

Child Family Survey

2017-18 Final Report



NATIONAL CORE INDICATORS

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



Human Services
Research Institute

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List of Abbreviations Used in This Report

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

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Executive Summary

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

The NCI Child Family Survey is administered to families who have a child with a developmental disability who lives in the family's home and receives at least one service other than case management.¹ 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 2017-18 data collection cycle, eight (8) states submitted a valid sample of Child Family Survey data: Arizona (AZ), Louisiana (LA), Missouri (MO), North Carolina (NC), Oregon (OR), Texas (TX), Utah (UT) and Wisconsin (WI). This Final Report provides a summary of results based on data submitted by June 30, 2018.

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.

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

2017-18 Child Family Survey

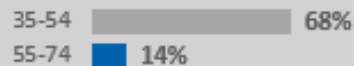
NCI Average Data

- All participating states
- Data are weighted

4,236 families/guardians participated in the 2017-18 Child Family Survey in 8 states*.

Respondents are families and/or guardians who share a home with a child who has I/DD and receives at least one public service in addition to case management from the state DD agency.

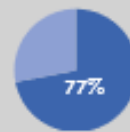
Most respondents are in the 35-54 age category, but **14% are 55+.**



29% reported an annual taxable household income of \$25K or less



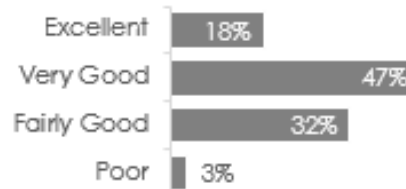
77% say their family gets needed supports



36% say they're always satisfied with services and supports



Self-Reported Health Status of Respondents



The child family member with I/DD . . .

66% are male

11 is the average age

Child takes part in community activities



Child spends time with children without I/DD



Child always has access to special equipment/accommodations



*AZ, LA, MO, NC, OR, TX, UT, WI; NCI Average is weighted

Respondents are families and/or guardians who share a home with a child who has I/DD and receives at least one public service in addition to case management from the state DD agency.

2017-18 Child Family Survey

Always receive enough info to help plan services for their child



Say the info they receive is always easy to understand



Can always choose or change the agency that provides supports



64%

Say support workers arrive on time and leave when they're supposed to



78%

Say their child gets all services listed in the service plan



80%

Say services are always delivered in a way that respects their family's culture

Results

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

Survey Development

The NCI Child Family Survey was first developed and administered in 2000–2001, in response to state interest in determining the level of satisfaction with services and supports among families of children with intellectual and developmental disabilities living at home. Since that time, NCI has routinely refined the survey instrument based on feedback from families and state staff.

Most participating states use the standard NCI survey instrument described here, but some states incorporate additional questions to look more deeply at specific issues. These supplementary questions are typically added after a state has participated in NCI for at least a year and established 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 family member with a developmental disability (e.g., age, race, type of disability) followed by a series of demographic questions pertaining to the survey respondent (e.g., age, health status, relationship to the individual with the developmental disability).

Services and Supports Received

A brief section of the survey asks the respondent to identify the services and supports that they and/or their family member with a developmental disability receive.

Questions Regarding Services and Supports

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

Each question is constructed so the respondent selects from either 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.

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 survey. For each question, the results are first shown in a graph that depicts the NCI Average and then in a set of tables that break out each state's percentages. 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, or significantly below the NCI Average. Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI Average range, their 'always' or 'yes' response was not statistically different from the NCI Average.

States 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 Texas sample: While the prescribed mode of administration for CFS is mail-in paper surveys or direct entry online, Texas sought to increase the response rate to the CFS surveys by allowing for three modes of administration: paper, web, and phone. Texas mailed out invitation letters to program participants asking them to participate and providing them with a telephone number and web link so that they could complete the survey by phone or web. Both options were available in both English and Spanish. After a month, Texas sent out paper surveys (available in Spanish and English) to everyone on the sampling frame who had not responded by phone or web.

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

Demographics

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	21%	79%	167
LA	18%	82%	269
MO	23%	77%	172
NC	22%	78%	219
OR	24%	76%	905
TX	21%	79%	1,236
UT	25%	75%	146
WI	19%	81%	974
NCI Average	21%	79%	4,088

Table 2. Child's Age

State	Age	N
AZ	9.8	172
LA	4.8	275
MO	10.6	177
NC	14.3	219
OR	11.9	909
TX	15.6	1,243
UT	13.0	149
WI	10.4	1,062
NCI Average	11.4	4,206

Table 3. Child's Gender

State	Male	Female	N
AZ	68%	32%	174
LA	62%	38%	272
MO	75%	25%	176
NC	69%	31%	220
OR	67%	33%	897
TX	62%	38%	1,238
UT	64%	36%	148
WI	65%	35%	1,006
NCI Average	66%	34%	4,131

Table 4a. Child's Disabilities ∞

State	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
AZ	37%	11%	56%	16%	7%	3%
LA	25%	7%	28%	7%	4%	5%
MO	28%	17%	59%	10%	7%	3%
NC	57%	21%	63%	20%	7%	2%
OR	49%	21%	58%	12%	6%	5%
TX	76%	26%	45%	25%	25%	11%
UT	59%	29%	53%	21%	11%	7%
WI	40%	16%	49%	12%	7%	5%
NCI Average	48%	17%	51%	16%	11%	6%

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

State	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
AZ	6%	17%	0%	10%	0%	3%	24%
LA	4%	15%	2%	8%	0%	1%	40%
MO	7%	18%	0%	9%	1%	0%	31%
NC	6%	27%	0%	14%	1%	1%	25%
OR	7%	21%	1%	10%	0%	6%	26%
TX	20%	45%	4%	14%	1%	1%	43%
UT	15%	31%	1%	14%	3%	1%	21%
WI	8%	24%	0%	15%	1%	1%	30%
NCI Average	10%	26%	1%	12%	0%	2%	31%

Table 5a. Child's Health Conditions ∞

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	13%	4%	0%	11%	13%
LA	20%	2%	2%	3%	3%
MO	11%	2%	0%	4%	7%
NC	17%	5%	0%	6%	6%
OR	11%	5%	3%	3%	7%
TX	15%	5%	2%	9%	9%
UT	14%	2%	3%	3%	0%
WI	14%	3%	2%	6%	3%
NCI Average	14%	4%	1%	8%	8%

∞ Categories are not mutually exclusive

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

State	Dysphagia	Pressure Ulcers	Oral Health or Dental Problems	Sleep Apnea	Other
AZ	13%	2%	11%	27%	51%
LA	16%	0%	9%	8%	44%
MO	14%	0%	7%	32%	44%
NC	16%	1%	6%	28%	50%
OR	22%	2%	14%	24%	43%
TX	37%	5%	19%	38%	54%
UT	34%	5%	20%	44%	34%
WI	23%	2%	16%	22%	49%
NCI Average	24%	3%	14%	29%	50%

Table 6. Child's Race and Ethnicity ∞

State	American Indian or Alaska Native	Asian	Black or African American	Hawaiian or Pacific Islander	White	Hispanic or Latino	Other	N
AZ	6%	4%	9%	1%	64%	31%	1%	174
LA	2%	2%	31%	0%	66%	6%	1%	265
MO	3%	5%	10%	0%	83%	5%	2%	176
NC	2%	2%	24%	0%	68%	7%	3%	223
OR	4%	8%	4%	1%	80%	16%	1%	907
TX	3%	4%	15%	0%	56%	44%	1%	1,231
UT	1%	3%	2%	3%	91%	11%	0%	149
WI	3%	3%	8%	0%	87%	7%	1%	1,018
NCI Average	4%	4%	13%	0%	69%	23%	1%	4,143

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	72%	20%	2%	5%	2%	176
LA	51%	34%	3%	2%	9%	272
MO	76%	14%	2%	6%	1%	173
NC	62%	27%	1%	4%	5%	218
OR	70%	19%	2%	6%	1%	894
TX	59%	26%	5%	6%	4%	1,184
UT	58%	37%	1%	3%	1%	147
WI	62%	25%	4%	6%	3%	990
NCI Average	65%	24%	3%	5%	3%	4,054

∞ Categories are not mutually exclusive

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

State	Extensive	Some	None	N
AZ	16%	47%	38%	173
LA	12%	29%	59%	266
MO	17%	46%	37%	172
NC	32%	39%	30%	222
OR	34%	46%	20%	899
TX	28%	33%	39%	1,219
UT	37%	45%	18%	148
WI	18%	36%	46%	1,020
NCI Average	22%	40%	39%	4,119

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

State	Extensive	Some	None	N
AZ	55%	43%	3%	176
LA	56%	36%	7%	267
MO	41%	41%	18%	175
NC	55%	39%	7%	220
OR	56%	41%	3%	916
TX	64%	31%	6%	1,239
UT	72%	27%	1%	149
WI	55%	39%	6%	1,035
NCI Average	56%	38%	6%	4,177

Respondents

This section provides demographic information about the respondent.

Table 10. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
AZ	18%	71%	11%	0%	177
LA	42%	46%	12%	0%	273
MO	21%	72%	7%	0%	173
NC	10%	69%	20%	1%	221
OR	11%	73%	16%	0%	920
TX	7%	70%	22%	1%	1,241
UT	13%	73%	14%	0%	149
WI	19%	69%	11%	1%	1,056
NCI Average	17%	68%	14%	0%	4,210

Table 11. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
AZ	20%	48%	31%	1%	177
LA	24%	46%	27%	3%	271
MO	16%	48%	32%	3%	177
NC	12%	48%	36%	4%	223
OR	16%	46%	35%	4%	916
TX	17%	43%	34%	7%	1,226
UT	21%	48%	28%	3%	149
WI	16%	52%	29%	2%	1,056
NCI Average	18%	47%	32%	3%	4,195

Table 12. Respondent's Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
AZ	97%	0%	2%	1%	176
LA	88%	0%	7%	5%	272
MO	100%	0%	0%	0%	177
NC	91%	0%	6%	2%	223
OR	93%	1%	6%	1%	919
TX	92%	0%	5%	3%	1,243
UT	99%	0%	1%	0%	149
WI	96%	0%	3%	1%	1,058
NCI Average	94%	0%	4%	2%	4,217

Table 13. Respondent or Other Family Member Provides Paid Support to Child

State	No	Respondent	Other Family Member	N
AZ	78%	3%	19%	175
LA	89%	7%	4%	272
MO	94%	3%	3%	176
NC	86%	5%	10%	221
OR	66%	6%	28%	911
TX	63%	12%	26%	1,226
UT	51%	1%	48%	149
WI	80%	7%	14%	1,050
NCI Average	76%	6%	18%	4,180

Table 14. Number of Adults in Household

State	One	Two	Three	Four or More	N
AZ	15%	62%	15%	8%	175
LA	25%	61%	9%	6%	268
MO	18%	68%	12%	2%	176
NC	20%	53%	19%	7%	221
OR	20%	60%	13%	8%	903
TX	18%	47%	23%	12%	1,227
UT	12%	58%	21%	9%	149
WI	17%	66%	13%	5%	1,050
NCI Average	18%	59%	16%	8%	4,169

Table 15. Number of Children in Household (including child receiving services about whom survey is being completed)

State	One	Two	Three	Four or More	N
AZ	32%	38%	18%	12%	172
LA	41%	36%	12%	11%	266
MO	30%	39%	22%	9%	172
NC	49%	33%	11%	7%	209
OR	37%	37%	15%	11%	871
TX	42%	35%	15%	8%	940
UT	25%	24%	24%	27%	149
WI	34%	37%	19%	10%	1,017
NCI Average	37%	37%	17%	10%	3,796

Table 16. 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	8%	18%	5%	16%	52%	173
LA	12%	23%	5%	17%	42%	270
MO	3%	17%	5%	18%	58%	175
NC	7%	19%	4%	20%	50%	224
OR	9%	14%	9%	21%	47%	903
TX	14%	16%	7%	21%	41%	1,221
UT	5%	9%	5%	26%	54%	149
WI	3%	16%	11%	19%	51%	1,051
NCI Average	9%	18%	7%	19%	48%	4,166

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

State	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	No Earned Income	Prefer Not to Say	N
AZ	7%	12%	17%	14%	29%	4%	17%	173
LA	20%	10%	12%	13%	26%	14%	4%	269
MO	10%	9%	17%	26%	25%	4%	9%	170
NC	11%	11%	18%	13%	24%	11%	12%	221
OR	10%	14%	19%	14%	27%	6%	11%	904
TX	15%	13%	20%	12%	21%	6%	12%	1,181
UT	3%	7%	17%	18%	35%	5%	15%	144
WI	7%	9%	16%	18%	33%	5%	11%	1,039
NCI Average	11%	12%	17%	15%	27%	6%	12%	4,101

Table 18. Residential Designation (Urban, Rural, or Suburban)

State	Urban or Suburban	Rural	N
AZ	87%	13%	164
LA	60%	40%	247
MO	64%	36%	170
NC	53%	47%	218
OR	77%	23%	878
TX	71%	29%	1,217
UT	77%	23%	144
WI	65%	35%	1,016
NCI Average	72%	28%	4,054

Services and Supports Received

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

Table 19. Services and Supports Received From IDD Agency

State	Financial Support	In-home Support	Out-of-home Respite	Early Intervention	Transportation	Other	Self-direction or Fiscal Intermediary Services
AZ	10%	63%	42%	20%	23%	90%	26%
LA	19%	31%	6%	66%	13%	70%	22%
MO	22%	22%	18%	13%	13%	72%	19%
NC	13%	77%	46%	2%	31%	74%	29%
OR	19%	76%	46%	7%	30%	61%	60%
TX	14%	66%	43%	2%	22%	55%	44%
UT	11%	75%	51%	4%	32%	60%	88%
WI	35%	42%	38%	23%	20%	76%	29%
NCI Average	17%	57%	37%	18%	22%	73%	34%

Table 20. Other Services or Supports Received

State	Social Security Payments (SSI/SSB)	Services or Supports from Other Agencies or Organizations
AZ	30%	66%
LA	26%	34%
MO	32%	78%
NC	53%	66%
OR	44%	75%
TX	67%	42%
UT	23%	78%
WI	33%	73%
NCI Average	41%	61%

Child Family Survey Results

Please Note:

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.

“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.

Gets Enough Information To Help Plan Services

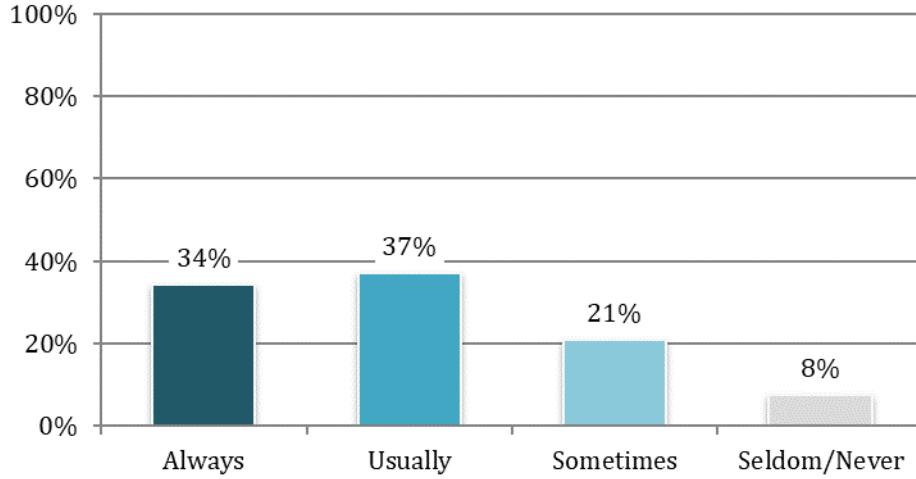


Table Q1. Do you get enough information to help you participate in planning services for your family?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	47%	31%	14%	8%	241

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	36%	28%	23%	12%	1,193
NCI Average	34%	37%	21%	8%	4,026
NC	34%	36%	25%	5%	217
UT	34%	51%	13%	1%	144
AZ	33%	40%	23%	5%	172
MO	32%	41%	17%	10%	162
OR	31%	44%	19%	6%	875
WI	31%	42%	20%	7%	1,022

Information About Services And Supports Is Easy To Understand

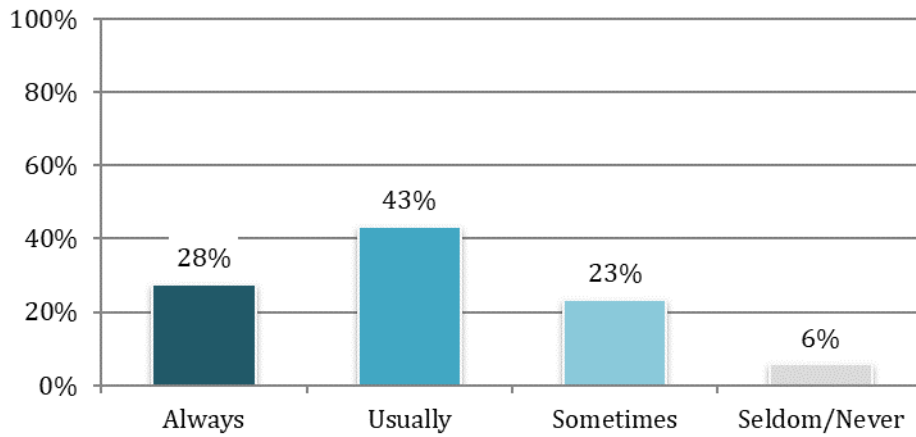


Table Q2. Is the information you receive easy to understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	38%	40%	18%	4%	255

