

# Adult Family Survey

2020-2021 Final Report





Human Services  
Research Institute

**Human Services Research Institute (HSRI)**

2336 Massachusetts Avenue  
Cambridge, MA 02140

**NASDDDS**

National Association of State Directors of Developmental Disabilities Services

**National Association of State Directors of Developmental Disabilities Services (NASDDDS)**

301 N Fairfax Street, Suite 101  
Alexandria, VA 22314

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## **List of Abbreviations Used in This Report**

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

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# Executive Summary

The National Core Indicators (NCI) are standard measures used across states to assess the outcomes of services provided to individuals with intellectual/developmental disabilities and their families. Indicators address key areas of concern such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that result from NCI 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 administer the Adult Family Survey on an annual basis. Of the 46 states, the District of Columbia and 22 sub-state entities that were members of NCI during the 2020-21 data collection cycle, 12 states submitted a valid sample of Adult Family Survey data: Arizona (AZ), Delaware (DE), Florida (FL), Georgia (GA), Louisiana (LA), Maryland (MD), Minnesota (MN), Missouri (MO), New Jersey (NJ), Oklahoma (OK), Pennsylvania (PA), and Virginia (VA). This Final Report provides a summary of results based on data submitted by June 30, 2021.

## *Important note on Impact of COVID-19*

The 2020-21 NCI Family Survey data collection cycle began July 1, 2020 and ended June 30, 2021. As COVID-19 continued to spread across the United States, states were impacted in various ways throughout the year. Because the family surveys do not collect information on the date of survey completion, these data cannot fully assess what impact the pandemic had on data collected at different times throughout the year. While these data will serve as an important baseline, and meaningful way for states to understand the overall impact of services on families of individuals being served, these data should be read with caution.

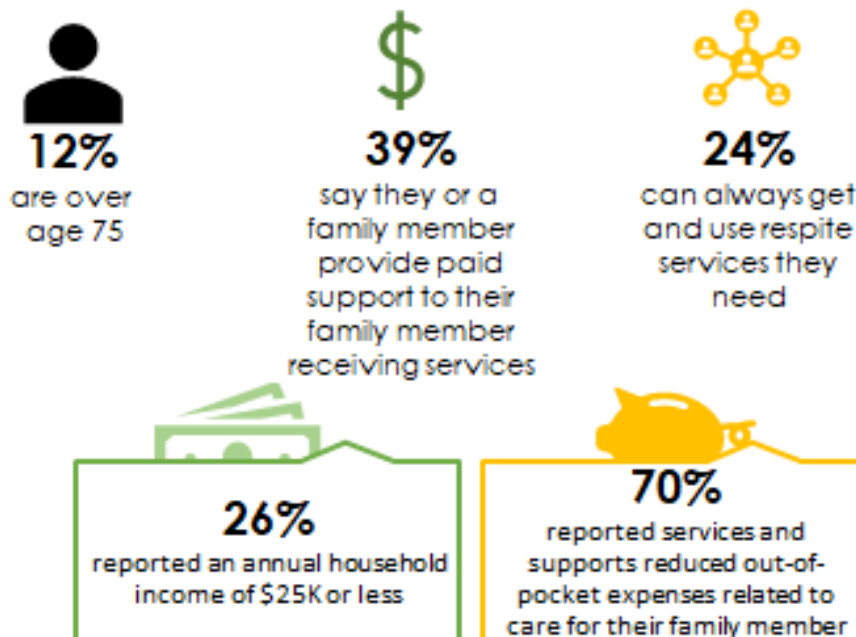
To help better understand the overall impact of COVID-19 on families, NCI-IDD added a state-optional COVID-19 Supplement to all NCI Surveys. The COVID-19 Supplement is intended to support the understanding of the experience of people with disabilities and their families at the beginning of the COVID-19 pandemic, and their interactions with services during that time. The NCI Family Survey COVID-19 Supplement can be found [here](#).



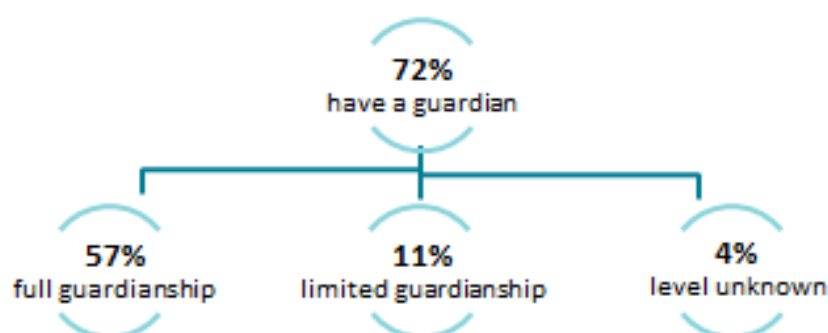
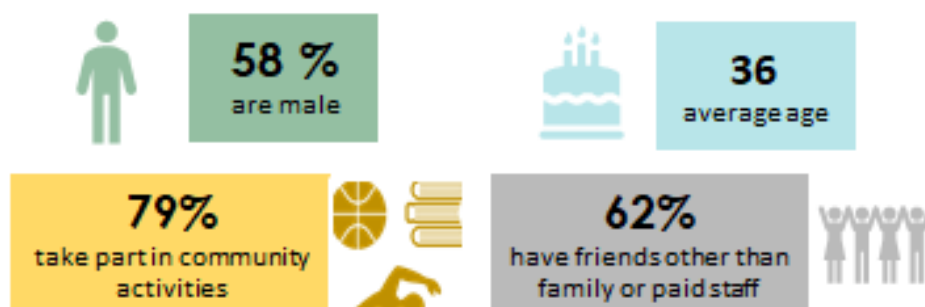
### Respondents

Family members and/or guardians of adults who have IDD and receive at least one service in addition to case management from the state DD service system. The respondent lives with the adult receiving services.

### Respondents . . .



### Family member with IDD . . .



## 2020–21 Adult Family Survey (AFS)

4,952 families  
participated across  
12 states\*

### NCI-IDD Averages:

- Include all participating states
- Data are weighted

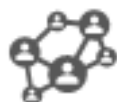
\*2020–21 AFS participating states were: AZ, DE, FL, GA, LA, MD, MN, MO, NJ, OK, PA, and VA

## 2020–21 Adult Family Survey



**73%**

have resources in the community the family can use that are not provided by the IDD agency



**17%**

take part in family-to-family networks



**95%**

feel services and supports have made a positive difference for their family member



**39%** say they *always* get enough information to help plan services



**41%** say services and supports *always* change when their family's needs change



**85%** say they or another family member helped make the service plan



**63%** say their family member with IDD helped make the service plan



**74%**

family member can *always* see health professionals when needed



**65%**

family member can *always* go to the dentist when needed



**51%**

crisis or emergency services were provided in the past year when needed

# I. Results

*This section provides state-by-state and national results for demographic and survey outcomes data.*

# Presentation of Data

In addition to basic demographic questions and questions on services received, the survey contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes. Each question is constructed so the respondent selects from either four possible responses ("always," "usually," "sometimes," "seldom/never") or two responses ("yes" or "no"). Respondents also have the option to indicate that they don't know the answer to a question or that the question is not applicable.

Demographic results are shown in table form with states listed alphabetically. Outcomes are shown first with a chart depicting the NCI Average. The charts are followed by accessible tables showing state outcomes and the NCI 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 Average range, their 'always' or 'yes' response was not statistically different from the NCI Average.

States with 20 or fewer respondents to a question **are not** included in tables; however, their data **are** included in the NCI Average.

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

**Note on NCI Averages:** The NCI 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 averages were calculated as the simple arithmetic mean of all state means (an approach known as "average of averages"), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.

**Note on language used in this report:** "You" and "Respondent" refers to the person (usually a parent or guardian) filling out the survey. "Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.

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

# Demographics

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

## *Family Member*

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

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

State	Yes	No	N
AZ	14%	86%	269
DE	21%	79%	148
FL	14%	86%	430
GA	17%	83%	414
LA	17%	83%	232
MD	10%	90%	1,165
MN	16%	84%	447
MO	11%	89%	269
NJ	13%	87%	280
OK	8%	92%	378
PA	15%	85%	576
VA	8%	92%	149
<b>Weighted NCI-IDD Average</b>	<b>14%</b>	<b>86%</b>	<b>4,757</b>

Table 2. Family Member's Age

State	Mean	N
AZ	31.2	269
DE	35.4	151
FL	37.2	441
GA	47.2	417
LA	32.4	225
MD	33.8	1,122
MN	31.7	412
MO	33.7	277
NJ	31.9	288
OK	37.0	387
PA	36.7	610
VA	35.9	153
<b>Weighted NCI-IDD Average</b>	<b>35.6</b>	<b>4,752</b>

Table 3. Family Member's Gender

State	Male	Female	N
AZ	57%	43%	274
DE	64%	36%	146
FL	62%	38%	443
GA	52%	48%	414
LA	54%	46%	227
MD	64%	36%	1,150
MN	60%	40%	424
MO	55%	45%	273
NJ	67%	33%	242
OK	54%	46%	389
PA	52%	48%	598
VA	56%	44%	152
Weighted NCI-IDD Average	58%	42%	4,732

Table 4. Family Member's Race and Ethnicity

All data 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	N
AZ	3%	3%	5%	0%	69%	26%	1%	281
DE	1%	5%	20%	0%	71%	4%	1%	147
FL	1%	4%	21%	0%	57%	22%	4%	438
GA	0%	0%	43%	0%	56%	0%	1%	418
LA	2%	2%	20%	0%	77%	3%	1%	234
MD	2%	8%	26%	0%	66%	4%	1%	1,185
MN	3%	6%	8%	0%	83%	4%	2%	453
MO	1%	2%	7%	0%	91%	2%	1%	274
NJ	0%	5%	10%	0%	79%	9%	2%	278
OK	18%	2%	10%	0%	74%	6%	1%	389
PA	1%	2%	9%	0%	86%	3%	2%	597
VA	1%	8%	24%	0%	67%	1%	4%	156
Weighted NCI-IDD Average	2%	4%	16%	0%	72%	10%	2%	4,850



**Table 5a. Family Member's Disabilities**

All data 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	Mental Illness or psychiatric diagnosis	Autism Spectrum Disorder	Cerebral palsy	Limited or no vision	Hearing loss (severe or profound)
AZ	66%	22%	40%	22%	11%	8%
DE	67%	21%	38%	9%	8%	2%
FL	66%	26%	36%	24%	9%	5%
GA	71%	26%	19%	25%	13%	8%
LA	66%	19%	35%	18%	8%	5%
MD	70%	22%	42%	16%	7%	4%
MN	69%	29%	40%	14%	9%	6%
MO	65%	24%	41%	20%	12%	6%
NJ	65%	20%	49%	18%	8%	4%
OK	76%	21%	24%	28%	11%	7%
PA	79%	22%	31%	19%	8%	7%
VA	72%	31%	40%	26%	12%	9%
<b>Weighted NCI-IDD Average</b>	<b>70%</b>	<b>24%</b>	<b>36%</b>	<b>21%</b>	<b>10%</b>	<b>6%</b>

**Table 5b. Family Member's Disabilities (continued)**

All data 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	Brain injury	Seizure or neurological disorder	Chemical dependency	Down syndrome	Prader-Willi syndrome	Fetal alcohol spectrum disorder (FASD)	Other
AZ	13%	32%	1%	18%	0%	1%	18%
DE	6%	20%	0%	14%	1%	2%	19%
FL	11%	32%	2%	13%	0%	0%	20%
GA	12%	36%	1%	15%	1%	0%	22%
LA	10%	36%	0%	14%	0%	0%	31%
MD	9%	22%	0%	15%	1%	1%	17%
MN	10%	26%	1%	18%	1%	2%	22%
MO	14%	31%	0%	17%	0%	1%	15%
NJ	8%	33%	0%	13%	1%	1%	19%
OK	17%	36%	0%	20%	1%	2%	16%
PA	7%	26%	0%	19%	0%	1%	19%
VA	8%	31%	0%	10%	0%	1%	20%
<b>Weighted NCI-IDD Average</b>	<b>10%</b>	<b>30%</b>	<b>1%</b>	<b>15%</b>	<b>0%</b>	<b>1%</b>	<b>20%</b>

**Table 6a. Family Member's Health Conditions**

All data 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%	17%	6%	19%	28%
DE	11%	22%	7%	31%	27%
FL	11%	17%	7%	35%	34%
GA	8%	28%	7%	44%	38%
LA	13%	23%	4%	33%	31%
MD	10%	15%	3%	29%	24%
MN	8%	17%	7%	20%	20%
MO	13%	20%	5%	32%	22%
NJ	13%	10%	7%	22%	38%
OK	12%	17%	6%	34%	21%
PA	9%	15%	5%	27%	29%
VA	13%	16%	8%	28%	33%
<b>Weighted NCI-IDD Average</b>	<b>11%</b>	<b>17%</b>	<b>6%</b>	<b>29%</b>	<b>31%</b>

**Table 6b. Family Member's Health Conditions (continued)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Dysphagia	Pressure ulcers	Alzheimer's disease or other dementia	Oral health problems	Sleep apnea	Other
AZ	13%	3%	2%	18%	26%	27%
DE	8%	0%	0%	11%	22%	19%
FL	11%	4%	3%	17%	14%	25%
GA	10%	4%	4%	15%	17%	24%
LA	17%	4%	1%	11%	22%	30%
MD	10%	3%	1%	10%	16%	28%
MN	14%	3%	2%	16%	22%	34%
MO	13%	2%	5%	18%	18%	28%
NJ	16%	4%	2%	10%	20%	43%
OK	17%	4%	1%	16%	23%	21%
PA	10%	1%	2%	5%	17%	35%
VA	9%	4%	3%	18%	14%	35%
<b>Weighted NCI-IDD Average</b>	<b>12%</b>	<b>3%</b>	<b>2%</b>	<b>13%</b>	<b>18%</b>	<b>30%</b>

**Table 7. Family Member's Preferred Means of Communication**

State	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
AZ	75%	16%	2%	4%	4%	279
DE	87%	9%	0%	1%	3%	148
FL	70%	17%	2%	2%	8%	441
GA	69%	21%	2%	1%	7%	414
LA	77%	15%	0%	1%	6%	232
MD	80%	13%	2%	2%	4%	1,187
MN	82%	11%	1%	3%	4%	432
MO	75%	19%	1%	1%	4%	265
NJ	75%	14%	0%	2%	9%	277
OK	72%	24%	1%	1%	2%	386
PA	82%	11%	1%	1%	5%	602
VA	62%	28%	2%	1%	6%	155
<b>Weighted NCI-IDD Average</b>	<b>75%</b>	<b>16%</b>	<b>1%</b>	<b>2%</b>	<b>6%</b>	<b>4,818</b>

**Table 8. Family Member Has Legal Court Appointed Guardian or Conservator**

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

State	No, does not have a guardian or conservator	Yes, limited guardianship	Yes, full guardianship	Yes, has a guardian but not sure whether it's full or limited	N
AZ	21%	6%	70%	3%	277
DE	48%	9%	40%	3%	141
FL	29%	18%	49%	5%	414
GA	31%	15%	50%	4%	385
LA	33%	10%	51%	6%	211
MD	52%	13%	32%	4%	1,111
MN	10%	6%	80%	4%	452
MO	21%	9%	67%	3%	264
NJ	2%	7%	88%	2%	282
OK	20%	10%	66%	4%	375
PA	40%	11%	43%	5%	553
VA	27%	11%	60%	2%	145
<b>Weighted NCI-IDD Average</b>	<b>28%</b>	<b>11%</b>	<b>57%</b>	<b>4%</b>	<b>4,610</b>

Table 9. Guardian or Conservator Relationship to Family Member

State	Family	Friend	Employee of state or guardianship agency	Other	N
AZ	98%	2%	0%	0%	213
DE	93%	2%	0%	5%	60
FL	88%	1%	0%	11%	285
GA	94%	1%	0%	5%	235
LA	99%	1%	0%	0%	139
MD	88%	0%	0%	11%	512
MN	98%	1%	1%	1%	399
MO	96%	0%	1%	3%	201
NJ	97%	0%	0%	3%	270
OK	97%	1%	0%	2%	292
PA	96%	1%	1%	1%	310
VA	93%	5%	0%	2%	98
Weighted NCI-IDD Average	95%	1%	0%	4%	3,014

Table 10. Family Member's Highest level of Education

State	Did not complete high school (and not currently in school)	Currently enrolled in high school	High school certificate (not a high school diploma or GED)	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	11%	5%	24%	45%	1%	8%	7%	271
DE	14%	1%	46%	24%	4%	6%	4%	145
FL	19%	2%	38%	26%	4%	5%	6%	420
GA	26%	0%	41%	27%	1%	2%	2%	386
LA	18%	4%	40%	15%	4%	9%	10%	230
MD	8%	1%	57%	19%	4%	6%	5%	1,172
MN	8%	3%	27%	50%	5%	4%	4%	440
MO	12%	1%	30%	47%	3%	4%	3%	256
NJ	11%	1%	28%	41%	2%	6%	11%	279
OK	12%	5%	25%	50%	3%	2%	4%	383
PA	13%	1%	24%	53%	2%	3%	3%	573
VA	15%	5%	46%	24%	4%	3%	3%	149
Weighted NCI-IDD Average	14%	2%	33%	37%	3%	5%	5%	4,704

Table 11. Family Member's Activities in the Past Two Weeks Included *Paid Individual Job in the Community*<sup>1</sup>

State	Yes	No	N
AZ	8%	92%	278
DE	24%	76%	143
FL	7%	93%	436
GA	4%	96%	414
LA	12%	88%	226
MD	22%	78%	1,172
MN	19%	81%	443
MO	13%	87%	270
NJ	15%	85%	270
OK	10%	90%	386
PA	16%	84%	594
VA	9%	91%	148
<b>Weighted NCI-IDD Average</b>	<b>12%</b>	<b>88%</b>	<b>4,780</b>

Table 12. Family Member's Activities in the Past Two Weeks Included *Paid Small Group Job in a Community-based Setting*<sup>2</sup>

State	Yes	No	N
AZ	5%	95%	274
DE	12%	88%	140
FL	3%	97%	430
GA	4%	96%	409
LA	7%	93%	219
MD	5%	95%	1,163
MN	9%	91%	425
MO	7%	93%	267
NJ	3%	97%	261
OK	10%	90%	384
PA	7%	93%	583
VA	3%	97%	147
<b>Weighted NCI-IDD Average</b>	<b>5%</b>	<b>95%</b>	<b>4,702</b>

<sup>1</sup> An individual job is defined as work at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (for example, competitive employment).

<sup>2</sup> A small group job is defined as work in an integrated setting, as part of a group of not more than 8 people with disabilities (for example, enclave, work crew).

**Table 13. Family Member's Activities in the Past Two Weeks Included *Paid Work in a Community Job That Primarily Hires People with Disabilities*<sup>3</sup>**

State	Yes	No	N
AZ	5%	95%	275
DE	9%	91%	139
FL	3%	97%	439
GA	2%	98%	405
LA	5%	95%	224
MD	8%	92%	1,153
MN	6%	94%	429
MO	7%	93%	266
NJ	4%	96%	264
OK	7%	93%	379
PA	8%	92%	574
VA	4%	96%	147
<b>Weighted NCI-IDD Average</b>	<b>5%</b>	<b>95%</b>	<b>4,694</b>

**Table 14. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in the Community*<sup>4</sup>**

State	Yes	No	N
AZ	15%	85%	278
DE	11%	89%	141
FL	10%	90%	433
GA	13%	87%	408
LA	11%	89%	221
MD	22%	78%	1,159
MN	18%	82%	426
MO	19%	81%	264
NJ	16%	84%	265
OK	15%	85%	381
PA	19%	81%	584
VA	10%	90%	147
<b>Weighted NCI-IDD Average</b>	<b>15%</b>	<b>85%</b>	<b>4,707</b>

<sup>3</sup> Paid work in a community job that primarily hires people with disabilities is defined as work in a setting where the person interacts with the non-disabled population; this is NOT in a traditional sheltered workshop and NOT an enclave.

<sup>4</sup> Unpaid work in the community includes: volunteering, skills training, and staff-supported community connections.

Table 15. Family Member's Activities in the Past Two Weeks Included *Paid Activity in a Facility-based Setting*<sup>5</sup>

State	Yes	No	N
AZ	7%	93%	274
DE	8%	92%	140
FL	8%	92%	438
GA	6%	94%	402
LA	8%	92%	219
MD	5%	95%	1,155
MN	15%	85%	432
MO	18%	82%	268
NJ	7%	93%	270
OK	12%	88%	380
PA	13%	87%	580
VA	3%	97%	148
<b>Weighted NCI-IDD Average</b>	<b>9%</b>	<b>91%</b>	<b>4,706</b>

Table 16. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in a Facility-based Setting*<sup>6</sup>

State	Yes	No	N
AZ	20%	80%	271
DE	18%	82%	140
FL	11%	89%	435
GA	22%	78%	390
LA	12%	88%	224
MD	16%	84%	1,150
MN	14%	86%	429
MO	27%	73%	264
NJ	31%	69%	266
OK	10%	90%	378
PA	16%	84%	576
VA	7%	93%	144
<b>Weighted NCI-IDD Average</b>	<b>17%</b>	<b>83%</b>	<b>4,667</b>

<sup>5</sup> Paid work performed in a facility-based setting is defined as work at a location developed specifically to provide work activity exclusively for people with disabilities; may be paid sub-minimum wage. Examples include traditional sheltered workshops or work activity centers.

<sup>6</sup> An unpaid activity in a facility-based setting includes day habilitation, senior programs, or drop-in centers.

