

# Adult Family Survey

2015-16 Final Report

*Edited 2/15/17*



**A Collaboration of**

**The National Association of State Directors of  
Developmental Disabilities Services  
and  
Human Services Research Institute**



Human Services  
Research Institute

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

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

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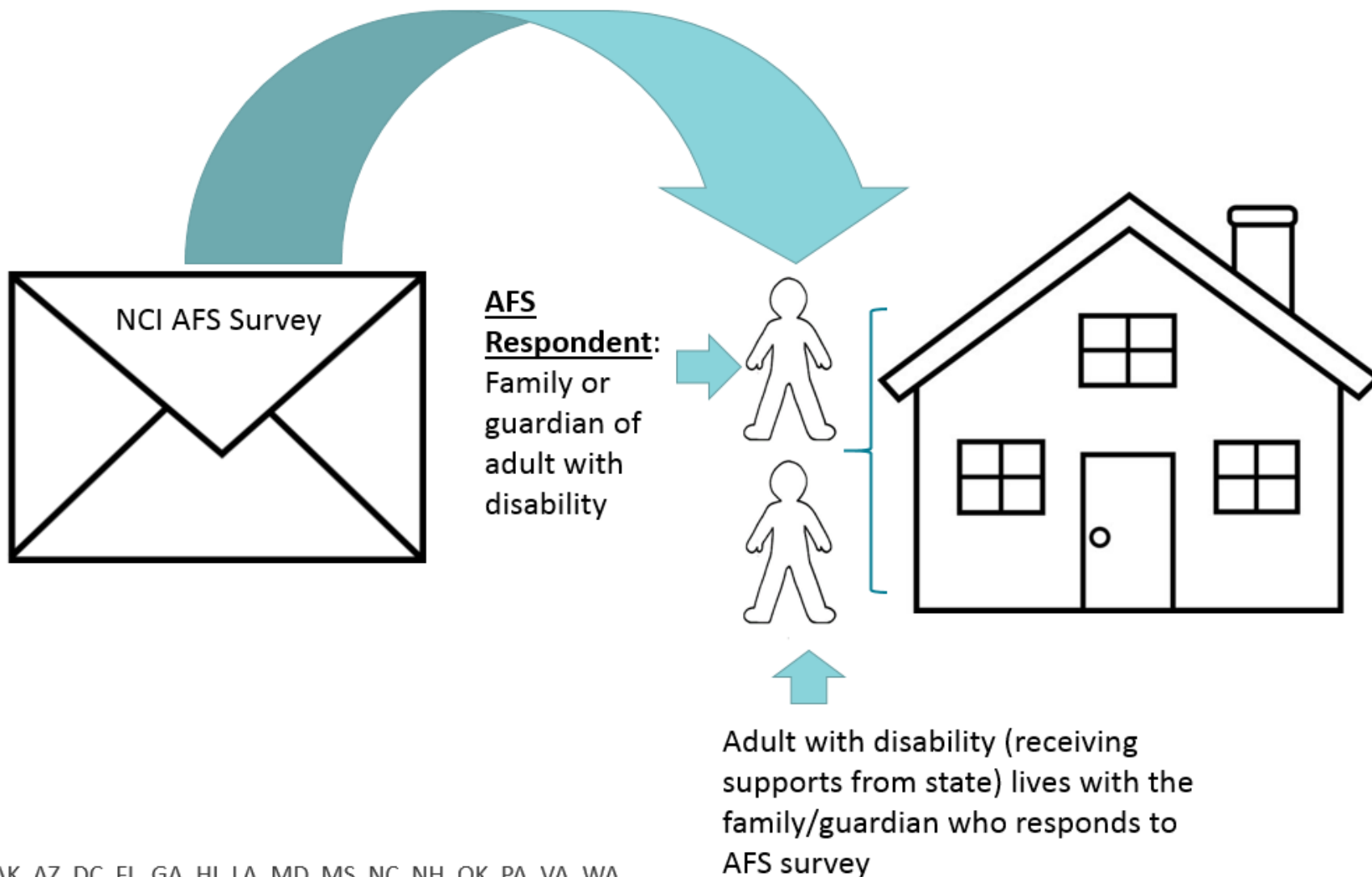
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# Adult Family Survey Highlights

## LOOKING AT THE 2015-16 ADULT FAMILY SURVEY (AFS)

**Respondents:** families or guardians of an adult (aged 18 and over) with an intellectual/developmental disability. The adult with the disability lives in the family home (with the respondent) and receives at least one service funded by the state developmental disability agency in addition to case management.  
**15 states\*:** Total sample: 5,716



\*AFS: AK, AZ, DC, FL, GA, HI, LA, MD, MS, NC, NH, OK, PA, VA, WA

### Demographics of sample of family members with disabilities receiving supports from the state

#### Average Age

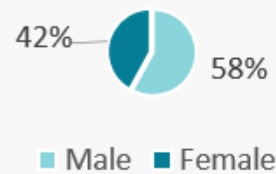
of the sample of family members with disabilities receiving supports from the state

34 years old

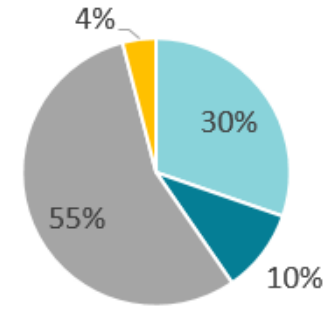
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#### Gender Breakdown

of the sample of family members with disabilities receiving supports from the state

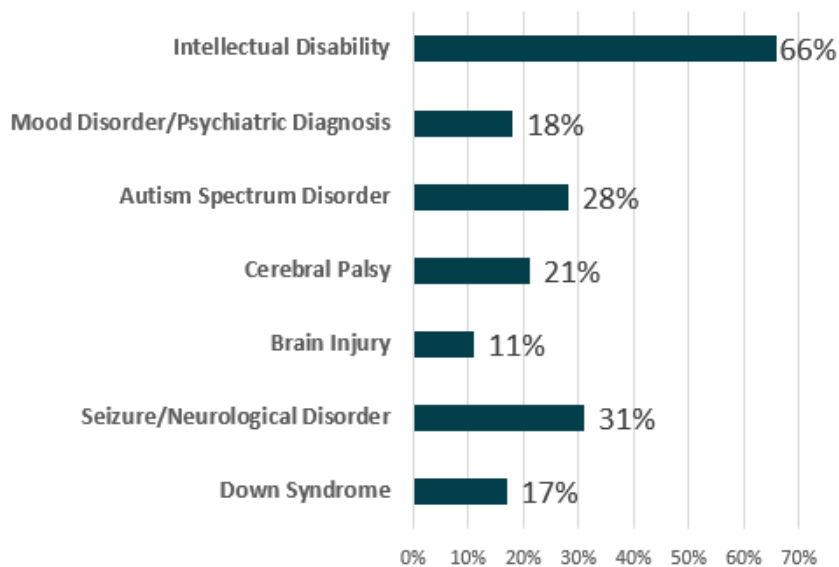


### Legal guardianship arrangement for adult with disabilities



■ None ■ Limited ■ Full ■ Has Guardianship -- Level is Unknown

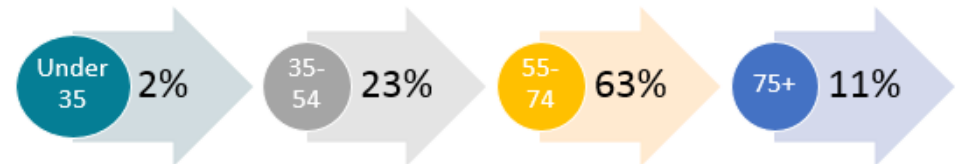
### Diagnoses of the sample of family members with disabilities receiving supports from the state



### Characteristics of respondents (family or guardian of the adult with disability)



#### Age of respondents

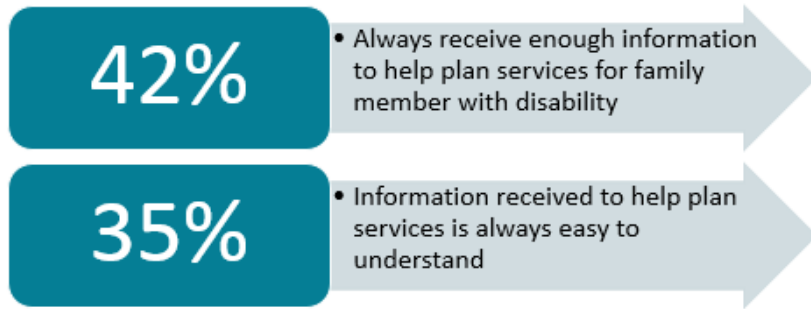


### Total taxable income of wage earners in the household over past year

44% of respondents report a total taxable income of \$25,000 per year or less

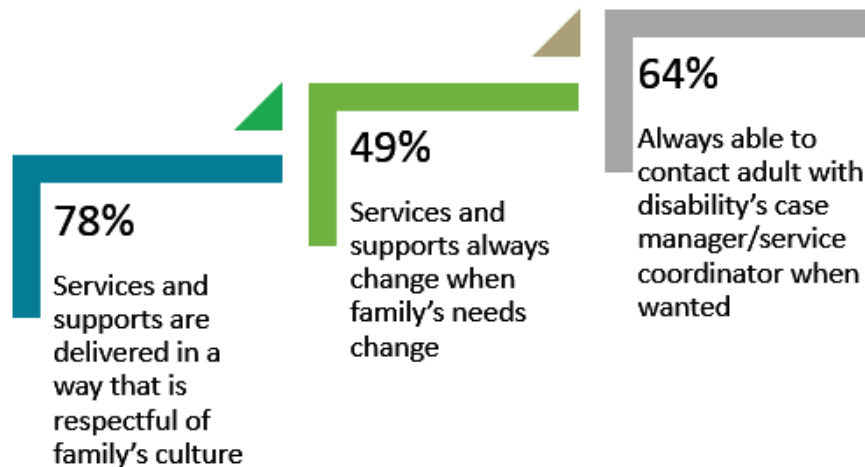
### Information and Planning

Respondents reported...



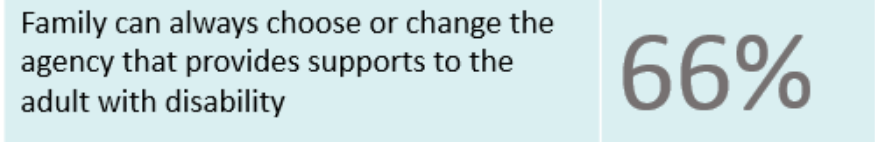
### Access and Delivery of Supports and Services

Respondents reported...



### Choice, Decision-making and Control

Respondents reported...

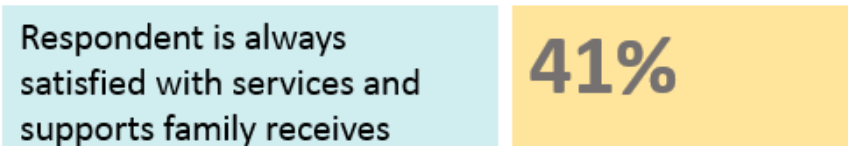


### Involvement in the Community

Respondents reported...



### Satisfaction with Services and Supports



# I. Results

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

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# Survey Development

The Adult Family Survey was developed and first utilized in 1997-99 by a technical advisory group to measure the experiences of families who had an adult family member with a developmental disability living at home. Results and feedback from the first administration of the survey demonstrated that it was relatively straightforward to administer, yielded good response rates, and provided sound feedback to the participating state DD agencies.

Many questions were drawn from survey instruments already in use in the field; others were developed specifically for NCI. NCI staff routinely refine the instrument based on feedback from families and state staff.

Most participating states use the basic survey tool developed by the project. However, some states opt to incorporate additional survey questions to look more deeply at specific issues. The addition of supplementary questions is typically done after a state participates in NCI for at least a year and establishes baseline results.

## Organization of the Adult Family Survey

The Adult Family Survey is composed of the three sections described below. Additionally, at the end of the survey, respondents may write open-ended comments concerning their family's participation in the service system.

### **Demographics**

The survey instrument begins with a series of questions on the characteristics of the family member with a developmental disability (e.g., age, race, type of disability) followed by a series of demographic questions on the survey respondent (e.g., age, health status, relationship to the individual with the developmental disability).

### **Services and Supports Received**

A brief section of the survey asks the respondent to identify the services and supports that they and/or their family member with a developmental disability receive.

## Questions Regarding Services and Supports

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 five 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.

**\*Please note: In the 2015-16 AFS survey tool, the "Seldom" and "Never" response options, which were separate in previous years, were combined into a "Seldom/Never" response option. This may affect comparisons from year to year.**

## Presentation of Data

Direct feedback from families is an important means for states to gauge service and support satisfaction and to pinpoint areas for quality improvement. All demographic and individual outcome results from the Adult Family Survey are presented in this report. Outcome results are presented in six subsections that correspond with the sections of the Adult Family Survey.

For each question, outcome results are first shown in a graph with the NCI Average and then in a table that shows a breakout of each state's percentage.

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. 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 are not included for a survey item if fewer than 20 people responded.

The NCI Average is the average of all individual state percentages.

**Note on Significance:** In some cases, a state (let's call it state A) with a lower (or higher) proportion than another state (let's call it state B) may be significantly above (or below) the NCI Average even though the other state that is further away from the NCI Average is not. This may happen because statistical significance depends in part on the sample size of the state. So, for example, when state A has a larger valid sample for the indicator than state B, state A may be significantly different from the average when state B is not, even though state B's difference from that average is larger than state A's. The larger the sample size of a state, the smaller the difference needs to be to be statistically significant.

**Note:**

**“Respondent” refers to the person (usually a parent or guardian) filling out the survey.**

**“Family Member” refers to the person receiving services who the respondent is answering questions about in this survey.**



# Demographics

## **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            |
|--------------------|------------|------------|--------------|
| AK                 | 14%        | 86%        | 138          |
| AZ                 | 15%        | 85%        | 322          |
| DC                 | 15%        | 85%        | 229          |
| FL                 | 17%        | 83%        | 427          |
| GA                 | 14%        | 86%        | 436          |
| HI                 | 10%        | 90%        | 209          |
| LA                 | 17%        | 83%        | 385          |
| MD                 | 13%        | 87%        | 733          |
| MS                 | 11%        | 89%        | 497          |
| NC                 | 13%        | 87%        | 244          |
| NH                 | 12%        | 88%        | 438          |
| OK                 | 12%        | 88%        | 470          |
| PA                 | 14%        | 86%        | 438          |
| VA                 | 12%        | 88%        | 162          |
| WA                 | 17%        | 83%        | 423          |
| <b>NCI Average</b> | <b>14%</b> | <b>86%</b> | <b>5,551</b> |

**Table 2. Family Member's Age**

| State              | Age         | N            |
|--------------------|-------------|--------------|
| AK                 | 30.8        | 133          |
| AZ                 | 32.0        | 328          |
| DC                 | 36.2        | 238          |
| FL                 | 35.7        | 390          |
| GA                 | 36.9        | 412          |
| HI                 | 34.5        | 195          |
| LA                 | 35.2        | 376          |
| MD                 | 33.9        | 669          |
| MS                 | 38.2        | 440          |
| NC                 | 32.5        | 221          |
| NH                 | 33.2        | 402          |
| OK                 | 34.4        | 427          |
| PA                 | 33.2        | 410          |
| VA                 | 35.1        | 160          |
| WA                 | 31.4        | 371          |
| <b>NCI Average</b> | <b>34.2</b> | <b>5,172</b> |

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

| State              | Male       | Female     | N            |
|--------------------|------------|------------|--------------|
| AK                 | 56%        | 44%        | 134          |
| AZ                 | 58%        | 42%        | 329          |
| DC                 | 66%        | 34%        | 237          |
| FL                 | 58%        | 42%        | 400          |
| GA                 | 54%        | 46%        | 421          |
| HI                 | 64%        | 36%        | 201          |
| LA                 | 53%        | 47%        | 372          |
| MD                 | 57%        | 43%        | 693          |
| MS                 | 55%        | 45%        | 466          |
| NC                 | 58%        | 42%        | 231          |
| NH                 | 58%        | 42%        | 417          |
| OK                 | 53%        | 47%        | 437          |
| PA                 | 58%        | 42%        | 425          |
| VA                 | 61%        | 39%        | 158          |
| WA                 | 63%        | 37%        | 385          |
| <b>NCI Average</b> | <b>58%</b> | <b>42%</b> | <b>5,306</b> |

Table 4. Family Member's Race and Ethnicity

| State              | American Indian or Alaska Native | Asian     | Black or African-American | Hawaiian or Pacific Islander | White      | Other or Unknown | Two or More Races | Hispanic or Latino | N            |
|--------------------|----------------------------------|-----------|---------------------------|------------------------------|------------|------------------|-------------------|--------------------|--------------|
| AK                 | 30%                              | 4%        | 3%                        | 2%                           | 76%        | 0%               | 15%               | 1%                 | 137          |
| AZ                 | 7%                               | 2%        | 6%                        | 0%                           | 67%        | 1%               | 8%                | 25%                | 327          |
| DC                 | 0%                               | 1%        | 91%                       | 0%                           | 3%         | 0%               | 0%                | 5%                 | 238          |
| FL                 | 1%                               | 3%        | 21%                       | 0%                           | 62%        | 2%               | 5%                | 17%                | 428          |
| GA                 | 1%                               | 1%        | 41%                       | 1%                           | 56%        | 0%               | 2%                | 2%                 | 441          |
| HI                 | 2%                               | 64%       | 3%                        | 30%                          | 30%        | 3%               | 28%               | 9%                 | 218          |
| LA                 | 1%                               | 1%        | 37%                       | 0%                           | 61%        | 1%               | 3%                | 2%                 | 391          |
| MD                 | 3%                               | 5%        | 31%                       | 0%                           | 63%        | 1%               | 5%                | 3%                 | 733          |
| MS                 | 1%                               | 1%        | 48%                       | 0%                           | 51%        | 0%               | 2%                | 1%                 | 500          |
| NC                 | 2%                               | 1%        | 30%                       | 0%                           | 68%        | 1%               | 4%                | 3%                 | 250          |
| NH                 | 2%                               | 2%        | 0%                        | 0%                           | 95%        | 1%               | 2%                | 2%                 | 441          |
| OK                 | 19%                              | 2%        | 11%                       | 0%                           | 77%        | 0%               | 11%               | 3%                 | 475          |
| PA                 | 2%                               | 1%        | 10%                       | 0%                           | 84%        | 0%               | 3%                | 5%                 | 445          |
| VA                 | 2%                               | 2%        | 26%                       | 0%                           | 69%        | 2%               | 4%                | 3%                 | 162          |
| WA                 | 4%                               | 9%        | 5%                        | 1%                           | 77%        | 2%               | 7%                | 10%                | 426          |
| <b>NCI Average</b> | <b>5%</b>                        | <b>7%</b> | <b>24%</b>                | <b>2%</b>                    | <b>63%</b> | <b>1%</b>        | <b>6%</b>         | <b>6%</b>          | <b>5,612</b> |

Table 5. Family Member's Disabilities

| State              | Intellectual Disability | Mood Illness or Psychiatric Disorder | Autism Spectrum Disorder | Cerebral Palsy | Limited or No Vision | Severe or Profound Hearing Loss | Brain Injury | Seizure Disorder or Neurological Problem | Chemical Dependency | Down Syndrome | Prader-Willi Syndrome | Fetal Alcohol Spectrum Disorder | Other      |
|--------------------|-------------------------|--------------------------------------|--------------------------|----------------|----------------------|---------------------------------|--------------|--|---------------------|---------------|-----------------------|---------------------------------|------------|
| AK                 | 74%                     | 14%                                  | 36%                      | 17%            | 9%                   | 7%                              | 7%           | 29%                                      | 0%                  | 19%           | 0%                    | 6%                              | 22%        |
| AZ                 | 61%                     | 18%                                  | 37%                      | 21%            | 12%                  | 5%                              | 12%          | 27%                                      | 1%                  | 18%           | 1%                    | 1%                              | 25%        |
| DC                 | 53%                     | 9%                                   | 27%                      | 22%            | 8%                   | 5%                              | 7%           | 20%                                      | 0%                  | 12%           | 0%                    | 2%                              | 16%        |
| FL                 | 61%                     | 19%                                  | 28%                      | 24%            | 9%                   | 8%                              | 12%          | 35%                                      | 3%                  | 19%           | 0%                    | 0%                              | 27%        |
| GA                 | 68%                     | 22%                                  | 25%                      | 20%            | 14%                  | 6%                              | 10%          | 29%                                      | 1%                  | 14%           | 0%                    | 0%                              | 14%        |
| HI                 | 66%                     | 16%                                  | 27%                      | 18%            | 13%                  | 6%                              | 11%          | 32%                                      | 2%                  | 19%           | 0%                    | 1%                              | 20%        |
| LA                 | 58%                     | 19%                                  | 23%                      | 17%            | 11%                  | 7%                              | 9%           | 28%                                      | 1%                  | 18%           | 1%                    | 0%                              | 23%        |
| MD                 | 69%                     | 17%                                  | 29%                      | 17%            | 8%                   | 6%                              | 9%           | 27%                                      | 0%                  | 18%           | 1%                    | 1%                              | 21%        |
| MS                 | 61%                     | 15%                                  | 18%                      | 25%            | 13%                  | 8%                              | 13%          | 38%                                      | 1%                  | 19%           | 0%                    | 1%                              | 26%        |
| NC                 | 63%                     | 22%                                  | 31%                      | 25%            | 13%                  | 5%                              | 12%          | 37%                                      | 0%                  | 13%           | 0%                    | 1%                              | 24%        |
| NH                 | 64%                     | 20%                                  | 32%                      | 14%            | 8%                   | 8%                              | 12%          | 27%                                      | 0%                  | 14%           | 0%                    | 1%                              | 20%        |
| OK                 | 75%                     | 15%                                  | 19%                      | 31%            | 13%                  | 9%                              | 15%          | 40%                                      | 1%                  | 17%           | 0%                    | 1%                              | 19%        |
| PA                 | 78%                     | 19%                                  | 27%                      | 18%            | 7%                   | 6%                              | 10%          | 27%                                      | 0%                  | 17%           | 0%                    | 0%                              | 18%        |
| VA                 | 66%                     | 19%                                  | 36%                      | 27%            | 15%                  | 9%                              | 10%          | 33%                                      | 1%                  | 14%           | 1%                    | 0%                              | 19%        |
| WA                 | 66%                     | 19%                                  | 29%                      | 17%            | 10%                  | 9%                              | 12%          | 32%                                      | 1%                  | 17%           | 0%                    | 4%                              | 25%        |
| <b>NCI Average</b> | <b>66%</b>              | <b>18%</b>                           | <b>28%</b>               | <b>21%</b>     | <b>11%</b>           | <b>7%</b>                       | <b>11%</b>   | <b>31%</b>                               | <b>1%</b>           | <b>17%</b>    | <b>0%</b>             | <b>1%</b>                       | <b>21%</b> |

Table 6. Family Member's Health Conditions

| State              | Cardiovascular Disease | Diabetes   | Cancer    | High Blood Pressure | High Cholesterol | Dysphagia  | Pressure Ulcers | Alzheimer's Disease or Other Dementia | Other      |
|--------------------|------------------------|------------|-----------|---------------------|------------------|------------|-----------------|---------------------------------------|------------|
| AK                 | 16%                    | 11%        | 8%        | 24%                 | 13%              | 6%         | 0%              | 0%                                    | 67%        |
| AZ                 | 9%                     | 23%        | 6%        | 31%                 | 32%              | 6%         | 2%              | 2%                                    | 44%        |
| DC                 | 7%                     | 21%        | 4%        | 51%                 | 27%              | 4%         | 0%              | 0%                                    | 31%        |
| FL                 | 10%                    | 14%        | 7%        | 32%                 | 33%              | 12%        | 4%              | 2%                                    | 43%        |
| GA                 | 11%                    | 22%        | 6%        | 44%                 | 36%              | 9%         | 3%              | 3%                                    | 23%        |
| HI                 | 7%                     | 22%        | 6%        | 21%                 | 34%              | 9%         | 1%              | 2%                                    | 50%        |
| LA                 | 12%                    | 19%        | 4%        | 36%                 | 28%              | 12%        | 4%              | 3%                                    | 39%        |
| MD                 | 11%                    | 17%        | 6%        | 30%                 | 33%              | 8%         | 2%              | 1%                                    | 38%        |
| MS                 | 11%                    | 19%        | 2%        | 44%                 | 29%              | 12%        | 3%              | 3%                                    | 36%        |
| NC                 | 4%                     | 18%        | 3%        | 29%                 | 32%              | 13%        | 2%              | 0%                                    | 43%        |
| NH                 | 12%                    | 15%        | 9%        | 24%                 | 33%              | 13%        | 6%              | 3%                                    | 36%        |
| OK                 | 12%                    | 17%        | 5%        | 28%                 | 25%              | 13%        | 2%              | 2%                                    | 45%        |
| PA                 | 12%                    | 13%        | 3%        | 25%                 | 24%              | 11%        | 2%              | 1%                                    | 49%        |
| VA                 | 10%                    | 20%        | 1%        | 27%                 | 35%              | 6%         | 1%              | 6%                                    | 52%        |
| WA                 | 15%                    | 18%        | 5%        | 24%                 | 25%              | 15%        | 2%              | 1%                                    | 44%        |
| <b>NCI Average</b> | <b>11%</b>             | <b>18%</b> | <b>5%</b> | <b>31%</b>          | <b>29%</b>       | <b>10%</b> | <b>2%</b>       | <b>2%</b>                             | <b>43%</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            |
|--------------------|------------|---------------------------|----------------------------------|-----------------------------|-----------|--------------|
| AK                 | 84%        | 7%                        | 4%                               | 2%                          | 3%        | 123          |
| AZ                 | 80%        | 13%                       | 1%                               | 3%                          | 3%        | 328          |
| DC                 | 74%        | 18%                       | 4%                               | 1%                          | 3%        | 231          |
| FL                 | 71%        | 18%                       | 3%                               | 3%                          | 6%        | 430          |
| GA                 | 76%        | 17%                       | 2%                               | 1%                          | 5%        | 437          |
| HI                 | 78%        | 17%                       | 1%                               | 2%                          | 3%        | 218          |
| LA                 | 77%        | 15%                       | 1%                               | 1%                          | 7%        | 391          |
| MD                 | 78%        | 17%                       | 2%                               | 1%                          | 3%        | 730          |
| MS                 | 69%        | 22%                       | 1%                               | 0%                          | 7%        | 449          |
| NC                 | 72%        | 22%                       | 2%                               | 2%                          | 2%        | 251          |
| NH                 | 84%        | 10%                       | 4%                               | 1%                          | 1%        | 447          |
| OK                 | 75%        | 19%                       | 2%                               | 0%                          | 3%        | 472          |
| PA                 | 85%        | 10%                       | 1%                               | 2%                          | 3%        | 442          |
| VA                 | 65%        | 29%                       | 1%                               | 1%                          | 4%        | 150          |
| WA                 | 76%        | 13%                       | 2%                               | 1%                          | 8%        | 432          |
| <b>NCI Average</b> | <b>76%</b> | <b>16%</b>                | <b>2%</b>                        | <b>1%</b>                   | <b>4%</b> | <b>5,531</b> |

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

| State              | None       | Limited    | Full       | Has Guardianship, Level Is Unknown | N            |
|--------------------|------------|------------|------------|------------------------------------|--------------|
| AK                 | 0%         | 4%         | 96%        | 0%                                 | 138          |
| AZ                 | 25%        | 8%         | 65%        | 1%                                 | 320          |
| DC                 | 29%        | 11%        | 50%        | 10%                                | 217          |
| FL                 | 36%        | 18%        | 42%        | 4%                                 | 400          |
| GA                 | 40%        | 15%        | 40%        | 5%                                 | 397          |
| HI                 | 17%        | 10%        | 71%        | 2%                                 | 206          |
| LA                 | 63%        | 6%         | 22%        | 9%                                 | 336          |
| MD                 | 50%        | 12%        | 32%        | 6%                                 | 671          |
| MS                 | 35%        | 10%        | 49%        | 6%                                 | 433          |
| NC                 | 15%        | 13%        | 67%        | 6%                                 | 248          |
| NH                 | 16%        | 9%         | 72%        | 2%                                 | 445          |
| OK                 | 22%        | 8%         | 66%        | 4%                                 | 460          |
| PA                 | 50%        | 10%        | 36%        | 4%                                 | 399          |
| VA                 | 22%        | 12%        | 64%        | 2%                                 | 153          |
| WA                 | 28%        | 11%        | 56%        | 4%                                 | 412          |
| <b>NCI Average</b> | <b>30%</b> | <b>10%</b> | <b>55%</b> | <b>4%</b>                          | <b>5,235</b> |



**Table 9. Guardian or Conservator Relationship to Family Member**

| State              | Family     | Friend    | State Employee or Guardianship Agency | Other     | N            |
|--------------------|------------|-----------|---------------------------------------|-----------|--------------|
| AK                 | 95%        | 3%        | 1%                                    | 1%        | 134          |
| AZ                 | 99%        | 0%        | 0%                                    | 0%        | 216          |
| DC                 | 96%        | 1%        | 2%                                    | 2%        | 127          |
| FL                 | 99%        | 0%        | 0%                                    | 1%        | 218          |
| GA                 | 93%        | 3%        | 1%                                    | 3%        | 186          |
| HI                 | 93%        | 3%        | 0%                                    | 4%        | 155          |
| LA                 | 93%        | 3%        | 0%                                    | 5%        | 108          |
| MD                 | 98%        | 1%        | 1%                                    | 0%        | 267          |
| MS                 | 98%        | 1%        | 0%                                    | 1%        | 213          |
| NC                 | 97%        | 1%        | 1%                                    | 2%        | 196          |
| NH                 | 98%        | 0%        | 1%                                    | 1%        | 353          |
| OK                 | 100%       | 0%        | 0%                                    | 0%        | 341          |
| PA                 | 99%        | 1%        | 1%                                    | 0%        | 168          |
| VA                 | 98%        | 1%        | 0%                                    | 1%        | 94           |
| WA                 | 98%        | 0%        | 0%                                    | 2%        | 276          |
| <b>NCI Average</b> | <b>97%</b> | <b>1%</b> | <b>0%</b>                             | <b>2%</b> | <b>3,052</b> |

