

Child Family Survey

2012-13 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

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

The NCI Child Family Survey is administered to families who have a child with a developmental disability who lives in the family's home and receives at least one service other than case management. Not all states that participate in NCI administer the Child Family Survey on an annual basis. Of the 34 states and 22 sub-state entities who participated in NCI during the 2012–2013 data collection cycle, ten (10) states submitted a valid sample of Child Family Survey data to be included in this report. This Final Report provides a summary of results based on data submitted by June 30, 2013.

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

Demographics

- The average age of the child receiving services in the household was 11 years old, and males accounted for a higher percentage than females (65% versus 35%).
- The most frequently indicated disability types were autism spectrum disorder (46%) and intellectual disability (45%); disability type categories are not mutually exclusive in the NCI surveys, and respondents can choose as many as apply.
- Almost half of children use a nonverbal form of communication (44%). (Notably though, fewer than one-third of respondents report that support workers can always communicate effectively with the child if the child is nonverbal.)
- In terms of daily activities, 42% of children require a complete level of help.

Services and Supports

- Among the services and supports specified in the survey, in-home support and social security benefits (62% and 44%, respectively) are the most commonly utilized.

Information and Planning

- Engagement in service planning was high among respondents (96% report that they helped develop their child's service plan). However, a much lower percentage of respondents consistently receive information about available supports (24% report they always receive this information).

Access and Delivery of Services and Supports

- Slightly more than half of all respondents report that they can always contact support workers and case managers/service coordinators when needed (54% and 53%, respectively), and slightly more than one-third report that services and supports are available when needed (35%).
- Two-thirds of respondents report that they are able to speak with support workers or translators in their preferred language (if other than English, 66%), and nearly three-quarters of all respondents report that services are delivered in a manner that is respectful to their family's culture (72%).
- Access to and satisfaction with health, dental, and mental health services were all very high (88% to 98%); however, access to respite services came in slightly lower at 78%.

Choice and Control

- While the majority of respondents determine the provider agencies and support workers who work with their family (60%), about one-quarter (27%) report that they know how much money the ID/DD agency spends on behalf of the child. And slightly over one-third of all respondents (39%) indicate that they have a say in how ID/DD agency money is spent.

Community Connections

- The vast majority of respondents report that the child participates in community activities (83%). More than four-fifths report that the child spends time with children who do not have DD (85%).

Satisfaction With Services and Supports

- More than one-third of all respondents indicate that they are always satisfied with the services and supports their family receives (36%).

Family Outcomes

- Nearly all respondents report that services and supports have made a positive difference in their family's life (94%). Most also indicate that services and supports have reduced the family's out-of-pocket expenses for the child's care (84%).
- Of the 35% of respondents who report that services or supports were reduced, suspended or terminated in the past year, 75% felt that this change impacted their family negatively.

I. Results

This section briefly describes the structure of the survey instrument and presents the results of the most recent data collection cycle.

Survey Development

The Child Family Survey was developed and first utilized in 2000-2001 in response to state interest in determining the level of satisfaction with services and supports among families of children with developmental disabilities living at home.

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 Child Family Survey

The Child 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 child 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 child 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 child with a developmental disability receive.

Questions Regarding Services and Supports

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

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

Presentation of Data

Direct feedback from families is an important means for states to gauge service and support satisfaction and to pinpoint areas for quality improvement. All demographic and individual outcome results from the Child Family Survey are presented in this report. Outcome results are presented in six subsections that correspond with the sections of the Child Family Survey. The beginning of each subsection provides an overall synopsis of findings across states.

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 are omitted from questions where 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) the NCI Average even though the other state that is further away from the NCI Average is not. This may occur 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.

Child

This section provides demographic information about the child receiving services.

- Average age among the children receiving services was 11 years old.
- A higher percentage are male 65% and 35% are female.
- The majority of children were identified as White (66%) or Black/African American (16%). Among the remainder, 2% were identified as American Indian or Alaska Native, 3% Asian, 1% another race not listed, and 8% were identified as being of two or more races; 12% of the children receiving services were identified as Hispanic.
- The most frequently indicated types of disabilities the children were reported as having were:
 - 46% autism spectrum disorder
 - 45% intellectual disability
 - 33% other disability not listed
 - 27% seizure disorder/neurological problem
 - 20% mental illness or psychiatric diagnosis
 - 19% cerebral palsy
- 55% of children were reported to communicate verbally, 30% with gestures or body language, 3% use sign language or finger spelling, 5% use a communication aid or device, and 6% use some other form of communication.
- 92% of children have English as their primary language.
- 62% of children need medical care less frequently than once a month.
- 23% of children need extensive behavioral support.
- 42% of children need a complete level of help for daily activities.

Table 1. Child's Age

State	Age	N
AZ	9	302
CT	14	177
LA	8	184
NC	14	297
OH	7	400
OR	11	422
SC	8	168
TX	15	1,364
VA	13	223
WA	13	296
NCI Average	11	3,833

Table 2. Child's Gender

State	Male	Female	N
AZ	67%	33%	305
CT	64%	36%	169
LA	67%	33%	184
NC	62%	38%	297
OH	63%	37%	394
OR	67%	33%	415
SC	69%	31%	168
TX	62%	38%	1,374
VA	63%	37%	220
WA	63%	37%	298
NCI Average	65%	35%	3,824

Table 3. Child's Race

State	American Indian/ Alaska Native	Asian	Black/African American	Hawaiian/ Pacific Islander	White	Other/ Unknown	Two or More Races	Hispanic/ Latino
AZ	4%	4%	6%	0%	56%	0%	12%	35%
CT	1%	3%	13%	1%	71%	0%	7%	12%
LA	1%	1%	28%	0%	63%	2%	6%	2%
NC	2%	1%	25%	0%	66%	0%	5%	3%
OH	1%	2%	15%	0%	75%	1%	9%	3%
OR	5%	6%	3%	1%	80%	2%	8%	11%
SC	2%	2%	31%	0%	60%	2%	8%	3%
TX	1%	4%	16%	0%	43%	1%	7%	37%
VA	1%	2%	16%	0%	79%	0%	6%	1%
WA	4%	8%	5%	1%	66%	1%	9%	15%
NCI Average	2%	3%	16%	0%	66%	1%	8%	12%

Table 4. Child's Type of Disability

State	AZ	CT	LA	NC	OH	OR	SC	TX	VA	WA	NCI Average
Intellectual Disability	30%	71%	26%	67%	22%	43%	20%	64%	60%	47%	45%
Mental Illness/ Psychiatric Diagnosis	15%	33%	13%	11%	16%	23%	18%	25%	25%	17%	20%
Autism Spectrum Disorder	44%	62%	35%	47%	28%	53%	58%	35%	55%	43%	46%
Cerebral Palsy	17%	16%	14%	28%	9%	14%	15%	25%	30%	21%	19%
Brain Injury	7%	7%	7%	9%	5%	9%	10%	11%	11%	16%	9%
Seizure Disorder/ Neurological Problem	17%	35%	19%	36%	13%	25%	20%	35%	33%	32%	27%
Chemical Dependency	0%	1%	1%	1%	1%	0%	0%	1%	0%	0%	1%
Limited or No Vision	8%	15%	9%	11%	5%	8%	8%	19%	11%	12%	10%
Severe or Profound Hearing Loss	5%	6%	5%	7%	5%	4%	3%	7%	8%	9%	6%
Down Syndrome	15%	7%	10%	9%	5%	13%	7%	11%	7%	14%	10%
Prader-Willi Syndrome	1%	0%	0%	1%	1%	0%	1%	1%	0%	0%	0%
Other	27%	28%	40%	37%	34%	29%	30%	40%	29%	32%	33%
No Other	2%	6%	7%	2%	14%	2%	5%	2%	4%	1%	5%
Don't Know	2%	2%	7%	1%	5%	1%	4%	1%	1%	3%	3%

Table 5. Child's Primary Means of Expression

State	Spoken	Gestures/ Body Language	Sign Language/ Finger Spelling	Communication Aid/Device	Other	N
AZ	56%	26%	4%	7%	7%	307
CT	47%	30%	4%	13%	7%	168
LA	64%	28%	1%	1%	7%	181
NC	50%	38%	3%	5%	3%	303
OH	62%	27%	5%	3%	3%	394
OR	58%	29%	1%	7%	5%	386
SC	57%	30%	6%	1%	6%	166
TX	53%	33%	3%	4%	7%	1,355
VA	48%	31%	5%	9%	8%	218
WA	56%	29%	3%	5%	7%	296
NCI Average	55%	30%	3%	5%	6%	3,774

Table 6. Child's Primary Language

State	English	Spanish	Other	N
AZ	81%	18%	1%	305
CT	97%	1%	2%	156
LA	95%	2%	3%	182
NC	99%	1%	0%	300
OH	97%	1%	2%	398
OR	93%	6%	2%	416
SC	97%	1%	2%	164
TX	83%	12%	4%	1,359
VA	95%	0%	5%	217
WA	84%	10%	6%	295
NCI Average	92%	5%	3%	3,792

Table 7. Frequency of Medical Care Needed for Child

State	Less Frequently Than Once a Month	At Least Once a Month, Less Than Once a Week	At Least Once a Week	N
AZ	67%	23%	10%	300
CT	50%	34%	16%	163
LA	60%	24%	16%	176
NC	66%	26%	8%	299
OH	66%	24%	10%	398
OR	72%	21%	7%	413
SC	61%	23%	16%	163
TX	54%	27%	19%	1,347
VA	61%	26%	13%	216
WA	61%	28%	11%	291
NCI Average	62%	26%	13%	3,766

Table 8. Amount of Behavioral Support Needed for Child

State	None	Some	Extensive	N
AZ	50%	39%	11%	217
CT	20%	41%	39%	171
LA	51%	31%	19%	177
NC	40%	38%	23%	300
OH	63%	23%	15%	307
OR	32%	43%	25%	417
SC	44%	35%	21%	165
TX	44%	37%	19%	1,359
VA	29%	42%	29%	217
WA	24%	50%	26%	296
NCI Average	40%	38%	23%	3,626

Table 9. Amount of Help Needed for Child's Daily Activities

State	None	Little	Moderate	Complete	N
AZ	6%	16%	42%	36%	308
CT	7%	6%	35%	53%	167
LA	7%	18%	41%	35%	184
NC	6%	15%	32%	47%	302
OH	15%	25%	30%	30%	398
OR	5%	19%	40%	35%	422
SC	8%	15%	36%	40%	168
TX	5%	14%	30%	50%	1,375
VA	4%	10%	38%	48%	222
WA	2%	14%	36%	47%	298
NCI Average	7%	15%	36%	42%	3,844

Respondents

This section provides demographic information about the respondent.

- 21% of respondents were under 35 years old, 65% were 35-54 years old, 14% were 55-74, and 1% of respondents were 75 or older.
- 92% of respondents are the child's parent.
- 98% of respondents are the child's primary caregiver.
- 25% of households have one adult in the house, 63% have two adults, 9% have three adults, and 3% have four or more adults in the house.
- The respondent's highest level of education was:
 - 10% less than a high school diploma or GED
 - 19% high school diploma or GED
 - 4% had gone to vocational school
 - 23% some college
 - 44% had a college degree
- The total taxable family income was:
 - 24% below \$15,000
 - 17% between \$15,001-\$25,000
 - 22% between \$25,001-\$50,000
 - 15% between \$50,001-\$75,000
 - 22% over \$75,000
- In terms of total out-of-pocket expenses for services related to the child's care in the past year:
 - 25% report that they spent nothing
 - 11% spent \$1-\$100
 - 29% spent \$101-\$1,000
 - 30% spent \$1,001-\$10,000
 - 5% spent over \$10,000.

Table 10. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
AZ	27%	60%	13%	0%	311
CT	5%	72%	22%	2%	165
LA	39%	51%	9%	1%	185
NC	13%	72%	14%	1%	303
OH	40%	52%	8%	0%	397
OR	14%	73%	12%	0%	421
SC	31%	59%	10%	0%	166
TX	13%	68%	18%	0%	1,379
VA	9%	71%	18%	2%	221
WA	12%	71%	16%	0%	297
NCI Average	21%	65%	14%	1%	3,845

Table 11. Respondent's Health

State	Excellent	Good	Fair	Poor	N
AZ	30%	52%	15%	3%	310
CT	17%	58%	20%	5%	166
LA	28%	49%	20%	3%	185
NC	20%	55%	21%	4%	304
OH	29%	51%	17%	4%	396
OR	19%	53%	25%	4%	424
SC	33%	43%	23%	1%	166
TX	19%	53%	23%	4%	1,378
VA	19%	45%	30%	6%	221
WA	15%	51%	27%	7%	300
NCI Average	23%	51%	22%	4%	3,850

Table 12. Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
AZ	97%	0%	2%	0%	312
CT	91%	1%	7%	1%	169
LA	96%	0%	2%	2%	186
NC	88%	0%	5%	6%	303
OH	89%	0%	9%	2%	397
OR	95%	1%	4%	1%	424
SC	94%	0%	5%	1%	167
TX	93%	0%	5%	2%	1,382
VA	87%	0%	9%	4%	222
WA	92%	1%	5%	2%	300
NCI Average	92%	0%	5%	2%	3,862

Table 13. Respondent Is Primary Caregiver

State	Yes	No	N
AZ	98%	2%	311
CT	97%	3%	170
LA	99%	1%	184
NC	99%	1%	302
OH	98%	3%	400
OR	99%	1%	423
SC	99%	1%	161
TX	98%	2%	1,384
VA	99%	1%	223
WA	94%	6%	300
NCI Average	98%	2%	3,858

Table 14. Number of Adults in Household

State	One	Two	Three	Four or More	N
AZ	20%	69%	8%	3%	310
CT	29%	60%	11%	1%	168
LA	34%	58%	4%	4%	186
NC	29%	61%	8%	2%	302
OH	18%	70%	9%	2%	399
OR	19%	72%	7%	2%	422
SC	24%	66%	8%	2%	167
TX	23%	56%	14%	7%	1,381
VA	27%	62%	10%	1%	220
WA	29%	57%	8%	7%	298
NCI Average	25%	63%	9%	3%	3,853

Table 15. Respondent's Highest Level of Education

State	Does Not Have High School Diploma/GED	High School Diploma/GED	Vocational School	Some College	College Degree	N
AZ	13%	14%	6%	30%	38%	302
CT	5%	26%	4%	24%	41%	168
LA	14%	25%	5%	20%	35%	183
NC	12%	16%	2%	24%	47%	303
OH	7%	19%	1%	29%	44%	397
OR	7%	19%	3%	24%	47%	399
SC	7%	18%	4%	14%	57%	164
TX	15%	20%	6%	24%	35%	1,367
VA	9%	15%	3%	20%	53%	223
WA	13%	18%	5%	23%	40%	298
NCI Average	10%	19%	4%	23%	44%	3,804

Table 16. Total Taxable Family Income of Wage Earners in the Past Year

State	Below \$15,000	\$15,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	Over \$75,000	N
AZ	20%	20%	23%	16%	20%	289
CT	20%	17%	19%	19%	25%	161
LA	30%	18%	14%	13%	24%	174
NC	26%	19%	21%	14%	21%	282
OH	24%	16%	27%	19%	15%	352
OR	24%	16%	25%	15%	20%	405
SC	24%	16%	23%	14%	23%	160
TX	26%	19%	22%	14%	18%	1,303
VA	22%	12%	24%	11%	32%	208
WA	22%	19%	26%	13%	21%	286
NCI Average	24%	17%	22%	15%	22%	3,620

Table 17. Out-of-Pocket Expenses for Family in the Past Year

State	Nothing	\$1 - \$100	\$101 - \$1,000	\$1,001 - \$10,000	Over \$10,000	N
AZ	32%	14%	28%	23%	4%	304
CT	17%	7%	29%	40%	7%	167
LA	30%	13%	23%	28%	6%	178
NC	30%	14%	30%	23%	2%	297
OH	30%	12%	28%	25%	4%	387
OR	12%	10%	28%	44%	5%	417
SC	26%	9%	32%	29%	4%	164
TX	29%	13%	31%	23%	4%	1,362
VA	19%	11%	29%	33%	7%	214
WA	23%	9%	36%	29%	2%	292
NCI Average	25%	11%	29%	30%	5%	3,782

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).

The majority of respondents indicate that their family receives other services and supports (65%) and in-home support (62%).

Table 18. Services and Supports Received From ID/DD Agency

State	Financial Support	In-Home Support	Out-of-Home Respite Care	Early Intervention	Transportation	Other Services/ Supports	Social Security Benefits
AZ	7%	67%	38%	30%	20%	84%	34%
CT	28%	76%	35%	1%	23%	57%	39%
LA	26%	43%	13%	36%	12%	55%	35%
NC	17%	83%	52%	5%	23%	69%	57%
OH	23%	26%	17%	40%	28%	72%	35%
OR	35%	46%	29%	12%	20%	46%	44%
SC	11%	39%	12%	37%	13%	69%	34%
TX	12%	74%	37%	6%	23%	61%	67%
VA	22%	92%	52%	5%	29%	75%	43%
WA	31%	71%	25%	5%	20%	61%	47%
NCI Average	21%	62%	31%	18%	21%	65%	44%

Child Family Survey Results

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.

Information and Planning

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

Just under one-quarter of respondents report that they always receive information about available services and supports (24%), and 30% report that the information they receive is always easy to understand. Just over one-third of respondents indicate that the information they receive always comes from the case manager/service coordinator (34%), and a similar percentage report that the case manager/service coordinator always informs the family about other available public services (32%).

Nearly all respondents report that they helped develop their child's service plan (96%). Around three-quarters indicate that the service plan includes everything their family wants (77%) and needs (71%). The majority of respondents also indicate that their family receives all the services listed in the plan (83%).

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Receives Information About Available Services and Supports

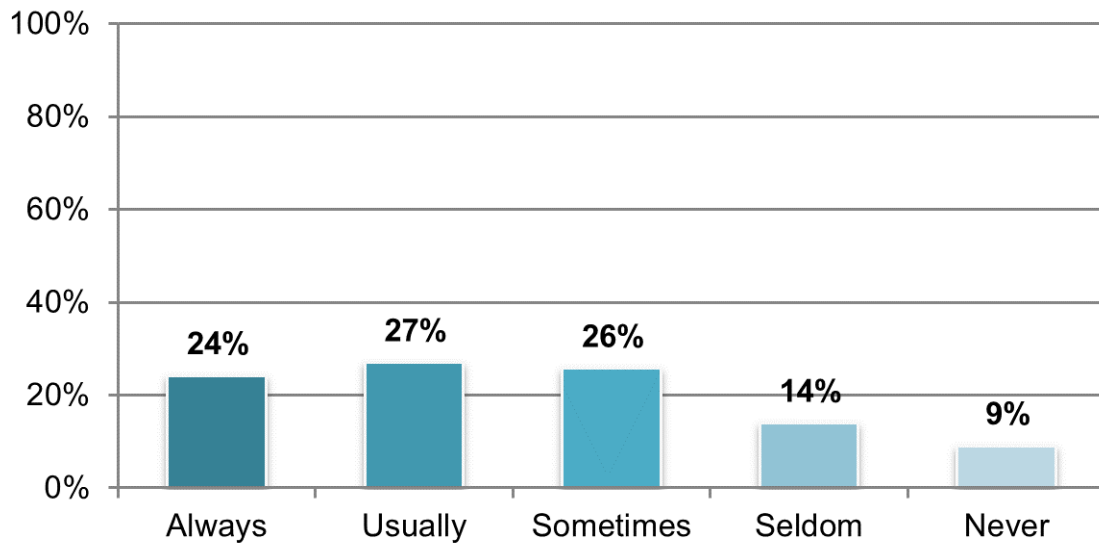


Table Q1. Do you receive information about the services and supports that are available to your child and family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
TX	29%	25%	28%	10%	7%	1,353
Within Average Range						
SC	28%	31%	17%	18%	6%	163
LA	26%	26%	22%	10%	15%	168
AZ	26%	28%	27%	12%	8%	303
OH	26%	18%	32%	11%	13%	388
NC	24%	30%	21%	15%	9%	300
WA	23%	27%	25%	16%	9%	300
OR	20%	32%	29%	12%	6%	409
CT	20%	22%	26%	21%	12%	170
VA	20%	31%	30%	15%	5%	223
NCI Average	24%	27%	26%	14%	9%	3,777

Information About Services and Supports Is Easy to Understand

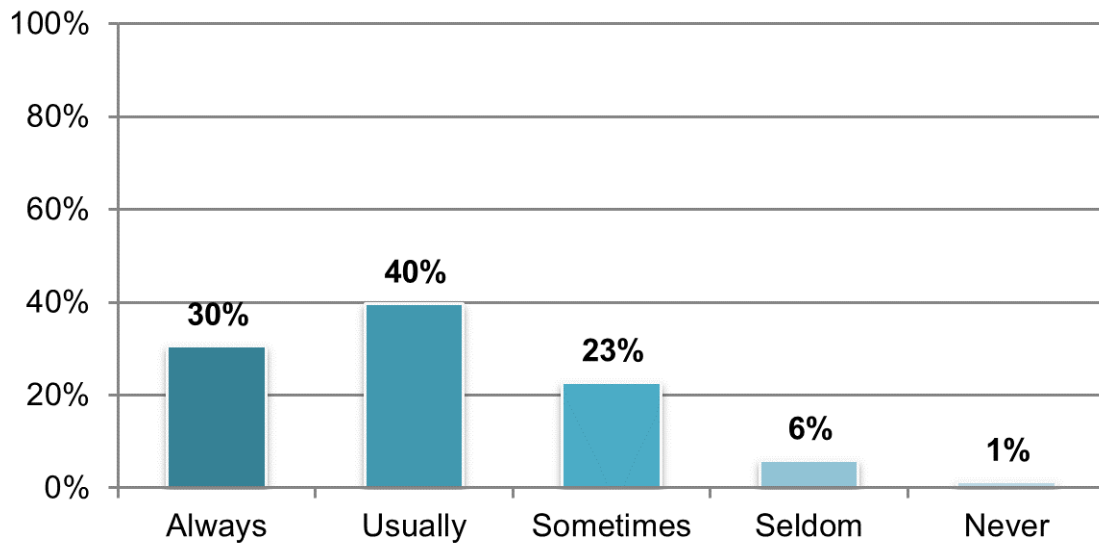


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	49%	28%	19%	3%	1%	341
Within Average Range						
SC	38%	42%	14%	4%	3%	148
LA	33%	38%	24%	6%	0%	143
AZ	32%	42%	21%	5%	0%	283
TX	31%	35%	26%	6%	1%	1,240
OR	30%	46%	16%	6%	2%	383
WA	26%	40%	25%	6%	2%	260
CT	24%	39%	29%	8%	1%	132
Significantly Below Average						
NC	21%	44%	26%	7%	2%	269
VA	20%	43%	28%	8%	0%	209
NCI Average	30%	40%	23%	6%	1%	3,408

