

Child Family Survey

2016-17 Final Report

Updated 6/28/2018 for 508 compliance



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

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

January 30, 2018

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

Table of Contents

Executive Summary	vi
Results	1
Survey Development	2
Organization of the Child Family Survey	2
Demographics.....	2
Services and Supports Received.....	2
Questions Regarding Services and Supports	2
Additional Comments	3
Presentation of Data	3
Demographics	4
Child.....	5
Table 1. More Than One Child Living in the Home Has IDD	6
Table 2. Child’s Age.....	6
Table 3. Child’s Gender	7
Table 4a. Child’s Disabilities.....	7
Table 4b. Child’s Disabilities (continued)	8
Table 5a. Child’s Health Conditions.....	8
Table 5b. Child’s Health Conditions (continued).....	9
Table 6. Child’s Race and Ethnicity.....	9
Table 7. Child’s Preferred Means of Communication	10
Table 8. Child’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	10
Table 9. Child’s Level of Help Needed With Personal Care Activities	11
Respondents	12
Table 10. Respondent’s Age.....	13

Table 11. Respondent's Health	13
Table 12. Respondent's Relationship to Child	14
Table 13. Respondent or Other Family Member Provides Paid Support to Child	14
Table 14. Number of Adults in Household	15
Table 15. Number of Children in Household	15
Table 16. Respondent's Highest Level of Education	16
Table 17. Total Taxable Household Income of Wage Earners in the Past Year	16
Table 18. Residential Designation (Urban, Rural, or Suburban)	17
Services and Supports Received	18
Table 19. Services and Supports Received From ID/DD Agency	19
Table 20. Other Services or Supports Received	19
Child Family Survey Results.....	20
Information and Planning	21
Table Q1. Do you get enough information to help you participate in planning services for your family?.....	22
Table Q2. Is the information you receive easy to understand?.....	23
Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?.....	24
Table Q4. Do you have enough information about other public services for which your family is eligible?	25
Table Q5. Do you need help planning for your child's future with respect to any of the following?	26
Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?.....	27
Table Q7. Does your child have a service plan?	28
Table Q8. Does the plan include all the services and supports your child needs?	29
Table Q9. Does your child receive all of the services listed in the plan?	30
Table Q10. Did you or another family member help develop the plan?	31
Table Q11. Did your child help develop the plan?.....	32
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?.....	33
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)?	34

Table Q14. If your child has a service plan, did you help make the transition plan?	35
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?.....	36
Access and Delivery of Services and Supports.....	37
Table Q16. Are you or your child able to contact his/her support workers when you want to?	38
Table Q17. Are you or your child able to contact his/her case manager or service coordinator when you want to?	39
Table Q18. Do support workers come and leave when they are supposed to?	40
Table Q19. Do services and supports change when your family's needs change?	41
Table Q20. Do support workers speak to you in a way that you understand?	42
Table Q21. Are services delivered in a way that is respectful of your family's culture?	43
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?	44
Table Q23. Do support workers have the right information and skills to meet your family's needs?	45
Table Q24. Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?.....	46
Table Q25. Can your child see health professionals when needed (for example, doctor, dentist, psychologist)?	47
Table Q26. Does your child's primary care doctor understand his/her needs related to his/her disability?	48
Table Q27. Do you have access to dental services for your child?.....	49
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?	50
Table Q29. If your child takes medications, do you know what they're for?	51
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)?	52
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?	53
Table Q32. If you need respite services, do you have access to them?	54
Table Q33. If respondent has access to respite services, are you satisfied with the quality of the respite services?	55
Table Q34. Does your family get the support and services needed?	56
Table Q35. If family does not get the support and services needed, what additional services are needed?.....	57
Choice, Decision Making and Control	58

