

Adult Family Survey

2016-17 Final Report

Update 6/28/2018 for 508 compliance



NATIONAL CORE INDICATORS

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



Human Services
Research Institute

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List of Abbreviations Used in This Report

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

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Executive Summary

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

The National Core Indicators (NCI) Adult Family Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who lives in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Adult Family Survey on an annual basis. Of the 46 states, the District of Columbia and 22 sub-state entities who participated in NCI during the 2016-17 data collection cycle, 16 states submitted a valid sample of Adult Family Survey data. This Final Report provides a summary of results based on data submitted by June 30, 2017.

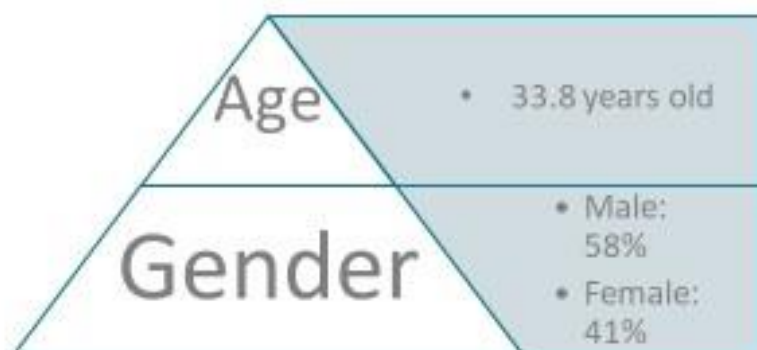
The following are NCI national averages for a selection of survey items. Complete breakouts by state for each item in the Adult Family Survey can be found in the Results section of this report.

Note: *All qualified Californians with a developmental disability have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. California law mandates that the intake process begin within 15 days of an individual's or family's request for services and that the Department of Developmental Services begin providing services within 120 days after intake. These statutory requirements make California's service system unique and could impact comparisons between its survey results and the results of other states.*

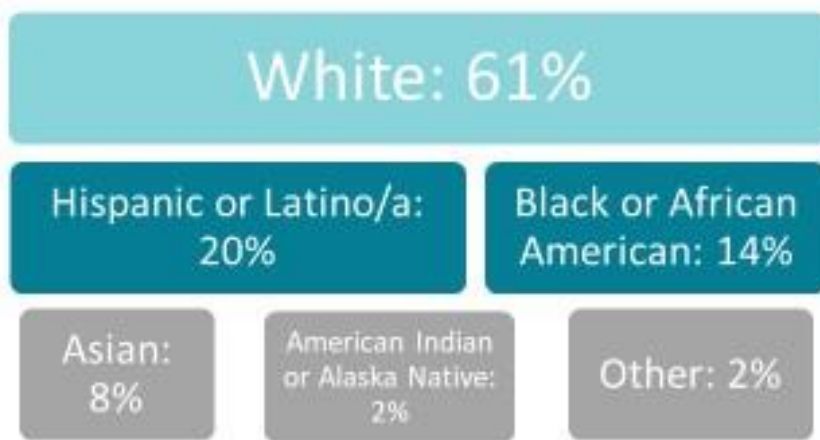
LOOKING AT THE 2016-17 ADULT FAMILY SURVEY (AFS)

Respondents: families or guardians adults (aged 18 and over) with an intellectual/developmental disability. The adult with the disability lives in the family home (with the respondent) and receives at least one service funded by the state developmental disability agency in addition to case management. 16 states*: Total sample: 11,419

Respondents reported the following about their family members:



Race/ethnicity



Legal guardianship



Respondents reported the following about themselves:

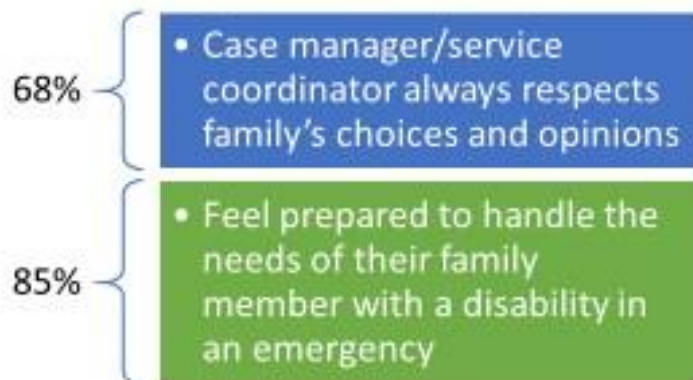


33% of responding families reported a household income of **\$25,000/year** or less

*AFS: CA, DC, DE, FL, GA, KY, LA, MD, MN, MO, MS, NC, NJ, OK, PA, UT; NCI average is weighted

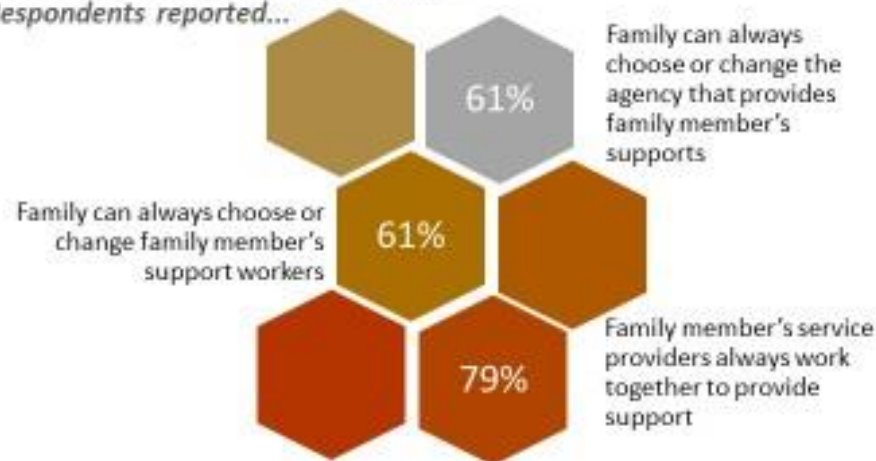
Information and Planning

Respondents reported...



Choice, Decision-making and Control

Respondents reported...



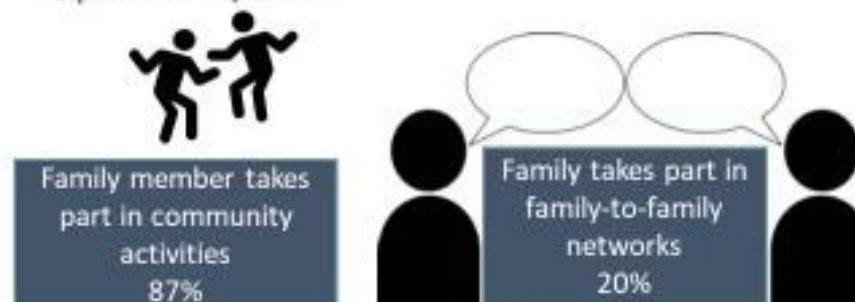
Access and Delivery of Supports and Services

Respondents reported...



Involvement in the Community

Respondents reported...



Satisfaction with Services and Supports



I. Results

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

Survey Development

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

Organization of the Adult Family Survey

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

Demographics

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

Services and Supports Received

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

Questions Regarding Services and Supports

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

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

Presentation of Data

Direct feedback from families is an important means for states to gauge service and support satisfaction and to pinpoint areas for quality improvement. All demographic and individual outcome results from the Adult Family Survey are presented in this report.

Outcome results are presented in six subsections that correspond with the sections of the survey. For each question, the results are first shown in a graph that depicts the NCI Average and then in a table that shows a breakout of each state's percentage.¹

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

States receive an 'n/a' designation in table presentations for a survey item if fewer than 20 people responded; however, their data are included in the NCI Average.

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

Important note on changes to reporting: In previous years, NCI average was calculated as the simple arithmetic mean of all state means (an approach known as "average of averages"). This year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states' systems. Beginning this year, the NCI averages contained in this report are "weighted" means; their calculations reflect the relative population sizes of participating states, as well as the sample sizes. See more about weighting in the Methodology section.

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

¹ Unlike in previous years, the NCI and state averages were weighted, see note below and "Weighting" in the Methodology section for more information.

Demographics

Family Member

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

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

State	Yes	No	N
CA	16%	84%	4,737
DC	16%	84%	235
DE	12%	88%	201
FL	18%	82%	191
GA	13%	87%	386
KY	11%	89%	157
LA	12%	88%	457
MD	10%	90%	1,055
MN	15%	85%	447
MO	11%	89%	244
MS	15%	85%	372
NC	14%	86%	246
NJ	8%	92%	700
OK	9%	91%	416
PA	10%	90%	789
UT	17%	83%	413
NCI Average	14%	86%	11,046

Table 2. Family Member's Age

State	Average Age	N
CA	32.9	4,830
DC	35.6	249
DE	30.6	203
FL	36.1	192
GA	37.0	398
KY	36.0	161
LA	36.6	472
MD	33.3	1,062
MN	30.3	451
MO	31.0	250
MS	36.5	380
NC	33.1	249
NJ	30.9	707
OK	35.0	420
PA	39.7	800
UT	32.9	421
NCI Average	33.8	11,245

Table 3. Family Member's Gender

State	Male	Female	N
CA	60%	40%	4,818
DC	60%	40%	247
DE	68%	32%	200
FL	57%	43%	193
GA	61%	39%	399
KY	60%	40%	160
LA	56%	44%	474
MD	61%	39%	1,055
MN	57%	43%	450
MO	58%	42%	249
MS	53%	47%	380
NC	58%	42%	250
NJ	64%	36%	703
OK	58%	42%	420
PA	55%	45%	799
UT	57%	43%	423
NCI Average	58%	41%	11,220

Table 4. Family Member's Race and Ethnicity

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other
CA	3%	14%	9%	1%	45%	37%	2%
DC	2%	2%	89%	1%	5%	3%	1%
DE	1%	2%	24%	0%	70%	6%	0%
FL	2%	3%	17%	0%	65%	17%	2%
GA	1%	1%	46%	0%	51%	2%	1%
KY	1%	2%	6%	0%	90%	1%	1%
LA	2%	1%	38%	0%	60%	2%	1%
MD	1%	6%	31%	0%	62%	3%	1%
MN	2%	6%	7%	0%	86%	4%	1%
MO	3%	3%	7%	0%	89%	2%	1%
MS	2%	0%	50%	0%	49%	1%	2%
NC	0%	1%	30%	0%	67%	2%	1%
NJ	1%	7%	10%	0%	79%	7%	2%
OK	17%	2%	9%	0%	77%	5%	0%
PA	1%	1%	5%	0%	93%	1%	0%
UT	2%	3%	0%	1%	93%	7%	0%
NCI Average	2%	8%	14%	0%	61%	20%	2%

Table 5a. Family Member's Disabilities

State	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
CA	61%	21%	33%	18%	9%	6%
DC	65%	18%	29%	18%	8%	5%
DE	66%	25%	37%	12%	8%	7%
FL	71%	22%	28%	28%	16%	9%
GA	68%	23%	33%	21%	12%	7%
KY	75%	25%	25%	20%	15%	9%
LA	60%	28%	23%	16%	13%	8%
MD	69%	19%	32%	16%	7%	6%
MN	69%	27%	32%	19%	10%	7%
MO	56%	20%	35%	15%	9%	7%
MS	66%	22%	25%	25%	13%	7%
NC	65%	24%	27%	28%	10%	8%
NJ	63%	23%	46%	16%	8%	3%
OK	77%	22%	21%	27%	16%	8%
PA	84%	22%	19%	21%	12%	7%
UT	78%	24%	28%	20%	14%	7%
NCI Average	65%	22%	31%	20%	10%	7%

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

State	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
CA	10%	24%	2%	15%	0%	1%	16%
DC	10%	21%	0%	13%	1%	4%	13%
DE	8%	25%	1%	18%	0%	1%	23%
FL	9%	35%	1%	18%	0%	1%	23%
GA	9%	33%	1%	15%	1%	2%	14%
KY	13%	32%	1%	16%	0%	1%	16%
LA	11%	33%	2%	15%	0%	1%	23%
MD	9%	24%	0%	18%	0%	0%	21%
MN	8%	28%	0%	18%	0%	2%	28%
MO	10%	30%	0%	14%	0%	1%	24%
MS	14%	39%	1%	13%	1%	1%	22%
NC	12%	37%	1%	15%	1%	1%	26%
NJ	10%	29%	0%	15%	1%	1%	23%
OK	15%	41%	0%	18%	1%	1%	20%
PA	11%	30%	1%	24%	1%	1%	19%
UT	14%	36%	0%	23%	1%	1%	20%
NCI Average	10%	28%	1%	16%	0%	1%	19%

Table 6a. Family Member's Health Conditions

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
CA	9%	17%	4%	27%	29%
DC	9%	19%	4%	52%	32%
DE	9%	10%	3%	17%	21%
FL	15%	22%	9%	30%	39%
GA	9%	19%	4%	40%	32%
KY	7%	13%	5%	29%	23%
LA	9%	15%	3%	39%	27%
MD	11%	14%	4%	27%	28%
MN	6%	13%	4%	18%	19%
MO	9%	11%	5%	15%	19%
MS	8%	18%	3%	39%	21%
NC	6%	17%	3%	17%	23%
NJ	13%	8%	3%	17%	29%
OK	13%	17%	5%	28%	23%
PA	14%	16%	6%	25%	29%
UT	12%	11%	6%	18%	18%
NCI Average	10%	16%	4%	26%	28%

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

State	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Oral Health or Dental Problems	Sleep Apnea	Other
CA	7%	2%	3%	16%	16%	34%
DC	5%	4%	2%	13%	17%	24%
DE	7%	0%	1%	10%	24%	49%
FL	12%	4%	4%	12%	16%	31%
GA	6%	3%	5%	11%	17%	26%
KY	12%	1%	3%	11%	18%	34%
LA	12%	4%	4%	11%	16%	35%
MD	7%	2%	2%	9%	17%	37%
MN	13%	3%	1%	14%	18%	45%
MO	3%	3%	1%	25%	18%	38%
MS	8%	3%	2%	21%	18%	30%
NC	12%	3%	3%	14%	20%	50%
NJ	10%	3%	1%	11%	11%	53%
OK	15%	1%	3%	15%	20%	34%
PA	11%	1%	3%	12%	17%	39%
UT	16%	5%	1%	14%	22%	42%
NCI Average	9%	2%	3%	15%	16%	37%

Table 7. Family Member's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	Total
CA	81%	12%	2%	1%	4%	4,728
DC	71%	20%	1%	1%	7%	230
DE	82%	10%	1%	2%	5%	203
FL	67%	19%	2%	1%	11%	192
GA	76%	19%	0%	1%	4%	399
KY	76%	19%	3%	1%	1%	160
LA	78%	15%	1%	1%	5%	477
MD	77%	13%	2%	1%	6%	1,066
MN	80%	11%	2%	3%	4%	418
MO	76%	14%	2%	2%	6%	250
MS	66%	24%	1%	1%	9%	350
NC	72%	20%	2%	0%	6%	254
NJ	78%	12%	1%	3%	7%	707
OK	70%	25%	2%	1%	2%	418
PA	75%	18%	2%	1%	4%	781
UT	70%	14%	1%	0%	15%	420
NCI Average	77%	14%	2%	1%	5%	11,053

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

State	None	Limited	Full	Has Guardianship but Level Is Unknown	Don't know	N
CA	44%	50%	0%	0%	6%	4,647
DC	33%	10%	45%	7%	6%	239
DE	44%	8%	42%	4%	4%	200
FL	30%	17%	46%	4%	2%	189
GA	38%	13%	39%	4%	5%	395
KY	6%	6%	85%	3%	0%	160
LA	40%	7%	37%	4%	12%	442
MD	53%	11%	28%	4%	4%	1,037
MN	7%	6%	83%	4%	0%	448
MO	19%	10%	69%	3%	0%	247
MS	30%	11%	47%	6%	6%	363
NC	19%	12%	63%	5%	1%	252
NJ	20%	8%	69%	2%	1%	710
OK	19%	10%	65%	3%	2%	418
PA	45%	9%	36%	4%	6%	777
UT	20%	12%	62%	4%	3%	416
NCI Average	36%	29%	28%	2%	5%	10,940

Table 9. Guardian or Conservator Relationship to Family Member

State	Family	Friend	State Employee or Guardianship Agency	Other	N
CA	97%	1%	1%	2%	2,153
DC	94%	0%	6%	0%	123
DE	98%	0%	1%	1%	95
FL	91%	0%	0%	9%	117
GA	90%	2%	1%	8%	200
KY	98%	1%	0%	1%	147
LA	95%	0%	1%	4%	194
MD	97%	0%	1%	2%	374
MN	98%	0%	0%	1%	404
MO	98%	1%	0%	1%	180
MS	96%	1%	0%	3%	197
NC	90%	1%	2%	7%	186
NJ	99%	0%	0%	1%	543
OK	99%	0%	0%	1%	310
PA	99%	0%	0%	1%	328
UT	98%	0%	0%	1%	297
NCI Average	96%	1%	1%	3%	5,848

Table 10. Family Member's Highest level of Education

State	Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
CA	20%	4%	34%	24%	5%	9%	5%	4,478
DC	21%	3%	32%	31%	8%	4%	2%	228
DE	14%	9%	43%	16%	6%	8%	4%	196
FL	20%	5%	38%	27%	2%	4%	5%	184
GA	18%	3%	46%	27%	2%	2%	4%	388
KY	15%	1%	49%	22%	4%	3%	5%	156
LA	25%	2%	47%	17%	4%	3%	2%	465
MD	10%	0%	57%	16%	4%	7%	6%	1,038
MN	8%	9%	33%	38%	4%	4%	4%	442
MO	14%	0%	25%	51%	1%	4%	5%	239
MS	27%	1%	51%	13%	3%	2%	3%	355
NC	22%	4%	44%	15%	5%	6%	4%	249
NJ	14%	1%	26%	42%	4%	5%	7%	682
OK	15%	3%	23%	51%	3%	3%	2%	406
PA	16%	4%	28%	45%	4%	2%	2%	740
UT	18%	5%	45%	20%	2%	2%	7%	404
NCI Average	18%	3%	35%	28%	4%	6%	5%	10,650

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

State	Usually/Often	Sometimes	Never Does This	N
CA	13%	5%	82%	3,666
DC	15%	7%	78%	184
DE	25%	7%	68%	174
FL	7%	2%	91%	152
GA	11%	4%	85%	314
KY	16%	4%	79%	134
LA	10%	3%	87%	386
MD	30%	7%	64%	781
MN	24%	5%	71%	327
MO	13%	1%	86%	204
MS	7%	3%	89%	321
NC	12%	5%	83%	216
NJ	16%	7%	76%	653
OK	10%	3%	87%	345
PA	15%	1%	83%	614
UT	18%	3%	79%	340
NCI Average	14%	4%	82%	8,811

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

State	Usually/Often	Sometimes	Never Does This	N
CA	15%	6%	79%	3,597
DC	8%	1%	91%	175
DE	10%	3%	87%	156
FL	5%	3%	92%	153
GA	9%	4%	86%	299
KY	9%	3%	87%	127
LA	14%	2%	85%	381
MD	19%	5%	75%	709
MN	24%	5%	71%	324
MO	4%	1%	95%	196
MS	8%	3%	89%	314
NC	5%	2%	93%	210
NJ	5%	3%	93%	613
OK	14%	1%	85%	341
PA	7%	2%	91%	582
UT	10%	3%	87%	327
NCI Average	12%	4%	84%	8,504

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

State	Usually/Often	Sometimes	Never Does This	N
CA	22%	13%	66%	3,616
DC	25%	16%	59%	183
DE	23%	24%	53%	165
FL	18%	8%	74%	153
GA	25%	12%	63%	299
KY	24%	13%	64%	127
LA	13%	9%	79%	363
MD	31%	19%	50%	725
MN	21%	25%	54%	314
MO	23%	18%	59%	204
MS	10%	8%	81%	306
NC	33%	16%	51%	215
NJ	20%	21%	59%	627
OK	23%	12%	65%	346
PA	21%	13%	66%	598
UT	23%	11%	66%	321
NCI Average	22%	14%	65%	8,562

Table 14. Family Member's Typical Day Activities – Paid Activity in a Facility-based Setting

