

Adult Family Survey

2014-15 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

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

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Executive Summary

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

The National Core Indicators (NCI) Adult Family Survey is administered to families who have an adult (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 40 states, the District of Columbia and 22 sub-state entities who participated in NCI during the 2014-2015 data collection cycle, 14 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, 2015.

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 34.7 years old, the majority in all states were male (58% nationally). Across states, nearly three quarters of family members were white (72%), 20% of family members were black/African American; and 4% were Hispanic. In most households, the family member for whom the survey was completed was the only person with ID/DD (89%).

For most, the primary means of communication for family members was either spoken language (74%) or gestures or body language (19%). Nearly all spoke English (95%) as their primary language while 1% had a primary language of Spanish and 4% spoke another language.

Nearly all respondents reported their family member's highest level of education was a high school diploma or GED (51%) or less (45%).

During the day, most family members attended a day program whether they were they were unpaid or paid (38% and 18%, respectively); Eighteen percent (18%) of individuals received in home day supports; Fifteen percent (15%) were engaged in paid community employment.

Eighty two percent (82%) of family members required medical care less than once a month, and fourteen percent (14%) required medical care at least once a month, but less than once a week; five percent (5%) required at least weekly medical care. The majority of family members did not require behavioral supports (59%), while 30% needed some behavioral support and 11% required extensive support. The amount of help individuals needed with daily activities was: 22% none; 23% little; 27% moderate; 27% complete.

Demographics and Characteristics of Respondents to the Survey

A large majority of respondents to the survey were 55 or older (60% were 55-74 and 11% were 75 or older); 4% were under 35 years old and 26% were 35-54. About three quarters reported they were in at least good health (15% excellent and 58% good); about while 23% were in fair health and 4% were in poor health.

Nearly all respondents were the family member's primary caregiver (96%). Thirty one percent of households (31%) had one adult aside from the adult family member receiving services, while 51% had two other adults. Nearly two thirds of respondents had full guardianship or conservatorship over their family member (67%) while 4% had limited guardianship or conservatorship; 28% were not the individual's guardian or conservator.

The highest level of education received by respondents was: 8% less than a high school diploma or GED; 29% high school diploma or GED; 5% vocational school; 23% some college completed; and 34% had a college degree.

One third of respondents reported the total family income in the past year was less than \$25,000. Nationally, family income in the past year was reported as: Less than \$15,000 (18%), \$15,001-\$25,000 (16%), \$25,001-\$50,000 (27%), \$50,001-\$75,000 (18%), more than \$75,000 (21%). The out-of-pocket expenses the family paid for their family member's care in the past year was: 22% nothing; \$1-\$100 (16%); \$101-\$1,000 (35%); \$1,001-\$10,000 (25%); and 2% spent more than \$10,000.

Services and Supports Received

The following services and supports provided by the state (with exception of social security benefits) were received by families: financial support (15%), in-home support (44%), out-of-home respite care (33%), day or employment supports (65%), transportation (64%), and 26% received other supports; 92% reported receiving social security benefits.

Information and Planning

Across states, 34% of respondents always received enough information to help plan services for their family and 31% reported that the information they receive about services and supports is always easy to understand. Fewer than half of respondents (39%) reported the information they get always comes from the case manager/service coordinator. More than two-thirds of respondents felt the case manager/service coordinator always respects the family's choices and opinions (67%). More than one-third of respondents reported the case manager/service coordinator always tells them about public services for which the family is eligible (38%)

Of the 89% of respondents nationally who reported the individual has a service plan, most indicated the plan includes all the services and supports the family wants (85%) and that their family member received all services listed in the plan (88%). Across states, about two-thirds of respondents reported their family member helped develop the service plan (68%); the majority of respondents across states reported they or another family member helped make the service plan (92%). Most felt the service plan includes all the services and support their family member needs (79%). Three-quarters (76%) reported they discussed how to handle emergencies related to their family member in the last planning meeting.

The majority of respondents reported they or their family member received information about their family member's rights (95%).

Access and Delivery of Services and Supports

More than half of respondents reported that they or their family member were always able to contact support workers (58%) and the case manager/service coordinator (56%) when needed. Forty percent (40%) reported services and supports were always available when needed; 45% indicated services and supports were always available reasonably close to home; and 41% felt services and supports always changed when their family member's needs changed. Of respondents whose primary language was English 70% reported support workers could always

communicate effectively in their primary language (70%). Just under than one-third of respondents whose family member did not communicate verbally, reported there were always support workers who could communicate effectively with their family member (31%). Most felt services and supports were always delivered in a manner respectful to their family's culture (73%). Fewer than half (49%) reported that their family member always has access to special equipment or accommodations needed. About two-thirds felt their family member's day or employment setting is always a healthy and safe environment (64%). Just more than half (54%) felt support workers always have the right training to meet their family member's needs; 59% reported support workers who come to the home arrive on time and when scheduled.

Of respondents whose family member transitioned from school services to state funded services in the past year, about three-quarters (76%) were happy with the transition. Most indicated crisis or emergency services were provided if requested in the past year (68%). The majority of respondents reported having access to health services (98%) and dental services (87%) for their family member; nearly all (99%) reported they can get needed medication for their family member. Most also reported having access to needed mental health services for their family member (90%). Just more than three-quarters reported having access to respite services (78%). Across states, 39% of respondents reported there were services needed that were not currently offered or available.

Choice and Control

More than half of respondents reported they always choose the provider agencies that work with their family (63%) while just more than one-third reported their family member always makes this choice (38%); two-thirds of respondents (66%) reported they can always choose another provider agency if they want. Fewer than half of respondents (45%) and less than one-third of family members (31%) always choose the individual support workers; 61% of respondents reported always being able to choose different support workers.

Across states, 27% of respondents and 18% of family members chose the case manager/service coordinator. About half of respondents reported they have control over the hiring or management of the family member's support workers (53%); just more than one-third of family members were reported to have this control (37%). Slightly less than one-third of respondents (32%) reported knowing how much money is spent by the ID/DD agency on their family member's behalf while 13% reported their family member had this knowledge. Of the 52% of respondents who reported they had a say in how ID/DD agency money is spent, 89% reported having all the information needed to decide how to spend the money. Similarly, of the 35% of respondents who reported

their family member has a say in how ID/DD agency money is spent on their behalf, 91% reported their family member had all the information needed to make these decisions.

Community Connections

Nationally, most respondents reported their family member participates in community activities (90%). Of the 10% whose family member did not partake in community activities the reasons why they did not were: lack of transportation (61%), cost (9%), lack of support staff (23%), negative attitudes from community members (18%), and 22% reported there were other reasons not given. More than three-quarters of respondents (80%) reported their family member have friends and relationships with people other than paid staff or family. Across states, most reported their family member has enough support to work or volunteer in the community (70%).

Satisfaction with Services and Supports

Across states, 39% of respondents reported they are always satisfied with the services and supports their family receives.

Nearly two-thirds of respondents reported they know the process for filing a complaint or grievance against provider agencies or staff (65%); most are satisfied how complaints or grievances are handled (83%). Across states, most respondents know how to report abuse or neglect (82%); of the 36% who reported abuse or neglect if it occurred in the past year, 93% reported the appropriate people were responsive to reports of abuse or neglect.

Family Outcomes

Nearly all respondents felt services and supports made a positive difference in their family's life (96%). Most indicated services and supports have reduced their family's out-of-pocket expenses related to their family member's care (85%). Of the fewer than one-quarter of respondents (19%) who reported their family or family member's services or supports were reduced, suspended, or terminated in the past year, three-quarters (76%) reported the lessening of services or supports 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 enough responses for a valid sample, and provided sound feedback to the participating state DD 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 survey 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. Additionally, at the end of the survey, respondents may 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

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 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 NCI Average Range, their 'always' or 'yes' response was not statistically different from the NCI Average.

States receive an 'N/A' designation for a survey item if fewer than 20 people responded. The NCI Average is the average of all individual state percentages.

Note on Significance: in some cases, a state (let's call it state A) with a lower (or higher) proportion than another state (let's call it state B) may be significantly above (or below) NCI Average even though the other state that is further away from the NCI Average is not. This may happen because statistical significance depends on both the difference between the average and the state's proportion and the sample size of the state. So, for example, when state A has a larger valid sample for the indicator than state B, state A may be significantly different from the average when state B is not, even though state B's difference from that average is larger than state A's. The larger the sample size of a state, the smaller the difference needs to be to be statistically significant.

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
CO	34.5	317
CT	36.2	295
DC	36.8	224
FL	36.0	407
GA	36.2	399
KY	36.2	134
LA	35.4	547
MD	34.0	414
MN	29.9	597
NC	33.6	233
OK	34.4	406
PA	36.9	405
SD	33.9	136
UT	33.0	615
WI	33.0	397
NCI Average	34.7	5,526

Table 2. Family Member's Gender

State	Male	Female	N
CO	59%	41%	313
CT	59%	41%	290
DC	67%	33%	222
FL	57%	43%	409
GA	63%	37%	398
KY	60%	40%	134
LA	58%	42%	542
MD	61%	39%	415
MN	57%	43%	603
NC	61%	39%	231
OK	55%	45%	405
PA	53%	47%	403
SD	54%	46%	135
UT	55%	45%	615
WI	55%	45%	399
NCI Average	58%	42%	5,514

Table 3. Family Member’s Race

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
CO	3%	2%	3%	0%	76%	1%	8%	17%
CT	0%	2%	11%	0%	81%	1%	3%	5%
DC	1%	0%	90%	0%	4%	0%	2%	3%
FL	1%	1%	18%	0%	62%	0%	3%	16%
GA	1%	1%	41%	0%	57%	0%	1%	1%
KY	3%	2%	7%	0%	92%	0%	0%	0%
LA	1%	1%	34%	0%	61%	0%	1%	1%
MD	1%	6%	30%	0%	61%	1%	3%	2%
MN	3%	5%	6%	0%	84%	0%	3%	2%
NC	3%	0%	32%	0%	61%	0%	2%	2%
OK	16%	2%	11%	0%	76%	0%	3%	1%
PA	1%	2%	5%	0%	89%	0%	2%	1%
SD	7%	2%	0%	0%	90%	1%	1%	1%
UT	2%	1%	1%	0%	93%	0%	3%	5%
WI	3%	3%	5%	0%	88%	0%	2%	1%
NCI Average	3%	2%	20%	0%	72%	0%	3%	4%

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

State	Yes	No	N
CO	10%	90%	314
CT	10%	90%	284
DC	12%	88%	217
FL	12%	88%	402
GA	15%	85%	398
KY	7%	93%	134
LA	13%	87%	532
MD	9%	91%	414
MN	16%	84%	593
NC	12%	88%	230
OK	10%	90%	400
PA	10%	90%	387
SD	11%	89%	134
UT	15%	85%	605
WI	9%	91%	269
NCI Average	11%	89%	5,313

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
CO	77%	14%	3%	1%	6%	314
CT	78%	15%	2%	2%	3%	279
DC	72%	22%	1%	0%	4%	203
FL	65%	25%	1%	4%	4%	406
GA	74%	21%	2%	1%	3%	396
KY	75%	19%	1%	1%	4%	135
LA	75%	17%	2%	1%	5%	528
MD	81%	13%	3%	1%	1%	410
MN	77%	17%	1%	2%	3%	561
NC	69%	25%	1%	3%	2%	233
OK	66%	26%	2%	2%	4%	410
PA	81%	14%	2%	1%	3%	393
SD	80%	13%	1%	1%	6%	127
UT	69%	25%	1%	0%	4%	610
WI	73%	17%	3%	3%	4%	398
NCI Average	74%	19%	2%	1%	4%	5,403

Table 6. Family Member’s Primary Language

State	English	Spanish	Other	N
CO	95%	1%	4%	313
CT	95%	2%	3%	273
DC	95%	1%	3%	220
FL	89%	6%	5%	405
GA	97%	0%	2%	386
KY	99%	0%	1%	134
LA	95%	0%	5%	539
MD	96%	1%	3%	413
MN	93%	1%	6%	597
NC	96%	0%	3%	235
OK	94%	0%	6%	413
PA	98%	0%	2%	400
SD	99%	0%	1%	129
UT	93%	1%	6%	616
WI	95%	0%	5%	397
NCI Average	95%	1%	4%	5,470

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
CO	33%	64%	2%	2%	0%	300
CT	36%	62%	1%	1%	0%	272
DC	60%	37%	3%	0%	0%	219
FL	50%	47%	2%	1%	1%	374
GA	39%	59%	1%	0%	0%	381
KY	55%	42%	1%	2%	0%	131
LA	65%	30%	3%	2%	1%	526
MD	54%	37%	3%	4%	1%	402
MN	34%	62%	2%	2%	0%	586
NC	55%	36%	4%	4%	0%	223
OK	25%	72%	3%	1%	0%	400
PA	33%	63%	4%	1%	0%	381
SD	46%	52%	1%	1%	1%	122
UT	57%	40%	2%	1%	0%	583
WI	39%	58%	1%	1%	0%	387
NCI Average	45%	51%	2%	2%	0%	5,287

Table 8. Family Member's Typical Day Activities

State	Out of Home Day Program (Unpaid)	Out of Home Day Program (Paid)	Vocational Training	Community Employment (Unpaid)	Community Employment (Paid)	In-home Day Supports	At Home (by Choice)	At Home (No Services)	At Home (Other)	Other
CO	56%	20%	8%	7%	16%	15%	18%	12%	9%	10%
CT	47%	27%	5%	6%	17%	11%	4%	5%	4%	11%
DC	66%	7%	5%	4%	8%	20%	6%	2%	3%	9%
FL	33%	11%	5%	2%	5%	16%	9%	3%	8%	14%
GA	52%	14%	4%	6%	7%	21%	9%	3%	5%	12%
KY	35%	20%	3%	4%	17%	22%	18%	5%	12%	16%
LA	28%	11%	4%	4%	8%	37%	15%	5%	6%	12%
MD	40%	20%	9%	13%	21%	8%	6%	4%	6%	10%
MN	27%	27%	10%	8%	17%	17%	12%	5%	8%	17%
NC	36%	14%	10%	6%	9%	34%	12%	4%	8%	21%
OK	13%	14%	7%	8%	16%	31%	25%	6%	13%	10%
PA	30%	23%	10%	9%	17%	9%	12%	8%	9%	15%
SD	37%	27%	10%	10%	22%	3%	10%	4%	3%	13%
UT	39%	18%	8%	5%	12%	18%	15%	5%	9%	19%
WI	32%	19%	7%	10%	26%	16%	19%	9%	11%	14%
NCI Average	38%	18%	7%	7%	15%	18%	13%	5%	8%	14%

Table 9. 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
CO	84%	10%	5%	317
CT	81%	15%	4%	267
DC	77%	16%	7%	203
FL	78%	17%	5%	380
GA	79%	16%	5%	374
KY	81%	14%	5%	133
LA	76%	18%	6%	525
MD	86%	8%	6%	392
MN	84%	12%	4%	590
NC	81%	15%	4%	221
OK	78%	16%	5%	401
PA	88%	8%	4%	382
SD	85%	12%	3%	133
UT	86%	13%	2%	604
WI	84%	13%	2%	386
NCI Average	82%	14%	5%	5,308

Table 10. Amount of Behavioral Support Needed for Family Member

State	None	Some	Extensive	N
CO	54%	36%	9%	311
CT	67%	24%	8%	279
DC	65%	25%	10%	223
FL	61%	29%	10%	399
GA	63%	29%	8%	388
KY	56%	30%	14%	132
LA	55%	33%	13%	528
MD	67%	24%	9%	408
MN	51%	35%	15%	601
NC	43%	40%	17%	232
OK	66%	27%	8%	408
PA	68%	25%	7%	396
SD	66%	25%	9%	133
UT	53%	37%	11%	607
WI	55%	32%	14%	396
NCI Average	59%	30%	11%	5,441

Table 11. Amount of Help Needed for Family Member's Daily Activities

State	None	Little	Moderate	Complete	N
CO	23%	28%	26%	23%	314
CT	29%	27%	23%	22%	292
DC	32%	25%	25%	18%	224
FL	19%	15%	31%	35%	408
GA	28%	24%	21%	27%	394
KY	16%	20%	32%	33%	135
LA	17%	19%	31%	33%	538
MD	31%	29%	23%	17%	415
MN	14%	23%	37%	27%	602
NC	20%	20%	26%	34%	235
OK	19%	20%	30%	31%	414
PA	25%	30%	22%	23%	402
SD	30%	24%	21%	24%	135
UT	17%	23%	28%	32%	611
WI	13%	25%	34%	29%	396
NCI Average	22%	23%	27%	27%	5,515

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
CO	1%	22%	65%	13%	319
CT	5%	15%	65%	14%	291
DC	3%	21%	60%	15%	207
FL	6%	27%	54%	13%	403
GA	6%	27%	58%	9%	397
KY	3%	25%	56%	16%	135
LA	6%	30%	53%	11%	542
MD	3%	19%	68%	9%	415
MN	6%	35%	55%	5%	603
NC	3%	38%	50%	9%	237
OK	3%	21%	64%	12%	411
PA	4%	21%	63%	13%	400
SD	1%	31%	58%	10%	132
UT	3%	27%	61%	10%	615
WI	3%	27%	63%	8%	399
NCI Average	4%	26%	60%	11%	5,506

Table 13. Respondent's Health

State	Excellent	Good	Fair	Poor	N
CO	19%	57%	23%	2%	317
CT	16%	55%	23%	6%	283
DC	15%	59%	25%	1%	217
FL	13%	52%	28%	7%	408
GA	13%	55%	28%	5%	395
KY	8%	59%	27%	5%	133
LA	13%	47%	31%	8%	543
MD	17%	57%	23%	4%	413
MN	22%	62%	15%	2%	601
NC	14%	59%	21%	6%	234
OK	14%	57%	26%	2%	406
PA	15%	58%	24%	3%	399
SD	20%	61%	15%	4%	130
UT	16%	61%	20%	3%	610
WI	16%	64%	18%	2%	273
NCI Average	15%	58%	23%	4%	5,362

Table 14. Respondent Is Primary Caregiver

State	Yes	No	N
CO	95%	5%	319
CT	96%	4%	282
DC	91%	9%	222
FL	96%	4%	406
GA	96%	4%	395
KY	96%	4%	135
LA	92%	8%	544
MD	97%	3%	414
MN	96%	4%	603
NC	94%	6%	233
OK	97%	3%	410
PA	98%	2%	400
SD	96%	4%	133
UT	98%	2%	609
WI	97%	3%	279
NCI Average	96%	4%	5,384

Table 15. Number of Adults in Household (Not Including Family Member Receiving Services)

State	One	Two	Three	Four or More	N
CO	29%	56%	12%	4%	315
CT	29%	47%	16%	8%	277
DC	47%	36%	14%	4%	221
FL	39%	46%	11%	4%	406
GA	32%	47%	18%	3%	394
KY	29%	56%	13%	2%	135
LA	37%	49%	10%	4%	536
MD	27%	53%	15%	5%	414
MN	25%	53%	15%	7%	600
NC	32%	49%	15%	4%	234
OK	33%	55%	9%	4%	406
PA	27%	52%	18%	3%	403
SD	27%	59%	10%	4%	132
UT	23%	52%	18%	7%	613
WI	24%	62%	12%	2%	269
NCI Average	31%	51%	14%	4%	5,355

Table 16. Respondent Is Family Member's Legal Guardian or Conservator

State	Yes, Full	Yes, Limited	No	N
CO	59%	4%	37%	319
CT	86%	6%	9%	279
DC	61%	8%	32%	218
FL	51%	8%	41%	398
GA	52%	4%	44%	382
KY	87%	3%	10%	135
LA	61%	3%	36%	522
MD	38%	6%	57%	400
MN	85%	3%	13%	598
NC	72%	6%	22%	231
OK	70%	5%	25%	411
PA	51%	3%	46%	381
SD	80%	1%	19%	135
UT	63%	7%	31%	600
WI	97%	2%	2%	399
NCI Average	67%	4%	28%	5,408

Table 17. 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
CO	6%	24%	5%	22%	42%	314
CT	9%	30%	2%	18%	41%	279
DC	17%	32%	2%	25%	23%	216
FL	14%	28%	5%	25%	28%	404
GA	13%	33%	6%	17%	31%	389
KY	7%	28%	2%	22%	41%	135
LA	16%	34%	6%	23%	21%	547
MD	7%	21%	2%	26%	44%	413
MN	3%	26%	12%	22%	37%	592
NC	4%	27%	5%	24%	40%	237
OK	6%	27%	6%	27%	34%	408
PA	9%	43%	4%	16%	29%	400
SD	2%	31%	8%	22%	37%	130
UT	5%	23%	5%	30%	38%	607
WI	5%	35%	10%	18%	32%	397
NCI Average	8%	29%	5%	23%	34%	5,468

Table 18. 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
CO	13%	15%	30%	20%	21%	279
CT	16%	13%	25%	22%	24%	241
DC	28%	23%	23%	14%	11%	196
FL	29%	20%	27%	12%	12%	360
GA	26%	21%	26%	13%	14%	349
KY	11%	17%	28%	24%	20%	123
LA	28%	20%	25%	13%	15%	469
MD	11%	12%	20%	21%	36%	365
MN	11%	12%	29%	23%	25%	553
NC	19%	22%	23%	19%	18%	220
OK	20%	17%	29%	17%	17%	362
PA	16%	14%	33%	17%	20%	333
SD	17%	12%	25%	15%	31%	118
UT	15%	11%	27%	24%	23%	560
WI	9%	15%	30%	19%	27%	370
NCI Average	18%	16%	27%	18%	21%	4,898

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
CO	23%	21%	32%	22%	2%	300
CT	21%	9%	33%	35%	2%	269
DC	34%	17%	30%	18%	0%	212
FL	19%	16%	34%	30%	2%	385
GA	17%	20%	34%	24%	4%	367
KY	17%	17%	44%	21%	2%	131
LA	25%	13%	32%	28%	2%	505
MD	20%	10%	37%	28%	5%	389
MN	25%	17%	30%	25%	3%	584
NC	20%	16%	37%	25%	2%	230
OK	19%	13%	40%	25%	3%	393
PA	18%	16%	39%	25%	2%	369
SD	34%	11%	33%	23%	0%	128
UT	16%	13%	38%	30%	3%	585
WI	20%	26%	32%	19%	2%	394
NCI Average	22%	16%	35%	25%	2%	5,241

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 20. Services and Supports Received From ID/DD Agency¹

State	Financial Support	In-Home Support	Out-of-Home Respite Care	Day or Employment Supports	Transportation	Other	Social Security Benefits
CO	20%	28%	27%	69%	66%	29%	94%
CT	29%	28%	39%	85%	81%	17%	94%
DC	11%	63%	37%	75%	83%	51%	89%
FL	13%	56%	28%	49%	54%	29%	90%
GA	13%	35%	21%	62%	65%	21%	89%
KY	17%	48%	50%	61%	55%	31%	94%
LA	10%	68%	29%	44%	53%	15%	92%
MD	8%	21%	19%	81%	75%	15%	87%
MN	27%	60%	44%	68%	73%	31%	91%
NC	10%	64%	47%	54%	47%	30%	91%
OK	17%	57%	17%	41%	47%	27%	92%
PA	17%	33%	34%	65%	61%	22%	93%
SD	9%	14%	20%	76%	57%	26%	90%
UT	10%	50%	43%	64%	63%	21%	93%
WI	16%	37%	39%	76%	71%	30%	94%
NCI Average	15%	44%	33%	65%	64%	26%	92%

¹ All services provided by the state ID/DD Agency except for social security benefits.