Table Q36. Can your family choose or change the agency that provides your child’s services?	59
Table Q37. Can your family choose or change your child’s support workers?.....	60
Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)? ..	61
Table Q39. Do service providers for your child work together to provide support?	62
Table Q40. Did you, your child, or someone else in your family choose your child’s case manager/service coordinator?.....	63
Involvement in the Community.....	64
Table Q41. Does your child take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?	65
Table Q42. For your child, what are the obstacles or barriers to participation in activities in the community? ..	66
Table Q43. Does your child spend time with children who do not have developmental disabilities?	67
Table Q44. In your community, are there resources that your family can use that are not provided by the I/DD agency?.....	68
Table Q45. Does your family take part in any family-to-family networks in your community?	69
Satisfaction With Services and Supports	70
Table Q46. Overall, are you satisfied with the services and supports your family currently receives?	71
Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?.....	72
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?	73
Table Q49. Do you know how to report abuse or neglect related to your child?	74
Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child?	75
Table Q51. Do you feel that services and supports have made a positive difference in the life of your family? ...	76
Table Q52. Do you feel that services and supports have reduced your family’s out-of-pocket expenses for your child’s care?	77
Table Q53. Do you feel that family supports have improved your ability to care for your child?	78
Table Q54. Have the services or supports that you or your child received during the past year been reduced, suspended, or terminated?	79
Table Q55. 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?	80
Table Q56. Have the services or supports that your child received been increased in the past year?	81
Table Q57. Are services and supports helping your child to live a good life?.....	82

NCI History and Activities.....	83
Overview of National Core Indicators.....	84
State Participation	85
NCI State Participation 2016-17	85
The Core Indicators.....	85
Sub-Domains and Concern Statements.....	86
Family Survey Sub-Domains and Concern Statements.....	86
How NCI Data Are Used.....	87
Caution and Limitations.....	87
Methodology.....	89
Sampling & Administration	90
Weighting.....	90
Significance Testing.....	91
Data Entry and Analysis	92
Response Rates.....	92
Child Family Survey: State Response Rates	93

Executive Summary

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

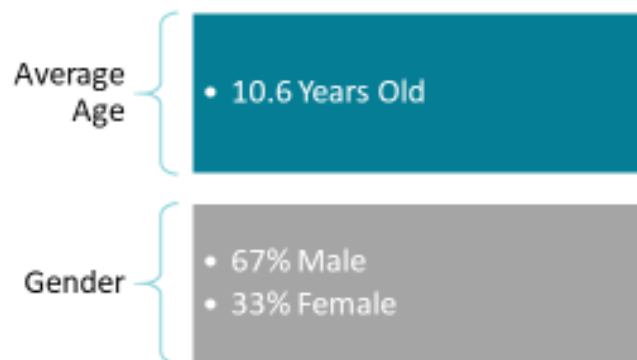
The NCI Child Family Survey is administered to families who have a child with a developmental disability who lives in the family's home and receives at least one service other than case management. Not all states that participate in NCI administer the Child Family Survey on an annual basis. Of the 46 states, District of Columbia and 22 sub-state entities who participated in NCI during the 2016-17 data collection cycle, nine (9) states submitted a valid sample of Child Family Survey data to be included in this report. This Final Report provides a summary of results.

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.

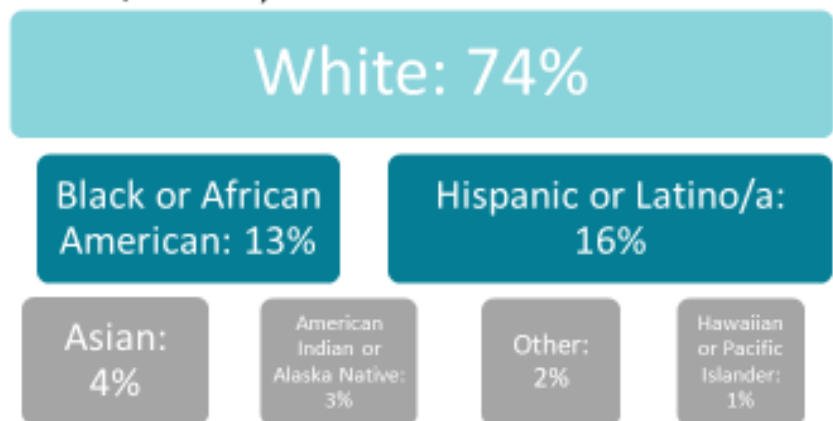
LOOKING AT THE 2016-17 CHILD FAMILY SURVEY (CFS)

