

# Family/Guardian Survey

2013-14 Final Report



**NATIONAL CORE  
INDICATORS**

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



Human Services  
Research Institute

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**List of Abbreviations Used in This Report**

AFS – Adult Family Survey

CFS – Child Family Survey FGS – Family/Guardian Survey

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities  
Services

NCI – National Core Indicators

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## Executive Summary

The National Core Indicators (NCI) are standard measures used across states to assess the outcomes of services provided to individuals with intellectual/developmental disabilities and their families. The indicators address key areas such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that result from NCI surveys are often used to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Many states also share the data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction.

The NCI Family/Guardian Survey is administered to families who have an adult family member (18 years or older) with a developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Family/Guardian Survey on an annual basis. Of the 39 states, the District of Columbia and 22 sub-state entities who participated in NCI during the 2013-14 data collection cycle, 12 states submitted a valid sample of Family/Guardian Survey data to be included in this report. This Final Report provides a summary of results based on data submitted by June 30, 2014.

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

### **Demographics and Characteristics of Family Members for Whom the Survey Was Completed**

Just over half of the adults for whom the survey was completed were residing in a group home (54%). Of the remainder, 17% were in their own home or apartment, 10% were in a specialized institutional facility, 8% were in an adult foster care or host home, 5% were in an agency-operated apartment, 1% were in a nursing home, and 5% were in another type of residence not listed.

The average age was 47 years old, and the majority were male (58%). In terms of race, most were white (81%), and 13% were black or African American. In terms of ethnicity, 2% were Hispanic.

For the vast majority of adult family members across states, the primary means of communication was either spoken language (72%) or gestures or body language (22%). Nearly all spoke English as their primary language (96%); 1% spoke Spanish while 3% had another primary language.

The majority of the adult family members required medical care less than once a month (64%); one-quarter (25%) needed medical care at least once a month and 11% required at least weekly medical care.

In terms of behavioral supports, 41% needed some support, 22% needed extensive support, and 37% did not require support. The amount of help individuals needed with daily activities was reported as: 21% none; 21% little; 32% moderate; and 26% complete.

### **Demographics and Characteristics of Respondents to the Survey**

Most survey respondents were either the parent (57%) or sibling (24%) of the adult for whom the survey was completed. About half of respondents had full guardianship or conservatorship (51%) and 13% had limited guardianship or conservatorship; 37% were not the person's guardian or conservator. The majority of survey respondents were 55 or older (61% were 55-74 and 21% were 75 or older); 2% were under 35 years old and 16% were 35-54.

More than half of respondents see the adult family member more than 12 times per year (59%). Among the others, 14% see them 7-12 times a year, 13% see them 4-6 times a year, 10% see them 1-3 times a year, and 4% see them less than once a year.

A little under two-thirds of respondents reported that their family's total household income in the past year was \$50,000 or less (17% reported less than \$15,000, 18% reported \$15,001-\$25,000, and 26% reported \$25,001-\$50,000); 17% earned \$50,001-\$75,000 and the remaining 21% earned more than \$75,000. In terms of past-year expenses for care for the adult family member, families reported paying the following out-of-pocket: 53% paid nothing; 11% paid \$1-\$100; 22% paid \$101-\$1,000; 12% paid \$1,001-\$10,000; and 1% spent more than \$10,000.

### **Services and Supports Received**

Respondents reported that their adult family member received the following state-provided services and supports: residential (93%), day or employment supports (73%), transportation (91%), and other supports (65%). Most respondents (95%) reported that their adult family member receives social security benefits.

### **Information and Planning**

Across states, 46% of respondents reported that they always receive enough information to help plan services for their family member, and half (50%) stated that the information they receive is always easy to understand. More than half (54%) were always kept informed about how their family member was doing.

Of the 95% of respondents who reported that their family member had a service plan, most felt the plan includes all the services and supports the person wants (88%) and needs (86%). Nearly all reported that the individual receives all the services listed in the plan (93%). Just over three-quarters (76%) of respondents discussed how to handle emergencies related to their family member in the last planning meeting.

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

Nearly two-thirds of respondents (63%) were always able to contact support workers and 58% could always contact the case manager/service coordinator when needed. Approximately two-thirds indicated that services and supports were always available reasonably close to their family member's residence (67%); 56% felt that services and supports always changed when their family member's needs changed.

Just over two-thirds reported that their family member always has access to special equipment or accommodations needed (68%). Just over half (53%) felt that support workers have the right training to meet their family member's needs. Most indicated that their family member's residential and day or employment setting is always a healthy and safe environment (72% and 70%, respectively).

### **Choice and Control**

About half of respondents reported that the agency that provides residential supports always involves their family member in important decisions (52%). Just over one-third indicated that their family member always chooses his or her provider agencies (37%), and 45% reported that their family member can always choose another provider agency if desired. Nineteen percent (19%) reported that their family member always chooses his or her individual support workers, and 31% reported that their family member was always able to choose different support workers.

In terms of money spent on services, 14% of respondents indicated that their family member knows how much money is spent by the ID/DD agency on their behalf. Further, 31% of respondents report that their family member has a say in how ID/DD agency money is spent; of those, 90% say their family member has all the information needed to make these decisions.

### **Community Connections**

Most respondents reported that their family member participates in community activities (93%). More than three-quarters (77%) reported that their family member have friends and relationships with people other than paid staff or family. And most say that their family member has enough support to work or volunteer in the community (77%).



## **Satisfaction With Services and Supports**

Across states, 49% of respondents are always satisfied with the services and supports their family member receives.

Approximately two-thirds of respondents (65%) say they know the process for filing a complaint or grievance against provider agencies or staff; and most are satisfied with the way complaints or grievances are handled (86%). More than three-quarters know how to report abuse or neglect (78%). Of the 52% who reported abuse or neglect in the past year, 86% say the appropriate people were responsive to the report.

## **Family Outcomes**

Nearly all respondents felt that services and supports made a positive difference in their family's life (97%). Most indicated that services and supports have reduced their family's out-of-pocket expenses related to their family member's care (90%). Eighteen percent (18%) reported that their family member's services or supports were reduced, suspended, or terminated in the past year; of these, two-thirds (67%) reported that this change had a negative impact on their family member.

# I. Results

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

# Survey Development

The Family/Guardian Survey was developed and first utilized in 1999-2000 in response to various states' interest in determining whether families were involved in the lives of family members with developmental disabilities who lived outside the home, whether these families had the support they needed to be involved, and whether they were satisfied with the service system that was intended to meet their family member's needs.

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 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 Family/Guardian Survey

The Family/Guardian Survey is composed of the three sections described below. There is also an opportunity for families to write open-ended comments concerning their family's participation in the service system.

### **Demographics**

The survey instrument begins with a series of questions relating to characteristics of the family member with a developmental disability (e.g., age, race, type of disability) followed by a series of demographic questions pertaining to 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," or "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.

## 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 Family/Guardian Survey are presented in this report. Outcome results are presented in six subsections that correspond with the sections of the Family/Guardian Survey.

For each question, outcome results are first shown in a graph with the NCI Average (the average of all individual state percentages) 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 range of the NCI Average, their 'always' or 'yes' response was not statistically different from the NCI Average.

**Note on Significance:** Statistical significance depends on both the state's sample size and the difference between the state's result and the national average. Consequently, there are instances where a state's result that is closer to the NCI Average is designated as significantly above or below the NCI Average while another whose result is further from the NCI Average is not. Take the following example: State A has a larger valid sample for a particular indicator than State B; State A may show as being significantly different from the average even though State B, which has a larger difference from the average, does not. The larger the sample size of a state, the smaller the difference needs to be to qualify as statistically significant.

**Note on California significance:** Due to the large N<sup>1</sup>, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (\*\*), an outcome is significant only due to the sample size.

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<sup>1</sup> 'N' refers to the number of valid responses.

## Demographics

**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.**

## Family Member

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

**Table 1. Family Member's Residence**

| State              | Specialized Facility for People with ID | Group Home | Agency-Owned Apartment | Independent Home or Apartment | Adult Foster Care or Host Home | Nursing Home | Other     | N            |
|--------------------|-----------------------------------------|------------|------------------------|-------------------------------|--------------------------------|--------------|-----------|--------------|
| CA                 | 13%                                     | 45%        | 3%                     | 30%                           | 2%                             | 2%           | 5%        | 3,090        |
| FL                 | 10%                                     | 64%        | 2%                     | 17%                           | 2%                             | 1%           | 4%        | 366          |
| GA                 | 9%                                      | 55%        | 4%                     | 15%                           | 13%                            | 1%           | 4%        | 322          |
| MD                 | 6%                                      | 54%        | 6%                     | 20%                           | 3%                             | 2%           | 9%        | 159          |
| MI                 | 0%                                      | 68%        | 2%                     | 21%                           | 4%                             | 1%           | 4%        | 443          |
| NC                 | 10%                                     | 72%        | 2%                     | 3%                            | 6%                             | 1%           | 6%        | 172          |
| NH                 | 3%                                      | 21%        | 3%                     | 31%                           | 33%                            | 0%           | 9%        | 307          |
| PA                 | 16%                                     | 56%        | 5%                     | 11%                           | 4%                             | 4%           | 3%        | 403          |
| SC                 | 13%                                     | 71%        | 10%                    | 3%                            | 1%                             | 0%           | 1%        | 234          |
| UT                 | 4%                                      | 55%        | 7%                     | 21%                           | 8%                             | 0%           | 4%        | 352          |
| VA                 | 25%                                     | 56%        | 1%                     | 5%                            | 9%                             | 2%           | 2%        | 361          |
| WA                 | 12%                                     | 34%        | 10%                    | 30%                           | 6%                             | 1%           | 8%        | 394          |
| <b>NCI Average</b> | <b>10%</b>                              | <b>54%</b> | <b>5%</b>              | <b>17%</b>                    | <b>8%</b>                      | <b>1%</b>    | <b>5%</b> | <b>6,603</b> |

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

| State              | Age       | N            |
|--------------------|-----------|--------------|
| CA                 | 45        | 3,063        |
| FL                 | 42        | 363          |
| GA                 | 47        | 319          |
| MD                 | 44        | 166          |
| MI                 | 49        | 434          |
| NC                 | 45        | 170          |
| NH                 | 46        | 299          |
| PA                 | 51        | 399          |
| SC                 | 50        | 220          |
| UT                 | 40        | 356          |
| VA                 | 50        | 353          |
| WA                 | 50        | 395          |
| <b>NCI Average</b> | <b>47</b> | <b>6,537</b> |

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

| State              | Male       | Female     | N            |
|--------------------|------------|------------|--------------|
| CA                 | 58%        | 42%        | 3,123        |
| FL                 | 54%        | 46%        | 367          |
| GA                 | 60%        | 40%        | 319          |
| MD                 | 57%        | 43%        | 163          |
| MI                 | 59%        | 41%        | 446          |
| NC                 | 61%        | 39%        | 176          |
| NH                 | 62%        | 38%        | 305          |
| PA                 | 56%        | 44%        | 407          |
| SC                 | 57%        | 43%        | 233          |
| UT                 | 58%        | 42%        | 363          |
| VA                 | 58%        | 42%        | 365          |
| WA                 | 55%        | 45%        | 399          |
| <b>NCI Average</b> | <b>58%</b> | <b>42%</b> | <b>6,666</b> |

**Table 4. Family Member's Race<sup>2</sup>**

| 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 |
|--------------------|----------------------------------|-----------|---------------------------|------------------------------|------------|------------------|-------------------|--------------------|
| CA                 | 2%                               | 5%        | 5%                        | 0%                           | 75%        | 1%               | 6%                | 11%                |
| FL                 | 1%                               | 1%        | 13%                       | 1%                           | 77%        | 0%               | 1%                | 7%                 |
| GA                 | 1%                               | 1%        | 24%                       | 1%                           | 72%        | 0%               | 1%                | 0%                 |
| MD                 | 1%                               | 3%        | 28%                       | 0%                           | 65%        | 1%               | 4%                | 1%                 |
| MI                 | 1%                               | 1%        | 8%                        | 0%                           | 89%        | 0%               | 1%                | 1%                 |
| NC                 | 2%                               | 1%        | 22%                       | 0%                           | 74%        | 0%               | 2%                | 1%                 |
| NH                 | 1%                               | 0%        | 1%                        | 0%                           | 96%        | 0%               | 2%                | 0%                 |
| PA                 | 0%                               | 1%        | 5%                        | 0%                           | 91%        | 0%               | 0%                | 1%                 |
| SC                 | 0%                               | 0%        | 22%                       | 0%                           | 76%        | 0%               | 0%                | 1%                 |
| UT                 | 3%                               | 1%        | 2%                        | 1%                           | 87%        | 0%               | 4%                | 4%                 |
| VA                 | 1%                               | 1%        | 22%                       | 1%                           | 75%        | 0%               | 1%                | 1%                 |
| WA                 | 4%                               | 1%        | 1%                        | 1%                           | 93%        | 1%               | 2%                | 1%                 |
| <b>NCI Average</b> | <b>1%</b>                        | <b>1%</b> | <b>13%</b>                | <b>0%</b>                    | <b>81%</b> | <b>0%</b>        | <b>2%</b>         | <b>2%</b>          |

<sup>2</sup> Multiple responses allowed. Therefore, state and national percentages may total more than 100%.



**Table 5. Family Member's Primary Means of Expression**

| State              | Spoken     | Gestures or Body Language | Sign Language or Finger Spelling | Communication Aid or Device | Other     | N            |
|--------------------|------------|---------------------------|----------------------------------|-----------------------------|-----------|--------------|
| CA                 | 75%        | 18%                       | 2%                               | 1%                          | 4%        | 3,145        |
| FL                 | 73%        | 21%                       | 2%                               | 1%                          | 4%        | 369          |
| GA                 | 71%        | 21%                       | 2%                               | 0%                          | 5%        | 327          |
| MD                 | 70%        | 22%                       | 4%                               | 1%                          | 4%        | 162          |
| MI                 | 71%        | 25%                       | 1%                               | 0%                          | 3%        | 425          |
| NC                 | 72%        | 21%                       | 2%                               | 0%                          | 4%        | 177          |
| NH                 | 75%        | 17%                       | 3%                               | 1%                          | 3%        | 306          |
| PA                 | 70%        | 24%                       | 1%                               | 0%                          | 5%        | 392          |
| SC                 | 78%        | 21%                       | 0%                               | 0%                          | 1%        | 239          |
| UT                 | 76%        | 21%                       | 2%                               | 0%                          | 1%        | 364          |
| VA                 | 51%        | 41%                       | 2%                               | 1%                          | 5%        | 370          |
| WA                 | 81%        | 15%                       | 2%                               | 1%                          | 2%        | 391          |
| <b>NCI Average</b> | <b>72%</b> | <b>22%</b>                | <b>2%</b>                        | <b>0%</b>                   | <b>3%</b> | <b>6,667</b> |

**Table 6. Family Member's Primary Language**

| State              | English    | Spanish   | Other     | N            |
|--------------------|------------|-----------|-----------|--------------|
| CA                 | 92%        | 2%        | 5%        | 3,154        |
| FL                 | 93%        | 3%        | 4%        | 376          |
| GA                 | 98%        | 0%        | 2%        | 321          |
| MD                 | 94%        | 1%        | 5%        | 167          |
| MI                 | 96%        | 0%        | 4%        | 445          |
| NC                 | 97%        | 0%        | 3%        | 177          |
| NH                 | 100%       | 0%        | 0%        | 292          |
| PA                 | 97%        | 0%        | 3%        | 381          |
| SC                 | 98%        | 0%        | 2%        | 244          |
| UT                 | 98%        | 0%        | 2%        | 363          |
| VA                 | 90%        | 0%        | 10%       | 372          |
| WA                 | 98%        | 0%        | 2%        | 392          |
| <b>NCI Average</b> | <b>96%</b> | <b>1%</b> | <b>3%</b> | <b>6,684</b> |

**Table 7. Family Member's Highest Level of Education**

| State              | No High School Diploma or GED | High School Diploma or GED | Vocational School | Some College | College Degree | N            |
|--------------------|-------------------------------|----------------------------|-------------------|--------------|----------------|--------------|
| CA                 | 59%                           | 32%                        | 2%                | 6%           | 1%             | 2,912        |
| FL                 | 69%                           | 28%                        | 2%                | 1%           | 1%             | 347          |
| GA                 | 63%                           | 34%                        | 2%                | 1%           | 0%             | 301          |
| MD                 | 63%                           | 28%                        | 3%                | 5%           | 1%             | 158          |
| MI                 | 76%                           | 19%                        | 5%                | 0%           | 0%             | 409          |
| NC                 | 75%                           | 21%                        | 2%                | 1%           | 1%             | 169          |
| NH                 | 57%                           | 34%                        | 2%                | 5%           | 3%             | 280          |
| PA                 | 67%                           | 30%                        | 2%                | 1%           | 0%             | 354          |
| SC                 | 78%                           | 19%                        | 3%                | 0%           | 0%             | 220          |
| UT                 | 64%                           | 33%                        | 1%                | 1%           | 1%             | 357          |
| VA                 | 81%                           | 17%                        | 2%                | 0%           | 1%             | 336          |
| WA                 | 57%                           | 38%                        | 2%                | 2%           | 1%             | 376          |
| <b>NCI Average</b> | <b>67%</b>                    | <b>28%</b>                 | <b>2%</b>         | <b>2%</b>    | <b>1%</b>      | <b>6,219</b> |

**Table 8. Frequency of Medical Care Needed for Family Member**

| State              | Less Frequently Than Once/Month | At Least Once/Month but Not Once/Week | Once/Week or More Frequently | N            |
|--------------------|---------------------------------|---------------------------------------|------------------------------|--------------|
| CA                 | 67%                             | 24%                                   | 9%                           | 2,926        |
| FL                 | 59%                             | 29%                                   | 12%                          | 355          |
| GA                 | 67%                             | 24%                                   | 9%                           | 306          |
| MD                 | 62%                             | 29%                                   | 9%                           | 159          |
| MI                 | 62%                             | 29%                                   | 9%                           | 440          |
| NC                 | 72%                             | 24%                                   | 5%                           | 172          |
| NH                 | 67%                             | 22%                                   | 10%                          | 292          |
| PA                 | 59%                             | 24%                                   | 17%                          | 369          |
| SC                 | 72%                             | 19%                                   | 10%                          | 215          |
| UT                 | 67%                             | 27%                                   | 6%                           | 355          |
| VA                 | 51%                             | 25%                                   | 24%                          | 353          |
| WA                 | 66%                             | 26%                                   | 8%                           | 376          |
| <b>NCI Average</b> | <b>64%</b>                      | <b>25%</b>                            | <b>11%</b>                   | <b>6,318</b> |

**Table 9. Amount of Behavioral Support Needed for Family Member**

| State              | No Support Needed | Some Support Needed | Extensive Support Needed | N            |
|--------------------|-------------------|---------------------|--------------------------|--------------|
| CA                 | 44%               | 40%                 | 16%                      | 3,060        |
| FL                 | 33%               | 36%                 | 31%                      | 374          |
| GA                 | 40%               | 36%                 | 24%                      | 316          |
| MD                 | 46%               | 37%                 | 18%                      | 167          |
| MI                 | 35%               | 46%                 | 19%                      | 443          |
| NC                 | 25%               | 50%                 | 25%                      | 173          |
| NH                 | 43%               | 40%                 | 17%                      | 295          |
| PA                 | 40%               | 37%                 | 23%                      | 391          |
| SC                 | 40%               | 45%                 | 15%                      | 239          |
| UT                 | 29%               | 43%                 | 28%                      | 359          |
| VA                 | 29%               | 39%                 | 31%                      | 370          |
| WA                 | 35%               | 45%                 | 19%                      | 391          |
| <b>NCI Average</b> | <b>37%</b>        | <b>41%</b>          | <b>22%</b>               | <b>6,578</b> |

**Table 10. Amount of Help Needed for Family Member's Daily Activities**

| State              | None       | Little     | Moderate   | Complete   | N            |
|--------------------|------------|------------|------------|------------|--------------|
| CA                 | 30%        | 22%        | 26%        | 22%        | 3,125        |
| FL                 | 18%        | 20%        | 33%        | 29%        | 367          |
| GA                 | 25%        | 20%        | 31%        | 24%        | 324          |
| MD                 | 30%        | 21%        | 20%        | 29%        | 168          |
| MI                 | 16%        | 17%        | 35%        | 32%        | 431          |
| NC                 | 12%        | 20%        | 44%        | 23%        | 177          |
| NH                 | 20%        | 26%        | 30%        | 24%        | 305          |
| PA                 | 21%        | 19%        | 27%        | 33%        | 406          |
| SC                 | 33%        | 22%        | 31%        | 14%        | 238          |
| UT                 | 20%        | 25%        | 33%        | 22%        | 359          |
| VA                 | 9%         | 17%        | 30%        | 44%        | 378          |
| WA                 | 14%        | 25%        | 38%        | 23%        | 394          |
| <b>NCI Average</b> | <b>21%</b> | <b>21%</b> | <b>32%</b> | <b>26%</b> | <b>6,672</b> |