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

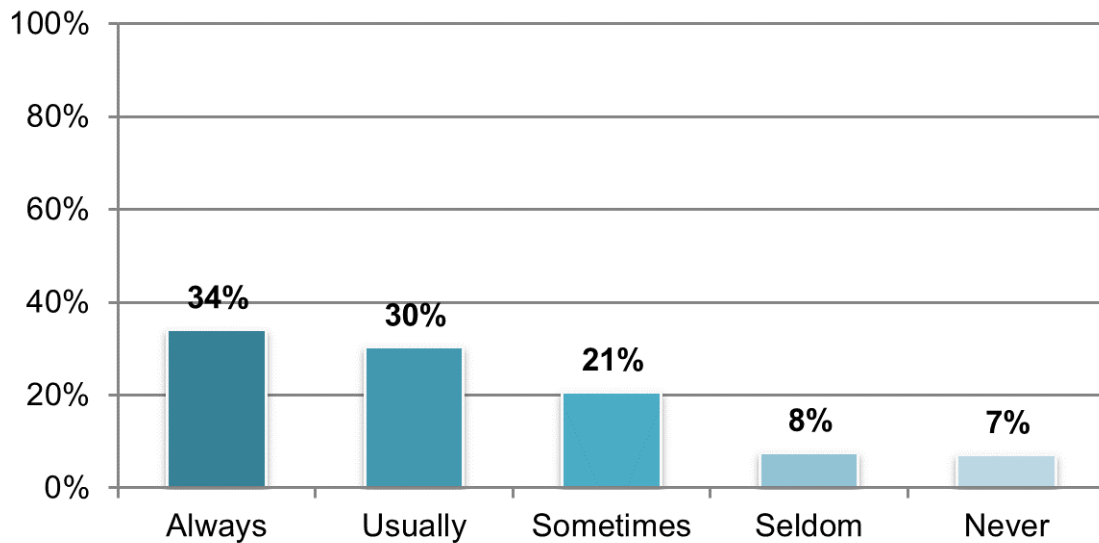


Table Q3. Does the information you receive primarily come from your case manager/service coordinator (as opposed to family, friends, and others outside of state services)?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
AZ	39%	26%	21%	8%	6%	295
OR	39%	35%	17%	6%	3%	386
SC	39%	34%	15%	7%	5%	153
TX	38%	30%	20%	6%	6%	1,282
LA	37%	25%	15%	11%	13%	142
VA	32%	35%	20%	8%	4%	210
WA	32%	28%	24%	8%	9%	267
CT	31%	26%	26%	10%	6%	137
OH	31%	27%	24%	5%	13%	311
Significantly Below Average						
NC	23%	38%	24%	7%	8%	265
NCI Average	34%	30%	21%	8%	7%	3,448

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

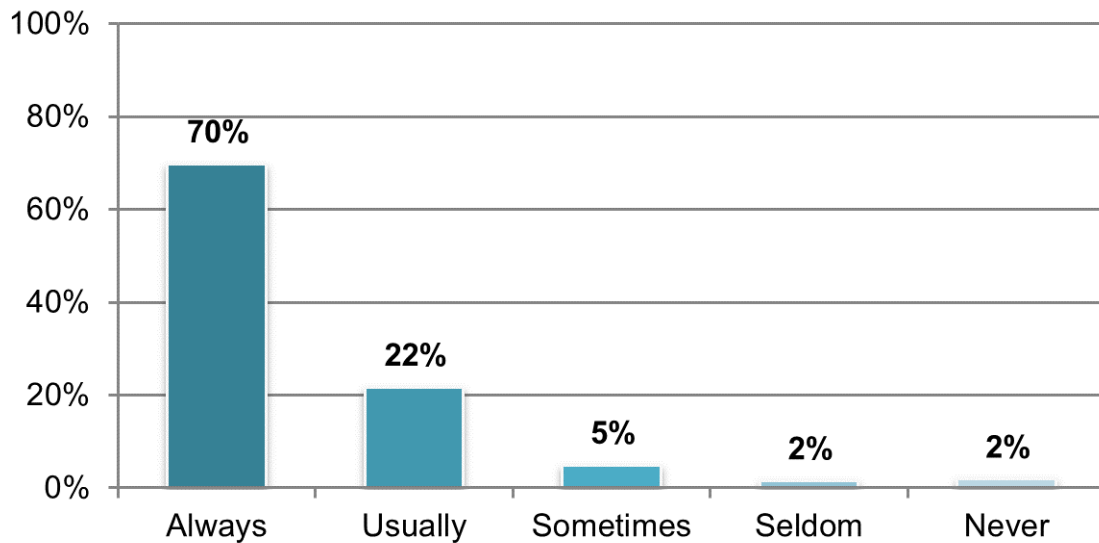


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	80%	12%	4%	1%	3%	311
Within Average Range						
SC	77%	17%	3%	2%	0%	155
TX	74%	20%	4%	1%	1%	1,307
VA	71%	23%	5%	0%	0%	215
AZ	71%	19%	7%	2%	1%	299
OR	68%	24%	5%	2%	1%	388
WA	68%	25%	5%	1%	1%	280
CT	65%	23%	7%	3%	2%	153
LA	62%	25%	5%	1%	7%	150
Significantly Below Average						
NC	62%	28%	5%	3%	2%	278
NCI Average	70%	22%	5%	2%	2%	3,536

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

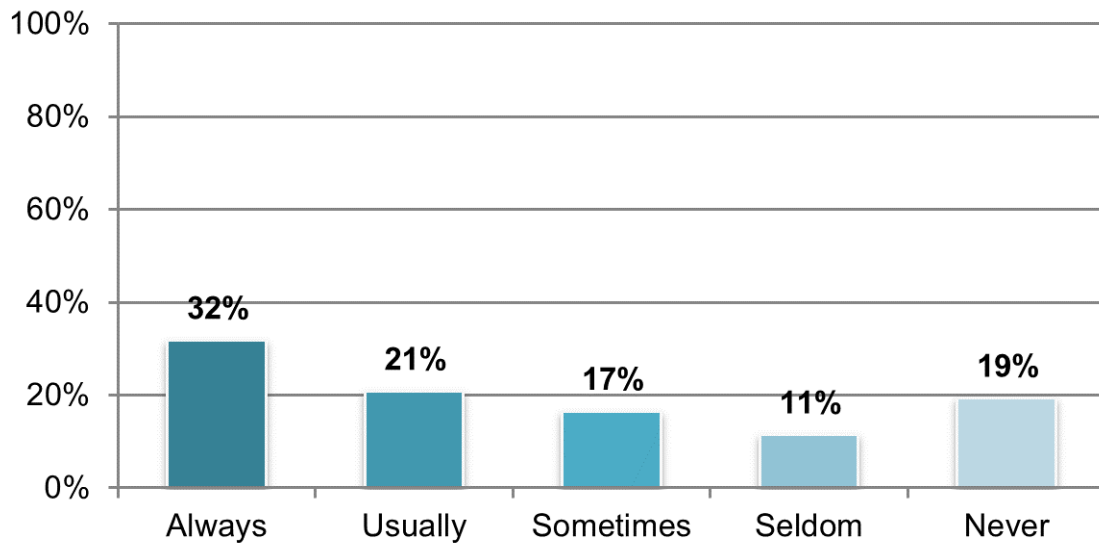


Table Q5. Does your case manager/service coordinator tell you about other public services that you are eligible for (e.g., food stamps, Early Period Screening Diagnosis and Treatment [EPSDT], Supplemental Security Income [SSI], housing subsidies, etc.)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	41%	13%	23%	6%	17%	315
TX	38%	21%	15%	11%	14%	1,287
Within Average Range						
LA	35%	14%	16%	12%	23%	150
OR	31%	26%	19%	11%	12%	381
WA	31%	23%	17%	12%	17%	279
SC	30%	26%	13%	9%	22%	148
VA	29%	25%	17%	14%	14%	215
AZ	28%	18%	18%	12%	23%	281
CT	28%	20%	13%	10%	28%	134
NC	25%	22%	14%	17%	23%	265
NCI Average	32%	21%	17%	11%	19%	3,455

Child Has a Service Plan

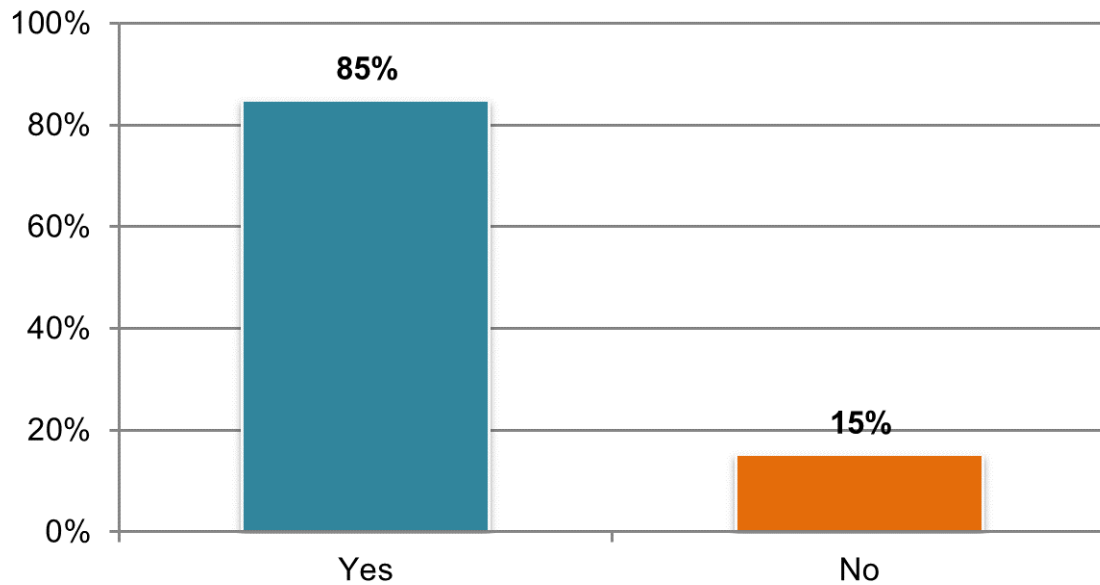


Table Q6. Does your child have a service plan?

State	Yes	No	N
Significantly Above Average			
VA	95%	5%	200
NC	95%	5%	284
AZ	92%	8%	286
Within Average Range			
CT	90%	10%	147
OR	87%	13%	338
TX	87%	13%	1,096
SC	83%	17%	129
Significantly Below Average			
WA	75%	25%	224
OH	75%	25%	360
LA	69%	31%	137
NCI Average	85%	15%	3,201

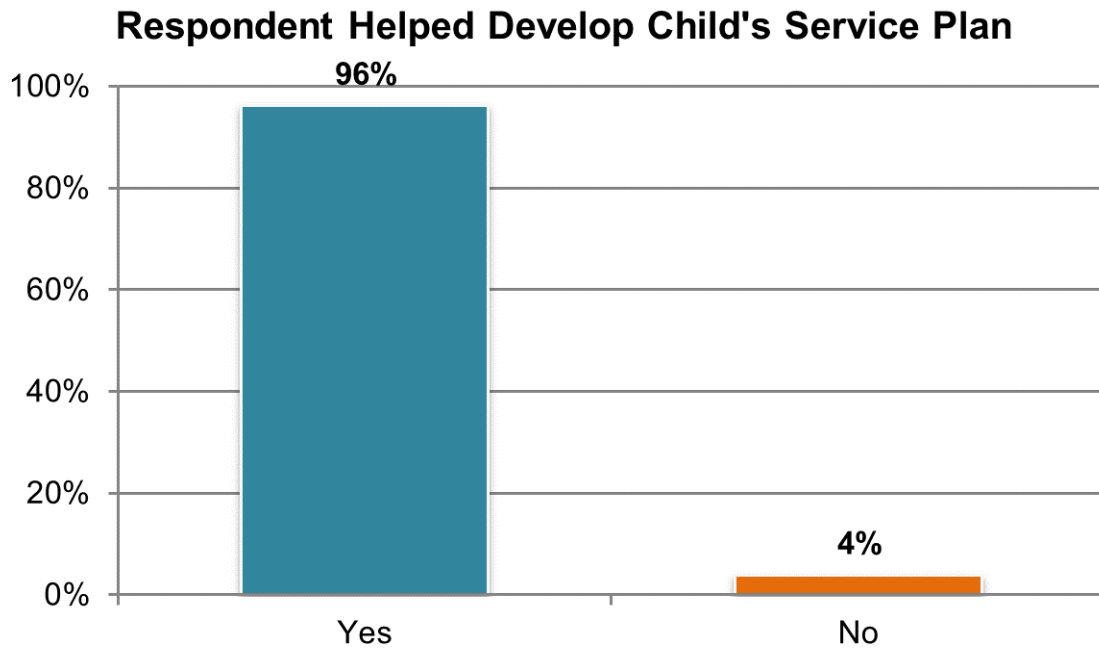


Table Q7. Did you help develop the plan?

State	Yes	No	N
Significantly Above Average			
OR	98%	2%	277
Within Average Range			
OH	98%	2%	266
LA	98%	2%	87
AZ	98%	2%	251
NC	97%	3%	272
SC	97%	3%	98
VA	97%	3%	190
TX	94%	6%	905
WA	93%	7%	148
CT	91%	9%	117
NCI Average	96%	4%	2,611

Service Plan Includes All the Services and Supports the Family Wants

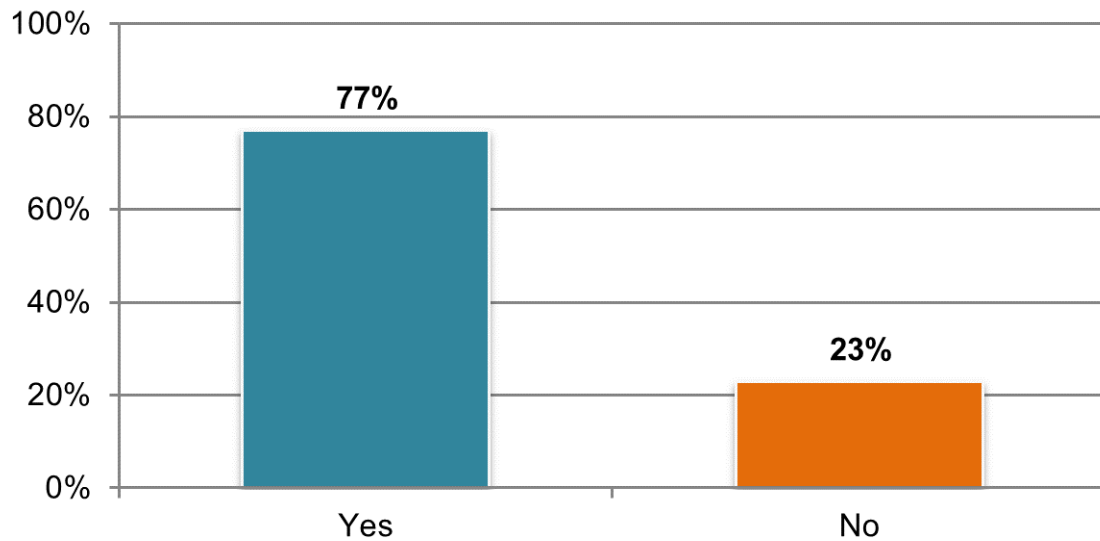


Table Q8. Does the plan include all the services and supports your family wants?

State	Yes	No	N
Significantly Above Average			
OH	88%	12%	258
Within Average Range			
VA	83%	17%	168
TX	81%	19%	853
SC	81%	19%	94
AZ	79%	21%	237
LA	78%	22%	82
NC	73%	27%	257
WA	70%	30%	142
CT	69%	31%	106
Significantly Below Average			
OR	68%	32%	250
NCI Average	77%	23%	2,447

Service Plan Includes All the Services and Supports the Family Needs

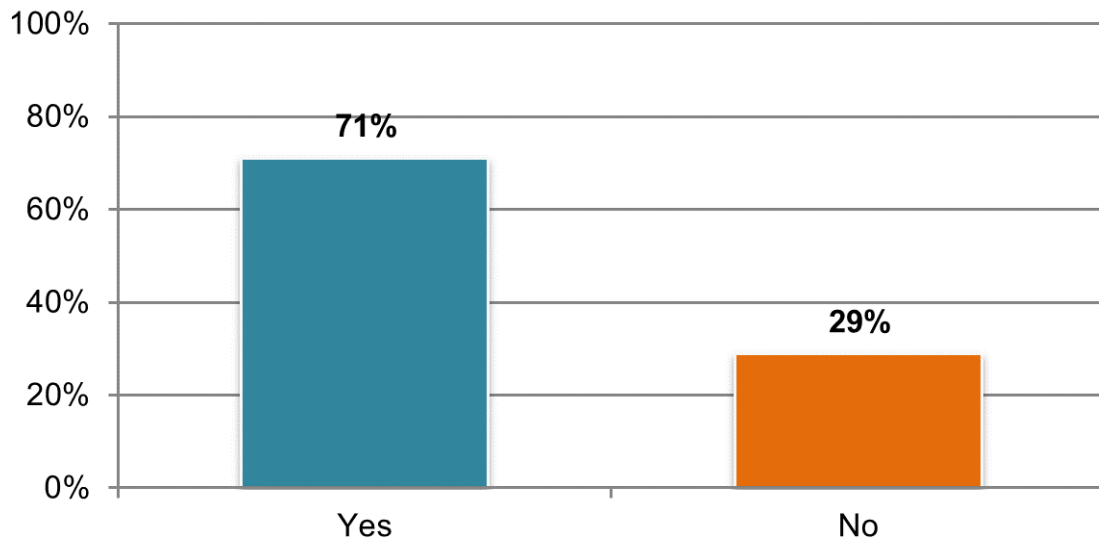


Table Q9. Does the plan include all the services and supports your family needs?

State	Yes	No	N
Significantly Above Average			
OH	84%	16%	260
TX	77%	23%	837
Within Average Range			
LA	80%	20%	80
SC	75%	25%	92
AZ	74%	26%	230
VA	73%	27%	162
NC	67%	33%	252
CT	62%	38%	107
WA	61%	39%	141
Significantly Below Average			
OR	59%	41%	251
NCI Average	71%	29%	2,412

Family Receives All Services Listed in the Service Plan

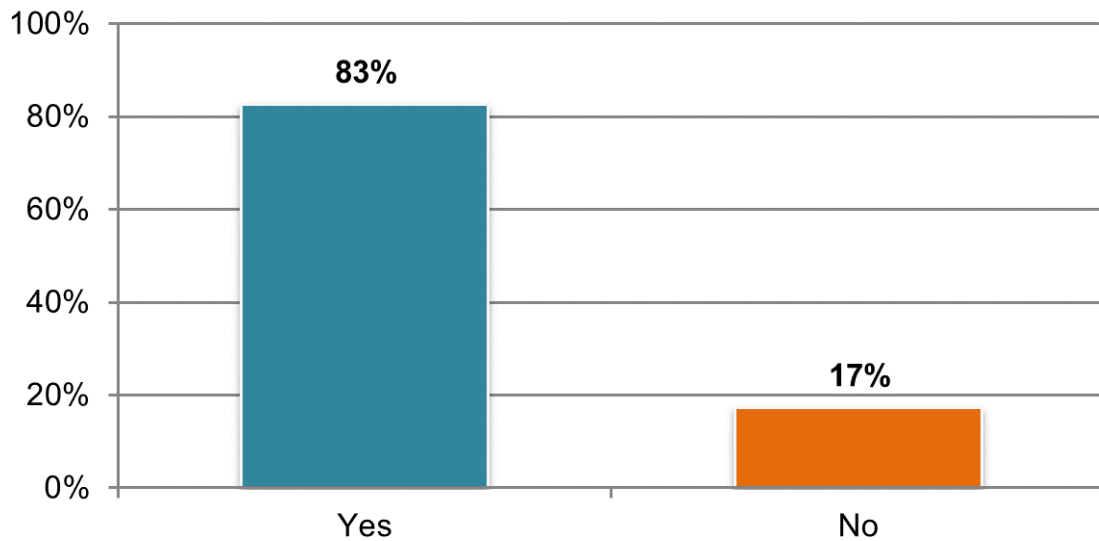


Table Q10. Does your family receive all of the services listed in the plan?