**Table 10. Family Member's Highest level of Education**

| State              | Middle or Junior High | Currently in High School | High School Certification | High School Diploma or GED | Vocational Training | Some College | College Degree or Higher | N            |
|--------------------|-----------------------|--------------------------|---------------------------|----------------------------|---------------------|--------------|--------------------------|--------------|
| AK                 | 4%                    | 2%                       | 59%                       | 26%                        | 2%                  | 3%           | 4%                       | 127          |
| AZ                 | 6%                    | 8%                       | 29%                       | 42%                        | 2%                  | 8%           | 4%                       | 290          |
| DC                 | 8%                    | 2%                       | 40%                       | 33%                        | 11%                 | 5%           | 2%                       | 190          |
| FL                 | 7%                    | 5%                       | 45%                       | 26%                        | 6%                  | 5%           | 5%                       | 363          |
| GA                 | 8%                    | 2%                       | 54%                       | 29%                        | 2%                  | 3%           | 3%                       | 380          |
| HI                 | 3%                    | 4%                       | 54%                       | 26%                        | 3%                  | 6%           | 4%                       | 188          |
| LA                 | 10%                   | 4%                       | 63%                       | 14%                        | 3%                  | 4%           | 4%                       | 335          |
| MD                 | 2%                    | 1%                       | 65%                       | 17%                        | 7%                  | 6%           | 3%                       | 675          |
| MS                 | 8%                    | 0%                       | 65%                       | 16%                        | 6%                  | 2%           | 2%                       | 389          |
| NC                 | 7%                    | 9%                       | 47%                       | 20%                        | 7%                  | 6%           | 5%                       | 232          |
| NH                 | 5%                    | 2%                       | 46%                       | 35%                        | 3%                  | 5%           | 5%                       | 410          |
| OK                 | 7%                    | 2%                       | 27%                       | 55%                        | 4%                  | 4%           | 2%                       | 427          |
| PA                 | 2%                    | 6%                       | 26%                       | 56%                        | 6%                  | 2%           | 3%                       | 400          |
| VA                 | 4%                    | 6%                       | 54%                       | 25%                        | 5%                  | 4%           | 2%                       | 142          |
| WA                 | 7%                    | 8%                       | 38%                       | 38%                        | 2%                  | 3%           | 5%                       | 412          |
| <b>NCI Average</b> | <b>6%</b>             | <b>4%</b>                | <b>47%</b>                | <b>31%</b>                 | <b>5%</b>           | <b>4%</b>    | <b>4%</b>                | <b>4,960</b> |

**Table 11. Family Member's Typical Day Activities – Paid Individual Job**

| State              | Never Does This | Usually/Often | Sometimes | N            |
|--------------------|-----------------|---------------|-----------|--------------|
| AK                 | 78%             | 20%           | 2%        | 128          |
| AZ                 | 90%             | 9%            | 1%        | 258          |
| DC                 | 82%             | 14%           | 4%        | 175          |
| FL                 | 88%             | 10%           | 2%        | 345          |
| GA                 | 85%             | 12%           | 3%        | 341          |
| HI                 | 88%             | 9%            | 3%        | 185          |
| LA                 | 90%             | 9%            | 2%        | 290          |
| MD                 | 67%             | 29%           | 5%        | 550          |
| MS                 | 89%             | 9%            | 2%        | 375          |
| NC                 | 82%             | 14%           | 3%        | 202          |
| NH                 | 58%             | 37%           | 6%        | 402          |
| OK                 | 84%             | 13%           | 2%        | 385          |
| PA                 | 77%             | 22%           | 2%        | 346          |
| VA                 | 92%             | 5%            | 4%        | 130          |
| WA                 | 67%             | 26%           | 6%        | 367          |
| <b>NCI Average</b> | <b>81%</b>      | <b>16%</b>    | <b>3%</b> | <b>4,479</b> |

**Table 12. Family Member's Typical Day Activities – Paid Small Group Job**

| State              | Never Does This | Usually/Often | Sometimes | N            |
|--------------------|-----------------|---------------|-----------|--------------|
| AK                 | 92%             | 5%            | 3%        | 121          |
| AZ                 | 86%             | 12%           | 2%        | 261          |
| DC                 | 88%             | 6%            | 5%        | 165          |
| FL                 | 95%             | 3%            | 2%        | 324          |
| GA                 | 90%             | 8%            | 3%        | 319          |
| HI                 | 91%             | 8%            | 1%        | 182          |
| LA                 | 89%             | 10%           | 1%        | 280          |
| MD                 | 74%             | 18%           | 8%        | 520          |
| MS                 | 89%             | 6%            | 4%        | 369          |
| NC                 | 93%             | 5%            | 2%        | 194          |
| NH                 | 87%             | 9%            | 4%        | 358          |
| OK                 | 86%             | 12%           | 2%        | 371          |
| PA                 | 91%             | 7%            | 2%        | 324          |
| VA                 | 91%             | 5%            | 3%        | 129          |
| WA                 | 92%             | 7%            | 1%        | 340          |
| <b>NCI Average</b> | <b>89%</b>      | <b>8%</b>     | <b>3%</b> | <b>4,257</b> |

**Table 13. Family Member's Typical Day Activities – Paid Facility-Based Activity**

| State              | Never Does This | Usually/Often | Sometimes | N            |
|--------------------|-----------------|---------------|-----------|--------------|
| AK                 | 85%             | 13%           | 2%        | 117          |
| AZ                 | 76%             | 22%           | 2%        | 268          |
| DC                 | 87%             | 8%            | 5%        | 166          |
| FL                 | 83%             | 13%           | 4%        | 335          |
| GA                 | 73%             | 20%           | 8%        | 333          |
| HI                 | 92%             | 6%            | 1%        | 173          |
| LA                 | 77%             | 19%           | 4%        | 295          |
| MD                 | 60%             | 30%           | 11%       | 549          |
| MS                 | 71%             | 22%           | 7%        | 391          |
| NC                 | 81%             | 16%           | 4%        | 198          |
| NH                 | 89%             | 8%            | 4%        | 359          |
| OK                 | 72%             | 26%           | 2%        | 398          |
| PA                 | 67%             | 30%           | 3%        | 361          |
| VA                 | 79%             | 16%           | 5%        | 134          |
| WA                 | 90%             | 8%            | 2%        | 336          |
| <b>NCI Average</b> | <b>79%</b>      | <b>17%</b>    | <b>4%</b> | <b>4,413</b> |

**Table 14. Family Member's Typical Day Activities – Unpaid Activity in the Community**

| State              | Never Does This | Usually/Often | Sometimes  | N            |
|--------------------|-----------------|---------------|------------|--------------|
| AK                 | 41%             | 41%           | 19%        | 123          |
| AZ                 | 71%             | 17%           | 12%        | 255          |
| DC                 | 55%             | 31%           | 14%        | 176          |
| FL                 | 72%             | 16%           | 12%        | 330          |
| GA                 | 56%             | 30%           | 13%        | 323          |
| HI                 | 61%             | 18%           | 21%        | 180          |
| LA                 | 76%             | 14%           | 10%        | 282          |
| MD                 | 56%             | 25%           | 19%        | 529          |
| MS                 | 84%             | 9%            | 7%         | 363          |
| NC                 | 55%             | 33%           | 12%        | 204          |
| NH                 | 34%             | 51%           | 15%        | 389          |
| OK                 | 66%             | 20%           | 14%        | 382          |
| PA                 | 60%             | 28%           | 13%        | 337          |
| VA                 | 64%             | 22%           | 14%        | 125          |
| WA                 | 62%             | 21%           | 17%        | 353          |
| <b>NCI Average</b> | <b>61%</b>      | <b>25%</b>    | <b>14%</b> | <b>4,351</b> |

**Table 15. Family Member's Typical Day Activities – Unpaid Activity in a Facility-Based Setting**

| State              | Never Does This | Usually/Often | Sometimes | N            |
|--------------------|-----------------|---------------|-----------|--------------|
| AK                 | 50%             | 45%           | 4%        | 121          |
| AZ                 | 53%             | 41%           | 7%        | 258          |
| DC                 | 47%             | 46%           | 7%        | 186          |
| FL                 | 68%             | 27%           | 5%        | 336          |
| GA                 | 54%             | 41%           | 5%        | 322          |
| HI                 | 64%             | 30%           | 6%        | 179          |
| LA                 | 74%             | 23%           | 3%        | 276          |
| MD                 | 55%             | 37%           | 8%        | 513          |
| MS                 | 62%             | 33%           | 5%        | 378          |
| NC                 | 67%             | 28%           | 5%        | 200          |
| NH                 | 77%             | 19%           | 3%        | 351          |
| OK                 | 86%             | 12%           | 2%        | 361          |
| PA                 | 67%             | 29%           | 4%        | 326          |
| VA                 | 52%             | 44%           | 4%        | 131          |
| WA                 | 87%             | 8%            | 5%        | 321          |
| <b>NCI Average</b> | <b>64%</b>      | <b>31%</b>    | <b>5%</b> | <b>4,259</b> |

**Table 16. Family Member's Typical Day Activities – School**

| State              | Never Does This | Usually/Often | Sometimes | N            |
|--------------------|-----------------|---------------|-----------|--------------|
| AK                 | 83%             | 12%           | 5%        | 111          |
| AZ                 | 73%             | 26%           | 1%        | 222          |
| DC                 | 75%             | 22%           | 3%        | 120          |
| FL                 | 72%             | 26%           | 1%        | 269          |
| GA                 | 86%             | 12%           | 2%        | 267          |
| HI                 | 84%             | 13%           | 3%        | 152          |
| LA                 | 83%             | 16%           | 1%        | 228          |
| MD                 | 87%             | 8%            | 5%        | 395          |
| MS                 | 93%             | 6%            | 1%        | 287          |
| NC                 | 67%             | 29%           | 4%        | 162          |
| NH                 | 86%             | 10%           | 4%        | 321          |
| OK                 | 90%             | 8%            | 2%        | 305          |
| PA                 | 81%             | 17%           | 2%        | 282          |
| VA                 | 80%             | 19%           | 1%        | 99           |
| WA                 | 81%             | 17%           | 2%        | 305          |
| <b>NCI Average</b> | <b>81%</b>      | <b>16%</b>    | <b>3%</b> | <b>3,525</b> |

**Table 17. Family Member's Typical Day Activities – Stays at Home**

| State              | Never Does This | Usually/Often | Sometimes  | N            |
|--------------------|-----------------|---------------|------------|--------------|
| AK                 | 13%             | 58%           | 29%        | 104          |
| AZ                 | 28%             | 49%           | 22%        | 211          |
| DC                 | 56%             | 32%           | 12%        | 117          |
| FL                 | 18%             | 61%           | 22%        | 274          |
| GA                 | 36%             | 41%           | 22%        | 264          |
| HI                 | 27%             | 51%           | 22%        | 138          |
| LA                 | 26%             | 62%           | 12%        | 234          |
| MD                 | 50%             | 30%           | 19%        | 381          |
| MS                 | 25%             | 55%           | 20%        | 309          |
| NC                 | 19%             | 64%           | 17%        | 165          |
| NH                 | 27%             | 49%           | 25%        | 309          |
| OK                 | 18%             | 68%           | 14%        | 352          |
| PA                 | 27%             | 55%           | 18%        | 287          |
| VA                 | 23%             | 53%           | 24%        | 108          |
| WA                 | 14%             | 74%           | 13%        | 323          |
| <b>NCI Average</b> | <b>27%</b>      | <b>53%</b>    | <b>19%</b> | <b>3,576</b> |

**Table 18. Family Member's Typical Day Activities – Other**

| State              | Never Does This | Usually/Often | Sometimes | N          |
|--------------------|-----------------|---------------|-----------|------------|
| AK                 | 38%             | 62%           | 0%        | 26         |
| AZ                 | 49%             | 40%           | 10%       | 77         |
| DC                 | 16%             | 76%           | 8%        | 37         |
| FL                 | 43%             | 54%           | 4%        | 80         |
| GA                 | 37%             | 51%           | 12%       | 67         |
| HI                 | 25%             | 63%           | 13%       | 56         |
| LA                 | 38%             | 53%           | 9%        | 64         |
| MD                 | 38%             | 51%           | 10%       | 107        |
| MS                 | 36%             | 55%           | 9%        | 76         |
| NC                 | 40%             | 56%           | 4%        | 48         |
| NH                 | 19%             | 68%           | 14%       | 74         |
| OK                 | 24%             | 66%           | 10%       | 79         |
| PA                 | 37%             | 56%           | 7%        | 54         |
| VA                 | 33%             | 50%           | 17%       | 30         |
| WA                 | 15%             | 72%           | 14%       | 81         |
| <b>NCI Average</b> | <b>33%</b>      | <b>58%</b>    | <b>9%</b> | <b>956</b> |

**Table 19. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors**

| State              | None       | Some       | Extensive  | N            |
|--------------------|------------|------------|------------|--------------|
| AK                 | 40%        | 32%        | 28%        | 136          |
| AZ                 | 53%        | 32%        | 15%        | 321          |
| DC                 | 60%        | 27%        | 13%        | 226          |
| FL                 | 52%        | 32%        | 16%        | 422          |
| GA                 | 54%        | 30%        | 16%        | 428          |
| HI                 | 47%        | 31%        | 22%        | 213          |
| LA                 | 54%        | 23%        | 23%        | 370          |
| MD                 | 60%        | 28%        | 13%        | 714          |
| MS                 | 55%        | 24%        | 21%        | 472          |
| NC                 | 46%        | 36%        | 18%        | 251          |
| NH                 | 57%        | 30%        | 13%        | 438          |
| OK                 | 60%        | 24%        | 16%        | 458          |
| PA                 | 61%        | 28%        | 11%        | 435          |
| VA                 | 47%        | 32%        | 22%        | 161          |
| WA                 | 40%        | 36%        | 24%        | 418          |
| <b>NCI Average</b> | <b>52%</b> | <b>30%</b> | <b>18%</b> | <b>5,463</b> |

**Table 20. Family Member's Level of Help Needed With Personal Care Activities**

| State              | None       | Some       | Extensive  | N            |
|--------------------|------------|------------|------------|--------------|
| AK                 | 18%        | 44%        | 39%        | 140          |
| AZ                 | 14%        | 46%        | 40%        | 329          |
| DC                 | 37%        | 38%        | 26%        | 226          |
| FL                 | 21%        | 36%        | 43%        | 428          |
| GA                 | 30%        | 35%        | 35%        | 434          |
| HI                 | 29%        | 33%        | 38%        | 212          |
| LA                 | 20%        | 40%        | 40%        | 386          |
| MD                 | 33%        | 37%        | 29%        | 734          |
| MS                 | 21%        | 31%        | 49%        | 491          |
| NC                 | 19%        | 35%        | 47%        | 249          |
| NH                 | 34%        | 37%        | 29%        | 449          |
| OK                 | 19%        | 36%        | 45%        | 472          |
| PA                 | 37%        | 38%        | 25%        | 443          |
| VA                 | 9%         | 32%        | 59%        | 165          |
| WA                 | 11%        | 41%        | 48%        | 428          |
| <b>NCI Average</b> | <b>23%</b> | <b>37%</b> | <b>39%</b> | <b>5,586</b> |

**Table 21. Family Member's Need for Help With Other Daily Activities**

| State              | None      | Some       | Extensive  | N            |
|--------------------|-----------|------------|------------|--------------|
| AK                 | 3%        | 18%        | 79%        | 141          |
| AZ                 | 4%        | 17%        | 80%        | 332          |
| DC                 | 12%       | 30%        | 57%        | 227          |
| FL                 | 5%        | 17%        | 77%        | 425          |
| GA                 | 7%        | 23%        | 70%        | 434          |
| HI                 | 7%        | 23%        | 71%        | 211          |
| LA                 | 6%        | 21%        | 73%        | 382          |
| MD                 | 7%        | 25%        | 68%        | 728          |
| MS                 | 5%        | 16%        | 79%        | 491          |
| NC                 | 4%        | 17%        | 79%        | 248          |
| NH                 | 4%        | 26%        | 69%        | 447          |
| OK                 | 2%        | 16%        | 82%        | 469          |
| PA                 | 6%        | 26%        | 68%        | 440          |
| VA                 | 2%        | 10%        | 88%        | 164          |
| WA                 | 3%        | 11%        | 86%        | 428          |
| <b>NCI Average</b> | <b>5%</b> | <b>20%</b> | <b>75%</b> | <b>5,567</b> |

## **Respondents**

*This section provides demographic information about the respondent.*



Table 22. Respondent's Age

| State              | Under 35  | 35-54      | 55-74      | 75 or Older | N            |
|--------------------|-----------|------------|------------|-------------|--------------|
| AK                 | 4%        | 24%        | 66%        | 6%          | 139          |
| AZ                 | 2%        | 31%        | 57%        | 10%         | 334          |
| DC                 | 2%        | 19%        | 62%        | 18%         | 227          |
| FL                 | 3%        | 23%        | 59%        | 15%         | 427          |
| GA                 | 3%        | 21%        | 63%        | 13%         | 441          |
| HI                 | 1%        | 21%        | 67%        | 11%         | 215          |
| LA                 | 4%        | 25%        | 60%        | 12%         | 389          |
| MD                 | 2%        | 17%        | 69%        | 11%         | 740          |
| MS                 | 2%        | 19%        | 63%        | 15%         | 503          |
| NC                 | 2%        | 39%        | 50%        | 10%         | 252          |
| NH                 | 2%        | 23%        | 67%        | 8%          | 448          |
| OK                 | 3%        | 18%        | 68%        | 11%         | 475          |
| PA                 | 2%        | 26%        | 60%        | 12%         | 446          |
| VA                 | 1%        | 19%        | 70%        | 9%          | 166          |
| WA                 | 1%        | 26%        | 68%        | 5%          | 436          |
| <b>NCI Average</b> | <b>2%</b> | <b>23%</b> | <b>63%</b> | <b>11%</b>  | <b>5,638</b> |

Table 23. Respondent's Health

| State              | Excellent  | Very Good  | Fairly Good | Poor      | N            |
|--------------------|------------|------------|-------------|-----------|--------------|
| AK                 | 18%        | 50%        | 29%         | 4%        | 139          |
| AZ                 | 18%        | 44%        | 34%         | 4%        | 326          |
| DC                 | 12%        | 54%        | 31%         | 3%        | 234          |
| FL                 | 11%        | 40%        | 41%         | 8%        | 424          |
| GA                 | 9%         | 45%        | 42%         | 4%        | 443          |
| HI                 | 11%        | 48%        | 37%         | 4%        | 215          |
| LA                 | 11%        | 34%        | 45%         | 10%       | 388          |
| MD                 | 13%        | 46%        | 36%         | 5%        | 742          |
| MS                 | 4%         | 35%        | 52%         | 9%        | 496          |
| NC                 | 15%        | 47%        | 36%         | 2%        | 249          |
| NH                 | 17%        | 52%        | 29%         | 2%        | 445          |
| OK                 | 13%        | 45%        | 40%         | 3%        | 471          |
| PA                 | 14%        | 48%        | 35%         | 3%        | 443          |
| VA                 | 13%        | 46%        | 37%         | 4%        | 163          |
| WA                 | 14%        | 46%        | 36%         | 4%        | 434          |
| <b>NCI Average</b> | <b>13%</b> | <b>45%</b> | <b>37%</b>  | <b>5%</b> | <b>5,612</b> |

**Table 24. Respondent's Relationship to Family Member**

| State              | Parent     | Sibling   | Spouse    | Grandparent | Other     | N            |
|--------------------|------------|-----------|-----------|-------------|-----------|--------------|
| AK                 | 88%        | 6%        | 0%        | 1%          | 5%        | 139          |
| AZ                 | 89%        | 5%        | 0%        | 3%          | 3%        | 332          |
| DC                 | 78%        | 7%        | 0%        | 8%          | 7%        | 228          |
| FL                 | 83%        | 9%        | 0%        | 3%          | 5%        | 430          |
| GA                 | 83%        | 8%        | 1%        | 3%          | 5%        | 440          |
| HI                 | 88%        | 7%        | 0%        | 2%          | 2%        | 217          |
| LA                 | 79%        | 9%        | 0%        | 4%          | 8%        | 394          |
| MD                 | 88%        | 4%        | 1%        | 4%          | 3%        | 738          |
| MS                 | 81%        | 10%       | 0%        | 4%          | 4%        | 493          |
| NC                 | 79%        | 8%        | 0%        | 6%          | 7%        | 252          |
| NH                 | 91%        | 7%        | 0%        | 0%          | 2%        | 447          |
| OK                 | 90%        | 4%        | 0%        | 4%          | 2%        | 477          |
| PA                 | 89%        | 7%        | 0%        | 4%          | 1%        | 444          |
| VA                 | 85%        | 8%        | 0%        | 3%          | 4%        | 166          |
| WA                 | 88%        | 4%        | 0%        | 3%          | 5%        | 436          |
| <b>NCI Average</b> | <b>85%</b> | <b>7%</b> | <b>0%</b> | <b>3%</b>   | <b>4%</b> | <b>5,633</b> |

**Table 25. Respondent or Other Family Member Provides Paid Support to Family Member**

| State              | Respondent | Other Family | No         | N            |
|--------------------|------------|--------------|------------|--------------|
| AK                 | 11%        | 14%          | 75%        | 138          |
| AZ                 | 35%        | 12%          | 53%        | 334          |
| DC                 | 17%        | 4%           | 79%        | 236          |
| FL                 | 12%        | 6%           | 82%        | 423          |
| GA                 | 6%         | 3%           | 91%        | 436          |
| HI                 | 16%        | 18%          | 66%        | 218          |
| LA                 | 3%         | 17%          | 81%        | 390          |
| MD                 | 10%        | 2%           | 88%        | 732          |
| MS                 | 2%         | 8%           | 90%        | 500          |
| NC                 | 22%        | 7%           | 71%        | 252          |
| NH                 | 22%        | 6%           | 72%        | 440          |
| OK                 | 40%        | 12%          | 48%        | 472          |
| PA                 | 7%         | 6%           | 86%        | 442          |
| VA                 | 17%        | 17%          | 66%        | 158          |
| WA                 | 67%        | 11%          | 21%        | 434          |
| <b>NCI Average</b> | <b>19%</b> | <b>10%</b>   | <b>71%</b> | <b>5,605</b> |

**Table 26. Number of Adults in Household (Not Including Family Member Receiving Services)**

| State              | One        | Two        | Three      | Four or More | N            |
|--------------------|------------|------------|------------|--------------|--------------|
| AK                 | 9%         | 29%        | 40%        | 22%          | 138          |
| AZ                 | 12%        | 33%        | 38%        | 18%          | 329          |
| DC                 | 21%        | 45%        | 25%        | 9%           | 231          |
| FL                 | 12%        | 36%        | 37%        | 15%          | 422          |
| GA                 | 12%        | 36%        | 39%        | 13%          | 436          |
| HI                 | 10%        | 25%        | 41%        | 24%          | 217          |
| LA                 | 14%        | 36%        | 38%        | 12%          | 381          |
| MD                 | 12%        | 31%        | 43%        | 14%          | 734          |
| MS                 | 16%        | 43%        | 33%        | 8%           | 488          |
| NC                 | 10%        | 30%        | 46%        | 14%          | 252          |
| NH                 | 8%         | 30%        | 49%        | 13%          | 446          |
| OK                 | 8%         | 35%        | 46%        | 11%          | 472          |
| PA                 | 9%         | 28%        | 43%        | 20%          | 444          |
| VA                 | 5%         | 31%        | 53%        | 11%          | 162          |
| WA                 | 5%         | 26%        | 50%        | 18%          | 431          |
| <b>NCI Average</b> | <b>11%</b> | <b>33%</b> | <b>41%</b> | <b>15%</b>   | <b>5,583</b> |

**Table 27. Number of Children (younger than age 18) in Household**

| State              | One       | Two       | Three     | Four or More | None       | N            |
|--------------------|-----------|-----------|-----------|--------------|------------|--------------|
| AK                 | 12%       | 3%        | 1%        | 4%           | 80%        | 138          |
| AZ                 | 10%       | 5%        | 4%        | 1%           | 79%        | 329          |
| DC                 | 8%        | 7%        | 2%        | 1%           | 82%        | 225          |
| FL                 | 5%        | 5%        | 1%        | 2%           | 87%        | 425          |
| GA                 | 8%        | 5%        | 2%        | 0%           | 84%        | 431          |
| HI                 | 10%       | 6%        | 2%        | 1%           | 81%        | 218          |
| LA                 | 10%       | 3%        | 1%        | 0%           | 85%        | 384          |
| MD                 | 8%        | 4%        | 1%        | 1%           | 87%        | 736          |
| MS                 | 6%        | 2%        | 1%        | 1%           | 89%        | 486          |
| NC                 | 12%       | 3%        | 1%        | 1%           | 82%        | 253          |
| NH                 | 5%        | 2%        | 1%        | 1%           | 92%        | 446          |
| OK                 | 7%        | 3%        | 2%        | 0%           | 88%        | 473          |
| PA                 | 8%        | 3%        | 1%        | 0%           | 88%        | 443          |
| VA                 | 10%       | 3%        | 1%        | 1%           | 86%        | 163          |
| WA                 | 10%       | 5%        | 2%        | 1%           | 83%        | 426          |
| <b>NCI Average</b> | <b>9%</b> | <b>4%</b> | <b>1%</b> | <b>1%</b>    | <b>85%</b> | <b>5,576</b> |

**Table 28. Respondent's Highest Level of Education**

| State              | No High School Diploma or GED | High School Diploma or GED | Vocational School | Some College | College Degree or Higher | N            |
|--------------------|-------------------------------|----------------------------|-------------------|--------------|--------------------------|--------------|
| AK                 | 4%                            | 21%                        | 4%                | 30%          | 41%                      | 129          |
| AZ                 | 12%                           | 19%                        | 7%                | 32%          | 30%                      | 329          |
| DC                 | 12%                           | 42%                        | 7%                | 20%          | 20%                      | 226          |
| FL                 | 12%                           | 26%                        | 7%                | 24%          | 31%                      | 427          |
| GA                 | 12%                           | 34%                        | 6%                | 19%          | 30%                      | 441          |
| HI                 | 6%                            | 25%                        | 9%                | 27%          | 34%                      | 215          |
| LA                 | 15%                           | 31%                        | 8%                | 19%          | 27%                      | 388          |
| MD                 | 5%                            | 25%                        | 3%                | 22%          | 44%                      | 736          |
| MS                 | 11%                           | 34%                        | 4%                | 22%          | 29%                      | 462          |
| NC                 | 7%                            | 23%                        | 6%                | 24%          | 40%                      | 252          |
| NH                 | 3%                            | 28%                        | 6%                | 17%          | 46%                      | 446          |
| OK                 | 5%                            | 28%                        | 9%                | 24%          | 34%                      | 474          |
| PA                 | 7%                            | 36%                        | 6%                | 21%          | 30%                      | 447          |
| VA                 | 5%                            | 25%                        | 7%                | 20%          | 44%                      | 162          |
| WA                 | 9%                            | 21%                        | 6%                | 29%          | 35%                      | 434          |
| <b>NCI Average</b> | <b>8%</b>                     | <b>28%</b>                 | <b>6%</b>         | <b>23%</b>   | <b>34%</b>               | <b>5,568</b> |

**Table 29. Total Taxable Household Income of Wage Earners in the Past Year**

| State              | Below \$15,000 | \$15,001-\$25,000 | \$25,001-\$50,000 | \$50,001-\$75,000 | Over \$75,000 | No Earned Income | N           |
|--------------------|----------------|-------------------|-------------------|-------------------|---------------|------------------|-------------|
| AK                 | 9%             | 7%                | 18%               | 29%               | 32%           | 5%               | 111         |
| AZ                 | 13%            | 19%               | 29%               | 12%               | 16%           | 11%              | 261         |
| DC                 | 22%            | 16%               | 19%               | 11%               | 10%           | 22%              | 183         |
| FL                 | 17%            | 21%               | 19%               | 11%               | 10%           | 21%              | 342         |
| GA                 | 17%            | 16%               | 19%               | 13%               | 15%           | 21%              | 351         |
| HI                 | 13%            | 14%               | 26%               | 18%               | 20%           | 9%               | 174         |
| LA                 | 19%            | 13%               | 24%               | 12%               | 14%           | 19%              | 311         |
| MD                 | 11%            | 12%               | 23%               | 15%               | 29%           | 11%              | 561         |
| MS                 | 21%            | 18%               | 20%               | 9%                | 5%            | 27%              | 394         |
| NC                 | 11%            | 14%               | 27%               | 16%               | 19%           | 13%              | 212         |
| NH                 | 12%            | 11%               | 26%               | 18%               | 22%           | 11%              | 335         |
| OK                 | 17%            | 14%               | 26%               | 16%               | 18%           | 9%               | 372         |
| PA                 | 13%            | 15%               | 25%               | 19%               | 16%           | 12%              | 334         |
| VA                 | 15%            | 15%               | 24%               | 10%               | 25%           | 12%              | 113         |
| WA                 | 12%            | 14%               | 28%               | 20%               | 21%           | 5%               | 349         |
| <b>NCI Average</b> | <b>15%</b>     | <b>15%</b>        | <b>24%</b>        | <b>15%</b>        | <b>18%</b>    | <b>14%</b>       | <b>4403</b> |

**Table 30. Residential Designation (Urban/Suburban or Rural)**

| State              | Urban or Suburban | Rural      | N            |
|--------------------|-------------------|------------|--------------|
| AK                 | 59%               | 41%        | 139          |
| AZ                 | 82%               | 18%        | 314          |
| DC                 | 99%               | 1%         | 171          |
| FL                 | 80%               | 20%        | 412          |
| GA                 | 61%               | 39%        | 421          |
| HI                 | 56%               | 44%        | 203          |
| LA                 | 55%               | 45%        | 370          |
| MD                 | 69%               | 31%        | 714          |
| MS                 | 52%               | 48%        | 479          |
| NC                 | 54%               | 46%        | 251          |
| NH                 | 47%               | 53%        | 438          |
| OK                 | 66%               | 34%        | 470          |
| PA                 | 61%               | 39%        | 423          |
| VA                 | 62%               | 38%        | 159          |
| WA                 | 70%               | 30%        | 422          |
| <b>NCI Average</b> | <b>65%</b>        | <b>35%</b> | <b>5,386</b> |

## Services and Supports Received

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

**Table 31. Services and Supports Received From IDD Agency**

| State              | Financial Support | In-home Support | Out-of-home Respite | Day or Employment Supports | Transportation | Other      | Self-direction or Fiscal Intermediary Services |
|--------------------|-------------------|-----------------|---------------------|----------------------------|----------------|------------|--|
| AK                 | 29%               | 65%             | 66%                 | 46%                        | 56%            | 28%        | 27%  |
| AZ                 | 15%               | 37%             | 49%                 | 61%                        | 64%            | 38%        | 21%  |
| DC                 | 16%               | 62%             | 33%                 | 67%                        | 82%            | 45%        | 0%   |
| FL                 | 17%               | 51%             | 24%                 | 42%                        | 53%            | 31%        | 38%  |
| GA                 | 16%               | 34%             | 21%                 | 64%                        | 71%            | 19%        | 32%  |
| HI                 | 15%               | 33%             | 30%                 | 54%                        | 60%            | 20%        | 29%  |
| LA                 | 8%                | 66%             | 23%                 | 41%                        | 55%            | 14%        | 22%  |
| MD                 | 8%                | 20%             | 18%                 | 76%                        | 77%            | 16%        | 15%  |
| MS                 | 10%               | 60%             | 22%                 | 55%                        | 61%            | 13%        | 14%  |
| NC                 | 8%                | 64%             | 47%                 | 49%                        | 51%            | 22%        | 20%  |
| NH                 | 38%               | 29%             | 38%                 | 57%                        | 61%            | 24%        | 42%  |
| OK                 | 19%               | 52%             | 13%                 | 38%                        | 46%            | 26%        | 24%  |
| PA                 | 10%               | 30%             | 26%                 | 59%                        | 59%            | 20%        | 24%  |
| VA                 | 12%               | 53%             | 28%                 | 60%                        | 63%            | 24%        | 45%  |
| WA                 | 27%               | 31%             | 35%                 | 38%                        | 44%            | 17%        | 25%  |
| <b>NCI Average</b> | <b>17%</b>        | <b>46%</b>      | <b>32%</b>          | <b>54%</b>                 | <b>60%</b>     | <b>24%</b> | <b>25%</b>                                     |

