

Adult Family Survey

2013-14 Final Report

Revised October 28, 2015



**NATIONAL CORE
INDICATORS**

A Collaboration of

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



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10/28/2015

List of Abbreviations Used in This Report

AFS – Adult Family Survey

CFS – Child Family Survey

FGS – Family/Guardian Survey

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities
Services

NCI – National Core Indicators

Note: The data set included in the initial version of this report did not reflect the complete set of surveys completed in 2013-14. This report was revised to update the California and National 'N' (totals), and has made slight changes to some of the averages reported for California.

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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. The Indicators cover key areas 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 NCI Adult Family Survey is administered to families who have an adult (18 years or older) with a developmental disability who lives in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Adult Family Survey on an annual basis. Of the 39 states, the District of Columbia and 22 sub-state entities who participated in NCI during the 2013-2014 data collection cycle, 13 states and the District of Columbia submitted a valid sample of Adult Family Survey data. This Final Report provides a summary of results based on data submitted by June 30, 2014.

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

Demographics and Characteristics of Family Members for Whom the Survey Was Completed

The average age of family members for whom the survey was completed was 35 years old, and the majority were male (57%). Across states, most family members were white (62%); one-quarter (25%) were black/African American; and 7% were Hispanic. In most households, the family member for whom the survey was completed was the only person with ID/DD (88%).

The primary means of communication for most was spoken language (72%), followed by gestures or body language (20%). Nearly all spoke English (92%) while 4% had a primary language of Spanish and 5% another language.

The vast majority required medical care less than once a month (78%) or at least once a month but less than once a week (16%); 5% required at least weekly medical care. Just over half did not require behavioral supports (56%), while 32% needed some behavioral support and 12% required extensive support. The reported amount of help needed with daily activities was: 21% none; 22% little; 28% moderate; and 29% complete.

Demographics and Characteristics of Respondents to the Survey

Two-thirds of respondents to the survey were 55 or older (55% fell in the range of 55 to 74 and 10% were 75 or older); 7% were under 35 years old and 27% were in the range of 35 to 54.

Nearly all respondents were the family member's primary caregiver (95%). Two-thirds of respondents had full or limited guardianship or conservatorship (60% full, 6% limited); 34% were not the individual's guardian or conservator.

More than two-thirds of respondents reported a total family income in the past year of less than \$50,001 (25% reported less than \$15,000, 19% reported between \$15,001 and \$25,000, and 25% reported between \$25,001 and \$50,000); 14% earned \$50,001-\$75,000 and the remaining 16% earned more than \$75,000 in the past year. The amounts that families reported paying out-of-pocket for their family member's care were: 23% nothing; 15% between \$1 and \$100; 36% between \$101 and \$1,000; 23% between \$1,001 and \$10,000; and 2% spent more than \$10,000.

Services and Supports Received

Families reported receiving the following state-provided services and supports: financial support (15%), in-home support (45%), out-of-home respite care (30%), day or employment supports (58%), and transportation (61%); 25% received supports that fell into the category of "other." A vast majority of families reported receiving social security benefits (91%).

Information and Planning

Across states, 35% of respondents say they always receive enough information to help plan services for their family, and 35% reported that the information they receive about services and supports is always easy to understand. More than two-thirds felt the case manager/service coordinator always respects the family's choices and opinions (68%). More than one-third reported that the case manager/service coordinator always tells them about public services for which their family is eligible (38%).

Of the 85% of respondents who reported that their family member has a service plan, most indicated that the plan includes all the services and supports the family member wants (84%) and that their family member received all services listed in the plan (88%). Most felt the service plan includes all the services and support their family member needs (78%). Three-quarters (75%) reported that they discussed how to handle emergencies related to their family member during the last planning meeting.

Access and Delivery of Supports and Services

More than half of respondents reported that they or their family member were always able to contact support workers (57%) and the case manager/service coordinator (54%) when needed. Forty-one percent (41%) reported that services and supports were always available when needed; 44% indicated that services and supports were always available reasonably close to home; and 41% felt that services and supports always changed when their family member's needs changed.

Among respondents whose family member transitioned from school services to state-funded services in the past year, about two-thirds (67%) were happy with the transition. Most indicated that crisis or emergency services were provided if requested in the past year (70%). The vast majority of respondents reported having access to health services (97%) and dental services (81%) for their family member; nearly all (98%) reported they can get needed medication for their family member. Most also reported having access to needed mental health services for their family member (87%). Just over three-quarters reported having access to respite services (78%). Across states, 44% of respondents reported that there were services needed that were not currently offered or available.

Choice and Control

Over half of all respondents reported that they always choose the provider agencies that work with their family (60%) while just over one-third reported that their family member always makes this choice (36%); two-thirds of respondents (66%) reported that they can always choose another provider agency if they want. Fewer than half of all respondents (45%) and less than one-third of family members (31%) always choose the individual support workers; 62% of respondents reported always being able to choose different support workers.

Slightly more than one-quarter of respondents (27%) reported knowing how much money is spent by the ID/DD agency on their family member's behalf while 13% reported that their family member had this knowledge. Of the 46% of respondents who reported they had a say in how ID/DD agency money is spent, 90% reported having all the information needed to decide how to spend the money. Similarly, of the 32% of respondents who reported that their family member has a say in how ID/DD agency money is spent on their behalf, 88% reported that their family member had all the information needed to make these decisions.

Community Connections

Most respondents reported that their family member participates in community activities (87%); among the remaining 13%, the reasons given for the lack of participation included lack of transportation (25%), cost (19%), lack of support staff (19%), negative attitudes from community members (10%), and “other” (56%). More than three-quarters of respondents (78%) reported that their family member has friends and relationships with people other than paid staff or family. Across states, most reported that their family member has enough support to work or volunteer in the community (63%).

Satisfaction with Services and Supports

Across states, 39% of respondents are always satisfied with the services and supports their family receives. More than half reported that they know the process for filing a complaint or grievance against provider agencies or staff (57%), and most are satisfied with the way complaints or grievances are handled (81%). More than three-quarters of respondents know how to report abuse or neglect (78%); of the 40% who reported abuse or neglect in the past year, 80% said that the appropriate people were responsive to the report.

Family Outcomes

Nearly all respondents say that services and supports have made a positive difference in their family’s life (95%), and most say that services and supports have reduced their family’s out-of-pocket expenses related to their family member’s care (81%). Of the one-quarter of respondents (26%) who reported that their family or family member’s services or supports were reduced, suspended, or terminated in the past year, three-quarters (75%) reported that this action had a negative impact on the family or family member.

I. Results

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

Survey Development

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

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

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

Organization of the Adult Family Survey

The Adult Family Survey is composed of the three sections described below. 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 five possible responses ("always," "usually," "sometimes," "seldom," or "never") or two responses ("yes" or "no"). Respondents also have the option to indicate that they don't know the answer to a question or that the question is not applicable.

Presentation of Data

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

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

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

Note on Significance: Statistical significance depends on both the sample size of the state and the difference between the state's result and the national average. Consequently, there are instances where a state's result that is closer to the NCI Average is designated as significantly above or below the NCI Average than a state whose result is further from the NCI Average. Take the following example: State A has a larger valid sample for a particular indicator than State B. State A may show as being significantly different from the average even though State B, which has a larger difference from the average, does not. The larger the sample size of a state, the smaller the difference needs to be to qualify as statistically significant.

Note on California significance: Due to the large N¹, many of California’s data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (**), an outcome is significant *only* due to the sample size.

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.

¹ ‘N’ refers to the number of valid responses.

Demographics

Note:

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

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

Family Member

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

Table 1. Family Member's Age

State	Age	N
AZ	32.4	370
CA	31.7	3,808
DC	36.7	239
FL	36.0	413
GA	35.3	406
LA	35.4	346
MD	32.7	365
NC	32.9	228
NH	34.1	381
OK	33.6	387
PA	36.9	403
SC	37.1	257
VA	36.6	147
WA	31.5	337
NCI Average	34.5	8,087

Table 2. Family Member's Gender

State	Male	Female	N
AZ	53%	47%	371
CA	61%	39%	3,843
DC	61%	39%	245
FL	61%	39%	407
GA	60%	40%	404
LA	54%	46%	346
MD	58%	42%	365
NC	58%	42%	230
NH	60%	40%	378
OK	54%	46%	388
PA	56%	44%	400
SC	60%	40%	255
VA	50%	50%	151
WA	55%	45%	327
NCI Average	57%	43%	8,110

Table 3. Family Member’s Race²

State	American Indian or Alaska Native	Asian	Black or African-American	Hawaiian or Pacific Islander	White	Other or Unknown	Two or More Races	Hispanic or Latino
AZ	6%	2%	6%	0%	65%	3%	7%	22%
CA	2%	12%	9%	1%	42%	1%	8%	34%
DC	0%	1%	92%	0%	4%	0%	2%	4%
FL	2%	1%	18%	0%	59%	1%	3%	18%
GA	1%	2%	48%	0%	47%	0%	2%	1%
LA	1%	1%	33%	0%	65%	0%	1%	0%
MD	1%	5%	28%	0%	65%	0%	3%	2%
NC	3%	1%	26%	0%	70%	0%	0%	1%
NH	2%	1%	1%	0%	94%	1%	3%	1%
OK	13%	2%	10%	0%	80%	0%	4%	3%
PA	0%	1%	6%	0%	86%	0%	3%	3%
SC	2%	1%	43%	0%	53%	0%	2%	1%
VA	1%	3%	24%	0%	70%	0%	1%	1%
WA	2%	7%	4%	1%	73%	1%	7%	8%
NCI Average	3%	3%	25%	0%	62%	1%	3%	7%

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

State	Yes	No	N
AZ	12%	88%	365
CA	14%	86%	3,803
DC	14%	86%	240
FL	13%	87%	403
GA	13%	88%	400
LA	13%	87%	345
MD	9%	91%	356
NC	11%	89%	227
NH	11%	89%	374
OK	8%	92%	381
PA	12%	88%	396
SC	12%	88%	260
VA	9%	91%	148
WA	15%	85%	326
NCI Average	12%	88%	8,024

² Multiple responses allowed. Therefore, state and national percentages may total more than 100%.

Table 5. Family Member’s Primary Means of Expression

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AZ	67%	24%	3%	4%	3%	357
CA	75%	15%	3%	2%	5%	3,814
DC	70%	21%	2%	1%	6%	222
FL	69%	22%	3%	2%	4%	412
GA	77%	15%	1%	1%	5%	403
LA	74%	17%	0%	1%	6%	345
MD	80%	15%	2%	2%	2%	362
NC	67%	25%	0%	2%	5%	226
NH	82%	12%	3%	2%	2%	379
OK	70%	25%	1%	1%	2%	386
PA	74%	19%	2%	1%	3%	382
SC	67%	22%	3%	0%	7%	258
VA	65%	30%	1%	1%	3%	144
WA	73%	20%	2%	2%	3%	328
NCI Average	72%	20%	2%	2%	4%	8,018

Table 6. Family Member’s Primary Language

State	English	Spanish	Other	N
AZ	81%	13%	6%	362
CA	73%	15%	12%	3,845
DC	96%	1%	3%	242
FL	86%	10%	4%	414
GA	98%	0%	2%	397
LA	95%	0%	5%	353
MD	98%	0%	2%	367
NC	98%	0%	2%	227
NH	97%	1%	2%	378
OK	96%	1%	3%	385
PA	94%	3%	3%	398
SC	92%	1%	7%	259
VA	94%	1%	5%	151
WA	88%	5%	8%	329
NCI Average	92%	4%	5%	7,623

Table 7. Family Member’s Highest level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree	N
AZ	39%	53%	4%	3%	1%	339
CA	49%	40%	4%	7%	1%	3,558
DC	59%	35%	6%	0%	0%	222
FL	49%	46%	3%	1%	1%	384
GA	41%	57%	1%	0%	0%	383
LA	65%	30%	2%	1%	2%	345
MD	55%	38%	3%	4%	1%	352
NC	60%	27%	10%	4%	0%	220
NH	40%	55%	2%	2%	1%	363
OK	23%	74%	2%	1%	0%	376
PA	39%	56%	4%	0%	0%	369
SC	62%	32%	4%	2%	0%	250
VA	51%	41%	4%	2%	1%	138
WA	34%	62%	2%	2%	0%	324
NCI Average	48%	46%	4%	2%	1%	7,623

Table 5. Frequency of Medical Care Needed for Family Member

State	Less Frequently Than Once a Month	At Least Once a Month, Not Once a Week	At Least Once a Week	N
AZ	82%	14%	4%	346
CA	78%	16%	5%	3,600
DC	73%	20%	7%	227
FL	73%	22%	6%	400
GA	78%	19%	4%	390
LA	70%	21%	9%	344
MD	80%	18%	2%	347
NC	79%	16%	5%	223
NH	87%	9%	4%	372
OK	80%	15%	5%	384
PA	84%	11%	4%	378
SC	74%	18%	8%	254
VA	79%	14%	7%	140
WA	78%	17%	5%	315
NCI Average	78%	16%	5%	7,720

Table 6. Amount of Behavioral Support Needed for Family Member

State	None	Some	Extensive	N
AZ	60%	28%	12%	361
CA	54%	32%	15%	3,761
DC	59%	29%	13%	239
FL	54%	33%	13%	406
GA	59%	32%	9%	404
LA	52%	32%	15%	349
MD	70%	23%	7%	366
NC	46%	42%	13%	228
NH	67%	25%	8%	375
OK	64%	28%	8%	384
PA	65%	24%	10%	396
SC	57%	34%	8%	261
VA	49%	38%	13%	142
WA	34%	45%	21%	329
NCI Average	56%	32%	12%	8,001

Table 7. Amount of Help Needed for Family Member's Daily Activities

State	None	Little	Moderate	Complete	N
AZ	10%	26%	34%	30%	368
CA	24%	22%	28%	26%	3,898
DC	34%	21%	23%	22%	248
FL	21%	20%	24%	35%	417
GA	27%	22%	24%	27%	410
LA	16%	17%	31%	36%	354
MD	41%	23%	20%	17%	367
NC	11%	20%	33%	35%	231
NH	33%	28%	21%	18%	384
OK	16%	26%	28%	30%	389
PA	24%	24%	27%	25%	402
SC	21%	23%	22%	34%	266
VA	9%	18%	36%	37%	152
WA	7%	18%	39%	35%	332
NCI Average	21%	22%	28%	29%	8,218

Table 8. Family Member’s Typical Day Activities³

State	Out of Home Day Program (Family Member Is Unpaid)	Out of Home Day Program (Family Member Is Paid)	Vocational Training	Community Employment (Family Member Is Unpaid)	Community Employment (Family Member Is Paid)	In-home Day Supports	At Home (by Choice)	At Home (No Services)	At Home (Other)	Other
AZ	51%	14%	9%	2%	7%	13%	15%	4%	9%	14%
CA	40%	15%	9%	5%	9%	13%	13%	9%	8%	16%
DC	66%	8%	6%	5%	6%	19%	5%	5%	7%	8%
FL	31%	12%	4%	4%	5%	18%	12%	6%	8%	14%
GA	48%	16%	5%	5%	7%	20%	8%	5%	5%	12%
LA	22%	16%	5%	4%	9%	34%	14%	4%	9%	15%
MD	35%	24%	7%	12%	24%	7%	8%	6%	3%	10%
NC	30%	12%	9%	8%	9%	40%	15%	4%	11%	19%
NH	44%	15%	5%	16%	26%	17%	12%	9%	7%	14%
OK	13%	16%	9%	5%	15%	32%	26%	7%	10%	13%
PA	35%	20%	11%	3%	14%	12%	11%	10%	7%	10%
SC	39%	26%	4%	3%	9%	11%	12%	8%	11%	9%
VA	44%	12%	6%	3%	8%	19%	13%	7%	11%	13%
WA	15%	6%	9%	13%	21%	24%	31%	19%	18%	16%
NCI Average	37%	15%	7%	6%	12%	20%	14%	7%	9%	13%

³ Multiple responses allowed. Therefore, state and national percentages may total more than 100%.

Respondents

This section provides demographic information about respondents to the survey.

Table 9. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
AZ	10%	32%	49%	9%	369
CA	16%	29%	47%	8%	3,840
DC	9%	23%	54%	14%	242
FL	8%	27%	52%	14%	410
GA	6%	29%	56%	9%	405
LA	11%	28%	52%	10%	350
MD	3%	26%	63%	8%	366
NC	4%	36%	52%	7%	229
NH	4%	28%	57%	12%	378
OK	7%	24%	60%	9%	388
PA	3%	24%	58%	16%	404
SC	11%	24%	56%	10%	262
VA	4%	23%	63%	11%	152
WA	10%	25%	58%	7%	324
NCI Average	7%	27%	55%	10%	8,119

Table 10. Respondent's Health

State	Excellent	Good	Fair	Poor	N
AZ	23%	51%	24%	2%	365
CA	17%	51%	28%	4%	3,828
DC	15%	56%	25%	4%	243
FL	9%	50%	30%	11%	398
GA	9%	54%	32%	6%	406
LA	12%	49%	31%	8%	343
MD	17%	60%	21%	2%	368
NC	14%	55%	24%	7%	228
NH	20%	63%	15%	2%	376
OK	17%	56%	24%	2%	383
PA	15%	53%	28%	3%	402
SC	13%	50%	32%	5%	262
VA	14%	53%	26%	7%	152
WA	16%	55%	26%	3%	334
NCI Average	15%	54%	26%	5%	8,088

Table 11. Respondent Is Primary Caregiver

State	Yes	No	N
AZ	96%	4%	370
CA	93%	7%	3,831
DC	92%	8%	241
FL	95%	5%	402
GA	96%	4%	408
LA	91%	9%	341
MD	94%	6%	368
NC	94%	6%	229
NH	96%	4%	378
OK	98%	2%	383
PA	94%	6%	402
SC	96%	4%	258
VA	94%	6%	151
WA	95%	5%	336
NCI Average	95%	5%	8,098

Table 12. Number of Adults in Household (Not Including Family Member Receiving Services)

State	One	Two	Three	Four or More	N
AZ	30%	47%	16%	7%	365
CA	25%	43%	20%	11%	3,803
DC	44%	36%	16%	4%	237
FL	33%	47%	14%	5%	403
GA	33%	44%	16%	7%	404
LA	34%	50%	12%	5%	341
MD	23%	50%	21%	6%	361
NC	30%	55%	12%	3%	226
NH	31%	49%	15%	5%	374
OK	35%	51%	10%	4%	385
PA	30%	48%	17%	4%	405
SC	33%	51%	13%	3%	258
VA	35%	53%	8%	3%	150
WA	23%	51%	18%	8%	331
NCI Average	31%	48%	15%	5%	8,043

Table 13. Respondent Is Family Member's Legal Guardian or Conservator

State	Full Guardianship/ Conservatorship	Limited Guardianship/ Conservatorship	No	N
AZ	65%	4%	31%	364
CA	50%	11%	40%	3,725
DC	60%	7%	33%	239
FL	50%	9%	41%	393
GA	51%	5%	44%	396
LA	66%	4%	31%	333
MD	42%	5%	53%	351
NC	68%	9%	23%	230
NH	76%	5%	19%	374
OK	72%	5%	24%	384
PA	56%	4%	40%	387
SC	61%	4%	34%	251
VA	66%	1%	33%	145
WA	65%	6%	29%	334
NCI Average	60%	6%	34%	7,906

Table 14. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree	N
AZ	15%	22%	5%	26%	33%	356
CA	18%	21%	6%	24%	31%	3,713
DC	17%	34%	5%	20%	23%	232
FL	13%	32%	7%	23%	24%	405
GA	14%	34%	5%	20%	26%	402
LA	15%	36%	8%	18%	23%	344
MD	5%	24%	3%	22%	46%	365
NC	11%	24%	4%	20%	41%	227
NH	5%	31%	4%	23%	38%	377
OK	8%	30%	6%	25%	31%	385
PA	10%	38%	5%	19%	29%	389
SC	17%	30%	3%	23%	28%	263
VA	18%	34%	5%	21%	22%	151
WA	10%	27%	5%	26%	31%	336
NCI Average	13%	30%	5%	22%	30%	7,945

Table 15. Total Taxable Family Income of Wage Earners in the Past Year

State	Below \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	N
AZ	27%	19%	23%	16%	15%	329
CA	23%	21%	26%	13%	17%	3,370
DC	33%	18%	24%	13%	12%	208
FL	37%	20%	25%	8%	10%	350
GA	31%	22%	20%	14%	13%	374
LA	36%	20%	19%	11%	14%	313
MD	11%	16%	20%	18%	35%	305
NC	18%	23%	28%	15%	17%	204
NH	16%	19%	28%	17%	20%	315
OK	22%	18%	28%	16%	16%	347
PA	24%	17%	29%	12%	17%	303
SC	32%	27%	21%	12%	7%	229
VA	29%	14%	23%	19%	15%	130
WA	13%	13%	37%	19%	17%	306
NCI Average	25%	19%	25%	14%	16%	7,083

Table 19. Out-of-Pocket Expenses for Family in the Past Year

State	Nothing	\$1- \$100	\$101- \$1,000	\$1,001- \$10,000	Over \$10,000	N
AZ	23%	15%	41%	19%	2%	352
CA	25%	13%	32%	26%	4%	3,559
DC	37%	16%	30%	17%	0%	221
FL	24%	13%	36%	24%	3%	387
GA	22%	14%	39%	22%	3%	391
LA	24%	11%	39%	23%	3%	333
MD	19%	13%	38%	25%	4%	335
NC	16%	14%	38%	31%	1%	216
NH	22%	12%	40%	25%	2%	360
OK	20%	14%	41%	24%	2%	368
PA	21%	20%	36%	21%	2%	360
SC	20%	33%	27%	18%	1%	249
VA	24%	15%	34%	24%	4%	140
WA	28%	8%	37%	23%	4%	320
NCI Average	23%	15%	36%	23%	2%	7,591

Services and Supports Received

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

Table 16. Services and Supports Received From ID/DD Agency

State	Financial Support	In-Home Support	Out-of-Home Respite Care	Day or Employment Supports	Transportation	Other	Social Security Benefits
AZ	9%	54%	52%	66%	65%	32%	94%
CA	10%	35%	22%	58%	58%	18%	84%
DC	11%	57%	35%	73%	87%	48%	95%
FL	12%	51%	28%	46%	52%	26%	92%
GA	12%	33%	21%	66%	68%	18%	93%
LA	10%	68%	24%	38%	53%	16%	91%
MD	8%	18%	18%	78%	73%	19%	84%
NC	10%	64%	45%	48%	47%	27%	93%
NH	37%	32%	42%	67%	69%	25%	93%
OK	19%	56%	16%	41%	44%	28%	92%
PA	17%	33%	32%	64%	64%	24%	91%
SC	11%	37%	19%	63%	68%	16%	90%
VA	15%	55%	36%	59%	59%	28%	90%
WA	26%	36%	27%	43%	45%	20%	91%
NCI Average	15%	45%	30%	58%	61%	25%	91%

Adult Family Survey Results

Information and Planning

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

Note: State outcomes with fewer than 20 responses were not reported.

Note on California significance: Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (**), an outcome is significant *only* due to the sample size.

