

Adult Family Survey

2012-13 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

Human Services Research Institute (HSRI)

2336 Massachusetts Avenue
Cambridge, MA 02140



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

113 Oronoco Street
Alexandria, VA 22314

3/25/14

List of Abbreviations Used in This Report

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

Contents

| | |
|--|--------------|
| Executive Summary | 1 |
| Demographics..... | 1 |
| Services and Supports | 2 |
| Information and Planning..... | 2 |
| Access and Delivery of Services and Supports..... | 2 |
| Choice and Control..... | 2 |
| Community Connections | 3 |
| Satisfaction With Services and Supports | 3 |
| Family Outcomes | 3 |
| I. Results | 4 |
| Survey Development | 5 |
| Organization of the Adult Family Survey | 5 |
| Presentation of Data..... | 6 |
| Demographics..... | 8 |
| Family Member | 9 |
| Table 1. Family Member's Age | 11 |
| Table 2. Family Member's Gender | 11 |
| Table 3. Family Member's Race | 12 |
| Table 4. More Than One Person Living in the Home Has ID/DD | 12 |
| Table 5. Family Member's Type of Disability | 13 |
| Table 6. Family Member's Primary Means of Expression | 14 |
| Table 7. Family Member's Primary Language | 14 |
| Table 8. Family Member's Highest Level of Education | 15 |
| Table 9. Family Member's Typical Day Activities | 16 |
| Table 10. Frequency of Medical Care Needed for Family Member | 17 |
| Table 11. Amount of Behavioral Support Needed for Family Member | 17 |
| Table 12. Amount of Help Needed for Family Member's Daily Activities | 18 |

| | |
|---|-----------|
| Respondents..... | 19 |
| Table 13. Respondent's Age | 20 |
| Table 14. Respondent's Health | 20 |
| Table 15. Respondent Is Primary Caregiver | 21 |
| Table 16. Number of Adults in Household (Not Including Family Member Receiving Services) .. | 21 |
| Table 17. Respondent Is Family Member's Legal Guardian or Conservator | 22 |
| Table 18. Respondent's Highest Level of Education | 22 |
| Table 19. Total Taxable Family Income of Wage Earners in the Past Year | 23 |
| Table 20. Out-of-Pocket Expenses for Family in the Past Year..... | 23 |
| Services and Supports Received..... | 24 |
| Table 21. Services and Supports Received From ID/DD Agency | 24 |
| Adult Family Survey Results..... | 25 |
| Information and Planning..... | 26 |
| Table Q1. Do you get enough information to help you participate in planning services for your family? | 27 |
| Table Q2. Is the information you receive easy to understand? | 28 |
| Table Q3. Does the information you receive come from your case manager/service coordinator? .. | 29 |
| Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?..... | 30 |
| Table Q5. Does the case manager/service coordinator tell you about other public services that your family is eligible for (food stamps, Supplemental Security Income [SSI], housing subsidies, etc.)? | 31 |
| Table Q6. Does your family member have a service plan? | 32 |
| Table Q7. Does the plan include all the services and supports your family member wants? | 33 |
| Table Q8. Does your family member receive all of the services listed in the plan? | 34 |
| Table Q9. Did your family member help develop the plan? | 35 |
| Table Q10. Did you or another family member help develop the plan? | 36 |
| Table Q11. Does the plan include all the services and supports your family member needs? | 37 |
| Table Q12. Did you discuss how to handle emergencies related to your family member at the last service planning meeting? | 38 |
| Table Q13. Have you or your family member received information about his/her rights? | 39 |
| Access and Delivery of Services and Supports..... | 40 |
| Table Q14. Are you or your family member able to contact his/her support workers when you need to? | 41 |

| | |
|---|----|
| Table Q15. Are you or your family member able to contact his/her case manager/service coordinator when you need to? | 42 |
| Table Q16. Are services and supports available when your family member needs them? | 43 |
| Table Q17. Are services and supports available within a reasonable distance from your home? | 44 |
| Table Q18. Do the services and supports change when your family member's needs change? | 45 |
| Table Q19. If English is not your primary language, are there support workers or translators who can speak to you in your language? | 46 |
| Table Q20. If English is your primary language, do the support workers speak to you effectively? | 47 |
| Table Q21. 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? | 48 |
| Table Q22. Are services delivered in a way that is respectful to your family's culture? | 49 |
| Table Q23. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)? | 50 |
| Table Q24. Do you feel that your family member's day/employment setting is a healthy and safe environment? | 51 |
| Table Q25. Do the support workers have the right training to meet your family's needs? | 52 |
| Table Q26. Do the support workers who come to your home arrive on time and when scheduled? | 53 |
| Table Q27. If your family member transitioned from school services to state-funded services during the past year, were you happy with the transition process? | 54 |
| Table Q28. If you asked for crisis or emergency services during the past year, were services provided when needed? | 55 |
| Table Q29. Do you have access to health services for your family member? | 56 |
| Table Q29a. If you have access to health services for your family member, are you satisfied with the quality of these providers? | 57 |
| Table Q30. Do you have access to dental services for your family member? | 58 |
| Table Q30a. If you have access to dental services for your family member, are you satisfied with the quality of these providers? | 59 |
| Table Q31. Are you able to get medications needed for your family member? | 60 |
| Table Q31a. If you are able to get needed medications for your family member, are you satisfied with how your family member's medication needs are monitored? | 61 |
| Table Q32. If needed, do you have access to mental health services for your family member? | 62 |
| Table Q32a. If you have access to needed mental health services, are you satisfied with the quality of these providers? | 63 |
| Table Q33. If you need respite services, do you have access to them? | 64 |
| Table Q33a. If you have access to needed respite services, are you satisfied with the quality of these providers? | 65 |

| | |
|--|-----------|
| Table Q34. Are there other services that your family member needs that are not currently offered or available? | 66 |
| Choice and Control..... | 67 |
| Table Q35. Do you choose the provider agencies who work with your family? | 68 |
| Table Q36. Does your family member choose the provider agencies who work with your family? | 69 |
| Table Q37. Can you choose a different provider agency if you want to? | 70 |
| Table Q38. Do you choose the individual support workers who work directly with your family? | 71 |
| Table Q39. Does your family member choose the individual support workers who work directly with your family? | 72 |
| Table Q40. Can you choose different support workers if you want to? | 73 |
| Table Q41. Did you choose your family member's case manager/service coordinator? | 74 |
| Table Q42. Did your family member choose his/her case manager/service coordinator? | 75 |
| Table Q43. Do you have control and/or input over the hiring and management of your family member's support workers? | 76 |
| Table Q44. Does your family member have control and/or input over the hiring and management of his/her support workers? | 77 |
| Table Q45. Do you know how much money is spent by the ID/DD agency on behalf of your family member with a developmental disability? | 78 |
| Table Q46. Does your family member know how much money is spent by the ID/DD agency on his/her behalf? | 79 |
| Table Q47. Do you have a say in how this money is spent? | 80 |
| Table Q47a. If you have a say in how ID/DD agency money is spent, do you have all the information you need to make decisions about how to spend this money? | 81 |
| Table Q48. Does your family member have a say in how this money is spent? | 82 |
| Table Q48a. If your family member has a say in how agency money is spent, does your family member have all the information s/he needs to make decisions about how to spend this money? | 83 |
| Community Connections | 84 |
| Table Q49. Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)? | 85 |
| Table Q49a. If your family member doesn't participate in community activities, why not? | 86 |
| Table Q50. Does your family member have friends or relationships with persons other than paid support workers or family? | 87 |
| Table Q51. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community? | 88 |
| Satisfaction With Services and Supports | 89 |

| | |
|---|------------|
| Table Q52. Overall, are you satisfied with the services and supports your family currently receives? | 90 |
| Table Q53. Do you know the process for filing a complaint or grievance against provider agencies or staff? | 91 |
| Table Q54. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved? | 92 |
| Table Q55. Do you know how to report abuse or neglect? | 93 |
| Table Q56. Within the past year, if abuse or neglect occurred, did you report it? | 94 |
| Table Q56a. If you reported abuse or neglect in the past year, were the appropriate people responsive to your report? | 95 |
| Family Outcomes | 96 |
| Table Q57. Do you feel that services and supports have made a positive difference in the life of your family? | 97 |
| Table Q58. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care? | 98 |
| Table Q59. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated? | 99 |
| Table Q59a. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively? | 100 |
| II. NCI History and Activities..... | 101 |
| Overview of National Core Indicators | 102 |
| State Participation | 103 |
| Chart 1. NCI State Participation 2012-13 | 103 |
| The Core Indicators | 103 |
| Sub-Domains and Concern Statements | 104 |
| Family Survey Sub-Domains and Concern Statements | 104 |
| How NCI Data Are Used | 105 |
| Caution and Limitations | 105 |
| III. Methodology | 107 |

Sampling & Administration..... 108

Data Entry and Analysis 108

Response Rates 109

 Adult Family Survey: State Response Rates 109

Executive Summary

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

The National Core Indicators (NCI) Adult Family Survey is administered to families who have an adult (18 years or older) with a developmental disability who lives in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Adult Family Survey on an annual basis. Of the 34 states and 22 sub-state entities who participated in NCI during the 2012-2013 data collection cycle, thirteen (13) states submitted a valid sample of Adult Family Survey data. This Final Report provides a summary of results based on data submitted by June 30, 2013.

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

Demographics

- The average age of the adult receiving services in the household was 34 years old, and males accounted for a higher percentage than females (56% versus 44%).
- The most frequently indicated disability types were intellectual disability (78%), seizure disorder/neurological problem (28%), and cerebral palsy (20%); disability type categories are not mutually exclusive in the NCI surveys, and respondents can choose as many as apply.
- In terms of level of education achieved, 51% of the individuals receiving services had less than a high school diploma or GED while 44% had graduated high school or earned a GED.
- In terms of daily activities, 13% are involved in paid community employment.

Services and Supports

- Among the services and supports specified in the survey, social security benefits were the most utilized (91%), followed by day/employment supports (59%) and transportation (59%).

Information and Planning

- Engagement in service planning among survey respondents (usually the parent or guardian of the adult receiving services) and the individuals themselves: 92% of respondents report that they helped develop their family member's service plan, and 68% report that their family member helped develop his or her own plan. However, a much lower percentage of respondents consistently receive information about available supports (35% report that they always receive this information) and 34% report that this information is always easy to understand.

Access and Delivery of Services and Supports

- Slightly more than half of all respondents report that they or their family member can always contact support workers (58%) and case managers/service coordinators (56%) when needed, and slightly less than half report that services are always available when needed (43%) and that services are always available reasonably close to home (48%). Just over two-thirds of respondents report that crisis or emergency services were provided if requested in the past year (70%), which may indicate an area with room for improvement.
- Access to and satisfaction with health and mental health services were very high (between 87% and 97%); however, access to dental services and respite services were slightly lower (80% and 78%, respectively).

Choice and Control

- While 81% of respondents always or usually determine the provider agencies and 58% always or usually determine the support workers who work with their family, the family member receiving services is much less likely to be making these determinations (45% and 38%, respectively).

- About one-third of respondents (30%) report that they know how much money the ID/DD agency spends on behalf of their family member, and 11% report that their family member knows how much the ID/DD agency spends on his or her behalf.

Community Connections

- The majority of respondents report that their family member participates in community activities (88%) and that their family member has friends or relationships with people other than paid support workers or family (79%).

Satisfaction With Services and Supports

- A total of 82% of respondents are always or usually satisfied with the services and supports their family receives.

Family Outcomes

- Nearly all respondents report that services and supports have made a positive difference in their family's life (94%). Just over four-fifths indicate that services and supports have reduced the family's out-of-pocket expenses for their family member's care (81%).
- Of the 24% of respondents who report that services or supports were reduced, suspended or terminated in the past year, 70% felt that this change had a negative impact on their family.

I. Results

This section briefly describes the structure of the survey instrument and presents the results of the most recent data collection cycle.

Survey Development

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

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

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

Organization of the Adult Family Survey

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

Demographics

The survey instrument begins with a series of questions 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 Adult Family Survey are presented in this report. Outcome results are presented in six subsections that correspond with the sections of the Adult Family Survey. The beginning of each subsection provides an overall synopsis of findings across states.

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

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, and significantly below the NCI Average. Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI Average Range, their 'always' or 'yes' response was not statistically different from the NCI Average.

States receive an 'n/a' designation for a survey item if fewer than 20 people responded.

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

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

larger the sample size of a state, the smaller the difference needs to be to be statistically significant.

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.

- The average age of the family member receiving services was 34 years old.
- Males make up a higher percentage than females (56% versus 44%).
- Most family members were identified as White (74%) or Black/African American (20%). Among the remainder, 2% were identified as American Indian or Alaska Native; 1% were identified as Asian; 2% were identified as being of two or more races; and 2% were identified as Hispanic.
- 13% of households had more than one person with ID/DD living in the home.
- The most frequently indicated disability types the family members were reported as having were:
 - 72% intellectual disability
 - 28% seizure disorder/neurological problem
 - 20% cerebral palsy
 - 19% autism spectrum disorder
 - 19% another disability not listed
 - 15% Down syndrome
 - 14% mental illness or psychiatric diagnosis
- 75% of family members were reported to communicate verbally, 18% communicate with gestures or body language, 2% use sign language or finger spelling, 1% use a communication aid or device, and 4% use some other form of communication.
- 97% of family members were reported as having English as their primary language.
- The highest level of education for family members was:
 - 51% less than a high school diploma or GED
 - 44% high school diploma or GED
 - 3% completed vocational school
 - 2% had some college experience
 - 1% had a college degree
- The most typical day activities of family members were:
 - 30% unpaid, out-of-home program
 - 20% paid, out-of-home program
 - 17% in-home day supports
 - 14% other, unlisted activities
 - 13% paid community employment
 - 13% at home by choice

- 81% of family members required medical care less frequently than once a month.
- 10% of family members needed extensive behavioral support.
- 27% of family members needed a complete level of help for daily activities.

Table 1. Family Member's Age

| State | Age | N |
|--------------------|-----------|--------------|
| FL | 35 | 376 |
| GA | 37 | 456 |
| KY | 34 | 157 |
| LA | 36 | 384 |
| MD | 33 | 377 |
| MI | 34 | 486 |
| MO | 34 | 396 |
| NC | 34 | 245 |
| OH | 34 | 436 |
| OK | 33 | 388 |
| PA | 34 | 411 |
| SC | 36 | 205 |
| UT | 32 | 643 |
| NCI Average | 34 | 4,960 |

Table 2. Family Member's Gender

| State | Male | Female | N |
|--------------------|------------|------------|--------------|
| FL | 56% | 44% | 381 |
| GA | 55% | 45% | 455 |
| KY | 62% | 38% | 155 |
| LA | 53% | 47% | 387 |
| MD | 56% | 44% | 374 |
| MI | 58% | 42% | 492 |
| MO | 53% | 47% | 396 |
| NC | 58% | 42% | 246 |
| OH | 55% | 45% | 431 |
| OK | 57% | 43% | 388 |
| PA | 53% | 47% | 399 |
| SC | 58% | 42% | 206 |
| UT | 55% | 45% | 644 |
| NCI Average | 56% | 44% | 4,954 |

Table 3. Family Member's Race

| State | American Indian/ Alaska Native | Asian | Black/African American | Hawaiian/ Pacific Islander | White | Other/ Unknown | Two or More Races | Hispanic/ Latino |
|--------------------|-----------------------------------|-----------|------------------------|-------------------------------|------------|-------------------|-------------------|---------------------|
| FL | 2% | 2% | 18% | 0% | 64% | 1% | 3% | 13% |
| GA | 2% | 1% | 43% | 0% | 52% | 1% | 2% | 1% |
| KY | 1% | 1% | 6% | 0% | 92% | 1% | 1% | 1% |
| LA | 2% | 1% | 29% | 0% | 69% | 1% | 2% | 0% |
| MD | 1% | 4% | 27% | 0% | 65% | 1% | 3% | 2% |
| MI | 1% | 1% | 26% | 0% | 71% | 0% | 2% | 2% |
| MO | 2% | 1% | 6% | 0% | 91% | 0% | 1% | 1% |
| NC | 1% | 2% | 30% | 0% | 64% | 0% | 2% | 1% |
| OH | 0% | 1% | 15% | 0% | 83% | 1% | 1% | 1% |
| OK | 11% | 1% | 9% | 0% | 80% | 0% | 6% | 2% |
| PA | 1% | 1% | 4% | 0% | 91% | 0% | 1% | 1% |
| SC | 1% | 0% | 45% | 0% | 51% | 0% | 2% | 1% |
| UT | 2% | 1% | 0% | 0% | 92% | 0% | 3% | 5% |
| NCI Average | 2% | 1% | 20% | 0% | 74% | 0% | 2% | 2% |

Table 4. More Than One Person Living in the Home Has ID/DD

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| FL | 12% | 88% | 374 |
| GA | 16% | 84% | 449 |
| KY | 10% | 90% | 152 |
| LA | 13% | 87% | 380 |
| MD | 11% | 89% | 366 |
| MI | 16% | 84% | 462 |
| MO | 14% | 86% | 394 |
| NC | 15% | 85% | 241 |
| OH | 18% | 82% | 432 |
| OK | 8% | 92% | 384 |
| PA | 13% | 87% | 390 |
| SC | 11% | 89% | 207 |
| UT | 16% | 84% | 639 |
| NCI Average | 13% | 87% | 4,870 |

Table 5. Family Member's Type of Disability

| State | FL | GA | KY | LA | MD | MI | MO | NC | OH | OK | PA | SC | UT | NCI Average |
|---|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-------------|
| Intellectual Disability | 72% | 75% | 80% | 69% | 57% | 66% | 65% | 76% | 60% | 82% | 85% | 67% | 76% | 72% |
| Mental Illness/ Psychiatric Diagnosis | 14% | 14% | 18% | 18% | 16% | 18% | 13% | 16% | 18% | 12% | 0% | 17% | 10% | 14% |
| Autism Spectrum Disorder | 18% | 17% | 19% | 18% | 24% | 25% | 19% | 26% | 20% | 17% | 3% | 13% | 25% | 19% |
| Cerebral Palsy | 26% | 20% | 23% | 23% | 17% | 18% | 19% | 26% | 21% | 28% | 2% | 17% | 21% | 20% |
| Brain Injury | 12% | 10% | 9% | 8% | 9% | 9% | 8% | 8% | 13% | 11% | 0% | 14% | 13% | 10% |
| Seizure Disorder/ Neurological Problem | 33% | 29% | 31% | 31% | 25% | 29% | 22% | 32% | 24% | 38% | 1% | 28% | 35% | 28% |
| Chemical Dependency | 1% | 1% | 2% | 1% | 1% | 1% | 0% | 0% | 1% | 0% | 0% | 1% | 1% | 1% |
| Limited or No Vision | 9% | 10% | 15% | 13% | 8% | 9% | 7% | 9% | 11% | 12% | 0% | 14% | 12% | 10% |
| Severe or Profound Hearing Loss | 4% | 6% | 9% | 6% | 7% | 4% | 2% | 5% | 7% | 8% | 0% | 12% | 6% | 6% |
| Alzheimer's Disease/ Other Dementia | 1% | 2% | 1% | 1% | 3% | 0% | 0% | 0% | 1% | 1% | 0% | 0% | 1% | 1% |
| Down Syndrome | 16% | 15% | 17% | 15% | 17% | 14% | 16% | 12% | 16% | 20% | 6% | 15% | 20% | 15% |
| Prader-Willi Syndrome | 1% | 2% | 1% | 2% | 2% | 0% | 1% | 1% | 0% | 1% | 0% | 0% | 0% | 1% |
| Other | 18% | 17% | 22% | 20% | 20% | 23% | 24% | 19% | 20% | 20% | 2% | 27% | 20% | 19% |
| Don't Know | 2% | 3% | 2% | 1% | 1% | 2% | 2% | 4% | 3% | 1% | 0% | 4% | 1% | 2% |

Table 6. Family Member's Primary Means of Expression

| State | Spoken | Gestures/Body Language | Sign Language/ Finger Spelling | Communication Aid/Device | Other | N |
|--------------------|------------|------------------------|-----------------------------------|-----------------------------|-----------|--------------|
| FL | 72% | 20% | 2% | 1% | 5% | 350 |
| GA | 78% | 16% | 1% | 0% | 5% | 445 |
| KY | 73% | 20% | 2% | 1% | 4% | 154 |
| LA | 71% | 20% | 1% | 2% | 7% | 382 |
| MD | 80% | 14% | 2% | 0% | 4% | 358 |
| MI | 79% | 14% | 1% | 1% | 5% | 434 |
| MO | 81% | 14% | 2% | 1% | 3% | 394 |
| NC | 73% | 20% | 2% | 2% | 3% | 244 |
| OH | 77% | 15% | 3% | 2% | 4% | 436 |
| OK | 68% | 25% | 2% | 2% | 3% | 387 |
| PA | 78% | 16% | 1% | 1% | 4% | 392 |
| SC | 74% | 16% | 2% | 1% | 6% | 203 |
| UT | 67% | 25% | 1% | 2% | 5% | 642 |
| NCI Average | 75% | 18% | 2% | 1% | 4% | 4,821 |

Table 7. Family Member's Primary Language

| State | English | Spanish | Other | N |
|--------------------|------------|-----------|-----------|--------------|
| FL | 91% | 5% | 4% | 366 |
| GA | 97% | 1% | 2% | 448 |
| KY | 99% | 0% | 1% | 152 |
| LA | 98% | 0% | 2% | 382 |
| MD | 96% | 0% | 3% | 365 |
| MI | 97% | 1% | 2% | 479 |
| MO | 99% | 0% | 1% | 391 |
| NC | 98% | 0% | 2% | 244 |
| OH | 97% | 0% | 3% | 435 |
| OK | 97% | 1% | 2% | 386 |
| PA | 98% | 0% | 2% | 401 |
| SC | 95% | 0% | 5% | 202 |
| UT | 95% | 1% | 4% | 630 |
| NCI Average | 97% | 1% | 3% | 4,881 |

Table 8. Family Member's Highest Level of Education

| State | Does Not Have High School Diploma/GED | High School Diploma/GED | Vocational School | Some College | College Degree | N |
|--------------------|---|----------------------------|----------------------|-----------------|-------------------|--------------|
| FL | 56% | 40% | 2% | 2% | 1% | 355 |
| GA | 47% | 52% | 1% | 0% | 0% | 420 |
| KY | 55% | 42% | 2% | 1% | 0% | 98 |
| LA | 69% | 27% | 3% | 1% | 1% | 363 |
| MD | 59% | 34% | 2% | 4% | 1% | 351 |
| MI | 57% | 32% | 9% | 1% | 1% | 445 |
| MO | 33% | 59% | 3% | 4% | 1% | 385 |
| NC | 60% | 31% | 5% | 3% | 1% | 237 |
| OH | 37% | 59% | 3% | 1% | 0% | 435 |
| OK | 24% | 73% | 1% | 1% | 0% | 376 |
| PA | 37% | 60% | 3% | 0% | 0% | 379 |
| SC | 62% | 34% | 1% | 2% | 1% | 189 |
| UT | 63% | 33% | 3% | 1% | 0% | 601 |
| NCI Average | 51% | 44% | 3% | 2% | 1% | 4,634 |

Table 9. Family Member's Typical Day Activities

| State | Out-of-Home Program (Unpaid) | Out-of-Home Program (Paid) | Vocational Training | Community Employment (Unpaid) | Community Employment (Paid) | In-Home Day Supports | At Home by Choice | At Home, No Services | At Home, Other | Other |
|--------------------|------------------------------|----------------------------|---------------------|-------------------------------|-----------------------------|----------------------|-------------------|----------------------|----------------|------------|
| FL | 35% | 13% | 5% | 4% | 7% | 20% | 13% | 8% | 12% | 22% |
| GA | 54% | 14% | 3% | 3% | 11% | 15% | 7% | 6% | 7% | 9% |
| KY | 37% | 22% | 6% | 5% | 17% | 17% | 13% | 5% | 6% | 20% |
| LA | 25% | 15% | 2% | 3% | 7% | 34% | 16% | 5% | 9% | 13% |
| MD | 41% | 20% | 6% | 9% | 24% | 5% | 5% | 5% | 6% | 13% |
| MI | 31% | 16% | 15% | 7% | 14% | 9% | 14% | 8% | 11% | 16% |
| MO | 24% | 12% | 3% | 4% | 12% | 15% | 22% | 11% | 9% | 15% |
| NC | 30% | 9% | 14% | 9% | 10% | 32% | 17% | 10% | 8% | 15% |
| OH | 17% | 44% | 8% | 3% | 19% | 3% | 7% | 1% | 3% | 13% |
| OK | 12% | 16% | 8% | 4% | 16% | 31% | 21% | 6% | 9% | 13% |
| PA | 30% | 13% | 9% | 5% | 13% | 5% | 8% | 2% | 4% | 11% |
| SC | 38% | 17% | 3% | 3% | 3% | 12% | 15% | 11% | 11% | 13% |
| UT | 16% | 46% | 5% | 5% | 13% | 17% | 15% | 5% | 8% | 15% |
| NCI Average | 30% | 20% | 7% | 5% | 13% | 17% | 13% | 6% | 8% | 14% |

Table 10. Frequency of Medical Care Needed for Family Member

| State | Less Frequently Than Once a Month | At Least Once a Month, Not Once a Week | At Least Once a Week | N |
|--------------------|-----------------------------------|--|----------------------|--------------|
| FL | 77% | 18% | 6% | 358 |
| GA | 78% | 18% | 4% | 442 |
| KY | 85% | 11% | 4% | 151 |
| LA | 79% | 15% | 6% | 380 |
| MD | 83% | 13% | 4% | 356 |
| MI | 78% | 17% | 5% | 477 |
| MO | 80% | 14% | 6% | 394 |
| NC | 77% | 19% | 3% | 237 |
| OH | 80% | 16% | 5% | 436 |
| OK | 80% | 16% | 4% | 382 |
| PA | 87% | 9% | 4% | 383 |
| SC | 80% | 13% | 7% | 197 |
| UT | 84% | 13% | 3% | 638 |
| NCI Average | 81% | 15% | 5% | 4,831 |

Table 11. Amount of Behavioral Support Needed for Family Member

| State | None | Some | Extensive | N |
|--------------------|------------|------------|------------|--------------|
| FL | 56% | 33% | 11% | 377 |
| GA | 58% | 31% | 11% | 450 |
| KY | 61% | 31% | 8% | 154 |
| LA | 50% | 34% | 16% | 379 |
| MD | 71% | 21% | 8% | 366 |
| MI | 58% | 32% | 10% | 486 |
| MO | 68% | 24% | 8% | 394 |
| NC | 52% | 38% | 10% | 242 |
| OH | 72% | 21% | 7% | 436 |
| OK | 63% | 29% | 8% | 381 |
| PA | 70% | 25% | 5% | 405 |
| SC | 56% | 31% | 14% | 203 |
| UT | 56% | 32% | 12% | 632 |
| NCI Average | 61% | 29% | 10% | 4,905 |

Table 12. Amount of Help Needed for Family Member's Daily Activities

| State | None | Little | Moderate | Complete | N |
|--------------------|------------|------------|------------|------------|--------------|
| FL | 19% | 21% | 29% | 31% | 377 |
| GA | 27% | 22% | 26% | 25% | 459 |
| KY | 23% | 21% | 34% | 22% | 157 |
| LA | 15% | 14% | 32% | 39% | 392 |
| MD | 35% | 26% | 20% | 19% | 371 |
| MI | 18% | 21% | 33% | 28% | 492 |
| MO | 29% | 24% | 27% | 21% | 395 |
| NC | 24% | 19% | 27% | 30% | 246 |
| OH | 35% | 23% | 18% | 24% | 436 |
| OK | 15% | 24% | 27% | 34% | 390 |
| PA | 34% | 24% | 19% | 23% | 408 |
| SC | 21% | 24% | 28% | 27% | 207 |
| UT | 15% | 21% | 30% | 34% | 644 |
| NCI Average | 24% | 22% | 27% | 27% | 4,974 |

Respondents

This section provides demographic information about the respondent.

