	211
NJ	34.7	464
NH	35.3	531
OK	33.3	400
PA	33.1	662
VA	34.9	213
Weighted NCI-IDD Average	34.0	18090

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	Male	Female	Other	N
AZ	54%	46%	0%	202
CA	63%	37%	0%	13485
DC	65%	35%	0%	127
GA	54%	46%	0%	468
IN	60%	40%	0%	349
MD	62%	38%	0%	567
MO	58%	42%	0%	257
MT	51%	49%	0%	197
NJ	64%	36%	0%	427
NH	60%	40%	0%	539
OK	59%	41%	0%	401
PA	62%	38%	0%	640
VA	63%	37%	0%	202
Weighted NCI-IDD Average	62%	38%	0%	17861

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	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer not to say
AZ	5%	4%	8%	1%	62%	28%	2%	4%
CA	2%	16%	8%	1%	42%	38%	2%	3%
DC	1%	1%	84%	0%	7%	4%	3%	3%
GA	0%	2%	38%	1%	57%	1%	1%	3%
IN	1%	3%	8%	0%	89%	2%	0%	1%
MD	1%	6%	32%	0%	56%	5%	2%	5%
MO	2%	2%	7%	0%	88%	2%	2%	2%
MT	5%	2%	2%	0%	89%	4%	1%	3%
NJ	0%	8%	11%	0%	71%	9%	1%	4%
NH	2%	2%	2%	1%	90%	2%	1%	3%
OK	14%	3%	12%	1%	74%	8%	2%	1%
PA	1%	5%	10%	0%	78%	6%	2%	2%
VA	2%	9%	26%	0%	61%	4%	4%	2%
Weighted NCI-IDD Average	2%	10%	12%	1%	57%	22%	2%	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	Intellectual Disability	Mood Illness or psychiatric diagnosis	Autism Spectrum Disorder	Cerebral Palsy
AZ	65%	19%	39%	21%
CA	60%	21%	46%	15%
DC	64%	14%	31%	16%
GA	73%	21%	23%	22%
IN	63%	26%	46%	15%
MD	70%	21%	50%	13%
MO	61%	23%	47%	19%
MT	65%	17%	26%	18%
NJ	62%	19%	47%	15%
NH	70%	32%	38%	10%
OK	77%	23%	32%	23%
PA	81%	28%	44%	12%
VA	69%	27%	43%	20%
Weighted NCI-IDD Average	65%	22%	44%	16%

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	Limited or No Vision	Hearing loss (severe or profound)	Brain Injury	Seizure or Neurological Disorder
AZ	8%	4%	8%	27%
CA	8%	5%	7%	21%
DC	7%	4%	5%	19%
GA	14%	11%	12%	34%
IN	6%	5%	7%	28%
MD	6%	6%	5%	22%
MO	11%	4%	9%	34%
MT	13%	6%	8%	25%
NJ	7%	4%	5%	24%
NH	8%	9%	7%	27%
OK	9%	7%	13%	30%
PA	5%	6%	5%	24%
VA	7%	8%	9%	27%
Weighted NCI-IDD Average	7%	5%	7%	24%

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	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
AZ	0%	17%	0%	1%	15%
CA	1%	13%	0%	1%	14%
DC	0%	12%	0%	1%	21%
GA	1%	13%	1%	0%	16%
IN	0%	14%	0%	4%	18%
MD	0%	12%	0%	0%	16%
MO	0%	13%	0%	1%	24%
MT	0%	23%	1%	1%	20%
NJ	0%	14%	0%	1%	17%
NH	0%	18%	0%	1%	12%
OK	0%	20%	1%	2%	20%
PA	0%	18%	0%	0%	16%
VA	0%	15%	1%	1%	27%
Weighted NCI-IDD Average	0%	14%	0%	1%	16%

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	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	6%	19%	7%	19%	25%
CA	8%	17%	4%	25%	30%
DC	8%	27%	5%	38%	34%
GA	9%	26%	6%	48%	44%
IN	9%	15%	4%	25%	22%
MD	12%	11%	2%	24%	24%
MO	10%	12%	3%	21%	27%
MT	11%	13%	4%	17%	22%
NJ	9%	12%	4%	22%	31%
NH	10%	14%	4%	20%	28%
OK	9%	17%	2%	26%	26%
PA	10%	16%	3%	21%	24%
VA	13%	16%	3%	23%	33%
Weighted NCI-IDD Average	9%	16%	4%	25%	29%

Table 7b. 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	Dysphagia	Pressure Ulcers	Alzheimer’s Disease or Dementia	Oral Health Problems	Sleep Apnea
AZ	12%	3%	3%	14%	22%
CA	7%	1%	2%	12%	18%
DC	6%	1%	0%	8%	9%
GA	9%	2%	4%	12%	16%
IN	11%	1%	2%	14%	24%
MD	10%	1%	2%	8%	15%
MO	15%	3%	2%	13%	22%
MT	11%	2%	3%	9%	28%
NJ	8%	1%	2%	9%	13%
NH	10%	3%	3%	8%	22%
OK	11%	1%	1%	12%	22%
PA	8%	2%	2%	10%	20%
VA	16%	5%	3%	13%	21%
Weighted NCI-IDD Average	9%	2%	2%	11%	19%

Table 7c. 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	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
AZ	31%	8%	5%	0%	23%
CA	19%	5%	3%	1%	23%
DC	29%	9%	9%	3%	8%
GA	10%	4%	3%	2%	11%
IN	24%	5%	4%	2%	24%
MD	17%	5%	2%	1%	35%
MO	12%	5%	5%	1%	27%
MT	19%	7%	2%	2%	23%
NJ	16%	3%	4%	3%	39%
NH	19%	5%	3%	2%	29%
OK	19%	4%	3%	1%	26%
PA	19%	3%	2%	1%	32%
VA	17%	7%	4%	1%	38%
Weighted NCI-IDD Average	19%	5%	3%	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	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
AZ	74%	13%	3%	5%	4%	208
CA	83%	10%	2%	2%	4%	13592
DC	79%	14%	1%	3%	2%	135
GA	75%	16%	2%	1%	6%	465
IN	87%	8%	2%	1%	2%	352
MD	75%	15%	2%	3%	4%	615
MO	74%	17%	2%	3%	3%	244
MT	73%	11%	1%	2%	13%	206
NJ	82%	10%	1%	2%	6%	455
NH	87%	9%	1%	2%	1%	545
OK	76%	16%	3%	2%	4%	398
PA	85%	9%	2%	2%	2%	658
VA	72%	21%	0%	3%	3%	209
Weighted NCI-IDD Average	81%	11%	2%	2%	4%	18082

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	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AZ	94%	3%	0%	0%	0%	2%	1%	205
CA	76%	14%	1%	1%	1%	0%	6%	13767
DC	96%	3%	0%	0%	0%	1%	0%	139
GA	96%	1%	0%	0%	0%	1%	2%	466
IN	98%	0%	0%	0%	0%	1%	1%	358
MD	96%	1%	0%	0%	0%	1%	2%	616
MO	98%	0%	0%	0%	0%	0%	2%	248
MT	96%	0%	0%	0%	0%	1%	3%	209
NJ	94%	2%	0%	0%	0%	0%	3%	452
NH	98%	0%	0%	0%	0%	1%	2%	548
OK	96%	1%	0%	0%	1%	1%	1%	397
PA	96%	2%	0%	0%	0%	1%	1%	655
VA	96%	0%	0%	0%	0%	0%	3%	213
Weighted NCI-IDD Average	86%	8%	1%	0%	1%	1%	4%	18273

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	No guardianship	Limited guardianship	Full guardianship	Has guardianship but level unknown	N
AZ	16%	6%	76%	2%	207
CA	41%	29%	25%	5%	13006
DC	36%	17%	42%	5%	132
GA	37%	12%	47%	4%	428
IN	25%	7%	65%	3%	350
MD	53%	7%	36%	4%	576
MO	21%	8%	68%	3%	257
MT	12%	10%	75%	2%	204
NJ	19%	7%	72%	2%	443
NH	14%	10%	73%	3%	542
OK	18%	8%	70%	3%	383
PA	48%	12%	35%	5%	596
VA	22%	11%	64%	3%	208
Weighted NCI-IDD Average	35%	19%	42%	4%	17332

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	Family	Friend	Employee of state or guardianship agency	Other	N
AZ	96%	0%	1%	3%	170
CA	97%	1%	0%	2%	6972
DC	89%	1%	3%	7%	76
GA	92%	1%	0%	6%	231
IN	96%	1%	1%	1%	251
MD	95%	1%	0%	4%	257
MO	97%	1%	0%	2%	197
MT	95%	1%	0%	4%	168
NJ	97%	0%	0%	3%	353
NH	99%	0%	0%	0%	456
OK	94%	0%	0%	6%	302
PA	94%	1%	1%	4%	287
VA	93%	0%	0%	7%	156
Weighted NCI-IDD Average	96%	1%	0%	3%	9876

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	Did not complete high school, Not currently in school	Currently enrolled in high school	High school certificate (NOT a high school diploma/GED)	N
AZ	13%	7%	30%	202
CA	16%	2%	37%	13095
DC	22%	0%	42%	137
GA	26%	0%	46%	444
IN	14%	3%	53%	347
MD	10%	2%	55%	610
MO	12%	2%	27%	250
MT	10%	1%	24%	207
NJ	12%	1%	25%	449
NH	10%	0%	42%	535
OK	9%	3%	22%	394
PA	6%	2%	24%	647
VA	11%	1%	40%	208
Weighted NCI-IDD Average	14%	2%	37%	17525

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	High school diploma/GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	37%	3%	5%	4%	202
CA	24%	4%	9%	7%	13095
DC	20%	13%	1%	2%	137
GA	24%	1%	1%	2%	444
IN	20%	3%	4%	3%	347
MD	17%	3%	6%	9%	610
MO	46%	2%	5%	6%	250
MT	58%	1%	2%	4%	207
NJ	45%	3%	6%	8%	449
NH	36%	2%	4%	5%	535
OK	59%	3%	2%	3%	394
PA	59%	3%	4%	3%	647
VA	34%	4%	4%	6%	208
Weighted NCI-IDD Average	31%	4%	7%	6%	17525

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	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
AZ	56%	33%	11%	204
CA	47%	31%	22%	13324
DC	66%	24%	10%	134
GA	58%	29%	14%	454
IN	58%	31%	12%	358
MD	55%	28%	17%	595
MO	52%	33%	15%	255
MT	63%	27%	10%	202
NJ	54%	29%	17%	449
NH	62%	30%	8%	531
OK	65%	23%	12%	395
PA	57%	31%	12%	646
VA	46%	29%	26%	202
Weighted NCI-IDD Average	51%	30%	18%	17749

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	No support needed; no issues with personal care activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed	N
AZ	14%	44%	42%	207
CA	27%	36%	37%	13704
DC	38%	38%	24%	136
GA	24%	35%	41%	469
IN	29%	43%	28%	360
MD	23%	40%	38%	608
MO	22%	36%	42%	262
MT	21%	41%	38%	206
NJ	16%	38%	46%	456
NH	28%	41%	31%	545
OK	22%	39%	39%	398
PA	32%	41%	28%	651
VA	14%	37%	49%	210
Weighted NCI-IDD Average	25%	38%	37%	18212

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	No support needed; no issues with other daily activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed	N
AZ	2%	17%	81%	209
CA	6%	26%	68%	13756
DC	14%	25%	61%	135
GA	4%	19%	77%	465
IN	4%	25%	71%	357
MD	3%	17%	80%	612
MO	4%	16%	80%	259
MT	2%	22%	75%	207
NJ	2%	16%	82%	457
NH	3%	22%	75%	543
OK	3%	19%	78%	397
PA	3%	24%	73%	648
VA	2%	12%	86%	203
Weighted NCI-IDD Average	5%	22%	73%	18248

Respondents

This section provides information about the survey respondent.

Table 16. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AZ	91%	7%	0%	0%	0%	0%	1%	210
CA	69%	21%	2%	1%	1%	0%	6%	13771
DC	96%	3%	0%	0%	0%	0%	1%	139
GA	99%	0%	0%	0%	0%	0%	0%	468
IN	99%	1%	0%	0%	0%	0%	0%	352
MD	96%	1%	0%	0%	0%	0%	2%	592
MO	98%	0%	0%	0%	0%	0%	1%	260
MT	99%	0%	0%	0%	0%	0%	1%	204
NJ	93%	3%	0%	1%	0%	0%	3%	450
NH	99%	1%	0%	0%	0%	0%	1%	552
OK	96%	3%	0%	0%	1%	0%	1%	400
PA	96%	2%	0%	0%	0%	0%	2%	652
VA	96%	1%	0%	1%	0%	0%	2%	210
Weighted NCI-IDD Average	83%	11%	1%	1%	1%	0%	4%	18260

Table note: “Chinese” includes Mandarin, Cantonese, and Hokkien. “Tagalog” includes Filipino.

Table 17. Respondent's Age

State	18 - 34	35 – 54	55 – 74	75 or older	N
AZ	4%	20%	64%	12%	210
CA	6%	21%	61%	11%	13860
DC	6%	17%	61%	17%	139
GA	2%	8%	59%	32%	463
IN	4%	22%	60%	14%	359
MD	5%	22%	67%	6%	615
MO	4%	22%	63%	11%	262
MT	2%	15%	68%	14%	209
NJ	2%	8%	76%	14%	458
NH	2%	15%	72%	11%	550
OK	2%	24%	60%	14%	399
PA	4%	16%	70%	10%	652
VA	1%	19%	66%	14%	208
Weighted NCI-IDD Average	5%	19%	64%	12%	18384

Table 18. Respondent's Health

State	Excellent	Very good	Good	Fair	Poor	N
AZ	18%	33%	36%	11%	2%	210
CA	11%	31%	39%	17%	2%	13884
DC	16%	36%	37%	9%	2%	139
GA	6%	26%	44%	21%	4%	467
IN	10%	31%	40%	17%	2%	357
MD	16%	35%	36%	11%	1%	617
MO	13%	38%	33%	13%	3%	261
MT	16%	38%	35%	9%	2%	206
NJ	11%	36%	39%	11%	2%	458
NH	14%	39%	35%	11%	1%	549
OK	9%	36%	44%	11%	1%	400
PA	13%	33%	36%	17%	2%	653
VA	13%	33%	39%	13%	2%	208
Weighted NCI-IDD Average	12%	32%	39%	15%	2%	18409

Table 19. Respondent's Relationship to Family Member

State	Parent (biological, adoptive, or foster)	Sibling	Spouse	Grandparent	Other	N
AZ	89%	5%	0%	4%	2%	211
CA	88%	6%	0%	2%	4%	13962
DC	77%	9%	1%	4%	8%	140
GA	74%	14%	0%	1%	11%	473
IN	86%	6%	1%	3%	4%	359
MD	92%	5%	0%	1%	2%	613
MO	89%	5%	0%	2%	4%	261
MT	95%	2%	0%	1%	1%	208
NJ	95%	4%	0%	0%	1%	456
NH	91%	5%	1%	2%	1%	549
OK	95%	2%	0%	1%	2%	402
PA	92%	5%	0%	2%	1%	658
VA	84%	9%	0%	2%	4%	206
Weighted NCI-IDD Average	88%	6%	0%	2%	3%	18498

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

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

State	No	Yes, respondent does	Yes, another family member does
AZ	41%	50%	20%
CA	46%	42%	16%
DC	56%	33%	12%
GA	85%	8%	7%
IN	69%	24%	8%
MD	55%	33%	21%
MO	73%	11%	17%
MT	52%	31%	24%
NJ	39%	36%	30%
NH	50%	40%	14%
OK	45%	43%	13%
PA	63%	26%	14%
VA	41%	41%	18%
Weighted NCI-IDD Average	51%	37%	16%

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	One	Two	Three	Four or more	N
AZ	7%	34%	38%	21%	210
CA	7%	25%	42%	26%	13850
DC	18%	42%	32%	7%	136
GA	10%	35%	44%	11%	471
IN	4%	23%	53%	19%	346
MD	7%	23%	47%	24%	611
MO	4%	31%	45%	20%	260
MT	8%	30%	48%	14%	207
NJ	4%	26%	49%	20%	451
NH	6%	27%	50%	16%	547
OK	7%	30%	49%	13%	399
PA	5%	27%	47%	21%	654
VA	9%	31%	42%	18%	211
Weighted NCI-IDD Average	7%	27%	44%	22%	18353

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

State	One	Two	Three	Four or more	None	N
AZ	10%	3%	2%	0%	85%	209
CA	10%	4%	1%	1%	84%	13918
DC	9%	4%	1%	0%	86%	139
GA	5%	2%	1%	0%	91%	470
IN	8%	2%	0%	0%	90%	349
MD	8%	3%	0%	0%	88%	616
MO	6%	3%	0%	1%	91%	262
MT	6%	2%	2%	0%	90%	207
NJ	4%	1%	0%	0%	94%	454
NH	4%	1%	1%	0%	94%	550
OK	9%	3%	0%	0%	88%	401
PA	5%	2%	1%	0%	92%	659
VA	5%	1%	0%	1%	92%	210
Weighted NCI-IDD Average	8%	3%	1%	1%	88%	18444

Table 23. Respondent's Highest Level of Education

State	No high school diploma or GED	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	8%	14%	7%	25%	46%	209
CA	15%	18%	6%	21%	39%	13653
DC	9%	34%	4%	21%	31%	140
GA	11%	38%	6%	17%	29%	463
IN	5%	27%	6%	18%	44%	351
MD	2%	13%	3%	17%	64%	602
MO	2%	22%	6%	25%	46%	252
MT	2%	24%	10%	20%	44%	203
NJ	2%	13%	3%	20%	62%	450
NH	3%	24%	4%	19%	49%	546
OK	6%	23%	5%	24%	41%	398
PA	4%	31%	8%	14%	43%	656
VA	6%	18%	3%	25%	48%	207
Weighted NCI-IDD Average	10%	20%	6%	20%	44%	18130

Table 24. Total Taxable Household Income of Wage Earners in the Past 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	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
AZ	9%	5%	8%	15%	17%	23%	23%	207
CA	8%	6%	9%	18%	13%	23%	22%	13508
DC	13%	6%	13%	21%	7%	16%	24%	136
GA	20%	9%	10%	18%	9%	9%	25%	456
IN	10%	5%	6%	16%	16%	26%	21%	348
MD	5%	2%	3%	10%	13%	39%	27%	610
MO	8%	5%	8%	20%	14%	21%	24%	257
MT	4%	6%	11%	17%	18%	24%	20%	204
NJ	4%	4%	5%	13%	15%	35%	25%	455
NH	8%	7%	5%	14%	13%	21%	31%	531
OK	8%	10%	11%	19%	12%	21%	18%	395
PA	10%	6%	7%	13%	13%	26%	26%	650
VA	9%	1%	9%	17%	9%	29%	23%	201
Weighted NCI-IDD Average	9%	6%	8%	16%	13%	25%	23%	17958

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 ID/DD Agency

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

State	Financial support	In home support	Out-of-home respite care	Day or employment supports
AZ	11%	38%	39%	50%
CA	20%	38%	25%	50%
DC	11%	63%	38%	55%
GA	18%	33%	17%	56%
IN	13%	26%	20%	44%
MD	15%	47%	23%	53%
MO	19%	39%	19%	49%
MT	28%	41%	25%	62%
NJ	26%	40%	20%	61%
NH	38%	24%	33%	47%
OK	15%	42%	13%	38%
PA	12%	41%	24%	54%
VA	18%	48%	21%	40%
Weighted NCI-IDD Average	18%	39%	24%	50%

Table 25b. Services and Supports Received from ID/DD Agency (Continued)

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

State	Transportation	Mental/behavioral health care or other treatments or therapies	Self-direction/fiscal intermediary services
AZ	51%	46%	31%
CA	39%	13%	23%
DC	68%	46%	26%
GA	59%	20%	38%
IN	44%	43%	41%
MD	62%	34%	47%
MO	53%	34%	51%
MT	65%	23%	59%
NJ	64%	36%	63%
NH	61%	28%	57%
OK	46%	24%	37%
PA	57%	30%	40%
VA	52%	37%	51%
Weighted NCI-IDD Average	47%	24%	34%

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

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

State	Social Security SSI/SSB	Services or supports from other agencies or organizations
AZ	93%	26%
CA	81%	24%
DC	88%	30%
GA	98%	24%
IN	89%	40%
MD	96%	28%
MO	94%	41%
MT	97%	49%
NJ	95%	29%
NH	93%	21%
OK	95%	24%
PA	95%	41%
VA	98%	31%
Weighted NCI-IDD Average	88%	28%

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?

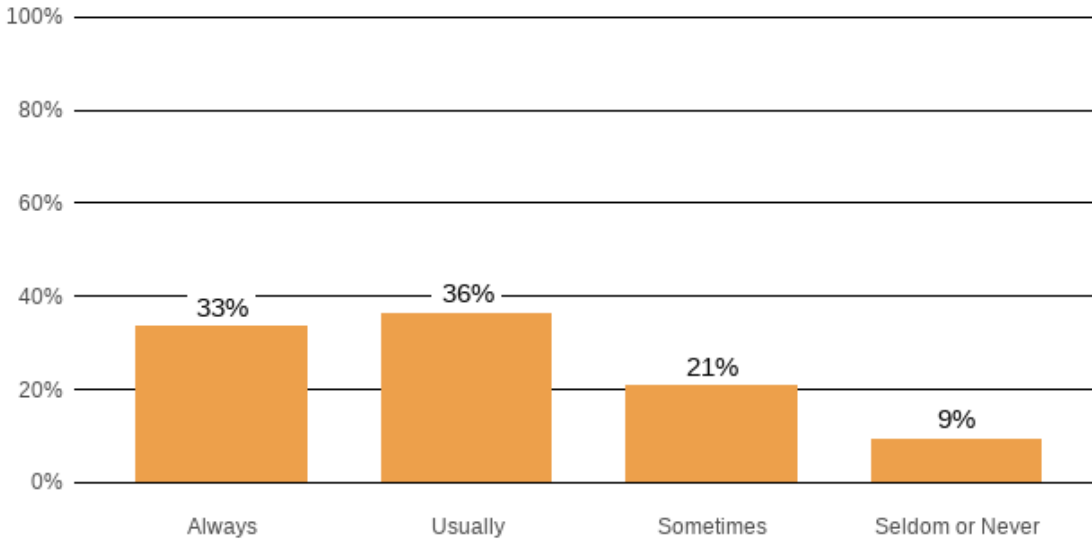


Table 27. Do you get enough information to take part in planning services for your family member?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	60%	21%	16%	4%	131
AZ ↑	44%	41%	11%	5%	200
VA ↑	43%	38%	15%	4%	199
PA	38%	38%	19%	5%	620
NH	38%	41%	17%	5%	520
IN	38%	39%	18%	5%	332
MO	37%	43%	12%	7%	253
MT	35%	40%	20%	5%	201
Weighted NCI-IDD Average	33%	36%	21%	9%	16742
OK	33%	41%	19%	7%	380
GA	32%	41%	19%	8%	412
MD	32%	39%	20%	9%	603
CA	29%	33%	25%	13%	12447
NJ	29%	44%	20%	7%	444

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

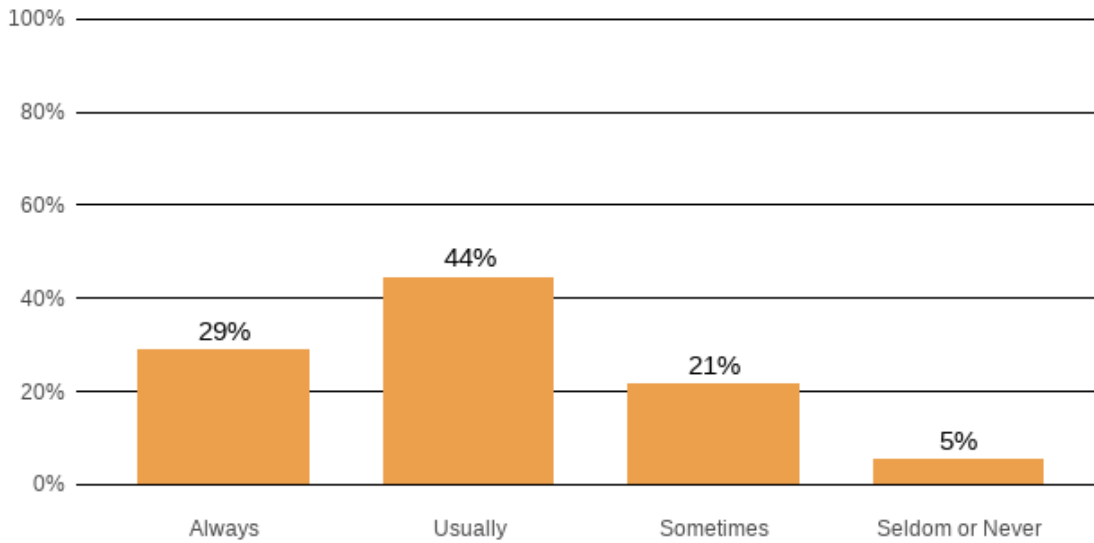


Table 28. Is the information you get about services and supports easy to understand?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	47%	34%	17%	3%	131
VA	33%	43%	20%	3%	202
GA	31%	46%	17%	6%	400
AZ	31%	53%	12%	4%	205
CA	31%	41%	23%	6%	12517
Weighted NCI-IDD Average	29%	44%	21%	5%	16807
NH	28%	52%	16%	3%	521
IN	27%	45%	23%	5%	340
MO	26%	54%	17%	3%	248
PA	25%	51%	20%	4%	620
MT	24%	47%	24%	5%	202
NJ	24%	47%	24%	5%	437
MD ↓	21%	45%	26%	9%	600
OK ↓	20%	49%	26%	5%	384

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

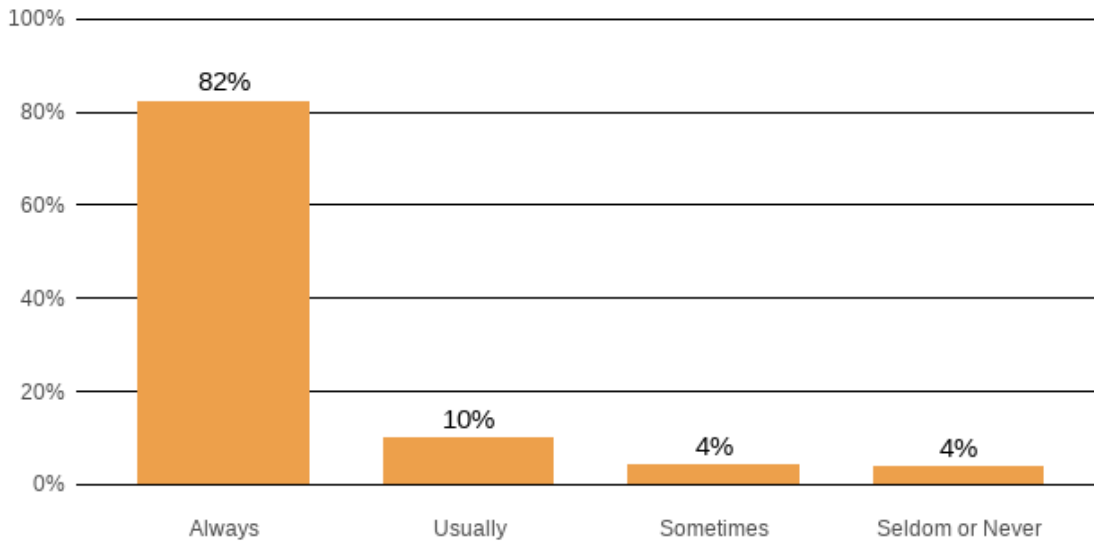


Table 29. Do you get information about services and supports in your preferred language?