State	Yes	No	N
Significantly Above Average			
OH	89%	11%	254
Within Average Range			
NC	86%	14%	257
WA	86%	14%	145
OR	85%	15%	251
CT	85%	15%	108
TX	84%	16%	830
VA	84%	16%	171
LA	83%	17%	86
SC	74%	26%	88
Significantly Below Average			
AZ	71%	29%	241
NCI Average	83%	17%	2,431

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

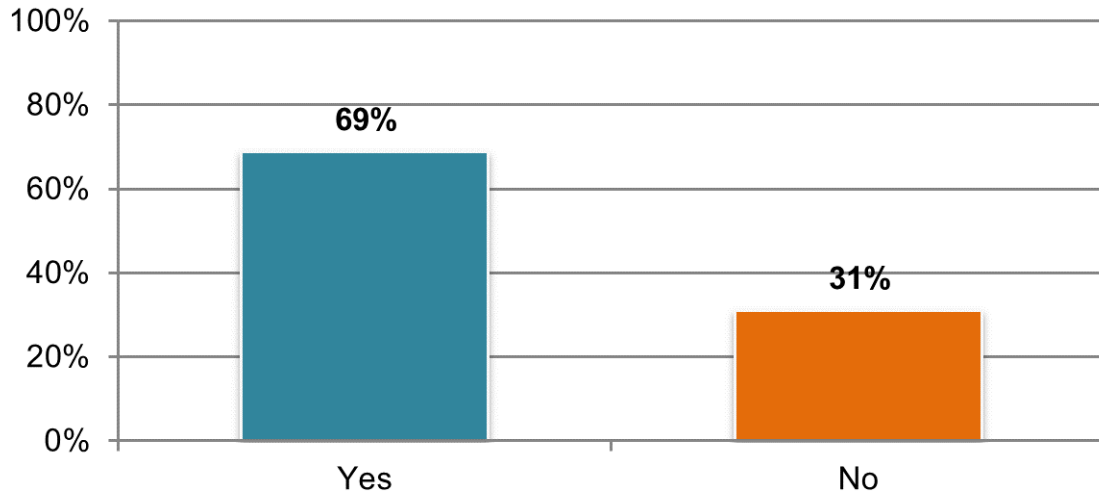


Table Q11. Did you discuss how to handle emergencies related to your child at the last service planning meeting?

State	Yes	No	N
Significantly Above Average			
LA	87%	13%	84
TX	82%	18%	858
NC	80%	20%	266
WA	78%	22%	146
Within Average Range			
AZ	72%	28%	230
OH	72%	28%	238
SC	67%	33%	90
Significantly Below Average			
CT	56%	44%	102
VA	48%	52%	165
OR	48%	53%	240
NCI Average	69%	31%	2,419

Respondents Received Information About Family's Rights

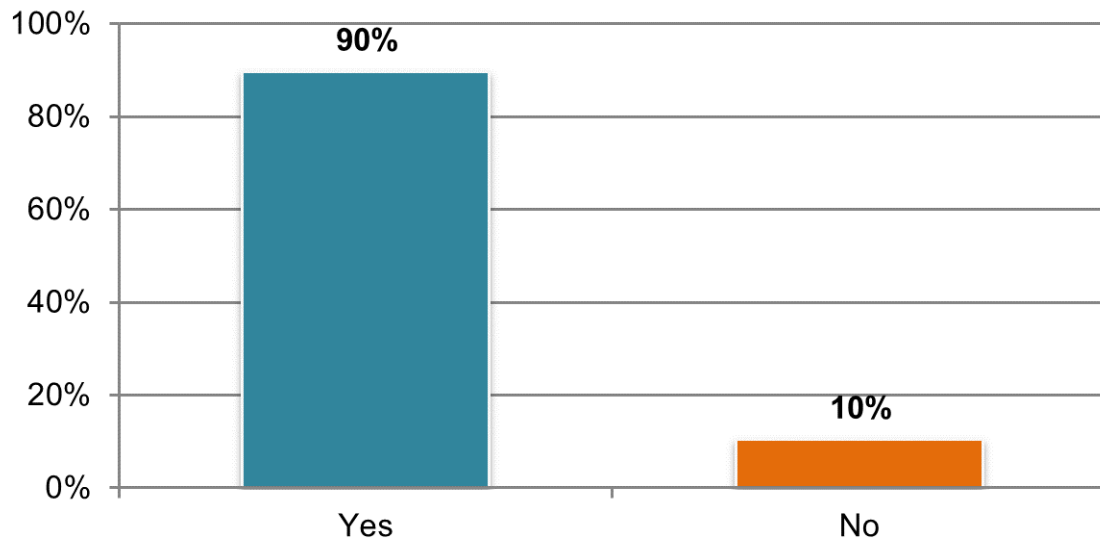


Table Q12. Have you received information about your family's rights?

State	Yes	No	N
Significantly Above Average			
OR	94%	6%	328
Within Average Range			
VA	93%	7%	199
AZ	93%	7%	279
TX	92%	8%	1,130
NC	90%	10%	276
OH	89%	11%	373
SC	88%	12%	137
CT	88%	12%	119
WA	87%	13%	212
LA	83%	17%	133
NCI Average	90%	10%	3,186

Access and Delivery of Services and Supports

Families and children with disabilities get the services and supports they need.

Just over half of all respondents report that they can always contact support workers (54%) and their case manager/service coordinator (53%) when needed. More than one-third indicate that supports and services are available when needed (35%) and supports change when needs change (38%). Among those respondents whose primary language is not English, two-thirds report that support workers or translators are always available to speak to their family members in their preferred language (66%). Among those whose primary language is English, 73% report that support workers always communicate effectively. However, fewer than one-third report that support workers can always communicate effectively with their child if the child is non-verbal (32%).

A majority of respondents report having access to the following services for their child: health services (98%), dental services (95%), necessary medications (98%), mental health services (88%), and respite services (78%). Just over half report that there are services needed that are not currently offered (55%).

Note: State outcomes denoted with an n/a means there were too few cases to report (less than 20 responses).

Respondent Is Able to Contact Support Workers When Needed

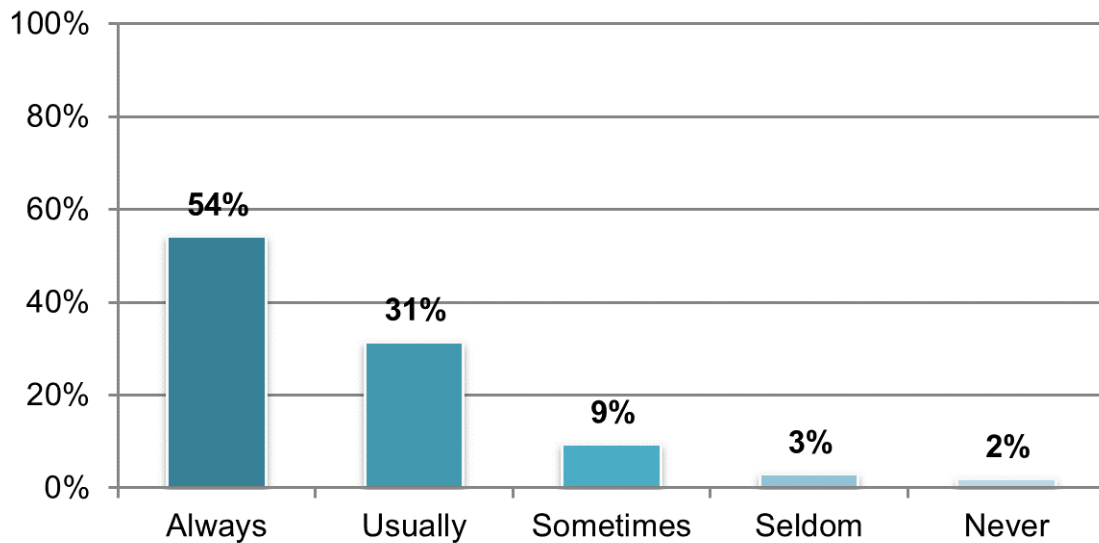


Table Q13. Are you able to contact your support workers when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	66%	20%	8%	3%	3%	357
SC	66%	25%	4%	3%	1%	143
TX	60%	30%	7%	2%	1%	1,295
Within Average Range						
LA	62%	25%	8%	2%	3%	143
AZ	57%	31%	9%	2%	2%	301
NC	50%	38%	8%	2%	2%	294
WA	46%	35%	14%	4%	1%	271
VA	46%	39%	10%	3%	1%	211
Significantly Below Average						
OR	46%	41%	9%	3%	1%	358
CT	42%	31%	18%	6%	4%	159
NCI Average	54%	31%	9%	3%	2%	3,532

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

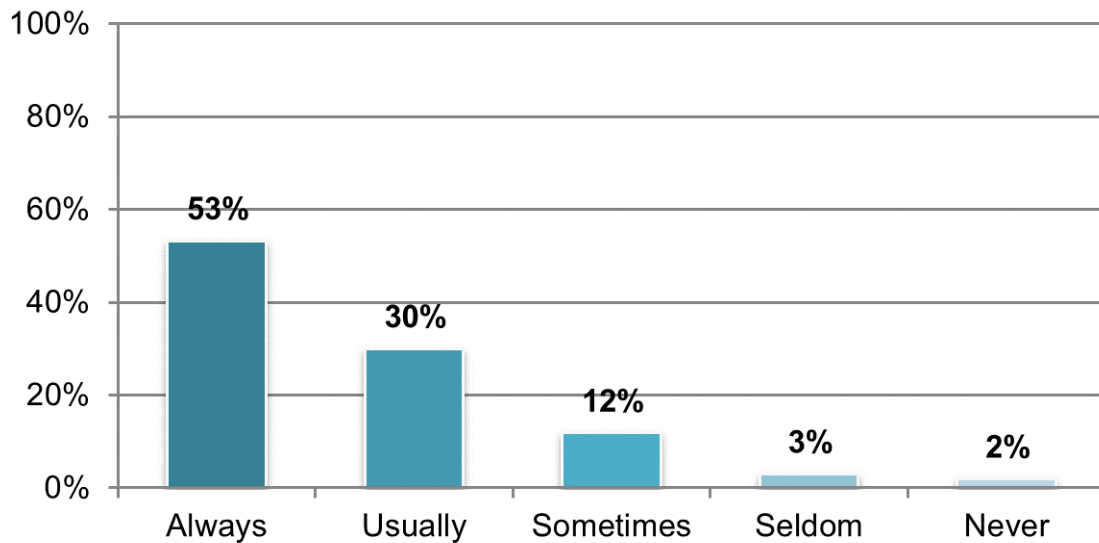


Table Q14. Are you able to contact your case manager/service coordinator when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
SC	67%	22%	6%	3%	1%	156
TX	62%	29%	7%	1%	1%	1,332
Within Average Range						
LA	59%	27%	10%	3%	1%	143
OH	59%	23%	12%	2%	4%	329
AZ	54%	28%	13%	3%	2%	307
VA	51%	33%	11%	3%	1%	218
WA	49%	32%	13%	5%	1%	296
NC	48%	36%	9%	3%	2%	285
Significantly Below Average						
OR	45%	39%	12%	3%	2%	394
CT	38%	30%	25%	4%	2%	162
NCI Average	53%	30%	12%	3%	2%	3,622

Service and Supports Are Available at Times They Are Needed

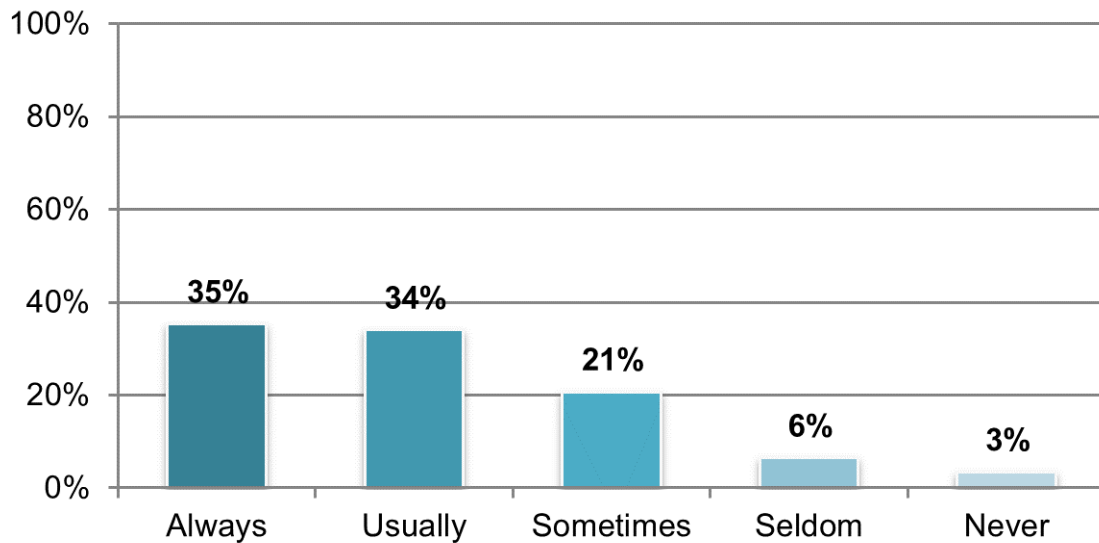


Table Q15. Are services and supports available when you need them?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	51%	26%	14%	4%	4%	140
OH	51%	28%	15%	2%	4%	377
TX	45%	33%	15%	4%	2%	1,300
Within Average Range						
AZ	38%	33%	20%	7%	3%	303
SC	37%	34%	20%	6%	3%	146
VA	33%	36%	23%	6%	2%	214
NC	30%	44%	17%	4%	5%	300
WA	30%	31%	27%	9%	3%	284
Significantly Below Average						
CT	19%	39%	29%	9%	4%	150
OR	19%	37%	28%	12%	4%	379
NCI Average	35%	34%	21%	6%	3%	3,593

Services and Supports Are Available Reasonably Close to Home

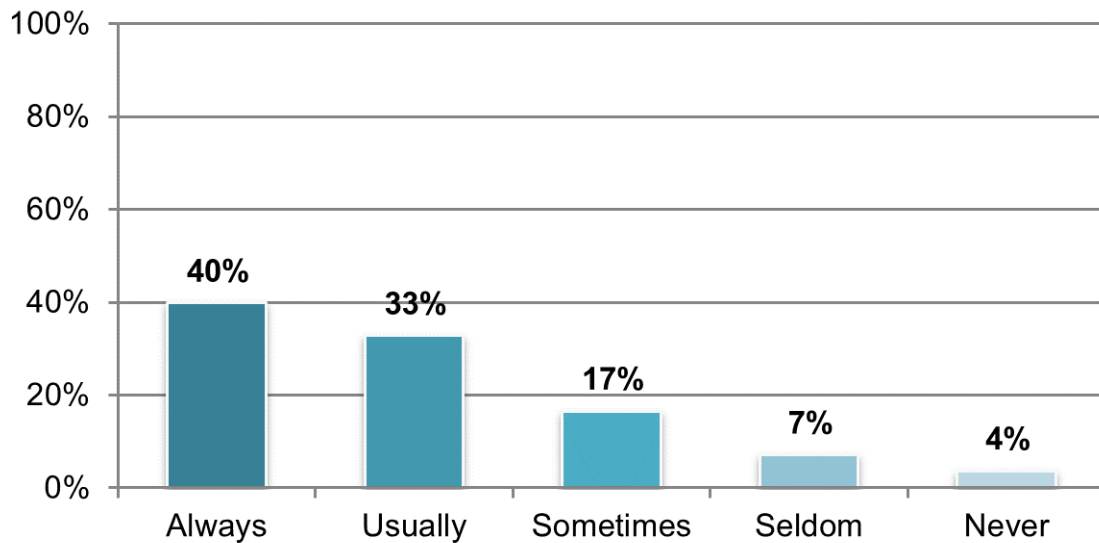


Table Q16. Are services and supports available within a reasonable distance from your home?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	64%	20%	10%	2%	4%	369
LA	51%	26%	15%	4%	4%	136
Within Average Range						
SC	45%	28%	17%	6%	4%	145
TX	44%	30%	16%	7%	3%	1,234
AZ	40%	34%	16%	7%	3%	295
NC	36%	38%	13%	7%	5%	255
VA	34%	35%	20%	7%	3%	204
Significantly Below Average						
OR	31%	36%	19%	10%	3%	342
WA	28%	44%	15%	8%	4%	254
CT	24%	36%	23%	12%	4%	137
NCI Average	40%	33%	17%	7%	4%	3,371

Services and Supports Change When Child's Needs Change

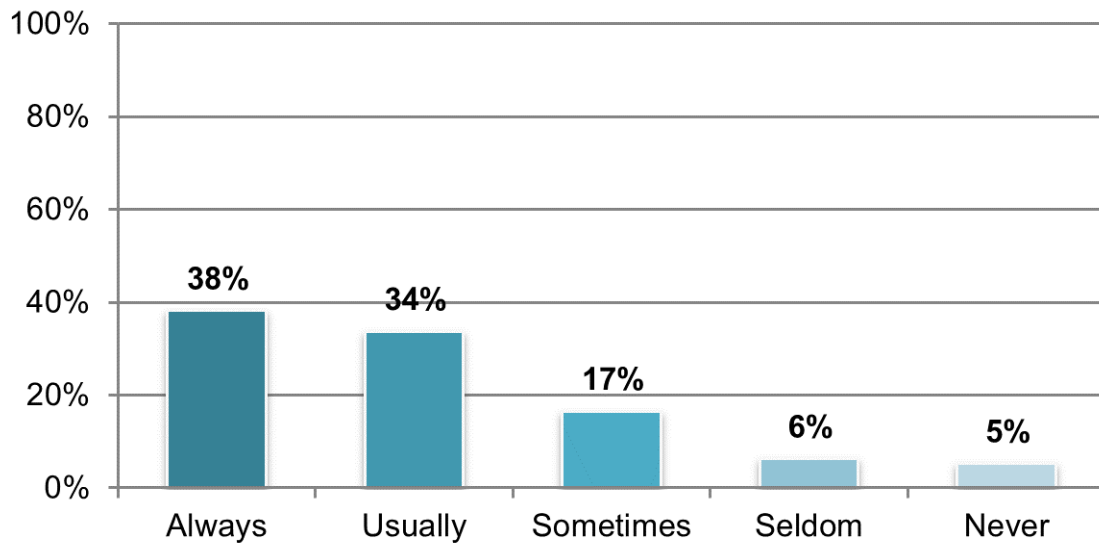


Table Q17. Do the services and supports change when your child's needs change?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	58%	23%	13%	1%	5%	337
SC	51%	30%	10%	4%	5%	130
TX	44%	32%	15%	5%	4%	1,136
Within Average Range						
LA	45%	30%	14%	3%	8%	128
NC	37%	41%	11%	7%	5%	283
AZ	37%	38%	16%	4%	5%	286
VA	34%	37%	18%	9%	2%	190
Significantly Below Average						
WA	30%	37%	18%	10%	5%	241
OR	29%	34%	25%	6%	6%	306
CT	18%	36%	25%	13%	8%	114
NCI Average	38%	34%	17%	6%	5%	3,151

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

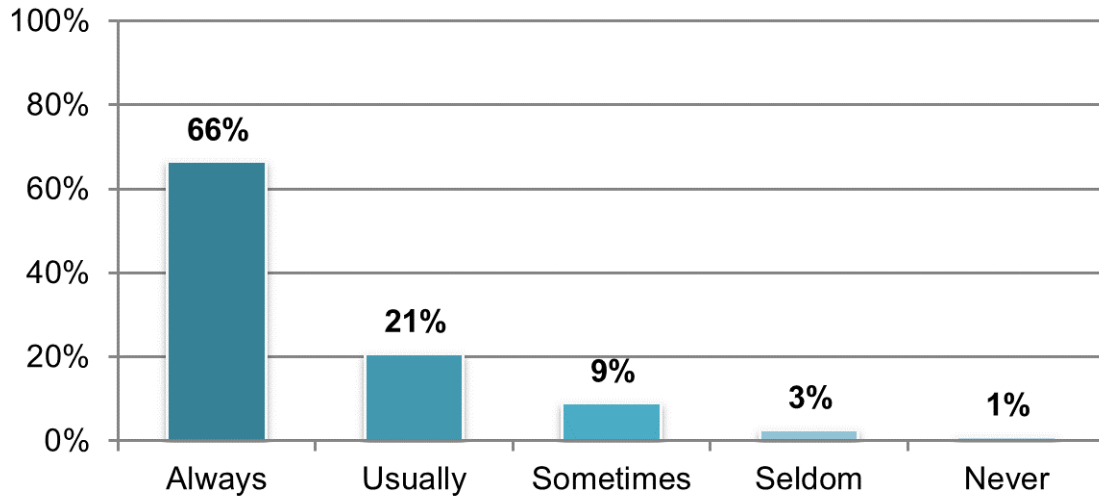


Table Q18. If English is not your primary language, are there support workers or translators who can speak with you in your language?¹

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
TX	72%	19%	8%	2%	0%	173
AZ	69%	17%	6%	4%	4%	52
WA	66%	21%	8%	5%	0%	38
OR	59%	26%	15%	0%	0%	27
CT	n/a	n/a	n/a	n/a	n/a	n/a
LA	n/a	n/a	n/a	n/a	n/a	n/a
NC	n/a	n/a	n/a	n/a	n/a	n/a
OH	n/a	n/a	n/a	n/a	n/a	n/a
SC	n/a	n/a	n/a	n/a	n/a	n/a
VA	n/a	n/a	n/a	n/a	n/a	n/a
NCI Average	66%	21%	9%	3%	1%	290

¹ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Support Workers Communicate Effectively in Respondent's Primary Language (If English)