- 5% of respondents were under age 35; 30% were aged 35-54; 56% were 55-74; and 10% were 75 or older.
- 15% of respondents indicated they were in excellent health, 54% had good health, 27% had fair health, and 4% indicated poor health.
- 96% of respondents were the family member's primary caregiver.
- 29% of households had one adult living there (not including the family member receiving services); 50% had two adults, 16% had three adults, and 5% had four or more adults in the home.
- 59% of respondents had full guardianship/conservatorship of the family member and 7% had limited guardianship/conservatorship.
- Respondent's highest level of education was:
 - 11% less than a high school diploma or GED
 - 32% high school diploma or GED
 - 5% had gone to vocational school
 - 23% had some college
 - 29% had a college degree
- Total taxable family income for the past year was:
 - 25% below \$15,000
 - 19% between \$15,001-\$25,000
 - 25% between \$25,001-\$50,000
 - 16% between \$50,001-\$75,000
 - 14% over \$75,000
- Out-of-pocket expenses for the family member in the past year were:
 - 21% spent \$0
 - 16% spent between \$1-\$100
 - 36% spent between \$101-\$1,000
 - 24% spent between \$1,001-\$10,000
 - 2% spent over \$10,000

Table 13. Respondent's Age

| State | Under 35 | 35-54 | 55-74 | 75 or Older | N |
|--------------------|-----------|------------|------------|-------------|--------------|
| FL | 4% | 34% | 51% | 11% | 376 |
| GA | 7% | 28% | 56% | 9% | 457 |
| KY | 4% | 36% | 50% | 10% | 157 |
| LA | 3% | 28% | 57% | 13% | 389 |
| MD | 5% | 27% | 60% | 8% | 361 |
| MI | 6% | 30% | 56% | 8% | 492 |
| MO | 3% | 36% | 51% | 9% | 395 |
| NC | 5% | 28% | 58% | 9% | 245 |
| OH | 1% | 31% | 57% | 10% | 435 |
| OK | 4% | 25% | 61% | 9% | 386 |
| PA | 6% | 29% | 57% | 8% | 407 |
| SC | 8% | 28% | 57% | 8% | 207 |
| UT | 4% | 33% | 52% | 11% | 643 |
| NCI Average | 5% | 30% | 56% | 10% | 4,950 |

Table 14. Respondent's Health

| State | Excellent | Good | Fair | Poor | N |
|--------------------|------------|------------|------------|-----------|--------------|
| FL | 15% | 50% | 29% | 6% | 373 |
| GA | 13% | 52% | 30% | 5% | 453 |
| KY | 12% | 50% | 34% | 4% | 156 |
| LA | 9% | 48% | 35% | 8% | 388 |
| MD | 17% | 56% | 24% | 3% | 369 |
| MI | 15% | 57% | 25% | 2% | 487 |
| MO | 14% | 57% | 23% | 6% | 392 |
| NC | 13% | 55% | 30% | 2% | 246 |
| OH | 24% | 48% | 23% | 5% | 436 |
| OK | 16% | 60% | 20% | 4% | 381 |
| PA | 17% | 56% | 25% | 2% | 404 |
| SC | 10% | 53% | 32% | 5% | 206 |
| UT | 20% | 54% | 22% | 3% | 642 |
| NCI Average | 15% | 54% | 27% | 4% | 4,933 |

Table 15. Respondent Is Primary Caregiver

| State | Yes | No | N |
|--------------------|------------|-----------|--------------|
| FL | 97% | 3% | 375 |
| GA | 96% | 4% | 453 |
| KY | 98% | 2% | 157 |
| LA | 91% | 9% | 386 |
| MD | 96% | 4% | 371 |
| MI | 97% | 3% | 490 |
| MO | 95% | 5% | 395 |
| NC | 96% | 4% | 245 |
| OH | 98% | 2% | 435 |
| OK | 96% | 4% | 384 |
| PA | 95% | 5% | 404 |
| SC | 95% | 5% | 208 |
| UT | 97% | 3% | 637 |
| NCI Average | 96% | 4% | 4,940 |

Table 16. Number of Adults in Household (Not Including Family Member Receiving Services)

| State | One | Two | Three | Four or More | N |
|--------------------|------------|------------|------------|--------------|--------------|
| FL | 34% | 46% | 15% | 5% | 372 |
| GA | 31% | 47% | 16% | 6% | 437 |
| KY | 32% | 46% | 18% | 4% | 156 |
| LA | 32% | 52% | 13% | 3% | 383 |
| MD | 22% | 52% | 19% | 7% | 372 |
| MI | 27% | 48% | 18% | 7% | 482 |
| MO | 29% | 50% | 15% | 6% | 394 |
| NC | 32% | 50% | 14% | 4% | 244 |
| OH | 28% | 49% | 17% | 6% | 436 |
| OK | 33% | 53% | 9% | 4% | 378 |
| PA | 27% | 52% | 15% | 6% | 401 |
| SC | 31% | 48% | 15% | 6% | 205 |
| UT | 20% | 54% | 19% | 7% | 642 |
| NCI Average | 29% | 50% | 16% | 5% | 4,902 |

Table 17. Respondent Is Family Member's Legal Guardian or Conservator

| State | Yes, Full Guardianship/Conservatorship | Yes, Limited Guardianship/Conservatorship | No | N |
|--------------------|--|---|------------|--------------|
| FL | 47% | 9% | 43% | 357 |
| GA | 53% | 4% | 44% | 440 |
| KY | 83% | 6% | 11% | 156 |
| LA | 65% | 5% | 30% | 369 |
| MD | 42% | 4% | 54% | 361 |
| MI | 58% | 16% | 26% | 491 |
| MO | 62% | 4% | 35% | 393 |
| NC | 66% | 9% | 24% | 244 |
| OH | 60% | 3% | 37% | 436 |
| OK | 68% | 5% | 26% | 382 |
| PA | 51% | 5% | 44% | 374 |
| SC | 58% | 9% | 33% | 199 |
| UT | 60% | 8% | 32% | 625 |
| NCI Average | 59% | 7% | 34% | 4,827 |

Table 18. Respondent's Highest Level of Education

| State | Does Not Have High School Diploma/GED | High School Diploma/GED | Vocational School | Some College | College Degree | N |
|--------------------|---------------------------------------|-------------------------|-------------------|--------------|----------------|--------------|
| FL | 11% | 28% | 7% | 24% | 30% | 374 |
| GA | 18% | 38% | 4% | 18% | 22% | 448 |
| KY | 9% | 27% | 4% | 22% | 38% | 156 |
| LA | 15% | 35% | 8% | 21% | 21% | 385 |
| MD | 6% | 25% | 4% | 25% | 39% | 370 |
| MI | 9% | 29% | 3% | 29% | 29% | 483 |
| MO | 9% | 39% | 5% | 26% | 21% | 395 |
| NC | 12% | 31% | 3% | 20% | 33% | 245 |
| OH | 7% | 39% | 3% | 21% | 30% | 436 |
| OK | 7% | 30% | 4% | 28% | 30% | 385 |
| PA | 12% | 49% | 6% | 12% | 22% | 392 |
| SC | 22% | 28% | 4% | 18% | 27% | 205 |
| UT | 6% | 21% | 7% | 29% | 37% | 638 |
| NCI Average | 11% | 32% | 5% | 23% | 29% | 4,912 |

Table 19. Total Taxable Family Income of Wage Earners in the Past Year

| State | Below \$15,000 | \$15,001-\$25,000 | \$25,001-\$50,000 | \$50,001-\$75,000 | Over \$75,000 | N |
|--------------------|----------------|-------------------|-------------------|-------------------|---------------|--------------|
| FL | 27% | 23% | 26% | 13% | 11% | 341 |
| GA | 35% | 21% | 22% | 15% | 7% | 403 |
| KY | 18% | 18% | 28% | 21% | 15% | 141 |
| LA | 31% | 22% | 23% | 11% | 13% | 341 |
| MD | 15% | 11% | 23% | 17% | 33% | 329 |
| MI | 24% | 24% | 28% | 14% | 10% | 451 |
| MO | 28% | 22% | 27% | 16% | 7% | 334 |
| NC | 25% | 19% | 27% | 16% | 13% | 219 |
| OH | 21% | 22% | 26% | 14% | 18% | 435 |
| OK | 23% | 15% | 29% | 18% | 15% | 331 |
| PA | 23% | 19% | 28% | 16% | 15% | 329 |
| SC | 39% | 22% | 18% | 12% | 9% | 181 |
| UT | 16% | 14% | 26% | 23% | 20% | 581 |
| NCI Average | 25% | 19% | 25% | 16% | 14% | 4,416 |

Table 20. 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 |
|--------------------|------------|------------|----------------|-------------------|---------------|--------------|
| FL | 22% | 11% | 33% | 31% | 3% | 353 |
| GA | 24% | 18% | 36% | 21% | 2% | 425 |
| KY | 19% | 20% | 43% | 17% | 1% | 150 |
| LA | 18% | 12% | 36% | 30% | 4% | 374 |
| MD | 20% | 9% | 37% | 32% | 2% | 357 |
| MI | 23% | 16% | 37% | 23% | 1% | 479 |
| MO | 22% | 16% | 41% | 19% | 1% | 365 |
| NC | 18% | 16% | 36% | 26% | 3% | 233 |
| OH | 35% | 17% | 30% | 17% | 2% | 436 |
| OK | 18% | 15% | 37% | 27% | 4% | 372 |
| PA | 25% | 21% | 33% | 20% | 1% | 354 |
| SC | 20% | 17% | 37% | 24% | 2% | 189 |
| UT | 14% | 15% | 40% | 28% | 3% | 615 |
| NCI Average | 21% | 16% | 36% | 24% | 2% | 4,702 |

Services and Supports Received

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

The majority of respondents indicate that their family member receives day or employment supports (59%) and transportation (59%), 41% receive in-home support, and 27% receive out-of-home respite care.

Table 21. Services and Supports Received From ID/DD Agency

| State | Financial Support | In-Home Support | Out-of-Home Respite Care | Day/ Employment Supports | Transportation | Other Services/ Supports | Social Security Benefits |
|--------------------|-------------------|-----------------|--------------------------|--------------------------|----------------|--------------------------|--------------------------|
| FL | 12% | 50% | 29% | 52% | 55% | 29% | 90% |
| GA | 12% | 28% | 16% | 68% | 70% | 13% | 94% |
| KY | 13% | 48% | 61% | 62% | 57% | 30% | 97% |
| LA | 10% | 68% | 28% | 46% | 53% | 14% | 92% |
| MD | 9% | 19% | 16% | 81% | 75% | 15% | 86% |
| MI | 13% | 35% | 30% | 62% | 63% | 31% | 92% |
| MO | 18% | 31% | 16% | 45% | 49% | 14% | 89% |
| NC | 8% | 51% | 32% | 50% | 45% | 16% | 92% |
| OH | 17% | 27% | 20% | 70% | 74% | 27% | 89% |
| OK | 16% | 58% | 14% | 46% | 49% | 27% | 92% |
| PA | 12% | 29% | 25% | 61% | 55% | 19% | 89% |
| SC | 8% | 31% | 19% | 62% | 62% | 16% | 86% |
| UT | 11% | 52% | 46% | 65% | 62% | 20% | 92% |
| NCI Average | 12% | 41% | 27% | 59% | 59% | 21% | 91% |

Adult Family Survey Results

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.

Information and Planning

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

Just over one-third of respondents report that they always receive enough information to help plan their family member's services (35%), and 34% report that this information is always easy to understand. The vast majority of respondents report that they took part in planning their family member's services (92%) and just over two-thirds report that their family member did the same (68%). Almost four-fifths indicate that the service plan meets their family member's needs (79%) and nearly nine out of ten report that their family member receives all the services listed in their plan (87%).

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Gets Enough Information to Help Plan Services

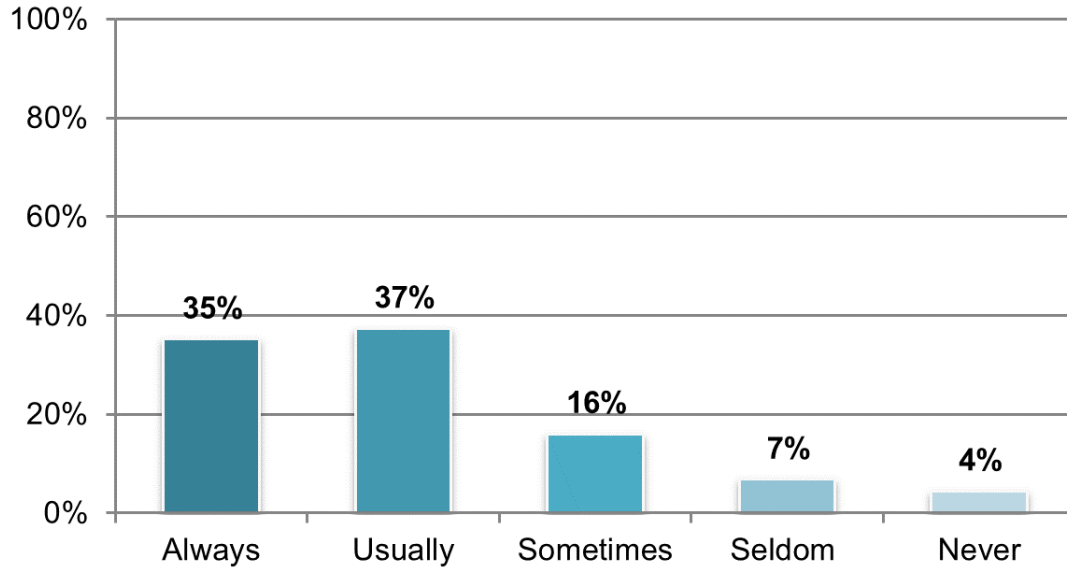


Table Q1. Do you get enough information to help you participate in planning services for your family?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 45% | 28% | 17% | 5% | 6% | 429 |
| Within Average Range | | | | | | |
| MO | 40% | 33% | 15% | 8% | 4% | 376 |
| KY | 39% | 38% | 13% | 5% | 5% | 152 |
| FL | 38% | 36% | 18% | 6% | 2% | 371 |
| OK | 38% | 42% | 13% | 5% | 2% | 371 |
| UT | 36% | 43% | 14% | 4% | 2% | 610 |
| LA | 35% | 44% | 13% | 5% | 3% | 371 |
| PA | 35% | 39% | 16% | 8% | 2% | 371 |
| SC | 34% | 34% | 17% | 7% | 8% | 191 |
| MI | 32% | 40% | 18% | 7% | 3% | 462 |
| GA | 32% | 34% | 18% | 9% | 7% | 415 |
| NC | 30% | 39% | 17% | 7% | 8% | 230 |
| Significantly Below Average | | | | | | |
| MD | 24% | 38% | 21% | 12% | 5% | 349 |
| NCI Average | 35% | 37% | 16% | 7% | 4% | 4,698 |

Information About Services and Supports Is Easy to Understand

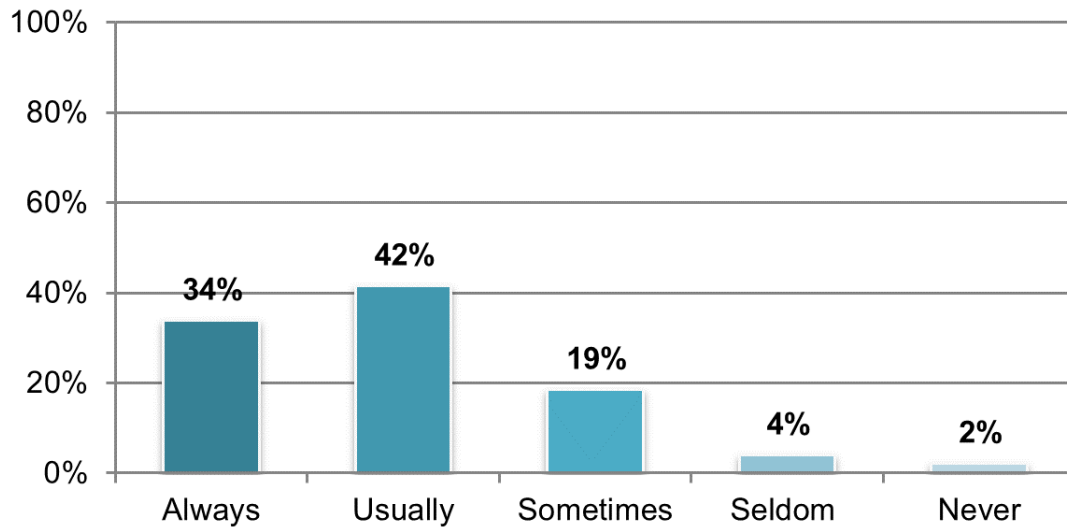


Table Q2. Is the information you receive easy to understand?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 48% | 33% | 15% | 4% | 1% | 421 |
| Within Average Range | | | | | | |
| MO | 39% | 37% | 18% | 4% | 2% | 371 |
| SC | 38% | 38% | 19% | 2% | 3% | 185 |
| FL | 37% | 35% | 23% | 5% | 1% | 366 |
| LA | 35% | 43% | 17% | 2% | 3% | 364 |
| KY | 34% | 42% | 17% | 6% | 1% | 149 |
| OK | 33% | 42% | 19% | 3% | 2% | 375 |
| MI | 33% | 44% | 18% | 4% | 2% | 455 |
| GA | 31% | 40% | 20% | 5% | 5% | 409 |
| PA | 30% | 45% | 19% | 4% | 2% | 373 |
| MD | 28% | 44% | 21% | 6% | 2% | 345 |
| NC | 26% | 46% | 20% | 4% | 4% | 220 |
| Significantly Below Average | | | | | | |
| UT | 28% | 51% | 16% | 4% | 1% | 608 |
| NCI Average | 34% | 42% | 19% | 4% | 2% | 4,641 |

Information About Services and Supports Comes From Case Manager/Service Coordinator

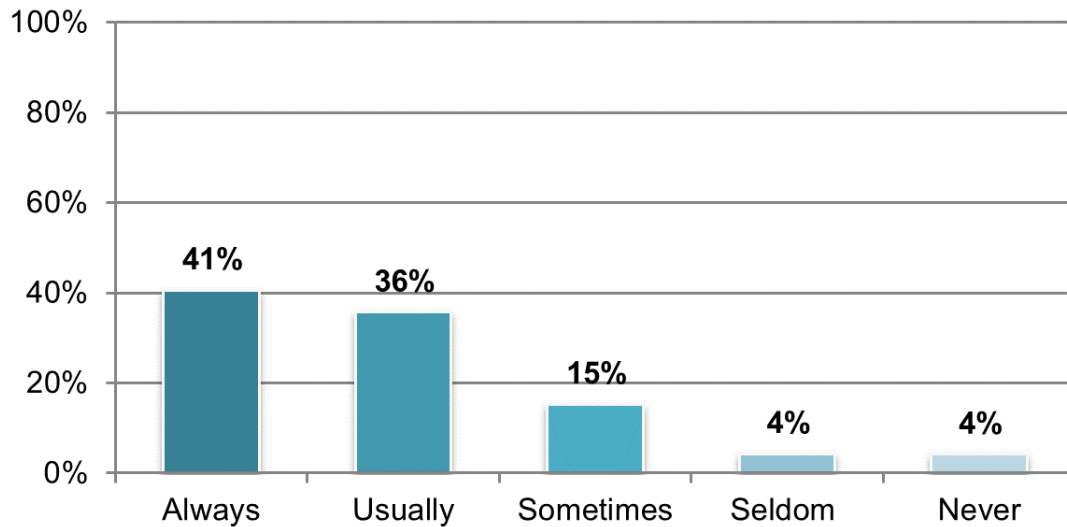


Table Q3. Does the information you receive come from your case manager/service coordinator?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| FL | 49% | 33% | 11% | 3% | 2% | 374 |
| MO | 48% | 31% | 14% | 3% | 4% | 375 |
| Within Average Range | | | | | | |
| SC | 51% | 30% | 12% | 3% | 4% | 182 |
| LA | 44% | 39% | 11% | 4% | 2% | 363 |
| OH | 43% | 30% | 16% | 3% | 7% | 405 |
| UT | 43% | 40% | 13% | 3% | 2% | 602 |
| OK | 40% | 42% | 12% | 4% | 2% | 365 |
| PA | 39% | 40% | 14% | 3% | 4% | 363 |
| KY | 39% | 34% | 20% | 5% | 3% | 148 |
| MI | 38% | 39% | 15% | 4% | 4% | 447 |
| Significantly Below Average | | | | | | |
| GA | 34% | 35% | 18% | 6% | 7% | 399 |
| MD | 33% | 33% | 22% | 8% | 4% | 347 |
| NC | 27% | 38% | 20% | 7% | 9% | 213 |
| NCI Average | 41% | 36% | 15% | 4% | 4% | 4,583 |

Case Manager/Service Coordinator Respects Family's Choices and Opinions

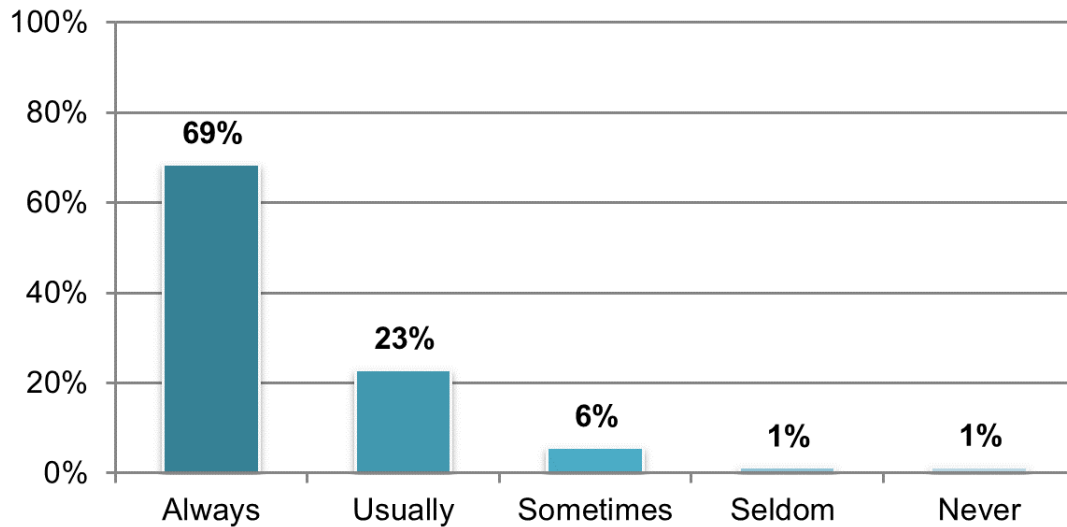


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 83% | 11% | 4% | 1% | 0% | 405 |
| UT | 79% | 18% | 3% | 0% | 0% | 615 |
| Within Average Range | | | | | | |
| FL | 75% | 19% | 5% | 0% | 1% | 369 |
| KY | 70% | 22% | 7% | 0% | 1% | 143 |
| MO | 70% | 21% | 6% | 2% | 2% | 377 |
| LA | 70% | 26% | 3% | 1% | 1% | 361 |
| PA | 69% | 22% | 5% | 2% | 1% | 373 |
| SC | 69% | 20% | 7% | 2% | 2% | 178 |
| MI | 66% | 24% | 7% | 1% | 1% | 452 |
| MD | 63% | 26% | 7% | 2% | 2% | 339 |
| Significantly Below Average | | | | | | |
| OK | 60% | 31% | 5% | 3% | 1% | 372 |
| GA | 60% | 29% | 7% | 2% | 3% | 406 |
| NC | 58% | 29% | 9% | 0% | 3% | 205 |
| NCI Average | 69% | 23% | 6% | 1% | 1% | 4,595 |

Case Manager/Service Coordinator Tells Family About Other Eligible Public Services

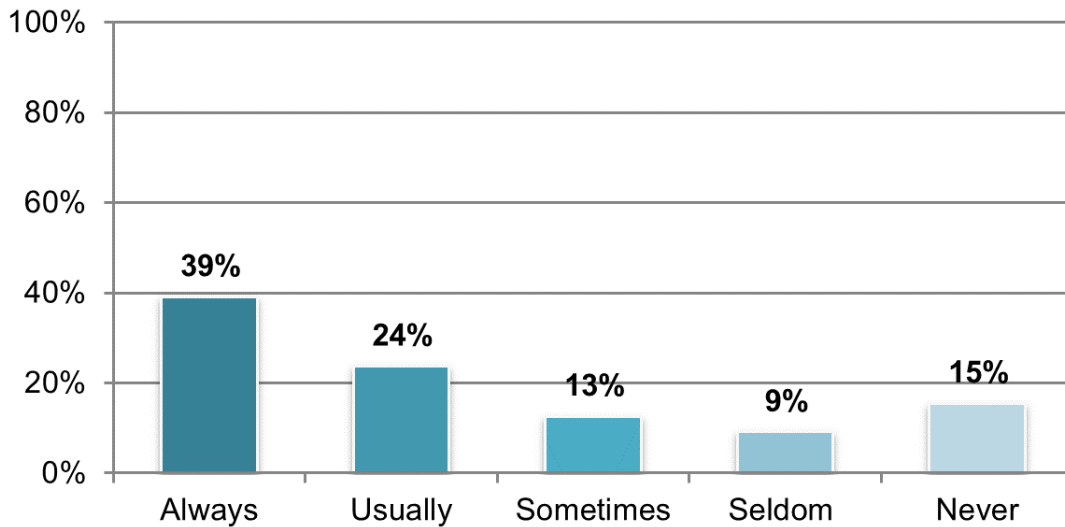
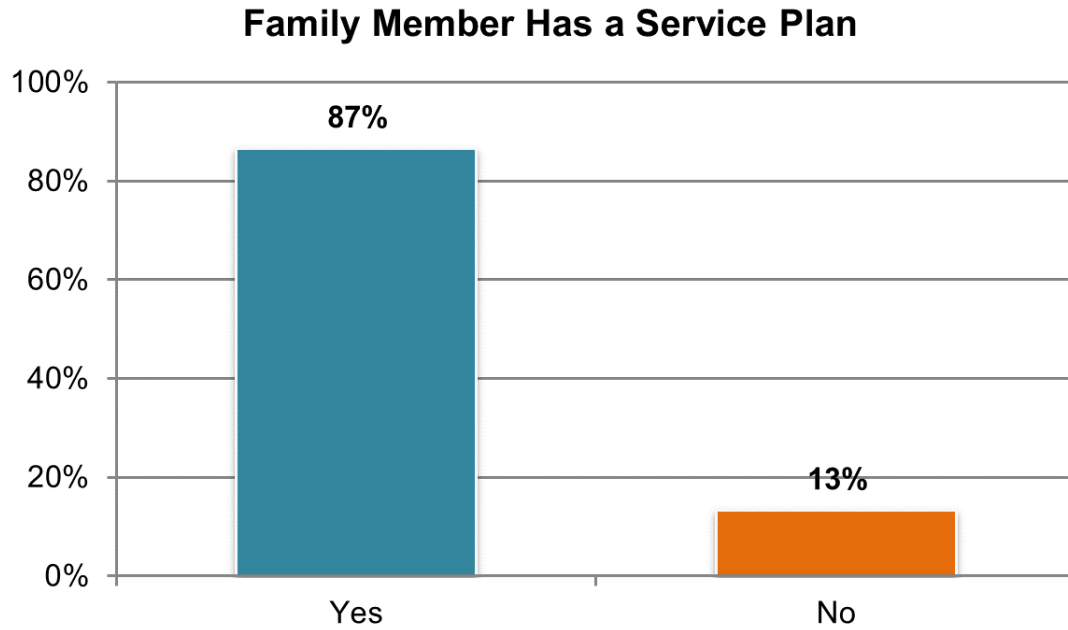


Table Q5. Does the case manager/service coordinator tell you about other public services that your family is eligible for (food stamps, Supplemental Security Income [SSI], housing subsidies, etc.)?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|------------|-----------|------------|--------------|
| Significantly Above Average | | | | | | |
| FL | 50% | 23% | 12% | 5% | 10% | 351 |
| MO | 47% | 23% | 12% | 8% | 10% | 362 |
| Within Average Range | | | | | | |
| SC | 46% | 15% | 10% | 10% | 19% | 175 |
| OH | 45% | 20% | 17% | 5% | 12% | 403 |
| PA | 43% | 28% | 10% | 9% | 11% | 351 |
| KY | 40% | 24% | 9% | 8% | 19% | 139 |
| UT | 40% | 29% | 13% | 9% | 9% | 563 |
| MI | 38% | 26% | 14% | 9% | 14% | 443 |
| OK | 37% | 30% | 14% | 8% | 11% | 354 |
| LA | 35% | 24% | 14% | 12% | 16% | 344 |
| Significantly Below Average | | | | | | |
| MD | 31% | 24% | 12% | 13% | 19% | 338 |
| GA | 31% | 20% | 12% | 11% | 27% | 380 |
| NC | 26% | 23% | 14% | 11% | 26% | 209 |
| NCI Average | 39% | 24% | 13% | 9% | 15% | 4,412 |

Table Q6. Does your family member have a service plan?¹

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| FL | 95% | 5% | 353 |
| OK | 93% | 7% | 334 |
| PA | 91% | 9% | 352 |
| UT | 90% | 10% | 535 |
| Within Average Range | | | |
| MD | 90% | 10% | 342 |
| MO | 90% | 10% | 346 |
| KY | 88% | 12% | 130 |
| LA | 87% | 13% | 333 |
| MI | 86% | 14% | 388 |
| Significantly Below Average | | | |
| GA | 78% | 22% | 343 |
| OH | 76% | 24% | 385 |
| SC | 76% | 24% | 169 |
| NC | n/a | n/a | n/a |
| NCI Average | 87% | 13% | 4,010 |

¹ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Service Plan Includes All the Services and Supports Family Member Wants

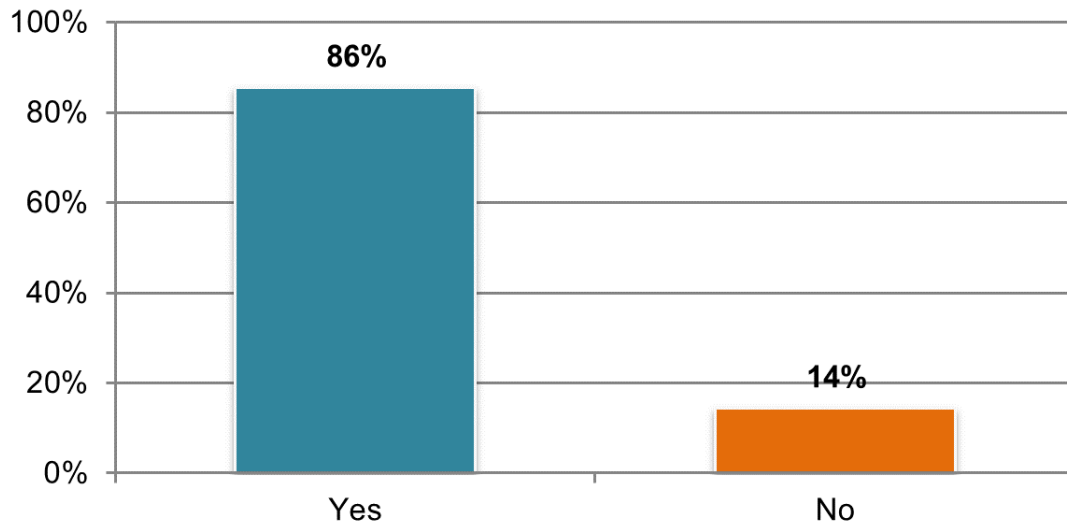


Table Q7. Does the plan include all the services and supports your family member wants?²

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| OH | 94% | 6% | 287 |
| PA | 91% | 9% | 292 |
| UT | 90% | 10% | 431 |
| Within Average Range | | | |
| LA | 88% | 12% | 261 |
| KY | 88% | 12% | 107 |
| MO | 87% | 13% | 278 |
| MI | 85% | 15% | 303 |
| OK | 85% | 15% | 276 |
| SC | 84% | 16% | 106 |
| GA | 80% | 20% | 244 |
| Significantly Below Average | | | |
| MD | 80% | 20% | 275 |
| FL | 76% | 24% | 304 |
| NC | n/a | n/a | n/a |
| NCI Average | 86% | 14% | 3,164 |