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

State	Always	Usually	Sometimes	Seldom or Never	N
MT ↑	94%	3%	1%	1%	209
NH ↑	93%	5%	1%	1%	538
IN ↑	92%	5%	1%	2%	346
MO ↑	92%	4%	0%	4%	254
DC ↑	91%	6%	1%	1%	134
PA ↑	90%	7%	2%	1%	633
NJ ↑	88%	7%	1%	3%	447
MD ↑	88%	7%	2%	3%	609
OK ↑	87%	9%	3%	2%	388
VA	88%	8%	1%	2%	203
AZ	86%	9%	3%	1%	206
GA	84%	9%	4%	4%	417
Weighted NCI-IDD Average	82%	10%	4%	4%	17701
CA ↓	75%	13%	7%	5%	13317

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

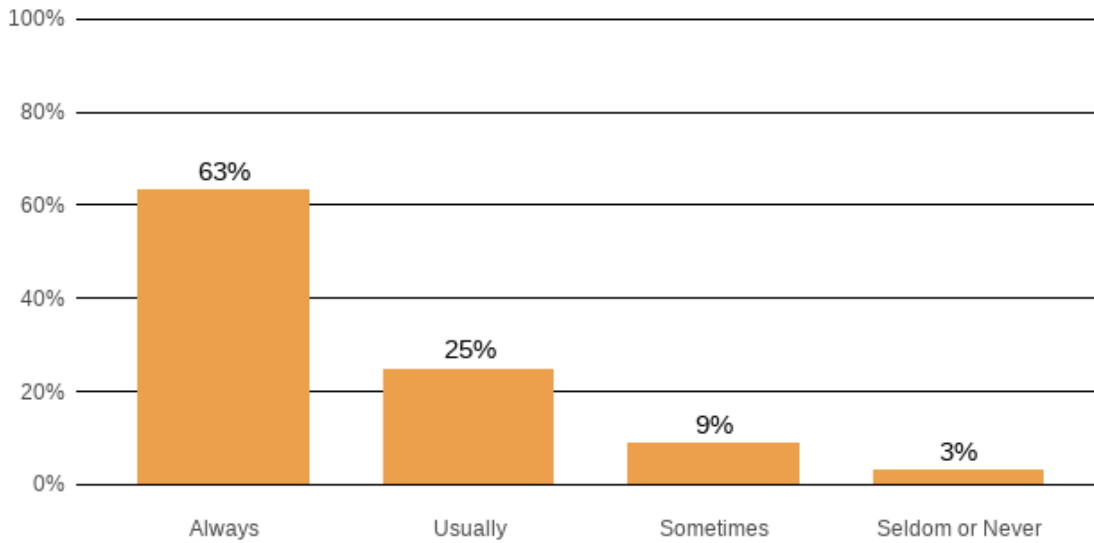


Table 30. Does the case manager/service coordinator listen to your family's choices and opinions?

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

State	Always	Usually	Sometimes	Seldom or Never	N
AZ ↑	78%	15%	7%	1%	205
DC ↑	76%	18%	6%	0%	131
NJ ↑	74%	20%	4%	1%	433
IN ↑	74%	20%	4%	2%	350
VA ↑	74%	21%	5%	0%	208
PA ↑	69%	23%	7%	1%	638
NH	67%	25%	6%	2%	534
MO	67%	25%	6%	2%	251
MD	65%	23%	9%	3%	575
OK	65%	27%	7%	2%	391
Weighted NCI-IDD Average	63%	25%	9%	3%	17230
GA	58%	29%	10%	3%	417
MT	56%	30%	12%	3%	199
CA ↓	55%	28%	12%	5%	12898

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

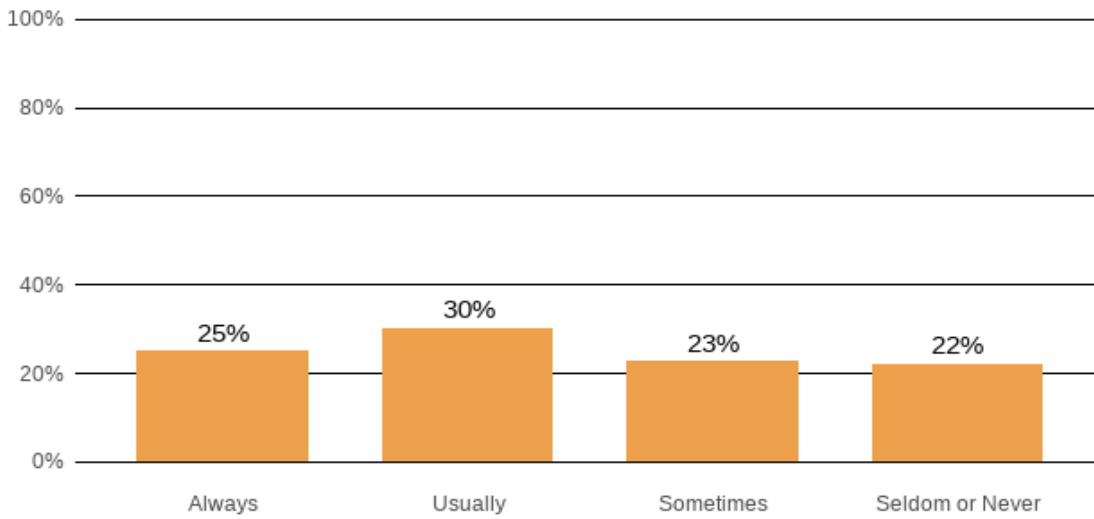


Table 31. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

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

State	Always	Usually	Sometimes	Seldom or Never	N
VA ↑	46%	27%	17%	10%	193
DC ↑	39%	34%	15%	11%	122
PA	27%	35%	23%	15%	546
NH	27%	34%	21%	17%	452
IN	26%	31%	20%	23%	298
MO	25%	33%	21%	21%	218
Weighted NCI-IDD Average	25%	30%	23%	22%	15055
NJ	24%	33%	24%	19%	404
OK	23%	36%	19%	23%	337
CA	22%	29%	24%	24%	11272
AZ	22%	25%	27%	25%	153
MT	22%	35%	21%	21%	192
GA	22%	33%	17%	29%	346
MD ↓	18%	30%	23%	29%	522

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

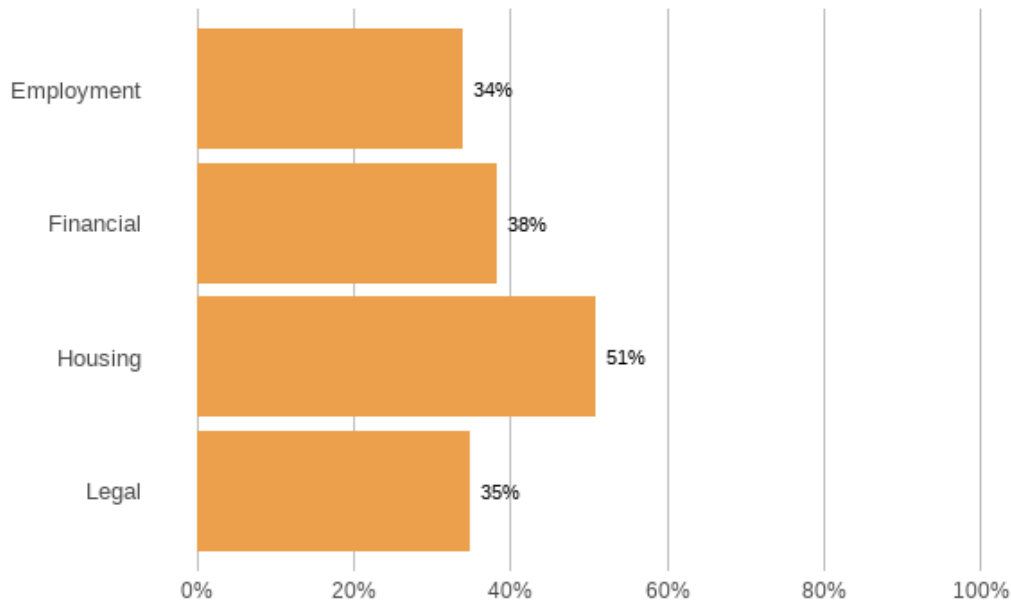


Table 32a. Do you need help planning for your family member’s future in any of the following areas?

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

State	Employment	Financial	Housing	Legal
AZ	30%	33%	40%	27%
CA	38%	38%	48%	34%
DC	25%	20%	36%	23%
GA	10%	25%	43%	39%
IN	35%	41%	55%	38%
MD	38%	42%	59%	38%
MO	22%	38%	51%	32%
MT	31%	35%	46%	34%
NJ	31%	37%	65%	29%
NH	39%	42%	61%	35%
OK	21%	27%	38%	33%
PA	29%	41%	59%	36%
VA	27%	43%	54%	46%
Weighted NCI-IDD Average	34%	38%	51%	35%

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

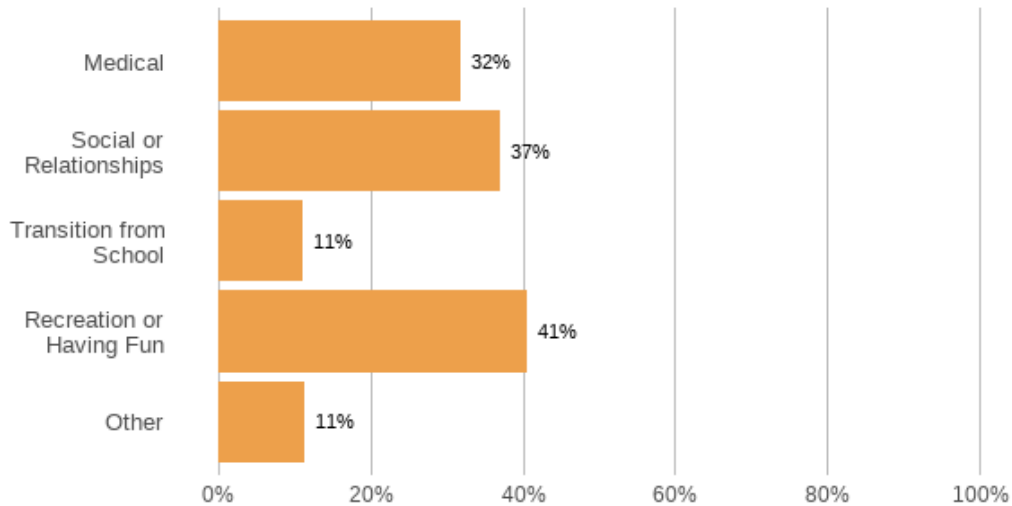


Table 32b. Do you need help planning for your family member's future in any of the following areas? (Continued)

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

State	Medical	Social or Relationships	Transition from School	Recreation or Having Fun	Other
AZ	24%	30%	11%	33%	9%
CA	34%	38%	14%	42%	10%
DC	20%	22%	3%	31%	14%
GA	33%	24%	3%	30%	17%
IN	27%	35%	12%	36%	13%
MD	31%	41%	7%	43%	15%
MO	26%	37%	8%	40%	24%
MT	27%	42%	4%	44%	14%
NJ	32%	39%	5%	37%	10%
NH	32%	45%	3%	44%	12%
OK	22%	23%	8%	32%	15%
PA	27%	34%	7%	40%	9%
VA	40%	45%	10%	46%	16%
Weighted NCI-IDD Average	32%	37%	11%	41%	11%

Has your family learned about alternatives to guardianship?

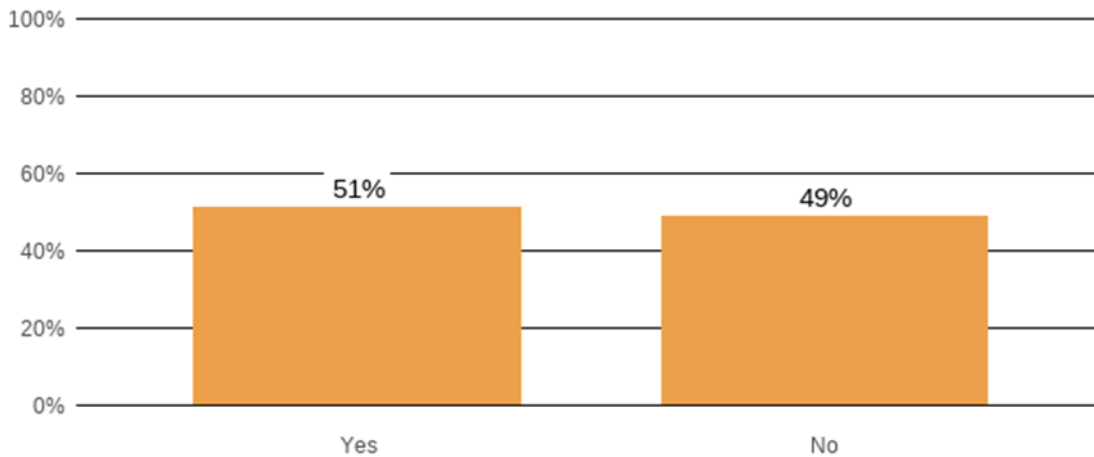


Table 33. Has your family learned about alternatives to guardianship?

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

State	Yes	No	N
DC ↑	64%	36%	113
VA	60%	40%	177
AZ	59%	41%	177
MO	57%	43%	231
IN	55%	45%	318
MT	55%	45%	175
PA	52%	48%	551
NH	52%	48%	455
Weighted NCI-IDD Average	51%	49%	14984
MD	50%	50%	546
NJ	49%	51%	394
CA	49%	51%	11154
OK	49%	51%	328
GA ↓	40%	60%	365

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?

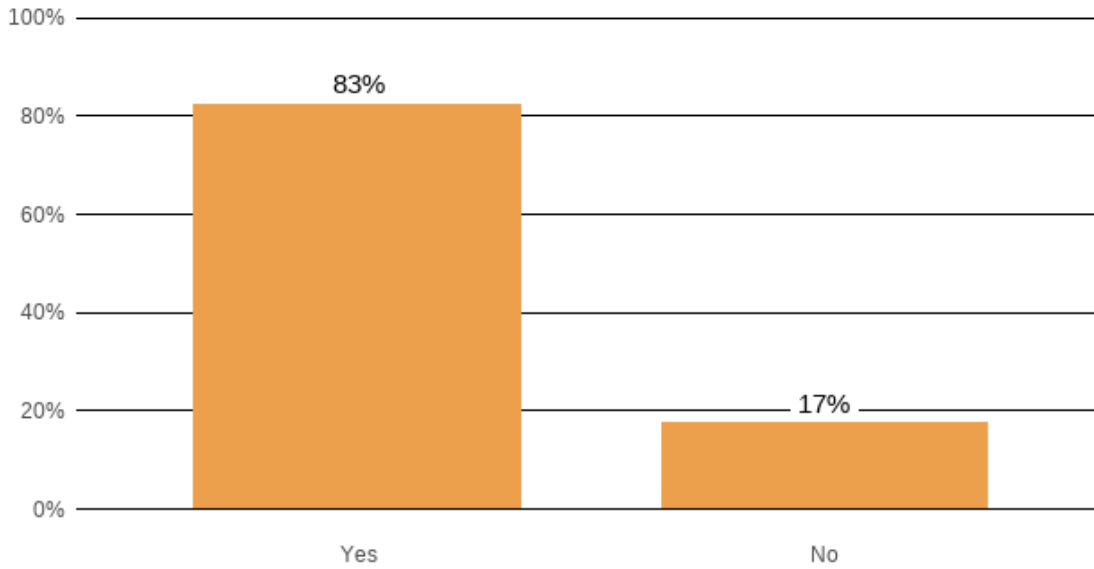


Table 34. Does your family member have a service plan?

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

State	Yes	No	N
PA ↑	97%	3%	632
MO ↑	94%	6%	245
MT ↑	93%	7%	195
DC ↑	93%	7%	123
NH ↑	92%	8%	495
MD ↑	91%	9%	564
OK ↑	90%	10%	368
VA	88%	12%	162
NJ	87%	13%	392
Weighted NCI-IDD Average	83%	17%	15776
IN	81%	19%	281
CA	80%	20%	11819
AZ ↓	62%	38%	156
GA ↓	61%	39%	344

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

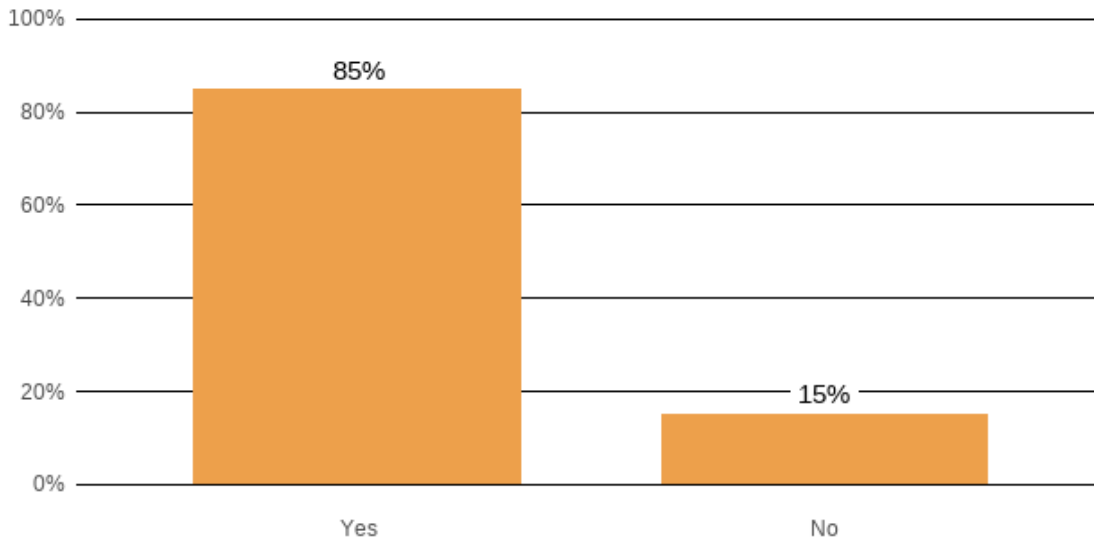


Table 35. Does the plan include all the services and supports your family member needs?

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

State	Yes	No	N
DC ↑	96%	4%	107
PA ↑	92%	8%	549
AZ	91%	9%	82
OK	88%	12%	293
GA	87%	13%	188
MO	87%	13%	200
NH	86%	14%	390
IN	85%	15%	203
Weighted NCI-IDD Average	85%	15%	10865
NJ	85%	15%	311
VA	85%	15%	123
CA	82%	18%	7805
MT	81%	19%	161
MD	81%	19%	453

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

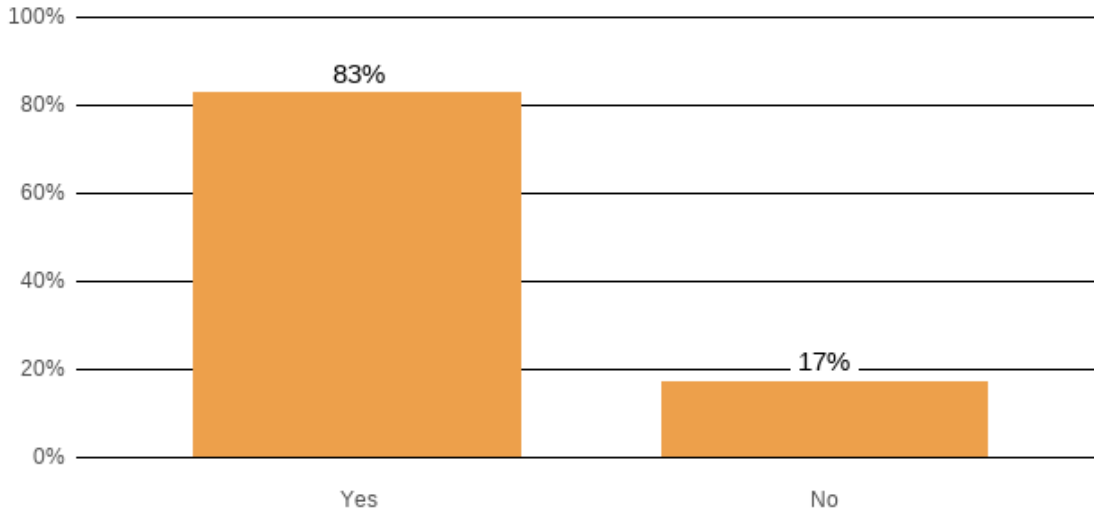


Table 36. Did you or someone else in your family (besides your family member with a disability) help make the plan?

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

State	Yes	No	N
MO ↑	92%	8%	220
MD ↑	90%	10%	502
MT	89%	11%	171
IN	88%	12%	219
AZ	87%	13%	87
PA	86%	14%	588
NH	86%	14%	431
DC	86%	14%	111
NJ	85%	15%	334
OK	85%	15%	322
Weighted NCI-IDD Average	83%	17%	12060
VA	81%	19%	135
CA	79%	21%	8745
GA	79%	21%	195

Did your family member help make the plan?