Gets Enough Information to Help Plan Services

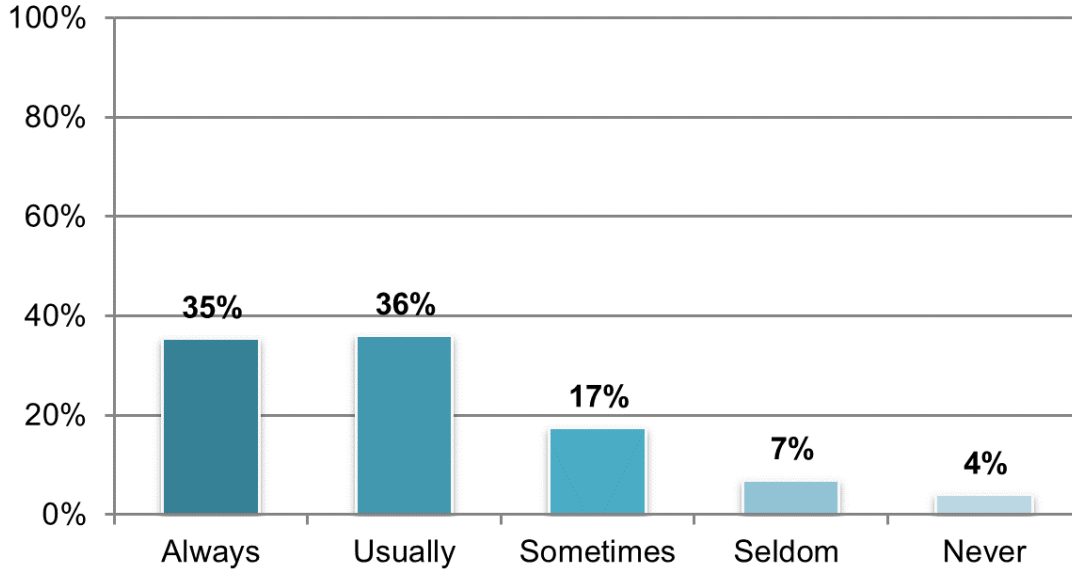


Table Q1. Do you get enough information to help you participate in planning services for your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	45%	31%	15%	8%	1%	331
Within Average Range						
NH	42%	40%	14%	2%	2%	370
NC	40%	36%	14%	4%	5%	215
AZ	40%	38%	15%	5%	2%	346
SC	39%	28%	17%	9%	7%	238
VA	39%	37%	17%	6%	2%	142
FL	38%	36%	16%	5%	5%	395
OK	37%	43%	13%	4%	3%	369
DC	34%	32%	21%	7%	6%	228
PA	33%	40%	16%	8%	2%	374
CA **	33%	30%	19%	10%	8%	3,452
Significantly Below Average						
WA	27%	41%	22%	8%	2%	299
MD	25%	36%	22%	13%	5%	346
GA	24%	36%	22%	9%	8%	372
NCI Average	35%	36%	17%	7%	4%	7,477

Information About Services and Supports Is Easy to Understand

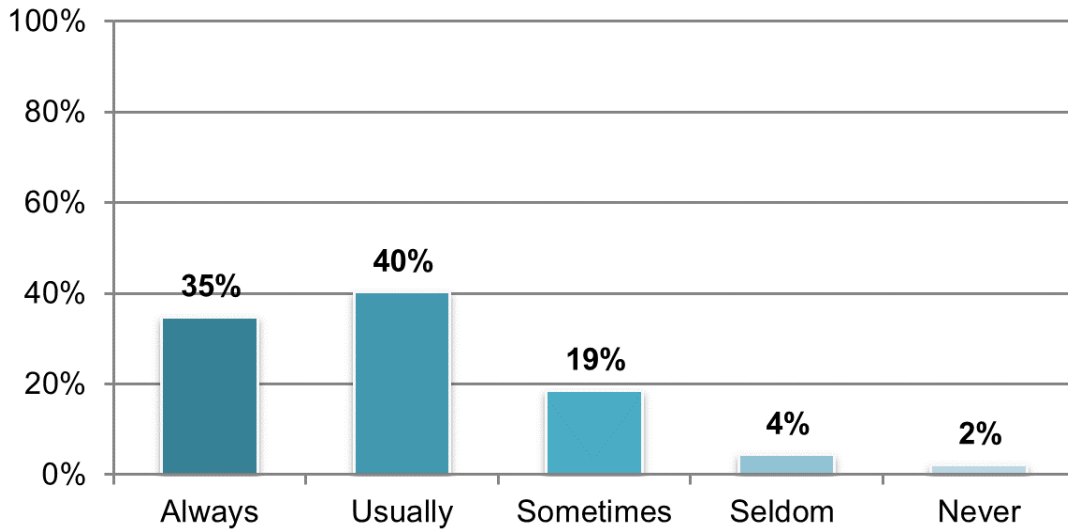


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	43%	36%	17%	3%	2%	327
NH	42%	43%	13%	1%	0%	374
Within Average Range						
SC	42%	36%	16%	3%	3%	240
DC	41%	33%	21%	3%	2%	229
CA **	39%	37%	17%	4%	3%	3,435
AZ	38%	41%	17%	3%	1%	352
FL	35%	38%	18%	6%	3%	399
OK	34%	45%	18%	2%	1%	368
VA	31%	43%	20%	6%	1%	143
PA	31%	43%	18%	5%	2%	363
NC	30%	43%	20%	5%	1%	212
GA	29%	37%	21%	7%	6%	364
Significantly Below Average						
MD	27%	46%	18%	6%	3%	338
WA	25%	43%	26%	5%	1%	304
NCI Average	35%	40%	19%	4%	2%	7, 448

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

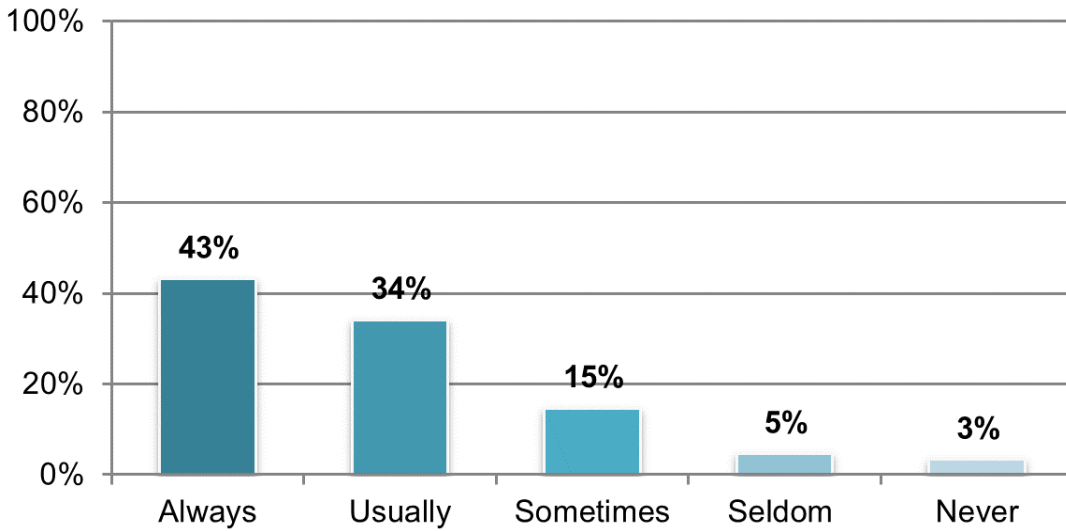


Table Q3. Does the information you receive come from your case manager/service coordinator?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	53%	30%	12%	4%	1%	399
SC	53%	26%	16%	3%	3%	239
AZ	52%	29%	12%	4%	3%	352
LA	52%	31%	12%	3%	3%	320
Within Average Range						
VA	47%	36%	12%	3%	3%	144
NH	46%	37%	12%	4%	1%	368
CA	45%	29%	15%	6%	6%	3,428
PA	42%	38%	14%	4%	1%	360
DC	40%	31%	19%	6%	5%	227
OK	40%	42%	14%	4%	1%	361
NC	38%	37%	17%	2%	4%	203
Significantly Below Average						
MD	36%	36%	17%	7%	4%	343
WA	34%	40%	15%	9%	2%	317
GA	28%	35%	20%	7%	9%	357
NCI Average	43%	34%	15%	5%	3%	7,418

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

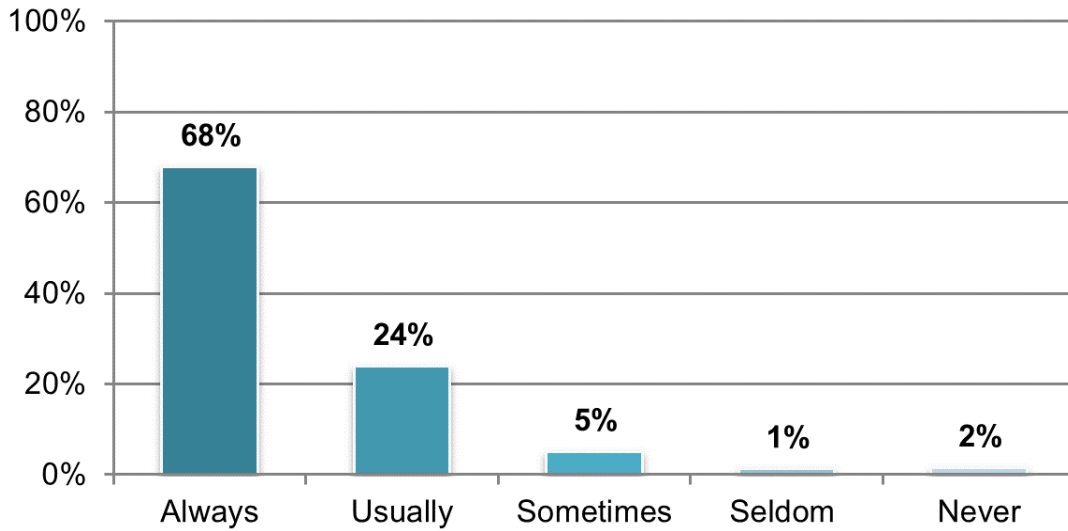


Table Q4. Does the case manager/service coordinator respect your family’s choices and opinions?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	79%	15%	3%	1%	1%	405
AZ	77%	19%	3%	1%	1%	359
Within Average Range						
NH	74%	21%	4%	1%	1%	368
LA	73%	20%	4%	2%	1%	327
SC	71%	22%	4%	1%	2%	241
WA	70%	22%	6%	1%	1%	306
PA	69%	25%	4%	2%	1%	375
CA	66%	23%	7%	2%	2%	3,483
NC	66%	25%	6%	1%	2%	203
OK	64%	28%	6%	1%	1%	372
DC	63%	25%	7%	3%	2%	227
VA	62%	32%	3%	1%	2%	144
Significantly Below Average						
MD	60%	30%	7%	1%	1%	336
GA	59%	29%	8%	2%	3%	358
NCI Average	68%	24%	5%	1%	2%	7,504

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

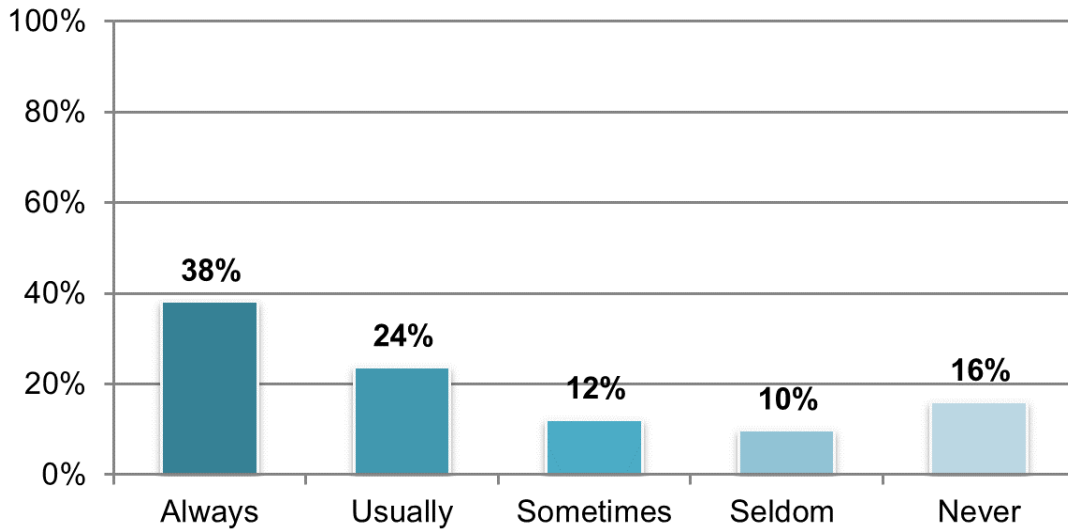


Table Q5. Does the case manager/service coordinator tell you about other public services that your family is eligible for (food stamps, Supplemental Security Income [SSI], housing subsidies, etc.)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	48%	24%	9%	7%	11%	387
Within Average Range						
LA	44%	24%	11%	8%	13%	306
WA	42%	28%	13%	9%	8%	301
PA	41%	26%	13%	9%	11%	350
NH	40%	27%	11%	9%	13%	313
AZ	40%	20%	14%	10%	16%	326
DC	39%	20%	10%	6%	24%	221
SC	39%	20%	13%	8%	20%	232
CA	38%	20%	14%	10%	19%	3,370
VA	36%	28%	12%	11%	13%	135
OK	34%	30%	14%	13%	9%	348
NC	34%	19%	11%	15%	22%	194
Significantly Below Average						
GA	31%	20%	12%	9%	28%	327
MD	28%	26%	14%	12%	20%	329
NCI Average	38%	24%	12%	10%	16%	7,139

Family Member Has a Service Plan

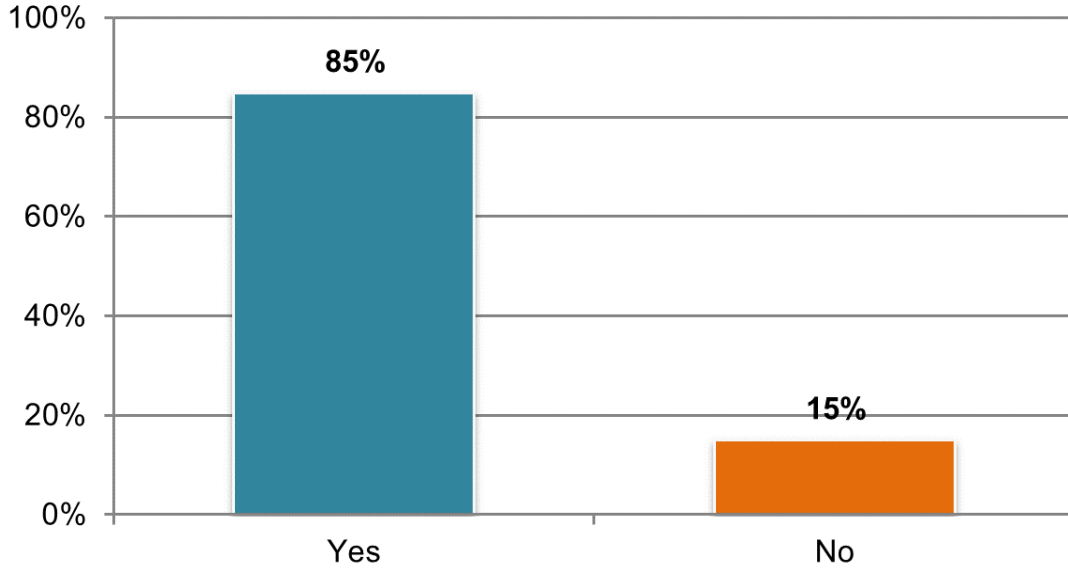


Table Q6. Does your family member have a service plan?

State	Yes	No	N
Significantly Above Average			
FL	94%	6%	384
NH	94%	6%	343
MD	91%	9%	334
OK	91%	9%	343
PA	89%	11%	368
Within Average Range			
AZ	88%	12%	313
NC	88%	12%	199
VA	87%	13%	123
LA	86%	14%	295
WA	84%	16%	247
Significantly Below Average			
DC	77%	23%	194
SC	75%	25%	220
GA	73%	27%	340
CA	72%	28%	3,104
NCI Average	85%	15%	6,807

Service Plan Includes All the Services and Supports Family Member Wants

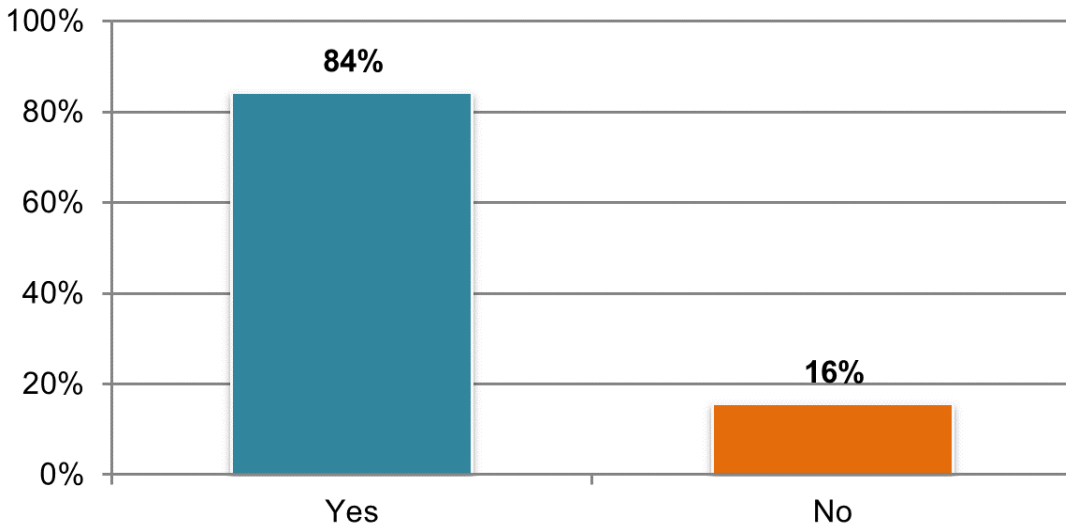


Table Q7. Does the plan include all the services and supports your family member wants?

State	Yes	No	N
Significantly Above Average			
DC	91%	9%	125
AZ	91%	9%	253
Within Average Range			
LA	88%	12%	233
NH	88%	12%	298
PA	88%	13%	288
VA	87%	13%	95
OK	86%	14%	282
CA	83%	17%	1,929
FL	81%	19%	334
NC	81%	19%	156
SC	81%	19%	145
MD	80%	20%	254
GA	77%	23%	223
Significantly Below Average			
WA	76%	24%	188
NCI Average	84%	16%	4,803

Family Member Receives All Services Listed in the Service Plan

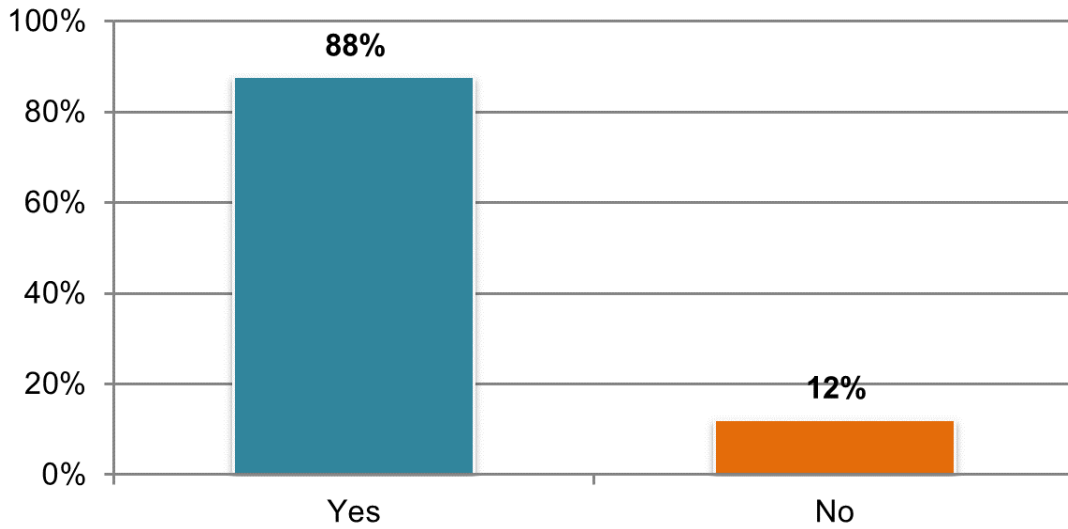


Table Q8. Does your family member receive all of the services listed in the plan?

State	Yes	No	N
Within Average Range			
VA	93%	7%	92
NH	91%	9%	302
OK	91%	9%	291
LA	90%	10%	236
AZ	90%	10%	260
SC	89%	11%	138
PA	88%	12%	279
FL	88%	12%	322
CA	87%	13%	1,881
NC	87%	13%	168
MD	86%	14%	258
GA	85%	15%	212
WA	84%	16%	179
DC	80%	20%	127
NCI Average	88%	12%	4,745

Family Member Helped Develop Service Plan

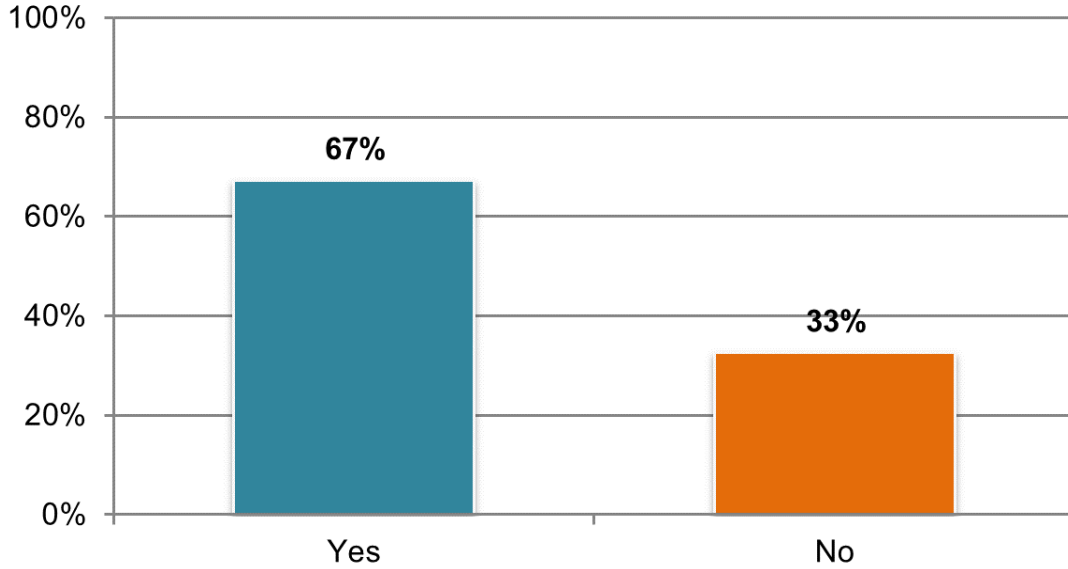


Table Q9. Did your family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
MD	80%	20%	282
NH	74%	26%	307
LA	73%	27%	240
CA	73%	28%	1,993
Within Average Range			
GA	73%	27%	225
FL	70%	30%	324
VA	70%	30%	96
DC	67%	33%	132
NC	65%	35%	167
PA	62%	38%	292
SC	62%	38%	146
OK	60%	40%	283
AZ	60%	40%	250
Significantly Below Average			
WA	53%	47%	195
NCI Average	67%	33%	4,937

Respondent or Another Family Member Helped Develop Service Plan

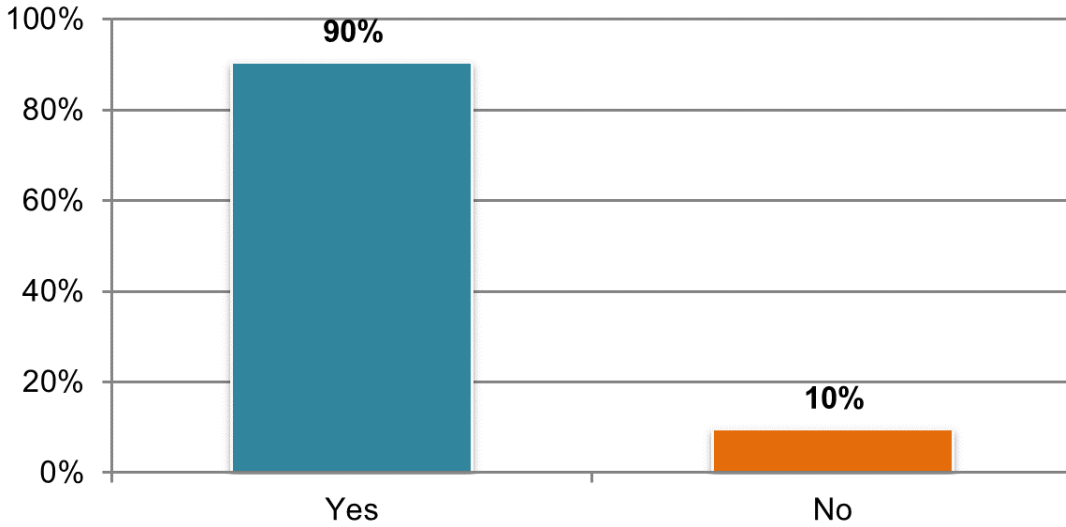


Table Q10. Did you or another family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
OK	96%	4%	301
AZ	96%	4%	265
NC	95%	5%	176
NH	95%	5%	312
Within Average Range			
VA	92%	8%	98
PA	91%	9%	297
WA	91%	9%	190
LA	89%	11%	245
MD	88%	12%	280
GA	88%	12%	240
SC	87%	13%	155
CA **	87%	13%	2,035
FL	86%	14%	337
DC	86%	14%	136
NCI Average	90%	10%	5,067

Service Plan Includes All the Services and Supports Family Member Needs

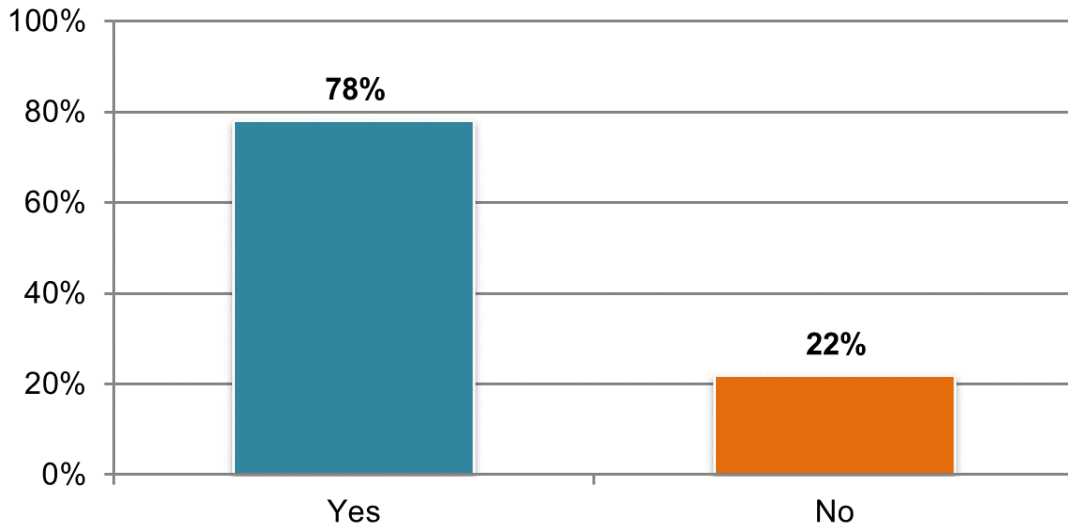


Table Q11. Does the plan include all the services and supports your family member needs?