² An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Family Member Receives All Services Listed in the Service Plan

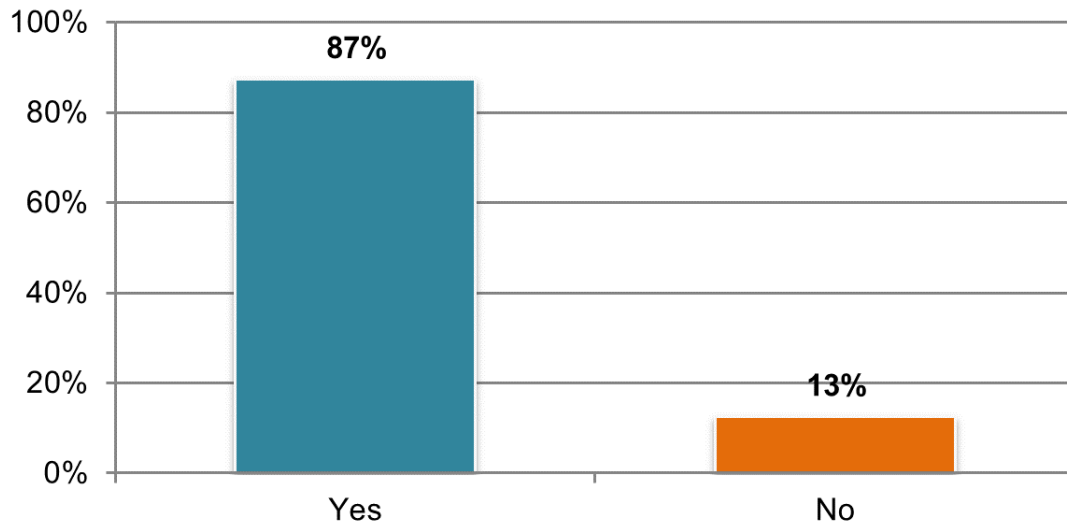


Table Q8. Does your family member receive all of the services listed in the plan?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| OK | 93% | 7% | 281 |
| LA | 92% | 8% | 260 |
| UT | 92% | 8% | 438 |
| Within Average Range | | | |
| OH | 89% | 11% | 280 |
| GA | 89% | 11% | 240 |
| FL | 88% | 12% | 286 |
| PA | 88% | 12% | 287 |
| MO | 88% | 12% | 285 |
| KY | 85% | 15% | 109 |
| MD | 84% | 16% | 264 |
| NC | 83% | 17% | 157 |
| SC | 83% | 17% | 111 |
| MI | 81% | 19% | 292 |
| NCI Average | 87% | 13% | 3,290 |

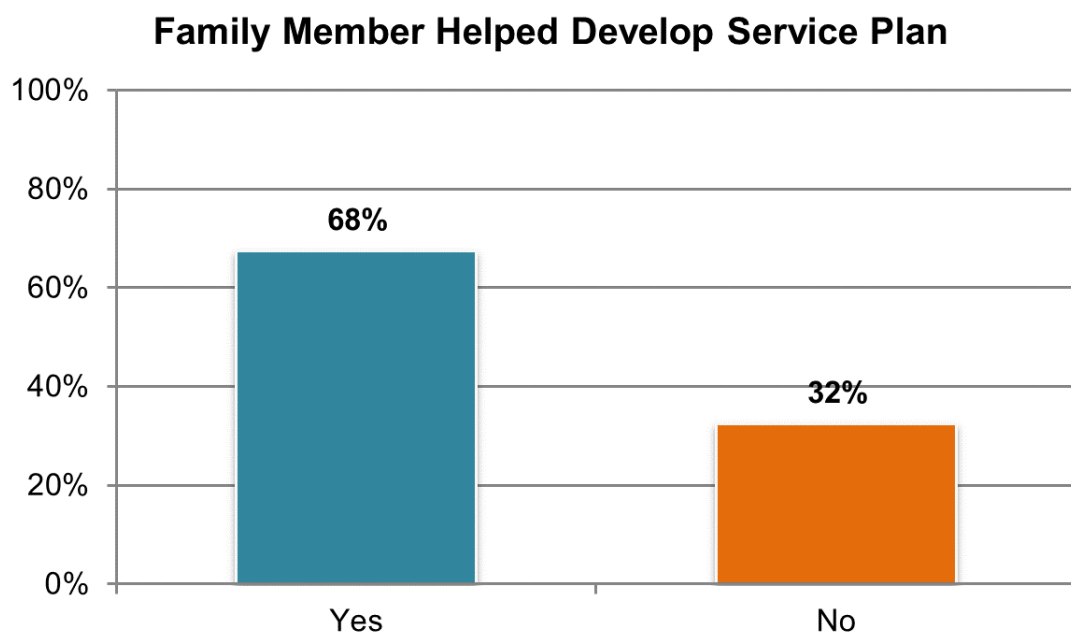


Table Q9. Did your family member help develop the plan?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| MD | 78% | 22% | 281 |
| Within Average Range | | | |
| MI | 74% | 26% | 311 |
| GA | 74% | 26% | 251 |
| MO | 70% | 30% | 296 |
| KY | 69% | 31% | 109 |
| LA | 68% | 32% | 262 |
| OH | 68% | 32% | 279 |
| FL | 67% | 33% | 305 |
| PA | 66% | 34% | 303 |
| OK | 64% | 36% | 284 |
| SC | 63% | 37% | 115 |
| UT | 63% | 37% | 443 |
| Significantly Below Average | | | |
| NC | 54% | 46% | 165 |
| NCI Average | 68% | 32% | 3,404 |

Respondent or Another Family Member Helped Develop Service Plan

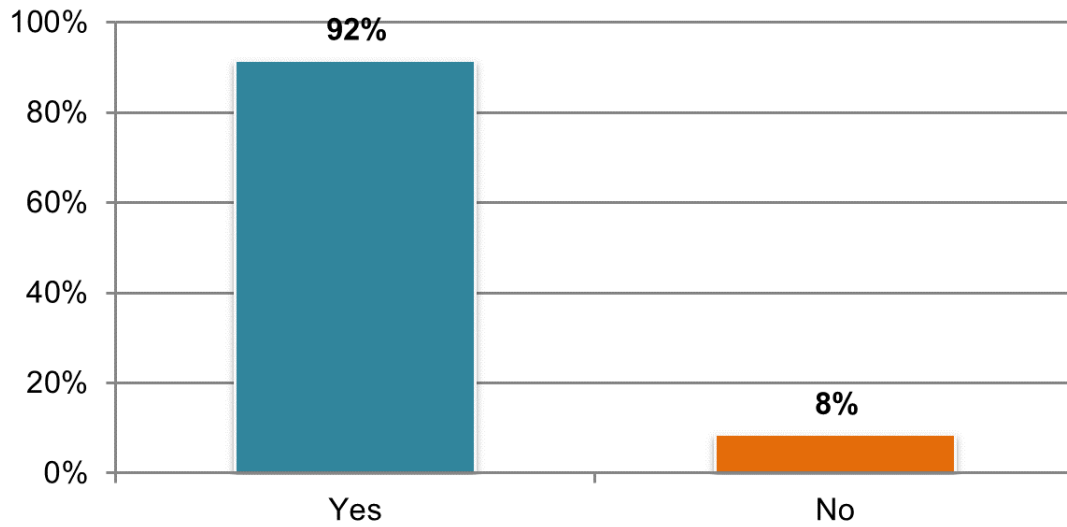


Table Q10. Did you or another family member help develop the plan?

| State | Yes | No | N |
|------------------------------------|------------|-----------|--------------|
| Significantly Above Average | | | |
| KY | 99% | 1% | 111 |
| UT | 96% | 4% | 464 |
| Within Average Range | | | |
| OK | 95% | 5% | 297 |
| LA | 95% | 5% | 274 |
| MO | 94% | 6% | 301 |
| OH | 93% | 7% | 290 |
| PA | 92% | 8% | 310 |
| MI | 90% | 10% | 321 |
| FL | 89% | 11% | 316 |
| MD | 89% | 11% | 289 |
| NC | 88% | 12% | 172 |
| GA | 87% | 13% | 258 |
| Significantly Below Average | | | |
| SC | 82% | 18% | 121 |
| NCI Average | 92% | 8% | 3,524 |

Service Plan Includes All the Services and Supports Family Member Needs

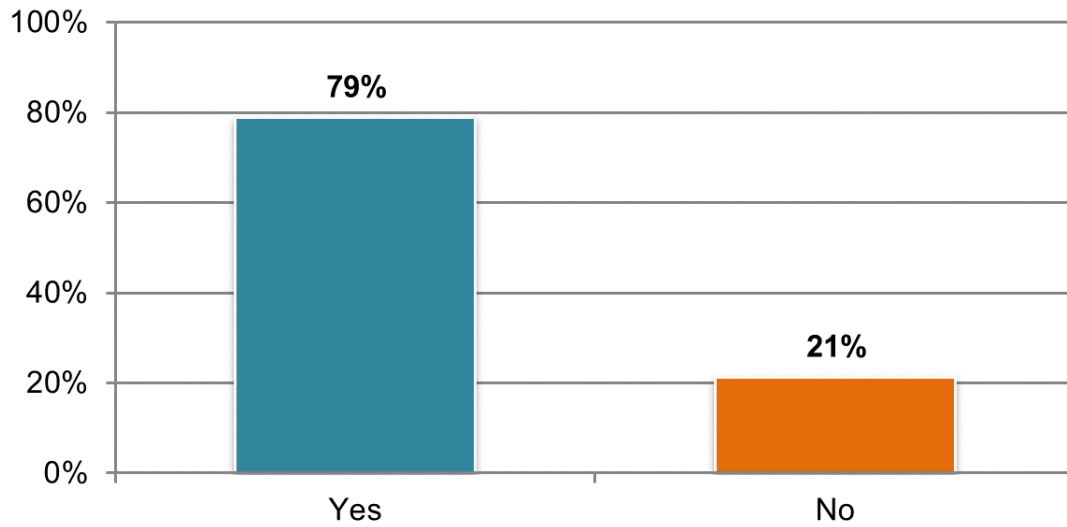


Table Q11. Does the plan include all the services and supports your family member needs?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| OH | 91% | 9% | 279 |
| UT | 86% | 14% | 429 |
| Within Average Range | | | |
| KY | 84% | 16% | 108 |
| MO | 84% | 16% | 282 |
| LA | 82% | 18% | 262 |
| PA | 82% | 18% | 284 |
| OK | 81% | 19% | 278 |
| SC | 79% | 21% | 104 |
| MI | 78% | 22% | 289 |
| GA | 72% | 28% | 241 |
| NC | 69% | 31% | 154 |
| Significantly Below Average | | | |
| MD | 69% | 31% | 272 |
| FL | 67% | 33% | 299 |
| NCI Average | 79% | 21% | 3,281 |

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

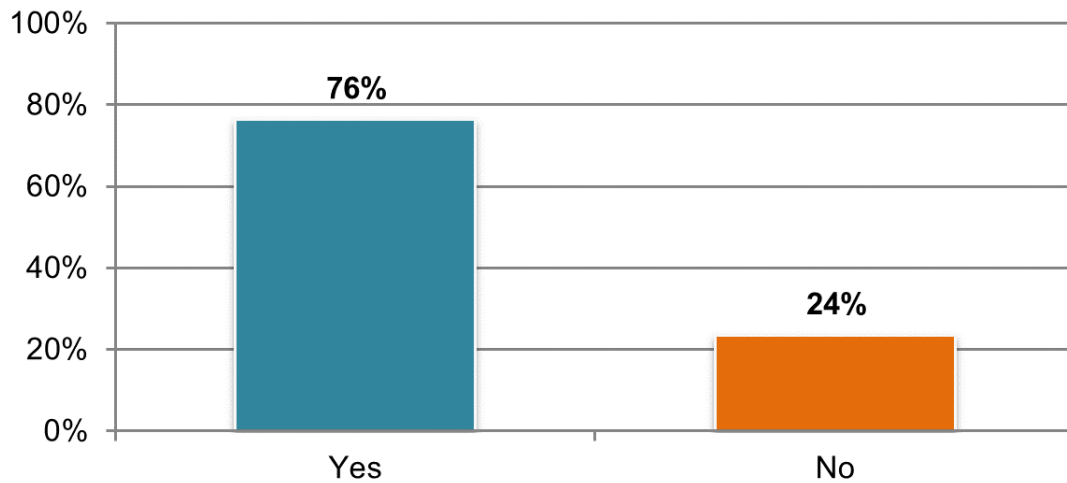


Table Q12. Did you discuss how to handle emergencies related to your family member at the last service planning meeting?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| LA | 93% | 7% | 275 |
| SC | 86% | 14% | 116 |
| OH | 86% | 14% | 271 |
| OK | 84% | 16% | 281 |
| Within Average Range | | | |
| FL | 81% | 19% | 299 |
| NC | 75% | 25% | 162 |
| PA | 75% | 25% | 295 |
| MO | 73% | 27% | 276 |
| UT | 73% | 27% | 413 |
| KY | 73% | 27% | 107 |
| MI | 70% | 30% | 293 |
| Significantly Below Average | | | |
| GA | 66% | 34% | 240 |
| MD | 58% | 42% | 275 |
| NCI Average | 76% | 24% | 3,303 |

Respondent or Family Member Received Information on Family Member's Rights

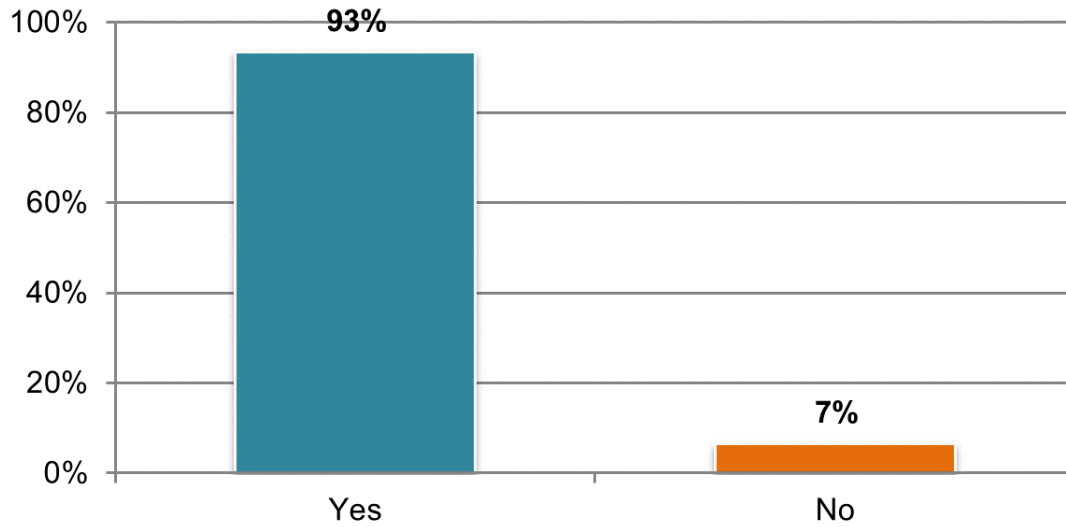


Table Q13. Have you or your family member received information about his/her rights?

| State | Yes | No | N |
|------------------------------------|------------|-----------|--------------|
| Significantly Above Average | | | |
| OK | 98% | 2% | 350 |
| FL | 98% | 2% | 351 |
| MI | 96% | 4% | 452 |
| UT | 96% | 4% | 551 |
| LA | 96% | 4% | 340 |
| Within Average Range | | | |
| KY | 96% | 4% | 135 |
| OH | 94% | 6% | 423 |
| PA | 93% | 7% | 352 |
| MO | 93% | 7% | 353 |
| MD | 91% | 9% | 317 |
| NC | 88% | 12% | 210 |
| SC | 87% | 13% | 175 |
| Significantly Below Average | | | |
| GA | 88% | 12% | 385 |
| NCI Average | 93% | 7% | 4,394 |

Access and Delivery of Services and Supports

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

More than half of all respondents report that they or their family member are always able to contact the family member's support workers (58%) and case manager/service coordinator (56%) when they need to. Fewer than half of all respondents indicate that services are always available when the family member needs them (43%) and fewer than half report that services are always available reasonably close to home (48%). More than half report that support workers always have the right training to meet the family's needs (57%). Slightly more than two-thirds of respondents report that crisis or emergency services were provided when needed (70%).

Nearly all respondents report that they have access to health services for their family member (97%), and 94% of respondents are satisfied with their family member's health providers. Four-fifths of respondents report that they have access to dental services for their family member (80%), and a vast majority report that they have access to medications needed for their family member (87%).

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Respondent or Family Member Is Able to Contact Support Workers When Needed

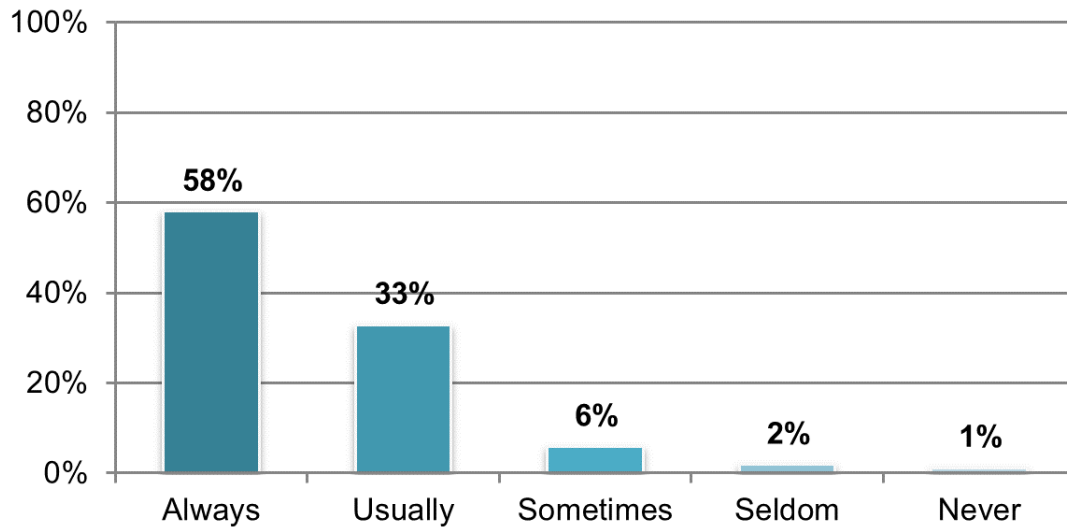


Table Q14. Are you or your family member able to contact his/her support workers when you need to?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 74% | 20% | 5% | 1% | 0% | 410 |
| LA | 67% | 29% | 2% | 1% | 1% | 371 |
| Within Average Range | | | | | | |
| KY | 64% | 29% | 3% | 3% | 1% | 147 |
| FL | 64% | 28% | 5% | 1% | 1% | 366 |
| UT | 62% | 35% | 2% | 0% | 0% | 622 |
| PA | 60% | 33% | 5% | 1% | 1% | 369 |
| MO | 59% | 31% | 7% | 1% | 1% | 337 |
| SC | 55% | 31% | 8% | 4% | 3% | 190 |
| GA | 55% | 34% | 7% | 2% | 2% | 424 |
| Significantly Below Average | | | | | | |
| MI | 50% | 39% | 8% | 2% | 1% | 465 |
| OK | 49% | 40% | 7% | 2% | 1% | 368 |
| MD | 49% | 39% | 8% | 3% | 1% | 353 |
| NC | 47% | 40% | 8% | 2% | 4% | 223 |
| NCI Average | 58% | 33% | 6% | 2% | 1% | 4,645 |

Respondent or Family Member Is Able to Contact Case Manager/Service Coordinator When Needed

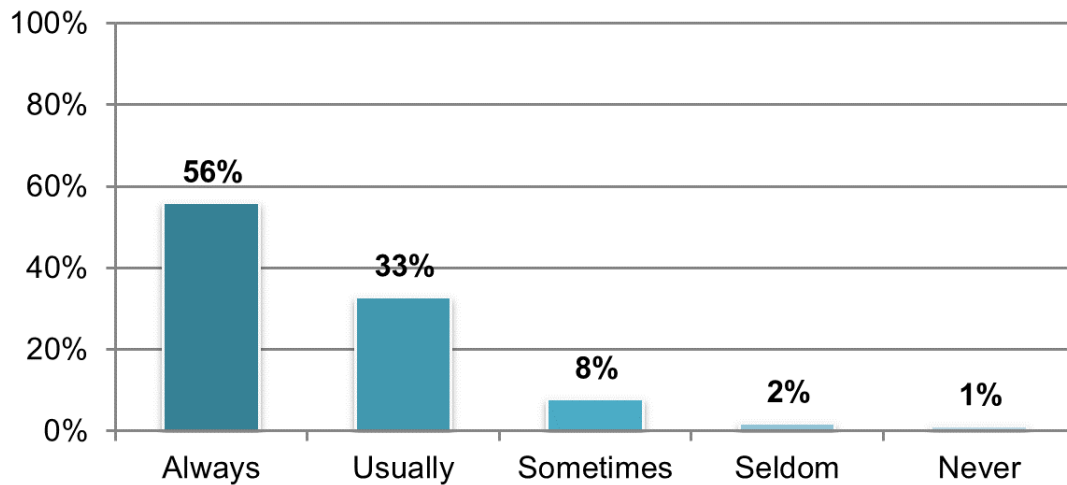


Table Q15. Are you or your family member able to contact his/her case manager/service coordinator when you need to?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 68% | 23% | 6% | 2% | 0% | 409 |
| LA | 64% | 31% | 4% | 1% | 0% | 361 |
| FL | 63% | 27% | 7% | 2% | 1% | 369 |
| UT | 63% | 32% | 4% | 1% | 0% | 622 |
| Within Average Range | | | | | | |
| KY | 66% | 27% | 5% | 2% | 0% | 150 |
| MO | 61% | 27% | 9% | 2% | 2% | 374 |
| PA | 59% | 34% | 6% | 1% | 1% | 380 |
| SC | 54% | 32% | 9% | 4% | 2% | 196 |
| GA | 51% | 33% | 11% | 2% | 3% | 421 |
| Significantly Below Average | | | | | | |
| MD | 48% | 37% | 11% | 3% | 1% | 357 |
| MI | 48% | 41% | 9% | 2% | 0% | 458 |
| OK | 46% | 40% | 11% | 2% | 1% | 381 |
| NC | 37% | 43% | 12% | 4% | 5% | 212 |
| NCI Average | 56% | 33% | 8% | 2% | 1% | 4,690 |

Services and Supports Are Available When Family Member Needs Them

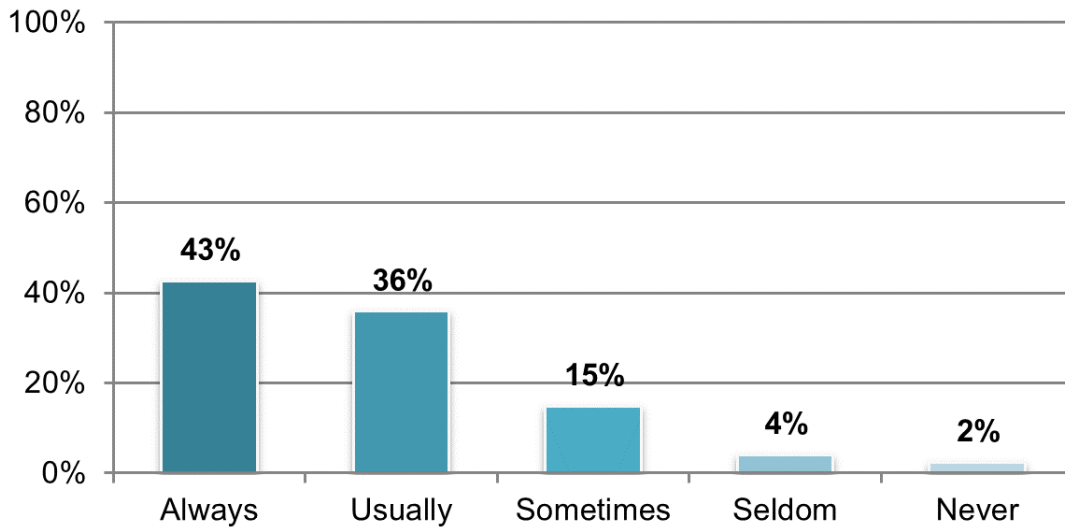


Table Q16. Are services and supports available when your family member needs them?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 61% | 27% | 9% | 2% | 1% | 405 |
| LA | 51% | 36% | 9% | 3% | 1% | 357 |
| Within Average Range | | | | | | |
| KY | 51% | 33% | 13% | 3% | 1% | 148 |
| MO | 45% | 35% | 13% | 5% | 3% | 344 |
| FL | 43% | 29% | 21% | 4% | 3% | 351 |
| UT | 43% | 46% | 9% | 2% | 1% | 608 |
| SC | 42% | 30% | 16% | 8% | 4% | 179 |
| PA | 41% | 39% | 16% | 2% | 2% | 361 |
| OK | 40% | 39% | 16% | 3% | 1% | 357 |
| GA | 38% | 38% | 16% | 4% | 4% | 408 |
| MI | 37% | 42% | 14% | 6% | 1% | 447 |
| Significantly Below Average | | | | | | |
| MD | 34% | 35% | 21% | 8% | 2% | 330 |
| NC | 29% | 39% | 21% | 5% | 7% | 217 |
| NCI Average | 43% | 36% | 15% | 4% | 2% | 4,512 |

Services and Supports Are Available Reasonably Close to Home

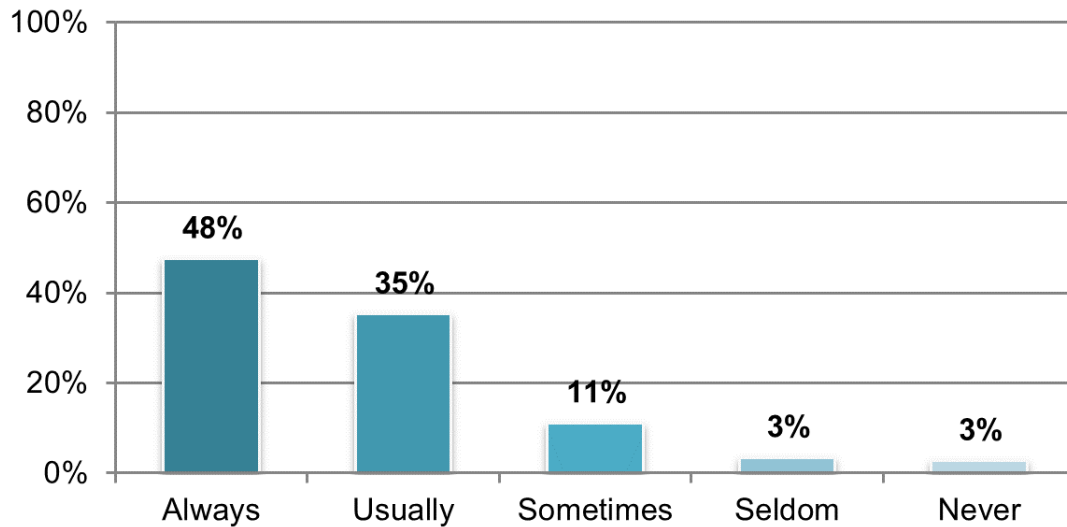


Table Q17. Are services and supports available within a reasonable distance from your home?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 66% | 25% | 7% | 1% | 1% | 403 |
| Within Average Range | | | | | | |
| KY | 53% | 34% | 6% | 4% | 3% | 145 |
| MO | 53% | 30% | 10% | 4% | 2% | 326 |
| LA | 51% | 37% | 8% | 1% | 2% | 340 |
| UT | 48% | 40% | 8% | 3% | 1% | 582 |
| MI | 46% | 38% | 9% | 5% | 2% | 432 |
| PA | 45% | 38% | 13% | 3% | 1% | 350 |
| SC | 45% | 33% | 13% | 3% | 6% | 172 |
| GA | 44% | 38% | 13% | 2% | 4% | 388 |
| FL | 44% | 33% | 17% | 4% | 2% | 327 |
| OK | 42% | 36% | 16% | 4% | 2% | 345 |
| NC | 40% | 38% | 11% | 5% | 5% | 203 |
| Significantly Below Average | | | | | | |
| MD | 40% | 39% | 14% | 4% | 4% | 314 |
| NCI Average | 48% | 35% | 11% | 3% | 3% | 4,327 |

Services and Supports Change When Family Member's Needs Change

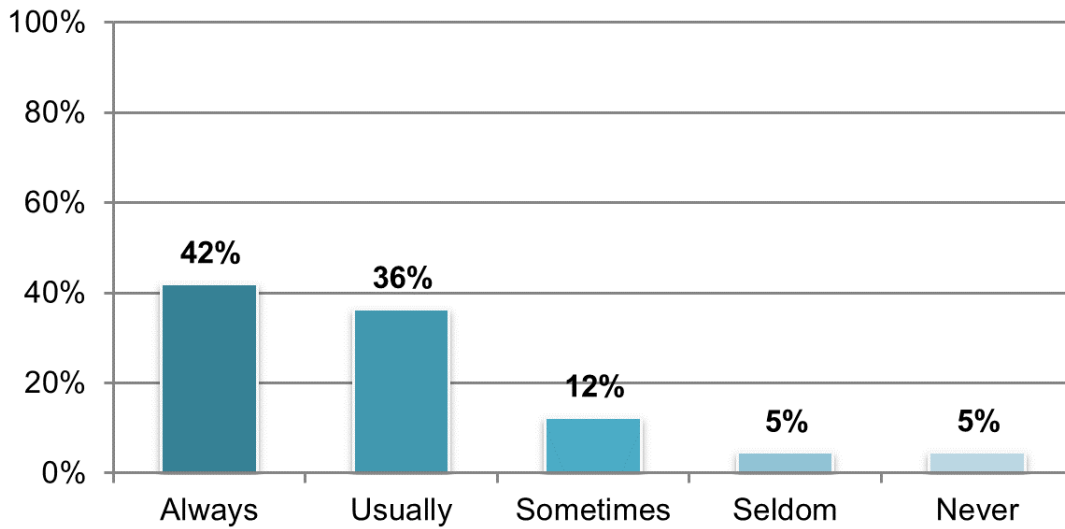


Table Q18. Do the services and supports change when your family member's needs change?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 57% | 28% | 8% | 3% | 5% | 369 |
| Within Average Range | | | | | | |
| KY | 50% | 36% | 7% | 5% | 2% | 127 |
| MO | 49% | 33% | 10% | 3% | 4% | 294 |
| LA | 47% | 34% | 12% | 4% | 4% | 308 |
| PA | 45% | 37% | 12% | 3% | 2% | 307 |
| UT | 43% | 44% | 9% | 3% | 1% | 541 |
| OK | 42% | 40% | 12% | 5% | 3% | 308 |
| SC | 39% | 33% | 16% | 5% | 7% | 154 |
| MI | 38% | 40% | 13% | 6% | 4% | 391 |
| GA | 37% | 37% | 14% | 4% | 7% | 338 |
| FL | 36% | 34% | 17% | 7% | 5% | 310 |
| Significantly Below Average | | | | | | |
| MD | 32% | 37% | 14% | 9% | 7% | 274 |
| NC | 30% | 40% | 17% | 3% | 9% | 195 |
| NCI Average | 42% | 36% | 12% | 5% | 5% | 3,916 |

