

Adult Family Survey

Final Report – July 2012
2010-2011 Data



**NATIONAL CORE
INDICATORS**

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

HUMAN SERVICES RESEARCH INSTITUTE

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Organization of Report

Nine states conducted the National Core Indicators (NCI) Adult Family Survey during 2010-2011. The Adult Family Survey was administered to families who have an adult family member with disabilities receiving services and living at the family's 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. Adult Family 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 Disability 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 Adult Family 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	Families/family members with disabilities get the services and supports they need.
Community Connections	Family members with disabilities use integrated community services and participate in everyday community activities.
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.
Family Outcomes	Individual and family supports make a positive difference in the lives of families.

II. Adult Family Survey

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

Survey Development

The Adult Family Survey was developed and tested during Phase I of NCI by a technical advisory group for the purpose of measuring the experiences of families who had an adult family member with a disability living at home. Results and feedback from Phase I demonstrated that the survey was relatively straightforward to administer, yielded good response rates, and provided sound feedback to the participating state DD agencies.

As mentioned previously, the Adult Family 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 Adult Family Survey to a randomly selected sample of families who meet two criteria:

1. An adult family member with a developmental disability lives in the household.
2. Either the individual or the family receives at least one service or support besides case management.

State Participation

Between 1998 and 2010, seven to 15 states have participated each year. Below is a figure indicating state participation in the Adult Family Survey since its inception.

TABLE 2. STATE PARTICIPATION IN NCI ADULT FAMILY SURVEY (ADULTS LIVING AT HOME WITH FAMILY)												
Field Test	1999-2000	2000-2001	2001-2002	2002-2003	2003-2004	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011
AZ	AZ	CT	AZ	CA - RCOC	AZ	CA - RCOC	AZ	CT	AZ	GA	AZ	FL
CT	CT	DE	CA - RCOC	CT	CA - RCOC	CT	CA - RCOC	DE	CA - RCOC	HI	DC	GA
MO	KY	IA	HI	DE	CT	HI	CT	GA	CT	IL	GA	LA
NE	NE	KY	IL	HI	ME	OK	GA	HI	GA	LA	LA	NC
PA	NC	MA	IA	IN	NC	PA	KY	ME	LA	ME	ME	NJ
VT	PA	MN	NE	IA	ND	SC	ME	NM	ME	MO	NH	NM
VA	VT	MT	NC	ME	OK	WV	NC	OK	MO	NM	NY	OH
	WA	NE	OK	MA	PA	WY	OK	PA	NC	OH	OK	OK
		NC	PA	NC	SC		PA	VT	NJ	OK	PA	PA
		PA	UT	OK	WA		SC	WV	OK	PA	WA	
		RI	VT	PA	WV		SD	WY	PA	SC		
		UT	WA	SC	WY		WA		SC			
			WV	SD			WV		WA			
			WY	WV			WY		WV			
				WY					WY			

Organization of the Adult Family Survey

The Adult Family 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 Adult Family Survey by selecting a random sample of at least 1,000 families who:

1. Have an adult family member with developmental disabilities living at 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, which conducted all of the surveys over the telephone. Thus, Ohio's results should be treated with caution when 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. The other six states met the sample size goal.

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 outside of 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 2010-2011, nine states administered the Adult Family Survey; their data are included in this report. The desired response rate (the percentage of surveys returned versus the number mailed) is 40%. Table 4 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. ADULT FAMILY SURVEY - STATE RESPONSE RATES				
State	Surveys Mailed	Surveys Returned	Response Rate (%)	Usable Surveys
Florida	1,700	471	28%	400
Georgia	2,424	648	27%	614
Louisiana	1,500	463	31%	419
New Jersey	1,050	275	26%	270
New Mexico	1,653	583	35%	583
North Carolina	1,250	289	23%	270
Ohio ⁴	724	401	55%	401
Oklahoma	1,529	448	29%	401
Pennsylvania	1,440	306	21%	296
Overall	13,270	3,884	29%	3,654

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 Adult Family 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 a developmental disability living in the household.

All states had a higher ratio of respondents whose family member with a disability was male (57%) than female (43%), and the average age of the family member with a disability was 34.4. The vast majority of respondents indicated their family member was White (65%). This was followed by African American/Black (19%) and American Indian/Alaska Native (4%). Nine percent (11%) of respondents indicated that their family member was Hispanic. About half indicated their family member's highest level of education was a high school diploma or GED (52%), and 43% had less than a high school diploma or GED.

Slightly more than one-half of respondents (51%) indicated there were two adults (not including their family member with a disability) living in the household. Another 29% indicated there was only one other adult in the household. A small but notable 12% indicated there was more than one person with a developmental disability living in the household.

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

- Intellectual disability (78%)
- Seizure disorder (31%)
- Communication disorder (28%)
- Physical disability (31%)
- Cerebral Palsy (21%)

Gender of Family Member

TABLE 4. GENDER OF FAMILY MEMBER		
State	Male	Female
FL	54%	46%
GA	55%	45%
LA	57%	43%
NC	56%	44%
NJ	57%	43%
NM	55%	45%
OH	60%	40%
OK	58%	42%
PA	57%	43%
Total N	2,038	1,562
NCI Average	57%	43%

Age of Family Member

TABLE 5. AGE OF FAMILY MEMBER		
State	Average Age	Range
FL	33.8	18-72
GA	36.4	18-78
LA	34.6	18-75
NC	32.6	18-75
NJ	33.7	18-69
NM	34.5	18-76
OH	34.8	18-68
OK	33.1	18-76
PA	34.2	18-67
Total N		3,576
NCI Average	34.4	

Race/Ethnicity of Family Member

In this category, respondents could indicate one or more race or ethnicity. 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
FL	64%	21%	1%	2%	1%	2%	1%	14%
GA	54%	42%	1%	1%	0%	2%	0%	1%
LA	66%	33%	0%	0%	0%	0%	0%	1%
NC	67%	28%	1%	1%	0%	3%	0%	2%
NJ	69%	14%	4%	1%	1%	3%	0%	12%
NM	37%	3%	1%	8%	0%	8%	0%	50%
OH	84%	13%	1%	3%	0%	3%	1%	1%
OK	79%	8%	1%	15%	0%	4%	0%	3%
PA	89%	3%	2%	3%	0%	2%	0%	1%
Total N	2,346	691	46	146	7	113	10	403
NCI Average	65%	19%	1%	4%	0%	3%	0%	11%

Number of Adults in the Household

TABLE 7. NUMBER OF ADULTS AT HOME (NOT INCLUDING FAMILY MEMBER WITH A DISABILITY)				
State	One	Two	Three	Four or More
FL	30%	51%	13%	5%
GA	29%	49%	17%	4%
LA	33%	51%	12%	4%
NC	27%	53%	16%	4%
NJ	24%	48%	20%	7%
NM	29%	52%	15%	5%
OH	32%	50%	15%	3%
OK	30%	56%	10%	4%
PA	22%	53%	19%	6%
Total N	1,024	1,811	528	165
NCI Average	29%	51%	15%	5%

More Than One Person with a Developmental Disability Living in Household

TABLE 8. MORE THAN ONE PERSON IN HOUSEHOLD WITH A DEVELOPMENTAL DISABILITY		
State	Yes	No
FL	10%	90%
GA	12%	88%
LA	15%	85%
NC	13%	87%
NJ	11%	89%
NM	12%	88%
OH	12%	88%
OK	8%	92%
PA	14%	86%
Total N	415	3,124
NCI Average	12%	88%

Family Member's Disabilities

TABLE 9A. DISABILITIES OF FAMILY MEMBER							
State	Alzheimer's Disease	Autism	Brain Injury	Cerebral Palsy	Chemical Dependency	Communication Disorder	Down Syndrome
FL	1%	19%	13%	27%	1%	26%	17%
GA	1%	16%	9%	17%	2%	22%	15%
LA	1%	18%	9%	22%	1%	26%	12%
NC	1%	29%	6%	21%	0%	21%	14%
NJ	2%	27%	7%	19%	1%	24%	18%
NM	1%	14%	9%	22%	1%	31%	22%
OH	1%	17%	16%	19%	3%	49%	15%
OK	1%	13%	15%	31%	0%	30%	18%
PA	1%	12%	6%	15%	1%	21%	21%
Total N	38	619	364	767	41	1,011	607
NCI Average	1%	17%	10%	21%	1%	28%	17%

Family Member's Disabilities (continued)

TABLE 9B. DISABILITIES OF FAMILY MEMBER								
State	Intellectual Disability	Mental Illness	Physical Disability	Prader-Willi Syndrome	Seizure Disorder	Vision/Hearing Impairment	Other Disability	Don't Know
FL	74%	13%	32%	2%	32%	20%	17%	3%
GA	79%	18%	25%	1%	28%	18%	11%	2%
LA	70%	13%	35%	1%	32%	18%	19%	3%
NC	73%	19%	29%	0%	30%	18%	21%	4%
NJ	69%	13%	21%	1%	34%	14%	16%	2%
NM	80%	14%	30%	1%	27%	20%	19%	1%
OH	86%	18%	36%	1%	31%	25%	16%	1%
OK	83%	12%	41%	1%	37%	23%	15%	1%
PA	84%	15%	22%	0%	27%	15%	12%	3%
Total N	2,793	536	1,098	33	1,101	694	568	77
NCI Average	78%	15%	31%	1%	31%	19%	16%	2%

Family Member's Primary Means of Expression

TABLE 10. FAMILY MEMBER'S PRIMARY MEANS OF EXPRESSION

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other
FL	73%	20%	1%	1%	5%
GA	73%	19%	2%	1%	4%
LA	70%	21%	1%	1%	6%
NC	72%	23%	1%	1%	3%
NJ	72%	20%	1%	1%	4%
NM	79%	16%	1%	2%	2%
OH	80%	13%	3%	1%	3%
OK	69%	26%	1%	0%	3%
PA	82%	13%	1%	1%	3%
Total N	2,649	673	56	41	130
NCI Average	75%	19%	2%	1%	4%

Family Member's Primary Language

TABLE 11. FAMILY MEMBER'S PRIMARY LANGUAGE

State	English	Spanish	Other
FL	89%	8%	4%
GA	98%	0%	1%
LA	95%	1%	4%
NC	98%	0%	2%
NJ	92%	4%	4%
NM	92%	6%	3%
OH	97%	0%	2%
OK	97%	1%	2%
PA	98%	1%	1%
Total N	3,419	83	94
NCI Average	95%	2%	3%

Family Member's 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
FL	53%	43%	3%	1%	0%
GA	49%	50%	1%	0%	0%
LA	69%	27%	3%	1%	0%
NC	53%	35%	7%	5%	0%
NJ	42%	53%	5%	0%	0%
NM	30%	66%	2%	2%	0%
OH	30%	63%	5%	1%	1%
OK	30%	67%	2%	1%	1%
PA	40%	57%	2%	0%	0%
Total N	1,467	1,776	100	37	9
NCI Average	43%	52%	3%	1%	0%

Family Member's Daily Activity

TABLE 13. 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
FL	18%	34%	5%	6%	11%	22%	15%	7%	12%	16%
GA	36%	38%	4%	4%	9%	18%	7%	6%	6%	9%
LA	16%	26%	3%	1%	10%	37%	15%	6%	10%	10%
NC	22%	26%	8%	8%	15%	24%	13%	9%	13%	18%
NJ	35%	43%	7%	5%	10%	8%	5%	6%	5%	9%
NM	20%	43%	4%	8%	20%	22%	23%	6%	15%	14%
OH	19%	56%	16%	2%	33%	24%	7%	3%	7%	18%
OK	7%	24%	7%	7%	14%	35%	26%	5%	11%	14%
PA	17%	34%	4%	4%	9%	3%	9%	7%	4%	9%
Total N	764	1,319	222	175	534	804	511	211	343	464
NCI Average	21%	37%	6%	5%	15%	22%	14%	6%	9%	13%

Help Needed with Daily Activities

TABLE 14. AMOUNT OF HELP NEEDED WITH DAILY ACTIVITIES				
State	None	Little	Moderate	Complete
FL	20%	21%	25%	34%
GA	28%	24%	25%	22%
LA	18%	17%	26%	38%
NC	27%	24%	21%	29%
NJ	23%	23%	25%	29%
NM	12%	19%	35%	34%
OH	54%	12%	15%	19%
OK	16%	20%	28%	36%
PA	32%	23%	24%	21%
Total N	906	731	924	1,072
NCI Average	25%	20%	25%	30%

Family Member's Behavioral Support Needs

TABLE 15. NEEDS SUPPORT FOR: SELF-INJURIOUS, DISRUPTIVE, OR DESTRUCTIVE BEHAVIOR			
State	No Support Needed	Some Support Needed	Extensive Support Needed
FL	54%	31%	16%
GA	56%	34%	10%
LA	53%	33%	13%
NC	53%	34%	12%
NJ	58%	28%	14%
NM	52%	38%	11%
OH	80%	13%	8%
OK	62%	29%	9%
PA	68%	24%	8%
Total N	2,130	1,086	395
NCI Average	59%	30%	11%

Family Member's Frequency of Medical Care

TABLE 16. 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
FL	75%	17%	7%
GA	81%	15%	5%
LA	77%	15%	8%
NC	75%	21%	4%
NJ	80%	15%	5%
NM	79%	18%	3%
OH	77%	17%	6%
OK	83%	12%	4%
PA	84%	12%	4%
Total N	2,774	556	181
NCI Average	79%	16%	5%

Demographics: Respondents

This section provides information about survey respondents. Respondents are the individuals who completed the survey forms, not the family member with a disability living in the household.

Across all states, 53% of respondents (individuals who completed the surveys) fell into the age category of 55 to 74 years old and 37% were under 55. Eleven (11%) percent of respondents were over age 75. The vast majority of respondents were the parent of the family member with a disability (84%); the remaining respondents included siblings (8%), and others (7%). Nearly all respondents (95%) were the primary caregiver and about two-thirds (67%) were the legal guardian of the family member with a disability. The majority of respondents considered themselves to be in either good (52%) or fair (28%) health.

Across states, more than one-half of respondents had either a high school diploma or GED (33%) or a college degree (27%) as their highest level of education. The remaining respondents had: completed some college coursework (21%); less than a high school diploma or GED (14%); or vocational school training (6%). Household incomes were recorded as: less than \$15,000 (27%), \$15,001-\$25,000 (19%), \$25,001-\$50,000 (28%), \$50,001-\$75,000 (13%), or over \$75,000 (12%) in the previous year. Respondents reported spending the following amounts in out-of-pocket expenses for their family member in the past year: nothing (19%), \$1-\$100 (16%), \$101-\$1,000 (36%), \$1,001-\$10,000 (26%), and over \$10,000 (3%).

Age of Respondent

TABLE 17. AGE OF RESPONDENT				
State	Under 35	35-54	55-74	75 and Over
FL	8%	33%	46%	13%
GA	7%	32%	53%	8%
LA	8%	30%	49%	14%
NC	5%	43%	45%	7%
NJ	7%	25%	58%	9%
NM	6%	30%	54%	10%
OH	1%	30%	60%	10%
OK	4%	28%	57%	12%
PA	5%	32%	51%	11%
Total N	201	1,132	1,925	383
NCI Average	6%	31%	53%	11%

Relationship of Respondent to Individual with Disabilities

TABLE 18. RELATIONSHIP TO INDIVIDUAL WITH DISABILITIES				
State	Parent	Sibling	Spouse	Other
FL	87%	7%	1%	6%
GA	78%	12%	0%	10%
LA	81%	8%	2%	10%
NC	82%	5%	1%	11%
NJ	85%	8%	1%	6%
NM	84%	9%	0%	7%
OH	87%	9%	0%	4%
OK	90%	4%	0%	6%
PA	87%	6%	0%	6%
Total N	3,063	294	16	265
NCI Average	84%	8%	0%	7%

Respondent's Role as Primary Caregiver

TABLE 19. RESPONDENT IS PRIMARY CAREGIVER		
State	Yes	No
FL	91%	9%
GA	97%	3%
LA	93%	7%
NC	95%	5%
NJ	97%	3%
NM	96%	4%
OH	96%	4%
OK	96%	4%
PA	97%	3%
Total N	3,449	169
NCI Average	95%	5%

Respondent's Role as Guardian or Conservator

TABLE 20. RESPONDENT IS LEGAL GUARDIAN OR CONSERVATOR		
State	Yes	No
FL	62%	38%
GA	58%	42%
LA	71%	29%
NC	67%	33%
NJ	78%	22%
NM	80%	20%
OH	57%	43%
OK	74%	26%
PA	58%	42%
Total N	2,380	1,155
NCI Average	67%	33%

Health of Respondent

State	Excellent	Good	Fair	Poor
FL	13%	45%	32%	10%
GA	8%	52%	35%	5%
LA	9%	44%	37%	10%
NC	18%	52%	25%	5%
NJ	12%	55%	29%	5%
NM	18%	61%	19%	2%
OH	23%	48%	25%	5%
OK	14%	60%	22%	4%
PA	20%	49%	28%	2%
Total N	534	1,906	1,020	186
NCI Average	15%	52%	28%	5%

Respondent's Highest Level of Education

State	Less Than High School Diploma/GED	High School Diploma/GED	Vocational School	Some College	College Degree
FL	14%	33%	4%	23%	27%
GA	18%	30%	7%	21%	24%
LA	18%	36%	9%	18%	19%
NC	12%	29%	4%	22%	33%
NJ	9%	32%	5%	18%	37%
NM	13%	28%	6%	24%	28%
OH	11%	42%	3%	19%	25%
OK	9%	27%	8%	25%	31%
PA	15%	45%	6%	14%	21%
Total N	488	1,191	211	756	961
NCI Average	14%	33%	6%	21%	27%

Household Income

TABLE 23. HOUSEHOLD INCOME					
State	Below \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000
FL	36%	21%	23%	12%	8%
GA	35%	19%	25%	10%	11%
LA	39%	19%	19%	13%	11%
NC	23%	19%	30%	13%	14%
NJ	16%	14%	21%	21%	28%
NM	28%	21%	30%	12%	9%
OH	12%	17%	40%	16%	14%
OK	20%	15%	37%	14%	13%
PA	26%	21%	25%	15%	13%
Total N	878	600	915	436	404
NCI Average	27%	19%	28%	13%	12%

Out-of-Pocket Expenses for Family Member Last Year

TABLE 24. 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
FL	18%	12%	36%	30%	3%
GA	17%	17%	41%	22%	2%
LA	19%	16%	35%	28%	2%
NC	25%	15%	33%	25%	2%
NJ	14%	12%	31%	38%	5%
NM	27%	17%	33%	20%	2%
OH	12%	12%	37%	36%	3%
OK	16%	17%	41%	24%	2%
PA	26%	23%	33%	16%	2%
Total N	671	542	1,245	897	88
NCI Average	19%	16%	36%	26%	3%

Services and Supports Received

This section, which consists of just one table, provides information about the services and supports received by the family member and/or family from the state ID/DD agency (excluding social security benefits). A larger percentage of respondents indicated that they or their family member received the following agency supports: transportation (61%), day or employment supports (59%), and in-home support (45%). Almost all (92%) of respondents reported that their family member received social security benefits.

Services and Supports Received

TABLE 25. SERVICES AND SUPPORTS RECEIVED							
State	Financial Support	In-Home Support	Out-of-Home Respite Care	Day or Employment Supports	Transportation	Other Services or Supports	Social Security Benefits
FL	16%	59%	30%	50%	55%	31%	90%
GA	12%	29%	19%	71%	69%	24%	93%
LA	10%	71%	28%	45%	54%	16%	92%
NC	12%	50%	43%	51%	50%	24%	90%
NJ	27%	27%	31%	78%	77%	16%	92%
NM	29%	49%	65%	61%	52%	80%	92%
OH	13%	24%	21%	72%	81%	21%	87%
OK	20%	64%	16%	43%	50%	32%	93%
PA	13%	26%	23%	62%	62%	22%	93%
Total N	606	1,601	1,119	2,121	2,174	1,158	3,282
NCI Average	17%	45%	31%	59%	61%	33%	92%

Adult Family Survey Results

This section of the report presents outcomes 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 determined at 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.

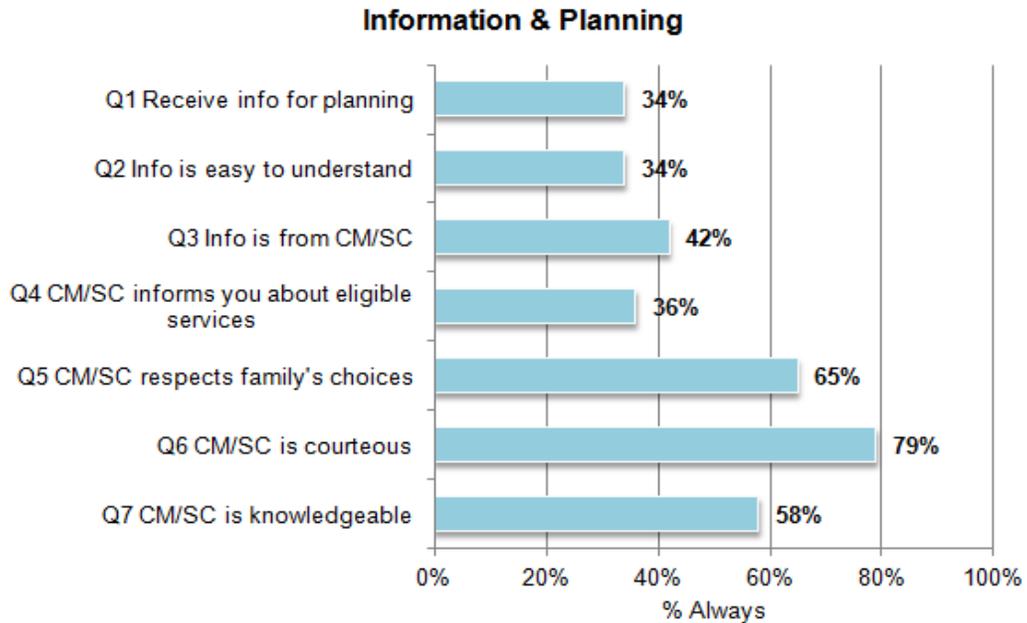
Information and Planning

Of the 12 questions in the Information and Planning section, five scored particularly high across the participating states. At least three-quarters (75%) of respondents recorded an “always” or “yes” response for these items, according to the NCI Averages.