State	Yes	No	N
Significantly Above Average			
LA	84%	16%	238
Within Average Range			
AZ	84%	16%	245
DC	83%	17%	128
OK	83%	17%	281
NH	82%	18%	301
PA	82%	18%	278
VA	81%	19%	94
CA	78%	22%	1,873
SC	78%	22%	139
NC	76%	24%	161
FL	75%	25%	204
MD	73%	27%	250
GA	70%	30%	202
Significantly Below Average			
WA	66%	34%	176
NCI Average	78%	22%	4,570

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

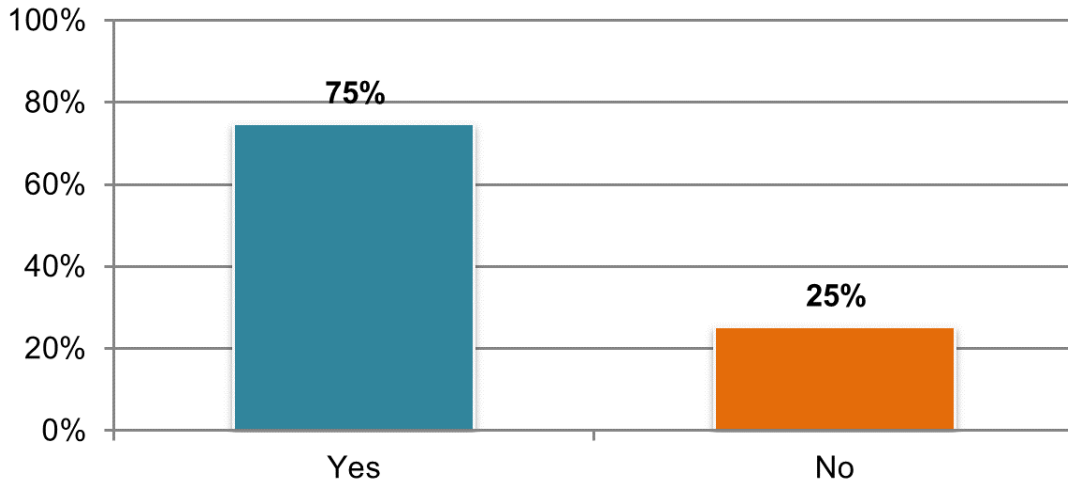


Table Q12. Did you discuss how to handle emergencies related to your family member at the last service planning meeting?

State	Yes	No	N
Significantly Above Average			
LA	92%	8%	247
OK	86%	14%	283
NC	85%	15%	163
WA	82%	18%	184
Within Average Range			
SC	82%	18%	144
AZ	77%	23%	249
FL	76%	24%	207
MD	72%	28%	267
DC	72%	28%	130
PA	70%	30%	274
VA	63%	37%	87
Significantly Below Average			
NH	64%	36%	276
GA	63%	37%	202
CA	63%	37%	1,910
NCI Average	75%	25%	4,623

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

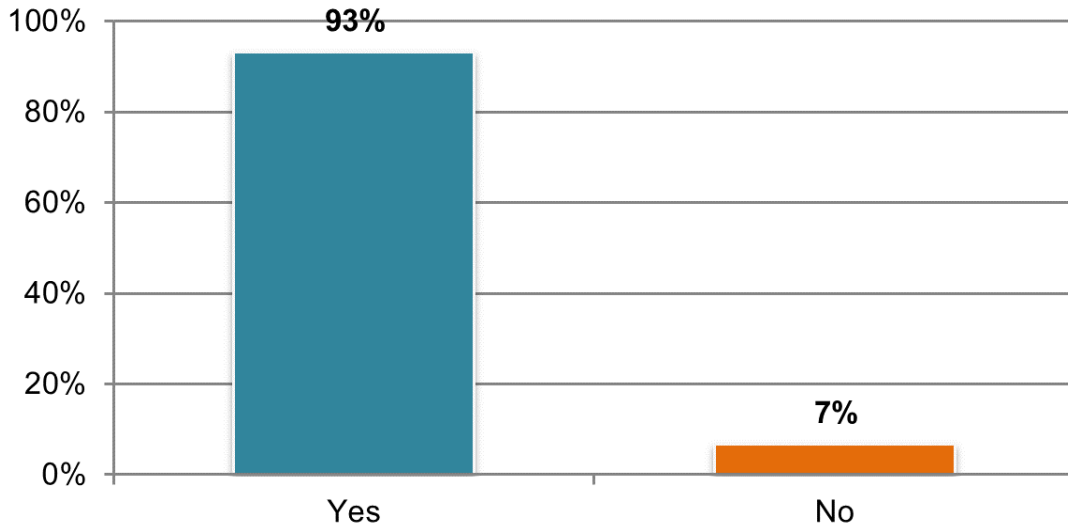


Table Q13. Have you or your family member received information about his/her rights?

State	Yes	No	N
Significantly Above Average			
NH	99%	1%	353
OK	98%	2%	358
FL	96%	4%	372
Within Average Range			
VA	97%	3%	127
NC	95%	5%	208
AZ	95%	5%	328
WA	95%	5%	264
LA	94%	6%	306
PA	94%	6%	336
MD	89%	11%	303
SC	88%	12%	226
DC	87%	13%	214
Significantly Below Average			
CA	88%	12%	3,159
GA	88%	12%	343
NCI Average	93%	7%	6,897

Access and Delivery of Services and Supports

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

Note: State outcomes with fewer than 20 responses were not reported.

Note on California significance: Due to the large N, many of California’s data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (**), an outcome is significant *only* due to the sample size.

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

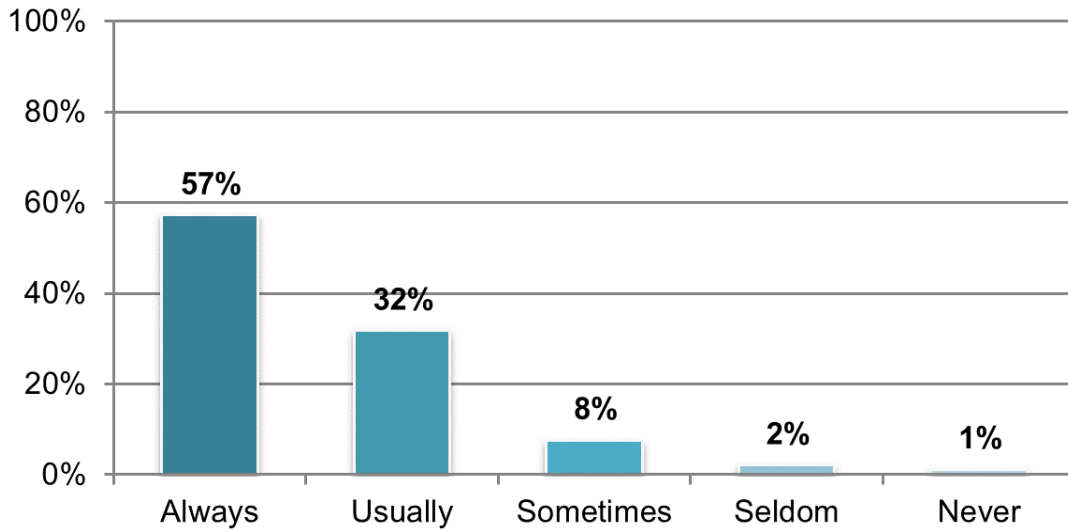


Table Q14. Are you or your family member able to contact his/her support workers when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	72%	18%	6%	2%	1%	408
LA	69%	27%	3%	2%	1%	331
Within Average Range						
PA	63%	31%	3%	2%	1%	374
NH	61%	32%	5%	1%	0%	367
VA	59%	31%	8%	1%	1%	145
NC	57%	34%	6%	1%	1%	212
AZ	56%	32%	6%	4%	1%	357
DC	56%	27%	12%	3%	3%	233
GA	55%	32%	10%	1%	2%	373
SC	54%	31%	10%	3%	2%	238
OK	53%	38%	6%	2%	0%	372
CA **	52%	30%	12%	4%	2%	3,602
MD	51%	35%	10%	4%	1%	352
Significantly Below Average						
WA	44%	45%	10%	0%	1%	295
NCI Average	57%	32%	8%	2%	1%	7,659

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

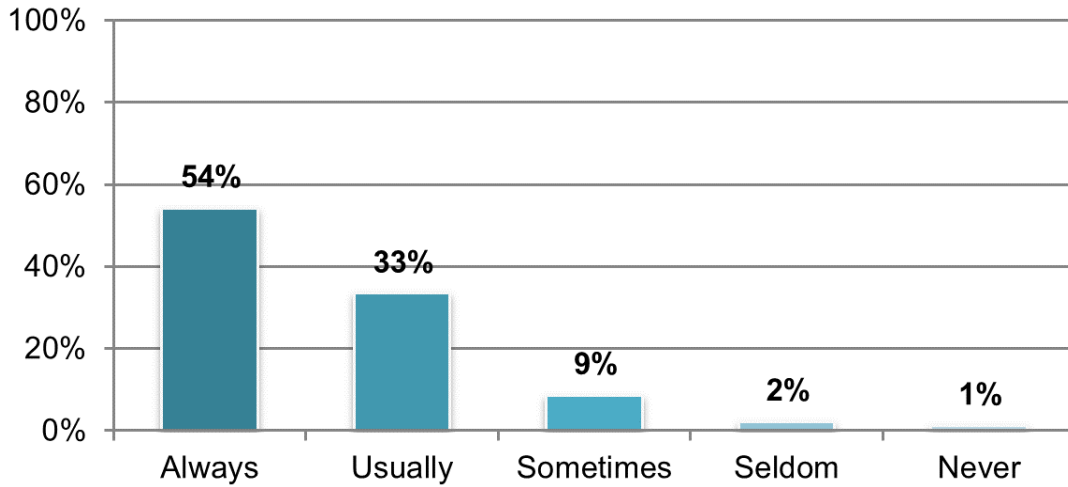


Table Q15. Are you or your family member able to contact his/her case manager/service coordinator when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	67%	22%	8%	2%	1%	410
LA	63%	30%	5%	1%	1%	335
Within Average Range						
NH	61%	31%	6%	1%	1%	365
PA	59%	33%	5%	1%	1%	384
AZ	56%	33%	8%	2%	1%	365
NC	54%	35%	8%	2%	1%	211
VA	53%	36%	7%	2%	1%	150
DC	53%	29%	13%	3%	3%	237
SC	53%	36%	8%	2%	1%	249
CA **	50%	32%	12%	4%	2%	3,669
OK	50%	37%	11%	2%	0%	380
GA	49%	34%	11%	3%	3%	382
Significantly Below Average						
MD	47%	39%	8%	4%	2%	355
WA	46%	42%	11%	2%	0%	324
NCI Average	54%	33%	9%	2%	1%	7,816

Services and Supports Are Available When Family Member Needs Them

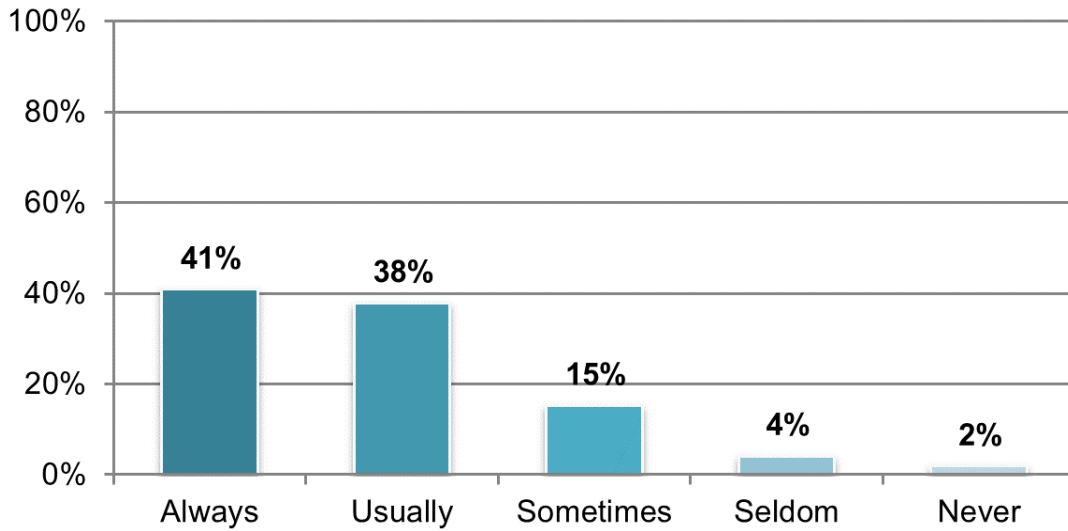


Table Q16. Are services and supports available when your family member needs them?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	54%	34%	9%	2%	2%	322
NH	50%	39%	9%	1%	1%	356
Within Average Range						
FL	47%	31%	15%	5%	2%	387
AZ	44%	42%	11%	2%	1%	351
DC	42%	35%	18%	4%	2%	228
NC	41%	40%	14%	4%	2%	204
SC	41%	35%	17%	5%	3%	236
CA	39%	33%	18%	6%	3%	3,412
PA	39%	42%	12%	4%	2%	358
OK	39%	40%	15%	5%	1%	360
VA	38%	38%	16%	6%	2%	143
GA	36%	37%	20%	4%	3%	359
Significantly Below Average						
MD	31%	42%	19%	6%	2%	327
WA	31%	43%	20%	4%	2%	294
NCI Average	41%	38%	15%	4%	2%	7,337

Services and Supports Are Available Reasonably Close to Home

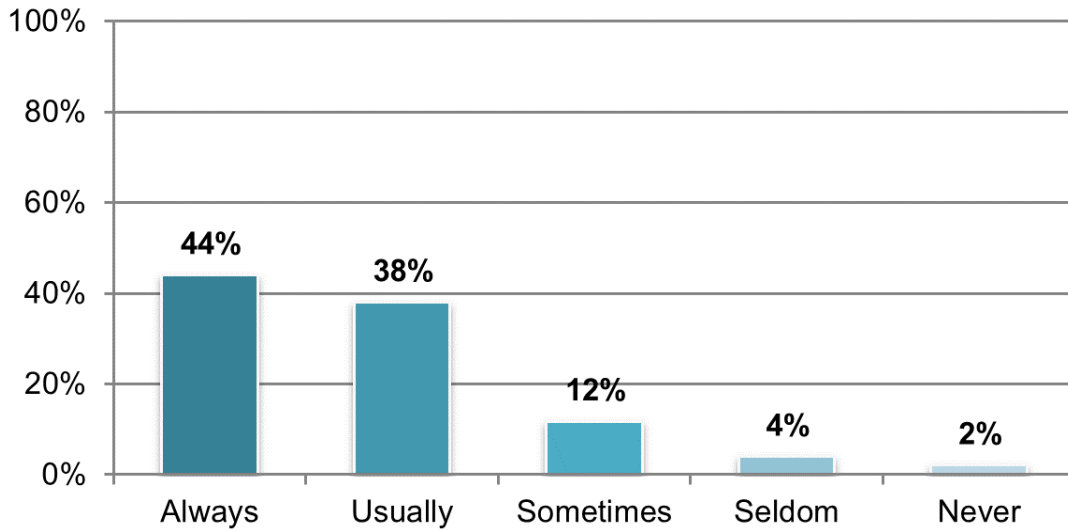


Table Q17. Are services and supports available within a reasonable distance from your home?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NH	58%	33%	7%	1%	1%	348
LA	53%	35%	8%	2%	1%	305
Within Average Range						
AZ	48%	38%	9%	4%	2%	328
NC	47%	36%	12%	4%	2%	195
FL	46%	34%	13%	4%	2%	364
VA	44%	41%	7%	5%	2%	138
SC	43%	35%	14%	5%	4%	213
CA	42%	34%	16%	5%	4%	3,214
DC	42%	41%	11%	4%	2%	210
MD	41%	42%	11%	4%	2%	306
OK	41%	38%	15%	5%	1%	346
GA	40%	37%	14%	5%	4%	320
PA	39%	45%	11%	4%	2%	347
Significantly Below Average						
WA	33%	42%	17%	6%	2%	282
NCI Average	44%	38%	12%	4%	2%	6,916

Services and Supports Change When Family Member's Needs Change

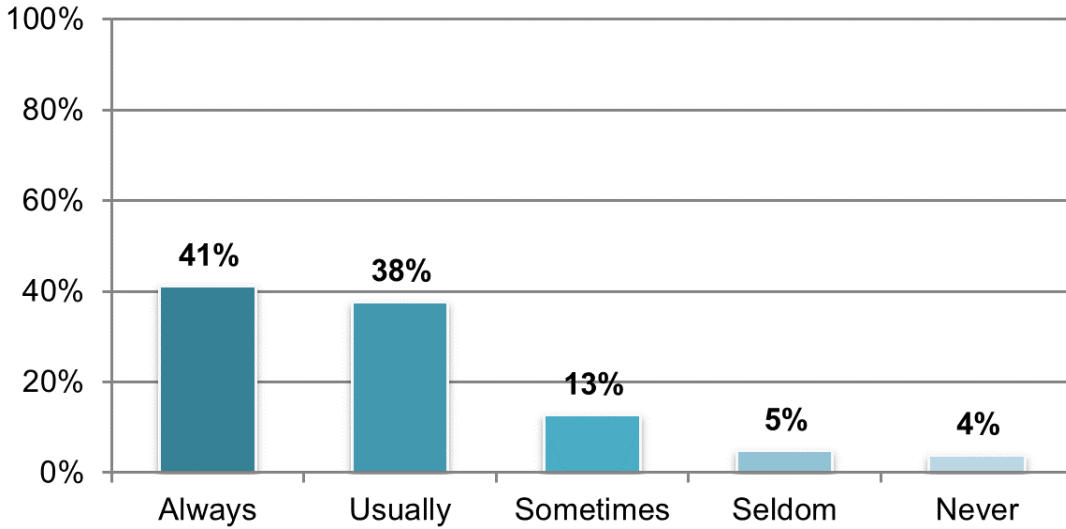


Table Q18. Do the services and supports change when your family member’s needs change?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NH	52%	34%	11%	1%	3%	300
LA	50%	34%	10%	3%	4%	279
Within Average Range						
AZ	46%	38%	11%	3%	2%	301
SC	45%	30%	15%	5%	6%	199
FL	44%	34%	11%	6%	5%	341
VA	43%	43%	7%	5%	2%	129
PA	43%	41%	9%	4%	3%	294
NC	41%	40%	14%	3%	3%	192
OK	39%	38%	15%	6%	2%	324
CA **	38%	33%	17%	6%	6%	2,802
DC	38%	40%	14%	3%	5%	196
GA	36%	36%	12%	9%	7%	280
Significantly Below Average						
MD	32%	42%	15%	6%	5%	254
WA	30%	44%	17%	7%	2%	249
NCI Average	41%	38%	13%	5%	4%	6,140

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

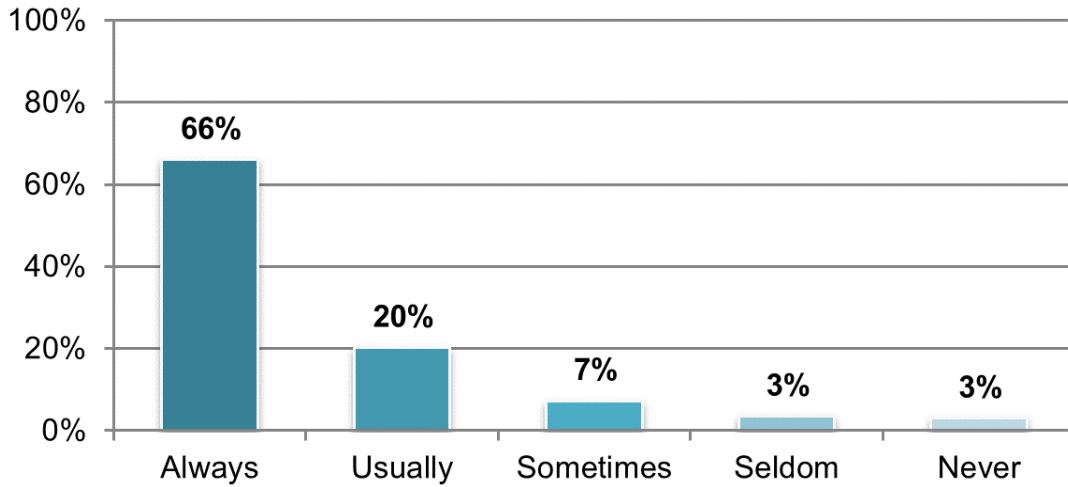


Table Q19. If English is not your primary language, are there support workers or translators who can speak to you in your language?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	82%	9%	2%	2%	5%	44
Within Average Range						
CA	67%	16%	12%	2%	3%	843
AZ	64%	22%	8%	2%	4%	50
WA	52%	33%	7%	7%	0%	27
NCI Average	66%	20%	7%	3%	3%	964

Support Workers Communicate Effectively in Primary Language (If English)

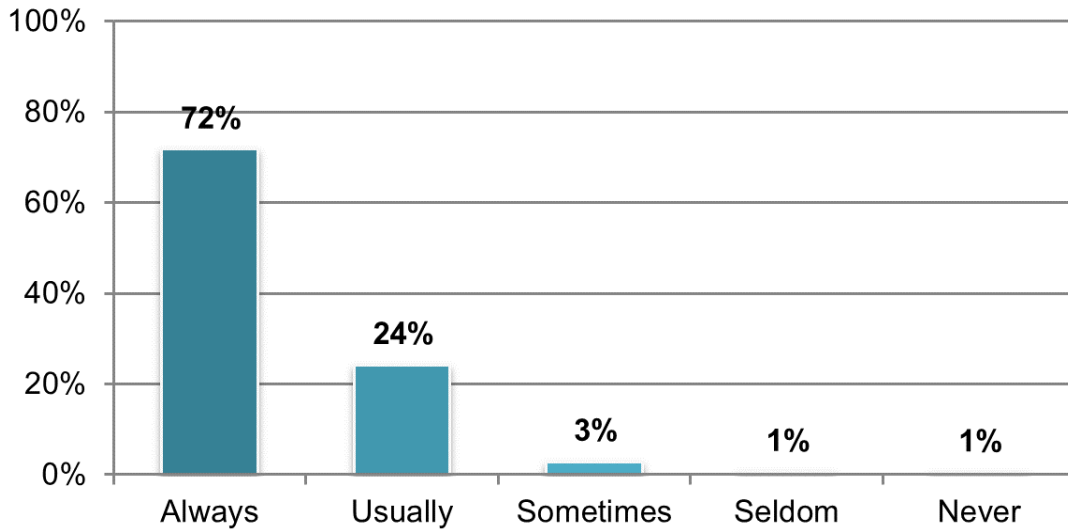


Table Q20. If English is your primary language, do the support workers speak to you effectively?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	81%	16%	2%	0%	1%	286
FL	79%	17%	2%	1%	1%	313
NH	78%	19%	2%	0%	0%	333
Within Average Range						
AZ	76%	22%	1%	0%	0%	273
PA	76%	22%	1%	1%	1%	334
SC	72%	23%	4%	1%	1%	199
CA	71%	24%	4%	1%	1%	2,408
OK	70%	28%	2%	0%	0%	322
GA	69%	24%	4%	2%	1%	336
VA	68%	31%	1%	0%	0%	124
MD	67%	25%	6%	1%	0%	327
DC	66%	27%	6%	1%	0%	197
NC	66%	30%	3%	1%	1%	184
WA	66%	31%	3%	0%	0%	239
NCI Average	72%	24%	3%	1%	1%	5,875