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

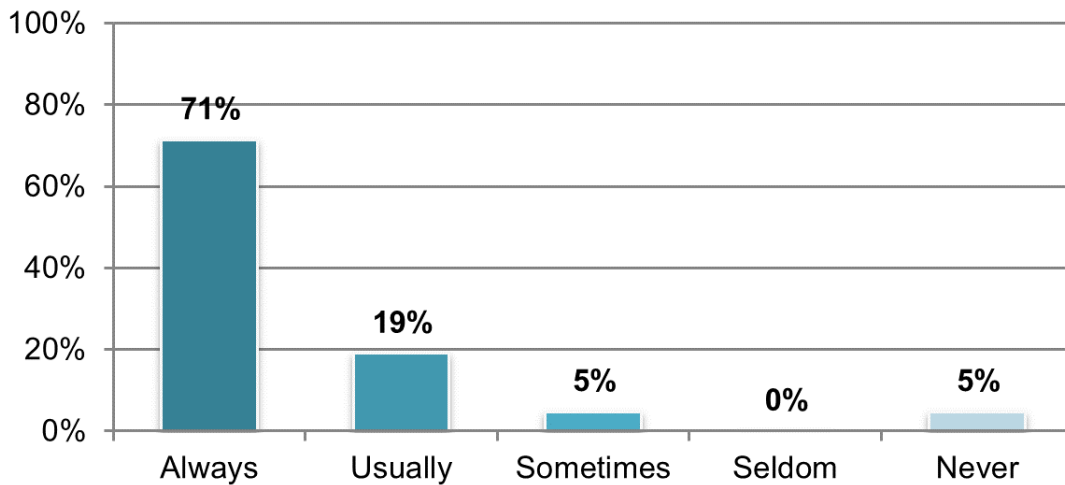


Table Q19. If English is not your primary language, are there support workers or translators who can speak to you in your language?³

| State | Always | Usually | Sometimes | Seldom | Never | N |
|-----------------------------|------------|------------|-----------|-----------|-----------|-----------|
| Within Average Range | | | | | | |
| FL | 71% | 19% | 5% | 0% | 5% | 21 |
| GA | n/a | n/a | n/a | n/a | n/a | n/a |
| KY | n/a | n/a | n/a | n/a | n/a | n/a |
| LA | n/a | n/a | n/a | n/a | n/a | n/a |
| MD | n/a | n/a | n/a | n/a | n/a | n/a |
| MI | n/a | n/a | n/a | n/a | n/a | n/a |
| MO | n/a | n/a | n/a | n/a | n/a | n/a |
| NC | n/a | n/a | n/a | n/a | n/a | n/a |
| OH | n/a | n/a | n/a | n/a | n/a | n/a |
| OK | n/a | n/a | n/a | n/a | n/a | n/a |
| PA | n/a | n/a | n/a | n/a | n/a | n/a |
| SC | n/a | n/a | n/a | n/a | n/a | n/a |
| UT | n/a | n/a | n/a | n/a | n/a | n/a |
| NCI Average | 71% | 19% | 5% | 0% | 5% | 21 |

³ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Support Workers Communicate Effectively in Primary Language (If English)

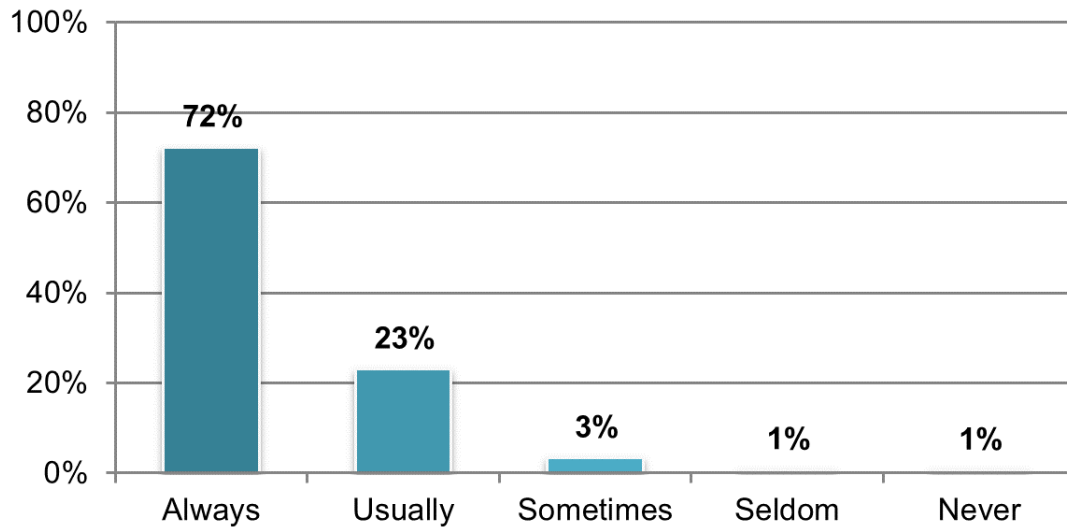


Table Q20. If English is your primary language, do the support workers speak to you effectively?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| LA | 80% | 17% | 2% | 1% | 0% | 325 |
| Within Average Range | | | | | | |
| FL | 76% | 22% | 1% | 0% | 0% | 301 |
| GA | 66% | 28% | 4% | 1% | 1% | 374 |
| OH | 79% | 16% | 3% | 1% | 1% | 383 |
| KY | 75% | 21% | 2% | 1% | 0% | 135 |
| PA | 74% | 23% | 2% | 1% | 0% | 322 |
| MO | 73% | 22% | 4% | 0% | 1% | 316 |
| UT | 73% | 23% | 3% | 0% | 0% | 551 |
| MI | 71% | 24% | 4% | 0% | 0% | 422 |
| SC | 71% | 22% | 7% | 1% | 0% | 161 |
| OK | 68% | 29% | 2% | 1% | 0% | 330 |
| MD | 67% | 26% | 5% | 1% | 1% | 315 |
| NC | 66% | 26% | 4% | 1% | 3% | 203 |
| NCI Average | 72% | 23% | 3% | 1% | 1% | 4,138 |

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

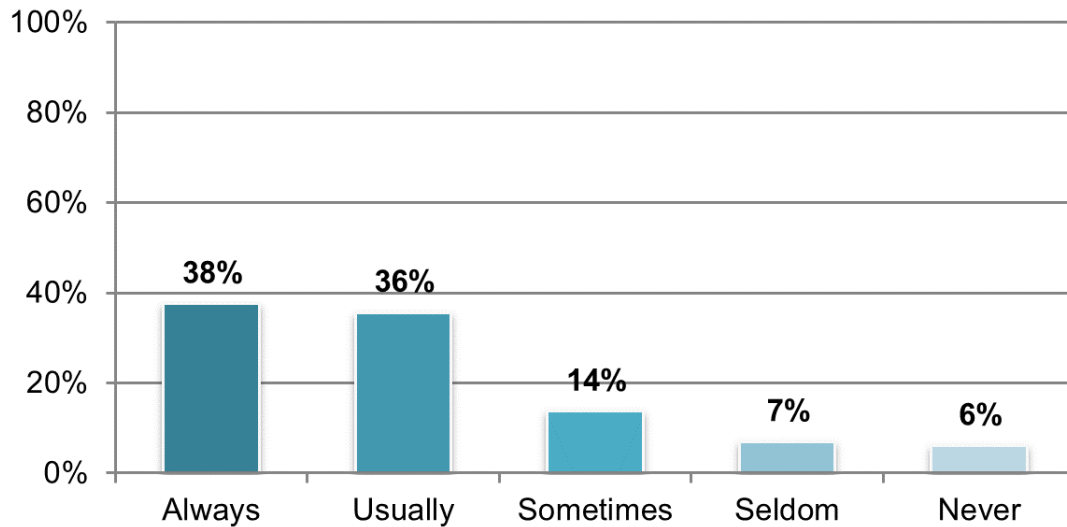


Table Q21. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|----------------------|------------|------------|------------|-----------|-----------|--------------|
| Within Average Range | | | | | | |
| MO | 52% | 28% | 13% | 2% | 5% | 61 |
| OH | 44% | 31% | 17% | 5% | 3% | 75 |
| KY | 42% | 31% | 17% | 8% | 3% | 36 |
| FL | 41% | 24% | 10% | 16% | 9% | 82 |
| LA | 41% | 39% | 11% | 4% | 5% | 98 |
| MD | 40% | 41% | 5% | 9% | 5% | 58 |
| PA | 39% | 37% | 9% | 9% | 7% | 82 |
| SC | 37% | 35% | 18% | 4% | 6% | 49 |
| OK | 33% | 37% | 16% | 8% | 7% | 106 |
| MI | 33% | 31% | 16% | 10% | 10% | 100 |
| GA | 31% | 37% | 18% | 5% | 9% | 87 |
| UT | 31% | 41% | 19% | 7% | 2% | 172 |
| NC | 25% | 53% | 8% | 5% | 8% | 60 |
| NCI Average | 38% | 36% | 14% | 7% | 6% | 1,066 |

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

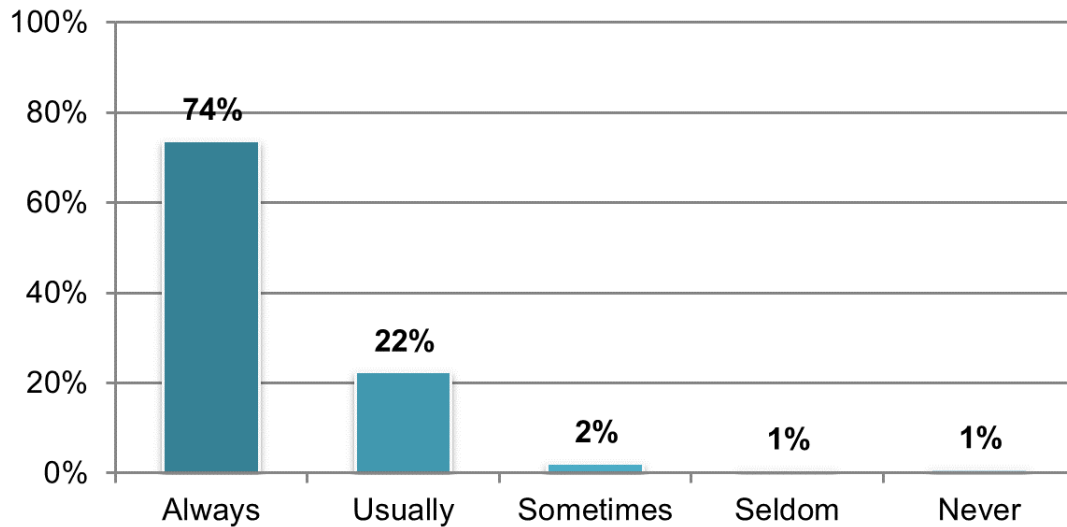


Table Q22. Are services delivered in a way that is respectful to your family's culture?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 88% | 9% | 1% | 0% | 1% | 422 |
| Within Average Range | | | | | | |
| KY | 82% | 14% | 3% | 1% | 0% | 142 |
| PA | 77% | 21% | 2% | 0% | 0% | 314 |
| UT | 77% | 22% | 1% | 0% | 0% | 575 |
| MO | 76% | 20% | 2% | 0% | 1% | 327 |
| LA | 76% | 21% | 2% | 0% | 1% | 329 |
| FL | 76% | 22% | 1% | 0% | 1% | 336 |
| SC | 72% | 22% | 3% | 2% | 1% | 164 |
| MI | 71% | 24% | 3% | 0% | 1% | 420 |
| OK | 69% | 28% | 2% | 1% | 1% | 333 |
| MD | 69% | 26% | 4% | 1% | 0% | 313 |
| Significantly Below Average | | | | | | |
| GA | 64% | 28% | 4% | 2% | 2% | 377 |
| NC | 61% | 34% | 2% | 0% | 4% | 200 |
| NCI Average | 74% | 22% | 2% | 1% | 1% | 4,252 |

Family Member Has Access to Special Equipment or Accommodations Needed

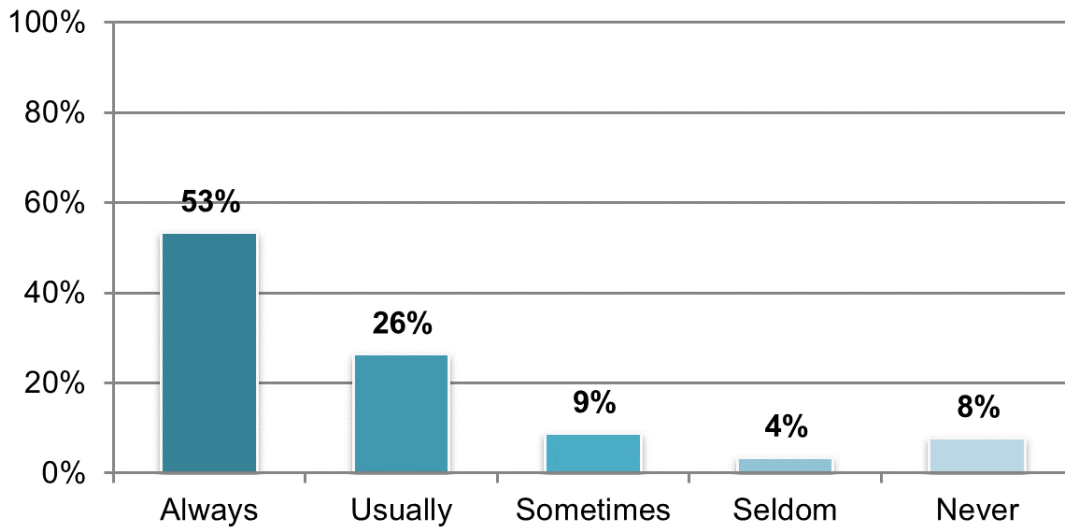


Table Q23. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 75% | 14% | 5% | 1% | 4% | 227 |
| Within Average Range | | | | | | |
| SC | 66% | 21% | 5% | 2% | 5% | 91 |
| LA | 59% | 24% | 6% | 3% | 8% | 192 |
| MO | 58% | 21% | 9% | 3% | 9% | 171 |
| KY | 54% | 23% | 11% | 4% | 8% | 79 |
| PA | 53% | 30% | 7% | 3% | 7% | 157 |
| OK | 51% | 29% | 9% | 5% | 5% | 212 |
| FL | 48% | 22% | 14% | 5% | 12% | 170 |
| UT | 47% | 36% | 10% | 2% | 4% | 328 |
| GA | 47% | 27% | 7% | 6% | 12% | 201 |
| MI | 45% | 32% | 9% | 4% | 10% | 192 |
| MD | 45% | 34% | 12% | 4% | 5% | 120 |
| NC | 44% | 29% | 11% | 2% | 13% | 126 |
| NCI Average | 53% | 26% | 9% | 4% | 8% | 2,266 |

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

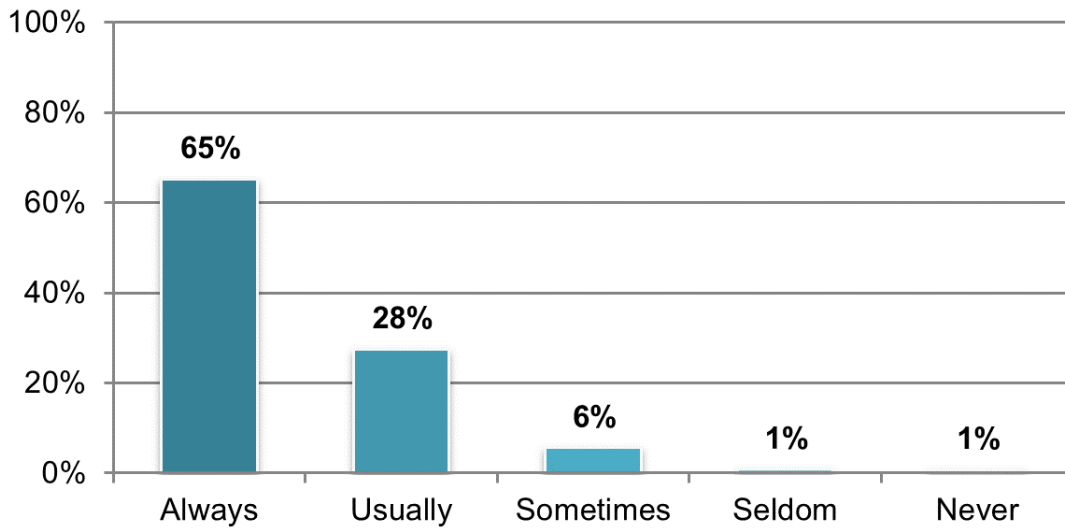


Table Q24. Do you feel that your family member's day/employment setting is a healthy and safe environment?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 81% | 16% | 2% | 0% | 0% | 403 |
| KY | 80% | 14% | 5% | 1% | 0% | 127 |
| MO | 72% | 22% | 4% | 1% | 1% | 279 |
| Within Average Range | | | | | | |
| LA | 70% | 24% | 4% | 1% | 1% | 276 |
| FL | 67% | 26% | 5% | 1% | 1% | 271 |
| PA | 64% | 28% | 6% | 1% | 1% | 316 |
| SC | 62% | 29% | 7% | 1% | 1% | 144 |
| OK | 61% | 30% | 7% | 1% | 0% | 258 |
| NC | 61% | 34% | 3% | 0% | 2% | 175 |
| GA | 61% | 28% | 9% | 1% | 1% | 370 |
| Significantly Below Average | | | | | | |
| MI | 58% | 35% | 6% | 1% | 1% | 377 |
| UT | 57% | 37% | 5% | 1% | 0% | 533 |
| MD | 54% | 34% | 10% | 1% | 1% | 341 |
| NCI Average | 65% | 28% | 6% | 1% | 1% | 3,870 |

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

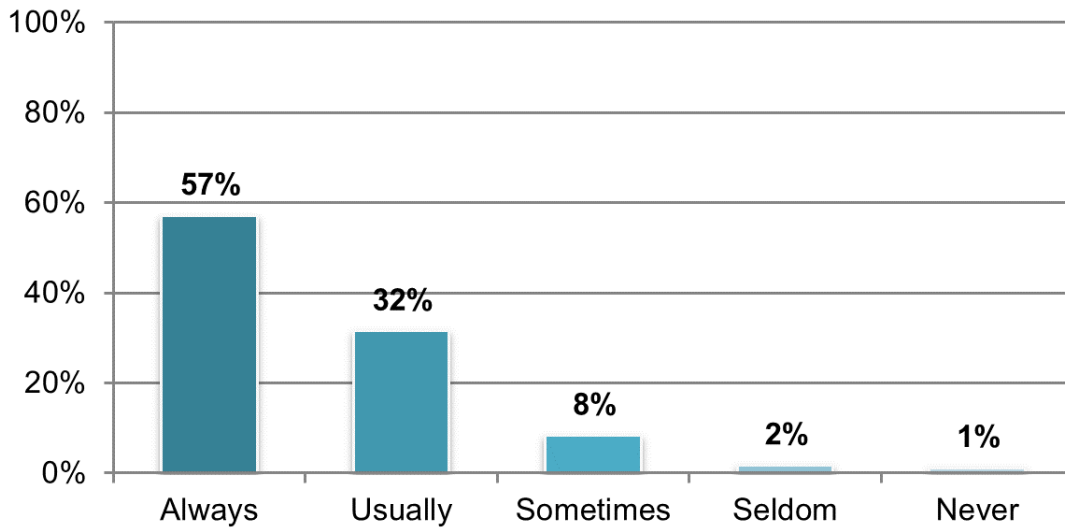


Table Q25. Do the support workers have the right training to meet your family's needs?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| KY | 68% | 24% | 5% | 1% | 1% | 143 |
| OH | 66% | 28% | 6% | 1% | 0% | 399 |
| Within Average Range | | | | | | |
| FL | 63% | 29% | 6% | 1% | 2% | 324 |
| MO | 60% | 25% | 11% | 3% | 1% | 294 |
| LA | 60% | 29% | 8% | 2% | 2% | 350 |
| SC | 59% | 29% | 11% | 1% | 1% | 158 |
| OK | 58% | 31% | 8% | 2% | 1% | 331 |
| PA | 57% | 33% | 7% | 2% | 1% | 333 |
| UT | 53% | 38% | 8% | 1% | 1% | 593 |
| MI | 51% | 38% | 7% | 3% | 1% | 419 |
| MD | 50% | 35% | 10% | 3% | 2% | 317 |
| NC | 49% | 36% | 12% | 1% | 2% | 203 |
| Significantly Below Average | | | | | | |
| GA | 49% | 35% | 11% | 3% | 2% | 371 |
| NCI Average | 57% | 32% | 8% | 2% | 1% | 4,235 |

Support Workers Who Come to the Home Arrive on Time and When Scheduled

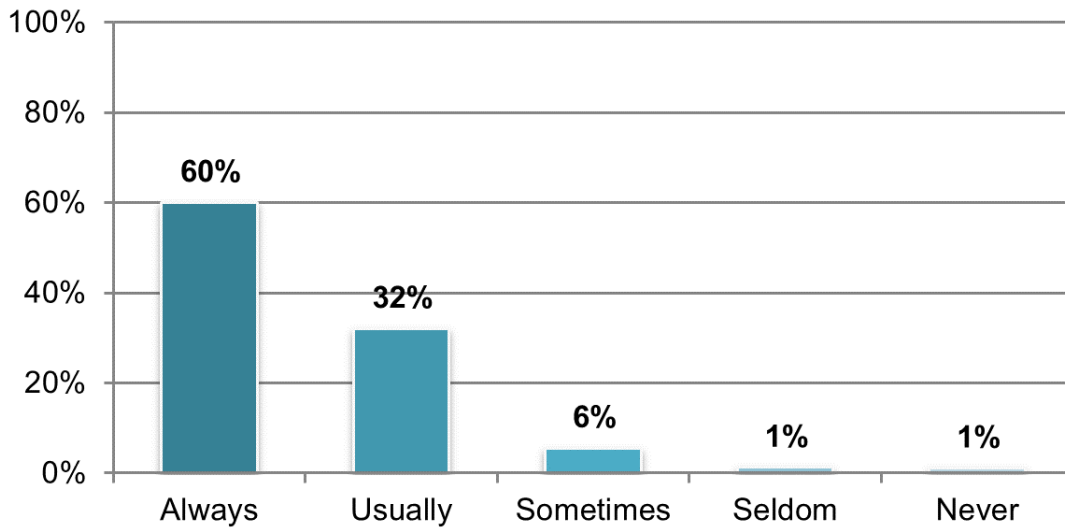


Table Q26. Do the support workers who come to your home arrive on time and when scheduled?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 77% | 20% | 3% | 0% | 0% | 292 |
| Within Average Range | | | | | | |
| FL | 66% | 27% | 4% | 2% | 1% | 331 |
| KY | 65% | 29% | 4% | 1% | 1% | 124 |
| MO | 65% | 27% | 6% | 0% | 2% | 252 |
| PA | 62% | 31% | 5% | 1% | 0% | 298 |
| LA | 61% | 32% | 6% | 1% | 0% | 338 |
| UT | 58% | 38% | 3% | 1% | 0% | 536 |
| MI | 58% | 33% | 7% | 1% | 1% | 373 |
| SC | 57% | 34% | 6% | 2% | 1% | 135 |
| NC | 54% | 35% | 6% | 2% | 2% | 171 |
| OK | 53% | 39% | 7% | 0% | 1% | 289 |
| MD | 52% | 39% | 6% | 2% | 1% | 215 |
| Significantly Below Average | | | | | | |
| GA | 51% | 34% | 9% | 3% | 4% | 283 |
| NCI Average | 60% | 32% | 6% | 1% | 1% | 3,637 |

Happy With Transition From School Services to State Funded Services (In Past Year)

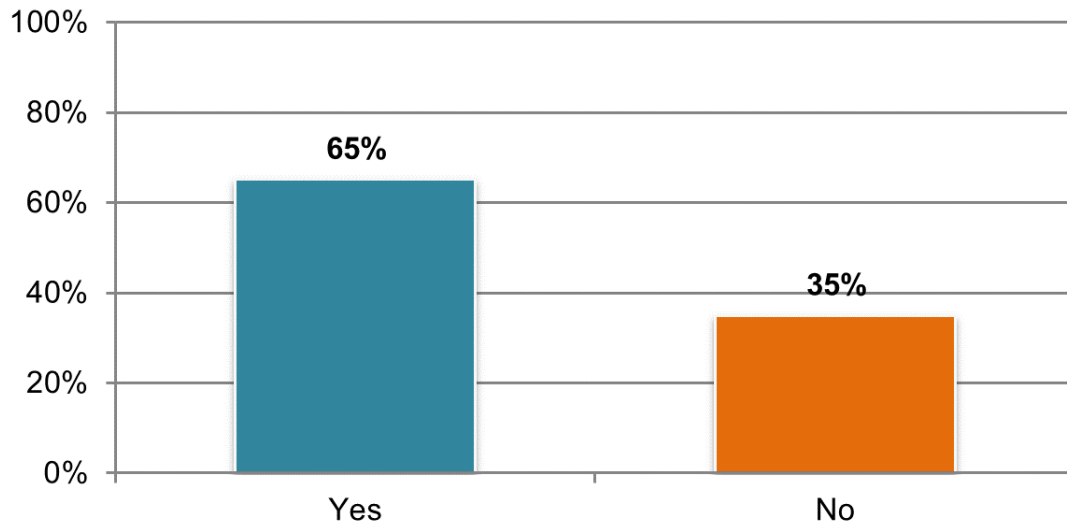


Table Q27. If your family member transitioned from school services to state-funded services during the past year, were you happy with the transition process?⁴

| State | Yes | No | N |
|-----------------------------|------------|------------|------------|
| Within Average Range | | | |
| MD | 73% | 27% | 30 |
| OH | 72% | 28% | 46 |
| PA | 71% | 29% | 31 |
| MI | 70% | 30% | 46 |
| UT | 69% | 31% | 68 |
| GA | 67% | 33% | 30 |
| MO | 65% | 35% | 40 |
| OK | 64% | 36% | 22 |
| LA | 56% | 44% | 27 |
| FL | 45% | 55% | 33 |
| KY | n/a | n/a | n/a |
| NC | n/a | n/a | n/a |
| SC | n/a | n/a | n/a |
| NCI Average | 65% | 35% | 373 |

⁴ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Crisis or Emergency Services Were Provided When Needed (If Requested)

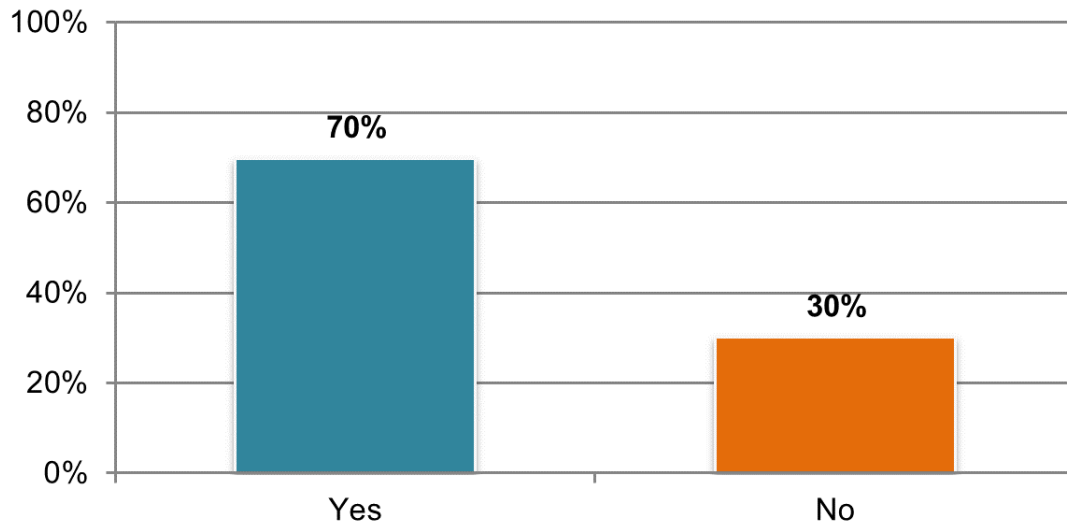


Table Q28. If you asked for crisis or emergency services during the past year, were services provided when needed?

| State | Yes | No | N |
|------------------------------------|------------|------------|------------|
| Significantly Above Average | | | |
| OH | 85% | 15% | 102 |
| Within Average Range | | | |
| KY | 81% | 19% | 21 |
| UT | 78% | 22% | 102 |
| OK | 75% | 25% | 57 |
| PA | 73% | 27% | 64 |
| MO | 72% | 28% | 72 |
| LA | 68% | 32% | 95 |
| MI | 67% | 33% | 89 |
| GA | 67% | 33% | 101 |
| SC | 64% | 36% | 44 |
| FL | 61% | 39% | 83 |
| MD | 61% | 39% | 59 |
| NC | 53% | 47% | 51 |
| NCI Average | 70% | 30% | 940 |

