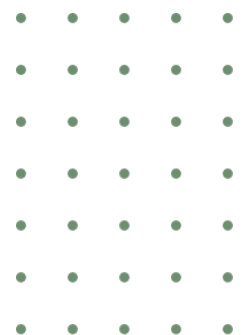


# National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)



## National Report 2024-25

### Adult Family Survey (AFS)





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## List of Acronyms Used in This Report

AFS Adult Family Survey

CMS Centers for Medicare & Medicaid Services

HSRI Human Services Research Institute

IDD Intellectual and developmental disabilities

NASDDDS National Association of State Directors of Developmental Disabilities Services

NCI National Core Indicators

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## Executive Summary

The National Core Indicators®-Intellectual and Developmental Disabilities (NCI-IDD) are standard measures used across states to assess the outcomes of services provided to individuals with intellectual/developmental disabilities and their families. Indicators address key areas of concern such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that results 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 2024-25 data collection cycle, 10 states submitted a valid sample of Adult Family Survey data: Arizona, Delaware, District of Columbia, Kentucky, Maryland, Minnesota, Missouri, New Jersey, Oklahoma, Pennsylvania. This State Report provides results based on data submitted by June 30, 2025.

### **What is the NCI-IDD Adult Family Survey?**

The NCI-IDD Adult Family Survey is used to gather data on family outcomes. It is mailed to families or guardians who have an adult family member who lives with the respondent and receives at least one service in addition to case management from the state DD agency. The survey collects demographic information on both the individual receiving services (family member) as well as the person who fills out the survey (the 'respondent') and information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

Please note that while the term “case manager” is used throughout this report, the same role may also be referred to as “service coordinator” or “supports coordinator” depending on the state.

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

### **What is included in this report?**

This report includes this state’s Adult Family Survey data compared to the NCI-IDD Average. State outcomes that are significantly higher or lower than the NCI-IDD Average are indicated with an arrow:

- Outcomes where the state is significantly above the NCI-IDD average are denoted with an up arrow ↑;
- Outcomes where the state is significantly below the NCI-IDD average are denoted with a down arrow ↓.

Significance is based on “Always” or “Yes” response.

**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.

The tables in this document, grouped by subdomain, display the state results alongside the average across states (NCI-IDD average). **Please note: the NCI-IDD averages shown throughout this report are weighted.** For more information see the [Methodology section](#).

“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 Adult Family Survey Response Rates [here](#).

To find out more about the development of the Adult Family Survey, data analysis and state samples, check out the [National Adult Family Survey Report](#).

## Results

This section provides state and NCI-IDD results for demographic and survey outcomes data.

## Presentation of the Data

- In addition to basic demographic questions and questions on services received, the survey contains seven groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, workforce, choice and control, community connections, health, welfare, and safety, and satisfaction.
- 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 have their data suppressed to only display “n/a”; however, their data **are** included in the NCI-IDD Average.
- **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 or conservator) 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.

## 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	16%	84%	220
DE	9%	91%	179
DC	15%	85%	153
KY	17%	83%	220
MD	12%	88%	498
MN	18%	82%	434
MO	12%	88%	229
NJ	11%	89%	490
OK	10%	90%	400
PA	13%	87%	259
<b>Weighted NCI-IDD Average</b>	<b>14%</b>	<b>86%</b>	<b>3082</b>

**Table 2. Family Member's Residential Designation**

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

State	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
AZ	83%	17%	208
DE	61%	39%	168
DC	99%	1%	148
KY	48%	52%	218
MD	73%	27%	498
MN	71%	29%	424
MO	61%	39%	231
NJ	75%	25%	480
OK	65%	35%	396
PA	54%	46%	258
<b>Weighted NCI-IDD Average</b>	<b>67%</b>	<b>33%</b>	<b>3029</b>

**Table 3. Family Member's Age**

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

State	Age	N
AZ	33.1	227
DC	38.2	157
DE	35.5	180
KY	36.7	215
MD	32.1	528
MN	31.4	444
MO	33.4	239
NJ	35.2	504
OK	37	409
PA	34.5	274
<b>Weighted NCI-IDD Average</b>	<b>34</b>	<b>3,177</b>

**Table 4. Family Member's Gender**

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

State	Male	Female	Other	N
AZ	60%	40%	0%	205
DE	62%	38%	1%	167
DC	64%	36%	0%	155
KY	58%	42%	0%	218
MD	66%	34%	0%	464
MN	60%	40%	0%	400
MO	60%	40%	0%	232
NJ	65%	35%	0%	463
OK	54%	46%	0%	404
PA	66%	34%	0%	256
<b>Weighted NCI-IDD Average</b>	<b>62%</b>	<b>37%</b>	<b>0%</b>	<b>2964</b>

**Table 5. Family Member's Race/Ethnicity**

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

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer Not to Say
<b>AZ</b>	4%	6%	4%	0%	64%	28%	2%	4%
<b>DE</b>	1%	5%	18%	1%	73%	3%	2%	2%
<b>DC</b>	1%	3%	83%	0%	10%	5%	1%	2%
<b>KY</b>	1%	0%	11%	0%	89%	1%	1%	0%
<b>MD</b>	1%	8%	25%	0%	58%	5%	1%	7%
<b>MN</b>	3%	6%	7%	0%	81%	5%	1%	2%
<b>MO</b>	2%	3%	7%	0%	84%	4%	0%	3%
<b>NJ</b>	1%	7%	9%	0%	76%	7%	2%	2%
<b>OK</b>	17%	2%	11%	0%	72%	6%	2%	1%
<b>PA</b>	1%	2%	9%	0%	82%	6%	1%	2%
<b>Weighted NCI-IDD Average</b>	<b>2%</b>	<b>5%</b>	<b>11%</b>	<b>0%</b>	<b>74%</b>	<b>9%</b>	<b>1%</b>	<b>3%</b>

**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/Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy
AZ	66%	24%	45%	23%
DE	68%	21%	40%	7%
DC	73%	14%	34%	15%
KY	75%	33%	38%	18%
MD	68%	24%	52%	16%
MN	73%	30%	43%	15%
MO	72%	24%	40%	21%
NJ	65%	21%	48%	14%
OK	78%	23%	33%	23%
PA	83%	26%	42%	11%
<b>Weighted NCI-IDD Average</b>	<b>73%</b>	<b>25%</b>	<b>44%</b>	<b>16%</b>

**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 – Legally Blind	Hearing Loss – Severe or Profound	Brain Injury	Seizure or Neurological Disorder	Chemical Dependency
AZ	12%	6%	8%	31%	0%
DE	7%	4%	2%	18%	0%
DC	8%	4%	2%	17%	0%
KY	13%	7%	8%	33%	1%
MD	7%	5%	7%	24%	0%
MN	11%	8%	9%	24%	1%
MO	13%	8%	14%	35%	0%
NJ	8%	4%	6%	25%	0%
OK	9%	10%	13%	32%	1%
PA	8%	5%	5%	22%	0%
<b>Weighted NCI-IDD Average</b>	<b>10%</b>	<b>6%</b>	<b>7%</b>	<b>26%</b>	<b>0%</b>

**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%	14%	0%	0%	17%
DE	0%	17%	1%	1%	16%
DC	0%	12%	1%	3%	17%
KY	1%	16%	1%	1%	23%
MD	0%	13%	0%	1%	27%
MN	1%	18%	0%	3%	20%
MO	0%	13%	0%	0%	19%
NJ	0%	16%	1%	1%	15%
OK	1%	19%	0%	1%	17%
PA	0%	12%	0%	0%	17%
<b>Weighted NCI-IDD Average</b>	<b>0%</b>	<b>14%</b>	<b>0%</b>	<b>1%</b>	<b>19%</b>

**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	13%	16%	5%	20%	23%
DE	5%	14%	4%	30%	30%
DC	1%	22%	2%	44%	26%
KY	11%	17%	6%	27%	28%
MD	12%	16%	3%	19%	29%
MN	13%	17%	3%	19%	21%
MO	8%	17%	4%	26%	20%
NJ	12%	16%	3%	20%	32%
OK	12%	15%	2%	29%	24%
PA	9%	20%	5%	27%	28%
<b>Weighted NCI-IDD Average</b>	<b>11%</b>	<b>17%</b>	<b>4%</b>	<b>23%</b>	<b>27%</b>

**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	Oral Health or Dental Problems	Alzheimer's Disease or Dementia	Sleep Apnea
<b>AZ</b>	9%	1%	11%	3%	18%
<b>DE</b>	2%	1%	8%	4%	32%
<b>DC</b>	4%	1%	2%	1%	13%
<b>KY</b>	12%	3%	13%	3%	20%
<b>MD</b>	9%	4%	12%	3%	17%
<b>MN</b>	10%	3%	15%	2%	26%
<b>MO</b>	13%	0%	13%	4%	20%
<b>NJ</b>	8%	1%	8%	1%	12%
<b>OK</b>	14%	3%	17%	1%	21%
<b>PA</b>	7%	2%	12%	0%	24%
<b>Weighted NCI-IDD Average</b>	<b>9%</b>	<b>2%</b>	<b>12%</b>	<b>2%</b>	<b>20%</b>

**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
<b>AZ</b>	23%	9%	4%	1%	29%
<b>DE</b>	20%	3%	2%	0%	23%
<b>DC</b>	23%	3%	5%	0%	19%
<b>KY</b>	19%	8%	7%	1%	28%
<b>MD</b>	14%	2%	3%	1%	33%
<b>MN</b>	21%	6%	5%	1%	33%
<b>MO</b>	18%	3%	3%	2%	28%
<b>NJ</b>	13%	4%	3%	2%	36%
<b>OK</b>	16%	5%	4%	1%	19%
<b>PA</b>	13%	3%	3%	1%	26%
<b>Weighted NCI-IDD Average</b>	<b>17%</b>	<b>5%</b>	<b>4%</b>	<b>1%</b>	<b>30%</b>

**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	77%	12%	0%	4%	7%	209
DE	93%	5%	0%	1%	1%	173
DC	82%	8%	3%	3%	4%	154
KY	79%	12%	3%	1%	4%	221
MD	76%	15%	1%	3%	5%	519
MN	84%	10%	1%	2%	3%	425
MO	77%	17%	1%	3%	2%	223
NJ	78%	9%	0%	4%	9%	500
OK	76%	16%	3%	1%	4%	404
PA	83%	6%	2%	3%	5%	269
<b>Weighted NCI-IDD Average</b>	<b>80%</b>	<b>11%</b>	<b>1%</b>	<b>3%</b>	<b>5%</b>	<b>3097</b>

**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
<b>AZ</b>	90%	5%	0%	0%	0%	1%	4%	219
<b>DE</b>	99%	0%	0%	0%	0%	0%	1%	174
<b>DC</b>	94%	1%	0%	0%	0%	3%	2%	155
<b>KY</b>	97%	0%	0%	0%	0%	1%	1%	222
<b>MD</b>	97%	1%	0%	0%	0%	0%	2%	520
<b>MN</b>	94%	1%	0%	0%	0%	1%	4%	431
<b>MO</b>	98%	0%	0%	0%	0%	1%	1%	231
<b>NJ</b>	95%	2%	0%	0%	0%	0%	3%	497
<b>OK</b>	95%	2%	0%	0%	0%	2%	0%	406
<b>PA</b>	97%	0%	0%	0%	0%	1%	1%	265
<b>Weighted NCI-IDD Average</b>	<b>95%</b>	<b>1%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>1%</b>	<b>2%</b>	<b>3120</b>

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 or Conservatorship	Limited Guardianship or Conservatorship	Full Guardianship or Conservatorship	Has Guardianship or Conservatorship but Level is Unknown	N
AZ	20%	10%	67%	3%	220
DE	45%	10%	42%	2%	168
DC	39%	14%	38%	9%	145
KY	18%	8%	71%	2%	213
MD	50%	9%	37%	3%	489
MN	12%	5%	81%	1%	433
MO	13%	7%	77%	3%	232
NJ	19%	9%	71%	1%	495
OK	20%	8%	70%	3%	395
PA	53%	12%	33%	2%	251
<b>Weighted NCI-IDD Average</b>	<b>31%</b>	<b>9%</b>	<b>58%</b>	<b>2%</b>	<b>3041</b>

**Table 11. Guardian or Conservator Relationship to Family Member**

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

State	Family	Friend	Employee of State or Guardianship or Conservatorship Agency	Other	N
AZ	98%	0%	0%	2%	165
DE	94%	0%	0%	6%	85
DC	89%	1%	4%	6%	83
KY	91%	5%	1%	3%	172
MD	97%	0%	0%	2%	235
MN	98%	0%	0%	2%	368
MO	97%	0%	1%	3%	198
NJ	97%	0%	0%	3%	400
OK	96%	1%	0%	3%	299
PA	93%	0%	0%	7%	109
<b>Weighted NCI-IDD Average</b>	<b>96%</b>	<b>0%</b>	<b>0%</b>	<b>3%</b>	<b>2114</b>

**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	14%	4%	29%	218
DE	9%	0%	54%	174
DC	22%	3%	41%	155
KY	14%	3%	51%	221
MD	9%	1%	54%	512
MN	7%	4%	32%	431
MO	11%	2%	28%	232
NJ	15%	0%	25%	485
OK	11%	0%	26%	398
PA	9%	1%	19%	261
<b>Weighted NCI-IDD Average</b>	<b>11%</b>	<b>2%</b>	<b>32%</b>	<b>3087</b>

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

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

State	High School Diploma/GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
AZ	44%	1%	2%	4%	218
DE	26%	4%	2%	5%	174
DC	25%	6%	3%	1%	155
KY	22%	1%	5%	4%	221
MD	19%	3%	7%	8%	512
MN	46%	3%	3%	3%	431
MO	49%	1%	5%	4%	232
NJ	41%	5%	6%	9%	485
OK	57%	2%	1%	3%	398
PA	62%	3%	2%	3%	261
<b>Weighted NCI-IDD Average</b>	<b>43%</b>	<b>3%</b>	<b>4%</b>	<b>5%</b>	<b>3087</b>

**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	52%	33%	16%	219
DE	74%	24%	2%	169
DC	63%	26%	10%	153
KY	55%	33%	12%	215
MD	51%	27%	22%	503
MN	39%	38%	23%	434
MO	57%	34%	9%	230
NJ	48%	33%	19%	492
OK	58%	27%	14%	401
PA	56%	31%	13%	264
<b>Weighted NCI-IDD Average</b>	<b>52%</b>	<b>32%</b>	<b>16%</b>	<b>3080</b>

**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; Frequent or Severe Enough to Require Regular Assistance	N
AZ	13%	42%	45%	223
DE	42%	41%	17%	170
DC	35%	39%	26%	153
KY	17%	37%	46%	218
MD	21%	35%	43%	514
MN	15%	41%	44%	435
MO	22%	37%	41%	234
NJ	15%	36%	49%	498
OK	23%	37%	40%	403
PA	27%	42%	32%	269
<b>Weighted NCI-IDD Average</b>	<b>20%</b>	<b>39%</b>	<b>41%</b>	<b>3117</b>

**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; Frequent or Severe Enough to Require Regular Assistance	N
AZ	3%	14%	83%	222
DE	6%	24%	70%	175
DC	5%	30%	65%	153
KY	4%	19%	76%	217
MD	3%	17%	80%	519
MN	3%	13%	84%	438
MO	2%	17%	81%	233
NJ	4%	16%	80%	500
OK	3%	18%	79%	399
PA	4%	23%	73%	267
<b>Weighted NCI-IDD Average</b>	<b>4%</b>	<b>18%</b>	<b>79%</b>	<b>3123</b>

## **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	89%	10%	0%	0%	0%	0%	1%	221
DE	98%	1%	0%	0%	0%	0%	1%	172
DC	97%	2%	0%	0%	0%	0%	1%	152
KY	100%	0%	0%	0%	0%	0%	0%	218
MD	95%	1%	0%	0%	0%	0%	3%	494
MN	93%	2%	0%	0%	0%	0%	4%	436
MO	100%	0%	0%	0%	0%	0%	0%	235
NJ	95%	3%	0%	0%	0%	0%	2%	484
OK	97%	2%	0%	0%	0%	0%	0%	407
PA	97%	2%	0%	0%	0%	0%	2%	264
<b>Weighted NCI-IDD Average</b>	<b>95%</b>	<b>3%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>2%</b>	<b>3083</b>

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	5%	24%	57%	14%	222
DE	4%	14%	67%	15%	176
DC	5%	20%	57%	18%	154
KY	2%	24%	59%	15%	220
MD	2%	20%	70%	8%	513
MN	5%	23%	63%	8%	438
MO	4%	18%	70%	8%	238
NJ	2%	8%	75%	14%	497
OK	2%	17%	62%	19%	406
PA	5%	14%	67%	13%	267
<b>Weighted NCI-IDD Average</b>	<b>4%</b>	<b>18%</b>	<b>66%</b>	<b>12%</b>	<b>3131</b>

Table 18. Respondent's Health

State	Excellent	Very Good	Good	Fair	Poor	N
AZ	12%	37%	38%	12%	2%	224
DE	9%	39%	40%	12%	1%	177
DC	16%	34%	34%	16%	0%	154
KY	10%	41%	33%	12%	4%	220
MD	15%	35%	37%	13%	1%	514
MN	12%	44%	35%	7%	1%	439
MO	9%	43%	33%	13%	2%	237
NJ	13%	36%	36%	13%	2%	499
OK	13%	30%	45%	13%	1%	406
PA	12%	35%	40%	12%	1%	270
<b>Weighted NCI-IDD Average</b>	<b>12%</b>	<b>37%</b>	<b>37%</b>	<b>12%</b>	<b>2%</b>	<b>3140</b>

**Table 19. Respondent's Relationship to Family Member**

State	Parent (Biological, Adoptive, or Foster)	Sibling	Spouse	Grandparent	Other	N
AZ	84%	7%	0%	4%	4%	224
DE	87%	4%	1%	4%	5%	174
DC	69%	10%	2%	6%	13%	154
KY	80%	4%	0%	5%	11%	221
MD	91%	5%	0%	1%	2%	515
MN	91%	4%	0%	2%	3%	439
MO	87%	7%	0%	3%	3%	239
NJ	94%	4%	0%	0%	2%	498
OK	83%	6%	0%	6%	5%	407
PA	91%	6%	0%	1%	1%	269
<b>Weighted NCI-IDD Average</b>	<b>89%</b>	<b>5%</b>	<b>0%</b>	<b>2%</b>	<b>3%</b>	<b>3140</b>

**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	39%	48%	21%
DE	91%	6%	3%
DC	66%	28%	9%
KY	41%	41%	22%
MD	54%	36%	18%
MN	29%	60%	28%
MO	76%	13%	13%
NJ	37%	38%	30%
OK	41%	46%	14%
PA	64%	28%	12%
<b>Weighted NCI-IDD Average</b>	<b>49%</b>	<b>38%</b>	<b>20%</b>

*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	10%	28%	42%	20%	221
DE	7%	18%	51%	23%	175
DC	27%	35%	27%	11%	153
KY	4%	30%	47%	19%	219
MD	6%	22%	45%	27%	510
MN	7%	25%	42%	26%	431
MO	5%	32%	47%	16%	239
NJ	7%	20%	53%	20%	491
OK	7%	35%	48%	11%	402
PA	6%	27%	46%	21%	266
<b>Weighted NCI-IDD Average</b>	<b>7%</b>	<b>26%</b>	<b>46%</b>	<b>21%</b>	<b>3107</b>

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

State	One	Two	Three	Four or More	None	N
AZ	9%	4%	2%	1%	84%	226
DE	3%	3%	0%	0%	94%	174
DC	10%	5%	1%	1%	84%	155
KY	8%	2%	0%	0%	89%	221
MD	7%	2%	1%	1%	89%	512
MN	9%	4%	1%	0%	85%	438
MO	7%	1%	0%	1%	90%	239
NJ	3%	1%	0%	0%	96%	497
OK	5%	2%	1%	0%	92%	406
PA	4%	2%	1%	0%	93%	270
<b>Weighted NCI-IDD Average</b>	<b>6%</b>	<b>2%</b>	<b>1%</b>	<b>0%</b>	<b>90%</b>	<b>3138</b>

**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
<b>AZ</b>	8%	15%	6%	24%	46%	217
<b>DE</b>	4%	23%	4%	17%	51%	171
<b>DC</b>	8%	36%	5%	17%	34%	152
<b>KY</b>	8%	27%	5%	17%	42%	219
<b>MD</b>	2%	11%	3%	18%	66%	505
<b>MN</b>	3%	17%	12%	16%	52%	429
<b>MO</b>	2%	23%	4%	19%	52%	226
<b>NJ</b>	2%	15%	4%	18%	61%	486
<b>OK</b>	4%	29%	6%	24%	37%	405
<b>PA</b>	5%	33%	6%	17%	40%	263
<b>Weighted NCI-IDD Average</b>	<b>4%</b>	<b>21%</b>	<b>6%</b>	<b>19%</b>	<b>50%</b>	<b>3073</b>