Table 17. Family Member's Activities in the Past Two Weeks Included *School*

State	Yes	No	N
AZ	10%	90%	275
DE	3%	97%	137
FL	10%	90%	431
GA	4%	96%	402
LA	7%	93%	222
MD	6%	94%	1,155
MN	9%	91%	419
MO	5%	95%	265
NJ	8%	92%	268
OK	6%	94%	376
PA	12%	88%	555
VA	13%	87%	135
Weighted NCI-IDD Average	9%	91%	4,640

Table 18. Family Member's Activities in the Past Two Weeks Included *Stay at Home*

State	Yes	No	N
AZ	72%	28%	268
DE	72%	28%	138
FL	72%	28%	425
GA	72%	28%	379
LA	80%	20%	222
MD	70%	30%	1,132
MN	67%	33%	420
MO	57%	43%	253
NJ	68%	32%	261
OK	78%	22%	370
PA	74%	26%	549
VA	81%	19%	134
Weighted NCI-IDD Average	72%	28%	4,551



Table 19. Family Member's Activities in the Past Two Weeks Included *Other Activities*

State	Yes	No	N
AZ	40%	60%	110
DE	27%	73%	41
FL	30%	70%	151
GA	39%	61%	134
LA	32%	68%	95
MD	42%	58%	411
MN	32%	68%	165
MO	41%	59%	87
NJ	50%	50%	113
OK	29%	71%	119
PA	50%	50%	161
VA	44%	56%	62
Weighted NCI-IDD Average	40%	60%	1,649

Table 20. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

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

State	No support needed	Some support needed	Extensive support needed	N
AZ	59%	30%	11%	279
DE	64%	30%	6%	143
FL	56%	29%	15%	441
GA	54%	29%	17%	405
LA	54%	32%	14%	231
MD	60%	27%	13%	1,178
MN	43%	36%	21%	449
MO	51%	32%	17%	265
NJ	50%	29%	21%	277
OK	63%	28%	10%	378
PA	64%	26%	10%	592
VA	39%	37%	24%	153
Weighted NCI-IDD Average	56%	30%	15%	4,791

**Table 21. Family Member's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)**

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

State	No support needed	Some support needed	Extensive support needed	N
AZ	20%	40%	41%	280
DE	42%	40%	18%	144
FL	23%	34%	43%	445
GA	23%	32%	46%	413
LA	19%	32%	49%	229
MD	34%	36%	30%	1,196
MN	18%	38%	44%	453
MO	26%	33%	41%	273
NJ	13%	35%	52%	280
OK	23%	35%	42%	391
PA	31%	39%	30%	602
VA	15%	33%	52%	155
<b>Weighted NCI-IDD Average</b>	<b>23%</b>	<b>36%</b>	<b>41%</b>	<b>4,861</b>

**Table 22. Family Member's Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)**

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

State	No support needed	Some support needed	Extensive support needed	N
AZ	2%	18%	80%	277
DE	10%	26%	64%	146
FL	7%	18%	75%	444
GA	7%	17%	76%	411
LA	6%	17%	77%	231
MD	6%	24%	69%	1,187
MN	4%	20%	76%	452
MO	5%	16%	79%	271
NJ	2%	12%	87%	282
OK	4%	17%	79%	389
PA	5%	24%	71%	595
VA	4%	14%	82%	155
<b>Weighted NCI-IDD Average</b>	<b>5%</b>	<b>19%</b>	<b>76%</b>	<b>4,840</b>

## *Respondents*

*This section provides demographic information about the respondent.*

Table 23. Language Usually Spoken at Home

State	English	Spanish	Other	N
AZ	88%	9%	4%	281
DE	97%	1%	2%	148
FL	88%	8%	4%	442
GA	100%	0%	0%	418
LA	99%	0%	1%	228
MD	95%	1%	4%	1,183
MN	95%	1%	3%	452
MO	100%	0%	0%	274
NJ	96%	1%	3%	274
OK	98%	1%	1%	390
PA	98%	1%	1%	593
VA	97%	0%	3%	155
<b>Weighted NCI-IDD Average</b>	<b>94%</b>	<b>3%</b>	<b>2%</b>	<b>4,838</b>

Table 24. Respondent's Age

State	Under 35	35-54	55-74	75 or older	N
AZ	4%	27%	61%	8%	282
DE	2%	15%	74%	9%	149
FL	3%	18%	63%	15%	449
GA	1%	12%	61%	26%	416
LA	3%	27%	63%	7%	231
MD	3%	13%	72%	12%	1,197
MN	5%	24%	65%	6%	454
MO	4%	22%	66%	9%	274
NJ	2%	14%	81%	3%	281
OK	2%	16%	68%	14%	390
PA	2%	16%	70%	12%	596
VA	4%	22%	56%	18%	157
<b>Weighted NCI-IDD Average</b>	<b>3%</b>	<b>19%</b>	<b>67%</b>	<b>12%</b>	<b>4,876</b>

Table 25. Respondent's Health

State	Excellent	Very good	Fairly good	Poor	N
AZ	16%	51%	29%	4%	278
DE	11%	52%	35%	1%	149
FL	12%	45%	40%	4%	447
GA	6%	40%	50%	4%	412
LA	14%	50%	30%	7%	230
MD	18%	48%	32%	2%	1,199
MN	15%	50%	33%	2%	454
MO	14%	46%	36%	5%	276
NJ	15%	51%	31%	2%	283
OK	13%	45%	38%	4%	389
PA	11%	52%	35%	2%	600
VA	12%	44%	39%	5%	154
Weighted NCI-IDD Average	13%	48%	36%	3%	4,871

Table 26. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Other	N
AZ	90%	7%	0%	2%	1%	281
DE	83%	8%	1%	3%	5%	149
FL	86%	7%	0%	1%	4%	447
GA	72%	17%	1%	2%	8%	418
LA	86%	7%	0%	3%	3%	232
MD	92%	5%	0%	0%	3%	1,197
MN	91%	5%	0%	2%	3%	453
MO	89%	4%	0%	3%	5%	273
NJ	92%	6%	0%	0%	1%	281
OK	87%	6%	0%	4%	3%	389
PA	86%	9%	0%	1%	3%	605
VA	82%	7%	1%	2%	8%	158
Weighted NCI-IDD Average	87%	8%	0%	2%	4%	4,883

**Table 27. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services**

Categories are not mutually exclusive

State	Yes, respondent is	Yes, another family member is	No	N
AZ	42%	23%	44%	281
DE	2%	6%	93%	148
FL	10%	8%	82%	441
GA	6%	7%	87%	408
LA	13%	21%	69%	226
MD	15%	10%	76%	1,190
MN	55%	30%	30%	453
MO	10%	11%	79%	274
NJ	32%	28%	42%	278
OK	46%	13%	43%	383
PA	16%	16%	70%	598
VA	31%	21%	49%	154
<b>Weighted NCI-IDD Average</b>	<b>22%</b>	<b>17%</b>	<b>64%</b>	<b>4,834</b>

**Table 28. Number of Adults in Household (Not Including Family Member Receiving Services)**

State	One	Two	Three	Four or More	N
AZ	6%	27%	47%	20%	280
DE	7%	22%	51%	20%	147
FL	6%	35%	43%	16%	440
GA	13%	36%	38%	12%	411
LA	5%	33%	52%	10%	229
MD	7%	25%	48%	19%	1,189
MN	5%	22%	52%	21%	452
MO	6%	23%	54%	17%	271
NJ	4%	20%	43%	34%	280
OK	10%	37%	45%	8%	386
PA	6%	27%	47%	20%	597
VA	7%	35%	46%	12%	151
<b>Weighted NCI-IDD Average</b>	<b>7%</b>	<b>29%</b>	<b>46%</b>	<b>19%</b>	<b>4,833</b>

Table 29. Number of Children (Under 18 Years Old) in Household

State	None	One	Two	Three	Four or More	N
AZ	81%	11%	3%	2%	4%	279
DE	89%	7%	2%	1%	1%	148
FL	90%	5%	3%	1%	0%	445
GA	92%	4%	2%	2%	0%	421
LA	89%	8%	2%	0%	1%	228
MD	89%	7%	2%	1%	0%	1,202
MN	87%	8%	3%	1%	1%	452
MO	89%	7%	2%	2%	0%	276
NJ	92%	4%	2%	1%	0%	281
OK	91%	5%	3%	1%	0%	392
PA	93%	5%	2%	1%	1%	598
VA	84%	13%	2%	1%	0%	154
Weighted NCI-IDD Average	89%	7%	2%	1%	1%	4,876

Table 30. Respondent's Highest Level of Education

State	No high school diploma or GED	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	6%	14%	6%	28%	46%	281
DE	3%	27%	3%	20%	47%	147
FL	9%	29%	7%	19%	37%	440
GA	14%	32%	9%	19%	27%	416
LA	5%	19%	6%	22%	48%	229
MD	3%	17%	2%	21%	56%	1,199
MN	4%	23%	12%	18%	42%	445
MO	5%	23%	5%	21%	45%	266
NJ	1%	16%	4%	18%	61%	281
OK	5%	26%	9%	25%	34%	390
PA	5%	38%	6%	17%	34%	594
VA	6%	26%	6%	20%	41%	156
Weighted NCI-IDD Average	6%	26%	7%	20%	42%	4,844

Table 31. Total Taxable Household Income of Wage Earners in the Past Year

State	No earned income	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	Prefer not to say	N
AZ	8%	6%	8%	18%	17%	24%	19%	277
DE	9%	4%	6%	18%	18%	25%	20%	146
FL	16%	8%	12%	19%	14%	13%	19%	419
GA	30%	9%	12%	16%	8%	8%	18%	402
LA	8%	6%	12%	15%	13%	21%	26%	229
MD	6%	4%	5%	14%	14%	33%	23%	1,162
MN	5%	4%	6%	19%	17%	28%	20%	436
MO	7%	6%	6%	19%	15%	25%	22%	267
NJ	5%	3%	4%	12%	14%	38%	24%	279
OK	8%	14%	9%	20%	13%	16%	20%	363
PA	11%	7%	9%	19%	14%	18%	22%	581
VA	11%	5%	6%	21%	18%	21%	18%	148
Weighted NCI-IDD Average	11%	6%	9%	17%	14%	21%	21%	4,709

Table 32. Residential Designation

State	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
AZ	82%	18%	274
DE	60%	40%	146
FL	81%	19%	427
GA	54%	47%	400
LA	55%	45%	226
MD	70%	30%	1,177
MN	74%	26%	440
MO	63%	37%	269
NJ	76%	24%	272
OK	69%	31%	386
PA	59%	41%	581
VA	62%	38%	149
Weighted NCI-IDD Average	69%	31%	4,747



## *Services and Supports Received*

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

**Table 33. Services and Supports Received from ID/DD Agency**

All data 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	Transportation	Other services or supports	Self-direction or fiscal intermediary services
AZ	9%	44%	42%	44%	46%	41%	31%
DE	8%	6%	19%	53%	57%	17%	21%
FL	19%	46%	17%	30%	45%	22%	40%
GA	16%	42%	19%	47%	59%	16%	44%
LA	14%	60%	14%	24%	41%	22%	43%
MD	12%	30%	15%	49%	55%	22%	27%
MN	33%	52%	32%	45%	54%	27%	62%
MO	18%	30%	25%	50%	55%	23%	39%
NJ	22%	32%	12%	59%	47%	29%	58%
OK	14%	54%	8%	26%	43%	20%	44%
PA	17%	37%	24%	44%	52%	20%	44%
VA	14%	53%	25%	42%	52%	26%	41%
<b>Weighted NCI-IDD Average</b>	<b>17%</b>	<b>42%</b>	<b>22%</b>	<b>42%</b>	<b>50%</b>	<b>25%</b>	<b>42%</b>

**Table 34. Additional Services and Supports Received (not from the IDD Agency)**

All data 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%	27%
DE	83%	41%
FL	95%	23%
GA	96%	17%
LA	92%	21%
MD	92%	31%
MN	96%	32%
MO	95%	28%
NJ	94%	21%
OK	96%	21%
PA	94%	33%
VA	99%	32%
<b>Weighted NCI-IDD Average</b>	<b>94%</b>	<b>27%</b>

# Adult Family Survey Results

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

## *Information and Planning*

*Families and family members with disabilities have the information and support necessary to plan for their services and supports.*

**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.

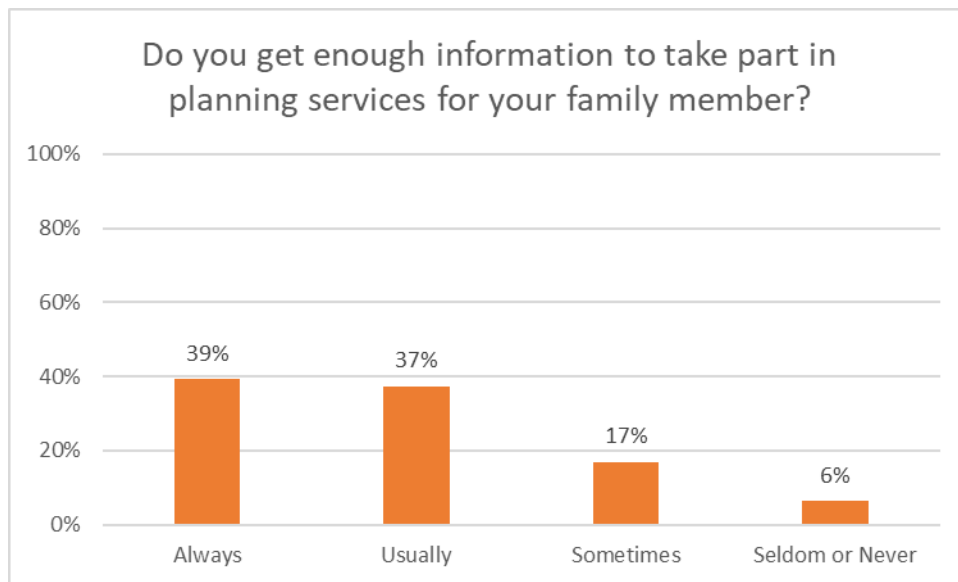


Table Q1. Do you get enough information to take part in planning services for your family member?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	50%	29%	15%	6%	390

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	45%	29%	20%	6%	224
AZ	43%	38%	15%	4%	271
VA	41%	42%	13%	4%	148
PA	41%	37%	15%	7%	552
OK	40%	39%	16%	5%	358
<b>Weighted NCI-IDD Average</b>	<b>39%</b>	<b>37%</b>	<b>17%</b>	<b>6%</b>	<b>4,576</b>
MN	36%	43%	15%	6%	439
GA	34%	38%	19%	9%	383
MO	33%	46%	15%	6%	265

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	31%	42%	19%	9%	1,128
DE	27%	40%	22%	11%	140
NJ	26%	41%	25%	8%	278

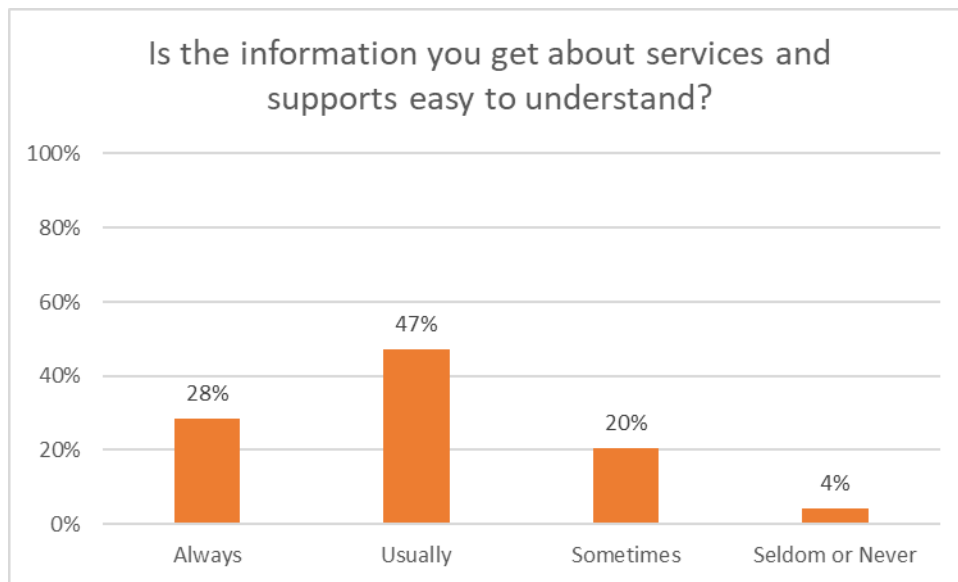


Table Q2. Is the information you get about services and supports easy to understand?

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	34%	47%	18%	1%	151
FL	33%	42%	22%	4%	409
LA	31%	47%	17%	4%	230
OK	31%	47%	20%	2%	367
PA	31%	48%	17%	4%	567
GA	30%	47%	19%	4%	389
AZ	30%	52%	15%	3%	274
<b>Weighted NCI-IDD Average</b>	<b>28%</b>	<b>47%</b>	<b>20%</b>	<b>4%</b>	<b>4,633</b>
MO	22%	56%	18%	3%	264
DE	22%	52%	23%	3%	137

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MD	23%	49%	22%	6%	1,127
MN	22%	51%	20%	6%	443
NJ	19%	40%	36%	5%	275

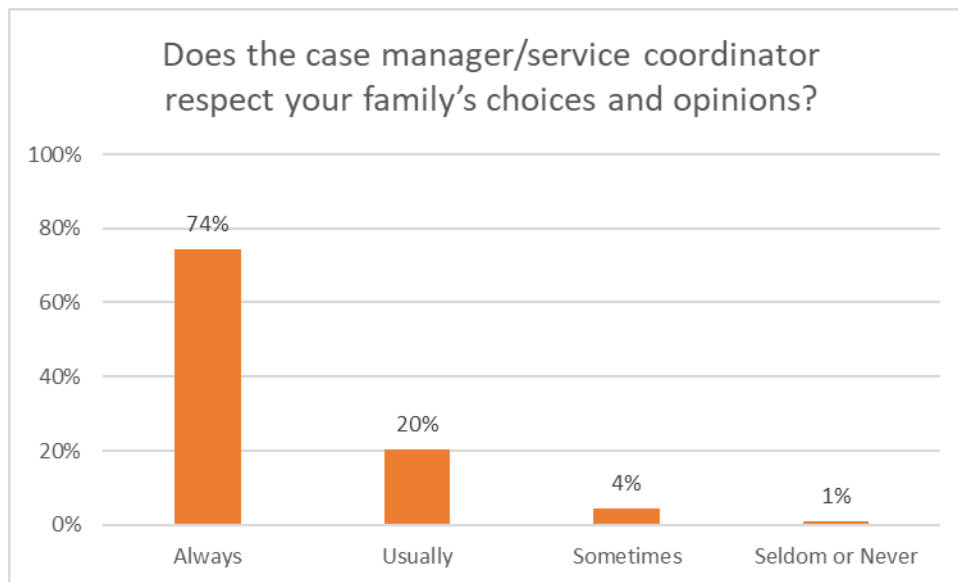


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
FL	81%	15%	4%	0%	425

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	80%	16%	3%	1%	276
LA	80%	16%	4%	0%	231
MN	79%	17%	3%	1%	438
<b>Weighted NCI-IDD Average</b>	<b>74%</b>	<b>20%</b>	<b>4%</b>	<b>1%</b>	<b>4,638</b>
VA	74%	20%	5%	0%	149
PA	73%	22%	5%	0%	575
NJ	73%	22%	4%	1%	274
MO	72%	22%	4%	2%	264
DE	69%	25%	4%	2%	135

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OK	68%	26%	4%	2%	377
MD	64%	28%	5%	2%	1,093
GA	60%	30%	7%	2%	401

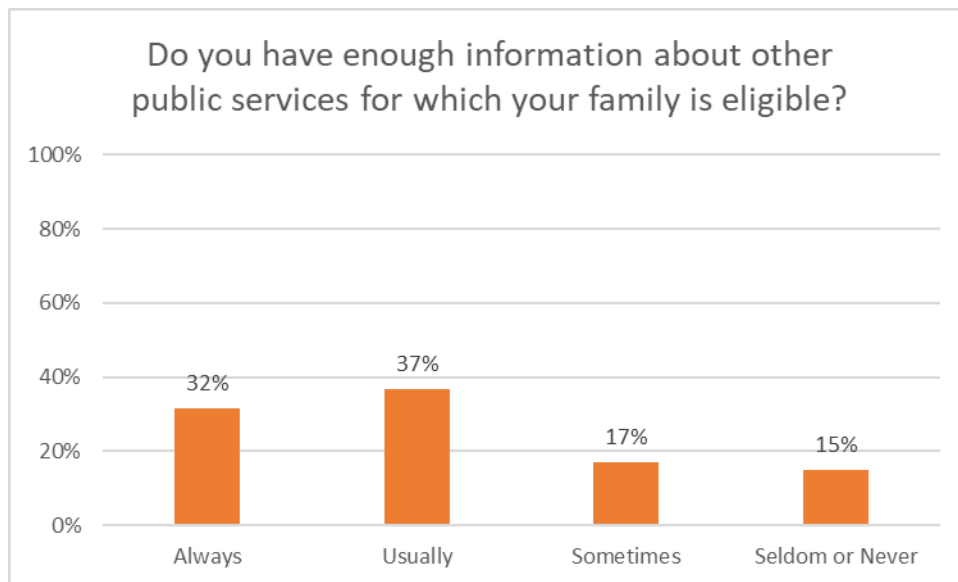


Table Q4. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	40%	30%	15%	15%	381

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	41%	37%	12%	9%	140
PA	35%	38%	15%	11%	510
OK	35%	40%	14%	12%	335
<b>Weighted NCI-IDD Average</b>	<b>32%</b>	<b>37%</b>	<b>17%</b>	<b>15%</b>	<b>4,188</b>
LA	31%	32%	19%	18%	196
AZ	30%	36%	17%	18%	242
GA	28%	40%	17%	15%	339
MN	28%	45%	14%	13%	414
MO	27%	44%	14%	15%	236

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	23%	38%	22%	17%	1,022
NJ	17%	36%	25%	22%	246
DE	17%	44%	24%	15%	127



Do you need help planning for your family member's future with respect to any of the following?