**Table 32. Additional Services and Supports Received (not from the IDD Agency)**

| State              | SSI/SSB    | Other Agencies or Organizations |
|--------------------|------------|---------------------------------|
| AK                 | 94%        | 47%                             |
| AZ                 | 95%        | 24%                             |
| DC                 | 90%        | 27%                             |
| FL                 | 94%        | 25%                             |
| GA                 | 98%        | 21%                             |
| HI                 | 91%        | 35%                             |
| LA                 | 95%        | 20%                             |
| MD                 | 91%        | 23%                             |
| MS                 | 95%        | 14%                             |
| NC                 | 97%        | 38%                             |
| NH                 | 93%        | 19%                             |
| OK                 | 97%        | 13%                             |
| PA                 | 93%        | 41%                             |
| VA                 | 98%        | 28%                             |
| WA                 | 93%        | 26%                             |
| <b>NCI Average</b> | <b>94%</b> | <b>27%</b>                      |

# Adult Family Survey Results



## Information and Planning

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

### Gets Enough Information to Help Plan Services

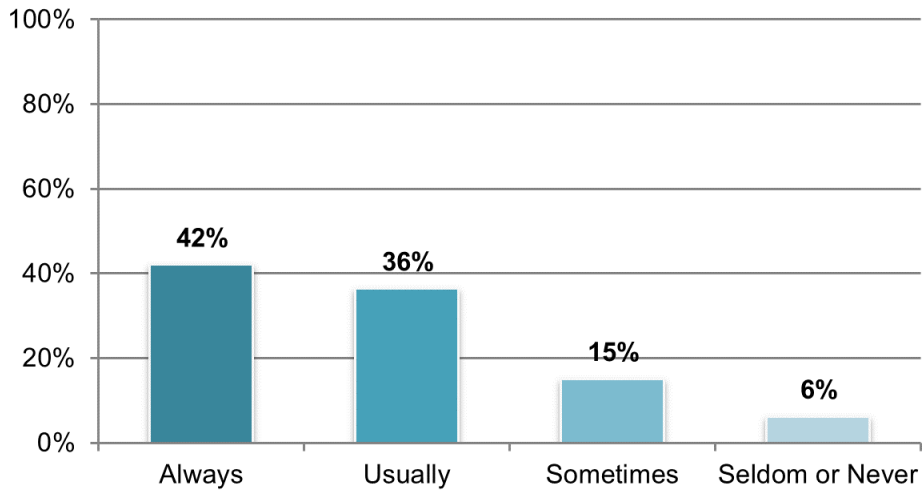


Table Q1. Do you get enough information to help you participate in planning services for your family?

| State                              | Always     | Usually    | Sometimes  | Seldom or Never | N            |
|------------------------------------|------------|------------|------------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |            |                 |              |
| LA                                 | 53%        | 30%        | 12%        | 4%              | 361          |
| <b>Within Average Range</b>        |            |            |            |                 |              |
| AK                                 | 50%        | 39%        | 9%         | 2%              | 137          |
| DC                                 | 47%        | 27%        | 22%        | 4%              | 214          |
| VA                                 | 46%        | 37%        | 13%        | 3%              | 157          |
| NC                                 | 44%        | 33%        | 14%        | 8%              | 236          |
| AZ                                 | 44%        | 39%        | 10%        | 7%              | 304          |
| OK                                 | 44%        | 40%        | 12%        | 4%              | 458          |
| HI                                 | 43%        | 41%        | 12%        | 5%              | 207          |
| NH                                 | 42%        | 37%        | 13%        | 7%              | 433          |
| FL                                 | 42%        | 37%        | 15%        | 7%              | 398          |
| PA                                 | 41%        | 37%        | 18%        | 4%              | 404          |
| MS                                 | 36%        | 36%        | 20%        | 8%              | 430          |
| <b>Significantly Below Average</b> |            |            |            |                 |              |
| WA                                 | 36%        | 44%        | 12%        | 8%              | 403          |
| GA                                 | 35%        | 33%        | 22%        | 11%             | 406          |
| MD                                 | 29%        | 38%        | 21%        | 12%             | 679          |
| <b>NCI Average</b>                 | <b>42%</b> | <b>36%</b> | <b>15%</b> | <b>6%</b>       | <b>5,227</b> |

### Information About Services and Supports Is Easy to Understand

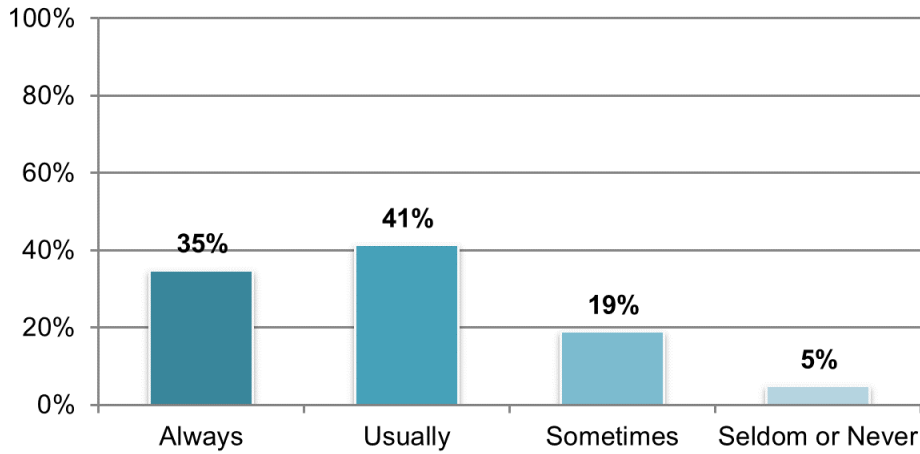


Table Q2. Is the information you receive easy to understand?

| State                              | Always     | Usually    | Sometimes  | Seldom or Never | N            |
|------------------------------------|------------|------------|------------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |            |                 |              |
| LA                                 | 45%        | 37%        | 16%        | 2%              | 363          |
| <b>Within Average Range</b>        |            |            |            |                 |              |
| DC                                 | 43%        | 33%        | 21%        | 3%              | 216          |
| VA                                 | 37%        | 40%        | 21%        | 2%              | 161          |
| NH                                 | 37%        | 43%        | 14%        | 6%              | 430          |
| AZ                                 | 36%        | 46%        | 14%        | 4%              | 311          |
| FL                                 | 36%        | 37%        | 22%        | 5%              | 393          |
| MS                                 | 35%        | 36%        | 23%        | 6%              | 452          |
| PA                                 | 35%        | 44%        | 18%        | 4%              | 413          |
| HI                                 | 34%        | 47%        | 17%        | 1%              | 212          |
| OK                                 | 34%        | 46%        | 16%        | 4%              | 455          |
| AK                                 | 32%        | 47%        | 17%        | 4%              | 137          |
| NC                                 | 31%        | 44%        | 18%        | 7%              | 236          |
| WA                                 | 30%        | 40%        | 21%        | 9%              | 412          |
| <b>Significantly Below Average</b> |            |            |            |                 |              |
| MD                                 | 29%        | 41%        | 21%        | 9%              | 675          |
| GA                                 | 28%        | 40%        | 24%        | 8%              | 398          |
| <b>NCI Average</b>                 | <b>35%</b> | <b>41%</b> | <b>19%</b> | <b>5%</b>       | <b>5,264</b> |

### Case Manager or Service Coordinator Respects Family's Choices and Opinions

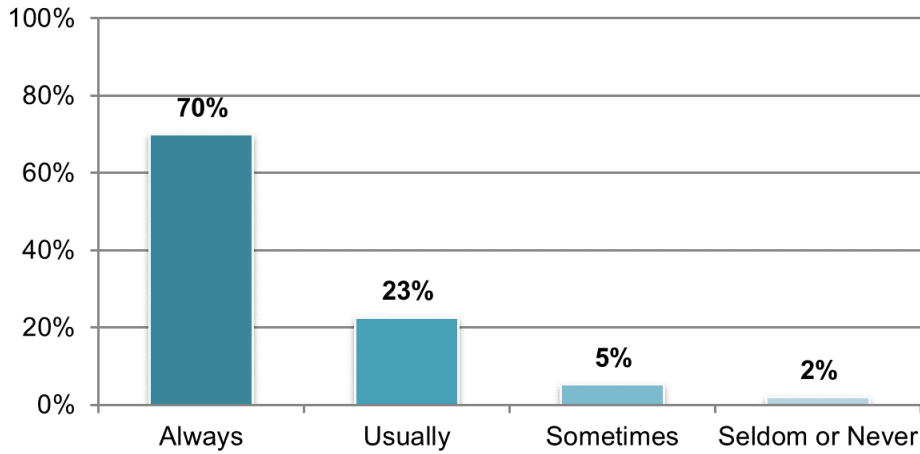


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| AK                                 | 79%        | 19%        | 1%        | 1%              | 135          |
| AZ                                 | 77%        | 18%        | 2%        | 2%              | 324          |
| FL                                 | 76%        | 17%        | 4%        | 3%              | 417          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| LA                                 | 75%        | 20%        | 4%        | 1%              | 376          |
| WA                                 | 73%        | 21%        | 4%        | 1%              | 419          |
| HI                                 | 71%        | 23%        | 4%        | 1%              | 214          |
| VA                                 | 71%        | 25%        | 4%        | 1%              | 163          |
| NC                                 | 70%        | 22%        | 5%        | 3%              | 230          |
| MS                                 | 70%        | 23%        | 6%        | 2%              | 460          |
| DC                                 | 68%        | 19%        | 10%       | 2%              | 224          |
| PA                                 | 68%        | 25%        | 6%        | 1%              | 410          |
| OK                                 | 67%        | 26%        | 6%        | 1%              | 469          |
| NH                                 | 66%        | 24%        | 7%        | 4%              | 429          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| MD                                 | 60%        | 29%        | 6%        | 4%              | 694          |
| GA                                 | 58%        | 29%        | 9%        | 3%              | 405          |
| <b>NCI Average</b>                 | <b>70%</b> | <b>23%</b> | <b>5%</b> | <b>2%</b>       | <b>5,369</b> |

### Gets Enough Information About Other Public Services for Which Family Is Eligible

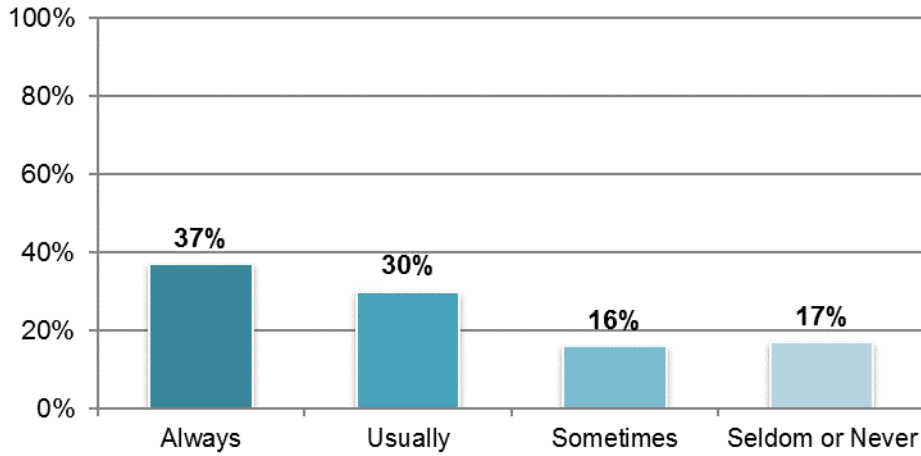


Table Q4. Do you get enough information about other public services for which your family is eligible?

| State                              | Always     | Usually    | Sometimes  | Seldom or Never | N            |
|------------------------------------|------------|------------|------------|-----------------|--------------|
| <b>Within Average Range</b>        |            |            |            |                 |              |
| DC                                 | 44%        | 23%        | 16%        | 17%             | 204          |
| LA                                 | 43%        | 26%        | 15%        | 16%             | 331          |
| AZ                                 | 41%        | 27%        | 14%        | 18%             | 294          |
| HI                                 | 41%        | 31%        | 13%        | 15%             | 193          |
| FL                                 | 40%        | 25%        | 16%        | 20%             | 374          |
| VA                                 | 39%        | 29%        | 16%        | 16%             | 145          |
| OK                                 | 38%        | 40%        | 12%        | 9%              | 432          |
| AK                                 | 38%        | 37%        | 16%        | 9%              | 132          |
| PA                                 | 38%        | 30%        | 16%        | 16%             | 374          |
| MS                                 | 37%        | 27%        | 16%        | 20%             | 398          |
| NH                                 | 36%        | 31%        | 15%        | 18%             | 398          |
| WA                                 | 32%        | 40%        | 17%        | 11%             | 406          |
| GA                                 | 31%        | 27%        | 19%        | 24%             | 364          |
| NC                                 | 31%        | 29%        | 22%        | 18%             | 215          |
| <b>Significantly Below Average</b> |            |            |            |                 |              |
| MD                                 | 23%        | 31%        | 21%        | 25%             | 611          |
| <b>NCI Average</b>                 | <b>37%</b> | <b>30%</b> | <b>16%</b> | <b>17%</b>      | <b>4,871</b> |

### Respondent Needs Help Planning for Family Member's Future Needs

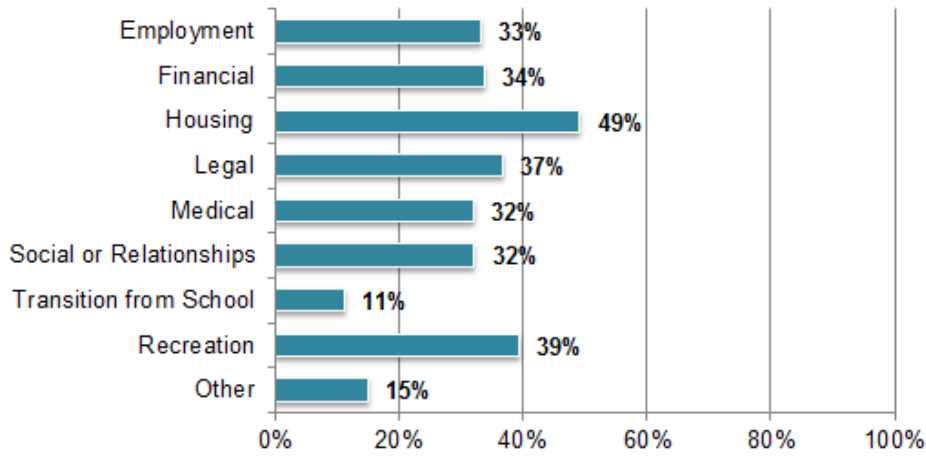


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

| State              | Employment | Financial  | Housing    | Legal      | Medical    | Social or Relationships | Transition From School | Recreation | Other      | N            |
|--------------------|------------|------------|------------|------------|------------|-------------------------|------------------------|------------|------------|--------------|
| AK                 | 47%        | 38%        | 52%        | 31%        | 33%        | 40%                     | 16%                    | 40%        | 19%        | 90           |
| AZ                 | 30%        | 31%        | 47%        | 36%        | 30%        | 28%                     | 12%                    | 40%        | 17%        | 178          |
| DC                 | 45%        | 24%        | 49%        | 33%        | 24%        | 28%                     | 9%                     | 45%        | 9%         | 148          |
| FL                 | 28%        | 33%        | 42%        | 42%        | 35%        | 30%                     | 14%                    | 42%        | 16%        | 281          |
| GA                 | 22%        | 35%        | 48%        | 37%        | 36%        | 26%                     | 8%                     | 40%        | 10%        | 250          |
| HI                 | 36%        | 41%        | 48%        | 51%        | 35%        | 33%                     | 16%                    | 30%        | 11%        | 130          |
| LA                 | 25%        | 25%        | 36%        | 28%        | 30%        | 24%                     | 11%                    | 35%        | 25%        | 206          |
| MD                 | 36%        | 39%        | 61%        | 38%        | 30%        | 38%                     | 5%                     | 42%        | 14%        | 485          |
| MS                 | 15%        | 22%        | 34%        | 34%        | 32%        | 22%                     | 5%                     | 29%        | 26%        | 268          |
| NC                 | 33%        | 36%        | 46%        | 41%        | 31%        | 36%                     | 16%                    | 45%        | 14%        | 160          |
| NH                 | 44%        | 43%        | 59%        | 29%        | 30%        | 44%                     | 6%                     | 39%        | 13%        | 268          |
| OK                 | 28%        | 32%        | 48%        | 35%        | 42%        | 29%                     | 9%                     | 35%        | 15%        | 186          |
| PA                 | 32%        | 31%        | 55%        | 32%        | 23%        | 33%                     | 10%                    | 40%        | 9%         | 244          |
| VA                 | 28%        | 41%        | 62%        | 44%        | 36%        | 38%                     | 15%                    | 47%        | 13%        | 86           |
| WA                 | 46%        | 35%        | 52%        | 40%        | 32%        | 32%                     | 14%                    | 41%        | 13%        | 259          |
| <b>NCI Average</b> | <b>33%</b> | <b>34%</b> | <b>49%</b> | <b>37%</b> | <b>32%</b> | <b>32%</b>              | <b>11%</b>             | <b>39%</b> | <b>15%</b> | <b>3,239</b> |

### Crisis or Emergency Services Were Provided When Needed (If Requested in the Past Year)

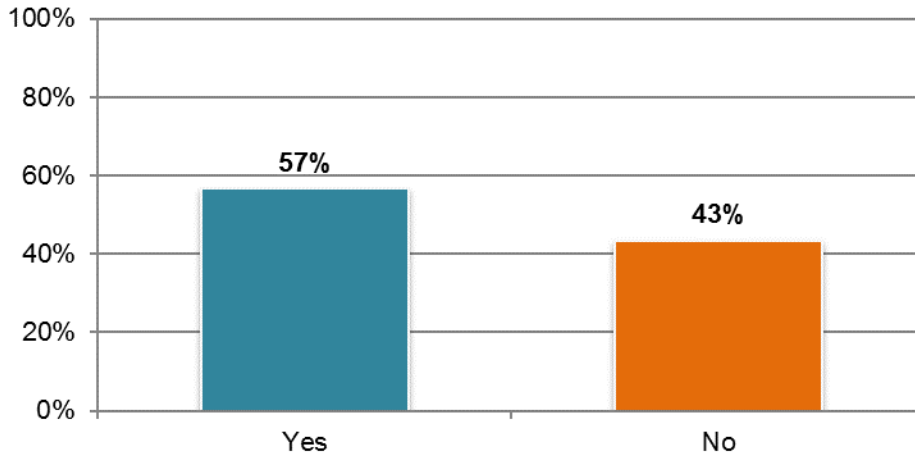


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Within Average Range</b>        |            |            |              |
| HI                                 | 70%        | 30%        | 47           |
| VA                                 | 70%        | 30%        | 33           |
| LA                                 | 69%        | 31%        | 96           |
| MS                                 | 62%        | 38%        | 143          |
| DC                                 | 61%        | 39%        | 83           |
| NC                                 | 57%        | 43%        | 60           |
| AK                                 | 56%        | 44%        | 27           |
| FL                                 | 55%        | 45%        | 110          |
| PA                                 | 53%        | 47%        | 92           |
| WA                                 | 53%        | 47%        | 81           |
| NH                                 | 53%        | 47%        | 97           |
| AZ                                 | 51%        | 49%        | 67           |
| GA                                 | 49%        | 51%        | 107          |
| OK                                 | 45%        | 55%        | 77           |
| <b>Significantly Below Average</b> |            |            |              |
| MD                                 | 45%        | 55%        | 137          |
| <b>NCI Average</b>                 | <b>57%</b> | <b>43%</b> | <b>1,257</b> |

### Family Member Has a Service Plan

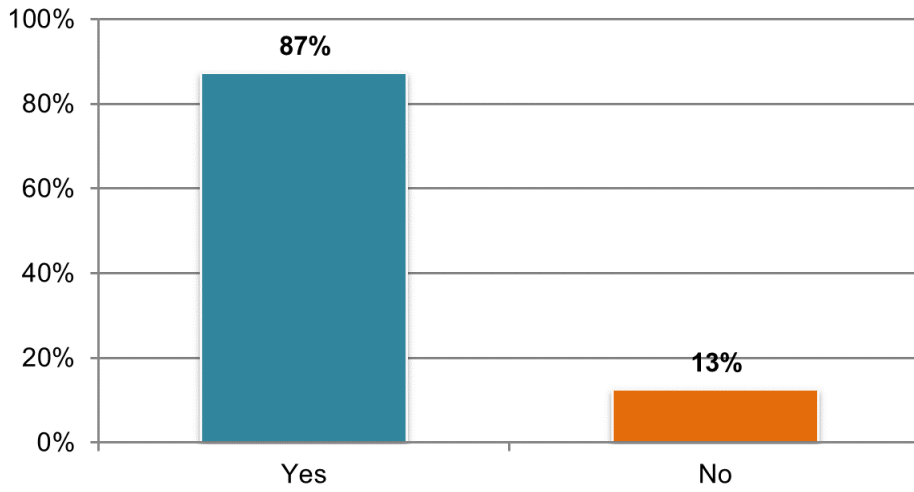


Table Q7. Does your family member have a service plan?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| AK                                 | 96%        | 4%         | 121          |
| PA                                 | 94%        | 6%         | 411          |
| HI                                 | 94%        | 6%         | 188          |
| OK                                 | 93%        | 7%         | 421          |
| FL                                 | 93%        | 7%         | 381          |
| <b>Within Average Range</b>        |            |            |              |
| AZ                                 | 91%        | 9%         | 291          |
| VA                                 | 89%        | 11%        | 139          |
| NH                                 | 87%        | 13%        | 386          |
| NC                                 | 86%        | 14%        | 213          |
| LA                                 | 86%        | 14%        | 315          |
| DC                                 | 83%        | 17%        | 199          |
| WA                                 | 83%        | 17%        | 349          |
| <b>Significantly Below Average</b> |            |            |              |
| MS                                 | 80%        | 20%        | 350          |
| MD                                 | 80%        | 20%        | 574          |
| GA                                 | 74%        | 26%        | 334          |
| <b>NCI Average</b>                 | <b>87%</b> | <b>13%</b> | <b>4,672</b> |



### Service Plan Includes All the Services and Supports Family Member Needs

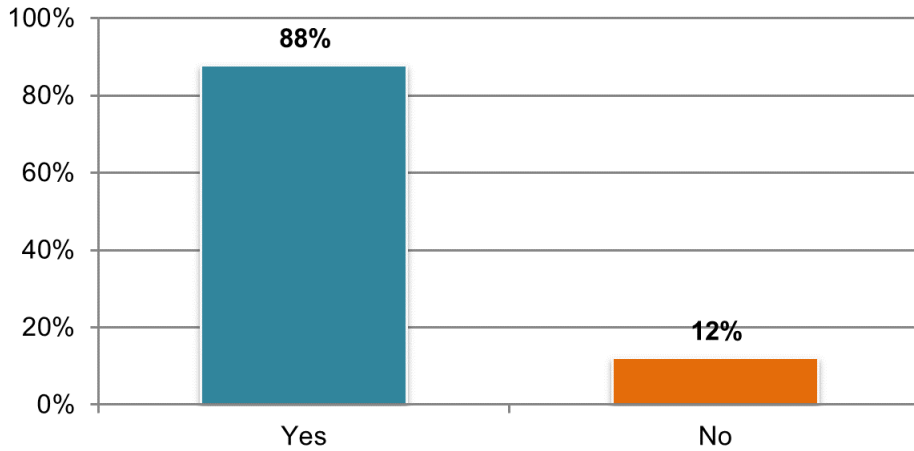


Table Q8. Does the plan include all the services and supports your family member needs?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| LA                                 | 96%        | 4%         | 248          |
| PA                                 | 95%        | 5%         | 352          |
| <b>Within Average Range</b>        |            |            |              |
| MS                                 | 92%        | 8%         | 259          |
| HI                                 | 91%        | 9%         | 165          |
| AZ                                 | 91%        | 9%         | 240          |
| DC                                 | 90%        | 10%        | 153          |
| NC                                 | 87%        | 13%        | 170          |
| VA                                 | 87%        | 13%        | 114          |
| WA                                 | 86%        | 14%        | 246          |
| OK                                 | 86%        | 14%        | 356          |
| FL                                 | 85%        | 15%        | 310          |
| NH                                 | 85%        | 15%        | 312          |
| GA                                 | 84%        | 16%        | 210          |
| AK                                 | 82%        | 18%        | 105          |
| <b>Significantly Below Average</b> |            |            |              |
| MD                                 | 82%        | 18%        | 388          |
| <b>NCI Average</b>                 | <b>88%</b> | <b>12%</b> | <b>3,628</b> |

### Family Member Receives All Services Listed in the Service Plan

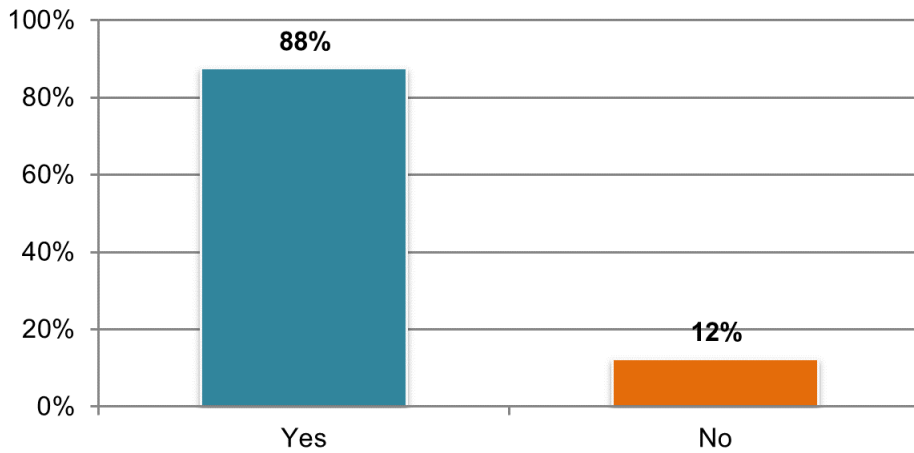


Table Q9. Does your family member receive all the services listed in the plan?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| PA                                 | 94%        | 6%         | 343          |
| <b>Within Average Range</b>        |            |            |              |
| NC                                 | 92%        | 8%         | 168          |
| LA                                 | 92%        | 8%         | 239          |
| VA                                 | 91%        | 9%         | 109          |
| NH                                 | 90%        | 10%        | 314          |
| OK                                 | 90%        | 10%        | 356          |
| MS                                 | 90%        | 10%        | 255          |
| HI                                 | 89%        | 11%        | 159          |
| FL                                 | 88%        | 12%        | 315          |
| GA                                 | 87%        | 13%        | 214          |
| WA                                 | 87%        | 13%        | 240          |
| AZ                                 | 86%        | 14%        | 247          |
| AK                                 | 80%        | 20%        | 110          |
| DC                                 | 80%        | 20%        | 155          |
| <b>Significantly Below Average</b> |            |            |              |
| MD                                 | 78%        | 22%        | 386          |
| <b>NCI Average</b>                 | <b>88%</b> | <b>12%</b> | <b>3,610</b> |

### Respondent or Other Family Member Helped Develop Service Plan

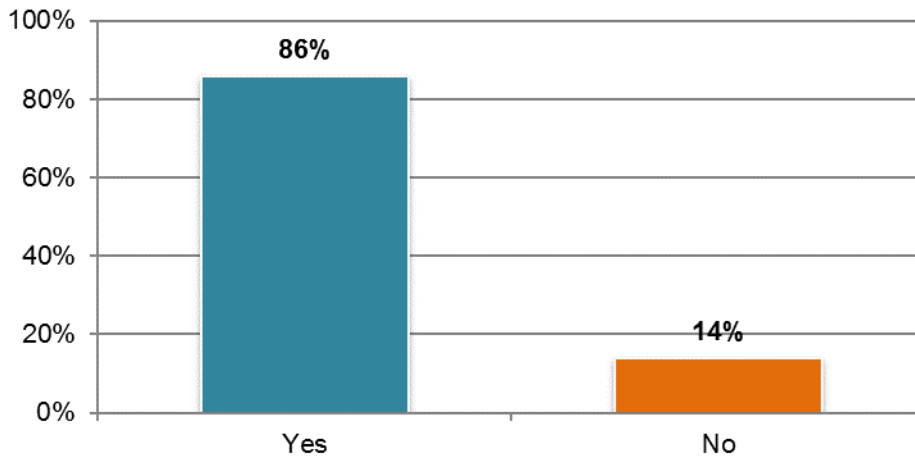


Table Q10. Did you or another family member help develop the plan?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| AK                                 | 94%        | 6%         | 113          |
| OK                                 | 93%        | 7%         | 381          |
| NH                                 | 91%        | 9%         | 327          |
| <b>Within Average Range</b>        |            |            |              |
| AZ                                 | 89%        | 11%        | 255          |
| PA                                 | 89%        | 11%        | 363          |
| NC                                 | 88%        | 12%        | 179          |
| VA                                 | 88%        | 13%        | 120          |
| WA                                 | 87%        | 13%        | 262          |
| MD                                 | 86%        | 14%        | 432          |
| HI                                 | 85%        | 15%        | 169          |
| FL                                 | 84%        | 16%        | 336          |
| LA                                 | 82%        | 18%        | 254          |
| MS                                 | 80%        | 20%        | 266          |
| <b>Significantly Below Average</b> |            |            |              |
| GA                                 | 79%        | 21%        | 229          |
| DC                                 | 75%        | 25%        | 159          |
| <b>NCI Average</b>                 | <b>86%</b> | <b>14%</b> | <b>3,845</b> |