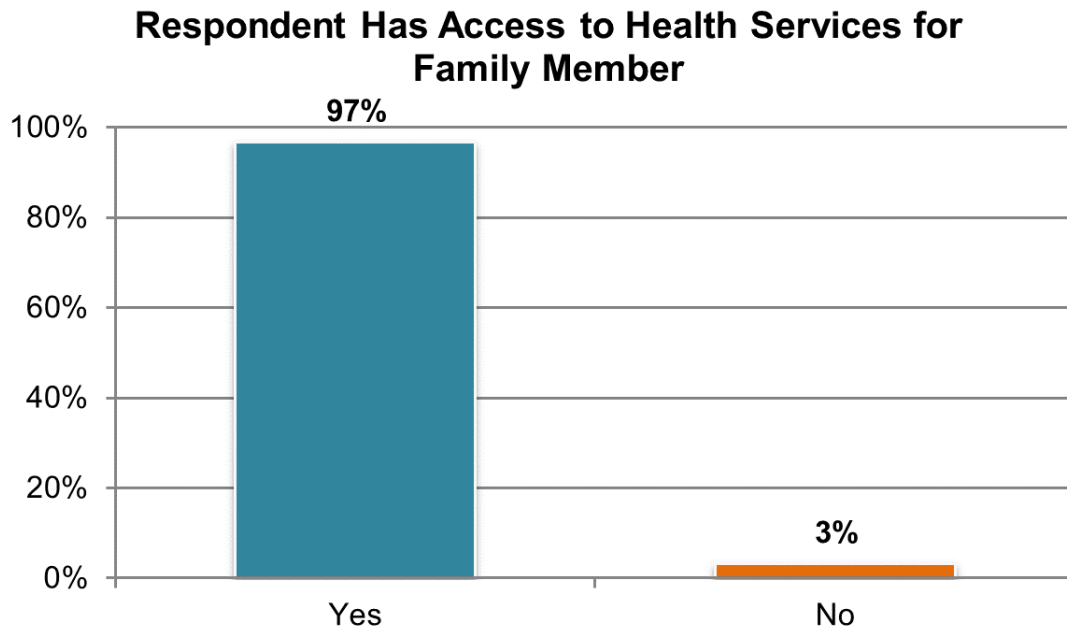


Table Q29. Do you have access to health services for your family member?

| State | Yes | No | N |
|------------------------------------|------------|-----------|--------------|
| Significantly Above Average | | | |
| OK | 99% | 1% | 355 |
| MO | 99% | 1% | 365 |
| Within Average Range | | | |
| LA | 98% | 2% | 363 |
| PA | 98% | 2% | 374 |
| UT | 98% | 2% | 618 |
| KY | 98% | 2% | 151 |
| MD | 97% | 3% | 326 |
| MI | 97% | 3% | 440 |
| OH | 97% | 3% | 429 |
| FL | 96% | 4% | 341 |
| SC | 96% | 4% | 179 |
| GA | 95% | 5% | 389 |
| Significantly Below Average | | | |
| NC | 91% | 9% | 227 |
| NCI Average | 97% | 3% | 4,557 |

Respondent Is Satisfied With Family Member's Health Providers

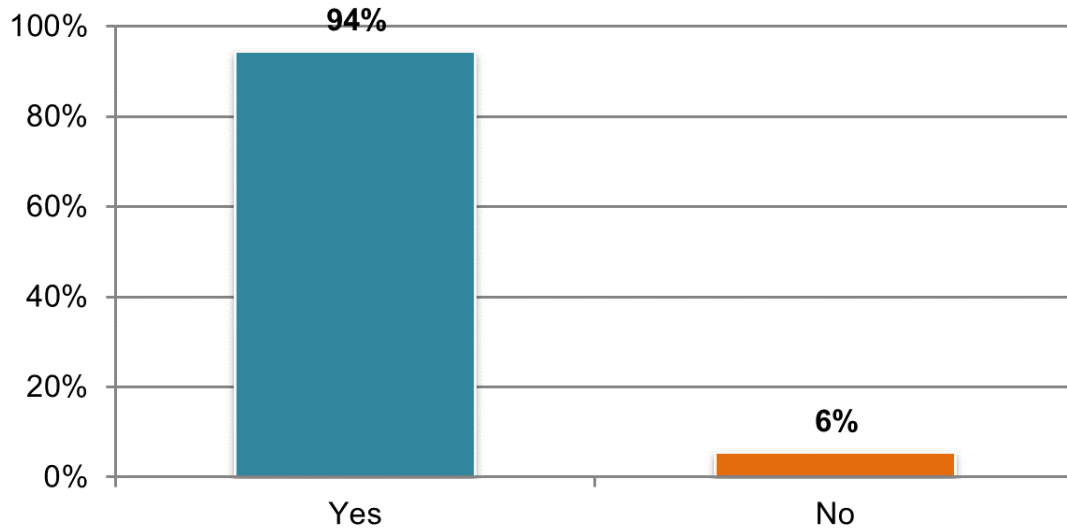


Table Q29a. If you have access to health services for your family member, are you satisfied with the quality of these providers?

| State | Yes | No | N |
|------------------------------------|------------|-----------|--------------|
| Significantly Above Average | | | |
| OH | 97% | 3% | 407 |
| UT | 97% | 3% | 587 |
| Within Average Range | | | |
| FL | 96% | 4% | 305 |
| MD | 96% | 4% | 307 |
| MO | 96% | 4% | 346 |
| GA | 95% | 5% | 352 |
| KY | 95% | 5% | 143 |
| OK | 95% | 5% | 332 |
| PA | 95% | 5% | 355 |
| MI | 94% | 6% | 399 |
| LA | 93% | 7% | 338 |
| SC | 92% | 8% | 155 |
| NC | 88% | 12% | 199 |
| NCI Average | 94% | 6% | 4,225 |

Respondent Has Access to Dental Services for Family Member

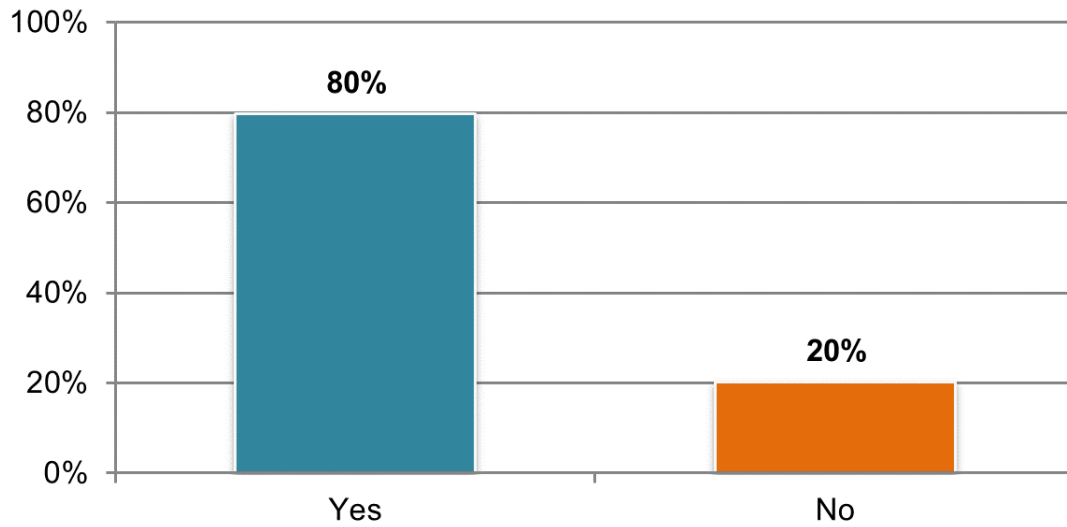


Table Q30. Do you have access to dental services for your family member?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| KY | 93% | 7% | 143 |
| PA | 92% | 8% | 368 |
| NC | 88% | 12% | 227 |
| OK | 87% | 13% | 351 |
| OH | 87% | 13% | 410 |
| Within Average Range | | | |
| UT | 82% | 18% | 601 |
| MI | 80% | 20% | 450 |
| MD | 79% | 21% | 325 |
| SC | 75% | 25% | 170 |
| Significantly Below Average | | | |
| MO | 71% | 29% | 363 |
| GA | 71% | 29% | 410 |
| FL | 67% | 33% | 327 |
| LA | 66% | 34% | 358 |
| NCI Average | 80% | 20% | 4,503 |

Respondent Is Satisfied With Family Member's Dental Providers

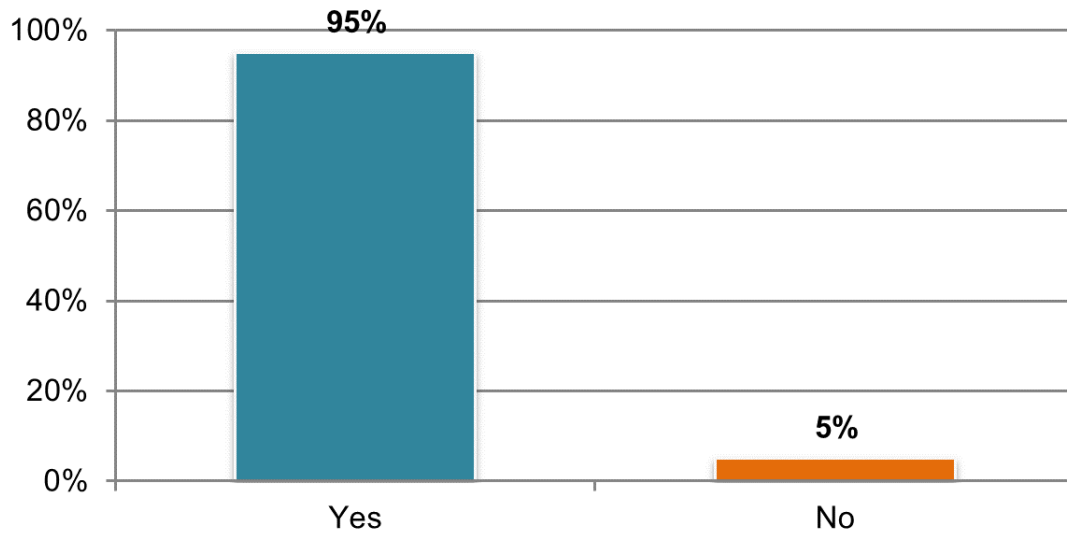


Table Q30a. If you have access to dental services for your family member, are you satisfied with the quality of these providers?

| State | Yes | No | N |
|-----------------------------|------------|-----------|--------------|
| Within Average Range | | | |
| NC | 97% | 3% | 198 |
| KY | 97% | 3% | 126 |
| LA | 96% | 4% | 226 |
| OH | 96% | 4% | 350 |
| UT | 96% | 4% | 461 |
| OK | 96% | 4% | 289 |
| GA | 95% | 5% | 271 |
| SC | 95% | 5% | 122 |
| MI | 95% | 5% | 335 |
| PA | 95% | 5% | 328 |
| MO | 93% | 7% | 252 |
| FL | 93% | 7% | 201 |
| MD | 91% | 9% | 232 |
| NCI Average | 95% | 5% | 3,391 |

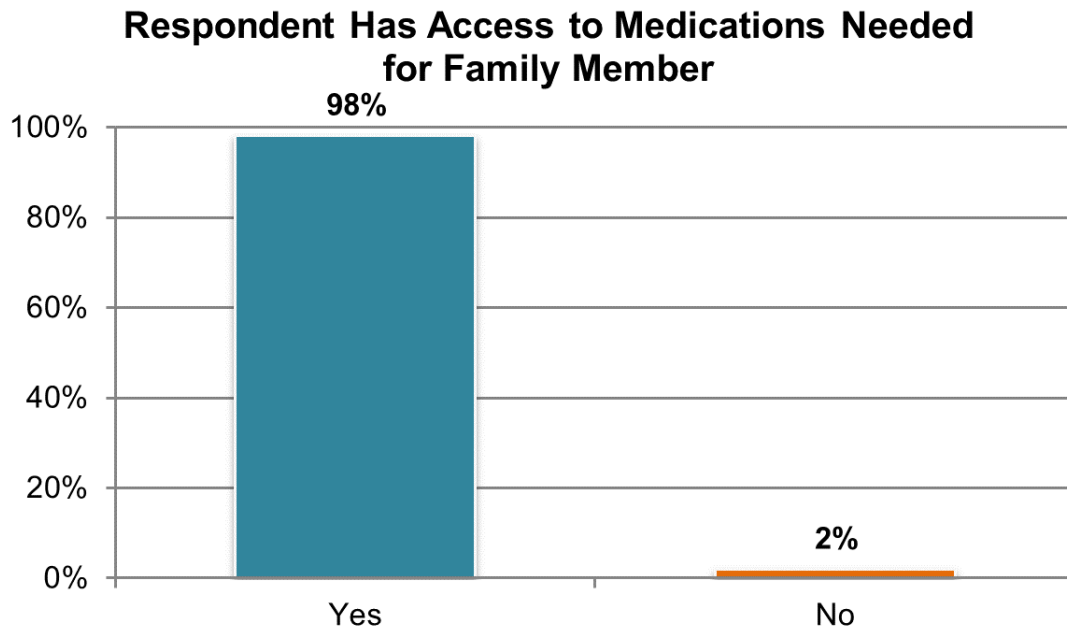


Table Q31. Are you able to get medications needed for your family member?

| State | Yes | No | N |
|------------------------------------|------------|-----------|--------------|
| Significantly Above Average | | | |
| UT | 99% | 1% | 613 |
| Within Average Range | | | |
| MO | 99% | 1% | 363 |
| FL | 99% | 1% | 339 |
| PA | 99% | 1% | 380 |
| MD | 98% | 2% | 323 |
| OK | 98% | 2% | 361 |
| OH | 98% | 2% | 415 |
| MI | 98% | 2% | 458 |
| NC | 98% | 2% | 231 |
| LA | 98% | 2% | 368 |
| KY | 97% | 3% | 149 |
| SC | 97% | 3% | 178 |
| GA | 96% | 4% | 402 |
| NCI Average | 98% | 2% | 4,580 |

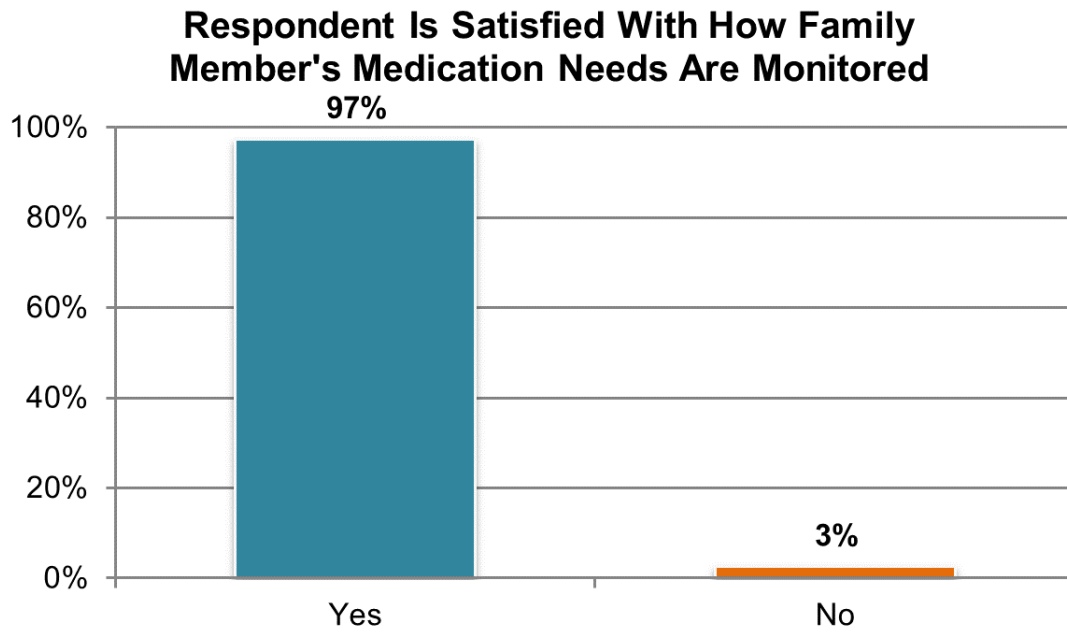


Table Q31a. If you are able to get needed medications for your family member, are you satisfied with how your family member's medication needs are monitored?

| State | Yes | No | N |
|------------------------------------|------------|-----------|--------------|
| Significantly Above Average | | | |
| FL | 99% | 1% | 312 |
| OH | 99% | 1% | 390 |
| Within Average Range | | | |
| GA | 98% | 2% | 355 |
| LA | 98% | 2% | 333 |
| KY | 98% | 2% | 137 |
| NC | 98% | 2% | 215 |
| UT | 98% | 2% | 569 |
| OK | 97% | 3% | 327 |
| PA | 97% | 3% | 353 |
| MI | 97% | 3% | 409 |
| MO | 97% | 3% | 337 |
| MD | 96% | 4% | 271 |
| SC | 95% | 5% | 153 |
| NCI Average | 97% | 3% | 4,161 |

Respondent Has Access to Needed Mental Health Services for Family Member

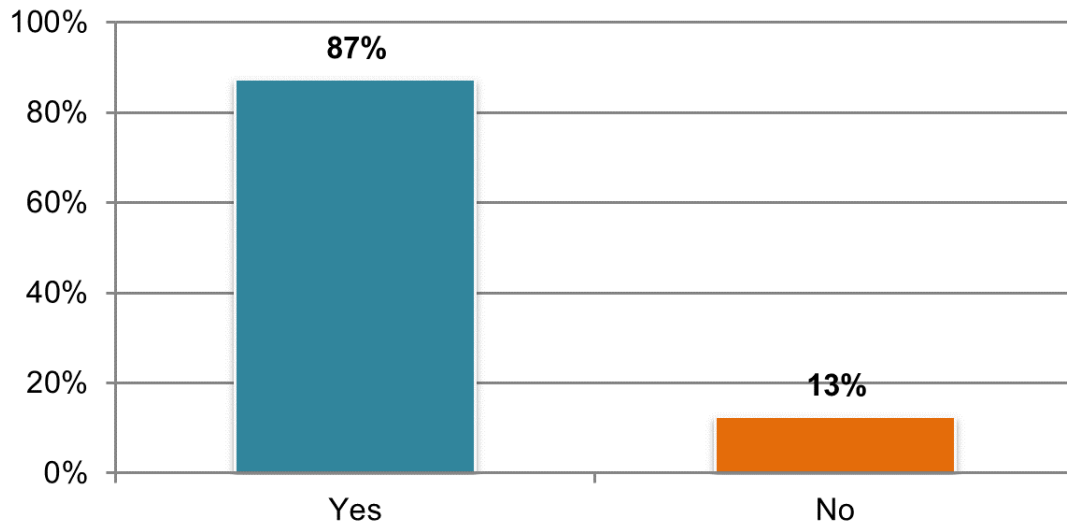


Table Q32. If needed, do you have access to mental health services for your family member?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| PA | 97% | 3% | 235 |
| MI | 93% | 7% | 351 |
| OH | 92% | 8% | 328 |
| Within Average Range | | | |
| KY | 92% | 8% | 102 |
| UT | 91% | 9% | 338 |
| MO | 89% | 11% | 213 |
| OK | 87% | 13% | 165 |
| FL | 85% | 15% | 188 |
| NC | 84% | 16% | 173 |
| MD | 84% | 16% | 190 |
| LA | 83% | 17% | 201 |
| GA | 81% | 19% | 259 |
| SC | 78% | 22% | 104 |
| NCI Average | 87% | 13% | 2,847 |

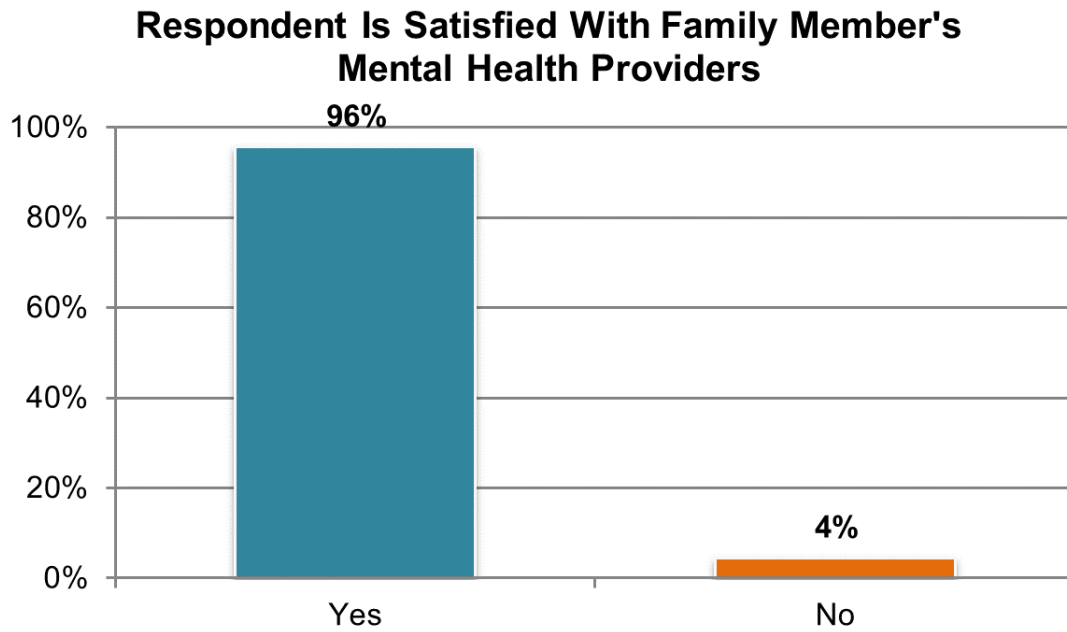


Table Q32a. If you have access to needed mental health services, are you satisfied with the quality of these providers?

| State | Yes | No | N |
|-----------------------------|------------|-----------|--------------|
| Within Average Range | | | |
| SC | 99% | 1% | 68 |
| OK | 98% | 3% | 120 |
| MD | 97% | 3% | 114 |
| FL | 97% | 3% | 125 |
| MO | 97% | 3% | 156 |
| GA | 97% | 3% | 178 |
| LA | 95% | 5% | 130 |
| UT | 95% | 5% | 230 |
| OH | 94% | 6% | 214 |
| MI | 94% | 6% | 269 |
| NC | 94% | 6% | 116 |
| KY | 93% | 7% | 73 |
| PA | 93% | 7% | 185 |
| NCI Average | 96% | 4% | 1,978 |

Respondent Has Access to Respite Services Needed for Family Member

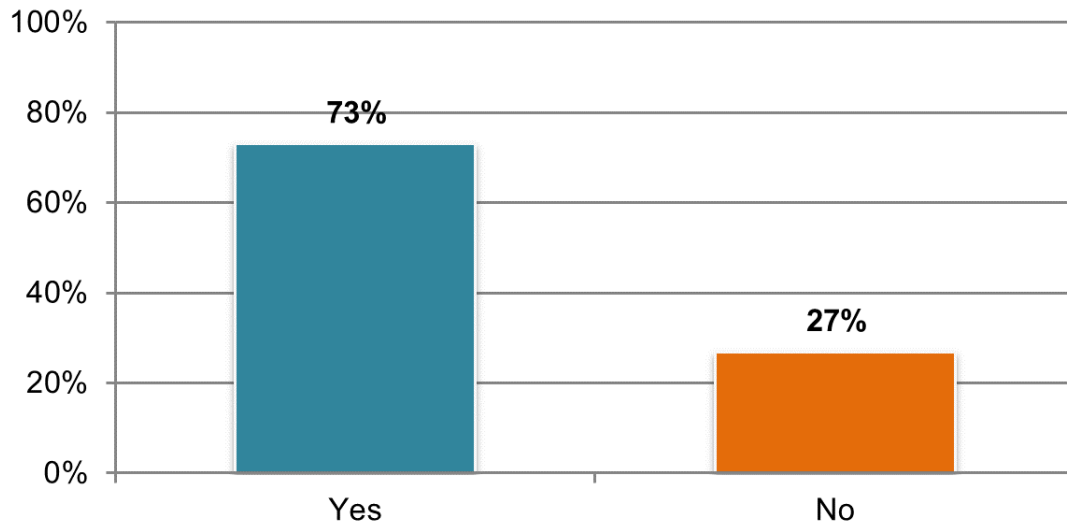


Table Q33. If you need respite services, do you have access to them?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| UT | 91% | 9% | 498 |
| KY | 90% | 10% | 134 |
| OH | 85% | 15% | 339 |
| LA | 82% | 18% | 241 |
| Within Average Range | | | |
| MI | 78% | 22% | 334 |
| PA | 75% | 25% | 218 |
| NC | 73% | 27% | 185 |
| SC | 71% | 29% | 121 |
| FL | 71% | 29% | 237 |
| MD | 68% | 32% | 170 |
| Significantly Below Average | | | |
| GA | 57% | 43% | 249 |
| MO | 57% | 43% | 215 |
| OK | 52% | 48% | 172 |
| NCI Average | 73% | 27% | 3,113 |

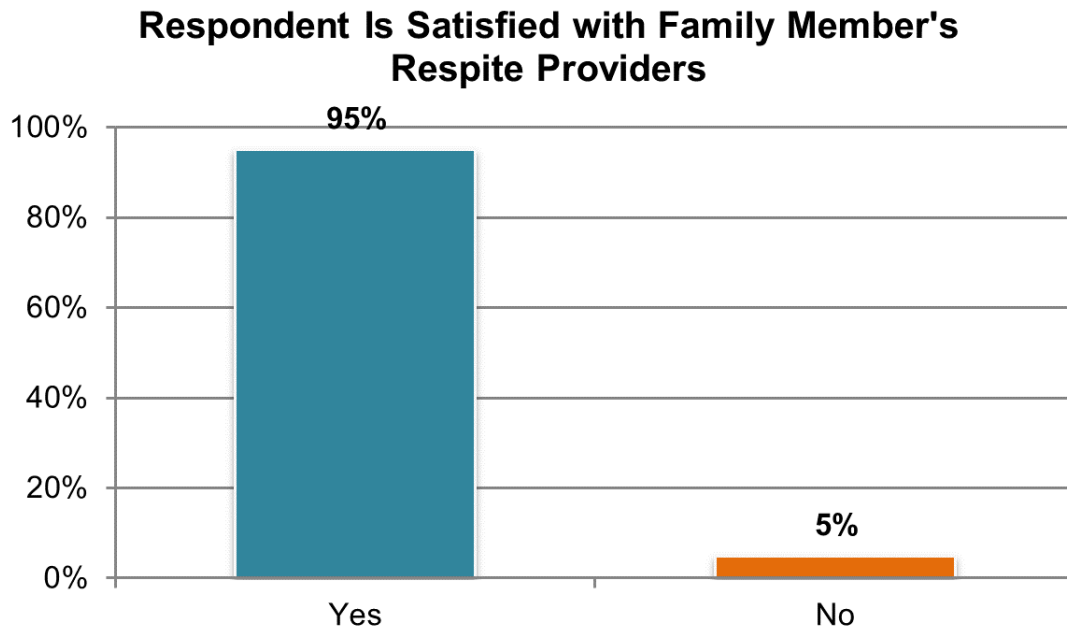


Table Q33a. If you have access to needed respite services, are you satisfied with the quality of these providers?

| State | Yes | No | N |
|-----------------------------|------------|-----------|--------------|
| Within Average Range | | | |
| SC | 99% | 1% | 69 |
| MO | 98% | 2% | 100 |
| OK | 97% | 3% | 73 |
| KY | 97% | 3% | 98 |
| MI | 96% | 4% | 211 |
| UT | 95% | 5% | 415 |
| LA | 95% | 5% | 174 |
| NC | 95% | 5% | 126 |
| OH | 95% | 5% | 188 |
| FL | 94% | 6% | 146 |
| GA | 93% | 7% | 121 |
| MD | 92% | 8% | 85 |
| PA | 90% | 10% | 143 |
| NCI Average | 95% | 5% | 1,949 |

Services Are Needed That Are Not Currently Offered or Available

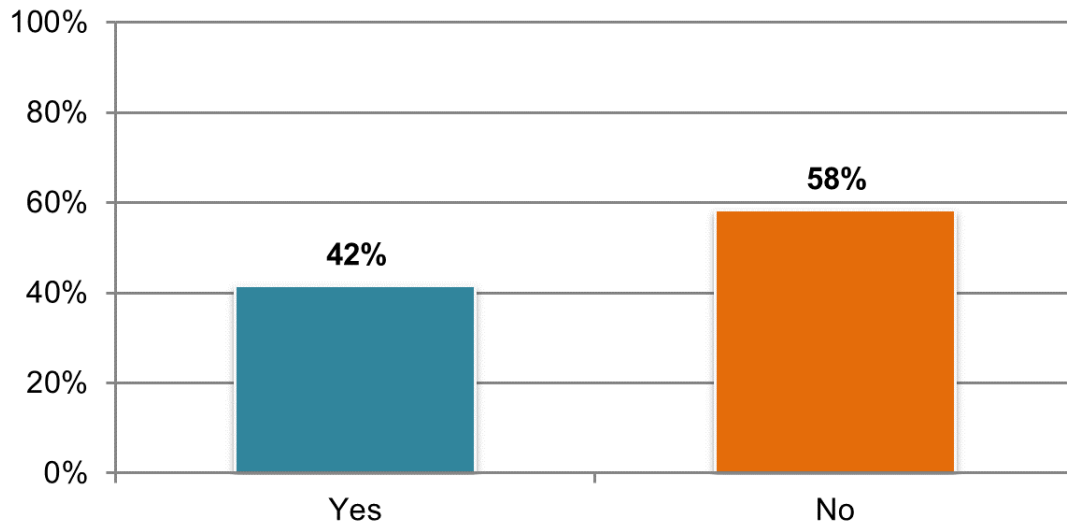


Table Q34. Are there other services that your family member needs that are not currently offered or available?⁵

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| FL | 57% | 43% | 251 |
| MD | 52% | 48% | 231 |
| GA | 50% | 50% | 279 |
| Within Average Range | | | |
| NC | 51% | 49% | 158 |
| SC | 50% | 50% | 94 |
| OK | 43% | 57% | 223 |
| KY | 40% | 60% | 112 |
| LA | 39% | 61% | 240 |
| PA | 38% | 62% | 254 |
| MI | 37% | 63% | 314 |
| MO | 36% | 64% | 248 |
| Significantly Below Average | | | |
| UT | 33% | 67% | 423 |
| OH | 15% | 85% | 385 |
| NCI Average | 42% | 58% | 3,212 |

⁵ The 'yes' response is the less desired response; a higher 'yes' average means more people reported they were in need of additional services that are not offered.

