

# Family/Guardian Survey

2018-19 Final Report



**NATIONAL CORE  
INDICATORS**

A Collaboration of  
the National Association of State Directors of  
Developmental Disabilities Services  
and the Human Services Research Institute



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Updated January 2020 to delete N's in Table 5 and Table Q40

## **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 NCI Family/Guardian Survey is administered to families who have an adult (18 years or older) with a developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Family/Guardian Survey on an annual basis. Of the 46 states, the District of Columbia, and 22 sub-state entities who participated in NCI during the 2018-19 data collection cycle, nine states submitted a valid sample of Family/Guardian Survey data: Arizona (AZ), Georgia (GA), Kentucky (KY), Louisiana (LA), Maryland (MD), North Carolina (NC), Ohio (OH), Pennsylvania (PA) and Virginia (VA). This Final Report provides a summary of results based on data submitted by June 30, 2019.

The following are NCI national weighted averages for a selection of survey items. Complete breakouts by state for each item in the Family/Guardian Survey can be found in the Results section of this report.



# 2018-19 Family/Guardian Survey

2,709 families participated across  
9 states (AZ, GA, KY, LA, MD, NC, OH, PA, VA)

### NCI Averages:

- Include all participating states
- Data are weighted

### Respondents

Family members and/or guardians of an adult who has I/DD who *does not* live in their home and receives one public service in addition to case management from the state DD agency.

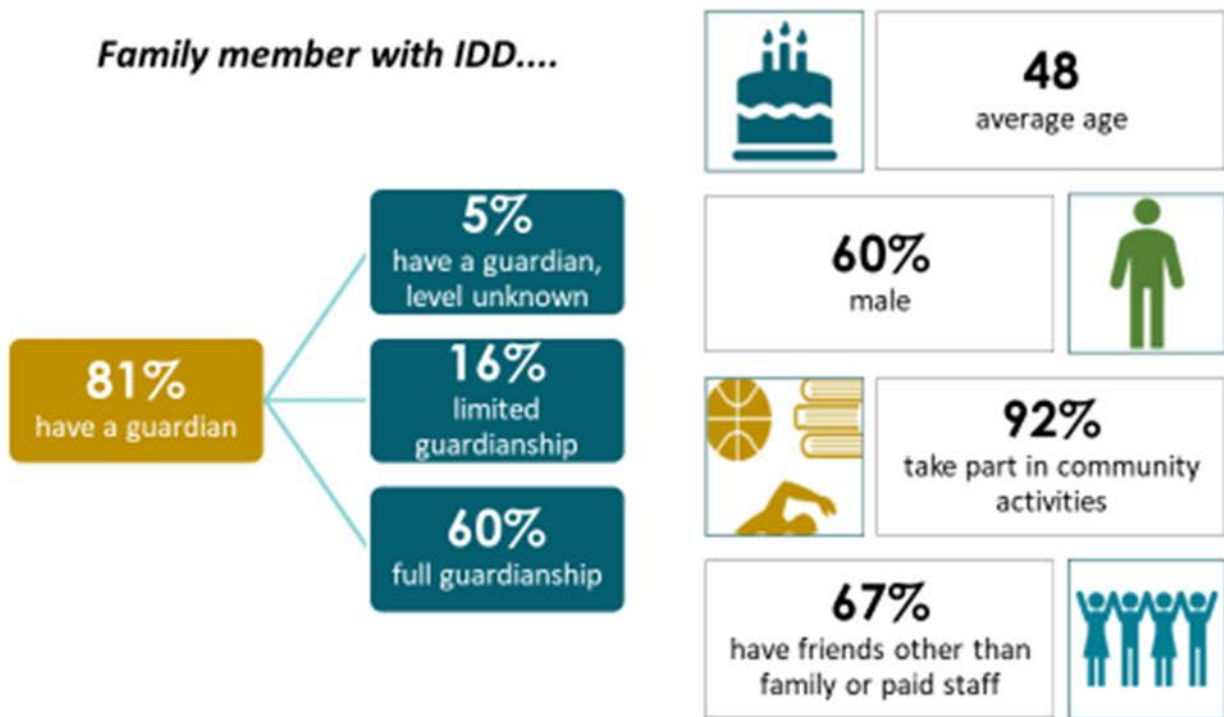


Most are over 55,  
**19%**  
are age 75 or older



**57%** say they visited  
their family member with  
IDD 12 or more times in  
the past year

### Family member with IDD....

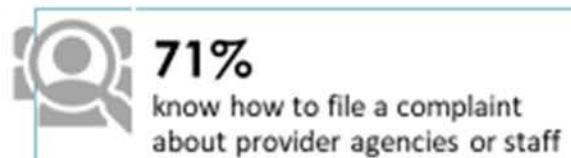
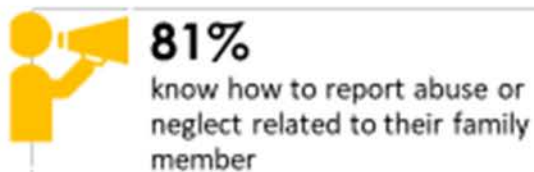
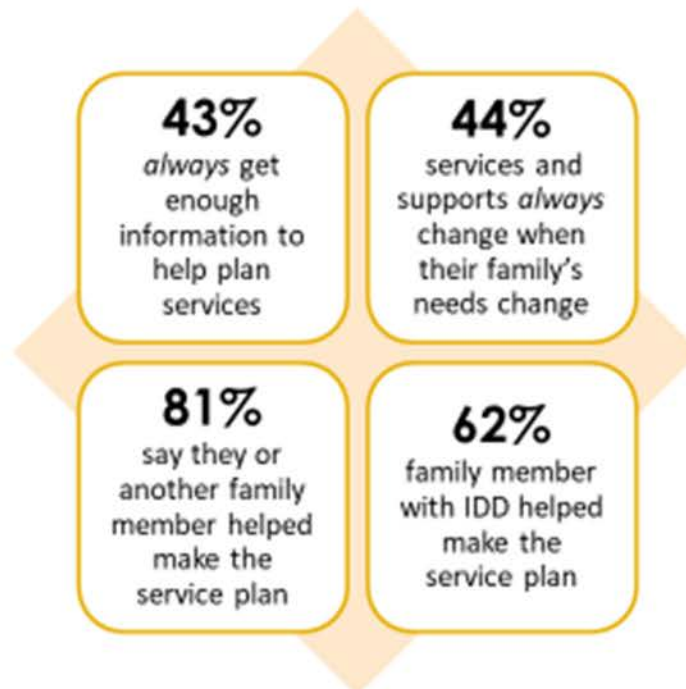


### Where family member lives...



- 14% specialized facility for people with ID
- 65% group home or agency-operated agency
- 11% own home or apartment
- 7% adult foster care or host home
- 3% other

# 2018-19 Family/Guardian Survey



# 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 and supports 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 fewer than 20 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. Family Member's Residence**

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

State	Specialized Facility for People With ID <sup>1</sup>	Group Home or Agency-operated Agency	Independent Home or Apartment	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
AZ	9%	71%	2%	12%	0%	0%	5%	244
GA	9%	64%	12%	16%	0%	0%	0%	363
KY	17%	59%	4%	13%	2%	0%	5%	156
LA	23%	22%	53%	1%	0%	0%	1%	176
MD	10%	84%	4%	1%	0%	0%	2%	517
NC	27%	50%	5%	17%	0%	0%	0%	207
OH	21%	50%	21%	4%	0%	0%	2%	247
PA	12%	68%	13%	4%	1%	0%	1%	552
VA	8%	71%	8%	10%	1%	0%	2%	195
<b>NCI Average</b>	<b>14%</b>	<b>65%</b>	<b>11%</b>	<b>7%</b>	<b>1%</b>	<b>0%</b>	<b>2%</b>	<b>2,657</b>

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

State	Urban or Suburban	Rural	N
AZ	90%	10%	241
GA	80%	20%	360
KY	72%	28%	156
LA	74%	26%	165
MD	76%	24%	517
NC	70%	30%	206
OH	76%	24%	242
PA	73%	27%	545
VA	78%	22%	186
<b>NCI Average</b>	<b>76%</b>	<b>24%</b>	<b>2,618</b>

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

State	Age	N
AZ	44.1	240
GA	45.3	360
KY	50.6	155
LA	47.8	185
MD	47.8	511
NC	44.3	209
OH	50.1	255
PA	48.3	560
VA	45.6	189
<b>NCI Average</b>	<b>47.6</b>	<b>2,664</b>

<sup>1</sup> ICF, state-run or other institutional setting

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

State	Male	Female	N
AZ	60%	40%	247
GA	58%	42%	363
KY	64%	36%	157
LA	60%	40%	185
MD	61%	39%	524
NC	67%	33%	209
OH	62%	38%	256
PA	56%	44%	556
VA	59%	41%	196
<b>NCI Average</b>	60%	40%	2,693

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

Reminder: 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 Native Alaska	Asian	Black or African American	Hawaiian or Pacific Islander	White	Hispanic or Latino	Other
AZ	11%	2%	4%	0%	76%	13%	2%
GA	1%	1%	16%	0%	82%	1%	1%
KY	4%	0%	6%	0%	92%	1%	0%
LA	1%	1%	23%	0%	77%	0%	1%
MD	2%	2%	16%	1%	72%	2%	9%
NC	1%	2%	26%	0%	72%	0%	0%
OH	1%	0%	15%	0%	83%	2%	0%
PA	1%	1%	7%	1%	90%	1%	0%
VA	1%	4%	17%	0%	80%	1%	1%
<b>NCI Average</b>	2%	2%	13%	0%	81%	2%	2%

**Table 6a. Family Member's Disabilities (not mutually exclusive)**

Reminder: 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	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
AZ	71%	38%	31%	21%	9%	7%
GA	80%	34%	30%	16%	11%	5%
KY	81%	37%	26%	20%	9%	5%
LA	72%	35%	25%	18%	9%	8%
MD	77%	33%	29%	20%	12%	8%
NC	77%	38%	33%	16%	11%	6%
OH	82%	59%	17%	15%	13%	7%
PA	82%	37%	21%	18%	9%	7%
VA	77%	32%	37%	12%	10%	7%
<b>NCI Average</b>	79%	40%	26%	17%	11%	7%



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

Reminder: 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 Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
AZ	13%	35%	0%	11%	0%	3%	16%
GA	10%	29%	0%	10%	2%	2%	14%
KY	13%	35%	1%	10%	0%	2%	6%
LA	12%	23%	1%	5%	0%	1%	14%
MD	11%	31%	1%	10%	0%	1%	13%
NC	9%	29%	2%	9%	1%	0%	13%
OH	6%	33%	0%	6%	0%	1%	13%
PA	10%	30%	0%	11%	1%	1%	10%
VA	9%	25%	0%	10%	1%	2%	13%
<b>NCI Average</b>	10%	30%	0%	9%	1%	1%	12%

**Table 7a. Family Member's Health Conditions**

Reminder: 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	9%	23%	5%	28%	34%
GA	9%	19%	8%	35%	35%
KY	9%	26%	5%	34%	26%
LA	10%	20%	8%	43%	30%
MD	8%	19%	9%	30%	31%
NC	7%	25%	5%	36%	35%
OH	11%	24%	4%	35%	26%
PA	12%	17%	6%	29%	31%
VA	7%	22%	5%	35%	31%
<b>NCI Average</b>	9%	21%	6%	33%	30%

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

Reminder: 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 or Other Dental Problems	Sleep Apnea	Other
AZ	10%	2%	7%	24%	9%	24%
GA	13%	1%	4%	14%	11%	24%
KY	16%	0%	9%	21%	22%	10%
LA	19%	1%	4%	15%	8%	17%
MD	12%	3%	8%	18%	4%	24%
NC	16%	4%	10%	22%	15%	19%
OH	12%	2%	7%	9%	13%	33%
PA	20%	4%	8%	12%	16%	19%
VA	12%	1%	2%	14%	16%	28%
<b>NCI Average</b>	14%	2%	7%	15%	13%	24%

**Table 8. 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	71%	17%	3%	2%	7%	244
GA	69%	22%	2%	0%	6%	357
KY	76%	19%	3%	1%	1%	155
LA	73%	20%	1%	1%	5%	177
MD	70%	20%	4%	2%	4%	520
NC	70%	25%	3%	1%	1%	205
OH	65%	29%	2%	0%	3%	252
PA	76%	17%	2%	2%	4%	552
VA	70%	25%	4%	0%	1%	196
<b>NCI Average</b>	71%	22%	3%	1%	3%	2,658

**Table 9. Family Member Has Legal Court Appointed Guardian or Conservator**

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

State	None	Limited	Full	Has Guardianship but Level is Unknown	N
AZ	12%	6%	79%	4%	243
GA	11%	13%	70%	5%	349
KY	2%	8%	85%	5%	155
LA	29%	22%	42%	8%	168
MD	33%	24%	38%	6%	480
NC	3%	15%	80%	3%	206
OH	1%	18%	79%	2%	250
PA	36%	15%	41%	8%	491
VA	27%	18%	50%	5%	191
<b>NCI Average</b>	<b>19%</b>	<b>16%</b>	<b>60%</b>	<b>5%</b>	<b>2,533</b>

**Table 10. Guardian or Conservator Relationship to Family Member**

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

State	Family	Friend	State Employee or Guardianship Agency	Other	N
AZ	88%	4%	6%	2%	209
GA	91%	3%	1%	5%	306
KY	92%	4%	1%	3%	150
LA	94%	0%	1%	6%	108
MD	83%	1%	8%	8%	297
NC	79%	2%	18%	1%	192
OH	34%	2%	58%	7%	241
PA	84%	1%	10%	4%	298
VA	93%	2%	3%	2%	127
<b>NCI Average</b>	<b>74%</b>	<b>2%</b>	<b>20%</b>	<b>5%</b>	<b>1,928</b>

**Table 11. Family Member's Highest level of Education**

State	Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational Training	Some College	College Degree or Higher	N
AZ	31%	2%	29%	25%	3%	3%	7%	229
GA	32%	1%	44%	15%	2%	2%	5%	331
KY	47%	0%	30%	14%	1%	2%	7%	146
LA	46%	1%	29%	14%	2%	4%	4%	167
MD	40%	0%	39%	11%	4%	3%	4%	483
NC	48%	1%	33%	8%	2%	5%	4%	195
OH	55%	0%	15%	23%	3%	1%	4%	200
PA	38%	0%	23%	30%	4%	2%	3%	529
VA	38%	0%	38%	13%	5%	3%	2%	180
<b>NCI Average</b>	42%	0%	29%	19%	3%	2%	4%	2,460

**Table 12. Family Member's Activities in the Past Two Weeks Included *Individual Paid Job in the Community*<sup>2</sup>**

Response options changed from previous years

State	Yes	No	N
AZ	8%	92%	239
GA	11%	89%	354
KY	8%	92%	149
LA	9%	91%	174
MD	13%	87%	497
NC	14%	86%	197
OH	7%	93%	241
PA	12%	88%	522
VA	11%	89%	157
<b>NCI Average</b>	11%	89%	2,530

<sup>2</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).

**Table 13. Family Member's Activities in the Past Two Weeks Included *Paid Small Group Job in a Community-based Setting*<sup>3</sup>**

Response options changed from previous years

State	Yes	No	N
AZ	13%	88%	232
GA	5%	95%	346
KY	12%	88%	132
LA	13%	87%	173
MD	12%	88%	489
NC	12%	88%	195
OH	14%	86%	235
PA	9%	91%	511
VA	10%	90%	146
<b>NCI Average</b>	11%	89%	2,459

**Table 14. Family Member's Activities in the Past Two Weeks Included *Paid Work in a Community Job That Primarily Hires People With Disabilities*<sup>4</sup>**

Response options changed from previous years

State	Yes	No	N
AZ	6%	94%	228
GA	3%	97%	347
KY	6%	94%	146
LA	7%	93%	177
MD	5%	95%	498
NC	7%	93%	199
OH	7%	93%	234
PA	4%	96%	517
VA	5%	95%	148
<b>NCI Average</b>	5%	95%	2,494

<sup>3</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).

<sup>4</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 enclave.

**Table 15. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in the Community*<sup>5</sup>**

Response options changed from previous years

State	Yes	No	N
AZ	12%	88%	235
GA	27%	73%	321
KY	18%	82%	140
LA	10%	90%	168
MD	29%	71%	473
NC	36%	64%	194
OH	26%	74%	233
PA	27%	73%	488
VA	40%	60%	154
<b>NCI Average</b>	28%	72%	2,406

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

Response options changed from previous years

State	Yes	No	N
AZ	22%	78%	237
GA	10%	90%	348
KY	24%	76%	146
LA	17%	83%	170
MD	18%	82%	488
NC	29%	71%	197
OH	34%	66%	238
PA	25%	75%	521
VA	10%	90%	146
<b>NCI Average</b>	23%	77%	2,491

<sup>5</sup> Unpaid work in the community includes: volunteering, skills training, and staff-supported community connections.

<sup>6</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.

**Table 17. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in a Facility-based Setting*<sup>7</sup>**

Response options changed from previous years

State	Yes	No	N
AZ	46%	54%	230
GA	51%	49%	336
KY	40%	60%	143
LA	19%	81%	160
MD	48%	52%	468
NC	37%	63%	186
OH	62%	38%	239
PA	34%	66%	497
VA	48%	52%	155
<b>NCI Average</b>	46%	54%	2,414

**Table 18. Family Member's Activities in the Past Two Weeks Included *School***

Response options changed from previous years

State	Yes	No	N
AZ	5%	95%	227
GA	5%	95%	345
KY	1%	99%	148
LA	8%	92%	173
MD	3%	97%	491
NC	9%	91%	197
OH	1%	99%	239
PA	4%	96%	518
VA	1%	99%	131
<b>NCI Average</b>	3%	97%	2,469

**Table 19. Family Member's Activities in the Past Two Weeks Included *Stays at Home***

Response options changed from previous years

State	Yes	No	N
AZ	19%	81%	225
GA	23%	77%	341
KY	15%	85%	149
LA	39%	61%	167
MD	16%	84%	481
NC	18%	82%	191
OH	18%	82%	240
PA	31%	69%	505
VA	26%	74%	135
<b>NCI Average</b>	22%	78%	2,434

<sup>7</sup> An unpaid activity in a facility-based setting includes day habilitation, senior programs, or drop-in centers.