### Family Member Helped Develop Service Plan

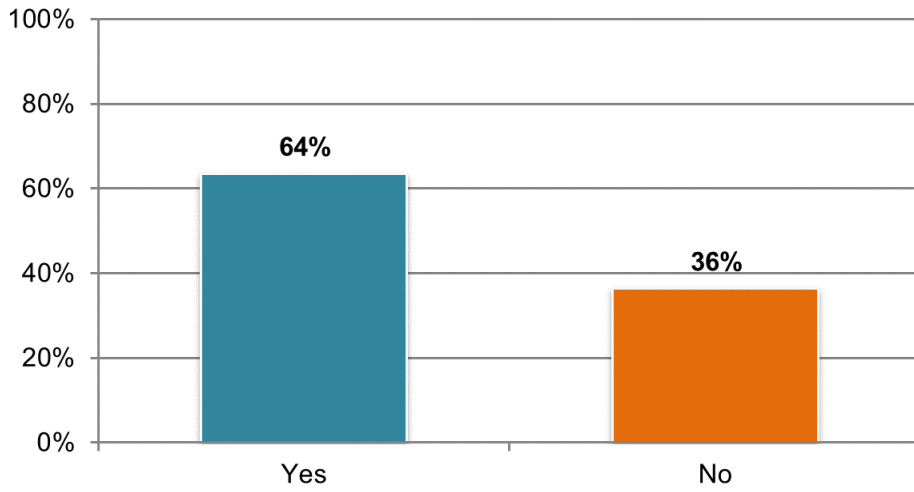


Table Q11. Did your family member help develop the plan?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| PA                                 | 73%        | 27%        | 358          |
| MD                                 | 71%        | 29%        | 416          |
| NH                                 | 71%        | 29%        | 326          |
| <b>Within Average Range</b>        |            |            |              |
| AK                                 | 67%        | 33%        | 113          |
| GA                                 | 67%        | 33%        | 233          |
| FL                                 | 66%        | 34%        | 330          |
| LA                                 | 64%        | 36%        | 255          |
| DC                                 | 64%        | 36%        | 154          |
| HI                                 | 63%        | 37%        | 165          |
| AZ                                 | 62%        | 38%        | 244          |
| OK                                 | 61%        | 39%        | 373          |
| WA                                 | 60%        | 40%        | 263          |
| VA                                 | 58%        | 42%        | 113          |
| NC                                 | 56%        | 44%        | 178          |
| <b>Significantly Below Average</b> |            |            |              |
| MS                                 | 50%        | 50%        | 267          |
| <b>NCI Average</b>                 | <b>64%</b> | <b>36%</b> | <b>3,788</b> |

### Respondent Discussed How to Handle Emergencies Related to Family Member at the Last Service Planning Meeting

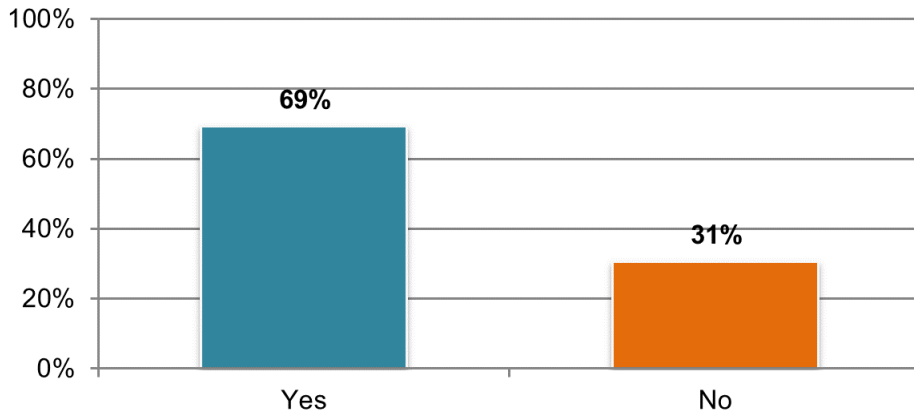


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| LA                                 | 94%        | 6%         | 262          |
| HI                                 | 84%        | 16%        | 164          |
| FL                                 | 83%        | 17%        | 324          |
| WA                                 | 81%        | 19%        | 253          |
| OK                                 | 78%        | 22%        | 360          |
| <b>Within Average Range</b>        |            |            |              |
| NC                                 | 77%        | 23%        | 171          |
| MS                                 | 70%        | 30%        | 253          |
| DC                                 | 69%        | 31%        | 153          |
| PA                                 | 66%        | 34%        | 323          |
| MD                                 | 64%        | 36%        | 410          |
| <b>Significantly Below Average</b> |            |            |              |
| AZ                                 | 58%        | 42%        | 245          |
| GA                                 | 58%        | 42%        | 212          |
| AK                                 | 53%        | 47%        | 109          |
| VA                                 | 53%        | 47%        | 115          |
| NH                                 | 52%        | 48%        | 304          |
| <b>NCI Average</b>                 | <b>69%</b> | <b>31%</b> | <b>3,658</b> |

### Respondent Feels Prepared to Handle the Needs of Family Member in an Emergency

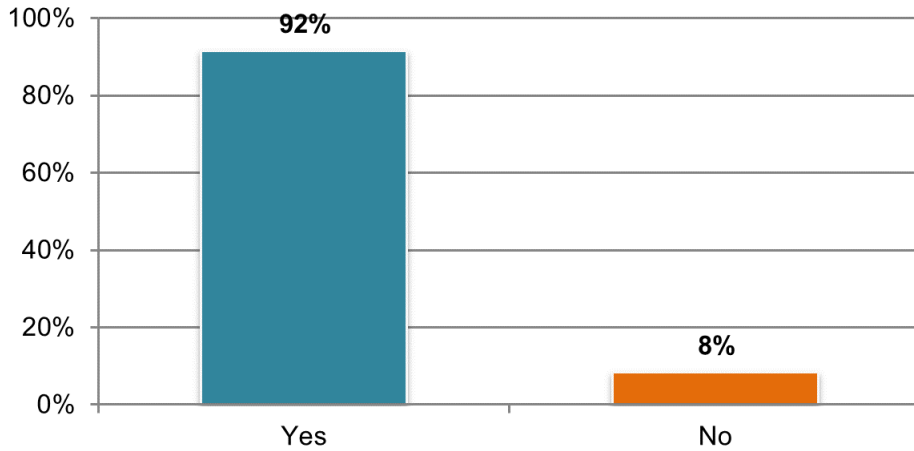


Table Q13. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| LA                                 | 97%        | 3%        | 259          |
| FL                                 | 96%        | 4%        | 336          |
| <b>Within Average Range</b>        |            |           |              |
| NC                                 | 95%        | 5%        | 172          |
| OK                                 | 94%        | 6%        | 377          |
| HI                                 | 94%        | 6%        | 165          |
| GA                                 | 93%        | 7%        | 229          |
| PA                                 | 93%        | 7%        | 352          |
| MS                                 | 93%        | 7%        | 269          |
| DC                                 | 92%        | 8%        | 157          |
| WA                                 | 91%        | 9%        | 271          |
| AZ                                 | 90%        | 10%       | 239          |
| NH                                 | 87%        | 13%       | 274          |
| VA                                 | 86%        | 14%       | 110          |
| AK                                 | 86%        | 14%       | 107          |
| <b>Significantly Below Average</b> |            |           |              |
| MD                                 | 87%        | 13%       | 415          |
| <b>NCI Average</b>                 | <b>92%</b> | <b>8%</b> | <b>3,732</b> |

### Family Member Had a Transition Plan (If Transitioned Out of School in the Past Year)

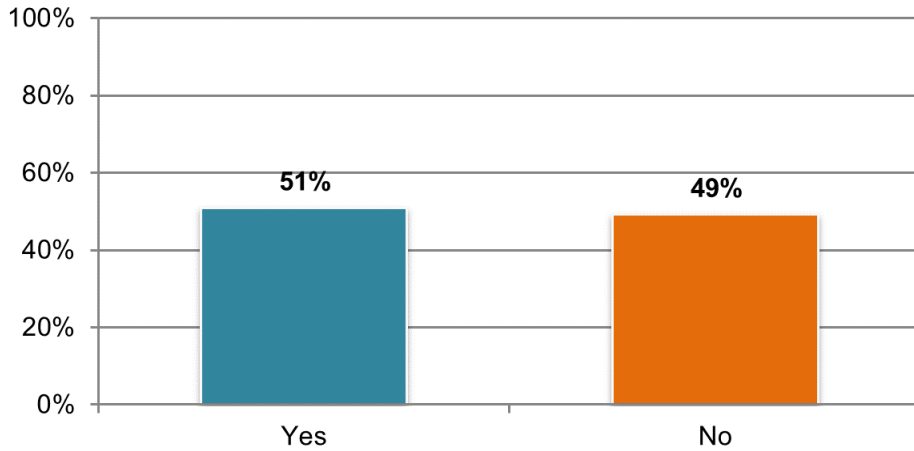


Table Q14. If your family member transitioned out of school services during the past year, did he/she have a transition plan?

| State                              | Yes        | No         | N          |
|------------------------------------|------------|------------|------------|
| <b>Significantly Above Average</b> |            |            |            |
| NH                                 | 78%        | 22%        | 37         |
| PA                                 | 75%        | 25%        | 52         |
| <b>Within Average Range</b>        |            |            |            |
| AK                                 | 65%        | 35%        | 20         |
| AZ                                 | 57%        | 43%        | 47         |
| NC                                 | 56%        | 44%        | 34         |
| MD                                 | 52%        | 48%        | 54         |
| HI                                 | 50%        | 50%        | 22         |
| FL                                 | 48%        | 52%        | 42         |
| WA                                 | 46%        | 54%        | 56         |
| GA                                 | 46%        | 54%        | 24         |
| OK                                 | 34%        | 66%        | 29         |
| <b>Significantly Below Average</b> |            |            |            |
| LA                                 | 28%        | 72%        | 46         |
| MS                                 | 25%        | 75%        | 24         |
| <b>NCI Average</b>                 | <b>51%</b> | <b>49%</b> | <b>487</b> |

**DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: DC, VA.**

### Transition Plan Included Getting or Continuing Work in a Paid Community Job

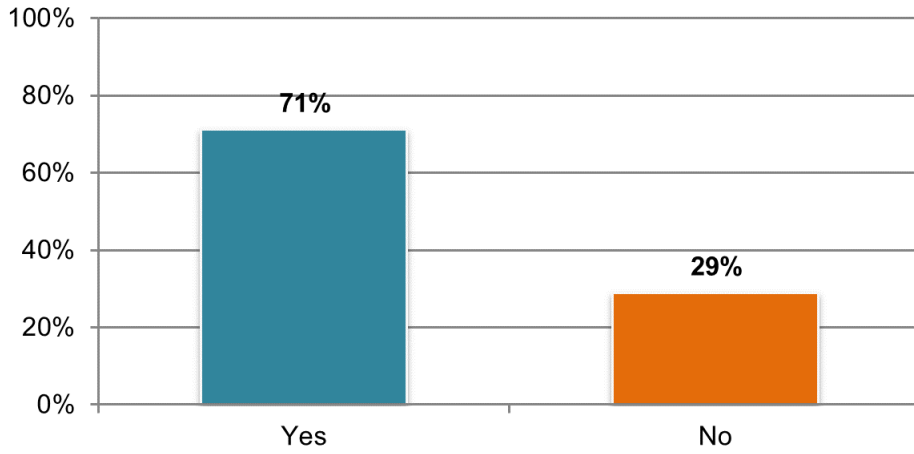


Table Q15. If yes to Q14, did the transition plan include getting or continuing work in a community job?

| State                              | Yes        | No         | N          |
|------------------------------------|------------|------------|------------|
| <b>Significantly Above Average</b> |            |            |            |
| WA                                 | 91%        | 9%         | 22         |
| <b>Within Average Range</b>        |            |            |            |
| MD                                 | 84%        | 16%        | 25         |
| NH                                 | 76%        | 24%        | 25         |
| PA                                 | 64%        | 36%        | 36         |
| AZ                                 | 41%        | 59%        | 22         |
| <b>NCI Average</b>                 | <b>71%</b> | <b>29%</b> | <b>130</b> |

**DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: AK, DC, FL, GA, HI, LA, MS, NC, OK, AND VA.**



### Family Member Has Enough Support to Work or Volunteer in the Community

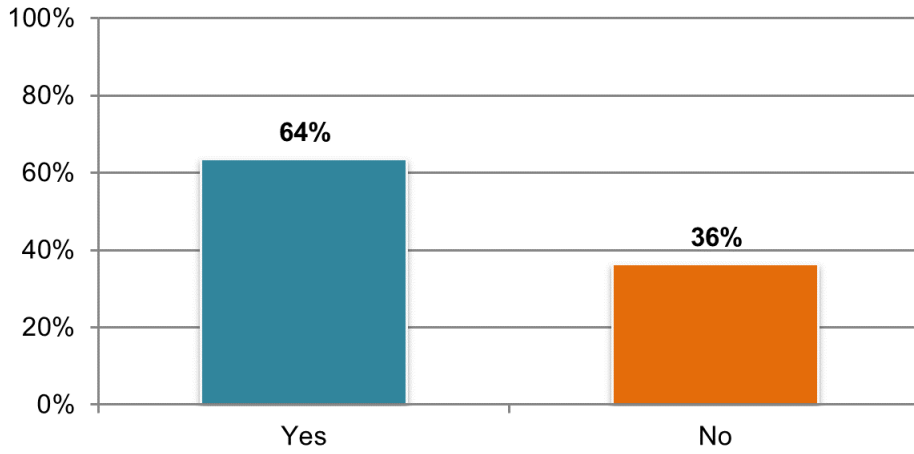


Table Q16. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| PA                                 | 74%        | 26%        | 298          |
| NH                                 | 73%        | 27%        | 350          |
| <b>Within Average Range</b>        |            |            |              |
| DC                                 | 71%        | 29%        | 160          |
| LA                                 | 69%        | 31%        | 222          |
| AK                                 | 69%        | 31%        | 104          |
| OK                                 | 67%        | 33%        | 294          |
| WA                                 | 66%        | 34%        | 294          |
| MD                                 | 64%        | 36%        | 495          |
| NC                                 | 61%        | 39%        | 191          |
| HI                                 | 61%        | 39%        | 114          |
| GA                                 | 59%        | 41%        | 278          |
| MS                                 | 58%        | 42%        | 276          |
| AZ                                 | 56%        | 44%        | 217          |
| VA                                 | 55%        | 45%        | 98           |
| <b>Significantly Below Average</b> |            |            |              |
| FL                                 | 52%        | 48%        | 263          |
| <b>NCI Average</b>                 | <b>64%</b> | <b>36%</b> | <b>3,654</b> |

## **Access and Delivery of Services and Supports**

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

### Respondent or Family Member Is Able to Contact Support Workers When S/He Wants

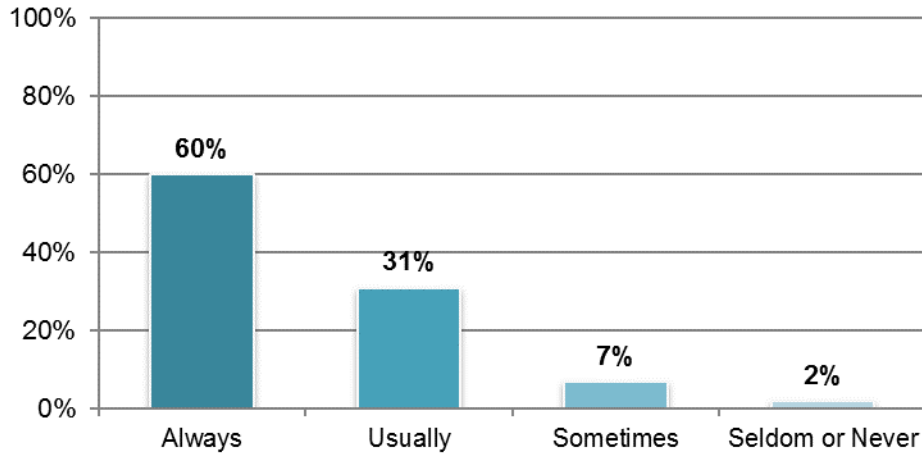


Table Q17. Are you or your family member able to contact his/her support workers when you want to?

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| FL                                 | 72%        | 22%        | 4%        | 1%              | 404          |
| LA                                 | 72%        | 23%        | 4%        | 1%              | 361          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| NC                                 | 67%        | 26%        | 7%        | 0%              | 223          |
| PA                                 | 65%        | 29%        | 4%        | 2%              | 384          |
| MS                                 | 64%        | 30%        | 5%        | 2%              | 458          |
| AZ                                 | 63%        | 31%        | 5%        | 1%              | 304          |
| DC                                 | 59%        | 23%        | 14%       | 4%              | 218          |
| VA                                 | 58%        | 37%        | 5%        | 1%              | 151          |
| AK                                 | 56%        | 37%        | 7%        | 0%              | 135          |
| NH                                 | 56%        | 34%        | 6%        | 4%              | 403          |
| HI                                 | 55%        | 35%        | 8%        | 2%              | 197          |
| GA                                 | 55%        | 33%        | 7%        | 4%              | 402          |
| WA                                 | 54%        | 36%        | 6%        | 3%              | 328          |
| OK                                 | 54%        | 38%        | 6%        | 1%              | 434          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| MD                                 | 51%        | 35%        | 10%       | 4%              | 640          |
| <b>NCI Average</b>                 | <b>60%</b> | <b>31%</b> | <b>7%</b> | <b>2%</b>       | <b>5,042</b> |

### Respondent or Family Member Is Able to Contact Case Manager or Service Coordinator When S/He Wants

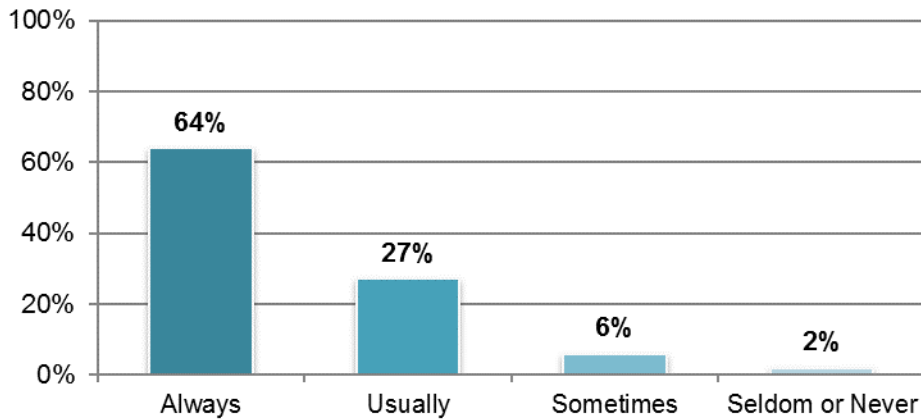


Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| FL                                 | 75%        | 20%        | 4%        | 1%              | 417          |
| LA                                 | 72%        | 22%        | 5%        | 1%              | 378          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| PA                                 | 68%        | 28%        | 3%        | 1%              | 419          |
| AZ                                 | 68%        | 26%        | 4%        | 2%              | 319          |
| NC                                 | 66%        | 25%        | 8%        | 1%              | 226          |
| AK                                 | 66%        | 29%        | 4%        | 1%              | 139          |
| MS                                 | 66%        | 28%        | 5%        | 2%              | 462          |
| VA                                 | 65%        | 28%        | 6%        | 1%              | 163          |
| HI                                 | 63%        | 25%        | 10%       | 2%              | 216          |
| NH                                 | 62%        | 28%        | 6%        | 4%              | 435          |
| WA                                 | 61%        | 29%        | 5%        | 4%              | 418          |
| DC                                 | 61%        | 24%        | 12%       | 3%              | 232          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| OK                                 | 58%        | 32%        | 8%        | 1%              | 464          |
| MD                                 | 55%        | 32%        | 8%        | 4%              | 694          |
| GA                                 | 55%        | 32%        | 8%        | 4%              | 409          |
| <b>NCI Average</b>                 | <b>64%</b> | <b>27%</b> | <b>6%</b> | <b>2%</b>       | <b>5,391</b> |

### Support Workers Come and Leave When They Are Supposed to

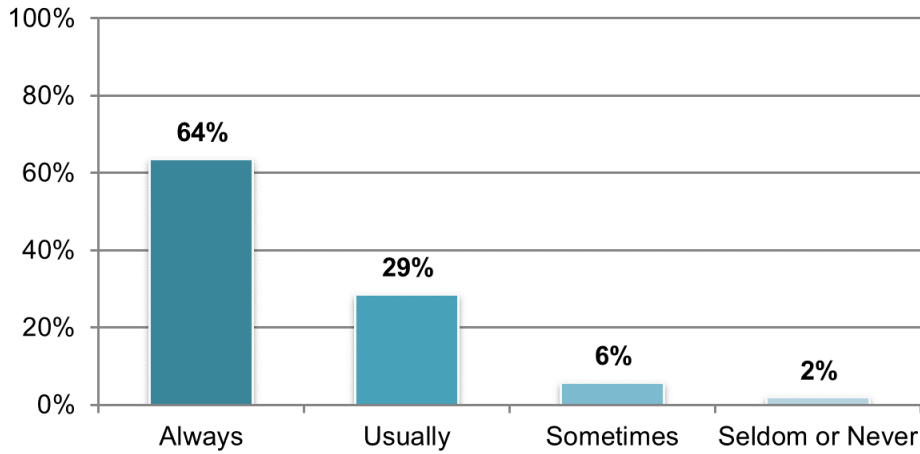


Table Q19. Do support workers come and leave when they are supposed to?

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| AZ                                 | 77%        | 17%        | 4%        | 2%              | 303          |
| FL                                 | 75%        | 20%        | 3%        | 2%              | 393          |
| LA                                 | 74%        | 20%        | 6%        | 0%              | 352          |
| PA                                 | 73%        | 23%        | 3%        | 1%              | 388          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| MS                                 | 66%        | 26%        | 6%        | 2%              | 453          |
| NC                                 | 64%        | 30%        | 6%        | 0%              | 214          |
| WA                                 | 64%        | 33%        | 3%        | 1%              | 284          |
| NH                                 | 63%        | 29%        | 4%        | 3%              | 357          |
| OK                                 | 62%        | 31%        | 6%        | 1%              | 412          |
| VA                                 | 61%        | 30%        | 5%        | 4%              | 137          |
| HI                                 | 59%        | 34%        | 6%        | 1%              | 182          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| MD                                 | 56%        | 31%        | 9%        | 5%              | 521          |
| GA                                 | 55%        | 32%        | 9%        | 4%              | 347          |
| DC                                 | 54%        | 27%        | 14%       | 5%              | 218          |
| AK                                 | 50%        | 46%        | 4%        | 0%              | 130          |
| <b>NCI Average</b>                 | <b>64%</b> | <b>29%</b> | <b>6%</b> | <b>2%</b>       | <b>4,691</b> |

### Services and Supports Change When Family's Needs Change

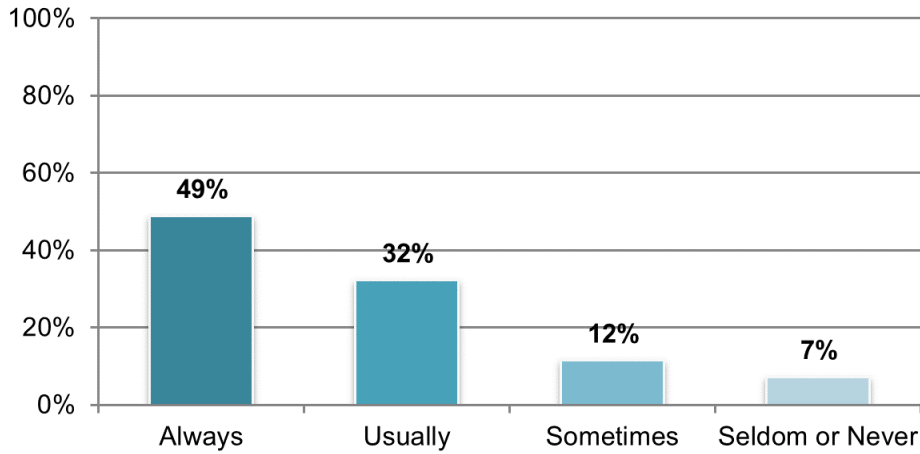


Table Q20. Do services and supports change when your family's needs change?

| State                              | Always     | Usually    | Sometimes  | Seldom or Never | N            |
|------------------------------------|------------|------------|------------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |            |                 |              |
| LA                                 | 61%        | 26%        | 8%         | 5%              | 298          |
| <b>Within Average Range</b>        |            |            |            |                 |              |
| AZ                                 | 56%        | 33%        | 8%         | 3%              | 258          |
| PA                                 | 55%        | 31%        | 10%        | 4%              | 315          |
| FL                                 | 54%        | 28%        | 12%        | 6%              | 334          |
| MS                                 | 52%        | 30%        | 11%        | 7%              | 369          |
| NC                                 | 51%        | 31%        | 12%        | 7%              | 190          |
| HI                                 | 49%        | 32%        | 12%        | 7%              | 162          |
| NH                                 | 49%        | 32%        | 9%         | 9%              | 318          |
| DC                                 | 49%        | 26%        | 14%        | 11%             | 179          |
| AK                                 | 46%        | 37%        | 10%        | 7%              | 126          |
| OK                                 | 45%        | 37%        | 10%        | 7%              | 341          |
| VA                                 | 44%        | 39%        | 14%        | 3%              | 118          |
| WA                                 | 41%        | 41%        | 11%        | 7%              | 246          |
| <b>Significantly Below Average</b> |            |            |            |                 |              |
| MD                                 | 42%        | 28%        | 16%        | 15%             | 425          |
| GA                                 | 40%        | 33%        | 17%        | 10%             | 277          |
| <b>NCI Average</b>                 | <b>49%</b> | <b>32%</b> | <b>12%</b> | <b>7%</b>       | <b>3,956</b> |

### Support Workers Speak in a Way Respondent Understands

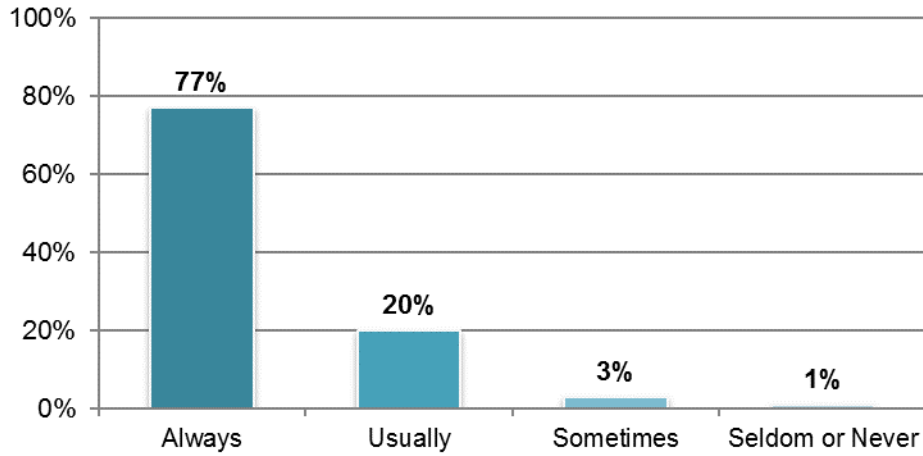


Table Q21. Do support workers speak to you in a way that you understand?

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| LA                                 | 87%        | 11%        | 1%        | 1%              | 354          |
| AZ                                 | 85%        | 12%        | 3%        | 1%              | 305          |
| PA                                 | 82%        | 16%        | 2%        | 1%              | 399          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| NC                                 | 81%        | 16%        | 3%        | 1%              | 222          |
| MS                                 | 80%        | 19%        | 1%        | 1%              | 462          |
| AK                                 | 79%        | 20%        | 0%        | 1%              | 134          |
| FL                                 | 79%        | 18%        | 2%        | 1%              | 401          |
| NH                                 | 76%        | 19%        | 4%        | 1%              | 380          |
| VA                                 | 75%        | 22%        | 1%        | 2%              | 146          |
| OK                                 | 74%        | 23%        | 2%        | 1%              | 428          |
| HI                                 | 72%        | 25%        | 2%        | 0%              | 189          |
| DC                                 | 72%        | 19%        | 5%        | 3%              | 220          |
| WA                                 | 71%        | 23%        | 3%        | 3%              | 300          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| MD                                 | 69%        | 25%        | 4%        | 2%              | 579          |
| GA                                 | 67%        | 25%        | 6%        | 2%              | 381          |
| <b>NCI Average</b>                 | <b>77%</b> | <b>20%</b> | <b>3%</b> | <b>1%</b>       | <b>4,900</b> |

### Services and Supports Are Delivered in a Way Respectful of Family's Culture

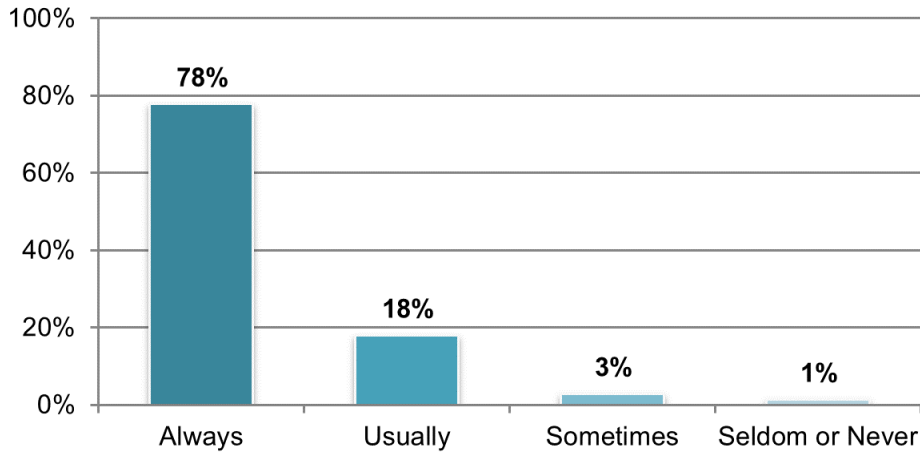


Table Q22. Are services delivered in a way that is respectful to your family's culture?

