

# Adult Family 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



**Human Services Research Institute (HSRI)**

2336 Massachusetts Avenue  
Cambridge, MA 02140



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

301 N Fairfax Street, Suite 101  
Alexandria, VA 22314

December 2019

---

## **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

---

# Contents

<b>Executive Summary .....</b>	<b>vii</b>
<b>I. Results .....</b>	<b>1</b>
<b>Presentation of Data.....</b>	<b>2</b>
<b>Demographics.....</b>	<b>1</b>
Family Member .....	2
Table 1. More Than One Person Living in the Home Has IDD.....	3
Table 2. Family Member’s Age .....	3
Table 3. Family Member’s Gender.....	4
Table 4. Family Member’s Race and Ethnicity .....	4
Table 5a. Family Member’s Disabilities .....	5
Table 5b. Family Member’s Disabilities (continued) .....	5
Table 6a. Family Member’s Health Conditions .....	6
Table 6b. Family Member’s Health Conditions (continued).....	6
Table 7. Family Member’s Preferred Means of Communication.....	7
Table 8. Family Member Has Legal Court Appointed Guardian or Conservator .....	7
Table 9. Guardian or Conservator Relationship to Family Member.....	8
Table 10. Family Member’s Highest level of Education .....	8
Table 11. Family Member’s Activities in the Past Two Weeks Included <i>Paid Individual Job in the Community</i> .....	9
Table 12. Family Member’s Activities in the Past Two Weeks Included <i>Paid Small Group Job in a Community-based Setting</i> .....	9
Table 13. Family Member’s Activities in the Past Two Weeks Included <i>Paid Work in a Community Job That Primarily Hires People With Disabilities</i> .....	10
Table 14. Family Member’s Activities in the Past Two Weeks Included <i>Unpaid Activity in the Community</i> .....	10
Table 15. Family Member’s Activities in the Past Two Weeks Included <i>Paid Activity in a Facility-based Setting</i> .....	11
Table 16. Family Member’s Activities in the Past Two Weeks Included <i>Unpaid Activity in a Facility-based Setting</i> .....	11
Table 17. Family Member’s Activities in the Past Two Weeks Included <i>School</i> .....	12
Table 18. Family Member’s Activities in the Past Two Weeks Included <i>Stay at Home</i> .....	12
Table 19. Family Member’s Activities in the Past Two Weeks Included <i>Other Activities</i> .....	13
Table 20. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors .....	13
Table 21. Family Member’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating).....	14
Table 22. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping).....	14
Respondents.....	15
Table 23. Language Usually Spoken at Home.....	16
Table 24. Respondent’s Age .....	16

Table 25. Respondent's Health .....	17
Table 26. Respondent's Relationship to Family Member.....	17
Table 27. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services. ....	18
Table 28. Number of Adults in Household (Not Including Family Member Receiving Services).....	18
Table 29. Number of Children (Under 18 Years Old) in Household.....	19
Table 30. Respondent's Highest Level of Education .....	19
Table 31. Total Taxable Household Income of Wage Earners in the Past Year.....	20
Table 32. Residential Designation (Urban, Suburban, or Rural) .....	20
<b>Services and Supports Received.....</b>	<b>21</b>
Table 33. Services and Supports Received From ID/DD Agency.....	22
Table 34. Additional Services and Supports Received (not from the IDD Agency) .....	22
<b>Adult Family Survey Results.....</b>	<b>23</b>
<b>Information and Planning.....</b>	<b>24</b>
Table Q1. Do you get enough information to take part in planning services for your family member? .....	25
Table Q2. Is the information you get about services and supports easy to understand? .....	26
Table Q3. Does the case manager/service coordinator respect your family's choices and opinions? .....	27
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.)? .....	28
Table Q5. Do you need help planning for your family member's future with respect to any of the following? ....	29
Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?.....	30
Table Q7. Does your family member have a service plan? .....	31
Table Q8. Does the plan include all the services and supports your family member needs? .....	32
Table Q9. Does your family member get all the services listed in the plan? .....	33
Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the plan? .....	34
Table Q11. Did your family member help make the service plan? .....	35
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?.....	36
Table Q13. If your family member left school services during the past year, did s/he have a transition plan?....	37
Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?.....	38
Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community? .....	39
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?.....	40
<b>Access and Delivery of Services and Supports.....</b>	<b>41</b>
Table Q17. Are you or your family member able to contact his/her support workers when you want?.....	42
Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want? .....	43

Table Q19. Do support workers come and go when they are supposed to?.....	44
Table Q20. Do services and supports change when your family's needs change?.....	45
Table Q21. Do support workers speak to you in a way you understand? .....	46
Table Q22. Are services delivered in a way that is respectful of your family's culture? .....	47
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 him/her?.....	48
Table Q24. Do support workers have the right information and skills to meet your family's needs?.....	49
Table Q25. Does your family member have the special equipment or accommodations that s/he needs? .....	50
Table Q26. Can your family member see health professionals when needed? .....	51
Table Q27. Does your family member's primary care doctor understand your family member's needs related to his/her disability?.....	52
Table Q28. Can your family member go to the dentist when needed?.....	53
Table Q29. Does your family member's dentist understand your family member's needs related to his/her disability? .....	54
Table Q30. If your family member takes medications, do you know what they're for? .....	55
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)? .....	56
Table Q32. If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?.....	57
Table Q33. If you need respite services, are you able to get/use them? .....	58
Table Q34. If you have used respite services in the past year, were you satisfied with the quality of the respite services? .....	59
Table Q35. Does your family get the supports and services it needs? .....	60
Table Q36. If family does not get the support and services needed, what additional services does your family need?.....	61
<b>Choice, Decision Making and Control .....</b>	<b>62</b>
Table Q37. Can your family choose or change the agency that provides your family member's services?.....	63
Table Q38. Can your family choose or change your family member's support workers?.....	64
Table Q39. Does your family directly manage support staff? .....	65
Table Q40. Do service providers for your family member work together to provide support?.....	66
Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator? .....	67
<b>Involvement in the Community .....</b>	<b>68</b>
Table Q42. Does your family member take part in activities in the community? .....	69
Table Q43. For your family member, what makes it hard to take part in activities in the community?.....	70
Table Q44. Does your family member have friends other than paid support workers or family?.....	71
Table Q45. In your community, are there resources that your family can use that are not provided by the I/DD agency? .....	72
Table Q46. Does your family take part in any family-to-family networks in your community? .....	73
<b>Satisfaction With Services and Supports .....</b>	<b>74</b>

Table Q47. Overall, are you satisfied with the services and supports your family member currently receives? .	75
Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff? .....	76
Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved? .....	77
Table Q50. Do you know how to report abuse or neglect related to your family member? .....	78
Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member? .....	79
Table Q52. Do you feel that services and supports have made a positive difference in the life of your family member? .....	80
Table Q53. Have services and supports reduced your family's out-of-pocket expenses for your family member's care? .....	81
Table Q54. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated? .....	82
Table Q55. 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?.....	83
Table Q56. Have the services or supports that your family member received been increased in the past year? .....	84
Table Q57. Are services and supports helping your family member to live a good life? .....	85
<b>II. NCI History and Activities.....</b>	<b>86</b>
<b>Overview of National Core Indicators .....</b>	<b>87</b>
State Participation .....	88
Figure 1. NCI State Participation 2018-19 .....	88
The Core Indicators .....	88
Figure 2. Family Survey Sub-Domains and Concern Statements.....	90
How NCI Data Are Used .....	90
<b>III. Methodology .....</b>	<b>92</b>
<b>Sampling &amp; Administration.....</b>	<b>93</b>
Weighting.....	93
Significance Testing.....	94
Data Entry and Analysis .....	95
Response Rates .....	95
Figure 3. Adult Family Survey: State Response Rates .....	96

---

# 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 2017-18 data collection cycle, 12 states submitted a valid sample of Adult Family Survey data: Arizona (AZ), Georgia (GA), Louisiana (LA), Maryland (MD), Minnesota (MN), Missouri (MO), North Carolina (NC), Ohio (OH), Oklahoma (OK), Pennsylvania (PA), Utah (UT) and Virginia (VA). This Final Report provides a summary of results based on data submitted by June 30, 2019.

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



## 2018-19 Adult Family Survey

4,836 families  
participated  
across  
12 states\*

### NCI Averages:

- Include all participating states
- Data are weighted

### Respondents

Family members and/or guardians of an adult who has I/DD who lives in their home and receives one public service in addition to case management from the state DD agency.



**11%**  
are over  
age 75



**36%**  
say they or a  
family  
member  
provide paid  
support



**33%**  
always have  
the respite  
services they  
need



**28%**  
reported an annual  
household income of \$25K or  
less



**73%**  
reported services and  
supports reduced out-of-  
pocket expenses related to  
care for their family member

### Person with IDD....



**60%**  
are male



**34**  
average age

**88%**

take part in  
community activities



**68%**

have friends other than  
family or paid staff



\*AZ, GA, LA MD,  
MN, MO, NC, OH,  
OK, PA, UT, VA



## 2018-19 Adult Family Survey



**79%**

have resources in the community the family can use



**15%**

take part in family-to-family networks



**96%**

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

**64%**

say their family member with IDD helped make the service plan



**78%**

family member can *always* see health professionals when needed



**68%**

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



**53%**

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 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. More Than One Person Living in the Home Has IDD

State	Yes	No	N
AZ	11%	89%	274
GA	15%	85%	364
LA	15%	85%	482
MD	10%	90%	433
MN	18%	82%	555
MO	14%	86%	299
NC	11%	89%	215
OH	16%	84%	374
OK	9%	91%	387
PA	14%	86%	662
UT	20%	80%	474
VA	10%	90%	170
<b>NCI Average</b>	<b>13%</b>	<b>87%</b>	<b>4,689</b>

Table 2. Family Member's Age

State	Average Age	N
AZ	32.9	286
GA	35.2	368
LA	34.2	487
MD	32.7	449
MN	29.9	571
MO	34.3	304
NC	32.3	224
OH	34.6	390
OK	35.2	392
PA	35.3	677
UT	33.2	481
VA	35.7	171
<b>NCI Average</b>	<b>34.1</b>	<b>4,800</b>

Table 3. Family Member's Gender

State	Male	Female	N
AZ	60%	40%	283
GA	56%	44%	353
LA	56%	44%	480
MD	63%	37%	450
MN	62%	38%	576
MO	57%	43%	302
NC	53%	47%	221
OH	65%	35%	388
OK	55%	45%	393
PA	56%	44%	673
UT	56%	44%	480
VA	68%	32%	171
<b>NCI Average</b>	<b>60%</b>	<b>40%</b>	<b>4,770</b>

Table 4. 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 Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other
AZ	6%	2%	4%	0%	71%	23%	1%
GA	1%	2%	40%	0%	58%	2%	1%
LA	2%	2%	28%	0%	69%	2%	0%
MD	1%	4%	24%	0%	70%	4%	1%
MN	2%	7%	8%	0%	82%	4%	1%
MO	3%	3%	7%	1%	89%	2%	1%
NC	3%	1%	23%	0%	73%	4%	0%
OH	2%	1%	12%	0%	87%	3%	0%
OK	15%	2%	11%	0%	78%	6%	1%
PA	2%	2%	11%	0%	83%	5%	1%
UT	3%	2%	1%	0%	93%	8%	1%
VA	2%	5%	21%	0%	73%	5%	0%
<b>NCI Average</b>	<b>3%</b>	<b>2%</b>	<b>14%</b>	<b>0%</b>	<b>78%</b>	<b>6%</b>	<b>1%</b>



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

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	62%	21%	31%	26%	12%	5%
GA	70%	23%	31%	21%	10%	7%
LA	65%	25%	29%	17%	11%	6%
MD	63%	18%	43%	16%	7%	6%
MN	67%	30%	40%	15%	8%	9%
MO	63%	26%	36%	21%	11%	5%
NC	74%	23%	41%	28%	11%	6%
OH	64%	25%	30%	15%	7%	4%
OK	76%	22%	20%	29%	13%	10%
PA	82%	26%	27%	16%	7%	7%
UT	77%	26%	33%	21%	13%	8%
VA	76%	31%	37%	23%	6%	6%
<b>NCI Average</b>	<b>71%</b>	<b>25%</b>	<b>32%</b>	<b>20%</b>	<b>9%</b>	<b>6%</b>

**Table 5b. 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%	27%	0%	18%	2%	0%	15%
GA	9%	30%	1%	14%	1%	1%	21%
LA	9%	35%	1%	15%	1%	1%	19%
MD	9%	26%	1%	16%	0%	0%	14%
MN	9%	27%	0%	16%	1%	3%	22%
MO	12%	38%	1%	10%	0%	1%	24%
NC	14%	36%	0%	17%	0%	1%	17%
OH	9%	25%	1%	14%	0%	0%	22%
OK	15%	38%	1%	21%	1%	1%	11%
PA	10%	29%	1%	18%	1%	1%	3%
UT	12%	32%	1%	21%	1%	1%	21%
VA	8%	32%	0%	11%	0%	0%	21%
<b>NCI Average</b>	<b>10%</b>	<b>30%</b>	<b>1%</b>	<b>16%</b>	<b>1%</b>	<b>1%</b>	<b>15%</b>

**Table 6a. 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	15%	16%	6%	24%	29%
GA	14%	18%	5%	36%	30%
LA	14%	20%	5%	35%	28%
MD	9%	13%	2%	22%	25%
MN	13%	11%	5%	22%	18%
MO	12%	17%	5%	24%	21%
NC	7%	14%	6%	22%	27%
OH	8%	18%	4%	32%	28%
OK	12%	18%	5%	29%	20%
PA	10%	20%	5%	28%	26%
UT	13%	17%	3%	18%	19%
VA	13%	14%	2%	30%	23%
<b>NCI Average</b>	<b>11%</b>	<b>17%</b>	<b>4%</b>	<b>28%</b>	<b>25%</b>

**Table 6b. 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 Dental Problems	Sleep Apnea	Other
AZ	12%	3%	6%	10%	18%	24%
GA	8%	3%	3%	14%	16%	22%
LA	12%	4%	1%	9%	17%	18%
MD	8%	3%	3%	11%	18%	27%
MN	13%	5%	3%	15%	24%	28%
MO	13%	6%	3%	14%	21%	29%
NC	11%	4%	6%	7%	21%	28%
OH	10%	2%	2%	7%	16%	27%
OK	21%	7%	2%	18%	19%	21%
PA	10%	2%	2%	11%	22%	17%
UT	10%	4%	2%	17%	30%	33%
VA	16%	4%	0%	15%	19%	38%
<b>NCI Average</b>	<b>12%</b>	<b>4%</b>	<b>3%</b>	<b>12%</b>	<b>20%</b>	<b>25%</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	79%	14%	2%	2%	2%	282
GA	80%	15%	1%	1%	4%	363
LA	75%	16%	2%	1%	5%	481
MD	76%	16%	2%	2%	4%	449
MN	80%	14%	2%	3%	1%	529
MO	77%	15%	2%	2%	4%	293
NC	68%	26%	0%	1%	4%	222
OH	84%	11%	1%	2%	2%	376
OK	71%	24%	2%	2%	1%	393
PA	78%	14%	2%	3%	3%	659
UT	75%	19%	1%	1%	4%	475
VA	70%	23%	2%	2%	3%	173
<b>NCI Average</b>	<b>77%</b>	<b>16%</b>	<b>2%</b>	<b>2%</b>	<b>3%</b>	<b>4,695</b>

Table 8. 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	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
AZ	25%	10%	63%	2%	274
GA	40%	11%	45%	4%	337
LA	40%	11%	44%	6%	432
MD	53%	13%	31%	3%	424
MN	10%	5%	83%	2%	572
MO	26%	8%	65%	1%	293
NC	8%	12%	78%	3%	222
OH	38%	13%	43%	5%	373
OK	19%	10%	69%	2%	377
PA	49%	9%	39%	3%	609
UT	18%	14%	66%	3%	461
VA	32%	12%	53%	3%	163
<b>NCI Average</b>	<b>32%</b>	<b>11%</b>	<b>54%</b>	<b>3%</b>	<b>4,537</b>

Table 9. Guardian or Conservator Relationship to Family Member

State	Family	Friend	State Employee or Guardianship Agency	Other	N
AZ	98%	1%	0%	0%	202
GA	88%	1%	0%	12%	190
LA	98%	1%	0%	1%	246
MD	92%	1%	1%	6%	180
MN	98%	0%	1%	0%	490
MO	98%	0%	0%	1%	208
NC	98%	0%	1%	1%	187
OH	100%	0%	0%	0%	221
OK	98%	1%	0%	1%	290
PA	97%	1%	0%	2%	292
UT	99%	0%	0%	0%	358
VA	99%	0%	0%	1%	101
<b>NCI Average</b>	<b>98%</b>	<b>1%</b>	<b>0%</b>	<b>1%</b>	<b>2,965</b>

Table 10. 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 School or Certificate Program	Some College	College Degree or Higher	N
AZ	15%	4%	29%	40%	0%	6%	5%	268
GA	16%	4%	41%	30%	2%	2%	4%	357
LA	23%	5%	48%	13%	3%	3%	4%	460
MD	12%	0%	58%	17%	3%	5%	6%	438
MN	8%	7%	29%	42%	4%	3%	7%	551
MO	15%	2%	30%	42%	3%	5%	4%	281
NC	18%	6%	45%	14%	4%	7%	6%	219
OH	14%	7%	19%	47%	5%	3%	4%	364
OK	13%	7%	25%	48%	1%	3%	4%	383
PA	11%	4%	25%	49%	5%	3%	3%	655
UT	18%	6%	44%	22%	3%	3%	4%	463
VA	16%	5%	44%	25%	1%	3%	5%	165
<b>NCI Average</b>	<b>14%</b>	<b>5%</b>	<b>32%</b>	<b>38%</b>	<b>3%</b>	<b>4%</b>	<b>5%</b>	<b>4,604</b>

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

Response options changed from previous years

State	Yes	No	N
AZ	9%	91%	282
GA	13%	87%	359
LA	10%	90%	475
MD	23%	77%	441
MN	24%	76%	568
MO	11%	89%	302
NC	13%	87%	221
OH	26%	74%	375
OK	11%	89%	389
PA	19%	81%	657
UT	20%	80%	467
VA	5%	95%	164
<b>NCI Average</b>	<b>16%</b>	<b>84%</b>	<b>4,700</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>**

Response options changed from previous years

State	Yes	No	N
AZ	11%	89%	275
GA	9%	91%	349
LA	10%	90%	472
MD	14%	86%	437
MN	22%	78%	563
MO	6%	94%	300
NC	5%	95%	220
OH	19%	81%	359
OK	11%	89%	385
PA	11%	89%	644
UT	7%	93%	466
VA	4%	96%	163
<b>NCI Average</b>	<b>12%</b>	<b>88%</b>	<b>4,633</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>**

Response options changed from previous years

State	Yes	No	N
AZ	6%	94%	269
GA	3%	97%	353
LA	5%	95%	470
MD	11%	89%	432
MN	12%	88%	556
MO	5%	95%	296
NC	3%	97%	220
OH	12%	88%	371
OK	7%	93%	386
PA	9%	91%	647
UT	6%	94%	468
VA	2%	98%	162
<b>NCI Average</b>	<b>8%</b>	<b>92%</b>	<b>4,630</b>

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

Response options changed from previous years

State	Yes	No	N
AZ	30%	70%	277
GA	35%	65%	350
LA	18%	82%	466
MD	44%	56%	432
MN	36%	64%	552
MO	33%	67%	298
NC	41%	59%	219
OH	28%	72%	359
OK	31%	69%	385
PA	36%	64%	644
UT	31%	69%	457
VA	37%	63%	156
<b>NCI Average</b>	<b>33%</b>	<b>67%</b>	<b>4,595</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 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>**

Response options changed from previous years

State	Yes	No	N
AZ	15%	85%	274
GA	11%	89%	348
LA	13%	87%	469
MD	15%	85%	435
MN	28%	72%	557
MO	18%	82%	297
NC	5%	95%	222
OH	31%	69%	377
OK	19%	81%	386
PA	20%	80%	643
UT	14%	86%	466
VA	7%	93%	163
<b>NCI Average</b>	<b>18%</b>	<b>82%</b>	<b>4,637</b>

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

Response options changed from previous years

State	Yes	No	N
AZ	38%	62%	272
GA	31%	69%	340
LA	18%	82%	466
MD	34%	66%	430
MN	22%	78%	558
MO	27%	73%	292
NC	27%	73%	214
OH	28%	72%	370
OK	15%	85%	385
PA	27%	73%	625
UT	28%	72%	456
VA	28%	72%	148
<b>NCI Average</b>	<b>27%</b>	<b>73%</b>	<b>4,556</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***

Response options changed from previous years

State	Yes	No	N
AZ	13%	87%	276
GA	10%	90%	354
LA	12%	88%	473
MD	5%	95%	432
MN	17%	83%	559
MO	6%	94%	301
NC	18%	82%	219
OH	11%	89%	374
OK	10%	90%	385
PA	5%	95%	644
UT	18%	82%	469
VA	16%	84%	130
<b>NCI Average</b>	<b>11%</b>	<b>89%</b>	<b>4,616</b>

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

Response options changed from previous years

State	Yes	No	N
AZ	48%	52%	258
GA	51%	49%	346
LA	66%	34%	462
MD	38%	62%	422
MN	48%	52%	532
MO	55%	45%	287
NC	66%	34%	211
OH	32%	68%	360
OK	66%	34%	371
PA	46%	54%	627
UT	48%	52%	449
VA	50%	50%	127
<b>NCI Average</b>	<b>48%</b>	<b>52%</b>	<b>4,452</b>



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

Response options changed from previous years

State	Yes	No	N
AZ	23%	77%	74
GA	28%	72%	165
LA	23%	77%	184
MD	24%	76%	179
MN	32%	68%	197
MO	35%	65%	134
NC	45%	55%	111
OH	32%	68%	174
OK	33%	67%	134
PA	43%	57%	230
UT	50%	50%	203
VA	63%	37%	82
<b>NCI Average</b>	<b>39%</b>	<b>61%</b>	<b>1,867</b>