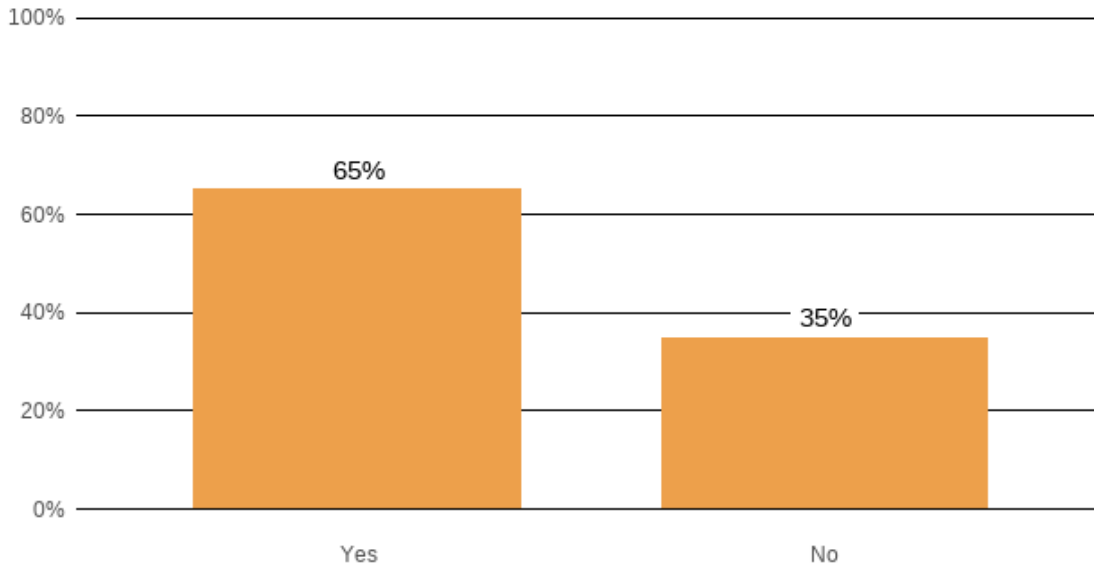


Table 37. Did your family member help make the plan?

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

State	Yes	No	N
MD ↑	79%	21%	495
MT	71%	29%	171
VA	70%	30%	134
NH	70%	30%	439
PA	70%	30%	574
DC	69%	31%	110
MO	67%	33%	223
IN	66%	34%	214
Weighted NCI-IDD Average	65%	35%	11996
CA	63%	37%	8707
NJ	59%	41%	335
GA	58%	42%	194
AZ	58%	42%	88
OK ↓	56%	44%	312

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

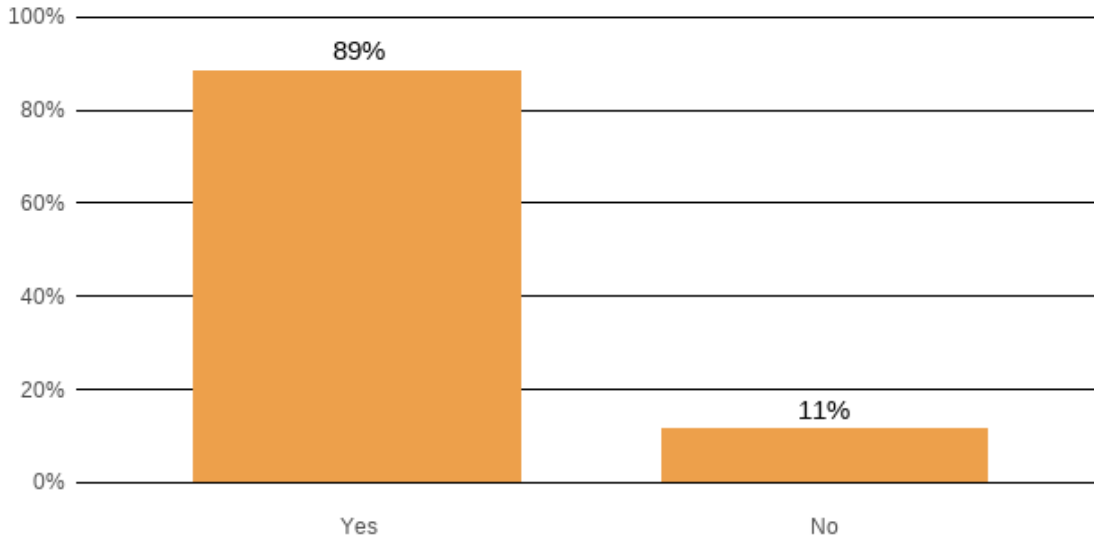


Table 38. Do you feel like your family had enough say or input in making the plan?

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

State	Yes	No	N
IN ↑	99%	1%	208
OK ↑	96%	4%	302
PA ↑	95%	5%	554
MO ↑	95%	5%	219
MT ↑	94%	6%	165
NJ ↑	94%	6%	327
NH ↑	94%	6%	420
AZ	94%	6%	87
VA	94%	6%	129
GA	92%	8%	183
DC	92%	8%	102
MD	92%	8%	476
Weighted NCI-IDD Average	89%	11%	11308
CA ↓	81%	19%	8136

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

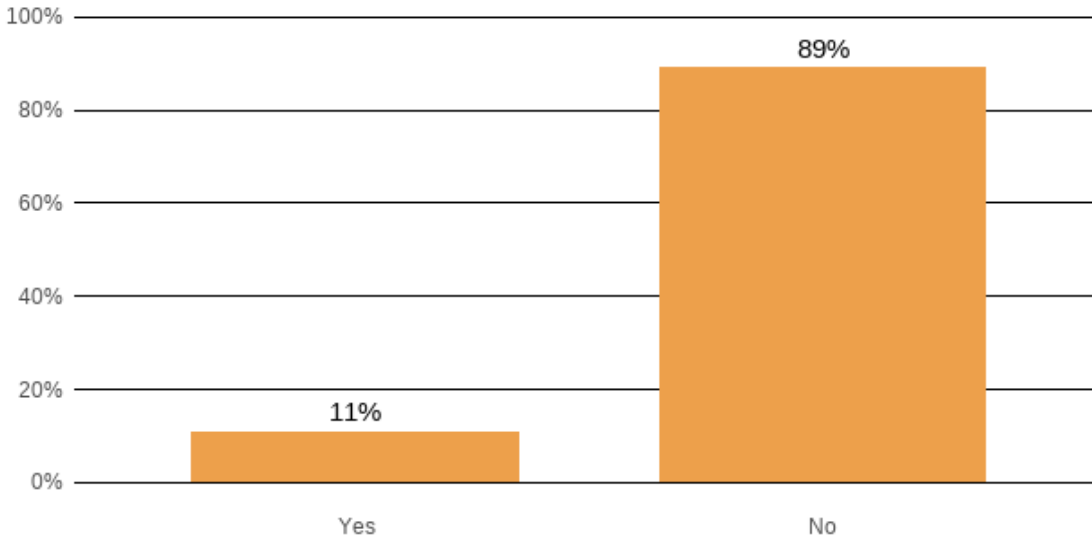


Table 39. Did your family member leave school services and begin adult services during the past 12 months?

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

State	Yes	No	N
CA ↑	17%	83%	12500
Weighted NCI-IDD Average	11%	89%	16820
MD	9%	91%	601
AZ	7%	93%	199
IN ↓	7%	93%	341
PA ↓	6%	94%	633
OK ↓	5%	95%	388
MT ↓	4%	96%	203
NH ↓	3%	97%	535
VA ↓	3%	97%	194
DC ↓	2%	98%	124
MO ↓	2%	98%	252
NJ ↓	2%	98%	433
GA ↓	1%	99%	417

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

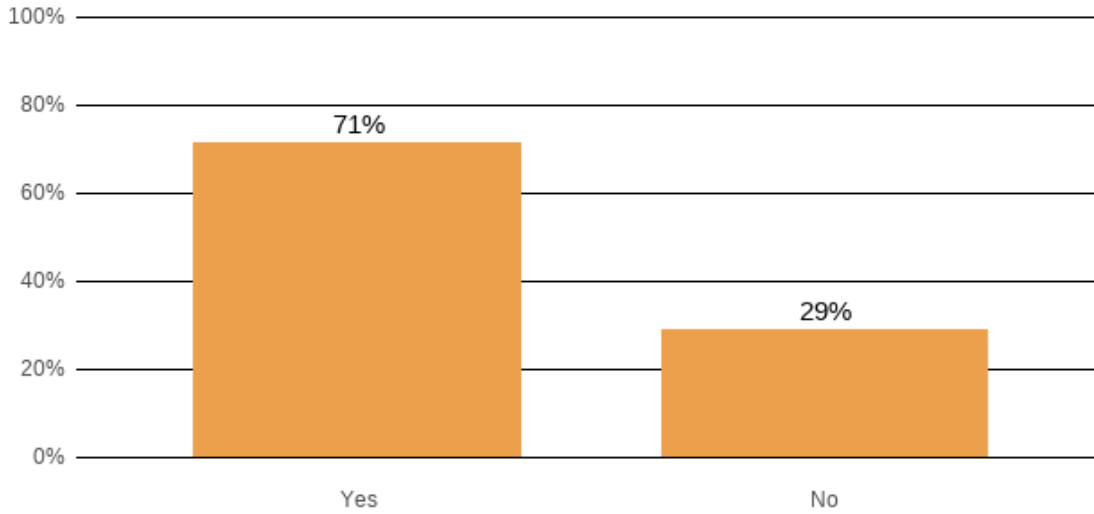


Table 40. If your family member left school services during the past 12 months, did they have a transition plan?

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

State	Yes	No	N
MD	85%	15%	52
PA	85%	15%	26
Weighted NCI-IDD Average	71%	29%	1724
CA	68%	32%	1569
AZ	n/a	n/a	n/a
DC	n/a	n/a	n/a
GA	n/a	n/a	n/a
IN	n/a	n/a	n/a
MO	n/a	n/a	n/a
MT	n/a	n/a	n/a
NJ	n/a	n/a	n/a
NH	n/a	n/a	n/a
OK	n/a	n/a	n/a
VA	n/a	n/a	n/a

Table note: The following states had an N of less than 20 and were not shown: AZ, DC, GA, IN, MO, MT, NH, NJ, OK, VA

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

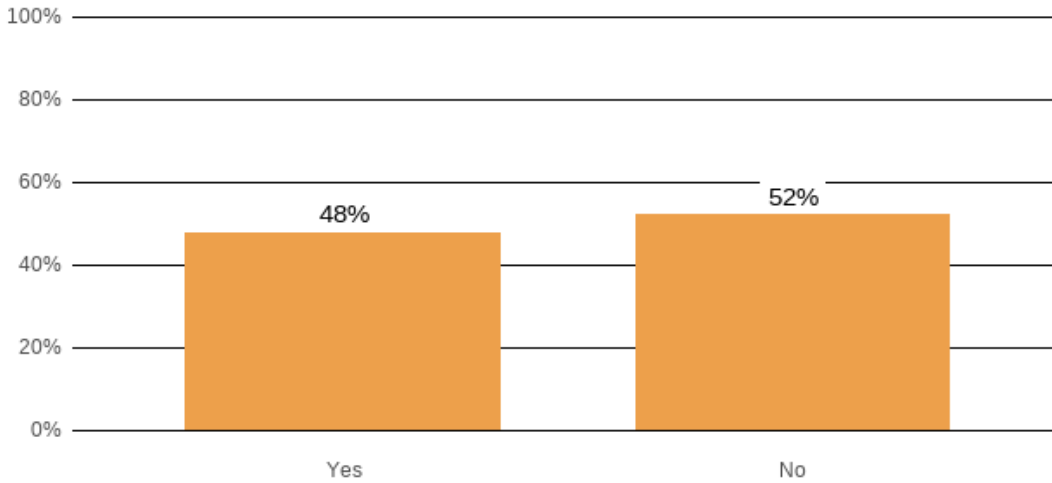


Table 41. If your family member had a transition plan, did the plan include getting or continuing work in a community job?

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

State	Yes	No	N
CA	49%	51%	925
Weighted NCI-IDD Average	48%	52%	1037
MD	41%	59%	39
AZ	n/a	n/a	n/a
DC	n/a	n/a	n/a
GA	n/a	n/a	n/a
IN	n/a	n/a	n/a
MO	n/a	n/a	n/a
MT	n/a	n/a	n/a
NJ	n/a	n/a	n/a
NH	n/a	n/a	n/a
OK	n/a	n/a	n/a
PA	n/a	n/a	n/a
VA	n/a	n/a	n/a

Table note: The following states had an N of less than 20 and were not shown: AZ, DC, GA, IN, MO, MT, NH, NJ, OK, VA

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?

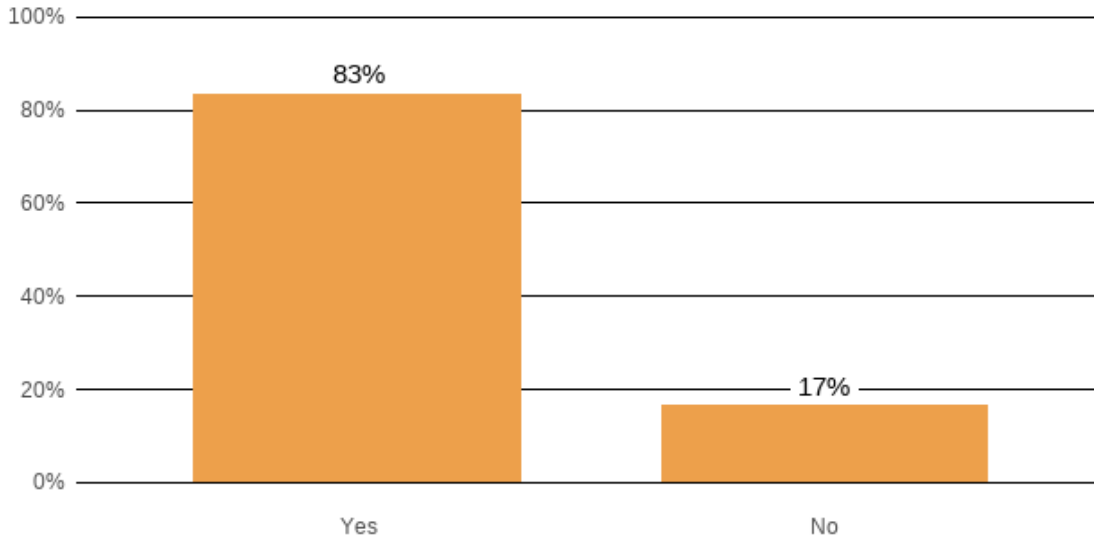


Table 42. Does your family member get all the services listed in the plan?

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

State	Yes	No	N
DC ↑	92%	8%	106
NJ ↑	91%	9%	316
OK ↑	89%	11%	294
NH ↑	88%	12%	402
PA	87%	13%	569
VA	85%	15%	121
MO	85%	15%	210
GA	84%	16%	182
Weighted NCI-IDD Average	83%	17%	10970
MT	83%	17%	156
IN	82%	18%	203
CA	82%	18%	7860
AZ	81%	19%	86
MD ↓	78%	22%	465

Does your family get the supports and services it needs?

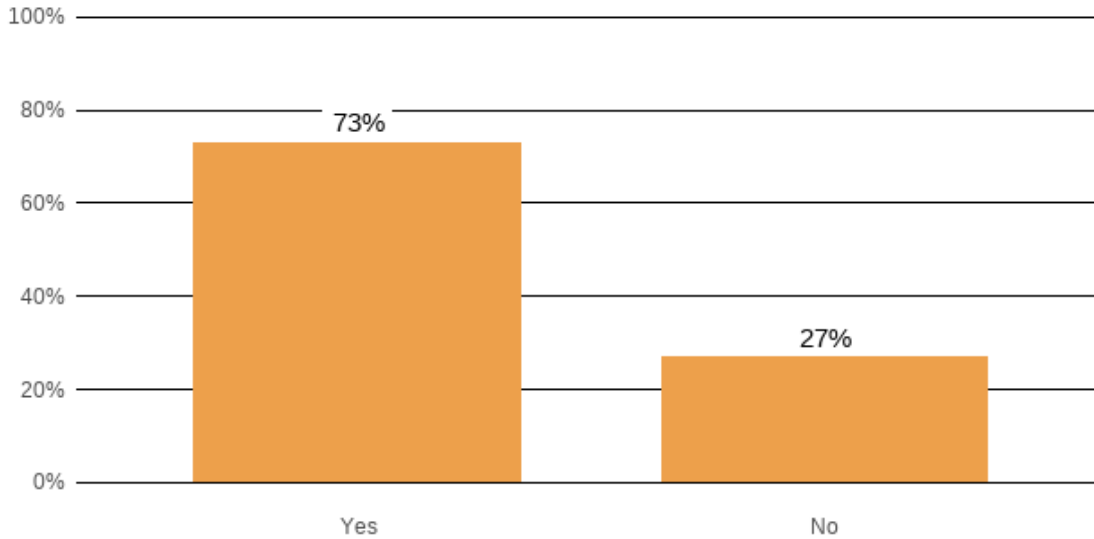


Table 43. Does your family get the supports and services it needs?

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

State	Yes	No	N
DC ↑	88%	12%	125
AZ	79%	21%	194
IN	77%	23%	313
PA	76%	24%	568
VA	74%	26%	187
OK	74%	26%	336
MO	74%	26%	231
Weighted NCI-IDD Average	73%	27%	14789
CA	72%	28%	10923
NJ	72%	28%	383
MT	71%	29%	182
GA	71%	29%	346
NH	71%	29%	472
MD ↓	66%	34%	529

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

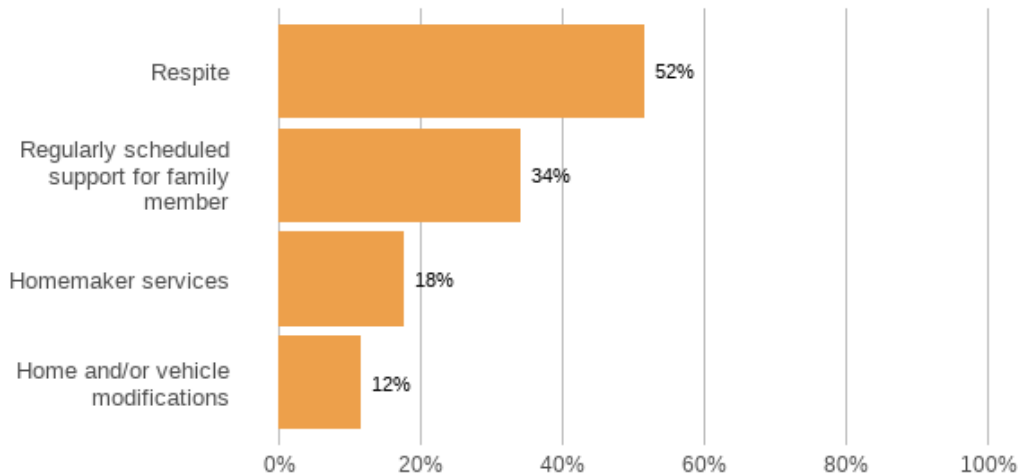


Table 44a. If your family does not get the support and services needed, what additional services does your family need?

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

State	Respite	Regularly scheduled support for family member	Homemaker services	Home and/or vehicle modifications
AZ	37%	26%	16%	3%
CA	43%	34%	19%	10%
DC	n/a	n/a	n/a	n/a
GA	58%	24%	22%	14%
IN	60%	40%	22%	14%
MD	59%	37%	16%	18%
MO	58%	36%	22%	22%
MT	81%	36%	21%	6%
NJ	61%	27%	9%	5%
NH	48%	43%	7%	7%
OK	64%	25%	16%	17%
PA	65%	35%	15%	13%
VA	70%	43%	21%	21%
Weighted NCI-IDD Average	52%	34%	18%	12%

Table note: The following states had an N of less than 20 and were not shown: DC

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

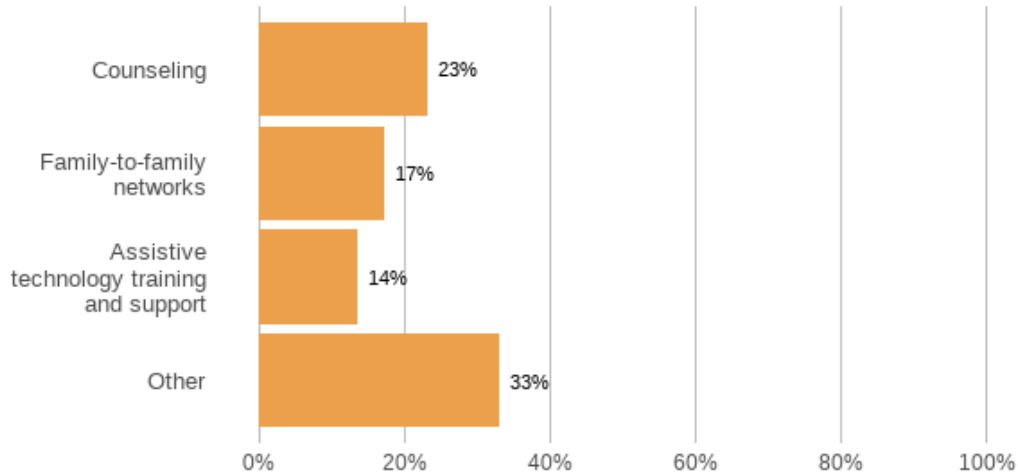


Table 44b. If your family does not get the support and services needed, what additional services does your family need? (Continued)

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

State	Counseling	Family-to-family networks	Assistive technology training and support	Other
AZ	18%	8%	5%	37%
CA	29%	19%	18%	33%
DC	n/a	n/a	n/a	n/a
GA	6%	8%	6%	28%
IN	18%	11%	6%	29%
MD	21%	24%	16%	34%
MO	15%	13%	13%	33%
MT	11%	11%	6%	30%
NJ	22%	16%	11%	31%
NH	15%	13%	4%	33%
OK	13%	11%	16%	23%
PA	9%	14%	5%	35%
VA	32%	28%	17%	34%
Weighted NCI-IDD Average	23%	17%	14%	33%

Table note: The following states had an N of less than 20 and were not shown: DC

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

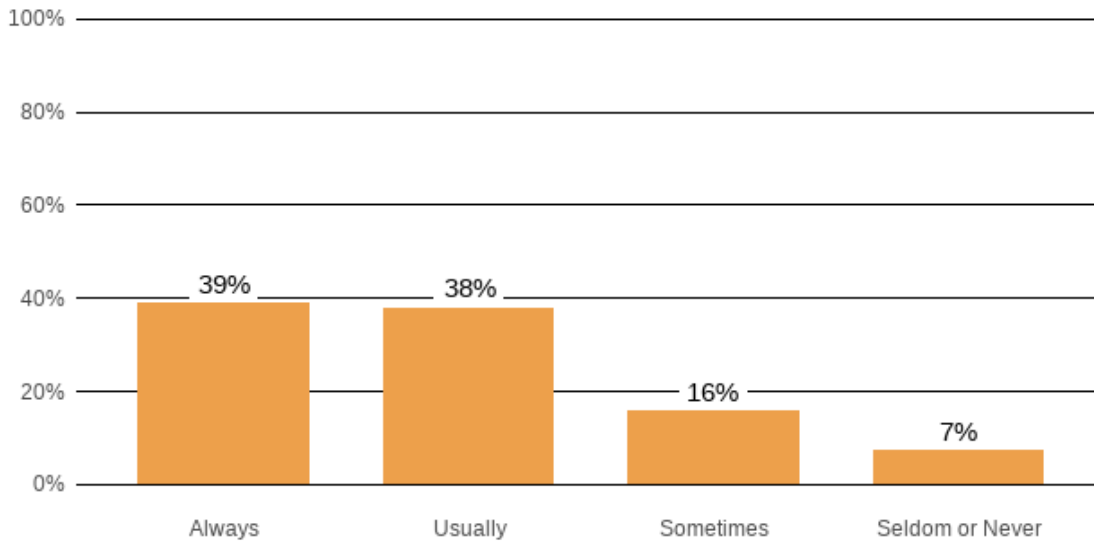


Table 45. Do services and supports change when your family's needs change?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	58%	29%	8%	6%	104
VA ↑	52%	29%	16%	2%	163
PA ↑	45%	37%	13%	5%	523
IN	45%	38%	13%	4%	255
MO	43%	40%	10%	7%	188
NJ	41%	39%	14%	5%	345
AZ	40%	44%	13%	2%	156
Weighted NCI-IDD Average	39%	38%	16%	7%	12442
OK	38%	45%	9%	8%	277
NH	37%	39%	14%	9%	359
GA	35%	47%	9%	10%	294
CA	34%	37%	19%	10%	9185
MT	34%	41%	17%	8%	155
MD	33%	41%	17%	9%	438

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

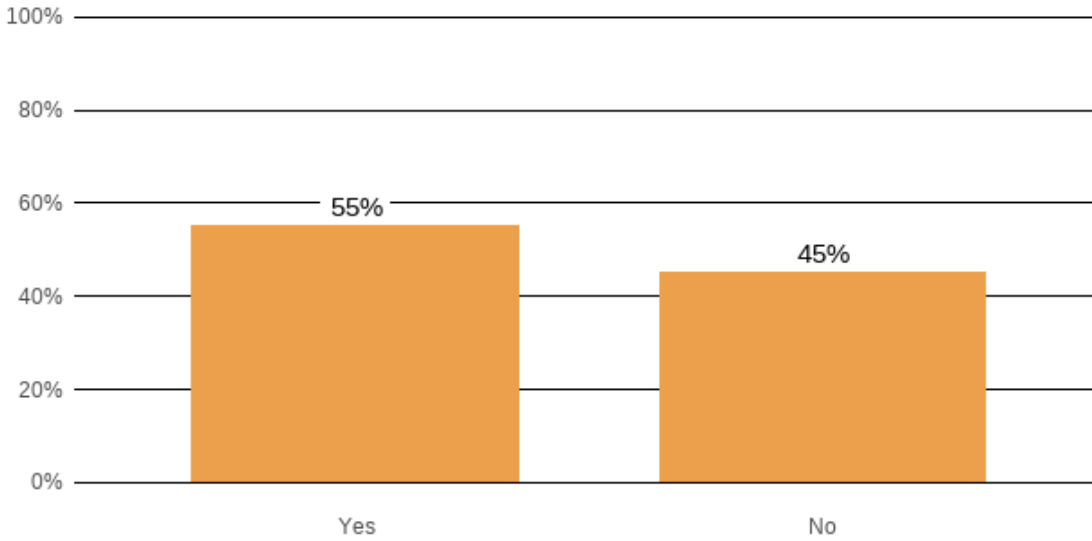


Table 46. Does your family member have enough supports to work or volunteer in the community?