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| AZ                                 | 86%        | 11%        | 2%        | 1%              | 311          |
| LA                                 | 85%        | 12%        | 2%        | 1%              | 370          |
| FL                                 | 84%        | 13%        | 2%        | 0%              | 410          |
| PA                                 | 83%        | 15%        | 1%        | 1%              | 405          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| NC                                 | 82%        | 13%        | 4%        | 1%              | 227          |
| MS                                 | 79%        | 20%        | 1%        | 0%              | 466          |
| NH                                 | 78%        | 16%        | 4%        | 2%              | 401          |
| OK                                 | 77%        | 19%        | 3%        | 0%              | 446          |
| WA                                 | 76%        | 20%        | 3%        | 1%              | 368          |
| VA                                 | 76%        | 21%        | 2%        | 1%              | 151          |
| HI                                 | 74%        | 21%        | 5%        | 1%              | 200          |
| DC                                 | 73%        | 19%        | 5%        | 3%              | 228          |
| AK                                 | 73%        | 25%        | 1%        | 1%              | 137          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| MD                                 | 71%        | 22%        | 4%        | 3%              | 641          |
| GA                                 | 70%        | 23%        | 4%        | 3%              | 400          |
| <b>NCI Average</b>                 | <b>78%</b> | <b>18%</b> | <b>3%</b> | <b>1%</b>       | <b>5,161</b> |



### Support Workers Can Communicate With Family Member (If Non-Verbal)

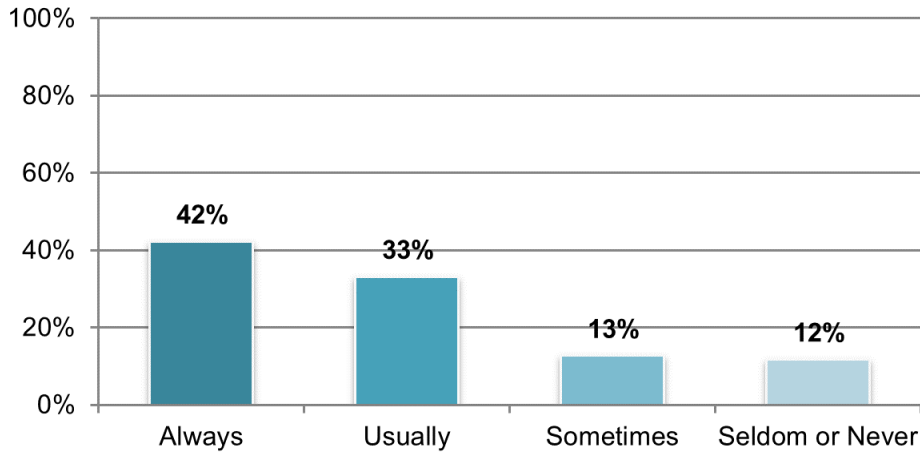


Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

| State                              | Always     | Usually    | Sometimes  | Seldom or Never | N            |
|------------------------------------|------------|------------|------------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |            |                 |              |
| NC                                 | 60%        | 25%        | 11%        | 5%              | 65           |
| <b>Within Average Range</b>        |            |            |            |                 |              |
| FL                                 | 54%        | 24%        | 10%        | 12%             | 109          |
| LA                                 | 52%        | 33%        | 6%         | 8%              | 84           |
| PA                                 | 50%        | 26%        | 17%        | 7%              | 58           |
| NH                                 | 48%        | 38%        | 5%         | 8%              | 60           |
| MS                                 | 48%        | 31%        | 12%        | 9%              | 156          |
| GA                                 | 45%        | 31%        | 9%         | 15%             | 93           |
| OK                                 | 39%        | 34%        | 11%        | 17%             | 113          |
| HI                                 | 37%        | 41%        | 11%        | 11%             | 46           |
| AZ                                 | 35%        | 26%        | 18%        | 21%             | 62           |
| VA                                 | 35%        | 39%        | 19%        | 6%              | 62           |
| DC                                 | 35%        | 33%        | 23%        | 8%              | 48           |
| WA                                 | 33%        | 33%        | 11%        | 24%             | 85           |
| AK                                 | 30%        | 50%        | 10%        | 10%             | 30           |
| <b>Significantly Below Average</b> |            |            |            |                 |              |
| MD                                 | 32%        | 34%        | 19%        | 15%             | 149          |
| <b>NCI Average</b>                 | <b>42%</b> | <b>33%</b> | <b>13%</b> | <b>12%</b>      | <b>1,220</b> |

### Support Workers Have the Right Information and Skills to Meet Family's Needs

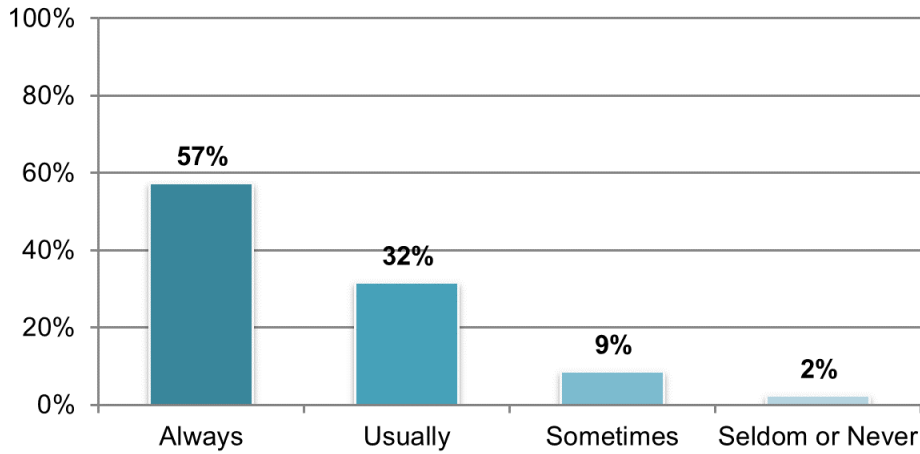
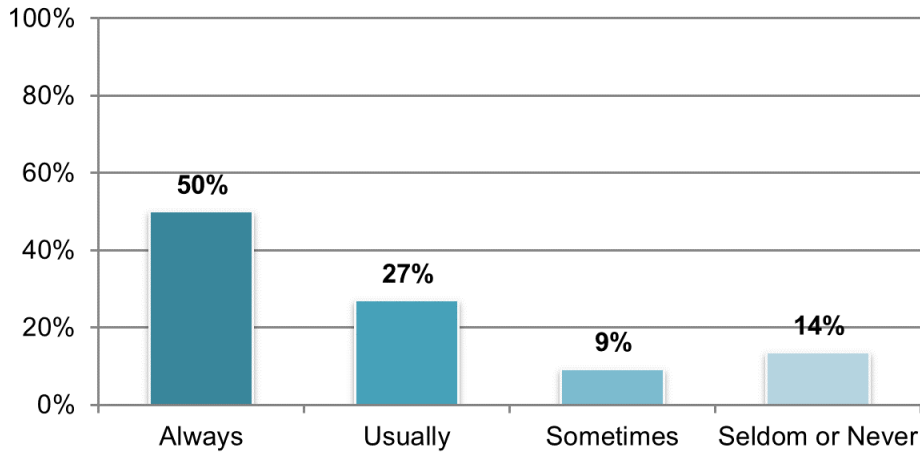


Table Q24. Do support workers have the right information and skills to meet your family's needs?

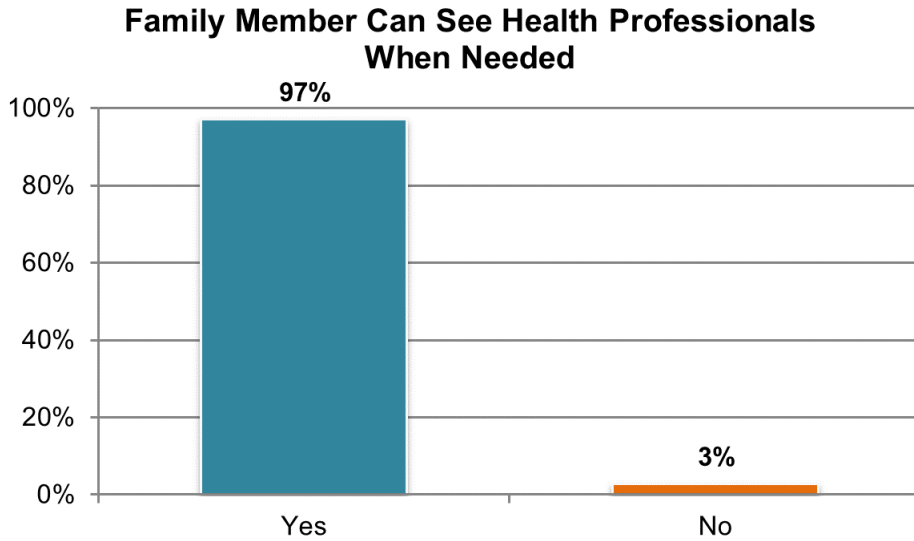
| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| LA                                 | 72%        | 22%        | 5%        | 1%              | 347          |
| FL                                 | 69%        | 24%        | 5%        | 2%              | 382          |
| AZ                                 | 65%        | 27%        | 5%        | 2%              | 297          |
| MS                                 | 64%        | 27%        | 8%        | 1%              | 444          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| PA                                 | 61%        | 32%        | 6%        | 1%              | 389          |
| NC                                 | 60%        | 31%        | 8%        | 0%              | 217          |
| DC                                 | 59%        | 25%        | 13%       | 3%              | 214          |
| OK                                 | 58%        | 35%        | 6%        | 1%              | 410          |
| NH                                 | 55%        | 31%        | 10%       | 4%              | 357          |
| HI                                 | 55%        | 34%        | 10%       | 2%              | 185          |
| VA                                 | 52%        | 34%        | 10%       | 4%              | 141          |
| GA                                 | 51%        | 33%        | 12%       | 4%              | 356          |
| WA                                 | 50%        | 39%        | 7%        | 4%              | 284          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| MD                                 | 48%        | 38%        | 10%       | 3%              | 553          |
| AK                                 | 42%        | 41%        | 14%       | 2%              | 132          |
| <b>NCI Average</b>                 | <b>57%</b> | <b>32%</b> | <b>9%</b> | <b>2%</b>       | <b>4,708</b> |

### Family Member Has Access to Special Equipment or Accommodations Needed



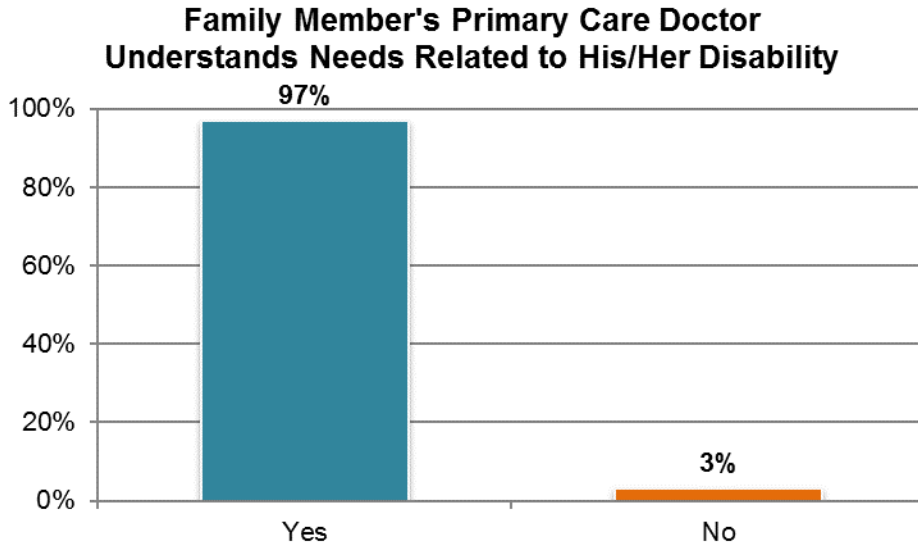
**Table Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?**

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Within Average Range</b>        |            |            |           |                 |              |
| VA                                 | 62%        | 22%        | 8%        | 9%              | 93           |
| LA                                 | 59%        | 24%        | 4%        | 13%             | 163          |
| DC                                 | 55%        | 18%        | 5%        | 22%             | 87           |
| OK                                 | 54%        | 27%        | 10%       | 10%             | 249          |
| PA                                 | 53%        | 25%        | 10%       | 13%             | 146          |
| AZ                                 | 53%        | 36%        | 7%        | 5%              | 137          |
| FL                                 | 52%        | 27%        | 7%        | 14%             | 208          |
| NH                                 | 52%        | 31%        | 8%        | 9%              | 164          |
| MS                                 | 50%        | 25%        | 12%       | 13%             | 268          |
| WA                                 | 50%        | 26%        | 9%        | 14%             | 171          |
| NC                                 | 46%        | 26%        | 12%       | 15%             | 125          |
| AK                                 | 45%        | 31%        | 16%       | 8%              | 62           |
| HI                                 | 41%        | 30%        | 9%        | 21%             | 91           |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| MD                                 | 40%        | 31%        | 12%       | 18%             | 226          |
| GA                                 | 38%        | 28%        | 14%       | 20%             | 179          |
| <b>NCI Average</b>                 | <b>50%</b> | <b>27%</b> | <b>9%</b> | <b>14%</b>      | <b>2,369</b> |



**Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?**

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| NH                                 | 99%        | 1%        | 442          |
| PA                                 | 99%        | 1%        | 438          |
| <b>Within Average Range</b>        |            |           |              |
| DC                                 | 99%        | 1%        | 231          |
| AK                                 | 99%        | 1%        | 135          |
| MD                                 | 98%        | 2%        | 725          |
| NC                                 | 98%        | 2%        | 252          |
| VA                                 | 98%        | 2%        | 164          |
| LA                                 | 97%        | 3%        | 386          |
| WA                                 | 97%        | 3%        | 420          |
| MS                                 | 97%        | 3%        | 488          |
| OK                                 | 97%        | 3%        | 471          |
| HI                                 | 96%        | 4%        | 218          |
| AZ                                 | 96%        | 4%        | 326          |
| GA                                 | 96%        | 4%        | 433          |
| FL                                 | 95%        | 5%        | 417          |
| <b>NCI Average</b>                 | <b>97%</b> | <b>3%</b> | <b>5,546</b> |



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

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| DC                                 | 100%       | 0%        | 224          |
| OK                                 | 99%        | 1%        | 455          |
| PA                                 | 99%        | 1%        | 416          |
| MD                                 | 98%        | 2%        | 704          |
| <b>Within Average Range</b>        |            |           |              |
| VA                                 | 97%        | 3%        | 156          |
| HI                                 | 97%        | 3%        | 210          |
| MS                                 | 97%        | 3%        | 468          |
| LA                                 | 97%        | 3%        | 373          |
| GA                                 | 97%        | 3%        | 413          |
| NH                                 | 96%        | 4%        | 423          |
| WA                                 | 96%        | 4%        | 398          |
| AZ                                 | 96%        | 4%        | 314          |
| FL                                 | 96%        | 4%        | 408          |
| NC                                 | 95%        | 5%        | 246          |
| AK                                 | 94%        | 6%        | 131          |
| <b>NCI Average</b>                 | <b>97%</b> | <b>3%</b> | <b>5,339</b> |

### Respondent Has Access to Dental Services for Family Member

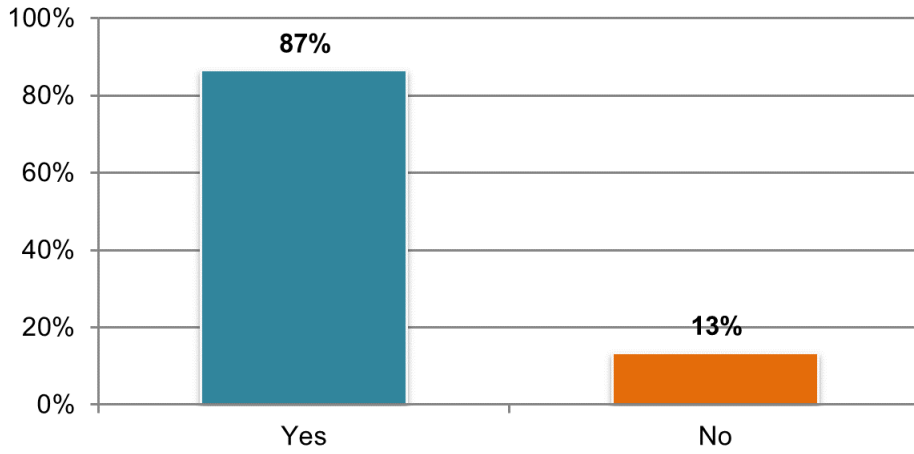
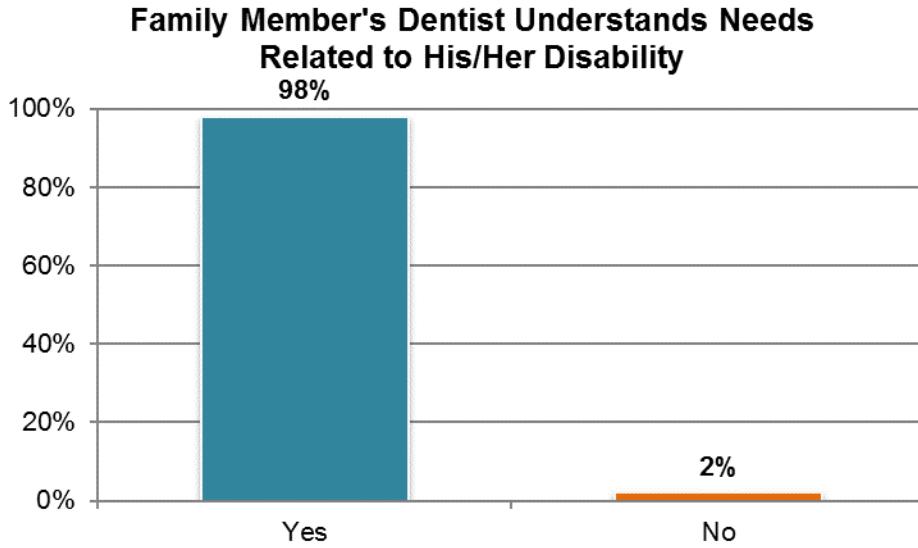


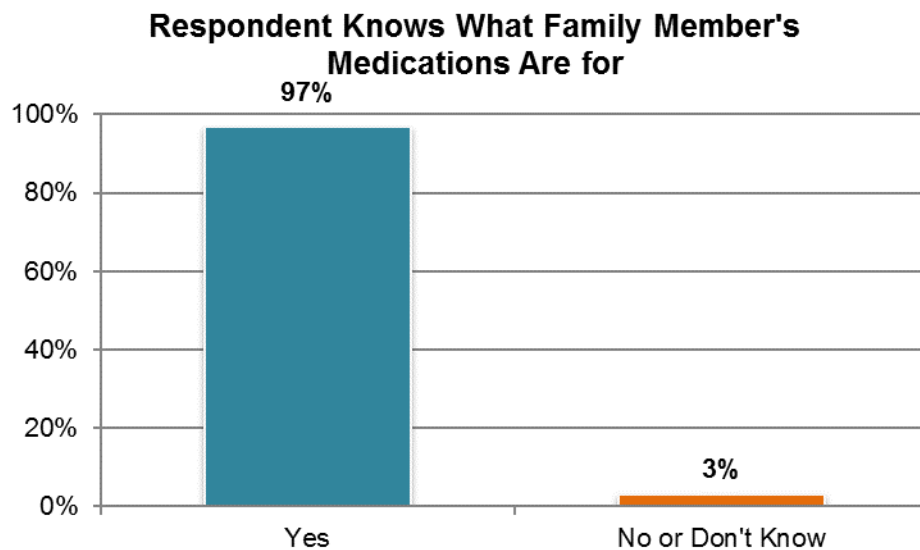
Table Q28. Do you have access to dental services for your family member?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| AK                                 | 96%        | 4%         | 135          |
| NC                                 | 94%        | 6%         | 246          |
| PA                                 | 94%        | 6%         | 428          |
| DC                                 | 93%        | 7%         | 233          |
| WA                                 | 92%        | 8%         | 423          |
| <b>Within Average Range</b>        |            |            |              |
| OK                                 | 89%        | 11%        | 459          |
| MD                                 | 87%        | 13%        | 730          |
| GA                                 | 85%        | 15%        | 420          |
| NH                                 | 84%        | 16%        | 443          |
| MS                                 | 83%        | 17%        | 462          |
| HI                                 | 83%        | 17%        | 210          |
| LA                                 | 82%        | 18%        | 370          |
| FL                                 | 82%        | 18%        | 395          |
| VA                                 | 81%        | 19%        | 157          |
| <b>Significantly Below Average</b> |            |            |              |
| AZ                                 | 74%        | 26%        | 321          |
| <b>NCI Average</b>                 | <b>87%</b> | <b>13%</b> | <b>5,432</b> |



**Table Q29. If yes to Q28, does your family member's dentist understand your family member's needs related to his/her disability?**

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| VA                                 | 100%       | 0%        | 120          |
| NC                                 | 100%       | 0%        | 216          |
| FL                                 | 99%        | 1%        | 300          |
| <b>Within Average Range</b>        |            |           |              |
| MS                                 | 99%        | 1%        | 347          |
| DC                                 | 98%        | 2%        | 201          |
| LA                                 | 98%        | 2%        | 283          |
| OK                                 | 98%        | 2%        | 374          |
| PA                                 | 98%        | 2%        | 368          |
| WA                                 | 98%        | 2%        | 348          |
| AZ                                 | 98%        | 2%        | 207          |
| GA                                 | 98%        | 2%        | 330          |
| NH                                 | 97%        | 3%        | 348          |
| AK                                 | 96%        | 4%        | 119          |
| MD                                 | 96%        | 4%        | 587          |
| HI                                 | 94%        | 6%        | 159          |
| <b>NCI Average</b>                 | <b>98%</b> | <b>2%</b> | <b>4,307</b> |



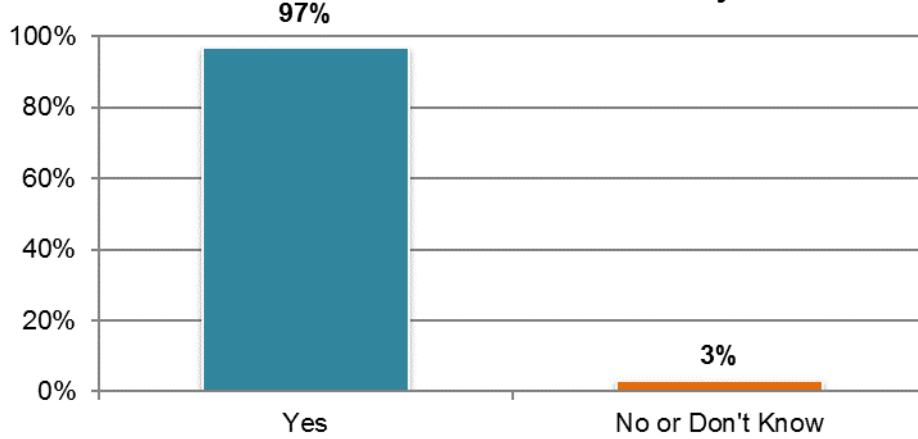
**Table Q30. If your family member takes medications, do you know what they're for?<sup>1</sup>**

| State                              | Yes        | No or Don't Know | N            |
|------------------------------------|------------|------------------|--------------|
| <b>Significantly Above Average</b> |            |                  |              |
| VA                                 | 99%        | 1%               | 145          |
| NC                                 | 99%        | 1%               | 219          |
| <b>Within Average Range</b>        |            |                  |              |
| OK                                 | 98%        | 2%               | 426          |
| WA                                 | 98%        | 2%               | 361          |
| LA                                 | 98%        | 2%               | 340          |
| AK                                 | 97%        | 3%               | 114          |
| PA                                 | 97%        | 3%               | 349          |
| NH                                 | 97%        | 3%               | 378          |
| MS                                 | 97%        | 3%               | 452          |
| FL                                 | 97%        | 3%               | 379          |
| GA                                 | 96%        | 4%               | 395          |
| HI                                 | 96%        | 4%               | 185          |
| MD                                 | 95%        | 5%               | 599          |
| AZ                                 | 94%        | 6%               | 281          |
| <b>Significantly Below Average</b> |            |                  |              |
| DC                                 | 90%        | 10%              | 192          |
| <b>NCI Average</b>                 | <b>97%</b> | <b>3%</b>        | <b>4,815</b> |

<sup>1</sup> For this question, 'no' and 'don't know' responses were combined.



**Respondent, Family Member, or Other Family Member Knows What Is Needed for Family Member to Take Medication Safely**

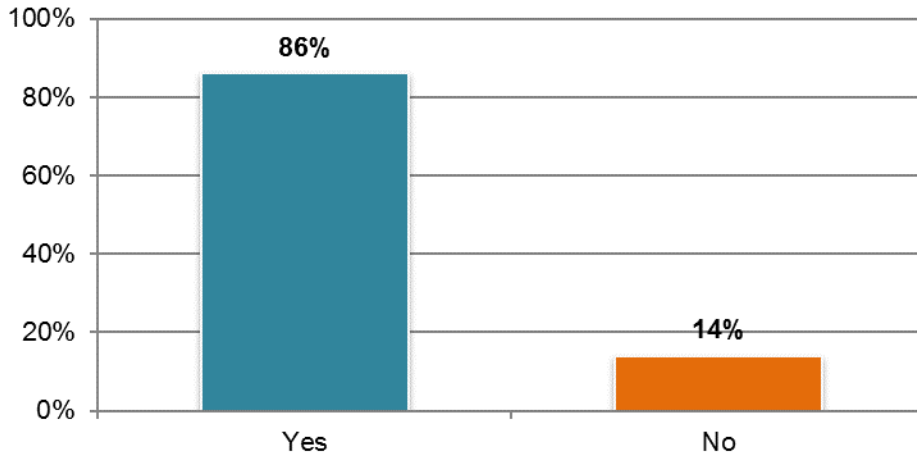


**Table Q31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?<sup>2</sup>**

| State                       | Yes        | No or Don't Know | N            |
|-----------------------------|------------|------------------|--------------|
| <b>Within Average Range</b> |            |                  |              |
| NC                          | 99%        | 1%               | 220          |
| VA                          | 99%        | 1%               | 145          |
| OK                          | 99%        | 1%               | 425          |
| LA                          | 98%        | 2%               | 344          |
| HI                          | 98%        | 2%               | 188          |
| AK                          | 97%        | 3%               | 113          |
| MS                          | 97%        | 3%               | 455          |
| PA                          | 97%        | 3%               | 350          |
| WA                          | 97%        | 3%               | 363          |
| FL                          | 97%        | 3%               | 381          |
| NH                          | 97%        | 3%               | 380          |
| GA                          | 96%        | 4%               | 393          |
| MD                          | 96%        | 4%               | 590          |
| AZ                          | 95%        | 5%               | 279          |
| DC                          | 92%        | 8%               | 185          |
| <b>NCI Average</b>          | <b>97%</b> | <b>3%</b>        | <b>4,811</b> |

<sup>2</sup> For this question, 'no' and 'don't know' responses were combined.

### Family Member's Mental Health Professional Understands Needs Related to His/Her Disability



**Table Q32. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability?**

| State                       | Yes        | No         | N            |
|-----------------------------|------------|------------|--------------|
| <b>Within Average Range</b> |            |            |              |
| PA                          | 92%        | 8%         | 169          |
| NH                          | 91%        | 9%         | 127          |
| NC                          | 91%        | 9%         | 113          |
| VA                          | 90%        | 10%        | 70           |
| MD                          | 88%        | 12%        | 231          |
| AZ                          | 88%        | 12%        | 114          |
| AK                          | 87%        | 13%        | 47           |
| OK                          | 86%        | 14%        | 110          |
| GA                          | 85%        | 15%        | 182          |
| FL                          | 84%        | 16%        | 168          |
| LA                          | 84%        | 16%        | 122          |
| DC                          | 83%        | 17%        | 114          |
| HI                          | 82%        | 18%        | 71           |
| MS                          | 81%        | 19%        | 176          |
| WA                          | 80%        | 20%        | 116          |
| <b>NCI Average</b>          | <b>86%</b> | <b>14%</b> | <b>1,930</b> |

### Respondent Has Access to Respite Services

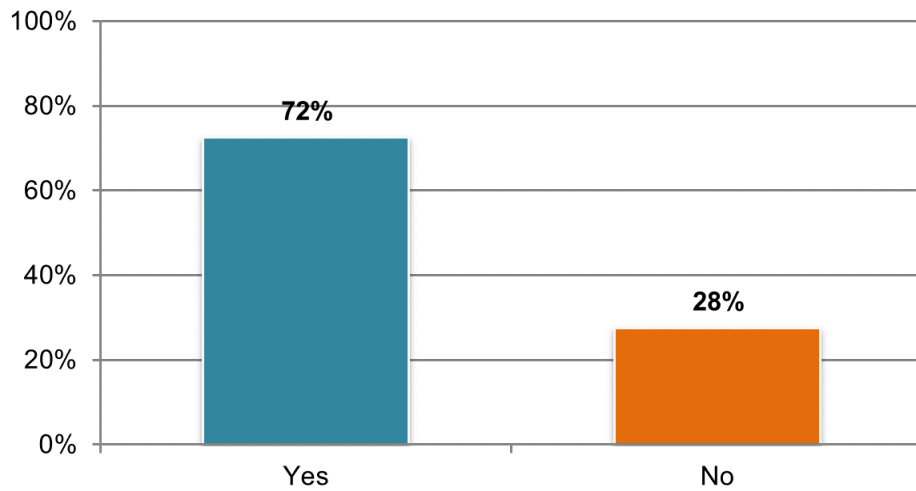


Table Q33. If you need respite services, do you have access to them?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| AZ                                 | 92%        | 8%         | 278          |
| DC                                 | 90%        | 10%        | 159          |
| NC                                 | 83%        | 17%        | 207          |
| WA                                 | 82%        | 18%        | 291          |
| <b>Within Average Range</b>        |            |            |              |
| AK                                 | 82%        | 18%        | 120          |
| NH                                 | 78%        | 22%        | 298          |
| VA                                 | 75%        | 25%        | 130          |
| HI                                 | 73%        | 27%        | 135          |
| PA                                 | 72%        | 28%        | 229          |
| LA                                 | 70%        | 30%        | 209          |
| MS                                 | 70%        | 30%        | 291          |
| FL                                 | 66%        | 34%        | 273          |
| <b>Significantly Below Average</b> |            |            |              |
| MD                                 | 58%        | 42%        | 360          |
| GA                                 | 50%        | 50%        | 240          |
| OK                                 | 47%        | 53%        | 211          |
| <b>NCI Average</b>                 | <b>72%</b> | <b>28%</b> | <b>3,431</b> |

### Respondent Is Satisfied With the Quality of Family Member's Respite Services

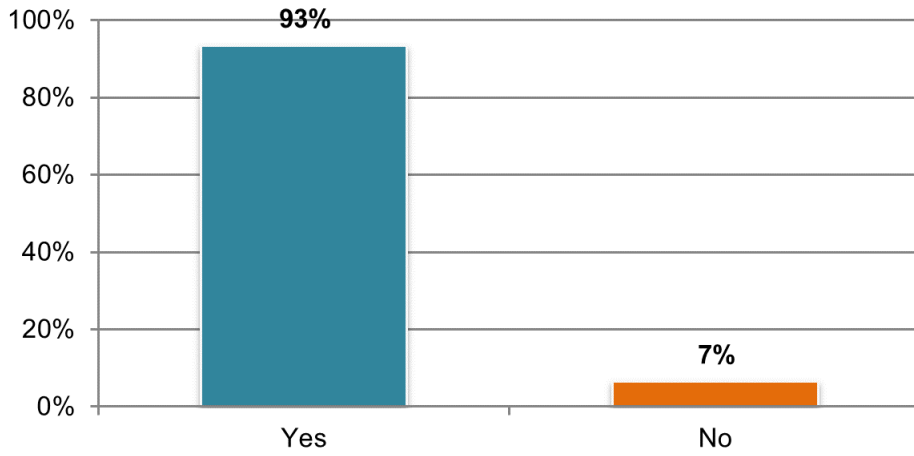


Table Q34. If Yes to Q33, are you satisfied with the quality of the respite services?