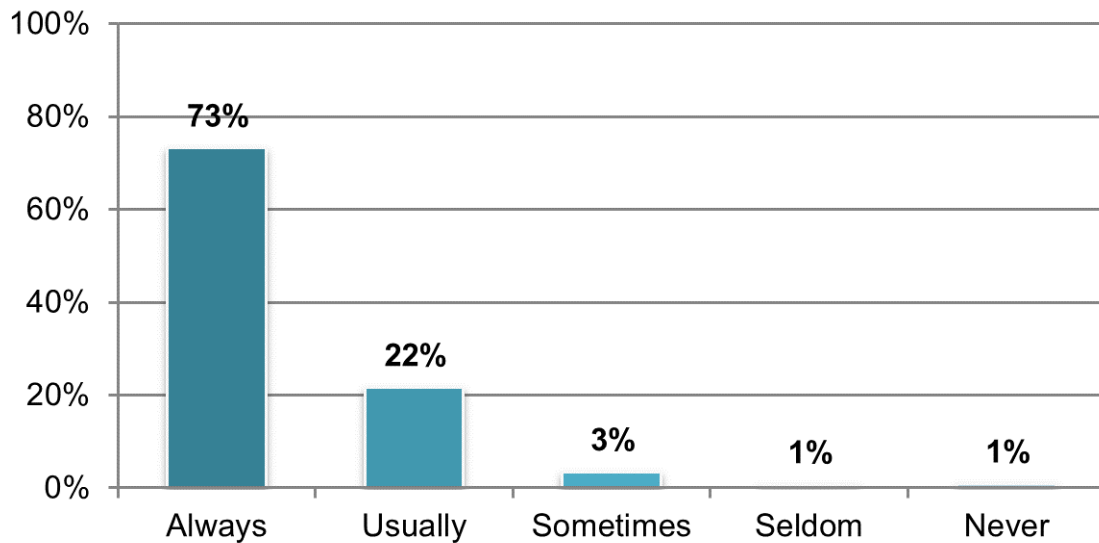


Table Q19. If English is your first language, do the support workers speak to you effectively?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
SC	82%	14%	2%	0%	2%	129
AZ	81%	15%	3%	1%	0%	232
OH	79%	14%	5%	1%	1%	351
TX	78%	20%	2%	0%	0%	1,021
Within Average Range						
VA	73%	23%	2%	1%	1%	188
LA	71%	24%	4%	0%	1%	129
NC	69%	25%	4%	1%	1%	272
CT	67%	27%	4%	2%	0%	135
OR	67%	26%	6%	1%	0%	335
Significantly Below Average						
WA	64%	30%	3%	1%	1%	216
NCI Average	73%	22%	3%	1%	1%	3,008

Support Workers Can Communicate With the Child (If Non-Verbal)

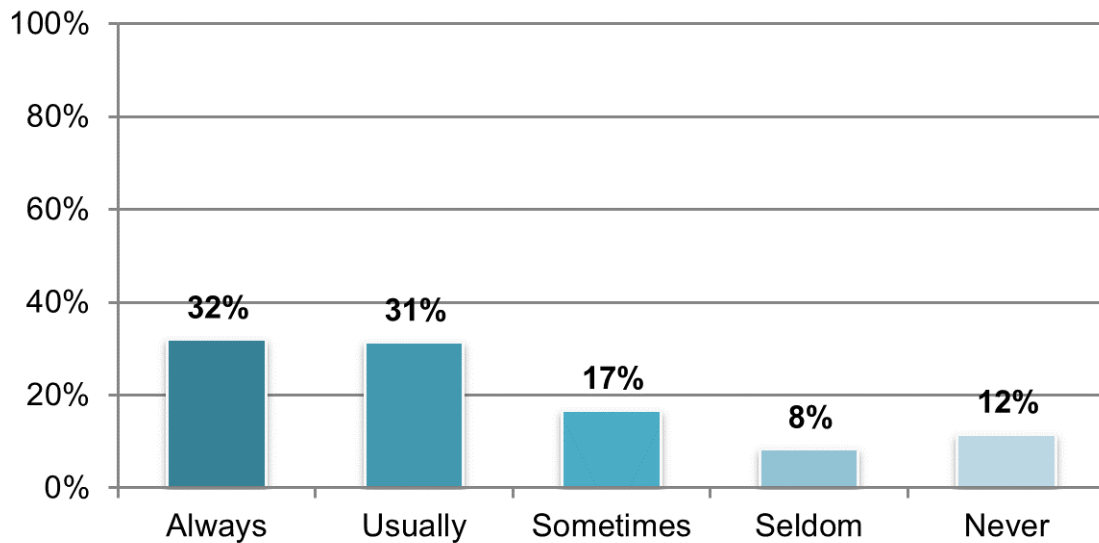


Table Q20. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
SC	53%	18%	7%	12%	11%	57
TX	38%	25%	15%	9%	12%	525
Within Average Range						
NC	40%	38%	11%	6%	5%	142
OH	36%	29%	14%	6%	15%	125
LA	32%	32%	23%	6%	6%	47
CT	32%	35%	15%	6%	12%	66
AZ	30%	35%	15%	8%	12%	106
VA	25%	33%	25%	8%	10%	113
Significantly Below Average						
WA	17%	38%	16%	13%	16%	100
OR	17%	32%	27%	8%	17%	138
NCI Average	32%	31%	17%	8%	12%	1,419

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

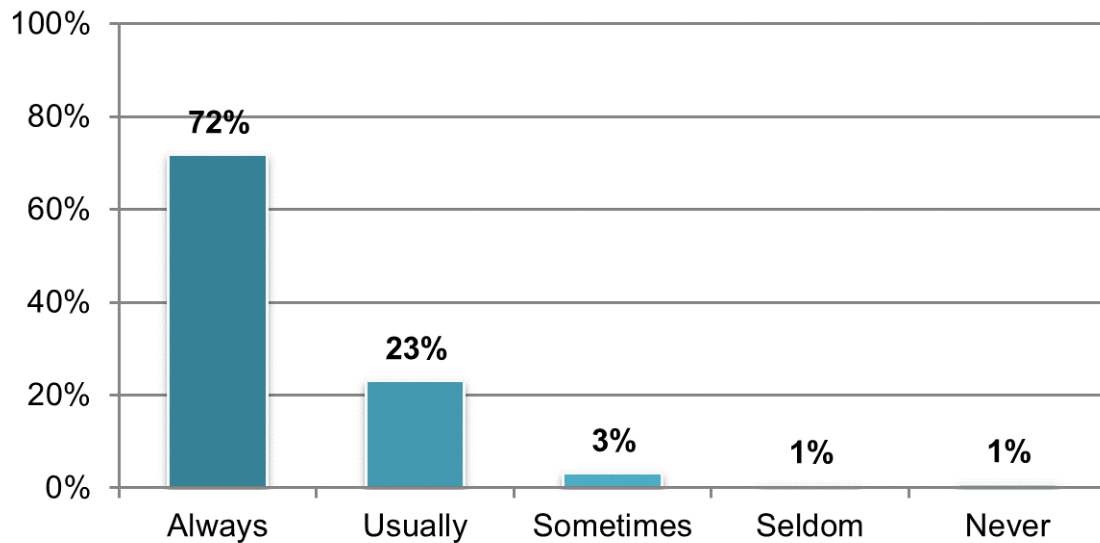


Table Q21. Are services delivered in a way that is respectful to your family's culture?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	89%	7%	2%	0%	1%	369
Within Average Range						
SC	78%	17%	4%	0%	1%	139
AZ	77%	20%	2%	1%	0%	289
TX	75%	21%	3%	1%	1%	1,273
LA	69%	25%	3%	1%	2%	132
VA	68%	27%	4%	1%	0%	205
NC	67%	27%	3%	1%	1%	288
WA	66%	29%	3%	1%	1%	266
OR	66%	31%	2%	1%	0%	347
CT	63%	28%	6%	2%	1%	140
NCI Average	72%	23%	3%	1%	1%	3,448

Child Has Access to Special Equipment or Accommodations Needed

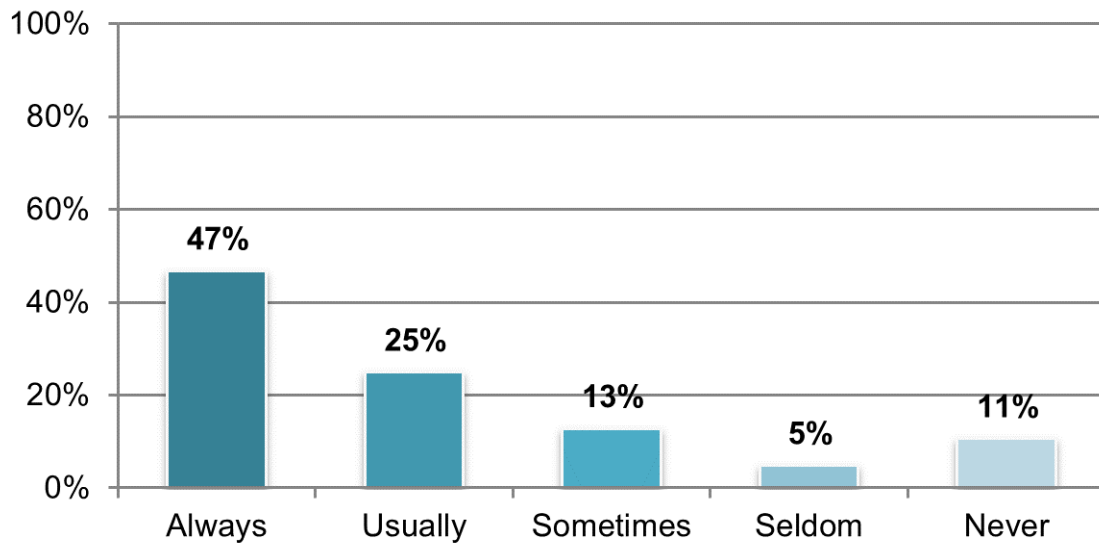


Table Q22. Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	64%	11%	11%	3%	11%	207
TX	54%	23%	10%	5%	9%	913
Within Average Range						
LA	51%	26%	10%	0%	13%	72
AZ	50%	23%	8%	6%	14%	154
SC	50%	21%	14%	4%	12%	78
CT	47%	26%	11%	6%	9%	95
VA	41%	33%	16%	6%	4%	166
NC	40%	31%	13%	6%	11%	224
Significantly Below Average						
WA	37%	26%	19%	7%	12%	199
OR	34%	31%	17%	6%	12%	253
NCI Average	47%	25%	13%	5%	11%	2,361

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

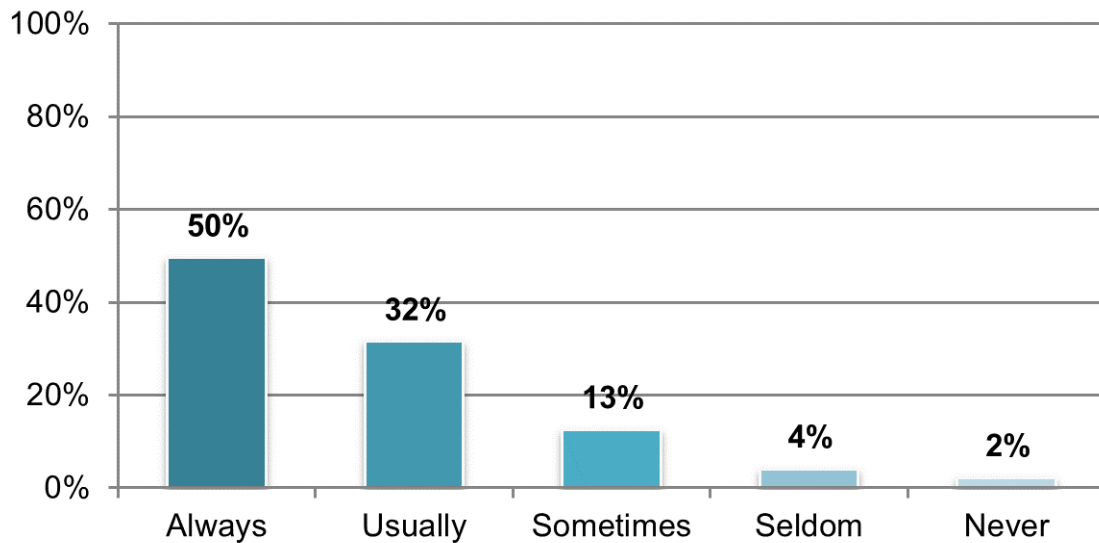


Table Q23. Do the support workers have the right training to meet your child's needs?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	65%	23%	9%	1%	3%	360
TX	58%	30%	9%	2%	1%	1,226
Within Average Range						
AZ	55%	31%	8%	5%	1%	287
LA	54%	32%	13%	0%	2%	130
SC	53%	27%	13%	5%	1%	141
WA	49%	29%	14%	6%	3%	241
NC	43%	33%	16%	5%	3%	288
VA	42%	34%	16%	7%	2%	209
Significantly Below Average						
OR	39%	38%	15%	6%	3%	314
CT	39%	40%	13%	4%	4%	134
NCI Average	50%	32%	13%	4%	2%	3,330

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

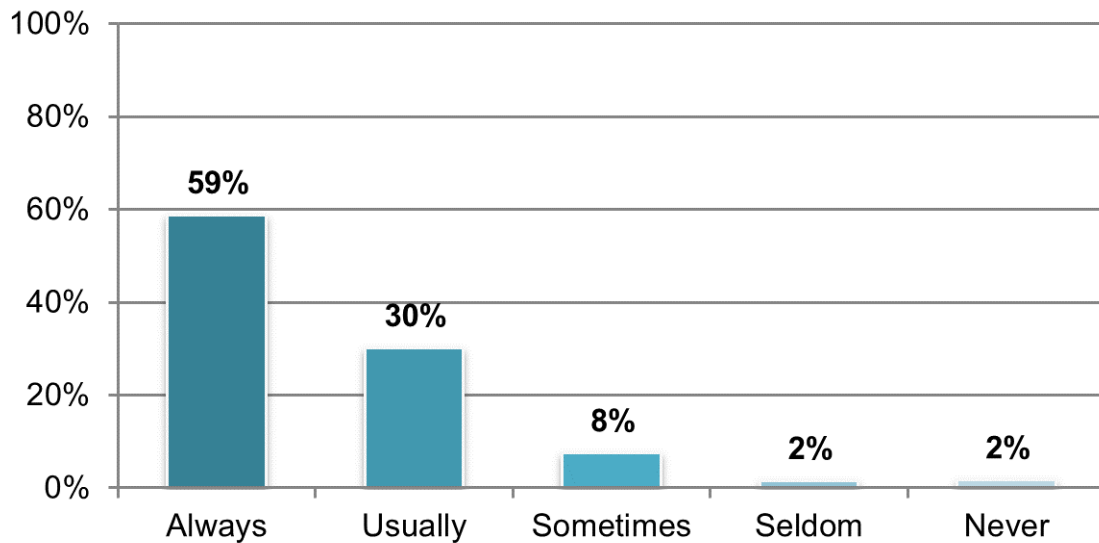


Table Q24. Do the support workers who come to your home arrive on time and when scheduled?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	73%	19%	3%	1%	3%	263
Within Average Range						
WA	66%	26%	5%	0%	2%	246
TX	63%	29%	7%	1%	1%	1,265
LA	61%	24%	11%	1%	3%	123
AZ	60%	29%	7%	2%	2%	295
SC	60%	28%	10%	2%	0%	134
OR	54%	37%	6%	1%	2%	303
CT	53%	34%	7%	4%	2%	124
Significantly Below Average						
NC	50%	35%	12%	2%	2%	289
VA	48%	42%	8%	2%	0%	211
NCI Average	59%	30%	8%	2%	2%	3,253

Crisis or Emergency Services Were Provided When Needed (If Requested)

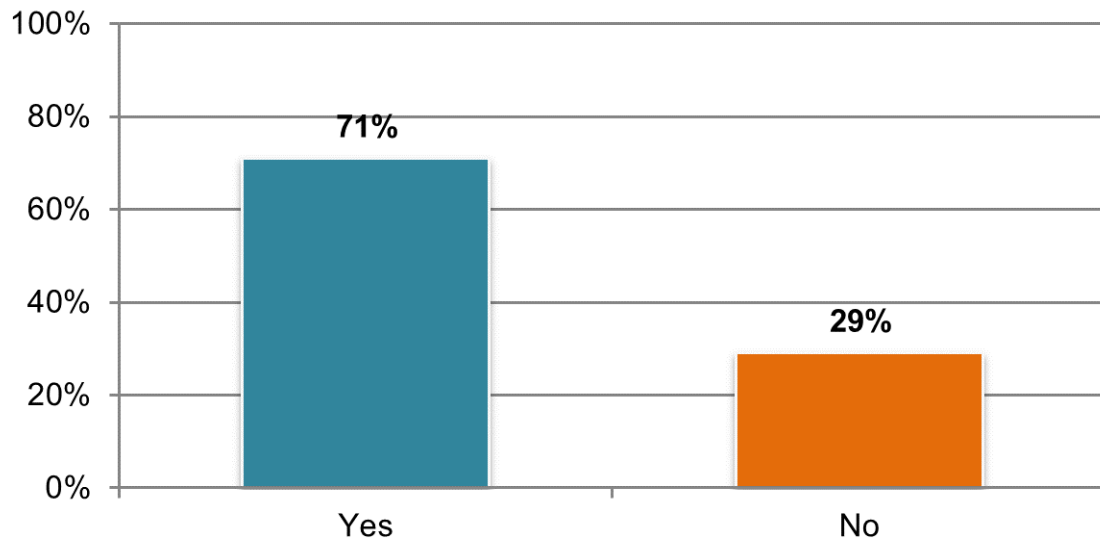


Table Q25. If you asked for crisis/emergency services during the past year, were services provided when needed?

State	Yes	No	N
Within Average Range			
AZ	76%	24%	62
VA	75%	25%	65
LA	73%	27%	45
TX	73%	27%	352
CT	72%	28%	36
WA	72%	28%	82
OR	72%	28%	92
NC	70%	30%	114
OH	66%	34%	116
SC	59%	41%	37
NCI Average	71%	29%	1,001

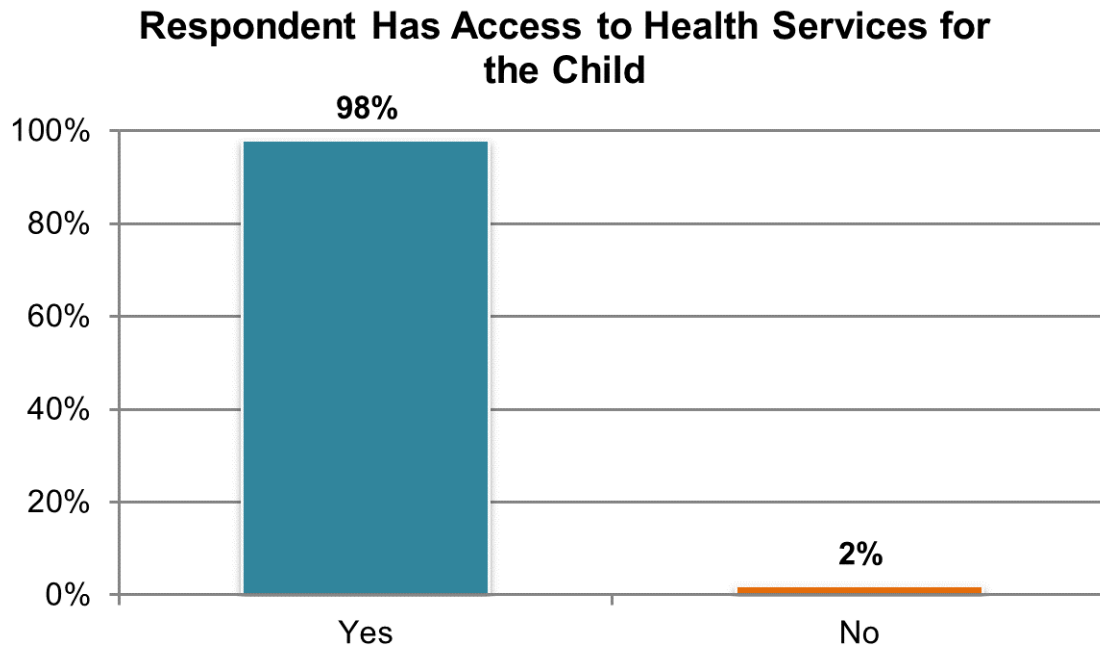


Table Q26. Do you have access to health services for your child?