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

State	Yes	No	N
DC ↑	74%	26%	103
PA ↑	70%	30%	484
NH ↑	67%	33%	440
MO ↑	66%	34%	177
MD ↑	62%	38%	451
MT	63%	37%	161
IN	58%	42%	242
OK	57%	43%	282
NJ	56%	44%	285
Weighted NCI-IDD Average	55%	45%	12095
AZ	53%	48%	120
VA	52%	48%	123
GA	51%	49%	268
CA ↓	50%	50%	8959

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

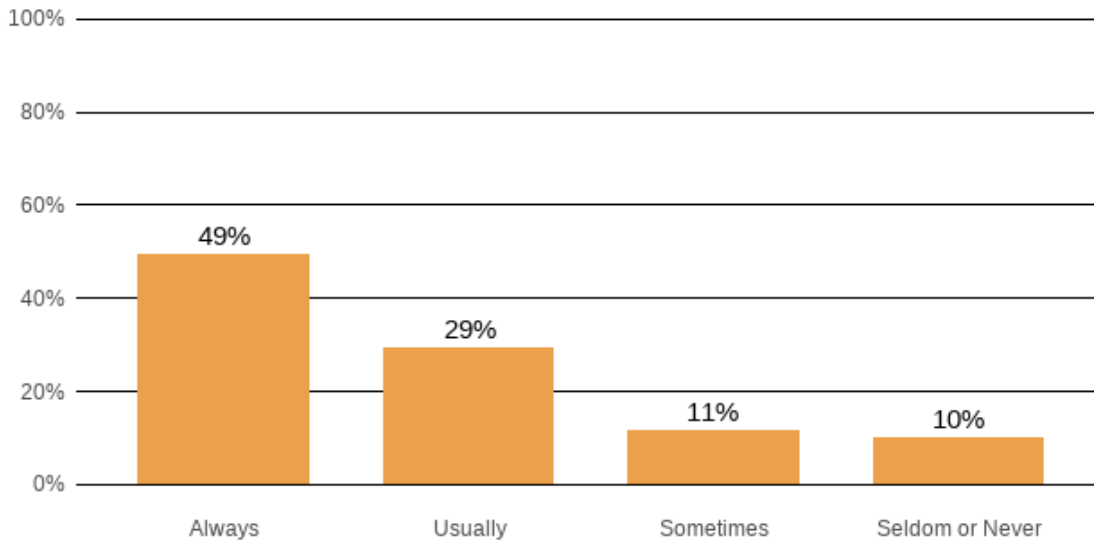


Table 47. Does your family member have the special equipment or accommodations they need?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	73%	13%	8%	6%	52
AZ	59%	26%	7%	8%	99
NH	58%	31%	8%	4%	195
IN	54%	32%	8%	7%	136
MT	52%	29%	16%	3%	94
NJ	52%	31%	9%	8%	170
Weighted NCI-IDD Average	49%	29%	11%	10%	6704
PA	49%	31%	12%	8%	225
MO	48%	32%	13%	7%	132
VA	48%	24%	15%	13%	122
CA	48%	29%	12%	12%	4810
GA	47%	34%	12%	7%	219
OK	44%	32%	14%	11%	186
MD	43%	34%	14%	10%	264

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

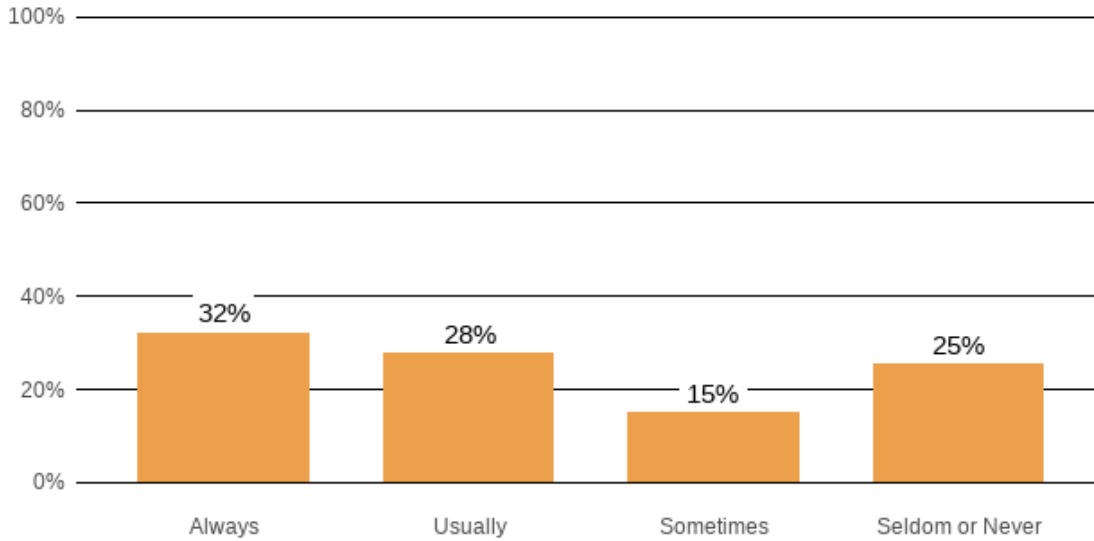


Table 48. If you need respite services, how often are you able to get them when needed?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	55%	27%	6%	11%	96
AZ ↑	42%	35%	11%	11%	168
CA	36%	28%	15%	20%	8121
Weighted NCI-IDD Average	32%	28%	15%	25%	10692
IN	30%	25%	13%	33%	175
VA	28%	23%	14%	36%	160
MD ↓	24%	23%	18%	35%	325
NH ↓	24%	35%	18%	23%	379
PA ↓	23%	28%	17%	33%	332
GA ↓	22%	26%	12%	39%	251
NJ ↓	22%	24%	19%	34%	221
MT ↓	19%	24%	19%	38%	134
OK ↓	18%	18%	19%	44%	195
MO ↓	15%	29%	16%	40%	135

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

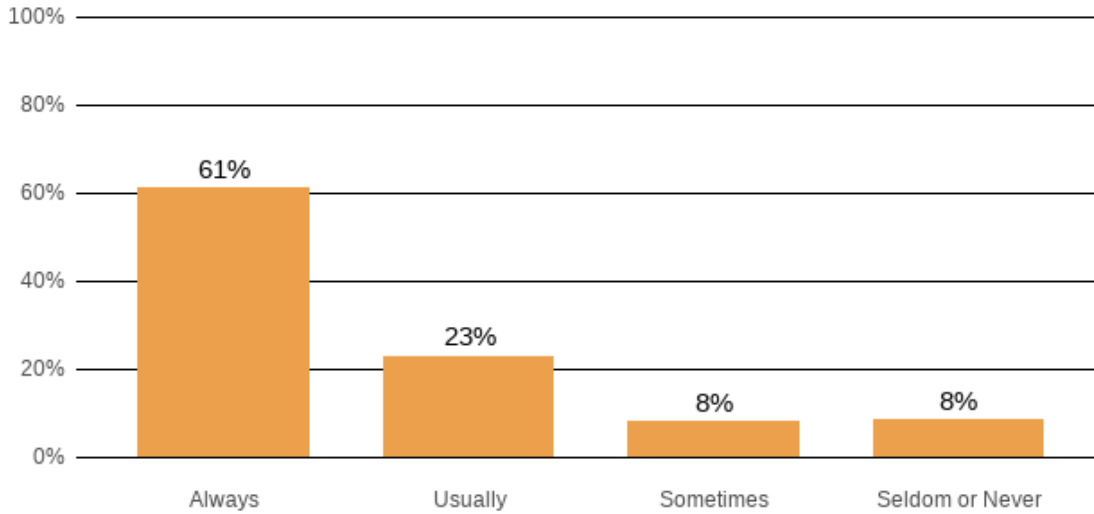


Table 49. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

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

State	Always	Usually	Sometimes	Seldom or Never	N
NH ↑	73%	17%	6%	4%	251
AZ ↑	72%	18%	7%	3%	137
MT	69%	19%	4%	7%	67
DC	68%	19%	8%	6%	53
VA	64%	15%	7%	14%	86
CA	62%	23%	8%	7%	5693
Weighted NCI-IDD Average	61%	23%	8%	8%	7042
MO	58%	32%	2%	8%	65
MD	57%	25%	7%	10%	167
OK	57%	18%	8%	16%	61
IN	57%	28%	6%	10%	90
PA	51%	27%	10%	13%	156
GA	50%	27%	6%	17%	109
NJ ↓	46%	35%	12%	7%	107

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

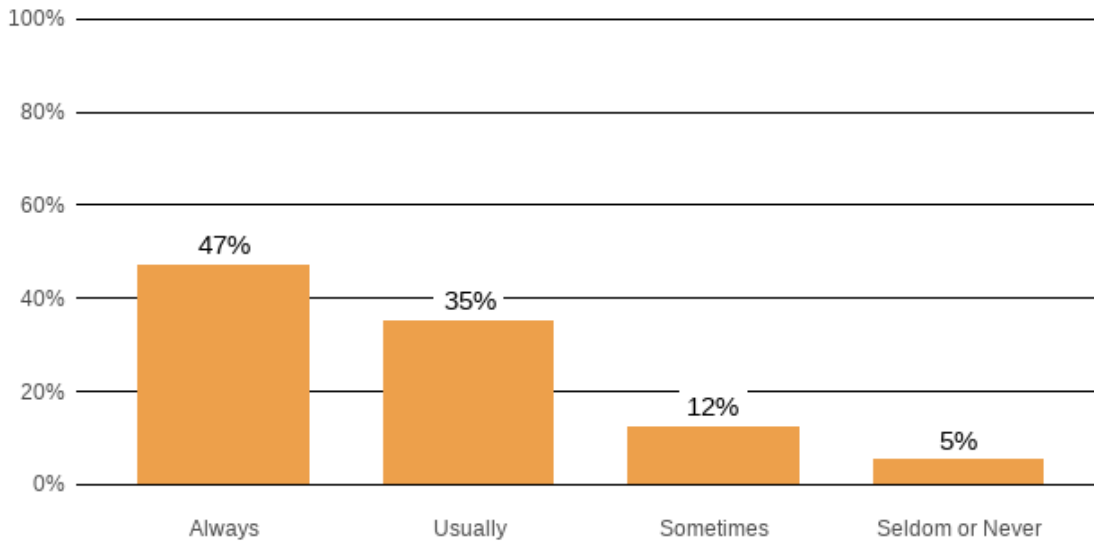


Table 50. Are you or your family member able to contact their support workers when you want?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	63%	32%	3%	2%	117
PA ↑	57%	35%	7%	1%	615
VA ↑	57%	29%	11%	3%	194
NJ ↑	56%	30%	11%	2%	374
AZ	55%	35%	6%	4%	186
IN	52%	38%	7%	3%	294
MO	52%	40%	6%	2%	217
MD	50%	34%	12%	4%	533
OK	48%	39%	9%	3%	332
Weighted NCI-IDD Average	47%	35%	12%	5%	15009
GA	46%	40%	9%	5%	408
NH	46%	41%	9%	4%	462
CA ↓	40%	35%	17%	8%	11092
MT ↓	34%	49%	13%	4%	185

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

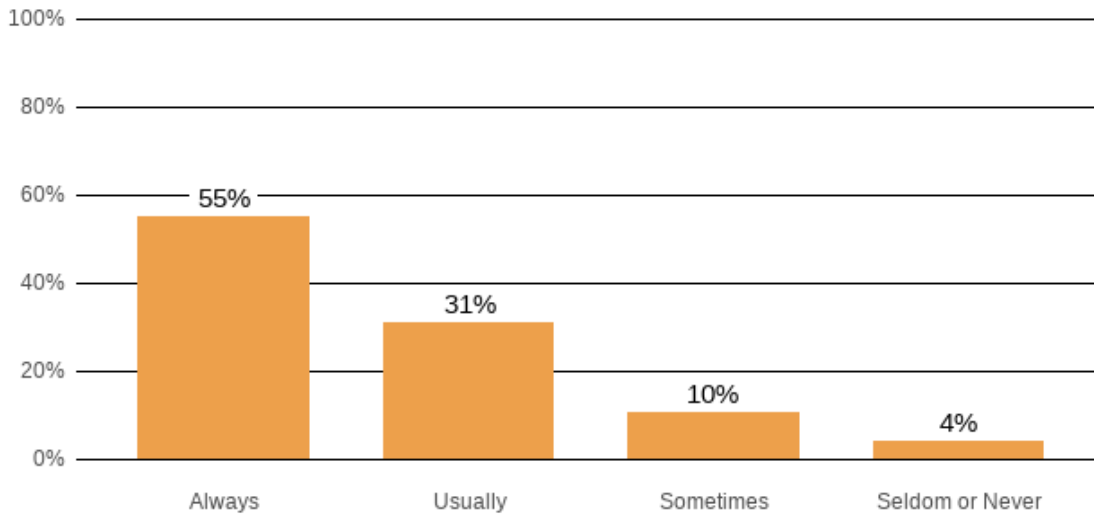


Table 51. Are you or your family member able to contact their case manager/service coordinator when you want?

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

State	Always	Usually	Sometimes	Seldom or Never	N
NJ ↑	74%	21%	5%	1%	431
IN ↑	72%	24%	3%	1%	349
DC ↑	71%	25%	4%	1%	126
VA ↑	66%	24%	10%	0%	207
PA ↑	63%	31%	5%	1%	642
MO	61%	32%	6%	1%	240
NH	60%	30%	8%	2%	535
AZ	57%	33%	6%	4%	202
OK	55%	35%	8%	2%	393
Weighted NCI-IDD Average	55%	31%	10%	4%	17199
MD	55%	32%	9%	4%	577
GA	51%	35%	9%	5%	428
CA ↓	46%	33%	15%	6%	12871
MT ↓	42%	40%	13%	5%	198

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

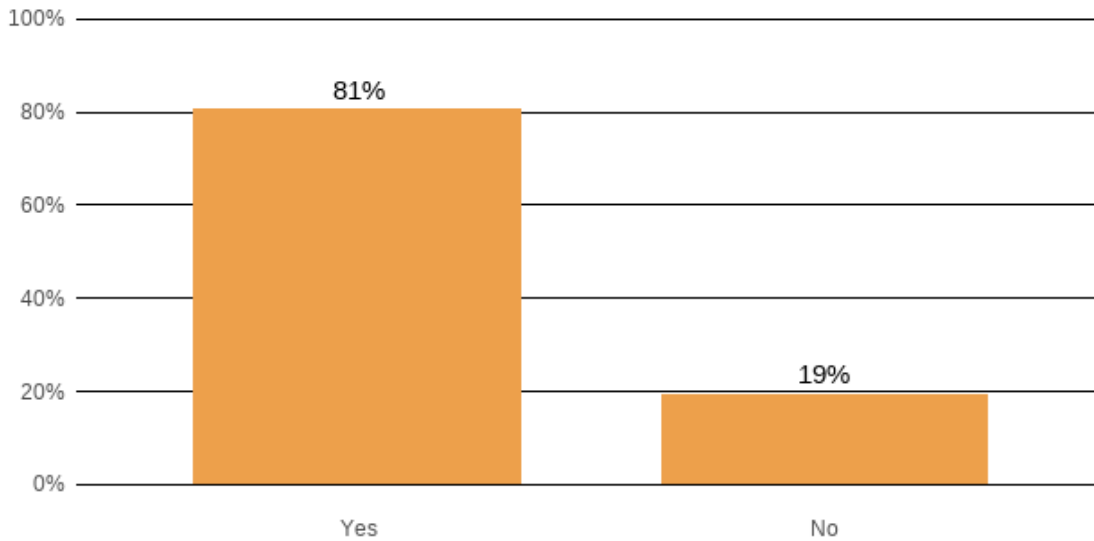


Table 52. Do service providers for your family member work together to provide support?

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

State	Yes	No	N
VA ↑	93%	7%	123
PA ↑	87%	13%	390
MT	88%	12%	117
DC	88%	12%	97
NH	87%	13%	224
IN	87%	13%	193
OK	86%	14%	174
NJ	85%	15%	232
MD	84%	16%	344
AZ	83%	17%	126
Weighted NCI-IDD Average	81%	19%	8992
MO	79%	21%	131
GA	77%	23%	232
CA ↓	74%	26%	6609

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

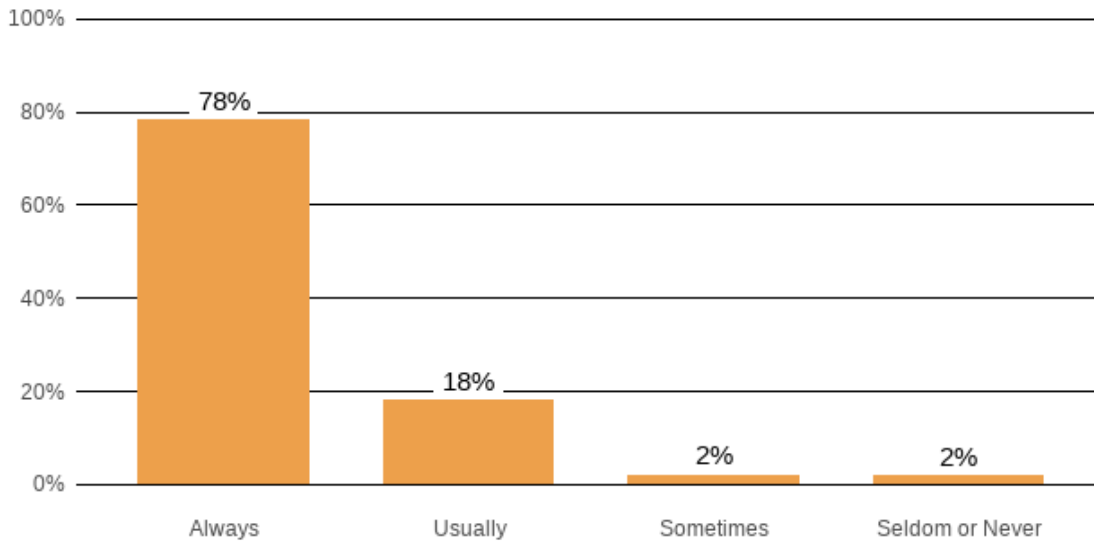


Table 53. Are services delivered in a way that is respectful of your family's culture?

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

State	Always	Usually	Sometimes	Seldom or Never	N
MT ↑	87%	11%	2%	1%	189
IN ↑	86%	13%	1%	0%	315
NJ ↑	85%	14%	0%	1%	397
PA ↑	85%	14%	1%	0%	627
MO	84%	13%	3%	1%	232
AZ	84%	13%	1%	3%	199
DC	84%	14%	2%	0%	124
VA	82%	16%	2%	1%	196
NH	81%	16%	1%	1%	486
MD	80%	16%	2%	2%	547
Weighted NCI-IDD Average	78%	18%	2%	2%	15443
OK	78%	20%	1%	1%	354
CA ↓	73%	21%	3%	3%	11393
GA ↓	68%	25%	3%	4%	384

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

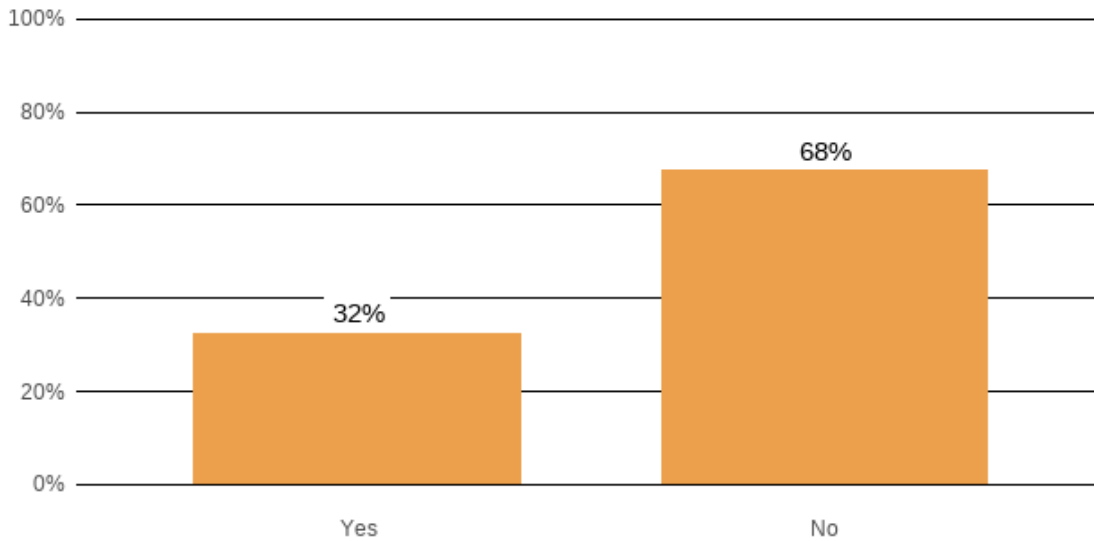


Table 54. Does your family member use technology in their everyday life to help them do things on their own?

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

State	Yes	No	N
MD ↑	40%	60%	566
NJ	37%	63%	414
CA	34%	66%	13042
VA	33%	67%	204
NH	33%	67%	531
Weighted NCI-IDD Average	32%	68%	17341
AZ	31%	69%	201
OK	31%	69%	385
IN	30%	70%	347
MT	30%	70%	197
DC	30%	70%	132
PA	28%	72%	624
MO	28%	72%	250
GA ↓	14%	86%	448

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

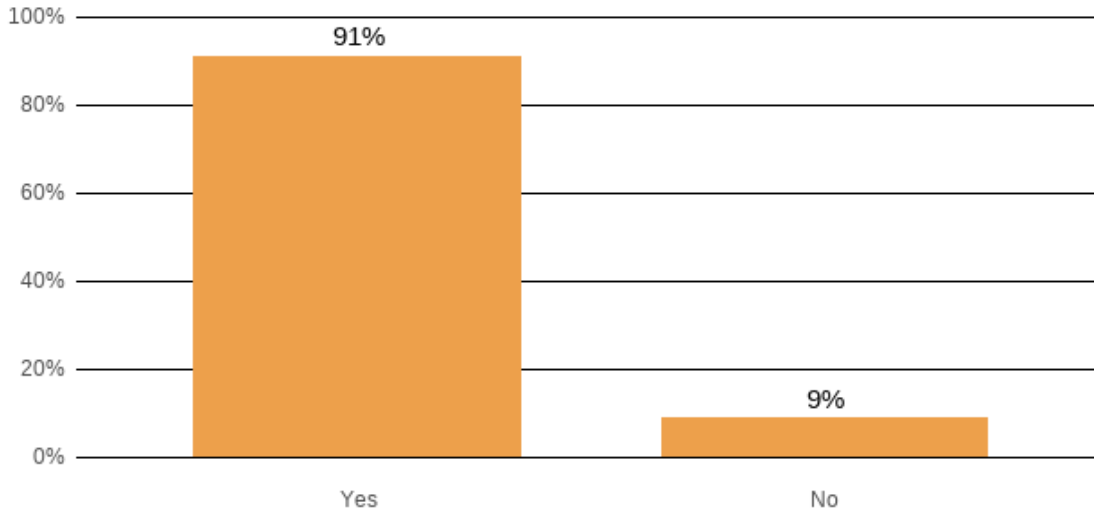


Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?