State	Usually/Often	Sometimes	Never Does This	N
CA	17%	5%	79%	3,576
DC	8%	3%	89%	173
DE	16%	4%	80%	161
FL	15%	3%	83%	157
GA	17%	5%	79%	307
KY	18%	6%	76%	128
LA	20%	3%	77%	390
MD	25%	8%	67%	718
MN	37%	6%	57%	345
MO	22%	0%	77%	206
MS	17%	3%	80%	327
NC	10%	3%	87%	209
NJ	13%	5%	82%	617
OK	24%	3%	74%	355
PA	34%	2%	63%	645
UT	23%	6%	70%	341
NCI Average	19%	4%	77%	8,655

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

State	Usually/Often	Sometimes	Never Does This	N
CA	22%	6%	72%	3,459
DC	38%	8%	54%	173
DE	26%	8%	65%	156
FL	24%	4%	73%	153
GA	42%	5%	53%	327
KY	36%	7%	57%	126
LA	20%	3%	77%	364
MD	39%	9%	52%	714
MN	25%	7%	67%	307
MO	35%	3%	62%	206
MS	36%	7%	57%	314
NC	27%	3%	70%	208
NJ	39%	7%	53%	615
OK	12%	5%	84%	328
PA	37%	3%	59%	607
UT	27%	5%	68%	323
NCI Average	27%	5%	68%	8,380

Table 16. Family Member's Typical Day Activities – School

State	Usually/Often	Sometimes	Never Does This	N
CA	30%	5%	65%	2,917
DC	22%	2%	75%	138
DE	33%	1%	66%	148
FL	21%	2%	77%	132
GA	13%	1%	86%	250
KY	3%	4%	93%	100
LA	7%	2%	91%	305
MD	6%	5%	89%	529
MN	24%	4%	72%	290
MO	5%	1%	94%	171
MS	10%	1%	89%	239
NC	23%	3%	73%	188
NJ	10%	5%	85%	550
OK	6%	2%	93%	271
PA	8%	1%	90%	514
UT	25%	2%	72%	275
NCI Average	22%	4%	75%	7,017

Table 17. Family Member's Typical Day Activities – Stay at Home

State	Usually/Often	Sometimes	Never Does This	N
CA	50%	19%	31%	2,748
DC	33%	15%	52%	131
DE	43%	29%	27%	146
FL	66%	19%	14%	134
GA	46%	23%	31%	238
KY	52%	25%	24%	102
LA	60%	15%	24%	328
MD	32%	23%	45%	547
MN	43%	24%	34%	276
MO	60%	15%	26%	178
MS	60%	21%	19%	259
NC	58%	20%	22%	184
NJ	36%	40%	24%	568
OK	67%	17%	16%	312
PA	46%	22%	32%	530
UT	54%	25%	21%	282
NCI Average	51%	21%	28%	6,963

Table 18. Family Member's Typical Day Activities – Other

State	Usually/Often	Sometimes	Never Does This	N
CA	65%	8%	27%	842
DC	77%	7%	16%	43
DE	43%	16%	41%	44
FL	56%	9%	35%	34
GA	62%	14%	24%	63
KY	81%	13%	6%	16
LA	49%	13%	38%	93
MD	62%	7%	30%	161
MN	67%	9%	24%	45
MO	64%	5%	31%	39
MS	54%	8%	38%	79
NC	69%	10%	22%	51
NJ	62%	13%	24%	202
OK	60%	18%	22%	78
PA	68%	13%	19%	78
UT	68%	8%	24%	78
NCI Average	63%	9%	27%	1,946

Table 19. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

State	Extensive support needed	Some support needed	No support needed	N
CA	21%	30%	49%	4,590
DC	15%	26%	59%	235
DE	11%	32%	57%	201
FL	18%	30%	52%	187
GA	15%	33%	52%	394
KY	13%	32%	55%	154
LA	23%	30%	47%	445
MD	12%	28%	60%	1,026
MN	23%	32%	44%	439
MO	16%	32%	52%	244
MS	21%	28%	50%	369
NC	23%	32%	45%	251
NJ	19%	36%	45%	700
OK	13%	25%	62%	413
PA	14%	28%	58%	762
UT	19%	35%	46%	409
NCI Average	19%	31%	50%	10,819

Table 20. Family Member's Level of Help Needed with Personal Care Activities

State	Extensive support needed	Some support needed	No support needed	N
CA	36%	36%	29%	4,773
DC	25%	34%	41%	241
DE	27%	38%	34%	203
FL	49%	30%	21%	190
GA	39%	34%	27%	399
KY	43%	37%	20%	158
LA	39%	38%	24%	480
MD	29%	35%	36%	1,060
MN	44%	38%	18%	451
MO	41%	33%	26%	250
MS	52%	33%	16%	378
NC	51%	35%	13%	254
NJ	46%	37%	17%	707
OK	45%	36%	20%	421
PA	37%	37%	26%	801
UT	40%	41%	19%	421
NCI Average	39%	35%	25%	11,187

Table 21. Family Member's Need for Help with Other Daily Activities

State	Extensive support needed	Some support needed	No support needed	N
CA	65%	28%	7%	4,736
DC	58%	29%	14%	241
DE	65%	28%	6%	201
FL	78%	17%	5%	191
GA	75%	18%	7%	400
KY	82%	15%	3%	158
LA	70%	25%	5%	470
MD	70%	24%	6%	1,061
MN	80%	18%	2%	451
MO	78%	19%	2%	250
MS	78%	17%	6%	378
NC	81%	15%	4%	255
NJ	84%	15%	2%	707
OK	81%	17%	2%	418
PA	77%	18%	4%	788
UT	82%	14%	5%	418
NCI Average	72%	23%	5%	11,123

Respondents

This section provides demographic information about the respondent.

Table 22. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
CA	5%	28%	57%	11%	4,837
DC	3%	21%	61%	15%	236
DE	2%	31%	62%	5%	203
FL	5%	21%	58%	16%	192
GA	3%	22%	64%	11%	404
KY	0%	20%	66%	14%	161
LA	4%	23%	60%	14%	476
MD	2%	16%	74%	9%	1,063
MN	3%	30%	60%	8%	454
MO	3%	26%	66%	5%	248
MS	3%	22%	63%	12%	381
NC	2%	28%	60%	9%	255
NJ	2%	21%	70%	8%	710
OK	1%	19%	68%	12%	422
PA	1%	13%	65%	22%	799
UT	1%	29%	59%	11%	423
NCI Average	4%	25%	60%	11%	11,264

Table 23. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
CA	15%	39%	41%	5%	4,819
DC	13%	47%	35%	4%	240
DE	17%	55%	26%	2%	204
FL	15%	35%	40%	10%	191
GA	13%	40%	42%	5%	402
KY	16%	38%	43%	4%	160
LA	11%	38%	42%	9%	473
MD	14%	45%	37%	3%	1,064
MN	18%	49%	31%	2%	451
MO	13%	46%	37%	4%	248
MS	5%	37%	52%	6%	379
NC	10%	53%	32%	5%	256
NJ	14%	46%	35%	5%	707
OK	12%	43%	42%	4%	422
PA	11%	41%	44%	4%	800
UT	15%	43%	38%	3%	422
NCI Average	14%	41%	40%	5%	11,238

Table 24. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Other	N
CA	87%	8%	0%	2%	3%	4,837
DC	78%	10%	1%	5%	6%	239
DE	86%	6%	0%	4%	3%	202
FL	82%	12%	0%	4%	1%	193
GA	79%	11%	0%	2%	8%	406
KY	88%	5%	1%	2%	4%	161
LA	77%	12%	1%	4%	7%	477
MD	90%	5%	0%	2%	3%	1,067
MN	93%	4%	1%	0%	2%	451
MO	82%	6%	1%	4%	6%	247
MS	83%	9%	0%	3%	5%	381
NC	83%	5%	1%	4%	7%	254
NJ	92%	6%	0%	1%	1%	710
OK	90%	5%	0%	3%	2%	422
PA	89%	10%	0%	0%	2%	797
UT	91%	5%	0%	2%	2%	422
NCI Average	86%	8%	0%	2%	3%	11,266

Table 25. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services

State	Respondent	Other Family Member	No	N
CA	32%	11%	58%	4,732
DC	16%	5%	80%	242
DE	13%	4%	85%	200
FL	13%	6%	81%	191
GA	4%	4%	91%	406
KY	27%	22%	56%	158
LA	4%	14%	82%	468
MD	7%	5%	89%	1,065
MN	44%	29%	42%	447
MO	9%	9%	83%	247
MS	2%	11%	87%	378
NC	27%	12%	61%	257
NJ	19%	13%	68%	707
OK	46%	12%	46%	420
PA	10%	11%	80%	791
UT	4%	29%	67%	407
NCI Average	24%	12%	66%	11,116

Table 26. Number of Adults in Household (Not Including Family Member Receiving Services)

State	One	Two	Three	Four or More	N
CA	10%	28%	39%	22%	4,730
DC	12%	42%	31%	15%	239
DE	5%	35%	44%	16%	201
FL	9%	33%	41%	17%	191
GA	11%	33%	44%	12%	394
KY	4%	29%	49%	18%	160
LA	11%	39%	41%	9%	469
MD	8%	27%	47%	19%	1,053
MN	4%	27%	50%	19%	447
MO	5%	29%	50%	16%	251
MS	14%	40%	33%	12%	371
NC	9%	29%	42%	19%	254
NJ	5%	24%	46%	25%	703
OK	9%	35%	49%	7%	412
PA	6%	33%	45%	16%	780
UT	4%	29%	46%	21%	414
NCI Average	9%	30%	42%	19%	11,069

Table 27. Number of Children in Household

State	One	Two	Three	Four or More	None	N
CA	12%	5%	2%	1%	80%	4,733
DC	11%	6%	1%	0%	81%	232
DE	12%	6%	1%	1%	80%	199
FL	10%	2%	1%	0%	87%	189
GA	11%	4%	1%	1%	83%	396
KY	6%	3%	1%	1%	89%	160
LA	11%	3%	1%	1%	84%	466
MD	6%	2%	1%	0%	91%	1,062
MN	11%	6%	2%	1%	80%	451
MO	10%	2%	2%	0%	86%	243
MS	7%	4%	1%	0%	88%	376
NC	6%	3%	0%	0%	91%	254
NJ	6%	3%	0%	0%	91%	703
OK	7%	3%	1%	0%	89%	412
PA	5%	3%	1%	0%	92%	783
UT	11%	4%	4%	2%	79%	419
NCI Average	10%	4%	1%	1%	84%	11,078

Table 28. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
CA	20%	19%	6%	23%	32%	4,704
DC	11%	35%	7%	22%	25%	237
DE	6%	20%	3%	23%	49%	203
FL	12%	26%	4%	21%	37%	190
GA	13%	29%	7%	17%	33%	406
KY	7%	22%	4%	27%	39%	161
LA	16%	34%	11%	18%	21%	472
MD	5%	21%	4%	22%	49%	1,065
MN	3%	18%	13%	22%	44%	450
MO	7%	28%	4%	26%	36%	250
MS	13%	30%	4%	22%	31%	358
NC	7%	23%	4%	26%	39%	254
NJ	2%	17%	2%	19%	60%	709
OK	6%	28%	9%	25%	32%	419
PA	7%	38%	7%	20%	29%	783
UT	4%	25%	8%	25%	39%	422
NCI Average	14%	23%	6%	23%	35%	11,083

Table 29. Total Taxable Household Income of Wage Earners in the Past Year

State	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	No Earned Income	Prefer Not to Say	N
CA	11%	12%	19%	11%	15%	11%	21%	4,484
DC	12%	11%	15%	9%	9%	20%	23%	222
DE	5%	8%	16%	13%	26%	11%	22%	198
FL	9%	13%	23%	8%	10%	18%	18%	179
GA	9%	12%	18%	14%	11%	20%	15%	383
KY	6%	10%	23%	19%	21%	8%	14%	155
LA	11%	10%	19%	9%	11%	23%	19%	452
MD	5%	9%	17%	14%	29%	7%	19%	1,006
MN	6%	6%	22%	18%	26%	4%	17%	435
MO	8%	11%	20%	15%	18%	12%	17%	240
MS	11%	15%	15%	8%	5%	26%	19%	359
NC	12%	9%	19%	15%	17%	9%	18%	248
NJ	4%	5%	15%	13%	35%	4%	24%	695
OK	16%	12%	23%	12%	11%	10%	18%	398
PA	10%	11%	19%	11%	12%	13%	25%	744
UT	8%	9%	24%	18%	17%	9%	16%	412
NCI Average	10%	11%	19%	12%	16%	12%	20%	10,610

Table 30. Residential Designation (Urban, Suburban, or Rural)

State	Urban or Suburban (in or Near a City or Large Town)	Rural (Outside of a City or Town)	Don't Know	N
CA	81%	13%	6%	4,687
DC	79%	1%	19%	212
DE	66%	30%	3%	202
FL	73%	19%	7%	188
GA	55%	40%	5%	398
KY	47%	53%	1%	161
LA	51%	44%	5%	475
MD	70%	27%	3%	1,060
MN	78%	19%	3%	450
MO	56%	42%	2%	248
MS	45%	51%	4%	381
NC	55%	44%	2%	256
NJ	76%	23%	1%	704
OK	64%	34%	3%	416
PA	57%	41%	2%	781
UT	79%	18%	2%	422
NCI Average	72%	24%	5%	11,041

Services and Supports Received

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

Table 31. Services and Supports Received From ID/DD Agency

State	Financial Support	In-home Support	Out-of-home Respite	Day or Employment Supports	Transportation	Other	Self-direction or Fiscal Intermediary Services
CA	14%	32%	21%	54%	49%	15%	11%
DC	11%	61%	26%	65%	78%	44%	0%
DE	15%	10%	23%	60%	57%	17%	9%
FL	16%	60%	23%	38%	50%	25%	35%
GA	13%	32%	16%	64%	68%	20%	36%
KY	10%	37%	50%	58%	49%	24%	49%
LA	7%	56%	20%	41%	56%	15%	25%
MD	9%	24%	19%	75%	72%	15%	17%
MN	28%	72%	38%	65%	70%	30%	47%
MO	15%	34%	22%	52%	59%	20%	32%
MS	9%	82%	30%	51%	62%	17%	24%*
NC	13%	69%	50%	47%	52%	30%	22%
NJ	19%	29%	22%	69%	65%	20%	52%
OK	19%	55%	11%	36%	48%	22%	25%
PA	14%	33%	29%	65%	66%	19%	29%
UT	12%	47%	45%	61%	60%	16%	49%
NCI Average	14%	39%	25%	54%	55%	19%	23%

Table 32. Additional Services and Supports Received (not from the IDD Agency)

State	Social Security Payments (SSI/SSB)	Services or Supports from Other Agencies or Organizations
CA	86%	24%
DC	93%	23%
DE	87%	39%
FL	95%	22%
GA	99%	18%
KY	99%	28%
LA	95%	20%
MD	92%	24%
MN	92%	35%
MO	97%	35%
MS	96%	18%
NC	96%	35%
NJ	93%	23%
OK	97%	14%
PA	96%	36%
UT	96%	31%
NCI Average	91%	26%

*MS does not offer these services through the waiver.

Adult Family Survey Results

Information and Planning

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

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

Gets Enough Information to Help Plan Services

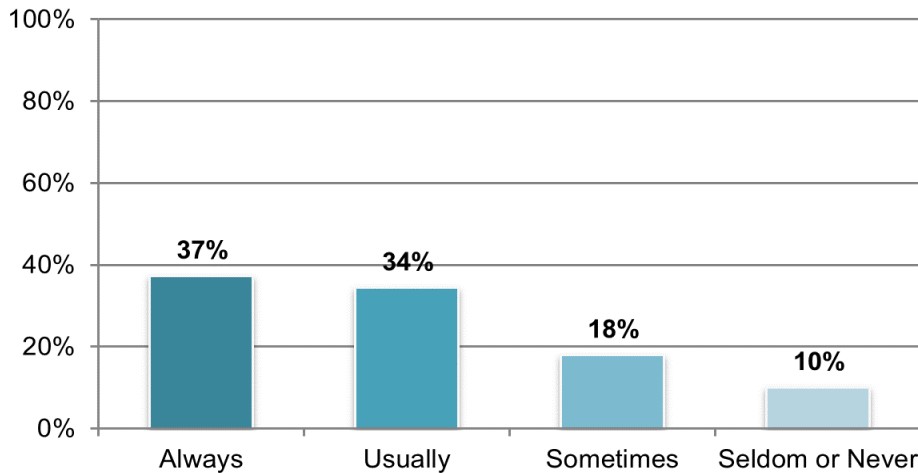


Table Q1. Do you get enough information to help you participate in planning services for your family?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	49%	37%	7%	7%	238
LA	46%	33%	14%	7%	430
UT	46%	39%	12%	4%	397
OK	44%	40%	13%	3%	398

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
FL	47%	31%	13%	9%	178
DC	46%	26%	21%	8%	219
KY	45%	41%	9%	5%	148
PA	41%	40%	15%	4%	733
MS	40%	41%	14%	5%	347
MN	39%	38%	16%	7%	428
NCI Average	37%	34%	18%	10%	10,139
CA*	35%	31%	21%	13%	4,181
MO	35%	43%	15%	8%	234
GA	32%	35%	23%	10%	368

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	28%	41%	21%	10%	976
DE	21%	28%	35%	17%	180
NJ	19%	38%	29%	14%	684

*The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Information About Services and Supports Is Easy to Understand

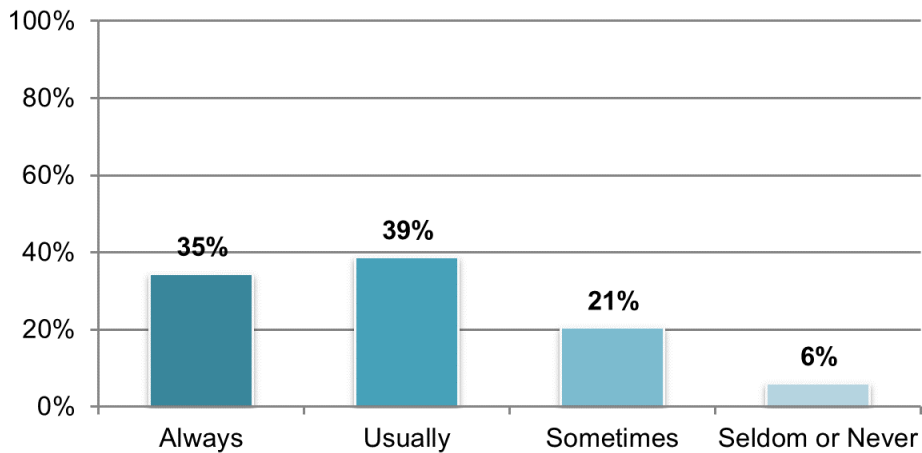


Table Q2. Is the information you receive easy to understand?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	43%	34%	19%	5%	221
FL	41%	39%	13%	7%	175
LA	40%	34%	21%	5%	435
CA [~]	39%	35%	20%	6%	4,255
KY	37%	43%	17%	4%	145
OK	36%	45%	16%	3%	407
NCI Average	35%	39%	21%	6%	10,236
PA	34%	45%	17%	4%	746
UT	34%	46%	17%	3%	398
MS	32%	47%	17%	4%	356
NC	31%	46%	20%	3%	237
GA	28%	36%	27%	8%	366
MO	27%	47%	20%	6%	233

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	27%	44%	23%	7%	971
MN	25%	43%	24%	8%	429
DE	17%	37%	34%	13%	180
NJ	12%	38%	36%	14%	682

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

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

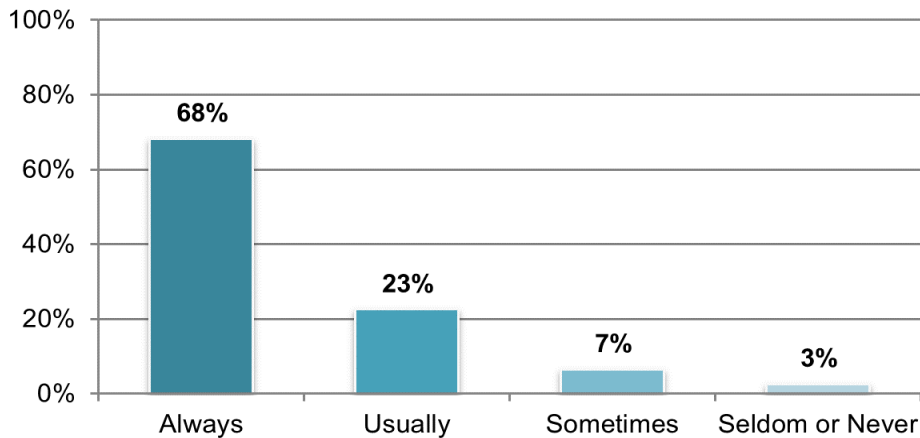


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	83%	14%	3%	1%	407
FL	81%	12%	5%	2%	184
MS	75%	22%	3%	1%	355
LA	74%	19%	6%	2%	449