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	32%	31%	28%	9%	1,210
AZ	29%	49%	19%	3%	177
NCI Average	28%	43%	23%	6%	4,072
MO	28%	48%	18%	6%	163
UT	19%	57%	23%	1%	145

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	22%	50%	22%	6%	900
WI	21%	46%	26%	7%	1,003
NC	19%	44%	32%	6%	219

Case Manager Or Service Coordinator Respects Family's Choices And Opinions

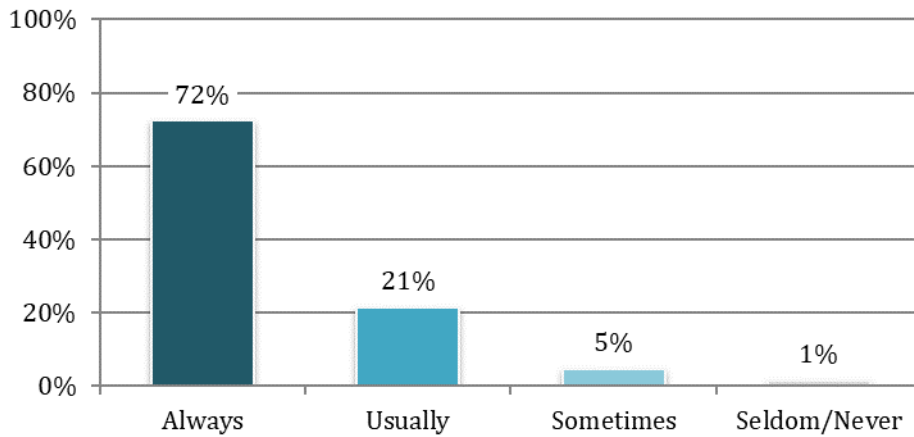


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	84%	14%	1%	0%	147
LA	83%	15%	2%	1%	247

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	74%	16%	7%	3%	1,180
AZ	73%	23%	3%	1%	172
NCI Average	72%	21%	5%	1%	3,964
OR	71%	23%	5%	1%	877
MO	70%	26%	2%	2%	153
NC	65%	28%	6%	1%	199

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	67%	26%	6%	1%	989

Gets Enough Information About Other Public Services For Which Family Is Eligible

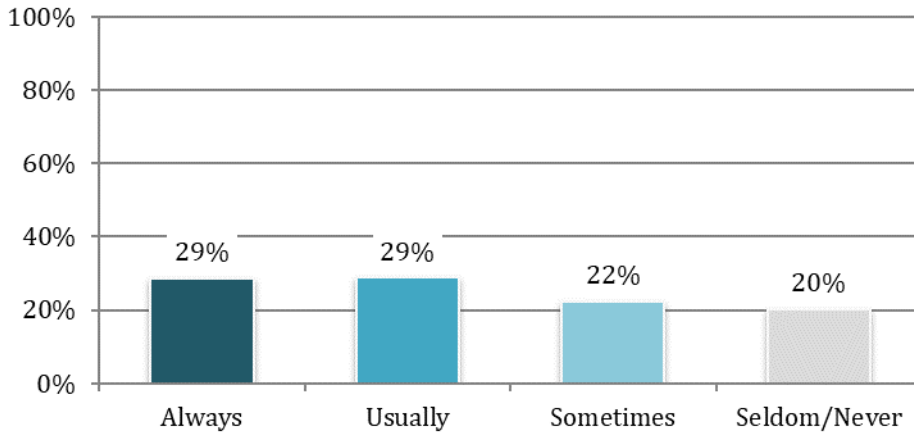


Table Q4. Do you have enough information about other public services for which your family is eligible?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	37%	27%	14%	22%	196
TX	31%	24%	24%	21%	1,156
NCI Average	29%	29%	22%	20%	3,540
AZ	28%	26%	23%	24%	137
OR	27%	37%	22%	13%	779
MO	26%	36%	22%	15%	137
NC	25%	31%	25%	19%	191
WI	25%	35%	23%	18%	828
UT	23%	42%	22%	13%	116

Respondent Needs Help Planning for Family Member's Future Needs

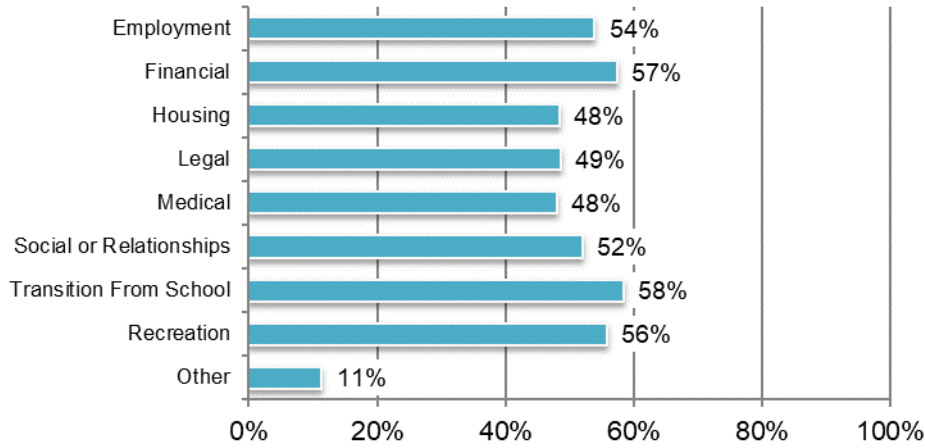


Table Q5. Do you need help planning for your child's future with respect to any of the following?

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition from School	Recreation	Other
AZ	53%	53%	47%	47%	44%	58%	60%	59%	8%
LA	33%	48%	32%	31%	47%	41%	43%	39%	15%
MO	54%	58%	47%	42%	49%	53%	56%	48%	16%
NC	56%	62%	53%	52%	38%	46%	61%	48%	13%
OR	63%	64%	55%	49%	49%	56%	62%	59%	8%
TX	57%	58%	48%	56%	57%	47%	58%	60%	15%
UT	52%	57%	46%	60%	42%	44%	66%	50%	8%
WI	56%	64%	54%	50%	48%	54%	60%	56%	9%
NCI Average	54%	57%	48%	49%	48%	52%	58%	56%	11%

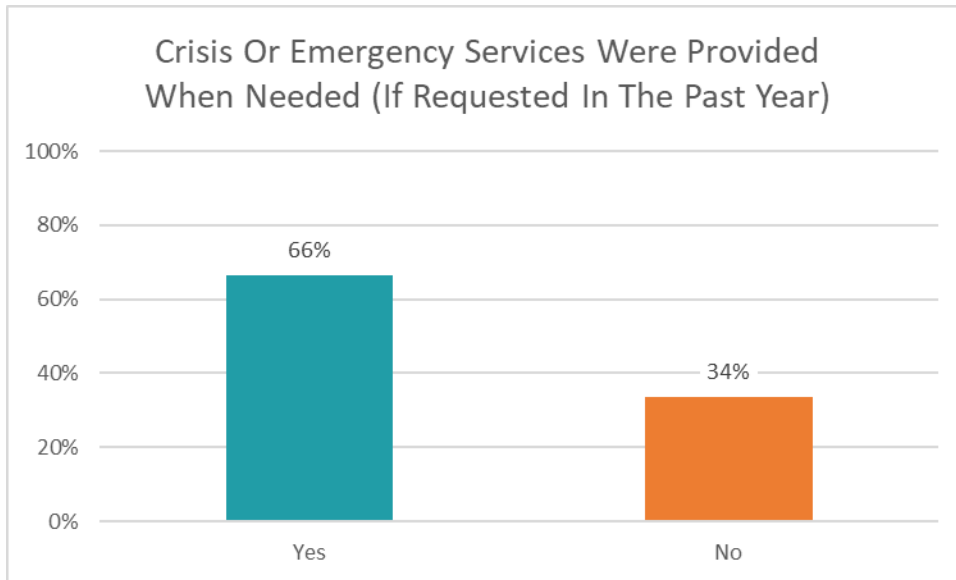


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

Within Average Range

State	Yes	No	N
AZ	74%	26%	57
TX	72%	28%	404
UT	67%	33%	24
NCI Average	66%	34%	1,012
NC	62%	38%	58
LA	61%	39%	54
MO	48%	52%	33

Significantly Below Average

State	Yes	No	N
WI	51%	49%	182
OR	50%	51%	200

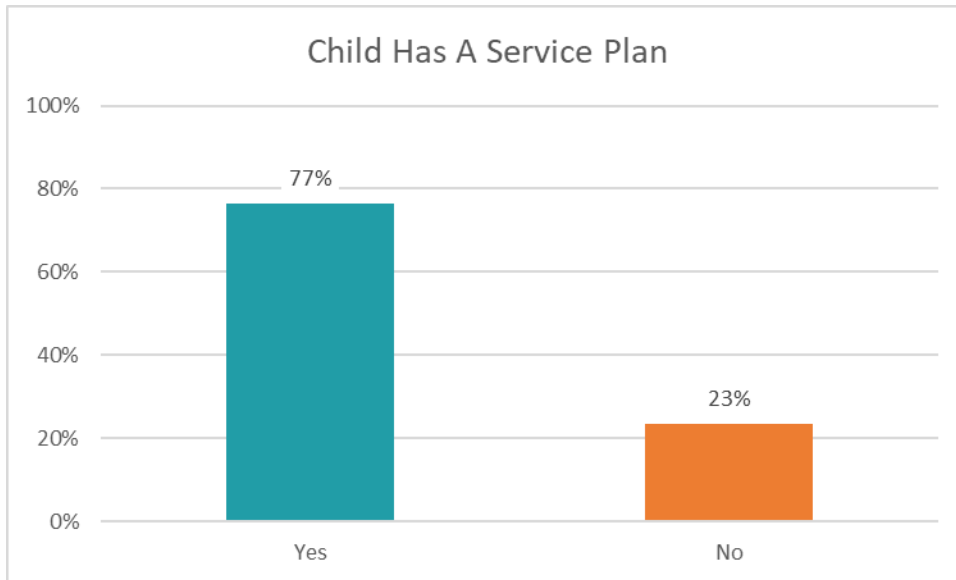


Table Q7. Does your child have a service plan?

Significantly Above Average

State	Yes	No	N
OR	86%	14%	770
AZ	86%	14%	152

Within Average Range

State	Yes	No	N
NC	83%	17%	203
UT	80%	20%	124
NCI Average	77%	23%	3,552
TX	76%	24%	1,041
MO	70%	30%	158

Significantly Below Average

State	Yes	No	N
WI	69%	31%	898
LA	50%	50%	206

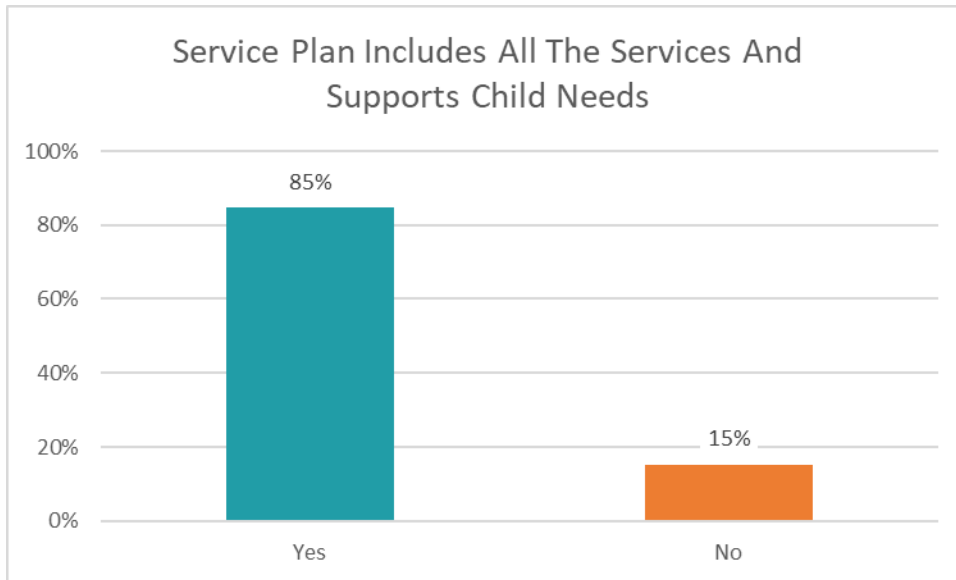


Table Q8. Does the plan include all the services and supports your child needs?

Significantly Above Average

State	Yes	No	N
LA	95%	5%	95
UT	93%	7%	95

Within Average Range

State	Yes	No	N
TX	87%	13%	745
OR	86%	14%	571
NCI Average	85%	15%	2,449
MO	84%	16%	101
WI	84%	16%	567
AZ	83%	17%	121
NC	81%	19%	154

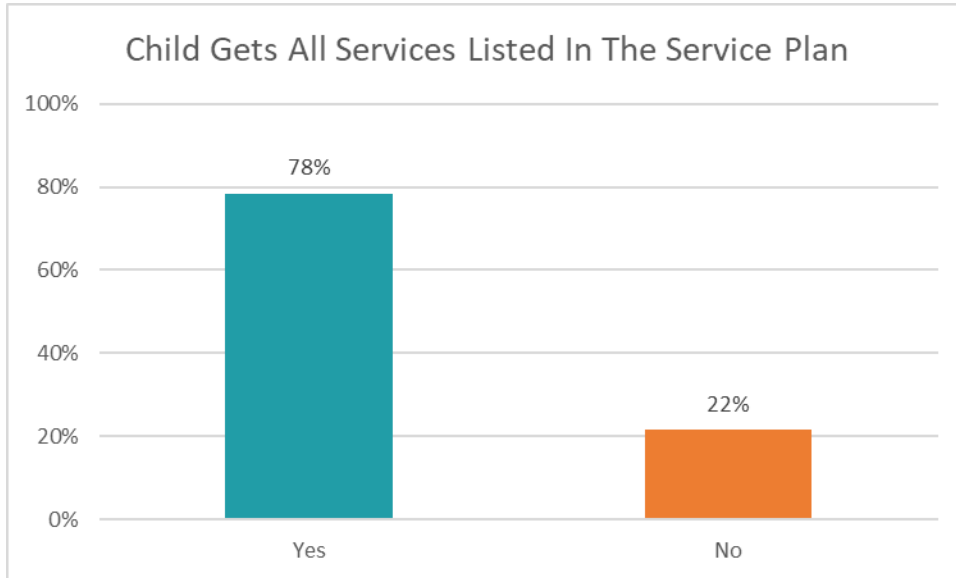


Table Q9. Does your child receive all of the services listed in the plan?

Significantly Above Average

State	Yes	No	N
UT	94%	6%	94
LA	90%	10%	94
WI	90%	10%	555

Within Average Range

State	Yes	No	N
MO	83%	17%	101
OR	82%	18%	577
NC	79%	21%	152
NCI Average	78%	22%	2,421
TX	77%	23%	725
AZ	71%	29%	123

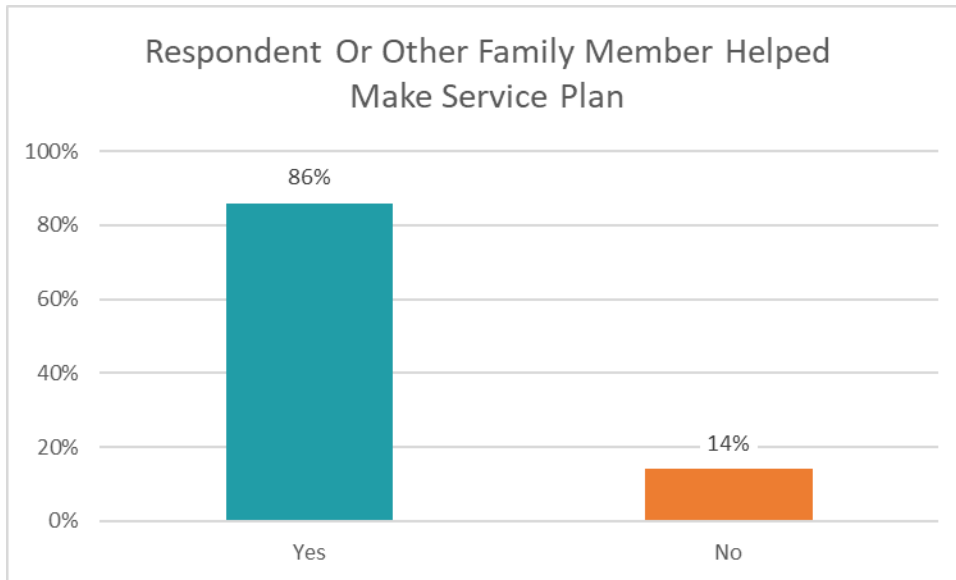


Table Q10. Did you or another family member help develop the plan?

