

Adult Family Survey

2017-18 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)

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N A S D D D S

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List of Abbreviations Used in This Report

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

Contents

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

| | |
|---|-----------|
| Respondents..... | 18 |
| Table 23. Respondent's Age | 19 |
| Table 24. Respondent's Health | 19 |
| Table 25. Respondent's Relationship to Family Member..... | 20 |
| Table 26. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services ∞ | 20 |
| Table 27. Number of Adults in Household (Not Including Family Member Receiving Services)..... | 21 |
| Table 28. Number of Children (<18 Years Old) in Household | 21 |
| Table 29. Respondent's Highest Level of Education | 22 |
| Table 30. Total Taxable Household Income of Wage Earners in the Past Year | 22 |
| Table 31. Residential Designation (Urban, Suburban, or Rural) | 23 |
| Services and Supports Received..... | 24 |
| Table 32. Services and Supports Received From ID/DD Agency ∞ | 25 |
| Table 33. Additional Services and Supports Received (not from the IDD Agency) ∞ | 25 |
| Adult Family Survey Results..... | 26 |
| Information and Planning..... | 27 |
| Table Q1. Do you get enough information to help you participate in planning services for your family?..... | 28 |
| Table Q2. Is the information you receive about services easy to understand? | 29 |
| Table Q3. Does the case manager/service coordinator respect your family's choices and opinions? | 30 |
| Table Q4. Do you get enough information about other public services for which your family is eligible? | 31 |
| Table Q5. Do you need help planning for your family member's future with respect to any of the following? ... | 32 |
| Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?..... | 33 |
| Table Q7. Does your family member have a service plan? | 34 |
| Table Q8. Does the plan include all the services and supports your family member needs? | 35 |
| Table Q9. Does your family member get all the services listed in the plan? | 36 |
| Table Q10. Did you or another family member help make the service plan? | 37 |
| Table Q11. Did your family member help make the service plan? | 38 |
| Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting? | 39 |
| Table Q13. If your family member transitioned out of school services during the past year, did s/he have a transition plan?..... | 40 |
| Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?..... | 41 |
| Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?..... | 42 |
| Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster? | 43 |
| Access and Delivery of Services and Supports..... | 44 |

| | |
|--|-----------|
| Table Q17. Are you or your family member able to contact his/her support workers when you want to? | 45 |
| Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to? | 46 |
| Table Q19. Do support workers come and leave when they are supposed to? (Do they show up on time? Do they show up when they say they will?) | 47 |
| Table Q20. Do services and supports change when your family's needs change? | 48 |
| Table Q21. Do support workers speak to you in a way that you understand? | 49 |
| Table Q22. Are services delivered in a way that is respectful to your family's culture? | 50 |
| Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her? | 51 |
| Table Q24. Do support workers have the right information and skills to meet your family's needs? | 52 |
| Table Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)? | 53 |
| Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)? | 54 |
| Table Q27. Does your family member's primary care doctor understand his/her needs related to his/her disability? | 55 |
| Table Q28. Do you have access to dental services for your family member? | 56 |
| Table Q29. If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability? | 57 |
| Table Q30. If your family member takes medications, do you know what they're for? | 58 |
| Table Q31. If your family member takes medications, do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)? | 59 |
| Table Q32. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability? | 60 |
| Table Q33. If you need respite services, do you have access to them? (Respite is support for family or other care-providers to allow them to take a break from providing care for a time-limited period.) | 61 |
| Table Q34. If you have access to respite services, are you satisfied with the quality of those services? | 62 |
| Table Q35. Does your family get the support and services needed? | 63 |
| Table Q36. If family does not get the support and services needed, what additional services are needed? ∞ | 64 |
| Choice, Decision Making and Control | 65 |
| Table Q37. Can your family choose or change the agency that provides your family member's services? | 66 |
| Table Q38. Can your family choose or change your family member's support workers? | 67 |
| Table Q39. Does your family directly manage support workers (for example, hiring and deciding schedule)? .. | 68 |
| Table Q40. Do service providers for your family member work together to provide support? | 69 |
| Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator? | 70 |
| Involvement in the Community | 71 |

| | |
|--|-----------|
| Table Q42. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?..... | 72 |
| Table Q43. For your family member, what are the obstacles or barriers to participation in activities in the community? ∞..... | 73 |
| Table Q44. Does your family member have friends other than paid support workers or family? | 74 |
| Table Q45. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)? ... | 75 |
| Table Q46. Does your family take part in any family-to-family networks in your community? (For example, Parent to Parent, sibling networks, etc.) | 76 |
| Satisfaction With Services and Supports | 77 |
| Table Q47. Overall, are you satisfied with the services and supports your family currently receives?..... | 78 |
| Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff? | 79 |
| Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved? | 80 |
| Table Q50. Do you know how to report abuse or neglect related to your family member? | 81 |
| Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member? | 82 |
| Table Q52. Do you feel that services and supports have made a positive difference in the life of your family?... 83 | |
| Table Q53. Do you feel that services and supports have reduced your family’s out-of-pocket expenses for your family member’s care?..... | 84 |
| Table Q54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated? | 85 |
| Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively? | 86 |
| Table Q56. Have the services or supports that your family member received been increased in the past year? 87 | |
| Table Q57. Are services and supports helping your family member to live a good life? | 88 |
| II. NCI History and Activities..... | 89 |
| Overview of National Core Indicators | 90 |
| State Participation | 91 |
| NCI State Membership 2017-18 | 91 |
| The Core Indicators | 91 |
| Family Survey Sub-Domains and Concern Statements | 92 |
| How NCI Data Are Used | 92 |
| III. Methodology | 94 |
| Sampling & Administration..... | 95 |
| Weighting..... | 95 |

Significance Testing.....96

Data Entry and Analysis97

Response Rates97

 Adult Family Survey: State Response Rates 98

Executive Summary

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

The National Core Indicators (NCI) Adult Family Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who lives in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Adult Family Survey on an annual basis. Of the 46 states, the District of Columbia and 22 sub-state entities that were members of NCI during the 2017-18 data collection cycle, 11 states and the District of Columbia submitted a valid sample of Adult Family Survey data: Arizona (AZ), District of Columbia (DC), Delaware (DE), Florida (FL), Georgia (GA), Maryland (MD), Missouri (MO), North Carolina (NC), New Hampshire (NH), Oklahoma (OK), Pennsylvania (PA), Washington (WA). This Final Report provides a summary of results based on data submitted by June 30, 2018.

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.

2017-18 Adult Family Survey

NCI Average Data

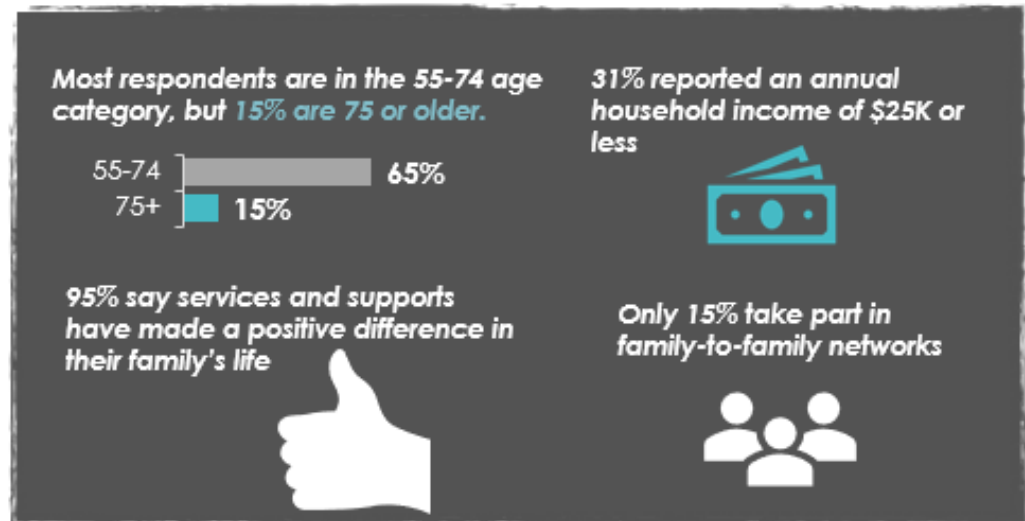
All participating
states

Data are
weighted

5,221 families participated in the 2017-18

Adult Family Survey in 11 states*

Respondents are family members and/or guardians who share a home with an adult who has I/DD and receives one public service in addition to case management from the state DD agency.



The family member with I/DD . . .

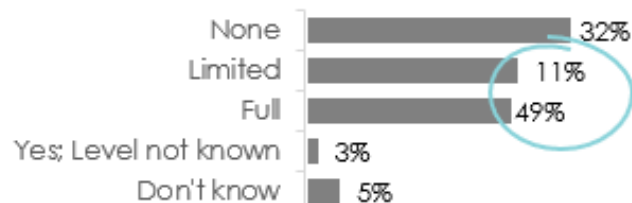
57% are male

36 is the average age

87% take part in community activities

78% can always see a health professional when needed

Legal Guardianship

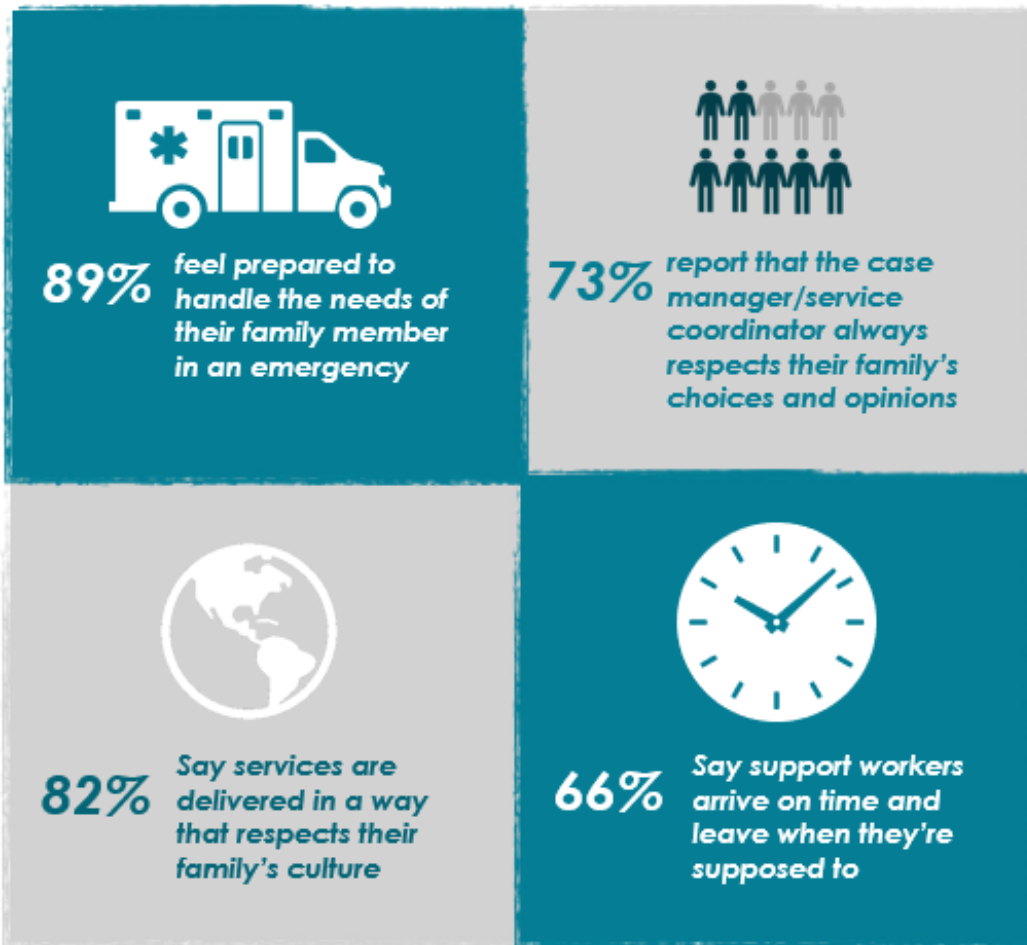
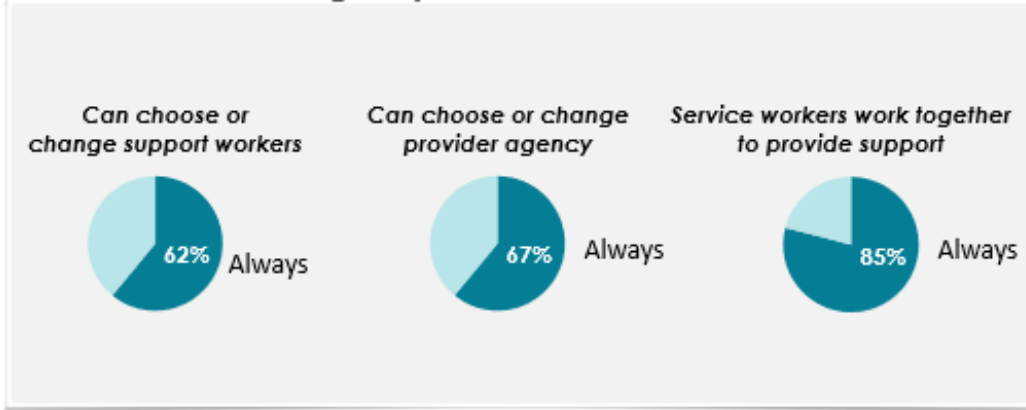


57% of respondents' family members with I/DD are reported to be under limited or full guardianship

* AZ, DC, DE, FL, GA, MD, MO, NC, NH, OK, PA, WA.

2017-18 Adult Family Survey

Respondents are families and/or guardians who share a home with an adult who has I/DD and receives one public service in addition to case management from the state DD agency.



All participating states

Data are

75+ 15%

95% say services and supports

Only 15% take part in

I. Results

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

Survey Development

The Adult Family Survey was first developed and administered in 1997-99 to measure the experiences of families who had an adult family member with an intellectual or developmental disability living at home. Since that time, NCI has routinely refined the survey instrument based on feedback from families and state staff. Most participating states use the standard NCI survey instrument described here, but some states incorporate additional questions to look more deeply at specific issues. These supplementary questions are typically added after a state has participated in NCI for at least a year and established baseline results.

Organization of the Adult Family Survey

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

Demographics

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

Services and Supports Received

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

Questions Regarding Services and Supports

The survey contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes.

Each question is constructed so the respondent selects from either four possible responses ("always," "usually," "sometimes," "seldom/never") or two responses ("yes" or "no"). Respondents also have the option to indicate that they don't know the answer to a question or that the question is not applicable.

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 survey. For each question, the results are first shown in a graph that depicts the NCI Average and then in a set of tables that break out each state's percentages. 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, or 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 with fewer than 20 respondents to a question *are not* included in tables; however, their data *are* included in the NCI Average.

Note on Significance: Statistical significance depends on both the amount by which a state differs from the average for a given item and the state's sample size for that item. So there may be instances where State A's difference from the average is larger than State B's, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.

Note on NCI Averages: The NCI averages contained in this report are "weighted" means; their calculations reflect the relative population sizes of participating states, as well as the states' sample sizes. Prior to 2016-17, NCI averages were calculated as the simple arithmetic mean of all state means (an approach known as "average of averages"), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.

Note on language used in this report: "Respondent" refers to the person (usually a parent or guardian) filling out the survey. "Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.

Demographics

Family Member

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

Table 1. More Than One Person Living in the Home Has IDD

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| AZ | 12% | 88% | 243 |
| DC | 15% | 84% | 236 |
| DE | 19% | 81% | 187 |
| FL | 13% | 87% | 356 |
| GA | 18% | 82% | 381 |
| MD | 14% | 86% | 928 |
| MO | 13% | 87% | 282 |
| NC | 13% | 87% | 252 |
| NH | 8% | 92% | 598 |
| OK | 8% | 91% | 416 |
| PA | 12% | 88% | 695 |
| WA | 14% | 86% | 460 |
| NCI Average | 13% | 87% | 5,034 |

Table 2. Family Member's Age

| State | Average Age | N |
|--------------------|-------------|--------------|
| AZ | 32.4 | 251 |
| DC | 36.2 | 245 |
| DE | 29.9 | 190 |
| FL | 36.3 | 361 |
| GA | 35.9 | 391 |
| MD | 33.3 | 953 |
| MO | 32.7 | 293 |
| NC | 33.0 | 258 |
| NH | 33.8 | 604 |
| OK | 36.1 | 425 |
| PA | 40.6 | 731 |
| WA | 31.4 | 473 |
| NCI Average | 36.1 | 5,175 |

Table 3. Family Member's Gender

| State | Male | Female | N |
|--------------------|------------|------------|--------------|
| AZ | 59% | 41% | 251 |
| DC | 65% | 35% | 245 |
| DE | 65% | 35% | 189 |
| FL | 56% | 44% | 356 |
| GA | 57% | 43% | 389 |
| MD | 61% | 39% | 934 |
| MO | 60% | 40% | 290 |
| NC | 53% | 47% | 255 |
| NH | 54% | 46% | 593 |
| OK | 55% | 45% | 424 |
| PA | 56% | 44% | 724 |
| WA | 57% | 43% | 469 |
| NCI Average | 57% | 43% | 5,119 |

Table 4. Family Member's Race and Ethnicity ∞

| State | American Indian or Alaska Native | Asian | Black or African American | Pacific Islander | White | Hispanic or Latino | Other |
|--------------------|----------------------------------|-----------|---------------------------|------------------|------------|--------------------|-----------|
| AZ | 5% | 4% | 6% | 1% | 72% | 22% | 2% |
| DC | 1% | 1% | 88% | 0% | 7% | 5% | 0% |
| DE | 2% | 5% | 20% | 0% | 74% | 4% | 3% |
| FL | 0% | 5% | 18% | 0% | 59% | 24% | 2% |
| GA | 1% | 2% | 35% | 1% | 62% | 3% | 1% |
| MD | 2% | 6% | 27% | 1% | 65% | 3% | 1% |
| MO | 2% | 2% | 9% | 0% | 89% | 2% | 2% |
| NC | 2% | 1% | 23% | 0% | 72% | 2% | 1% |
| NH | 2% | 1% | 1% | 0% | 97% | 1% | 0% |
| OK | 13% | 2% | 11% | 0% | 79% | 5% | 0% |
| PA | 1% | 1% | 7% | 0% | 91% | 2% | 1% |
| WA | 4% | 11% | 5% | 2% | 76% | 12% | 2% |
| NCI Average | 2% | 4% | 13% | 0% | 77% | 9% | 1% |

∞ Categories are not mutually exclusive

Table 5a. Family Member's Disabilities ∞

| State | Intellectual Disability | Mood Illness or Psychiatric Disorder | Autism Spectrum Disorder | Cerebral Palsy | Limited or No Vision | Severe or Profound Hearing Loss |
|--------------------|-------------------------|--------------------------------------|--------------------------|----------------|----------------------|---------------------------------|
| AZ | 60% | 20% | 38% | 21% | 9% | 6% |
| DC | 69% | 14% | 30% | 20% | 8% | 7% |
| DE | 63% | 22% | 42% | 6% | 5% | 3% |
| FL | 63% | 23% | 27% | 27% | 13% | 8% |
| GA | 71% | 23% | 29% | 21% | 9% | 6% |
| MD | 68% | 20% | 34% | 15% | 9% | 6% |
| MO | 56% | 26% | 46% | 21% | 12% | 8% |
| NC | 69% | 28% | 40% | 23% | 10% | 8% |
| NH | 66% | 30% | 32% | 13% | 9% | 7% |
| OK | 77% | 18% | 18% | 27% | 15% | 7% |
| PA | 84% | 21% | 20% | 23% | 11% | 7% |
| WA | 68% | 24% | 28% | 14% | 10% | 5% |
| NCI Average | 71% | 23% | 29% | 22% | 11% | 7% |

Table 5b. Family Member's Disabilities (continued) ∞

| State | Brain Injury | Seizure Disorder or Neurological Problem | Chemical Dependency | Down Syndrome | Prader-Willi Syndrome | Fetal Alcohol Spectrum Disorder | Other |
|--------------------|--------------|--|---------------------|---------------|-----------------------|---------------------------------|------------|
| AZ | 11% | 30% | 0% | 19% | 2% | 1% | 15% |
| DC | 10% | 21% | 1% | 12% | 0% | 3% | 13% |
| DE | 5% | 17% | 0% | 20% | 1% | 1% | 20% |
| FL | 9% | 32% | 2% | 17% | 0% | 1% | 21% |
| GA | 7% | 32% | 1% | 13% | 1% | 1% | 18% |
| MD | 9% | 24% | 0% | 16% | 0% | 1% | 16% |
| MO | 10% | 31% | 0% | 12% | 0% | 0% | 29% |
| NC | 12% | 40% | 1% | 14% | 0% | 1% | 17% |
| NH | 10% | 27% | 0% | 17% | 1% | 0% | 9% |
| OK | 14% | 39% | 0% | 21% | 0% | 1% | 16% |
| PA | 10% | 29% | 0% | 22% | 0% | 0% | 18% |
| WA | 8% | 30% | 1% | 17% | 1% | 3% | 22% |
| NCI Average | 10% | 31% | 1% | 18% | 1% | 1% | 19% |

∞ Categories are not mutually exclusive

Table 6a. Family Member's Health Conditions ∞

| State | Cardiovascular Disease | Diabetes | Cancer | High Blood Pressure | High Cholesterol |
|--------------------|------------------------|------------|-----------|---------------------|------------------|
| AZ | 12% | 17% | 6% | 26% | 33% |
| DC | 15% | 23% | 7% | 49% | 35% |
| DE | 12% | 12% | 7% | 14% | 27% |
| FL | 11% | 19% | 4% | 31% | 35% |
| GA | 11% | 18% | 7% | 38% | 25% |
| MD | 12% | 15% | 6% | 29% | 27% |
| MO | 8% | 14% | 5% | 25% | 23% |
| NC | 13% | 24% | 3% | 31% | 28% |
| NH | 12% | 18% | 5% | 24% | 24% |
| OK | 12% | 17% | 8% | 31% | 20% |
| PA | 15% | 18% | 4% | 29% | 30% |
| WA | 13% | 20% | 5% | 25% | 19% |
| NCI Average | 13% | 19% | 5% | 29% | 29% |

Table 6b. Family Member's Health Conditions (continued)

| State | Dysphagia | Pressure Ulcers | Alzheimer's Disease or Other Dementia | Oral Health or Dental Problems | Sleep Apnea | Other |
|--------------------|------------|-----------------|---------------------------------------|--------------------------------|-------------|------------|
| AZ | 7% | 1% | 1% | 13% | 19% | 25% |
| DC | 7% | 1% | 3% | 9% | 20% | 19% |
| DE | 2% | 0% | 4% | 5% | 20% | 37% |
| FL | 12% | 2% | 3% | 16% | 20% | 25% |
| GA | 8% | 2% | 2% | 13% | 16% | 25% |
| MD | 8% | 2% | 2% | 8% | 16% | 18% |
| MO | 8% | 7% | 5% | 20% | 21% | 37% |
| NC | 13% | 3% | 2% | 17% | 21% | 22% |
| NH | 10% | 3% | 1% | 8% | 21% | 16% |
| OK | 15% | 3% | 1% | 13% | 18% | 23% |
| PA | 11% | 2% | 2% | 10% | 17% | 28% |
| WA | 11% | 3% | 2% | 11% | 20% | 25% |
| NCI Average | 10% | 2% | 3% | 13% | 19% | 26% |

∞ Categories are not mutually exclusive

Table 7. Family Member's Preferred Means of Communication

| State | Spoken | Gestures or Body Language | Sign Language or Finger Spelling | Communication Aid or Device | Other | Total |
|--------------------|------------|---------------------------|----------------------------------|-----------------------------|-----------|--------------|
| AZ | 72% | 18% | 2% | 4% | 4% | 254 |
| DC | 76% | 20% | 2% | 1% | 1% | 235 |
| DE | 90% | 4% | 1% | 2% | 3% | 189 |
| FL | 69% | 20% | 2% | 1% | 9% | 362 |
| GA | 71% | 20% | 2% | 1% | 6% | 390 |
| MD | 79% | 15% | 2% | 2% | 2% | 938 |
| MO | 71% | 19% | 1% | 3% | 6% | 288 |
| NC | 71% | 21% | 2% | 2% | 3% | 257 |
| NH | 87% | 8% | 2% | 2% | 1% | 601 |
| OK | 72% | 23% | 1% | 1% | 2% | 427 |
| PA | 77% | 14% | 2% | 1% | 6% | 718 |
| WA | 75% | 15% | 3% | 2% | 5% | 470 |
| NCI Average | 74% | 16% | 2% | 2% | 6% | 5,129 |