Adult Family Survey Results

Information and Planning

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

Gets Enough Information to Help Plan Services

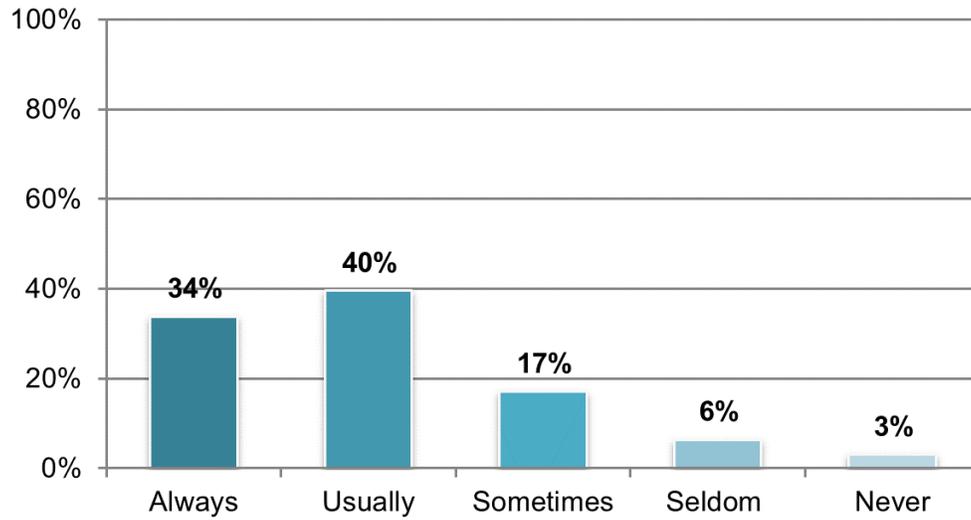


Table Q1. Do you get enough information to help you participate in planning services for your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	44%	36%	13%	5%	2%	509
FL	42%	36%	14%	6%	3%	394
Within Average Range						
DC	41%	31%	18%	6%	4%	219
WI	40%	43%	12%	3%	1%	387
UT	39%	45%	11%	3%	2%	574
PA	36%	43%	14%	5%	2%	374
NC	34%	34%	21%	7%	4%	221
OK	34%	44%	14%	5%	3%	396
CO	33%	46%	16%	4%	2%	303
SD	31%	37%	22%	8%	2%	129
CT	29%	34%	24%	8%	4%	270
GA	29%	36%	20%	7%	8%	385
KY	29%	47%	13%	8%	2%	121
Significantly Below Average						
MN	28%	42%	21%	6%	3%	585
MD	19%	39%	23%	14%	4%	386
NCI Average	34%	40%	17%	6%	3%	5,253

Information About Services and Supports Is Easy to Understand

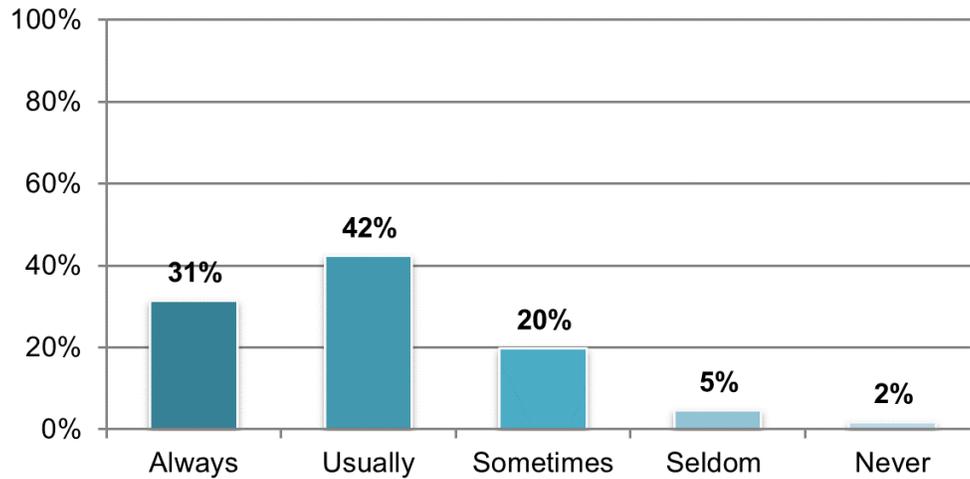


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
DC	41%	35%	19%	5%	1%	217
FL	40%	40%	15%	4%	2%	392
LA	40%	38%	18%	3%	2%	518
Within Average Range						
SD	36%	41%	19%	2%	2%	125
OK	34%	44%	16%	4%	2%	392
PA	33%	44%	16%	4%	2%	368
GA	33%	38%	21%	5%	3%	370
UT	32%	49%	15%	3%	1%	577
WI	31%	43%	23%	2%	1%	384
CT	30%	38%	26%	4%	3%	261
NC	29%	44%	19%	6%	1%	216
CO	28%	45%	21%	5%	2%	302
Significantly Below Average						
MN	23%	43%	25%	6%	3%	589
MD	23%	44%	23%	8%	2%	375
KY	19%	48%	23%	9%	1%	126
NCI Average	31%	42%	20%	5%	2%	5,212

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

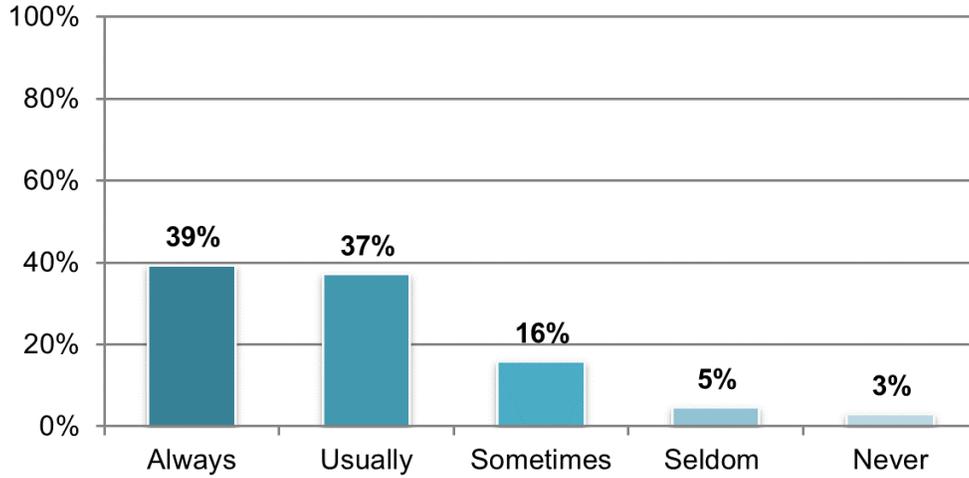


Table Q3. Does the information you receive come from your case manager/service coordinator?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	52%	30%	11%	3%	4%	395
WI	49%	38%	11%	2%	0%	317
UT	49%	38%	10%	2%	1%	577
LA	48%	34%	14%	3%	2%	509
Within Average Range						
DC	45%	28%	18%	5%	4%	211
OK	43%	36%	13%	6%	2%	399
PA	42%	38%	15%	4%	2%	365
NC	38%	36%	16%	6%	4%	213
CT	37%	37%	19%	4%	3%	257
CO	36%	45%	13%	4%	2%	292
SD	35%	43%	16%	4%	2%	122
KY	32%	40%	18%	8%	2%	125
Significantly Below Average						
GA	32%	33%	21%	6%	8%	369
MD	29%	39%	18%	7%	7%	374
MN	23%	41%	24%	8%	3%	579
NCI Average	39%	37%	16%	5%	3%	5,104

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

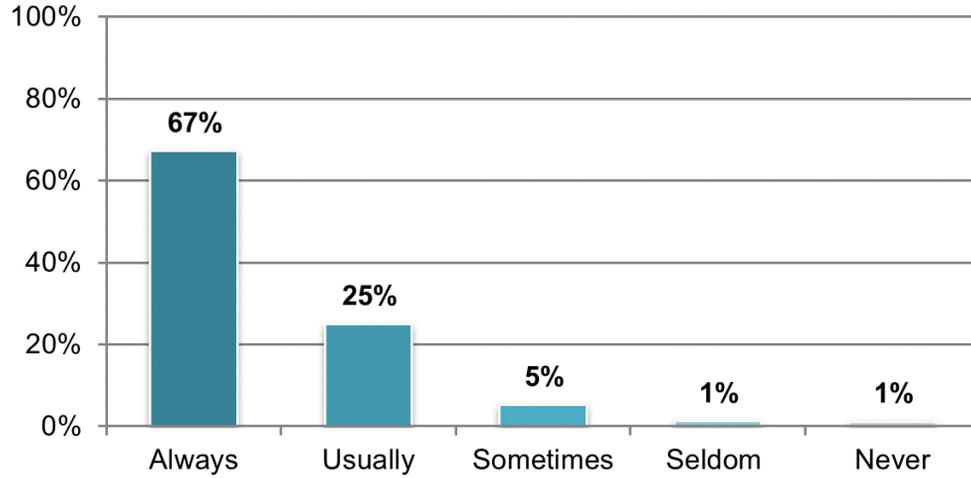


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
UT	80%	17%	2%	1%	0%	579
FL	78%	16%	5%	0%	2%	399
WI	75%	21%	4%	0%	0%	266
PA	73%	22%	4%	0%	0%	371
LA	73%	23%	3%	0%	0%	522
Within Average Range						
CT	72%	22%	5%	0%	1%	261
NC	67%	27%	3%	2%	1%	207
KY	65%	25%	6%	2%	2%	126
MN	64%	29%	5%	2%	1%	577
CO	63%	31%	3%	2%	1%	294
DC	63%	20%	12%	3%	3%	216
OK	63%	30%	5%	1%	1%	401
SD	56%	32%	10%	2%	1%	125
Significantly Below Average						
GA	61%	29%	6%	2%	3%	370
MD	57%	33%	7%	2%	1%	361
NCI Average	67%	25%	5%	1%	1%	5,075

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

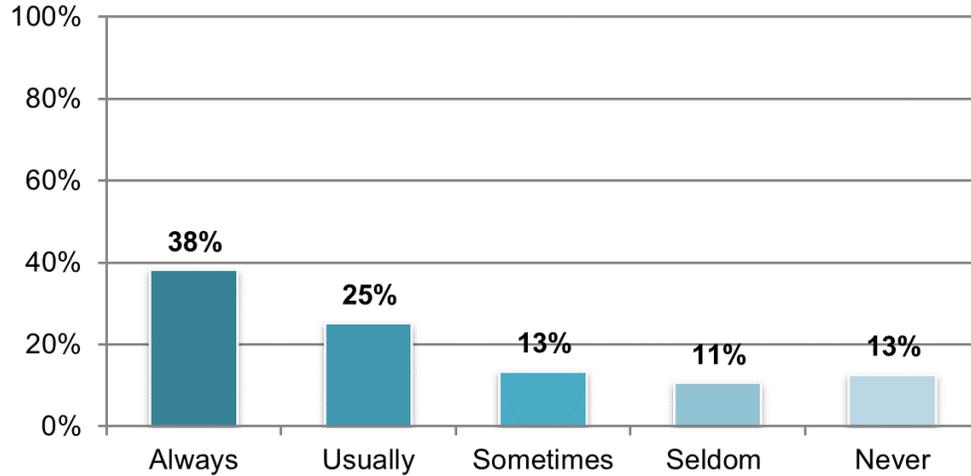


Table Q5. Does the case manager/service coordinator tell you about other public services that your family is eligible for (food stamps, Supplemental Security Income [SSI], housing subsidies, etc.)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	53%	20%	9%	7%	11%	389
CT	49%	21%	14%	8%	8%	261
UT	44%	27%	13%	6%	9%	542
LA	44%	25%	12%	6%	13%	498
Within Average Range						
WI	41%	32%	11%	10%	6%	243
DC	41%	19%	15%	9%	16%	207
PA	40%	25%	13%	11%	10%	352
OK	37%	28%	16%	9%	9%	379
KY	34%	23%	9%	16%	18%	117
NC	34%	25%	15%	13%	13%	196
CO	33%	33%	13%	11%	10%	283
SD	32%	24%	12%	17%	14%	115
Significantly Below Average						
MN	32%	28%	18%	12%	10%	550
GA	30%	23%	12%	12%	22%	351
MD	27%	23%	21%	10%	19%	365
NCI Average	38%	25%	13%	11%	13%	4,848

Family Member Has a Service Plan

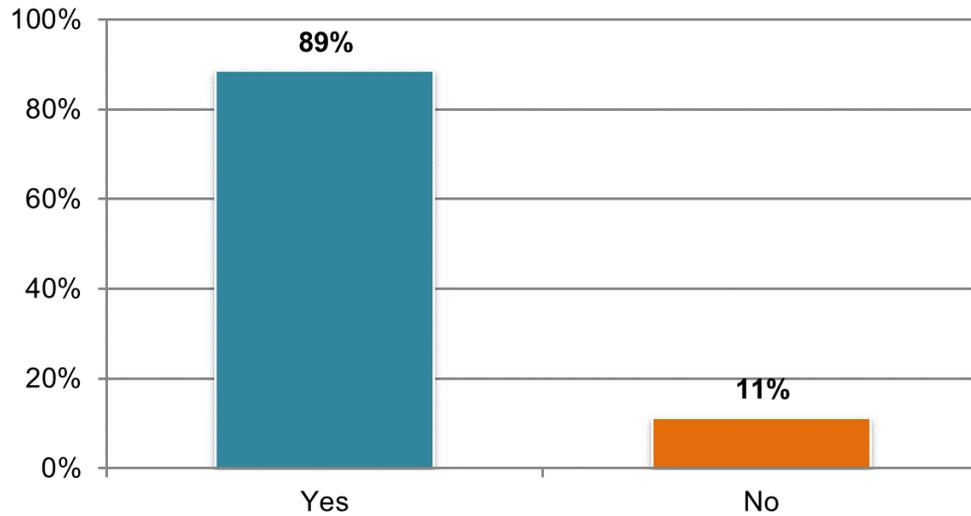


Table Q6. Does your family member have a service plan?

State	Yes	No	N
Significantly Above Average			
FL	95%	5%	381
PA	93%	7%	353
Within Average Range			
CO	91%	9%	291
OK	90%	10%	378
WI	90%	10%	347
UT	90%	10%	536
MN	90%	10%	532
MD	89%	11%	364
NC	89%	11%	212
SD	89%	11%	106
GA	88%	12%	342
LA	87%	13%	471
KY	86%	14%	113
CT	83%	17%	236
Significantly Below Average			
DC	80%	20%	187
NCI Average	89%	11%	4,849

Service Plan Includes All the Services and Supports Family Member Wants

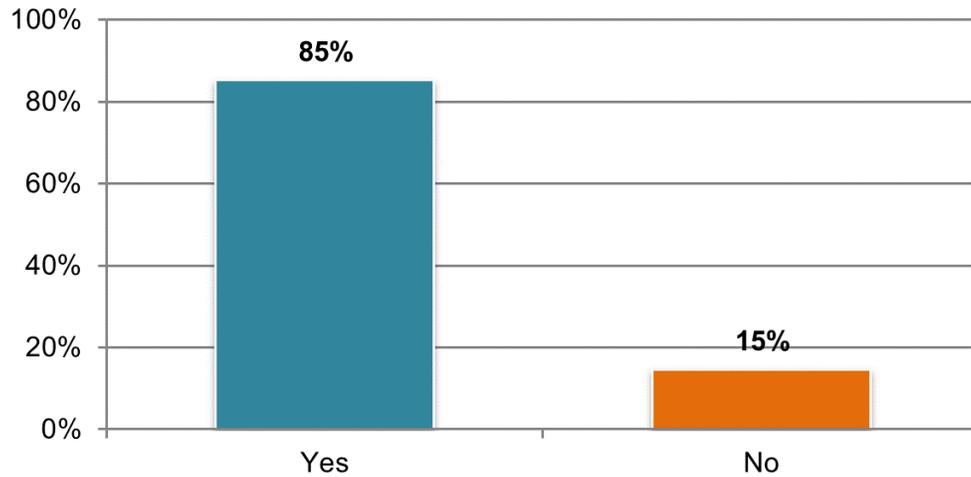


Table Q7. Does the plan include all the services and supports your family member wants?

State	Yes	No	N
Within Average Range			
PA	93%	7%	298
UT	93%	7%	437
LA	92%	8%	377
DC	91%	9%	143
OK	86%	14%	315
MN	86%	14%	424
KY	85%	15%	92
SD	85%	15%	85
FL	84%	16%	333
NC	84%	16%	167
WI	82%	18%	291
GA	81%	19%	264
CO	81%	19%	246
MD	80%	20%	284
CT	77%	23%	170
NCI Average	85%	15%	3,926

Family Member Receives All Services Listed in the Service Plan

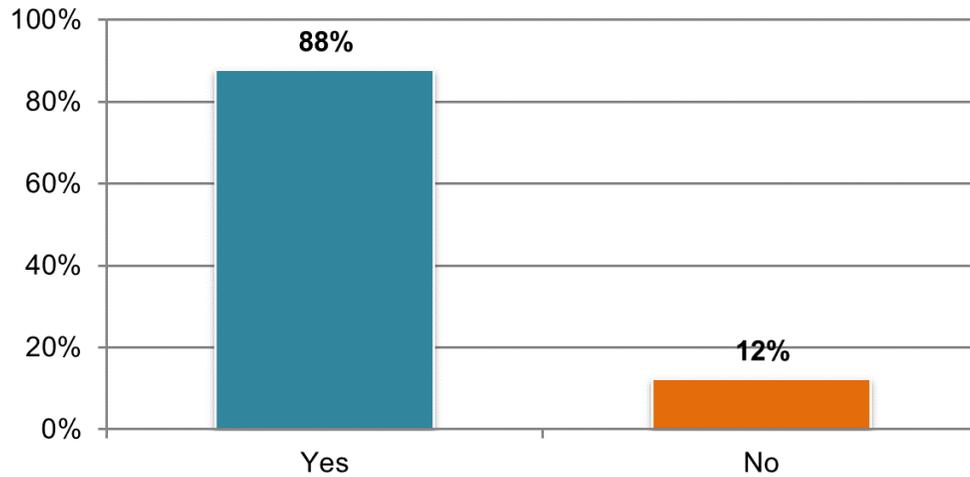


Table Q8. Does your family member receive all of the services listed in the plan?

State	Yes	No	N
Significantly Above Average			
UT	93%	7%	445
LA	93%	7%	369
MN	92%	8%	440
OK	92%	8%	316
Within Average Range			
CO	91%	9%	248
FL	90%	10%	329
WI	90%	10%	293
PA	89%	11%	284
GA	88%	12%	251
NC	88%	12%	166
SD	86%	14%	88
CT	84%	16%	169
MD	83%	17%	276
KY	81%	19%	88
Significantly Below Average			
DC	75%	25%	142
NCI Average	88%	12%	3,904

Family Member Helped Develop Service Plan

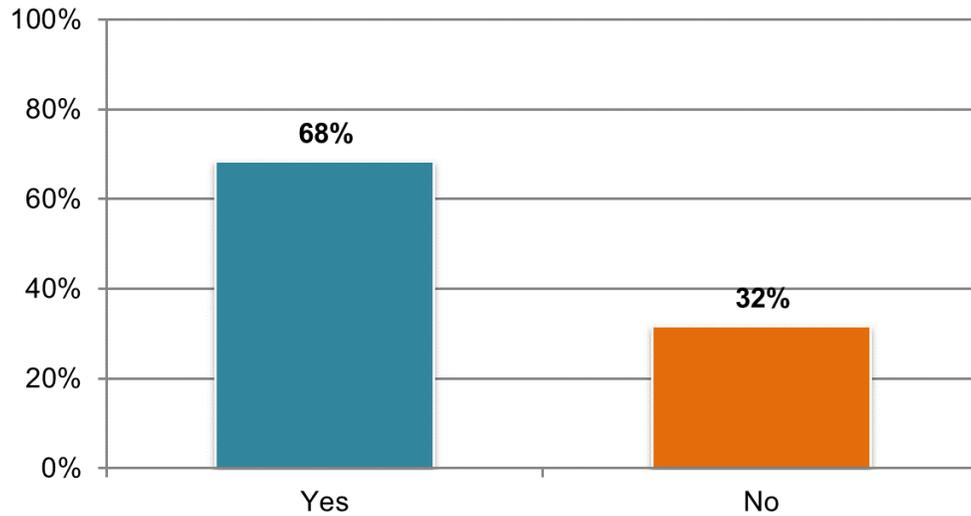


Table Q9. Did your family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
SD	84%	16%	86
Within Average Range			
DC	74%	26%	145
MD	74%	26%	301
KY	73%	27%	90
GA	72%	28%	272
PA	71%	29%	298
FL	70%	30%	324
CO	69%	31%	251
LA	68%	32%	379
UT	66%	34%	438
NC	64%	36%	171
OK	62%	38%	310
WI	61%	39%	285
Significantly Below Average			
MN	60%	40%	449
CT	58%	42%	173
NCI Average	68%	32%	3,972

Respondent or Another Family Member Helped Develop Service Plan

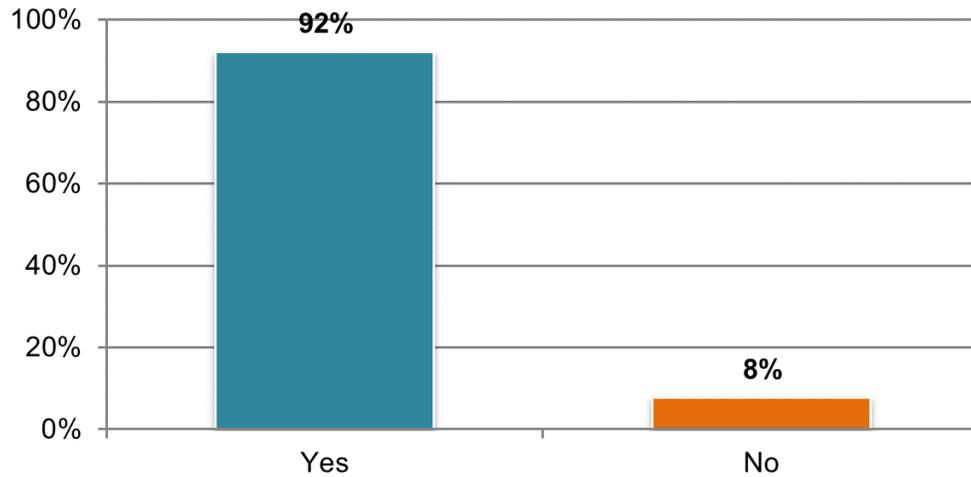


Table Q10. Did you or another family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
UT	96%	4%	466
CO	96%	4%	261
MN	95%	5%	460
Within Average Range			
OK	95%	5%	327
WI	95%	5%	301
KY	95%	5%	93
PA	94%	6%	308
SD	93%	7%	92
LA	93%	7%	385
NC	92%	8%	182
FL	89%	11%	339
MD	89%	11%	308
DC	88%	12%	144
CT	87%	13%	181
Significantly Below Average			
GA	86%	14%	280
NCI Average	92%	8%	4,127

Service Plan Includes All the Services and Supports Family Member Needs

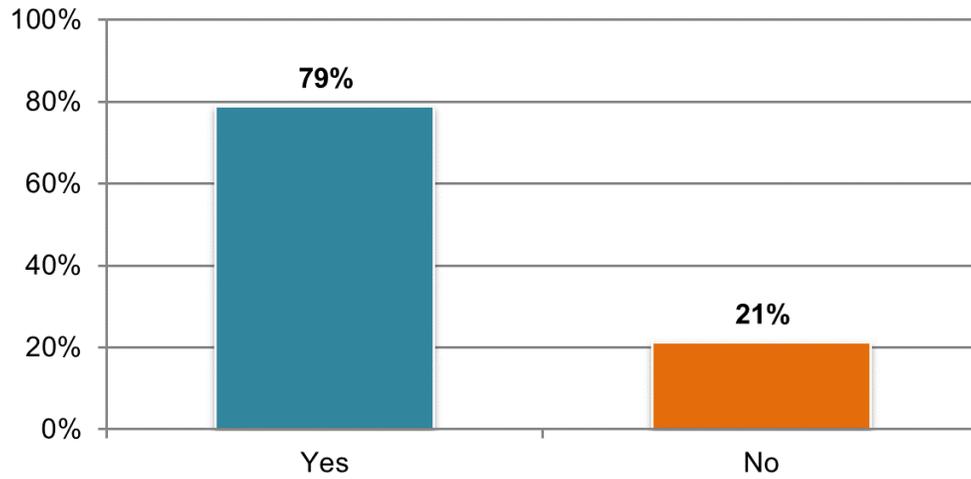


Table Q11. Does the plan include all the services and supports your family member needs?

