

Child Family Survey

2013-14 Final Report



**NATIONAL CORE
INDICATORS**

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



Human Services
Research Institute

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List of Abbreviations Used in This Report

AFS – Adult Family Survey

CFS – Child Family Survey

FGS – Family/Guardian Survey

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities
Services

NCI – National Core Indicators

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Executive Summary

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

The NCI 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 39 states, the District of Columbia, and 22 sub-state entities who participated in NCI during the 2013-2014 data collection cycle, eight 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, 2014.

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 and Characteristics of Children for Whom the Survey Was Completed

The average age of children for whom the survey was completed was 12 years old, and the majority were male (68%). In terms of race, most of the children were white (70%), 16% were black or African American, and 6% were two or more races. In terms of ethnicity, 9% were Hispanic. Nearly one-quarter of households surveyed (23%) had more than one child with a disability living in the home.

The primary means of communication among most of the children was spoken language (57%), followed by gestures or body language (30%). Nearly all spoke English (93%) as their primary language; 3% spoke Spanish, and 4% spoke another language.

The majority of children required medical care less than once a month (65%); approximately one-quarter (24%) needed medical care at least once a month but less than once a week; and 11% required at least weekly medical care. Just over one-third of respondents indicated that the child needed no behavioral supports (34%); 43% needed some behavioral support and 23% required

extensive support. The amount of help children needed with daily activities was: 6% none, 18% little, 36% moderate, and 40% needed complete help.

Demographics and Characteristics of Respondents to the Survey

The majority of respondents to the survey reported that they themselves were younger than age 55 (17% were under 35, and 67% were in the range of 35-54); 15% were in the range of 55-74 and 1% were over 75.

Survey respondents were most commonly the child's parent (92%) and grandparents represented 6% of respondents; 2% had some other relationship to the child. Nearly all respondents were the child's primary caregiver (98%).

Nearly one-quarter of respondents (23%) reported that their total household income in the past year was less than \$15,000; 14% earned between \$15,001 and \$25,000; 24% earned between \$25,001 and \$50,000; 17% earned between \$50,001 and \$75,000; and the remaining 22% earned more than \$75,000. The amount that families reported paying out-of-pocket for their child's care in the past year was: 19% paid nothing; 12% paid \$1-\$100; 32% paid \$101-\$1,000; 32% paid \$1,001-\$10,000; and 5% spent more than \$10,000.

Services and Supports Received

Families reported receiving the following state-provided services and supports: financial support (21%), in-home support (64%), out-of-home respite care (34%), early intervention (11%), and transportation (20%); 61% received supports that fell into the category of "other." Just under half of the families surveyed (48%) reported receiving social security benefits.

Information and Planning

Across states, 24% of respondents said they always receive information about the services and supports that their family and the child can receive, and 28% said that information is always easy to understand. Most felt the case manager/service coordinator always respects the family's choices and opinions (72%).

Of the 88% of respondents who reported that the child has a service plan, most indicated that the service plan includes all the services and supports the family wants (78%) and needs (70%); most also reported that the family receives all services listed in the plan (85%). The majority of respondents had discussed how to handle emergencies related to the child during the last planning meeting (70%).

Access and Delivery of Supports and Services

More than half of all respondents were always able to contact support workers (56%) and the case manager/service coordinator (55%) when needed. About one-third (35%) said that services and supports were always available when needed and 40% felt services and supports were always available reasonably close to home; 38% reported services and supports always changed when their child's needs changed.

Most respondents indicated that crisis or emergency services were provided if requested in the past year (69%). A vast majority reported having access to health services (98%), dental services (95%), and mental health services (90%) for the child. Nearly all (98%) reported that they can get needed medication for the child. Most (81%) had access to respite services. Almost half of all respondents (48%) indicated that services were needed that were not currently offered or available.

Choice and Control

About two-thirds of respondents always choose the provider agencies that work with their family (65%) and most reported that they can always choose another provider agency if they want (71%). More than half of respondents always choose the individual support workers who work with the family (54%), and a little over two-thirds of respondents reported always being able to choose different support workers 68%.

Just under one-third (31%) knew how much money is spent by the ID/DD agency on their child's behalf. Of the 42% of respondents who had a say in how ID/DD agency money is spent, 86% reported having all the information needed to decide how to spend the money.

Community Connections

Most respondents indicated that the child participates in community activities (84%). Of the 16% whose child did not partake in community activities, the reasons given were: lack of transportation (18%), cost (28%), lack of support staff (24%), and negative attitudes from community members (23%); 60% cited other reasons not given. Most respondents reported that the child spends time with children who do not have developmental disabilities (86%).

Satisfaction With Services and Supports

Across states, 38% of respondents are always satisfied with the services and supports their family receives.

More than half of all respondents reported that they know the process for filing a complaint or grievance against provider agencies or staff (56%); and most respondents are satisfied with the way that complaints or grievances are handled (81%). Across states, most respondents know how to report abuse or neglect (79%); 40% reported abuse or neglect in the past year.

Family Outcomes

Nearly all respondents felt that services and supports made a positive difference in their family's life (93%). Most indicated that services and supports have reduced their family's out-of-pocket expenses related to the child's care (85%) and that services and supports have improved their ability to care for the child (89%). One-quarter of respondents (25%) reported that their family or child's services or supports were reduced, suspended, or terminated in the past year; of those, 79% reported that the change had a negative impact on the family.

I. Results

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

Survey Development

The Child Family Survey was developed and first utilized during 2000-2001 in response to state interest in determining the level of satisfaction with services and supports among families who have a child (or children) with developmental disabilities living in the 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 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. There is also an opportunity for families to write open-ended comments concerning their family's participation in the service system.

Demographics

The survey instrument begins with a series of questions relating to characteristics of the 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.

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

The 'N' listed refers to the number of valid responses.

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

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

Demographics

Child

This section provides demographic information about the child receiving services.

Table 1. Child's Age

State	Age	N
LA	10.2	315
MO	10.4	396
NC	13.9	196
OR	11.8	196
SC	9.1	178
TX	15.3	407
UT	11.1	280
VA	14.8	180
NCI Average	12.1	2,148

Table 2. Child's Gender

State	Male	Female	N
LA	66%	34%	312
MO	75%	25%	397
NC	63%	37%	195
OR	70%	30%	194
SC	67%	33%	178
TX	66%	34%	409
UT	72%	28%	277
VA	63%	37%	179
NCI Average	68%	32%	2,141

Table 3. Child's Race¹

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
LA	1%	2%	34%	0%	59%	0%	6%	3%
MO	2%	2%	12%	1%	82%	1%	5%	4%
NC	3%	2%	23%	1%	65%	2%	6%	3%
OR	3%	5%	4%	3%	80%	1%	7%	11%
SC	3%	4%	22%	1%	68%	1%	2%	7%
TX	1%	3%	15%	0%	50%	1%	7%	33%
UT	1%	2%	2%	1%	86%	1%	5%	8%
VA	2%	3%	18%	1%	75%	0%	6%	3%
NCI Average	2%	3%	16%	1%	70%	1%	6%	9%

Table 4. More Than One Child With a Disability in the Home

State	Yes	No	N
LA	19%	81%	315
MO	29%	71%	399
NC	22%	78%	194
OR	26%	74%	190
SC	16%	84%	175
TX	21%	79%	408
UT	30%	70%	279
VA	17%	83%	170
NCI Average	23%	77%	2,130

¹ Multiple responses allowed. Therefore, state and national percentages may total more than 100%.

Table 5. Child's Primary Means of Expression

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
LA	45%	43%	2%	4%	6%	318
MO	79%	13%	3%	2%	3%	400
NC	56%	36%	2%	3%	3%	198
OR	67%	20%	4%	5%	4%	195
SC	53%	33%	5%	2%	7%	192
TX	57%	30%	3%	4%	6%	415
UT	52%	34%	2%	4%	6%	282
VA	49%	33%	3%	8%	6%	180
NCI Average	57%	30%	3%	4%	5%	2,180

Table 6. Child's Primary Language

State	English	Spanish	Other	N
LA	93%	1%	6%	320
MO	96%	1%	3%	401
NC	96%	2%	2%	196
OR	94%	3%	3%	195
SC	95%	3%	3%	193
TX	85%	10%	5%	409
UT	92%	3%	5%	278
VA	92%	0%	8%	179
NCI Average	93%	3%	4%	2,171

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
LA	55%	30%	15%	317
MO	70%	26%	4%	396
NC	68%	23%	9%	194
OR	76%	18%	6%	193
SC	60%	22%	18%	192
TX	54%	26%	20%	407
UT	73%	22%	5%	278
VA	64%	23%	13%	181
NCI Average	65%	24%	11%	2,158

Table 8. Amount of Behavioral Support Needed for Child

State	None	Some	Extensive	N
LA	42%	38%	20%	316
MO	34%	46%	20%	398
NC	30%	40%	30%	198
OR	29%	50%	21%	196
SC	39%	39%	22%	190
TX	48%	30%	21%	405
UT	20%	53%	28%	279
VA	33%	46%	22%	180
NCI Average	34%	43%	23%	2,162

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

State	None	Little	Moderate	Complete	N
LA	3%	14%	33%	50%	318
MO	14%	34%	33%	20%	402
NC	7%	11%	40%	42%	196
OR	10%	23%	42%	26%	198
SC	3%	19%	38%	40%	193
TX	4%	15%	32%	49%	416
UT	4%	16%	37%	43%	283
VA	4%	11%	34%	50%	180
NCI Average	6%	18%	36%	40%	2,186

Respondents

Table 10. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
LA	25%	63%	11%	1%	319
MO	26%	66%	8%	0%	400
NC	11%	68%	20%	2%	198
OR	11%	71%	19%	0%	198
SC	28%	63%	8%	1%	192
TX	7%	69%	22%	1%	416
UT	22%	72%	6%	0%	283
VA	7%	68%	23%	2%	181
NCI Average	17%	67%	15%	1%	2,187

Table 9. Respondent's Health

State	Excellent	Good	Fair	Poor	N
LA	25%	49%	22%	4%	316
MO	20%	54%	21%	4%	399
NC	17%	56%	25%	3%	197
OR	17%	58%	22%	4%	198
SC	25%	52%	21%	1%	189
TX	23%	52%	22%	3%	414
UT	26%	54%	14%	5%	281
VA	19%	49%	28%	4%	180
NCI Average	21%	53%	22%	4%	2,174

Table 10. Respondent's Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
LA	91%	0%	7%	1%	315
MO	99%	0%	1%	0%	400
NC	87%	0%	9%	4%	196
OR	92%	0%	6%	2%	196
SC	93%	1%	6%	1%	189
TX	90%	0%	7%	3%	414
UT	96%	0%	3%	1%	281
VA	91%	0%	8%	2%	180
NCI Average	92%	0%	6%	2%	2,171

Table 11. Respondent Is Child's Primary Caregiver

State	Yes	No	N
LA	98%	2%	315
MO	99%	1%	398
NC	98%	2%	196
OR	99%	1%	196
SC	97%	3%	188
TX	97%	3%	417
UT	100%	0%	279
VA	96%	4%	176
NCI Average	98%	2%	2,165

Table 12. Number of Adults in the Household

State	One	Two	Three	Four or More	N
LA	37%	57%	4%	2%	316
MO	24%	66%	8%	3%	398
NC	31%	55%	12%	3%	196
OR	20%	69%	7%	5%	195
SC	17%	71%	7%	5%	190
TX	19%	62%	13%	6%	415
UT	11%	74%	9%	6%	282
VA	28%	60%	10%	3%	176
NCI Average	23%	64%	9%	4%	2,168

Table 13. 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
LA	12%	22%	9%	23%	34%	317
MO	6%	21%	4%	24%	45%	399
NC	8%	21%	4%	21%	46%	195
OR	7%	19%	5%	27%	43%	197
SC	7%	18%	2%	20%	54%	189
TX	13%	19%	3%	26%	39%	406
UT	2%	14%	5%	30%	49%	277
VA	6%	18%	2%	20%	55%	174
NCI Average	8%	19%	4%	24%	46%	2,154

Table 14. Total Taxable Family Income of Wage Earners in the Household in the Past Year

State	Below \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	N
LA	33%	15%	22%	14%	17%	310
MO	24%	13%	28%	13%	22%	381
NC	29%	18%	20%	16%	16%	184
OR	24%	16%	27%	15%	17%	189
SC	23%	12%	24%	16%	25%	181
TX	22%	17%	23%	15%	23%	375
UT	13%	8%	28%	28%	23%	265
VA	15%	10%	22%	20%	33%	169
NCI Average	23%	14%	24%	17%	22%	2,054

Table 15. Out-of-Pocket Expenses for Child in the Past Year

State	Nothing	\$1-\$100	\$101-\$1,000	\$1,001-\$10,000	Over \$10,000	N
LA	24%	9%	30%	32%	4%	309
MO	16%	13%	33%	33%	5%	392
NC	32%	15%	29%	21%	2%	194
OR	13%	12%	34%	37%	4%	193
SC	17%	13%	25%	41%	4%	183
TX	20%	12%	34%	27%	6%	398
UT	14%	10%	40%	30%	6%	267
VA	17%	10%	30%	33%	9%	178
NCI Average	19%	12%	32%	32%	5%	2,114

Services and Supports Received

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

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

State	Financial Support	In-Home Support	Out-of-Home Respite Care	Early Intervention	Transportation	Other	Social Security Benefits
LA	50%	57%	15%	19%	16%	57%	51%
MO	17%	32%	19%	2%	11%	51%	42%
NC	15%	83%	52%	4%	27%	69%	61%
OR	23%	53%	34%	10%	20%	46%	54%
SC	12%	49%	18%	26%	10%	76%	37%
TX	14%	71%	39%	7%	17%	59%	67%
UT	14%	77%	52%	18%	29%	57%	29%
VA	23%	88%	45%	1%	28%	71%	42%
NCI Average	21%	64%	34%	11%	20%	61%	48%

Child Family Survey Results

Information and Planning

Families have the information and support necessary to plan for their child's services and supports.