**Table 11. Family Member's Typical Day Activity<sup>3</sup>**

| State              | Out of Home Day Program (Family Member Is Unpaid) | Out of Home Day Program (Family Member Is Paid) | Vocational Training | Community Employment (Family Member Is Unpaid) | Community Employment (Family Member Is Paid) | In-home Day Supports | At Home (by Choice) | At Home (No Services) | At Home (Other) | Other      |
|--------------------|---------------------------------------------------|-------------------------------------------------|---------------------|------------------------------------------------|----------------------------------------------|----------------------|---------------------|-----------------------|-----------------|------------|
| CA                 | 43%                                               | 14%                                             | 7%                  | 6%                                             | 12%                                          | 11%                  | 8%                  | 3%                    | 5%              | 17%        |
| FL                 | 39%                                               | 12%                                             | 11%                 | 3%                                             | 6%                                           | 13%                  | 4%                  | 3%                    | 3%              | 22%        |
| GA                 | 48%                                               | 13%                                             | 4%                  | 5%                                             | 10%                                          | 12%                  | 4%                  | 1%                    | 3%              | 25%        |
| MD                 | 39%                                               | 15%                                             | 11%                 | 7%                                             | 16%                                          | 10%                  | 6%                  | 2%                    | 4%              | 17%        |
| MI                 | 31%                                               | 10%                                             | 14%                 | 7%                                             | 12%                                          | 23%                  | 12%                 | 3%                    | 7%              | 18%        |
| NC                 | 44%                                               | 13%                                             | 19%                 | 7%                                             | 9%                                           | 8%                   | 2%                  | 1%                    | 2%              | 22%        |
| NH                 | 37%                                               | 10%                                             | 4%                  | 13%                                            | 13%                                          | 24%                  | 7%                  | 3%                    | 4%              | 20%        |
| PA                 | 32%                                               | 14%                                             | 7%                  | 5%                                             | 9%                                           | 11%                  | 7%                  | 4%                    | 3%              | 24%        |
| SC                 | 34%                                               | 21%                                             | 13%                 | 3%                                             | 9%                                           | 3%                   | 3%                  | 0%                    | 3%              | 22%        |
| UT                 | 38%                                               | 21%                                             | 8%                  | 4%                                             | 15%                                          | 15%                  | 5%                  | 2%                    | 4%              | 16%        |
| VA                 | 36%                                               | 9%                                              | 8%                  | 3%                                             | 7%                                           | 13%                  | 7%                  | 2%                    | 4%              | 28%        |
| WA                 | 15%                                               | 6%                                              | 11%                 | 13%                                            | 19%                                          | 35%                  | 19%                 | 5%                    | 11%             | 23%        |
| <b>NCI Average</b> | <b>36%</b>                                        | <b>13%</b>                                      | <b>10%</b>          | <b>6%</b>                                      | <b>11%</b>                                   | <b>15%</b>           | <b>7%</b>           | <b>2%</b>             | <b>5%</b>       | <b>21%</b> |

<sup>3</sup> Multiple responses allowed. Therefore, state and national percentages may total more than 100%.

## Respondents

*This section provides demographic information about the respondent.*

**Table 12. Respondent's Age**

| State              | Under 35  | 35-54      | 55-74      | 75 or Older | N            |
|--------------------|-----------|------------|------------|-------------|--------------|
| CA                 | 2%        | 14%        | 55%        | 29%         | 3,114        |
| FL                 | 1%        | 19%        | 61%        | 19%         | 362          |
| GA                 | 2%        | 16%        | 61%        | 21%         | 327          |
| MD                 | 2%        | 14%        | 59%        | 24%         | 167          |
| MI                 | 3%        | 17%        | 65%        | 15%         | 446          |
| NC                 | 3%        | 24%        | 59%        | 15%         | 178          |
| NH                 | 1%        | 18%        | 62%        | 19%         | 300          |
| PA                 | 2%        | 12%        | 62%        | 24%         | 402          |
| SC                 | 3%        | 11%        | 58%        | 28%         | 240          |
| UT                 | 3%        | 20%        | 64%        | 13%         | 346          |
| VA                 | 2%        | 17%        | 55%        | 26%         | 370          |
| WA                 | 2%        | 14%        | 67%        | 18%         | 393          |
| <b>NCI Average</b> | <b>2%</b> | <b>16%</b> | <b>61%</b> | <b>21%</b>  | <b>6,645</b> |

**Table 13. Respondent's Relationship to Family Member**

| State              | Parent     | Sibling    | Spouse    | Public Guardian | Private Guardian | Other     | N            |
|--------------------|------------|------------|-----------|-----------------|------------------|-----------|--------------|
| CA                 | 78%        | 14%        | 0%        | 2%              | 1%               | 6%        | 3,144        |
| FL                 | 60%        | 18%        | 0%        | 5%              | 9%               | 8%        | 374          |
| GA                 | 56%        | 27%        | 2%        | 2%              | 3%               | 10%       | 319          |
| MD                 | 68%        | 20%        | 0%        | 1%              | 1%               | 10%       | 167          |
| MI                 | 40%        | 20%        | 0%        | 23%             | 8%               | 8%        | 370          |
| NC                 | 54%        | 20%        | 0%        | 8%              | 8%               | 10%       | 178          |
| NH                 | 57%        | 30%        | 0%        | 2%              | 7%               | 4%        | 307          |
| PA                 | 52%        | 38%        | 0%        | 2%              | 1%               | 6%        | 406          |
| SC                 | 52%        | 28%        | 0%        | 3%              | 2%               | 16%       | 240          |
| UT                 | 66%        | 15%        | 0%        | 10%             | 2%               | 6%        | 361          |
| VA                 | 53%        | 30%        | 1%        | 6%              | 2%               | 9%        | 376          |
| WA                 | 45%        | 29%        | 0%        | 7%              | 8%               | 11%       | 401          |
| <b>NCI Average</b> | <b>57%</b> | <b>24%</b> | <b>0%</b> | <b>6%</b>       | <b>4%</b>        | <b>9%</b> | <b>6,643</b> |

**Table 14. Respondent Is Family Member's Legal Guardian or Conservator**

| State              | Full Guardianship or Conservatorship | Limited Guardianship or Conservatorship | No         | N            |
|--------------------|--------------------------------------|-----------------------------------------|------------|--------------|
| CA                 | 30%                                  | 16%                                     | 54%        | 3,051        |
| FL                 | 62%                                  | 14%                                     | 25%        | 371          |
| GA                 | 33%                                  | 8%                                      | 58%        | 318          |
| MD                 | 31%                                  | 9%                                      | 60%        | 159          |
| MI                 | 69%                                  | 19%                                     | 12%        | 447          |
| NC                 | 79%                                  | 13%                                     | 8%         | 173          |
| NH                 | 80%                                  | 8%                                      | 12%        | 305          |
| PA                 | 38%                                  | 8%                                      | 54%        | 378          |
| SC                 | 37%                                  | 10%                                     | 53%        | 221          |
| UT                 | 46%                                  | 19%                                     | 34%        | 354          |
| VA                 | 52%                                  | 10%                                     | 37%        | 361          |
| WA                 | 50%                                  | 17%                                     | 33%        | 398          |
| <b>NCI Average</b> | <b>51%</b>                           | <b>13%</b>                              | <b>37%</b> | <b>6,536</b> |

**Table 15. Number of Times Respondent Sees Family Member in a Year**

| State              | Less Than Once | 1-3 Times  | 4-6 Times  | 7-12 Times | More Than 12 Times | N            |
|--------------------|----------------|------------|------------|------------|--------------------|--------------|
| CA                 | 6%             | 12%        | 10%        | 11%        | 62%                | 3,107        |
| FL                 | 4%             | 8%         | 12%        | 14%        | 63%                | 374          |
| GA                 | 5%             | 11%        | 12%        | 13%        | 59%                | 323          |
| MD                 | 2%             | 9%         | 5%         | 10%        | 73%                | 166          |
| MI                 | 2%             | 9%         | 24%        | 13%        | 52%                | 446          |
| NC                 | 1%             | 4%         | 17%        | 20%        | 57%                | 178          |
| NH                 | 3%             | 11%        | 15%        | 11%        | 61%                | 308          |
| PA                 | 7%             | 13%        | 13%        | 13%        | 53%                | 408          |
| SC                 | 2%             | 6%         | 13%        | 13%        | 66%                | 237          |
| UT                 | 1%             | 9%         | 11%        | 14%        | 65%                | 358          |
| VA                 | 7%             | 15%        | 17%        | 16%        | 45%                | 374          |
| WA                 | 7%             | 11%        | 10%        | 17%        | 55%                | 397          |
| <b>NCI Average</b> | <b>4%</b>      | <b>10%</b> | <b>13%</b> | <b>14%</b> | <b>59%</b>         | <b>6,676</b> |

**Table 16. Respondent's Highest Level of Education**

| State              | No High School Diploma or GED | High School Diploma or GED | Vocational School | Some College | College Degree | N            |
|--------------------|-------------------------------|----------------------------|-------------------|--------------|----------------|--------------|
| CA                 | 6%                            | 17%                        | 3%                | 29%          | 45%            | 3,101        |
| FL                 | 6%                            | 23%                        | 5%                | 22%          | 44%            | 372          |
| GA                 | 11%                           | 29%                        | 10%               | 20%          | 30%            | 324          |
| MD                 | 5%                            | 20%                        | 2%                | 28%          | 45%            | 164          |
| MI                 | 6%                            | 24%                        | 3%                | 23%          | 45%            | 433          |
| NC                 | 7%                            | 20%                        | 5%                | 20%          | 47%            | 176          |
| NH                 | 4%                            | 20%                        | 5%                | 22%          | 50%            | 298          |
| PA                 | 6%                            | 36%                        | 5%                | 18%          | 35%            | 393          |
| SC                 | 9%                            | 26%                        | 4%                | 21%          | 40%            | 236          |
| UT                 | 4%                            | 18%                        | 5%                | 29%          | 45%            | 360          |
| VA                 | 13%                           | 24%                        | 2%                | 20%          | 40%            | 370          |
| WA                 | 3%                            | 18%                        | 7%                | 29%          | 43%            | 397          |
| <b>NCI Average</b> | <b>7%</b>                     | <b>23%</b>                 | <b>5%</b>         | <b>23%</b>   | <b>42%</b>     | <b>6,624</b> |

**Table 17. Total Taxable Family Income of Wage Earners in the Household in the Past Year**

| State              | Below \$15,000 | \$15,001-\$25,000 | \$25,001-\$50,000 | \$50,001-\$75,000 | Over \$75,000 | N            |
|--------------------|----------------|-------------------|-------------------|-------------------|---------------|--------------|
| CA                 | 18%            | 17%               | 25%               | 15%               | 25%           | 2,435        |
| FL                 | 18%            | 20%               | 29%               | 14%               | 18%           | 283          |
| GA                 | 24%            | 25%               | 24%               | 11%               | 15%           | 245          |
| MD                 | 11%            | 11%               | 25%               | 22%               | 31%           | 134          |
| MI                 | 16%            | 15%               | 30%               | 23%               | 16%           | 381          |
| NC                 | 14%            | 20%               | 28%               | 17%               | 22%           | 144          |
| NH                 | 15%            | 15%               | 30%               | 14%               | 24%           | 214          |
| PA                 | 16%            | 17%               | 30%               | 17%               | 20%           | 294          |
| SC                 | 23%            | 24%               | 19%               | 18%               | 16%           | 188          |
| UT                 | 14%            | 14%               | 27%               | 22%               | 23%           | 293          |
| VA                 | 23%            | 18%               | 23%               | 19%               | 19%           | 297          |
| WA                 | 17%            | 19%               | 27%               | 18%               | 19%           | 306          |
| <b>NCI Average</b> | <b>17%</b>     | <b>18%</b>        | <b>26%</b>        | <b>17%</b>        | <b>21%</b>    | <b>5,214</b> |

**Table 18. Out-of-Pocket Expenses for Family in the Past Year**

| State              | Nothing    | \$1- \$100 | \$101- \$1,000 | \$1,001-\$10,000 | Over \$10,000 | N            |
|--------------------|------------|------------|----------------|------------------|---------------|--------------|
| CA                 | 46%        | 12%        | 26%            | 14%              | 2%            | 2,906        |
| FL                 | 41%        | 11%        | 28%            | 17%              | 3%            | 346          |
| GA                 | 53%        | 13%        | 23%            | 10%              | 1%            | 311          |
| MD                 | 46%        | 7%         | 24%            | 20%              | 3%            | 156          |
| MI                 | 61%        | 15%        | 15%            | 9%               | 1%            | 433          |
| NC                 | 51%        | 14%        | 24%            | 10%              | 1%            | 168          |
| NH                 | 45%        | 9%         | 25%            | 20%              | 2%            | 280          |
| PA                 | 61%        | 8%         | 19%            | 11%              | 1%            | 365          |
| SC                 | 60%        | 9%         | 22%            | 8%               | 0%            | 223          |
| UT                 | 50%        | 13%        | 24%            | 11%              | 1%            | 334          |
| VA                 | 69%        | 8%         | 17%            | 7%               | 0%            | 359          |
| WA                 | 57%        | 12%        | 21%            | 9%               | 0%            | 369          |
| <b>NCI Average</b> | <b>53%</b> | <b>11%</b> | <b>22%</b>     | <b>12%</b>       | <b>1%</b>     | <b>6,250</b> |



## Services and Supports Received

*This section provides information about the services and supports received by the family member from the state ID/DD agency (social security benefits being the exception).*

**Table 19. Services and Supports Received From ID/DD Agency**

| State              | Residential Supports | Day or Employment Supports | Transportation | Other      | Social Security Benefits |
|--------------------|----------------------|----------------------------|----------------|------------|--------------------------|
| CA                 | 87%                  | 75%                        | 82%            | 53%        | 91%                      |
| FL                 | 96%                  | 71%                        | 92%            | 68%        | 94%                      |
| GA                 | 93%                  | 77%                        | 92%            | 60%        | 97%                      |
| MD                 | 81%                  | 80%                        | 88%            | 61%        | 92%                      |
| MI                 | 95%                  | 62%                        | 95%            | 73%        | 98%                      |
| NC                 | 96%                  | 90%                        | 97%            | 72%        | 98%                      |
| NH                 | 95%                  | 64%                        | 88%            | 54%        | 95%                      |
| PA                 | 94%                  | 67%                        | 86%            | 68%        | 94%                      |
| SC                 | 97%                  | 87%                        | 97%            | 69%        | 97%                      |
| UT                 | 93%                  | 83%                        | 93%            | 70%        | 96%                      |
| VA                 | 96%                  | 66%                        | 94%            | 73%        | 95%                      |
| WA                 | 93%                  | 55%                        | 87%            | 59%        | 95%                      |
| <b>NCI Average</b> | <b>93%</b>           | <b>73%</b>                 | <b>91%</b>     | <b>65%</b> | <b>95%</b>               |

# Family/Guardian Survey Results

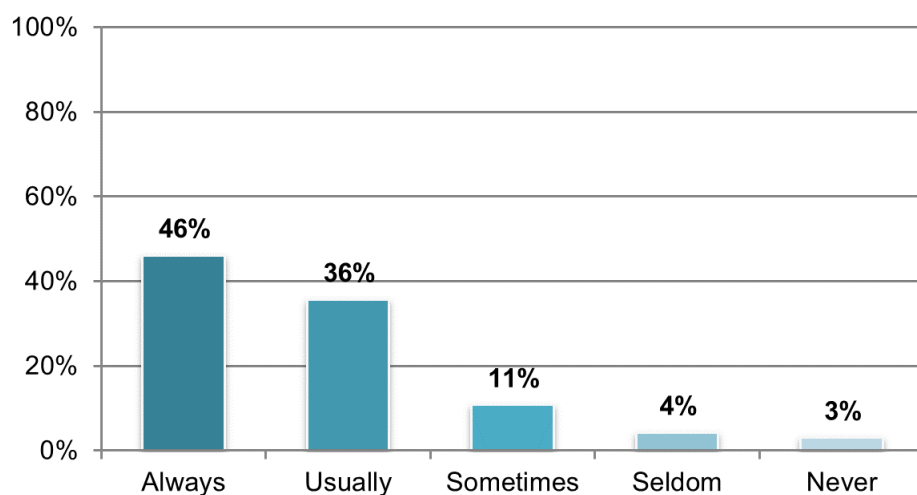
## Information and Planning

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

**Note:** State outcomes with fewer than 20 responses were not reported.

**Note on California significance:** Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (\*\*), an outcome is significant *only* due to the sample size.

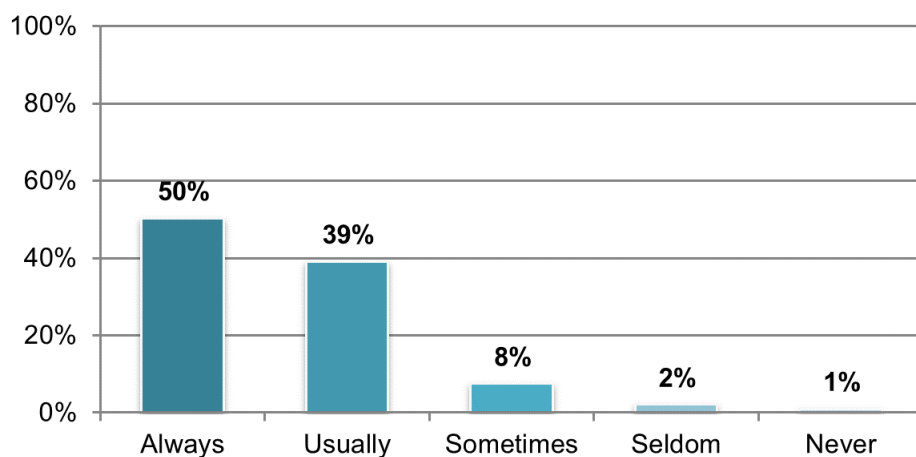
### Gets Enough Information to Help Plan Services



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

| State                              | Always     | Usually    | Sometimes  | Seldom    | Never     | N            |
|------------------------------------|------------|------------|------------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |            |           |           |              |
| VA                                 | 59%        | 26%        | 10%        | 3%        | 2%        | 345          |
| MI                                 | 58%        | 32%        | 7%         | 3%        | 1%        | 440          |
| <b>Within Average Range</b>        |            |            |            |           |           |              |
| NC                                 | 51%        | 39%        | 7%         | 2%        | 1%        | 174          |
| MD                                 | 49%        | 34%        | 11%        | 3%        | 4%        | 158          |
| WA                                 | 48%        | 37%        | 8%         | 5%        | 1%        | 382          |
| FL                                 | 47%        | 37%        | 10%        | 3%        | 3%        | 362          |
| SC                                 | 44%        | 33%        | 14%        | 6%        | 4%        | 228          |
| NH                                 | 44%        | 45%        | 9%         | 2%        | 1%        | 299          |
| UT                                 | 43%        | 34%        | 14%        | 6%        | 3%        | 356          |
| PA                                 | 40%        | 40%        | 12%        | 5%        | 4%        | 369          |
| <b>Significantly Below Average</b> |            |            |            |           |           |              |
| CA                                 | 39%        | 32%        | 13%        | 9%        | 7%        | 2,855        |
| GA                                 | 34%        | 39%        | 15%        | 5%        | 6%        | 310          |
| <b>NCI Average</b>                 | <b>46%</b> | <b>36%</b> | <b>11%</b> | <b>4%</b> | <b>3%</b> | <b>6,278</b> |

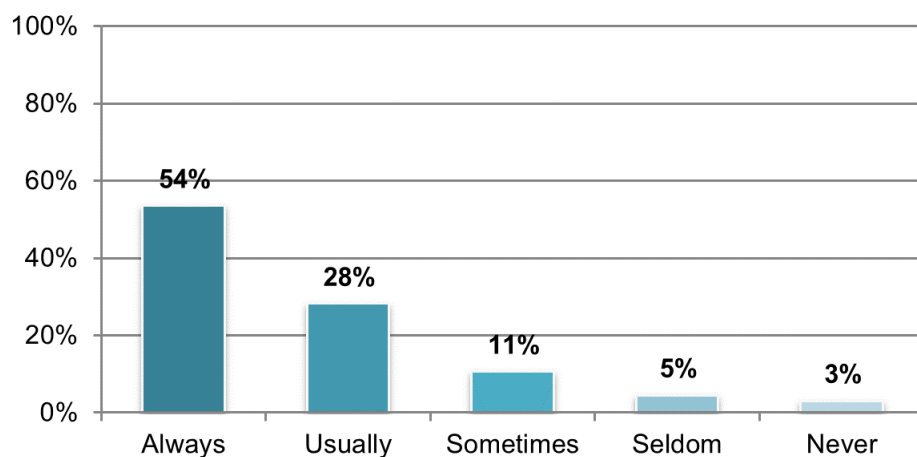
### Information About Services and Supports Is Easy to Understand