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	73%	21%	4%	2%	231
KY	73%	24%	3%	0%	150
MO	72%	20%	5%	3%	240
PA	71%	24%	4%	0%	766
NCI Average	68%	23%	7%	3%	10,493
DC	67%	20%	10%	3%	234
OK	66%	27%	6%	1%	416
CA [~]	66%	23%	8%	3%	4,384
MN	64%	27%	6%	2%	422
MD [~]	64%	28%	6%	2%	1,001

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	58%	31%	8%	2%	686
GA	55%	33%	8%	4%	383
DE	55%	31%	9%	5%	185

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

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

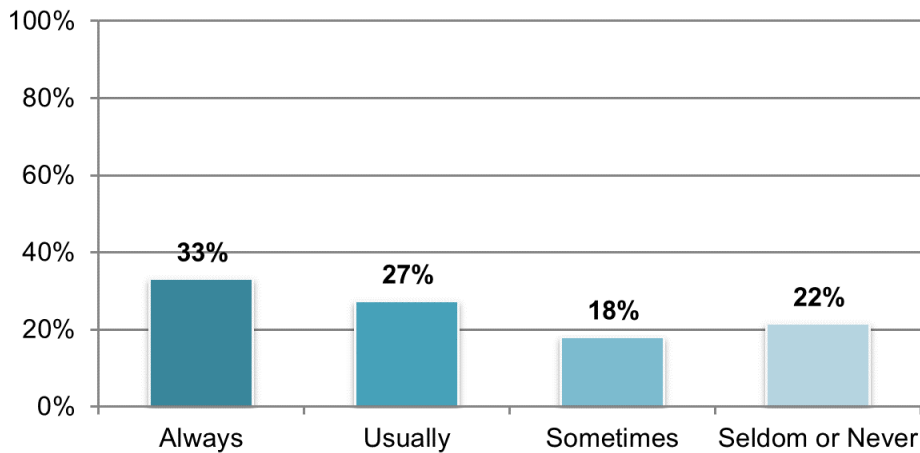


Table Q4. Do you get enough information about other public services for which your family is eligible?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
DC	50%	19%	14%	17%	220
FL	44%	21%	17%	18%	156
LA	42%	27%	15%	17%	405
OK	41%	34%	14%	10%	384
UT	40%	34%	15%	10%	360

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MS	40%	28%	12%	20%	324
KY	39%	32%	17%	12%	128
NC	38%	29%	17%	15%	214
PA	35%	33%	17%	15%	656
NCI Average	33%	27%	18%	22%	9,401
CA	33%	25%	18%	24%	3,904
MO	28%	39%	14%	20%	219
MN	28%	34%	19%	20%	404

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	27%	31%	18%	24%	899
GA	25%	22%	26%	27%	336
DE	20%	26%	26%	28%	168
NJ	11%	29%	30%	30%	624

Respondent Needs Help Planning for Family Member's Future Needs

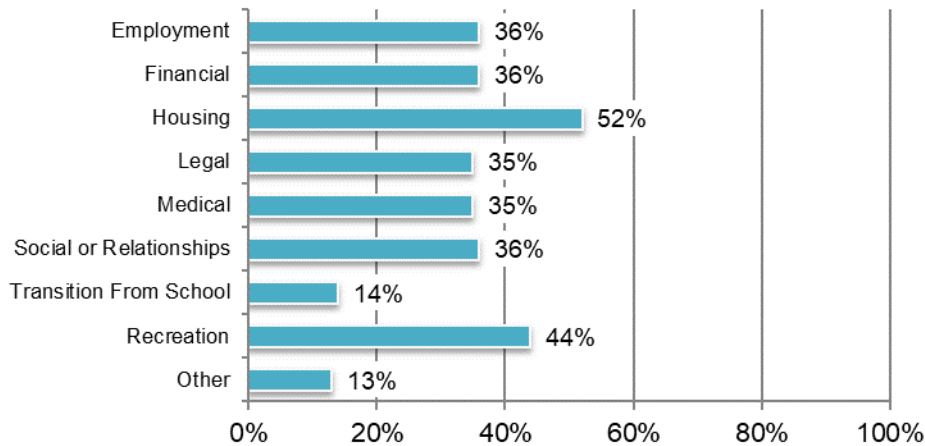


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition From School	Recreation or Having Fun	Other	N
CA	40%	36%	50%	35%	37%	38%	18%	46%	11%	3,173
DC	40%	33%	55%	38%	28%	37%	20%	41%	11%	160
DE	42%	45%	60%	42%	37%	39%	18%	45%	7%	153
FL	26%	29%	41%	30%	35%	34%	14%	44%	23%	116
GA	20%	31%	47%	38%	34%	32%	8%	44%	17%	234
KY	37%	40%	56%	41%	37%	22%	2%	24%	14%	63
LA	26%	35%	45%	36%	37%	30%	7%	39%	11%	238
MD	38%	38%	61%	44%	36%	38%	4%	41%	12%	720
MN	37%	41%	66%	32%	27%	32%	18%	36%	13%	298
MO	32%	32%	59%	31%	32%	42%	5%	45%	17%	149
MS	14%	25%	36%	40%	34%	28%	7%	40%	24%	220
NC	31%	46%	56%	38%	31%	29%	15%	37%	16%	140
NJ	41%	45%	75%	38%	40%	45%	8%	48%	12%	610
OK	31%	26%	40%	31%	35%	24%	8%	40%	12%	172
PA	28%	35%	57%	39%	33%	29%	7%	40%	9%	417
UT	39%	29%	43%	33%	35%	34%	24%	41%	15%	237
NCI Average	36%	36%	52%	35%	35%	36%	14%	44%	13%	7,100

Crisis or Emergency Services Were Provided When Needed (If Requested in the Past Year)

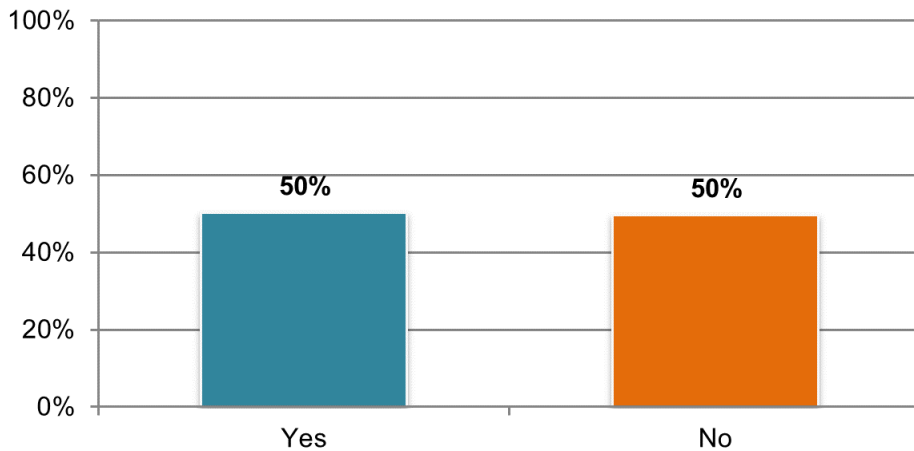


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

Significantly Above Average

State	Yes	No	N
PA	63%	37%	126
LA	62%	38%	151

Within Average Range

State	Yes	No	N
KY	71%	29%	28
FL	67%	33%	51
NC	64%	36%	66
DC	62%	38%	87
OK	61%	39%	67
UT	58%	42%	81
MS	56%	44%	117
NCI Average	50%	50%	2,489
GA	48%	52%	84
MD	42%	58%	163
MN	41%	59%	76
MO	39%	61%	49
DE	36%	64%	33

Significantly Below Average

State	Yes	No	N
CA	45%	55%	1,196
NJ	32%	68%	114

Family Member Has a Service Plan

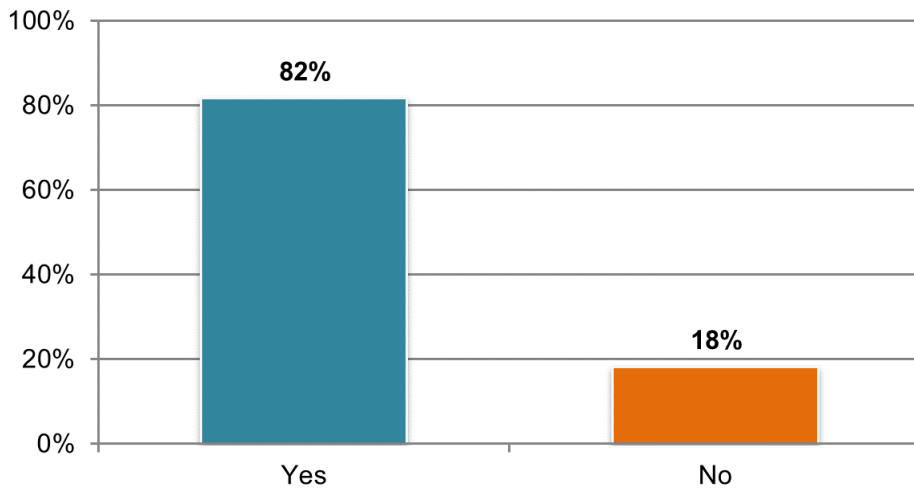


Table Q7. Does your family member have a service plan?

Significantly Above Average

State	Yes	No	N
PA	95%	5%	704
FL	93%	7%	178
MO	92%	8%	210
UT	87%	13%	336

Within Average Range

State	Yes	No	N
NC	85%	15%	217
OK	82%	18%	348
NCI Average	82%	18%	9,066
MS	82%	18%	267
KY	81%	19%	142
DC	81%	19%	213
MN	80%	20%	388
LA	79%	21%	359
MD	79%	21%	835
CA*	78%	22%	3,834

Significantly Below Average

State	Yes	No	N
NJ	76%	24%	599
GA	68%	32%	293
DE	42%	58%	143

*The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Service Plan Includes All the Services and Supports Family Member Needs

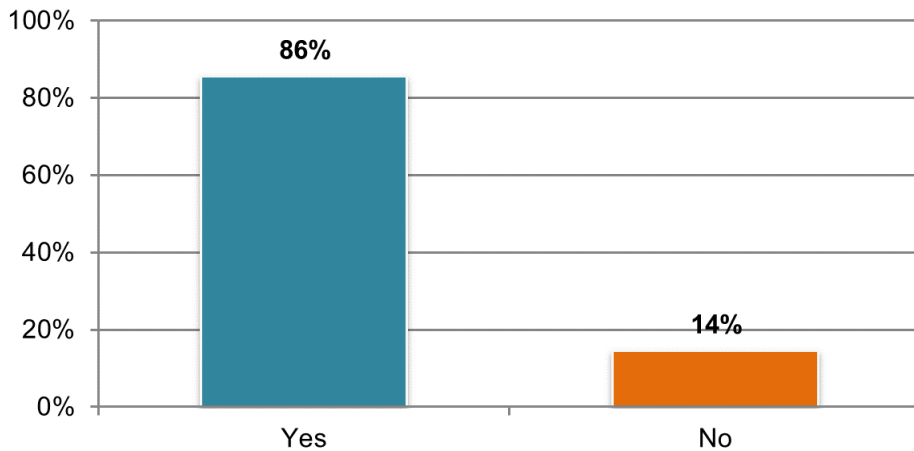


Table Q8. Does the plan include all the services and supports your family member needs?

Significantly Above Average

State	Yes	No	N
LA	95%	5%	256
UT	93%	7%	253
DC	92%	8%	151
PA	90%	10%	591
OK	90%	10%	259

Within Average Range

State	Yes	No	N
MN	89%	11%	279
NC	88%	12%	176
FL	88%	12%	148
KY	87%	13%	114
MO	86%	14%	167
NCI Average	86%	14%	6,383
MD	85%	15%	581
CA	84%	16%	2,589
MS	84%	16%	196
DE	82%	18%	38
GA	82%	18%	179

Significantly Below Average

State	Yes	No	N
NJ	65%	35%	406
NCI Average	86%	14%	6,383

Family Member Gets All Services Listed in the Service Plan

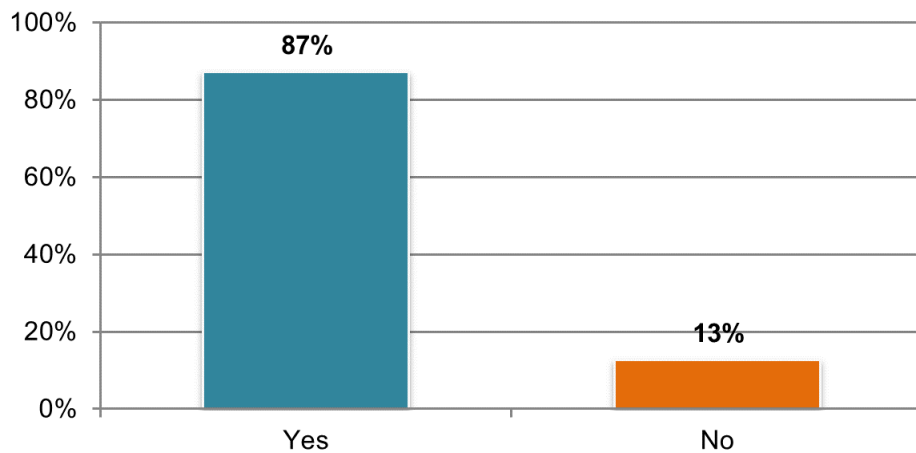


Table Q9. Does your family member get all the services listed in the plan?

Significantly Above Average

State	Yes	No	N
UT	95%	5%	258
PA	90%	10%	596

Within Average Range

State	Yes	No	N
OK	91%	9%	257
MO	90%	10%	174
MN	89%	11%	285
LA	88%	12%	248
CA	88%	12%	2,555
NC	88%	12%	178
NCI Average	87%	13%	6,364
MS	87%	13%	192
FL	86%	14%	152
GA	85%	15%	182
MD	84%	16%	580
DC	84%	16%	150
KY	84%	16%	106
DE	74%	26%	47

Significantly Below Average

State	Yes	No	N
NJ	77%	23%	404

Respondent or Other Family Member Helped Make Service Plan

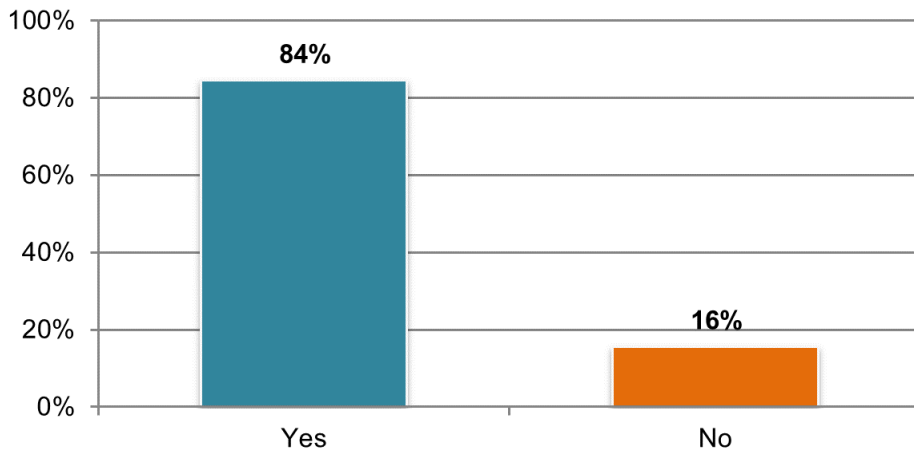


Table Q10. Did you or another family member help make the plan?

Significantly Above Average

State	Yes	No	N
UT	93%	7%	274
OK	93%	7%	277
MN	93%	7%	301
MO	92%	8%	183
NJ	92%	8%	444
PA	89%	11%	641

Within Average Range

State	Yes	No	N
KY	91%	9%	111
NC	90%	10%	180
MD	87%	13%	630
GA	85%	15%	186
DE	85%	15%	55
MS	85%	15%	204
LA	85%	15%	263
NCI Average	84%	16%	6,846
FL	83%	17%	157

Significantly Below Average

State	Yes	No	N
CA	79%	21%	2,778
DC	75%	25%	162

Family Member Helped Make Service Plan

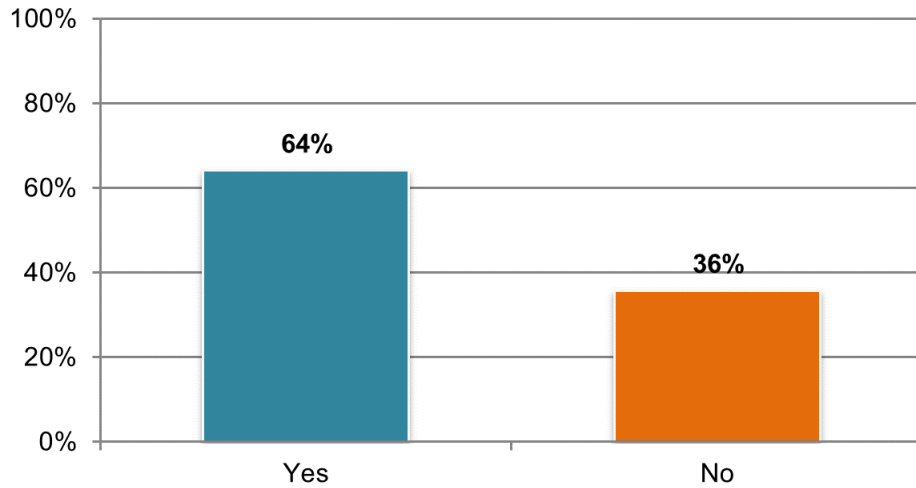


Table Q11. Did your family member help make the plan?

Significantly Above Average

State	Yes	No	N
MD	71%	29%	622

Within Average Range

State	Yes	No	N
LA	67%	33%	264
NJ	66%	34%	445
DC	66%	34%	160
MO	66%	34%	180
CA	66%	34%	2,748
MN	65%	35%	296
NCI Average	64%	36%	6,772
FL	64%	36%	157
GA	63%	37%	188
PA	63%	37%	625
UT	63%	37%	267
DE	62%	38%	55
KY	59%	41%	110
OK	59%	41%	266
MS	57%	43%	208
NC	56%	44%	181

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

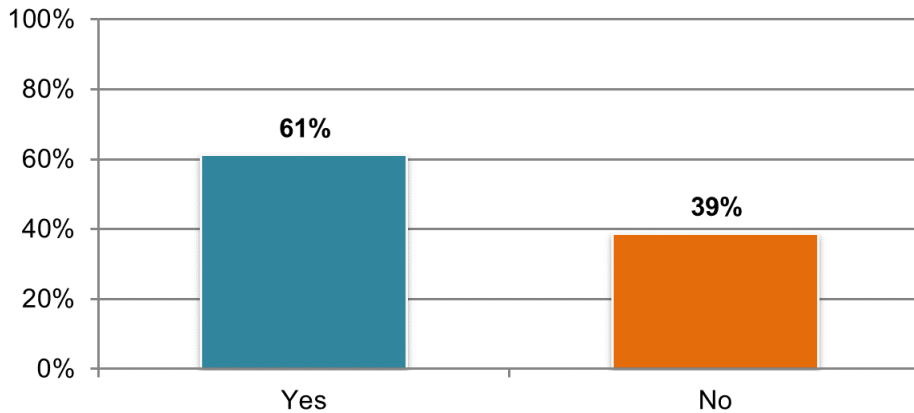


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?