State	Yes	No	N
Significantly Above Average			
PA	90%	10%	287
LA	88%	12%	376
UT	87%	13%	424
Within Average Range			
DC	83%	17%	140
MN	82%	18%	426
WI	81%	19%	289
OK	80%	20%	308
FL	80%	20%	322
SD	78%	22%	88
KY	77%	23%	92
CO	74%	26%	248
NC	74%	26%	173
Significantly Below Average			
MD	71%	29%	270
CT	69%	31%	169
GA	69%	31%	258
NCI Average	79%	21%	3,870

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

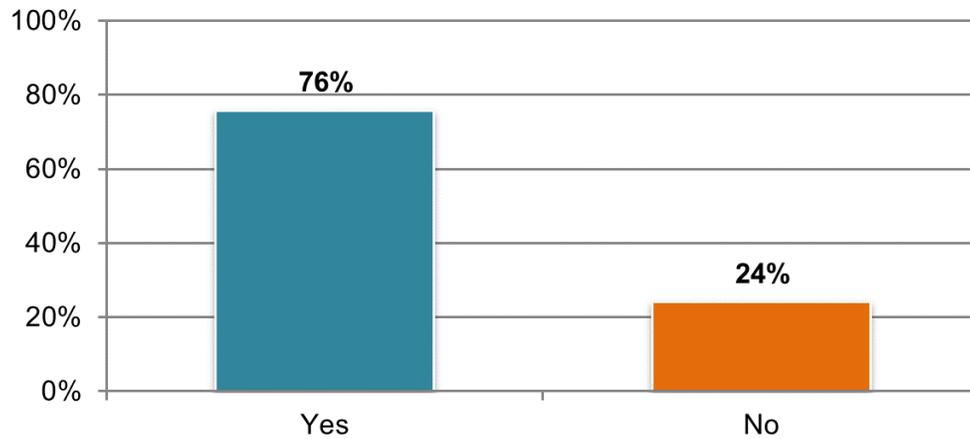


Table Q12. Did you discuss how to handle emergencies related to your family member at the last service planning meeting?

State	Yes	No	N
Significantly Above Average			
LA	94%	6%	391
OK	82%	18%	310
FL	82%	18%	328
Within Average Range			
KY	84%	16%	87
NC	81%	19%	173
DC	78%	22%	134
MN	77%	23%	432
PA	76%	24%	280
CO	73%	27%	248
WI	70%	30%	272
SD	67%	33%	86
MD	71%	29%	284
Significantly Below Average			
UT	69%	31%	426
CT	69%	31%	166
GA	65%	35%	264
NCI Average	76%	24%	3,881

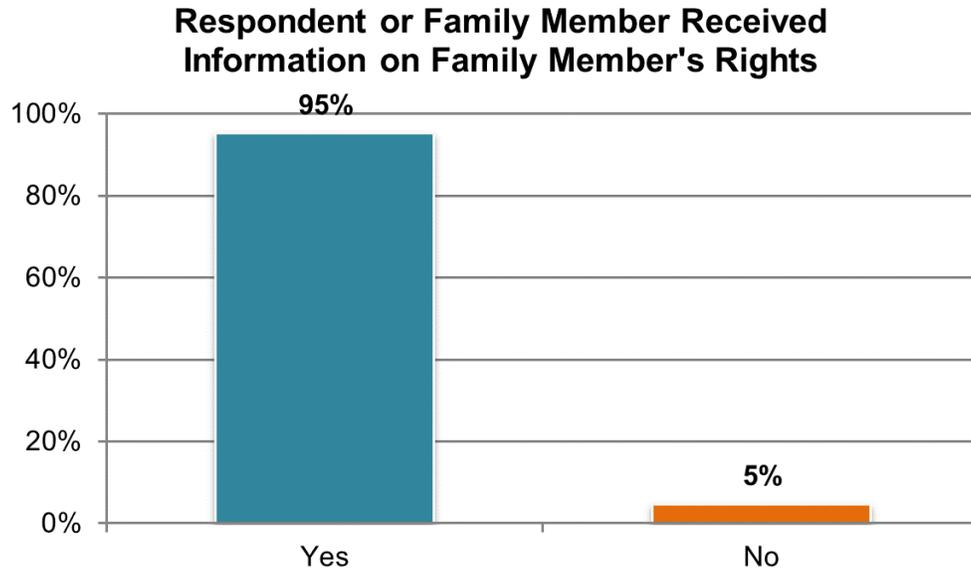


Table Q13. Have you or your family member received information about his/her rights?

State	Yes	No	N
Significantly Above Average			
KY	99%	1%	110
WI	98%	2%	340
Within Average Range			
UT	97%	3%	525
OK	97%	3%	384
LA	97%	3%	471
CO	96%	4%	297
PA	96%	4%	349
FL	96%	4%	383
MN	96%	4%	519
SD	95%	5%	117
NC	95%	5%	210
MD	94%	6%	335
GA	93%	7%	349
DC	92%	8%	202
CT	91%	9%	213
NCI Average	95%	5%	4,804

Access and Delivery of Services and Supports

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

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

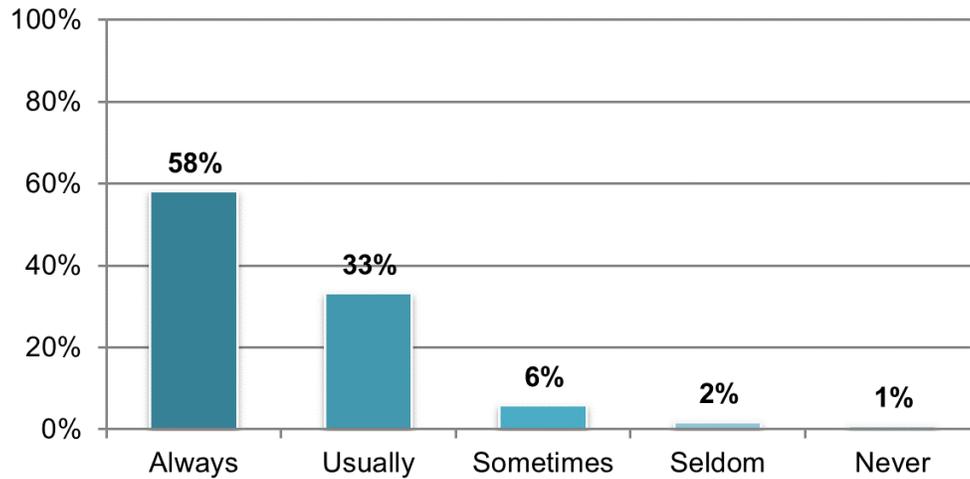


Table Q14. Are you or your family member able to contact his/her support workers when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	74%	18%	5%	1%	1%	405
LA	69%	26%	4%	2%	0%	518
UT	66%	30%	3%	1%	0%	591
PA	65%	30%	4%	1%	0%	381
Within Average Range						
WI	62%	34%	3%	0%	1%	388
GA	59%	29%	6%	2%	4%	379
NC	58%	34%	5%	1%	2%	220
DC	57%	27%	11%	3%	2%	219
CT	57%	34%	6%	3%	1%	265
SD	54%	41%	5%	1%	0%	123
KY	54%	38%	6%	2%	0%	125
CO	53%	40%	5%	2%	0%	309
OK	52%	38%	7%	1%	1%	402
Significantly Below Average						
MN	49%	39%	9%	2%	0%	584
MD	44%	42%	9%	4%	1%	393
NCI Average	58%	33%	6%	2%	1%	5,302

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

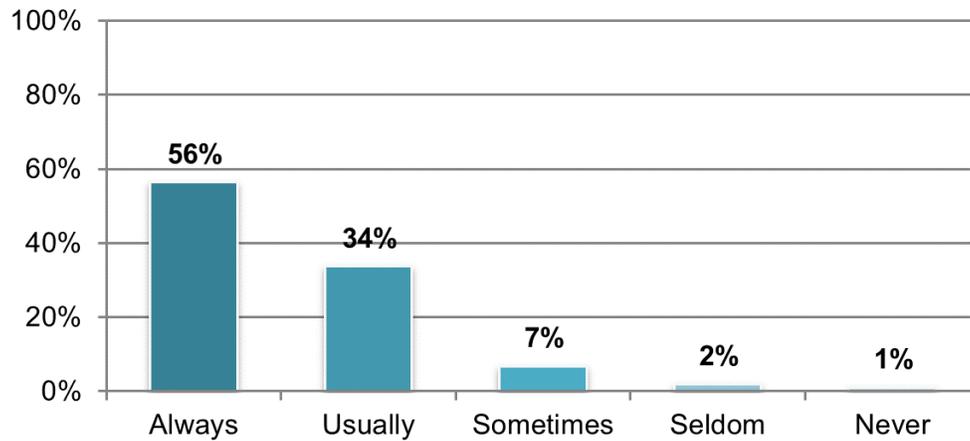


Table Q15. Are you or your family member able to contact his/her case manager/service coordinator when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	72%	19%	6%	1%	1%	401
UT	67%	28%	4%	1%	0%	588
LA	67%	27%	5%	1%	0%	526
WI	63%	33%	3%	0%	0%	391
Within Average Range						
CT	63%	26%	6%	3%	1%	279
PA	62%	32%	4%	2%	0%	382
NC	58%	32%	6%	2%	2%	217
DC	55%	30%	10%	3%	1%	224
GA	52%	36%	6%	2%	4%	380
OK	51%	36%	11%	1%	1%	406
KY	49%	39%	8%	2%	2%	128
SD	47%	44%	8%	1%	0%	125
Significantly Below Average						
CO	47%	46%	5%	2%	1%	306
MN	47%	40%	10%	3%	1%	587
MD	46%	38%	10%	5%	2%	389
NCI Average	56%	34%	7%	2%	1%	5,329

Services and Supports Are Available When Family Member Needs Them

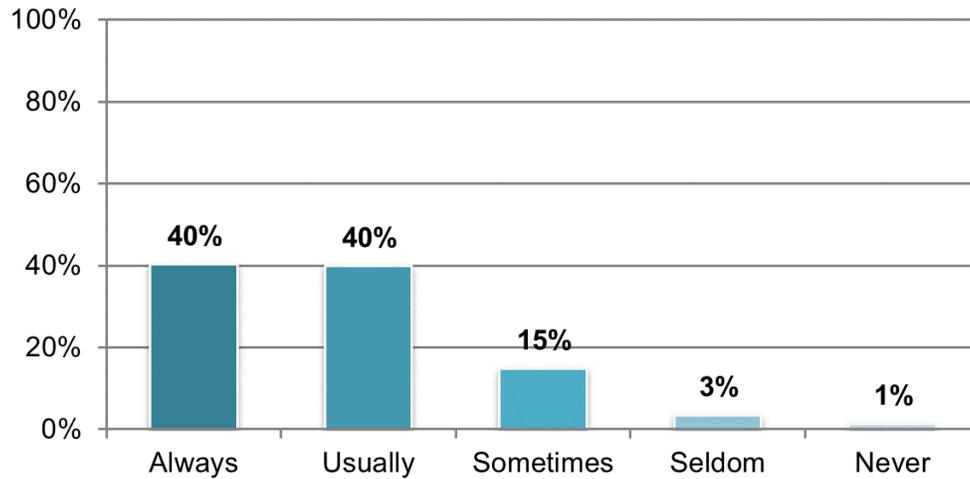


Table Q16. Are services and supports available when your family member needs them?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	53%	35%	9%	2%	0%	512
FL	49%	30%	15%	2%	3%	392
Within Average Range						
DC	48%	33%	14%	5%	1%	222
WI	47%	41%	11%	1%	0%	351
UT	44%	45%	9%	2%	0%	564
OK	41%	40%	14%	3%	2%	389
GA	40%	38%	14%	5%	4%	362
PA	40%	39%	17%	3%	2%	367
NC	39%	40%	15%	4%	2%	216
CT	37%	36%	18%	6%	3%	255
SD	37%	42%	19%	2%	1%	125
KY	35%	43%	18%	3%	1%	126
CO	34%	48%	14%	3%	1%	298
Significantly Below Average						
MN	30%	47%	18%	4%	1%	568
MD	29%	43%	19%	7%	1%	354
NCI Average	40%	40%	15%	3%	1%	5,101

Services and Supports Are Available a Reasonable Distance from Home

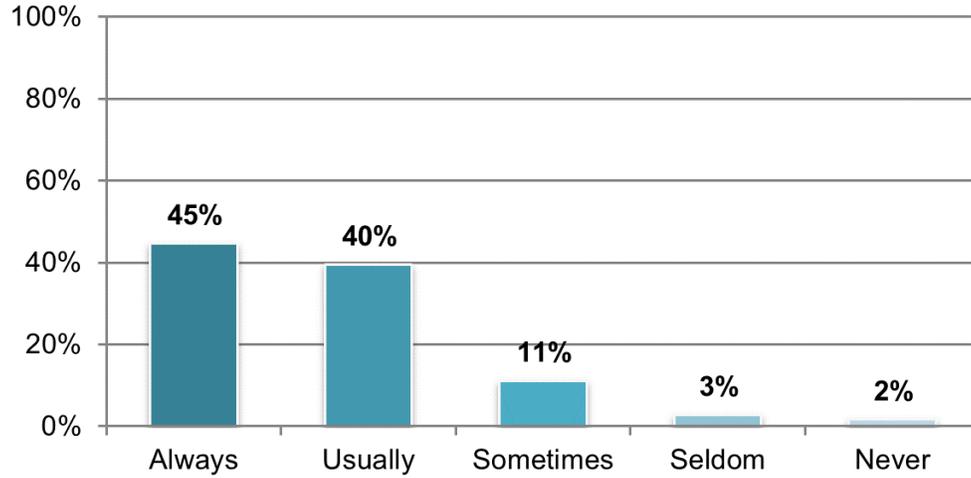


Table Q17. Are services and supports available within a reasonable distance from your home?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	58%	31%	9%	2%	1%	500
WI	54%	34%	9%	2%	1%	376
Within Average Range						
FL	50%	34%	12%	2%	2%	366
SD	50%	40%	9%	1%	0%	120
DC	48%	37%	12%	1%	2%	201
GA	47%	33%	11%	4%	5%	350
UT	45%	42%	10%	2%	1%	546
OK	45%	39%	11%	3%	2%	376
PA	44%	38%	12%	3%	3%	347
CT	43%	37%	14%	5%	2%	244
NC	42%	42%	10%	4%	2%	205
CO	39%	45%	12%	2%	2%	296
Significantly Below Average						
MN	38%	42%	14%	5%	1%	553
MD	34%	49%	12%	4%	1%	336
KY	33%	51%	11%	4%	1%	125
NCI Average	45%	40%	11%	3%	2%	4,941

Services and Supports Change When Family Member's Needs Change

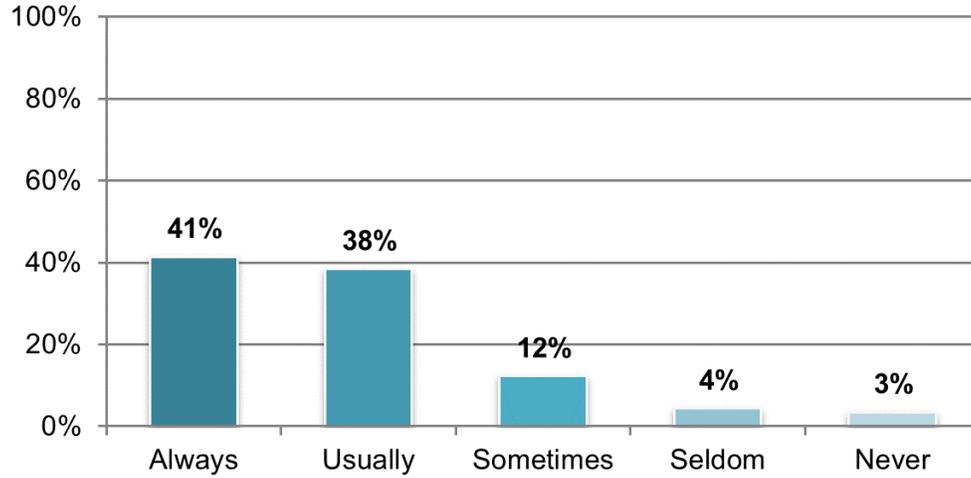


Table Q18. Do the services and supports change when your family member's needs change?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	54%	32%	8%	3%	3%	449
UT	47%	40%	9%	3%	1%	510
Within Average Range						
FL	47%	33%	14%	3%	4%	331
DC	45%	34%	15%	2%	4%	202
CO	44%	42%	10%	2%	3%	262
NC	42%	39%	10%	5%	4%	196
PA	42%	35%	16%	5%	3%	307
OK	42%	41%	10%	5%	3%	337
KY	41%	38%	8%	10%	2%	107
WI	40%	43%	13%	2%	2%	323
SD	40%	39%	17%	2%	3%	113
GA	40%	36%	13%	4%	7%	317
CT	33%	42%	10%	5%	10%	196
Significantly Below Average						
MN	34%	43%	15%	6%	2%	500
MD	30%	40%	16%	9%	4%	282
NCI Average	41%	38%	12%	4%	3%	4,432

Support Workers Speak Effectively in Primary Language (If English)

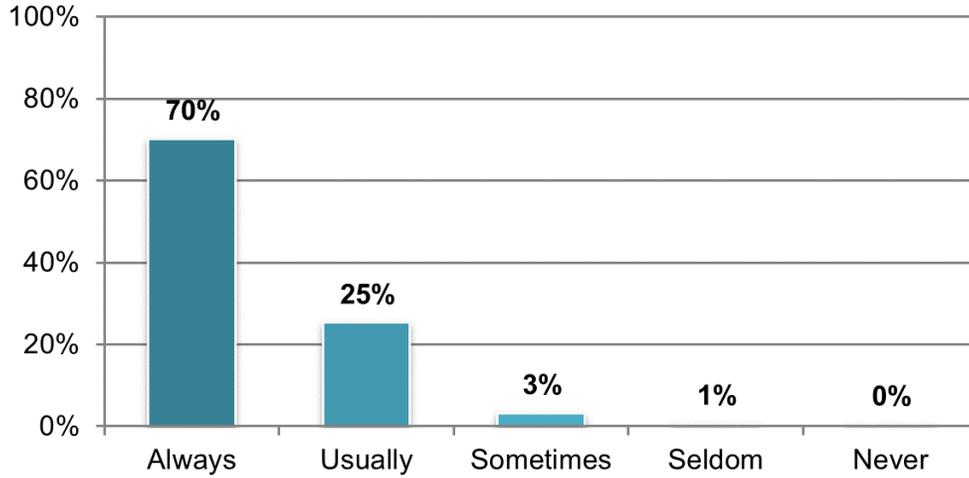


Table Q20. If English is your primary language, do the support workers speak to you effectively?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	81%	15%	3%	0%	1%	305
UT	77%	22%	1%	0%	0%	519
LA	77%	21%	2%	0%	1%	450
WI	77%	21%	2%	0%	0%	345
Within Average Range						
PA	75%	24%	1%	0%	0%	351
OK	70%	25%	4%	0%	1%	351
DC	69%	21%	7%	2%	1%	163
CO	69%	27%	3%	1%	0%	270
NC	69%	25%	4%	2%	1%	185
KY	68%	27%	4%	1%	0%	115
MN	68%	28%	4%	0%	0%	495
CT	67%	28%	1%	1%	2%	229
GA	66%	26%	4%	2%	2%	327
SD	64%	32%	4%	0%	0%	108
Significantly Below Average						
MD	57%	37%	5%	1%	0%	355
NCI Average	70%	25%	3%	1%	0%	4,568

