

Family Guardian Survey

Final Report – July 2012
2010-2011 Data



**NATIONAL CORE
INDICATORS**

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

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Organization of Report

Eleven states conducted the National Core Indicators (NCI) Family Guardian Survey during 2010-2011. The Family Guardian Survey was administered to families who have an adult family member with disabilities living outside their home. This Final Report provides a summary of results based on data submitted by June 30, 2011.

This report is organized as follows:

I. Introduction

This section gives a brief overview of NCI history and activities, and presents the core indicators measured with the Family Surveys.

II. Family Guardian Survey

This section briefly describes the structure of the survey instrument.

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 Program staff to aggregate and analyze the data.

IV. Results

This section provides aggregate and state-by-state results for demographic, service utilization, service information and planning, service access and delivery, choice and control, community connections, satisfaction and outcome data.

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List of Abbreviations

AFS – Adult Family Survey

CFS – Child Family Survey

CM/SC – Case Manager/Service Coordinator

CMS – Centers for Medicare and 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

I. Introduction

This section gives a brief overview of the history of NCI, its current activities, and the core indicators.

Overview of National Core Indicators¹

The National Core Indicators (NCI) program was established through a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) in order to create a standard set of performance measures and outcomes for developmental disabilities (DD) service and support systems. Originally, 15 states formed the National Core Indicators steering committee to collaborate on the development of valid and reliable data collection protocols. As of 2010-2011, NCI included 24 of the 50 states.

In this multi-state effort, NCI states use their resources and knowledge to create performance monitoring systems, identify common performance indicators, work out comparable data collection strategies, and share results. The indicators, which were developed through a consensus process with the original 15 states, are intended to provide a system-level “snapshot” of how well each state is performing. The states were guided by a set of criteria designed to select indicators that were:

- measurable,
- related to issues the states had some ability to influence, and
- important to all individuals they served, regardless of level of disability or residential setting.

NCI filled a critical information gap for public DD system managers. While other health and human services systems had developed benchmarking capabilities (e.g., within the fields of health care, long-term care, and mental health services), NCI was the first of its kind in the DD field.

NCI data are collected using several protocols. The primary data collection tools include a face-to-face interview with individuals receiving services (the Adult Consumer Survey) and

¹ For a complete history of NCI visit: <http://www.nationalcoreindicators.org>

three surveys of families – one aimed at families of adults living at home (the Adult Family Survey), one for families or guardians/conservators of adults living outside the home (the Family Guardian Survey), and one for families of children living at home (the Child Family Survey).

The Core Indicators

The core indicators are the foundation of the effort. 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. Each indicator is associated with one of the four main data sources from which the data are collected. The four main data sources provide information for the various areas of concern: an adult consumer survey (e.g., rights and choice issues), family surveys (e.g., satisfaction with supports), a provider survey (e.g., staff turnover), and system data from state administrative records (e.g., incidents and mortality rates).

The core indicators provide one source of 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 HCBS waiver quality management systems and include the information in support of evidentiary reports to 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).

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 with direction from the participating states in order to reflect current and future priorities.²

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. This report includes only those data collected using the Family Guardian Survey. Details on the design and testing of this tool are provided in the next section.

Family Indicators

The original Family Indicators were developed and approved by the NCI Steering Committee in 2002. All three family surveys were revised for the 2009-2010 data collection cycle to better align the NCI indicators with CMS waiver assurances. The Family Surveys used in 2010-2011 not only ask families to express their overall level of satisfaction with services and supports, they also probe specific aspects of the service system's capabilities and effectiveness. The information gathered provides an understanding of the experiences of individuals and families with the supports and services they receive. Along with demographic information, the surveys include questions related to:

1. Communication between individuals and families and the service system
2. Information and planning for services and supports
3. Access and delivery of services and supports
4. Choice and control
5. Connections with the community
6. Satisfaction
7. Outcomes

² For a complete list of Core Indicators, visit the NCI program website at www.nationalcoreindicators.org.

Table 1 below details the Family Sub-Domains and the concern statement associated with each. This report illustrates outcomes for all indicators within each sub-domain.

TABLE 1. FAMILY SURVEY SUB-DOMAINS AND CONCERN STATEMENTS

| Sub-Domain | Concern |
|--------------------------------------|--|
| Information and Planning | Families/family members with disabilities have the information and support necessary to plan for their services and supports. |
| Choice & Control | Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them. |
| Access & Support Delivery | Family members with disabilities get the services and supports they need. |
| Community Connections | Family members with disabilities use integrated community services and participate in everyday community activities. |
| Family Involvement | Families maintain connections with family members not living at home. |
| Satisfaction | Family members with disabilities receive adequate and satisfactory supports. |

II. Family Guardian Survey

This section briefly describes the development and organization of the survey instrument.

Survey Development

The Family Guardian Survey was developed and first utilized during Phase II of the Core Indicators Project (1999-2000), in response to various states' interest in finding out whether families of individuals with disabilities were involved in their family members' lives, whether they were supported in their efforts to be involved, and their level of satisfaction with how the service system was meeting the needs of their family member with disabilities. In this effort, seven states administered the Family Guardian Survey.

As mentioned previously, the Family Guardian Survey was significantly revised during the 2009-2010 data collection cycle to better align the NCI indicators with CMS waiver assurances.

States are instructed to mail the Family Guardian Survey to a randomly selected sample of families who meet two criteria:

1. An adult family member with a developmental disability lives outside of the family home.
2. The individual receives at least one service or support besides case management.

State Participation

Between 2001 and 2010, six to 12 states have participated each year. Below is a figure indicating state participation in the Family Guardian Survey since its inception.

TABLE 2. STATE PARTICIPATION IN NCI FAMILY GUARDIAN SURVEY (ADULTS LIVING OUTSIDE OF FAMILY'S HOME)

| 1999-2000 | 2000-2001 | 2001-2002 | 2002-2003 | 2003-2004 | 2004-2005 | 2005-2006 | 2006-2007 | 2007-2008 | 2008-2009 | 2009-2010 | 2010-2011 |
|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| CT | AZ | CA-RCOC | AZ | AZ | AZ | CA-RCOC | AZ | CA-RCOC | AZ | GA | AZ |
| KY | DE | HI | CA-RCOC | CA-RCOC | CA-RCOC | CT | CT | GA | CT | LA | FL |
| MN | MA | NE | HI | CT | CT | GA | DE | LA | GA | ME | GA |
| NE | MN | NC | IN | ME | HI | ME | GA | ME | IL | NH | KY |
| PA | NC | PA | MA | NC | PA | NC | HI | MO | LA | PA | LA |
| VA | PA | UT | NC | ND | SC | PA | ME | NC | ME | WA | MO |
| WA | RI | WA | PA | PA | WY | SC | NM | NJ | MO | | NC |
| | | | SC | SC | | SD | PA | PA | NO | | NJ |
| | | | SD | WA | | WA | WY | SC | OH | | NM |
| | | | WY | WY | | WY | | WA | PA | | OH |
| | | | | | | | | WY | SC | | PA |
| | | | | | | | | | WY | | |

Organization of the Family Guardian Survey

The Family Guardian Survey is composed of three main sections (demographics; the type of services and supports received; and questions regarding those services and supports). There is also an opportunity for families to write open-ended comments concerning their family's experience with the service system.

Demographics

The survey instrument begins with a series of questions tied to characteristics of the family member with a developmental disability (e.g., individual's age, race, type of disability). It is then followed by a series of demographic questions that pertain to the respondent (e.g., respondent's age, health status, relationship to the individual with the disability).

Services and Supports Received

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

Questions Regarding Services and Supports

The survey contains several groupings of questions that probe specific areas of quality service provision (e.g., information and planning, access and delivery of services, choice and control, community connections, satisfaction). Each question is constructed so that the respondent can select from either five possible responses ("always", "usually", "sometimes", "seldom", or "never") or two responses ("yes", "no") depending on the question. Respondents also have the option to indicate that they don't know the answer to a question, or that the question is not applicable.

Additional Comments

The survey also provides an opportunity for respondents to make additional open-ended comments concerning their family's experience with the service system.

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 Program staff to aggregate and analyze the data.

Sampling & Administration

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

1. Have an adult family member with developmental disabilities living outside of the family home; and
2. Receive at least one direct service or support besides service coordination.

Adults were defined as individuals age 18 or older with disabilities. A sample size of 1,000 was selected in anticipation that states would obtain at least a 40% return rate, yielding 400 or more usable responses per state. However, most states decided to sample more than 1,000 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.

All states mailed out a paper survey to families selected in their sample. The only exception was Ohio who conducted all of the surveys over the telephone. Thus, Ohio's results should be treated with caution in comparing their results to other states.

The following states did not meet the number of usable surveys needed to guarantee a +/-5% margin of error and a 95% confidence level but met a +/-7% margin of error and 95% confidence level: New Jersey, North Carolina, and Pennsylvania.

Data Entry and Analysis

Each state entered their survey responses into the ODESA (Online Data Entry Survey Application) or a standard file format and submitted the data to HSRI for analysis. 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 three criteria:

1. The respondent indicated that their family member with disabilities lives in the family home.

2. The respondent indicated that their family member with disabilities is under the age of 18.
3. 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 average³; significance is shown at the $p < .01$ level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

³ The "NCI Average" is the average of the state averages.

Response Rates

During 2010-11, 11 states administered the Family Guardian Survey; their data are included in this report. The desired response rate (the percentage of surveys returned versus the number mailed) is 40%. Table 3 shows the number of surveys each state mailed, surveys returned, response rates, and the number of valid surveys accepted for inclusion in data analysis.

| TABLE 3. FAMILY GUARDIAN SURVEY - STATE RESPONSE RATES | | | | |
|--|----------------|------------------|---------------|----------------|
| State | Surveys Mailed | Surveys Returned | Response Rate | Usable Surveys |
| Arizona | 1,000 | 278 | 28% | 224 |
| Florida | 1,100 | 308 | 28% | 289 |
| Georgia | 2,500 | 458 | 18% | 410 |
| Kentucky | 1,100 | 328 | 30% | 264 |
| Louisiana | 1,500 | 613 | 41% | 381 |
| Missouri | 907 | 420 | 46% | 420 |
| New Jersey | 1,000 | 224 | 23% | 217 |
| New Mexico | 1,342 | 414 | 31% | 414 |
| North Carolina | 1,250 | 223 | 18% | 203 |
| Ohio ⁴ | 825 | 400 | 48% | 398 |
| Pennsylvania | 1,440 | 273 | 19% | 262 |
| Overall | 13,964 | 4,102 | 29% | 3,482 |

⁴ All surveys were conducted via phone interview.

IV. Results

This section provides aggregate and state-by-state results for demographic, service utilization, service planning, access and delivery, satisfaction and outcome data.

Note:

“Family Member” refers to the individual receiving services. “Respondent” refers to the person (usually a parent, or guardian) filling out the survey.

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 are presented in this report. Outcome results are presented in six subsections corresponding to the sections of the Family Guardian Survey. The beginning of each subsection provides an overall synopsis of findings across states, displaying the NCI Average for “yes” or “always” responses for all questions within that section. The NCI Average is the average of all individual state averages.

For each question, outcomes are first shown in a graph with the NCI Average for response categories, followed by a table which shows a breakdown of each state’s averages.

Tables are formatted whereby all states⁵ are listed in descending order and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, and significantly below the NCI Average. Statistical significance is taken to be at or below the $p < .01$ level. For those states that fall within the NCI Average Range, their “always” or “yes” response was not statistically different from the average NCI Average.

It should be noted that the survey was slightly revised in 2010-2011 based upon feedback from participating states. The revisions included some changes in wording and in some cases, broadening of response options. Questions that remained the same may be compared to previous results; however, items that changed may not be directly comparable.

⁵ For some items, state averages are not shown due to an insufficient number of survey responses to report (fewer than 20).

Demographics: Family Members

This section provides information about the individual with disabilities living outside of the family's home.

Across states, a higher percentage of family members was male (57%) compared to female (43%), and the average age of family members was 44.6 years old. The majority of respondents indicated that their family member was white (80%), while 12% were Black/African American; 4% of respondents identified their family member as Hispanic.

On average across states, two-thirds (66%) of respondents indicated that their family member had less than a high school diploma or GED, and 30% did have a high school diploma or GED; the remaining 3% had vocational school training and 1% had completed some college coursework.

While the majority of respondents reported that their family member lived in a group home (58%), 14% lived independently, 13% resided in a specialized facility, 6% in adult foster care, 4% in an agency operated apartment, 2% in a nursing home, and 4% lived in another type of residence.

The amount of help needed with daily activities was evenly dispersed between none (22%), little (25%), moderate (28%), and complete (26%).

The most common disabilities respondents listed their family member as having included:

- Intellectual disability, 82%
- Seizure Disorder, 27%
- Mental Illness, 25%
- Physical Disability, 25%
- Communication Disorder, 23%

Gender of Family Member

| TABLE 4. GENDER | | |
|--------------------|--------------|--------------|
| State | Male | Female |
| AZ | 55% | 45% |
| FL | 58% | 42% |
| GA | 56% | 44% |
| KY | 62% | 38% |
| LA | 56% | 44% |
| MO | 62% | 38% |
| NC | 54% | 46% |
| NJ | 57% | 43% |
| NM | 55% | 45% |
| OH | 54% | 46% |
| PA | 59% | 41% |
| Total N | 1,970 | 1,489 |
| NCI Average | 57% | 43% |

Age of Family Member

| TABLE 5. AGE OF FAMILY MEMBER | | |
|-------------------------------|-------------|--------------|
| State | Average Age | Range |
| AZ | 43.5 | 18-91 |
| FL | 41.4 | 18-82 |
| GA | 44.1 | 18-79 |
| KY | 43.8 | 18-86 |
| LA | 46.6 | 18-78 |
| MO | 41.0 | 18-85 |
| NC | 43.9 | 22-90 |
| NJ | 43.8 | 18-82 |
| NM | 45.2 | 18-84 |
| OH | 47.7 | 19-89 |
| PA | 49.2 | 19-85 |
| Total N | | 3,391 |
| NCI Average | 44.6 | |

Race/Ethnicity of Family Member

In this category, respondents could indicate one or more races/ethnicities. For this reason, the percentages may not total 100%.

| TABLE 6. RACE/ETHNICITY OF FAMILY MEMBER | | | | | | | | |
|--|--------------|-------------------------------|-----------|---|----------------------------------|----------------------|-------------------|---------------------|
| State | White | Black/ African American | Asian | American Indian/ Alaska Native | Hawaiian/ Pacific Islander | Two or More Races | Other/ Unknown | Hispanic/ Latino |
| AZ | 80% | 1% | 0% | 5% | 0% | 3% | 1% | 12% |
| FL | 76% | 17% | 0% | 0% | 0% | 4% | 0% | 4% |
| GA | 69% | 30% | 1% | 1% | 1% | 0% | 0% | 0% |
| KY | 93% | 4% | 0% | 0% | 0% | 2% | 0% | 0% |
| LA | 75% | 22% | 0% | 1% | 0% | 2% | 0% | 1% |
| MO | 92% | 5% | 0% | 1% | 0% | 2% | 0% | 0% |
| NC | 72% | 26% | 0% | 1% | 0% | 1% | 0% | 0% |
| NJ | 86% | 9% | 5% | 0% | 1% | 2% | 0% | 2% |
| NM | 56% | 2% | 1% | 11% | 0% | 7% | 1% | 27% |
| OH | 86% | 12% | 1% | 2% | 0% | 2% | 1% | 1% |
| PA | 95% | 2% | 1% | 1% | 0% | 0% | 0% | 0% |
| Total N | 2,739 | 417 | 23 | 90 | 7 | 85 | 14 | 170 |
| NCI Avg | 80% | 12% | 1% | 2% | 0% | 2% | 0% | 4% |

Type of Residence

| TABLE 7. TYPE OF RESIDENCE IN WHICH FAMILY MEMBER LIVES | | | | | | | |
|---|-------------------------|--------------|------------------------|-------------------------------|---------------------------------------|--------------|------------|
| State | Specialized ID Facility | Group Home | Agency Owned Apartment | Independent Home or Apartment | Adult Foster Care or Host Family Home | Nursing Home | Other |
| AZ | 10% | 71% | 1% | 0% | 12% | 2% | 2% |
| FL | 27% | 55% | 1% | 11% | 1% | 1% | 3% |
| GA | 7% | 49% | 8% | 19% | 11% | 1% | 6% |
| KY | 5% | 83% | 2% | 1% | 8% | 1% | 0% |
| LA | 31% | 48% | 1% | 17% | 0% | 1% | 2% |
| MO | 13% | 39% | 7% | 34% | 1% | 2% | 4% |
| NC | 12% | 69% | 3% | 3% | 5% | 1% | 5% |
| NJ | 5% | 76% | 7% | 5% | 6% | 0% | 1% |
| NM | 6% | 49% | 5% | 24% | 11% | 0% | 6% |
| OH | 10% | 44% | 6% | 29% | 2% | 6% | 5% |
| PA | 13% | 56% | 1% | 13% | 4% | 7% | 6% |
| Total N | 439 | 1,890 | 143 | 575 | 185 | 73 | 128 |
| NCI Average | 13% | 58% | 4% | 14% | 6% | 2% | 4% |

Other Disabilities of Family Member

| TABLE 8A. OTHER DISABILITIES OF FAMILY MEMBER | | | | | | | |
|---|---------------------|------------|--------------|----------------|---------------------|------------------------|---------------|
| State | Alzheimer's Disease | Autism | Brain Injury | Cerebral Palsy | Chemical Dependency | Communication Disorder | Down Syndrome |
| AZ | 1% | 13% | 11% | 20% | 0% | 19% | 10% |
| FL | 4% | 27% | 11% | 12% | 2% | 27% | 10% |
| GA | 1% | 15% | 8% | 12% | 1% | 21% | 10% |
| KY | 1% | 18% | 13% | 18% | 0% | 20% | 12% |
| LA | 2% | 11% | 10% | 17% | 1% | 28% | 9% |
| MO | 2% | 12% | 7% | 13% | 0% | 15% | 8% |
| NC | 2% | 16% | 12% | 15% | 1% | 18% | 10% |
| NJ | 1% | 29% | 9% | 6% | 2% | 18% | 11% |
| NM | 1% | 12% | 8% | 21% | 1% | 26% | 8% |
| OH | 5% | 16% | 15% | 14% | 3% | 43% | 8% |
| PA | 2% | 8% | 10% | 17% | 1% | 20% | 12% |
| Total N | 74 | 528 | 345 | 513 | 45 | 821 | 330 |
| NCI Average | 2% | 16% | 10% | 15% | 1% | 23% | 10% |

Other Disabilities of Family Member (continued)

| TABLE 8B. OTHER DISABILITIES OF FAMILY MEMBER | | | | | | | | |
|---|-------------------------|----------------|---------------------|-----------------------|------------------|---------------------------|------------------|------------|
| State | Intellectual Disability | Mental Illness | Physical Disability | Prader-Willi Syndrome | Seizure Disorder | Vision/Hearing Impairment | Other Disability | Don't Know |
| AZ | 84% | 23% | 27% | 1% | 32% | 14% | 9% | 4% |
| FL | 82% | 21% | 23% | 0% | 26% | 15% | 19% | 4% |
| GA | 83% | 21% | 26% | 1% | 22% | 14% | 8% | 6% |
| KY | 86% | 22% | 25% | 2% | 29% | 10% | 10% | 2% |
| LA | 83% | 24% | 28% | 0% | 28% | 19% | 15% | 5% |
| MO | 85% | 36% | 19% | 1% | 25% | 9% | 14% | 1% |
| NC | 80% | 24% | 27% | 1% | 25% | 17% | 14% | 3% |
| NJ | 66% | 19% | 11% | 1% | 21% | 4% | 12% | 1% |
| NM | 80% | 19% | 29% | 0% | 29% | 17% | 16% | 4% |
| OH | 93% | 44% | 33% | 1% | 31% | 25% | 16% | 1% |
| PA | 85% | 22% | 27% | 1% | 25% | 9% | 9% | 4% |
| Total N | 2,839 | 885 | 872 | 31 | 915 | 192 | 447 | 107 |
| NCI Average | 82% | 25% | 25% | 1% | 27% | 14% | 13% | 3% |

Primary Means of Expression

| TABLE 9. FAMILY MEMBER'S PRIMARY MEANS OF EXPRESSION | | | | | |
|--|--------------|---------------------------|----------------------------------|-----------------------------|------------|
| State | Spoken | Gestures or Body Language | Sign Language or Finger Spelling | Communication or Aid Device | Other |
| AZ | 74% | 19% | 1% | 2% | 5% |
| FL | 76% | 17% | 2% | 1% | 4% |
| GA | 74% | 21% | 2% | 0% | 3% |
| KY | 79% | 17% | 0% | 1% | 3% |
| LA | 66% | 25% | 0% | 1% | 8% |
| MO | 80% | 17% | 1% | 1% | 2% |
| NC | 67% | 22% | 2% | 2% | 5% |
| NJ | 78% | 15% | 2% | 1% | 4% |
| NM | 69% | 24% | 1% | 3% | 3% |
| OH | 75% | 18% | 3% | 1% | 4% |
| PA | 69% | 36% | 0% | 1% | 4% |
| Total N | 2,483 | 684 | 49 | 39 | 136 |
| NCI Average | 73% | 20% | 1% | 1% | 4% |

Primary Language

| TABLE 10. FAMILY MEMBER'S PRIMARY LANGUAGE | | | |
|---|----------------|----------------|--------------|
| State | English | Spanish | Other |
| AZ | 94% | 3% | 3% |
| FL | 98% | 1% | 1% |
| GA | 97% | 0% | 2% |
| KY | 99% | 0% | 1% |
| LA | 96% | 0% | 4% |
| MO | 98% | 0% | 2% |
| NC | 98% | 0% | 2% |
| NJ | 97% | 1% | 2% |
| NM | 90% | 5% | 5% |
| OH | 96% | 0% | 4% |
| PA | 98% | 1% | 1% |
| Total N | 3,261 | 37 | 92 |
| NCI Average | 96% | 1% | 3% |