**Table 20. Family Member's Activities in the Past Two Weeks Included *Other Activities***

Response options changed from previous years

State	Yes	No	N
AZ	38%	62%	73
GA	38%	62%	125
KY	39%	61%	62
LA	32%	68%	74
MD	40%	60%	166
NC	43%	57%	91
OH	26%	74%	110
PA	53%	47%	214
VA	45%	55%	83
<b>NCI Average</b>	41%	59%	998

**Table 21. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors**

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

State	None	Some	Extensive	N
AZ	32%	41%	27%	241
GA	30%	40%	30%	361
KY	22%	44%	34%	154
LA	34%	34%	32%	177
MD	37%	38%	25%	517
NC	24%	39%	37%	208
OH	29%	44%	26%	251
PA	32%	41%	28%	549
VA	23%	47%	29%	196
<b>NCI Average</b>	30%	42%	29%	2,654

**Table 22. Family Member's Level of Help Needed With Personal Care Activities (e.g., bathing, dressing, eating)**

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

State	None	Some	Extensive	N
AZ	13%	42%	45%	242
GA	17%	36%	48%	361
KY	15%	39%	46%	155
LA	22%	37%	42%	183
MD	17%	41%	42%	516
NC	17%	38%	45%	208
OH	12%	38%	50%	251
PA	25%	36%	39%	553
VA	14%	44%	42%	197
<b>NCI Average</b>	17%	39%	44%	2,666



**Table 23. Family Member’s Need for Help With Other Daily Activities (e.g., scheduling, managing money, or shopping)**

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

State	None	Some	Extensive	N
AZ	2%	16%	82%	241
GA	1%	13%	87%	360
KY	0%	16%	84%	155
LA	4%	19%	77%	182
MD	2%	16%	82%	517
NC	2%	14%	83%	208
OH	0%	16%	83%	255
PA	3%	22%	75%	551
VA	2%	15%	84%	190
<b>NCI Average</b>	2%	17%	81%	2,659

## *Respondents*

*This section provides demographic information about the respondent.*

**Table 24. Language Spoken at Home**

New question in 2018-19

State	English	Spanish	Other	N
AZ	96%	2%	2%	245
GA	99%	0%	1%	361
KY	99%	0%	1%	153
LA	99%	0%	1%	181
MD	99%	0%	1%	519
NC	99%	0%	1%	209
OH	99%	0%	1%	253
PA	99%	0%	1%	545
VA	97%	0%	3%	198
<b>NCI Average</b>	98%	0%	1%	2,664

**Table 25. Respondent's Age**

State	Under 35	35-54	55-74	75 and Older	N
AZ	2%	17%	61%	19%	244
GA	0%	13%	65%	22%	362
KY	1%	5%	73%	22%	155
LA	2%	16%	62%	20%	184
MD	1%	8%	61%	30%	516
NC	1%	17%	66%	15%	207
OH	14%	35%	48%	3%	252
PA	0%	10%	65%	24%	547
VA	2%	11%	68%	20%	198
<b>NCI Average</b>	4%	16%	62%	19%	2,665

**Table 26. Respondent's Health**

State	Excellent	Very Good	Fairly Good	Poor	N
AZ	22%	47%	28%	3%	242
GA	16%	48%	30%	6%	358
KY	11%	37%	44%	8%	156
LA	13%	37%	46%	4%	182
MD	18%	44%	34%	4%	520
NC	13%	47%	34%	7%	208
OH	20%	47%	30%	2%	253
PA	16%	46%	36%	3%	541
VA	11%	44%	39%	7%	197
<b>NCI Average</b>	16%	45%	34%	4%	2,657

Table 27. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
AZ	57%	22%	0%	2%	6%	6%	7%	245
GA	59%	26%	0%	3%	2%	3%	7%	360
KY	54%	29%	1%	1%	0%	4%	11%	156
LA	53%	29%	0%	2%	1%	1%	14%	184
MD	62%	30%	0%	1%	1%	1%	5%	517
NC	51%	22%	0%	2%	11%	8%	4%	201
OH	22%	11%	0%	1%	48%	10%	9%	255
PA	59%	31%	0%	2%	1%	1%	6%	544
VA	61%	24%	1%	2%	1%	3%	10%	198
<b>NCI Average</b>	51%	24%	0%	1%	11%	4%	8%	2,660

Table 28. Respondent's Frequency of Visits With Family Member Last Year

State	Did not Visit	1-3 times	4-6 times	7-12 times	More Than 12 Times	N
AZ	2%	9%	8%	11%	70%	247
GA	3%	12%	12%	13%	61%	356
KY	1%	5%	14%	15%	65%	156
LA	5%	8%	10%	8%	69%	182
MD	3%	9%	11%	12%	66%	519
NC	1%	11%	21%	11%	55%	209
OH	0%	6%	56%	8%	30%	248
PA	4%	8%	11%	14%	63%	547
VA	6%	8%	15%	11%	60%	193
<b>NCI Average</b>	3%	8%	21%	11%	57%	2,657

Table 29. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School Certificate Program	Some College	College Degree or Higher	N
AZ	1%	14%	7%	38%	40%	242
GA	4%	20%	9%	18%	50%	361
KY	6%	24%	3%	28%	39%	155
LA	10%	24%	8%	21%	37%	179
MD	2%	18%	3%	19%	58%	519
NC	4%	16%	5%	19%	55%	207
OH	4%	11%	2%	8%	75%	253
PA	5%	29%	7%	19%	41%	550
VA	2%	21%	4%	26%	47%	198
<b>NCI Average</b>	3%	19%	5%	20%	52%	2,664

**Table 30. 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	9%	3%	10%	14%	15%	17%	32%	202
GA	14%	5%	11%	16%	11%	17%	27%	304
KY	11%	7%	13%	18%	15%	15%	21%	136
LA	7%	7%	12%	24%	8%	12%	29%	149
MD	9%	5%	6%	11%	12%	25%	32%	424
NC	11%	4%	9%	15%	13%	19%	29%	168
OH	5%	2%	2%	24%	12%	15%	39%	173
PA	12%	7%	9%	17%	11%	14%	29%	457
VA	5%	7%	5%	19%	16%	20%	28%	158
<b>NCI Average</b>	9%	5%	7%	17%	13%	18%	31%	2,171

## *Services and Supports Received*

*This section provides information about the services and supports received by the family.*

**Table 31. Services and Supports Received From ID/DD Agency**

Reminder: 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	Residential Support	Day or Employment Supports	Transportation	Other	Self-direction or Fiscal Intermediary Services
AZ	21%	24%	92%	75%	92%	64%	19%
GA	32%	41%	94%	71%	96%	51%	25%
KY	22%	40%	94%	75%	94%	74%	36%
LA	26%	61%	74%	41%	81%	42%	29%
MD	32%	44%	97%	79%	97%	54%	11%
NC	34%	29%	92%	70%	93%	66%	18%
OH	51%	76%	92%	77%	98%	68%	38%
PA	25%	43%	89%	64%	91%	62%	23%
VA	23%	25%	89%	76%	94%	55%	22%
<b>NCI Average</b>	31%	44%	92%	73%	94%	61%	24%

**Table 32. Additional Services and Supports Received**

Reminder: 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 Payments (SSI/SSB)	Other Agencies or Organizations
AZ	95%	23%
GA	98%	23%
KY	99%	24%
LA	92%	23%
MD	95%	25%
NC	99%	32%
OH	99%	48%
PA	97%	32%
VA	93%	33%
<b>NCI Average</b>	96%	32%

# Family/Guardian 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.



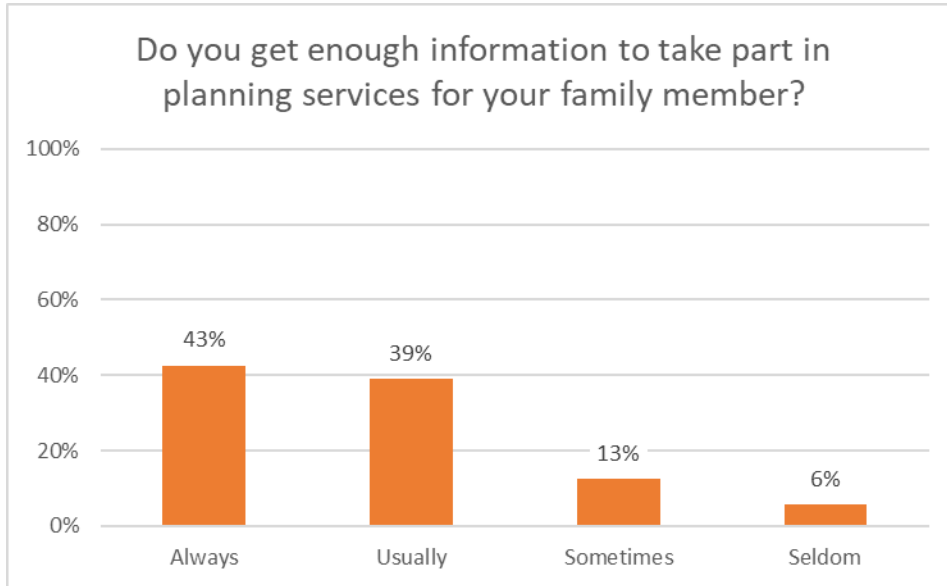
## *Information and Planning*

*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
NC	55%	31%	10%	4%	202
OH	51%	42%	5%	2%	248

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	50%	36%	10%	4%	181
LA	44%	35%	14%	7%	167
<b>NCI Average</b>	<b>43%</b>	<b>39%</b>	<b>13%</b>	<b>6%</b>	<b>2,473</b>
KY	41%	39%	10%	9%	145
AZ	40%	42%	15%	3%	234
PA	38%	40%	16%	6%	492

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	31%	43%	20%	7%	331
MD	29%	41%	19%	12%	473

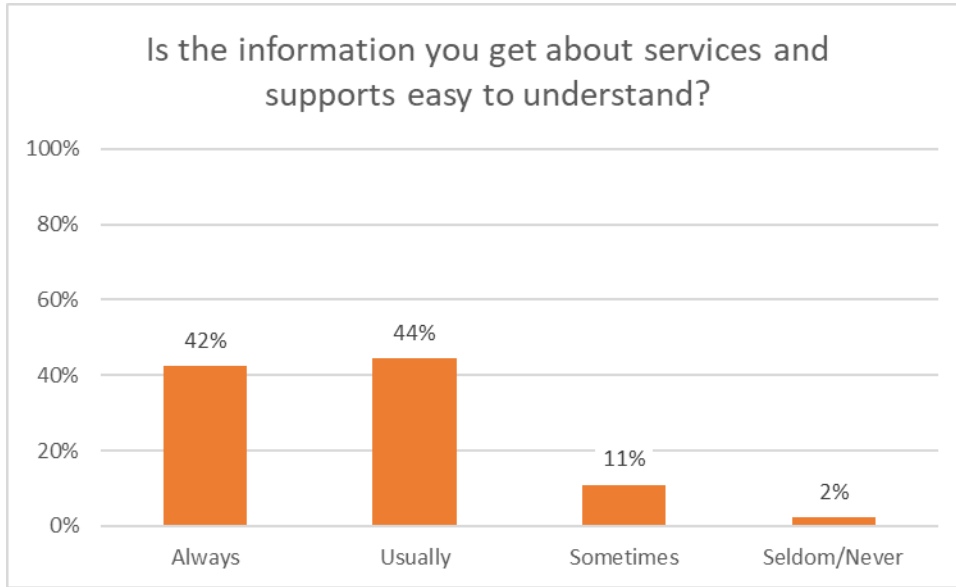


Table Q2. Is the information you get about services and supports easy to understand?

#### Significantly Above Average

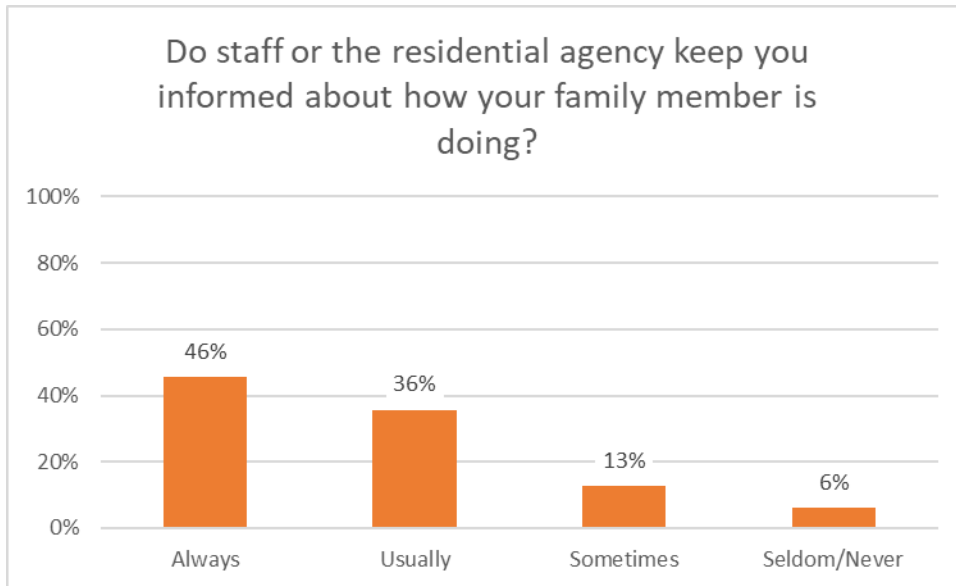
State	Always	Usually	Sometimes	Seldom or Never	N
OH	56%	38%	5%	1%	248

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	48%	40%	11%	1%	187
NC	44%	43%	12%	1%	205
LA	43%	42%	12%	3%	174
<b>NCI Average</b>	<b>42%</b>	<b>44%</b>	<b>11%</b>	<b>2%</b>	<b>2,512</b>
PA	40%	46%	12%	2%	516
AZ	36%	50%	12%	2%	242
KY	34%	50%	12%	3%	143

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	33%	46%	17%	4%	332
MD	31%	51%	15%	4%	465



**Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?**

**Significantly Above Average**

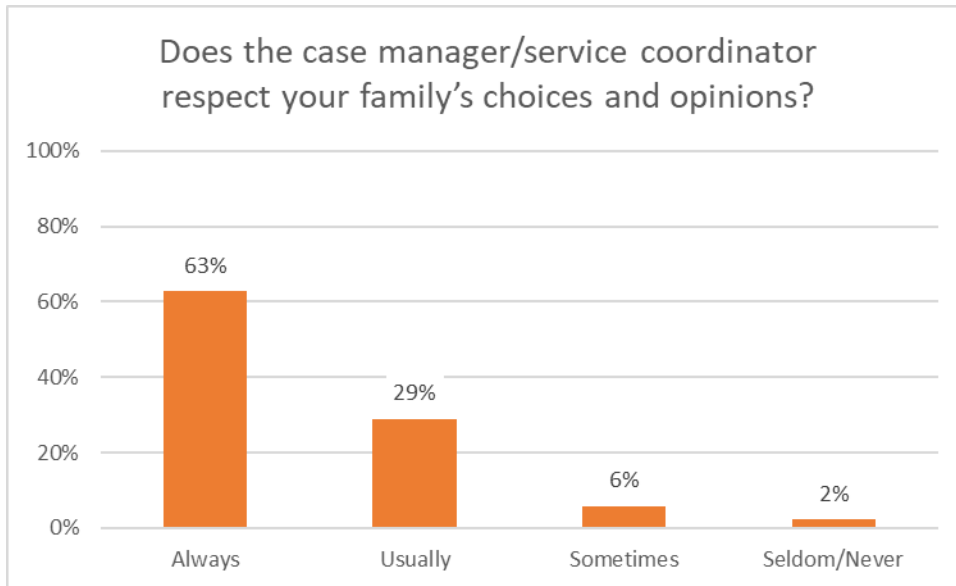
State	Always	Usually	Sometimes	Seldom or Never	N
VA	57%	31%	9%	3%	192
NC	57%	31%	11%	1%	207

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	53%	32%	12%	3%	161
KY	52%	32%	11%	5%	149
PA	47%	33%	13%	7%	543
<b>NCI Average</b>	<b>46%</b>	<b>36%</b>	<b>13%</b>	<b>6%</b>	<b>2,613</b>
AZ	44%	36%	16%	3%	244
GA	43%	33%	16%	8%	358
OH	41%	45%	11%	3%	242

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MD	32%	37%	18%	13%	517



**Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?**

**Significantly Above Average**

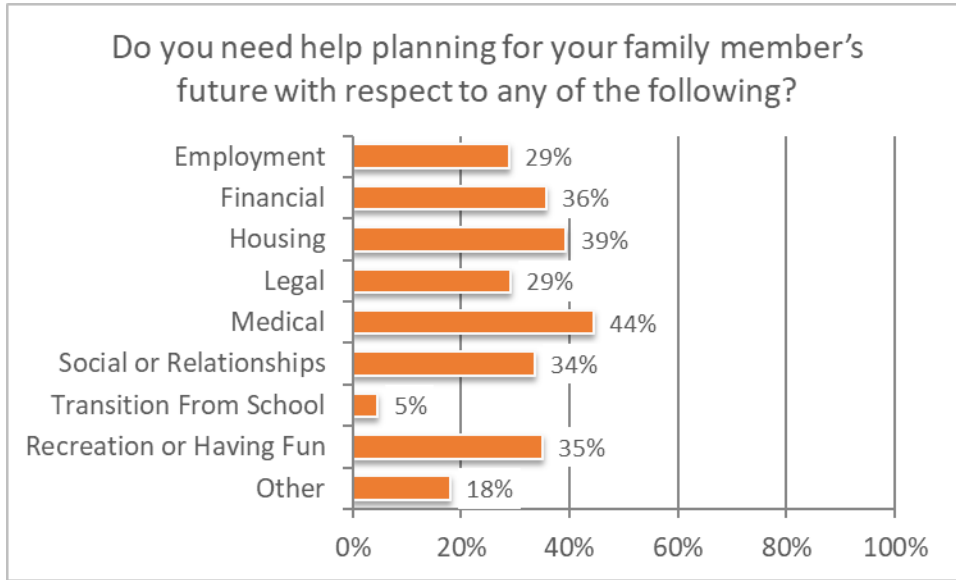
State	Always	Usually	Sometimes	Seldom or Never	N
VA	73%	21%	5%	1%	189
NC	72%	21%	5%	1%	203

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
KY	70%	24%	5%	1%	152
LA	65%	27%	6%	2%	174
<b>NCI Average</b>	<b>63%</b>	<b>29%</b>	<b>6%</b>	<b>2%</b>	<b>2,531</b>
OH	63%	34%	2%	1%	236
AZ	61%	30%	8%	2%	239
PA	60%	30%	7%	3%	515

**Significantly Below Average**

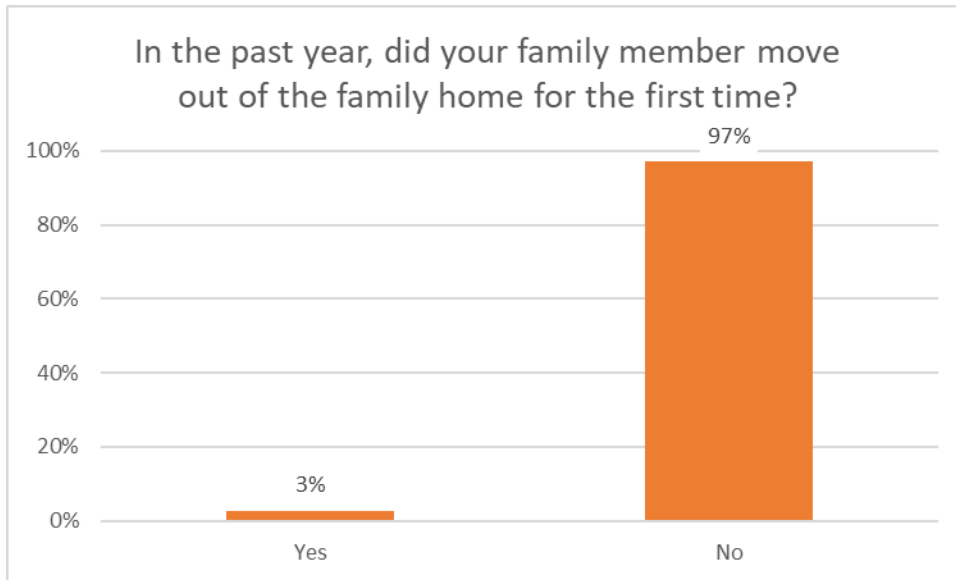
State	Always	Usually	Sometimes	Seldom or Never	N
MD	53%	34%	8%	4%	483
GA	51%	32%	11%	5%	340



**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	24%	24%	38%	21%	37%	31%	3%	37%	27%
GA	22%	32%	42%	33%	43%	33%	5%	33%	22%
KY	13%	23%	29%	16%	41%	30%	1%	29%	17%
LA	21%	29%	38%	22%	40%	26%	3%	36%	34%
MD	30%	33%	35%	32%	42%	28%	3%	41%	22%
NC	31%	41%	40%	34%	48%	27%	4%	31%	10%
OH	41%	48%	45%	27%	54%	40%	6%	38%	12%
PA	20%	26%	36%	30%	35%	30%	4%	28%	21%
VA	35%	47%	45%	34%	53%	47%	9%	39%	12%
<b>NCI Average</b>	<b>29%</b>	<b>36%</b>	<b>39%</b>	<b>29%</b>	<b>44%</b>	<b>34%</b>	<b>5%</b>	<b>35%</b>	<b>18%</b>



**Table Q6. In the past year, did your family member move out of the family home for the first time?**

**Within Average Range**

State	Yes	No	N
NC	6%	94%	201
LA	5%	95%	177
MD	4%	96%	513
AZ	3%	97%	244
<b>NCI Average</b>	<b>3%</b>	<b>97%</b>	<b>2,602</b>
PA	3%	97%	538
GA	3%	97%	359
KY	2%	98%	154
OH	2%	98%	228

**Significantly Below Average**

State	Yes	No	N
VA	1%	99%	188

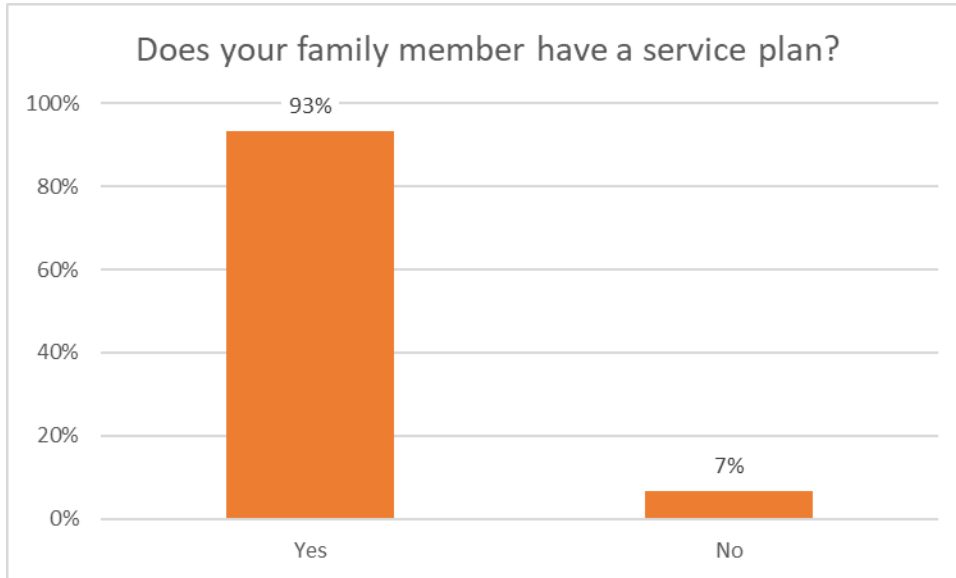


Table Q7. Does your family member have a service plan?