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

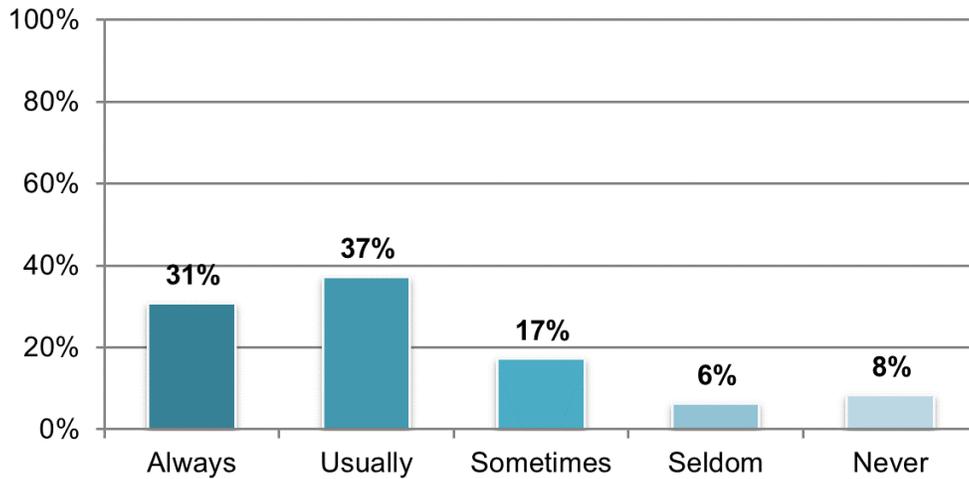


Table Q21. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	49%	29%	9%	3%	9%	116
Within Average Range						
NC	45%	44%	9%	0%	2%	64
DC	40%	35%	19%	2%	3%	62
PA	37%	29%	16%	7%	10%	68
GA	36%	36%	17%	2%	9%	81
FL	34%	33%	18%	8%	7%	106
UT	33%	34%	17%	6%	9%	158
MN	29%	32%	15%	14%	11%	122
CO	27%	27%	27%	12%	8%	60
WI	25%	41%	22%	3%	9%	88
MD	24%	35%	18%	14%	9%	66
KY	24%	48%	12%	12%	4%	25
OK	24%	38%	24%	4%	9%	117
CT	24%	36%	24%	2%	14%	42
Significantly Below Average						
SD	12%	62%	12%	4%	12%	26
NCI Average	31%	37%	17%	6%	8%	1,201

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

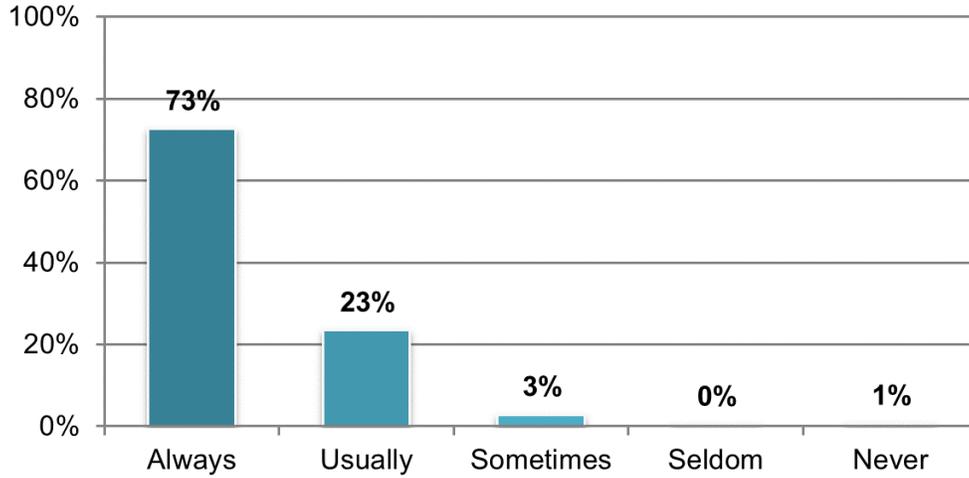


Table Q22. Are services delivered in a way that is respectful to your family’s culture?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	80%	17%	2%	1%	0%	367
UT	80%	19%	1%	0%	0%	558
WI	79%	19%	2%	0%	0%	330
Within Average Range						
PA	78%	20%	2%	0%	0%	332
LA	76%	21%	2%	1%	1%	499
CT	76%	19%	4%	0%	1%	224
CO	74%	23%	2%	0%	1%	272
MN	73%	23%	3%	0%	0%	487
NC	70%	26%	3%	1%	1%	200
OK	70%	27%	3%	0%	1%	360
SD	69%	28%	3%	0%	0%	98
KY	67%	29%	3%	1%	1%	119
GA	67%	26%	5%	1%	2%	344
DC	64%	28%	5%	1%	2%	196
Significantly Below Average						
MD	65%	29%	5%	1%	0%	332
NCI Average	73%	23%	3%	0%	1%	4,718

Family Member Has Access to Special Equipment or Accommodations Needed

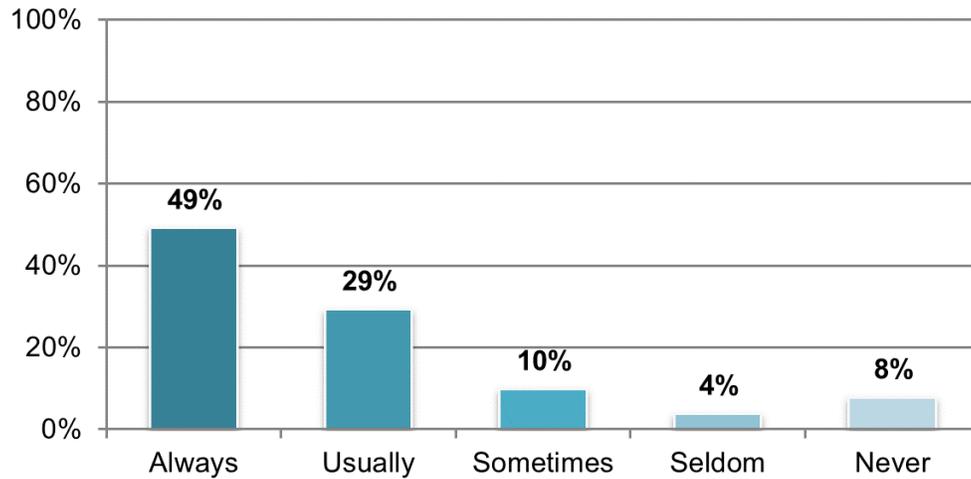


Table Q23. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
WI	62%	25%	7%	3%	3%	182
LA	59%	19%	8%	2%	11%	244
Within Average Range						
FL	55%	23%	11%	2%	10%	188
NC	53%	28%	13%	2%	4%	116
SD	52%	32%	8%	6%	1%	71
CO	48%	36%	9%	3%	3%	128
PA	48%	27%	11%	3%	10%	131
CT	48%	24%	11%	2%	15%	92
DC	48%	15%	11%	6%	20%	84
OK	47%	34%	7%	8%	6%	200
KY	44%	31%	12%	7%	7%	59
MN	44%	38%	12%	4%	2%	268
GA	44%	28%	10%	4%	15%	176
MD	43%	38%	10%	3%	7%	119
UT	43%	42%	9%	4%	3%	291
NCI Average	49%	29%	10%	4%	8%	2,349

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

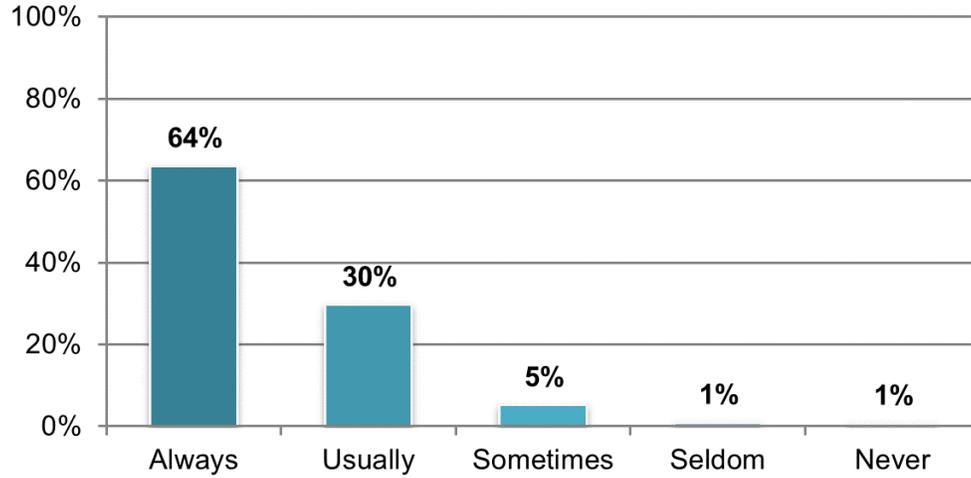


Table Q24. Do you feel that your family member’s day/employment setting is a healthy and safe environment?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	75%	20%	4%	0%	1%	409
WI	75%	21%	4%	0%	0%	347
FL	72%	26%	2%	0%	1%	285
Within Average Range						
PA	67%	27%	5%	1%	0%	324
OK	66%	28%	5%	0%	0%	281
KY	66%	28%	5%	0%	1%	111
DC	65%	21%	10%	1%	2%	187
NC	64%	28%	6%	2%	0%	177
GA	63%	27%	6%	2%	2%	315
CT	60%	31%	6%	2%	0%	252
UT	60%	35%	4%	1%	1%	499
CO	59%	34%	5%	1%	1%	258
MN	58%	34%	6%	1%	0%	509
Significantly Below Average						
MD	53%	39%	5%	2%	2%	371
SD	49%	46%	4%	1%	0%	120
NCI Average	64%	30%	5%	1%	1%	4,445

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

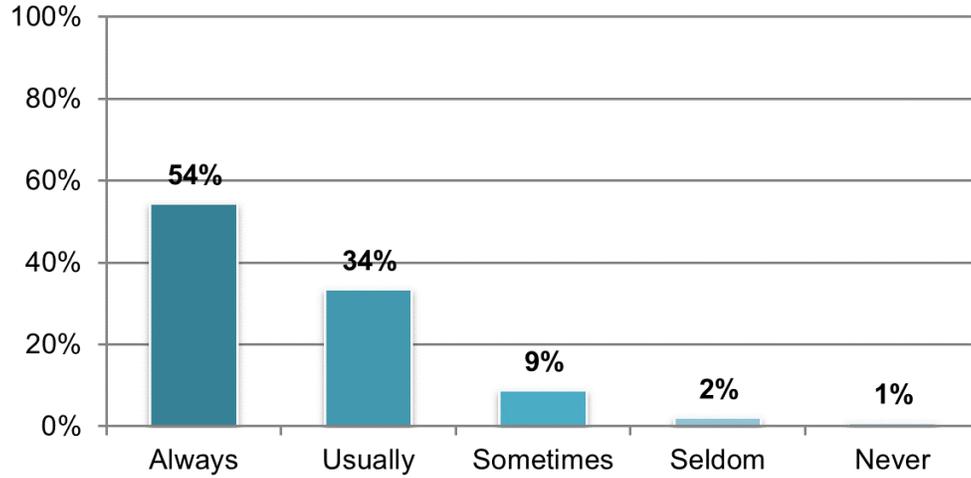


Table Q25. Do the support workers have the right training to meet your family's needs?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	66%	27%	4%	2%	1%	357
LA	66%	27%	5%	2%	1%	498
Within Average Range						
OK	60%	30%	7%	1%	1%	348
PA	60%	33%	5%	1%	1%	334
WI	58%	34%	7%	2%	0%	362
UT	58%	34%	7%	1%	0%	534
DC	56%	27%	12%	3%	3%	200
NC	56%	30%	11%	4%	0%	200
GA	54%	31%	11%	1%	3%	330
CT	52%	36%	10%	2%	1%	242
MN	51%	40%	7%	3%	0%	534
CO	49%	38%	10%	2%	1%	259
KY	48%	37%	14%	1%	1%	117
Significantly Below Average						
MD	43%	39%	14%	3%	1%	336
SD	42%	41%	11%	6%	0%	116
NCI Average	54%	34%	9%	2%	1%	4,767

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

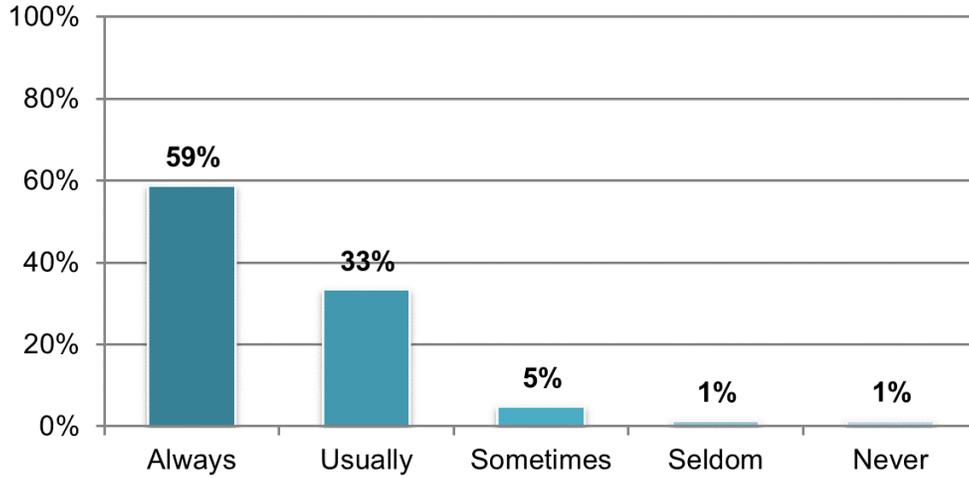


Table Q26. Do the support workers who come to your home arrive on time and when scheduled?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
WI	71%	24%	3%	1%	0%	209
FL	70%	23%	4%	1%	2%	354
PA	68%	29%	2%	1%	1%	308
LA	67%	25%	6%	1%	0%	486
Within Average Range						
OK	61%	31%	5%	2%	1%	314
CT	59%	33%	3%	1%	4%	162
UT	58%	37%	4%	1%	0%	524
CO	58%	36%	4%	2%	1%	228
MN	56%	38%	5%	0%	0%	490
NC	56%	34%	8%	1%	2%	189
DC	55%	28%	7%	7%	3%	195
KY	55%	37%	6%	0%	2%	105
SD	50%	44%	6%	0%	0%	48
Significantly Below Average						
MD	50%	43%	5%	1%	0%	230
GA	49%	39%	6%	1%	4%	277
NCI Average	59%	33%	5%	1%	1%	4,119

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

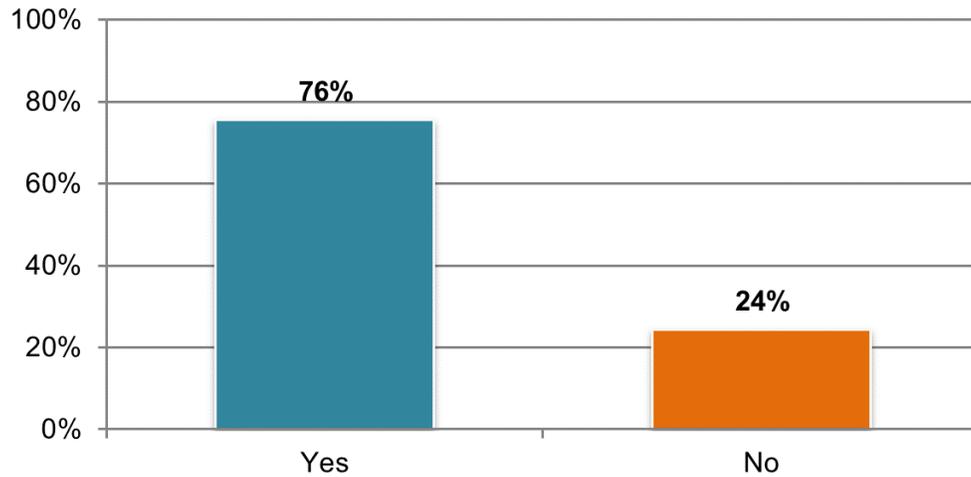


Table Q27. If your family member transitioned from school services to state-funded services during the past year, were you happy with the transition process?

State	Yes	No	N
Within Average Range			
MN	83%	17%	76
UT	83%	17%	58
GA	80%	20%	25
DC	78%	22%	23
OK	77%	23%	22
WI	77%	23%	39
MD	76%	24%	46
LA	76%	24%	37
FL	67%	33%	42
PA	59%	41%	32
NCI Average	76%	24%	400
N < 20			
CO	N/A	N/A	N/A
CT	N/A	N/A	N/A
KY	N/A	N/A	N/A
NC	N/A	N/A	N/A
SD	N/A	N/A	N/A

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

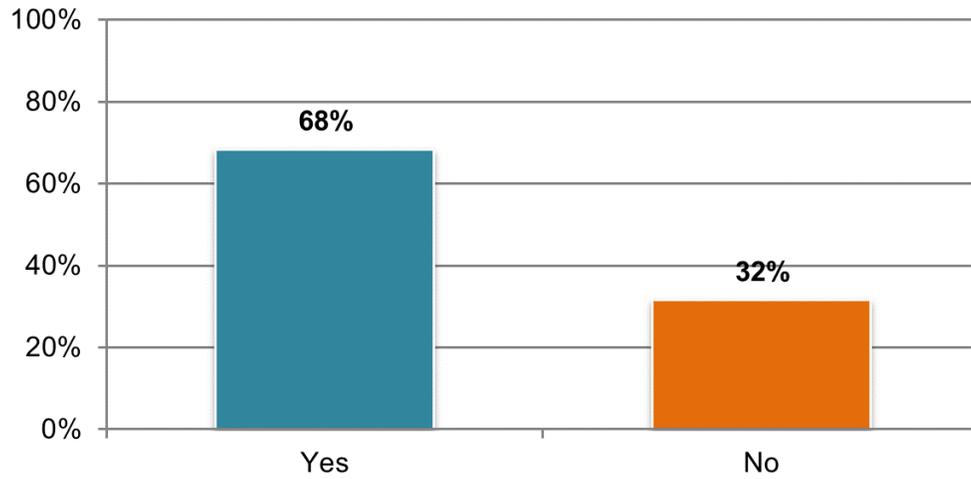


Table Q28. If you asked for crisis or emergency services during the past year, were services provided when needed?

State	Yes	No	N
Significantly Above Average			
LA	84%	16%	144
Within Average Range			
OK	78%	22%	67
UT	75%	25%	87
WI	74%	26%	43
DC	73%	27%	73
GA	72%	28%	76
CO	70%	30%	57
PA	70%	30%	56
FL	69%	31%	87
NC	68%	32%	65
MN	64%	36%	78
CT	60%	40%	57
SD	59%	41%	22
KY	57%	43%	28
MD	54%	46%	39
NCI Average	68%	32%	979

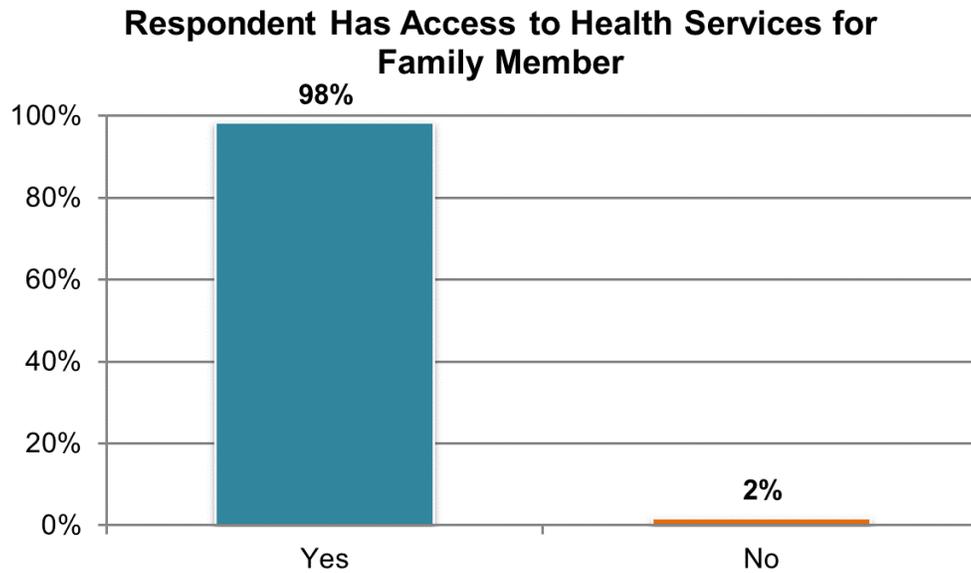


Table Q29. Do you have access to health services for your family member?

State	Yes	No	N
Significantly Above Average			
WI	100%	0%	261
MN	99%	1%	578
Within Average Range			
OK	99%	1%	394
PA	99%	1%	376
UT	99%	1%	589
SD	98%	2%	130
CT	98%	2%	257
KY	98%	2%	128
NC	98%	2%	222
LA	98%	2%	505
CO	97%	3%	306
MD	97%	3%	378
DC	97%	3%	211
GA	97%	3%	360
FL	97%	3%	370
NCI Average	98%	2%	5,065

Respondent Is Satisfied With Family Member's Health Providers

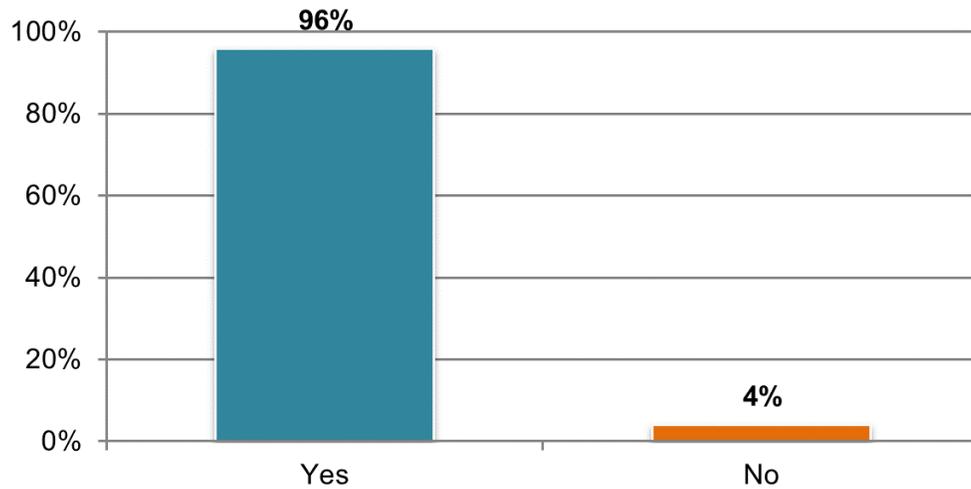


Table Q29a. If you have access to health services for your family member, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
SD	99%	1%	123
PA	98%	2%	345
Within Average Range			
GA	98%	2%	335
OK	97%	3%	370
CO	97%	3%	291
WI	97%	3%	255
UT	97%	3%	566
MN	97%	3%	557
LA	96%	4%	473
MD	96%	4%	344
NC	94%	6%	210
KY	94%	6%	122
FL	94%	6%	337
DC	93%	7%	188
CT	92%	8%	239
NCI Average	96%	4%	4,755

Respondent Has Access to Dental Services for Family Member

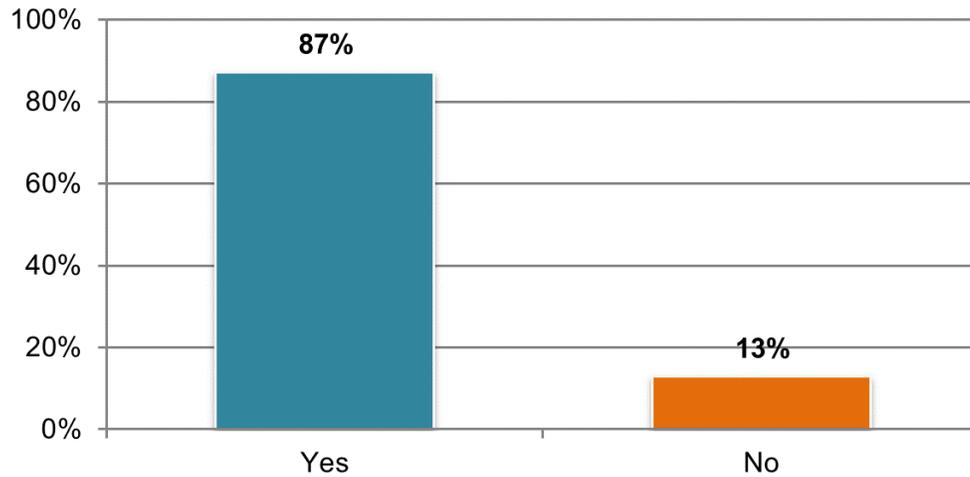


Table Q30. Do you have access to dental services for your family member?

