

Family/Guardian Survey

2013-14 Final Report



**NATIONAL CORE
INDICATORS**

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



Human Services
Research Institute

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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

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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 address 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 Family/Guardian Survey is administered to families who have an adult family member (18 years or older) with a developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Family/Guardian Survey on an annual basis. Of the 39 states, the District of Columbia and 22 sub-state entities who participated in NCI during the 2013-14 data collection cycle, 12 states submitted a valid sample of Family/Guardian Survey data to be included in this report. 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 Family/Guardian Survey can be found in the Results section of this report.

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

Just over half of the adults for whom the survey was completed were residing in a group home (54%). Of the remainder, 17% were in their own home or apartment, 10% were in a specialized institutional facility, 8% were in an adult foster care or host home, 5% were in an agency-operated apartment, 1% were in a nursing home, and 5% were in another type of residence not listed.

The average age was 47 years old, and the majority were male (58%). In terms of race, most were white (81%), and 13% were black or African American. In terms of ethnicity, 2% were Hispanic.

For the vast majority of adult family members across states, the primary means of communication was either spoken language (72%) or gestures or body language (22%). Nearly all spoke English as their primary language (96%); 1% spoke Spanish while 3% had another primary language.

The majority of the adult family members required medical care less than once a month (64%); one-quarter (25%) needed medical care at least once a month and 11% required at least weekly medical care.

In terms of behavioral supports, 41% needed some support, 22% needed extensive support, and 37% did not require support. The amount of help individuals needed with daily activities was reported as: 21% none; 21% little; 32% moderate; and 26% complete.

Demographics and Characteristics of Respondents to the Survey

Most survey respondents were either the parent (57%) or sibling (24%) of the adult for whom the survey was completed. About half of respondents had full guardianship or conservatorship (51%) and 13% had limited guardianship or conservatorship; 37% were not the person's guardian or conservator. The majority of survey respondents were 55 or older (61% were 55-74 and 21% were 75 or older); 2% were under 35 years old and 16% were 35-54.

More than half of respondents see the adult family member more than 12 times per year (59%). Among the others, 14% see them 7-12 times a year, 13% see them 4-6 times a year, 10% see them 1-3 times a year, and 4% see them less than once a year.

A little under two-thirds of respondents reported that their family's total household income in the past year was \$50,000 or less (17% reported less than \$15,000, 18% reported \$15,001-\$25,000, and 26% reported \$25,001-\$50,000); 17% earned \$50,001-\$75,000 and the remaining 21% earned more than \$75,000. In terms of past-year expenses for care for the adult family member, families reported paying the following out-of-pocket: 53% paid nothing; 11% paid \$1-\$100; 22% paid \$101-\$1,000; 12% paid \$1,001-\$10,000; and 1% spent more than \$10,000.

Services and Supports Received

Respondents reported that their adult family member received the following state-provided services and supports: residential (93%), day or employment supports (73%), transportation (91%), and other supports (65%). Most respondents (95%) reported that their adult family member receives social security benefits.

Information and Planning

Across states, 46% of respondents reported that they always receive enough information to help plan services for their family member, and half (50%) stated that the information they receive is always easy to understand. More than half (54%) were always kept informed about how their family member was doing.

Of the 95% of respondents who reported that their family member had a service plan, most felt the plan includes all the services and supports the person wants (88%) and needs (86%). Nearly all reported that the individual receives all the services listed in the plan (93%). Just over three-quarters (76%) of respondents discussed how to handle emergencies related to their family member in the last planning meeting.

Access and Delivery of Supports and Services

Nearly two-thirds of respondents (63%) were always able to contact support workers and 58% could always contact the case manager/service coordinator when needed. Approximately two-thirds indicated that services and supports were always available reasonably close to their family member's residence (67%); 56% felt that services and supports always changed when their family member's needs changed.

Just over two-thirds reported that their family member always has access to special equipment or accommodations needed (68%). Just over half (53%) felt that support workers have the right training to meet their family member's needs. Most indicated that their family member's residential and day or employment setting is always a healthy and safe environment (72% and 70%, respectively).

Choice and Control

About half of respondents reported that the agency that provides residential supports always involves their family member in important decisions (52%). Just over one-third indicated that their family member always chooses his or her provider agencies (37%), and 45% reported that their family member can always choose another provider agency if desired. Nineteen percent (19%) reported that their family member always chooses his or her individual support workers, and 31% reported that their family member was always able to choose different support workers.

In terms of money spent on services, 14% of respondents indicated that their family member knows how much money is spent by the ID/DD agency on their behalf. Further, 31% of respondents report that their family member has a say in how ID/DD agency money is spent; of those, 90% say their family member has all the information needed to make these decisions.

Community Connections

Most respondents reported that their family member participates in community activities (93%). More than three-quarters (77%) reported that their family member have friends and relationships with people other than paid staff or family. And most say that their family member has enough support to work or volunteer in the community (77%).

Satisfaction With Services and Supports

Across states, 49% of respondents are always satisfied with the services and supports their family member receives.

Approximately two-thirds of respondents (65%) say they know the process for filing a complaint or grievance against provider agencies or staff; and most are satisfied with the way complaints or grievances are handled (86%). More than three-quarters know how to report abuse or neglect (78%). Of the 52% who reported abuse or neglect in the past year, 86% say the appropriate people were responsive to the report.

Family Outcomes

Nearly all respondents felt that services and supports made a positive difference in their family's life (97%). Most indicated that services and supports have reduced their family's out-of-pocket expenses related to their family member's care (90%). Eighteen percent (18%) reported that their family member's services or supports were reduced, suspended, or terminated in the past year; of these, two-thirds (67%) reported that this change had a negative impact on their family member.

I. Results

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

Survey Development

The Family/Guardian Survey was developed and first utilized in 1999-2000 in response to various states' interest in determining whether families were involved in the lives of family members with developmental disabilities who lived outside the home, whether these families had the support they needed to be involved, and whether they were satisfied with the service system that was intended to meet their family member's needs.

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 Family/Guardian Survey

The Family/Guardian 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 Family/Guardian Survey are presented in this report. Outcome results are presented in six subsections that correspond with the sections of the Family/Guardian 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 the 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 state's sample size 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 while another whose result is further from the NCI Average is not. 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 Residence

State	Specialized Facility for People with ID	Group Home	Agency-Owned Apartment	Independent Home or Apartment	Adult Foster Care or Host Home	Nursing Home	Other	N
CA	13%	45%	3%	30%	2%	2%	5%	3,090
FL	10%	64%	2%	17%	2%	1%	4%	366
GA	9%	55%	4%	15%	13%	1%	4%	322
MD	6%	54%	6%	20%	3%	2%	9%	159
MI	0%	68%	2%	21%	4%	1%	4%	443
NC	10%	72%	2%	3%	6%	1%	6%	172
NH	3%	21%	3%	31%	33%	0%	9%	307
PA	16%	56%	5%	11%	4%	4%	3%	403
SC	13%	71%	10%	3%	1%	0%	1%	234
UT	4%	55%	7%	21%	8%	0%	4%	352
VA	25%	56%	1%	5%	9%	2%	2%	361
WA	12%	34%	10%	30%	6%	1%	8%	394
NCI Average	10%	54%	5%	17%	8%	1%	5%	6,603

Table 2. Family Member's Age

State	Age	N
CA	45	3,063
FL	42	363
GA	47	319
MD	44	166
MI	49	434
NC	45	170
NH	46	299
PA	51	399
SC	50	220
UT	40	356
VA	50	353
WA	50	395
NCI Average	47	6,537

Table 3. Family Member's Gender

State	Male	Female	N
CA	58%	42%	3,123
FL	54%	46%	367
GA	60%	40%	319
MD	57%	43%	163
MI	59%	41%	446
NC	61%	39%	176
NH	62%	38%	305
PA	56%	44%	407
SC	57%	43%	233
UT	58%	42%	363
VA	58%	42%	365
WA	55%	45%	399
NCI Average	58%	42%	6,666

Table 4. 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
CA	2%	5%	5%	0%	75%	1%	6%	11%
FL	1%	1%	13%	1%	77%	0%	1%	7%
GA	1%	1%	24%	1%	72%	0%	1%	0%
MD	1%	3%	28%	0%	65%	1%	4%	1%
MI	1%	1%	8%	0%	89%	0%	1%	1%
NC	2%	1%	22%	0%	74%	0%	2%	1%
NH	1%	0%	1%	0%	96%	0%	2%	0%
PA	0%	1%	5%	0%	91%	0%	0%	1%
SC	0%	0%	22%	0%	76%	0%	0%	1%
UT	3%	1%	2%	1%	87%	0%	4%	4%
VA	1%	1%	22%	1%	75%	0%	1%	1%
WA	4%	1%	1%	1%	93%	1%	2%	1%
NCI Average	1%	1%	13%	0%	81%	0%	2%	2%

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
CA	75%	18%	2%	1%	4%	3,145
FL	73%	21%	2%	1%	4%	369
GA	71%	21%	2%	0%	5%	327
MD	70%	22%	4%	1%	4%	162
MI	71%	25%	1%	0%	3%	425
NC	72%	21%	2%	0%	4%	177
NH	75%	17%	3%	1%	3%	306
PA	70%	24%	1%	0%	5%	392
SC	78%	21%	0%	0%	1%	239
UT	76%	21%	2%	0%	1%	364
VA	51%	41%	2%	1%	5%	370
WA	81%	15%	2%	1%	2%	391
NCI Average	72%	22%	2%	0%	3%	6,667

Table 6. Family Member's Primary Language

State	English	Spanish	Other	N
CA	92%	2%	5%	3,154
FL	93%	3%	4%	376
GA	98%	0%	2%	321
MD	94%	1%	5%	167
MI	96%	0%	4%	445
NC	97%	0%	3%	177
NH	100%	0%	0%	292
PA	97%	0%	3%	381
SC	98%	0%	2%	244
UT	98%	0%	2%	363
VA	90%	0%	10%	372
WA	98%	0%	2%	392
NCI Average	96%	1%	3%	6,684

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
CA	59%	32%	2%	6%	1%	2,912
FL	69%	28%	2%	1%	1%	347
GA	63%	34%	2%	1%	0%	301
MD	63%	28%	3%	5%	1%	158
MI	76%	19%	5%	0%	0%	409
NC	75%	21%	2%	1%	1%	169
NH	57%	34%	2%	5%	3%	280
PA	67%	30%	2%	1%	0%	354
SC	78%	19%	3%	0%	0%	220
UT	64%	33%	1%	1%	1%	357
VA	81%	17%	2%	0%	1%	336
WA	57%	38%	2%	2%	1%	376
NCI Average	67%	28%	2%	2%	1%	6,219

Table 8. Frequency of Medical Care Needed for Family Member

State	Less Frequently Than Once/Month	At Least Once/Month but Not Once/Week	Once/Week or More Frequently	N
CA	67%	24%	9%	2,926
FL	59%	29%	12%	355
GA	67%	24%	9%	306
MD	62%	29%	9%	159
MI	62%	29%	9%	440
NC	72%	24%	5%	172
NH	67%	22%	10%	292
PA	59%	24%	17%	369
SC	72%	19%	10%	215
UT	67%	27%	6%	355
VA	51%	25%	24%	353
WA	66%	26%	8%	376
NCI Average	64%	25%	11%	6,318

Table 9. Amount of Behavioral Support Needed for Family Member

State	No Support Needed	Some Support Needed	Extensive Support Needed	N
CA	44%	40%	16%	3,060
FL	33%	36%	31%	374
GA	40%	36%	24%	316
MD	46%	37%	18%	167
MI	35%	46%	19%	443
NC	25%	50%	25%	173
NH	43%	40%	17%	295
PA	40%	37%	23%	391
SC	40%	45%	15%	239
UT	29%	43%	28%	359
VA	29%	39%	31%	370
WA	35%	45%	19%	391
NCI Average	37%	41%	22%	6,578

Table 10. Amount of Help Needed for Family Member's Daily Activities

State	None	Little	Moderate	Complete	N
CA	30%	22%	26%	22%	3,125
FL	18%	20%	33%	29%	367
GA	25%	20%	31%	24%	324
MD	30%	21%	20%	29%	168
MI	16%	17%	35%	32%	431
NC	12%	20%	44%	23%	177
NH	20%	26%	30%	24%	305
PA	21%	19%	27%	33%	406
SC	33%	22%	31%	14%	238
UT	20%	25%	33%	22%	359
VA	9%	17%	30%	44%	378
WA	14%	25%	38%	23%	394
NCI Average	21%	21%	32%	26%	6,672

Table 11. Family Member's Typical Day Activity³

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
CA	43%	14%	7%	6%	12%	11%	8%	3%	5%	17%
FL	39%	12%	11%	3%	6%	13%	4%	3%	3%	22%
GA	48%	13%	4%	5%	10%	12%	4%	1%	3%	25%
MD	39%	15%	11%	7%	16%	10%	6%	2%	4%	17%
MI	31%	10%	14%	7%	12%	23%	12%	3%	7%	18%
NC	44%	13%	19%	7%	9%	8%	2%	1%	2%	22%
NH	37%	10%	4%	13%	13%	24%	7%	3%	4%	20%
PA	32%	14%	7%	5%	9%	11%	7%	4%	3%	24%
SC	34%	21%	13%	3%	9%	3%	3%	0%	3%	22%
UT	38%	21%	8%	4%	15%	15%	5%	2%	4%	16%
VA	36%	9%	8%	3%	7%	13%	7%	2%	4%	28%
WA	15%	6%	11%	13%	19%	35%	19%	5%	11%	23%
NCI Average	36%	13%	10%	6%	11%	15%	7%	2%	5%	21%

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

Respondents

This section provides demographic information about the respondent.