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

State	Yes	No	N
AZ ↑	95%	5%	209
NJ ↑	94%	6%	425
NH ↑	94%	6%	543
MD ↑	94%	6%	575
PA	92%	8%	648
CA	91%	9%	13725
Weighted NCI-IDD Average	91%	9%	18136
MO	90%	10%	261
IN	89%	11%	353
MT	89%	11%	199
VA	89%	11%	208
DC	87%	13%	135
OK ↓	86%	14%	401
GA ↓	80%	20%	454

How well does internet work in your home?

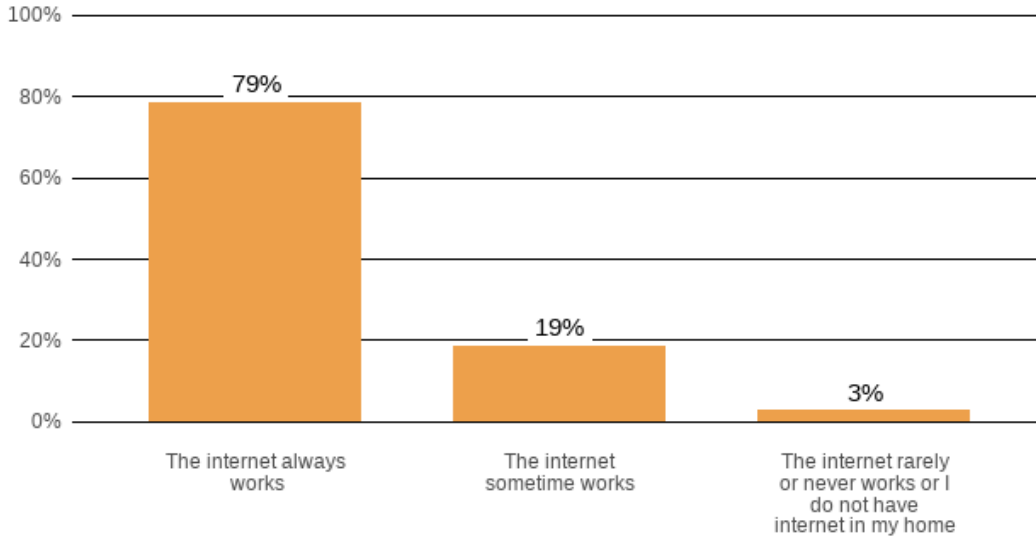


Table 56. How well does the internet work in your home?

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

State	The internet always works	The internet sometime works	The internet rarely or never works or I do not have internet in my home	N
NH ↑	87%	12%	1%	538
NJ ↑	85%	13%	1%	427
PA ↑	83%	15%	2%	639
MD	83%	16%	2%	579
DC	81%	14%	5%	130
VA	80%	17%	3%	207
Weighted NCI-IDD Average	79%	19%	3%	17869
AZ	78%	19%	3%	210
IN	78%	17%	5%	342
OK	77%	17%	6%	390
CA	77%	21%	3%	13516
MO	75%	20%	4%	257
MT	74%	21%	5%	198
GA ↓	71%	22%	7%	436

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?

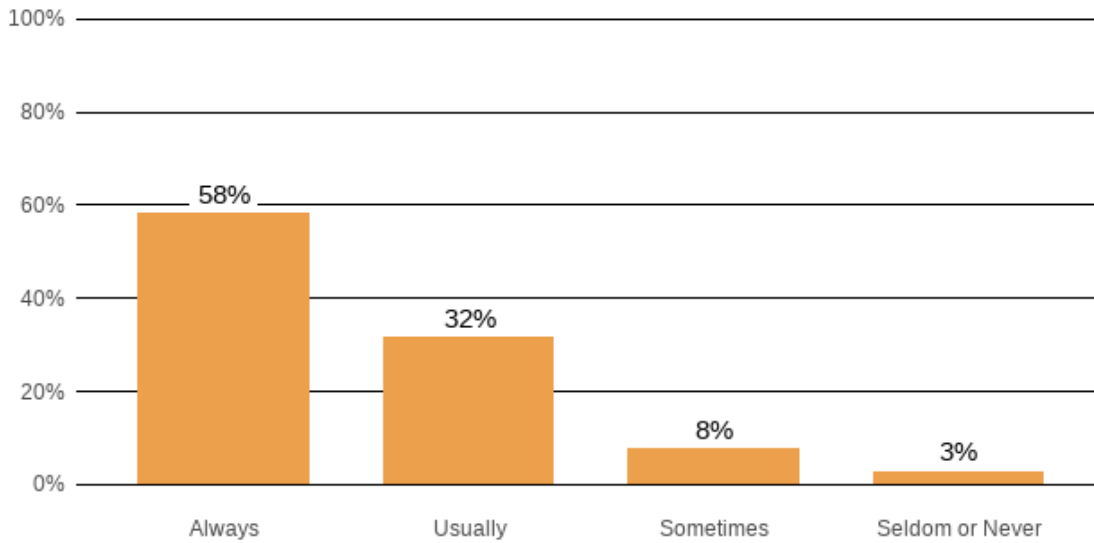


Table 57. Do support workers come and go when they are supposed to?

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

State	Always	Usually	Sometimes	Seldom or Never	N
AZ ↑	72%	22%	5%	1%	185
NJ ↑	65%	27%	6%	1%	351
PA ↑	65%	28%	7%	1%	595
VA	67%	24%	7%	2%	183
DC	66%	21%	9%	4%	110
IN	62%	29%	8%	1%	261
MO	59%	35%	4%	2%	190
Weighted NCI-IDD Average	58%	32%	8%	3%	13056
NH	58%	35%	5%	1%	386
OK	57%	34%	7%	2%	295
MD	54%	36%	8%	3%	495
MT	52%	37%	8%	3%	161
GA	51%	38%	6%	5%	333
CA ↓	52%	35%	9%	4%	9511

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

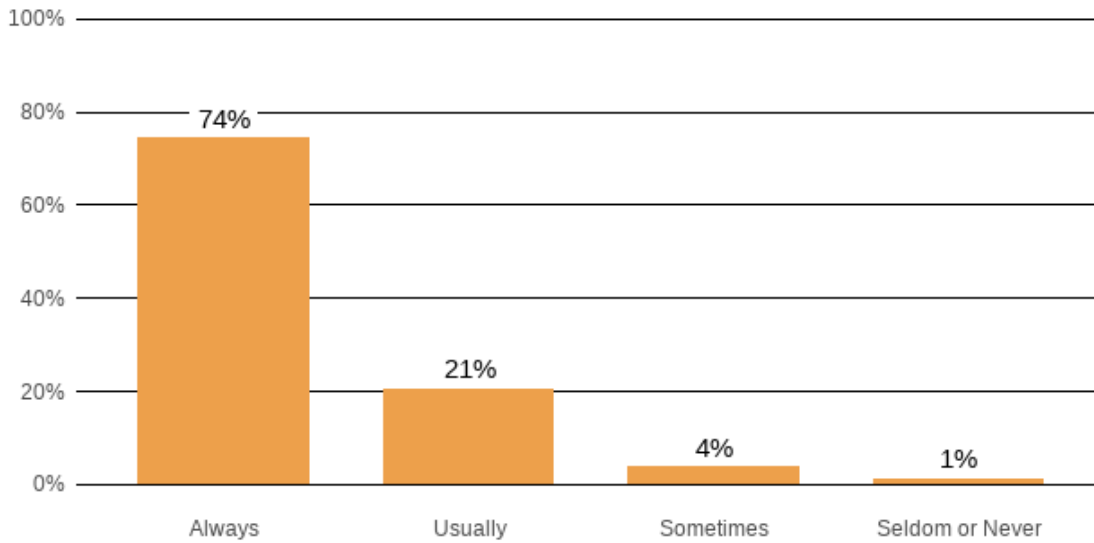


Table 58. Do support workers speak to you in a way you understand?

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

State	Always	Usually	Sometimes	Seldom or Never	N
IN ↑	83%	16%	2%	0%	288
NJ ↑	81%	15%	4%	0%	362
PA ↑	79%	18%	2%	1%	604
DC	83%	15%	1%	1%	115
NH	79%	18%	3%	0%	419
VA	78%	19%	3%	0%	190
MO	76%	20%	3%	1%	209
AZ	76%	20%	3%	1%	191
OK	76%	19%	4%	1%	319
MT	75%	21%	3%	0%	178
Weighted NCI-IDD Average	74%	21%	4%	1%	14474
MD	72%	22%	4%	1%	509
GA	72%	24%	4%	1%	381
CA	70%	23%	5%	2%	10709

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

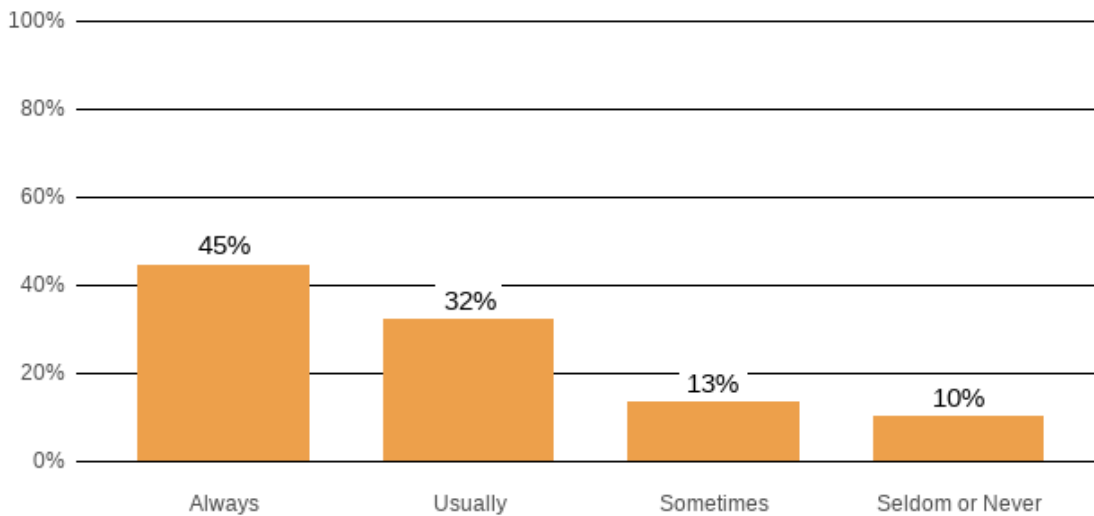


Table 59. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC	61%	25%	10%	3%	59
VA	57%	25%	11%	7%	109
IN	54%	33%	8%	4%	114
PA	48%	34%	14%	5%	225
MD	46%	31%	14%	8%	252
NH	46%	34%	15%	5%	154
Weighted NCI-IDD Average	45%	32%	13%	10%	6942
NJ	44%	39%	8%	9%	151
CA	42%	30%	15%	13%	5211
MO	40%	38%	12%	11%	113
AZ	39%	40%	14%	7%	92
OK	39%	31%	18%	12%	169
GA	37%	44%	12%	7%	206
MT	37%	41%	13%	9%	87

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

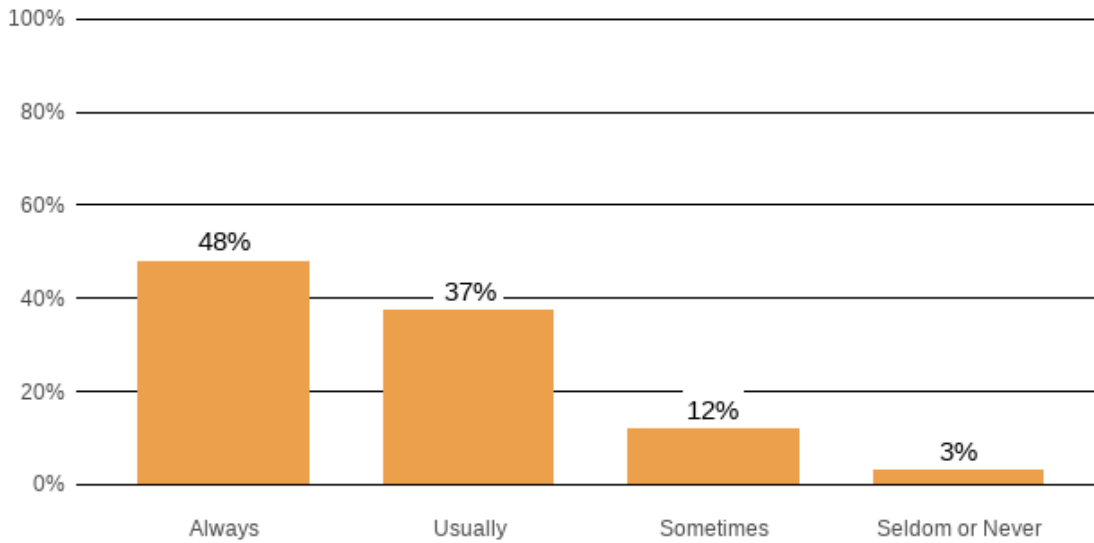


Table 60. Do support workers have the right information and skills to meet your family's needs?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	68%	26%	5%	1%	113
IN ↑	58%	35%	6%	1%	281
VA ↑	58%	27%	13%	2%	183
PA ↑	56%	33%	10%	1%	585
NJ	53%	36%	9%	2%	351
AZ	53%	36%	9%	2%	190
OK	53%	37%	7%	2%	305
NH	51%	39%	8%	2%	399
Weighted NCI-IDD Average	48%	37%	12%	3%	13801
MO	48%	40%	11%	1%	202
MD	44%	39%	13%	4%	490
GA	43%	45%	10%	2%	371
MT	39%	49%	11%	1%	176
CA ↓	42%	40%	14%	4%	10155

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

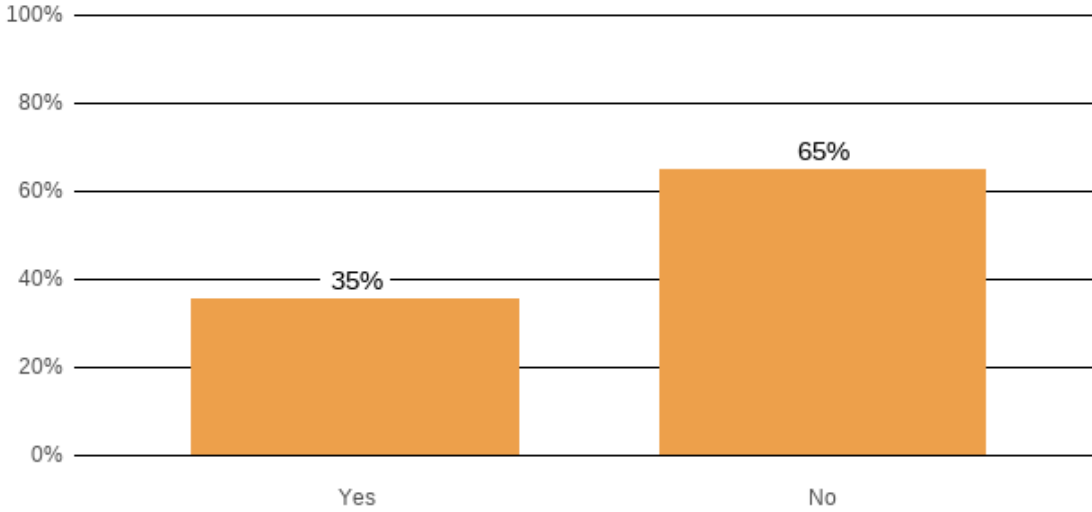


Table 61. Do your family member’s support workers change too often? Is there too much “turnover” of support workers?

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

State	Yes	No	N
MD ↑	42%	58%	471
MT	39%	61%	165
NH	38%	62%	380
VA	37%	63%	175
CA	37%	63%	9329
Weighted NCI-IDD Average	35%	65%	12750
PA	35%	65%	557
IN	34%	66%	261
AZ	33%	67%	174
MO	33%	67%	184
GA	32%	68%	343
NJ ↓	28%	72%	338
OK ↓	22%	78%	265
DC ↓	13%	87%	108

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

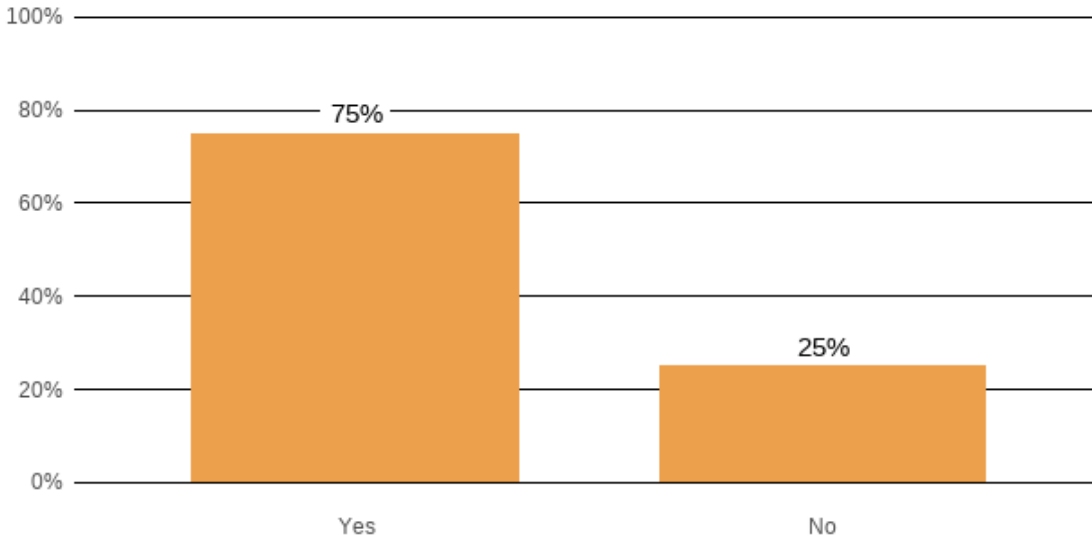


Table 62. Is there always a staff person available to support your family member when support is needed?

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

State	Yes	No	N
DC ↑	90%	10%	116
AZ	81%	19%	161
NJ	79%	21%	330
GA	77%	23%	337
PA	77%	23%	546
OK	77%	23%	264
Weighted NCI-IDD Average	75%	25%	12645
VA	74%	26%	180
CA	74%	26%	9219
MT	72%	28%	158
IN	72%	28%	262
MO	71%	29%	187
MD	70%	30%	474
NH ↓	66%	34%	411

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?

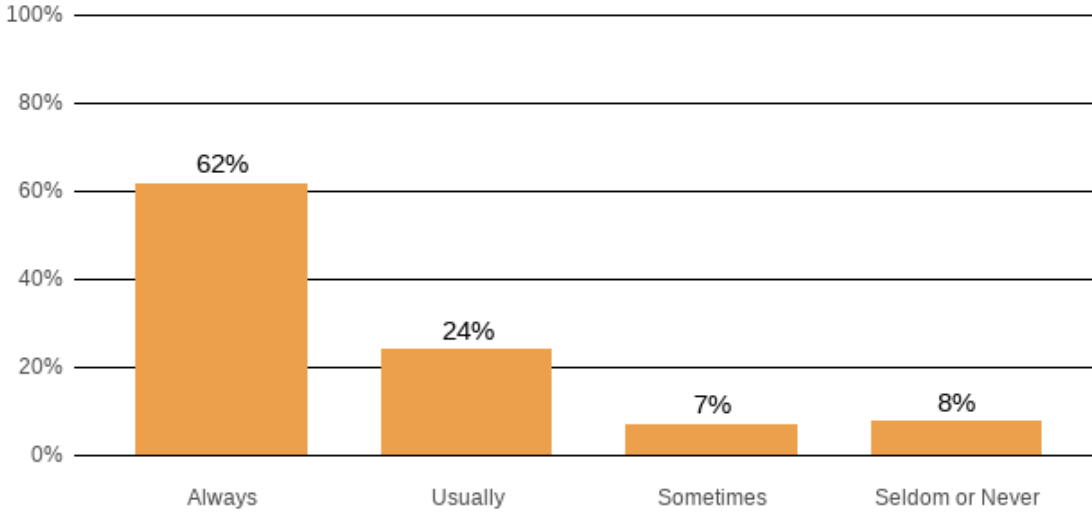


Table 63. Can your family choose or change the agency that provides your family member's services?

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

State	Always	Usually	Sometimes	Seldom or Never	N
IN ↑	82%	15%	2%	1%	308
OK ↑	74%	17%	4%	5%	250
AZ ↑	72%	20%	5%	3%	172
MD ↑	70%	20%	5%	5%	427
NH ↑	69%	19%	4%	7%	322
NJ ↑	69%	20%	6%	6%	306
DC	70%	21%	3%	7%	107
PA	66%	24%	5%	5%	496
MT	65%	20%	6%	9%	120
MO	62%	24%	6%	9%	161
Weighted NCI-IDD Average	62%	24%	7%	8%	10234
VA	60%	23%	9%	7%	141
GA	58%	27%	6%	8%	266
CA ↓	51%	28%	9%	12%	7158

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

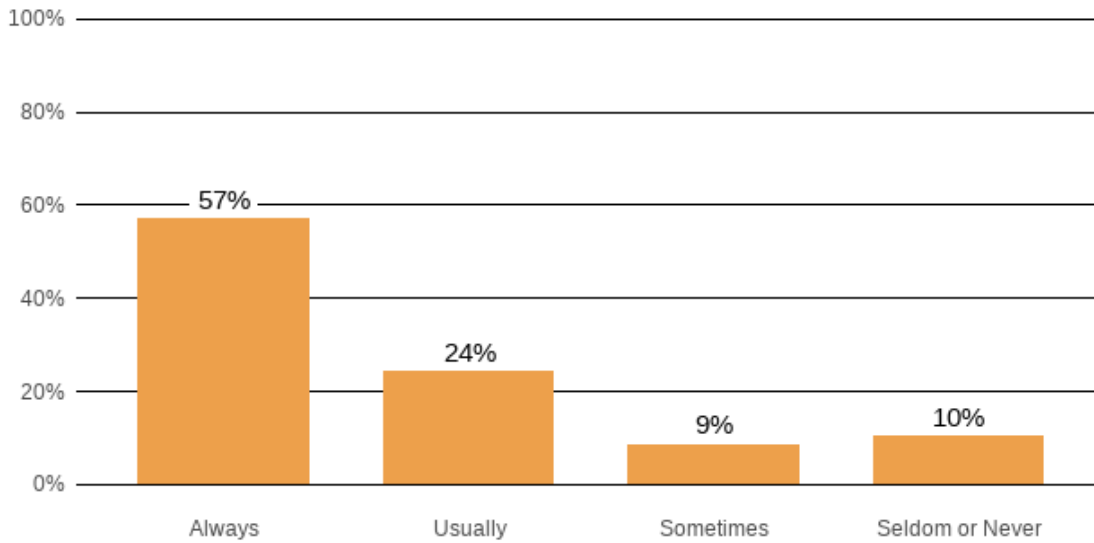


Table 64. Can your family choose or change your family member's support workers?

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

State	Always	Usually	Sometimes	Seldom or Never	N
IN ↑	72%	20%	5%	3%	264
OK ↑	66%	20%	5%	8%	228
PA ↑	63%	22%	7%	7%	469
MO	64%	17%	8%	12%	157
NJ	63%	21%	8%	8%	279
DC	62%	19%	4%	14%	93
NH	62%	18%	9%	11%	336
AZ	61%	26%	8%	5%	155
MD	61%	23%	7%	9%	404
MT	59%	22%	9%	10%	119
VA	57%	20%	9%	14%	147
Weighted NCI-IDD Average	57%	24%	9%	10%	9896
GA	50%	29%	6%	15%	233
CA ↓	49%	27%	11%	14%	7012

Can someone in your family directly manage support staff?

