

# Child Family Survey

2018-19 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 (HSRI)**

2336 Massachusetts Avenue  
Cambridge, MA 02140



**National Association of State Directors of Developmental Disabilities Services (NASDDDS)**

301 N Fairfax Street, Suite 101  
Alexandria, VA 22314

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Updated 3/5/2020: changed N in table 10  
Updated 3/27 column labels table 1

## **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.<sup>1</sup> Not all states that participate in NCI administer the Child Family Survey on an annual basis. Of the 46 states, District of Columbia, and 22 sub-state entities who participated in NCI during the 2018-19 data collection cycle, 12 states submitted a valid sample of Child Family Survey data: Arizona (AZ), California (CA), Colorado (CO), Louisiana (LA), Minnesota (MN), Missouri (MO), North Carolina (NC), Ohio (OH), Oregon (OR), South Dakota (SD), Washington (WA) and Wisconsin (WI). This Final Report provides a summary of results based on data submitted by June 30, 2019.

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.

**Note:** *All qualified Californians with a developmental disability have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. California law mandates that the intake process begin within 15 days of an individual's or family's request for services and that the Department of Developmental Services begin providing services within 120 days after intake. These statutory requirements make California's service system unique and could impact comparisons between its survey results and the results of other states.*

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<sup>1</sup> A Child Family Survey could be completed for an individual up to 22 years if still receiving "child" services.

**Respondents**

Family members and/or guardians of a child who has I/DD who lives in their home and receives at least one public service in addition to case management from the state DD agency.

**14%**

are under  
age 35

**33%**

say they or a  
family  
member  
provide paid  
support

**39%**

always have  
the respite  
services they  
need

**39%**

reported an annual  
household income of \$25K or  
less

**73%**

reported services and  
supports reduced out-of-  
pocket expenses related to  
care for their family member

**Child with IDD....****69%**

male

**11**

average age

**81%**

child takes part in  
community activities

**88%**

child spends time with  
children without DD

**81%**

have resources in the  
community the family  
can use

**21%**

take part in family-to-  
family networks



## 2018-19 Child Family Survey

**14,816**  
families  
participated  
across  
**12**  
states\*

### NCI Averages:

- Include all participating states
- Data are weighted

\*AZ, CA, CO, LA,  
MN, MO, NC, OH,  
OR, SD, WA, WI



**50%**  
family can *always* choose or change the agency that provides services



**50%**  
family can *always* choose or change their child's support workers



**73%**  
child's service providers work together to provide support

## 2018-19 Child Family Survey

# Results

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

## Presentation of Data

In addition to basic demographic questions and questions on services and supports received, 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 four possible responses ("always," "usually," "sometimes," "seldom/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.

Demographic results are shown in table form with states listed alphabetically. Outcomes are shown first with a chart depicting the NCI Average. The charts are followed by accessible tables showing state outcomes and the NCI Average listed in descending order, grouped by level of significance.

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 with fewer than 20 respondents to a question **are not** included in tables; however, their data **are** included in the NCI Average.

**Note on Significance:** Statistical significance depends on both the amount by which a state differs from the average for a given item and the state's sample size for that item. So, there may be instances where State A's difference from the average is larger than State B's, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.

**Note on NCI Averages:** The NCI averages contained in this report are "weighted" means; their calculations reflect the relative population sizes of participating states, as well as the states' sample sizes. Prior to 2016-17, NCI averages were calculated as the simple arithmetic mean of all state means (an approach known as "average of averages"), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.

**Note on language used in this report:** "You" and "Respondent" refers to the person (usually a parent or guardian) filling out the survey. "Child" refers to the person receiving services whom the respondent is answering questions about in this survey.

**Note on responses:** All data are reported by the respondent based on their understanding of the child's demographics, diagnoses and personal characteristics.

# Demographics

**Note on responses:** All data are reported by the respondent based on their understanding of the child's demographics, diagnoses and personal characteristics.

## *Child*

*This section provides demographic information about the child for whom the survey was completed.*

Table 1. More Than One Child Living in the Home Has IDD

State	Yes	No	N
AZ	26%	74%	170
CA	25%	75%	10,288
CO	29%	71%	191
LA	23%	77%	400
MN	30%	70%	422
MO	24%	76%	242
NC	21%	79%	200
OH	28%	72%	260
OR	23%	77%	657
SD	16%	84%	281
WA	25%	75%	293
WI	22%	78%	896
<b>NCI Average</b>	<b>26%</b>	<b>74%</b>	<b>14,300</b>

Table 2. Child's Age

State	Age	N
AZ	9.5	166
CA	11.0	10,267
CO	11.3	195
LA	6.5	403
MN	12.0	415
MO	11.2	242
NC	14.6	199
OH	11.1	268
OR	11.5	663
SD	12.1	283
WA	10.9	287
WI	10.8	986
<b>NCI Average</b>	<b>10.9</b>	<b>14,374</b>

Table 3. Child's Gender

State	Male	Female	N
AZ	64%	36%	167
CA <sup>2</sup>	72%	28%	10,276
CO	62%	38%	195
LA	61%	39%	401
MN	67%	33%	416
MO	76%	24%	241
NC	62%	38%	200
OH	68%	32%	260
OR	67%	33%	654
SD	66%	34%	283
WA	62%	38%	289
WI	67%	33%	946
<b>NCI Average</b>	<b>69%</b>	<b>31%</b>	<b>14,329</b>

Table 4a. Child's Disabilities

Reminder: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
AZ	39%	17%	57%	12%	9%	5%
CA	35%	10%	69%	10%	6%	4%
CO	68%	21%	60%	21%	18%	8%
LA	31%	11%	28%	13%	9%	6%
MN	49%	25%	56%	9%	7%	6%
MO	32%	22%	88%	9%	5%	3%
NC	62%	25%	61%	20%	11%	3%
OH	37%	24%	51%	11%	5%	4%
OR	49%	23%	53%	10%	6%	5%
SD	46%	13%	38%	14%	8%	3%
WA	44%	15%	54%	10%	11%	8%
WI	45%	20%	51%	10%	7%	5%
<b>NCI Average</b>	<b>38%</b>	<b>16%</b>	<b>61%</b>	<b>11%</b>	<b>6%</b>	<b>4%</b>

<sup>2</sup> CA added response option "other"; those (5) cases are not included in these data.

**Table 4b. Child's Disabilities (continued)**

Reminder: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
AZ	6%	19%	2%	12%	0%	1%	28%
CA	5%	14%	0%	9%	0%	1%	17%
CO	15%	43%	1%	6%	0%	4%	45%
LA	9%	21%	2%	9%	1%	1%	30%
MN	7%	24%	0%	13%	1%	4%	34%
MO	5%	18%	0%	2%	0%	0%	26%
NC	7%	25%	1%	16%	1%	1%	20%
OH	5%	20%	0%	9%	1%	3%	36%
OR	8%	21%	1%	12%	0%	8%	30%
SD	10%	26%	0%	24%	1%	2%	31%
WA	6%	20%	1%	14%	0%	1%	27%
WI	9%	22%	0%	14%	1%	3%	28%
NCI Average	6%	18%	1%	10%	1%	2%	24%

**Table 5a. Child's Health Conditions**

Reminder: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	13%	5%	2%	2%	3%
CA	12%	3%	3%	4%	7%
CO	13%	1%	1%	3%	3%
LA	15%	1%	3%	6%	4%
MN	20%	5%	5%	3%	2%
MO	15%	3%	1%	1%	4%
NC	9%	3%	1%	4%	5%
OH	10%	6%	1%	3%	3%
OR	13%	5%	2%	2%	6%
SD	16%	5%	5%	7%	3%
WA	11%	2%	3%	1%	3%
WI	16%	2%	3%	5%	5%
NCI Average	13%	4%	2%	4%	5%

**Table 5b. Child's Health Conditions (continued)**

Reminder: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Dysphagia	Pressure Ulcers	Oral Health or Dental Problems	Sleep Apnea	Other
AZ	18%	0%	8%	13%	52%
CA	12%	1%	13%	24%	45%
CO	43%	1%	10%	43%	35%
LA	20%	2%	12%	26%	51%
MN	20%	1%	18%	23%	47%
MO	15%	0%	14%	24%	51%
NC	25%	0%	14%	26%	49%
OH	15%	2%	18%	23%	41%
OR	27%	1%	16%	30%	36%
SD	16%	0%	6%	38%	41%
WA	30%	2%	19%	31%	37%
WI	21%	2%	16%	23%	46%
NCI Average	17%	1%	14%	24%	45%

**Table 6. Child's Race and Ethnicity**

Reminder: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	American Indian or Alaska Native	Asian	Black or African American	Hawaiian or Pacific Islander	White	Hispanic or Latino	Other
AZ	4%	8%	6%	0%	60%	37%	4%
CA	2%	20%	8%	1%	36%	48%	3%
CO	2%	9%	11%	1%	80%	14%	2%
LA	2%	2%	28%	0%	71%	5%	1%
MN	5%	7%	16%	0%	74%	10%	2%
MO	5%	2%	10%	0%	88%	7%	0%
NC	4%	5%	20%	0%	74%	5%	1%
OH	2%	6%	12%	0%	85%	5%	2%
OR	5%	8%	5%	2%	84%	14%	1%
SD	9%	2%	4%	0%	89%	4%	0%
WA	4%	19%	5%	2%	62%	22%	2%
WI	4%	4%	9%	0%	84%	9%	1%
NCI Average	3%	13%	9%	1%	57%	30%	2%

Table 7. Child's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AZ	55%	26%	6%	8%	5%	170
CA	71%	18%	3%	4%	5%	10,255
CO	49%	23%	4%	14%	10%	195
LA	53%	33%	4%	3%	8%	401
MN	73%	17%	1%	7%	3%	380
MO	75%	15%	0%	5%	5%	234
NC	69%	20%	2%	6%	4%	200
OH	79%	12%	0%	6%	3%	251
OR	68%	18%	3%	6%	4%	659
SD	68%	23%	2%	5%	2%	264
WA	57%	21%	4%	11%	7%	294
WI	62%	22%	3%	8%	6%	960
NCI Average	69%	18%	3%	5%	5%	14,263

Table 8. Child's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

**Reminder:** All data are reported by the respondent based on their understanding of the child's demographics, diagnoses and personal characteristics

State	None	Some	Extensive	N
AZ	33%	46%	20%	162
CA	26%	44%	30%	10,217
CO	14%	24%	62%	191
LA	58%	29%	14%	392
MN	21%	42%	38%	413
MO	34%	48%	18%	243
NC	35%	37%	27%	198
OH	43%	38%	18%	260
OR	22%	47%	31%	652
SD	38%	49%	13%	281
WA	27%	40%	34%	289
WI	38%	40%	22%	961
NCI Average	31%	42%	26%	14,259

**Table 9. Child's Level of Help Needed With Personal Care Activities**

**Reminder:** All data are reported by the respondent based on their understanding of the child's demographics, diagnoses and personal characteristics

State	None	Some	Extensive	N
AZ	8%	37%	54%	167
CA	8%	42%	50%	10,425
CO	0%	13%	87%	196
LA	7%	36%	56%	403
MN	4%	34%	63%	421
MO	13%	50%	38%	245
NC	4%	47%	50%	200
OH	13%	53%	34%	264
OR	5%	41%	55%	660
SD	6%	48%	47%	282
WA	2%	34%	64%	297
WI	5%	44%	51%	975
<b>NCI Average</b>	<b>8%</b>	<b>43%</b>	<b>49%</b>	<b>14,535</b>

## *Respondents*

*This section provides demographic information about the respondent.*

**Table 10. Language usually spoken at home**

New question in 2018-19

State	English	Spanish	Other	N
AZ	82%	11%	7%	167
CA	64%	25%	11%	10,472 <sup>3</sup>
CO	93%	3%	4%	197
LA	97%	2%	1%	409
MN	91%	4%	5%	412
MO	97%	1%	2%	247
NC	98%	1%	1%	201
OH	95%	2%	4%	263
OR	91%	4%	5%	672
SD	99%	1%	1%	285
WA	69%	17%	13%	298
WI	96%	2%	2%	980
<b>NCI Average</b>	<b>78%</b>	<b>15%</b>	<b>8%</b>	<b>14,603<sup>4</sup></b>

**Table 11. Respondent's Age**

State	Under 35	35-54	55-74	75 and Older	N
AZ	18%	67%	14%	1%	169
CA	12%	76%	11%	0%	10,491
CO	10%	76%	15%	0%	196
LA	35%	55%	10%	0%	410
MN	12%	76%	12%	0%	427
MO	15%	79%	5%	0%	247
NC	8%	70%	22%	1%	199
OH	14%	69%	16%	0%	264
OR	11%	71%	17%	1%	675
SD	19%	69%	12%	0%	288
WA	15%	71%	14%	1%	299
WI	15%	70%	14%	1%	984
<b>NCI Average</b>	<b>14%</b>	<b>73%</b>	<b>13%</b>	<b>0%</b>	<b>14,649</b>

<sup>3</sup> Edited 3/5/2020<sup>4</sup> Edited 3/5/2020

Table 12. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
AZ	24%	49%	25%	2%	170
CA	21%	49%	27%	3%	10,485
CO	20%	50%	29%	1%	195
LA	25%	46%	26%	2%	411
MN	19%	50%	28%	4%	422
MO	19%	46%	31%	4%	246
NC	17%	51%	30%	3%	198
OH	18%	50%	29%	4%	262
OR	18%	46%	32%	3%	676
SD	19%	51%	29%	1%	286
WA	12%	38%	44%	6%	301
WI	19%	49%	29%	3%	981
<b>NCI Average</b>	<b>20%</b>	<b>49%</b>	<b>28%</b>	<b>3%</b>	<b>14,633</b>

Table 13. Respondent's Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
AZ	94%	0%	4%	2%	169
CA	96%	0%	3%	1%	10,532
CO	97%	0%	2%	0%	195
LA	92%	0%	6%	1%	409
MN	97%	0%	3%	0%	427
MO	99%	0%	1%	0%	247
NC	95%	0%	3%	2%	200
OH	90%	0%	8%	1%	265
OR	93%	0%	5%	1%	675
SD	97%	0%	2%	0%	288
WA	96%	0%	3%	1%	298
WI	94%	0%	4%	2%	982
<b>NCI Average</b>	<b>95%</b>	<b>0%</b>	<b>4%</b>	<b>1%</b>	<b>14,687</b>

Table 14. Respondent or Other Family Member Provides Paid Support to Child

State	No	Respondent	Other Family Member	N
AZ	79%	4%	17%	168
CA	55%	32%	14%	10,326
CO	41%	51%	11%	196
LA	89%	5%	6%	407
MN	30%	54%	28%	427
MO	91%	3%	6%	245
NC	80%	6%	14%	201
OH	90%	5%	6%	261
OR	68%	5%	28%	671
SD	84%	4%	13%	285
WA	81%	5%	15%	295
WI	80%	6%	14%	977
<b>NCI Average</b>	<b>68%</b>	<b>20%</b>	<b>13%</b>	<b>14,459</b>

Table 15. Number of Adults in Household

State	One	Two	Three	Four or More	N
AZ	17%	59%	16%	8%	169
CA	16%	58%	18%	9%	10,436
CO	20%	62%	13%	5%	193
LA	25%	65%	6%	3%	408
MN	18%	61%	15%	6%	427
MO	21%	64%	13%	2%	247
NC	22%	57%	17%	4%	200
OH	19%	61%	14%	5%	264
OR	17%	64%	14%	5%	672
SD	12%	64%	19%	5%	286
WA	16%	62%	15%	6%	299
WI	16%	64%	15%	6%	978
<b>NCI Average</b>	<b>17%</b>	<b>60%</b>	<b>16%</b>	<b>7%</b>	<b>14,579</b>

**Table 16. Number of Children in Household (including child receiving services about whom survey is being completed)**

State	One	Two	Three	Four or More	N
AZ	30%	36%	19%	15%	162
CA	35%	40%	18%	8%	10,255
CO	32%	37%	20%	10%	191
LA	36%	34%	19%	11%	403
MN	35%	36%	18%	11%	420
MO	36%	36%	20%	8%	242
NC	58%	28%	8%	6%	184
OH	32%	39%	19%	11%	264
OR	36%	37%	16%	10%	661
SD	36%	32%	21%	12%	270
WA	31%	38%	19%	12%	298
WI	34%	39%	17%	10%	947
<b>NCI Average</b>	<b>34%</b>	<b>38%</b>	<b>18%</b>	<b>10%</b>	<b>14,297</b>

**Table 17. Respondent's Highest Level of Education**

State	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
AZ	10%	13%	6%	22%	48%	165
CA	15%	18%	7%	18%	42%	10,435
CO	1%	7%	6%	14%	71%	194
LA	7%	19%	9%	17%	48%	410
MN	7%	17%	11%	19%	47%	418
MO	5%	11%	7%	19%	59%	242
NC	6%	17%	7%	18%	52%	201
OH	5%	20%	3%	21%	50%	266
OR	7%	14%	5%	22%	51%	667
SD	4%	17%	16%	14%	48%	286
WA	12%	18%	4%	21%	45%	297
WI	3%	16%	11%	18%	52%	984
<b>NCI Average</b>	<b>11%</b>	<b>17%</b>	<b>7%</b>	<b>19%</b>	<b>46%</b>	<b>14,565</b>

Table 18. Total Taxable Household Income of Wage Earners in the Past Year

State	No Earned Income	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	Prefer Not to Say	N
AZ	9%	10%	14%	15%	29%	8%	15%	162
CA	8%	14%	20%	11%	27%	5%	15%	10,286
CO	2%	8%	20%	15%	34%	1%	19%	195
LA	14%	12%	14%	14%	22%	8%	16%	405
MN	8%	9%	25%	22%	27%	4%	5%	416
MO	10%	11%	21%	17%	29%	6%	6%	244
NC	6%	13%	21%	14%	28%	10%	10%	200
OH	11%	11%	19%	16%	27%	7%	9%	263
OR	7%	10%	17%	15%	33%	8%	10%	661
SD	6%	11%	21%	18%	29%	5%	10%	284
WA	6%	10%	19%	15%	27%	9%	14%	298
WI	7%	7%	17%	18%	34%	5%	12%	975
<b>NCI Average</b>	<b>9%</b>	<b>12%</b>	<b>19%</b>	<b>14%</b>	<b>28%</b>	<b>6%</b>	<b>13%</b>	<b>14,389</b>

Table 19. Residential Designation (Urban, Rural, or Suburban)

State	Urban or Suburban	Rural	N
AZ	84%	16%	160
CA	92%	8%	9,557
CO	89%	11%	192
LA	62%	38%	376
MN	76%	24%	412
MO	71%	29%	242
NC	55%	45%	195
OH	65%	35%	259
OR	76%	24%	660
SD	66%	34%	280
WA	74%	26%	281
WI	66%	34%	946
<b>NCI Average</b>	<b>81%</b>	<b>19%</b>	<b>13,560</b>

## *Services and Supports Received*

*This section provides information about the services and supports received by the family from the state ID/DD agency.*

**Table 20. Services and Supports Received From IDD Agency**

Reminder: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Financial Support	In-home Support	Out-of-home Respite	Early Intervention	Transportation	Other	Self-direction or Fiscal Intermediary Services
AZ	9%	60%	40%	22%	25%	91%	24%
CA	13%	38%	32%	1%	5%	24%	13%
CO	34%	63%	49%	4%	25%	92%	38%
LA	19%	41%	8%	56%	15%	74%	29%
MN	55%	57%	27%	15%	37%	81%	73%
MO	31%	32%	21%	7%	19%	82%	33%
NC	16%	83%	52%	7%	30%	71%	29%
OH	41%	17%	16%	9%	18%	80%	20%
OR	19%	74%	50%	7%	30%	72%	61%
SD	67%	13%	43%	14%	31%	77%	45%
WA	25%	52%	36%	9%	21%	72%	44%
WI	41%	37%	47%	18%	22%	74%	32%
NCI Average	22%	39%	31%	12%	14%	54%	24%

**Table 21. Other Services or Supports Received**

Reminder: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Social Security Payments (SSI/SSB)	Services or Supports from Other Agencies or Organizations
AZ	33%	76%
CA	37%	63%
CO	25%	78%
LA	33%	39%
MN	39%	85%
MO	37%	83%
NC	46%	73%
OH	36%	78%
OR	37%	75%
SD	39%	80%
WA	35%	67%
WI	31%	75%
NCI Average	36%	69%

# Child Family Survey Results

**Note on Significance:** Statistical significance depends on both the amount by which a state differs from the average for a given item and the state's sample size for that item. There may be instances where State A's difference from the average is larger than State B's, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.