Table 12. Respondent’s Age

State	Under 35	35-54	55-74	75 or Older	N
CA	2%	14%	55%	29%	3,114
FL	1%	19%	61%	19%	362
GA	2%	16%	61%	21%	327
MD	2%	14%	59%	24%	167
MI	3%	17%	65%	15%	446
NC	3%	24%	59%	15%	178
NH	1%	18%	62%	19%	300
PA	2%	12%	62%	24%	402
SC	3%	11%	58%	28%	240
UT	3%	20%	64%	13%	346
VA	2%	17%	55%	26%	370
WA	2%	14%	67%	18%	393
NCI Average	2%	16%	61%	21%	6,645

Table 13. Respondent’s Relationship to Family Member

State	Parent	Sibling	Spouse	Public Guardian	Private Guardian	Other	N
CA	78%	14%	0%	2%	1%	6%	3,144
FL	60%	18%	0%	5%	9%	8%	374
GA	56%	27%	2%	2%	3%	10%	319
MD	68%	20%	0%	1%	1%	10%	167
MI	40%	20%	0%	23%	8%	8%	370
NC	54%	20%	0%	8%	8%	10%	178
NH	57%	30%	0%	2%	7%	4%	307
PA	52%	38%	0%	2%	1%	6%	406
SC	52%	28%	0%	3%	2%	16%	240
UT	66%	15%	0%	10%	2%	6%	361
VA	53%	30%	1%	6%	2%	9%	376
WA	45%	29%	0%	7%	8%	11%	401
NCI Average	57%	24%	0%	6%	4%	9%	6,643

Table 14. Respondent Is Family Member’s Legal Guardian or Conservator

State	Full Guardianship or Conservatorship	Limited Guardianship or Conservatorship	No	N
CA	30%	16%	54%	3,051
FL	62%	14%	25%	371
GA	33%	8%	58%	318
MD	31%	9%	60%	159
MI	69%	19%	12%	447
NC	79%	13%	8%	173
NH	80%	8%	12%	305
PA	38%	8%	54%	378
SC	37%	10%	53%	221
UT	46%	19%	34%	354
VA	52%	10%	37%	361
WA	50%	17%	33%	398
NCI Average	51%	13%	37%	6,536

Table 15. Number of Times Respondent Sees Family Member in a Year

State	Less Than Once	1-3 Times	4-6 Times	7-12 Times	More Than 12 Times	N
CA	6%	12%	10%	11%	62%	3,107
FL	4%	8%	12%	14%	63%	374
GA	5%	11%	12%	13%	59%	323
MD	2%	9%	5%	10%	73%	166
MI	2%	9%	24%	13%	52%	446
NC	1%	4%	17%	20%	57%	178
NH	3%	11%	15%	11%	61%	308
PA	7%	13%	13%	13%	53%	408
SC	2%	6%	13%	13%	66%	237
UT	1%	9%	11%	14%	65%	358
VA	7%	15%	17%	16%	45%	374
WA	7%	11%	10%	17%	55%	397
NCI Average	4%	10%	13%	14%	59%	6,676

Table 16. 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
CA	6%	17%	3%	29%	45%	3,101
FL	6%	23%	5%	22%	44%	372
GA	11%	29%	10%	20%	30%	324
MD	5%	20%	2%	28%	45%	164
MI	6%	24%	3%	23%	45%	433
NC	7%	20%	5%	20%	47%	176
NH	4%	20%	5%	22%	50%	298
PA	6%	36%	5%	18%	35%	393
SC	9%	26%	4%	21%	40%	236
UT	4%	18%	5%	29%	45%	360
VA	13%	24%	2%	20%	40%	370
WA	3%	18%	7%	29%	43%	397
NCI Average	7%	23%	5%	23%	42%	6,624

Table 17. Total Taxable Family Income of Wage Earners in the Household in the Past Year

State	Below \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	N
CA	18%	17%	25%	15%	25%	2,435
FL	18%	20%	29%	14%	18%	283
GA	24%	25%	24%	11%	15%	245
MD	11%	11%	25%	22%	31%	134
MI	16%	15%	30%	23%	16%	381
NC	14%	20%	28%	17%	22%	144
NH	15%	15%	30%	14%	24%	214
PA	16%	17%	30%	17%	20%	294
SC	23%	24%	19%	18%	16%	188
UT	14%	14%	27%	22%	23%	293
VA	23%	18%	23%	19%	19%	297
WA	17%	19%	27%	18%	19%	306
NCI Average	17%	18%	26%	17%	21%	5,214

Table 18. 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
CA	46%	12%	26%	14%	2%	2,906
FL	41%	11%	28%	17%	3%	346
GA	53%	13%	23%	10%	1%	311
MD	46%	7%	24%	20%	3%	156
MI	61%	15%	15%	9%	1%	433
NC	51%	14%	24%	10%	1%	168
NH	45%	9%	25%	20%	2%	280
PA	61%	8%	19%	11%	1%	365
SC	60%	9%	22%	8%	0%	223
UT	50%	13%	24%	11%	1%	334
VA	69%	8%	17%	7%	0%	359
WA	57%	12%	21%	9%	0%	369
NCI Average	53%	11%	22%	12%	1%	6,250

Services and Supports Received

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

Table 19. Services and Supports Received From ID/DD Agency

State	Residential Supports	Day or Employment Supports	Transportation	Other	Social Security Benefits
CA	87%	75%	82%	53%	91%
FL	96%	71%	92%	68%	94%
GA	93%	77%	92%	60%	97%
MD	81%	80%	88%	61%	92%
MI	95%	62%	95%	73%	98%
NC	96%	90%	97%	72%	98%
NH	95%	64%	88%	54%	95%
PA	94%	67%	86%	68%	94%
SC	97%	87%	97%	69%	97%
UT	93%	83%	93%	70%	96%
VA	96%	66%	94%	73%	95%
WA	93%	55%	87%	59%	95%
NCI Average	93%	73%	91%	65%	95%

Family/Guardian 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: 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

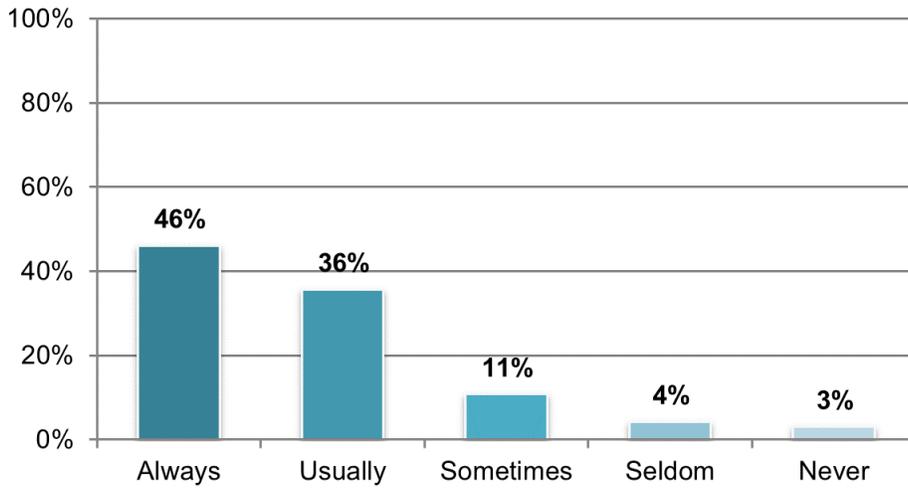


Table Q1. Do you get enough information to help you participate in planning services for your family member?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	59%	26%	10%	3%	2%	345
MI	58%	32%	7%	3%	1%	440
Within Average Range						
NC	51%	39%	7%	2%	1%	174
MD	49%	34%	11%	3%	4%	158
WA	48%	37%	8%	5%	1%	382
FL	47%	37%	10%	3%	3%	362
SC	44%	33%	14%	6%	4%	228
NH	44%	45%	9%	2%	1%	299
UT	43%	34%	14%	6%	3%	356
PA	40%	40%	12%	5%	4%	369
Significantly Below Average						
CA	39%	32%	13%	9%	7%	2,855
GA	34%	39%	15%	5%	6%	310
NCI Average	46%	36%	11%	4%	3%	6,278

Information About Services and Supports Is Easy to Understand

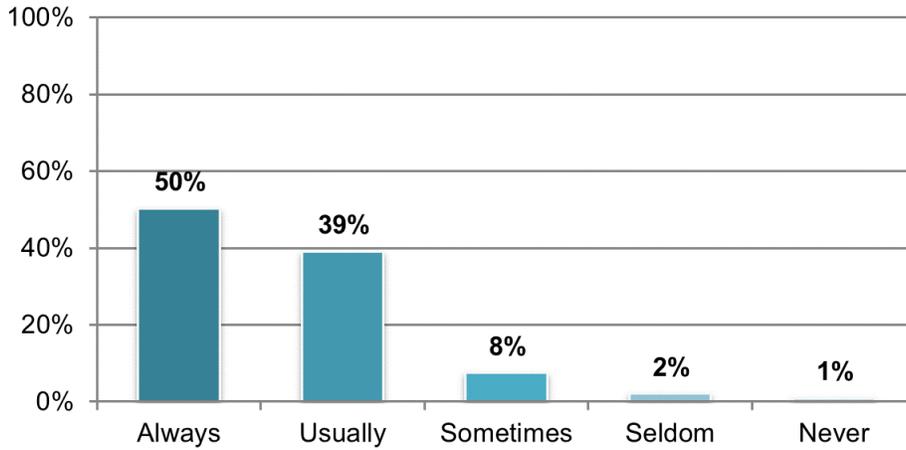


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	58%	34%	7%	0%	1%	352
MI	58%	35%	5%	1%	0%	439
Within Average Range						
SC	55%	35%	5%	3%	2%	225
CA	52%	35%	8%	3%	2%	2,740
NC	51%	40%	8%		1%	175
WA	51%	39%	7%	3%	0%	381
MD	50%	40%	9%	1%	0%	153
UT	49%	39%	7%	3%	2%	348
FL	48%	38%	10%	4%	0%	356
NH	47%	47%	5%	1%	0%	300
PA	46%	42%	9%	1%	2%	372
Significantly Below Average						
GA	39%	46%	10%	4%	2%	300
NCI Average	50%	39%	8%	2%	1%	6,141

Kept Informed About How Family Member Is Doing

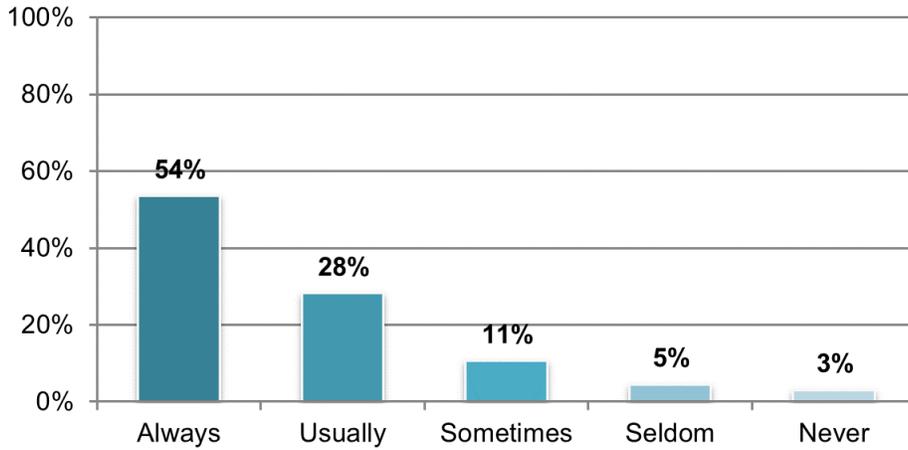


Table Q3. Are you kept informed about how your family member is doing?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	65%	24%	8%	2%	1%	366
MI	61%	25%	9%	3%	2%	446
Within Average Range						
NC	60%	26%	10%	3%	1%	175
FL	60%	25%	9%	4%	2%	364
PA	56%	27%	11%	4%	2%	386
WA	53%	32%	7%	5%	3%	390
NH	53%	36%	7%	2%	2%	300
SC	49%	25%	14%	7%	5%	232
GA	47%	27%	15%	7%	3%	322
MD	45%	31%	13%	4%	7%	162
Significantly Below Average						
CA	47%	26%	12%	8%	7%	2,952
UT	46%	33%	14%	5%	3%	354
NCI Average	54%	28%	11%	5%	3%	6,449

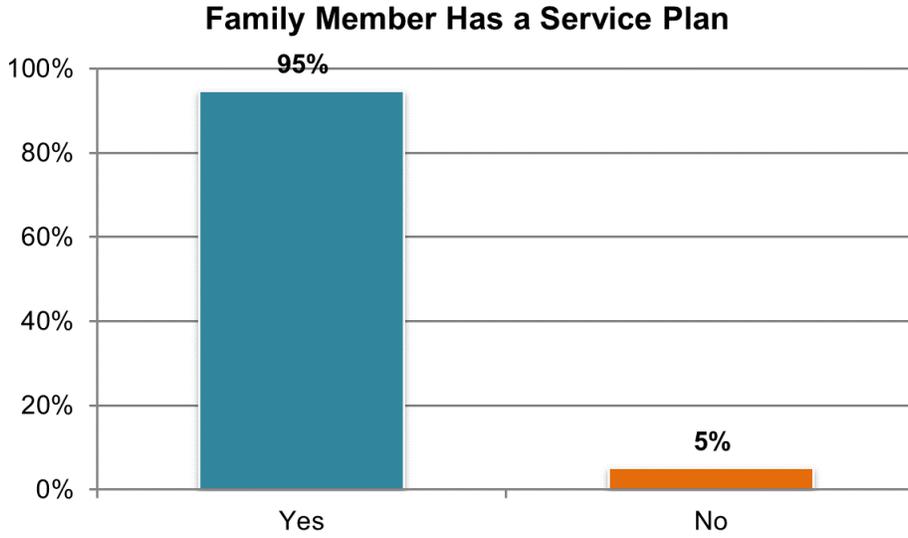


Table Q4. Does your family member have a service plan?