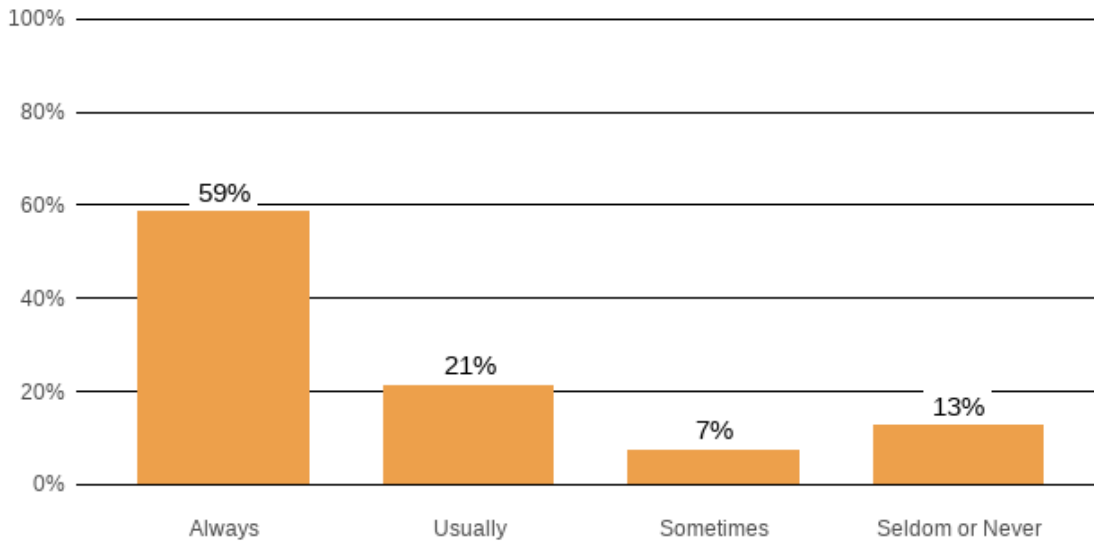


Table 65. Can someone in your family directly manage support staff?

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

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	66%	22%	6%	6%	143
NJ	66%	20%	7%	8%	259
MT	66%	16%	8%	10%	116
IN	65%	17%	6%	12%	231
NH	65%	15%	6%	14%	322
MO	65%	18%	3%	14%	145
OK	65%	20%	5%	10%	221
VA	64%	16%	6%	13%	152
PA	63%	18%	7%	12%	413
DC	61%	23%	6%	10%	88
MD	61%	18%	7%	14%	394
Weighted NCI-IDD Average	59%	21%	7%	13%	9417
GA	52%	22%	4%	23%	222
CA ↓	52%	25%	9%	14%	6711

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

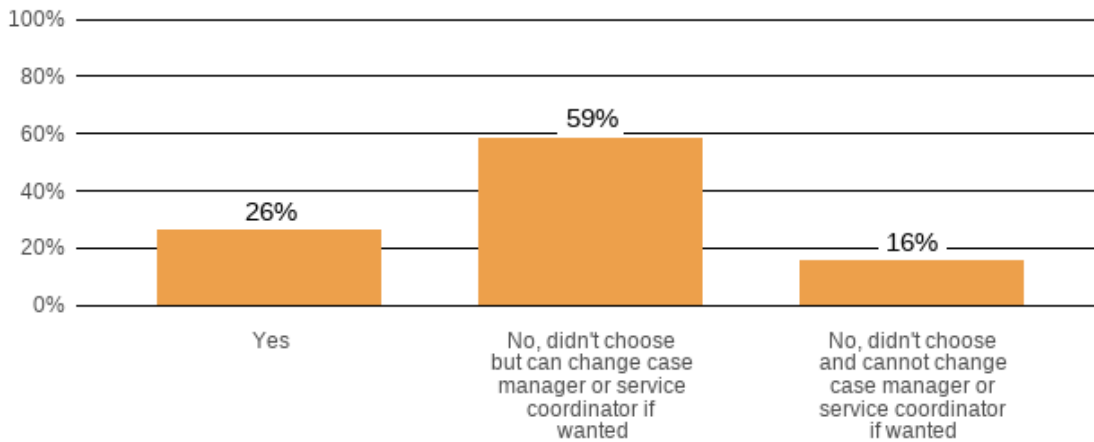


Table 66. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

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

State	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
NJ ↑	55%	37%	8%	376
IN ↑	54%	43%	2%	334
MD ↑	46%	44%	10%	506
DC ↑	40%	50%	10%	112
PA ↑	31%	57%	12%	566
VA	28%	61%	11%	166
MO	27%	55%	17%	195
Weighted NCI-IDD Average	26%	59%	16%	13687
AZ	19%	72%	8%	178
MT	19%	55%	26%	174
NH ↓	19%	68%	13%	477
GA ↓	18%	56%	26%	322
CA ↓	14%	64%	22%	9970
OK ↓	10%	65%	26%	311

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?

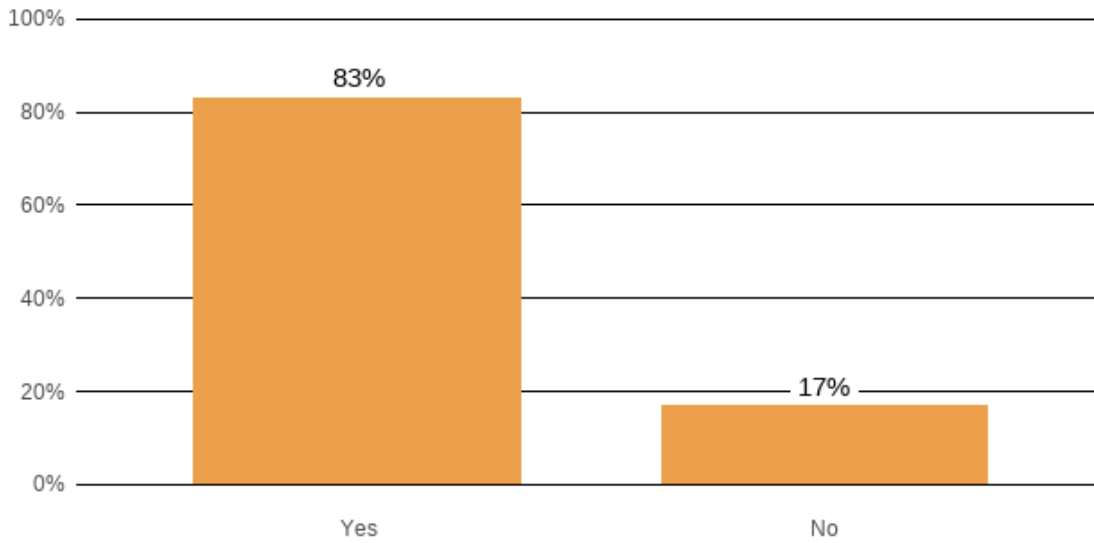


Table 67. Does your family member do things in the community?

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

State	Yes	No	N
NH ↑	93%	7%	536
PA ↑	91%	9%	644
MD ↑	91%	9%	559
DC ↑	91%	9%	131
MT ↑	91%	9%	205
IN ↑	89%	11%	350
OK ↑	87%	13%	398
MO	87%	13%	256
NJ	86%	14%	409
AZ	85%	15%	205
Weighted NCI-IDD Average	83%	17%	17917
VA	82%	18%	206
GA	80%	20%	463
CA	79%	21%	13555

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

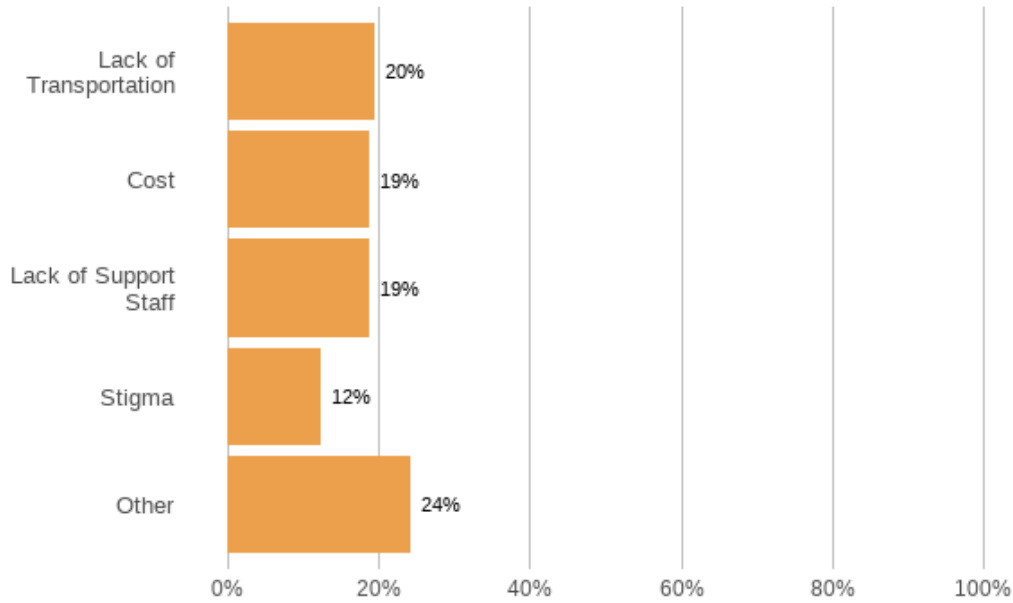


Table 68. For your family member, what makes it hard to do things in the community?

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

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	17%	23%	15%	15%	29%
CA	20%	20%	19%	13%	23%
DC	13%	15%	5%	9%	9%
GA	12%	15%	13%	8%	23%
IN	24%	13%	20%	8%	21%
MD	21%	20%	25%	12%	27%
MO	18%	21%	16%	12%	32%
MT	17%	21%	25%	10%	29%
NJ	23%	17%	23%	12%	26%
NH	23%	14%	28%	6%	24%
OK	17%	14%	12%	10%	24%
PA	16%	18%	19%	10%	24%
VA	17%	14%	18%	14%	30%
Weighted NCI-IDD Average	20%	19%	19%	12%	24%

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

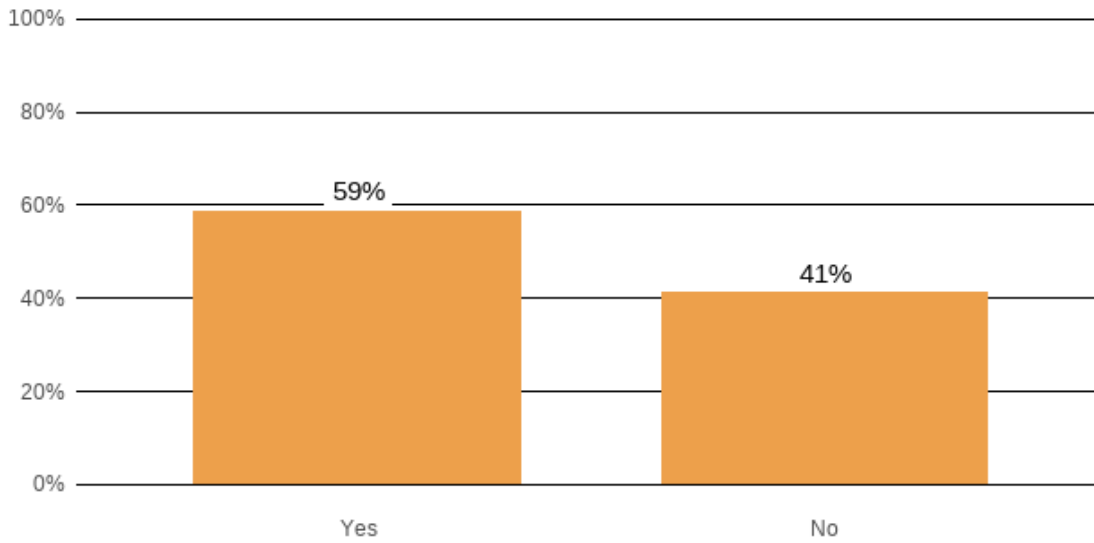


Table 69. Does your family member have friends other than paid support workers or family?

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

State	Yes	No	N
GA ↑	69%	31%	447
OK ↑	68%	32%	387
MT ↑	68%	32%	197
IN ↑	66%	34%	348
NH ↑	65%	35%	533
DC	68%	32%	132
AZ	65%	35%	198
PA	62%	38%	628
MO	59%	41%	249
Weighted NCI-IDD Average	59%	41%	17419
VA	58%	42%	205
NJ	58%	42%	412
MD	57%	43%	545
CA	55%	45%	13138

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

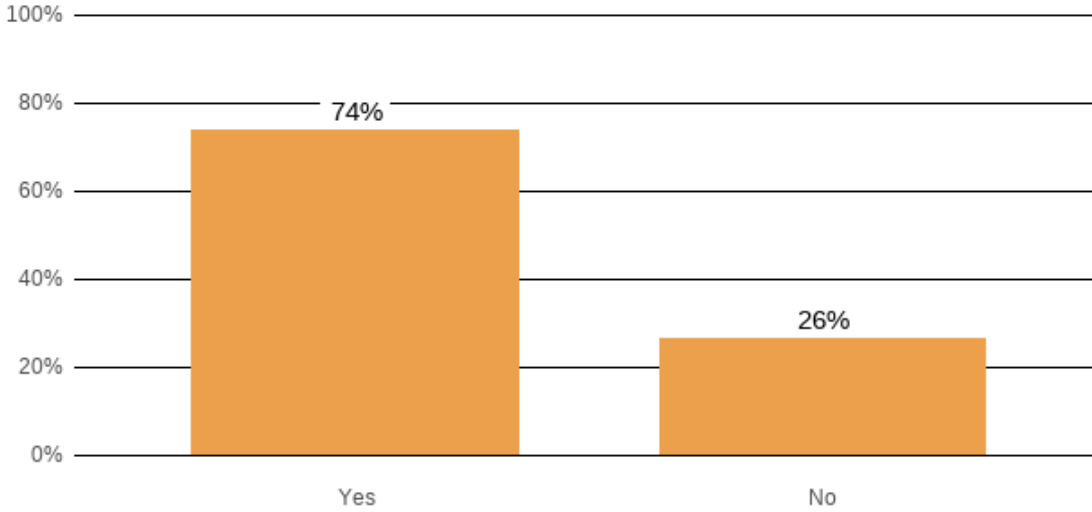


Table 70. In your community, are there resources that your family can use that are not provided by the I/DD agency? (for example, recreational programs, community housing, library programs, religious groups, etc)?

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

State	Yes	No	N
DC ↑	86%	14%	112
MO ↑	82%	18%	190
AZ	80%	20%	151
MD	78%	22%	455
NH	78%	22%	389
IN	77%	23%	245
PA	76%	24%	474
MT	75%	25%	164
Weighted NCI-IDD Average	74%	26%	12548
OK	73%	27%	298
VA	73%	27%	157
CA	72%	28%	9280
NJ	71%	29%	313
GA ↓	65%	35%	320

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

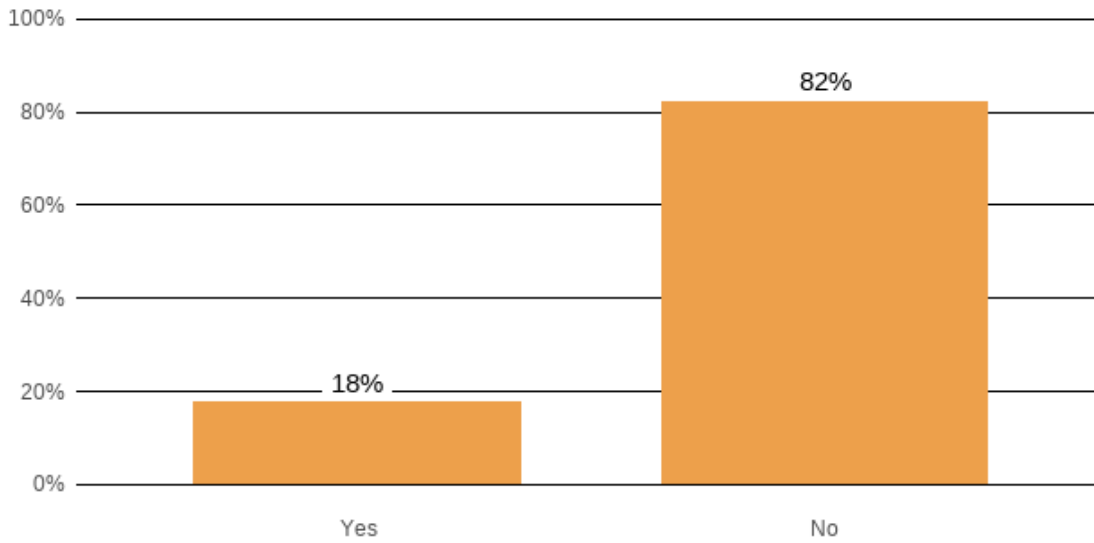


Table 71. Does your family take part in any family-to-family networks in your community?

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

State	Yes	No	N
DC ↑	32%	68%	114
VA	26%	74%	174
MD	22%	78%	482
OK	21%	79%	329
GA	20%	80%	365
NJ	19%	81%	357
Weighted NCI-IDD Average	18%	82%	15563
CA	17%	83%	11844
MT	17%	83%	166
IN	17%	83%	298
AZ	17%	83%	181
PA	15%	85%	560
NH ↓	12%	88%	480
MO ↓	8%	92%	213

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?

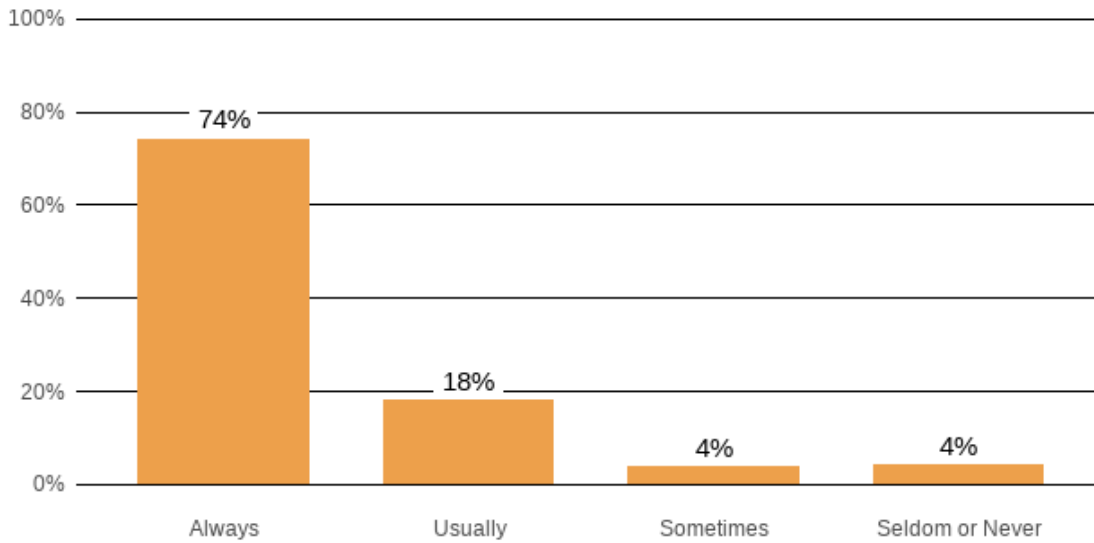


Table 72. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

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

State	Always	Usually	Sometimes	Seldom or Never	N
NH ↑	86%	11%	1%	2%	547
OK ↑	84%	13%	1%	2%	389
PA ↑	82%	15%	2%	1%	641
NJ ↑	81%	14%	2%	2%	409
IN ↑	81%	15%	2%	3%	356
MD ↑	80%	16%	2%	1%	557
DC	83%	14%	2%	2%	133
MO	79%	16%	3%	2%	256
GA	76%	17%	3%	4%	451
VA	75%	18%	3%	4%	206
MT	75%	21%	2%	2%	200
Weighted NCI-IDD Average	74%	18%	4%	4%	17615
AZ	73%	24%	0%	2%	203
CA ↓	69%	19%	6%	6%	13267

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

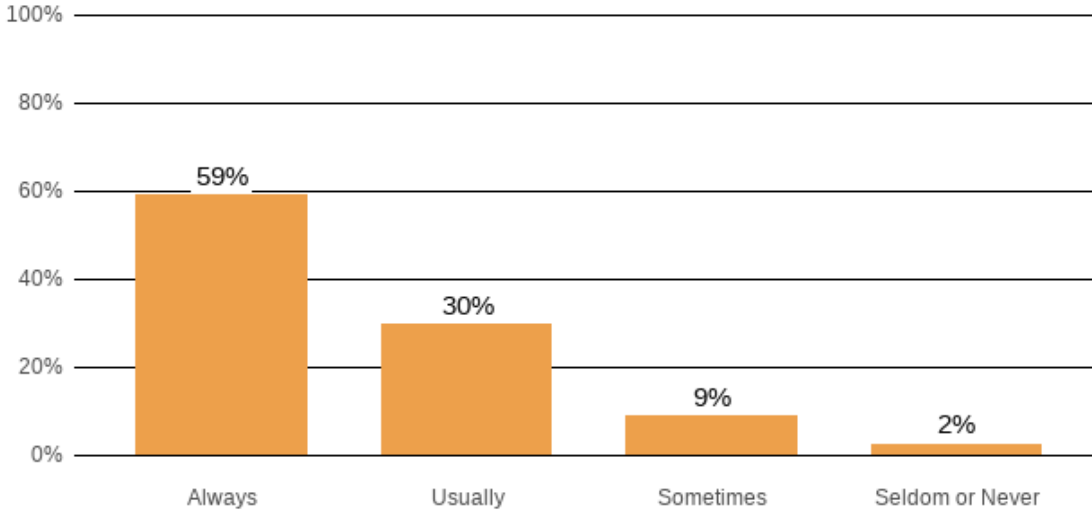


Table 73. Does your family member’s primary care doctor understand your family member’s needs related to their disability?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	76%	21%	2%	1%	131
VA ↑	70%	21%	7%	2%	209
OK ↑	66%	28%	5%	1%	382
NJ ↑	66%	24%	7%	3%	411
PA	63%	30%	7%	1%	648
IN	62%	31%	5%	2%	349
MD	62%	27%	9%	1%	554
NH	61%	30%	8%	1%	524
GA	61%	31%	6%	2%	454
Weighted NCI-IDD Average	59%	30%	9%	2%	17304
AZ	57%	33%	8%	2%	202
MO	56%	36%	6%	2%	255
CA	55%	31%	11%	3%	12987
MT	54%	39%	6%	1%	198

Can your family member go to the dentist when needed?