State	Yes	No	N
Significantly Above Average			
SD	95%	5%	131
CO	95%	5%	305
MN	95%	5%	583
KY	95%	5%	128
CT	92%	8%	264
Within Average Range			
WI	90%	10%	250
PA	90%	10%	375
NC	89%	11%	224
DC	89%	11%	215
OK	87%	13%	381
MD	83%	17%	379
Significantly Below Average			
FL	78%	22%	380
UT	78%	22%	574
GA	78%	22%	359
LA	73%	27%	478
NCI Average	87%	13%	5,026

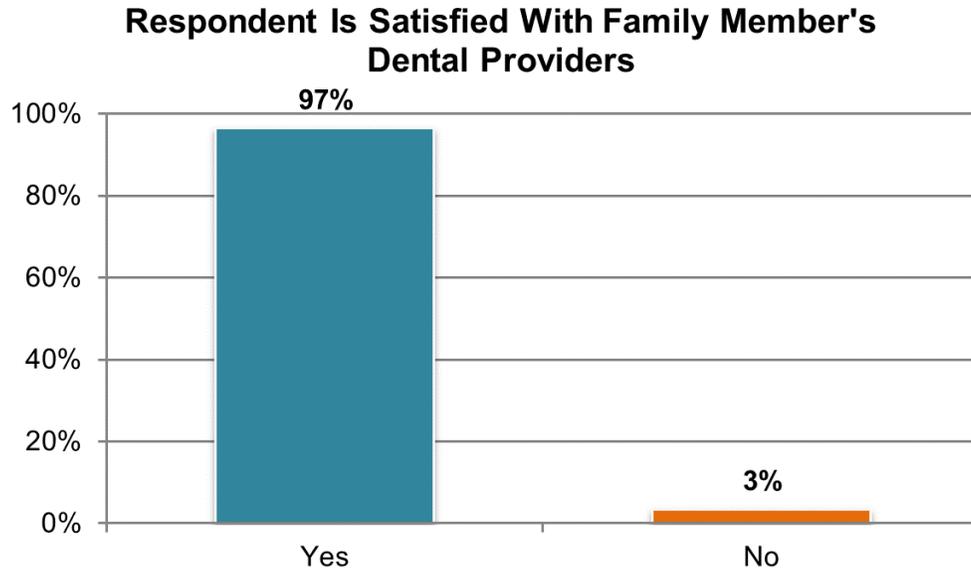


Table Q30a. If you have access to dental services for your family member, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
SD	100%	0%	119
UT	99%	1%	423
Within Average Range			
KY	98%	2%	116
PA	98%	2%	314
OK	98%	2%	303
LA	98%	2%	327
GA	97%	3%	261
WI	97%	3%	221
CO	97%	3%	280
MD	97%	3%	295
DC	95%	5%	169
FL	94%	6%	275
CT	94%	6%	225
NC	94%	6%	191
Significantly Below Average			
MN	94%	6%	524
NCI Average	97%	3%	4,043

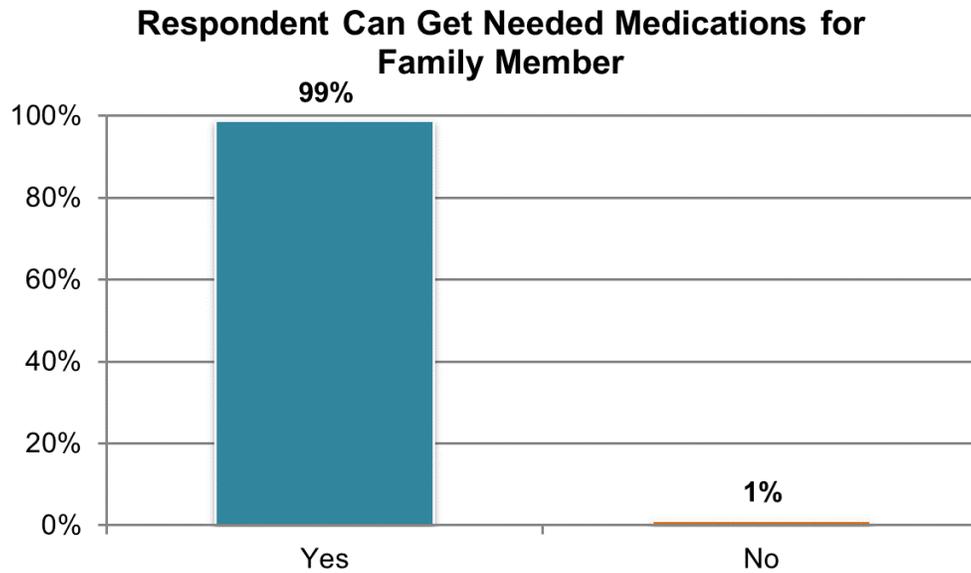


Table Q31. Are you able to get medications needed for your family member?

State	Yes	No	N
Significantly Above Average			
SD	100%	0%	130
WI	100%	0%	255
CO	100%	0%	301
MN	100%	0%	581
Within Average Range			
OK	99%	1%	398
KY	99%	1%	130
PA	99%	1%	379
UT	99%	1%	596
MD	99%	1%	375
FL	98%	2%	382
NC	98%	2%	223
LA	98%	2%	509
GA	98%	2%	353
CT	97%	3%	256
DC	97%	3%	209
NCI Average	99%	1%	5,077

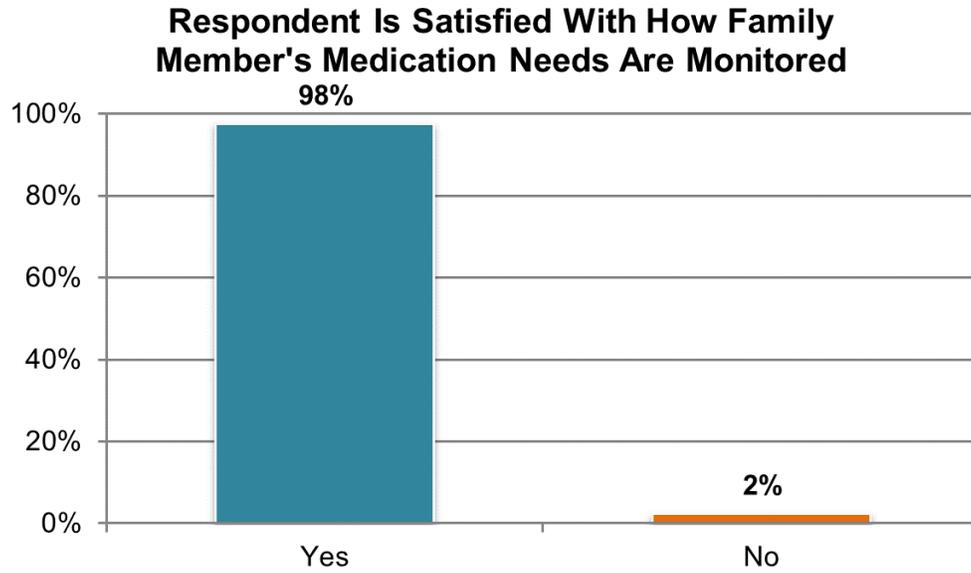


Table Q31a. If you are able to get needed medications for your family member, are you satisfied with how your family member's medication needs are monitored?

State	Yes	No	N
Significantly Above Average			
OK	99%	1%	365
PA	99%	1%	347
Within Average Range			
KY	99%	1%	124
SD	99%	1%	124
FL	99%	1%	346
WI	98%	2%	240
LA	98%	2%	467
MD	98%	2%	328
UT	97%	3%	545
CO	97%	3%	282
MN	97%	3%	546
DC	97%	3%	179
NC	97%	3%	208
GA	97%	3%	319
CT	96%	4%	245
NCI Average	98%	2%	4,665

Respondent Has Access to Needed Mental Health Services for Family Member

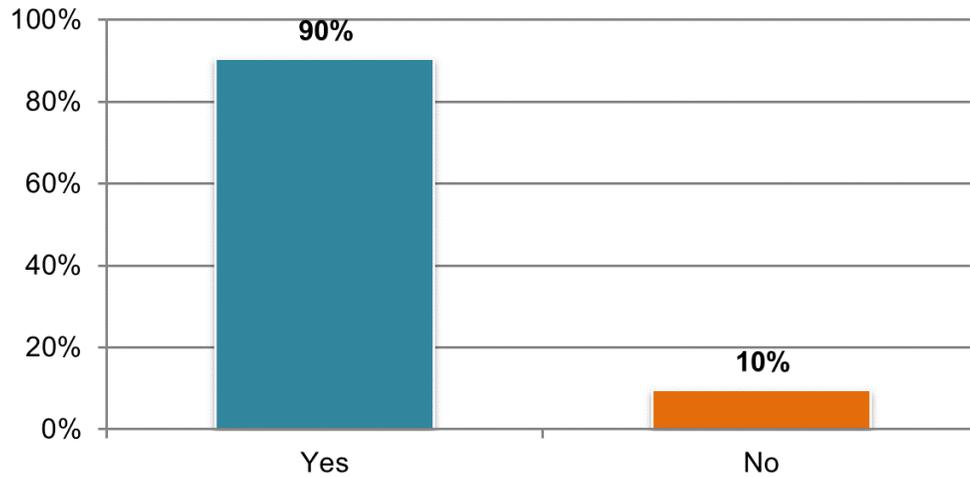


Table Q32. If needed, do you have access to mental health services for your family member?

State	Yes	No	N
Significantly Above Average			
NC	95%	5%	169
MN	94%	6%	357
Within Average Range			
KY	94%	6%	86
SD	94%	6%	64
WI	93%	7%	122
PA	92%	8%	214
UT	91%	9%	324
OK	90%	10%	194
CO	89%	11%	171
GA	89%	11%	241
FL	88%	12%	205
MD	88%	12%	221
DC	87%	13%	141
LA	86%	14%	295
CT	86%	14%	130
NCI Average	90%	10%	2,934

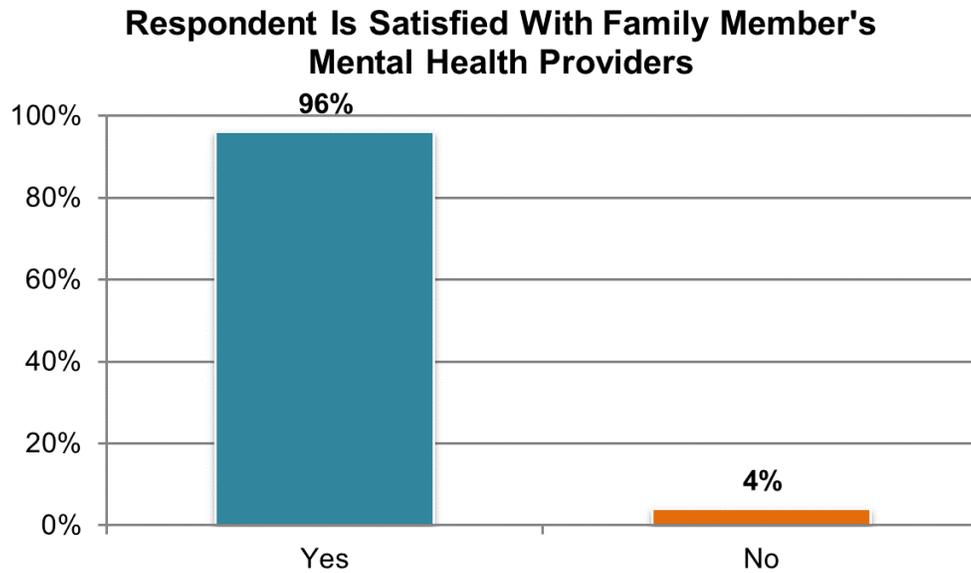


Table Q32a. If you have access to needed mental health services, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
SD	100%	0%	47
OK	99%	1%	134
Within Average Range			
DC	98%	2%	98
KY	97%	3%	70
NC	97%	3%	131
PA	97%	3%	153
LA	96%	4%	209
CT	95%	5%	85
MD	95%	5%	147
CO	95%	5%	114
MN	95%	5%	261
FL	94%	6%	144
GA	94%	6%	180
UT	94%	6%	201
WI	94%	6%	95
NCI Average	96%	4%	2,069

Respondent Has Access to Respite Services Needed for Family Member

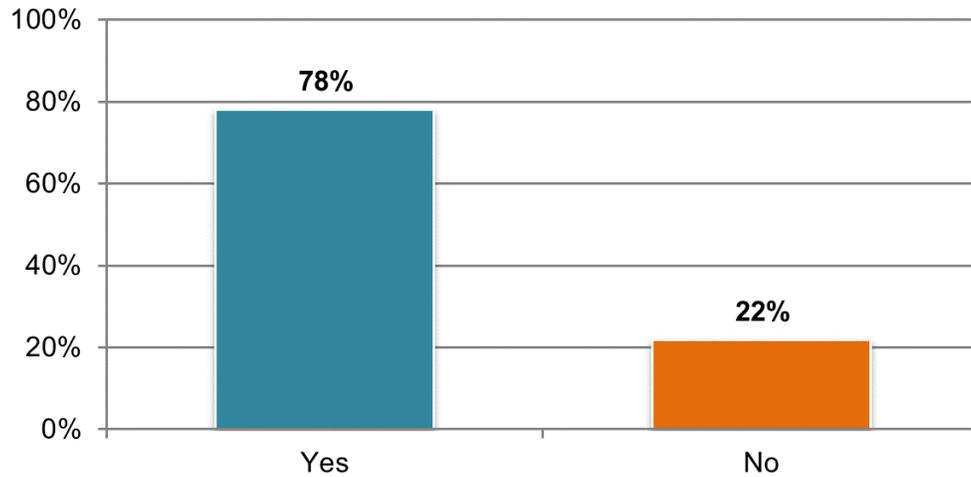


Table Q33. If you need respite services, do you have access to them?

State	Yes	No	N
Significantly Above Average			
KY	88%	12%	113
UT	88%	12%	459
DC	88%	12%	147
PA	85%	15%	227
WI	85%	15%	181
LA	84%	16%	301
Within Average Range			
NC	85%	15%	195
MN	82%	18%	396
CT	81%	19%	165
CO	78%	22%	201
FL	76%	24%	269
SD	69%	31%	64
Significantly Below Average			
MD	65%	35%	198
GA	59%	41%	218
OK	59%	41%	176
NCI Average	78%	22%	3,310

Respondent Is Satisfied With Family Member's Respite Providers

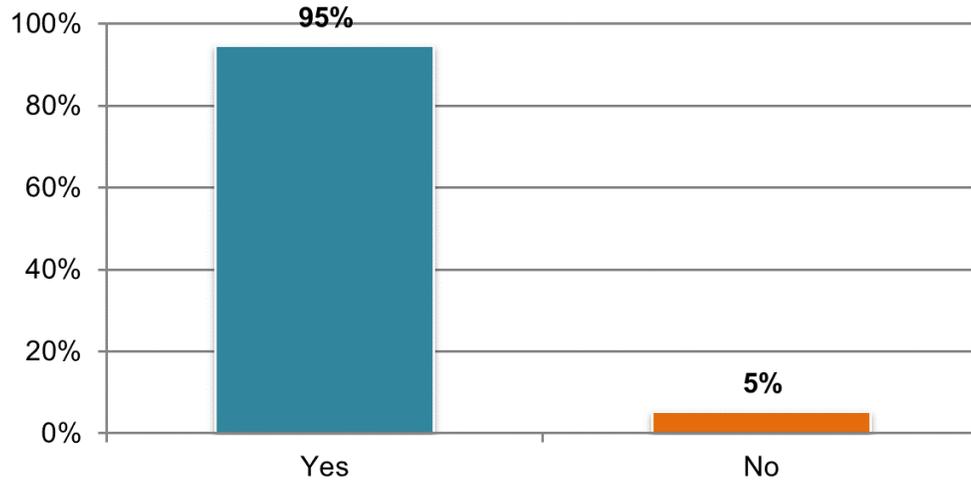


Table Q33a. If you have access to needed respite services, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
FL	99%	1%	174
LA	98%	2%	226
UT	97%	3%	371
Within Average Range			
KY	96%	4%	95
MN	95%	5%	274
CT	95%	5%	103
PA	95%	5%	162
WI	95%	5%	140
NC	94%	6%	154
CO	93%	7%	122
OK	93%	7%	87
SD	93%	7%	42
DC	93%	7%	95
GA	92%	8%	114
MD	92%	8%	99
NCI Average	95%	5%	2,258

Services Are Needed That Are Not Currently Offered or Available

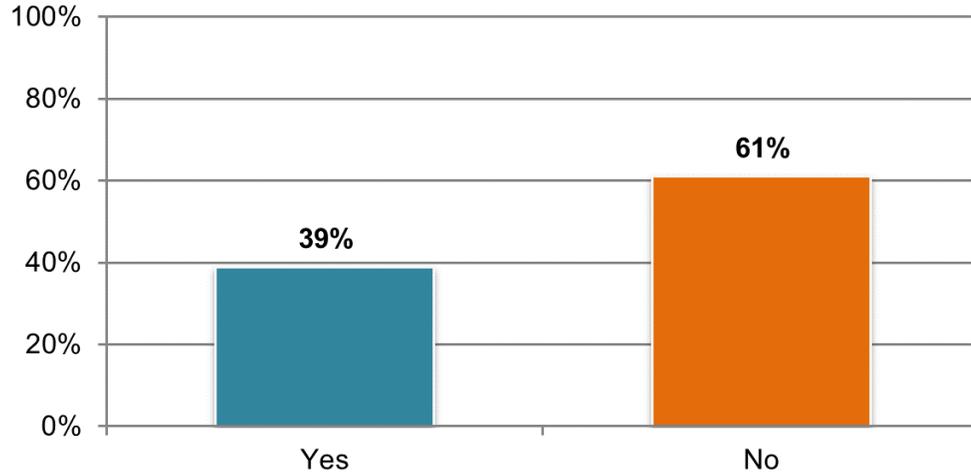


Table Q34. Are there other services that your family member needs that are not currently offered or available?²

State	Yes	No	N
Within Average Range			
CT	47%	53%	167
GA	46%	54%	226
NC	45%	55%	162
FL	45%	55%	280
MD	44%	56%	243
DC	44%	56%	153
CO	41%	59%	199
WI	38%	62%	175
OK	38%	62%	256
KY	37%	63%	92
MN	36%	64%	381
LA	36%	64%	342
SD	27%	73%	79
Significantly Below Average			
UT	30%	70%	435
PA	29%	71%	231
NCI Average	39%	61%	3,421

² The 'yes' response is the less desired response, a higher average means more people reported they were in need of additional services that are not offered.