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

| State | No Guardianship | Limited | Full | Has Guardianship but Level Is Unknown | Don't know | N |
|--------------------|-----------------|------------|------------|---------------------------------------|------------|--------------|
| AZ | 24% | 8% | 67% | 1% | 1% | 248 |
| DC | 35% | 11% | 44% | 7% | 4% | 243 |
| DE | 54% | 7% | 31% | 3% | 5% | 189 |
| FL | 32% | 16% | 42% | 5% | 4% | 356 |
| GA | 39% | 7% | 47% | 2% | 5% | 372 |
| MD | 50% | 12% | 29% | 5% | 4% | 911 |
| MO | 26% | 9% | 63% | 1% | 1% | 285 |
| NC | 9% | 14% | 69% | 6% | 1% | 257 |
| NH | 16% | 10% | 70% | 3% | 0% | 605 |
| OK | 20% | 10% | 67% | 2% | 1% | 422 |
| PA | 39% | 11% | 39% | 3% | 8% | 706 |
| WA | 27% | 10% | 54% | 4% | 5% | 465 |
| NCI Average | 32% | 11% | 49% | 3% | 5% | 5,059 |

Table 9. Guardian or Conservator Relationship to Family Member

| State | Family | Friend | State Employee or Guardianship Agency | Other | N |
|--------------------|------------|-----------|---------------------------------------|-----------|--------------|
| AZ | 99% | 1% | 0% | 1% | 180 |
| DC | 92% | 0% | 5% | 3% | 132 |
| DE | 100% | 0% | 0% | 0% | 78 |
| FL | 89% | 0% | 0% | 10% | 216 |
| GA | 92% | 0% | 0% | 8% | 192 |
| MD | 95% | 2% | 1% | 2% | 374 |
| MO | 98% | 1% | 1% | 1% | 194 |
| NC | 96% | 1% | 1% | 1% | 221 |
| NH | 97% | 1% | 1% | 1% | 497 |
| OK | 98% | 1% | 0% | 1% | 311 |
| PA | 96% | 0% | 0% | 4% | 333 |
| WA | 97% | 1% | 1% | 2% | 304 |
| NCI Average | 96% | 0% | 0% | 4% | 3,032 |

Table 10. Family Member's Highest level of Education

| State | Did Not Complete High School (and Not Currently Enrolled) | Currently Enrolled in High School | High School Certification | High School Diploma or GED | Vocational School or Certificate Program | Some College | College Degree or Higher | N |
|--------------------|---|-----------------------------------|---------------------------|----------------------------|--|--------------|--------------------------|--------------|
| AZ | 14% | 7% | 28% | 42% | 2% | 6% | 2% | 243 |
| DC | 25% | 1% | 42% | 21% | 9% | 1% | 1% | 232 |
| DE | 13% | 7% | 44% | 25% | 4% | 5% | 2% | 187 |
| FL | 19% | 4% | 41% | 20% | 5% | 6% | 5% | 350 |
| GA | 16% | 2% | 51% | 24% | 1% | 2% | 3% | 374 |
| MD | 10% | 1% | 60% | 17% | 4% | 4% | 4% | 927 |
| MO | 17% | 5% | 25% | 40% | 4% | 7% | 4% | 276 |
| NC | 20% | 7% | 46% | 16% | 4% | 5% | 3% | 250 |
| NH | 14% | 2% | 41% | 34% | 2% | 4% | 4% | 597 |
| OK | 14% | 2% | 26% | 50% | 1% | 3% | 3% | 416 |
| PA | 16% | 3% | 29% | 45% | 4% | 1% | 2% | 668 |
| WA | 13% | 11% | 28% | 37% | 3% | 3% | 5% | 461 |
| NCI Average | 16% | 5% | 35% | 34% | 4% | 4% | 3% | 4,981 |

Table 11. Family Member's Typical Day Activities – Paid Individual Job in the Community

| State | Usually/Often | Sometimes | Never Does This | N |
|--------------------|---------------|-----------|-----------------|--------------|
| AZ | 9% | 3% | 88% | 235 |
| DC | 13% | 7% | 80% | 215 |
| DE | 30% | 5% | 65% | 175 |
| FL | 13% | 3% | 84% | 348 |
| GA | 13% | 2% | 85% | 367 |
| MD | 27% | 5% | 68% | 873 |
| MO | 13% | 2% | 86% | 277 |
| NC | 11% | 2% | 87% | 248 |
| NH | 38% | 7% | 55% | 594 |
| OK | 12% | 2% | 86% | 403 |
| PA | 16% | 3% | 80% | 690 |
| WA | 27% | 3% | 70% | 443 |
| NCI Average | 16% | 3% | 80% | 4,868 |

Table 12. Family Member's Typical Day Activities – Paid Small Group Job in a Community-based Setting

| State | Usually/Often | Sometimes | Never Does This | N |
|--------------------|---------------|-----------|-----------------|--------------|
| AZ | 10% | 2% | 88% | 241 |
| DC | 8% | 4% | 88% | 218 |
| DE | 11% | 3% | 86% | 166 |
| FL | 7% | 2% | 92% | 334 |
| GA | 8% | 2% | 89% | 362 |
| MD | 22% | 6% | 72% | 883 |
| MO | 5% | 2% | 93% | 271 |
| NC | 4% | 3% | 93% | 243 |
| NH | 8% | 3% | 89% | 584 |
| OK | 15% | 2% | 83% | 405 |
| PA | 11% | 2% | 87% | 683 |
| WA | 7% | 2% | 91% | 434 |
| NCI Average | 9% | 2% | 89% | 4,824 |

Table 13. Family Member's Typical Day Activities – Unpaid Activity in the Community

| State | Usually/Often | Sometimes | Never Does This | N |
|--------------------|---------------|------------|-----------------|--------------|
| AZ | 21% | 9% | 70% | 244 |
| DC | 28% | 11% | 61% | 223 |
| DE | 26% | 17% | 57% | 171 |
| FL | 14% | 10% | 76% | 344 |
| GA | 27% | 17% | 56% | 372 |
| MD | 34% | 18% | 49% | 888 |
| MO | 23% | 17% | 60% | 279 |
| NC | 33% | 13% | 54% | 248 |
| NH | 49% | 19% | 32% | 592 |
| OK | 17% | 14% | 69% | 408 |
| PA | 21% | 13% | 66% | 692 |
| WA | 22% | 14% | 65% | 443 |
| NCI Average | 22% | 13% | 65% | 4,904 |

Table 14. Family Member's Typical Day Activities – Paid Work in a Community Job That Primarily Hires People With Disabilities ¹

| State | Usually/Often | Sometimes | Never Does This | N |
|--------------------|---------------|-----------|-----------------|--------------|
| AZ | 6% | 1% | 93% | 240 |
| DC | 10% | 3% | 87% | 229 |
| DE | 9% | 3% | 88% | 168 |
| FL | 4% | 1% | 95% | 347 |
| GA | 5% | 2% | 93% | 368 |
| MD | 16% | 6% | 78% | 883 |
| MO | 3% | 1% | 96% | 271 |
| NC | 4% | 2% | 94% | 248 |
| NH | 15% | 4% | 82% | 583 |
| OK | 9% | 1% | 90% | 409 |
| PA | 6% | 1% | 92% | 688 |
| WA | 11% | 3% | 86% | 431 |
| NCI Average | 6% | 2% | 92% | 4,865 |

¹ New item added to the survey in 2017-18

Table 15. Family Member's Typical Day Activities – Paid Activity in a Facility-based Setting

| State | Usually/Often | Sometimes | Never Does This | N |
|--------------------|---------------|-----------|-----------------|--------------|
| AZ | 18% | 1% | 80% | 245 |
| DC | 5% | 4% | 91% | 229 |
| DE | 9% | 4% | 88% | 164 |
| FL | 12% | 1% | 87% | 349 |
| GA | 12% | 3% | 86% | 365 |
| MD | 23% | 8% | 69% | 888 |
| MO | 16% | 0% | 84% | 282 |
| NC | 9% | 2% | 89% | 246 |
| NH | 4% | 2% | 94% | 577 |
| OK | 22% | 1% | 77% | 410 |
| PA | 26% | 2% | 72% | 692 |
| WA | 5% | 2% | 92% | 437 |
| NCI Average | 17% | 2% | 81% | 4,884 |

Table 16. Family Member's Typical Day Activities – Unpaid Activity in a Facility-based Setting

| State | Usually/Often | Sometimes | Never Does This | N |
|--------------------|---------------|-----------|-----------------|--------------|
| AZ | 42% | 3% | 55% | 247 |
| DC | 45% | 8% | 47% | 233 |
| DE | 24% | 5% | 71% | 170 |
| FL | 20% | 3% | 77% | 347 |
| GA | 37% | 5% | 58% | 365 |
| MD | 35% | 7% | 59% | 875 |
| MO | 25% | 2% | 72% | 276 |
| NC | 30% | 6% | 65% | 249 |
| NH | 16% | 9% | 74% | 577 |
| OK | 12% | 4% | 85% | 408 |
| PA | 29% | 5% | 66% | 686 |
| WA | 11% | 4% | 84% | 437 |
| NCI Average | 27% | 5% | 69% | 4,870 |

Table 17. Family Member's Typical Day Activities – School

| State | Usually/Often | Sometimes | Never Does This | N |
|--------------------|---------------|-----------|-----------------|--------------|
| AZ | 13% | 1% | 86% | 239 |
| DC | 13% | 3% | 84% | 224 |
| DE | 20% | 2% | 78% | 171 |
| FL | 12% | 2% | 86% | 338 |
| GA | 10% | 2% | 88% | 365 |
| MD | 11% | 5% | 84% | 859 |
| MO | 10% | 2% | 88% | 268 |
| NC | 17% | 2% | 80% | 248 |
| NH | 6% | 2% | 92% | 576 |
| OK | 3% | 1% | 96% | 402 |
| PA | 5% | 1% | 94% | 678 |
| WA | 17% | 3% | 81% | 432 |
| NCI Average | 11% | 2% | 88% | 4,800 |

Table 18. Family Member's Typical Day Activities – Stay at Home

| State | Usually/Often | Sometimes | Never Does This | N |
|--------------------|---------------|------------|-----------------|--------------|
| AZ | 47% | 21% | 32% | 231 |
| DC | 28% | 15% | 57% | 216 |
| DE | 42% | 21% | 36% | 165 |
| FL | 55% | 21% | 24% | 331 |
| GA | 46% | 26% | 28% | 337 |
| MD | 30% | 19% | 50% | 837 |
| MO | 55% | 22% | 24% | 260 |
| NC | 52% | 21% | 27% | 237 |
| NH | 48% | 24% | 28% | 565 |
| OK | 63% | 19% | 18% | 391 |
| PA | 47% | 22% | 31% | 617 |
| WA | 74% | 12% | 14% | 420 |
| NCI Average | 51% | 20% | 28% | 4,607 |

Table 19. Family Member's Typical Day Activities – Other

| State | Usually/Often | Sometimes | Never Does This | N |
|--------------------|---------------|-----------|-----------------|--------------|
| AZ | 55% | 10% | 34% | 29 |
| DC | 85% | 3% | 13% | 39 |
| DE | 38% | 10% | 52% | 52 |
| FL | 46% | 6% | 48% | 140 |
| GA | 50% | 13% | 38% | 127 |
| MD | 57% | 6% | 37% | 142 |
| MO | 53% | 9% | 38% | 98 |
| NC | 68% | 6% | 26% | 78 |
| NH | 76% | 8% | 16% | 79 |
| OK | 48% | 9% | 43% | 119 |
| PA | 51% | 5% | 44% | 173 |
| WA | 54% | 11% | 35% | 142 |
| NCI Average | 52% | 7% | 41% | 1,218 |

Table 20. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

| State | No Support Needed | Some Support Needed | Extensive Support Needed | N |
|--------------------|-------------------|---------------------|--------------------------|--------------|
| AZ | 58% | 26% | 16% | 251 |
| DC | 64% | 23% | 13% | 240 |
| DE | 71% | 17% | 12% | 186 |
| FL | 57% | 28% | 15% | 360 |
| GA | 50% | 34% | 16% | 375 |
| MD | 62% | 25% | 13% | 931 |
| MO | 55% | 27% | 18% | 280 |
| NC | 49% | 30% | 21% | 258 |
| NH | 61% | 31% | 8% | 595 |
| OK | 67% | 23% | 11% | 420 |
| PA | 61% | 27% | 11% | 714 |
| WA | 45% | 34% | 21% | 464 |
| NCI Average | 57% | 28% | 15% | 5,074 |

Table 21. Family Member's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)

| State | No Support Needed | Some Support Needed | Extensive Support Needed | N |
|--------------------|-------------------|---------------------|--------------------------|--------------|
| AZ | 17% | 40% | 44% | 254 |
| DC | 41% | 35% | 24% | 248 |
| DE | 47% | 38% | 15% | 188 |
| FL | 24% | 29% | 47% | 363 |
| GA | 27% | 31% | 41% | 379 |
| MD | 38% | 34% | 28% | 939 |
| MO | 22% | 33% | 44% | 286 |
| NC | 15% | 32% | 54% | 257 |
| NH | 34% | 36% | 30% | 597 |
| OK | 26% | 29% | 45% | 426 |
| PA | 31% | 32% | 38% | 730 |
| WA | 13% | 40% | 47% | 466 |
| NCI Average | 25% | 33% | 42% | 5,133 |

Table 22. Family Member's Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)

| State | No Support Needed | Some Support Needed | Extensive Support Needed | N |
|--------------------|-------------------|---------------------|--------------------------|--------------|
| AZ | 3% | 13% | 84% | 253 |
| DC | 11% | 26% | 63% | 246 |
| DE | 8% | 28% | 64% | 191 |
| FL | 5% | 19% | 76% | 361 |
| GA | 6% | 20% | 75% | 380 |
| MD | 9% | 22% | 70% | 945 |
| MO | 5% | 19% | 77% | 286 |
| NC | 3% | 9% | 88% | 257 |
| NH | 4% | 23% | 73% | 601 |
| OK | 6% | 17% | 77% | 425 |
| PA | 3% | 17% | 79% | 720 |
| WA | 3% | 14% | 83% | 467 |
| NCI Average | 4% | 17% | 79% | 5,132 |

Respondents

This section provides demographic information about the respondent.

Table 23. Respondent's Age

| State | Under 35 | 35-54 | 55-74 | 75 or Older | N |
|--------------------|-----------|------------|------------|-------------|--------------|
| AZ | 0% | 25% | 62% | 13% | 251 |
| DC | 2% | 23% | 61% | 14% | 232 |
| DE | 2% | 31% | 59% | 8% | 190 |
| FL | 3% | 18% | 64% | 14% | 366 |
| GA | 2% | 17% | 72% | 9% | 382 |
| MD | 2% | 16% | 71% | 12% | 940 |
| MO | 3% | 29% | 59% | 9% | 292 |
| NC | 2% | 25% | 66% | 7% | 259 |
| NH | 2% | 22% | 70% | 7% | 605 |
| OK | 0% | 17% | 70% | 13% | 427 |
| PA | 1% | 12% | 65% | 22% | 731 |
| WA | 4% | 26% | 62% | 8% | 468 |
| NCI Average | 2% | 19% | 65% | 15% | 5,143 |

Table 24. Respondent's Health

| State | Excellent | Very Good | Fairly Good | Poor | N |
|--------------------|------------|------------|-------------|-----------|--------------|
| AZ | 19% | 50% | 30% | 1% | 252 |
| DC | 14% | 51% | 33% | 2% | 248 |
| DE | 17% | 51% | 31% | 1% | 191 |
| FL | 15% | 40% | 38% | 7% | 368 |
| GA | 11% | 44% | 41% | 3% | 384 |
| MD | 18% | 50% | 29% | 4% | 943 |
| MO | 12% | 49% | 34% | 5% | 290 |
| NC | 18% | 48% | 30% | 4% | 258 |
| NH | 21% | 50% | 27% | 2% | 602 |
| OK | 12% | 45% | 39% | 4% | 428 |
| PA | 14% | 44% | 37% | 5% | 727 |
| WA | 14% | 46% | 37% | 3% | 465 |
| NCI Average | 15% | 45% | 35% | 4% | 5,156 |

Table 25. Respondent's Relationship to Family Member

| State | Parent | Sibling | Spouse | Grandparent | Other | N |
|--------------------|------------|-----------|-----------|-------------|-----------|--------------|
| AZ | 85% | 6% | 0% | 4% | 5% | 254 |
| DC | 74% | 13% | 1% | 6% | 6% | 246 |
| DE | 86% | 7% | 0% | 6% | 2% | 191 |
| FL | 85% | 9% | 1% | 2% | 3% | 364 |
| GA | 86% | 7% | 0% | 2% | 5% | 384 |
| MD | 86% | 8% | 1% | 3% | 3% | 929 |
| MO | 90% | 6% | 0% | 1% | 2% | 293 |
| NC | 88% | 4% | 0% | 3% | 5% | 259 |
| NH | 88% | 8% | 0% | 1% | 2% | 602 |
| OK | 90% | 4% | 0% | 3% | 3% | 428 |
| PA | 85% | 12% | 0% | 1% | 1% | 729 |
| WA | 86% | 6% | 1% | 4% | 4% | 470 |
| NCI Average | 86% | 9% | 0% | 2% | 3% | 5,149 |

Table 26. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services ∞

| State | Respondent Provides Paid Support | Other Family Member Provides Paid Support | No One in Family Provides Paid Support | N |
|--------------------|----------------------------------|---|--|--------------|
| AZ | 38% | 18% | 48% | 252 |
| DC | 14% | 8% | 79% | 247 |
| DE | 3% | 3% | 95% | 190 |
| FL | 10% | 10% | 80% | 361 |
| GA | 5% | 4% | 92% | 380 |
| MD | 10% | 5% | 85% | 926 |
| MO | 6% | 7% | 87% | 285 |
| NC | 30% | 15% | 58% | 254 |
| NH | 29% | 10% | 62% | 603 |
| OK | 38% | 13% | 50% | 417 |
| PA | 11% | 11% | 79% | 710 |
| WA | 55% | 26% | 26% | 467 |
| NCI Average | 20% | 12% | 70% | 5,092 |

∞ Categories are not mutually exclusive

Table 27. Number of Adults in Household (Not Including Family Member Receiving Services)

| State | One | Two | Three | Four or More | N |
|--------------------|-----------|------------|------------|--------------|--------------|
| AZ | 12% | 25% | 50% | 14% | 250 |
| DC | 18% | 38% | 33% | 11% | 243 |
| DE | 7% | 27% | 46% | 21% | 188 |
| FL | 12% | 35% | 39% | 15% | 364 |
| GA | 9% | 31% | 44% | 16% | 385 |
| MD | 7% | 27% | 46% | 19% | 914 |
| MO | 8% | 29% | 51% | 12% | 292 |
| NC | 7% | 36% | 42% | 15% | 257 |
| NH | 8% | 28% | 46% | 18% | 606 |
| OK | 11% | 32% | 49% | 8% | 422 |
| PA | 10% | 29% | 46% | 15% | 717 |
| WA | 4% | 27% | 51% | 17% | 468 |
| NCI Average | 9% | 30% | 45% | 15% | 5,106 |

Table 28. Number of Children (<18 Years Old) in Household

| State | None | One | Two | Three | Four or More | N |
|--------------------|------------|-----------|-----------|-----------|--------------|--------------|
| AZ | 83% | 9% | 4% | 2% | 1% | 253 |
| DC | 86% | 8% | 5% | 1% | 0% | 249 |
| DE | 84% | 12% | 3% | 1% | 1% | 189 |
| FL | 89% | 8% | 2% | 1% | 0% | 368 |
| GA | 86% | 7% | 4% | 2% | 1% | 384 |
| MD | 86% | 7% | 6% | 1% | 0% | 938 |
| MO | 86% | 9% | 5% | 0% | 0% | 288 |
| NC | 90% | 6% | 2% | 2% | 0% | 257 |
| NH | 89% | 6% | 4% | 1% | 0% | 598 |
| OK | 89% | 7% | 3% | 1% | 0% | 427 |
| PA | 91% | 5% | 2% | 1% | 1% | 724 |
| WA | 82% | 8% | 4% | 3% | 2% | 468 |
| NCI Average | 88% | 7% | 3% | 1% | 1% | 5,143 |

Table 29. Respondent's Highest Level of Education

| State | No High School Diploma or GED | High School Diploma or GED | Vocational School or Certificate Program | Some College | College Degree or Higher | N |
|--------------------|-------------------------------|----------------------------|--|--------------|--------------------------|--------------|
| AZ | 7% | 22% | 6% | 29% | 37% | 252 |
| DC | 13% | 35% | 8% | 20% | 24% | 246 |
| DE | 4% | 21% | 3% | 22% | 49% | 189 |
| FL | 11% | 25% | 6% | 22% | 35% | 363 |
| GA | 7% | 26% | 10% | 19% | 39% | 384 |
| MD | 4% | 23% | 5% | 19% | 50% | 942 |
| MO | 6% | 24% | 6% | 24% | 40% | 291 |
| NC | 4% | 24% | 7% | 22% | 44% | 255 |
| NH | 3% | 24% | 6% | 20% | 47% | 608 |
| OK | 6% | 27% | 7% | 29% | 31% | 423 |
| PA | 7% | 38% | 7% | 17% | 32% | 719 |
| WA | 10% | 24% | 8% | 24% | 34% | 468 |
| NCI Average | 7% | 29% | 7% | 21% | 36% | 5,140 |

Table 30. Total Taxable Household Income of Wage Earners in the Past Year

| State | Up to \$15,000 | \$15,001-\$25,000 | \$25,001-\$50,000 | \$50,001-\$75,000 | Over \$75,000 | No Earned Income | Prefer Not to Say | N |
|--------------------|----------------|-------------------|-------------------|-------------------|---------------|------------------|-------------------|--------------|
| AZ | 7% | 16% | 19% | 18% | 16% | 7% | 18% | 245 |
| DC | 10% | 7% | 21% | 7% | 12% | 16% | 28% | 229 |
| DE | 6% | 7% | 16% | 14% | 25% | 7% | 24% | 189 |
| FL | 9% | 12% | 23% | 12% | 10% | 17% | 18% | 352 |
| GA | 9% | 11% | 18% | 14% | 14% | 14% | 21% | 370 |
| MD | 4% | 9% | 17% | 12% | 31% | 5% | 21% | 890 |
| MO | 8% | 10% | 17% | 17% | 17% | 10% | 20% | 284 |
| NC | 8% | 16% | 18% | 11% | 18% | 11% | 19% | 251 |
| NH | 5% | 9% | 18% | 13% | 20% | 7% | 28% | 575 |
| OK | 10% | 12% | 21% | 14% | 13% | 9% | 21% | 402 |
| PA | 10% | 12% | 19% | 10% | 15% | 12% | 22% | 673 |
| WA | 5% | 9% | 24% | 16% | 20% | 5% | 20% | 455 |
| NCI Average | 8% | 12% | 20% | 13% | 16% | 11% | 21% | 4,915 |

Table 31. Residential Designation (Urban, Suburban, or Rural)

| State | Urban or Suburban (in or Near a City or Large Town) | Rural (Outside of a City or Town) | Don't Know | N |
|--------------------|---|-----------------------------------|------------|--------------|
| AZ | 82% | 15% | 2% | 248 |
| DC | 86% | 1% | 13% | 231 |
| DE | 58% | 40% | 2% | 189 |
| FL | 76% | 19% | 5% | 362 |
| GA | 62% | 36% | 2% | 384 |
| MD | 67% | 31% | 2% | 926 |
| MO | 66% | 33% | 1% | 288 |
| NC | 49% | 50% | 1% | 255 |
| NH | 46% | 52% | 1% | 605 |
| OK | 68% | 30% | 2% | 427 |
| PA | 64% | 35% | 1% | 725 |
| WA | 68% | 29% | 3% | 470 |
| NCI Average | 67% | 31% | 2% | 5,110 |

Services and Supports Received

This section provides information about the services and supports received by the family from the state ID/DD agency.