## *Information and Planning*

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

**Note: Significance is based on “Always” or “Yes” response.**

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

**“Child”** refers to the person receiving services whom the respondent is answering questions about in this survey.

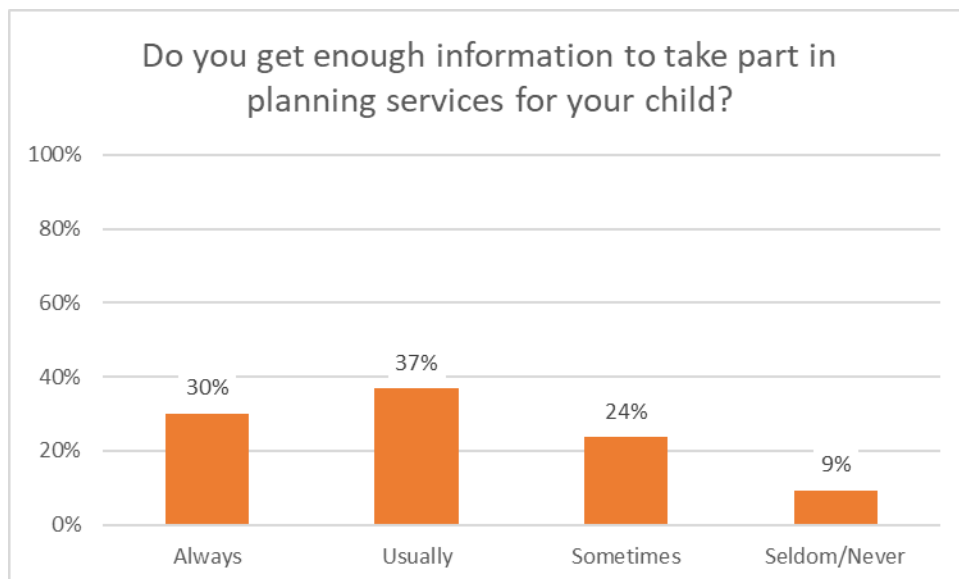


Table Q1. Do you get enough information to take part in planning services for your child?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	43%	33%	18%	6%	383
NC	41%	37%	16%	6%	196

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	40%	40%	17%	3%	162
SD	37%	46%	15%	2%	276
OR	35%	43%	17%	4%	652
MN	32%	40%	21%	8%	409
WI	31%	41%	23%	5%	940
OH	30%	40%	22%	8%	244
<b>NCI Average</b>	<b>30%</b>	<b>37%</b>	<b>24%</b>	<b>9%</b>	<b>13,545</b>
MO	28%	41%	19%	12%	235
CA	27%	33%	27%	13%	9,584
CO	23%	47%	25%	5%	185

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
WA	23%	38%	29%	10%	279

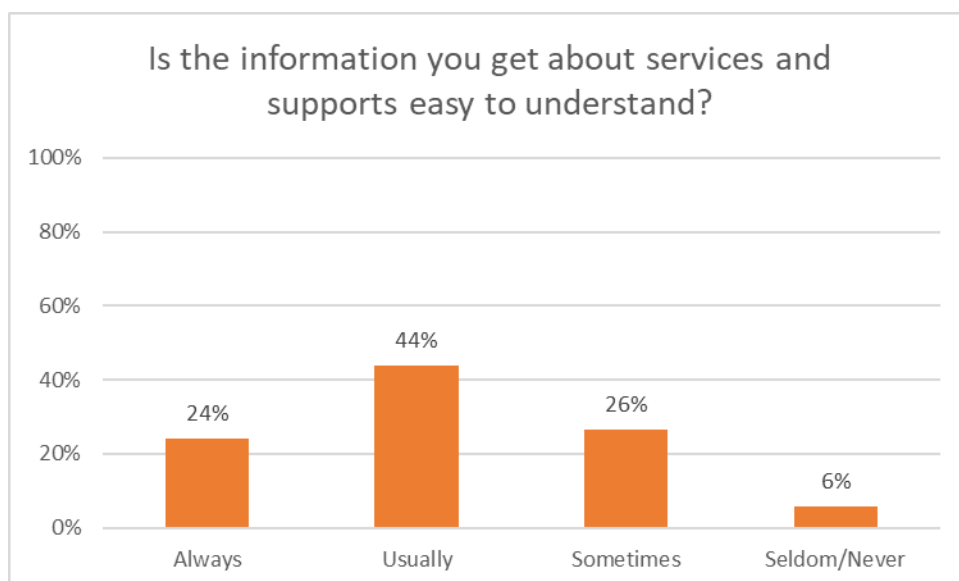


Table Q2. Is the information you get about services and supports easy to understand?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	35%	42%	20%	3%	389

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	31%	46%	21%	2%	171
SD	30%	53%	15%	3%	280
CA	25%	42%	27%	6%	9,749
<b>NCI Average</b>	<b>24%</b>	<b>44%</b>	<b>26%</b>	<b>6%</b>	<b>13,765</b>
OR	22%	52%	22%	4%	664
NC	21%	47%	25%	7%	197
WI	21%	45%	28%	6%	947
OH	20%	48%	27%	6%	244
MN	19%	41%	31%	9%	417
MO	18%	48%	29%	4%	233
CO	17%	42%	33%	8%	185

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
WA	14%	41%	37%	8%	289

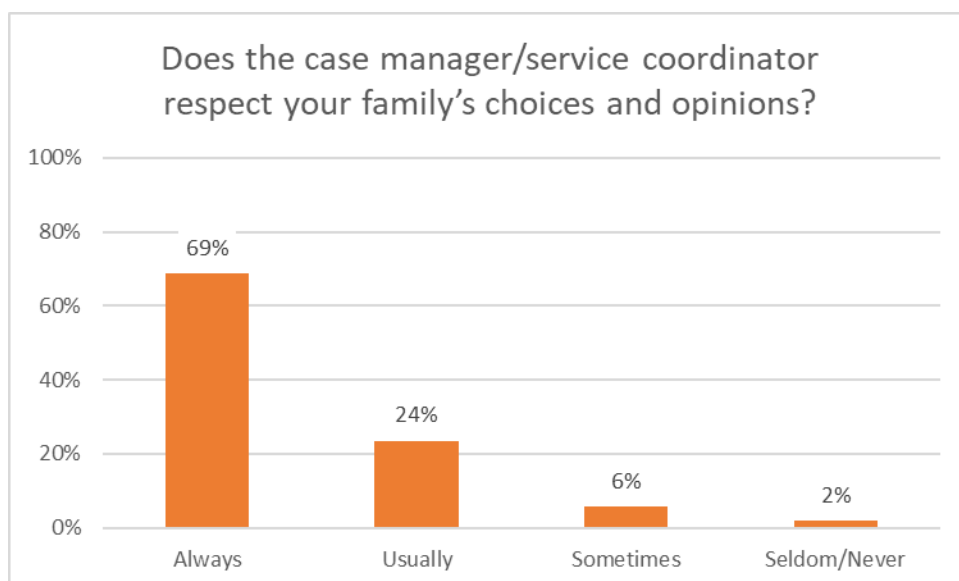


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	80%	18%	2%	0%	270
WA	77%	19%	3%	1%	280
LA	77%	19%	3%	1%	376
OR	76%	18%	5%	1%	661

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	77%	18%	5%	0%	166
MO	71%	22%	5%	2%	235
WI	70%	23%	6%	1%	946
CO	69%	28%	2%	1%	180
<b>NCI Average</b>	<b>69%</b>	<b>24%</b>	<b>6%</b>	<b>2%</b>	<b>13,829</b>
NC	68%	26%	5%	1%	189
CA	66%	25%	7%	2%	9,931
MN	65%	25%	8%	2%	399
OH	65%	26%	6%	4%	196

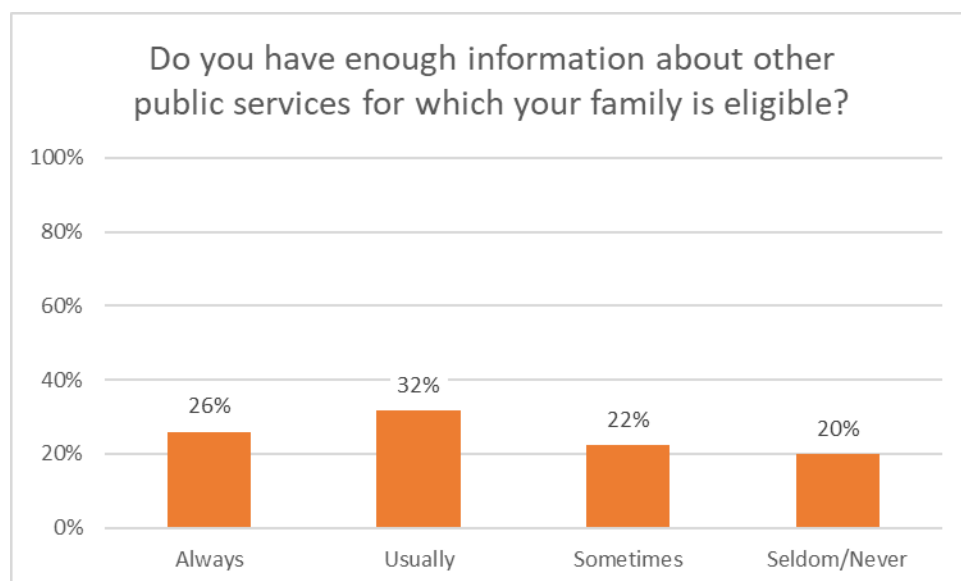


Table Q4. Do you have enough information about other public services for which your family is eligible?

#### Significantly Above Average

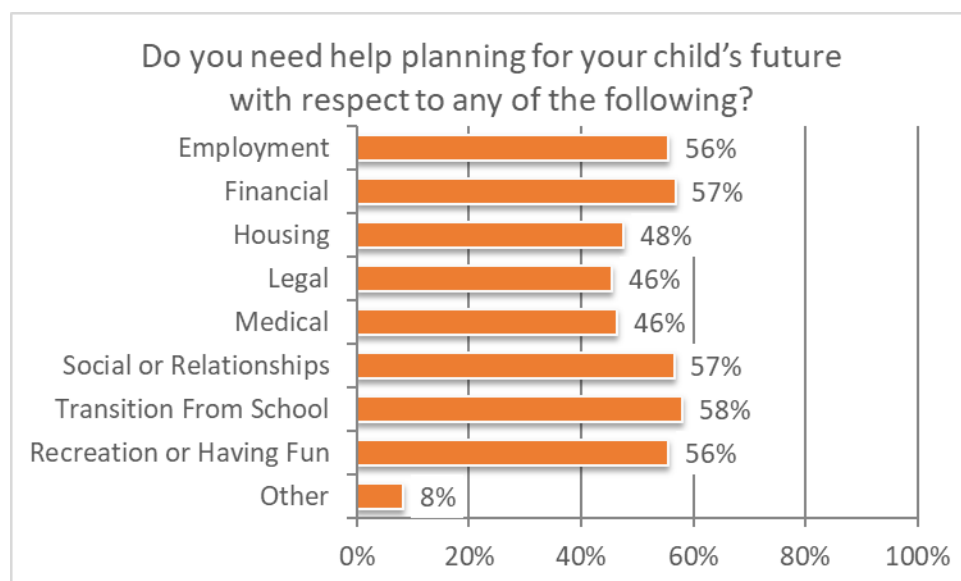
State	Always	Usually	Sometimes	Seldom or Never	N
SD	35%	41%	18%	6%	238
LA	35%	27%	19%	19%	313

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OH	30%	30%	23%	17%	201
MO	29%	29%	20%	22%	195
AZ	27%	31%	21%	21%	135
NCI Average	26%	32%	22%	20%	11,920
MN	26%	37%	20%	17%	354
OR	26%	37%	24%	13%	544
CA	25%	31%	22%	22%	8,618
WI	24%	37%	23%	16%	784
NC	23%	38%	23%	17%	155
WA	21%	37%	26%	17%	235

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CO	16%	36%	28%	20%	148



**Table Q5. Do you need help planning for your child's future with respect to any of the following?**

Categories are not mutually exclusive, therefore N is not shown

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition From School	Recreation or Having Fun	Other
AZ	55%	59%	46%	46%	48%	56%	58%	51%	4%
CA	54%	54%	48%	44%	46%	59%	56%	58%	9%
CO	55%	67%	61%	63%	57%	57%	69%	59%	11%
LA	33%	49%	27%	38%	42%	40%	53%	40%	14%
MN	62%	65%	59%	52%	48%	56%	64%	60%	7%
MO	60%	62%	47%	46%	48%	62%	58%	57%	9%
NC	56%	56%	48%	55%	38%	48%	64%	51%	7%
OH	58%	58%	41%	45%	43%	54%	59%	49%	9%
OR	60%	63%	55%	48%	44%	61%	64%	57%	6%
SD	59%	56%	55%	40%	44%	45%	55%	44%	6%
WA	60%	62%	56%	48%	56%	56%	64%	60%	11%
WI	59%	64%	54%	50%	51%	56%	60%	59%	7%
<b>NCI Average</b>	<b>56%</b>	<b>57%</b>	<b>48%</b>	<b>46%</b>	<b>46%</b>	<b>57%</b>	<b>58%</b>	<b>56%</b>	<b>8%</b>

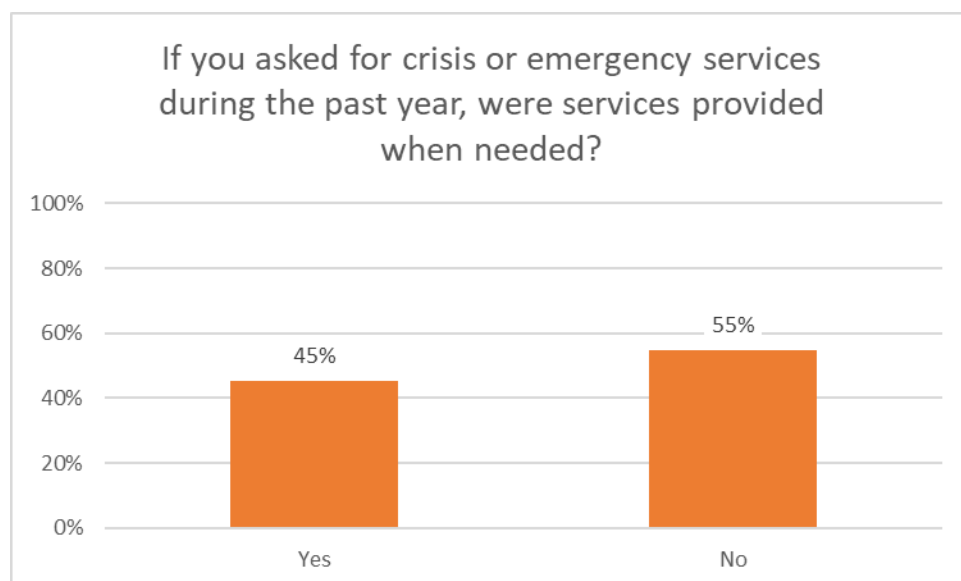


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

**Within Average Range**

State	Yes	No	N
MN	59%	41%	79
MO	59%	41%	41
CO	57%	43%	37
LA	56%	44%	77
NC	55%	45%	51
OR	51%	49%	123
SD	51%	49%	45
AZ	50%	50%	40
WI	49%	51%	174
OH	46%	54%	52
<b>NCI Average</b>	<b>45%</b>	<b>55%</b>	<b>3,383</b>
WA	44%	56%	72
CA	41%	59%	2,592

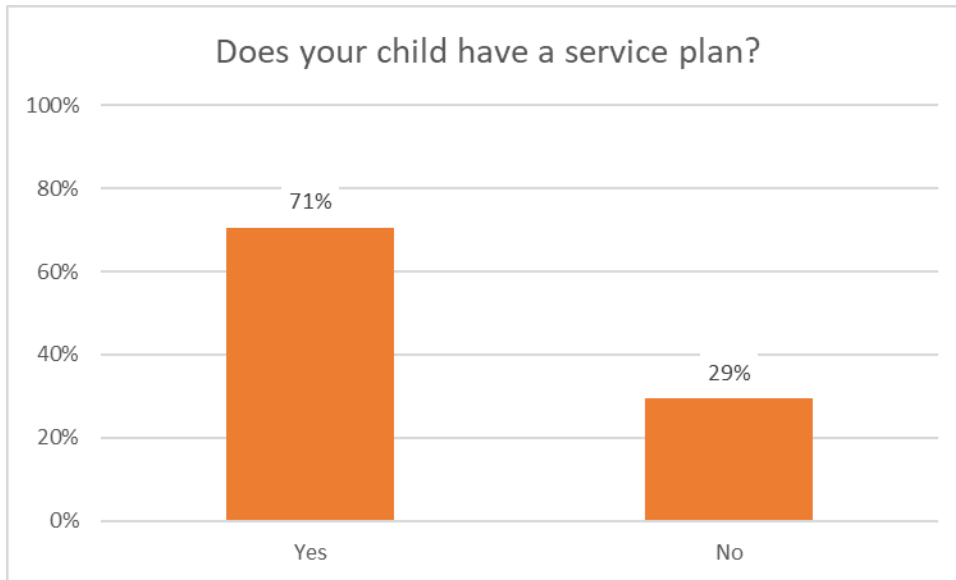


Table Q7. Does your child have a service plan?

**Significantly Above Average**

State	Yes	No	N
CO	88%	12%	182
OR	84%	16%	580
NC	82%	18%	177
CA	78%	22%	8,757

**Within Average Range**

State	Yes	No	N
AZ	77%	23%	143
MO	74%	26%	212
SD	74%	26%	236
WI	72%	28%	830
<b>NCI Average</b>	<b>71%</b>	<b>29%</b>	<b>12,219</b>
MN	69%	31%	360

**Significantly Below Average**

State	Yes	No	N
LA	55%	45%	318
WA	53%	47%	202
OH	46%	54%	222

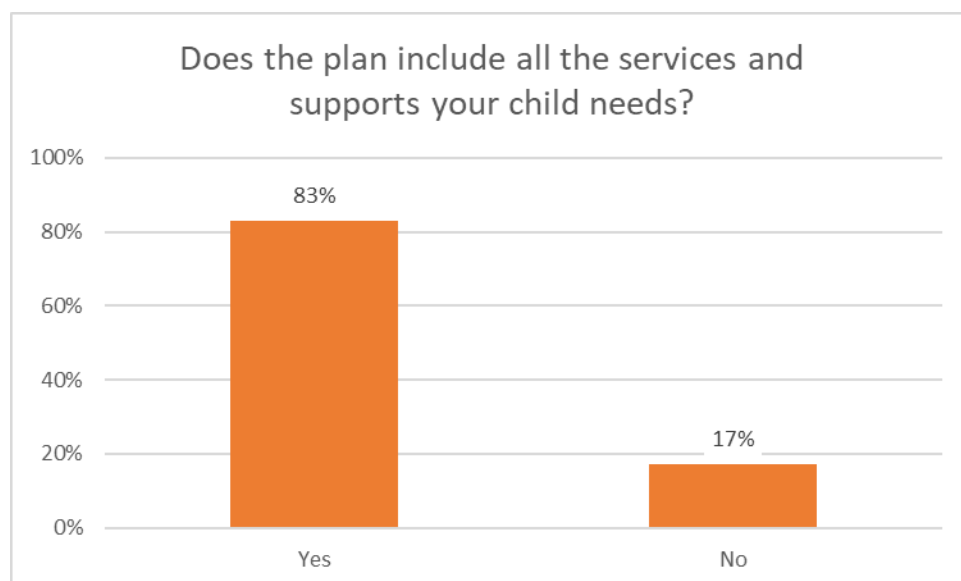


Table Q8. Does the plan include all the services and supports your child needs?

#### Significantly Above Average

State	Yes	No	N
SD	94%	6%	155
AZ	91%	9%	98
LA	90%	10%	160

#### Within Average Range

State	Yes	No	N
WA	90%	10%	89
MN	86%	14%	220
OR	86%	14%	431
NC	84%	16%	133
<b>NCI Average</b>	<b>83%</b>	<b>17%</b>	<b>7,494</b>
WI	83%	17%	520
OH	82%	18%	85
CA	81%	19%	5,317
MO	78%	22%	144

#### Significantly Below Average

State	Yes	No	N
CO	66%	34%	142

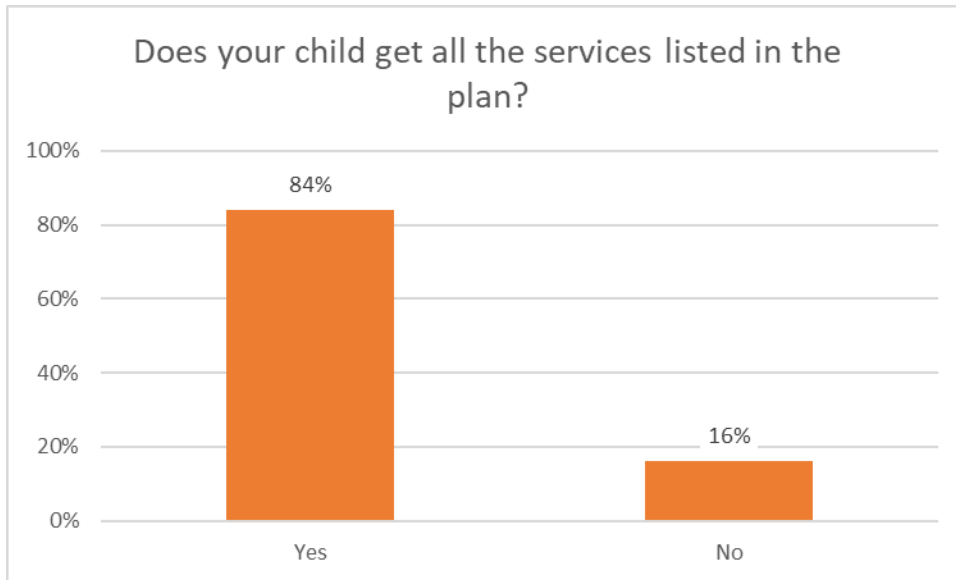


Table Q9. Does your child receive all of the services listed in the plan?