**Table 20. 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	No Support Needed	Some Support Needed	Extensive Support Needed	N
AZ	60%	26%	14%	277
GA	53%	32%	14%	355
LA	51%	31%	19%	473
MD	60%	26%	14%	444
MN	43%	35%	22%	573
MO	57%	29%	14%	295
NC	48%	30%	22%	221
OH	65%	26%	9%	385
OK	65%	22%	12%	387
PA	61%	28%	11%	658
UT	44%	36%	19%	469
VA	41%	39%	20%	171
<b>NCI Average</b>	<b>56%</b>	<b>29%</b>	<b>14%</b>	<b>4,708</b>

**Table 21. Family Member's Level of Help Needed with Personal Care Activities (for example, 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	No Support Needed	Some Support Needed	Extensive Support Needed	N
AZ	17%	42%	40%	281
GA	31%	36%	32%	362
LA	22%	37%	41%	480
MD	31%	35%	34%	448
MN	17%	43%	39%	580
MO	26%	31%	43%	301
NC	14%	33%	54%	220
OH	38%	39%	22%	385
OK	20%	35%	45%	397
PA	35%	36%	30%	671
UT	21%	35%	44%	477
VA	9%	45%	46%	170
<b>NCI Average</b>	<b>26%</b>	<b>38%</b>	<b>36%</b>	<b>4,772</b>

**Table 22. Family Member's Need for Help with Other Daily Activities (for example, 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	No Support Needed	Some Support Needed	Extensive Support Needed	N
AZ	3%	16%	81%	280
GA	7%	21%	71%	361
LA	5%	22%	73%	474
MD	6%	30%	64%	447
MN	3%	20%	77%	578
MO	3%	17%	80%	298
NC	2%	14%	84%	219
OH	8%	30%	62%	386
OK	4%	16%	80%	395
PA	6%	23%	72%	671
UT	5%	12%	83%	472
VA	2%	13%	85%	170
<b>NCI Average</b>	<b>5%</b>	<b>21%</b>	<b>74%</b>	<b>4,751</b>

## *Respondents*

*This section provides demographic information about the respondent.*

Table 23. Language Usually Spoken at Home

New question in 2018-19

State	English	Spanish	Other	N
AZ	87%	10%	3%	279
GA	97%	1%	2%	364
LA	99%	0%	1%	486
MD	96%	1%	2%	449
MN	96%	1%	3%	564
MO	99%	0%	1%	303
NC	99%	1%	0%	221
OH	99%	0%	1%	380
OK	98%	1%	1%	396
PA	98%	2%	1%	673
UT	96%	1%	3%	477
VA	98%	1%	2%	172
<b>NCI Average</b>	<b>97%</b>	<b>2%</b>	<b>1%</b>	<b>4,764</b>

Table 24. Respondent's Age

State	Under 35	35-54	55-74	75 and Older	N
AZ	2%	30%	58%	9%	283
GA	4%	24%	62%	10%	364
LA	3%	27%	58%	12%	489
MD	3%	12%	74%	11%	452
MN	4%	29%	61%	6%	581
MO	2%	25%	64%	9%	298
NC	2%	20%	70%	8%	221
OH	3%	24%	60%	12%	386
OK	2%	19%	68%	12%	397
PA	2%	20%	65%	13%	673
UT	2%	26%	61%	11%	477
VA	1%	21%	64%	13%	174
<b>NCI Average</b>	<b>2%</b>	<b>23%</b>	<b>64%</b>	<b>11%</b>	<b>4,795</b>

Table 25. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
AZ	18%	47%	31%	4%	281
GA	15%	48%	33%	3%	363
LA	13%	41%	39%	7%	484
MD	15%	48%	34%	3%	449
MN	20%	49%	29%	2%	578
MO	10%	41%	42%	7%	302
NC	19%	50%	29%	2%	222
OH	16%	47%	34%	3%	385
OK	12%	44%	39%	4%	395
PA	12%	45%	38%	4%	670
UT	14%	46%	36%	4%	475
VA	13%	40%	42%	5%	173
<b>NCI Average</b>	<b>15%</b>	<b>46%</b>	<b>36%</b>	<b>4%</b>	<b>4,777</b>

Table 26. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Other	N
AZ	84%	8%	0%	5%	3%	282
GA	79%	8%	1%	4%	8%	364
LA	82%	9%	0%	4%	6%	489
MD	92%	5%	1%	1%	2%	448
MN	91%	6%	1%	2%	2%	576
MO	89%	5%	0%	2%	3%	300
NC	90%	5%	0%	3%	2%	220
OH	87%	7%	0%	3%	2%	388
OK	88%	5%	0%	4%	3%	395
PA	92%	6%	0%	1%	1%	672
UT	92%	6%	1%	1%	1%	477
VA	80%	9%	1%	3%	7%	174
<b>NCI Average</b>	<b>87%</b>	<b>6%</b>	<b>0%</b>	<b>3%</b>	<b>3%</b>	<b>4,785</b>

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

Categories are not exclusive, therefore N is not shown

State	No	Respondent Provides Paid Support	Other Family Member Provides Paid Support	N
AZ	48%	40%	18%	278
GA	92%	4%	5%	361
LA	81%	3%	17%	482
MD	83%	10%	9%	444
MN	33%	53%	27%	573
MO	81%	10%	10%	301
NC	56%	33%	16%	222
OH	83%	13%	5%	382
OK	50%	38%	15%	389
PA	73%	14%	13%	660
UT	64%	3%	33%	469
VA	59%	18%	24%	170
<b>NCI Average</b>	<b>67%</b>	<b>21%</b>	<b>15%</b>	<b>4,731</b>

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

State	One	Two	Three	Four or More	N
AZ	13%	25%	42%	20%	282
GA	11%	29%	43%	18%	359
LA	10%	36%	42%	12%	481
MD	6%	26%	49%	19%	448
MN	6%	26%	46%	22%	580
MO	5%	29%	49%	17%	303
NC	10%	30%	42%	18%	221
OH	8%	29%	46%	17%	384
OK	11%	35%	45%	8%	396
PA	6%	21%	48%	25%	666
UT	5%	23%	45%	27%	470
VA	6%	29%	54%	11%	173
<b>NCI Average</b>	<b>8%</b>	<b>27%</b>	<b>46%</b>	<b>18%</b>	<b>4,763</b>

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

State	None	One	Two	Three	Four or More	N
AZ	77%	11%	7%	4%	2%	282
GA	85%	10%	3%	1%	1%	362
LA	88%	10%	1%	1%	0%	485
MD	90%	7%	2%	0%	0%	450
MN	82%	10%	5%	2%	2%	579
MO	88%	7%	3%	1%	1%	302
NC	90%	8%	1%	0%	0%	223
OH	91%	6%	2%	0%	1%	384
OK	85%	9%	4%	1%	1%	393
PA	91%	6%	2%	1%	0%	667
UT	80%	10%	4%	2%	3%	475
VA	85%	11%	3%	1%	0%	173
<b>NCI Average</b>	<b>87%</b>	<b>8%</b>	<b>3%</b>	<b>1%</b>	<b>1%</b>	<b>4,775</b>

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	9%	16%	7%	30%	39%	280
GA	9%	27%	7%	20%	36%	362
LA	11%	31%	8%	21%	29%	481
MD	3%	19%	3%	21%	55%	447
MN	4%	19%	13%	18%	46%	555
MO	3%	26%	6%	21%	43%	295
NC	7%	17%	7%	21%	49%	223
OH	7%	33%	5%	20%	35%	382
OK	5%	27%	6%	27%	35%	395
PA	5%	37%	7%	19%	31%	664
UT	3%	17%	7%	29%	43%	470
VA	8%	23%	3%	23%	44%	172
<b>NCI Average</b>	<b>6%</b>	<b>27%</b>	<b>6%</b>	<b>22%</b>	<b>38%</b>	<b>4,726</b>

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	7%	11%	17%	17%	11%	18%	19%	275
GA	14%	11%	9%	19%	12%	19%	17%	351
LA	19%	9%	12%	17%	10%	14%	19%	469
MD	7%	4%	5%	14%	13%	32%	24%	436
MN	4%	5%	9%	22%	16%	26%	18%	570
MO	12%	9%	9%	17%	18%	16%	20%	294
NC	6%	10%	11%	20%	13%	20%	21%	219
OH	9%	10%	9%	19%	11%	19%	23%	377
OK	8%	13%	11%	18%	11%	16%	22%	370
PA	13%	7%	8%	18%	12%	18%	22%	654
UT	9%	5%	7%	20%	17%	20%	21%	467
VA	12%	5%	8%	18%	15%	21%	22%	165
<b>NCI Average</b>	<b>10%</b>	<b>8%</b>	<b>10%</b>	<b>18%</b>	<b>13%</b>	<b>20%</b>	<b>21%</b>	<b>4,647</b>

Table 32. Residential Designation (Urban, Suburban, or Rural)

State	Urban or Suburban	Rural	N
AZ	81%	19%	278
GA	65%	35%	359
LA	51%	49%	467
MD	64%	36%	439
MN	78%	22%	572
MO	66%	34%	297
NC	53%	47%	219
OH	68%	32%	377
OK	69%	31%	388
PA	59%	41%	656
UT	82%	18%	473
VA	57%	43%	168
<b>NCI Average</b>	<b>65%</b>	<b>35%</b>	<b>4,693</b>



## *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**

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	Out-of-home Respite	Day or Employment Supports	Transportation	Other	Self-direction or Fiscal Intermediary Services
AZ	11%	39%	53%	58%	58%	42%	33%
GA	15%	32%	18%	52%	59%	22%	40%
LA	10%	65%	18%	32%	45%	23%	38%
MD	13%	33%	22%	65%	75%	23%	28%
MN	35%	56%	34%	56%	68%	33%	64%
MO	15%	35%	26%	46%	58%	21%	39%
NC	12%	67%	51%	42%	52%	24%	40%
OH	15%	20%	20%	63%	74%	25%	32%
OK	19%	55%	13%	32%	42%	29%	45%
PA	14%	36%	30%	55%	58%	25%	41%
UT	10%	53%	48%	57%	63%	25%	71%
VA	7%	49%	25%	60%	66%	28%	46%
<b>NCI Average</b>	<b>14%</b>	<b>41%</b>	<b>29%</b>	<b>54%</b>	<b>61%</b>	<b>27%</b>	<b>41%</b>

**Table 34. Additional Services and Supports Received (not from the IDD 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	Social Security Payments (SSI/SSB)	Services or Supports from Other Agencies or Organizations
AZ	94%	30%
GA	97%	23%
LA	95%	23%
MD	94%	28%
MN	93%	39%
MO	94%	38%
NC	95%	30%
OH	89%	30%
OK	96%	17%
PA	93%	35%
UT	96%	31%
VA	97%	31%
<b>NCI Average</b>	<b>93%</b>	<b>30%</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.

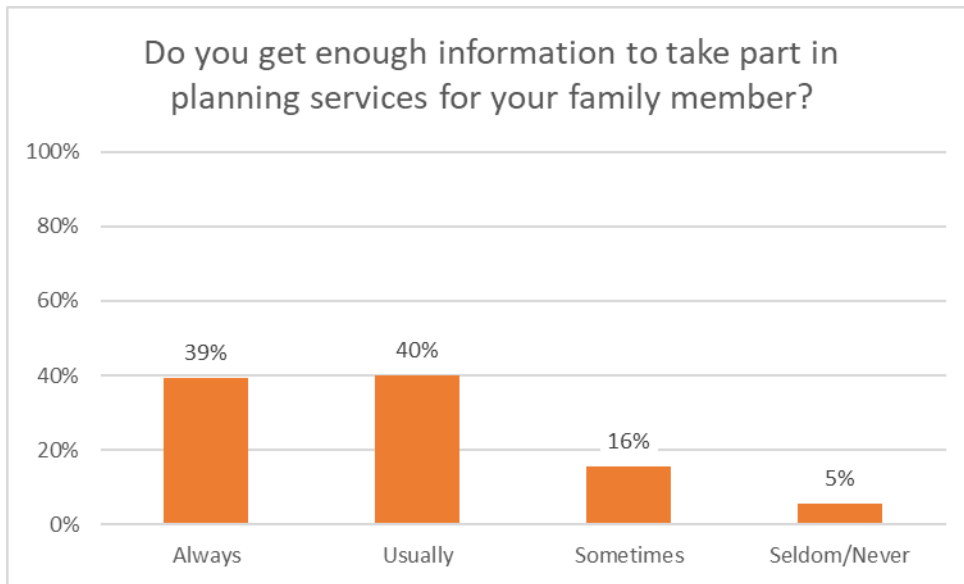


Table Q1. Do you get enough information to take part in planning services for your family member?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	47%	38%	11%	4%	213
AZ	42%	37%	16%	4%	279
OK	42%	38%	15%	5%	375
PA	41%	39%	15%	5%	619
LA	41%	35%	17%	7%	437
OH	41%	40%	13%	6%	365
<b>NCI Average</b>	<b>39%</b>	<b>40%</b>	<b>16%</b>	<b>5%</b>	<b>4,502</b>
UT	39%	47%	12%	2%	457
VA	35%	44%	16%	4%	165
MN	35%	40%	20%	5%	557

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	32%	40%	19%	9%	295
MD	30%	44%	18%	9%	428
GA	22%	40%	24%	14%	312

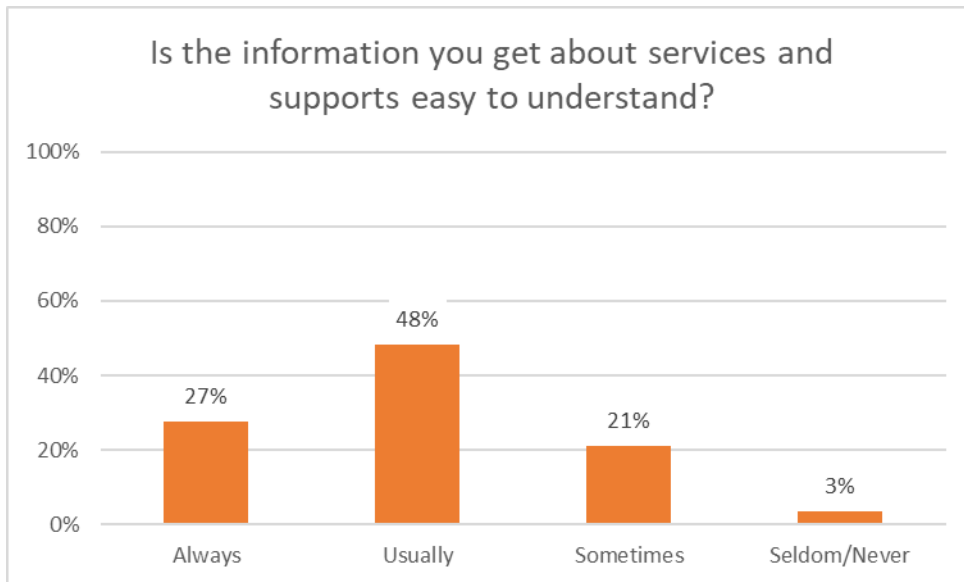


Table Q2. Is the information you get about services and supports easy to understand?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	33%	40%	22%	5%	165
OK	32%	49%	16%	2%	372
NC	30%	47%	21%	1%	216
LA	30%	45%	21%	4%	452
AZ	28%	51%	17%	3%	278
<b>NCI Average</b>	<b>27%</b>	<b>48%</b>	<b>21%</b>	<b>3%</b>	<b>4,533</b>
PA	27%	49%	22%	2%	643
OH	25%	51%	21%	3%	365
UT	25%	55%	18%	2%	460
MO	23%	51%	20%	7%	286

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	22%	48%	25%	5%	561
MD	22%	50%	21%	8%	427
GA	20%	44%	27%	9%	308

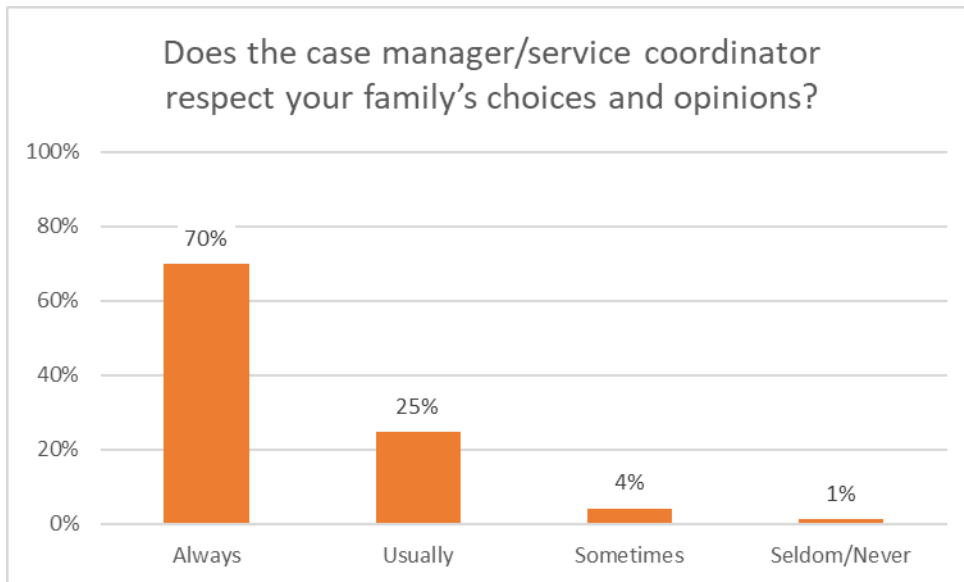


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

#### Significantly Above Average

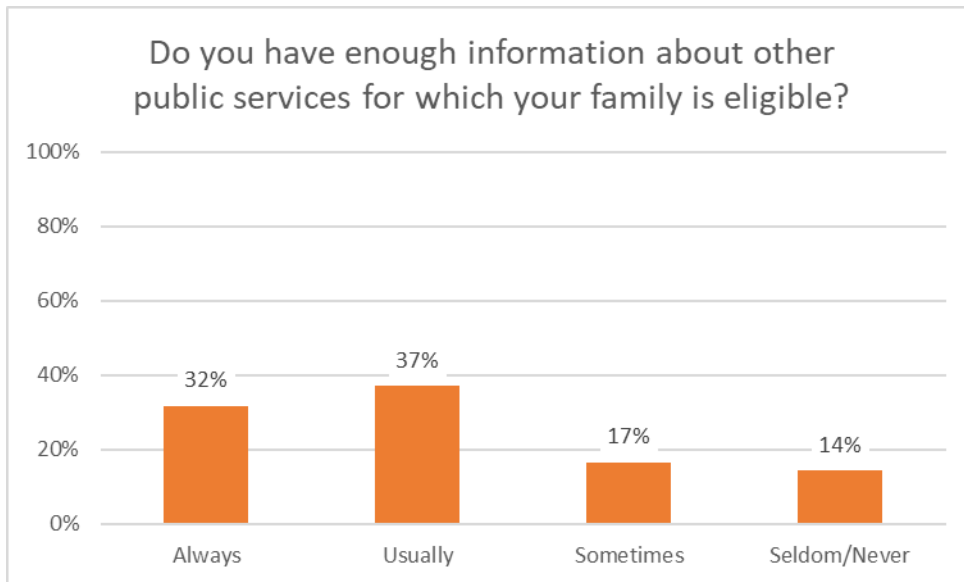
State	Always	Usually	Sometimes	Seldom or Never	N
UT	81%	16%	2%	0%	467

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	73%	21%	5%	0%	165
AZ	73%	23%	3%	1%	278
PA	73%	23%	4%	1%	649
LA	71%	23%	5%	2%	466
OH	70%	26%	3%	1%	345
<b>NCI Average</b>	<b>70%</b>	<b>25%</b>	<b>4%</b>	<b>1%</b>	<b>4,544</b>
NC	70%	25%	3%	1%	213
MD	65%	25%	6%	3%	421
OK	65%	27%	5%	3%	389
MN	65%	27%	7%	2%	562
MO	64%	28%	5%	3%	290

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	54%	38%	5%	4%	299



**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.)?**

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	39%	34%	15%	12%	147
OK	35%	36%	17%	12%	346
OH	34%	42%	14%	10%	336
LA	33%	33%	16%	18%	406
PA	33%	37%	15%	15%	592
NC	33%	35%	18%	15%	185
<b>NCI Average</b>	<b>32%</b>	<b>37%</b>	<b>17%</b>	<b>14%</b>	<b>4,120</b>
UT	31%	43%	18%	8%	414
AZ	28%	35%	18%	19%	253
MO	28%	37%	14%	21%	257

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	23%	38%	18%	21%	381
MN	23%	38%	25%	15%	513
GA	17%	34%	21%	27%	290



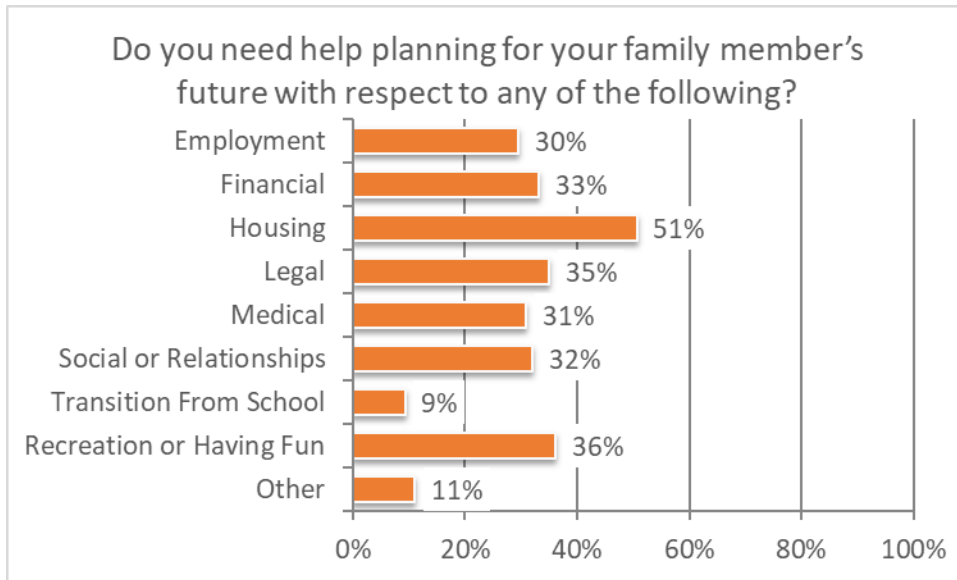


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

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	32%	36%	58%	38%	32%	36%	12%	39%	12%
GA	24%	28%	41%	31%	27%	23%	5%	31%	7%
LA	25%	30%	43%	31%	27%	26%	6%	31%	8%
MD	40%	39%	62%	40%	40%	40%	15%	43%	16%
MN	38%	38%	62%	40%	35%	37%	15%	43%	15%
MO	26%	31%	43%	33%	29%	28%	10%	34%	8%
NC	30%	35%	53%	38%	31%	34%	11%	37%	12%
OH	29%	34%	51%	37%	30%	31%	10%	35%	11%
OK	23%	26%	34%	28%	26%	23%	2%	31%	5%
PA	26%	31%	44%	34%	29%	30%	10%	34%	9%
UT	28%	33%	50%	35%	30%	31%	10%	35%	9%
VA	32%	36%	58%	39%	33%	36%	13%	40%	13%
<b>NCI Average</b>	<b>30%</b>	<b>33%</b>	<b>51%</b>	<b>35%</b>	<b>31%</b>	<b>32%</b>	<b>9%</b>	<b>36%</b>	<b>11%</b>