State	Yes	No	N
Significantly Above Average			
NC	99%	1%	155
MD	99%	1%	150
NH	98%	2%	275
Within Average Range			
FL	97%	3%	347
MI	96%	4%	396
WA	96%	4%	320
PA	95%	5%	336
UT	94%	6%	296
SC	92%	8%	178
VA	91%	9%	286
GA	90%	10%	226
Significantly Below Average			
CA	91%	9%	2364
NCI Average	95%	5%	5,329

Family Member Helped Develop Service Plan

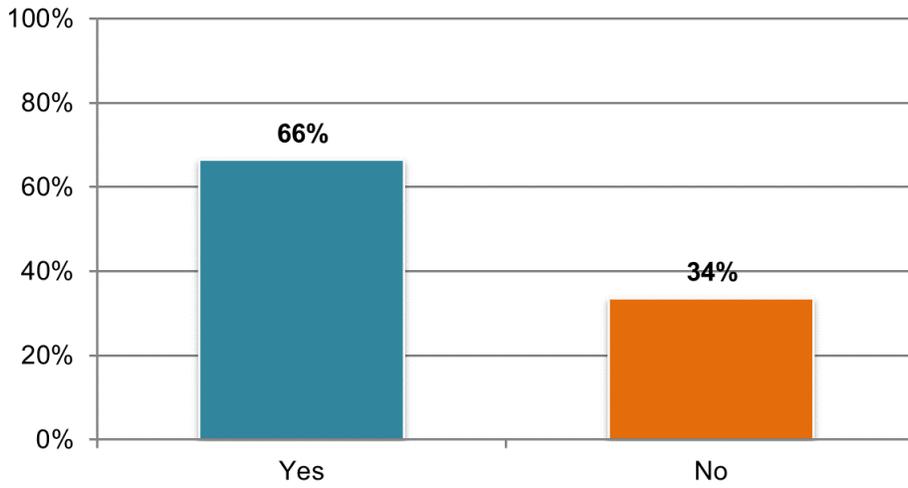


Table Q5. Did your family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
UT	75%	25%	252
Within Average Range			
MI	72%	28%	344
GA	71%	29%	182
SC	70%	30%	139
MD	70%	30%	125
CA	68%	32%	1,808
WA	68%	32%	268
NH	68%	32%	234
FL	65%	35%	289
PA	60%	40%	258
NC	58%	42%	136
Significantly Below Average			
VA	53%	47%	231
NCI Average	66%	34%	4,266

Respondent or Another Family Member Helped Develop Service Plan

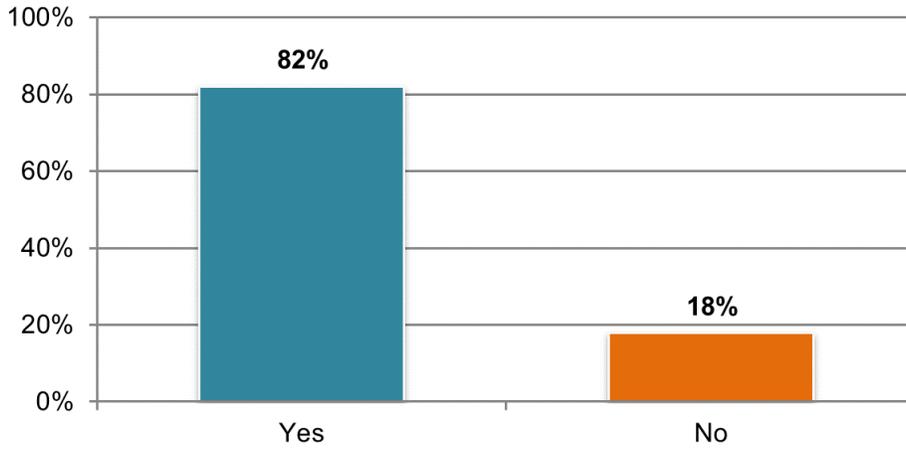


Table Q6. Did you or another family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
NH	93%	7%	257
NC	91%	9%	147
UT	91%	9%	263
Within Average Range			
MD	88%	12%	138
MI	85%	15%	367
GA	84%	16%	192
FL	83%	17%	313
WA	82%	18%	282
VA	76%	24%	246
SC	76%	24%	156
Significantly Below Average			
CA	70%	30%	1,969
PA	67%	33%	291
NCI Average	82%	18%	4,621

Service Plan Includes All the Services and Supports Family Member Wants

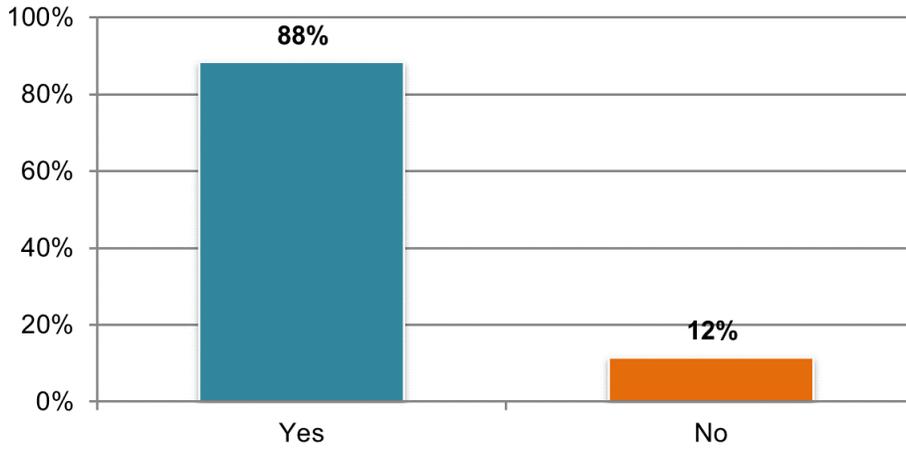


Table Q7. Does the plan include all the services and supports your family member wants?

State	Yes	No	N
Significantly Above Average			
VA	94%	6%	213
MI	93%	7%	350
Within Average Range			
PA	92%	8%	247
UT	91%	9%	239
WA	90%	10%	261
SC	89%	11%	132
GA	89%	11%	169
NC	88%	12%	130
NH	87%	13%	238
CA	86%	14%	1,710
MD	81%	19%	115
Significantly Below Average			
FL	80%	20%	288
NCI Average	88%	12%	4,092

Service Plan Includes All the Services and Supports Family Member Needs

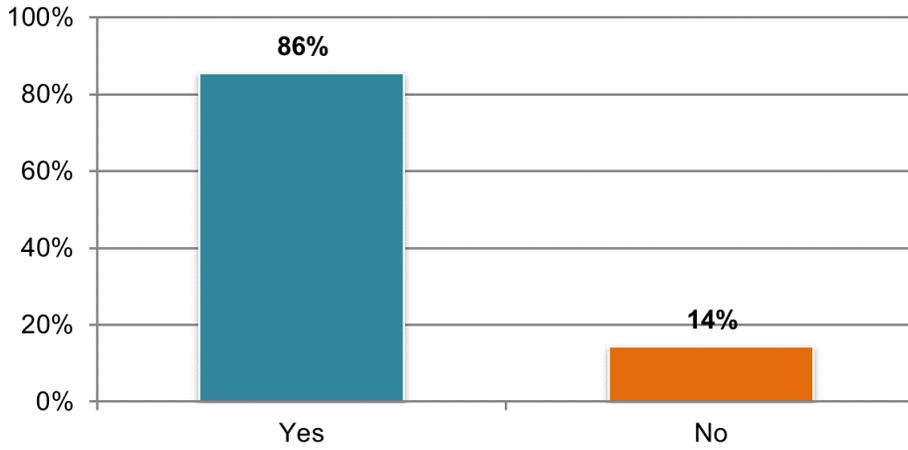


Table Q8. Does the plan include all the services and supports your family member needs?

State	Yes	No	N
Significantly Above Average			
MI	91%	9%	347
VA	90%	10%	241
Within Average Range			
SC	91%	9%	137
PA	90%	10%	270
WA	90%	10%	267
NC	89%	11%	143
UT	86%	14%	246
NH	84%	16%	245
CA **	83%	17%	1,772
GA	82%	18%	177
Significantly Below Average			
FL	78%	22%	290
MD	75%	25%	123
NCI Average	86%	14%	4,258

Family Member Receives All Services Listed in Service Plan

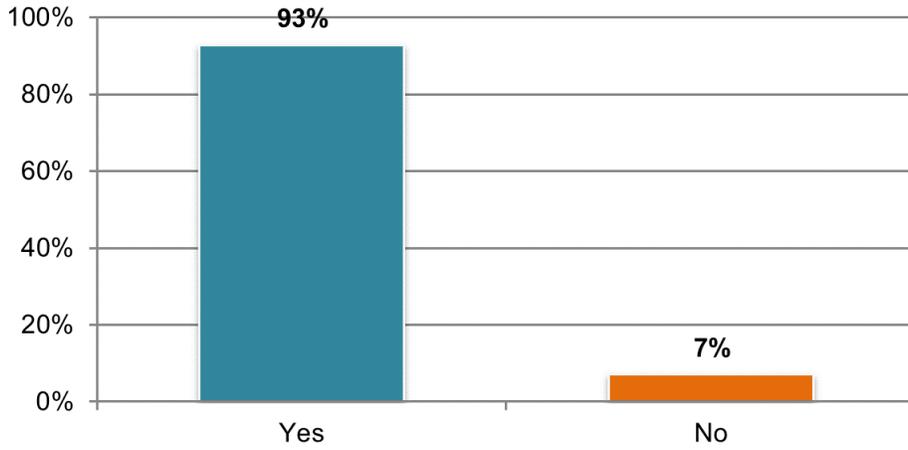


Table Q9. Does your family member receive all of the services listed in the plan?

State	Yes	No	N
Significantly Above Average			
PA	97%	3%	246
Within Average Range			
NC	95%	5%	140
WA	95%	5%	251
MI	95%	5%	345
VA	94%	6%	232
SC	93%	7%	127
CA	93%	7%	1,627
FL	93%	7%	163
UT	92%	8%	235
NH	92%	8%	240
GA	91%	9%	140
MD	86%	14%	120
NCI Average	93%	7%	3,866

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

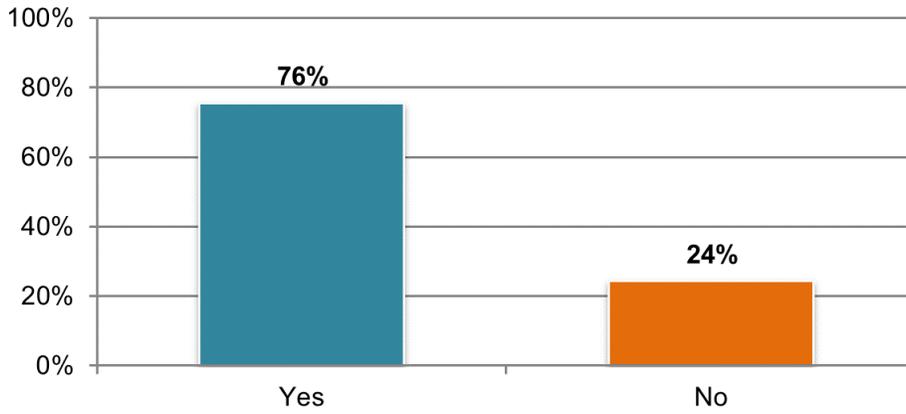


Table Q10. Did you discuss how to handle emergencies related to your family member at the last service planning meeting?

State	Yes	No	N
Significantly Above Average			
WA	84%	16%	262
Within Average Range			
NC	82%	18%	147
FL	81%	19%	171
UT	80%	20%	246
MI	79%	21%	349
SC	77%	23%	136
VA	77%	23%	232
MD	75%	25%	130
NH	74%	26%	225
PA	72%	28%	259
GA	68%	33%	160
Significantly Below Average			
CA	60%	40%	1,719
NCI Average	76%	24%	4,036

Respondent or Family Member Has Received Information About Family Member's Rights

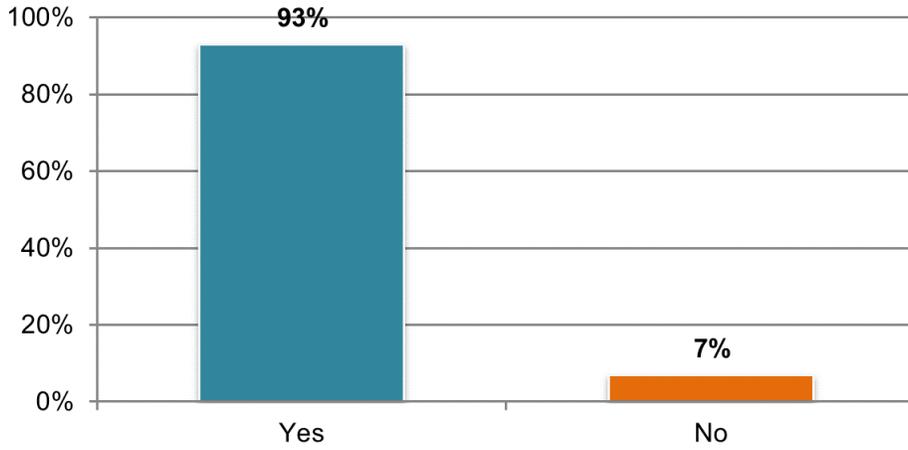


Table Q11. Have you or your family member received information about his/her rights?

State	Yes	No	N
Significantly Above Average			
NH	98%	2%	257
MI	98%	2%	380
VA	97%	3%	333
Within Average Range			
NC	96%	4%	170
WA	96%	4%	339
FL	95%	5%	350
UT	93%	7%	309
PA	92%	8%	335
MD	90%	10%	143
SC	87%	13%	207
Significantly Below Average			
CA	88%	12%	2,464
GA	87%	13%	273
NCI Average	93%	7%	5,560

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 Is Able to Contact Support Workers When Needed

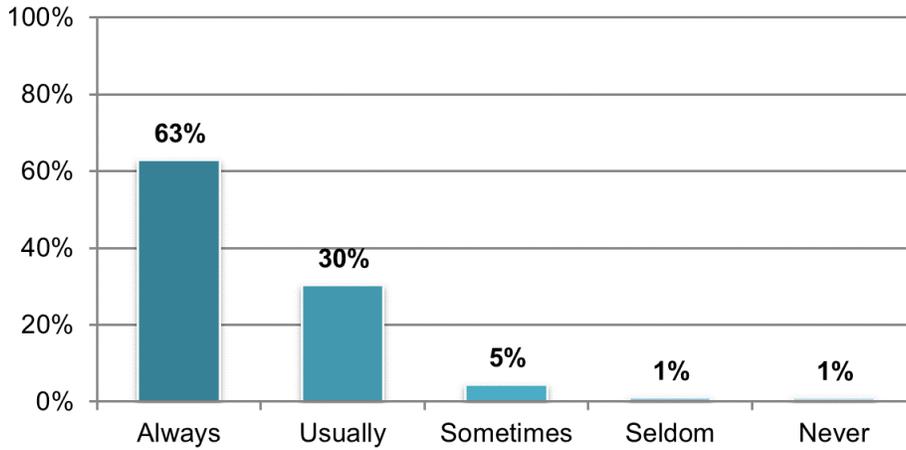


Table Q12. Are you able to contact your family member’s support workers when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	71%	24%	4%	1%	0%	372
Within Average Range						
NC	67%	30%	2%	0%	0%	175
FL	67%	26%	5%	1%	1%	371
WA	66%	29%	3%	1%	1%	388
MI	66%	30%	4%	0%	0%	435
PA	65%	29%	4%	0%	1%	391
SC	62%	31%	4%	3%	1%	235
NH	61%	34%	4%	1%	0%	301
UT	58%	35%	4%	1%	1%	361
CA **	58%	29%	7%	2%	3%	2,960
GA	57%	34%	5%	2%	2%	320
MD	57%	33%	8%	0%	3%	169
NCI Average	63%	30%	5%	1%	1%	6,478