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

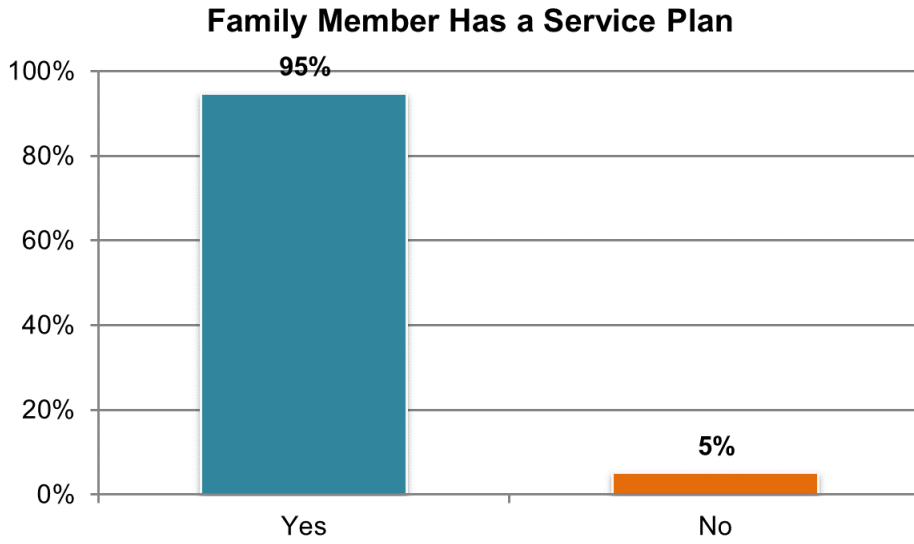
| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| VA                                 | 58%        | 34%        | 7%        | 0%        | 1%        | 352          |
| MI                                 | 58%        | 35%        | 5%        | 1%        | 0%        | 439          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| SC                                 | 55%        | 35%        | 5%        | 3%        | 2%        | 225          |
| CA                                 | 52%        | 35%        | 8%        | 3%        | 2%        | 2,740        |
| NC                                 | 51%        | 40%        | 8%        |           | 1%        | 175          |
| WA                                 | 51%        | 39%        | 7%        | 3%        | 0%        | 381          |
| MD                                 | 50%        | 40%        | 9%        | 1%        | 0%        | 153          |
| UT                                 | 49%        | 39%        | 7%        | 3%        | 2%        | 348          |
| FL                                 | 48%        | 38%        | 10%       | 4%        | 0%        | 356          |
| NH                                 | 47%        | 47%        | 5%        | 1%        | 0%        | 300          |
| PA                                 | 46%        | 42%        | 9%        | 1%        | 2%        | 372          |
| <b>Significantly Below Average</b> |            |            |           |           |           |              |
| GA                                 | 39%        | 46%        | 10%       | 4%        | 2%        | 300          |
| <b>NCI Average</b>                 | <b>50%</b> | <b>39%</b> | <b>8%</b> | <b>2%</b> | <b>1%</b> | <b>6,141</b> |

### Kept Informed About How Family Member Is Doing



**Table Q3. Are you kept informed about how your family member is doing?**

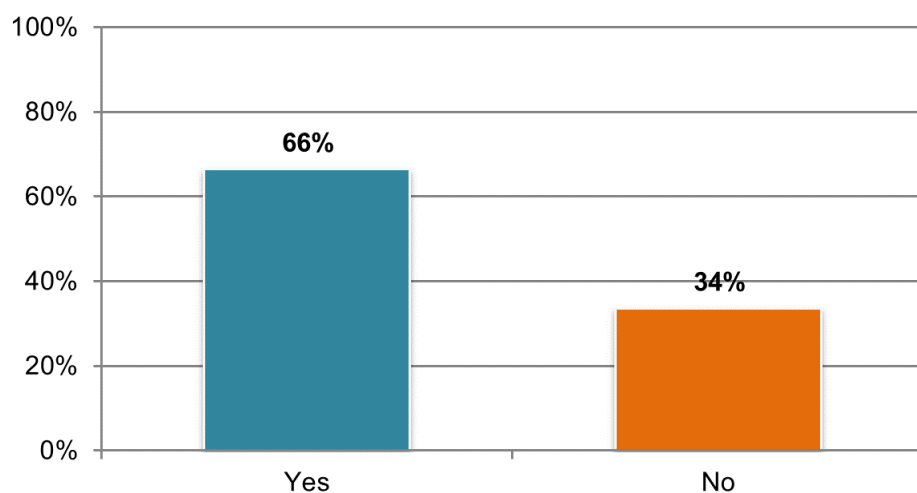
| State                              | Always     | Usually    | Sometimes  | Seldom    | Never     | N            |
|------------------------------------|------------|------------|------------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |            |           |           |              |
| VA                                 | 65%        | 24%        | 8%         | 2%        | 1%        | 366          |
| MI                                 | 61%        | 25%        | 9%         | 3%        | 2%        | 446          |
| <b>Within Average Range</b>        |            |            |            |           |           |              |
| NC                                 | 60%        | 26%        | 10%        | 3%        | 1%        | 175          |
| FL                                 | 60%        | 25%        | 9%         | 4%        | 2%        | 364          |
| PA                                 | 56%        | 27%        | 11%        | 4%        | 2%        | 386          |
| WA                                 | 53%        | 32%        | 7%         | 5%        | 3%        | 390          |
| NH                                 | 53%        | 36%        | 7%         | 2%        | 2%        | 300          |
| SC                                 | 49%        | 25%        | 14%        | 7%        | 5%        | 232          |
| GA                                 | 47%        | 27%        | 15%        | 7%        | 3%        | 322          |
| MD                                 | 45%        | 31%        | 13%        | 4%        | 7%        | 162          |
| <b>Significantly Below Average</b> |            |            |            |           |           |              |
| CA                                 | 47%        | 26%        | 12%        | 8%        | 7%        | 2,952        |
| UT                                 | 46%        | 33%        | 14%        | 5%        | 3%        | 354          |
| <b>NCI Average</b>                 | <b>54%</b> | <b>28%</b> | <b>11%</b> | <b>5%</b> | <b>3%</b> | <b>6,449</b> |



**Table Q4. Does your family member have a service plan?**

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| NC                                 | 99%        | 1%        | 155          |
| MD                                 | 99%        | 1%        | 150          |
| NH                                 | 98%        | 2%        | 275          |
| <b>Within Average Range</b>        |            |           |              |
| FL                                 | 97%        | 3%        | 347          |
| MI                                 | 96%        | 4%        | 396          |
| WA                                 | 96%        | 4%        | 320          |
| PA                                 | 95%        | 5%        | 336          |
| UT                                 | 94%        | 6%        | 296          |
| SC                                 | 92%        | 8%        | 178          |
| VA                                 | 91%        | 9%        | 286          |
| GA                                 | 90%        | 10%       | 226          |
| <b>Significantly Below Average</b> |            |           |              |
| CA                                 | 91%        | 9%        | 2364         |
| <b>NCI Average</b>                 | <b>95%</b> | <b>5%</b> | <b>5,329</b> |

### Family Member Helped Develop Service Plan

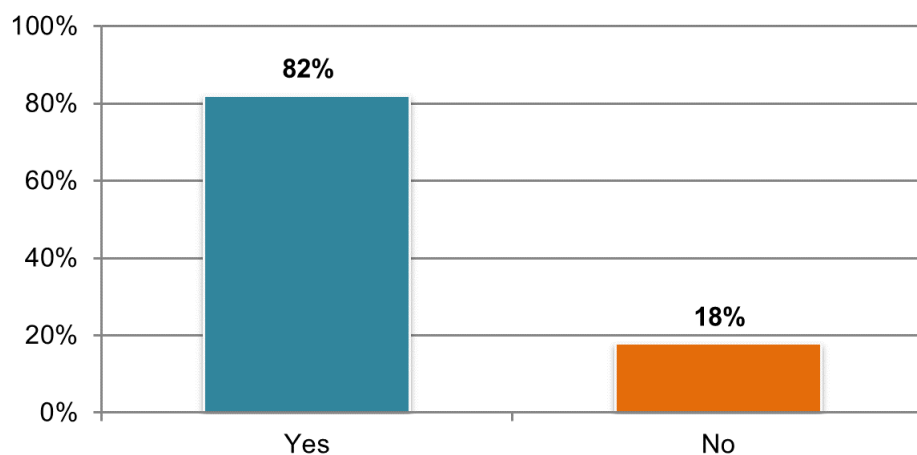


**Table Q5. Did your family member help develop the plan?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| UT                                 | 75%        | 25%        | 252          |
| <b>Within Average Range</b>        |            |            |              |
| MI                                 | 72%        | 28%        | 344          |
| GA                                 | 71%        | 29%        | 182          |
| SC                                 | 70%        | 30%        | 139          |
| MD                                 | 70%        | 30%        | 125          |
| CA                                 | 68%        | 32%        | 1,808        |
| WA                                 | 68%        | 32%        | 268          |
| NH                                 | 68%        | 32%        | 234          |
| FL                                 | 65%        | 35%        | 289          |
| PA                                 | 60%        | 40%        | 258          |
| NC                                 | 58%        | 42%        | 136          |
| <b>Significantly Below Average</b> |            |            |              |
| VA                                 | 53%        | 47%        | 231          |
| <b>NCI Average</b>                 | <b>66%</b> | <b>34%</b> | <b>4,266</b> |



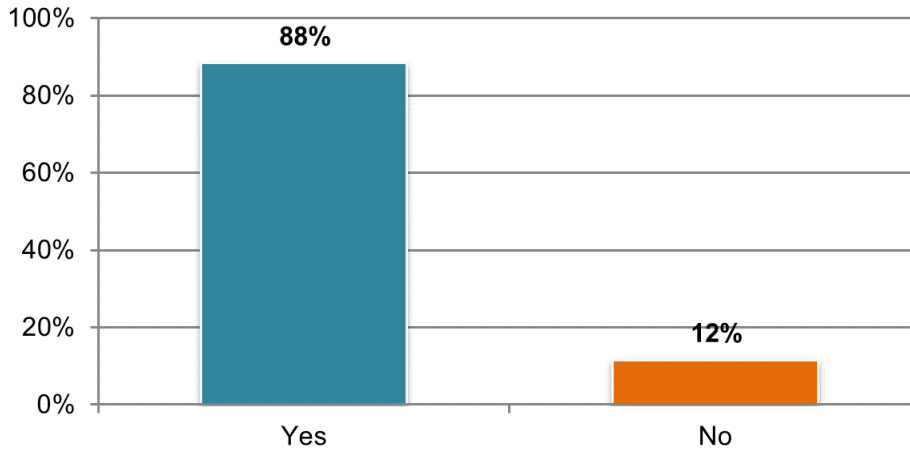
### Respondent or Another Family Member Helped Develop Service Plan



**Table Q6. Did you or another family member help develop the plan?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| NH                                 | 93%        | 7%         | 257          |
| NC                                 | 91%        | 9%         | 147          |
| UT                                 | 91%        | 9%         | 263          |
| <b>Within Average Range</b>        |            |            |              |
| MD                                 | 88%        | 12%        | 138          |
| MI                                 | 85%        | 15%        | 367          |
| GA                                 | 84%        | 16%        | 192          |
| FL                                 | 83%        | 17%        | 313          |
| WA                                 | 82%        | 18%        | 282          |
| VA                                 | 76%        | 24%        | 246          |
| SC                                 | 76%        | 24%        | 156          |
| <b>Significantly Below Average</b> |            |            |              |
| CA                                 | 70%        | 30%        | 1,969        |
| PA                                 | 67%        | 33%        | 291          |
| <b>NCI Average</b>                 | <b>82%</b> | <b>18%</b> | <b>4,621</b> |

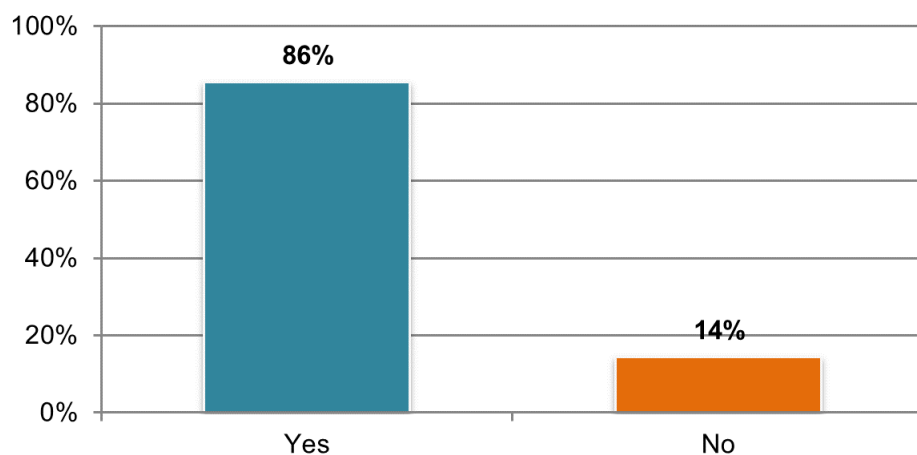
### Service Plan Includes All the Services and Supports Family Member Wants



**Table Q7. Does the plan include all the services and supports your family member wants?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| VA                                 | 94%        | 6%         | 213          |
| MI                                 | 93%        | 7%         | 350          |
| <b>Within Average Range</b>        |            |            |              |
| PA                                 | 92%        | 8%         | 247          |
| UT                                 | 91%        | 9%         | 239          |
| WA                                 | 90%        | 10%        | 261          |
| SC                                 | 89%        | 11%        | 132          |
| GA                                 | 89%        | 11%        | 169          |
| NC                                 | 88%        | 12%        | 130          |
| NH                                 | 87%        | 13%        | 238          |
| CA                                 | 86%        | 14%        | 1,710        |
| MD                                 | 81%        | 19%        | 115          |
| <b>Significantly Below Average</b> |            |            |              |
| FL                                 | 80%        | 20%        | 288          |
| <b>NCI Average</b>                 | <b>88%</b> | <b>12%</b> | <b>4,092</b> |

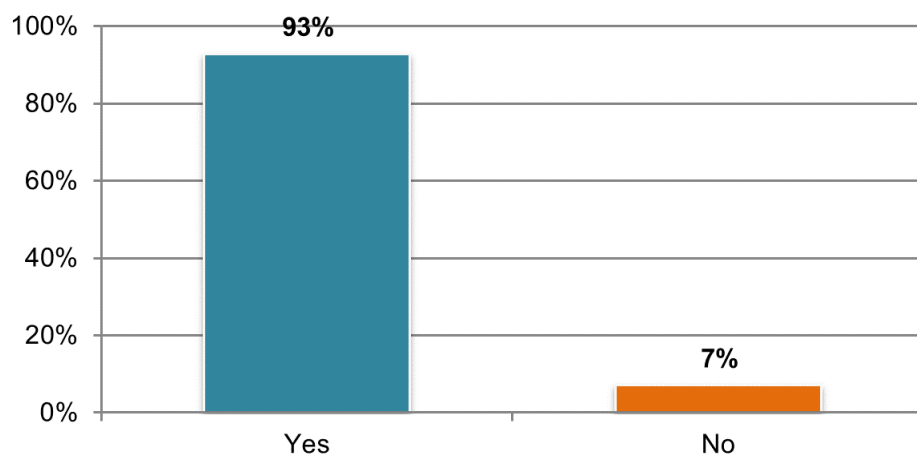
### Service Plan Includes All the Services and Supports Family Member Needs



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

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| MI                                 | 91%        | 9%         | 347          |
| VA                                 | 90%        | 10%        | 241          |
| <b>Within Average Range</b>        |            |            |              |
| SC                                 | 91%        | 9%         | 137          |
| PA                                 | 90%        | 10%        | 270          |
| WA                                 | 90%        | 10%        | 267          |
| NC                                 | 89%        | 11%        | 143          |
| UT                                 | 86%        | 14%        | 246          |
| NH                                 | 84%        | 16%        | 245          |
| CA **                              | 83%        | 17%        | 1,772        |
| GA                                 | 82%        | 18%        | 177          |
| <b>Significantly Below Average</b> |            |            |              |
| FL                                 | 78%        | 22%        | 290          |
| MD                                 | 75%        | 25%        | 123          |
| <b>NCI Average</b>                 | <b>86%</b> | <b>14%</b> | <b>4,258</b> |

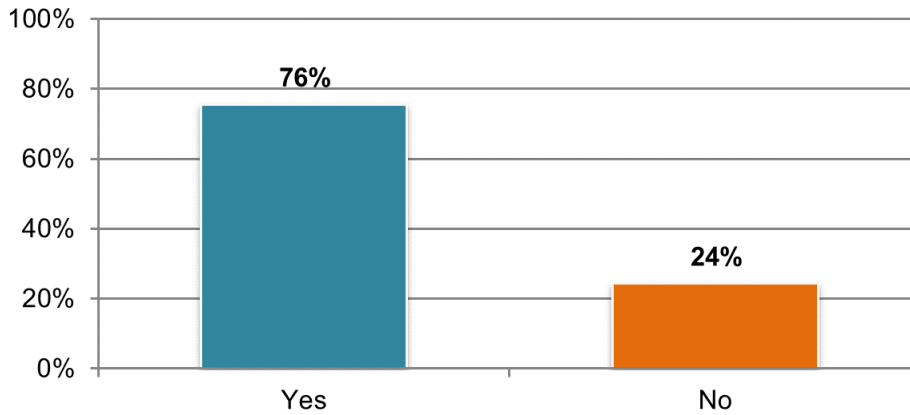
### Family Member Receives All Services Listed in Service Plan



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

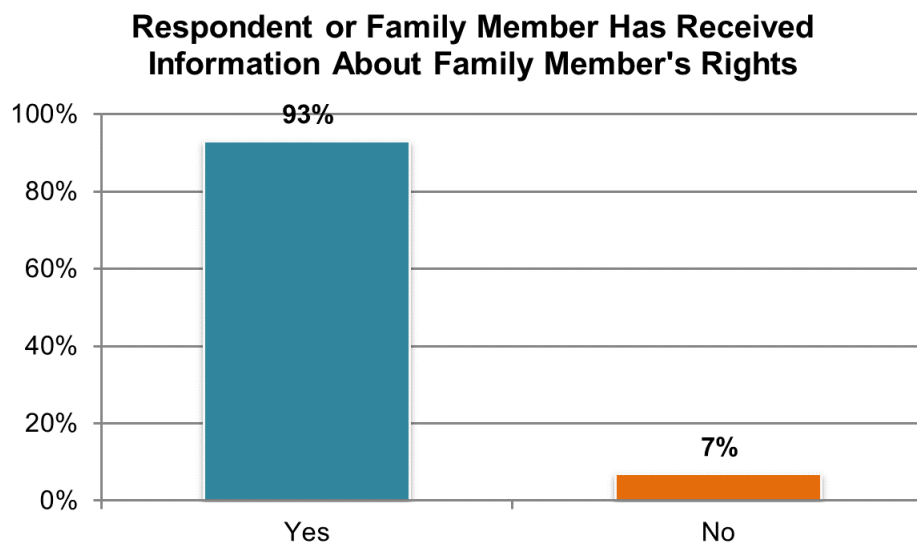
| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| PA                                 | 97%        | 3%        | 246          |
| <b>Within Average Range</b>        |            |           |              |
| NC                                 | 95%        | 5%        | 140          |
| WA                                 | 95%        | 5%        | 251          |
| MI                                 | 95%        | 5%        | 345          |
| VA                                 | 94%        | 6%        | 232          |
| SC                                 | 93%        | 7%        | 127          |
| CA                                 | 93%        | 7%        | 1,627        |
| FL                                 | 93%        | 7%        | 163          |
| UT                                 | 92%        | 8%        | 235          |
| NH                                 | 92%        | 8%        | 240          |
| GA                                 | 91%        | 9%        | 140          |
| MD                                 | 86%        | 14%       | 120          |
| <b>NCI Average</b>                 | <b>93%</b> | <b>7%</b> | <b>3,866</b> |