Table 32. Services and Supports Received From ID/DD Agency ∞

| State | Financial Support | In-home Support | Out-of-home Respite | Day or Employment Supports | Transportation | Other | Self-direction or Fiscal Intermediary Services |
|--------------------|-------------------|-----------------|---------------------|----------------------------|----------------|------------|--|
| AZ | 10% | 40% | 53% | 65% | 62% | 40% | 36% |
| DC | 14% | 63% | 33% | 74% | 83% | 50% | 35% |
| DE | 8% | 3% | 19% | 52% | 59% | 21% | 9% |
| FL | 19% | 48% | 23% | 41% | 51% | 28% | 44% |
| GA | 18% | 41% | 26% | 60% | 69% | 25% | 48% |
| MD | 13% | 27% | 25% | 68% | 71% | 21% | 27% |
| MO | 27% | 38% | 30% | 46% | 51% | 28% | 35% |
| NC | 14% | 67% | 45% | 50% | 58% | 24% | 33% |
| NH | 40% | 27% | 38% | 55% | 64% | 30% | 56% |
| OK | 19% | 56% | 11% | 35% | 48% | 22% | 42% |
| PA | 16% | 35% | 30% | 65% | 70% | 23% | 43% |
| WA | 27% | 33% | 32% | 41% | 53% | 22% | 36% |
| NCI Average | 18% | 40% | 32% | 55% | 62% | 26% | 39% |

Table 33. Additional Services and Supports Received (not from the IDD Agency) ∞

| State | Social Security Payments (SSI/SSB) | Services or Supports from Other Agencies or Organizations |
|--------------------|------------------------------------|---|
| AZ | 94% | 26% |
| DC | 94% | 31% |
| DE | 81% | 45% |
| FL | 93% | 27% |
| GA | 97% | 25% |
| MD | 81% | 33% |
| MO | 89% | 33% |
| NC | 97% | 34% |
| NH | 93% | 24% |
| OK | 96% | 11% |
| PA | 95% | 36% |
| WA | 95% | 30% |
| NCI Average | 94% | 31% |

∞ Categories are not mutually exclusive

Adult Family Survey Results

Please Note:

Note on Significance: Statistical significance depends on both the amount by which a state differs from the average for a given item and the state's sample size for that item. There may be instances where State A's difference from the average is larger than State B's, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.

Information and Planning

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

Note: Significance is based on “Always” or “Yes” response.

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

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

Gets Enough Information To Help Plan Services

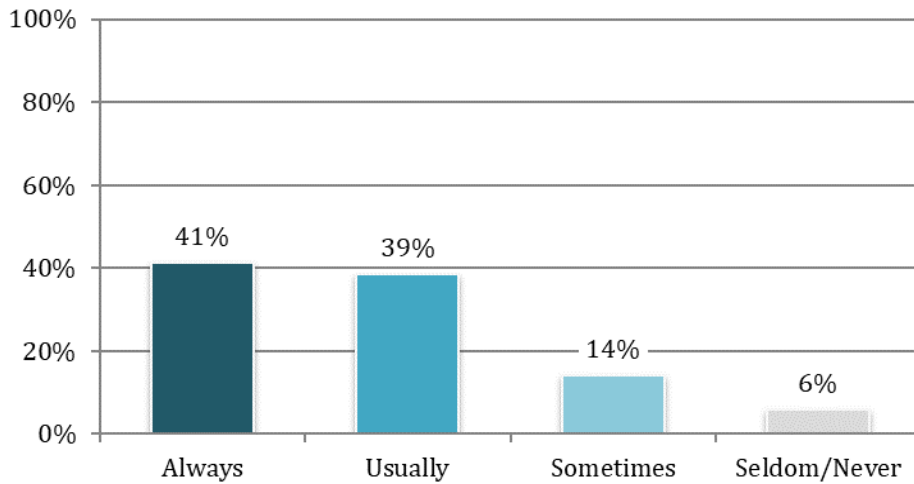


Table Q1. Do you get enough information to help you participate in planning services for your family?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|------------|-----------------|--------------|
| NC | 49% | 35% | 12% | 4% | 249 |
| AZ | 47% | 37% | 11% | 4% | 237 |
| DC | 44% | 30% | 18% | 8% | 235 |
| FL | 44% | 37% | 10% | 9% | 345 |
| NH | 44% | 39% | 12% | 5% | 576 |
| PA | 43% | 39% | 14% | 4% | 660 |
| NCI Average | 41% | 39% | 14% | 6% | 4,819 |
| OK | 40% | 42% | 14% | 4% | 409 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| WA | 35% | 42% | 19% | 4% | 431 |
| MD | 31% | 42% | 19% | 8% | 868 |
| MO | 31% | 44% | 18% | 7% | 278 |
| GA | 29% | 39% | 23% | 8% | 357 |
| DE | 25% | 39% | 22% | 14% | 174 |

Information About Services And Supports Is Easy To Understand

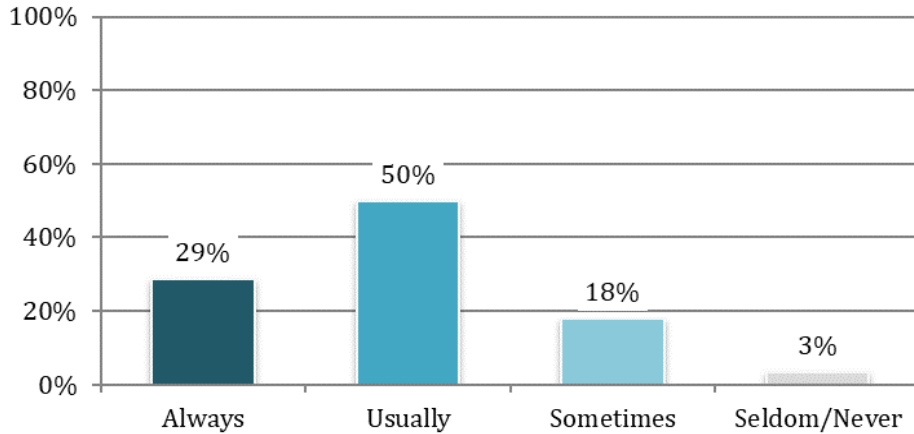


Table Q2. Is the information you receive about services easy to understand?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| DC | 39% | 37% | 22% | 3% | 236 |
| AZ | 38% | 48% | 12% | 2% | 242 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|------------|-----------------|--------------|
| NH | 32% | 49% | 16% | 3% | 586 |
| FL | 31% | 47% | 19% | 3% | 343 |
| NC | 30% | 49% | 17% | 4% | 251 |
| PA | 29% | 53% | 15% | 2% | 679 |
| NCI Average | 29% | 50% | 18% | 3% | 4,863 |
| OK | 28% | 51% | 18% | 3% | 411 |
| MD | 26% | 50% | 19% | 5% | 879 |
| MO | 24% | 51% | 22% | 3% | 272 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| GA | 22% | 47% | 24% | 6% | 356 |
| WA | 22% | 48% | 24% | 5% | 438 |
| DE | 20% | 46% | 25% | 9% | 170 |

Case Manager Or Service Coordinator Respects Family's Choices And Opinions

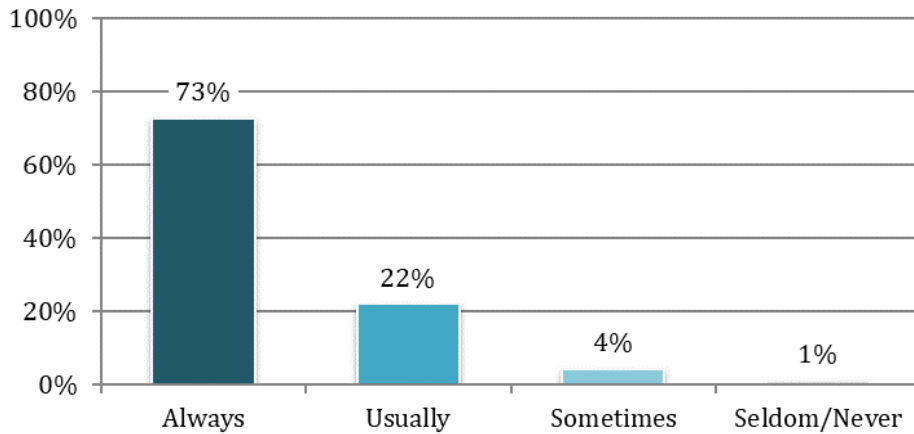


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 81% | 15% | 3% | 1% | 351 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| PA | 74% | 22% | 4% | 0% | 712 |
| AZ | 74% | 21% | 4% | 1% | 251 |
| NCI Average | 73% | 22% | 4% | 1% | 4,945 |
| NC | 72% | 22% | 5% | 1% | 242 |
| WA | 71% | 24% | 4% | 2% | 453 |
| MO | 70% | 23% | 6% | 1% | 283 |
| OK | 67% | 26% | 6% | 0% | 414 |
| DC | 66% | 23% | 8% | 3% | 238 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| NH | 65% | 28% | 5% | 2% | 590 |
| DE | 59% | 27% | 9% | 5% | 169 |
| GA | 59% | 32% | 7% | 3% | 358 |
| MD | 54% | 34% | 9% | 3% | 884 |

Gets Enough Information About Other Public Services For Which Family Is Eligible

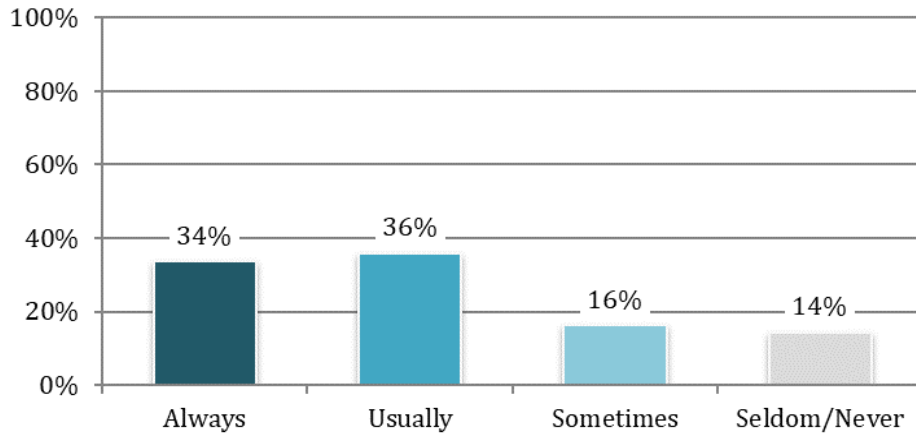


Table Q4. Do you get enough information about other public services for which your family is eligible?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|------------|-----------------|--------------|
| FL | 41% | 31% | 15% | 13% | 308 |
| NC | 37% | 34% | 12% | 16% | 218 |
| OK | 36% | 43% | 13% | 9% | 374 |
| PA | 36% | 35% | 15% | 14% | 617 |
| DC | 34% | 27% | 21% | 18% | 206 |
| NCI Average | 34% | 36% | 16% | 14% | 4,395 |
| WA | 33% | 40% | 17% | 10% | 420 |
| NH | 32% | 39% | 18% | 11% | 520 |
| AZ | 28% | 39% | 17% | 16% | 221 |
| MO | 27% | 41% | 20% | 12% | 251 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MD | 23% | 37% | 22% | 18% | 775 |
| GA | 20% | 37% | 19% | 24% | 323 |
| DE | 20% | 35% | 25% | 20% | 162 |

Respondent Needs Help Planning For Family Member's Future Needs

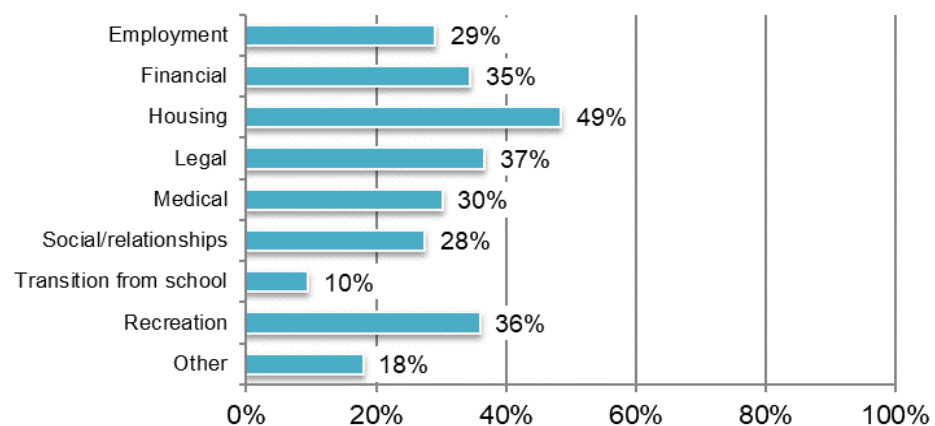


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

| State | Employment | Financial | Housing | Legal | Medical | Social or Relationships | Transition From School | Recreation or Having Fun | Other | N |
|--------------------|------------|------------|------------|------------|------------|-------------------------|------------------------|--------------------------|------------|--------------|
| AZ | 33% | 36% | 44% | 34% | 31% | 20% | 14% | 30% | 14% | 146 |
| DC | 40% | 29% | 44% | 39% | 24% | 34% | 6% | 40% | 7% | 161 |
| DE | 50% | 45% | 56% | 46% | 32% | 44% | 16% | 41% | 8% | 144 |
| FL | 29% | 41% | 53% | 46% | 40% | 32% | 13% | 42% | 17% | 246 |
| GA | 17% | 33% | 46% | 43% | 25% | 23% | 7% | 35% | 23% | 242 |
| MD | 37% | 41% | 57% | 38% | 29% | 31% | 3% | 41% | 9% | 639 |
| MO | 28% | 36% | 50% | 33% | 28% | 35% | 11% | 39% | 24% | 209 |
| NC | 34% | 37% | 45% | 39% | 27% | 27% | 13% | 37% | 25% | 161 |
| NH | 44% | 47% | 67% | 36% | 35% | 44% | 6% | 44% | 6% | 354 |
| OK | 22% | 25% | 35% | 32% | 31% | 24% | 5% | 31% | 18% | 170 |
| PA | 21% | 29% | 50% | 33% | 27% | 23% | 6% | 32% | 18% | 428 |
| WA | 38% | 27% | 37% | 28% | 27% | 28% | 12% | 36% | 20% | 320 |
| NCI Average | 29% | 35% | 49% | 37% | 30% | 28% | 10% | 36% | 18% | 3,220 |

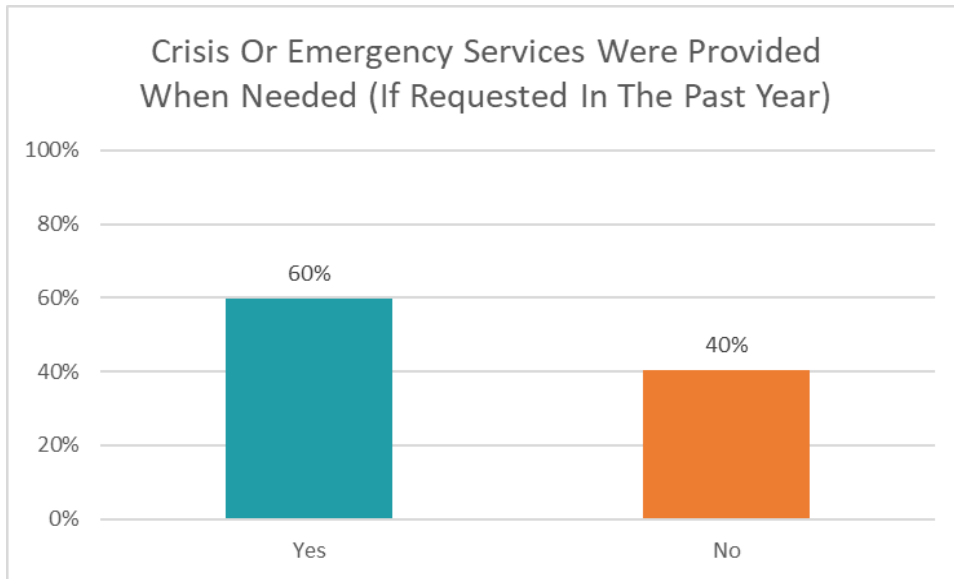


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|------------|
| NC | 71% | 29% | 56 |
| PA | 65% | 35% | 121 |
| FL | 62% | 38% | 104 |
| DC | 61% | 39% | 62 |
| NCI Average | 60% | 40% | 995 |
| WA | 58% | 42% | 71 |
| OK | 57% | 43% | 63 |
| MO | 55% | 45% | 51 |
| NH | 54% | 46% | 101 |
| AZ | 51% | 49% | 55 |
| GA | 49% | 51% | 85 |
| DE | 39% | 61% | 28 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 36% | 64% | 198 |

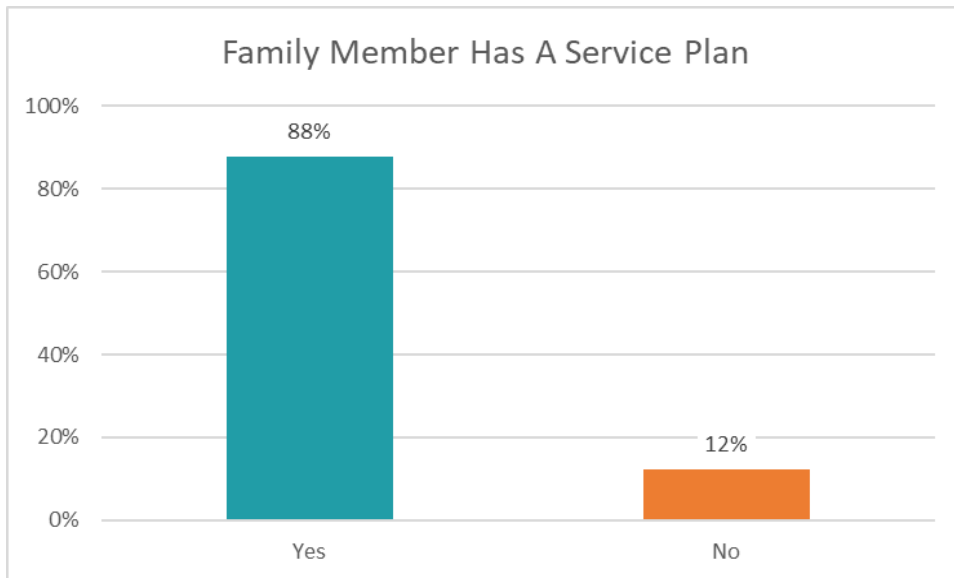


Table Q7. Does your family member have a service plan?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| PA | 95% | 5% | 664 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| FL | 90% | 10% | 342 |
| NC | 88% | 12% | 230 |
| MO | 88% | 12% | 245 |
| NCI Average | 88% | 12% | 4,290 |
| NH | 86% | 14% | 541 |
| AZ | 85% | 15% | 222 |
| OK | 85% | 15% | 338 |
| DC | 82% | 18% | 205 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| WA | 79% | 21% | 345 |
| GA | 74% | 26% | 298 |
| MD | 70% | 30% | 725 |
| DE | 42% | 58% | 135 |

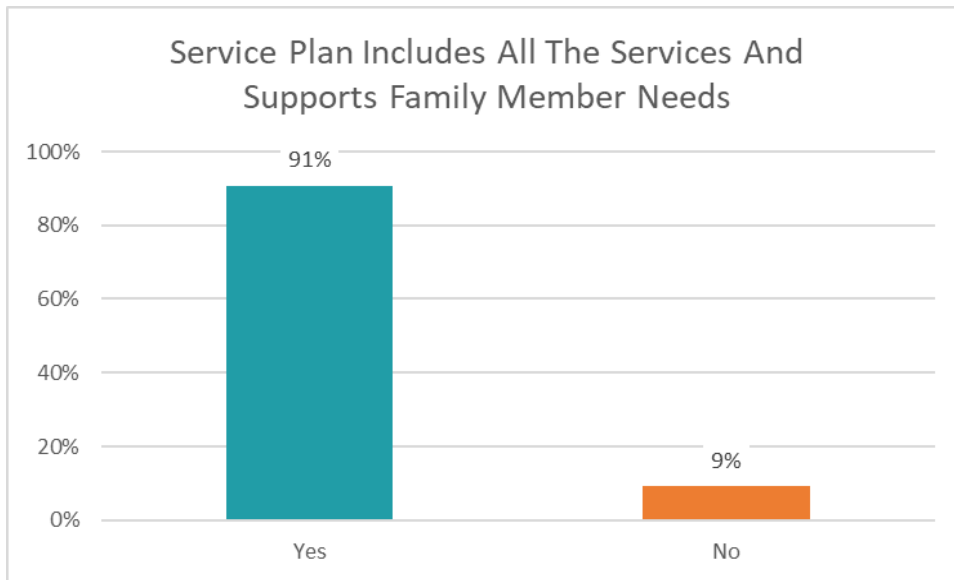


Table Q8. Does the plan include all the services and supports your family member needs?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| PA | 94% | 6% | 570 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|-----------|--------------|
| DC | 93% | 7% | 153 |
| AZ | 92% | 8% | 168 |
| WA | 92% | 8% | 238 |
| NCI Average | 91% | 9% | 3,170 |
| FL | 90% | 10% | 277 |
| NC | 88% | 12% | 193 |
| MO | 88% | 13% | 192 |
| OK | 87% | 13% | 261 |
| DE | 86% | 14% | 49 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| NH | 86% | 14% | 428 |
| MD | 81% | 19% | 450 |
| GA | 81% | 19% | 191 |

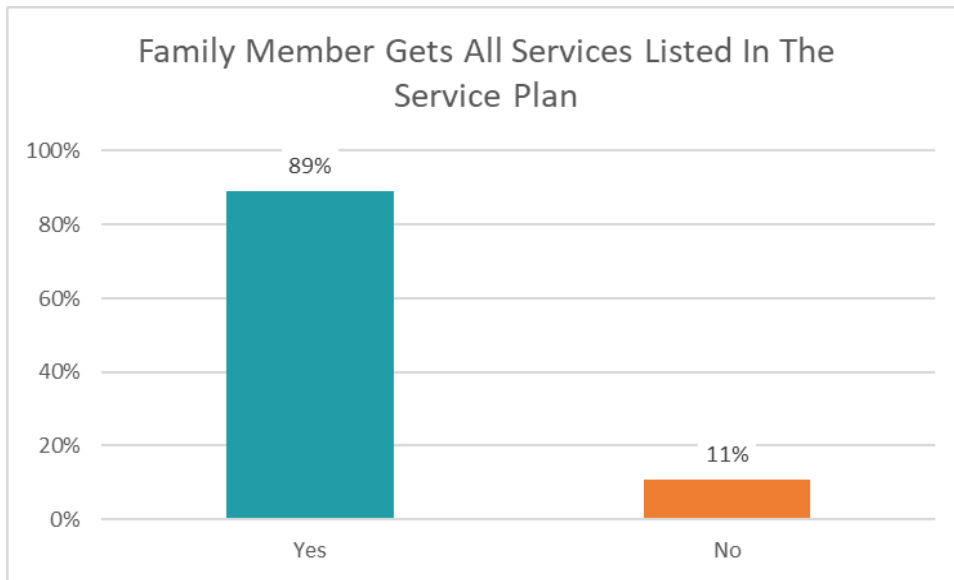


Table Q9. Does your family member get all the services listed in the plan?