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

Receives Information About Available Services and Supports

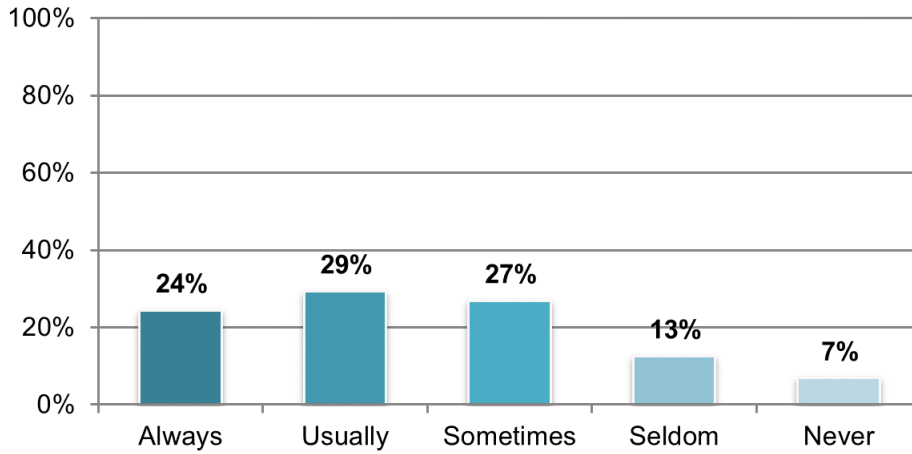


Table Q1. Do you receive information about the services and supports that are available to your child and family?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
TX	30%	31%	25%	8%	6%	402
MO	29%	27%	22%	10%	12%	391
LA	26%	26%	24%	15%	9%	302
SC	26%	22%	32%	14%	6%	188
NC	25%	28%	27%	13%	6%	194
UT	21%	34%	26%	13%	6%	273
VA	20%	35%	30%	9%	6%	181
OR	19%	31%	28%	17%	5%	190
NCI Average	24%	29%	27%	13%	7%	2,121

Information About Services and Supports Is Easy to Understand

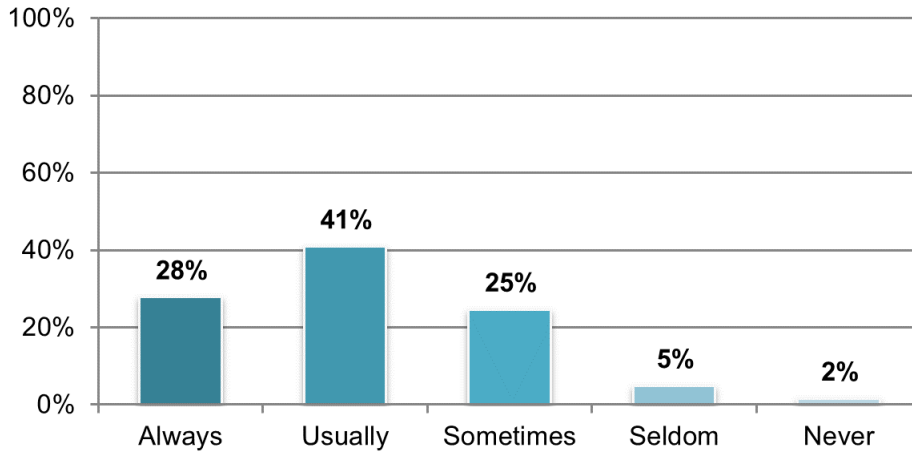


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
MO	38%	37%	19%	4%	1%	339
Within Average Range						
TX	32%	32%	29%	5%	2%	377
LA	30%	43%	19%	7%	1%	267
SC	27%	41%	26%	5%	1%	174
UT	26%	43%	27%	3%	1%	251
NC	26%	42%	23%	6%	3%	178
OR	22%	43%	27%	3%	4%	180
VA	22%	46%	26%	6%	1%	168
NCI Average	28%	41%	25%	5%	2%	1,934

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

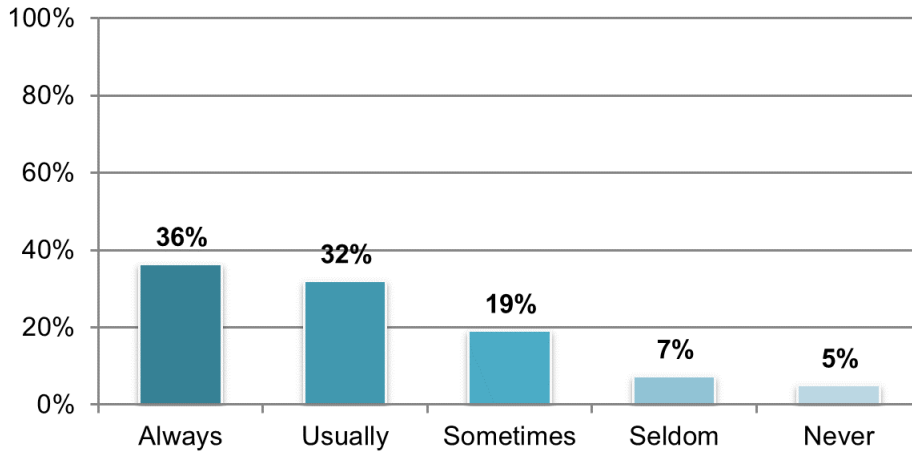


Table Q3. Does the information you receive come from your case manager/service coordinator (as opposed to family, friends, and others outside of state services)?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
TX	41%	31%	18%	6%	4%	385
MO	40%	28%	17%	8%	7%	358
UT	39%	35%	19%	5%	3%	262
LA	38%	31%	15%	9%	7%	261
SC	36%	31%	21%	6%	7%	181
OR	36%	32%	21%	7%	5%	180
VA	34%	38%	20%	6%	3%	176
NC	30%	32%	22%	12%	4%	184
NCI Average	36%	32%	19%	7%	5%	1,987

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

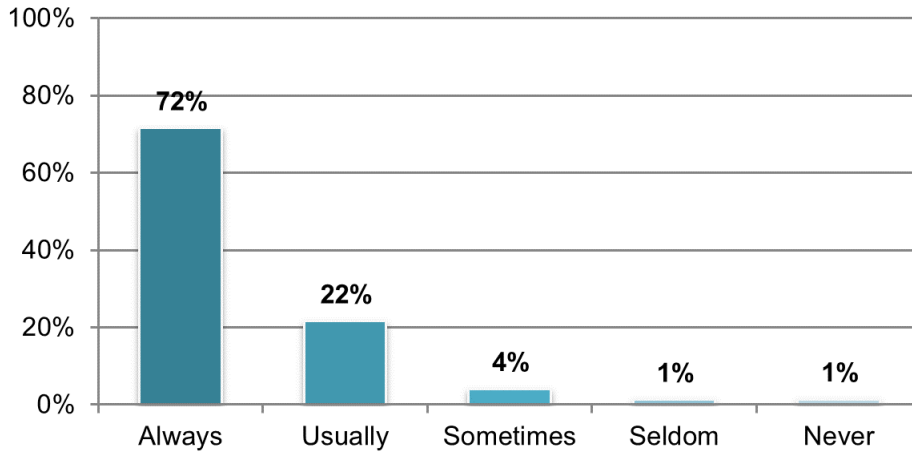


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
UT	85%	13%	2%	0%	0%	271
Within Average Range						
SC	76%	18%	3%	1%	2%	178
TX	74%	21%	3%	2%	1%	397
LA	70%	21%	5%	1%	3%	271
VA	69%	27%	2%	0%	2%	173
MO	68%	23%	5%	3%	2%	360
OR	66%	25%	7%	2%	1%	177
NC	65%	26%	6%	3%	1%	189
NCI Average	72%	22%	4%	1%	1%	2,016

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

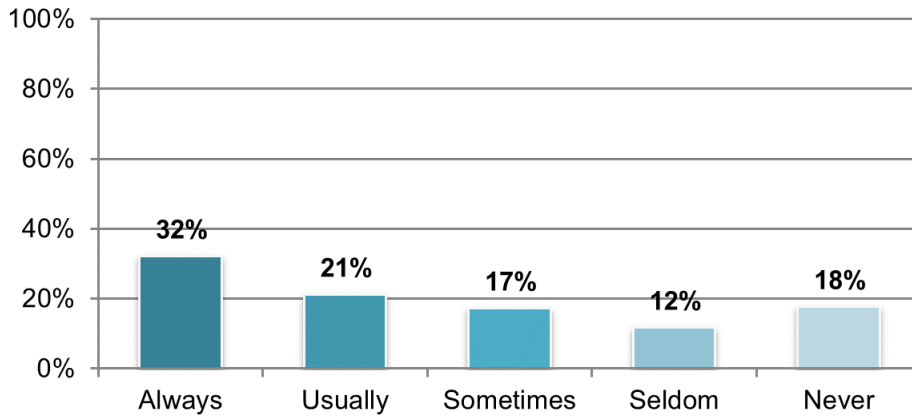


Table Q5. Does your case manager/service coordinator tell you about other public services that you are eligible for (e.g., food stamps, Early Period Screening Diagnosis and Treatment [EPSDT], Supplemental Security Income [SSI], housing subsidies, etc.)?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
MO	39%	18%	11%	8%	24%	353
LA	38%	18%	14%	12%	18%	271
TX	37%	21%	19%	9%	14%	387
SC	37%	19%	17%	7%	20%	176
OR	28%	24%	21%	15%	13%	178
NC	27%	19%	17%	15%	22%	184
UT	27%	26%	17%	12%	19%	248
VA	25%	25%	22%	15%	13%	169
NCI Average	32%	21%	17%	12%	18%	1,966

Child Has a Service Plan

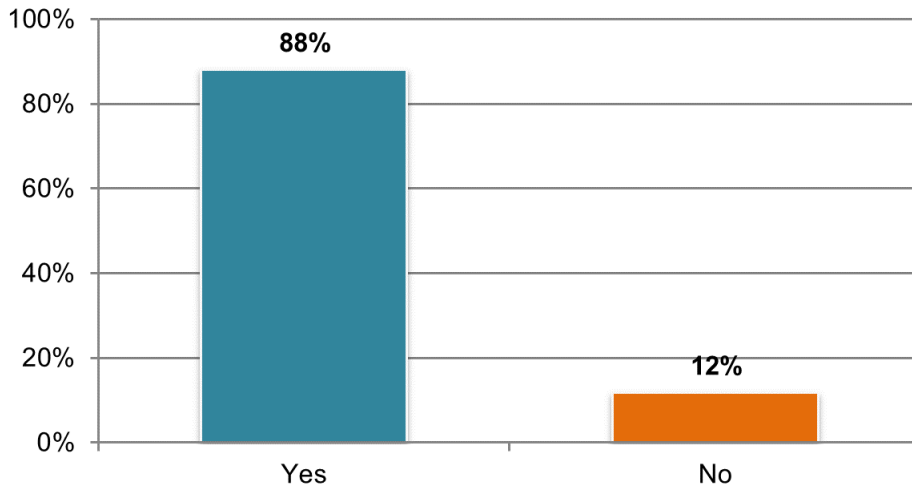


Table Q6. Does your child have a service plan?

State	Yes	No	N
Significantly Above Average			
VA	95%	5%	153
NC	95%	5%	189
Within Average Range			
UT	91%	9%	244
OR	91%	9%	166
MO	91%	9%	363
TX	83%	17%	338
Significantly Below Average			
LA	80%	20%	234
SC	79%	21%	151
NCI Average	88%	12%	1,838

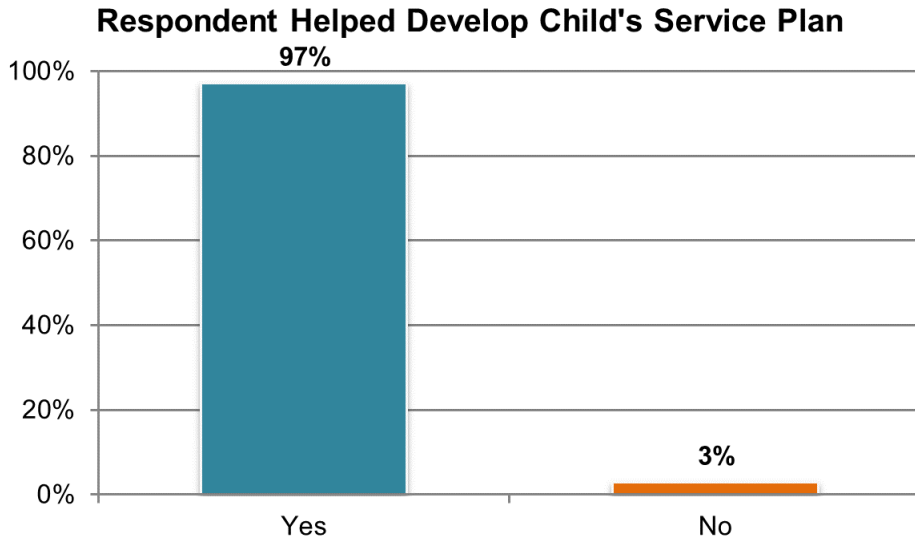


Table Q7. Did you help develop the plan?

State	Yes	No	N
Significantly Above Average			
MO	99%	1%	321
Within Average Range			
VA	99%	1%	143
NC	98%	2%	177
OR	97%	3%	142
LA	97%	3%	178
SC	96%	4%	114
UT	96%	4%	219
TX	95%	5%	273
NCI Average	97%	3%	1,567

Service Plan Includes All the Services and Supports the Family Wants

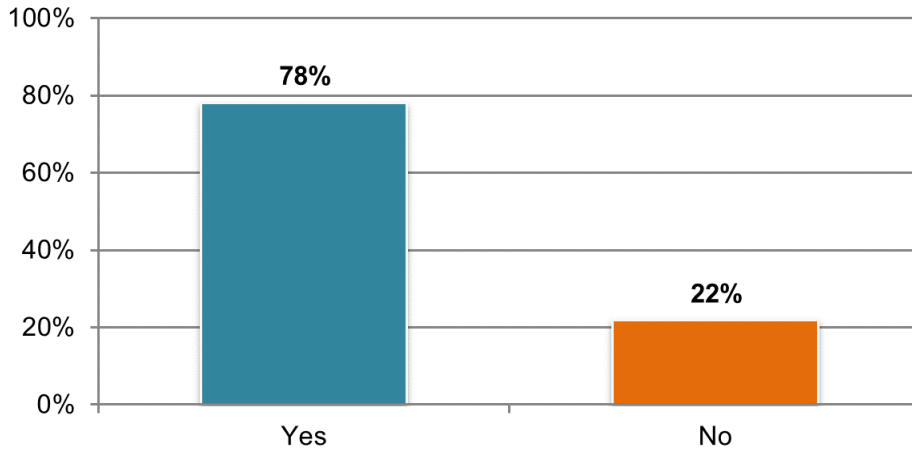


Table Q8. Does the plan include all the services and supports your family wants?

State	Yes	No	N
Significantly Above Average			
LA	86%	14%	166
Within Average Range			
UT	82%	18%	205
TX	81%	19%	253
NC	79%	21%	169
VA	78%	22%	130
SC	78%	22%	99
MO	73%	27%	292
OR	68%	32%	121
NCI Average	78%	22%	1,435

Service Plan Includes All the Services and Supports the Family Needs

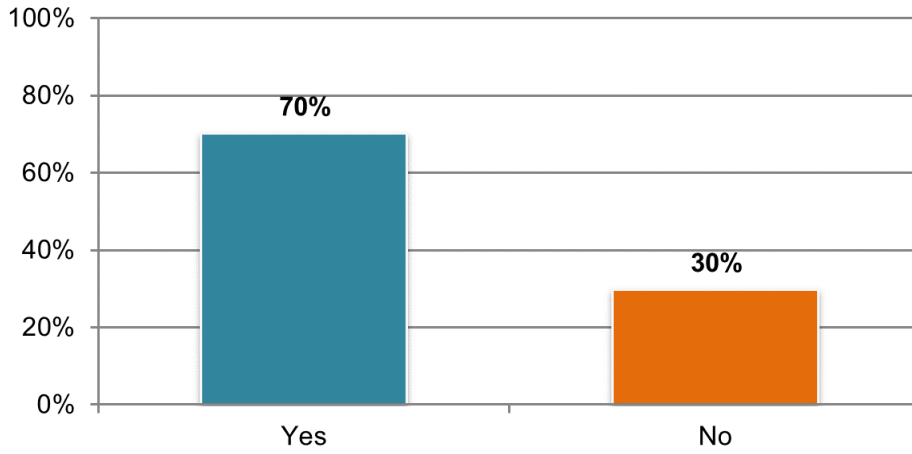


Table Q9. Does the plan include all the services and supports your family needs?

State	Yes	No	N
Significantly Above Average			
UT	78%	22%	196
Within Average Range			
LA	78%	22%	162
NC	76%	24%	165
TX	75%	25%	245
VA	73%	27%	126
SC	64%	36%	99
OR	61%	39%	132
Significantly Below Average			
MO	57%	43%	296
NCI Average	70%	30%	1,421

Family Receives All Services Listed in the Service Plan

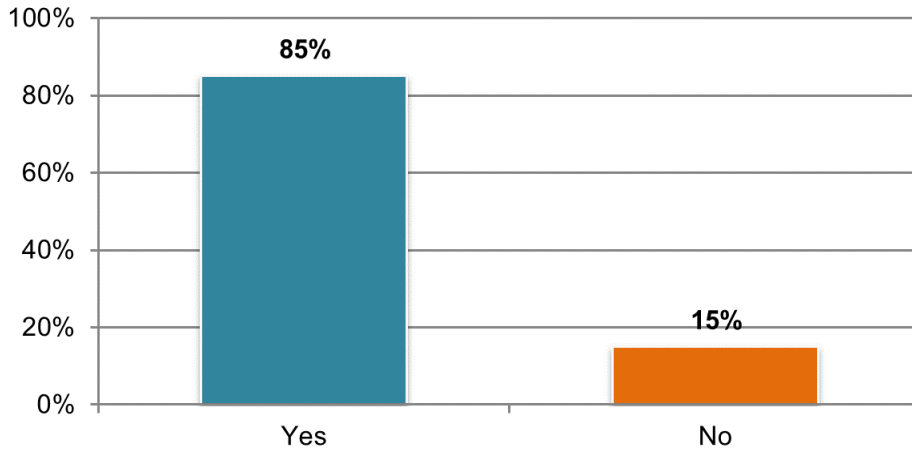


Table Q10. Does your family receive all of the services listed in the plan?