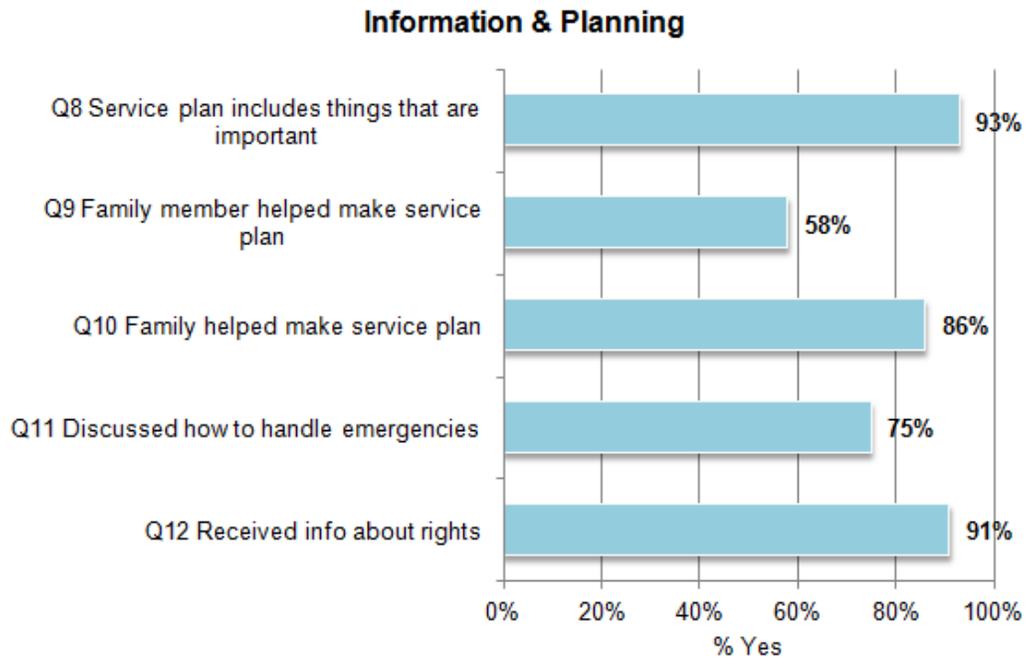
- 75% discussed how to handle emergencies at the last planning meeting; the range between states was 56% to 86%
- 79% indicated the case manager/service coordinator for planning is always courteous; the range between states was 63% to 89%
- 86% reported they or another family member helped develop their family member’s service plan; the range between states was 73% to 93%
- 91% received information about their family member’s rights; the range between states was 64% to 98%
- 93% indicated the service plan includes services and supports important to the family; the range between states was 75% to 97%

Two states consistently rated significantly above the NCI Average: New Mexico was significantly above the NCI Average on 11 of 12 questions, and Ohio was significantly above the NCI Average on 9 of 12 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.



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

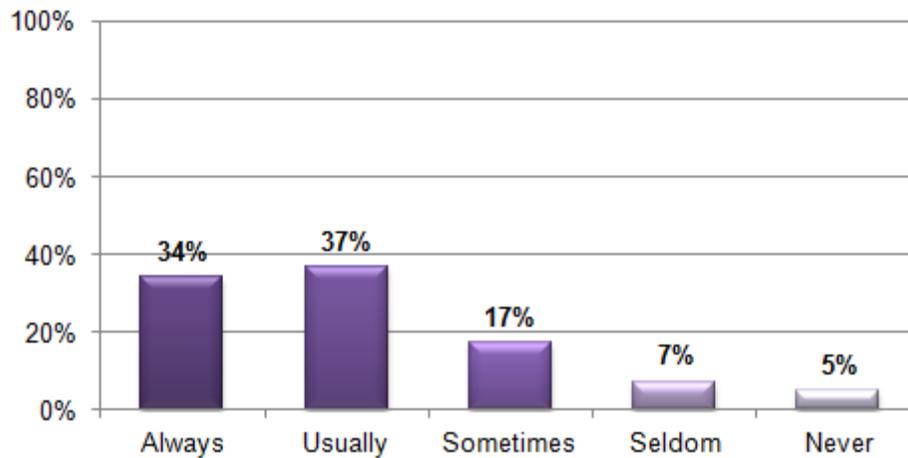


TABLE Q1: DO YOU GET ENOUGH INFORMATION TO HELP YOU PARTICIPATE IN PLANNING SERVICES FOR YOUR FAMILY?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	47%	40%	10%	2%	1%	576
Within NCI Average Range						
FL	40%	31%	18%	6%	5%	376
OH	40%	27%	23%	6%	5%	389
LA	39%	35%	16%	8%	3%	399
NC	34%	40%	13%	5%	8%	249
OK	33%	44%	16%	7%	1%	407
PA	32%	45%	14%	5%	4%	275
Significantly Below NCI Average						
GA	27%	38%	21%	8%	6%	561
NJ	17%	30%	25%	18%	10%	260
NCI Average	34%	37%	17%	7%	5%	3,492

Q2. Is the information you receive easy to understand?

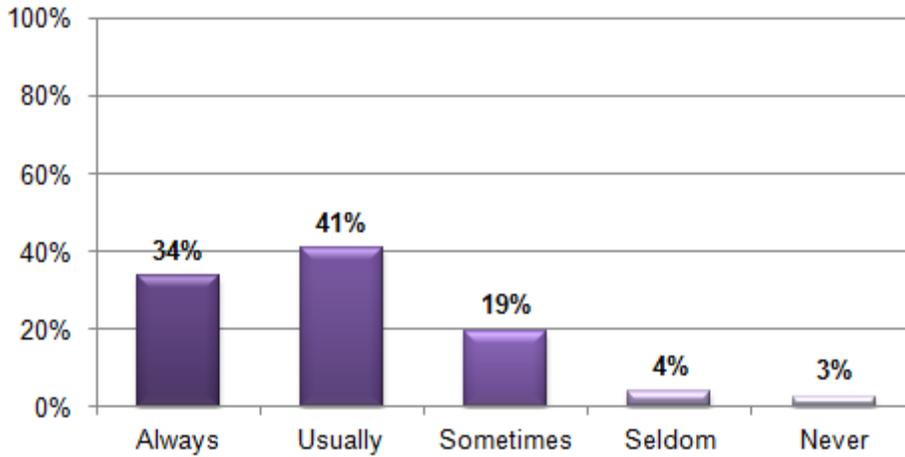


TABLE Q2: IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND?						
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	44%	30%	22%	2%	3%	387
Within NCI Average Range						
LA	39%	36%	18%	5%	2%	384
NM	38%	44%	15%	2%	0%	573
FL	36%	35%	20%	4%	4%	366
OK	33%	44%	18%	3%	2%	396
PA	32%	48%	16%	3%	2%	265
NC	29%	48%	16%	3%	4%	243
Significantly Below NCI Average						
GA	27%	41%	23%	6%	3%	523
NJ	25%	40%	26%	6%	3%	235
NCI Average	34%	41%	19%	4%	3%	3,372

Q3. Does the information you receive primarily come from your family member's case manager/service coordinator?

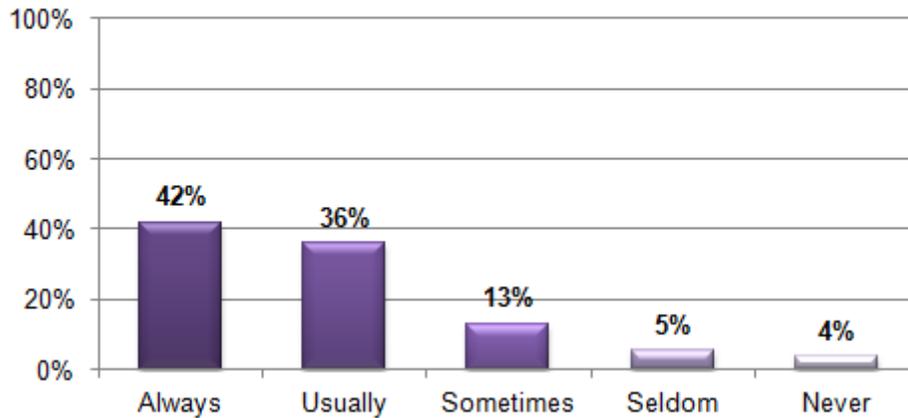


TABLE Q3: DOES THE INFORMATION YOU RECEIVE PRIMARILY COME FROM YOUR FAMILY MEMBER'S CASE MANAGER/SERVICE COORDINATOR (AS OPPOSED TO FAMILY, FRIENDS, AND OTHERS OUTSIDE STATE SERVICES)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	53%	37%	7%	3%	1%	567
LA	49%	31%	11%	5%	4%	389
FL	49%	33%	10%	4%	4%	381
Within NCI Average Range						
OH	48%	29%	17%	3%	2%	386
NC	43%	37%	11%	6%	3%	236
PA	42%	41%	12%	3%	2%	273
OK	37%	46%	11%	5%	1%	404
Significantly Below NCI Average						
GA	33%	38%	17%	7%	5%	542
NJ	22%	33%	20%	13%	12%	256
NCI Average	42%	36%	13%	5%	4%	3,434

Q4. Does the case manager/service coordinator tell you about public services you are eligible for?

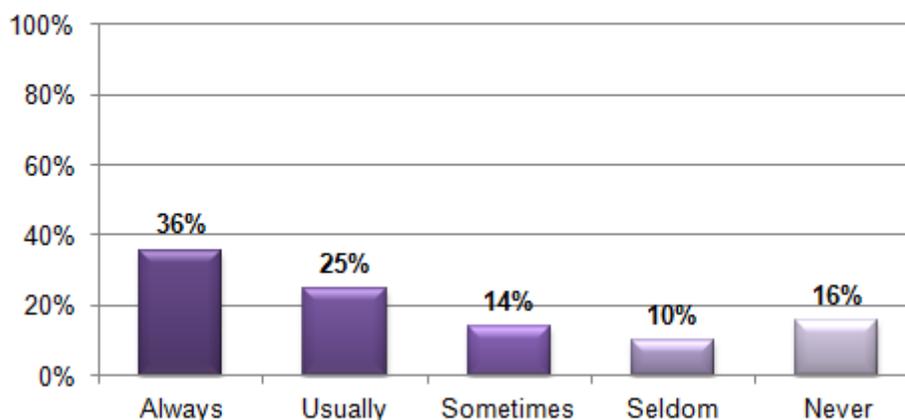


TABLE Q4: DOES YOUR FAMILY MEMBER'S CASE MANAGER/SERVICE COORDINATOR TELL YOU ABOUT PUBLIC SERVICES THAT YOU ARE ELIGIBLE FOR (E.G., FOOD STAMPS, SUPPLEMENTAL SECURITY INCOME [SSI], HOUSING SUBSIDIES, ETC.)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
FL	47%	25%	12%	8%	8%	370
NM	45%	25%	11%	7%	12%	543
OH	44%	20%	18%	7%	10%	374
Within NCI Average Range						
LA	38%	23%	12%	9%	17%	385
PA	36%	32%	12%	11%	9%	253
NC	35%	25%	13%	11%	17%	241
OK	35%	30%	16%	10%	10%	405
Significantly Below NCI Average						
GA	23%	24%	15%	13%	25%	541
NJ	15%	20%	18%	15%	33%	246
NCI Average	36%	25%	14%	10%	16%	3,358

Q5. Does the case manager/service coordinator who assists your family with planning respect your family's choices and opinions?

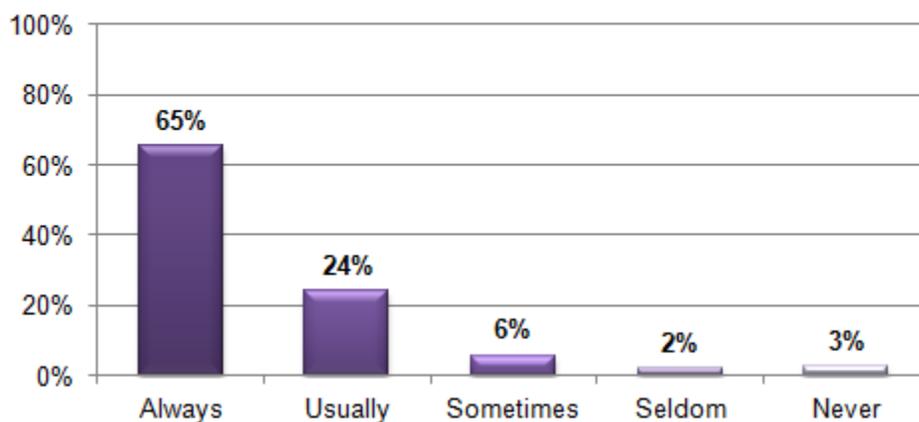


TABLE Q5: DOES THE CASE MANAGER/SERVICE COORDINATOR WHO ASSISTS YOUR FAMILY WITH PLANNING RESPECT YOUR FAMILY'S CHOICES AND OPINIONS?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	78%	17%	3%	1%	1%	575
FL	74%	21%	3%	1%	1%	384
OH	73%	17%	8%	1%	2%	392
Within NCI Average Range						
NC	70%	23%	3%	1%	3%	242
LA	68%	23%	5%	3%	1%	392
PA	65%	28%	2%	2%	2%	272
OK	64%	27%	7%	2%	1%	412
Significantly Below NCI Average						
GA	53%	32%	9%	2%	5%	542
NJ	45%	31%	10%	6%	9%	230
NCI Average	65%	24%	6%	2%	3%	3,441

Q6. Is the case manager/service coordinator who assists your family with planning generally courteous?

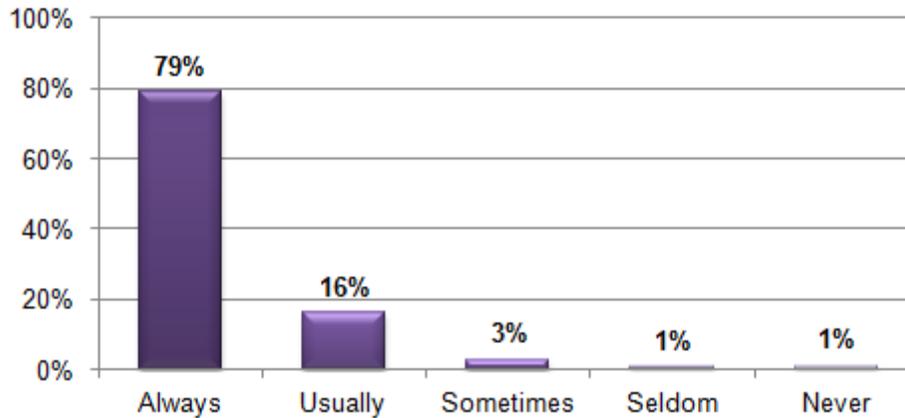


TABLE Q6: IS THE CASE MANAGER/SERVICE COORDINATOR WHO ASSISTS YOUR FAMILY WITH PLANNING GENERALLY COURTEOUS?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	89%	7%	3%	1%	1%	393
NM	86%	11%	2%	0%	1%	576
FL	85%	10%	3%	0%	1%	392
Within NCI Average Range						
PA	83%	14%	1%	1%	1%	279
NC	83%	15%	2%	0%	1%	246
LA	80%	15%	3%	1%	1%	394
OK	75%	21%	3%	0%	0%	415
Significantly Below NCI Average						
GA	68%	25%	5%	1%	2%	545
NJ	63%	28%	4%	2%	2%	243
NCI Average	79%	16%	3%	1%	1%	3,483

Q7. Is the case manager/service coordinator who assists your family with planning generally knowledgeable?

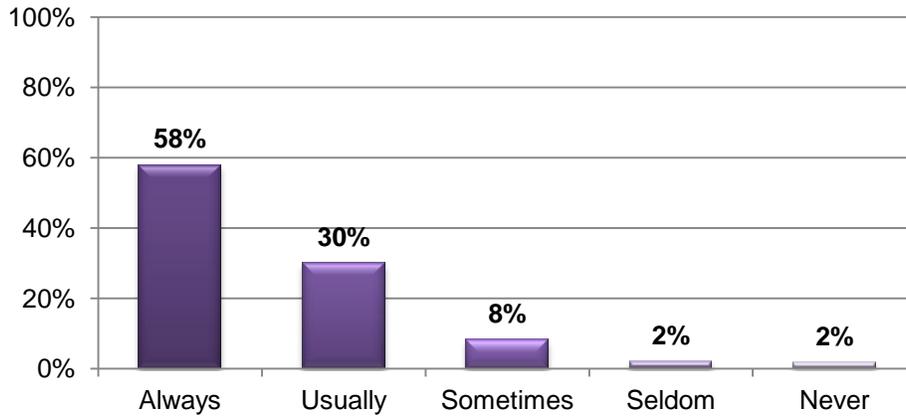


TABLE Q7: IS THE CASE MANAGER/SERVICE COORDINATOR WHO ASSISTS YOUR FAMILY WITH PLANNING GENERALLY KNOWLEDGEABLE?						
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	69%	20%	9%	1%	2%	390
NM	69%	24%	5%	1%	1%	557
FL	68%	21%	7%	2%	2%	391
Within NCI Average Range						
NC	61%	30%	6%	2%	1%	244
PA	59%	35%	4%	2%	1%	276
OK	55%	32%	10%	2%	0%	406
LA	55%	32%	9%	3%	1%	387
Significantly Below NCI Average						
GA	44%	39%	12%	3%	3%	542
NJ	42%	35%	12%	6%	5%	236
NCI Average	58%	30%	8%	2%	2%	3,429

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

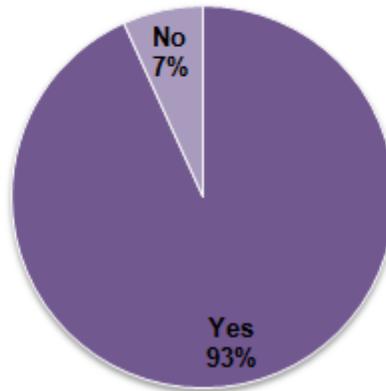


TABLE Q8: IF YOUR FAMILY MEMBER HAS A SERVICE PLAN, DOES THE PLAN INCLUDE SERVICES AND SUPPORTS THAT ARE IMPORTANT TO YOUR FAMILY?

State	Yes	No	N
Significantly Above NCI Average			
NM	97%	3%	530
OH	97%	3%	286
LA	96%	4%	340
OK	96%	4%	379
Within NCI Average Range			
PA	96%	4%	203
FL	95%	5%	338
NC	94%	6%	220
GA	92%	8%	448
Significantly Below NCI Average			
NJ	75%	25%	153
NCI Average	93%	7%	2,897

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

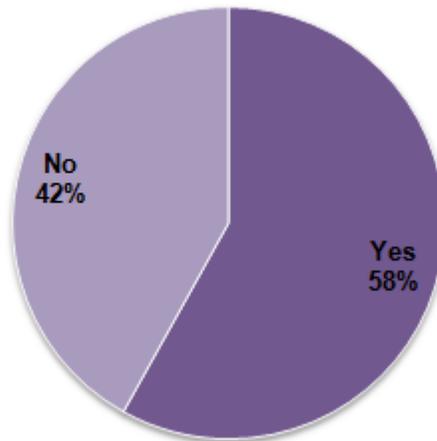


TABLE Q9: IF YOUR FAMILY MEMBER HAS A SERVICE PLAN, DID S/HE HELP DEVELOP THE PLAN?

State	Yes	No	N
Significantly Above NCI Average			
NM	73%	27%	513
OH	69%	31%	283
Within NCI Average Range			
PA	64%	36%	189
FL	64%	36%	320
NC	55%	45%	208
LA	54%	46%	333
GA	53%	47%	423
OK	53%	47%	366
Significantly Below NCI Average			
NJ	38%	62%	146
NCI Average	58%	42%	2,781

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

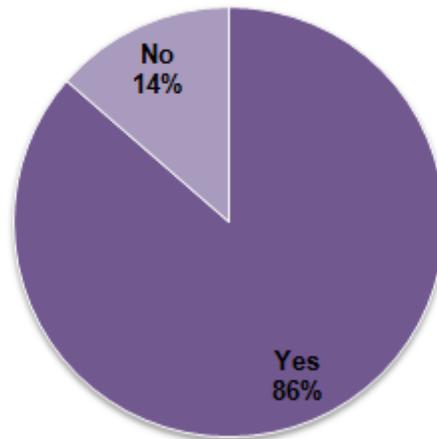


TABLE Q10: IF YOUR FAMILY MEMBER HAS A SERVICE PLAN, DID YOU OR ANOTHER FAMILY MEMBER HELP DEVELOP THE PLAN?

State	Yes	No	N
Significantly Above NCI Average			
OK	93%	7%	380
NM	93%	7%	537
Within NCI Average Range			
PA	90%	10%	210
OH	90%	10%	286
FL	86%	14%	348
NC	86%	14%	226
LA	85%	15%	353
GA	82%	18%	477
Significantly Below NCI Average			
NJ	73%	27%	146
NCI Average	86%	14%	2,963

Q11. Did you discuss how to handle emergencies related to your family member at the last service planning meeting?