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

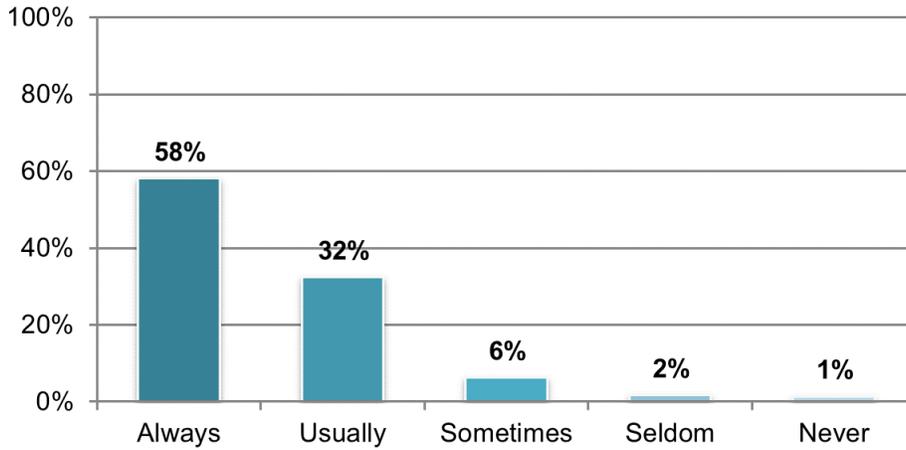


Table Q13. Are you able to contact your family member’s case manager/service coordinator when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	71%	22%	5%	1%	1%	364
VA	67%	27%	3%	1%	1%	373
Within Average Range						
NC	61%	33%	6%	0%	0%	174
MI	61%	32%	6%	0%	1%	438
UT	60%	31%	5%	2%	2%	353
PA	59%	34%	4%	1%	1%	377
NH	57%	35%	6%	1%	0%	301
SC	55%	34%	8%	2%	1%	236
WA	54%	37%	5%	3%	1%	389
MD	52%	34%	11%	2%	2%	161
Significantly Below Average						
CA	51%	31%	10%	4%	4%	2,883
GA	49%	38%	8%	4%	2%	309
NCI Average	58%	32%	6%	2%	1%	6,358

Services and Supports Are Available Reasonably Close to Family Member's Home

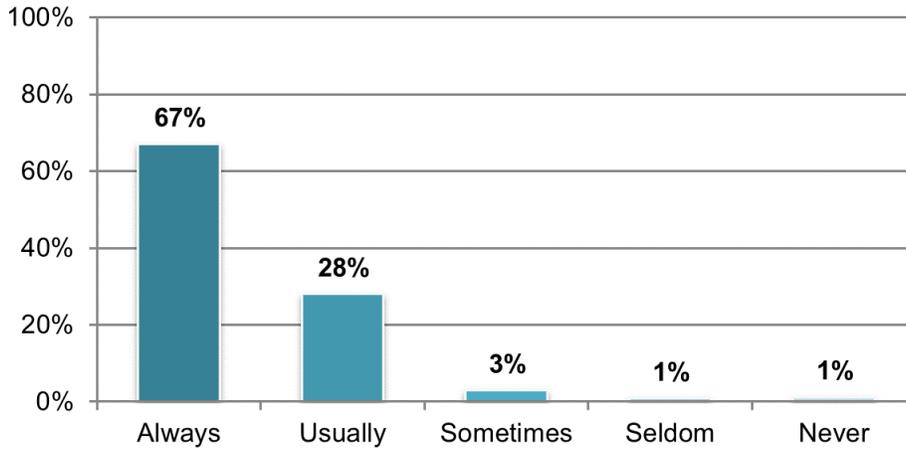


Table Q14. Are services and supports available within a reasonable distance from your family member's home?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
MI	74%	23%	2%	0%	0%	426
Within Average Range						
VA	73%	24%	2%	0%	1%	340
SC	72%	23%	3%	0%	1%	208
NH	71%	26%	1%	1%	0%	289
NC	68%	29%	2%	0%	1%	170
UT	68%	28%	2%	1%	1%	330
FL	67%	29%	2%	1%	1%	337
MD	66%	28%	3%	1%	3%	153
PA	64%	31%	4%	1%	1%	359
WA	63%	30%	4%	1%	2%	372
Significantly Below Average						
CA	61%	31%	5%	2%	2%	2,665
GA	58%	33%	5%	2%	1%	277
NCI Average	67%	28%	3%	1%	1%	5,926

Services and Supports Change When Family Member's Needs Change

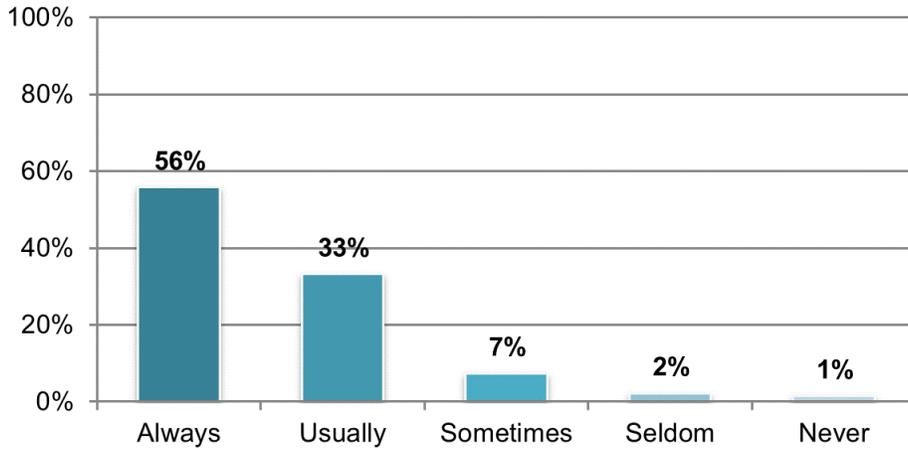


Table Q15. Do the services and supports change when your family member’s needs change?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	66%	28%	4%	1%	1%	313
MI	63%	29%	6%	1%	1%	404
Within Average Range						
NC	60%	34%	4%	1%	1%	164
PA	58%	34%	5%	2%	1%	330
SC	56%	31%	9%	3%	1%	176
FL	56%	31%	10%	2%	2%	331
WA	55%	33%	8%	2%	2%	356
UT	53%	36%	7%	2%	1%	321
MD	52%	34%	7%	3%	4%	134
NH	52%	39%	6%	2%	1%	275
CA **	50%	34%	10%	3%	3%	2,321
Significantly Below Average						
GA	47%	36%	11%	5%	1%	249
NCI Average	56%	33%	7%	2%	1%	5,374

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

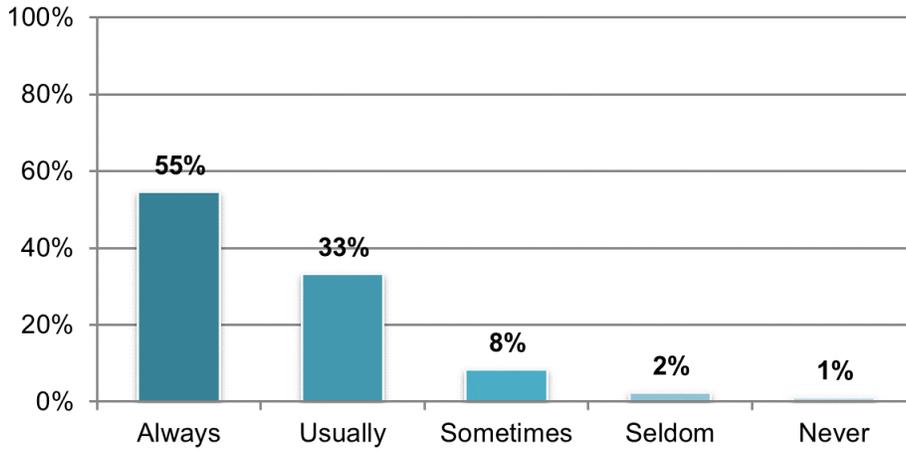


Table Q16. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
MI	66%	23%	9%	2%	0%	137
Within Average Range						
WA	64%	28%	5%	1%	1%	74
VA	61%	31%	7%	1%	0%	172
GA	57%	27%	14%	2%	0%	81
FL	56%	29%	10%	3%	2%	91
SC	56%	36%	8%	0%	0%	50
CA	52%	33%	9%	3%	3%	653
NH	51%	37%	10%	1%	0%	70
UT	51%	36%	10%	2%	1%	84
PA	49%	40%	7%	1%	3%	109
NC	47%	42%	7%	2%	2%	43
MD	45%	38%	6%	9%	2%	53
NCI Average	55%	33%	8%	2%	1%	1,617

Support Workers Communicate Effectively with Family Member in Primary Language (If English)

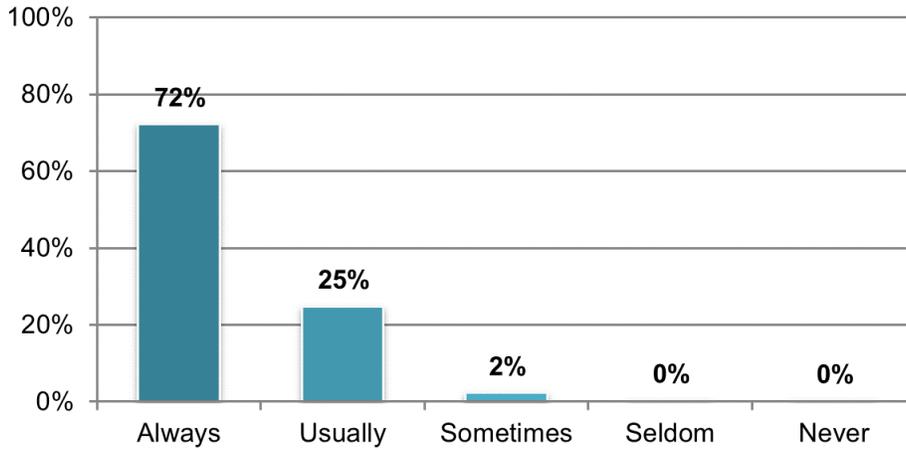


Table Q17. If English is your family member’s first language, do the support workers speak to him/her effectively?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
MI	77%	21%	1%	1%	0%	395
SC	77%	21%	1%	1%	0%	201
VA	76%	22%	2%	0%	0%	308
NC	75%	24%	1%	0%	0%	161
FL	74%	22%	2%	1%	0%	325
PA	74%	23%	3%	0%	0%	342
UT	71%	25%	4%	0%	0%	335
CA	71%	25%	3%	1%	0%	2,509
WA	70%	26%	4%	0%	0%	365
GA	68%	29%	2%	0%	0%	278
NH	67%	30%	3%	0%	0%	276
MD	66%	30%	3%	0%	1%	146
NCI Average	72%	25%	2%	0%	0%	5,641

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

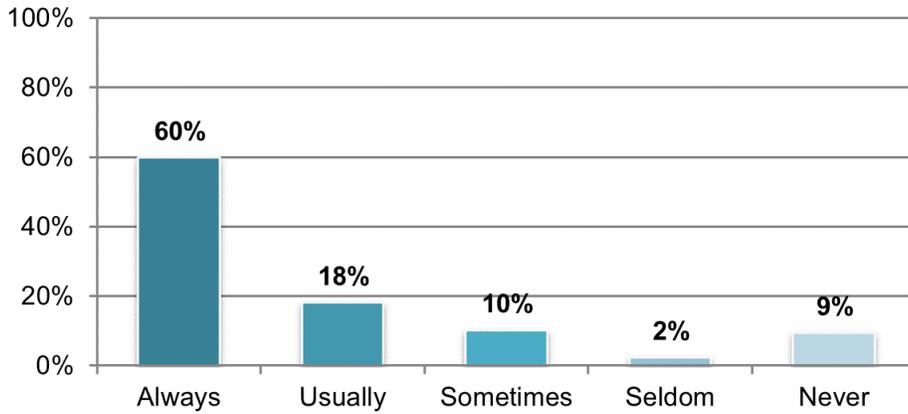


Table Q18. If English is not your family member’s first language, are there support workers or translators who can speak with him/her in the preferred language?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
CA	60%	18%	10%	2%	9%	127
NCI Average	60%	18%	10%	2%	9%	127

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

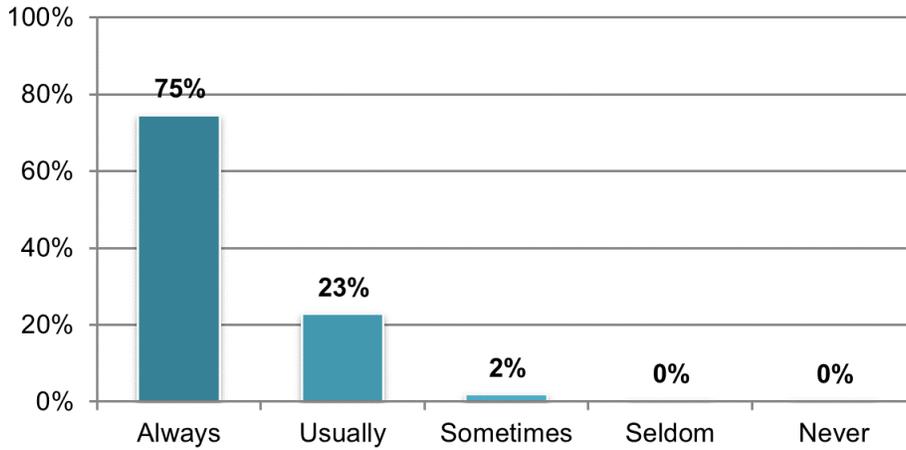


Table Q19. Are services delivered in a way that is respectful to your family member’s culture?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
FL	80%	18%	2%	1%	0%	333
VA	79%	20%	1%	0%	0%	335
NH	78%	20%	2%	0%	0%	262
MI	78%	21%	1%	0%	0%	394
PA	76%	22%	2%	0%	0%	327
NC	76%	24%	0%	0%	0%	165
CA	74%	21%	3%	1%	1%	2,474
SC	74%	22%	3%	1%	0%	209
WA	72%	26%	1%	1%	0%	350
MD	72%	26%	1%	1%	0%	146
GA	69%	26%	4%	0%	0%	273
UT	68%	27%	3%	0%	1%	324
NCI Average	75%	23%	2%	0%	0%	5,592

Family Member Has Access to Special Equipment or Accommodations Needed

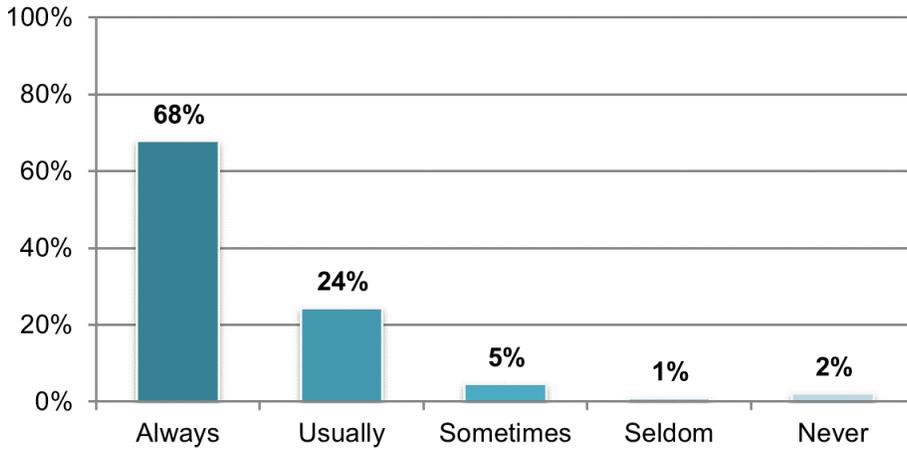


Table Q20. Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	79%	19%	1%	0%	1%	262
Within Average Range						
SC	72%	17%	6%	1%	4%	138
PA	71%	22%	4%	2%	1%	238
MI	70%	22%	6%	0%	2%	264
UT	69%	24%	3%	1%	3%	193
FL	69%	23%	5%	1%	3%	192
NC	66%	25%	8%	0%	1%	97
NH	65%	30%	5%	0%	1%	168
WA	64%	29%	4%	1%	2%	225
GA	64%	30%	2%	1%	3%	165
MD	63%	24%	8%	2%	3%	89
CA **	63%	28%	4%	1%	4%	1,351
NCI Average	68%	24%	5%	1%	2%	3,382