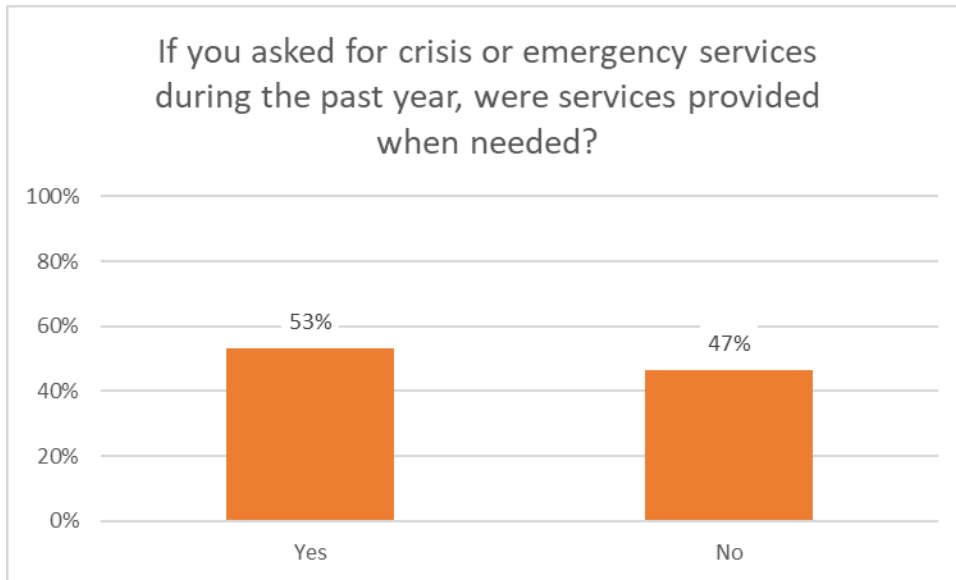


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

#### Within Average Range

State	Yes	No	N
LA	63%	37%	123
NC	62%	38%	55
AZ	60%	40%	89
MO	59%	41%	46
VA	56%	44%	32
OH	55%	45%	66
UT	54%	46%	82
<b>NCI Average</b>	<b>53%</b>	<b>47%</b>	<b>1,018</b>
PA	50%	50%	181
MN	47%	53%	107
OK	46%	54%	72
GA	45%	55%	88

#### Significantly Below Average

State	Yes	No	N
MD	34%	66%	77

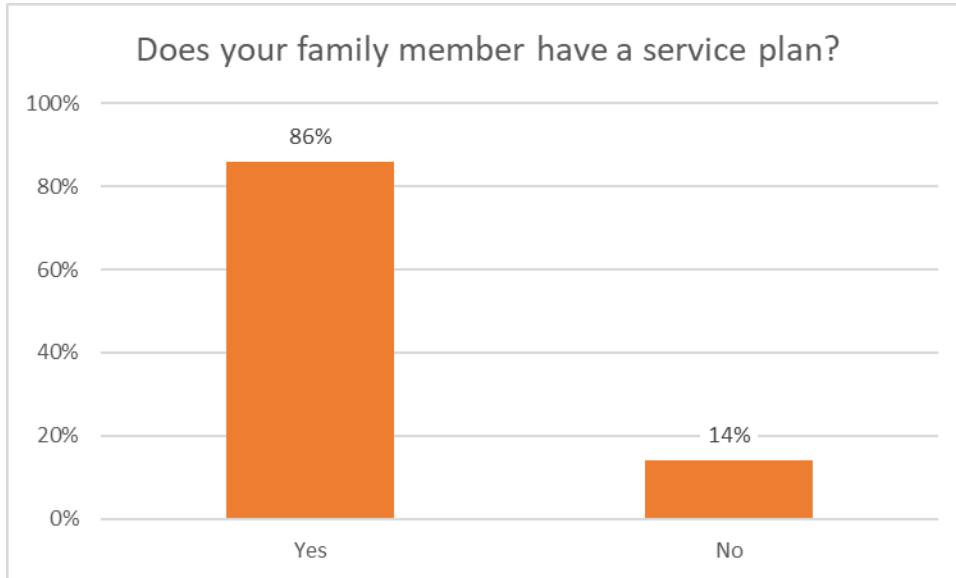


Table Q7. Does your family member have a service plan?

**Significantly Above Average**

State	Yes	No	N
PA	96%	4%	626
OK	95%	5%	375

**Within Average Range**

State	Yes	No	N
NC	87%	13%	197
<b>NCI Average</b>	<b>86%</b>	<b>14%</b>	<b>4,052</b>
MN	85%	15%	492
UT	85%	15%	369
MD	84%	16%	388
AZ	84%	16%	254
MO	84%	16%	256
VA	83%	17%	140

**Significantly Below Average**

State	Yes	No	N
OH	79%	21%	323
LA	78%	22%	373
GA	53%	47%	259

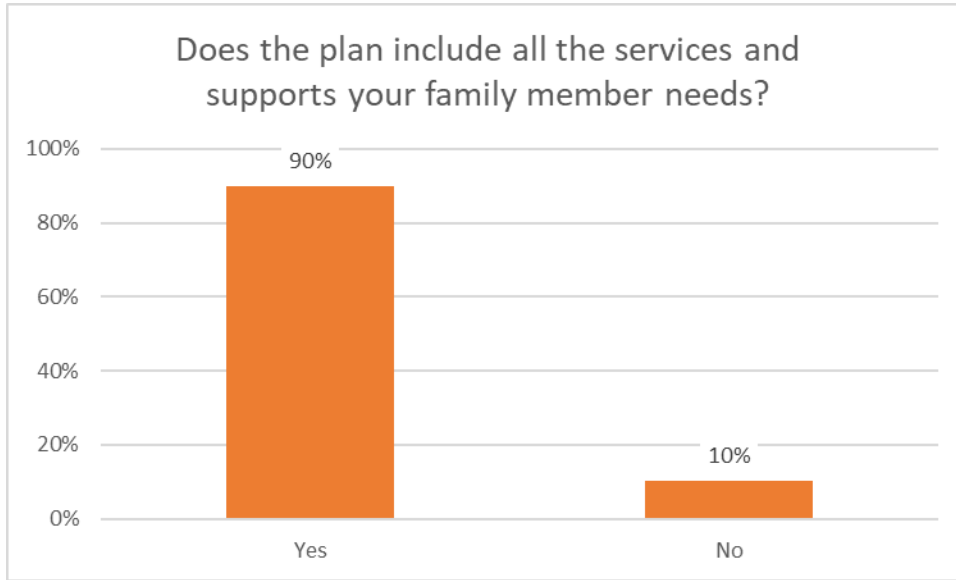


Table Q8. Does the plan include all the services and supports your family member needs?

#### Within Average Range

State	Yes	No	N
OH	93%	7%	228
AZ	93%	7%	198
UT	93%	7%	261
LA	92%	8%	259
PA	92%	8%	540
<b>NCI Average</b>	<b>90%</b>	<b>10%</b>	<b>3,012</b>
NC	88%	12%	157
OK	88%	12%	312
MN	87%	13%	376
MO	85%	15%	188
VA	84%	16%	103
GA	84%	16%	109

#### Significantly Below Average

State	Yes	No	N
MD	84%	16%	281

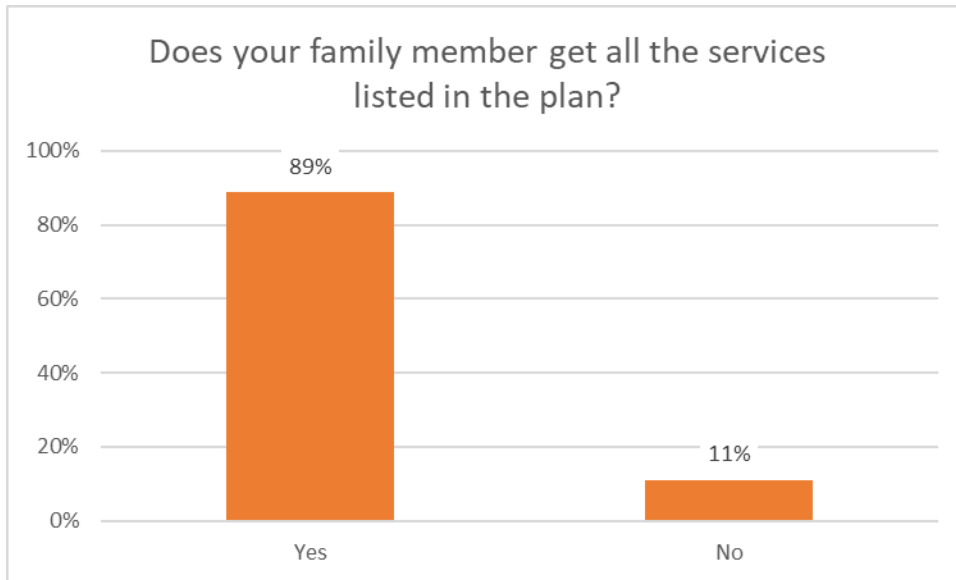


Table Q9. Does your family member get all the services listed in the plan?

**Significantly Above Average**

State	Yes	No	N
UT	94%	6%	258

**Within Average Range**

State	Yes	No	N
OH	92%	8%	226
PA	91%	9%	530
OK	90%	10%	318
NC	90%	10%	158
MN	89%	11%	372
<b>NCI Average</b>	<b>89%</b>	<b>11%</b>	<b>2,995</b>
LA	88%	12%	242
GA	88%	13%	112
MO	86%	15%	200
AZ	85%	15%	192
VA	83%	17%	99

**Significantly Below Average**

State	Yes	No	N
MD	81%	19%	288

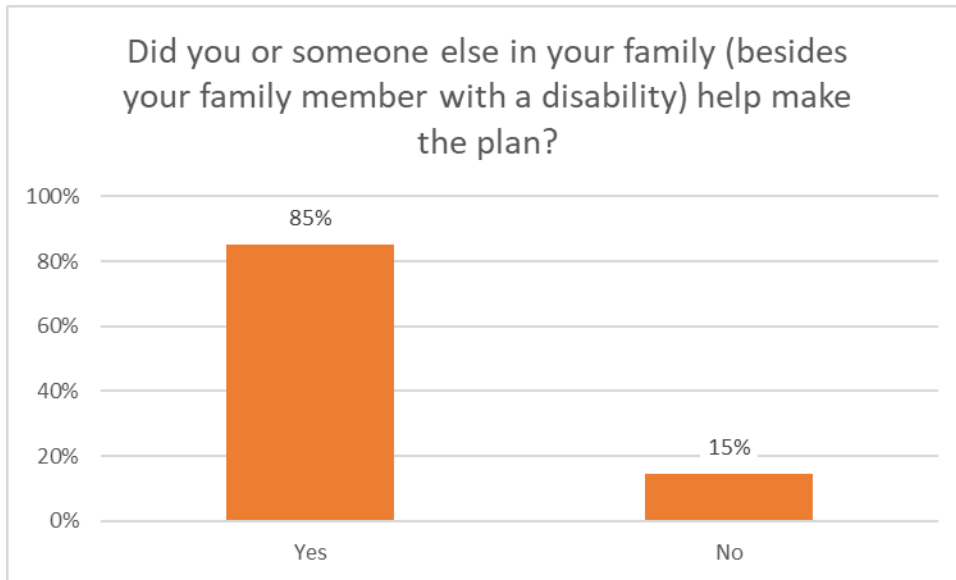


Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the plan?

**Within Average Range**

State	Yes	No	N
NC	90%	10%	165
UT	89%	11%	284
OK	89%	11%	340
MN	88%	12%	398
VA	87%	13%	110
MO	87%	13%	208
OH	87%	13%	245
<b>NCI Average</b>	<b>85%</b>	<b>15%</b>	<b>3,231</b>
MD	84%	16%	313
PA	83%	17%	573
GA	81%	19%	123
LA	81%	19%	269
AZ	80%	20%	203

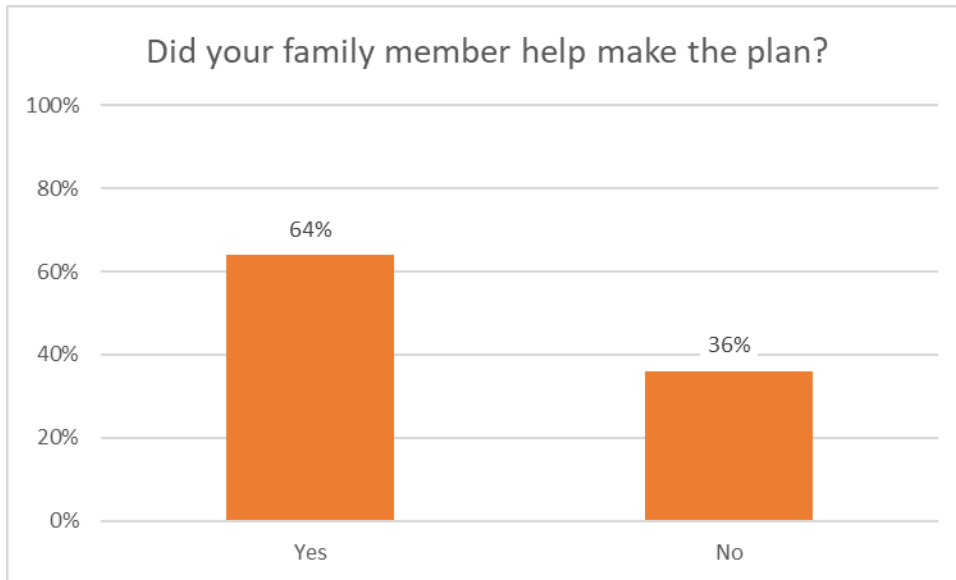


Table Q11. Did your family member help make the service plan?

**Significantly Above Average**

State	Yes	No	N
MD	75%	25%	306
OH	73%	27%	243

**Within Average Range**

State	Yes	No	N
MN	67%	33%	395
<b>NCI Average</b>	<b>64%</b>	<b>36%</b>	<b>3,207</b>
PA	64%	36%	568
OK	64%	36%	338
MO	63%	37%	205
UT	63%	37%	284
VA	61%	39%	110
GA	58%	42%	123
AZ	57%	43%	201
NC	55%	45%	166

**Significantly Below Average**

State	Yes	No	N
LA	54%	46%	268

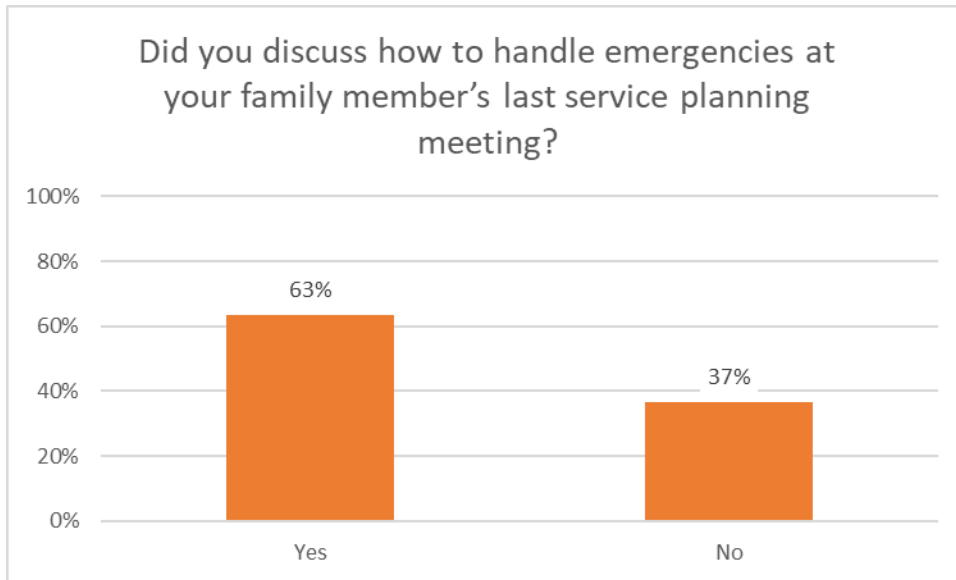


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or natural disaster) at your family member's last service planning meeting?

#### Significantly Above Average

State	Yes	No	N
LA	93%	7%	278
OK	78%	22%	316
NC	75%	25%	163

#### Within Average Range

State	Yes	No	N
MD	65%	35%	289
<b>NCI Average</b>	<b>63%</b>	<b>37%</b>	<b>3,004</b>
OH	62%	38%	226
PA	61%	39%	510
GA	61%	39%	112
MO	60%	40%	193
MN	59%	41%	373
VA	54%	46%	99

#### Significantly Below Average

State	Yes	No	N
AZ	53%	47%	195
UT	50%	50%	250



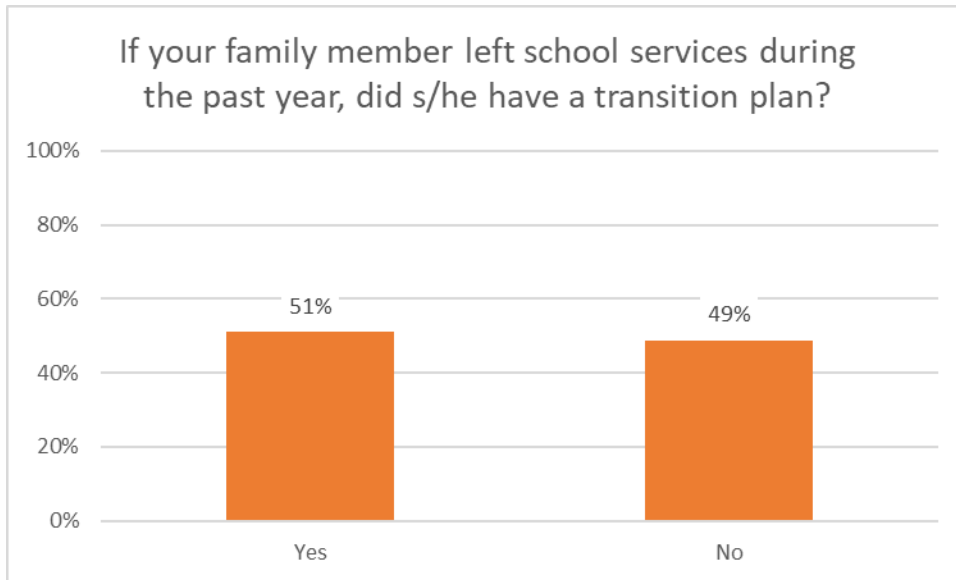


Table Q13. If your family member left school services during the past year, did s/he have a transition plan?<sup>7</sup>

#### Within Average Range

State	Yes	No	N
GA	69%	31%	26
UT	67%	33%	42
MN	59%	41%	87
NC	56%	44%	25
OH	56%	44%	36
PA	54%	46%	37
MD	53%	47%	30
<b>NCI Average</b>	<b>51%</b>	<b>49%</b>	<b>423</b>
AZ	48%	52%	44
OK	45%	55%	22
LA	42%	58%	45

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

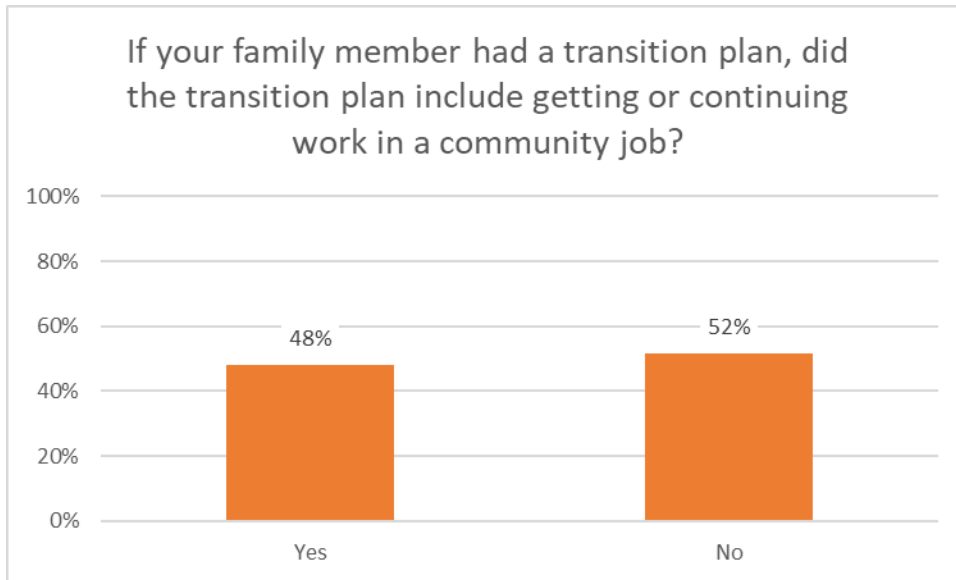


Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?<sup>8</sup>

#### Significantly Above Average

State	Yes	No	N
UT	77%	23%	26

#### Within Average Range

State	Yes	No	N
MN	64%	36%	47
AZ	55%	45%	20
OH	50%	50%	20
PA	50%	50%	20
<b>NCI Average</b>	<b>48%</b>	<b>52%</b>	<b>212</b>

<sup>8</sup> The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: GA, LA, MD, MO, NC, OK, VA