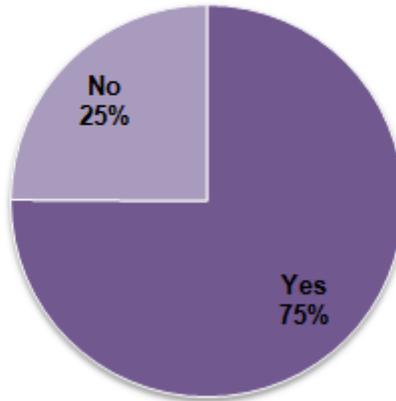


TABLE Q11: IF YOUR FAMILY MEMBER HAS A SERVICE PLAN, DID YOU DISCUSS HOW TO HANDLE EMERGENCIES RELATED TO YOUR FAMILY MEMBER AT THE LAST SERVICE PLANNING MEETING?

State	Yes	No	N
Significantly Above NCI Average			
LA	86%	14%	357
NM	86%	14%	513
OH	84%	16%	280
Within NCI Average Range			
NC	81%	19%	216
OK	80%	20%	358
FL	72%	28%	318
PA	66%	34%	195
Significantly Below NCI Average			
GA	66%	34%	433
NJ	56%	44%	143
NCI Average	75%	25%	2,813

Q12. Have you or your family member received information about your family member's rights?

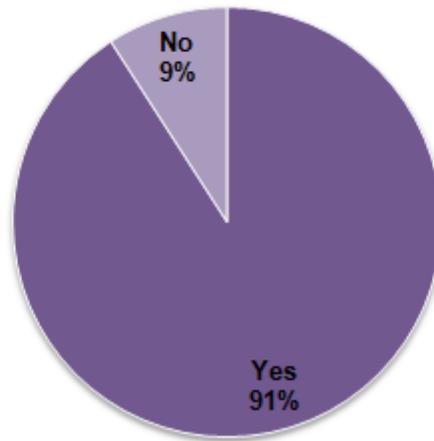


TABLE Q12: HAVE YOU OR YOUR FAMILY MEMBER RECEIVED INFORMATION ABOUT YOUR FAMILY MEMBER'S RIGHTS?

State	Yes	No	N
Significantly Above NCI Average			
NM	98%	2%	552
OK	96%	4%	390
FL	95%	5%	353
OH	95%	5%	397
Within NCI Average Range			
LA	94%	6%	370
NC	94%	6%	232
PA	92%	8%	219
GA	90%	10%	499
Significantly Below NCI Average			
NJ	64%	36%	183
NCI Average	91%	9%	3,195

Access and Delivery of Supports

For the majority of the 30 questions⁶ that compose the Access and Delivery of Supports subsection, the large majority of states fell within the NCI Average range. Some examples of the few questions that did show variance among the states include:

- Always able to contact support workers when needed – three states were significantly above, four within, and two significantly below the NCI Average; states ranged between 37% and 73%.
- Always able to contact case manager/service coordinator when needed – three states were significantly above, three were within, and three were significantly below the NCI Average; state results ranged between 32% and 70%.
- Services and supports always available when needed – two states were significantly above, four within, and three were significantly below the NCI Average; state results ranged between 22% and 49%.
- Has access to dental services – three states were significantly above, three were within, and three were significantly below the NCI Average; state results ranged between 61% and 95%.

The majority of respondents indicated that their family member had access to: health services (97%), needed medication (98%), and mental health services (84%). However, on average, a lower percentage of people across states reported that their family member had access to dental services (80%) or respite services (75%). These questions also showed more variance among states (61%-95% and 48%-86%, respectively). Three other questions also showed greater differentiation among states:

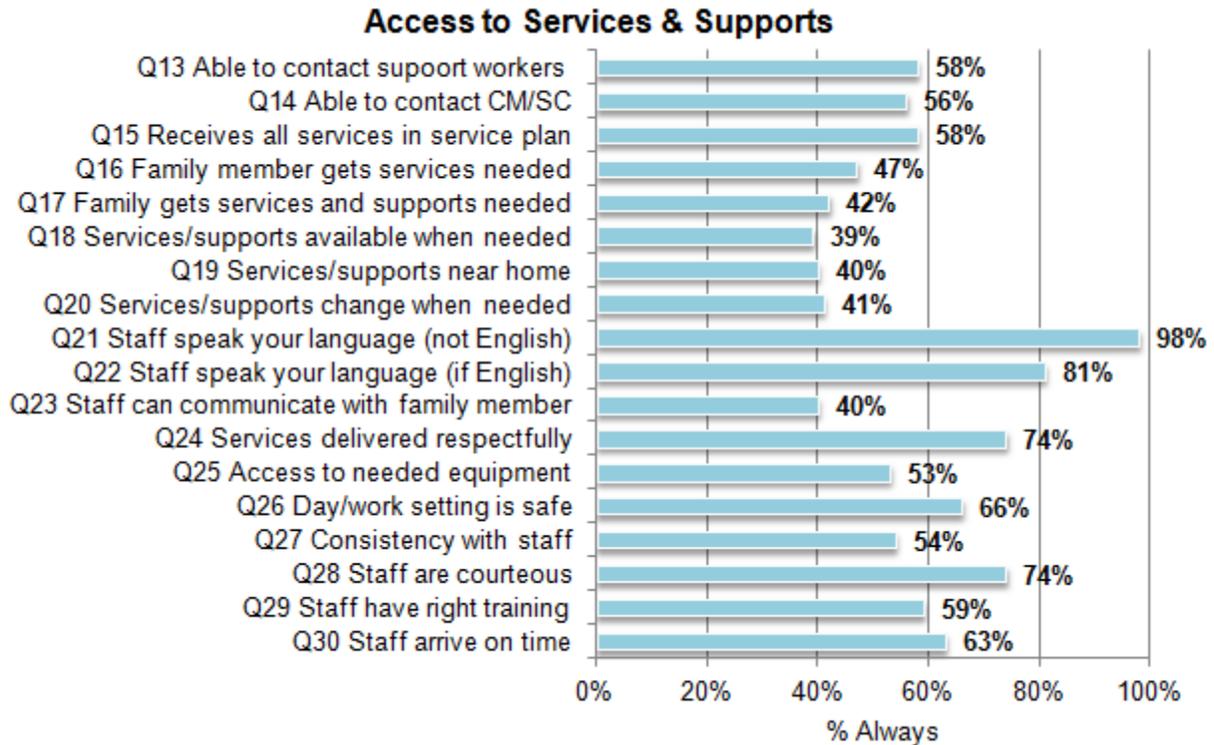
- Services are needed that are not currently offered or available; states ranged from 12% to 68%

⁶ Only one state provided responses to Question 21.

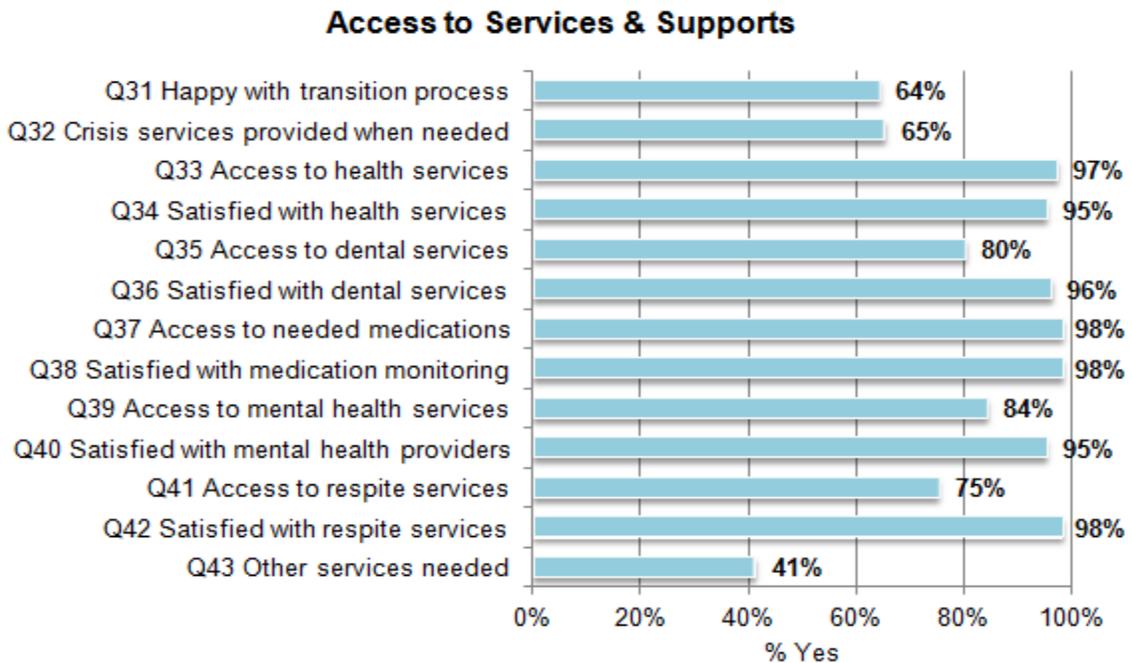
- Happy with the transition process from school services to state-funded services; states ranged from 26% to 83%
- Crisis/emergency services were provided when needed; states ranged from 21 to 86%

For this section, Ohio and New Mexico were the two states who rated significantly above the NCI Average (for 18 and 12 questions, respectively) most frequently. In addition, both Ohio and New Mexico rated significantly below the NCI Average where lower percentages indicate a positive result (e.g., need other services not available).

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



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



Q13. Are you or your family member able to contact your family member's support workers when you need to?

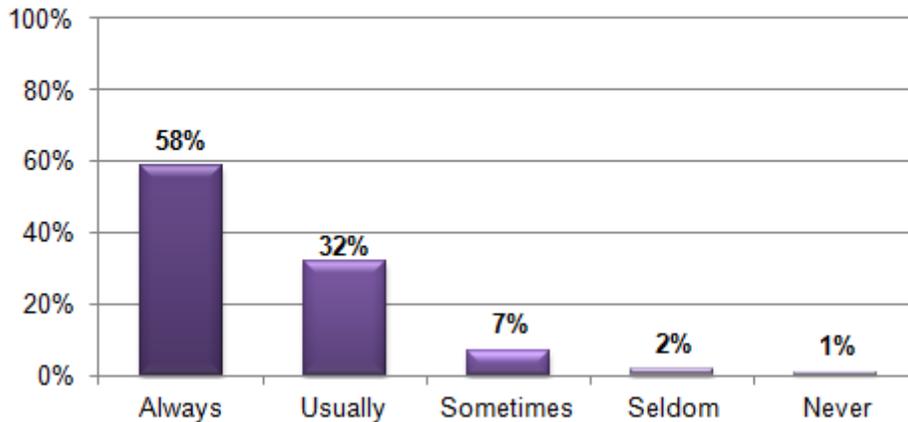


TABLE Q13: ARE YOU OR YOUR FAMILY MEMBER ABLE TO CONTACT YOUR FAMILY MEMBER'S SUPPORT WORKERS WHEN YOU NEED TO?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	73%	18%	8%	1%	1%	395
FL	71%	22%	5%	1%	0%	380
NM	66%	29%	5%	1%	0%	573
Within NCI Average Range						
LA	63%	31%	5%	1%	1%	400
NC	61%	33%	3%	2%	1%	244
PA	56%	38%	5%	0%	1%	263
OK	52%	39%	6%	2%	0%	402
Significantly Below NCI Average						
GA	47%	38%	11%	1%	3%	561
NJ	37%	40%	16%	6%	2%	227
NCI Average	58%	32%	7%	2%	1%	3,445

Q14. Are you or your family member able to contact your family member's case manager/service coordinator when you need to?

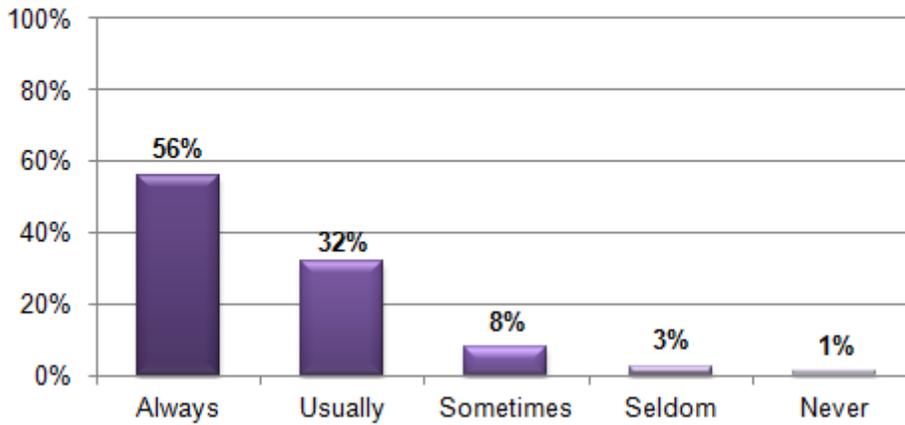


TABLE Q14: ARE YOU OR YOUR FAMILY MEMBER ABLE TO CONTACT HIS/HER CASE MANAGER/SERVICE COORDINATOR WHEN YOU NEED TO?						
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	70%	22%	7%	1%	1%	392
NM	68%	26%	4%	1%	1%	576
FL	68%	25%	5%	2%	1%	386
Within NCI Average Range						
NC	61%	30%	7%	1%	1%	240
LA	59%	34%	6%	1%	1%	393
PA	55%	36%	7%	1%	1%	272
Significantly Below NCI Average						
OK	48%	41%	8%	2%	0%	410
GA	43%	40%	11%	2%	3%	555
NJ	32%	36%	18%	12%	3%	241
NCI Average	56%	32%	8%	3%	1%	3,465

Q15. Does your family member receive all of the services listed in the service plan?

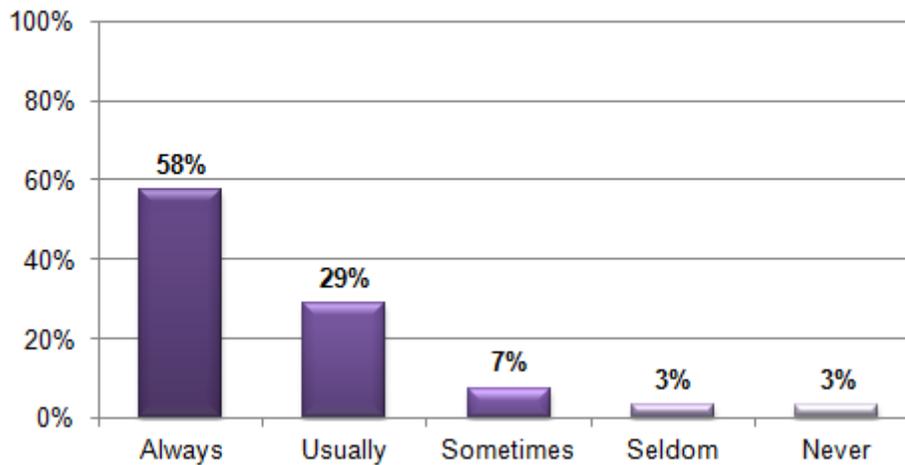


TABLE Q15: DOES YOUR FAMILY MEMBER RECEIVE ALL OF THE SERVICES LISTED IN THE SERVICE PLAN?						
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	69%	25%	4%	1%	0%	301
NM	69%	23%	5%	2%	1%	545
Within NCI Average Range						
FL	63%	28%	5%	3%	2%	345
PA	60%	28%	7%	2%	3%	218
NC	59%	28%	5%	5%	3%	221
LA	58%	27%	11%	1%	2%	340
OK	57%	31%	8%	3%	1%	368
Significantly Below NCI Average						
GA	46%	35%	10%	5%	4%	450
NJ	37%	33%	10%	9%	11%	156
NCI Average	58%	29%	7%	3%	3%	2,944

Q16. Does your family member get the services and supports that s/he needs?

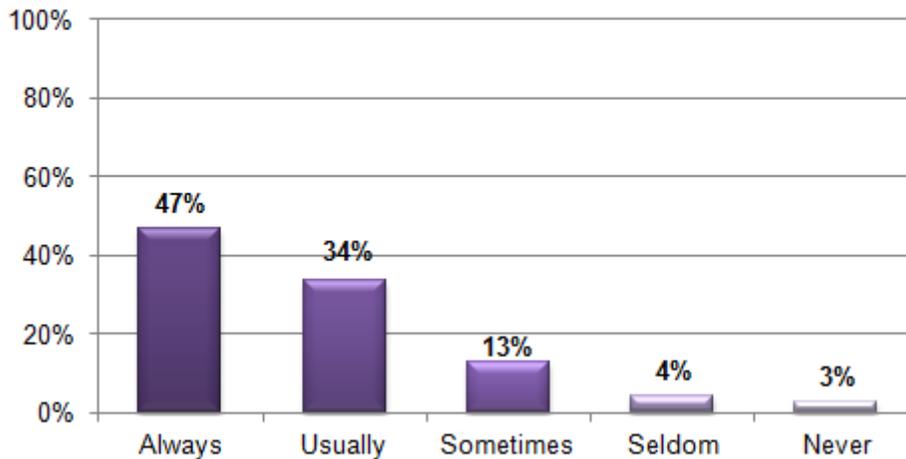


TABLE Q16: DOES YOUR FAMILY MEMBER GET THE SERVICES AND SUPPORTS THAT S/HE NEEDS?						
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	62%	30%	6%	2%	1%	566
OH	62%	25%	10%	2%	1%	398
Within NCI Average Range						
LA	51%	29%	15%	3%	2%	380
FL	49%	33%	14%	3%	2%	368
PA	47%	38%	11%	1%	3%	253
OK	44%	39%	12%	3%	1%	404
NC	44%	34%	13%	6%	4%	248
Significantly Below NCI Average						
GA	37%	38%	18%	4%	3%	538
NJ	25%	37%	19%	12%	7%	213
NCI Average	47%	34%	13%	4%	3%	3,368

Q17. Does your family get the services and supports you need?

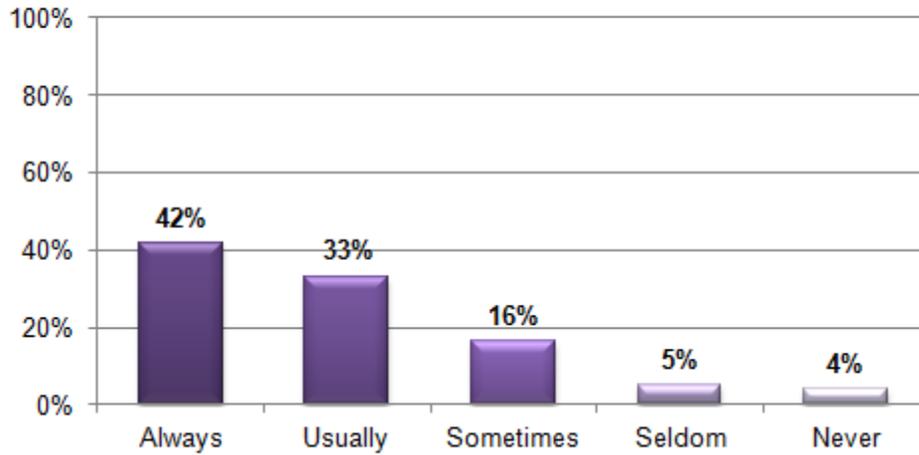


TABLE Q17: DOES YOUR FAMILY GET THE SERVICES AND SUPPORTS YOU NEED?						
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	57%	31%	9%	2%	1%	557
OH	56%	27%	11%	2%	4%	378
Within NCI Average Range						
FL	45%	30%	17%	6%	2%	364
LA	44%	34%	14%	5%	3%	385
OK	41%	37%	15%	4%	3%	396
PA	40%	36%	16%	3%	4%	255
NC	35%	40%	15%	5%	6%	248
Significantly Below NCI Average						
GA	34%	35%	22%	4%	5%	535
NJ	23%	28%	26%	13%	10%	206
NCI Average	42%	33%	16%	5%	4%	3,324

Q18. Are services and supports available at the times that your family member needs them?

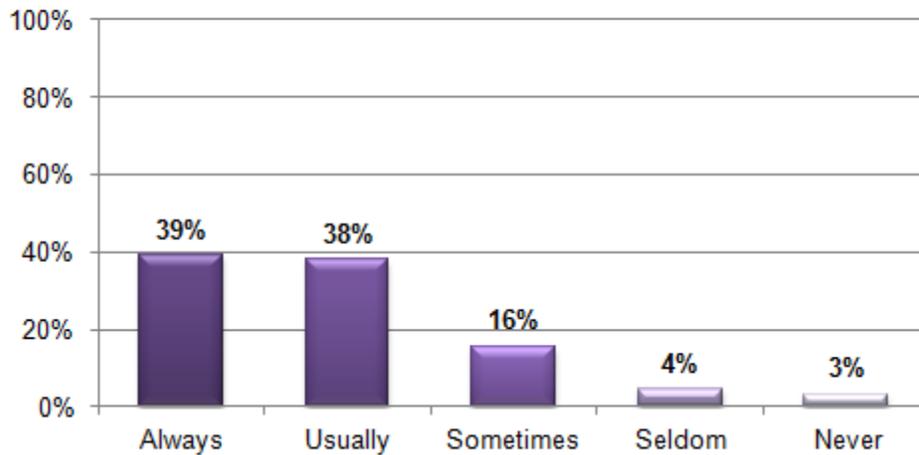


TABLE Q18: ARE SERVICES AND SUPPORTS AVAILABLE AT THE TIMES THAT YOUR FAMILY MEMBER NEEDS THEM?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	49%	37%	10%	2%	1%	564
OH	48%	34%	13%	4%	1%	394
Within NCI Average Range						
FL	45%	34%	16%	2%	2%	370
LA	44%	36%	16%	3%	2%	377
OK	39%	41%	13%	6%	1%	393
PA	38%	42%	14%	4%	2%	248
Significantly Below NCI Average						
GA	33%	40%	18%	4%	5%	535
NC	33%	44%	15%	3%	5%	241
NJ	22%	34%	23%	11%	10%	197
NCI Average	39%	38%	16%	4%	3%	3,319

Q19. Are service and supports available within a reasonable distance from your family home?