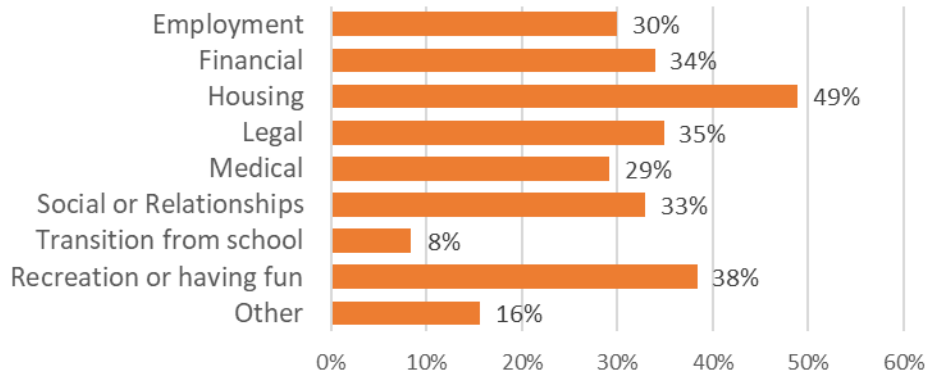


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

Categories are not mutually exclusive, therefore N is not shown

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition From School	Recreation or Having Fun	Other
AZ	39%	35%	46%	40%	28%	36%	9%	39%	7%
DE	45%	39%	50%	32%	31%	39%	4%	38%	10%
FL	22%	34%	39%	34%	34%	32%	12%	37%	20%
GA	8%	22%	32%	34%	25%	14%	3%	28%	20%
LA	31%	39%	43%	39%	32%	35%	15%	38%	15%
MD	43%	40%	56%	36%	31%	37%	6%	40%	16%
MN	41%	31%	54%	28%	22%	30%	10%	38%	17%
MO	22%	32%	55%	36%	26%	32%	6%	37%	10%
NJ	30%	42%	65%	36%	37%	35%	7%	40%	10%
OK	33%	28%	46%	33%	30%	29%	12%	34%	16%
PA	30%	31%	50%	34%	22%	34%	4%	41%	20%
VA	31%	30%	57%	32%	30%	39%	13%	45%	12%
Weighted NCI-IDD Average	30%	34%	49%	35%	29%	33%	8%	38%	16%

Note, some state outcomes appear out of order due to sample and effect size. Learn more about sample and effect size [here](#).

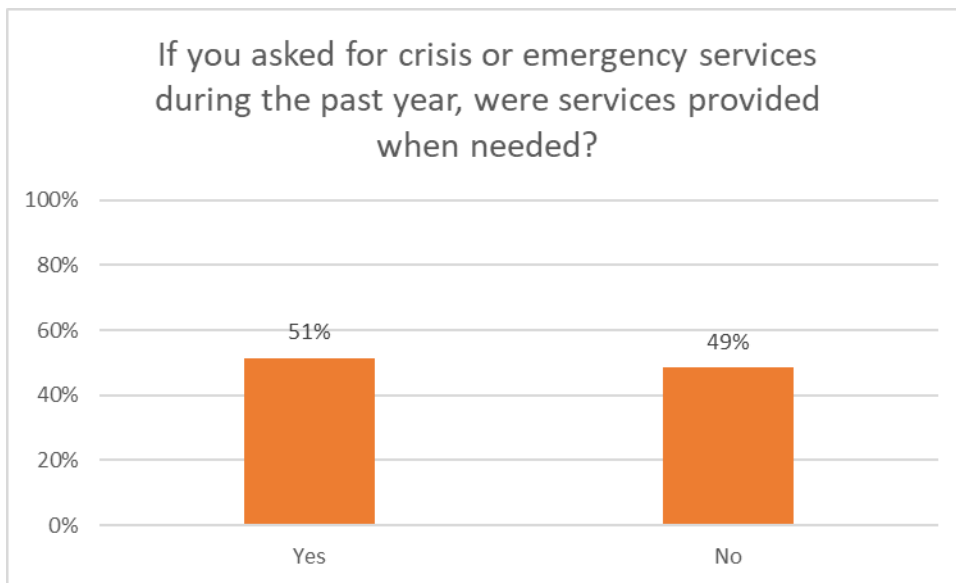


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

#### Within Average Range

State	Yes	No	N
VA	68%	32%	31
FL	63%	37%	99
LA	55%	45%	55
GA	53%	47%	103
<b>Weighted NCI-IDD Average</b>	<b>51%</b>	<b>49%</b>	<b>881</b>
PA	50%	50%	76
AZ	49%	51%	55
OK	46%	54%	72
MN	46%	54%	68
MO	45%	55%	51

#### Significantly Below Average

State	Yes	No	N
MD	39%	61%	201
NJ	31%	69%	42
DE	25%	75%	28

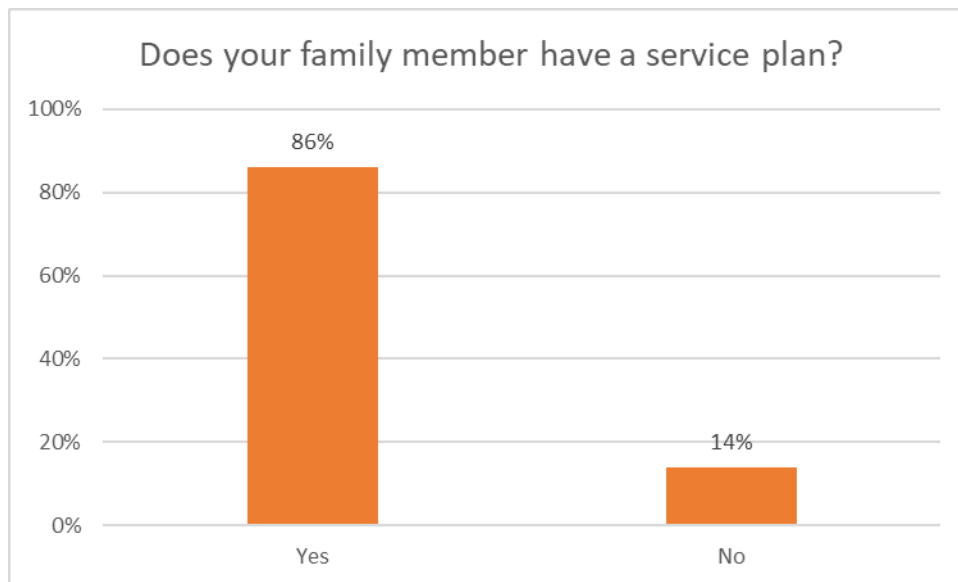


Table Q7. Does your family member have a service plan?

**Significantly Above Average**

State	Yes	No	N
PA	93%	7%	567
FL	90%	10%	395

**Within Average Range**

State	Yes	No	N
MN	90%	10%	385
NJ	89%	11%	245
MO	88%	12%	251
LA	87%	13%	192
VA	87%	13%	119
<b>Weighted NCI-IDD Average</b>	<b>86%</b>	<b>14%</b>	<b>4,101</b>
MD	85%	15%	1,009

**Significantly Below Average**

State	Yes	No	N
OK	78%	22%	311
AZ	72%	28%	224
GA	68%	32%	292
DE	63%	37%	111

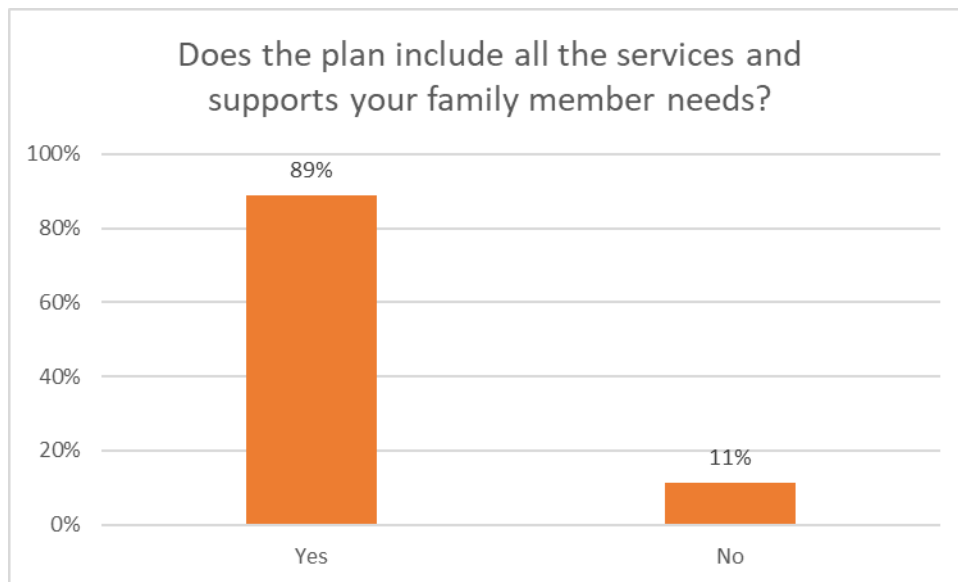


Table Q8. Does the plan include all the services and supports your family member needs?

#### Significantly Above Average

State	Yes	No	N
LA	94%	6%	153
PA	93%	7%	475

#### Within Average Range

State	Yes	No	N
VA	94%	6%	93
AZ	93%	7%	145
FL	91%	9%	325
MN	90%	10%	301
DE	90%	10%	50
<b>Weighted NCI-IDD Average</b>	<b>89%</b>	<b>11%</b>	<b>3,056</b>
MD	85%	15%	735
OK	85%	15%	216
GA	83%	17%	170
MO	83%	17%	201

#### Significantly Below Average

State	Yes	No	N
NJ	72%	28%	192

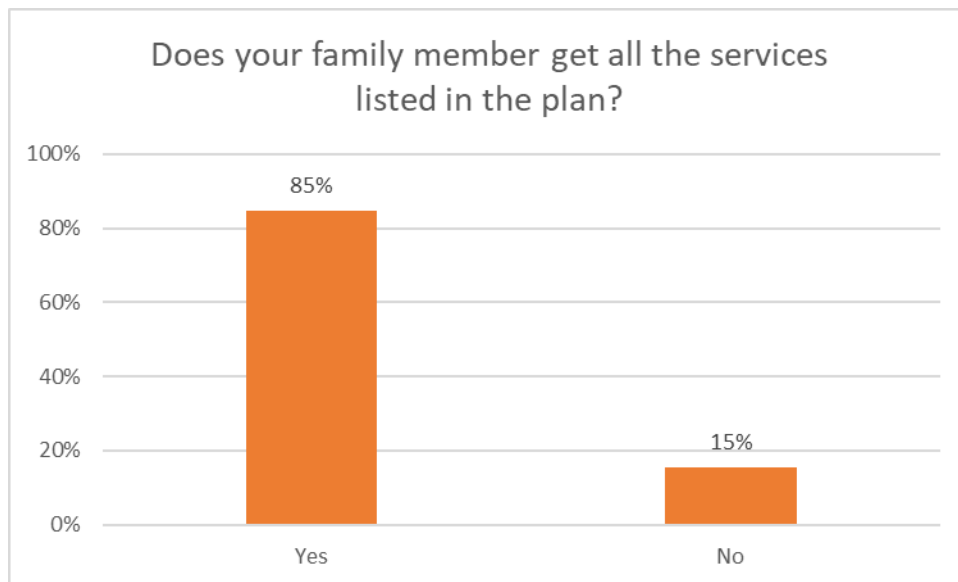


Table Q9. Does your family member get all the services listed in the plan?

**Significantly Above Average**

State	Yes	No	N
MN	89%	11%	306

**Within Average Range**

State	Yes	No	N
PA	88%	12%	464
AZ	87%	13%	151
LA	87%	13%	144
FL	85%	15%	314
OK	85%	15%	210
<b>Weighted NCI-IDD Average</b>	<b>85%</b>	<b>15%</b>	<b>3,004</b>
VA	84%	16%	92
NJ	80%	20%	197
MO	78%	22%	200
GA	78%	22%	162
DE	66%	34%	44

**Significantly Below Average**

State	Yes	No	N
MD	78%	22%	720

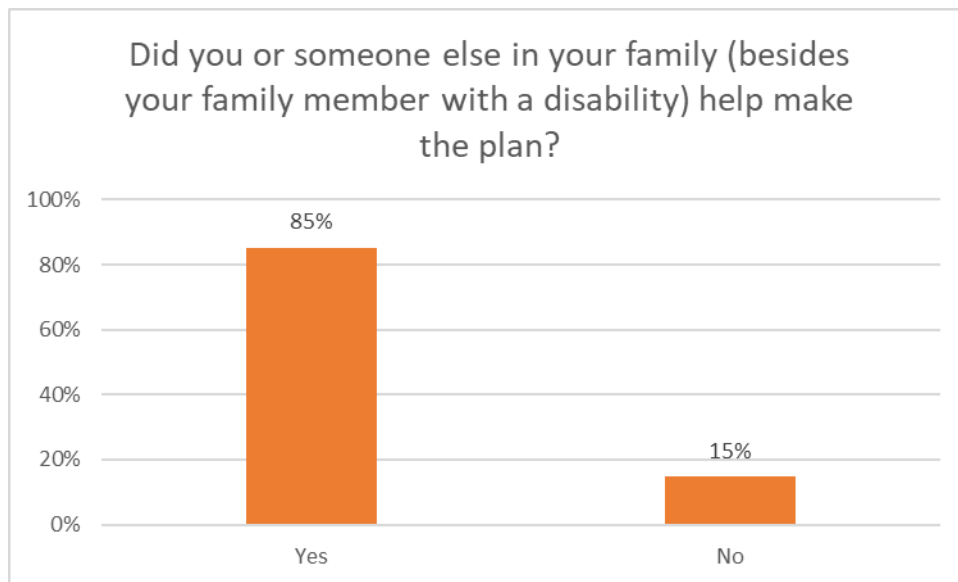


Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the plan?

**Within Average Range**

State	Yes	No	N
LA	91%	9%	159
MN	89%	11%	333
VA	89%	11%	100
MO	88%	12%	215
NJ	87%	13%	215
PA	87%	13%	501
DE	86%	14%	58
MD	86%	14%	804
OK	86%	14%	229
<b>Weighted NCI-IDD Average</b>	<b>85%</b>	<b>15%</b>	<b>3,285</b>
AZ	84%	16%	152
FL	80%	20%	338
GA	78%	22%	181

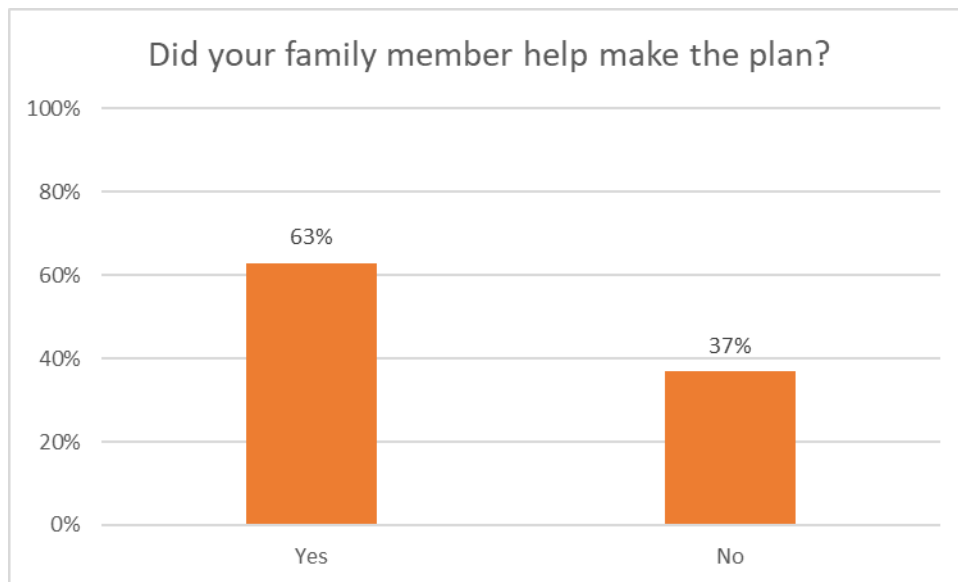


Table Q11. Did your family member help make the service plan?

**Significantly Above Average**

State	Yes	No	N
MD	75%	25%	799
MN	72%	28%	328

**Within Average Range**

State	Yes	No	N
VA	68%	32%	97
PA	66%	34%	494
DE	64%	36%	59
<b>Weighted NCI-IDD Average</b>	<b>63%</b>	<b>37%</b>	<b>3,253</b>
FL	62%	38%	334
OK	62%	38%	226
LA	61%	39%	161
MO	59%	41%	211
GA	58%	42%	177
AZ	56%	44%	153

**Significantly Below Average**

State	Yes	No	N
NJ	50%	50%	214

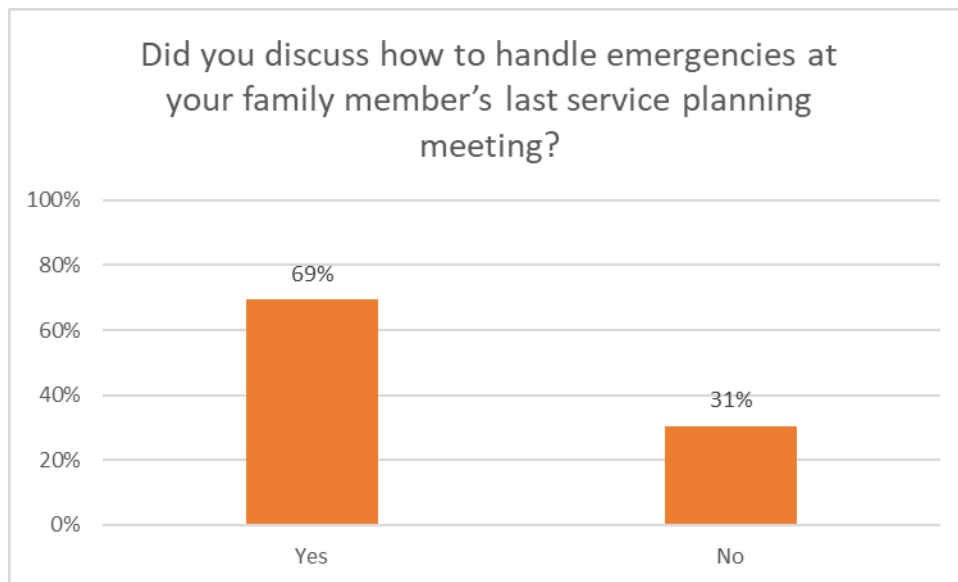


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or natural disaster) at your family member's last service planning meeting?

#### Significantly Above Average

State	Yes	No	N
LA	98%	2%	160
FL	88%	12%	330
OK	79%	21%	222

#### Within Average Range

State	Yes	No	N
PA	69%	31%	453
<b>Weighted NCI-IDD Average</b>	<b>69%</b>	<b>31%</b>	<b>3,047</b>
MN	66%	34%	306
MO	64%	36%	203
VA	64%	36%	85

#### Significantly Below Average

State	Yes	No	N
MD	59%	41%	735
GA	58%	42%	163
NJ	56%	44%	193
AZ	49%	51%	144
DE	47%	53%	53



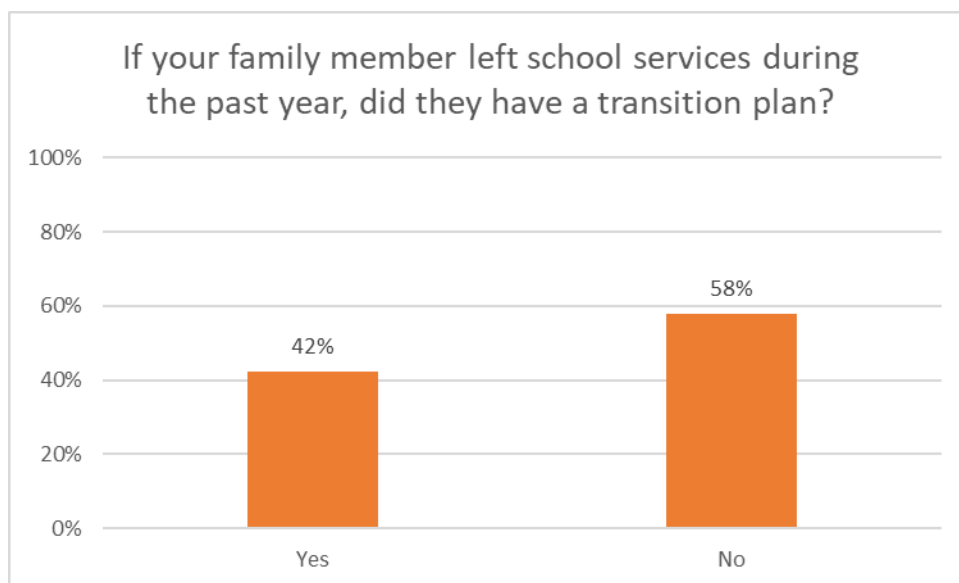


Table Q13. If your family member left school services during the past year, did they have a transition plan?<sup>7</sup>

**Significantly Above Average**

State	Yes	No	N
MD	59%	41%	100

**Within Average Range**

State	Yes	No	N
PA	61%	39%	23
OK	48%	52%	23
FL	44%	56%	32
<b>Weighted NCI-IDD Average</b>	<b>42%</b>	<b>58%</b>	<b>420</b>
MN	37%	63%	82
NJ	36%	64%	50
AZ	35%	65%	52
LA	33%	67%	21

<sup>7</sup> The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: DE, GA, MO, VA.

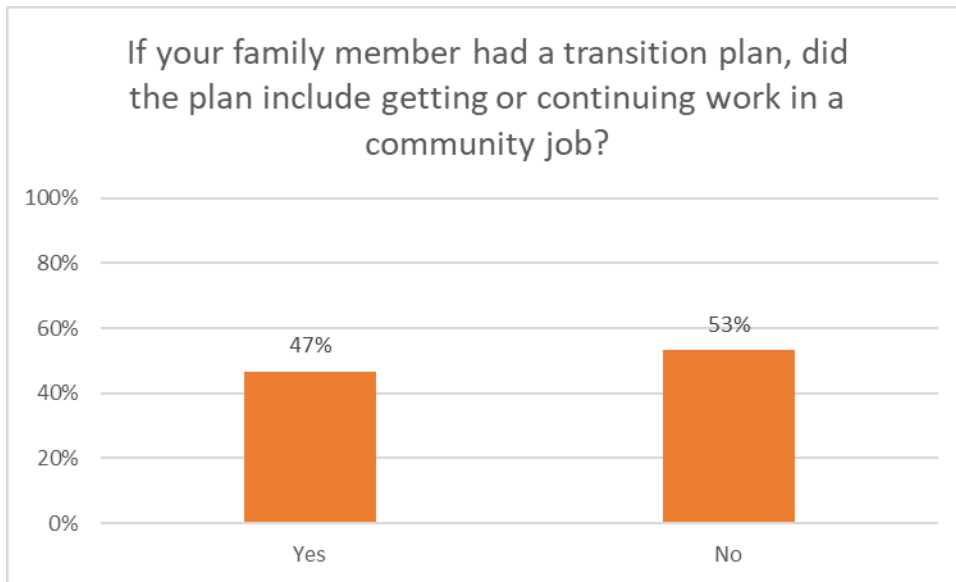


Table Q14. If family member had a transition plan, did the plan include getting or continuing work in a community job? <sup>8</sup>

**Within Average Range**

State	Yes	No	N
MN	57%	43%	30
MD	52%	48%	52
<b>Weighted NCI-IDD Average</b>	<b>47%</b>	<b>53%</b>	<b>177</b>

<sup>8</sup> The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: AZ, DE, FL, GA, LA, MO, NJ, OK, PA, VA.