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

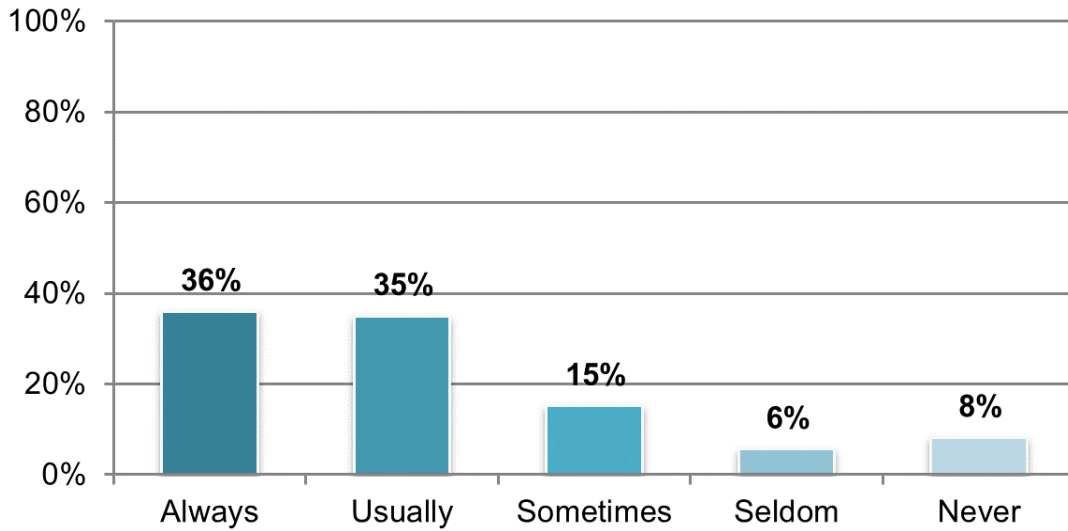


Table Q21. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
LA	49%	32%	11%	0%	8%	74
NH	47%	33%	12%	3%	5%	66
VA	46%	29%	17%	4%	4%	48
AZ	44%	32%	10%	3%	10%	87
NC	42%	29%	23%	5%	2%	65
FL	41%	26%	13%	6%	13%	99
PA	34%	41%	11%	5%	8%	97
CA	34%	26%	14%	9%	16%	652
SC	33%	34%	13%	8%	11%	61
OK	31%	41%	15%	8%	5%	93
MD	31%	45%	20%	0%	4%	55
DC	28%	37%	25%	1%	8%	71
GA	27%	42%	14%	7%	10%	71
Significantly Below Average						
WA	19%	40%	13%	19%	10%	70
NCI Average	36%	35%	15%	6%	8%	1,609

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

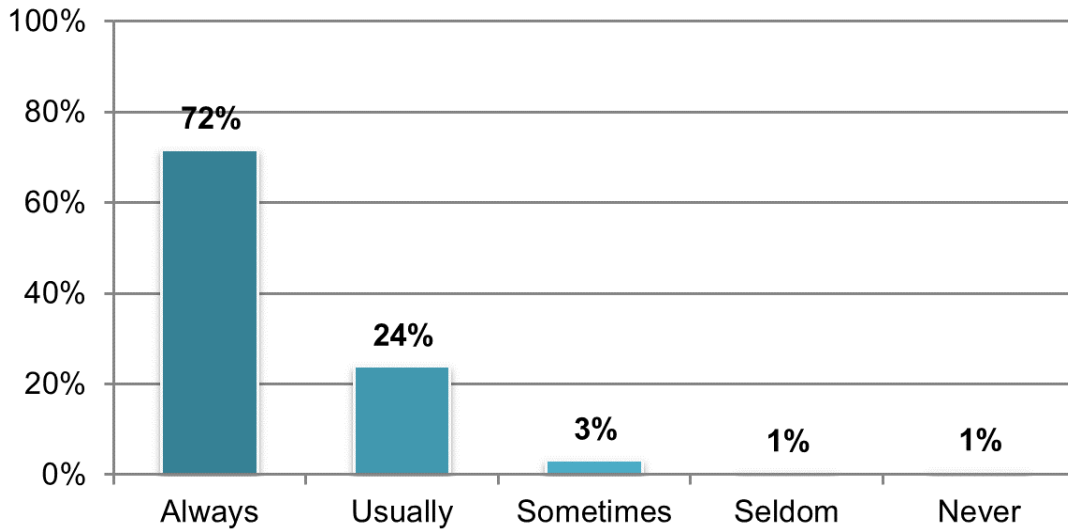


Table Q22. Are services delivered in a way that is respectful to your family’s culture?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	79%	17%	3%	0%	0%	312
PA	78%	20%	1%	0%	0%	335
NH	78%	19%	2%	1%	0%	310
FL	77%	20%	1%	0%	1%	371
Within Average Range						
AZ	77%	20%	3%	1%	0%	316
NC	72%	24%	3%	1%	1%	199
VA	71%	25%	4%	0%	0%	135
SC	71%	24%	3%	0%	1%	213
CA	70%	23%	4%	1%	1%	3,145
WA	69%	29%	2%	0%	0%	270
OK	69%	27%	3%	1%	1%	338
Significantly Below Average						
MD	64%	30%	4%	0%	2%	303
GA	64%	27%	6%	1%	1%	338
DC	63%	29%	6%	0%	2%	207
NCI Average	72%	24%	3%	1%	1%	6,792

Family Member Has Access to Special Equipment or Accommodations Needed

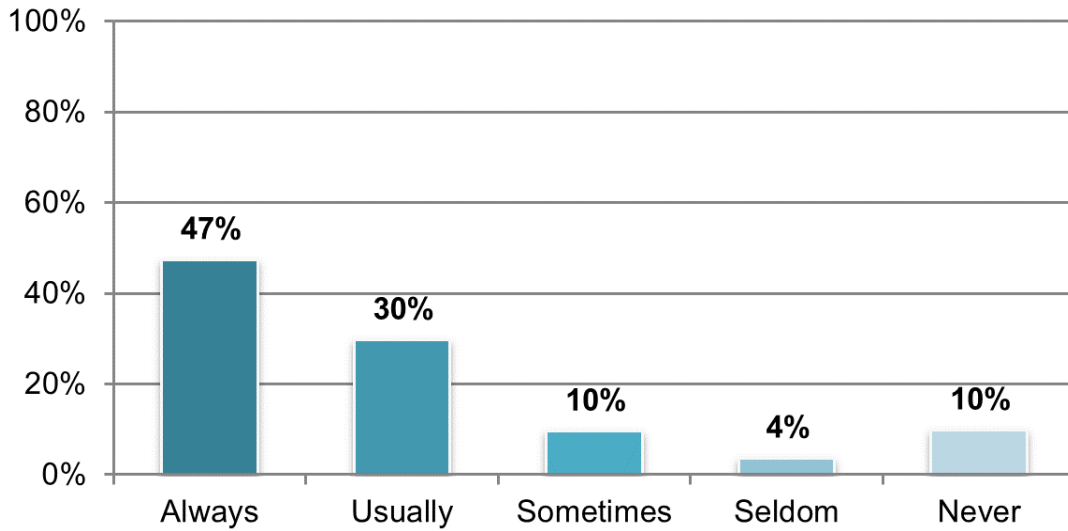


Table Q23. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NH	62%	29%	3%	4%	3%	140
AZ	59%	26%	8%	3%	5%	151
Within Average Range						
LA	56%	27%	8%	1%	8%	173
SC	53%	31%	6%	2%	9%	133
FL	48%	31%	7%	4%	9%	180
DC	47%	23%	10%	1%	19%	81
PA	46%	32%	12%	4%	6%	145
VA	46%	27%	16%	8%	2%	85
OK	45%	35%	10%	4%	6%	193
CA **	44%	27%	9%	4%	16%	1,319
GA	44%	32%	5%	1%	18%	170
WA	40%	30%	14%	7%	9%	146
NC	38%	30%	16%	4%	12%	117
MD	36%	37%	8%	3%	16%	119
NCI Average	47%	30%	10%	4%	10%	3,152

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

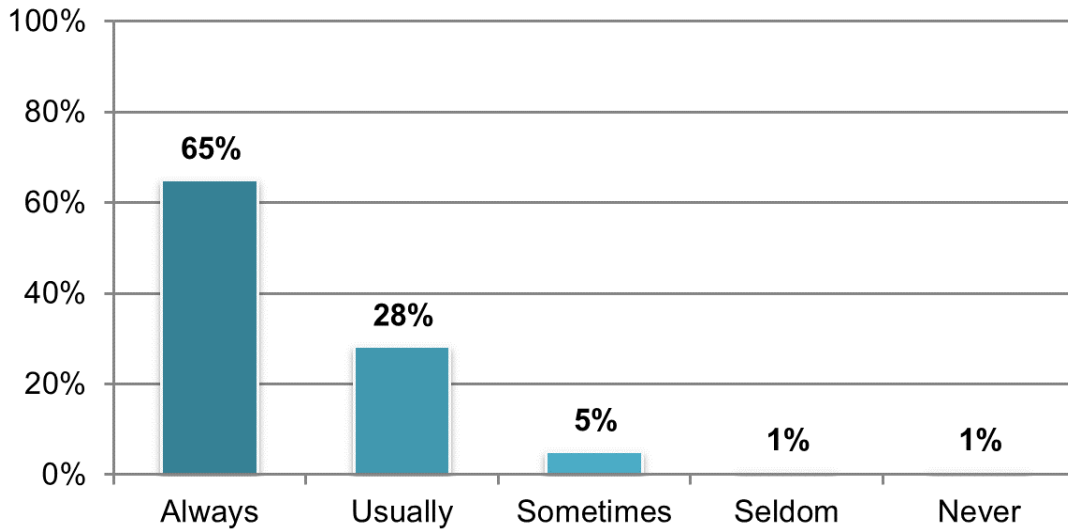


Table Q24. Do you feel that your family member's day/employment setting is a healthy and safe environment?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	80%	16%	3%	0%	1%	254
Within Average Range						
DC	69%	20%	8%	1%	2%	192
AZ	68%	28%	4%	1%	0%	292
FL	68%	26%	4%	0%	2%	296
NH	68%	28%	4%	1%	0%	333
NC	67%	30%	2%	0%	1%	165
OK	67%	28%	4%	1%	0%	259
PA	66%	30%	3%	1%	0%	325
CA	64%	27%	7%	1%	1%	3,023
SC	61%	28%	8%	1%	1%	210
VA	61%	32%	7%	0%	0%	121
GA	61%	32%	6%	1%	0%	317
WA	60%	34%	4%	0%	2%	233
Significantly Below Average						
MD	52%	37%	8%	3%	0%	332
NCI Average	65%	28%	5%	1%	1%	6,352

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

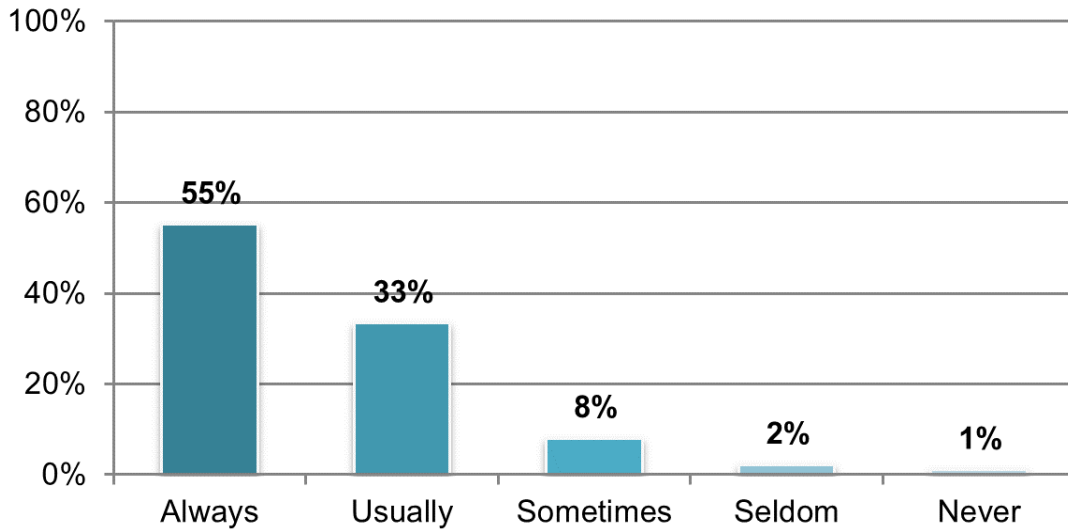


Table Q25. Do the support workers have the right training to meet your family’s needs?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	64%	28%	4%	1%	2%	319
FL	63%	28%	7%	1%	1%	351
Within Average Range						
PA	59%	32%	7%	1%	1%	324
AZ	58%	30%	10%	1%	1%	318
OK	58%	31%	7%	2%	1%	324
NC	58%	32%	8%	2%	0%	208
DC	56%	32%	8%	3%	1%	206
NH	56%	35%	8%	2%	1%	330
SC	55%	32%	10%	2%	2%	220
CA	54%	32%	10%	3%	2%	2,978
GA	52%	33%	11%	2%	1%	327
WA	48%	43%	6%	2%	1%	251
VA	48%	39%	9%	5%	0%	127
Significantly Below Average						
MD	43%	41%	11%	4%	1%	311
NCI Average	55%	33%	8%	2%	1%	6,594

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

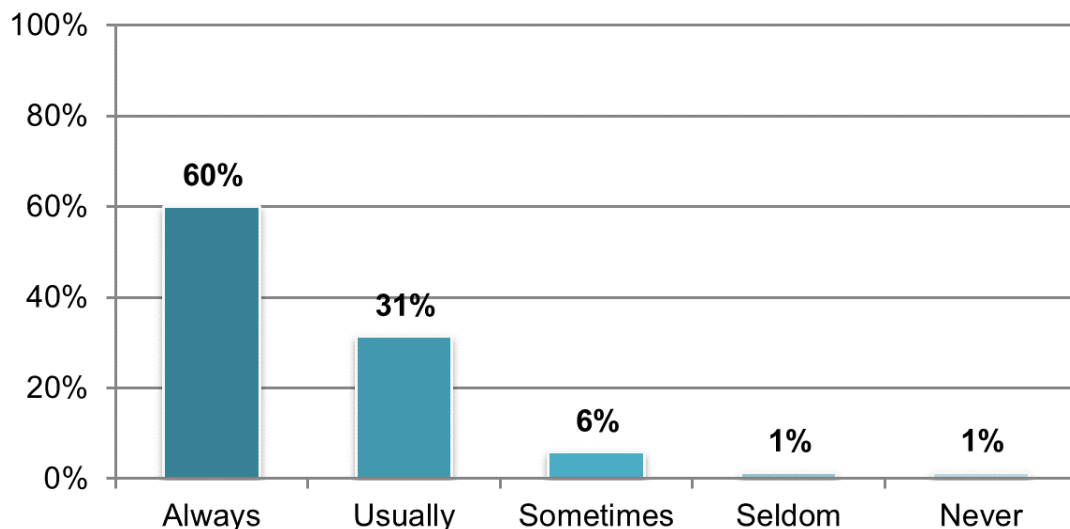


Table Q26. Do the support workers who come to your home arrive on time and when scheduled?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
AZ	69%	27%	3%	1%	1%	305
LA	69%	23%	7%	1%	1%	318
PA	67%	27%	4%	0%	1%	311
Within Average Range						
FL	66%	26%	4%	2%	1%	357
WA	64%	32%	3%	0%	1%	215
CA **	63%	28%	7%	1%	2%	2,636
SC	62%	27%	7%	2%	1%	193
DC	60%	28%	10%	0%	1%	204
NH	59%	34%	5%	1%	1%	293
OK	57%	32%	8%	3%	1%	293
MD	56%	36%	7%	1%	1%	227
NC	53%	40%	6%	1%	1%	188
VA	48%	40%	6%	3%	2%	122
Significantly Below Average						
GA	49%	38%	5%	3%	5%	273
NCI Average	60%	31%	6%	1%	1%	5,935

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

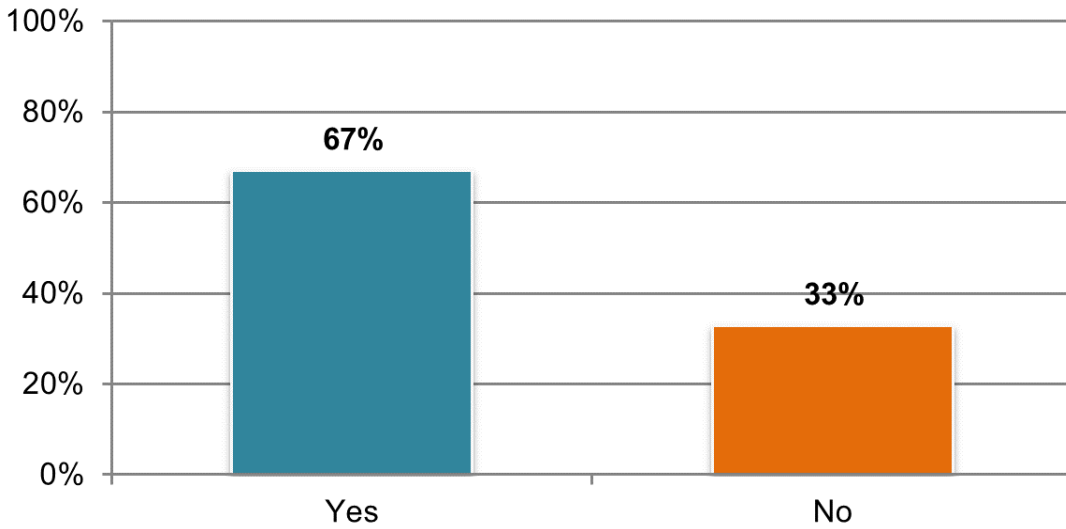


Table Q27. If your family member transitioned from school services to state-funded services during the past year, were you happy with the transition process?

State	Yes	No	N
Significantly Above Average			
MD	88%	13%	32
Within Average Range			
NH	78%	22%	37
WA	76%	24%	33
AZ	75%	25%	53
DC	73%	27%	22
CA	72%	28%	638
SC	71%	29%	21
PA	67%	33%	24
LA	62%	38%	21
NC	52%	48%	21
FL	52%	48%	27
Significantly Below Average			
GA	39%	61%	33
NCI Average	67%	33%	962

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

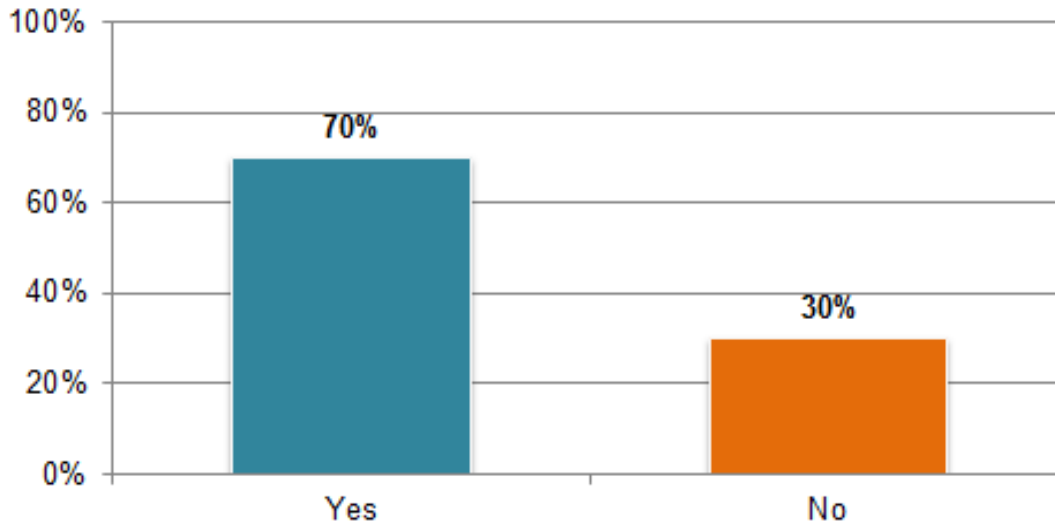


Table Q28. If you asked for crisis or emergency services during the past year, were services provided when needed?

State	Yes	No	N
Significantly Above Average			
NH	83%	17%	82
Within Average Range			
AZ	77%	23%	52
LA	75%	25%	110
WA	74%	26%	70
NC	72%	28%	61
MD	71%	29%	62
SC	70%	30%	76
DC	70%	30%	79
OK	69%	31%	52
FL	68%	32%	107
VA	67%	33%	33
CA **	64%	37%	888
PA	62%	38%	77
GA	61%	39%	80
NCI Average	70%	30%	1,829

Respondent Has Access to Health Services for Family Member

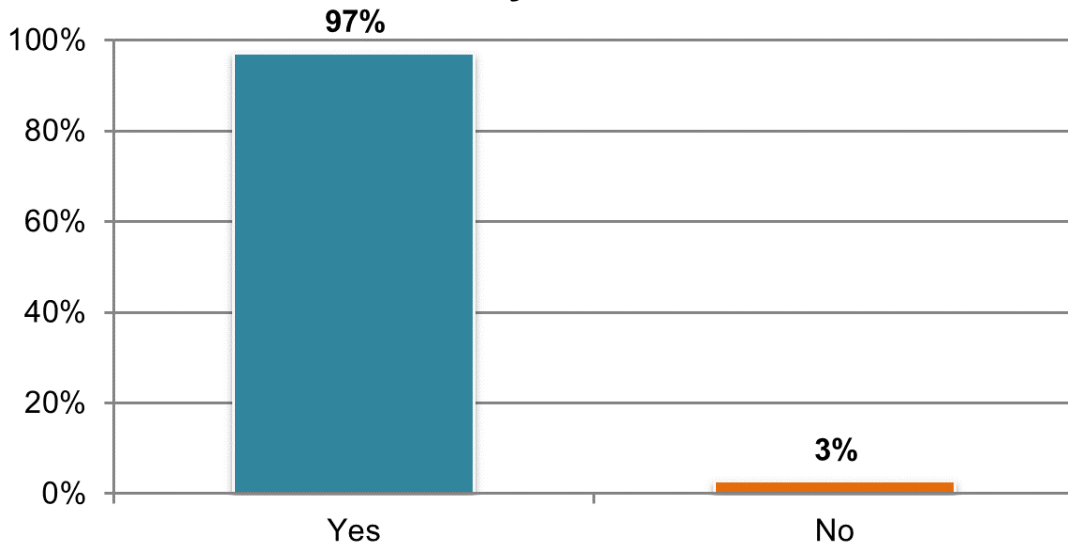


Table Q29. Do you have access to health services for your family member?

State	Yes	No	N
Significantly Above Average			
VA	99%	1%	141
OK	99%	1%	355
AZ	99%	1%	352
Within Average Range			
NC	99%	1%	213
NH	98%	2%	344
PA	98%	2%	375
WA	97%	3%	316
LA	97%	3%	325
MD	97%	3%	338
GA	96%	4%	358
FL	96%	4%	364
SC	96%	4%	235
DC	96%	4%	229
CA **	94%	6%	3,421
NCI Average	97%	3%	7,366

Respondent Is Satisfied With Family Member's Health Providers

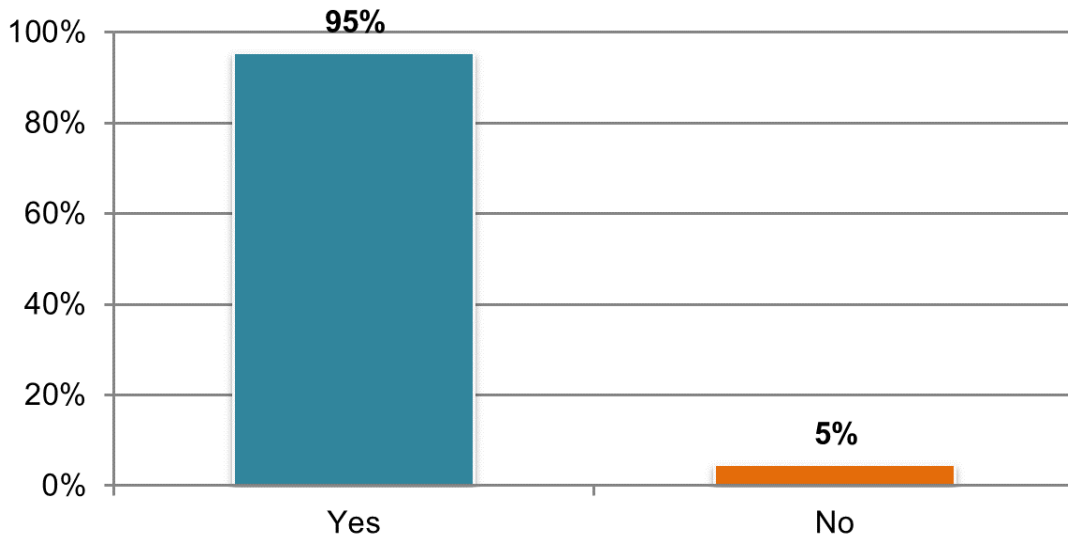


Table Q29a. If you have access to health services for your family member, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
GA	98%	2%	329
Within Average Range			
VA	98%	2%	133
OK	97%	3%	343
DC	96%	4%	209
NH	96%	4%	328
SC	96%	4%	216
AZ	96%	4%	329
LA	95%	5%	300
NC	95%	5%	201
MD	95%	5%	305
CA **	94%	6%	2,995
PA	94%	6%	347
WA	94%	6%	294
FL	93%	7%	339
NCI Average	95%	5%	6,668

Respondent Has Access to Dental Services for Family Member

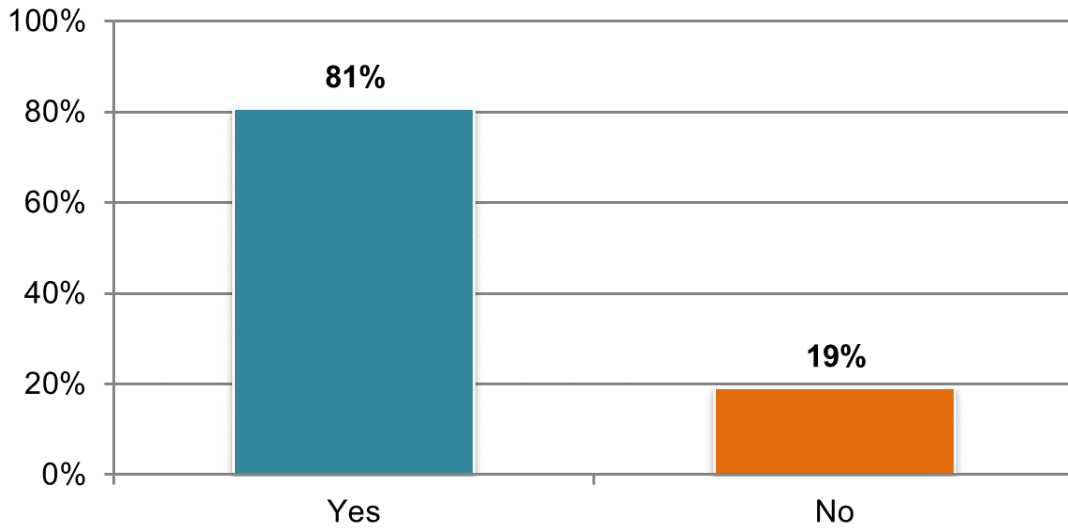


Table Q30. Do you have access to dental services for your family member?