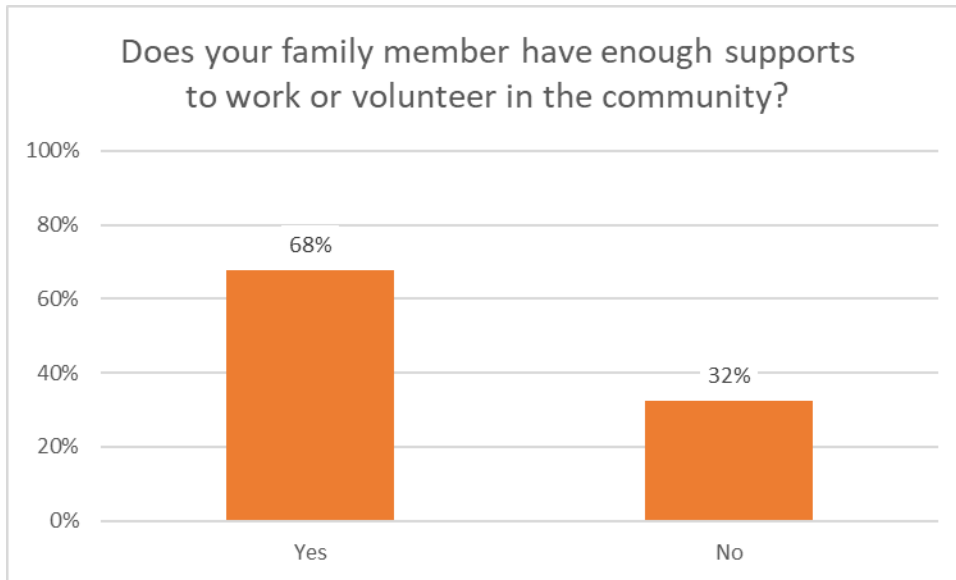


Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

#### Significantly Above Average

State	Yes	No	N
OH	76%	24%	276

#### Within Average Range

State	Yes	No	N
NC	73%	27%	153
UT	71%	29%	301
PA	70%	30%	461
<b>NCI Average</b>	<b>68%</b>	<b>32%</b>	<b>3,245</b>
MN	66%	34%	437
VA	63%	37%	114
OK	63%	37%	277
AZ	62%	38%	184
MO	60%	40%	210
LA	60%	40%	283

#### Significantly Below Average

State	Yes	No	N
MD	60%	40%	321
GA	54%	46%	228

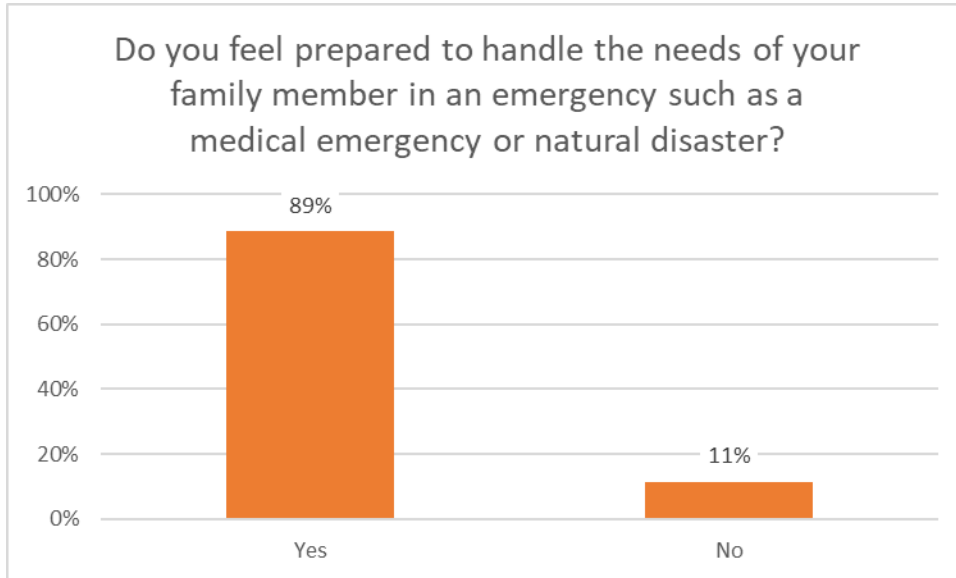


Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?

#### Significantly Above Average

State	Yes	No	N
LA	95%	5%	463
OH	93%	7%	358
OK	93%	7%	371

#### Within Average Range

State	Yes	No	N
<b>NCI Average</b>	<b>89%</b>	<b>11%</b>	<b>4,363</b>
PA	88%	12%	602
AZ	88%	12%	264
MO	87%	13%	267
MD	87%	13%	409
NC	87%	13%	209
MN	86%	14%	533
GA	85%	15%	326
VA	83%	17%	145

#### Significantly Below Average

State	Yes	No	N
UT	79%	21%	416

## *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.

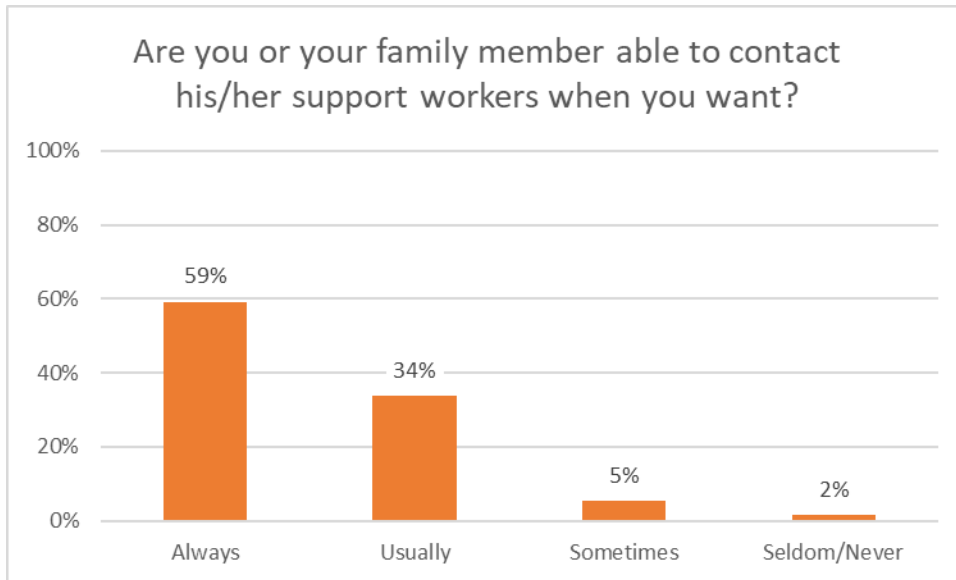


Table Q17. Are you or your family member able to contact his/her support workers when you want?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
PA	66%	28%	4%	2%	636
LA	65%	30%	3%	2%	460

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
UT	64%	33%	3%	0%	453
OH	62%	32%	5%	1%	331
NC	61%	34%	4%	0%	210
VA	60%	35%	6%	0%	159
<b>NCI Average</b>	<b>59%</b>	<b>34%</b>	<b>5%</b>	<b>2%</b>	<b>4,380</b>
AZ	57%	33%	8%	3%	276
OK	53%	40%	6%	1%	360

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MN	51%	40%	7%	3%	545
MD	49%	41%	7%	2%	408
GA	47%	43%	7%	3%	281
MO	47%	43%	7%	3%	261

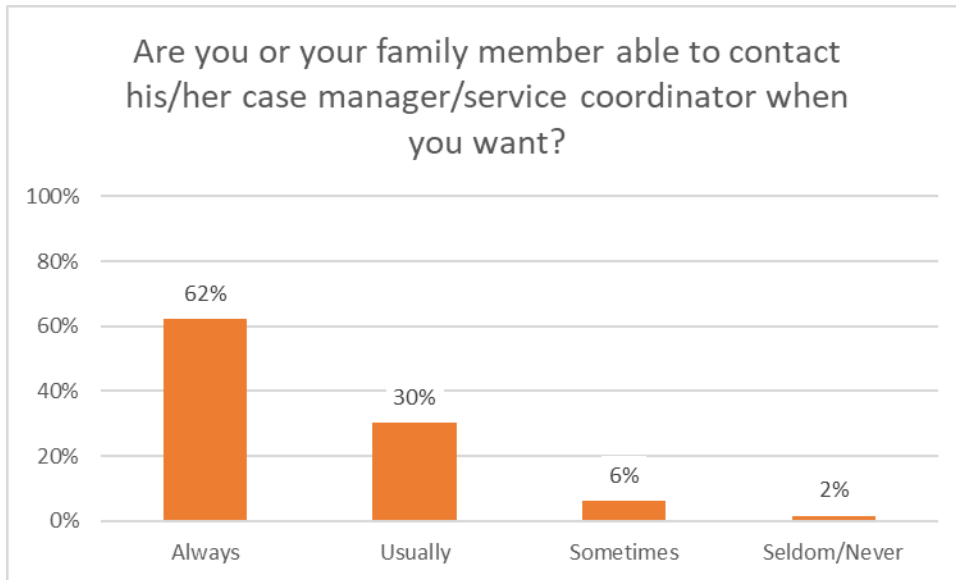


Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	69%	26%	5%	0%	466

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	66%	27%	5%	2%	646
LA	66%	30%	3%	2%	471
OH	65%	29%	5%	1%	347
NC	65%	30%	5%	0%	213
VA	64%	27%	9%	1%	168
AZ	64%	28%	6%	2%	280
<b>NCI Average</b>	<b>62%</b>	<b>30%</b>	<b>6%</b>	<b>2%</b>	<b>4,562</b>
OK	56%	36%	6%	2%	390

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	54%	35%	9%	2%	563
MD	54%	35%	8%	4%	431
MO	48%	42%	6%	5%	290
GA	47%	40%	8%	5%	297

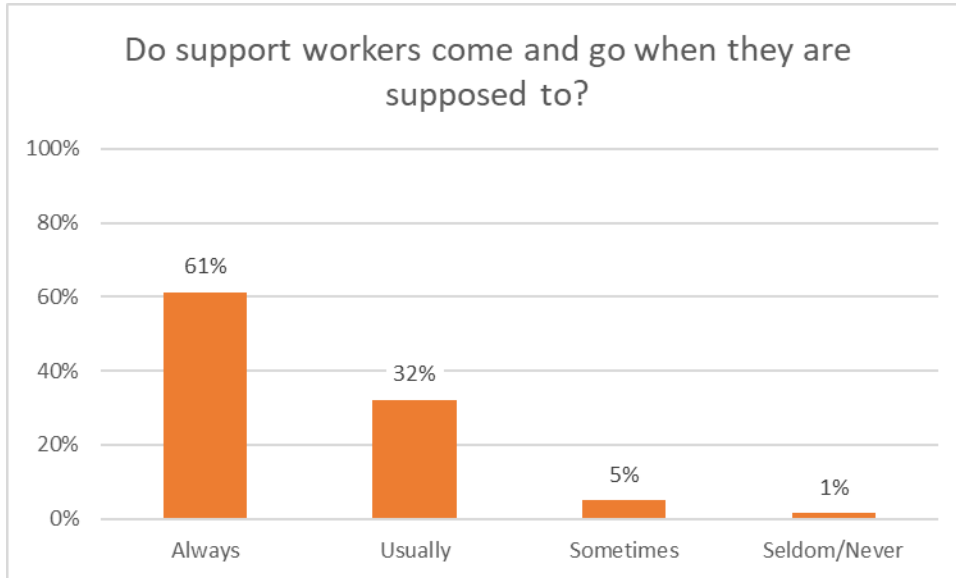


Table Q19. Do support workers come and go when they are supposed to?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
PA	67%	28%	4%	1%	599

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	66%	28%	4%	2%	442
AZ	66%	26%	6%	2%	263
VA	62%	33%	4%	1%	144
<b>NCI Average</b>	<b>61%</b>	<b>32%</b>	<b>5%</b>	<b>1%</b>	<b>3,888</b>
OH	60%	35%	4%	1%	248
MN	59%	36%	4%	2%	492
OK	58%	36%	4%	2%	302
NC	57%	36%	5%	1%	202
UT	55%	40%	4%	1%	427

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MD	52%	36%	11%	1%	340
MO	51%	37%	9%	4%	215
GA	45%	43%	7%	4%	214



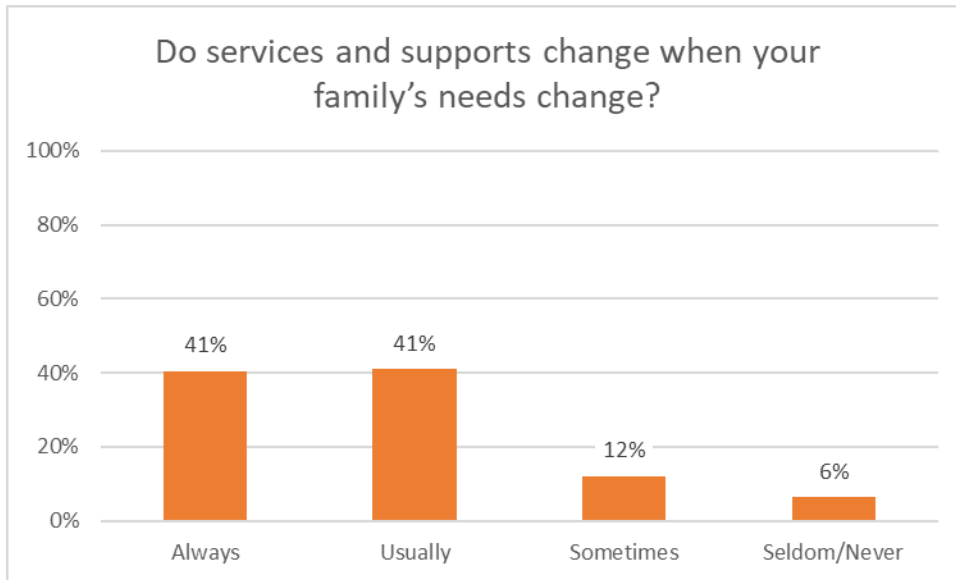


Table Q20. Do services and supports change when your family's needs change?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	47%	39%	9%	5%	366
AZ	45%	38%	12%	5%	232
OH	43%	43%	10%	4%	236
PA	43%	41%	12%	4%	515
VA	42%	33%	13%	12%	123
NC	42%	40%	11%	7%	187
<b>NCI Average</b>	<b>41%</b>	<b>41%</b>	<b>12%</b>	<b>6%</b>	<b>3,440</b>
OK	40%	42%	11%	7%	272
UT	38%	47%	12%	3%	370

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	32%	42%	16%	11%	300
MN	29%	47%	17%	7%	433
MO	27%	50%	14%	8%	214
GA	25%	47%	15%	13%	192

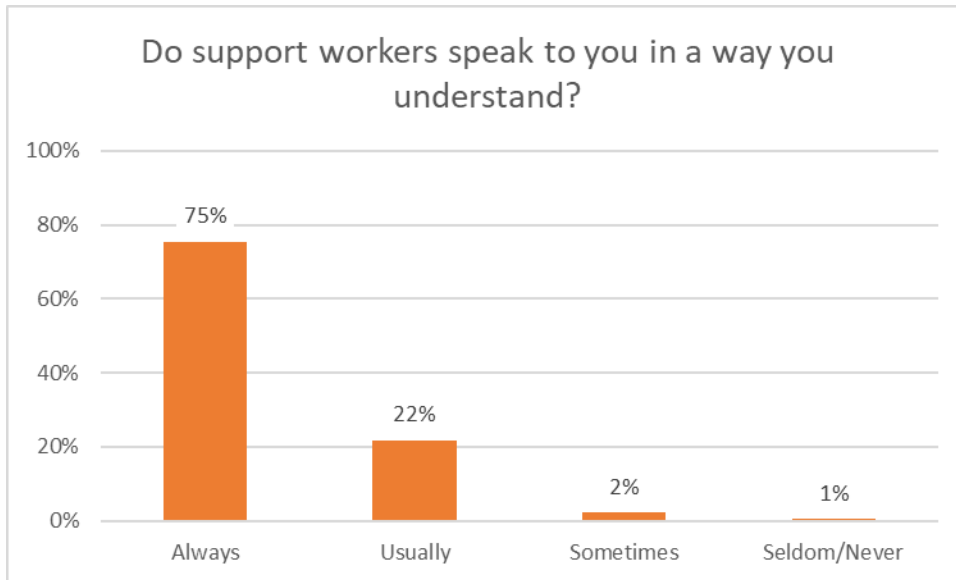


Table Q21. Do support workers speak to you in a way you understand?

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
NC	81%	17%	1%	0%	206
LA	80%	17%	3%	0%	457
VA	80%	19%	1%	0%	152
UT	77%	20%	2%	0%	442
AZ	77%	20%	3%	0%	276
PA	77%	21%	2%	0%	615
<b>NCI Average</b>	<b>75%</b>	<b>22%</b>	<b>2%</b>	<b>1%</b>	<b>4,174</b>
OK	75%	22%	1%	2%	329
OH	73%	25%	2%	0%	297
MN	71%	25%	3%	1%	521
MO	70%	25%	3%	1%	240

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MD	67%	28%	4%	1%	382
GA	63%	32%	4%	1%	257

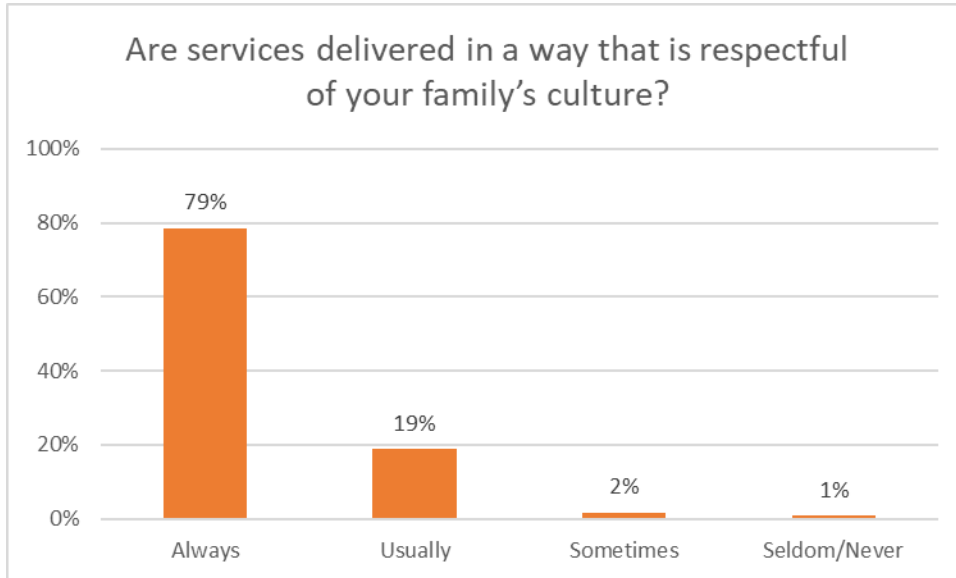


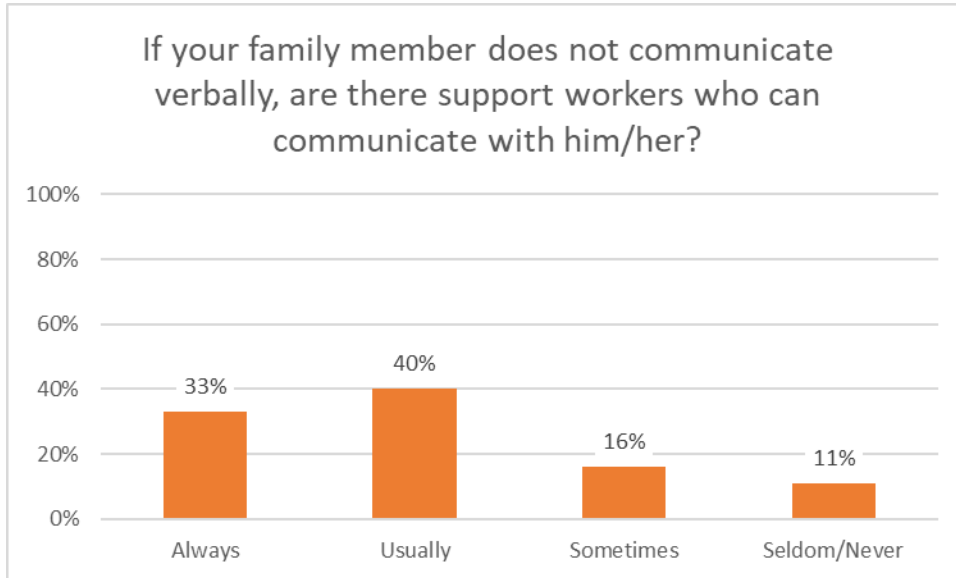
Table Q22. Are services delivered in a way that is respectful of your family's culture?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	83%	15%	2%	1%	281
UT	82%	18%	1%	0%	457
NC	81%	17%	1%	1%	210
VA	81%	18%	1%	0%	158
PA	81%	17%	2%	1%	635
LA	80%	17%	3%	1%	466
<b>NCI Average</b>	<b>79%</b>	<b>19%</b>	<b>2%</b>	<b>1%</b>	<b>4,441</b>
OK	78%	20%	1%	1%	363
MN	78%	19%	3%	1%	555
OH	77%	21%	2%	0%	341

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	71%	24%	2%	3%	278
MD	68%	26%	4%	2%	417
GA	63%	31%	2%	4%	280



**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 him/her?**

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	46%	40%	4%	10%	70
LA	37%	44%	10%	8%	108
GA	37%	38%	14%	11%	114
OH	36%	48%	9%	8%	105
MN	35%	40%	17%	9%	139
AZ	34%	28%	25%	13%	53
<b>NCI Average</b>	<b>33%</b>	<b>40%</b>	<b>16%</b>	<b>11%</b>	<b>1,149</b>
OK	33%	38%	16%	13%	98
UT	31%	45%	16%	9%	121
MO	30%	45%	15%	9%	66
PA	30%	39%	21%	10%	134
MD	24%	47%	15%	15%	88
VA	23%	34%	28%	15%	53