Respondents: families or guardians of children with intellectual/developmental disability. The child with the disability lives in the family home (with the respondent) and receives at least one service funded by the state developmental disability agency in addition to case management. 9 states*: Total sample: 3,352

Respondents reported the following about their children with disabilities:



Respondents reported the following about the race/ethnicity of their children with disabilities:



Respondents reported the following about themselves:

Respondents' Age



Respondents' Health Status



27%

• Report a total taxable income of less than \$25,000/year

*CFS: AZ, LA, MN, MO, NC, OR, SD, WA, WI; NCI Average is weighted

Information and Planning



Respondents reported...

34% Always receive enough information to help plan services for children with disabilities

26% Report that the information received to help plan services is always easy to understand

79% Report that child gets all services listed in service plan

Access and Delivery of Supports and Services

Respondents reported...



72%

Family gets needed supports



79%

Services are always delivered in a way that is respectful of family's culture



61%

Support workers always come and leave when they're supposed to



42%

Child always has access to special equipment or accommodations s/he needs

Choice, Decision-making and Control



Respondents reported...

Family can always choose or change the agency that provides supports

61%

Involvement in the Community

Respondents reported...

84%

- Child takes part in community activities (for example, going out to a restaurant, movie, or sporting event)

86%

- Child with disability spends time with children without I/DD

Satisfaction with Services and Supports

Respondent is always satisfied with services and supports family receives

32%

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 child with a developmental disability (e.g., age, race, type of disability) followed by a series of demographic questions pertaining to the survey respondent (e.g., age, health status, relationship to the child with the developmental disability).

Services and Supports Received

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

Questions Regarding Services and Supports

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

Each question is constructed so the respondent selects from either 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.

Additional Comments

At the end of each section, the survey contains a prompt and an area for respondents to make additional open-ended comments concerning their child's participation in the service system.

Presentation of Data

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

For each question, outcome results are first shown in a graph with the NCI Average and then in a table that shows a breakout of each state's percentage.¹

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

States receive an 'n/a' designation within the tables if fewer than 20 people responded to the item; however, their data are still 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 you may see 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.

Important note on changes to reporting: In previous years, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as "average of averages"). This year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states' systems. Beginning this year, 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. See more about weighting in the Methodology section.

¹ Unlike in previous years, the NCI and state averages were weighted; see note below and "Weighting" in the Methodology section for more information.

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	16%	84%	232
LA	22%	78%	268
MN	32%	68%	449
MO	19%	81%	176
NC	22%	78%	235
OR	21%	79%	416
SD	15%	85%	203
WA	15%	85%	371
WI	15%	85%	934
NCI Average	20%	80%	3,284

Table 2. Child's Age

State	Age	N
AZ	9.0	233
LA	8.4	279
MN	12.0	452
MO	13.2	177
NC	14.6	239
OR	11.1	418
SD	12.3	181
WA	11.3	374
WI	10.1	942
NCI Average	10.6	3,295

Table 3. Child's Gender

State	Male	Female	N
AZ	71%	29%	233
LA	64%	36%	273
MN	66%	34%	454
MO	61%	39%	179
NC	72%	28%	238
OR	64%	36%	416
SD	69%	31%	189
WA	67%	33%	376
WI	66%	34%	941
NCI Average	67%	33%	3,299

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	34%	10%	55%	18%	8%	5%
LA	27%	12%	38%	13%	5%	5%
MN	53%	25%	53%	13%	8%	5%
MO	59%	20%	56%	22%	18%	7%
NC	60%	22%	61%	18%	8%	4%
OR	49%	23%	53%	14%	9%	6%
SD†	46%	13%	40%	12%	8%	6%
WA	53%	18%	56%	12%	10%	7%
WI	41%	16%	49%	13%	9%	6%
NCI Average	44%	17%	52%	15%	9%	5%

† In the 2016-17 data cycle, SD used the 2015-16 survey tool. Due to changes made in the 2016-17 survey tool, examinations of SD's data should be made with caution.