**Significantly Above Average**

State	Yes	No	N
OH	97%	3%	244
PA	97%	3%	492

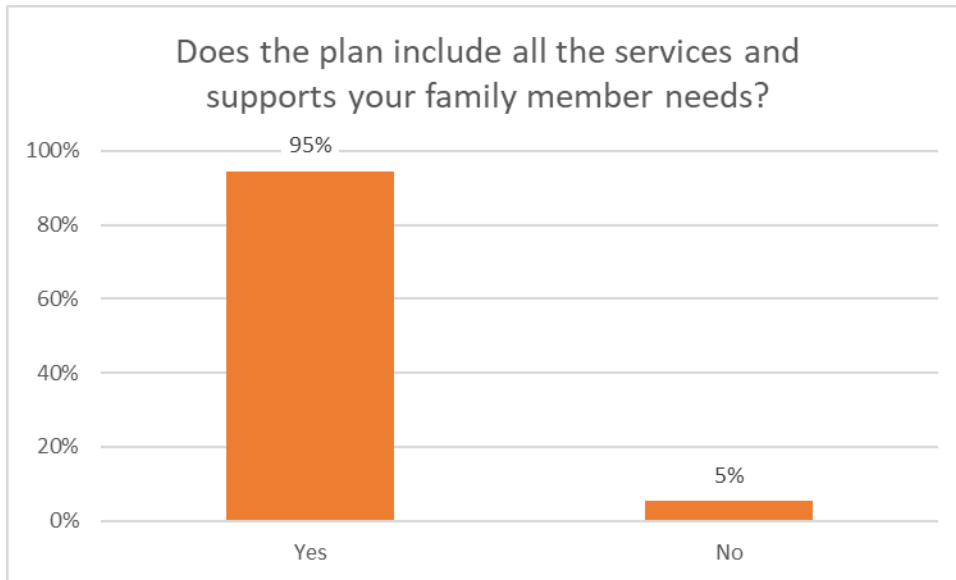
**Within Average Range**

State	Yes	No	N
NC	94%	6%	180
<b>NCI Average</b>	<b>93%</b>	<b>7%</b>	<b>2,246</b>
VA	93%	7%	162
AZ	92%	8%	221

**Significantly Below Average**

State	Yes	No	N
MD	89%	11%	407
GA	88%	12%	276
KY	85%	15%	131
LA	80%	20%	133





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

**Significantly Above Average**

State	Yes	No	N
NC	98%	2%	152

**Within Average Range**

State	Yes	No	N
OH	97%	3%	231
KY	96%	4%	100
VA	95%	5%	140
PA	95%	5%	426
<b>NCI Average</b>	<b>95%</b>	<b>5%</b>	<b>1,860</b>
LA	91%	9%	93
MD	91%	9%	323
GA	89%	11%	209
AZ	89%	11%	186

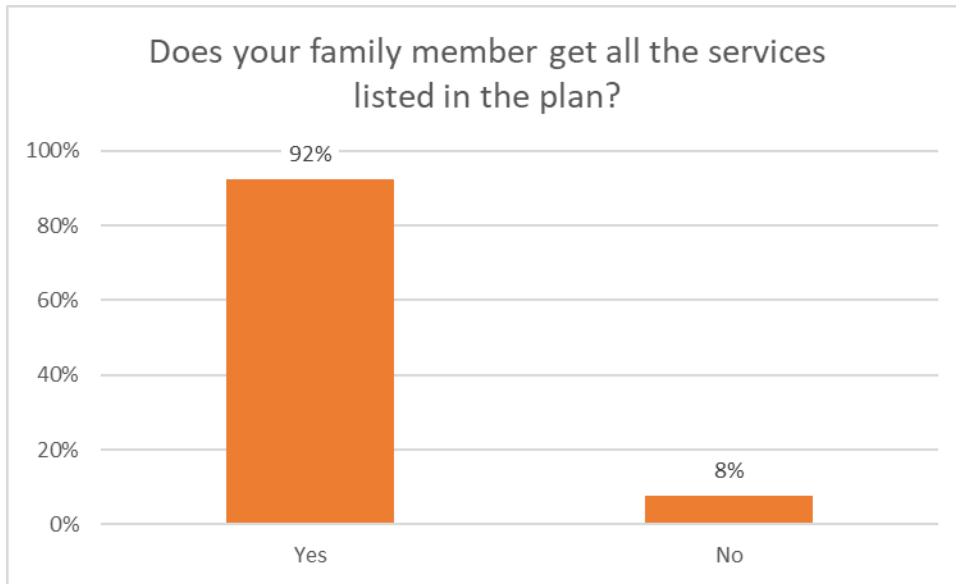


Table Q9. Does your family member get all of the services listed in the plan?

#### Significantly Above Average

State	Yes	No	N
NC	97%	3%	148
OH	96%	4%	222

#### Within Average Range

State	Yes	No	N
LA	94%	6%	90
PA	93%	7%	391
VA	93%	7%	132
<b>NCI Average</b>	<b>92%</b>	<b>8%</b>	<b>1,744</b>
AZ	91%	9%	184
GA	89%	11%	183
KY	87%	13%	93

#### Significantly Below Average

State	Yes	No	N
MD	84%	16%	301

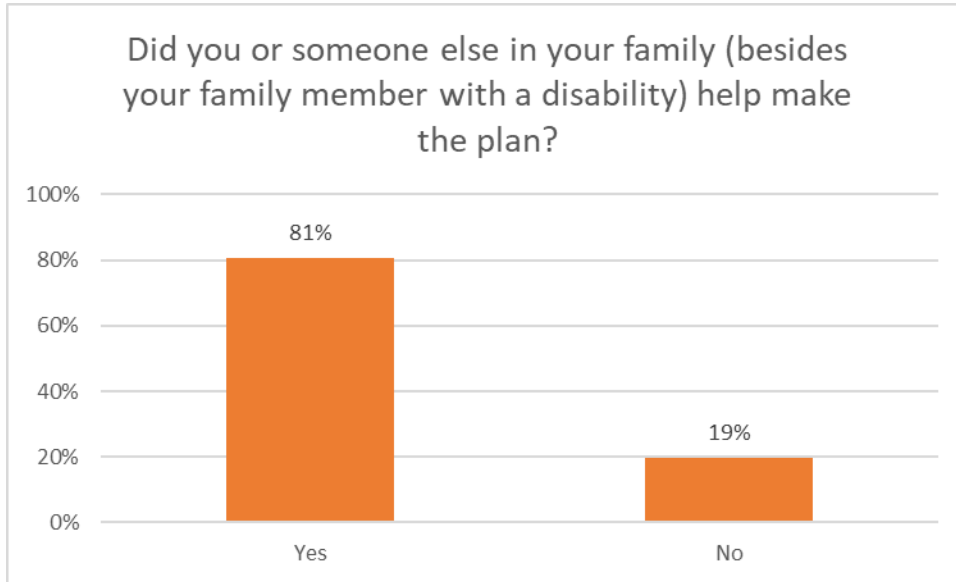


Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the plan?

#### Significantly Above Average

State	Yes	No	N
OH	90%	10%	227

#### Within Average Range

State	Yes	No	N
GA	83%	17%	222
AZ	83%	17%	193
VA	82%	18%	142
MD	81%	19%	345
NC	81%	19%	158
<b>NCI Average</b>	<b>81%</b>	<b>19%</b>	<b>1,931</b>
KY	80%	20%	107
LA	74%	26%	96

#### Significantly Below Average

State	Yes	No	N
PA	69%	31%	441

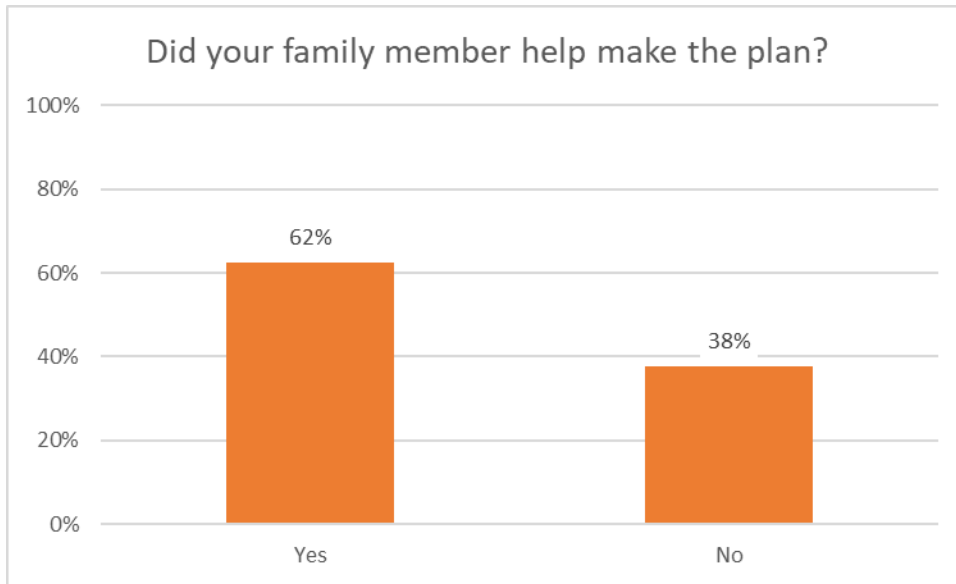


Table Q11. Did your family member help make the plan?

**Significantly Above Average**

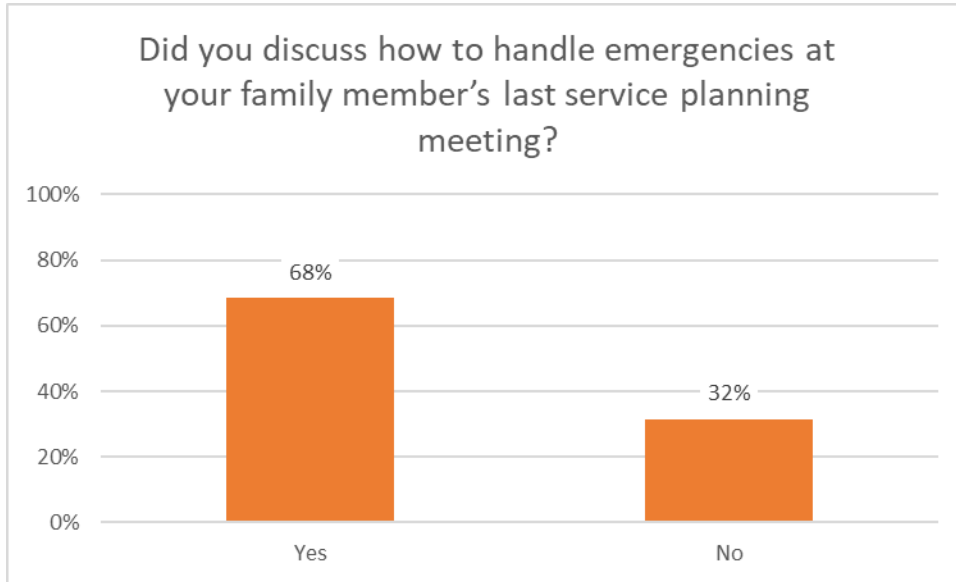
State	Yes	No	N
OH	76%	24%	226

**Within Average Range**

State	Yes	No	N
KY	66%	34%	107
<b>NCI Average</b>	<b>62%</b>	<b>38%</b>	<b>1,890</b>
MD	61%	39%	338
VA	60%	40%	134
LA	60%	40%	95
NC	59%	41%	153
GA	56%	44%	220

**Significantly Below Average**

State	Yes	No	N
PA	54%	46%	426
AZ	50%	50%	191



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

#### Significantly Above Average

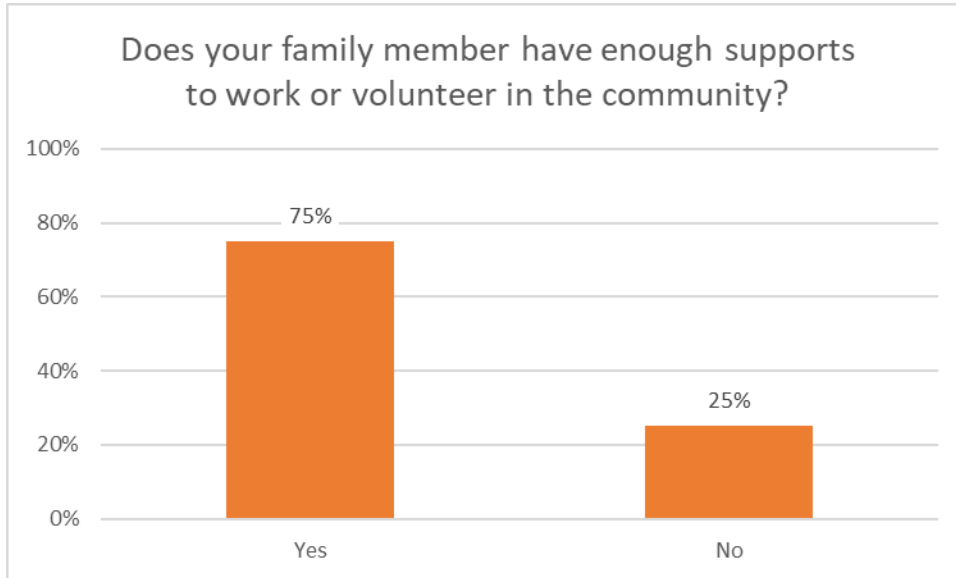
State	Yes	No	N
LA	87%	13%	99
KY	81%	19%	97
OH	81%	19%	215

#### Within Average Range

State	Yes	No	N
NC	76%	24%	157
<b>NCI Average</b>	<b>68%</b>	<b>32%</b>	<b>1,789</b>
PA	64%	36%	379
VA	60%	40%	131

#### Significantly Below Average

State	Yes	No	N
MD	59%	41%	329
GA	58%	42%	199
AZ	57%	43%	183



**Table Q13. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?**

#### Significantly Above Average

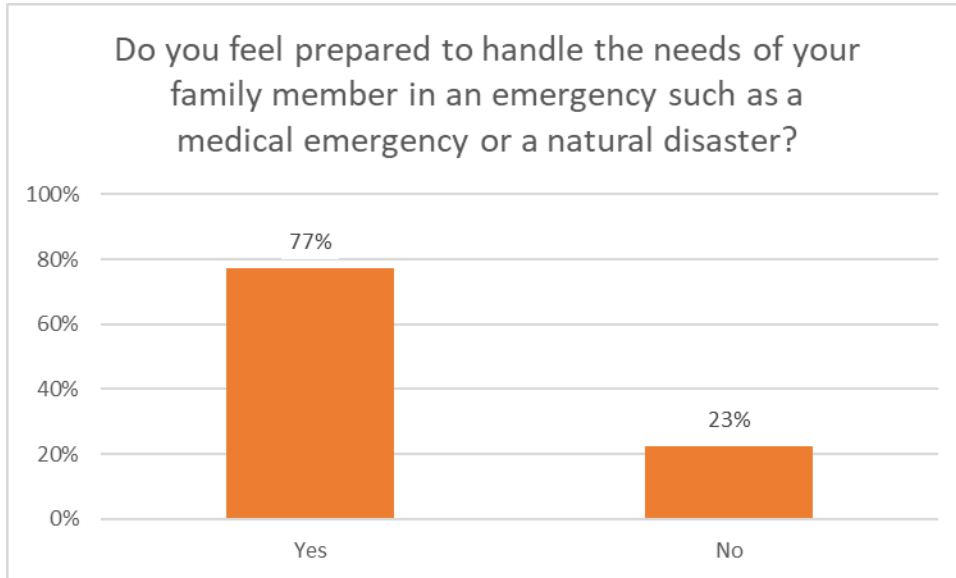
State	Yes	No	N
OH	88%	12%	180

#### Within Average Range

State	Yes	No	N
VA	81%	19%	120
PA	78%	22%	331
<b>NCI Average</b>	<b>75%</b>	<b>25%</b>	<b>1,667</b>
NC	74%	26%	148

#### Significantly Below Average

State	Yes	No	N
MD	64%	36%	307
GA	60%	40%	229
AZ	60%	40%	148
KY	60%	40%	92
LA	59%	41%	112



**Table Q14. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?**

#### Significantly Above Average

State	Yes	No	N
OH	93%	7%	223

#### Within Average Range

State	Yes	No	N
KY	80%	20%	137
LA	79%	21%	154
<b>NCI Average</b>	<b>77%</b>	<b>23%</b>	<b>2,243</b>
VA	75%	25%	151
AZ	75%	25%	216
NC	75%	25%	187
PA	74%	26%	436