#### Significantly Above Average

State	Yes	No	N
SD	93%	7%	160
WI	89%	11%	537

#### Within Average Range

State	Yes	No	N
MN	88%	12%	212
CA	87%	13%	5,364
OR	85%	15%	435
LA	84%	16%	154
<b>NCI Average</b>	<b>84%</b>	<b>16%</b>	<b>7,547</b>
OH	84%	16%	79
NC	82%	18%	130
MO	82%	18%	141
WA	74%	26%	85
AZ	73%	27%	101

#### Significantly Below Average

State	Yes	No	N
CO	68%	32%	149

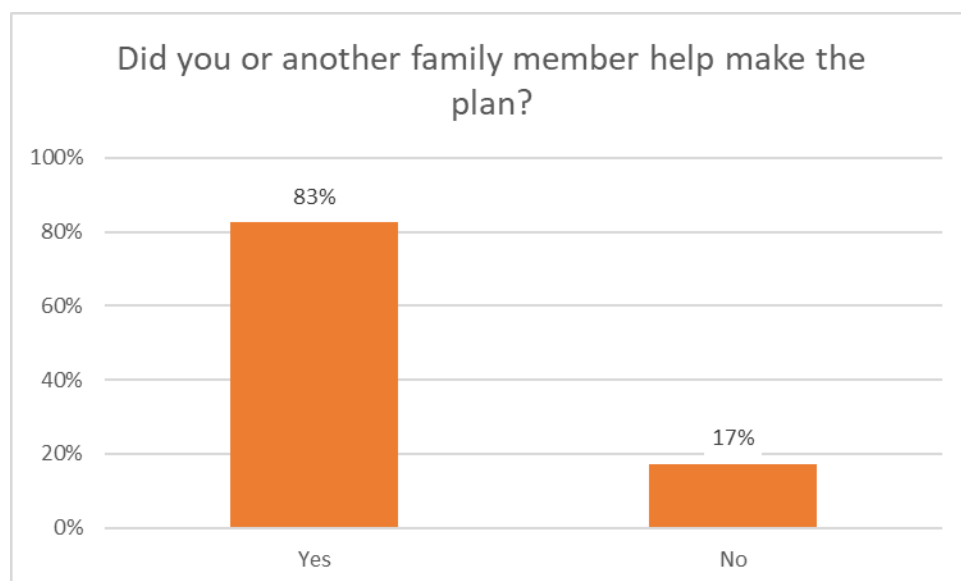


Table Q10. Did you or another family member help make the plan?

#### Significantly Above Average

State	Yes	No	N
SD	94%	6%	164
OR	93%	7%	468
MO	92%	8%	154
WI	92%	8%	571
NC	91%	9%	138
MN	90%	10%	236
CO	89%	11%	151

#### Within Average Range

State	Yes	No	N
OH	88%	12%	94
AZ	85%	15%	101
WA	84%	16%	97
NCI Average	83%	17%	8,207
LA	82%	18%	170

#### Significantly Below Average

State	Yes	No	N
CA	77%	23%	5,863

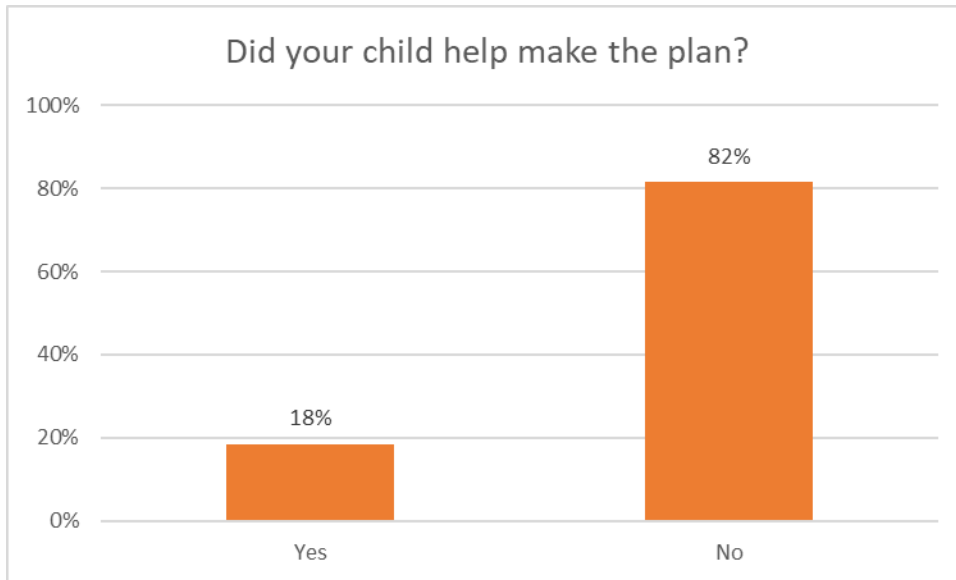


Table Q11. Did your child help make the plan?

**Within Average Range**

State	Yes	No	N
SD	27%	73%	166
MO	25%	75%	153
OH	25%	75%	97
OR	22%	78%	472
NC	22%	78%	142
MN	20%	80%	240
<b>NCI Average</b>	<b>18%</b>	<b>82%</b>	<b>8,224</b>
CA	18%	82%	5,847
WI	17%	83%	580
WA	15%	85%	97
AZ	13%	87%	104

**Significantly Below Average**

State	Yes	No	N
CO	8%	92%	156
LA	8%	92%	170

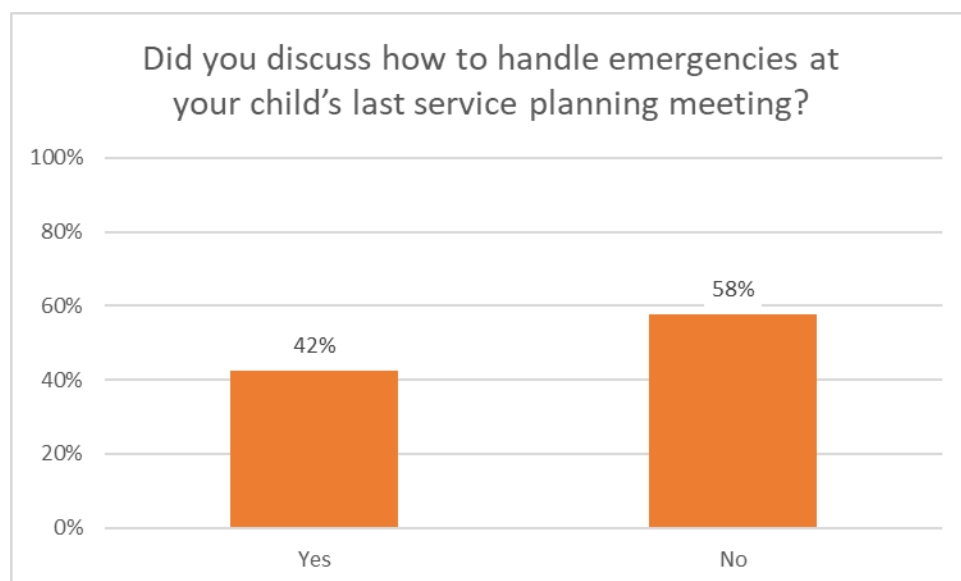


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your child's last service planning meeting?

#### Significantly Above Average

State	Yes	No	N
LA	69%	31%	153
SD	65%	35%	153
NC	63%	37%	136
WA	60%	40%	96
OR	53%	47%	424
MN	52%	48%	217

#### Within Average Range

State	Yes	No	N
MO	47%	53%	145
CO	46%	54%	136
NCI Average	42%	58%	7,672
OH	42%	58%	83
CA	41%	59%	5,499
AZ	32%	68%	98

#### Significantly Below Average

State	Yes	No	N
WI	36%	64%	532

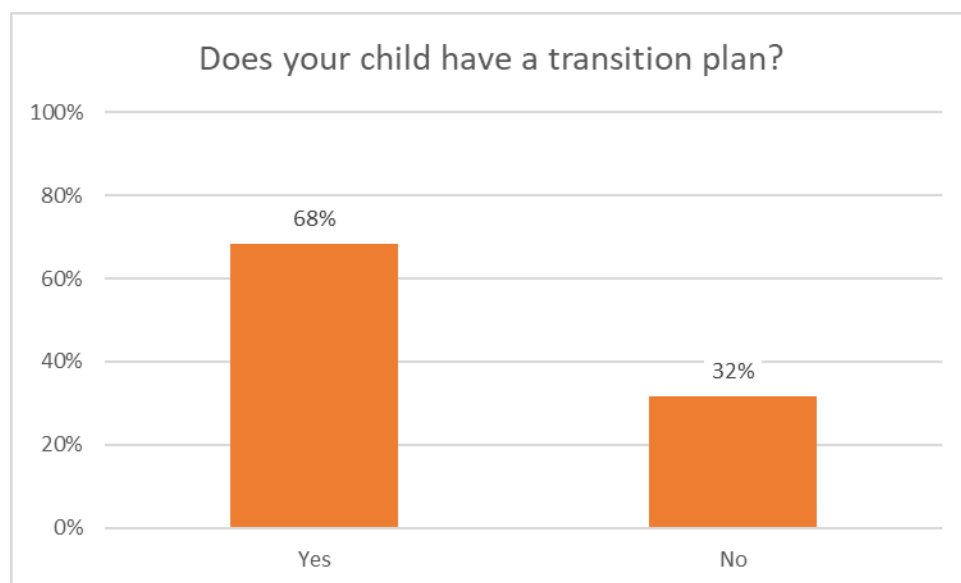


Table Q13. Does your child have a transition plan (as part of an IEP or Section 504 plan through his/her high school, usually starting at age 14)?

#### Significantly Above Average

State	Yes	No	N
WI	77%	23%	311

#### Within Average Range

State	Yes	No	N
OH	80%	20%	76
MN	71%	29%	147
CO	70%	30%	60
<b>NCI Average</b>	<b>68%</b>	<b>32%</b>	<b>4,165</b>
CA	66%	34%	2,873
AZ	63%	37%	46
SD	62%	38%	111
MO	62%	38%	68
WA	62%	38%	78
NC	58%	42%	124
LA	56%	44%	55

#### Significantly Below Average

State	Yes	No	N
OR	55%	45%	216

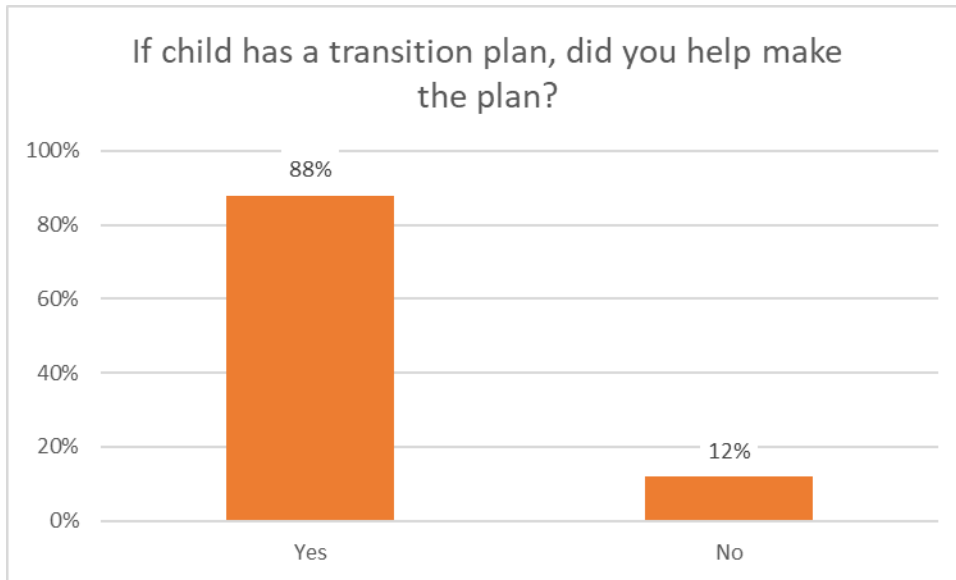


Table Q14. If your child has a transition plan, did you help make the plan?

#### Significantly Above Average

State	Yes	No	N
CO	98%	3%	40
NC	96%	4%	71

#### Within Average Range

State	Yes	No	N
SD	94%	6%	69
OH	93%	7%	59
AZ	93%	7%	28
MO	93%	7%	42
WI	89%	11%	233
<b>NCI Average</b>	<b>88%</b>	<b>12%</b>	<b>2,518</b>
MN	87%	13%	98
OR	85%	15%	110
LA	79%	21%	29
WA	77%	23%	44

#### Significantly Below Average

State	Yes	No	N
CA	84%	16%	1,695

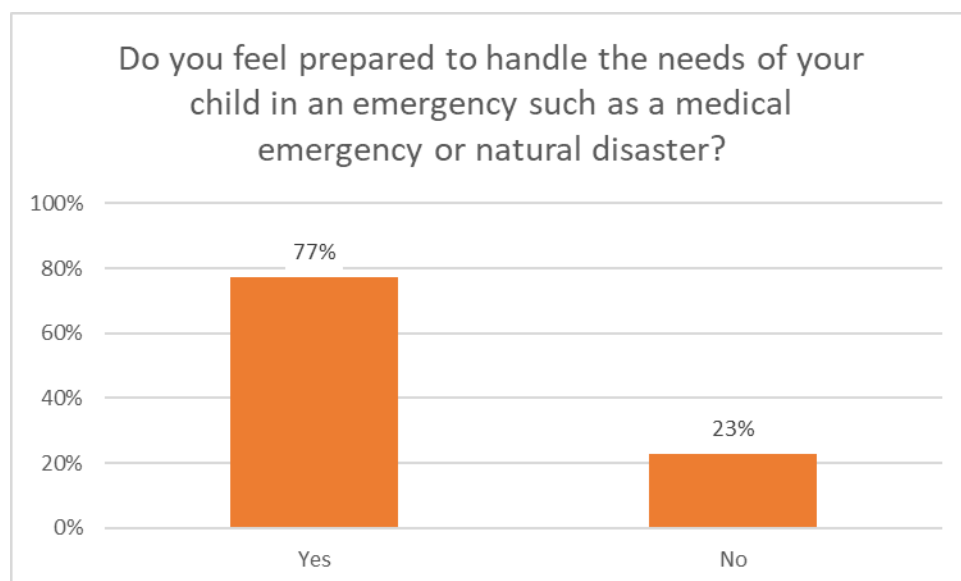


Table Q15. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster?

#### Significantly Above Average

State	Yes	No	N
LA	93%	7%	384
SD	90%	10%	262
NC	89%	11%	180
OH	86%	14%	238
MN	84%	16%	358

#### Within Average Range

State	Yes	No	N
AZ	81%	19%	146
MO	80%	20%	210
WI	80%	20%	862
NCI Average	77%	23%	12,450
OR	77%	23%	575
WA	71%	29%	248
CO	70%	30%	177

#### Significantly Below Average

State	Yes	No	N
CA	71%	29%	8,810

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## *Access and Delivery of Services and Supports*

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

**Note: Significance is based on “Always” or “Yes” response.**

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

**“Child”** refers to the person receiving services whom the respondent is answering questions about in this survey.

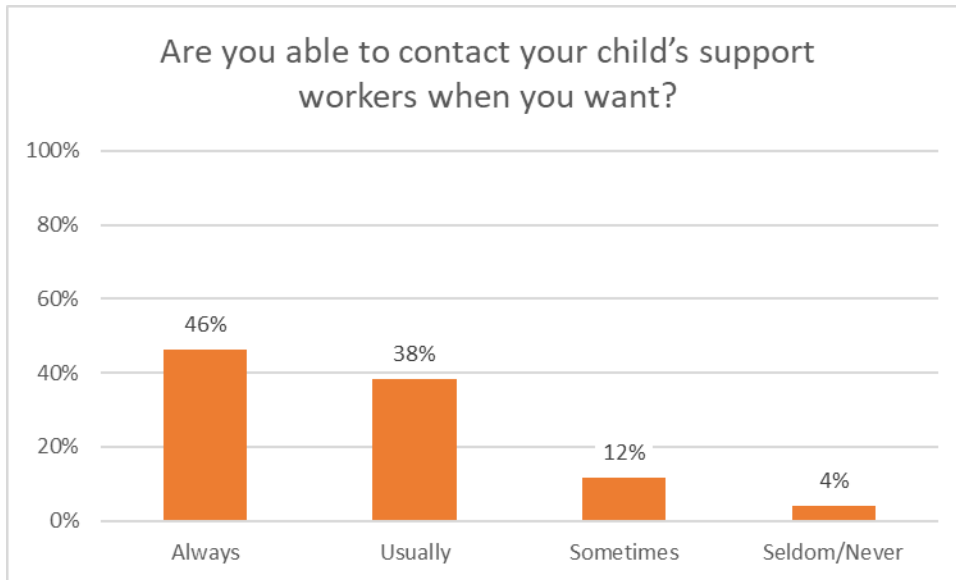


Table Q16. Are you able to contact your child's support workers when you want?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	65%	28%	6%	1%	355
SD	63%	34%	2%	0%	241
OR	54%	37%	7%	2%	639

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
NC	55%	34%	8%	2%	192
WI	51%	40%	8%	2%	895
CA	47%	35%	14%	5%	9,304
<b>NCI Average</b>	<b>46%</b>	<b>38%</b>	<b>12%</b>	<b>4%</b>	<b>12,994</b>
MN	45%	42%	11%	2%	382
MO	45%	41%	12%	2%	202
WA	44%	38%	12%	6%	245
AZ	43%	46%	10%	1%	157
OH	40%	42%	12%	6%	199
CO	40%	50%	9%	1%	183

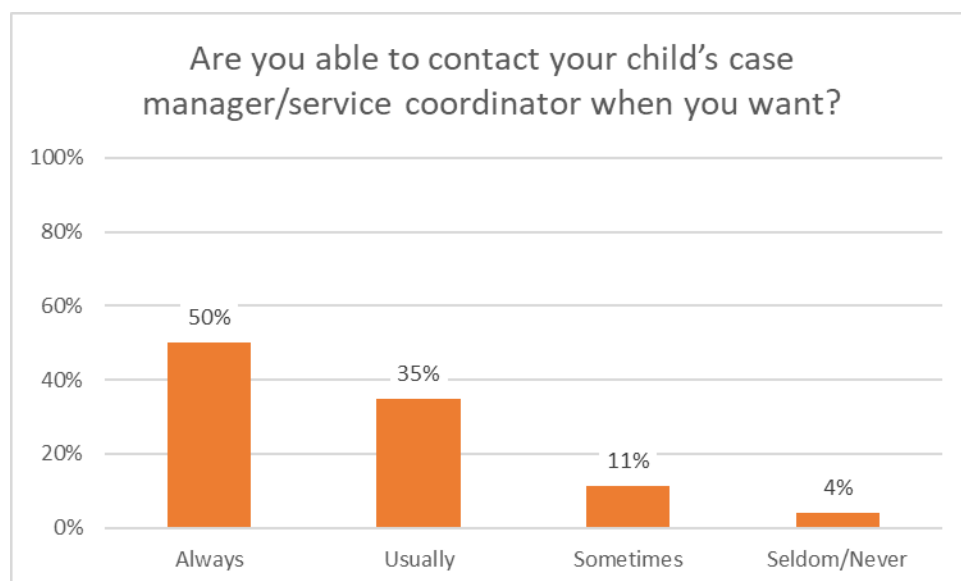


Table Q17. Are you able to contact your child's case manager/service coordinator when you want?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
SD	74%	23%	3%	0%	268
LA	65%	28%	6%	1%	370
WI	59%	32%	6%	2%	946

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
NC	57%	35%	6%	1%	189
WA	55%	31%	12%	3%	283
OR	54%	35%	8%	2%	663
MN	52%	37%	9%	3%	405
<b>NCI Average</b>	<b>50%</b>	<b>35%</b>	<b>11%</b>	<b>4%</b>	<b>13,911</b>
CA	50%	33%	13%	5%	9,991
MO	48%	37%	13%	2%	230
CO	47%	43%	9%	1%	191
AZ	46%	39%	13%	2%	165
OH	44%	40%	10%	6%	210

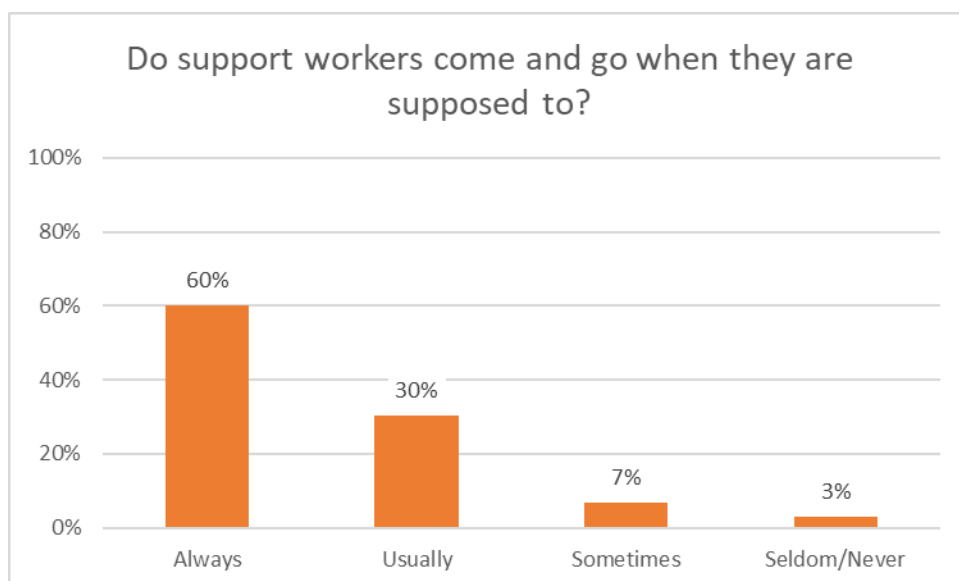


Table Q18. Do support workers come and go when they are supposed to?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
SD	78%	19%	2%	1%	196
LA	71%	24%	5%	1%	343