**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 or conservator/administrator, or if they represent a financial institution or guardianship or conservatorship agency. Does not include state/federal benefits such as SSI, SSDI etc.*

State	No Earned Income	Up to \$15,000	\$15,001 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	Prefer Not to Say	N
<b>AZ</b>	9%	5%	7%	17%	14%	20%	27%	216
<b>DE</b>	13%	4%	5%	11%	15%	29%	23%	173
<b>DC</b>	10%	8%	8%	22%	5%	16%	31%	154
<b>KY</b>	13%	5%	5%	16%	21%	18%	21%	219
<b>MD</b>	5%	1%	5%	9%	13%	37%	30%	504
<b>MN</b>	5%	4%	4%	17%	18%	31%	21%	429
<b>MO</b>	9%	6%	6%	19%	14%	29%	18%	234
<b>NJ</b>	5%	3%	6%	9%	14%	39%	25%	490
<b>OK</b>	9%	11%	12%	18%	12%	16%	22%	396
<b>PA</b>	10%	6%	5%	19%	10%	23%	28%	263
<b>Weighted NCI-IDD Average</b>	<b>8%</b>	<b>4%</b>	<b>6%</b>	<b>15%</b>	<b>14%</b>	<b>27%</b>	<b>25%</b>	<b>3078</b>

## Services and Supports Received

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

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

**Table 25a. Services and Supports Received from ID/DD Agency**

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

State	Financial Support	In Home Support	Out-of-Home Respite Care	Day or Employment Supports
<b>AZ</b>	15%	42%	38%	50%
<b>DE</b>	10%	9%	24%	82%
<b>DC</b>	9%	64%	29%	48%
<b>KY</b>	13%	30%	30%	43%
<b>MD</b>	15%	50%	27%	55%
<b>MN</b>	34%	56%	23%	53%
<b>MO</b>	18%	38%	17%	62%
<b>NJ</b>	27%	39%	21%	59%
<b>OK</b>	15%	56%	8%	34%
<b>PA</b>	16%	45%	24%	50%
<b>Weighted NCI-IDD Average</b>	<b>19%</b>	<b>44%</b>	<b>26%</b>	<b>52%</b>

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

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

State	Transportation	Mental/Behavioral Health Care or Other Treatments or Therapies	Self-direction/Fiscal Intermediary Services
AZ	59%	48%	31%
DE	80%	21%	29%
DC	66%	43%	19%
KY	51%	41%	51%
MD	67%	33%	49%
MN	66%	31%	63%
MO	55%	32%	48%
NJ	63%	35%	63%
OK	50%	29%	39%
PA	54%	34%	39%
<b>Weighted NCI-IDD Average</b>	<b>59%</b>	<b>36%</b>	<b>47%</b>

**Table 26. Additional Services and Supports Received (not from the ID/DD Agency)**

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

State	Social Security SSI/SSB	Services or Supports from Other Agencies or Organizations
AZ	91%	28%
DE	91%	43%
DC	84%	29%
KY	94%	30%
MD	92%	28%
MN	92%	32%
MO	97%	37%
NJ	94%	25%
OK	98%	19%
PA	92%	43%
<b>Weighted NCI-IDD Average</b>	<b>93%</b>	<b>32%</b>

## Main Survey Results

## Information and Planning

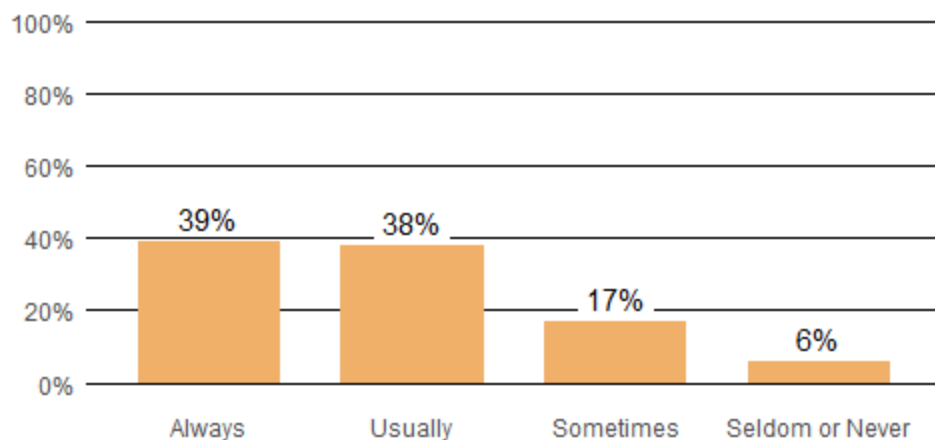
Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state developmental disabilities system.

**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.

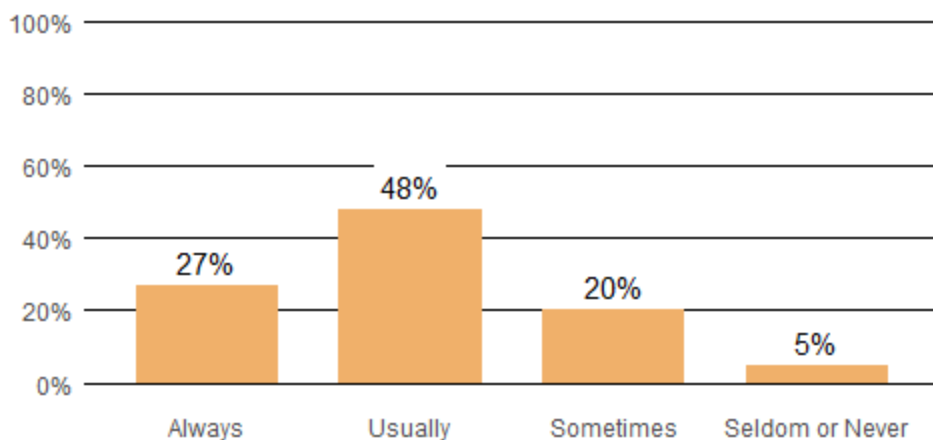
**Do you get enough information to take part in planning services for your family member?**



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

State	Always	Usually	Sometimes	Seldom or Never	N
DC	47%	33%	16%	4%	147
AZ	47%	36%	12%	6%	218
KY	44%	40%	10%	7%	210
OK	42%	36%	15%	7%	376
MO	41%	34%	16%	8%	227
<b>Weighted NCI-IDD Average</b>	<b>39%</b>	<b>38%</b>	<b>17%</b>	<b>6%</b>	<b>3017</b>
PA	38%	37%	21%	4%	254
NJ	35%	40%	18%	6%	487
MN	35%	45%	16%	4%	426
MD	33%	38%	20%	8%	504
DE	30%	36%	27%	8%	168

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

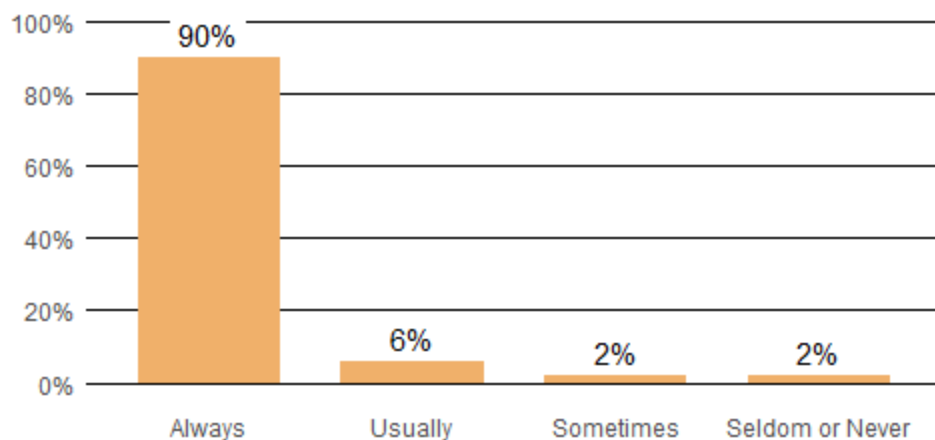


**Table 28. Is the information you get about services and supports easy to understand?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>DC</b> ↑	39%	42%	15%	3%	150
<b>AZ</b> ↑	39%	44%	13%	4%	219
<b>MO</b>	30%	47%	19%	4%	218
<b>DE</b>	28%	40%	24%	8%	170
<b>KY</b>	28%	56%	13%	2%	202
<b>OK</b>	27%	48%	19%	5%	376
<b>Weighted NCI-IDD Average</b>	<b>27%</b>	<b>48%</b>	<b>20%</b>	<b>5%</b>	<b>3022</b>
<b>NJ</b>	24%	48%	22%	6%	491
<b>MD</b>	24%	42%	24%	10%	507
<b>PA</b>	23%	52%	22%	3%	258
<b>MN</b> ↓	21%	48%	25%	5%	431

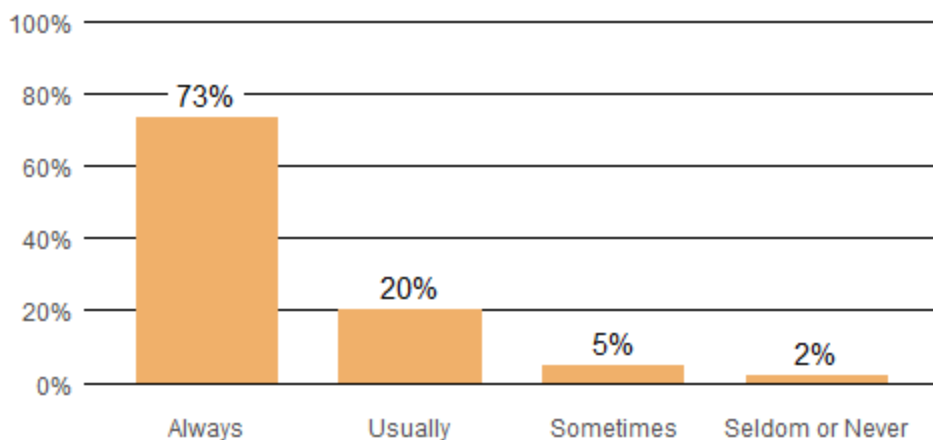
**Do you get information about services and supports  
in your preferred language?**



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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	93%	7%	1%	0%	261
KY	92%	3%	1%	3%	213
MO	92%	4%	0%	3%	229
<b>Weighted NCI-IDD Average</b>	<b>90%</b>	<b>6%</b>	<b>2%</b>	<b>2%</b>	<b>3070</b>
NJ	90%	6%	2%	2%	492
DE	90%	5%	4%	1%	174
MD	89%	6%	2%	3%	513
OK	89%	6%	2%	3%	380
MN	89%	6%	2%	3%	437
DC	88%	9%	2%	1%	152
AZ	88%	6%	5%	1%	219

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

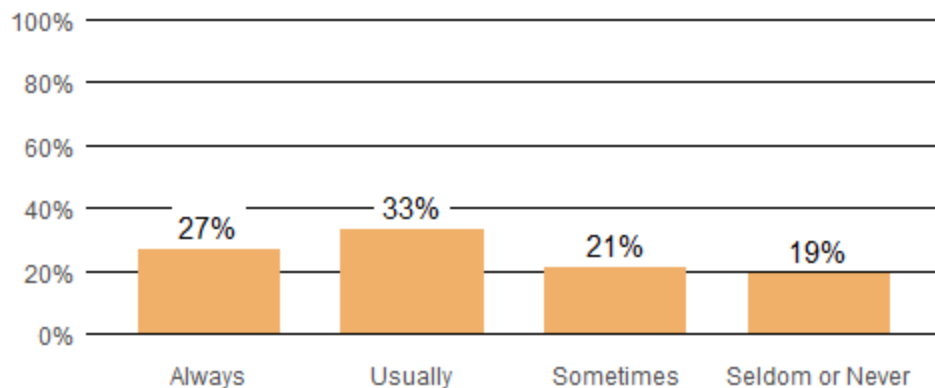


**Table 30. Does the case manager/service coordinator listen to your family's choices and opinions?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>KY</b> ↑	87%	11%	0%	2%	214
<b>NJ</b> ↑	78%	16%	4%	1%	481
<b>AZ</b>	77%	16%	5%	2%	221
<b>Weighted NCI-IDD Average</b>	<b>73%</b>	<b>20%</b>	<b>5%</b>	<b>2%</b>	<b>3026</b>
<b>DC</b>	72%	21%	6%	1%	151
<b>PA</b>	71%	22%	6%	1%	254
<b>MO</b>	70%	22%	5%	2%	223
<b>MD</b> ↓	65%	24%	9%	2%	492
<b>MN</b> ↓	65%	27%	6%	2%	429
<b>OK</b> ↓	64%	26%	8%	3%	384
<b>DE</b> ↓	63%	25%	9%	3%	177

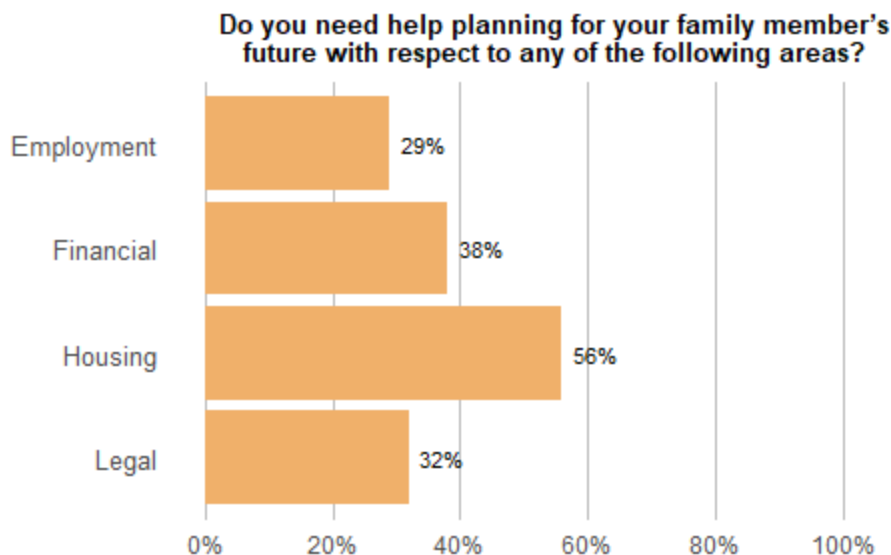
Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc)?



**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

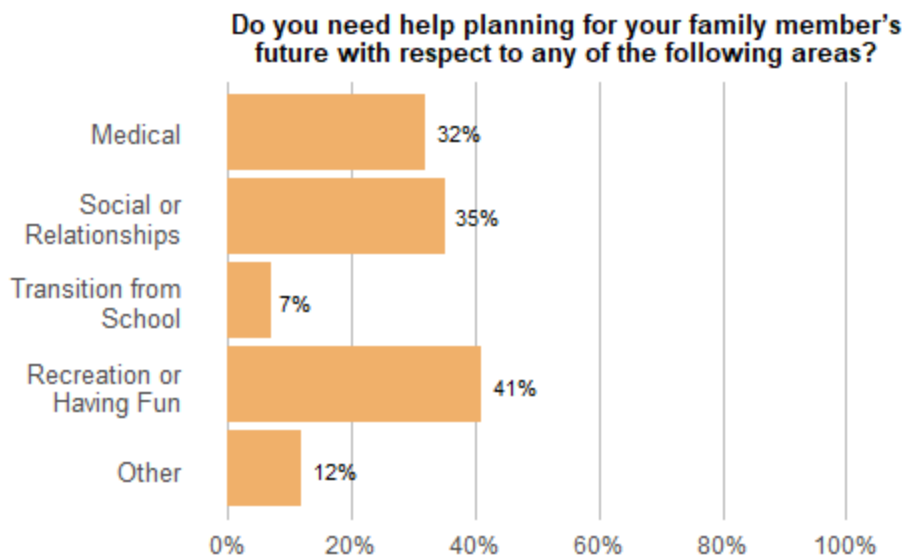
State	Always	Usually	Sometimes	Seldom or Never	N
DC	36%	28%	18%	18%	141
KY	32%	32%	16%	19%	170
AZ	31%	28%	18%	23%	199
MO	29%	38%	17%	16%	191
PA	28%	36%	19%	16%	222
<b>Weighted NCI-IDD Average</b>	<b>27%</b>	<b>33%</b>	<b>21%</b>	<b>19%</b>	<b>2683</b>
OK	26%	35%	17%	21%	334
NJ	26%	34%	24%	16%	445
DE	23%	29%	22%	25%	153
MN	22%	35%	26%	17%	391
MD ↓	22%	32%	22%	24%	437



**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
<b>AZ</b>	30%	34%	47%	33%
<b>DE</b>	31%	33%	57%	36%
<b>DC</b>	28%	26%	46%	24%
<b>KY</b>	18%	31%	43%	22%
<b>MD</b>	35%	46%	63%	38%
<b>MN</b>	40%	34%	55%	24%
<b>MO</b>	13%	32%	54%	28%
<b>NJ</b>	27%	42%	66%	36%
<b>OK</b>	21%	27%	36%	29%
<b>PA</b>	29%	38%	56%	32%
<b>Weighted NCI-IDD Average</b>	<b>29%</b>	<b>38%</b>	<b>56%</b>	<b>32%</b>

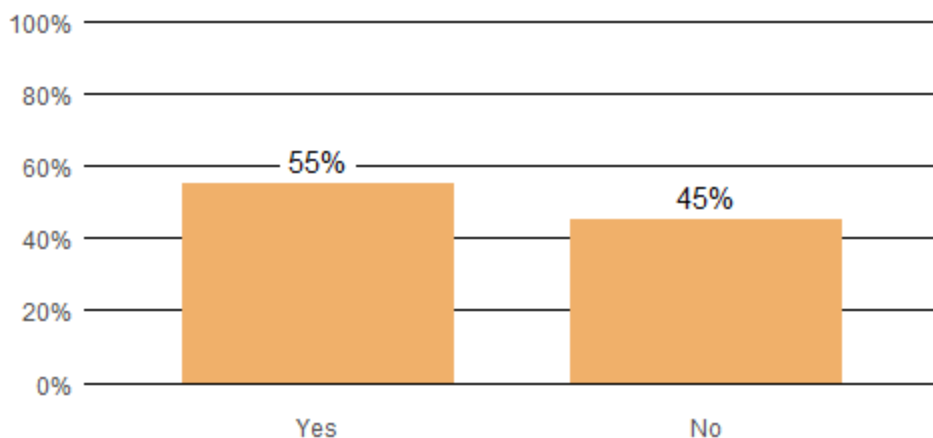


**Table 32b. Do you need help planning for your family member's future in any of the following areas? (continued)**

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

State	Medical	Social or Relationships	Transition from School	Recreation or Having Fun	Other
<b>AZ</b>	34%	33%	10%	43%	11%
<b>DE</b>	21%	33%	1%	42%	14%
<b>DC</b>	27%	31%	3%	32%	15%
<b>KY</b>	29%	33%	7%	37%	13%
<b>MD</b>	37%	41%	6%	40%	12%
<b>MN</b>	25%	32%	14%	35%	17%
<b>MO</b>	29%	25%	3%	34%	11%
<b>NJ</b>	37%	39%	4%	44%	9%
<b>OK</b>	24%	23%	5%	31%	12%
<b>PA</b>	30%	33%	8%	45%	12%
<b>Weighted NCI-IDD Average</b>	<b>32%</b>	<b>35%</b>	<b>7%</b>	<b>41%</b>	<b>12%</b>

### Has your family learned about alternatives to guardianship/conservatorship?



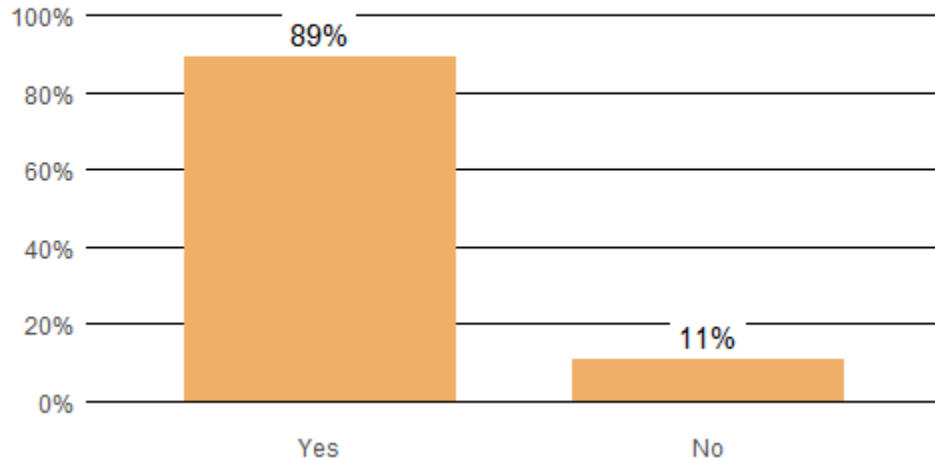
**Table 33. Has your family learned about alternatives to guardianship/conservatorship?**

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

State	Yes	No	N
DC ↑	68%	32%	140
KY ↑	65%	35%	179
AZ	63%	37%	195
MN	59%	41%	368
OK	57%	43%	329
<b>Weighted NCI-IDD Average</b>	<b>55%</b>	<b>45%</b>	<b>2682</b>
MD	53%	47%	460
MO	50%	50%	202
NJ	49%	51%	444
PA	48%	52%	216
DE	48%	52%	149

Alternatives to guardianship/conservatorship 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.