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| PA                                 | 98%        | 2%        | 129          |
| <b>Within Average Range</b>        |            |           |              |
| AZ                                 | 96%        | 4%        | 235          |
| FL                                 | 96%        | 4%        | 144          |
| NC                                 | 96%        | 4%        | 162          |
| VA                                 | 95%        | 5%        | 81           |
| MS                                 | 95%        | 5%        | 186          |
| LA                                 | 95%        | 5%        | 128          |
| NH                                 | 94%        | 6%        | 213          |
| OK                                 | 94%        | 6%        | 88           |
| HI                                 | 93%        | 7%        | 76           |
| GA                                 | 93%        | 7%        | 100          |
| WA                                 | 93%        | 7%        | 209          |
| MD                                 | 91%        | 9%        | 181          |
| DC                                 | 90%        | 10%       | 110          |
| <b>Significantly Below Average</b> |            |           |              |
| AK                                 | 83%        | 17%       | 95           |
| <b>NCI Average</b>                 | <b>93%</b> | <b>7%</b> | <b>2,137</b> |

### Family Gets Needed Supports

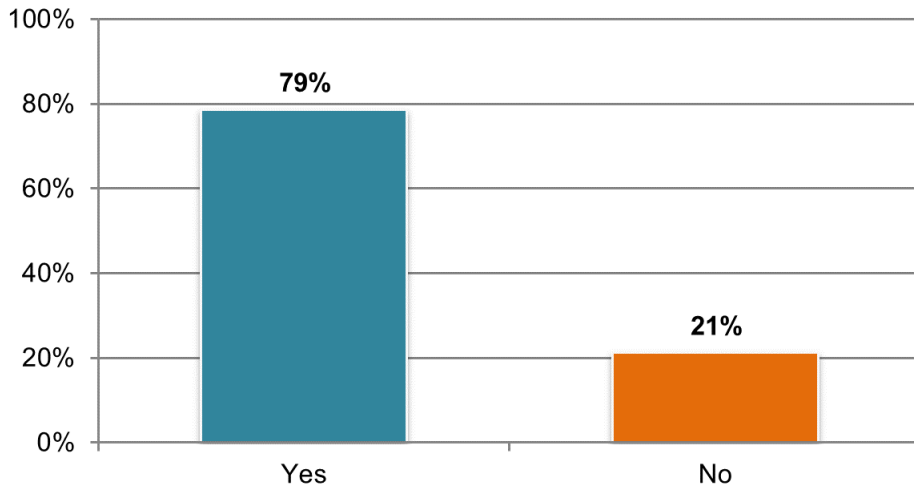


Table Q35. Does your family get the support needed?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| AZ                                 | 89%        | 11%        | 309          |
| LA                                 | 86%        | 14%        | 353          |
| MS                                 | 85%        | 15%        | 426          |
| <b>Within Average Range</b>        |            |            |              |
| PA                                 | 83%        | 17%        | 390          |
| HI                                 | 83%        | 17%        | 195          |
| FL                                 | 82%        | 18%        | 381          |
| OK                                 | 80%        | 20%        | 425          |
| NH                                 | 79%        | 21%        | 406          |
| AK                                 | 79%        | 21%        | 132          |
| NC                                 | 75%        | 25%        | 232          |
| WA                                 | 73%        | 27%        | 387          |
| DC                                 | 73%        | 27%        | 215          |
| VA                                 | 72%        | 28%        | 148          |
| <b>Significantly Below Average</b> |            |            |              |
| MD                                 | 72%        | 28%        | 614          |
| GA                                 | 70%        | 30%        | 369          |
| <b>NCI Average</b>                 | <b>79%</b> | <b>21%</b> | <b>4,982</b> |

### Reasons Family Member Does Not Take Part in Community Activities

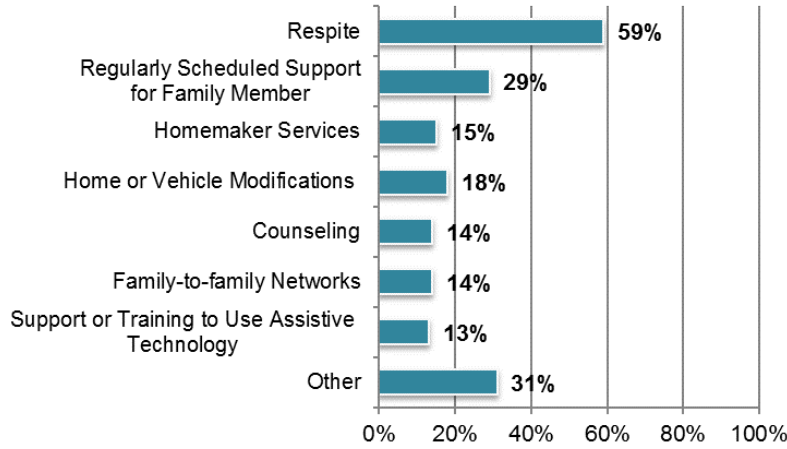


Table Q36. If no to Q35, what additional services are needed?

| 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      | N          |
|--------------------|------------|---|--------------------|-------------------------------|------------|---------------------------|---|------------|------------|
| AK                 | 56%        | 37%   | 15%                | 11%                           | 15%        | 7%                        | 7%  | 59%        | 27         |
| AZ                 | 50%        | 21%   | 18%                | 21%                           | 14%        | 25%                       | 14%   | 43%        | 28         |
| DC                 | 27%        | 17%   | 13%                | 17%                           | 19%        | 12%                       | 17%   | 23%        | 52         |
| FL                 | 60%        | 27%   | 23%                | 20%                           | 22%        | 18%                       | 18%   | 33%        | 60         |
| GA                 | 64%        | 28%   | 13%                | 18%                           | 6%         | 17%                       | 8%  | 17%        | 95         |
| HI                 | 72%        | 31%   | 13%                | 19%                           | 25%        | 6%                        | 13%   | 25%        | 32         |
| LA                 | 45%        | 34%   | 11%                | 14%                           | 14%        | 14%                       | 11%   | 30%        | 44         |
| MD                 | 62%        | 38%   | 14%                | 12%                           | 13%        | 11%                       | 12%   | 36%        | 153        |
| MS                 | 65%        | 21%   | 26%                | 33%                           | 12%        | 9%                        | 14%   | 25%        | 57         |
| NC                 | 58%        | 34%   | 12%                | 14%                           | 18%        | 20%                       | 20%   | 46%        | 50         |
| NH                 | 56%        | 36%   | 11%                | 10%                           | 11%        | 7%                        | 10%   | 34%        | 73         |
| OK                 | 76%        | 24%   | 11%                | 25%                           | 7%         | 12%                       | 8%  | 21%        | 76         |
| PA                 | 57%        | 25%   | 13%                | 9%                            | 9%         | 13%                       | 2%  | 30%        | 53         |
| VA                 | 79%        | 38%   | 12%                | 21%                           | 10%        | 21%                       | 26%   | 21%        | 42         |
| WA                 | 59%        | 27%   | 21%                | 19%                           | 15%        | 13%                       | 15%   | 25%        | 97         |
| <b>NCI Average</b> | <b>59%</b> | <b>29%</b>                                    | <b>15%</b>         | <b>18%</b>                    | <b>14%</b> | <b>14%</b>                | <b>13%</b>                                      | <b>31%</b> | <b>939</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.*

### Family Can Choose or Change Family Member's Provider Agency

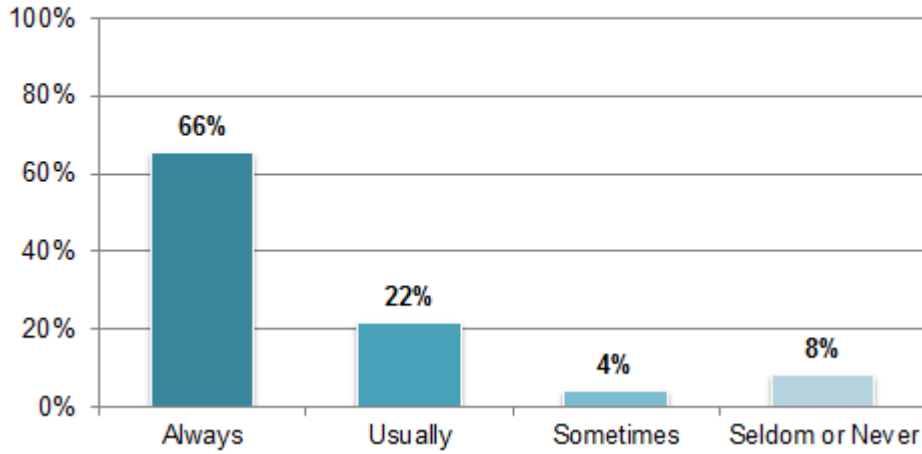


Table Q37. Can your family choose or change the agency that provides your family member's services?

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| NC                                 | 80%        | 11%        | 4%        | 6%              | 198          |
| LA                                 | 76%        | 19%        | 1%        | 4%              | 303          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| OK                                 | 71%        | 19%        | 2%        | 8%              | 355          |
| FL                                 | 70%        | 20%        | 3%        | 7%              | 317          |
| AK                                 | 69%        | 19%        | 6%        | 7%              | 122          |
| VA                                 | 68%        | 20%        | 4%        | 9%              | 111          |
| PA                                 | 67%        | 26%        | 3%        | 4%              | 270          |
| MS                                 | 65%        | 21%        | 4%        | 10%             | 333          |
| NH                                 | 65%        | 17%        | 3%        | 15%             | 243          |
| DC                                 | 63%        | 21%        | 6%        | 10%             | 172          |
| WA                                 | 60%        | 26%        | 5%        | 8%              | 194          |
| AZ                                 | 60%        | 28%        | 4%        | 7%              | 232          |
| MD                                 | 60%        | 24%        | 6%        | 10%             | 443          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| GA                                 | 57%        | 24%        | 7%        | 13%             | 241          |
| HI                                 | 55%        | 31%        | 6%        | 9%              | 143          |
| <b>NCI Average</b>                 | <b>66%</b> | <b>22%</b> | <b>4%</b> | <b>8%</b>       | <b>3,677</b> |



### Family Can Choose or Change Family Member's Support Workers

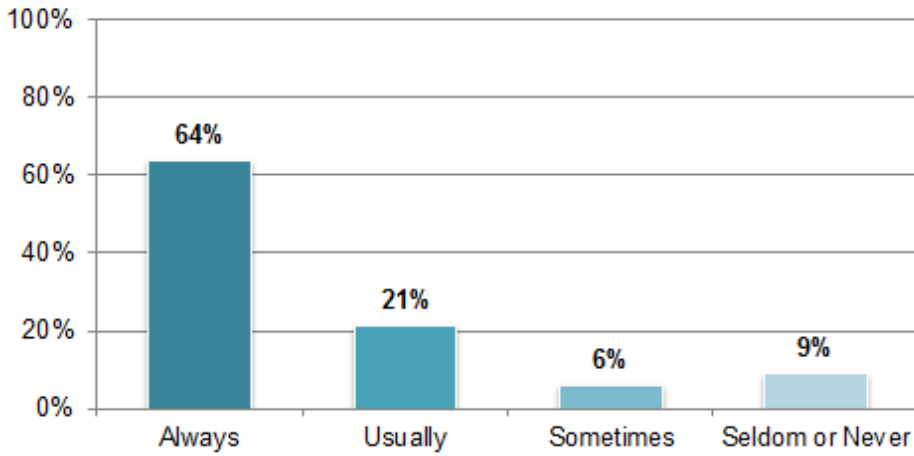


Table Q38. Can your family choose or change your family member's support workers?

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| LA                                 | 76%        | 15%        | 4%        | 5%              | 304          |
| NC                                 | 75%        | 13%        | 4%        | 7%              | 201          |
| FL                                 | 71%        | 19%        | 3%        | 7%              | 340          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| OK                                 | 69%        | 19%        | 4%        | 9%              | 341          |
| VA                                 | 68%        | 19%        | 6%        | 6%              | 109          |
| AZ                                 | 65%        | 22%        | 6%        | 7%              | 229          |
| MS                                 | 64%        | 24%        | 3%        | 9%              | 336          |
| DC                                 | 62%        | 23%        | 6%        | 8%              | 180          |
| NH                                 | 62%        | 20%        | 7%        | 11%             | 284          |
| PA                                 | 60%        | 27%        | 7%        | 5%              | 278          |
| WA                                 | 59%        | 23%        | 8%        | 10%             | 203          |
| AK                                 | 59%        | 25%        | 9%        | 8%              | 128          |
| GA                                 | 58%        | 22%        | 6%        | 13%             | 243          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| MD                                 | 54%        | 21%        | 9%        | 16%             | 395          |
| HI                                 | 52%        | 27%        | 7%        | 14%             | 146          |
| <b>NCI Average</b>                 | <b>64%</b> | <b>21%</b> | <b>6%</b> | <b>9%</b>       | <b>3,717</b> |

### Family Directly Manages Support Workers

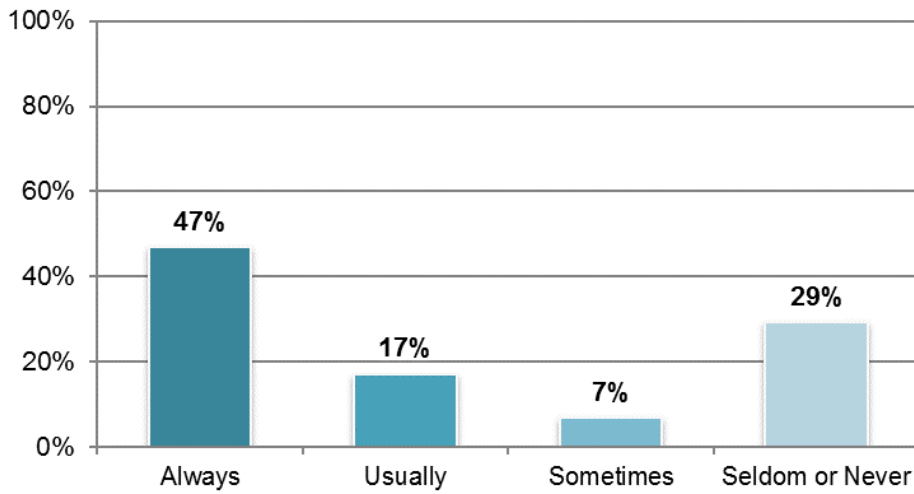


Table Q39. Does your family directly manage support workers (for example, hiring and deciding schedule)?

| State                              | Always     | Usually    | Sometimes | Seldom or Never | N            |
|------------------------------------|------------|------------|-----------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |                 |              |
| FL                                 | 56%        | 19%        | 4%        | 21%             | 324          |
| OK                                 | 56%        | 14%        | 7%        | 23%             | 332          |
| <b>Within Average Range</b>        |            |            |           |                 |              |
| VA                                 | 57%        | 14%        | 6%        | 23%             | 118          |
| LA                                 | 53%        | 18%        | 5%        | 25%             | 280          |
| WA                                 | 51%        | 18%        | 7%        | 23%             | 202          |
| AZ                                 | 51%        | 21%        | 7%        | 20%             | 216          |
| NH                                 | 48%        | 12%        | 5%        | 35%             | 299          |
| GA                                 | 47%        | 9%         | 7%        | 37%             | 254          |
| HI                                 | 45%        | 15%        | 7%        | 33%             | 135          |
| NC                                 | 45%        | 16%        | 12%       | 27%             | 194          |
| MS                                 | 44%        | 23%        | 6%        | 27%             | 344          |
| DC                                 | 44%        | 20%        | 7%        | 28%             | 166          |
| <b>Significantly Below Average</b> |            |            |           |                 |              |
| PA                                 | 39%        | 18%        | 8%        | 34%             | 264          |
| AK                                 | 35%        | 27%        | 5%        | 33%             | 127          |
| MD                                 | 32%        | 12%        | 8%        | 48%             | 405          |
| <b>NCI Average</b>                 | <b>47%</b> | <b>17%</b> | <b>7%</b> | <b>29%</b>      | <b>3,660</b> |

### Family Member's Service Providers Work Together to Provide Support

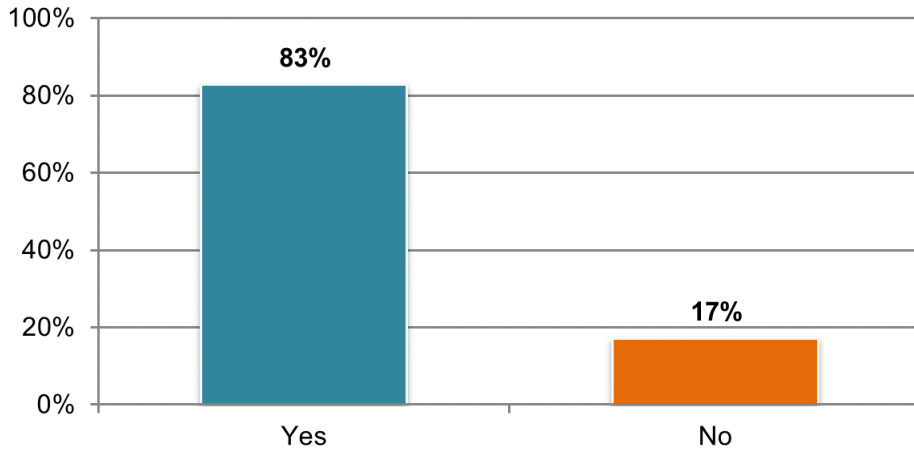


Table Q40. Do service providers for your family member work together to provide support?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| LA                                 | 89%        | 11%        | 216          |
| <b>Within Average Range</b>        |            |            |              |
| AZ                                 | 89%        | 11%        | 172          |
| MS                                 | 88%        | 12%        | 281          |
| OK                                 | 86%        | 14%        | 236          |
| AK                                 | 86%        | 14%        | 91           |
| HI                                 | 86%        | 14%        | 125          |
| NC                                 | 85%        | 15%        | 143          |
| PA                                 | 83%        | 17%        | 233          |
| DC                                 | 82%        | 18%        | 163          |
| NH                                 | 82%        | 18%        | 218          |
| GA                                 | 80%        | 20%        | 218          |
| VA                                 | 80%        | 20%        | 99           |
| MD                                 | 78%        | 22%        | 345          |
| FL                                 | 77%        | 23%        | 241          |
| <b>Significantly Below Average</b> |            |            |              |
| WA                                 | 73%        | 27%        | 142          |
| <b>NCI Average</b>                 | <b>83%</b> | <b>17%</b> | <b>2,923</b> |

### Respondent, Family Member, or Other Family Member Chose or Can Change Case Manager or Service Coordinator

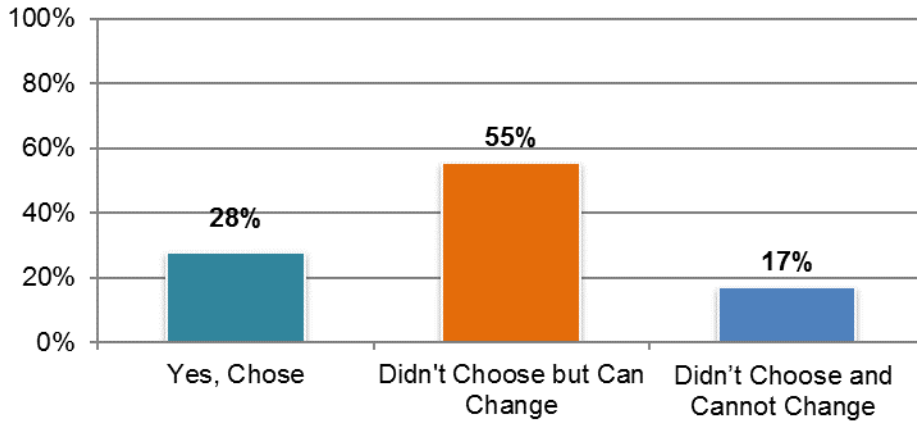


Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

| State                              | Yes, chose | Didn't Choose but Can Change | Didn't Choose and Cannot Change | N           |
|------------------------------------|------------|------------------------------|---------------------------------|-------------|
| <b>Significantly Above Average</b> |            |                              |                                 |             |
| AK                                 | 74%        | 20%                          | 5%                              | 129         |
| FL                                 | 70%        | 26%                          | 4%                              | 381         |
| LA                                 | 46%        | 46%                          | 8%                              | 328         |
| <b>Within Average Range</b>        |            |                              |                                 |             |
| NC                                 | 28%        | 53%                          | 19%                             | 203         |
| MS                                 | 24%        | 57%                          | 19%                             | 317         |
| DC                                 | 24%        | 63%                          | 13%                             | 182         |
| PA                                 | 24%        | 65%                          | 11%                             | 323         |
| VA                                 | 24%        | 57%                          | 20%                             | 136         |
| <b>Significantly Below Average</b> |            |                              |                                 |             |
| MD                                 | 19%        | 62%                          | 18%                             | 586         |
| HI                                 | 18%        | 59%                          | 23%                             | 165         |
| OK                                 | 16%        | 62%                          | 21%                             | 360         |
| NH                                 | 16%        | 63%                          | 21%                             | 362         |
| AZ                                 | 13%        | 72%                          | 15%                             | 282         |
| GA                                 | 12%        | 62%                          | 26%                             | 325         |
| WA                                 | 8%         | 61%                          | 30%                             | 312         |
| <b>NCI Average</b>                 | <b>28%</b> | <b>55%</b>                   | <b>17%</b>                      | <b>4391</b> |

## **Involvement in the Community**

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

### Family Member Takes Part in Activities in Community

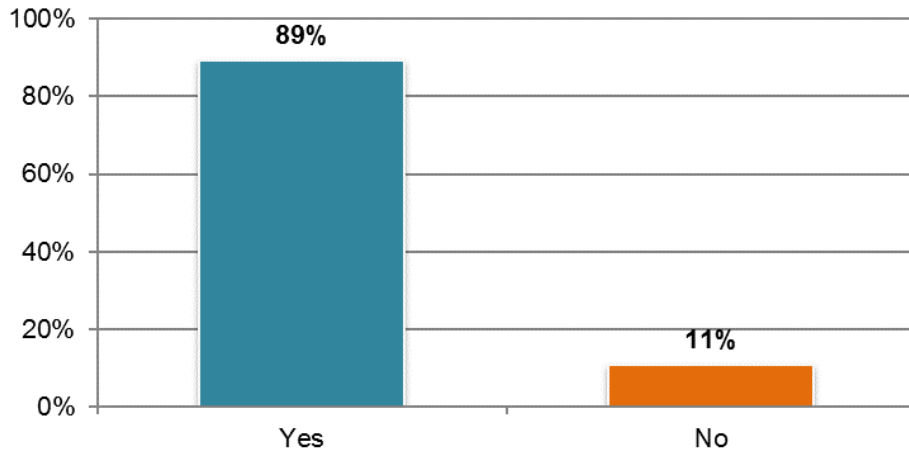


Table Q42. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Within Average Range</b>        |            |            |              |
| NC                                 | 92%        | 8%         | 250          |
| AZ                                 | 92%        | 8%         | 324          |
| OK                                 | 91%        | 9%         | 467          |
| AK                                 | 91%        | 9%         | 132          |
| VA                                 | 91%        | 9%         | 163          |
| NH                                 | 90%        | 10%        | 443          |
| DC                                 | 90%        | 10%        | 226          |
| MD                                 | 89%        | 11%        | 726          |
| LA                                 | 89%        | 11%        | 380          |
| GA                                 | 89%        | 11%        | 426          |
| HI                                 | 89%        | 11%        | 215          |
| PA                                 | 89%        | 11%        | 436          |
| WA                                 | 88%        | 12%        | 425          |
| FL                                 | 85%        | 15%        | 422          |
| <b>Significantly Below Average</b> |            |            |              |
| MS                                 | 83%        | 17%        | 481          |
| <b>NCI Average</b>                 | <b>89%</b> | <b>11%</b> | <b>5,516</b> |

### Reasons Family Member Does Not Take Part in Community Activities

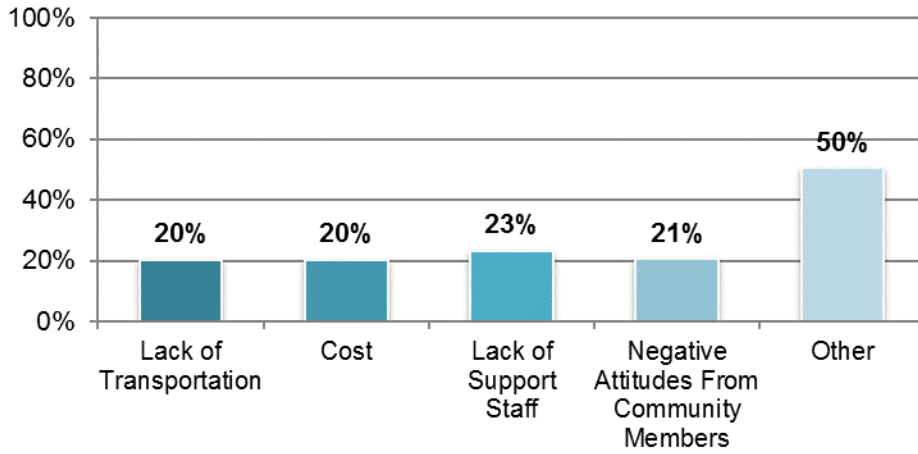


Table Q43. If no to Q42, why does your family member not take part in community activities? \*

| State              | Lack of Transportation | Cost       | Lack of Support Staff | Negative Attitudes From Community Members | Other      | N          |
|--------------------|------------------------|------------|-----------------------|---|------------|------------|
| AZ                 | 14%                    | 33%        | 10%                   | 29%                                       | 57%        | 21         |
| FL                 | 25%                    | 25%        | 29%                   | 19%                                       | 48%        | 52         |
| GA                 | 22%                    | 22%        | 22%                   | 19%                                       | 41%        | 37         |
| HI                 | 17%                    | 21%        | 29%                   | 21%                                       | 46%        | 24         |
| LA                 | 11%                    | 9%         | 14%                   | 29%                                       | 66%        | 35         |
| MD                 | 31%                    | 26%        | 39%                   | 16%                                       | 39%        | 61         |
| MS                 | 15%                    | 13%        | 18%                   | 18%                                       | 56%        | 68         |
| NH                 | 33%                    | 21%        | 28%                   | 15%                                       | 44%        | 39         |
| OK                 | 19%                    | 11%        | 25%                   | 17%                                       | 58%        | 36         |
| PA                 | 20%                    | 27%        | 17%                   | 17%                                       | 46%        | 41         |
| WA                 | 17%                    | 17%        | 26%                   | 28%                                       | 54%        | 46         |
| <b>NCI Average</b> | <b>20%</b>             | <b>20%</b> | <b>23%</b>            | <b>21%</b>                                | <b>50%</b> | <b>460</b> |

\*CATEGORIES ARE NOT MUTUALLY EXCLUSIVE

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: AK, DC, NC, AND VA.