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OH	63%	22%	11%	5%	151
WI	61%	32%	5%	2%	799
CA	61%	30%	6%	3%	8,866
OR	61%	30%	8%	1%	624
<b>NCI Average</b>	<b>60%</b>	<b>30%</b>	<b>7%</b>	<b>3%</b>	<b>12,254</b>
MN	59%	33%	6%	2%	360
MO	58%	33%	8%	2%	172
WA	57%	35%	6%	2%	220
AZ	55%	35%	6%	3%	161

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CO	50%	43%	7%	1%	173
NC	42%	40%	15%	3%	189

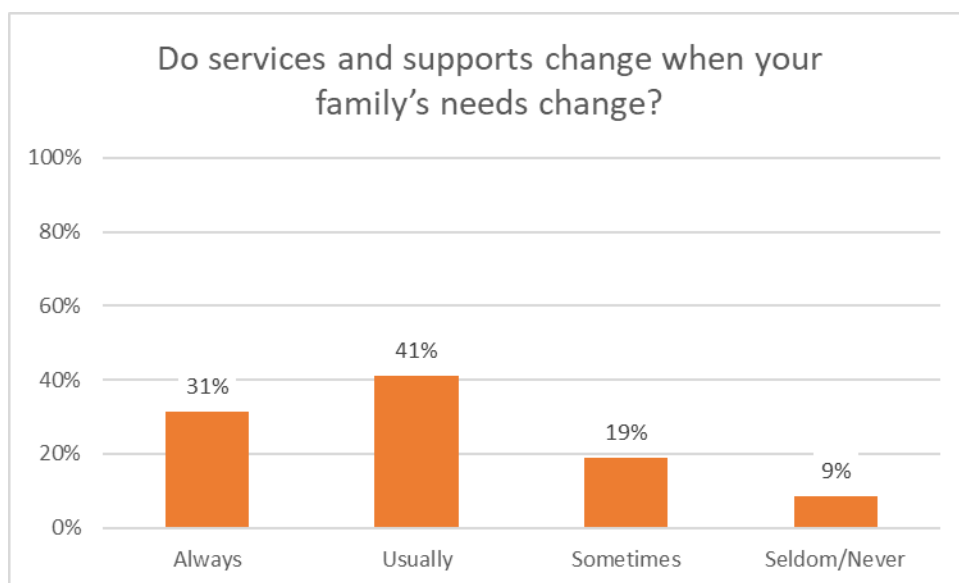


Table Q19. Do services and supports change when your family's needs change?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	57%	30%	7%	5%	283
SD	46%	38%	10%	6%	233

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
WI	36%	40%	18%	6%	754
AZ	35%	41%	19%	4%	144
NC	34%	45%	15%	6%	176
CA	32%	40%	19%	10%	7,652
WA	32%	33%	25%	11%	195
<b>NCI Average</b>	<b>31%</b>	<b>41%</b>	<b>19%</b>	<b>9%</b>	<b>10,823</b>
MO	31%	43%	15%	11%	180
CO	23%	47%	23%	7%	176
OH	23%	44%	21%	12%	160

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	25%	52%	17%	5%	538
MN	25%	46%	23%	6%	332

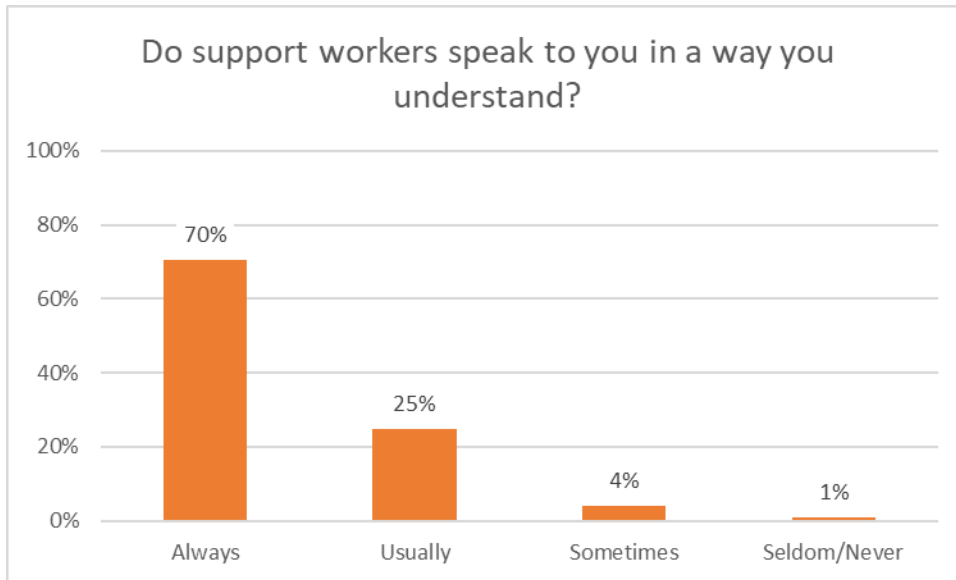


Table Q20. Do support workers speak to you in a way that you understand?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	84%	15%	1%	0%	349
OR	75%	22%	2%	0%	630

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
SD	76%	21%	3%	0%	238
NC	73%	23%	3%	1%	191
WI	72%	25%	2%	0%	844
AZ	72%	25%	2%	1%	166
CA	71%	24%	4%	1%	9,602
<b>NCI Average</b>	<b>70%</b>	<b>25%</b>	<b>4%</b>	<b>1%</b>	<b>13,171</b>
WA	68%	27%	5%	0%	237
MO	67%	28%	4%	1%	183
CO	66%	30%	3%	1%	182
MN	66%	29%	5%	0%	373
OH	65%	29%	5%	1%	176

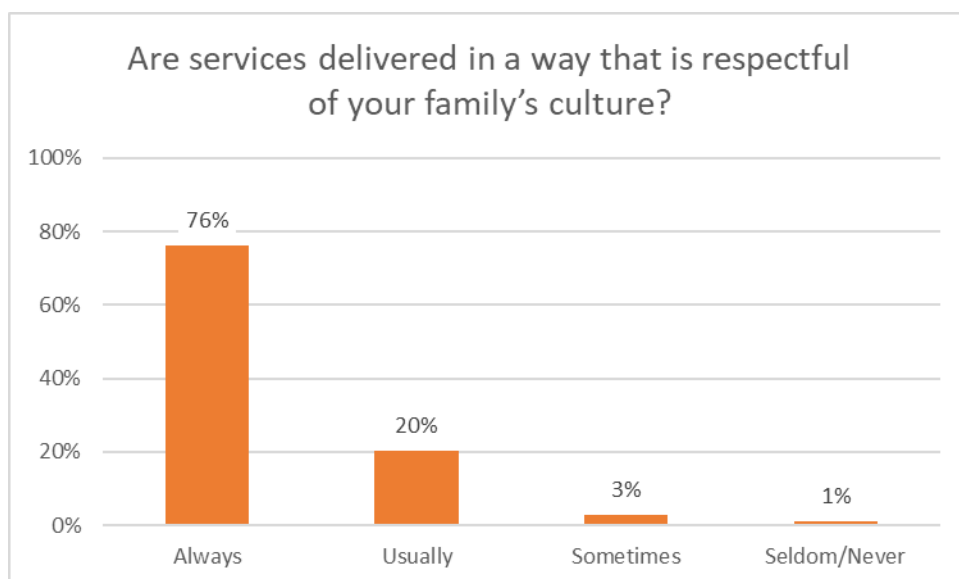


Table Q21. Are services delivered in a way that is respectful of your family's culture?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	84%	14%	1%	1%	377
SD	83%	16%	1%	0%	270

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	80%	17%	2%	1%	168
OR	80%	18%	2%	0%	653
WI	77%	20%	2%	1%	929
<b>NCI Average</b>	<b>76%</b>	<b>20%</b>	<b>3%</b>	<b>1%</b>	<b>13,738</b>
CA	75%	21%	3%	1%	9,842
OH	75%	21%	3%	2%	224
NC	75%	21%	4%	1%	195
MO	75%	22%	3%	1%	216
WA	74%	21%	3%	2%	263
MN	73%	22%	4%	1%	407
CO	73%	23%	4%	0%	194

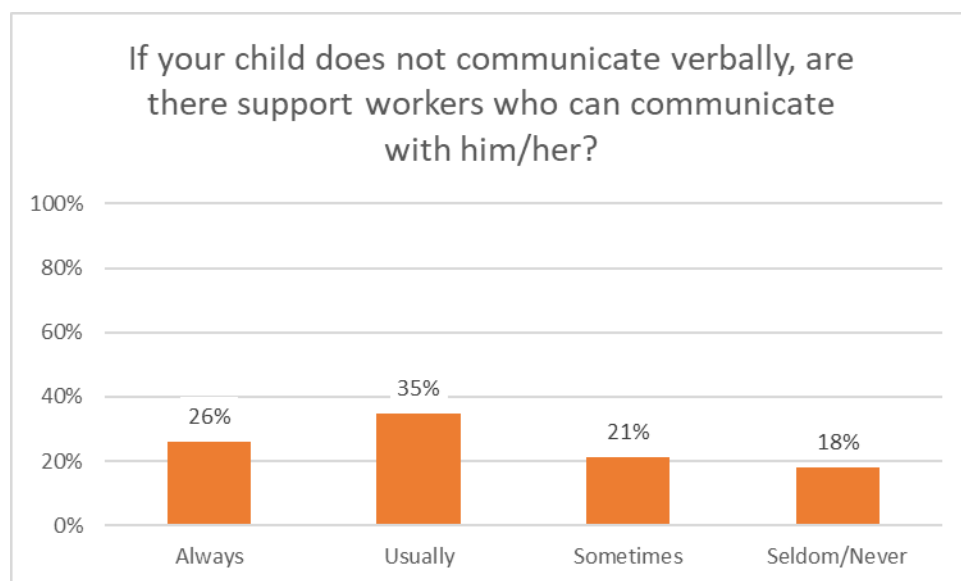


Table Q22. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?<sup>5</sup>

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	41%	24%	28%	7%	29
NC	35%	44%	15%	6%	48
OR	34%	41%	14%	11%	64
CA	27%	33%	16%	24%	796
MN	26%	34%	30%	9%	53
<b>NCI Average</b>	<b>26%</b>	<b>35%</b>	<b>21%</b>	<b>18%</b>	<b>1,232</b>
WA	25%	32%	21%	21%	28
SD	21%	36%	18%	24%	33
WI	19%	35%	26%	21%	107

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CO	4%	41%	37%	19%	27

<sup>5</sup> The following states are not included in the table due to low N (>20), responses from those states are included in the NCI Average: AZ, MO, OH

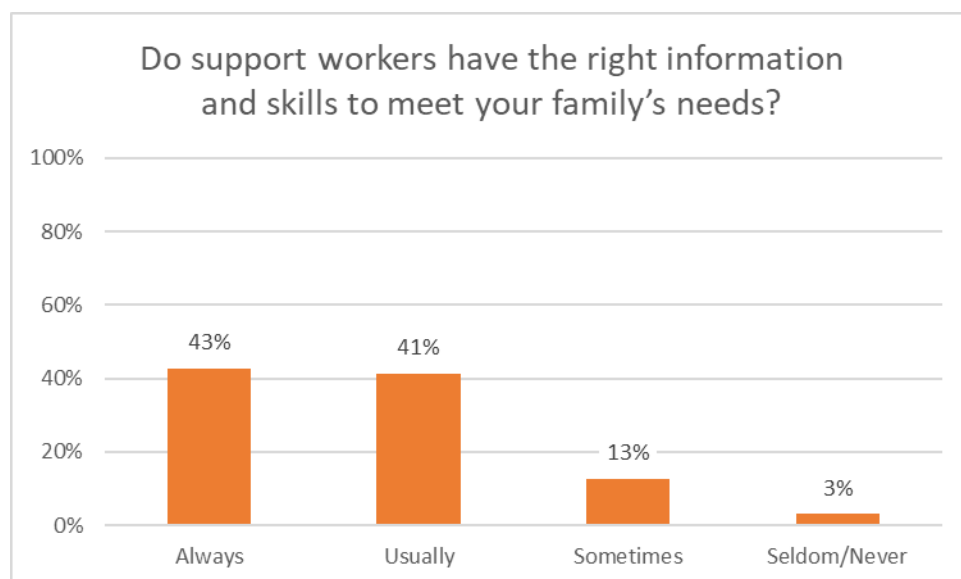


Table Q23. Do support workers have the right information and skills to meet your family's needs?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	63%	27%	8%	2%	346

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
SD	51%	42%	7%	0%	224
MN	44%	43%	10%	3%	362
OR	44%	44%	11%	2%	620
AZ	43%	42%	11%	4%	163
CA	43%	40%	13%	4%	8,902
<b>NCI Average</b>	<b>43%</b>	<b>41%</b>	<b>13%</b>	<b>3%</b>	<b>12,390</b>
WI	42%	44%	12%	3%	827
WA	42%	42%	12%	4%	226
MO	41%	42%	15%	2%	182
OH	41%	44%	14%	1%	169
NC	36%	44%	16%	4%	187

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CO	31%	49%	15%	4%	182



Table Q24. Does your child have the special equipment or accommodations that s/he needs?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
SD	49%	36%	12%	4%	183

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
CA	41%	32%	14%	12%	3,576
LA	40%	37%	15%	7%	183
AZ	39%	37%	20%	4%	84
MO	39%	39%	16%	6%	109
MN	38%	41%	15%	5%	273
<b>NCI Average</b>	<b>37%</b>	<b>35%</b>	<b>18%</b>	<b>10%</b>	<b>5,922</b>
NC	36%	47%	12%	6%	103
WI	34%	38%	21%	6%	576
OH	34%	32%	21%	13%	117
CO	30%	52%	16%	3%	159

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
WA	27%	36%	26%	11%	168
OR	26%	44%	22%	8%	391

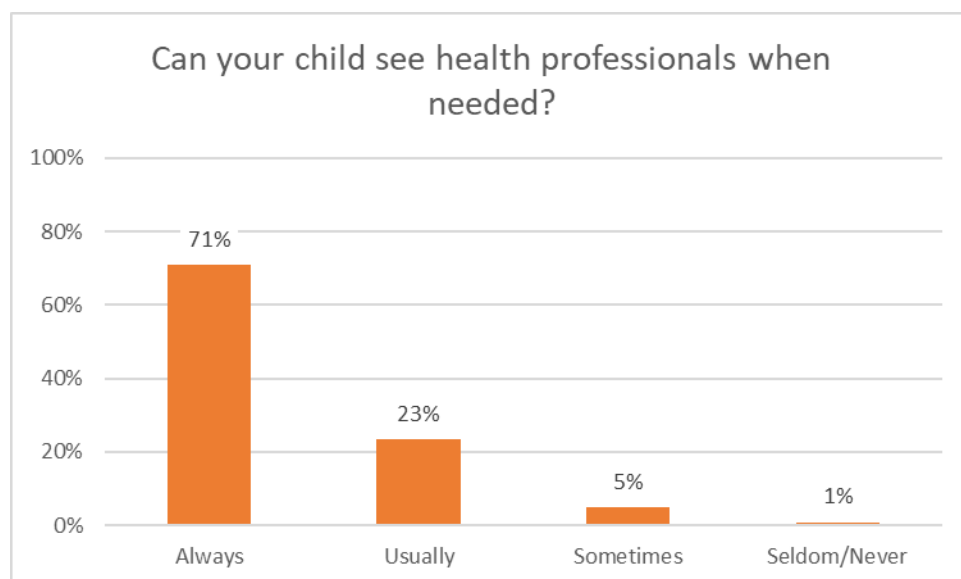


Table Q25. Can your child see health professionals when needed?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	85%	13%	2%	0%	407
SD	80%	17%	4%	0%	289

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OH	75%	22%	3%	0%	265
MN	72%	26%	2%	0%	423
<b>NCI Average</b>	<b>71%</b>	<b>23%</b>	<b>5%</b>	<b>1%</b>	<b>14,457</b>
MO	71%	23%	5%	0%	244
CA	71%	23%	6%	1%	10,335
OR	70%	25%	5%	0%	677
AZ	68%	26%	5%	1%	167
NC	68%	29%	4%	0%	200
WI	67%	26%	6%	1%	974
WA	64%	26%	7%	3%	283

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CO	61%	33%	5%	2%	193

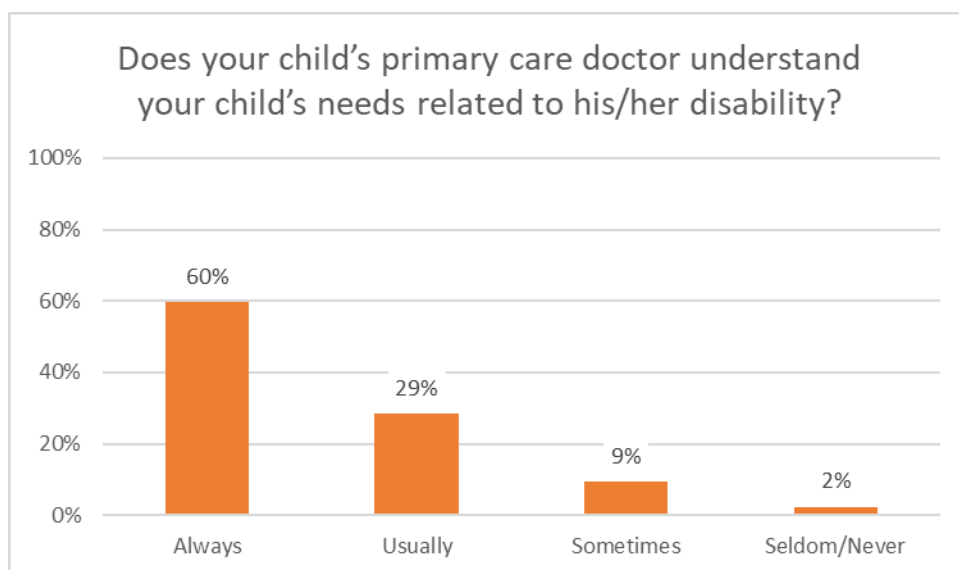


Table Q26. Does your child's primary care doctor understand his/her needs related to his/her disability?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	76%	17%	5%	2%	407

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	66%	27%	6%	1%	169
OH	63%	26%	8%	2%	260
CO	62%	26%	10%	1%	194
MN	62%	30%	6%	2%	420
<b>NCI Average</b>	<b>60%</b>	<b>29%</b>	<b>9%</b>	<b>2%</b>	<b>14,230</b>
WI	58%	30%	10%	2%	965
CA	58%	29%	11%	3%	10,140
NC	58%	31%	10%	2%	200
SD	56%	36%	7%	2%	284

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	55%	34%	10%	2%	673
MO	49%	36%	13%	2%	237
WA	48%	35%	14%	3%	281

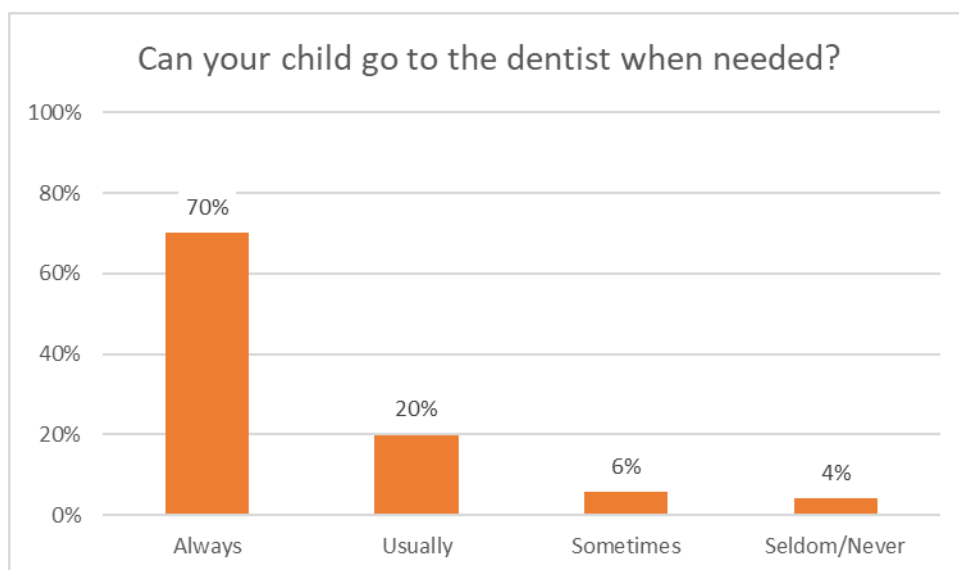


Table Q27. Can your child go to the dentist when needed?