#### Significantly Below Average

State	Yes	No	N
GA	69%	31%	301
MD	67%	33%	438

## *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.



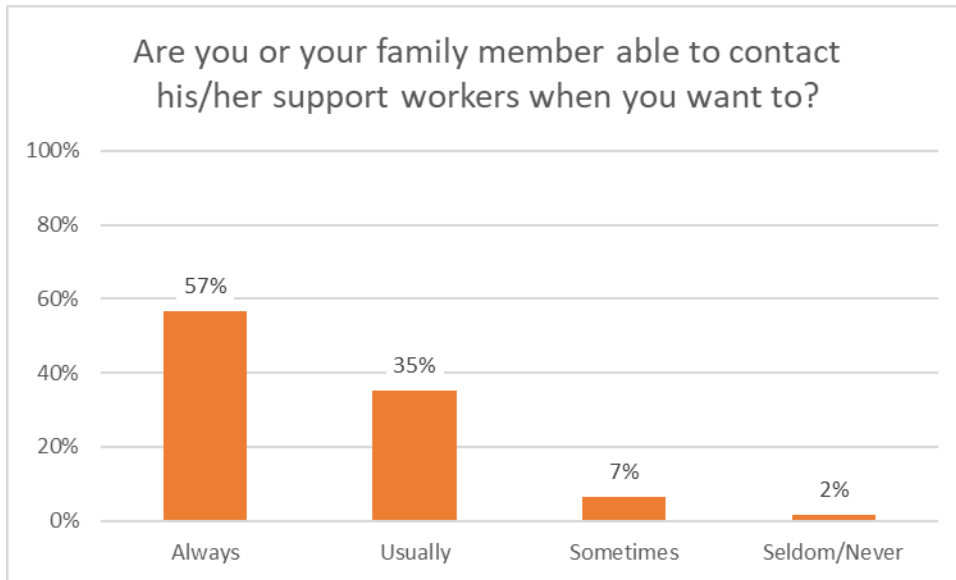


Table Q15. Are you or your family member able to contact his/her support workers when you want to?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	65%	27%	8%	0%	204
LA	64%	31%	4%	2%	169
VA	61%	34%	4%	1%	184
KY	60%	34%	5%	1%	153
OH	60%	34%	5%	1%	248
PA	57%	35%	6%	2%	528
<b>NCI Average</b>	<b>57%</b>	<b>35%</b>	<b>7%</b>	<b>2%</b>	<b>2,543</b>
GA	51%	39%	8%	3%	340

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	46%	40%	10%	3%	482
AZ	46%	42%	11%	1%	235

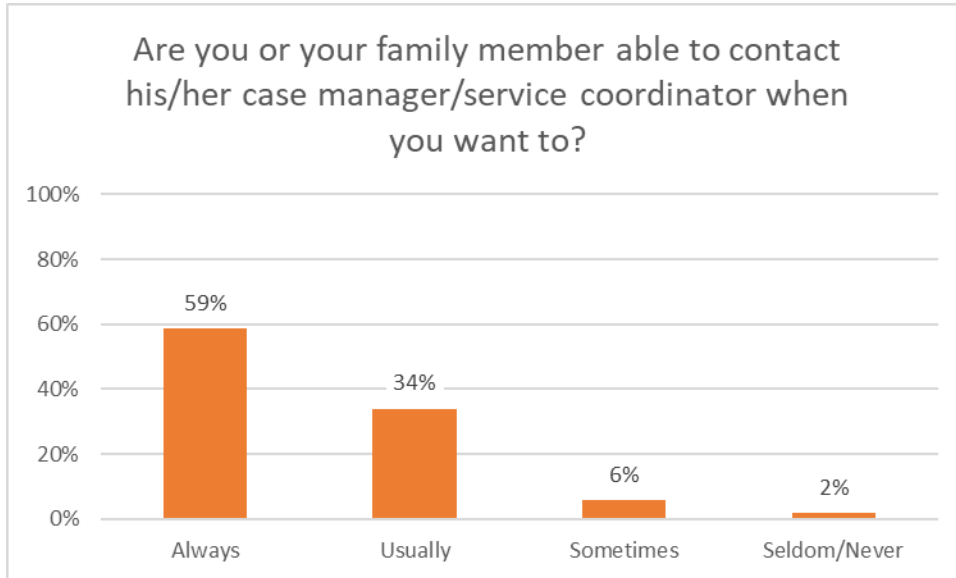


Table Q16. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	65%	29%	5%	0%	204
VA	64%	32%	4%	1%	187
OH	63%	34%	2%	1%	247
KY	62%	34%	4%	0%	152
LA	60%	34%	4%	2%	175
PA	59%	33%	5%	2%	526
<b>NCI Average</b>	<b>59%</b>	<b>34%</b>	<b>6%</b>	<b>2%</b>	<b>2,564</b>

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	50%	36%	10%	4%	492
GA	48%	40%	8%	4%	347
AZ	47%	40%	11%	3%	234

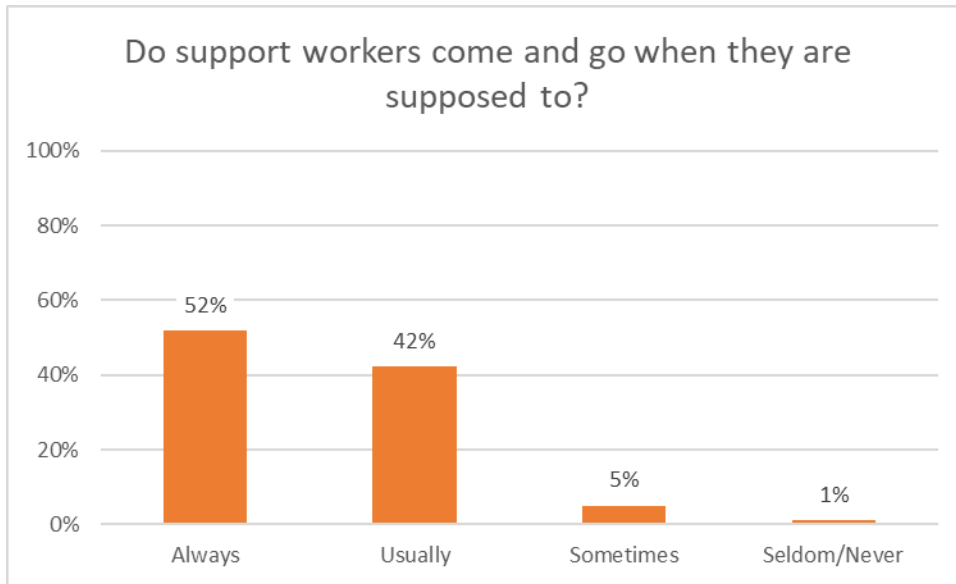


Table Q17. Do support workers come and go when they are supposed to?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
VA	71%	27%	0%	2%	115

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	62%	32%	6%	1%	125
NC	60%	34%	6%	0%	136
KY	56%	39%	5%	0%	111
<b>NCI Average</b>	<b>52%</b>	<b>42%</b>	<b>5%</b>	<b>1%</b>	<b>1,712</b>
PA	50%	44%	4%	2%	321
GA	47%	42%	9%	1%	215
OH	46%	50%	3%	1%	206
MD	45%	46%	9%	1%	297

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	37%	51%	11%	1%	186

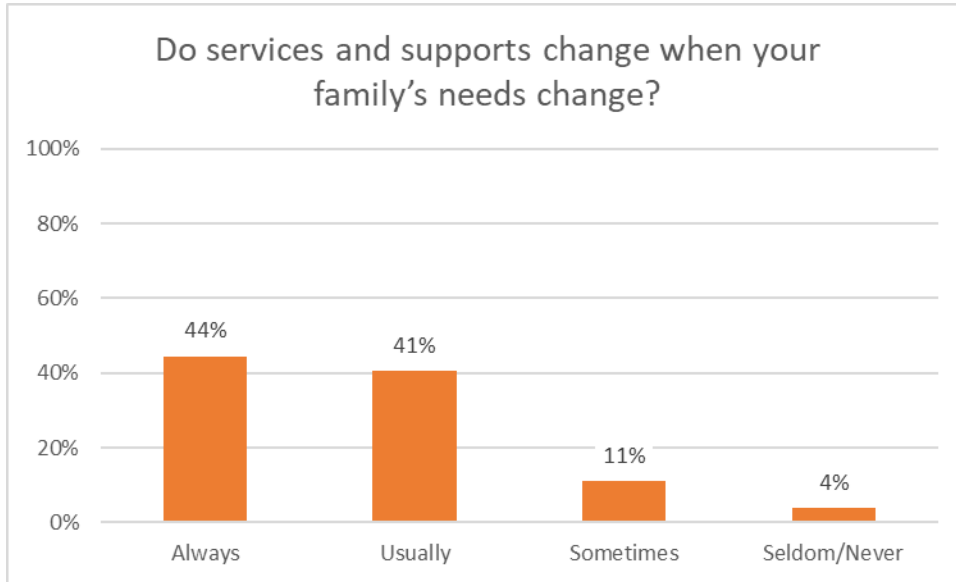


Table Q18. Do services and supports change when your family's needs change?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
VA	65%	25%	8%	2%	130

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OH	49%	43%	6%	2%	204
NC	48%	37%	11%	4%	150
LA	45%	42%	10%	3%	119
<b>NCI Average</b>	<b>44%</b>	<b>41%</b>	<b>11%</b>	<b>4%</b>	<b>1,756</b>
PA	41%	43%	13%	3%	352
KY	38%	47%	12%	3%	114
GA	36%	44%	14%	6%	214

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	32%	47%	16%	5%	172
MD	31%	46%	16%	8%	301

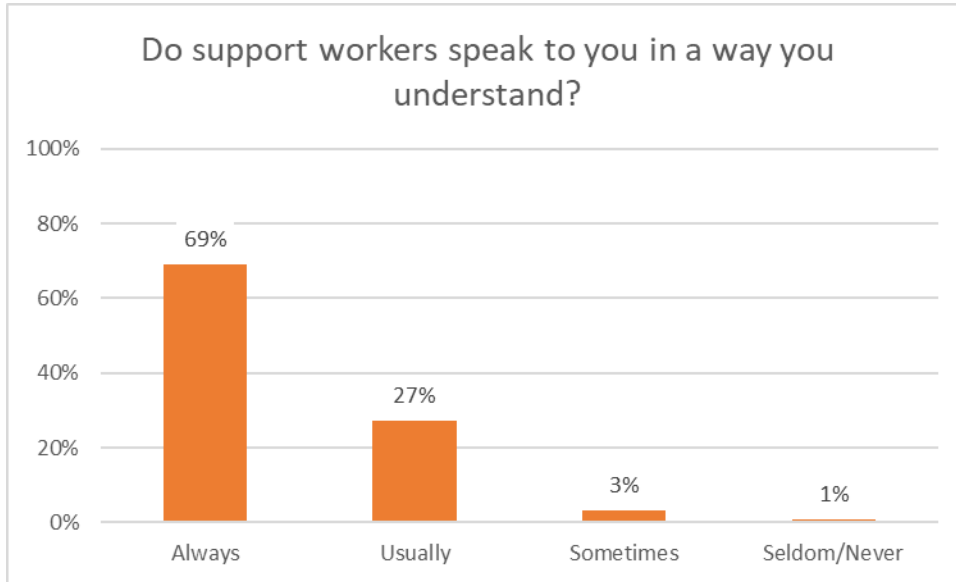


Table Q19. Do support workers speak to you in a way you understand?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	80%	17%	2%	1%	179
NC	79%	19%	2%	0%	192

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	74%	25%	1%	0%	167
PA	70%	25%	4%	1%	507
OH	70%	30%	0%	0%	240
<b>NCI Average</b>	<b>69%</b>	<b>27%</b>	<b>3%</b>	<b>1%</b>	<b>2,472</b>
KY	67%	32%	1%	0%	149
AZ	64%	32%	3%	1%	232

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	61%	35%	4%	1%	337
MD	56%	35%	8%	1%	469

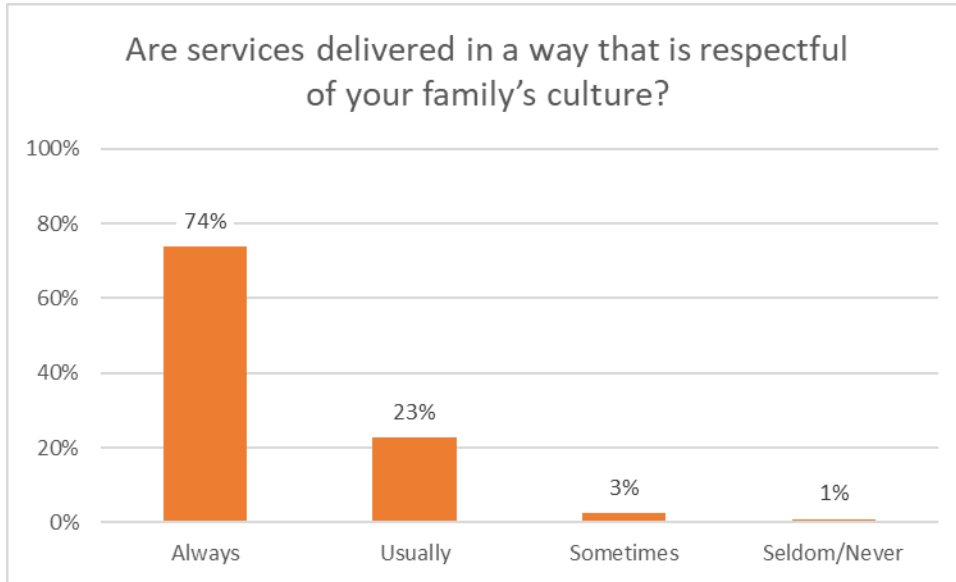


Table Q20. Are services delivered in a way that is respectful of your family's culture?

#### Significantly Above Average

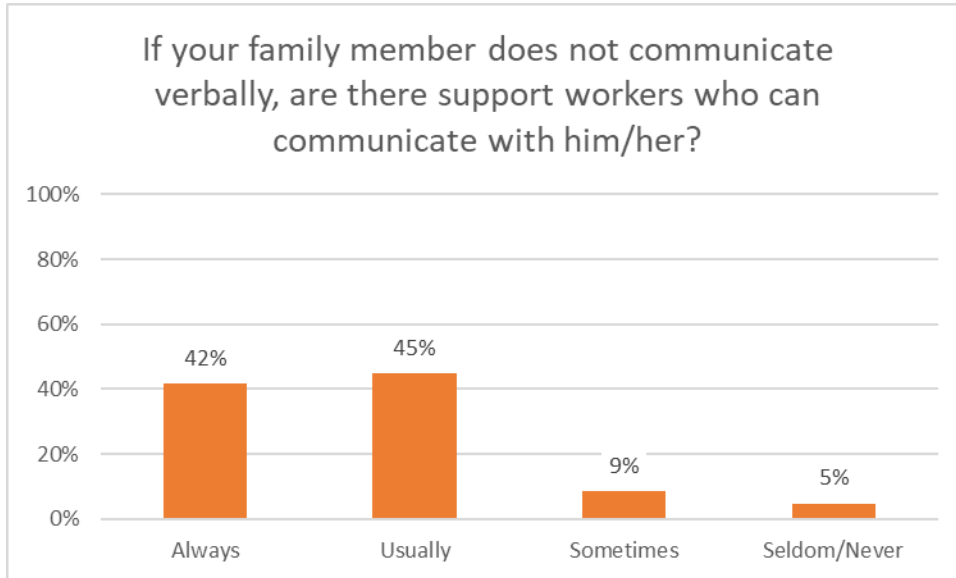
State	Always	Usually	Sometimes	Seldom or Never	N
VA	84%	14%	2%	0%	175

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	80%	19%	2%	0%	199
PA	76%	20%	3%	1%	507
LA	75%	23%	1%	1%	167
KY	74%	23%	3%	0%	148
<b>NCI Average</b>	<b>74%</b>	<b>23%</b>	<b>3%</b>	<b>1%</b>	<b>2,461</b>
OH	73%	25%	1%	1%	237
AZ	71%	25%	3%	1%	231

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	65%	29%	5%	2%	326
MD	63%	31%	4%	2%	471



**Table Q21. If your family member does not communicate verbally (for example, uses gestures or sign language, or a communication aid), are there support workers who can communicate with him/her?**

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	55%	36%	8%	2%	64
VA	51%	37%	8%	4%	51

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	44%	42%	8%	5%	133
LA	43%	43%	9%	6%	47
<b>NCI Average</b>	<b>42%</b>	<b>45%</b>	<b>9%</b>	<b>5%</b>	<b>714</b>
KY	39%	48%	9%	3%	33
OH	37%	54%	4%	6%	82
MD	36%	45%	15%	4%	137
GA	33%	53%	12%	2%	100
AZ	31%	45%	12%	12%	67

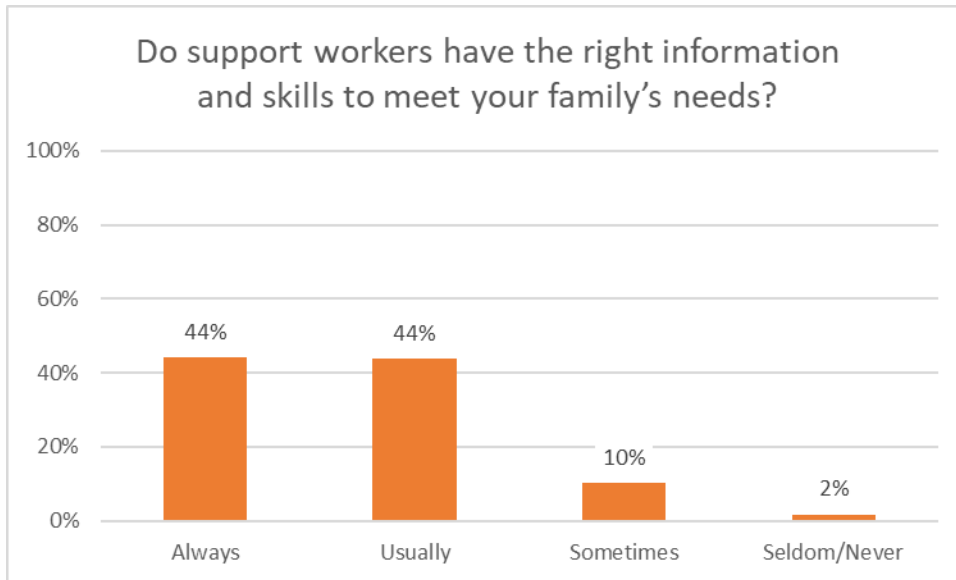


Table Q22. Do support workers have the right information and skills to meet your family's needs?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	54%	39%	7%	0%	188
VA	54%	37%	6%	2%	174

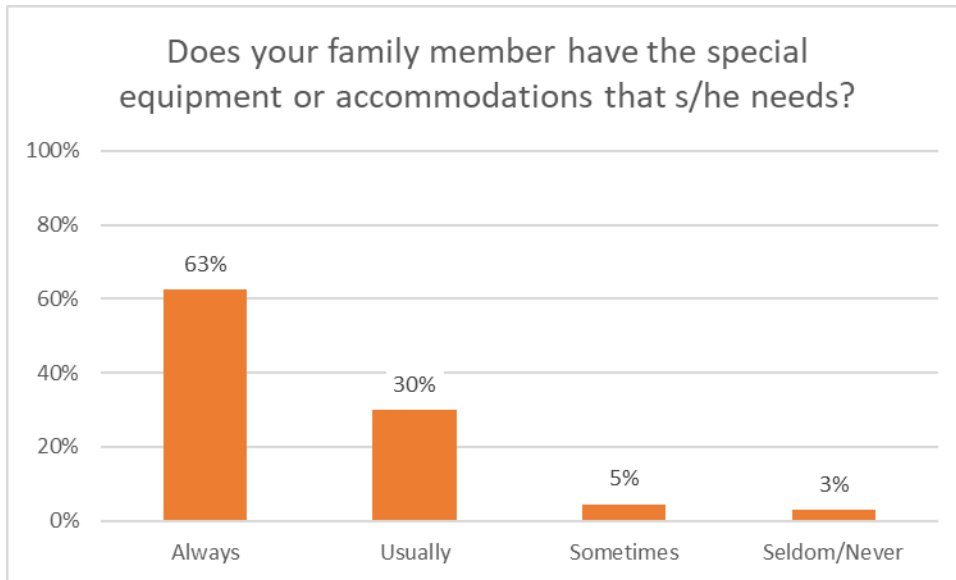
#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	46%	43%	10%	2%	480
OH	44%	47%	8%	1%	239
<b>NCI Average</b>	<b>44%</b>	<b>44%</b>	<b>10%</b>	<b>2%</b>	<b>2,364</b>
KY	44%	42%	12%	1%	145
LA	41%	49%	8%	1%	160

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	36%	50%	11%	3%	324
MD	34%	46%	18%	3%	439
AZ	30%	53%	14%	3%	215