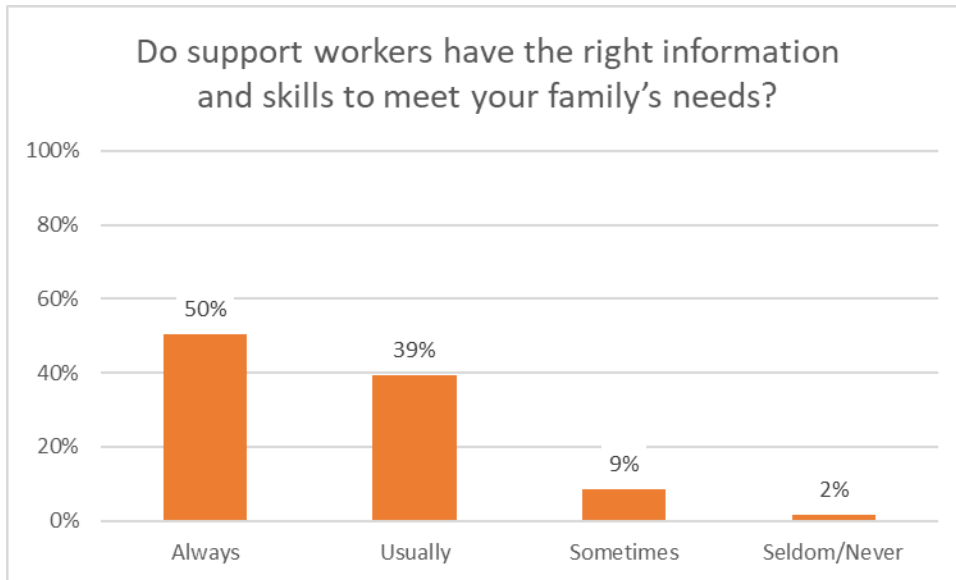


Table Q24. Do support workers have the right information and skills to meet your family's needs?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	61%	32%	6%	2%	445

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OK	55%	40%	4%	1%	319
NC	54%	36%	8%	2%	205
OH	52%	41%	6%	1%	281
UT	51%	45%	3%	0%	441
PA	51%	38%	9%	2%	594
AZ	50%	40%	8%	2%	266
<b>NCI Average</b>	<b>50%</b>	<b>39%</b>	<b>9%</b>	<b>2%</b>	<b>4,042</b>
VA	49%	37%	14%	0%	152
MN	46%	42%	10%	2%	511
MO	42%	43%	13%	2%	230

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	42%	42%	11%	5%	246
MD	36%	48%	13%	3%	352

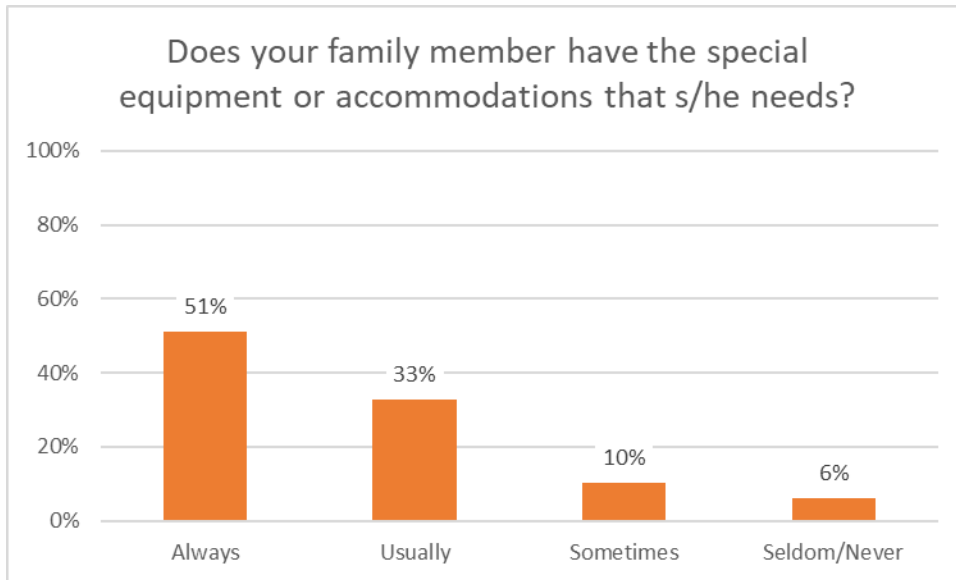


Table Q25. Does your family member have the special equipment or accommodations that s/he needs?

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	60%	28%	6%	6%	146
OH	55%	34%	8%	4%	131
NC	54%	31%	10%	6%	123
LA	53%	29%	11%	7%	249
MN	51%	34%	11%	3%	270
<b>NCI Average</b>	<b>51%</b>	<b>33%</b>	<b>10%</b>	<b>6%</b>	<b>2,176</b>
MO	50%	34%	11%	5%	140
OK	49%	35%	10%	6%	220
VA	49%	32%	10%	8%	96
PA	47%	33%	13%	7%	238
GA	45%	36%	11%	8%	142
UT	45%	38%	10%	7%	248
MD	42%	39%	13%	6%	173

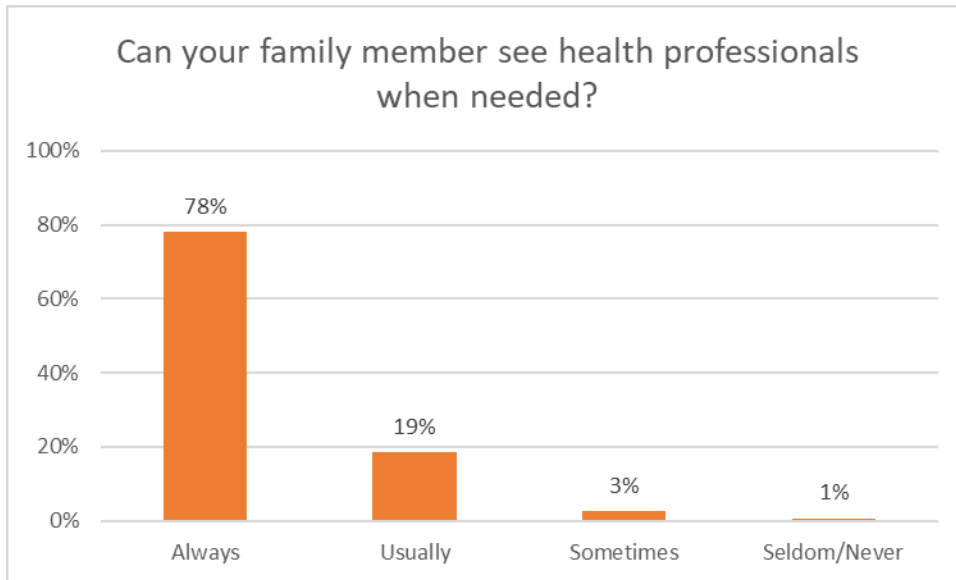


Table Q26. Can your family member see health professionals when needed?

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OH	83%	16%	1%	1%	383
PA	81%	17%	2%	0%	672
MD	80%	18%	2%	0%	445
OK	79%	18%	3%	1%	393
<b>NCI Average</b>	<b>78%</b>	<b>19%</b>	<b>3%</b>	<b>1%</b>	<b>4,755</b>
NC	78%	18%	4%	0%	222
AZ	77%	20%	3%	0%	284
GA	75%	21%	3%	0%	352
LA	75%	21%	4%	1%	484
MN	74%	21%	4%	1%	575
VA	74%	20%	3%	3%	170
MO	71%	24%	3%	2%	298

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
UT	70%	26%	3%	0%	477

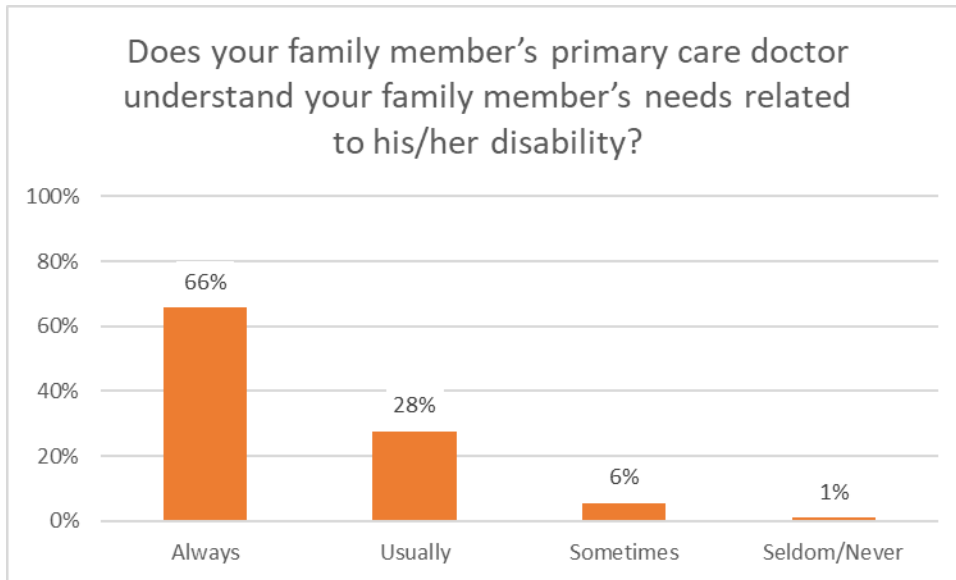


Table Q27. Does your family member's primary care doctor understand your family member's needs related to his/her disability?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	75%	21%	3%	0%	483

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	68%	26%	4%	1%	660
OH	68%	26%	5%	1%	377
NC	68%	25%	6%	0%	217
VA	67%	23%	8%	2%	169
OK	67%	28%	5%	0%	387
<b>NCI Average</b>	<b>66%</b>	<b>28%</b>	<b>6%</b>	<b>1%</b>	<b>4,676</b>
GA	64%	29%	5%	1%	352
AZ	64%	29%	5%	1%	281
MD	63%	32%	5%	0%	439

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	53%	38%	7%	2%	463
MN	53%	38%	9%	1%	559
MO	50%	41%	7%	1%	289



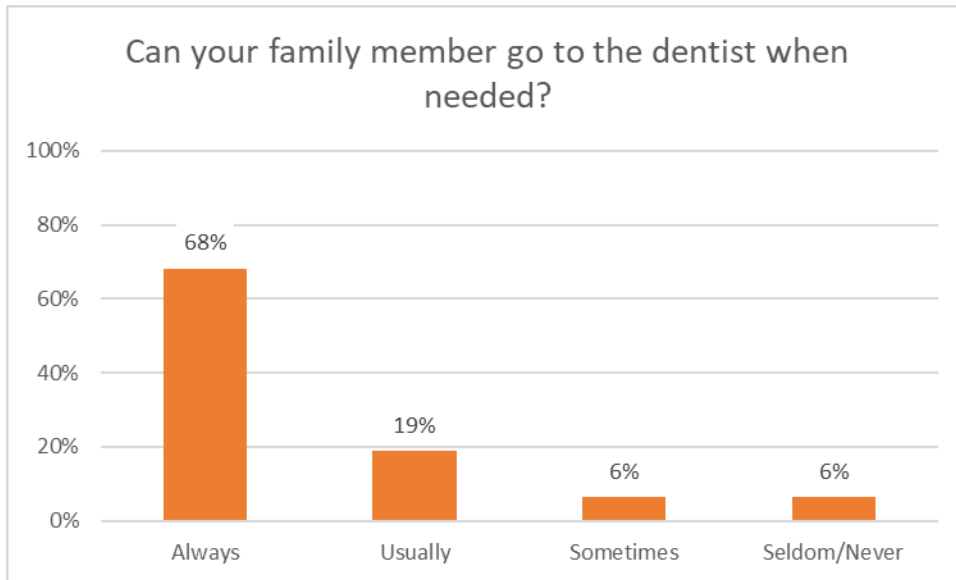


Table Q28. Can your family member go to the dentist when needed?

Question is rephrased from previous years

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	75%	16%	5%	4%	654
MD	74%	15%	4%	7%	438

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OH	72%	17%	7%	4%	380
NC	71%	17%	5%	7%	219
<b>NCI Average</b>	<b>68%</b>	<b>19%</b>	<b>6%</b>	<b>6%</b>	<b>4,699</b>
UT	66%	24%	7%	3%	471
OK	65%	22%	7%	6%	388
AZ	65%	19%	8%	7%	281
MO	63%	21%	7%	8%	297
VA	61%	22%	5%	12%	164

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	61%	25%	10%	5%	578
GA	61%	20%	10%	10%	355
LA	60%	20%	9%	11%	474

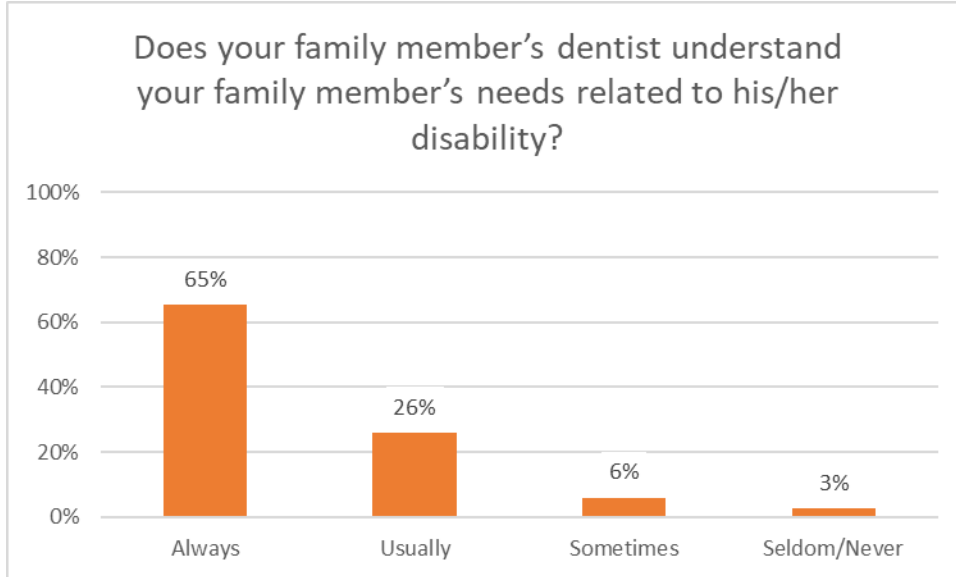


Table Q29. Does your family member's dentist understand your family member's needs related to his/her disability?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	72%	21%	4%	3%	203
MD	69%	22%	5%	3%	406
VA	69%	25%	3%	3%	146
PA	68%	24%	6%	2%	605
AZ	67%	23%	6%	3%	252
LA	66%	25%	6%	4%	406
<b>NCI Average</b>	<b>65%</b>	<b>26%</b>	<b>6%</b>	<b>3%</b>	<b>4,245</b>
OH	64%	28%	6%	3%	356
OK	63%	27%	8%	2%	350
UT	59%	31%	8%	2%	446
GA	59%	32%	5%	4%	305
MO	58%	33%	8%	2%	251

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	53%	33%	11%	3%	519

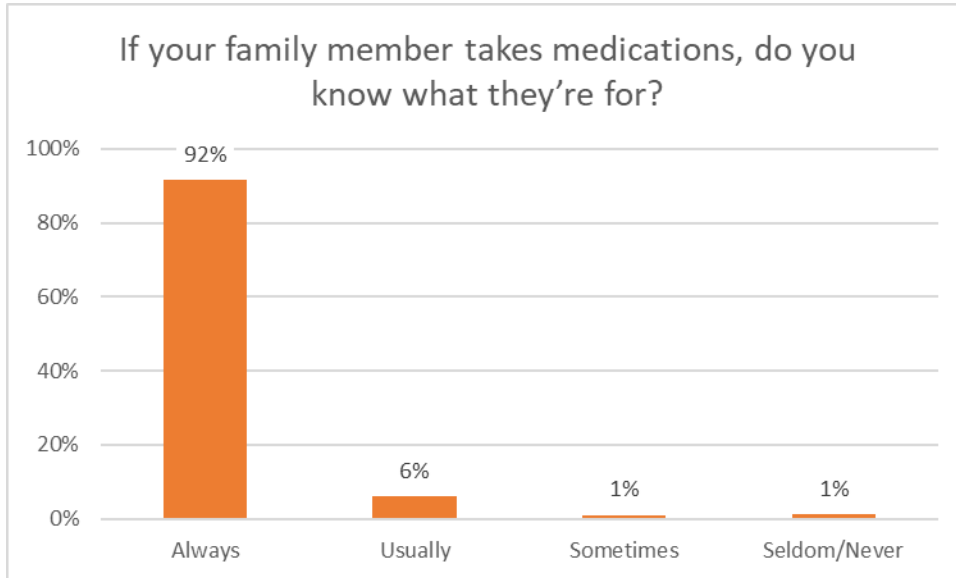


Table Q30. If your family member takes medications, do you know what they're for?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	95%	4%	0%	0%	243

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
NC	94%	4%	0%	2%	194
UT	94%	6%	0%	0%	406
MD	92%	5%	1%	2%	368
LA	92%	6%	2%	0%	448
MN	92%	6%	2%	1%	496
<b>NCI Average</b>	<b>92%</b>	<b>6%</b>	<b>1%</b>	<b>1%</b>	<b>4,159</b>
PA	91%	5%	2%	2%	575
OH	91%	7%	1%	1%	323
GA	91%	6%	2%	1%	323
VA	90%	7%	1%	1%	161
MO	90%	9%	1%	0%	268
OK	89%	9%	0%	2%	354

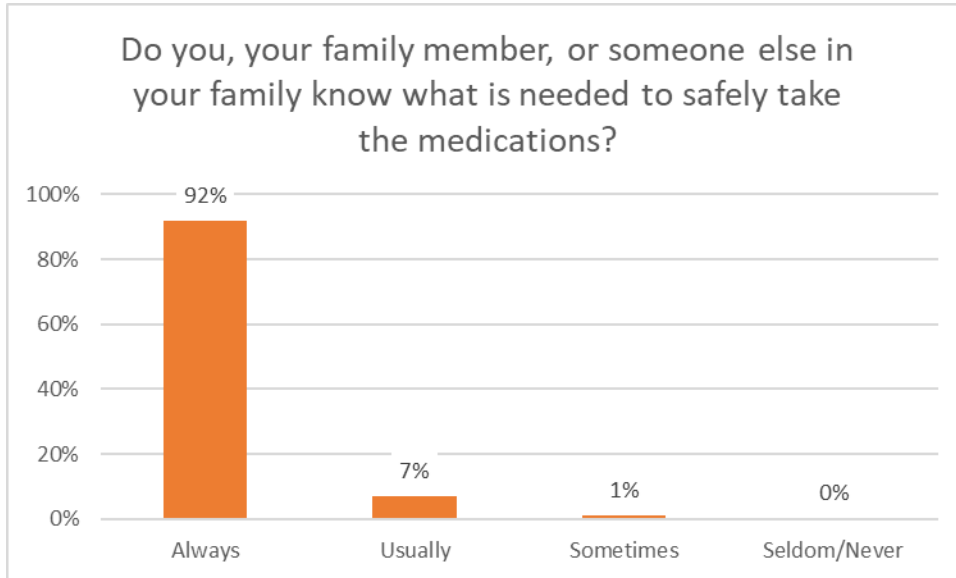
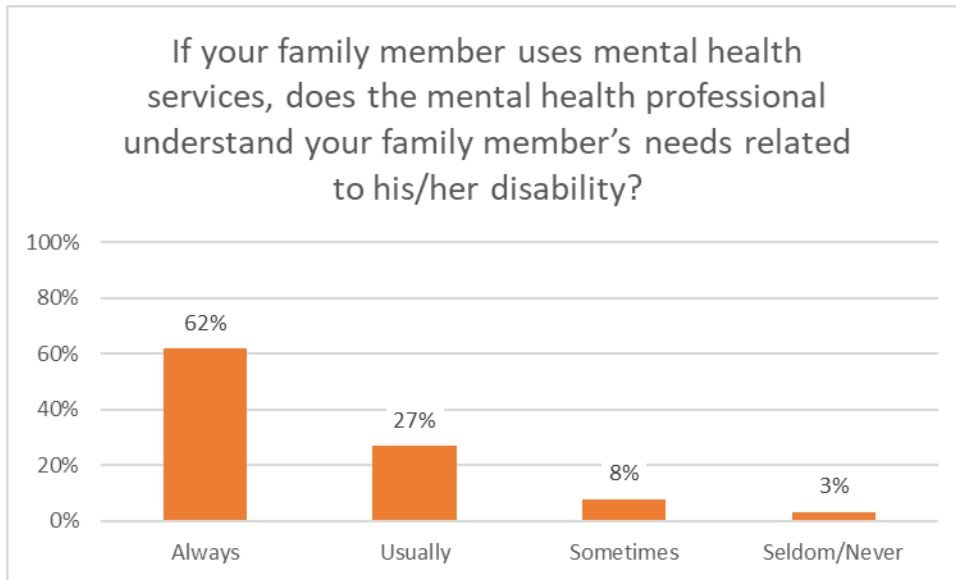


Table Q31. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OH	94%	5%	1%	0%	320
NC	94%	6%	0%	1%	189
VA	93%	5%	1%	1%	161
AZ	93%	6%	1%	0%	242
<b>NCI Average</b>	<b>92%</b>	<b>7%</b>	<b>1%</b>	<b>0%</b>	<b>4,128</b>
MN	92%	7%	1%	0%	494
LA	91%	8%	1%	0%	450
GA	91%	9%	0%	0%	315
OK	91%	8%	1%	1%	354
MD	91%	8%	1%	1%	358
PA	90%	8%	2%	0%	566
UT	88%	10%	1%	1%	413
MO	88%	9%	2%	1%	266



**Table Q32. 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
OH	71%	21%	4%	4%	114
VA	67%	25%	6%	2%	84
AZ	66%	21%	8%	5%	97
<b>NCI Average</b>	<b>62%</b>	<b>27%</b>	<b>8%</b>	<b>3%</b>	<b>1,642</b>
MD	61%	30%	6%	3%	145
LA	61%	29%	7%	4%	168
GA	61%	25%	5%	9%	129
PA	60%	27%	12%	1%	244
OK	58%	30%	8%	4%	100
MO	57%	31%	10%	2%	106
MN	54%	35%	6%	4%	235
NC	51%	36%	9%	3%	86