State	Yes	No	N
Within Average Range			
VA	99%	1%	219
CT	99%	1%	153
AZ	99%	1%	303
WA	99%	1%	285
TX	99%	1%	1,330
LA	98%	2%	158
NC	98%	2%	296
SC	98%	2%	161
OR	97%	3%	387
OH	97%	3%	392
NCI Average	98%	2%	3,684

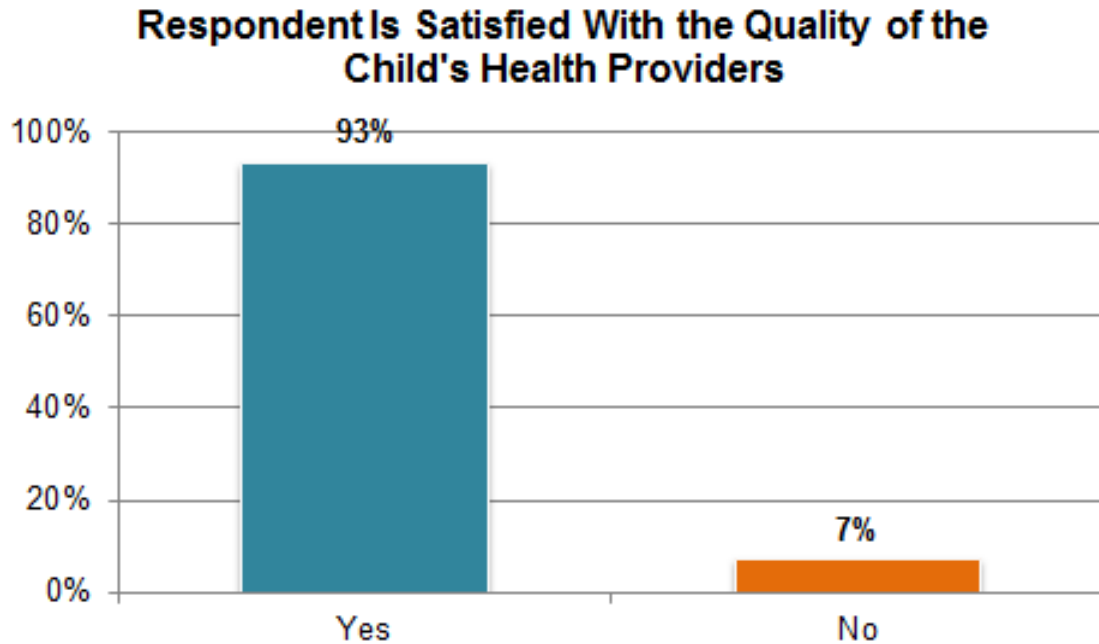


Table 26a. If you have access to health services for your child, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
NC	96%	4%	285
TX	96%	4%	1,258
Within Average Range			
SC	96%	4%	149
OH	95%	5%	370
LA	94%	6%	145
WA	93%	7%	271
VA	93%	7%	204
AZ	93%	7%	283
OR	90%	10%	350
CT	86%	14%	133
NCI Average	93%	7%	3,448

Respondent Has Access to Dental Services for the Child

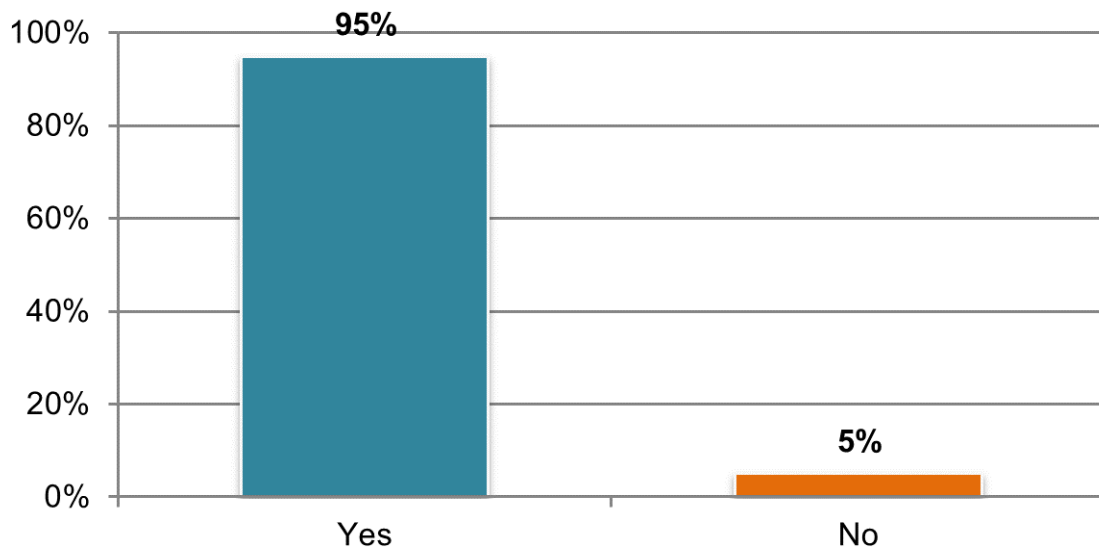


Table Q27. Do you have access to dental services for your child?

State	Yes	No	N
Significantly Above Average			
WA	98%	2%	293
TX	97%	3%	1,341
Within Average Range			
SC	97%	3%	154
VA	96%	4%	218
OR	96%	4%	388
CT	96%	4%	158
AZ	94%	6%	293
NC	93%	7%	299
OH	93%	7%	385
LA	90%	10%	154
NCI Average	95%	5%	3,683

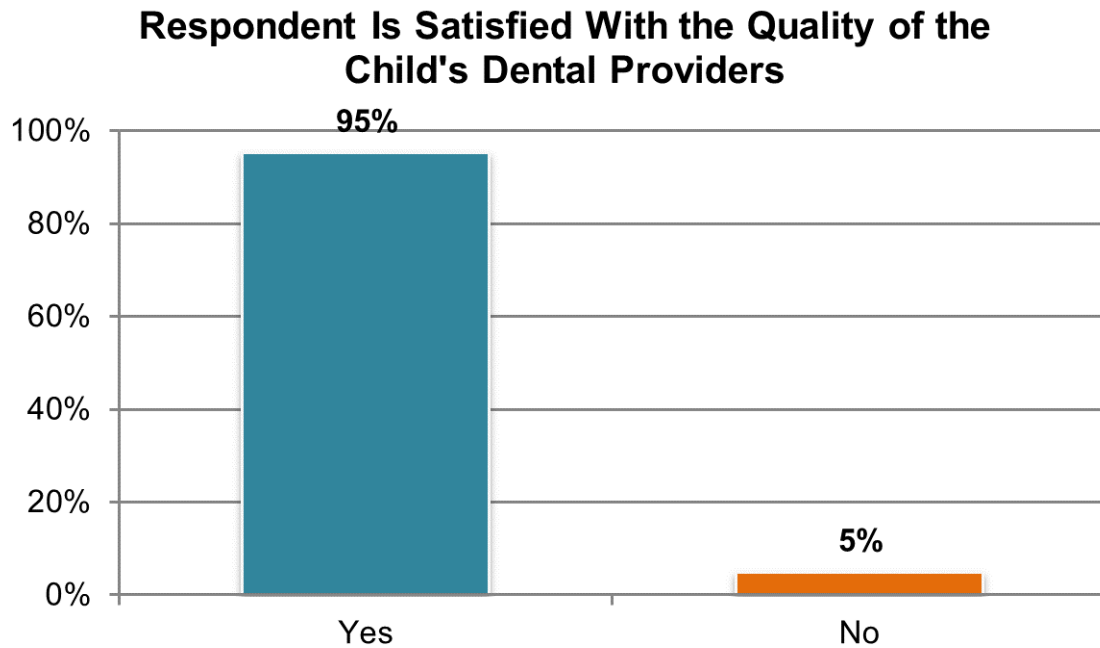


Table 27a. If you have access to dental services for your child, are you satisfied with the quality of these providers?

State	Yes	No	N
Within Average Range			
LA	98%	2%	128
AZ	97%	3%	253
VA	96%	4%	199
SC	96%	4%	140
WA	96%	4%	266
OH	96%	4%	328
NC	95%	5%	274
TX	94%	6%	1,227
OR	92%	8%	334
CT	91%	9%	133
NCI Average	95%	5%	3,282

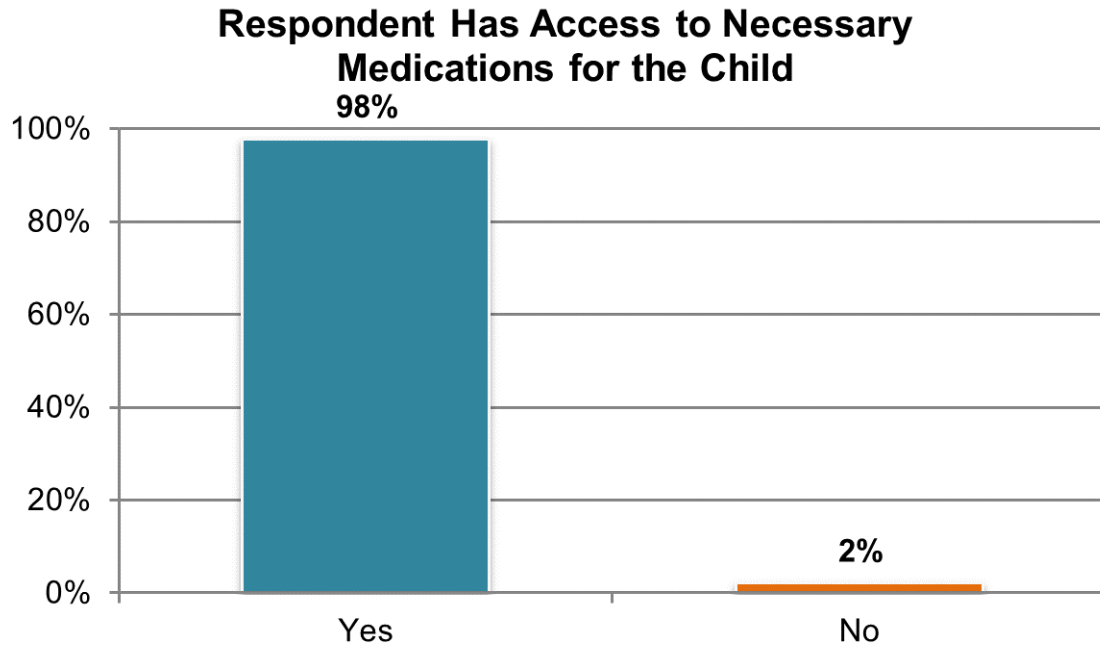


Table Q28. Are you able to get medications needed for your child?

State	Yes	No	N
Significantly Above Average			
NC	100%	0%	294
Within Average Range			
OH	99%	1%	383
TX	99%	1%	1,330
SC	99%	1%	152
CT	99%	1%	150
AZ	98%	2%	276
VA	98%	2%	218
OR	96%	4%	370
LA	96%	4%	154
WA	96%	4%	279
NCI Average	98%	2%	3,606

Respondent Is Satisfied With How the Child's Medication Needs Are Monitored

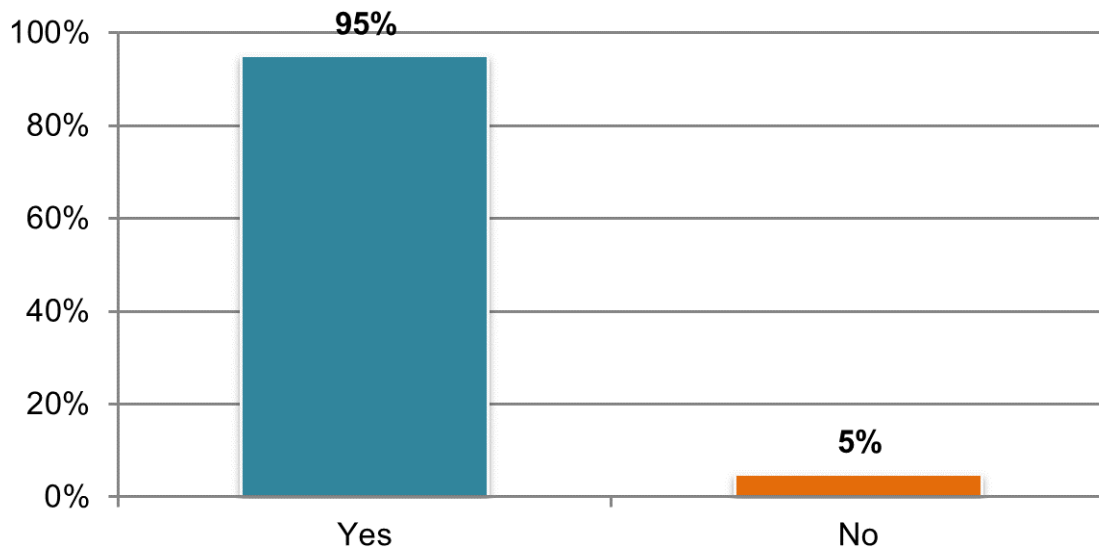


Table Q28a. If you have access to needed medications for your child, are you satisfied with how your child's medication needs are monitored?

State	Yes	No	N
Significantly Above Average			
TX	97%	3%	1,248
Within Average Range			
OH	97%	3%	361
VA	97%	4%	200
WA	96%	4%	253
NC	96%	4%	287
LA	96%	4%	138
SC	96%	4%	134
OR	94%	6%	323
CT	93%	7%	127
AZ	90%	10%	124
NCI Average	95%	5%	3,195

Respondent Has Access to Mental Health Services for the Child

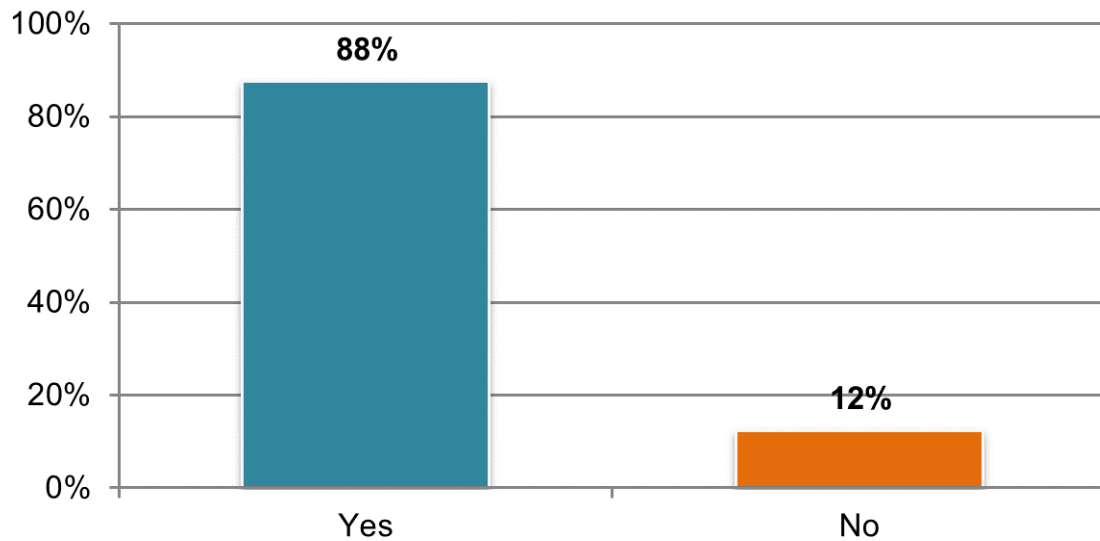


Table Q29. If needed, do you have access to mental health services for your child?

State	Yes	No	N
Significantly Above Average			
OH	93%	7%	294
Within Average Range			
VA	92%	8%	145
AZ	92%	8%	168
NC	91%	9%	222
TX	88%	12%	911
OR	86%	14%	260
SC	85%	15%	96
CT	84%	16%	99
WA	83%	17%	179
LA	82%	18%	99
NCI Average	88%	12%	2,473

Respondent Is Satisfied With the Quality of the Child's Mental Health Providers

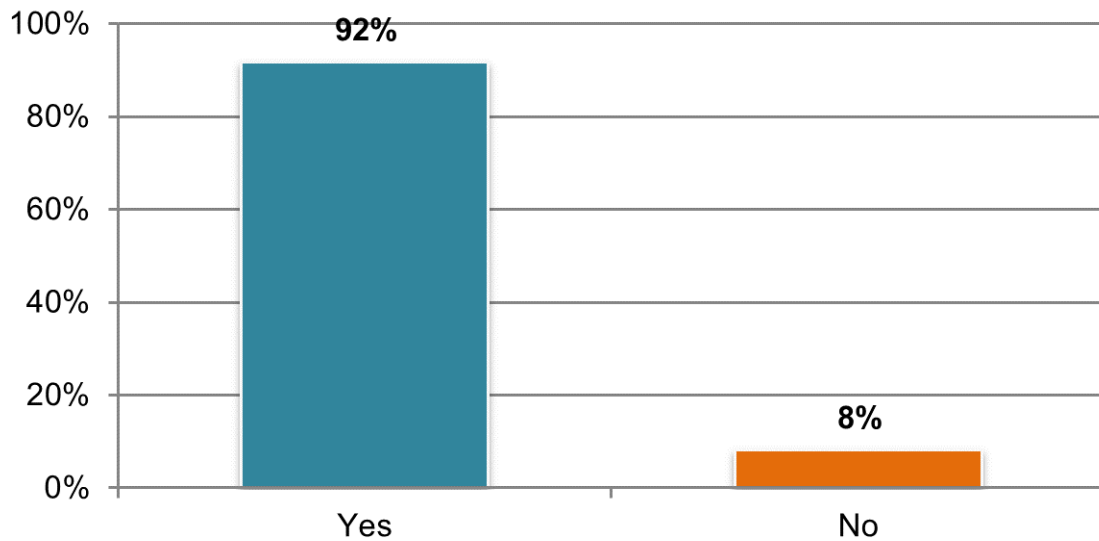


Table Q29a. If you have access to mental health services for your child, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
TX	96%	4%	678
Within Average Range			
SC	97%	3%	67
LA	95%	5%	62
CT	94%	6%	65
OH	92%	8%	194
VA	92%	8%	120
NC	91%	9%	164
WA	91%	9%	120
OR	86%	14%	160
AZ	84%	16%	102
NCI Average	92%	8%	1,732

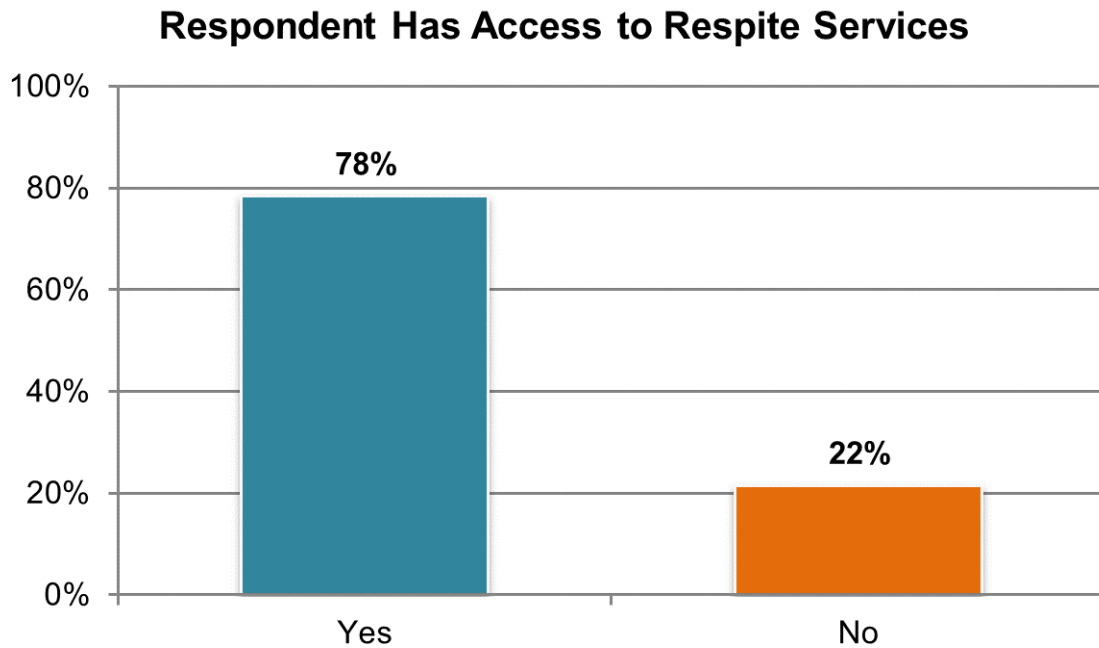


Table Q30. If you need respite services, do you have access to them?

State	Yes	No	N
Significantly Above Average			
AZ	92%	8%	251
TX	89%	11%	1,194
VA	88%	12%	201
NC	85%	15%	281
Within Average Range			
LA	76%	24%	74
OR	74%	26%	336
OH	74%	26%	282
WA	73%	27%	228
SC	69%	31%	85
Significantly Below Average			
CT	64%	36%	121
NCI Average	78%	22%	3,053

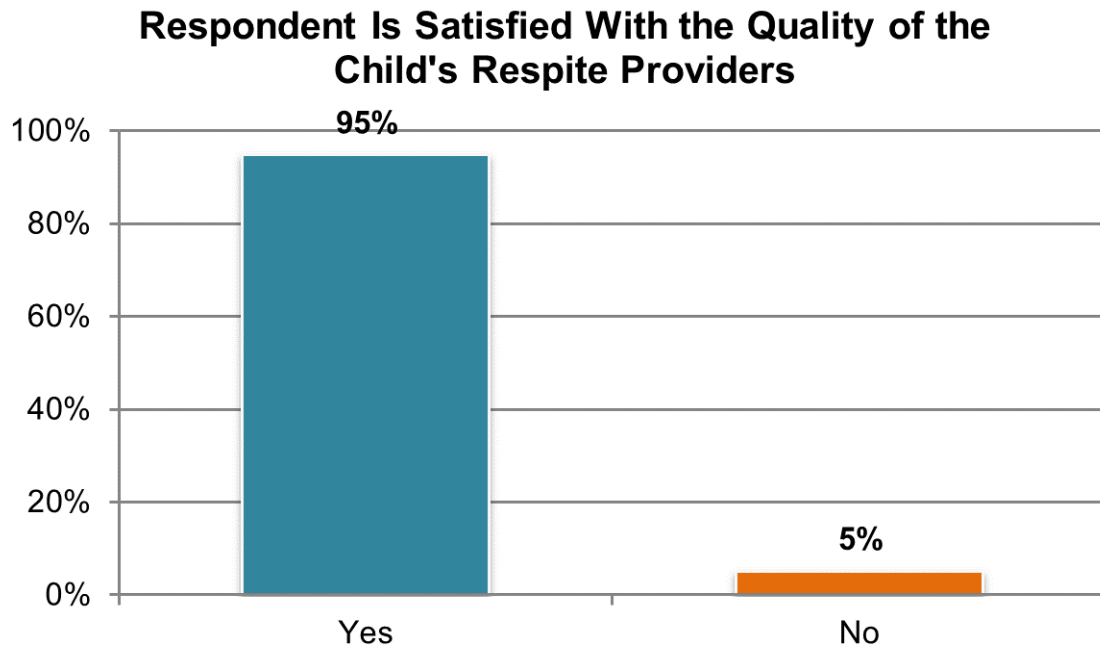


Table Q30a. If you have access to needed respite services, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
TX	98%	2%	985
Within Average Range			
LA	98%	2%	45
OH	97%	3%	146
VA	95%	5%	157
OR	95%	5%	206
AZ	95%	5%	205
WA	93%	7%	148
SC	93%	7%	43
CT	93%	7%	57
NC	93%	7%	221
NCI Average	95%	5%	2,213

Services Are Needed That Are Not Currently Offered or Available

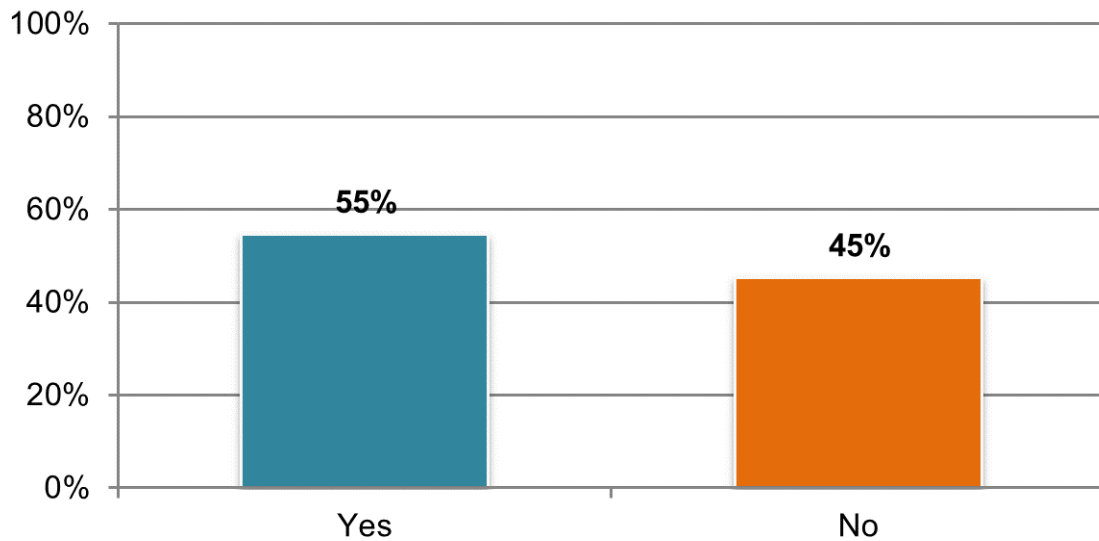


Table Q31. Are there other services that your family needs that are not currently offered or available?²

State	Yes	No	N
Significantly Above Average			
AZ	71%	29%	116
OR	65%	35%	266
Within Average Range			
CT	67%	33%	105
SC	61%	39%	104
WA	60%	40%	156
VA	55%	45%	158
NC	53%	47%	224
LA	48%	52%	91
Significantly Below Average			
TX	46%	54%	917
OH	22%	78%	367
NCI Average	55%	45%	2,504

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 determine the services and supports they receive and the individuals or agencies who provide them.