Choice and Control

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

Almost three-fifths of respondents report that they always choose the provider agencies that work with their family (58%) while nearly one-third indicate that their family member always make this choice (30%). Just over two-fifths of respondents report that they always choose the individual support workers who work directly with family (43%) and just over one-fourth indicate that their family member always does so (26%).

Nearly one-half of all respondents report that they have control or input over the hiring and management of support workers (48%), while almost one-third of respondents report that their family member has such control or input (32%). Almost one-third of respondents report that they know how much money is spent by the ID/DD agency on behalf of their family member (30%), and 11% report that their family member knows how much money is spent by ID/DD agency on his/her behalf.

Note: An ‘n/a’ designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Respondent Chooses Provider Agencies Who Work With Family

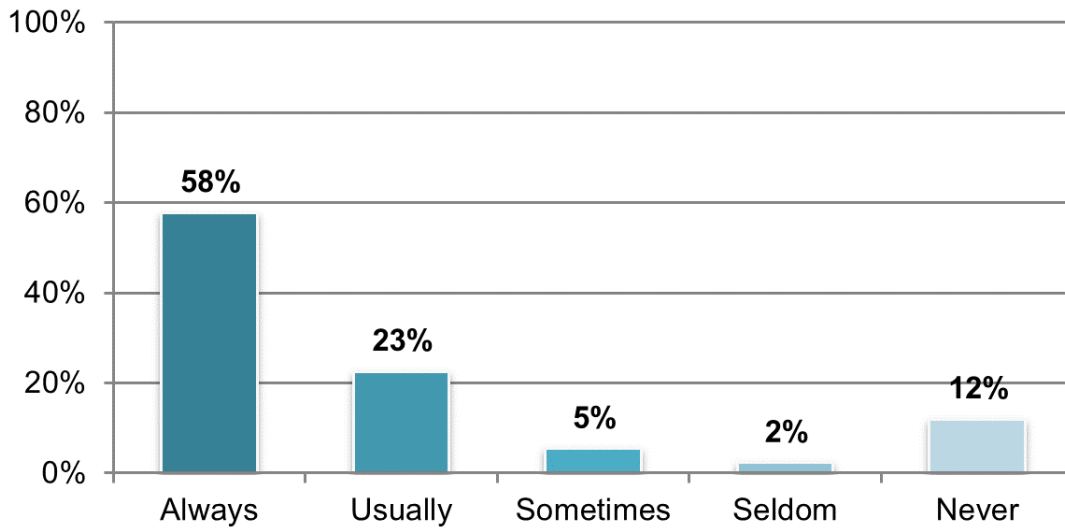


Table Q35. Do you choose the provider agencies who work with your family?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|------------|--------------|
| Significantly Above Average | | | | | | |
| LA | 72% | 17% | 3% | 1% | 7% | 353 |
| UT | 71% | 23% | 2% | 1% | 4% | 579 |
| OK | 67% | 22% | 4% | 1% | 6% | 342 |
| Within Average Range | | | | | | |
| KY | 67% | 22% | 5% | 4% | 2% | 142 |
| OH | 61% | 15% | 5% | 2% | 17% | 379 |
| FL | 59% | 25% | 6% | 1% | 9% | 336 |
| MO | 57% | 21% | 8% | 3% | 11% | 316 |
| NC | 56% | 23% | 4% | 1% | 15% | 209 |
| MD | 53% | 25% | 5% | 2% | 15% | 319 |
| SC | 50% | 25% | 5% | 4% | 17% | 175 |
| Significantly Below Average | | | | | | |
| MI | 47% | 25% | 11% | 3% | 14% | 408 |
| GA | 47% | 21% | 7% | 2% | 24% | 348 |
| PA | 46% | 30% | 6% | 4% | 14% | 311 |
| NCI Average | 58% | 23% | 5% | 2% | 12% | 4,217 |

Family Member Chooses Provider Agencies Who Work With Family

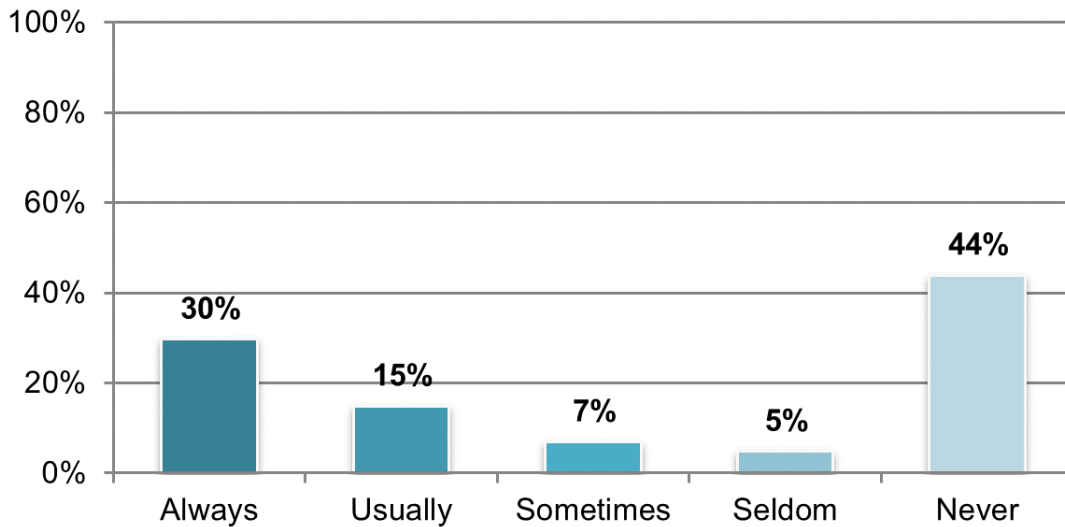


Table Q36. Does your family member choose the provider agencies who work with your family?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|------------|--------------|
| Significantly Above Average | | | | | | |
| LA | 40% | 12% | 6% | 3% | 39% | 316 |
| FL | 39% | 19% | 8% | 5% | 30% | 301 |
| Within Average Range | | | | | | |
| KY | 37% | 22% | 8% | 2% | 30% | 125 |
| OK | 35% | 15% | 6% | 6% | 39% | 300 |
| OH | 31% | 9% | 4% | 2% | 54% | 360 |
| MD | 30% | 13% | 9% | 6% | 42% | 282 |
| UT | 29% | 14% | 5% | 6% | 46% | 500 |
| PA | 27% | 16% | 8% | 8% | 41% | 290 |
| MO | 27% | 16% | 7% | 6% | 43% | 291 |
| GA | 25% | 11% | 6% | 6% | 52% | 324 |
| SC | 23% | 11% | 8% | 4% | 54% | 158 |
| NC | 23% | 15% | 4% | 3% | 55% | 194 |
| Significantly Below Average | | | | | | |
| MI | 22% | 18% | 10% | 6% | 44% | 375 |
| NCI Average | 30% | 15% | 7% | 5% | 44% | 3,816 |

Respondent Can Choose a Different Provider Agency If Desired

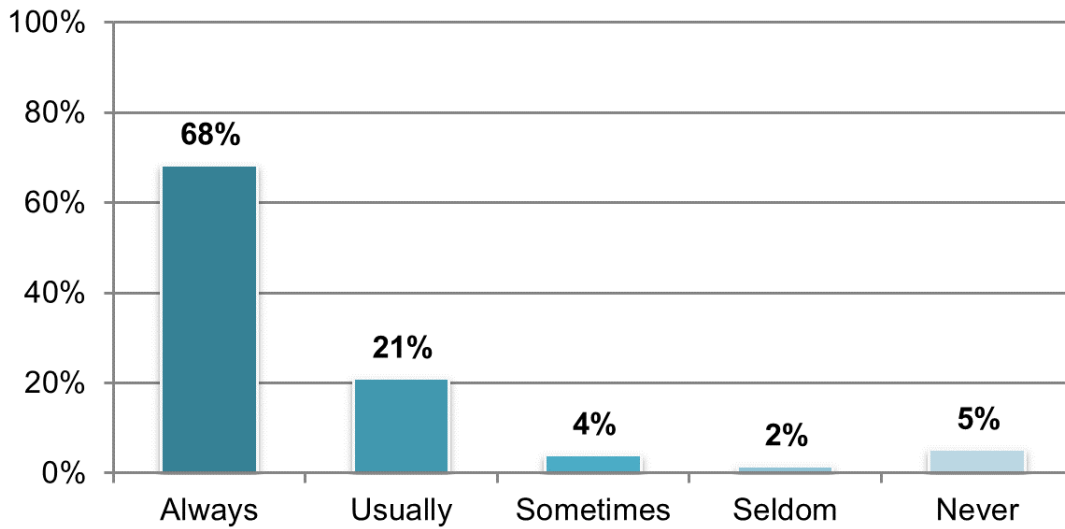


Table Q37. Can you choose a different provider agency if you want to?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| LA | 80% | 14% | 3% | 1% | 3% | 312 |
| OH | 80% | 9% | 2% | 1% | 8% | 333 |
| Within Average Range | | | | | | |
| KY | 78% | 15% | 4% | 1% | 2% | 117 |
| UT | 74% | 21% | 2% | 0% | 2% | 494 |
| OK | 73% | 22% | 2% | 0% | 2% | 296 |
| FL | 69% | 22% | 4% | 2% | 3% | 291 |
| SC | 66% | 23% | 3% | 3% | 6% | 120 |
| NC | 65% | 25% | 4% | 2% | 4% | 171 |
| GA | 63% | 22% | 4% | 2% | 9% | 240 |
| PA | 61% | 25% | 7% | 1% | 7% | 207 |
| MO | 60% | 23% | 3% | 5% | 9% | 235 |
| MD | 60% | 25% | 7% | 0% | 7% | 234 |
| Significantly Below Average | | | | | | |
| MI | 58% | 28% | 5% | 3% | 6% | 282 |
| NCI Average | 68% | 21% | 4% | 2% | 5% | 3,332 |

Respondent Chooses Individual Support Workers Who Work Directly With Family

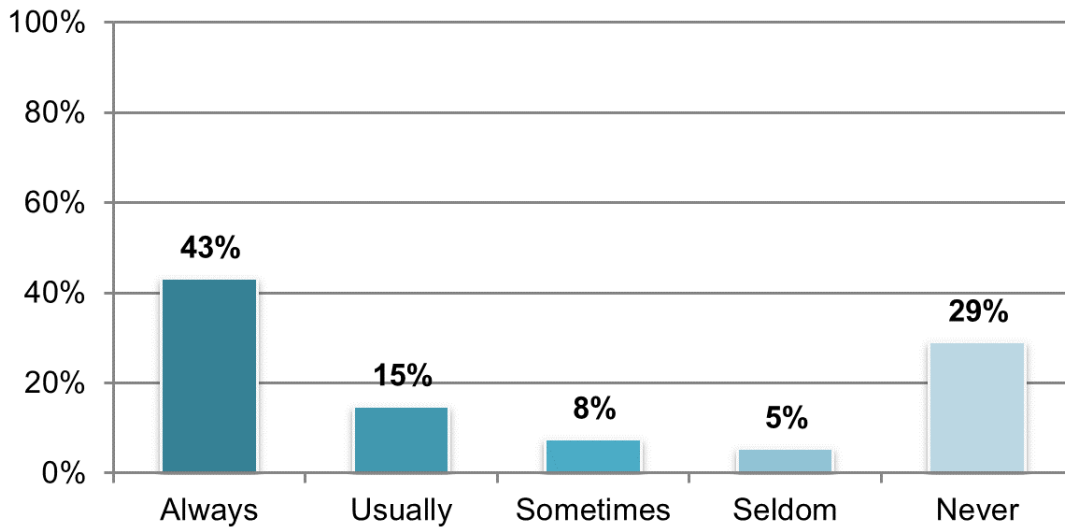


Table Q38. Do you choose the individual support workers who work directly with your family?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|------------|--------------|
| Significantly Above Average | | | | | | |
| OK | 61% | 16% | 9% | 4% | 11% | 313 |
| FL | 60% | 21% | 4% | 2% | 12% | 316 |
| LA | 59% | 12% | 8% | 4% | 18% | 346 |
| UT | 58% | 17% | 6% | 4% | 15% | 566 |
| Within Average Range | | | | | | |
| NC | 50% | 20% | 6% | 3% | 21% | 193 |
| KY | 50% | 17% | 6% | 7% | 21% | 138 |
| OH | 44% | 9% | 6% | 4% | 37% | 383 |
| SC | 34% | 12% | 10% | 5% | 38% | 163 |
| Significantly Below Average | | | | | | |
| MO | 35% | 16% | 6% | 10% | 33% | 286 |
| GA | 33% | 9% | 7% | 7% | 44% | 337 |
| MI | 32% | 15% | 8% | 6% | 39% | 384 |
| PA | 30% | 16% | 11% | 7% | 35% | 285 |
| MD | 15% | 11% | 11% | 9% | 54% | 316 |
| NCI Average | 43% | 15% | 8% | 5% | 29% | 4,026 |

Family Member Chooses Individual Support Workers Who Work Directly With Family

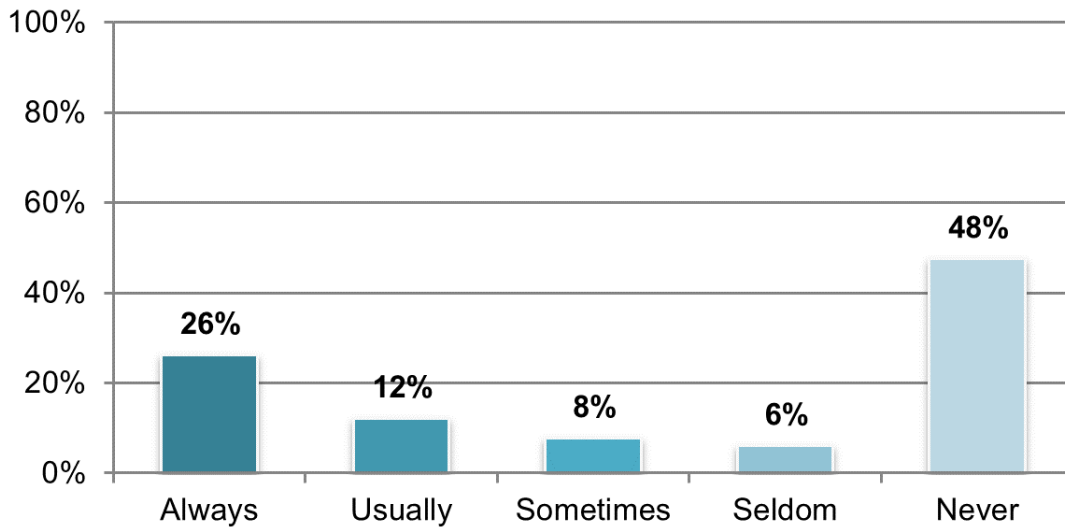


Table Q39. Does your family member choose the individual support workers who work directly with your family?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|------------|--------------|
| Significantly Above Average | | | | | | |
| OK | 41% | 10% | 7% | 8% | 34% | 284 |
| FL | 40% | 17% | 7% | 5% | 31% | 298 |
| LA | 35% | 12% | 9% | 4% | 40% | 315 |
| Within Average Range | | | | | | |
| KY | 30% | 18% | 7% | 7% | 39% | 120 |
| NC | 29% | 16% | 7% | 3% | 45% | 179 |
| UT | 29% | 12% | 8% | 7% | 44% | 513 |
| OH | 24% | 6% | 6% | 3% | 61% | 361 |
| MO | 22% | 15% | 6% | 9% | 47% | 276 |
| PA | 21% | 12% | 8% | 7% | 53% | 277 |
| MI | 21% | 12% | 9% | 6% | 51% | 369 |
| GA | 20% | 8% | 9% | 8% | 55% | 324 |
| SC | 19% | 9% | 11% | 5% | 55% | 150 |
| Significantly Below Average | | | | | | |
| MD | 11% | 11% | 8% | 8% | 62% | 282 |
| NCI Average | 26% | 12% | 8% | 6% | 48% | 3,748 |

Respondent Can Choose Different Support Workers If Desired

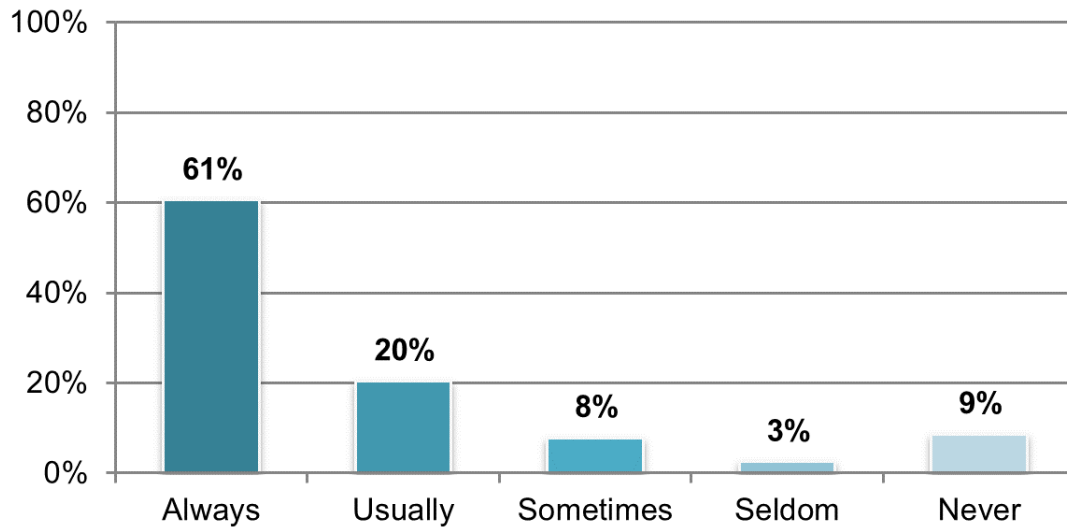


Table Q40. Can you choose different support workers if you want to?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| FL | 72% | 21% | 3% | 2% | 3% | 273 |
| UT | 70% | 19% | 5% | 1% | 5% | 484 |
| Within Average Range | | | | | | |
| LA | 67% | 19% | 6% | 5% | 3% | 310 |
| OK | 67% | 18% | 8% | 2% | 5% | 281 |
| OH | 66% | 16% | 7% | 2% | 10% | 311 |
| KY | 65% | 18% | 8% | 3% | 7% | 118 |
| MO | 60% | 20% | 7% | 2% | 10% | 205 |
| NC | 59% | 29% | 6% | 1% | 5% | 162 |
| GA | 58% | 19% | 7% | 3% | 14% | 222 |
| SC | 56% | 16% | 15% | 2% | 11% | 114 |
| MI | 55% | 23% | 9% | 2% | 11% | 258 |
| PA | 52% | 27% | 8% | 4% | 9% | 202 |
| Significantly Below Average | | | | | | |
| MD | 41% | 21% | 14% | 5% | 21% | 175 |
| NCI Average | 61% | 20% | 8% | 3% | 9% | 3,115 |

Respondent Chose Case Manager/Service Coordinator

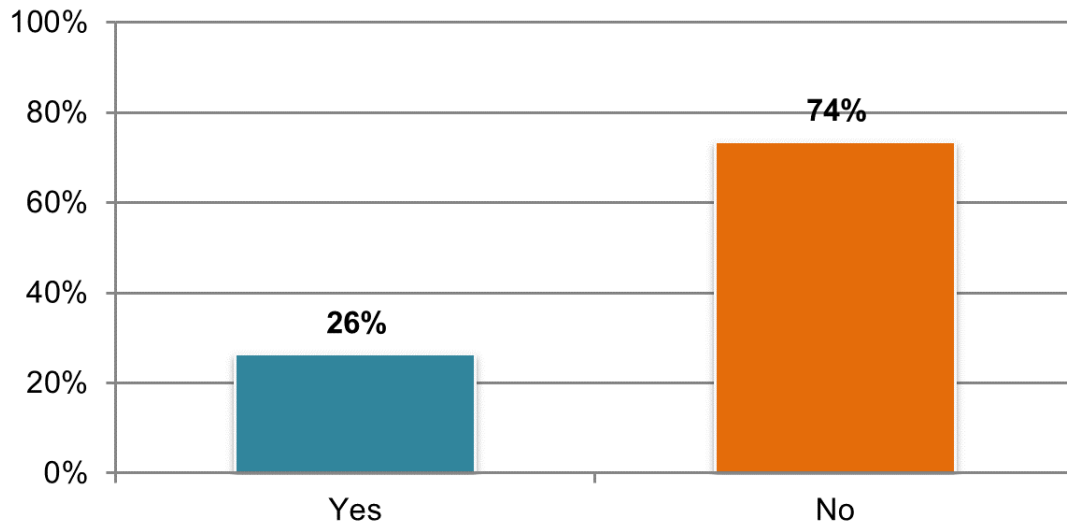


Table Q41. Did you choose your family member's case manager/service coordinator?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| UT | 67% | 33% | 597 |
| FL | 66% | 34% | 334 |
| LA | 51% | 49% | 342 |
| Within Average Range | | | |
| KY | 26% | 74% | 142 |
| PA | 20% | 80% | 345 |
| NC | 20% | 80% | 203 |
| Significantly Below Average | | | |
| SC | 16% | 84% | 181 |
| OK | 16% | 84% | 344 |
| MI | 15% | 85% | 438 |
| GA | 14% | 86% | 400 |
| MD | 13% | 87% | 352 |
| OH | 10% | 90% | 401 |
| MO | 10% | 90% | 365 |
| NCI Average | 26% | 74% | 4,444 |

Family Member Chose Case Manager/Service Coordinator

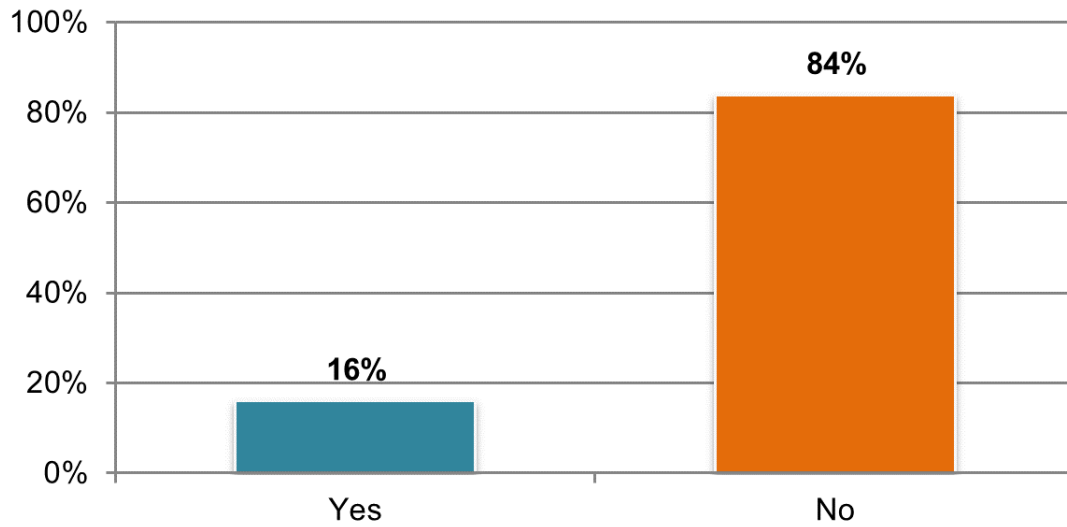


Table Q42. Did your family member choose his/her case manager/service coordinator?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| FL | 43% | 57% | 324 |
| UT | 31% | 69% | 556 |
| LA | 27% | 73% | 333 |
| Within Average Range | | | |
| KY | 16% | 84% | 140 |
| OK | 13% | 87% | 332 |
| PA | 12% | 88% | 341 |
| NC | 12% | 88% | 202 |
| SC | 10% | 90% | 175 |
| Significantly Below Average | | | |
| MD | 11% | 89% | 346 |
| MI | 10% | 90% | 435 |
| GA | 10% | 90% | 395 |
| OH | 7% | 93% | 394 |
| MO | 6% | 94% | 363 |
| NCI Average | 16% | 84% | 4,336 |

Respondent Has Control or Input Over Hiring and Management of Support Workers

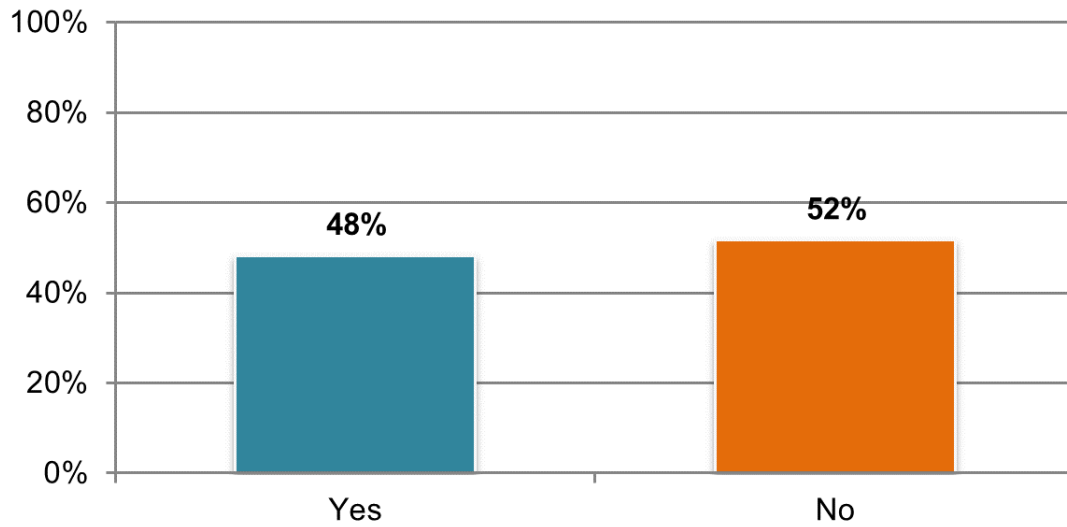


Table Q43. Do you have control and/or input over the hiring and management of your family member's support workers?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| FL | 77% | 23% | 285 |
| UT | 71% | 29% | 524 |
| OK | 67% | 33% | 296 |
| LA | 66% | 34% | 329 |
| Within Average Range | | | |
| NC | 57% | 43% | 182 |
| KY | 53% | 47% | 131 |
| Significantly Below Average | | | |
| PA | 40% | 60% | 276 |
| MI | 39% | 61% | 347 |
| OH | 39% | 61% | 368 |
| MO | 35% | 65% | 271 |
| GA | 29% | 71% | 346 |
| SC | 28% | 72% | 155 |
| MD | 25% | 75% | 273 |
| NCI Average | 48% | 52% | 3,783 |

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

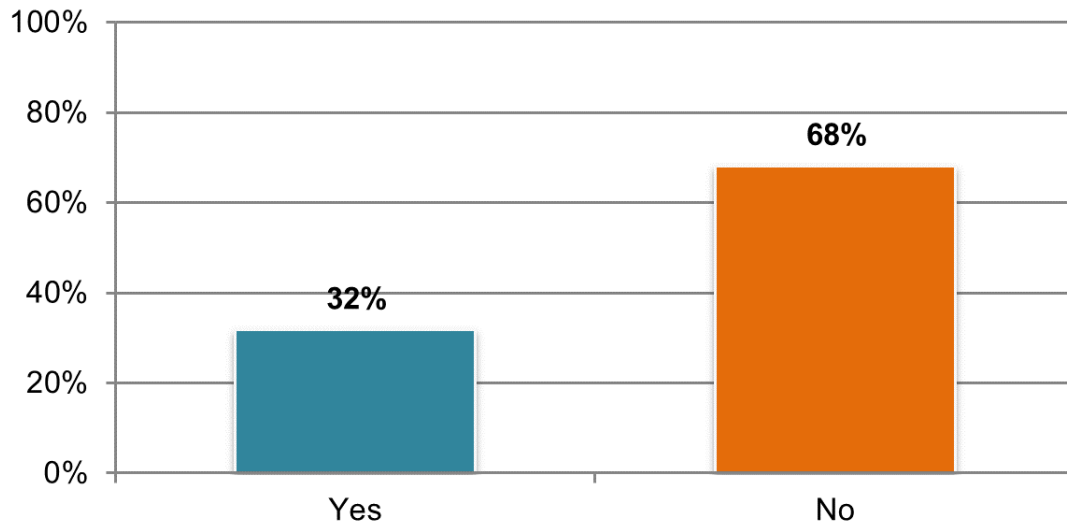


Table Q44. Does your family member have control and/or input over the hiring and management of his/her support workers?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| FL | 54% | 46% | 270 |
| OK | 45% | 55% | 278 |
| Within Average Range | | | |
| NC | 40% | 60% | 169 |
| LA | 38% | 62% | 312 |
| KY | 38% | 62% | 134 |
| UT | 36% | 64% | 495 |
| MI | 30% | 70% | 357 |
| MO | 27% | 73% | 266 |
| PA | 27% | 73% | 275 |
| Significantly Below Average | | | |
| OH | 25% | 75% | 358 |
| GA | 19% | 81% | 336 |
| SC | 18% | 82% | 147 |
| MD | 17% | 83% | 270 |
| NCI Average | 32% | 68% | 3,667 |

Respondent Knows How Much Money Is Spent by the ID/DD Agency on Family Member's Behalf

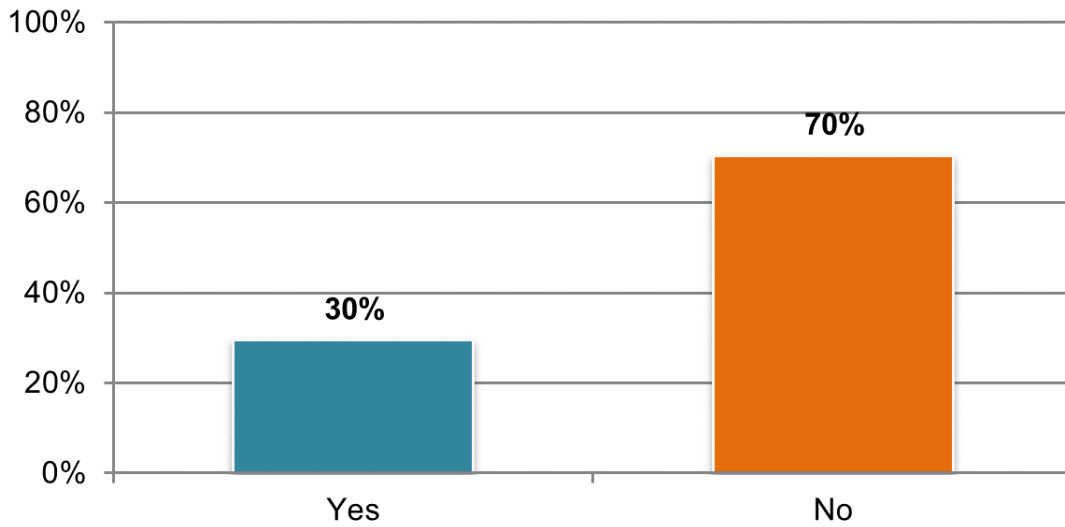


Table Q45. Do you know how much money is spent by the ID/DD agency on behalf of your family member with a developmental disability?⁶

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| FL | 62% | 38% | 352 |
| OK | 51% | 49% | 375 |
| UT | 45% | 55% | 627 |
| Within Average Range | | | |
| KY | 33% | 67% | 147 |
| SC | 29% | 71% | 193 |
| PA | 28% | 72% | 369 |
| GA | 27% | 73% | 426 |
| Significantly Below Average | | | |
| LA | 24% | 76% | 370 |
| MO | 19% | 81% | 372 |
| OH | 18% | 82% | 425 |
| MI | 18% | 82% | 467 |
| MD | 16% | 84% | 361 |
| NC | 15% | 85% | 220 |
| NCI Average | 30% | 70% | 4,704 |

⁶ 'Don't know' responses are included with 'no' responses.