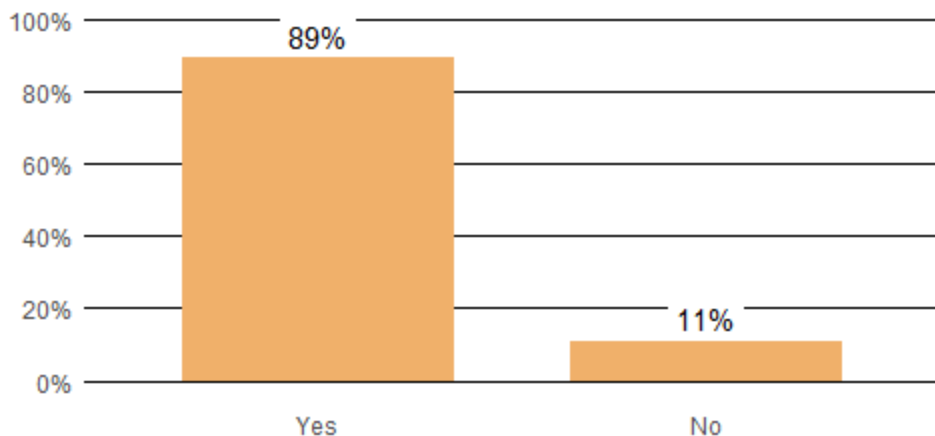
## Does your family member have a service plan?

**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 ↑	96%	4%	258
DC ↑	95%	5%	141
MD ↑	95%	5%	480
OK ↑	93%	7%	356
MO	90%	10%	219
<b>Weighted NCI-IDD Average</b>	<b>89%</b>	<b>11%</b>	<b>2734</b>
NJ	89%	11%	438
MN	86%	14%	350
AZ ↓	77%	23%	180
KY ↓	76%	24%	182
DE ↓	74%	26%	130

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

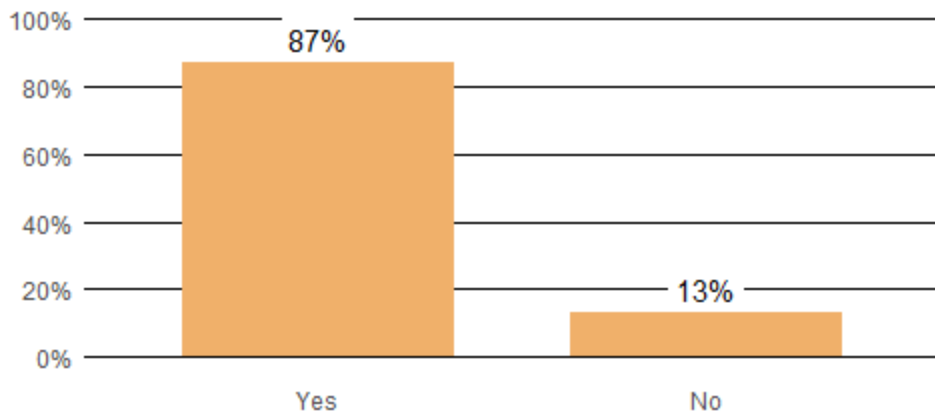


**Table 35. Does the plan include all the services and supports your family member needs?**

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

State	Yes	No	N
DC	94%	6%	121
KY	93%	7%	124
AZ	92%	8%	123
PA	91%	9%	223
MN	91%	9%	269
OK	89%	11%	289
<b>Weighted NCI-IDD Average</b>	<b>89%</b>	<b>11%</b>	<b>2183</b>
DE	89%	11%	87
MO	88%	12%	180
NJ	87%	13%	354
MD ↓	81%	19%	413

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

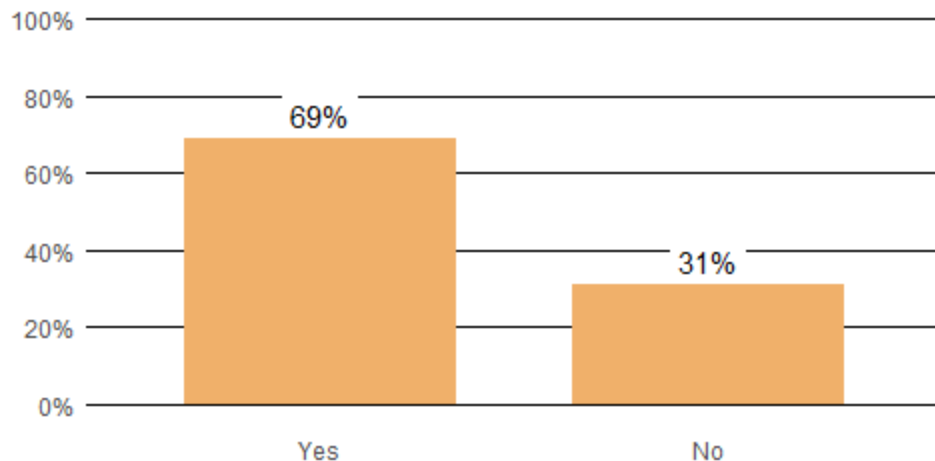


**Table 36. Did you or someone else in your family (besides your family member with a disability) help make the plan?**

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

State	Yes	No	N
MO	91%	9%	192
MD	90%	10%	442
MN	90%	10%	289
<b>Weighted NCI-IDD Average</b>	<b>87%</b>	<b>13%</b>	<b>2330</b>
PA	86%	14%	241
NJ	86%	14%	376
AZ	85%	15%	131
KY	85%	15%	128
OK	82%	18%	317
DE	79%	21%	87
DC ↓	77%	23%	127

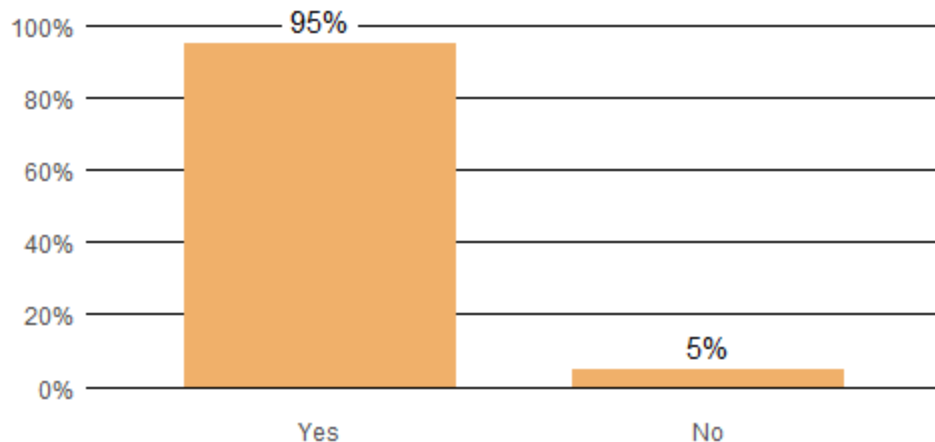
## Did your family member help make the plan?

**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%	443
PA	73%	27%	237
DE	70%	30%	88
MO	69%	31%	190
MN	69%	31%	282
<b>Weighted NCI-IDD Average</b>	<b>69%</b>	<b>31%</b>	<b>2317</b>
DC	66%	34%	128
KY	63%	37%	127
AZ	62%	38%	131
NJ ↓	60%	40%	377
OK ↓	59%	41%	314

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

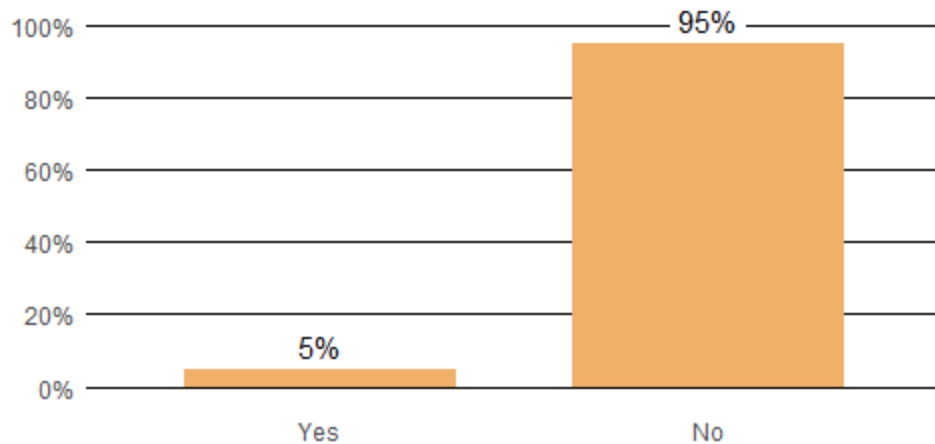


**Table 38. Do you feel like your family had enough say or input in making the plan?**

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

State	Yes	No	N
MO ↑	98%	2%	182
KY	98%	2%	125
PA	97%	3%	230
DE	96%	4%	82
MN	96%	4%	278
NJ	96%	4%	364
<b>Weighted NCI-IDD Average</b>	<b>95%</b>	<b>5%</b>	<b>2239</b>
OK	94%	6%	302
AZ	92%	8%	127
MD	92%	8%	426
DC ↓	86%	14%	123

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

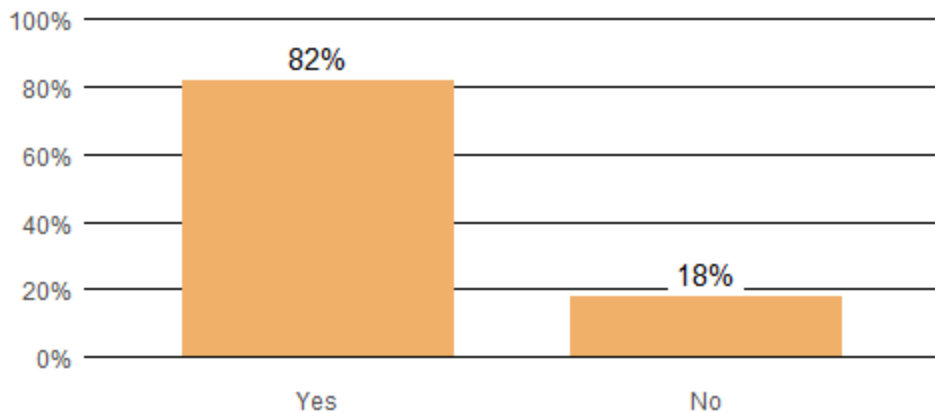


**Table 39. Did your family member leave school services and begin adult services during the past 12 months?**

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

State	Yes	No	N
<b>MN</b> ↑	9%	91%	420
<b>AZ</b>	9%	91%	213
<b>DC</b>	8%	92%	144
<b>DE</b>	6%	94%	165
<b>MD</b>	5%	95%	497
<b>Weighted NCI-IDD Average</b>	<b>5%</b>	<b>95%</b>	<b>2993</b>
<b>PA</b>	4%	96%	258
<b>OK</b>	4%	96%	390
<b>KY</b>	2%	98%	208
<b>NJ</b> ↓	1%	99%	471
<b>MO</b> ↓	1%	99%	227

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

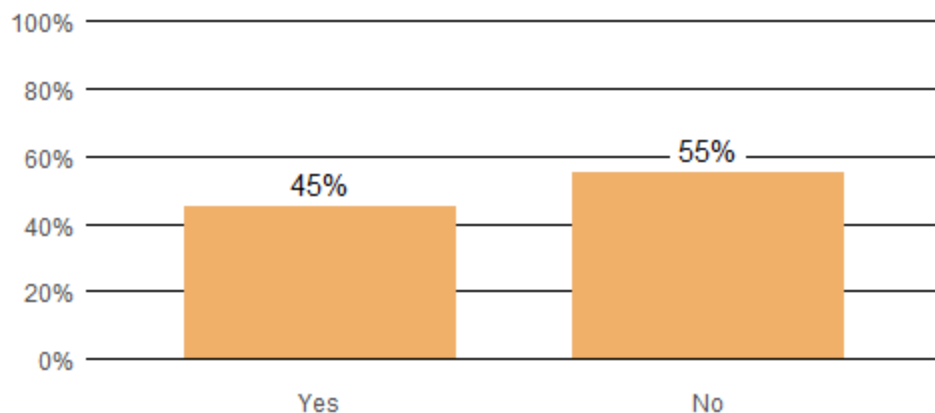


**Table 40. If your family member left school services during the past 12 months, did they have a transition plan?**

State	Yes	No	N
MD	85%	15%	27
<b>Weighted NCI-IDD Average</b>	<b>82%</b>	<b>18%</b>	<b>119</b>
MN	81%	19%	31
AZ	n/a	n/a	n/a
DE	n/a	n/a	n/a
DC	n/a	n/a	n/a
KY	n/a	n/a	n/a
MO	n/a	n/a	n/a
NJ	n/a	n/a	n/a
OK	n/a	n/a	n/a
PA	n/a	n/a	n/a

Table note: The following states had an N of less than 20 so their data is reported as n/a: AZ, DE, DC, KY, MO, NJ, OK, PA. They are included in the Weighted NCI-IDD Average.

**If your family member had a transition plan, did the transition 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?**

State	Yes	No	N
<b>MN</b>	48%	52%	21
<b>Weighted NCI-IDD Average</b>	<b>45%</b>	<b>55%</b>	<b>85</b>
<b>AZ</b>	n/a	n/a	n/a
<b>DE</b>	n/a	n/a	n/a
<b>DC</b>	n/a	n/a	n/a
<b>KY</b>	n/a	n/a	n/a
<b>MD</b>	n/a	n/a	n/a
<b>MO</b>	n/a	n/a	n/a
<b>NJ</b>	n/a	n/a	n/a
<b>OK</b>	n/a	n/a	n/a
<b>PA</b>	n/a	n/a	n/a

*Table note: The following states had an N of less than 20 so their data is reported as n/a: AZ, DE, DC, KY, MD, MO, NJ, OK, PA. They are included in the Weighted NCI-IDD Average.*

## Access and Delivery of Services and Supports

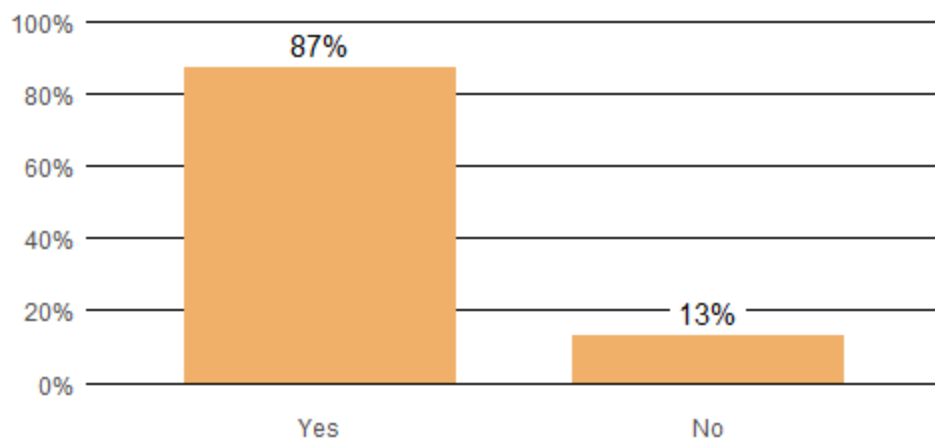
Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state developmental disabilities system.

**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?**

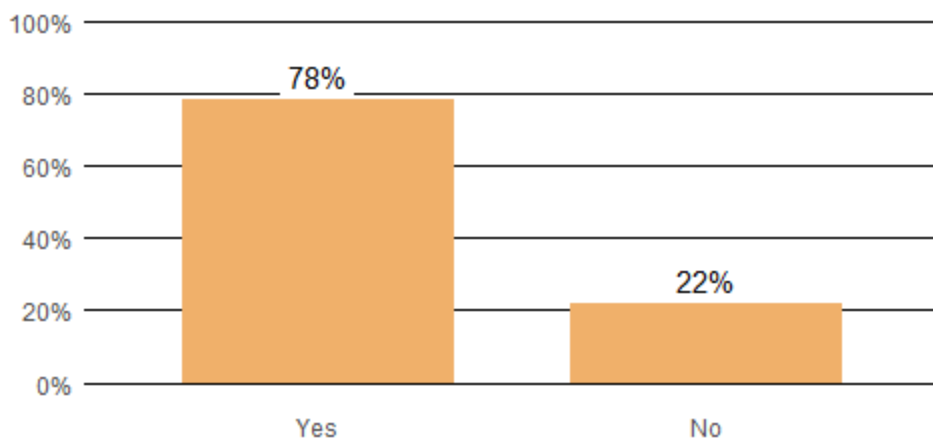


**Table 42. Does your family member get all the services listed in the plan?**

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

State	Yes	No	N
<b>KY</b> ↑	93%	7%	123
<b>OK</b> ↑	93%	7%	294
<b>NJ</b> ↑	92%	8%	363
<b>MN</b>	90%	10%	279
<b>AZ</b>	88%	12%	121
<b>PA</b>	88%	12%	223
<b>MO</b>	88%	12%	185
<b>Weighted NCI-IDD Average</b>	<b>87%</b>	<b>13%</b>	<b>2201</b>
<b>DC</b>	83%	18%	120
<b>DE</b>	83%	18%	80
<b>MD</b> ↓	74%	26%	413

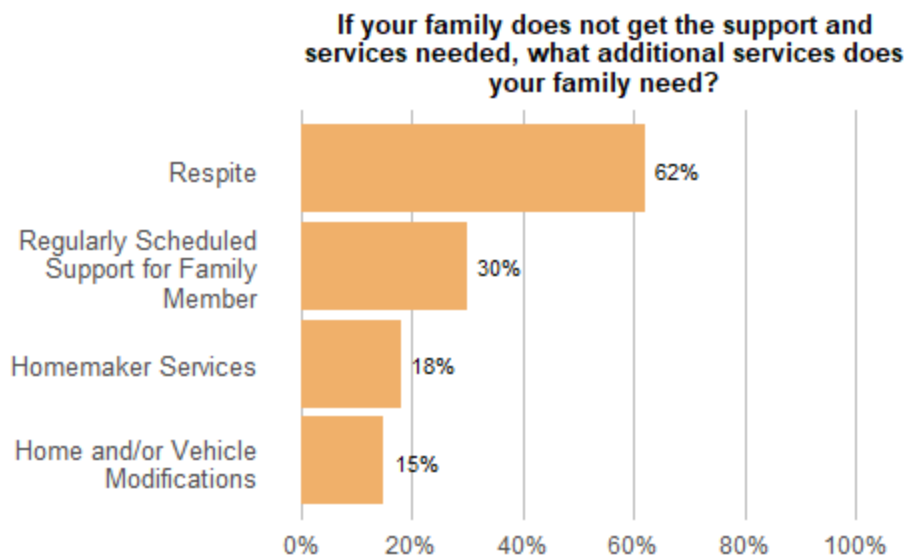
**Does your family get the supports and services it needs?**



**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 ↑	87%	13%	140
KY	84%	16%	189
PA	82%	18%	225
OK	78%	22%	338
<b>Weighted NCI-IDD Average</b>	<b>78%</b>	<b>22%</b>	<b>2695</b>
AZ	77%	23%	200
DE	76%	24%	140
NJ	75%	25%	421
MN	75%	25%	384
MO	73%	27%	212
MD ↓	72%	28%	446

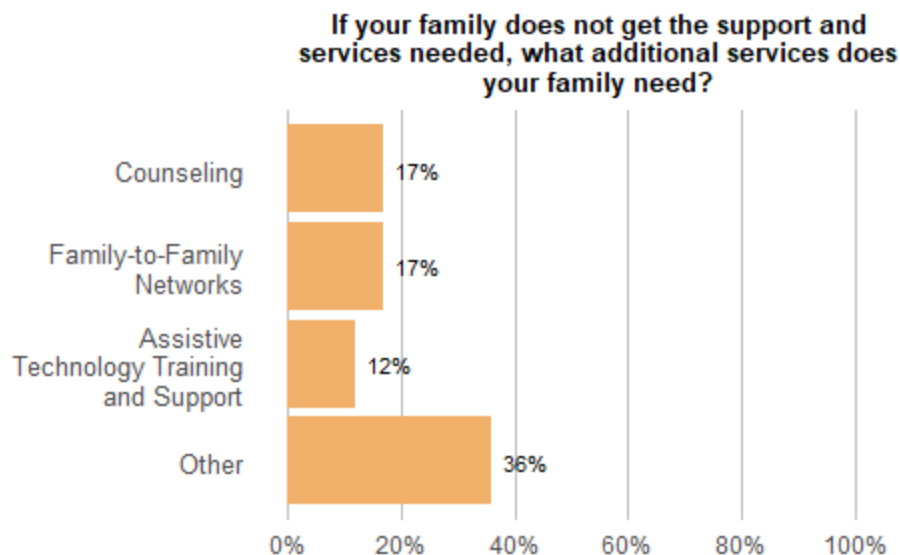


**Table 44a. If your family does not get the support and services needed, what additional services does your family need?**

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	58%	27%	13%	22%
DE	62%	35%	9%	3%
DC	n/a	n/a	n/a	n/a
KY	57%	14%	29%	14%
MD	54%	42%	22%	13%
MN	71%	36%	29%	13%
MO	67%	24%	16%	16%
NJ	74%	31%	20%	5%
OK	69%	26%	15%	9%
PA	57%	27%	5%	22%
<b>Weighted NCI-IDD Average</b>	<b>62%</b>	<b>30%</b>	<b>18%</b>	<b>15%</b>

Table note: The following states had an N of less than 20 so their data is reported as n/a: DC. They are included in the Weighted NCI-IDD Average.