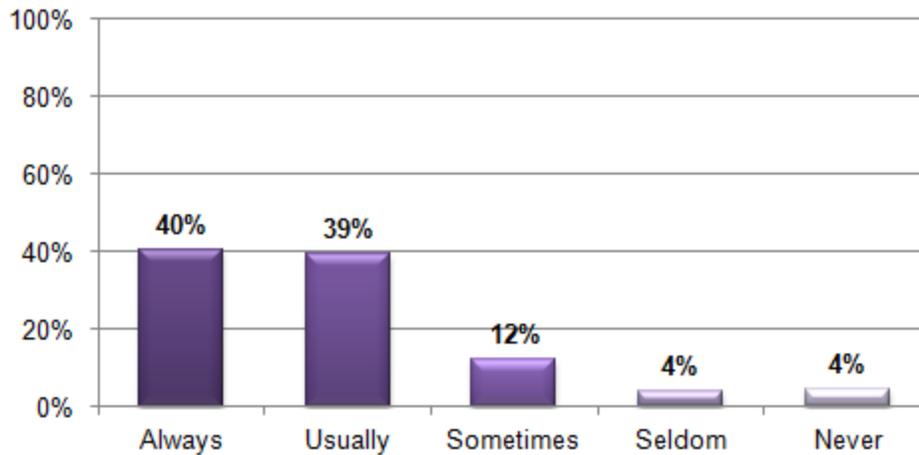


TABLE Q19: ARE SERVICE AND SUPPORTS, RECEIVED OUTSIDE THE FAMILY HOME, AVAILABLE WITHIN A REASONABLE DISTANCE FROM YOUR FAMILY HOME?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	49%	32%	13%	4%	2%	374
NM	47%	37%	10%	2%	3%	537
Within NCI Average Range						
LA	45%	35%	10%	4%	6%	325
FL	45%	39%	12%	3%	2%	296
GA	40%	42%	11%	3%	4%	488
NC	39%	40%	12%	1%	8%	218
PA	36%	43%	12%	6%	4%	226
OK	35%	44%	15%	4%	2%	353
Significantly Below NCI Average						
NJ	27%	40%	16%	7%	9%	193
NCI Average	40%	39%	12%	4%	4%	3,010

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

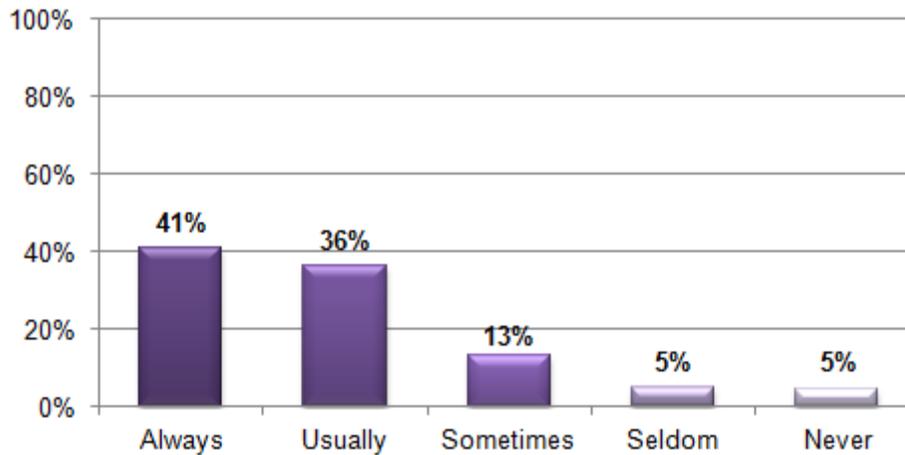


TABLE Q20: DO THE SERVICES AND SUPPORTS CHANGE WHEN YOUR FAMILY MEMBER'S NEEDS CHANGE?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	52%	34%	11%	2%	2%	522
OH	51%	30%	14%	2%	3%	364
Within NCI Average Range						
FL	46%	34%	12%	6%	3%	322
LA	44%	35%	12%	5%	4%	342
PA	40%	43%	10%	4%	3%	197
NC	39%	41%	12%	1%	6%	218
OK	38%	41%	13%	7%	2%	359
Significantly Below NCI Average						
GA	33%	38%	18%	5%	6%	456
NJ	24%	32%	19%	12%	13%	150
NCI Average	41%	36%	13%	5%	5%	2,930

Q21. If English is not your first language, are there support workers or translators available to speak with you in your preferred language?

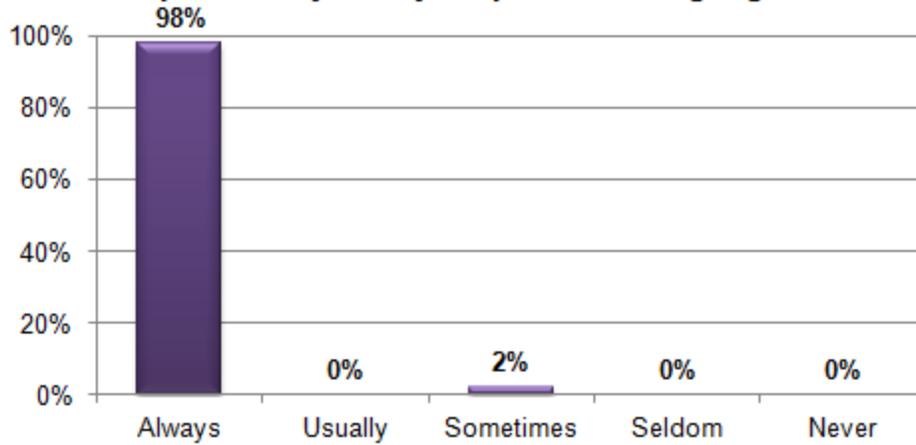


TABLE Q21: IF ENGLISH IS NOT YOUR FIRST LANGUAGE, ARE THERE SUPPORT WORKERS OR TRANSLATORS AVAILABLE TO SPEAK WITH YOU IN YOUR PREFERRED LANGUAGE?

State	Always	Usually	Sometimes	Seldom	Never	N
OH	98%	0%	2%	0%	0%	40

Q22. If English is your first language, do the support workers communicate with you effectively in English?

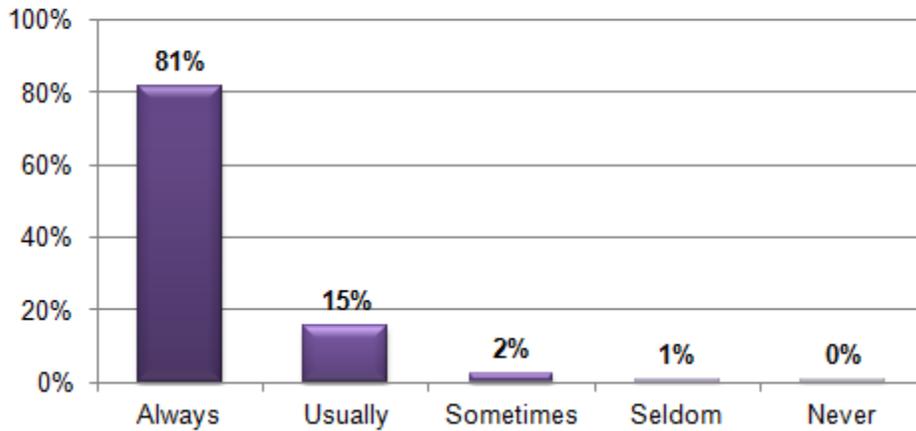


TABLE Q22: IF ENGLISH IS YOUR FIRST LANGUAGE, DO THE SUPPORT WORKERS COMMUNICATE WITH YOU EFFECTIVELY IN YOUR PRIMARY LANGUAGE?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	91%	5%	3%	0%	1%	360
Within NCI Average Range						
NC	87%	11%	2%	0%	1%	199
FL	86%	13%	1%	0%	0%	277
PA	85%	13%	1%	1%	0%	220
NM	85%	14%	1%	0%	0%	412
LA	80%	18%	2%	0%	0%	299
OK	79%	20%	1%	0%	0%	331
Significantly Below NCI Average						
GA	72%	24%	3%	0%	0%	425
NJ	67%	20%	8%	3%	2%	173
NCI Average	81%	15%	2%	1%	0%	2,696

Q23. If your family member does not speak English or uses another way to communicate, can support workers communicate with him/her?

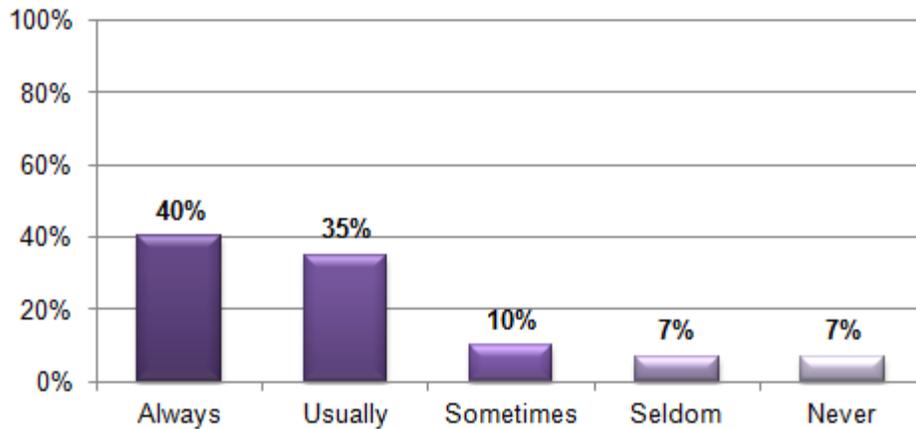


TABLE Q23: IF YOUR FAMILY MEMBER DOES NOT SPEAK ENGLISH OR USES A DIFFERENT WAY TO COMMUNICATE (FOR EXAMPLE, SIGN LANGUAGE), ARE THERE ENOUGH SUPPORT WORKERS AVAILABLE WHO CAN COMMUNICATE WITH HIM/HER?

State	Always	Usually	Sometimes	Seldom	Never	N
Within NCI Average Range						
OH	54%	25%	11%	6%	3%	79
LA	52%	32%	1%	4%	11%	75
FL	46%	35%	9%	5%	5%	82
NM	40%	30%	15%	9%	6%	98
NC	39%	45%	5%	5%	5%	38
GA	35%	47%	6%	7%	5%	85
OK	31%	35%	16%	7%	10%	68
NJ	23%	33%	18%	15%	10%	39
NCI Average	40%	35%	10%	7%	7%	564

Q24. Are services delivered to your family in a manner that is respectful to your family's culture(s)?

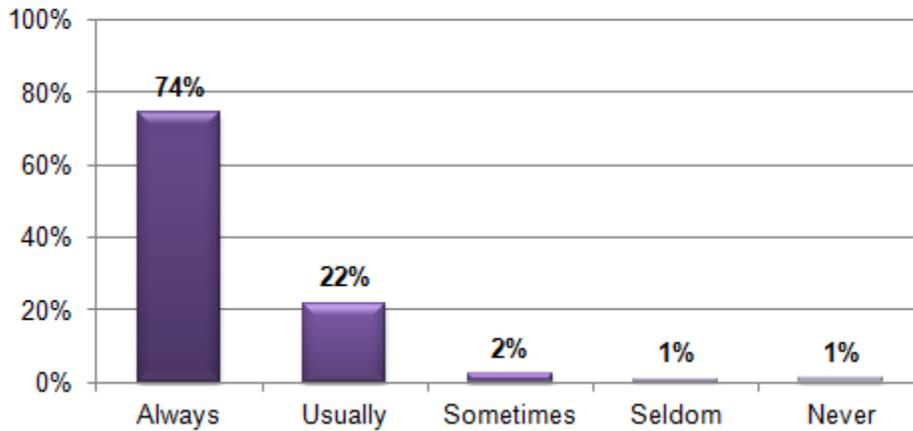


TABLE Q24: ARE SERVICES DELIVERED TO YOUR FAMILY IN A MANNER THAT IS RESPECTFUL TO YOUR FAMILY'S CULTURE(S)?						
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	83%	11%	5%	0%	1%	392
Within NCI Average Range						
FL	80%	18%	1%	0%	1%	341
NC	77%	18%	3%	1%	1%	216
LA	77%	21%	1%	1%	1%	353
NM	77%	21%	1%	1%	0%	538
PA	76%	18%	2%	0%	2%	207
OK	73%	25%	2%	0%	0%	350
Significantly Below NCI Average						
GA	64%	30%	3%	1%	2%	487
NJ	60%	33%	3%	2%	2%	172
NCI Average	74%	22%	2%	1%	1%	3,056

Q25. Does your family member have access to the special equipment or accommodations needed?

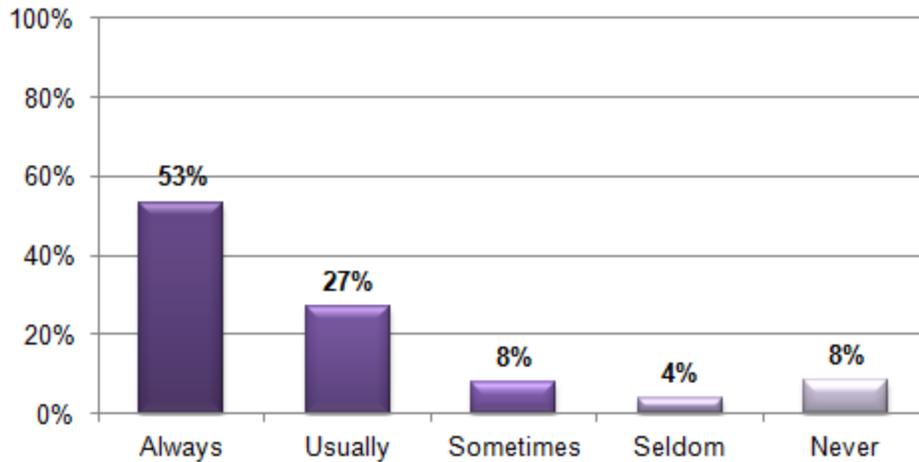


TABLE Q25: DOES YOUR FAMILY MEMBER HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT S/HE NEEDS (FOR EXAMPLE, WHEELCHAIR, RAMP, COMMUNICATION BOARD)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	72%	15%	5%	1%	6%	195
Within NCI Average Range						
NM	60%	27%	5%	4%	4%	294
FL	56%	24%	12%	3%	5%	186
NC	55%	22%	9%	4%	11%	113
OK	52%	31%	10%	3%	3%	224
LA	52%	31%	6%	4%	9%	200
GA	51%	28%	9%	3%	8%	265
PA	47%	35%	7%	3%	7%	95
Significantly Below NCI Average						
NJ	34%	29%	7%	8%	22%	76
NCI Average	53%	27%	8%	4%	8%	1,648

Q26. Do you feel that your family member's day/employment setting is a healthy and safe environment?

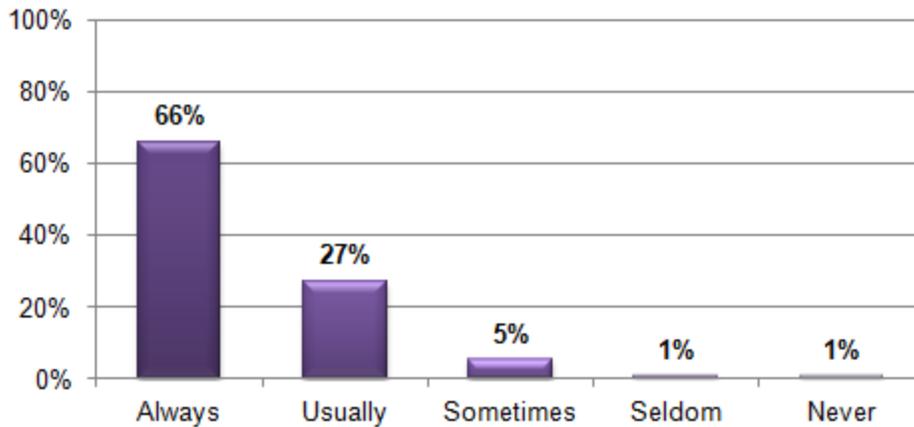


TABLE Q26: DO YOU FEEL THAT YOUR FAMILY MEMBER'S DAY/EMPLOYMENT SETTING IS A HEALTHY AND SAFE ENVIRONMENT?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	77%	17%	5%	0%	1%	388
Within NCI Average Range						
NC	73%	23%	4%	0%	1%	182
OK	71%	25%	2%	1%	0%	286
LA	70%	23%	6%	0%	1%	274
FL	67%	27%	5%	0%	1%	294
PA	65%	29%	4%	1%	1%	224
NM	60%	32%	6%	1%	1%	433
Significantly Below NCI Average						
GA	57%	34%	7%	1%	1%	485
NJ	53%	35%	9%	2%	2%	231
NCI Average	66%	27%	5%	1%	1%	2,797

Q27. Do you feel there is consistency with the support workers who provide services to your family member?

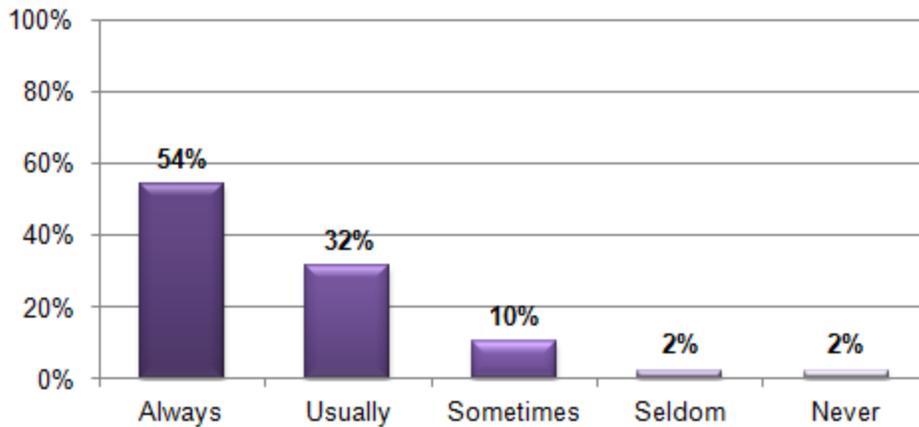


TABLE Q27: DO YOU FEEL THERE IS CONSISTENCY WITH THE SUPPORT WORKERS WHO PROVIDE SERVICES TO YOUR FAMILY MEMBER?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
OH	63%	25%	10%	1%	1%	390
Within NCI Average Range						
LA	57%	28%	10%	3%	2%	367
PA	57%	30%	8%	3%	1%	238
FL	57%	32%	9%	2%	1%	362
NM	56%	31%	11%	1%	1%	540
NC	54%	31%	9%	2%	3%	235
OK	51%	36%	9%	2%	2%	377
Significantly Below NCI Average						
GA	48%	35%	12%	3%	3%	544
NJ	42%	35%	13%	5%	5%	220
NCI Average	54%	32%	10%	2%	2%	3,273

Q28. Are support workers generally courteous?

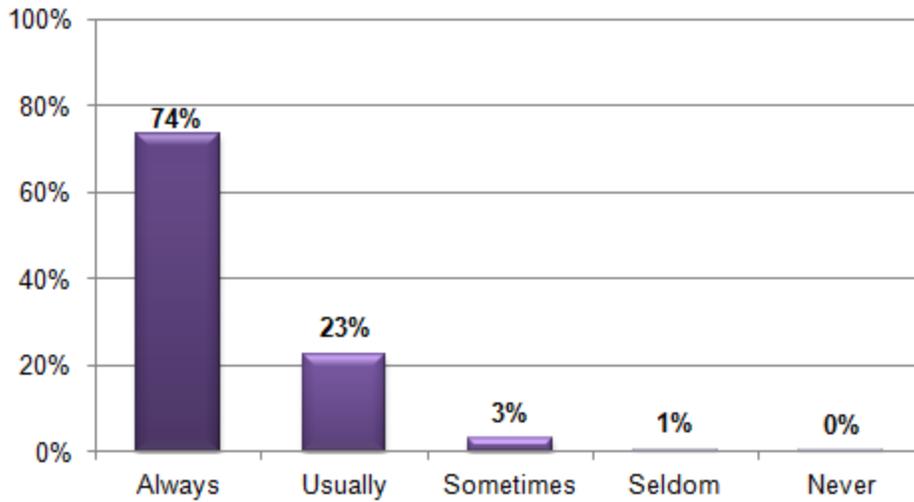


TABLE Q28: ARE SUPPORT WORKERS GENERALLY COURTEOUS?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
FL	81%	17%	2%	0%	0%	370
OH	79%	16%	3%	1%	0%	390
Within NCI Average Range						
NC	79%	17%	2%	0%	1%	241
PA	79%	19%	2%	0%	1%	244
LA	75%	23%	2%	1%	0%	384
NM	73%	22%	4%	1%	0%	555
OK	69%	28%	2%	1%	0%	384
Significantly Below NCI Average						
GA	65%	30%	4%	0%	0%	551
NJ	62%	31%	7%	0%	0%	226
NCI Average	74%	23%	3%	1%	0%	3,345

Q29. Do the support workers have the right training to meet your family's needs?

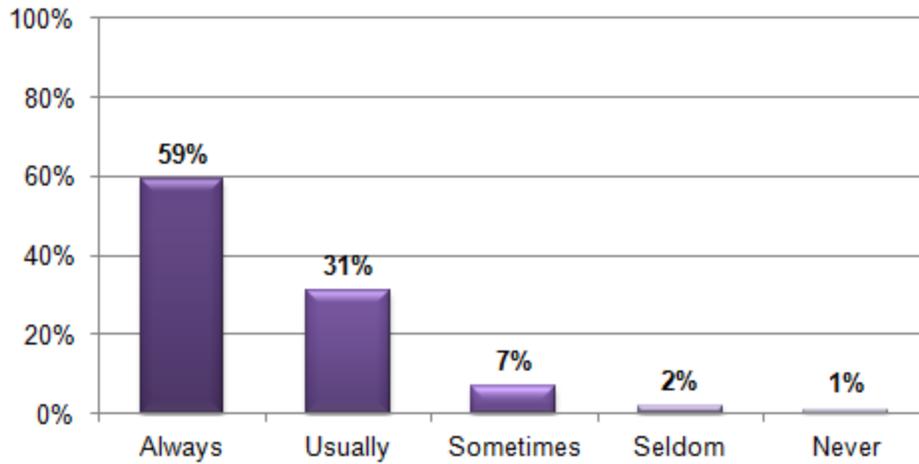


TABLE Q29: DO THE SUPPORT WORKERS HAVE THE RIGHT TRAINING TO MEET YOUR FAMILY'S NEEDS?