Choice and Control

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

Respondent Chooses Provider Agencies That Work With Family

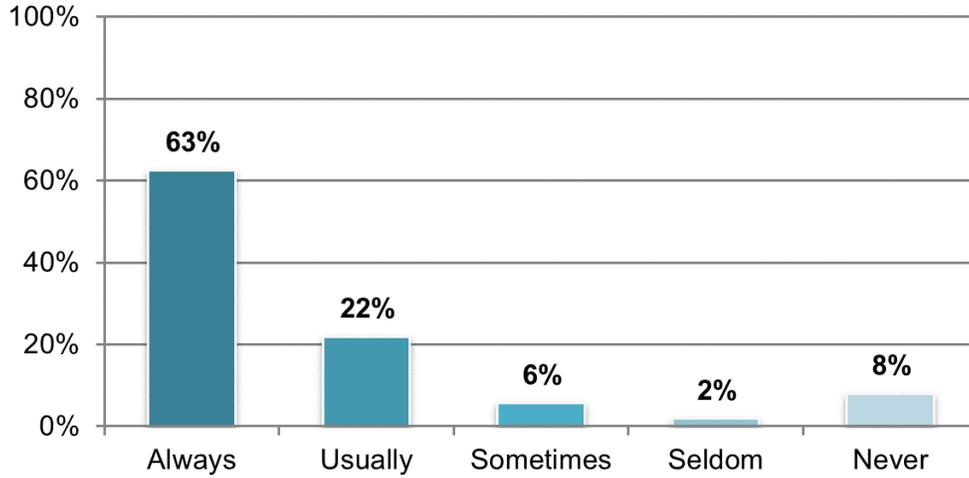


Table Q35. Do you choose the provider agencies who work with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	84%	11%	2%	1%	3%	479
KY	76%	16%	5%	1%	2%	114
NC	73%	17%	5%	0%	5%	208
Within Average Range						
OK	67%	23%	4%	1%	5%	366
UT	67%	22%	5%	1%	5%	563
CO	65%	24%	5%	1%	5%	284
GA	62%	15%	4%	4%	15%	305
FL	61%	20%	5%	2%	12%	368
WI	59%	22%	7%	1%	10%	272
MN	58%	30%	6%	2%	4%	544
PA	57%	24%	6%	3%	10%	338
CT	57%	23%	7%	4%	10%	220
MD	57%	27%	7%	2%	8%	343
Significantly Below Average						
SD	49%	33%	8%	3%	8%	113
DC	47%	21%	10%	3%	18%	192
NCI Average	63%	22%	6%	2%	8%	4,709

Family Member Chooses Provider Agencies Who Work With Family

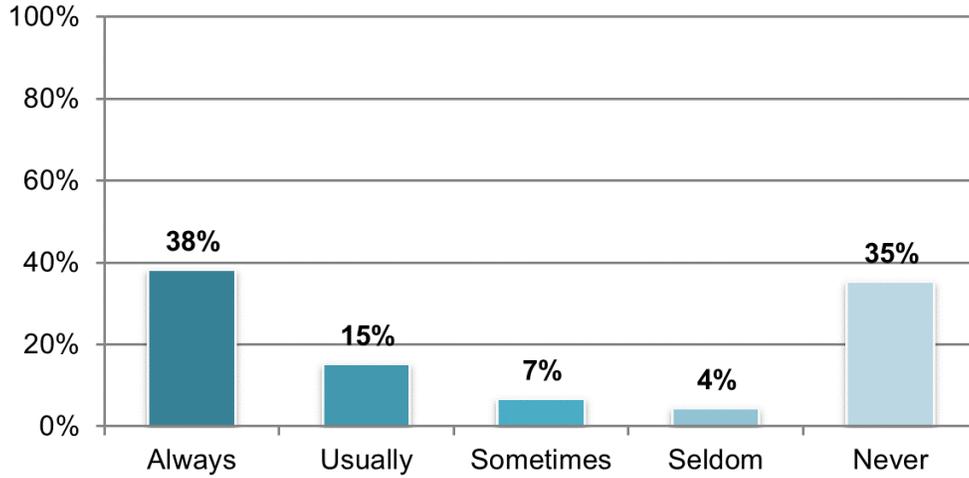


Table Q36. Does your family member choose the provider agencies who work with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	57%	11%	4%	1%	27%	428
Within Average Range						
CO	42%	16%	6%	5%	31%	245
OK	42%	18%	5%	3%	32%	309
KY	42%	11%	6%	2%	39%	96
FL	42%	18%	8%	3%	29%	325
WI	40%	15%	5%	5%	35%	261
MD	38%	19%	7%	5%	30%	302
NC	38%	11%	5%	5%	41%	185
GA	36%	9%	5%	3%	46%	260
UT	35%	15%	9%	7%	34%	458
SD	35%	23%	7%	3%	32%	98
CT	33%	12%	8%	5%	42%	190
DC	32%	16%	8%	5%	38%	180
Significantly Below Average						
MN	32%	19%	8%	6%	35%	454
PA	30%	12%	10%	8%	39%	293
NCI Average	38%	15%	7%	4%	35%	4,084

Respondent Can Choose a Different Provider Agency If Desired

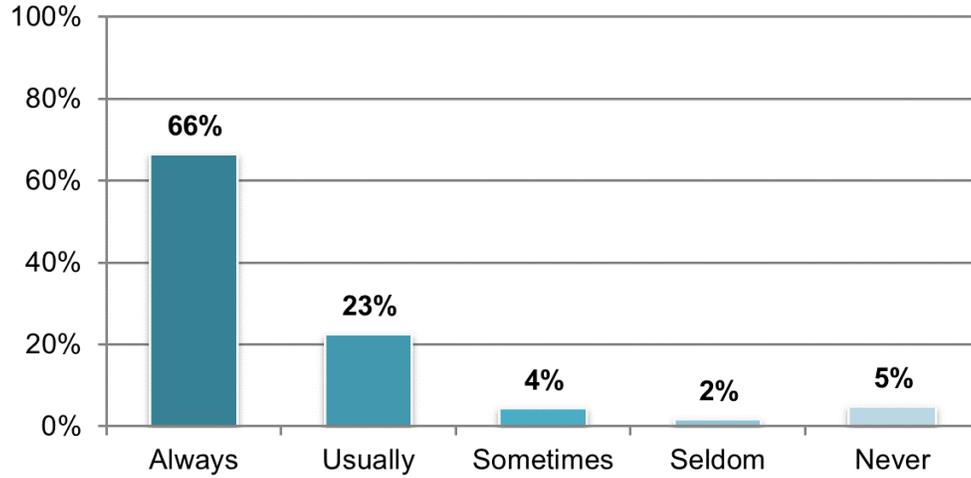


Table Q37. Can you choose a different provider agency if you want to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	80%	16%	1%	0%	2%	458
Within Average Range						
NC	73%	21%	1%	1%	3%	177
OK	72%	23%	3%	2%	1%	315
FL	72%	17%	6%	1%	4%	327
GA	71%	20%	3%	1%	4%	215
UT	69%	22%	6%	1%	2%	496
DC	69%	23%	3%	1%	4%	159
KY	67%	23%	2%	3%	6%	108
SD	64%	23%	3%	3%	8%	78
PA	63%	23%	7%	1%	6%	237
MN	62%	25%	7%	2%	4%	428
CT	61%	22%	4%	6%	8%	133
CO	61%	27%	6%	1%	6%	230
MD	59%	28%	7%	2%	4%	261
Significantly Below Average						
WI	54%	25%	7%	1%	13%	212
NCI Average	66%	23%	4%	2%	5%	3,834

Respondent Chooses Individual Support Workers Who Work Directly With Family

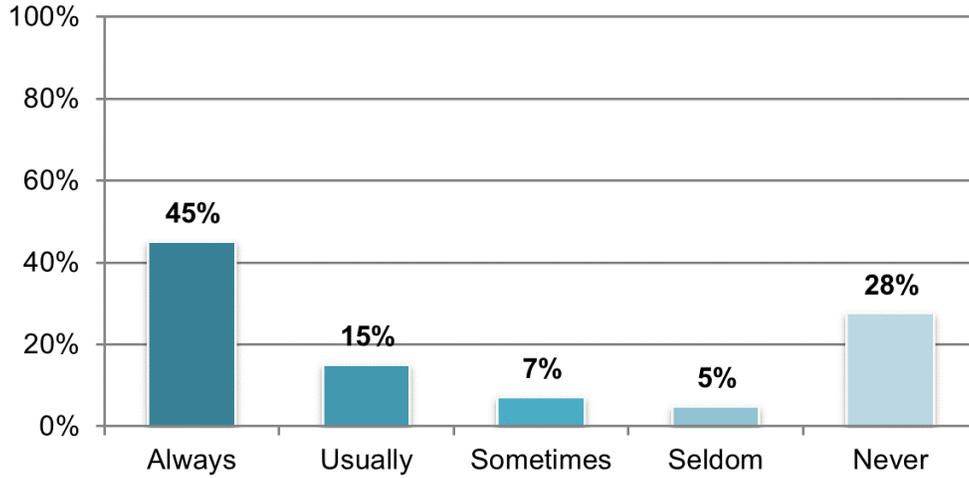


Table Q38. Do you choose the individual support workers who work directly with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	64%	11%	5%	2%	17%	470
OK	63%	12%	6%	5%	14%	348
FL	62%	17%	5%	2%	14%	348
UT	59%	15%	7%	3%	15%	531
NC	58%	19%	4%	6%	12%	201
MN	51%	19%	9%	6%	15%	521
Within Average Range						
KY	47%	16%	9%	4%	23%	116
DC	46%	18%	6%	2%	28%	181
WI	40%	17%	10%	6%	27%	250
PA	39%	14%	8%	4%	35%	319
CO	38%	22%	10%	7%	24%	253
Significantly Below Average						
GA	37%	9%	6%	4%	44%	313
CT	35%	11%	7%	7%	40%	189
MD	25%	14%	8%	7%	47%	318
SD	13%	12%	6%	9%	61%	104
NCI Average	45%	15%	7%	5%	28%	4,462

Family Member Chooses Individual Support Workers Who Work Directly With Family

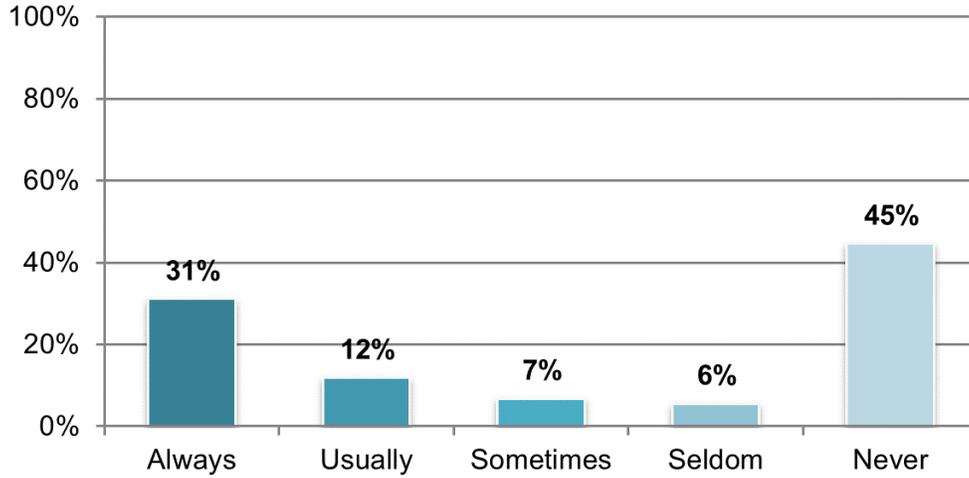


Table Q39. Does your family member choose the individual support workers who work directly with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	49%	11%	4%	3%	34%	421
OK	45%	13%	5%	6%	31%	320
FL	42%	15%	7%	2%	33%	312
DC	42%	13%	5%	5%	35%	164
Within Average Range						
NC	36%	15%	5%	6%	38%	185
UT	35%	11%	7%	6%	40%	448
WI	33%	13%	6%	7%	41%	263
MN	32%	14%	11%	7%	36%	474
PA	27%	8%	7%	6%	52%	301
CO	27%	14%	9%	6%	44%	233
GA	26%	8%	5%	3%	58%	286
KY	26%	14%	10%	3%	48%	105
Significantly Below Average						
CT	22%	9%	5%	8%	57%	173
MD	17%	11%	9%	6%	57%	287
SD	8%	9%	7%	10%	66%	101
NCI Average	31%	12%	7%	6%	45%	4,073

Respondent Can Choose Different Support Workers If Desired

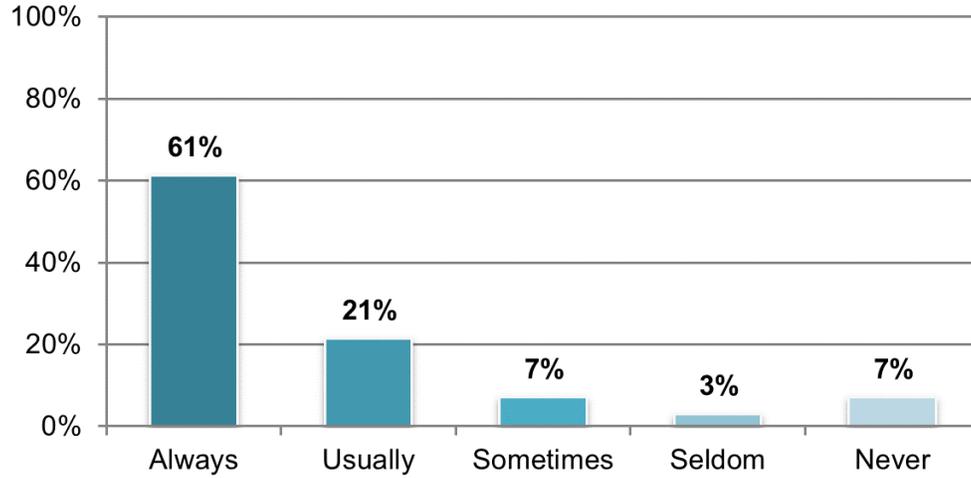


Table Q40. Can you choose different support workers if you want to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	76%	18%	4%	1%	2%	438
UT	74%	18%	4%	1%	3%	451
FL	73%	17%	4%	1%	4%	312
OK	69%	18%	4%	4%	5%	303
Within Average Range						
NC	70%	20%	4%	3%	3%	180
GA	64%	19%	6%	0%	11%	203
MN	63%	23%	8%	2%	4%	422
DC	61%	29%	4%	2%	4%	148
CO	61%	21%	9%	4%	5%	201
PA	61%	23%	6%	3%	7%	231
CT	59%	14%	8%	7%	13%	119
KY	59%	20%	9%	5%	8%	102
WI	54%	25%	7%	4%	10%	212
Significantly Below Average						
MD	46%	28%	11%	6%	9%	183
SD	31%	29%	17%	3%	19%	58
NCI Average	61%	21%	7%	3%	7%	3,563

Respondent Chose Case Manager/Service Coordinator

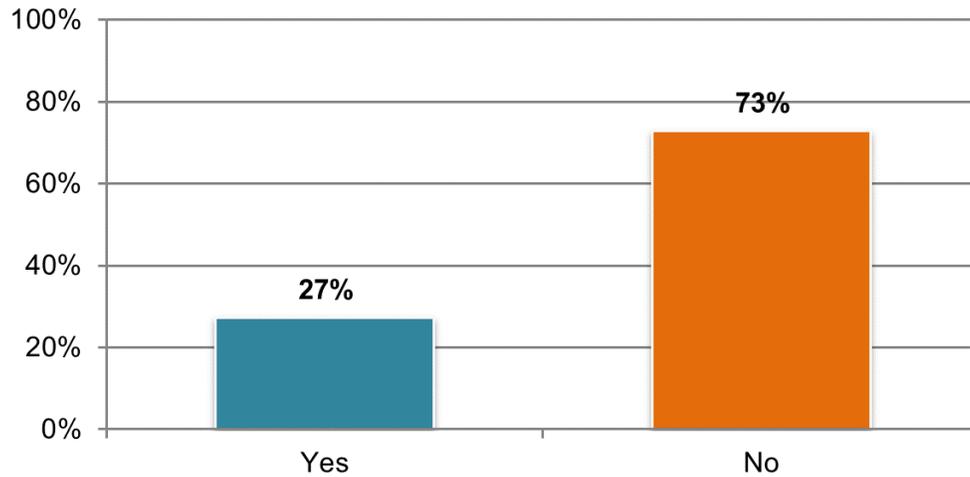


Table Q41. Did you choose your family member’s case manager/service coordinator?

State	Yes	No	N
Significantly Above Average			
UT	68%	32%	561
FL	66%	34%	371
LA	52%	48%	491
WI	34%	66%	318
Within Average Range			
KY	28%	72%	126
PA	28%	72%	346
NC	27%	73%	211
MD	26%	74%	375
DC	22%	78%	203
Significantly Below Average			
OK	14%	86%	381
GA	14%	86%	352
MN	10%	90%	568
SD	9%	91%	121
CO	7%	93%	300
CT	4%	96%	275
NCI Average	27%	73%	4,999

Family Member Chose Case Manager/Service Coordinator

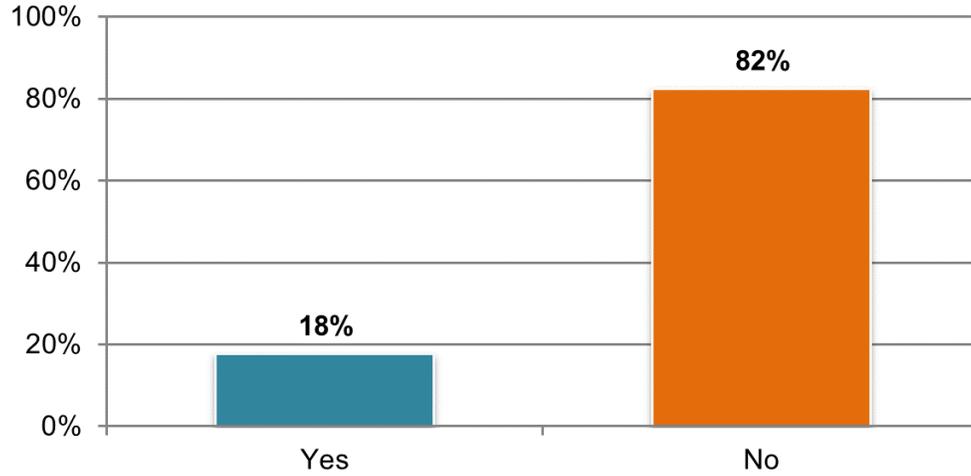


Table Q42. Did your family member choose his/her case manager/service coordinator?

State	Yes	No	N
Significantly Above Average			
FL	46%	54%	340
UT	36%	64%	511
LA	34%	66%	465
WI	24%	76%	335
Within Average Range			
DC	20%	80%	200
PA	19%	81%	349
MD	16%	84%	352
NC	13%	88%	200
KY	11%	89%	123
Significantly Below Average			
OK	12%	88%	382
GA	9%	91%	343
MN	8%	92%	557
CO	6%	94%	289
SD	6%	94%	117
CT	4%	96%	270
NCI Average	18%	82%	4,833

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

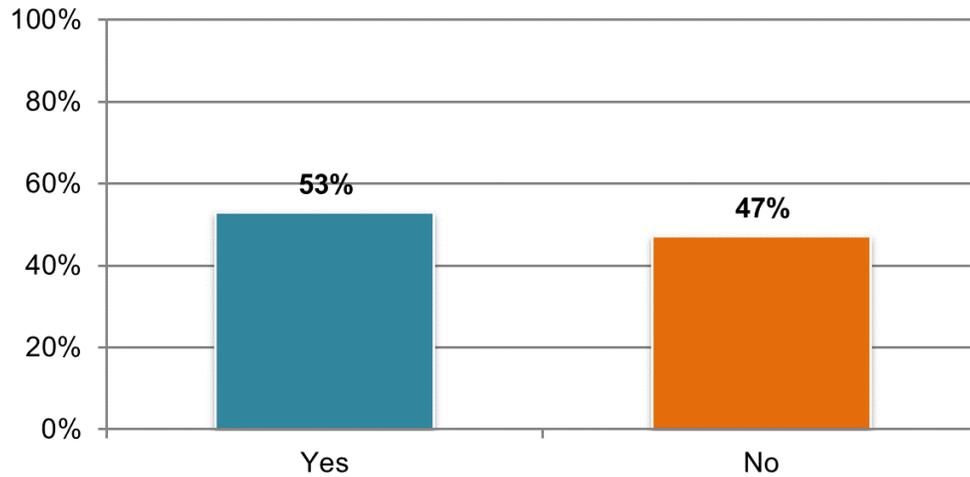


Table Q43. Do you have control and/or input over the hiring and management of your family member’s support workers?

State	Yes	No	N
Significantly Above Average			
FL	75%	25%	334
UT	75%	25%	491
LA	74%	26%	442
OK	67%	33%	325
NC	64%	36%	195
MN	61%	39%	500
Within Average Range			
KY	57%	43%	112
DC	54%	46%	177
PA	51%	49%	293
WI	48%	52%	265
Significantly Below Average			
CT	43%	57%	191
GA	39%	61%	305
CO	38%	62%	254
MD	34%	66%	301
SD	16%	84%	103
NCI Average	53%	47%	4,288

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

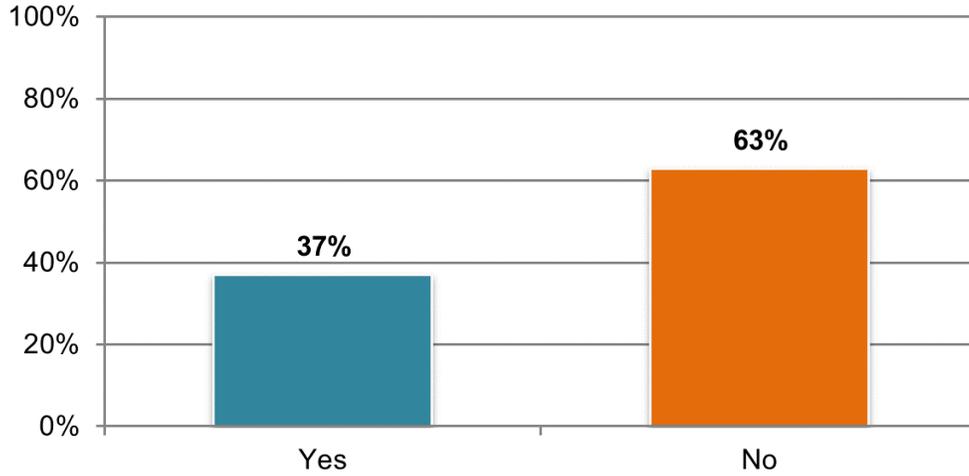


Table Q44. Does your family member have control and/or input over the hiring and management of his/her support workers?

State	Yes	No	N
Significantly Above Average			
FL	55%	45%	307
LA	52%	48%	403
OK	49%	51%	311
MN	43%	57%	487
Within Average Range			
DC	43%	57%	169
UT	42%	58%	448
KY	40%	60%	107
WI	38%	62%	293
NC	36%	64%	181
PA	35%	65%	289
Significantly Below Average			
CO	28%	72%	248
GA	28%	72%	289
CT	26%	74%	190
MD	24%	76%	291
SD	15%	85%	99
NCI Average	37%	63%	4,112

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

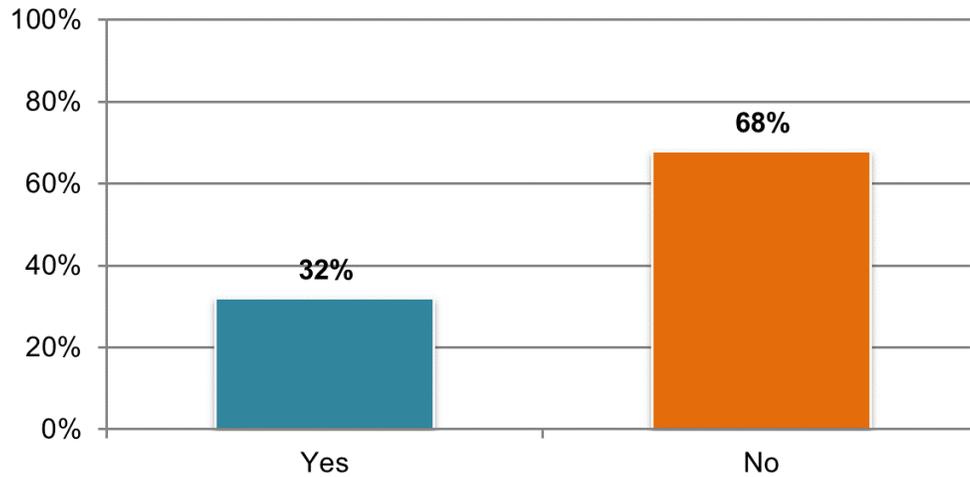


Table Q45. Do you know how much money is spent by the ID/DD agency on behalf of your family member with a developmental disability?

State	Yes	No	N
Significantly Above Average			
FL	61%	39%	390
MN	53%	47%	592
UT	47%	53%	604
OK	45%	55%	402
GA	39%	61%	371
Within Average Range			
CO	37%	63%	308
WI	33%	67%	329
CT	32%	68%	277
PA	32%	68%	378
KY	28%	72%	126
NC	25%	75%	221
Significantly Below Average			
LA	23%	77%	507
MD	15%	85%	386
DC	7%	93%	213
SD	3%	97%	127
NCI Average	32%	68%	5,231

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

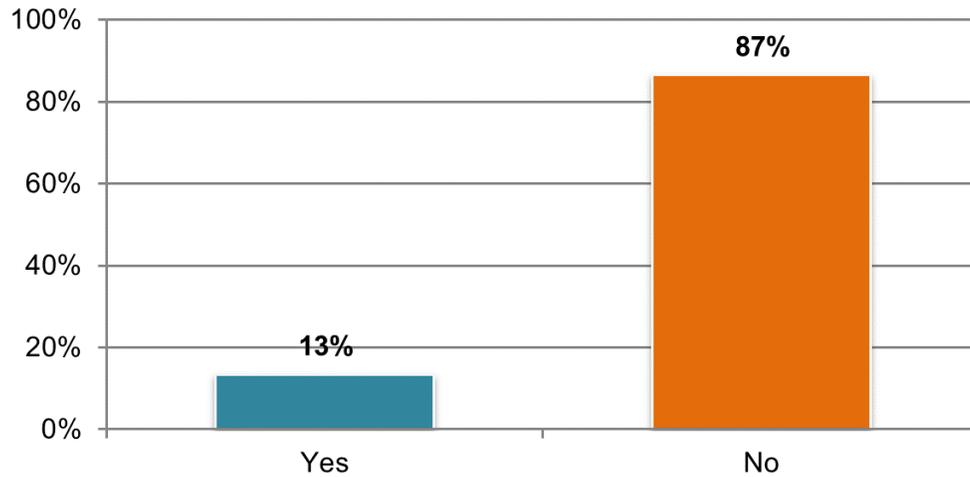


Table Q46. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?