Significantly Above Average

State	Yes	No	N
UT	95%	5%	98
NC	92%	8%	164

Within Average Range

State	Yes	No	N
OR	89%	11%	635
NCI Average	86%	14%	2,585
LA	86%	14%	99
AZ	86%	14%	125
TX	85%	15%	764
WI	85%	15%	591
MO	80%	20%	109

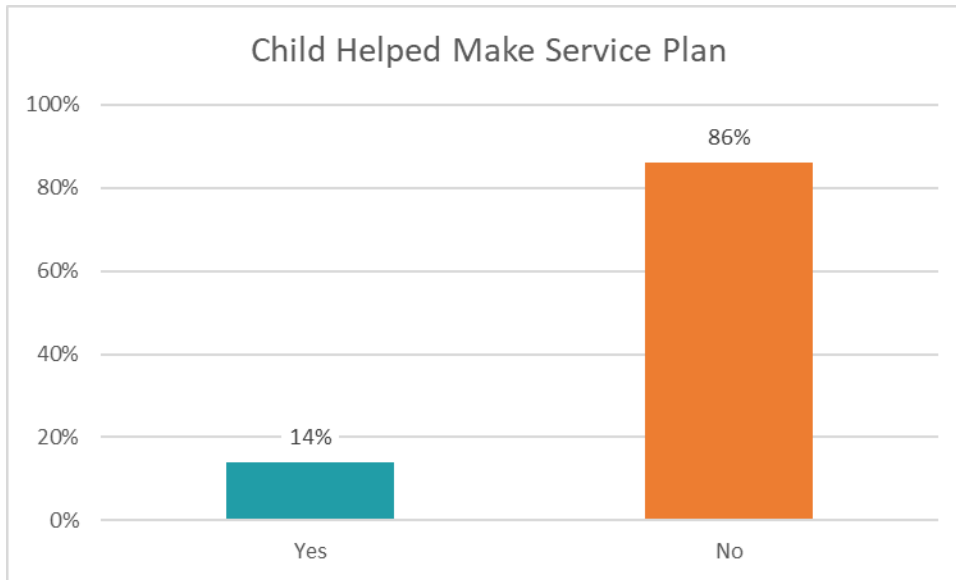


Table Q11. Did your child help develop the plan?

Significantly Above Average

State	Yes	No	N
TX	20%	80%	772
OR	20%	80%	641

Within Average Range

State	Yes	No	N
NCI Average	14%	86%	2,613
WI	14%	86%	601
UT	13%	87%	99
NC	11%	89%	166
MO	11%	89%	108
AZ	10%	90%	127
LA	7%	93%	99

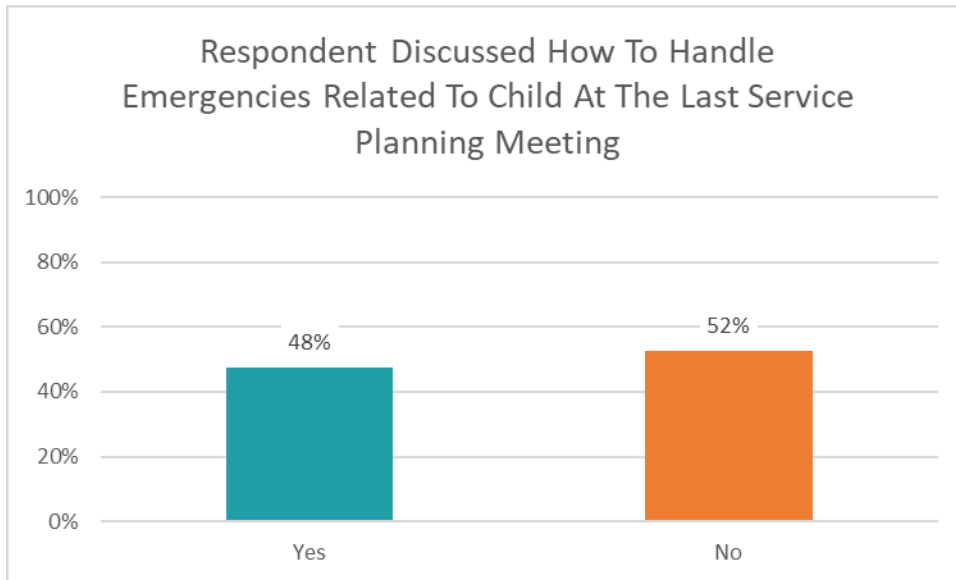


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your child's last service planning meeting?

Significantly Above Average

State	Yes	No	N
TX	69%	31%	730
LA	63%	37%	82
NC	63%	37%	155
OR	57%	43%	571

Within Average Range

State	Yes	No	N
UT	53%	47%	89
NCI Average	48%	52%	2,357
MO	36%	64%	94

Significantly Below Average

State	Yes	No	N
WI	32%	68%	529
AZ	30%	70%	107

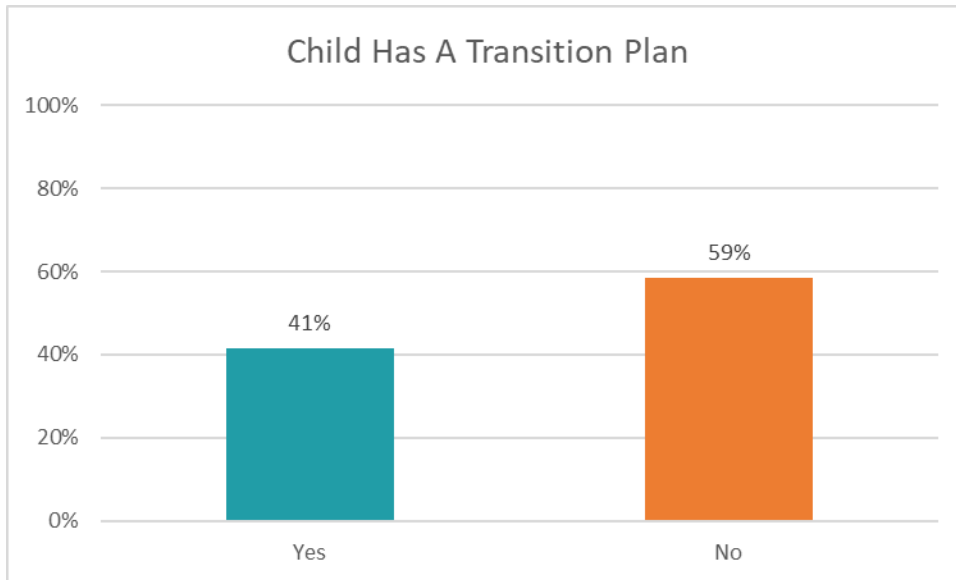


Table Q13. Does your child have a transition plan (as part of an IEP or Section 504 plan through his/her high school, usually starting at age 14)?

Significantly Above Average

State	Yes	No	N
WI	68%	32%	311

Within Average Range

State	Yes	No	N
UT	71%	29%	65
NC	62%	38%	123
MO	62%	38%	47
OR	61%	39%	305
NCI Average	59%	41%	1697
TX	56%	44%	768
LA	55%	45%	29
AZ	55%	45%	49

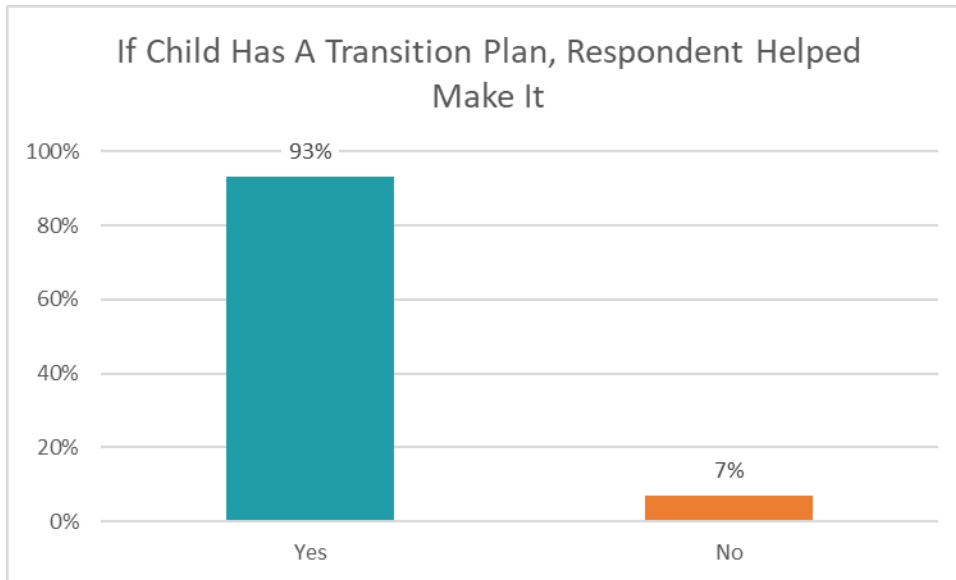


Table Q14. If your child has a transition plan, did you help make the transition plan?

Within Average Range

State	Yes	No	N
MO	100%	0%	28
AZ	96%	4%	26
NCI Average	93%	7%	925
WI	92%	8%	198
TX	92%	8%	364
OR	91%	9%	179
NC	90%	10%	73
UT	88%	12%	43

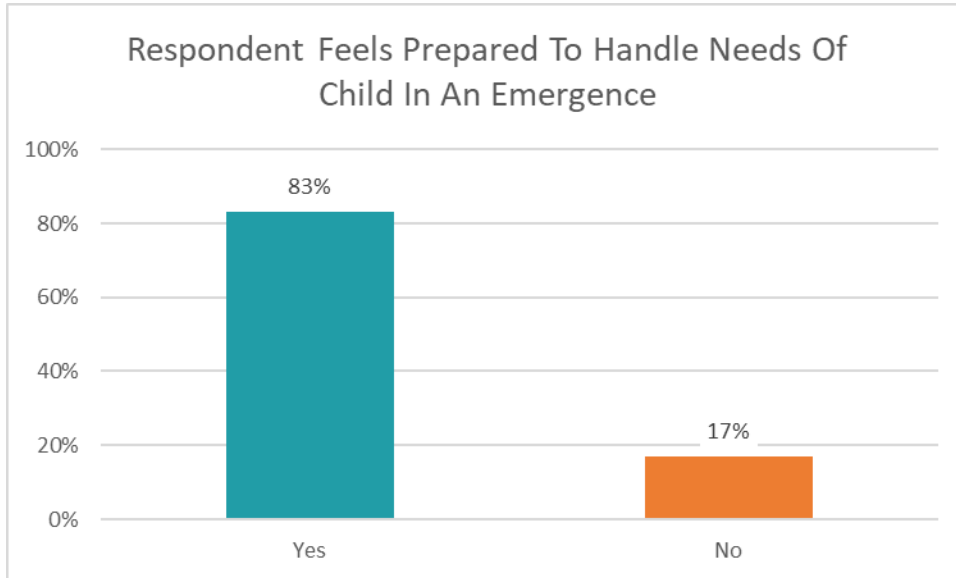


Table Q15. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster?

Significantly Above Average

State	Yes	No	N
LA	94%	6%	242
TX	91%	9%	1,177

Within Average Range

State	Yes	No	N
NC	85%	15%	205
NCI Average	83%	17%	3,764
WI	82%	18%	917
MO	81%	19%	154
AZ	77%	23%	149

Significantly Below Average

State	Yes	No	N
OR	75%	25%	789
UT	69%	31%	131

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.

“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.

Respondent Is Able To Contact Support Workers When Wants

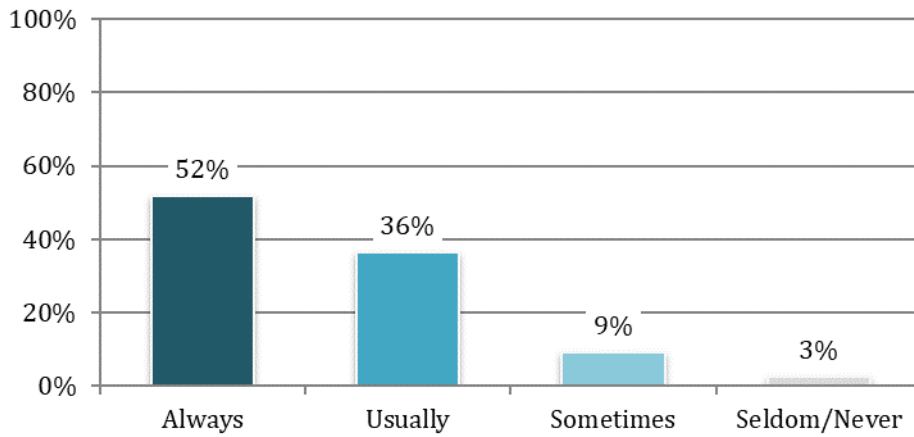


Table Q16. Are you or your child able to contact his/her support workers when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	69%	26%	3%	1%	234
UT	63%	29%	7%	1%	147
TX	57%	29%	10%	4%	1,166

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	54%	35%	9%	2%	205
OR	52%	37%	9%	2%	872
NCI Average	52%	36%	9%	3%	3,869
WI	51%	39%	9%	1%	940
MO	48%	34%	11%	8%	141
AZ	43%	45%	10%	2%	164

Respondent Is Able To Contact Case Manager Or Service Coordinator When Wants

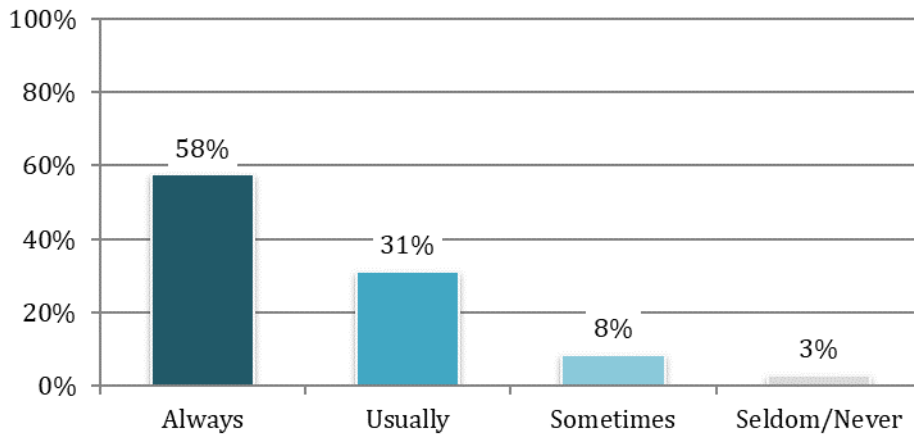


Table Q17. Are you or your child able to contact his/her case manager or service coordinator when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	74%	20%	4%	2%	145
LA	74%	20%	4%	2%	240

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
WI	60%	32%	7%	1%	971
TX	60%	27%	9%	4%	1,183
NC	58%	33%	8%	1%	207
NCI Average	58%	31%	8%	3%	3,960
MO	55%	27%	9%	9%	152
AZ	51%	37%	9%	2%	171

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	51%	36%	11%	2%	891

Support Workers Come And Leave When They Are Supposed To

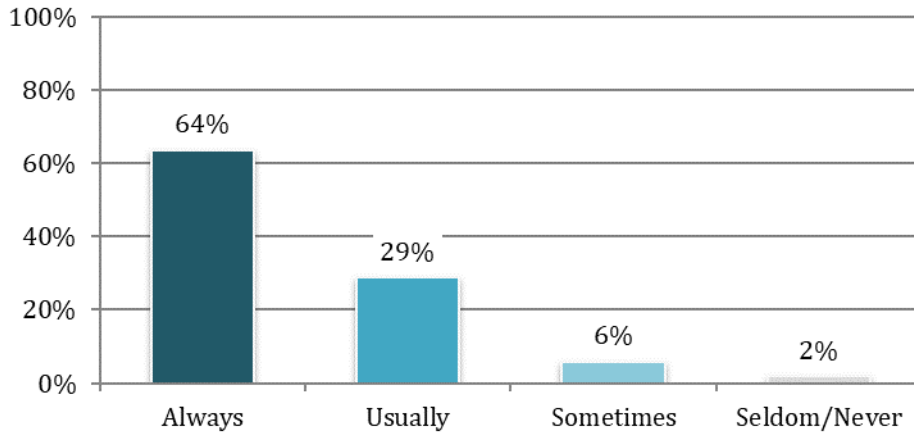


Table Q18. Do support workers come and leave when they are supposed to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	73%	22%	4%	0%	220

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	66%	24%	7%	3%	1,120
AZ	65%	30%	5%	1%	166
WI	65%	29%	5%	1%	886
NCI Average	64%	29%	6%	2%	3,712
UT	63%	31%	6%	0%	144
MO	60%	25%	6%	9%	122

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	58%	34%	6%	2%	853
NC	45%	43%	10%	1%	201

Services And Supports Change When Family's Needs Change

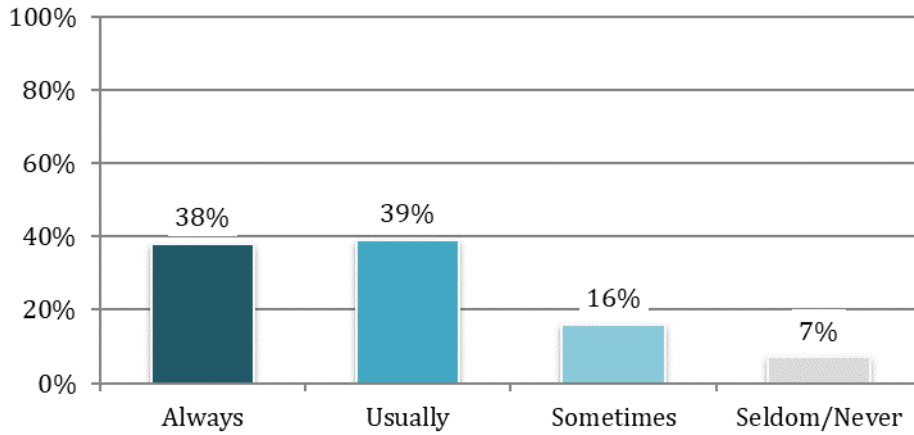


Table Q19. Do services and supports change when your family's needs change?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	66%	24%	7%	3%	180