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	50%	34%	10%	7%	134

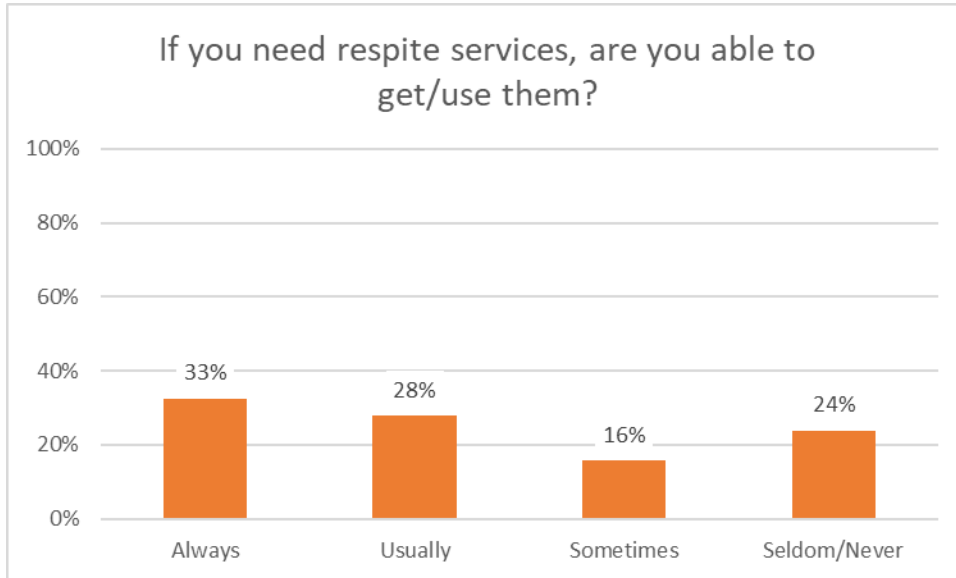


Table Q33. If you need respite services, are you able to get/use them?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	55%	27%	11%	7%	254

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
UT	38%	42%	14%	7%	356
NC	38%	38%	12%	12%	186
LA	36%	31%	12%	21%	233
<b>NCI Average</b>	<b>33%</b>	<b>28%</b>	<b>16%</b>	<b>24%</b>	<b>2,734</b>
OH	30%	27%	14%	29%	161
PA	30%	29%	19%	23%	347
MN	28%	26%	19%	26%	354
VA	24%	23%	20%	33%	126

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OK	22%	17%	15%	45%	163
MD	22%	25%	15%	38%	222
GA	18%	25%	18%	39%	153
MO	15%	31%	18%	36%	179

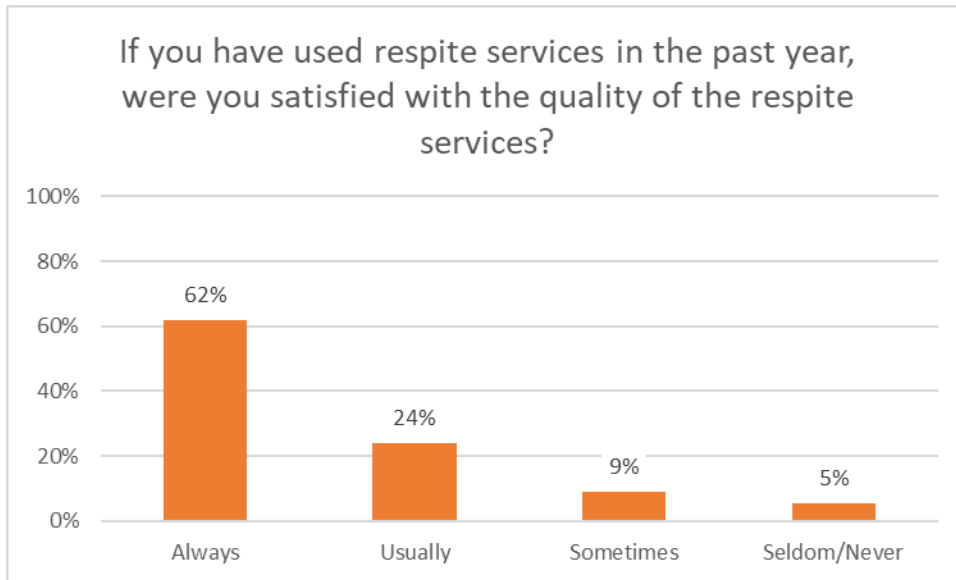


Table Q34. If you have used respite services in the past year, were you satisfied with the quality of the respite services?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	75%	14%	8%	3%	230

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	64%	25%	10%	1%	162
PA	64%	21%	8%	7%	219
<b>NCI Average</b>	<b>62%</b>	<b>24%</b>	<b>9%</b>	<b>5%</b>	<b>1,830</b>
UT	61%	32%	5%	2%	313
MN	61%	27%	7%	6%	241
GA	58%	24%	6%	12%	78
OK	57%	22%	10%	12%	60
MO	57%	34%	8%	2%	106
OH	55%	26%	12%	8%	86
LA	53%	29%	9%	9%	146
VA	51%	31%	11%	8%	75
MD	50%	34%	9%	7%	114

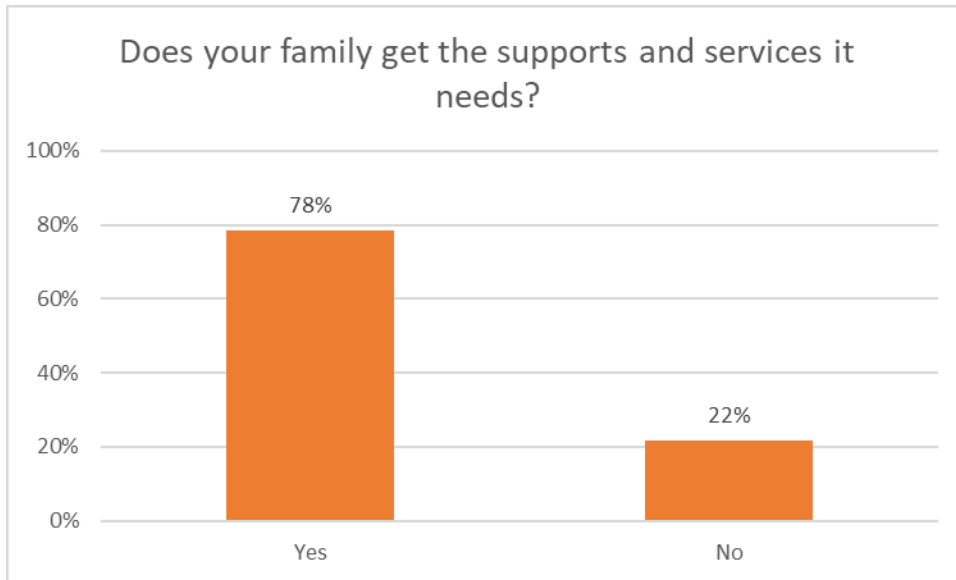


Table Q35. Does your family get the supports and services it needs?

**Significantly Above Average**

State	Yes	No	N
AZ	85%	15%	269

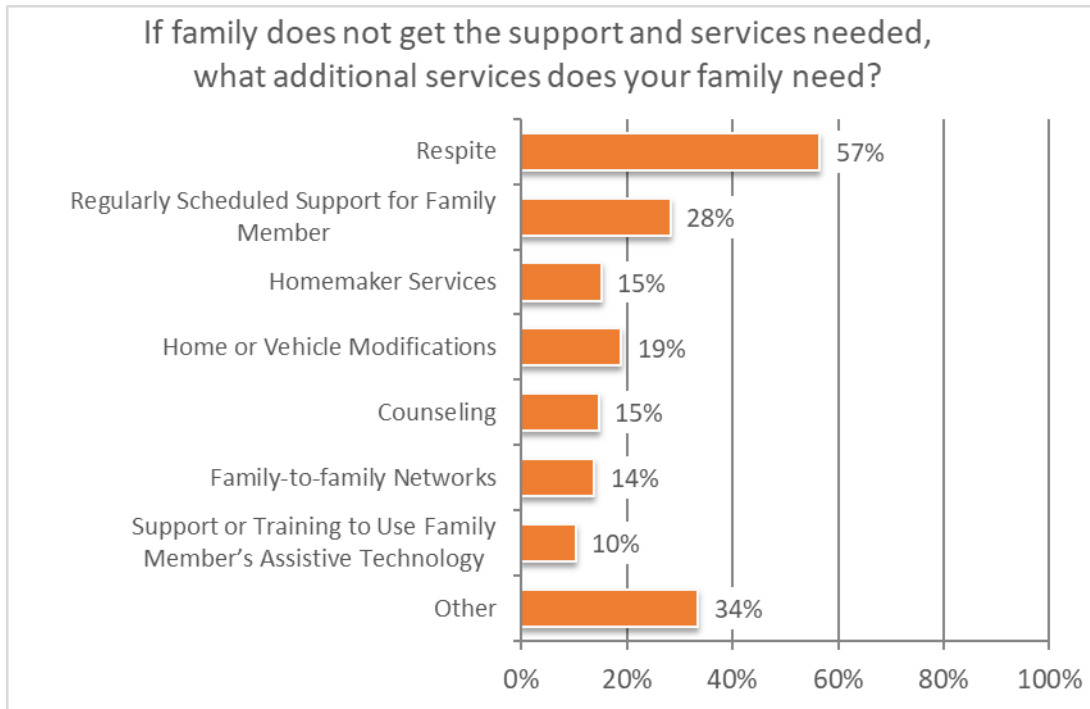
**Within Average Range**

State	Yes	No	N
LA	83%	17%	429
OH	83%	17%	324
PA	82%	18%	576
UT	82%	18%	429
<b>NCI Average</b>	<b>78%</b>	<b>22%</b>	<b>4,175</b>
NC	77%	23%	203
MN	76%	24%	516
OK	74%	26%	355
MO	71%	29%	254
VA	71%	29%	151

**Significantly Below Average**

State	Yes	No	N
MD	69%	31%	378
GA	62%	38%	291





**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	41%	21%	13%	15%	21%	15%	3%	41%
GA	64%	40%	20%	21%	15%	17%	14%	33%
LA	54%	37%	10%	22%	18%	9%	7%	28%
MD	61%	33%	16%	11%	17%	17%	6%	28%
MN	52%	31%	25%	8%	14%	15%	10%	44%
MO	70%	31%	18%	13%	24%	25%	7%	34%
NC	63%	33%	18%	20%	18%	13%	10%	25%
OH	37%	21%	8%	13%	17%	15%	13%	40%
OK	79%	26%	17%	22%	9%	9%	10%	28%
PA	58%	24%	15%	22%	9%	9%	8%	32%
UT	44%	18%	12%	18%	12%	7%	10%	38%
VA	61%	34%	15%	29%	15%	17%	17%	29%
<b>NCI Average</b>	<b>57%</b>	<b>28%</b>	<b>15%</b>	<b>19%</b>	<b>15%</b>	<b>14%</b>	<b>10%</b>	<b>34%</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.

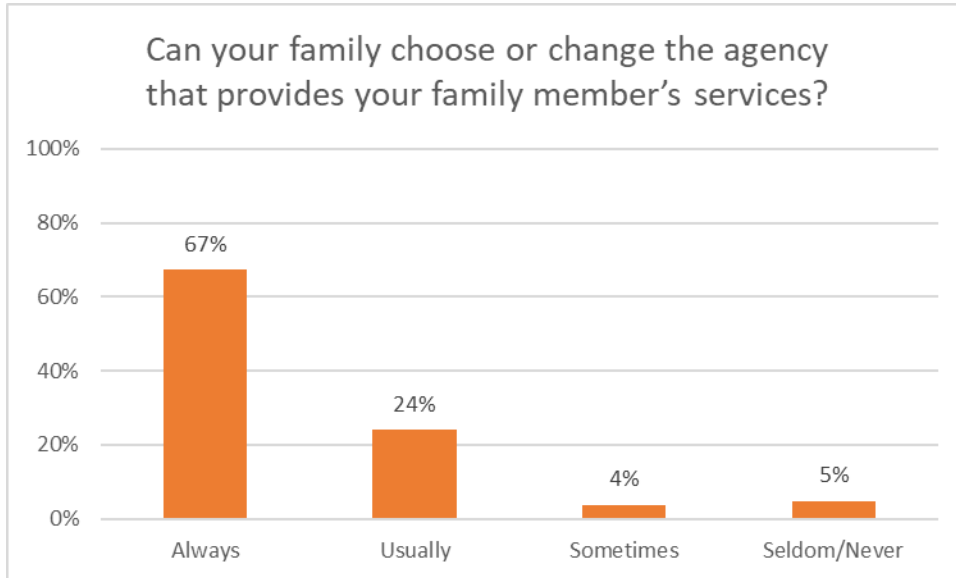


Table Q37. Can your family choose or change the agency that provides your family member's services?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	77%	19%	2%	2%	396
OK	76%	16%	4%	4%	273

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	73%	20%	3%	4%	189
UT	72%	20%	5%	3%	350
OH	71%	23%	3%	4%	228
<b>NCI Average</b>	<b>67%</b>	<b>24%</b>	<b>4%</b>	<b>5%</b>	<b>3,317</b>
AZ	65%	26%	3%	6%	230
VA	65%	25%	5%	5%	110
PA	64%	27%	4%	6%	448
MN	63%	28%	5%	4%	445
MD	61%	26%	6%	6%	295
GA	58%	33%	4%	5%	178
MO	58%	23%	9%	10%	175

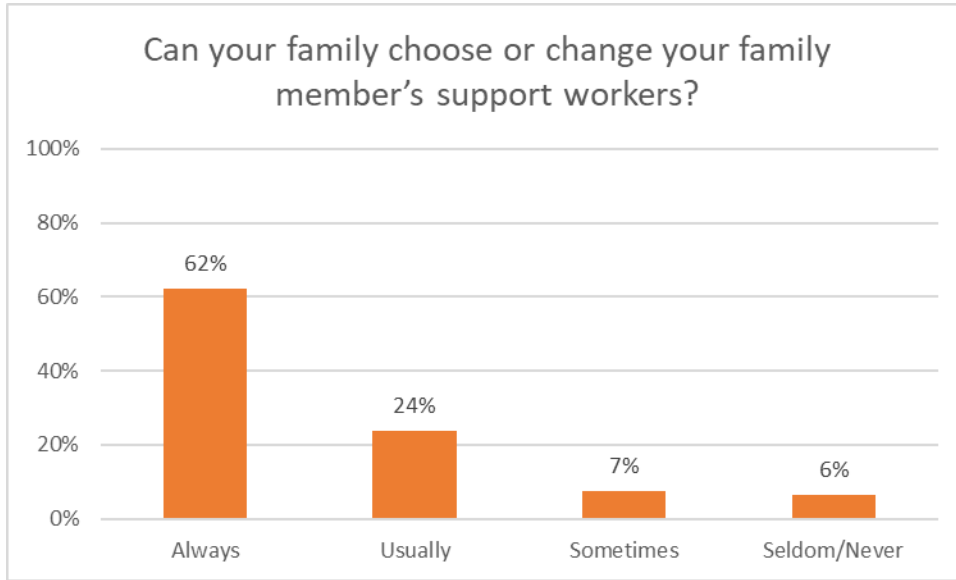


Table Q38. Can your family choose or change your family member's support workers?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	72%	22%	2%	4%	379
UT	71%	20%	5%	5%	387

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OK	67%	21%	8%	4%	272
NC	65%	18%	10%	6%	191
<b>NCI Average</b>	<b>62%</b>	<b>24%</b>	<b>7%</b>	<b>6%</b>	<b>3,269</b>
VA	62%	24%	7%	7%	113
AZ	62%	25%	6%	7%	223
PA	62%	24%	7%	7%	445
OH	61%	25%	7%	6%	197
MO	60%	21%	9%	10%	173
MN	58%	27%	9%	5%	439

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MD	52%	28%	11%	9%	274
GA	49%	32%	8%	11%	176

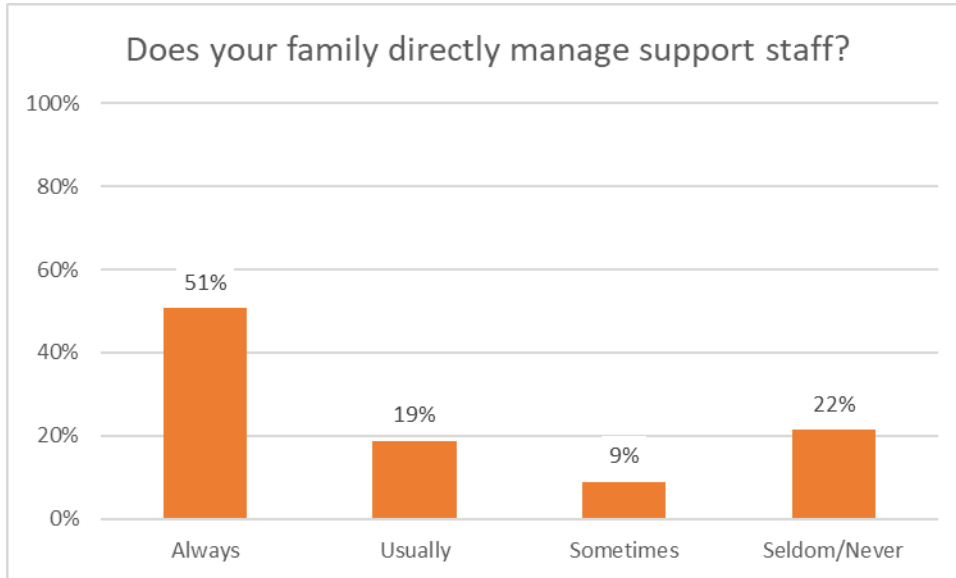


Table Q39. Does your family directly manage support staff?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
MN	66%	15%	7%	11%	465
UT	59%	15%	10%	16%	387

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OK	57%	20%	8%	15%	239
LA	55%	17%	8%	19%	349
VA	54%	17%	3%	25%	118
AZ	52%	22%	8%	18%	198
GA	51%	14%	6%	29%	175
NC	51%	22%	11%	16%	165
<b>NCI Average</b>	<b>51%</b>	<b>19%</b>	<b>9%</b>	<b>22%</b>	<b>3,129</b>
MO	50%	15%	9%	27%	179
OH	46%	16%	10%	28%	164

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
PA	43%	22%	12%	23%	419
MD	35%	20%	11%	35%	271

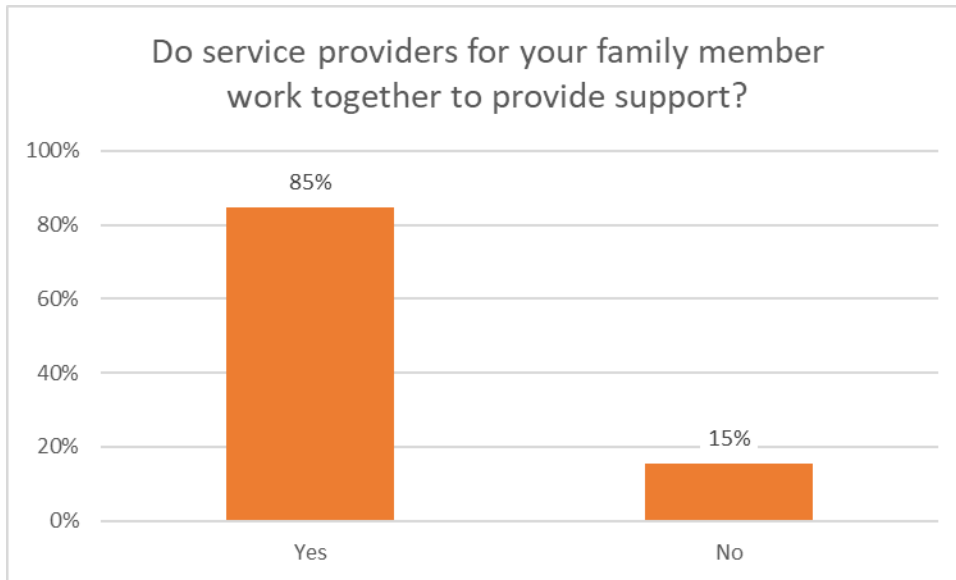


Table Q40. Do service providers for your family member work together to provide support?