Three-fifths of respondents report that they always choose the provider agencies that work with their family (60%) and 56% always choose the individual support workers who work directly with their family.

Sixty-one percent (61%) of respondents report that they have control or input over the hiring and management of support workers. More than one-quarter of respondents report that they know how much money the ID/DD agency spends on behalf of their child (27%). Of the 39% of respondents who indicate that they have a say in how ID/DD agency money is spent, 82% report that they have all the necessary information to make those decisions.

Note: An ‘n/a’ designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Respondent Chooses the Provider Agencies Who Work With the Family

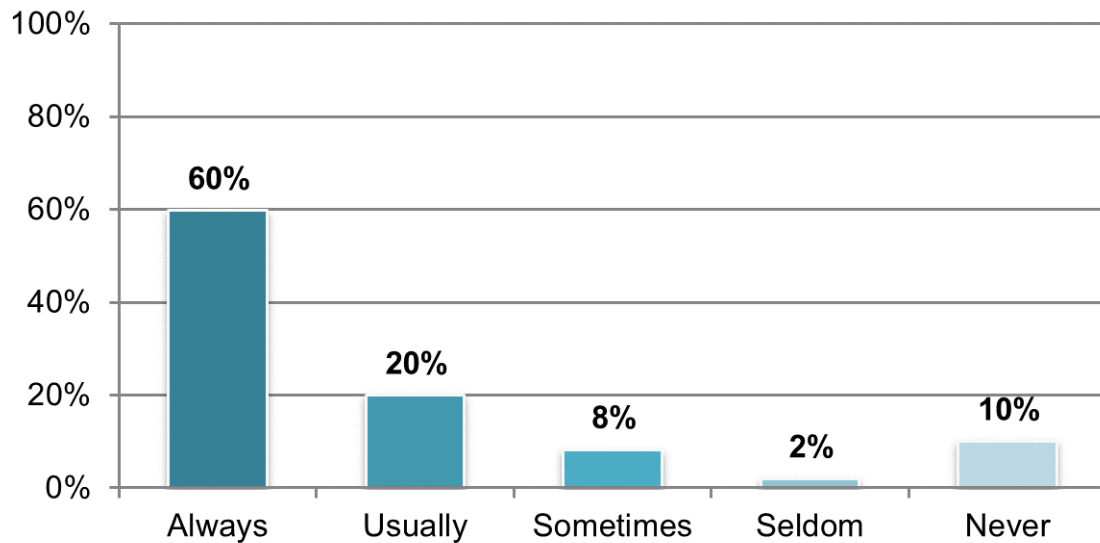


Table Q32. Do you choose the provider agencies who work with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
TX	78%	14%	3%	1%	3%	1,325
NC	72%	19%	6%	1%	2%	289
Within Average Range						
SC	67%	20%	4%	1%	8%	145
VA	67%	20%	8%	0%	4%	208
LA	64%	14%	7%	3%	11%	134
AZ	59%	19%	10%	4%	7%	299
OH	57%	10%	10%	1%	22%	338
WA	56%	26%	8%	2%	9%	247
Significantly Below Average						
CT	43%	28%	12%	1%	15%	130
OR	35%	29%	13%	6%	18%	290
NCI Average	60%	20%	8%	2%	10%	3,405

Respondent Can Choose a Different Provider Agency If Desired

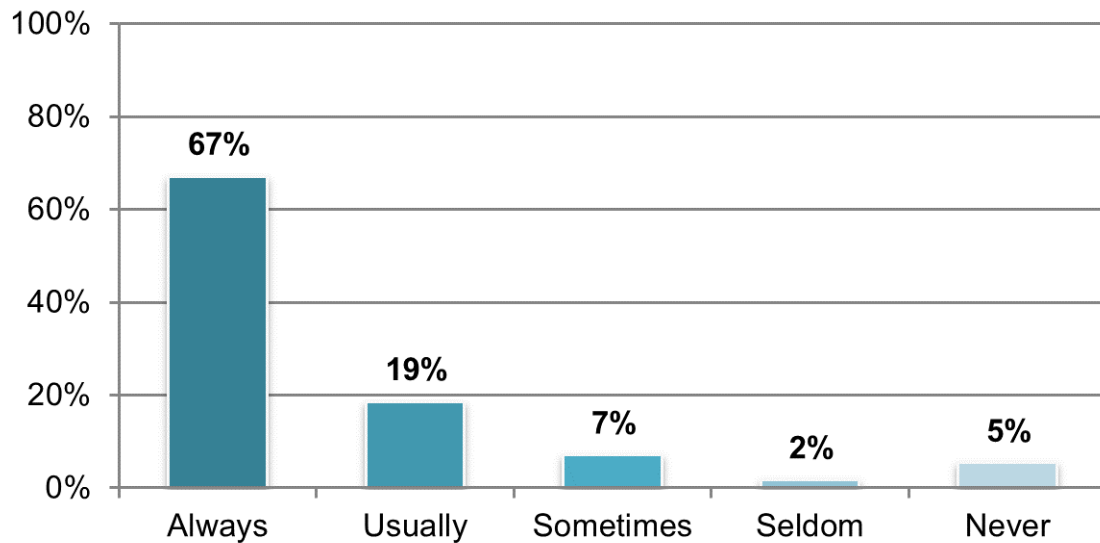


Table Q33. Can you choose a different provider agency if you want to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NC	83%	13%	2%	2%	1%	265
TX	82%	13%	3%	1%	2%	1,266
Within Average Range						
SC	77%	16%	2%	2%	3%	125
LA	73%	20%	4%	1%	3%	107
OH	72%	9%	6%	2%	11%	285
AZ	70%	18%	8%	1%	3%	264
VA	63%	23%	10%	1%	3%	179
CT	61%	22%	9%	1%	7%	100
Significantly Below Average						
WA	53%	27%	10%	2%	7%	201
OR	39%	25%	16%	5%	14%	187
NCI Average	67%	19%	7%	2%	5%	2,979

Respondent Chooses Individual Support Workers Who Work With the Family

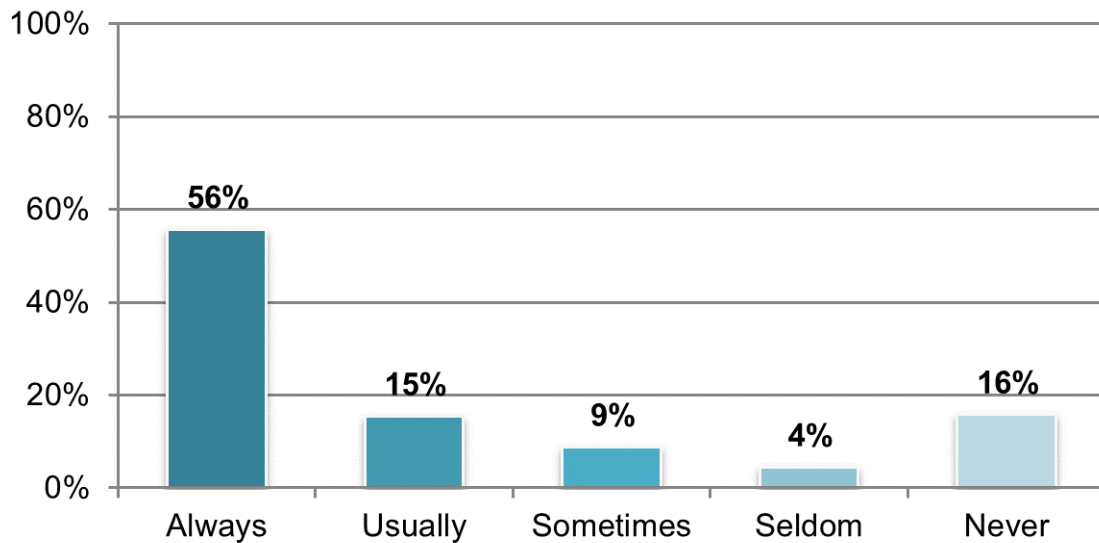


Table Q34. Do you choose the individual support workers who work directly with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
TX	68%	12%	7%	2%	10%	1,270
NC	64%	20%	9%	2%	5%	292
Within Average Range						
VA	64%	16%	9%	4%	8%	210
WA	63%	17%	7%	2%	10%	244
LA	63%	12%	3%	6%	16%	119
CT	52%	20%	11%	3%	14%	138
SC	51%	13%	8%	9%	19%	133
AZ	51%	19%	11%	4%	14%	273
OR	49%	17%	8%	6%	20%	284
Significantly Below Average						
OH	32%	7%	14%	5%	42%	332
NCI Average	56%	15%	9%	4%	16%	3,295

Respondent Can Choose Different Support Workers If Desired

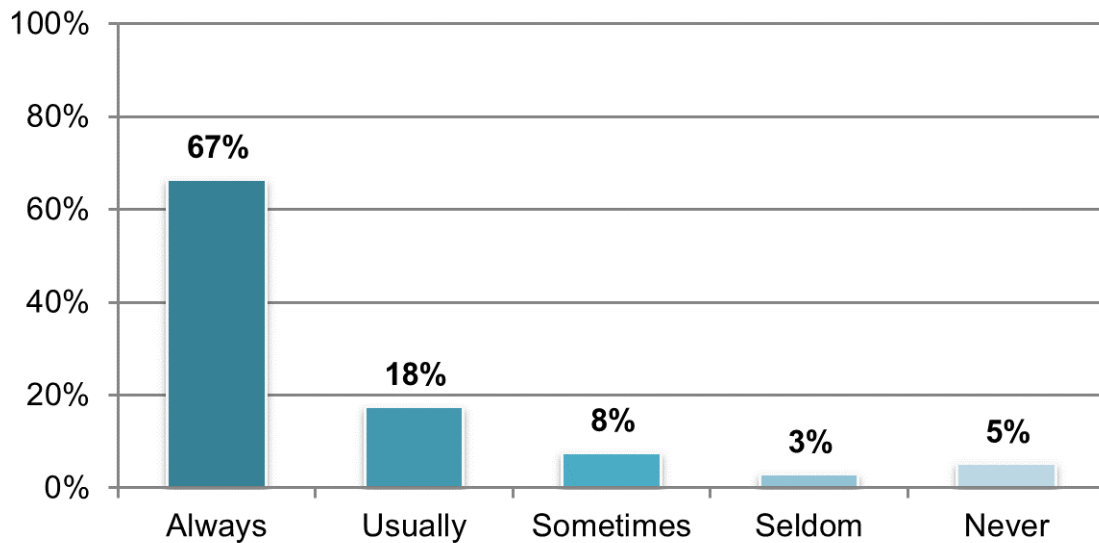


Table Q35. Can you choose different support workers if you want to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
TX	78%	13%	4%	2%	3%	1,149
NC	74%	16%	5%	3%	2%	274
Within Average Range						
LA	74%	15%	3%	2%	7%	103
VA	71%	19%	7%	1%	3%	190
SC	65%	22%	7%	4%	3%	111
AZ	64%	19%	11%	2%	4%	241
OR	62%	19%	7%	6%	6%	222
CT	61%	20%	11%	2%	6%	114
OH	60%	12%	11%	4%	13%	280
Significantly Below Average						
WA	57%	21%	10%	6%	6%	216
NCI Average	67%	18%	8%	3%	5%	2,900

Respondent Chose Case Manager/Service Coordinator

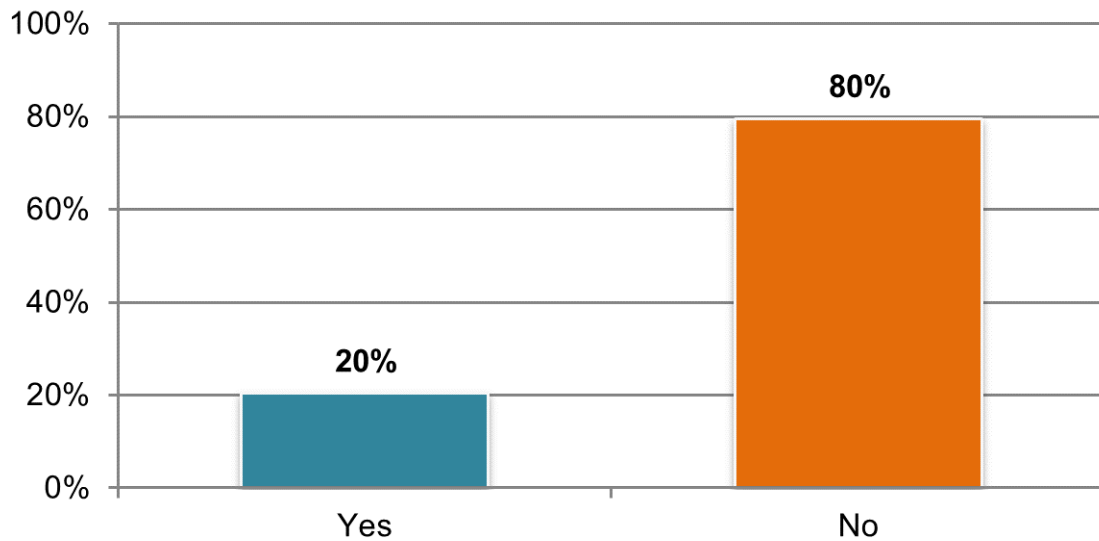


Table Q36. Did you choose your case manager/service coordinator?

State	Yes	No	N
Significantly Above Average			
LA	43%	57%	133
SC	37%	63%	144
NC	33%	67%	283
Within Average Range			
VA	26%	74%	213
TX	25%	75%	1,255
AZ	15%	85%	287
Significantly Below Average			
OH	9%	91%	328
CT	6%	94%	149
WA	5%	95%	276
OR	4%	96%	383
NCI Average	20%	80%	3,451

Respondent Has Control or Input Over the Hiring and Management of Family's Support Workers

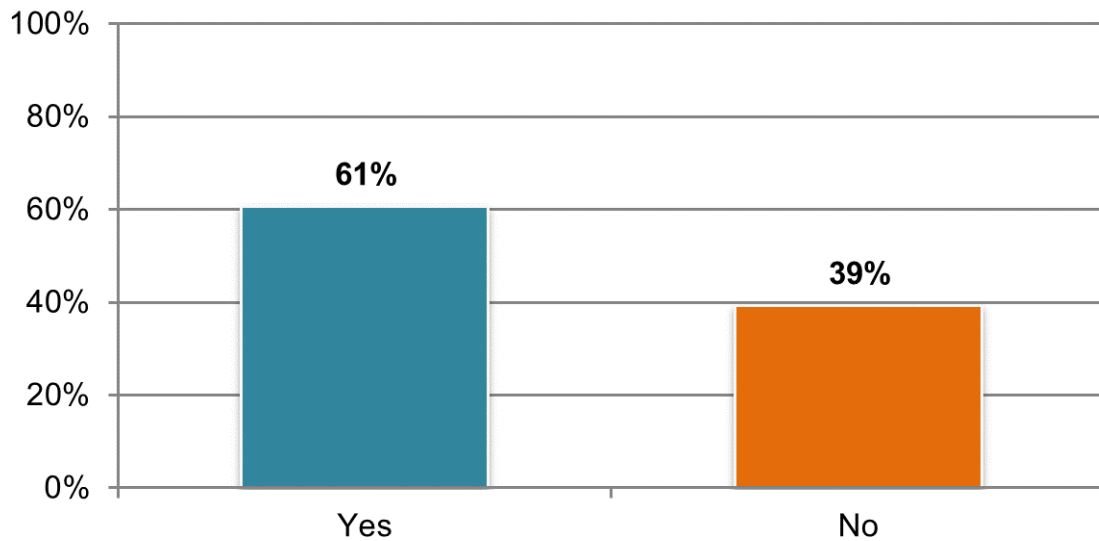


Table Q37. Do you have control and/or input over the hiring and management of your family's support workers?

State	Yes	No	N
Significantly Above Average			
NC	81%	19%	266
VA	79%	21%	192
TX	72%	28%	1,171
Within Average Range			
WA	68%	32%	225
CT	65%	35%	123
LA	55%	45%	111
OR	53%	47%	261
SC	51%	49%	107
Significantly Below Average			
AZ	50%	50%	214
OH	32%	68%	319
NCI Average	61%	39%	2,989

Respondent Knows How Much Money Is Spent by the ID/DD Agency on Behalf of Child

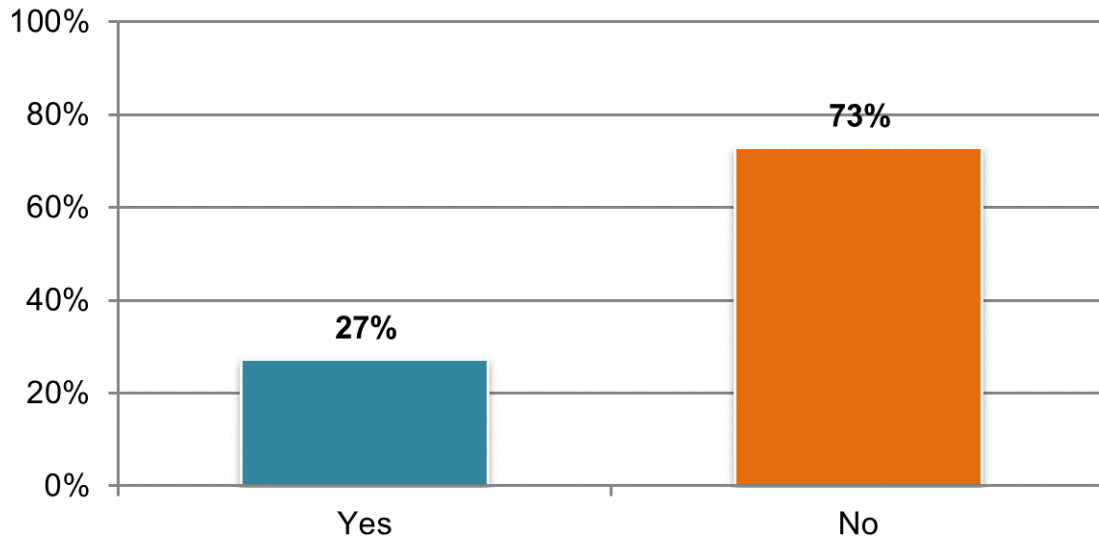


Table Q38. Do you know how much money is spent by the ID/DD agency on behalf of your child?³

State	Yes	No	N
Significantly Above Average			
CT	59%	41%	158
TX	38%	62%	1,343
OR	33%	67%	388
Within Average Range			
LA	36%	64%	147
NC	24%	76%	292
WA	23%	77%	295
SC	20%	80%	165
Significantly Below Average			
VA	19%	81%	216
OH	10%	90%	394
AZ	8%	92%	300
NCI Average	27%	73%	3,698

³ 'Don't know' responses are included with 'no' responses.

Respondent Has Say in How ID/DD Agency Money Is Spent

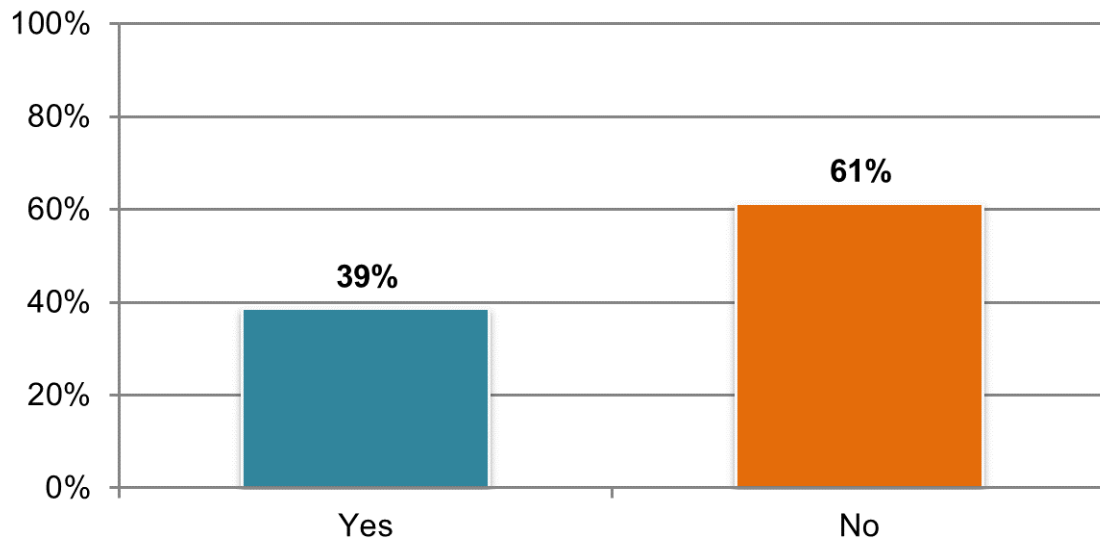


Table Q39. Do you have a say in how this money is spent?