State	Yes	No	N
Significantly Above Average			
UT	92%	8%	201
Within Average Range			
VA	87%	13%	131
NC	86%	14%	171
LA	86%	14%	166
OR	85%	15%	127
SC	85%	15%	98
TX	82%	18%	260
Significantly Below Average			
MO	78%	22%	284
NCI Average	85%	15%	1,438

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

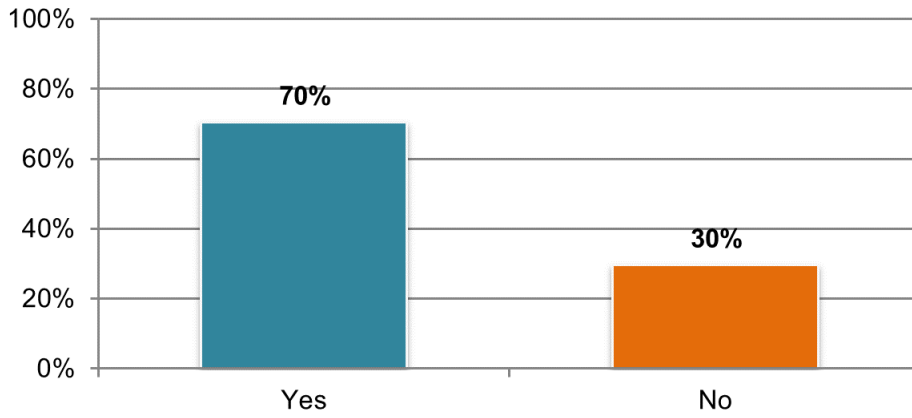


Table Q11. Did you discuss how to handle emergencies related to your child at the last service planning meeting?

State	Yes	No	N
Significantly Above Average			
NC	85%	15%	170
TX	84%	16%	262
LA	83%	17%	174
Within Average Range			
SC	76%	24%	100
UT	73%	27%	182
Significantly Below Average			
MO	57%	43%	263
VA	54%	46%	124
OR	51%	49%	127
NCI Average	70%	30%	1,402

Respondent Received Information About Family's Rights

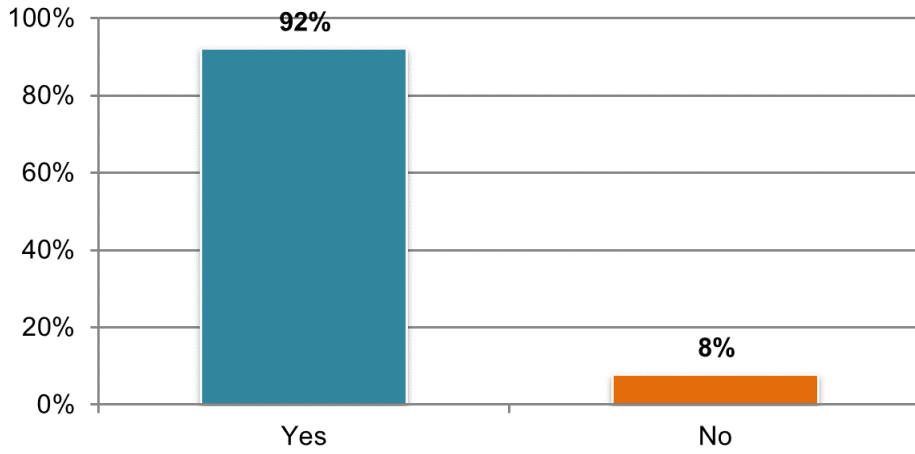


Table Q12. Have you received information about your family's rights?

State	Yes	No	N
Significantly Above Average			
VA	96%	4%	156
UT	96%	4%	215
Within Average Range			
OR	93%	7%	163
MO	92%	8%	338
NC	92%	8%	185
LA	91%	9%	246
TX	90%	10%	372
SC	87%	13%	160
NCI Average	92%	8%	1,835

Access and Delivery of Services and Supports

Families and children get the services and supports they need.

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

Respondent Is Able to Contact Support Workers When Needed

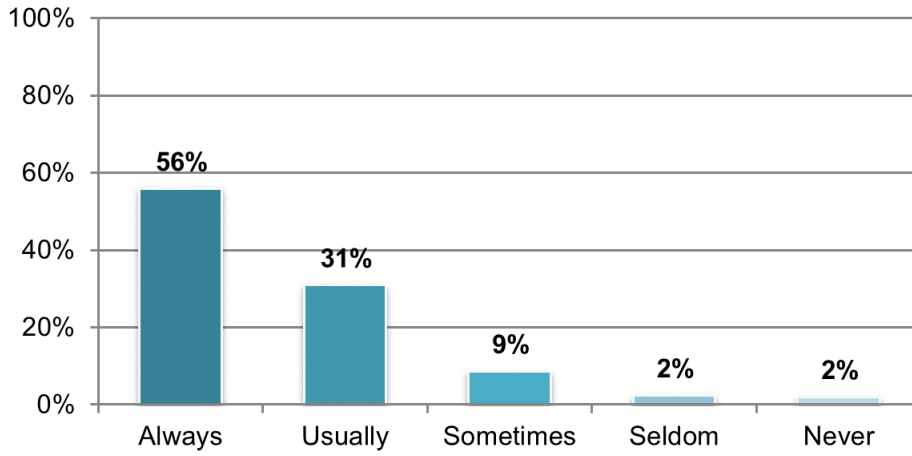


Table Q13. Are you able to contact your support workers when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
UT	64%	31%	5%	0%	0%	278
Within Average Range						
LA	63%	28%	5%	1%	2%	274
TX	61%	26%	9%	3%	2%	393
NC	56%	29%	10%	3%	2%	192
VA	55%	34%	8%	1%	3%	178
SC	55%	31%	8%	3%	2%	166
MO	52%	28%	12%	4%	4%	338
Significantly Below Average						
OR	41%	41%	13%	4%	1%	175
NCI Average	56%	31%	9%	2%	2%	1,994

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

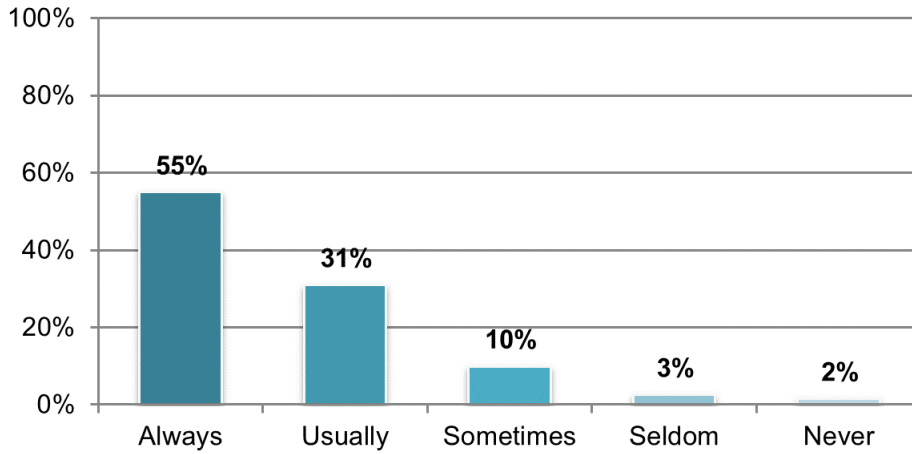


Table Q14. Are you able to contact your case manager/service coordinator when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
UT	65%	28%	6%	0%	1%	283
Within Average Range						
TX	63%	25%	7%	3%	2%	405
SC	61%	28%	8%	2%	2%	184
LA	59%	30%	7%	1%	2%	282
MO	54%	28%	10%	5%	3%	378
VA	52%	35%	10%	1%	2%	181
NC	49%	31%	15%	5%	1%	192
Significantly Below Average						
OR	36%	43%	16%	4%	1%	184
NCI Average	55%	31%	10%	3%	2%	2,089

Service and Supports Are Available When They Are Needed

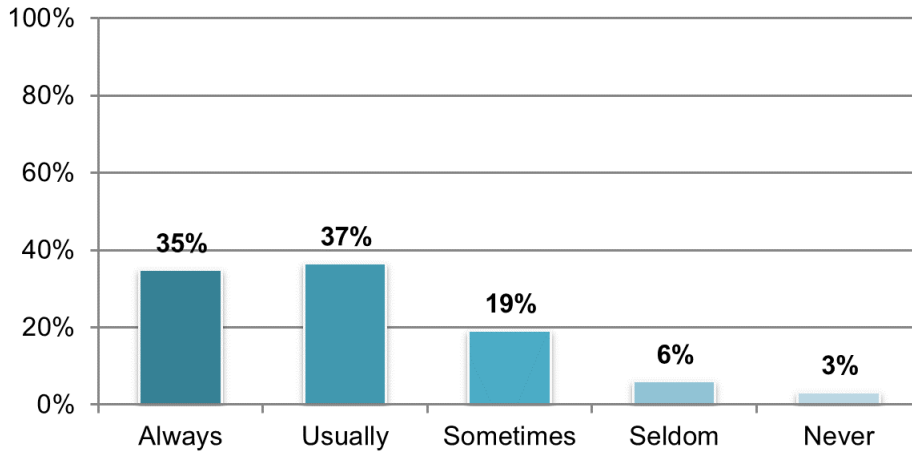


Table Q15. Are services and supports available when you need them?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	44%	38%	11%	4%	3%	272
TX	44%	32%	18%	4%	2%	398
Within Average Range						
UT	38%	42%	17%	1%	1%	276
NC	35%	40%	17%	5%	2%	189
MO	33%	28%	18%	12%	8%	345
VA	32%	38%	22%	5%	3%	176
SC	31%	37%	22%	8%	2%	171
Significantly Below Average						
OR	21%	36%	29%	9%	4%	179
NCI Average	35%	37%	19%	6%	3%	2,006

Services and Supports Are Available Within a Reasonable Distance From Family Home

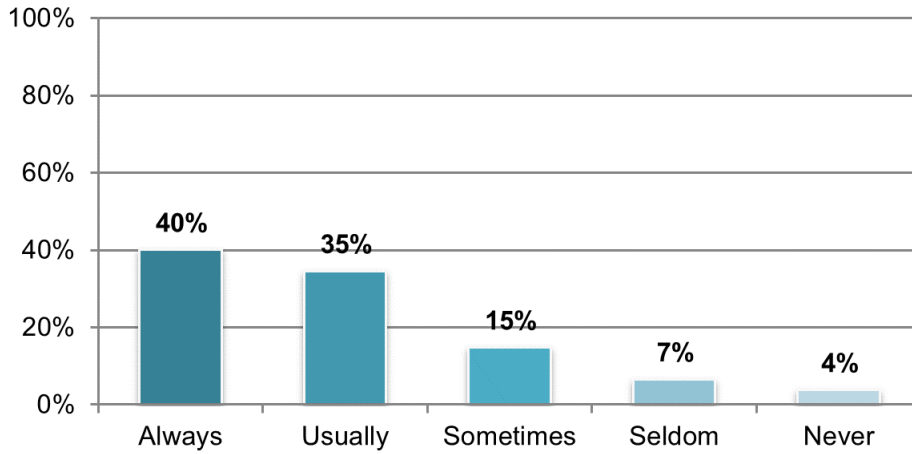


Table Q16. Are services and supports available within a reasonable distance from your home?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	51%	30%	11%	4%	4%	253
UT	51%	32%	13%	3%	1%	262
Within Average Range						
NC	44%	35%	13%	4%	4%	188
TX	39%	37%	16%	5%	2%	373
SC	37%	36%	16%	7%	4%	164
MO	36%	29%	16%	13%	6%	324
VA	33%	38%	15%	8%	6%	168
Significantly Below Average						
OR	30%	41%	18%	8%	4%	166
NCI Average	40%	35%	15%	7%	4%	1,898

Services and Supports Change When Child's Needs Change

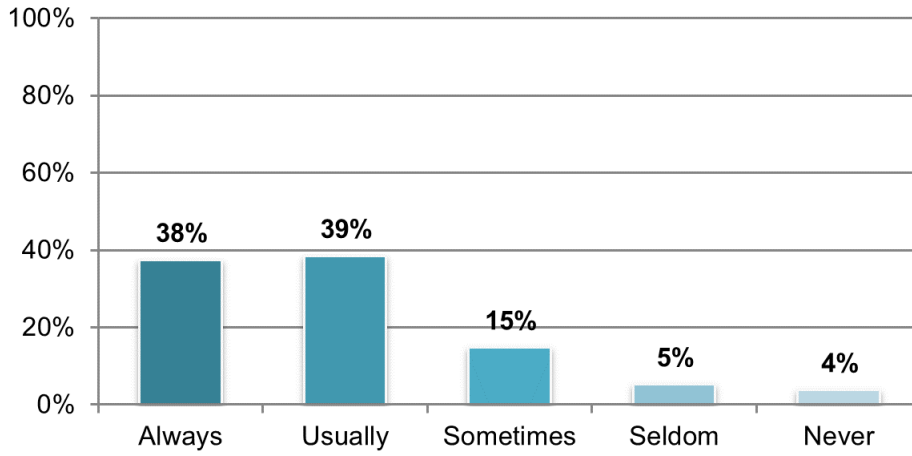


Table Q17. Do the services and supports change when your child's needs change?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
NC	45%	32%	14%	6%	3%	187
LA	42%	36%	10%	5%	7%	241
TX	41%	35%	17%	4%	3%	346
UT	40%	41%	15%	3%	0%	246
MO	36%	35%	15%	7%	6%	308
SC	34%	43%	15%	5%	3%	149
VA	33%	49%	12%	3%	4%	156
OR	29%	38%	21%	10%	3%	146
NCI Average	38%	39%	15%	5%	4%	1,779

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

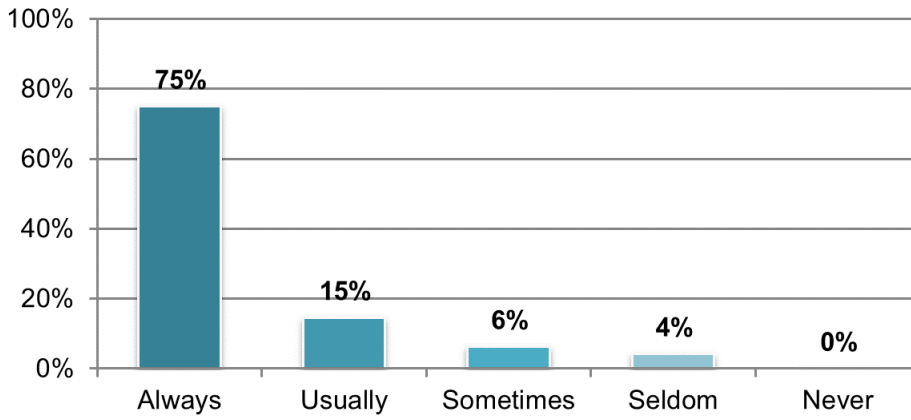


Table Q18. If English is not your primary language, are there support workers or translators who can speak with you in your language?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
TX	75%	15%	6%	4%	0%	48
NCI Average	75%	15%	6%	4%	0%	48

Support Workers Communicate Effectively in Primary Language (If English)