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| NH | 92% | 8% | 432 |
| PA | 92% | 8% | 563 |
| FL | 90% | 10% | 274 |
| OK | 90% | 10% | 263 |
| NCI Average | 89% | 11% | 3,163 |
| NC | 89% | 11% | 192 |
| MO | 88% | 12% | 190 |
| GA | 86% | 14% | 188 |
| AZ | 85% | 15% | 176 |
| WA | 85% | 15% | 235 |
| DC | 81% | 19% | 151 |
| DE | 77% | 23% | 48 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 80% | 20% | 451 |

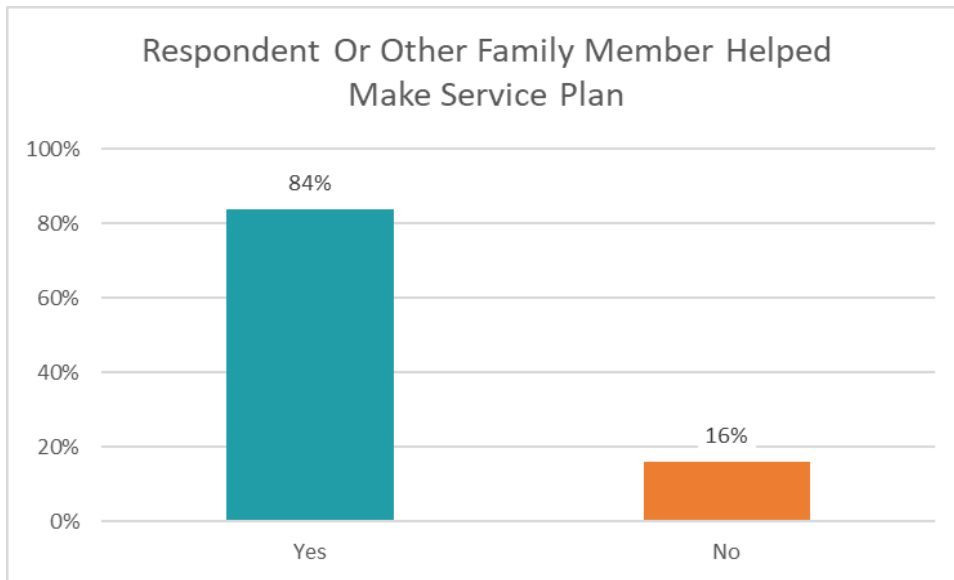


Table Q10. Did you or another family member help make the service plan?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| NH | 92% | 8% | 455 |
| NC | 90% | 10% | 199 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| OK | 88% | 12% | 275 |
| MO | 87% | 13% | 207 |
| PA | 86% | 14% | 587 |
| WA | 85% | 15% | 257 |
| NCI Average | 84% | 16% | 3,354 |
| DE | 83% | 17% | 54 |
| AZ | 83% | 17% | 175 |
| MD | 82% | 18% | 484 |
| GA | 81% | 19% | 207 |
| DC | 78% | 22% | 157 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| FL | 77% | 23% | 297 |

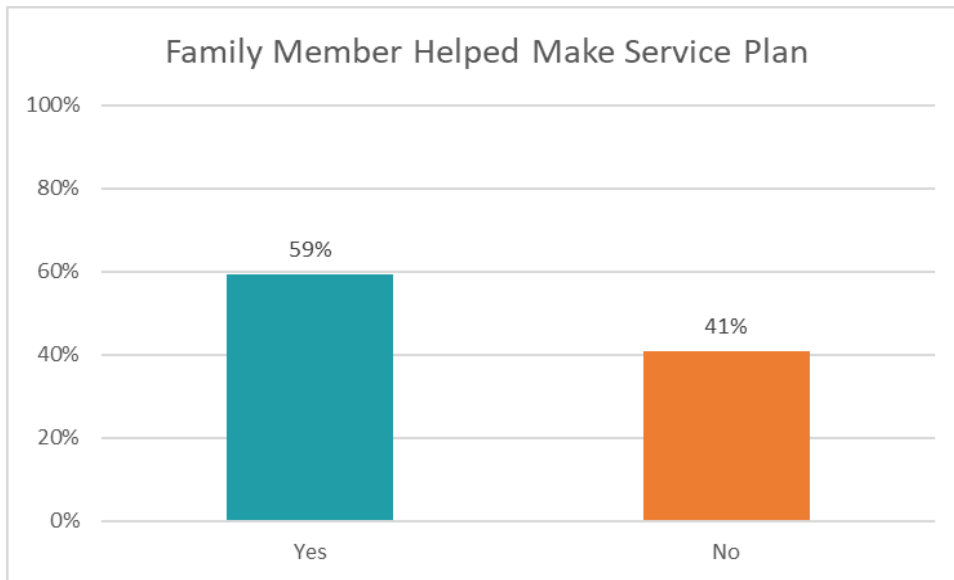


Table Q11. Did your family member help make the service plan?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 69% | 31% | 478 |
| NH | 69% | 31% | 456 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| DE | 70% | 30% | 54 |
| PA | 63% | 37% | 571 |
| GA | 62% | 38% | 207 |
| WA | 61% | 39% | 261 |
| DC | 60% | 40% | 154 |
| OK | 60% | 40% | 275 |
| NCI Average | 59% | 41% | 3,325 |
| FL | 59% | 41% | 292 |
| MO | 55% | 45% | 203 |
| AZ | 50% | 50% | 177 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| NC | 49% | 51% | 197 |

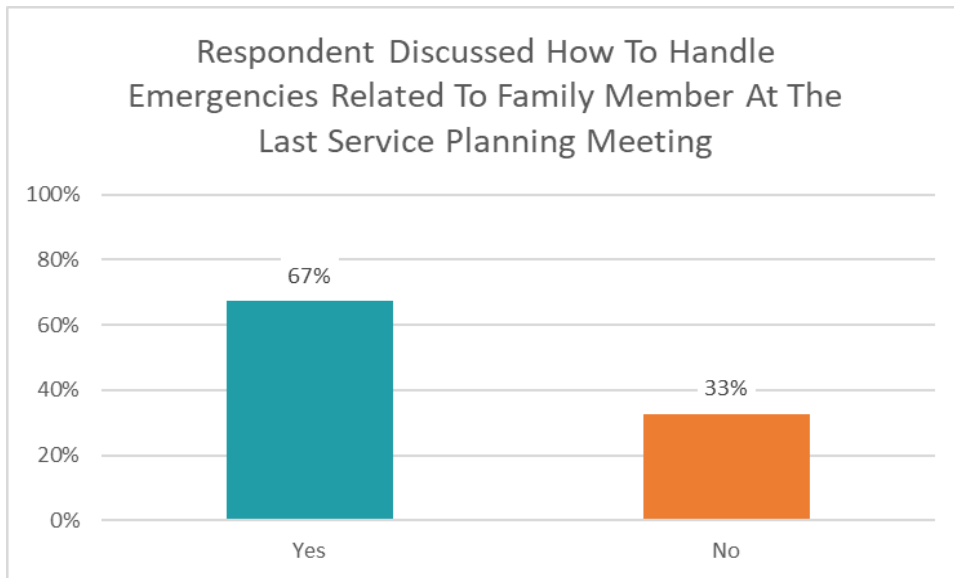


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| WA | 87% | 13% | 232 |
| OK | 85% | 15% | 266 |
| FL | 80% | 20% | 276 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| NC | 72% | 28% | 193 |
| DC | 71% | 29% | 146 |
| NCI Average | 67% | 33% | 3,069 |
| MD | 66% | 34% | 454 |
| MO | 61% | 39% | 187 |
| GA | 59% | 41% | 194 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| PA | 61% | 39% | 514 |
| AZ | 51% | 49% | 159 |
| DE | 43% | 57% | 46 |
| NH | 42% | 58% | 402 |

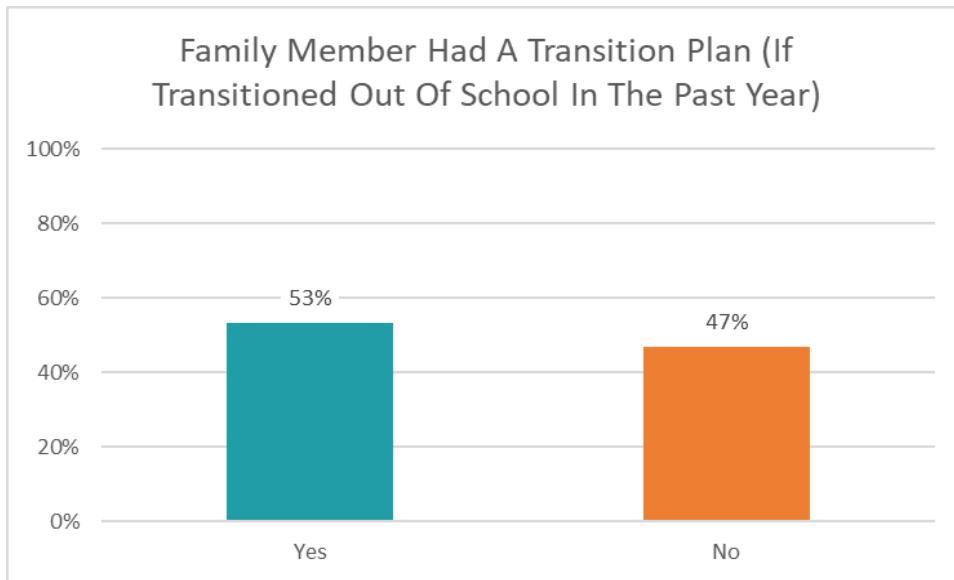


Table Q13. If your family member transitioned out of school services during the past year, did s/he have a transition plan?

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|------------|
| PA | 70% | 30% | 30 |
| MO | 64% | 36% | 22 |
| NH | 61% | 39% | 38 |
| AZ | 56% | 44% | 34 |
| DC | 55% | 45% | 22 |
| NCI Average | 53% | 47% | 356 |
| WA | 47% | 53% | 60 |
| FL | 47% | 53% | 30 |
| DE | 46% | 54% | 39 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|----|
| MD | 25% | 75% | 28 |

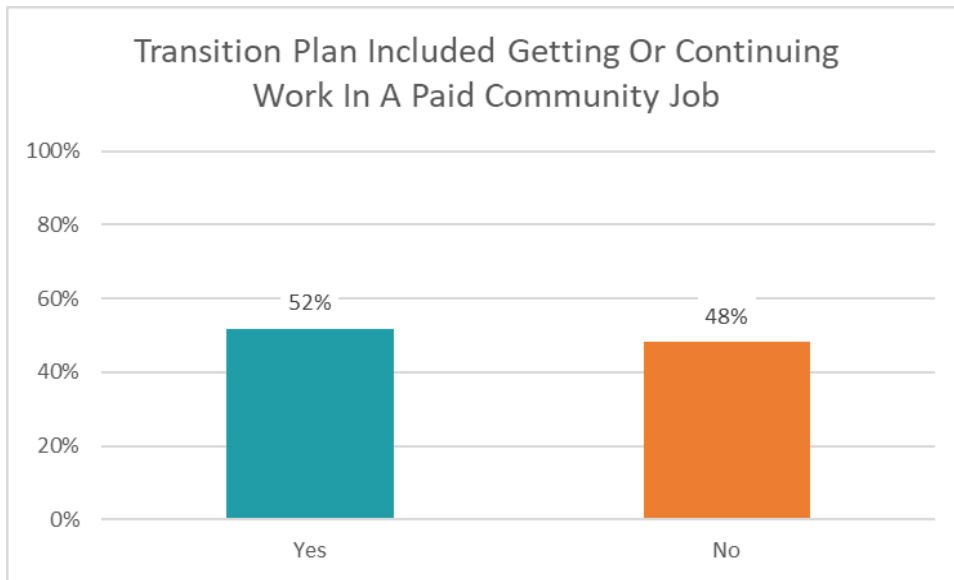


Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|----|
| WA | 82% | 18% | 22 |

Within Average Range

| State | Yes | No | N |
|-------------|-----|-----|-----|
| NCI Average | 52% | 48% | 161 |
| NH | 43% | 57% | 21 |

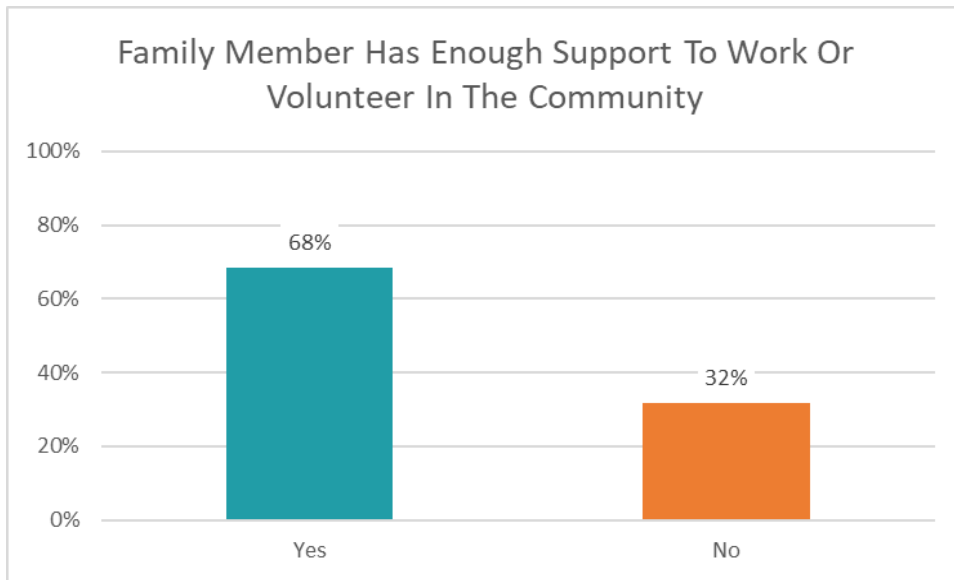


Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| NH | 75% | 25% | 488 |
| PA | 74% | 26% | 460 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| NC | 71% | 29% | 181 |
| WA | 71% | 29% | 319 |
| DE | 69% | 31% | 133 |
| NCI Average | 68% | 32% | 3,450 |
| OK | 68% | 32% | 251 |
| AZ | 68% | 32% | 141 |
| DC | 67% | 33% | 165 |
| MO | 59% | 41% | 178 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 62% | 38% | 675 |
| GA | 60% | 40% | 240 |
| FL | 58% | 42% | 219 |

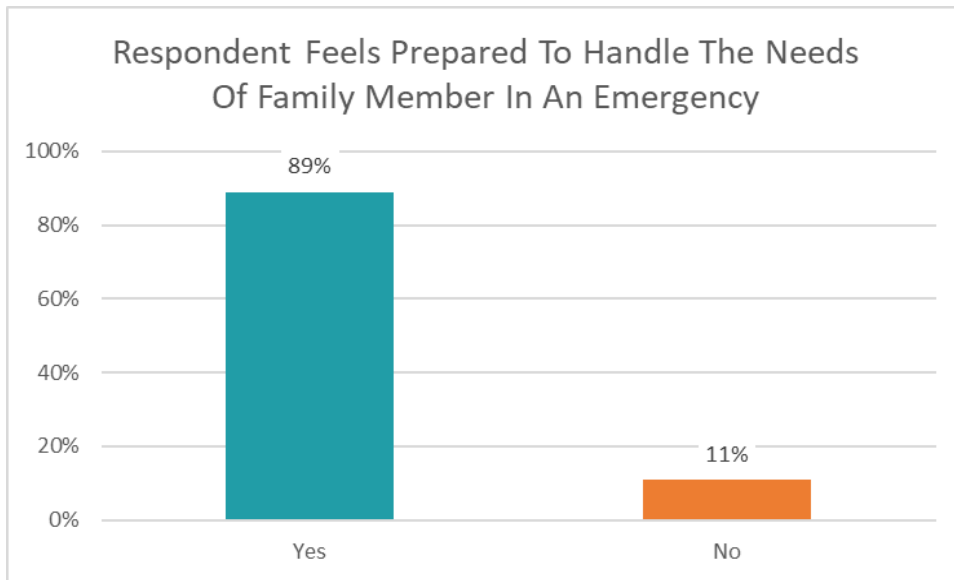


Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| OK | 96% | 4% | 393 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| FL | 92% | 8% | 332 |
| WA | 90% | 10% | 418 |
| NC | 90% | 10% | 233 |
| NCI Average | 89% | 11% | 4,614 |
| DC | 89% | 11% | 229 |
| AZ | 89% | 11% | 227 |
| NH | 89% | 11% | 550 |
| PA | 88% | 12% | 651 |
| GA | 88% | 12% | 338 |
| DE | 87% | 13% | 163 |
| MO | 84% | 16% | 264 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 81% | 19% | 816 |

Access and Delivery of Services and Supports

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

Note: Significance is based on “Always” or “Yes” response.

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

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

Respondent or Family Member Is Able To Contact Support Workers When Wants

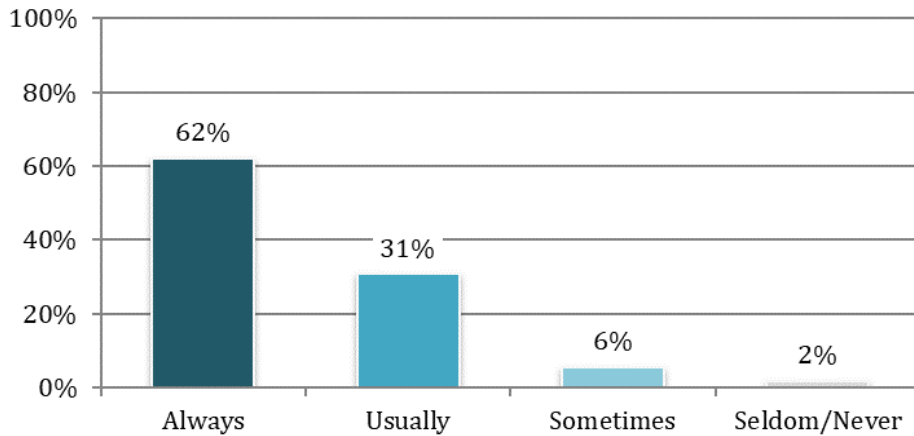


Table Q17. Are you or your family member able to contact his/her support workers when you want to?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 75% | 19% | 5% | 2% | 338 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| PA | 66% | 30% | 4% | 1% | 681 |
| NC | 65% | 31% | 4% | 0% | 241 |
| NCI Average | 62% | 31% | 6% | 2% | 4,665 |
| NH | 59% | 35% | 5% | 2% | 542 |
| AZ | 58% | 35% | 6% | 2% | 235 |
| DC | 54% | 34% | 9% | 3% | 233 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| OK | 54% | 37% | 7% | 2% | 393 |
| WA | 52% | 38% | 8% | 3% | 383 |
| MO | 50% | 38% | 11% | 1% | 263 |
| GA | 49% | 38% | 9% | 5% | 350 |
| DE | 45% | 36% | 14% | 5% | 152 |
| MD | 41% | 42% | 12% | 5% | 854 |

Respondent Or Family Member Is Able To Contact Case Manager Or Service Coordinator When Wants

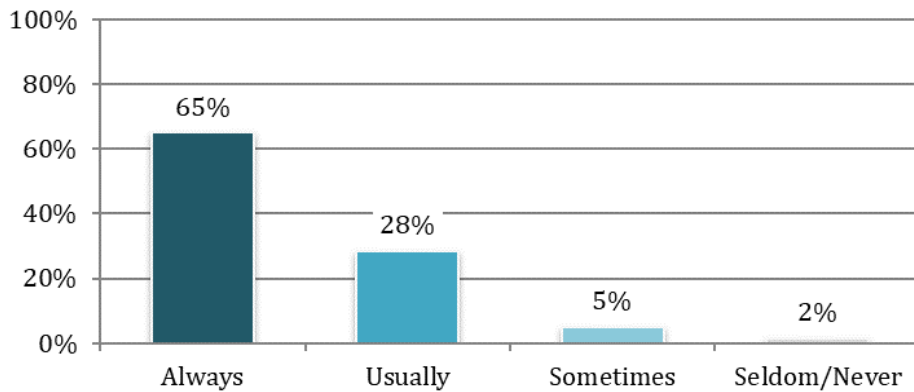


Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 76% | 18% | 4% | 2% | 348 |
| PA | 70% | 26% | 3% | 1% | 708 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| NCI Average | 65% | 28% | 5% | 2% | 4,935 |
| NC | 63% | 30% | 6% | 0% | 246 |
| AZ | 63% | 31% | 4% | 2% | 242 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| NH | 59% | 33% | 5% | 2% | 592 |
| WA | 57% | 36% | 7% | 1% | 444 |
| DC | 57% | 33% | 7% | 3% | 240 |
| OK | 55% | 35% | 9% | 1% | 417 |
| MO | 53% | 35% | 9% | 2% | 281 |
| DE | 50% | 34% | 12% | 4% | 172 |
| MD | 49% | 40% | 7% | 3% | 885 |
| GA | 49% | 38% | 9% | 5% | 360 |

Support Workers Come and Leave When They Are Supposed To

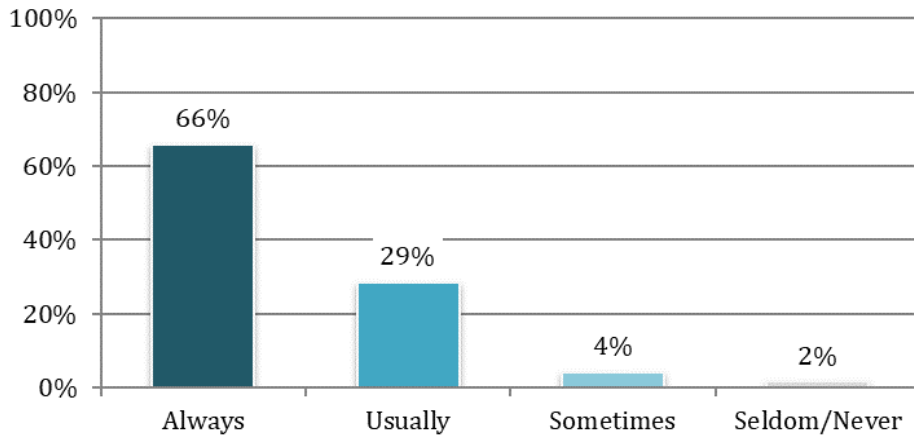


Table Q19. Do support workers come and leave when they are supposed to? (Do they show up on time? Do they show up when they say they will?)