Significantly Above Average

State	Yes	No	N
LA	91%	9%	266
FL	83%	17%	151
OK	79%	21%	262
NC	76%	24%	173
DC	72%	28%	155
MS	71%	29%	194
MD	69%	31%	593

Within Average Range

State	Yes	No	N
MO	62%	38%	169
PA	62%	38%	578
NCI Average	61%	39%	6,325
MN	60%	40%	278
GA	60%	40%	171
UT	56%	44%	240
KY	54%	46%	103
DE	43%	57%	51

Significantly Below Average

State	Yes	No	N
CA	52%	48%	2,525
NJ	45%	55%	416

Family Member Had a Transition Plan (If Transitioned Out of School in the Past Year)

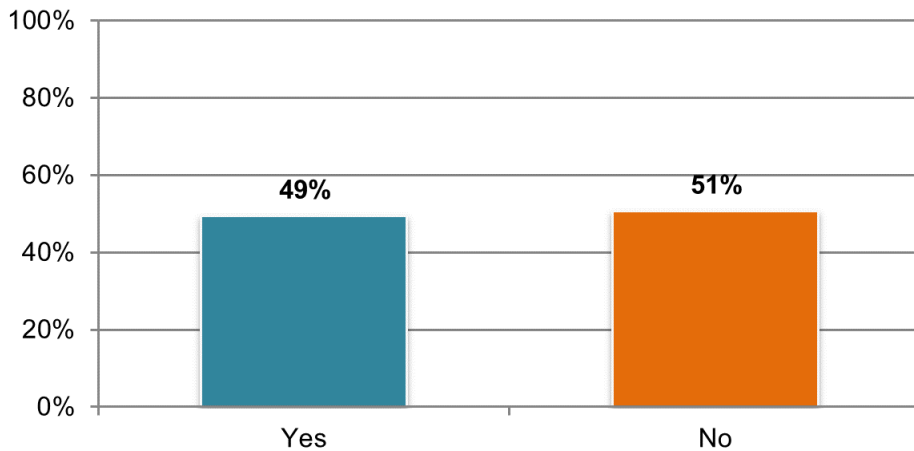


Table Q13. If your family member transitioned out of school services during the past year, did s/he have a transition plan?

Significantly Above Average

State	Yes	No	N
UT	74%	26%	34
NJ	70%	30%	88
MD	70%	30%	40

Within Average Range

State	Yes	No	N
PA	73%	27%	22
DC	68%	32%	22
MN	61%	39%	62
DE	58%	42%	26
CA	51%	49%	545
MS	50%	50%	22
NCI Average	49%	51%	1,110
OK	26%	74%	23

Significantly Below Average

State	Yes	No	N
LA	17%	83%	146

*Due to low N's (<20) the following states are not represented in tables, but their data are included in the NCI Average: FL, GA, KY, MO, NC

Transition Plan Included Getting or Continuing Work in a Paid Community Job

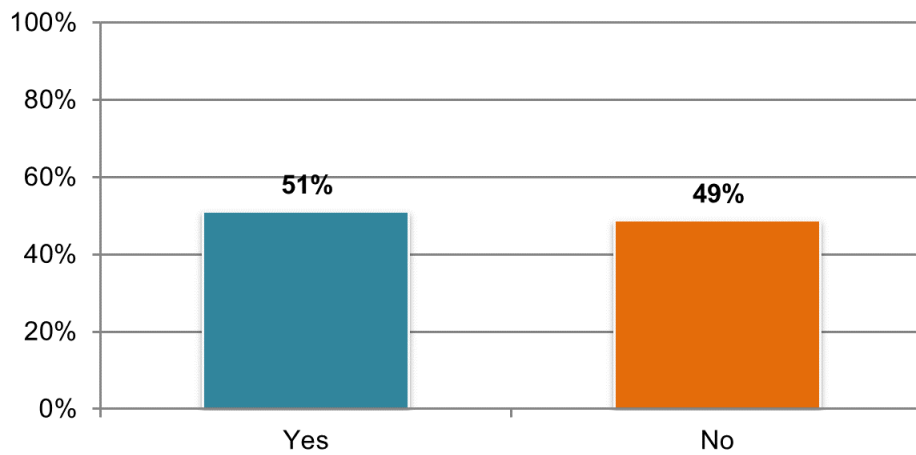


Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?

Within Average Range

State	Yes	No	N
MD	63%	38%	24
UT	61%	39%	23
MN	56%	44%	34
CA	55%	45%	232
NCI Average	51%	49%	480
NJ	46%	54%	59

*Due to low N's (<20) the following states are not represented in tables, but their data are included in the NCI Average: DE, PA, DC, LA, MO, MS, FL, GA, NC, OK, KY

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

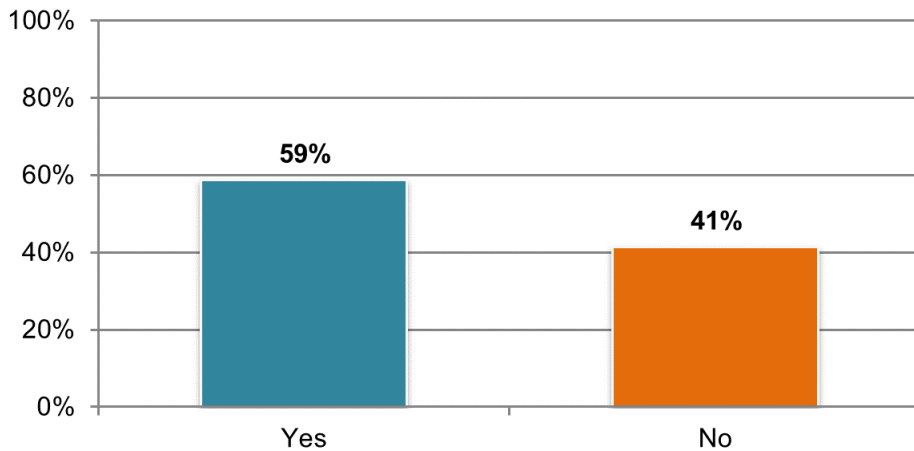


Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

Significantly Above Average

State	Yes	No	N
MD	69%	31%	708
UT	69%	31%	248
PA	68%	32%	430
OK	68%	32%	232
MN	67%	33%	310

Within Average Range

State	Yes	No	N
DC	68%	32%	163
LA	66%	34%	196
NC	66%	34%	190
KY	65%	35%	98
MO	63%	37%	158
NCI Average	59%	41%	6,777
DE	57%	43%	124
CA	57%	43%	2,908
MS	57%	43%	208
GA	55%	45%	228
FL	52%	48%	112

Significantly Below Average

State	Yes	No	N
NJ	36%	64%	464

Respondent Feels Prepared to Handle the Needs of Family Member in an Emergency

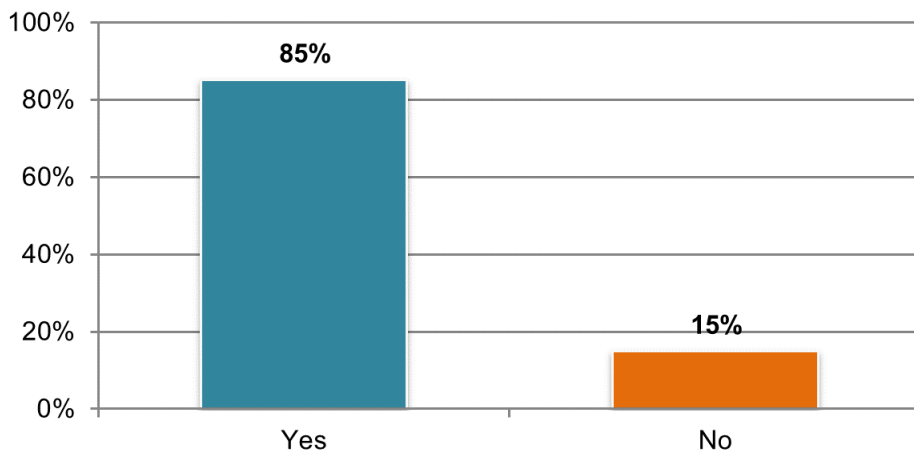


Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

Significantly Above Average

State	Yes	No	N
LA	94%	6%	439
OK	94%	6%	370
NC	92%	8%	236

Within Average Range

State	Yes	No	N
FL	89%	11%	171
KY	89%	11%	147
PA	88%	12%	686
GA	88%	12%	338
MS	88%	12%	329
DC	86%	14%	215
MD	86%	14%	892
MN	85%	15%	393
NCI Average	85%	15%	9,555
MO	85%	15%	221
CA*	83%	17%	3,988
DE	82%	18%	173
UT	81%	19%	349

Significantly Below Average

State	Yes	No	N
NJ	75%	25%	608

*The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Access and Delivery of Services and Supports

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

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

Respondent or Family Member Is Able to Contact Support Workers When S/He Wants

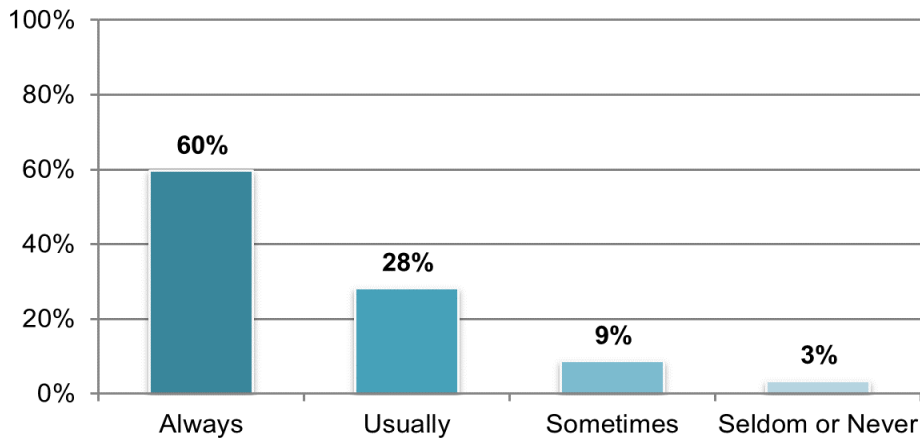


Table Q17. Are you or your family member able to contact his/her support workers when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	76%	20%	3%	1%	172
LA	72%	21%	5%	2%	447
PA	65%	30%	4%	1%	715
UT	67%	28%	4%	1%	406
MS	66%	28%	5%	1%	354

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	67%	29%	3%	1%	146
NC	66%	30%	2%	2%	225
DC	65%	23%	9%	3%	219
NCI Average	60%	28%	9%	3%	9,825
MO	58%	35%	3%	4%	223
CA ¹	56%	26%	13%	5%	4,117
OK	56%	34%	7%	2%	376
MN	56%	34%	9%	1%	415

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	52%	34%	11%	3%	360
MD	49%	42%	7%	2%	943
NJ	49%	38%	9%	3%	556
DE	44%	40%	9%	7%	151

¹The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent or Family Member Is Able to Contact Case Manager or Service Coordinator When S/He Wants

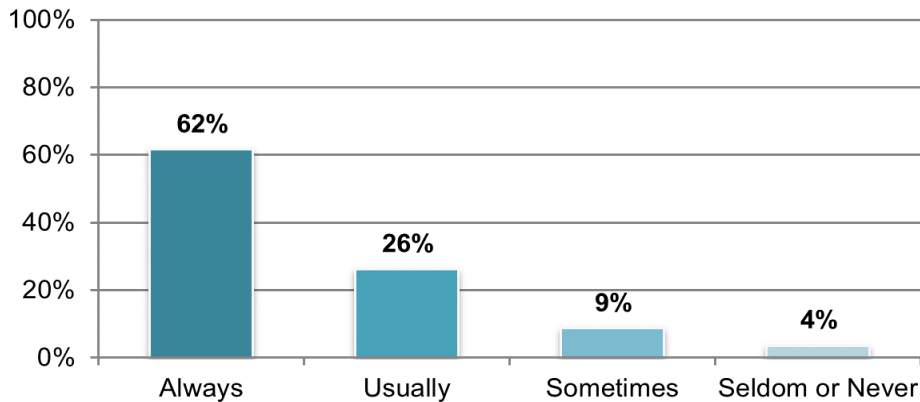


Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	78%	18%	3%	2%	185
UT	76%	19%	4%	1%	412
LA	71%	22%	6%	2%	460
PA	69%	27%	4%	0%	758
MS	70%	26%	4%	1%	354

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	69%	27%	3%	2%	230
KY	66%	29%	5%	0%	152
DC	65%	20%	11%	4%	237
MO	64%	26%	6%	3%	238
NCI Average	62%	26%	9%	4%	10,588
MN	59%	31%	8%	3%	434
OK	58%	33%	7%	3%	409
GA	57%	30%	9%	3%	370
CA~	57%	26%	12%	5%	4,470

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	56%	35%	6%	3%	1,018
NJ	53%	35%	10%	3%	679
DE	42%	41%	10%	7%	182

~The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Support Workers Come and Leave When They Are Supposed to

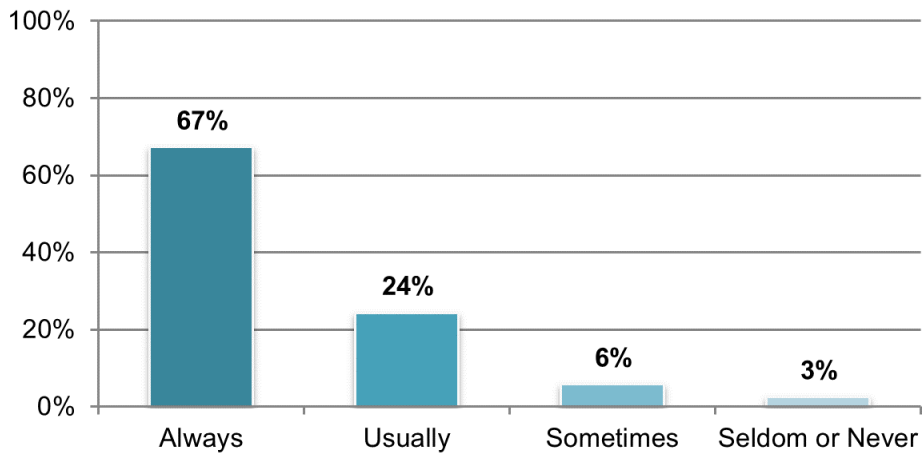


Table Q19. Do support workers come and leave when they are supposed to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	78%	15%	4%	3%	171
PA	76%	22%	2%	0%	675

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	73%	24%	3%	0%	138
LA	73%	23%	3%	2%	426
UT	72%	25%	3%	1%	393
MS	69%	26%	4%	0%	354
NCI Average	67%	24%	6%	3%	9027
CA	67%	23%	7%	3%	3758
OK	65%	26%	8%	2%	344
MO	65%	26%	7%	3%	196
MN	63%	30%	6%	2%	399
DC	60%	25%	10%	5%	219
DE	57%	35%	6%	2%	123

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	59%	33%	7%	1%	222
NJ	57%	34%	4%	4%	495
MD	55%	36%	7%	2%	806
GA	55%	31%	9%	5%	308

Services and Supports Change When Family's Needs Change

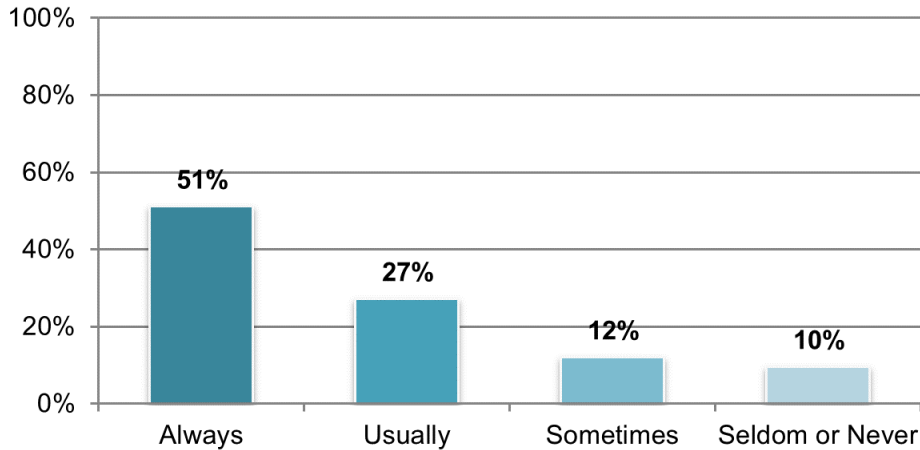


Table Q20. Do services and supports change when your family's needs change?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	68%	15%	7%	10%	149

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	57%	34%	5%	5%	111
LA	57%	24%	10%	10%	351
UT	54%	29%	13%	4%	338
DC	54%	24%	12%	10%	194
PA	53%	31%	12%	4%	581
OK	53%	30%	11%	6%	300
MS	53%	30%	12%	6%	304
NCI Average	51%	27%	12%	10%	7,625
CA	51%	24%	14%	11%	3,214
MO	49%	37%	7%	7%	172
NC	49%	34%	9%	9%	209

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	42%	33%	15%	10%	346
GA	41%	35%	14%	10%	239
MD	39%	38%	15%	9%	633
NJ	28%	40%	20%	12%	398
DE	27%	35%	19%	20%	86

Support Workers Speak in a Way Respondent Understands

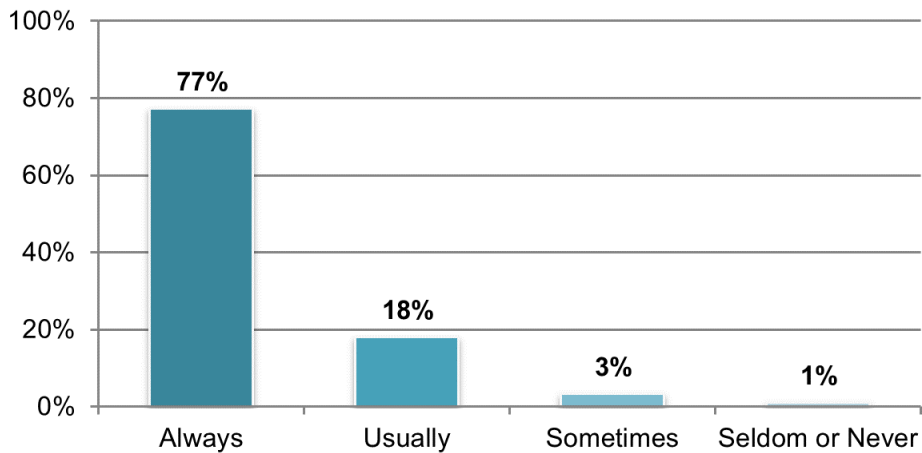


Table Q21. Do support workers speak to you in a way that you understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	88%	11%	1%	1%	173
LA	83%	16%	1%	0%	424
PA	82%	16%	1%	0%	704

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MS	82%	16%	1%	0%	357
UT	80%	17%	2%	0%	402
KY	80%	20%	0%	1%	143
MO	79%	18%	3%	0%	206
NC	78%	19%	3%	0%	226
NCI Average	77%	18%	3%	1%	9,497
DC	77%	15%	6%	2%	219
CA	76%	18%	5%	2%	3,965
OK	75%	22%	2%	1%	363
MN	72%	24%	3%	1%	404

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	71%	24%	3%	1%	890
GA	70%	23%	4%	3%	338
DE	66%	30%	4%	0%	144
NJ	64%	29%	5%	1%	539

Services and Supports Are Delivered in a Way Respectful of Family's Culture

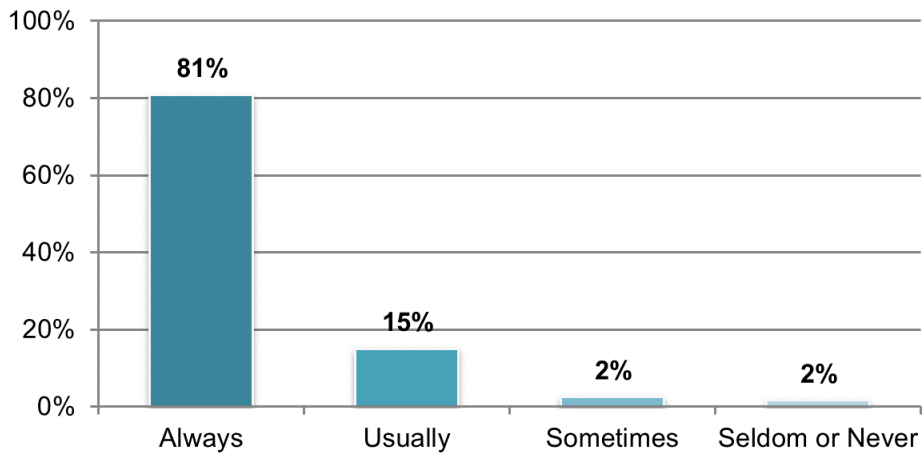


Table Q22. Are services delivered in a way that is respectful to your family's culture?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	89%	10%	1%	1%	174

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MO	84%	13%	3%	1%	734
PA	84%	15%	1%	0%	236
UT	83%	16%	1%	0%	405
LA	82%	15%	1%	1%	449
MS	81%	16%	2%	0%	353
KY	81%	18%	1%	1%	148
CA	81%	14%	3%	2%	4,270
NCI Average	81%	15%	2%	2%	10,124
MN	79%	18%	3%	1%	424
NC	78%	18%	1%	3%	235
OK	76%	22%	1%	1%	386
DC	74%	17%	7%	2%	229
DE	72%	24%	3%	1%	159