State	Yes	No	N
Significantly Above Average			
DC	94%	6%	232
PA	91%	9%	372
WA	89%	11%	307
OK	87%	13%	337
Within Average Range			
NC	87%	13%	210
NH	86%	14%	332
MD	81%	19%	340
SC	80%	20%	232
CA **	76%	24%	3,259
GA	75%	25%	360
VA	75%	25%	138
Significantly Below Average			
FL	72%	28%	373
LA	71%	29%	308
AZ	68%	32%	314
NCI Average	81%	19%	7,114

Respondent Is Satisfied With Family Member's Dental Providers

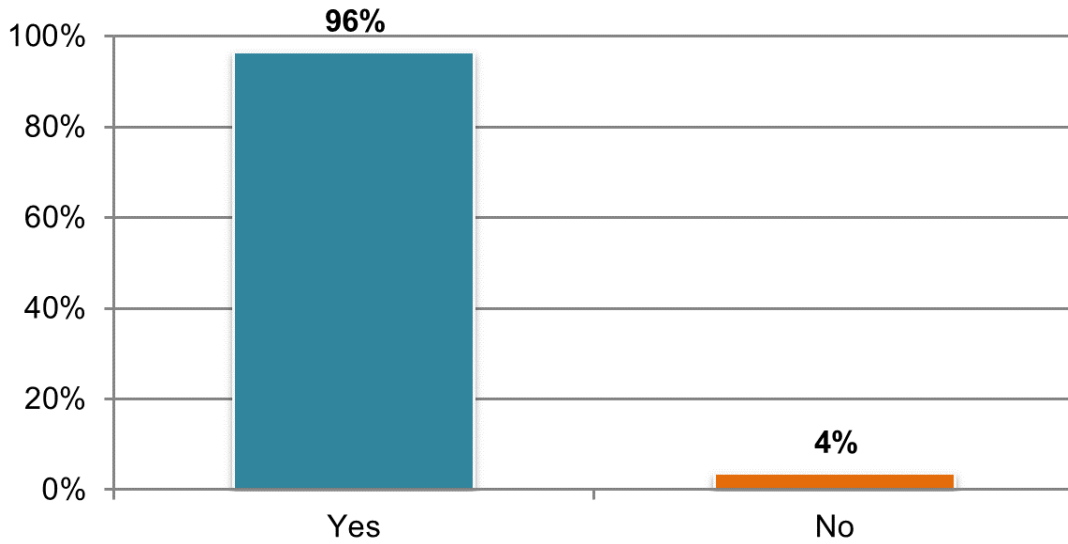


Table Q30a. If you have access to dental services for your family member, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
AZ	99%	1%	182
Within Average Range			
LA	99%	1%	201
NH	98%	2%	270
OK	97%	3%	275
NC	97%	3%	171
VA	97%	3%	98
PA	97%	3%	318
GA	96%	4%	239
MD	96%	4%	253
DC	95%	5%	196
FL	95%	5%	246
WA	95%	5%	254
CA **	94%	6%	2,227
SC	94%	6%	175
NCI Average	96%	4%	5,105

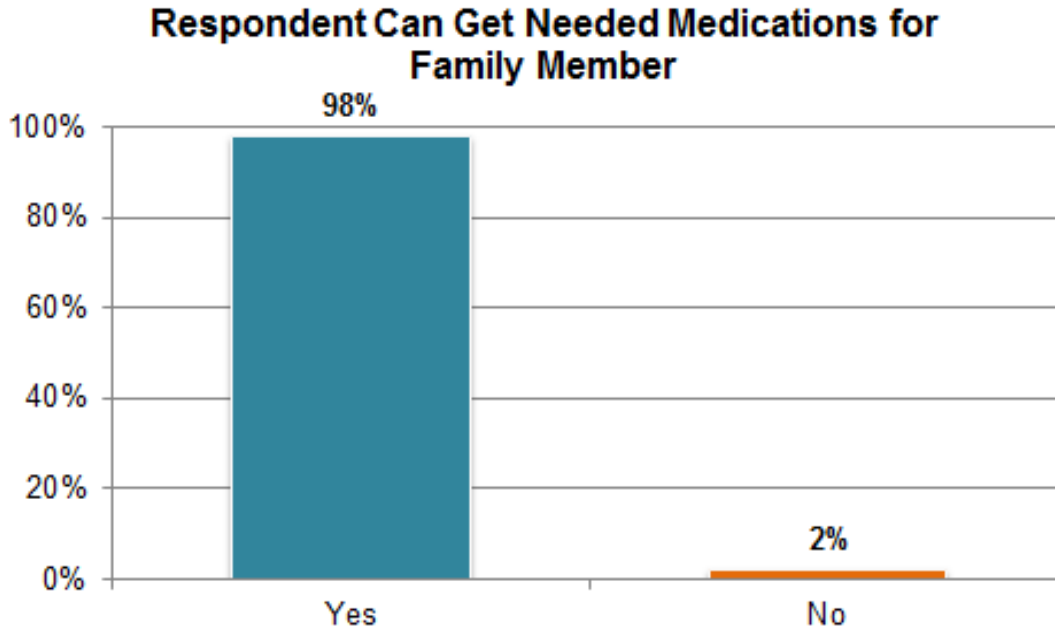


Table Q31. Are you able to get medications needed for your family member?

State	Yes	No	N
Significantly Above Average			
MD	100%	0%	335
NC	100%	0%	210
Within Average Range			
VA	99%	1%	144
PA	99%	1%	382
NH	99%	1%	345
AZ	99%	1%	342
OK	98%	2%	368
GA	98%	2%	360
SC	98%	2%	237
LA	97%	3%	331
DC	97%	3%	220
WA	97%	3%	306
FL	96%	4%	370
CA **	96%	4%	3,323
NCI Average	98%	2%	7,273

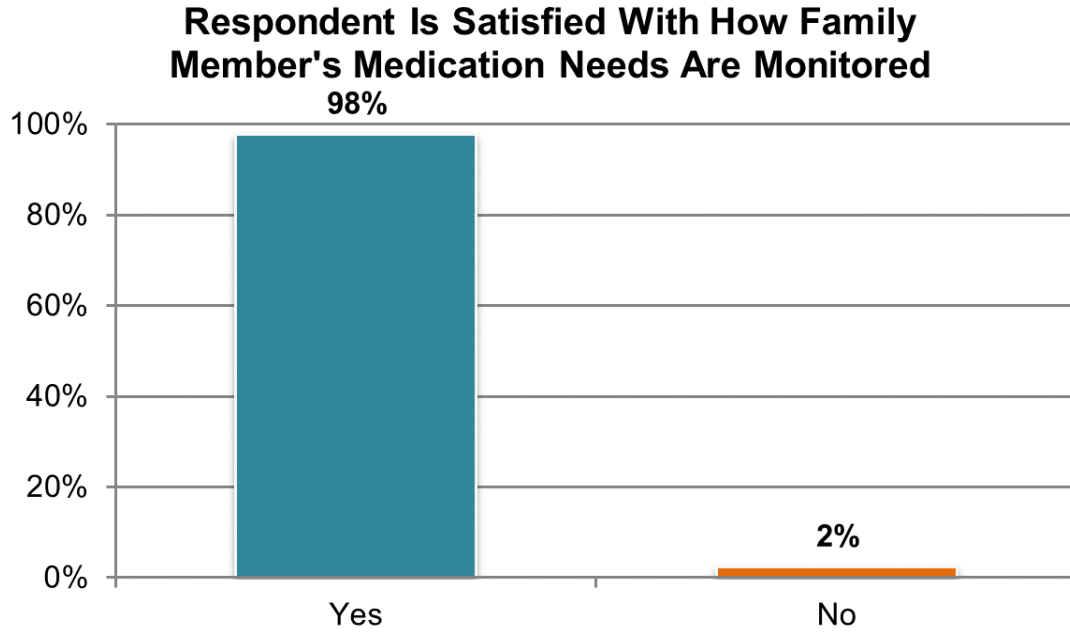


Table Q31a. If you are able to get needed medications for your family member, are you satisfied with how your family member’s medication needs are monitored?

State	Yes	No	N
Within Average Range			
VA	99%	1%	131
OK	99%	1%	344
PA	99%	1%	340
FL	98%	2%	327
GA	98%	2%	321
AZ	98%	2%	319
SC	98%	2%	219
LA	98%	2%	297
NH	97%	3%	308
MD	97%	3%	293
DC	97%	3%	193
NC	97%	3%	193
WA	97%	3%	282
CA **	97%	3%	2,908
NCI Average	98%	2%	6,475

Respondent Has Access to Needed Mental Health Services for Family Member

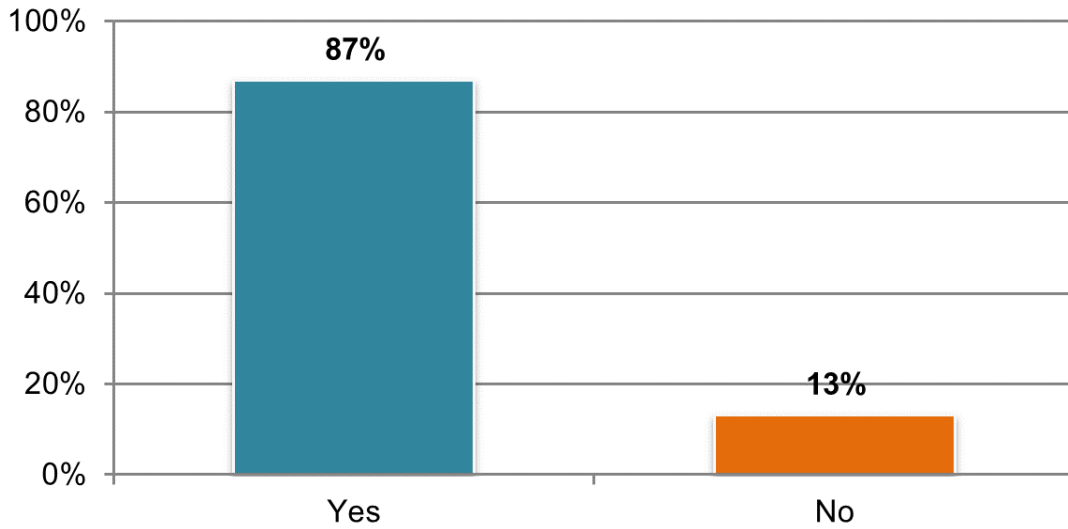


Table Q32. If needed, do you have access to mental health services for your family member?

State	Yes	No	N
Significantly Above Average			
NC	94%	6%	141
Within Average Range			
VA	92%	8%	102
NH	91%	9%	198
AZ	91%	9%	195
LA	91%	9%	184
PA	91%	9%	215
MD	89%	11%	196
WA	89%	11%	180
DC	85%	15%	166
OK	84%	16%	184
FL	82%	18%	234
Significantly Below Average			
CA	80%	20%	2,144
GA	80%	20%	232
SC	78%	22%	143
NCI Average	87%	13%	4,514

Respondent Is Satisfied With Family Member's Mental Health Providers

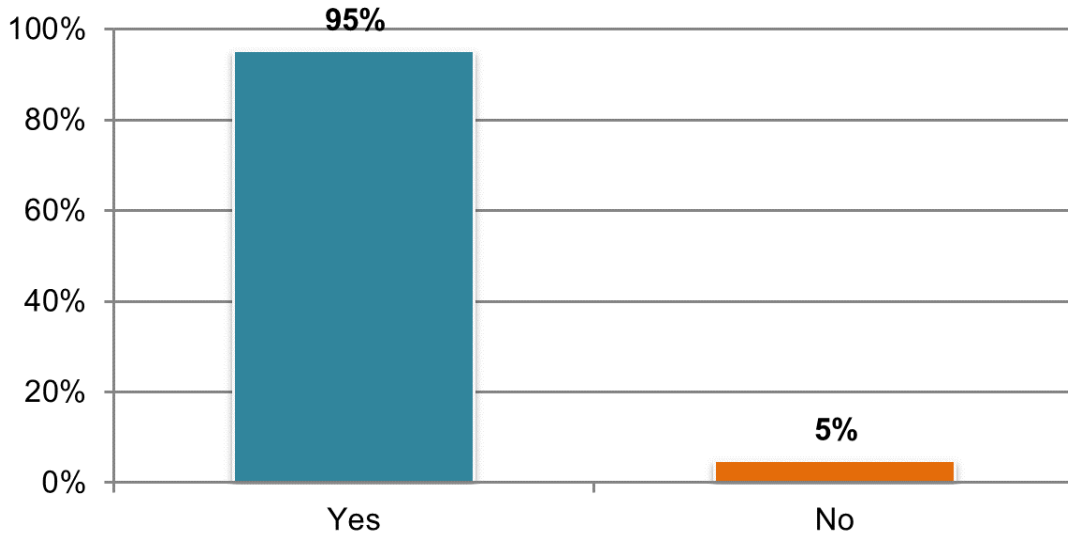


Table Q32a. If you have access to needed mental health services, are you satisfied with the quality of these providers?

State	Yes	No	N
Within Average Range			
OK	97%	3%	118
LA	97%	3%	139
PA	97%	3%	147
WA	96%	4%	120
SC	96%	4%	95
AZ	96%	4%	141
GA	95%	5%	153
NC	95%	5%	108
FL	95%	5%	147
NH	95%	5%	136
MD	95%	5%	130
CA	94%	6%	1,336
DC	93%	7%	115
VA	91%	9%	79
NCI Average	95%	5%	2,964

Respondent Has Access to Respite Services Needed for Family Member

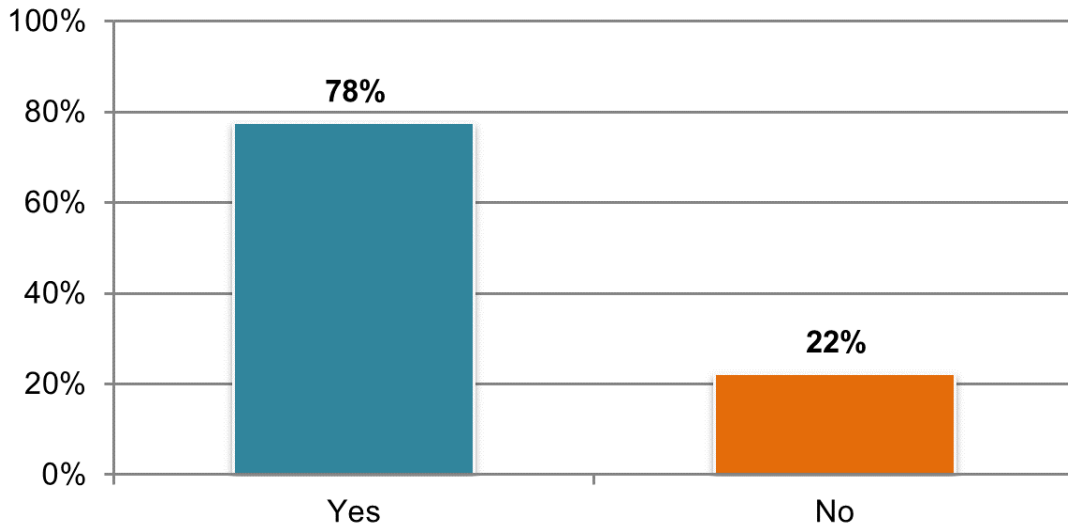


Table Q33. If you need respite services, do you have access to them?

State	Yes	No	N
Significantly Above Average			
AZ	96%	4%	311
DC	89%	11%	157
VA	89%	11%	119
NH	87%	13%	270
NC	86%	14%	179
SC	85%	15%	175
Within Average Range			
LA	80%	20%	199
PA	79%	21%	235
WA	78%	22%	241
CA	77%	23%	2,166
Significantly Below Average			
FL	74%	26%	244
MD	62%	38%	169
GA	57%	43%	213
OK	47%	53%	166
NCI Average	78%	22%	4,844

Respondent Is Satisfied With Family Member's Respite Providers

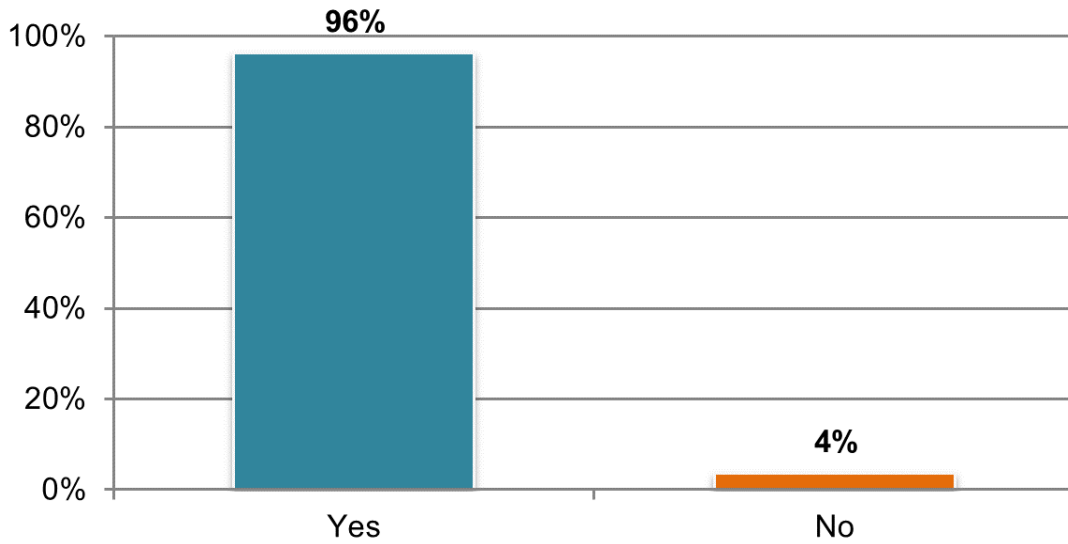


Table Q33a. If you have access to needed respite services, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
AZ	98%	2%	260
Within Average Range			
VA	99%	1%	93
OK	98%	2%	59
NH	97%	3%	207
DC	97%	3%	95
GA	97%	3%	93
PA	97%	3%	147
MD	96%	4%	82
FL	96%	4%	157
LA	96%	4%	141
SC	95%	5%	125
CA	95%	5%	1,398
WA	94%	6%	160
NC	93%	7%	139
NCI Average	96%	4%	3,156

Services Are Needed That Are Not Currently Offered or Available

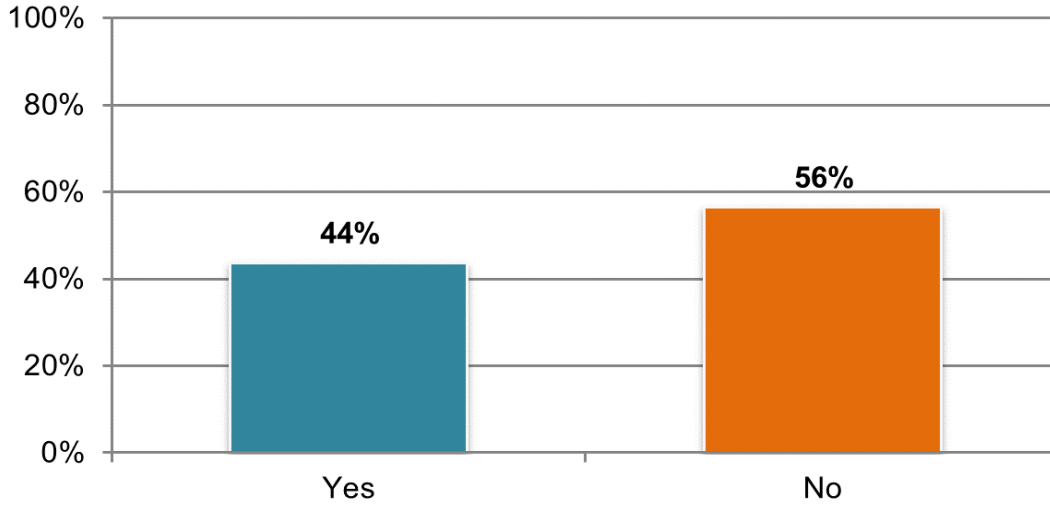


Table Q34. Are there other services that your family member needs that are not currently offered or available?⁴

State	Yes	No	N
Significantly Above Average			
MD	54%	46%	216
FL	53%	47%	295
CA **	49%	51%	2,121
Within Average Range			
SC	53%	47%	159
GA	47%	53%	218
WA	47%	53%	195
VA	47%	53%	103
NC	46%	54%	144
DC	41%	59%	144
PA	38%	62%	258
Significantly Below Average			
LA	35%	65%	235
NH	34%	66%	239
OK	34%	66%	219
AZ	34%	66%	234
NCI Average	44%	56%	4,780

⁴ The 'yes' response is the less desired response.

Choice and Control

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

Note: State outcomes with fewer than 20 responses were not reported.

Note on California significance: Due to the large N, many of California’s data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (**), an outcome is significant *only* due to the sample size.