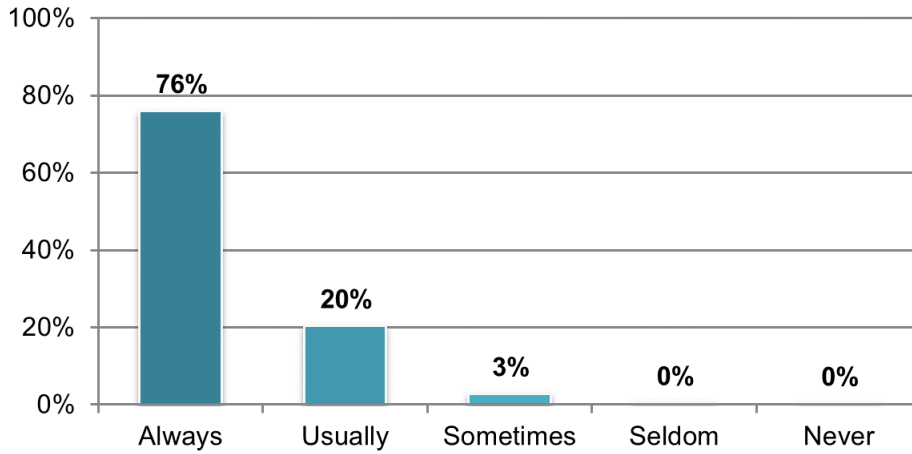


Table Q19. If English is your first language, do the support workers speak to you effectively?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
NC	82%	15%	3%	0%	0%	179
TX	79%	18%	3%	0%	0%	319
LA	79%	18%	2%	0%	1%	234
UT	78%	19%	2%	0%	0%	240
MO	76%	20%	3%	1%	0%	316
SC	75%	23%	1%	1%	1%	159
VA	71%	25%	4%	0%	0%	154
OR	69%	25%	4%	1%	1%	159
NCI Average	76%	20%	3%	0%	0%	1,760

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

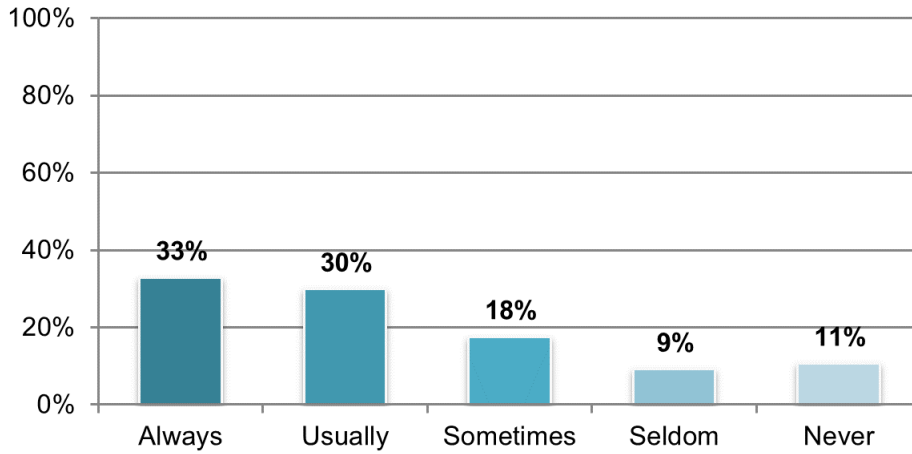


Table Q20. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NC	52%	28%	16%	3%	0%	86
Within Average Range						
LA	39%	28%	16%	6%	11%	124
UT	32%	42%	15%	5%	5%	117
VA	32%	31%	16%	12%	9%	75
MO	32%	23%	18%	18%	11%	57
TX	29%	30%	17%	11%	13%	150
SC	26%	26%	22%	9%	16%	68
OR	20%	31%	20%	9%	20%	55
NCI Average	33%	30%	18%	9%	11%	732

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

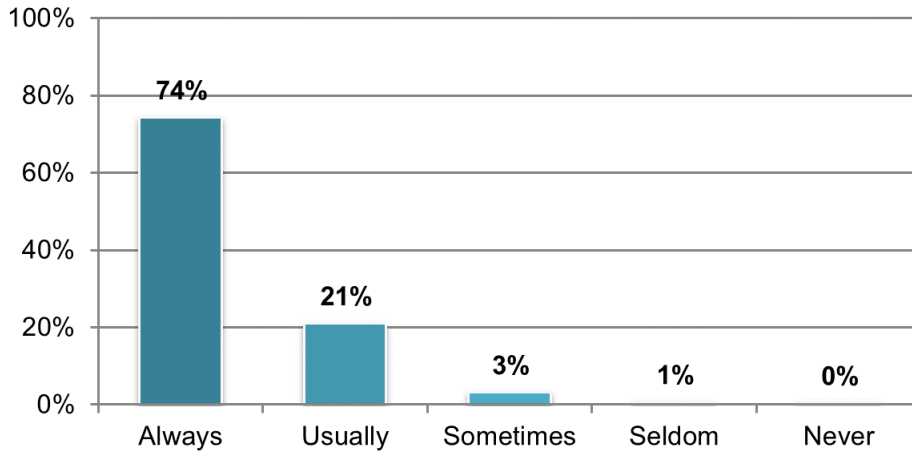


Table Q21. Are services delivered in a way that is respectful to your family's culture?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
UT	83%	15%	2%	0%	0%	265
Within Average Range						
TX	79%	17%	3%	1%	1%	396
MO	75%	21%	3%	1%	1%	314
LA	74%	20%	4%	2%	1%	256
NC	73%	21%	4%	1%	1%	184
VA	72%	24%	3%	1%	0%	165
SC	71%	25%	4%	0%	1%	170
OR	69%	26%	4%	1%	0%	162
NCI Average	74%	21%	3%	1%	0%	1,912

Child Has Access to Special Equipment or Accommodations Needed

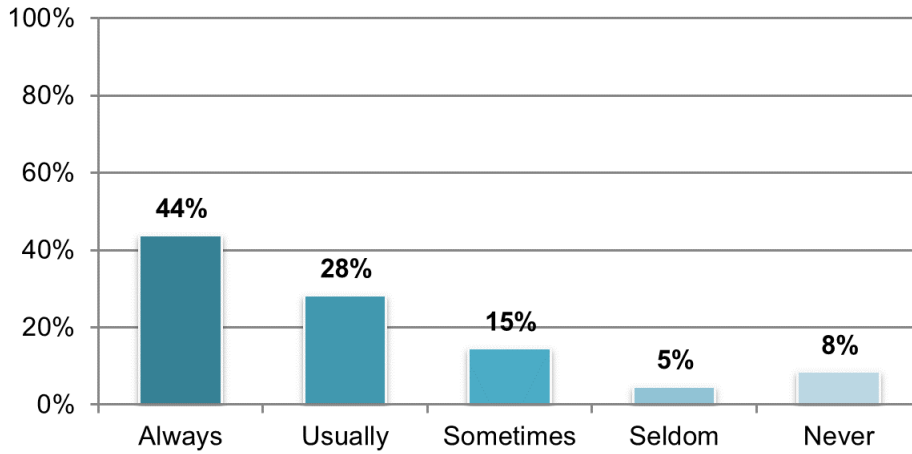


Table Q22. Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
TX	50%	22%	12%	5%	10%	286
NC	50%	27%	14%	2%	7%	125
LA	48%	18%	17%	4%	13%	166
MO	47%	25%	11%	7%	9%	150
VA	42%	38%	10%	5%	5%	131
OR	41%	32%	17%	4%	5%	115
UT	40%	40%	15%	2%	3%	174
SC	34%	23%	21%	8%	14%	91
NCI Average	44%	28%	15%	5%	8%	1,238

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

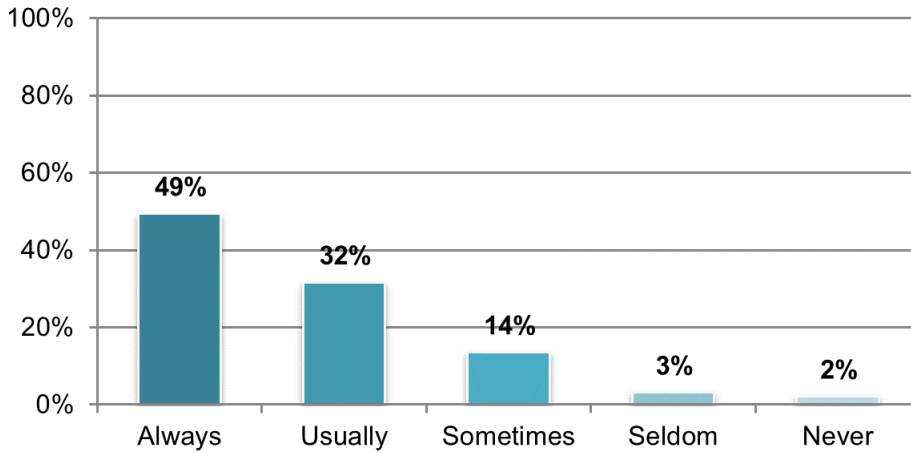


Table Q23. Do the support workers have the right training to meet your child's needs?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	61%	25%	8%	3%	3%	241
Within Average Range						
NC	54%	27%	12%	4%	2%	186
UT	52%	38%	9%	1%	0%	261
TX	50%	31%	14%	2%	2%	388
MO	48%	30%	17%	2%	3%	289
SC	45%	33%	15%	4%	3%	157
VA	45%	34%	15%	5%	2%	164
OR	40%	35%	19%	3%	3%	152
NCI Average	49%	32%	14%	3%	2%	1,838

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

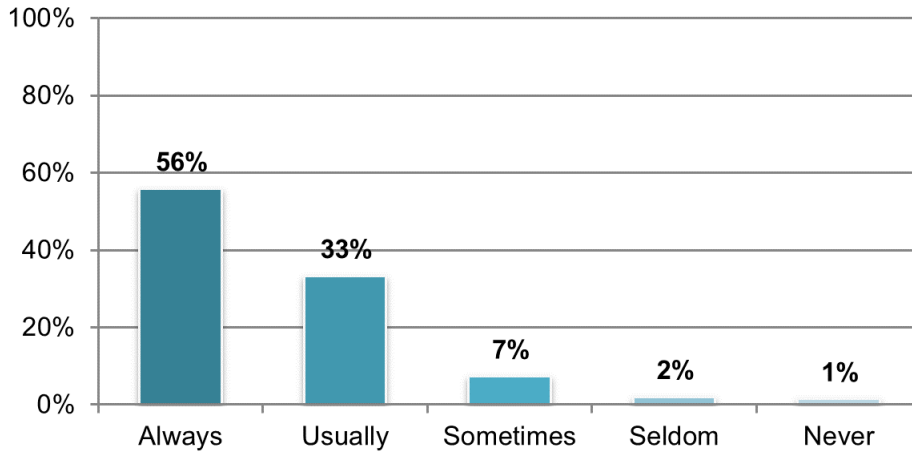


Table Q24. Do the support workers who come to your home arrive on time and when scheduled?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	65%	26%	4%	3%	3%	237
Within Average Range						
TX	62%	28%	8%	1%	1%	386
OR	57%	35%	5%	1%	1%	141
MO	56%	32%	5%	4%	2%	276
UT	54%	38%	8%	0%	0%	268
SC	52%	36%	7%	2%	3%	157
VA	51%	35%	10%	3%	1%	172
NC	50%	36%	11%	3%	1%	189
NCI Average	56%	33%	7%	2%	1%	1,826

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

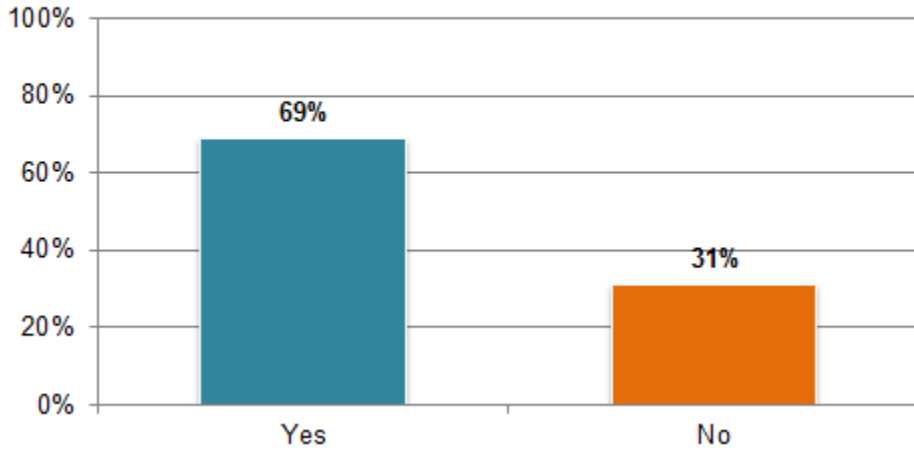


Table Q25. If you asked for crisis/emergency services during the past year, were services provided when needed?

State	Yes	No	N
Significantly Above Average			
UT	87%	13%	61
Within Average Range			
TX	76%	24%	118
NC	74%	26%	70
LA	73%	27%	82
SC	63%	37%	43
MO	63%	38%	88
VA	62%	38%	39
OR	56%	44%	57
NCI Average	69%	31%	558

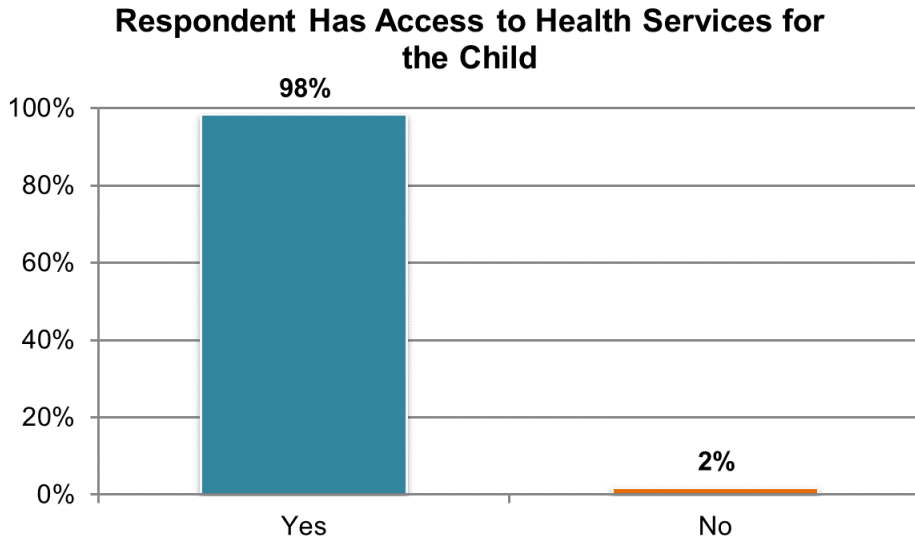


Table Q26. Do you have access to health services for your child?

State	Yes	No	N
Significantly Above Average			
UT	100%	0%	271
Within Average Range			
SC	99%	1%	188
TX	99%	1%	405
NC	98%	2%	195
OR	98%	2%	188
LA	98%	2%	283
VA	98%	2%	176
MO	96%	4%	362
NCI Average	98%	2%	2,068

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

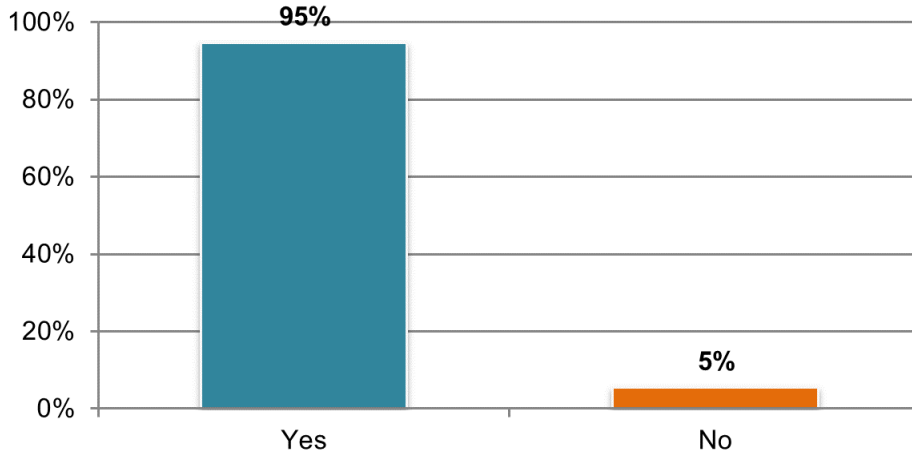


Table Q26a. If you have access to health services for your child, are you satisfied with the quality of these providers?