State	Always	Usually	Sometimes	Seldom	Never	N
Within NCI Average Range						
NC	66%	28%	4%	1%	0%	226
FL	65%	27%	7%	1%	0%	352
NM	63%	29%	5%	2%	1%	539
OH	63%	28%	7%	2%	1%	374
PA	62%	29%	6%	2%	1%	228
LA	59%	31%	7%	2%	0%	366
OK	59%	35%	4%	1%	1%	367
Significantly Below NCI Average						
GA	52%	36%	10%	1%	1%	495
NJ	45%	37%	12%	4%	3%	200
NCI Average	59%	31%	7%	2%	1%	3,147

Q30. Do the support workers who come to your home arrive on time and when scheduled?

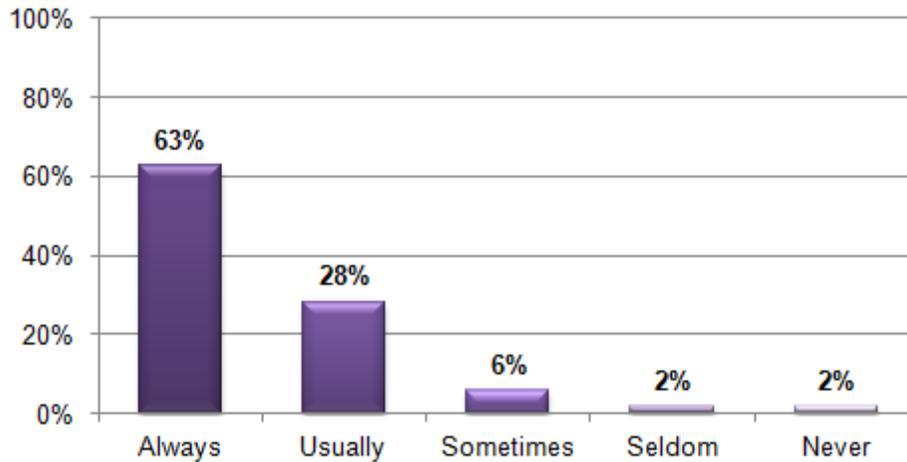


TABLE Q30: DO THE SUPPORT WORKERS WHO COME TO YOUR HOME ARRIVE ON TIME AND WHEN SCHEDULED?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
PA	75%	20%	1%	2%	2%	201
OH	71%	20%	5%	3%	1%	286
Within NCI Average Range						
FL	67%	25%	6%	1%	2%	350
LA	63%	28%	7%	1%	0%	360
NC	61%	30%	5%	2%	2%	210
OK	61%	30%	7%	1%	0%	340
NM	61%	31%	6%	1%	0%	514
NJ	55%	33%	6%	1%	5%	141
Significantly Below NCI Average						
GA	50%	36%	8%	2%	4%	396
NCI Average	63%	28%	6%	2%	2%	2,798

Q31. Were you happy with your family member's transition from school services to State funded services during the past year?

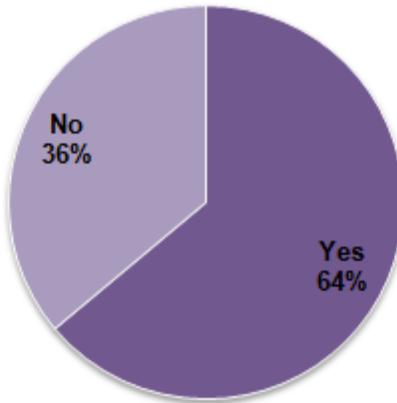


TABLE Q31: IF YOUR FAMILY MEMBER TRANSITIONED FROM SCHOOL SERVICES TO STATE FUNDED SERVICES DURING THE PAST YEAR, WERE YOU HAPPY WITH THE TRANSITION PROCESS?

State	Yes	No	N
Significantly Above NCI Average			
NC	83%	17%	36
Within NCI Average Range			
NJ	71%	29%	34
NM	70%	30%	53
OK	70%	30%	23
LA	66%	34%	32
GA	64%	36%	39
PA	63%	37%	30
FL	63%	37%	43
Significantly Below NCI Average			
OH	26%	74%	50
NCI Average	64%	36%	340

Q32. If you asked for crisis/emergency services during the past year, were services provided when needed?

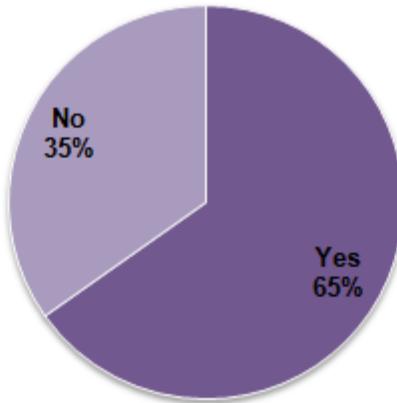


TABLE Q32: IF YOU ASKED FOR CRISIS/EMERGENCY SERVICES DURING THE PAST YEAR, WERE SERVICES PROVIDED WHEN NEEDED?

State	Yes	No	N
Significantly Above NCI Average			
NM	86%	14%	137
LA	79%	21%	108
Within NCI Average Range			
NC	73%	27%	64
FL	70%	30%	97
OK	68%	32%	62
PA	68%	33%	40
GA	65%	35%	138
NJ	58%	42%	59
Significantly Below NCI Average			
OH	21%	79%	87
NCI Average	65%	35%	792

Q33. Do you have access to health services for your family member?

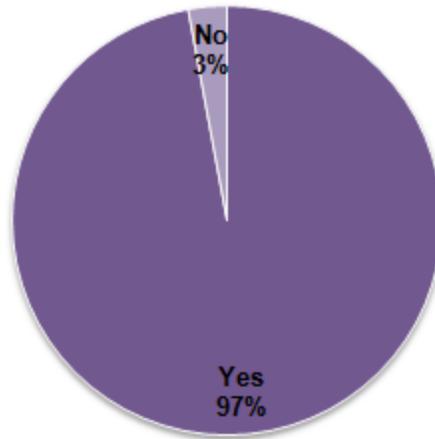


TABLE Q33: DO YOU HAVE ACCESS TO HEALTH SERVICES FOR YOUR FAMILY MEMBER?

State	Yes	No	N
Significantly Above NCI Average			
NM	99%	1%	561
OK	99%	1%	399
Within NCI Average Range			
NC	98%	2%	258
LA	97%	3%	383
PA	97%	3%	263
GA	96%	4%	550
FL	96%	4%	359
OH	96%	4%	390
NJ	95%	5%	226
NCI Average	97%	3%	3,389

Q34. Are you satisfied with the quality of health service providers?

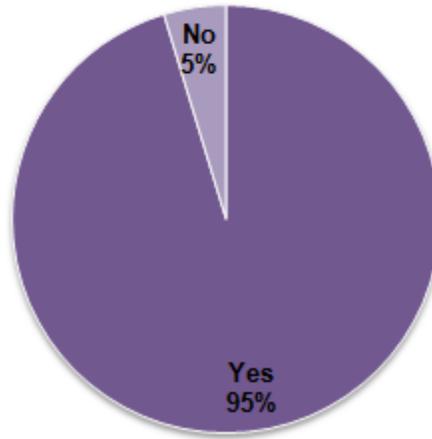


TABLE Q34: IF "YES" (TO Q33), ARE YOU SATISFIED WITH THE QUALITY OF THESE PROVIDERS?

State	Yes	No	N
Significantly Above NCI Average			
OK	98%	2%	380
Within NCI Average Range			
OH	97%	3%	371
NM	96%	4%	534
LA	96%	4%	355
GA	96%	4%	490
PA	95%	5%	237
NC	94%	6%	247
FL	94%	6%	326
NJ	92%	8%	190
NCI Average	95%	5%	3,130

Q35. Do you have access to dental services for your family member?

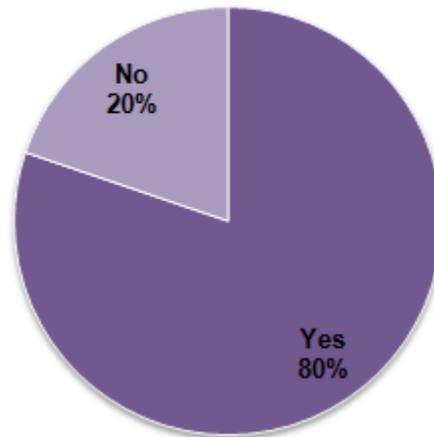


TABLE Q35: DO YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR FAMILY MEMBER?

State	Yes	No	N
Significantly Above NCI Average			
NM	95%	5%	560
NC	90%	10%	248
OH	86%	14%	383
Within NCI Average Range			
NJ	86%	14%	229
PA	81%	19%	255
OK	80%	20%	376
Significantly Below NCI Average			
GA	75%	25%	549
FL	67%	33%	334
LA	61%	39%	358
NCI Average	80%	20%	3,292

Q36. Are you satisfied with the quality of dental service providers?

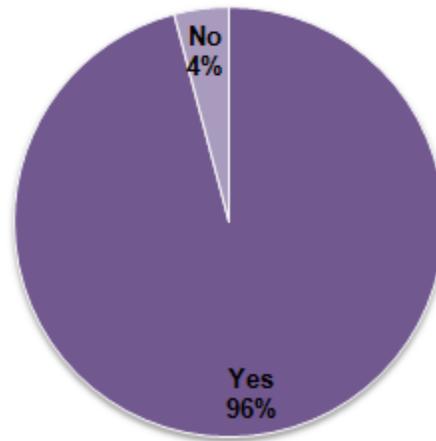


TABLE Q36: IF "YES" (TO Q35), ARE YOU SATISFIED WITH THE QUALITY OF THESE PROVIDERS?

State	Yes	No	N
Within NCI Average Range			
LA	98%	2%	209
PA	98%	2%	199
OK	98%	2%	281
OH	96%	4%	324
NC	96%	4%	214
GA	96%	4%	373
NJ	95%	5%	179
NM	95%	5%	517
Significantly Below NCI Average			
FL	91%	9%	201
NCI Average	96%	4%	2,497

Q37. Do you have access to necessary medications for your family member?

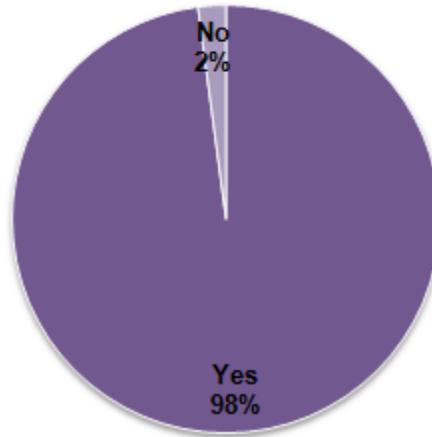


TABLE Q37: DO YOU HAVE ACCESS TO NECESSARY MEDICATIONS FOR YOUR FAMILY MEMBER?

State	Yes	No	N
Within NCI Average Range			
OK	99%	1%	386
NM	99%	1%	550
LA	98%	2%	384
OH	98%	2%	363
PA	98%	2%	253
NC	98%	2%	252
FL	97%	3%	358
GA	97%	3%	552
NJ	96%	4%	226
NCI Average	98%	2%	3,324

Q38. Are you satisfied with how your family member's medication needs are monitored?

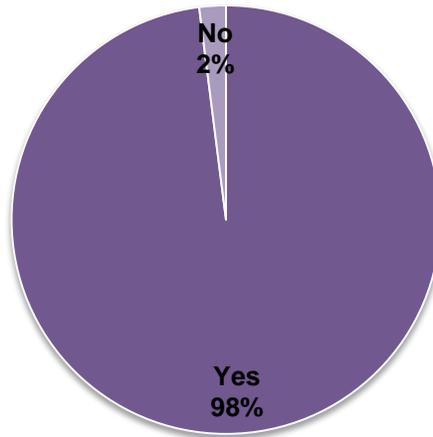


TABLE Q38: IF "YES" (TO Q37), ARE YOU SATISFIED WITH HOW YOUR FAMILY MEMBER'S MEDICATION NEEDS ARE MONITORED?

State	Yes	No	N
Significantly Above NCI Average			
OK	100%	0%	354
Within NCI Average Range			
PA	99%	1%	233
NM	98%	2%	519
NJ	98%	2%	188
OH	98%	2%	342
NC	97%	3%	238
GA	97%	3%	488
LA	97%	3%	359
FL	96%	4%	328
NCI Average	98%	2%	3,049

Q39. If applicable, do you have access to mental health services for your family member?

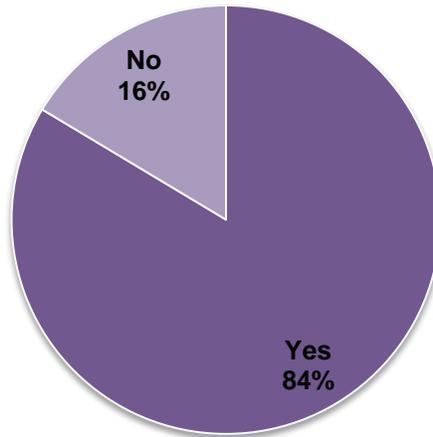


TABLE Q39: IF APPLICABLE, DO YOU HAVE ACCESS TO MENTAL HEALTH SERVICES FOR YOUR FAMILY MEMBER?			
State	Yes	No	N
Significantly Above NCI Average			
OH	91%	9%	317
Within NCI Average Range			
NM	89%	11%	262
NC	89%	11%	157
PA	89%	11%	131
OK	87%	13%	157
GA	83%	17%	326
FL	77%	23%	175
LA	76%	24%	191
Significantly Below NCI Average			
NJ	72%	28%	128
NCI Average	84%	16%	1,844

Q40. Are you satisfied with the quality of mental health service providers?

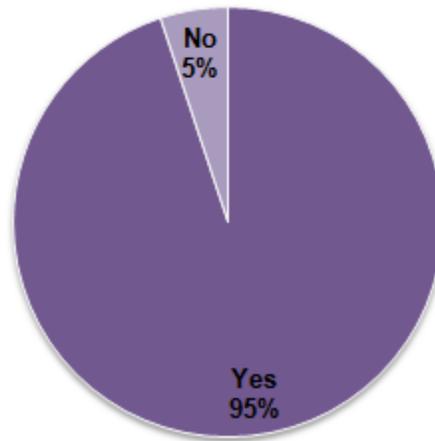


TABLE Q40: IF "YES" (TO Q39), ARE YOU SATISFIED WITH THE QUALITY OF THESE PROVIDERS?

State	Yes	No	N
Within NCI Average Range			
OK	98%	2%	117
LA	97%	3%	137
NM	96%	4%	207
OH	96%	4%	230
FL	95%	5%	114
GA	94%	6%	226
NJ	94%	6%	79
NC	92%	8%	129
PA	92%	8%	102
NCI Average	95%	5%	1,341

Q41. If applicable, do you have access to quality respite services for your family?

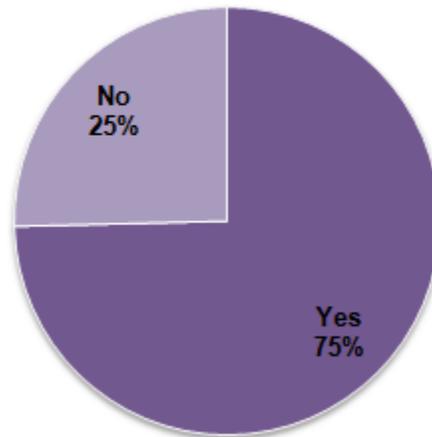


TABLE Q41: IF APPLICABLE, DO YOU HAVE ACCESS TO QUALITY RESPITE SERVICES FOR YOUR FAMILY?

State	Yes	No	N
Significantly Above NCI Average			
NM	86%	14%	471
FL	83%	17%	255
OH	82%	18%	291
LA	82%	18%	232
Within NCI Average Range			
PA	78%	22%	139
NC	78%	22%	180
NJ	71%	29%	161
Significantly Below NCI Average			
GA	61%	39%	322
OK	48%	52%	188
NCI Average	75%	25%	2,239

Q42. Are you satisfied with the quality of respite providers?

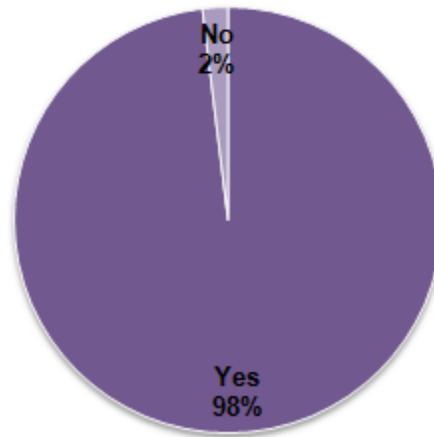


TABLE Q42: IF "YES" (TO Q41), ARE YOU SATISFIED WITH THE QUALITY OF THESE PROVIDERS?

State	Yes	No	N
Within NCI Average Range			
OK	100%	0%	81
OH	98%	2%	199
NC	98%	2%	131
NM	98%	2%	378
PA	98%	2%	98
FL	98%	2%	183
LA	98%	2%	176
GA	97%	3%	159
NJ	97%	3%	92
NCI Average	98%	2%	1,497

Q43. Are there other services that your family member needs that are not currently offered or available?

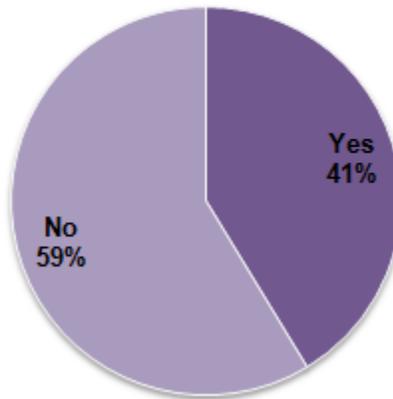


TABLE Q43: ARE THERE OTHER SERVICES THAT YOUR FAMILY MEMBER NEEDS THAT ARE NOT CURRENTLY OFFERED OR AVAILABLE?⁷

State	Yes	No	N
Significantly Above NCI Average			
NJ	68%	32%	144
FL	53%	47%	262
GA	49%	51%	374
Within NCI Average Range			
LA	43%	57%	249
NC	42%	58%	178
OK	38%	62%	273
PA	34%	66%	160
Significantly Below NCI Average			
NM	32%	68%	392
OH	12%	88%	387
NCI Average	41%	59%	2,419

⁷ For this question, states who are “significantly below NCI average” are seen as having the more positive outcomes.

Choices and Control

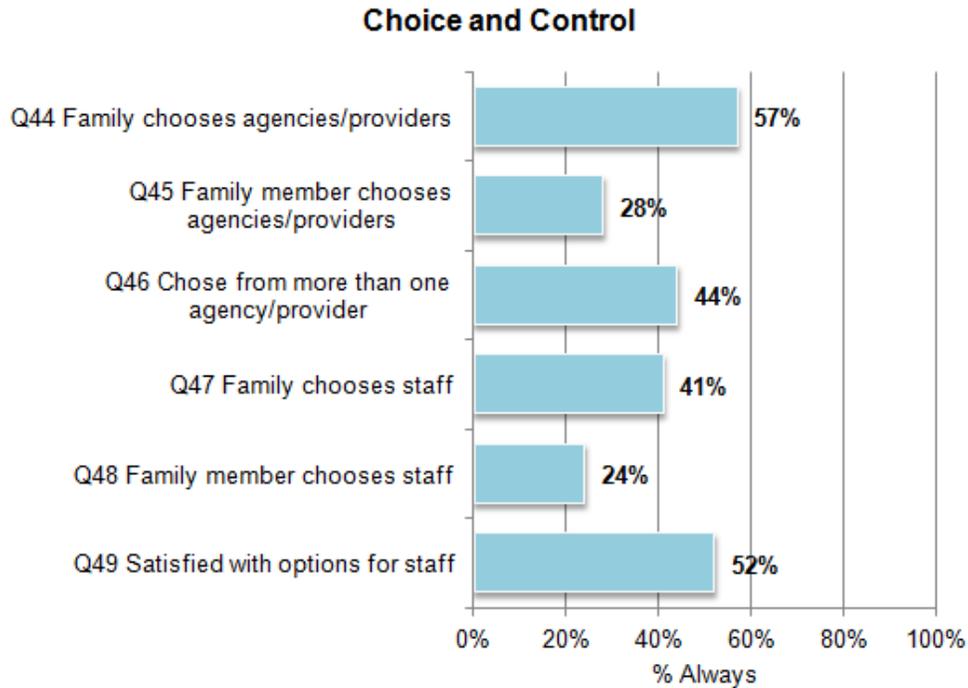
Overall across states, scores for the 18 Choices and Control questions were relatively low: Many averages tended to be lower than 50% for those who answered questions with an “always” or “yes” response. In addition, the ranges between the highest and lowest ranking states also tended to be greater than in other sections. Still, four states often rated significantly above the NCI Average: New Mexico on 16 questions; Florida on 15; Oklahoma on 11; and Louisiana on 7.