Respondent Chooses Provider Agencies That Work With Family

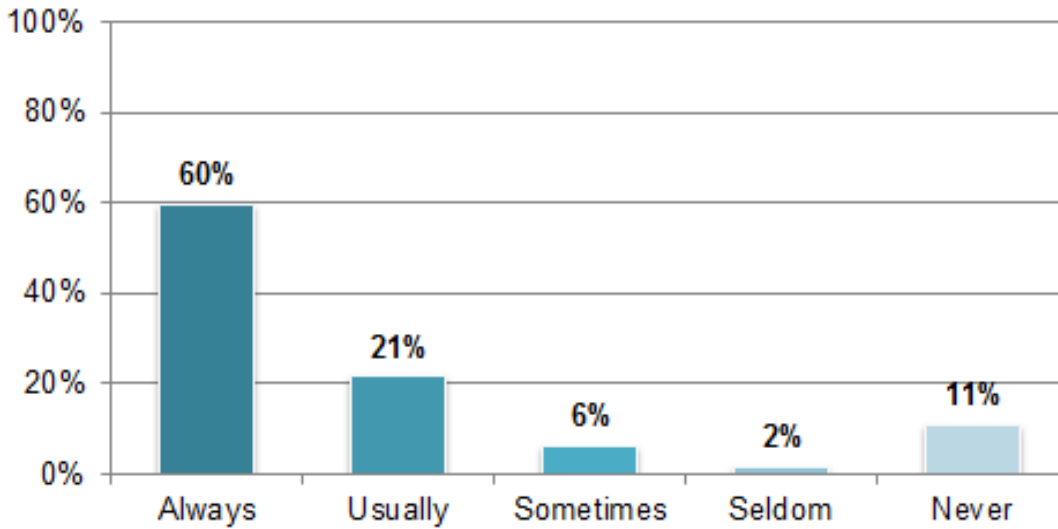


Table Q35. Do you choose the provider agencies who work with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	83%	10%	2%	0%	5%	308
AZ	72%	18%	5%	2%	3%	321
NH	70%	18%	2%	1%	8%	297
OK	67%	21%	4%	1%	6%	341
Within Average Range						
NC	68%	21%	3%	0%	7%	205
FL	62%	20%	5%	2%	11%	380
PA	59%	26%	7%	2%	7%	324
WA	55%	20%	12%	3%	10%	245
GA	54%	20%	5%	1%	19%	305
MD	54%	23%	7%	2%	14%	303
VA	52%	27%	8%	3%	10%	129
Significantly Below Average						
SC	49%	29%	6%	0%	16%	212
CA	45%	23%	10%	4%	18%	2,781
DC	44%	23%	11%	2%	21%	200
NCI Average	60%	21%	6%	2%	11%	6,351

Family Member Chooses Provider Agencies Who Work With Family

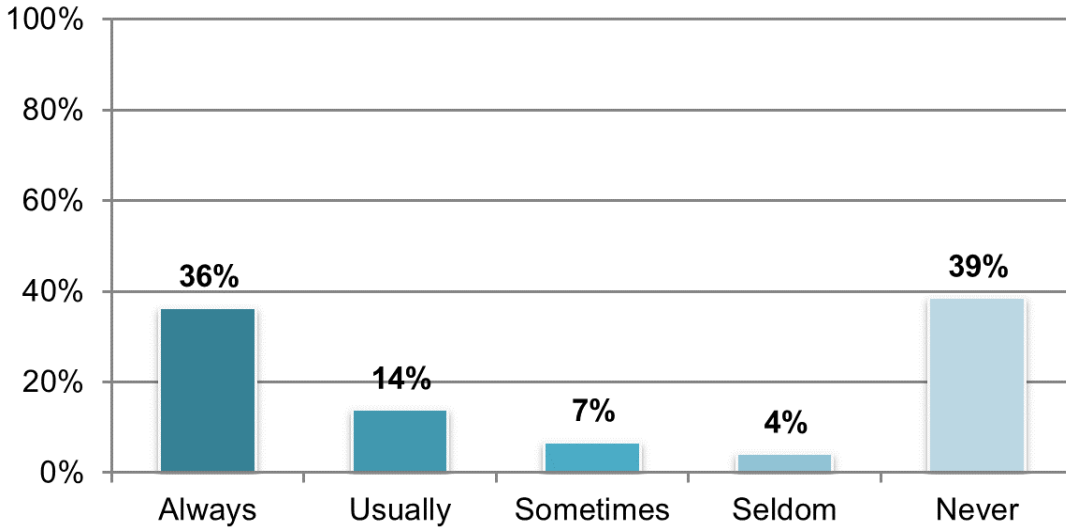


Table Q36. Does your family member choose the provider agencies who work with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	56%	11%	4%	1%	29%	264
FL	46%	15%	6%	6%	27%	330
NH	45%	14%	5%	5%	31%	254
Within Average Range						
NC	41%	16%	4%	1%	38%	175
AZ	38%	9%	8%	6%	38%	265
OK	37%	15%	4%	3%	40%	291
DC	35%	13%	9%	4%	38%	178
GA	34%	7%	6%	4%	49%	273
MD	33%	16%	9%	4%	38%	273
SC	32%	19%	8%	2%	40%	172
CA **	31%	16%	9%	6%	38%	2,474
VA	29%	14%	5%	5%	47%	104
Significantly Below Average						
WA	28%	11%	11%	7%	42%	222
PA	27%	17%	8%	4%	45%	275
NCI Average	36%	14%	7%	4%	39%	5,550

Respondent Can Choose a Different Provider Agency If Desired

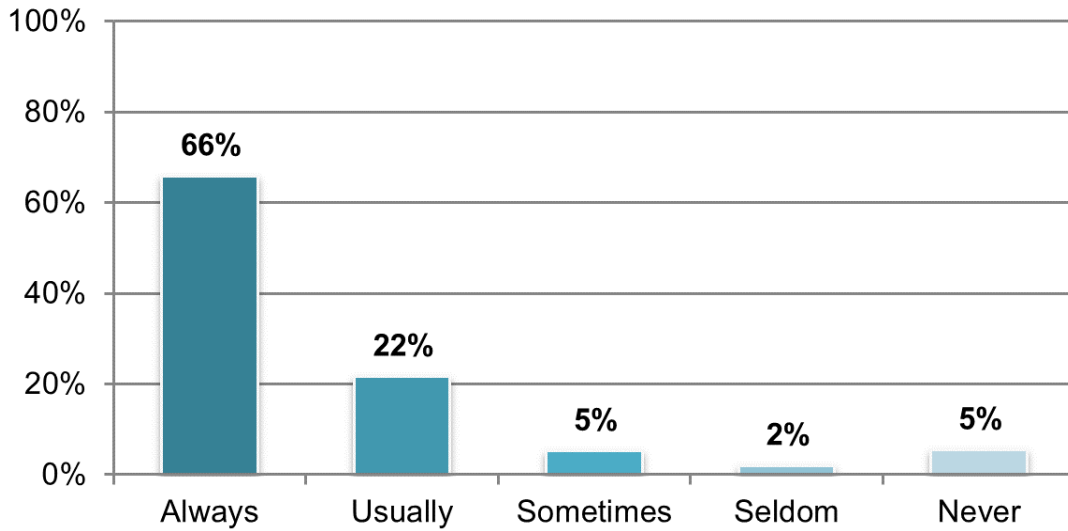


Table Q37. Can you choose a different provider agency if you want to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	79%	16%	2%	0%	2%	295
OK	74%	20%	4%	1%	2%	296
Within Average Range						
NC	73%	20%	5%	1%	2%	178
NH	71%	15%	6%	3%	5%	198
FL	70%	20%	4%	2%	4%	328
AZ	70%	22%	4%	1%	3%	258
MD	68%	20%	5%	2%	5%	247
SC	64%	18%	4%	2%	12%	138
DC	64%	25%	5%	1%	4%	157
PA	64%	28%	4%	1%	3%	225
GA	61%	26%	5%	4%	4%	226
VA	59%	23%	7%	1%	9%	86
WA	56%	23%	7%	4%	9%	166
Significantly Below Average						
CA	49%	26%	9%	4%	12%	1,810
NCI Average	66%	22%	5%	2%	5%	4,608

Respondent Chooses Individual Support Workers Who Work Directly With Family

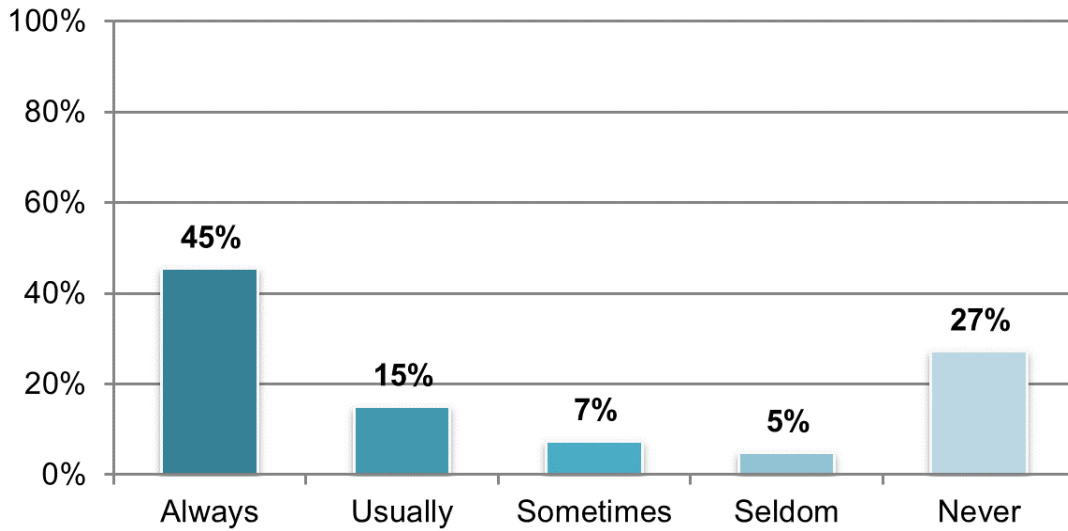


Table Q38. Do you choose the individual support workers who work directly with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	65%	11%	4%	2%	18%	297
AZ	64%	12%	6%	3%	15%	282
FL	63%	14%	4%	1%	17%	341
OK	62%	13%	6%	5%	15%	307
NC	58%	19%	8%	3%	11%	192
Within Average Range						
NH	47%	13%	5%	7%	28%	304
WA	40%	19%	9%	10%	21%	225
GA	40%	11%	6%	4%	39%	301
VA	39%	13%	13%	5%	30%	123
DC	39%	18%	8%	3%	31%	206
Significantly Below Average						
PA	36%	13%	7%	6%	38%	300
CA	35%	16%	8%	6%	35%	2,436
SC	27%	16%	9%	4%	44%	197
MD	21%	22%	8%	9%	40%	285
NCI Average	45%	15%	7%	5%	27%	5,796

Family Member Chooses Individual Support Workers Who Work Directly With Family

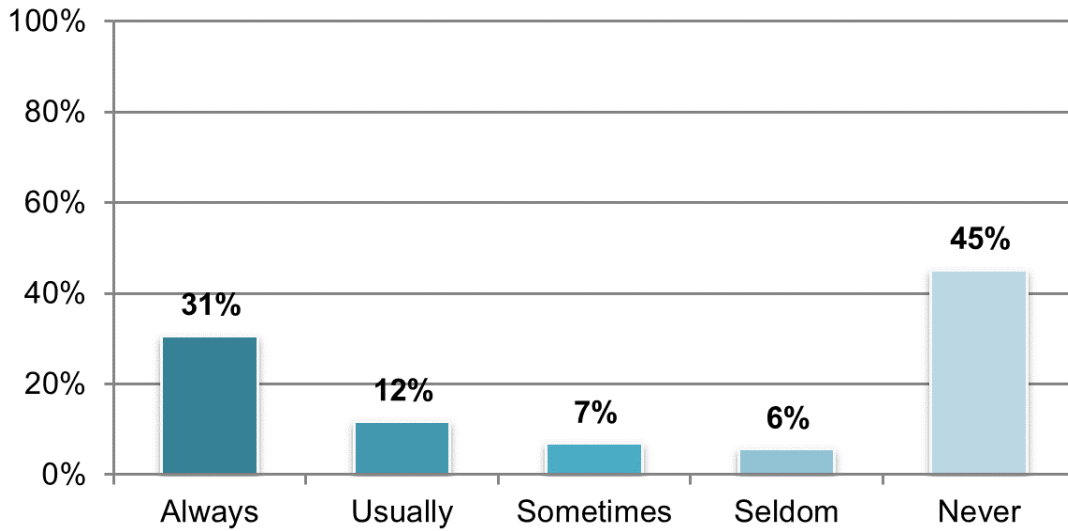


Table Q39. Does your family member choose the individual support workers who work directly with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	48%	10%	5%	6%	32%	305
LA	47%	7%	8%	3%	35%	274
OK	40%	12%	5%	5%	38%	278
Within Average Range						
AZ	38%	9%	6%	7%	40%	250
NH	36%	9%	9%	4%	42%	275
NC	32%	20%	10%	4%	34%	180
DC	30%	14%	6%	5%	46%	192
VA	27%	9%	8%	6%	50%	107
CA	25%	12%	7%	6%	50%	2,236
GA	24%	8%	6%	6%	56%	277
SC	23%	9%	6%	4%	58%	174
Significantly Below Average						
WA	22%	14%	5%	10%	48%	212
PA	20%	11%	5%	5%	60%	274
MD	17%	21%	8%	9%	46%	273
NCI Average	31%	12%	7%	6%	45%	5,334

Respondent Can Choose Different Support Workers If Desired

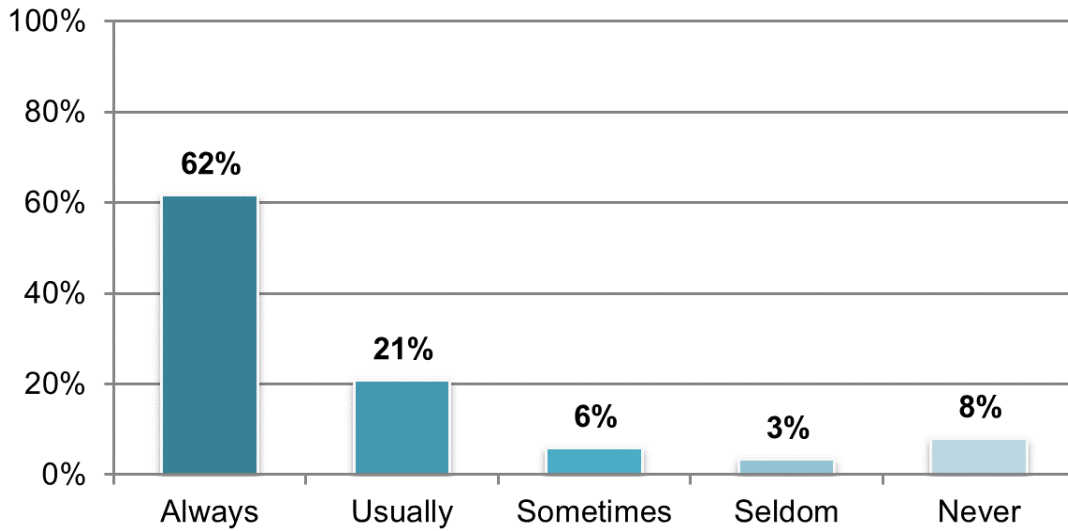


Table Q40. Can you choose different support workers if you want to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	75%	13%	5%	3%	5%	276
AZ	74%	16%	3%	4%	3%	251
FL	72%	17%	3%	1%	6%	323
OK	71%	16%	5%	4%	4%	275
Within Average Range						
NC	69%	21%	4%	4%	2%	181
NH	67%	16%	9%	2%	5%	227
GA	62%	16%	8%	3%	10%	202
DC	61%	26%	8%	1%	4%	157
PA	56%	26%	4%	4%	10%	215
WA	55%	23%	6%	7%	9%	172
VA	51%	31%	3%	7%	7%	94
Significantly Below Average						
CA	54%	23%	9%	4%	11%	1,797
SC	48%	24%	8%	2%	18%	130
MD	48%	24%	6%	5%	17%	189
NCI Average	62%	21%	6%	3%	8%	4,489

Respondent Chose Case Manager/Service Coordinator

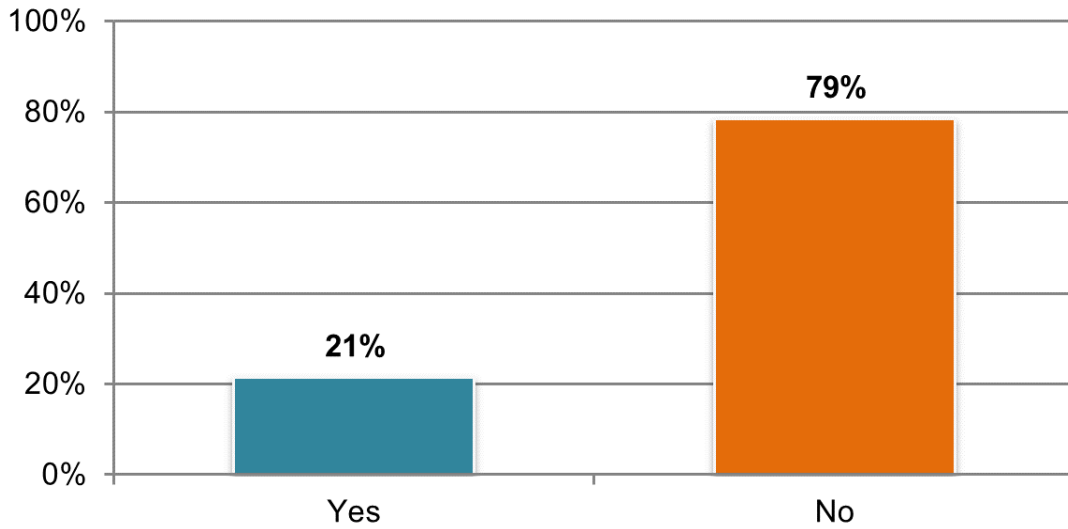


Table Q41. Did you choose your family member’s case manager/service coordinator?

State	Yes	No	N
Significantly Above Average			
FL	62%	38%	376
LA	48%	52%	314
Within Average Range			
NC	26%	74%	203
PA	20%	80%	358
DC	19%	81%	226
MD	19%	81%	348
VA	18%	82%	141
SC	17%	83%	243
AZ	16%	84%	335
Significantly Below Average			
NH	13%	87%	359
GA	12%	88%	352
CA	12%	88%	3,348
OK	12%	88%	351
WA	7%	93%	318
NCI Average	21%	79%	7,272

Family Member Chose Case Manager/Service Coordinator

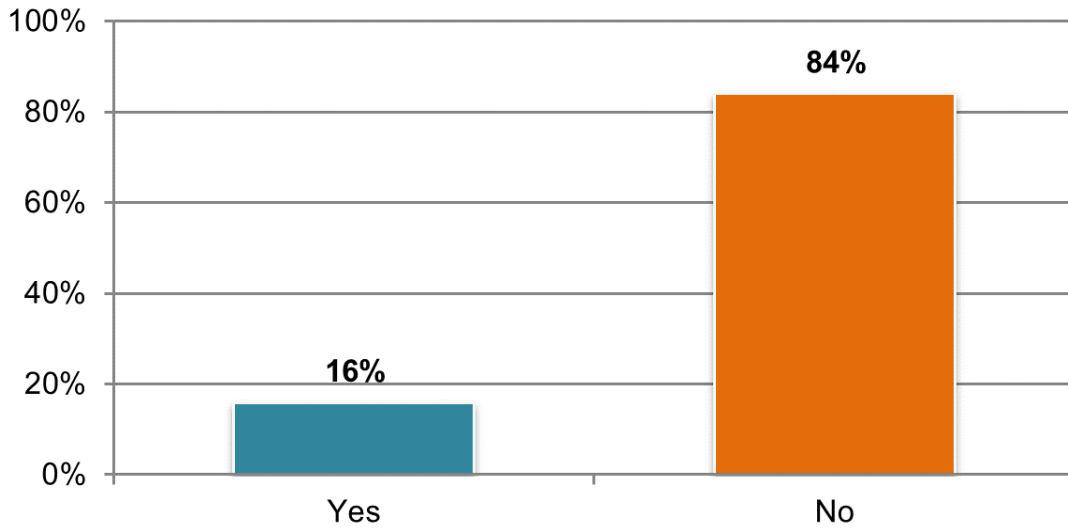


Table Q42. Did your family member choose his/her case manager/service coordinator?

State	Yes	No	N
Significantly Above Average			
FL	46%	54%	349
LA	33%	67%	304
Within Average Range			
SC	16%	84%	226
NC	15%	85%	192
DC	15%	85%	223
VA	15%	85%	137
AZ	13%	87%	318
MD	12%	88%	338
NH	12%	88%	355
Significantly Below Average			
GA	10%	90%	341
PA	10%	90%	342
OK	10%	90%	341
CA	10%	91%	3,263
WA	6%	94%	321
NCI Average	16%	84%	7,050

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

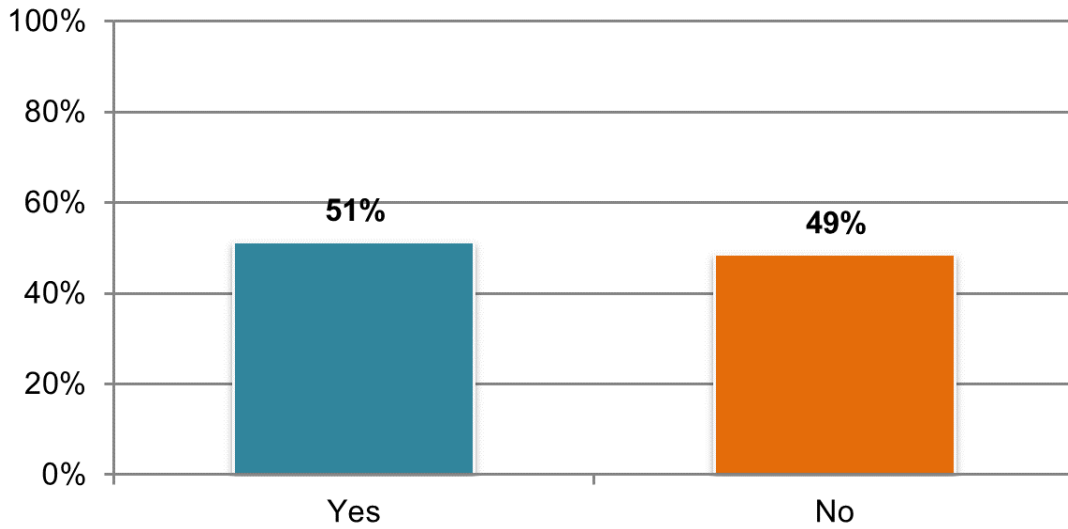


Table Q43. Do you have control and/or input over the hiring and management of your family member’s support workers?

State	Yes	No	N
Significantly Above Average			
LA	71%	29%	297
NC	71%	29%	185
FL	69%	31%	327
OK	67%	33%	308
Within Average Range			
NH	57%	43%	293
AZ	56%	44%	266
WA	55%	45%	228
VA	48%	52%	131
DC	47%	53%	191
Significantly Below Average			
PA	43%	57%	293
CA	42%	58%	2,480
GA	41%	59%	296
SC	27%	73%	199
MD	24%	76%	279
NCI Average	51%	49%	5,773

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

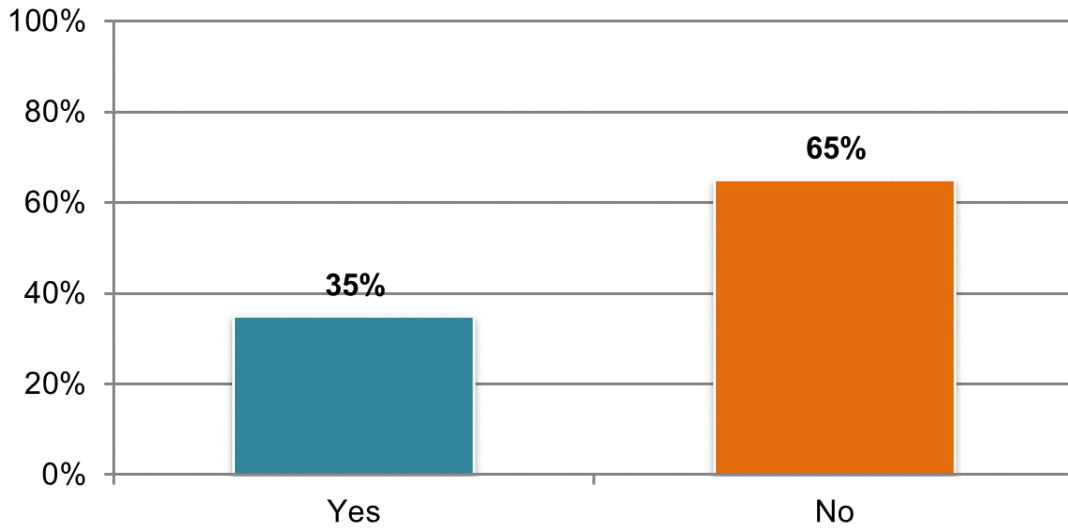


Table Q44. Does your family member have control and/or input over the hiring and management of his/her support workers?

State	Yes	No	N
Significantly Above Average			
FL	56%	44%	309
LA	50%	50%	273
OK	45%	55%	291
NC	44%	56%	182
NH	42%	58%	285
Within Average Range			
DC	34%	66%	183
VA	34%	66%	122
AZ	33%	67%	252
CA **	31%	69%	2,445
WA	30%	70%	230
Significantly Below Average			
GA	27%	73%	285
PA	25%	75%	284
MD	20%	80%	267
SC	18%	82%	180
NCI Average	35%	65%	5,588

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

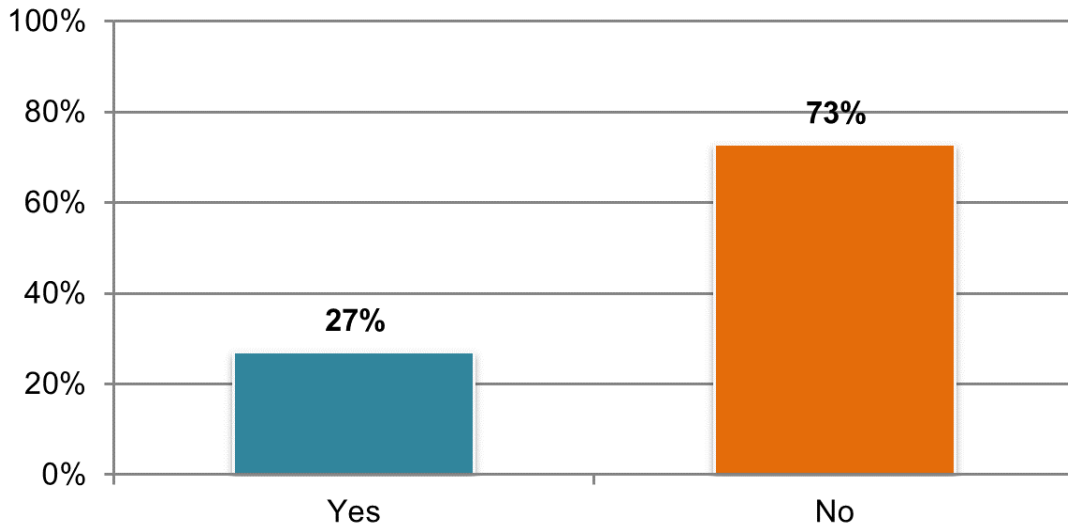


Table Q45. Do you know how much money is spent by the ID/DD agency on behalf of your family member with a developmental disability?