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	74%	22%	2%	2%	955
GA	74%	20%	3%	3%	356
NJ	71%	24%	2%	2%	611

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

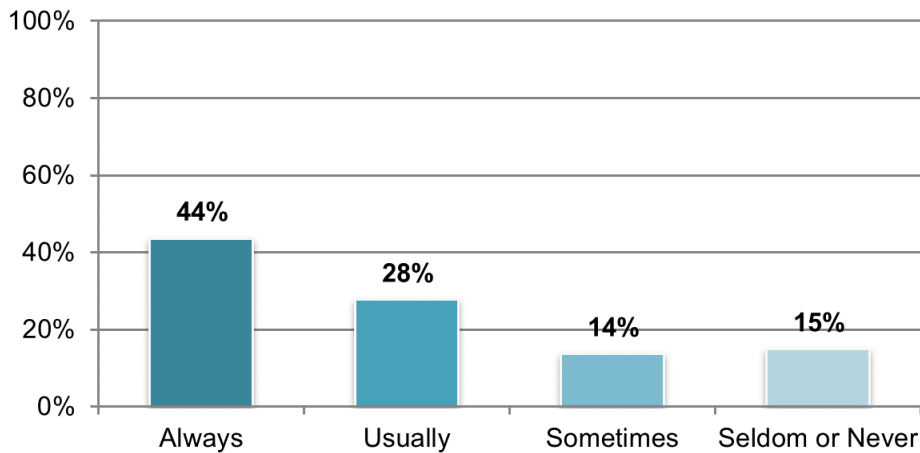


Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	62%	15%	10%	13%	92

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	56%	24%	8%	12%	66
FL	51%	29%	14%	6%	51
MS	48%	26%	13%	13%	120
NC	46%	38%	3%	13%	63
GA	46%	31%	17%	6%	87
CA	45%	24%	12%	20%	712
NCI Average	44%	28%	14%	15%	2,131
OK	43%	26%	18%	13%	111
UT	43%	30%	17%	10%	109
MD	42%	30%	14%	14%	203
KY	41%	35%	8%	16%	37
PA	39%	30%	20%	10%	185
MN	38%	32%	15%	16%	101
MO	31%	33%	24%	12%	51
DE	24%	24%	14%	38%	29

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	30%	26%	25%	19%	114

Support Workers Have the Right Information and Skills to Meet Family's Needs

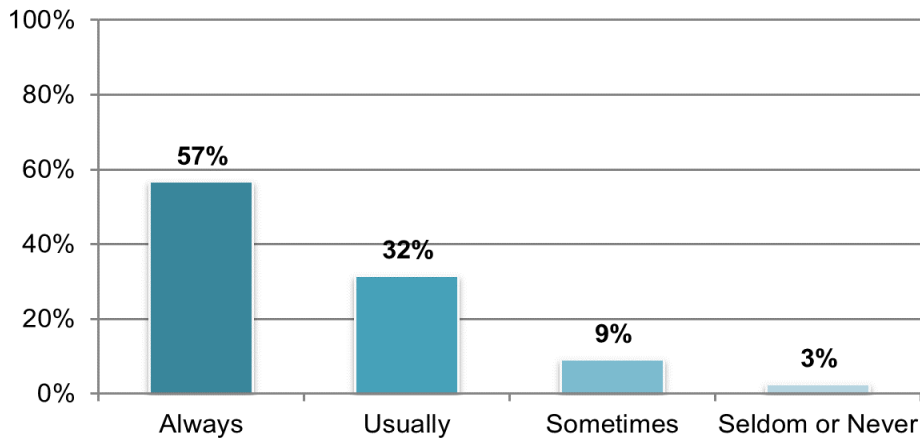


Table Q24. Do support workers have the right information and skills to meet your family's needs?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	71%	20%	8%	1%	417
FL	70%	22%	6%	1%	166
MS	63%	29%	6%	2%	344
UT	63%	31%	5%	1%	397

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	63%	23%	9%	5%	221
KY	61%	33%	4%	2%	142
PA	61%	32%	6%	1%	687
OK	59%	34%	5%	1%	351
NC	58%	32%	7%	2%	224
NCI Average	57%	32%	9%	3%	9,024
MO	56%	35%	7%	2%	204
GA	55%	32%	9%	4%	318
CA [~]	54%	32%	11%	3%	3,653
MN	52%	35%	11%	3%	407

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	48%	39%	10%	3%	860
DE	39%	47%	13%	1%	121
NJ	36%	45%	14%	5%	512

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Family Member Has Access to Special Equipment or Accommodations Needed

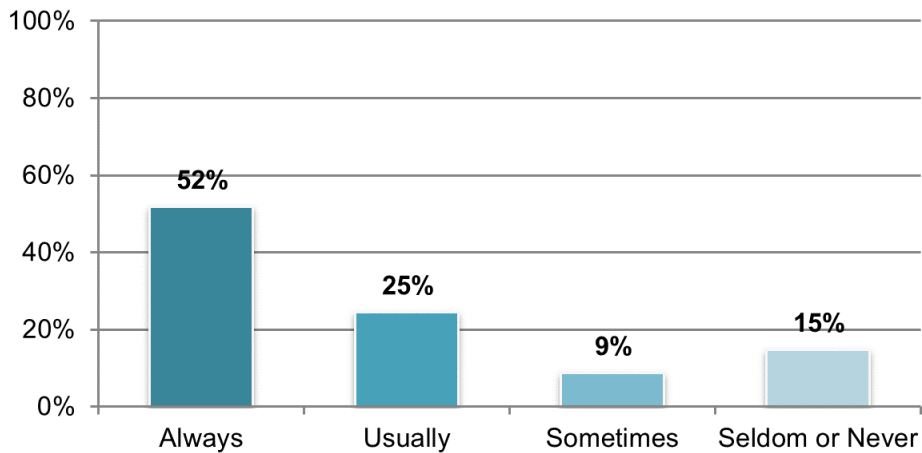


Table Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	59%	19%	8%	14%	211
UT	57%	27%	9%	7%	206
MN	54%	28%	7%	10%	202
OK	54%	28%	7%	11%	210
KY	54%	29%	5%	12%	65
FL	54%	23%	9%	14%	95
CA	54%	20%	9%	18%	1,691
NC	53%	31%	7%	9%	131
NCI Average	52%	25%	9%	15%	4,276
MS	51%	23%	11%	14%	192
PA	51%	29%	10%	10%	306
DC	49%	17%	6%	28%	83
DE	46%	34%	15%	5%	65
GA	45%	31%	8%	16%	148
MO	42%	37%	6%	15%	110

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	43%	31%	12%	14%	325
NJ	40%	28%	16%	16%	236

Family Member Can See Health Professionals When Needed

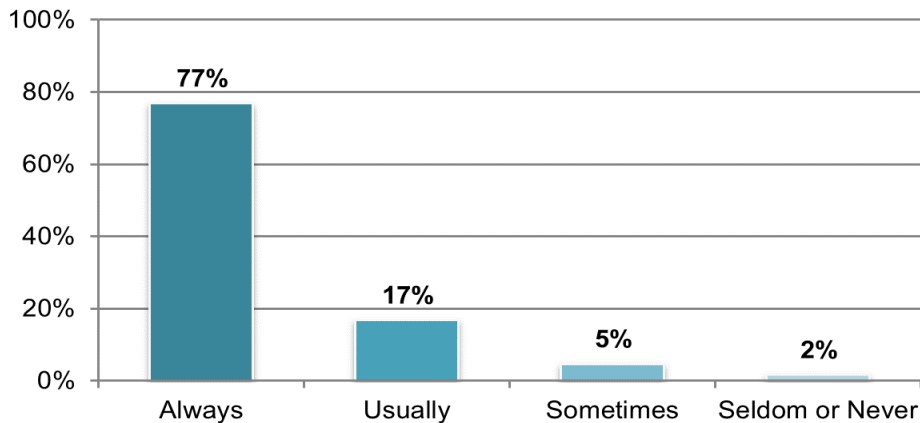


Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	85%	14%	1%	0%	156
LA	82%	14%	3%	1%	470
PA	82%	15%	2%	1%	784
MD	82%	15%	3%	1%	1,043

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
FL	83%	11%	6%	1%	191
NC	82%	16%	1%	1%	252
DC	82%	15%	3%	1%	240
OK	81%	17%	2%	0%	419
MN	79%	17%	3%	1%	444
MO	77%	20%	3%	0%	248
NCI Average	77%	17%	5%	2%	10,962
DE	77%	18%	4%	1%	198
GA	76%	19%	3%	2%	393
MS	75%	20%	4%	0%	371
UT	74%	22%	3%	0%	415
CA~	74%	17%	6%	3%	4,640

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	72%	22%	5%	1%	698

~The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

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

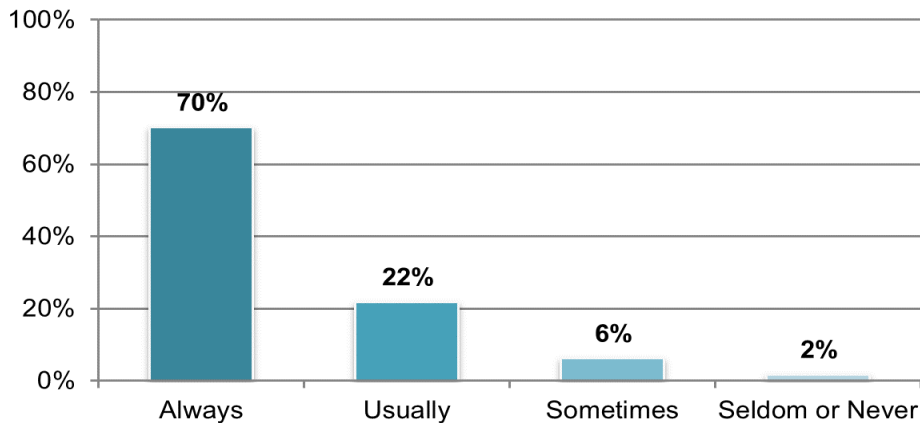


Table Q27. Does your family member's primary care doctor understand his/her needs related to his/her disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	82%	14%	4%	1%	469
FL	79%	14%	4%	3%	187
PA	75%	20%	4%	1%	778
DC	79%	15%	4%	1%	239

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OK	74%	21%	4%	0%	406
GA	72%	24%	3%	1%	391
DE	71%	24%	4%	1%	196
MO	71%	25%	4%	0%	242
MS	71%	24%	4%	1%	368
MD	71%	24%	4%	1%	1,038
KY	70%	24%	4%	2%	158
NCI Average	70%	22%	6%	2%	10,791
NC	69%	27%	3%	0%	251
CA*	68%	21%	8%	2%	4,529
UT	66%	27%	7%	1%	409
MN	66%	27%	6%	2%	438

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	60%	30%	8%	2%	692

*The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent Has Access to Dental Services for Family Member

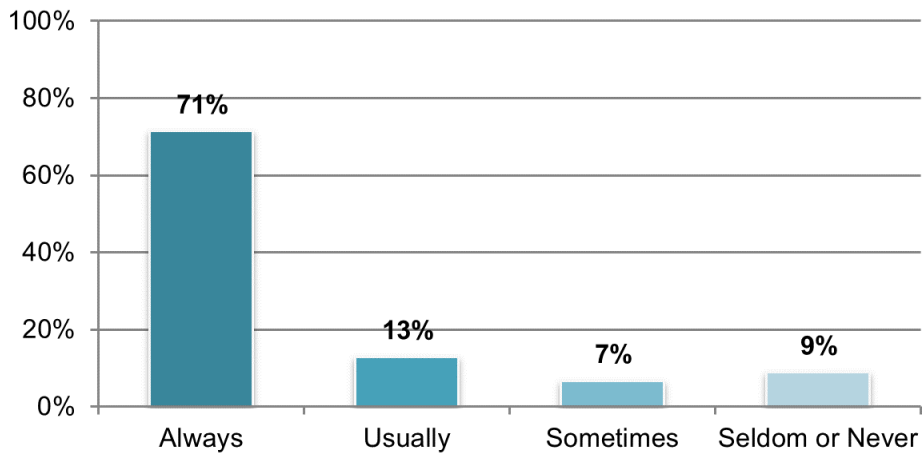


Table Q28. Do you have access to dental services for your family member?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	84%	10%	4%	3%	154
DC	83%	7%	6%	3%	240
PA	80%	11%	3%	6%	764
MN	78%	13%	5%	4%	432
NJ	77%	14%	4%	5%	687
MD	77%	10%	5%	9%	1,015

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	78%	11%	5%	6%	251
OK	76%	12%	4%	8%	395
NCI Average	71%	13%	7%	9%	10,640
CA	71%	14%	8%	8%	4,509
DE	70%	14%	5%	11%	191
UT	69%	14%	6%	10%	410
FL	66%	12%	8%	13%	182

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	64%	13%	6%	17%	439
GA	64%	12%	7%	17%	384
MS	63%	14%	8%	15%	354
MO	61%	14%	11%	15%	233

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

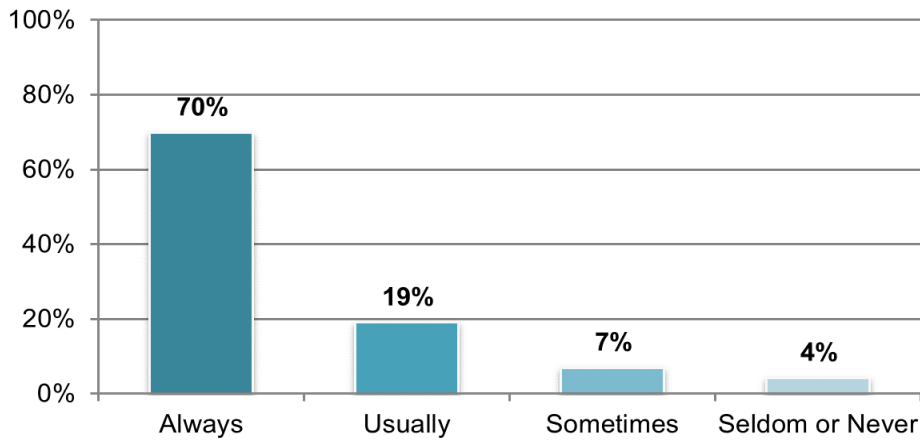


Table Q29. If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
OK	79%	14%	5%	3%	355
DC	78%	13%	7%	2%	223
PA	75%	17%	5%	2%	714

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	76%	19%	3%	2%	149
FL	75%	16%	5%	5%	153
NC	74%	20%	4%	1%	227
MD [*]	74%	17%	5%	4%	920
LA	72%	16%	4%	7%	365
MN	71%	20%	7%	3%	414
GA	70%	20%	6%	4%	320
NCI Average	70%	19%	7%	4%	9,600
DE	69%	22%	5%	4%	170
CA	68%	19%	8%	5%	4,045
UT	67%	21%	9%	3%	379
MS	65%	21%	8%	6%	311
MO	63%	25%	7%	5%	198

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	64%	25%	8%	3%	657

^{*}The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent Knows What Family Member's Medications Are For

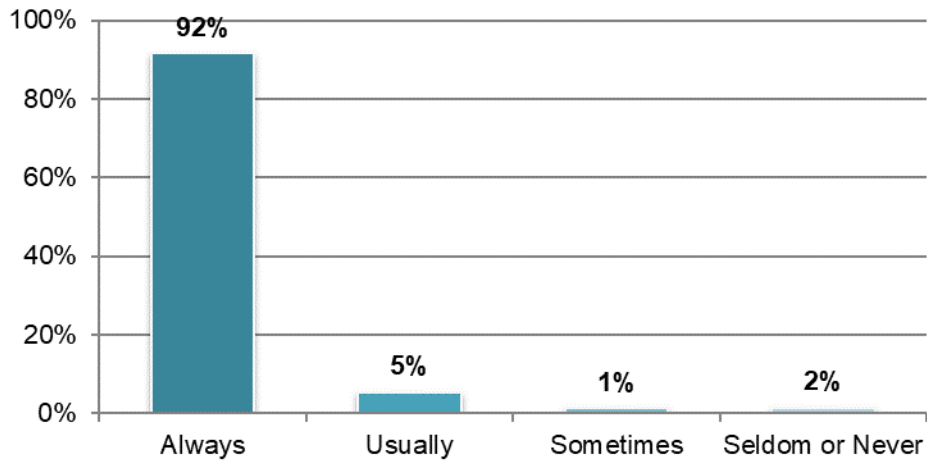


Table Q30. If your family member takes medications, do you know what they're for?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	95%	3%	1%	1%	581

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	94%	4%	1%	1%	141
OK	94%	5%	0%	1%	380
UT	94%	5%	0%	1%	366
NC	94%	4%	1%	1%	231
MD	93%	5%	2%	1%	838
DE	93%	6%	1%	1%	162
GA	93%	5%	1%	1%	360
PA	92%	6%	1%	1%	702
FL	92%	5%	1%	2%	170
NCI Average	92%	5%	1%	2%	9,299
MS	92%	5%	2%	1%	351
LA	91%	5%	2%	1%	431
DC	91%	5%	4%	1%	198
CA	91%	5%	2%	2%	3,778
MN	91%	7%	2%	1%	389
MO	90%	9%	1%	1%	221

Respondent, Family Member, or Other Family Member Knows What Is Needed for Family Member to Take Medication Safely

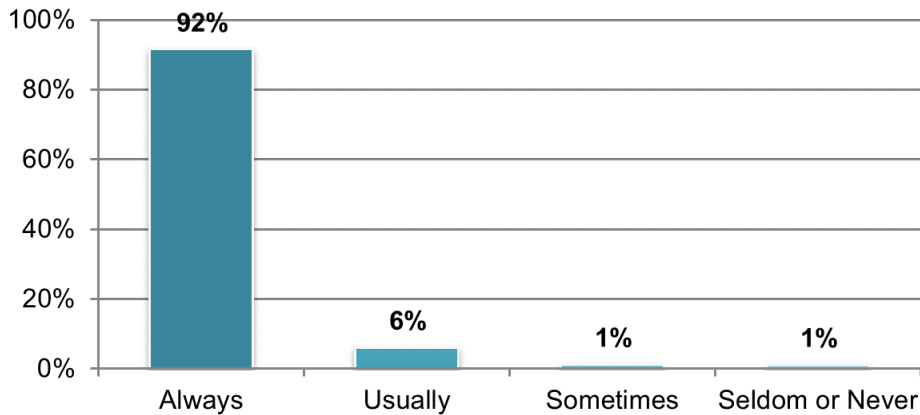


Table Q31. If your family member takes medications, do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
OK	96%	3%	1%	0%	378

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
GA	94%	5%	0%	0%	356
LA	94%	4%	1%	1%	428
MD [~]	94%	5%	1%	1%	834
UT	94%	6%	0%	1%	363
NC	93%	5%	1%	0%	230
DE	93%	4%	1%	1%	161
FL	93%	6%	1%	0%	171
KY	93%	6%	0%	1%	141
PA	93%	5%	1%	1%	700
MN	92%	6%	1%	1%	387
NJ	92%	6%	1%	1%	576
MS	92%	6%	2%	1%	348
NCI Average	92%	6%	1%	1%	9,188
MO	90%	8%	1%	1%	221
CA [~]	90%	6%	2%	2%	3,697
DC	88%	6%	5%	1%	197

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

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

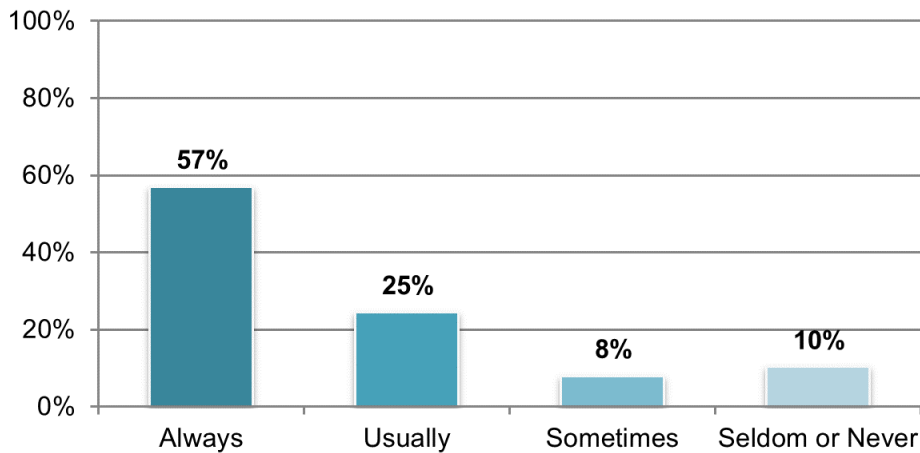


Table Q32. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MO	66%	23%	2%	8%	83
FL	64%	23%	2%	11%	64
GA	63%	26%	3%	8%	156
MD	62%	24%	8%	6%	345
DE	60%	24%	13%	4%	72
KY	59%	34%	3%	3%	59
OK	59%	28%	6%	8%	104
LA	58%	20%	12%	10%	156
DC	58%	17%	13%	13%	111
NCI Average	57%	25%	8%	10%	3,867
NC	57%	32%	6%	6%	106
PA	56%	29%	6%	9%	238
UT	56%	25%	12%	8%	102
MS	55%	28%	6%	10%	155
CA	55%	22%	10%	13%	1,712
MN	52%	31%	11%	6%	177
NJ	51%	26%	14%	9%	227