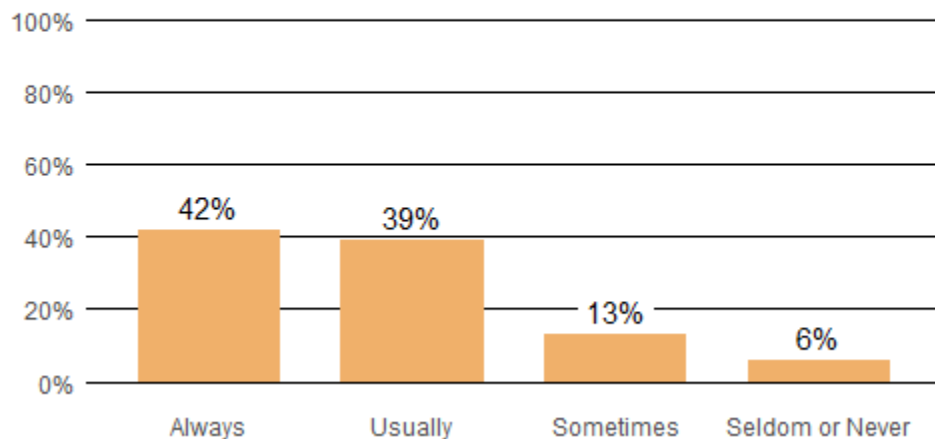
**Table 44b. If your family does not get the support and services needed, what additional services does your family need? (continued)**

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

State	Counseling	Family-to-Family Networks	Assistive Technology Training and Support	Other
AZ	18%	20%	16%	42%
DE	15%	12%	6%	35%
DC	n/a	n/a	n/a	n/a
KY	7%	14%	7%	39%
MD	24%	27%	18%	37%
MN	15%	16%	13%	29%
MO	7%	11%	5%	29%
NJ	23%	20%	13%	40%
OK	12%	12%	12%	22%
PA	14%	8%	5%	35%
<b>Weighted NCI-IDD Average</b>	<b>17%</b>	<b>17%</b>	<b>12%</b>	<b>36%</b>

Table note: The following states had an N of less than 20 so their data is reported as n/a: DC. They are included in the Weighted NCI-IDD Average.

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

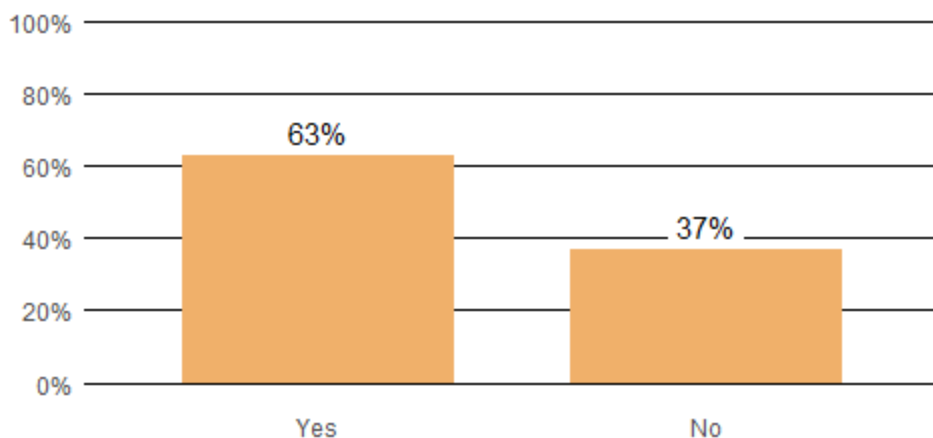


**Table 45. Do services and supports change when your family's needs change?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>KY</b> ↑	57%	35%	4%	4%	159
<b>DC</b>	50%	35%	12%	3%	121
<b>AZ</b>	44%	35%	15%	6%	183
<b>MO</b>	43%	42%	8%	7%	166
<b>PA</b>	43%	42%	11%	5%	206
<b>OK</b>	42%	39%	11%	9%	280
<b>Weighted NCI-IDD Average</b>	<b>42%</b>	<b>39%</b>	<b>13%</b>	<b>6%</b>	<b>2266</b>
<b>NJ</b>	42%	40%	13%	6%	361
<b>MD</b>	35%	35%	20%	9%	366
<b>MN</b> ↓	30%	46%	16%	8%	328
<b>DE</b> ↓	24%	43%	17%	17%	96

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

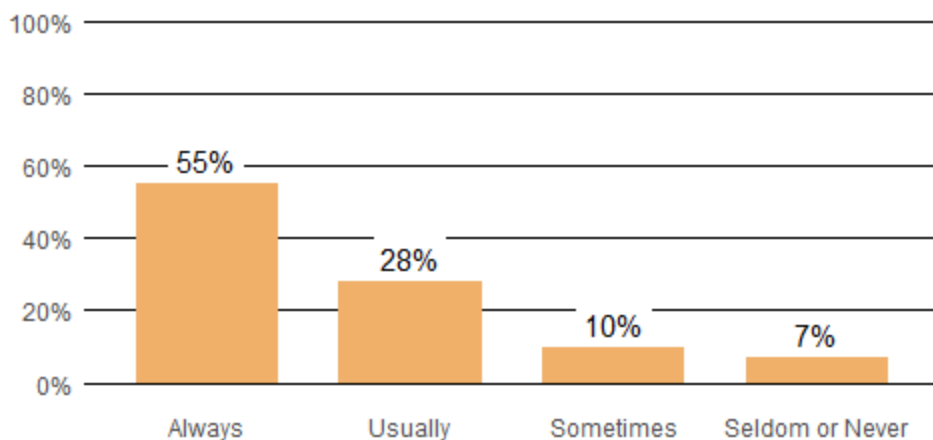


**Table 46. Does your family member have enough supports to work or volunteer in the community?**

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

State	Yes	No	N
PA	70%	30%	192
DC	68%	32%	107
DE	67%	33%	134
MO	67%	33%	167
MD	67%	33%	369
KY	66%	34%	131
MN	66%	34%	311
OK	64%	36%	253
<b>Weighted NCI-IDD Average</b>	<b>63%</b>	<b>37%</b>	<b>2116</b>
NJ	58%	42%	306
AZ ↓	51%	49%	146

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

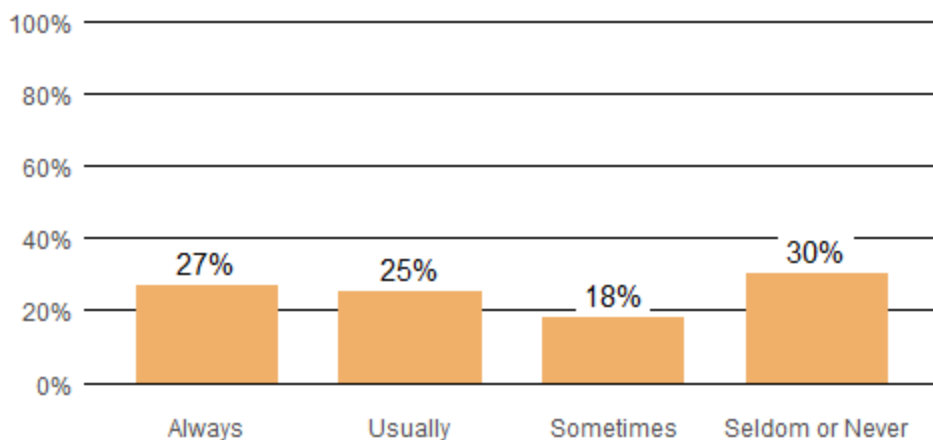


**Table 47. Does your family member have the special equipment or accommodations they need?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC	67%	21%	6%	6%	52
MO	63%	28%	4%	5%	122
PA	61%	24%	5%	9%	98
AZ	61%	23%	11%	6%	120
DE	60%	21%	10%	8%	48
KY	58%	30%	6%	7%	106
<b>Weighted NCI-IDD Average</b>	<b>55%</b>	<b>28%</b>	<b>10%</b>	<b>7%</b>	<b>1375</b>
NJ	50%	32%	12%	6%	199
MN	48%	31%	11%	9%	203
OK ↓	45%	31%	14%	10%	210
MD ↓	45%	33%	18%	5%	217

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

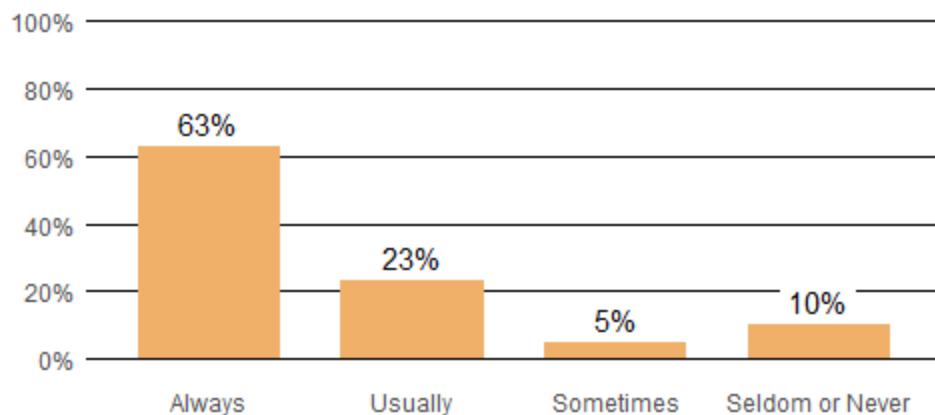


**Table 48. If you need respite services, how often are you able to get them when needed?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>DC</b> ↑	52%	27%	11%	10%	98
<b>AZ</b> ↑	39%	27%	19%	15%	181
<b>KY</b>	37%	32%	10%	21%	153
<b>DE</b>	31%	26%	15%	28%	86
<b>Weighted NCI-IDD Average</b>	<b>27%</b>	<b>25%</b>	<b>18%</b>	<b>30%</b>	<b>1731</b>
<b>PA</b>	26%	23%	18%	33%	131
<b>MD</b>	22%	26%	20%	33%	267
<b>OK</b>	21%	16%	13%	51%	182
<b>NJ</b> ↓	18%	19%	21%	42%	238
<b>MO</b> ↓	17%	23%	14%	46%	139
<b>MN</b> ↓	16%	25%	20%	39%	256

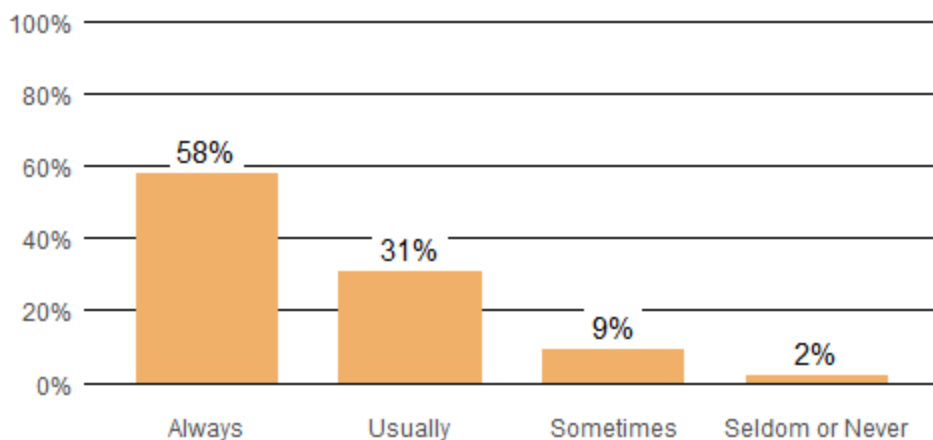
**If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?**



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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>KY</b>	69%	24%	2%	5%	93
<b>PA</b>	68%	18%	2%	12%	57
<b>MO</b>	68%	25%	4%	4%	56
<b>AZ</b>	66%	22%	5%	7%	140
<b>DC</b>	63%	16%	6%	14%	49
<b>Weighted NCI-IDD Average</b>	<b>63%</b>	<b>23%</b>	<b>5%</b>	<b>10%</b>	<b>861</b>
<b>MN</b>	58%	19%	9%	13%	130
<b>DE</b>	57%	27%	7%	9%	44
<b>NJ</b>	53%	26%	8%	13%	88
<b>MD</b>	53%	28%	8%	11%	153
<b>OK</b>	47%	24%	8%	22%	51

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

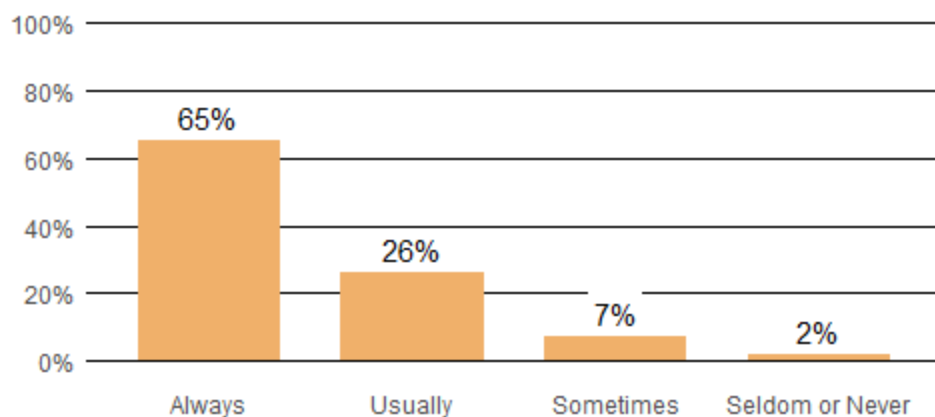


**Table 50. Are you or your family member able to contact their support workers when you want?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>KY</b> ↑	67%	25%	5%	3%	195
<b>DC</b>	66%	29%	2%	2%	136
<b>PA</b>	63%	28%	8%	2%	244
<b>AZ</b>	59%	28%	11%	1%	197
<b>NJ</b>	59%	30%	9%	1%	391
<b>Weighted NCI-IDD Average</b>	<b>58%</b>	<b>31%</b>	<b>9%</b>	<b>2%</b>	<b>2714</b>
<b>MO</b>	54%	35%	9%	2%	208
<b>OK</b>	53%	33%	9%	5%	354
<b>MD</b>	52%	32%	11%	4%	447
<b>MN</b> ↓	45%	39%	13%	3%	388
<b>DE</b> ↓	42%	44%	10%	4%	154

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

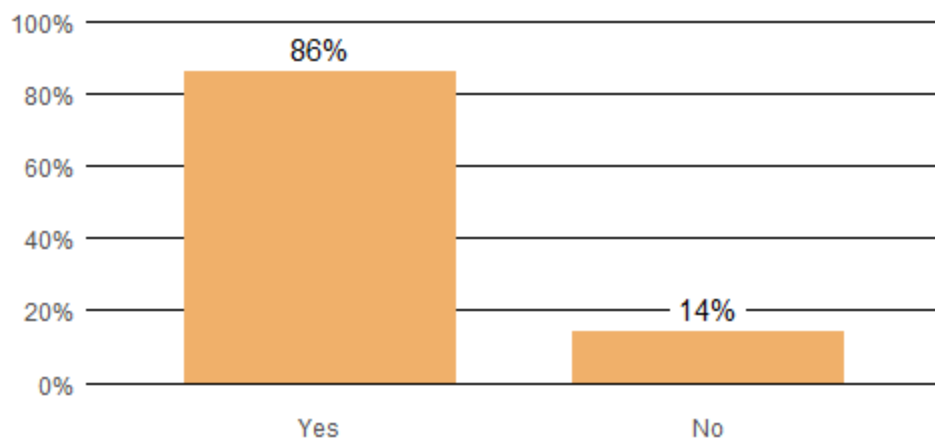


**Table 51. Are you or your family member able to contact their case manager/service coordinator when you want?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>KY</b> ↑	77%	19%	2%	1%	216
<b>NJ</b> ↑	74%	21%	5%	1%	471
<b>DC</b>	74%	22%	2%	1%	152
<b>AZ</b>	68%	24%	8%	0%	217
<b>Weighted NCI-IDD Average</b>	<b>65%</b>	<b>26%</b>	<b>7%</b>	<b>2%</b>	<b>3017</b>
<b>MO</b>	65%	28%	5%	1%	222
<b>PA</b>	64%	27%	7%	1%	258
<b>MD</b>	60%	29%	8%	3%	487
<b>DE</b>	57%	33%	8%	2%	168
<b>OK</b> ↓	55%	33%	8%	4%	399
<b>MN</b> ↓	53%	35%	9%	2%	427

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

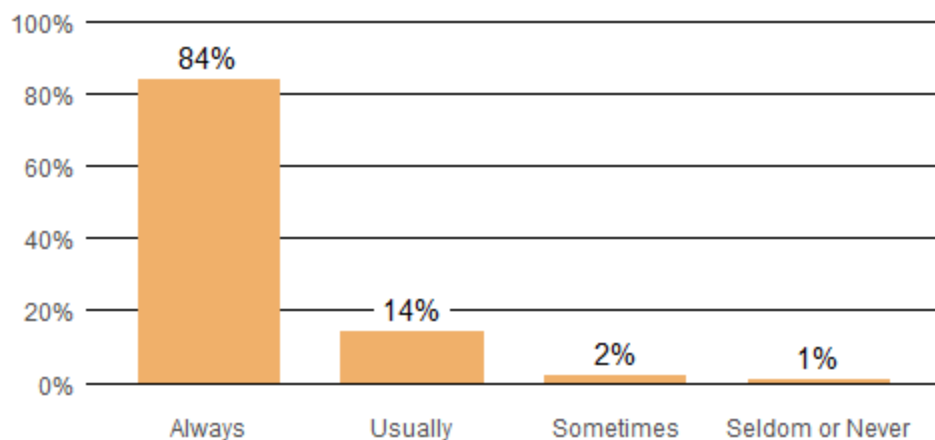


**Table 52. Do service providers for your family member work together to provide support?**

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

State	Yes	No	N
PA ↑	93%	8%	160
KY	91%	9%	115
MO	91%	9%	116
DC	89%	11%	112
OK	87%	13%	190
<b>Weighted NCI-IDD Average</b>	<b>86%</b>	<b>14%</b>	<b>1708</b>
MD	86%	14%	305
AZ	82%	18%	124
MN	82%	18%	251
NJ	81%	19%	255
DE	74%	26%	80