Family Member's Daily Activity

TABLE 11. FAMILY MEMBER'S DAILY ACTIVITY

| State | Out of Home Day Program (unpaid) | Out of Home Day Program (paid) | Vocational Training | Community Employment (unpaid) | Community Employment (paid) | In-home Day Supports | At Home (by choice) | At Home (because no services) | At Home (other) | Other |
|--------------------|----------------------------------|--------------------------------|---------------------|-------------------------------|-----------------------------|----------------------|---------------------|-------------------------------|-----------------|------------|
| AZ | 35% | 43% | 4% | 3% | 6% | 12% | 3% | 1% | 3% | 10% |
| FL | 11% | 52% | 8% | 0% | 7% | 7% | 0% | 2% | 4% | 10% |
| GA | 31% | 42% | 7% | 4% | 9% | 10% | 3% | 3% | 5% | 12% |
| KY | 34% | 51% | 0% | 0% | 7% | 1% | 0% | 0% | 0% | 5% |
| LA | 20% | 30% | 12% | 2% | 10% | 19% | 6% | 1% | 3% | 27% |
| MO | 15% | 25% | 3% | 4% | 15% | 24% | 10% | 3% | 8% | 11% |
| NC | 32% | 35% | 12% | 12% | 14% | 13% | 1% | 1% | 5% | 20% |
| NJ | 38% | 43% | 5% | 5% | 12% | 4% | 3% | 0% | 2% | 5% |
| NM | 32% | 43% | 6% | 7% | 24% | 20% | 9% | 1% | 5% | 11% |
| OH | 27% | 56% | 15% | 2% | 17% | 62% | 4% | 5% | 7% | 17% |
| PA | 19% | 35% | 7% | 8% | 13% | 12% | 8% | 6% | 4% | 17% |
| Total N | 859 | 1,340 | 243 | 143 | 426 | 639 | 160 | 78 | 153 | 446 |
| NCI Average | 27% | 41% | 7% | 4% | 12% | 17% | 4% | 2% | 4% | 13% |

Highest Level of Education

TABLE 12. FAMILY MEMBER'S HIGHEST LEVEL OF EDUCATION

| State | Less than High School Diploma/GED | High School Diploma/GED | Vocational School | Some College | College Degree |
|--------------------|-----------------------------------|-------------------------|-------------------|--------------|----------------|
| AZ | 64% | 34% | 0% | 0% | 0% |
| FL | 64% | 31% | 4% | 0% | 0% |
| GA | 64% | 33% | 3% | 0% | 0% |
| KY | 69% | 29% | 1% | 0% | 0% |
| LA | 83% | 13% | 3% | 1% | 0% |
| MO | 66% | 32% | 1% | 1% | 0% |
| NC | 70% | 23% | 5% | 1% | 1% |
| NJ | 50% | 42% | 5% | 3% | 1% |
| NM | 58% | 39% | 1% | 1% | 0% |
| OH | 65% | 30% | 3% | 1% | 0% |
| PA | 70% | 27% | 3% | 0% | 0% |
| Total N | 2,123 | 975 | 83 | 24 | 6 |
| NCI Average | 66% | 30% | 3% | 1% | 0% |

Amount of Help Needed with Daily Activities

| TABLE 13. AMOUNT OF HELP NEEDED WITH DAILY ACTIVITIES | | | | |
|--|-------------|---------------|-----------------|-----------------|
| State | None | Little | Moderate | Complete |
| AZ | 13% | 23% | 33% | 31% |
| FL | 16% | 30% | 22% | 32% |
| GA | 23% | 25% | 29% | 23% |
| KY | 16% | 27% | 36% | 21% |
| LA | 21% | 17% | 27% | 35% |
| MO | 23% | 28% | 28% | 21% |
| NC | 16% | 25% | 37% | 22% |
| NJ | 29% | 29% | 25% | 17% |
| NM | 23% | 22% | 23% | 32% |
| OH | 39% | 17% | 23% | 21% |
| PA | 24% | 26% | 24% | 27% |
| Total N | 777 | 826 | 944 | 890 |
| NCI Average | 22% | 25% | 28% | 26% |

Behavioral Supports Needed

TABLE 14. NEEDS SUPPORT FOR: SELF-INJURIOUS, DISRUPTIVE, OR DESTRUCTIVE BEHAVIOR

| State | No Support Needed | Some Support Needed | Extensive Support Needed |
|--------------------|-------------------|---------------------|--------------------------|
| AZ | 38% | 39% | 23% |
| FL | 37% | 39% | 25% |
| GA | 41% | 43% | 16% |
| KY | 34% | 43% | 24% |
| LA | 31% | 41% | 28% |
| MO | 36% | 40% | 23% |
| NC | 33% | 49% | 18% |
| NJ | 45% | 44% | 11% |
| NM | 27% | 48% | 26% |
| OH | 55% | 31% | 13% |
| PA | 38% | 40% | 22% |
| Total N | 1,284 | 1,399 | 712 |
| NCI Average | 38% | 42% | 21% |

Frequency of Medical Care

| TABLE 15. FREQUENCY OF MEDICAL CARE | | | |
|-------------------------------------|------------------------|---|----------------------|
| State | Less than once a month | More than once a month, less than once a week | At least once a week |
| AZ | 71% | 21% | 8% |
| FL | 60% | 35% | 5% |
| GA | 72% | 22% | 6% |
| KY | 62% | 29% | 9% |
| LA | 52% | 23% | 25% |
| MO | 65% | 27% | 8% |
| NC | 70% | 19% | 11% |
| NJ | 66% | 25% | 9% |
| NM | 54% | 29% | 17% |
| OH | 46% | 34% | 19% |
| PA | 60% | 22% | 17% |
| Total N | 2,015 | 884 | 424 |
| NCI Average | 62% | 26% | 12% |

Demographics: Respondents

This section provides information about survey respondents. Respondents are the individuals who completed the survey forms, not the individual with disabilities living outside of the household.

The majority of respondents across states were between 55 and 74 years old (58%); 23% were 35-54 years old, 16% were 75 or older, and 3% were under 35. Just over half the respondents (55%) were the parent of the person with a disability; the remaining respondents included siblings (25%) and others (20%). Three-quarters (75%) were the legal guardian of their family member.

Across states, 39% of respondents had earned a college degree, while about half had either a high school diploma or GED (25%) or had completed some college coursework (23%); 8% had less than a high school diploma or GED and 5% had vocational school training. Respondents' household incomes varied: less than \$15,000 (21%), \$15,001 - \$25,000 (17%), \$25,001 - \$50,000 (28%), \$50,001 - \$75,000 (17%), and over \$75,000 (17%). While just over half (52%) the respondents reported not having used out-of-pocket expenses on services and supports for their family member in the previous year, 11% spent \$1-\$100, 22% spent \$101- \$1,000, 13% spent \$1,001- \$10,000, and 2% spent over \$10,000.

Age of Respondent

| TABLE 16. AGE OF RESPONDENT | | | | |
|------------------------------------|-----------------|--------------|--------------|--------------------|
| State | Under 35 | 35-54 | 55-74 | 75 or Older |
| AZ | 6% | 20% | 64% | 10% |
| FL | 2% | 20% | 70% | 8% |
| GA | 5% | 27% | 53% | 15% |
| KY | 2% | 28% | 57% | 14% |
| LA | 1% | 24% | 55% | 21% |
| MO | 2% | 30% | 52% | 16% |
| NC | 1% | 22% | 62% | 16% |
| NJ | 0% | 16% | 54% | 30% |
| NM | 3% | 24% | 58% | 16% |
| OH | 8% | 27% | 54% | 11% |
| PA | 2% | 18% | 57% | 23% |
| Total N | 101 | 811 | 1,936 | 547 |
| NCI Average | 3% | 23% | 58% | 16% |

Relationship of Respondent to Individual with Disabilities

| TABLE 17. RELATIONSHIP TO INDIVIDUAL | | | | |
|---|---------------|----------------|---------------|--------------|
| State | Parent | Sibling | Spouse | Other |
| AZ | 56% | 19% | 0% | 25% |
| FL | 56% | 27% | 1% | 17% |
| GA | 55% | 25% | 0% | 19% |
| KY | 59% | 38% | 0% | 2% |
| LA | 55% | 31% | 0% | 14% |
| MO | 57% | 8% | 0% | 36% |
| NC | 55% | 19% | 1% | 26% |
| NJ | 72% | 17% | 1% | 10% |
| NM | 55% | 25% | 0% | 19% |
| OH | 38% | 21% | 0% | 41% |
| PA | 49% | 43% | 1% | 7% |
| Total N | 1,852 | 831 | 12 | 719 |
| NCI Average | 55% | 25% | 0% | 20% |

Frequency of Visits between Respondent and Individual with Disabilities

TABLE 18. FREQUENCY OF VISITS WITH FAMILY MEMBER

| State | Less than once a year | 1-3 times a year | 4-6 times a year | 7-12 times a year | More than 12 time a year |
|--------------------|-----------------------|------------------|------------------|-------------------|--------------------------|
| AZ | 2% | 5% | 13% | 11% | 69% |
| FL | 1% | 5% | 6% | 22% | 67% |
| GA | 3% | 7% | 9% | 14% | 67% |
| KY | 2% | 6% | 12% | 15% | 65% |
| LA | 8% | 17% | 18% | 13% | 44% |
| MO | 2% | 22% | 16% | 14% | 47% |
| NC | 2% | 7% | 21% | 12% | 59% |
| NJ | 2% | 7% | 7% | 15% | 68% |
| NM | 4% | 10% | 9% | 10% | 67% |
| OH | 1% | 3% | 21% | 13% | 61% |
| PA | 7% | 11% | 14% | 14% | 55% |
| Total N | 106 | 333 | 463 | 478 | 2,075 |
| NCI Average | 3% | 9% | 13% | 14% | 61% |

Respondent's Role as Legal Guardian or Conservator

| TABLE 19. RESPONDENT IS LEGAL GUARDIAN OR CONSERVATOR | | |
|--|--------------|------------|
| State | Yes | No |
| AZ | 82% | 18% |
| FL | 78% | 22% |
| GA | 53% | 47% |
| KY | 98% | 2% |
| LA | 63% | 37% |
| MO | 87% | 13% |
| NC | 87% | 13% |
| NJ | 77% | 23% |
| NM | 81% | 19% |
| OH | 69% | 31% |
| PA | 53% | 47% |
| Total N | 2,538 | 869 |
| NCI Average | 75% | 25% |

Respondents Highest Level of Education

| TABLE 20. RESPONDENT'S HIGHEST LEVEL OF EDUCATION | | | | | |
|--|---|-----------------------------------|--------------------------|---------------------|-----------------------|
| State | Less than High School Diploma or GED | High School Diploma or GED | Vocational School | Some College | College Degree |
| AZ | 6% | 17% | 3% | 35% | 39% |
| FL | 6% | 21% | 4% | 31% | 38% |
| GA | 13% | 28% | 6% | 22% | 31% |
| KY | 8% | 29% | 7% | 23% | 34% |
| LA | 13% | 24% | 6% | 23% | 35% |
| MO | 10% | 28% | 3% | 26% | 33% |
| NC | 7% | 28% | 4% | 15% | 46% |
| NJ | 5% | 22% | 3% | 19% | 51% |
| NM | 10% | 19% | 7% | 27% | 38% |
| OH | 3% | 24% | 4% | 17% | 52% |
| PA | 7% | 36% | 6% | 19% | 32% |
| Total N | 279 | 840 | 168 | 792 | 1,294 |
| NCI Average | 8% | 25% | 5% | 23% | 39% |

Household Income

| Table 21. Household Income | | | | | |
|-----------------------------------|-----------------------|----------------------------|----------------------------|----------------------------|----------------------|
| State | Below \$15,000 | \$15,001 - \$25,000 | \$25,001 - \$50,000 | \$50,001 - \$75,000 | Over \$75,000 |
| AZ | 21% | 17% | 28% | 15% | 19% |
| FL | 26% | 18% | 28% | 14% | 14% |
| GA | 30% | 18% | 28% | 15% | 9% |
| KY | 18% | 20% | 24% | 18% | 21% |
| LA | 29% | 17% | 25% | 12% | 17% |
| MO | 22% | 15% | 34% | 21% | 9% |
| NC | 19% | 16% | 26% | 16% | 24% |
| NJ | 15% | 11% | 30% | 14% | 29% |
| NM | 23% | 19% | 24% | 21% | 13% |
| OH | 6% | 12% | 39% | 23% | 20% |
| PA | 23% | 23% | 28% | 11% | 15% |
| Total N | 574 | 445 | 756 | 447 | 430 |
| NCI Average | 21% | 17% | 28% | 17% | 17% |

Out-of-Pocket Expenses in the Past Year

Table 22. Out-of-pocket money spent in the past year for services/supports for individual

| State | Nothing | \$1-\$100 | \$101-\$1,000 | \$1,001-\$10,000 | Over \$10,000 |
|--------------------|----------------|------------------|----------------------|-------------------------|----------------------|
| AZ | 39% | 10% | 31% | 19% | 1% |
| FL | 32% | 18% | 28% | 11% | 11% |
| GA | 46% | 18% | 26% | 10% | 1% |
| KY | 47% | 14% | 24% | 15% | 1% |
| LA | 58% | 11% | 18% | 12% | 0% |
| MO | 68% | 9% | 15% | 8% | 1% |
| NC | 57% | 12% | 20% | 11% | 1% |
| NJ | 36% | 8% | 25% | 29% | 3% |
| NM | 57% | 11% | 23% | 8% | 1% |
| OH | 66% | 6% | 19% | 9% | 0% |
| PA | 66% | 9% | 18% | 7% | 1% |
| Total N | 1,698 | 363 | 697 | 369 | 54 |
| NCI Average | 52% | 11% | 22% | 13% | 2% |

Services and Supports Received

This section, which consists of just one table, provides information about the services and supports received by the family member from the state ID/DD agency. Almost all respondents indicated that their family member received residential supports (93%) and transportation (91%). Three-quarters (75%) of respondents reported their family member received day/employment supports.

Services and Supports Received

| TABLE 23. SERVICES AND SUPPORTS RECEIVED | | | | |
|--|----------------------|----------------------------|----------------|--------------|
| State | Residential supports | Day or Employment supports | Transportation | Other |
| AZ | 97% | 86% | 92% | 61% |
| FL | 98% | 70% | 95% | 68% |
| GA | 89% | 73% | 91% | 49% |
| KY | 97% | 93% | 98% | 68% |
| LA | 94% | 61% | 90% | 63% |
| MO | 95% | 57% | 81% | 47% |
| NC | 96% | 76% | 94% | 64% |
| NJ | 95% | 86% | 94% | 58% |
| NM | 92% | 76% | 92% | 89% |
| OH | 84% | 81% | 92% | 49% |
| PA | 85% | 62% | 79% | 50% |
| Total N | 3,173 | 2,484 | 3,074 | 2,040 |
| NCI Average | 93% | 75% | 91% | 61% |

Family Guardian Survey Results

This section of the report presents results at the state and national level for all questions. It is divided into six subsections:

- Information and Planning
- Access and Delivery of Services and Supports
- Choice and Control
- Community Connections
- Satisfaction with Services and Supports
- Outcomes

Results are presented first in graph form and then in table form showing each state's average for all response options. Within the tables, states are listed in descending order: significantly above the NCI Average, within the NCI Average, and significantly below the NCI Average. Significance is taken to be at or below the $p < .01$ level, and is based on the "always" or "yes" responses.

The beginning of each section provides a brief observation of outcomes in that area as well as a condensed graph showing the NCI Average for the "always" or "yes" responses for each question.

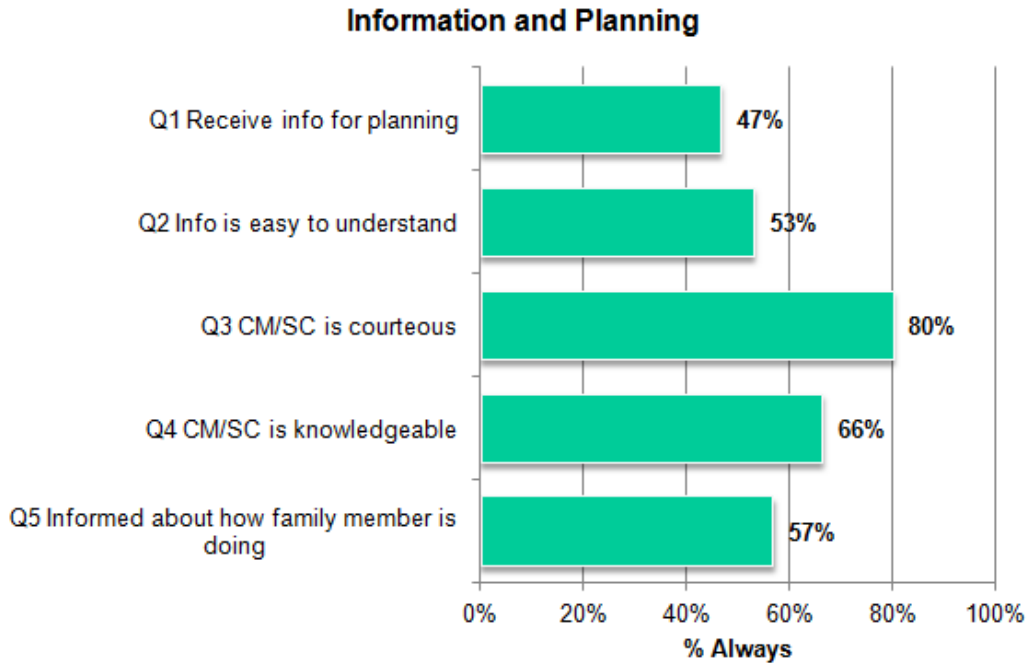
Information and Planning

Results from the 11 questions in the information and planning section illustrate that case managers/service coordinators across states are courteous and families were generally involved in service planning. Two states, Ohio and Missouri, consistently rated significantly above the NCI Average (on nine and six questions in this section respectively).

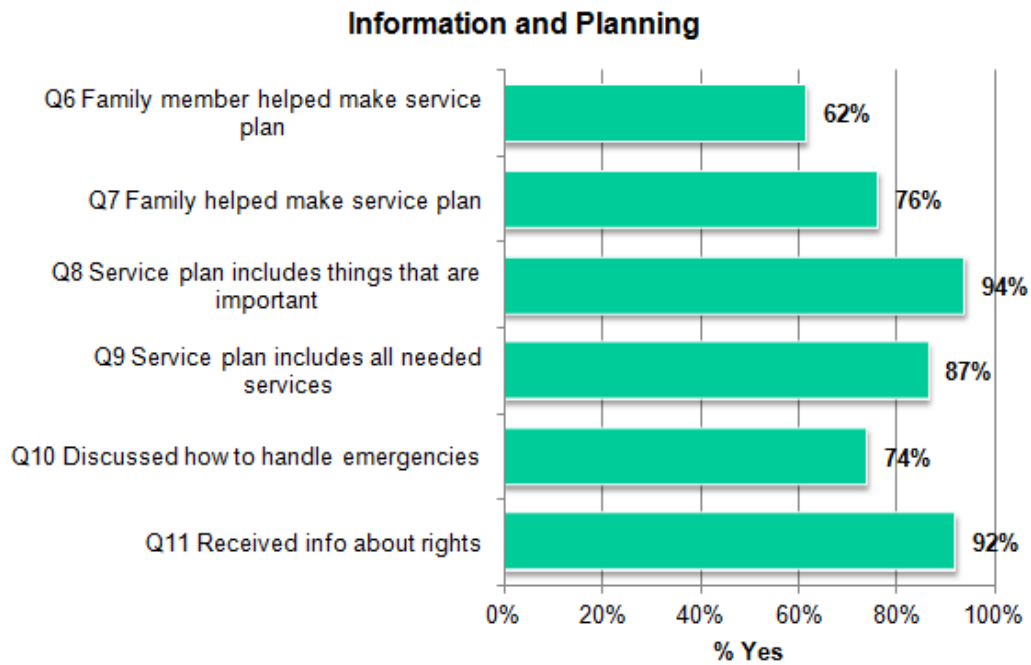
Several questions showed consistently positive results:

- The service plan includes services and supports important to their family member, 94%; state averages ranged between 88% - 99%.
- They or their family member received information their family member's rights, 92%; state averages ranged between 82% - 96%.
- The service plan includes all the services and supports needed, 87%; state averages ranged between 78% - 94%.
- The case manager/service coordinator is generally respectful and courteous, 80%; state averages ranged between 69% - 88%.
- A family member helped develop the service plan, 76%; state averages ranged between 60% - 89%.

The graph below shows the NCI Average for questions with “always” responses.



The graph below shows the NCI Average for questions with “yes” responses.