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	41%	31%	18%	11%	1,072
MO	41%	33%	17%	9%	118
NCI Average	38%	39%	16%	7%	3,358
AZ	36%	44%	14%	6%	151
UT	32%	47%	16%	4%	117

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	33%	45%	18%	5%	797
OR	29%	46%	18%	8%	741
NC	26%	47%	20%	7%	182

Support Workers Speak In A Way Respondent Understands

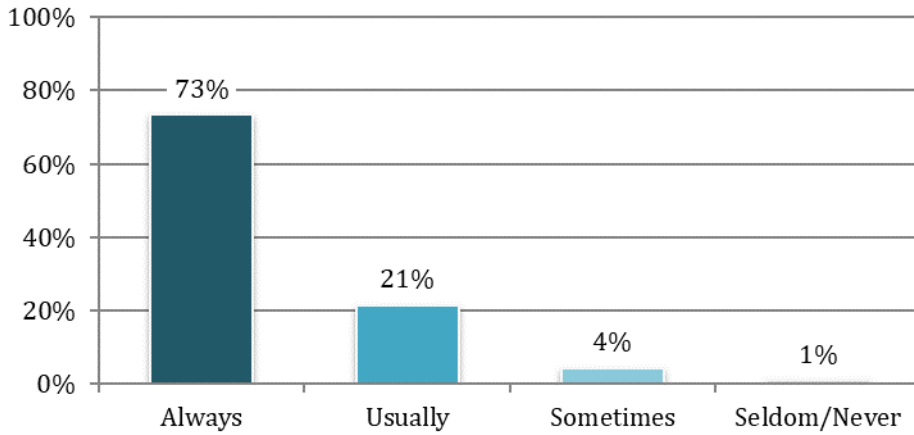


Table Q20. Do support workers speak to you in a way that you understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	85%	13%	2%	0%	226

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OR	74%	23%	2%	1%	874
UT	74%	24%	2%	0%	147
TX	74%	18%	6%	2%	1,139
NCI Average	73%	21%	4%	1%	3,828
MO	73%	21%	4%	2%	135
AZ	72%	23%	5%	1%	169
NC	71%	24%	4%	1%	211
WI	71%	25%	3%	1%	927

Services And Supports Are Delivered In A Way Respectful Of Family's Culture

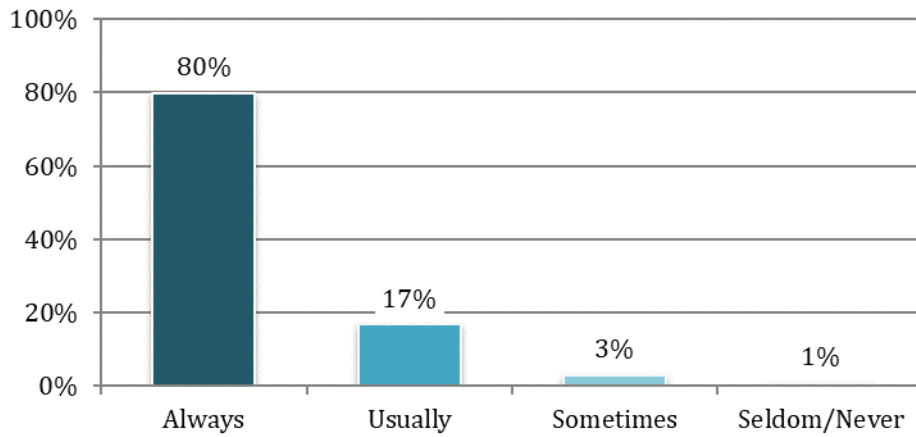


Table Q21. Are services delivered in a way that is respectful of your family's culture?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	92%	7%	1%	0%	245

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
UT	84%	15%	1%	0%	148
TX	82%	12%	4%	2%	1,207
MO	81%	16%	1%	2%	151
NCI Average	80%	17%	3%	1%	4,022
OR	79%	18%	2%	1%	892
WI	79%	18%	3%	0%	994
AZ	77%	20%	3%	0%	172

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	71%	25%	3%	1%	213

If Child Is Non-Verbal, Support Workers Can Communicate With Him/Her

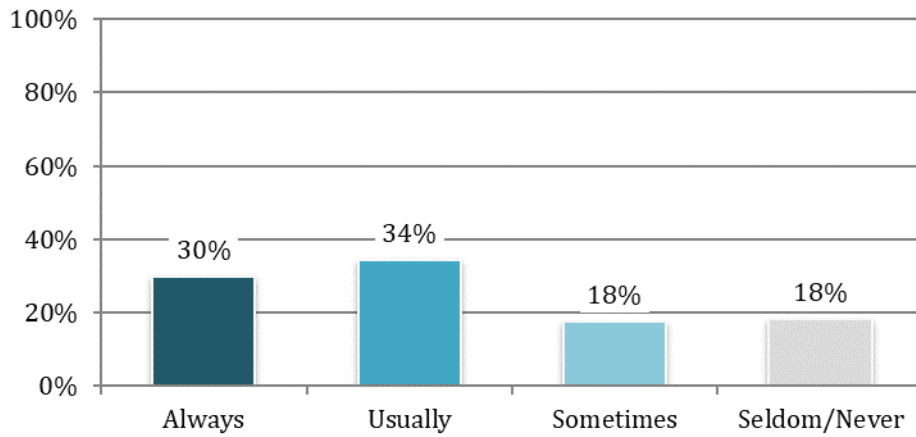


Table Q22. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	33%	27%	19%	21%	361
NC	31%	51%	16%	2%	55
OR	31%	43%	11%	15%	91
UT	30%	32%	24%	14%	37
NCI Average	30%	34%	18%	18%	682
WI	24%	31%	24%	22%	106

Support Workers Have The Right Information And Skills To Meet Family's Needs

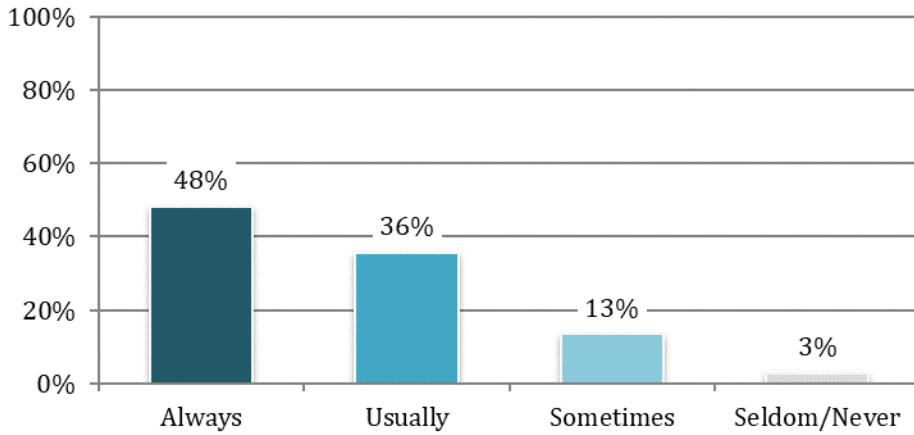


Table Q23. Do support workers have the right information and skills to meet your family's needs?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	69%	26%	4%	1%	217

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	53%	30%	13%	4%	1,115
UT	51%	39%	9%	1%	146
NCI Average	48%	36%	13%	3%	3,739
AZ	47%	35%	16%	2%	163
OR	45%	41%	13%	2%	855
MO	44%	40%	9%	7%	132

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	41%	43%	13%	3%	904
NC	36%	43%	19%	1%	207

Child Has Access To Special Equipment Or Accommodations Needed

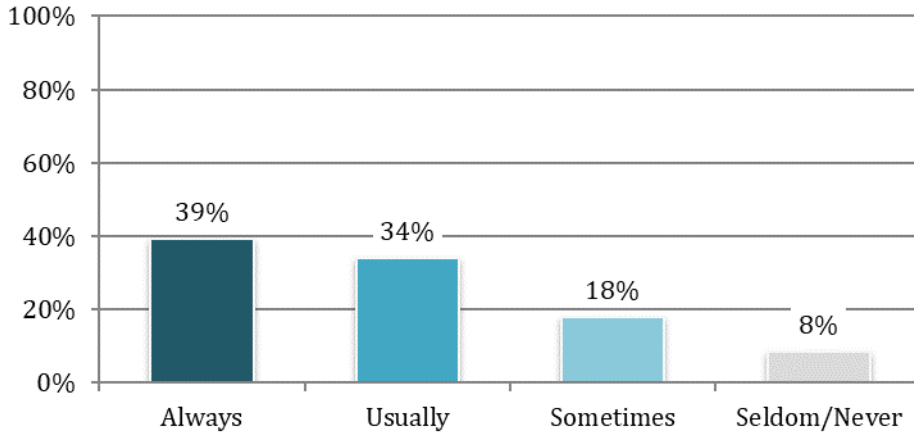


Table Q24. Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	48%	25%	14%	12%	934

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	45%	28%	18%	8%	88
NCI Average	39%	34%	18%	8%	2,555
AZ	37%	40%	19%	4%	91
MO	36%	37%	19%	9%	81
NC	34%	34%	21%	10%	137
UT	31%	37%	22%	9%	86

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	31%	42%	19%	8%	609
OR	30%	37%	25%	8%	529

Child Can See Health Professionals When Needed

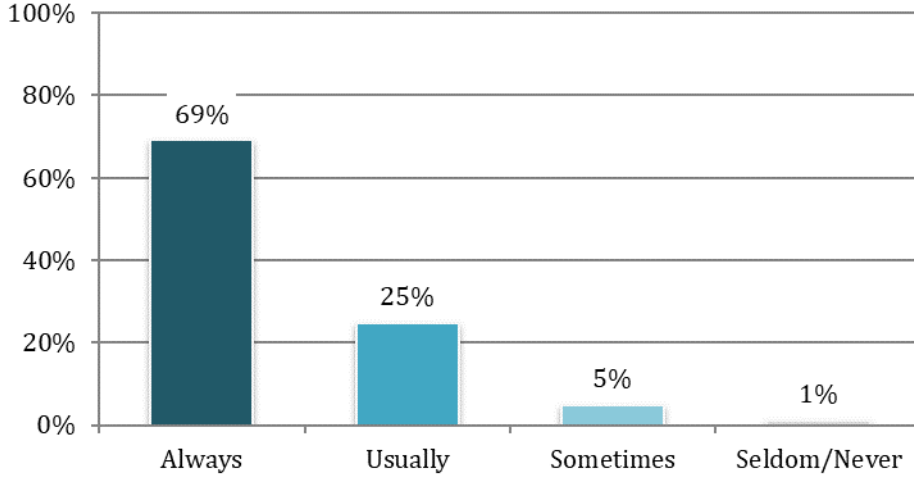


Table Q25. Can your child see health professionals when needed (for example, doctor, dentist, psychologist)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	85%	14%	1%	0%	270

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MO	74%	22%	3%	1%	175
UT	70%	26%	3%	1%	149
OR	69%	25%	5%	1%	919
NCI Average	69%	25%	5%	1%	4,194
NC	68%	27%	4%	0%	223
AZ	68%	27%	4%	1%	174
TX	66%	23%	8%	3%	1,238
WI	65%	29%	5%	1%	1,046

Child's Primary Care Doctor Understands Needs Related To Child's Disability

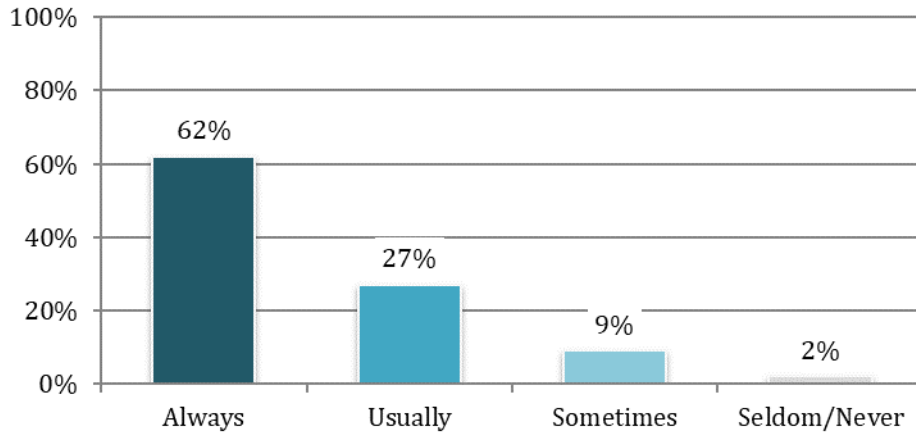


Table Q26. Does your child's primary care doctor understand his/her needs related to his/her disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	73%	19%	6%	2%	261
TX	66%	21%	9%	3%	1,219

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NCI Average	62%	27%	9%	2%	4,125
AZ	60%	29%	10%	1%	174
NC	59%	30%	9%	2%	219
OR	57%	31%	10%	2%	903
WI	57%	32%	9%	2%	1,030
MO	56%	34%	7%	2%	170
UT	56%	32%	11%	1%	149

Respondent Has Access To Dental Services For Child

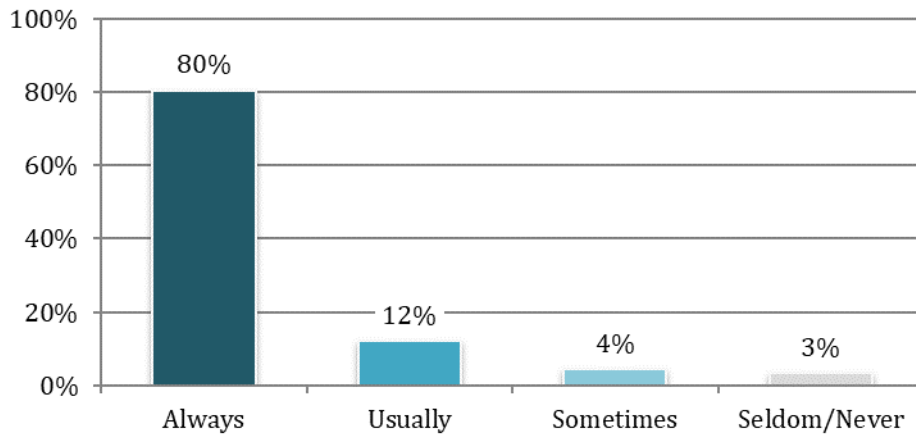


Table Q27. Do you have access to dental services for your child?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	86%	9%	2%	4%	246
AZ	84%	11%	3%	2%	171
UT	83%	15%	1%	1%	149
NCI Average	80%	12%	4%	3%	4,090
MO	80%	12%	4%	4%	172
NC	79%	15%	4%	2%	220
TX	77%	10%	7%	5%	1,226
WI	77%	14%	5%	4%	1,007
OR	77%	16%	4%	3%	899

Child's Dentist Understands Needs Related To Child's Disability

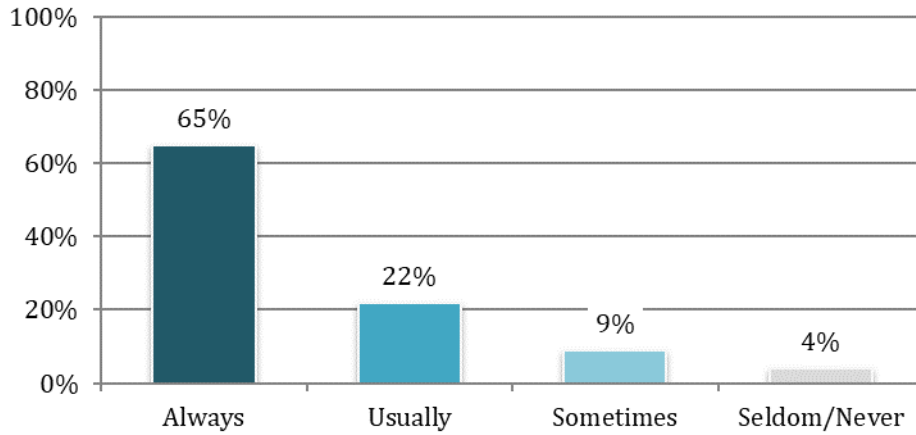


Table Q28. If respondent has access to dental services for the child, does your child's dentist understand his/her needs related to his/her disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	72%	17%	7%	4%	197
AZ	68%	21%	9%	2%	163
TX	67%	18%	10%	5%	1,170
MO	66%	22%	7%	5%	150
NCI Average	65%	22%	9%	4%	3,771
NC	64%	25%	9%	2%	210
UT	59%	29%	10%	2%	146

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	60%	27%	10%	4%	889
OR	54%	29%	11%	6%	846