State	Yes	No	N
Significantly Above Average			
FL	60%	40%	384
OK	53%	47%	377
NH	41%	59%	362
Within Average Range			
GA	32%	68%	368
CA	28%	72%	3,586
SC	27%	73%	248
LA	23%	77%	338
WA	23%	77%	315
PA	22%	78%	375
NC	20%	80%	217
Significantly Below Average			
MD	19%	81%	362
VA	14%	86%	141
AZ	9%	91%	346
DC	7%	93%	229
NCI Average	27%	73%	7,648

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

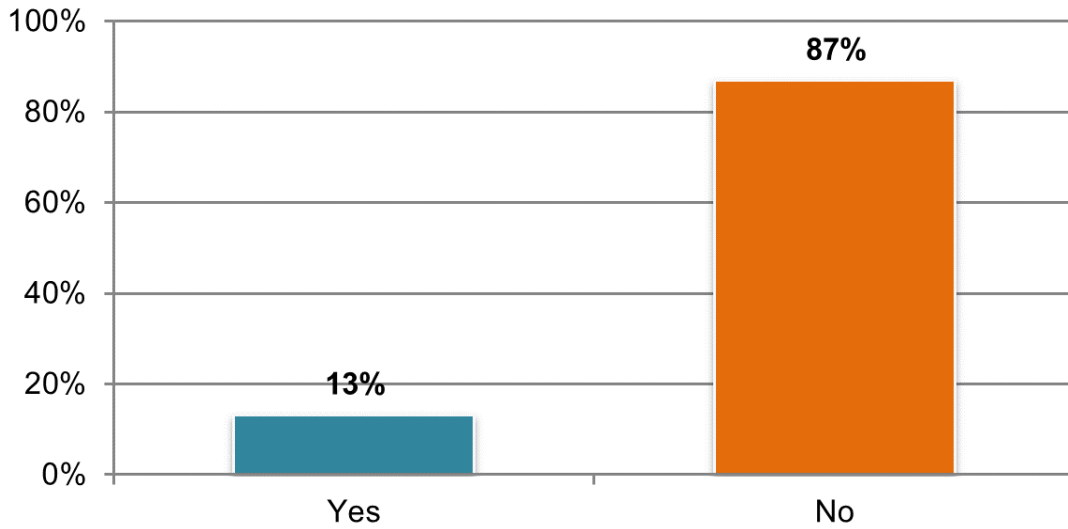


Table Q46. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?

State	Yes	No	N
Significantly Above Average			
FL	36%	64%	361
OK	21%	79%	345
Within Average Range			
NH	18%	82%	340
SC	15%	85%	230
LA	14%	86%	315
CA	13%	87%	3,444
GA	12%	88%	357
WA	12%	88%	305
PA	10%	90%	354
Significantly Below Average			
MD	9%	91%	352
NC	8%	92%	200
VA	6%	94%	134
DC	6%	94%	230
AZ	5%	95%	322
NCI Average	13%	87%	7,289

Respondent Has a Say in How ID/DD Agency Money Is Spent on Family Member's Behalf

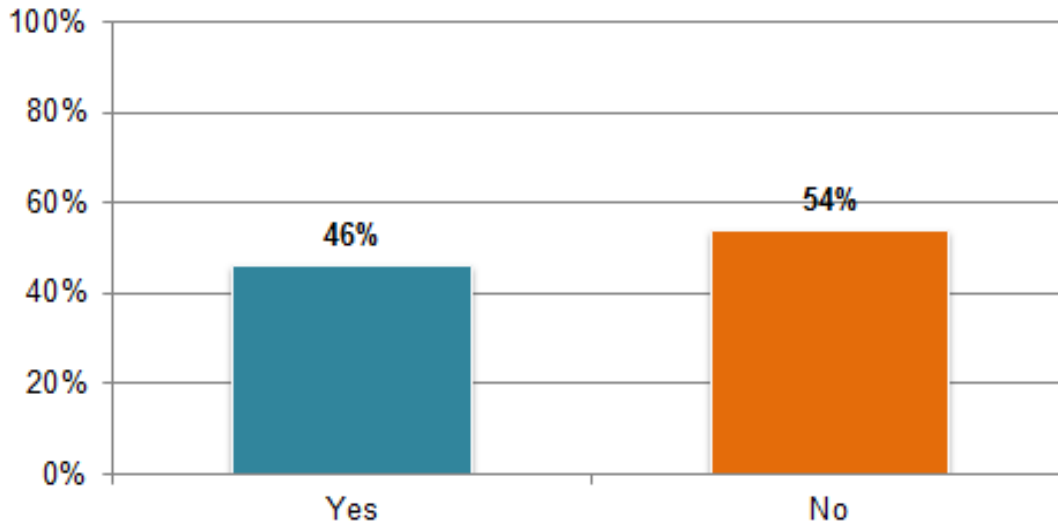


Table Q47. Do you have a say in how this money is spent?

State	Yes	No	N
Significantly Above Average			
OK	73%	27%	292
FL	70%	30%	316
NH	62%	38%	289
PA	60%	40%	261
Within Average Range			
GA	52%	48%	288
WA	52%	48%	235
DC	41%	59%	177
LA	41%	59%	245
NC	40%	60%	157
AZ	39%	61%	214
Significantly Below Average			
CA	35%	65%	2,346
MD	32%	68%	263
SC	29%	71%	182
VA	24%	76%	103
NCI Average	46%	54%	5,368

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

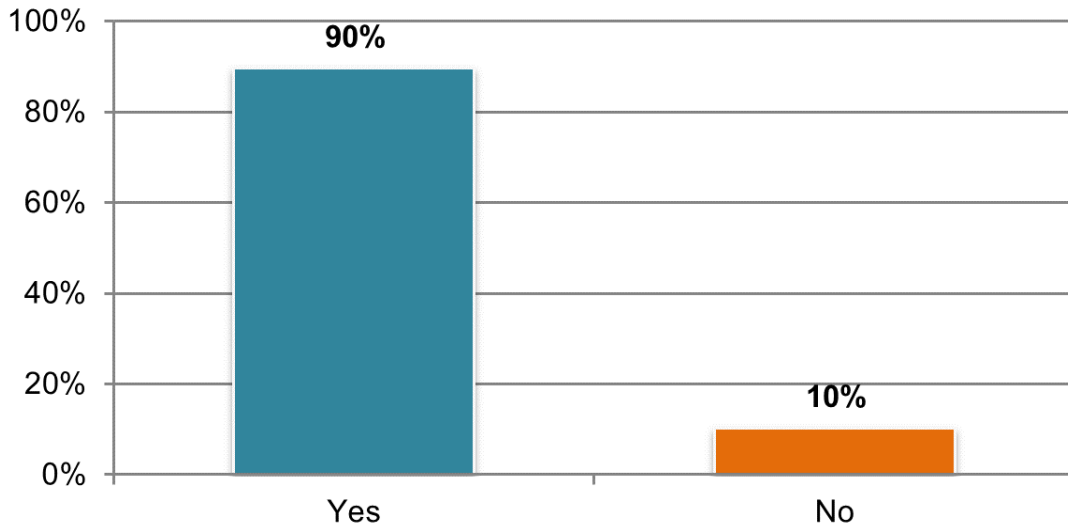


Table Q47a. If you have a say in how ID/DD agency money is spent, do you have all the information you need to make decisions about how to spend this money?

State	Yes	No	N
Significantly Above Average			
VA	100%	0%	24
Within Average Range			
MD	95%	5%	73
LA	94%	6%	89
PA	93%	7%	136
FL	93%	7%	194
AZ	92%	8%	76
WA	90%	10%	108
CA	89%	11%	715
DC	88%	12%	67
NH	88%	12%	164
OK	87%	13%	188
NC	84%	16%	57
GA	83%	17%	130
SC	79%	21%	43
NCI Average	90%	10%	2,064

Family Member Has Say in How ID/DD Agency Money Is Spent on His/Her Behalf

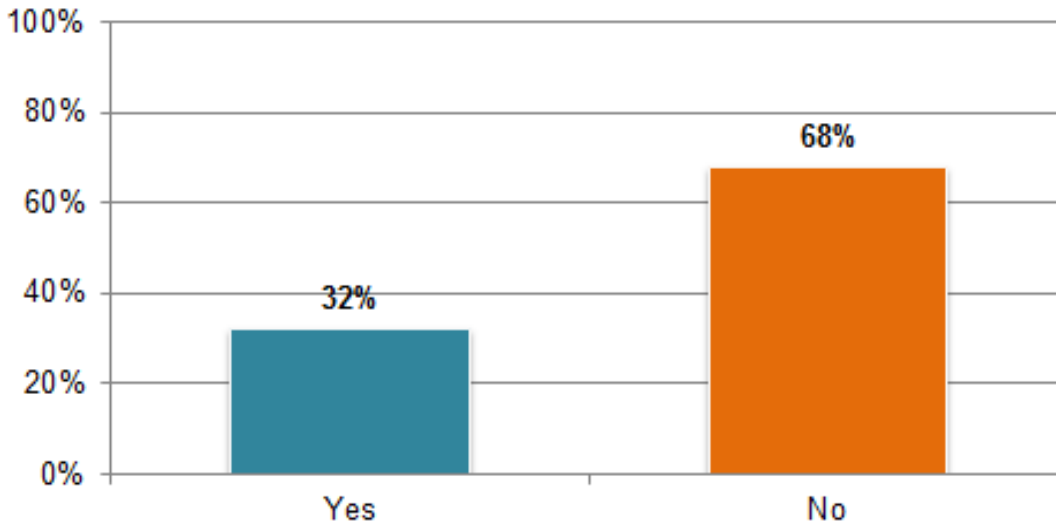


Table Q48. Does your family member have a say in how this money is spent?

State	Yes	No	N
Significantly Above Average			
FL	55%	45%	278
OK	44%	56%	265
NH	42%	58%	273
Within Average Range			
PA	35%	65%	249
GA	35%	65%	261
WA	31%	69%	234
DC	30%	70%	166
MD	27%	73%	263
LA	26%	74%	232
SC	25%	75%	158
NC	24%	76%	152
Significantly Below Average			
CA	24%	76%	2,270
AZ	23%	77%	223
VA	19%	81%	94
NCI Average	32%	68%	5,118

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

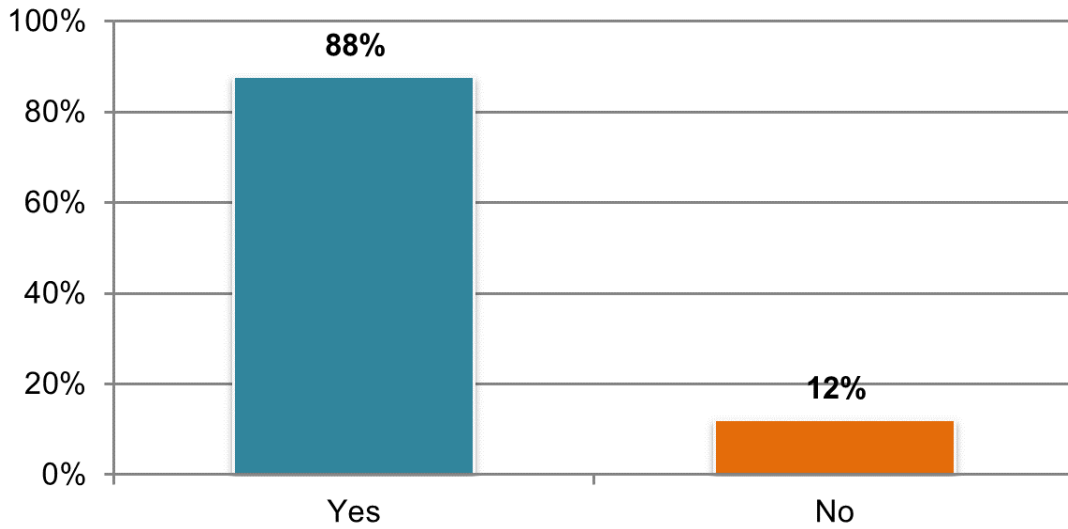


Table Q48a. If your family member has a say in how agency money is spent, does your family member have all the information s/he needs to make decisions about how to spend this money?

State	Yes	No	N
Significantly Above Average			
LA	96%	4%	52
Within Average Range			
MD	92%	8%	62
CA**	92%	9%	481
PA	91%	9%	77
FL	91%	9%	139
OK	90%	10%	102
WA	90%	10%	67
GA	89%	11%	75
NC	85%	15%	33
NH	85%	15%	99
AZ	83%	17%	47
SC	81%	19%	32
DC	78%	22%	45
NCI Average	88%	12%	1,311

Community Connections

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

Note: State outcomes with fewer than 20 responses were not reported.

Note on California significance: Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (**), an outcome is significant *only* due to the sample size.

Family Member Participates in Community Activities

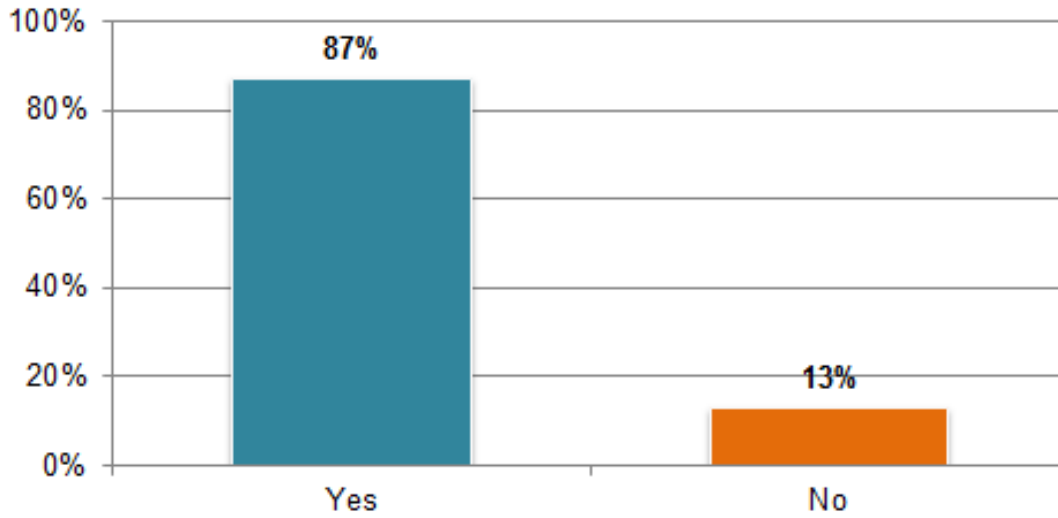


Table Q49. Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?

State	Yes	No	N
Significantly Above Average			
NH	92%	8%	369
OK	91%	9%	374
Within Average Range			
AZ	91%	9%	349
VA	90%	10%	146
DC	90%	10%	236
NC	89%	11%	223
PA	88%	12%	386
WA	87%	13%	324
MD	87%	13%	356
GA	87%	13%	375
LA	86%	14%	334
FL	85%	15%	358
Significantly Below Average			
CA	80%	20%	3,558
SC	80%	20%	242
NCI Average	87%	13%	7,630

Reasons Family Member Does Not Participate in Community Activities

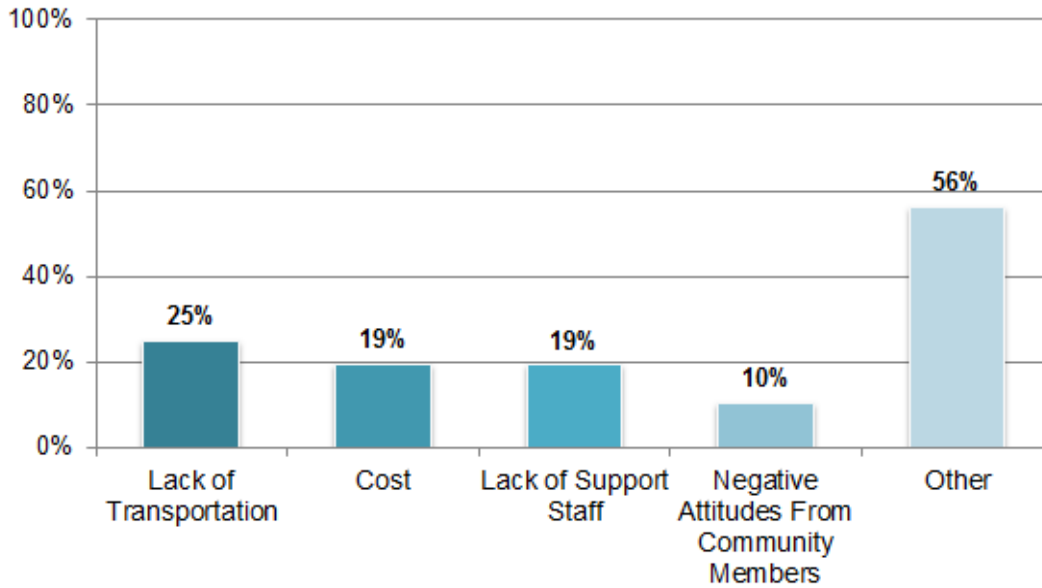


Table Q49a. If your family member doesn't participate in community activities, why not?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes From Community Members	Other
AZ	13%	22%	17%	17%	61%
CA	27%	26%	26%	9%	50%
FL	14%	24%	17%	7%	64%
GA	32%	25%	29%	0%	32%
LA	24%	13%	13%	11%	55%
MD	21%	21%	24%	3%	63%
NC	29%	10%	10%	19%	52%
OK	27%	12%	12%	12%	58%
PA	24%	15%	24%	6%	70%
SC	40%	23%	21%	14%	53%
WA	25%	22%	19%	17%	58%
NCI Average	25%	19%	19%	10%	56%

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

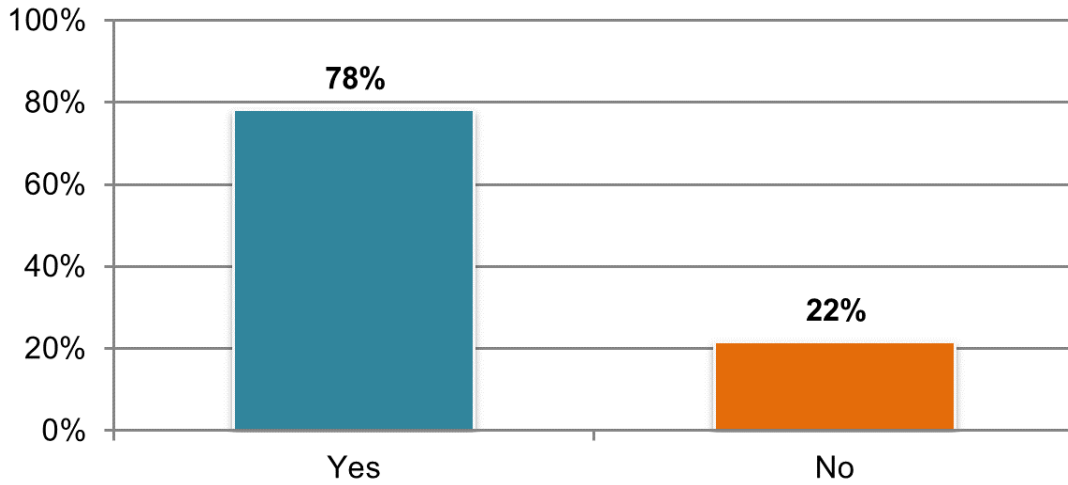


Table Q50. Does your family member have friends or relationships with persons other than paid support workers or family?

State	Yes	No	N
Significantly Above Average			
OK	88%	12%	365
NH	83%	17%	367
Within Average Range			
AZ	81%	19%	345
NC	80%	20%	220
VA	79%	21%	146
LA	79%	21%	340
GA	79%	21%	369
FL	79%	21%	387
WA	78%	22%	319
PA	78%	22%	378
DC	76%	24%	228
SC	74%	26%	250
MD	74%	26%	358
Significantly Below Average			
CA	68%	32%	3,410
NCI Average	78%	22%	7,482

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

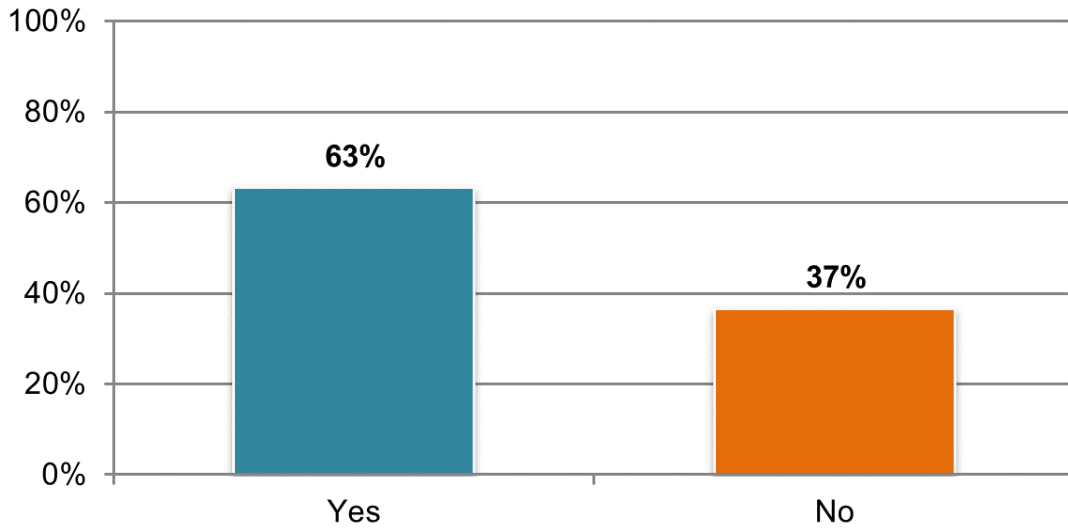


Table Q51. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

State	Yes	No	N
Significantly Above Average			
NH	78%	22%	318
Within Average Range			
OK	68%	32%	279
MD	68%	32%	289
AZ	67%	33%	232
DC	67%	33%	192
PA	66%	34%	268
NC	64%	36%	178
LA	62%	38%	275
GA	59%	41%	288
WA	59%	41%	267
CA **	59%	41%	2,754
VA	58%	42%	111
FL	56%	44%	288
SC	55%	45%	188
NCI Average	63%	37%	5,927

Satisfaction With Services and Supports

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

Note: State outcomes with fewer than 20 responses were not reported.

Note on California significance: Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (**), an outcome is significant *only* due to the sample size.

Respondent Is Satisfied With the Services and Supports Family Receives

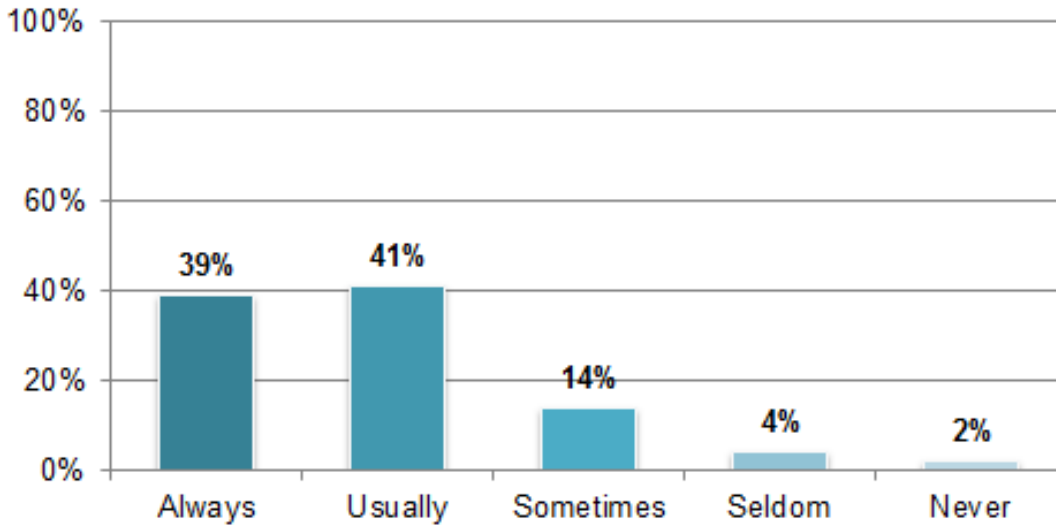


Table Q52. Overall, are you satisfied with the services and supports your family currently receives?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	50%	36%	11%	2%	2%	340
Within Average Range						
NH	46%	41%	10%	2%	2%	367
AZ	46%	42%	11%	1%	1%	352
FL	43%	35%	15%	5%	2%	388
CA	41%	36%	16%	4%	3%	3,575
DC	41%	33%	19%	5%	2%	232
SC	40%	40%	13%	5%	2%	253
VA	39%	41%	14%	5%	1%	145
PA	38%	45%	13%	3%	2%	387
NC	37%	40%	18%	4%	2%	222
GA	37%	42%	14%	5%	2%	369
OK	35%	50%	11%	4%	1%	363
Significantly Below Average						
MD	30%	44%	19%	4%	3%	356
WA	27%	53%	14%	4%	1%	314
NCI Average	39%	41%	14%	4%	2%	7,663

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

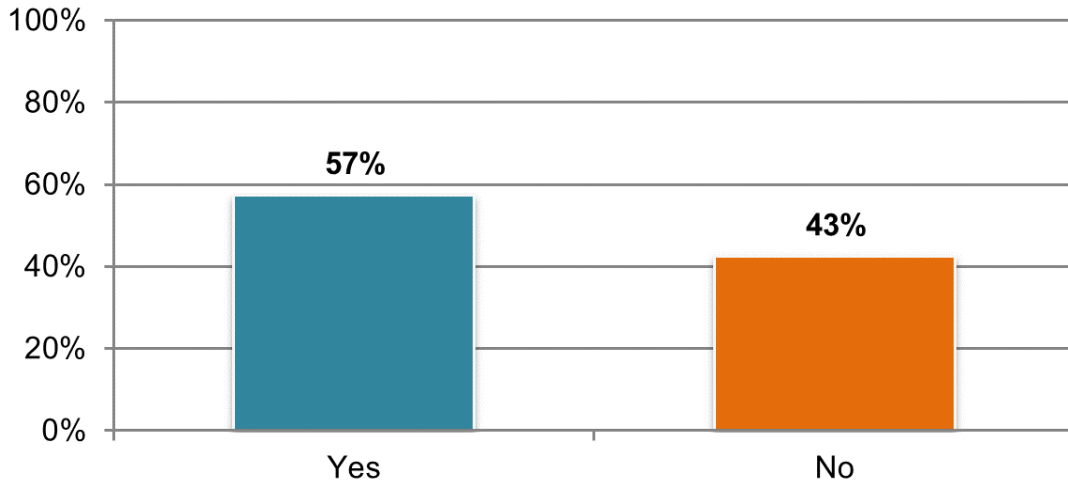


Table Q53. Do you know the process for filing a complaint or grievance against provider agencies or staff?⁵

State	Yes	No	N
Significantly Above Average			
OK	80%	20%	362
LA	76%	24%	340
FL	70%	30%	389
NH	69%	31%	359
Within Average Range			
NC	64%	36%	223
PA	58%	42%	374
WA	58%	42%	310
AZ	57%	43%	345
VA	53%	47%	141
DC	51%	49%	235
Significantly Below Average			
SC	47%	53%	252
CA	45%	55%	3,578
GA	41%	59%	374
MD	36%	64%	356
NCI Average	57%	43%	7,638

⁵ 'Don't know' responses are included with 'no' responses.