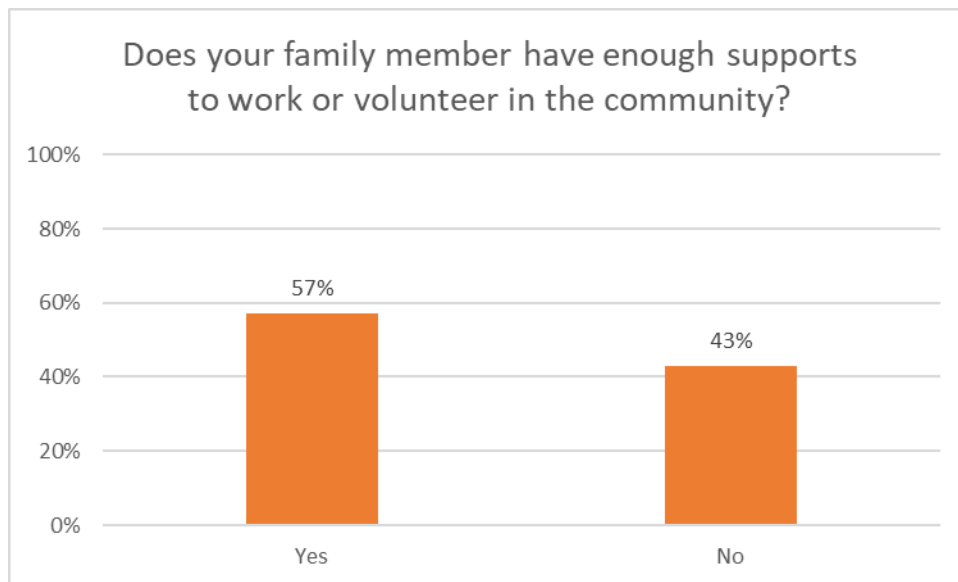


Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

#### Significantly Above Average

State	Yes	No	N
PA	69%	31%	398

#### Within Average Range

State	Yes	No	N
DE	63%	37%	100
OK	62%	38%	261
MD	60%	40%	866
MO	60%	40%	179
AZ	58%	42%	178
VA	58%	42%	95
<b>Weighted NCI-IDD Average</b>	<b>57%</b>	<b>43%</b>	<b>2,977</b>
GA	56%	44%	228
MN	54%	46%	98
LA	54%	46%	140
FL	50%	50%	260

#### Significantly Below Average

State	Yes	No	N
NJ	40%	60%	174

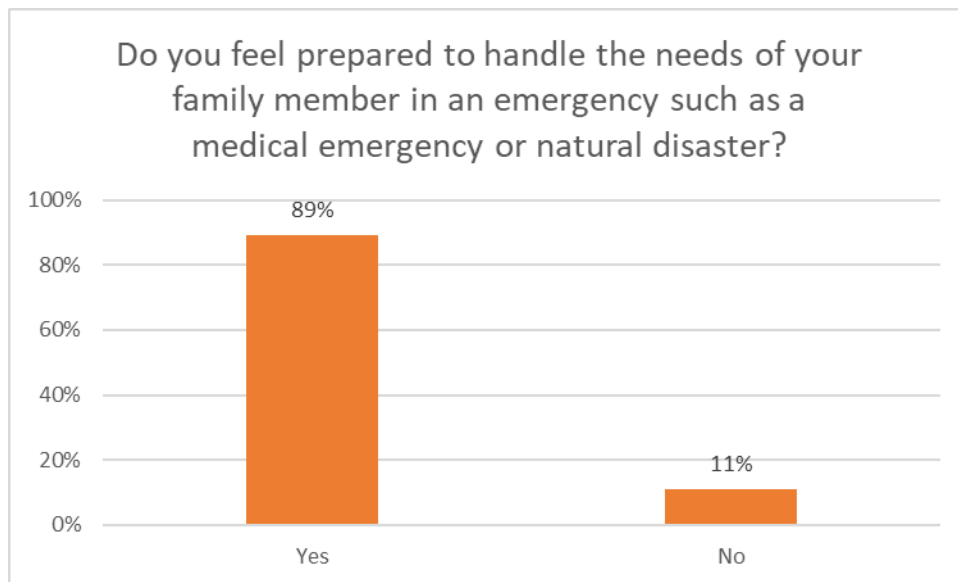


Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?

#### Significantly Above Average

State	Yes	No	N
LA	97%	3%	202
MN	94%	6%	406
OK	93%	7%	373
FL	93%	7%	406

#### Within Average Range

State	Yes	No	N
PA	91%	9%	543
AZ	90%	10%	257
GA	90%	10%	376
<b>Weighted NCI-IDD Average</b>	<b>89%</b>	<b>11%</b>	<b>4,384</b>
MO	87%	13%	241
DE	87%	13%	131
VA	81%	19%	131

#### Significantly Below Average

State	Yes	No	N
MD	85%	15%	1,075
NJ	77%	23%	243

## *Access and Delivery of Services and Supports*

*Families and family members with disabilities get the services and supports they need.*

**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.

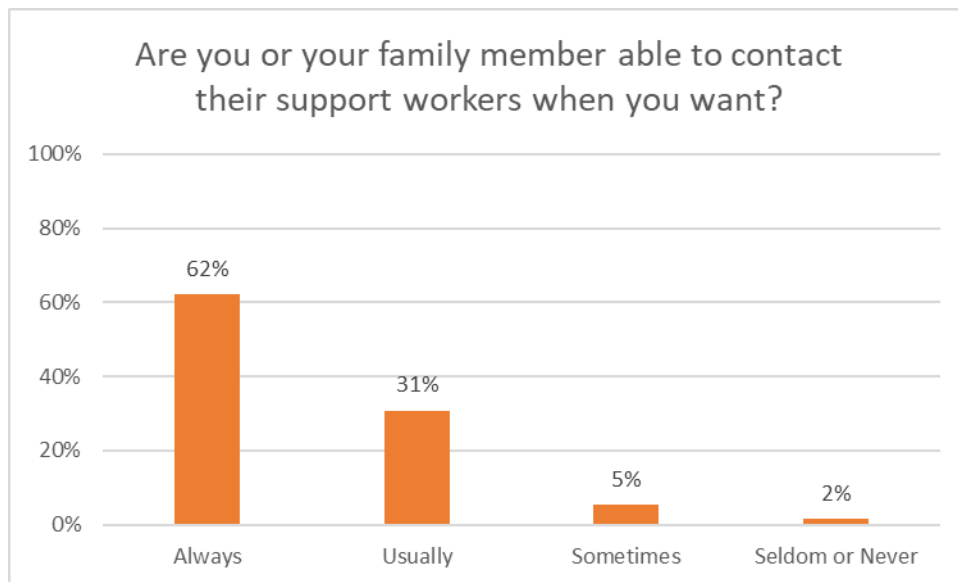


Table Q17. Are you or your family member able to contact their support workers when you want?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	73%	22%	3%	1%	405
LA	72%	23%	3%	1%	203

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	67%	27%	4%	1%	557
NJ	63%	31%	5%	2%	228
<b>Weighted NCI-IDD Average</b>	<b>62%</b>	<b>31%</b>	<b>5%</b>	<b>2%</b>	<b>4,343</b>
VA	60%	35%	4%	1%	144
MN	60%	32%	7%	2%	425
MO	58%	34%	6%	2%	228
AZ	56%	36%	5%	2%	255
DE	51%	32%	11%	5%	133

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	52%	38%	7%	2%	374
OK	51%	40%	8%	1%	345
MD	44%	43%	10%	3%	1,046

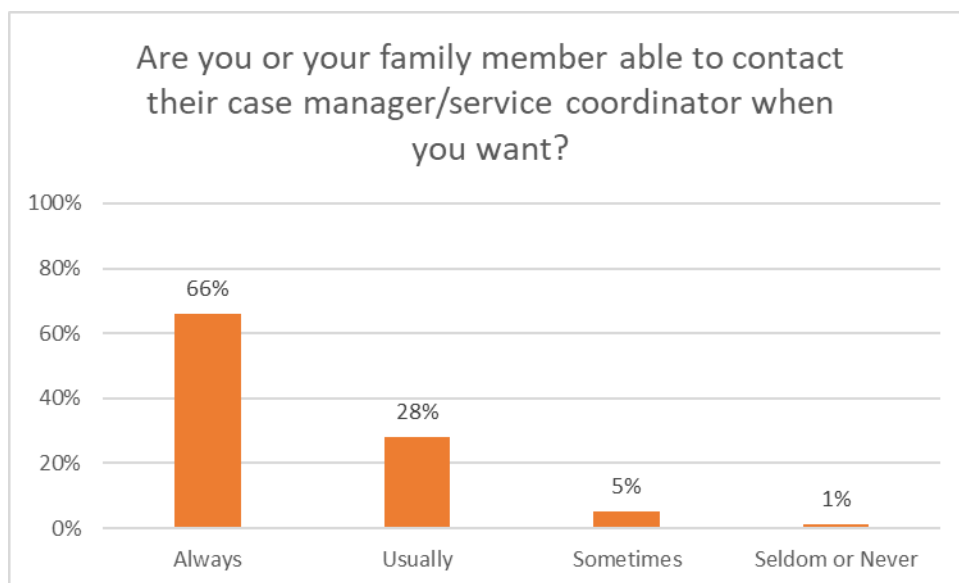


Table Q18. Are you or your family member able to contact their case manager/service coordinator when you want?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
FL	77%	20%	3%	0%	433

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
PA	70%	25%	4%	1%	575
LA	70%	24%	5%	0%	213
VA	69%	24%	6%	1%	152
NJ	66%	27%	6%	1%	256
<b>Weighted NCI-IDD Average</b>	<b>66%</b>	<b>28%</b>	<b>5%</b>	<b>1%</b>	<b>4,615</b>
MN	63%	30%	6%	1%	446
MO	61%	33%	4%	2%	257
AZ	59%	35%	5%	2%	278
DE	56%	32%	11%	1%	140

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	56%	35%	7%	2%	378
OK	53%	37%	9%	1%	380
MD	51%	37%	10%	2%	1,107

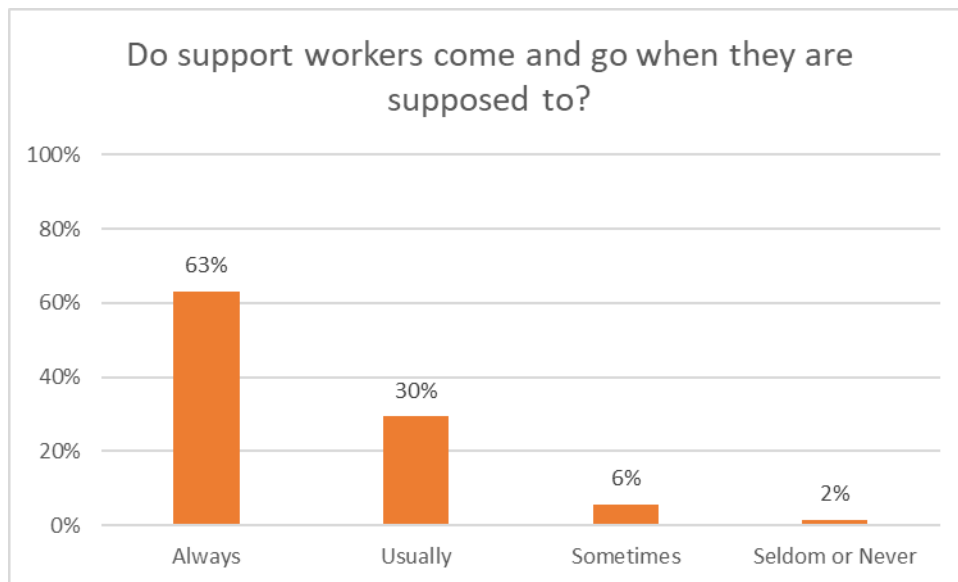


Table Q19. Do support workers come and go when they are supposed to?

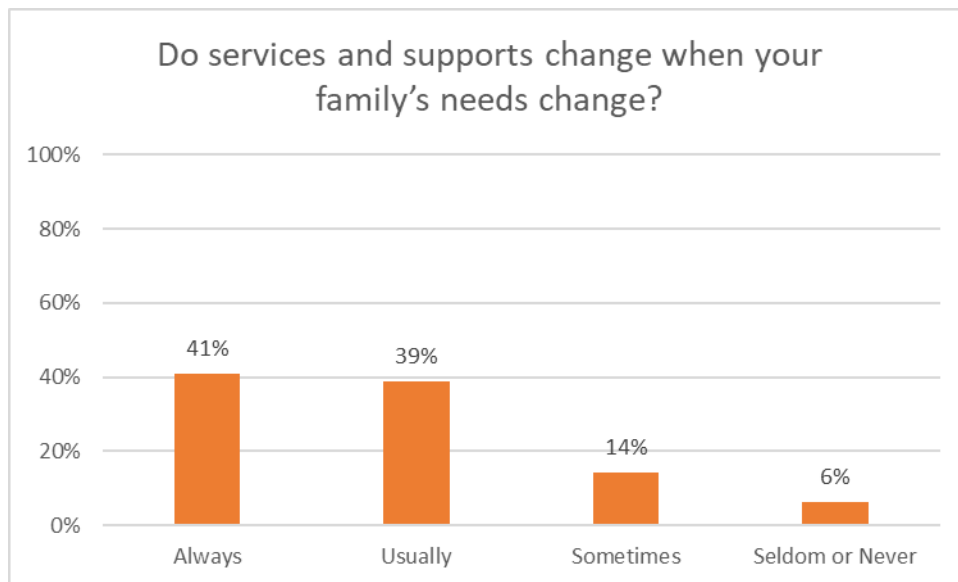
**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
FL	69%	24%	5%	1%	372
LA	68%	22%	8%	3%	194
PA	66%	28%	5%	1%	510
MN	65%	30%	4%	1%	360
VA	65%	28%	4%	2%	134
AZ	65%	31%	3%	1%	232
<b>Weighted NCI-IDD Average</b>	<b>63%</b>	<b>30%</b>	<b>6%</b>	<b>2%</b>	<b>3,674</b>
OK	63%	29%	6%	3%	284
NJ	61%	32%	7%	0%	194
MO	58%	35%	5%	1%	182

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	49%	38%	10%	3%	300
DE	49%	35%	8%	8%	88
MD	48%	39%	10%	3%	824





**Table Q20. Do services and supports change when your family's needs change?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
FL	48%	33%	15%	4%	338

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	51%	30%	13%	6%	123
LA	48%	31%	13%	8%	170
PA	44%	41%	10%	5%	455
OK	43%	38%	11%	9%	247
AZ	42%	42%	12%	4%	215
<b>Weighted NCI-IDD Average</b>	<b>41%</b>	<b>39%</b>	<b>14%</b>	<b>6%</b>	<b>3,343</b>
MN	36%	41%	17%	6%	336
DE	32%	38%	15%	15%	73

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	31%	41%	20%	8%	187
GA	29%	43%	17%	11%	273
MO	29%	44%	18%	9%	182
MD	27%	45%	17%	12%	744

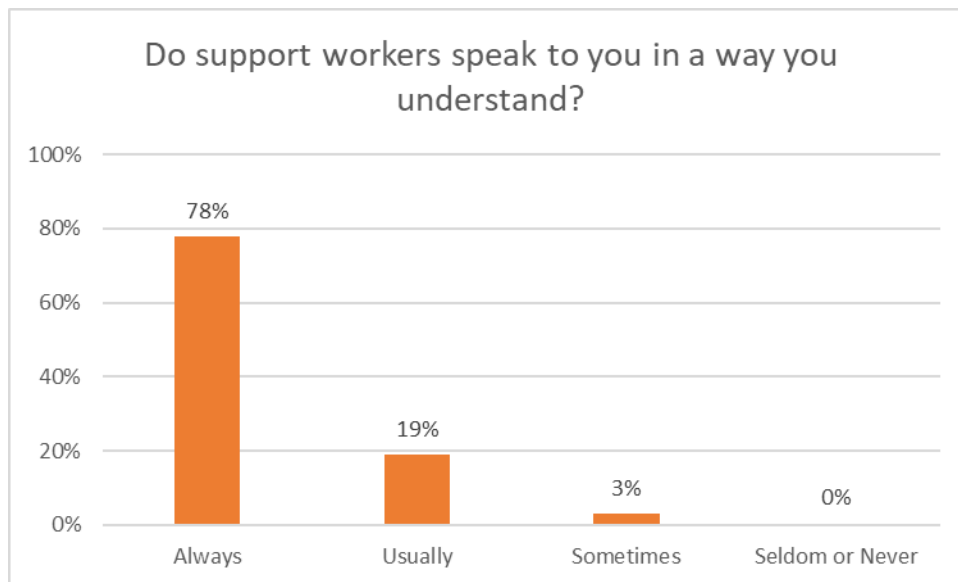


Table Q21. Do support workers speak to you in a way you understand?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
PA	82%	15%	2%	0%	554

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	82%	17%	2%	0%	193
FL	80%	15%	4%	0%	394
NJ	78%	19%	3%	0%	219
MN	78%	20%	2%	0%	387
AZ	78%	17%	4%	1%	243
<b>Weighted NCI-IDD Average</b>	<b>78%</b>	<b>19%</b>	<b>3%</b>	<b>0%</b>	<b>4,104</b>
VA	77%	21%	3%	0%	145
OK	76%	19%	3%	1%	319
DE	76%	19%	4%	1%	115

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	71%	26%	2%	1%	365
MO	68%	28%	3%	0%	212
MD	65%	29%	5%	1%	958

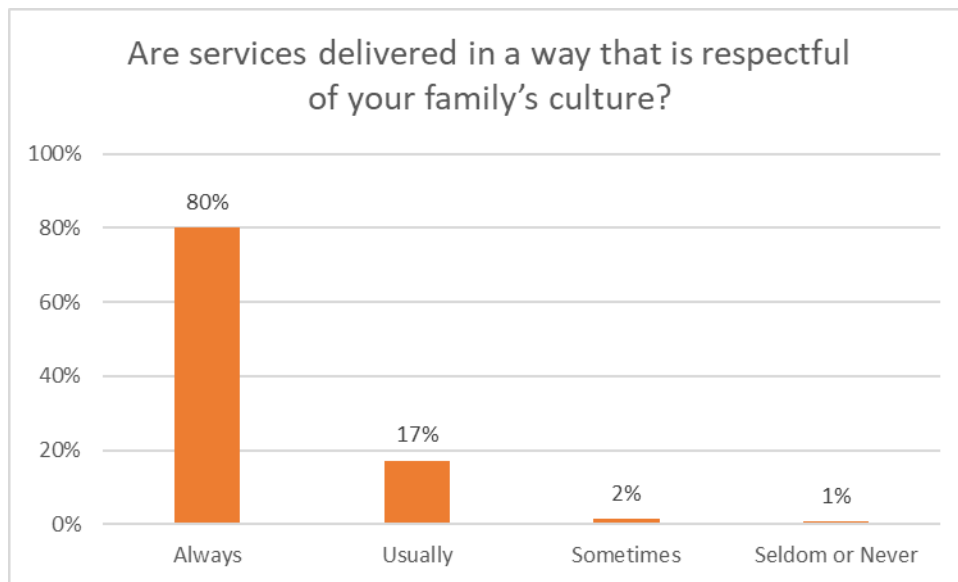


Table Q22. Are services delivered in a way that is respectful of your family's culture?

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
FL	84%	13%	1%	1%	406
PA	83%	15%	1%	1%	562
MN	82%	16%	2%	0%	423
LA	82%	15%	3%	0%	211
AZ	81%	15%	2%	2%	259
OK	80%	16%	3%	1%	351
<b>Weighted NCI-IDD Average</b>	<b>80%</b>	<b>17%</b>	<b>2%</b>	<b>1%</b>	<b>4,407</b>
VA	79%	19%	1%	0%	149
NJ	78%	20%	1%	1%	244
MO	77%	20%	1%	1%	240
DE	76%	19%	2%	3%	128

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	72%	24%	3%	1%	375
MD	69%	26%	3%	2%	1,059

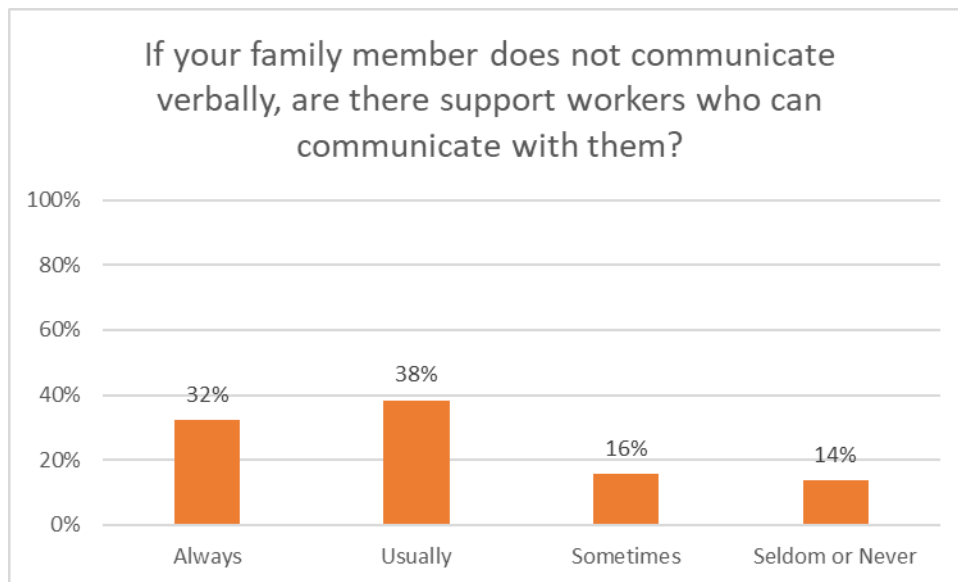


Table Q23. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them? <sup>9</sup>

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	45%	34%	10%	11%	114

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	47%	36%	11%	7%	45
OK	40%	31%	19%	11%	95
MN	38%	38%	17%	8%	88
NJ	34%	30%	20%	16%	50
PA	34%	40%	11%	15%	89
<b>Weighted NCI-IDD Average</b>	<b>32%</b>	<b>38%</b>	<b>16%</b>	<b>14%</b>	<b>975</b>
GA	30%	44%	16%	10%	105
AZ	25%	32%	25%	17%	59
MO	25%	40%	21%	14%	57

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	21%	49%	18%	12%	203
VA	7%	51%	18%	24%	55

<sup>9</sup> DE not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average.