State	Yes	No	N
Significantly Above Average			
CT	67%	33%	131
OR	62%	38%	277
TX	52%	48%	977
Within Average Range			
WA	40%	60%	205
LA	35%	65%	100
VA	34%	66%	155
Significantly Below Average			
NC	31%	69%	227
OH	28%	72%	338
SC	22%	78%	93
AZ	17%	83%	180
NCI Average	39%	61%	2,683

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

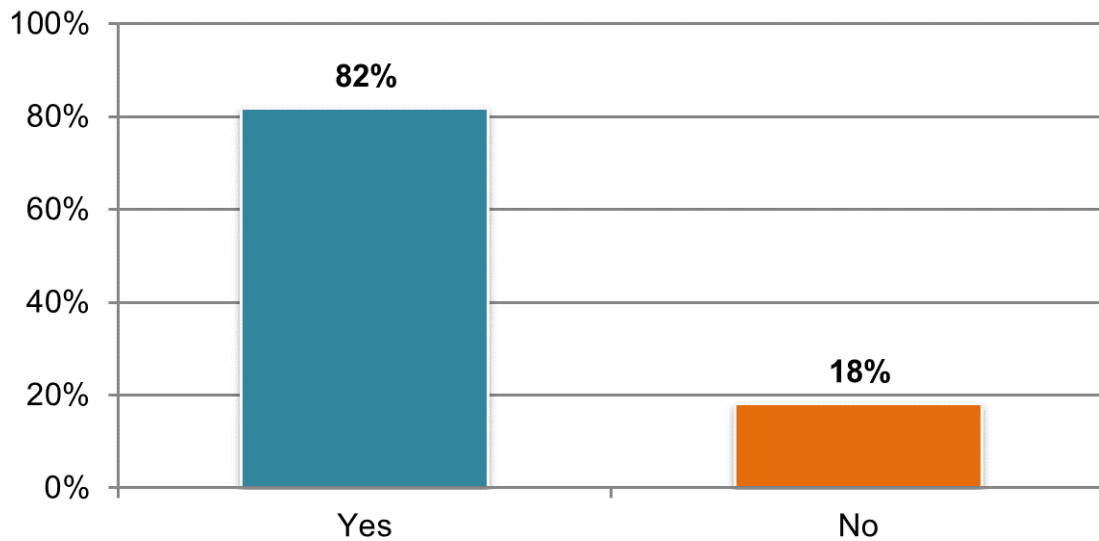


Table Q39a. If you have a say in how this money is spent, do you have all the information you need to make decisions about how to spend this money?⁴

State	Yes	No	N
Significantly Above Average			
LA	100%	0%	28
TX	93%	7%	445
Within Average Range			
CT	85%	15%	65
SC	n/a	n/a	n/a
OR	82%	18%	144
OH	81%	19%	90
VA	79%	21%	43
WA	77%	23%	73
AZ	76%	24%	25
Significantly Below Average			
NC	64%	36%	61
NCI Average	82%	18%	991

⁴ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Community Connections

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

The vast majority of respondents report that the child participates in community activities (83%). More than four-fifths report that the child spends time with children who do not have DD (85%).

Note: An ‘n/a’ designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Child Participates in Community Activities

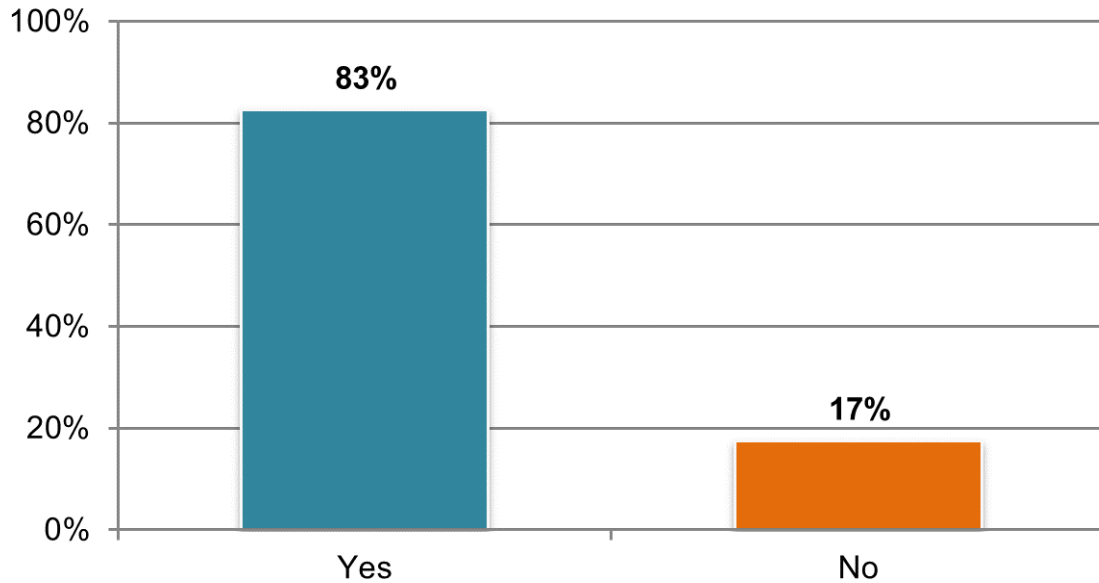


Table Q40. Does your child participate in community activities (such as going out to a restaurant, movie, or sporting event)?

State	Yes	No	N
Significantly Above Average			
OH	89%	11%	398
NC	89%	11%	296
Within Average Range			
VA	85%	15%	215
LA	84%	16%	175
TX	83%	17%	1,365
CT	82%	18%	154
AZ	81%	19%	299
OR	80%	20%	400
SC	78%	22%	163
Significantly Below Average			
WA	74%	26%	298
NCI Average	83%	17%	3,763

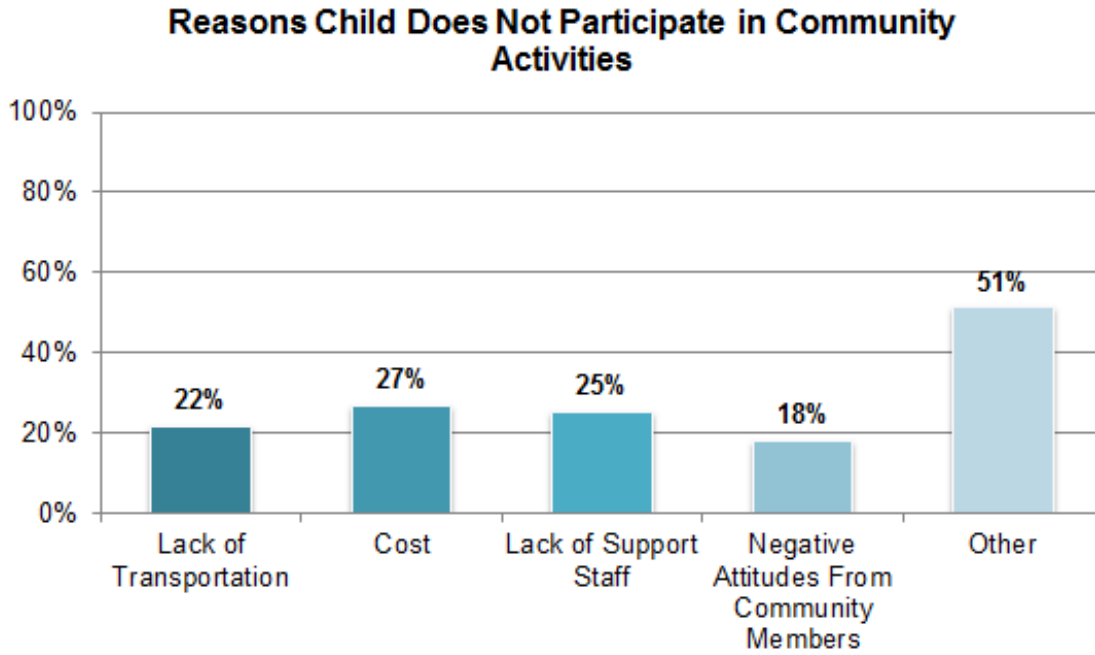


Table Q40a. If your child doesn't participate in community activities, why not?⁵

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes From Community Members	Other
Within Average Range					
AZ	19%	38%	8%	19%	46%
LA	15%	25%	15%	20%	65%
NC	18%	29%	53%	18%	41%
OH	9%	12%	0%	7%	77%
OR	22%	35%	19%	26%	64%
SC	61%	13%	35%	13%	4%
TX	19%	28%	28%	18%	60%
WA	10%	32%	43%	22%	53%
CT	n/a	n/a	n/a	n/a	n/a
VA	n/a	n/a	n/a	n/a	n/a
NCI Average	22%	27%	25%	18%	51%

⁵ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Child Spends Time With Children Without DD

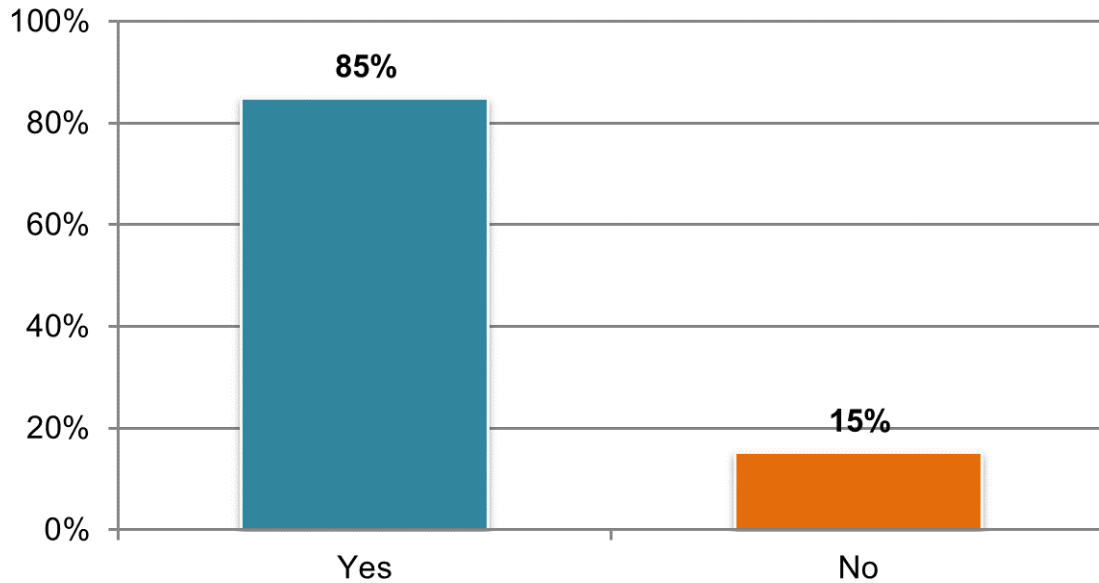


Table Q41. Does your child spend time with children who do not have developmental disabilities?

State	Yes	No	N
Significantly Above Average			
OH	92%	8%	397
LA	92%	8%	179
Within Average Range			
AZ	89%	11%	298
TX	87%	13%	1,346
SC	86%	14%	159
OR	85%	15%	396
WA	84%	16%	292
NC	83%	17%	295
VA	80%	20%	211
Significantly Below Average			
CT	72%	28%	137
NCI Average	85%	15%	3,710

Satisfaction With Services and Supports

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

More than one-third of all respondents indicate that they are always satisfied with the services and supports their family currently receives (36%). One-half report that they know the process for filing a complaint or grievance against provider agencies or staff (50%), and three-quarters indicate that they know how to report abuse or neglect (75%).

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Respondent Is Satisfied With Services and Supports Family Receives

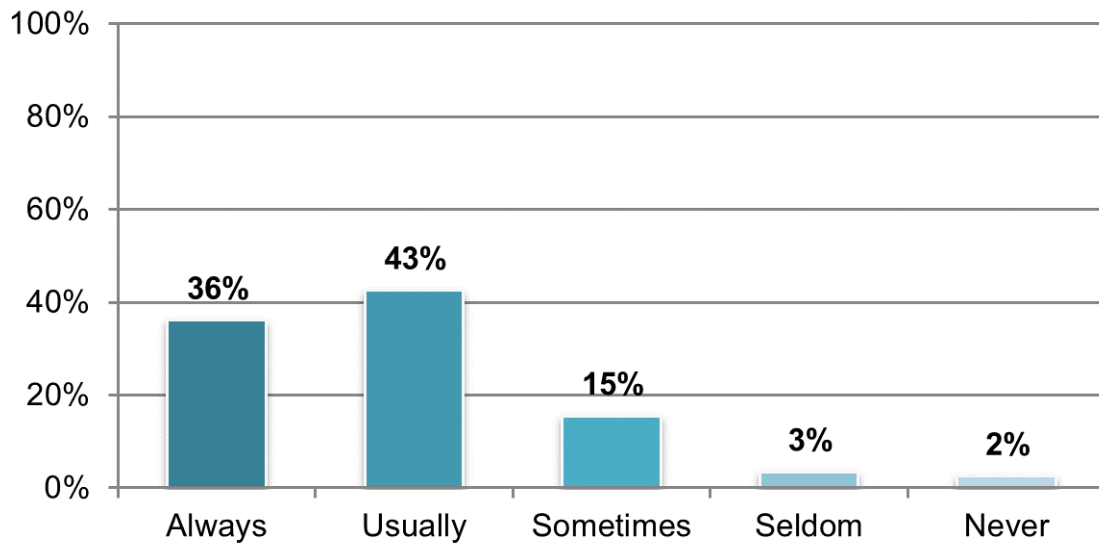


Table Q42. Overall, are you satisfied with the services and supports your family currently receives?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
TX	52%	34%	11%	2%	1%	1,349
OH	51%	30%	16%	1%	2%	391
Within Average Range						
AZ	41%	42%	12%	2%	2%	305
LA	41%	38%	15%	2%	4%	165
SC	40%	40%	15%	4%	2%	159
WA	33%	44%	17%	3%	2%	293
VA	30%	52%	15%	1%	1%	214
Significantly Below Average						
NC	27%	53%	13%	3%	5%	294
CT	24%	48%	18%	7%	3%	159
OR	23%	44%	22%	8%	3%	389
NCI Average	36%	43%	15%	3%	2%	3,718

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

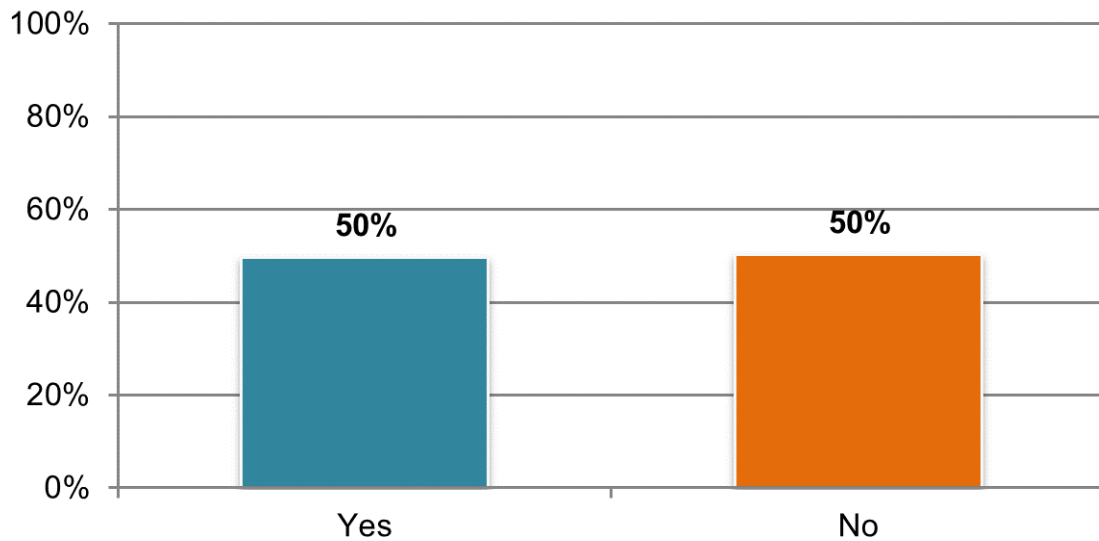


Table Q43. Do you know the process for filing a complaint or grievance against provider agencies or staff?⁶

State	Yes	No	N
Significantly Above Average			
TX	72%	28%	1,358
OH	63%	37%	395
Within Average Range			
OR	54%	46%	396
NC	53%	47%	293
VA	52%	48%	217
WA	45%	55%	289
LA	42%	58%	165
SC	40%	60%	161
Significantly Below Average			
AZ	41%	59%	307
CT	33%	67%	148
NCI Average	50%	50%	3,729

⁶ '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

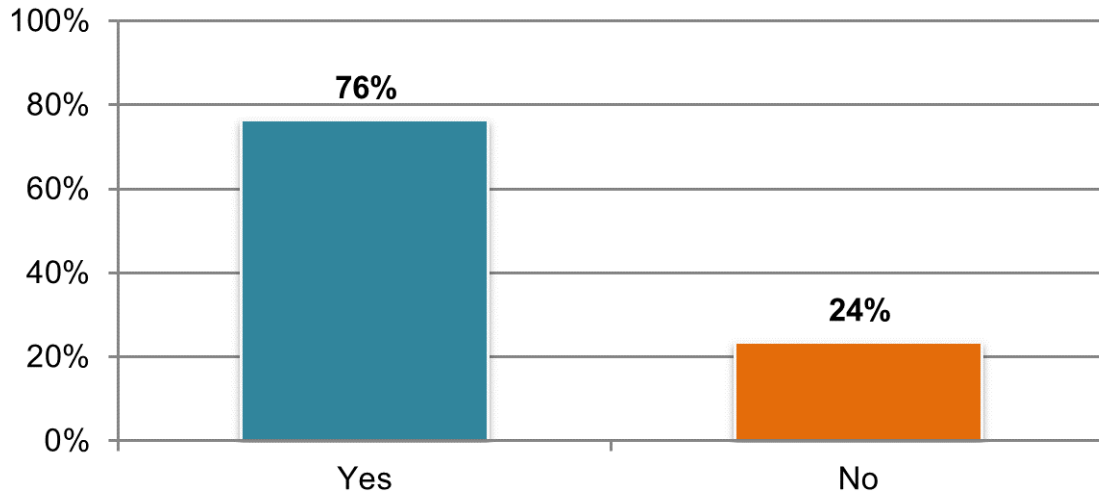


Table Q44. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

State	Yes	No	N
Significantly Above Average			
OH	86%	14%	170
TX	86%	14%	605
Within Average Range			
SC	80%	20%	44
OR	79%	21%	102
VA	78%	22%	76
NC	76%	24%	130
LA	72%	28%	61
AZ	71%	29%	103
CT	69%	31%	35
WA	68%	32%	93
NCI Average	76%	24%	1,419

Respondent Knows How to Report Abuse or Neglect

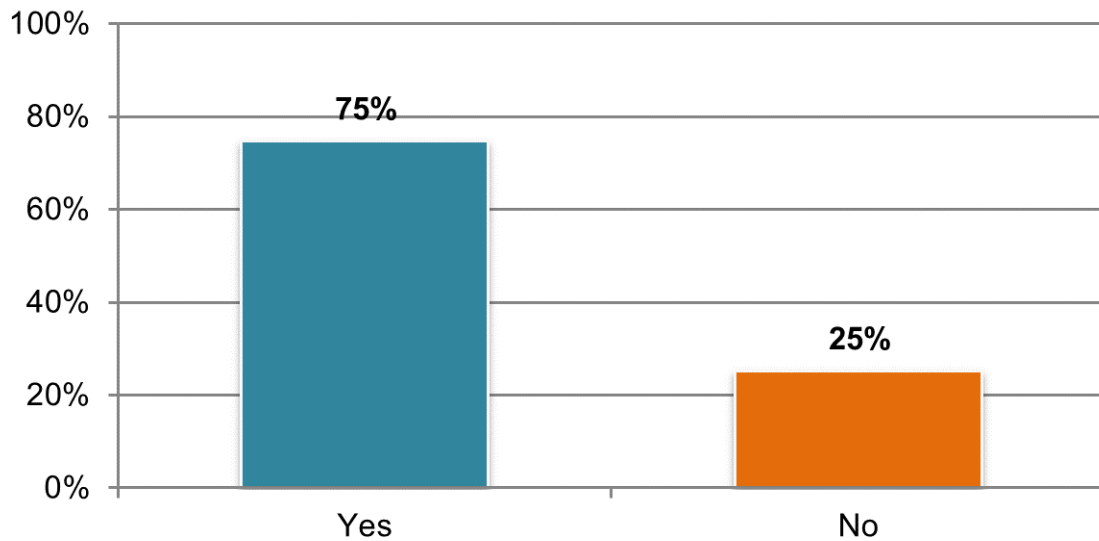


Table Q45. Do you know how to report abuse or neglect?⁷

State	Yes	No	N
Significantly Above Average			
TX	86%	14%	1,353
OH	84%	16%	392
OR	82%	18%	400
Within Average Range			
NC	78%	22%	288
VA	73%	27%	213
CT	72%	28%	147
WA	72%	28%	283
SC	70%	30%	155
Significantly Below Average			
AZ	66%	34%	285
LA	64%	36%	164
NCI Average	75%	25%	3,680

⁷ 'Don't know' responses are included with 'no' responses.