#### Significantly Above Average

State	Yes	No	N
PA	90%	10%	346

#### Within Average Range

State	Yes	No	N
UT	89%	11%	288
NC	88%	13%	136
LA	86%	14%	238
OH	85%	15%	174
<b>NCI Average</b>	<b>85%</b>	<b>15%</b>	<b>2,485</b>
OK	84%	16%	167
AZ	84%	16%	173
MD	83%	17%	233
VA	80%	20%	103
MO	80%	20%	137
MN	79%	21%	343

#### Significantly Below Average

State	Yes	No	N
GA	73%	27%	147

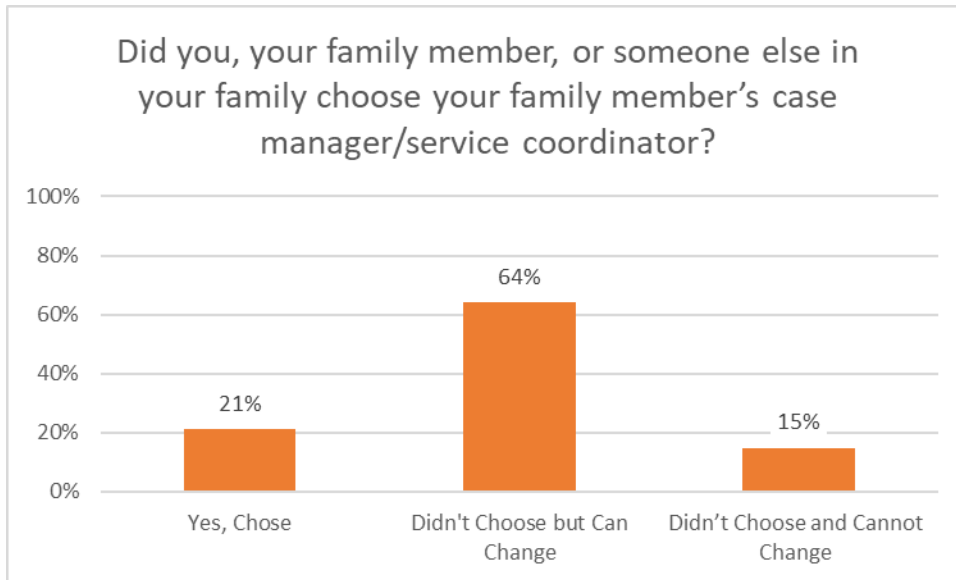


Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

#### Significantly Above Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
UT	69%	27%	3%	412
LA	46%	45%	9%	405

#### Within Average Range

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
NC	26%	57%	17%	195
MD	25%	58%	17%	366
PA	24%	66%	10%	556
VA	22%	65%	13%	138
<b>NCI Average</b>	<b>21%</b>	<b>64%</b>	<b>15%</b>	<b>3,845</b>
MN	19%	59%	21%	456
GA	19%	55%	26%	234
OK	18%	59%	23%	306

#### Significantly Below Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
AZ	12%	75%	13%	252
OH	12%	73%	15%	267
MO	11%	67%	22%	258

## *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.



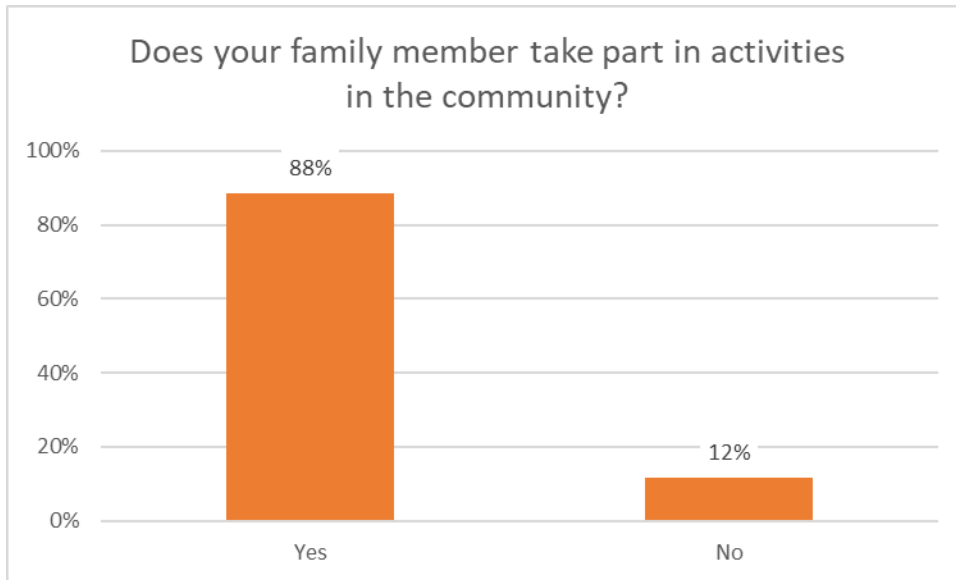


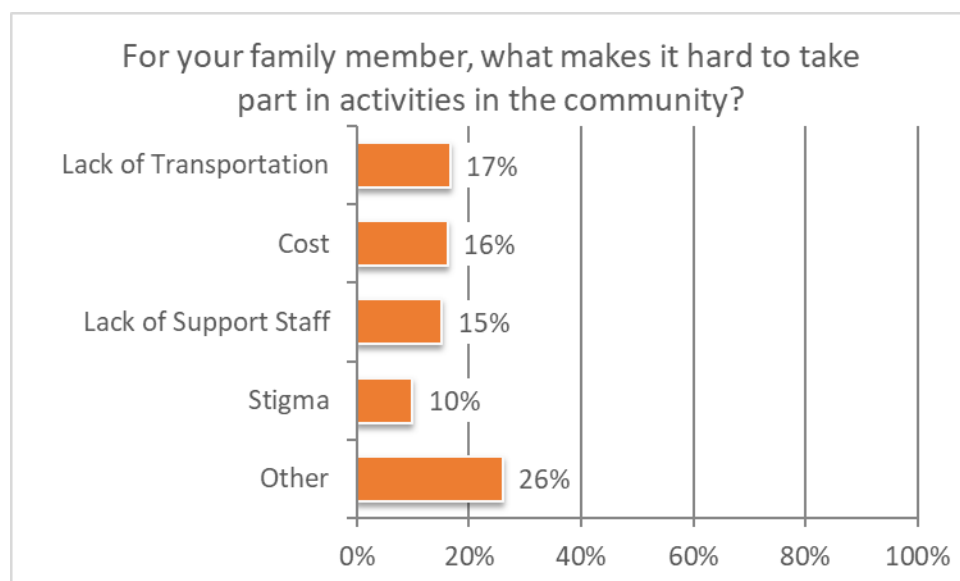
Table Q42. Does your family member take part in activities in the community?

#### Within Average Range

State	Yes	No	N
NC	93%	7%	219
OH	90%	10%	375
MN	90%	10%	574
PA	89%	11%	664
OK	89%	11%	393
VA	89%	11%	166
<b>NCI Average</b>	<b>88%</b>	<b>12%</b>	<b>4,725</b>
UT	88%	12%	473
MO	88%	12%	302
MD	88%	12%	439
GA	84%	16%	357
AZ	84%	16%	281

#### Significantly Below Average

State	Yes	No	N
LA	82%	18%	482



**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	12%	20%	13%	7%	23%
GA	17%	18%	15%	8%	21%
LA	12%	16%	13%	10%	25%
MD	20%	15%	22%	13%	17%
MN	24%	21%	26%	14%	32%
MO	18%	15%	22%	10%	33%
NC	10%	14%	15%	13%	27%
OH	17%	11%	11%	7%	24%
OK	13%	17%	12%	10%	23%
PA	19%	18%	15%	9%	24%
UT	15%	16%	17%	14%	40%
VA	20%	16%	18%	13%	37%
<b>NCI Average</b>	<b>17%</b>	<b>16%</b>	<b>15%</b>	<b>10%</b>	<b>26%</b>

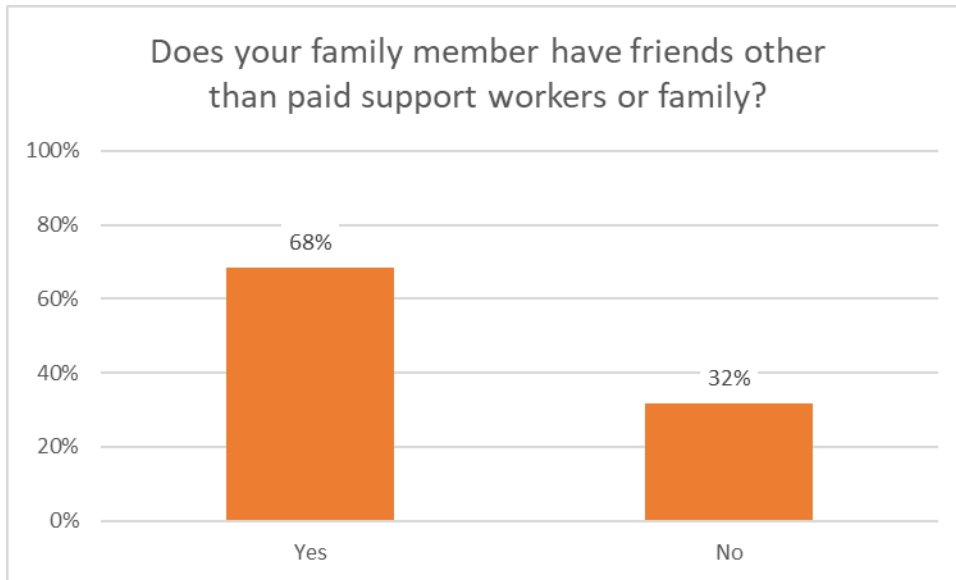


Table Q44. Does your family member have friends other than paid support workers or family?

**Significantly Above Average**

State	Yes	No	N
OK	77%	23%	390

**Within Average Range**

State	Yes	No	N
OH	72%	28%	362
NC	71%	29%	216
AZ	69%	31%	278
GA	69%	31%	353
<b>NCI Average</b>	<b>68%</b>	<b>32%</b>	<b>4,632</b>
PA	68%	32%	649
LA	66%	34%	468
MN	65%	35%	560
MO	64%	36%	288
VA	62%	38%	164

**Significantly Below Average**

State	Yes	No	N
MD	62%	38%	437
UT	61%	39%	467

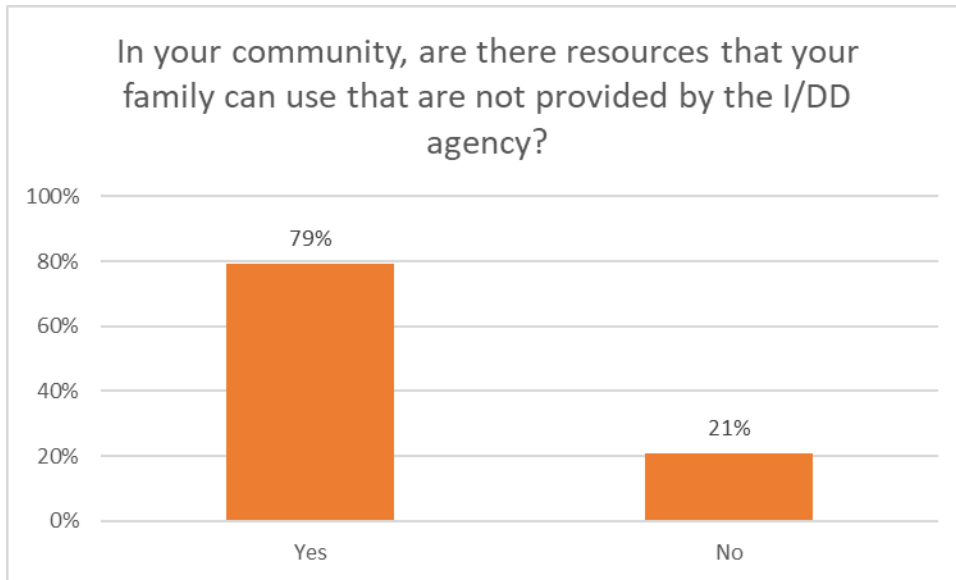


Table Q45. In your community, are there resources that your family can use that are not provided by the I/DD agency?

#### Significantly Above Average

State	Yes	No	N
UT	85%	15%	361

#### Within Average Range

State	Yes	No	N
VA	83%	17%	122
MN	82%	18%	445
MO	82%	18%	216
PA	82%	18%	457
AZ	82%	18%	208
NC	81%	19%	190
<b>NCI Average</b>	<b>79%</b>	<b>21%</b>	<b>3,501</b>
MD	79%	21%	329
OK	78%	22%	310
OH	75%	25%	272

#### Significantly Below Average

State	Yes	No	N
GA	71%	29%	259
LA	71%	29%	332

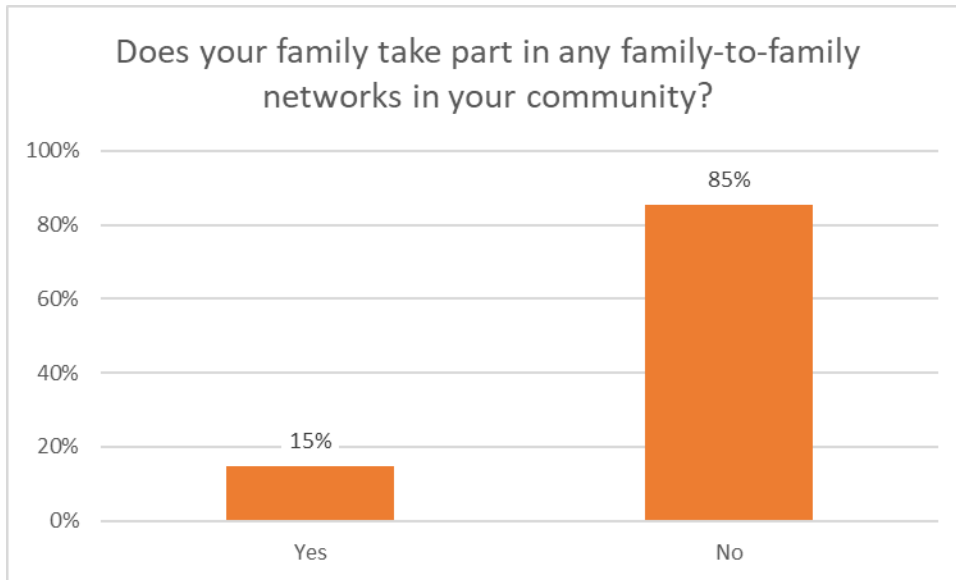


Table Q46. Does your family take part in any family-to-family networks in your community?

#### Significantly Above Average

State	Yes	No	N
LA	22%	78%	384

#### Within Average Range

State	Yes	No	N
NC	21%	79%	197
GA	21%	79%	286
OK	18%	82%	322
AZ	17%	83%	247
MD	15%	85%	378
UT	15%	85%	421
MN	15%	85%	506
<b>NCI Average</b>	<b>15%</b>	<b>85%</b>	<b>4,005</b>
PA	13%	87%	554
VA	11%	89%	142
OH	11%	89%	313

#### Significantly Below Average

State	Yes	No	N
MO	9%	91%	255

## *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.

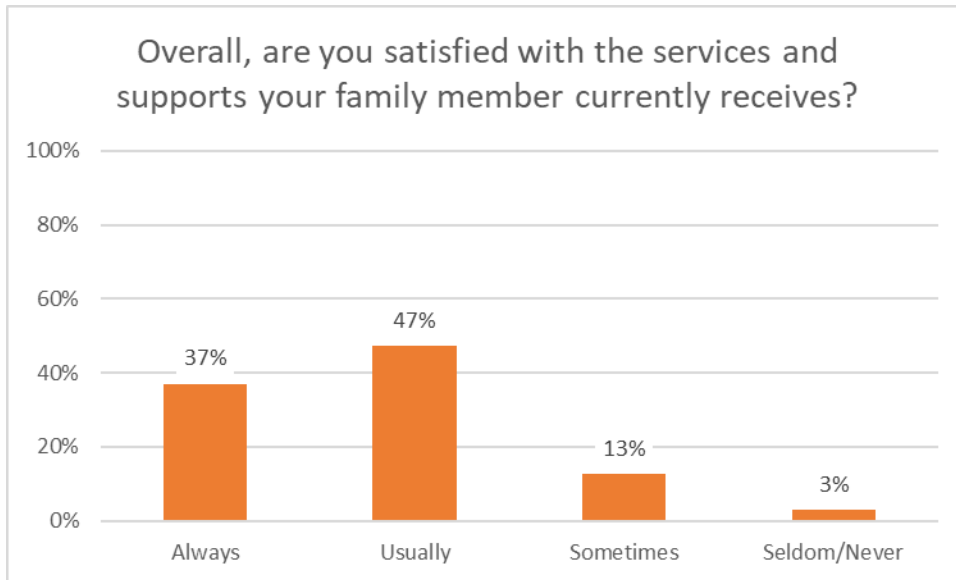


Table Q47. Overall, are you satisfied with the services and supports your family member currently receives?

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	44%	40%	12%	4%	486

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	43%	49%	6%	3%	282
OH	40%	46%	12%	1%	365
NC	39%	44%	13%	4%	216
OK	38%	46%	12%	4%	386
PA	38%	47%	12%	3%	658
<b>NCI Average</b>	<b>37%</b>	<b>47%</b>	<b>13%</b>	<b>3%</b>	<b>4,662</b>
VA	36%	47%	15%	3%	169
UT	35%	57%	7%	1%	471

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	29%	42%	22%	8%	329
MN	27%	56%	14%	3%	572
MO	27%	52%	18%	3%	294
MD	24%	51%	18%	7%	434

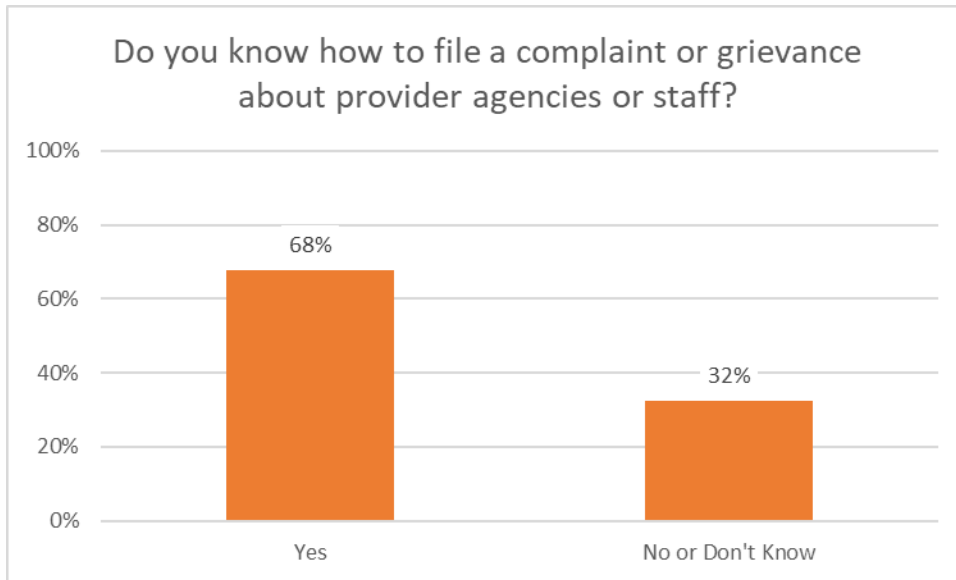


Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff?<sup>9</sup>

#### Significantly Above Average

State	Yes	No or Don't Know	N
OK	82%	18%	394
LA	76%	24%	488
PA	74%	26%	669

#### Within Average Range

State	Yes	No or Don't Know	N
NC	73%	27%	219
UT	70%	30%	474
OH	70%	30%	379
<b>NCI Average</b>	<b>68%</b>	<b>32%</b>	<b>4,753</b>
MN	65%	35%	575
MO	61%	39%	302
VA	61%	39%	168

#### Significantly Below Average

State	Yes	No or Don't Know	N
AZ	59%	41%	282
MD	50%	50%	443
GA	41%	59%	360

<sup>9</sup> 'Don't Know' responses were included in 'No' responses for this question.



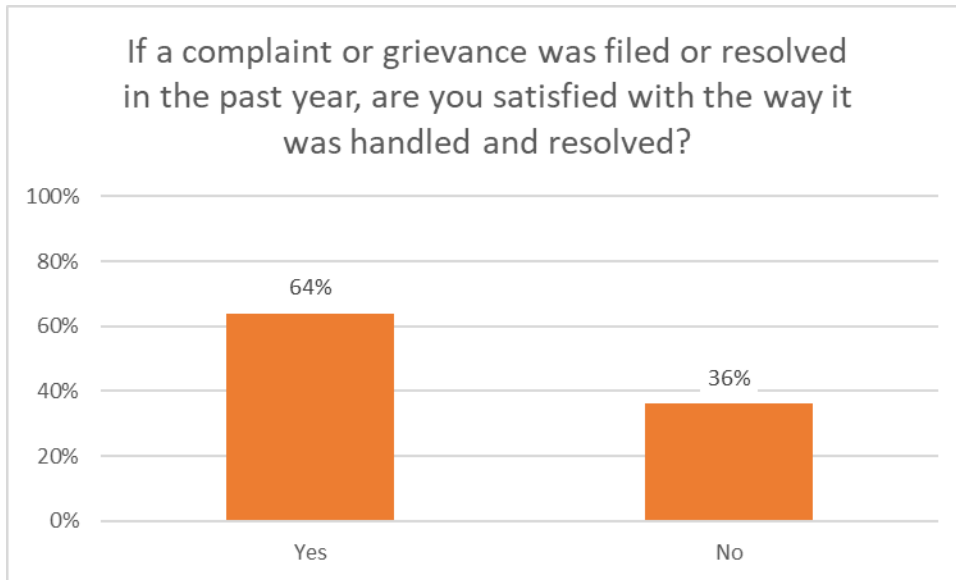


Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?<sup>10</sup>

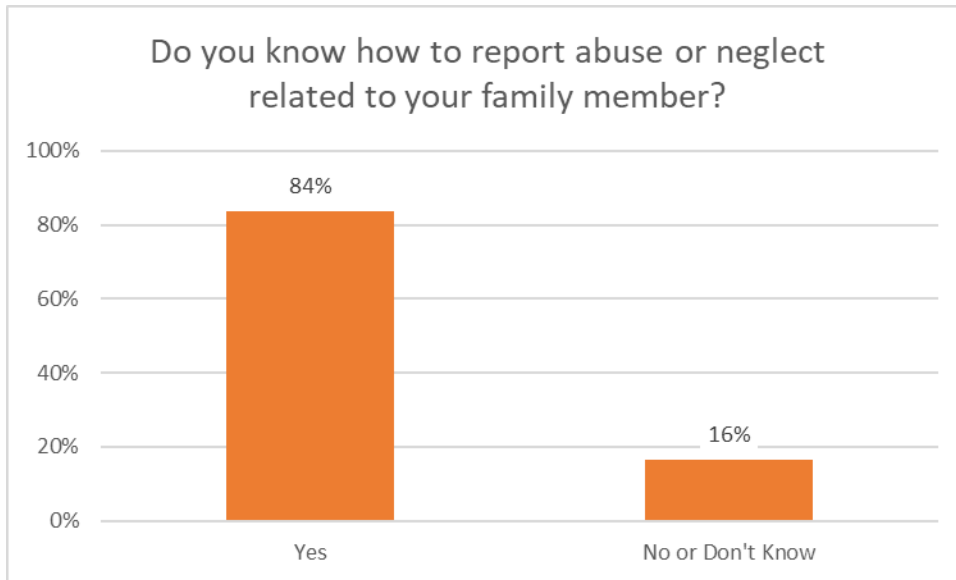
#### Within Average Range

State	Yes	No	N
MO	75%	25%	32
OK	71%	29%	28
NC	69%	31%	39
UT	68%	32%	31
PA	64%	36%	64
<b>NCI Average</b>	<b>64%</b>	<b>36%</b>	<b>420</b>
LA	62%	38%	47
AZ	62%	38%	26
MN	62%	38%	52
OH	57%	43%	28
GA	50%	50%	26

#### Significantly Below Average

State	Yes	No	N
MD	29%	71%	28

<sup>10</sup> VA is not included in the table due to low N (>20), but the VA responses are included in the NCI Average.