Question is rephrased from previous years

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	80%	16%	2%	2%	388
AZ	80%	16%	3%	2%	166
NC	80%	14%	5%	3%	200

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	76%	18%	3%	4%	285
OH	75%	18%	3%	3%	266
OR	71%	21%	5%	3%	675
WA	70%	19%	5%	5%	281
<b>NCI Average</b>	<b>70%</b>	<b>20%</b>	<b>6%</b>	<b>4%</b>	<b>14,351</b>
CA	66%	21%	7%	5%	10,285
CO	66%	25%	5%	4%	196
MN	66%	24%	7%	3%	416
WI	66%	22%	7%	6%	947

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	62%	26%	7%	5%	246

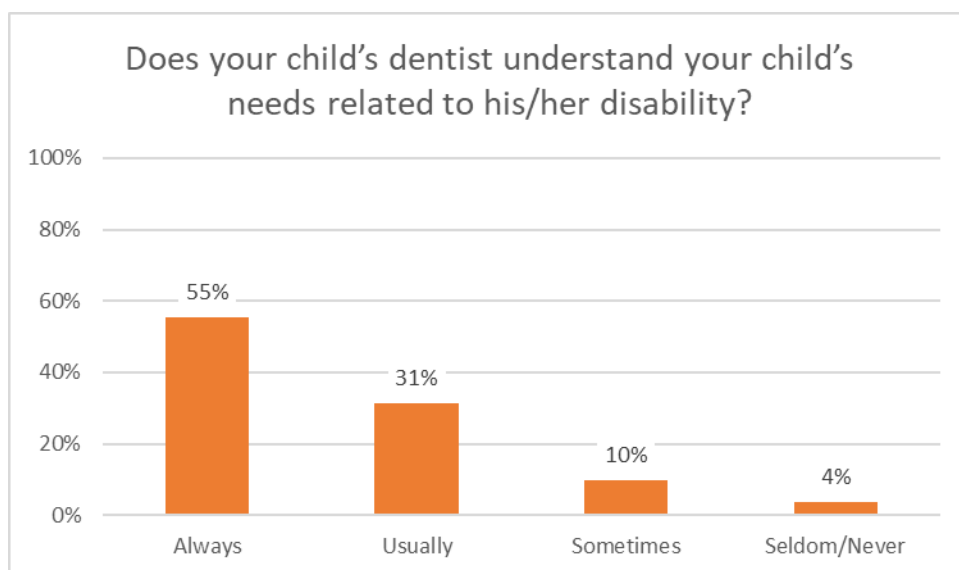


Table Q28. Does your child's dentist understand your child's needs related to his/her disability?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	71%	22%	6%	1%	308
NC	66%	25%	8%	2%	198

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	64%	30%	6%	0%	153
SD	58%	33%	7%	2%	269
OH	56%	36%	6%	3%	245
WI	55%	30%	10%	4%	878
<b>NCI Average</b>	<b>55%</b>	<b>31%</b>	<b>10%</b>	<b>4%</b>	<b>13,374</b>
MN	54%	33%	11%	2%	405
OR	53%	33%	9%	4%	633
CA	53%	30%	12%	5%	9,599
WA	53%	32%	12%	4%	274
MO	52%	33%	10%	5%	222
CO	51%	35%	9%	4%	190

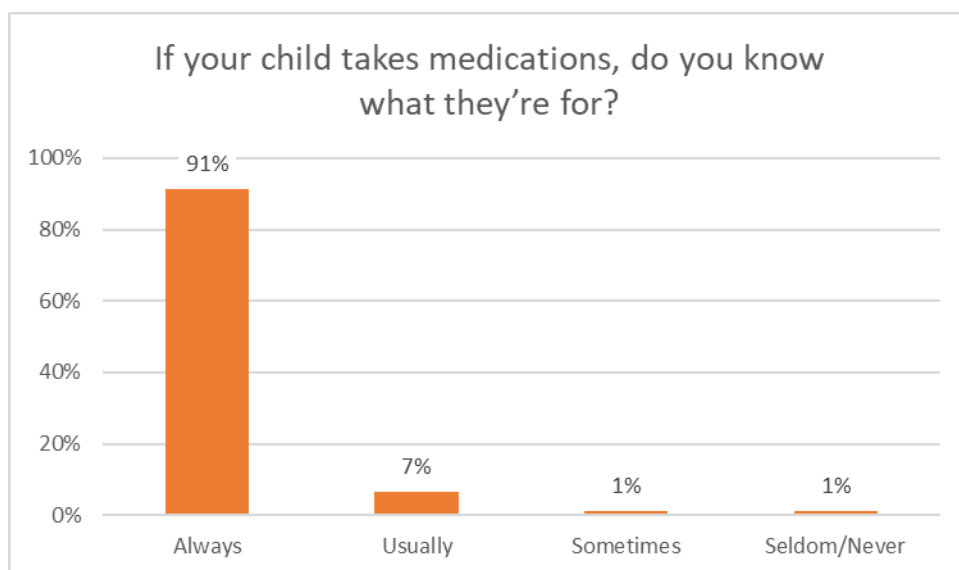


Table Q29. If your child takes medications, do you know what they're for?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
NC	96%	3%	1%	0%	178

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
MO	94%	5%	1%	0%	198
CO	94%	5%	1%	1%	173
LA	93%	3%	1%	3%	300
OH	93%	6%	0%	1%	193
OR	92%	5%	2%	1%	528
SD	92%	6%	1%	1%	235
AZ	91%	8%	0%	1%	114
<b>NCI Average</b>	<b>91%</b>	<b>7%</b>	<b>1%</b>	<b>1%</b>	<b>9,688</b>
MN	91%	6%	1%	1%	350
WI	91%	7%	1%	1%	762
CA	90%	7%	2%	2%	6,445
WA	90%	7%	3%	1%	212

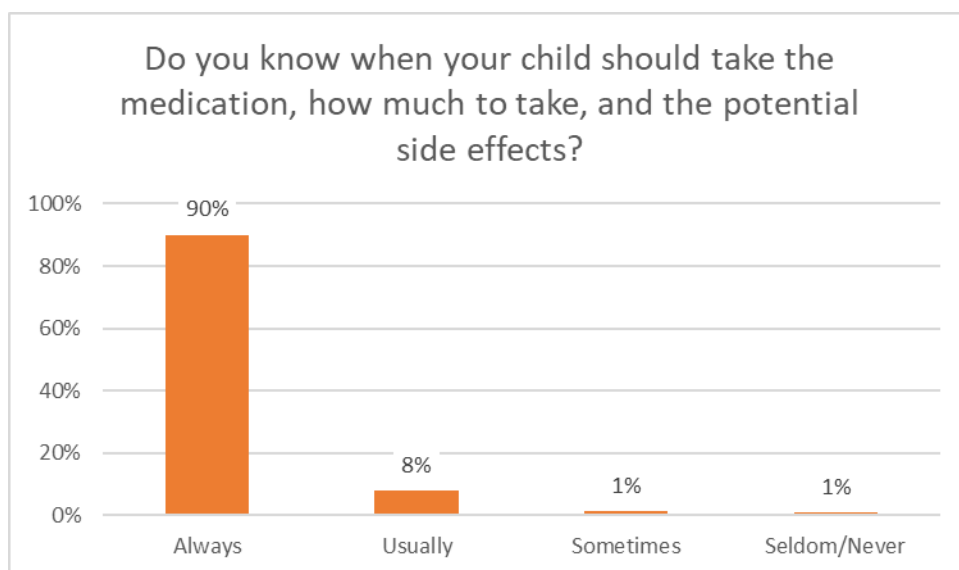


Table Q30. Do you know when your child should take the medication, how much to take, and the potential side effects?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	96%	3%	1%	0%	296
MO	95%	4%	1%	0%	195
MN	95%	5%	0%	1%	348

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
NC	93%	7%	0%	1%	178
OH	92%	5%	0%	3%	194
WI	91%	8%	1%	1%	756
AZ	91%	6%	3%	1%	109
OR	91%	8%	1%	0%	523
WA	90%	7%	2%	0%	210
<b>NCI Average</b>	<b>90%</b>	<b>8%</b>	<b>1%</b>	<b>1%</b>	<b>9,563</b>
SD	90%	10%	1%	0%	231
CO	89%	10%	0%	1%	172
CA	87%	10%	2%	1%	6,351

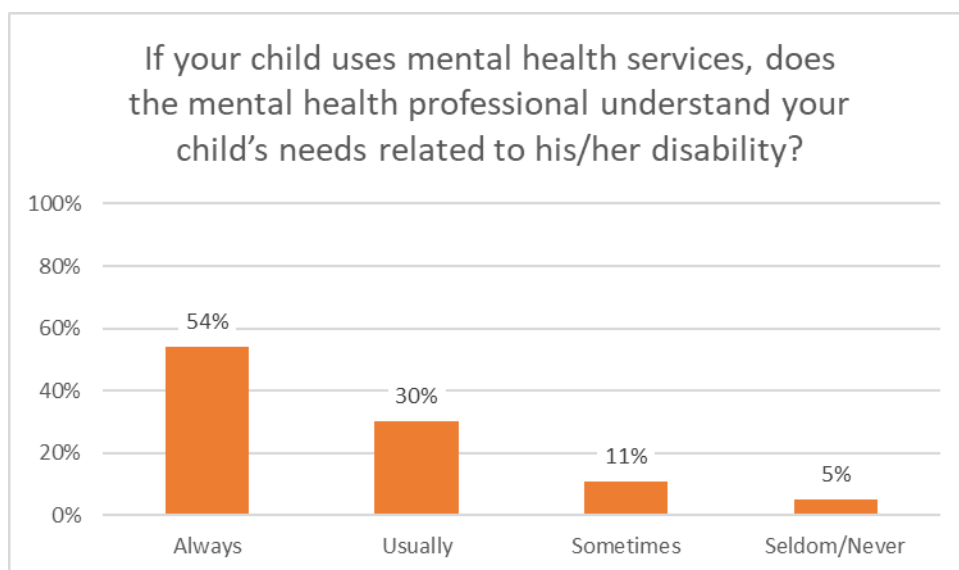


Table Q31. If your child uses mental health services, does the mental health professional understand your child's needs related to his/her disability?

#### Significantly Above Average

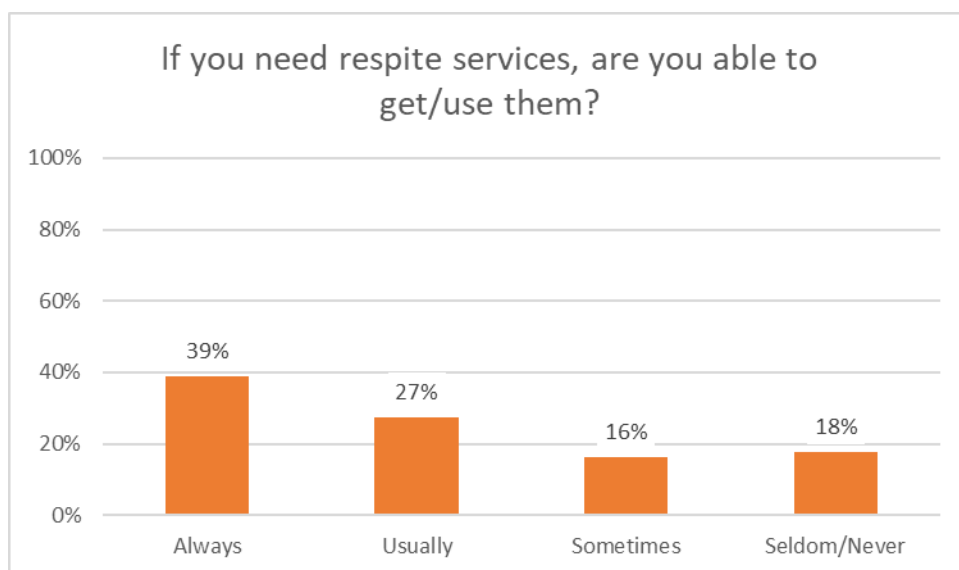
State	Always	Usually	Sometimes	Seldom or Never	N
LA	69%	23%	6%	2%	99

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OH	63%	22%	11%	4%	107
MO	61%	34%	4%	0%	119
SD	59%	35%	5%	1%	95
WA	56%	29%	10%	5%	98
MN	55%	38%	6%	2%	198
NC	54%	31%	11%	4%	101
<b>NCI Average</b>	<b>54%</b>	<b>30%</b>	<b>11%</b>	<b>5%</b>	<b>5,500</b>
CA	52%	32%	11%	5%	3,929
OR	52%	31%	13%	4%	272
AZ	47%	28%	14%	11%	64
CO	44%	40%	9%	8%	80

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	47%	36%	13%	4%	338



**Table Q32. If you need respite services, are you able to get/use them?**

Question is rephrased from previous years

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	48%	28%	13%	10%	7,810

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NCI Average	39%	27%	16%	18%	10,647
AZ	36%	29%	19%	16%	135
NC	32%	28%	20%	19%	176
SD	32%	33%	16%	19%	209

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	32%	32%	21%	15%	576
WI	31%	33%	19%	16%	756
WA	27%	22%	26%	26%	188
MN	25%	18%	25%	32%	257
OH	22%	21%	16%	41%	117
MO	21%	31%	16%	32%	138
LA	21%	32%	13%	33%	105
CO	15%	24%	28%	33%	180

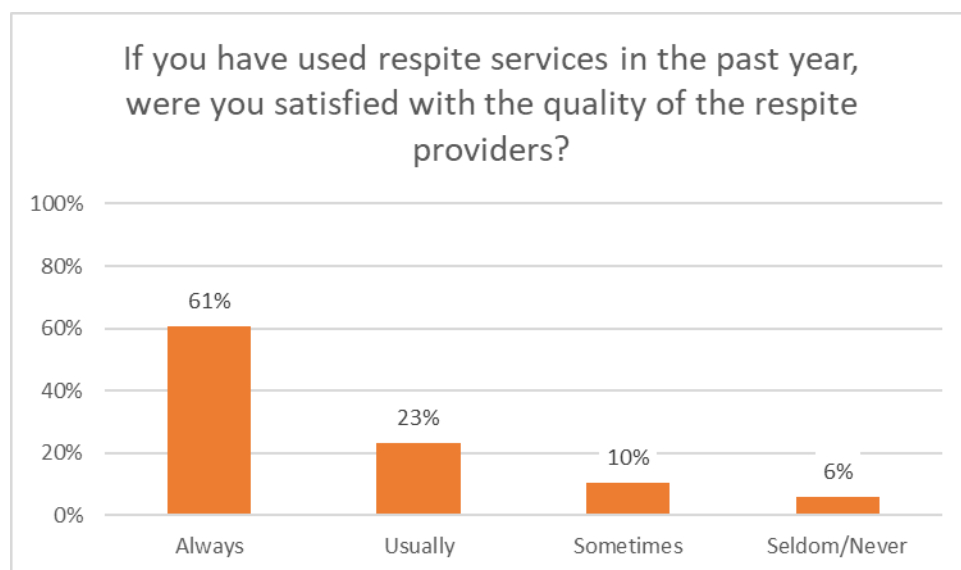


Table Q33. If you have used respite services in the past year, were you satisfied with the quality of the respite providers?

#### Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	71%	24%	2%	4%	169
WI	66%	23%	8%	4%	623

#### Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
CA	62%	23%	10%	5%	6,611
MO	62%	23%	11%	4%	81
<b>NCI Average</b>	<b>61%</b>	<b>23%</b>	<b>10%</b>	<b>6%</b>	<b>8,715</b>
OH	61%	21%	11%	7%	61
MN	59%	29%	7%	4%	134
OR	59%	29%	10%	2%	458
AZ	59%	20%	12%	9%	116
NC	51%	34%	8%	7%	156
CO	51%	29%	11%	9%	136
LA	43%	39%	15%	4%	54

#### Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	48%	27%	16%	9%	116

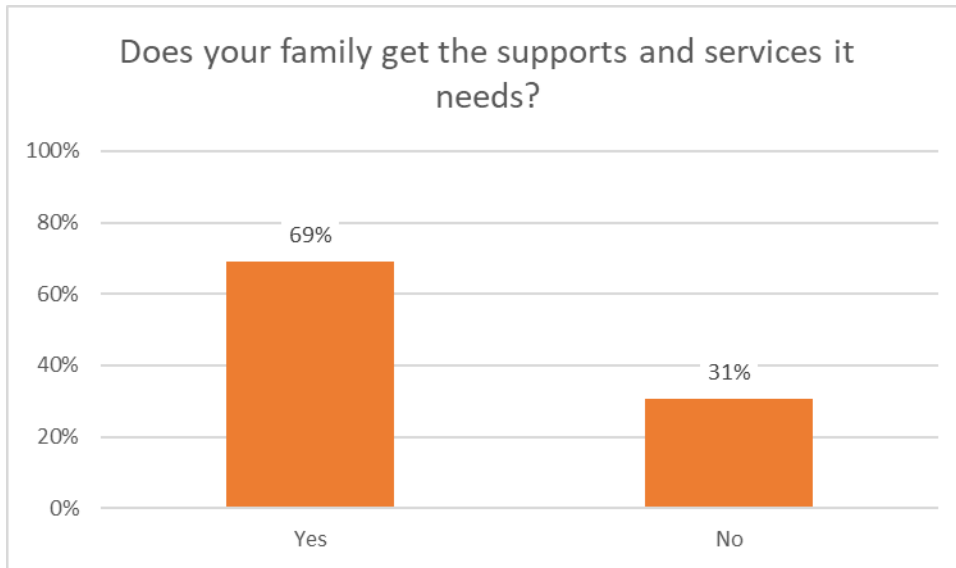


Table Q34. Does your family get the supports and services it needs?

**Significantly Above Average**

State	Yes	No	N
SD	86%	14%	258
LA	77%	23%	345

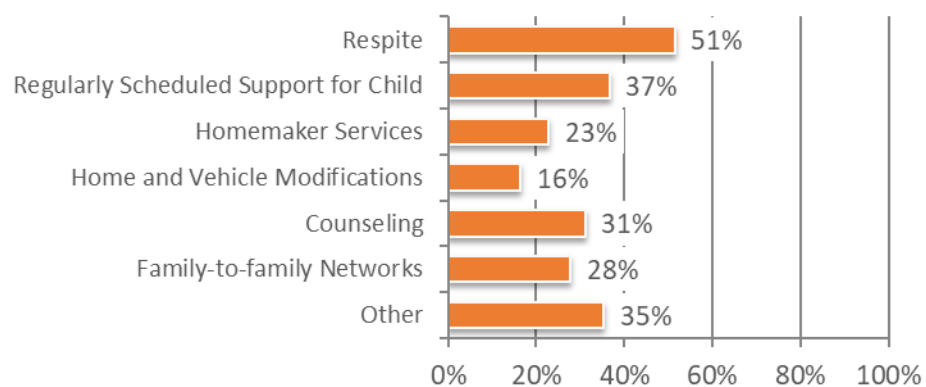
**Within Average Range**

State	Yes	No	N
AZ	77%	23%	159
MO	73%	27%	213
OR	72%	28%	606
MN	70%	30%	378
CA	70%	30%	8,430
<b>NCI Average</b>	<b>69%</b>	<b>31%</b>	<b>12,104</b>
WI	68%	32%	890
NC	68%	32%	187
OH	64%	36%	215

**Significantly Below Average**

State	Yes	No	N
WA	59%	41%	235
CO	54%	46%	188

If family does not get the support and services needed, what additional services does your family need?