Respondent Reported Abuse or Neglect in the Past Year

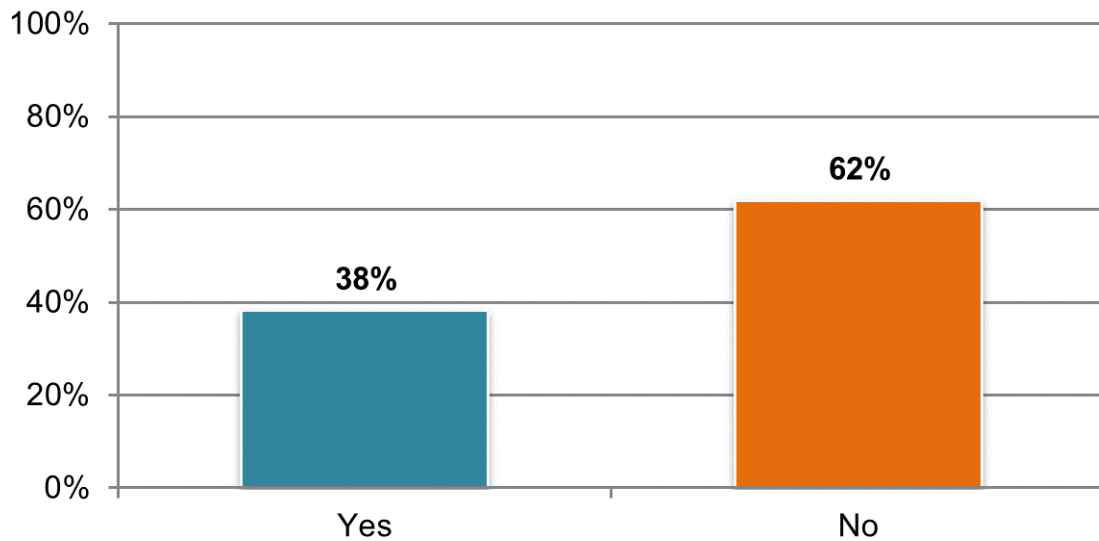


Table Q46. Within the past year, if abuse or neglect occurred, did you report it?

State	Yes	No	N
Significantly Above Average			
OH	60%	40%	57
TX	48%	52%	233
Within Average Range			
OR	55%	45%	49
VA	44%	56%	34
CT	40%	60%	20
SC	37%	63%	27
LA	34%	66%	32
WA	33%	67%	57
AZ	25%	75%	60
Significantly Below Average			
NC	5%	95%	248
NCI Average	38%	62%	817

Appropriate People Were Responsive to Report of Abuse or Neglect (Past Year)

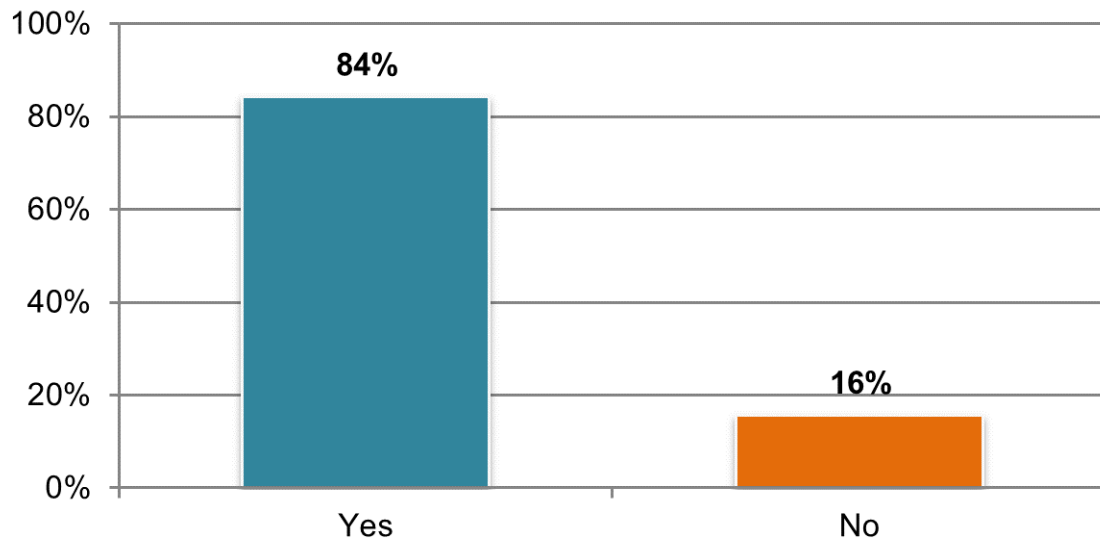


Table Q46a. If you reported abuse or neglect within the past year, were the appropriate people responsive to your report?⁸

State	Yes	No	N
Within Average Range			
OH	90%	10%	30
OR	83%	17%	23
TX	80%	20%	96
AZ	n/a	n/a	n/a
CT	n/a	n/a	n/a
LA	n/a	n/a	n/a
NC	n/a	n/a	n/a
SC	n/a	n/a	n/a
VA	n/a	n/a	n/a
WA	n/a	n/a	n/a
NCI Average	84%	16%	149

⁸ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Family Outcomes

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

Nearly all respondents report that services and supports have made a positive difference in the life of their family (94%). Most also indicate that services and supports have reduced the family's out-of-pocket expenses for the child's care (84%). Of the 35% of respondents who report that services or supports were reduced, suspended or terminated in the past year, 75% felt that this change affected their family negatively.

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

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

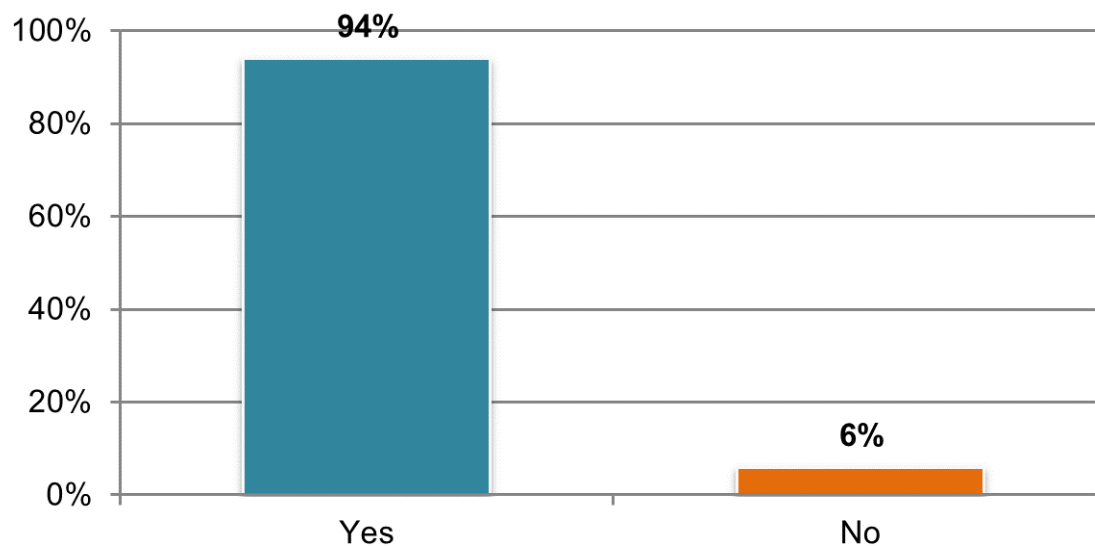


Table Q47. Do you feel that family supports have made a positive difference in the life of your family?

State	Yes	No	N
Significantly Above Average			
TX	96%	4%	1,263
Within Average Range			
AZ	96%	4%	286
VA	96%	4%	199
NC	95%	5%	274
LA	94%	6%	150
OH	94%	6%	383
CT	94%	6%	127
WA	94%	6%	254
SC	92%	8%	139
OR	90%	10%	344
NCI Average	94%	6%	3,419

Services and Supports Have Reduced Out-of-Pocket Expenses

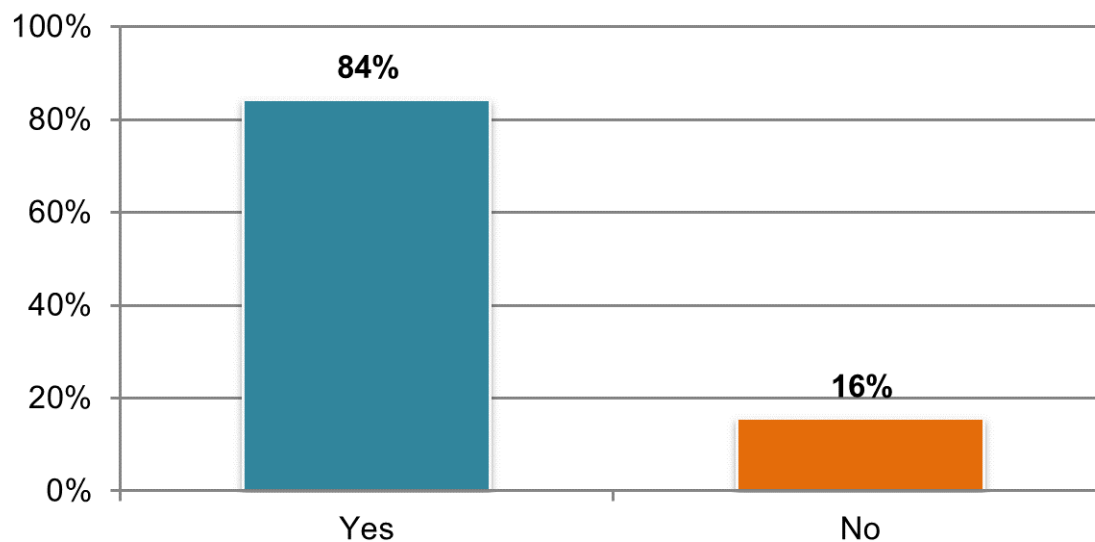


Table Q48. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your child's care?

State	Yes	No	N
Significantly Above Average			
VA	93%	8%	200
TX	89%	11%	1,241
Within Average Range			
AZ	88%	12%	277
NC	87%	13%	267
SC	87%	13%	143
WA	83%	17%	264
CT	82%	18%	130
LA	80%	20%	148
OH	80%	20%	372
Significantly Below Average			
OR	76%	24%	352
NCI Average	84%	16%	3,394

Family Supports Have Improved Respondent's Ability to Care for the Child

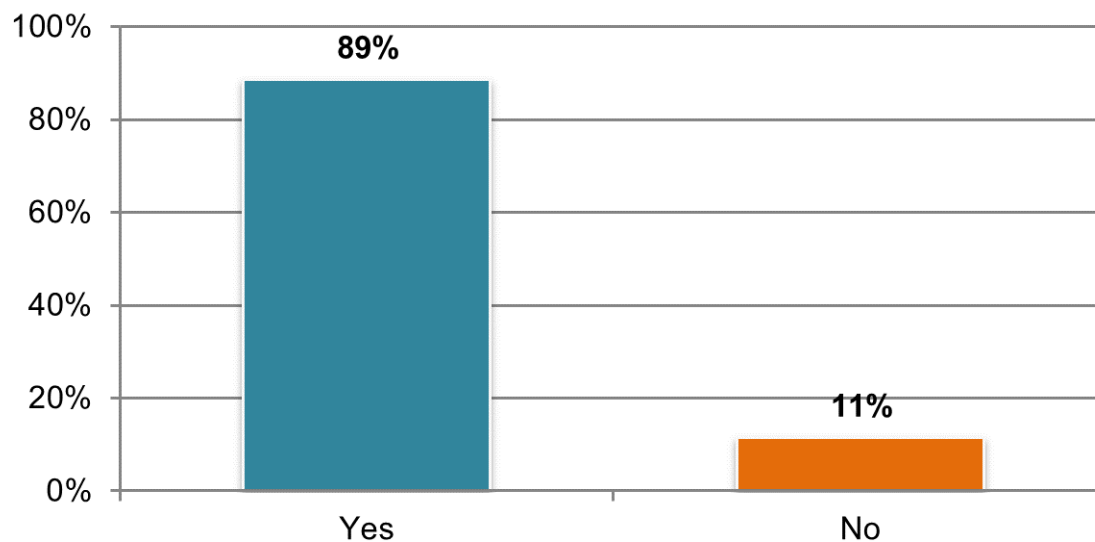


Table Q49. Do you feel that family supports have improved your ability to care for your child?

State	Yes	No	N
Significantly Above Average			
TX	95%	5%	1,270
AZ	94%	6%	284
Within Average Range			
VA	92%	8%	205
CT	88%	12%	130
LA	88%	12%	146
NC	88%	12%	275
OH	87%	13%	391
SC	87%	13%	143
WA	86%	14%	263
Significantly Below Average			
OR	81%	19%	352
NCI Average	89%	11%	3,459

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

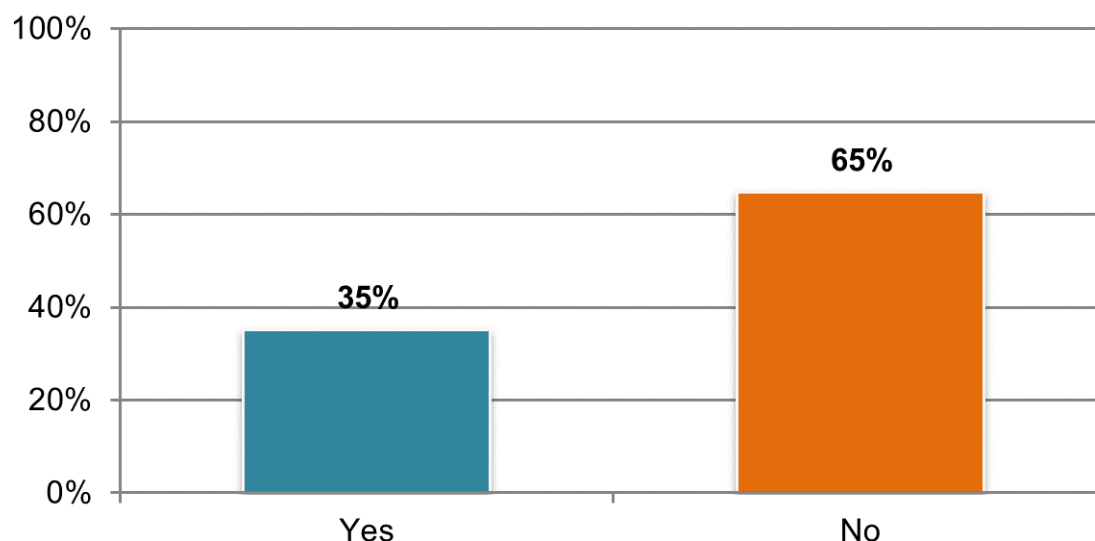


Table Q50. Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?⁹

State	Yes	No	N
Significantly Above Average			
OR	46%	54%	330
Within Average Range			
AZ	42%	58%	280
WA	41%	59%	266
LA	38%	62%	145
SC	37%	63%	149
VA	35%	65%	198
NC	33%	67%	270
CT	33%	67%	132
Significantly Below Average			
OH	25%	75%	379
TX	22%	78%	1,221
NCI Average	35%	65%	3,370

⁹ 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.

Reduction, Suspension, or Termination of Services in the Past Year Affected the Family Negatively

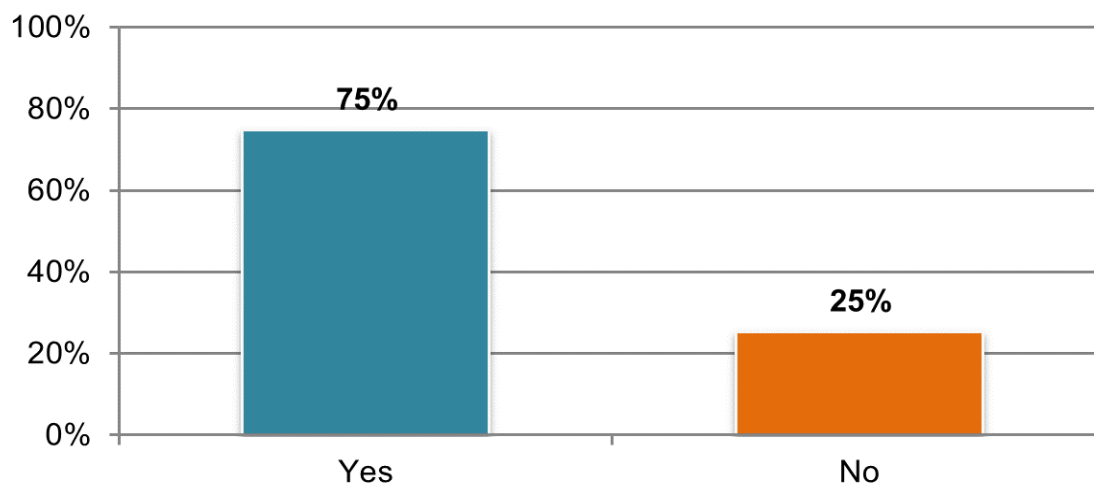


Table Q50a. If services or supports received by your family were reduced, suspended, or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family negatively?¹⁰

State	Yes	No	N
Significantly Above Average			
OR	90%	10%	138
WA	85%	15%	103
Within Average Range			
CT	86%	14%	36
VA	82%	18%	61
TX	79%	21%	233
SC	76%	24%	46
LA	71%	29%	45
NC	68%	32%	79
AZ	66%	34%	104
Significantly Below Average			
OH	43%	57%	92
NCI Average	75%	25%	937

¹⁰ 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 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

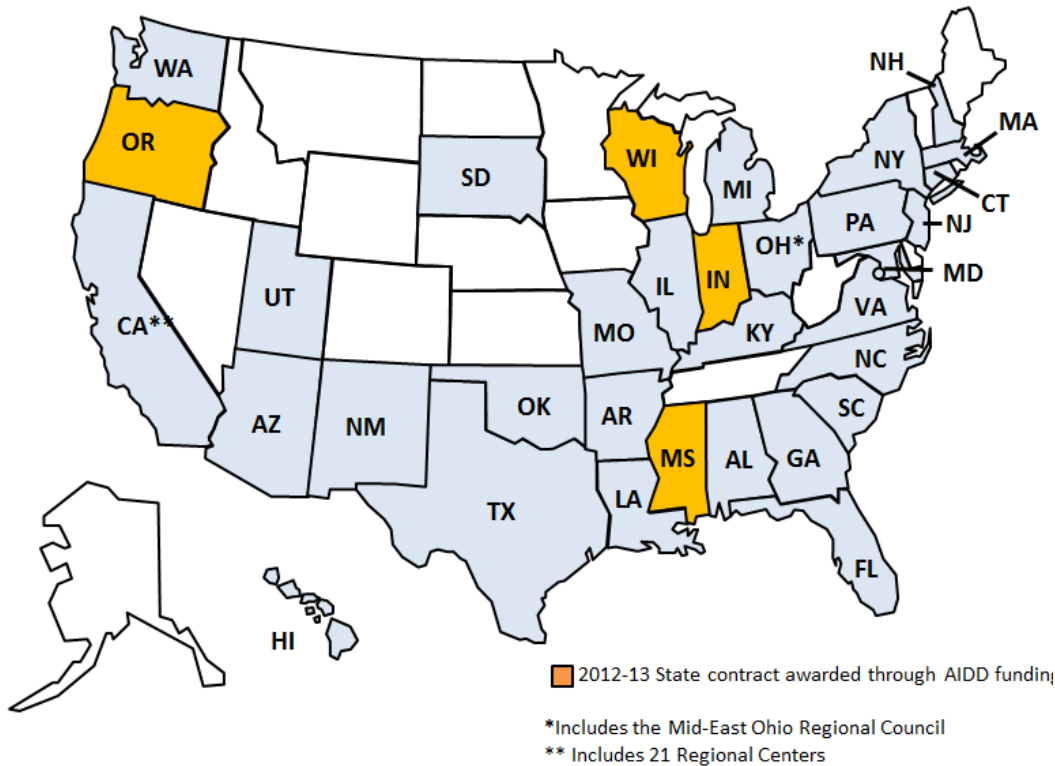
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states 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 2012-2013 data collection cycle, 34 states 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 2012-13



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 individual, 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 the table below). 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 the current and future priorities of participating states.

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

Sub-Domains and Concern Statements

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

Family Survey Sub-Domains and Concern Statements

Sub-Domain	Concern
Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.
Choice & Control	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
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. 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 Child Family Survey by selecting a random sample of at least 1,000 families who:

1. Had a child¹¹ 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 sample¹². 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 no greater than +/- 7%.¹³

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 that the child lived outside the family home.
2. Demographic information was entered into the file but no survey questions were answered.

¹¹ “Child” is defined as an individual age 18 or younger; however, a Child Family Survey could be completed for an individual up to 22 years if still receiving “child” services (e.g., still in public school).

¹² Ohio conducted surveys via phone, their data should be reviewed with caution.

¹³ 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 average¹⁴; 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 2012-2013, 10 states administered the Child Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% and lower) 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 children receiving services who were eligible to be drawn into the sample, and each state’s margin of error.

Child Family Survey: State Response Rates¹⁵

State	Number Eligible to Be Drawn Into the Sample	Surveys Mailed	Usable Surveys Returned	Response Rate	Margin of Error
AZ	12,967	1,000	312	31%	5.5%
CT	655	655	180	27%	6.2%
LA	4,844	2,000	187	9%	7.0%
NC	5,890	1,200	304	25%	5.5%
OR	2,005	2,005	426	21%	4.2%
SC	2,308	1,000	169	17%	7.3%
TX	10,701	4,500	1,397	31%	2.4%
VA	748	748	224	30%	5.5%

¹⁴ The NCI Average is the sum of all state averages divided by the total number of states.

¹⁵ OH and WA did not provide sampling information.