For three questions, fewer than one-quarter of respondents answered with either an “always” or “yes” response:

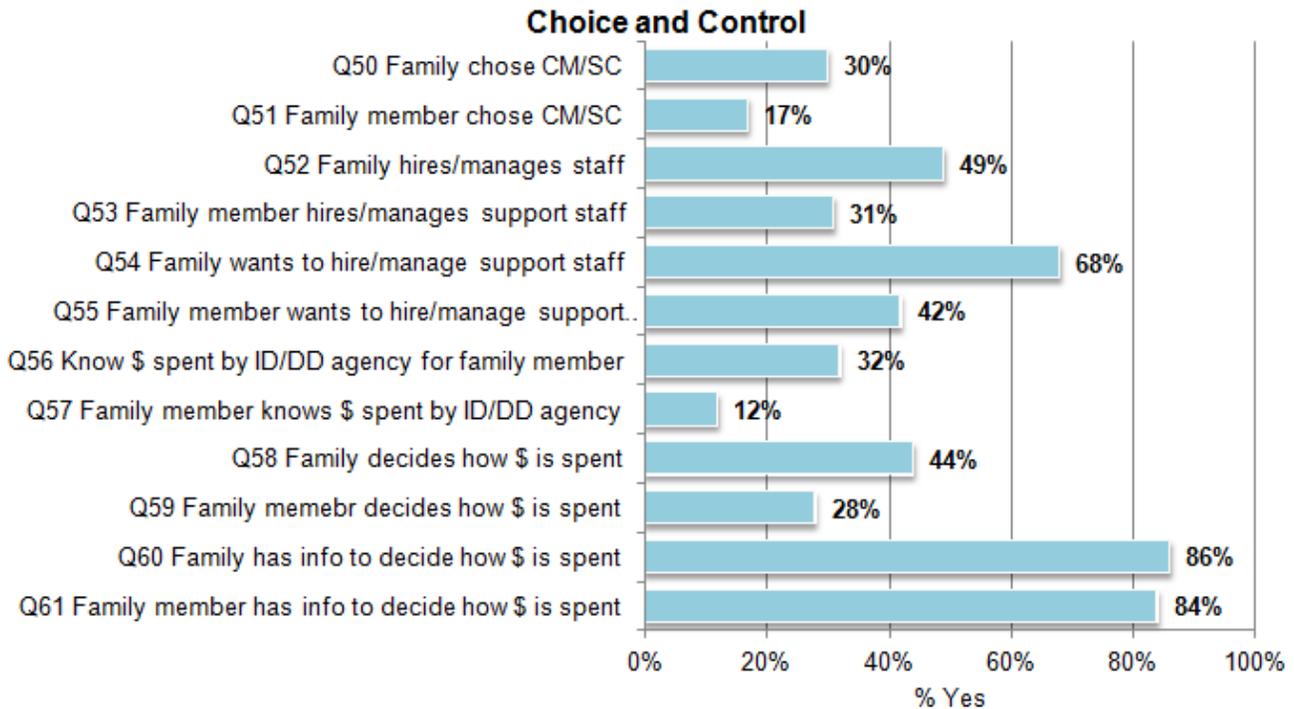
- 12% reported their family member knows how much money is spent by the ID/DD agency on his or her behalf; state averages ranged from 4% to 25%.
- 17% indicated their family member chose his or her case manager/service coordinator; state averages ranged from 3% to 40%.
- 24% indicated their family member always chooses his or her individual support workers; state averages of ‘always’ responses ranged from 12% to 37%.

While 44% of respondents indicated they had a say in how to spend their family member’s ID/DD money, only 28% indicated their family member had this choice. Most of those who reported that they or their family member decided how to spend ID/DD agency money indicated they received enough information to do so (86% and 84%, 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.



Q44. Do you choose the agencies or provider organizations who work with your family?

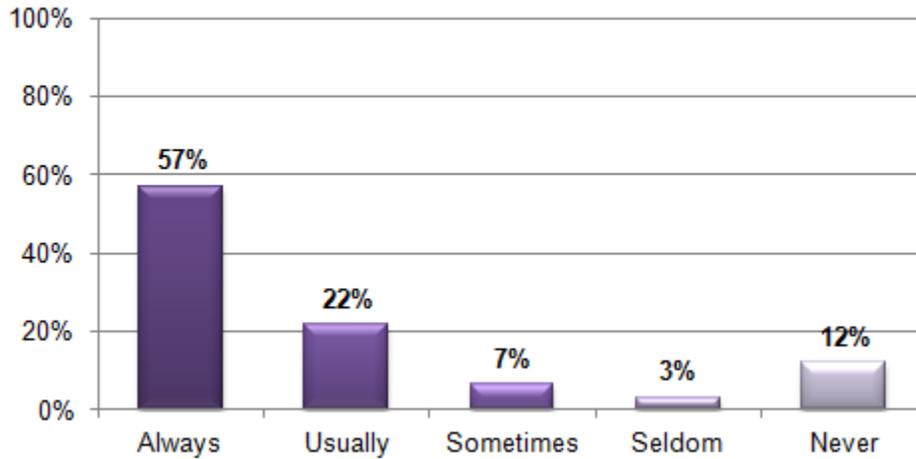


TABLE Q44: DO YOU CHOOSE THE AGENCIES OR PROVIDER ORGANIZATIONS WHO WORK WITH YOUR FAMILY?						
State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	77%	18%	2%	0%	2%	555
LA	74%	16%	2%	0%	6%	371
OK	73%	17%	4%	2%	4%	396
Within NCI Average Range						
NC	62%	25%	5%	2%	6%	236
FL	58%	21%	5%	2%	14%	354
Significantly Below NCI Average						
OH	48%	16%	15%	4%	17%	369
PA	41%	28%	10%	7%	14%	223
GA	40%	30%	6%	4%	20%	489
NJ	39%	22%	10%	6%	24%	200
NCI Average	57%	22%	7%	3%	12%	3,193

Q45. Does your family member choose the agencies or provider organizations who work with your family?

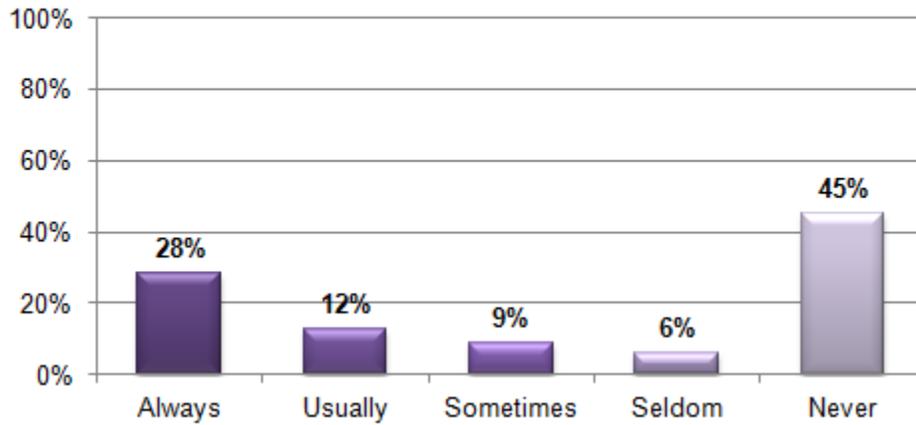


TABLE Q45: DOES YOUR FAMILY MEMBER CHOOSE THE AGENCIES OR PROVIDER ORGANIZATIONS WHO WORK WITH YOUR FAMILY?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
LA	41%	11%	6%	4%	39%	327
FL	40%	15%	5%	3%	36%	321
NM	38%	15%	13%	6%	28%	497
OK	37%	11%	7%	5%	40%	334
Within NCI Average Range						
NC	25%	15%	9%	7%	44%	202
PA	21%	15%	10%	6%	48%	199
Significantly Below NCI Average						
GA	21%	17%	6%	8%	49%	460
OH	19%	8%	15%	5%	52%	350
NJ	12%	6%	7%	8%	68%	179
NCI Average	28%	12%	9%	6%	45%	2,869

Q46. Do you or your family member choose from more than one agency/provider organization?

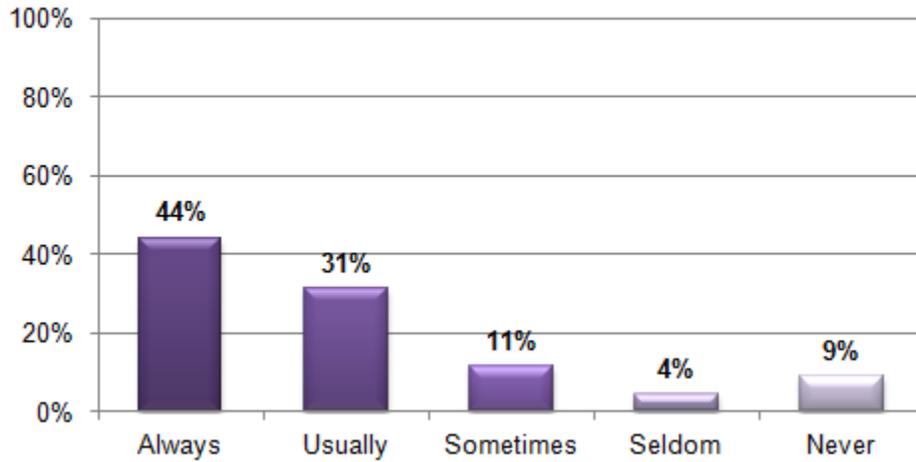


TABLE Q46: IF YOU OR YOUR FAMILY MEMBER AT LEAST SOMETIMES CHOOSE THE AGENCIES OR PROVIDER ORGANIZATIONS, DO YOU HAVE MORE THAN ONE AGENCY/PROVIDER ORGANIZATION TO CHOOSE FROM?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	60%	30%	6%	3%	1%	307
LA	60%	26%	6%	2%	6%	164
Within NCI Average Range						
NC	51%	30%	9%	3%	7%	89
FL	48%	41%	4%	2%	5%	170
OK	46%	34%	11%	3%	6%	145
OH	43%	23%	16%	4%	14%	141
GA	34%	31%	13%	6%	16%	159
PA	29%	38%	14%	10%	10%	73
NJ	27%	27%	24%	5%	16%	37
NCI Average	44%	31%	11%	4%	9%	1,285

Q47. Do you choose the individual support workers who work directly with your family?

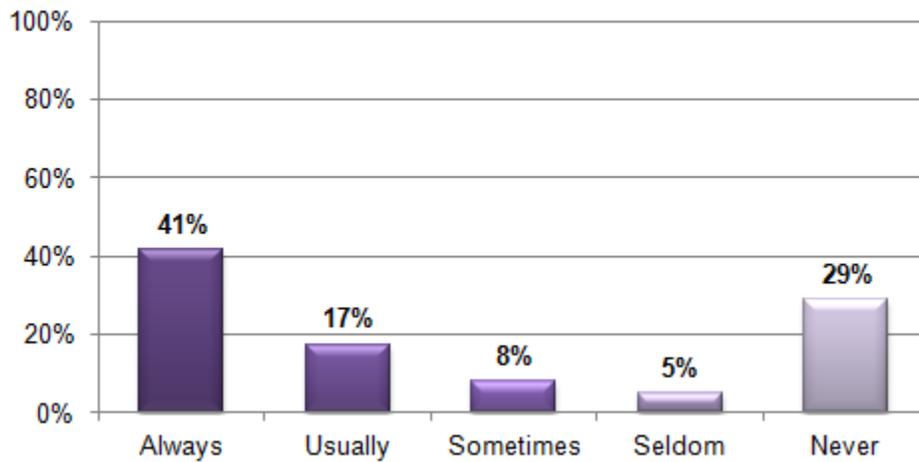


TABLE Q47: DO YOU CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH YOUR FAMILY?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
LA	57%	18%	5%	4%	16%	358
OK	54%	19%	8%	5%	13%	360
FL	54%	20%	6%	2%	18%	349
NM	54%	22%	10%	4%	10%	528
Within NCI Average Range						
NC	46%	22%	8%	8%	17%	235
OH	35%	12%	10%	4%	39%	375
Significantly Below NCI Average						
NJ	26%	15%	6%	3%	50%	177
GA	26%	13%	9%	6%	47%	468
PA	21%	15%	10%	7%	47%	207
NCI Average	41%	17%	8%	5%	29%	3,057

Q48. Does your family member choose the individual support workers who work directly with your family?

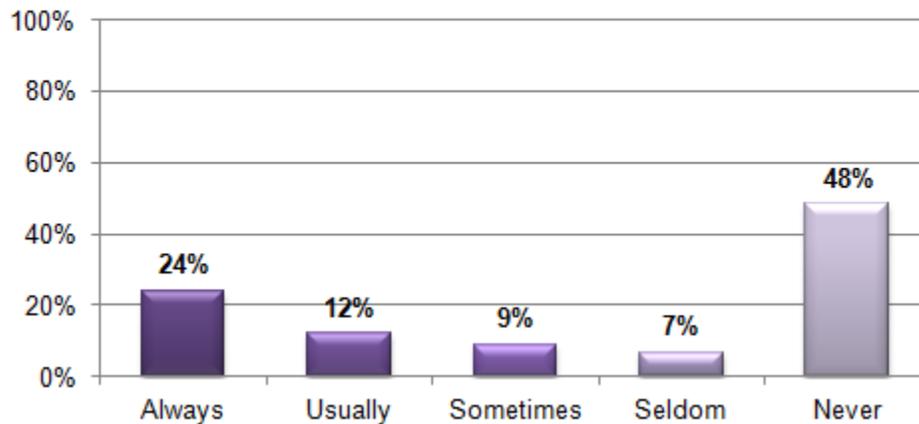


TABLE Q48: DOES YOUR FAMILY MEMBER CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH YOUR FAMILY?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
FL	37%	16%	7%	4%	36%	318
LA	35%	10%	9%	6%	41%	334
NM	31%	19%	13%	9%	28%	499
Within NCI Average Range						
OK	29%	16%	10%	7%	39%	314
NC	26%	13%	10%	8%	42%	213
Significantly Below NCI Average						
OH	18%	7%	11%	4%	59%	359
GA	16%	10%	8%	6%	59%	437
PA	12%	12%	8%	9%	59%	196
NJ	12%	7%	4%	6%	72%	163
NCI Average	24%	12%	9%	7%	48%	2,833

Q49. Are you satisfied with the choices for individual support workers who work directly with your family?

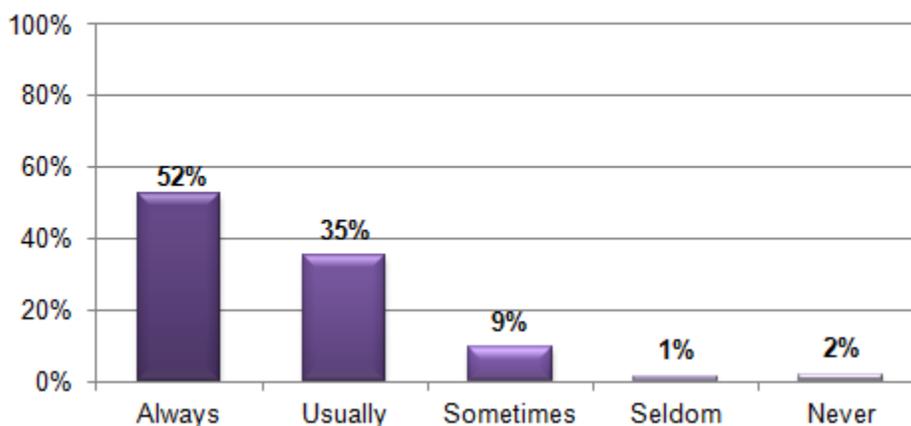


TABLE Q49: IF YOU OR YOUR FAMILY MEMBER AT LEAST SOMETIMES CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH YOUR FAMILY, ARE YOU SATISFIED WITH THE OPTIONS AVAILABLE?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
LA	63%	24%	9%	2%	2%	174
NM	60%	30%	9%	1%	0%	311
Within NCI Average Range						
OH	59%	28%	12%	2%	0%	130
FL	57%	35%	7%	1%	0%	186
OK	55%	34%	8%	2%	0%	169
GA	48%	33%	12%	1%	5%	155
NC	47%	40%	11%	0%	2%	105
NJ	42%	44%	11%	0%	3%	36
PA	40%	46%	6%	1%	6%	67
NCI Average	52%	35%	9%	1%	2%	1,333

Q50. Did you choose your family member's case manager/service coordinator?

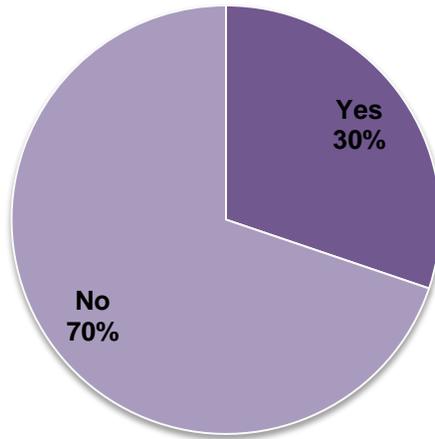


TABLE Q50: DID YOU CHOOSE YOUR FAMILY MEMBER'S CASE MANAGER/SERVICE COORDINATOR?

State	Yes	No	N
Significantly Above NCI Average			
NM	71%	29%	555
FL	66%	34%	374
LA	46%	54%	369
NC	42%	58%	239
Significantly Below NCI Average			
OK	13%	87%	387
GA	11%	89%	534
OH	9%	91%	396
PA	8%	92%	245
NJ	5%	95%	243
NCI Average	30%	70%	3,342

Q51. Did your family member choose his/her case manager/service coordinator?

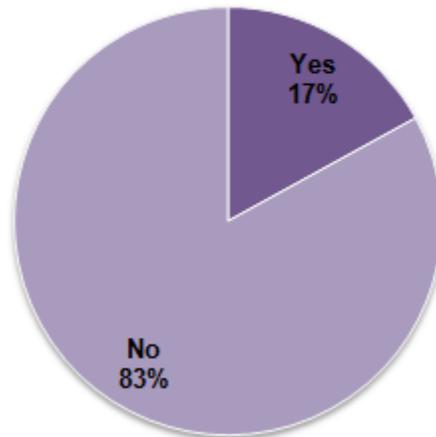


TABLE Q51: DID YOUR FAMILY MEMBER CHOOSE HIS/HER CASE MANAGER/SERVICE COORDINATOR?

State	Yes	No	N
Significantly Above NCI Average			
FL	40%	60%	339
NM	37%	63%	526
Within NCI Average Range			
LA	22%	78%	353
NC	20%	80%	224
Significantly Below NCI Average			
OK	9%	91%	376
GA	7%	93%	509
OH	7%	93%	383
PA	7%	93%	244
NJ	3%	97%	236
NCI Average	17%	83%	3,190

Q52. Do you have control and/or input over the hiring and management of your family member's support workers?

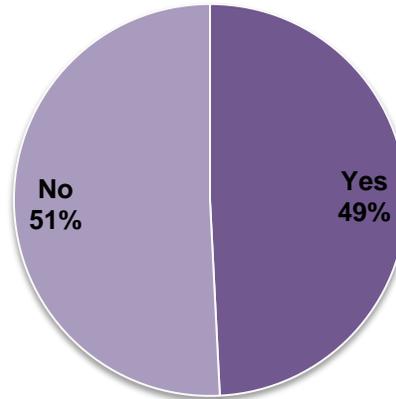


TABLE Q52: DO YOU HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF YOUR FAMILY MEMBER'S SUPPORT WORKERS?

State	Yes	No	N
Significantly Above NCI Average			
FL	73%	27%	345
NM	73%	27%	513
OK	64%	36%	342
LA	63%	38%	352
NC	61%	39%	231
Significantly Below NCI Average			
OH	32%	68%	372
PA	30%	70%	210
GA	26%	74%	483
NJ	21%	79%	196
NCI Average	49%	51%	3,044

Q53. Do your family member have control and/or input over the hiring and management of his/her support workers?

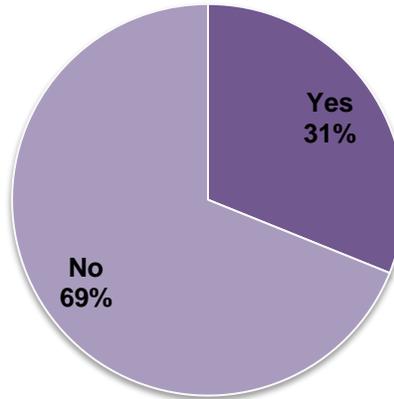


TABLE Q53: DOES YOUR FAMILY MEMBER HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF YOUR FAMILY MEMBER'S SUPPORT WORKERS?

State	Yes	No	N
Significantly Above NCI Average			
FL	51%	49%	304
NM	50%	50%	477
OK	39%	61%	318
Within NCI Average Range			
LA	38%	62%	325
NC	35%	65%	212
Significantly Below NCI Average			
OH	21%	79%	363
PA	19%	81%	201
GA	18%	82%	478
NJ	9%	91%	180
NCI Average	31%	69%	2,858

Q54. Do you want to have control and/or input over the hiring and management of your family member's support workers?

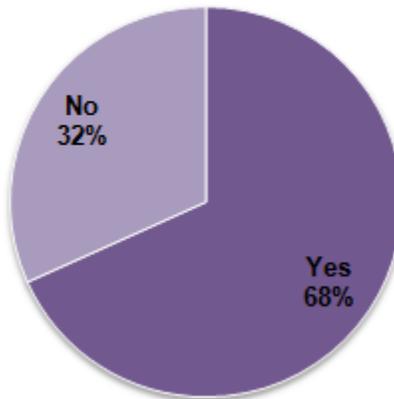


TABLE Q54: DO YOU WANT TO HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF YOUR FAMILY MEMBER'S SUPPORT WORKERS?

State	Yes	No	N
Significantly Above NCI Average			
NM	84%	16%	475
FL	83%	17%	311
OK	82%	18%	342
NC	76%	24%	211
Within NCI Average Range			
LA	74%	26%	336
NJ	66%	34%	163
Significantly Below NCI Average			
GA	54%	46%	439
OH	48%	52%	384
PA	47%	53%	190
NCI Average	68%	32%	2,851

Q55. Does your family member want to have control and/or input over the hiring and management of support workers?