### Family Member Has Friends Other Than Paid Support Workers or Family

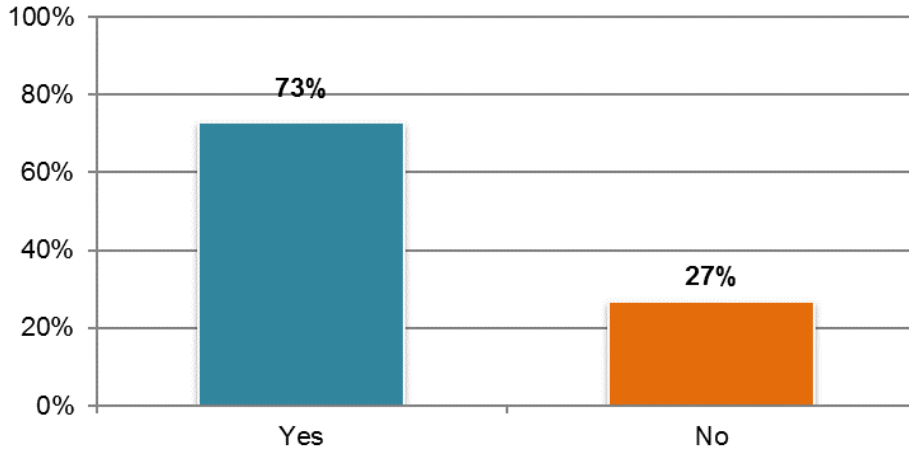


Table Q44. Does your family member have friends other than paid support workers or family?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| OK                                 | 82%        | 18%        | 460          |
| GA                                 | 81%        | 19%        | 426          |
| <b>Within Average Range</b>        |            |            |              |
| LA                                 | 76%        | 24%        | 375          |
| NH                                 | 74%        | 26%        | 438          |
| HI                                 | 74%        | 26%        | 211          |
| PA                                 | 74%        | 26%        | 423          |
| AK                                 | 73%        | 27%        | 132          |
| DC                                 | 72%        | 28%        | 218          |
| WA                                 | 72%        | 28%        | 415          |
| MS                                 | 72%        | 28%        | 478          |
| VA                                 | 71%        | 29%        | 161          |
| AZ                                 | 71%        | 29%        | 316          |
| NC                                 | 71%        | 29%        | 248          |
| FL                                 | 69%        | 31%        | 411          |
| <b>Significantly Below Average</b> |            |            |              |
| MD                                 | 68%        | 32%        | 703          |
| <b>NCI Average</b>                 | <b>73%</b> | <b>27%</b> | <b>5,415</b> |



### There Are Resources in the Community the Family Member Can Use That Are Not Provided by the IDD Agency

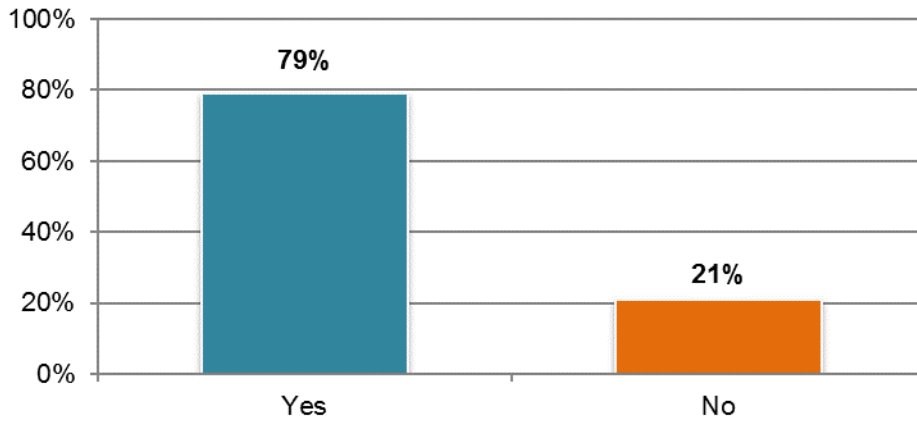


Table Q45. In your community, are there resources that your family can use that are not provided by the I/DD agency?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| WA                                 | 86%        | 14%        | 339          |
| <b>Within Average Range</b>        |            |            |              |
| NC                                 | 84%        | 16%        | 216          |
| PA                                 | 83%        | 17%        | 321          |
| AZ                                 | 82%        | 18%        | 252          |
| AK                                 | 82%        | 18%        | 115          |
| OK                                 | 82%        | 18%        | 380          |
| DC                                 | 80%        | 20%        | 193          |
| GA                                 | 79%        | 21%        | 311          |
| MD                                 | 79%        | 21%        | 555          |
| NH                                 | 79%        | 21%        | 356          |
| HI                                 | 78%        | 22%        | 139          |
| FL                                 | 76%        | 24%        | 335          |
| LA                                 | 76%        | 24%        | 305          |
| VA                                 | 75%        | 25%        | 132          |
| <b>Significantly Below Average</b> |            |            |              |
| MS                                 | 66%        | 34%        | 351          |
| <b>NCI Average</b>                 | <b>79%</b> | <b>21%</b> | <b>4,300</b> |

### Family Takes Part in Family-to-family Networks

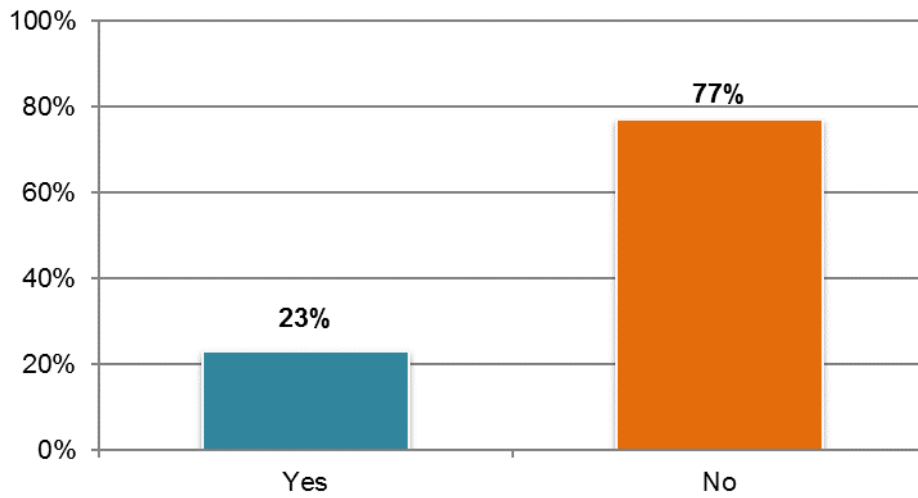


Table Q46. Does your family take part in any family-to-family networks in your community?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| HI                                 | 39%        | 61%        | 162          |
| DC                                 | 36%        | 64%        | 183          |
| LA                                 | 31%        | 69%        | 306          |
| <b>Within Average Range</b>        |            |            |              |
| AK                                 | 25%        | 75%        | 114          |
| AZ                                 | 24%        | 76%        | 281          |
| GA                                 | 23%        | 77%        | 363          |
| OK                                 | 23%        | 77%        | 380          |
| MS                                 | 22%        | 78%        | 375          |
| MD                                 | 21%        | 79%        | 633          |
| VA                                 | 19%        | 81%        | 130          |
| NC                                 | 19%        | 81%        | 219          |
| FL                                 | 19%        | 81%        | 367          |
| PA                                 | 18%        | 82%        | 369          |
| <b>Significantly Below Average</b> |            |            |              |
| WA                                 | 18%        | 82%        | 373          |
| NH                                 | 15%        | 85%        | 395          |
| <b>NCI Average</b>                 | <b>23%</b> | <b>77%</b> | <b>4,650</b> |

## **Satisfaction With Services and Supports**

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

### Overall, Respondent Is Satisfied With Services and Supports Family Receives

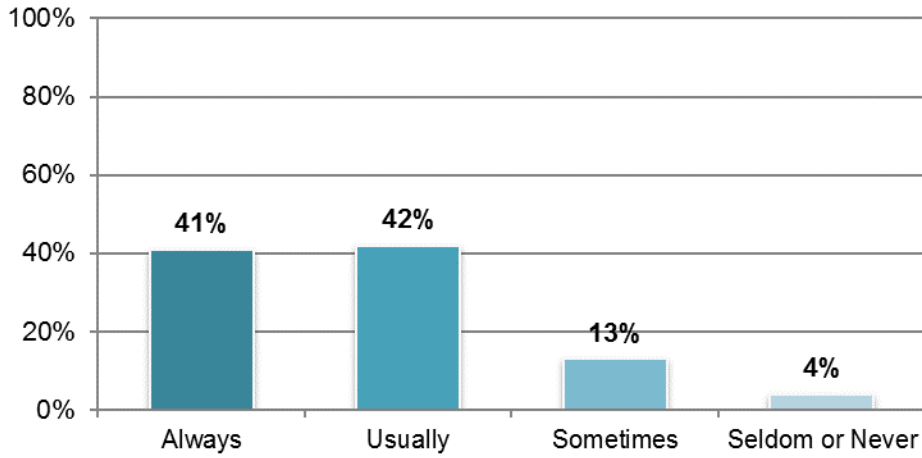


Table Q47. Overall, are you satisfied with the services and supports your family currently receives?

| State                              | Always     | Usually    | Sometimes  | Seldom or Never | N            |
|------------------------------------|------------|------------|------------|-----------------|--------------|
| <b>Significantly Above Average</b> |            |            |            |                 |              |
| LA                                 | 56%        | 33%        | 8%         | 3%              | 378          |
| <b>Within Average Range</b>        |            |            |            |                 |              |
| DC                                 | 47%        | 33%        | 18%        | 3%              | 227          |
| MS                                 | 47%        | 40%        | 12%        | 2%              | 488          |
| HI                                 | 45%        | 40%        | 12%        | 2%              | 218          |
| FL                                 | 45%        | 38%        | 14%        | 3%              | 424          |
| PA                                 | 45%        | 40%        | 11%        | 4%              | 428          |
| AZ                                 | 42%        | 48%        | 7%         | 3%              | 320          |
| OK                                 | 41%        | 48%        | 9%         | 2%              | 457          |
| NH                                 | 39%        | 42%        | 13%        | 6%              | 441          |
| NC                                 | 38%        | 42%        | 14%        | 6%              | 248          |
| VA                                 | 38%        | 42%        | 16%        | 4%              | 161          |
| AK                                 | 35%        | 47%        | 13%        | 5%              | 137          |
| <b>Significantly Below Average</b> |            |            |            |                 |              |
| WA                                 | 35%        | 49%        | 11%        | 5%              | 415          |
| GA                                 | 33%        | 44%        | 19%        | 4%              | 426          |
| MD                                 | 31%        | 47%        | 14%        | 7%              | 709          |
| <b>NCI Average</b>                 | <b>41%</b> | <b>42%</b> | <b>13%</b> | <b>4%</b>       | <b>5,477</b> |

### Respondent Knows How to File a Complaint or Grievance About Provider Agencies or Staff

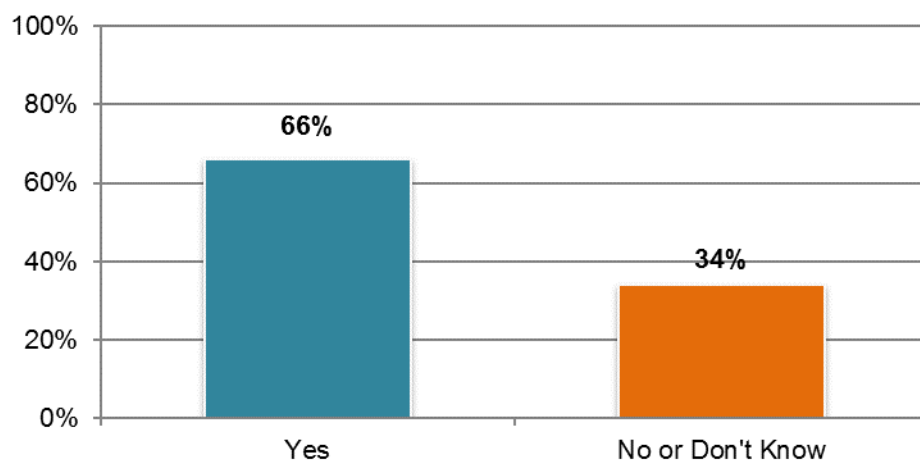
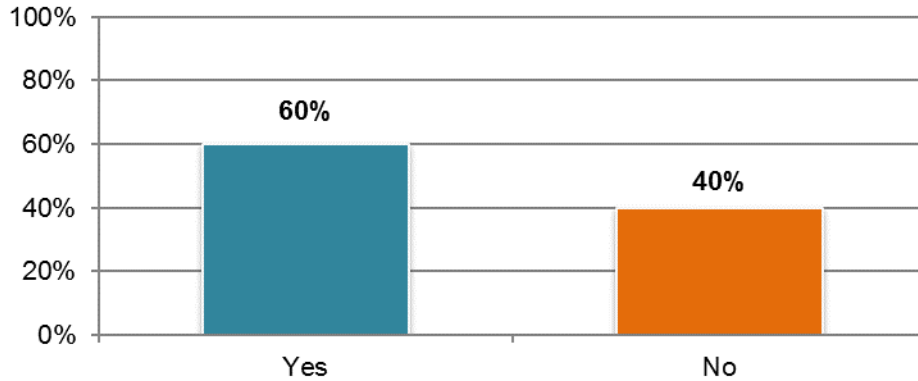


Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff?<sup>3</sup>

| State                              | Yes        | No or Don't Know | N            |
|------------------------------------|------------|------------------|--------------|
| <b>Significantly Above Average</b> |            |                  |              |
| OK                                 | 82%        | 18%              | 460          |
| LA                                 | 81%        | 19%              | 378          |
| FL                                 | 74%        | 26%              | 422          |
| <b>Within Average Range</b>        |            |                  |              |
| NC                                 | 71%        | 29%              | 248          |
| PA                                 | 71%        | 29%              | 433          |
| MS                                 | 70%        | 30%              | 489          |
| DC                                 | 69%        | 31%              | 229          |
| NH                                 | 69%        | 31%              | 440          |
| VA                                 | 69%        | 31%              | 159          |
| AK                                 | 68%        | 32%              | 136          |
| WA                                 | 64%        | 36%              | 422          |
| HI                                 | 58%        | 42%              | 211          |
| <b>Significantly Below Average</b> |            |                  |              |
| AZ                                 | 59%        | 41%              | 324          |
| GA                                 | 50%        | 50%              | 429          |
| MD                                 | 41%        | 59%              | 708          |
| <b>NCI Average</b>                 | <b>66%</b> | <b>34%</b>       | <b>5,488</b> |

<sup>3</sup> 'Don't Know' responses were included in 'No' responses for this question.

**Respondent Is Satisfied With the Way Complaints or Grievances About Provider Agencies or Staff Were Handled and Resolved (If Filed in the Past Year)**



**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?**

| State                              | Yes        | No         | N          |
|------------------------------------|------------|------------|------------|
| <b>Significantly Above Average</b> |            |            |            |
| LA                                 | 78%        | 22%        | 54         |
| <b>Within Average Range</b>        |            |            |            |
| MS                                 | 68%        | 32%        | 66         |
| HI                                 | 66%        | 34%        | 29         |
| PA                                 | 63%        | 38%        | 40         |
| NC                                 | 62%        | 38%        | 39         |
| WA                                 | 62%        | 38%        | 39         |
| GA                                 | 60%        | 40%        | 58         |
| OK                                 | 60%        | 40%        | 35         |
| AZ                                 | 59%        | 41%        | 41         |
| DC                                 | 53%        | 47%        | 64         |
| FL                                 | 53%        | 47%        | 59         |
| NH                                 | 50%        | 50%        | 56         |
| MD                                 | 49%        | 51%        | 96         |
| <b>NCI Average</b>                 | <b>60%</b> | <b>40%</b> | <b>676</b> |

**DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: AK AND VA.**

### Respondent Knows How to Report Abuse or Neglect

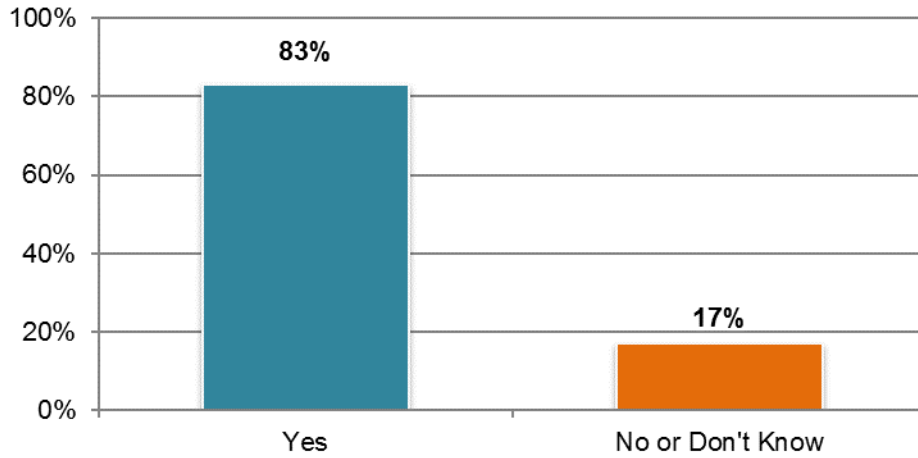


Table Q50. Do you know how to report abuse or neglect related to your family member?<sup>4</sup>

| State                              | Yes        | No or Don't Know | N            |
|------------------------------------|------------|------------------|--------------|
| <b>Significantly Above Average</b> |            |                  |              |
| OK                                 | 93%        | 7%               | 469          |
| FL                                 | 91%        | 9%               | 425          |
| LA                                 | 90%        | 10%              | 386          |
| <b>Within Average Range</b>        |            |                  |              |
| NC                                 | 88%        | 12%              | 251          |
| AK                                 | 88%        | 12%              | 137          |
| PA                                 | 87%        | 13%              | 436          |
| DC                                 | 87%        | 13%              | 233          |
| MS                                 | 86%        | 14%              | 493          |
| VA                                 | 84%        | 16%              | 164          |
| NH                                 | 83%        | 17%              | 445          |
| WA                                 | 81%        | 19%              | 426          |
| AZ                                 | 77%        | 23%              | 320          |
| <b>Significantly Below Average</b> |            |                  |              |
| HI                                 | 73%        | 27%              | 217          |
| GA                                 | 69%        | 31%              | 432          |
| MD                                 | 67%        | 33%              | 721          |
| <b>NCI Average</b>                 | <b>83%</b> | <b>17%</b>       | <b>5,555</b> |

<sup>4</sup> 'Don't Know' responses were included in 'No' responses for this question.

### Abuse or Neglect Was Reported on Behalf of Family Member in the Past Year

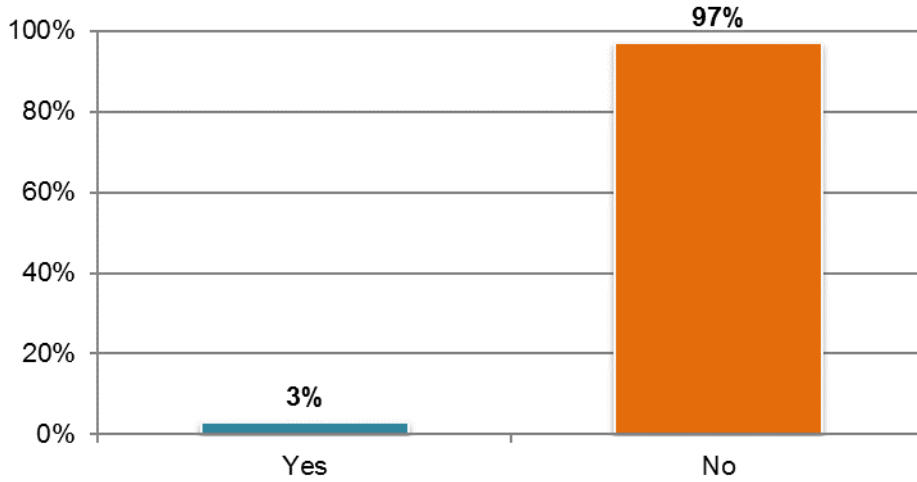


Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

| State                              | Yes       | No         | N            |
|------------------------------------|-----------|------------|--------------|
| <b>Within Average Range</b>        |           |            |              |
| DC                                 | 5%        | 95%        | 220          |
| NH                                 | 4%        | 96%        | 426          |
| WA                                 | 4%        | 96%        | 416          |
| PA                                 | 4%        | 96%        | 421          |
| GA                                 | 4%        | 96%        | 407          |
| LA                                 | 3%        | 97%        | 374          |
| AK                                 | 3%        | 97%        | 131          |
| HI                                 | 3%        | 97%        | 201          |
| FL                                 | 3%        | 97%        | 380          |
| MS                                 | 3%        | 97%        | 481          |
| VA                                 | 3%        | 97%        | 156          |
| AZ                                 | 2%        | 98%        | 309          |
| MD                                 | 2%        | 98%        | 691          |
| NC                                 | 2%        | 98%        | 247          |
| <b>Significantly Below Average</b> |           |            |              |
| OK                                 | 1%        | 99%        | 460          |
| <b>NCI Average</b>                 | <b>3%</b> | <b>97%</b> | <b>5,320</b> |



## Family Outcomes

*Individual and family supports make a positive difference in the lives of families.*

### Services and Supports Have Made a Positive Difference in Family's Life

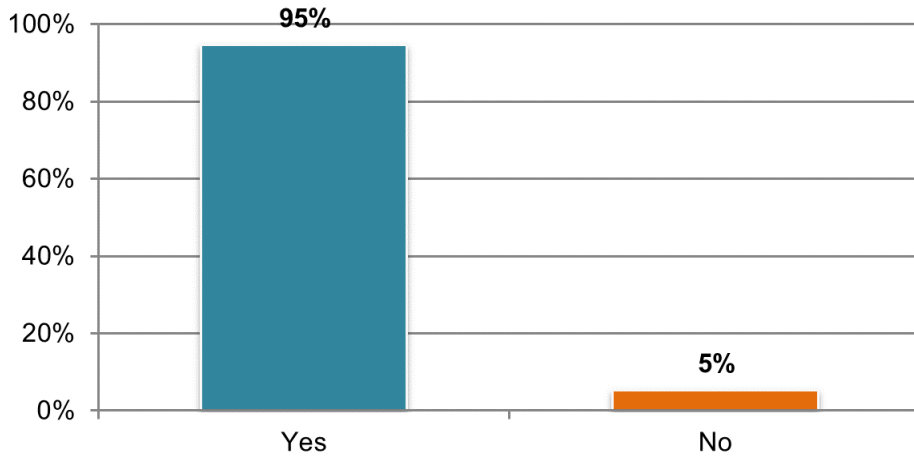


Table Q52. Do you feel that services and supports have made a positive difference in the life of your family?

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| OK                                 | 98%        | 2%        | 449          |
| <b>Within Average Range</b>        |            |           |              |
| VA                                 | 97%        | 3%        | 155          |
| HI                                 | 97%        | 3%        | 204          |
| MS                                 | 96%        | 4%        | 449          |
| AK                                 | 96%        | 4%        | 130          |
| WA                                 | 96%        | 4%        | 359          |
| AZ                                 | 95%        | 5%        | 304          |
| LA                                 | 94%        | 6%        | 358          |
| FL                                 | 94%        | 6%        | 392          |
| NC                                 | 94%        | 6%        | 230          |
| DC                                 | 94%        | 6%        | 192          |
| GA                                 | 93%        | 7%        | 391          |
| PA                                 | 92%        | 8%        | 390          |
| NH                                 | 91%        | 9%        | 410          |
| <b>Significantly Below Average</b> |            |           |              |
| MD                                 | 91%        | 9%        | 642          |
| <b>NCI Average</b>                 | <b>95%</b> | <b>5%</b> | <b>5,055</b> |

### Services and Supports Have Reduced Family's Out-of-Pocket Expenses for Family Member's Care

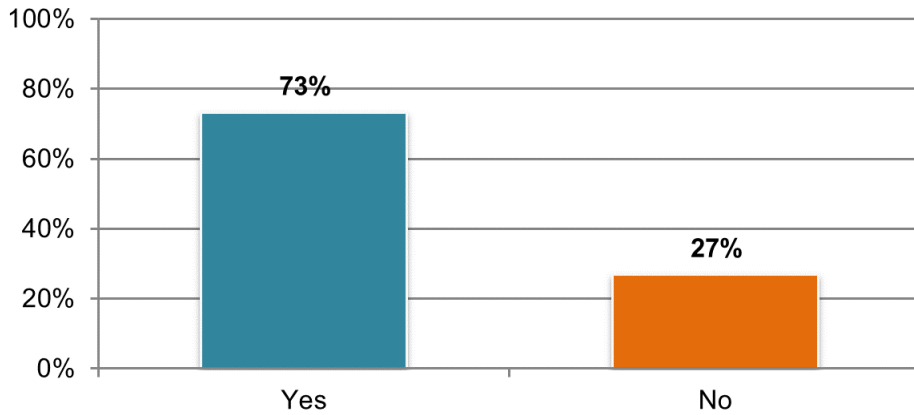


Table Q53. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| OK                                 | 87%        | 13%        | 439          |
| <b>Within Average Range</b>        |            |            |              |
| WA                                 | 78%        | 22%        | 363          |
| FL                                 | 76%        | 24%        | 386          |
| HI                                 | 76%        | 24%        | 189          |
| AZ                                 | 75%        | 25%        | 289          |
| VA                                 | 74%        | 26%        | 149          |
| NH                                 | 74%        | 26%        | 398          |
| NC                                 | 74%        | 26%        | 230          |
| MS                                 | 74%        | 26%        | 428          |
| AK                                 | 74%        | 26%        | 117          |
| LA                                 | 72%        | 28%        | 340          |
| PA                                 | 71%        | 29%        | 385          |
| GA                                 | 69%        | 31%        | 378          |
| <b>Significantly Below Average</b> |            |            |              |
| MD                                 | 65%        | 35%        | 622          |
| DC                                 | 57%        | 43%        | 198          |
| <b>NCI Average</b>                 | <b>73%</b> | <b>27%</b> | <b>4,911</b> |

### Services or Supports Were Reduced, Suspended, or Terminated in the Past Year

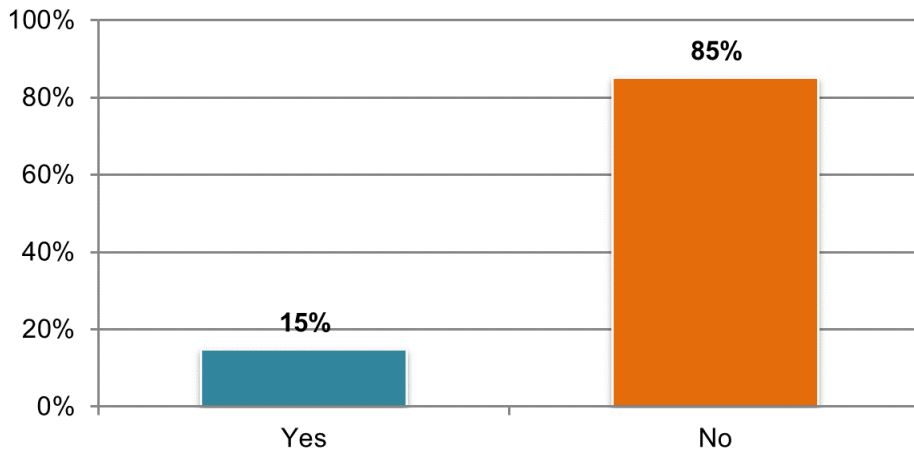


Table Q54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Within Average Range</b>        |            |            |              |
| FL                                 | 20%        | 80%        | 385          |
| NH                                 | 19%        | 81%        | 406          |
| VA                                 | 18%        | 82%        | 149          |
| NC                                 | 18%        | 82%        | 233          |
| LA                                 | 17%        | 83%        | 360          |
| AK                                 | 17%        | 83%        | 125          |
| WA                                 | 16%        | 84%        | 372          |
| DC                                 | 16%        | 84%        | 199          |
| OK                                 | 14%        | 86%        | 435          |
| MD                                 | 14%        | 86%        | 623          |
| AZ                                 | 13%        | 87%        | 295          |
| HI                                 | 13%        | 87%        | 198          |
| GA                                 | 11%        | 89%        | 395          |
| <b>Significantly Below Average</b> |            |            |              |
| PA                                 | 10%        | 90%        | 392          |
| MS                                 | 8%         | 92%        | 448          |
| <b>NCI Average</b>                 | <b>15%</b> | <b>85%</b> | <b>5,015</b> |

### Service Reduction, Suspension, or Termination Affected the Family or the Family Member Negatively

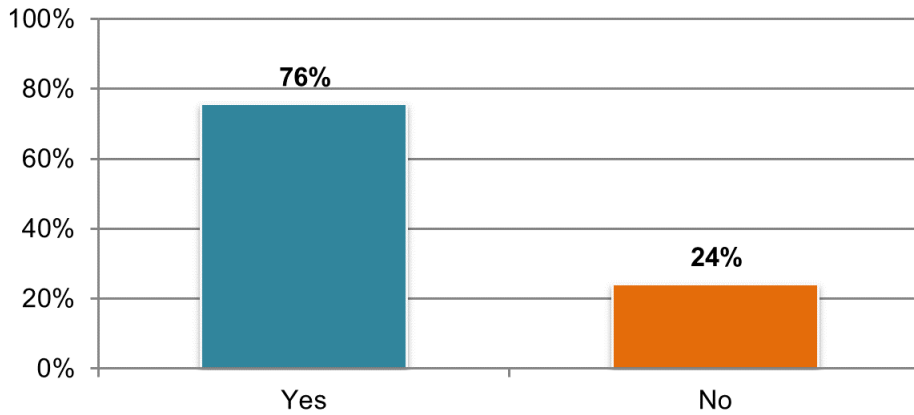


Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?

| State                       | Yes        | No         | N          |
|-----------------------------|------------|------------|------------|
| <b>Within Average Range</b> |            |            |            |
| PA                          | 88%        | 12%        | 33         |
| HI                          | 86%        | 14%        | 22         |
| VA                          | 83%        | 17%        | 23         |
| NH                          | 80%        | 20%        | 71         |
| FL                          | 80%        | 20%        | 64         |
| NC                          | 78%        | 22%        | 37         |
| AZ                          | 78%        | 22%        | 32         |
| GA                          | 77%        | 23%        | 35         |
| MS                          | 75%        | 25%        | 28         |
| MD                          | 71%        | 29%        | 69         |
| LA                          | 67%        | 33%        | 48         |
| OK                          | 67%        | 33%        | 57         |
| WA                          | 67%        | 33%        | 51         |
| DC                          | 64%        | 36%        | 25         |
| <b>NCI Average</b>          | <b>76%</b> | <b>24%</b> | <b>595</b> |

**DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATE WAS NOT INCLUDED IN THIS ANALYSIS: AK.**

### Services or Supports Were Increased in the Past Year

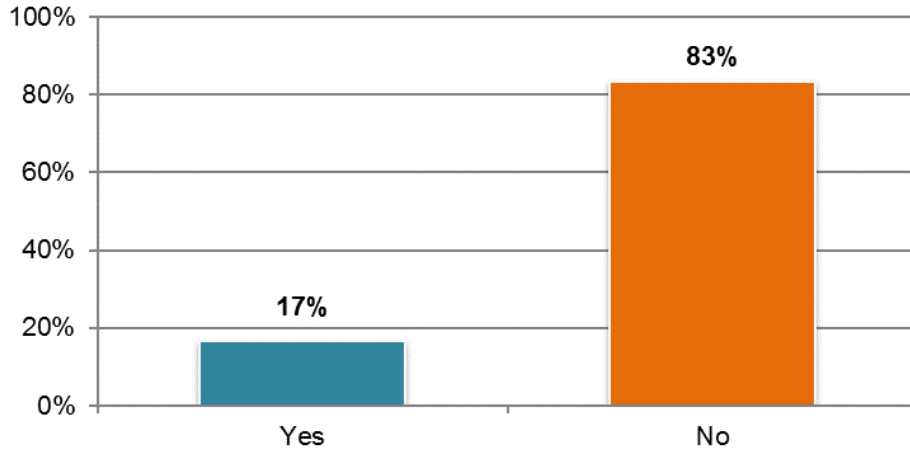


Table Q56. Have the services or supports that your family member received been increased in the past year?

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| WA                                 | 25%        | 75%        | 366          |
| DC                                 | 25%        | 75%        | 195          |
| FL                                 | 24%        | 76%        | 372          |
| <b>Within Average Range</b>        |            |            |              |
| NC                                 | 18%        | 82%        | 240          |
| GA                                 | 17%        | 83%        | 368          |
| AZ                                 | 17%        | 83%        | 291          |
| PA                                 | 17%        | 83%        | 387          |
| HI                                 | 16%        | 84%        | 192          |
| MD                                 | 16%        | 84%        | 630          |
| MS                                 | 16%        | 84%        | 437          |
| VA                                 | 15%        | 85%        | 149          |
| NH                                 | 13%        | 87%        | 414          |
| LA                                 | 13%        | 87%        | 349          |
| AK                                 | 11%        | 89%        | 128          |
| <b>Significantly Below Average</b> |            |            |              |
| OK                                 | 7%         | 93%        | 418          |
| <b>NCI Average</b>                 | <b>17%</b> | <b>83%</b> | <b>4,936</b> |

### Services or Supports Help Family Member Live a Good Life

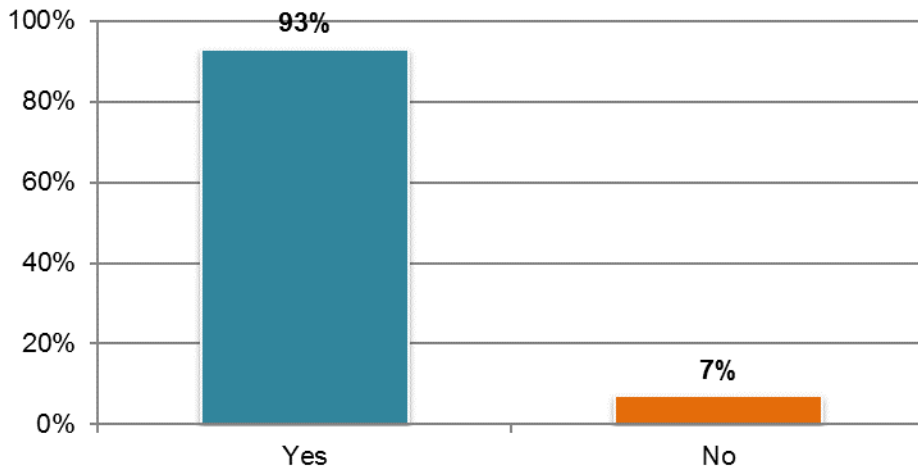


Table Q57. Are services and supports helping your family member to live a good life?