Respondent Knows What Child's Medications Are For

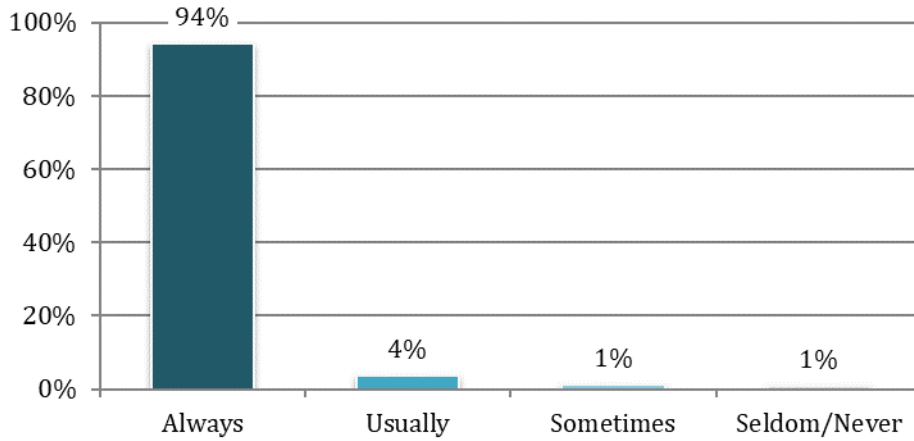


Table Q29. If your child takes medications, do you know what they're for?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	96%	2%	1%	1%	1,167
MO	95%	4%	1%	1%	129
AZ	94%	3%	1%	2%	123
UT	94%	5%	1%	0%	121
NCI Average	94%	4%	1%	1%	3,424
OR	93%	6%	0%	1%	725
WI	93%	5%	1%	1%	790
NC	93%	5%	2%	1%	192
LA	93%	4%	2%	1%	177

Respondent, Child, Or Other Family Member
Knows What Is Needed For Child To Take
Medication Safely

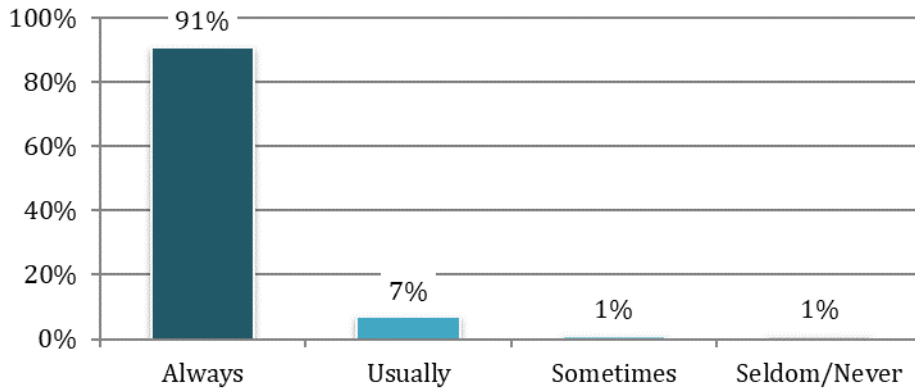


Table Q30. If your child takes medications, do you, your child, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	94%	4%	1%	1%	121
TX	92%	5%	2%	2%	1,158
NCI Average	91%	7%	1%	1%	3,389
OR	90%	9%	1%	1%	713
LA	90%	8%	1%	1%	172
UT	90%	8%	1%	1%	121
MO	88%	8%	3%	1%	129
NC	86%	12%	2%	0%	191

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	87%	10%	1%	1%	784

Child's Mental Health Professional Understands Needs Related To Child's Disability

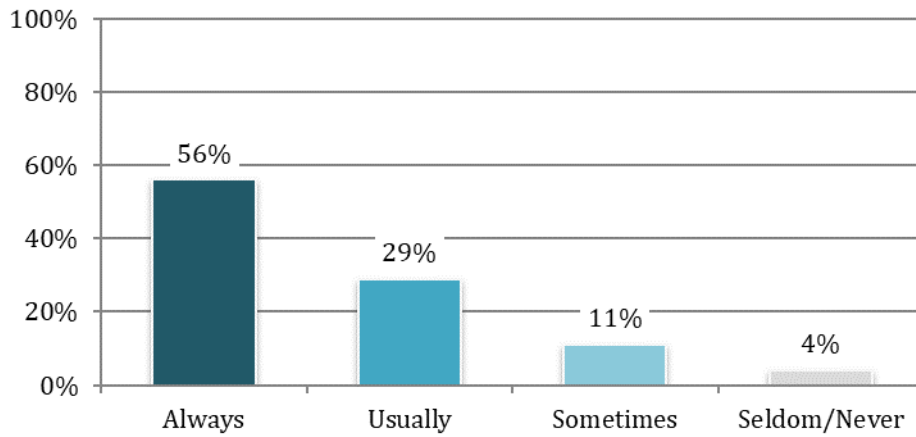


Table Q31. If your child uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your child's needs related to his/her disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	62%	19%	11%	8%	595

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	61%	33%	2%	4%	46
MO	60%	35%	2%	3%	60
WI	58%	25%	13%	3%	329
UT	56%	29%	11%	4%	55
NCI Average	56%	29%	11%	4%	1,604
AZ	52%	33%	13%	2%	60
OR	50%	34%	10%	5%	355
NC	44%	46%	9%	1%	104

Respondent Has Access To Respite Services If Needed

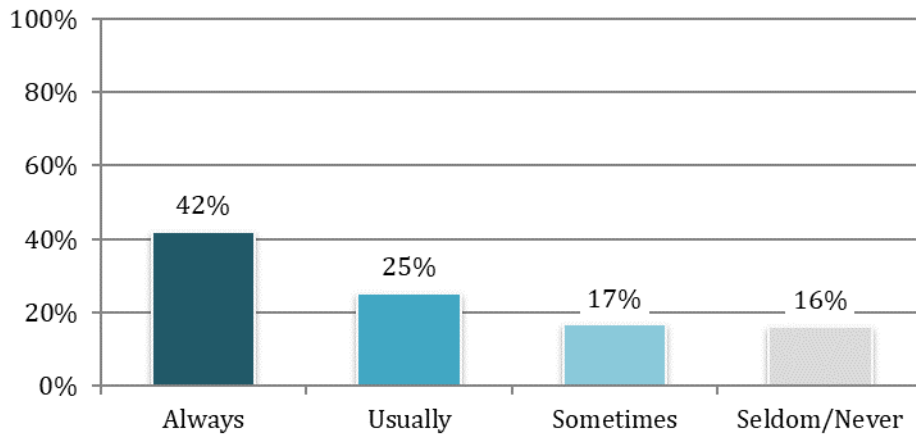


Table Q32. If you need respite services, do you have access to them?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	52%	21%	13%	14%	1,138

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	44%	25%	18%	13%	142
NCI Average	42%	25%	17%	16%	3,303
UT	42%	41%	13%	5%	143
NC	38%	30%	16%	15%	190

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	36%	32%	18%	14%	775
WI	31%	29%	22%	18%	761
MO	26%	24%	15%	35%	96
LA	26%	16%	14%	45%	58

If Family Used Respite Services In The Past Year,
Respondent Is Satisfied With The Quality Of
Respite Providers

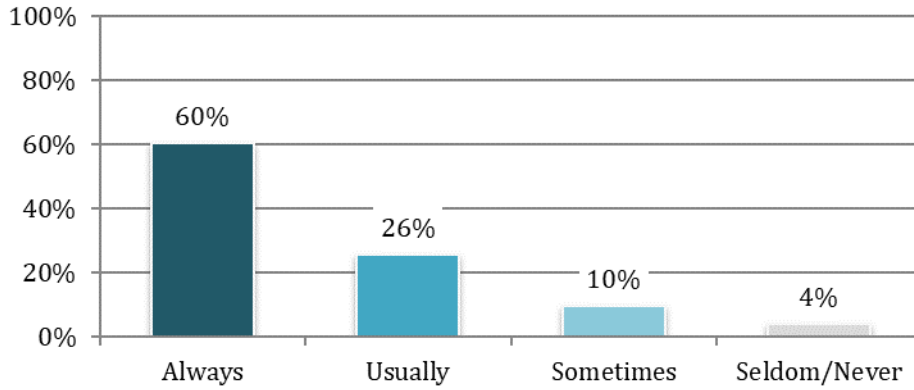


Table Q33. If respondent has access to respite services, are you satisfied with the quality of the respite services?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	70%	17%	8%	5%	909

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
WI	64%	25%	7%	4%	618
MO	61%	24%	14%	0%	49
NCI Average	60%	26%	10%	4%	2,620
UT	56%	35%	8%	1%	136
OR	56%	30%	11%	3%	618
AZ	55%	30%	11%	4%	118
NC	50%	36%	8%	5%	147
LA	48%	28%	16%	8%	25

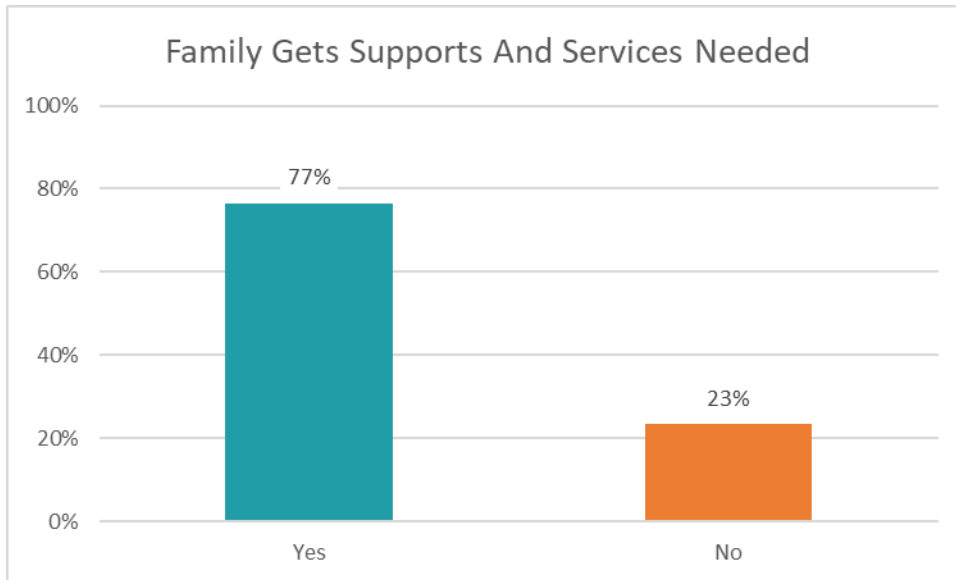


Table Q34. Does your family get the support and services needed?

Significantly Above Average

State	Yes	No	N
TX	85%	15%	1,174

Within Average Range

State	Yes	No	N
AZ	80%	20%	166
LA	79%	21%	232
NCI Average	77%	23%	3,840
UT	76%	24%	143

Significantly Below Average

State	Yes	No	N
OR	71%	29%	821
WI	69%	31%	931
MO	65%	35%	165
NC	64%	36%	208

Additional Supports And Services Needed

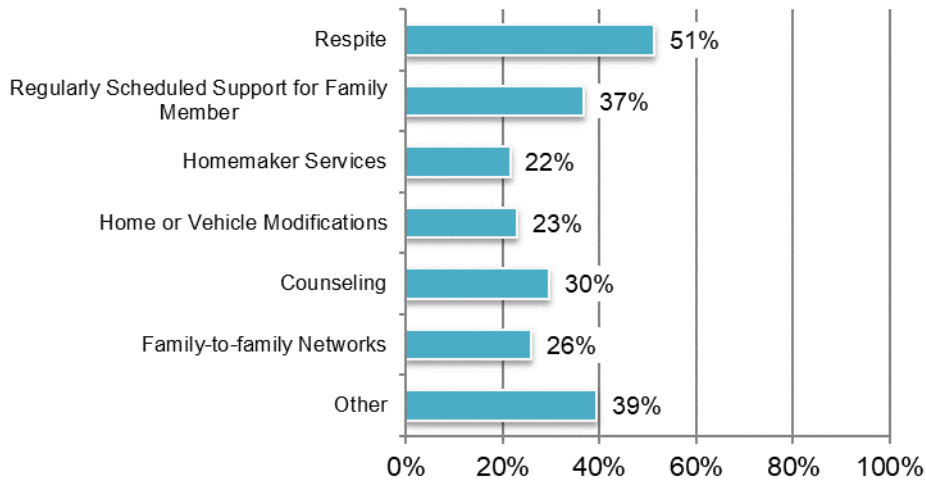


Table Q35. If family does not get the support and services needed, what additional services are needed?

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Other	N
AZ	42%	29%	13%	13%	32%	19%	48%	31
LA	51%	24%	13%	18%	36%	29%	27%	45
MO	58%	42%	21%	26%	26%	26%	28%	57
NC	46%	33%	19%	24%	28%	22%	33%	72
OR	45%	40%	21%	25%	27%	27%	34%	237
TX	64%	55%	42%	44%	39%	38%	52%	165
UT	38%	38%	18%	24%	24%	6%	35%	34
WI	58%	35%	22%	18%	22%	27%	36%	278
NCI Average	51%	37%	22%	23%	30%	26%	39%	919

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.

“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.

Family Can Choose Or Change Child's Provider Agency

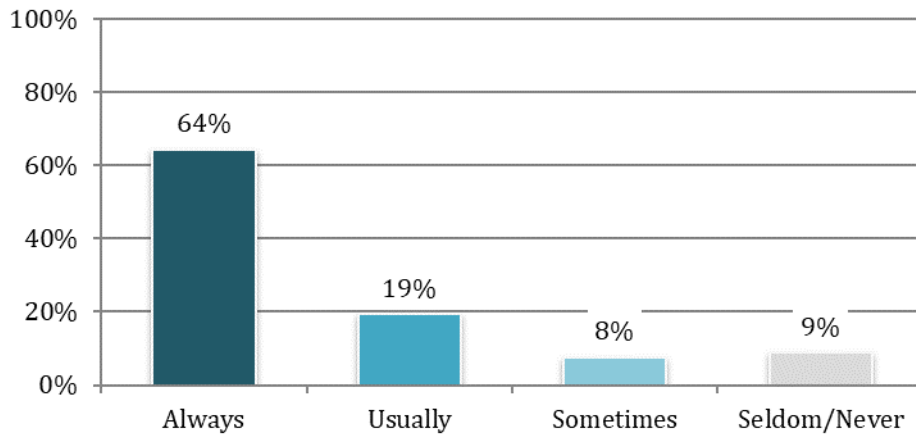


Table Q36. Can your family choose or change the agency that provides your child's services?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	82%	9%	2%	7%	164
UT	77%	20%	1%	2%	122
TX	73%	14%	7%	7%	1,142

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	71%	19%	5%	5%	188
NCI Average	64%	19%	8%	9%	2,842
MO	60%	17%	10%	13%	87
AZ	59%	23%	9%	8%	145

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	49%	26%	10%	16%	463
WI	47%	27%	9%	17%	531

Family Can Choose Or Change Child's Support Workers

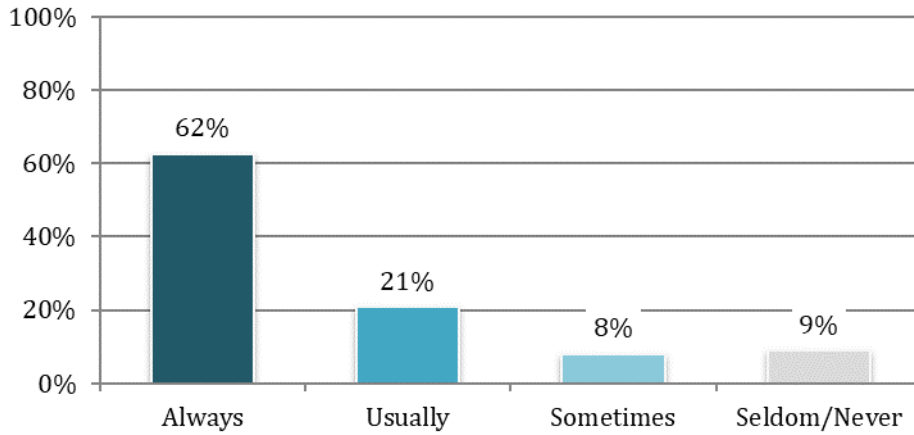


Table Q37. Can your family choose or change your child's support workers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	80%	15%	3%	2%	167
UT	80%	16%	3%	1%	137
OR	69%	19%	7%	5%	735
TX	69%	14%	8%	9%	1,078

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	66%	21%	8%	5%	189
NCI Average	62%	21%	8%	9%	3,052
AZ	56%	26%	7%	11%	135
MO	53%	23%	12%	12%	75

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	47%	29%	12%	11%	536

Family Directly Manages Support Workers

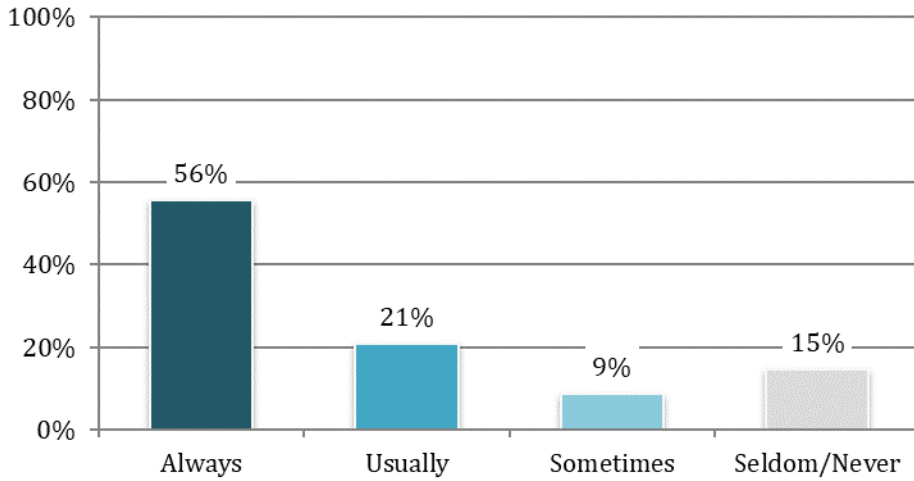


Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	83%	12%	3%	3%	139
OR	75%	16%	6%	3%	804