**Table Q23. Does your family member have the special equipment or accommodations that s/he needs?**

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	69%	24%	3%	4%	113
NC	69%	25%	2%	4%	122
OH	66%	29%	3%	2%	162
PA	64%	29%	4%	3%	312
<b>NCI Average</b>	<b>63%</b>	<b>30%</b>	<b>5%</b>	<b>3%</b>	<b>1,532</b>
LA	59%	23%	8%	9%	98
MD	55%	32%	9%	3%	283
GA	55%	37%	4%	4%	199
AZ	53%	39%	4%	3%	148
KY	53%	39%	7%	1%	95

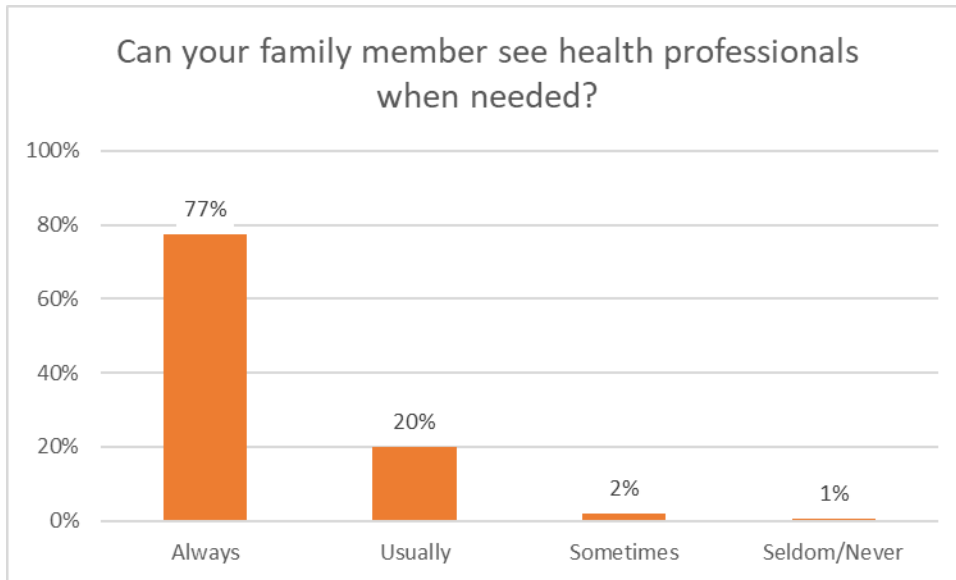


Table Q24. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
VA	85%	13%	2%	1%	189

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OH	82%	17%	0%	0%	249
PA	80%	18%	2%	0%	535
NC	78%	18%	2%	1%	208
<b>NCI Average</b>	<b>77%</b>	<b>20%</b>	<b>2%</b>	<b>1%</b>	<b>2,618</b>
GA	73%	25%	1%	1%	355
KY	68%	29%	2%	1%	154

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	71%	26%	2%	1%	508
AZ	68%	28%	3%	1%	246
LA	68%	29%	3%	1%	174

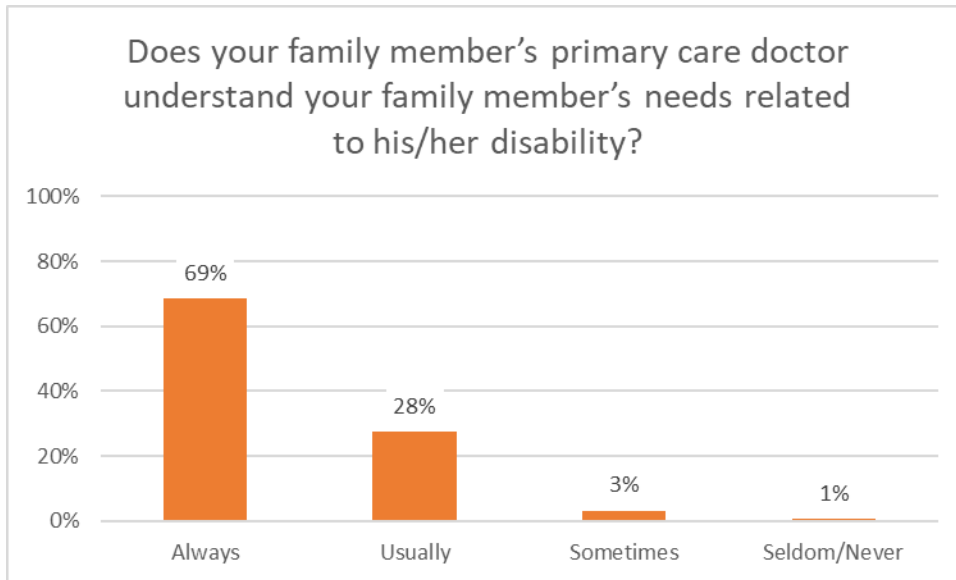


Table Q25. Does your family member's primary care doctor understand your family member's needs related to his/her disability?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
VA	79%	18%	2%	2%	177

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OH	71%	26%	2%	0%	244
<b>NCI Average</b>	<b>69%</b>	<b>28%</b>	<b>3%</b>	<b>1%</b>	<b>2,373</b>
PA	68%	27%	5%	0%	462
NC	68%	30%	2%	1%	193
LA	67%	26%	5%	1%	163
MD	65%	30%	4%	1%	438
AZ	62%	34%	3%	1%	228
KY	61%	35%	4%	0%	150

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	58%	37%	4%	1%	318

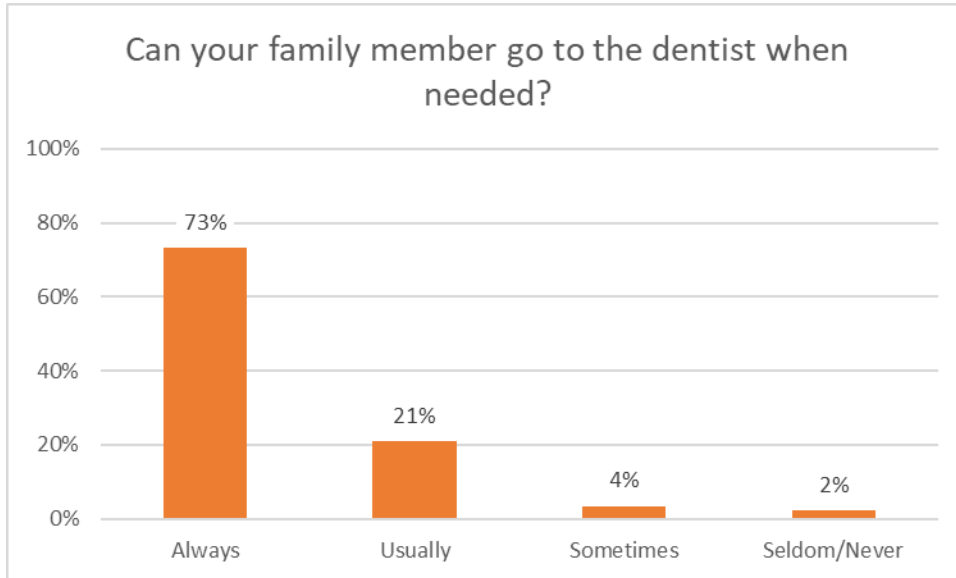


Table Q26. Can your family member go to the dentist when needed?<sup>8</sup>

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
PA	78%	19%	2%	2%	348

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	78%	14%	4%	3%	237
OH	76%	19%	3%	2%	152
<b>NCI Average</b>	<b>73%</b>	<b>21%</b>	<b>4%</b>	<b>2%</b>	<b>2,542</b>
NC	73%	23%	4%	0%	168
MD	70%	23%	4%	3%	482
AZ	68%	23%	5%	4%	205
KY	63%	32%	4%	1%	245

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	58%	32%	6%	4%	522
LA	57%	26%	5%	11%	183

<sup>8</sup> Question is rephrased from previous years

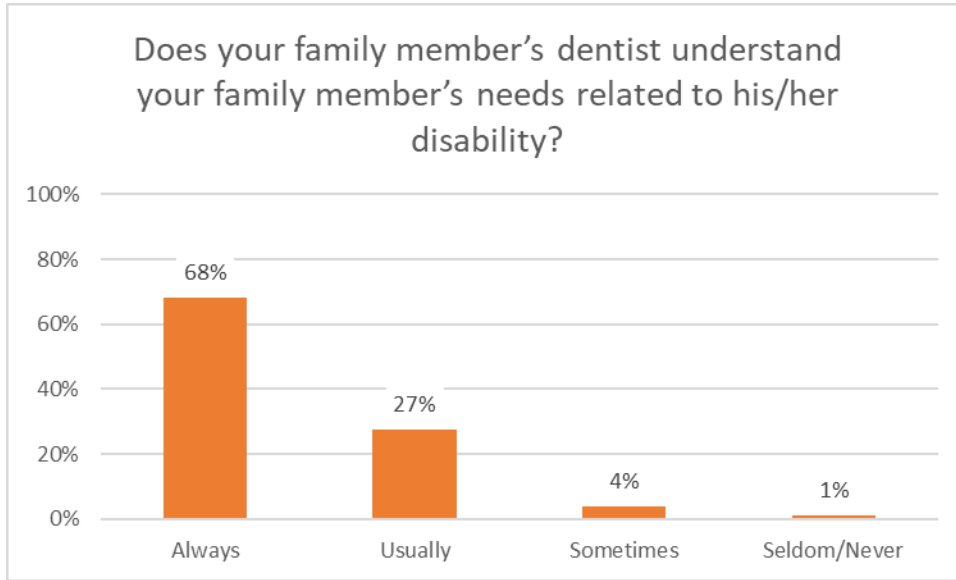


Table Q27. Does your family member's dentist understand your family member's needs related to his/her disability?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	79%	16%	4%	1%	156

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
MD	70%	24%	5%	1%	414
NC	69%	26%	4%	1%	183
<b>NCI Average</b>	<b>68%</b>	<b>27%</b>	<b>4%</b>	<b>1%</b>	<b>2,159</b>
PA	67%	29%	3%	1%	437
OH	66%	31%	2%	1%	213
KY	64%	34%	2%	0%	138
AZ	60%	35%	5%	0%	213
LA	57%	36%	5%	2%	129

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
GA	60%	35%	4%	1%	276

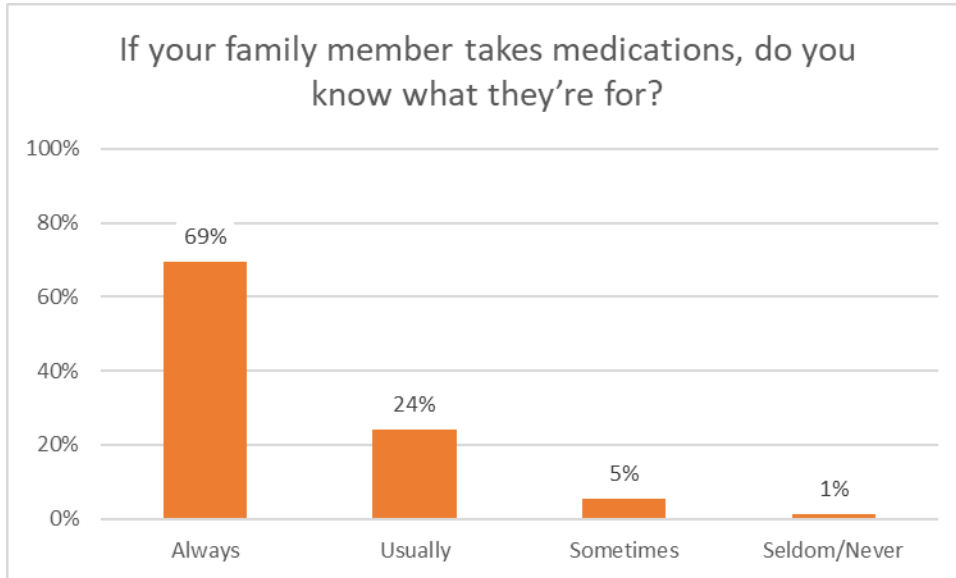


Table Q28. If your family member takes medications, do you know what they're for?

#### Significantly Above Average

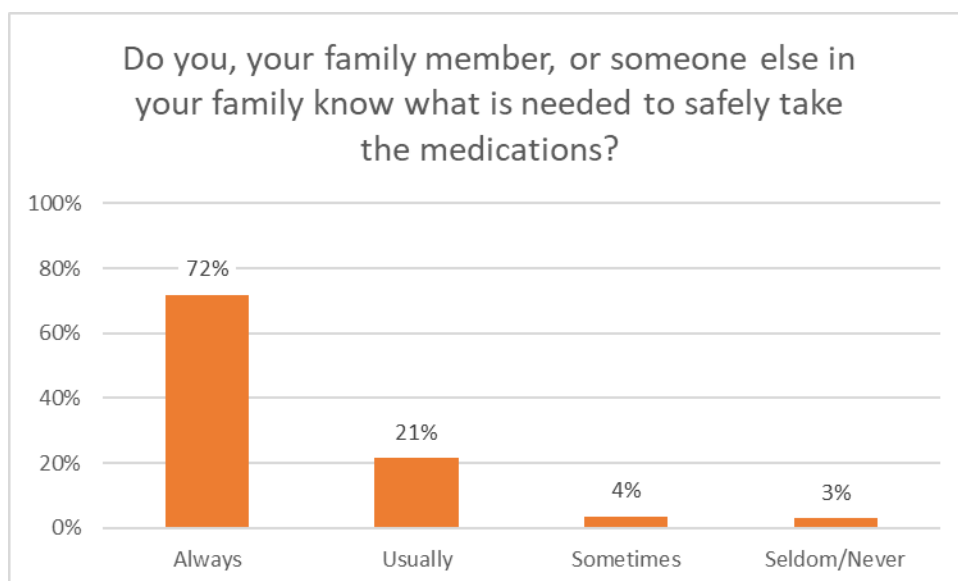
State	Always	Usually	Sometimes	Seldom or Never	N
LA	82%	15%	2%	1%	169
NC	77%	17%	5%	1%	199

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	75%	20%	4%	1%	230
VA	73%	22%	5%	0%	180
<b>NCI Average</b>	<b>69%</b>	<b>24%</b>	<b>5%</b>	<b>1%</b>	<b>2,457</b>
OH	69%	25%	5%	1%	239
GA	68%	22%	9%	2%	327
PA	68%	24%	6%	2%	491
KY	65%	29%	5%	1%	147

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	63%	29%	6%	2%	475



**Table Q29. 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)?**

#### Significantly Above Average

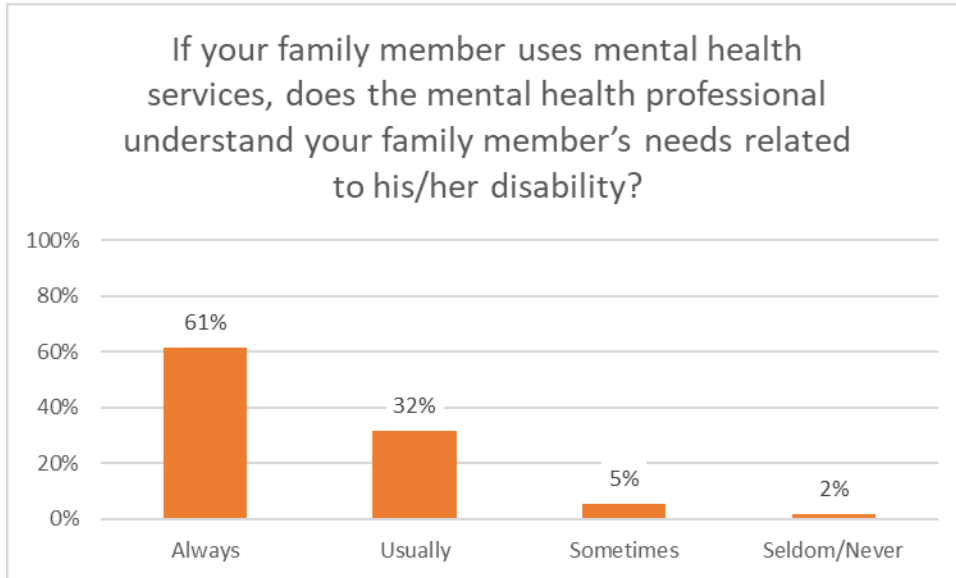
State	Always	Usually	Sometimes	Seldom or Never	N
NC	81%	18%	1%	1%	186

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	80%	17%	2%	1%	156
VA	77%	16%	2%	4%	166
GA	74%	18%	5%	3%	306
PA	72%	18%	5%	5%	450
<b>NCI Average</b>	<b>72%</b>	<b>21%</b>	<b>4%</b>	<b>3%</b>	<b>2,279</b>
KY	71%	25%	2%	2%	138
OH	69%	27%	2%	2%	227
AZ	69%	23%	6%	2%	219

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	66%	25%	6%	3%	431



**Table Q30. If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?**

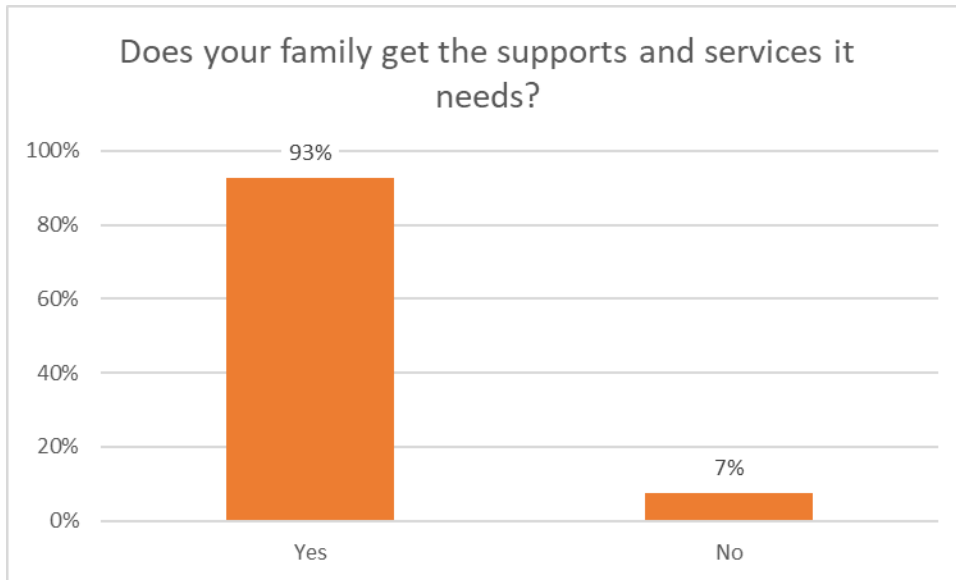
#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	72%	21%	7%	0%	121
OH	65%	30%	4%	1%	186
LA	64%	29%	4%	3%	99
NC	63%	33%	3%	1%	144
<b>NCI Average</b>	<b>61%</b>	<b>32%</b>	<b>5%</b>	<b>2%</b>	<b>1,586</b>
PA	60%	33%	5%	1%	305
MD	58%	34%	4%	4%	270
GA	53%	37%	7%	2%	209
AZ	52%	37%	7%	4%	152