Respondent Has Access to Respite Services

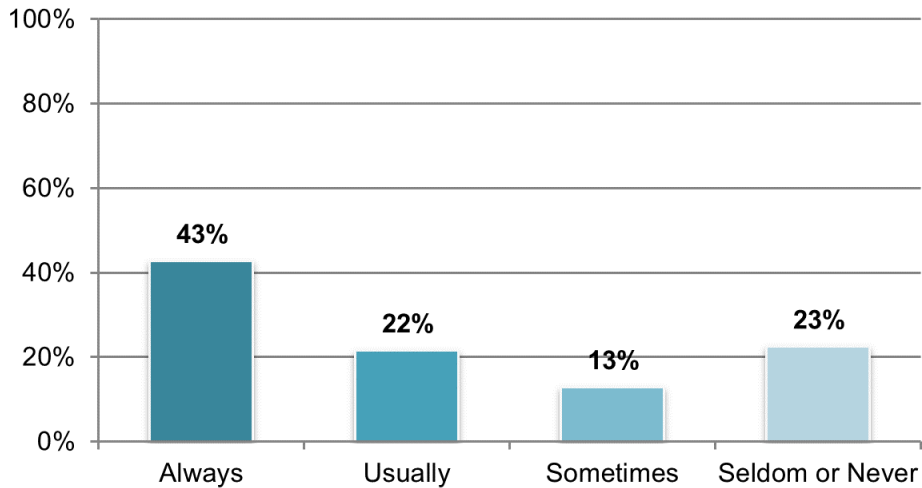


Table Q33. If you need respite services, do you have access to them?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
DC	57%	16%	13%	15%	141
KY	54%	27%	8%	11%	129
UT	51%	28%	12%	10%	318
CA	49%	19%	12%	20%	2,614

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	52%	23%	16%	10%	217
LA	49%	19%	9%	23%	239
MS	45%	20%	13%	22%	225
NCI Average	43%	22%	13%	23%	6,255
FL	39%	25%	8%	28%	115
PA	38%	25%	16%	20%	444
MN	36%	22%	18%	24%	285
DE	32%	28%	16%	25%	122

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	29%	14%	15%	43%	206
MD	27%	23%	13%	38%	488
MO	26%	31%	13%	30%	126
OK	24%	13%	11%	51%	176
NJ	13%	21%	18%	48%	410

Respondent Is Satisfied With the Quality of Family Member's Respite Services

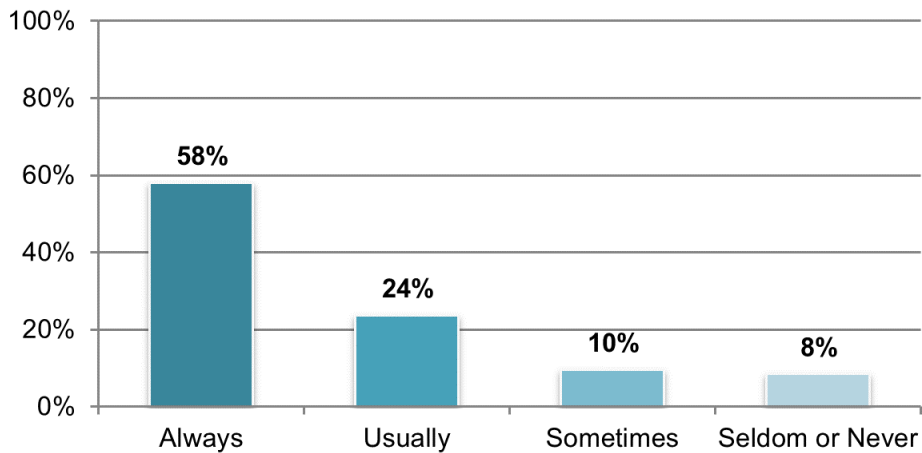


Table Q34. If you have access to respite services, are you satisfied with the quality of those services?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	69%	21%	5%	6%	121
OK	67%	13%	10%	10%	82
FL	64%	23%	5%	8%	77
NC	61%	23%	10%	5%	192
CA	61%	20%	10%	9%	2,067
DC	60%	15%	14%	11%	112
NCI Average	58%	24%	10%	8%	4,675
PA	58%	29%	8%	6%	332
UT	57%	31%	8%	3%	289
MS	57%	26%	9%	7%	178
MN	56%	23%	12%	9%	219
LA	56%	26%	7%	11%	191
DE	51%	26%	13%	10%	91

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	44%	34%	9%	12%	291
GA	43%	30%	10%	16%	115
MO	43%	37%	14%	6%	84
NJ	30%	38%	15%	17%	234

Family Gets Supports and Services Needed

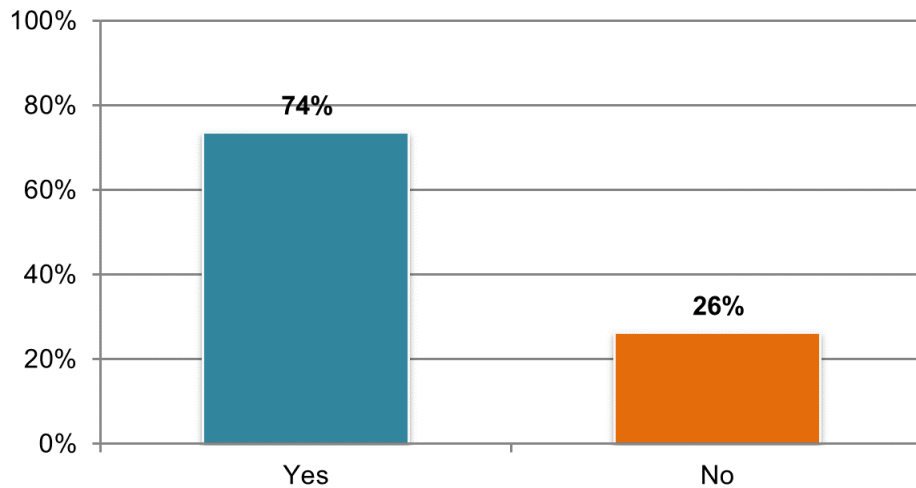


Table Q35. Does your family get the support and services needed?

Significantly Above Average

State	Yes	No	N
PA	83%	17%	704
LA	82%	18%	410
NC	82%	18%	229
MS	80%	20%	325
UT	79%	21%	391

Within Average Range

State	Yes	No	N
KY	78%	22%	149
MO	76%	24%	211
MN	76%	24%	411
FL	75%	25%	165
NCI Average	74%	26%	9,734
CA [~]	72%	28%	4,078
DC	72%	28%	225
OK	71%	29%	375
DE	67%	33%	175
GA	67%	33%	332

Significantly Below Average

State	Yes	No	N
MD	68%	32%	926
NJ	58%	42%	628

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Additional Services Needed

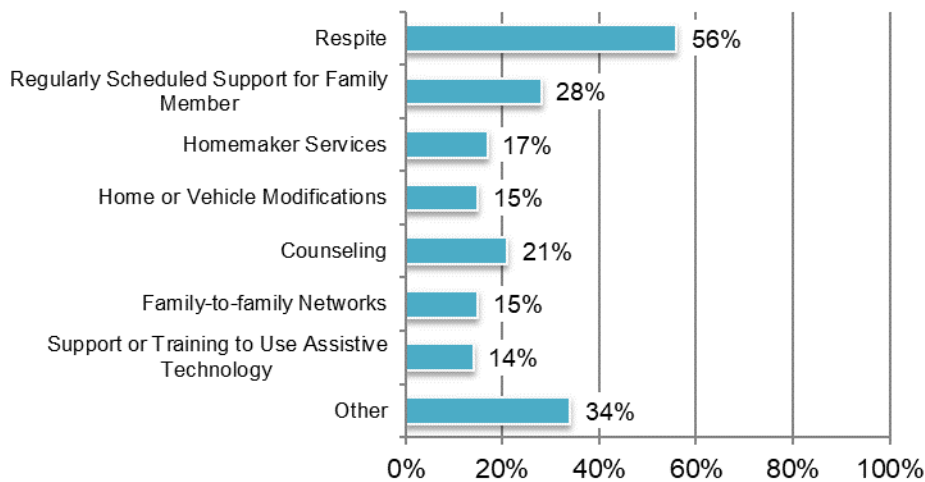


Table Q36. If family does not get the support and services needed, what additional services are needed?

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Support or Training to Use Assistive Technology	Other
CA	49%	27%	18%	14%	24%	15%	17%	35%
DC	50%	50%	23%	18%	25%	20%	13%	21%
DE	58%	40%	12%	10%	28%	18%	12%	28%
FL	68%	23%	20%	13%	15%	13%	13%	35%
GA	64%	24%	15%	18%	13%	19%	5%	35%
KY	67%	23%	13%	17%	10%	10%	13%	20%
LA	54%	29%	16%	29%	14%	10%	11%	27%
MD	66%	26%	18%	11%	23%	17%	14%	27%
MN	71%	35%	16%	17%	20%	19%	12%	37%
MO	57%	30%	16%	11%	20%	16%	11%	34%
MS	64%	20%	20%	33%	19%	9%	5%	31%
NC	53%	43%	13%	23%	28%	13%	15%	33%
NJ	68%	32%	22%	14%	19%	18%	13%	43%
OK	74%	21%	7%	20%	7%	4%	6%	21%
PA	56%	28%	11%	16%	13%	13%	11%	32%
UT	44%	30%	22%	13%	10%	13%	13%	29%
NCI Average	56%	28%	17%	15%	21%	15%	14%	34%

Choice, Decision Making and Control

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

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

Family Can Choose or Change Family Member's Provider Agency

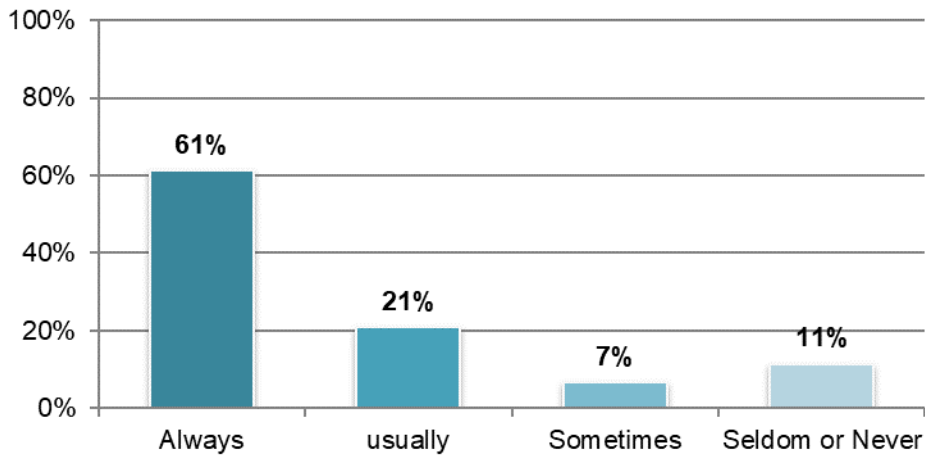


Table Q37. Can your family choose or change the agency that provides your family member's services?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	79%	12%	4%	5%	211
FL	79%	14%	1%	6%	138
KY	73%	16%	2%	8%	123
LA	73%	18%	4%	4%	368
OK	72%	20%	4%	4%	309
UT	70%	24%	3%	3%	301
MS	68%	23%	2%	7%	291

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	68%	16%	9%	7%	174
PA	66%	24%	4%	6%	478
MN	65%	24%	3%	8%	343
MD	62%	24%	6%	8%	675
NCI Average	61%	21%	7%	11%	6,304
GA	59%	19%	8%	14%	239
MO	58%	25%	5%	12%	141
DE	58%	26%	8%	7%	95

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	51%	30%	10%	9%	430
CA	48%	22%	11%	19%	1,988

Family Can Choose or Change Family Member's Support Workers

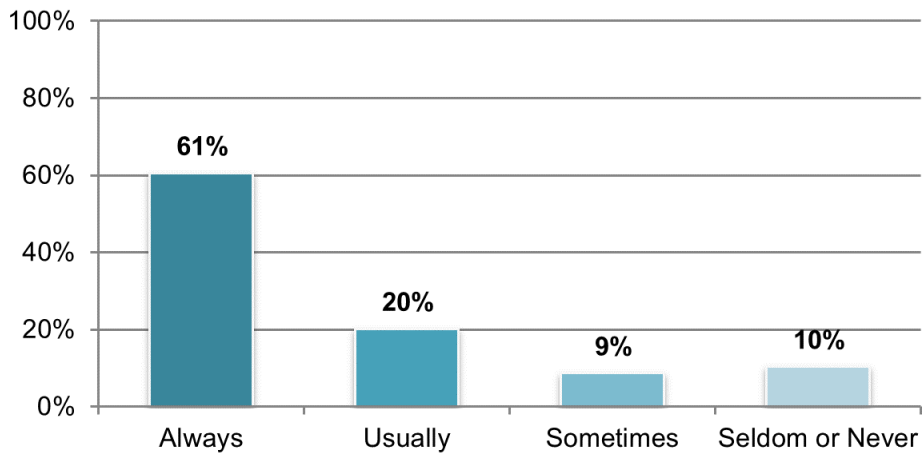


Table Q38. Can your family choose or change your family member's support workers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	77%	13%	4%	7%	152
DC	75%	11%	4%	10%	175
LA	73%	17%	4%	5%	349
NC	72%	17%	6%	5%	216
UT	71%	18%	7%	4%	334
OK	70%	18%	6%	7%	285
MS	68%	22%	3%	7%	304

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	68%	20%	6%	6%	123
PA	66%	23%	6%	6%	488
MN	64%	21%	7%	8%	366
GA	63%	18%	8%	11%	238
NCI Average	61%	20%	9%	10%	6,354
MD	57%	22%	9%	12%	590
MO	57%	23%	13%	7%	152
DE	51%	27%	8%	14%	59

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	50%	22%	12%	16%	2,157
NJ	44%	31%	13%	12%	366

Family Directly Manages Support Workers

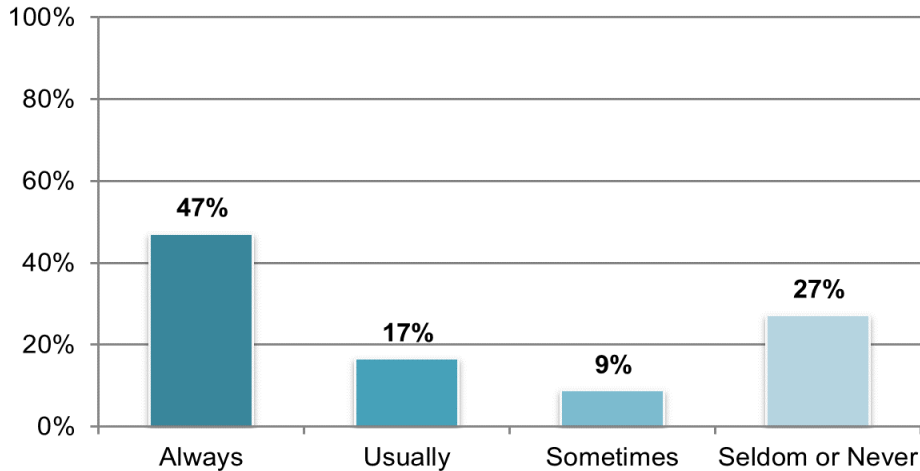


Table Q39. Does your family directly manage support workers (for example, hiring and deciding schedule)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	64%	14%	8%	15%	324
FL	60%	13%	5%	22%	144
MN	59%	17%	7%	17%	374
LA	55%	16%	8%	20%	321
OK	55%	18%	5%	22%	280

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	52%	15%	9%	25%	124
DC	51%	18%	8%	24%	164
MS*	48%	21%	9%	22%	300
NCI Average	47%	17%	9%	27%	6,431
PA	47%	18%	9%	26%	473
GA	45%	18%	6%	31%	227
MO	44%	17%	9%	30%	145
CA~	44%	14%	10%	32%	2,329
NJ	42%	25%	9%	24%	388
NC	39%	25%	11%	24%	202

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	33%	18%	9%	40%	566
DE	30%	27%	7%	36%	70

*MS does not offer these services through the waiver.

~The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Family Member's Service Providers Work Together to Provide Support

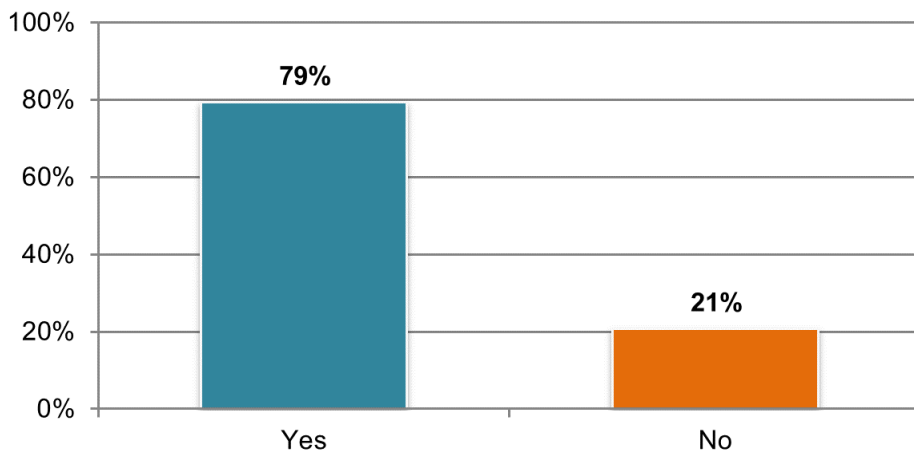


Table Q40. Do service providers for your family member work together to provide support?