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

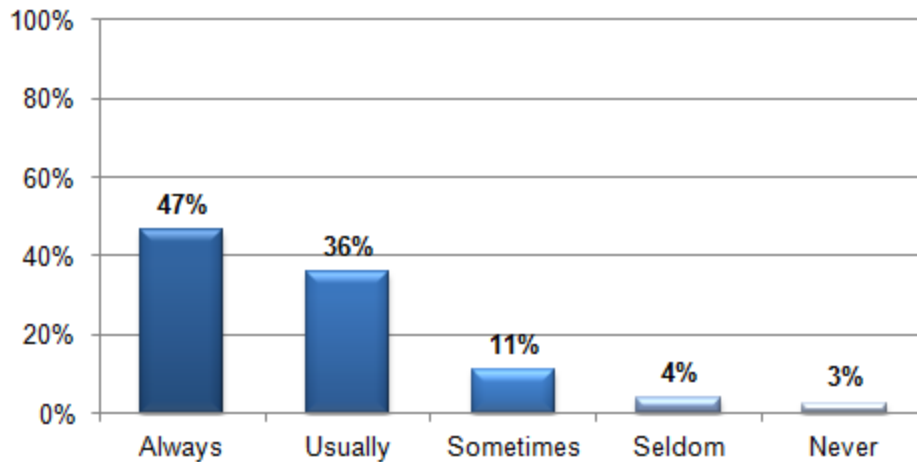
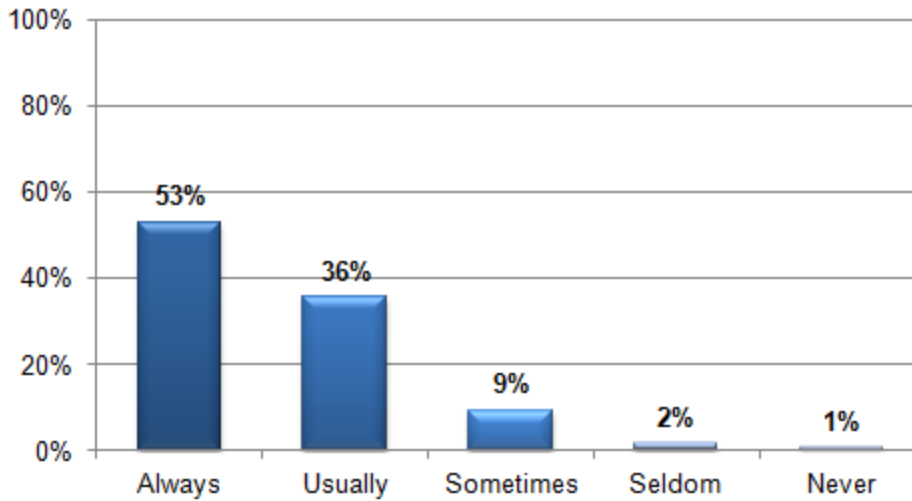


TABLE Q1. DO YOU GET ENOUGH INFORMATION TO HELP YOU PARTICIPATE IN PLANNING SERVICES FOR YOUR FAMILY MEMBER?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| LA | 57% | 26% | 11% | 4% | 3% | 360 |
| MO | 56% | 32% | 5% | 4% | 2% | 405 |
| OH | 54% | 30% | 10% | 4% | 2% | 388 |
| Within NCI Average Range | | | | | | |
| NM | 51% | 31% | 12% | 3% | 3% | 406 |
| FL | 48% | 39% | 10% | 2% | 1% | 289 |
| AZ | 47% | 36% | 9% | 6% | 1% | 236 |
| NC | 47% | 38% | 12% | 3% | 1% | 194 |
| PA | 43% | 41% | 9% | 3% | 4% | 237 |
| KY | 41% | 44% | 13% | 2% | 0% | 254 |
| Significantly Below NCI Average | | | | | | |
| GA | 34% | 39% | 16% | 7% | 4% | 386 |
| NJ | 34% | 40% | 15% | 5% | 6% | 205 |
| NCI Average | 47% | 36% | 11% | 4% | 3% | 3,360 |

Q2. Is the information you receive easy to understand?



| TABLE Q2. IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND? | | | | | | |
|--|------------|------------|-----------|-----------|-----------|--------------|
| State | Always | Usually | Sometimes | Seldom | Never | N |
| Significantly Above NCI Average | | | | | | |
| OH | 68% | 22% | 9% | 1% | 1% | 385 |
| LA | 60% | 31% | 5% | 2% | 1% | 351 |
| Within NCI Average Range | | | | | | |
| MO | 60% | 33% | 6% | 1% | 0% | 398 |
| FL | 55% | 34% | 11% | 0% | 0% | 288 |
| NM | 53% | 34% | 10% | 2% | 1% | 397 |
| NC | 53% | 39% | 8% | 1% | 0% | 195 |
| AZ | 50% | 38% | 10% | 2% | 0% | 232 |
| PA | 48% | 42% | 7% | 3% | 0% | 233 |
| NJ | 47% | 36% | 12% | 2% | 2% | 201 |
| KY | 47% | 41% | 11% | 1% | 0% | 251 |
| Significantly Below NCI Average | | | | | | |
| GA | 42% | 41% | 14% | 2% | 1% | 375 |
| NCI Average | 53% | 36% | 9% | 2% | 1% | 3,306 |

Q3. Is the case manager/service coordinator who assists your family member with planning generally respectful and courteous?

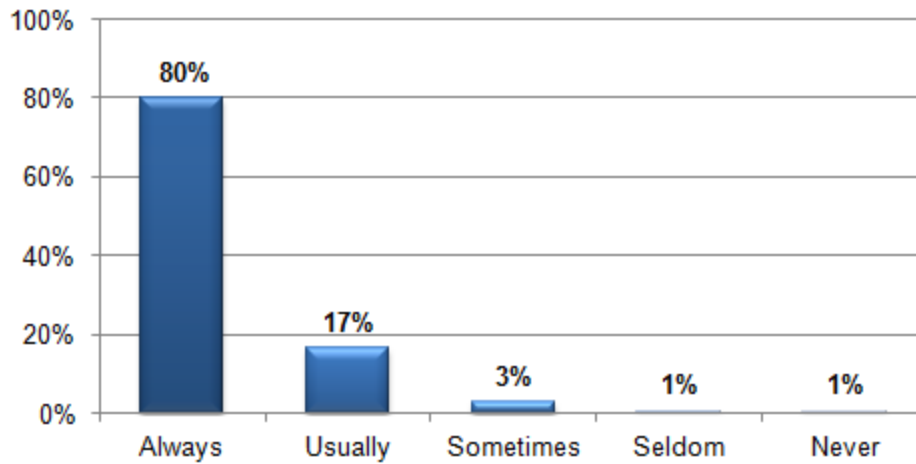


TABLE Q3. IS THE CASE MANAGER/SERVICE COORDINATOR WHO ASSISTS YOUR FAMILY MEMBER WITH PLANNING GENERALLY RESPECTFUL AND COURTEOUS?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| FL | 88% | 11% | 0% | 0% | 1% | 288 |
| Within NCI Average Range | | | | | | |
| PA | 85% | 14% | 1% | 0% | 0% | 232 |
| MO | 83% | 14% | 1% | 1% | 1% | 390 |
| OH | 83% | 13% | 4% | 1% | 0% | 383 |
| KY | 82% | 16% | 2% | 0% | 0% | 251 |
| NC | 81% | 15% | 4% | 0% | 1% | 192 |
| LA | 79% | 17% | 2% | 1% | 1% | 353 |
| NM | 79% | 16% | 4% | 1% | 1% | 400 |
| AZ | 77% | 18% | 3% | 1% | 0% | 237 |
| NJ | 73% | 21% | 2% | 2% | 2% | 201 |
| Significantly Below NCI Average | | | | | | |
| GA | 69% | 27% | 2% | 1% | 1% | 378 |
| NCI Average | 80% | 17% | 3% | 1% | 1% | 3,305 |

Q4. Is the case manager/service coordinator who assists your family member with planning generally knowledgeable?

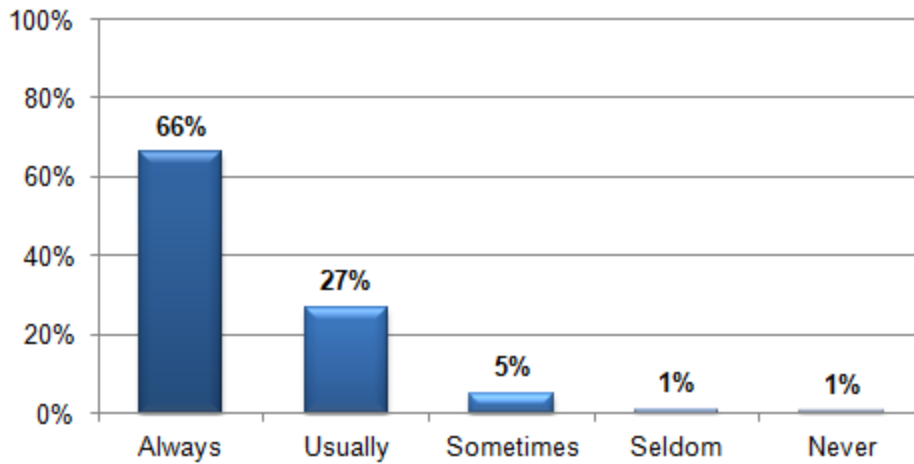


TABLE Q4. IS THE CASE MANAGER/SERVICE COORDINATOR WHO ASSISTS YOUR FAMILY MEMBER WITH PLANNING GENERALLY KNOWLEDGEABLE?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| MO | 73% | 21% | 4% | 1% | 1% | 390 |
| OH | 73% | 21% | 5% | 1% | 0% | 382 |
| Within NCI Average Range | | | | | | |
| NM | 72% | 21% | 6% | 1% | 1% | 398 |
| FL | 71% | 27% | 1% | 0% | 1% | 281 |
| PA | 70% | 27% | 3% | 0% | 0% | 229 |
| NC | 68% | 27% | 4% | 1% | 0% | 191 |
| LA | 68% | 25% | 7% | 0% | 1% | 348 |
| AZ | 62% | 28% | 6% | 3% | 0% | 234 |
| KY | 61% | 33% | 4% | 1% | 0% | 255 |
| NJ | 59% | 27% | 8% | 3% | 3% | 199 |
| Significantly Below NCI Average | | | | | | |
| GA | 53% | 38% | 7% | 1% | 1% | 375 |
| NCI Average | 66% | 27% | 5% | 1% | 1% | 3,282 |

Q5. Are you generally kept informed about how your family member is doing?

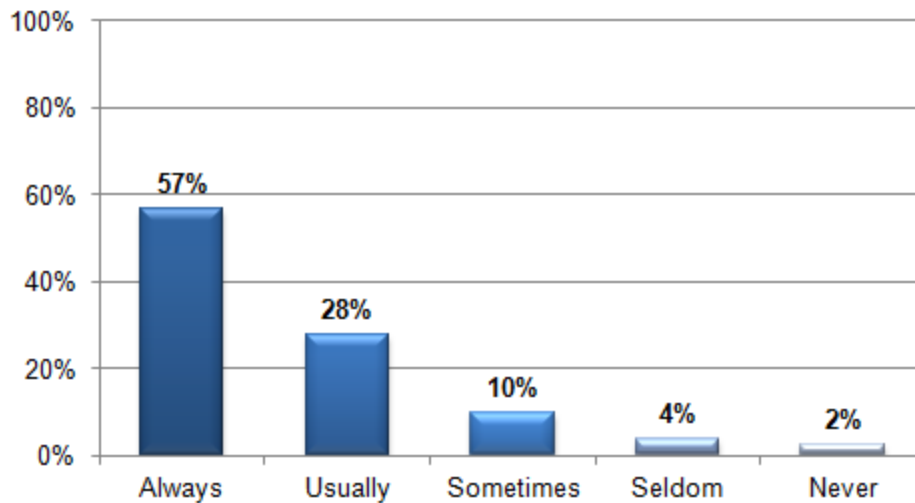
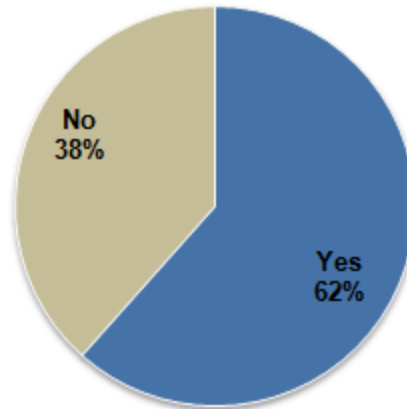


TABLE Q5. ARE YOU GENERALLY KEPT INFORMED ABOUT HOW YOUR FAMILY MEMBER IS DOING?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| MO | 65% | 23% | 6% | 3% | 2% | 410 |
| Within NCI Average Range | | | | | | |
| LA | 62% | 24% | 9% | 3% | 2% | 372 |
| AZ | 59% | 27% | 8% | 5% | 1% | 234 |
| NM | 58% | 24% | 11% | 4% | 2% | 409 |
| OH | 58% | 29% | 8% | 4% | 2% | 398 |
| PA | 58% | 29% | 8% | 2% | 4% | 246 |
| KY | 57% | 29% | 11% | 2% | 0% | 255 |
| NC | 54% | 31% | 11% | 2% | 2% | 197 |
| FL | 54% | 30% | 12% | 2% | 2% | 289 |
| Significantly Below NCI Average | | | | | | |
| GA | 51% | 30% | 12% | 3% | 4% | 388 |
| NJ | 47% | 29% | 11% | 8% | 5% | 204 |
| NCI Average | 57% | 28% | 10% | 4% | 2% | 3,402 |

Q6. Did your family member help develop the service plan?



| TABLE Q6. IF YOUR FAMILY MEMBER HAS A SERVICE PLAN, DID S/HE HELP DEVELOP THE PLAN? | | | |
|--|------------|------------|--------------|
| State | Yes | No | N |
| Significantly Above NCI Average | | | |
| OH | 84% | 16% | 318 |
| FL | 78% | 22% | 234 |
| Within NCI Average Range | | | |
| MO | 67% | 33% | 369 |
| NM | 65% | 35% | 329 |
| GA | 59% | 41% | 295 |
| NC | 59% | 41% | 159 |
| KY | 58% | 42% | 206 |
| PA | 57% | 43% | 177 |
| NJ | 54% | 46% | 151 |
| AZ | 52% | 48% | 194 |
| Significantly Below NCI Average | | | |
| LA | 45% | 55% | 245 |
| NCI Average | 62% | 38% | 2,677 |

Q7. Did you or another family member help develop the service plan?

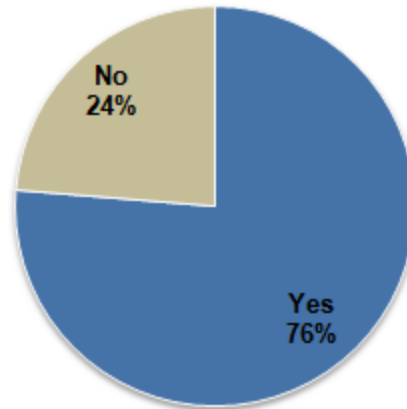


TABLE Q7. IF YOUR FAMILY MEMBER HAS A SERVICE PLAN, DID YOU OR ANOTHER FAMILY MEMBER HELP DEVELOP THE PLAN?

| State | Yes | No | N |
|--|------------|------------|--------------|
| Significantly Above NCI Average | | | |
| OH | 89% | 11% | 317 |
| AZ | 87% | 13% | 215 |
| MO | 86% | 14% | 388 |
| FL | 82% | 18% | 266 |
| NM | 82% | 18% | 373 |
| Within NCI Average Range | | | |
| NC | 79% | 21% | 180 |
| KY | 78% | 22% | 228 |
| NJ | 69% | 31% | 175 |
| Significantly Below NCI Average | | | |
| GA | 66% | 34% | 345 |
| LA | 62% | 38% | 308 |
| PA | 60% | 40% | 203 |
| NCI Average | 76% | 24% | 2,998 |

Q8. Does your family member's service plan include services and supports that are important to your family?

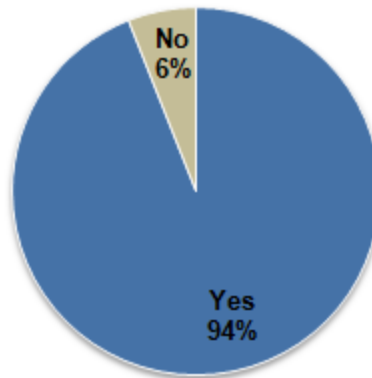


TABLE Q8. IF YOUR FAMILY MEMBER HAS A SERVICE PLAN, DOES THE PLAN INCLUDE SERVICES AND SUPPORTS THAT ARE IMPORTANT TO HIM/HER?

| State | Yes | No | N |
|--|------------|-----------|--------------|
| Significantly Above NCI Average | | | |
| OH | 99% | 1% | 314 |
| NM | 97% | 3% | 365 |
| Within NCI Average Range | | | |
| MO | 95% | 5% | 380 |
| KY | 95% | 5% | 219 |
| NC | 95% | 5% | 173 |
| LA | 94% | 6% | 290 |
| AZ | 93% | 7% | 210 |
| PA | 93% | 7% | 194 |
| FL | 93% | 7% | 253 |
| GA | 91% | 9% | 298 |
| NJ | 88% | 12% | 154 |
| NCI Average | 94% | 6% | 2,850 |

Q9. Does the service plan include all the services and supports your family member needs?

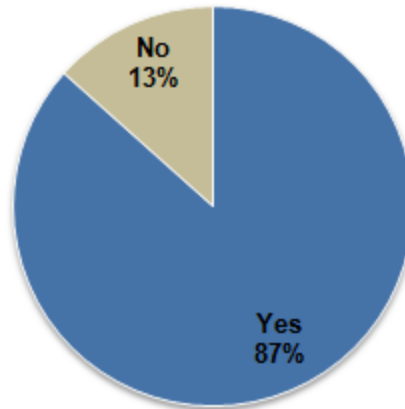


TABLE Q9. DOES THE SERVICE PLAN INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER NEEDS?

| State | Yes | No | N |
|--|------------|------------|--------------|
| Significantly Above NCI Average | | | |
| OH | 94% | 6% | 315 |
| MO | 93% | 7% | 374 |
| Within NCI Average Range | | | |
| LA | 90% | 10% | 279 |
| PA | 89% | 11% | 184 |
| NM | 89% | 11% | 351 |
| AZ | 87% | 13% | 205 |
| NC | 87% | 13% | 167 |
| KY | 84% | 16% | 217 |
| FL | 81% | 19% | 232 |
| Significantly Below NCI Average | | | |
| GA | 80% | 20% | 301 |
| NJ | 78% | 22% | 147 |
| NCI Average | 87% | 13% | 2,772 |

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

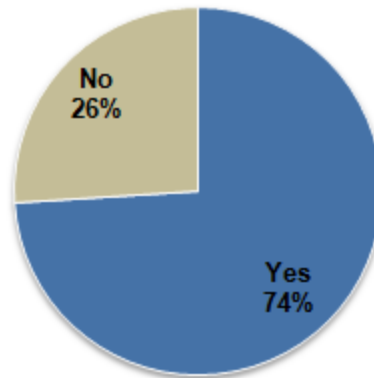


TABLE Q10. IF YOUR FAMILY MEMBER HAS A SERVICE PLAN, DID YOU DISCUSS HOW TO HANDLE EMERGENCIES RELATED TO YOUR FAMILY MEMBER AT THE LAST SERVICE PLANNING MEETING?

| State | Yes | No | N |
|--|------------|------------|--------------|
| Significantly Above NCI Average | | | |
| OH | 88% | 12% | 293 |
| Within NCI Average Range | | | |
| NC | 81% | 19% | 179 |
| AZ | 80% | 20% | 213 |
| KY | 80% | 20% | 231 |
| MO | 79% | 21% | 355 |
| NM | 74% | 26% | 363 |
| LA | 71% | 29% | 301 |
| NJ | 70% | 30% | 148 |
| Significantly Below NCI Average | | | |
| FL | 65% | 35% | 244 |
| GA | 64% | 36% | 314 |
| PA | 62% | 38% | 189 |
| NCI Average | 74% | 26% | 2,830 |

Q11. Have you or your family member received information about your family member's rights?