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	45%	40%	12%	3%	100





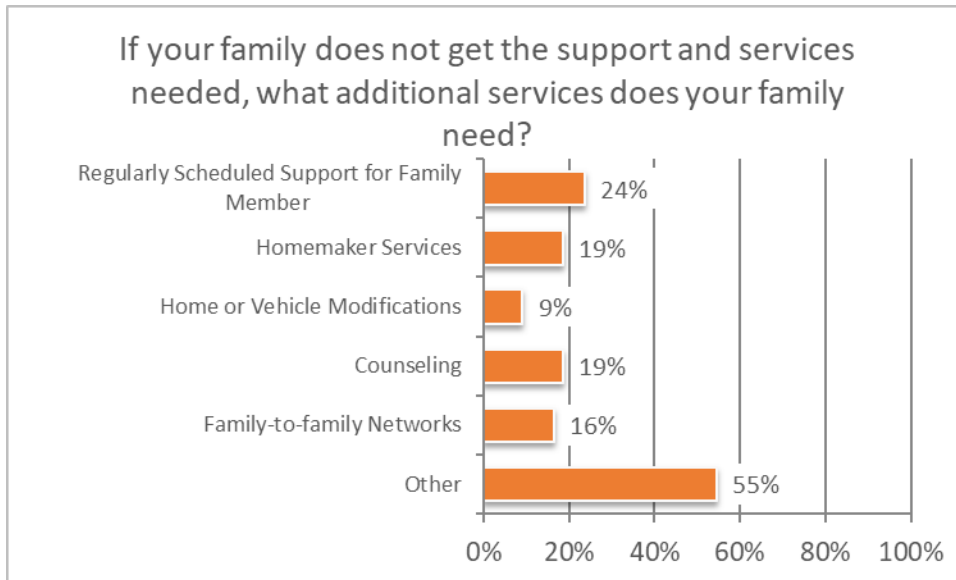
**Table Q31. Does your family get the supports and services it needs?**

**Within Average Range**

State	Yes	No	N
NC	95%	5%	198
OH	95%	5%	234
VA	95%	5%	173
KY	94%	6%	140
PA	93%	7%	479
<b>NCI Average</b>	<b>93%</b>	<b>7%</b>	<b>2,347</b>
LA	90%	10%	156
MD	89%	11%	441
AZ	89%	11%	218

**Significantly Below Average**

State	Yes	No	N
GA	85%	15%	308



**Table Q32. If your family does not get the support and services needed, what additional services does your family need?<sup>9</sup>**

Categories are not mutually exclusive, therefore N is not shown

State	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Other
AZ	26%	13%	0%	30%	13%	65%
GA	38%	15%	5%	30%	25%	50%
MD	30%	10%	8%	20%	18%	63%
PA	21%	32%	11%	18%	14%	39%
<b>NCI Average</b>	<b>24%</b>	<b>19%</b>	<b>9%</b>	<b>19%</b>	<b>16%</b>	<b>55%</b>

<sup>9</sup> The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: KY, LA, NC, OH, VA

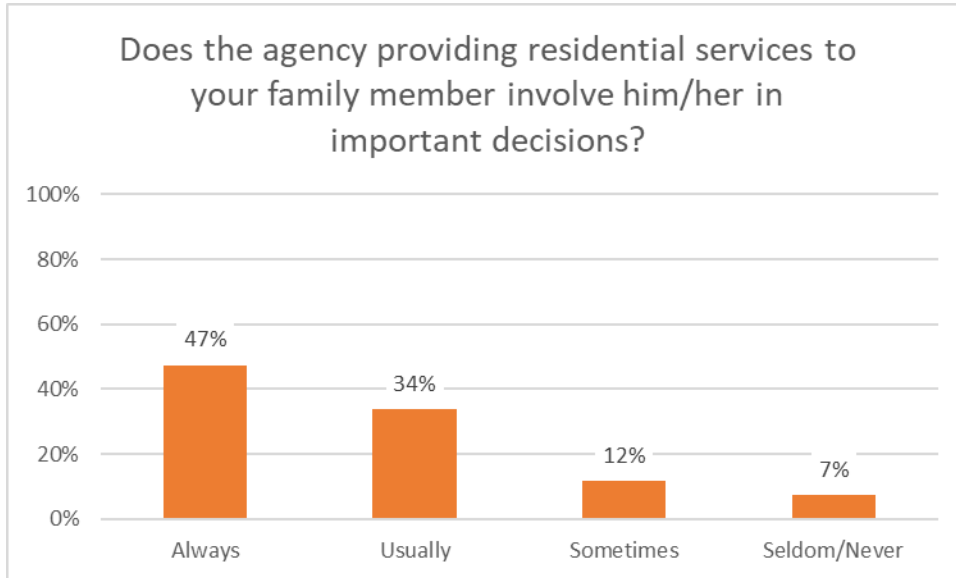
## *Choice, Decision Making and Control*

*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 Q33. Does the agency providing residential services to your family member involve him/her in important decisions?**

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
VA	63%	24%	9%	4%	160

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OH	50%	39%	8%	3%	231
KY	49%	34%	9%	8%	140
LA	49%	30%	12%	9%	138
<b>NCI Average</b>	<b>47%</b>	<b>34%</b>	<b>12%</b>	<b>7%</b>	<b>2,226</b>
PA	47%	34%	12%	7%	434
NC	44%	33%	17%	6%	183

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	41%	34%	13%	12%	442
GA	34%	37%	18%	11%	282
AZ	32%	37%	15%	16%	216

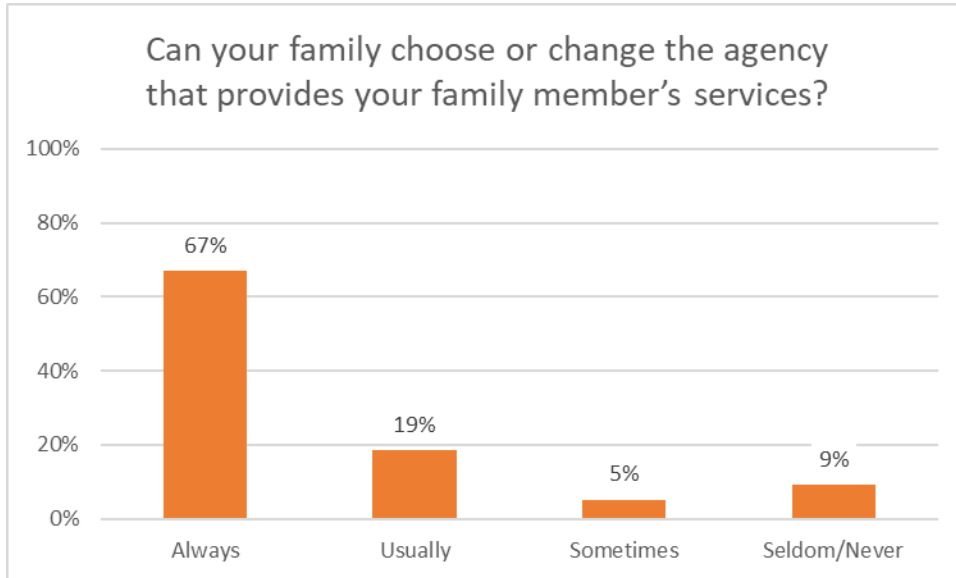


Table Q34. Can your family choose or change the agency that provides your family member's services?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OH	75%	18%	4%	3%	223

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	74%	13%	3%	11%	136
KY	73%	16%	5%	6%	130
LA	71%	18%	3%	8%	128
<b>NCI Average</b>	<b>67%</b>	<b>19%</b>	<b>5%</b>	<b>9%</b>	<b>1,757</b>
NC	67%	17%	5%	11%	148
GA	63%	22%	7%	8%	251
PA	62%	20%	6%	12%	273

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MD	56%	22%	7%	15%	294
AZ	48%	29%	11%	12%	174

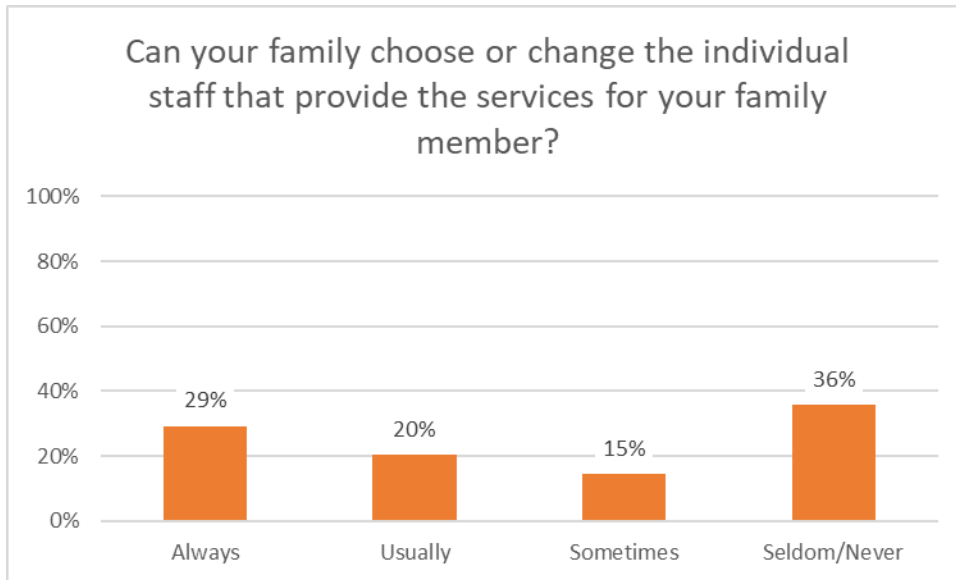


Table Q35. Can your family choose or change the individual staff that provide the services for your family member?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	45%	24%	10%	21%	126

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
NC	38%	19%	14%	29%	143
OH	36%	26%	16%	22%	198
VA	35%	14%	9%	42%	120
KY	32%	27%	8%	33%	111
GA	31%	19%	13%	37%	227
<b>NCI Average</b>	<b>29%</b>	<b>20%</b>	<b>15%</b>	<b>36%</b>	<b>1,702</b>
AZ	21%	24%	16%	39%	170

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
PA	22%	23%	15%	40%	284
MD	16%	13%	20%	51%	323

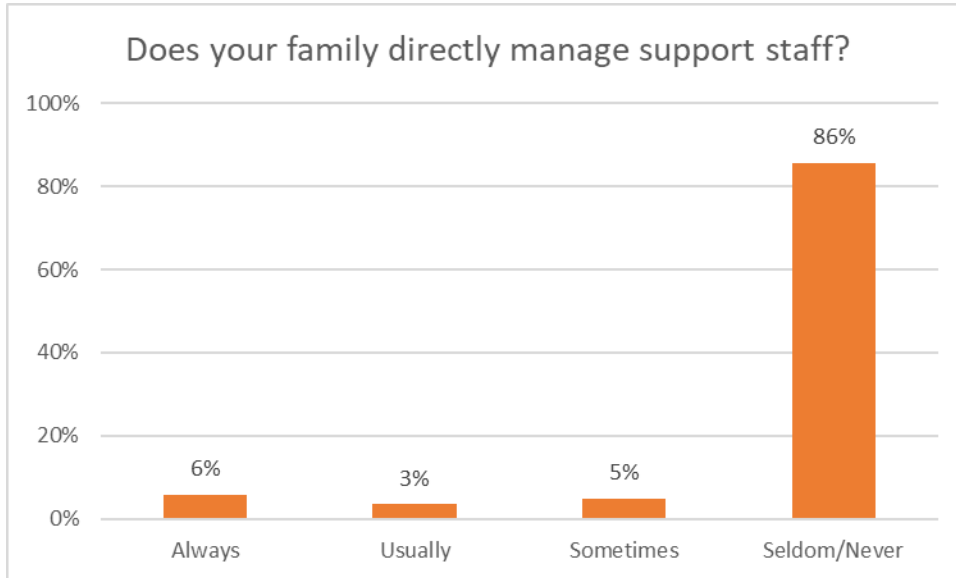


Table Q36. Does your family directly manage support staff?

**Significantly Above Average**

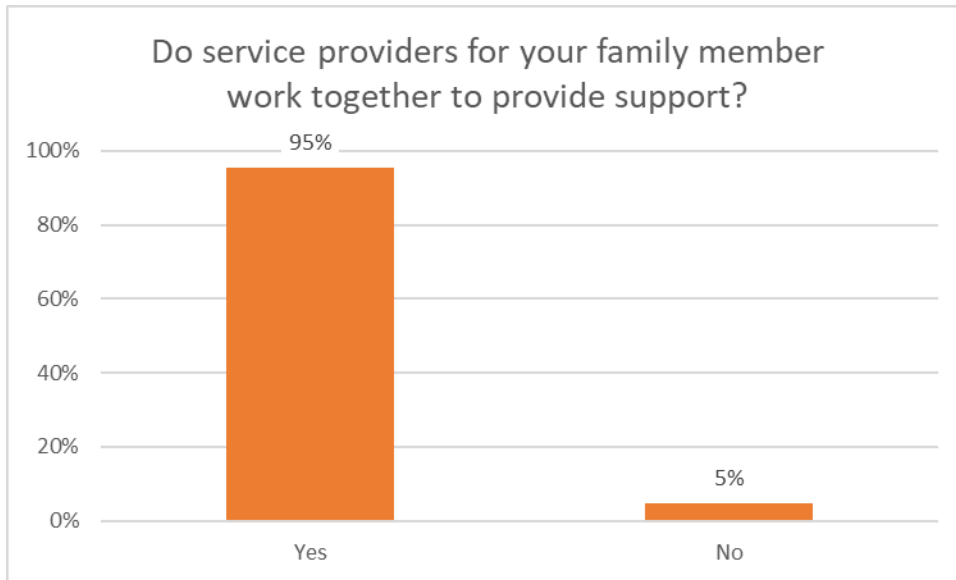
State	Always	Usually	Sometimes	Seldom or Never	N
LA	23%	6%	10%	62%	124

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
VA	11%	4%	5%	81%	149
NC	10%	1%	4%	84%	143
GA	8%	5%	8%	80%	266
<b>NCI Average</b>	<b>6%</b>	<b>3%</b>	<b>5%</b>	<b>86%</b>	<b>1,925</b>
OH	5%	5%	4%	86%	194
KY	4%	9%	6%	81%	114
AZ	3%	1%	8%	88%	175

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
PA	3%	2%	5%	89%	378
MD	3%	2%	4%	92%	382



**Table Q37. Do service providers for your family member work together to provide support?**

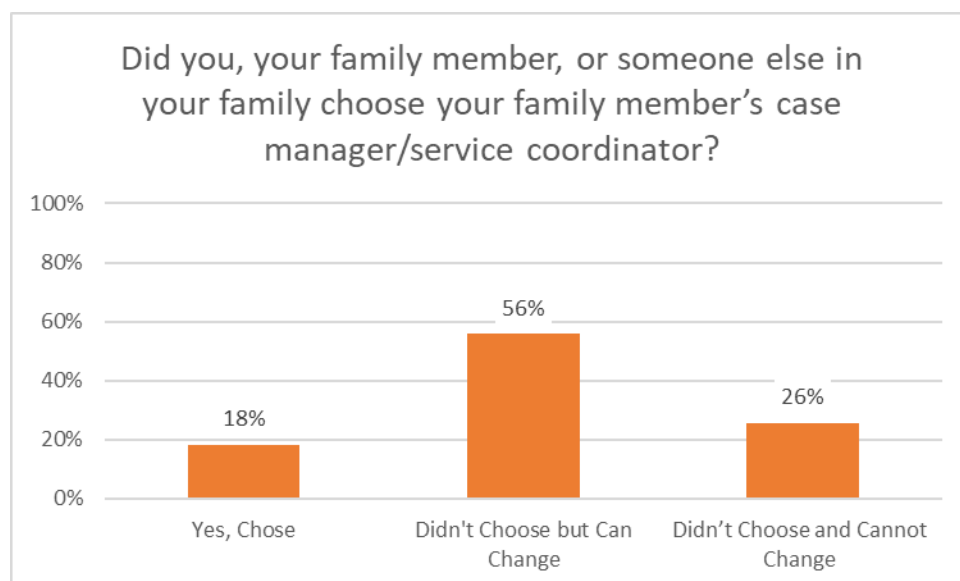
**Significantly Above Average**

State	Yes	No	N
OH	98%	2%	219

**Within Average Range**

State	Yes	No	N
VA	97%	3%	157
PA	95%	5%	354
<b>NCI Average</b>	<b>95%</b>	<b>5%</b>	<b>1,953</b>
GA	95%	5%	262
NC	95%	5%	155
AZ	94%	6%	179
MD	93%	7%	383
LA	92%	8%	118
KY	90%	10%	126





**Table Q38. 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	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
KY	49%	36%	14%	140
LA	33%	38%	29%	146

#### Within Average Range

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
VA	24%	60%	17%	157
<b>NCI Average</b>	<b>18%</b>	<b>56%</b>	<b>26%</b>	<b>2,187</b>
NC	16%	48%	36%	159
OH	15%	69%	16%	208
MD	15%	52%	32%	441
GA	15%	52%	33%	305
PA	14%	51%	35%	412

#### Significantly Below Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
AZ	6%	73%	21%	219

## *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.

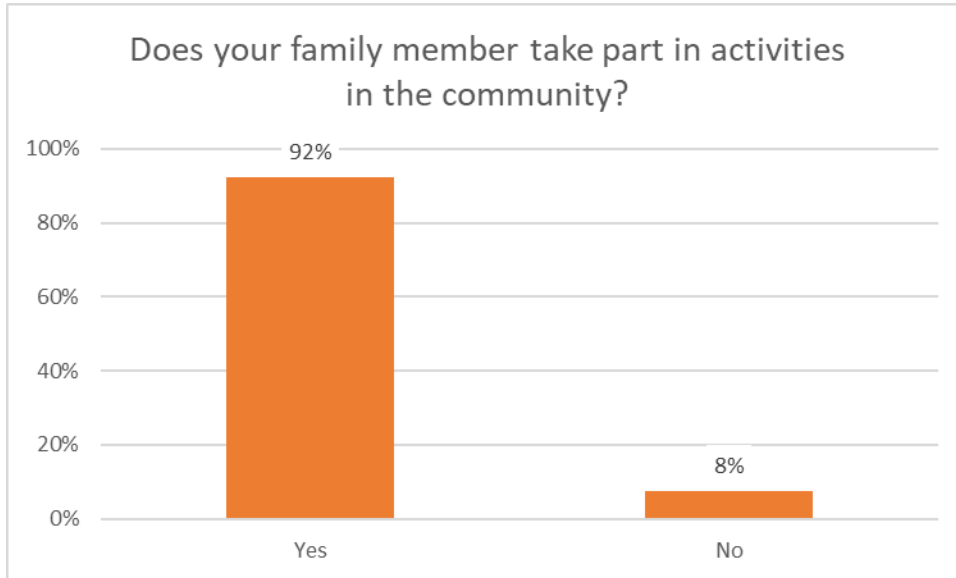


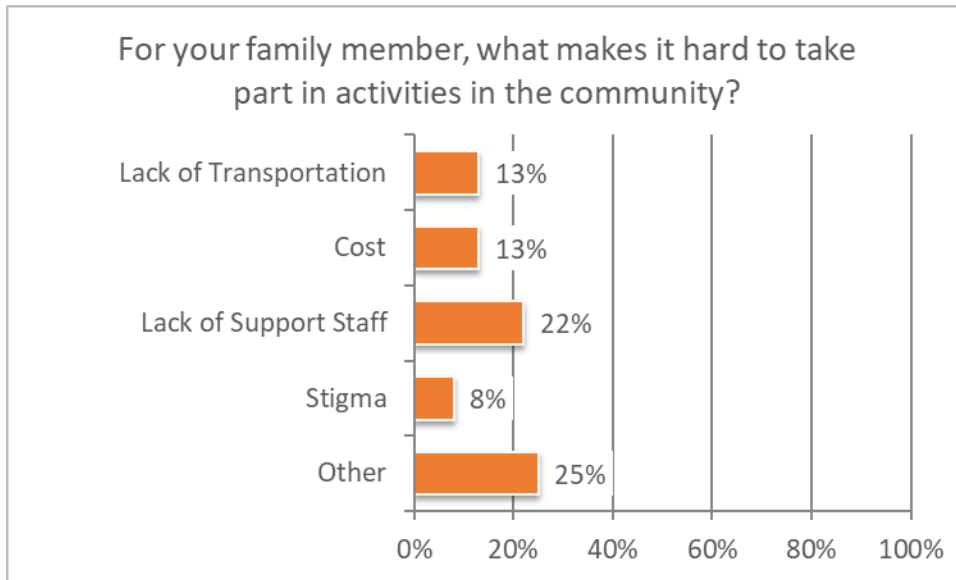
Table Q39. Does your family member take part in activities in the community?