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

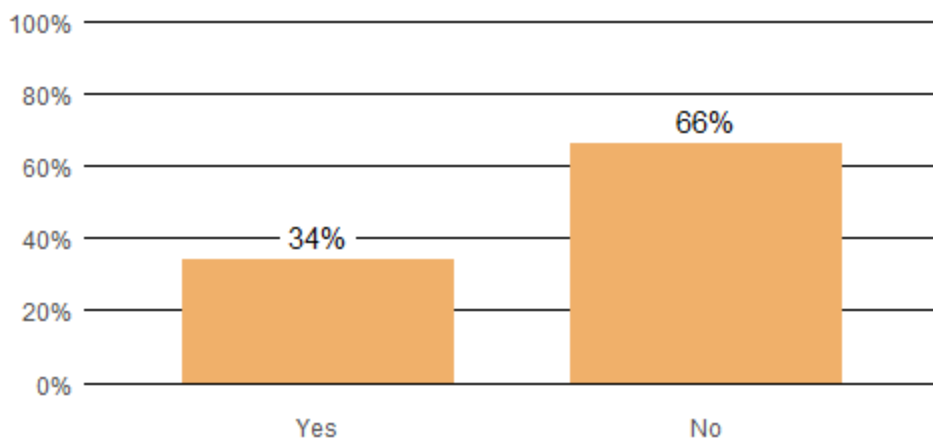


**Table 53. Are services delivered in a way that is respectful of your family's culture?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	87%	11%	1%	1%	245
AZ	87%	10%	3%	1%	210
MO	86%	13%	0%	1%	220
<b>Weighted NCI-IDD Average</b>	<b>84%</b>	<b>14%</b>	<b>2%</b>	<b>1%</b>	<b>2869</b>
OK	84%	14%	1%	1%	364
NJ	83%	14%	1%	1%	447
KY	83%	15%	1%	0%	202
MN	82%	16%	1%	0%	409
DE	79%	17%	3%	1%	156
DC	77%	17%	3%	2%	144
MD ↓	76%	20%	2%	1%	472

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

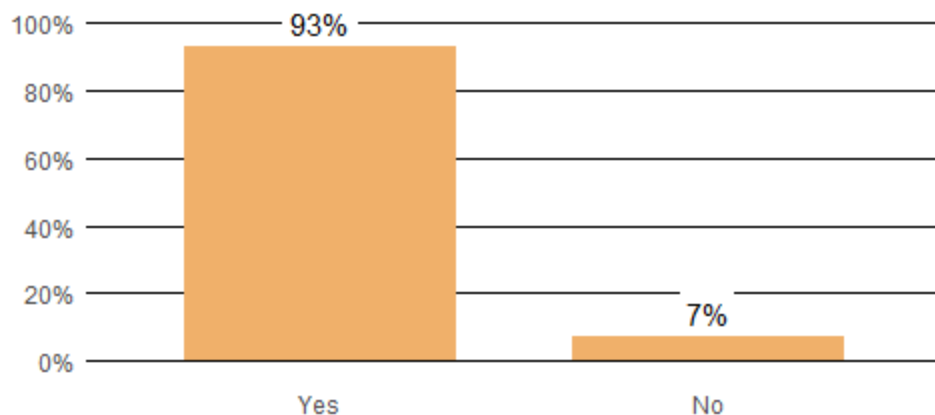


**Table 54. Does your family member use technology in their everyday life to help them do things on their own?**

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

State	Yes	No	N
MD ↑	41%	59%	476
NJ	38%	62%	465
MN	37%	63%	424
<b>Weighted NCI-IDD Average</b>	<b>34%</b>	<b>66%</b>	<b>2986</b>
AZ	33%	67%	218
DE	31%	69%	164
PA	31%	69%	252
KY	30%	70%	211
DC	30%	70%	149
OK	29%	71%	395
MO	28%	72%	232

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

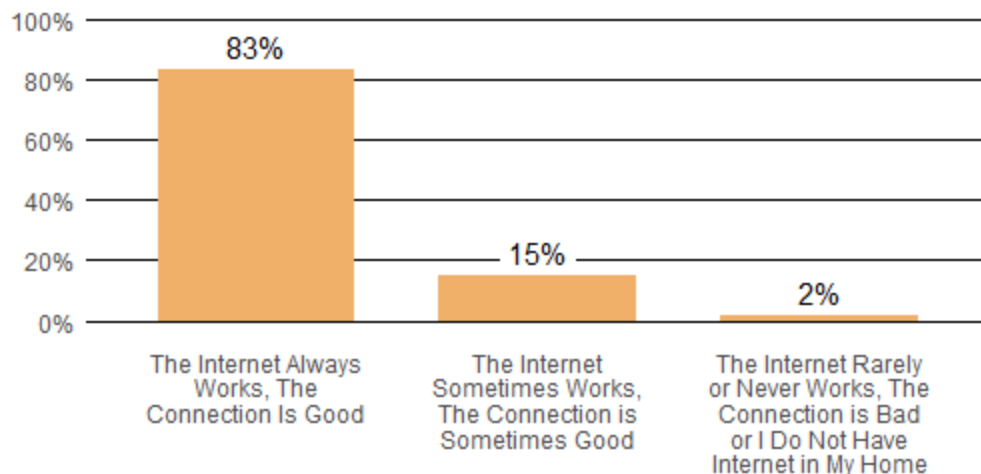


**Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?**

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

State	Yes	No	N
MD ↑	97%	3%	488
NJ	94%	6%	472
KY	94%	6%	221
MN	94%	6%	431
<b>Weighted NCI-IDD Average</b>	<b>93%</b>	<b>7%</b>	<b>3055</b>
DE	92%	8%	170
PA	92%	8%	263
AZ	91%	9%	221
DC	89%	11%	151
MO	89%	11%	234
OK ↓	85%	15%	404

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



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

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

State	The Internet Always Works, The Connection Is Good	The Internet Sometimes Works, The Connection is Sometimes Good	The Internet Rarely or Never Works, The Connection is Bad or I Do Not Have Internet in My Home	N
NJ ↑	89%	11%	0%	473
DE	88%	11%	1%	170
PA	85%	13%	2%	259
MD	85%	14%	1%	491
<b>Weighted NCI-IDD Average</b>	<b>83%</b>	<b>15%</b>	<b>2%</b>	<b>3038</b>
DC	82%	14%	3%	147
MO	82%	15%	3%	235
AZ	79%	20%	1%	220
MN	79%	18%	3%	426
KY	77%	21%	2%	220
OK ↓	74%	20%	6%	397

## Workforce

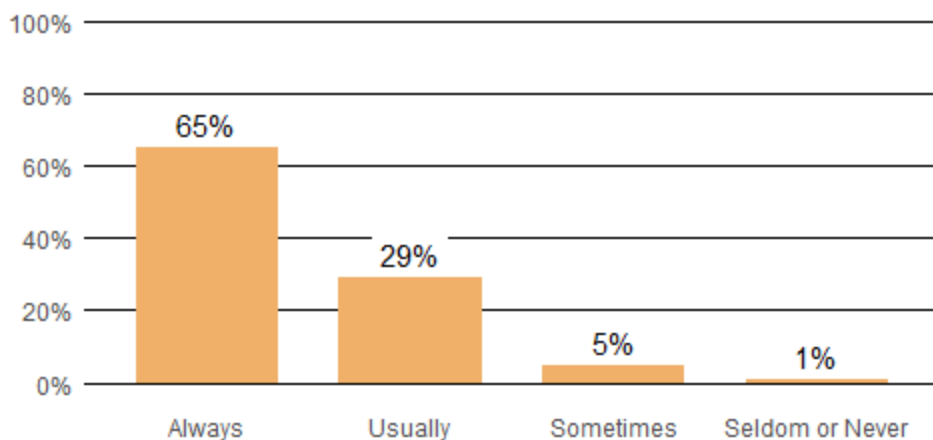
There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.

**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
<b>KY</b> ↑	79%	19%	2%	1%	187
<b>AZ</b>	70%	23%	7%	1%	197
<b>PA</b>	67%	29%	3%	1%	234
<b>Weighted NCI-IDD Average</b>	<b>65%</b>	<b>29%</b>	<b>5%</b>	<b>1%</b>	<b>2508</b>
<b>NJ</b>	65%	27%	6%	2%	371
<b>DC</b>	64%	26%	8%	2%	129
<b>OK</b>	60%	31%	6%	3%	308
<b>MN</b>	59%	36%	4%	1%	334
<b>MO</b>	58%	37%	4%	2%	190
<b>MD</b> ↓	57%	34%	8%	2%	429
<b>DE</b> ↓	53%	33%	7%	6%	129

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

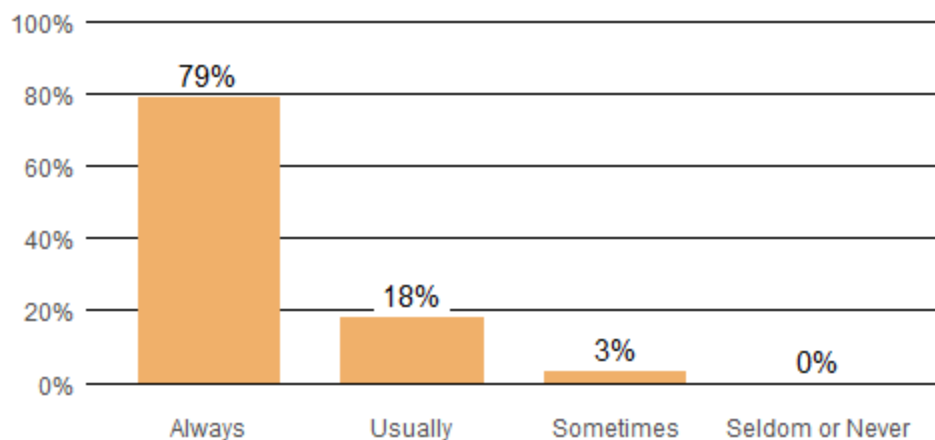
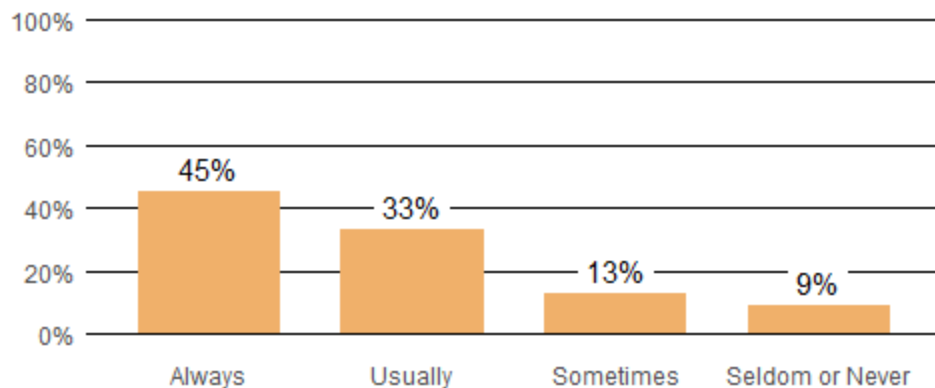


Table 58. Do support workers speak to you in a way you understand?

State	Always	Usually	Sometimes	Seldom or Never	N
KY	85%	14%	1%	0%	199
DC	84%	14%	1%	1%	137
PA	83%	15%	2%	0%	238
AZ	80%	17%	3%	0%	203
<b>Weighted NCI-IDD Average</b>	<b>79%</b>	<b>18%</b>	<b>3%</b>	<b>0%</b>	<b>2651</b>
NJ	78%	18%	4%	0%	383
OK	78%	19%	2%	1%	338
MO	76%	22%	1%	0%	204
MD	75%	20%	4%	1%	442
MN	74%	24%	2%	0%	367
DE	72%	22%	4%	2%	140

**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?**

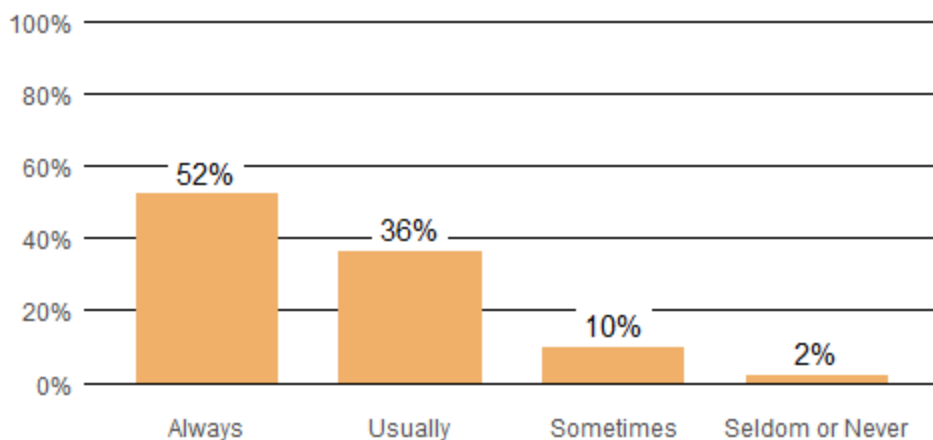


**Table 59. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	61%	31%	8%	0%	75
KY	51%	31%	13%	5%	86
NJ	48%	30%	11%	11%	185
PA	46%	33%	10%	11%	91
MO	46%	34%	17%	4%	103
OK	45%	32%	14%	9%	175
<b>Weighted NCI-IDD Average</b>	<b>45%</b>	<b>33%</b>	<b>13%</b>	<b>9%</b>	<b>1208</b>
AZ	43%	30%	17%	11%	101
MN	41%	33%	17%	9%	149
MD	41%	39%	12%	8%	212
DE	32%	29%	23%	16%	31

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

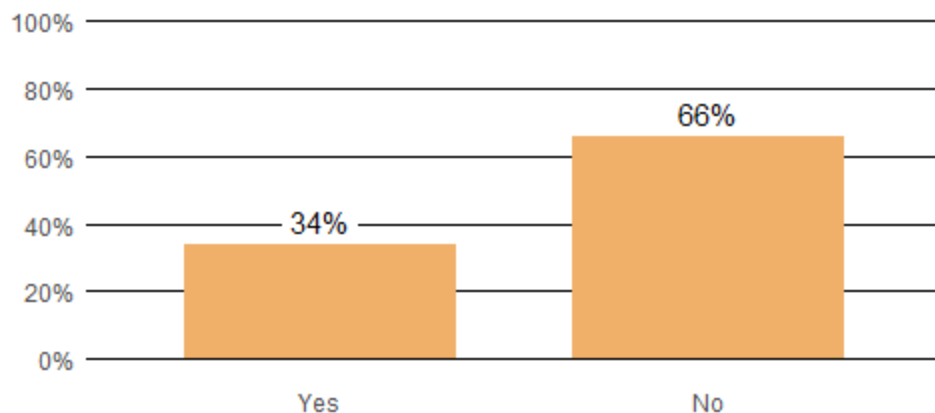


**Table 60. Do support workers have the right information and skills to meet your family's needs?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>KY ↑</b>	65%	28%	6%	1%	189
<b>DC</b>	63%	27%	9%	1%	139
<b>OK</b>	56%	37%	6%	2%	324
<b>NJ</b>	54%	32%	12%	2%	377
<b>AZ</b>	54%	31%	14%	2%	198
<b>PA</b>	53%	37%	7%	3%	229
<b>Weighted NCI-IDD Average</b>	<b>52%</b>	<b>36%</b>	<b>10%</b>	<b>2%</b>	<b>2577</b>
<b>MO</b>	50%	45%	5%	1%	197
<b>MD</b>	47%	36%	14%	3%	432
<b>MN ↓</b>	43%	47%	9%	2%	352
<b>DE ↓</b>	37%	44%	14%	5%	140

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

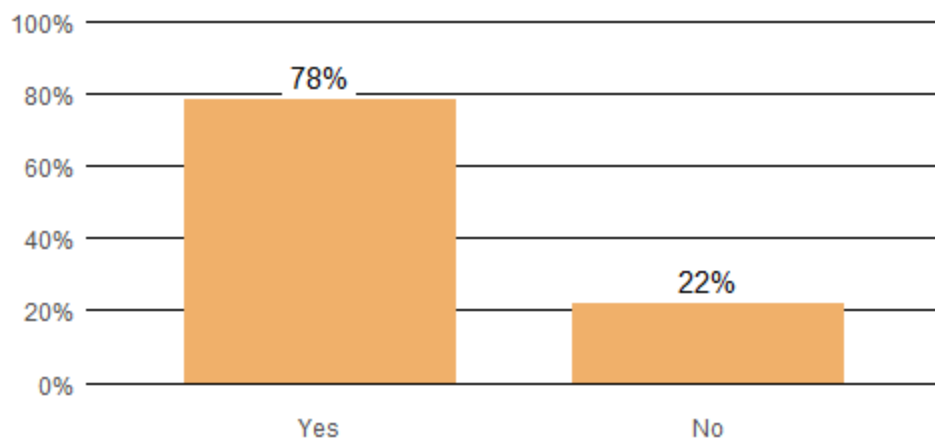


**Table 61. Do your family member's support workers change too often? Is there too much "turnover" of support workers?**

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

State	Yes	No	N
DE ↑	57%	43%	129
AZ	42%	58%	187
MD	37%	63%	408
PA	36%	64%	218
MN	35%	65%	333
<b>Weighted NCI-IDD Average</b>	<b>34%</b>	<b>66%</b>	<b>2410</b>
MO	32%	68%	185
NJ	30%	70%	350
OK	29%	71%	295
KY ↓	17%	83%	175
DC ↓	11%	89%	130

**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 ↑	93%	7%	134
KY ↑	87%	13%	181
PA	81%	19%	220
NJ	80%	20%	343
MO	79%	21%	183
OK	79%	21%	273
AZ	78%	22%	176
<b>Weighted NCI-IDD Average</b>	<b>78%</b>	<b>22%</b>	<b>2387</b>
DE	72%	28%	114
MD ↓	71%	29%	420
MN ↓	67%	33%	343

## Choice, Decision Making and Control

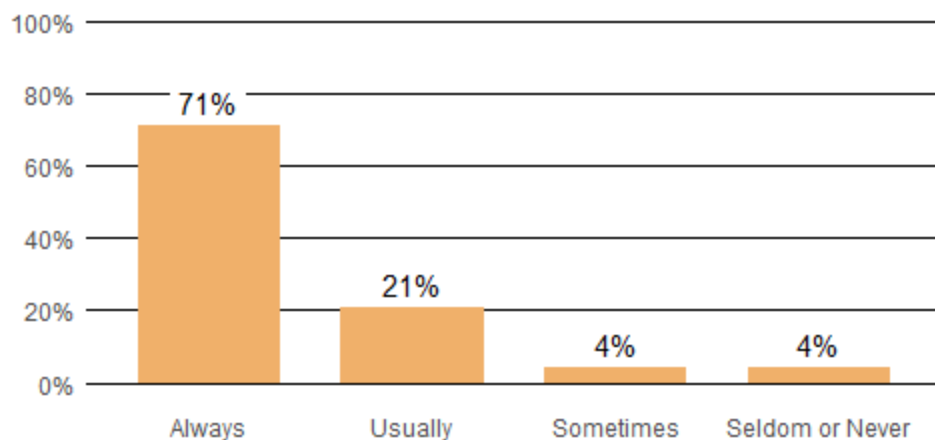
Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.