**Table Q35. If family does not get the support and services needed, what additional services does your family need?**

Categories are not mutually exclusive, therefore N is not shown

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Other
AZ	36%	14%	22%	11%	17%	19%	36%
CA	40%	36%	22%	15%	38%	28%	38%
CO	65%	24%	33%	15%	32%	20%	26%
LA	51%	26%	14%	27%	23%	26%	30%
MN	64%	36%	27%	18%	23%	36%	28%
MO	64%	40%	24%	16%	40%	35%	38%
NC	42%	45%	8%	22%	18%	37%	28%
OH	73%	44%	25%	17%	27%	28%	32%
OR	56%	35%	24%	24%	30%	30%	34%
SD	42%	33%	14%	14%	17%	19%	36%
WA	64%	51%	23%	24%	35%	25%	38%
WI	56%	40%	22%	20%	28%	31%	35%
<b>NCI Average</b>	<b>51%</b>	<b>37%</b>	<b>23%</b>	<b>16%</b>	<b>31%</b>	<b>28%</b>	<b>35%</b>

## *Choice, Decision Making and Control*

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

**Note: Significance is based on “Always” or “Yes” response.**

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

**“Child”** refers to the person receiving services whom the respondent is answering questions about in this survey.

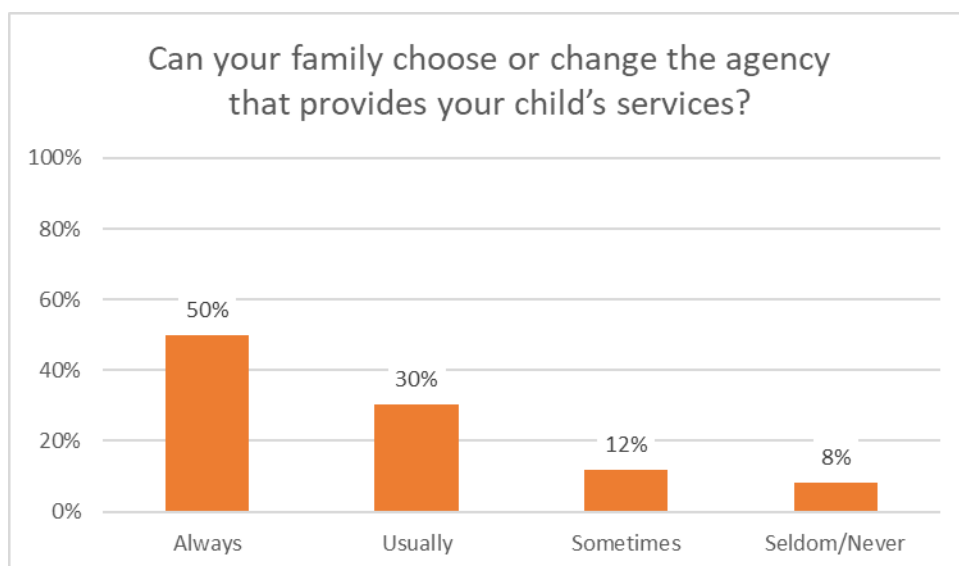


Table Q36. Can your family choose or change the agency that provides your child's services?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	76%	15%	4%	5%	279
NC	72%	22%	4%	2%	184
MN	64%	27%	7%	2%	336
SD	63%	28%	5%	4%	170

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OH	55%	21%	11%	13%	110
AZ	52%	33%	9%	6%	132
OR	51%	26%	12%	11%	370
WA	51%	27%	15%	8%	156
<b>NCI Average</b>	<b>50%</b>	<b>30%</b>	<b>12%</b>	<b>8%</b>	<b>9,626</b>
CO	48%	27%	14%	12%	154
WI	44%	26%	12%	18%	516
MO	41%	31%	16%	11%	135

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CA	45%	34%	14%	7%	7,084

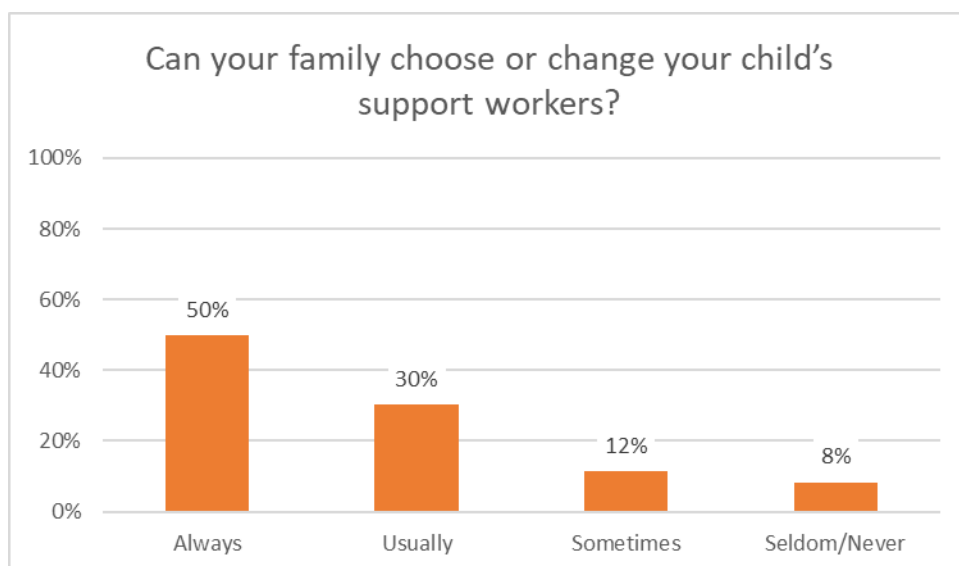


Table Q37. Can your family choose or change your child's support workers?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	71%	21%	5%	4%	275
SD	67%	25%	5%	3%	155
NC	66%	23%	9%	2%	182
OR	66%	22%	8%	4%	567

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OH	58%	24%	9%	9%	90
MN	56%	28%	8%	8%	286
WI	52%	24%	13%	11%	498
WA	50%	30%	11%	9%	169
AZ	50%	33%	10%	7%	132
NCI Average	50%	30%	12%	8%	9,062
MO	49%	30%	9%	12%	124

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CA	44%	33%	14%	9%	6,435
CO	39%	34%	16%	11%	149

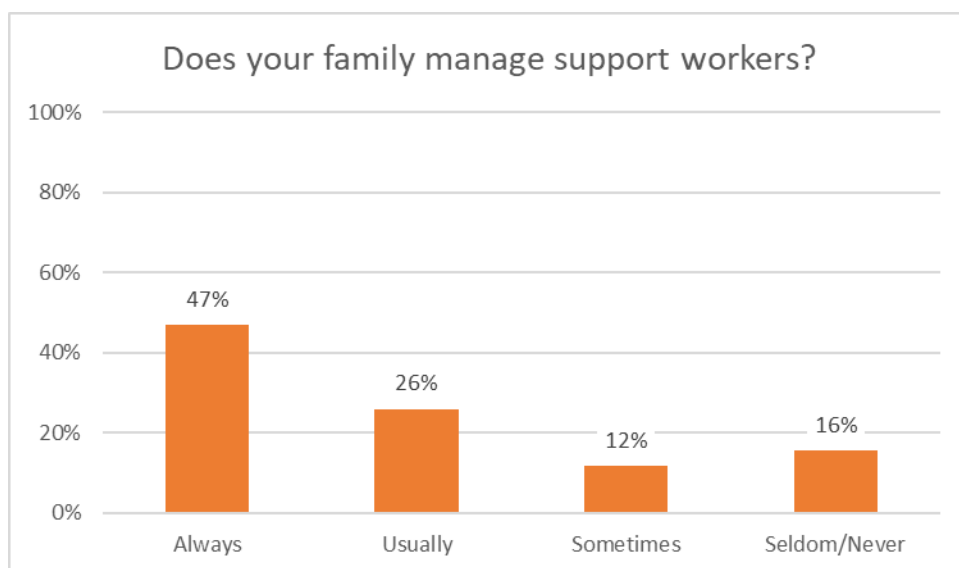


Table Q38. Does your family manage support workers?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	72%	18%	5%	5%	609
MN	66%	19%	7%	8%	311
LA	56%	23%	9%	12%	243

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
WA	55%	25%	12%	7%	170
<b>NCI Average</b>	<b>47%</b>	<b>26%</b>	<b>12%</b>	<b>16%</b>	<b>8,923</b>
OH	46%	17%	6%	31%	94
WI	45%	22%	12%	20%	582
NC	45%	28%	12%	14%	183
AZ	45%	31%	12%	12%	131
CA	44%	28%	14%	14%	6,210
SD	43%	26%	9%	22%	122
MO	42%	25%	12%	21%	115

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CO	29%	35%	18%	18%	153

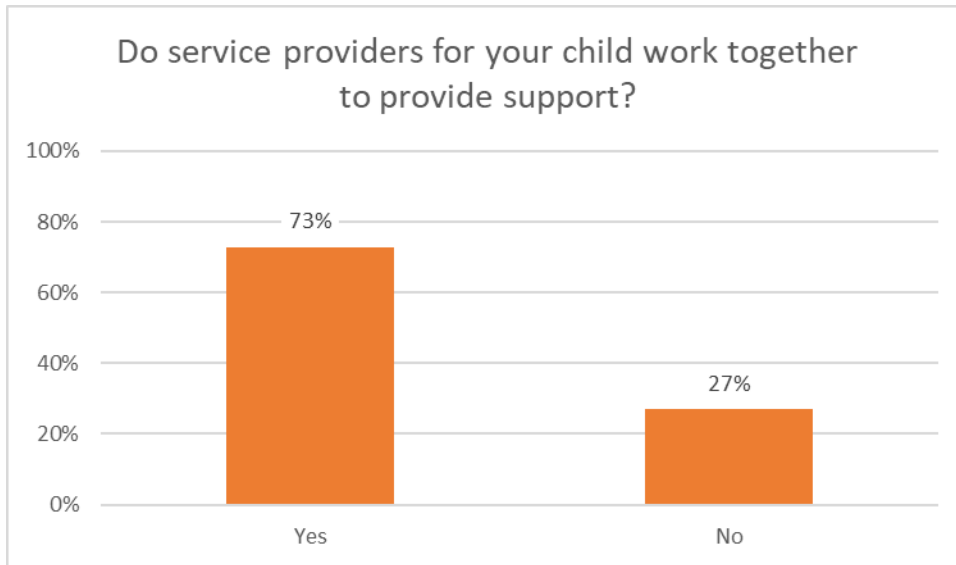


Table Q39. Do service providers for your child work together to provide support?

**Significantly Above Average**

State	Yes	No	N
LA	90%	10%	167
NC	85%	15%	104

**Within Average Range**

State	Yes	No	N
SD	83%	17%	89
WI	78%	22%	378
OH	77%	23%	62
MO	76%	24%	80
AZ	76%	24%	91
OR	74%	26%	311
<b>NCI Average</b>	<b>73%</b>	<b>27%</b>	<b>6,168</b>
MN	73%	27%	199
CA	69%	31%	4,460
WA	69%	31%	109
CO	69%	31%	118

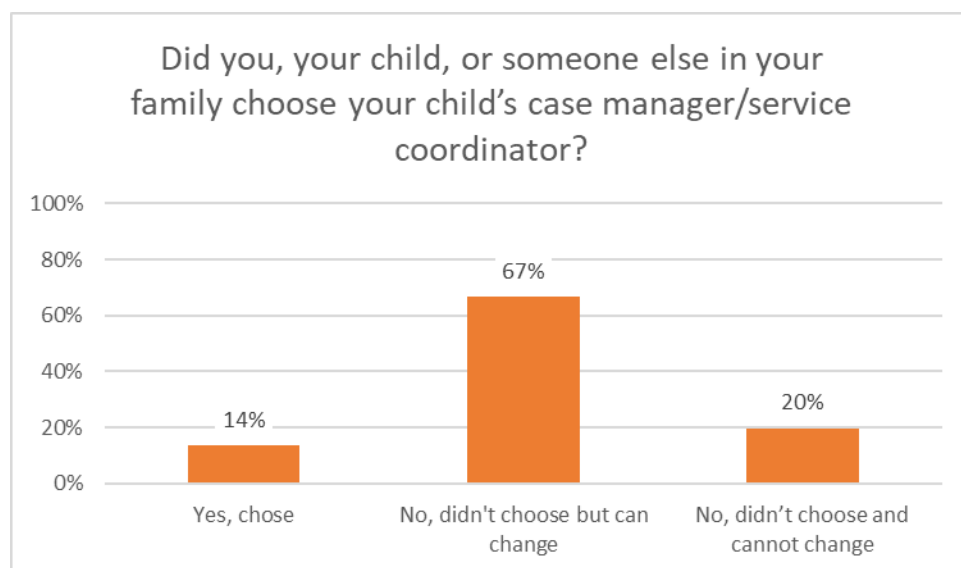


Table Q40. Did you, your child, or someone else in your family choose your child's case manager/service coordinator?

#### Significantly Above Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
LA	49%	45%	6%	314
NC	28%	55%	16%	177
MN	20%	54%	27%	331

#### Within Average Range

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
SD	17%	72%	11%	217
WA	16%	59%	25%	208
NCI Average	14%	67%	20%	10,358
CO	14%	60%	27%	169
CA	13%	70%	17%	7,189
WI	12%	56%	32%	710
OR	12%	68%	20%	559
OH	9%	63%	28%	142
AZ	9%	76%	15%	147

#### Significantly Below Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
MO	6%	71%	23%	195

## *Involvement in the Community*

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

**Note: Significance is based on “Always” or “Yes” response.**

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**“Child”** refers to the person receiving services whom the respondent is answering questions about in this survey.

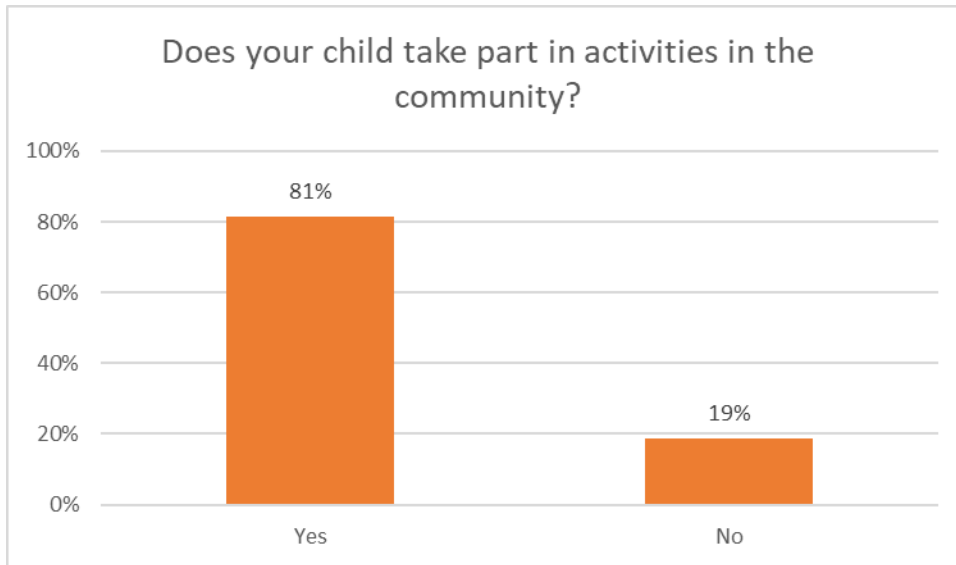


Table Q41. Does your child take part in activities in the community?

**Significantly Above Average**

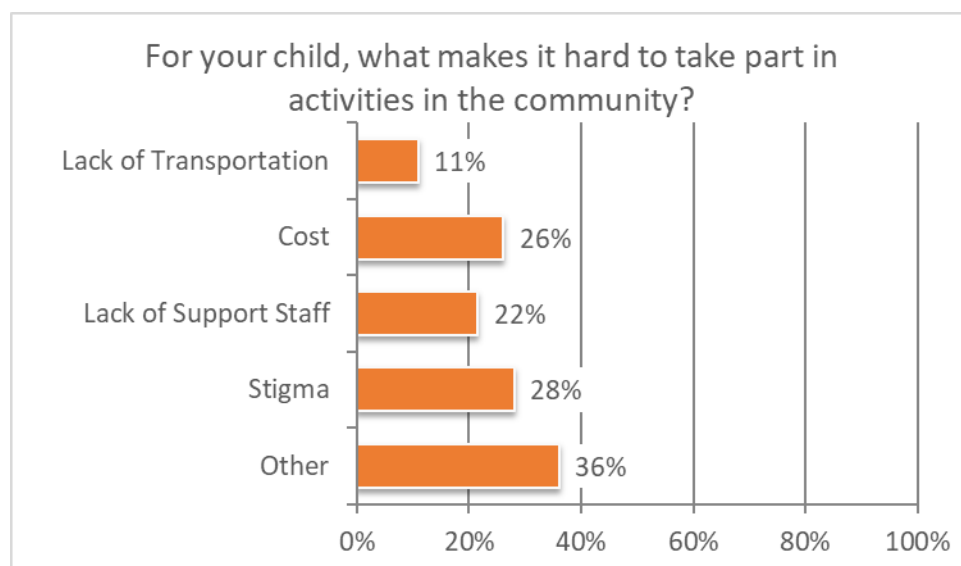
State	Yes	No	N
NC	88%	12%	199
MO	88%	12%	243
OR	87%	13%	664
SD	87%	13%	285

**Within Average Range**

State	Yes	No	N
AZ	87%	13%	163
OH	86%	14%	265
MN	85%	15%	423
WI	84%	16%	964
LA	83%	17%	404
<b>NCI Average</b>	<b>81%</b>	<b>19%</b>	<b>14,351</b>
CO	81%	19%	192
CA	78%	22%	10,269

**Significantly Below Average**

State	Yes	No	N
WA	69%	31%	280



**Table Q42. For your child, what makes it hard to take part in activities in the community?**

Categories are not mutually exclusive, therefore N is not shown

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	13%	28%	14%	26%	30%
CA	10%	25%	21%	29%	31%
CO	9%	27%	40%	40%	52%
LA	7%	20%	11%	15%	31%
MN	9%	22%	29%	31%	46%
MO	7%	31%	18%	39%	43%
NC	9%	26%	23%	24%	40%
OH	14%	27%	19%	26%	43%
OR	10%	30%	28%	33%	46%
SD	14%	30%	18%	22%	43%
WA	15%	33%	35%	31%	40%
WI	11%	28%	32%	28%	45%
<b>NCI Average</b>	<b>11%</b>	<b>26%</b>	<b>22%</b>	<b>28%</b>	<b>36%</b>

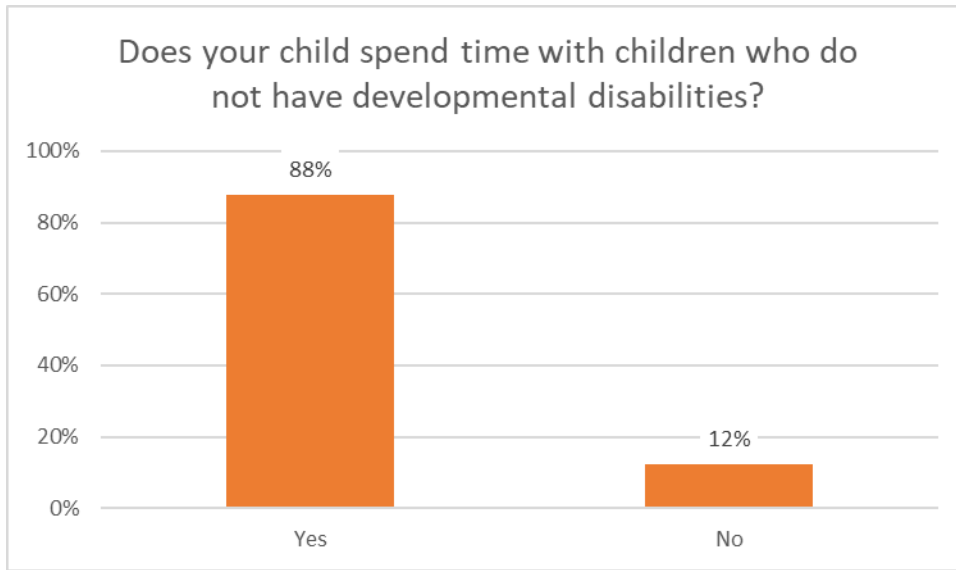


Table Q43. Does your child spend time with children who do not have developmental disabilities?

**Significantly Above Average**

State	Yes	No	N
SD	93%	7%	284

**Within Average Range**

State	Yes	No	N
MO	90%	10%	245
OH	90%	10%	262
MN	90%	10%	422
WI	90%	10%	961
OR	89%	11%	668
LA	89%	11%	401
<b>NCI Average</b>	<b>88%</b>	<b>12%</b>	<b>14,410</b>
AZ	87%	13%	166
CA	87%	13%	10,330
CO	84%	16%	192
WA	84%	16%	282
NC	82%	18%	197

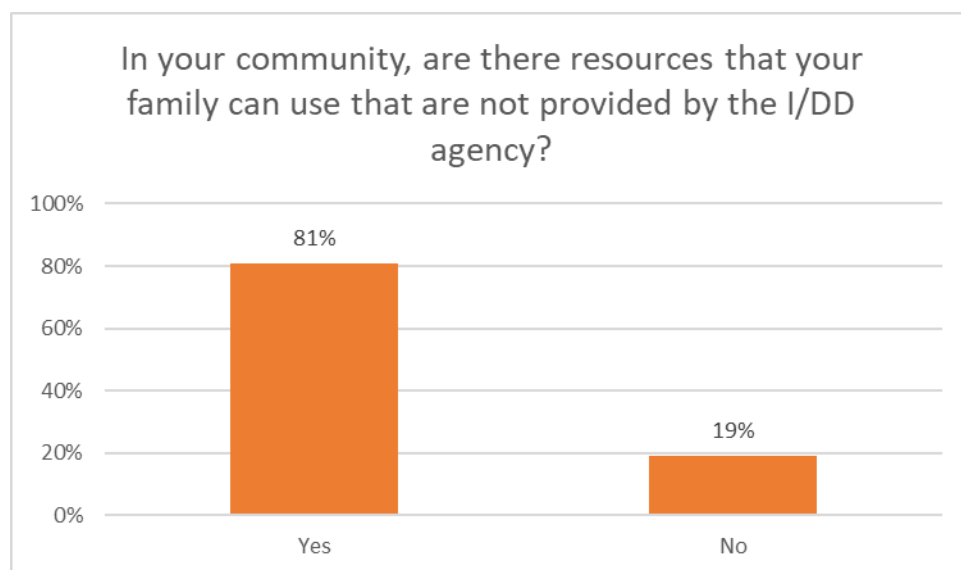


Table Q44. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

#### Significantly Above Average

State	Yes	No	N
MO	88%	12%	186
OR	86%	14%	546

#### Within Average Range

State	Yes	No	N
AZ	83%	17%	118
MN	82%	18%	342
WI	82%	18%	699
SD	81%	19%	223
<b>NCI Average</b>	<b>81%</b>	<b>19%</b>	<b>10,470</b>
OH	81%	19%	237
CA	80%	20%	7,331
CO	80%	20%	150
NC	79%	21%	163
LA	78%	22%	279
WA	77%	23%	196

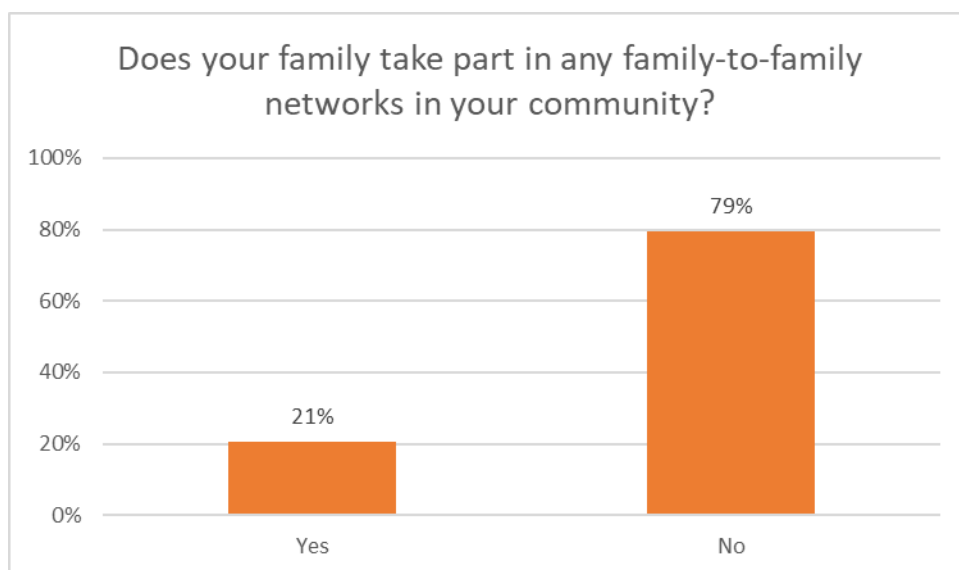


Table Q45. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?