**Within Average Range**

State	Yes	No	N
OH	96%	4%	248
VA	94%	6%	189
PA	94%	6%	532
NC	93%	7%	201
<b>NCI Average</b>	<b>92%</b>	<b>8%</b>	<b>2,563</b>
GA	91%	9%	349
MD	90%	10%	487
AZ	88%	12%	236
KY	88%	12%	149

**Significantly Below Average**

State	Yes	No	N
LA	81%	19%	172

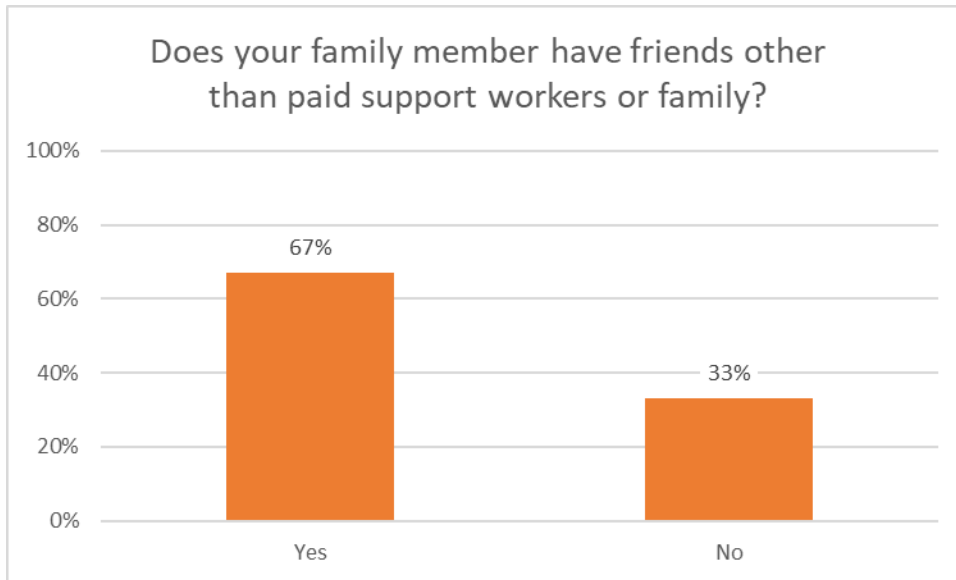


**Table Q40. For your family member, what makes it hard to take part in activities in the community?<sup>10</sup>**

Categories are not mutually exclusive, therefore N is not shown

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	15%	13%	25%	10%	31%
GA	11%	16%	25%	7%	26%
KY	11%	12%	21%	5%	28%
LA	18%	18%	16%	9%	23%
MD	14%	11%	27%	6%	26%
NC	9%	16%	25%	7%	20%
OH	17%	20%	26%	10%	19%
PA	11%	10%	15%	8%	28%
VA	10%	10%	22%	9%	24%
<b>NCI Average</b>	<b>13%</b>	<b>13%</b>	<b>22%</b>	<b>8%</b>	<b>25%</b>

<sup>10</sup> Question is rephrased from previous years



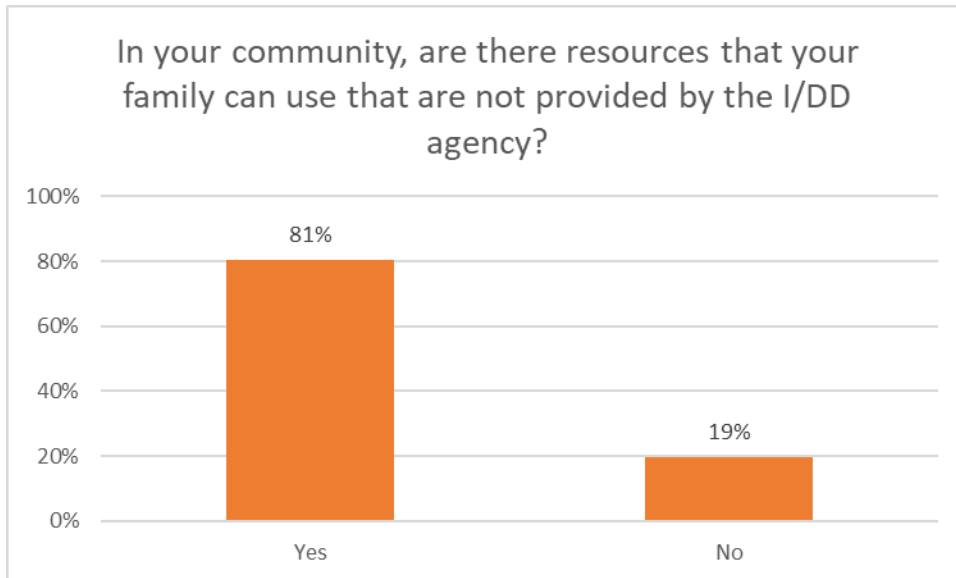
**Table Q41. Does your family member have friends other than paid support workers or family?**

**Within Average Range**

State	Yes	No	N
VA	73%	27%	164
GA	72%	28%	323
PA	71%	29%	477
<b>NCI Average</b>	<b>67%</b>	<b>33%</b>	<b>2,339</b>
KY	65%	35%	139
NC	65%	35%	186
OH	65%	35%	202
MD	64%	36%	459
LA	62%	38%	165

**Significantly Below Average**

State	Yes	No	N
AZ	55%	45%	224



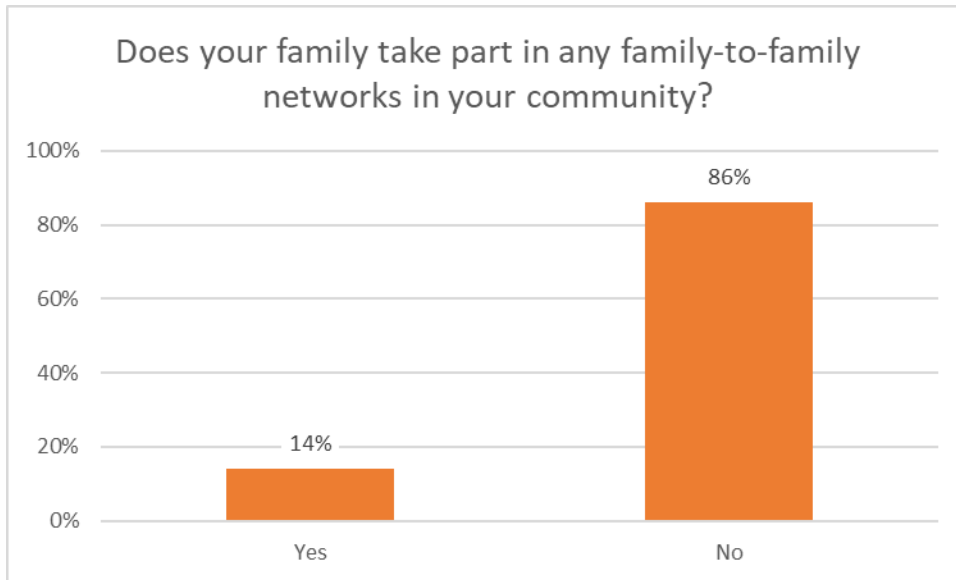
**Table Q42. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?**

#### Within Average Range

State	Yes	No	N
GA	86%	14%	239
VA	83%	17%	131
PA	82%	18%	317
NC	81%	19%	159
OH	81%	19%	194
<b>NCI Average</b>	<b>81%</b>	<b>19%</b>	<b>1,790</b>
MD	79%	21%	345
KY	78%	22%	108
AZ	75%	25%	180

#### Significantly Below Average

State	Yes	No	N
LA	68%	32%	117



**Table Q43. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?**

#### Within Average Range

State	Yes	No	N
LA	21%	79%	148
VA	21%	79%	155
GA	17%	83%	292
NC	15%	85%	178
PA	15%	85%	426
<b>NCI Average</b>	<b>14%</b>	<b>86%</b>	<b>2,173</b>
MD	13%	87%	441
KY	11%	89%	125
OH	9%	91%	193

#### Significantly Below Average

State	Yes	No	N
AZ	9%	91%	215

## *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.



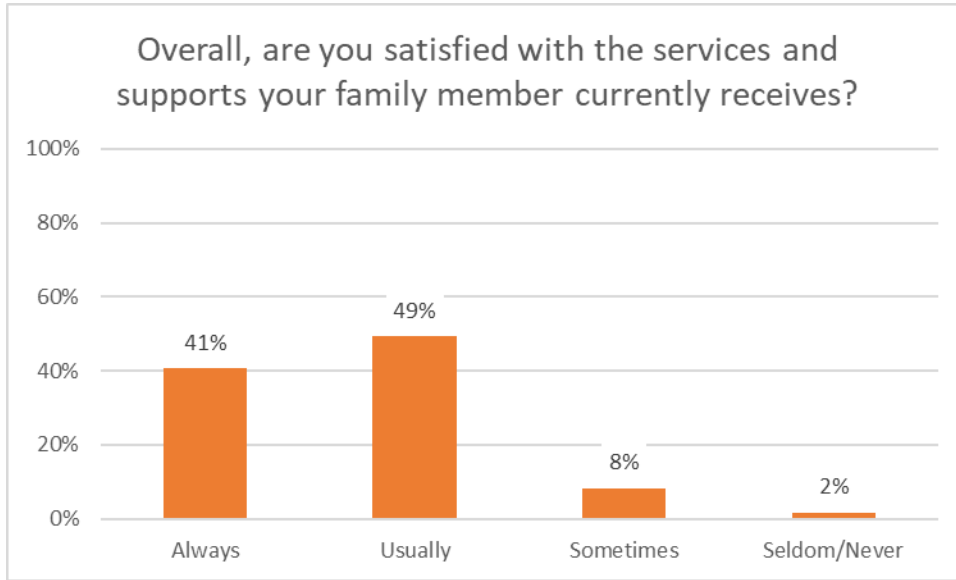


Table Q44. Overall, are you satisfied with the services and supports your family member currently receives?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
VA	53%	43%	4%	1%	190

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	49%	40%	9%	2%	174
NC	49%	41%	9%	1%	207
PA	45%	45%	9%	1%	539
<b>NCI Average</b>	<b>41%</b>	<b>49%</b>	<b>8%</b>	<b>2%</b>	<b>2,617</b>
GA	36%	48%	14%	2%	358
KY	36%	54%	8%	2%	153
OH	35%	59%	5%	1%	250
AZ	33%	56%	10%	1%	241

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	32%	51%	13%	4%	505

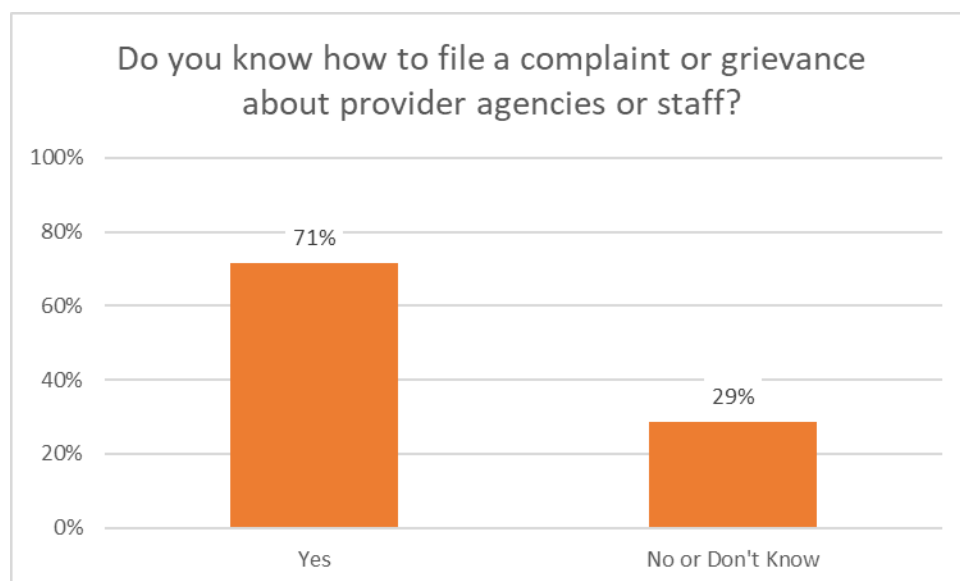


Table Q45. Do you know how to file a complaint or grievance about provider agencies or staff?<sup>11</sup>

#### Significantly Above Average

State	Yes	No or Don't Know	N
OH	86%	14%	253
KY	82%	18%	154

#### Within Average Range

State	Yes	No or Don't Know	N
LA	77%	23%	180
NC	77%	23%	206
<b>NCI Average</b>	<b>71%</b>	<b>29%</b>	<b>2,634</b>
VA	71%	29%	186
AZ	68%	32%	244
GA	67%	33%	360

#### Significantly Below Average

State	Yes	No or Don't Know	N
PA	64%	36%	536
MD	59%	41%	515

<sup>11</sup> 'Don't Know' responses were included in 'No' responses for this question.



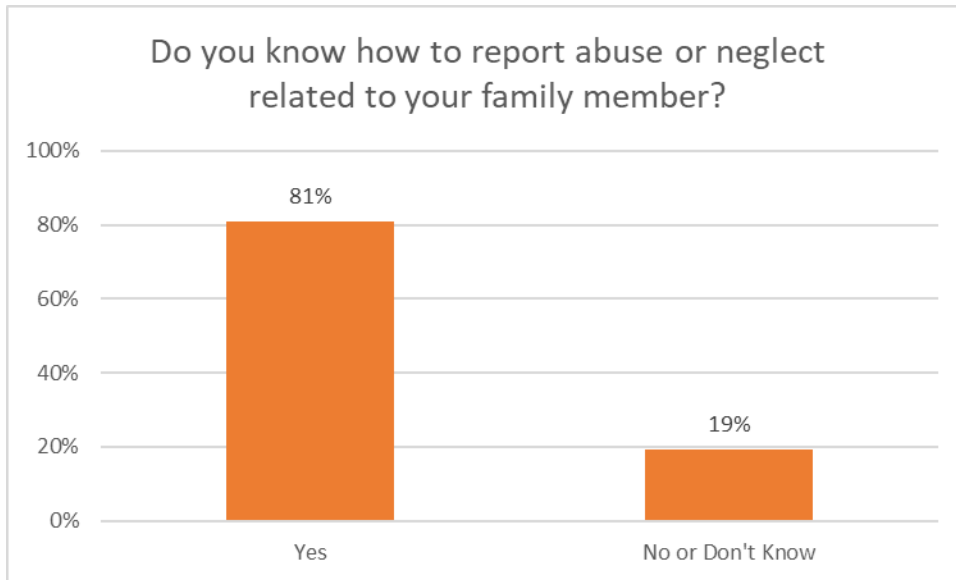
**Table Q46. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?**

#### Within Average Range

State	Yes	No	N
PA	87%	13%	67
OH	85%	15%	46
VA	84%	16%	25
<b>NCI Average</b>	<b>76%</b>	<b>24%</b>	<b>386</b>
KY	75%	25%	20
LA	74%	26%	34
NC	71%	29%	31
AZ	68%	33%	40

#### Significantly Below Average

State	Yes	No	N
MD	54%	46%	67
GA	52%	48%	56



**Table Q47. 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
OH	93%	7%	256
NC	90%	10%	205

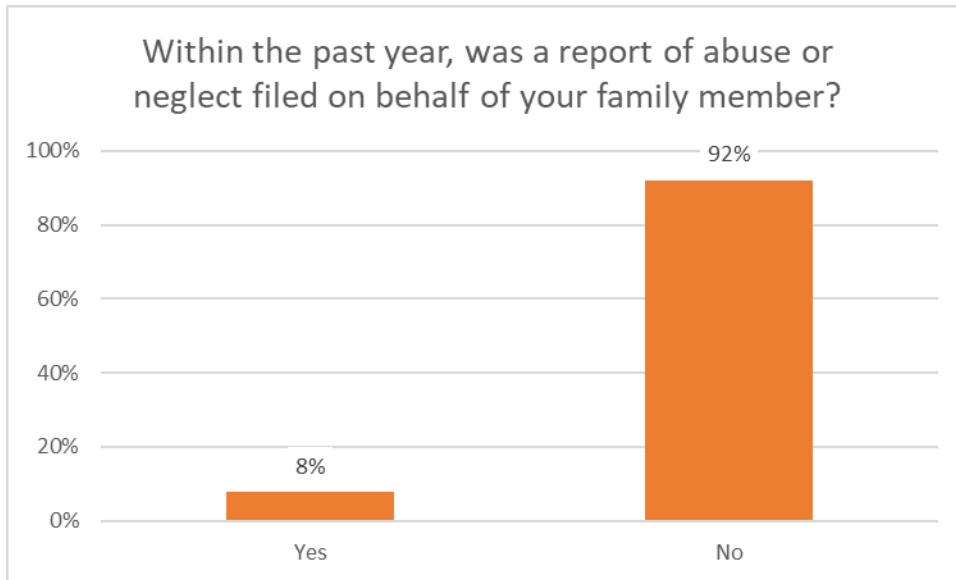
#### Within Average Range

State	Yes	No or Don't Know	N
KY	86%	14%	152
VA	82%	18%	192
AZ	81%	19%	243
LA	81%	19%	179
<b>NCI Average</b>	<b>81%</b>	<b>19%</b>	<b>2,652</b>
GA	78%	22%	361

#### Significantly Below Average

State	Yes	No or Don't Know	N
PA	74%	26%	549
MD	69%	31%	515

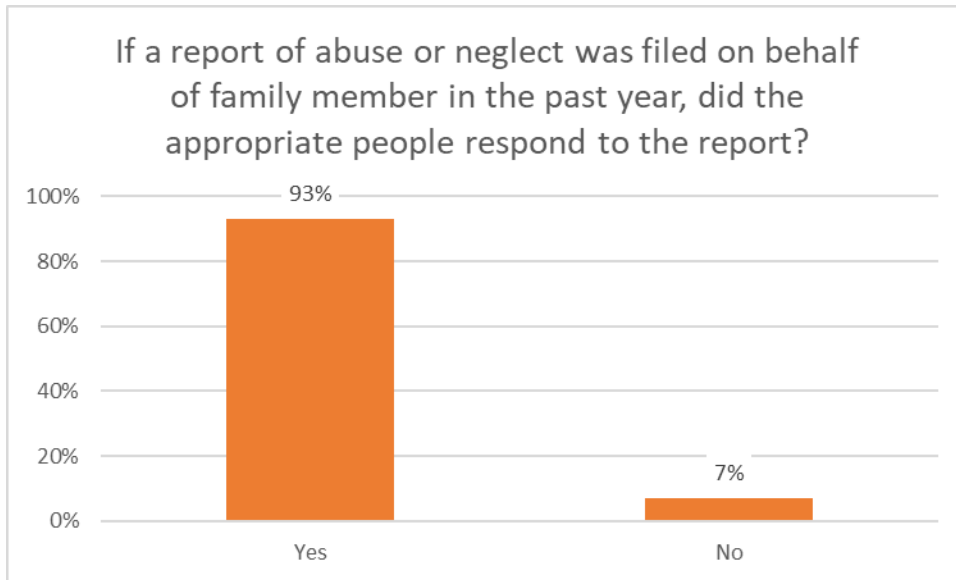
<sup>12</sup> 'Don't Know' responses were included in 'No' responses for this question.