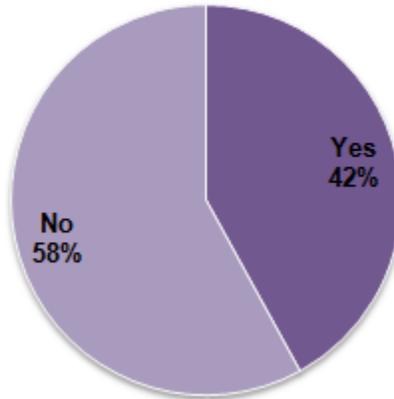


TABLE Q55: DOES YOUR FAMILY MEMBER WANT TO HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF YOUR FAMILY MEMBER'S SUPPORT WORKERS?

State	Yes	No	N
Significantly Above NCI Average			
FL	56%	44%	264
NM	55%	45%	404
Within NCI Average Range			
OK	49%	51%	282
NC	47%	53%	179
LA	46%	54%	291
NJ	39%	61%	143
Significantly Below NCI Average			
GA	33%	67%	402
OH	29%	71%	358
PA	24%	76%	181
NCI Average	42%	58%	2,504

Q56. Do you know how much money is spent by the ID/DD agency on behalf of your family member with a developmental disability?

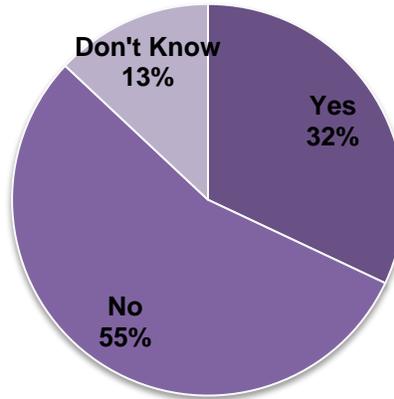


TABLE Q56: DO YOU KNOW HOW MUCH MONEY IS SPENT BY THE ID/DD AGENCY ON BEHALF OF YOUR FAMILY MEMBER WITH A DEVELOPMENTAL DISABILITY?

State	Yes	No	Don't Know	N
Significantly Above NCI Average				
FL	59%	31%	10%	372
OK	55%	33%	12%	403
NM	50%	35%	15%	557
Within NCI Average Range				
GA	28%	61%	11%	574
PA	25%	60%	15%	267
Significantly Below NCI Average				
LA	22%	60%	18%	387
NC	18%	69%	12%	242
OH	18%	82%	1%	401
NJ	15%	68%	17%	236
NCI Average	32%	55%	13%	3,439

Q57. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?



TABLE Q57: 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
Significantly Above NCI Average				
FL	25%	65%	10%	322
NM	19%	67%	14%	518
OK	18%	71%	10%	346
Within NCI Average Range				
LA	12%	75%	13%	369
GA	11%	77%	11%	533
PA	9%	78%	13%	255
Significantly Below NCI Average				
NC	5%	86%	9%	228
NJ	5%	80%	16%	219
OH	4%	93%	3%	401
NCI Average	12%	77%	11%	3,191

Q58. Do you have a say in how ID/DD agency money is spent?

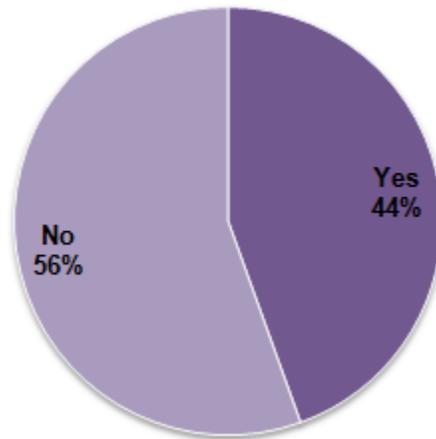


TABLE Q58: DO YOU HAVE A SAY IN HOW THIS MONEY IS SPENT?

State	Yes	No	N
Significantly Above NCI Average			
NM	74%	26%	466
OK	72%	28%	351
FL	65%	35%	309
Within NCI Average Range			
GA	39%	61%	469
PA	39%	61%	201
Significantly Below NCI Average			
OH	34%	66%	383
NC	26%	74%	189
LA	26%	74%	281
NJ	25%	75%	185
NCI Average	44%	56%	2,834

Q59. Does your family member have a say in how ID/DD agency money is spent?

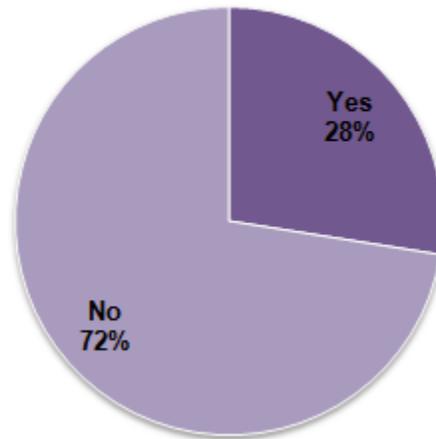


TABLE Q59: DOES YOUR FAMILY MEMBER HAVE A SAY IN HOW THIS MONEY IS SPENT?

State	Yes	No	N
Significantly Above NCI Average			
NM	49%	51%	444
FL	40%	60%	280
OK	40%	60%	308
Within NCI Average Range			
PA	29%	71%	198
GA	24%	76%	451
Significantly Below NCI Average			
OH	19%	81%	376
LA	17%	83%	293
NC	15%	85%	189
NJ	14%	86%	176
NCI Average	28%	72%	2,715

Q60. Do you have the information needed to decide how to spend ID/DD agency money?

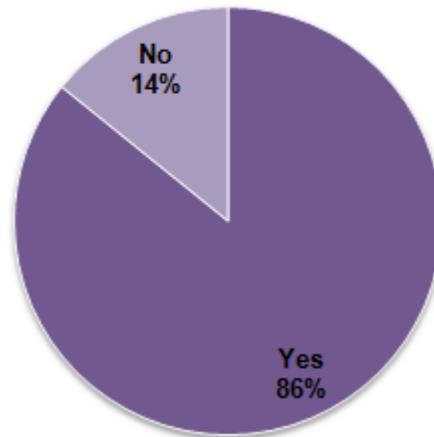


TABLE Q60: IF "YES" (TO Q58), DO YOU HAVE ALL THE INFORMATION YOU NEED TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?

State	Yes	No	N
Significantly Above NCI Average			
FL	95%	5%	168
OK	92%	8%	212
Within NCI Average Range			
NC	92%	8%	37
LA	89%	11%	66
NM	87%	13%	301
PA	85%	15%	68
OH	81%	19%	126
NJ	78%	22%	37
Significantly Below NCI Average			
GA	72%	28%	154
NCI Average	86%	14%	1,169

Q61. Does your family member have the information needed to decide how to spend ID/DD agency money?

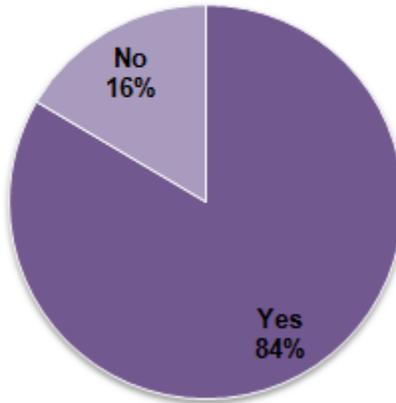


TABLE Q61: IF "YES" (TO Q59), DOES YOUR FAMILY MEMBER HAVE ALL THE INFORMATION S/HE NEEDS TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?

State	Yes	No	N
Within NCI Average Range			
LA	91%	9%	45
OK	90%	10%	106
PA	87%	13%	47
FL	86%	14%	96
NC	84%	16%	25
NM	82%	18%	178
OH	77%	23%	69
GA	73%	27%	83
NCI Average	84%	16%	649

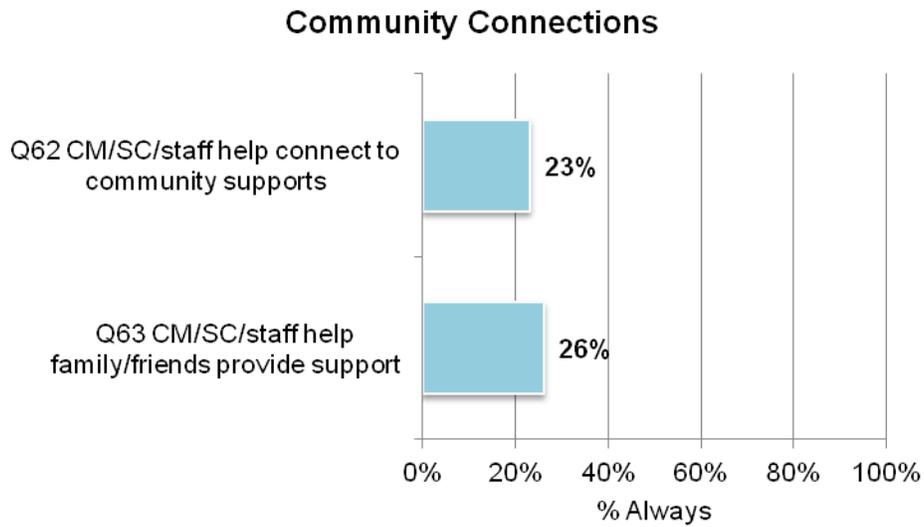
Community Connections

The Community Connections section is composed of five questions that pertain to the family member's involvement in community activities and their relationships. While two of these questions showed relatively low results, three had more positive findings. On all five questions, New Mexico scored significantly above the NCI Average; Oklahoma rated significantly above the NCI Average on three questions.

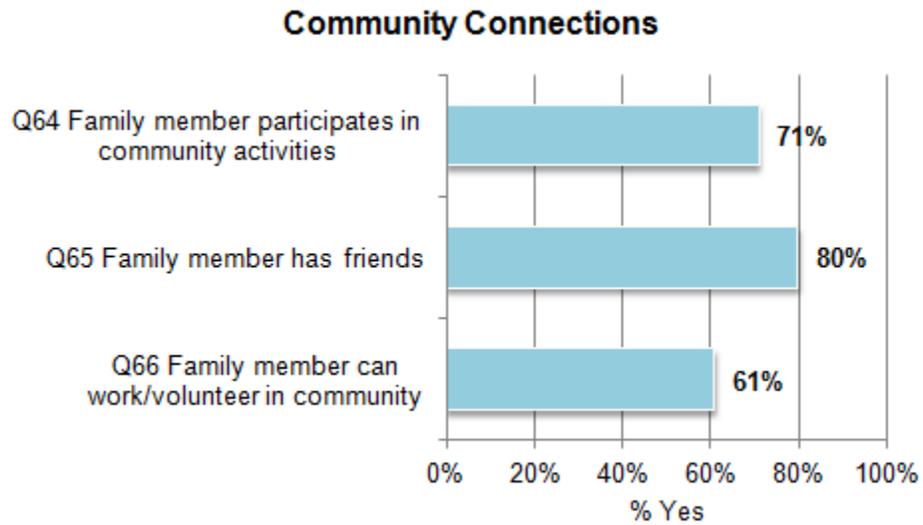
Just 23% of respondents reported that their family member's case manager/service coordinator or support workers always help them to use community supports (such as recreation departments or churches). Similarly, 26% reported their family member's case manager/service coordinator or support workers always help family, friends, or neighbors provide support.

Still, 61% reported their family member has enough support to work or volunteer in the community; 71% report that their family member participates in community activities; and 80% report that their family member has friends or relationships with people other than family or staff.

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



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



Q62. Does the case manager/service coordinator or the support workers help connect you to community supports?

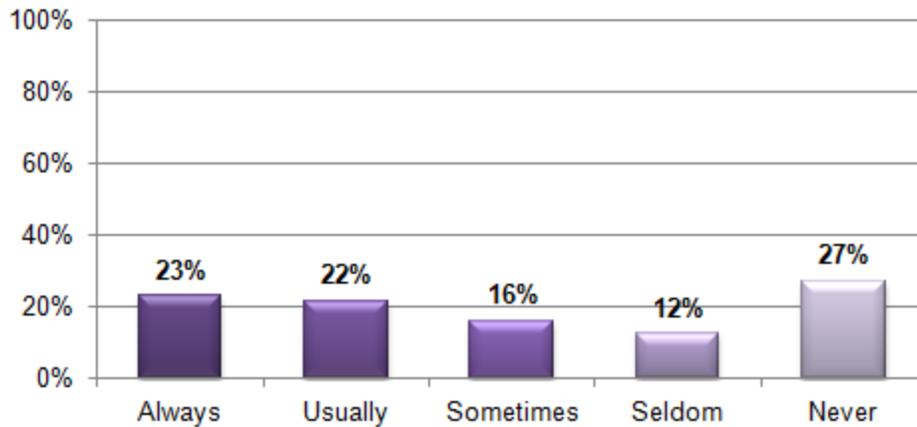


TABLE Q62: IF YOU WANT TO USE TYPICAL SUPPORTS IN YOUR COMMUNITY (FOR EXAMPLE, THROUGH RECREATION DEPARTMENTS OR CHURCHES), DO EITHER THE CASE MANAGER/SERVICE COORDINATOR WHO HELPS PLAN OR THE SUPPORT WORKERS WHO PROVIDE SUPPORT HELP CONNECT YOU TO THESE SUPPORTS?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	36%	29%	16%	8%	11%	462
FL	31%	19%	20%	8%	21%	252
Within NCI Average Range						
PA	24%	27%	17%	12%	20%	153
OK	24%	19%	17%	13%	27%	290
NC	24%	26%	16%	12%	22%	197
OH	22%	19%	20%	13%	26%	222
LA	22%	21%	12%	14%	31%	259
GA	18%	19%	15%	16%	33%	389
Significantly Below NCI Average						
NJ	6%	15%	12%	14%	53%	156
NCI Average	23%	22%	16%	12%	27%	2,380

Q63. Does the case manager/service coordinator or the support workers help family, friends, and neighbors provide support?

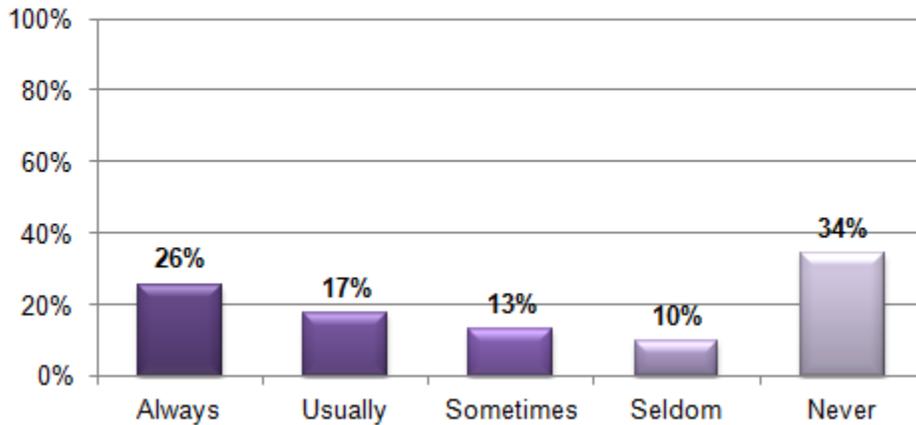


TABLE Q63: IF YOU WOULD LIKE TO USE FAMILY, FRIENDS, OR NEIGHBORS TO PROVIDE SOME OF THE SUPPORTS YOUR FAMILY NEEDS, DO EITHER THE CASE MANAGER/SERVICE COORDINATOR WHO HELPS PLAN OR THE SUPPORT WORKERS WHO PROVIDE SUPPORT HELP YOU DO THIS?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	43%	26%	11%	7%	13%	443
Within NCI Average Range						
FL	33%	19%	13%	8%	26%	247
OK	30%	20%	14%	10%	27%	285
NC	29%	19%	9%	9%	34%	161
PA	28%	18%	12%	10%	32%	154
LA	25%	20%	11%	9%	34%	263
OH	19%	10%	22%	12%	38%	209
Significantly Below NCI Average						
GA	16%	16%	12%	12%	43%	362
NJ	6%	9%	12%	11%	61%	142
NCI Average	26%	17%	13%	10%	34%	2,266

Q64. Does your family member participate in community activities?

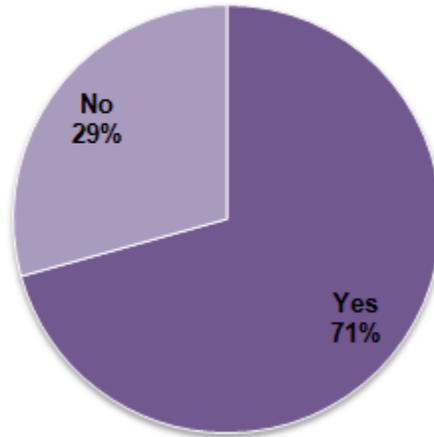


TABLE Q64: DOES YOUR FAMILY MEMBER PARTICIPATE IN COMMUNITY ACTIVITIES?

State	Yes	No	N
Significantly Above NCI Average			
NM	89%	11%	558
OK	81%	19%	392
Within NCI Average Range			
GA	74%	26%	543
NC	74%	26%	250
PA	67%	33%	265
FL	67%	33%	365
LA	66%	34%	380
OH	66%	34%	401
Significantly Below NCI Average			
NJ	53%	47%	242
NCI Average	71%	29%	3,396

Q65. Does your family member have friends or relationships with persons other than support workers or family?

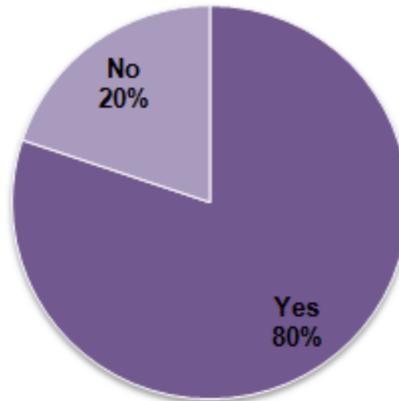


TABLE Q65: DOES YOUR FAMILY MEMBER HAVE FRIENDS OR RELATIONSHIPS WITH PERSONS OTHER THAN PAID SUPPORT WORKERS OR FAMILY?

State	Yes	No	N
Significantly Above NCI Average			
OK	90%	10%	392
NM	88%	12%	559
Within NCI Average Range			
PA	84%	16%	256
FL	82%	18%	362
GA	79%	21%	536
LA	79%	21%	378
OH	77%	23%	398
NC	76%	24%	246
Significantly Below NCI Average			
NJ	67%	33%	239
NCI Average	80%	20%	3,366

Q66. Does your family member have enough supports to work or volunteer in the community?

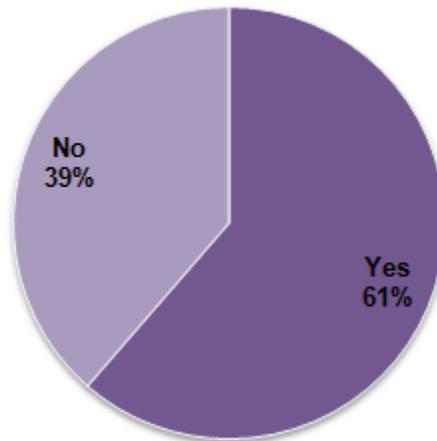


TABLE Q66: DOES YOUR FAMILY MEMBER HAVE ENOUGH SUPPORTS (E.G., SUPPORT WORKERS, COMMUNITY RESOURCES) TO WORK OR VOLUNTEER IN THE COMMUNITY?

State	Yes	No	N
Significantly Above NCI Average			
NM	74%	26%	464
OK	69%	31%	313
Within NCI Average Range			
PA	69%	31%	188
OH	66%	34%	361
NC	63%	37%	200
GA	61%	39%	429
LA	60%	40%	269
FL	58%	42%	266
Significantly Below NCI Average			
NJ	31%	69%	162
NCI Average	61%	39%	2,652

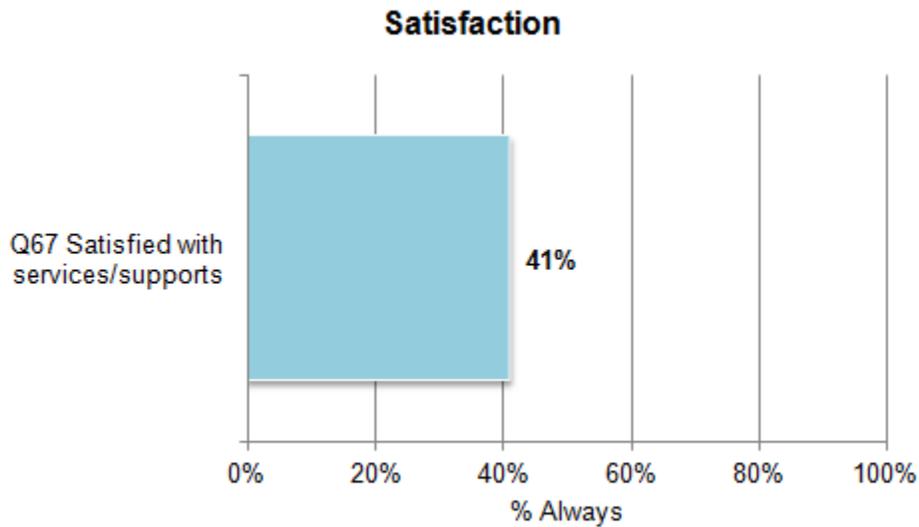
Satisfaction with Services and Supports

Though overall results in the Satisfaction section were positive, most questions revealed a high level of variation among states. Notably, results for many questions included a 40-percentage-point differential across states. New Mexico was significantly above the NCI Average on four of the six questions in this section.