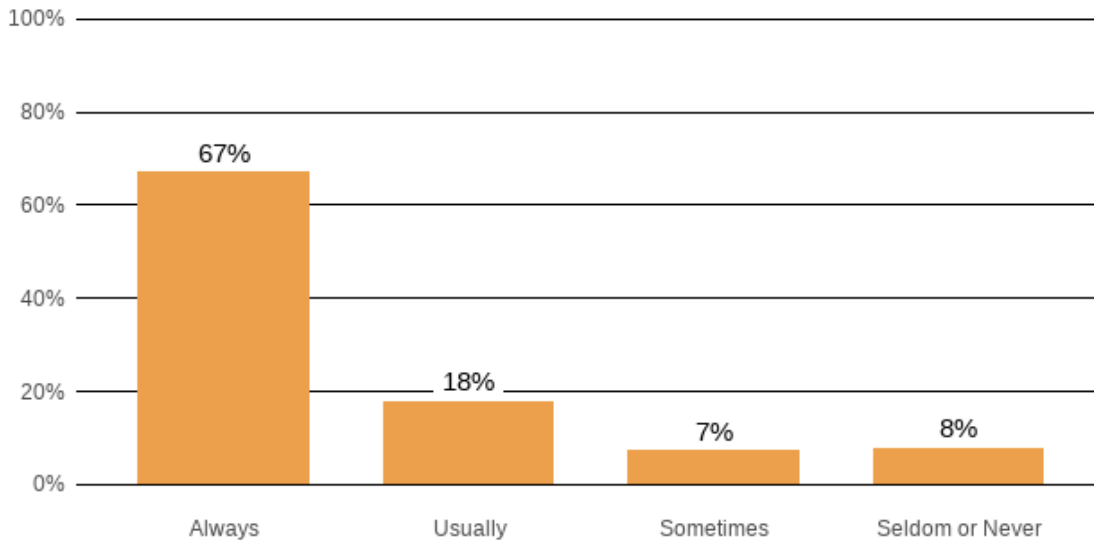


Table 74. Can your family member go to the dentist when needed?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	77%	13%	5%	5%	132
IN ↑	75%	14%	4%	7%	350
NJ ↑	74%	14%	5%	7%	417
PA ↑	73%	16%	6%	5%	648
NH ↑	73%	15%	5%	7%	538
MD ↑	73%	15%	5%	7%	555
MT	72%	19%	4%	4%	202
OK	70%	18%	5%	7%	387
Weighted NCI-IDD Average	67%	18%	7%	8%	17852
VA	66%	16%	7%	11%	205
AZ	65%	20%	9%	6%	205
MO	64%	16%	8%	12%	252
CA	64%	19%	9%	8%	13509
GA ↓	58%	20%	7%	15%	452

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

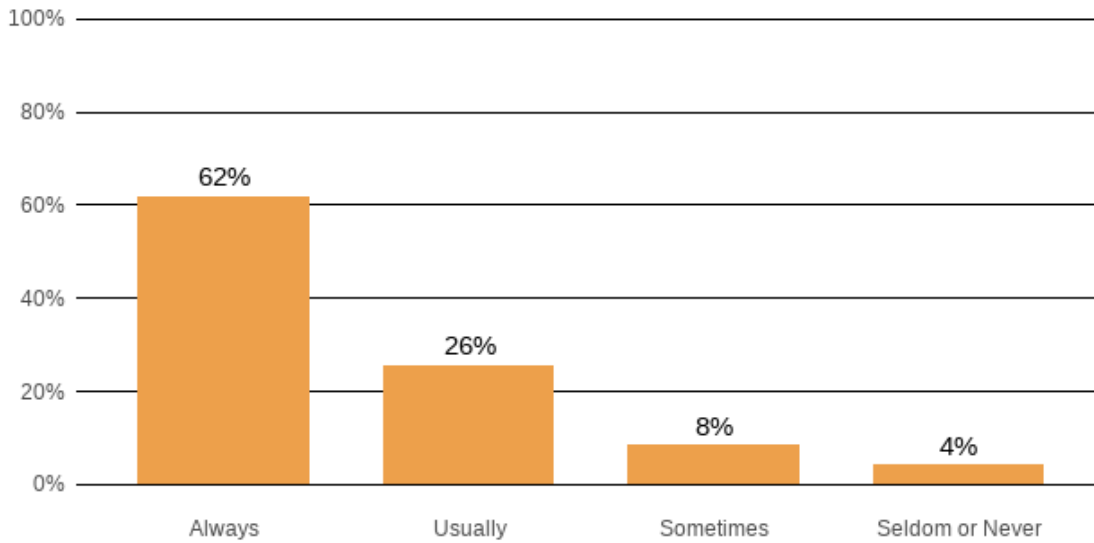


Table 75. Does your family member's dentist understand your family member's needs related to their disability?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	75%	20%	3%	2%	129
VA ↑	74%	15%	6%	5%	186
NJ	68%	23%	7%	3%	382
MT	67%	28%	4%	1%	192
OK	66%	25%	6%	4%	359
PA	66%	25%	7%	2%	600
IN	64%	27%	7%	2%	323
GA	64%	25%	7%	4%	384
MD	62%	25%	8%	5%	523
Weighted NCI-IDD Average	62%	26%	8%	4%	16129
AZ	62%	28%	7%	3%	186
NH	60%	29%	7%	3%	479
CA	58%	27%	10%	5%	12164
MO	55%	34%	7%	4%	222

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

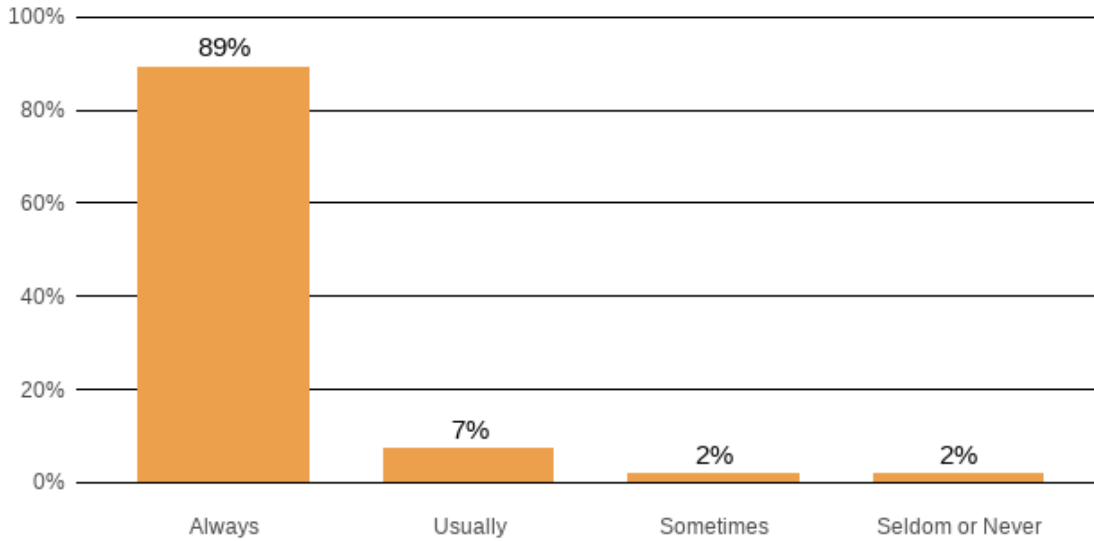


Table 76. If your family member takes prescription medications, do you know what they're for?

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

State	Always	Usually	Sometimes	Seldom or Never	N
MT ↑	94%	5%	0%	1%	175
NJ ↑	93%	4%	2%	0%	334
IN	93%	6%	1%	1%	311
NH	92%	5%	2%	1%	483
MD	92%	5%	2%	2%	453
AZ	92%	5%	1%	2%	183
PA	92%	6%	1%	1%	545
OK	91%	7%	1%	0%	357
MO	90%	6%	2%	2%	226
VA	90%	6%	2%	2%	196
Weighted NCI-IDD Average	89%	7%	2%	2%	14760
GA	88%	9%	2%	1%	430
DC	88%	7%	3%	2%	110
CA	87%	8%	2%	2%	10957

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

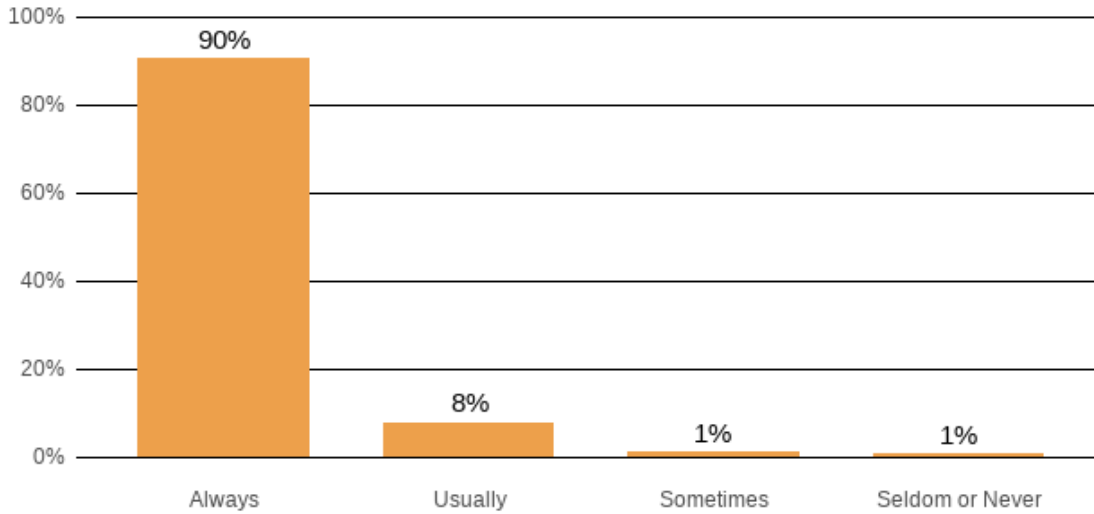


Table 77. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

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

State	Always	Usually	Sometimes	Seldom or Never	N
IN ↑	96%	4%	1%	0%	314
NJ ↑	94%	5%	1%	1%	343
MT	94%	5%	1%	0%	175
MO	94%	4%	0%	2%	225
NH	93%	6%	0%	0%	477
OK	93%	5%	1%	1%	356
PA	93%	7%	0%	0%	548
AZ	92%	8%	1%	0%	182
GA	92%	7%	1%	0%	433
MD	92%	7%	1%	1%	461
DC	91%	7%	1%	1%	108
Weighted NCI-IDD Average	90%	8%	1%	1%	14623
VA	90%	8%	1%	1%	195
CA	88%	10%	2%	1%	10806

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

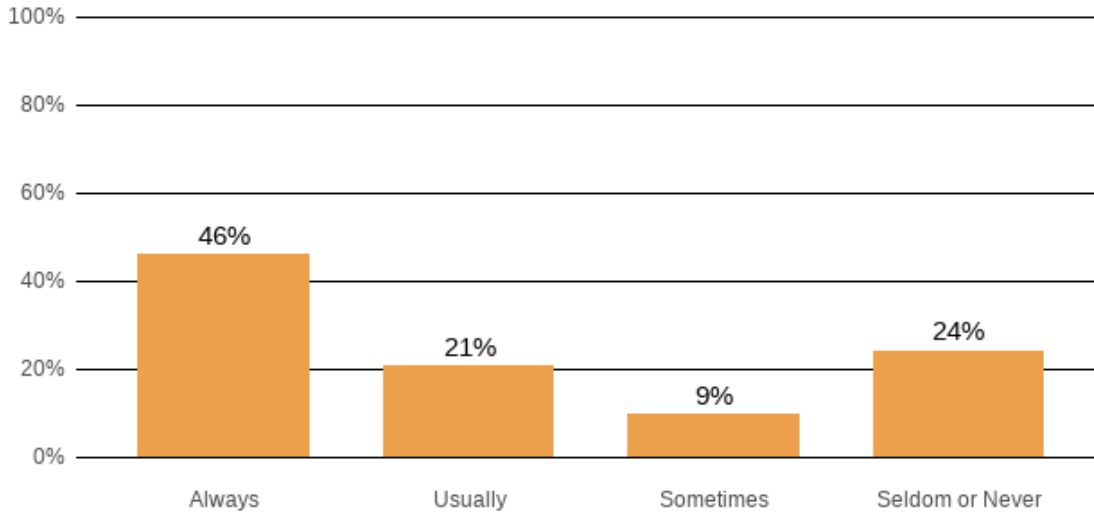


Table 78. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	58%	16%	8%	18%	106
VA ↑	58%	17%	9%	16%	162
IN ↑	55%	24%	6%	15%	262
PA ↑	53%	22%	8%	17%	484
MD ↑	53%	19%	9%	19%	419
NH	51%	20%	6%	22%	393
AZ	51%	16%	8%	24%	135
OK	51%	21%	5%	23%	280
MT	48%	20%	9%	23%	128
NJ	47%	17%	8%	28%	288
MO	46%	21%	9%	23%	182
Weighted NCI-IDD Average	46%	21%	9%	24%	13080
CA ↓	40%	21%	11%	28%	9937
GA ↓	37%	26%	5%	32%	304

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

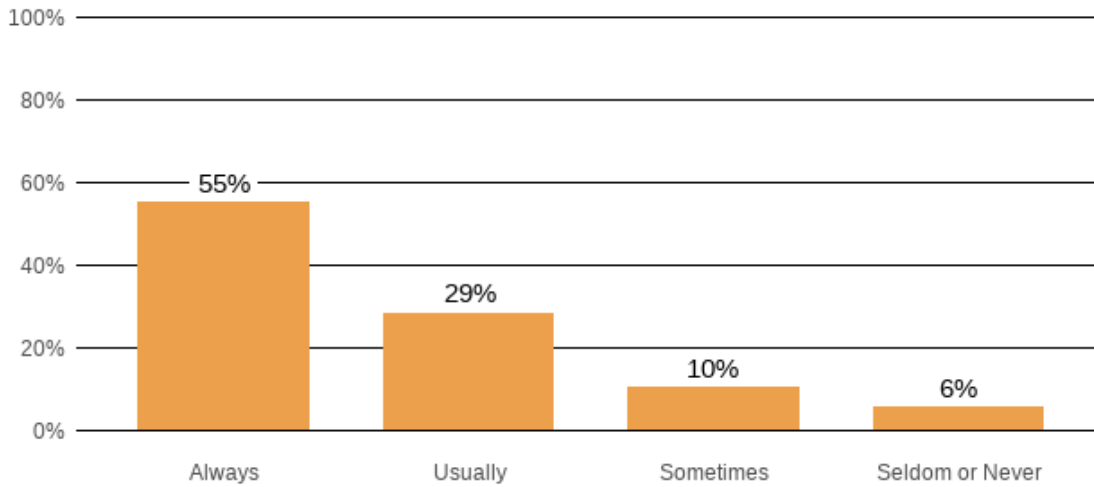


Table 79. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	71%	19%	5%	5%	83
VA	63%	22%	8%	7%	139
NH	61%	29%	5%	4%	231
IN	61%	27%	9%	3%	189
OK	59%	28%	10%	3%	188
AZ	59%	27%	8%	6%	97
PA	58%	31%	9%	2%	345
MD	57%	26%	11%	5%	280
MT	56%	27%	13%	4%	85
Weighted NCI-IDD Average	55%	29%	10%	6%	9624
NJ	54%	30%	9%	6%	204
GA	54%	32%	9%	5%	252
MO	54%	32%	10%	5%	132
CA	52%	29%	12%	7%	7399

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

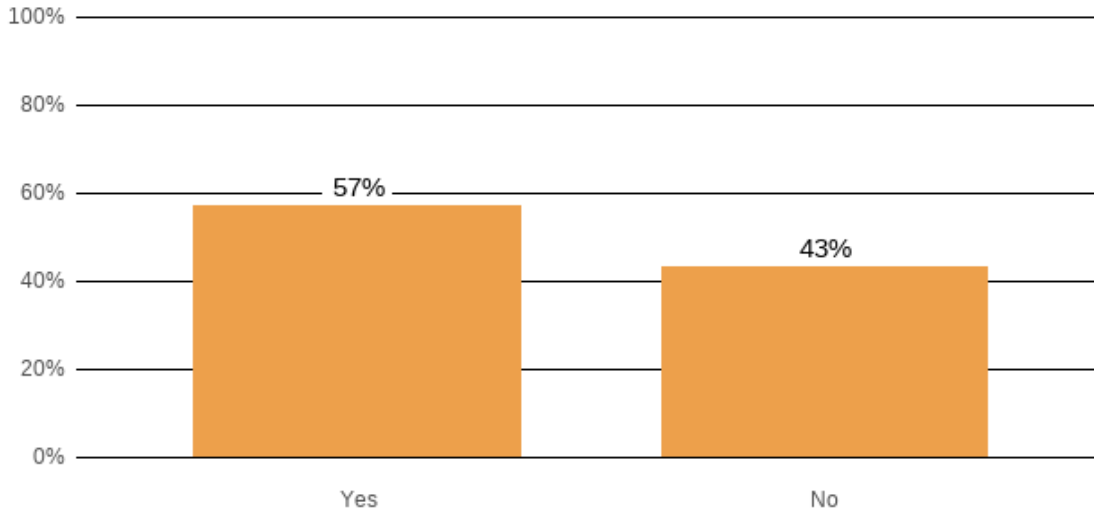


Table 80. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

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

State	Yes	No	N
OK ↑	76%	24%	72
AZ	71%	29%	34
MT	65%	35%	37
NH	62%	38%	79
MO	62%	38%	47
IN	60%	40%	63
VA	60%	40%	47
GA	59%	41%	91
PA	59%	41%	110
Weighted NCI-IDD Average	57%	43%	4376
CA	55%	45%	3592
NJ	51%	49%	61
MD	48%	52%	100
DC	47%	53%	43

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

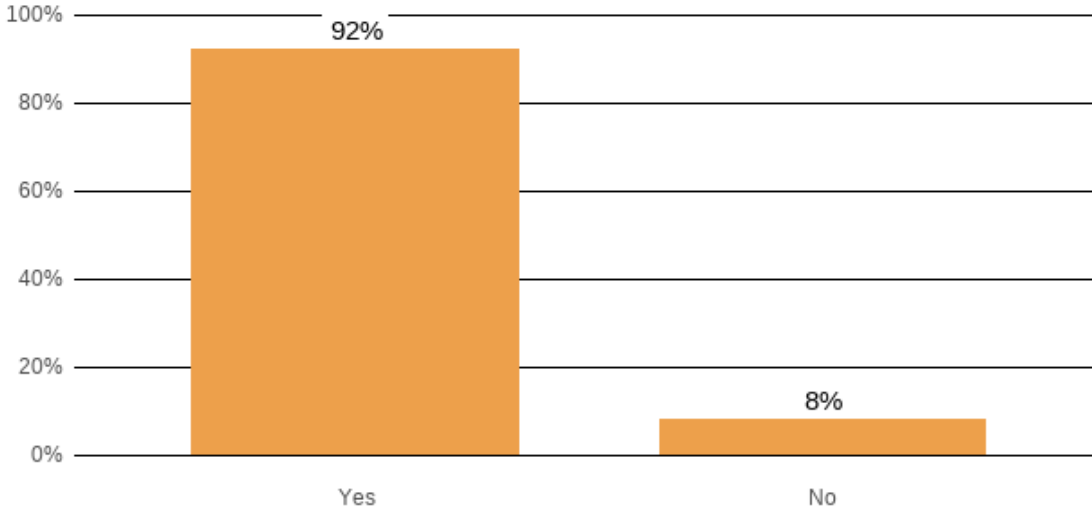


Table 81. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?

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

State	Yes	No	N
DC ↑	98%	2%	128
GA ↑	96%	4%	431
IN ↑	96%	4%	331
PA ↑	96%	4%	602
OK ↑	95%	5%	380
NH ↑	95%	5%	511
NJ	94%	6%	376
AZ	93%	7%	187
VA	93%	7%	199
MD	92%	8%	506
MO	92%	8%	240
Weighted NCI-IDD Average	92%	8%	16533
CA	90%	10%	12445
MT	89%	11%	197

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

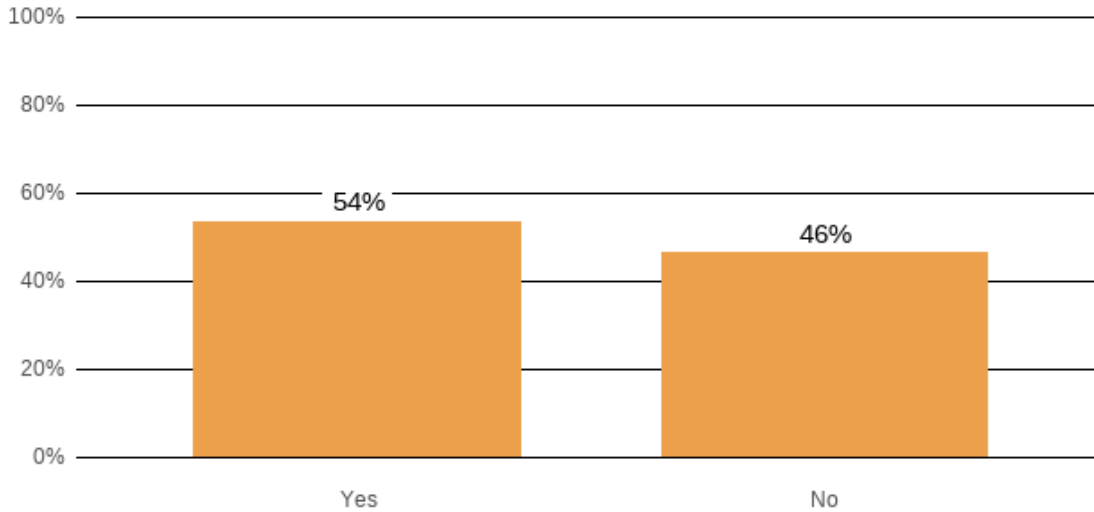


Table 82. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/service coordinator?

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

State	Yes	No	N
DC ↑	75%	25%	129
VA ↑	66%	34%	194
OK ↑	63%	37%	372
IN ↑	61%	39%	320
PA ↑	60%	40%	597
MO	59%	41%	238
NJ	55%	45%	396
Weighted NCI-IDD Average	54%	46%	16420
MD	53%	47%	511
CA	50%	50%	12349
GA	50%	50%	425
AZ	47%	53%	190
NH ↓	46%	54%	508
MT ↓	42%	58%	191

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

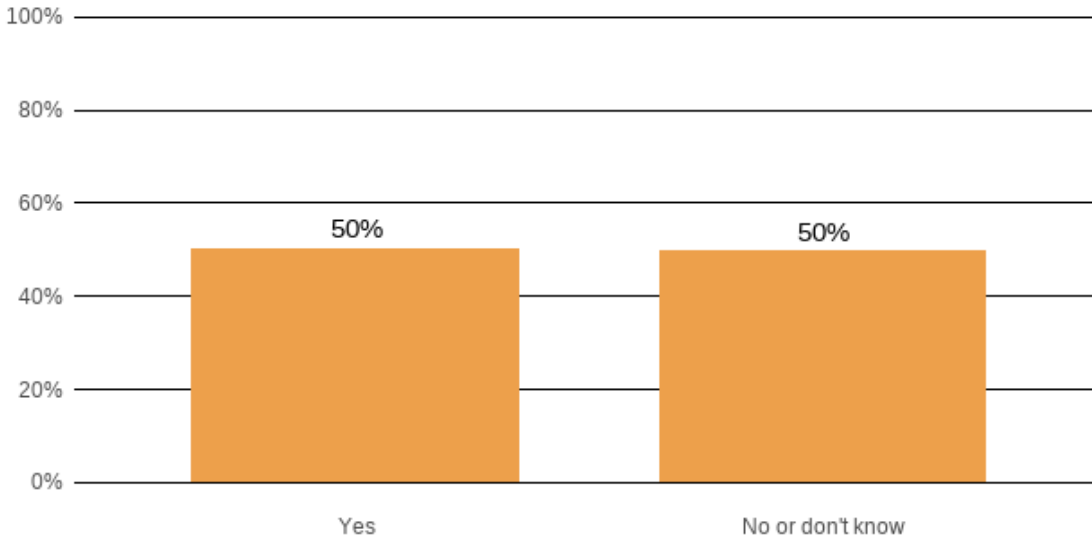


Table 83. Do you know how to file a complaint or grievance about provider agencies or staff?

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

State	Yes	No or don't know	N
DC ↑	77%	23%	132
PA ↑	70%	30%	637
OK ↑	68%	32%	396
IN ↑	64%	36%	351
NH ↑	63%	37%	546
AZ	59%	41%	206
MT	56%	44%	203
MO	55%	45%	260
VA	50%	50%	204
Weighted NCI-IDD Average	50%	50%	18077
GA	45%	55%	454
MD	45%	55%	557
NJ ↓	44%	56%	413
CA ↓	44%	56%	13718

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

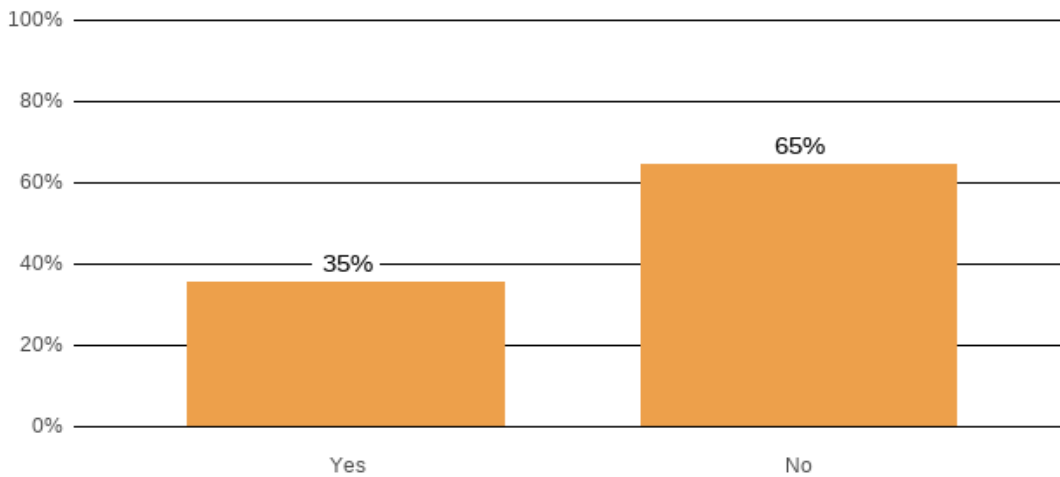


Table 84. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

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

State	Yes	No	N
IN ↑	73%	27%	22
PA ↑	53%	47%	66
VA	50%	50%	28
GA	49%	51%	47
DC	47%	53%	30
NH	41%	59%	44
MO	38%	63%	24
OK	38%	63%	24
Weighted NCI-IDD Average	35%	65%	2508
MD	33%	67%	64
NJ	31%	69%	36
CA ↓	29%	71%	2089
AZ	n/a	n/a	n/a
MT	n/a	n/a	n/a

Table note: The following states had an N of less than 20 and were not shown: AZ, MT

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

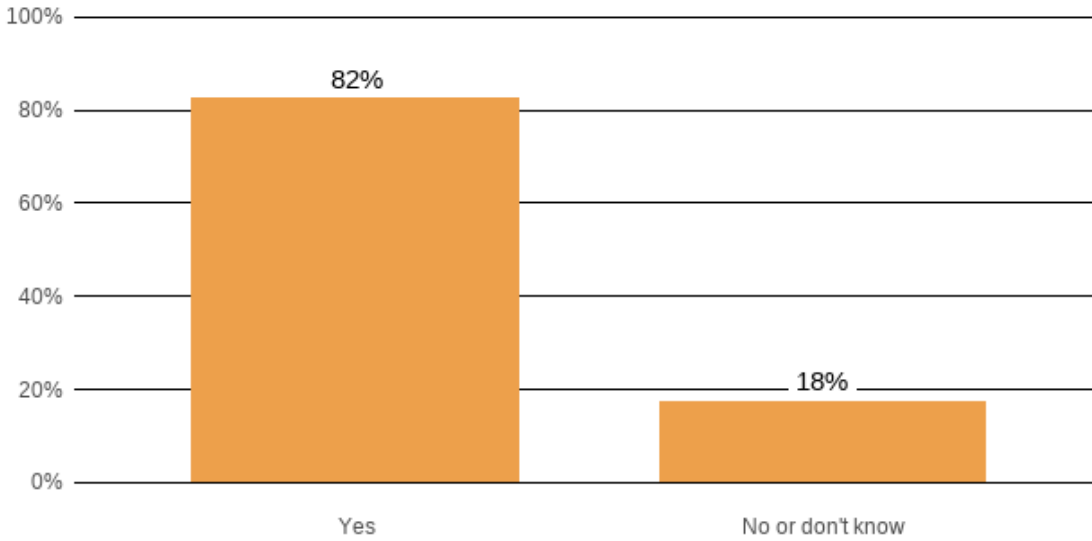


Table 85. Do you know how to report abuse or neglect related to your family member?