State	Yes	No	N
Within Average Range			
SC	97%	3%	177
UT	97%	3%	263
NC	97%	3%	184
TX	95%	5%	382
MO	93%	7%	334
LA	93%	7%	266
OR	92%	8%	172
VA	92%	8%	166
NCI Average	95%	5%	1,944

Respondent Has Access to Dental Services for the Child

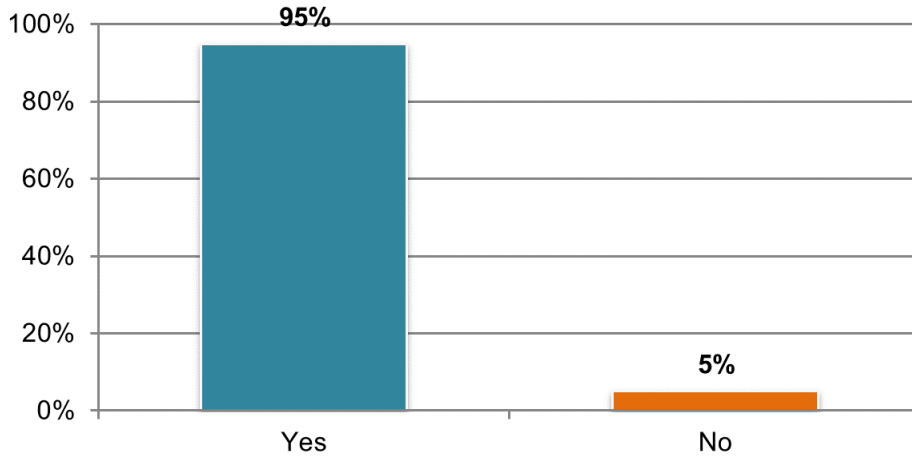


Table Q27. Do you have access to dental services for your child?

State	Yes	No	N
Significantly Above Average			
UT	97%	3%	277
Within Average Range			
OR	97%	3%	188
SC	96%	4%	185
NC	95%	5%	197
TX	95%	5%	400
LA	95%	5%	279
VA	94%	6%	178
Significantly Below Average			
MO	91%	9%	382
NCI Average	95%	5%	2,086

Respondent Is Satisfied With the Quality of the Child's Dental Providers

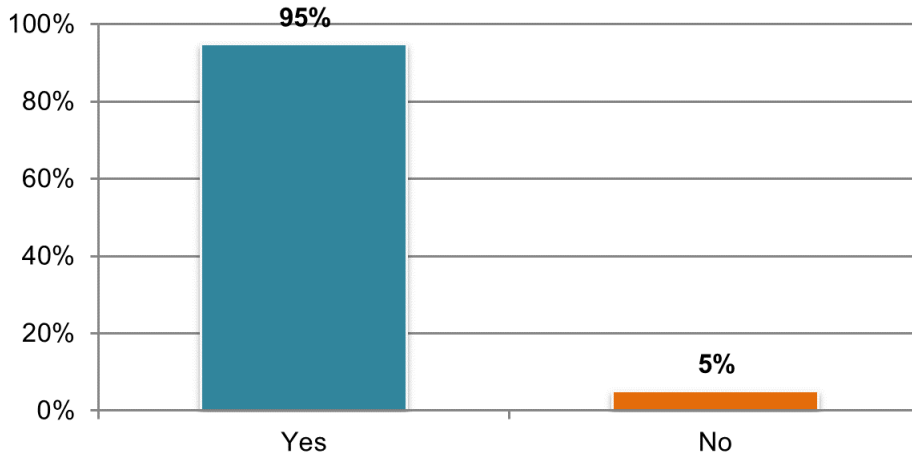


Table Q27a. If you have access to dental services for your child, are you satisfied with the quality of these providers?

State	Yes	No	N
Within Average Range			
SC	98%	2%	173
UT	97%	3%	259
LA	96%	4%	252
NC	96%	4%	182
TX	95%	5%	366
MO	94%	6%	336
VA	93%	7%	161
OR	90%	10%	168
NCI Average	95%	5%	1,897

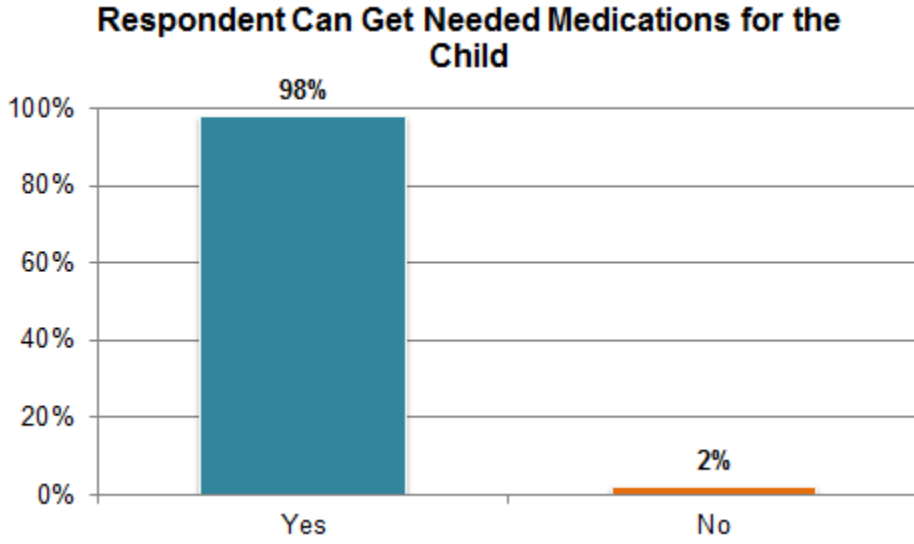


Table Q28. Are you able to get medications needed for your child?

State	Yes	No	N
Significantly Above Average			
NC	99%	1%	193
SC	99%	1%	173
UT	99%	1%	261
Within Average Range			
LA	98%	2%	284
VA	97%	3%	168
TX	97%	3%	402
MO	96%	4%	365
OR	95%	5%	181
NCI Average	98%	2%	2,027

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

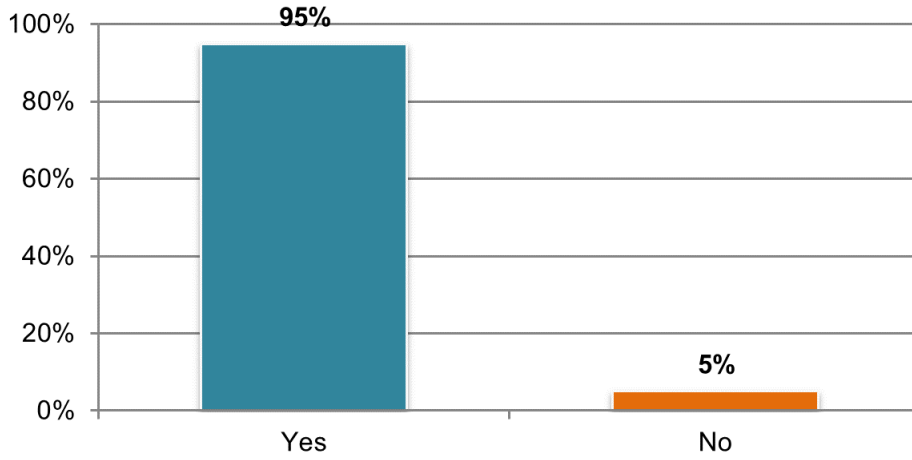


Table Q28a. If you have access to needed medications for your child, are you satisfied with how your child's medication needs are monitored?

State	Yes	No	N
Within Average Range			
MO	97%	3%	342
NC	97%	3%	185
UT	97%	3%	246
LA	96%	4%	264
TX	95%	5%	368
SC	94%	6%	161
VA	93%	7%	158
OR	91%	9%	160
NCI Average	95%	5%	1,884

Respondent Has Access to Mental Health Services for the Child

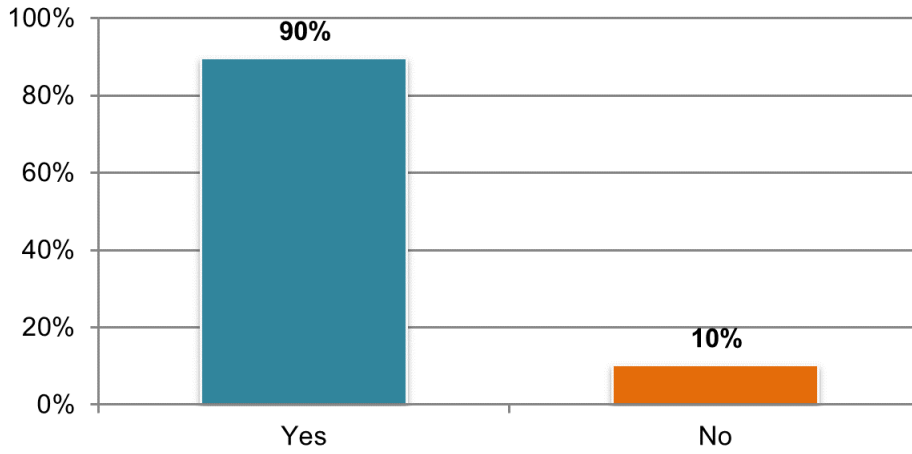


Table Q29. If needed, do you have access to mental health services for your child?

State	Yes	No	N
Significantly Above Average			
NC	97%	3%	149
Within Average Range			
MO	91%	9%	276
TX	91%	9%	275
VA	91%	9%	117
UT	89%	11%	185
LA	88%	12%	175
OR	86%	14%	128
SC	86%	14%	99
NCI Average	90%	10%	1,404

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

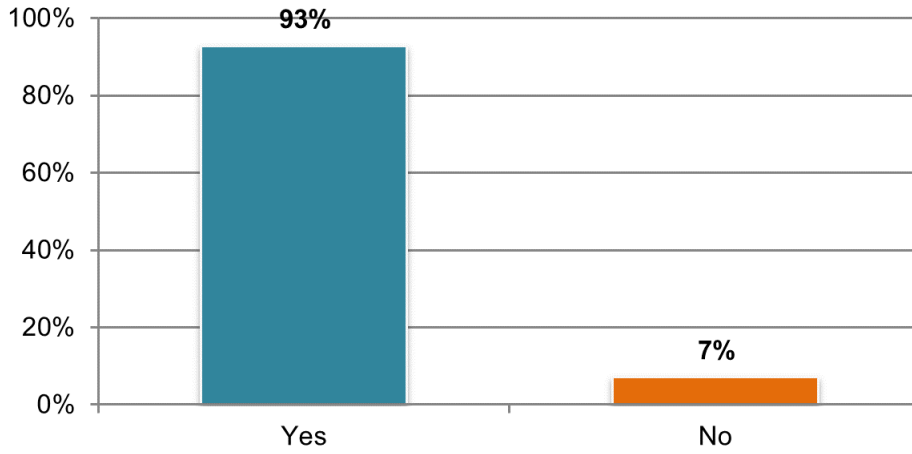


Table Q29a. If you have access to mental health services for your child, are you satisfied with the quality of these providers?

State	Yes	No	N
Significantly Above Average			
LA	98%	2%	124
Within Average Range			
TX	96%	4%	187
VA	96%	4%	92
NC	95%	5%	125
UT	93%	7%	126
MO	92%	8%	217
SC	90%	10%	67
OR	83%	17%	81
NCI Average	93%	7%	1,019

Respondent Has Access to Respite Services

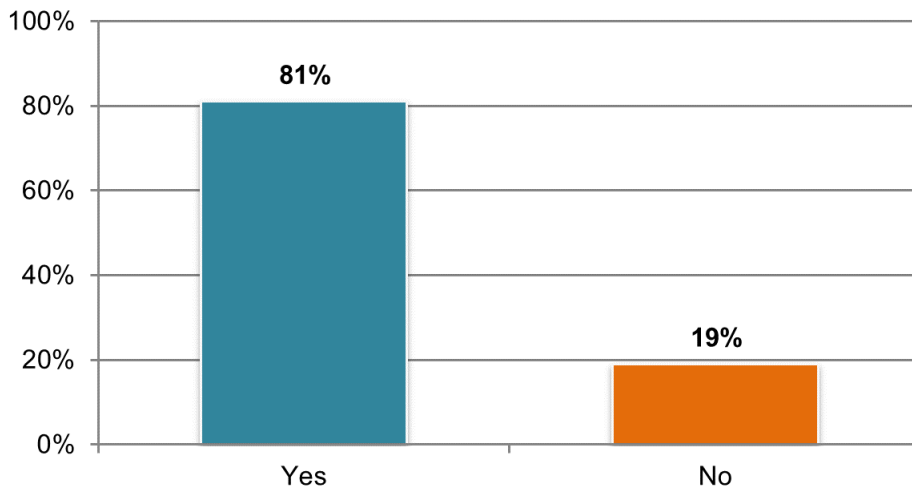


Table Q30. If you need respite services, do you have access to them?

State	Yes	No	N
Significantly Above Average			
UT	96%	4%	262
NC	90%	10%	172
TX	89%	11%	367
Within Average Range			
VA	83%	17%	167
OR	80%	20%	154
LA	79%	21%	156
Significantly Below Average			
SC	67%	33%	125
MO	64%	36%	263
NCI Average	81%	19%	1,666

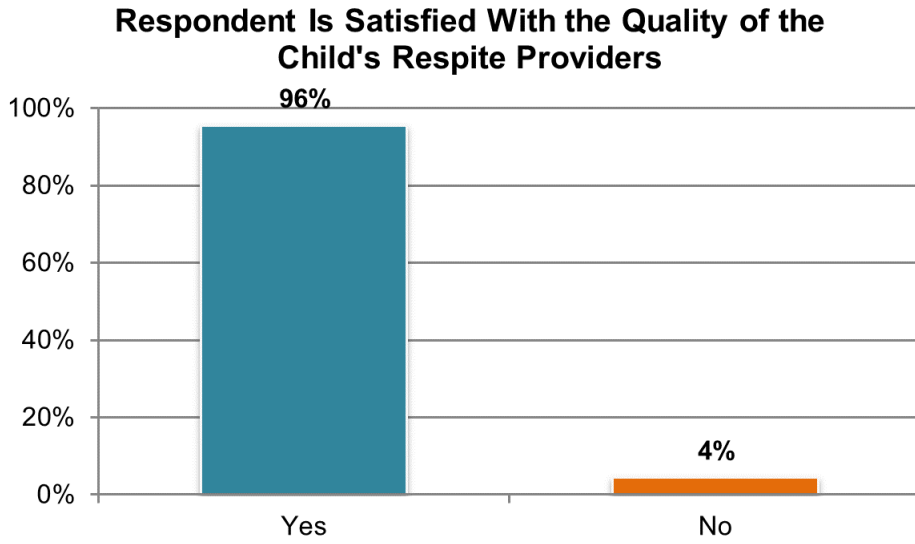


Table Q30a. If you have access to needed respite services, are you satisfied with the quality of these providers?