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| OK                                 | 98%        | 2%        | 442          |
| AZ                                 | 96%        | 4%        | 295          |
| <b>Within Average Range</b>        |            |           |              |
| AK                                 | 97%        | 3%        | 127          |
| MS                                 | 95%        | 5%        | 439          |
| VA                                 | 94%        | 6%        | 151          |
| GA                                 | 94%        | 6%        | 377          |
| HI                                 | 94%        | 6%        | 196          |
| FL                                 | 93%        | 7%        | 379          |
| NH                                 | 92%        | 8%        | 402          |
| NC                                 | 92%        | 8%        | 235          |
| LA                                 | 92%        | 8%        | 353          |
| PA                                 | 91%        | 9%        | 391          |
| WA                                 | 91%        | 9%        | 360          |
| DC                                 | 90%        | 10%       | 197          |
| <b>Significantly Below Average</b> |            |           |              |
| MD                                 | 90%        | 10%       | 607          |
| <b>NCI Average</b>                 | <b>93%</b> | <b>7%</b> | <b>4,951</b> |

## 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 Consumer 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 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 <http://www.nationalcoreindicators.org>.



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 (please see Figure 2, below). Four data sources are used to assess outcomes: the Adult Consumer Survey, three Family Surveys, a Staff Stability Survey (e.g., staff turnover).

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI program is a dynamic effort that allows for measures to be added, dropped, or changed to reflect current and future priorities of participating states.

The data collection tools used to gather indicator data are regularly refined and tested to ensure they remain valid, reliable, and applicable to current issues within the field. Details on the design and testing of this tool are provided in the next section of this report.

## Sub-Domains and Concern Statements

The following table lists the sub-domains under the “Family Outcomes” domain.

Figure 2. Family Survey Sub-Domains and Concern Statements

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

## How NCI Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI as a data source for supplemental performance measures in their home and community-based services (HCBS) waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

## 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, policymakers, 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/developmental disability living at home; and
2. The adult individual with an intellectual/developmental disability living at home received at least one direct service or support other than service coordination.

All states mailed out a paper survey to families selected in their sample. 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>5</sup>

In 2015-16, NCI piloted the Direct Entry Mode for the Adult Family Survey in four states (NH, HI, WA, and SD). NCI endeavored to operationalize online data collection for the (traditionally mail-out) family surveys because of requests from states to make the administration of the family survey more cost-effective and less resource intensive. States also felt that more respondents would complete the survey if it were available online. The pilot was conducted to assess the feasibility of this mode of administration, as well as to assess whether the mode would affect the outcomes.

For the 2016-17 data cycle, NCI opened the direct data entry option to all states for all surveys. For more information about the 2015-16 direct entry pilot or the national rollout of direct entry, please contact please contact Dorothy Hiersteiner ([dhiersteiner@hsri.org](mailto:dhiersteiner@hsri.org)).

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<sup>5</sup> See "Response Rates" section for information on total surveys mailed and received by states as well as each state's margin of error.

## 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 a 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>6</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

In 2015-16, 14 states and the District of Columbia 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 table below shows the number of surveys each state mailed, 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.

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<sup>6</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**

| State        | Number Eligible to Be Drawn Into the Sample | Surveys Mailed | Usable Surveys Returned | Response Rate | Margin of Error |
|--------------|---|----------------|-------------------------|---------------|-----------------|
| AK           | 445   | 445            | 141                     | 32%           | 6.83%           |
| AZ           | 8300  | 1400           | 335                     | 24%           | 5.25%           |
| DC           | 608   | 608            | 239                     | 39%           | 4.94%           |
| FL           | 14587                                       | 1700           | 435                     | 26%           | 4.63%           |
| GA           | 5926  | 2493           | 453                     | 18%           | 4.43%           |
| HI           | 1395  | 1395           | 222                     | 16%           | 6.03%           |
| LA           | 7730  | 2000           | 396                     | 20%           | 4.80%           |
| MD           | 2990  | 2900           | 748                     | 26%           | 3.10%           |
| MS           | 1231  | 1231           | 506                     | 41%           | 3.34%           |
| NC           | 16000                                       | 1200           | 254                     | 21%           | 6.10%           |
| NH           | 1766  | 1766           | 453                     | 26%           | 3.97%           |
| OK           | 1679  | 1679           | 479                     | 29%           | 3.79%           |
| PA           | 4466  | 1285           | 448                     | 35%           | 4.39%           |
| VA           | 618   | 618            | 166                     | 27%           | 6.51%           |
| WA           | 8000  | 1415           | 441                     | 31%           | 4.54%           |
| <b>Total</b> |   |                | 5716                    |               |                 |

## IV. Appendix A

*Adult Family Survey Changes Between 2014-16 and 2015-16 Survey  
Cycles*

| 2015-2016                              |  | 2014-2015 |  | Change Made   | Note  | AFS | FGS | CFS |
|--|--|-----------|--|---|---|-----|-----|-----|
| <b>Information About Family Member</b> |  |           |  |   |   |     |     |     |
| A                                      | Does your family member with a disability live at home with you?                               | A         | Does this person live at home with you?  | No change   | NA  | X   | X   | X   |
| B                                      | Is there more than one person with an intellectual/developmental disability in your household? | B         | Is there more than one person with an intellectual/developmental disability in your household? | No change   | NA  | X   | -   | X   |
| C                                      | How old is your family member with a disability?   | C         | How old is your family member with a disability?   | No change   | NA  | X   | X   | X   |
| D                                      | What is the gender of your family member?  | D         | What is the gender of this person?   | No change   | NA  | X   | X   | X   |
| E                                      | Has your family member been diagnosed with any of the conditions listed below?                 | E         | Has this person been diagnosed with any of the following disabilities listed below?            | Modified<br>Changed response options from "yes", "no", "don't know" to "check all that apply"<br><br>Added vision and hearing response options<br>Added Fetal Alcohol Syndrome (FAS)<br><br>Added explanations to some response options | NA- Beginning 2015-16, conditions can be compared to years prior to 2013-14 | X   | X   | X   |

| 2015-2016 |   | 2014-2015 |  | Change Made   | Note   | AFS | FGS | CFS |
|-----------|---|-----------|--|---|--|-----|-----|-----|
| F         | Has your family member with a disability been diagnosed with any of the health conditions listed below?               | E2        | Has this person been diagnosed with any of the following health conditions listed below? | Changed response options from "yes", "no", "don't know" to check all that apply<br><br>Deleted vision and hearing response options<br><br>Added explanations to some response options | NA   | x   | x   | x   |
| G         | What is your family member's race and ethnicity?  | F         | What is this person's race?  | Added "and ethnicity"   | NA<br>(question always captured race and ethnicity)            | x   | x   | x   |
| H         | What is your family member's preferred means of communication?  | G         | What is this person's primary means of expression?                                       | Modified<br><br>Added open text for "other" response  | NA   | x   | x   | x   |
| I         | Does your family member have a legal/court-appointed guardian or conservator?   |           |  | Replaces former question S  | Parallel comparisons cannot be made from previous years' data. | x   | x   | -   |
| J         | If your family member has a legal/court-appointed guardian, what's the guardian's relationship to your family member? |           |  | New question<br><br>Distinguish who conserves individuals   | NA   | x   | x   | -   |

| 2015-2016 |  | 2014-2015 |   | Change Made   | Note   | AFS | FGS | CFS |
|-----------|--|-----------|---|---|--|-----|-----|-----|
| K         | What is your family member's highest completed level of education?   | I         | What is this person's highest education level?  | Added/changed response options:<br>Added response- "middle school" and "currently enrolled in HS"<br><br>"Certificate program"<br><br>Changed responses:<br>"High school certificate ( <b>NOT a high school diploma/GED</b> )"<br><br>and added "college or higher" | Comparisons to previous years' data should be made with caution. | X   | X   | -   |
| L         | What does your family member do during the day?  | J         | What does this person typically do during the day?  | Changed response options<br><br>Changed response categories to reflect frequency of each activity   | Comparisons to previous years' data should be made with caution. | X   | X   | -   |
| M         | If your family member needs support to manage self-injurious, disruptive, or destructive behavior, how much support is needed?               | L         | Does this person need support to manage any of the following behaviors: self-injurious behavior, disruptive behavior, destructive behavior? | Modified<br><br>Added explanation to response options   | Comparisons to previous years' data should be made with caution. | X   | X   | X   |
| N         | If your family member needs help (support) with personal care activities (for example, bathing, dressing, eating), please indicate how much. | M         | About how much help does this person need with daily activities (such as bathing, dressing, eating)?  | Modified<br><br>Changed response options  | Comparisons to previous years' data should be made with caution. | X   | X   | X   |

| 2015-2016   |  | 2014-2015 |                                     | Change Made  | Note   | AFS | FGS | CFS |
|---|--|-----------|-------------------------------------|--|--|-----|-----|-----|
| O   | If your family member needs help (support) with other daily activities (for example, scheduling, managing money, or shopping), please indicate how much. |           |                                     | New question<br>More clearly distinguishes ADL and IADL  | NA   | X   | X   | -   |
| <b>Deleted or Rephrased Questions- Information About Family Member</b>  |  |           |                                     |  |  |     |     |     |
| <b>H. What is this person's primary language? (*this question will be re-added in future years)</b>                 |  |           |                                     |  |  |     |     |     |
| <b>K. How often does this person require medical care by a trained medical provider (e.g., nurse or physician)?</b> |  |           |                                     |  |  |     |     |     |
| <b>Information About Respondent</b>   |  |           |                                     |  |  |     |     |     |
| P   | What is your age?  | N         | What is your age?                   | No change  | NA   | X   | X   | X   |
| Q   | How would you describe your health?  | O         | How would you describe your health? | Modified<br>Changed response options "good" and "fair" to "very good" and "fairly good"          | Comparisons to previous years' data should be made with caution. | X   | X   | X   |
| R   | How are you related to the family member with a disability?  | P         | How are you related to this person? | Modified<br>Added "grandparent" to responses   | NA   | X   | X   | X   |
| S   | Is anyone in your family <b>paid</b> to provide support to your family member with a disability?   |           |                                     | New question<br>Provide additional context to data, possible begin to look into caregiver burden | NA   | X   | -   | X   |

| 2015-2016 |  | 2014-2015 |  | Change Made  | Note   | AFS | FGS | CFS |
|-----------|--|-----------|--|--|--|-----|-----|-----|
| T         | How many adults (over age 18) live in the household?   | R         | Not including this person, how many adults live in your household?                       | Modified<br>Deleted “not including this person”<br>Added the parentheses: (‘over age 18’). In future years will be (‘18 or over’)                                      | NA   | X   | -   | X   |
| U         | How many children under age 18 live in the household?  |           |  | New question<br>Gives better overall picture of home   | NA   | X   | -   | X   |
| V         | What is your highest education level?  | T         | What is your highest education level?  | Modified<br>Added response options: “Vocational school to “vocational school <b>or certificate program</b> ”<br>“College degree” to “college degree <b>or higher</b> ” | Comparisons to previous years’ data should be made with caution. | X   | X   | X   |
| W         | What was the total income last year of all wage earners in your household? Do not include state/federal benefits such as SSI, SSDI, etc. | U         | What was the total taxable income last year of all the wage earner(s) in your household? | Modified<br>Deleted “taxable”<br>Added additional explanatory text<br>Added response option “prefer not to say”  | Comparisons to previous years’ data should be made with caution. | X   | X   | X   |
| X         | What <u>county</u> do you currently live in?   | W         | What County do you currently live in   | No change  | NA   | X   | X   | X   |

| 2015-2016  |  | 2014-2015 |  | Change Made  | Note | AFS | FGS | CFS |
|--|--|-----------|--|--|------|-----|-----|-----|
| Y  | Do you live in an urban or rural area?   |           |  | New question<br><br>This could be important for states to drill down by outcomes based on the person's setting | NA   | X   | X   | X   |
| <b>Deleted or Rephrased Questions- Information About Family Member</b>   |  |           |  |  |      |     |     |     |
| <b>Q. Are you a primary caregiver for this person?</b>   |  |           |  |  |      |     |     |     |
| <b>S. Are you a legal guardian (e.g., you have been appointed by the court) or conservator for this person?</b>  |  |           |  |  |      |     |     |     |
| <b>V. Approximately how much out-of-pocket money did you spend last year on this person's medical services, equipment, supplies, therapies, and other supports/services?</b> |  |           |  |  |      |     |     |     |
| <b>Services and Supports Received</b>  |  |           |  |  |      |     |     |     |
| i-vii  | Services received  | i-vi      | NA   | Modified<br><br>Added "self-direction/fiscal intermediary services"  | NA   | X   | X   | X   |
| viii   | Does your family member receive Social Security payments (SSI or SSDI, survivor benefits, etc.)?                                     | Vii       | Does your family member receive Social Security payments (SSI or SSDI, survivor benefits, etc.)? | No change  | NA   | X   | X   | X   |
| ix   | Does your family member receive services or supports from other agencies or organizations (school services, vocational rehab, etc.)? |           |  | New question<br><br>Determine additional non-state funded supports the person receives                         | NA   | X   | X   | X   |



| 2015-2016  | 2014-2015   | Change Made | Note  | AFS  | FGS  | CFS |   |   |
|--|---|-------------|---|--|--|-----|---|---|
| <b>Part 2: Questions About Services and Supports</b>   |   |             |   |  |  |     |   |   |
| Overall changes:<br>Combined Seldom and Never responses<br>Included explanatory text for NA responses where applicable |   |             |   |  |  |     |   |   |
| <b>Information and Planning</b>  |   |             |   |  |  |     |   |   |
| 1  | Do you get enough information to take part in planning services for your family member?   | 1           | Do you get enough information to help you participate in planning services for your family?   | No change  | NA   | X   | X | X |
| 2  | Is the information you get about services and supports easy to understand?  | 2           | Is the information you receive easy to understand?  | Modified   | Comparisons to previous years' data should be made with caution. | X   | X | X |
| 3  | Does the case manager/service coordinator respect your family's choices and opinions?   | 4           | Does the case manager/service coordinator respect your family's choices and opinions?   | No change  | NA   | X   | X | X |
| 4  | Do you have enough information about other public services for which your family is eligible (public services such as food stamps, SSI, or housing subsidies, for example)? | 5           | Does the case manager/service coordinator tell you about other public services that your family is eligible for (e.g., food stamps, Supplemental Security Income [SSI], housing subsidies, etc.)? | Modified<br>No longer captures only information from the case manager/service coordinator                    | Parallel comparisons to previous years' data cannot be made.     | X   | - | X |
| 5  | Do you need help planning for your family member's future with respect to any of the following?   |             |   | New question<br>Adds information about future planning; all other questions are about current services/needs | NA   | X   | X | X |

| 2015-2016 |   | 2014-2015 |   | Change Made  | Note   | AFS | FGS | CFS |
|-----------|---|-----------|---|--|--|-----|-----|-----|
| 6         | If you asked for crisis or emergency services during the past year, were services provided when needed?   | 28        | If you asked for crisis or emergency services during the past year, were services provided when needed?       | Question moved from Access and Delivery of Services    | NA   | X   | -   | X   |
| 7         | Does your family member have a service plan? <i>(Does your family member have a list of services his/her case manager/service coordinator will help get?)</i> | 6         | Does your family member have a service plan?  | Modified<br>Added additional explanatory text          | Comparisons to previous years' data should be made with caution. | X   | X   | X   |
| 8         | Does the plan include all the services and supports your family member needs?   | 11        | Does the plan include all the services and supports your family member needs?                                 | Changed order of questions                             | NA   | X   | X   | X   |
| 9         | Does your family member get all the services listed in the plan?  | 8         | Does your family member receive all of the services listed in the plan?                                       | Changed order of questions                             | NA   | X   | X   | X   |
| 10        | Did you or another family member (besides your family member with a disability) help make the plan?   | 10        | Did you or another family member help develop the plan?   | Changed order of questions                             | NA   | X   | X   | X   |
| 11        | Did your family member help make the plan?  | 9         | Did your family member help develop the plan?   | Changed order of questions                             | NA   | X   | X   | X   |
| 12        | Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?          | 12        | Did you discuss how to handle emergencies related to your family member at the last service planning meeting? | Modified<br>Rephrased with additional explanatory text | Comparisons to previous years' data should be made with caution. | X   | X   | X   |

| 2015-2016 |   | 2014-2015 |  | Change Made  | Note | AFS | FGS | CFS |
|-----------|---|-----------|--|--|------|-----|-----|-----|
| 13        | Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?       |           |  | New question<br>Builds on emergency preparedness and adequacy of ER plans from Q13                     | NA   | X   | X   | X   |
| 14        | If your family member transitioned out of school services during the past year, did he/she have a transition plan?                      |           |  | New question<br>Provides information about transition process for families                             | NA   | X   | X   | -   |
| 15        | If yes to Q14, did the transition plan include getting or continuing work in a community job?   |           |  | New question<br>Provides information about transition process and employment opportunities/preparation | NA   | X   | X   | -   |
| 16        | Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community? | 51        | Does your family member have enough supports (e.g., support workers, community resources) to work or volunteer in the community? | Moved from Community Participation   | NA   | X   | X   | -   |

#### Deleted or Rephrased Questions- Information and Planning

**3. Does the information you receive come from your case manager/service coordinator?**

**7. Does the plan include all the services and supports your family member wants?**

**13. Have you or your family member received information about his/her rights?**

#### Access and Delivery of Services and Supports

| 2015-2016 |   | 2014-2015 |  | Change Made   | Note  | AFS | FGS | CFS |
|-----------|---|-----------|--|---|---|-----|-----|-----|
| 17        | Are you or your family member able to contact his/her support workers when you want to?   | 14        | Are you or your family member able to contact his/her support workers when you need to?                  | Modified<br>Changed "need" to "want"  | Comparisons to previous years' data should be made with caution.                | x   | x   | x   |
| 18        | Are you or your family member able to contact his/her case manager/service coordinator when you want to? <i>(If you call or email do they get back to you?)</i> | 15        | Are you or your family member able to contact his/her case manager/service coordinator when you need to? | Modified<br>Added additional explanatory text<br>Changed "need" to "want"   | Comparisons to previous years' data should be made with caution.                | x   | x   | x   |
| 19        | Do support workers come and leave when they are supposed to? <i>(Do they show up on time? Do they show up when they say they will?)</i>                         | 26        | Do the support workers who come to your home arrive on time and when scheduled?                          | Modified<br>Added additional explanatory text<br>Changed order of questions | Comparisons to previous years' data should be made with caution.                | x   | x   | x   |
| 20        | Do services and supports change when your family's needs change?  | 18        | Do the services and supports change when your family member's needs change?                              | Modified  | Comparisons to previous years' data should be made with caution.                | x   | x   | x   |
| 21        | Do support workers speak to you in a way that you understand? <i>(Do they use words you understand? Do they speak to you in the language you prefer?)</i>       |           |  | New question<br>Replaces former Q19-Q20                                     | In future years, this question will be able to be analyzed by primary language. | x   | x   | x   |
| 22        | Are services delivered in a way that is respectful of your family's culture?  | 22        | Are services delivered in a way that is respectful to your family's culture?                             | Changed order of questions  | NA  | x   | x   | x   |

| 2015-2016 |  | 2014-2015 |  | Change Made                                    | Note   | AFS | FGS | CFS |
|-----------|--|-----------|--|--|--|-----|-----|-----|
| 23        | If your family member does not communicate verbally (for example, uses gestures or sign language, uses communication aid), are there support workers who can communicate with him/her? | 21        | If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her? | Changed order of questions                     | NA   | x   | x   | x   |
| 24        | Do support workers have the right information and skills to meet your family's needs?  |           |  | New question<br>Replaces former Q25            | NA   | x   | x   | x   |
| 25        | Does your family member have the special equipment or accommodations that s/he needs ( <i>some examples include wheelchair, ramp, communication board</i> )?                           | 23        | Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?           | No change                                      | NA   | x   | x   | x   |
| 26        | Can your family member see health professionals (for example, doctor, dentist, psychologist) when needed?  | 29        | Do you have access to health services for your family member?  | Modified                                       | Parallel comparisons to previous years' data cannot be made. | x   | x   | x   |
| 27        | Does your family member's primary care doctor understand his/her needs related to his/her disability?  |           |  | New question<br>Better gets at quality of care | NA   | x   | x   | x   |
| 28        | Do you have access to dental services for your family member?  | 30        | Do you have access to dental services for your family member?  | No change                                      | NA   | x   | x   | x   |

| 2015-2016 |   | 2014-2015 |   | Change Made   | Note   | AFS | FGS | CFS |
|-----------|---|-----------|---|---|--|-----|-----|-----|
| 29        | If yes to Q28, does your family member's dentist understand his/her needs related to his/her disability?  |           |   | New question<br>Gets at quality of care                                       | NA   | X   | X   | X   |
| 30        | If your family member takes medications, do you know what they're for?  |           |   | New question<br>Gets at family understanding of medication use                | NA   | X   | X   | X   |
| 31        | If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications ( <i>when it should be taken, how much to take, potential side effects</i> )? |           |   | New question<br>Better get at family understanding of using medication safely | NA   | X   | X   | X   |
| 32        | If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability?                    |           |   | New question<br>Gets at quality of care                                       | NA   | X   | X   | X   |
| 33        | If you need respite services, do you have access to them? ( <i>Respite is support for family or other care-providers to allow them to take a break from providing care for a time-limited period</i> ).                             | 33        | If you need respite services, do you have access to them? | Modified<br>Added additional explanatory text                                 | Comparisons to previous years' data should be made with caution. | X   | -   | X   |

| 2015-2016 |  | 2014-2015 |   | Change Made                          | Note   | AFS | FGS | CFS |
|-----------|--|-----------|---|--------------------------------------|--|-----|-----|-----|
| 34        | If Yes to Q33, are you satisfied with the quality of the respite services? | 33a       | If Yes to Q33, are you satisfied with the quality of these providers?                               | Modified                             | NA   | x   | -   | x   |
| 35        | Does your family get the support needed?                                   | 34        | Are there other services that your family member needs that are not currently offered or available? | Modified                             | Comparisons to previous years' data should be made with caution. | x   | x   | x   |
| 36        | If no to Q35, what additional services are needed?                         | 34a       | If Yes to Q34, what services are needed (list here):  | Modified<br>Response options offered | Comparisons to previous years' data should be made with caution. | x   | x   | x   |

**Deleted or Rephrased Questions- Access and Delivery of Services and Supports**

**16. Are services and supports available when your family member needs them?**

**17. Are services and supports available within a reasonable distance from your home?**

**19. If English is not your primary language, are there support workers or translators who can speak to you in your language?**

**20. If English is your primary language, do the support workers speak to you effectively?**

**24. Do you feel that your family member's day/employment setting is a healthy and safe environment?**

**25. Do the support workers have the right training to meet your family's needs?**

**27. If your family member transitioned from school services to State funded services during the past year, were you happy with the transition process?**

**29a. If Yes to Q29, are you satisfied with the quality of these providers?**

**30a. If Yes to Q30, are you satisfied with the quality of these providers?**

**31. Are you able to get medications needed for your family member?**

**31a. If Yes to Q31, are you satisfied with how your family member's medication needs are monitored?**

**32. If needed, do you have access to mental health services for your family member?**

**32a. If Yes to Q32, are you satisfied with the quality of these providers?**

| 2015-2016 | 2014-2015 | Change Made | Note | AFS | FGS | CFS |
|-----------|-----------|-------------|------|-----|-----|-----|
|-----------|-----------|-------------|------|-----|-----|-----|

| Choice, Decision Making, and Control |   |  |  |  |   |   |   |
|--------------------------------------|---|--|--|--|---|---|---|
| 37                                   | Can your family choose or change the agency that provides your family member's services?      |  | New question<br>Replaces former Q35-Q37, now includes all family and whether family can chose or can change agencies | Parallel comparisons to previous years' data cannot be made.     | x | x | x |
| 38                                   | Can your family choose or change your family member's support workers?                        |  | New question<br>Replaces former Q38-Q40, now includes all family and whether family chose or can change workers.     | Parallel comparisons to previous years' data cannot be made.     | x | x | x |
| 39                                   | Does your family directly manage support workers (for example, hiring and deciding schedule)? |  | New question<br>Replaces former Q43  | Comparisons to previous years' data should be made with caution. | x | x | x |



| 2015-2016 |   | 2014-2015 | Change Made   | Note   | AFS | FGS | CFS |
|-----------|---|-----------|---|--|-----|-----|-----|
| 40        | Do service providers for your family member work together to provide support? (For example, does the agency providing transportation work together with the agency providing in-home support if necessary?) |           | New question<br>Determines whether multiple providers work together to support families   | NA   | x   | x   | x   |
| 41        | Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?   |           | New question<br>Replaces former Q41-Q42, now includes all family and whether family chose or can request a change to case manager | Parallel comparisons to previous years' data cannot be made. | x   | x   | x   |

| 2015-2016  |  | 2014-2015 |  | Change Made | Note | AFS | FGS | CFS |
|--|--|-----------|--|-------------|------|-----|-----|-----|
| <b>Deleted or Modified- Choice and Decision-Making</b>   |  |           |  |             |      |     |     |     |
| 35. Did you choose the provider agencies who work with your family?  |  |           |  |             |      |     |     |     |
| 36. Did your family member choose the provider agencies who work with your family?   |  |           |  |             |      |     |     |     |
| 37. Can you choose a different provider agency if you want to?   |  |           |  |             |      |     |     |     |
| 38. Did you choose the individual support workers who work directly with your family?  |  |           |  |             |      |     |     |     |
| 39. Did your family member choose the individual support workers who work directly with your family?                             |  |           |  |             |      |     |     |     |
| 40. Can you choose different support workers if you want to?   |  |           |  |             |      |     |     |     |
| 41. Did you choose your family member's case manager/service coordinator?  |  |           |  |             |      |     |     |     |
| 42. Did your family member choose his/her case manager/service coordinator?  |  |           |  |             |      |     |     |     |
| 43. Do you have control and/or input over the hiring and management of your family member's support workers?                     |  |           |  |             |      |     |     |     |
| 44. Does your family member have control and/or input over the hiring and management of his/her support workers?                 |  |           |  |             |      |     |     |     |
| 45. Do you know how much money is spent by the ID/DD agency on behalf of your family member?                                     |  |           |  |             |      |     |     |     |
| 46. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?                                  |  |           |  |             |      |     |     |     |
| 47. Do you have a say in how this money is spent?  |  |           |  |             |      |     |     |     |
| 47a. If Yes to Q47, do you have all the information you need to make decisions about how to spend this money?                    |  |           |  |             |      |     |     |     |
| 48. Does your family member have a say in how this money is spent?   |  |           |  |             |      |     |     |     |
| 48a. If Yes to Q48, does your family member have all the information s/he needs to make decisions about how to spend this money? |  |           |  |             |      |     |     |     |
| <b>Involvement in the Community</b>  |  |           |  |             |      |     |     |     |
| 42   | Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)? | 49        | Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)? | No change   | NA   | X   | X   | X   |
| 43   | If no to Q42, why not?   | 49a       | If no to Q49, why not?   | No change   | NA   | X   | X   | X   |

| 2015-2016 |   | 2014-2015 |   | Change Made   | Note | AFS | FGS | CFS |
|-----------|---|-----------|---|---|------|-----|-----|-----|
| 44        | Does your family member have friends other than paid support workers or family?   | 50        | Does your family member have friends or relationships with persons other than paid support workers or family? | Modified<br>Deleted "or relationships"  | NA   | x   | x   | x   |
| 45        | In your community, are there resources that your family can use that are not provided by the I/DD agency? (For example, recreational programs, community housing, library programs, religious groups, etc.) |           |   | New question<br>Determines whether families have access to non-traditional supports | NA   | x   | x   | x   |
| 46        | Does your family take part in any family-to-family networks in your community? (For example, Parent to Parent, sibling networks, etc.)  |           |   | New question<br>Determines whether families have access to support networks         | NA   | x   | x   | x   |

### Satisfaction

|    |   |    |   |           |    |   |   |   |
|----|---|----|---|-----------|----|---|---|---|
| 47 | Overall, are you satisfied with the services and supports your family currently receives? | 52 | Overall, are you satisfied with the services and supports your family currently receives? | No change | NA | x | x | x |
|----|---|----|---|-----------|----|---|---|---|

| 2015-2016 |   | 2014-2015 |   | Change Made  | Note   | AFS | FGS | CFS |
|-----------|---|-----------|---|--|--|-----|-----|-----|
| 48        | Do you know how to file a complaint or grievance about provider agencies or staff?  | 43        | Do you know the process for filing a complaint or grievance against provider agencies or staff? | Modified   | NA   | X   | X   | X   |
| 49        | If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?                                   |           |   | New question<br>Replaces former Q54  | Parallel comparisons to previous years' data cannot be made.                                   | X   | X   | X   |
| 50        | Do you know how to report abuse or neglect related to your family member?   | 55        | Do you know how to report abuse or neglect?   | Modified   | NA   | X   | X   | X   |
| 51        | Within the past year, was a report of abuse or neglect filed on behalf of your family member?   | 56        | Within the past year, if abuse or neglect occurred, did you report it?                          | Modified   | Parallel comparisons to previous years' data cannot be made.                                   | X   | X   | X   |
| 52        | If yes to Q51, did the appropriate people respond to the report?  | 57        | If Yes (to Q56), were the appropriate people responsive to your report?                         | Modified   | Due to rephrasing of Q51 and Q52, parallel comparisons to previous years' data cannot be made. | X   | X   | X   |
| 53        | If Yes to Q51, if someone other than you or another family member reported abuse or neglect in the past year, were you notified of the report in a timely manner? |           |   | New question<br>Follow-up to assess whether family is kept apprised of abuse/neglect reports | NA   | X   | X   | X   |

**Deleted or Rephrased Questions- Satisfaction****54. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?****Outcomes**

| 2015-2016 |   | 2014-2015 |   | Change Made  | Note | AFS | FGS | CFS |
|-----------|---|-----------|---|--|------|-----|-----|-----|
| 54        | Do you feel that services and supports have made a positive difference in the life of your family?  | 57        | Do you feel that services and supports have made a positive difference in the life of your family?  | No change  | NA   | X   | X   | X   |
| 55        | Have services and supports reduced your family's out-of-pocket expenses for your family member's care?  | 58        | Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care?                         | No change  | NA   | X   | -   | X   |
| 56        | Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?              | 59        | Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?              | No change  | NA   | X   | X   | X   |
| 57        | If Yes to Q56, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively? | 60        | If Yes to Q59, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively? | No change  | NA   | X   | X   | X   |
| 58        | Have the services or supports that your family member received been increased in the past year?   |           |   | New question<br>This gets at the reverse of previous question (whether services were reduced); may give some insight to other outcomes | NA   | X   | X   | X   |
| 59        | Are services and supports helping your family member to live a good life?   |           |   | New question<br>Helps determine overall satisfaction with service delivery   | NA   | X   | X   | X   |