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

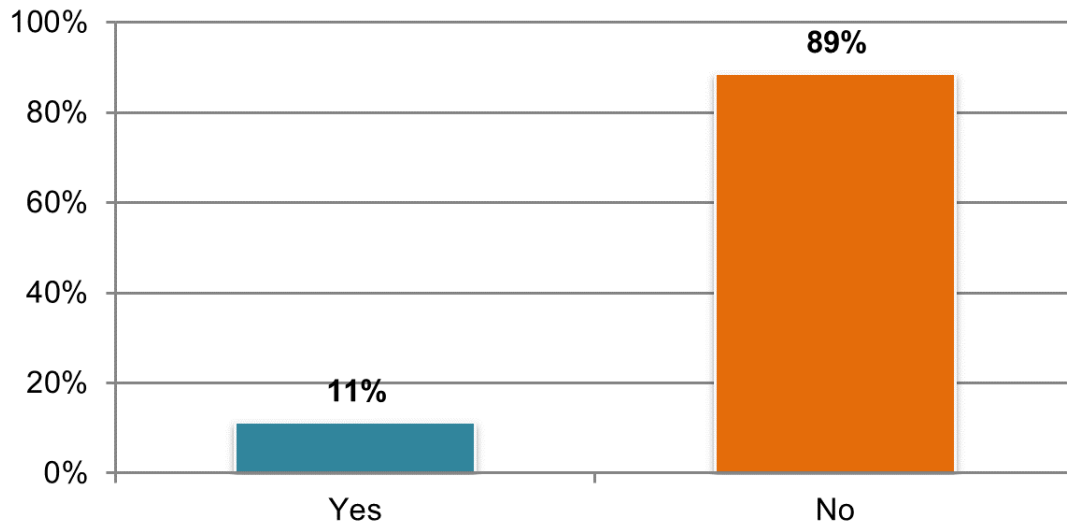


Table Q46. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| FL | 30% | 70% | 323 |
| OK | 19% | 81% | 346 |
| Within Average Range | | | |
| KY | 15% | 85% | 138 |
| SC | 13% | 87% | 180 |
| GA | 12% | 88% | 406 |
| UT | 12% | 88% | 564 |
| PA | 10% | 90% | 345 |
| LA | 9% | 91% | 340 |
| Significantly Below Average | | | |
| NC | 6% | 94% | 211 |
| MD | 6% | 94% | 354 |
| MO | 6% | 94% | 357 |
| MI | 5% | 95% | 453 |
| OH | 4% | 96% | 413 |
| NCI Average | 11% | 89% | 4,430 |

Respondent Has a Say in How ID/DD Agency Money Is Spent

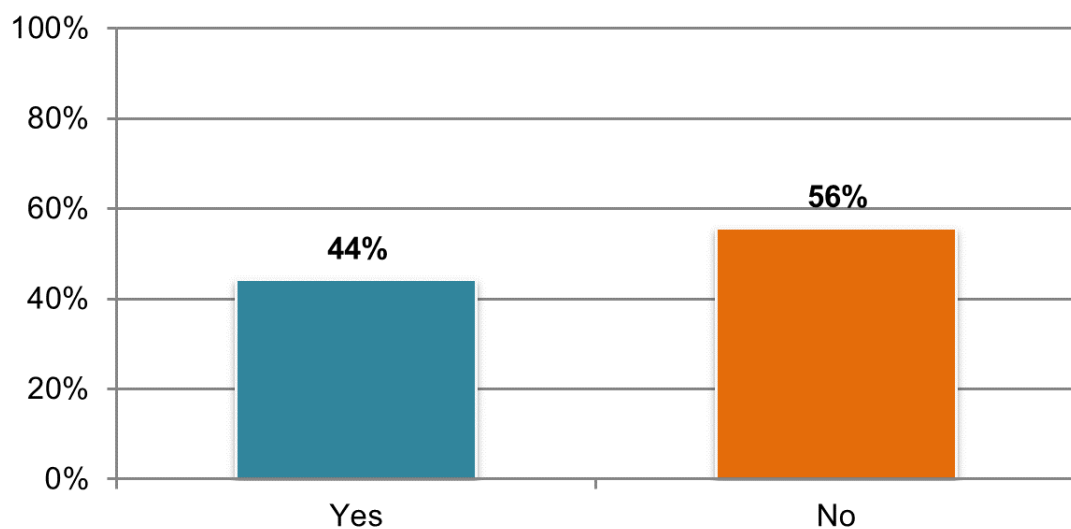


Table Q47. Do you have a say in how this money is spent?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| UT | 75% | 25% | 507 |
| OK | 69% | 31% | 308 |
| FL | 67% | 33% | 293 |
| KY | 57% | 43% | 116 |
| Within Average Range | | | |
| PA | 50% | 50% | 233 |
| OH | 48% | 52% | 361 |
| GA | 42% | 58% | 325 |
| Significantly Below Average | | | |
| MO | 36% | 64% | 276 |
| SC | 31% | 69% | 128 |
| LA | 30% | 70% | 269 |
| MI | 26% | 74% | 320 |
| NC | 23% | 77% | 162 |
| MD | 22% | 78% | 253 |
| NCI Average | 44% | 56% | 3,551 |

Respondent Has All Information Needed to Decide How to Spend ID/DD Agency Money

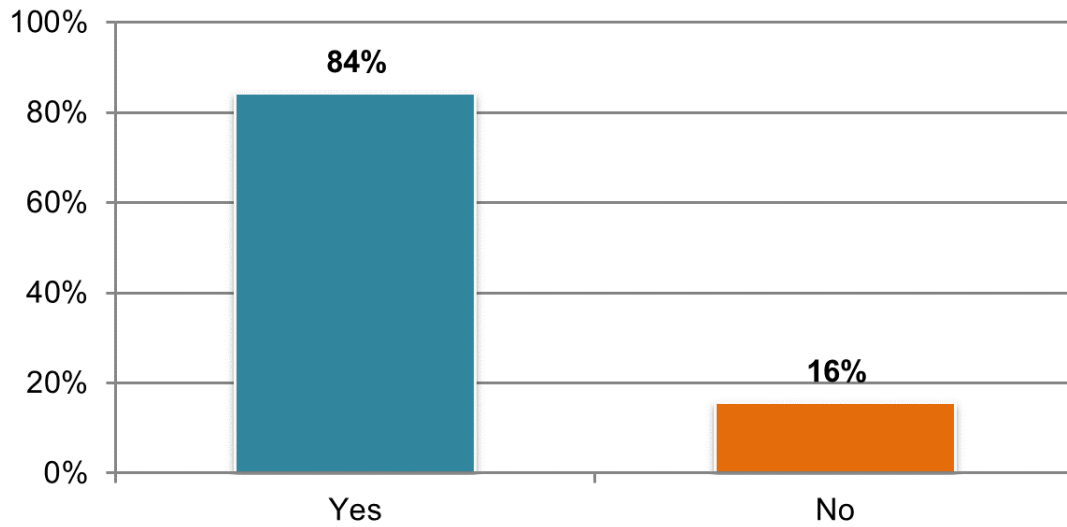


Table Q47a. If you have a say in how ID/DD agency money is spent, do you have all the information you need to make decisions about how to spend this money?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| OH | 93% | 7% | 164 |
| MO | 92% | 8% | 88 |
| FL | 92% | 8% | 174 |
| OK | 91% | 9% | 195 |
| UT | 90% | 10% | 329 |
| Within Average Range | | | |
| SC | 88% | 13% | 32 |
| MI | 86% | 14% | 74 |
| PA | 86% | 14% | 106 |
| LA | 83% | 17% | 66 |
| KY | 81% | 19% | 63 |
| MD | 73% | 27% | 45 |
| NC | 69% | 31% | 32 |
| Significantly Below Average | | | |
| GA | 72% | 28% | 117 |
| NCI Average | 84% | 16% | 1,485 |

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

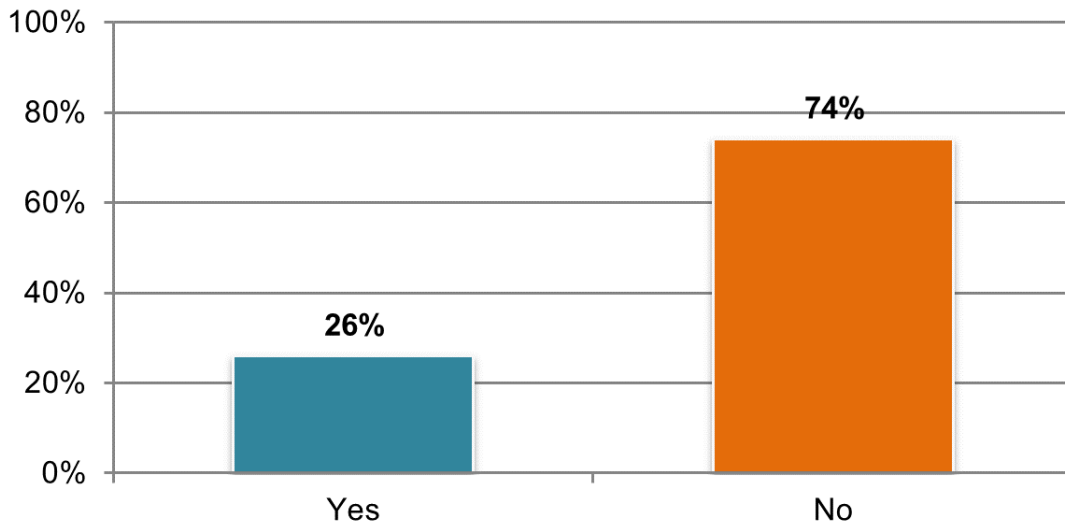


Table Q48. Does your family member have a say in how this money is spent?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| OK | 42% | 58% | 285 |
| FL | 41% | 59% | 269 |
| UT | 32% | 68% | 448 |
| Within Average Range | | | |
| KY | 32% | 68% | 113 |
| PA | 29% | 71% | 230 |
| LA | 26% | 74% | 207 |
| OH | 24% | 76% | 354 |
| GA | 22% | 78% | 301 |
| SC | 20% | 80% | 112 |
| Significantly Below Average | | | |
| MI | 19% | 81% | 317 |
| MO | 18% | 82% | 263 |
| MD | 18% | 82% | 242 |
| NC | 15% | 85% | 157 |
| NCI Average | 26% | 74% | 3,298 |

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

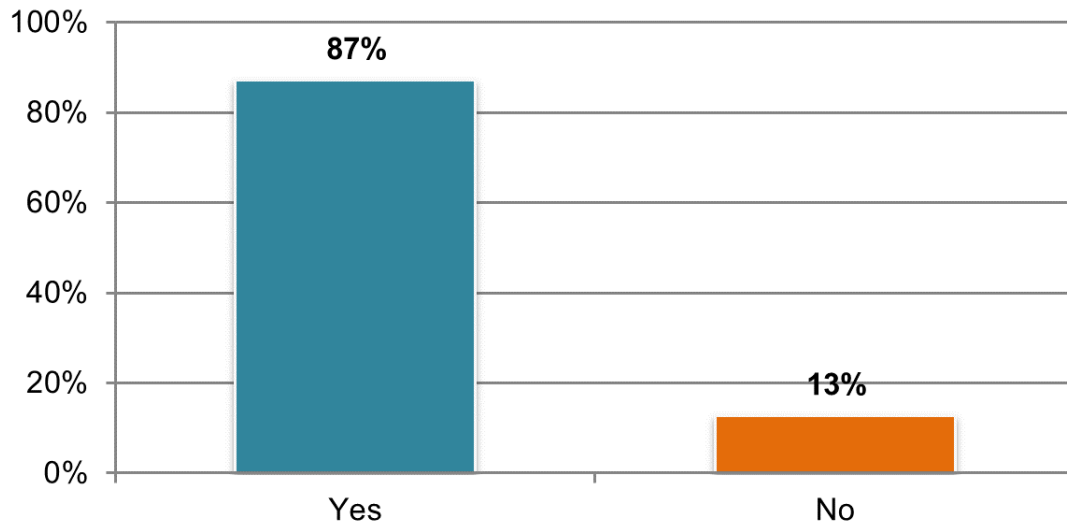


Table Q48a. If your family member has a say in how agency money is spent, does your family member have all the information s/he needs to make decisions about how to spend this money?⁷

| State | Yes | No | N |
|------------------------------------|------------|------------|------------|
| Significantly Above Average | | | |
| FL | 96% | 4% | 96 |
| Within Average Range | | | |
| OH | 92% | 8% | 77 |
| UT | 92% | 8% | 114 |
| PA | 92% | 8% | 61 |
| OK | 92% | 8% | 107 |
| MO | 88% | 12% | 43 |
| LA | 88% | 12% | 51 |
| SC | 86% | 14% | 21 |
| GA | 84% | 16% | 58 |
| MI | 83% | 17% | 52 |
| KY | 80% | 20% | 30 |
| MD | 74% | 26% | 38 |
| NC | n/a | n/a | n/a |
| NCI Average | 87% | 13% | 748 |

⁷ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Community Connections

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

The vast majority of respondents report that their family member participates in community activities (88%); among those who don't, nearly one-quarter cite a lack of transportation as the main cause (23%). Nearly eight out of ten respondents report that their family member has friends or relationships with people other than paid support workers or family (79%). Almost two-thirds of respondents report that their family member has enough support to work or volunteer in the community (64%).

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Family Member Participates in Community Activities

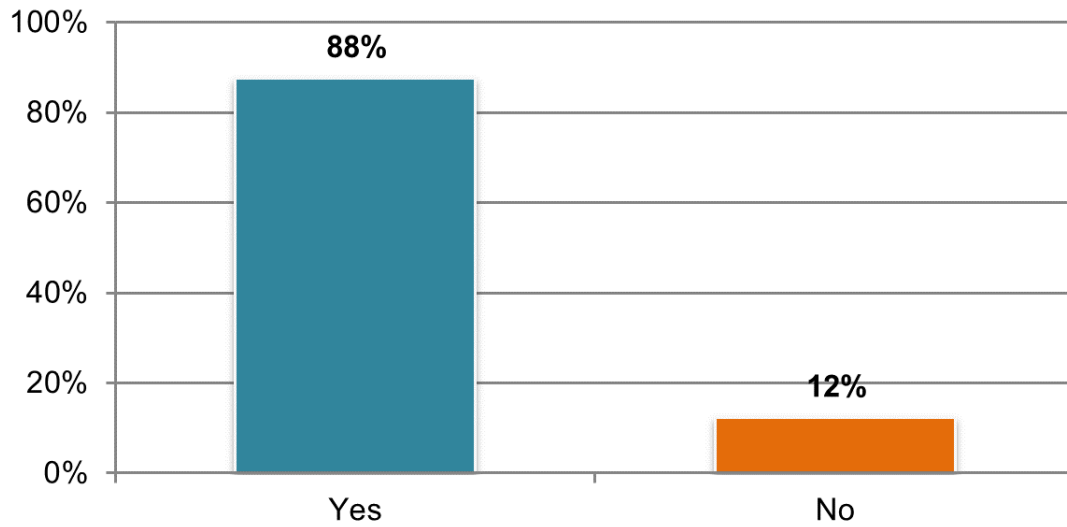
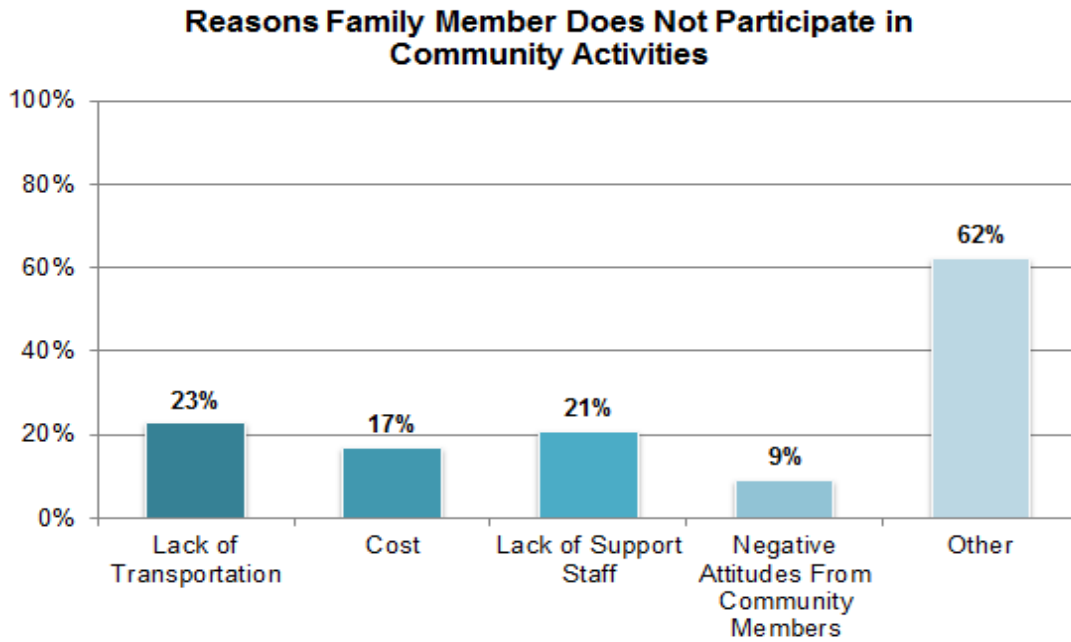


Table Q49. Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| KY | 95% | 5% | 149 |
| OH | 94% | 6% | 431 |
| OK | 92% | 8% | 375 |
| Within Average Range | | | |
| PA | 91% | 9% | 392 |
| UT | 90% | 10% | 629 |
| MI | 89% | 11% | 476 |
| GA | 88% | 12% | 419 |
| LA | 87% | 13% | 376 |
| FL | 86% | 14% | 342 |
| MD | 85% | 15% | 362 |
| NC | 84% | 16% | 236 |
| Significantly Below Average | | | |
| MO | 81% | 19% | 383 |
| SC | 78% | 22% | 200 |
| NCI Average | 88% | 12% | 4,770 |

Table Q49a. If your family member doesn't participate in community activities, why not?⁸

| State | Lack of Transportation | Cost | Lack of Support Staff | Negative Attitudes From Community Members | Other |
|-----------------------------|------------------------|------------|-----------------------|---|------------|
| Within Average Range | | | | | |
| FL | 21% | 36% | 18% | 23% | 46% |
| GA | 33% | 15% | 21% | 12% | 24% |
| KY | n/a | n/a | n/a | n/a | n/a |
| LA | 27% | 10% | 24% | 10% | 63% |
| MD | 30% | 15% | 34% | 6% | 53% |
| MI | 43% | 36% | 43% | 11% | 49% |
| MO | 31% | 25% | 8% | 8% | 54% |
| NC | 19% | 19% | 22% | 14% | 57% |
| OH | 0% | 4% | 7% | 4% | 86% |
| OK | 19% | 15% | 23% | 12% | 73% |
| PA | 9% | 5% | 9% | 9% | 68% |
| SC | 29% | 24% | 24% | 7% | 49% |
| UT | 20% | 18% | 14% | 12% | 70% |
| NCI Average | 23% | 17% | 21% | 9% | 62% |

⁸ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Family Member Has Friends or Relationships With People Other Than Paid Support Workers or Family

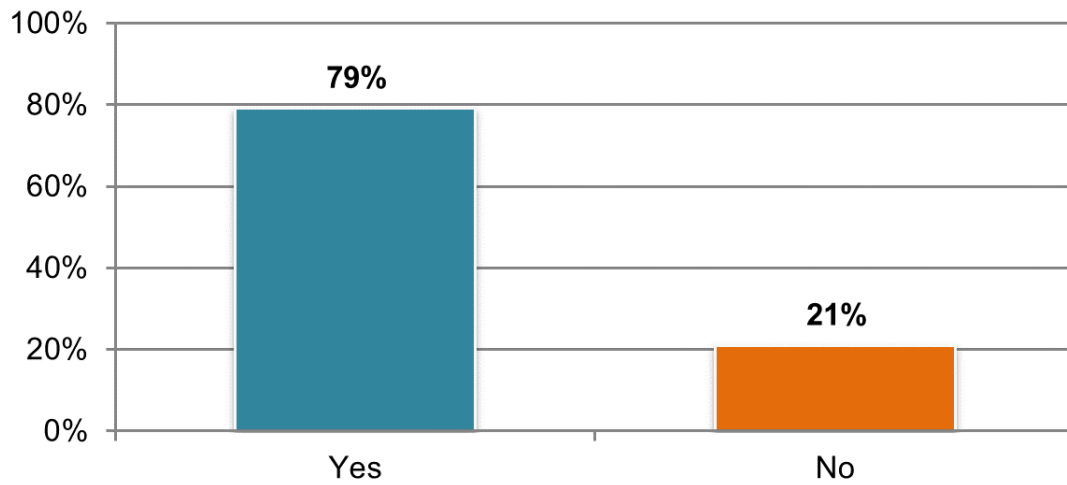


Table Q50. Does your family member have friends or relationships with persons other than paid support workers or family?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| OK | 86% | 14% | 367 |
| Within Average Range | | | |
| KY | 84% | 16% | 148 |
| PA | 82% | 18% | 381 |
| MO | 81% | 19% | 383 |
| OH | 80% | 20% | 430 |
| MD | 79% | 21% | 354 |
| FL | 79% | 21% | 331 |
| GA | 78% | 22% | 416 |
| LA | 78% | 22% | 363 |
| MI | 77% | 23% | 460 |
| SC | 76% | 24% | 196 |
| UT | 75% | 25% | 629 |
| NC | 73% | 27% | 236 |
| NCI Average | 79% | 21% | 4,694 |

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

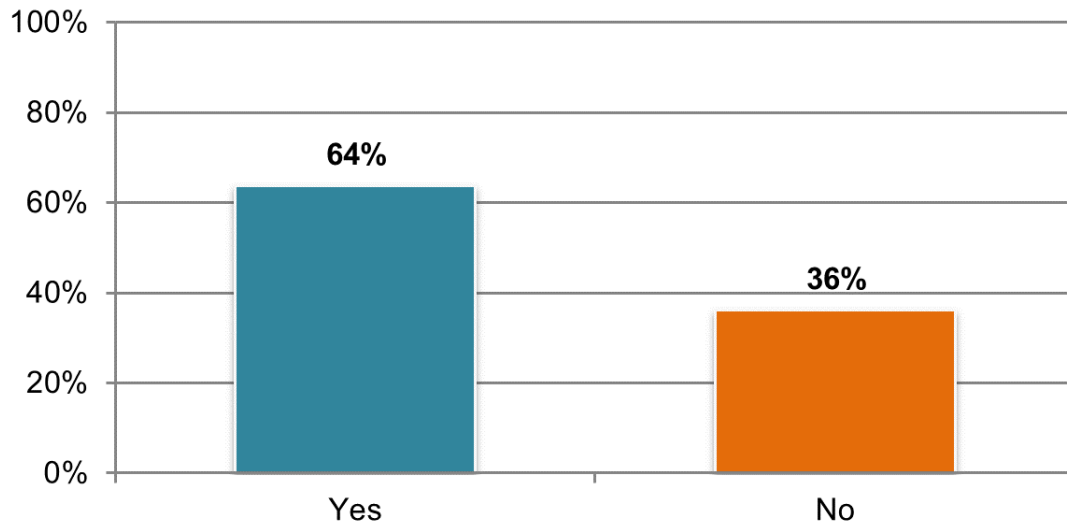


Table Q51. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Within Average Range | | | |
| KY | 72% | 28% | 126 |
| PA | 71% | 29% | 283 |
| OK | 69% | 31% | 294 |
| MD | 67% | 33% | 276 |
| MI | 66% | 34% | 373 |
| MO | 66% | 34% | 294 |
| UT | 65% | 35% | 458 |
| GA | 64% | 36% | 337 |
| OH | 63% | 37% | 383 |
| NC | 61% | 39% | 194 |
| LA | 60% | 40% | 282 |
| SC | 54% | 46% | 145 |
| Significantly Below Average | | | |
| FL | 51% | 49% | 247 |
| NCI Average | 64% | 36% | 3,692 |

Satisfaction With Services and Supports

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

Two-fifths of respondents report that they are always satisfied with the services and supports their family receives (40%). Almost two-thirds report that they know the process for filing a complaint or grievance against provider agencies or staff (62%) and four-fifths indicate that they know how to report abuse or neglect (80%).

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Respondent Is Satisfied With the Services and Supports Family Receives

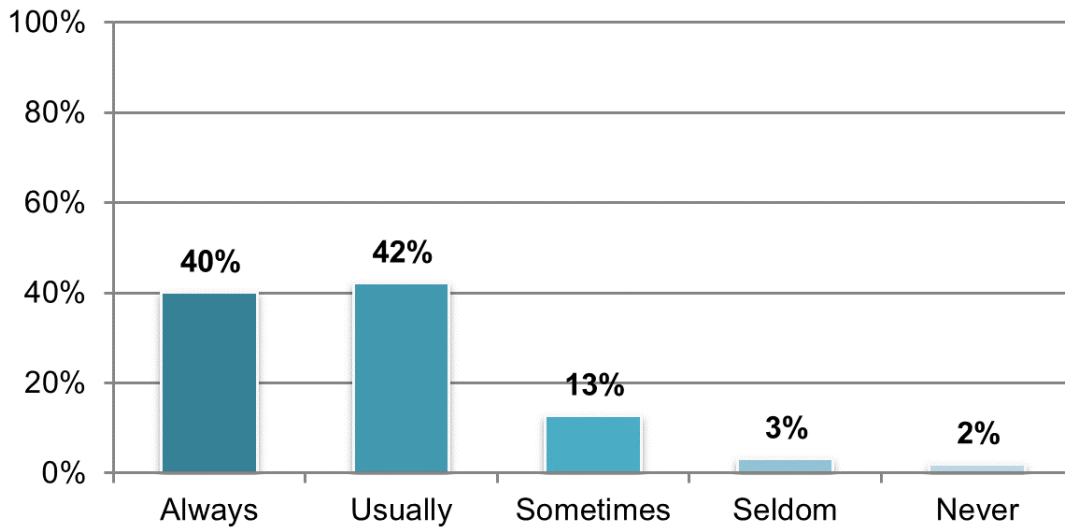


Table Q52. Overall, are you satisfied with the services and supports your family currently receives?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|------------------------------------|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above Average | | | | | | |
| OH | 58% | 30% | 9% | 1% | 1% | 424 |
| LA | 48% | 35% | 14% | 1% | 2% | 371 |
| MO | 48% | 36% | 9% | 4% | 3% | 374 |
| Within Average Range | | | | | | |
| SC | 44% | 32% | 15% | 5% | 3% | 183 |
| UT | 40% | 53% | 6% | 1% | 1% | 634 |
| PA | 40% | 45% | 12% | 2% | 1% | 367 |
| GA | 37% | 42% | 15% | 4% | 2% | 413 |
| FL | 37% | 41% | 17% | 4% | 1% | 340 |
| OK | 36% | 47% | 12% | 4% | 1% | 368 |
| KY | 35% | 52% | 9% | 3% | 1% | 150 |
| MI | 35% | 45% | 15% | 4% | 2% | 453 |
| Significantly Below Average | | | | | | |
| MD | 31% | 45% | 17% | 5% | 3% | 357 |
| NC | 30% | 45% | 15% | 4% | 5% | 228 |
| NCI Average | 40% | 42% | 13% | 3% | 2% | 4,662 |

Respondent Knows Process for Filing a Complaint or Grievance Against Provider Agencies or Staff

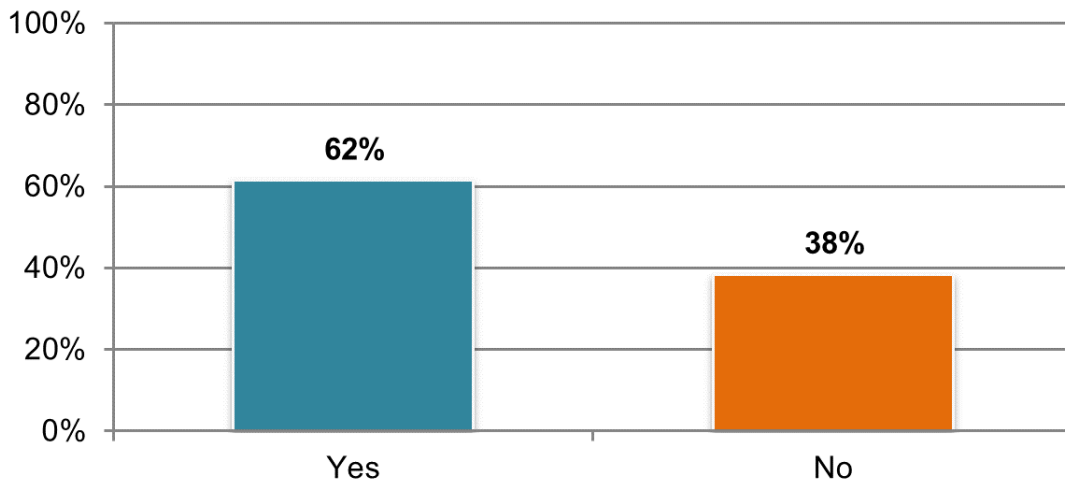


Table Q53. Do you know the process for filing a complaint or grievance against provider agencies or staff?⁹

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| OK | 84% | 16% | 364 |
| LA | 78% | 22% | 373 |
| FL | 73% | 27% | 338 |
| OH | 71% | 29% | 424 |
| MI | 69% | 31% | 457 |
| Within Average Range | | | |
| PA | 67% | 33% | 360 |
| KY | 65% | 35% | 147 |
| UT | 63% | 37% | 618 |
| NC | 57% | 43% | 230 |
| Significantly Below Average | | | |
| MO | 53% | 47% | 361 |
| SC | 46% | 54% | 192 |
| GA | 40% | 60% | 416 |
| MD | 34% | 66% | 364 |
| NCI Average | 62% | 38% | 4,644 |

⁹ 'Don't know' responses are included with 'no' responses.