State	Yes	No	N
Within Average Range			
LA	98%	2%	107
UT	97%	3%	224
NC	97%	3%	140
TX	97%	3%	299
OR	95%	5%	104
SC	94%	6%	72
VA	93%	7%	129
MO	93%	7%	147
NCI Average	96%	4%	1,222

Services Are Needed That Are Not Currently Offered or Available

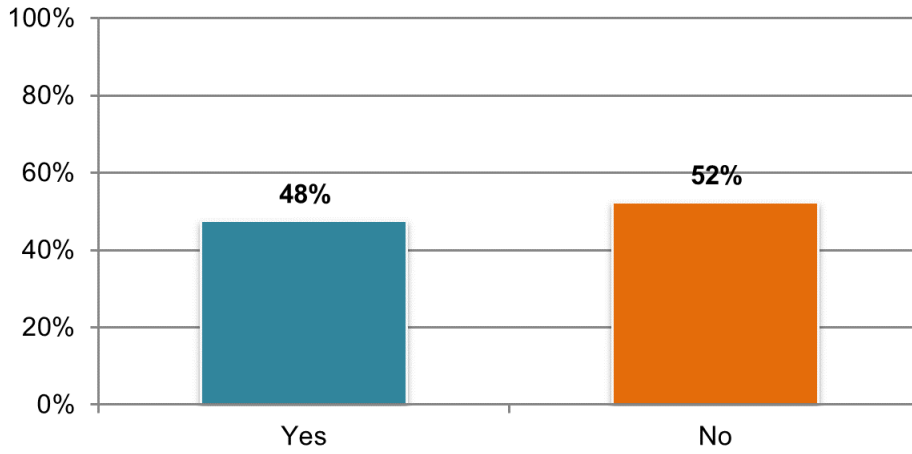


Table Q31. Are there other services that your family needs that are not currently offered or available?²

State	Yes	No	N
Significantly Above Average			
OR	60%	40%	108
MO	60%	40%	264
Within Average Range			
SC	56%	44%	121
VA	48%	52%	136
NC	43%	57%	150
TX	42%	58%	292
LA	40%	60%	166
Significantly Below Average			
UT	32%	68%	175
NCI Average	48%	52%	1,412

² The 'yes' response is the less desired response.

Choice and Control

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

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

Respondent Chooses the Provider Agencies Who Work With the Family

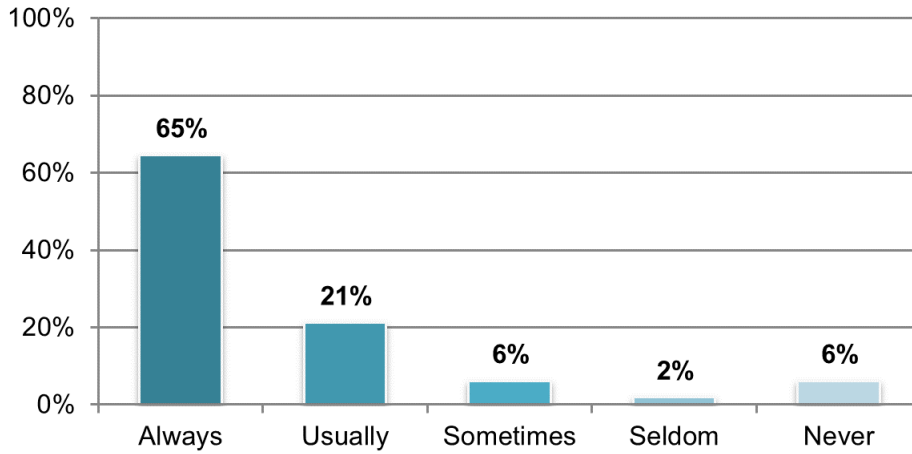


Table Q32. Do you choose the provider agencies who work with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	80%	11%	3%	0%	5%	245
TX	77%	16%	5%	1%	1%	397
UT	76%	12%	6%	1%	4%	265
Within Average Range						
NC	76%	18%	2%	2%	3%	185
VA	60%	26%	8%	2%	5%	163
SC	58%	30%	5%	2%	5%	168
Significantly Below Average						
MO	47%	24%	11%	3%	15%	297
OR	42%	32%	10%	4%	11%	151
NCI Average	65%	21%	6%	2%	6%	1,871

Respondent Can Choose a Different Provider Agency If Desired

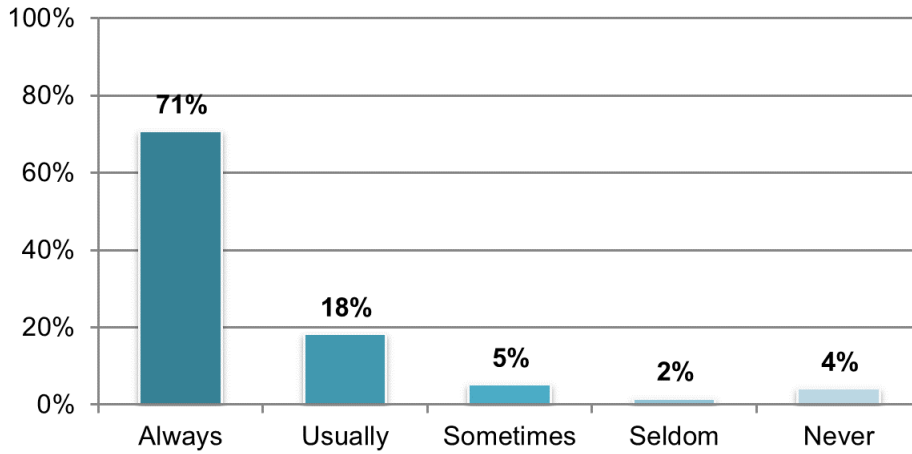


Table Q33. Can you choose a different provider agency if you want to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
TX	82%	13%	2%	1%	1%	374
LA	81%	14%	3%	0%	3%	227
NC	80%	14%	2%	1%	3%	177
Within Average Range						
UT	77%	15%	6%	0%	2%	245
VA	69%	22%	5%	1%	3%	139
SC	67%	26%	3%	2%	2%	150
Significantly Below Average						
OR	56%	20%	12%	3%	9%	124
MO	55%	22%	8%	4%	11%	223
NCI Average	71%	18%	5%	2%	4%	1,659

Respondent Chooses Individual Support Workers Who Work With the Family

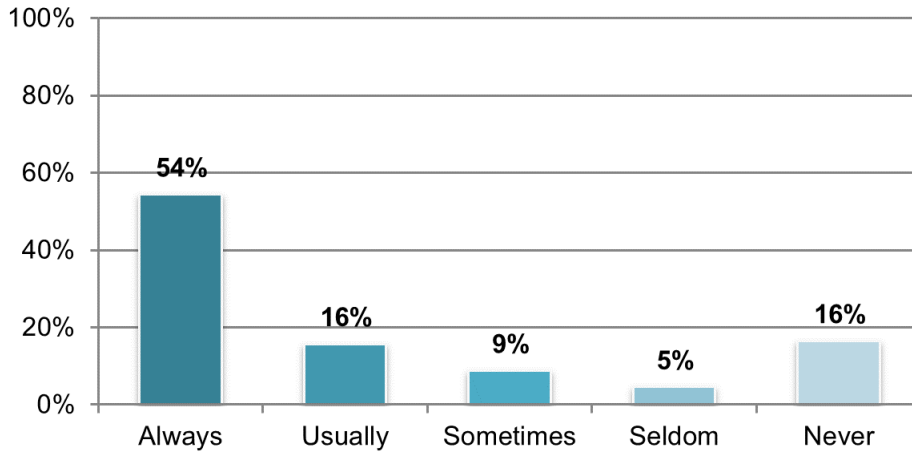


Table Q34. Do you choose the individual support workers who work directly with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NC	71%	12%	8%	3%	6%	188
LA	65%	10%	6%	3%	16%	237
TX	64%	15%	5%	3%	13%	379
Within Average Range						
VA	62%	17%	6%	2%	14%	167
UT	56%	17%	9%	6%	11%	259
OR	52%	21%	9%	5%	14%	148
Significantly Below Average						
SC	34%	20%	15%	8%	23%	158
MO	31%	13%	13%	7%	35%	282
NCI Average	54%	16%	9%	5%	16%	1,818

Respondent Can Choose Different Support Workers If Desired

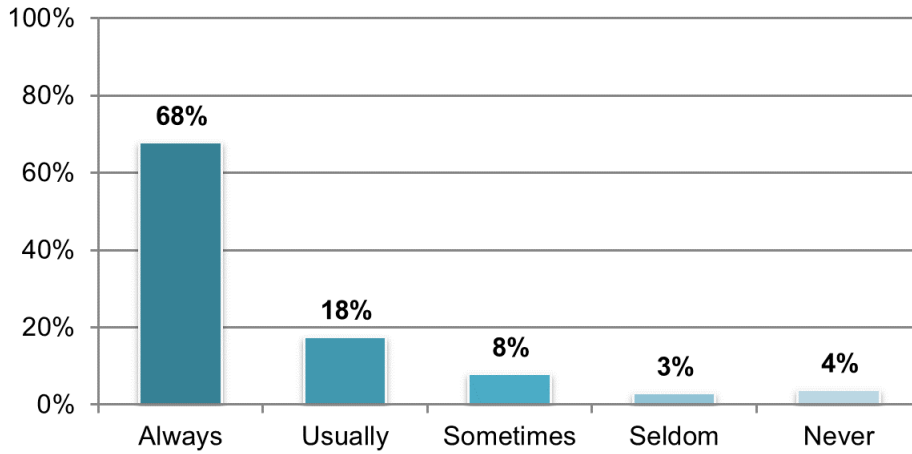


Table Q35. Can you choose different support workers if you want to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	78%	13%	6%	0%	2%	213
TX	74%	17%	4%	1%	3%	337
Within Average Range						
NC	74%	11%	8%	5%	2%	180
UT	72%	18%	7%	2%	2%	240
VA	67%	21%	8%	0%	3%	147
OR	62%	19%	9%	4%	6%	113
SC	61%	20%	9%	6%	4%	127
Significantly Below Average						
MO	54%	21%	12%	5%	8%	200
NCI Average	68%	18%	8%	3%	4%	1,557

Respondent Chose Case Manager/Service Coordinator

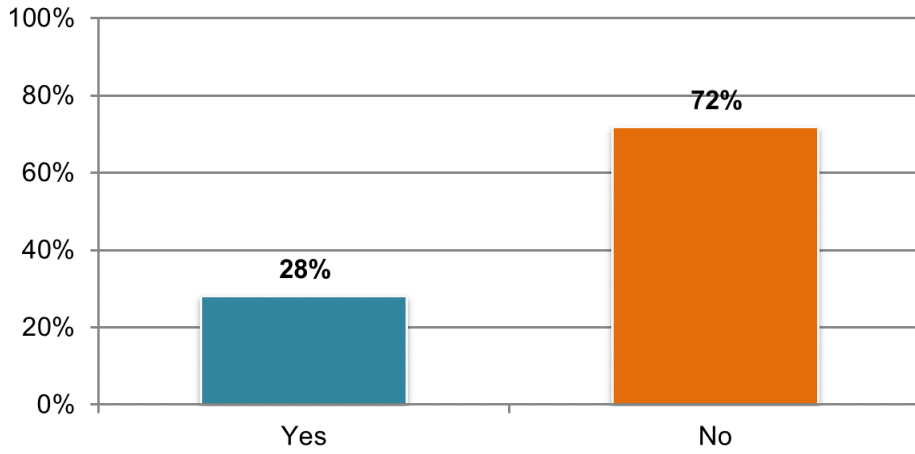


Table Q36. Did you choose your case manager/service coordinator?

State	Yes	No	N
Significantly Above Average			
UT	58%	42%	274
LA	38%	62%	259
Within Average Range			
SC	30%	70%	179
NC	28%	72%	187
TX	28%	72%	392
VA	26%	74%	178
Significantly Below Average			
OR	9%	91%	178
MO	8%	92%	378
NCI Average	28%	72%	2,025

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

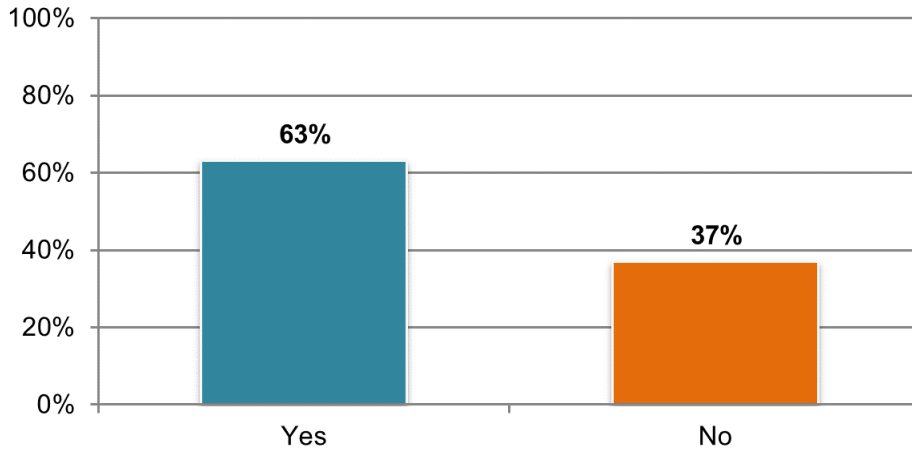


Table Q37. Do you have control and/or input over the hiring and management of your family's support workers?

State	Yes	No	N
Significantly Above Average			
UT	78%	22%	238
NC	77%	23%	173
TX	75%	25%	350
VA	74%	26%	165
Within Average Range			
LA	64%	36%	208
OR	60%	40%	144
Significantly Below Average			
SC	48%	52%	139
MO	28%	72%	237
NCI Average	63%	37%	1,654

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

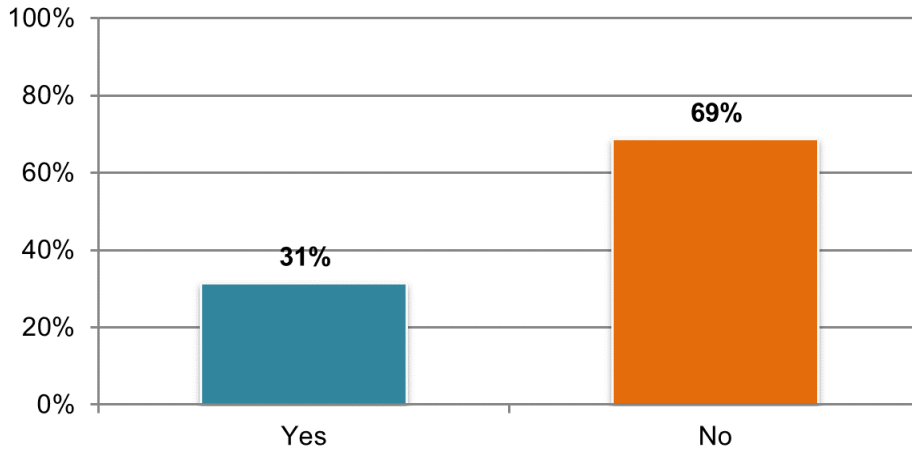


Table Q38. Do you know how much money is spent by the ID/DD agency on behalf of your child?

State	Yes	No	N
Significantly Above Average			
UT	53%	47%	281
TX	43%	57%	406
Within Average Range			
LA	39%	61%	290
OR	28%	72%	187
SC	28%	72%	185
Significantly Below Average			
NC	23%	77%	186
MO	20%	80%	370
VA	17%	83%	173
NCI Average	31%	69%	2,078

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

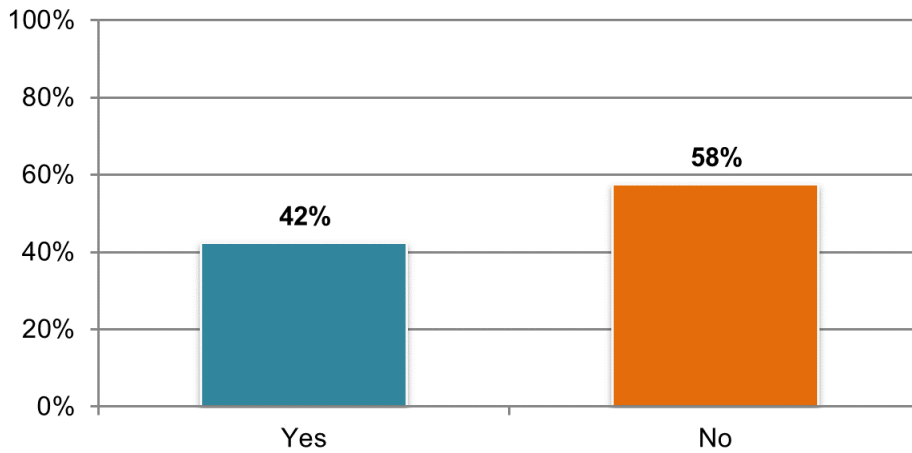


Table Q39. Do you have a say in how this money is spent?