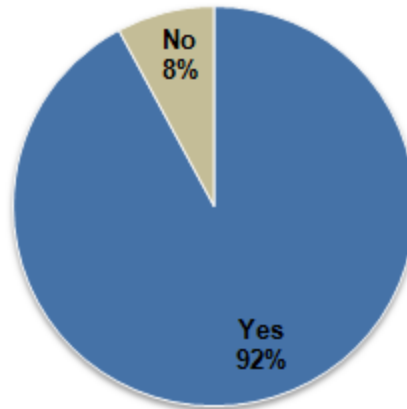


TABLE Q11. HAVE YOU OR YOUR FAMILY MEMBER RECEIVED INFORMATION ABOUT YOUR FAMILY MEMBER'S RIGHTS?

| State | Yes | No | N |
|--|------------|-----------|--------------|
| Significantly Above NCI Average | | | |
| KY | 97% | 3% | 247 |
| OH | 96% | 4% | 389 |
| MO | 96% | 4% | 385 |
| Within NCI Average Range | | | |
| AZ | 94% | 6% | 222 |
| NC | 94% | 6% | 190 |
| NM | 93% | 7% | 390 |
| FL | 93% | 7% | 249 |
| LA | 91% | 9% | 325 |
| PA | 90% | 10% | 202 |
| Significantly Below NCI Average | | | |
| GA | 87% | 13% | 341 |
| NJ | 82% | 18% | 171 |
| NCI Average | 92% | 8% | 3,111 |

Access and Delivery of Services and Supports

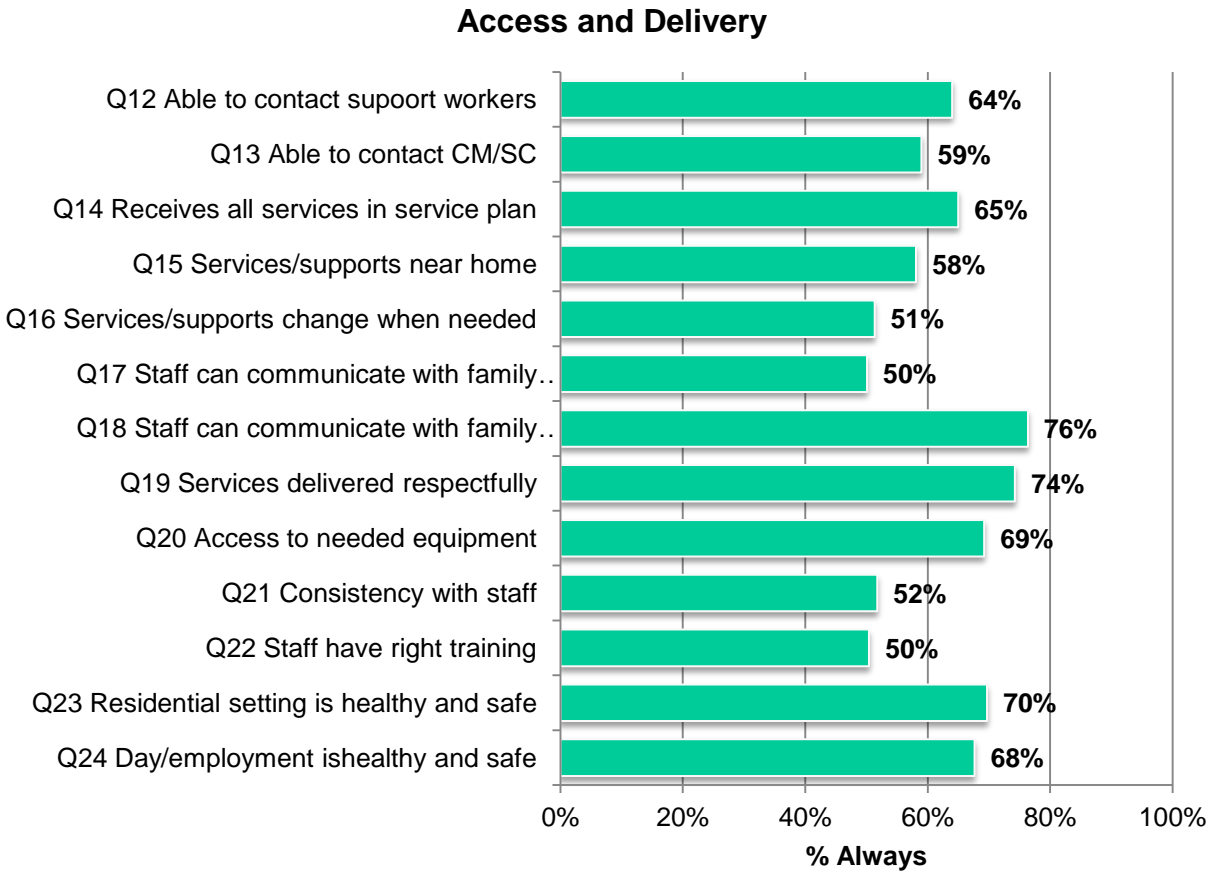
The 14 Access questions showed mixed results. For two questions, a large majority of respondents, over three-quarters, reported:

- Support workers are able to communicate effectively with their family member whose primary language was English, 76%; state averages ranged between 69% and 83%.
- They were happy with the transition from school services to State funded services during the past year, 84%⁶

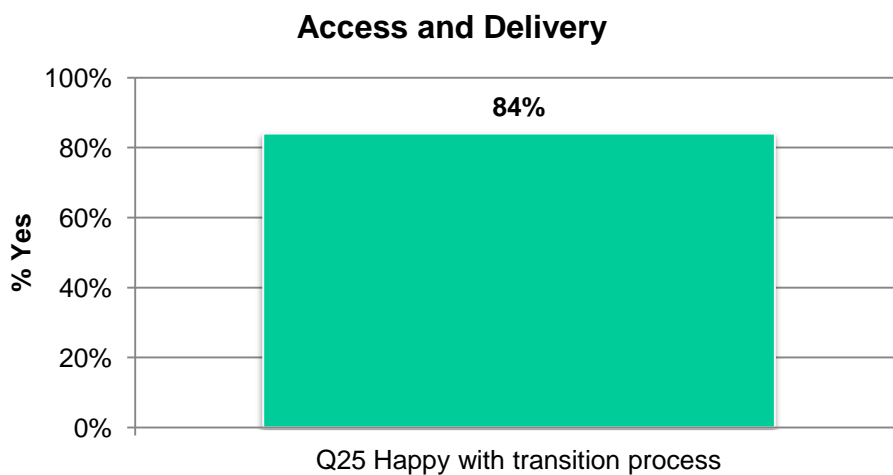
Results from Missouri and Ohio were significantly above the NCI Average on eight and six questions, respectively.

⁶ Represents the NCI Average; all state results had too few cases to report individually

The graph below shows the NCI Average for questions with “always” responses.



The graph below shows the NCI Average for questions with “yes” responses.



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

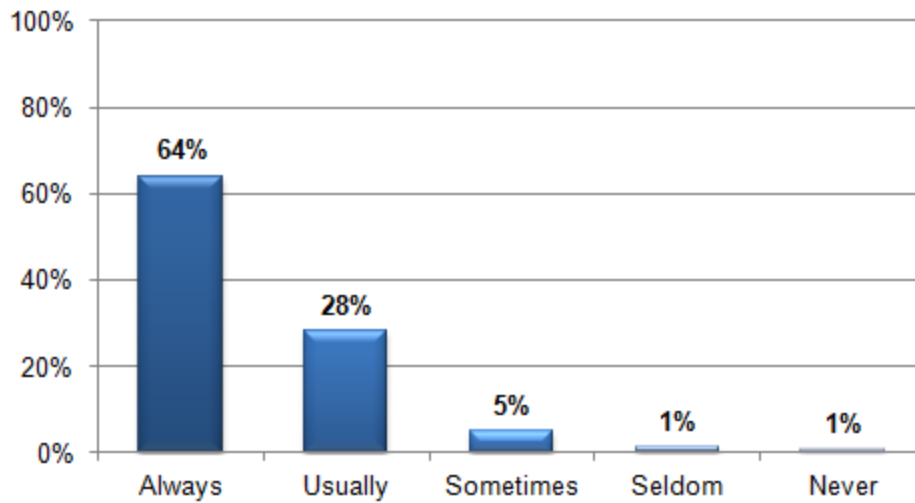


TABLE Q12. ARE YOU ABLE TO CONTACT YOUR FAMILY MEMBER'S SUPPORT WORKERS WHEN YOU NEED TO?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| MO | 75% | 21% | 2% | 1% | 1% | 407 |
| OH | 72% | 21% | 5% | 2% | 0% | 392 |
| Within NCI Average Range | | | | | | |
| FL | 69% | 22% | 6% | 2% | 0% | 259 |
| LA | 68% | 24% | 5% | 1% | 1% | 356 |
| KY | 67% | 29% | 3% | 1% | 0% | 261 |
| PA | 65% | 28% | 5% | 1% | 2% | 247 |
| NC | 63% | 34% | 2% | 1% | 1% | 197 |
| AZ | 61% | 30% | 5% | 3% | 0% | 230 |
| NM | 60% | 30% | 8% | 2% | 0% | 407 |
| Significantly Below NCI Average | | | | | | |
| GA | 56% | 34% | 7% | 1% | 2% | 387 |
| NJ | 53% | 36% | 8% | 1% | 1% | 207 |
| NCI Average | 64% | 28% | 5% | 1% | 1% | 3,350 |

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

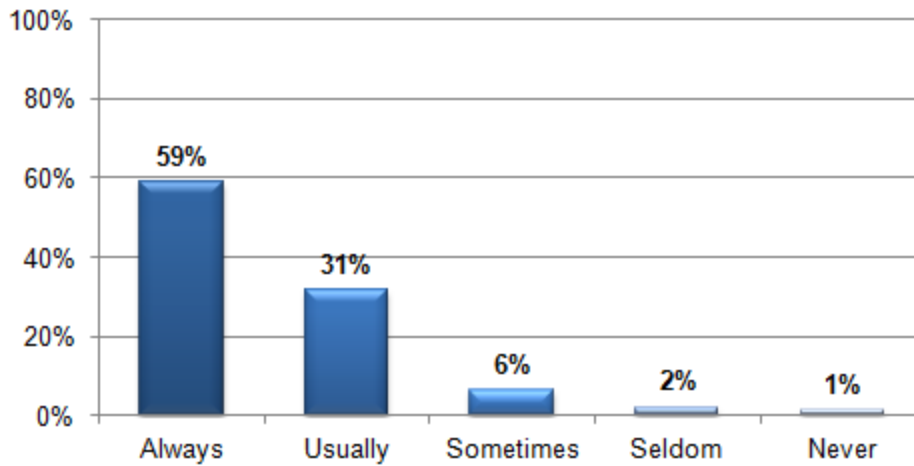


TABLE Q13. ARE YOU ABLE TO CONTACT YOUR FAMILY MEMBER'S CASE MANAGER/SERVICE COORDINATOR WHEN YOU NEED TO?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| OH | 69% | 25% | 5% | 1% | 1% | 377 |
| MO | 68% | 26% | 4% | 1% | 1% | 385 |
| Within NCI Average Range | | | | | | |
| FL | 63% | 31% | 5% | 1% | 0% | 258 |
| KY | 62% | 33% | 3% | 1% | 0% | 261 |
| LA | 62% | 28% | 5% | 3% | 2% | 353 |
| PA | 62% | 30% | 4% | 2% | 2% | 240 |
| NM | 60% | 29% | 8% | 2% | 1% | 406 |
| NC | 59% | 33% | 6% | 2% | 1% | 197 |
| AZ | 55% | 33% | 8% | 3% | 1% | 230 |
| Significantly Below NCI Average | | | | | | |
| GA | 48% | 38% | 9% | 2% | 2% | 377 |
| NJ | 40% | 40% | 11% | 5% | 4% | 191 |
| NCI Average | 59% | 31% | 6% | 2% | 1% | 3,275 |

Q14. Does your family member receive all of the services listed in the service plan?

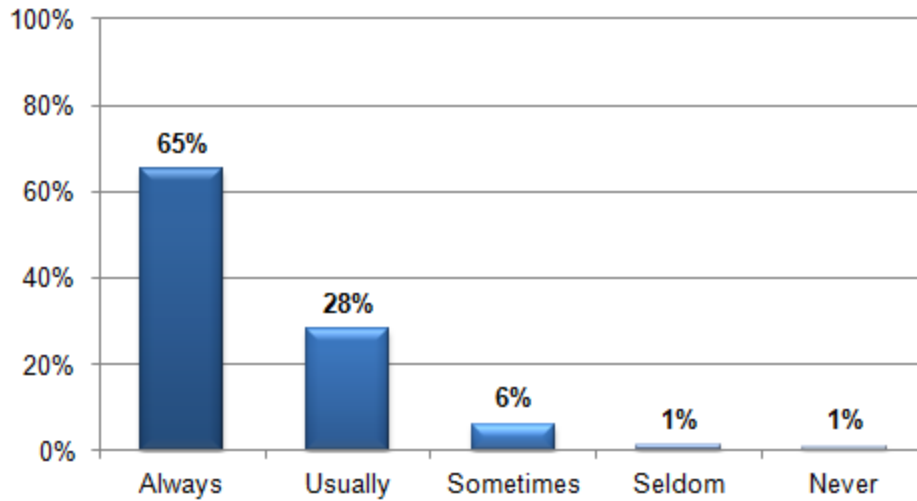


TABLE Q14. DOES YOUR FAMILY MEMBER RECEIVE ALL OF THE SERVICES LISTED IN THE SERVICE PLAN?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| OH | 73% | 23% | 4% | 0% | 0% | 338 |
| MO | 72% | 22% | 3% | 2% | 0% | 367 |
| Within NCI Average Range | | | | | | |
| PA | 69% | 27% | 2% | 1% | 1% | 177 |
| LA | 69% | 26% | 4% | 1% | 0% | 287 |
| NC | 67% | 27% | 4% | 1% | 1% | 167 |
| NM | 64% | 26% | 8% | 1% | 1% | 364 |
| AZ | 64% | 28% | 6% | 1% | 0% | 208 |
| FL | 64% | 30% | 6% | 0% | 0% | 217 |
| KY | 63% | 27% | 8% | 1% | 1% | 219 |
| Significantly Below NCI Average | | | | | | |
| GA | 52% | 36% | 7% | 3% | 2% | 288 |
| NJ | 51% | 33% | 10% | 3% | 3% | 154 |
| NCI Average | 65% | 28% | 6% | 1% | 1% | 2,786 |

Q15. Are service and supports available within a reasonable distance from your family member's home?

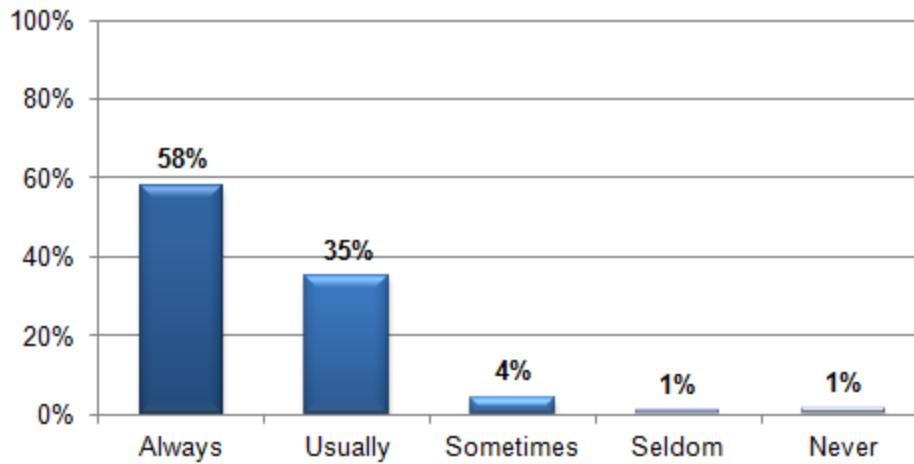


TABLE Q15. ARE SERVICE AND SUPPORTS AVAILABLE WITHIN A REASONABLE DISTANCE FROM YOUR FAMILY MEMBER'S HOME?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| OH | 71% | 25% | 4% | 1% | 0% | 387 |
| FL | 68% | 27% | 4% | 0% | 1% | 262 |
| Within NCI Average Range | | | | | | |
| MO | 65% | 31% | 3% | 1% | 1% | 388 |
| NM | 64% | 30% | 4% | 1% | 1% | 383 |
| LA | 60% | 32% | 5% | 1% | 2% | 310 |
| PA | 57% | 37% | 2% | 2% | 1% | 207 |
| GA | 56% | 36% | 4% | 1% | 3% | 347 |
| KY | 54% | 37% | 6% | 1% | 2% | 252 |
| NC | 52% | 42% | 5% | 0% | 1% | 186 |
| Significantly Below NCI Average | | | | | | |
| AZ | 47% | 46% | 5% | 1% | 0% | 220 |
| NJ | 45% | 47% | 5% | 1% | 2% | 187 |
| NCI Average | 58% | 35% | 4% | 1% | 1% | 3,129 |

Q16. Do the services and supports change when your family member's needs change?

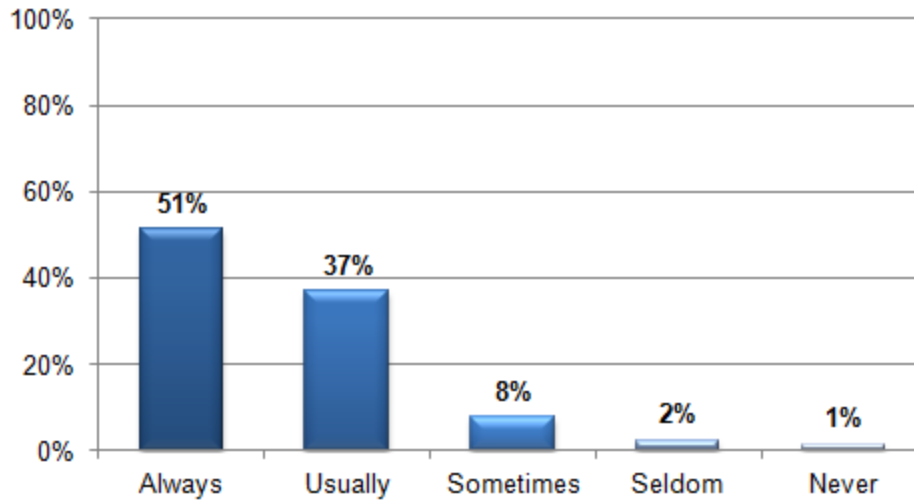


TABLE Q16. DO THE SERVICES AND SUPPORTS CHANGE WHEN YOUR FAMILY MEMBER'S NEEDS CHANGE?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| OH | 62% | 31% | 5% | 1% | 1% | 383 |
| MO | 59% | 33% | 7% | 2% | 0% | 366 |
| Within NCI Average Range | | | | | | |
| NM | 58% | 30% | 8% | 3% | 1% | 365 |
| LA | 57% | 36% | 4% | 2% | 2% | 298 |
| PA | 53% | 39% | 4% | 2% | 2% | 191 |
| GA | 48% | 41% | 6% | 2% | 2% | 306 |
| NC | 48% | 43% | 6% | 2% | 1% | 173 |
| KY | 48% | 39% | 10% | 2% | 1% | 226 |
| FL | 47% | 33% | 14% | 5% | 0% | 224 |
| AZ | 45% | 39% | 12% | 2% | 1% | 209 |
| Significantly Below NCI Average | | | | | | |
| NJ | 40% | 42% | 10% | 3% | 4% | 158 |
| NCI Average | 51% | 37% | 8% | 2% | 1% | 2,899 |

Q17. If your family member does not speak English or uses another way to communicate can support workers to communicate with him/her?

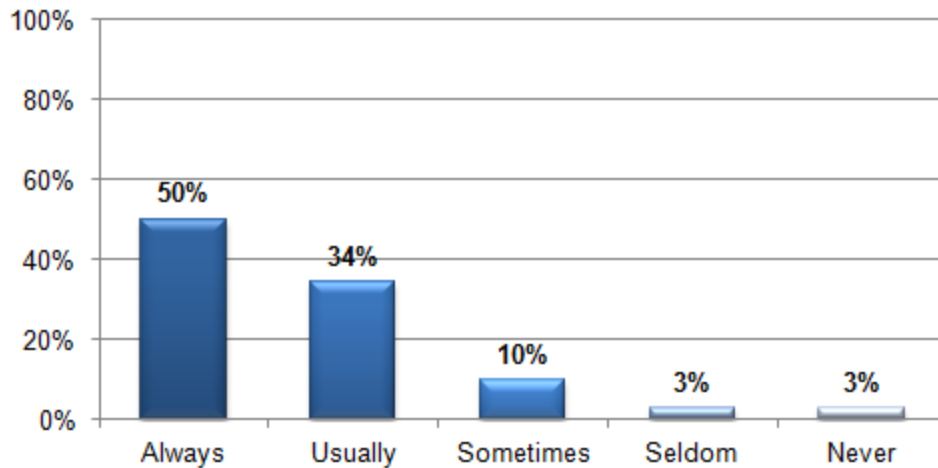


TABLE Q17. IF YOUR FAMILY MEMBER DOES NOT SPEAK ENGLISH OR USES A DIFFERENT WAY TO COMMUNICATE (FOR EXAMPLE, SIGN LANGUAGE), ARE THERE ENOUGH SUPPORT WORKERS AVAILABLE WHO CAN COMMUNICATE WITH HIM/HER?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|---------------------------------|------------|------------|------------|-----------|-----------|------------|
| Within NCI Average Range | | | | | | |
| MO | 60% | 31% | 6% | 2% | 2% | 65 |
| PA | 60% | 27% | 8% | 6% | 0% | 52 |
| OH | 57% | 31% | 10% | 0% | 2% | 99 |
| AZ | 55% | 29% | 13% | 0% | 4% | 55 |
| LA | 55% | 34% | 5% | 2% | 3% | 91 |
| NC | 53% | 37% | 10% | 0% | 0% | 49 |
| NM | 51% | 31% | 15% | 1% | 2% | 128 |
| FL | 46% | 36% | 14% | 1% | 1% | 69 |
| KY | 42% | 44% | 8% | 3% | 2% | 59 |
| NJ | 38% | 35% | 8% | 5% | 14% | 37 |
| GA | 35% | 43% | 10% | 10% | 1% | 69 |
| NCI Average | 50% | 34% | 10% | 3% | 3% | 773 |

Q18. If English is your family member's first language, do the support workers communicate with you effectively in English?