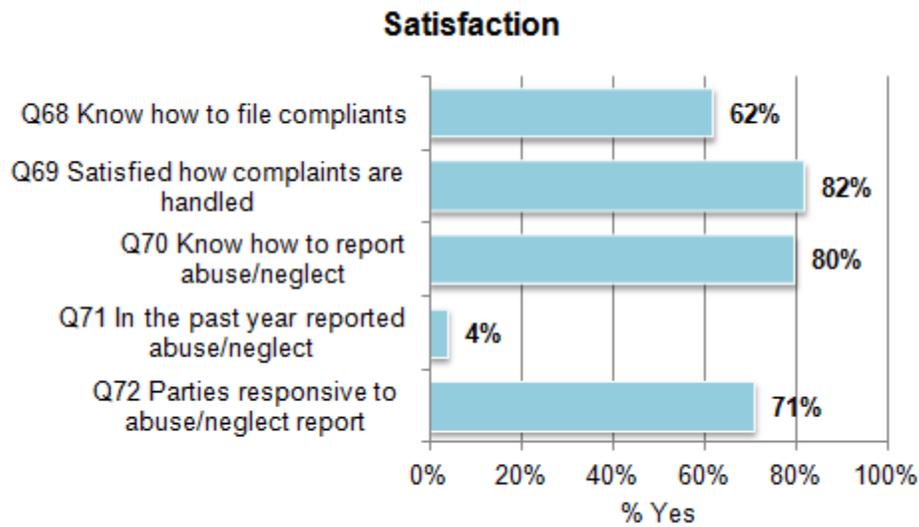
Across states, 41% of respondents were always satisfied with services and supports (an additional 43% were usually satisfied).

- 82% of respondents were satisfied with the way complaints or grievances regarding provider agencies or staff were handled (state averages ranged from 53% to 93%.)
- 80% knew how to report abuse or neglect claims (state averages ranged from 52% to 96%)
- 62% knew how to file a complaint or grievance (state averages ranged from 20% to 86%)

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.



Q67. Overall, are you satisfied with the services and supports your family and family member currently receive?

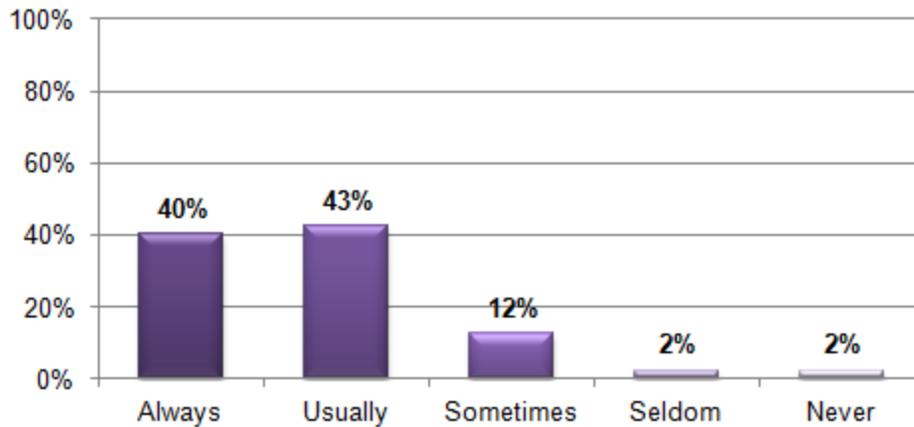


TABLE Q67: OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS YOUR FAMILY AND FAMILY MEMBER CURRENTLY RECEIVE?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above NCI Average						
NM	54%	39%	5%	2%	0%	570
OH	51%	35%	11%	2%	1%	400
Within NCI Average Range						
LA	44%	41%	12%	1%	1%	393
FL	41%	45%	11%	2%	1%	367
OK	40%	47%	11%	2%	0%	410
NC	39%	44%	10%	3%	4%	248
GA	37%	41%	16%	2%	4%	567
PA	36%	48%	13%	2%	2%	263
Significantly Below NCI Average						
NJ	22%	43%	21%	6%	7%	233
NCI Average	40%	43%	12%	2%	2%	3,451

Q68. Are you familiar with the process for filing a complaint or grievance against your provider agency/agencies or staff that provide services?

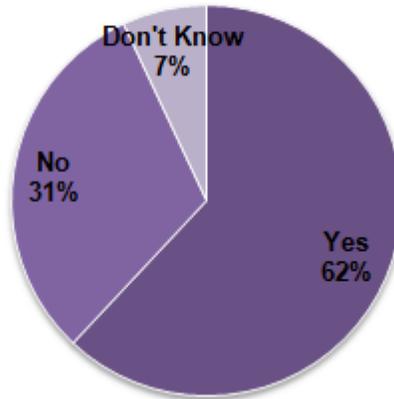


TABLE Q68: ARE YOU FAMILIAR WITH THE PROCESS FOR FILING A COMPLAINT OR GRIEVANCE REGARDING PROBLEMS WITH YOUR PROVIDER AGENCY/AGENCIES OR STAFF THAT PROVIDE SERVICES?

State	Yes	No	Don't Know	N
Significantly Above NCI Average				
NM	86%	12%	2%	567
OK	77%	18%	4%	387
OH	75%	24%	1%	401
LA	71%	24%	4%	394
FL	70%	23%	8%	371
Within NCI Average Range				
NC	59%	32%	9%	246
PA	59%	28%	13%	255
Significantly Below NCI Average				
GA	41%	48%	10%	551
NJ	20%	68%	12%	240
NCI Average	62%	31%	7%	3,412

Q69. Are you satisfied with the way complaints/grievances regarding provider agencies or staff are handled and resolved?

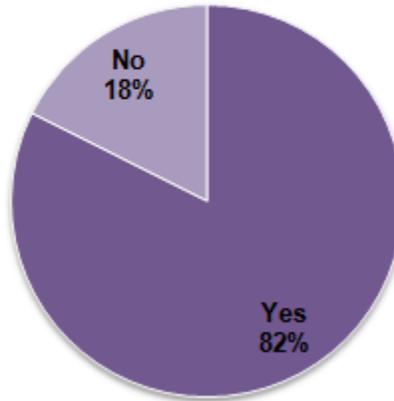


TABLE Q69: ARE YOU SATISFIED WITH THE WAY COMPLAINTS/GRIEVANCES REGARDING PROVIDER AGENCIES OR STAFF ARE HANDLED AND RESOLVED?

State	Yes	No	N
Significantly Above NCI Average			
PA	93%	7%	83
LA	91%	9%	234
NM	89%	11%	366
Within NCI Average Range			
OH	88%	13%	256
OK	86%	14%	203
FL	86%	14%	195
NC	83%	17%	131
Significantly Below NCI Average			
GA	73%	27%	269
NJ	53%	47%	53
NCI Average	82%	18%	1,790

Q70. Do you know how to report abuse and neglect?

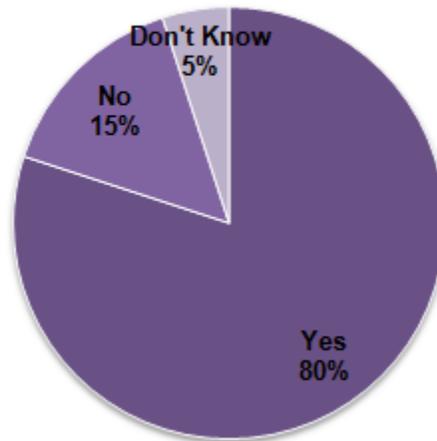


TABLE Q70: DO YOU KNOW HOW TO REPORT ABUSE AND NEGLECT?

State	Yes	No	Don't Know	N
Significantly Above NCI Average				
NM	96%	3%	1%	571
OK	90%	6%	4%	383
FL	87%	9%	3%	375
Within NCI Average Range				
LA	85%	10%	6%	395
OH	85%	14%	1%	401
NC	83%	13%	4%	254
PA	78%	14%	8%	247
Significantly Below NCI Average				
GA	63%	30%	7%	553
NJ	52%	38%	10%	229
NCI Average	80%	15%	5%	3,408

Q71. In the past year, did you report abuse and neglect?

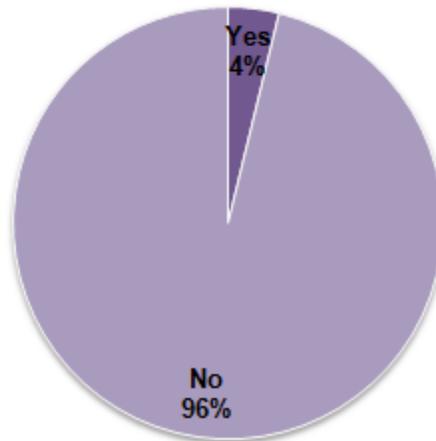


TABLE Q71: IN THE PAST YEAR, DID YOU REPORT ABUSE AND NEGLECT?⁸

State	Yes	No	N
Significantly Above NCI Average			
GA	7%	93%	524
Within NCI Average Range			
NM	5%	95%	552
NJ	5%	95%	231
FL	4%	96%	373
LA	4%	96%	375
OK	3%	97%	382
OH	2%	98%	401
NC	2%	98%	245
Significantly Below NCI Average			
PA	1%	99%	251
NCI Average	4%	96%	3,334

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

Q72. If you reported abuse or neglect in the past year, were the appropriate parties responsive to your report?

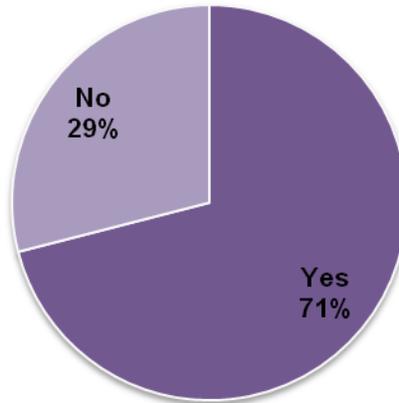


TABLE Q72: IF "YES" (TO Q71), WERE THE APPROPRIATE PARTIES RESPONSIVE TO YOUR REPORT?

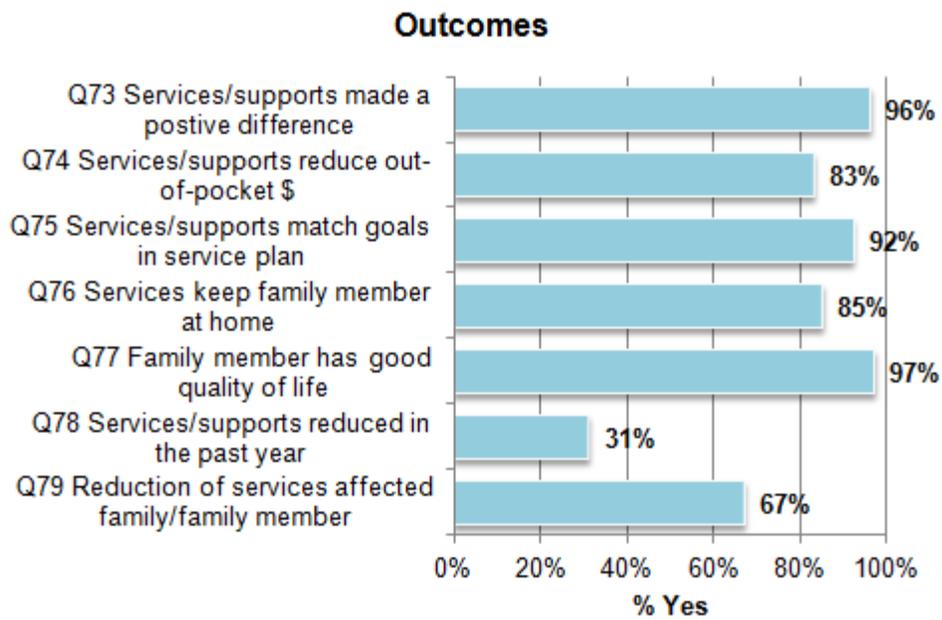
State	Yes	No	N
Within NCI Average Range			
NM	75%	25%	20
GA	67%	33%	24
KY	71%	29%	44
NCI Average	71%	29%	88

Outcomes

Results from the seven Outcomes questions showed particularly high ratings with little variance among states. Nearly all respondents felt that: their family member had a good quality of life (97%); services and supports made a positive difference in their family's life (96%); and services and supports addressed goals in their family member's service plan (92%).

Just 31% of respondents across states indicated their family member's services or supports had been reduced, suspended, or terminated in the past year; of those, 67% felt the reduction impacted their family member's life in some way. Interestingly, while New Mexico had the second highest percentage of respondents who indicated that supports were reduced in some capacity, the state scored significantly above the NCI average on five questions where higher averages indicated more positive results. Oklahoma also rated significantly above the NCI average on five questions.

The graph below shows the state average for all Outcomes questions.



Q73. Do you feel that services and supports have made a positive difference in the life of your family?

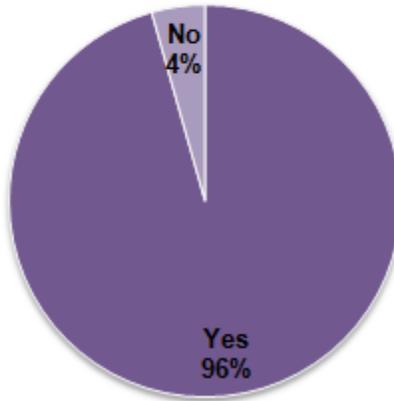


Table Q73: Do you feel that services and supports have made a positive difference in the life of your family?

State	Yes	No	N
Significantly Above NCI Average			
OK	99%	1%	384
LA	98%	2%	378
NM	98%	2%	556
Within NCI Average Range			
FL	97%	3%	352
PA	97%	3%	238
GA	96%	4%	533
NC	94%	6%	236
OH	92%	8%	394
Significantly Below NCI Average			
NJ	88%	12%	208
NCI Average	96%	4%	3,279

Q74. Do you feel that services and supports have reduced your family's out-of-pocket expenses related to your family member's care?

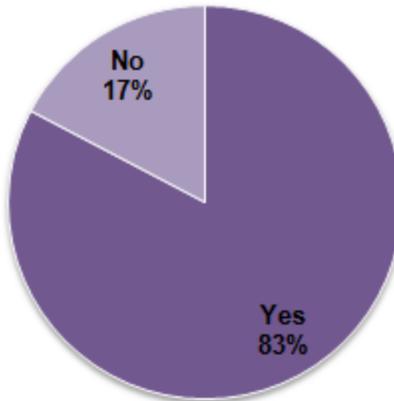


TABLE Q74: DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE REDUCED YOUR FAMILY'S OUT-OF-POCKET EXPENSES RELATED TO YOUR FAMILY MEMBER'S CARE?

State	Yes	No	N
Significantly Above NCI Average			
OK	91%	9%	374
FL	89%	11%	335
NM	88%	12%	519
Within NCI Average Range			
PA	86%	14%	207
LA	82%	18%	365
NC	80%	20%	213
GA	78%	22%	509
Significantly Below NCI Average			
OH	76%	24%	382
NJ	73%	27%	207
NCI Average	83%	17%	3,111

Q75. Do you feel that services and supports address the goals outlined in your family member's service plan?

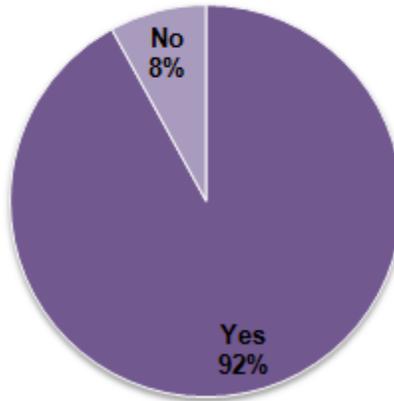


TABLE Q75: DO YOU FEEL THAT SERVICES AND SUPPORTS ADDRESS THE GOALS OUTLINED IN YOUR FAMILY MEMBER'S SERVICE PLAN?

State	Yes	No	N
Significantly Above NCI Average			
NM	96%	4%	535
PA	96%	4%	197
OK	96%	4%	375
Within NCI Average Range			
LA	95%	5%	347
OH	95%	5%	310
FL	93%	7%	334
GA	90%	10%	477
NC	90%	10%	223
Significantly Below NCI Average			
NJ	77%	23%	162
NCI Average	92%	8%	2,960

Q76. Have services made a difference in helping keep your family member at home?

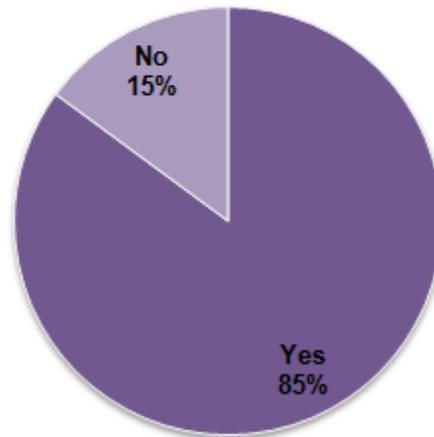


TABLE Q76: HAVE SERVICES MADE A DIFFERENCE IN HELPING KEEP YOUR FAMILY MEMBER AT HOME?

State	Yes	No	N
Significantly Above NCI Average			
NM	95%	5%	532
LA	92%	8%	354
OK	91%	9%	378
Within NCI Average Range			
FL	89%	11%	332
NC	87%	13%	211
GA	83%	17%	473
PA	79%	21%	216
Significantly Below NCI Average			
NJ	76%	24%	192
OH	74%	26%	386
NCI Average	85%	15%	3,074

Q77. Overall, do you feel your family member has a good quality of life?

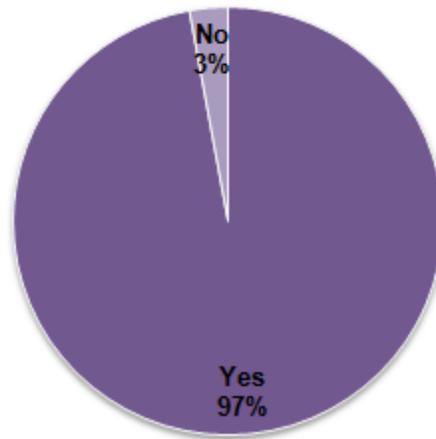


TABLE Q77: OVERALL, DO YOU FEEL YOUR FAMILY MEMBER HAS A GOOD QUALITY OF LIFE?

State	Yes	No	N
Significantly Above NCI Average			
OK	99%	1%	393
NM	99%	1%	553
Within NCI Average Range			
OH	99%	2%	400
LA	98%	2%	394
PA	97%	3%	265
FL	96%	4%	358
GA	96%	4%	545
NC	95%	5%	247
NJ	95%	5%	230
NCI Average	97%	3%	3,385

Q78. Have the services or supports received been either reduced, suspended, or terminated in the past year?

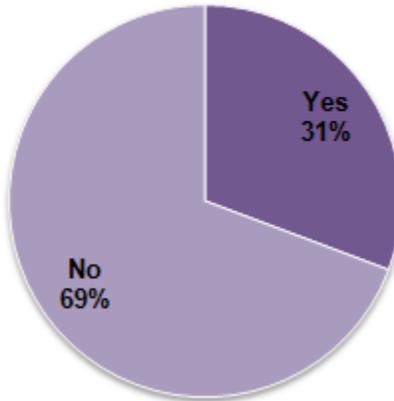


TABLE Q78: HAVE THE SERVICES OR SUPPORTS THAT YOU OR YOUR FAMILY MEMBER HAS RECEIVED DURING THE PAST YEAR BEEN EITHER REDUCED, SUSPENDED, OR TERMINATED?⁹

State	Yes	No	N
Significantly Above NCI Average			
FL	46%	54%	336
NM	44%	56%	517
Within NCI Average Range			
NC	36%	64%	224
NJ	33%	67%	199
LA	32%	68%	364
GA	26%	74%	521
Significantly Below NCI Average			
OK	23%	77%	374
PA	22%	78%	234
OH	13%	87%	387
NCI Average	31%	69%	3,156

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

Q79. Did the reduction of these services or supports affect your family or your family member's home, job, relationships, etc.?

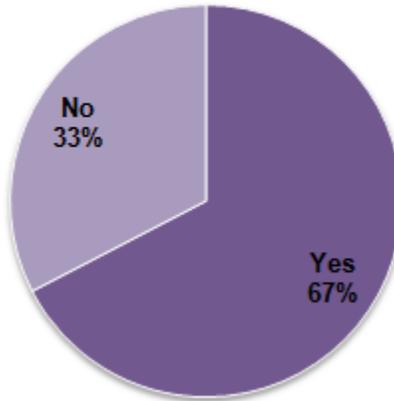


TABLE Q79: IF “YES” (TO Q78), DID THE REDUCTION/SUSPENSION/TERMINATION OF THESE SERVICES OR SUPPORTS AFFECT YOUR FAMILY OR YOUR FAMILY MEMBER’S HOME, JOB, RELATIONSHIPS, ETC.?¹⁰

State	Yes	No	N
Within NCI Average Range			
FL	75%	25%	129
NJ	75%	25%	59
OK	74%	26%	73
LA	73%	27%	101
GA	73%	27%	113
NC	68%	32%	73
NM	68%	32%	192
PA	59%	41%	41
Significantly Below NCI Average			
OH	42%	58%	50
NCI Average	67%	33%	831

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 overall percentage of positive (i.e., above average) results by section and overall for each state. Table 26 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. Three questions were excluded from this overall analysis; one because there were not enough answers to break out the results by state (Q21) and the other two because it was determined that the questions did not indicate a positive or negative result (Q54 and Q55).

TABLE 26. OVERALL STATE RESULTS							
State	Information/ Planning	Access/ Delivery	Choice/ Control	Community Connections	Satisfaction	Outcomes	Total
FL	50%	13%	75%	20%	33%	14%	32%
GA	0%	0%	0%	0%	0%	0%	0%
LA	25%	7%	50%	0%	33%	29%	22%
NC	0%	7%	13%	0%	0%	0%	5%
NJ	0%	0%	0%	0%	0%	0%	0%
NM	92%	43%	88%	100%	67%	71%	68%
OH	75%	63%	0%	0%	33%	29%	42%
OK	25%	10%	63%	60%	33%	86%	36%
PA	0%	3%	0%	0%	33%	29%	7%