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 74% | 20% | 3% | 3% | 320 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| AZ | 71% | 26% | 3% | 0% | 235 |
| PA | 70% | 26% | 3% | 0% | 627 |
| NCI Average | 66% | 29% | 4% | 2% | 4,264 |
| WA | 63% | 32% | 3% | 1% | 321 |
| OK | 59% | 33% | 6% | 2% | 360 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| NH | 56% | 38% | 4% | 1% | 512 |
| NC | 56% | 37% | 6% | 1% | 238 |
| MO | 54% | 39% | 5% | 2% | 224 |
| DE | 51% | 34% | 11% | 4% | 127 |
| DC | 51% | 35% | 9% | 4% | 226 |
| GA | 50% | 39% | 7% | 4% | 313 |
| MD | 45% | 43% | 9% | 3% | 761 |

Services And Supports Change When Family's Needs Change

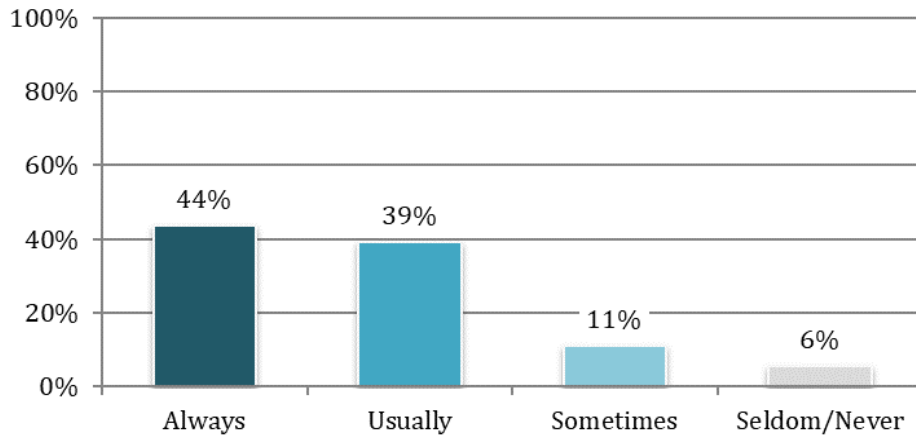


Table Q20. Do services and supports change when your family's needs change?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|------------|-----------------|--------------|
| FL | 48% | 37% | 12% | 4% | 284 |
| PA | 48% | 40% | 8% | 5% | 507 |
| AZ | 46% | 37% | 11% | 6% | 192 |
| DC | 46% | 33% | 15% | 6% | 185 |
| NCI Average | 44% | 39% | 11% | 6% | 3,605 |
| NC | 41% | 41% | 10% | 8% | 218 |
| WA | 40% | 42% | 13% | 5% | 290 |
| NH | 40% | 38% | 15% | 7% | 439 |
| MO | 37% | 41% | 16% | 6% | 204 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| OK | 35% | 45% | 14% | 6% | 297 |
| MD | 33% | 44% | 16% | 7% | 653 |
| GA | 30% | 44% | 15% | 11% | 249 |
| DE | 25% | 32% | 24% | 18% | 87 |

Support Workers Speak In A Way Respondent Understands

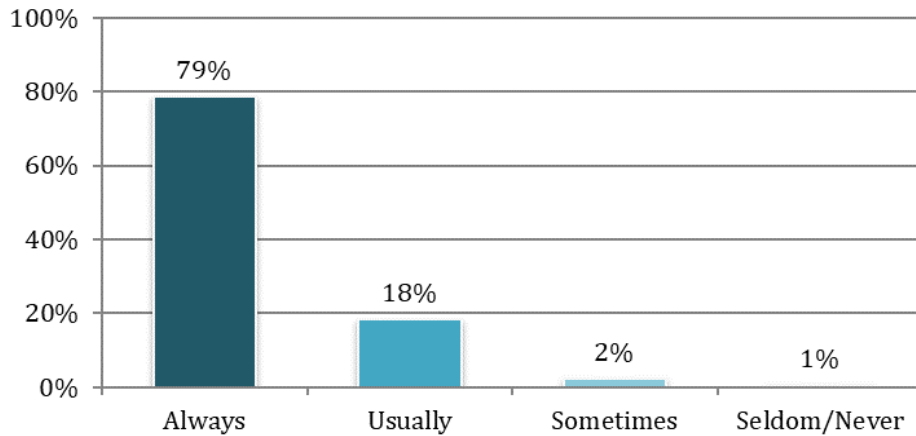


Table Q21. Do support workers speak to you in a way that you understand?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 85% | 13% | 2% | 0% | 324 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| AZ | 83% | 16% | 1% | | 237 |
| NC | 81% | 17% | 0% | 2% | 242 |
| PA | 80% | 18% | 2% | 0% | 661 |
| NH | 80% | 17% | 2% | 1% | 536 |
| NCI Average | 79% | 18% | 2% | 1% | 4,508 |
| DC | 73% | 20% | 6% | 1% | 228 |
| WA | 73% | 23% | 4% | 0% | 357 |
| MO | 72% | 24% | 2% | 1% | 243 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| OK | 70% | 27% | 2% | 1% | 382 |
| GA | 69% | 27% | 2% | 2% | 349 |
| DE | 68% | 21% | 10% | 2% | 145 |
| MD | 60% | 28% | 9% | 3% | 804 |

Services and Supports Are Delivered In A Way Respectful Of Family's Culture

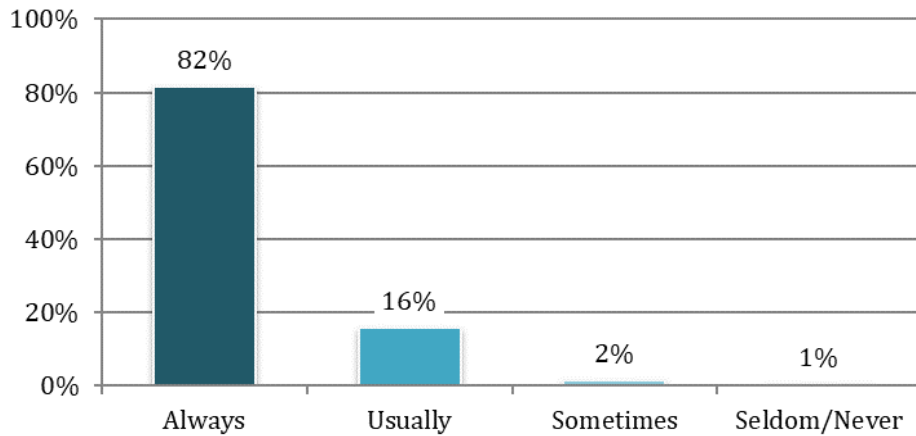


Table Q22. Are services delivered in a way that is respectful to your family's culture?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 88% | 10% | 1% | 1% | 347 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| PA | 84% | 14% | 1% | 0% | 689 |
| AZ | 83% | 15% | 2% | 0% | 242 |
| NCI Average | 82% | 16% | 2% | 1% | 4,760 |
| NC | 80% | 17% | 2% | 1% | 248 |
| NH | 79% | 19% | 1% | 1% | 570 |
| WA | 79% | 19% | 1% | 1% | 401 |
| MO | 78% | 21% | 1% | 0% | 260 |
| OK | 76% | 21% | 1% | 1% | 398 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| GA | 72% | 24% | 2% | 2% | 356 |
| DE | 70% | 23% | 3% | 4% | 159 |
| DC | 68% | 26% | 5% | 1% | 231 |
| MD | 65% | 27% | 6% | 2% | 859 |

If Family Member Is Non-verbal, Support Workers Can Communicate With Him/Her

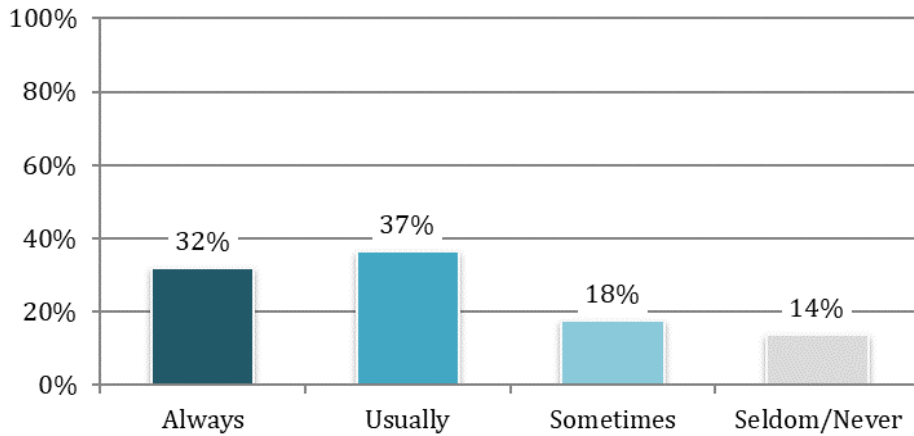


Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|------------|-----------------|--------------|
| FL | 40% | 29% | 12% | 19% | 98 |
| DC | 39% | 32% | 25% | 4% | 56 |
| NH | 38% | 35% | 16% | 11% | 74 |
| GA | 38% | 46% | 11% | 6% | 101 |
| NC | 35% | 39% | 20% | 6% | 71 |
| MO | 32% | 44% | 13% | 11% | 72 |
| NCI Average | 32% | 37% | 18% | 14% | 1,075 |
| OK | 31% | 42% | 14% | 13% | 107 |
| MD | 30% | 41% | 19% | 9% | 175 |
| PA | 29% | 38% | 21% | 12% | 156 |
| WA | 28% | 35% | 22% | 15% | 88 |
| AZ | 21% | 37% | 19% | 23% | 62 |

Support Workers Have The Right Information And Skills To Meet Family's Needs

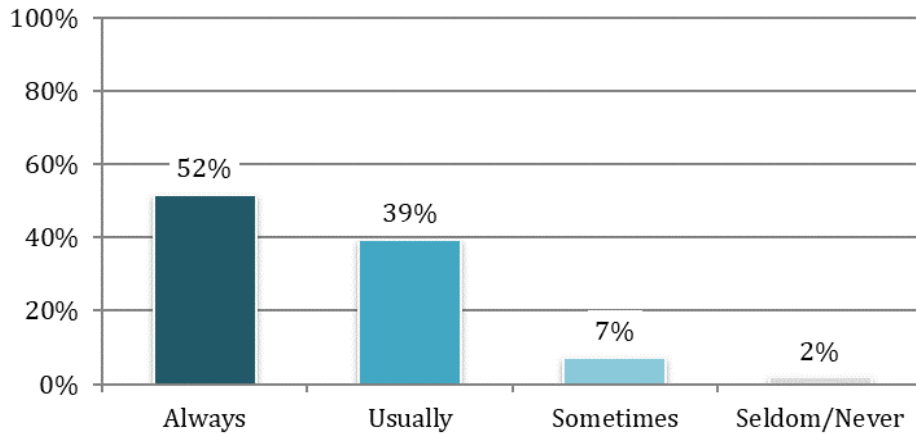


Table Q24. Do support workers have the right information and skills to meet your family's needs?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 63% | 30% | 5% | 1% | 312 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| OK | 54% | 38% | 6% | 2% | 362 |
| PA | 54% | 38% | 6% | 2% | 623 |
| NCI Average | 52% | 39% | 7% | 2% | 4,259 |
| DC | 50% | 37% | 10% | 3% | 225 |
| WA | 49% | 40% | 8% | 2% | 330 |
| NC | 49% | 40% | 9% | 2% | 237 |
| NH | 48% | 40% | 10% | 2% | 505 |
| AZ | 44% | 46% | 9% | 1% | 230 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| GA | 44% | 45% | 9% | 2% | 326 |
| MO | 41% | 51% | 7% | 2% | 227 |
| MD | 37% | 47% | 12% | 3% | 749 |
| DE | 34% | 47% | 14% | 5% | 133 |

Family Member Has Access To Special Equipment Or Accommodations Needed

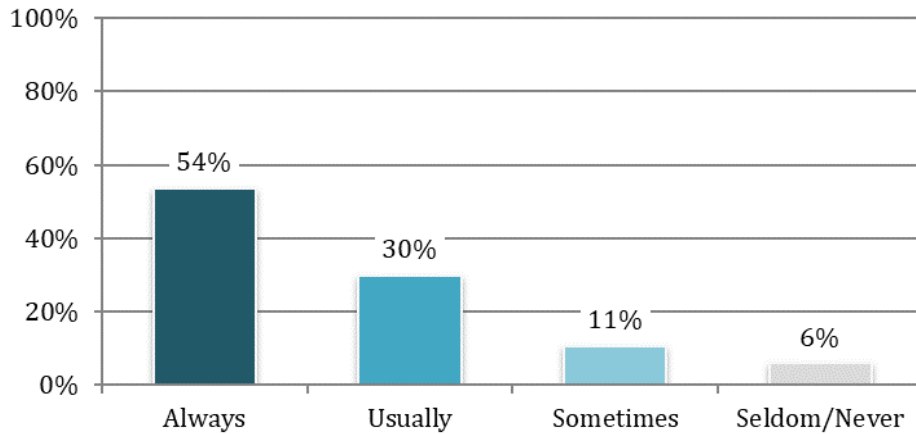


Table Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|------------|-----------------|--------------|
| FL | 60% | 25% | 10% | 4% | 192 |
| NC | 57% | 27% | 7% | 8% | 136 |
| AZ | 56% | 30% | 10% | 5% | 122 |
| NCI Average | 54% | 30% | 11% | 6% | 2,372 |
| PA | 53% | 30% | 11% | 6% | 336 |
| NH | 52% | 34% | 10% | 4% | 241 |
| GA | 50% | 27% | 12% | 11% | 185 |
| OK | 50% | 36% | 10% | 4% | 225 |
| DC | 49% | 29% | 11% | 10% | 97 |
| WA | 49% | 35% | 9% | 7% | 191 |
| MO | 46% | 39% | 11% | 4% | 144 |
| DE | 42% | 29% | 18% | 11% | 45 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MD | 41% | 37% | 17% | 4% | 458 |

Family Member Can See Health Professionals When Needed

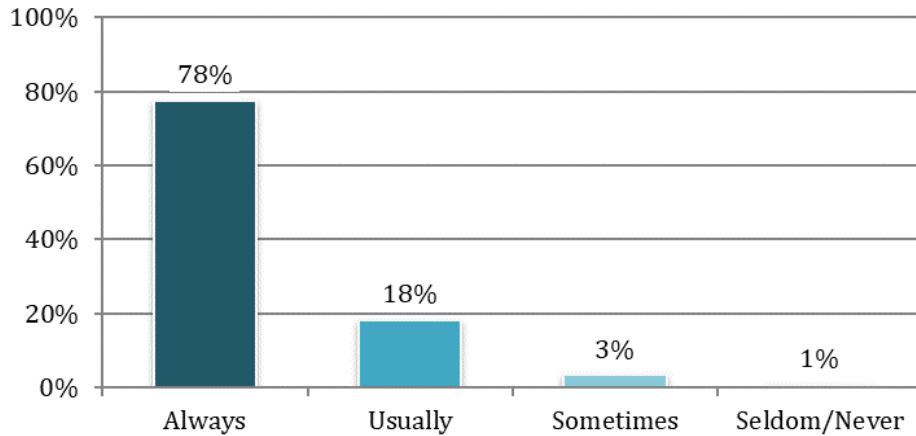


Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| PA | 81% | 17% | 2% | 0% | 731 |
| FL | 81% | 15% | 3% | 1% | 363 |
| NC | 80% | 16% | 3% | 0% | 256 |
| DC | 80% | 16% | 4% | 0% | 245 |
| DE | 80% | 16% | 4% | 1% | 184 |
| NCI Average | 78% | 18% | 3% | 1% | 5,097 |
| NH | 77% | 19% | 3% | 1% | 604 |
| GA | 76% | 19% | 4% | 1% | 382 |
| OK | 76% | 20% | 3% | 1% | 424 |
| AZ | 71% | 23% | 6% | 0% | 251 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| WA | 72% | 23% | 4% | 1% | 465 |
| MO | 70% | 25% | 3% | 1% | 291 |
| MD | 66% | 23% | 8% | 3% | 901 |

Family Member's Primary Care Doctor Understands Needs Related To His/Her Disability

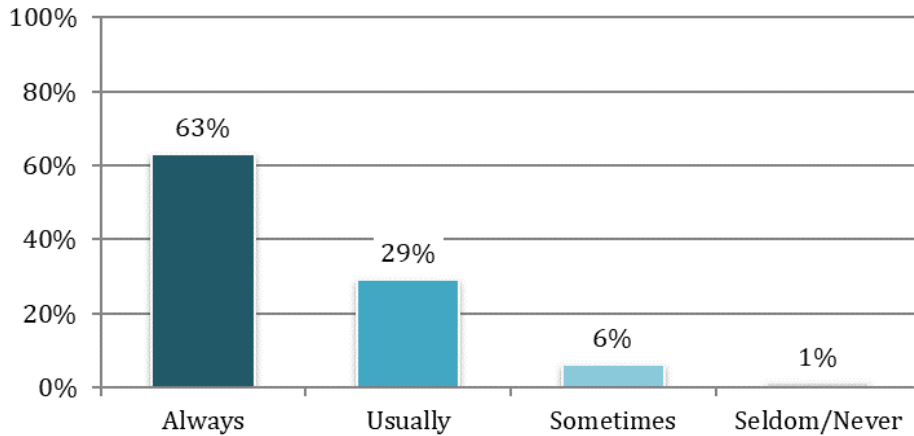


Table Q27. Does your family member's primary care doctor understand his/her needs related to his/her disability?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| DC | 74% | 22% | 4% | 0% | 237 |
| OK | 70% | 25% | 4% | 1% | 420 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| DE | 69% | 26% | 5% | 1% | 173 |
| PA | 66% | 28% | 5% | 1% | 711 |
| FL | 66% | 27% | 6% | 1% | 354 |
| NC | 65% | 28% | 6% | 1% | 252 |
| NCI Average | 63% | 29% | 6% | 1% | 4,990 |
| NH | 62% | 31% | 6% | 2% | 589 |
| GA | 60% | 33% | 6% | 1% | 370 |
| MD | 60% | 31% | 9% | 1% | 905 |
| WA | 58% | 32% | 8% | 2% | 450 |
| AZ | 56% | 33% | 9% | 2% | 249 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MO | 54% | 37% | 7% | 2% | 280 |

Respondent Has Access To Dental Services For Family Member

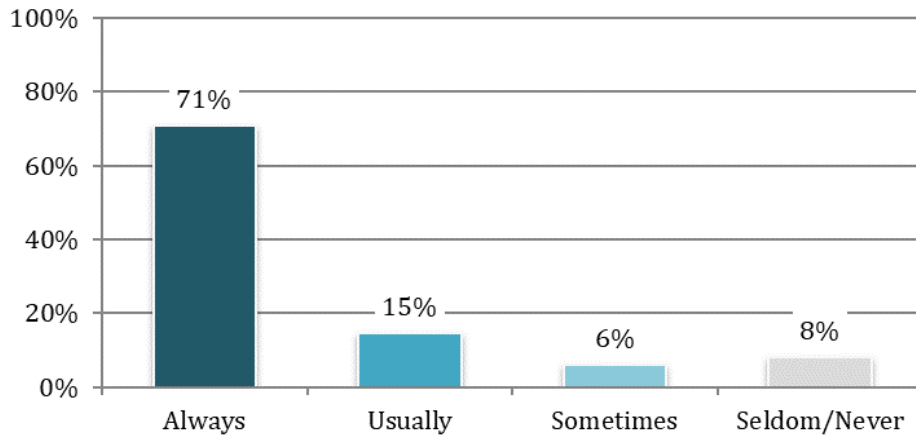


Table Q28. Do you have access to dental services for your family member?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| NC | 79% | 11% | 5% | 6% | 253 |
| PA | 77% | 11% | 5% | 6% | 697 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| DC | 76% | 13% | 6% | 5% | 244 |
| NH | 74% | 12% | 5% | 9% | 586 |
| WA | 72% | 16% | 5% | 7% | 438 |
| NCI Average | 71% | 15% | 6% | 8% | 4,884 |
| DE | 71% | 9% | 9% | 11% | 174 |
| OK | 70% | 14% | 6% | 9% | 406 |
| MD | 66% | 18% | 8% | 7% | 867 |
| AZ | 64% | 21% | 6% | 8% | 235 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| GA | 64% | 17% | 6% | 13% | 362 |
| FL | 63% | 18% | 8% | 11% | 341 |
| MO | 59% | 17% | 9% | 15% | 281 |

Family Member's Dentist Understands Needs Related To His/Her Disability

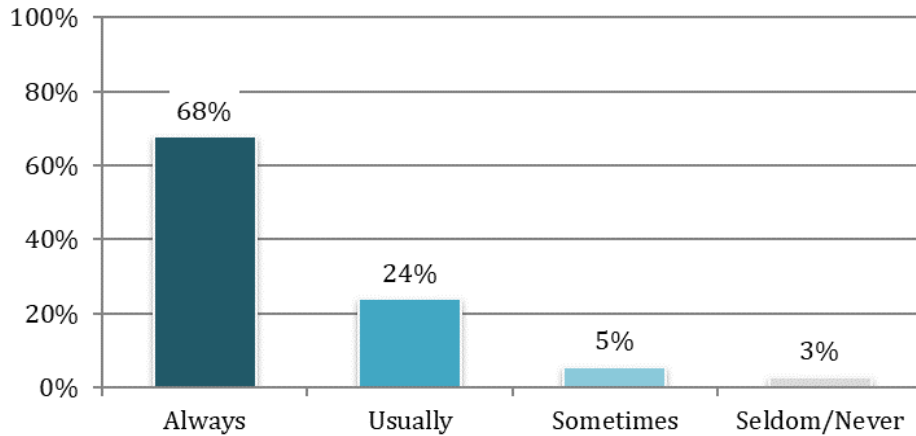


Table Q29. If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| DC | 74% | 17% | 8% | 1% | 229 |
| NC | 72% | 22% | 4% | 2% | 235 |
| PA | 72% | 22% | 4% | 2% | 631 |
| DE | 69% | 20% | 8% | 3% | 153 |
| NCI Average | 68% | 24% | 5% | 3% | 4,415 |
| OK | 67% | 24% | 7% | 2% | 364 |
| NH | 67% | 25% | 4% | 3% | 528 |
| FL | 66% | 24% | 6% | 4% | 309 |
| GA | 65% | 25% | 5% | 5% | 327 |
| WA | 63% | 27% | 8% | 1% | 405 |
| MO | 63% | 25% | 8% | 5% | 239 |
| AZ | 61% | 31% | 6% | 2% | 212 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MD | 63% | 26% | 8% | 3% | 783 |

Respondent Knows What Family Member's Medications Are For

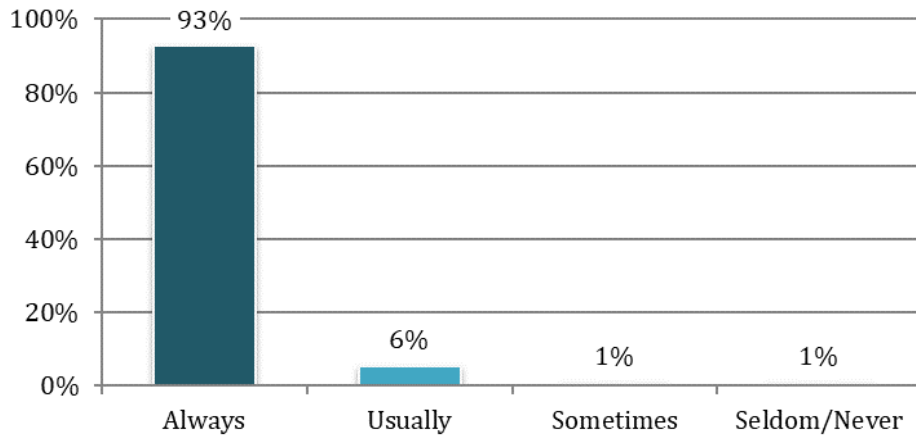


Table Q30. If your family member takes medications, do you know what they're for?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|-----------|-----------|-----------------|--------------|
| DE | 95% | 2% | 1% | 2% | 146 |
| AZ | 95% | 4% | 1% | 0% | 213 |
| NC | 95% | 4% | 0% | 1% | 239 |
| GA | 94% | 5% | 1% | 0% | 344 |
| PA | 93% | 5% | 1% | 0% | 645 |
| NH | 93% | 5% | 1% | 2% | 522 |
| NCI Average | 93% | 6% | 1% | 1% | 4,399 |
| OK | 93% | 6% | 1% | 1% | 377 |
| WA | 92% | 5% | 1% | 2% | 400 |
| FL | 92% | 6% | 0% | 2% | 318 |
| DC | 91% | 6% | 2% | 1% | 198 |
| MO | 89% | 9% | 2% | 1% | 246 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MD | 80% | 13% | 5% | 2% | 751 |

Respondent, Family Member, Or Other Family Member Knows What Is Needed For Family Member To Take Medication Safely

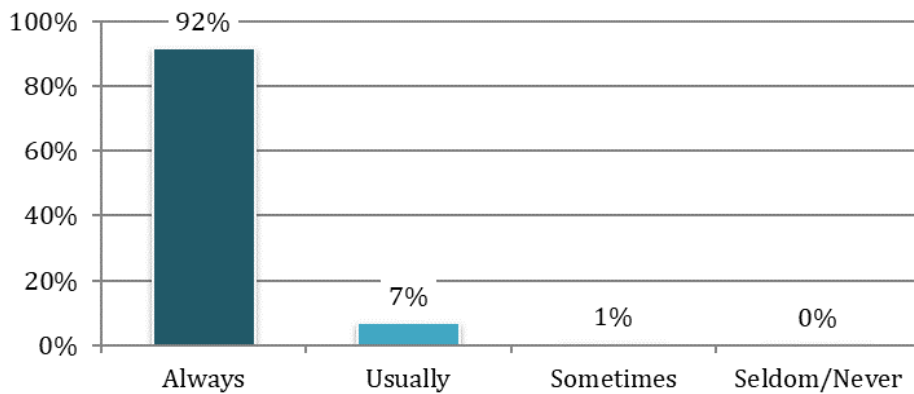


Table Q31. If your family member takes medications, do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|-----------|-----------|-----------------|--------------|
| NC | 95% | 5% | 0% | 0% | 238 |
| WA | 94% | 6% | 0% | 0% | 399 |
| DE | 93% | 4% | 1% | 1% | 144 |
| OK | 93% | 6% | 0% | 1% | 374 |
| AZ | 92% | 7% | 1% | 0% | 213 |
| FL | 92% | 6% | 1% | 1% | 314 |
| NCI Average | 92% | 7% | 1% | 0% | 4,349 |
| NH | 92% | 8% | 1% | 0% | 506 |
| PA | 91% | 8% | 1% | 0% | 645 |
| GA | 91% | 8% | 1% | 0% | 341 |
| DC | 91% | 7% | 2% | 1% | 193 |
| MO | 90% | 9% | 1% | 0% | 247 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MD | 79% | 16% | 4% | 1% | 735 |