Table Q50. Do you know how to report abuse or neglect related to your family member?<sup>11</sup>**Significantly Above Average**

State	Yes	No or Don't Know	N
OK	93%	7%	394

**Within Average Range**

State	Yes	No or Don't Know	N
PA	86%	14%	666
LA	86%	14%	480
NC	85%	15%	220
MN	85%	15%	570
OH	85%	15%	384
<b>NCI Average</b>	<b>84%</b>	<b>16%</b>	<b>4,730</b>
MO	82%	18%	300
AZ	81%	19%	279
UT	80%	20%	474
VA	79%	21%	168

**Significantly Below Average**

State	Yes	No or Don't Know	N
MD	72%	28%	437
GA	69%	31%	358

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

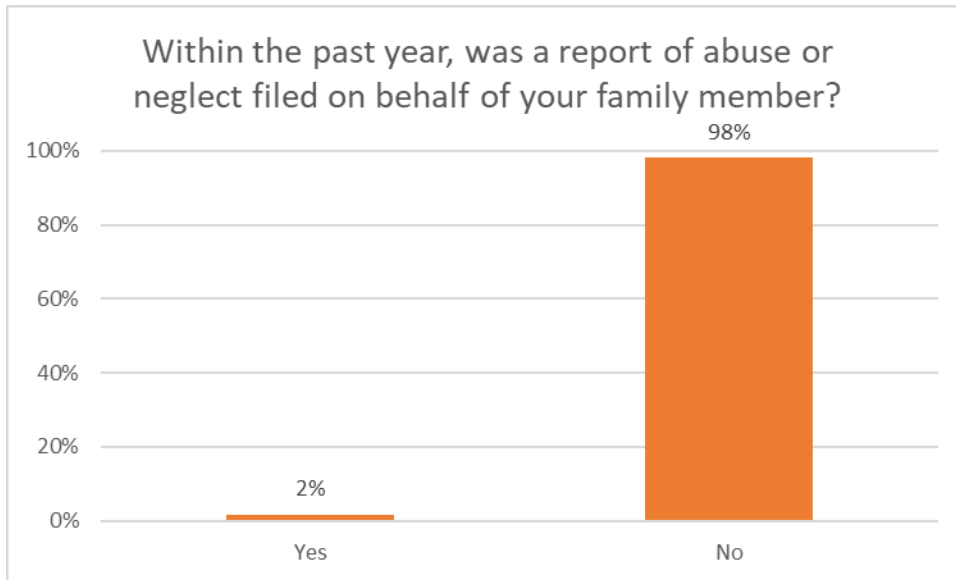


Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

#### Within Average Range

State	Yes	No	N
MO	4%	96%	292
MN	3%	97%	563
VA	3%	97%	159
LA	2%	98%	477
PA	2%	98%	650
UT	2%	98%	470
<b>NCI Average</b>	<b>2%</b>	<b>98%</b>	<b>4,653</b>
AZ	1%	99%	277
OH	1%	99%	373
MD	1%	99%	434
GA	1%	99%	349
NC	1%	99%	220

#### Significantly Below Average

State	Yes	No	N
OK	1%	99%	389

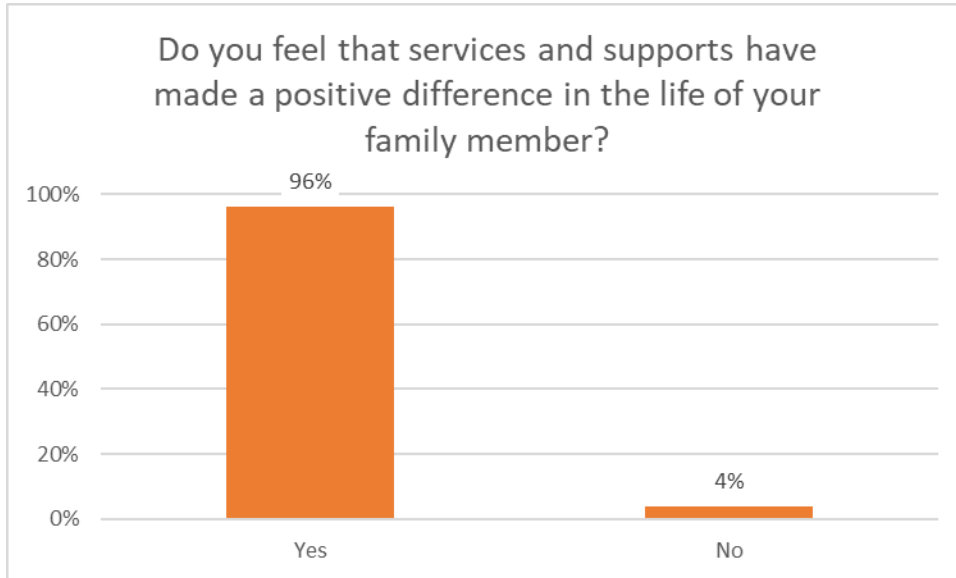


Table Q52. Do you feel that services and supports have made a positive difference in the life of your family member?

#### Significantly Above Average

State	Yes	No	N
UT	99%	1%	465

#### Within Average Range

State	Yes	No	N
NC	98%	2%	213
PA	97%	3%	613
OH	97%	3%	337
OK	97%	3%	366
MN	97%	3%	545
VA	96%	4%	162
<b>NCI Average</b>	<b>96%</b>	<b>4%</b>	<b>4,395</b>
AZ	95%	5%	261
MO	94%	6%	278
LA	94%	6%	447

#### Significantly Below Average

State	Yes	No	N
MD	92%	8%	414
GA	91%	9%	294

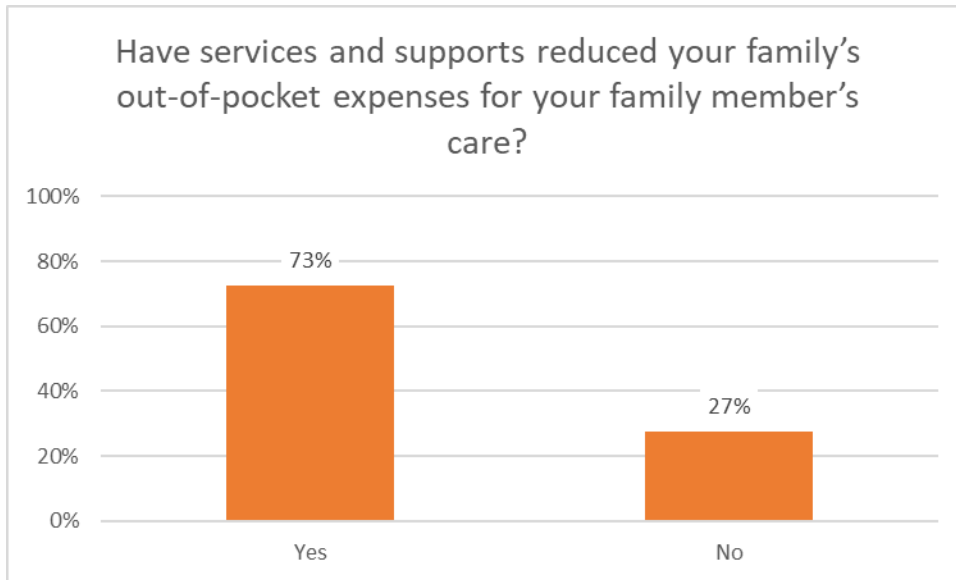


Table Q53. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

#### Significantly Above Average

State	Yes	No	N
UT	84%	16%	439
OK	81%	19%	360
MN	79%	21%	517

#### Within Average Range

State	Yes	No	N
NC	80%	20%	207
VA	78%	22%	157
AZ	75%	25%	266
<b>NCI Average</b>	<b>73%</b>	<b>27%</b>	<b>4,250</b>
LA	72%	28%	426
PA	71%	29%	584
MO	67%	33%	278

#### Significantly Below Average

State	Yes	No	N
OH	65%	35%	320
MD	63%	37%	389
GA	63%	37%	307

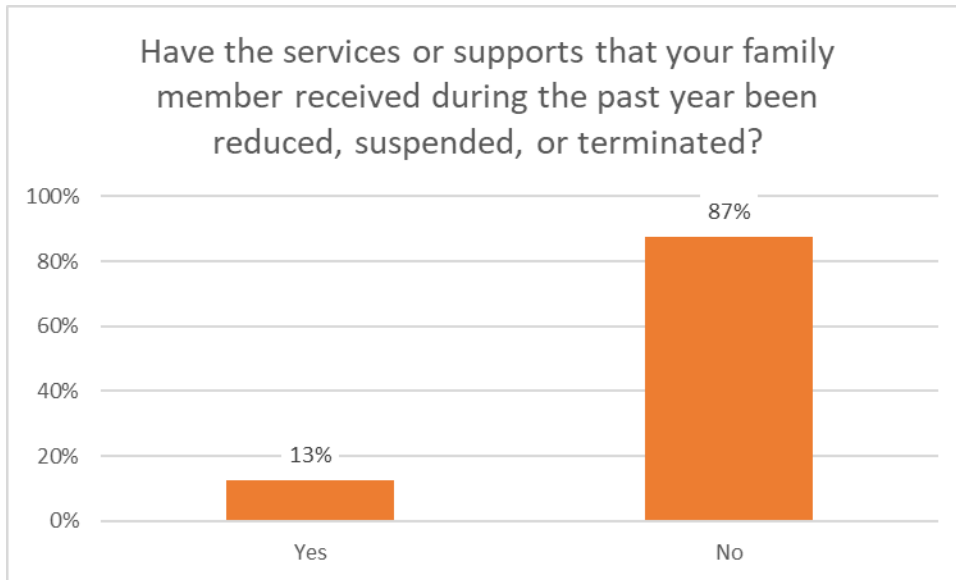


Table Q54. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

#### Significantly Above Average

State	Yes	No	N
UT	20%	80%	446
MD	17%	83%	409

#### Within Average Range

State	Yes	No	N
NC	19%	81%	209
MO	19%	81%	281
MN	15%	85%	521
<b>NCI Average</b>	<b>13%</b>	<b>87%</b>	<b>4,389</b>
GA	12%	88%	314
PA	12%	88%	613
OK	12%	88%	367
LA	12%	88%	449
OH	12%	88%	346
AZ	9%	91%	275
VA	9%	91%	159

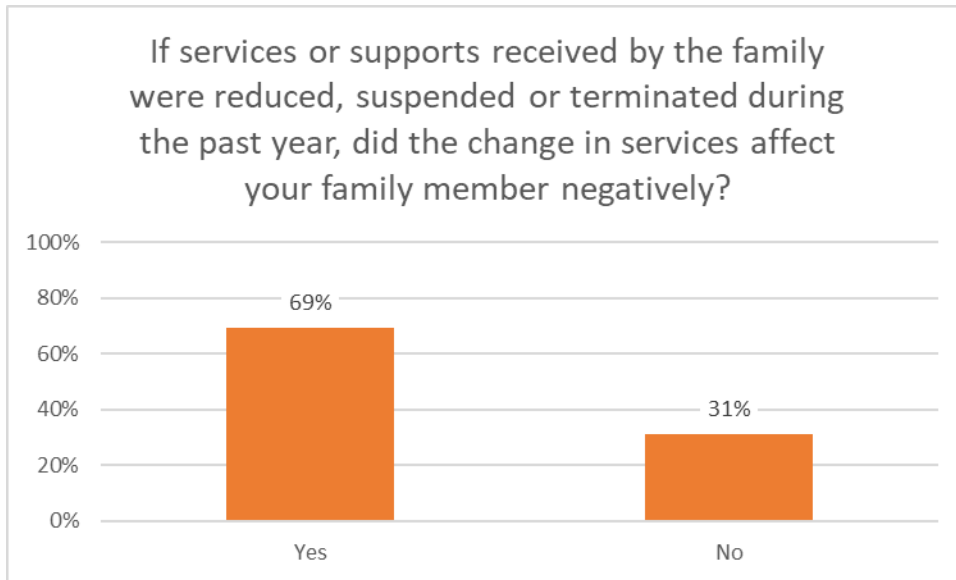


Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?<sup>12</sup>

#### Within Average Range

State	Yes	No	N
MO	83%	17%	48
MD	75%	25%	69
NC	74%	26%	38
MN	74%	26%	68
<b>NCI Average</b>	<b>69%</b>	<b>31%</b>	<b>545</b>
AZ	68%	32%	22
GA	68%	32%	31
OH	68%	32%	34
LA	67%	33%	45
OK	64%	36%	36
PA	60%	40%	67

#### Significantly Below Average

State	Yes	No	N
UT	53%	47%	74

<sup>12</sup> VA is not included in the table due to low N (>20), but the VA responses are included in the NCI Average

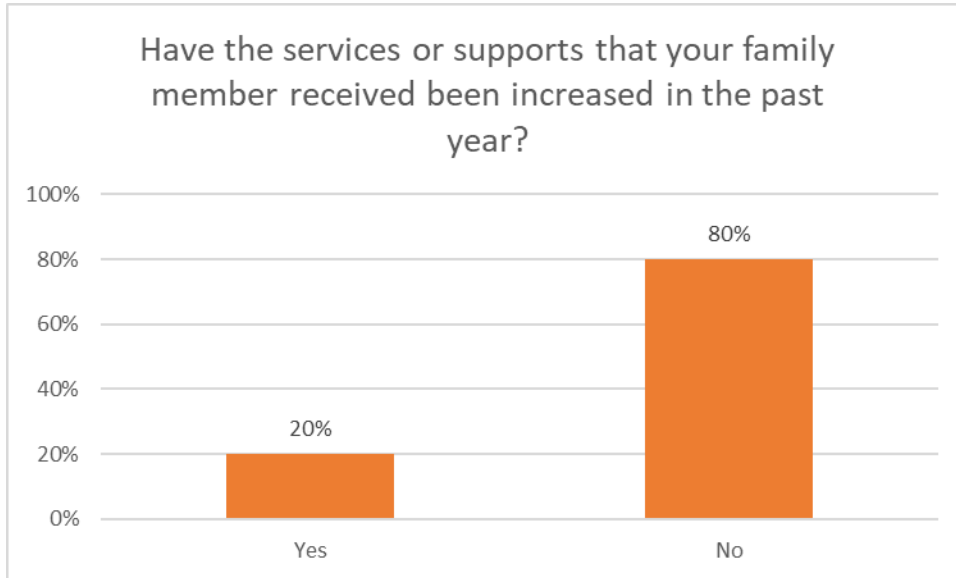


Table Q56. Have the services or supports that your family member received been increased in the past year?

#### Within Average Range

State	Yes	No	N
MO	24%	76%	267
PA	23%	77%	579
AZ	23%	77%	262
MN	23%	77%	513
UT	20%	80%	398
<b>NCI Average</b>	<b>20%</b>	<b>80%</b>	<b>4,189</b>
OH	19%	81%	334
GA	18%	82%	298
VA	18%	82%	149
OK	17%	83%	349
MD	17%	83%	400
NC	16%	84%	202

#### Significantly Below Average

State	Yes	No	N
LA	13%	87%	438



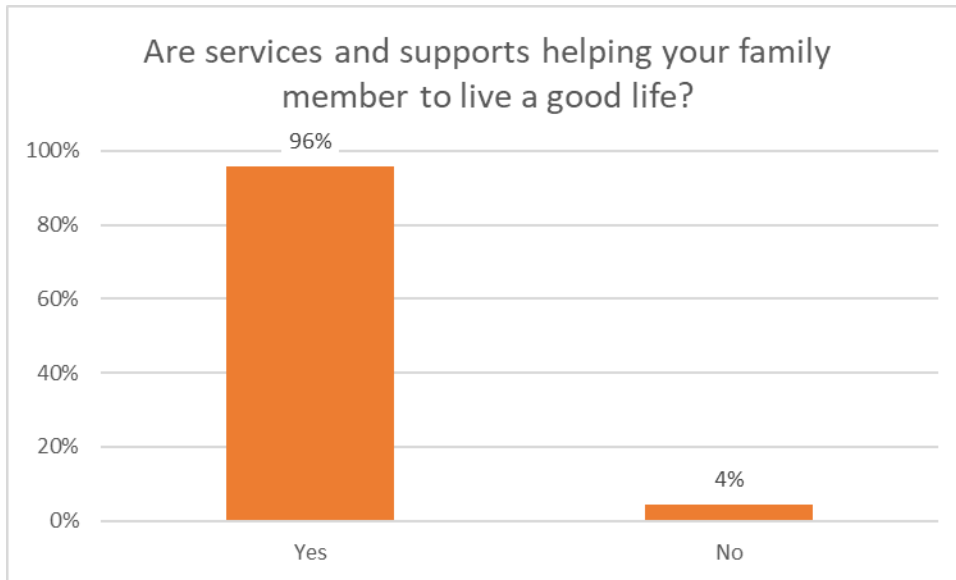


Table Q57. Are services and supports helping your family member to live a good life?

#### Significantly Above Average

State	Yes	No	N
UT	99%	1%	448
AZ	98%	2%	263

#### Within Average Range

State	Yes	No	N
NC	98%	2%	203
OH	97%	3%	340
OK	97%	3%	369
VA	97%	3%	153
MN	97%	3%	539
<b>NCI Average</b>	<b>96%</b>	<b>4%</b>	<b>4,335</b>
LA	94%	6%	441
PA	94%	6%	603
MO	92%	8%	268

#### Significantly Below Average

State	Yes	No	N
MD	92%	8%	405
GA	86%	14%	303

## 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.

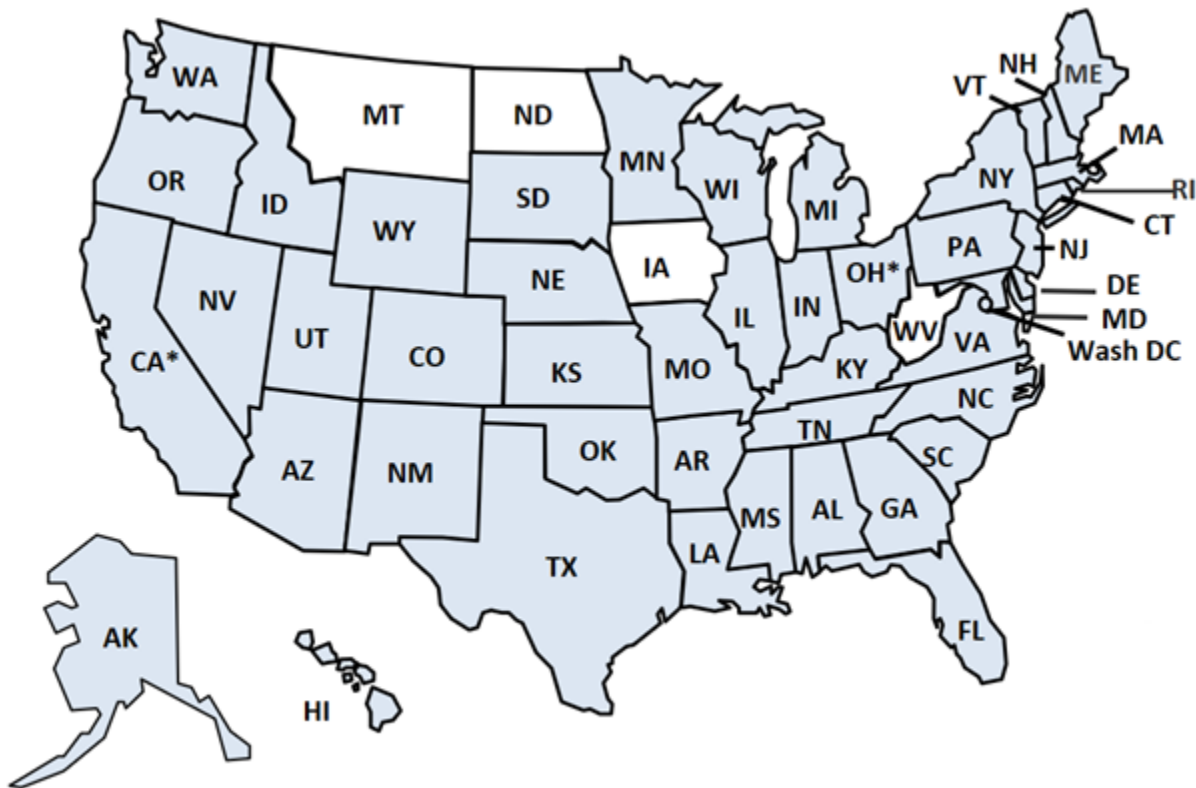
Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI continues to develop and refine the indicators and expand state participation. For more information about NCI states,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

<https://www.nationalcoreindicators.org/>.

## State Participation

During the 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 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>13</sup>

<sup>13</sup> Located on the National Core Indicators website: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org) →Resources →Technical Reports

---

## 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 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 five states had at least a portion of surveys completed via direct entry for the 2018-19 data collection cycle.<sup>14</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>15</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.

---

<sup>14</sup> States that used the direct entry or mail and direct entry options were: LA, MD, NC, OH, UT.

<sup>15</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  $d = \frac{2t}{\sqrt{df}}$ . A cutoff point of Cohen's  $d = 0.2$  was chosen for the effect size to be considered “meaningfully significant,” following the standard interpretation offered by Cohen (1988) that Cohen's  $d$  of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

## Data Entry and Analysis

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

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

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

Statistical significance testing was conducted on each state's “yes” or “always” response compared to the NCI average<sup>16</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, 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 surveys each state sent, usable surveys returned, response rates, the number of individuals receiving services who were eligible to be drawn into the sample, and each state's margin of error.

---

<sup>16</sup> The NCI Average is the sum of all state averages divided by the total number of states.

Figure 3. Adult Family Survey: State Response Rates <sup>17</sup>

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	10,641	1,400	288	20.6%	5.7%	100%	0%
GA	4,018	1,700	369	21.7%	4.9%	100%	0%
LA	4,405	2,155	491	22.8%	4.2%	95%	5%
MD	4,611	3,435	454	13.2%	4.4%	86%	14%
MN	7,122	1,597	585	36.6%	3.9%	100%	0%
MO	3,041	1,000 – 1,500	304	20.3% - 30.4%	5.3%	100%	0%
NC	8,449	1,200	224	18.7%	6.5%	93%	7%
OH	20,907	1,200	391	32.6%	4.9%	12%	88%
OK	8,500	1,435	398	27.7%	4.8%	100%	0%
PA	23,300	1,850 – 2,000	677	33.9% - 33.6%	3.7%	100%	0%
UT	2,200	1000	481	48.1%	4.0%	91%	9%
VA	11,993	703	174	24.8%	7.4%	100%	0%
<b>Total</b>	<b>109,187</b>	<b>18,675</b>	<b>4,836</b>	<b>26.7% -27.8%</b>	<b>5.0%</b>	<b>82%</b>	<b>18%</b>

<sup>17</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.