#### Significantly Above Average

State	Yes	No	N
WA	31%	69%	245

#### Within Average Range

State	Yes	No	N
CO	27%	73%	190
MN	24%	76%	367
CA	23%	77%	8,996
LA	23%	77%	321
OR	23%	77%	595
NCI Average	21%	79%	12,496
WI	19%	81%	813
NC	18%	82%	172
AZ	17%	83%	148
SD	16%	84%	231

#### Significantly Below Average

State	Yes	No	N
OH	14%	86%	221
MO	11%	89%	197

## *Satisfaction With Services and Supports*

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

**Note: Significance is based on “Always” or “Yes” response.**

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**“Child”** refers to the person receiving services whom the respondent is answering questions about in this survey.

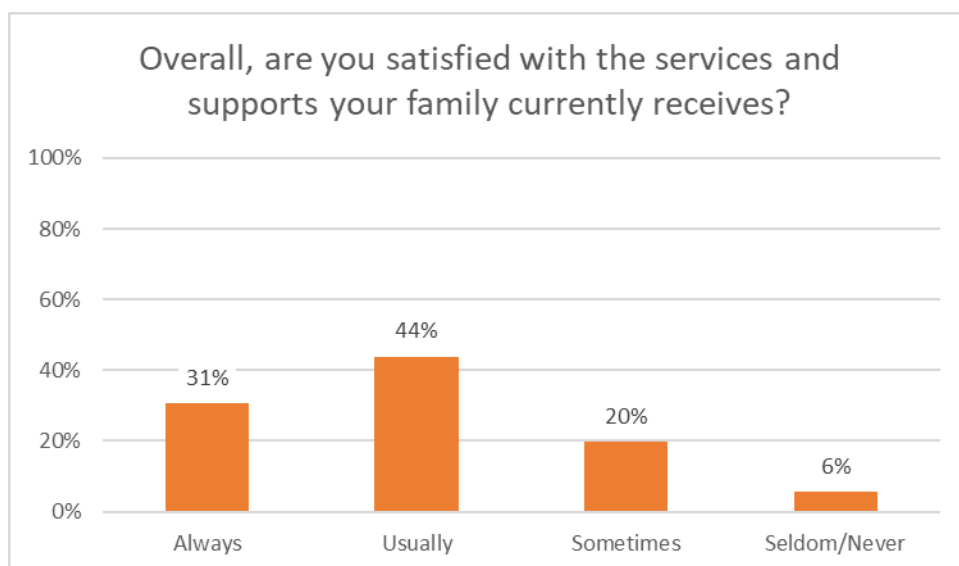


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	52%	29%	14%	4%	393
SD	39%	50%	9%	2%	282

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	37%	45%	16%	2%	168
CA	32%	41%	21%	6%	10,100
<b>NCI Average</b>	<b>31%</b>	<b>44%</b>	<b>20%</b>	<b>6%</b>	<b>14,142</b>
MN	30%	50%	17%	3%	419
WI	28%	47%	19%	5%	945
OR	27%	53%	17%	3%	668
OH	25%	47%	20%	8%	257
NC	25%	52%	19%	4%	197
MO	24%	46%	22%	7%	241

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
WA	21%	44%	28%	7%	278
CO	20%	53%	21%	6%	194

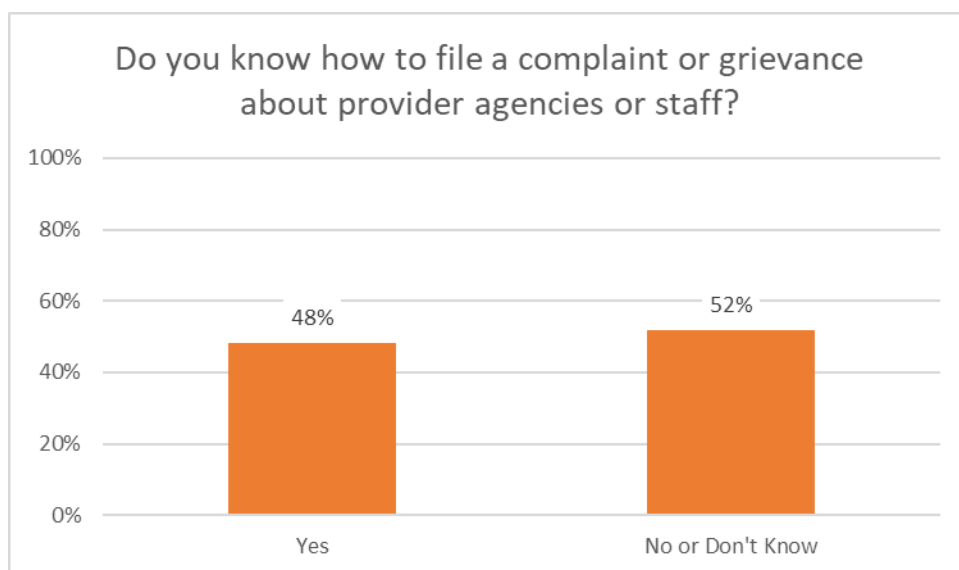


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?<sup>6</sup>

#### Significantly Above Average

State	Yes	No or Don't Know	N
CO	73%	27%	195
SD	71%	29%	288
NC	67%	34%	200
LA	63%	37%	398
WI	61%	39%	957
OR	60%	40%	670

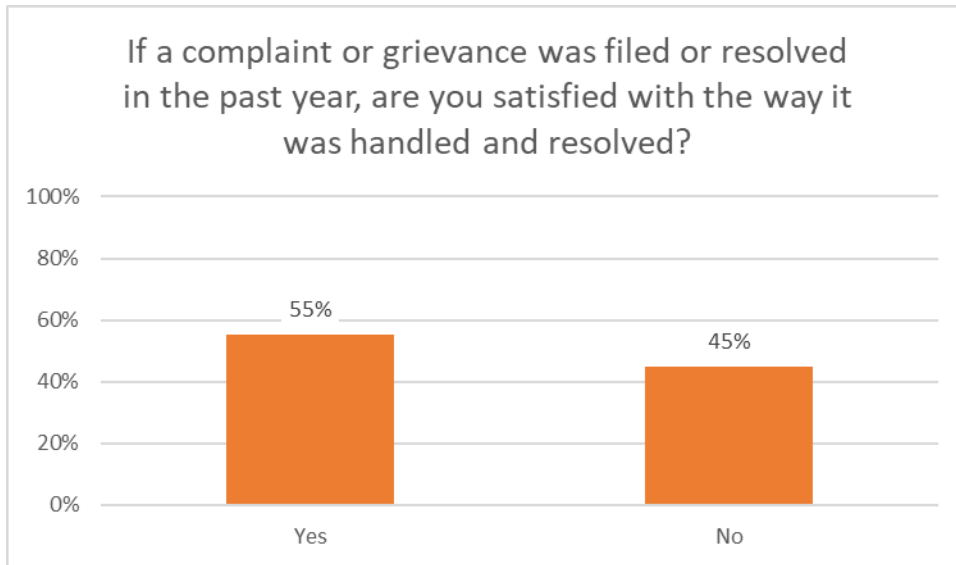
#### Within Average Range

State	Yes	No or Don't Know	N
MO	54%	46%	246
MN	51%	49%	424
WA	51%	49%	286
NCI Average	48%	52%	14,494
OH	48%	52%	263
AZ	47%	53%	167

#### Significantly Below Average

State	Yes	No or Don't Know	N
CA	43%	57%	10,400

<sup>6</sup> Don't Know' responses were included in 'No' responses for this question.

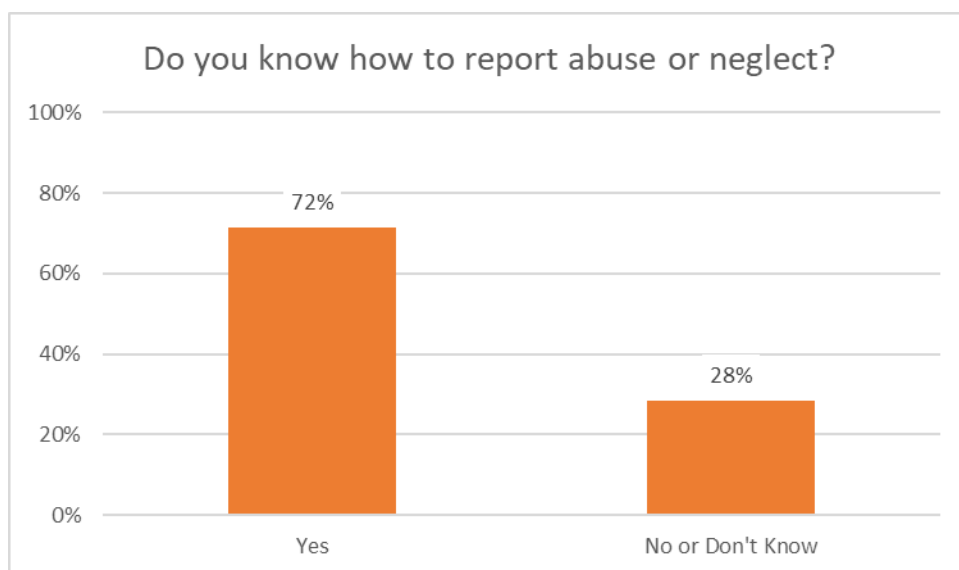


**Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?<sup>7</sup>**

**Within Average Range**

State	Yes	No	N
MN	79%	21%	28
LA	67%	33%	45
NC	62%	38%	21
OR	56%	44%	41
CA	56%	44%	1,237
<b>NCI Average</b>	<b>55%</b>	<b>45%</b>	<b>1,522</b>
WI	44%	56%	48
WA	40%	60%	25

<sup>7</sup> The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, CO, MO, OH, SD

Table Q49. Do you know how to report abuse or neglect?<sup>8</sup>**Significantly Above Average**

State	Yes	No or Don't Know	N
SD	90%	10%	288
OR	87%	13%	677
CO	84%	16%	197
WI	83%	17%	956
MO	83%	17%	246
LA	82%	18%	405
MN	81%	19%	426
NC	81%	19%	202

**Within Average Range**

State	Yes	No or Don't Know	N
OH	78%	22%	263
WA	74%	26%	281
NCI Average	72%	28%	14,466
AZ	65%	35%	167

**Significantly Below Average**

State	Yes	No or Don't Know	N
CA	65%	35%	10,358

<sup>8</sup> Don't Know' responses were included in 'No' responses for this question.

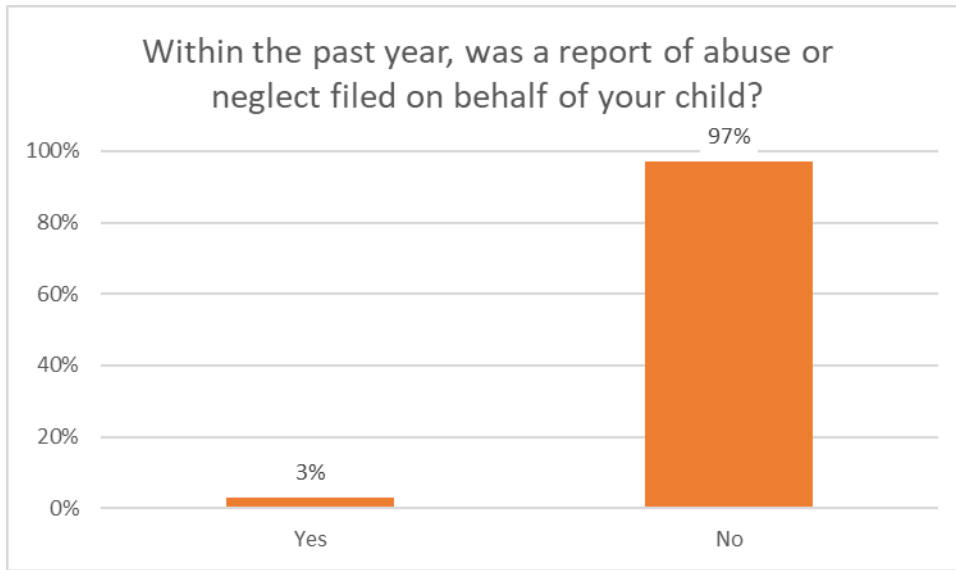


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child?

#### Significantly Above Average

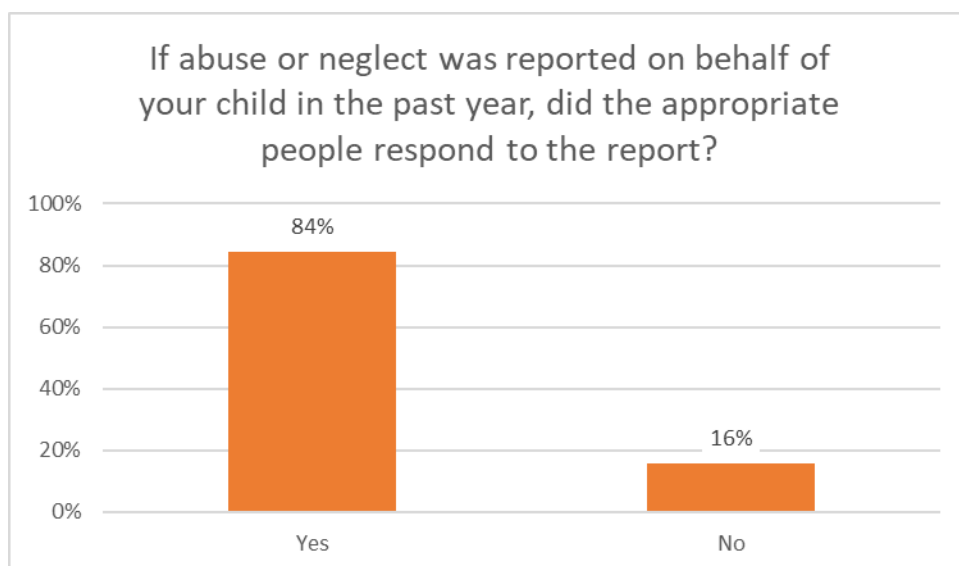
State	Yes	No	N
OR	6%	94%	649

#### Within Average Range

State	Yes	No	N
CO	6%	94%	185
MO	5%	95%	241
MN	4%	96%	411
AZ	4%	96%	167
NC	4%	96%	197
<b>NCI Average</b>	<b>3%</b>	<b>97%</b>	<b>13,838</b>
OH	3%	97%	263
CA	3%	97%	9,836
WA	3%	97%	273
WI	2%	98%	942
SD	2%	98%	284

#### Significantly Below Average

State	Yes	No	N
LA	1%	99%	390



**Table Q51. If abuse or neglect was reported on behalf of your child in the past year, did the appropriate people respond to the report?<sup>9</sup>**

**Within Average Range**

State	Yes	No	N
WI	95%	5%	20
OR	89%	11%	36
<b>NCI Average</b>	<b>84%</b>	<b>16%</b>	<b>329</b>
CA	78%	22%	209

<sup>9</sup> The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, CO, LA, MN, MO, NC, OH, SD, WA

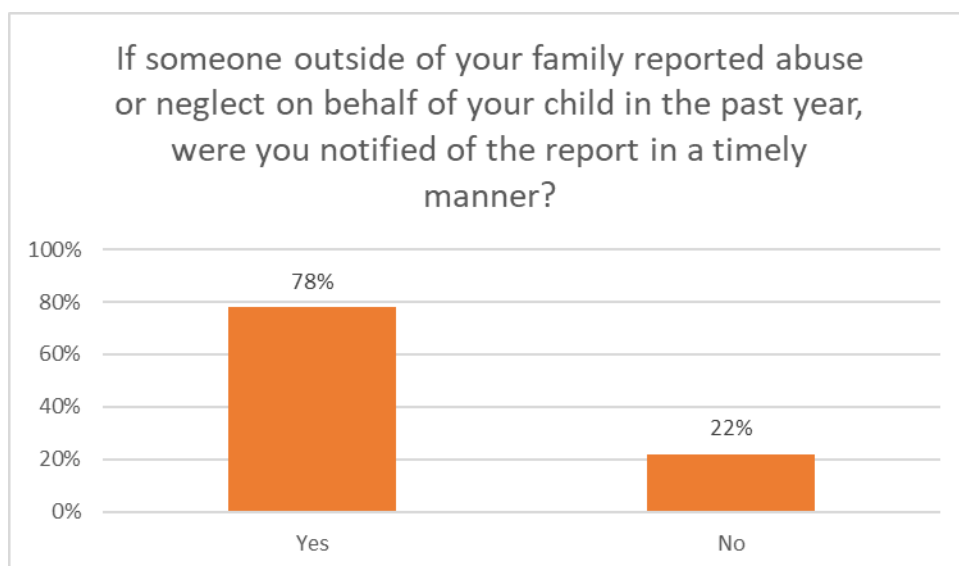


Table Q52. If someone outside of your family reported abuse or neglect on behalf of your child in the past year, were you notified of the report in a timely manner?<sup>10</sup>

#### Within Average Range

State	Yes	No	N
NCI Average	78%	22%	261
OR	78%	22%	27
CA	72%	28%	172

<sup>10</sup> The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, CO, LA, MN, MO, NC, OH, SD, WA, WI

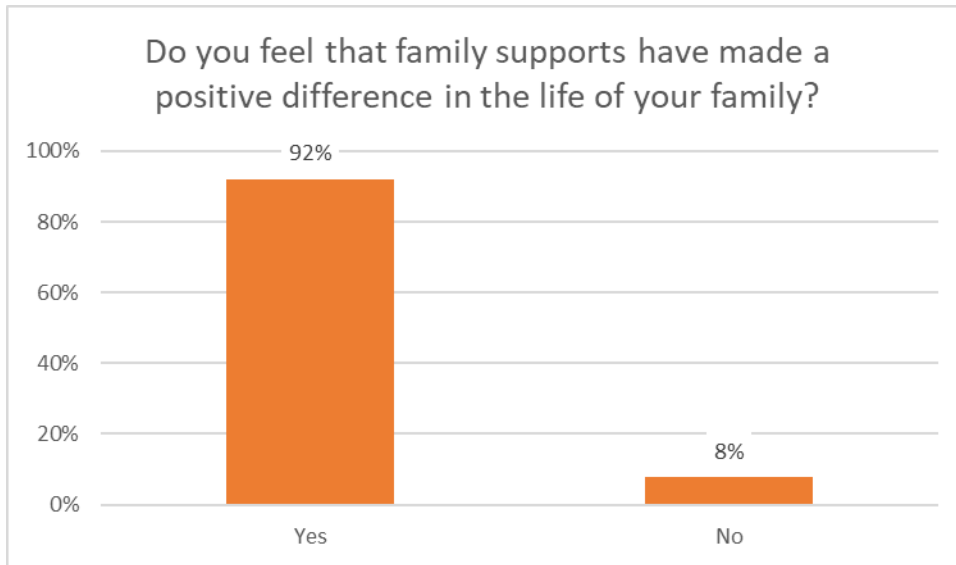


Table Q53. Do you feel that family supports have made a positive difference in the life of your family?

#### Significantly Above Average

State	Yes	No	N
SD	99%	1%	276
OR	97%	3%	630
AZ	97%	3%	153
CO	97%	3%	178
MN	96%	4%	380

#### Within Average Range

State	Yes	No	N
NC	96%	4%	190
LA	94%	6%	367
WI	94%	6%	852
<b>NCI Average</b>	<b>92%</b>	<b>8%</b>	<b>12,595</b>
CA	91%	9%	8,908
MO	90%	10%	208
WA	90%	10%	235
OH	89%	11%	218

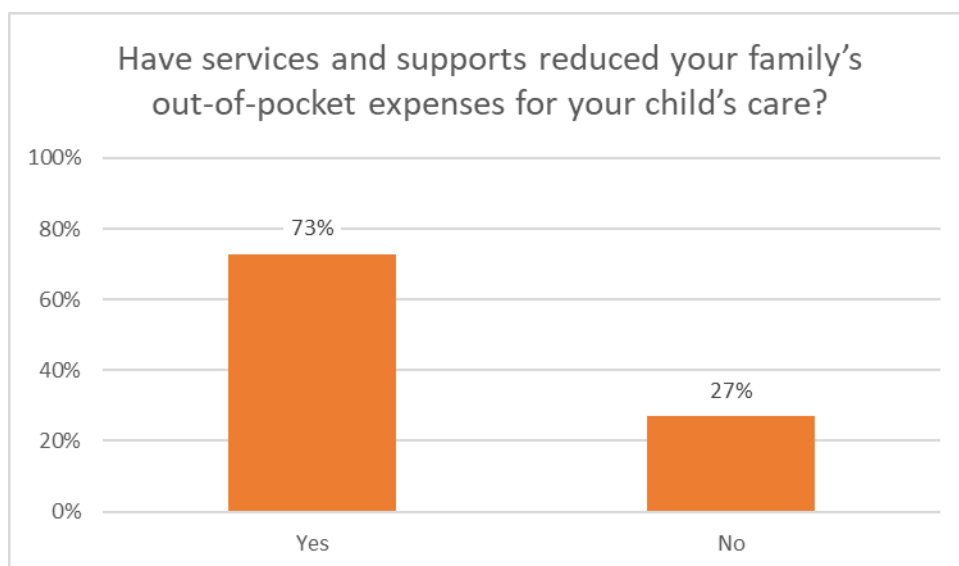


Table Q54. Have services and supports reduced your family's out-of-pocket expenses for your child's care?