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

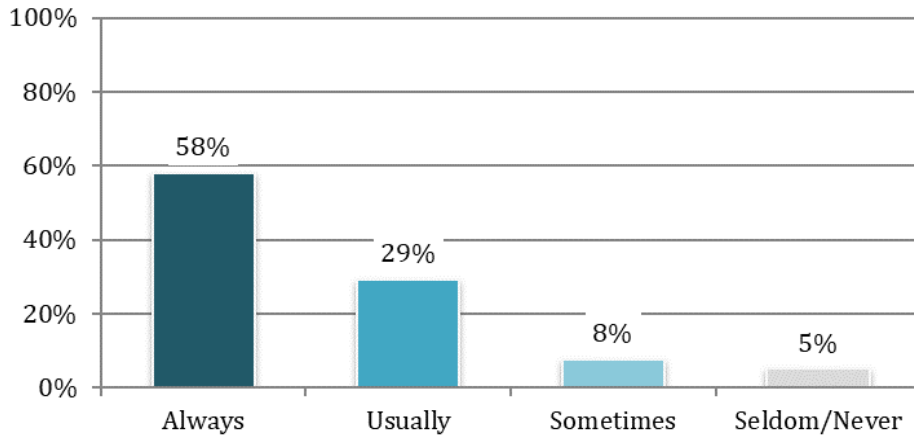


Table Q32. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| OK | 66% | 22% | 7% | 5% | 100 |
| DE | 66% | 26% | 3% | 5% | 61 |
| FL | 65% | 24% | 6% | 5% | 117 |
| DC | 61% | 24% | 11% | 5% | 114 |
| MO | 60% | 32% | 5% | 3% | 106 |
| NH | 60% | 25% | 8% | 7% | 197 |
| PA | 59% | 29% | 8% | 5% | 239 |
| NCI Average | 58% | 29% | 8% | 5% | 1,817 |
| WA | 55% | 29% | 10% | 6% | 119 |
| GA | 54% | 33% | 8% | 5% | 144 |
| NC | 54% | 32% | 9% | 5% | 111 |
| AZ | 54% | 34% | 6% | 6% | 82 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MD | 46% | 32% | 14% | 8% | 427 |

Respondent Has Access To Respite Services If Needed

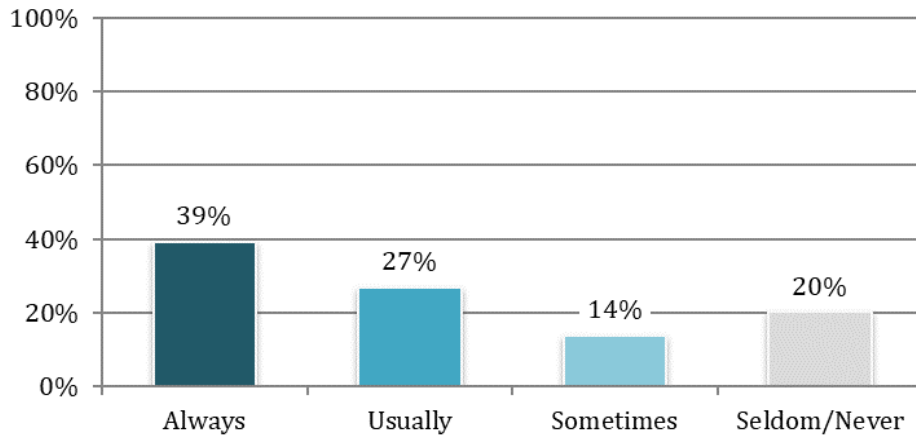


Table Q33. If you need respite services, do you have access to them? (Respite is support for family or other care-providers to allow them to take a break from providing care for a time-limited period.)

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| AZ | 58% | 29% | 9% | 5% | 233 |
| DC | 56% | 25% | 7% | 11% | 148 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|------------|-----------------|--------------|
| NC | 43% | 28% | 14% | 15% | 226 |
| DE | 42% | 23% | 11% | 23% | 99 |
| WA | 41% | 32% | 11% | 15% | 294 |
| NH | 39% | 28% | 18% | 16% | 387 |
| NCI Average | 39% | 27% | 14% | 20% | 3,053 |
| PA | 36% | 25% | 14% | 24% | 426 |
| MO | 32% | 27% | 20% | 21% | 183 |
| FL | 31% | 26% | 16% | 27% | 196 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MD | 26% | 31% | 16% | 27% | 470 |
| GA | 22% | 22% | 16% | 40% | 199 |
| OK | 21% | 20% | 8% | 51% | 192 |

Respondent Is Satisfied With The Quality Of Family Member's Respite Services

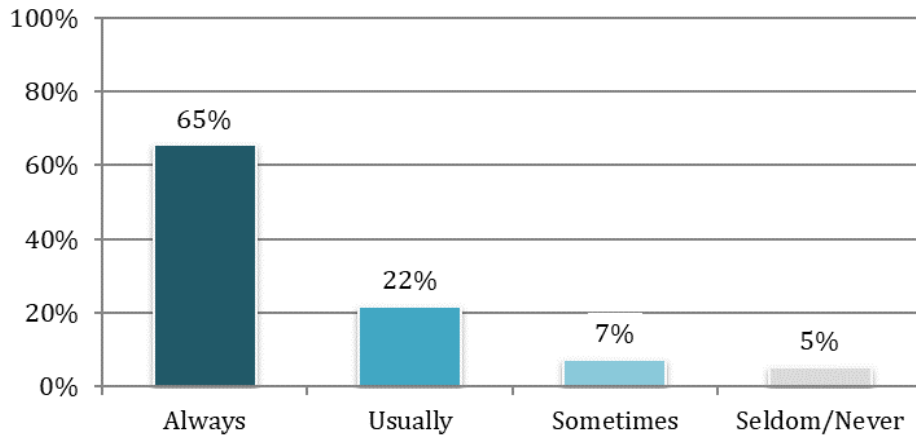


Table Q34. If you have access to respite services, are you satisfied with the quality of those services? ²

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| AZ | 75% | 17% | 5% | 3% | 205 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| NH | 70% | 22% | 5% | 3% | 304 |
| DE | 68% | 15% | 8% | 9% | 53 |
| NC | 66% | 25% | 5% | 3% | 186 |
| NCI Average | 65% | 22% | 7% | 5% | 1,978 |
| PA | 65% | 24% | 7% | 5% | 238 |
| WA | 63% | 25% | 9% | 3% | 208 |
| FL | 62% | 16% | 12% | 10% | 108 |
| OK | 62% | 19% | 6% | 13% | 68 |
| MO | 61% | 28% | 4% | 7% | 118 |
| GA | 53% | 25% | 9% | 13% | 106 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| DC | 49% | 20% | 14% | 17% | 88 |
| MD | 45% | 33% | 14% | 8% | 296 |

² Wording changed for this question in 2017-18

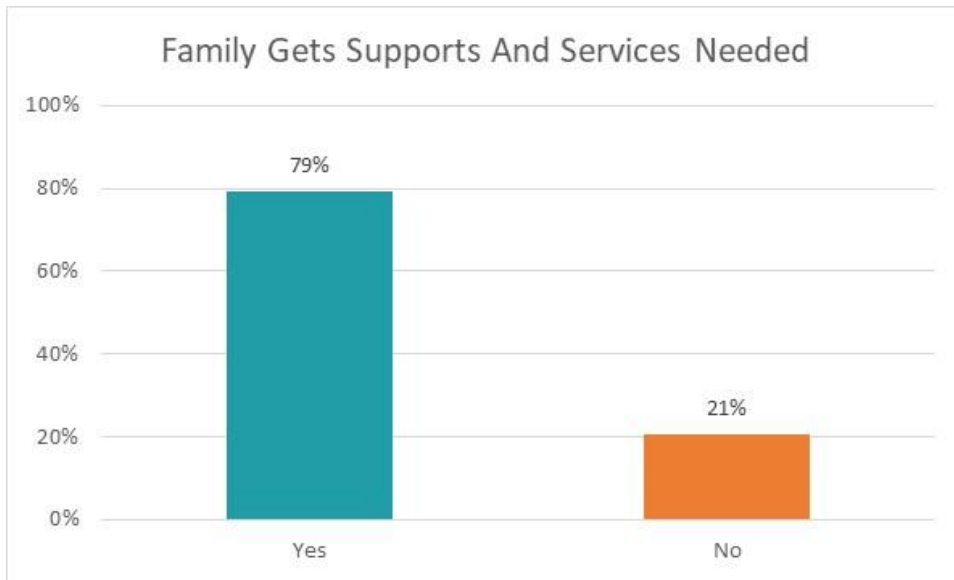


Table Q35. Does your family get the support and services needed?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| AZ | 89% | 11% | 235 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| WA | 82% | 18% | 396 |
| PA | 81% | 19% | 656 |
| NCI Average | 79% | 21% | 4,419 |
| FL | 79% | 21% | 320 |
| NH | 77% | 23% | 549 |
| NC | 75% | 25% | 245 |
| OK | 75% | 25% | 354 |
| DC | 73% | 27% | 236 |
| DE | 70% | 30% | 155 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| GA | 70% | 30% | 318 |
| MD | 70% | 30% | 688 |
| MO | 70% | 30% | 267 |

Additional Supports And Services Needed

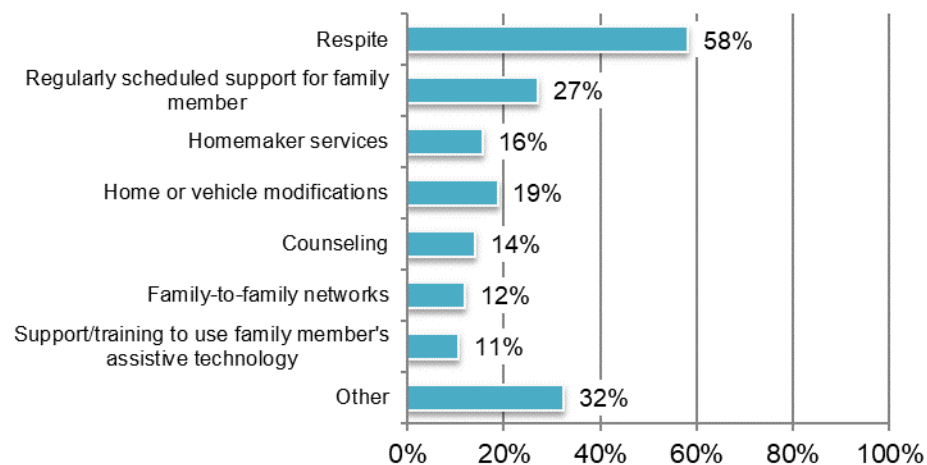


Table Q36. If family does not get the support and services needed, what additional services are needed? ∞

| State | Respite | Regularly Scheduled Support for Family Member | Homemaker Services | Home or Vehicle Modifications | Counseling | Family-to-family Networks | Support or Training to Use Assistive Technology | Other |
|--------------------|------------|---|--------------------|-------------------------------|------------|---------------------------|---|------------|
| AZ | 38% | 24% | 29% | 29% | 19% | 0% | 19% | 24% |
| DC | 37% | 23% | 22% | 25% | 20% | 23% | 28% | 8% |
| DE | 51% | 31% | 22% | 7% | 20% | 20% | 4% | 42% |
| FL | 48% | 23% | 14% | 25% | 16% | 16% | 11% | 36% |
| GA | 70% | 27% | 13% | 14% | 11% | 18% | 10% | 24% |
| MD | 65% | 35% | 15% | 16% | 17% | 9% | 9% | 25% |
| MO | 60% | 36% | 10% | 17% | 14% | 14% | 13% | 25% |
| NC | 73% | 41% | 14% | 14% | 17% | 15% | 7% | 34% |
| NH | 53% | 38% | 10% | 13% | 19% | 18% | 10% | 21% |
| OK | 61% | 18% | 11% | 16% | 5% | 1% | 3% | 39% |
| PA | 59% | 22% | 19% | 21% | 8% | 7% | 12% | 34% |
| WA | 60% | 22% | 10% | 10% | 25% | 18% | 9% | 36% |
| NCI Average | 58% | 27% | 16% | 19% | 14% | 12% | 11% | 32% |

∞ Categories are not mutually exclusive

Choice, Decision Making and Control

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

Note: Significance is based on “Always” or “Yes” response.

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

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

Family Can Choose Or Change Family Member's Provider Agency

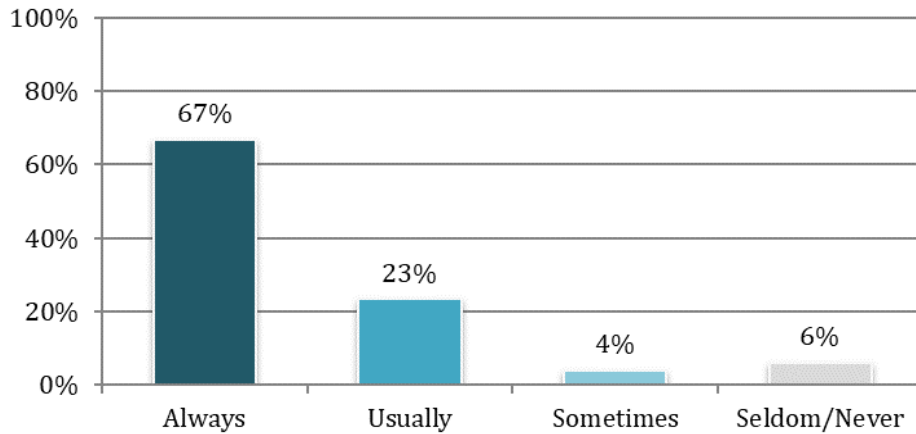


Table Q37. Can your family choose or change the agency that provides your family member's services?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 75% | 18% | 2% | 5% | 257 |
| NC | 75% | 18% | 2% | 5% | 220 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| OK | 71% | 19% | 4% | 6% | 307 |
| NCI Average | 67% | 23% | 4% | 6% | 3,296 |
| PA | 66% | 26% | 3% | 5% | 458 |
| NH | 65% | 21% | 3% | 11% | 343 |
| DC | 65% | 25% | 5% | 6% | 181 |
| AZ | 64% | 26% | 5% | 6% | 188 |
| GA | 63% | 24% | 6% | 7% | 250 |
| WA | 62% | 26% | 6% | 7% | 222 |
| DE | 59% | 24% | 6% | 10% | 86 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MO | 51% | 28% | 9% | 12% | 174 |
| MD | 47% | 33% | 14% | 6% | 610 |

Family Can Choose Or Change Family Member's Support Workers

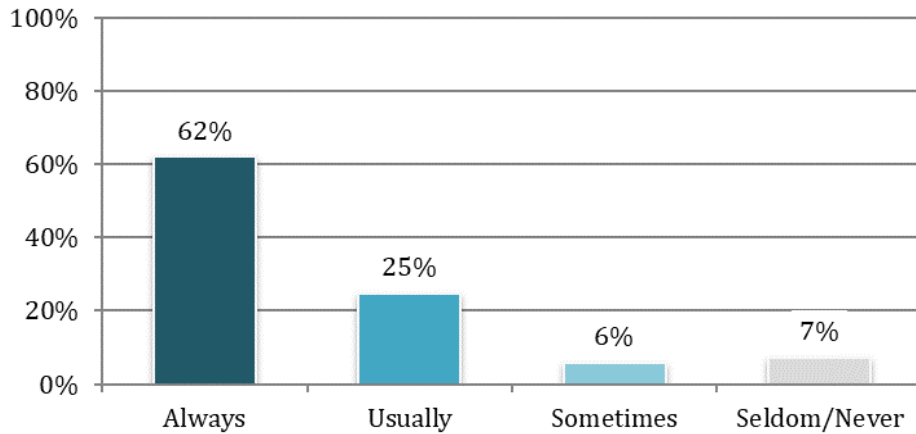


Table Q38. Can your family choose or change your family member's support workers?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 72% | 18% | 5% | 4% | 261 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| OK | 68% | 20% | 4% | 7% | 303 |
| NC | 68% | 21% | 7% | 5% | 231 |
| PA | 62% | 25% | 5% | 8% | 456 |
| NCI Average | 62% | 25% | 6% | 7% | 3,382 |
| DC | 62% | 21% | 10% | 7% | 183 |
| GA | 59% | 27% | 4% | 9% | 247 |
| AZ | 56% | 30% | 6% | 7% | 188 |
| WA | 55% | 30% | 7% | 8% | 246 |
| DE | 50% | 28% | 9% | 13% | 64 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| NH | 53% | 27% | 8% | 12% | 430 |
| MO | 51% | 32% | 5% | 13% | 168 |
| MD | 44% | 35% | 14% | 8% | 605 |

Family Directly Manages Support Workers

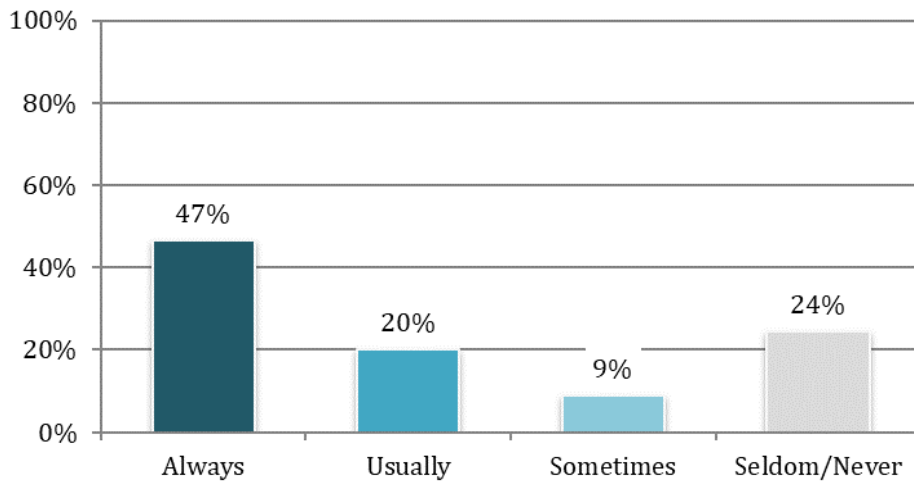


Table Q39. Does your family directly manage support workers (for example, hiring and deciding schedule)?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| OK | 62% | 18% | 5% | 15% | 277 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|-----------|-----------------|--------------|
| FL | 53% | 19% | 6% | 21% | 247 |
| WA | 53% | 20% | 9% | 18% | 238 |
| GA | 49% | 14% | 4% | 32% | 242 |
| AZ | 48% | 25% | 7% | 19% | 174 |
| NH | 47% | 16% | 7% | 30% | 437 |
| NCI Average | 47% | 20% | 9% | 24% | 3,233 |
| PA | 47% | 18% | 9% | 26% | 440 |
| MO | 40% | 21% | 10% | 29% | 163 |
| DC | 39% | 22% | 7% | 31% | 169 |
| NC | 38% | 24% | 16% | 23% | 208 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MD | 32% | 24% | 11% | 33% | 575 |
| DE | 16% | 14% | 6% | 63% | 63 |

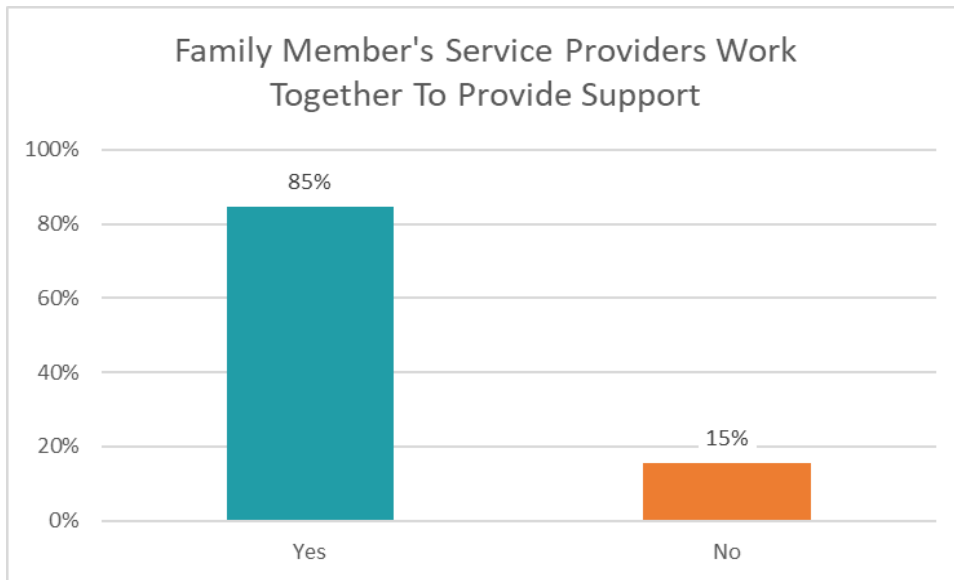


Table Q40. Do service providers for your family member work together to provide support?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| OK | 92% | 8% | 200 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| NC | 90% | 10% | 147 |
| NH | 89% | 11% | 274 |
| DC | 88% | 12% | 179 |
| PA | 87% | 13% | 399 |
| NCI Average | 85% | 15% | 2,663 |
| FL | 84% | 16% | 212 |
| AZ | 83% | 17% | 163 |
| WA | 83% | 17% | 178 |
| GA | 81% | 19% | 206 |
| MO | 80% | 20% | 123 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| DE | 68% | 32% | 82 |
| MD | 68% | 32% | 500 |

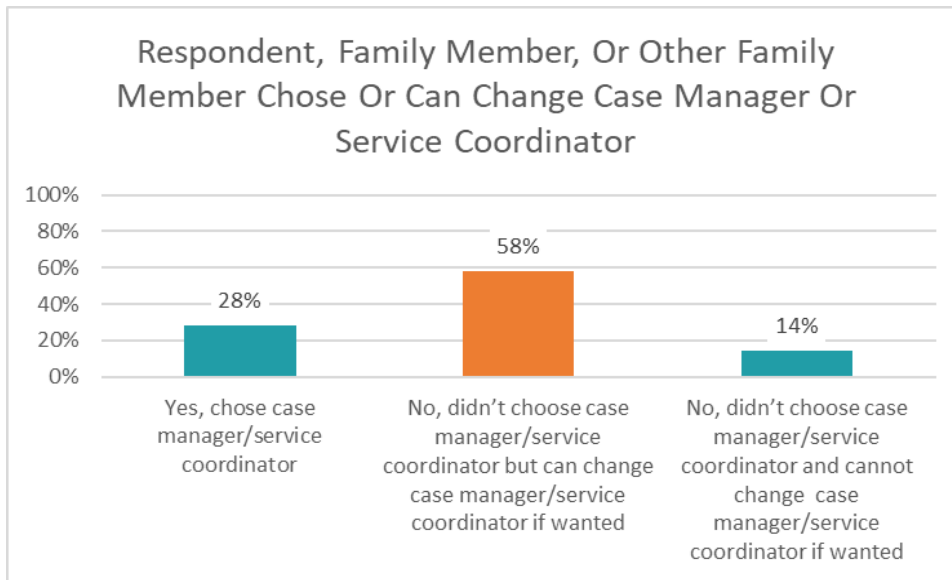


Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

Significantly Above Average

| State | Yes, Chose | Didn't Choose but Can Change | Didn't Choose and Cannot Change | N |
|-------|------------|------------------------------|---------------------------------|-----|
| FL | 67% | 31% | 3% | 316 |

Within Average Range

| State | Yes, Chose | Didn't Choose but Can Change | Didn't Choose and Cannot Change | N |
|-------------|------------|------------------------------|---------------------------------|-------|
| NCI Average | 28% | 58% | 14% | 4,206 |
| NC | 21% | 57% | 22% | 219 |

Significantly Below Average

| State | Yes, Chose | Didn't Choose but Can Change | Didn't Choose and Cannot Change | N |
|-------|------------|------------------------------|---------------------------------|-----|
| PA | 23% | 64% | 12% | 593 |
| DC | 21% | 67% | 12% | 224 |
| AZ | 20% | 68% | 12% | 234 |
| MD | 17% | 58% | 24% | 759 |
| OK | 15% | 61% | 24% | 310 |
| NH | 14% | 70% | 16% | 525 |
| MO | 14% | 65% | 21% | 242 |
| GA | 13% | 64% | 23% | 333 |
| DE | 12% | 57% | 31% | 134 |
| WA | 10% | 67% | 23% | 317 |

Involvement in the Community

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

Note: Significance is based on “Always” or “Yes” response.