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



**Table Q10. Did you discuss how to handle emergencies related to your family member at the last service planning meeting?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| WA                                 | 84%        | 16%        | 262          |
| <b>Within Average Range</b>        |            |            |              |
| NC                                 | 82%        | 18%        | 147          |
| FL                                 | 81%        | 19%        | 171          |
| UT                                 | 80%        | 20%        | 246          |
| MI                                 | 79%        | 21%        | 349          |
| SC                                 | 77%        | 23%        | 136          |
| VA                                 | 77%        | 23%        | 232          |
| MD                                 | 75%        | 25%        | 130          |
| NH                                 | 74%        | 26%        | 225          |
| PA                                 | 72%        | 28%        | 259          |
| GA                                 | 68%        | 33%        | 160          |
| <b>Significantly Below Average</b> |            |            |              |
| CA                                 | 60%        | 40%        | 1,719        |
| <b>NCI Average</b>                 | <b>76%</b> | <b>24%</b> | <b>4,036</b> |



**Table Q11. Have you or your family member received information about his/her rights?**

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| NH                                 | 98%        | 2%        | 257          |
| MI                                 | 98%        | 2%        | 380          |
| VA                                 | 97%        | 3%        | 333          |
| <b>Within Average Range</b>        |            |           |              |
| NC                                 | 96%        | 4%        | 170          |
| WA                                 | 96%        | 4%        | 339          |
| FL                                 | 95%        | 5%        | 350          |
| UT                                 | 93%        | 7%        | 309          |
| PA                                 | 92%        | 8%        | 335          |
| MD                                 | 90%        | 10%       | 143          |
| SC                                 | 87%        | 13%       | 207          |
| <b>Significantly Below Average</b> |            |           |              |
| CA                                 | 88%        | 12%       | 2,464        |
| GA                                 | 87%        | 13%       | 273          |
| <b>NCI Average</b>                 | <b>93%</b> | <b>7%</b> | <b>5,560</b> |

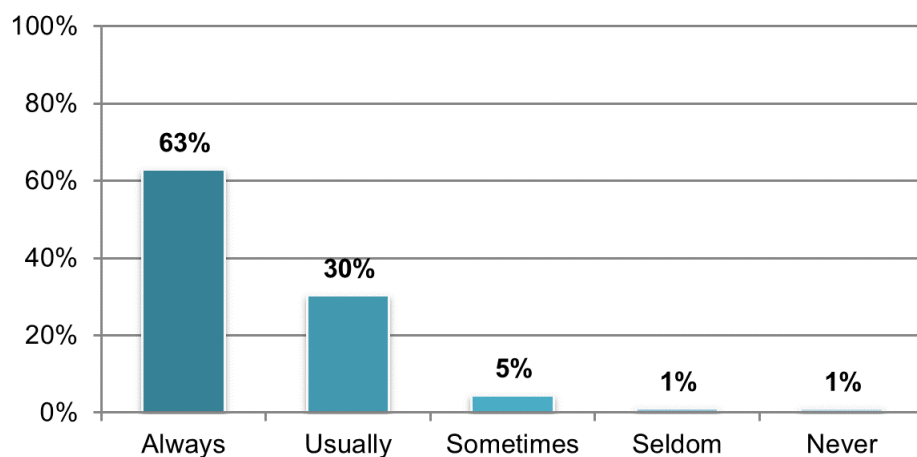
## Access and Delivery of Services and Supports

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

**Note:** State outcomes with fewer than 20 responses were not reported.

**Note on California significance:** Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (\*\*), an outcome is significant *only* due to the sample size.

### Respondent Is Able to Contact Support Workers When Needed

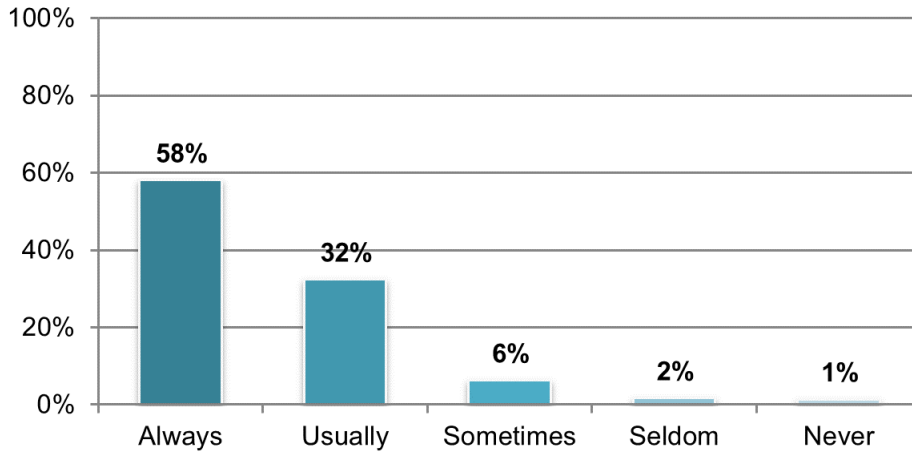


**Table Q12. Are you able to contact your family member's support workers when you need to?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| VA                                 | 71%        | 24%        | 4%        | 1%        | 0%        | 372          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| NC                                 | 67%        | 30%        | 2%        | 0%        | 0%        | 175          |
| FL                                 | 67%        | 26%        | 5%        | 1%        | 1%        | 371          |
| WA                                 | 66%        | 29%        | 3%        | 1%        | 1%        | 388          |
| MI                                 | 66%        | 30%        | 4%        | 0%        | 0%        | 435          |
| PA                                 | 65%        | 29%        | 4%        | 0%        | 1%        | 391          |
| SC                                 | 62%        | 31%        | 4%        | 3%        | 1%        | 235          |
| NH                                 | 61%        | 34%        | 4%        | 1%        | 0%        | 301          |
| UT                                 | 58%        | 35%        | 4%        | 1%        | 1%        | 361          |
| CA **                              | 58%        | 29%        | 7%        | 2%        | 3%        | 2,960        |
| GA                                 | 57%        | 34%        | 5%        | 2%        | 2%        | 320          |
| MD                                 | 57%        | 33%        | 8%        | 0%        | 3%        | 169          |
| <b>NCI Average</b>                 | <b>63%</b> | <b>30%</b> | <b>5%</b> | <b>1%</b> | <b>1%</b> | <b>6,478</b> |



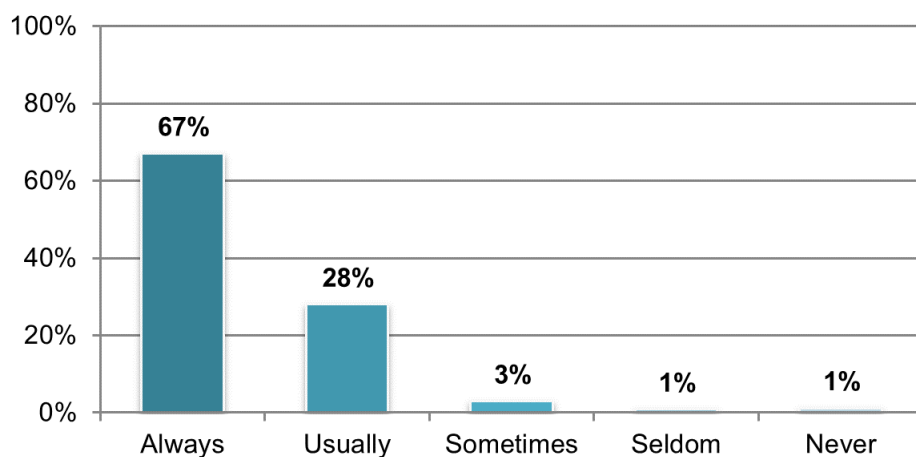
### Respondent Is Able to Contact Case Manager/Service Coordinator When Needed



**Table Q13. Are you able to contact your family member's case manager/service coordinator when you need to?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| FL                                 | 71%        | 22%        | 5%        | 1%        | 1%        | 364          |
| VA                                 | 67%        | 27%        | 3%        | 1%        | 1%        | 373          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| NC                                 | 61%        | 33%        | 6%        | 0%        | 0%        | 174          |
| MI                                 | 61%        | 32%        | 6%        | 0%        | 1%        | 438          |
| UT                                 | 60%        | 31%        | 5%        | 2%        | 2%        | 353          |
| PA                                 | 59%        | 34%        | 4%        | 1%        | 1%        | 377          |
| NH                                 | 57%        | 35%        | 6%        | 1%        | 0%        | 301          |
| SC                                 | 55%        | 34%        | 8%        | 2%        | 1%        | 236          |
| WA                                 | 54%        | 37%        | 5%        | 3%        | 1%        | 389          |
| MD                                 | 52%        | 34%        | 11%       | 2%        | 2%        | 161          |
| <b>Significantly Below Average</b> |            |            |           |           |           |              |
| CA                                 | 51%        | 31%        | 10%       | 4%        | 4%        | 2,883        |
| GA                                 | 49%        | 38%        | 8%        | 4%        | 2%        | 309          |
| <b>NCI Average</b>                 | <b>58%</b> | <b>32%</b> | <b>6%</b> | <b>2%</b> | <b>1%</b> | <b>6,358</b> |

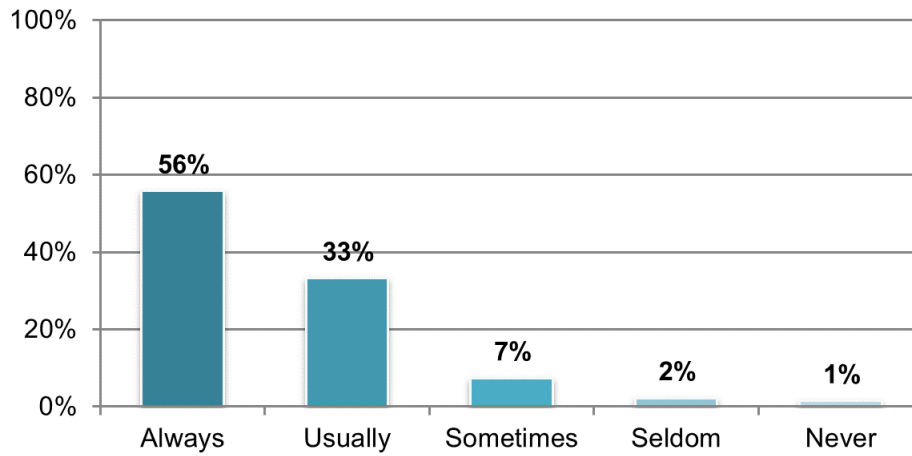
### Services and Supports Are Available Reasonably Close to Family Member's Home



**Table Q14. Are services and supports available within a reasonable distance from your family member's home?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| MI                                 | 74%        | 23%        | 2%        | 0%        | 0%        | 426          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| VA                                 | 73%        | 24%        | 2%        | 0%        | 1%        | 340          |
| SC                                 | 72%        | 23%        | 3%        | 0%        | 1%        | 208          |
| NH                                 | 71%        | 26%        | 1%        | 1%        | 0%        | 289          |
| NC                                 | 68%        | 29%        | 2%        | 0%        | 1%        | 170          |
| UT                                 | 68%        | 28%        | 2%        | 1%        | 1%        | 330          |
| FL                                 | 67%        | 29%        | 2%        | 1%        | 1%        | 337          |
| MD                                 | 66%        | 28%        | 3%        | 1%        | 3%        | 153          |
| PA                                 | 64%        | 31%        | 4%        | 1%        | 1%        | 359          |
| WA                                 | 63%        | 30%        | 4%        | 1%        | 2%        | 372          |
| <b>Significantly Below Average</b> |            |            |           |           |           |              |
| CA                                 | 61%        | 31%        | 5%        | 2%        | 2%        | 2,665        |
| GA                                 | 58%        | 33%        | 5%        | 2%        | 1%        | 277          |
| <b>NCI Average</b>                 | <b>67%</b> | <b>28%</b> | <b>3%</b> | <b>1%</b> | <b>1%</b> | <b>5,926</b> |

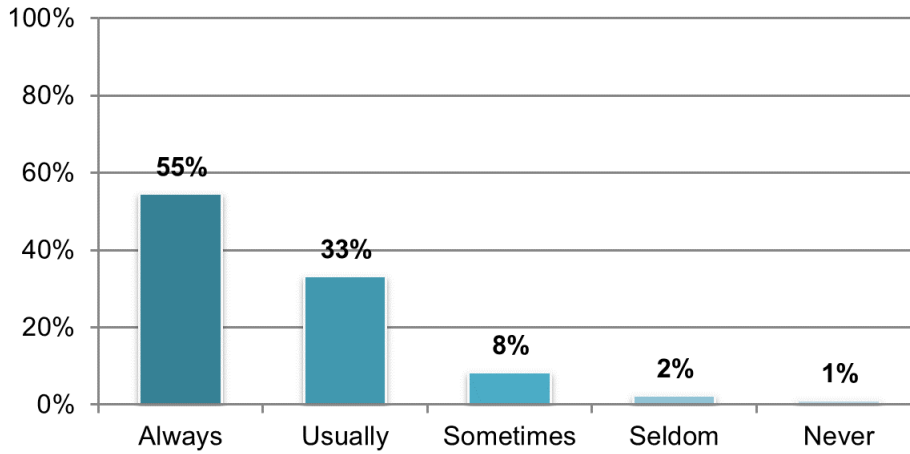
### Services and Supports Change When Family Member's Needs Change



**Table Q15. Do the services and supports change when your family member's needs change?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| VA                                 | 66%        | 28%        | 4%        | 1%        | 1%        | 313          |
| MI                                 | 63%        | 29%        | 6%        | 1%        | 1%        | 404          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| NC                                 | 60%        | 34%        | 4%        | 1%        | 1%        | 164          |
| PA                                 | 58%        | 34%        | 5%        | 2%        | 1%        | 330          |
| SC                                 | 56%        | 31%        | 9%        | 3%        | 1%        | 176          |
| FL                                 | 56%        | 31%        | 10%       | 2%        | 2%        | 331          |
| WA                                 | 55%        | 33%        | 8%        | 2%        | 2%        | 356          |
| UT                                 | 53%        | 36%        | 7%        | 2%        | 1%        | 321          |
| MD                                 | 52%        | 34%        | 7%        | 3%        | 4%        | 134          |
| NH                                 | 52%        | 39%        | 6%        | 2%        | 1%        | 275          |
| CA **                              | 50%        | 34%        | 10%       | 3%        | 3%        | 2,321        |
| <b>Significantly Below Average</b> |            |            |           |           |           |              |
| GA                                 | 47%        | 36%        | 11%       | 5%        | 1%        | 249          |
| <b>NCI Average</b>                 | <b>56%</b> | <b>33%</b> | <b>7%</b> | <b>2%</b> | <b>1%</b> | <b>5,374</b> |

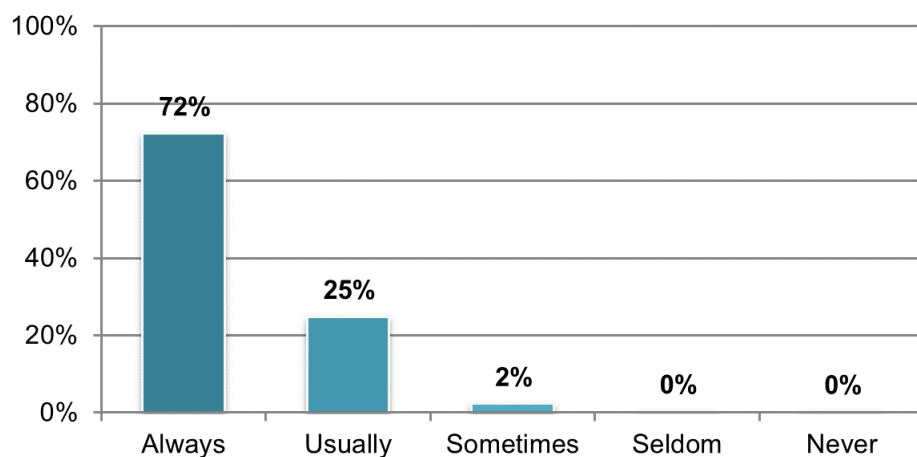
### Support Workers Can Communicate with Family Member (If Non-Verbal)



**Table Q16. 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    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| MI                                 | 66%        | 23%        | 9%        | 2%        | 0%        | 137          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| WA                                 | 64%        | 28%        | 5%        | 1%        | 1%        | 74           |
| VA                                 | 61%        | 31%        | 7%        | 1%        | 0%        | 172          |
| GA                                 | 57%        | 27%        | 14%       | 2%        | 0%        | 81           |
| FL                                 | 56%        | 29%        | 10%       | 3%        | 2%        | 91           |
| SC                                 | 56%        | 36%        | 8%        | 0%        | 0%        | 50           |
| CA                                 | 52%        | 33%        | 9%        | 3%        | 3%        | 653          |
| NH                                 | 51%        | 37%        | 10%       | 1%        | 0%        | 70           |
| UT                                 | 51%        | 36%        | 10%       | 2%        | 1%        | 84           |
| PA                                 | 49%        | 40%        | 7%        | 1%        | 3%        | 109          |
| NC                                 | 47%        | 42%        | 7%        | 2%        | 2%        | 43           |
| MD                                 | 45%        | 38%        | 6%        | 9%        | 2%        | 53           |
| <b>NCI Average</b>                 | <b>55%</b> | <b>33%</b> | <b>8%</b> | <b>2%</b> | <b>1%</b> | <b>1,617</b> |

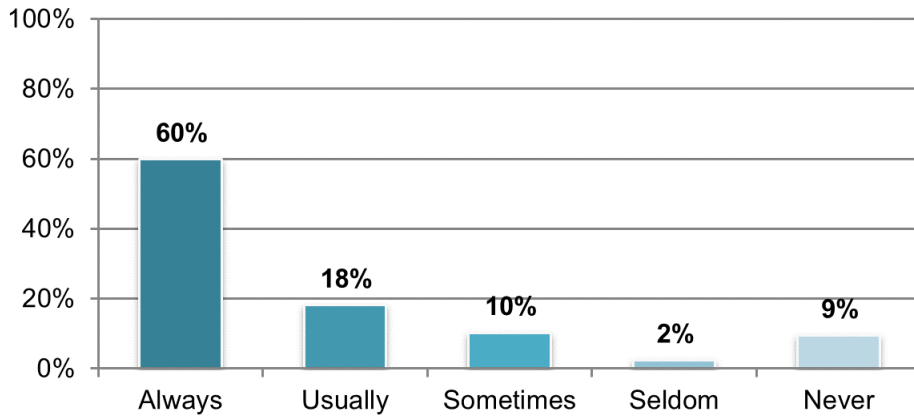
### Support Workers Communicate Effectively with Family Member in Primary Language (If English)



**Table Q17. If English is your family member's first language, do the support workers speak to him/her effectively?**

| State                       | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|-----------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Within Average Range</b> |            |            |           |           |           |              |
| MI                          | 77%        | 21%        | 1%        | 1%        | 0%        | 395          |
| SC                          | 77%        | 21%        | 1%        | 1%        | 0%        | 201          |
| VA                          | 76%        | 22%        | 2%        | 0%        | 0%        | 308          |
| NC                          | 75%        | 24%        | 1%        | 0%        | 0%        | 161          |
| FL                          | 74%        | 22%        | 2%        | 1%        | 0%        | 325          |
| PA                          | 74%        | 23%        | 3%        | 0%        | 0%        | 342          |
| UT                          | 71%        | 25%        | 4%        | 0%        | 0%        | 335          |
| CA                          | 71%        | 25%        | 3%        | 1%        | 0%        | 2,509        |
| WA                          | 70%        | 26%        | 4%        | 0%        | 0%        | 365          |
| GA                          | 68%        | 29%        | 2%        | 0%        | 0%        | 278          |
| NH                          | 67%        | 30%        | 3%        | 0%        | 0%        | 276          |
| MD                          | 66%        | 30%        | 3%        | 0%        | 1%        | 146          |
| <b>NCI Average</b>          | <b>72%</b> | <b>25%</b> | <b>2%</b> | <b>0%</b> | <b>0%</b> | <b>5,641</b> |