State	Yes	No	N
Significantly Above Average			
FL	37%	63%	340
OK	20%	80%	368
MN	20%	80%	544
Within Average Range			
WI	18%	82%	345
GA	17%	83%	357
CO	13%	87%	289
LA	12%	88%	490
UT	12%	88%	536
KY	11%	89%	120
CT	10%	90%	244
PA	10%	90%	366
NC	9%	91%	209
Significantly Below Average			
MD	7%	93%	366
DC	6%	94%	210
SD	1%	99%	126
NCI Average	13%	87%	4,910

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

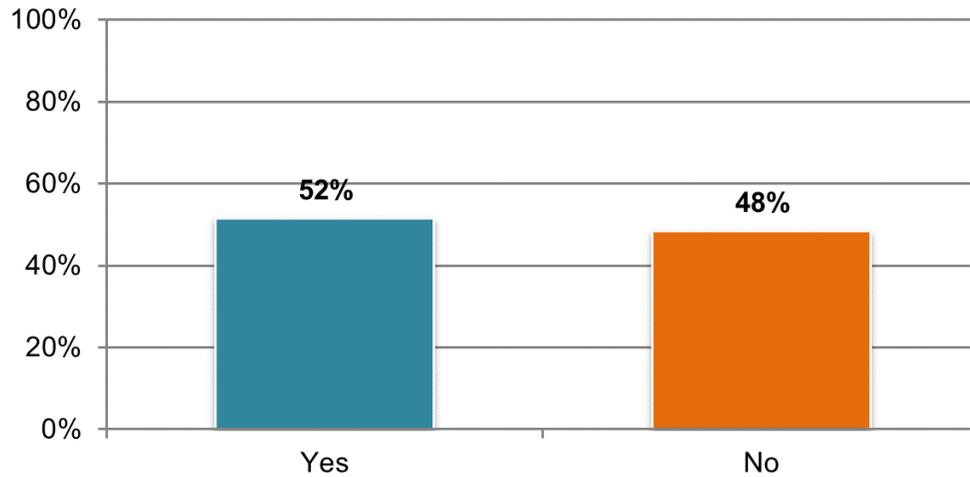


Table Q47. Do you have a say in how this money is spent?

State	Yes	No	N
Significantly Above Average			
UT	77%	23%	477
OK	73%	27%	330
FL	73%	27%	327
CO	72%	28%	248
MN	63%	37%	450
Within Average Range			
PA	58%	42%	250
WI	56%	44%	254
GA	50%	50%	294
CT	49%	51%	206
KY	49%	51%	92
NC	43%	57%	168
Significantly Below Average			
LA	36%	64%	314
MD	27%	73%	278
DC	26%	74%	151
SD	20%	80%	81
NCI Average	52%	48%	3,920

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

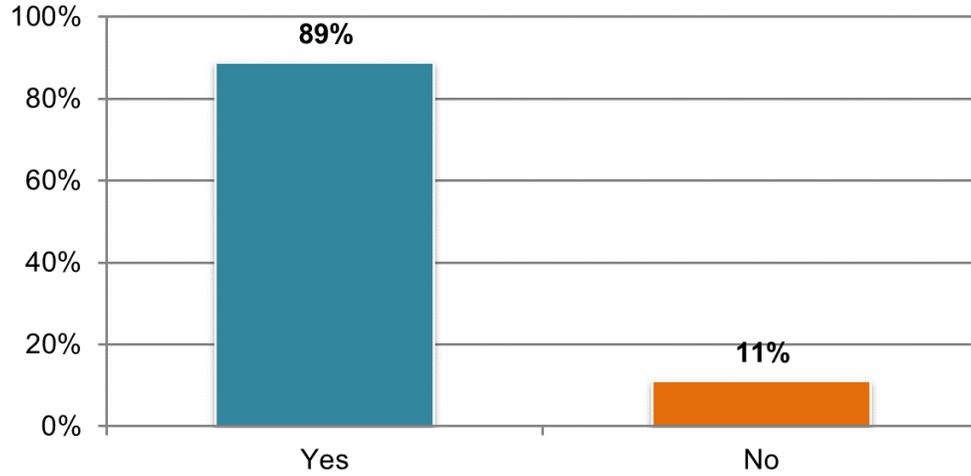


Table Q47a. If you have a say in how ID/DD agency money is spent, do you have all the information you need to make decisions about how to spend this money?

State	Yes	No	N
Significantly Above Average			
OK	94%	6%	220
Within Average Range			
FL	93%	7%	221
UT	92%	8%	312
CT	92%	8%	85
LA	92%	8%	95
KY	90%	10%	40
MN	88%	12%	248
PA	88%	12%	128
GA	87%	13%	134
WI	87%	13%	126
DC	87%	13%	31
NC	86%	14%	65
MD	85%	15%	68
CO	83%	17%	154
NCI Average	89%	11%	1,927
N < 20			
SD	N/A	N/A	N/A

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

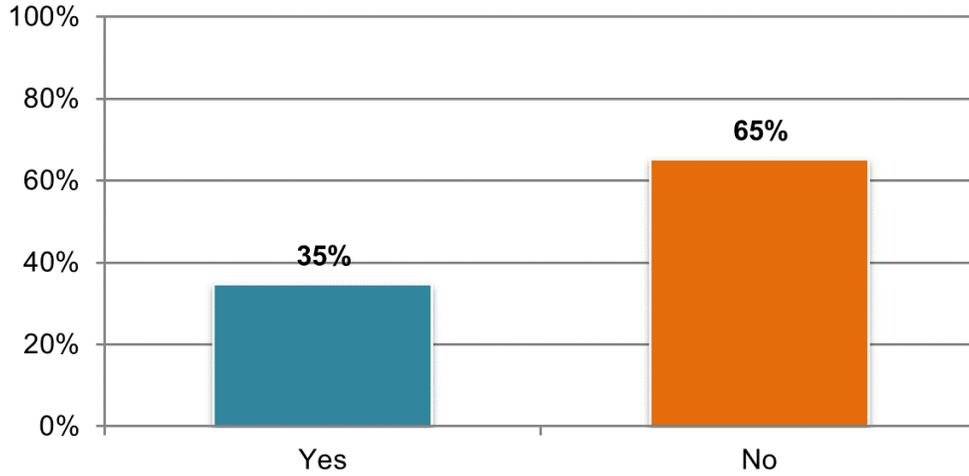


Table Q48. Does your family member have a say in how this money is spent?

State	Yes	No	N
Significantly Above Average			
FL	50%	50%	280
OK	49%	51%	305
CO	48%	52%	220
Within Average Range			
WI	42%	58%	267
PA	39%	61%	237
UT	38%	62%	410
MN	38%	62%	438
CT	34%	66%	185
GA	31%	69%	265
KY	30%	70%	82
LA	30%	70%	286
Significantly Below Average			
MD	25%	75%	261
DC	24%	76%	148
NC	24%	76%	157
SD	20%	80%	84
NCI Average	35%	65%	3,625

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

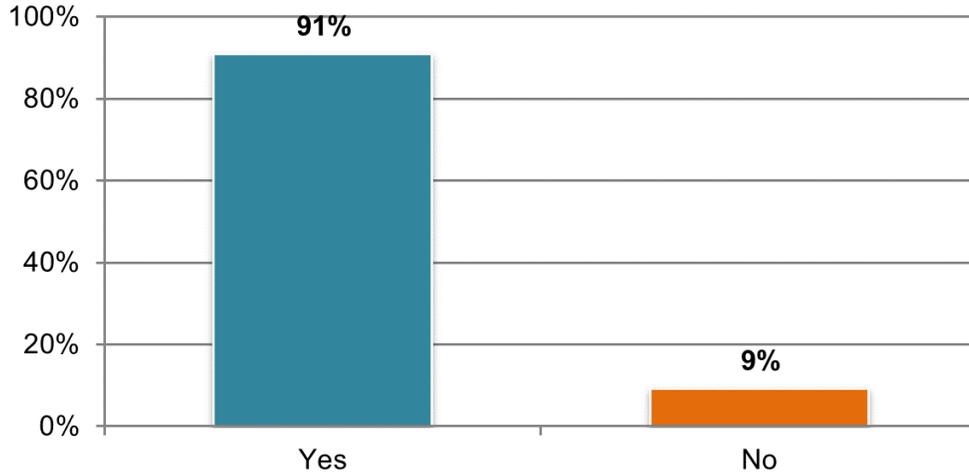


Table Q48a. If your family member has a say in how agency money is spent, does your family member have all the information s/he needs to make decisions about how to spend this money?

State	Yes	No	N
FL	95%	5%	128
NC	94%	6%	35
WI	94%	6%	103
OK	94%	6%	128
UT	93%	7%	128
MN	91%	9%	149
KY	91%	9%	22
GA	90%	10%	73
DC	90%	10%	31
CT	90%	10%	48
LA	88%	12%	77
PA	88%	12%	85
CO	87%	13%	89
MD	86%	14%	56
NCI Average	91%	9%	1,152
N < 20			
SD	N/A	N/A	N/A

Community Connections

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

Family Member Participates in Community Activities

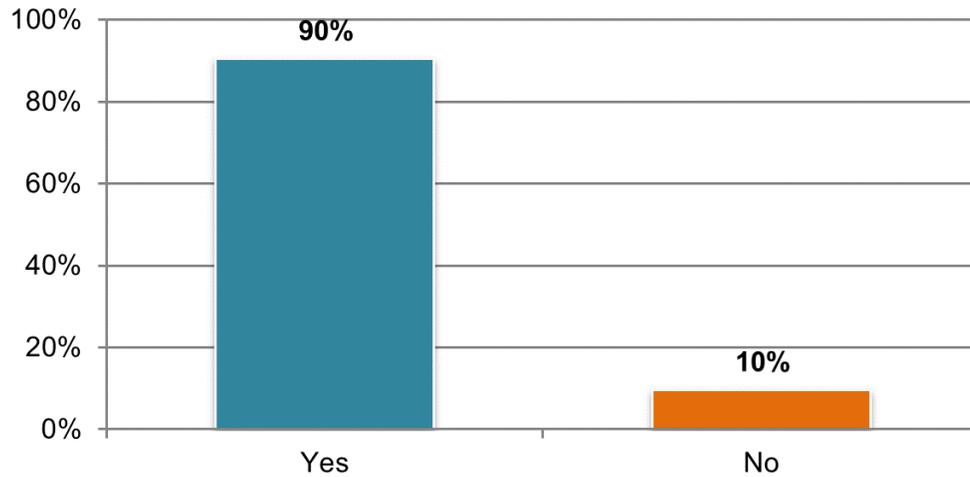


Table Q49. Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?

State	Yes	No	N
Significantly Above Average			
WI	95%	5%	387
MN	94%	6%	592
Within Average Range			
KY	93%	7%	132
OK	92%	8%	404
NC	92%	8%	225
SD	91%	9%	129
GA	91%	9%	375
LA	91%	9%	523
FL	91%	9%	370
PA	90%	10%	386
UT	90%	10%	597
DC	90%	10%	218
CO	88%	12%	303
Significantly Below Average			
MD	85%	15%	403
CT	83%	17%	269
NCI Average	90%	10%	5,313

Reasons Family Member Does Not Participate in Community Activities

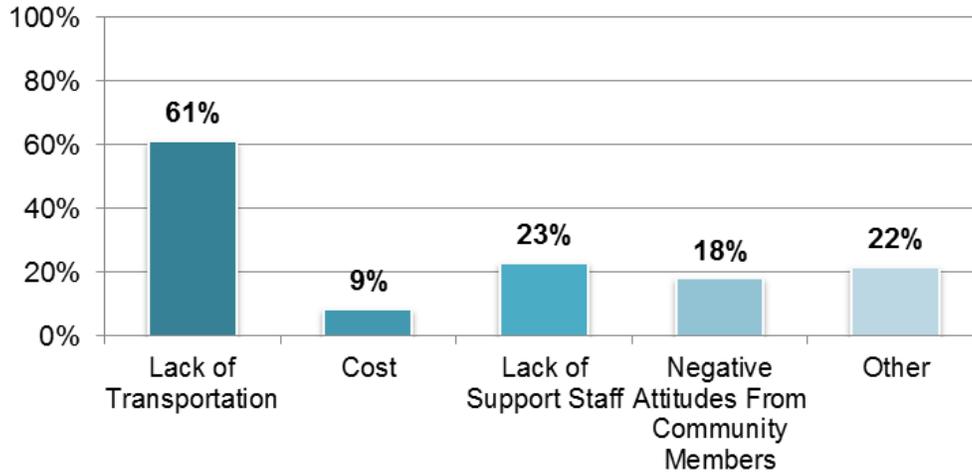


Table Q49a. If your family member doesn't participate in community activities, why not?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes From Community Members	Other
CO	74%	11%	19%	19%	7%
CT	43%	8%	31%	22%	29%
FL	60%	12%	16%	20%	16%
GA	41%	0%	36%	23%	36%
LA	81%	12%	12%	12%	16%
MD	73%	6%	27%	14%	16%
MN	53%	17%	23%	33%	27%
OK	63%	3%	17%	13%	23%
PA	58%	8%	23%	12%	27%
UT	67%	10%	27%	15%	21%
N < 20					
DC	N/A	N/A	N/A	N/A	N/A
KY	N/A	N/A	N/A	N/A	N/A
NC	N/A	N/A	N/A	N/A	N/A
SD	N/A	N/A	N/A	N/A	N/A
WI	N/A	N/A	N/A	N/A	N/A
NCI Average	22%	18%	23%	9%	61%

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

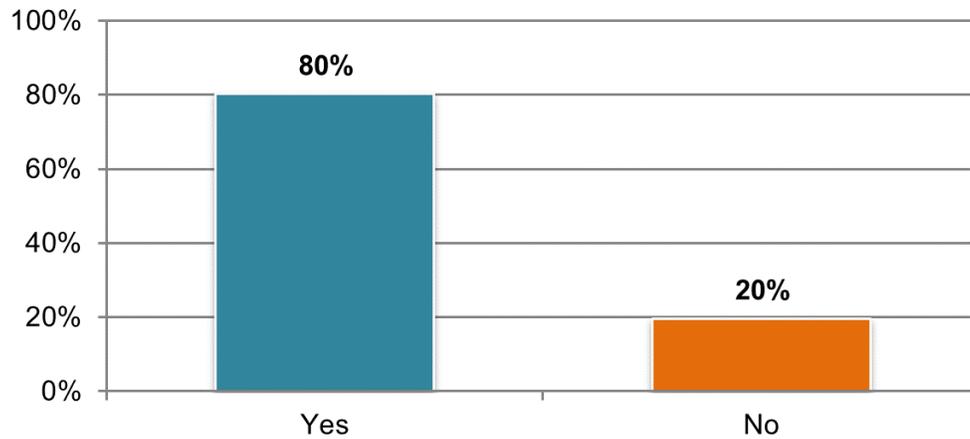


Table Q50. Does your family member have friends or relationships with persons other than paid support workers or family?

State	Yes	No	N
Significantly Above Average			
OK	90%	11%	400
KY	88%	12%	130
Within Average Range			
SD	86%	14%	130
GA	84%	16%	375
PA	82%	18%	391
NC	81%	19%	221
WI	81%	19%	377
LA	80%	20%	521
FL	80%	20%	383
MN	78%	22%	586
DC	78%	22%	209
MD	77%	23%	395
UT	76%	24%	587
CO	74%	26%	306
Significantly Below Average			
CT	69%	31%	266
NCI Average	80%	20%	5,277

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

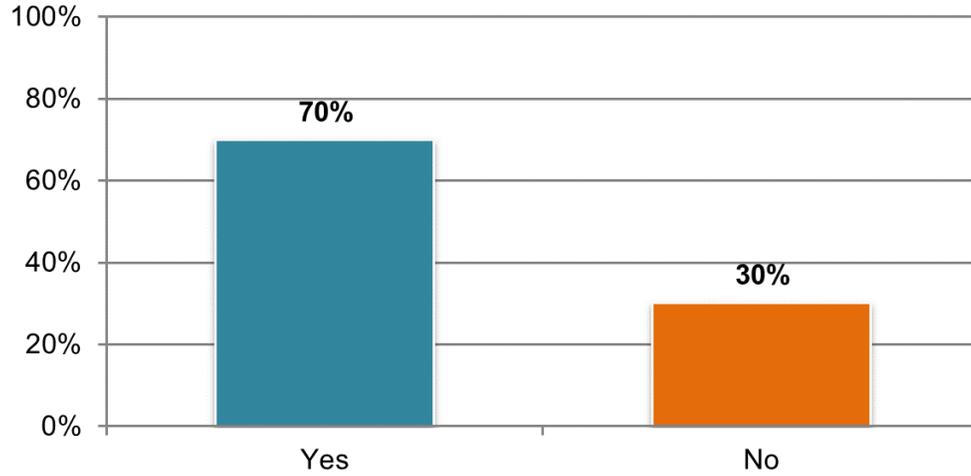


Table Q51. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

State	Yes	No	N
Significantly Above Average			
SD	81%	19%	109
Within Average Range			
LA	73%	27%	409
MN	73%	27%	490
DC	73%	27%	182
WI	72%	28%	320
OK	71%	29%	311
CO	71%	29%	248
CT	70%	30%	209
UT	70%	30%	413
PA	69%	31%	303
GA	67%	33%	299
MD	66%	34%	322
NC	66%	34%	184
KY	64%	36%	106
FL	63%	37%	284
NCI Average	70%	30%	4,189

Satisfaction With Services and Supports

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

Respondent Is Satisfied With the Services and Supports Family Receives

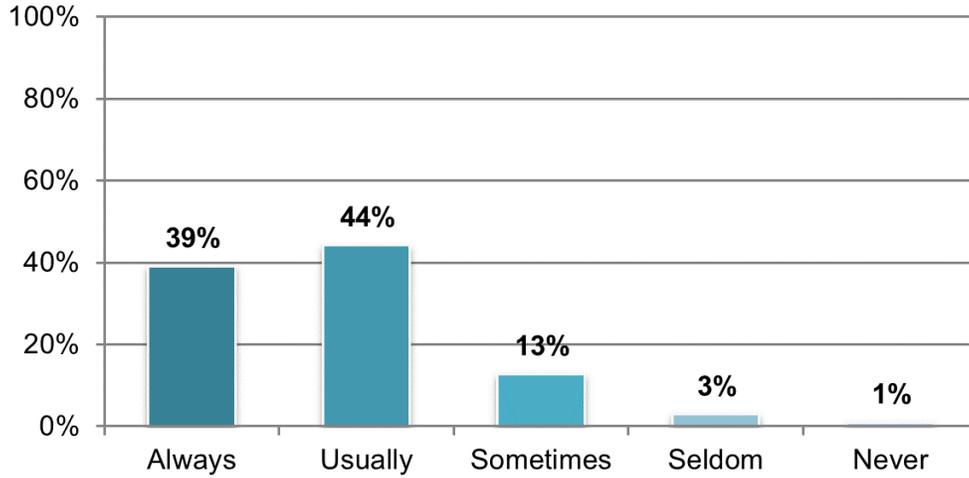


Table Q52. Overall, are you satisfied with the services and supports your family currently receives?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	54%	35%	9%	2%	0%	525
UT	46%	46%	7%	1%	1%	595
Within Average Range						
DC	45%	38%	10%	6%	2%	215
FL	44%	39%	12%	3%	2%	390
PA	41%	45%	11%	2%	1%	388
WI	41%	48%	11%	1%	0%	385
OK	40%	46%	11%	3%	0%	397
KY	40%	43%	15%	2%	1%	131
NC	39%	39%	16%	3%	2%	217
GA	36%	46%	12%	3%	2%	375
CT	34%	45%	17%	4%	0%	260
MN	34%	48%	14%	3%	1%	594
CO	34%	49%	14%	2%	1%	307
SD	33%	47%	17%	4%	0%	132
Significantly Below Average						
MD	26%	50%	18%	5%	1%	392
NCI Average	39%	44%	13%	3%	1%	5,303

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

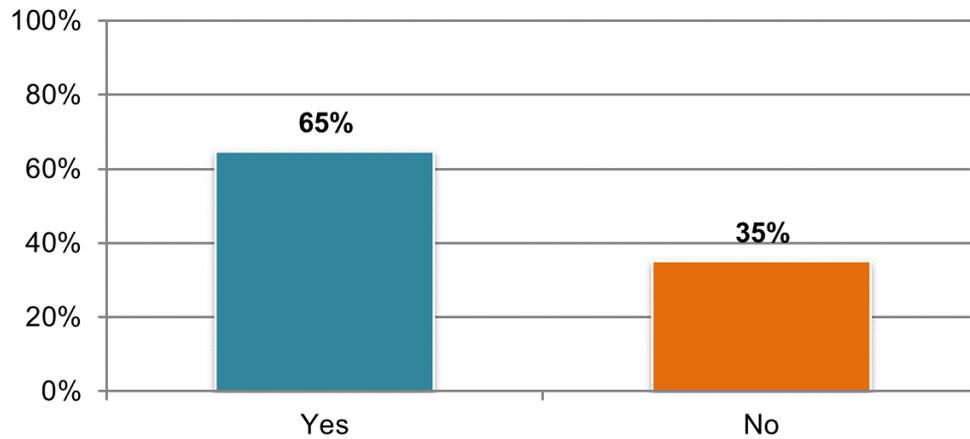


Table Q53. Do you know the process for filing a complaint or grievance against provider agencies or staff?³

State	Yes	No	N
Significantly Above Average			
OK	83%	17%	395
LA	77%	23%	526
FL	76%	24%	386
CO	75%	25%	307
PA	71%	29%	378
Within Average Range			
WI	69%	31%	379
UT	69%	31%	589
SD	68%	32%	129
MN	67%	33%	587
KY	67%	33%	129
NC	66%	34%	218
DC	62%	38%	218
Significantly Below Average			
GA	46%	54%	370
CT	42%	58%	265
MD	36%	64%	390
NCI Average	65%	35%	5,266