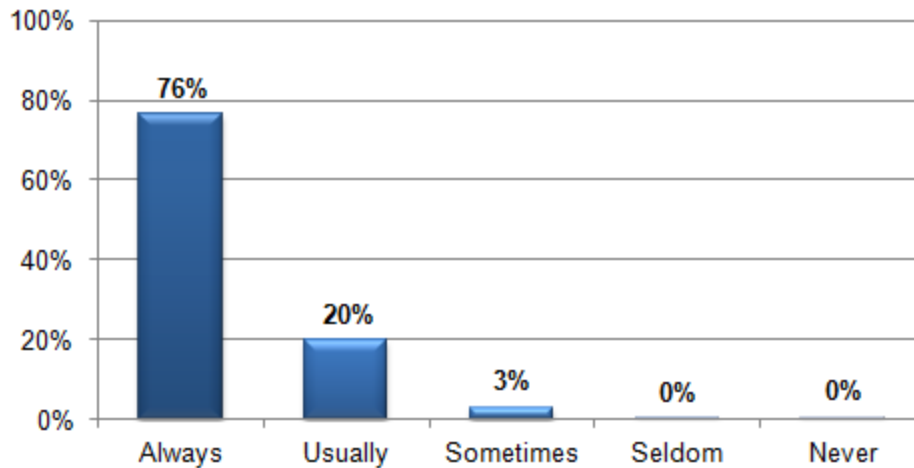


TABLE Q18. IF ENGLISH IS YOUR FAMILY MEMBER'S FIRST LANGUAGE, DO THE SUPPORT WORKERS COMMUNICATE WITH HIM/HER EFFECTIVELY IN HIS/HER PRIMARY LANGUAGE?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| PA | 83% | 13% | 3% | 0% | 0% | 212 |
| Within NCI Average Range | | | | | | |
| MO | 81% | 17% | 2% | 0% | 0% | 364 |
| FL | 81% | 16% | 2% | 0% | 1% | 253 |
| LA | 79% | 19% | 1% | 0% | 1% | 299 |
| NC | 78% | 19% | 3% | 0% | 0% | 183 |
| NM | 75% | 20% | 4% | 1% | 1% | 354 |
| AZ | 74% | 19% | 5% | 1% | 0% | 207 |
| OH | 74% | 20% | 6% | 0% | 1% | 372 |
| GA | 73% | 25% | 2% | 0% | 0% | 325 |
| NJ | 72% | 24% | 2% | 0% | 1% | 184 |
| KY | 69% | 26% | 4% | 0% | 0% | 234 |
| NCI Average | 76% | 20% | 3% | 0% | 0% | 2,987 |

Q19. Are services delivered to your family member in a manner that is respectful to your family member's culture(s)?

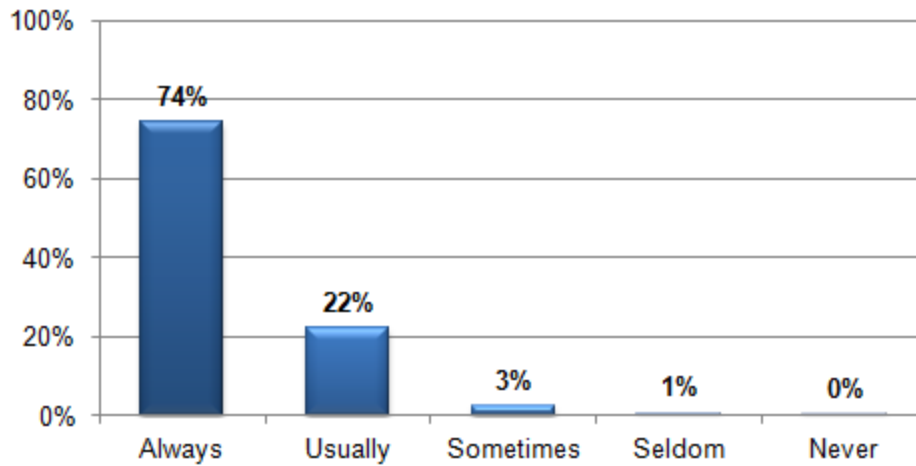


TABLE Q19. ARE SERVICES DELIVERED TO YOUR FAMILY MEMBER IN A MANNER THAT IS RESPECTFUL TO YOUR FAMILY MEMBER'S CULTURE(S)?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| FL | 83% | 16% | 0% | 0% | 0% | 252 |
| MO | 81% | 17% | 1% | 1% | 0% | 386 |
| Within NCI Average Range | | | | | | |
| PA | 77% | 22% | 0% | 0% | 0% | 215 |
| OH | 77% | 18% | 4% | 1% | 1% | 391 |
| LA | 77% | 21% | 2% | 1% | 0% | 325 |
| NC | 74% | 23% | 3% | 1% | 0% | 186 |
| NJ | 72% | 22% | 4% | 1% | 1% | 181 |
| KY | 72% | 25% | 3% | 0% | 0% | 240 |
| AZ | 71% | 26% | 2% | 1% | 0% | 214 |
| NM | 70% | 25% | 4% | 1% | 1% | 386 |
| Significantly Below NCI Average | | | | | | |
| GA | 63% | 29% | 6% | 1% | 1% | 344 |
| NCI Average | 74% | 22% | 3% | 1% | 0% | 3,120 |

Q20. Does your family member have access to the special equipment or accommodations needed?

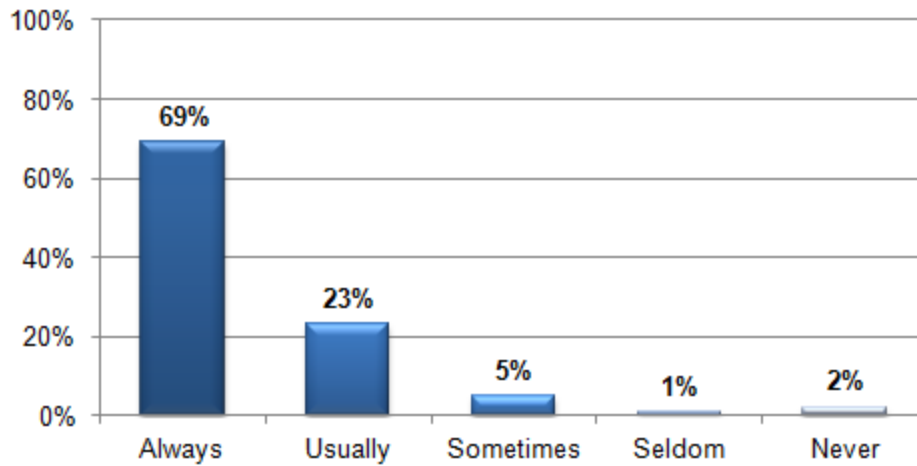


TABLE Q20. DOES YOUR FAMILY MEMBER HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT HE/SHE NEEDS (FOR EXAMPLE, WHEELCHAIRS, RAMPS, COMMUNICATION BOARDS)?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| OH | 80% | 12% | 5% | 1% | 2% | 270 |
| MO | 79% | 16% | 4% | 1% | 1% | 220 |
| Within NCI Average Range | | | | | | |
| LA | 74% | 20% | 3% | 1% | 2% | 244 |
| PA | 73% | 23% | 3% | 0% | 1% | 148 |
| NJ | 69% | 17% | 5% | 3% | 6% | 77 |
| NM | 69% | 24% | 4% | 1% | 1% | 283 |
| FL | 68% | 27% | 2% | 0% | 2% | 126 |
| AZ | 66% | 28% | 6% | 0% | 0% | 143 |
| KY | 65% | 26% | 7% | 1% | 1% | 167 |
| NC | 65% | 30% | 2% | 2% | 1% | 126 |
| Significantly Below NCI Average | | | | | | |
| GA | 54% | 31% | 9% | 2% | 4% | 241 |
| NCI Average | 69% | 23% | 5% | 1% | 2% | 2,045 |

Q21. Do you feel there is consistency with the support workers who provide services to your family member?

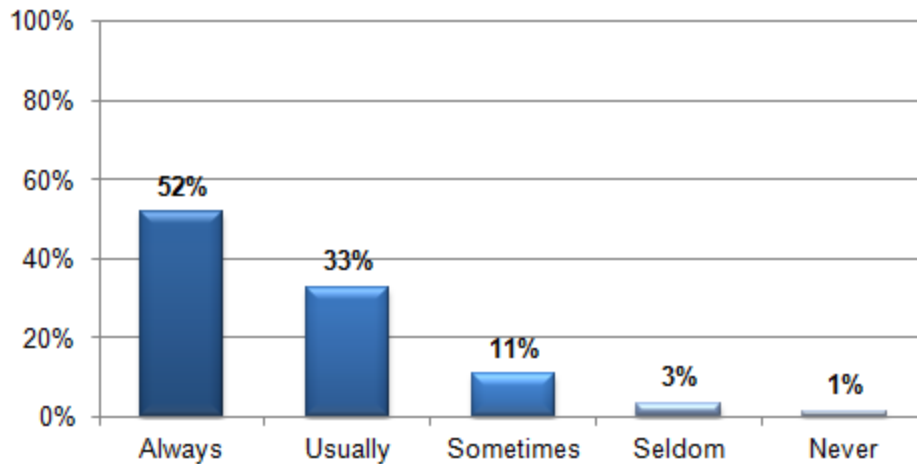


TABLE Q21. DO YOU FEEL THERE IS CONSISTENCY WITH THE SUPPORT WORKERS WHO PROVIDE SERVICES TO YOUR FAMILY MEMBER?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|------------|-----------|-----------|--------------|
| Significantly above NCI Average | | | | | | |
| MO | 61% | 25% | 8% | 4% | 2% | 397 |
| LA | 61% | 28% | 9% | 2% | 1% | 335 |
| Within NCI Average range | | | | | | |
| OH | 56% | 31% | 10% | 1% | 2% | 393 |
| FL | 54% | 20% | 19% | 7% | 0% | 251 |
| PA | 52% | 36% | 7% | 4% | 1% | 226 |
| GA | 52% | 33% | 12% | 2% | 2% | 362 |
| AZ | 50% | 33% | 10% | 4% | 3% | 229 |
| NC | 49% | 39% | 7% | 3% | 1% | 188 |
| KY | 48% | 37% | 11% | 2% | 2% | 252 |
| NM | 48% | 36% | 11% | 3% | 1% | 395 |
| Significantly below NCI Average | | | | | | |
| NJ | 37% | 41% | 15% | 5% | 2% | 195 |
| NCI Average | 52% | 33% | 11% | 3% | 1% | 3,223 |

Q22. Do the support workers have the right training to meet your family member's needs?

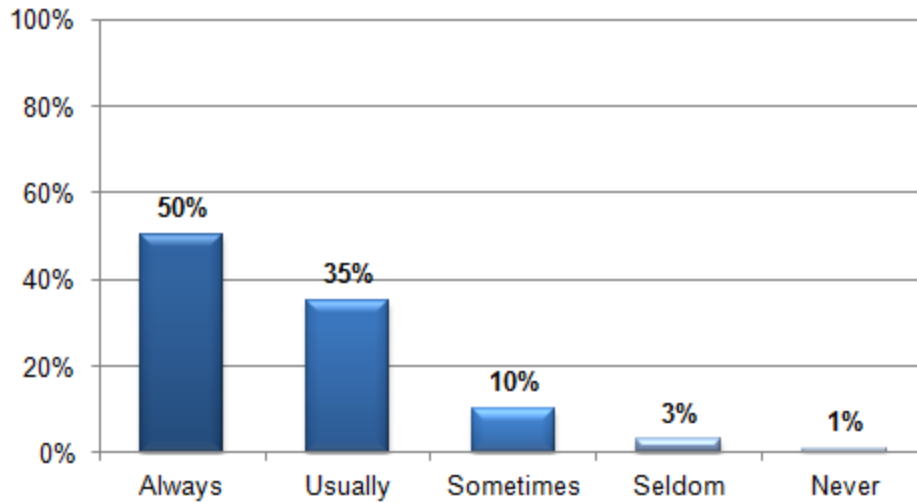
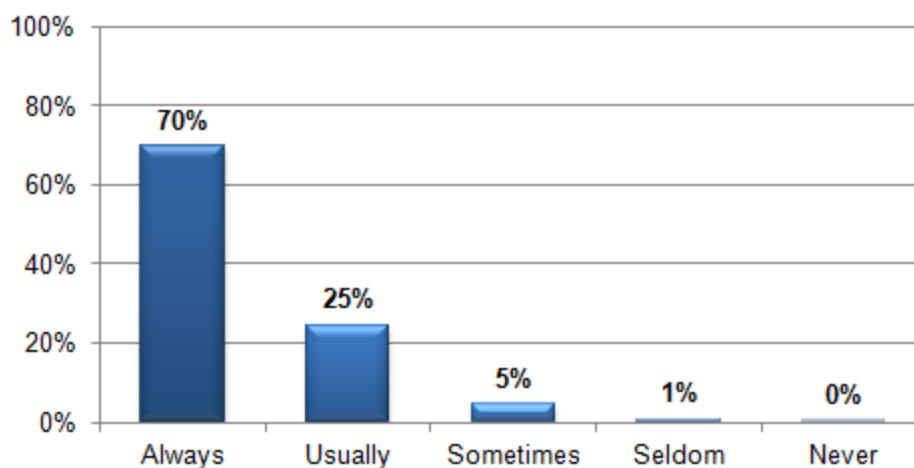


TABLE Q22. DO THE SUPPORT WORKERS HAVE THE RIGHT TRAINING TO MEET YOUR FAMILY MEMBER'S NEEDS?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| MO | 59% | 28% | 10% | 1% | 1% | 380 |
| Within NCI Average Range | | | | | | |
| LA | 57% | 33% | 8% | 3% | 0% | 313 |
| FL | 54% | 25% | 13% | 7% | 1% | 239 |
| PA | 53% | 38% | 8% | 0% | 0% | 208 |
| NC | 52% | 38% | 9% | 1% | 1% | 176 |
| OH | 51% | 33% | 14% | 2% | 1% | 384 |
| GA | 49% | 36% | 11% | 3% | 1% | 350 |
| NM | 49% | 39% | 10% | 1% | 1% | 353 |
| KY | 47% | 40% | 8% | 4% | 1% | 227 |
| AZ | 46% | 38% | 9% | 6% | 1% | 221 |
| Significantly Below NCI Average | | | | | | |
| NJ | 38% | 41% | 13% | 6% | 2% | 167 |
| NCI Average | 50% | 35% | 10% | 3% | 1% | 3,018 |

Q23. Do you feel that your family member's residential setting is a healthy and safe environment?



| TABLE Q23. DO YOU FEEL THAT YOUR FAMILY MEMBER'S RESIDENTIAL SETTING IS A HEALTHY AND SAFE ENVIRONMENT? | | | | | | |
|---|------------|------------|-----------|-----------|-----------|--------------|
| State | Always | Usually | Sometimes | Seldom | Never | N |
| Within NCI Average Range | | | | | | |
| MO | 76% | 22% | 2% | 0% | 1% | 395 |
| PA | 73% | 22% | 4% | 0% | 0% | 243 |
| OH | 73% | 21% | 5% | 1% | 0% | 394 |
| GA | 72% | 21% | 5% | 1% | 1% | 374 |
| AZ | 71% | 23% | 5% | 1% | 0% | 238 |
| LA | 70% | 25% | 2% | 2% | 0% | 365 |
| NC | 68% | 30% | 2% | 0% | 0% | 198 |
| FL | 67% | 23% | 9% | 0% | 0% | 264 |
| KY | 67% | 28% | 4% | 1% | 0% | 256 |
| NM | 66% | 27% | 5% | 2% | 1% | 399 |
| NJ | 63% | 27% | 8% | 1% | 0% | 205 |
| NCI Average | 70% | 25% | 5% | 1% | 0% | 3,331 |

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

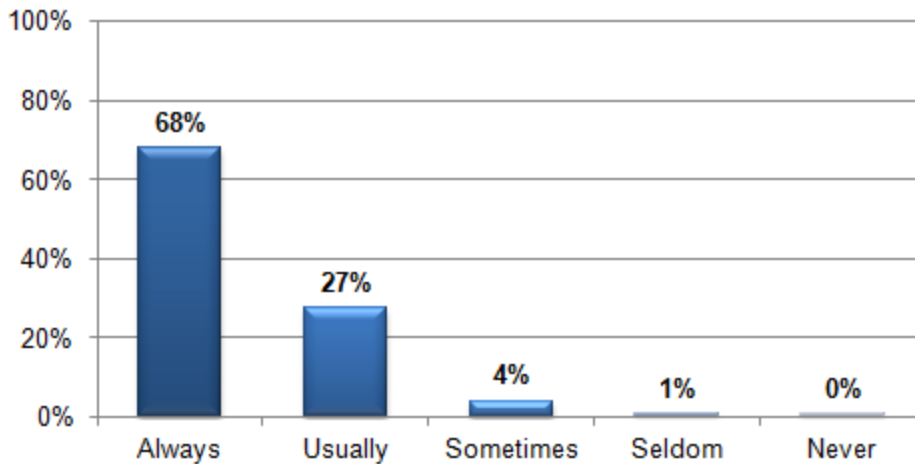


TABLE Q24. DO YOU FEEL THAT YOUR FAMILY MEMBER'S DAY/ EMPLOYMENT SETTING IS A HEALTHY AND SAFE ENVIRONMENT?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Within NCI Average Range | | | | | | |
| PA | 72% | 24% | 3% | 1% | 0% | 185 |
| MO | 72% | 26% | 2% | 0% | 0% | 288 |
| LA | 72% | 23% | 3% | 2% | 0% | 259 |
| OH | 71% | 23% | 5% | 1% | 0% | 369 |
| AZ | 69% | 26% | 4% | 0% | 0% | 208 |
| NC | 69% | 29% | 2% | 0% | 0% | 160 |
| KY | 66% | 28% | 5% | 1% | 0% | 213 |
| FL | 66% | 29% | 5% | 0% | 0% | 203 |
| NJ | 64% | 30% | 5% | 0% | 1% | 176 |
| NM | 63% | 33% | 2% | 1% | 2% | 326 |
| Significantly Below NCI Average | | | | | | |
| GA | 60% | 31% | 7% | 1% | 1% | 322 |
| NCI Average | 68% | 27% | 4% | 1% | 0% | 2,709 |

Q25. Were you happy with your family member's transition from school services to State funded services during the past year?

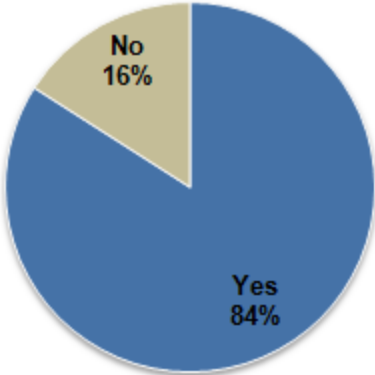


TABLE Q25. IF YOUR FAMILY MEMBER TRANSITIONED FROM SCHOOL SERVICES TO STATE FUNDED SERVICES DURING THE PAST YEAR, WERE YOU HAPPY WITH THE TRANSITION PROCESS?

| State ⁷ | Yes | No | N |
|--------------------|-----|-----|----|
| NCI Average | 84% | 16% | 97 |

⁷ All N's too small to report by State.

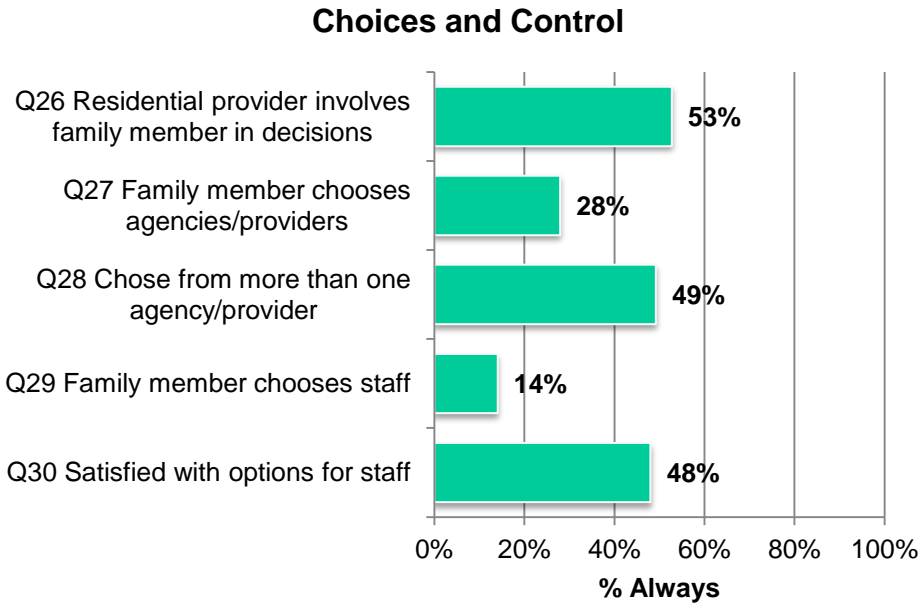
Choice and Control

Results from the 11 Choice and Control questions were lower compared to other sections. Most respondents reported that they and their family member had little input in choosing staff, provider organizations, and how to spend money from the ID/DD agency. Across states, just 15% of respondents or fewer reported:

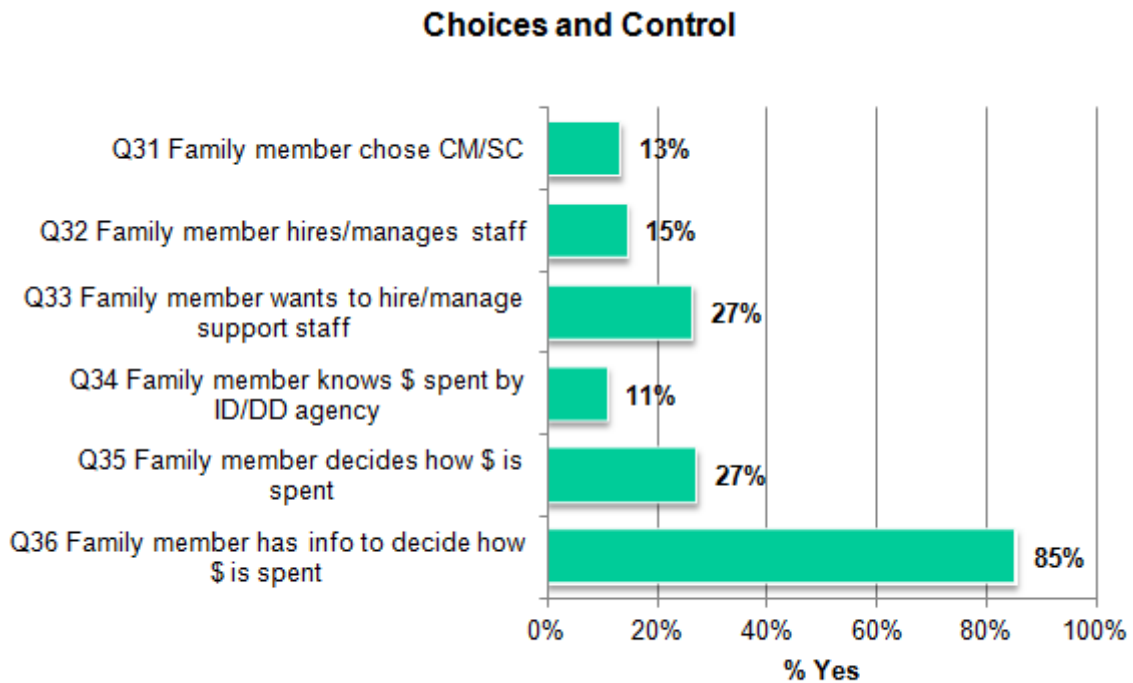
- Their family member knows how much money is spent by the ID/DD agency on his or her behalf, 11%; state average ranged between 6% and 18%.
- Their family member chose the case manager/service coordinator, 13%; state averages ranged between 1% and 45%.
- Their family member chooses the individual support workers, 14%; state averages ranged between 6% and 32%.
- Their family member has control and/or input over the hiring and management of support workers, 15%; state averages ranged between 2% and 38%.