Respondent Is Satisfied With the Way Complaints or Grievances Against Provider Agencies or Staff Are Handled and Resolved

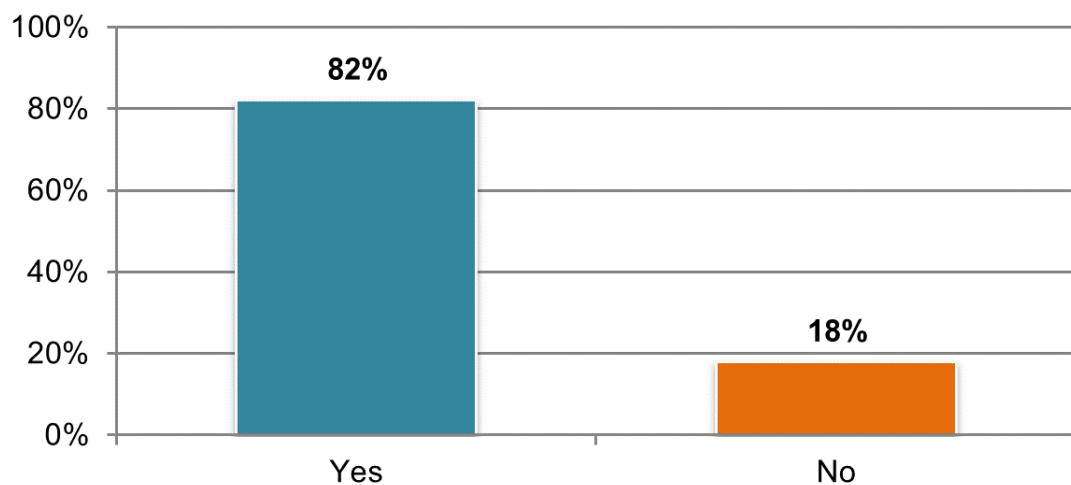


Table Q54. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| OH | 90% | 10% | 200 |
| UT | 89% | 11% | 239 |
| Within Average Range | | | |
| LA | 88% | 13% | 208 |
| PA | 86% | 14% | 132 |
| MO | 86% | 14% | 138 |
| KY | 85% | 15% | 62 |
| OK | 83% | 17% | 190 |
| GA | 83% | 17% | 176 |
| MI | 82% | 18% | 181 |
| SC | 81% | 19% | 72 |
| FL | 80% | 20% | 157 |
| Significantly Below Average | | | |
| NC | 69% | 31% | 104 |
| MD | 65% | 35% | 95 |
| NCI Average | 82% | 18% | 1,954 |

Respondent Knows How to Report Abuse or Neglect

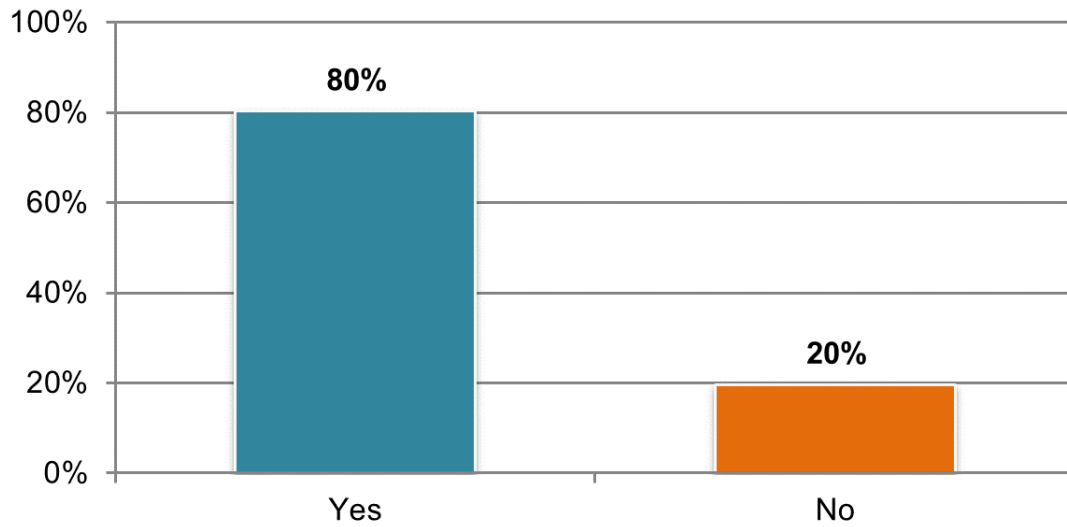


Table Q55. Do you know how to report abuse or neglect?¹⁰

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| FL | 93% | 7% | 331 |
| OK | 92% | 8% | 354 |
| KY | 89% | 11% | 143 |
| LA | 88% | 12% | 367 |
| OH | 87% | 13% | 433 |
| Within Average Range | | | |
| MI | 83% | 17% | 450 |
| PA | 81% | 19% | 358 |
| NC | 79% | 21% | 223 |
| MO | 78% | 22% | 377 |
| UT | 77% | 23% | 612 |
| SC | 72% | 28% | 187 |
| Significantly Below Average | | | |
| GA | 67% | 33% | 410 |
| MD | 59% | 41% | 343 |
| NCI Average | 80% | 20% | 4,588 |

¹⁰ 'Don't know' responses are included with 'no' responses.

Respondent Reported Abuse or Neglect in the Past Year

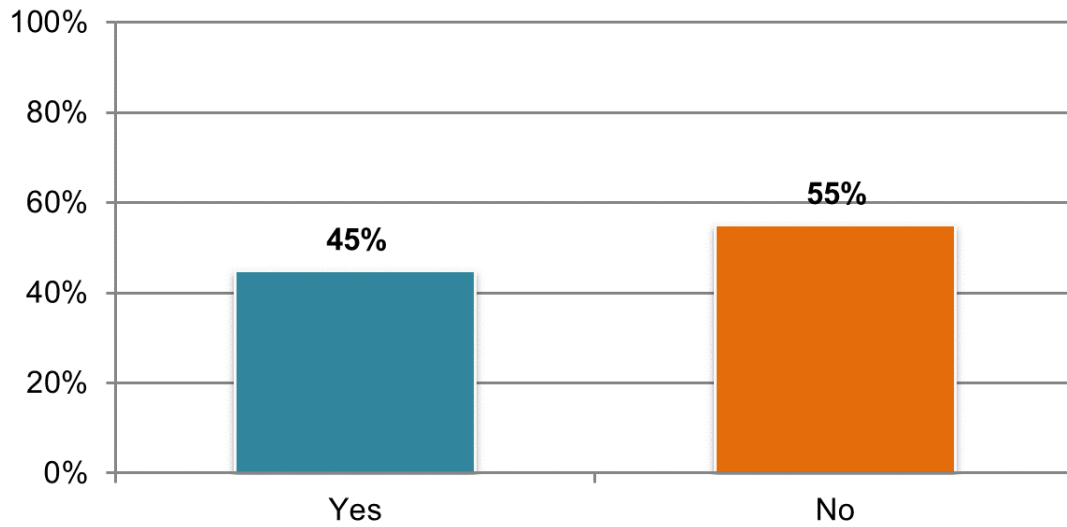


Table Q56. Within the past year, if abuse or neglect occurred, did you report it?¹¹

| State | Yes | No | N |
|------------------------------------|------------|------------|------------|
| Significantly Above Average | | | |
| NC | 76% | 24% | 46 |
| Within Average Range | | | |
| UT | 54% | 46% | 81 |
| GA | 53% | 47% | 75 |
| SC | 49% | 51% | 37 |
| MI | 47% | 53% | 74 |
| PA | 46% | 54% | 54 |
| LA | 45% | 55% | 53 |
| OK | 41% | 59% | 54 |
| FL | 33% | 67% | 51 |
| MD | 33% | 67% | 45 |
| MO | 31% | 69% | 68 |
| OH | 29% | 71% | 48 |
| KY | n/a | n/a | n/a |
| NCI Average | 45% | 55% | 686 |

¹¹ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Appropriate People Were Responsive to Report of Abuse or Neglect (Past Year)

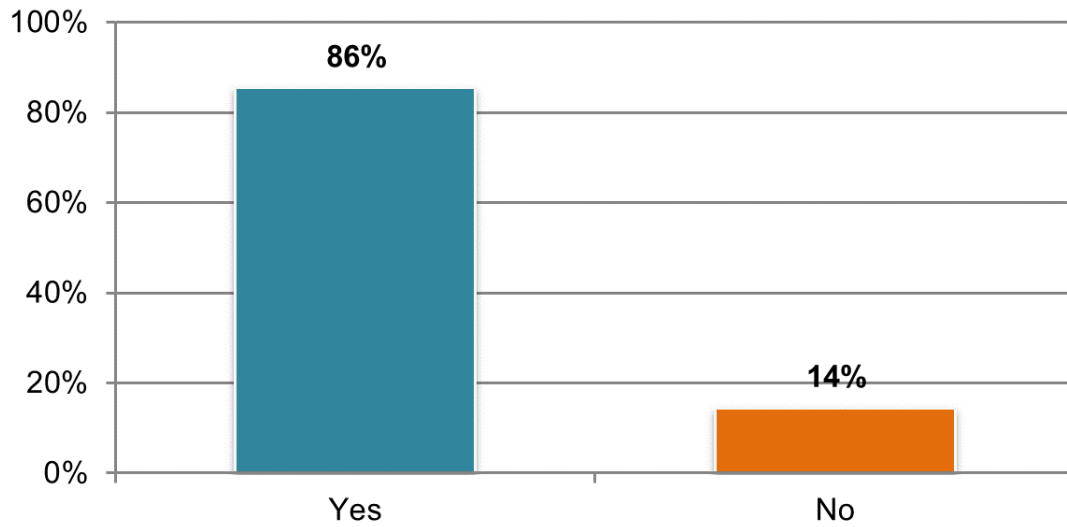


Table Q56a. If you reported abuse or neglect in the past year, were the appropriate people responsive to your report?¹²

| State | Yes | No | N |
|-----------------------------|------------|------------|------------|
| Within Average Range | | | |
| PA | 95% | 5% | 22 |
| LA | 90% | 10% | 20 |
| UT | 88% | 12% | 33 |
| GA | 87% | 13% | 30 |
| NC | 85% | 15% | 27 |
| MI | 68% | 32% | 28 |
| FL | n/a | n/a | n/a |
| KY | n/a | n/a | n/a |
| MD | n/a | n/a | n/a |
| MO | n/a | n/a | n/a |
| OH | n/a | n/a | n/a |
| OK | n/a | n/a | n/a |
| SC | n/a | n/a | n/a |
| NCI Average | 86% | 14% | 160 |

¹² An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Family Outcomes

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

The vast majority of all respondents indicate that services and supports have made a positive difference in the life of their family (94%). Eighty-one percent (81%) report that services and supports have reduced the family's out-of-pocket expenses for the family member's care. Almost one-quarter of all respondents report that services or supports were reduced, suspended, or terminated in the past year (24%); 70% of those respondents state that the change had a negative impact on the family or the family member.

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

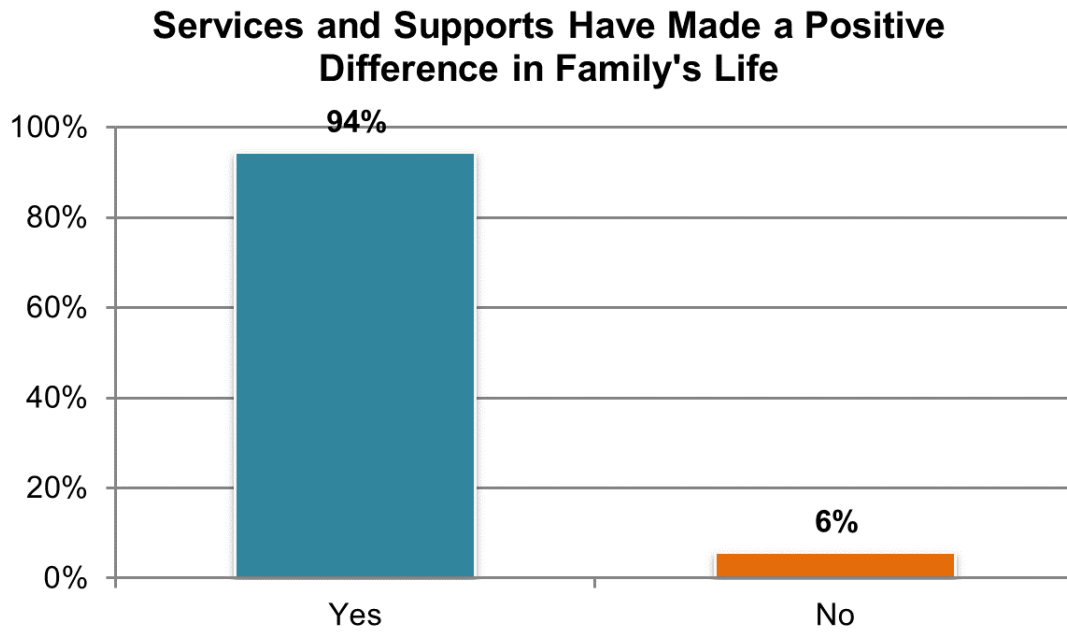


Table Q57. Do you feel that services and supports have made a positive difference in the life of your family?

| State | Yes | No | N |
|------------------------------------|------------|-----------|--------------|
| Significantly Above Average | | | |
| UT | 99% | 1% | 611 |
| Within Average Range | | | |
| KY | 97% | 3% | 149 |
| OK | 96% | 4% | 351 |
| PA | 96% | 4% | 345 |
| LA | 96% | 4% | 369 |
| FL | 95% | 5% | 320 |
| OH | 95% | 5% | 423 |
| MO | 94% | 6% | 337 |
| GA | 93% | 7% | 402 |
| MI | 92% | 8% | 421 |
| SC | 92% | 8% | 177 |
| NC | 92% | 8% | 212 |
| MD | 91% | 9% | 334 |
| NCI Average | 94% | 6% | 4,451 |

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

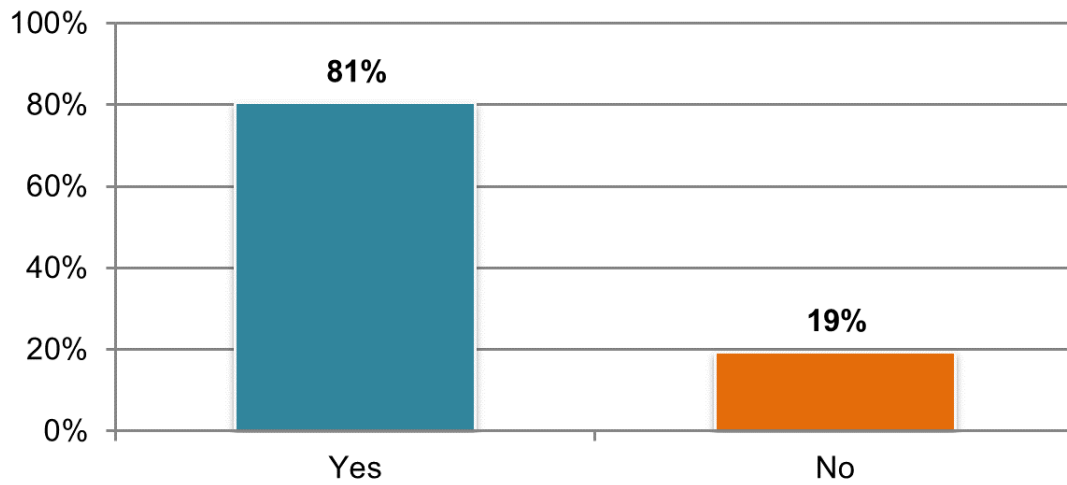


Table Q58. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care?

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| UT | 93% | 7% | 590 |
| OK | 91% | 9% | 339 |
| LA | 86% | 14% | 341 |
| Within Average Range | | | |
| KY | 88% | 12% | 138 |
| FL | 82% | 18% | 312 |
| GA | 81% | 19% | 367 |
| PA | 79% | 21% | 320 |
| OH | 78% | 22% | 405 |
| NC | 76% | 24% | 203 |
| MI | 76% | 24% | 388 |
| Significantly Below Average | | | |
| MD | 74% | 26% | 318 |
| MO | 72% | 28% | 289 |
| SC | 70% | 30% | 169 |
| NCI Average | 81% | 19% | 4,179 |

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

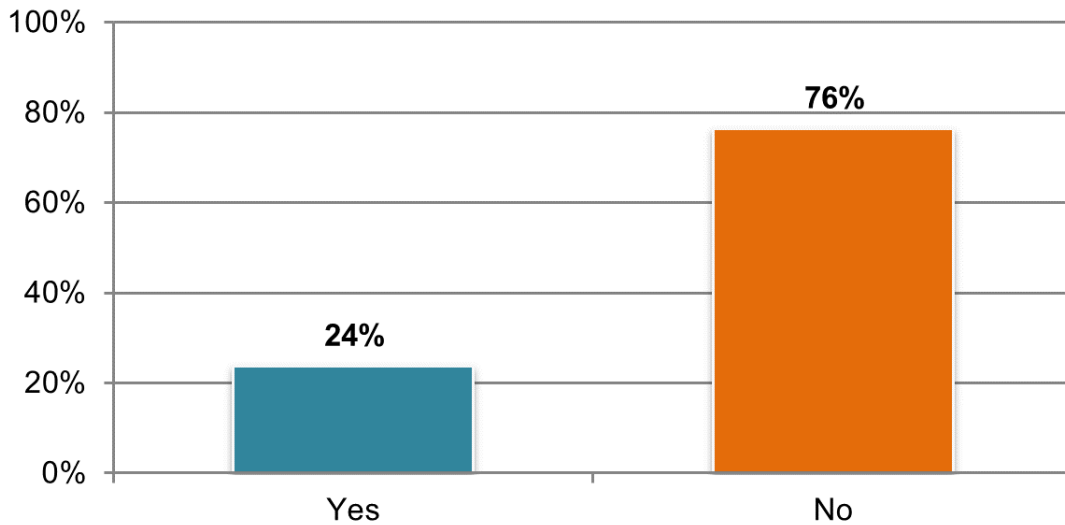


Table Q59. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?¹³

| State | Yes | No | N |
|------------------------------------|------------|------------|--------------|
| Significantly Above Average | | | |
| FL | 58% | 42% | 298 |
| NC | 43% | 57% | 206 |
| Within Average Range | | | |
| LA | 25% | 75% | 327 |
| GA | 23% | 77% | 339 |
| MI | 22% | 78% | 382 |
| OK | 22% | 78% | 315 |
| SC | 22% | 78% | 153 |
| PA | 20% | 80% | 313 |
| Significantly Below Average | | | |
| MD | 17% | 83% | 292 |
| MO | 17% | 83% | 305 |
| OH | 15% | 85% | 414 |
| KY | 12% | 88% | 145 |
| UT | 10% | 90% | 558 |
| NCI Average | 24% | 76% | 4,047 |

¹³ The 'yes' response is the less desired response; a higher average means more people reported services or supports were reduced, suspended or terminated in the past year.

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

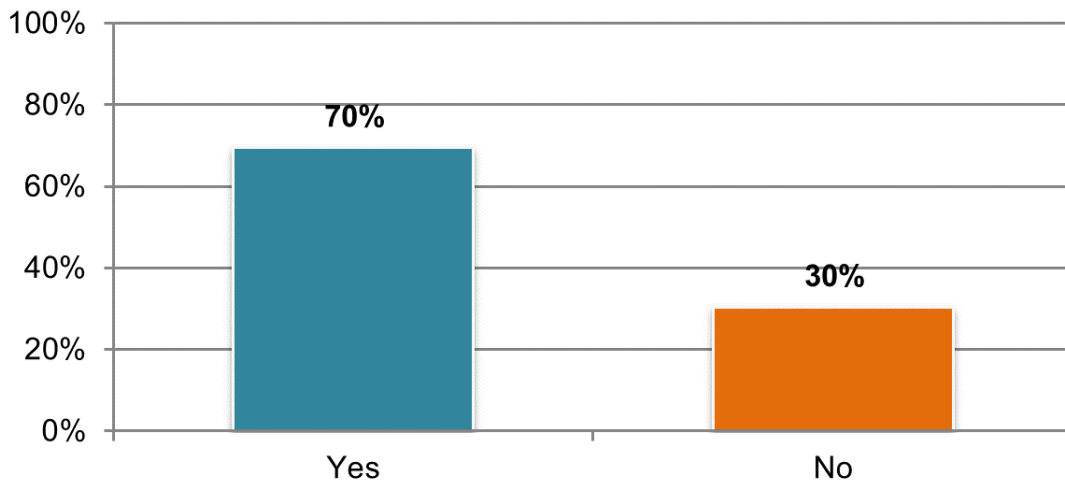


Table Q59a. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?¹⁴

| State | Yes | No | N |
|------------------------------------|------------|------------|------------|
| Significantly Above Average | | | |
| FL | 87% | 13% | 158 |
| Within Average Range | | | |
| MO | 77% | 23% | 44 |
| SC | 77% | 23% | 26 |
| MI | 75% | 25% | 76 |
| OK | 75% | 25% | 52 |
| MD | 73% | 27% | 44 |
| GA | 70% | 30% | 63 |
| NC | 68% | 32% | 72 |
| LA | 66% | 34% | 68 |
| PA | 58% | 42% | 45 |
| UT | 56% | 44% | 41 |
| OH | 53% | 47% | 62 |
| KY | n/a | n/a | n/a |
| NCI Average | 70% | 30% | 751 |

¹⁴ The 'yes' response is the less desired response; a higher average means more people reported reduction, suspension, or termination of services had a negative impact on the family.

An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

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 Human Services Research Institute (HSRI), launched the Core Indicators Project (CIP). The aim of the project was to support state developmental disabilities authorities in the development and implementation of performance and outcome indicators—and related data collection strategies—so that they could measure service delivery system performance. This effort, now called National Core Indicators (NCI), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI facilitates pooled knowledge, expertise, and resources among the states.

In 1997, 15 states convened to discuss the scope and content of a potential performance measurement framework. Directors and staff from these 15 states worked to identify the major domains and sub-domains of performance, indicators, measures, and data sources. The original 61 indicators, developed through a consensus process, were intended to provide a system-level “snapshot” of how well each state was performing. The states were guided by a set of criteria that was designed to select indicators that were:

1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of disability or residential setting

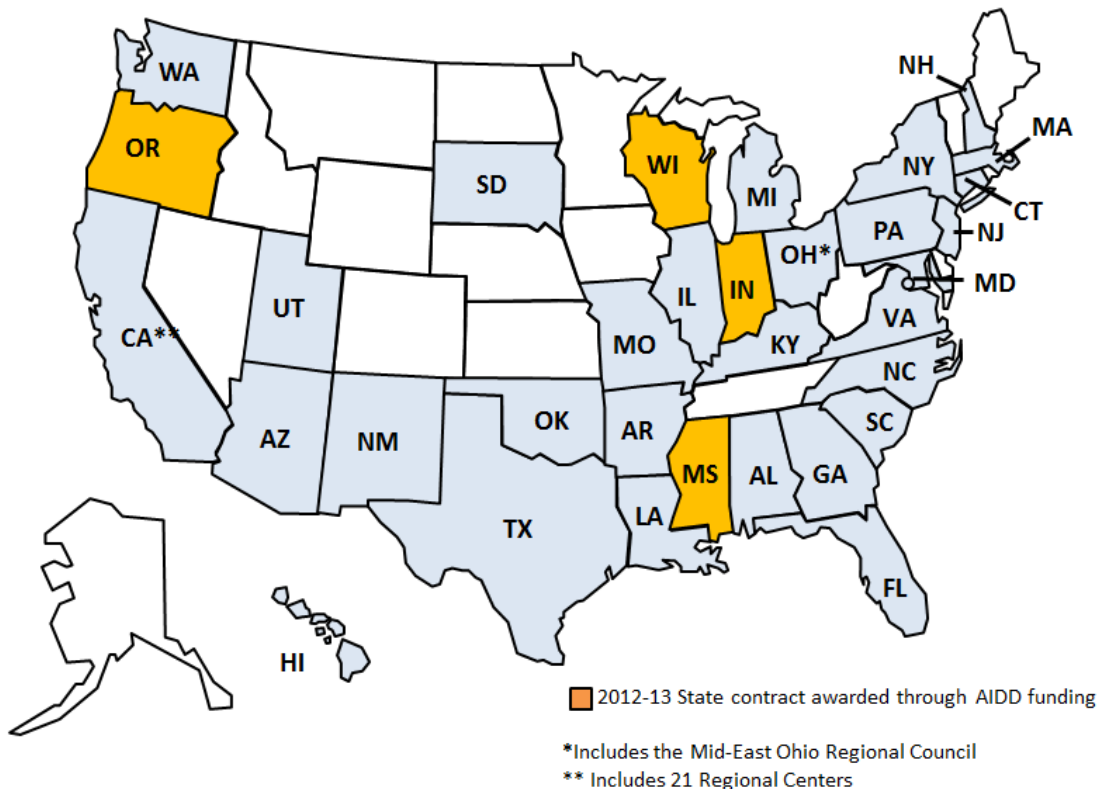
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

Since the initial field test, NCI 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 2012-2013 data collection cycle, 34 states and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and the participating states are shown in the chart below.

Chart 1. NCI State Participation 2012-13



The Core Indicators

The Core Indicators are the standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern, including employment, respect/rights, service planning, community inclusion, choice, and health and safety. An example of a Core Indicator would be, “The proportion of people who have a paid job in the community.” To see the entire list of Core Indicators, please visit <http://www.nationalcoreindicators.org/indicators>.

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly

participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

The current set of performance indicators includes approximately 100 consumer, family, system, and health and safety outcomes—outcomes that are important to understanding the overall health of public developmental disabilities agencies. Indicators are organized across five broad domains: Individual Outcomes; Health, Welfare and Rights; Staff Stability and Competency; Family Outcomes; and System Performance. Each domain is broken down into sub-domains (please see Table 1 on the following page). Four data sources are used to assess outcomes: the Adult Consumer Survey, three Family Surveys, a Provider Survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates).

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

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

Sub-Domains and Concern Statements

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

Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

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

Caution and Limitations

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

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

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

III. Methodology

This section describes the protocol used by states to select families to participate in the survey, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by NCI staff to aggregate and analyze the data.

Sampling & Administration

States were asked to administer the Adult Family Survey by selecting a random sample of at least 1,000 families who:

1. Had an adult individual with a developmental disability living at 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.¹⁵ 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%.¹⁶

Data Entry and Analysis

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

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

1. The respondent indicated the individual with a developmental disability lived outside the family home.
2. Demographic information was entered into the file but no survey questions were answered.

¹⁵ Ohio conducted surveys via phone, their data should be reviewed with caution.

¹⁶ See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

Statistical significance testing was conducted on each state’s “yes” or “always” response compared to the NCI average¹⁷; significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

Response Rates

During 2012-2013, 13 states administered the Adult Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The table below shows the number of surveys each state mailed, usable surveys returned, response rates, the number of individuals receiving services who were eligible to be drawn into the sample, and each state’s margin of error.

Adult Family Survey: State Response Rates¹⁸

| State | Number Eligible to Be Drawn Into the Sample | Surveys Mailed | Usable Surveys Returned | Response Rate | Margin of Error |
|-------|---|----------------|-------------------------|---------------|-----------------|
| FL | 14,414 | 1,700 | 381 | 22% | 5.0% |
| GA | 5,459 | 1,500 | 461 | 31% | 4.4% |
| LA | 3,158 | 1,500 | 393 | 26% | 4.6% |
| MD | 3,558 | 1,000 | 377 | 38% | 4.8% |
| MI | 12,954 | 1,500 | 493 | 33% | 4.3% |
| NC | 8,350 | 1,200 | 246 | 21% | 6.2% |
| OK | 1,519 | 1,519 | 391 | 26% | 4.3% |
| SC | 3,262 | 1,000 | 211 | 21% | 6.5% |
| UT | 1,800 | 1,400 | 653 | 47% | 3.1% |

¹⁷ The NCI Average is the sum of all state averages divided by the total number of states.

¹⁸ Kentucky, Missouri, Ohio, and Pennsylvania did not provide sampling information.