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	61%	11%	8%	21%	1,057
LA	59%	19%	7%	14%	140
NCI Average	56%	21%	9%	15%	3,147
AZ	52%	30%	8%	11%	132
NC	47%	26%	12%	15%	179
MO	44%	23%	13%	20%	64

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	45%	23%	11%	21%	632

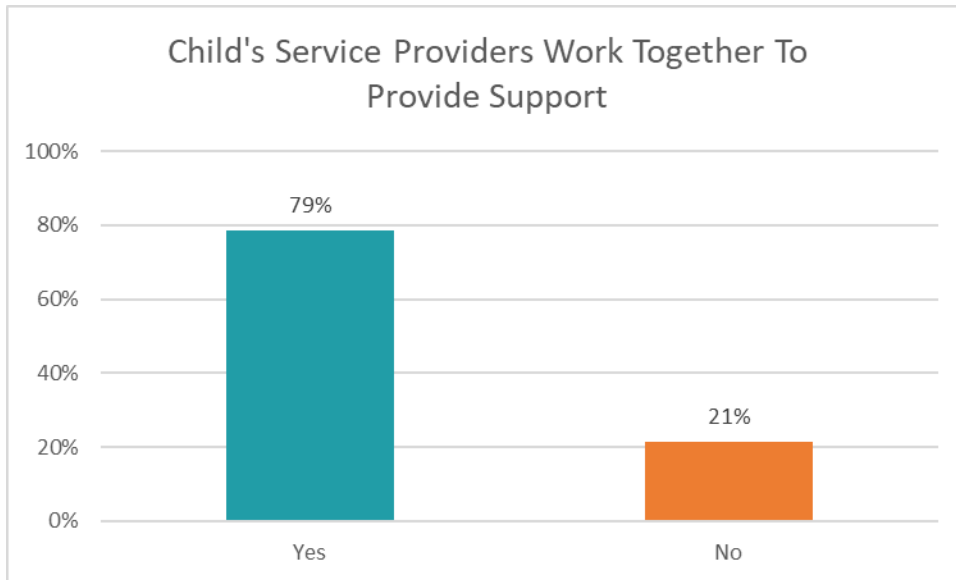


Table Q39. Do service providers for your child work together to provide support?

Significantly Above Average

State	Yes	No	N
TX	83%	17%	922

Within Average Range

State	Yes	No	N
UT	82%	18%	73
NC	82%	18%	121
LA	81%	19%	107
NCI Average	79%	21%	2,236
MO	77%	23%	52
WI	76%	24%	459
AZ	74%	26%	94
OR	74%	26%	408

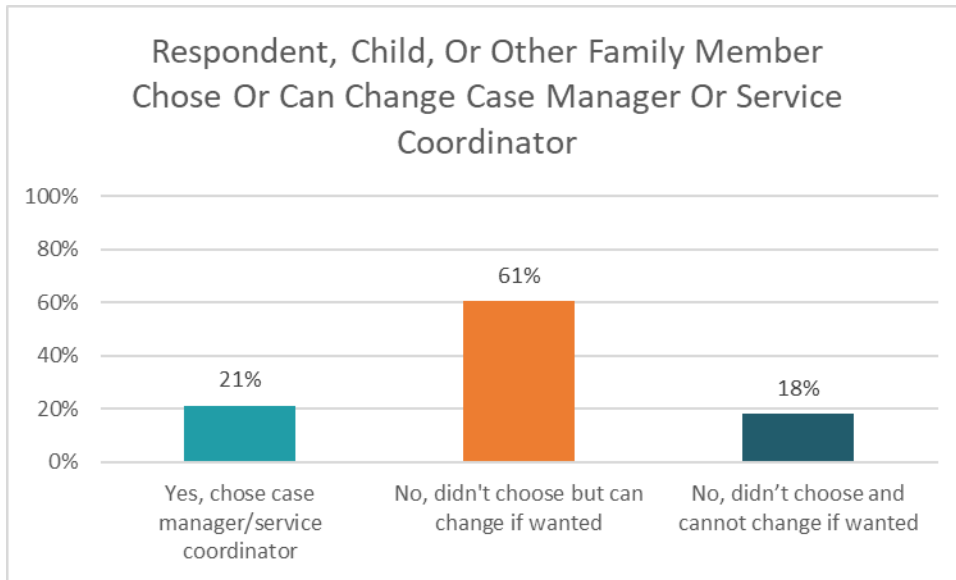


Table Q40. Did you, your child, or someone else in your family choose your child's case manager/service coordinator?

Significantly Above Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
UT	83%	15%	3%	143
LA	49%	44%	7%	207
TX	28%	53%	19%	992

Within Average Range

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
NC	29%	58%	14%	177
NCI Average	21%	61%	18%	3,245

Significantly Below Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
WI	13%	57%	30%	742
AZ	13%	72%	15%	158
OR	13%	60%	27%	707
MO	9%	69%	22%	119

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.

“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.

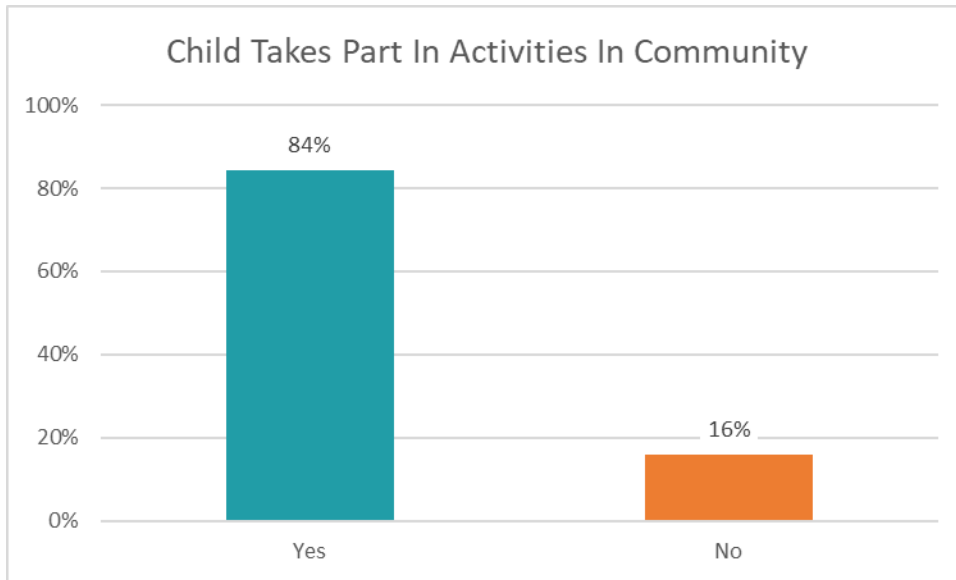


Table Q41. Does your child take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

Within Average Range

State	Yes	No	N
MO	88%	13%	176
OR	87%	13%	896
NC	87%	13%	220
AZ	87%	13%	175
WI	85%	15%	1,038
UT	85%	15%	149
NCI Average	84%	16%	4,166
TX	82%	18%	1,241

Significantly Below Average

State	Yes	No	N
LA	74%	26%	271

Obstacles Or Barriers To Child's Participation In Activities In The Community

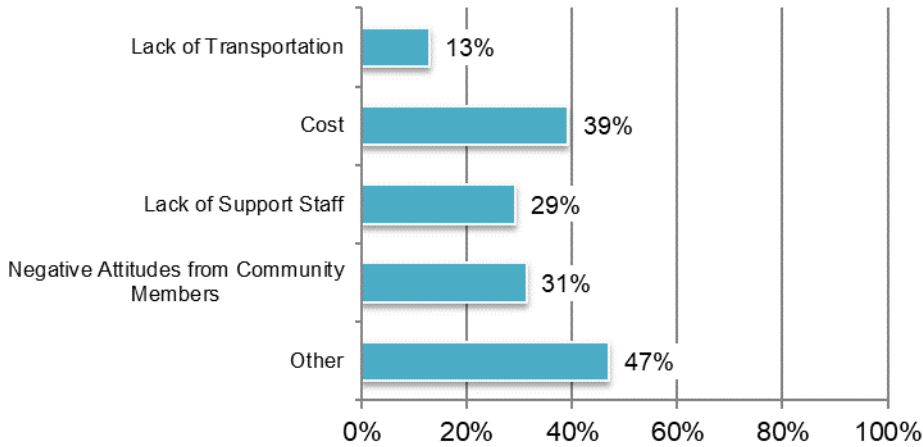


Table Q42. For your child, what are the obstacles or barriers to participation in activities in the community?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes from Community Members	Other	N
TX	25%	45%	36%	40%	69%	210
NC	15%	41%	36%	39%	56%	191
OR	15%	37%	34%	33%	51%	785
MO	14%	37%	33%	32%	51%	136
WI	13%	36%	29%	30%	50%	922
UT	11%	35%	28%	29%	50%	131
AZ	11%	35%	21%	26%	44%	141
LA	9%	25%	13%	21%	38%	176
NCI Average	13%	39%	29%	31%	47%	2,692

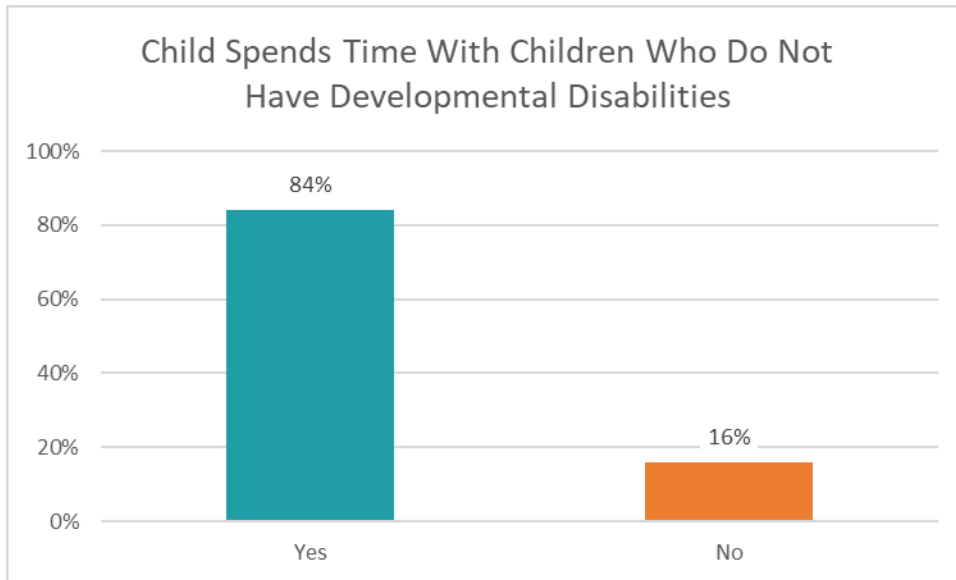


Table Q43. Does your child spend time with children who do not have developmental disabilities?

Within Average Range

State	Yes	No	N
MO	89%	11%	170
LA	87%	13%	261
WI	87%	13%	1,022
UT	86%	14%	149
NCI Average	84%	16%	4,139
AZ	84%	16%	176
OR	82%	18%	906
NC	82%	18%	218
TX	82%	18%	1,237

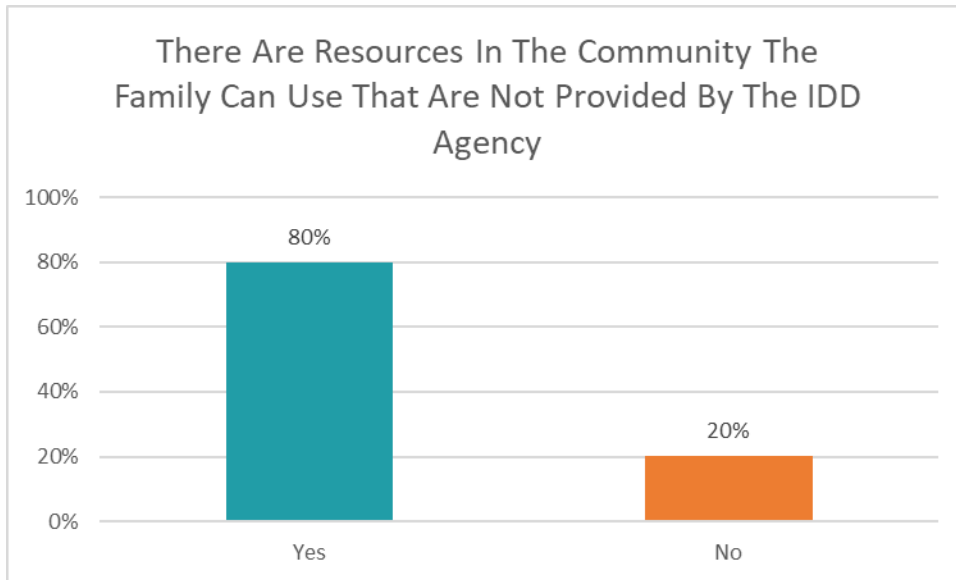


Table Q44. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

Significantly Above Average

State	Yes	No	N
OR	84%	16%	711

Within Average Range

State	Yes	No	N
AZ	86%	14%	133
UT	84%	16%	109
MO	83%	17%	135
WI	83%	17%	732
LA	82%	18%	175
NCI Average	80%	20%	3,229
NC	79%	21%	182

Significantly Below Average

State	Yes	No	N
TX	69%	31%	1,052

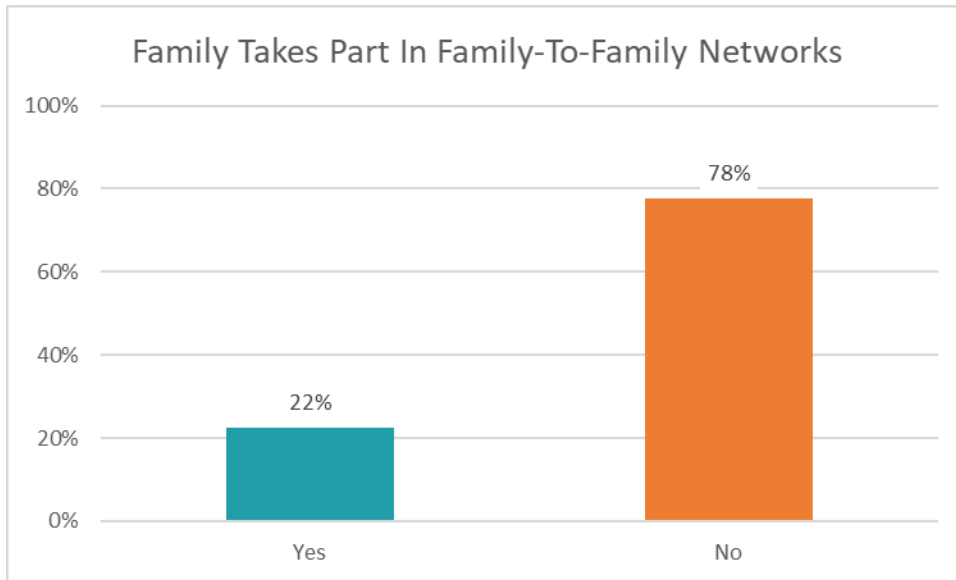


Table Q45. Does your family take part in any family-to-family networks in your community?

Significantly Above Average

State	Yes	No	N
TX	29%	71%	1,137

Within Average Range

State	Yes	No	N
UT	26%	74%	137
NCI Average	22%	78%	3,651
OR	22%	78%	811
AZ	22%	78%	152
NC	19%	81%	198
WI	19%	81%	879
LA	18%	82%	191
MO	16%	84%	146

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.

“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.