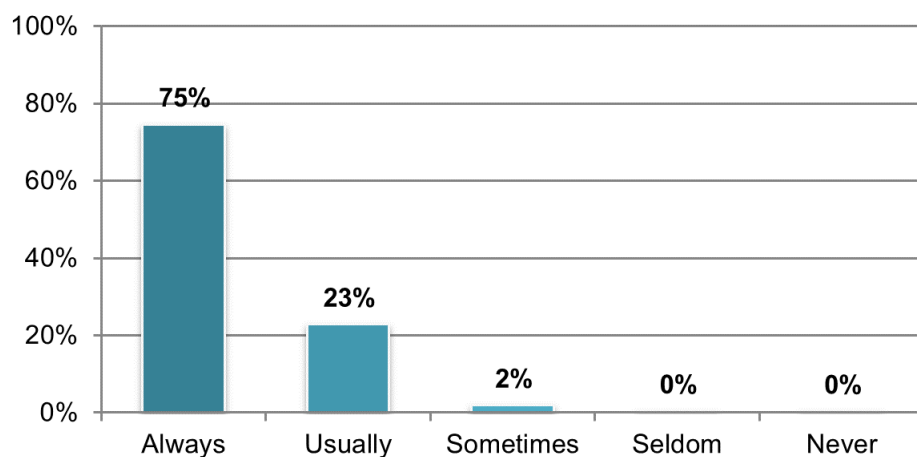
**Support Workers or Translators Are Available  
Who Can Speak to Family Member in His/Her  
Preferred Language (If Not English)**



**Table Q18. If English is not your family member's first language, are there support workers or translators who can speak with him/her in the preferred language?**

| State                | Always | Usually | Sometimes | Seldom | Never | N   |
|----------------------|--------|---------|-----------|--------|-------|-----|
| Within Average Range |        |         |           |        |       |     |
| CA                   | 60%    | 18%     | 10%       | 2%     | 9%    | 127 |
| NCI Average          | 60%    | 18%     | 10%       | 2%     | 9%    | 127 |

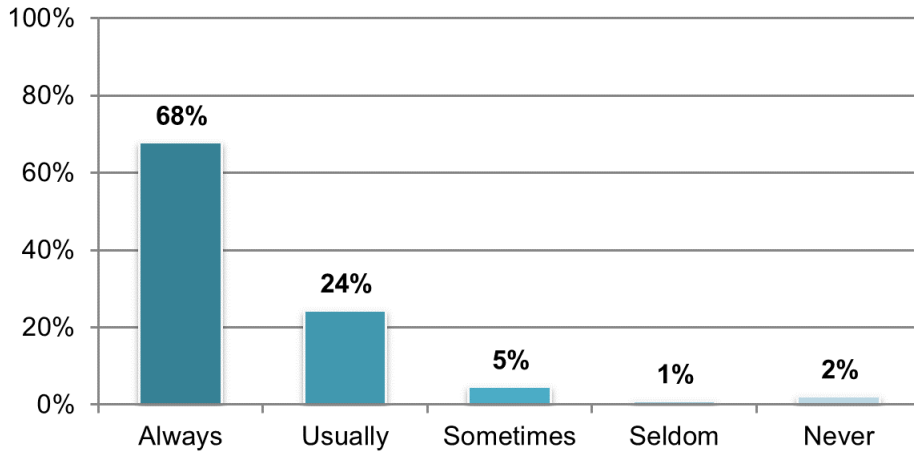
### Services Are Delivered in a Manner That Is Respectful to Family Member's Culture



**Table Q19. Are services delivered in a way that is respectful to your family member's culture?**

| State                       | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|-----------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Within Average Range</b> |            |            |           |           |           |              |
| FL                          | 80%        | 18%        | 2%        | 1%        | 0%        | 333          |
| VA                          | 79%        | 20%        | 1%        | 0%        | 0%        | 335          |
| NH                          | 78%        | 20%        | 2%        | 0%        | 0%        | 262          |
| MI                          | 78%        | 21%        | 1%        | 0%        | 0%        | 394          |
| PA                          | 76%        | 22%        | 2%        | 0%        | 0%        | 327          |
| NC                          | 76%        | 24%        | 0%        | 0%        | 0%        | 165          |
| CA                          | 74%        | 21%        | 3%        | 1%        | 1%        | 2,474        |
| SC                          | 74%        | 22%        | 3%        | 1%        | 0%        | 209          |
| WA                          | 72%        | 26%        | 1%        | 1%        | 0%        | 350          |
| MD                          | 72%        | 26%        | 1%        | 1%        | 0%        | 146          |
| GA                          | 69%        | 26%        | 4%        | 0%        | 0%        | 273          |
| UT                          | 68%        | 27%        | 3%        | 0%        | 1%        | 324          |
| <b>NCI Average</b>          | <b>75%</b> | <b>23%</b> | <b>2%</b> | <b>0%</b> | <b>0%</b> | <b>5,592</b> |

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

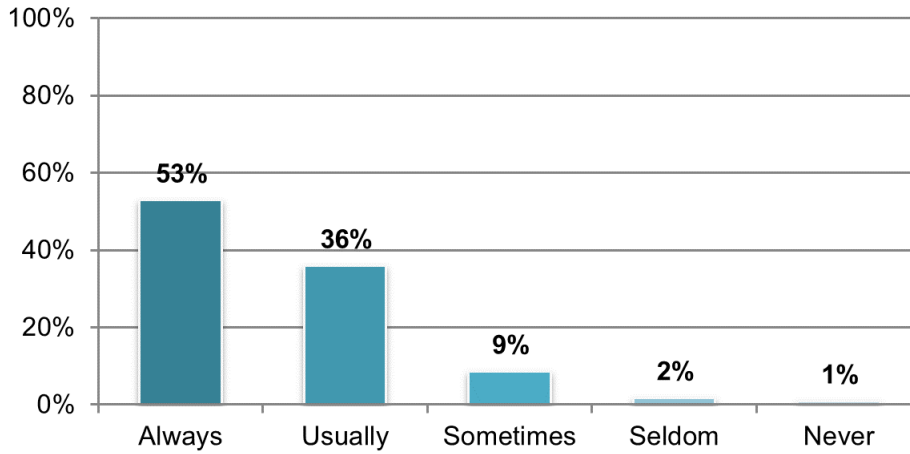


**Table Q20. Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| VA                                 | 79%        | 19%        | 1%        | 0%        | 1%        | 262          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| SC                                 | 72%        | 17%        | 6%        | 1%        | 4%        | 138          |
| PA                                 | 71%        | 22%        | 4%        | 2%        | 1%        | 238          |
| MI                                 | 70%        | 22%        | 6%        | 0%        | 2%        | 264          |
| UT                                 | 69%        | 24%        | 3%        | 1%        | 3%        | 193          |
| FL                                 | 69%        | 23%        | 5%        | 1%        | 3%        | 192          |
| NC                                 | 66%        | 25%        | 8%        | 0%        | 1%        | 97           |
| NH                                 | 65%        | 30%        | 5%        | 0%        | 1%        | 168          |
| WA                                 | 64%        | 29%        | 4%        | 1%        | 2%        | 225          |
| GA                                 | 64%        | 30%        | 2%        | 1%        | 3%        | 165          |
| MD                                 | 63%        | 24%        | 8%        | 2%        | 3%        | 89           |
| CA **                              | 63%        | 28%        | 4%        | 1%        | 4%        | 1,351        |
| <b>NCI Average</b>                 | <b>68%</b> | <b>24%</b> | <b>5%</b> | <b>1%</b> | <b>2%</b> | <b>3,382</b> |



### Support Workers Have the Right Training to Meet Family Member's Needs



**Table Q21. Do the support workers have the right training to meet your family member's needs?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| VA                                 | 67%        | 26%        | 6%        | 1%        | 0%        | 344          |
| MI                                 | 61%        | 31%        | 7%        | 1%        | 1%        | 413          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| FL                                 | 59%        | 33%        | 5%        | 2%        | 2%        | 331          |
| PA                                 | 54%        | 36%        | 7%        | 2%        | 1%        | 346          |
| NH                                 | 54%        | 38%        | 7%        | 1%        | 0%        | 279          |
| WA                                 | 52%        | 36%        | 10%       | 1%        | 1%        | 351          |
| CA                                 | 51%        | 37%        | 9%        | 2%        | 1%        | 2,465        |
| GA                                 | 51%        | 38%        | 9%        | 1%        | 1%        | 267          |
| SC                                 | 50%        | 35%        | 12%       | 2%        | 1%        | 204          |
| NC                                 | 48%        | 42%        | 9%        | 1%        | 1%        | 164          |
| MD                                 | 44%        | 39%        | 14%       | 2%        | 2%        | 148          |
| <b>Significantly Below Average</b> |            |            |           |           |           |              |
| UT                                 | 45%        | 41%        | 10%       | 3%        | 1%        | 331          |
| <b>NCI Average</b>                 | <b>53%</b> | <b>36%</b> | <b>9%</b> | <b>2%</b> | <b>1%</b> | <b>5,643</b> |

### Family Member's Residential Setting Is a Healthy and Safe Environment

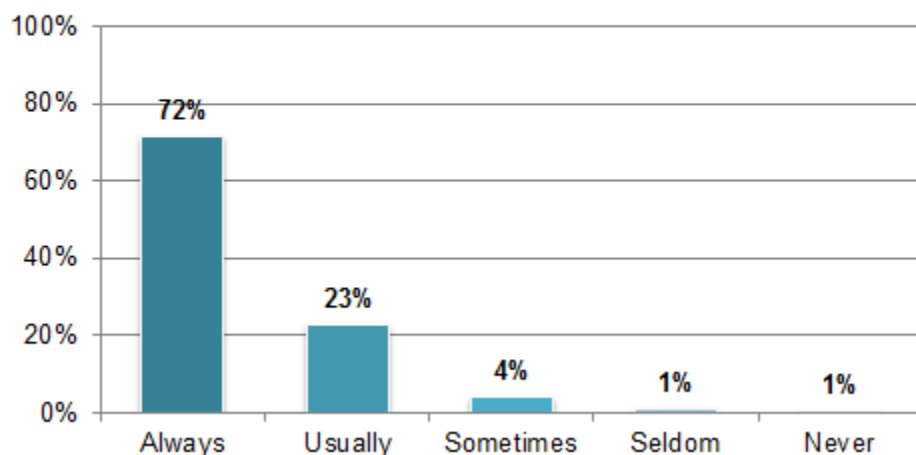
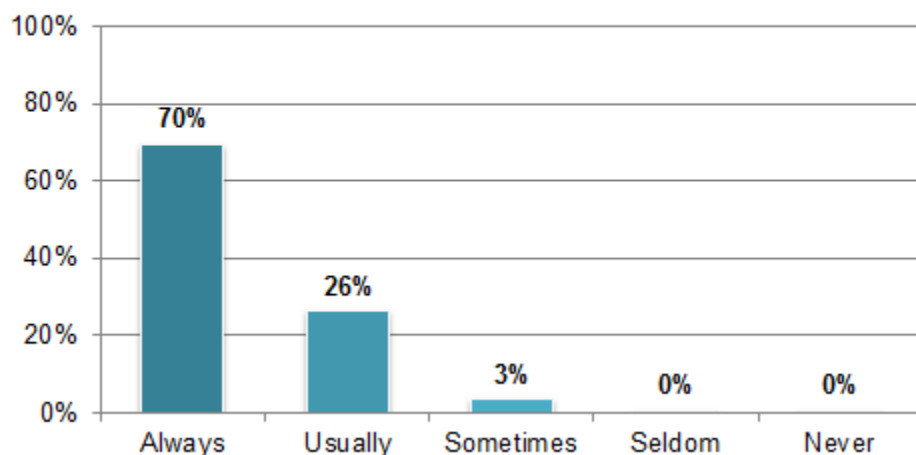


Table Q22. Do you feel that your family member's residential setting is a healthy and safe environment?

| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| VA                                 | 79%        | 17%        | 3%        | 0%        | 0%        | 367          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| MI                                 | 76%        | 20%        | 2%        | 1%        | 0%        | 441          |
| NH                                 | 76%        | 18%        | 4%        | 0%        | 1%        | 291          |
| FL                                 | 73%        | 20%        | 5%        | 1%        | 0%        | 369          |
| NC                                 | 73%        | 25%        | 1%        | 1%        | 0%        | 174          |
| PA                                 | 72%        | 22%        | 5%        | 1%        | 0%        | 389          |
| CA                                 | 70%        | 23%        | 4%        | 1%        | 1%        | 2,962        |
| SC                                 | 70%        | 22%        | 7%        | 1%        | 0%        | 235          |
| GA                                 | 68%        | 26%        | 4%        | 1%        | 1%        | 299          |
| WA                                 | 68%        | 24%        | 5%        | 1%        | 1%        | 380          |
| MD                                 | 68%        | 24%        | 3%        | 2%        | 3%        | 153          |
| <b>Significantly Below Average</b> |            |            |           |           |           |              |
| UT                                 | 64%        | 30%        | 4%        | 1%        | 1%        | 358          |
| <b>NCI Average</b>                 | <b>72%</b> | <b>23%</b> | <b>4%</b> | <b>1%</b> | <b>1%</b> | <b>6,418</b> |

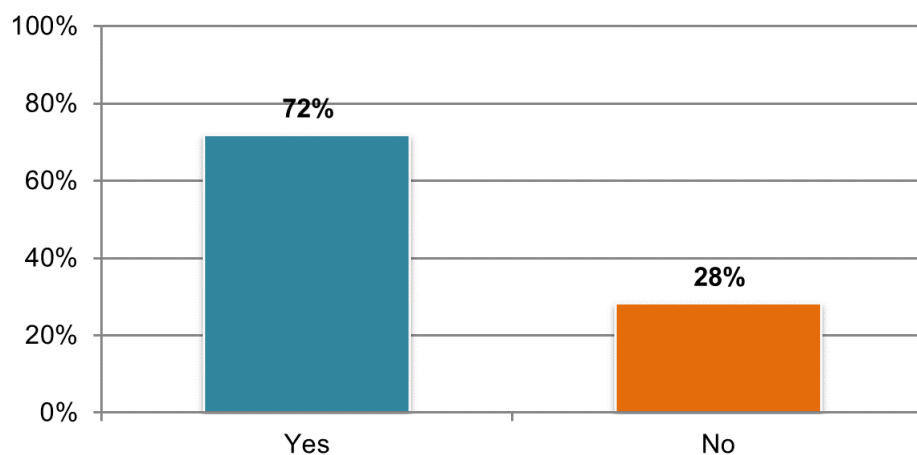
### Family Member's Day/Employment Setting Is a Healthy and Safe Environment



**Table Q23. Do you feel that your family member's day/employment setting is a healthy and safe environment?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| VA                                 | 81%        | 17%        | 2%        | 0%        | 0%        | 280          |
| MI                                 | 76%        | 22%        | 1%        | 1%        | 0%        | 334          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| PA                                 | 72%        | 24%        | 3%        | 1%        | 0%        | 289          |
| NC                                 | 69%        | 27%        | 3%        | 0%        | 0%        | 154          |
| CA                                 | 69%        | 26%        | 4%        | 1%        | 1%        | 2,426        |
| GA                                 | 69%        | 29%        | 2%        | 0%        | 0%        | 258          |
| FL                                 | 68%        | 26%        | 5%        | 0%        | 0%        | 288          |
| SC                                 | 68%        | 24%        | 6%        | 1%        | 1%        | 197          |
| MD                                 | 67%        | 29%        | 4%        | 0%        | 0%        | 131          |
| NH                                 | 66%        | 29%        | 5%        | 0%        | 0%        | 244          |
| UT                                 | 65%        | 29%        | 4%        | 1%        | 0%        | 312          |
| WA                                 | 65%        | 32%        | 1%        | 1%        | 1%        | 270          |
| <b>NCI Average</b>                 | <b>70%</b> | <b>26%</b> | <b>3%</b> | <b>0%</b> | <b>0%</b> | <b>5,183</b> |

### Happy with Transition from School Services to State-Funded Services (In Past Year)



**Table Q24. If your family member transitioned from school services to state-funded services in the past year, were you happy with the transition process?**

| State                | Yes | No  | N  |
|----------------------|-----|-----|----|
| Within Average Range |     |     |    |
| CA                   | 72% | 28% | 78 |
| NCI Average          | 72% | 28% | 78 |

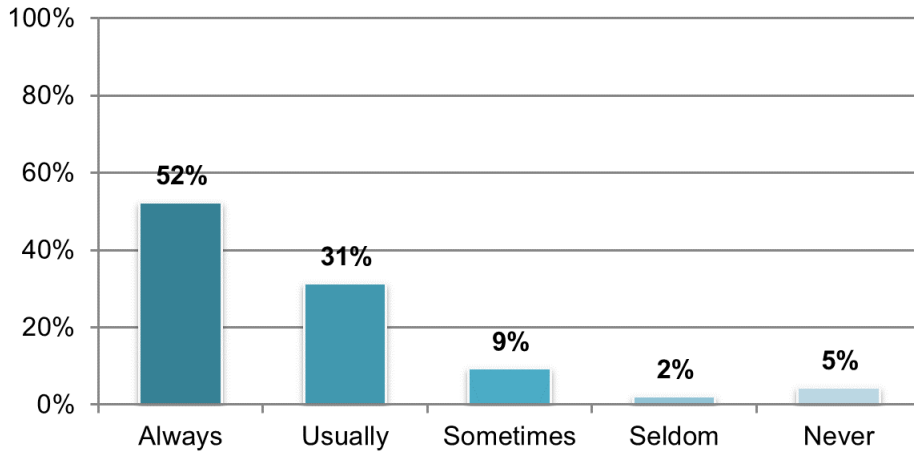
## Choice and Control

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

**Note:** State outcomes with fewer than 20 responses were not reported.

**Note on California significance:** Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (\*\*), an outcome is significant *only* due to the sample size.

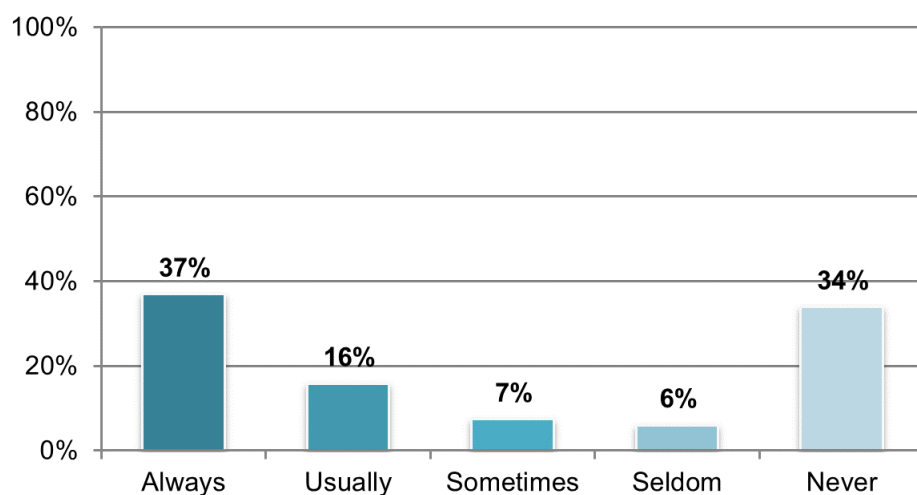
### Residential Service Agency Involves Family Member in Important Decisions



**Table Q25. Does the agency providing residential services to your family member involve him/her in important decisions?**

| State                       | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|-----------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Within Average Range</b> |            |            |           |           |           |              |
| VA                          | 60%        | 29%        | 6%        | 2%        | 4%        | 252          |
| SC                          | 57%        | 26%        | 10%       | 5%        | 2%        | 175          |
| FL                          | 56%        | 28%        | 10%       | 1%        | 5%        | 263          |
| PA                          | 54%        | 30%        | 8%        | 1%        | 7%        | 259          |
| MI                          | 53%        | 34%        | 9%        | 1%        | 3%        | 350          |
| CA                          | 53%        | 29%        | 10%       | 2%        | 6%        | 1,956        |
| WA                          | 53%        | 28%        | 13%       | 2%        | 4%        | 309          |
| NH                          | 52%        | 35%        | 8%        | 3%        | 3%        | 235          |
| MD                          | 52%        | 32%        | 9%        | 2%        | 6%        | 114          |
| NC                          | 49%        | 38%        | 8%        | 1%        | 3%        | 145          |
| UT                          | 48%        | 35%        | 11%       | 2%        | 5%        | 285          |
| GA                          | 44%        | 33%        | 11%       | 5%        | 7%        | 219          |
| <b>NCI Average</b>          | <b>52%</b> | <b>31%</b> | <b>9%</b> | <b>2%</b> | <b>5%</b> | <b>4,562</b> |