#### Significantly Above Average

State	Yes	No	N
SD	94%	6%	281
CO	85%	15%	184
MN	82%	18%	394
OR	82%	18%	631
WI	82%	18%	885

#### Within Average Range

State	Yes	No	N
WA	77%	23%	249
AZ	74%	26%	155
<b>NCI Average</b>	<b>73%</b>	<b>27%</b>	<b>12,783</b>
CA	72%	28%	8,998
NC	71%	29%	191
MO	68%	32%	225
LA	68%	32%	355
OH	66%	34%	235

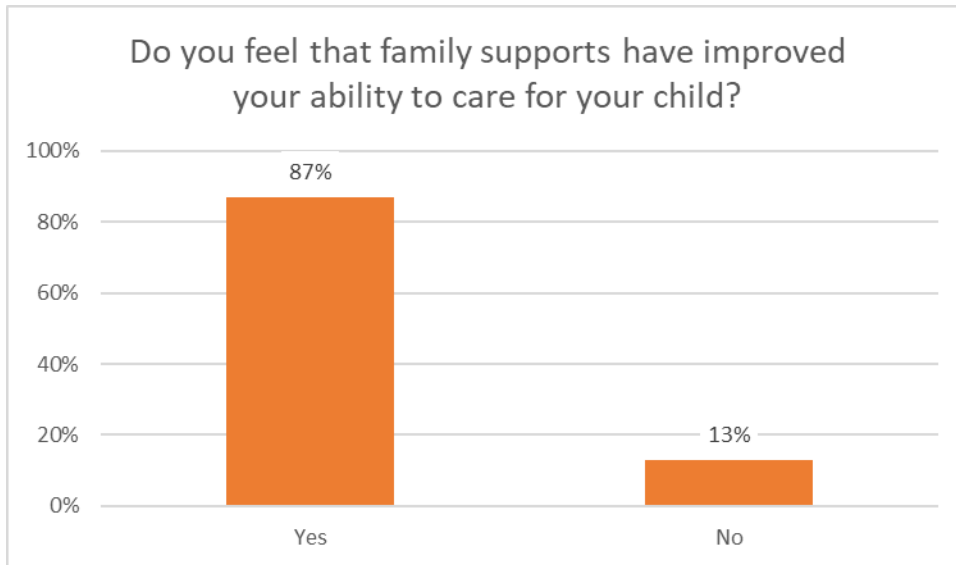


Table Q55. Do you feel that family supports have improved your ability to care for your child?

#### Significantly Above Average

State	Yes	No	N
SD	96%	4%	273
AZ	95%	5%	159
MN	95%	5%	389
OR	94%	6%	627

#### Within Average Range

State	Yes	No	N
NC	91%	9%	194
CO	90%	10%	187
LA	89%	11%	373
WI	88%	12%	870
<b>NCI Average</b>	<b>87%</b>	<b>13%</b>	<b>12,485</b>
CA	87%	13%	8,744
MO	86%	14%	205
WA	83%	17%	245

#### Significantly Below Average

State	Yes	No	N
OH	79%	21%	219

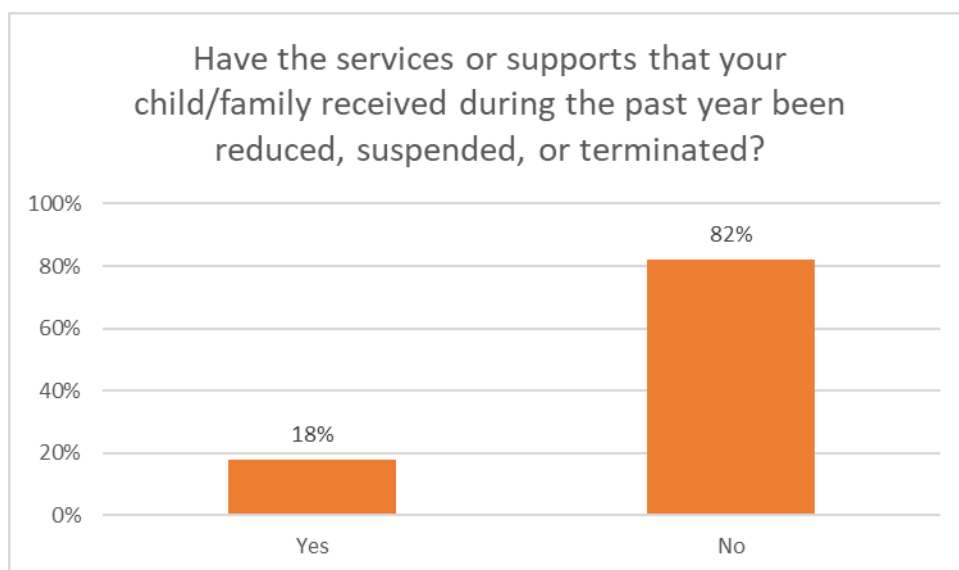


Table Q56. Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?

#### Significantly Above Average

State	Yes	No	N
NC	26%	74%	189

#### Within Average Range

State	Yes	No	N
LA	22%	78%	376
AZ	21%	79%	155
MN	20%	80%	397
CO	19%	81%	183
CA	18%	82%	9,163
<b>NCI Average</b>	<b>18%</b>	<b>82%</b>	<b>12,940</b>
WI	18%	82%	900
MO	17%	83%	224
OH	15%	85%	226
WA	15%	85%	246

#### Significantly Below Average

State	Yes	No	N
OR	9%	91%	616
SD	8%	92%	265

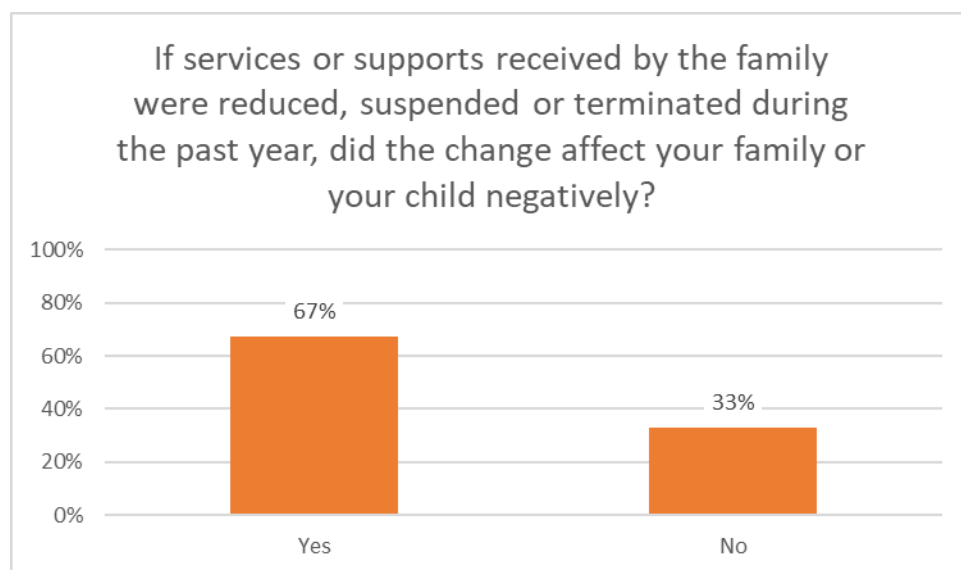


Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change affect your family or your child negatively?<sup>11</sup>

#### Significantly Above Average

State	Yes	No	N
WI	80%	20%	145

#### Within Average Range

State	Yes	No	N
CO	84%	16%	32
OR	81%	19%	53
MN	79%	21%	70
WA	78%	22%	32
MO	70%	30%	33
OH	68%	32%	31
NCI Average	67%	33%	1,992
CA	66%	34%	1,427
NC	64%	36%	47
AZ	62%	38%	29

#### Significantly Below Average

State	Yes	No	N
LA	35%	65%	77

<sup>11</sup> SD is not included in the table due to low N (>20), but SD responses are included in the NCI Average.

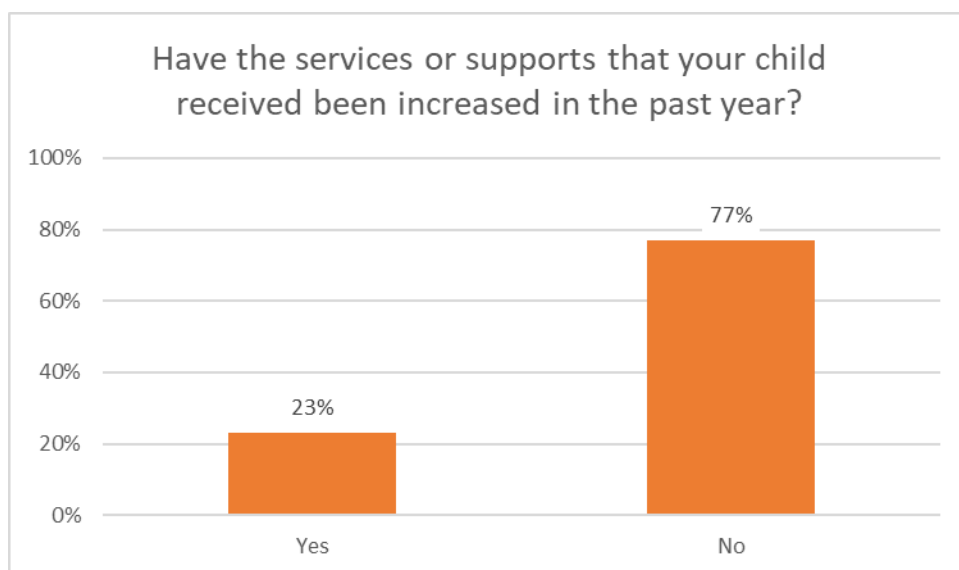


Table Q58. Have the services or supports that your child received been increased in the past year?

#### Within Average Range

State	Yes	No	N
LA	29%	71%	381
MN	28%	72%	378
WA	27%	73%	237
OR	26%	74%	596
CO	26%	74%	185
AZ	26%	74%	159
WI	25%	75%	865
CA	25%	75%	9,231
<b>NCI Average</b>	<b>23%</b>	<b>77%</b>	<b>12,898</b>
SD	22%	78%	230
MO	20%	80%	229

#### Significantly Below Average

State	Yes	No	N
NC	15%	85%	183
OH	15%	85%	224

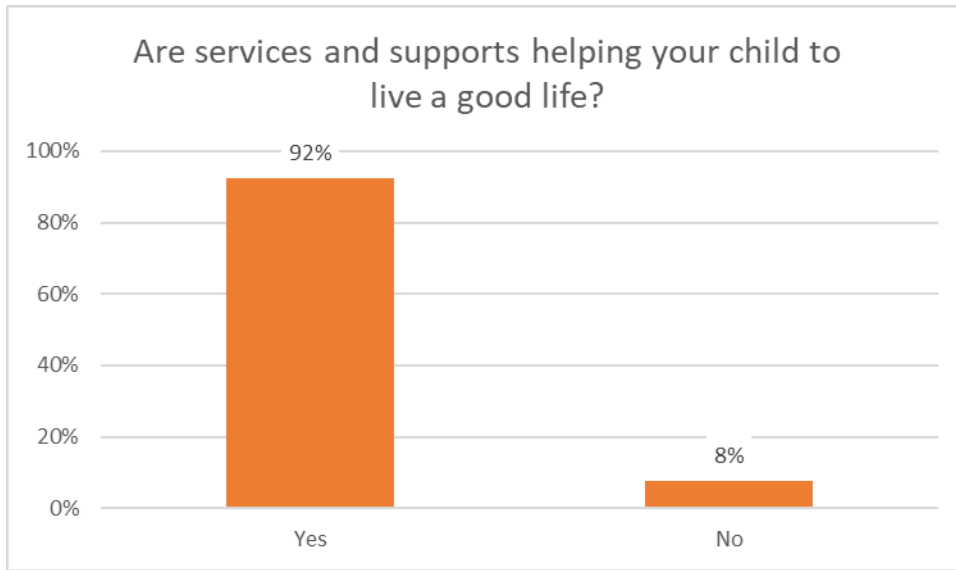


Table Q59. Are services and supports helping your child to live a good life?

#### Significantly Above Average

State	Yes	No	N
MN	97%	3%	396
OR	97%	3%	626
SD	97%	3%	269
AZ	97%	3%	161
WI	95%	5%	856

#### Within Average Range

State	Yes	No	N
CO	96%	4%	181
MO	94%	6%	211
LA	94%	6%	379
NC	94%	6%	188
<b>NCI Average</b>	<b>92%</b>	<b>8%</b>	<b>12,655</b>
CA	91%	9%	8,944
WA	91%	9%	239
OH	89%	11%	205

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

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

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

During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person 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.

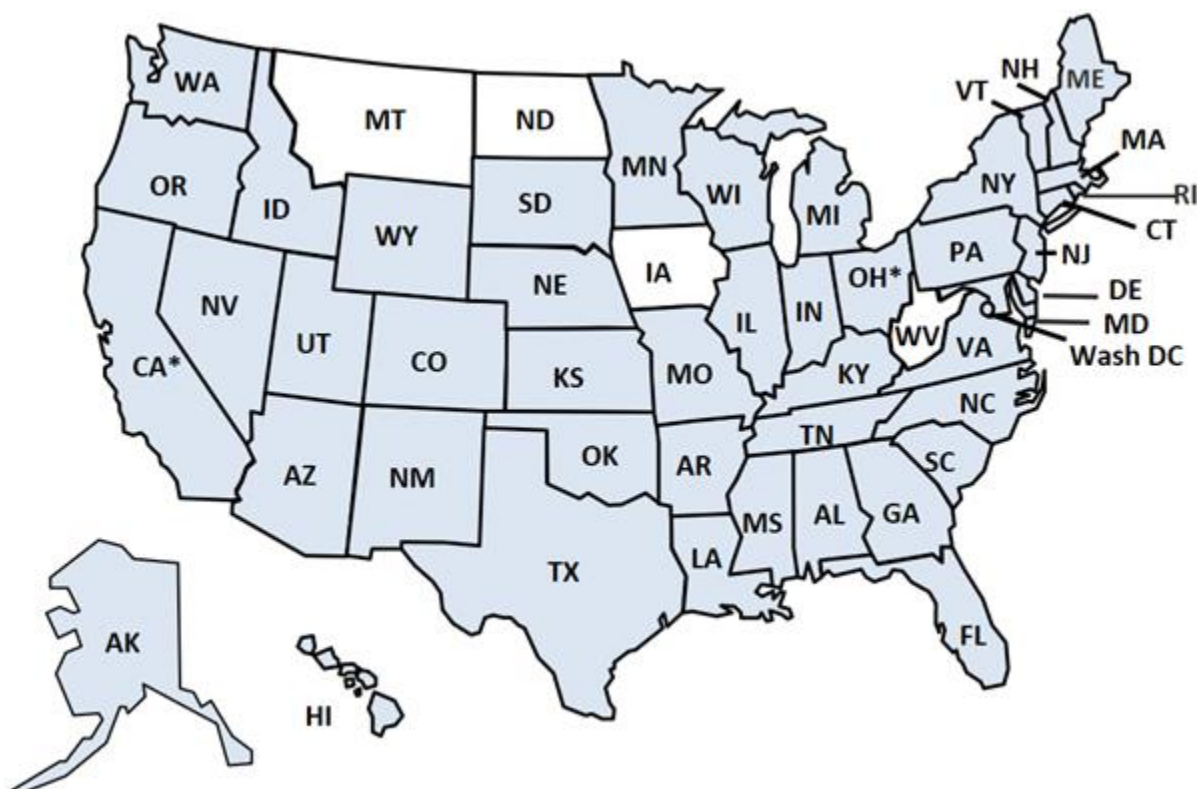
Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI continues to develop and refine the indicators and expand state participation. For more information about NCI states,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

<https://www.nationalcoreindicators.org/>.

## State Participation

During the 2018-19 data collection cycle, 46 states, the District of Columbia, and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and the participating states are shown on the map below.

Figure 1. NCI State Participation 2018-19



## 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 complete list of Core Indicators, please visit the Indicators page on the NCI website at <https://www.nationalcoreindicators.org/indicators>.

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly

participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

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

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

The data collection tools used to gather indicator data are regularly refined and tested to ensure they remain valid, reliable, and applicable to current issues within the field. Details on the design and 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.

Figure 2. 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, Decision Making & 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.
Involvement in the Community	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 (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).

For more information on how to use these data for quality improvement, please see this handbook: [Using National Core Indicators for Quality Improvement Initiatives](#).<sup>12</sup>

<sup>12</sup> Located on the National Core Indicators website: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org) →Resources →Technical Reports

## 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.

# 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 child<sup>13</sup> with a developmental disability living at home; and
2. Received at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys. A total of eight states had at least a portion of surveys completed via direct entry for the 2018-19 data collection cycle.<sup>14</sup>

A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.<sup>15</sup>

### Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI reports, we use “NCI average” to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). The approach has since been enhanced to consider the relative numbers of people receiving services through participating states’ systems. The NCI averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states, as well as the sample sizes.

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<sup>13</sup> A Child Family Survey could be completed for an individual up to 22 years if still receiving “child” services.

<sup>14</sup> States that used the direct entry or mail and direct entry options were: CA, CO, LA, NC, OH, OR, WA and WI.

<sup>15</sup> See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average—that is, the state’s contribution to the NCI average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.

## Significance Testing

For each of the items in the report, each state’s percentage was compared to the weighted NCI average (described above), and the differences between the two were tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state’s result depends in part on the size of the state’s sample—the larger the sample, the more likely it is that even a small difference will be found *statistically* significant. A statistically significant difference for a state with a large sample size, in and by itself, does not necessarily mean there is a *practically* significant difference. The inclusion of effect sizes allows us to present “meaningfully significant” results, which take the magnitude or size of the differences into account.

The state percentages in this report are categorized into one of three classes:

1. **Significantly above the NCI average**, where the difference between the state’s percentage and the weighted NCI average: a) was in favor of the state, b) was statistically significant (i.e.,  $p < .01$ ), **and** c) met the effect size criterion (i.e., Cohen’s  $d > 0.2$ , see below for details);
2. **Within the NCI average range**, where the difference between the state’s percentage and the weighted NCI average was: a) not statistically significant (i.e.,  $p \geq .01$ ), **or** b) did not meet the effect size criterion (i.e., Cohen’s  $d \leq 0.2$ ); or
3. **Significantly below the NCI average**, where the difference between the state’s percentage and the weighted NCI average: a) was in favor of the NCI average, b) was statistically significant (i.e.,  $p < .01$ ), **and** c) met the effect size criterion (i.e., Cohen’s  $d > 0.2$ ).

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.

## Technical Details

The comparisons were done through one sample t-tests using the weighted NCI average as the benchmark. A conservative cut-off point (alpha) of  $p < .01$  was used to detect statistically significant differences. Effect sizes are calculated using the formula: Cohen's  $d = \frac{2t}{\sqrt{df}}$ . A cutoff point of Cohen's  $d = 0.2$  was chosen for the effect size to be considered “meaningfully significant,” following the standard interpretation offered by Cohen (1988) that Cohen's  $d$  of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

## Data Entry and Analysis

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

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

1. The respondent indicated the child with an intellectual or developmental disability receiving services lived outside of the family home.
2. Demographic information was entered into the file but no survey questions were answered.

Statistical significance testing was conducted on each state's “yes” or “always” response compared to the NCI average<sup>16</sup>; 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 2018-19, 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 following table shows the number of surveys each state sent, surveys returned, response rates, and the number of valid surveys accepted for inclusion in data analysis.

<sup>16</sup> The NCI Average is the sum of all state averages divided by the total number of states.

Child Family Survey: State Response Rates <sup>17</sup>

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	15,420	1,400	172	12.3%	7.4%	100%	0%
CA	71,236	71,236	10,630	14.9%	0.9%	86%	14%
CO	1,763	1,600	197	12.3%	6.6%	0%	100%
LA	3,922	3,784	411	10.9%	4.6%	84%	16%
MN	5,244	TBD	429	TBD	4.5%	100%	0%
MO	3,763	1,500	247	16.5%	6.0%	100%	0%
NC	2,753	1,200	202	16.8%	6.6%	87%	13%
OH	26,738	1,200	268	22.3%	6.0%	9%	91%
OR	3,892	3,883	681	17.5%	3.4%	90%	10%
SD	921	921	289	31.4%	4.8%	100%	0%
WA	5,651	2,000	303	15.2%	5.5%	46%	54%
WI	9,018	8,732	987	11.3%	2.9%	65%	35%
<b>Total</b>	<b>150,021</b>	<b>97,456</b>	<b>14,816</b>	<b>15.2%</b>	<b>4.9%</b>	<b>71%</b>	<b>29%</b>

<sup>17</sup> Please note: The family surveys are mail out surveys or completed online by respondents who choose to take part in the survey. As such, the final sample is a sample of convenience and cannot be considered representative of the entire service population in the state.