**Table Q48. 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
OH	10%	90%	242
VA	10%	90%	166
LA	8%	92%	173
KY	8%	92%	149
<b>NCI Average</b>	<b>8%</b>	<b>92%</b>	<b>2,503</b>
PA	8%	92%	515
AZ	7%	93%	228
MD	6%	94%	488
NC	6%	94%	200
GA	5%	95%	342

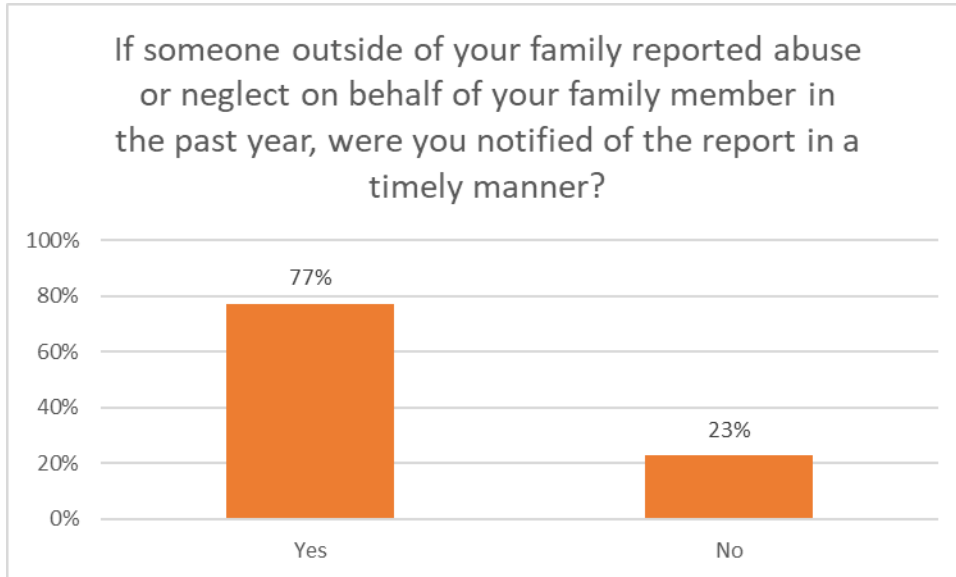


**Table Q49. If a report of abuse or neglect was filed on behalf of your family member in the past year, did the appropriate people respond to the report?<sup>13</sup>**

**Within Average Range**

State	Yes	No	N
PA	97%	3%	30
<b>NCI Average</b>	<b>93%</b>	<b>7%</b>	<b>142</b>
OH	92%	8%	24
MD	85%	15%	27

<sup>13</sup> The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average:  
AZ, GA, KY, LA, NC, VA



**Table Q50. If someone outside of your family reported abuse or neglect on behalf of your family member in the past year, were you notified of the report in a timely manner?<sup>14</sup>**

**Within Average Range**

State	Yes	No	N
OH	79%	21%	24
PA	77%	23%	26
<b>NCI Average</b>	<b>77%</b>	<b>23%</b>	<b>121</b>
MD	55%	45%	20

<sup>14</sup> The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average:  
AZ, GA, KY, LA, NC, VA

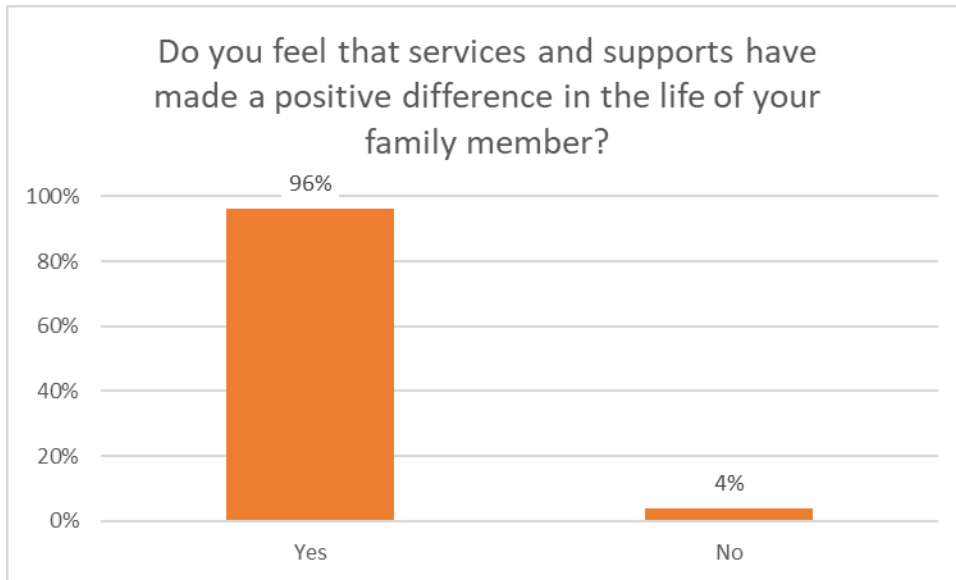


Table Q51. Do you feel that services and supports have made a positive difference in the life of your family member?

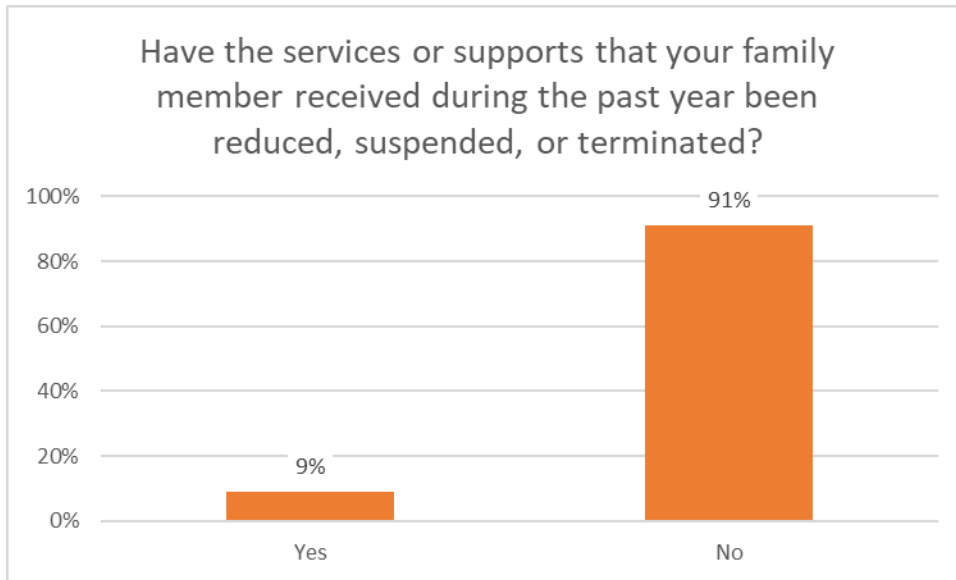
#### Within Average Range

State	Yes	No	N
KY	98%	2%	150
OH	98%	2%	242
PA	97%	3%	516
VA	97%	3%	178
LA	97%	3%	163
AZ	97%	3%	231
<b>NCI Average</b>	<b>96%</b>	<b>4%</b>	<b>2,505</b>
NC	96%	4%	201
GA	94%	6%	336

#### Significantly Below Average

State	Yes	No	N
MD	92%	8%	488

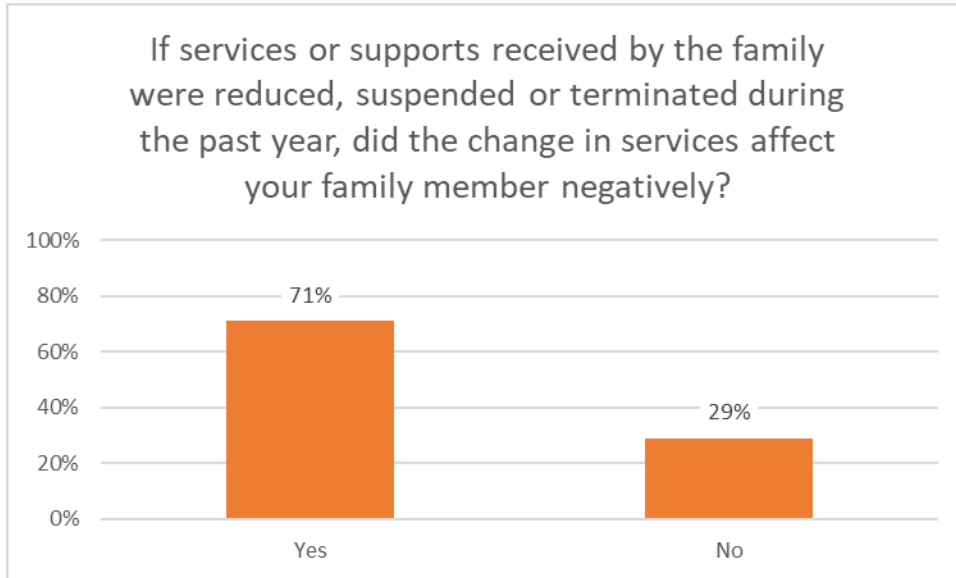




**Table Q52. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?**

**Within Average Range**

State	Yes	No	N
KY	17%	83%	142
NC	13%	87%	188
LA	12%	88%	153
GA	11%	89%	312
MD	10%	90%	440
PA	9%	91%	487
<b>NCI Average</b>	<b>9%</b>	<b>91%</b>	<b>2,348</b>
AZ	8%	92%	220
OH	5%	95%	239
VA	5%	95%	167



**Table Q53. 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?<sup>15</sup>**

#### Significantly Above Average

State	Yes	No	N
MD	96%	4%	27

#### Within Average Range

State	Yes	No	N
GA	80%	20%	25
PA	78%	22%	27
KY	75%	25%	20
<b>NCI Average</b>	<b>71%</b>	<b>29%</b>	<b>172</b>
NC	64%	36%	22

<sup>15</sup> The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average:  
AZ, LA, OH, VA

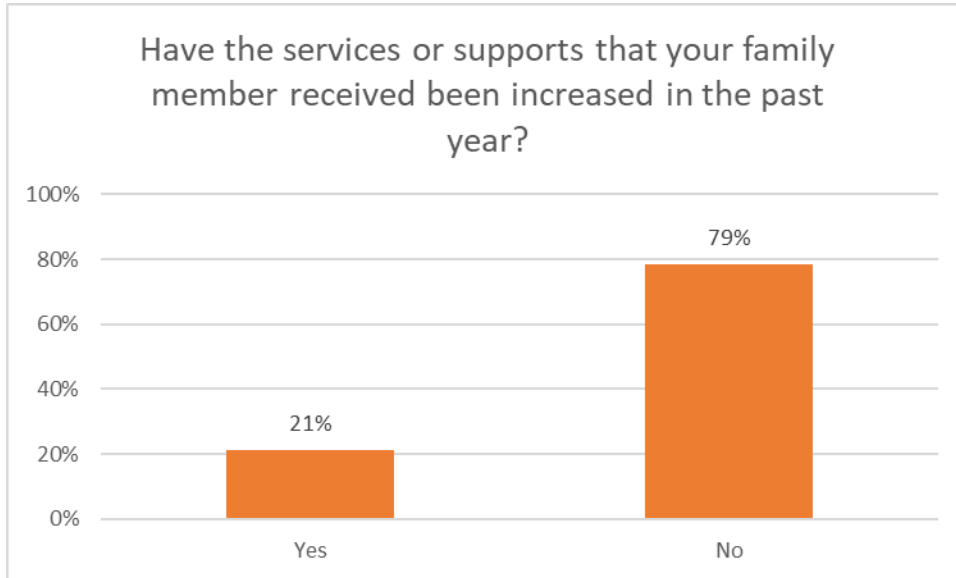


Table Q54. Have the services or supports that your family member received been increased in the past year?

#### Significantly Above Average

State	Yes	No	N
NC	35%	65%	172

#### Within Average Range

State	Yes	No	N
VA	28%	72%	140
PA	22%	78%	385
<b>NCI Average</b>	<b>21%</b>	<b>79%</b>	<b>1,998</b>
MD	18%	82%	370
LA	18%	82%	141
KY	17%	83%	123
GA	17%	83%	243
OH	17%	83%	214
AZ	16%	84%	210

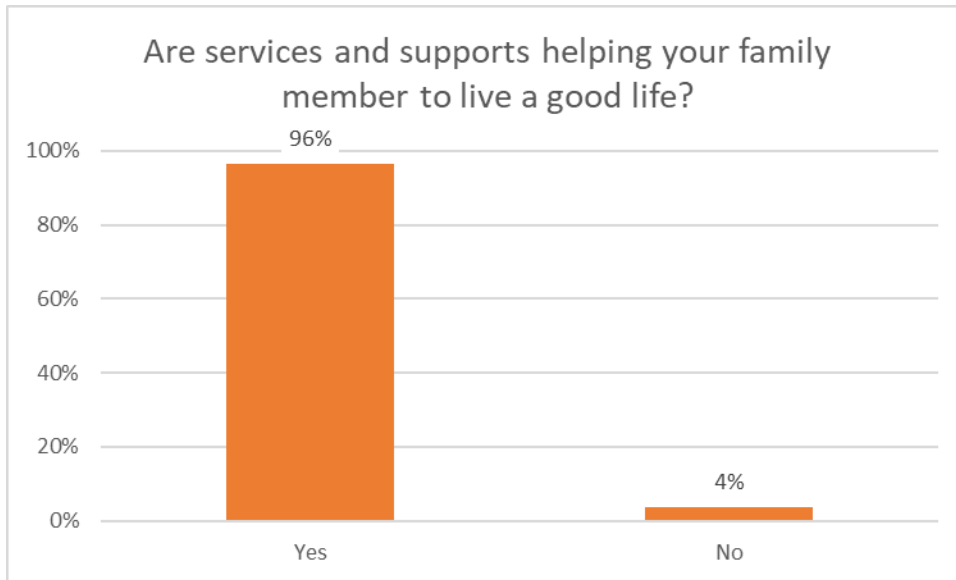


Table Q55. Are services and supports helping your family member to live a good life?

#### Significantly Above Average

State	Yes	No	N
LA	99%	1%	164

#### Within Average Range

State	Yes	No	N
NC	98%	2%	192
OH	98%	2%	241
KY	97%	3%	147
AZ	97%	3%	229
PA	96%	4%	512
<b>NCI Average</b>	<b>96%</b>	<b>4%</b>	<b>2,472</b>
VA	96%	4%	179
GA	96%	4%	336

#### Significantly Below Average

State	Yes	No	N
MD	92%	8%	472

## 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. 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

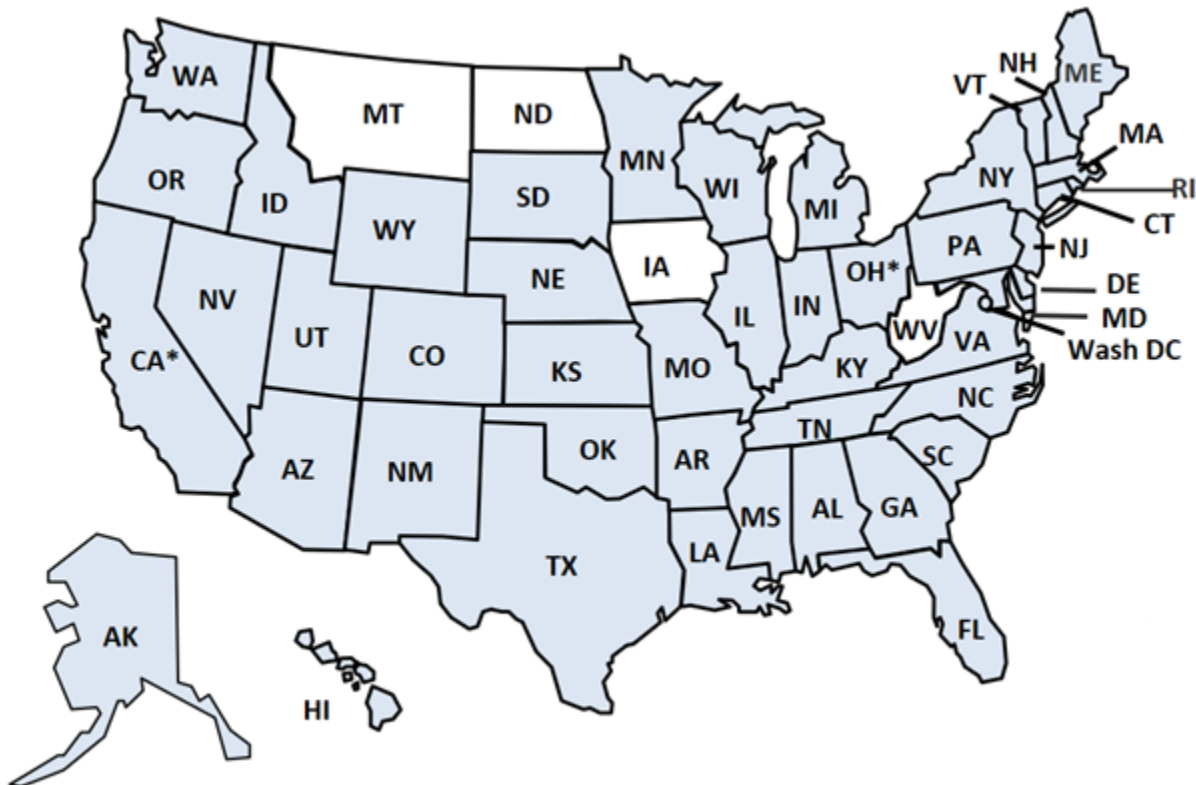
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven 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 2018-19 data collection cycle, 46 states, the District of Columbia and 22 sub-state entities participated in NCI. 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 2018-19



## 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 complete 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

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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 Provider 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
<b>Information and Planning</b>	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
<b>Choice, Decision Making &amp; Control</b>	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
<b>Access &amp; Support Delivery</b>	Families/family members with disabilities get the services and supports they need.
<b>Involvement in the Community</b>	Family members with disabilities use integrated community services and participate in everyday community activities.
<b>Satisfaction</b>	Families/family members with disabilities receive adequate and satisfactory supports.
<b>Outcomes</b>	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>16</sup>

<sup>16</sup> Located on the National Core Indicators website: <https://www.nationalcoreindicators.org> → Resources → Technical Reports

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## Caution and Limitations

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

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.

# 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 Family/Guardian Survey by selecting a random sample of at least 1,000 families who:

1. Had an adult individual with a developmental disability NOT living in the family home; and
2. 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 four states had at least a portion of surveys completed via direct entry for the 2018-19 data collection cycle.<sup>17</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>18</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”

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<sup>17</sup> States that used the direct entry or mail and direct entry options were: LA, MD, NC and OH.

<sup>18</sup> See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

means; their calculations reflect the relative population sizes of participating states, as well as the sample sizes.

Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall 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  $d = \frac{2t}{\sqrt{df}}$ . A cutoff point of Cohen's  $d = 0.2$  was chosen for the effect size to be considered “meaningfully significant,” following the standard interpretation offered by Cohen (1988) that Cohen's  $d$  of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

## Data Entry and Analysis

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

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

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

Statistical significance testing was conducted on each state's “always” or “yes” response compared to the NCI average<sup>19</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 2018-19, nine states administered the Family/Guardian 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 table below shows the number of surveys each state sent, usable surveys returned, and the response rates.

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<sup>19</sup> The NCI Average is the sum of all state averages divided by the total number of states.

**Figure 3. Family/Guardian Survey: State Response Rates<sup>20</sup>**

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
<b>AZ</b>	4,130	1,400	247	17.6%	6%	100%	0%
<b>GA</b>	3,370	1,700	366	21.5%	5%	100%	0%
<b>KY</b>	4,796	822	157	19.1%	7%	100%	0%
<b>LA</b>	1,448	1,448	185	12.8%	7%	94%	6%
<b>MD</b>	14,398	8,707	526	6.0%	4%	85%	15%
<b>NC</b>	7,679	900	209	23.2%	7%	91%	9%
<b>OH</b>	16,509	1,200	258	21.5%	6%	4%	96%
<b>PA</b>	18,035	1,850 - 2,000	560	28.0% - 30.3%	4%	100%	0%
<b>VA</b>	11,993	741	201	27.1%	7%	100%	0%
<b>Total</b>	<b>82,358</b>	<b>18,768 - 18,918</b>	<b>2,709</b>	<b>20%</b>	<b>6%</b>	<b>78%</b>	<b>22%</b>

<sup>20</sup> Please note: The family surveys are mail out 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.