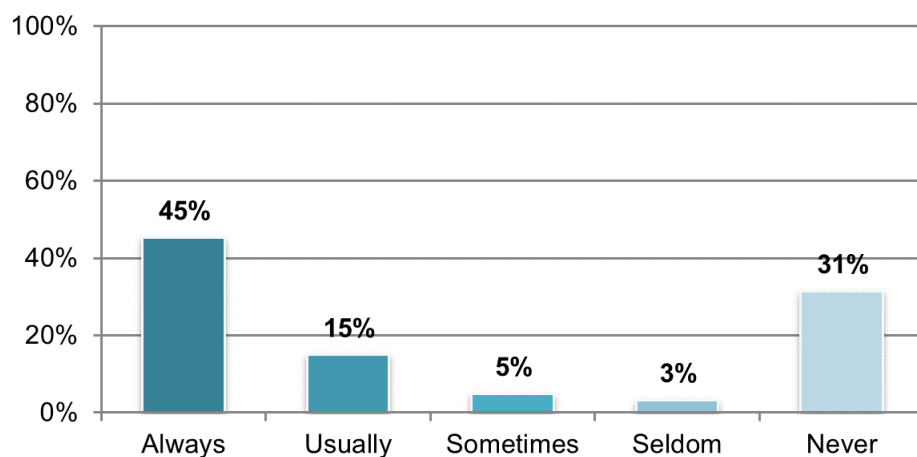
### Family Member Chooses Provider Agencies



**Table Q26. Does your family member choose the provider agencies that work with him or her?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never      | N            |
|------------------------------------|------------|------------|-----------|-----------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |            |              |
| UT                                 | 50%        | 14%        | 5%        | 6%        | 26%        | 226          |
| <b>Within Average Range</b>        |            |            |           |           |            |              |
| NH                                 | 42%        | 13%        | 8%        | 2%        | 35%        | 168          |
| GA                                 | 39%        | 16%        | 7%        | 6%        | 32%        | 183          |
| SC                                 | 39%        | 20%        | 7%        | 7%        | 28%        | 120          |
| VA                                 | 38%        | 16%        | 6%        | 5%        | 34%        | 190          |
| FL                                 | 36%        | 16%        | 11%       | 5%        | 33%        | 256          |
| PA                                 | 36%        | 10%        | 6%        | 8%        | 41%        | 181          |
| CA                                 | 35%        | 16%        | 7%        | 6%        | 35%        | 1,640        |
| NC                                 | 34%        | 16%        | 6%        | 7%        | 37%        | 114          |
| MI                                 | 32%        | 18%        | 10%       | 8%        | 32%        | 259          |
| WA                                 | 32%        | 21%        | 7%        | 5%        | 36%        | 253          |
| MD                                 | 29%        | 15%        | 9%        | 7%        | 40%        | 94           |
| <b>NCI Average</b>                 | <b>37%</b> | <b>16%</b> | <b>7%</b> | <b>6%</b> | <b>34%</b> | <b>3,684</b> |

### Family Member Can Choose a Different Provider Agency If Desired

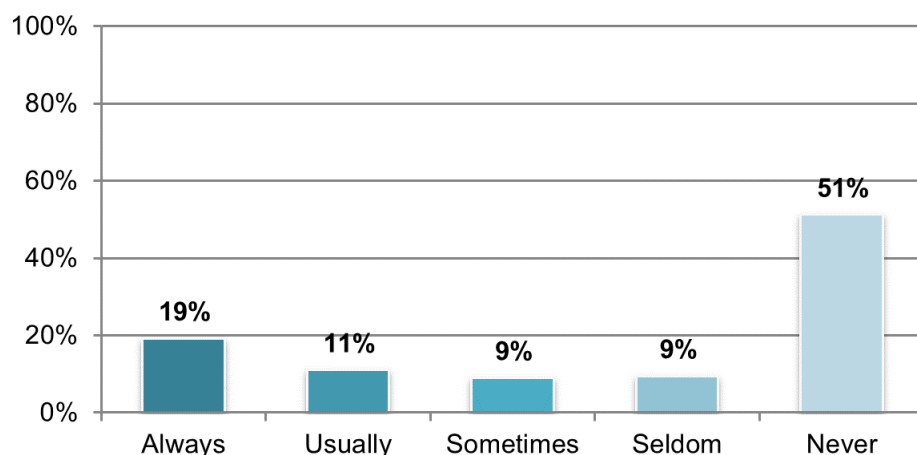


**Table 27. Can your family member choose a different provider agency if s/he wants to?**

| State                       | Always     | Usually    | Sometimes | Seldom    | Never      | N            |
|-----------------------------|------------|------------|-----------|-----------|------------|--------------|
| <b>Within Average Range</b> |            |            |           |           |            |              |
| UT                          | 52%        | 15%        | 5%        | 1%        | 26%        | 204          |
| MD                          | 49%        | 8%         | 4%        | 4%        | 34%        | 71           |
| WA                          | 49%        | 19%        | 4%        | 3%        | 26%        | 216          |
| MI                          | 48%        | 18%        | 5%        | 7%        | 22%        | 238          |
| NH                          | 48%        | 13%        | 8%        | 1%        | 30%        | 135          |
| FL                          | 48%        | 19%        | 6%        | 2%        | 25%        | 233          |
| SC                          | 48%        | 10%        | 4%        | 5%        | 35%        | 84           |
| NC                          | 46%        | 16%        | 5%        | 2%        | 31%        | 100          |
| VA                          | 41%        | 14%        | 4%        | 2%        | 38%        | 162          |
| GA                          | 40%        | 16%        | 6%        | 3%        | 35%        | 158          |
| CA **                       | 38%        | 19%        | 6%        | 5%        | 31%        | 1,286        |
| PA                          | 36%        | 12%        | 2%        | 5%        | 44%        | 129          |
| <b>NCI Average</b>          | <b>45%</b> | <b>15%</b> | <b>5%</b> | <b>3%</b> | <b>31%</b> | <b>3,016</b> |



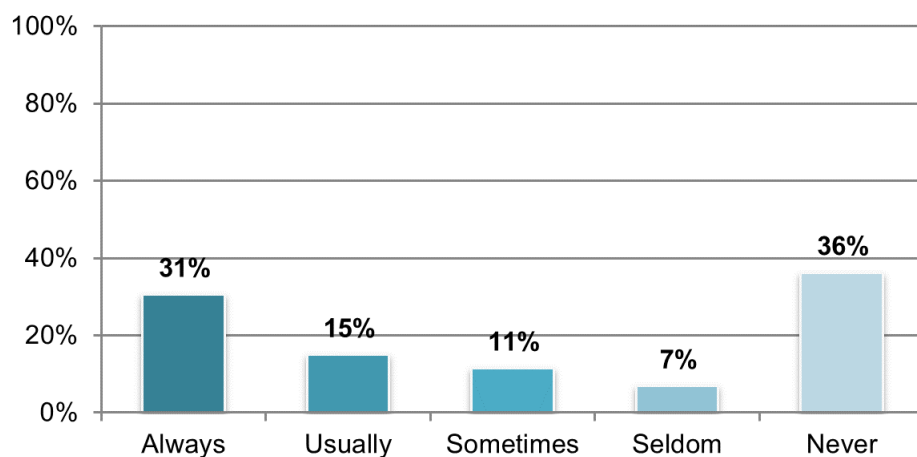
### Family Member Chooses Individual Support Workers That Work Directly With Him/Her



**Table Q28. Does your family member choose the individual support workers who work directly with him/her?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never      | N            |
|------------------------------------|------------|------------|-----------|-----------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |            |              |
| FL                                 | 38%        | 10%        | 9%        | 4%        | 39%        | 240          |
| <b>Within Average Range</b>        |            |            |           |           |            |              |
| UT                                 | 25%        | 12%        | 14%       | 7%        | 42%        | 220          |
| VA                                 | 21%        | 5%         | 3%        | 8%        | 63%        | 185          |
| GA                                 | 20%        | 9%         | 8%        | 6%        | 57%        | 173          |
| WA                                 | 19%        | 12%        | 7%        | 15%       | 47%        | 248          |
| NH                                 | 18%        | 14%        | 14%       | 9%        | 46%        | 177          |
| MI                                 | 18%        | 12%        | 14%       | 16%       | 40%        | 274          |
| CA                                 | 18%        | 13%        | 11%       | 8%        | 50%        | 1,705        |
| SC                                 | 17%        | 7%         | 5%        | 9%        | 62%        | 109          |
| NC                                 | 16%        | 12%        | 9%        | 11%       | 52%        | 117          |
| MD                                 | 13%        | 15%        | 10%       | 13%       | 50%        | 115          |
| <b>Significantly Below Average</b> |            |            |           |           |            |              |
| PA                                 | 10%        | 10%        | 6%        | 8%        | 66%        | 193          |
| <b>NCI Average</b>                 | <b>19%</b> | <b>11%</b> | <b>9%</b> | <b>9%</b> | <b>51%</b> | <b>3,756</b> |

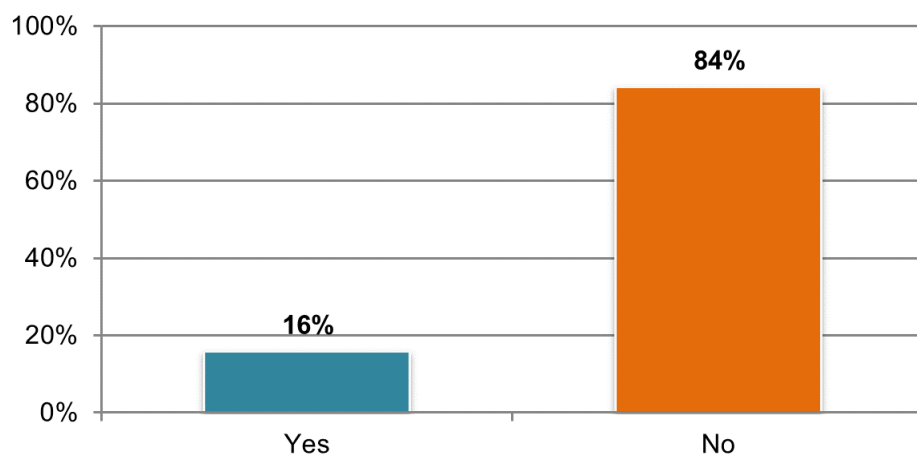
### Family Member Can Choose Different Support Workers If Desired



**Table Q29. Can your family member choose different support workers if s/he wants to?**

| State                              | Always     | Usually    | Sometimes  | Seldom    | Never      | N            |
|------------------------------------|------------|------------|------------|-----------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |            |           |            |              |
| FL                                 | 46%        | 13%        | 9%         | 4%        | 28%        | 226          |
| <b>Within Average Range</b>        |            |            |            |           |            |              |
| UT                                 | 38%        | 13%        | 15%        | 6%        | 28%        | 203          |
| WA                                 | 33%        | 20%        | 11%        | 10%       | 26%        | 217          |
| MI                                 | 32%        | 18%        | 16%        | 8%        | 25%        | 244          |
| CA                                 | 31%        | 19%        | 13%        | 5%        | 32%        | 1,421        |
| GA                                 | 31%        | 11%        | 15%        | 5%        | 39%        | 150          |
| NC                                 | 30%        | 14%        | 10%        | 5%        | 41%        | 100          |
| VA                                 | 30%        | 11%        | 8%         | 4%        | 47%        | 159          |
| NH                                 | 29%        | 17%        | 15%        | 10%       | 29%        | 150          |
| MD                                 | 24%        | 14%        | 11%        | 11%       | 40%        | 88           |
| SC                                 | 23%        | 14%        | 6%         | 6%        | 51%        | 84           |
| <b>Significantly Below Average</b> |            |            |            |           |            |              |
| PA                                 | 20%        | 15%        | 8%         | 7%        | 50%        | 149          |
| <b>NCI Average</b>                 | <b>31%</b> | <b>15%</b> | <b>11%</b> | <b>7%</b> | <b>36%</b> | <b>3,191</b> |

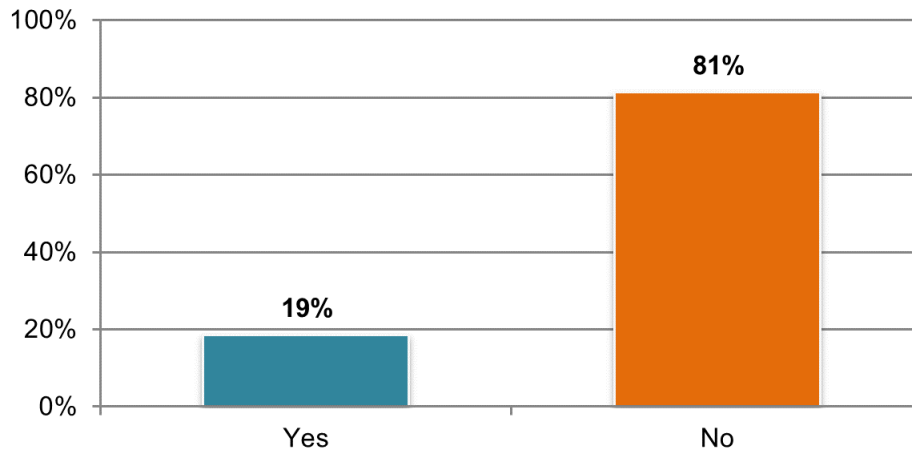
### Family Member Chose Case Manager/Service Coordinator



**Table Q30. Did your family member choose his/her case manager/service coordinator?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| FL                                 | 45%        | 55%        | 288          |
| UT                                 | 36%        | 64%        | 247          |
| <b>Within Average Range</b>        |            |            |              |
| MI                                 | 17%        | 83%        | 345          |
| GA                                 | 15%        | 85%        | 211          |
| NH                                 | 15%        | 85%        | 237          |
| SC                                 | 14%        | 86%        | 151          |
| MD                                 | 10%        | 90%        | 124          |
| <b>Significantly Below Average</b> |            |            |              |
| CA                                 | 10%        | 90%        | 2,168        |
| NC                                 | 9%         | 91%        | 138          |
| VA                                 | 8%         | 92%        | 261          |
| PA                                 | 7%         | 93%        | 256          |
| WA                                 | 4%         | 96%        | 308          |
| <b>NCI Average</b>                 | <b>16%</b> | <b>84%</b> | <b>4,734</b> |

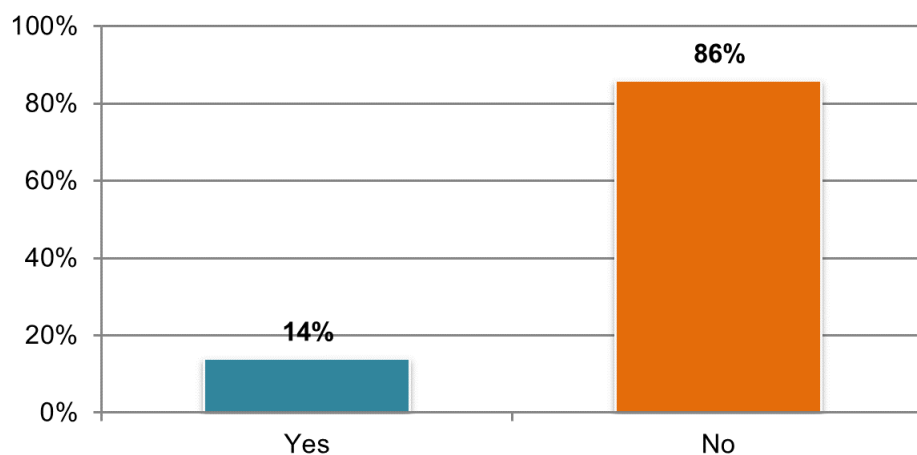
### Family Member Has Control or Input Over Hiring and Management of Support Workers



**Table Q31. Does your family member have control and/or input over the hiring and management of his/her support workers?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| FL                                 | 36%        | 64%        | 287          |
| UT                                 | 26%        | 74%        | 231          |
| <b>Within Average Range</b>        |            |            |              |
| CA **                              | 23%        | 77%        | 1,968        |
| WA                                 | 22%        | 78%        | 291          |
| NH                                 | 21%        | 79%        | 216          |
| MI                                 | 18%        | 82%        | 343          |
| MD                                 | 17%        | 83%        | 125          |
| GA                                 | 16%        | 84%        | 206          |
| NC                                 | 13%        | 87%        | 138          |
| SC                                 | 13%        | 87%        | 151          |
| <b>Significantly Below Average</b> |            |            |              |
| PA                                 | 10%        | 90%        | 245          |
| VA                                 | 8%         | 92%        | 246          |
| <b>NCI Average</b>                 | <b>19%</b> | <b>81%</b> | <b>4,447</b> |

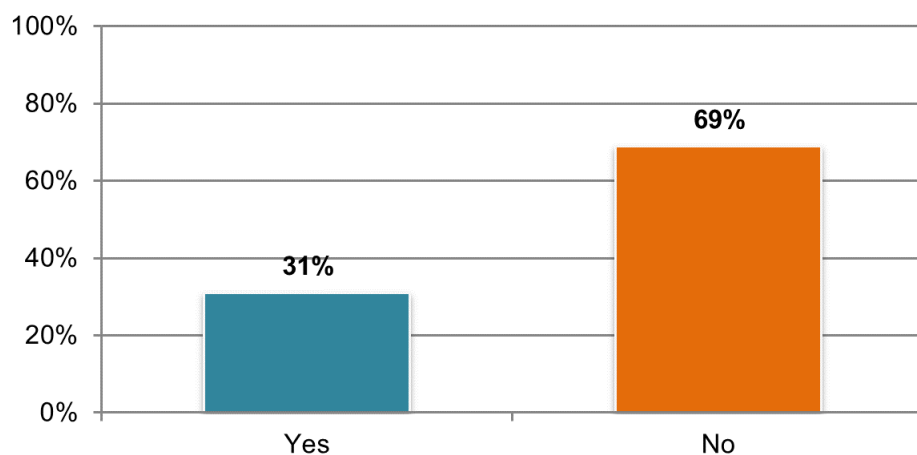
### Family Member Knows How Much Money Is Spent by ID/DD Agency on His/Her Behalf



**Table Q32. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| FL                                 | 26%        | 74%        | 327          |
| SC                                 | 22%        | 78%        | 211          |
| MI                                 | 19%        | 81%        | 394          |
| <b>Within Average Range</b>        |            |            |              |
| VA                                 | 14%        | 86%        | 287          |
| UT                                 | 13%        | 87%        | 311          |
| GA                                 | 12%        | 88%        | 275          |
| MD                                 | 12%        | 88%        | 145          |
| CA **                              | 12%        | 88%        | 2,670        |
| NC                                 | 11%        | 89%        | 152          |
| NH                                 | 11%        | 89%        | 265          |
| <b>Significantly Below Average</b> |            |            |              |
| WA                                 | 9%         | 91%        | 364          |
| PA                                 | 7%         | 93%        | 326          |
| <b>NCI Average</b>                 | <b>14%</b> | <b>86%</b> | <b>5,727</b> |

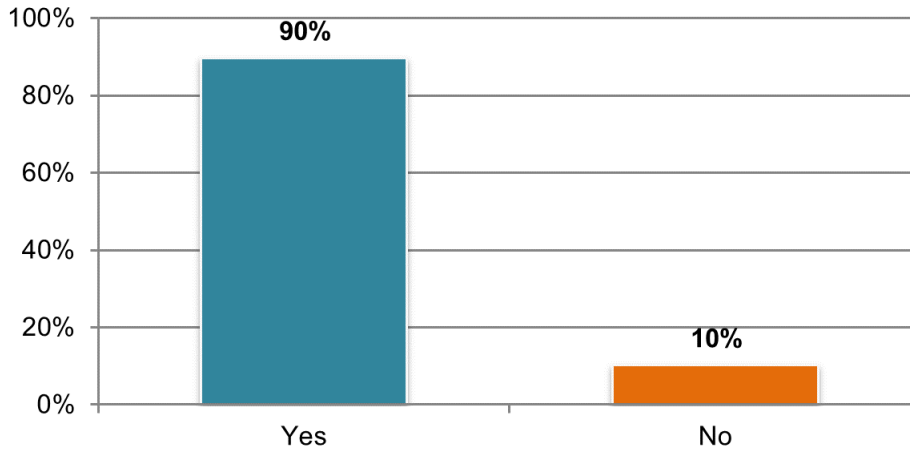
### Family Member Has a Say in How ID/DD Agency Money Is Spent



**Table Q33. Does your family member have a say in how this money is spent?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| UT                                 | 40%        | 60%        | 248          |
| <b>Within Average Range</b>        |            |            |              |
| SC                                 | 37%        | 63%        | 155          |
| FL                                 | 35%        | 65%        | 254          |
| MI                                 | 34%        | 66%        | 323          |
| WA                                 | 32%        | 68%        | 267          |
| PA                                 | 31%        | 69%        | 231          |
| CA                                 | 31%        | 69%        | 1,914        |
| VA                                 | 28%        | 72%        | 243          |
| MD                                 | 28%        | 72%        | 115          |
| NH                                 | 28%        | 72%        | 209          |
| GA                                 | 27%        | 73%        | 205          |
| <b>Significantly Below Average</b> |            |            |              |
| NC                                 | 22%        | 78%        | 129          |
| <b>NCI Average</b>                 | <b>31%</b> | <b>69%</b> | <b>4,293</b> |

### Family Member Has All Information Needed to Decide How to Spend ID/DD Agency Money



**Table Q33a. If your family member has a say in how agency money is spent, does s/he have all the information s/he needs to make decisions about how to spend this money?**

| State                       | Yes        | No         | N            |
|-----------------------------|------------|------------|--------------|
| <b>Within Average Range</b> |            |            |              |
| MD                          | 96%        | 4%         | 26           |
| VA                          | 93%        | 7%         | 58           |
| SC                          | 93%        | 7%         | 43           |
| NC                          | 91%        | 9%         | 22           |
| FL                          | 91%        | 9%         | 75           |
| MI                          | 90%        | 10%        | 97           |
| PA                          | 89%        | 11%        | 55           |
| CA                          | 89%        | 11%        | 462          |
| UT                          | 88%        | 13%        | 72           |
| NH                          | 87%        | 13%        | 39           |
| GA                          | 86%        | 14%        | 44           |
| WA                          | 84%        | 16%        | 77           |
| <b>NCI Average</b>          | <b>90%</b> | <b>10%</b> | <b>1,070</b> |

## Community Connections

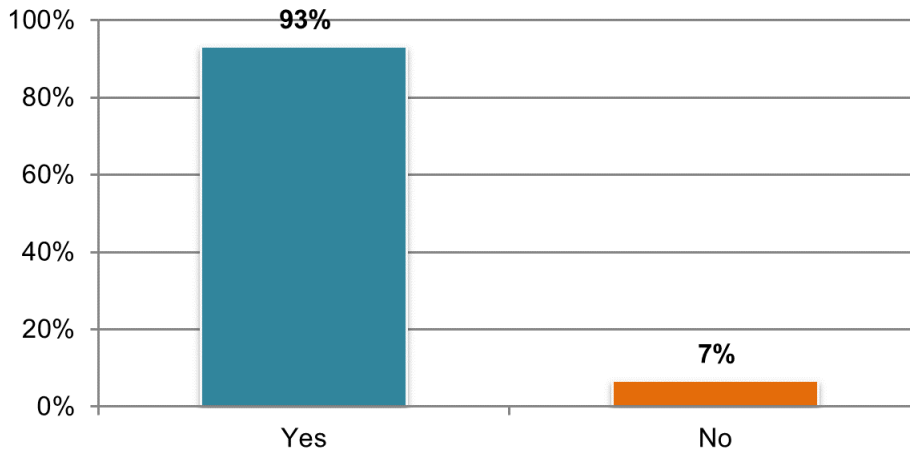
*Family members with disabilities use integrated community services and participate in everyday community activities.*

**Note:** State outcomes with fewer than 20 responses were not reported.

**Note on California significance:** Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (\*\*), an outcome is significant *only* due to the sample size.