³ '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

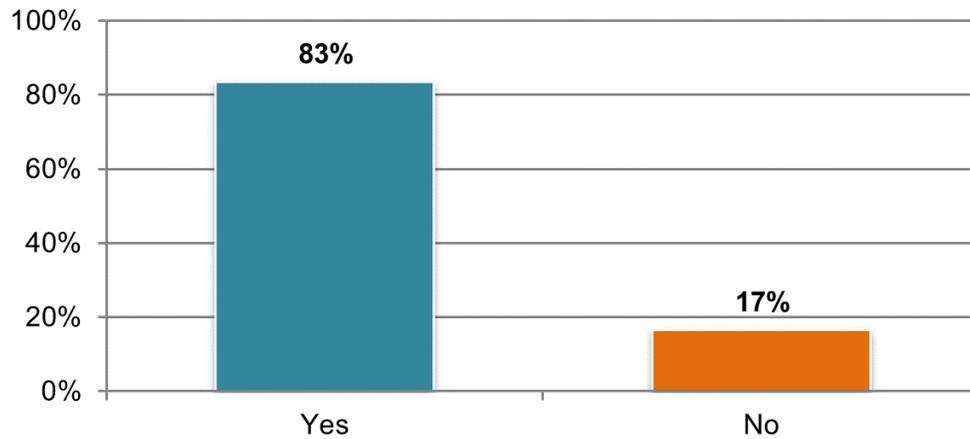


Table Q54. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

State	Yes	No	N
Significantly Above Average			
UT	92%	8%	244
LA	91%	9%	281
Within Average Range			
WI	89%	11%	142
OK	89%	11%	182
NC	88%	12%	116
PA	87%	13%	127
MN	87%	13%	223
FL	85%	15%	169
CO	85%	15%	124
GA	84%	16%	146
SD	79%	21%	56
KY	78%	22%	51
DC	76%	24%	113
MD	73%	27%	112
CT	70%	30%	74
NCI Average	83%	17%	2,160

Respondent Knows How to Report Abuse or Neglect

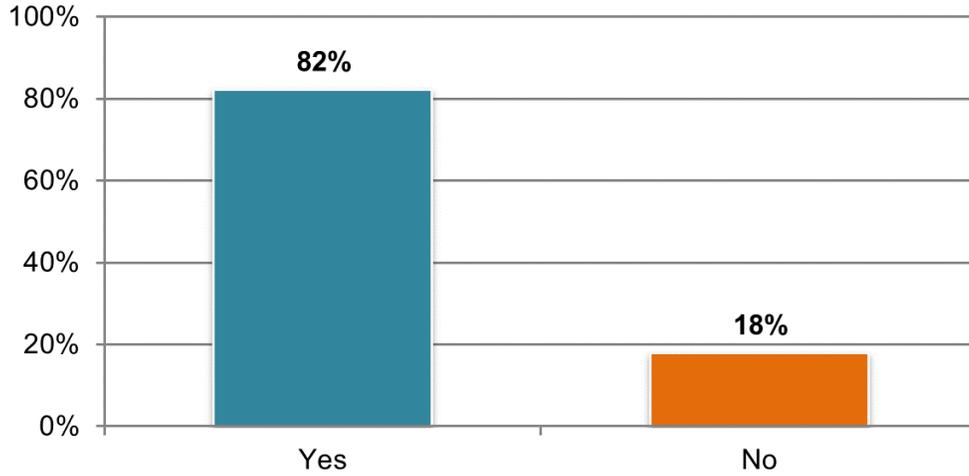


Table Q55. Do you know how to report abuse or neglect?⁴

State	Yes	No	N
Significantly Above Average			
OK	93%	7%	396
KY	92%	8%	130
LA	90%	10%	521
FL	89%	11%	377
Within Average Range			
DC	88%	12%	211
MN	88%	12%	581
CO	84%	16%	308
PA	84%	16%	370
WI	84%	16%	372
NC	83%	17%	218
UT	81%	19%	585
SD	80%	20%	124
Significantly Below Average			
GA	68%	32%	361
CT	68%	32%	258
MD	61%	39%	390
NCI Average	82%	18%	5,202

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

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

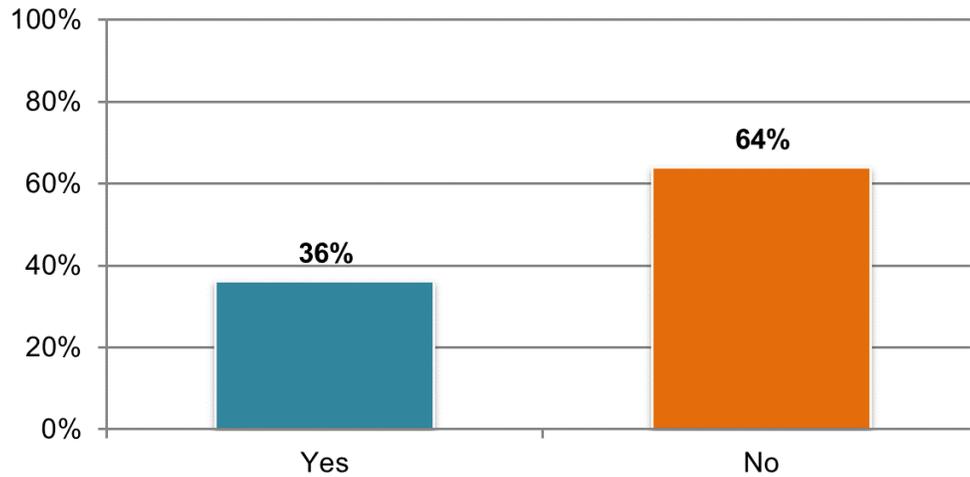


Table Q56. Within the past year, if abuse or neglect occurred, did you report it?

State	Yes	No	N
Within Average Range			
DC	44%	56%	59
CT	43%	57%	42
GA	43%	57%	63
OK	39%	61%	51
FL	39%	61%	59
CO	38%	62%	45
UT	37%	63%	70
NC	35%	65%	34
WI	34%	66%	50
PA	34%	66%	53
MN	32%	68%	77
MD	25%	75%	59
LA	25%	75%	87
NCI Average	36%	64%	749
N < 20			
KY	N/A	N/A	N/A
SD	N/A	N/A	N/A

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

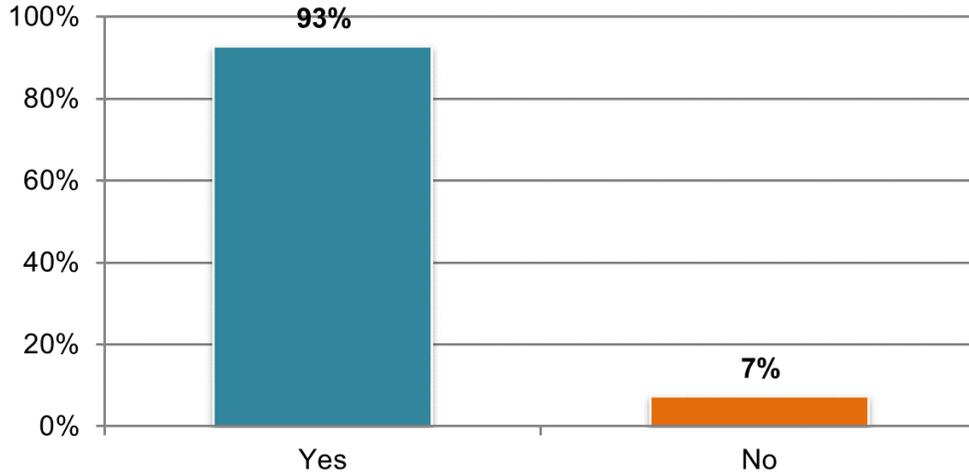


Table Q56a. If you reported abuse or neglect in the past year, were the appropriate people responsive to your report?

State	Yes	No	N
Within Average Range			
LA	95%	5%	20
DC	90%	10%	21
NCI Average	93%	7%	41
N < 20			
CO	N/A	N/A	N/A
CT	N/A	N/A	N/A
FL	N/A	N/A	N/A
GA	N/A	N/A	N/A
KY	N/A	N/A	N/A
MD	N/A	N/A	N/A
MN	N/A	N/A	N/A
NC	N/A	N/A	N/A
OK	N/A	N/A	N/A
PA	N/A	N/A	N/A
SD	N/A	N/A	N/A
UT	N/A	N/A	N/A
WI	N/A	N/A	N/A

Family Outcomes

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

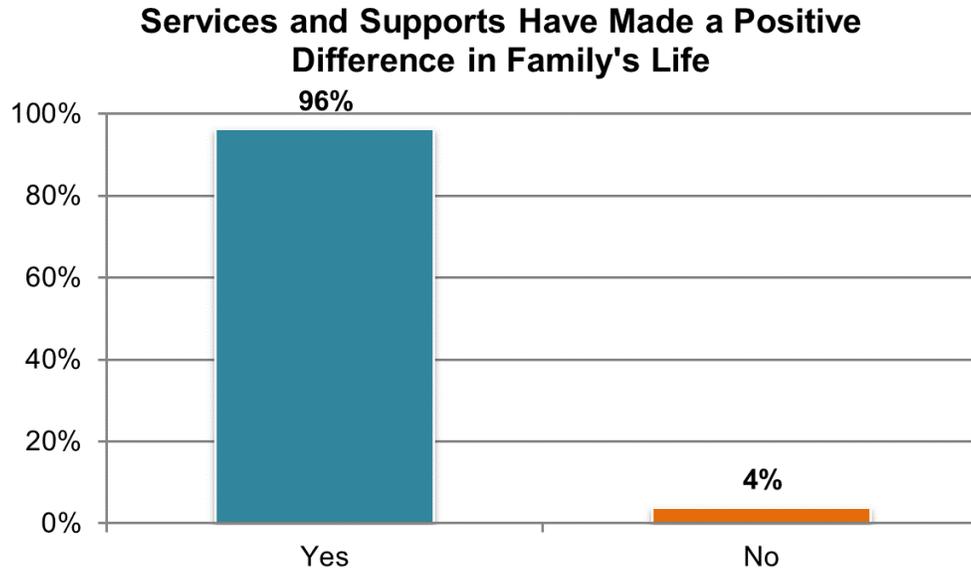


Table Q57. Do you feel that services and supports have made a positive difference in the life of your family?

State	Yes	No	N
Significantly Above Average			
UT	99%	1%	579
WI	99%	1%	377
Within Average Range			
KY	98%	2%	127
MN	98%	2%	569
OK	97%	3%	380
CO	97%	3%	296
LA	96%	4%	511
FL	96%	4%	372
MD	96%	4%	363
CT	96%	4%	254
PA	96%	4%	356
NC	95%	5%	206
SD	95%	5%	119
GA	94%	6%	349
DC	92%	9%	200
NCI Average	96%	4%	5,058

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

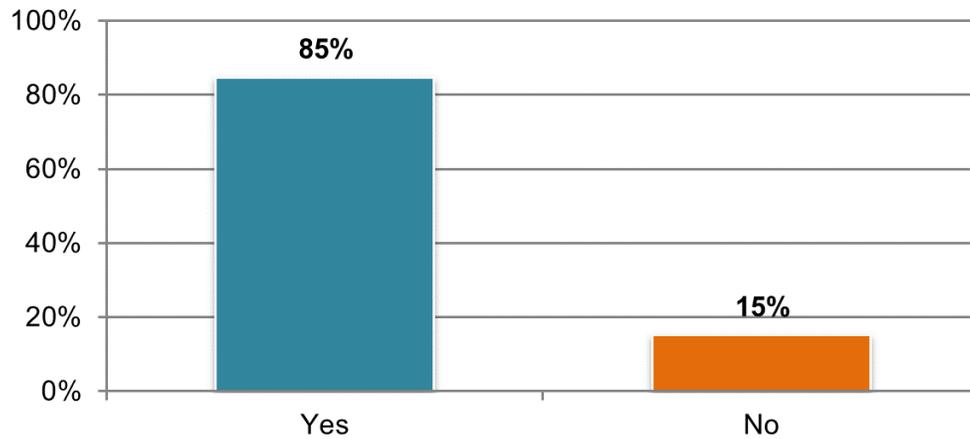


Table Q58. Do you feel that services and supports have reduced your family’s out-of-pocket expenses for your family member’s care?

State	Yes	No	N
Significantly Above Average			
UT	93%	7%	556
WI	92%	8%	361
MN	91%	9%	548
Within Average Range			
KY	91%	9%	122
OK	89%	11%	362
CO	88%	12%	287
FL	86%	14%	348
PA	86%	14%	343
LA	85%	15%	467
CT	84%	16%	245
NC	83%	17%	193
SD	79%	21%	108
Significantly Below Average			
GA	78%	22%	327
MD	76%	24%	336
DC	71%	29%	178
NCI Average	85%	15%	4,781

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

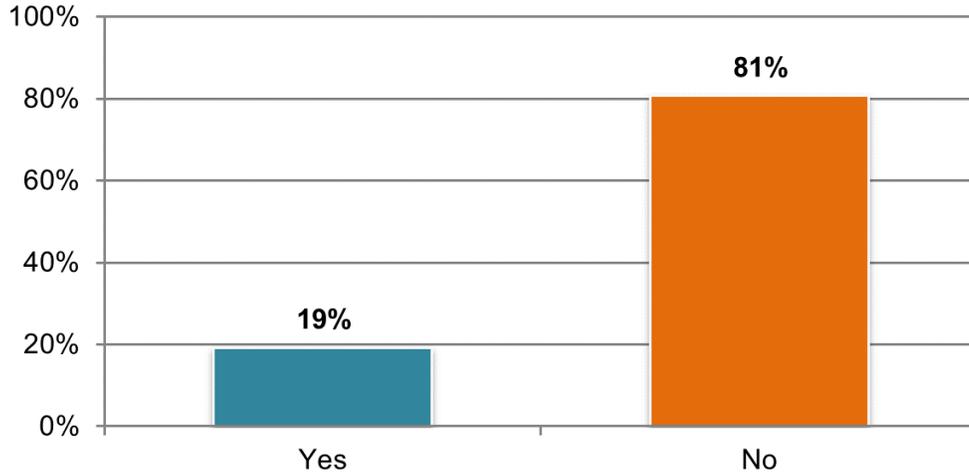


Table Q59. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?⁵

State	Yes	No	N
Significantly Above Average			
FL	33%	67%	336
NC	33%	67%	198
Within Average Range			
CT	25%	75%	231
KY	22%	78%	124
MN	20%	80%	546
WI	19%	81%	355
OK	18%	82%	358
GA	18%	82%	319
LA	17%	83%	461
CO	17%	83%	276
SD	16%	84%	118
DC	16%	84%	183
PA	14%	86%	326
Significantly Below Average			
MD	14%	86%	321
UT	8%	92%	544
NCI Average	19%	81%	4,696

⁵ The 'yes' response is the less desired response, a higher average means more people reported services or supports were reduced, suspended or terminated in the past year.

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

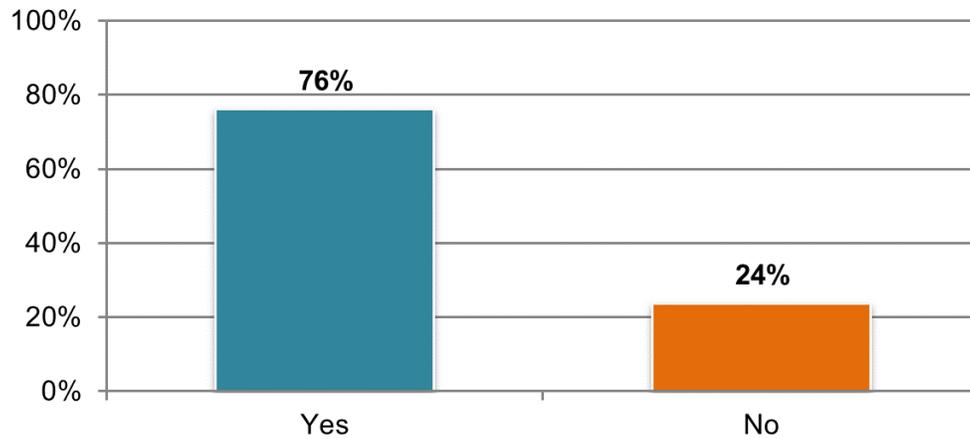


Table Q59a. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?⁶

State	Yes	No	N
Within Average Range			
KY	86%	14%	21
NC	85%	15%	53
MD	82%	18%	34
MN	80%	20%	95
DC	78%	22%	23
OK	77%	23%	48
FL	76%	24%	88
LA	76%	24%	58
CT	74%	26%	46
GA	73%	27%	41
UT	72%	28%	36
WI	72%	28%	61
CO	70%	30%	40
PA	65%	35%	40
NCI Average	76%	24%	684
N < 20			
SD	N/A	N/A	N/A

⁶ The 'yes' response is the less desired response, a higher average means more people reported reduction, suspension, or termination of services had a negative impact on the family.

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

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

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

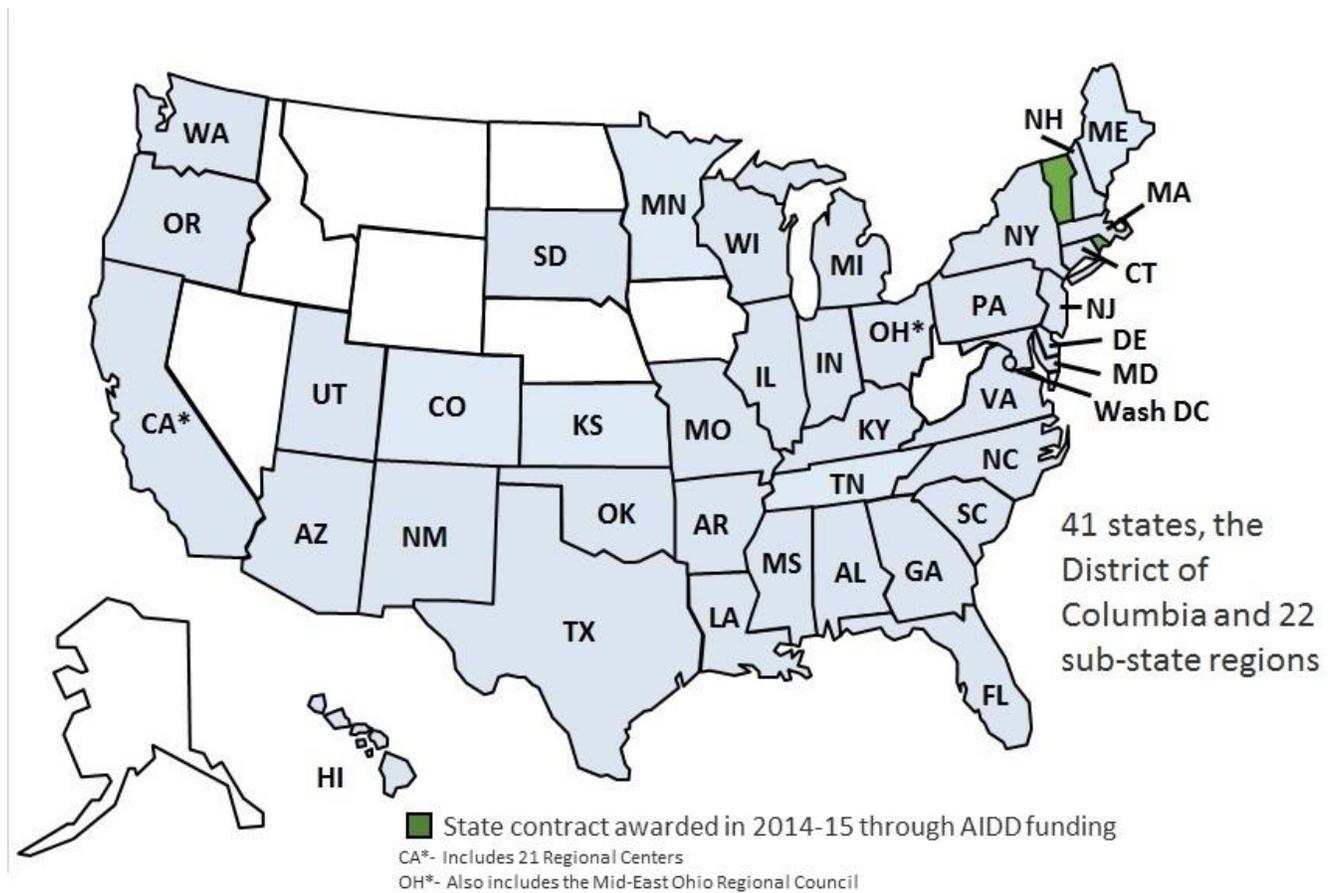
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

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

State Participation

During the 2014-15 data collection cycle, 41 states, the District of Columbia and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and the participating states are shown in the chart below.

Chart 1. NCI State Participation 2014-15



The Core Indicators

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

<http://www.nationalcoreindicators.org/indicators>.

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

The current set of performance indicators includes approximately 100 consumer, family, system, and health and safety outcomes—outcomes that are important to understanding the overall health of public developmental disabilities agencies. Indicators are organized across five broad domains: Individual Outcomes; Health, Welfare and Rights; Staff Stability and Competency; Family Outcomes; and System Performance. Each domain is broken down into sub-domains (please see Table 1 on the following page). Four data sources are used to assess outcomes: the Adult Consumer Survey, three Family Surveys, a Provider Survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates).

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

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

Sub-Domains and Concern Statements

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

Family Survey Sub-Domains and Concern Statements

Sub-Domain	Concern Statement
Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
Choice & Control	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.
Community Connections	Family members with disabilities use integrated community services and participate in everyday community activities.

Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.
Family Outcomes	Individual and family supports make a positive difference in the lives of families.

How NCI Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI as a data source for supplemental performance measures in their home and community-based services (HCBS) waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction.

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

Moreover, the NCI Average should not be interpreted as defining “acceptable” levels of performance or satisfaction. Instead, it represents a multi-state “norm” that describes average levels of performance or satisfaction across the participating states. In some instances there are

few significant differences among states; this denotes that the majority of states are performing similarly. Instances in which several states' results are especially high (considerably above the average level) indicate the levels of performance or satisfaction achieved in those states might define a level of performance that may serve as a guidepost for other states.

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

III. Methodology

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

Sampling & Administration

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

1. Had an adult individual 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%.⁷

Data Entry and Analysis

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

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

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

⁷ 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 average⁸; significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

Response Rates

During 2014-2015, 14 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, usable surveys returned, response rates, the number of individuals receiving services who were eligible to be drawn into the sample, and each state's margin of error.

Adult Family Survey: State Response Rates

State	Useable Surveys Returned	Surveys Mailed	Response Rate
CO	322	1067	30.2%
CT	298	1200	24.8%
DC	227	584	38.9%
FL	414	1510	27.4%
GA	402	1500	26.8%
KY	135	682	19.8%
LA	551	2220	24.8%
MD	418	1200	34.8%
MN	609	1941	31.4%
NC	238	1200	19.8%
OK	420	1642	25.6%
PA	405	1200	33.8%
SD	136	389	35.0%
UT	619	1400	44.2%
WI	401	1200	33.4%
NCI Average	5595	18935	29.5%

⁸ The NCI Average is the sum of all state averages divided by the total number of states.