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

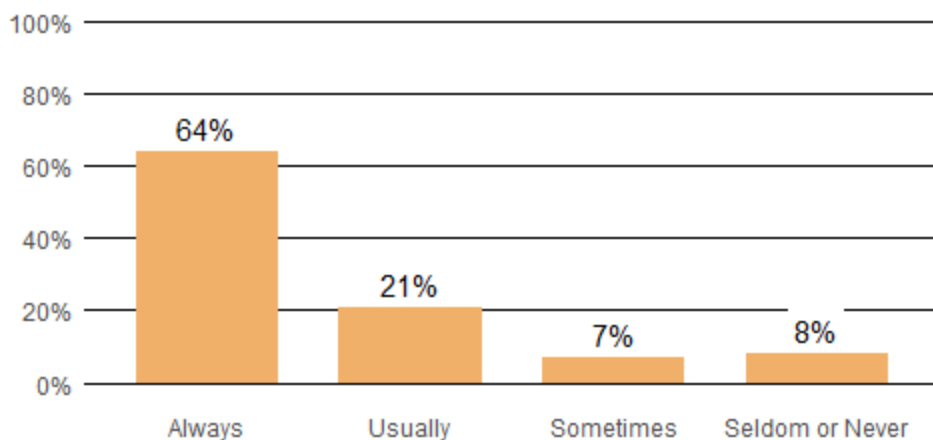


**Table 63. Can your family choose or change the agency that provides your family member's services?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
OK ↑	79%	14%	3%	5%	265
DC	78%	11%	3%	8%	109
MD	74%	18%	5%	4%	346
KY	73%	19%	2%	5%	147
AZ	72%	22%	3%	3%	173
PA	72%	21%	4%	3%	190
<b>Weighted NCI-IDD Average</b>	<b>71%</b>	<b>21%</b>	<b>4%</b>	<b>4%</b>	<b>2086</b>
MO	68%	22%	4%	6%	142
NJ	68%	22%	5%	5%	331
MN	67%	24%	6%	3%	286
DE ↓	56%	33%	2%	9%	97

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

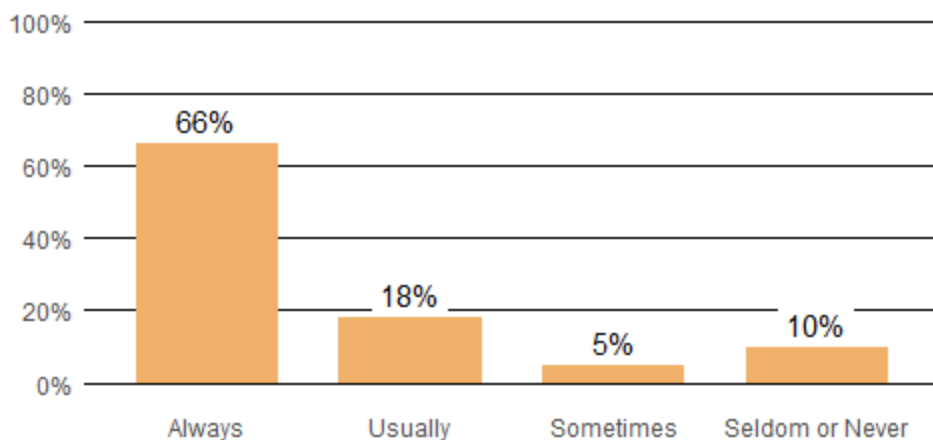


**Table 64. Can your family choose or change your family member's support workers?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
OK ↑	74%	17%	2%	7%	241
KY	72%	20%	3%	4%	138
DC	69%	12%	9%	9%	106
PA	66%	20%	5%	8%	182
<b>Weighted NCI-IDD Average</b>	<b>64%</b>	<b>21%</b>	<b>7%</b>	<b>8%</b>	<b>1974</b>
MD	64%	20%	7%	8%	362
AZ	62%	22%	8%	8%	162
MN	61%	24%	7%	8%	294
MO	60%	22%	5%	12%	129
NJ	60%	22%	9%	8%	286
DE	51%	23%	11%	15%	74

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

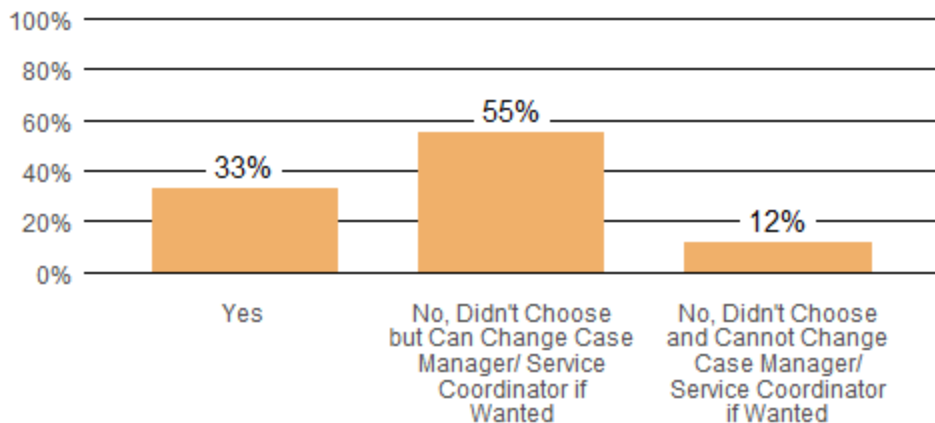


**Table 65. Can someone in your family directly manage support staff?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
OK	72%	17%	5%	7%	215
DC	71%	14%	4%	11%	93
KY	70%	19%	5%	6%	122
MN	70%	17%	5%	8%	301
AZ	70%	18%	5%	7%	152
<b>Weighted NCI-IDD Average</b>	<b>66%</b>	<b>18%</b>	<b>5%</b>	<b>10%</b>	<b>1849</b>
NJ	66%	22%	5%	8%	279
MD	64%	15%	7%	14%	335
MO	62%	21%	2%	15%	124
PA	62%	19%	7%	13%	169
DE ↓	47%	22%	15%	15%	59

**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 or 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/Service Coordinator if Wanted	No, Didn't Choose and Cannot Change Case Manager/Service Coordinator if Wanted	N
NJ ↑	60%	34%	6%	415
MD ↑	40%	52%	8%	425
<b>Weighted NCI-IDD Average</b>	<b>33%</b>	<b>55%</b>	<b>12%</b>	<b>2552</b>
PA	32%	56%	12%	211
KY	32%	58%	10%	176
DC	29%	58%	13%	128
AZ ↓	23%	69%	7%	188
MO ↓	20%	62%	19%	188
DE ↓	16%	51%	33%	139
OK ↓	16%	63%	22%	316
MN ↓	11%	62%	27%	366

## Community Connections

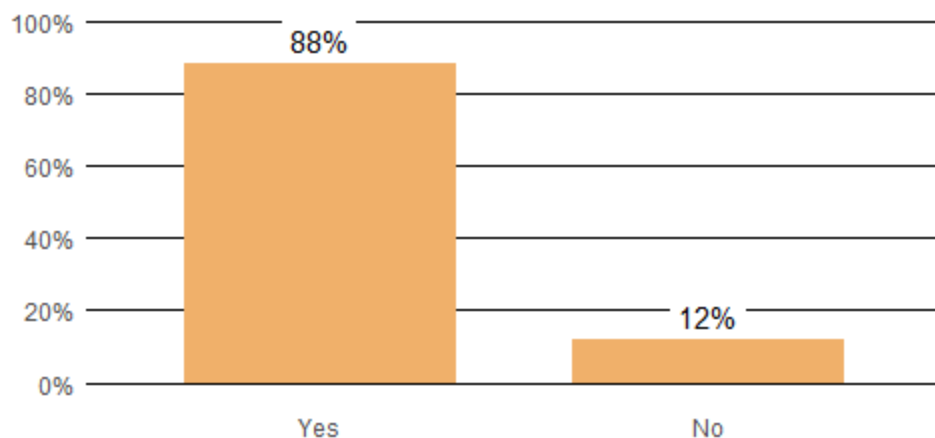
Family members receiving services and supports from the state Developmental disabilities system are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.

**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.

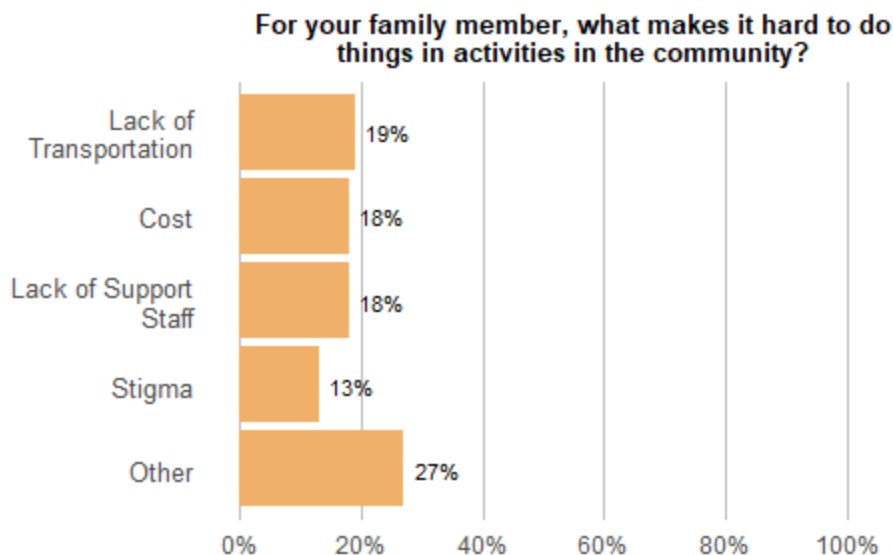
**Does your family member do things in the community?**



**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
MD ↑	92%	8%	463
DC	91%	9%	153
MN	91%	9%	427
KY	90%	10%	216
PA	90%	10%	258
DE	89%	11%	169
<b>Weighted NCI-IDD Average</b>	<b>88%</b>	<b>12%</b>	<b>2995</b>
OK	87%	13%	401
NJ	85%	15%	453
AZ	85%	15%	220
MO	84%	16%	235

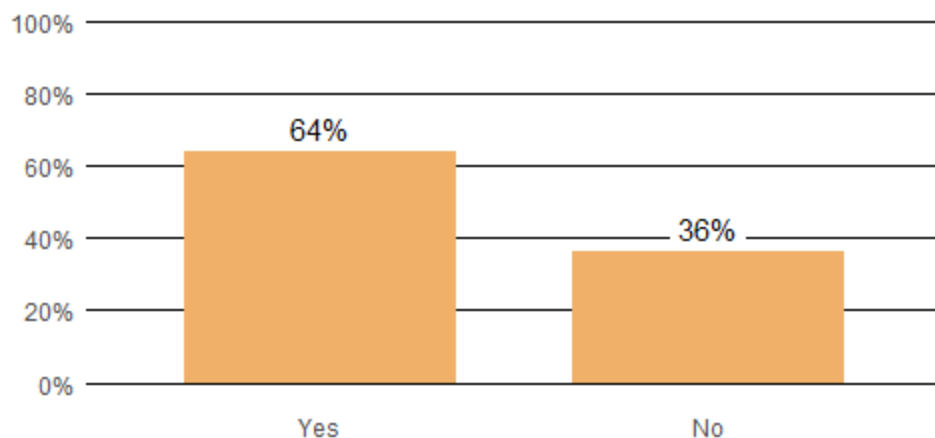


**Table 68. For your family member, what makes it hard to do things in the community?**

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

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
<b>AZ</b>	19%	21%	16%	11%	35%
<b>DE</b>	19%	13%	18%	10%	22%
<b>DC</b>	10%	9%	3%	9%	15%
<b>KY</b>	10%	16%	10%	11%	31%
<b>MD</b>	20%	17%	24%	16%	26%
<b>MN</b>	23%	21%	27%	15%	26%
<b>MO</b>	20%	18%	21%	9%	27%
<b>NJ</b>	23%	18%	21%	13%	28%
<b>OK</b>	12%	18%	11%	12%	27%
<b>PA</b>	19%	17%	16%	12%	21%
<b>Weighted NCI-IDD Average</b>	<b>19%</b>	<b>18%</b>	<b>18%</b>	<b>13%</b>	<b>27%</b>

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

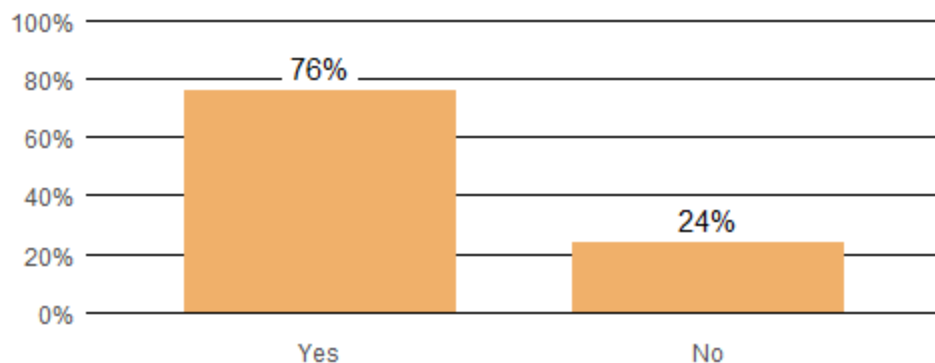


**Table 69. Does your family member have friends other than paid support workers or family?**

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

State	Yes	No	N
KY ↑	78%	22%	211
OK ↑	71%	29%	394
DC	68%	32%	149
MN	66%	34%	417
PA	66%	34%	259
<b>Weighted NCI-IDD Average</b>	<b>64%</b>	<b>36%</b>	<b>2964</b>
DE	64%	36%	170
MD	61%	39%	462
MO	61%	39%	233
NJ	59%	41%	453
AZ	56%	44%	216

**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)?**

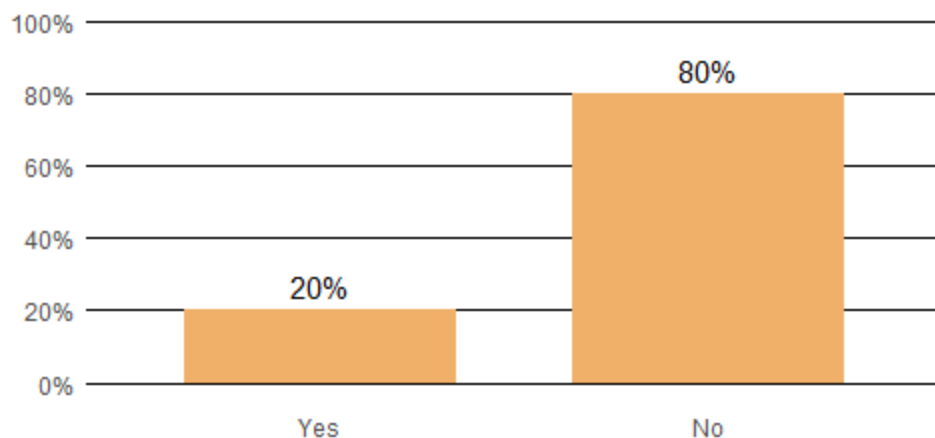


**Table 70. In your community, are there resources that your family can use that are not provided by the I/DD agency? (for example, recreational programs, community housing, library programs, religious groups, etc.)?**

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

State	Yes	No	N
MD ↑	82%	18%	368
MN	81%	19%	320
DC	80%	20%	116
KY	77%	23%	160
MO	77%	23%	172
<b>Weighted NCI-IDD Average</b>	<b>76%</b>	<b>24%</b>	<b>2206</b>
PA	75%	25%	183
OK	75%	25%	295
DE	74%	26%	103
NJ	73%	27%	331
AZ	71%	29%	158

**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	29%	71%	130
KY	26%	74%	170
NJ	25%	75%	400
OK	24%	76%	321
AZ	23%	77%	195
<b>Weighted NCI-IDD Average</b>	<b>20%</b>	<b>80%</b>	<b>2602</b>
MD	19%	81%	427
MN	17%	83%	368
PA	16%	84%	235
DE	14%	86%	146
<b>MO ↓</b>	11%	89%	210

## Health, Welfare, and Safety

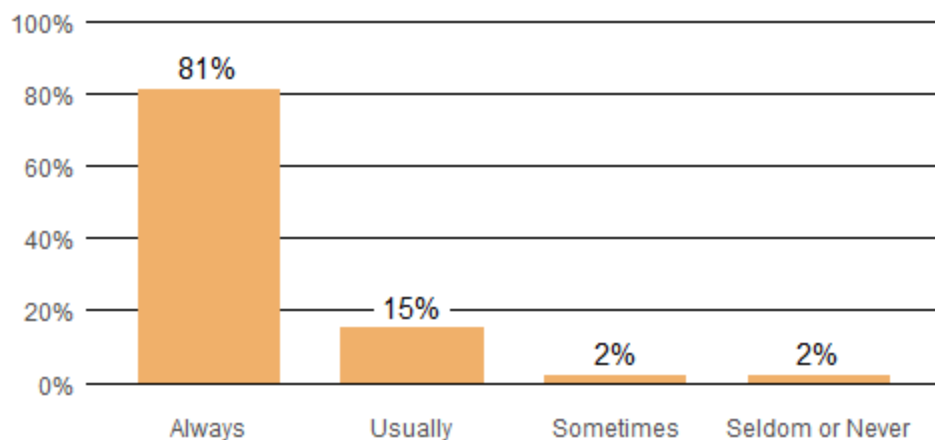
Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state developmental disabilities system.

**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?**

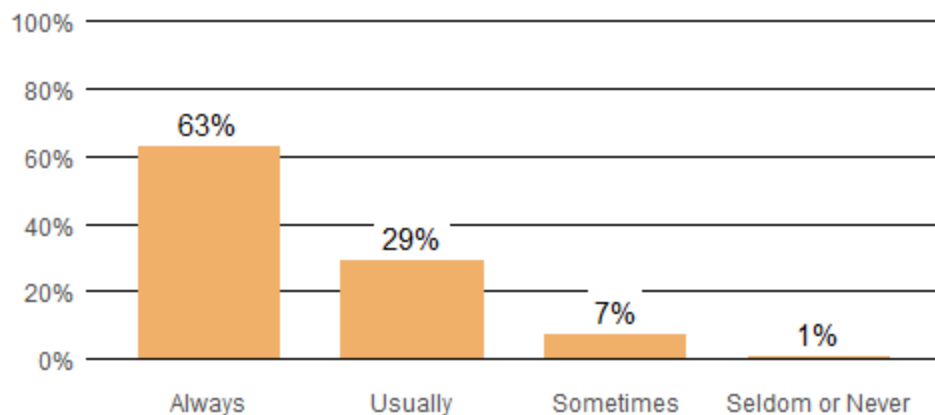


**Table 72. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>MD</b> ↑	86%	11%	2%	1%	464
<b>KY</b>	85%	12%	1%	1%	213
<b>OK</b>	84%	14%	1%	1%	402
<b>PA</b>	84%	12%	3%	1%	260
<b>MO</b>	82%	16%	0%	2%	234
<b>Weighted NCI-IDD Average</b>	<b>81%</b>	<b>15%</b>	<b>2%</b>	<b>2%</b>	<b>2988</b>
<b>NJ</b>	80%	16%	2%	3%	454
<b>DE</b>	77%	17%	4%	2%	168
<b>DC</b>	77%	16%	4%	3%	153
<b>MN</b>	77%	19%	3%	1%	426
<b>AZ</b> ↓	73%	22%	2%	3%	214

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

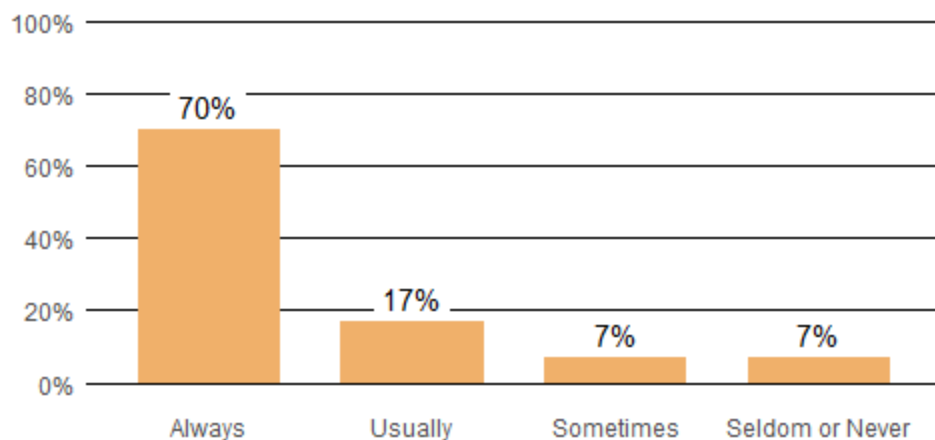


**Table 73. Does your family member's primary care doctor understand your family member's needs related to their disability?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC ↑	78%	17%	5%	0%	150
PA	70%	23%	7%	0%	258
DE	69%	23%	8%	1%	168
KY	69%	26%	4%	0%	213
OK	64%	29%	5%	1%	404
<b>Weighted NCI-IDD Average</b>	<b>63%</b>	<b>29%</b>	<b>7%</b>	<b>1%</b>	<b>2992</b>
NJ	62%	31%	5%	2%	457
MD	60%	32%	7%	1%	466
MN	57%	35%	7%	1%	424
MO	56%	37%	6%	0%	236
AZ	56%	32%	10%	2%	216

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

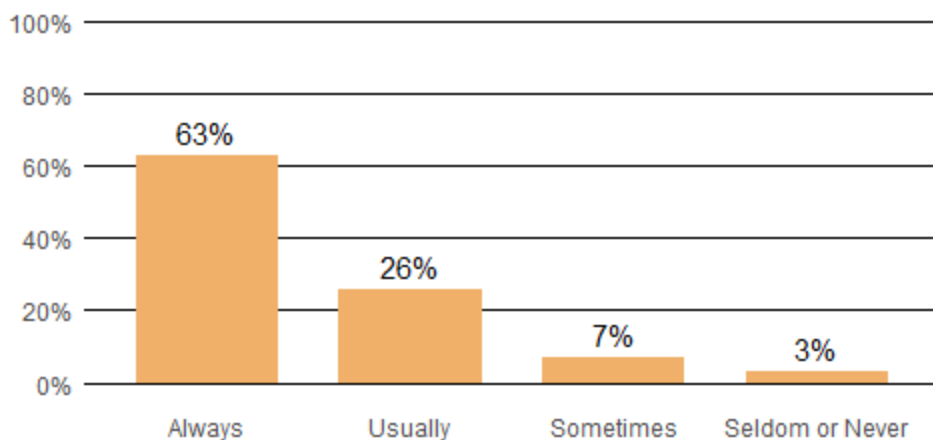


**Table 74. Can your family member go to the dentist when needed?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>NJ</b>	74%	14%	6%	6%	462
<b>PA</b>	73%	13%	8%	6%	263
<b>MD</b>	72%	15%	6%	7%	468
<b>DE</b>	72%	13%	7%	8%	165
<b>DC</b>	71%	23%	5%	1%	150
<b>Weighted NCI-IDD Average</b>	<b>70%</b>	<b>17%</b>	<b>7%</b>	<b>7%</b>	<b>3002</b>
<b>KY</b>	68%	18%	7%	7%	214
<b>AZ</b>	66%	23%	6%	5%	217
<b>OK</b>	66%	21%	5%	8%	400
<b>MO</b>	63%	20%	8%	9%	235
<b>MN ↓</b>	63%	20%	9%	8%	428