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

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

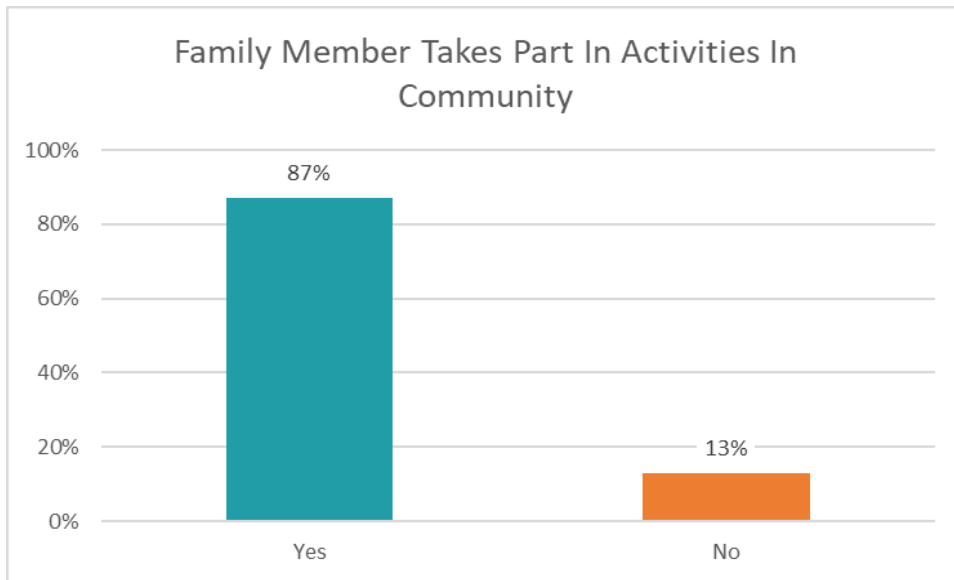


Table Q42. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| OK | 91% | 9% | 425 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| AZ | 90% | 10% | 249 |
| NH | 90% | 10% | 595 |
| GA | 90% | 10% | 385 |
| PA | 89% | 11% | 724 |
| NC | 89% | 11% | 250 |
| NCI Average | 87% | 13% | 4,979 |
| WA | 86% | 14% | 462 |
| MO | 86% | 14% | 287 |
| DC | 84% | 16% | 244 |
| FL | 83% | 17% | 361 |
| DE | 80% | 20% | 186 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 79% | 21% | 811 |

Obstacles Or Barriers To Family Member's Participation In Activities In The Community

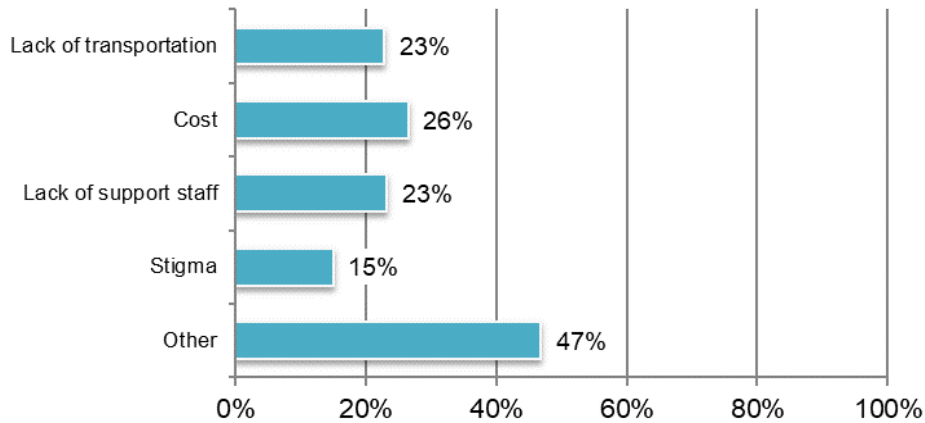


Table Q43. For your family member, what are the obstacles or barriers to participation in activities in the community? ∞

| State | Lack of Transportation | Cost | Lack of Support Staff | Negative Attitudes from Community Members | Other |
|--------------------|------------------------|------------|-----------------------|---|------------|
| AZ | 24% | 34% | 19% | 23% | 38% |
| DC | 34% | 38% | 20% | 23% | 29% |
| DE | 23% | 27% | 23% | 19% | 48% |
| FL | 21% | 30% | 21% | 14% | 46% |
| GA | 27% | 26% | 19% | 14% | 43% |
| MD | 31% | 34% | 30% | 17% | 26% |
| MO | 26% | 30% | 29% | 19% | 44% |
| NC | 13% | 20% | 24% | 17% | 53% |
| NH | 34% | 32% | 33% | 14% | 28% |
| OK | 21% | 25% | 17% | 14% | 47% |
| PA | 23% | 23% | 25% | 11% | 53% |
| WA | 24% | 25% | 22% | 15% | 47% |
| NCI Average | 23% | 26% | 23% | 15% | 47% |

∞ Categories are not mutually exclusive

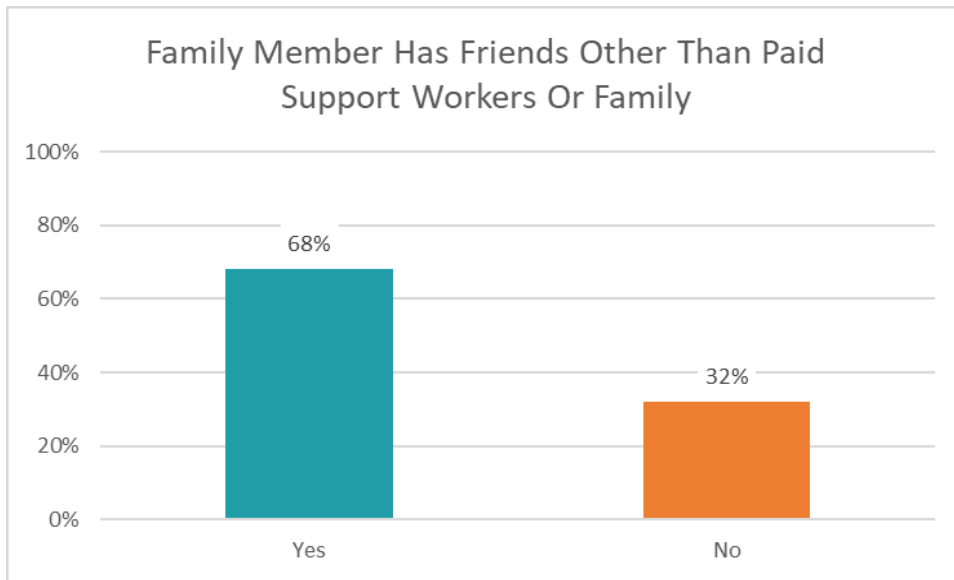


Table Q44. Does your family member have friends other than paid support workers or family?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| OK | 78% | 22% | 418 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| NC | 72% | 28% | 248 |
| GA | 71% | 29% | 381 |
| DC | 71% | 29% | 233 |
| AZ | 69% | 31% | 241 |
| PA | 69% | 31% | 712 |
| WA | 69% | 31% | 444 |
| NCI Average | 68% | 32% | 4,901 |
| NH | 68% | 32% | 583 |
| MO | 65% | 35% | 282 |
| DE | 65% | 35% | 174 |
| FL | 64% | 36% | 351 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 61% | 39% | 834 |

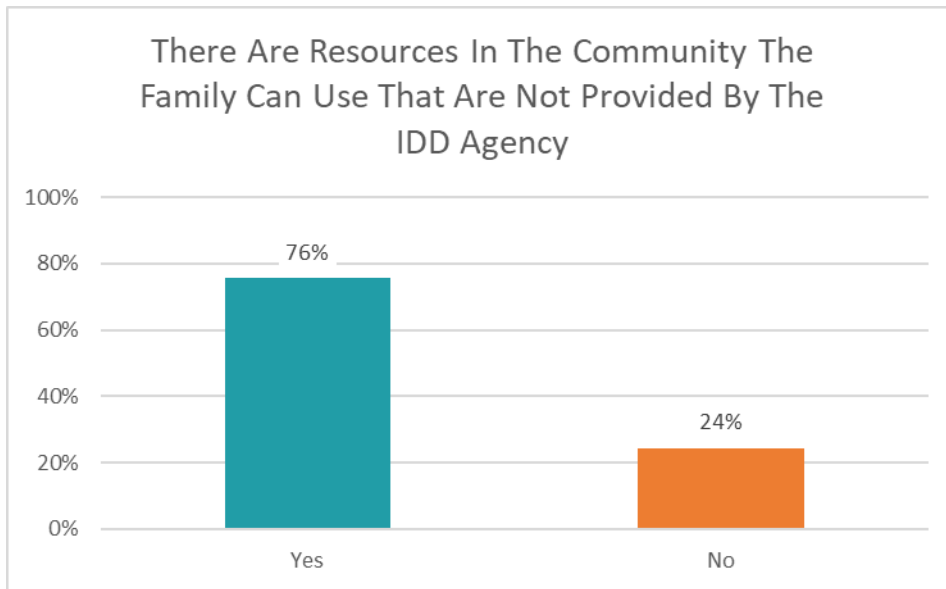


Table Q45. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| WA | 89% | 11% | 324 |
| DC | 86% | 14% | 192 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| DE | 79% | 21% | 121 |
| OK | 77% | 23% | 315 |
| NC | 77% | 23% | 214 |
| NH | 77% | 23% | 454 |
| MO | 76% | 24% | 207 |
| GA | 76% | 24% | 273 |
| NCI Average | 76% | 24% | 3,796 |
| AZ | 74% | 26% | 182 |
| PA | 74% | 26% | 493 |
| FL | 73% | 27% | 259 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 60% | 40% | 762 |

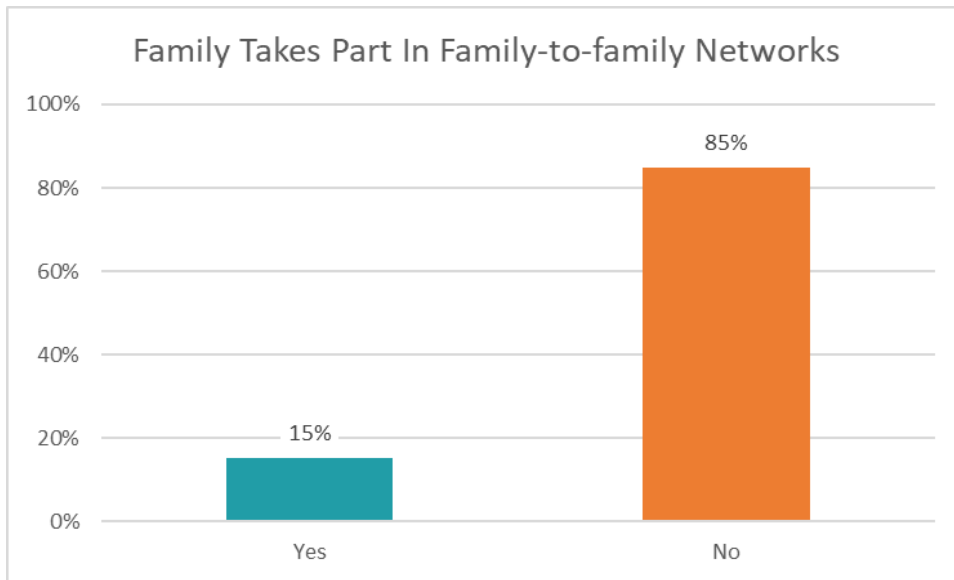


Table Q46. Does your family take part in any family-to-family networks in your community? (For example, Parent to Parent, sibling networks, etc.)

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| DC | 33% | 67% | 208 |
| MD | 21% | 79% | 776 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| GA | 20% | 80% | 314 |
| OK | 20% | 80% | 343 |
| WA | 19% | 81% | 396 |
| DE | 16% | 84% | 163 |
| AZ | 16% | 84% | 223 |
| NCI Average | 15% | 85% | 4,361 |
| FL | 15% | 85% | 313 |
| NC | 15% | 85% | 227 |
| PA | 13% | 87% | 622 |
| MO | 11% | 89% | 238 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| NH | 11% | 89% | 538 |

Satisfaction With Services and Supports

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

Note: Significance is based on “Always” or “Yes” response.

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

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

Overall, Respondent Is Satisfied With Services And Supports Family Receives

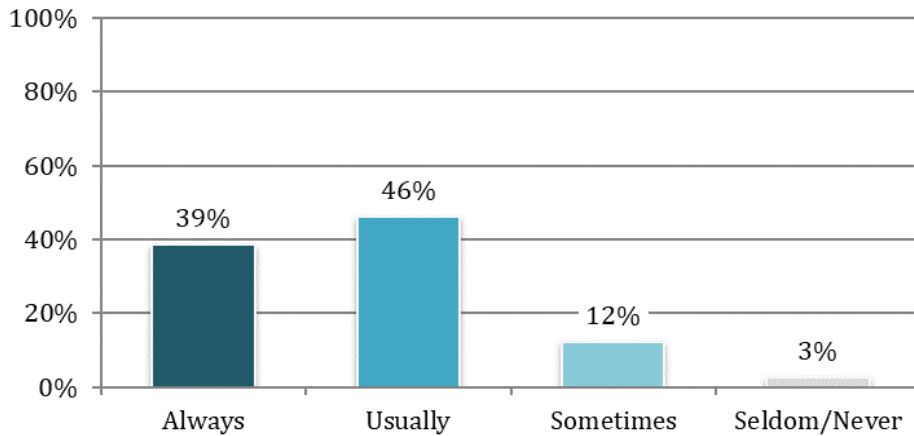


Table Q47. Overall, are you satisfied with the services and supports your family currently receives?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|--------------------|------------|------------|------------|-----------------|--------------|
| AZ | 45% | 46% | 8% | 1% | 253 |
| DC | 44% | 38% | 15% | 4% | 238 |
| FL | 42% | 44% | 11% | 2% | 354 |
| PA | 41% | 47% | 11% | 2% | 696 |
| OK | 40% | 44% | 13% | 2% | 417 |
| NCI Average | 39% | 46% | 12% | 3% | 4,942 |
| NC | 37% | 42% | 16% | 5% | 252 |
| WA | 35% | 48% | 15% | 3% | 456 |
| GA | 33% | 48% | 14% | 5% | 376 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| NH | 33% | 50% | 13% | 4% | 593 |
| MO | 31% | 56% | 11% | 2% | 288 |
| MD | 28% | 47% | 21% | 5% | 842 |
| DE | 22% | 48% | 19% | 11% | 177 |

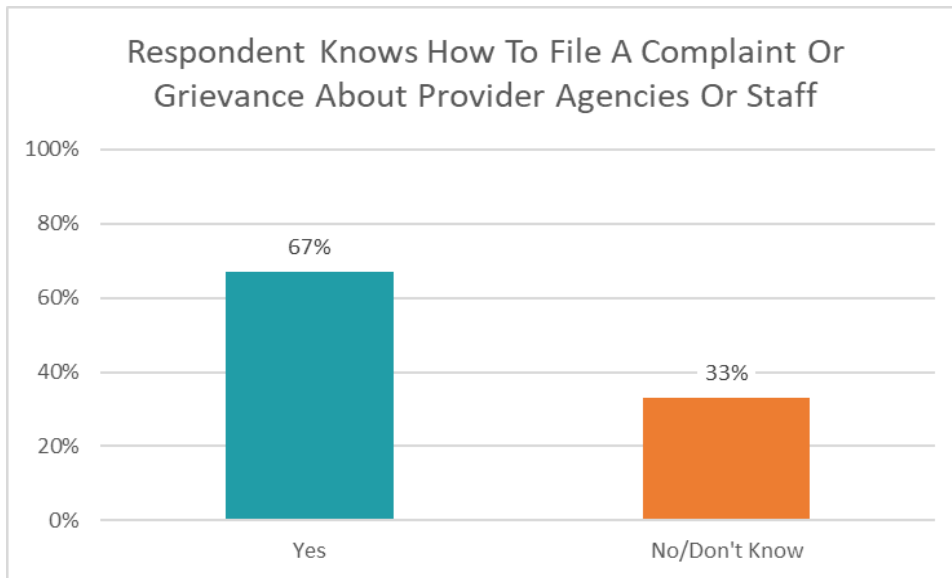


Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff?³

Significantly Above Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-----|
| OK | 81% | 19% | 416 |
| DC | 75% | 25% | 239 |
| PA | 74% | 26% | 707 |

Within Average Range

| State | Yes | No or Don't Know | N |
|--------------------|------------|------------------|--------------|
| FL | 71% | 29% | 362 |
| NH | 70% | 30% | 599 |
| NC | 70% | 30% | 254 |
| NCI Average | 67% | 33% | 5,058 |
| WA | 66% | 34% | 463 |
| AZ | 59% | 41% | 250 |

Significantly Below Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-----|
| MO | 55% | 45% | 287 |
| GA | 50% | 50% | 384 |
| MD | 41% | 59% | 915 |
| DE | 35% | 65% | 182 |

³ 'Don't Know' responses were included in 'No' responses for this question.

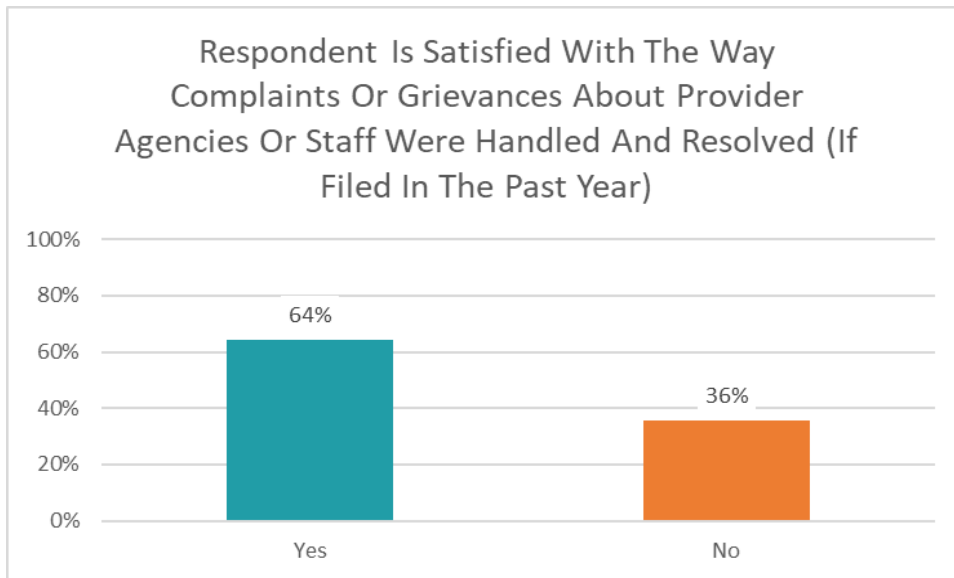


Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|------------|
| FL | 78% | 22% | 32 |
| PA | 71% | 29% | 48 |
| WA | 69% | 31% | 32 |
| NCI Average | 64% | 36% | 600 |
| GA | 61% | 39% | 38 |
| NC | 60% | 40% | 43 |
| DC | 58% | 42% | 50 |
| AZ | 56% | 44% | 25 |
| NH | 53% | 47% | 53 |
| OK | 43% | 57% | 28 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 47% | 53% | 221 |

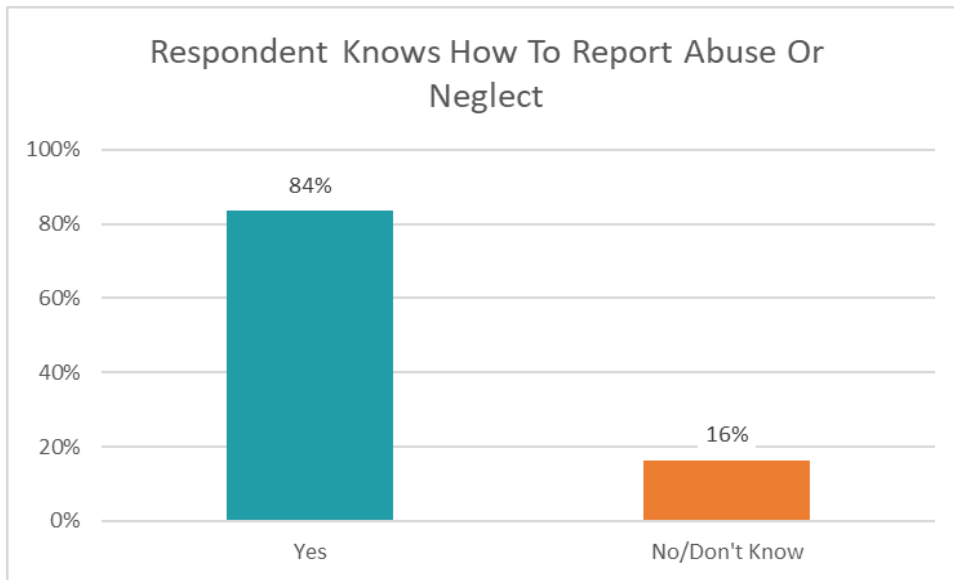


Table Q50. Do you know how to report abuse or neglect related to your family member?⁴

Significantly Above Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-----|
| OK | 92% | 8% | 417 |
| PA | 87% | 13% | 697 |

Within Average Range

| State | Yes | No or Don't Know | N |
|--------------------|------------|------------------|--------------|
| FL | 88% | 12% | 360 |
| NC | 88% | 12% | 250 |
| DC | 86% | 14% | 243 |
| NCI Average | 84% | 16% | 5,020 |
| WA | 83% | 17% | 461 |
| NH | 83% | 17% | 595 |
| AZ | 82% | 18% | 242 |
| MO | 78% | 22% | 285 |

Significantly Below Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-----|
| GA | 74% | 26% | 385 |
| DE | 63% | 37% | 181 |
| MD | 54% | 46% | 904 |

⁴ 'Don't Know' responses were included in 'No' responses for this question.