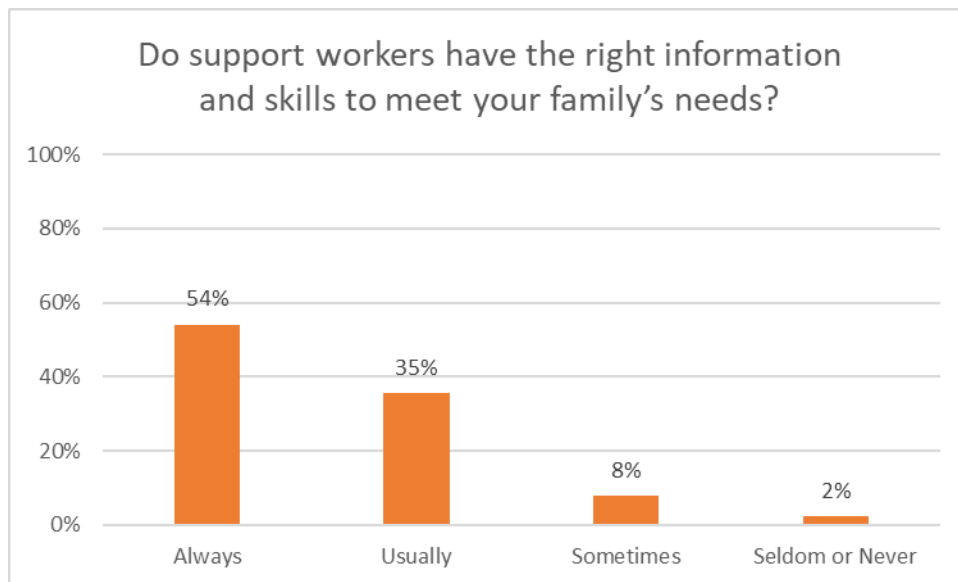


Table Q24. Do support workers have the right information and skills to meet your family's needs?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
FL	64%	28%	6%	2%	386

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	62%	26%	9%	3%	197
PA	60%	33%	5%	2%	521
OK	55%	35%	8%	2%	303
<b>Weighted NCI-IDD Average</b>	<b>54%</b>	<b>35%</b>	<b>8%</b>	<b>2%</b>	<b>3,930</b>
MN	52%	40%	7%	1%	381
VA	51%	35%	11%	3%	140
AZ	51%	39%	7%	2%	233
MO	50%	38%	10%	2%	208
NJ	46%	38%	13%	3%	213
DE	44%	43%	11%	1%	99

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	43%	44%	9%	5%	346
MD	40%	43%	13%	4%	903



Table Q25. Does your family member have the special equipment or accommodations they need?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	58%	29%	9%	4%	117
PA	56%	30%	10%	4%	221
FL	53%	28%	9%	9%	232
VA	51%	27%	13%	10%	93
<b>Weighted NCI-IDD Average</b>	<b>50%</b>	<b>33%</b>	<b>11%</b>	<b>7%</b>	<b>2,151</b>
MN	50%	34%	8%	9%	210
MO	48%	38%	6%	9%	138
NJ	47%	30%	16%	7%	105
OK	46%	35%	12%	7%	198
GA	44%	33%	12%	11%	209
AZ	42%	44%	9%	5%	139
DE	36%	28%	22%	14%	36

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	42%	37%	13%	8%	453

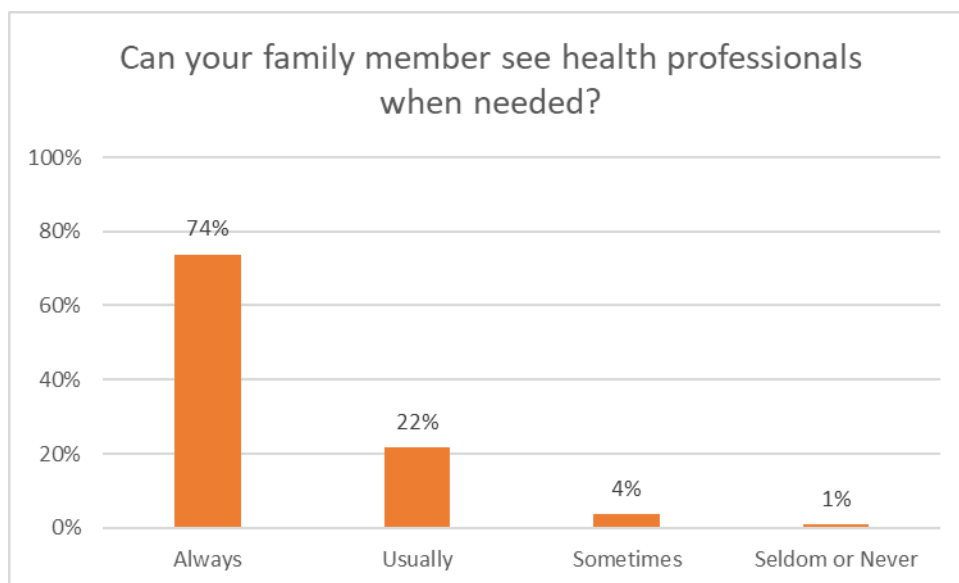


Table Q26. Can your family member see health professionals when needed?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	78%	21%	1%	0%	593
LA	77%	15%	6%	1%	216
OK	77%	20%	3%	1%	384
DE	75%	18%	4%	4%	142
MN	75%	22%	3%	0%	445
MD	74%	21%	4%	1%	1,185
<b>Weighted NCI-IDD Average</b>	<b>74%</b>	<b>22%</b>	<b>4%</b>	<b>1%</b>	<b>4,776</b>
FL	73%	18%	6%	3%	442
VA	72%	24%	3%	1%	152
NJ	72%	23%	4%	1%	260
GA	72%	23%	4%	0%	413
MO	71%	25%	4%	0%	269
AZ	69%	29%	2%	0%	275

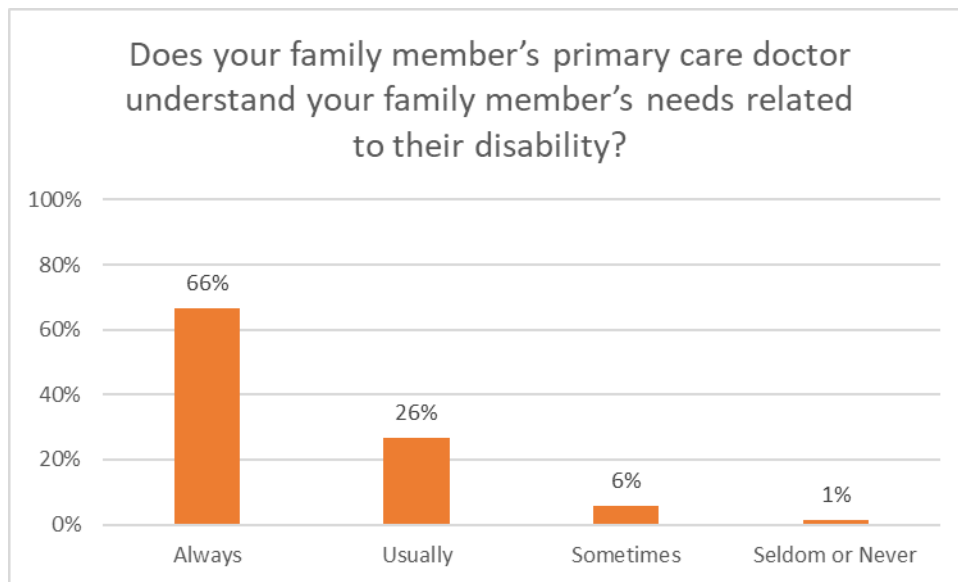


Table Q27. Does your family member's primary care doctor understand your family member's needs related to their disability?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	73%	21%	5%	1%	591

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	72%	22%	4%	1%	214
DE	71%	23%	4%	2%	136
GA	70%	25%	4%	1%	406
FL	69%	23%	6%	2%	430
OK	66%	26%	6%	2%	386
<b>Weighted NCI-IDD Average</b>	<b>66%</b>	<b>26%</b>	<b>6%</b>	<b>1%</b>	<b>4,696</b>
VA	64%	28%	6%	2%	152
NJ	63%	29%	7%	1%	258
MN	63%	31%	5%	2%	435
MD	62%	30%	6%	1%	1,157
AZ	59%	32%	7%	2%	273

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	52%	39%	8%	1%	258



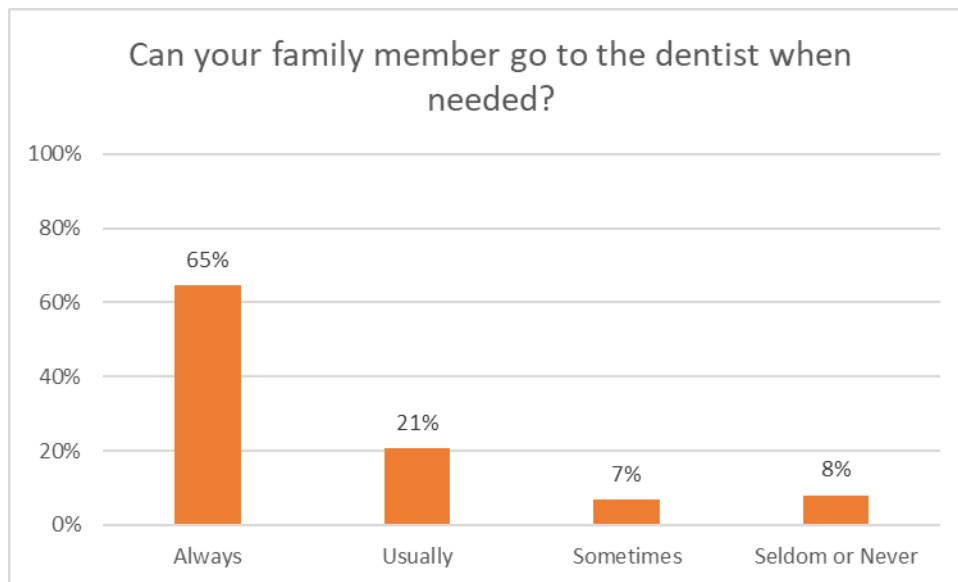


Table Q28. Can your family member go to the dentist when needed?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
PA	75%	18%	4%	3%	590
MD	70%	17%	6%	7%	1,177

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	69%	18%	7%	6%	259
OK	68%	21%	5%	6%	379
AZ	65%	23%	4%	7%	275
<b>Weighted NCI-IDD Average</b>	<b>65%</b>	<b>21%</b>	<b>7%</b>	<b>8%</b>	<b>4,728</b>
MN	63%	21%	10%	6%	444
LA	62%	19%	8%	11%	214
VA	61%	23%	8%	9%	150
DE	60%	18%	10%	12%	139
MO	60%	22%	7%	10%	268

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
FL	57%	22%	8%	13%	430
GA	53%	24%	10%	12%	403

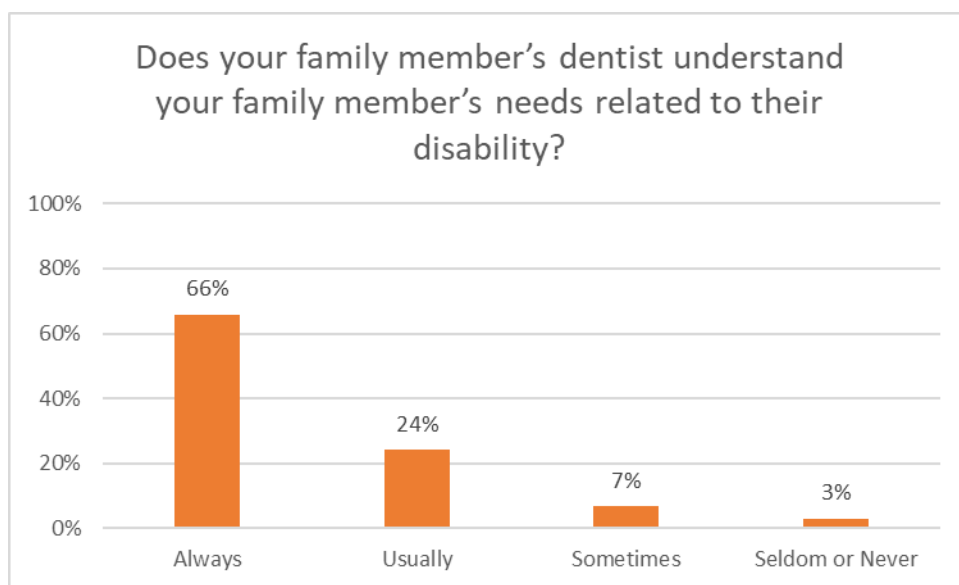


Table Q29. Does your family member's dentist understand your family member's needs related to their disability?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	71%	22%	6%	2%	550
NJ	68%	20%	9%	3%	248
LA	68%	22%	6%	4%	186
MD	67%	25%	5%	3%	1,078
FL	66%	22%	8%	4%	378
VA	66%	24%	6%	4%	136
<b>Weighted NCI-IDD Average</b>	<b>66%</b>	<b>24%</b>	<b>7%</b>	<b>3%</b>	<b>4,256</b>
OK	65%	27%	5%	3%	355
DE	63%	25%	7%	4%	115
GA	63%	28%	6%	3%	338
AZ	62%	28%	7%	3%	242

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	59%	28%	9%	4%	394
MO	55%	36%	6%	3%	236

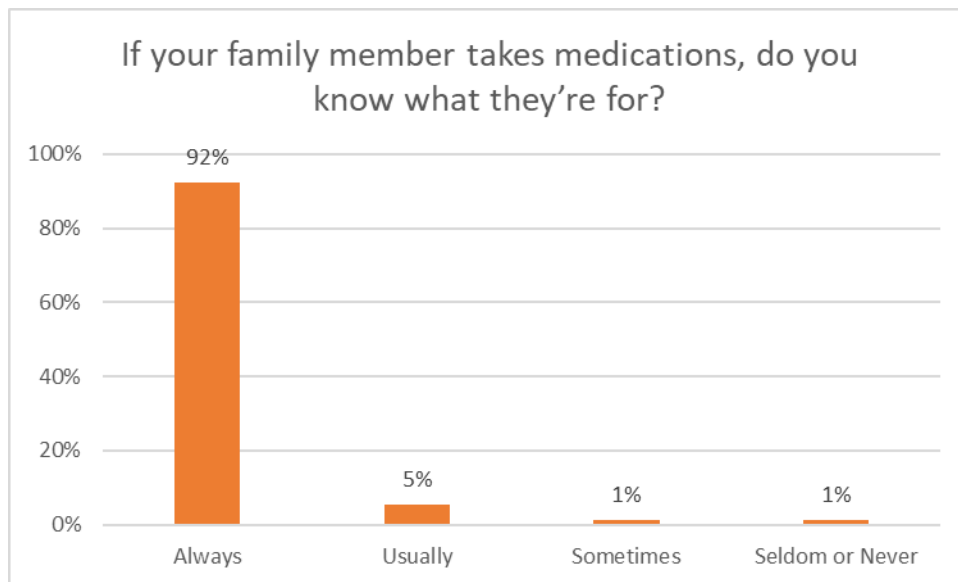


Table Q30. If your family member takes medications, do you know what they're for?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	96%	2%	1%	1%	218

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	95%	4%	0%	1%	199
FL	94%	4%	2%	1%	393
DE	93%	4%	1%	2%	121
MN	93%	4%	2%	1%	389
<b>Weighted NCI-IDD Average</b>	<b>92%</b>	<b>5%</b>	<b>1%</b>	<b>1%</b>	<b>4,216</b>
AZ	92%	6%	0%	2%	246
PA	91%	6%	1%	1%	500
OK	91%	7%	1%	1%	347
VA	91%	6%	1%	1%	145
MD	90%	7%	1%	2%	1,015
GA	89%	8%	2%	1%	394
MO	88%	9%	2%	1%	249

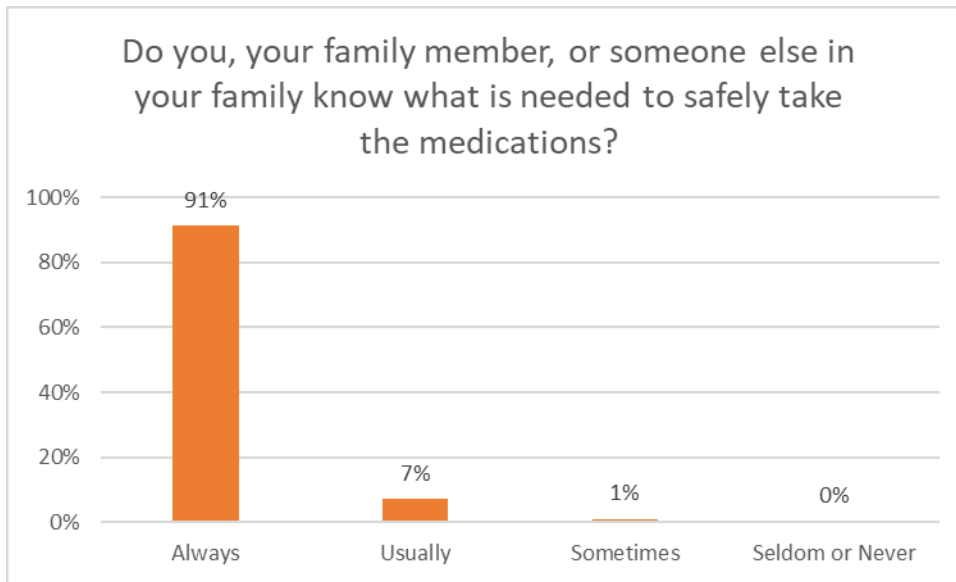


Table Q31. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	93%	6%	1%	0%	199
DE	93%	4%	1%	2%	121
PA	93%	6%	1%	1%	503
MN	92%	7%	1%	0%	389
OK	92%	6%	2%	0%	345
FL	92%	6%	2%	0%	389
NJ	92%	7%	1%	0%	220
<b>Weighted NCI-IDD Average</b>	<b>91%</b>	<b>7%</b>	<b>1%</b>	<b>0%</b>	<b>4,199</b>
VA	91%	9%	0%	0%	145
MD	90%	8%	1%	1%	1,005
AZ	90%	8%	1%	0%	248
GA	89%	10%	1%	1%	389
MO	89%	9%	1%	1%	246

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

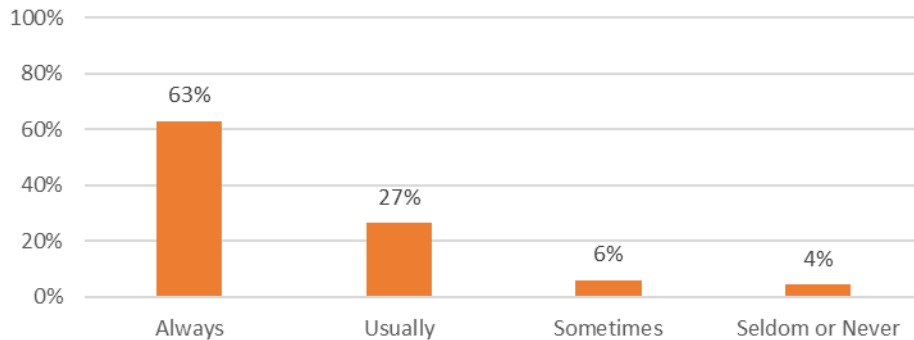


Table Q32. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	71%	22%	3%	4%	73
PA	68%	24%	3%	5%	209
NJ	67%	25%	6%	2%	87
FL	65%	22%	6%	7%	145
<b>Weighted NCI-IDD Average</b>	<b>63%</b>	<b>27%</b>	<b>6%</b>	<b>4%</b>	<b>1,637</b>
MD	62%	27%	7%	4%	418
LA	62%	26%	8%	5%	65
DE	61%	32%	5%	2%	44
OK	59%	24%	10%	7%	91
MN	58%	31%	9%	2%	183
GA	58%	32%	9%	1%	137
AZ	54%	34%	6%	6%	95
MO	53%	30%	13%	3%	90

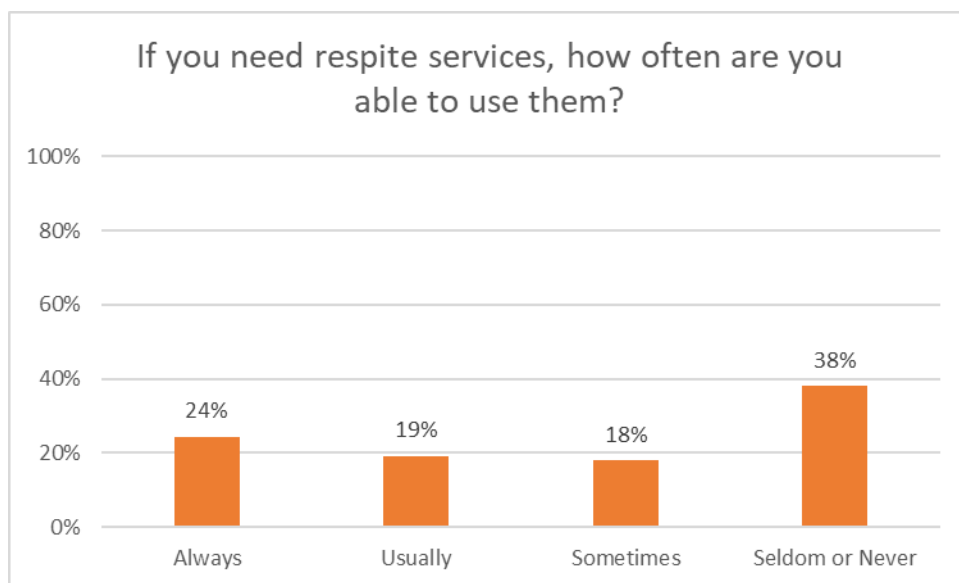


Table Q33. If you need respite services, how often are you able to use them?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	41%	26%	16%	16%	220