State	Yes	No	N
Significantly Above Average			
UT	70%	30%	224
TX	62%	38%	314
Within Average Range			
OR	54%	46%	125
LA	44%	56%	182
Significantly Below Average			
MO	34%	66%	244
NC	31%	69%	143
VA	23%	77%	108
SC	22%	78%	120
NCI Average	42%	58%	1,460

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

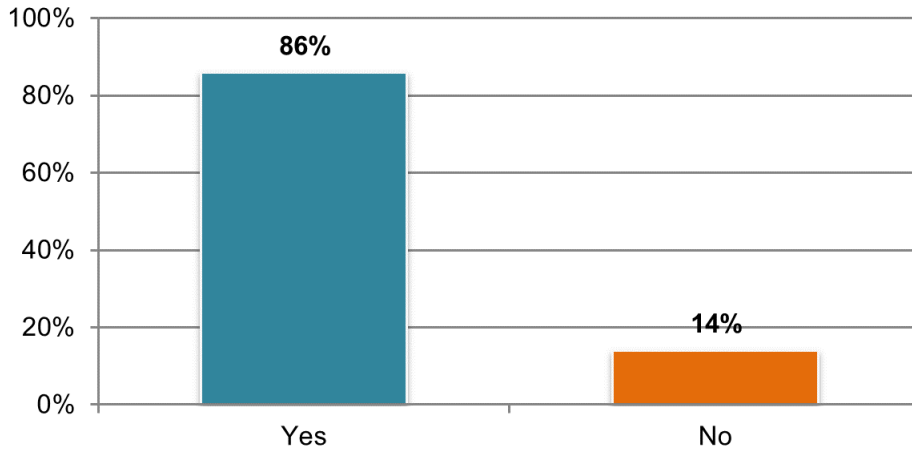


Table 39a. If you have a say in how this money is spent, do you have all the information you need to make decisions about how to spend this money?

State	Yes	No	N
Within Average Range			
MO	92%	8%	74
LA	90%	10%	70
TX	90%	10%	173
UT	87%	13%	136
SC	86%	14%	22
OR	80%	20%	50
NC	77%	23%	39
NCI Average	86%	14%	564

Community Connections

Children use integrated community services and participate in everyday community activities.

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

Child Participates in Community Activities

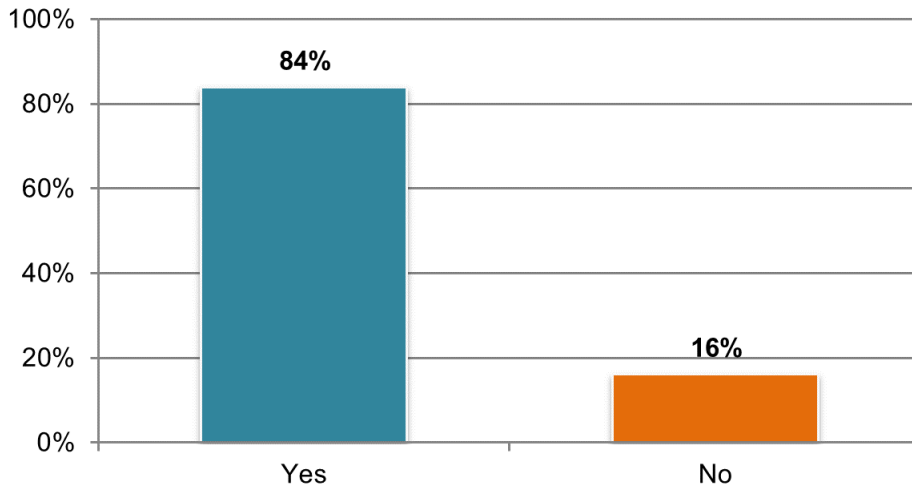


Table Q40. Does your child participate in community activities (such as going out to a restaurant, movie, or sporting event)?

State	Yes	No	N
Within Average Range			
NC	90%	10%	191
UT	87%	13%	279
VA	85%	15%	175
LA	85%	15%	310
TX	85%	15%	414
OR	81%	19%	188
MO	80%	20%	395
SC	78%	22%	187
NCI Average	84%	16%	2,139

Reasons Child Does Not Participate in Community Activities

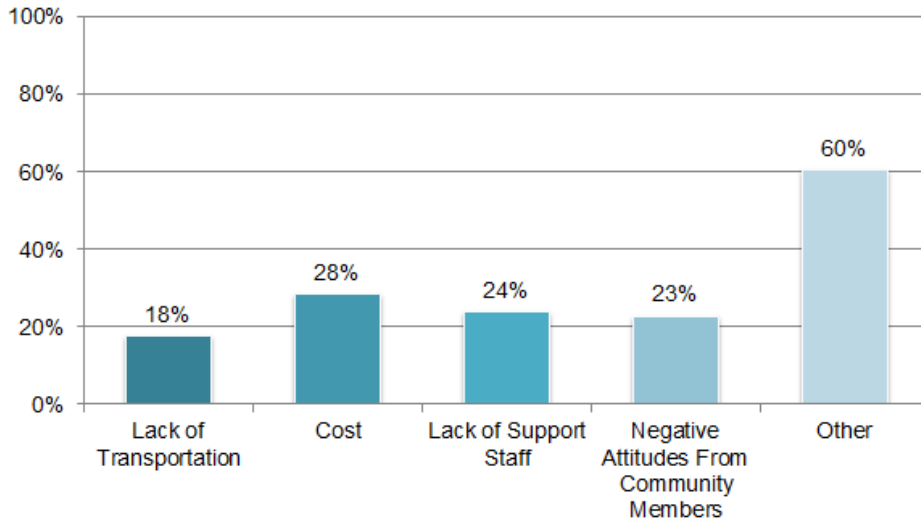


Table Q40a. If your child does not participate in community activities, why not?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes From Community Members	Other
Within Average Range					
LA	18%	23%	14%	23%	59%
MO	25%	46%	25%	12%	59%
OR	12%	42%	24%	21%	52%
SC	6%	36%	31%	42%	61%
TX	26%	23%	16%	16%	72%
UT	3%	12%	24%	29%	74%
VA	33%	17%	33%	17%	46%
NCI Average	18%	28%	24%	23%	60%

Child Spends Time With Children Who Do Not Have Developmental Disabilities

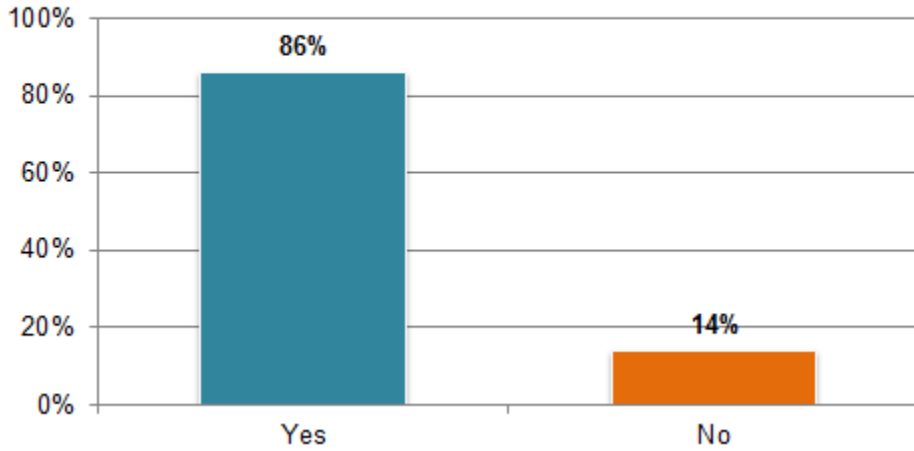


Table Q41. Does your child spend time with children who do not have developmental disabilities?

State	Yes	No	N
Significantly Above Average			
MO	91%	9%	390
Within Average Range			
LA	90%	10%	310
UT	88%	12%	263
SC	87%	13%	178
NC	86%	14%	187
TX	83%	17%	404
VA	83%	17%	174
OR	82%	18%	177
NCI Average	86%	14%	2,083

Satisfaction With Services and Supports

Families and children receive adequate and satisfactory supports.

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

Respondent Is Satisfied With Services and Supports Family Receives

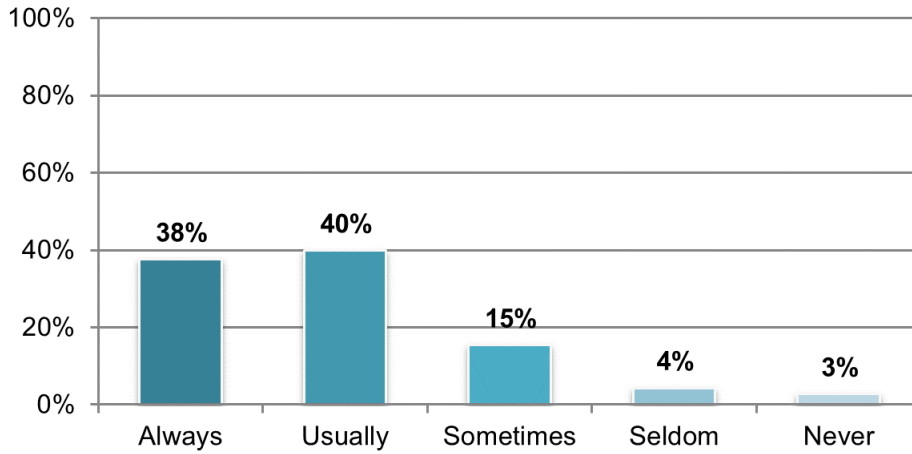


Table Q42. Overall, are you satisfied with the services and supports your family currently receives?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	50%	34%	12%	3%	2%	302
Within Average Range						
TX	46%	37%	11%	3%	2%	411
UT	43%	50%	6%	0%	0%	278
NC	38%	41%	13%	5%	3%	187
VA	36%	39%	22%	2%	1%	180
MO	32%	35%	17%	9%	6%	384
SC	31%	42%	20%	4%	3%	182
Significantly Below Average						
OR	24%	40%	22%	9%	5%	188
NCI Average	38%	40%	15%	4%	3%	2,112

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

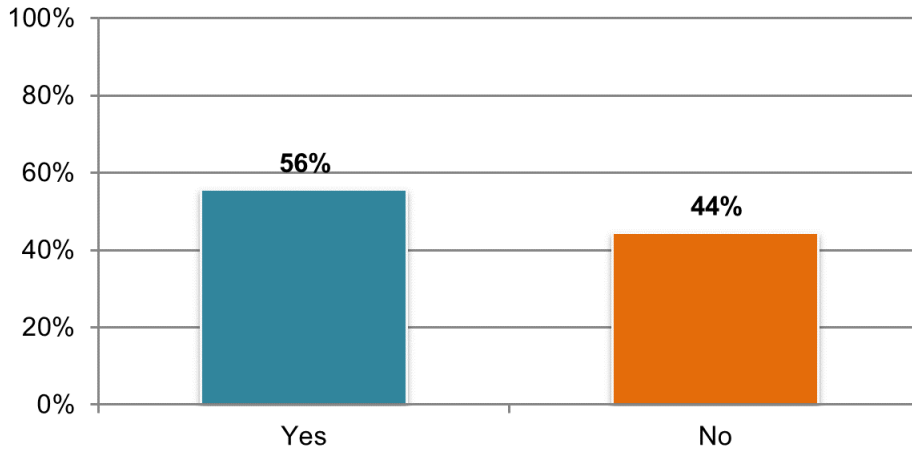


Table Q43. Do you know the process for filing a complaint or grievance against provider agencies or staff?³

State	Yes	No	N
Significantly Above Average			
TX	74%	26%	412
NC	65%	35%	193
Within Average Range			
UT	59%	41%	279
LA	58%	42%	304
OR	53%	47%	192
SC	46%	54%	184
Significantly Below Average			
MO	46%	54%	378
VA	44%	56%	180
NCI Average	56%	44%	2,122

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

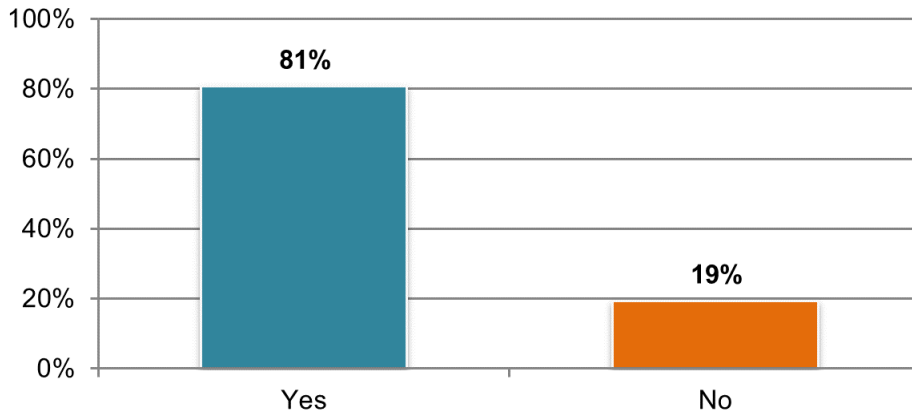


Table Q44. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

State	Yes	No	N
Significantly Above Average			
UT	96%	4%	117
LA	90%	10%	140
TX	87%	13%	189
Within Average Range			
NC	77%	23%	96
SC	76%	24%	54
VA	75%	25%	53
OR	74%	26%	46
MO	70%	30%	104
NCI Average	81%	19%	799

Respondent Knows How to Report Abuse or Neglect

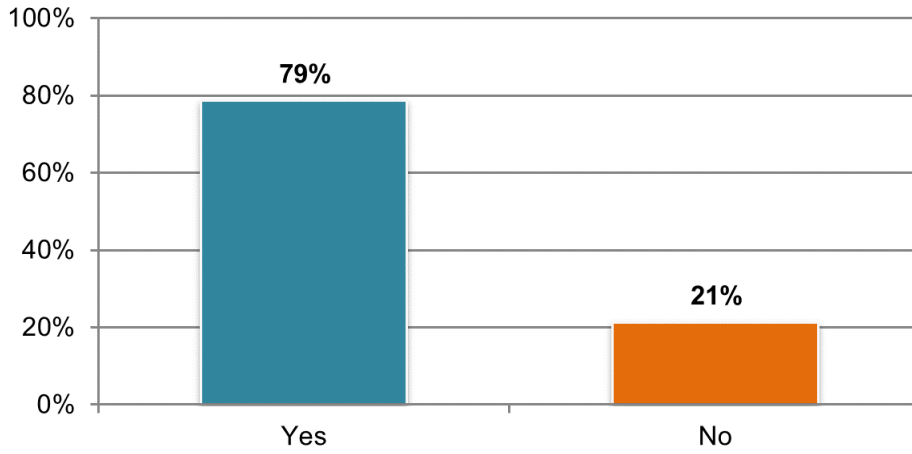


Table Q45. Do you know how to report abuse or neglect?⁴

State	Yes	No	N
Significantly Above Average			
TX	85%	15%	402
Within Average Range			
NC	83%	17%	190
OR	82%	18%	186
LA	78%	22%	308
UT	78%	22%	270
SC	76%	24%	184
MO	75%	25%	380
VA	73%	27%	174
NCI Average	79%	21%	2,094

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

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

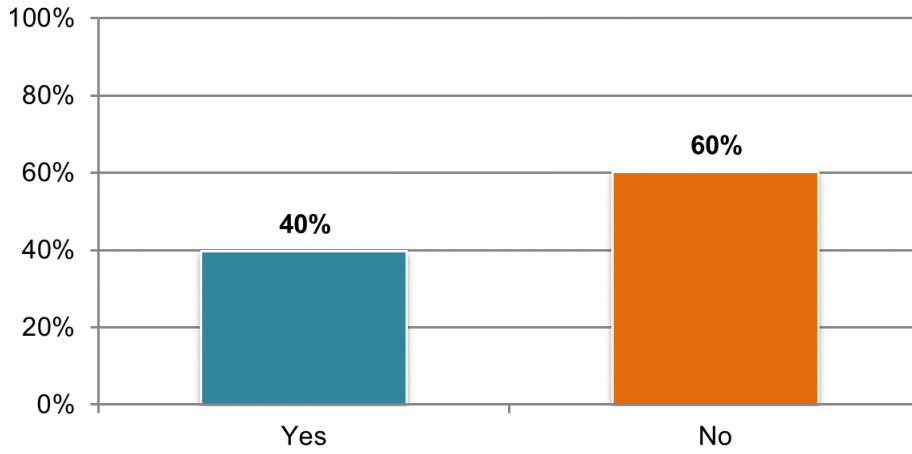


Table Q46. Within the past year, if abuse or neglect occurred, did you report it?