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

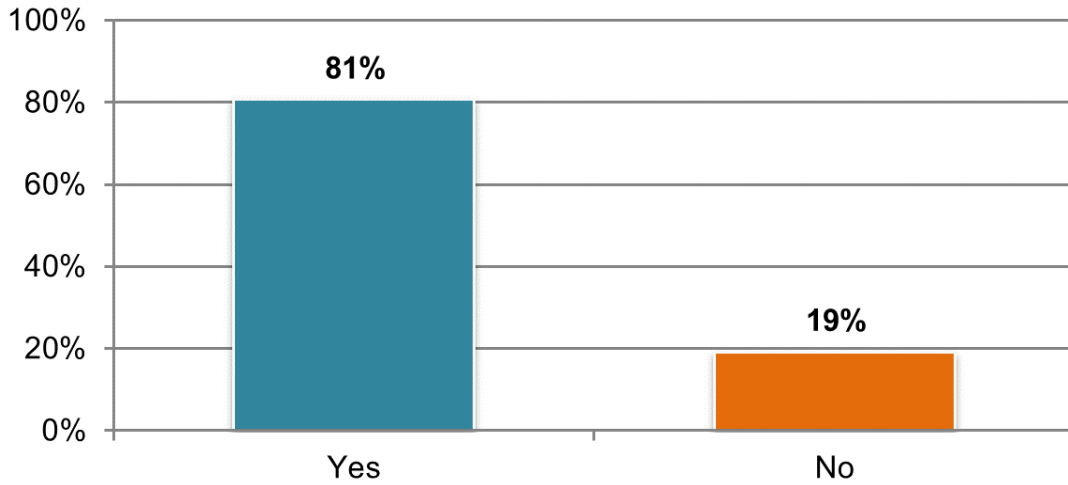


Table Q54. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

State	Yes	No	N
Significantly Above Average			
OK	90%	10%	174
LA	89%	11%	201
Within Average Range			
PA	86%	14%	146
FL	86%	14%	195
NH	84%	16%	140
AZ	84%	16%	118
NC	83%	17%	117
WA	81%	19%	103
GA	79%	21%	143
VA	76%	24%	62
CA**	75%	25%	1,434
DC	75%	25%	114
SC	74%	26%	113
Significantly Below Average			
MD	69%	31%	121
NCI Average	81%	19%	3,181

Respondent Knows How to Report Abuse or Neglect

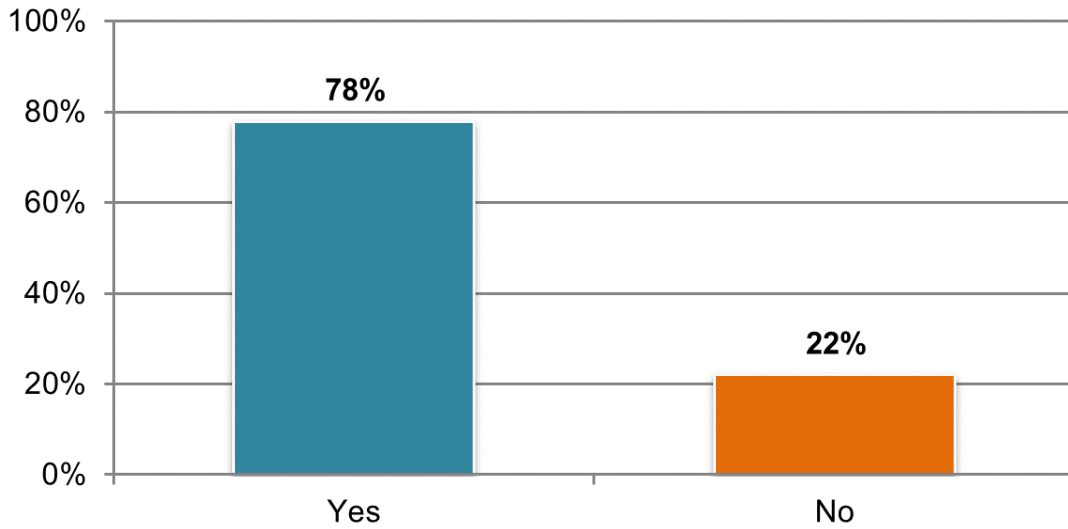


Table Q55. Do you know how to report abuse or neglect?⁶

State	Yes	No	N
Significantly Above Average			
OK	91%	9%	349
FL	88%	12%	383
LA	87%	13%	327
Within Average Range			
NH	83%	17%	354
NC	81%	19%	215
WA	79%	21%	303
DC	79%	21%	230
VA	78%	22%	144
AZ	78%	22%	338
PA	77%	23%	366
SC	75%	25%	244
Significantly Below Average			
GA	70%	30%	363
CA	65%	35%	3,483
MD	61%	39%	348
NCI Average	78%	22%	7,447

⁶‘Don’t know’ responses are included with ‘no’ responses.

Respondent Reported Abuse or Neglect If it Occurred in the Past Year

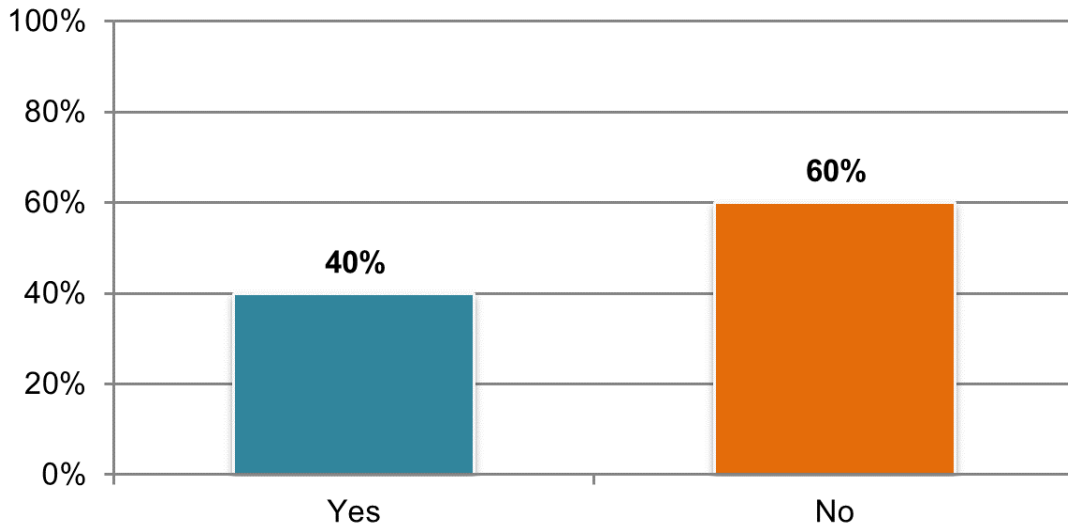


Table Q56. Within the past year, if abuse or neglect occurred, did you report it?

State	Yes	No	N
Within Average Range			
NH	57%	43%	51
MD	52%	48%	56
LA	50%	50%	54
NC	46%	54%	35
SC	44%	56%	57
OK	41%	59%	41
FL	38%	62%	71
AZ	38%	62%	58
PA	36%	64%	66
GA	32%	68%	59
DC	31%	69%	62
WA	27%	73%	59
Significantly Below Average			
CA	26%	74%	826
NCI Average	40%	60%	1,495

Appropriate People Were Responsive to Report of Abuse or Neglect if Reported in the Past Year

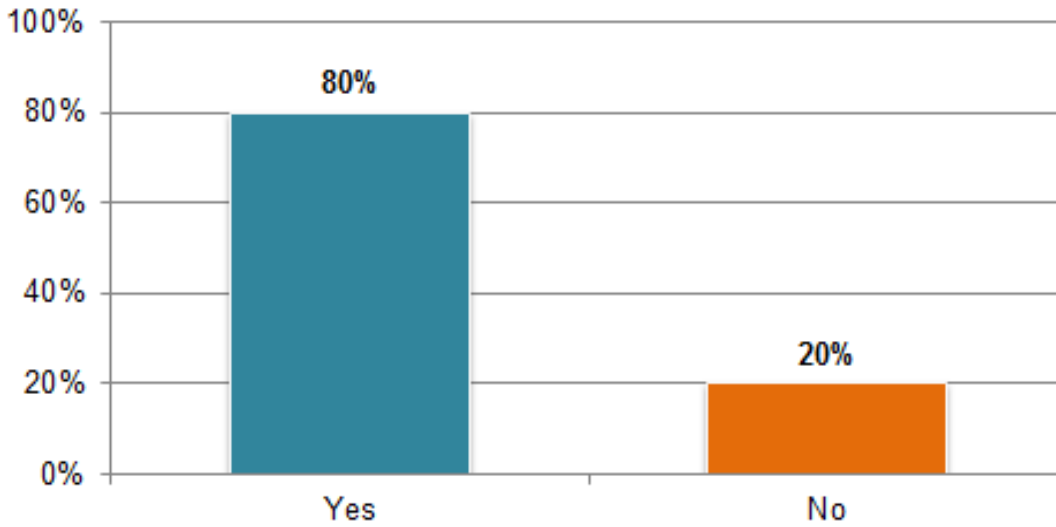


Table Q56a. If you reported abuse or neglect in the past year, were the appropriate people responsive to your report?

State	Yes	No	N
Within Average Range			
CA	83%	17%	168
MD	80%	20%	25
SC	76%	24%	21
NCI Average	80%	20%	214

Family Outcomes

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

Note: State outcomes with fewer than 20 responses were not reported.

Note on California significance: Due to the large N, many of California's data show significant outcomes. For the purposes of this report, the California data are only shown as significant if those outcomes remain significant when controlled for the number of respondents. Where the CA average is denoted with two asterisks (**), an outcome is significant *only* due to the sample size.

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

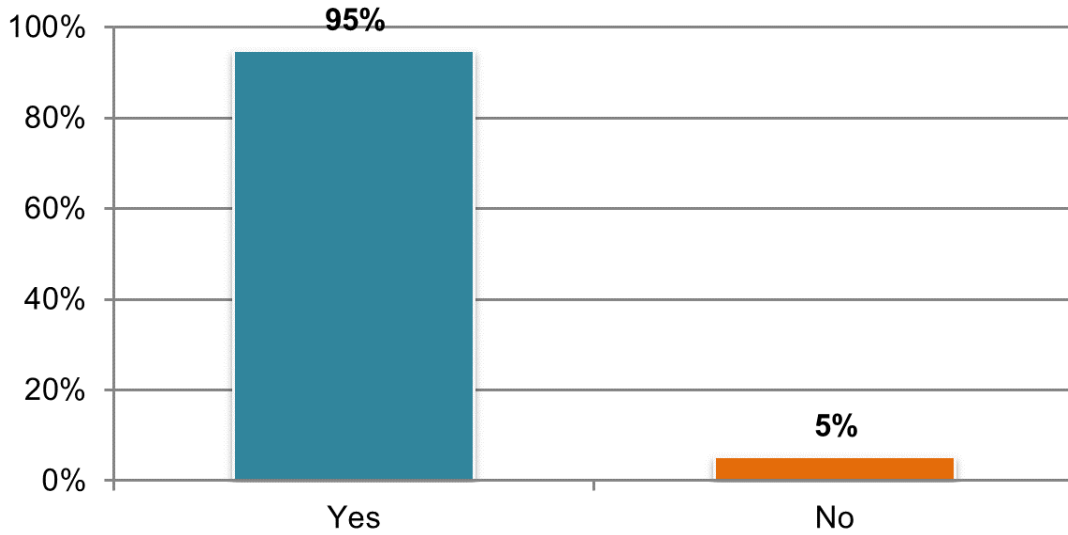


Table Q57. Do you feel that services and supports have made a positive difference in the life of your family?

State	Yes	No	N
Significantly Above Average			
OK	98%	2%	346
NC	98%	2%	209
Within Average Range			
AZ	97%	3%	335
LA	95%	5%	326
MD	95%	5%	330
PA	95%	5%	355
NH	94%	6%	360
VA	94%	6%	137
GA	94%	6%	350
WA	94%	6%	291
FL	94%	6%	361
DC	93%	7%	218
SC	93%	7%	236
Significantly Below Average			
CA **	92%	8%	3,281
NCI Average	95%	5%	7,135

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

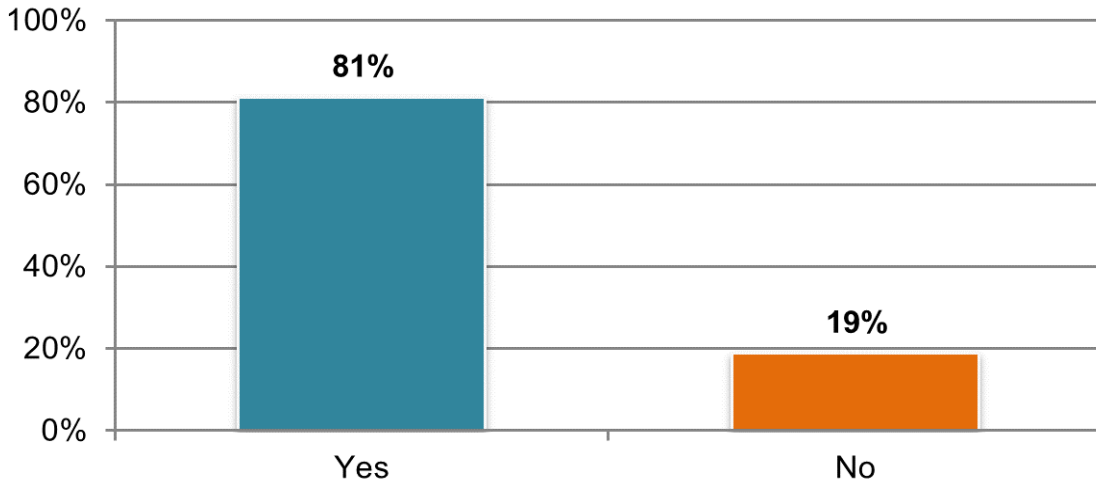


Table Q58. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care?

State	Yes	No	N
Significantly Above Average			
OK	90%	10%	336
Within Average Range			
AZ	86%	14%	316
LA	84%	16%	305
PA	83%	17%	330
VA	82%	18%	129
NH	82%	18%	332
WA	82%	18%	277
MD	81%	19%	314
SC	80%	20%	224
NC	80%	20%	201
FL	79%	21%	353
CA **	78%	22%	3,064
GA	78%	22%	323
DC	73%	27%	184
NCI Average	81%	19%	6,688

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

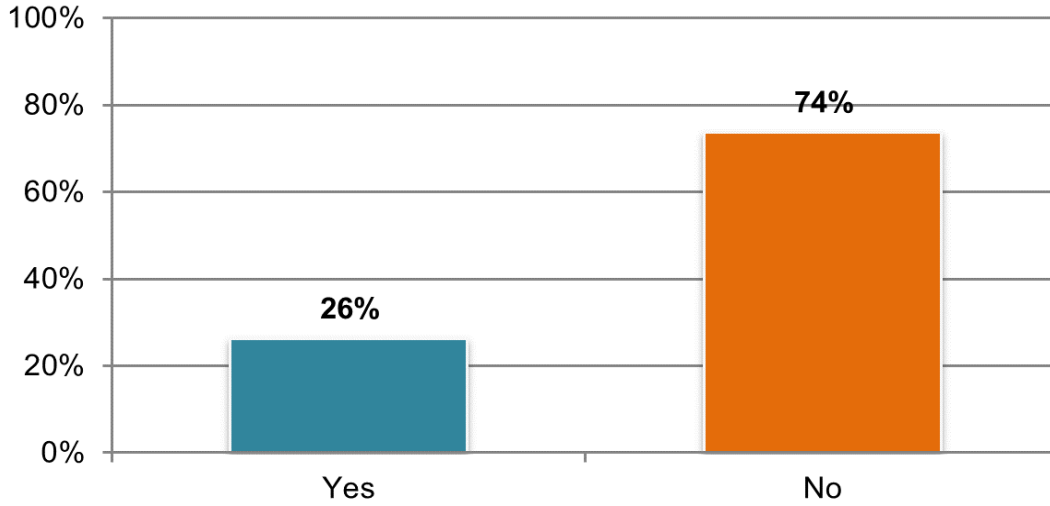


Table Q59. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?⁷

State	Yes	No	N
Significantly Above Average			
FL	59%	41%	344
Within Average Range			
NC	34%	66%	199
CA **	32%	68%	2,985
WA	32%	68%	286
AZ	30%	70%	318
SC	29%	71%	198
VA	23%	77%	124
GA	21%	79%	313
MD	21%	79%	298
LA	20%	80%	303
Significantly Below Average			
OK	19%	81%	319
PA	17%	83%	313
DC	16%	84%	191
NH	14%	86%	337
NCI Average	26%	74%	6,528

⁷The 'yes' response is the less desired response.

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

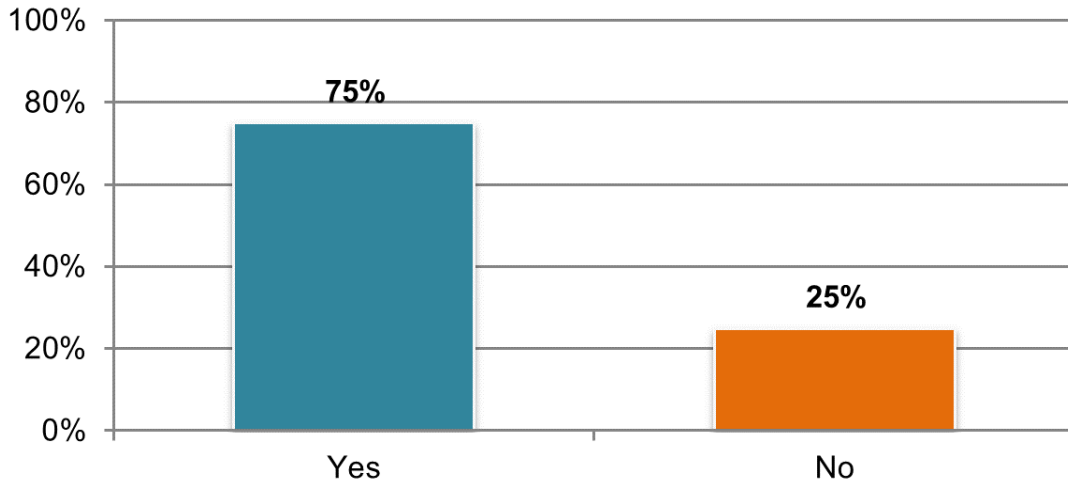


Table Q59a. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?⁸

State	Yes	No	N
Within Average Range			
VA	86%	14%	22
AZ	83%	17%	71
NC	82%	18%	57
FL	81%	19%	169
PA	78%	22%	41
CA	78%	22%	746
SC	77%	23%	43
DC	75%	25%	24
OK	74%	26%	43
WA	74%	26%	77
MD	72%	28%	53
GA	69%	31%	49
LA	69%	31%	48
NH	52%	48%	29
NCI Average	75%	25%	1,472

⁸ The 'yes' response is the less desired response.

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

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

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

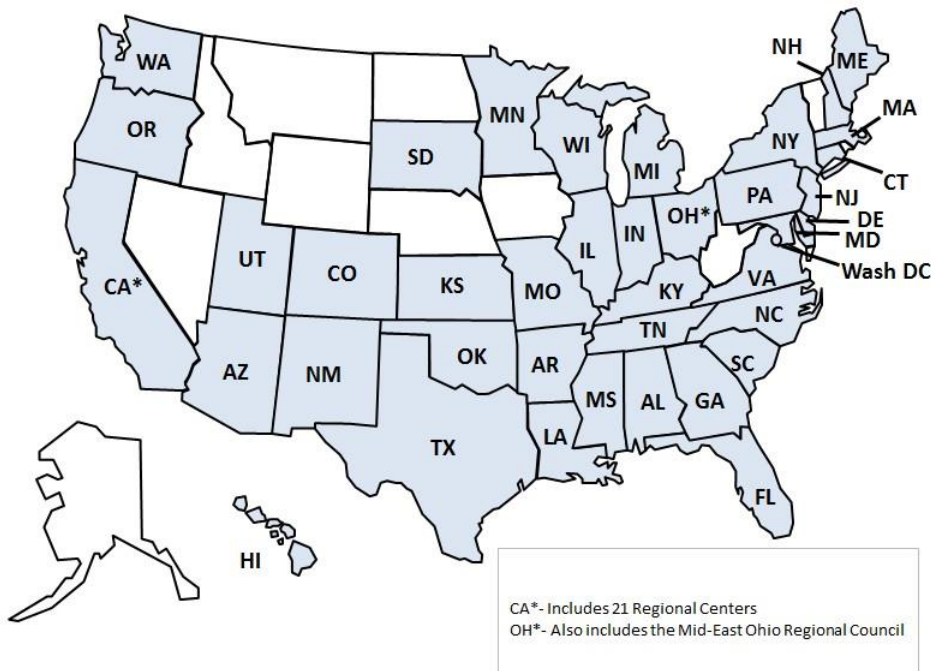
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

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

State Participation

During the 2013-14 data collection cycle, 39 states, the District of Columbia, and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and participating states are highlighted on the map below.

NCI State Participation 2013-14



Sub-Domains and Concern Statements

The following table lists the sub-domains and concern statements that compose 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 & Control	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.
Community Connections	Family members with disabilities use integrated community services and participate in everyday community activities.
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.
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 waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services. Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

Caution and Limitations

This report does not provide benchmarks for acceptable or unacceptable levels of performance. Rather, it is up to each state to decide whether its score or percentage is acceptable. 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 where several states’ results are especially high (considerably above the average level) may indicate that some states are attaining a level of performance that could serve as a guidepost for other states.

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

III. Methodology

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

Sampling & Administration

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

1. Had an adult individual with a developmental disability living at home; and
2. Received at least one direct service or support other than service coordination.

All states mailed out a paper survey to families selected in their sample. 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%.⁹

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, on the following two bases:

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

⁹ See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

Statistical significance testing was conducted on each state’s “yes” or “always” response compared to the NCI average¹⁰; significance is shown at the .01 level and cited in tables. Demographic data and data on services received were not tested for statistically significant differences.

Response Rates

During 2013-2014, 13 states and the District of Columbia administered the Adult Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The table below shows the number of surveys each state mailed, the number of usable surveys returned, and the response rate for each state.

Adult Family Survey: State Response Rates

State	Surveys Mailed ¹¹	Usable Surveys Returned	Response Rate
AZ	1,000	372	37%
CA	16,500	3,772	23%
DC	600	250	42%
FL	1,700	418	25%
GA	1,500	413	28%
LA	1,500	356	24%
MD	1,000	372	37%
NC	1,400	231	17%
NH	1,000	385	39%
OK	1,594	391	25%
PA	861	407	47%
SC	1,200	267	22%
VA	489	152	31%
WA	1,250	337	27%
NCI Average	31,594	8,123	30%

¹⁰ The NCI Average is the sum of all state averages divided by the total number of states.

¹¹ Some numbers may be approximates.