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	28%	19%	11%	42%	97
FL	26%	16%	18%	40%	215
MN	25%	20%	19%	36%	277
<b>Weighted NCI-IDD Average</b>	<b>24%</b>	<b>19%</b>	<b>18%</b>	<b>38%</b>	<b>2,370</b>
PA	23%	23%	18%	35%	261
GA	22%	15%	18%	46%	200
VA	19%	22%	22%	36%	107

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OK	16%	11%	13%	61%	132
MO	16%	16%	32%	37%	145
MD	13%	14%	19%	54%	518
DE	12%	14%	19%	55%	73
NJ	10%	10%	14%	67%	125

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

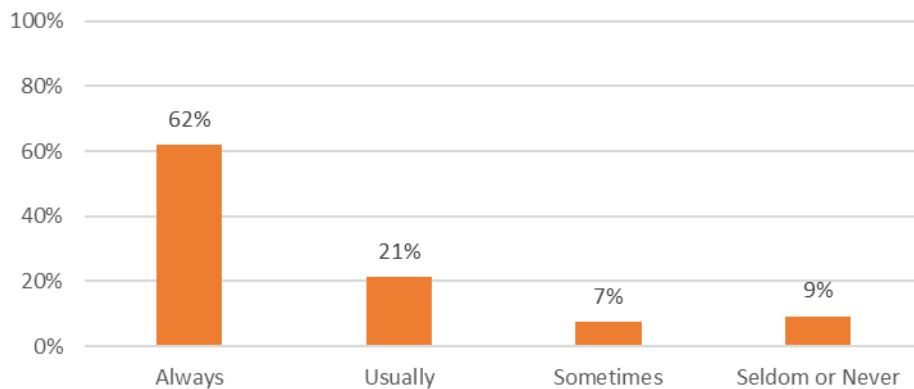


Table Q34. If you have used respite services in the past year, were you satisfied with the quality of the respite services?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	71%	20%	4%	5%	128
MN	70%	22%	5%	4%	165
AZ	68%	21%	6%	4%	182
LA	63%	15%	12%	10%	52
<b>Weighted NCI-IDD Average</b>	<b>62%</b>	<b>21%</b>	<b>7%</b>	<b>9%</b>	<b>1,182</b>
DE	60%	0%	10%	30%	20
VA	59%	22%	8%	11%	64
MO	58%	27%	3%	13%	78
OK	55%	19%	4%	21%	47
GA	55%	19%	13%	13%	104
FL	54%	22%	9%	15%	116
NJ	41%	21%	18%	21%	34

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	45%	28%	10%	18%	192

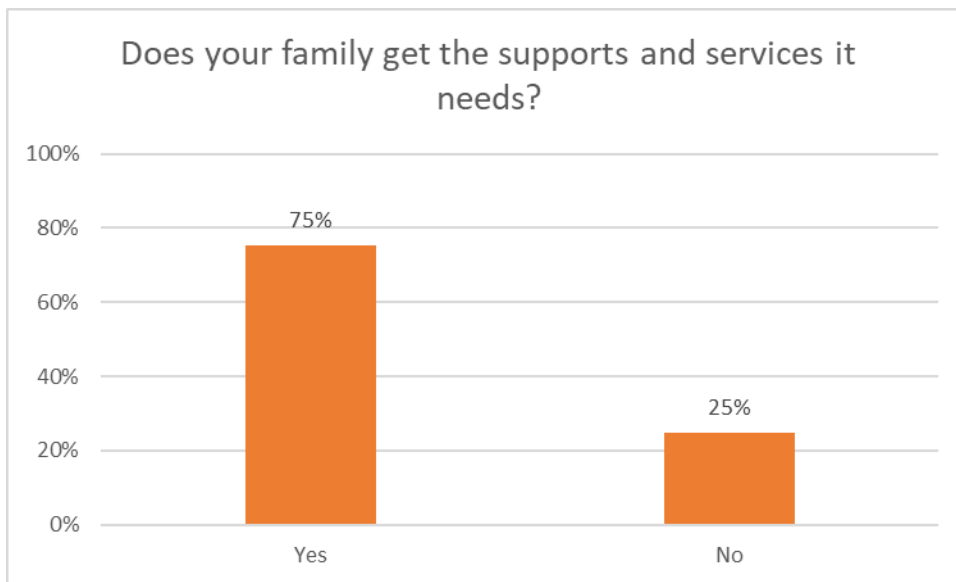


Table Q35. Does your family get the supports and services it needs?

**Significantly Above Average**

State	Yes	No	N
PA	82%	18%	536
AZ	82%	18%	261

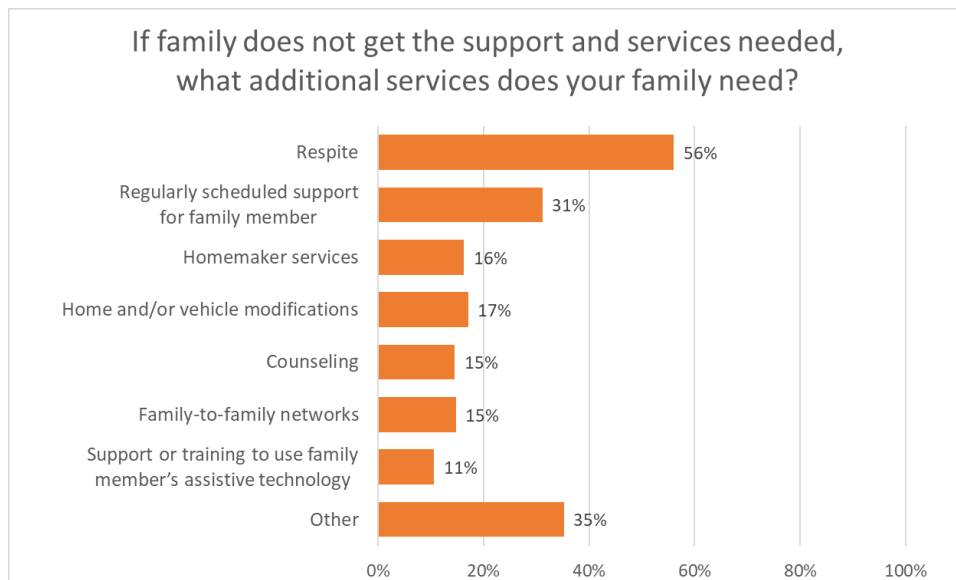
**Within Average Range**

State	Yes	No	N
LA	77%	23%	202
MN	76%	24%	404
VA	76%	24%	122
OK	76%	24%	347
DE	76%	24%	120
MO	76%	24%	231
<b>Weighted NCI-IDD Average</b>	<b>75%</b>	<b>25%</b>	<b>4,241</b>
GA	75%	25%	362
FL	72%	28%	396

**Significantly Below Average**

State	Yes	No	N
MD	67%	33%	1,026
NJ	61%	39%	234





**Table Q36. If 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 or Vehicle Modifications	Counseling	Family-to-family Networks	Support or Training to Use Assistive Technology	Other
AZ	48%	11%	16%	20%	23%	11%	9%	30%
DE	44%	33%	19%	7%	15%	19%	15%	56%
FL	55%	36%	21%	22%	19%	18%	13%	29%
GA	55%	31%	23%	23%	13%	10%	6%	27%
LA	49%	29%	20%	22%	13%	18%	13%	40%
MD	56%	41%	13%	10%	14%	15%	10%	33%
MN	59%	37%	18%	12%	11%	21%	8%	44%
MO	54%	43%	17%	13%	15%	9%	17%	39%
NJ	71%	34%	13%	14%	14%	16%	12%	37%
OK	56%	22%	13%	18%	16%	10%	10%	31%
PA	50%	25%	10%	13%	10%	7%	5%	46%
VA	56%	26%	15%	19%	4%	22%	22%	30%
<b>Weighted NCI-IDD Average</b>	<b>56%</b>	<b>31%</b>	<b>16%</b>	<b>17%</b>	<b>15%</b>	<b>15%</b>	<b>11%</b>	<b>35%</b>

## *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.

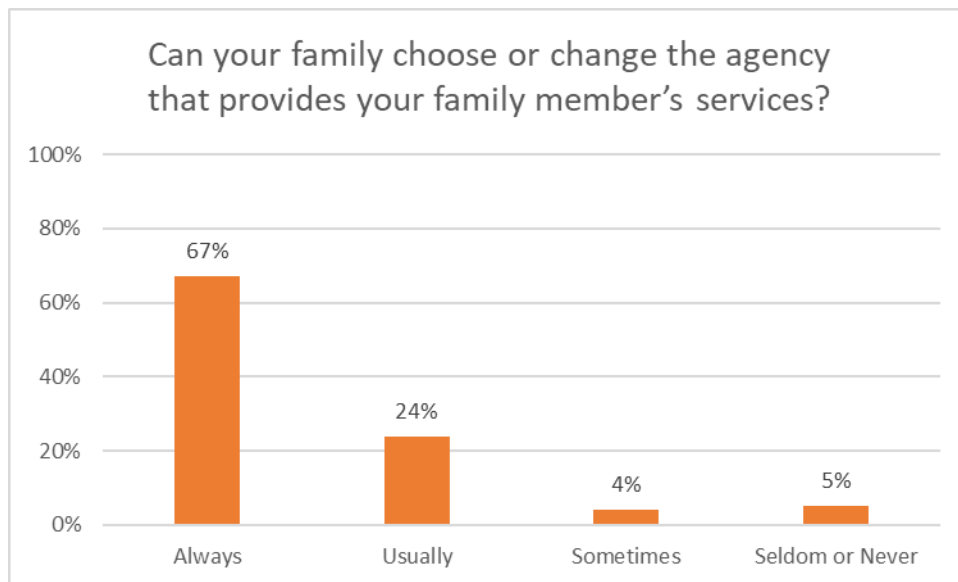


Table Q37. Can your family choose or change the agency that provides your family member's services?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	79%	16%	2%	3%	177

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	75%	18%	5%	2%	102
FL	71%	21%	4%	4%	328
OK	70%	22%	4%	4%	271
MN	68%	23%	4%	5%	332
<b>Weighted NCI-IDD Average</b>	<b>67%</b>	<b>24%</b>	<b>4%</b>	<b>5%</b>	<b>3,287</b>
PA	67%	26%	3%	4%	398
NJ	65%	22%	5%	7%	179
AZ	64%	24%	6%	5%	222
DE	57%	28%	8%	7%	72

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MD	61%	28%	6%	5%	792
GA	57%	31%	4%	8%	251
MO	51%	35%	6%	9%	163

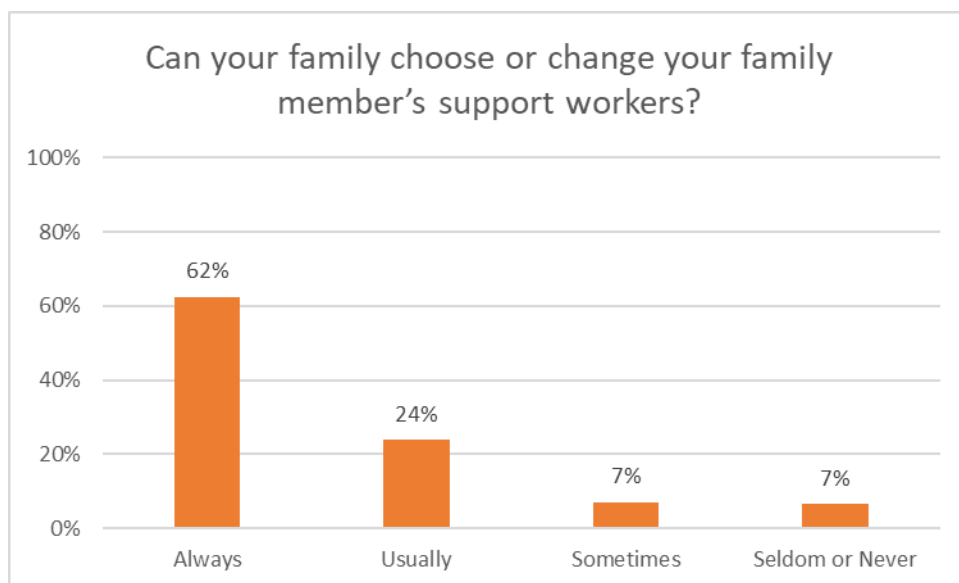


Table Q38. Can your family choose or change your family member's support workers?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
FL	70%	21%	4%	6%	353

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	69%	20%	7%	4%	188
VA	68%	19%	6%	6%	114
MN	67%	20%	6%	7%	338
OK	66%	21%	8%	6%	262
PA	64%	26%	5%	5%	396
<b>Weighted NCI-IDD Average</b>	<b>62%</b>	<b>24%</b>	<b>7%</b>	<b>7%</b>	<b>3,203</b>
AZ	60%	26%	8%	6%	204
MO	56%	26%	10%	8%	154
NJ	54%	26%	12%	8%	155

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	52%	29%	8%	11%	252
MD	47%	28%	14%	11%	731
DE	38%	34%	13%	16%	56

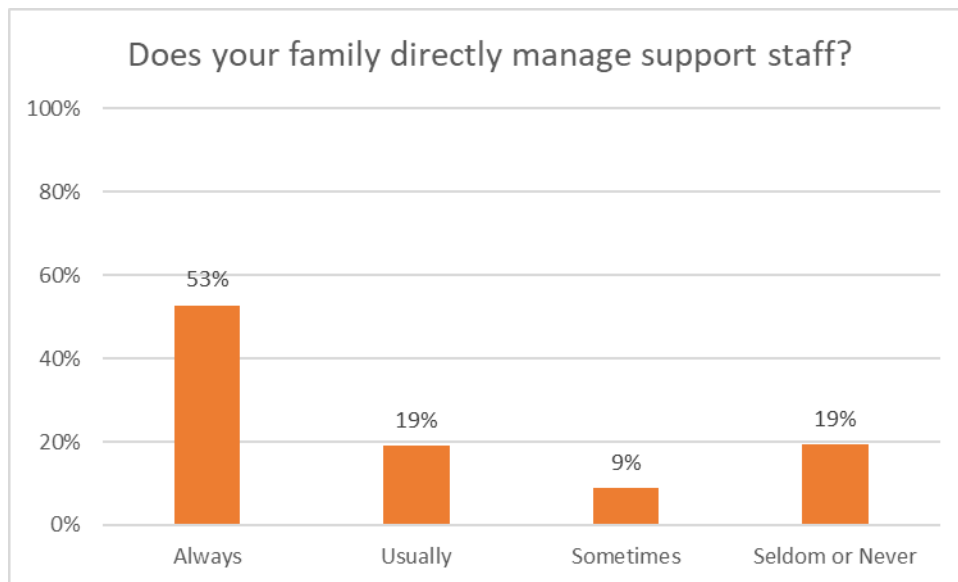


Table Q39. Does your family directly manage support staff?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MN	76%	10%	7%	8%	311
LA	66%	11%	10%	13%	163

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OK	58%	19%	9%	14%	248
FL	55%	20%	8%	18%	302
<b>Weighted NCI-IDD Average</b>	<b>53%</b>	<b>19%</b>	<b>9%</b>	<b>19%</b>	<b>2,879</b>
NJ	52%	24%	7%	16%	153
VA	51%	18%	10%	20%	105
AZ	51%	25%	11%	13%	175
PA	49%	21%	9%	22%	354
GA	47%	16%	9%	29%	220
MO	44%	19%	6%	31%	136

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MD	33%	15%	13%	39%	671
DE	22%	15%	15%	49%	41

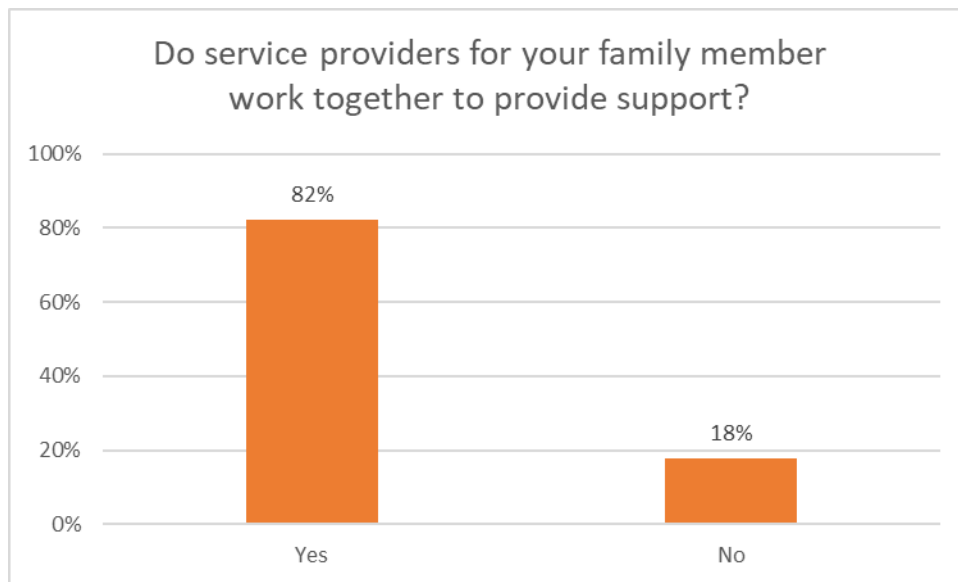


Table Q40. Do service providers for your family member work together to provide support?

**Significantly Above Average**

State	Yes	No	N
LA	92%	8%	109
PA	89%	11%	333

**Within Average Range**

State	Yes	No	N
OK	86%	14%	171
VA	83%	17%	103
MN	82%	18%	244
<b>Weighted NCI-IDD Average</b>	<b>82%</b>	<b>18%</b>	<b>2,477</b>
FL	81%	19%	242
AZ	80%	20%	147
NJ	77%	23%	121
MO	77%	23%	137
GA	75%	25%	201
DE	75%	25%	67

**Significantly Below Average**

State	Yes	No	N
MD	77%	23%	602

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

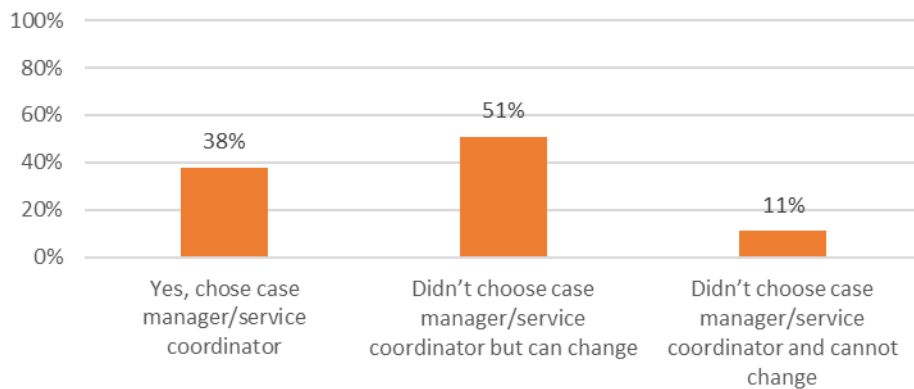


Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

Significantly Above Average

State	Yes, chose case manager/ service coordinator	No, didn't choose case manager/ service coordinator but can change if wanted	No, didn't choose case manager/ service coordinator and cannot change if wanted	N
FL	69%	27%	4%	399
NJ	55%	35%	10%	227
LA	52%	40%	9%	200

Within Average Range

State	Yes, chose case manager/ service coordinator	No, didn't choose case manager/ service coordinator but can change if wanted	No, didn't choose case manager/ service coordinator and cannot change if wanted	N
MD	39%	49%	12%	919
Weighted NCI-IDD Average	38%	51%	11%	3,886

Significantly Below Average

State	Yes, chose case manager/ service coordinator	No, didn't choose case manager/ service coordinator but can change if wanted	No, didn't choose case manager/ service coordinator and cannot change if wanted	N
PA	28%	62%	10%	485
VA	26%	57%	16%	129
AZ	24%	69%	8%	242
MO	23%	59%	18%	213
OK	21%	58%	21%	296
GA	16%	61%	23%	302
MN	15%	63%	21%	379
DE	6%	65%	28%	95

## *Involvement in the Community*

*Family members with disabilities use integrated community services and participate in everyday community activities.*

**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.



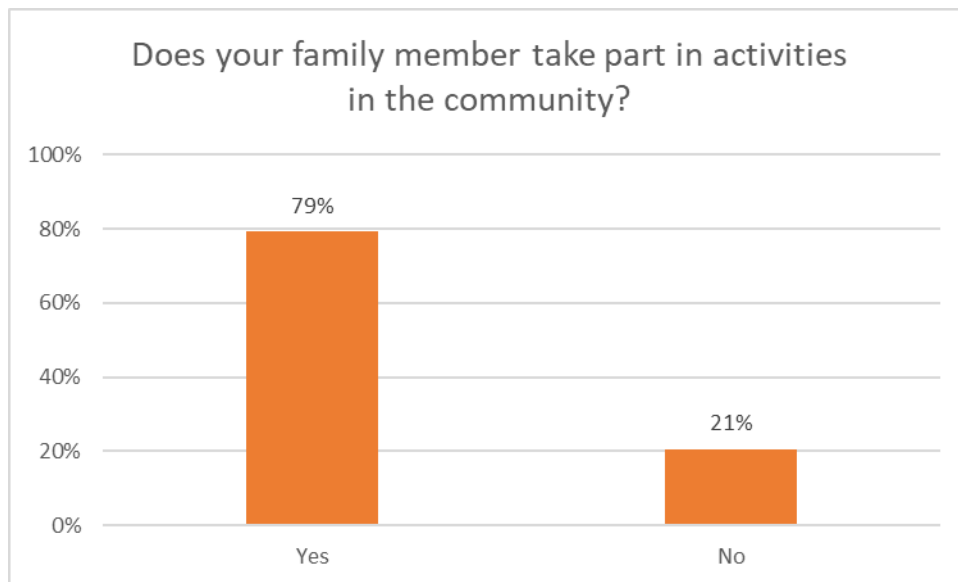


Table Q42. Does your family member take part in activities in the community?