Significantly Above Average

State	Yes	No	N
UT	90%	10%	239
OK	89%	11%	188
MS	87%	13%	225
PA	86%	14%	403
MD	85%	15%	549

Within Average Range

State	Yes	No	N
MO	86%	14%	132
KY	86%	14%	94
DC	86%	14%	168
NC	85%	15%	150
LA	82%	18%	248
FL	80%	20%	113
NCI Average	79%	21%	5,574
GA	79%	21%	196
MN	76%	24%	276
CA~	76%	24%	2,218
DE	71%	29%	66

Significantly Below Average

State	Yes	No	N
NJ	68%	32%	309

~The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent, Family Member, or Other Family Member Chose or Can Change Case Manager or Service Coordinator

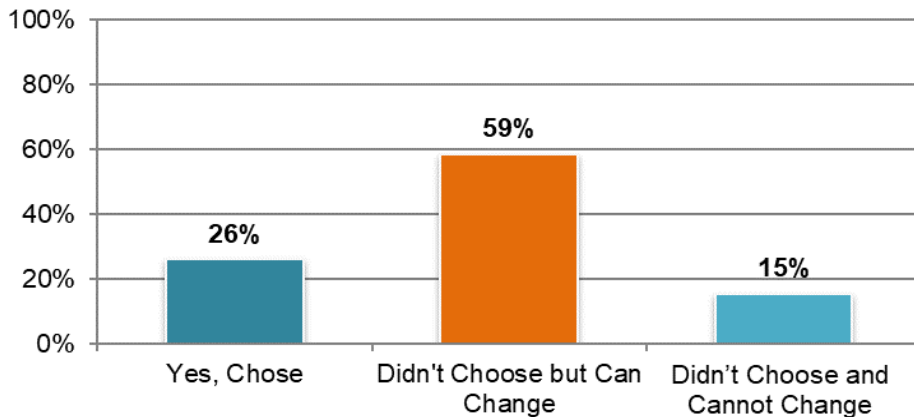


Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

Significantly Above Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
FL	68%	29%	3%	177
UT	67%	28%	5%	372
KY	47%	46%	8%	129
NJ	45%	36%	20%	595
LA	42%	46%	12%	360

Within Average Range

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
MS	29%	56%	14%	292
NC	26%	60%	14%	202
NCI Average	26%	59%	15%	8,241
PA	23%	69%	8%	575
DC	21%	67%	12%	204

Significantly Below Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
MD	17%	65%	17%	880
MO	16%	64%	20%	205
CA	14%	68%	17%	3,120
MN	14%	58%	28%	362
GA	13%	64%	23%	302
OK	13%	60%	27%	331
DE	12%	56%	32%	135

Involvement in the Community

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

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

Family Member Takes Part in Community Activities

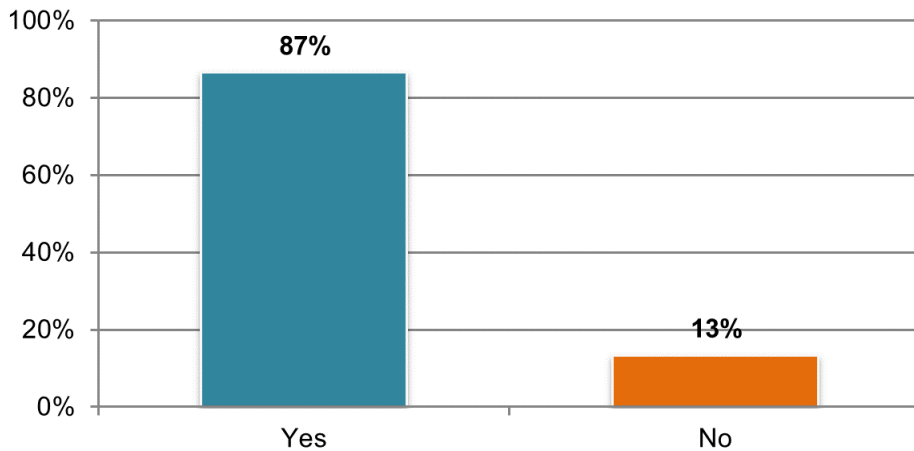


Table Q42. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

Significantly Above Average

State	Yes	No	N
MO	94%	6%	241
MN	94%	6%	450
DE	93%	7%	192
UT	91%	9%	410
GA	91%	9%	387
OK	91%	9%	413
MD	90%	10%	1,021

Within Average Range

State	Yes	No	N
KY	92%	8%	154
FL	90%	10%	191
NC	89%	11%	250
DC	88%	12%	232
PA	88%	12%	762
NJ	87%	13%	687
NCI Average	87%	13%	10,762
MS	84%	16%	373
CA~	83%	17%	4,534
LA	83%	17%	465

~The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Obstacles/Barriers to Family Member's Participation in Community

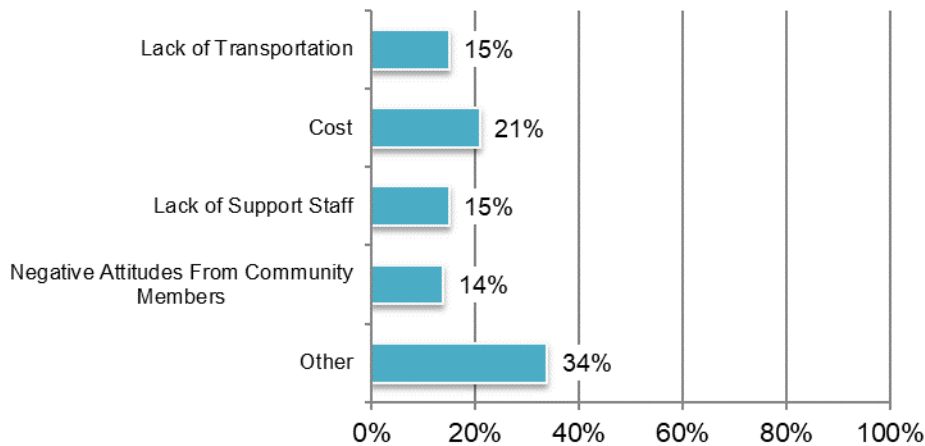


Table Q43. For your family member, what are the obstacles or barriers to participation in activities in the community?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes from Community Members	Other
CA	27%	32%	25%	20%	38%
DC	33%	40%	17%	18%	32%
DE	30%	30%	26%	23%	35%
FL	17%	27%	16%	15%	55%
GA	27%	34%	25%	17%	36%
KY	26%	32%	26%	12%	33%
LA	24%	29%	15%	19%	39%
MD	32%	28%	33%	17%	35%
MN	31%	26%	37%	17%	39%
MO	22%	30%	23%	18%	47%
MS	22%	24%	19%	15%	52%
NC	23%	32%	25%	21%	43%
NJ	41%	26%	38%	16%	38%
OK	24%	27%	20%	16%	40%
PA	30%	33%	31%	15%	35%
UT	28%	32%	28%	22%	50%
NCI Average	27%	31%	25%	18%	40%

Family Member Has Friends Other Than Paid Support Workers or Family

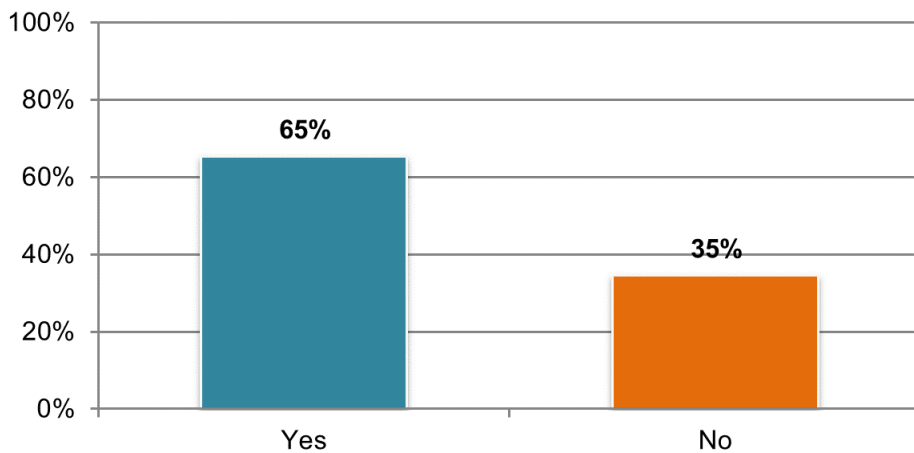


Table Q44. Does your family member have friends other than paid support workers or family?

Significantly Above Average

State	Yes	No	N
KY	85%	15%	156
OK	77%	23%	405
GA	77%	23%	377
LA	71%	29%	462

Within Average Range

State	Yes	No	N
DC	72%	28%	225
NC	71%	29%	249
MN	71%	29%	434
FL	71%	29%	180
PA	70%	30%	742
DE	70%	30%	187
MO	69%	31%	242
MS	68%	32%	362
MD	67%	33%	986
UT	66%	34%	404
NCI Average	65%	35%	10,493
CA~	61%	39%	4,402

Significantly Below Average

State	Yes	No	N
NJ	52%	48%	680

~The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

There Are Resources in the Community the Family Member Can Use That Are Not Provided by the IDD Agency

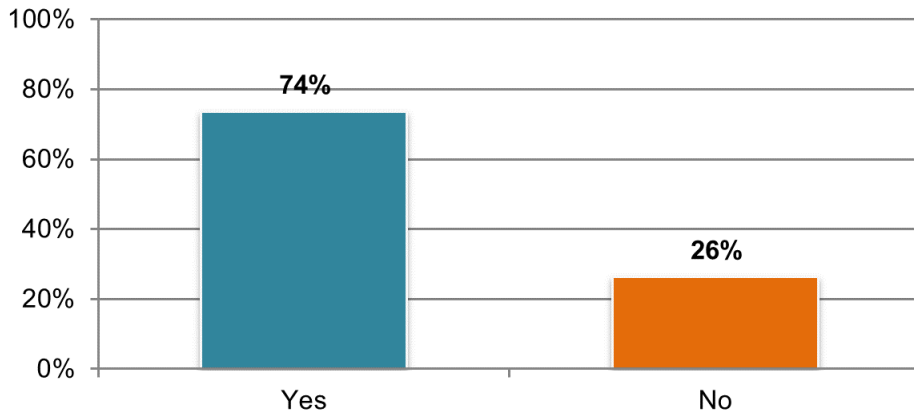


Table Q45. In your community, are there resources that your family can use that are not provided by the IDD agency?

Significantly Above Average

State	Yes	No	N
MN	91%	9%	358
UT	80%	20%	304
MD	80%	20%	741

Within Average Range

State	Yes	No	N
OK	79%	21%	327
DE	77%	23%	132
PA	77%	23%	501
NC	76%	24%	219
DC	76%	24%	178
KY	76%	24%	119
GA	74%	26%	255
NCI Average	74%	26%	7,794
CA	73%	27%	3,277
FL	72%	28%	139
MO	71%	29%	163

Significantly Below Average

State	Yes	No	N
NJ	68%	32%	503
MS	62%	38%	258
LA	61%	39%	320

Family Takes Part in Family-to-family Networks

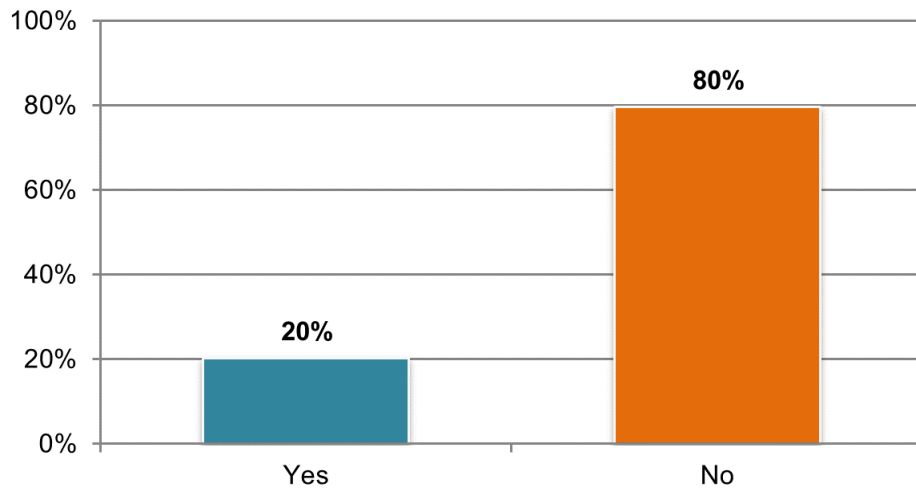


Table Q46. Does your family take part in any family-to-family networks in your community?

Significantly Above Average

State	Yes	No	N
DC	42%	58%	153
KY	34%	66%	96
LA	29%	71%	296

Within Average Range

State	Yes	No	N
FL	28%	72%	126
DE	25%	75%	144
GA	24%	76%	238
OK	24%	76%	258
MN	23%	77%	364
MD	21%	79%	717
MS	21%	79%	292
NCI Average	20%	80%	8,350
NC	20%	80%	204
NJ	19%	81%	570
CA	19%	81%	3,922
UT	16%	84%	311
MO	14%	86%	166

Significantly Below Average

State	Yes	No	N
PA	16%	84%	493

Satisfaction With Services and Supports

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

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

Overall, Respondent Is Satisfied With Services and Supports Family Receives

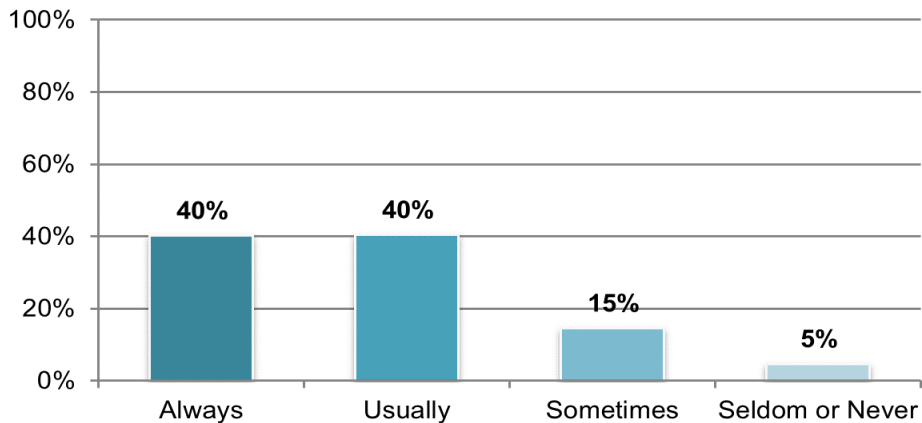


Table Q47. Overall, are you satisfied with the services and supports your family currently receives?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	52%	33%	12%	4%	181
LA	51%	32%	11%	6%	462
DC	50%	29%	17%	3%	235
MS	49%	38%	12%	1%	371

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
CA~	43%	36%	16%	5%	4,603
UT	43%	47%	9%	2%	416
KY	42%	47%	9%	2%	156
NCI Average	40%	40%	15%	5%	10,797
PA	39%	50%	8%	2%	769
NC	39%	46%	9%	6%	248
OK	38%	48%	10%	4%	415
GA	36%	39%	21%	4%	378
MO	33%	49%	13%	5%	239

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	30%	49%	16%	5%	1,021
MN	29%	56%	12%	3%	440
DE	17%	46%	27%	10%	187
NJ	17%	48%	27%	8%	676

~The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

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

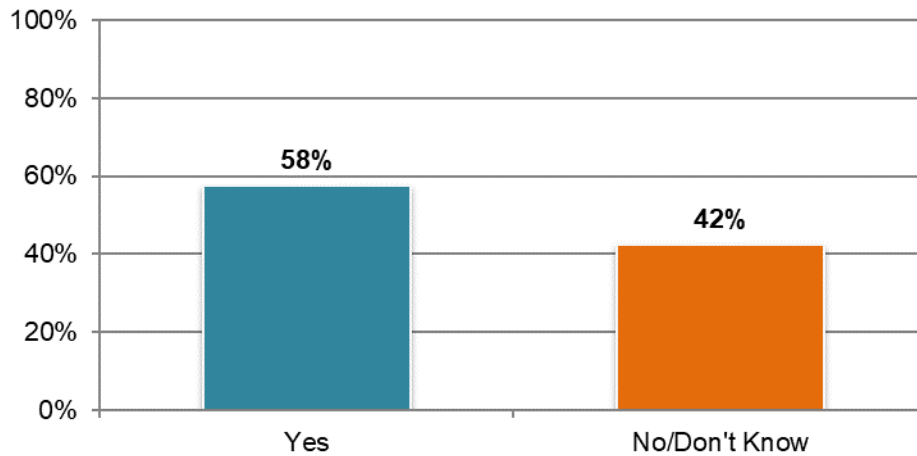


Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff?²

Significantly Above Average

State	Yes	No or Don't Know	N
OK	83%	17%	413
MS	77%	23%	368
LA	76%	24%	466
FL	75%	25%	186
KY	74%	26%	155
DC	72%	28%	234
MN	71%	29%	444
NC	71%	29%	252
PA	70%	30%	767
UT	69%	31%	413

Within Average Range

State	Yes	No or Don't Know	N
MO	62%	38%	240
NCI Average	58%	42%	10,866
GA	53%	47%	387
CA ²	50%	50%	4,620

Significantly Below Average

State	Yes	No or Don't Know	N
MD	48%	52%	1,028
DE	30%	70%	198
NJ	30%	70%	695

¹The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

²'Don't Know' responses were included in 'No' responses for this question.

**Respondent Is Satisfied With the Way
Complaints or Grievances About Provider
Agencies or Staff Were Handled and Resolved (If
Filed in the Past Year)**

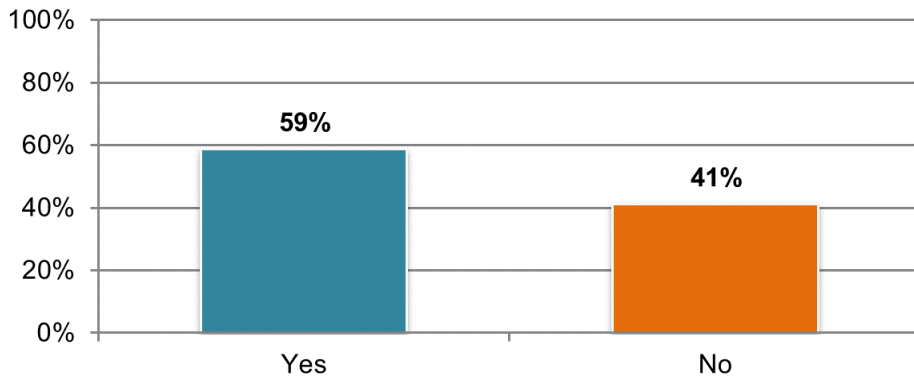


Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

Within Average Range

State	Yes	No	N
UT	71%	29%	35
OK	65%	35%	26
DC	63%	37%	62
MD	63%	37%	105
MN	63%	38%	40
LA	62%	38%	76
NCI Average	59%	41%	1,344
PA	59%	41%	46
NC	58%	42%	50
CA	58%	42%	725
MS	51%	49%	43
GA	51%	49%	49

Significantly Below Average

State	Yes	No	N
NJ	36%	64%	42

*Due to low N's (<20) the following states are not represented in tables, but their data are included in the NCI Average: FL, DE, KY, MO

Respondent Knows How to Report Abuse or Neglect

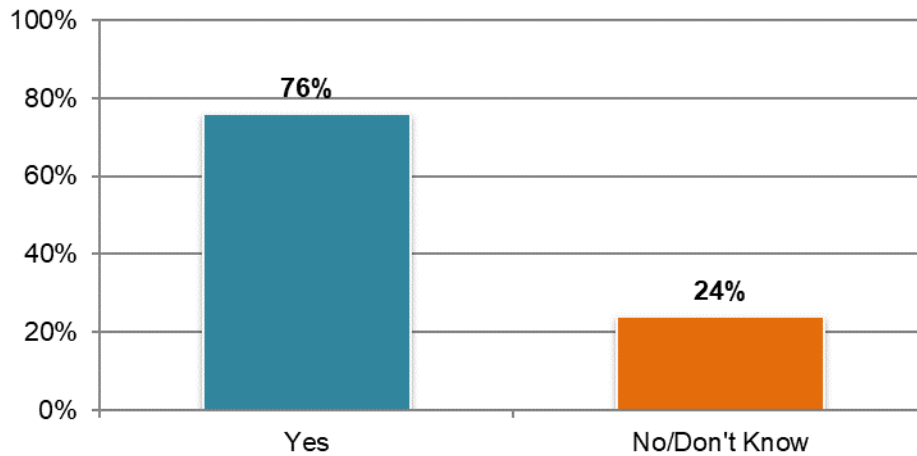


Table Q50. Do you know how to report abuse or neglect related to your family member?³

Significantly Above Average

State	Yes	No or Don't Know	N
OK	92%	8%	410
MN	89%	11%	446
NC	89%	11%	254
FL	88%	12%	187
KY	87%	13%	156
MS	87%	13%	371
LA	85%	15%	465
PA	85%	15%	768
DC	83%	17%	228

Within Average Range

State	Yes	No or Don't Know	N
UT	79%	21%	415
MO	77%	23%	244
NCI Average	76%	24%	10,875
GA	73%	27%	382
CA [~]	71%	29%	4,627

Significantly Below Average

State	Yes	No or Don't Know	N
MD	68%	32%	1,029
DE	65%	35%	199
NJ	53%	47%	694

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

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

Abuse or Neglect Was Reported on Behalf of Family Member in the Past Year

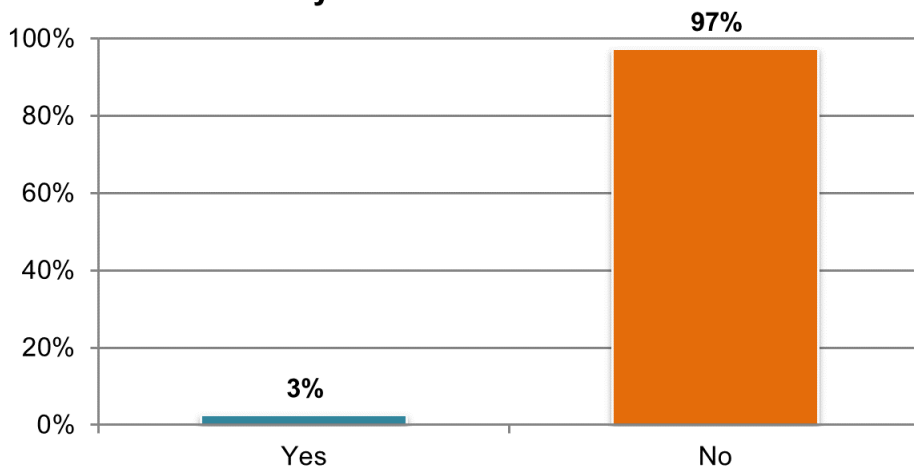


Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

Within Average Range

State	Yes	No	N
DC	6%	94%	201
GA	4%	96%	342
MO	4%	96%	224
LA	4%	96%	423
MN	4%	96%	413
CA	3%	97%	4,301
NCI Average	3%	97%	10,121
DE	3%	97%	191
MD	2%	98%	967
OK	2%	98%	362
UT	2%	98%	397
PA	2%	98%	730
NC	2%	98%	241
FL	1%	99%	168

Significantly Below Average

State	Yes	No	N
MS	1%	99%	352
KY	1%	99%	143
NJ	1%	99%	666

Services and Supports Have Made a Positive Difference in Family's Life

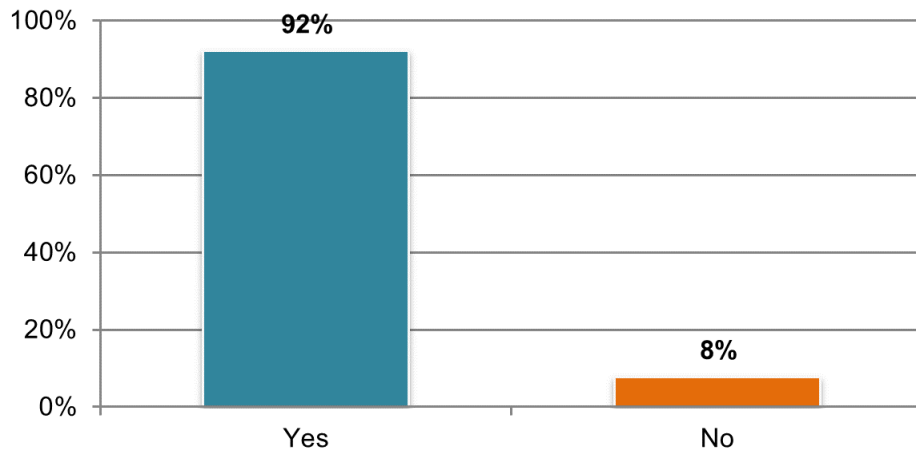


Table Q52. Do you feel that services and supports have made a positive difference in the life of your family?