State	Yes	No	N
Within Average Range			
LA	51%	49%	37
UT	50%	50%	36
VA	43%	57%	28
OR	37%	63%	30
MO	35%	65%	77
TX	35%	65%	69
NC	34%	66%	35
SC	33%	67%	24
NCI Average	40%	60%	336

Appropriate People Were Responsive to Report of Abuse or Neglect (If Reported in the Past Year)

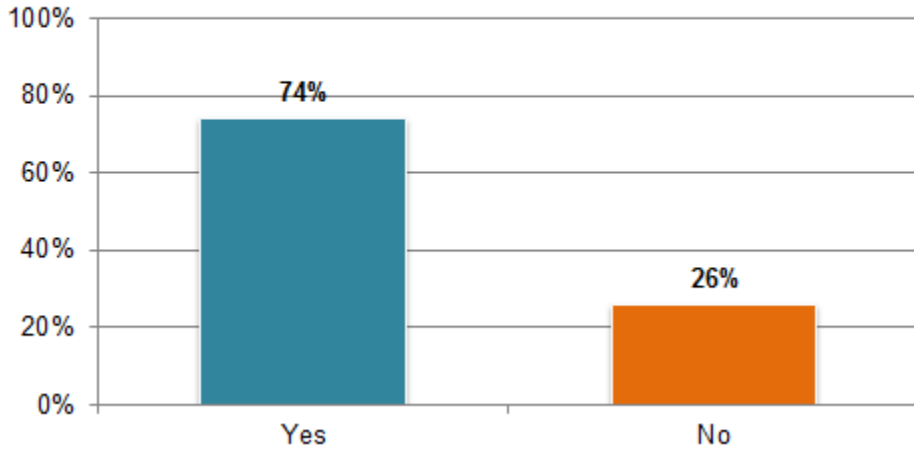


Table Q46a. If you reported abuse or neglect within the past year, were the appropriate people responsive to your report?

State	Yes	No	N
Within Average Range			
TX	80%	20%	20
MO	68%	32%	22
NCI Average	74%	26%	42

Family Outcomes

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

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

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

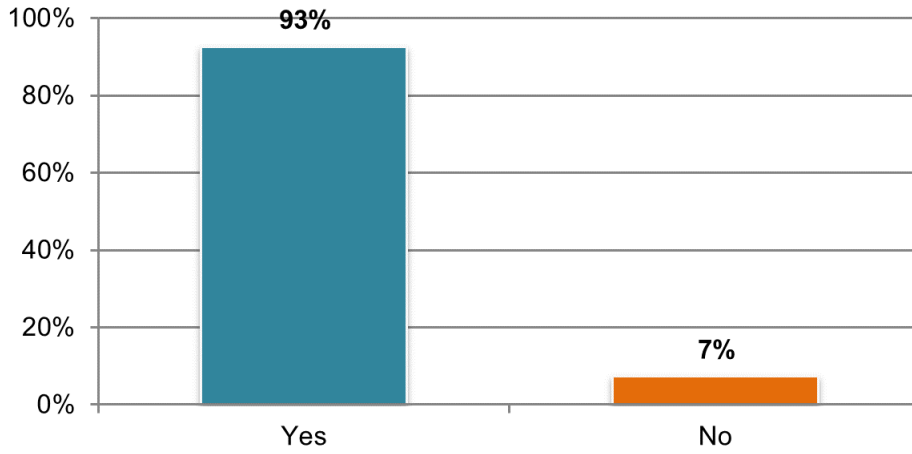


Table Q47. Do you feel that family supports have made a positive difference in the life of your family?

State	Yes	No	N
Significantly Above Average			
UT	99%	1%	269
LA	96%	4%	275
Within Average Range			
TX	95%	5%	383
NC	93%	7%	180
VA	92%	8%	171
SC	91%	9%	170
MO	89%	11%	339
OR	86%	14%	170
NCI Average	93%	7%	1,957

Services and Supports Have Reduced Out-of-Pocket Expenses

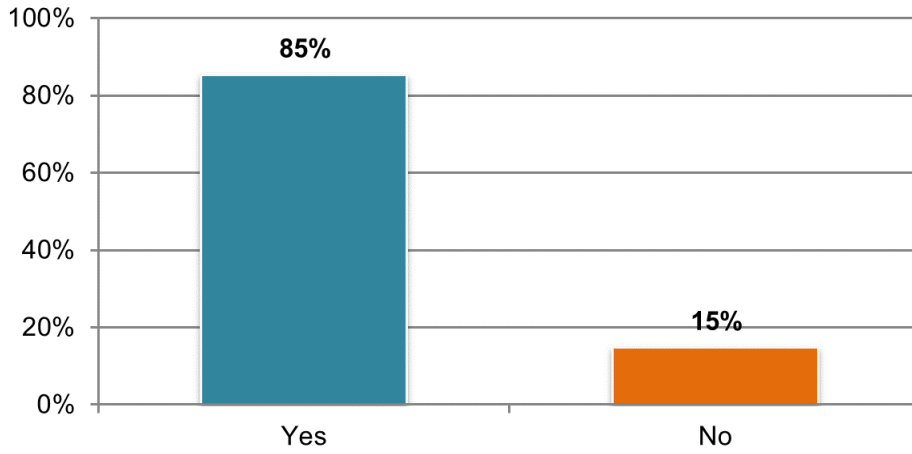


Table Q48. Do you feel that services and supports have reduced your family’s out-of-pocket expenses for your child’s care?

State	Yes	No	N
Significantly Above Average			
UT	95%	5%	265
VA	92%	8%	168
TX	90%	10%	388
Within Average Range			
NC	90%	10%	177
LA	88%	12%	276
SC	78%	22%	170
Significantly Below Average			
OR	76%	24%	171
MO	73%	27%	321
NCI Average	85%	15%	1,936

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

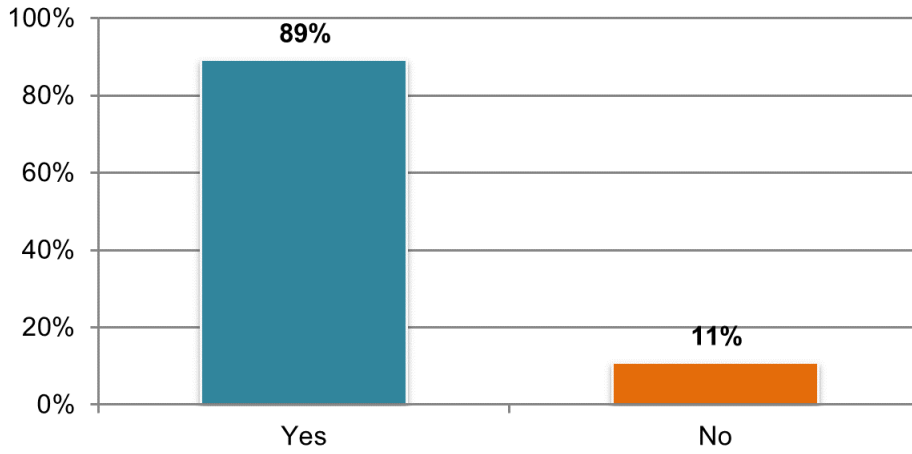


Table Q49. Do you feel that family supports have improved your ability to care for your child?

State	Yes	No	N
Significantly Above Average			
UT	98%	2%	278
TX	95%	5%	386
Within Average Range			
VA	93%	7%	162
LA	91%	9%	272
NC	89%	11%	179
SC	87%	13%	171
Significantly Below Average			
MO	82%	18%	338
OR	79%	21%	165
NCI Average	89%	11%	1,951

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

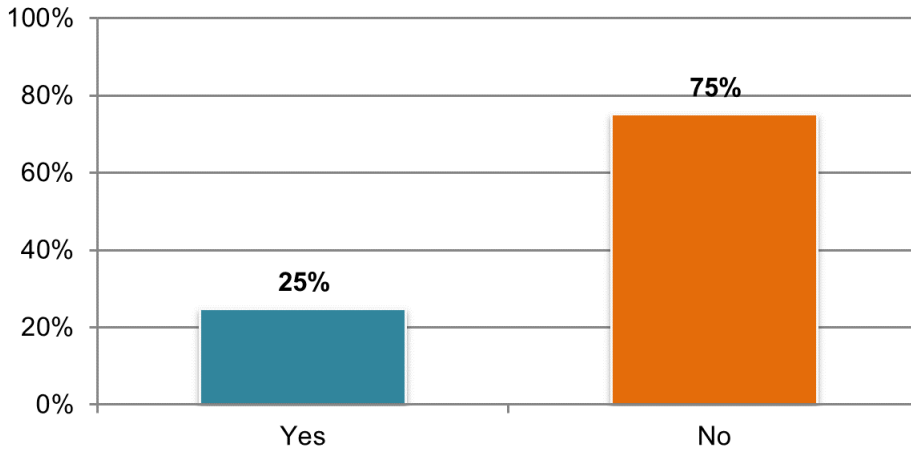


Table Q50. Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?⁵

State	Yes	No	N
Significantly Above Average			
OR	38%	63%	160
SC	36%	64%	165
Within Average Range			
NC	28%	72%	181
VA	25%	75%	165
MO	24%	76%	307
TX	21%	79%	386
Significantly Below Average			
LA	16%	84%	268
UT	11%	89%	255
NCI Average	25%	75%	1,887

⁵ The 'yes' response is the less desired response.

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

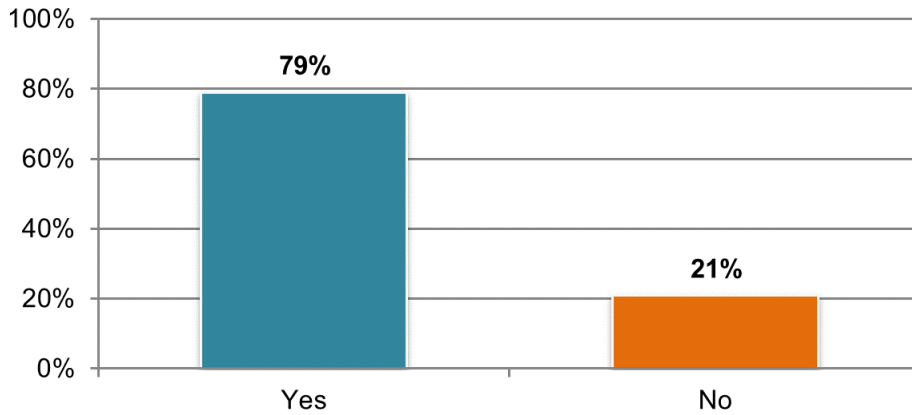


Table Q50a. If services or supports received by your family were reduced, suspended, or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family negatively?⁶

State	Yes	No	N
Significantly Above Average			
TX	92%	8%	77
Within Average Range			
VA	90%	10%	39
OR	85%	15%	48
NC	82%	18%	45
SC	78%	22%	55
MO	77%	23%	56
UT	74%	26%	23
Significantly Below Average			
LA	54%	46%	37
NCI Average	79%	21%	380

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

II. NCI History and Activities

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

Overview of National Core Indicators

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

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

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

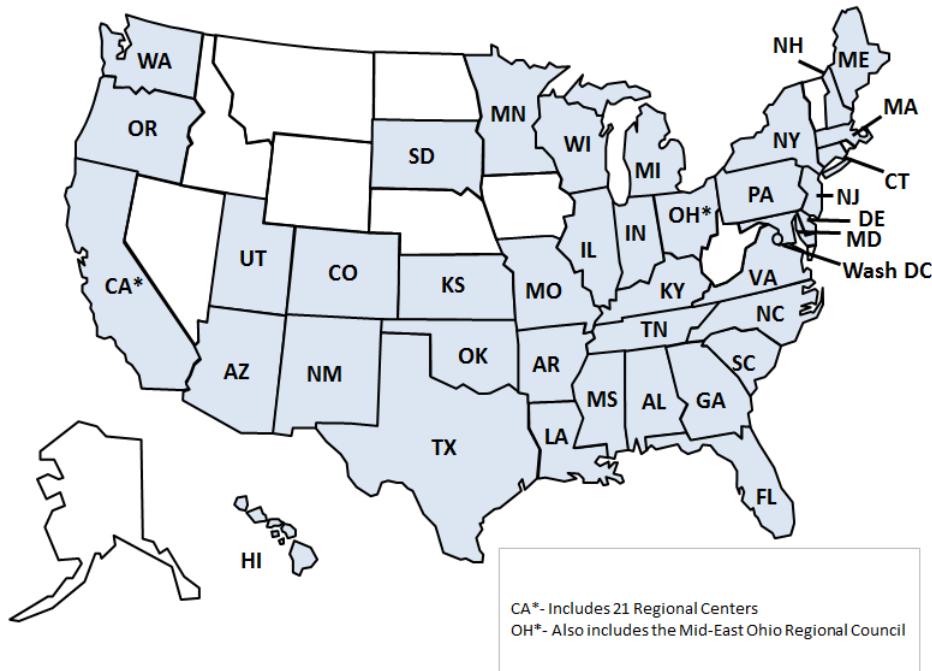
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

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

State Participation

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

NCI State Participation 2013-14



Sub-Domains and Concern Statements

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

Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

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

Cautions and Limitations

This report does not provide benchmarks for acceptable or unacceptable levels of performance. Rather, it is up to each state to decide whether its score or percentage is acceptable. States that fall into the “below average” tier on any scale or indicator are not necessarily underperforming; instead, this placement indicates only that the state’s scale score or indicator percentage is significantly lower than the average of all states—where “significantly” means “not due to chance.” The results tables throughout this report display states’ scores relative to one another and show

which states tend to have similar results. Notably, the difference between a “below average” state and the average across the other states may be very small, and it is up to public managers, policy-makers, and other stakeholders to decide whether a state’s result relative to the NCI Average suggests that changes or further investigation are necessary.

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

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

III. Methodology

This section describes the protocol used by states to select families to participate in the survey, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by NCI Program 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 child⁷ 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 no greater than +/- 7%.⁸

Data Entry and Analysis

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

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

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

⁷ “Child” is defined as an individual age 18 or younger with a disability; however, a Child Family Survey could be completed for an individual up to 22 years if they were still receiving “child” services.

⁸ 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 average⁹; significance is shown at the .01 level and cited in tables. Demographic data and data on services received were not tested for statistically significant differences.

Response Rates

During 2013-2014, eight 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% margin of error; their data are included in this report. The table below shows the number of surveys each state mailed, the number of usable surveys returned, and the response rates.

Child Family Survey: State Response Rates

State ¹⁰	Surveys Mailed ¹¹	Usable Surveys Returned	Response Rate
LA	1,500	322	22%
MO	1,800	403	22%
NC	1,400	198	14%
OR	1,719	198	12%
SC	1,200	194	16%
UT	734	284	39%
VA	844	182	22%
NCI Average			21%

¹⁰ Information was not available for TX.

¹¹ Some numbers may be approximates.