Overall, Respondent Is Satisfied With Services And Supports Family Receives

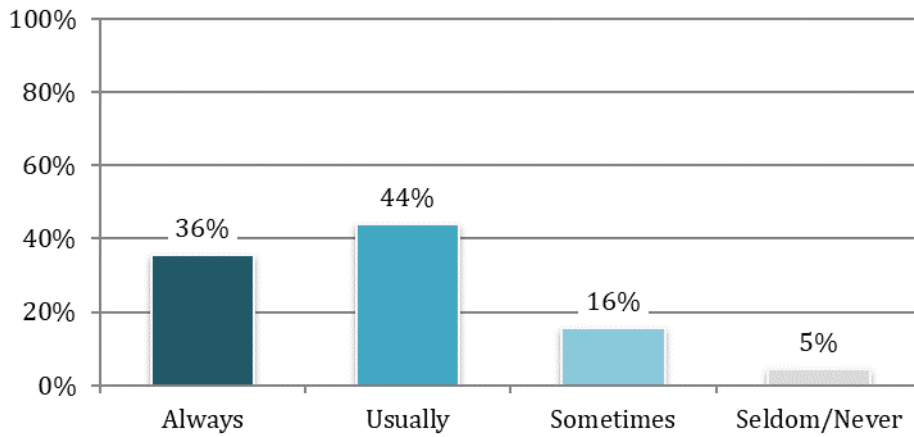


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	57%	31%	10%	2%	246
TX	42%	37%	16%	5%	1,238

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
UT	37%	48%	13%	2%	150
NCI Average	36%	44%	16%	5%	4,110
AZ	34%	48%	14%	3%	173
MO	32%	41%	16%	11%	167

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	29%	50%	18%	3%	893
WI	29%	48%	19%	4%	1,026
NC	23%	51%	21%	6%	217

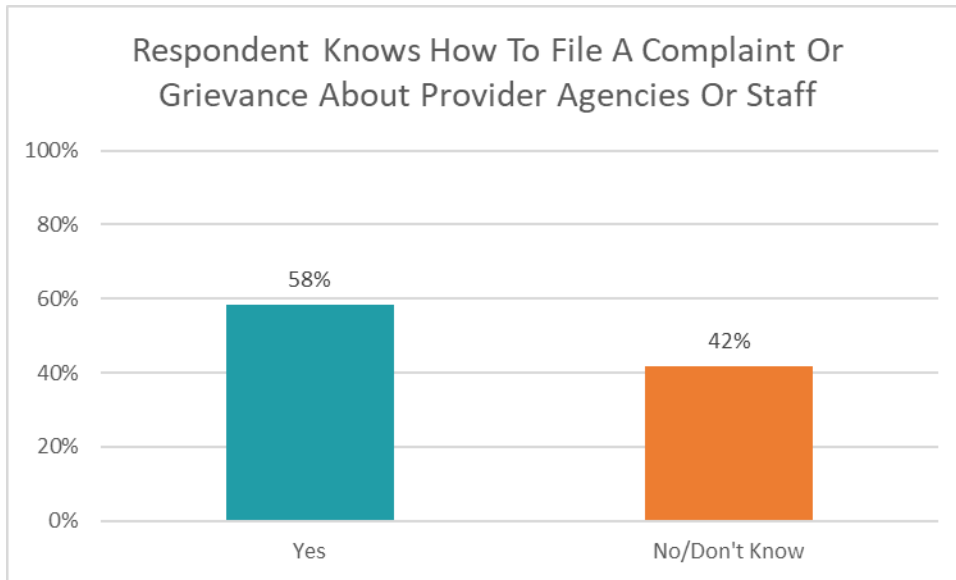


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?²

Significantly Above Average

State	Yes	No/Don't Know	N
TX	74%	26%	1,243

Within Average Range

State	Yes	No/Don't Know	N
WI	63%	37%	1,040
UT	65%	35%	148
NC	62%	38%	221
NCI Average	58%	42%	4,185
OR	54%	46%	915
LA	53%	47%	268
AZ	49%	51%	175

Significantly Below Average

State	Yes	No/Don't Know	N
MO	41%	59%	175

² Don't Know' responses were included in 'No' responses for this question.

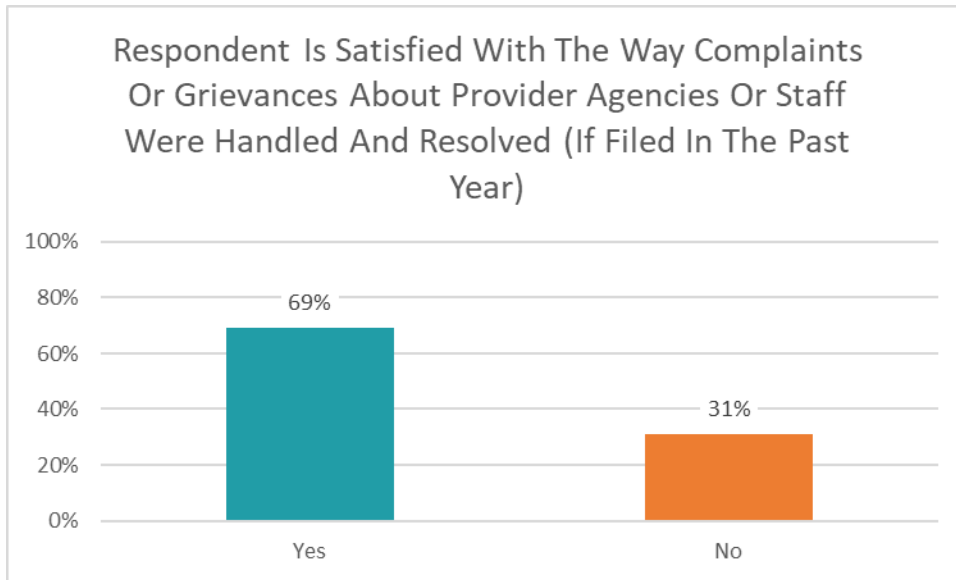


Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

Within Average Range

State	Yes	No	N
LA	81%	19%	21
TX	75%	25%	300
NCI Average	69%	31%	525
OR	62%	38%	74
NC	58%	42%	36

Significantly Below Average

State	Yes	No/Don't Know	N
WI	52%	48%	67

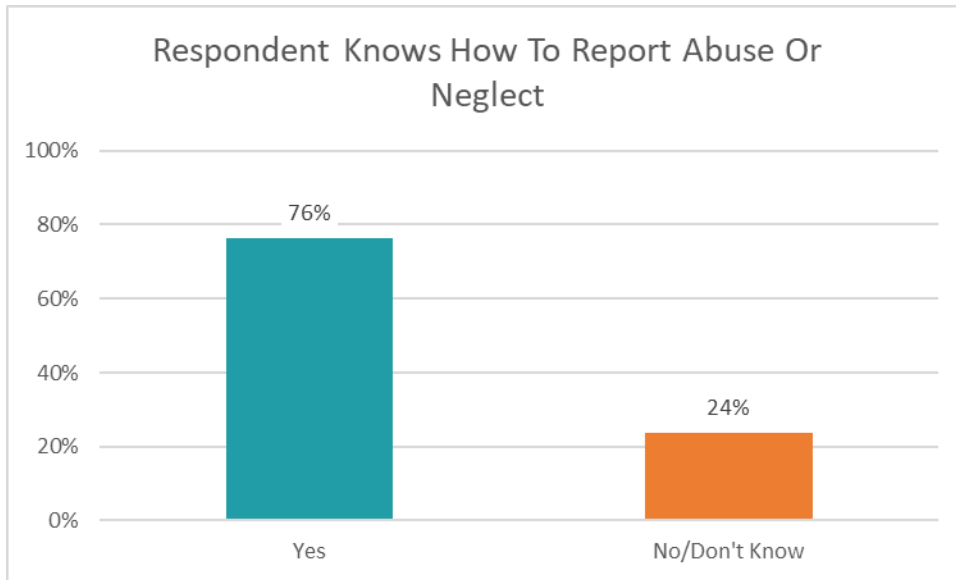


Table Q49. Do you know how to report abuse or neglect related to your child?³

Significantly Above Average

State	Yes	No/Don't Know	N
TX	86%	14%	1,243
NC	84%	16%	221
OR	83%	17%	916
WI	81%	19%	1,030

Within Average Range

State	Yes	No/Don't Know	N
UT	82%	18%	148
LA	78%	22%	267
NCI Average	76%	24%	4,172
MO	75%	25%	175

Significantly Below Average

State	Yes	No/Don't Know	N
AZ	62%	38%	172

³ Don't Know' responses were included in 'No' responses for this question.

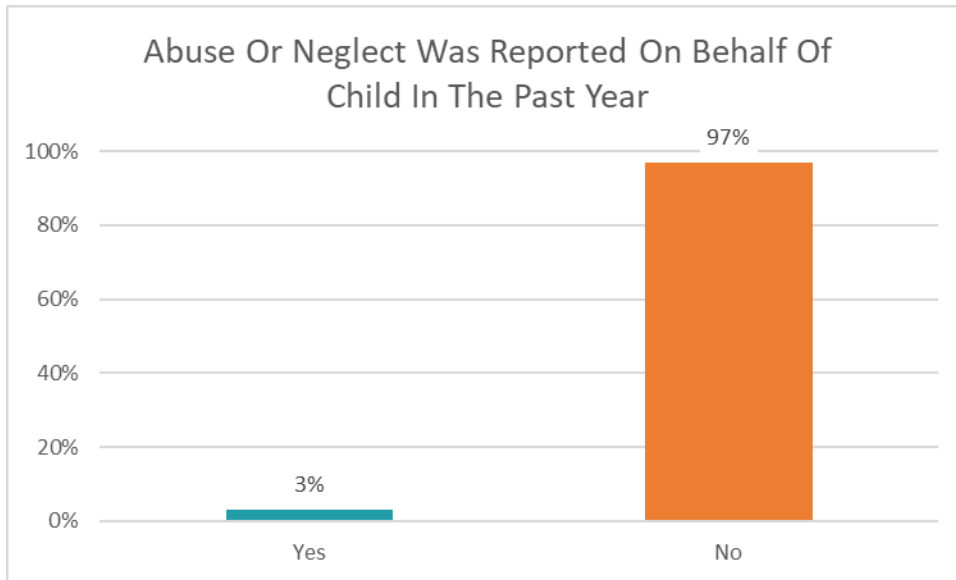


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child?

Within Average Range

State	Yes	No	N
OR	5%	95%	901
TX	4%	96%	1,215
MO	4%	96%	173
WI	3%	97%	1,016
NCI Average	3%	97%	4,103
NC	3%	97%	218
LA	3%	97%	261
UT	2%	98%	145
AZ	2%	98%	174

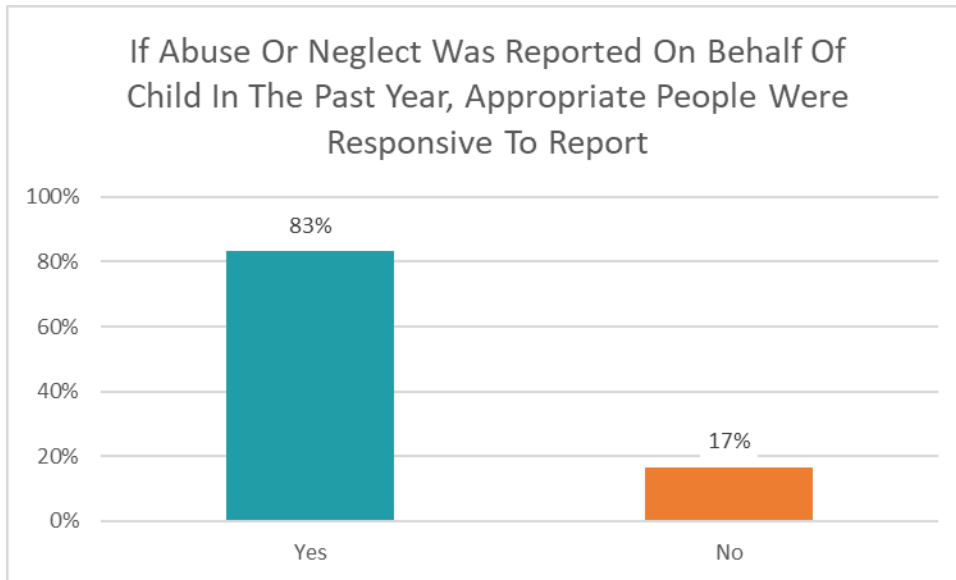


Table Q51. If abuse or neglect was reported on behalf of your child in the past year, did the appropriate people respond to the report?

Within Average Range

State	Yes	No	N
TX	90%	10%	51
OR	87%	13%	39
NCI Average	83%	17%	143
WI	83%	17%	29

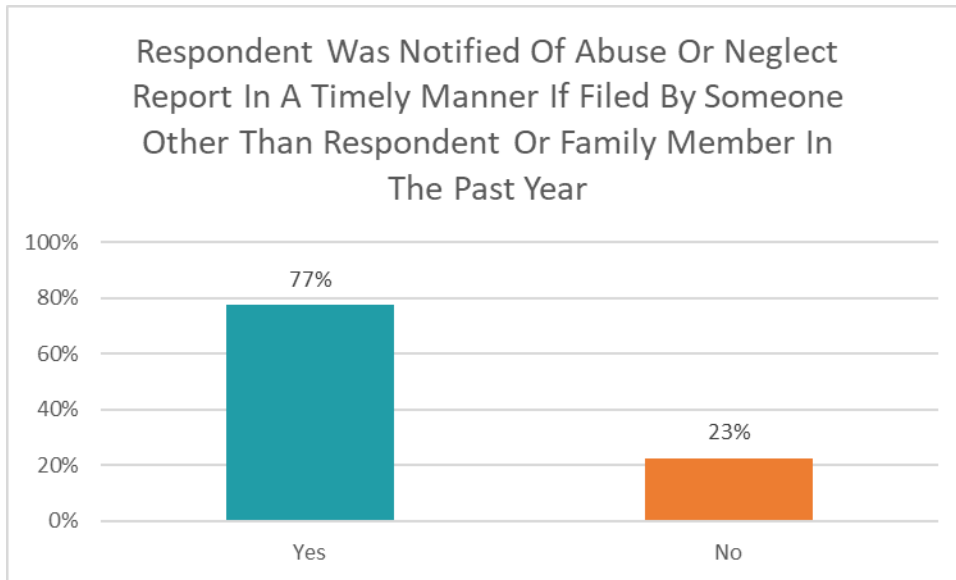


Table Q52. if someone other than you reported abuse or neglect on behalf of your child, were you notified of the report in a timely manner?

Within Average Range

State	Yes	No	N
WI	86%	14%	21
OR	79%	21%	29
NCI Average	77%	23%	110
TX	76%	24%	42

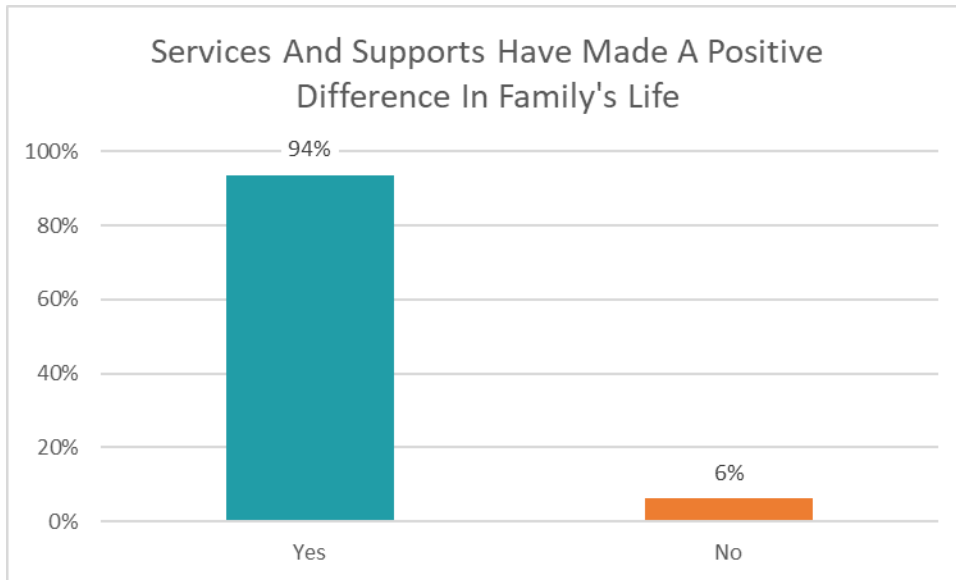


Table Q53. Do you feel that services and supports have made a positive difference in the life of your family?

Significantly Above Average

State	Yes	No	N
UT	98%	2%	144
OR	96%	4%	836

Within Average Range

State	Yes	No	N
LA	96%	4%	227
NC	96%	4%	198
AZ	94%	6%	156
NCI Average	94%	6%	3,820
WI	93%	7%	946
TX	92%	8%	1,170
MO	90%	10%	143

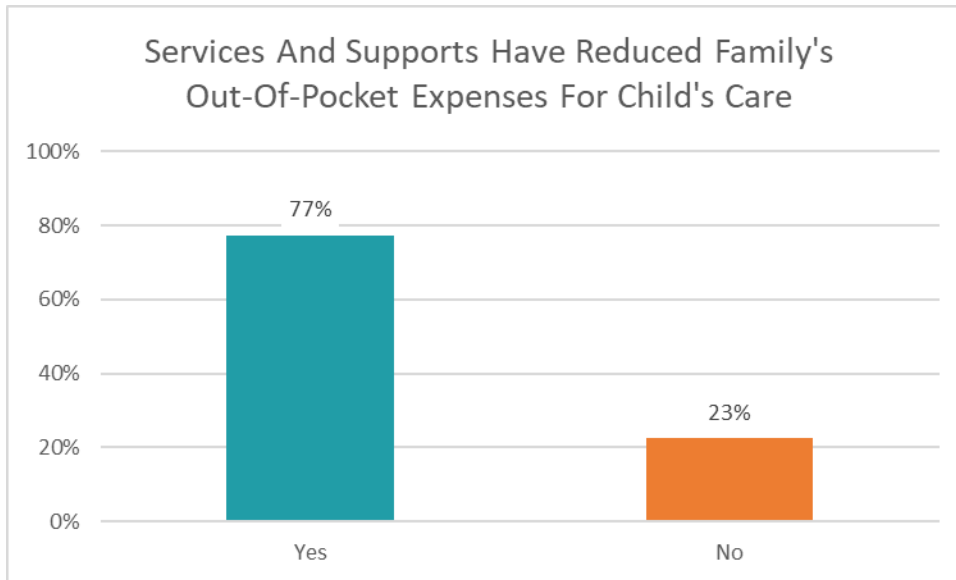


Table Q54. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your child's care?