**Significantly Above Average**

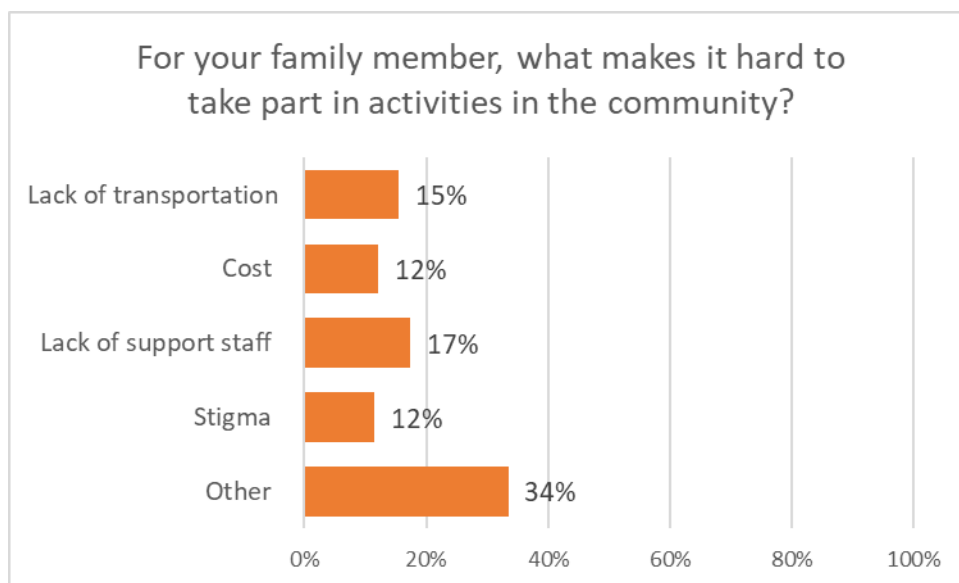
State	Yes	No	N
MN	87%	13%	437

**Within Average Range**

State	Yes	No	N
PA	83%	17%	589
MD	81%	19%	1,168
AZ	81%	19%	275
<b>Weighted NCI-IDD Average</b>	<b>79%</b>	<b>21%</b>	<b>4,717</b>
MO	79%	21%	269
NJ	79%	21%	250
VA	79%	21%	149
OK	78%	22%	389
LA	78%	22%	211
GA	77%	23%	409
DE	76%	24%	142

**Significantly Below Average**

State	Yes	No	N
FL	74%	26%	429



**Table Q43. For your family member, what makes it hard to take part in activities in the community?**

Categories are not mutually exclusive, therefore N is not shown

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	15%	14%	14%	14%	39%
DE	17%	11%	12%	10%	24%
FL	12%	12%	14%	11%	39%
GA	9%	13%	14%	8%	33%
LA	13%	14%	17%	17%	32%
MD	19%	13%	25%	11%	27%
MN	20%	11%	24%	14%	35%
MO	15%	14%	24%	13%	33%
NJ	29%	12%	29%	16%	32%
OK	11%	9%	12%	8%	30%
PA	14%	10%	14%	9%	28%
VA	14%	11%	19%	11%	39%
<b>Weighted NCI-IDD Average</b>	<b>15%</b>	<b>12%</b>	<b>17%</b>	<b>12%</b>	<b>34%</b>

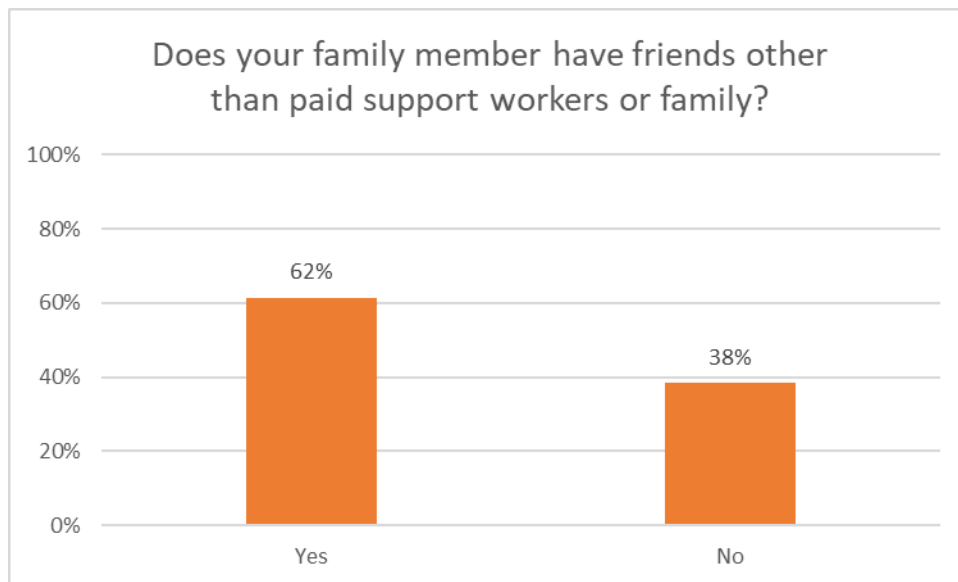


Table Q44. Does your family member have friends other than paid support workers or family?

#### Significantly Above Average

State	Yes	No	N
OK	73%	27%	378
GA	69%	31%	406
PA	67%	33%	575

#### Within Average Range

State	Yes	No	N
LA	65%	35%	213
DE	65%	35%	140
MN	64%	36%	435
VA	63%	37%	145
MO	63%	37%	265
MD	62%	38%	1,157
<b>Weighted NCI-IDD Average</b>	<b>62%</b>	<b>38%</b>	<b>4,663</b>
FL	58%	42%	429

#### Significantly Below Average

State	Yes	No	N
AZ	53%	47%	270
NJ	51%	49%	250

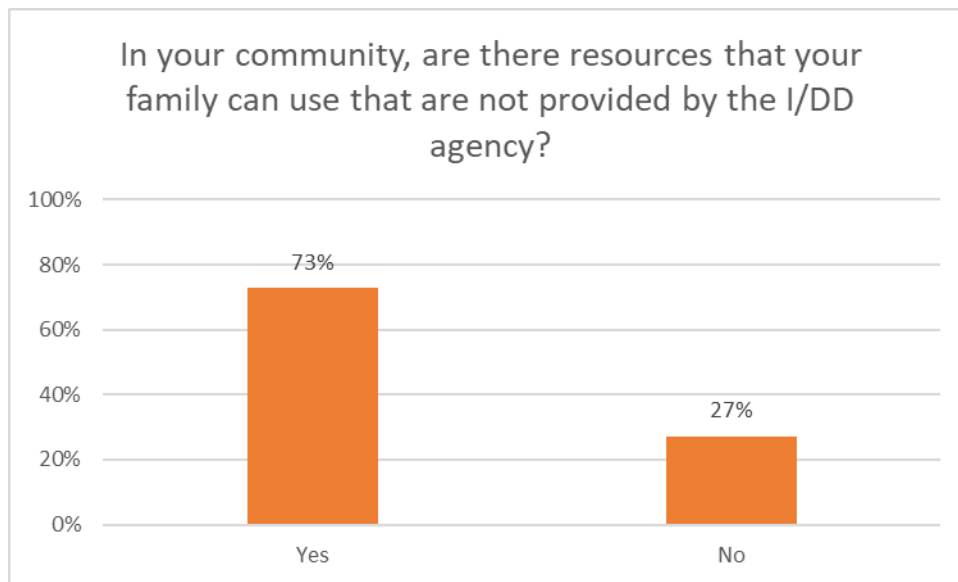


Table Q45. In your community, are there resources that your family can use that are not provided by the I/DD agency?

#### Significantly Above Average

State	Yes	No	N
OK	82%	18%	285
MD	79%	21%	900

#### Within Average Range

State	Yes	No	N
MN	78%	22%	316
VA	78%	22%	124
DE	78%	22%	109
AZ	77%	23%	198
MO	74%	26%	198
PA	73%	27%	401
<b>Weighted NCI-IDD Average</b>	<b>73%</b>	<b>27%</b>	<b>3,462</b>
LA	71%	29%	149
GA	69%	31%	308
FL	68%	32%	291

#### Significantly Below Average

State	Yes	No	N
NJ	61%	39%	183

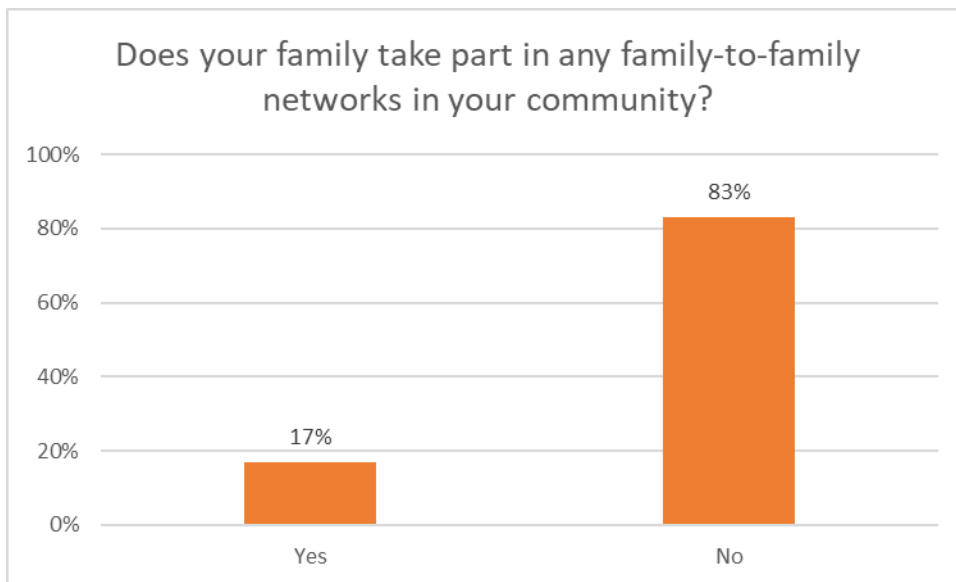


Table Q46. Does your family take part in any family-to-family networks in your community?

**Significantly Above Average**

State	Yes	No	N
GA	25%	75%	326

**Within Average Range**

State	Yes	No	N
LA	24%	76%	176
OK	20%	80%	320
FL	18%	82%	369
VA	18%	82%	129
MN	18%	82%	375
MD	17%	83%	1,032
<b>Weighted NCI-IDD Average</b>	<b>17%</b>	<b>83%</b>	<b>4,039</b>
DE	15%	85%	122
AZ	15%	85%	245
PA	15%	85%	494
NJ	13%	87%	215

**Significantly Below Average**

State	Yes	No	N
MO	11%	89%	236

## *Satisfaction With Services and Supports*

*Families and family members with disabilities receive adequate and satisfactory supports.*

**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.

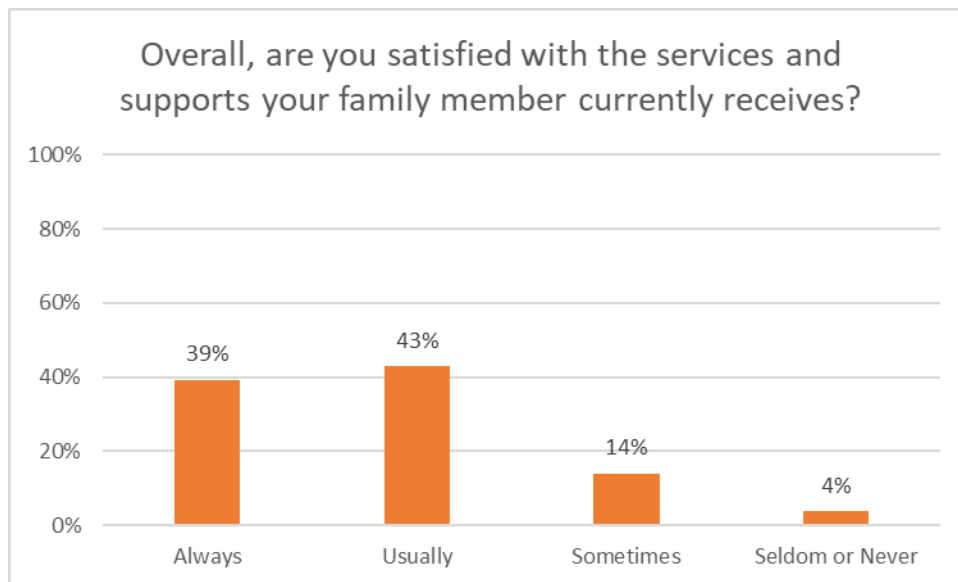


Table Q47. Overall, are you satisfied with the services and supports your family member currently receives?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
FL	49%	33%	14%	4%	427
PA	45%	40%	12%	2%	584

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	42%	42%	17%	0%	151
GA	41%	41%	13%	5%	401
AZ	40%	49%	9%	3%	279
<b>Weighted NCI-IDD Average</b>	<b>39%</b>	<b>43%</b>	<b>14%</b>	<b>4%</b>	<b>4,684</b>
LA	36%	46%	15%	3%	215
OK	36%	46%	14%	3%	377
DE	30%	46%	13%	11%	141

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MN	33%	52%	13%	2%	441
MO	31%	51%	12%	5%	267
MD	26%	46%	21%	7%	1,145
NJ	26%	47%	19%	8%	256

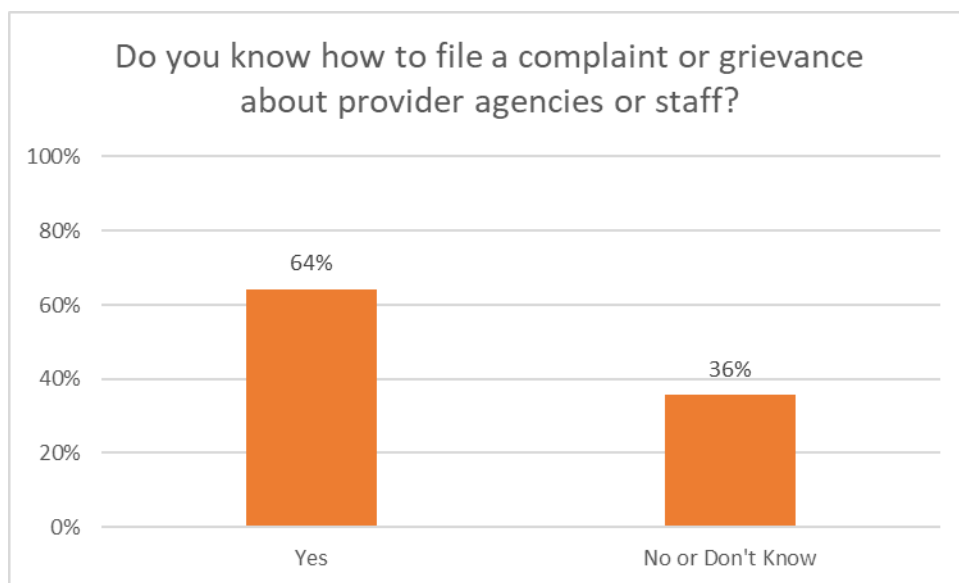


Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff?<sup>10</sup>

#### Significantly Above Average

State	Yes	No or Don't Know	N
OK	79%	21%	386
LA	77%	23%	214
PA	75%	25%	592

#### Within Average Range

State	Yes	No or Don't Know	N
MN	69%	31%	439
FL	69%	31%	434
MO	67%	33%	273
<b>Weighted NCI-IDD Average</b>	<b>64%</b>	<b>36%</b>	<b>4,756</b>
AZ	63%	37%	279
VA	55%	45%	150

#### Significantly Below Average

State	Yes	No or Don't Know	N
GA	57%	43%	412
NJ	48%	52%	256
MD	47%	53%	1,178
DE	34%	66%	143

<sup>10</sup> 'Don't Know' responses were included in 'No' responses for this question.





Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled? <sup>11</sup>

#### Within Average Range

State	Yes	No	N
GA	63%	37%	49
FL	60%	40%	43
PA	59%	41%	27
<b>Weighted NCI-IDD Average</b>	<b>59%</b>	<b>41%</b>	<b>341</b>
AZ	56%	44%	27

#### Significantly Below Average

State	Yes	No	N
OK	50%	50%	20
MD	48%	52%	83
MN	40%	60%	25

<sup>11</sup> The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: DE, LA, MO, NJ, VA.

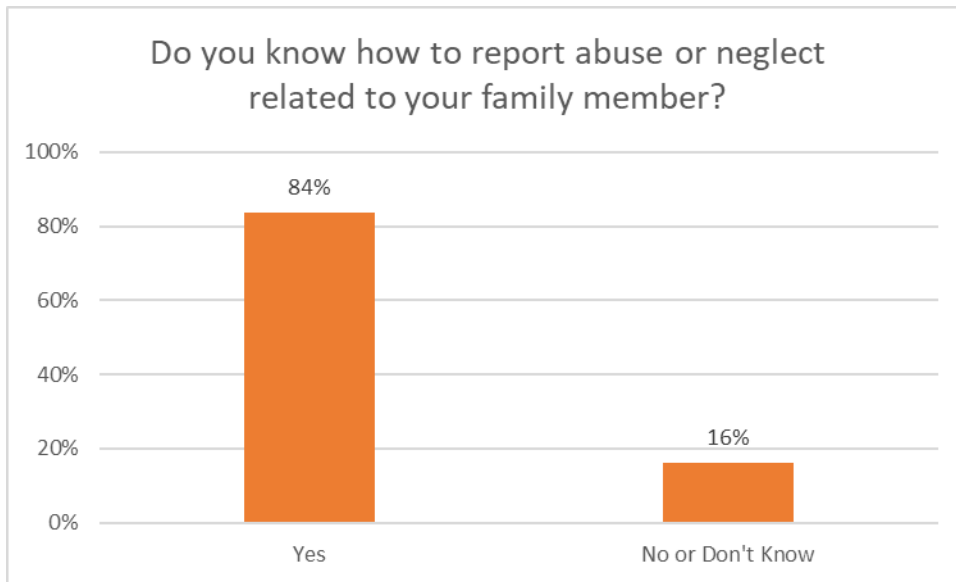


Table Q50. Do you know how to report abuse or neglect related to your family member?<sup>12</sup>

**Significantly Above Average**

State	Yes	No or Don't Know	N
PA	91%	9%	591
LA	90%	10%	214
FL	90%	10%	440
OK	89%	11%	385

**Within Average Range**

State	Yes	No or Don't Know	N
MN	88%	12%	443
MO	85%	15%	268
<b>Weighted NCI-IDD Average</b>	<b>84%</b>	<b>16%</b>	<b>4,735</b>
AZ	81%	19%	279
DE	76%	24%	140
VA	75%	25%	145

**Significantly Below Average**

State	Yes	No or Don't Know	N
GA	77%	23%	410
NJ	75%	25%	247
MD	69%	31%	1,173

<sup>12</sup> 'Don't Know' responses were included in 'No' responses for this question.