Of the 27% of respondents whose family member has some input in how to spend his or her ID/DD agency money, 85% indicated their family member receives enough information to make this decision. Results from Florida and New Mexico were significantly above the NCI Average on five and four questions, respectively.

The graph below shows the NCI Average for questions with “always” responses.



The graph below shows the NCI Average for questions with “yes” responses.



Q26. Does the agency providing residential services to your family member involve your family member in important decisions?

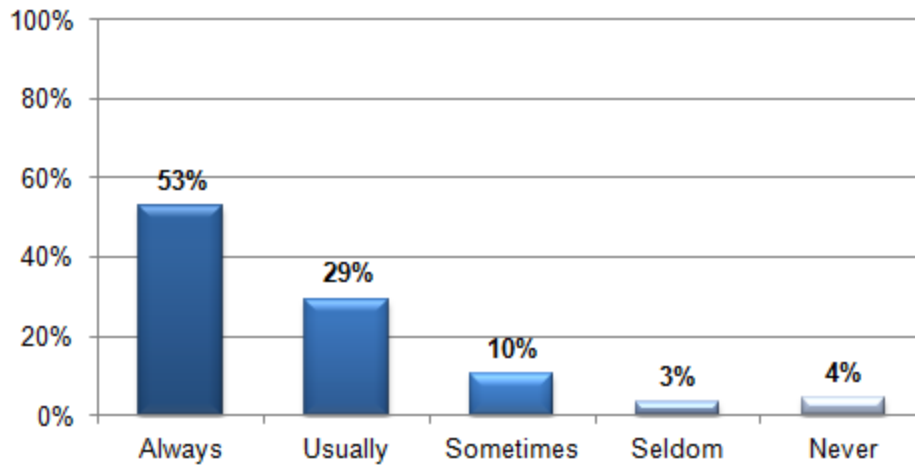


TABLE Q26. DOES THE AGENCY PROVIDING RESIDENTIAL SERVICES TO YOUR FAMILY MEMBER INVOLVE YOUR FAMILY MEMBER IN IMPORTANT DECISIONS?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| AZ | 63% | 25% | 8% | 2% | 3% | 208 |
| Within NCI Average Range | | | | | | |
| LA | 61% | 25% | 7% | 2% | 4% | 274 |
| NC | 57% | 27% | 10% | 1% | 5% | 166 |
| PA | 55% | 32% | 6% | 4% | 3% | 180 |
| KY | 53% | 34% | 8% | 3% | 2% | 218 |
| MO | 52% | 27% | 14% | 3% | 4% | 347 |
| NM | 52% | 33% | 9% | 3% | 3% | 357 |
| NJ | 49% | 31% | 12% | 3% | 5% | 165 |
| OH | 48% | 32% | 13% | 3% | 4% | 358 |
| GA | 47% | 30% | 12% | 4% | 7% | 317 |
| Significantly Below NCI Average | | | | | | |
| FL | 42% | 28% | 16% | 6% | 9% | 223 |
| NCI Average | 53% | 29% | 10% | 3% | 4% | 2,813 |

Q27. Does your family member choose the agencies or provider organizations that support him or her?

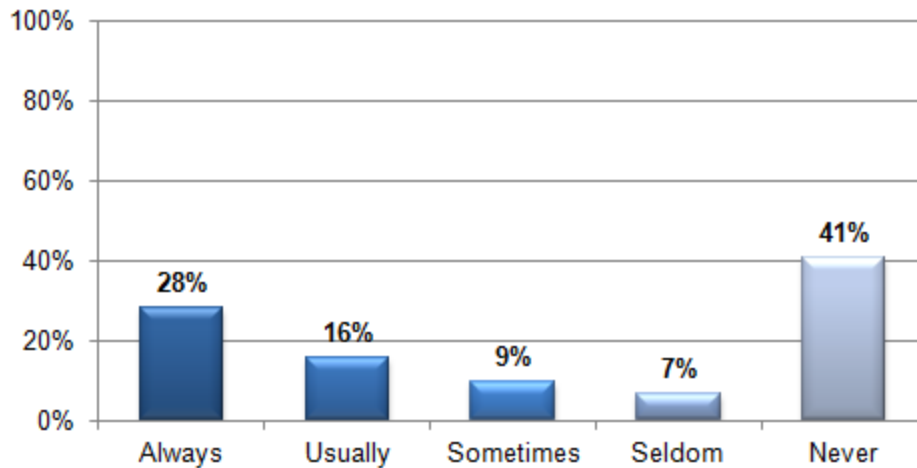


TABLE Q27. DOES YOUR FAMILY MEMBER CHOOSE THE AGENCIES OR PROVIDER ORGANIZATIONS THAT SUPPORT HIM OR HER?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|------------|--------------|
| Significantly Above NCI Average | | | | | | |
| NM | 37% | 18% | 11% | 7% | 27% | 315 |
| Within NCI Average Range | | | | | | |
| LA | 35% | 12% | 4% | 3% | 46% | 203 |
| AZ | 32% | 14% | 9% | 9% | 36% | 162 |
| OH | 30% | 20% | 10% | 5% | 34% | 352 |
| FL | 28% | 23% | 8% | 8% | 33% | 229 |
| KY | 27% | 16% | 11% | 8% | 39% | 179 |
| GA | 27% | 15% | 9% | 8% | 41% | 264 |
| NC | 25% | 16% | 12% | 5% | 42% | 146 |
| PA | 25% | 13% | 13% | 6% | 44% | 125 |
| MO | 22% | 14% | 9% | 6% | 49% | 312 |
| NJ | 19% | 12% | 7% | 7% | 54% | 114 |
| NCI Average | 28% | 16% | 9% | 7% | 41% | 2,401 |

Q28. Does your family member choose from more than one agency/provider organization?

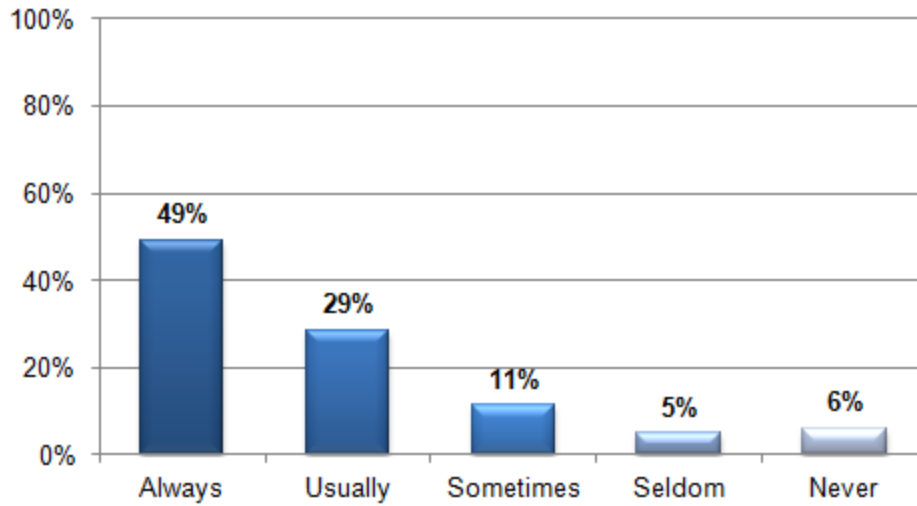


TABLE Q28. IF YOUR FAMILY MEMBER AT LEAST SOMETIMES CHOOSES THE AGENCIES OR PROVIDER ORGANIZATIONS, DOES S/HE HAVE MORE THAN ONE AGENCY/PROVIDER ORGANIZATION TO CHOOSE FROM?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|---------------------------------|------------|------------|------------|-----------|-----------|--------------|
| Within NCI Average Range | | | | | | |
| LA | 62% | 29% | 4% | 1% | 4% | 79 |
| FL | 60% | 30% | 5% | 4% | 2% | 104 |
| OH | 53% | 23% | 14% | 5% | 6% | 199 |
| NM | 52% | 36% | 8% | 2% | 3% | 180 |
| AZ | 50% | 26% | 8% | 8% | 9% | 66 |
| PA | 50% | 23% | 11% | 9% | 7% | 44 |
| KY | 49% | 25% | 13% | 5% | 8% | 77 |
| NC | 49% | 33% | 11% | 7% | 0% | 61 |
| MO | 48% | 28% | 17% | 3% | 4% | 109 |
| GA | 38% | 35% | 13% | 5% | 9% | 105 |
| NJ | 31% | 27% | 19% | 8% | 15% | 26 |
| NCI Average | 49% | 29% | 11% | 5% | 6% | 1,050 |

Q29. Does your family member choose the individual support workers who work directly with him/her?

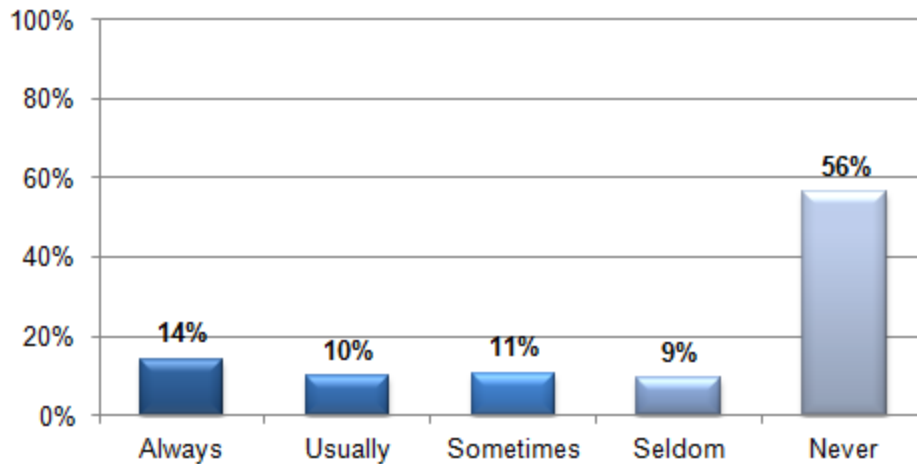


TABLE Q29. DOES YOUR FAMILY MEMBER CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH HIM/HER?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|------------|-----------|------------|--------------|
| Significantly Above NCI Average | | | | | | |
| FL | 32% | 15% | 8% | 1% | 44% | 197 |
| Within NCI Average Range | | | | | | |
| OH | 17% | 9% | 15% | 9% | 50% | 356 |
| GA | 15% | 14% | 10% | 8% | 52% | 243 |
| LA | 15% | 9% | 11% | 8% | 57% | 195 |
| PA | 15% | 10% | 7% | 12% | 57% | 129 |
| NM | 14% | 11% | 18% | 13% | 44% | 294 |
| AZ | 12% | 8% | 4% | 9% | 67% | 156 |
| NC | 10% | 16% | 10% | 14% | 49% | 138 |
| MO | 9% | 7% | 9% | 10% | 65% | 290 |
| KY | 9% | 5% | 18% | 11% | 57% | 175 |
| Significantly Below NCI Average | | | | | | |
| NJ | 6% | 5% | 6% | 8% | 76% | 123 |
| NCI Average | 14% | 10% | 11% | 9% | 56% | 2,296 |

Q30. Is your family member satisfied with the choices for support workers?

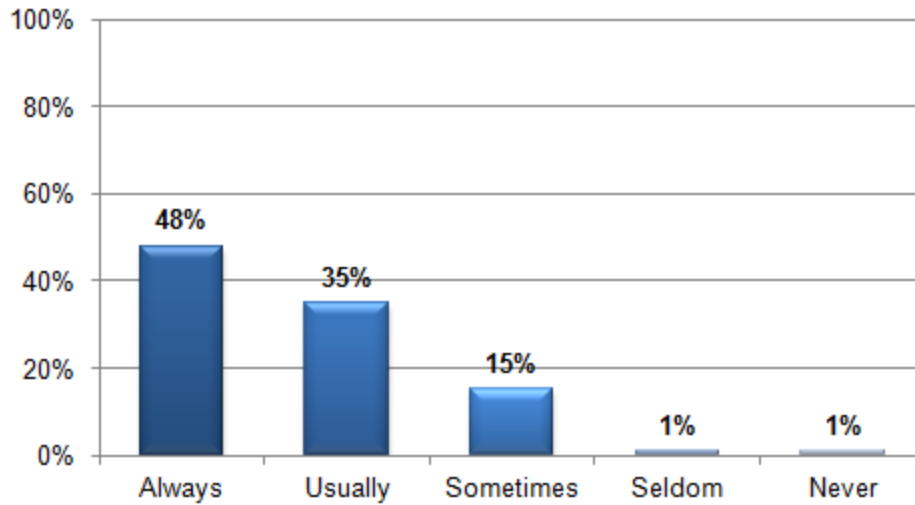
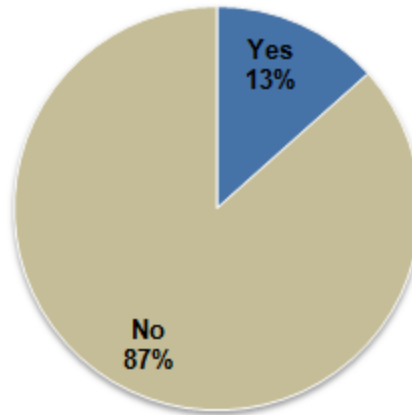


TABLE Q30. IF YOUR FAMILY MEMBER AT LEAST SOMETIMES CHOOSES THE SUPPORT WORKERS, IS S/HE SATISFIED WITH THE OPTIONS AVAILABLE?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|---------------------------------|------------|------------|------------|-----------|-----------|------------|
| Within NCI Average Range | | | | | | |
| FL | 55% | 29% | 15% | 1% | 0% | 105 |
| AZ | 53% | 30% | 18% | 0% | 0% | 40 |
| PA | 49% | 29% | 15% | 5% | 2% | 41 |
| MO | 49% | 36% | 13% | 0% | 3% | 72 |
| OH | 48% | 33% | 16% | 3% | 1% | 147 |
| LA | 48% | 41% | 8% | 0% | 3% | 61 |
| KY | 45% | 35% | 20% | 0% | 0% | 55 |
| NM | 45% | 37% | 17% | 0% | 1% | 122 |
| NC | 45% | 41% | 12% | 0% | 2% | 49 |
| GA | 45% | 42% | 11% | 0% | 2% | 92 |
| NCI Average | 48% | 35% | 15% | 1% | 1% | 784 |

Q31. Did your family member choose his/her case manager/service coordinator?



| TABLE Q31. DID YOUR FAMILY MEMBER CHOOSE HIS/HER CASE MANAGER/SERVICE COORDINATOR? | | | |
|---|------------|------------|--------------|
| State | Yes | No | N |
| Significantly Above NCI Average | | | |
| FL | 45% | 55% | 212 |
| NM | 25% | 75% | 324 |
| Within NCI Average Range | | | |
| NC | 16% | 84% | 158 |
| OH | 11% | 89% | 348 |
| KY | 11% | 89% | 205 |
| GA | 10% | 90% | 300 |
| LA | 10% | 90% | 240 |
| PA | 8% | 92% | 170 |
| Significantly Below NCI Average | | | |
| AZ | 6% | 94% | 194 |
| MO | 5% | 95% | 337 |
| NJ | 1% | 99% | 162 |
| NCI Average | 13% | 87% | 2,650 |

Q32. Does your family member have control and/or input over the hiring and management of his/her support workers?

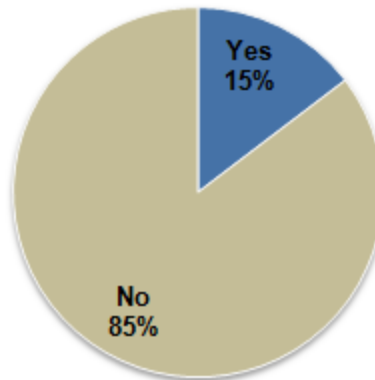


TABLE Q32. DOES YOUR FAMILY MEMBER HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF HIS/HER SUPPORT WORKERS?

| State | Yes | No | N |
|--|------------|------------|--------------|
| Significantly Above NCI Average | | | |
| FL | 38% | 62% | 194 |
| NM | 25% | 75% | 320 |
| Within NCI Average Range | | | |
| OH | 19% | 81% | 366 |
| LA | 16% | 84% | 247 |
| NC | 14% | 86% | 153 |
| GA | 12% | 88% | 287 |
| PA | 9% | 91% | 166 |
| AZ | 9% | 91% | 178 |
| Significantly Below NCI Average | | | |
| MO | 10% | 90% | 337 |
| KY | 7% | 93% | 199 |
| NJ | 2% | 98% | 164 |
| NCI Average | 15% | 85% | 2,611 |

Q33. Does your family member want control and/or input over the hiring and management of support workers?

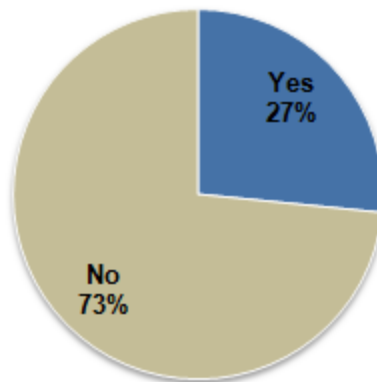


TABLE Q33. DOES YOUR FAMILY MEMBER WANT TO HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF HIS/HER SUPPORT WORKERS?

| State | Yes | No | N |
|--|------------|------------|--------------|
| Significantly Above NCI Average | | | |
| FL | 46% | 54% | 188 |
| Within NCI Average Range | | | |
| NM | 36% | 64% | 239 |
| OH | 30% | 70% | 337 |
| NC | 27% | 73% | 127 |
| LA | 26% | 74% | 215 |
| GA | 25% | 75% | 237 |
| MO | 24% | 76% | 240 |
| NJ | 23% | 77% | 115 |
| KY | 21% | 79% | 169 |
| AZ | 21% | 79% | 154 |
| Significantly Below NCI Average | | | |
| PA | 15% | 85% | 138 |
| NCI Average | 27% | 73% | 2,159 |

Q34. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?

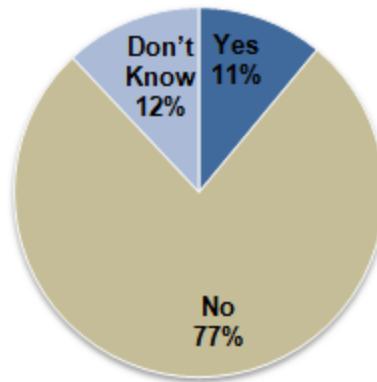
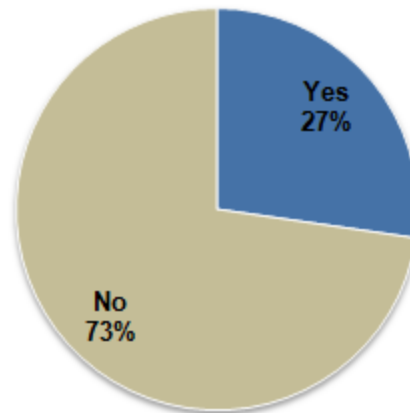


TABLE Q34. DOES YOUR FAMILY MEMBER KNOW HOW MUCH MONEY IS SPENT BY THE ID/DD AGENCY ON HIS/HER BEHALF?

| State | Yes | No | Don't Know | N |
|--|------------|------------|------------|--------------|
| Within NCI Average Range | | | | |
| FL | 18% | 73% | 10% | 228 |
| NM | 15% | 71% | 14% | 374 |
| GA | 14% | 74% | 12% | 351 |
| KY | 12% | 79% | 9% | 227 |
| OH | 12% | 81% | 8% | 398 |
| AZ | 11% | 79% | 10% | 208 |
| LA | 9% | 73% | 18% | 307 |
| NC | 8% | 80% | 13% | 176 |
| PA | 8% | 75% | 17% | 214 |
| NJ | 7% | 85% | 8% | 178 |
| Significantly Below NCI Average | | | | |
| MO | 6% | 81% | 13% | 380 |
| NCI Average | 11% | 77% | 12% | 3,041 |

Q35. Does your family member have a say in how ID/DD agency money is spent?



| TABLE Q35. DOES YOUR FAMILY MEMBER HAVE A SAY IN HOW THIS MONEY IS SPENT? | | | |
|--|------------|------------|--------------|
| State | Yes | No | N |
| Significantly Above NCI Average | | | |
| OH | 38% | 62% | 356 |
| NM | 37% | 63% | 303 |
| Within NCI Average Range | | | |
| FL | 30% | 70% | 178 |
| KY | 27% | 73% | 196 |
| NC | 26% | 74% | 152 |
| LA | 26% | 74% | 240 |
| GA | 26% | 74% | 294 |
| NJ | 24% | 76% | 146 |
| PA | 23% | 77% | 156 |
| MO | 23% | 77% | 306 |
| AZ | 21% | 79% | 194 |
| NCI Average | 27% | 73% | 2,521 |

Q36. Does your family member have the information needed to decide how to spend ID/DD agency money?