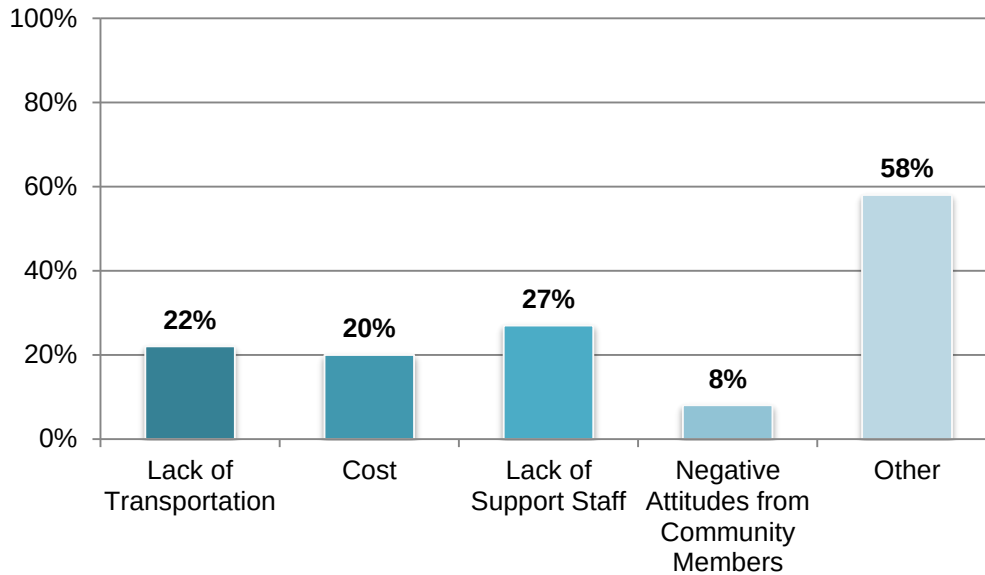
### Family Member Participates in Community Activities



**Table Q34. Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?**

| State                              | Yes        | No        | N            |
|------------------------------------|------------|-----------|--------------|
| <b>Significantly Above Average</b> |            |           |              |
| NC                                 | 97%        | 3%        | 167          |
| NH                                 | 96%        | 4%        | 291          |
| <b>Within Average Range</b>        |            |           |              |
| UT                                 | 95%        | 5%        | 349          |
| SC                                 | 95%        | 5%        | 218          |
| MI                                 | 95%        | 5%        | 439          |
| VA                                 | 94%        | 6%        | 340          |
| GA                                 | 94%        | 6%        | 287          |
| WA                                 | 93%        | 7%        | 378          |
| FL                                 | 92%        | 8%        | 334          |
| PA                                 | 92%        | 8%        | 370          |
| <b>Significantly Below Average</b> |            |           |              |
| CA                                 | 89%        | 11%       | 2,787        |
| MD                                 | 86%        | 14%       | 160          |
| <b>NCI Average</b>                 | <b>93%</b> | <b>7%</b> | <b>6,120</b> |

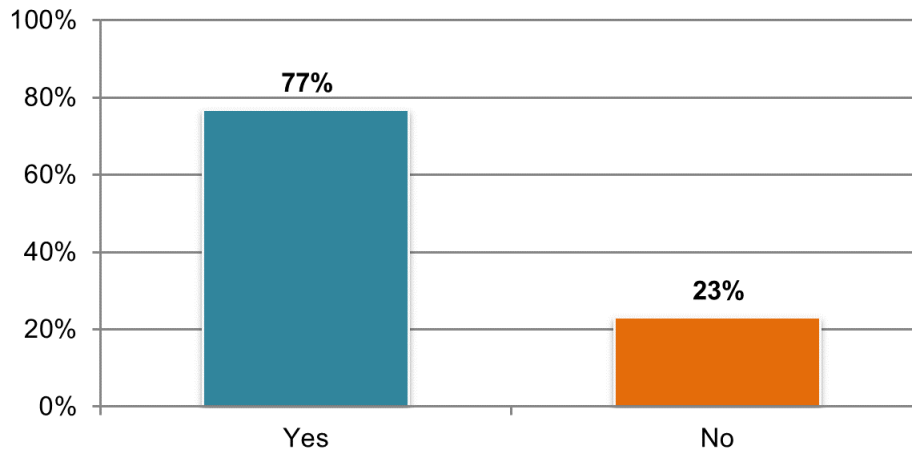
### Reasons Why Family Member Does Not Participate in Community Activities



**Table Q34a. If your family member doesn't participate in community activities, why not?**

| State                       | Lack of Transportation | Cost       | Lack of Support Staff | Negative Attitudes from Community Members | Other      |
|-----------------------------|------------------------|------------|-----------------------|-------------------------------------------|------------|
| <b>Within Average Range</b> |                        |            |                       |                                           |            |
| CA                          | 27%                    | 21%        | 28%                   | 10%                                       | 55%        |
| PA                          | 8%                     | 12%        | 24%                   | 4%                                        | 68%        |
| WA                          | 30%                    | 26%        | 30%                   | 9%                                        | 52%        |
| <b>NCI Average</b>          | <b>22%</b>             | <b>20%</b> | <b>27%</b>            | <b>8%</b>                                 | <b>58%</b> |

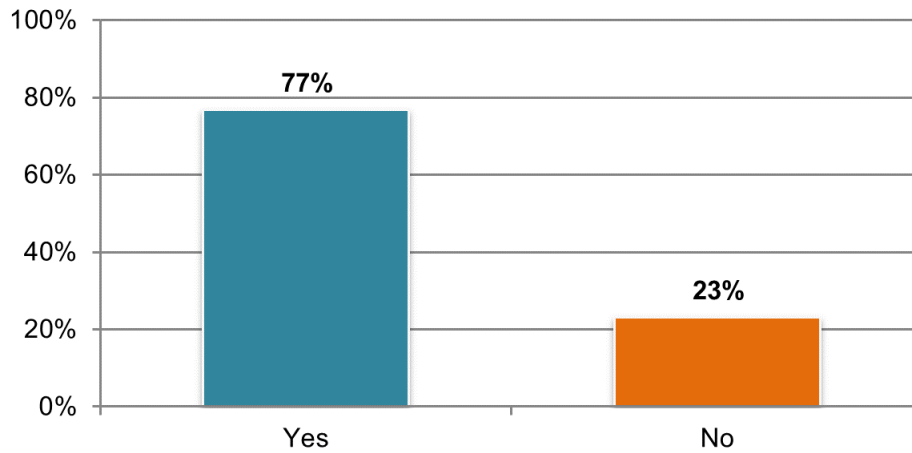
### Family Member Has Friends or Relationships With People Other Than Paid Staff or Family



**Table Q35. Does your family member have friends or relationships with persons other than paid staff or family?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| NH                                 | 85%        | 15%        | 273          |
| WA                                 | 83%        | 17%        | 360          |
| <b>Within Average Range</b>        |            |            |              |
| SC                                 | 80%        | 20%        | 213          |
| NC                                 | 79%        | 21%        | 162          |
| GA                                 | 79%        | 21%        | 269          |
| UT                                 | 78%        | 22%        | 331          |
| PA                                 | 77%        | 23%        | 335          |
| MD                                 | 76%        | 24%        | 148          |
| FL                                 | 75%        | 25%        | 327          |
| <b>Significantly Below Average</b> |            |            |              |
| CA **                              | 74%        | 26%        | 2,690        |
| MI                                 | 68%        | 32%        | 388          |
| VA                                 | 68%        | 32%        | 317          |
| <b>NCI Average</b>                 | <b>77%</b> | <b>23%</b> | <b>5,813</b> |

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



**Table Q36. Does your family member have enough support (support workers, community resources, etc.) to work or volunteer in the community?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| NC                                 | 87%        | 13%        | 126          |
| NH                                 | 84%        | 16%        | 231          |
| <b>Within Average Range</b>        |            |            |              |
| WA                                 | 81%        | 19%        | 303          |
| UT                                 | 79%        | 21%        | 258          |
| VA                                 | 78%        | 22%        | 233          |
| PA                                 | 77%        | 23%        | 254          |
| GA                                 | 76%        | 24%        | 208          |
| CA                                 | 75%        | 25%        | 2,097        |
| MI                                 | 74%        | 26%        | 323          |
| SC                                 | 73%        | 27%        | 164          |
| MD                                 | 72%        | 28%        | 109          |
| <b>Significantly Below Average</b> |            |            |              |
| FL                                 | 69%        | 31%        | 245          |
| <b>NCI Average</b>                 | <b>77%</b> | <b>23%</b> | <b>4,551</b> |

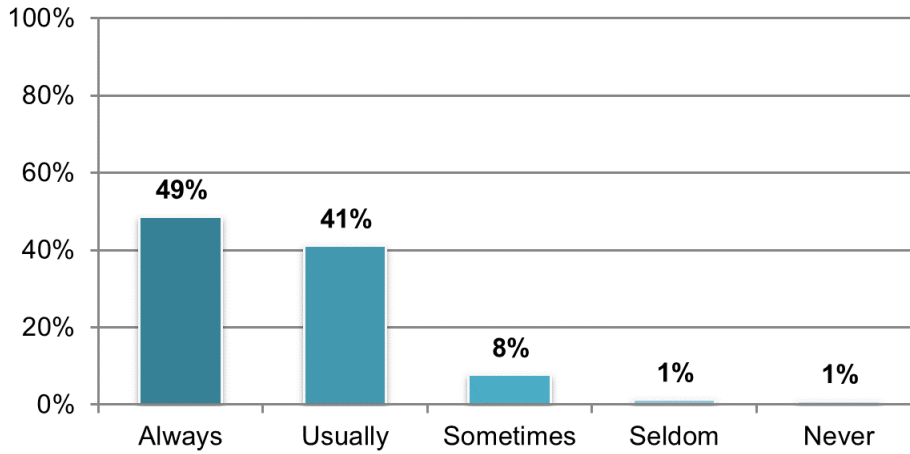
## Satisfaction With Services and Supports

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

**Note:** State outcomes with fewer than 20 responses were not reported.

**Note on California significance:** Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (\*\*), an outcome is significant *only* due to the sample size.

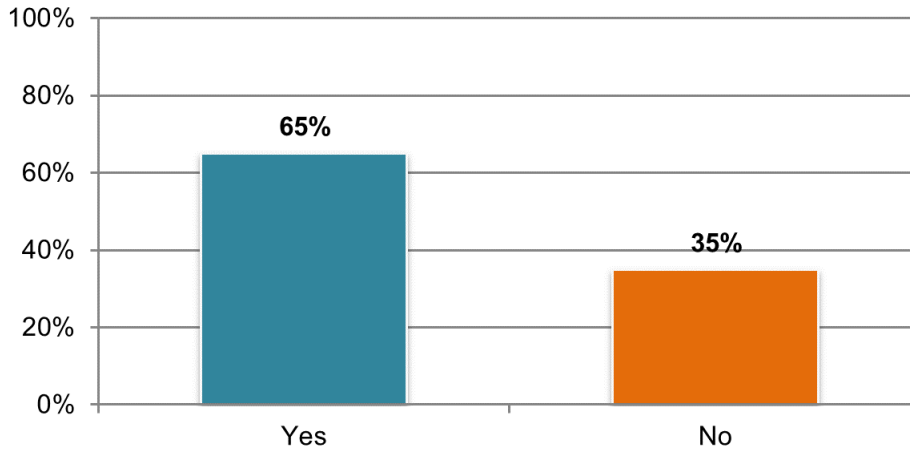
### Respondent Is Overall Satisfied With Services and Supports Family Member Receives



**Table Q37. Overall, are you satisfied with the services and supports your family member currently receives?**

| State                              | Always     | Usually    | Sometimes | Seldom    | Never     | N            |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| <b>Significantly Above Average</b> |            |            |           |           |           |              |
| VA                                 | 60%        | 35%        | 4%        | 1%        | 0%        | 361          |
| <b>Within Average Range</b>        |            |            |           |           |           |              |
| MI                                 | 53%        | 41%        | 5%        | 1%        | 0%        | 435          |
| PA                                 | 52%        | 36%        | 10%       | 1%        | 1%        | 383          |
| WA                                 | 49%        | 44%        | 5%        | 2%        | 0%        | 387          |
| SC                                 | 49%        | 40%        | 10%       | 2%        | 0%        | 239          |
| GA                                 | 48%        | 38%        | 11%       | 1%        | 2%        | 298          |
| CA                                 | 48%        | 39%        | 9%        | 3%        | 2%        | 3,001        |
| NC                                 | 47%        | 45%        | 7%        | 1%        | 1%        | 173          |
| NH                                 | 46%        | 46%        | 5%        | 2%        | 1%        | 299          |
| UT                                 | 45%        | 42%        | 9%        | 2%        | 1%        | 354          |
| FL                                 | 45%        | 44%        | 7%        | 3%        | 1%        | 357          |
| MD                                 | 42%        | 45%        | 12%       | 0%        | 1%        | 158          |
| <b>NCI Average</b>                 | <b>49%</b> | <b>41%</b> | <b>8%</b> | <b>1%</b> | <b>1%</b> | <b>6,445</b> |

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

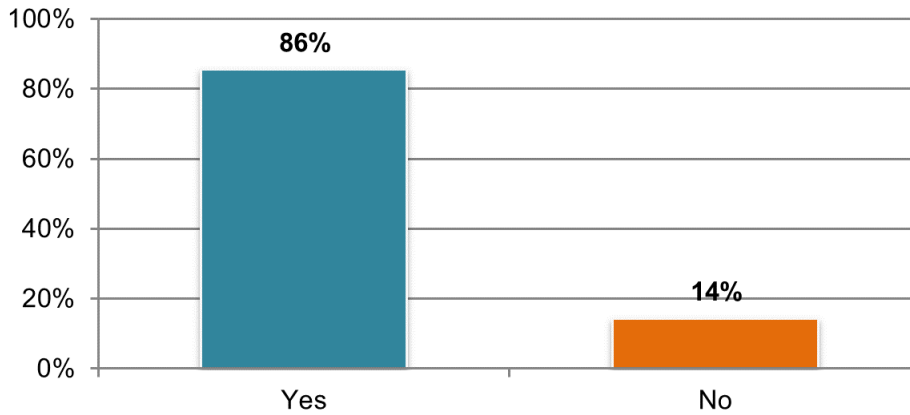


**Table Q38. Do you know the process for filing a complaint or grievance against provider agencies or staff?<sup>4</sup>**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| MI                                 | 83%        | 17%        | 443          |
| FL                                 | 81%        | 19%        | 370          |
| NC                                 | 80%        | 20%        | 171          |
| NH                                 | 76%        | 24%        | 297          |
| WA                                 | 71%        | 29%        | 385          |
| <b>Within Average Range</b>        |            |            |              |
| VA                                 | 66%        | 34%        | 355          |
| UT                                 | 62%        | 38%        | 359          |
| <b>Significantly Below Average</b> |            |            |              |
| PA                                 | 56%        | 44%        | 387          |
| SC                                 | 56%        | 44%        | 239          |
| MD                                 | 51%        | 49%        | 163          |
| CA                                 | 50%        | 50%        | 2,992        |
| GA                                 | 49%        | 51%        | 306          |
| <b>NCI Average</b>                 | <b>65%</b> | <b>35%</b> | <b>6,467</b> |

<sup>4</sup> 'Don't know' responses are included with 'no' responses.

**Respondent Is Satisfied With How Complaints or Grievances Against Provider Agencies or Staff Are Handled and Resolved**

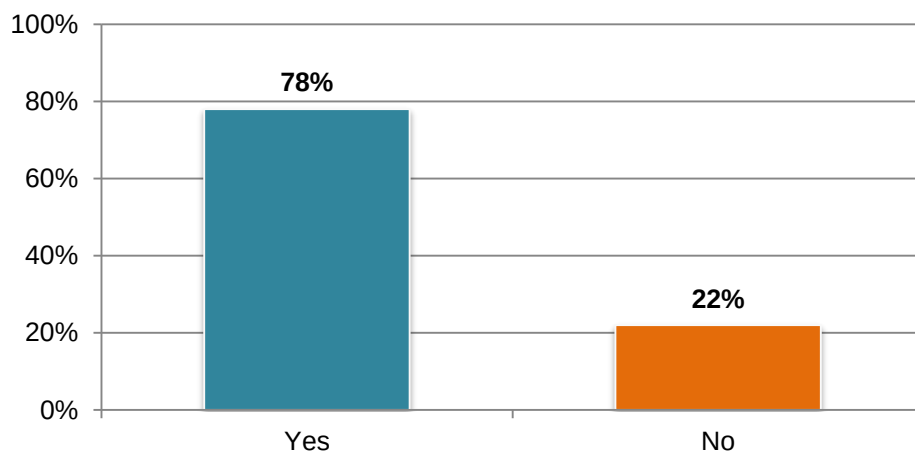


**Table Q39. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?**

| State                       | Yes        | No         | N            |
|-----------------------------|------------|------------|--------------|
| <b>Within Average Range</b> |            |            |              |
| NC                          | 91%        | 9%         | 111          |
| NH                          | 90%        | 10%        | 166          |
| VA                          | 89%        | 11%        | 189          |
| WA                          | 89%        | 11%        | 215          |
| PA                          | 88%        | 12%        | 188          |
| MI                          | 87%        | 13%        | 299          |
| UT                          | 86%        | 14%        | 207          |
| FL                          | 86%        | 14%        | 225          |
| CA **                       | 82%        | 18%        | 1,326        |
| SC                          | 82%        | 18%        | 137          |
| GA                          | 81%        | 19%        | 145          |
| MD                          | 76%        | 24%        | 72           |
| <b>NCI Average</b>          | <b>86%</b> | <b>14%</b> | <b>3,280</b> |



### Respondent Knows How To Report Abuse or Neglect

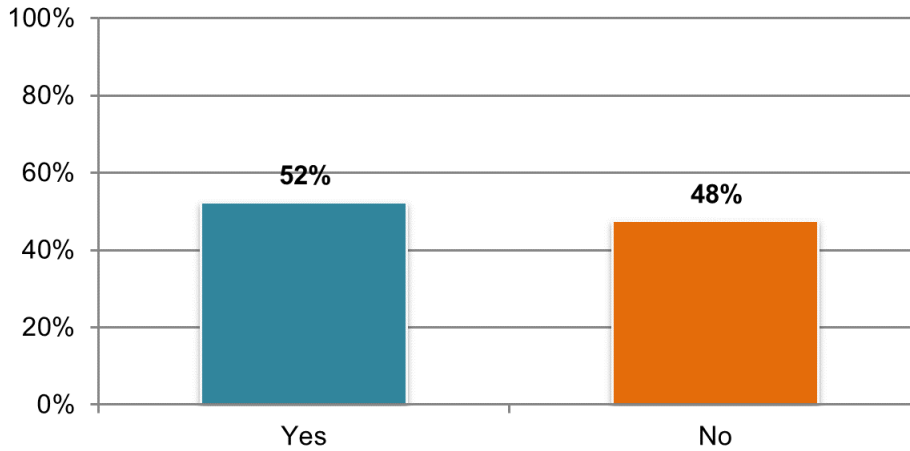


**Table Q40. Do you know how to report abuse or neglect?<sup>5</sup>**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| NC                                 | 89%        | 11%        | 171          |
| FL                                 | 89%        | 11%        | 353          |
| MI                                 | 88%        | 12%        | 425          |
| NH                                 | 86%        | 14%        | 294          |
| WA                                 | 85%        | 15%        | 383          |
| <b>Within Average Range</b>        |            |            |              |
| VA                                 | 77%        | 23%        | 349          |
| UT                                 | 76%        | 24%        | 353          |
| SC                                 | 72%        | 28%        | 236          |
| MD                                 | 71%        | 29%        | 159          |
| <b>Significantly Below Average</b> |            |            |              |
| PA                                 | 72%        | 28%        | 376          |
| CA                                 | 68%        | 32%        | 2,892        |
| GA                                 | 67%        | 33%        | 295          |
| <b>NCI Average</b>                 | <b>78%</b> | <b>22%</b> | <b>6,286</b> |

<sup>5</sup> 'Don't know' responses are included with 'no' responses.