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

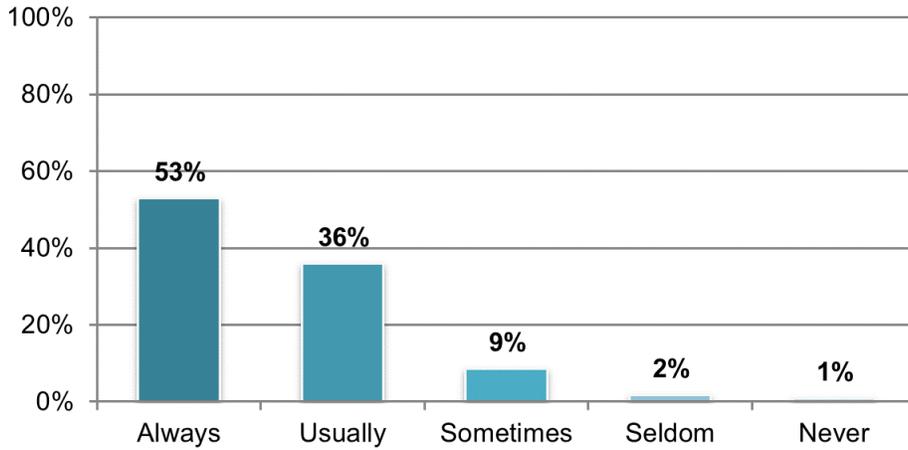


Table Q21. Do the support workers have the right training to meet your family member's needs?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	67%	26%	6%	1%	0%	344
MI	61%	31%	7%	1%	1%	413
Within Average Range						
FL	59%	33%	5%	2%	2%	331
PA	54%	36%	7%	2%	1%	346
NH	54%	38%	7%	1%	0%	279
WA	52%	36%	10%	1%	1%	351
CA	51%	37%	9%	2%	1%	2,465
GA	51%	38%	9%	1%	1%	267
SC	50%	35%	12%	2%	1%	204
NC	48%	42%	9%	1%	1%	164
MD	44%	39%	14%	2%	2%	148
Significantly Below Average						
UT	45%	41%	10%	3%	1%	331
NCI Average	53%	36%	9%	2%	1%	5,643

Family Member's Residential Setting Is a Healthy and Safe Environment

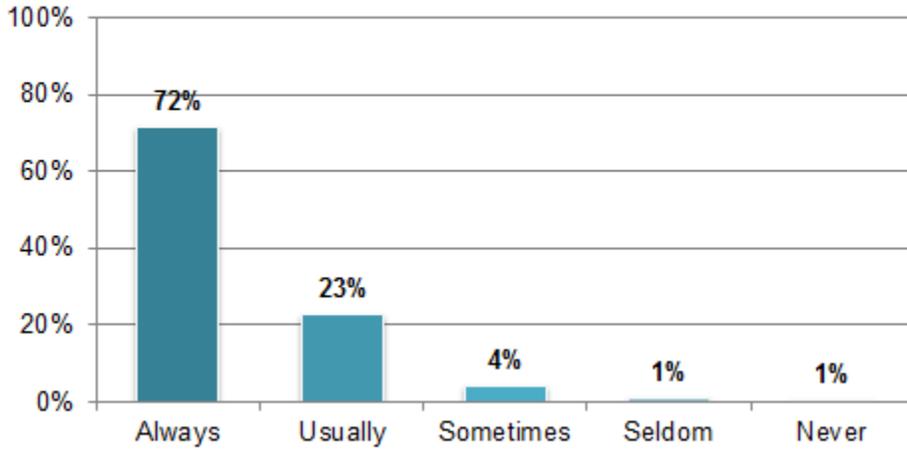


Table Q22. Do you feel that your family member's residential setting is a healthy and safe environment?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	79%	17%	3%	0%	0%	367
Within Average Range						
MI	76%	20%	2%	1%	0%	441
NH	76%	18%	4%	0%	1%	291
FL	73%	20%	5%	1%	0%	369
NC	73%	25%	1%	1%	0%	174
PA	72%	22%	5%	1%	0%	389
CA	70%	23%	4%	1%	1%	2,962
SC	70%	22%	7%	1%	0%	235
GA	68%	26%	4%	1%	1%	299
WA	68%	24%	5%	1%	1%	380
MD	68%	24%	3%	2%	3%	153
Significantly Below Average						
UT	64%	30%	4%	1%	1%	358
NCI Average	72%	23%	4%	1%	1%	6,418

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

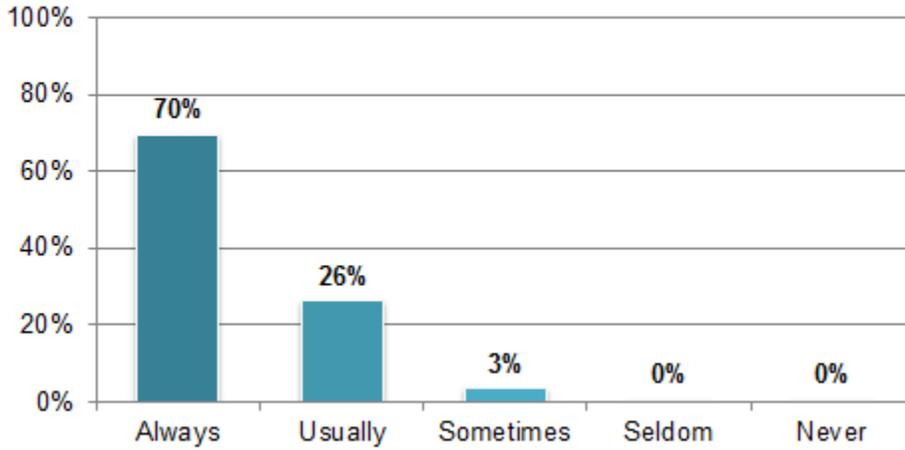


Table Q23. Do you feel that your family member’s day/employment setting is a healthy and safe environment?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	81%	17%	2%	0%	0%	280
MI	76%	22%	1%	1%	0%	334
Within Average Range						
PA	72%	24%	3%	1%	0%	289
NC	69%	27%	3%	0%	0%	154
CA	69%	26%	4%	1%	1%	2,426
GA	69%	29%	2%	0%	0%	258
FL	68%	26%	5%	0%	0%	288
SC	68%	24%	6%	1%	1%	197
MD	67%	29%	4%	0%	0%	131
NH	66%	29%	5%	0%	0%	244
UT	65%	29%	4%	1%	0%	312
WA	65%	32%	1%	1%	1%	270
NCI Average	70%	26%	3%	0%	0%	5,183

Happy with Transition from School Services to State-Funded Services (In Past Year)

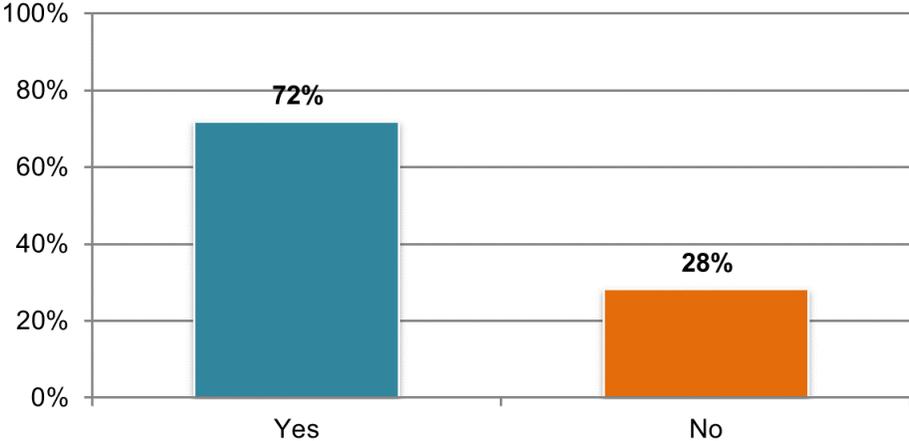


Table Q24. If your family member transitioned from school services to state-funded services in the past year, were you happy with the transition process?

State	Yes	No	N
Within Average Range			
CA	72%	28%	78
NCI Average	72%	28%	78

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.

Residential Service Agency Involves Family Member in Important Decisions

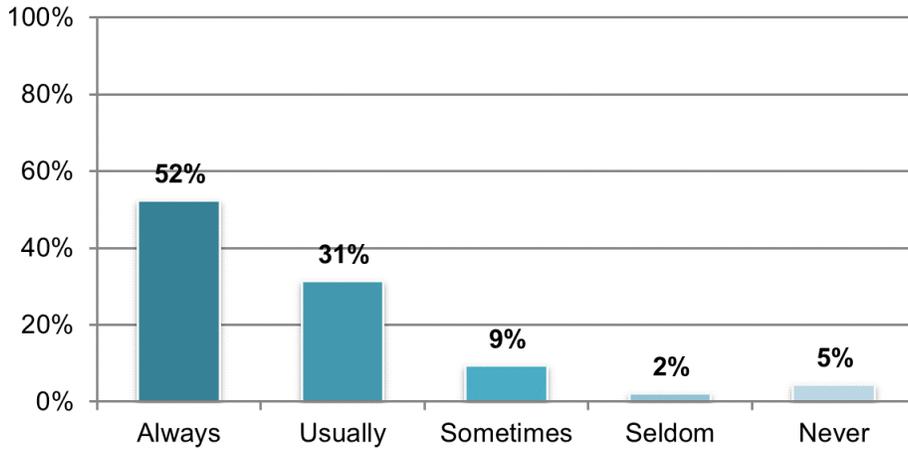


Table Q25. Does the agency providing residential services to your family member involve him/her in important decisions?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
VA	60%	29%	6%	2%	4%	252
SC	57%	26%	10%	5%	2%	175
FL	56%	28%	10%	1%	5%	263
PA	54%	30%	8%	1%	7%	259
MI	53%	34%	9%	1%	3%	350
CA	53%	29%	10%	2%	6%	1,956
WA	53%	28%	13%	2%	4%	309
NH	52%	35%	8%	3%	3%	235
MD	52%	32%	9%	2%	6%	114
NC	49%	38%	8%	1%	3%	145
UT	48%	35%	11%	2%	5%	285
GA	44%	33%	11%	5%	7%	219
NCI Average	52%	31%	9%	2%	5%	4,562

Family Member Chooses Provider Agencies

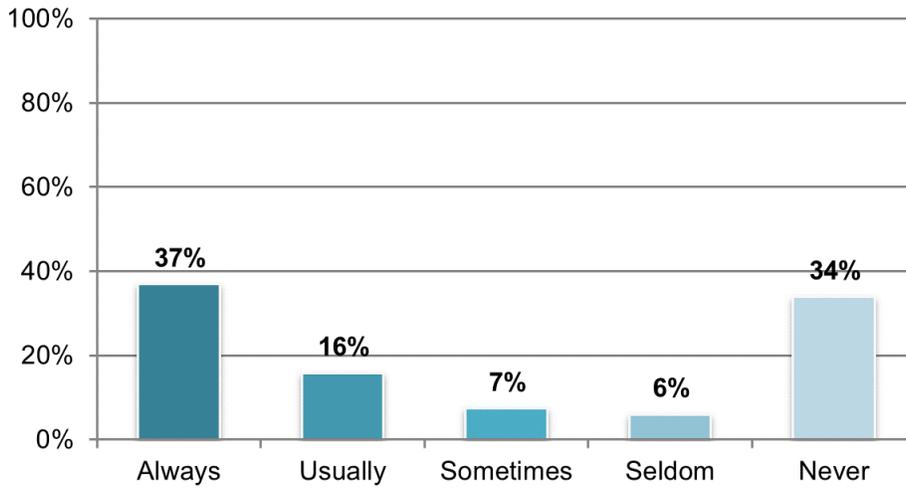


Table Q26. Does your family member choose the provider agencies that work with him or her?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
UT	50%	14%	5%	6%	26%	226
Within Average Range						
NH	42%	13%	8%	2%	35%	168
GA	39%	16%	7%	6%	32%	183
SC	39%	20%	7%	7%	28%	120
VA	38%	16%	6%	5%	34%	190
FL	36%	16%	11%	5%	33%	256
PA	36%	10%	6%	8%	41%	181
CA	35%	16%	7%	6%	35%	1,640
NC	34%	16%	6%	7%	37%	114
MI	32%	18%	10%	8%	32%	259
WA	32%	21%	7%	5%	36%	253
MD	29%	15%	9%	7%	40%	94
NCI Average	37%	16%	7%	6%	34%	3,684

Family Member Can Choose a Different Provider Agency If Desired

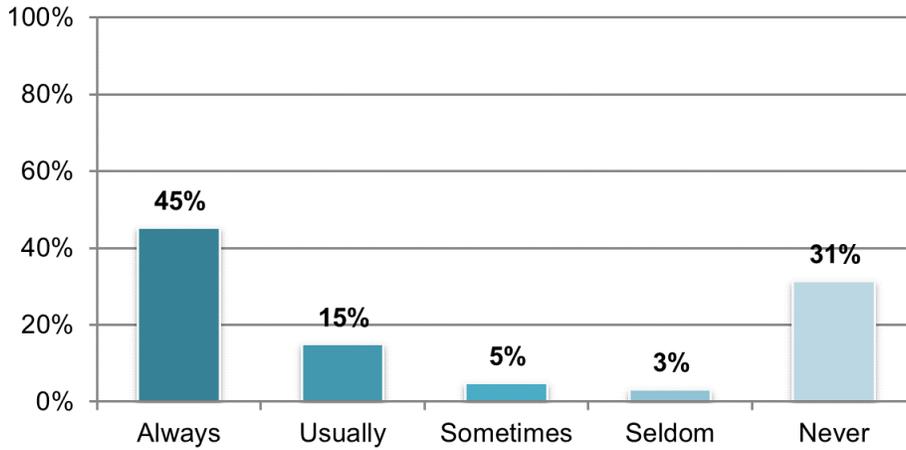


Table 27. Can your family member choose a different provider agency if s/he wants to?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
UT	52%	15%	5%	1%	26%	204
MD	49%	8%	4%	4%	34%	71
WA	49%	19%	4%	3%	26%	216
MI	48%	18%	5%	7%	22%	238
NH	48%	13%	8%	1%	30%	135
FL	48%	19%	6%	2%	25%	233
SC	48%	10%	4%	5%	35%	84
NC	46%	16%	5%	2%	31%	100
VA	41%	14%	4%	2%	38%	162
GA	40%	16%	6%	3%	35%	158
CA **	38%	19%	6%	5%	31%	1,286
PA	36%	12%	2%	5%	44%	129
NCI Average	45%	15%	5%	3%	31%	3,016