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

State	Yes	No or don't know	N
PA ↑	93%	7%	606
IN ↑	90%	10%	332
OK ↑	89%	11%	374
MO ↑	89%	11%	247
DC	89%	11%	130
VA	88%	12%	187
AZ	87%	13%	190
MT	86%	14%	192
GA	85%	15%	417
NH	85%	15%	491
Weighted NCI-IDD Average	82%	18%	16134
NJ	80%	20%	371
CA ↓	78%	22%	12096
MD ↓	76%	24%	501

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

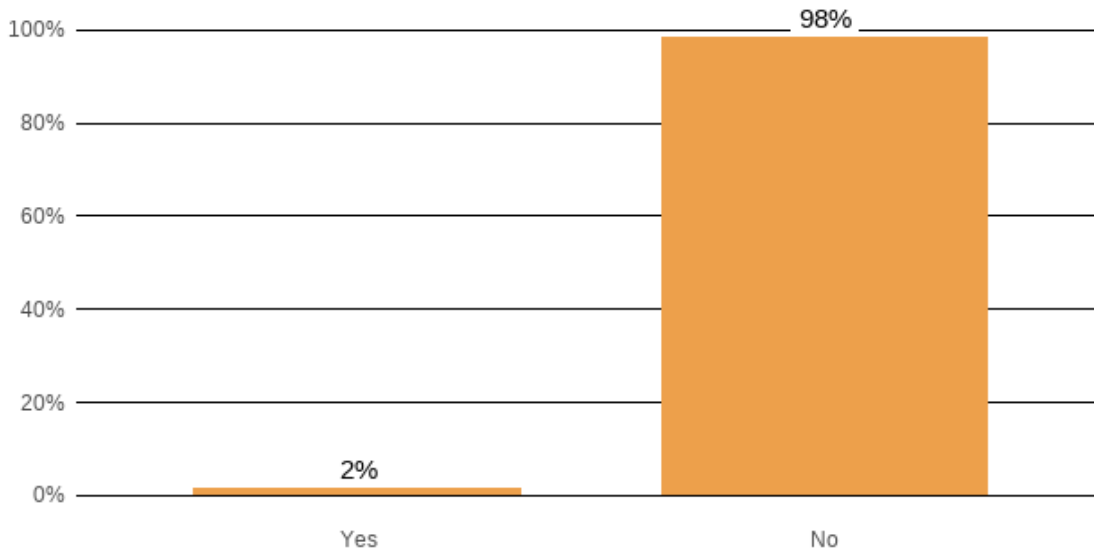


Table 86. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

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

State	Yes	No	N
DC	4%	96%	127
AZ	3%	97%	201
PA	3%	97%	621
OK	2%	98%	388
Weighted NCI-IDD Average	2%	98%	17445
NJ	1%	99%	403
IN	1%	99%	349
CA	1%	99%	13184
NH	1%	99%	535
MD	1%	99%	542
VA	1%	99%	199
MO	1%	99%	254
MT	1%	99%	197
GA ↓	0%	100%	445

If a report of abuse or neglect was filed on behalf of your family member, or 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?

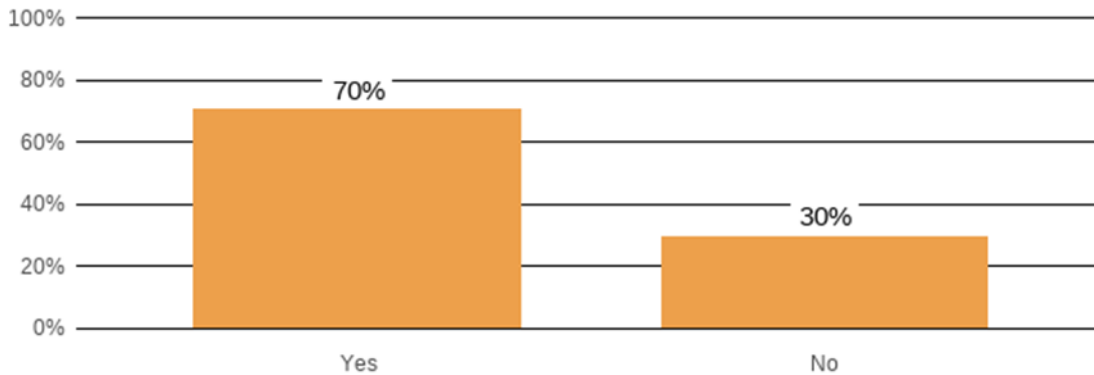


Table 87. If a report of abuse or neglect was filed on behalf of your family member, or if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

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

State	Yes	No	N
CA	70%	30%	115
Weighted NCI-IDD Average	70%	30%	160
AZ	n/a	n/a	n/a
DC	n/a	n/a	n/a
GA	n/a	n/a	n/a
IN	n/a	n/a	n/a
MD	n/a	n/a	n/a
MO	n/a	n/a	n/a
MT	n/a	n/a	n/a
NJ	n/a	n/a	n/a
NH	n/a	n/a	n/a
OK	n/a	n/a	n/a
PA	n/a	n/a	n/a
VA	n/a	n/a	n/a

Table note: The following states had an N of less than 20 and were not shown: AZ, DC, GA, IN, MD, MO, MT, NH, NJ, OK, PA, VA

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?

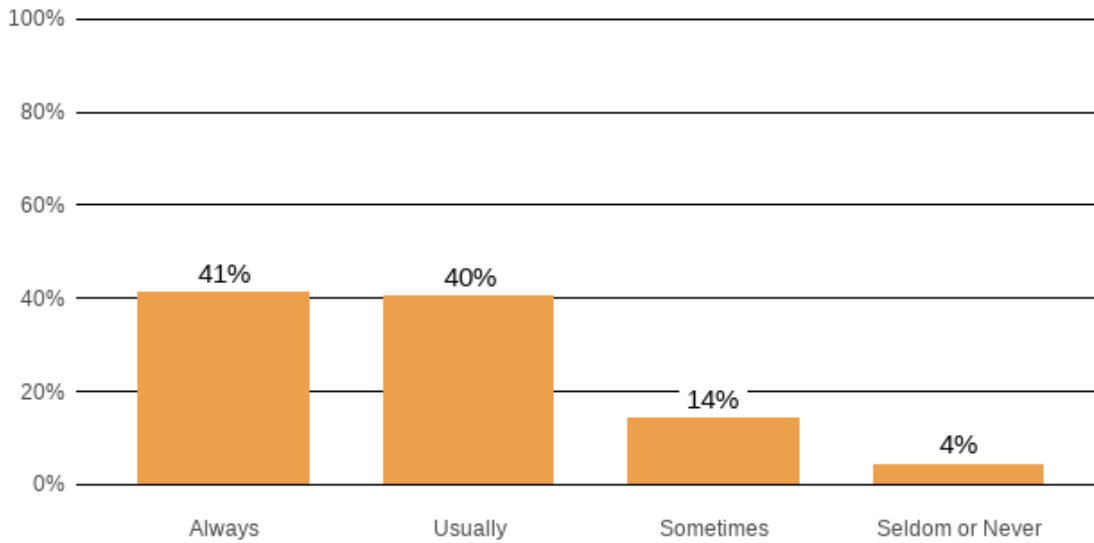


Table 88. Overall, are you satisfied with the services and supports your family member currently receives?

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	64%	26%	10%	0%	132
AZ	49%	41%	7%	2%	205
GA	46%	42%	9%	3%	442
PA	46%	41%	12%	2%	643
VA	45%	38%	14%	3%	208
IN	44%	41%	12%	3%	351
NJ	42%	42%	12%	4%	409
Weighted NCI-IDD Average	41%	40%	14%	4%	17756
NH	41%	41%	13%	4%	539
OK	41%	45%	10%	4%	389
CA	39%	40%	16%	5%	13436
MO	38%	49%	8%	5%	257
MT	34%	51%	13%	2%	197
MD ↓	35%	41%	18%	6%	548

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

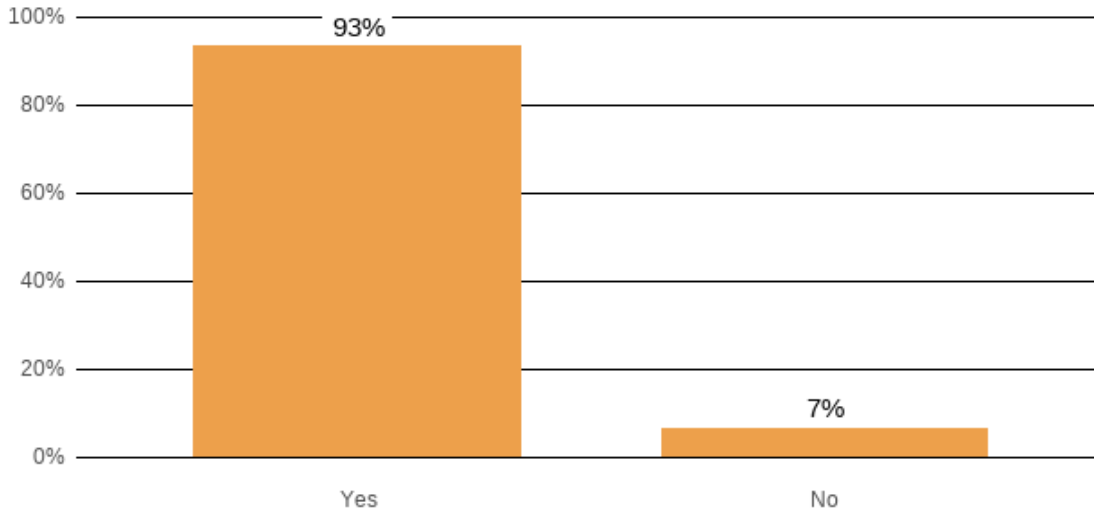


Table 89. Do you feel that services and supports have made a positive difference in the life of your family member?

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

State	Yes	No	N
MT ↑	98%	2%	187
PA ↑	97%	3%	616
AZ	96%	4%	194
MO	96%	4%	245
VA	95%	5%	198
DC	95%	5%	126
OK	95%	5%	370
IN	95%	5%	330
NJ	94%	6%	397
GA	94%	6%	420
Weighted NCI-IDD Average	93%	7%	16655
NH	93%	7%	511
CA	92%	8%	12541
MD	92%	8%	520

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

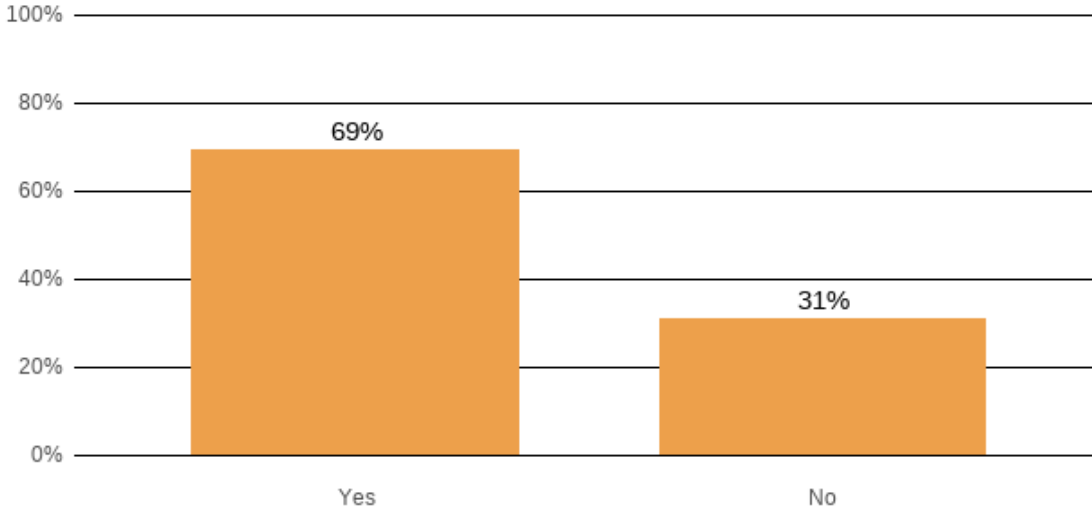


Table 90. Have services and supports reduced your family’s out-of-pocket expenses for your family member’s care?

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

State	Yes	No	N
NJ ↑	82%	18%	389
MT ↑	78%	22%	187
VA	75%	25%	190
AZ	75%	25%	190
MD	73%	27%	516
MO	71%	29%	245
Weighted NCI-IDD Average	69%	31%	15649
NH	69%	31%	474
OK	69%	31%	360
IN	69%	31%	305
CA	67%	33%	11723
PA ↓	64%	36%	562
GA ↓	60%	40%	392
DC ↓	51%	49%	116

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

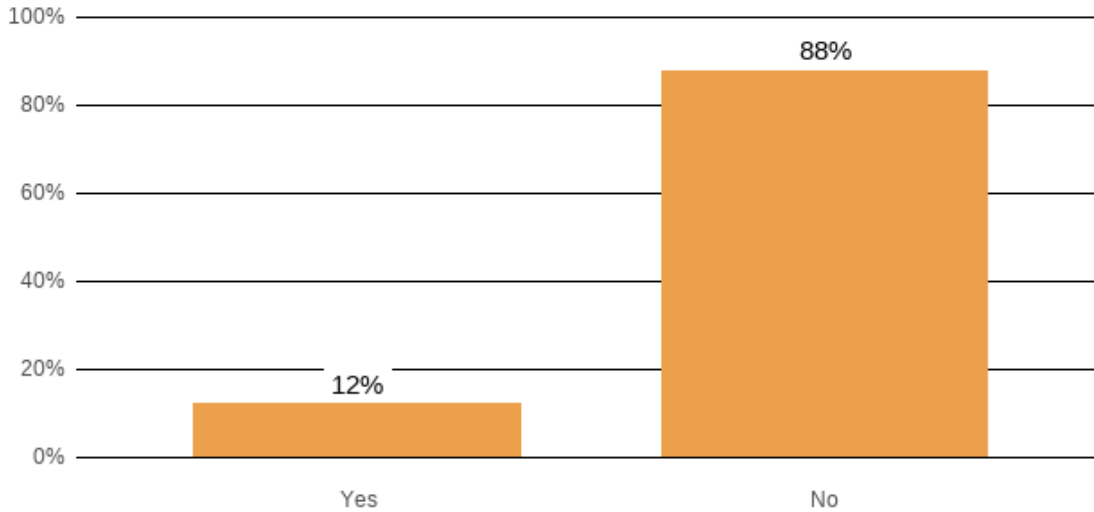


Table 91. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

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

State	Yes	No	N
NH	16%	84%	513
GA	14%	86%	412
MO	13%	87%	239
VA	13%	87%	196
PA	13%	87%	605
MD	13%	87%	536
MT	13%	87%	196
CA	12%	88%	12350
Weighted NCI-IDD Average	12%	88%	16464
IN	11%	89%	324
NJ	10%	90%	403
OK	9%	91%	374
AZ	9%	91%	198
DC	8%	92%	118

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?

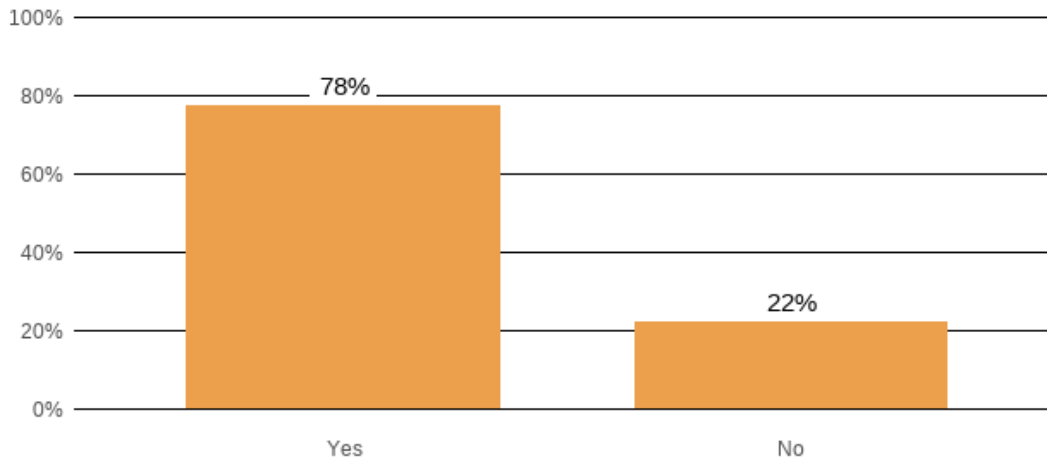


Table 92. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?

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

State	Yes	No	N
MT	92%	8%	24
MD	83%	17%	63
VA	82%	18%	22
Weighted NCI-IDD Average	78%	22%	1756
NJ	78%	23%	40
CA	77%	23%	1292
PA	77%	23%	74
IN	74%	26%	31
NH	74%	26%	73
GA	74%	26%	53
MO	72%	28%	29
OK	60%	40%	30
AZ	n/a	n/a	n/a
DC	n/a	n/a	n/a

Table note: The following states had an N of less than 20 and were not shown: AZ, DC

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

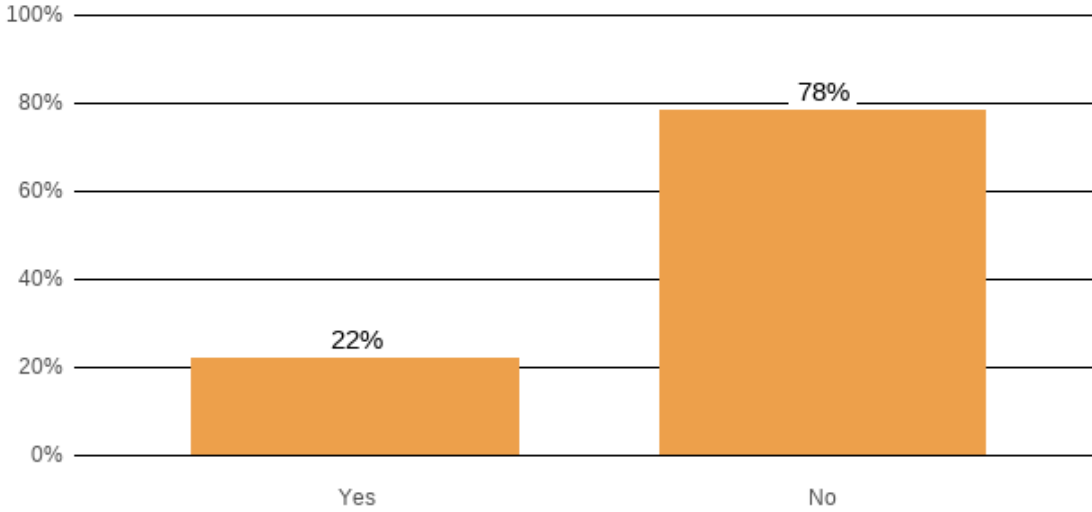


Table 93. Have the services or supports that your family member received been increased in the past 12 months?

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

State	Yes	No	N
MD ↑	34%	66%	511
MO	26%	74%	229
NJ	25%	75%	379
DC	24%	76%	111
PA	23%	77%	575
CA	22%	78%	12149
Weighted NCI-IDD Average	22%	78%	16050
OK	21%	79%	339
IN	21%	79%	302
MT	20%	80%	177
NH	18%	82%	501
AZ	17%	83%	194
GA ↓	17%	83%	399
VA ↓	15%	85%	184

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

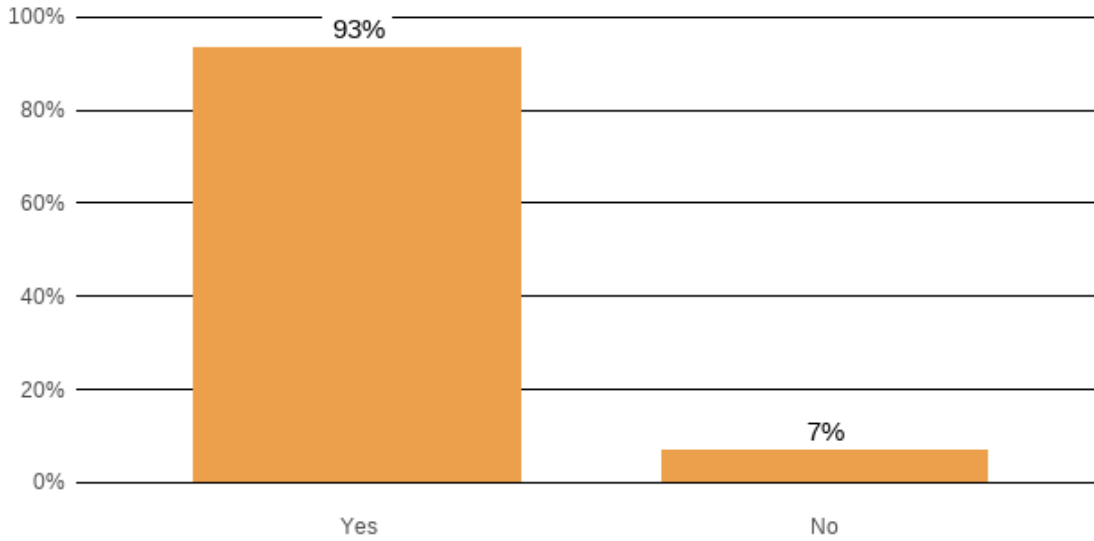


Table 94. Are services and supports helping your family member to live a good life?

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

State	Yes	No	N
MT ↑	97%	3%	196
PA ↑	96%	4%	590
DC	97%	3%	125
AZ	96%	4%	193
MO	95%	5%	240
VA	95%	5%	194
IN	95%	5%	322
OK	95%	5%	358
GA	94%	6%	398
Weighted NCI-IDD Average	93%	7%	16043
MD	93%	7%	501
NH	92%	8%	504
NJ	92%	8%	397
CA	92%	8%	12025

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/>.

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 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	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 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 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 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 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 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 2023-24, 13 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.

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.

Adult Family Survey: State Response Rates

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	13217	1400	212	15%	6.2%	92%	8%
CA	100465	84000	14131	17%	0.8%	83%	17%
DC	600	600	141	24%	7.6%	74%	26%
GA	7588	1700	475	28%	4.1%	100%	0%
IN	15024	1500	363	24%	4.7%	70%	30%
MD	10768	8810	628	7%	3.6%	3%	97%
MO	4090	1500	264	18%	5.5%	88%	13%
MT	785	785	211	27%	6.2%	91%	9%
NH	2344	2344	554	24%	3.8%	100%	0%
NJ	13293	13293	464	3%	4.2%	0%	100%
OK	2615	2000	406	20%	4.5%	100%	0%
PA	20161	2000	662	33%	3.5%	87%	13%
VA	13669	1152	213	18%	6.2%	100%	0%
Total	204619	121084	18724	15%	0.7%	80%	20%