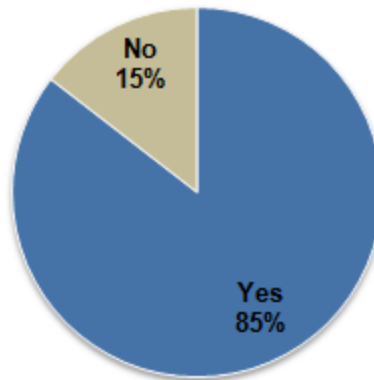


TABLE Q36. IF "YES" (TO Q35), DOES YOUR FAMILY MEMBER HAVE ALL THE INFORMATION S/HE NEEDS TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?

| State | Yes | No | N |
|--|------------|------------|------------|
| Significantly Above NCI Average | | | |
| PA | 96% | 4% | 28 |
| FL | 96% | 4% | 45 |
| Within NCI Average Range | | | |
| AZ | 93% | 7% | 29 |
| MO | 91% | 9% | 54 |
| OH | 87% | 13% | 123 |
| LA | 86% | 14% | 51 |
| KY | 83% | 17% | 48 |
| NC | 80% | 20% | 30 |
| cNJ | 77% | 23% | 26 |
| GA | 77% | 23% | 60 |
| NM | 74% | 26% | 93 |
| NCI Average | 85% | 15% | 587 |

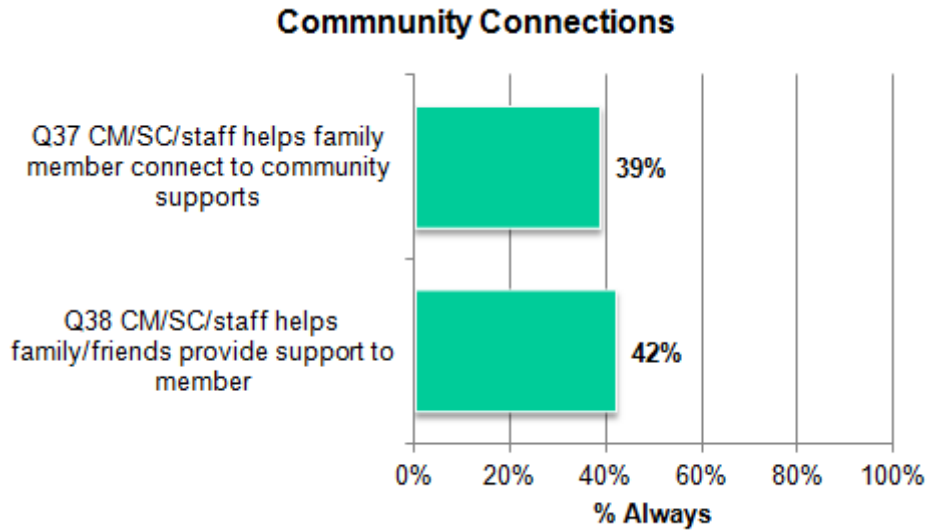
Community Connections

Across states, the results from the five Community Connection questions were relatively positive. For the three questions, at least two-thirds of respondents across states answer in the affirmative that:

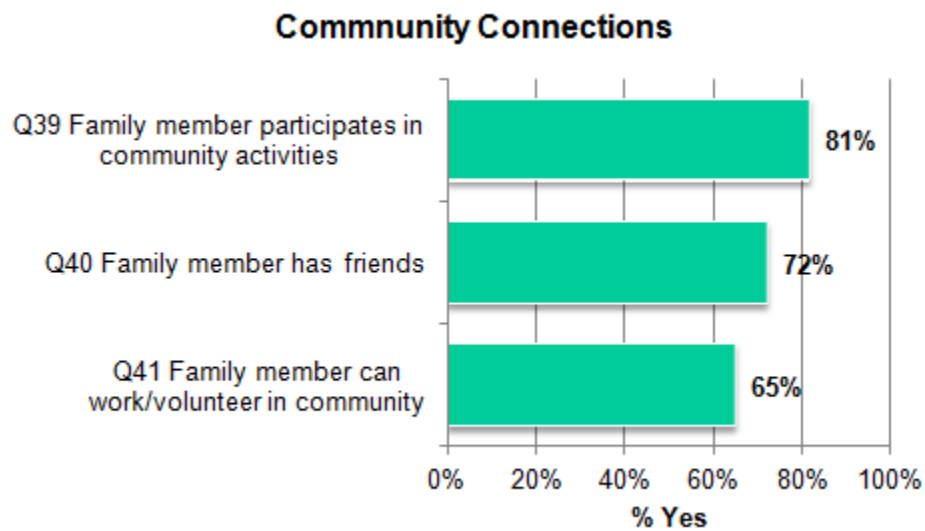
- Their family member participates in community activities, 81%; state averages ranged between 65% and 90%.
- Their family member has friends or relationships with persons other than paid staff or other family members, 72%; state averages ranged between 62% and 80%.
- Their family member has enough support to work or volunteer in the community, 65%; state averages ranged between 53% and 76%.

Missouri rated significantly above the NCI Average on three of the five questions.

The graph below shows the NCI Average for questions with “always” responses.



The graph below shows the NCI Average for questions with “yes” responses.



Q37. Does the case manager/service coordinator or the support workers help connect your family member to community supports?

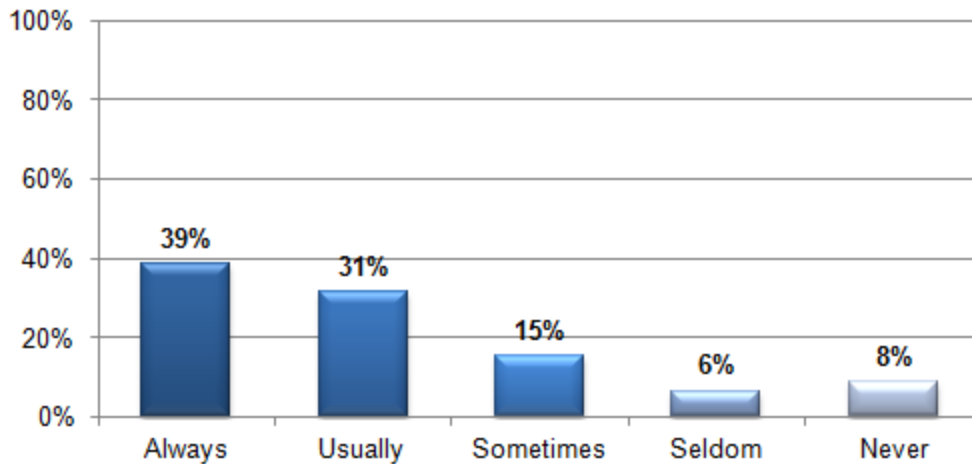


TABLE Q37. IF YOUR FAMILY MEMBER WANTS TO USE TYPICAL SUPPORTS IN YOUR COMMUNITY (FOR EXAMPLE, THROUGH RECREATION DEPARTMENTS OR CHURCHES), DO EITHER THE CASE MANAGER/SERVICE COORDINATOR WHO HELPS PLAN OR THE SUPPORT WORKERS WHO PROVIDE SUPPORT HELP CONNECT HIM/HER TO THESE SUPPORTS?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|------------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| MO | 51% | 26% | 12% | 6% | 5% | 310 |
| Within NCI Average Range | | | | | | |
| PA | 46% | 33% | 8% | 4% | 8% | 130 |
| NM | 45% | 32% | 13% | 5% | 6% | 334 |
| LA | 41% | 33% | 10% | 6% | 9% | 205 |
| GA | 41% | 29% | 12% | 8% | 11% | 240 |
| FL | 36% | 33% | 19% | 5% | 7% | 193 |
| OH | 36% | 30% | 23% | 5% | 7% | 240 |
| NC | 35% | 39% | 16% | 3% | 8% | 141 |
| AZ | 34% | 27% | 21% | 8% | 10% | 155 |
| KY | 30% | 31% | 20% | 11% | 7% | 174 |
| NJ | 29% | 32% | 13% | 11% | 16% | 114 |
| NCI Average | 39% | 31% | 15% | 6% | 8% | 2,236 |

Q38. Does the case manager/service coordinator or the support workers help family, friends, and neighbors provide support?

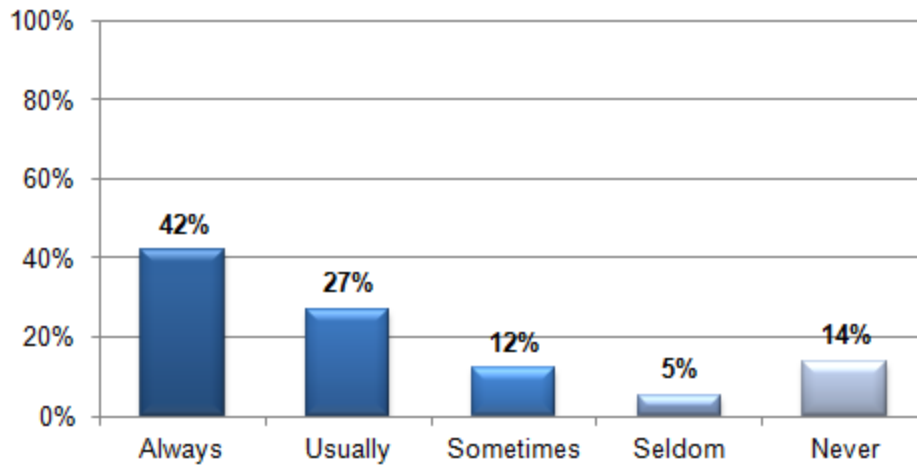
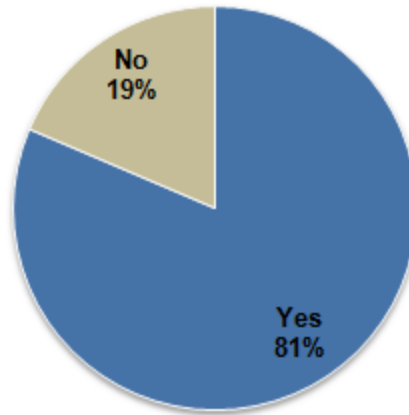


TABLE Q38. IF YOUR FAMILY MEMBER WOULD LIKE TO USE FAMILY, FRIENDS, OR NEIGHBORS TO PROVIDE SOME OF THE SUPPORTS S/HE NEEDS, DO EITHER THE CASE MANAGER/SERVICE COORDINATOR WHO HELPS PLAN OR THE SUPPORT WORKERS WHO PROVIDE SUPPORT HELP HIM/HER DO THIS?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|---------------------------------|------------|------------|------------|-----------|------------|--------------|
| Within NCI Average Range | | | | | | |
| FL | 52% | 15% | 18% | 3% | 12% | 164 |
| NM | 48% | 25% | 11% | 5% | 11% | 276 |
| PA | 46% | 26% | 9% | 5% | 15% | 109 |
| GA | 46% | 24% | 8% | 7% | 15% | 239 |
| LA | 44% | 31% | 8% | 5% | 11% | 171 |
| MO | 42% | 23% | 13% | 7% | 15% | 227 |
| KY | 40% | 35% | 9% | 4% | 11% | 140 |
| OH | 38% | 29% | 19% | 7% | 7% | 231 |
| AZ | 37% | 26% | 14% | 7% | 16% | 132 |
| NC | 35% | 36% | 12% | 2% | 15% | 110 |
| NJ | 33% | 26% | 10% | 6% | 24% | 99 |
| NCI Average | 42% | 27% | 12% | 5% | 14% | 1,898 |

Q39. Does your family member participate in community activities?



| TABLE Q39. DOES YOUR FAMILY MEMBER PARTICIPATE IN COMMUNITY ACTIVITIES? | | | |
|--|------------|------------|--------------|
| State | Yes | No | N |
| Significantly Above NCI Average | | | |
| FL | 90% | 10% | 221 |
| NC | 89% | 11% | 175 |
| NM | 87% | 13% | 364 |
| MO | 86% | 14% | 368 |
| Within NCI Average Range | | | |
| KY | 81% | 19% | 211 |
| AZ | 81% | 19% | 203 |
| LA | 80% | 20% | 282 |
| PA | 80% | 21% | 200 |
| GA | 79% | 21% | 327 |
| OH | 77% | 23% | 388 |
| Significantly Below NCI Average | | | |
| NJ | 65% | 35% | 168 |
| NCI Average | 81% | 19% | 2,907 |

Q40. Does your family member have friends or relationships with persons other than support workers or family?

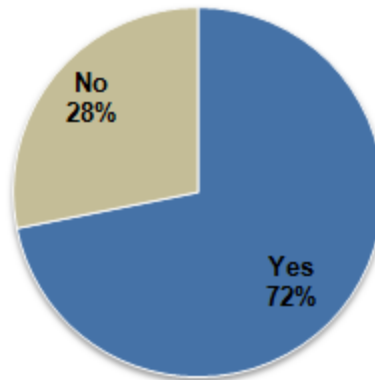
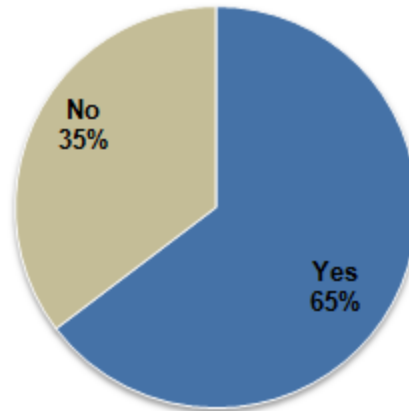


TABLE Q40. DOES YOUR FAMILY MEMBER HAVE FRIENDS OR RELATIONSHIPS WITH PERSONS OTHER THAN PAID STAFF OR OTHER FAMILY MEMBERS?

| State | Yes | No | N |
|--|------------|------------|--------------|
| Within NCI Average Range | | | |
| FL | 80% | 20% | 203 |
| NM | 75% | 25% | 314 |
| OH | 75% | 25% | 389 |
| AZ | 75% | 25% | 204 |
| GA | 74% | 26% | 324 |
| PA | 73% | 27% | 175 |
| NC | 73% | 27% | 171 |
| MO | 71% | 29% | 344 |
| NJ | 67% | 33% | 160 |
| KY | 66% | 34% | 186 |
| Significantly Below NCI Average | | | |
| LA | 62% | 38% | 269 |
| NCI Average | 72% | 28% | 2,739 |

Q41. Does your family member have enough supports to work or volunteer in the community?



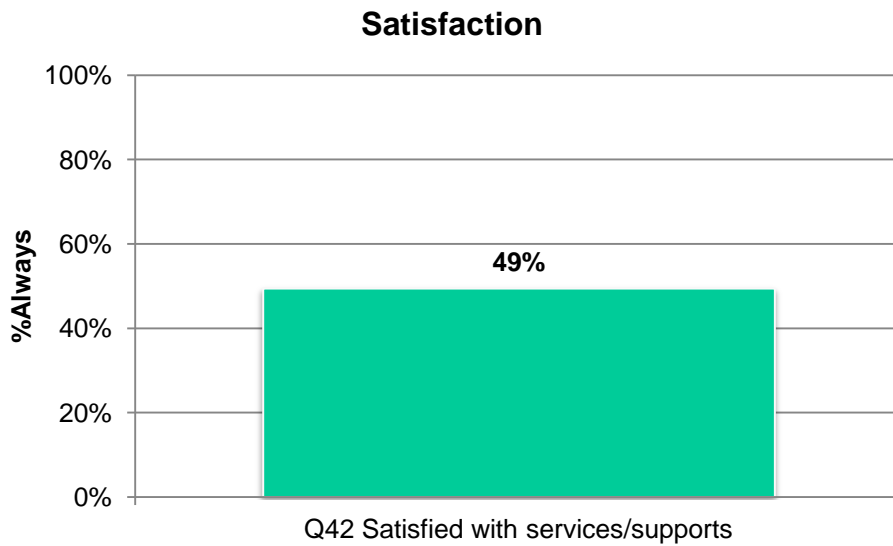
| TABLE Q41. DOES YOUR FAMILY MEMBER HAVE ENOUGH SUPPORT (E.G., SUPPORT WORKERS, COMMUNITY RESOURCES) TO WORK OR VOLUNTEER IN THE COMMUNITY? | | | |
|---|------------|------------|--------------|
| State | Yes | No | N |
| Significantly Above NCI Average | | | |
| MO | 76% | 24% | 283 |
| Within NCI Average Range | | | |
| NC | 70% | 30% | 132 |
| GA | 70% | 30% | 251 |
| OH | 69% | 31% | 344 |
| FL | 69% | 31% | 160 |
| NM | 67% | 33% | 269 |
| PA | 62% | 38% | 126 |
| LA | 58% | 42% | 195 |
| AZ | 58% | 42% | 146 |
| KY | 58% | 42% | 134 |
| NJ | 53% | 47% | 108 |
| NCI Average | 65% | 35% | 2,148 |

Satisfaction with Services and Supports

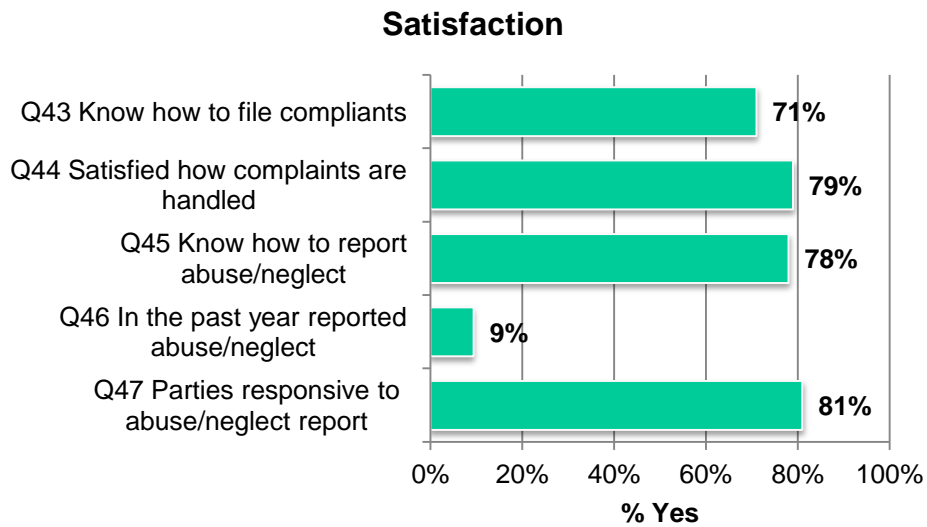
The results across six Satisfaction questions varied. Just less than half (49%) of respondents across states reported that they were always satisfied with services and supports. However, results relating to filing complaints or reporting of abuse and neglect were more positive. Ohio rated significantly above the NCI Average on three questions.

Overall, 71% of respondents reported that they were aware of how to file a grievance or complaint against a provider or staff, and 78% knew how to report abuse and neglect. Most reported that they were satisfied with how grievances and complaints were resolved (79%) and that appropriate parties were responsive to reports of abuse and neglect (81%).

The graph below shows the NCI Average for the one question with an “always” response.



The graph below shows the NCI Average for questions with “yes” responses.



Q42. Overall, are you satisfied with the services and supports your family member currently receives?

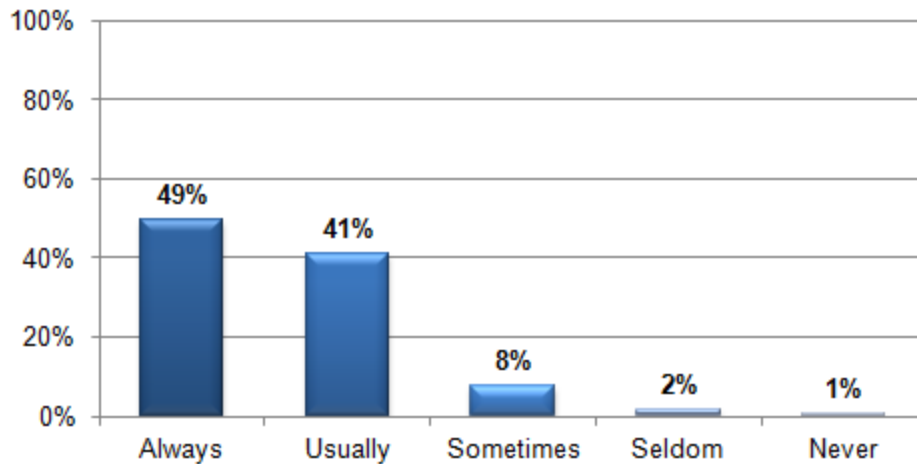


TABLE Q42. OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER CURRENTLY RECEIVES?

| State | Always | Usually | Sometimes | Seldom | Never | N |
|--|------------|------------|-----------|-----------|-----------|--------------|
| Significantly Above NCI Average | | | | | | |
| MO | 61% | 33% | 4% | 1% | 0% | 404 |
| LA | 57% | 35% | 6% | 2% | 1% | 363 |
| Within NCI Average Range | | | | | | |
| OH | 53% | 38% | 7% | 1% | 1% | 394 |
| GA | 51% | 40% | 7% | 1% | 1% | 376 |
| PA | 50% | 43% | 5% | 1% | 1% | 232 |
| FL | 50% | 40% | 7% | 2% | 0% | 281 |
| NM | 48% | 41% | 9% | 0% | 1% | 403 |
| AZ | 47% | 43% | 7% | 2% | 0% | 229 |
| KY | 46% | 42% | 9% | 2% | 0% | 245 |
| NC | 45% | 45% | 8% | 2% | 1% | 195 |
| Significantly Below NCI Average | | | | | | |
| NJ | 35% | 48% | 15% | 2% | 1% | 193 |
| NCI Average | 49% | 41% | 8% | 2% | 1% | 3,315 |

Q43. Are you familiar with the process for filing a complaint or against your provider agency/agencies or staff that provide services?