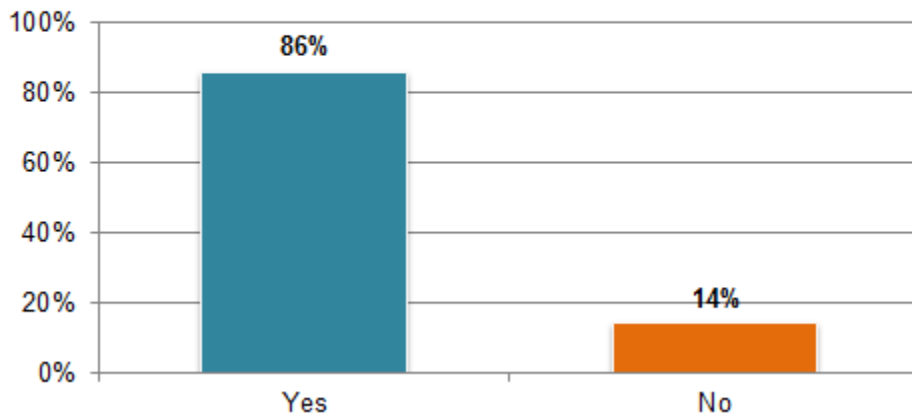
### Respondent Reported Abuse or Neglect If it Occurred in the Past Year



**Table Q41. Within the past year, if abuse or neglect occurred, did you report it?**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| NC                                 | 74%        | 26%        | 31           |
| MI                                 | 68%        | 32%        | 79           |
| <b>Within Average Range</b>        |            |            |              |
| UT                                 | 64%        | 36%        | 83           |
| SC                                 | 62%        | 38%        | 52           |
| GA                                 | 58%        | 42%        | 77           |
| WA                                 | 53%        | 47%        | 51           |
| FL                                 | 52%        | 48%        | 84           |
| MD                                 | 44%        | 56%        | 32           |
| CA **                              | 42%        | 58%        | 518          |
| PA                                 | 41%        | 59%        | 59           |
| NH                                 | 40%        | 60%        | 45           |
| <b>Significantly Below Average</b> |            |            |              |
| VA                                 | 32%        | 68%        | 57           |
| <b>NCI Average</b>                 | <b>52%</b> | <b>48%</b> | <b>1,168</b> |

**Appropriate People Were Responsive to Abuse/Neglect Report if Reported in the Past Year**



**Table Q41a. If you reported abuse or neglect in the past year, were the appropriate people responsive to your report?**

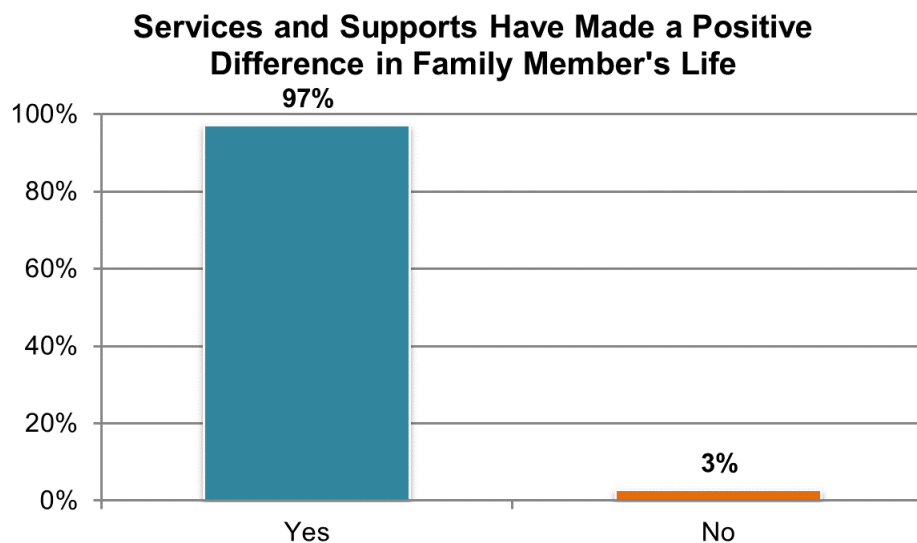
| State                              | Yes        | No         | N          |
|------------------------------------|------------|------------|------------|
| <b>Significantly Above Average</b> |            |            |            |
| MI                                 | 96%        | 4%         | 50         |
| <b>Within Average Range</b>        |            |            |            |
| NC                                 | 95%        | 5%         | 21         |
| FL                                 | 93%        | 7%         | 29         |
| PA                                 | 85%        | 15%        | 20         |
| SC                                 | 85%        | 15%        | 26         |
| WA                                 | 83%        | 17%        | 23         |
| CA                                 | 79%        | 21%        | 172        |
| UT                                 | 78%        | 22%        | 46         |
| GA                                 | 78%        | 23%        | 40         |
| <b>NCI Average</b>                 | <b>86%</b> | <b>14%</b> | <b>427</b> |

## Family Outcomes

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

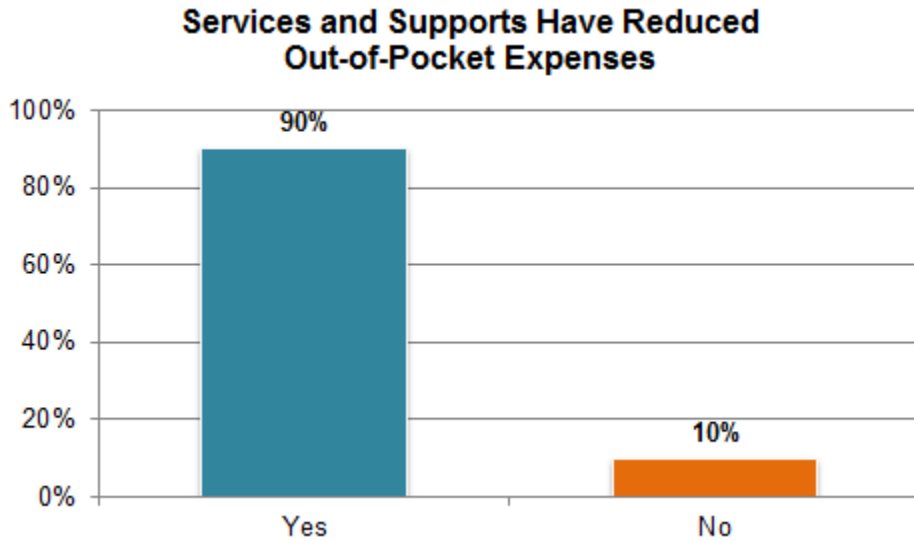
**Note:** State outcomes with fewer than 20 responses were not reported.

**Note on California significance:** Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (\*\*), an outcome is significant *only* due to the sample size.



**Table Q42. Do you feel that services and supports have made a positive difference in the life of your family member?**

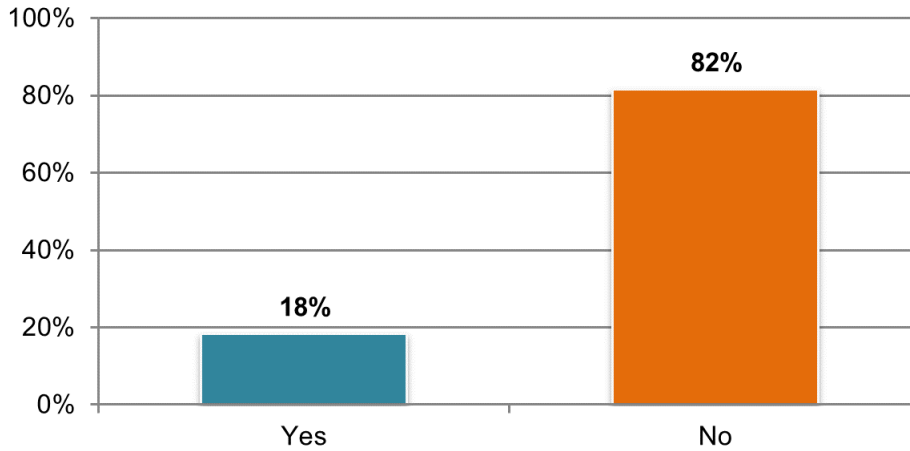
| State                       | Yes        | No        | N            |
|-----------------------------|------------|-----------|--------------|
| <b>Within Average Range</b> |            |           |              |
| NH                          | 98%        | 2%        | 284          |
| NC                          | 98%        | 2%        | 170          |
| MI                          | 98%        | 2%        | 430          |
| WA                          | 98%        | 2%        | 370          |
| UT                          | 98%        | 2%        | 350          |
| VA                          | 98%        | 2%        | 347          |
| FL                          | 97%        | 3%        | 340          |
| PA                          | 97%        | 3%        | 365          |
| SC                          | 96%        | 4%        | 218          |
| MD                          | 96%        | 4%        | 155          |
| GA                          | 96%        | 4%        | 282          |
| CA **                       | 96%        | 4%        | 2,835        |
| <b>NCI Average</b>          | <b>97%</b> | <b>3%</b> | <b>6,146</b> |



**Table Q43. 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> |            |            |              |
| UT                                 | 95%        | 5%         | 294          |
| <b>Within Average Range</b>        |            |            |              |
| WA                                 | 92%        | 8%         | 301          |
| FL                                 | 91%        | 9%         | 293          |
| NC                                 | 91%        | 9%         | 127          |
| GA                                 | 90%        | 10%        | 242          |
| SC                                 | 90%        | 10%        | 192          |
| NH                                 | 90%        | 10%        | 231          |
| CA                                 | 89%        | 11%        | 2,435        |
| VA                                 | 89%        | 11%        | 245          |
| PA                                 | 89%        | 11%        | 290          |
| MD                                 | 88%        | 12%        | 136          |
| MI                                 | 88%        | 12%        | 320          |
| <b>NCI Average</b>                 | <b>90%</b> | <b>10%</b> | <b>5,106</b> |

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

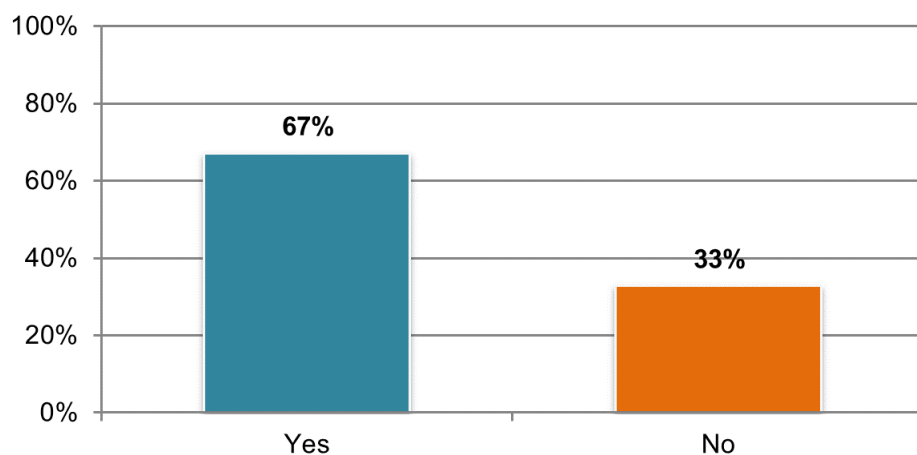


**Table Q44. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?<sup>6</sup>**

| State                              | Yes        | No         | N            |
|------------------------------------|------------|------------|--------------|
| <b>Significantly Above Average</b> |            |            |              |
| FL                                 | 51%        | 49%        | 285          |
| <b>Within Average Range</b>        |            |            |              |
| NC                                 | 23%        | 77%        | 147          |
| CA                                 | 19%        | 81%        | 2,227        |
| WA                                 | 19%        | 81%        | 302          |
| MI                                 | 16%        | 84%        | 364          |
| NH                                 | 15%        | 85%        | 234          |
| GA                                 | 14%        | 86%        | 216          |
| SC                                 | 14%        | 86%        | 160          |
| PA                                 | 14%        | 86%        | 291          |
| MD                                 | 13%        | 87%        | 135          |
| <b>Significantly Below Average</b> |            |            |              |
| VA                                 | 12%        | 88%        | 282          |
| UT                                 | 10%        | 90%        | 280          |
| <b>NCI Average</b>                 | <b>18%</b> | <b>82%</b> | <b>4,923</b> |

<sup>6</sup> The 'yes' response is the less desired response.

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



**Table Q44a. If services or supports received by your family member were reduced, suspended, or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family member negatively?<sup>7</sup>**

| State                              | Yes        | No         | N          |
|------------------------------------|------------|------------|------------|
| <b>Significantly Above Average</b> |            |            |            |
| UT                                 | 87%        | 13%        | 23         |
| FL                                 | 81%        | 19%        | 120        |
| <b>Within Average Range</b>        |            |            |            |
| PA                                 | 80%        | 20%        | 30         |
| GA                                 | 77%        | 23%        | 26         |
| CA **                              | 76%        | 24%        | 335        |
| VA                                 | 69%        | 31%        | 26         |
| MI                                 | 60%        | 40%        | 47         |
| WA                                 | 52%        | 48%        | 48         |
| NC                                 | 48%        | 52%        | 25         |
| NH                                 | 42%        | 58%        | 26         |
| <b>NCI Average</b>                 | <b>67%</b> | <b>33%</b> | <b>706</b> |

<sup>7</sup> The 'yes' response is the less desired response.



## 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. 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

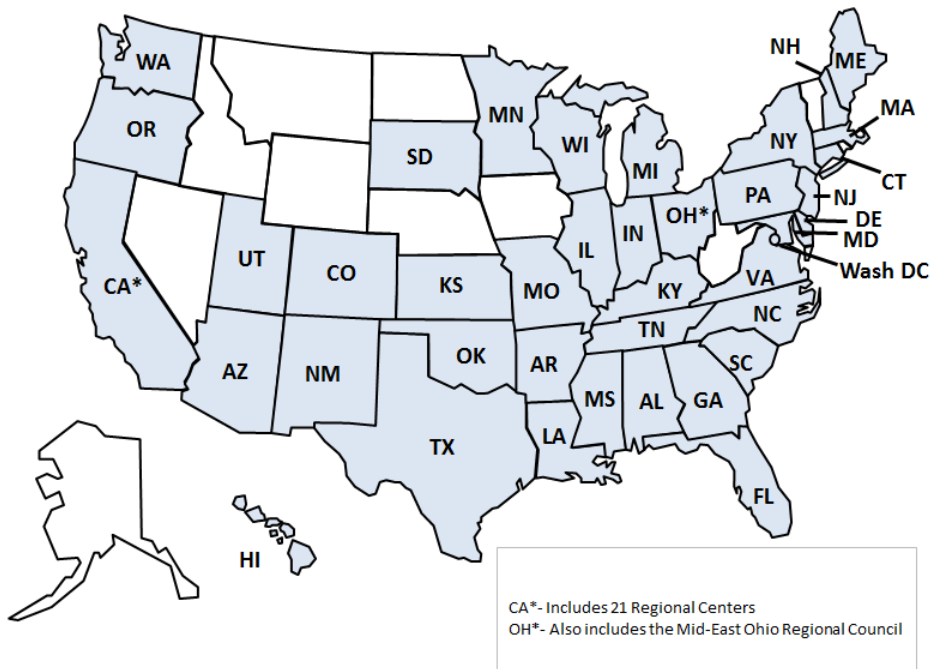
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

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

## State Participation

During the 2013-14 data collection cycle, 39 states, the District of Columbia and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and participating states are highlighted on the map below.

NCI State Participation 2013-14



## Sub-Domains and Concern Statements

The following table lists the sub-domains and concern statements that compose the “Family Outcomes” domain.

## 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 &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>Community Connections</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 waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services. 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 acceptable. States that fall into the “below average” tier on any scale or indicator are not necessarily underperforming; instead, this placement indicates only that the state’s scale score or indicator percentage is significantly lower than the average of all states—where “significantly” means “not due to chance.” The results tables throughout this report display states’ scores relative to one another and show

which states tend to have similar results. Notably, the difference between a “below average” state and the average across the other states may be very small, and it is up to public managers, policy-makers, and other stakeholders to decide whether a state’s result relative to the NCI Average suggests that changes or further investigation are necessary.

Moreover, the NCI Average should not be interpreted as defining “acceptable” levels of performance or satisfaction. Instead, it represents a multi-state “norm” that describes average levels of performance or satisfaction across the participating states. In some instances there are few significant differences among states; this denotes that the majority of states are performing similarly. Instances where several states’ results are especially high (considerably above the average level) may indicate that some states are attaining a level of performance that could serve as a guidepost for others.

Data from previous years are not presented in this report. Comparisons of results from year to year should be made with caution: even slight changes in wording or response options of certain questions may affect comparability of results from one year to the next; the mix of participating states differs slightly each year and may affect the NCI Averages; and states draw new samples each year rather than following the same group of individuals.

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

1. Had an adult individual with a developmental disability NOT living in the family home; and
2. Received at least one direct service or support other than service coordination.

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>8</sup>

## 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, on the following two bases:

1. The respondent indicated the individual with a developmental disability lived inside 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>9</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.

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<sup>8</sup> See "Response Rates" section for information on total surveys mailed and received by states as well as each state's margin of error.

<sup>9</sup> The NCI Average is the sum of all state averages divided by the total number of states.

## Response Rates

During 2013-2014, 12 states administered the Family/Guardian Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The table below shows the number of surveys each state mailed, usable surveys returned, and the response rates.

**Family/Guardian Survey: State Response Rates<sup>10</sup>**

| State              | Surveys Mailed | Usable Surveys Returned | Response Rate |
|--------------------|----------------|-------------------------|---------------|
| CA                 | 16,000         | 3,210                   | 20%           |
| FL                 | 1,699          | 377                     | 22%           |
| GA                 | 1,600          | 331                     | 21%           |
| MD                 | 1,800          | 170                     | 9%            |
| MI                 | 1,500          | 452                     | 30%           |
| NC                 | 1,000          | 178                     | 18%           |
| NH                 | 1,000          | 310                     | 31%           |
| PA                 | 1,096          | 410                     | 37%           |
| SC                 | 1,200          | 245                     | 20%           |
| UT                 | 919            | 367                     | 40%           |
| VA                 | 1,208          | 380                     | 31%           |
| WA                 | 1,250          | 405                     | 32%           |
| <b>NCI Average</b> |                |                         | 26%           |

<sup>10</sup> Some numbers may be approximates.