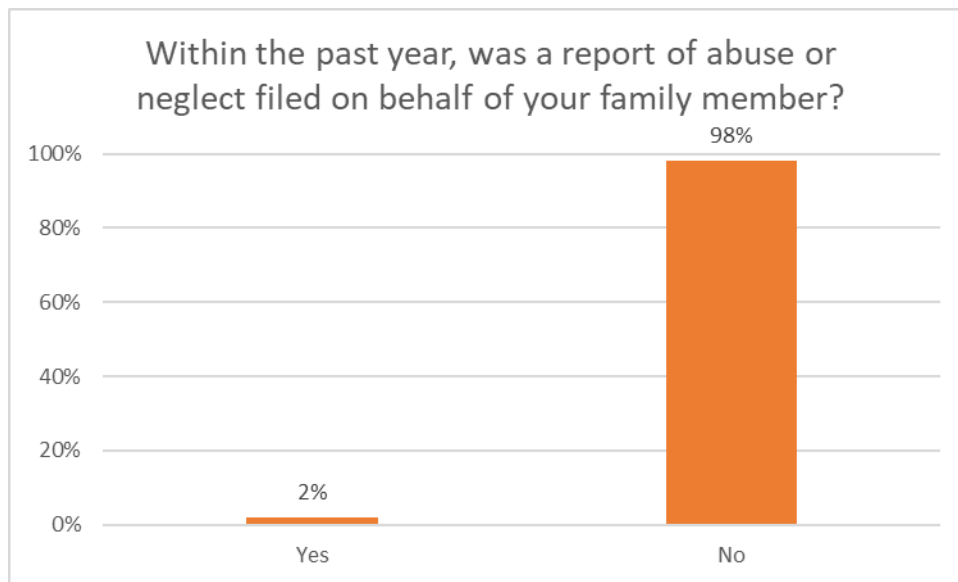
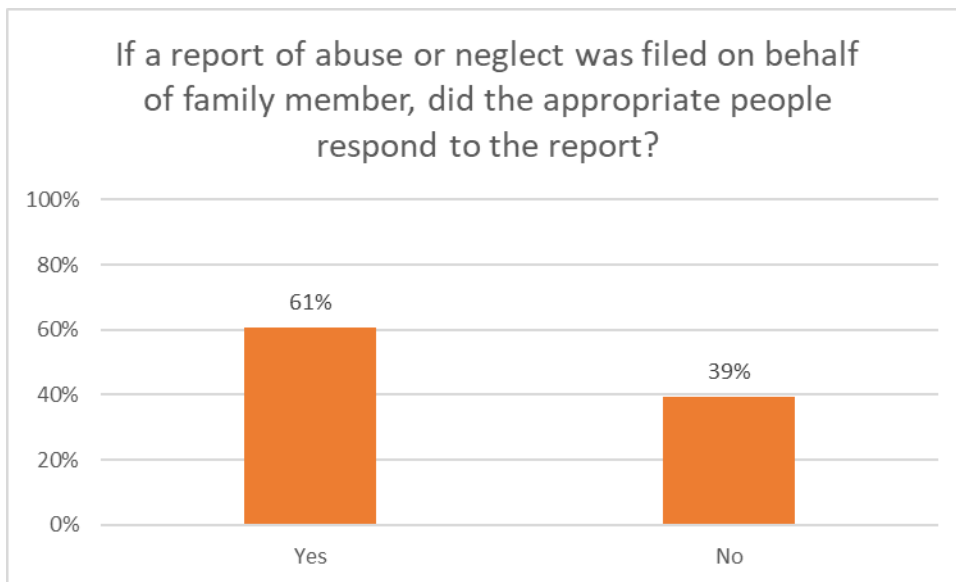


Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

**Within Average Range**

State	Yes	No	N
GA	3%	97%	411
AZ	3%	97%	277
VA	2%	98%	139
LA	2%	98%	217
<b>Weighted NCI-IDD Average</b>	<b>2%</b>	<b>98%</b>	<b>4,697</b>
MN	2%	98%	445
PA	2%	98%	587
FL	2%	98%	431
MO	1%	99%	268
MD	1%	99%	1,156
NJ	1%	99%	245
DE	1%	99%	136
OK	0%	100%	385



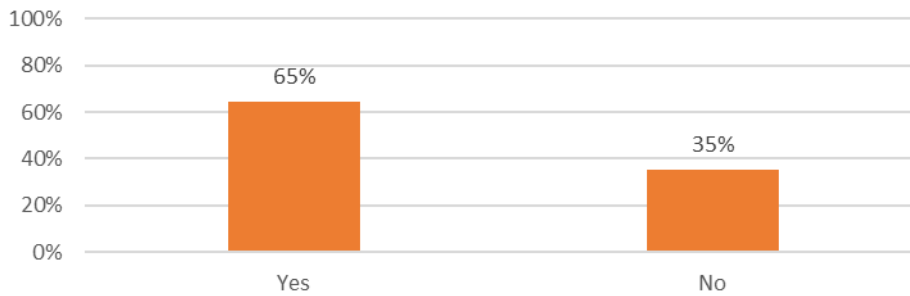
**Table Q52. If a report of abuse or neglect was filed on behalf of family member, did the appropriate people respond to the report?** <sup>13</sup>

**Within Average Range**

State	Yes	No	N
Weighted NCI-IDD Average	61%	39%	53

<sup>13</sup> No states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average

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



**Table Q53.** If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past year, were you notified of the report in a timely manner? <sup>14</sup>

**Within Average Range**

State	Yes	No	N
Weighted NCI-IDD Average	65%	35%	39

<sup>14</sup> No states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average

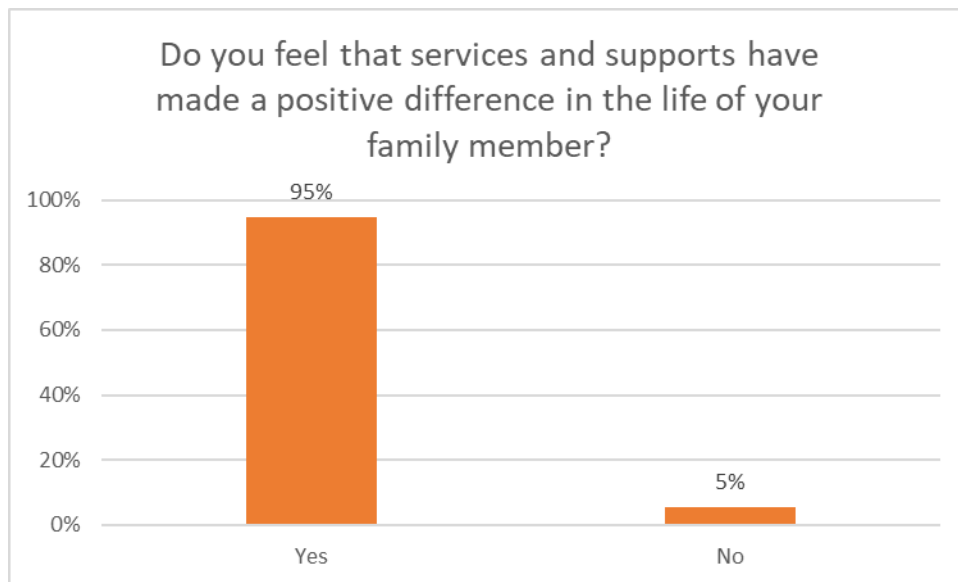


Table Q54. Do you feel that services and supports have made a positive difference in the life of your family member?

#### Significantly Above Average

State	Yes	No	N
VA	99%	1%	135
MN	98%	2%	415

#### Within Average Range

State	Yes	No	N
PA	96%	4%	563
OK	96%	4%	361
AZ	96%	4%	265
MO	95%	5%	249
<b>Weighted NCI-IDD Average</b>	<b>95%</b>	<b>5%</b>	<b>4,397</b>
LA	94%	6%	201
GA	94%	6%	373
FL	93%	7%	413
NJ	92%	8%	241
DE	88%	13%	128

#### Significantly Below Average

State	Yes	No	N
MD	91%	9%	1,053

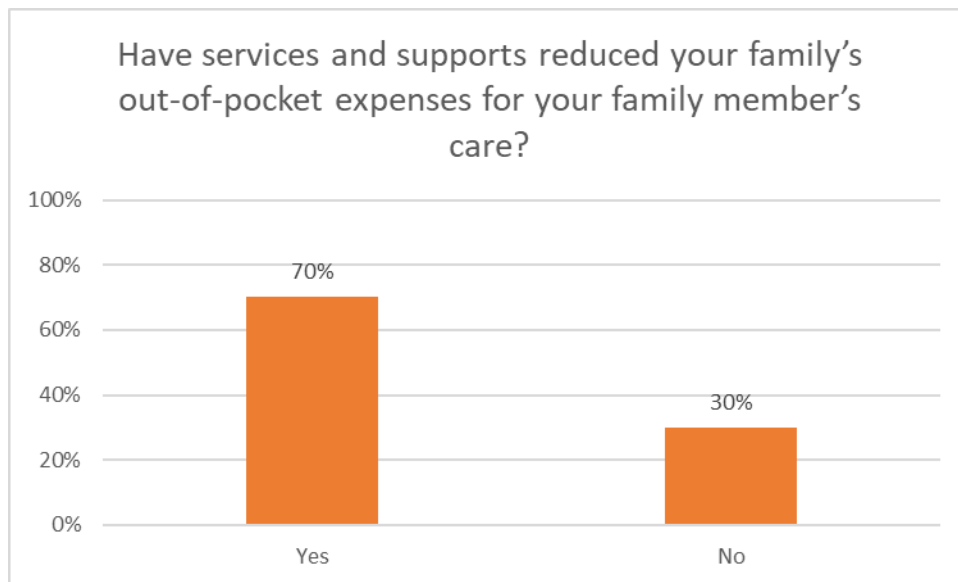


Table Q55. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

#### Significantly Above Average

State	Yes	No	N
OK	77%	23%	351
AZ	77%	23%	265

#### Within Average Range

State	Yes	No	N
VA	77%	23%	132
NJ	76%	24%	217
LA	76%	24%	197
FL	75%	25%	398
MN	73%	27%	417
MO	72%	28%	240
<b>Weighted NCI-IDD Average</b>	<b>70%</b>	<b>30%</b>	<b>4,249</b>
GA	64%	36%	355

#### Significantly Below Average

State	Yes	No	N
MD	62%	38%	1,032
PA	60%	40%	524
DE	45%	55%	121

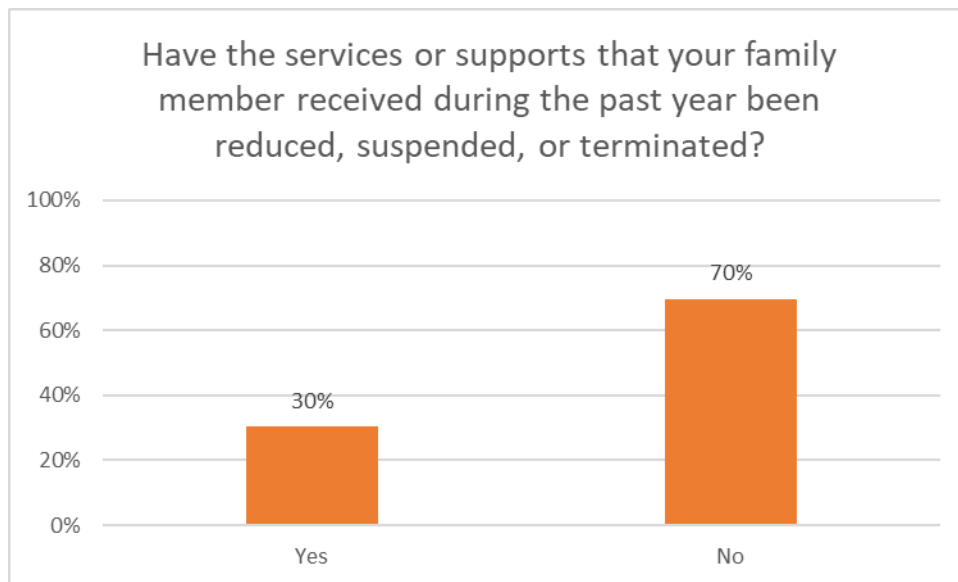


Table Q56. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

#### Significantly Above Average

State	Yes	No	N
MD	41%	59%	1,086
PA	36%	64%	563

#### Within Average Range

State	Yes	No	N
DE	37%	63%	128
MO	36%	64%	248
VA	33%	67%	145
NJ	32%	68%	237
<b>Weighted NCI-IDD Average</b>	<b>30%</b>	<b>70%</b>	<b>4,431</b>
FL	30%	70%	393
MN	27%	73%	425
GA	25%	75%	370

#### Significantly Below Average

State	Yes	No	N
AZ	22%	78%	270
LA	18%	82%	206
OK	18%	83%	360



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

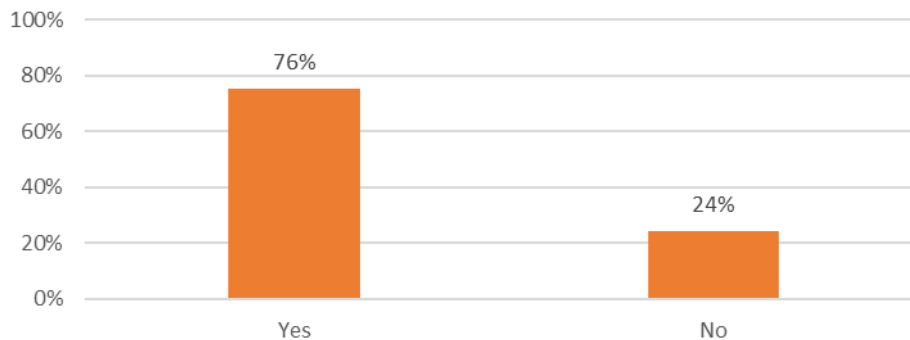


Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?

#### Significantly Above Average

State	Yes	No	N
NJ	91%	9%	69

#### Within Average Range

State	Yes	No	N
MO	85%	15%	73
VA	84%	16%	43
LA	81%	19%	31
FL	79%	21%	99
OK	77%	23%	53
<b>Weighted NCI-IDD Average</b>	<b>76%</b>	<b>24%</b>	<b>1,227</b>
MN	73%	27%	106
MD	72%	28%	400
GA	71%	29%	83
PA	71%	29%	174
DE	67%	33%	45
AZ	65%	35%	51

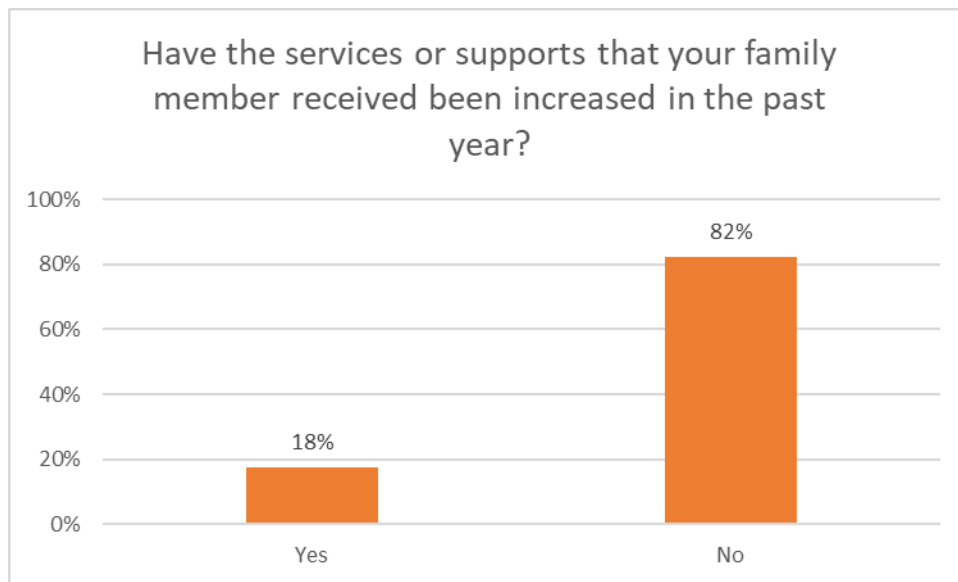


Table Q58. Have the services or supports that your family member received been increased in the past year?

#### Significantly Above Average

State	Yes	No	N
AZ	27%	73%	257

#### Within Average Range

State	Yes	No	N
GA	21%	79%	356
MD	19%	81%	1,084
VA	19%	81%	137
NJ	18%	82%	229
MN	18%	82%	405
<b>Weighted NCI-IDD Average</b>	<b>18%</b>	<b>82%</b>	<b>4,279</b>
LA	16%	85%	200
MO	15%	85%	251
PA	14%	86%	515
FL	14%	86%	368

#### Significantly Below Average

State	Yes	No	N
OK	13%	87%	347
DE	8%	92%	130

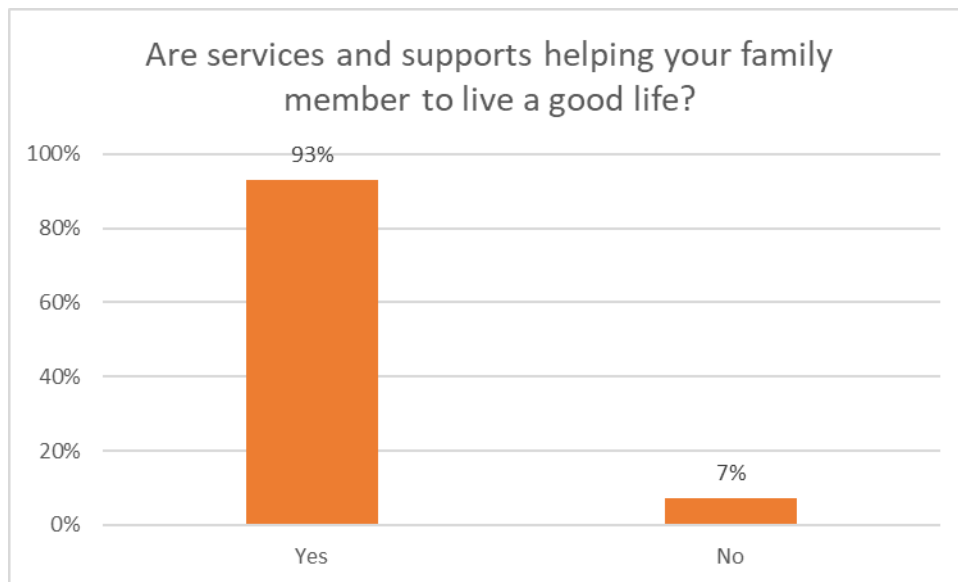


Table Q59. Are services and supports helping your family member to live a good life?

**Significantly Above Average**

State	Yes	No	N
OK	97%	3%	353
AZ	96%	4%	255
PA	95%	5%	537

**Within Average Range**

State	Yes	No	N
MN	95%	5%	419
LA	94%	6%	192
VA	94%	6%	134
MO	94%	6%	236
<b>Weighted NCI-IDD Average</b>	<b>93%</b>	<b>7%</b>	<b>4,218</b>
NJ	92%	8%	218
FL	90%	10%	398
GA	90%	10%	357
DE	85%	15%	117

**Significantly Below Average**

State	Yes	No	N
MD	88%	12%	1,002

## II. 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 (NCI), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI 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

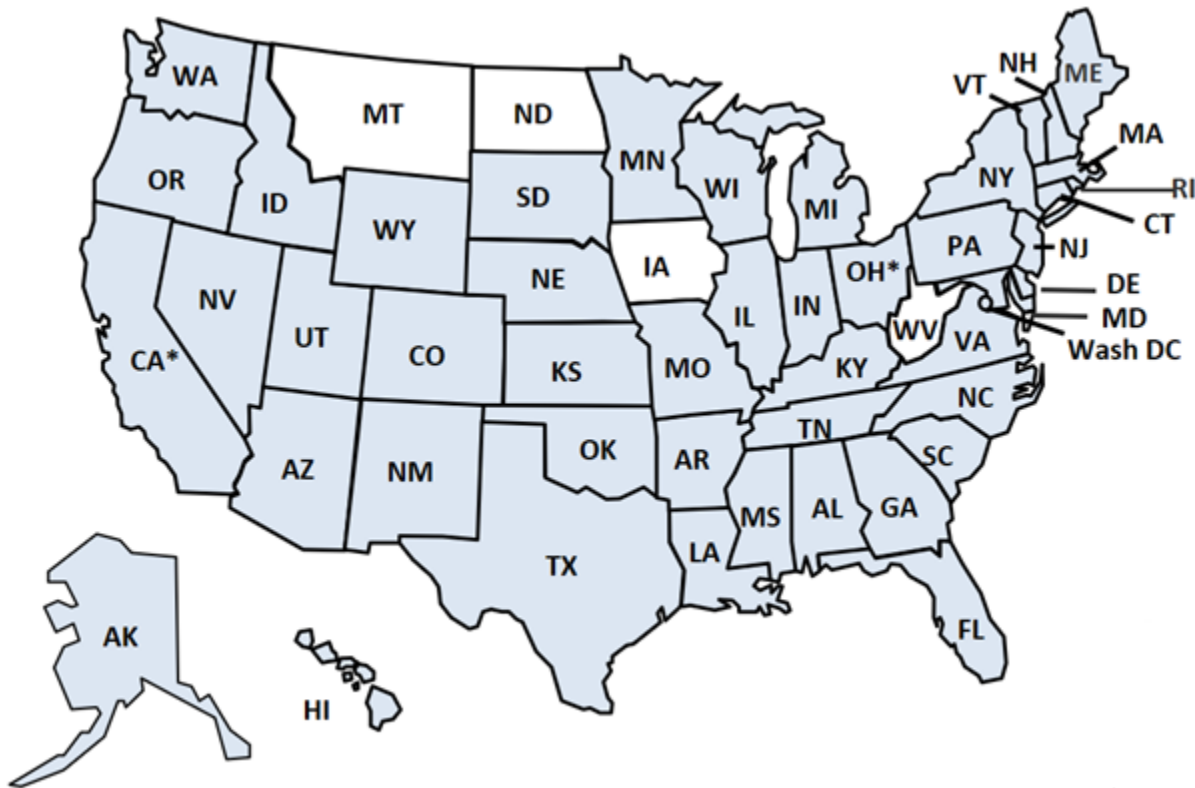
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven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

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

## State Participation

During the 2020-21 data collection cycle, 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 State Participation 2019-20



## 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 website at <https://www.nationalcoreindicators.org/indicators>.

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 five broad domains: Individual Outcomes; Health, Welfare, and Rights; Staff Stability and Competency; Family Outcomes; 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 Adult In-Person Survey, three Family Surveys, a Staff Stability Survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates).

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 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	Concern Statement
Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
Choice, Decision Making & Control	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.
Involvement in the Community	Family members with disabilities use integrated community services and participate in everyday community activities.
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.
Outcomes	Individual and family supports make a positive difference in the lives of families.

## How NCI 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 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](#).<sup>15</sup>

## 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

<sup>15</sup> Located on the National Core Indicators website: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org) → Resources → Technical Reports



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 NCI Average suggests that changes or further investigation are necessary.

Moreover, the NCI 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 NCI Averages; and states draw new samples each year rather than following the same group of individuals.

## III. 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 total of six states had at least a portion of surveys completed via direct entry for the 2019-20 data collection cycle.<sup>16</sup>

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%.<sup>17</sup>

## Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI reports, we use “NCI average” to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI 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 NCI averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the sample sizes.

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<sup>16</sup> States that used the direct entry or mail and direct entry options were: CA, DE, MD, MO, NC, WA.

<sup>17</sup> See “Response Rates” for information on total surveys mailed and received by states as well as each state’s margin of error.

Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average—that is, the state’s contribution to the NCI average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.

## Significance Testing

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

## Technical Details

The comparisons were done through one sample t-tests using the weighted NCI 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  $d = 2t / \sqrt{df}$ . 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 NCI average<sup>18</sup>; 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 2020-21, 12 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.

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<sup>18</sup> The NCI Average is a weighted average. Please see the section “Weighting” for more details.

**Figure 3. Adult Family Survey: State Response Rates** <sup>19</sup>

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	11,268	1,400	284	20.3%	5.74%	100%	0%
DE	1,169	400	151	37.8%	7.45%	54%	46%
FL	17,606	1,750	450	25.7%	4.56%	100%	0%
GA	7,338	1,700	430	25.3%	4.59%	100%	0%
LA	5,106	5,106	239	4.7%	6.19%	0%	100%
MD	7,207	8,900	1,212	13.6%	2.57%	87%	13%
MN	6,919	1,600	458	28.6%	4.43%	83%	17%
MO	3,466	1,500	277	18.5%	5.65%	90%	10%
NJ	8,980	8,980	288	3.2%	5.68%	0%	100%
OK	1,874	1,874	394	21.0%	4.39%	100%	0%
PA	18,982	2,000	610	30.5%	3.90%	100%	0%
VA	5,590	661	159	24.1%	7.66%	100%	0%
<b>Total</b>	<b>95,505</b>	<b>35,871</b>	<b>4,952</b>	<b>21.1%</b>	<b>5.23%</b>	<b>83%</b>	<b>17%</b>

<sup>19</sup> Please note: The family surveys are mail surveys or completed online by respondents who choose to take part in the survey. As such, the final sample is a sample of convenience and cannot be considered representative of the entire service population in the state.