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

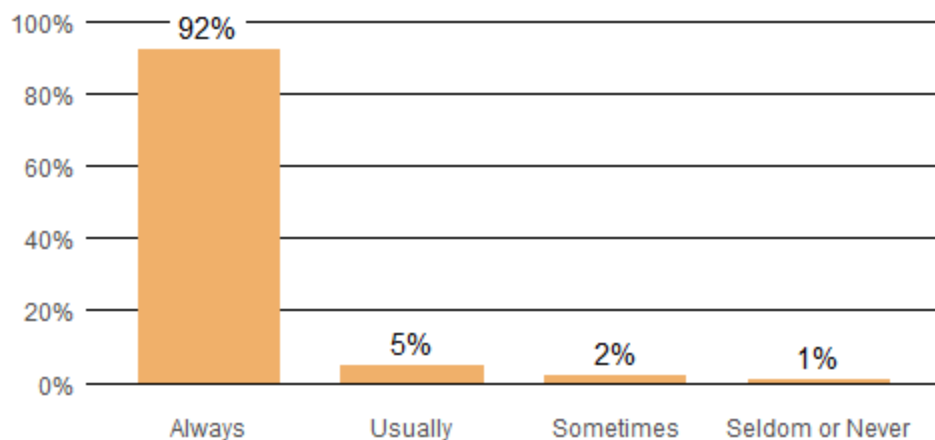


**Table 75. Does your family member's dentist understand your family member's needs related to their disability?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
DC	71%	21%	8%	1%	145
KY	71%	21%	4%	4%	192
PA	67%	23%	7%	3%	239
MD	67%	22%	6%	5%	436
NJ	66%	26%	6%	2%	441
DE	64%	28%	5%	3%	148
<b>Weighted NCI-IDD Average</b>	<b>63%</b>	<b>26%</b>	<b>7%</b>	<b>3%</b>	<b>2775</b>
OK	63%	26%	7%	4%	363
MO	63%	24%	10%	3%	208
AZ	55%	32%	11%	3%	209
MN ↓	56%	32%	8%	4%	394

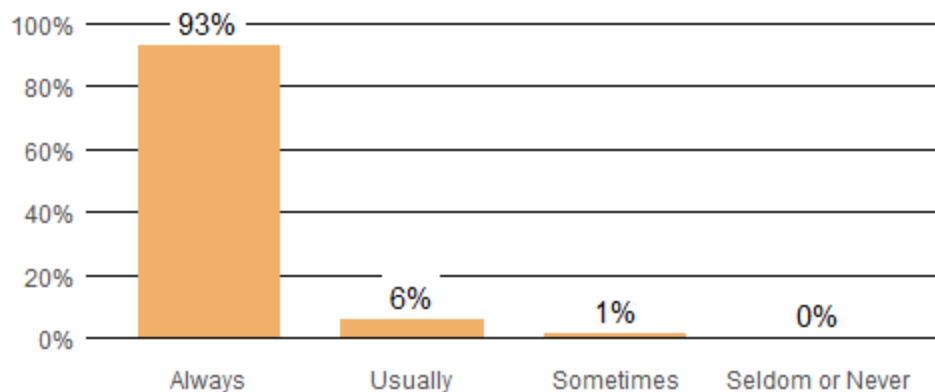
**If your family member takes prescription medications, do you know what they're for?**



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

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	95%	3%	2%	1%	185
KY	94%	3%	1%	1%	201
DC	94%	3%	2%	2%	115
NJ	94%	3%	2%	1%	385
MD	94%	3%	1%	2%	396
MO	93%	6%	1%	0%	212
OK	92%	6%	1%	1%	355
<b>Weighted NCI-IDD Average</b>	<b>92%</b>	<b>5%</b>	<b>2%</b>	<b>1%</b>	<b>2590</b>
DE	91%	5%	2%	2%	147
PA	89%	6%	3%	2%	216
MN	89%	8%	1%	2%	378

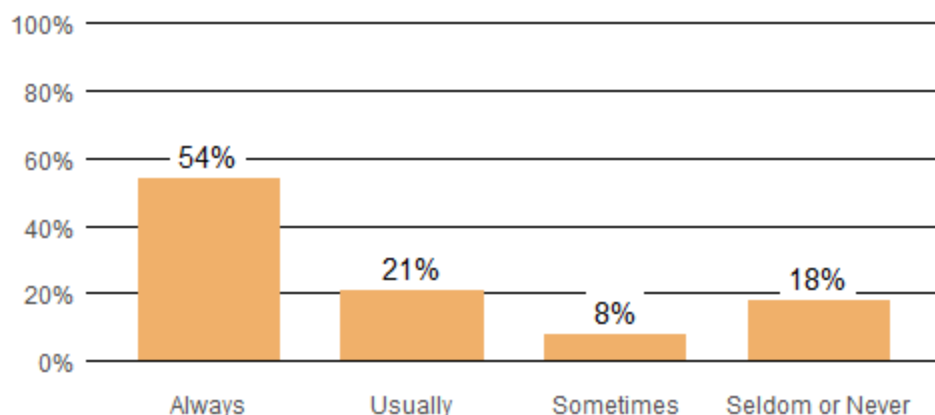
Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?



**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)?**

State	Always	Usually	Sometimes	Seldom or Never	N
KY	96%	4%	0%	0%	198
AZ	95%	4%	1%	1%	185
DC	95%	3%	1%	1%	117
MD	95%	4%	0%	0%	401
DE	95%	3%	2%	1%	148
NJ	94%	6%	0%	0%	385
MO	93%	5%	0%	1%	214
<b>Weighted NCI-IDD Average</b>	<b>93%</b>	<b>6%</b>	<b>1%</b>	<b>0%</b>	<b>2596</b>
OK	93%	6%	1%	1%	354
PA	91%	6%	3%	0%	215
MN	89%	9%	1%	1%	379

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

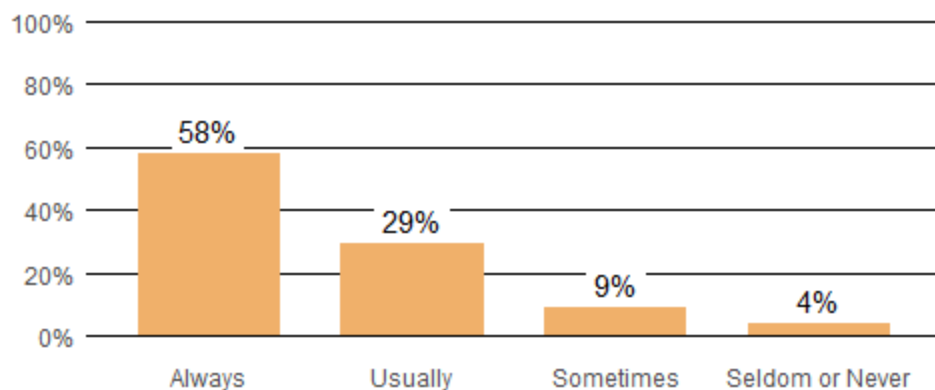


**Table 78. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>KY</b> ↑	66%	16%	5%	13%	168
<b>PA</b>	61%	20%	4%	14%	182
<b>MO</b>	54%	20%	9%	17%	162
<b>Weighted NCI-IDD Average</b>	<b>54%</b>	<b>21%</b>	<b>8%</b>	<b>18%</b>	<b>2176</b>
<b>MD</b>	53%	17%	12%	19%	363
<b>DC</b>	52%	23%	8%	17%	113
<b>DE</b>	51%	30%	4%	15%	111
<b>NJ</b>	49%	18%	9%	24%	321
<b>MN</b>	49%	28%	8%	15%	328
<b>OK</b>	48%	22%	5%	25%	261
<b>AZ</b>	47%	25%	10%	19%	167

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

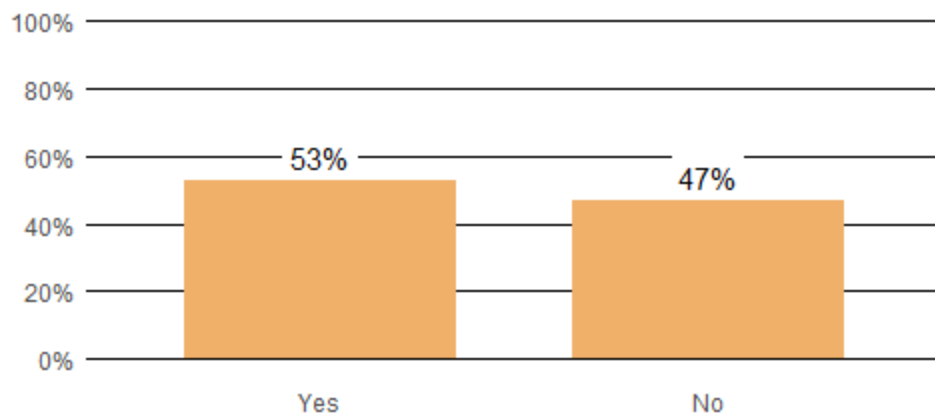


**Table 79. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>KY</b> ↑	74%	20%	4%	2%	127
<b>DC</b>	69%	20%	7%	4%	90
<b>OK</b>	62%	29%	5%	4%	177
<b>DE</b>	61%	30%	8%	1%	76
<b>PA</b>	60%	30%	6%	3%	141
<b>MO</b>	59%	34%	4%	3%	114
<b>Weighted NCI-IDD Average</b>	<b>58%</b>	<b>29%</b>	<b>9%</b>	<b>4%</b>	<b>1560</b>
<b>NJ</b>	57%	27%	11%	5%	216
<b>AZ</b>	54%	31%	11%	4%	113
<b>MD</b>	52%	25%	17%	5%	267
<b>MN</b>	51%	36%	9%	4%	239

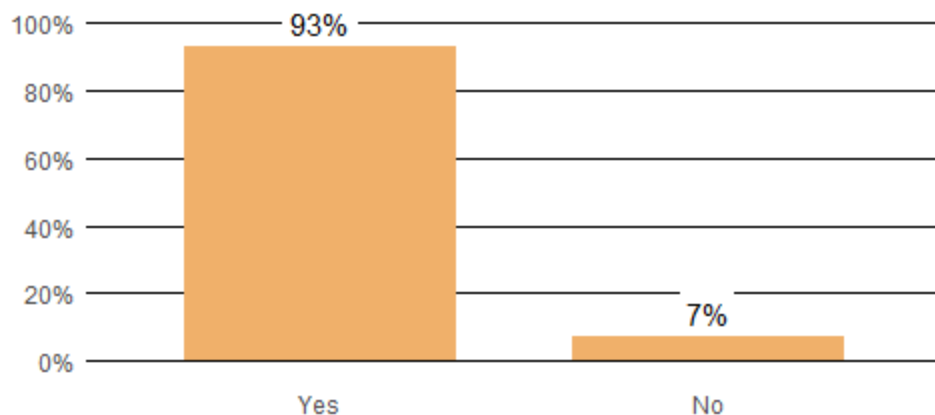
**If you asked for crisis or emergency services during the past 12 months, were services provided when needed?**



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

State	Yes	No	N
MN	67%	33%	79
KY	67%	33%	33
OK	61%	39%	71
MO	55%	45%	38
NJ	55%	45%	71
<b>Weighted NCI-IDD Average</b>	<b>53%</b>	<b>47%</b>	<b>535</b>
MD	53%	47%	93
DC	51%	49%	41
DE	48%	52%	21
AZ	47%	53%	51
PA	46%	54%	37

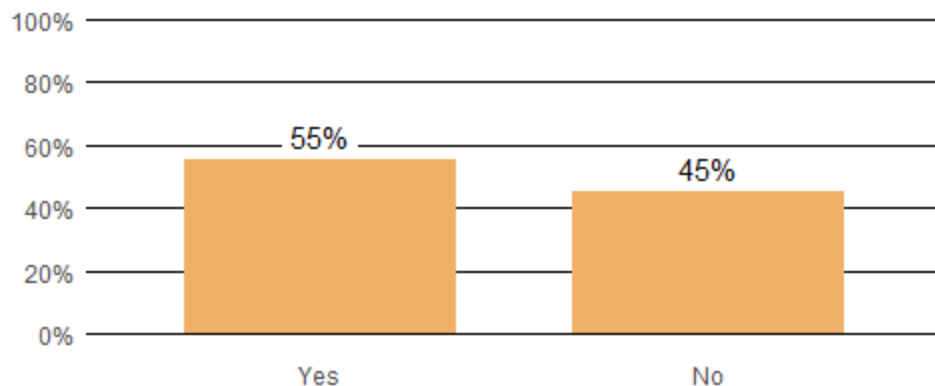
**Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?**



**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?**

State	Yes	No	N
OK	95%	5%	382
KY	94%	6%	208
DC	94%	6%	138
PA	94%	6%	240
MN	94%	6%	399
<b>Weighted NCI-IDD Average</b>	<b>93%</b>	<b>7%</b>	<b>2817</b>
MO	92%	8%	225
MD	92%	8%	429
DE	92%	8%	161
NJ	91%	9%	427
AZ	90%	10%	208

**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?**

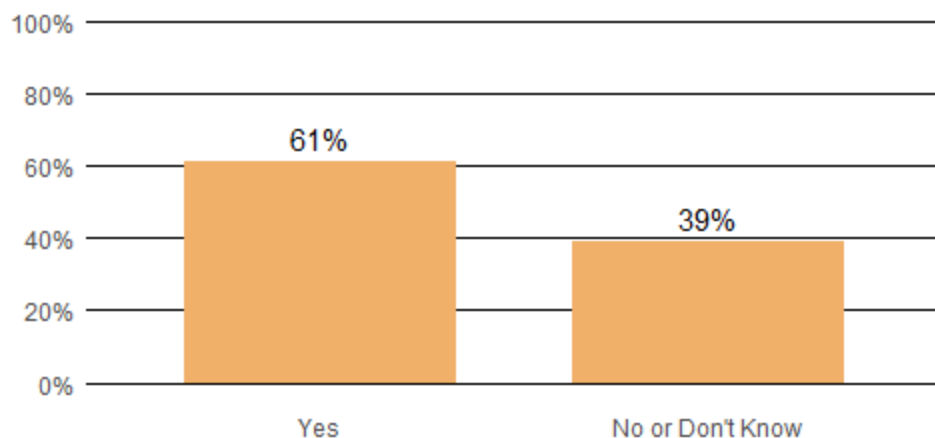


**Table 82. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/service coordinator?**

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

State	Yes	No	N
OK ↑	64%	36%	379
NJ ↑	62%	38%	438
DC	66%	34%	145
KY	59%	41%	202
PA	57%	43%	241
MO	57%	43%	221
<b>Weighted NCI-IDD Average</b>	<b>55%</b>	<b>45%</b>	<b>2841</b>
MD	50%	50%	433
AZ	50%	50%	211
MN	49%	51%	404
DE ↓	37%	63%	167

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

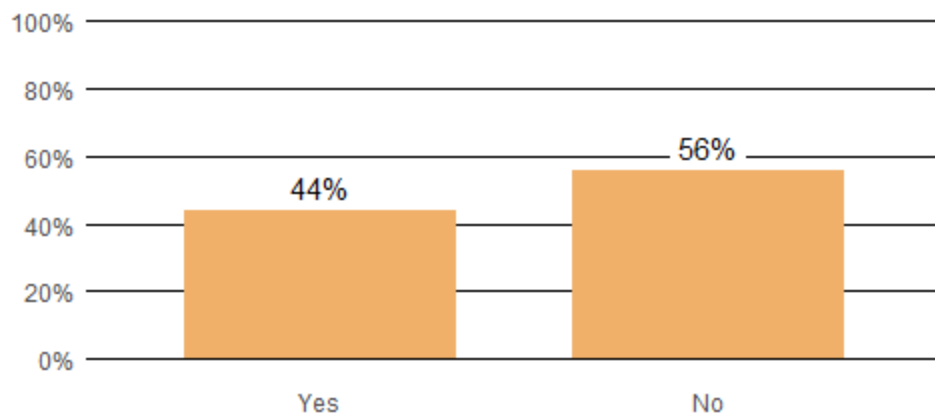


**Table 83. Do you know how to file a complaint or grievance about provider agencies or staff?**

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

State	Yes	No or Don't Know	N
DC ↑	80%	20%	153
PA ↑	73%	27%	253
KY ↑	70%	30%	215
OK	66%	34%	403
AZ	61%	39%	222
<b>Weighted NCI-IDD Average</b>	<b>61%</b>	<b>39%</b>	<b>3009</b>
MO	60%	40%	235
MN	58%	42%	433
MD ↓	48%	52%	468
NJ ↓	47%	53%	459
DE ↓	34%	66%	168

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

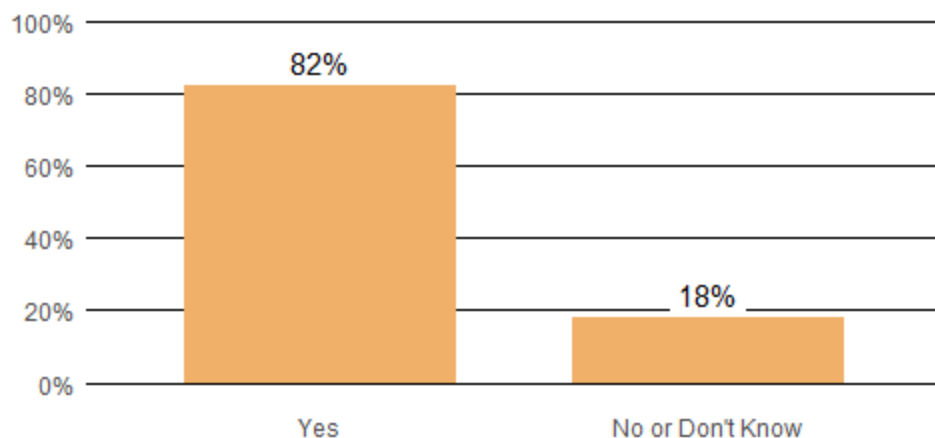


**Table 84. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?**

State	Yes	No	N
<b>MN</b>	46%	54%	37
<b>DC</b>	46%	54%	35
<b>Weighted NCI-IDD Average</b>	<b>44%</b>	<b>56%</b>	<b>218</b>
<b>MD</b>	38%	63%	56
<b>AZ</b>	n/a	n/a	n/a
<b>DE</b>	n/a	n/a	n/a
<b>KY</b>	n/a	n/a	n/a
<b>MO</b>	n/a	n/a	n/a
<b>NJ</b>	n/a	n/a	n/a
<b>OK</b>	n/a	n/a	n/a
<b>PA</b>	n/a	n/a	n/a

*Table note: The following states had an N of less than 20 so their data is reported as n/a: AZ, DE, KY, MO, NJ, PA. They are included in the Weighted NCI-IDD Average.*

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

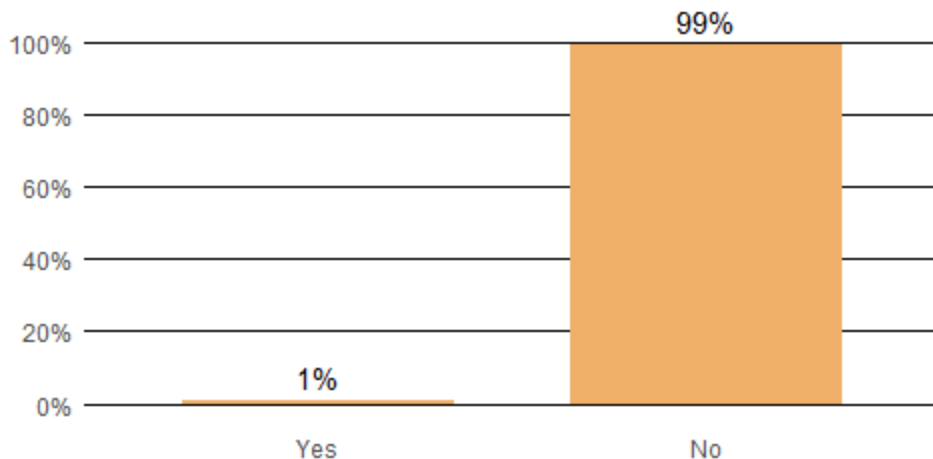


**Table 85. Do you know how to report abuse or neglect related to your family member?**

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

State	Yes	No or Don't Know	N
<b>KY</b> ↑	90%	10%	218
<b>PA</b> ↑	88%	12%	261
<b>DC</b>	87%	13%	151
<b>MN</b>	85%	15%	431
<b>OK</b>	82%	18%	405
<b>AZ</b>	82%	18%	223
<b>Weighted NCI-IDD Average</b>	<b>82%</b>	<b>18%</b>	<b>3030</b>
<b>MO</b>	80%	20%	235
<b>NJ</b> ↓	74%	26%	465
<b>MD</b> ↓	71%	29%	471
<b>DE</b> ↓	68%	32%	170