Significantly Above Average

State	Yes	No	N
UT	92%	8%	147
WI	81%	19%	956

Within Average Range

State	Yes	No	N
AZ	84%	16%	152
OR	80%	20%	850
NCI Average	77%	23%	3,885
TX	77%	23%	1,190
NC	75%	25%	207

Significantly Below Average

State	Yes	No	N
LA	61%	39%	231
MO	60%	40%	152

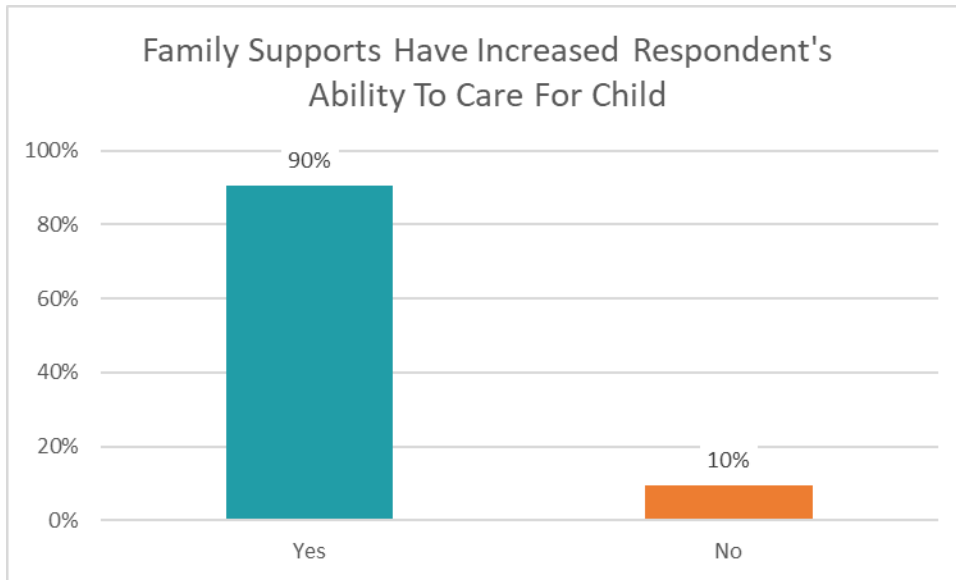


Table Q55. Do you feel that family supports have improved your ability to care for your child?

Significantly Above Average

State	Yes	No	N
UT	97%	3%	146
AZ	95%	5%	165

Within Average Range

State	Yes	No	N
OR	92%	8%	852
NCI Average	90%	10%	3,884
TX	90%	10%	1,192
NC	90%	10%	204
LA	89%	11%	228

Significantly Below Average

State	Yes	No	N
WI	86%	14%	951
MO	79%	21%	146

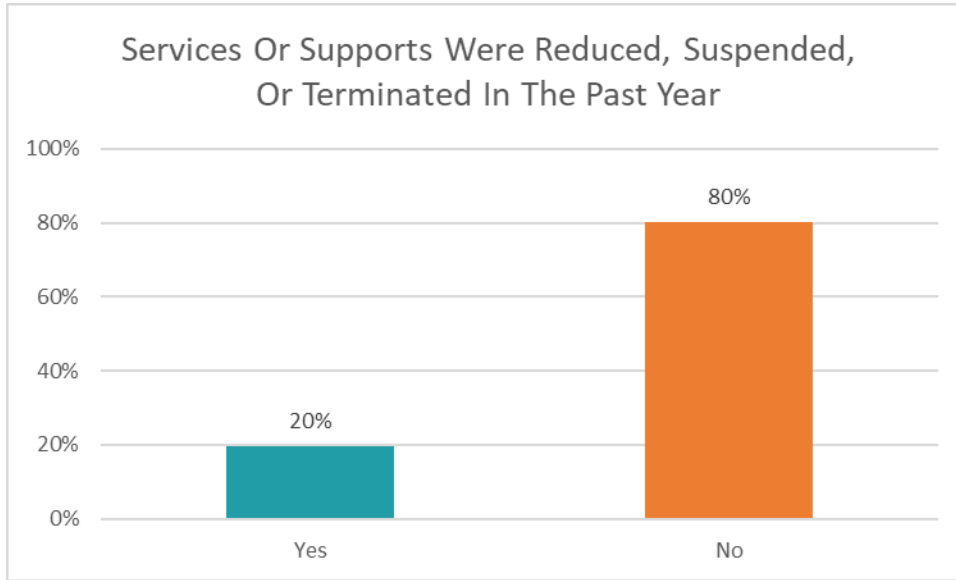


Table Q56. Have the services or supports that you or your child received during the past year been reduced, suspended, or terminated?

Significantly Above Average

State	Yes	No	N
TX	24%	76%	1,210

Within Average Range

State	Yes	No	N
NC	26%	74%	203
MO	25%	75%	160
LA	24%	76%	248
WI	21%	79%	980
OR	20%	80%	854
NCI Average	20%	80%	3,965
UT	19%	81%	145

Significantly Below Average

State	Yes	No	N
AZ	12%	88%	165

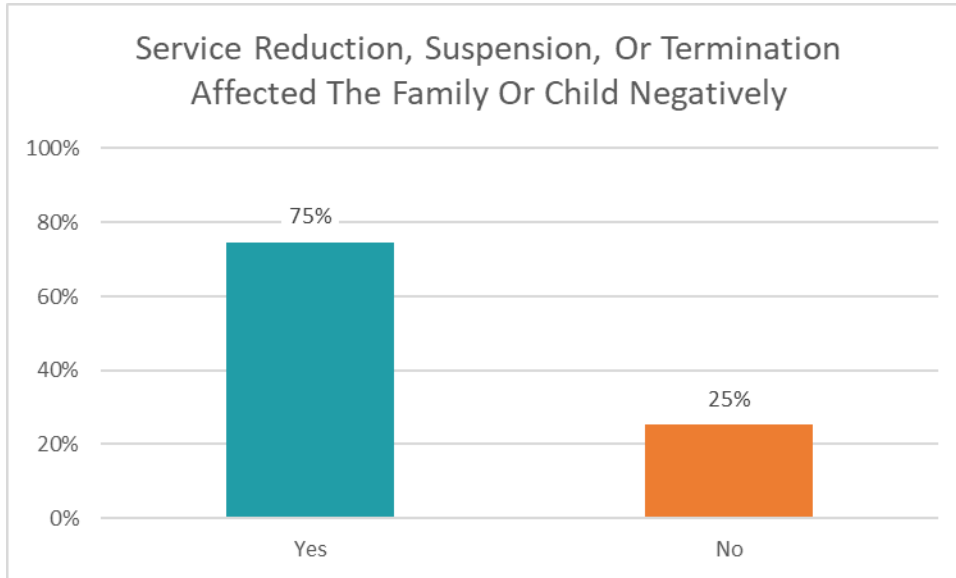


Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your child negatively?

Within Average Range

State	Yes	No	N
NC	82%	18%	45
TX	80%	20%	285
WI	79%	21%	185
OR	78%	22%	160
NCI Average	75%	25%	804
MO	62%	38%	37
UT	61%	39%	23

Significantly Below Average

State	Yes	No	N
LA	33%	67%	52

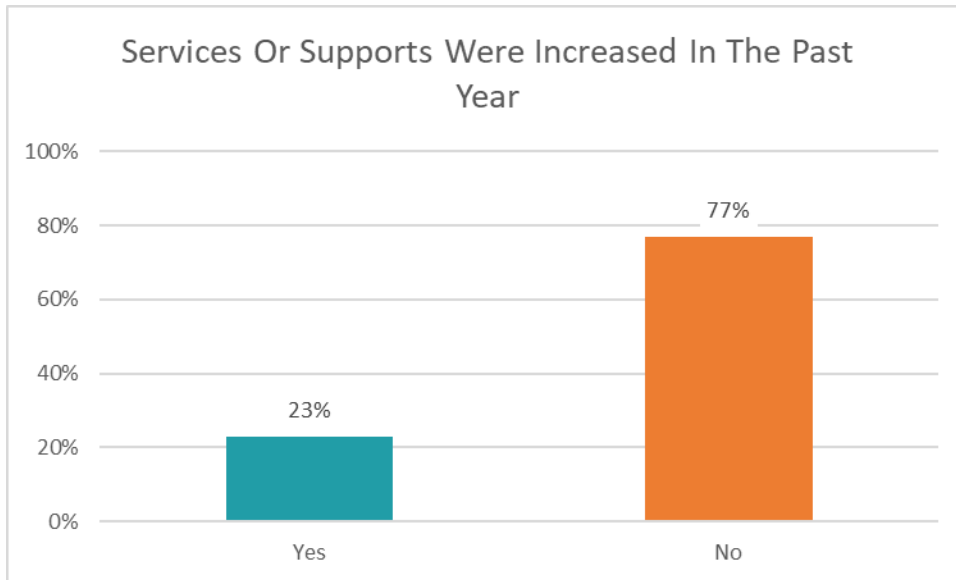


Table Q58. Have the services or supports that your child received been increased in the past year?

Significantly Above Average

State	Yes	No	N
OR	38%	62%	829

Within Average Range

State	Yes	No	N
LA	29%	71%	240
AZ	23%	77%	158
NCI Average	23%	77%	3,839
WI	23%	77%	932
NC	19%	81%	195
TX	19%	81%	1,199
UT	19%	81%	127

Significantly Below Average

State	Yes	No	N
MO	14%	86%	159

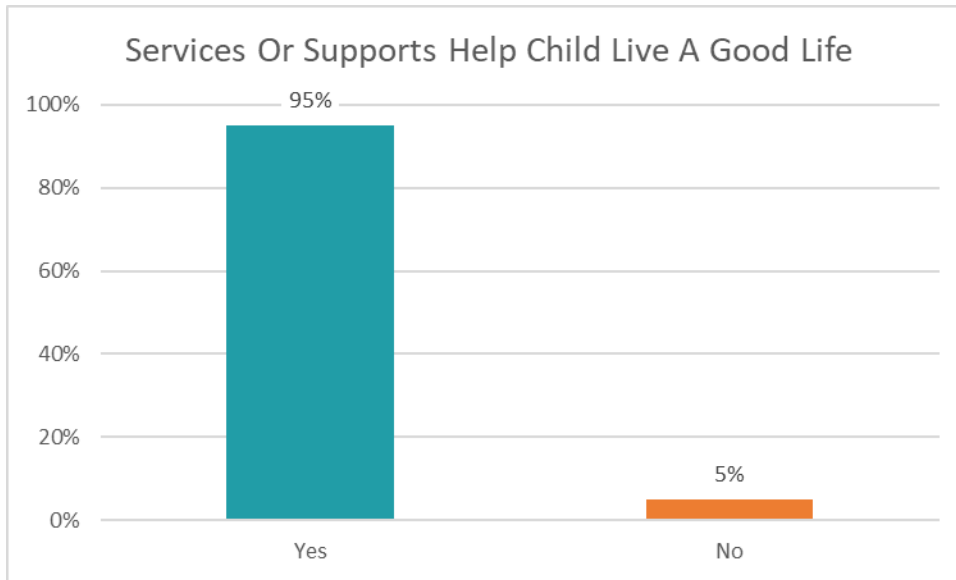


Table Q59. Are services and supports helping your child to live a good life?

Significantly Above Average

State	Yes	No	N
OR	98%	2%	838
UT	97%	3%	146

Within Average Range

State	Yes	No	N
TX	97%	3%	1,200
AZ	96%	4%	163
NCI Average	95%	5%	3,878
LA	95%	5%	237
WI	94%	6%	943
NC	93%	7%	207

Significantly Below Average

State	Yes	No	N
MO	86%	14%	144

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.

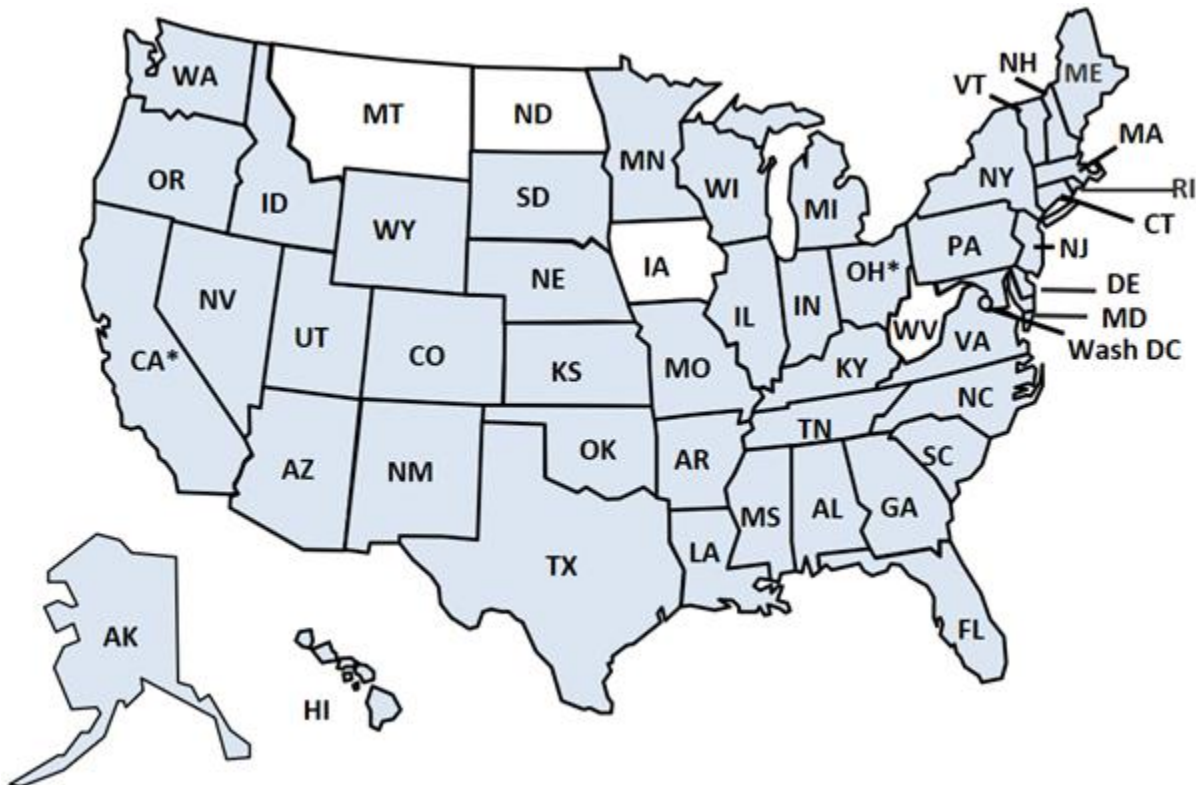
Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI continues to develop and refine the indicators and expand state participation. For more information about NCI states,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

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

State Participation

During the 2017-18 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.

NCI State Participation 2017-18



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

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

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

The current set of performance indicators includes approximately 100 consumer, family, system, and health and safety outcomes—outcomes that are important to understanding the overall health of public developmental disabilities agencies. Indicators are organized across five broad domains: Individual Outcomes; Health, Welfare and Rights; Staff Stability and Competency; Family Outcomes; and System Performance. Each domain is broken down into sub-domains, 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.

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](#).⁴

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

⁴ Located on the National Core Indicators website: www.nationalcoreindicators.org →Resources →Technical Reports

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 child⁵ 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 five states had at least a portion of surveys completed via direct entry for the 2017-18 data collection cycle.^{6,7}

Note on Texas sample: While the prescribed mode of administration for CFS is mail-in paper surveys or direct entry online, Texas sought to increase the response rate to the CFS surveys by allowing for three modes of administration: paper, web, and phone. Texas mailed out invitation letters to program participants asking them to participate and providing them with a telephone number and web link so that they could complete the survey by phone or web. Both options were available in both English and Spanish. After a month, Texas sent out paper surveys (available in Spanish and English) to everyone on the sampling frame who had not responded by phone or web.

A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.⁸

⁵ “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 still receiving “child” services.

⁶ States that used the direct entry or mail and direct entry options were: LA, NC, OR, UT and WI.

⁷ TX uses three modes of administration – mail, direct entry, or phone

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

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”). Last year, the approach was 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.

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. No symbol was used for the state’s percentage being “within” the NCI average range due to lack of statistical significance (i.e., $p \geq .01$).

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

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

Response Rates

During 2017-18, 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 mailed, surveys returned, response rates, and the number of valid surveys accepted for inclusion in data analysis.

Child Family Survey: State Response Rates ¹⁰

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	16,372	1400	177	12.6%	7.33%	100%	0%
LA	5,085	2500	275	11.0%	5.75%	87%	13%
MO	3,829	1000	177	17.7%	7.19%	100%	0%
NC	4,000	1200	224	18.7%	6.36%	91%	9%
OR	4,568	4568	927	20.3%	2.87%	91%	9%
TX ¹¹	12,897	4215	1,243	29.5%	2.64%		0%
UT	484	484	150	31.0%	6.65%	81%	19%
WI	8,474	8124	1,063	13.1%	2.81%	75%	25%
Total	55,709		4,236			93%	7%

¹⁰ 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.

¹¹ TX uses three modes of administration – mailed-out paper survey, direct entry, or phone (for more information see Note on TX Sample in Methodology section).