Significantly Above Average

State	Yes	No	N
KY	98%	2%	145
MS	98%	2%	350
FL	98%	2%	172
UT	97%	3%	399
OK	95%	5%	389

Within Average Range

State	Yes	No	N
NC	95%	5%	233
PA	94%	6%	714
MO	93%	7%	219
MN	93%	7%	427
MD	92%	8%	930
NCI Average	92%	8%	9,777
LA	92%	8%	435
GA	91%	9%	351
CA [~]	90%	10%	3,990
DC	88%	12%	222

Significantly Below Average

State	Yes	No	N
DE	83%	17%	168
NJ	89%	11%	633

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

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

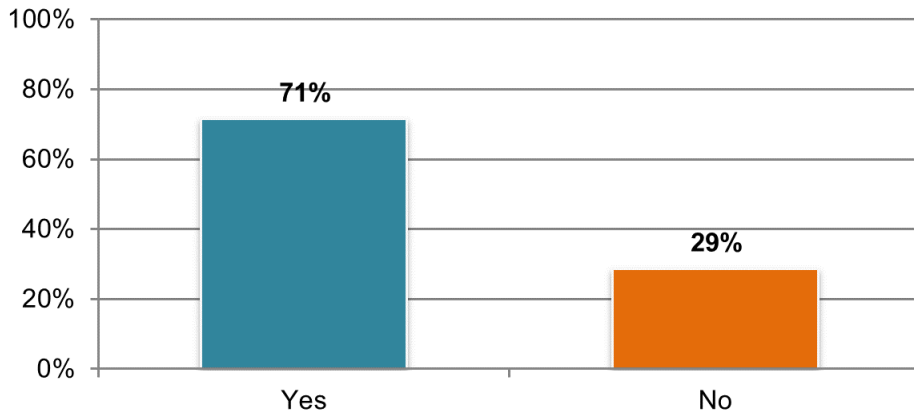


Table Q53. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care?

Significantly Above Average

State	Yes	No	N
KY	86%	14%	146
UT	86%	14%	380
OK	81%	19%	381

Within Average Range

State	Yes	No	N
MN	77%	23%	405
FL	73%	27%	159
MO	73%	27%	221
MS	72%	28%	345
PA	72%	28%	676
CA	72%	28%	3,823
NCI Average	71%	29%	9,384
NC	69%	31%	229
NJ	68%	32%	616
LA	68%	32%	404

Significantly Below Average

State	Yes	No	N
MD	64%	36%	897
GA	62%	38%	327
DC	60%	41%	200
DE	54%	46%	175

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

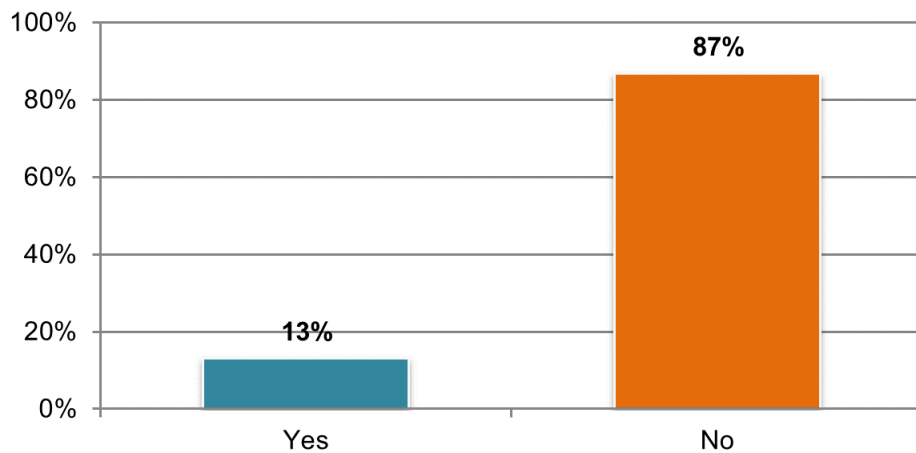


Table Q54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?

Significantly Above Average

State	Yes	No	N
NJ	18%	82%	626

Within Average Range

State	Yes	No	N
UT	18%	82%	399
KY	17%	83%	143
OK	16%	84%	358
NC	15%	85%	240
FL	14%	86%	160
DC	14%	86%	203
MN	14%	86%	417
LA	13%	87%	402
MO	13%	87%	214
NCI Average	13%	87%	9,696
CA	13%	87%	4,083
DE	12%	88%	168
MD	11%	89%	912
GA	10%	90%	330

Significantly Below Average

State	Yes	No	N
PA	9%	91%	694
MS	8%	92%	347

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

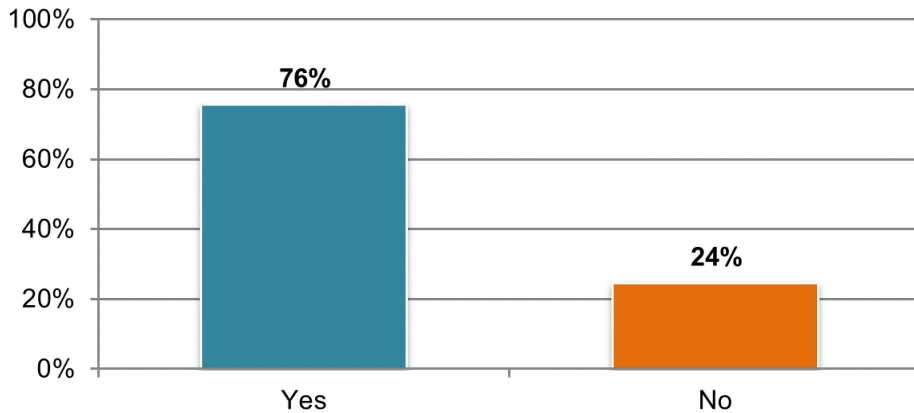


Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?

Significantly Above Average

State	Yes	No	N
NJ	87%	13%	108

Within Average Range

State	Yes	No	N
KY	91%	9%	22
OK	86%	14%	50
NC	84%	16%	32
MO	80%	20%	25
MN	80%	20%	49
MS	77%	23%	22
PA	77%	23%	52
GA	76%	24%	25
NCI Average	76%	24%	1,072
LA	74%	26%	43
MD	74%	26%	93
DC	73%	27%	22
UT	72%	28%	64

Significantly Below Average

State	Yes	No	N
CA	69%	31%	429

*Due to low N's (<20) the following states are not represented in tables, but their data are included in the NCI Average: DE, FL

Services or Supports Were Increased in the Past Year

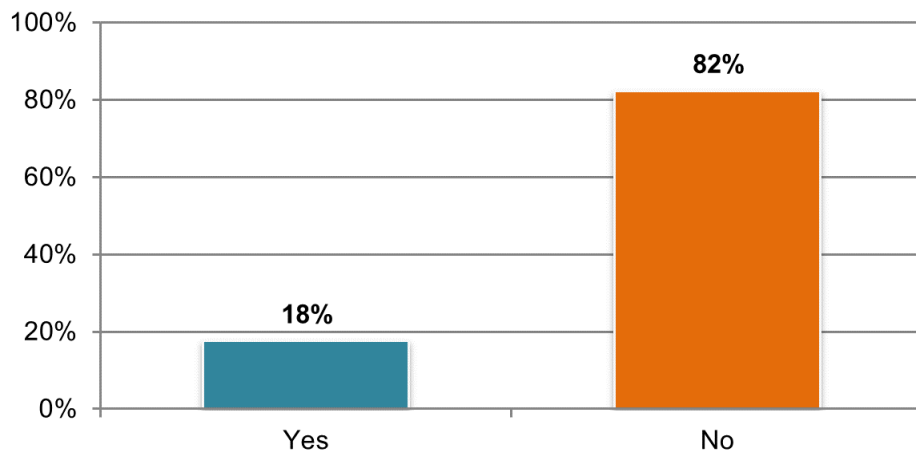


Table Q56. Have the services or supports that your family member received been increased in the past year?

Within Average Range

State	Yes	No	N
DC	25%	75%	202
NC	23%	77%	237
MO	23%	77%	229
MN	21%	79%	404
UT	20%	80%	374
PA	19%	81%	679
MS	19%	81%	343
FL	19%	81%	167
MD	18%	82%	910
NCI Average	18%	82%	9,501
CA	17%	83%	3,951
DE	16%	84%	171
NJ	15%	85%	602
KY	12%	88%	141

Significantly Below Average

State	Yes	No	N
LA	13%	87%	401
GA	12%	88%	337
OK	8%	92%	353

Services or Supports Help Family Member Live a Good Life

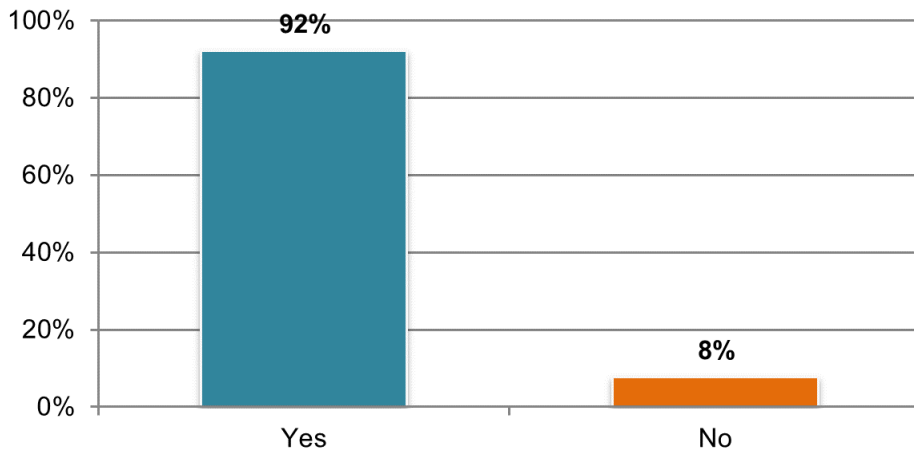


Table Q57. Are services and supports helping your family member to live a good life?

Significantly Above Average

State	Yes	No	N
UT	99%	1%	393
KY	97%	3%	152
FL	97%	3%	165
OK	96%	4%	390
NC	96%	4%	237
MN	96%	4%	430
MS	95%	5%	355
PA	95%	5%	704

Within Average Range

State	Yes	No	N
MO	95%	5%	215
MD	93%	7%	914
DC	93%	7%	204
NCI Average	92%	8%	9,641
LA	91%	9%	418
GA	90%	10%	346
CA~	90%	10%	3,974
DE	85%	15%	151

Significantly Below Average

State	Yes	No	N
NJ	87%	13%	593

~The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

II. NCI History and Activities

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

Overview of National Core Indicators

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

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

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

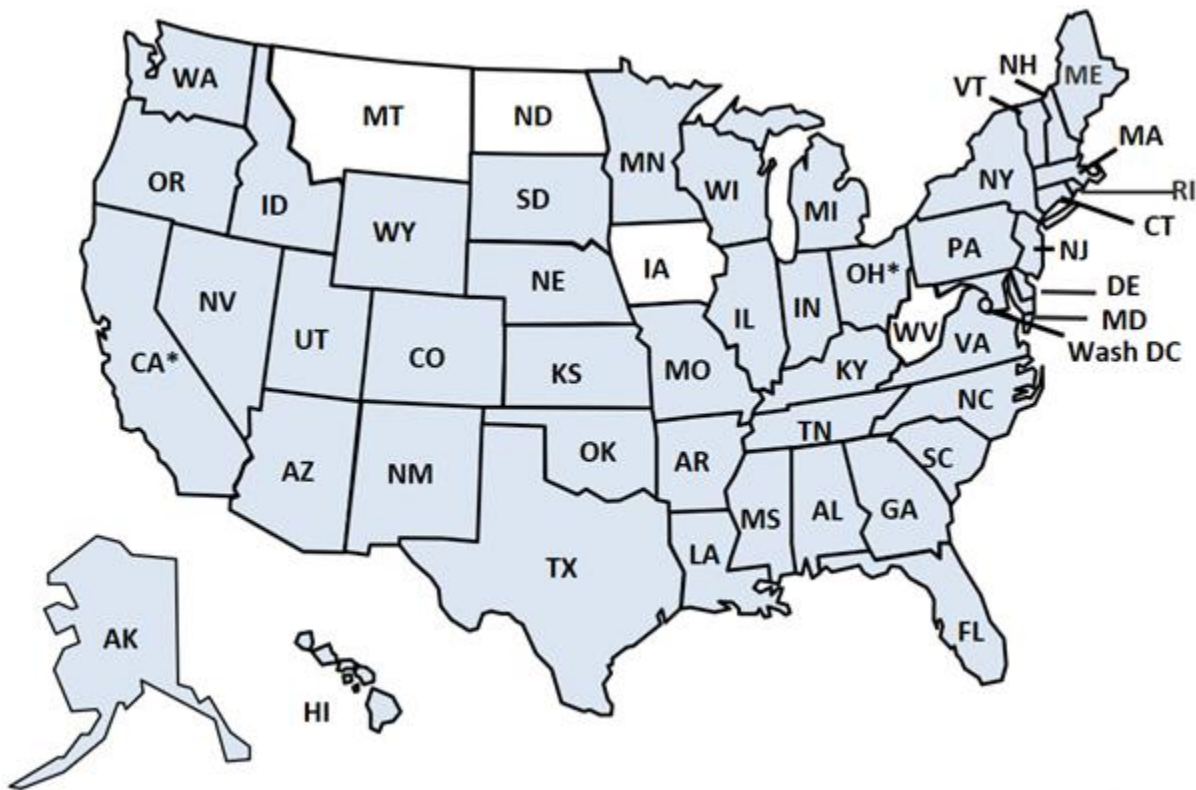
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

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

State Participation

During the 2016-17 data collection cycle, 46 states, the District of Columbia, and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and the participating states are shown on the map below.

NCI State Participation 2016-17



The Core Indicators

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

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

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

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

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

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

Sub-Domains and Concern Statements

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

Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

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

For more information on how to use these data for quality improvement, please see this handbook: [Using National Core Indicators for Quality Improvement Initiatives](#).⁴

Caution and Limitations

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

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

⁴ Located on the National Core Indicators website: www.nationalcoreindicators.org →Resources →Technical Reports

average level) indicate the levels of performance or satisfaction achieved in those states might define a level of performance that may serve as a guidepost for other states.

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

III. Methodology

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

Sampling & Administration

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

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

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. In previous years states only had the option to mail paper surveys. A total of seven states had at least a portion of surveys completed via the new direct entry mode.⁵

A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.⁶

Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI reports, we use “NCI average” to demonstrate the typical performance of all the states that conducted the survey. In previous years, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). This year, the approach has been enhanced to consider the relative numbers of people receiving services through participating states’ systems. Beginning this year, the NCI averages contained in this report are

⁵ States that used the direct entry or mail and direct entry options were: DE, KY, LA, MO, MS, NC, and NJ.

⁶ See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

“weighted” means; their calculations reflect the relative population sizes of participating states, as well as the sample sizes.

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

Significance Testing

Starting this survey cycle (2016-17), for each of the non-adjusted items, each state’s percentage will be compared to the weighted NCI average (described above), and the differences between the two will be tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state’s result depends, in part, on the size of the state’s sample – the larger the sample, the more likely it is that even a small difference will be found *statistically* significant. A statistically significant difference for a state with a large sample size, in and by itself, does not necessarily mean there is a *practically* significant difference. The inclusion of effect sizes as a new criterion allows us to present “meaningfully significant” results, which take consideration of the magnitude or size of the differences into account.

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

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

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the NCI Average, within the

range of the NCI Average, and significantly below the NCI Average. A state that falls “within” the NCI average range due to the difference not meeting the effect size criterion are denoted with a Caron symbol (̂). No symbol was used for the state’s percentage being “within” the NCI average range due to lack of statistical significance (i.e., $p \geq .01$).

Technical Details

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

Data Entry and Analysis

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

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

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

Statistical significance testing was conducted on each state’s “yes” or “always” response compared to the NCI average⁷; significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

Response Rates

During 2016-17, 16 states and the District of Columbia administered the Adult Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level

⁷ The NCI Average is the sum of all state averages divided by the total number of states.

with +/- 7% (7.49% or less) margin of error; their data are included in this report. The following table shows the number of surveys each state mailed, usable surveys returned, response rates, the number of individuals receiving services who were eligible to be drawn into the sample, and each state's margin of error.

Adult Family Survey: State Response Rates ⁸

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
CA	94,511	22,348	4,917	22.00%	1.36%	n/a	n/a
DC	634	634	250	39.43%	4.83%	n/a	n/a
DE	3,000	1,082	206	19.04%	6.59%	50.0%	50.0%
FL	16,652	1,200-1,500	193		7.01%	n/a	n/a
GA	5,967	1,500-1,800	412		4.66%	n/a	n/a
KY	4,351*	605	161	26.61%	7.58%	95.7%	4.3%
LA	7,730*	2,300	483	21.00%	4.32%	97.3%	2.7%
MD	3,611	3,611	1,075	29.77%	2.51%	n/a	n/a
MN	7,709	1,169	455	38.92%	4.46%	n/a	n/a
MO	10,968	1,000	252	25.20%	6.10%	97.2%	2.8%
MS	2,156	1,017	385	37.86%	4.53%	93.0%	7.0%
NC	11,000*	1,200	258	21.50%	6.03%	97.7%	2.3%
NJ	8,930	8,930	720	8.06%	3.50%	20.0%	80.0%
OK	1,510	1,510	425	28.15%	4.03%	n/a	n/a
PA	Up to 15,500	1,600	803	50.19%		n/a	n/a
UT	1,900*	1,000	424	42.40%	4.20%	n/a	n/a
Total			11,419			90.7%	9.3%

*Estimate

⁸ Please note: The family surveys are mail out surveys or completed online by respondents who choose to take part in the survey. As such, the final sample is a sample of convenience and cannot be considered representative of the entire service population in the state.