Family Member Chooses Individual Support Workers That Work Directly With Him/Her

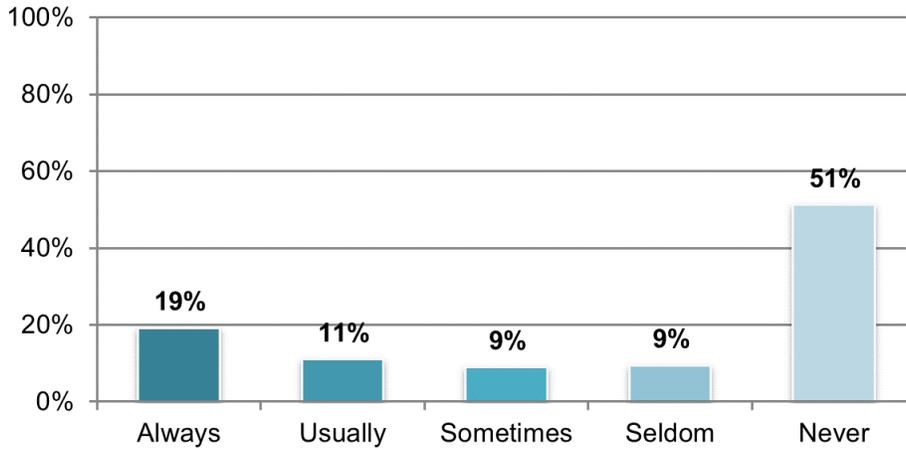


Table Q28. Does your family member choose the individual support workers who work directly with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	38%	10%	9%	4%	39%	240
Within Average Range						
UT	25%	12%	14%	7%	42%	220
VA	21%	5%	3%	8%	63%	185
GA	20%	9%	8%	6%	57%	173
WA	19%	12%	7%	15%	47%	248
NH	18%	14%	14%	9%	46%	177
MI	18%	12%	14%	16%	40%	274
CA	18%	13%	11%	8%	50%	1,705
SC	17%	7%	5%	9%	62%	109
NC	16%	12%	9%	11%	52%	117
MD	13%	15%	10%	13%	50%	115
Significantly Below Average						
PA	10%	10%	6%	8%	66%	193
NCI Average	19%	11%	9%	9%	51%	3,756

Family Member Can Choose Different Support Workers If Desired

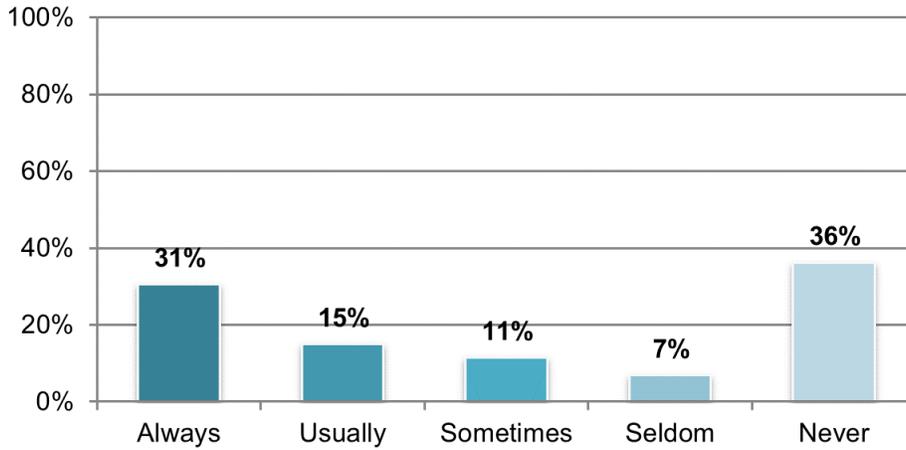


Table Q29. Can your family member choose different support workers if s/he wants to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	46%	13%	9%	4%	28%	226
Within Average Range						
UT	38%	13%	15%	6%	28%	203
WA	33%	20%	11%	10%	26%	217
MI	32%	18%	16%	8%	25%	244
CA	31%	19%	13%	5%	32%	1,421
GA	31%	11%	15%	5%	39%	150
NC	30%	14%	10%	5%	41%	100
VA	30%	11%	8%	4%	47%	159
NH	29%	17%	15%	10%	29%	150
MD	24%	14%	11%	11%	40%	88
SC	23%	14%	6%	6%	51%	84
Significantly Below Average						
PA	20%	15%	8%	7%	50%	149
NCI Average	31%	15%	11%	7%	36%	3,191

Family Member Chose Case Manager/Service Coordinator

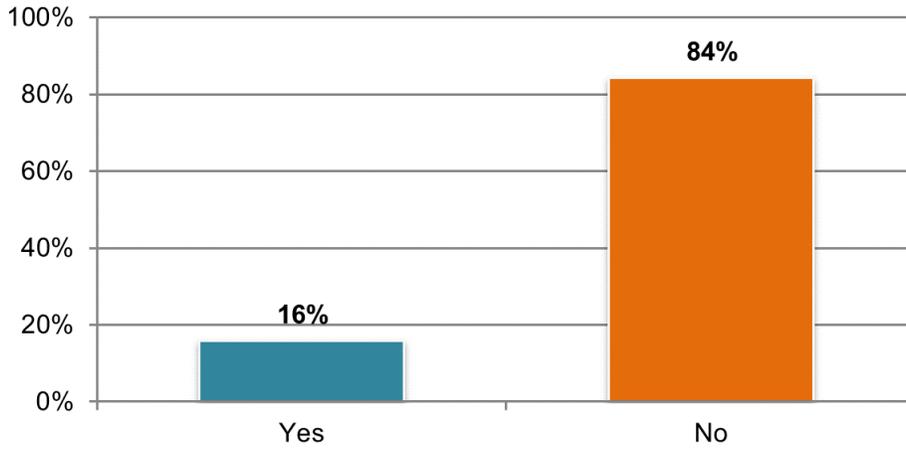


Table Q30. Did your family member choose his/her case manager/service coordinator?

State	Yes	No	N
Significantly Above Average			
FL	45%	55%	288
UT	36%	64%	247
Within Average Range			
MI	17%	83%	345
GA	15%	85%	211
NH	15%	85%	237
SC	14%	86%	151
MD	10%	90%	124
Significantly Below Average			
CA	10%	90%	2,168
NC	9%	91%	138
VA	8%	92%	261
PA	7%	93%	256
WA	4%	96%	308
NCI Average	16%	84%	4,734

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

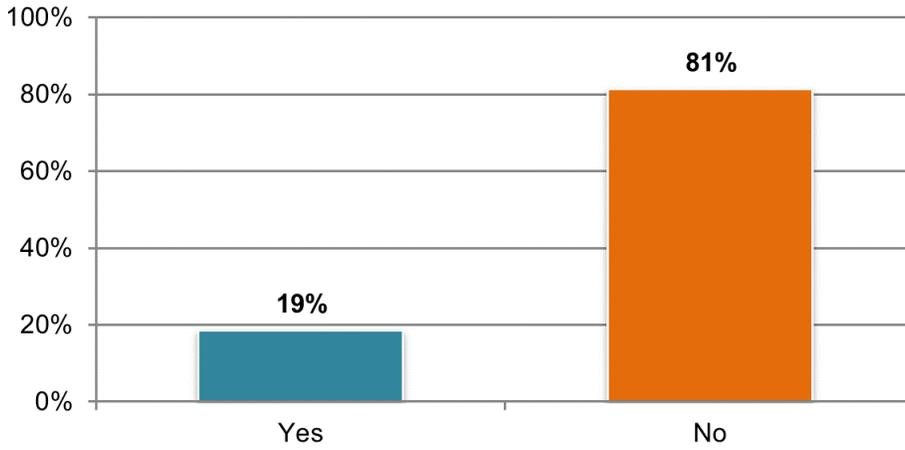


Table Q31. Does your family member have control and/or input over the hiring and management of his/her support workers?

State	Yes	No	N
Significantly Above Average			
FL	36%	64%	287
UT	26%	74%	231
Within Average Range			
CA **	23%	77%	1,968
WA	22%	78%	291
NH	21%	79%	216
MI	18%	82%	343
MD	17%	83%	125
GA	16%	84%	206
NC	13%	87%	138
SC	13%	87%	151
Significantly Below Average			
PA	10%	90%	245
VA	8%	92%	246
NCI Average	19%	81%	4,447

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

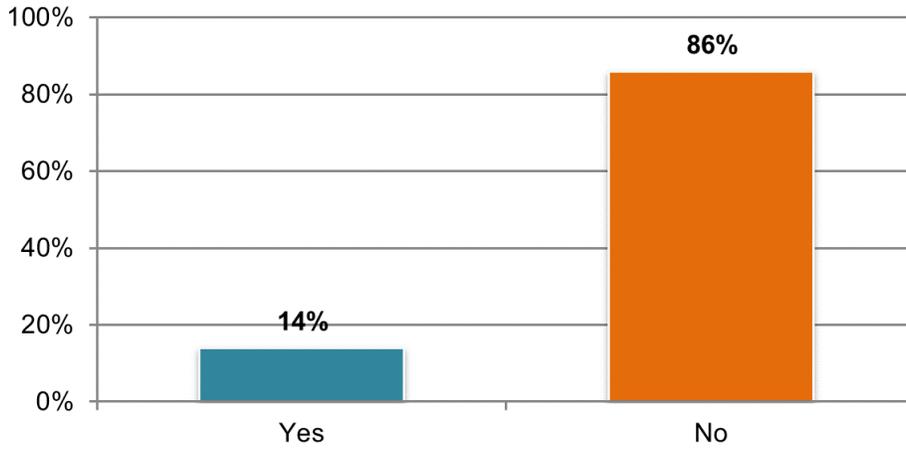


Table Q32. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?

State	Yes	No	N
Significantly Above Average			
FL	26%	74%	327
SC	22%	78%	211
MI	19%	81%	394
Within Average Range			
VA	14%	86%	287
UT	13%	87%	311
GA	12%	88%	275
MD	12%	88%	145
CA **	12%	88%	2,670
NC	11%	89%	152
NH	11%	89%	265
Significantly Below Average			
WA	9%	91%	364
PA	7%	93%	326
NCI Average	14%	86%	5,727

Family Member Has a Say in How ID/DD Agency Money Is Spent

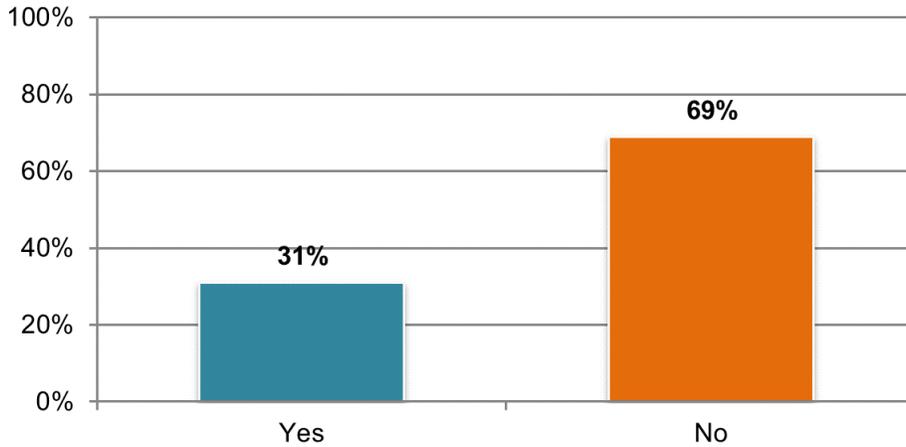


Table Q33. Does your family member have a say in how this money is spent?

State	Yes	No	N
Significantly Above Average			
UT	40%	60%	248
Within Average Range			
SC	37%	63%	155
FL	35%	65%	254
MI	34%	66%	323
WA	32%	68%	267
PA	31%	69%	231
CA	31%	69%	1,914
VA	28%	72%	243
MD	28%	72%	115
NH	28%	72%	209
GA	27%	73%	205
Significantly Below Average			
NC	22%	78%	129
NCI Average	31%	69%	4,293

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

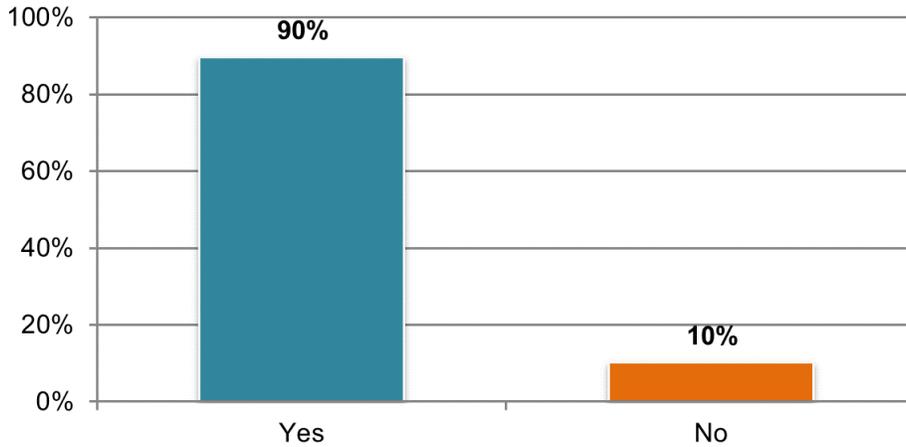


Table Q33a. If your family member has a say in how agency money is spent, does s/he have all the information s/he needs to make decisions about how to spend this money?