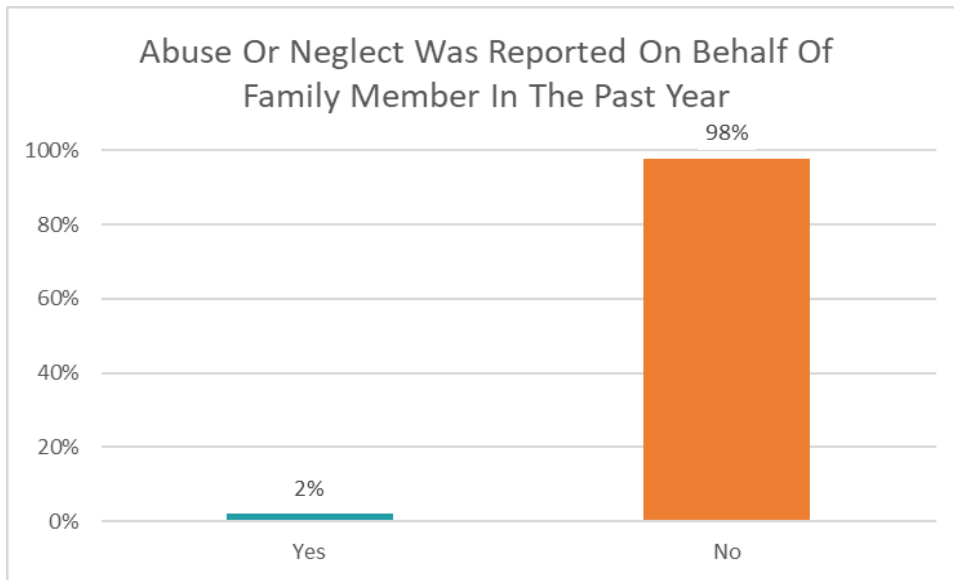


Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

Significantly Above Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-----|
| MD | 5% | 95% | 851 |

Within Average Range

| State | Yes | No | N |
|--------------------|-----------|------------|--------------|
| DC | 4% | 96% | 240 |
| GA | 3% | 97% | 369 |
| AZ | 3% | 97% | 237 |
| PA | 2% | 98% | 685 |
| WA | 2% | 98% | 453 |
| NCI Average | 2% | 98% | 4,885 |
| FL | 2% | 98% | 351 |
| NC | 2% | 98% | 250 |
| NH | 1% | 99% | 577 |
| OK | 1% | 99% | 415 |
| MO | 1% | 99% | 282 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| DE | 1% | 99% | 175 |

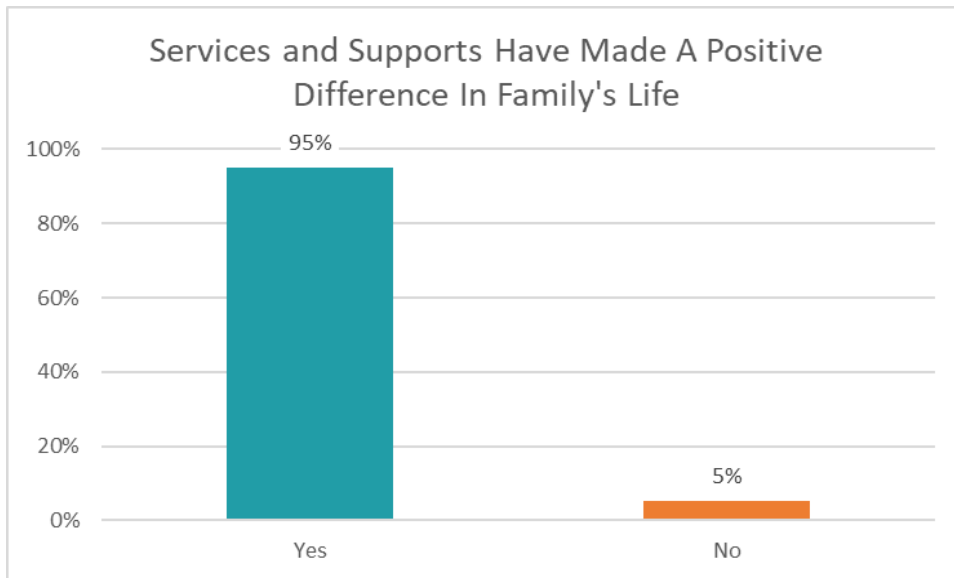


Table Q52. Do you feel that services and supports have made a positive difference in the life of your family?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| AZ | 99% | 1% | 228 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|-----------|--------------|
| OK | 97% | 3% | 395 |
| MO | 96% | 4% | 268 |
| FL | 96% | 4% | 342 |
| PA | 95% | 5% | 682 |
| NH | 95% | 5% | 568 |
| NCI Average | 95% | 5% | 4,638 |
| NC | 94% | 6% | 246 |
| GA | 94% | 6% | 332 |
| WA | 93% | 7% | 421 |
| DC | 91% | 9% | 231 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 84% | 16% | 767 |
| DE | 84% | 16% | 158 |

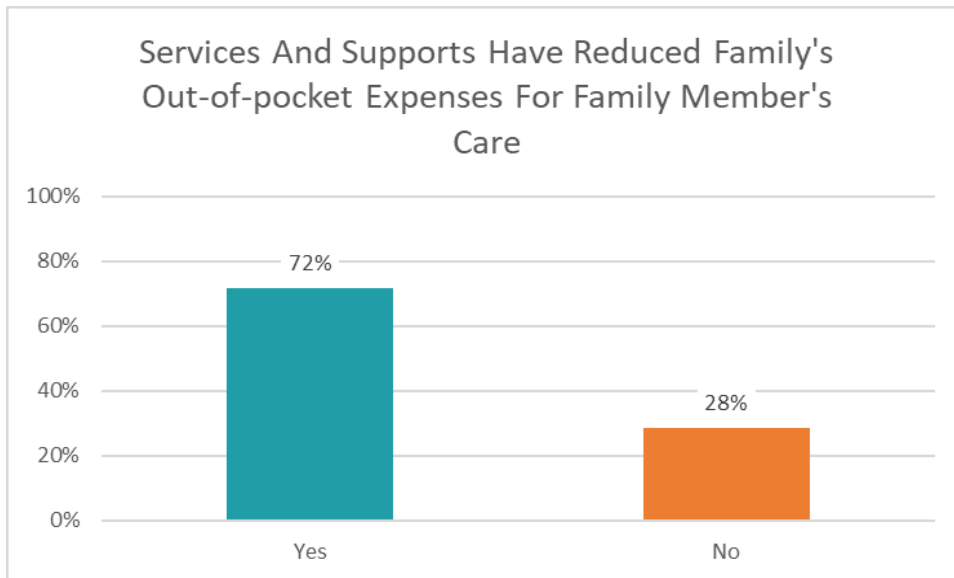


Table Q53. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| WA | 77% | 23% | 418 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| OK | 77% | 23% | 385 |
| MO | 75% | 25% | 262 |
| AZ | 75% | 25% | 222 |
| NC | 74% | 26% | 231 |
| FL | 74% | 26% | 326 |
| NH | 73% | 27% | 535 |
| NCI Average | 72% | 28% | 4,520 |
| PA | 69% | 31% | 634 |
| GA | 69% | 31% | 338 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 60% | 40% | 799 |
| DC | 59% | 41% | 216 |
| DE | 52% | 48% | 154 |

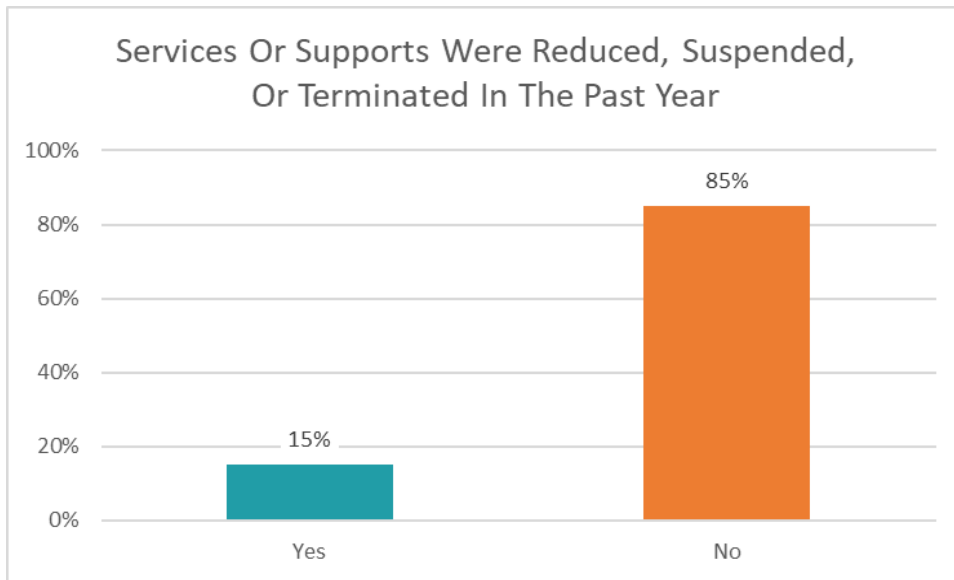


Table Q54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| NC | 31% | 69% | 244 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| WA | 18% | 82% | 408 |
| OK | 17% | 83% | 382 |
| FL | 15% | 85% | 328 |
| NCI Average | 15% | 85% | 4,611 |
| MD | 15% | 85% | 789 |
| MO | 15% | 85% | 271 |
| NH | 15% | 85% | 556 |
| DE | 15% | 85% | 157 |
| DC | 13% | 87% | 232 |
| PA | 12% | 88% | 654 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| GA | 10% | 90% | 354 |
| AZ | 9% | 91% | 236 |

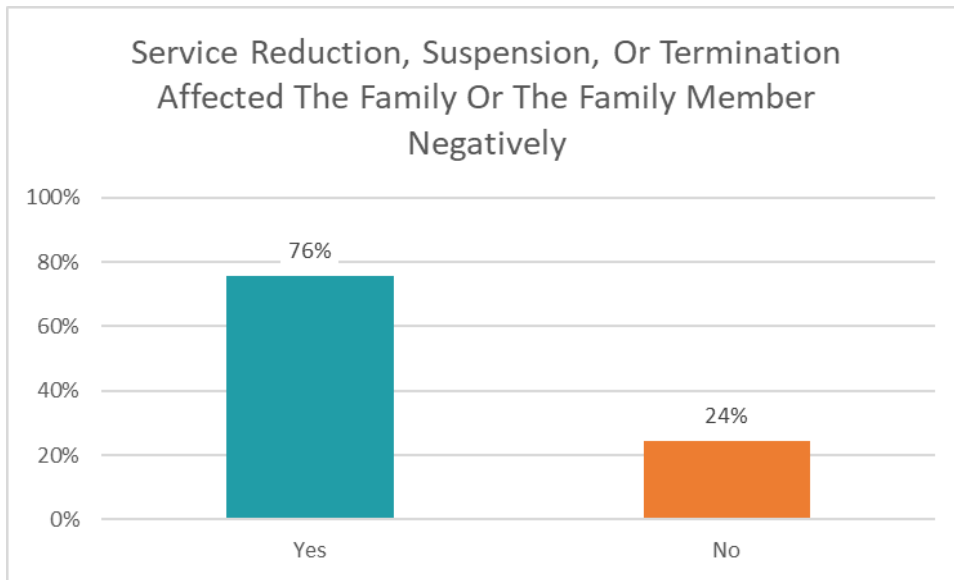


Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|------------|
| FL | 84% | 16% | 43 |
| NC | 80% | 20% | 69 |
| WA | 79% | 21% | 66 |
| OK | 78% | 22% | 54 |
| MO | 77% | 23% | 30 |
| NCI Average | 76% | 24% | 592 |
| DE | 71% | 29% | 21 |
| PA | 71% | 29% | 65 |
| NH | 70% | 30% | 73 |
| GA | 65% | 35% | 31 |
| DC | 52% | 48% | 25 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|----|
| MD | 61% | 39% | 96 |

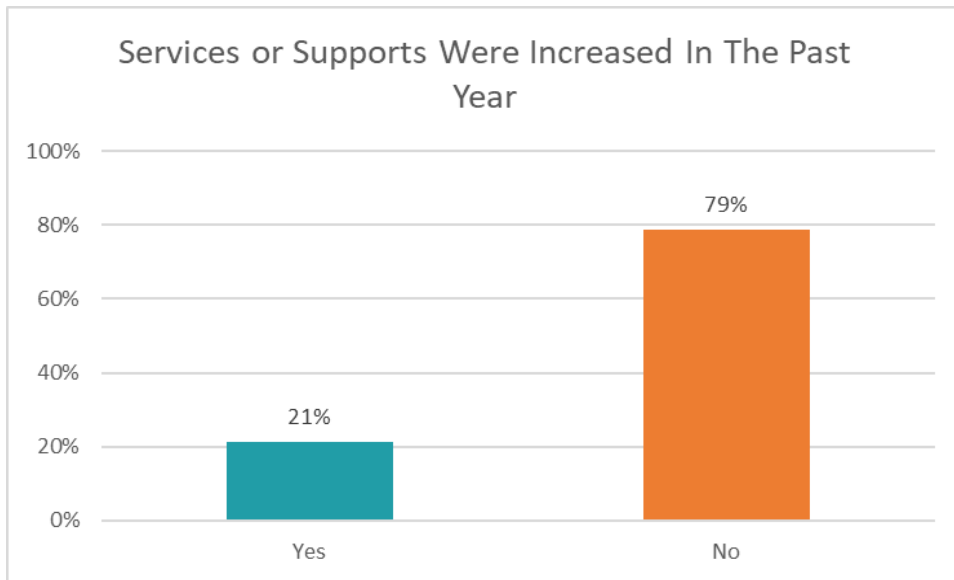


Table Q56. Have the services or supports that your family member received been increased in the past year?

Within Average Range

| State | Yes | No | N |
|--------------------|------------|------------|--------------|
| WA | 24% | 76% | 377 |
| AZ | 24% | 76% | 232 |
| DC | 23% | 77% | 213 |
| PA | 23% | 77% | 619 |
| MO | 22% | 78% | 258 |
| NCI Average | 21% | 79% | 4,496 |
| NC | 21% | 79% | 233 |
| MD | 20% | 80% | 815 |
| GA | 20% | 80% | 327 |
| DE | 19% | 81% | 154 |
| FL | 18% | 82% | 315 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| NH | 9% | 91% | 565 |
| OK | 9% | 91% | 388 |

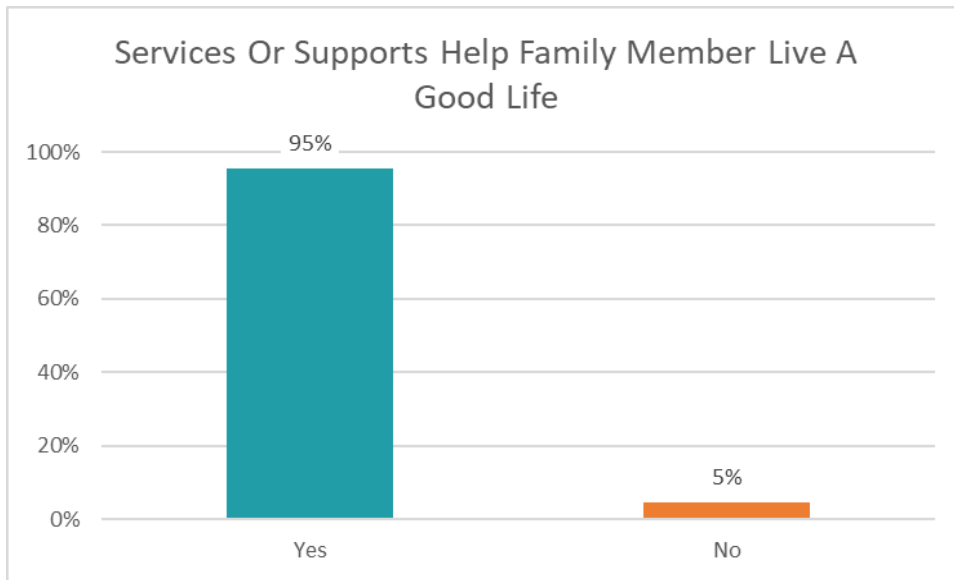


Table Q57. Are services and supports helping your family member to live a good life?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| AZ | 99% | 1% | 237 |

Within Average Range

| State | Yes | No | N |
|--------------------|------------|-----------|--------------|
| PA | 97% | 3% | 667 |
| OK | 96% | 4% | 398 |
| NC | 96% | 4% | 245 |
| NCI Average | 95% | 5% | 4,672 |
| MO | 95% | 5% | 265 |
| WA | 95% | 5% | 415 |
| NH | 95% | 5% | 551 |
| FL | 95% | 5% | 339 |
| DC | 94% | 6% | 218 |
| GA | 93% | 7% | 352 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 87% | 13% | 834 |
| DE | 79% | 21% | 151 |

II. NCI History and Activities

This section briefly describes the history of the National Core Indicators and NCI surveys.

Overview of National Core Indicators

In December 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI), launched the Core Indicators Project (CIP). The aim of the project was to support state developmental disabilities authorities in the development and implementation of performance and outcome indicators—and related data collection strategies—so that they could measure service delivery system performance. This effort, now called National Core Indicators (NCI), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI facilitates pooled knowledge, expertise, and resources among the states.

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

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

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

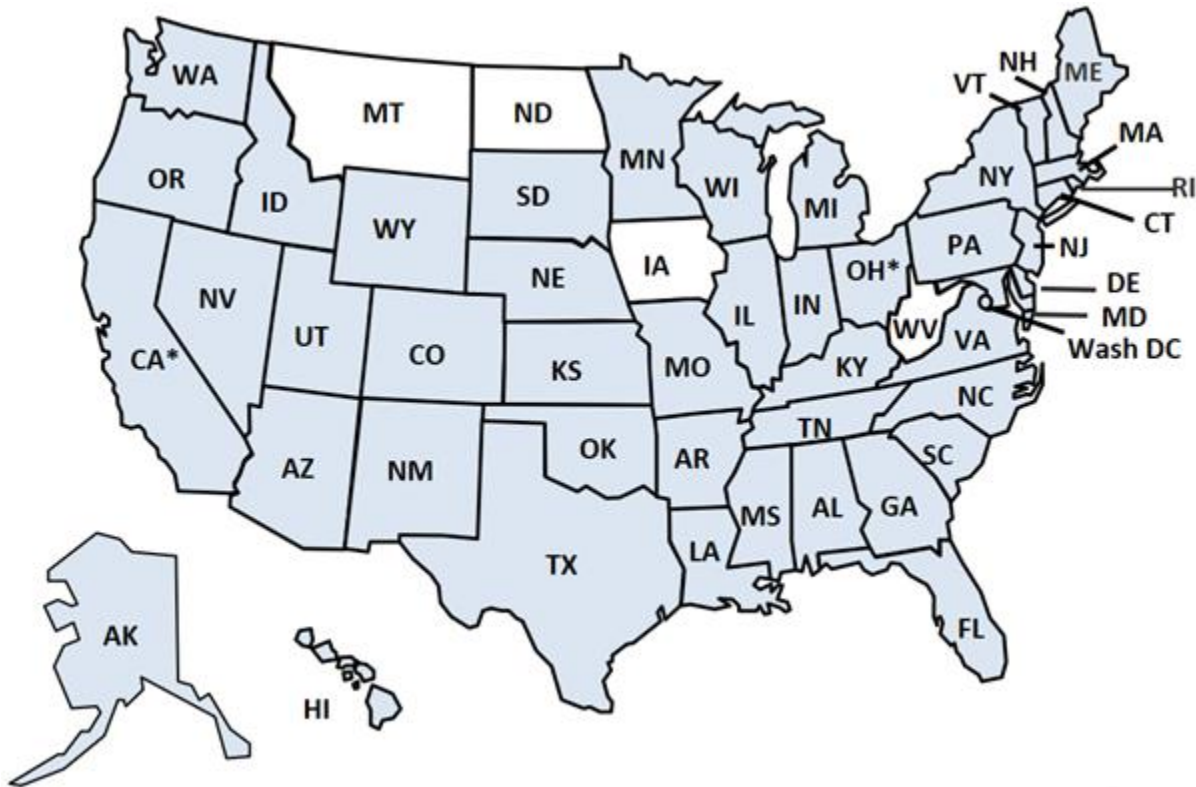
Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI continues to develop and refine the indicators and expand state participation. For more information about NCI states,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

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

State Participation

During the 2017-18 data collection cycle, 46 states, the District of Columbia, and 22 sub-state entities were members of NCI. State participation is entirely voluntary, and the member states are shown on the map below.

NCI State Membership 2017-18



The Core Indicators

The Core Indicators are the standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern, including employment, respect/rights, service planning, community inclusion, choice, and health and safety. An example of a Core Indicator would be, “The proportion of people who have a paid job in the community.” To see the entire list of Core Indicators, please visit the Indicators page on the NCI website at <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, as shown in the following table. Four data sources are used to assess outcomes: the Adult In-Person Survey, three Family Surveys, a Staff Stability Survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates).

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

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

Sub-Domains and Concern Statements

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

Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to

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

For more information on how to use these data for quality improvement, please see this handbook: [Using National Core Indicators for Quality Improvement Initiatives](#).⁵

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.

⁵ Located on the National Core Indicators website: www.nationalcoreindicators.org →Resources →Technical Reports

III. Methodology

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

Sampling & Administration

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

1. Had an adult individual (aged 18 or over) with an intellectual or developmental disability living at home; and
2. The adult individual with an intellectual or developmental disability living at home received at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys. A total of four states had at least a portion of surveys completed via direct entry for the 2017-18 data collection cycle.⁶

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%.⁷

Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI reports, we use “NCI average” to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). Last year, the approach was enhanced to consider the relative numbers of people receiving services through participating states’ systems. The NCI averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states, as well as the sample sizes.

⁶ States that used the direct entry or mail and direct entry options were: DE, FL, NC, and WA.

⁷ See “Response Rates” for information on total surveys mailed and received by states as well as each state’s margin of error.

Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average—that is, the state’s contribution to the NCI average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.

Significance Testing

For each of the items in the report, each state’s percentage was compared to the weighted NCI average (described above), and the differences between the two were tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state’s result depends in part on the size of the state’s sample—the larger the sample, the more likely it is that even a small difference will be found *statistically* significant. A statistically significant difference for a state with a large sample size, in and by itself, does not necessarily mean there is a *practically* significant difference. The inclusion of effect sizes allows us to present “meaningfully significant” results, which take the magnitude or size of the differences into account.

The state percentages in this report are categorized into one of three classes:

1. **Significantly above the NCI average**, where the difference between the state’s percentage and the weighted NCI average: a) was in favor of the state, b) was statistically significant (i.e., $p < .01$), **and** c) met the effect size criterion (i.e., Cohen’s $d > 0.2$, see below for details);
2. **Within the NCI average range**, where the difference between the state’s percentage and the weighted NCI average was: a) not statistically significant (i.e., $p \geq .01$), **or** b) did not meet the effect size criterion (i.e., Cohen’s $d \leq 0.2$); or
3. **Significantly below the NCI average**, where the difference between the state’s percentage and the weighted NCI average: a) was in favor of the NCI average, b) was statistically significant (i.e., $p < .01$), **and** c) met the effect size criterion (i.e., Cohen’s $d > 0.2$).

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, and significantly below the NCI Average. No symbol was used for the state’s percentage being “within” the NCI average range due to lack of statistical significance (i.e., $p \geq .01$).

Technical Details

The comparisons were done through one sample t-tests using the weighted NCI average as the benchmark. A conservative cut-off point (alpha) of $p < .01$ was used to detect statistically significant differences. Effect sizes are calculated using the formula: Cohen's $d = \frac{2t}{\sqrt{df}}$. A cutoff point of Cohen's $d = 0.2$ was chosen for the effect size to be considered “meaningfully significant,” following the standard interpretation offered by Cohen (1988) that Cohen's d of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

Data Entry and Analysis

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

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

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

Statistical significance testing was conducted on each state's “yes” or “always” response compared to the NCI average⁸; 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 2017-18, 11 states and the District of Columbia administered the Adult Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The following table 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.

⁸ The NCI Average is the sum of all state averages divided by the total number of states.

Adult Family Survey: State Response Rates ⁹

| State | Total Population | Surveys Sent | Usable Surveys | Response Rate | Margin of Error ¹⁰ | Paper Submission | Direct Entry Submission |
|------------------|------------------|--------------|----------------|---------------|-------------------------------|------------------|-------------------------|
| AZ | 9,549 | 1,400 | 255 | 18.2% | 6.05% | 100.0% | |
| DC | 632 | 632 | 251 | 39.7% | 4.81% | 100.0% | |
| DE ¹¹ | 2,500 | 2,500 | 192 | 7.7% | 6.80% | 19.3% | 80.7% |
| FL | 17,000 | 1,200-1,500 | 369 | | 5.05% | 90.2% | 9.8% |
| GA | 3,850 | 1,700 | 393 | 23.1% | 4.68% | 100.0% | |
| MD | 3,484 | 3,471 | 959 | 27.6% | 2.69% | 100.0% | |
| MO | 4,712 | 1,000 | 293 | 29.3% | 5.54% | 100.0% | |
| NC | 8,483 | 1,200 | 259 | 21.6% | 6.00% | 91.1% | 8.9% |
| NH | 1,977 | 1,977 | 609 | 30.8% | 3.30% | 100.0% | |
| OK | 1,500 | 1,500 | 430 | 28.7% | 3.99% | 100.0% | |
| PA | 32,654 | 1,800-2,000 | 736 | | 3.57% | 100.0% | |
| WA | 9,740 | 2,000 | 475 | 23.8% | 4.39% | 73.3% | 26.7% |
| Total | | | 5,221 | | | | |

⁹ Please note: The family surveys are mail surveys or completed online by respondents who choose to take part in the survey. As such, the final sample is a sample of convenience and cannot be considered representative of the entire service population in the state.

¹⁰ Calculated using <http://www.raosoft.com/samplesize.html>

¹¹ DE was unable to receive contact information from one provider. Therefore, its sample is not fully representative of individuals served in the state.