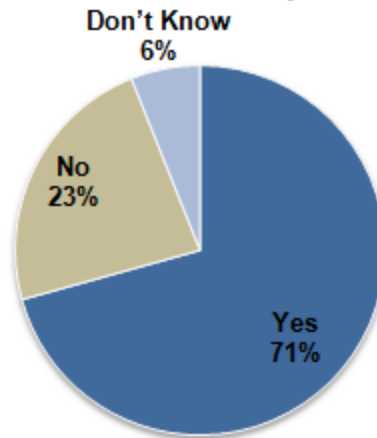


TABLE Q43. ARE YOU FAMILIAR WITH THE PROCESS FOR FILING A COMPLAINT OR GRIEVANCE REGARDING PROBLEMS WITH YOUR FAMILY MEMBER'S PROVIDER AGENCY/AGENCIES OR STAFF THAT PROVIDE SERVICES?

| State | Yes | No | Don't Know | N |
|--|------------|------------|------------|--------------|
| Significantly Above NCI Average | | | | |
| OH | 82% | 16% | 2% | 398 |
| NM | 81% | 15% | 5% | 400 |
| NC | 79% | 16% | 5% | 193 |
| Within NCI Average Range | | | | |
| KY | 75% | 20% | 5% | 238 |
| AZ | 73% | 22% | 5% | 230 |
| MO | 71% | 23% | 6% | 403 |
| FL | 71% | 24% | 5% | 265 |
| LA | 70% | 25% | 5% | 360 |
| Significantly Below NCI Average | | | | |
| PA | 60% | 25% | 15% | 232 |
| GA | 59% | 32% | 9% | 373 |
| NJ | 55% | 37% | 8% | 204 |
| NCI Average | 71% | 23% | 6% | 3,296 |

Q44. Are you satisfied with the way complaints/grievances regarding provider agencies or staff are handled and resolved?

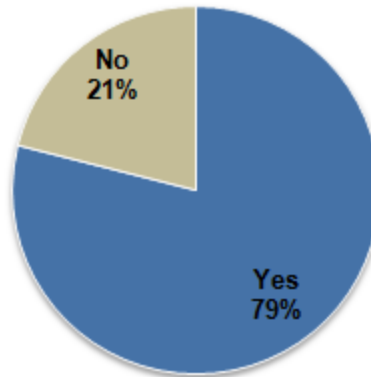
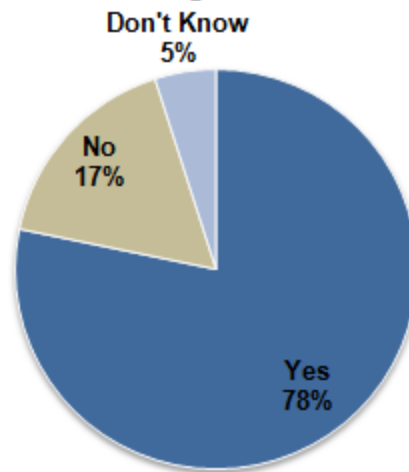


TABLE Q44. ARE YOU SATISFIED WITH THE WAY COMPLAINTS/GRIEVANCES REGARDING PROVIDER AGENCIES OR STAFF ARE HANDLED AND RESOLVED?

| State | Yes | No | N |
|--|------------|------------|--------------|
| Significantly Above NCI Average | | | |
| OH | 91% | 9% | 310 |
| Within NCI Average Range | | | |
| FL | 84% | 16% | 169 |
| LA | 83% | 17% | 245 |
| NC | 81% | 19% | 132 |
| MO | 80% | 20% | 253 |
| NM | 79% | 21% | 293 |
| PA | 78% | 22% | 133 |
| KY | 77% | 23% | 167 |
| AZ | 77% | 23% | 136 |
| GA | 75% | 25% | 231 |
| Significantly Below NCI Average | | | |
| NJ | 62% | 38% | 109 |
| NCI Average | 79% | 21% | 2,178 |

Q45. Do you know how to report abuse and neglect?



| TABLE Q45. DO YOU KNOW HOW TO REPORT ABUSE AND NEGLECT? | | | | |
|---|------------|------------|------------|--------------|
| State | Yes | No | Don't Know | N |
| Significantly Above NCI Average | | | | |
| OH | 86% | 13% | 1% | 398 |
| NM | 86% | 12% | 3% | 396 |
| Within NCI Average Range | | | | |
| NC | 84% | 11% | 5% | 191 |
| AZ | 83% | 13% | 4% | 228 |
| MO | 81% | 14% | 5% | 395 |
| KY | 81% | 13% | 6% | 236 |
| FL | 80% | 16% | 4% | 285 |
| LA | 79% | 18% | 3% | 354 |
| Significantly Below NCI Average | | | | |
| GA | 72% | 22% | 6% | 369 |
| PA | 68% | 22% | 10% | 231 |
| NJ | 64% | 29% | 7% | 194 |
| NCI Average | 78% | 17% | 5% | 3,277 |

Q46. In the past year, did you report abuse and neglect?

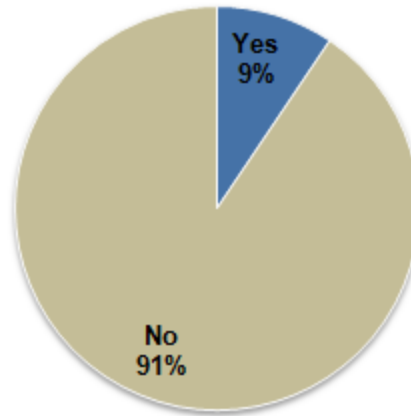
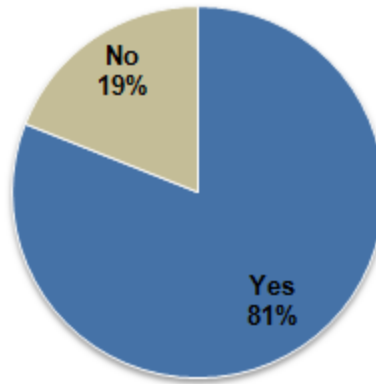


TABLE Q46. IN THE PAST YEAR, DID YOU REPORT ABUSE AND NEGLECT? ⁸

| State | Yes | No | N |
|--|-----------|------------|--------------|
| Significantly Above NCI Average | | | |
| FL | 17% | 83% | 205 |
| Within NCI Average Range | | | |
| AZ | 16% | 84% | 204 |
| NM | 11% | 89% | 319 |
| MO | 11% | 89% | 340 |
| GA | 11% | 89% | 314 |
| LA | 8% | 92% | 305 |
| KY | 8% | 92% | 186 |
| NC | 7% | 93% | 172 |
| PA | 6% | 94% | 196 |
| OH | 6% | 94% | 396 |
| NJ | 5% | 95% | 171 |
| NCI Average | 9% | 91% | 2,808 |

⁸ For this question, states who are “significantly below NCI average” could be seen as having the more positive outcomes

Q47. If you reported abuse or neglect in the past year, were the appropriate parties responsive to your report?



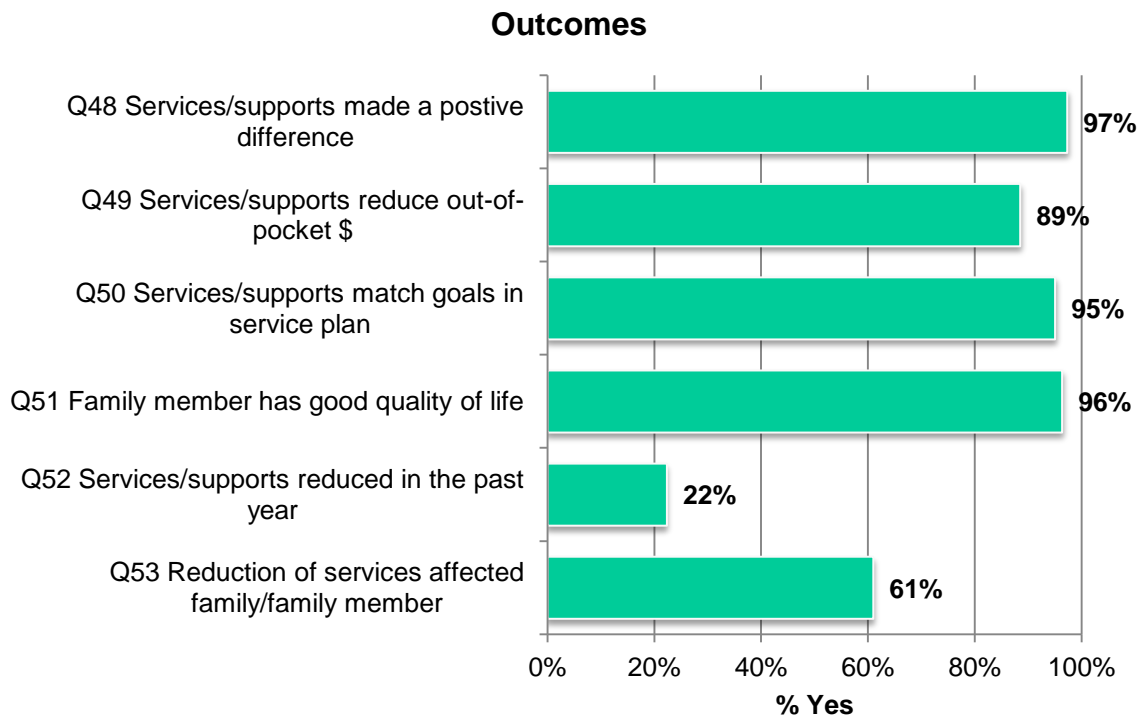
| TABLE Q47. IF "YES" (TO Q46), WERE THE APPROPRIATE PARTIES RESPONSIVE TO YOUR REPORT? | | | |
|--|------------|------------|------------|
| State | Yes | No | N |
| Within NCI Average Range | | | |
| FL | 100% | 0% | 30 |
| MO | 90% | 10% | 30 |
| OH | 86% | 14% | 22 |
| NM | 82% | 18% | 28 |
| LA | 76% | 24% | 21 |
| GA | 50% | 50% | 22 |
| NCI Average | 81% | 19% | 153 |

Outcomes

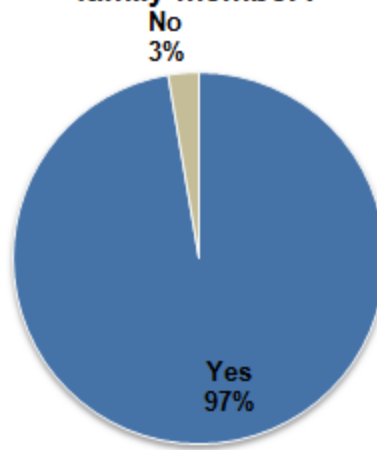
Across states, most of the results for the six Outcomes questions were very positive. The majority of respondents in all states reported that services and supports made a positive difference in their family member's life (97%, state averages ranged between 95% and 100%) and their family member had a good quality of life (96%, state averages ranged between 93% and 98%).

Of the 22% of respondents who reported services or supports had been reduced over the past year, 61% reported that the reduction in services affected their family member's life.

Below is a condensed graph showing all NCI Averages for the Outcomes section.

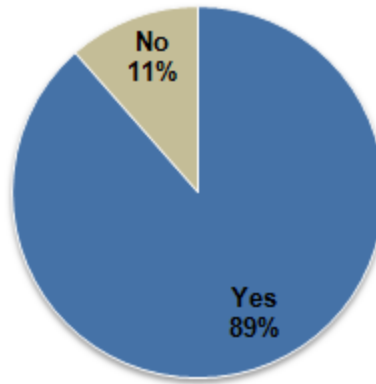


Q48. Do you feel that services and supports have made a positive difference in the life of your family member?



| TABLE Q48. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE MADE A POSITIVE DIFFERENCE IN THE LIFE OF YOUR FAMILY MEMBER? | | | |
|---|------------|-----------|--------------|
| State | Yes | No | N |
| Significantly Above NCI Average | | | |
| FL | 100% | 0% | 276 |
| Within NCI Average Range | | | |
| NC | 99% | 1% | 187 |
| MO | 98% | 2% | 391 |
| OH | 98% | 2% | 393 |
| NM | 97% | 3% | 393 |
| AZ | 97% | 3% | 221 |
| GA | 97% | 3% | 366 |
| LA | 97% | 3% | 341 |
| KY | 97% | 3% | 231 |
| NJ | 95% | 5% | 185 |
| PA | 95% | 5% | 224 |
| NCI Average | 97% | 3% | 3,208 |

Q49. Do you feel that services and supports have reduced your family's out-of-pocket expenses related to your family member's care?



| TABLE Q49. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE REDUCED YOUR FAMILY'S OUT-OF-POCKET EXPENSES RELATED TO YOUR FAMILY MEMBER'S CARE? | | | |
|--|------------|------------|--------------|
| State | Yes | No | N |
| Significantly Above NCI Average | | | |
| LA | 93% | 7% | 306 |
| Within NCI Average Range | | | |
| FL | 92% | 8% | 264 |
| NC | 90% | 10% | 144 |
| PA | 90% | 10% | 178 |
| MO | 89% | 11% | 303 |
| GA | 89% | 11% | 321 |
| KY | 88% | 12% | 206 |
| OH | 87% | 13% | 323 |
| NM | 87% | 13% | 320 |
| NJ | 85% | 15% | 168 |
| AZ | 82% | 18% | 193 |
| NCI Average | 89% | 11% | 2,726 |

Q50. Do you feel that the services and supports received address the goals outlined in your family member's service plan?

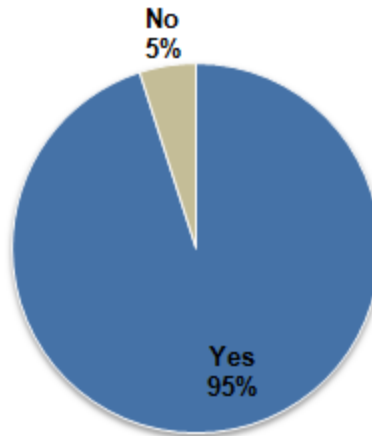
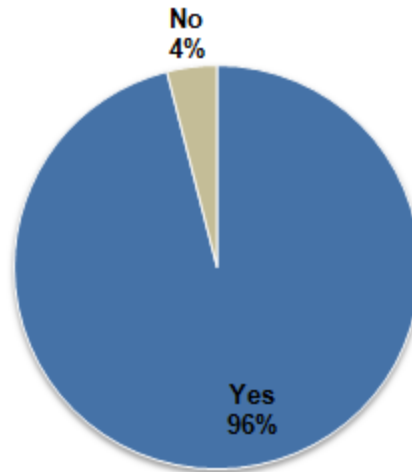


TABLE Q 50. DO YOU FEEL THAT THE SERVICES AND SUPPORTS RECEIVED ADDRESS THE GOALS OUTLINED IN YOUR FAMILY MEMBER'S SERVICE PLAN?

| State | Yes | No | N |
|--|------------|-----------|--------------|
| Significantly Above NCI Average | | | |
| OH | 99% | 1% | 344 |
| Within NCI Average Range | | | |
| MO | 97% | 3% | 372 |
| PA | 96% | 4% | 197 |
| NC | 96% | 4% | 168 |
| LA | 96% | 4% | 307 |
| NM | 96% | 4% | 352 |
| AZ | 96% | 4% | 209 |
| GA | 94% | 6% | 299 |
| FL | 93% | 7% | 254 |
| KY | 93% | 7% | 208 |
| NJ | 89% | 11% | 158 |
| NCI Average | 95% | 5% | 2,868 |

Q51. Overall, do you feel that your family member has a good quality of life?



| TABLE Q51. OVERALL, DO YOU FEEL THAT YOUR FAMILY MEMBER HAS A GOOD QUALITY OF LIFE? | | | |
|--|------------|-----------|--------------|
| State | Yes | No | N |
| Within NCI Average Range | | | |
| NC | 98% | 2% | 188 |
| FL | 98% | 2% | 281 |
| AZ | 97% | 3% | 224 |
| GA | 97% | 3% | 359 |
| LA | 97% | 3% | 340 |
| PA | 97% | 3% | 239 |
| OH | 96% | 4% | 396 |
| MO | 96% | 4% | 397 |
| NJ | 96% | 4% | 183 |
| NM | 96% | 4% | 388 |
| KY | 93% | 7% | 233 |
| NCI Average | 96% | 4% | 3,228 |

Q52. Have the services or supports received been either reduced, suspended, or terminated in the past year?

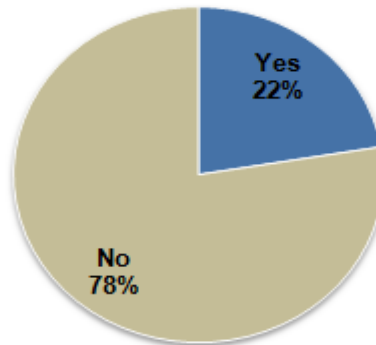


TABLE Q52. HAVE THE SERVICES OR SUPPORTS THAT YOUR FAMILY MEMBER HAS RECEIVED DURING THE PAST YEAR BEEN EITHER REDUCED, SUSPENDED, OR TERMINATED? (%)⁹

| State | Yes | No | N |
|--|------------|------------|--------------|
| Significantly Above NCI Average | | | |
| FL | 42% | 58% | 246 |
| AZ | 37% | 63% | 196 |
| NM | 34% | 66% | 327 |
| Within NCI Average Range | | | |
| NC | 27% | 73% | 158 |
| LA | 25% | 75% | 264 |
| GA | 19% | 81% | 313 |
| Significantly Below NCI Average | | | |
| OH | 14% | 86% | 387 |
| MO | 14% | 86% | 341 |
| NJ | 14% | 86% | 153 |
| KY | 11% | 89% | 206 |
| PA | 10% | 90% | 180 |
| NCI Average | 22% | 78% | 2,771 |

⁹ For this question, states who are “significantly below NCI average” are seen as having the more positive outcomes

Q53. Did the reduction of these services or supports affect your family or your family member's home, job, relationships, etc.?

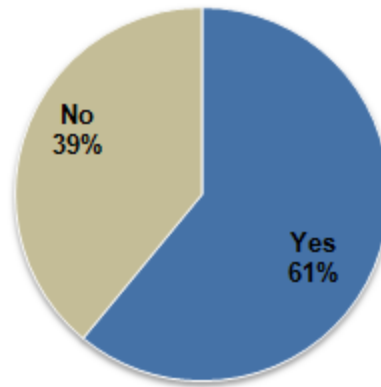


TABLE Q53. IF "YES" (TO Q52), DID THE REDUCTION/SUSPENSION/TERMINATION OF THESE SERVICES OR SUPPORTS AFFECT YOUR FAMILY MEMBER'S HOME, JOB, RELATIONSHIPS, ETC.? (%)¹⁰

| State | Yes | No | N |
|---------------------------------|------------|------------|------------|
| Within NCI Average Range | | | |
| GA | 68% | 32% | 44 |
| NC | 65% | 35% | 37 |
| MO | 62% | 38% | 34 |
| AZ | 62% | 38% | 60 |
| LA | 62% | 38% | 52 |
| NM | 60% | 40% | 96 |
| FL | 60% | 40% | 95 |
| OH | 45% | 55% | 53 |
| NCI Average | 61% | 39% | 471 |

¹⁰ For this question, states who are "significantly below NCI average" are seen as having the more positive outcomes

Overall State Results

To summarize each state's performance, we tabulated the percentage of positive (i.e., above average) results by section and overall for each state. Table 24 below shows the percentage of questions in each section where the state's "always" or "yes" results were significantly above the NCI Average. For questions where "above the NCI Average" is a negative result (e.g., in the past year, respondent reported abuse and neglect), we included those states whose results were significantly below the NCI Average (indicating a more positive result) in the calculation. Two questions were excluded from this analysis: one because there were not enough answers to break out the results by state (Q25), and the other because it was determined that the question did not indicate a positive or negative result (Q33).

TABLE 24. OVERALL PERCENTAGE OF POSITIVE RESULTS, BY SECTION AND BY STATE

| State | Information/Planning | Access/ Delivery | Choice/ Control | Community Connections | Satisfaction | Outcomes | Total |
|--------------|-----------------------------|-----------------------------|----------------------------|----------------------------------|---------------------|-----------------|--------------|
| AZ | 9% | 0% | 10% | 0% | 0% | 0% | 4% |
| FL | 27% | 15% | 40% | 20% | 0% | 17% | 22% |
| GA | 0% | 0% | 0% | 0% | 0% | 0% | 0% |
| KY | 9% | 0% | 0% | 0% | 0% | 17% | 4% |
| LA | 18% | 8% | 0% | 0% | 17% | 17% | 10% |
| MO | 55% | 62% | 0% | 60% | 17% | 17% | 37% |
| NC | 0% | 0% | 0% | 20% | 17% | 0% | 4% |
| NJ | 0% | 0% | 0% | 0% | 0% | 17% | 2% |
| NM | 18% | 0% | 40% | 20% | 33% | 0% | 18% |
| OH | 82% | 46% | 10% | 0% | 50% | 33% | 41% |
| PA | 0% | 8% | 10% | 0% | 0% | 17% | 6% |