State	Yes	No	N
Within Average Range			
MD	96%	4%	26
VA	93%	7%	58
SC	93%	7%	43
NC	91%	9%	22
FL	91%	9%	75
MI	90%	10%	97
PA	89%	11%	55
CA	89%	11%	462
UT	88%	13%	72
NH	87%	13%	39
GA	86%	14%	44
WA	84%	16%	77
NCI Average	90%	10%	1,070

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

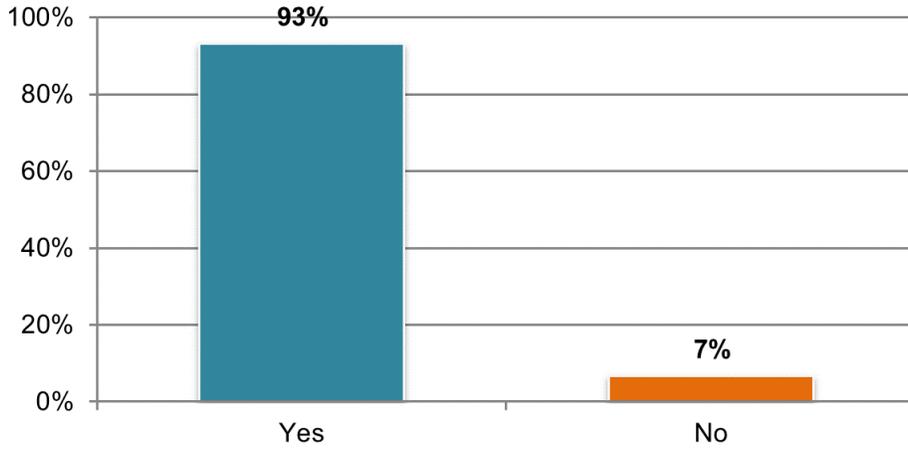


Table Q34. Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?

State	Yes	No	N
Significantly Above Average			
NC	97%	3%	167
NH	96%	4%	291
Within Average Range			
UT	95%	5%	349
SC	95%	5%	218
MI	95%	5%	439
VA	94%	6%	340
GA	94%	6%	287
WA	93%	7%	378
FL	92%	8%	334
PA	92%	8%	370
Significantly Below Average			
CA	89%	11%	2,787
MD	86%	14%	160
NCI Average	93%	7%	6,120

Reasons Why Family Member Does Not Participate in Community Activities

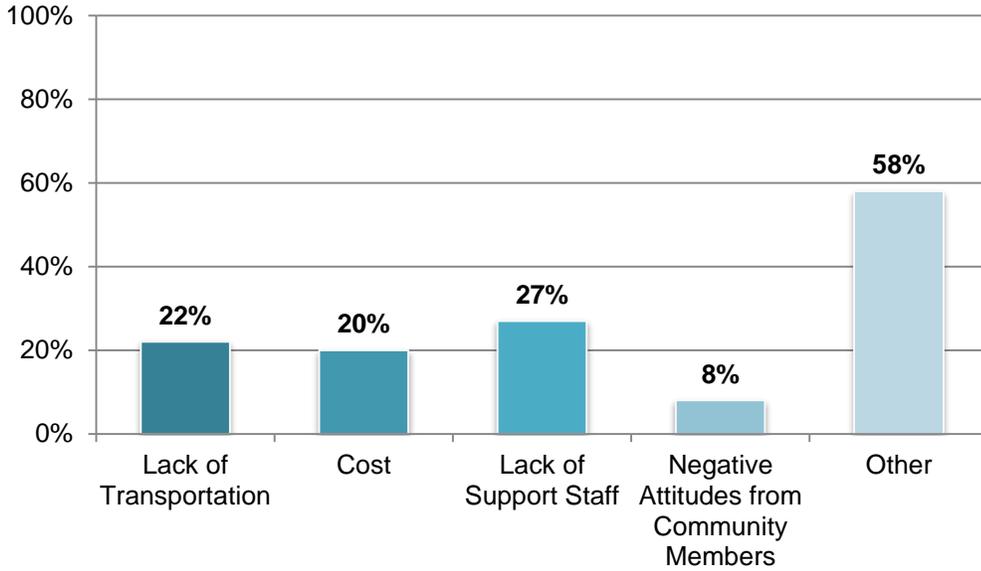


Table Q34a. If your family member doesn't participate in community activities, why not?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes from Community Members	Other
Within Average Range					
CA	27%	21%	28%	10%	55%
PA	8%	12%	24%	4%	68%
WA	30%	26%	30%	9%	52%
NCI Average	22%	20%	27%	8%	58%

Family Member Has Friends or Relationships With People Other Than Paid Staff or Family

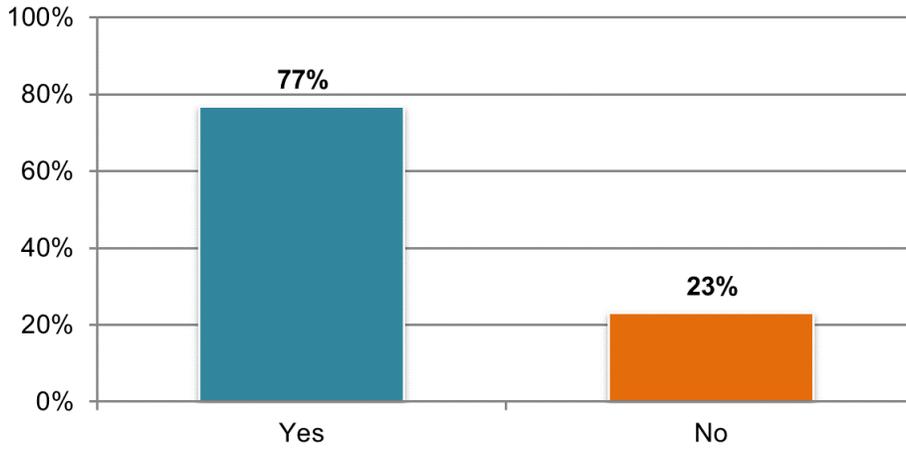


Table Q35. Does your family member have friends or relationships with persons other than paid staff or family?

State	Yes	No	N
Significantly Above Average			
NH	85%	15%	273
WA	83%	17%	360
Within Average Range			
SC	80%	20%	213
NC	79%	21%	162
GA	79%	21%	269
UT	78%	22%	331
PA	77%	23%	335
MD	76%	24%	148
FL	75%	25%	327
Significantly Below Average			
CA **	74%	26%	2,690
MI	68%	32%	388
VA	68%	32%	317
NCI Average	77%	23%	5,813

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

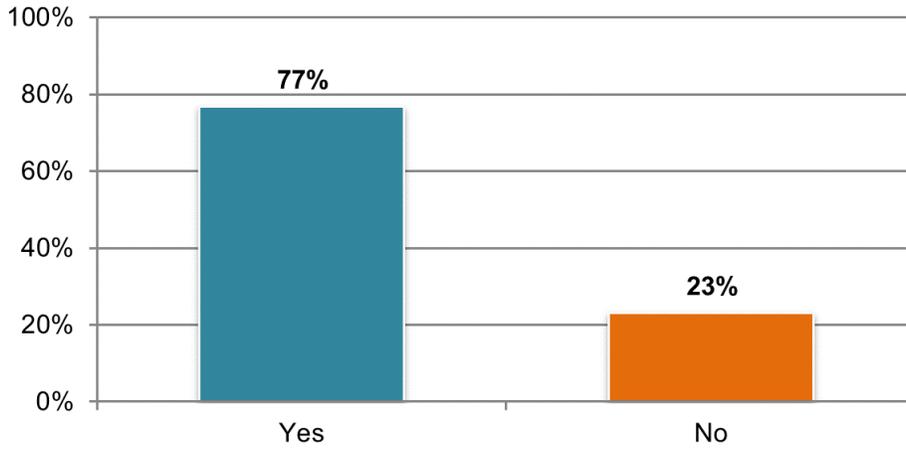


Table Q36. Does your family member have enough support (support workers, community resources, etc.) to work or volunteer in the community?

State	Yes	No	N
Significantly Above Average			
NC	87%	13%	126
NH	84%	16%	231
Within Average Range			
WA	81%	19%	303
UT	79%	21%	258
VA	78%	22%	233
PA	77%	23%	254
GA	76%	24%	208
CA	75%	25%	2,097
MI	74%	26%	323
SC	73%	27%	164
MD	72%	28%	109
Significantly Below Average			
FL	69%	31%	245
NCI Average	77%	23%	4,551

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 Overall Satisfied With Services and Supports Family Member Receives

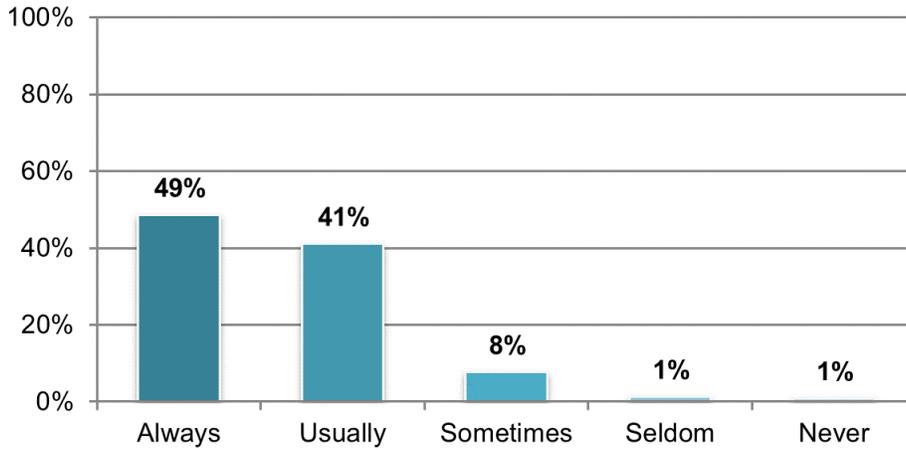


Table Q37. Overall, are you satisfied with the services and supports your family member currently receives?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
VA	60%	35%	4%	1%	0%	361
Within Average Range						
MI	53%	41%	5%	1%	0%	435
PA	52%	36%	10%	1%	1%	383
WA	49%	44%	5%	2%	0%	387
SC	49%	40%	10%	2%	0%	239
GA	48%	38%	11%	1%	2%	298
CA	48%	39%	9%	3%	2%	3,001
NC	47%	45%	7%	1%	1%	173
NH	46%	46%	5%	2%	1%	299
UT	45%	42%	9%	2%	1%	354
FL	45%	44%	7%	3%	1%	357
MD	42%	45%	12%	0%	1%	158
NCI Average	49%	41%	8%	1%	1%	6,445

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

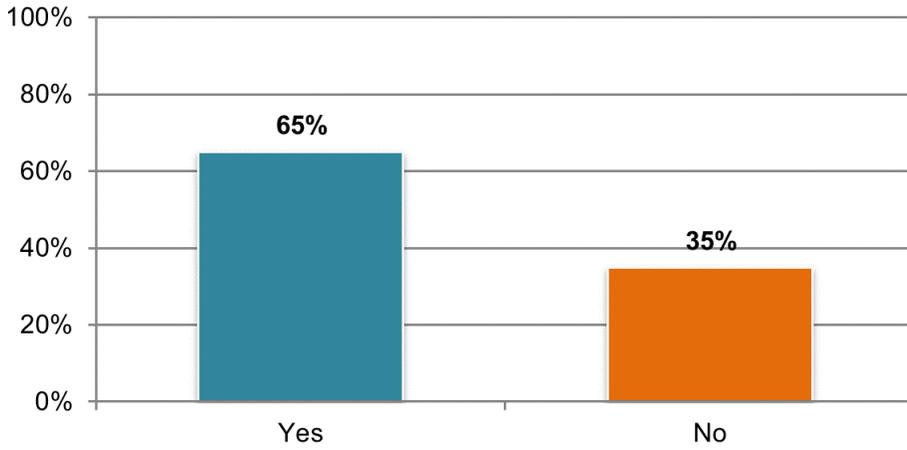


Table Q38. Do you know the process for filing a complaint or grievance against provider agencies or staff?⁴

State	Yes	No	N
Significantly Above Average			
MI	83%	17%	443
FL	81%	19%	370
NC	80%	20%	171
NH	76%	24%	297
WA	71%	29%	385
Within Average Range			
VA	66%	34%	355
UT	62%	38%	359
Significantly Below Average			
PA	56%	44%	387
SC	56%	44%	239
MD	51%	49%	163
CA	50%	50%	2,992
GA	49%	51%	306
NCI Average	65%	35%	6,467

⁴ 'Don't know' responses are included with 'no' responses.

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

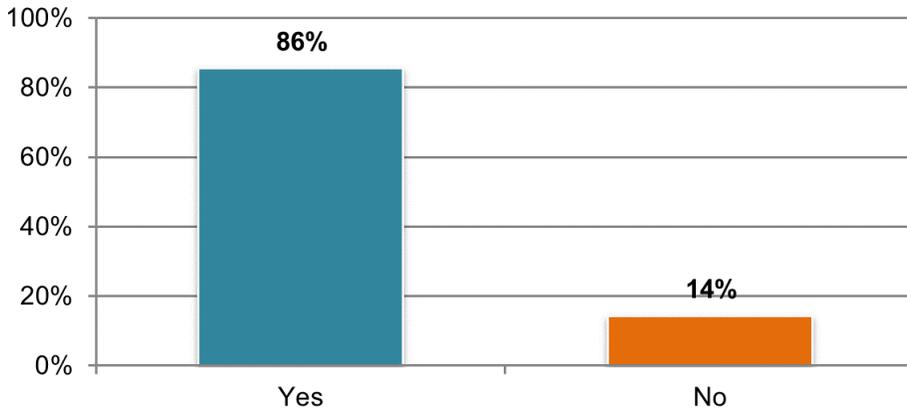


Table Q39. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

State	Yes	No	N
Within Average Range			
NC	91%	9%	111
NH	90%	10%	166
VA	89%	11%	189
WA	89%	11%	215
PA	88%	12%	188
MI	87%	13%	299
UT	86%	14%	207
FL	86%	14%	225
CA **	82%	18%	1,326
SC	82%	18%	137
GA	81%	19%	145
MD	76%	24%	72
NCI Average	86%	14%	3,280

Respondent Knows How To Report Abuse or Neglect

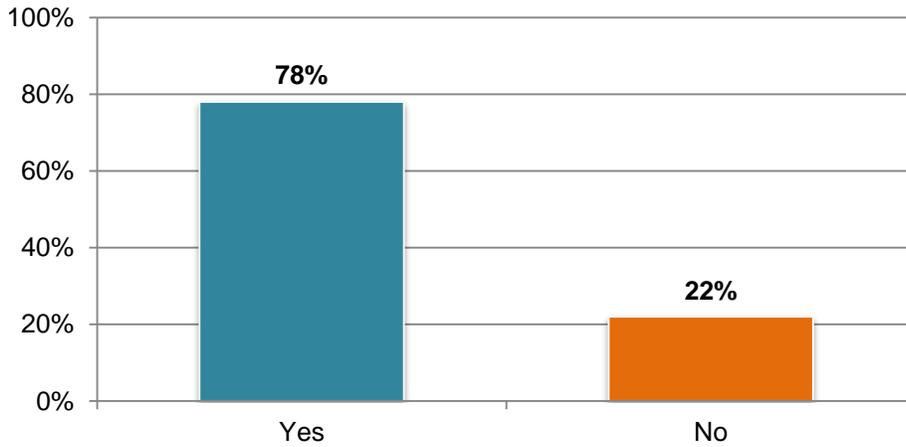


Table Q40. Do you know how to report abuse or neglect?⁵

State	Yes	No	N
Significantly Above Average			
NC	89%	11%	171
FL	89%	11%	353
MI	88%	12%	425
NH	86%	14%	294
WA	85%	15%	383
Within Average Range			
VA	77%	23%	349
UT	76%	24%	353
SC	72%	28%	236
MD	71%	29%	159
Significantly Below Average			
PA	72%	28%	376
CA	68%	32%	2,892
GA	67%	33%	295
NCI Average	78%	22%	6,286

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

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

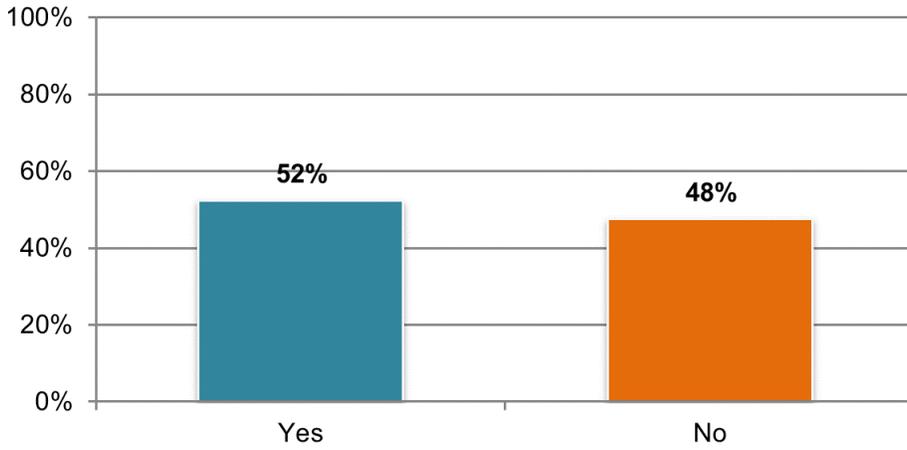


Table Q41. Within the past year, if abuse or neglect occurred, did you report it?