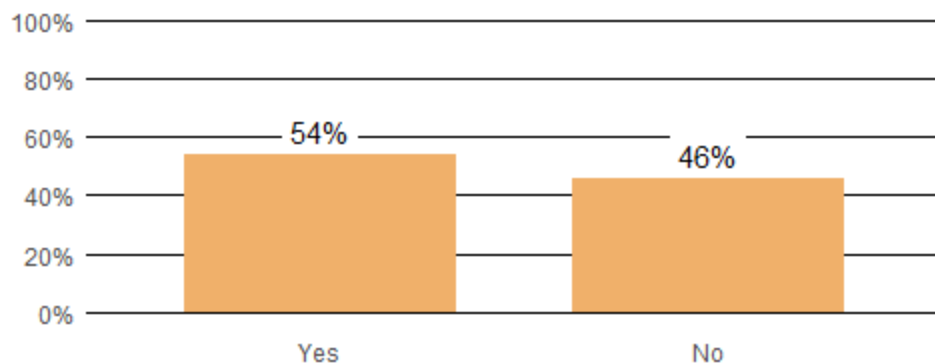
**Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?**



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

State	Yes	No	N
DC	4%	96%	148
AZ	2%	98%	218
NJ	2%	98%	455
OK	2%	98%	395
MD	2%	98%	461
<b>Weighted NCI-IDD Average</b>	<b>1%</b>	<b>99%</b>	<b>2970</b>
MN	1%	99%	424
PA	1%	99%	255
DE	1%	99%	167
KY	0%	100%	216
MO	0%	100%	231

**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?**

State	Yes	No	N
<b>Weighted NCI-IDD Average</b>	<b>54%</b>	<b>46%</b>	<b>27</b>
<b>AZ</b>	n/a	n/a	n/a
<b>DE</b>	n/a	n/a	n/a
<b>DC</b>	n/a	n/a	n/a
<b>KY</b>	n/a	n/a	n/a
<b>MD</b>	n/a	n/a	n/a
<b>MN</b>	n/a	n/a	n/a
<b>MO</b>	n/a	n/a	n/a
<b>NJ</b>	n/a	n/a	n/a
<b>OK</b>	n/a	n/a	n/a
<b>PA</b>	n/a	n/a	n/a

*Table note: The following states had an N of less than 20 so their data is reported as n/a: AZ, DE, DC, KY, MD, MN, MO, NJ, OK, PA. They are included in the Weighted NCI-IDD Average.*

## Family Satisfaction

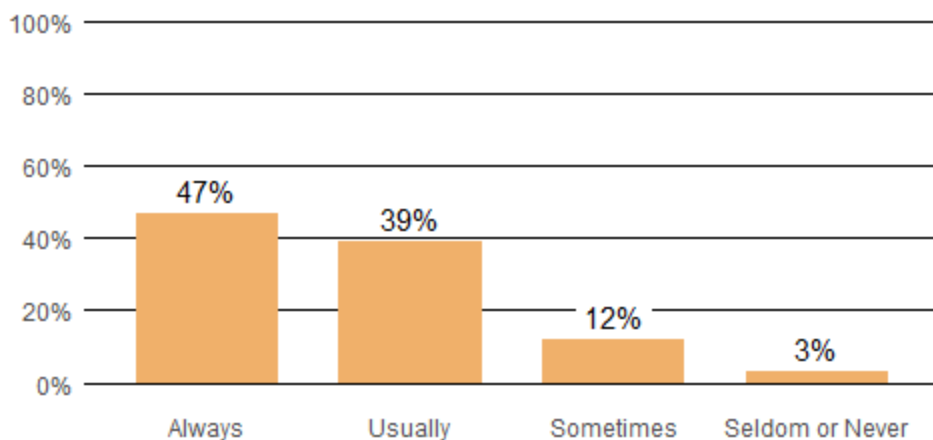
Services and supports lead to better lives for people with disabilities and their families.

**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?**

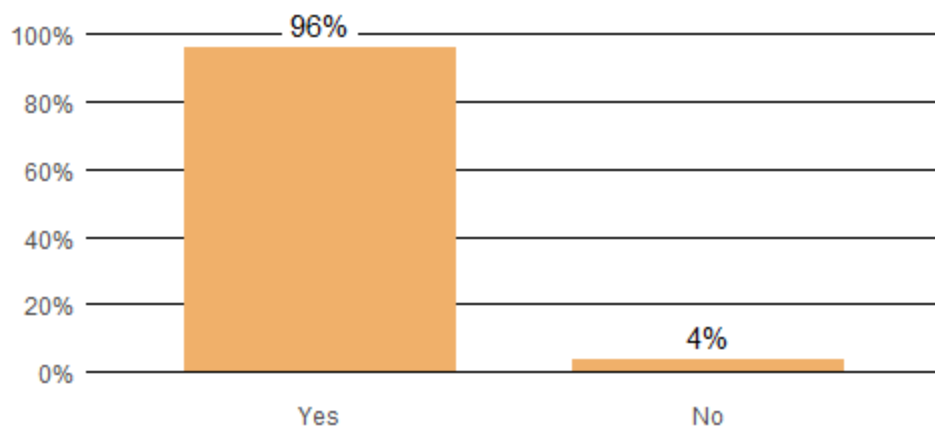


**Table 88. Overall, are you satisfied with the services and supports your family member currently receives?**

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

State	Always	Usually	Sometimes	Seldom or Never	N
<b>KY</b> ↑	63%	31%	6%	1%	216
<b>DC</b> ↑	61%	31%	5%	3%	150
<b>PA</b>	51%	36%	10%	3%	260
<b>AZ</b>	48%	36%	15%	1%	221
<b>OK</b>	48%	39%	10%	4%	398
<b>Weighted NCI-IDD Average</b>	<b>47%</b>	<b>39%</b>	<b>12%</b>	<b>3%</b>	<b>2989</b>
<b>NJ</b>	46%	42%	9%	3%	452
<b>MO</b>	44%	43%	10%	4%	236
<b>MD</b> ↓	39%	39%	17%	5%	457
<b>MN</b> ↓	38%	48%	11%	2%	427
<b>DE</b> ↓	30%	43%	23%	4%	172

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

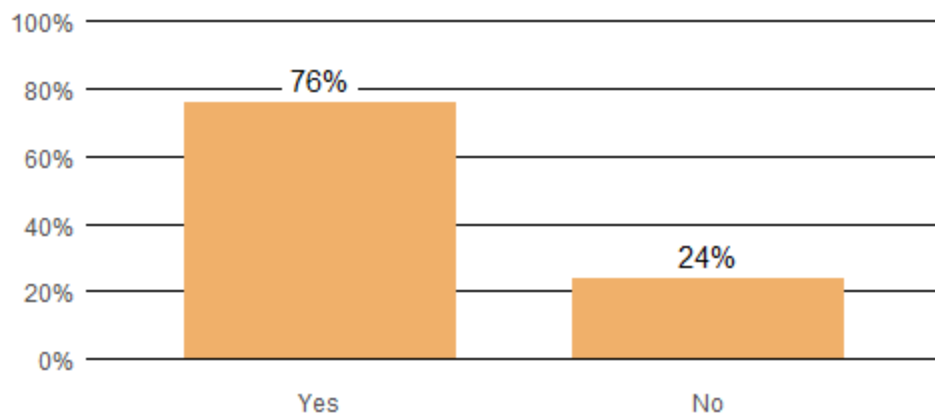


**Table 89. Do you feel that services and supports have made a positive difference in the life of your family member?**

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

State	Yes	No	N
KY	98%	2%	209
OK	97%	3%	376
DC	96%	4%	142
NJ	96%	4%	448
MN	96%	4%	411
<b>Weighted NCI-IDD Average</b>	<b>96%</b>	<b>4%</b>	<b>2873</b>
PA	96%	4%	248
AZ	96%	4%	215
MD	96%	4%	441
MO	95%	5%	227
DE ↓	88%	12%	156

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

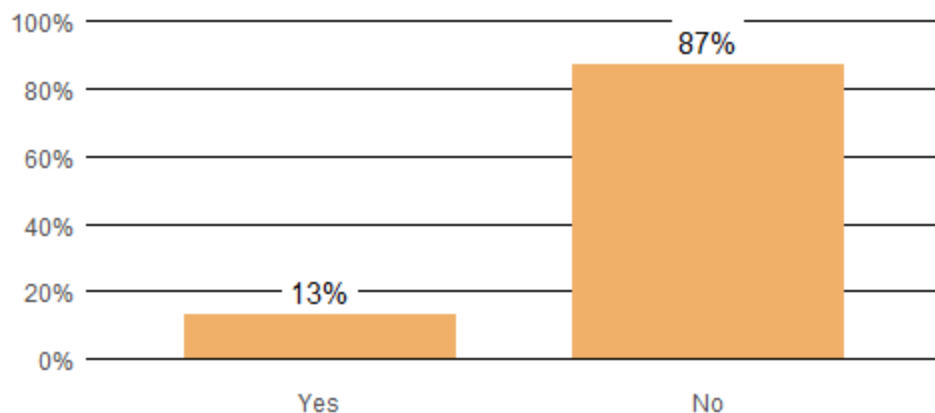


**Table 90. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?**

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

State	Yes	No	N
<b>AZ</b> ↑	84%	16%	204
<b>NJ</b> ↑	82%	18%	438
<b>MN</b>	78%	22%	388
<b>KY</b>	77%	23%	206
<b>Weighted NCI-IDD Average</b>	<b>76%</b>	<b>24%</b>	<b>2747</b>
<b>OK</b>	76%	24%	349
<b>MD</b>	74%	26%	432
<b>PA</b>	71%	29%	225
<b>MO</b> ↓	67%	33%	217
<b>DC</b> ↓	58%	42%	137
<b>DE</b> ↓	54%	46%	151

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

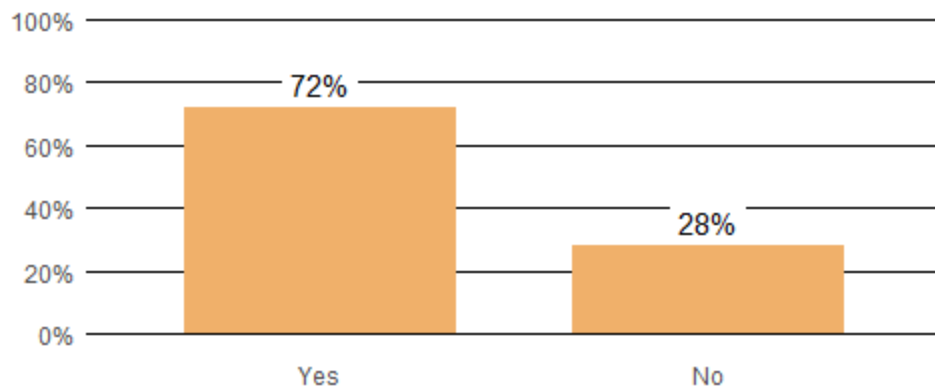


**Table 91. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?**

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

State	Yes	No	N
MD ↑	23%	77%	451
MN	17%	83%	406
MO	16%	84%	223
DC	15%	85%	144
PA	13%	87%	246
<b>Weighted NCI-IDD Average</b>	<b>13%</b>	<b>87%</b>	<b>2888</b>
DE	12%	88%	163
NJ	10%	90%	448
OK	9%	91%	382
AZ	9%	91%	213
KY ↓	5%	95%	212

**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?**



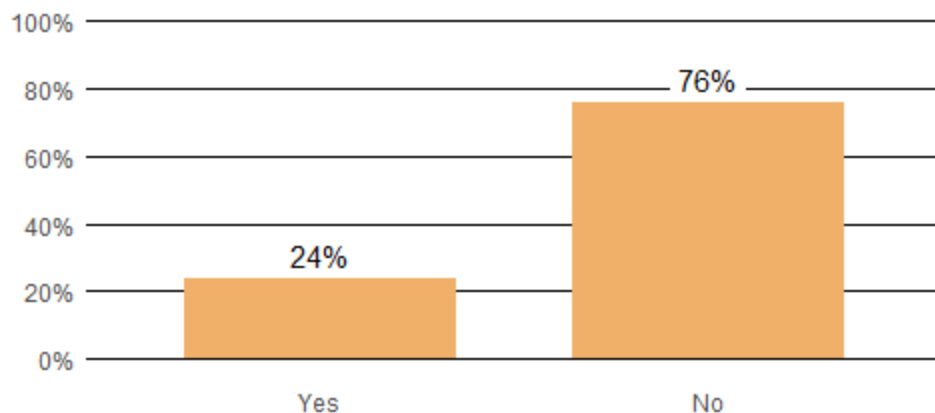
**Table 92. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?**

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

State	Yes	No	N
MD ↑	85%	15%	97
NJ	75%	25%	40
<b>Weighted NCI-IDD Average</b>	<b>72%</b>	<b>28%</b>	<b>351</b>
MO	70%	30%	33
MN	68%	32%	56
OK	61%	39%	33
PA	59%	41%	29
AZ	n/a	n/a	n/a
DE	n/a	n/a	n/a
DC	n/a	n/a	n/a
KY	n/a	n/a	n/a

Table note: The following states had an N of less than 20 so their data is reported as n/a: AZ, DE, DC, KY. They are included in the Weighted NCI-IDD Average.

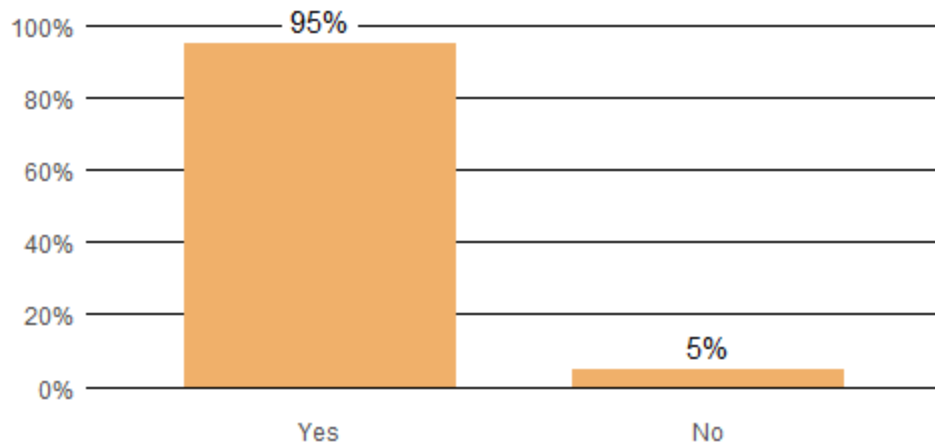
Have the services or supports that your family member received been increased in the past 12 months?



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

State	Yes	No	N
KY	33%	67%	195
MN	26%	74%	375
NJ	25%	75%	409
OK	25%	75%	345
AZ	25%	75%	207
<b>Weighted NCI-IDD Average</b>	<b>24%</b>	<b>76%</b>	<b>2711</b>
PA	23%	78%	240
MD	22%	78%	432
MO	20%	80%	213
DE	18%	82%	158
DC	18%	82%	137

**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
<b>MN</b> ↑	98%	2%	407
<b>KY</b>	96%	4%	211
<b>MO</b>	96%	4%	222
<b>OK</b>	96%	4%	377
<b>NJ</b>	95%	5%	421
<b>Weighted NCI-IDD Average</b>	<b>95%</b>	<b>5%</b>	<b>2802</b>
<b>PA</b>	95%	5%	244
<b>MD</b>	95%	5%	429
<b>DC</b>	94%	6%	139
<b>AZ</b>	93%	7%	208
<b>DE</b>	90%	10%	144

## NCI History and Activities

This section briefly describes the history of the National Core Indicators and NCI 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-Intellectual and Developmental Disabilities (NCI-IDD), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI-IDD facilitates pooled knowledge, expertise, and resources among the states.

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

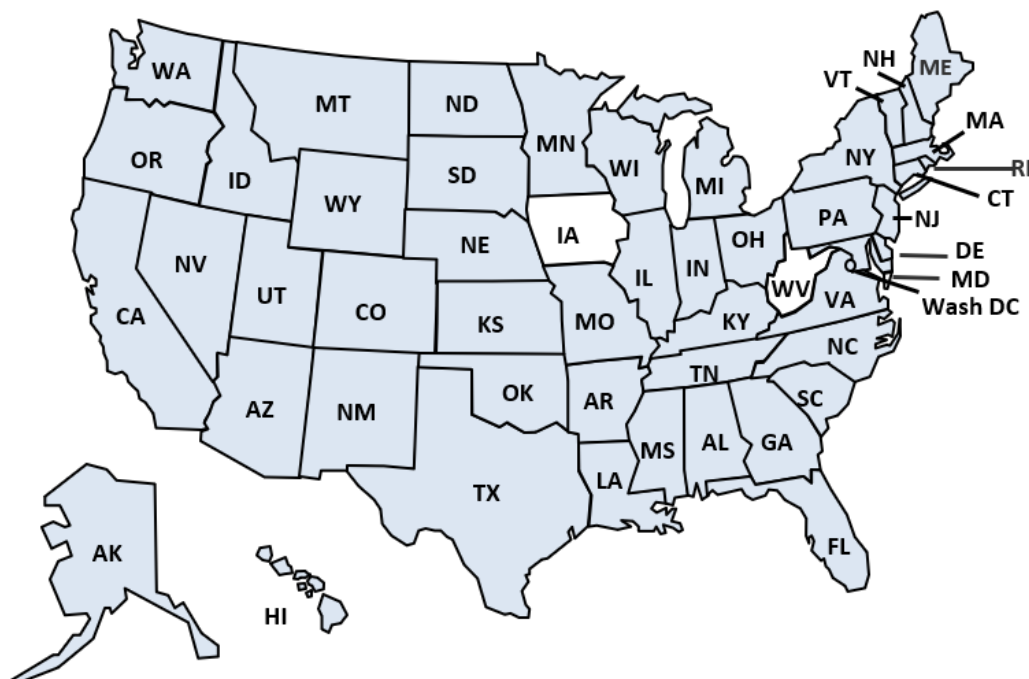
1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of disability or residential setting

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

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

### State Participation

During the 2024-25 data collection cycle, 48 states, the District of Columbia and 22 sub-state entities participated in NCI-IDD. State participation is entirely voluntary, and participating states are highlighted on the map below. Not all states participate in all surveys each year.

**Figure 1. NCI-IDD State Participation 2024-25**

## 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 NCI State of the Workforce Survey for IDD.

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI-IDD program 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.

**Figure 2. Family Survey Sub-Domains and Concern Statements**

Sub-Domain	Value Statement
<b>Information and Planning</b>	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.
<b>Choice and Decision Making</b>	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.
<b>Access &amp; Support Delivery</b>	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.
<b>Workforce</b>	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.
<b>Community Connections</b>	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.
<b>Health, Welfare, and Safety</b>	Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state Developmental disabilities system.
<b>Family Satisfaction</b>	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 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 2024-25, 10 states administered the Adult Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The following table shows the number of individuals receiving services who were eligible to be drawn into the sample (“total population”), the number of surveys each state sent, complete surveys, response rates, margins of error, and survey submission modes.

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.

**Figure 3. Adult Family Survey: State Response Rates**

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	14101	1400	227	16%	6.0%	74%	26%
DE	666	666	180	27%	6.7%	67%	33%
DC	761	761	157	21%	7.2%	69%	31%
KY	6956	1889	223	12%	6.0%	79%	21%
MD	11880	8930	528	6%	3.9%	2%	98%
MN	8886	1600	444	28%	4.3%	83%	17%
MO	5001	1500	239	16%	5.8%	87%	13%
NJ	13293	13293	504	4%	4.0%	1%	99%
OK	3327	2000	409	20%	4.4%	100%	0%
PA	20815	2000	274	14%	5.4%	48%	52%
<b>Total</b>	<b>85686</b>	<b>34039</b>	<b>3185</b>	<b>9%</b>	<b>1.6%</b>	<b>54%</b>	<b>46%</b>