State	Yes	No	N
Significantly Above Average			
NC	74%	26%	31
MI	68%	32%	79
Within Average Range			
UT	64%	36%	83
SC	62%	38%	52
GA	58%	42%	77
WA	53%	47%	51
FL	52%	48%	84
MD	44%	56%	32
CA **	42%	58%	518
PA	41%	59%	59
NH	40%	60%	45
Significantly Below Average			
VA	32%	68%	57
NCI Average	52%	48%	1,168

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

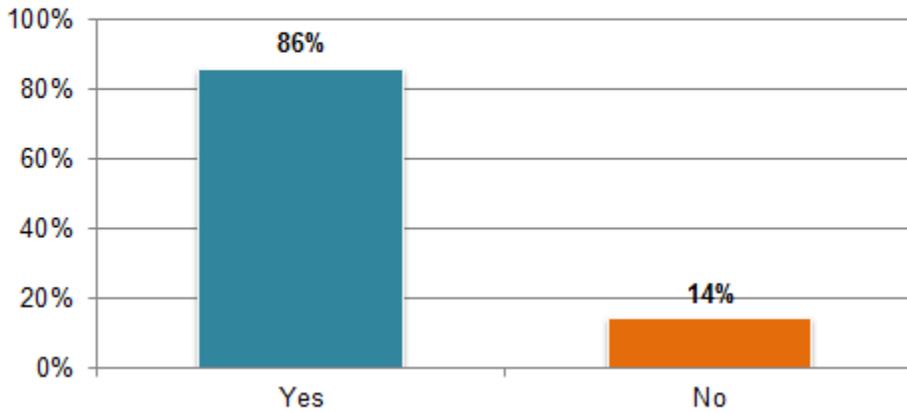


Table Q41a. If you reported abuse or neglect in the past year, were the appropriate people responsive to your report?

State	Yes	No	N
Significantly Above Average			
MI	96%	4%	50
Within Average Range			
NC	95%	5%	21
FL	93%	7%	29
PA	85%	15%	20
SC	85%	15%	26
WA	83%	17%	23
CA	79%	21%	172
UT	78%	22%	46
GA	78%	23%	40
NCI Average	86%	14%	427

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.

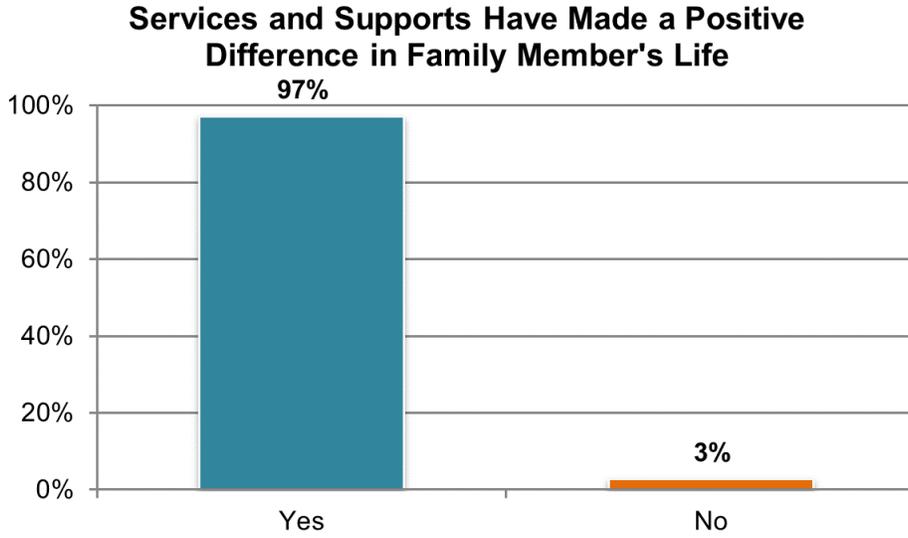


Table Q42. Do you feel that services and supports have made a positive difference in the life of your family member?

State	Yes	No	N
Within Average Range			
NH	98%	2%	284
NC	98%	2%	170
MI	98%	2%	430
WA	98%	2%	370
UT	98%	2%	350
VA	98%	2%	347
FL	97%	3%	340
PA	97%	3%	365
SC	96%	4%	218
MD	96%	4%	155
GA	96%	4%	282
CA **	96%	4%	2,835
NCI Average	97%	3%	6,146

Services and Supports Have Reduced Out-of-Pocket Expenses

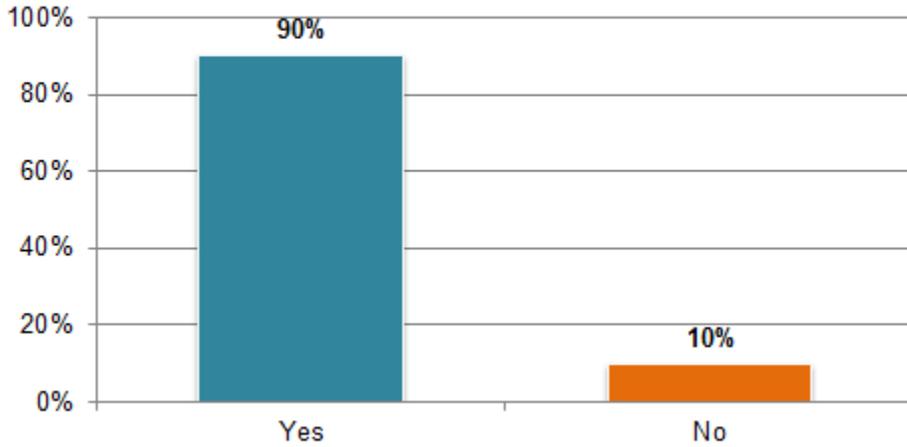


Table Q43. Do you feel that services and supports have reduced your family’s out-of-pocket expenses for your family member’s care?

State	Yes	No	N
Significantly Above Average			
UT	95%	5%	294
Within Average Range			
WA	92%	8%	301
FL	91%	9%	293
NC	91%	9%	127
GA	90%	10%	242
SC	90%	10%	192
NH	90%	10%	231
CA	89%	11%	2,435
VA	89%	11%	245
PA	89%	11%	290
MD	88%	12%	136
MI	88%	12%	320
NCI Average	90%	10%	5,106

Services or Supports Have Been Reduced, Suspended, or Terminated in the Past Year

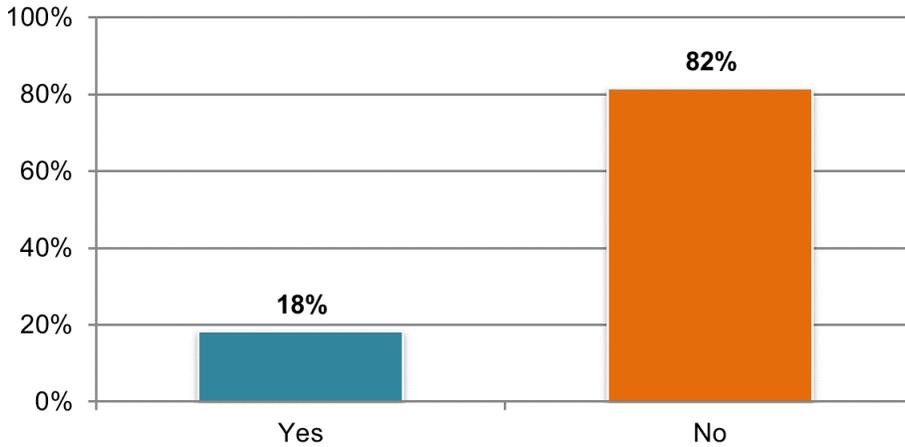


Table Q44. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?⁶

State	Yes	No	N
Significantly Above Average			
FL	51%	49%	285
Within Average Range			
NC	23%	77%	147
CA	19%	81%	2,227
WA	19%	81%	302
MI	16%	84%	364
NH	15%	85%	234
GA	14%	86%	216
SC	14%	86%	160
PA	14%	86%	291
MD	13%	87%	135
Significantly Below Average			
VA	12%	88%	282
UT	10%	90%	280
NCI Average	18%	82%	4,923

⁶ The 'yes' response is the less desired response.

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

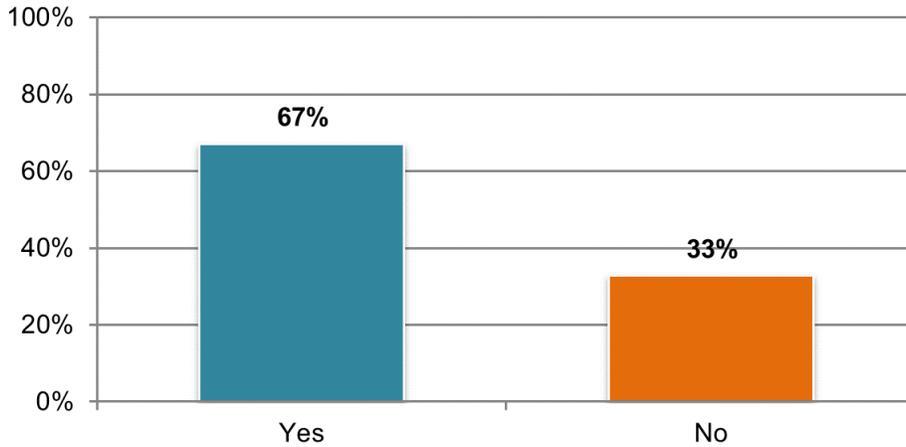


Table Q44a. If services or supports received by your family member were reduced, suspended, or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family member negatively?⁷

State	Yes	No	N
Significantly Above Average			
UT	87%	13%	23
FL	81%	19%	120
Within Average Range			
PA	80%	20%	30
GA	77%	23%	26
CA **	76%	24%	335
VA	69%	31%	26
MI	60%	40%	47
WA	52%	48%	48
NC	48%	52%	25
NH	42%	58%	26
NCI Average	67%	33%	706

⁷ 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

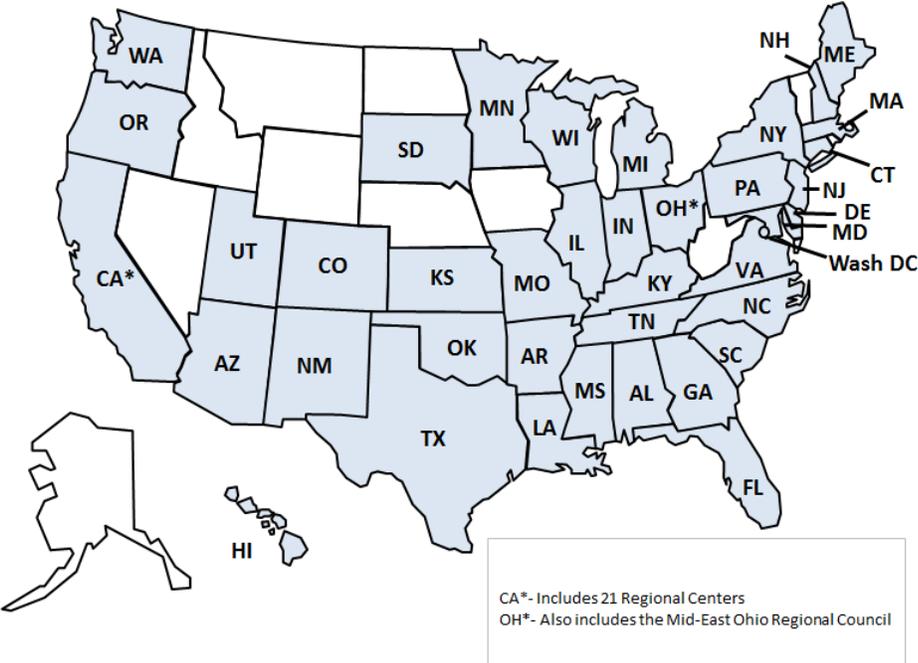
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states 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 others.

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

1. Had an adult individual with a developmental disability NOT living in the family 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%.⁸

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 inside 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 average⁹; 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.

⁸ See "Response Rates" section for information on total surveys mailed and received by states as well as each state's margin of error.

⁹ The NCI Average is the sum of all state averages divided by the total number of states.

Response Rates

During 2013-2014, 12 states administered the Family/Guardian 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, usable surveys returned, and the response rates.

Family/Guardian Survey: State Response Rates¹⁰

State	Surveys Mailed	Usable Surveys Returned	Response Rate
CA	16,000	3,210	20%
FL	1,699	377	22%
GA	1,600	331	21%
MD	1,800	170	9%
MI	1,500	452	30%
NC	1,000	178	18%
NH	1,000	310	31%
PA	1,096	410	37%
SC	1,200	245	20%
UT	919	367	40%
VA	1,208	380	31%
WA	1,250	405	32%
NCI Average			26%

¹⁰ Some numbers may be approximates.