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	8%	21%	0%	12%	0%	0%	27%
LA	6%	22%	1%	9%	1%	3%	45%
MN	8%	24%	0%	14%	0%	5%	32%
MO	12%	40%	0%	6%	0%	1%	38%
NC	6%	28%	0%	10%	2%	0%	25%
OR	8%	24%	1%	11%	0%	8%	31%
SD	7%	23%	0%	22%	1%	2%	31%
WA	9%	26%	0%	13%	1%	1%	28%
WI	9%	27%	0%	14%	0%	2%	33%
NCI Average	8%	24%	0%	12%	0%	2%	32%

Table 5a. Child's Health Conditions

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	10%	1%	1%	7%	10%
LA	14%	2%	2%	7%	3%
MN	10%	7%	3%	4%	5%
MO	10%	2%	1%	9%	7%
NC	8%	8%	2%	7%	4%
OR	14%	4%	1%	2%	2%
SD	12%	6%	8%	9%	2%
WA	13%	2%	2%	2%	1%
WI	15%	4%	2%	6%	3%
NCI Average	11%	4%	2%	6%	5%

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

State	Dysphagia	Pressure Ulcers	Oral Health or Dental Problems	Sleep Apnea	Other
AZ	13%	0%	12%	18%	59%
LA	10%	1%	7%	15%	63%
MN	17%	2%	14%	15%	56%
MO	26%	5%	14%	20%	63%
NC	14%	1%	5%	18%	58%
OR	30%	1%	15%	27%	54%
SD†	18%	0%	n/a	n/a	70%
WA	27%	1%	14%	38%	56%
WI	23%	3%	13%	19%	55%
NCI Average	18%	1%	12%	22%	58%

† In the 2016-17 data cycle, SD used the 2015-16 survey tool. Due to changes made in the 2016-17 survey tool, examinations of SD's data should be made with caution.

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	3%	4%	8%	0%	65%	35%	1%	232
LA	1%	1%	38%	0%	57%	6%	1%	280
MN	3%	7%	12%	0%	76%	10%	2%	455
MO	2%	3%	7%	0%	90%	3%	2%	180
NC	2%	3%	23%	0%	71%	6%	2%	240
OR	4%	4%	5%	1%	84%	14%	2%	421
SD	6%	2%	5%	0%	90%	5%	1%	197
WA	4%	9%	7%	2%	80%	12%	4%	378
WI	3%	3%	7%	0%	86%	8%	1%	936
NCI Average	3%	4%	13%	1%	74%	16%	2%	3,319

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	68%	22%	3%	3%	3%	229
LA	55%	33%	2%	3%	7%	271
MN	67%	19%	1%	6%	7%	407
MO	47%	31%	2%	9%	11%	171
NC	68%	22%	1%	5%	5%	238
OR	63%	22%	2%	8%	5%	418
SD	71%	16%	3%	4%	6%	196
WA	57%	24%	2%	8%	8%	379
WI	54%	26%	3%	5%	12%	939
NCI Average	62%	24%	2%	5%	7%	3,248

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

State	Extensive	Some	None	N
AZ	19%	42%	39%	223
LA	19%	29%	53%	270
MN	37%	43%	20%	443
MO	31%	41%	29%	175
NC	22%	51%	28%	231
OR	36%	43%	21%	417
SD	12%	42%	47%	190
WA	36%	43%	22%	372
WI	19%	41%	41%	911
NCI Average	26%	41%	33%	3,232

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

State	Extensive	Some	None	N
AZ	51%	43%	5%	230
LA	52%	40%	8%	268
MN	67%	30%	2%	453
MO	72%	22%	7%	179
NC	53%	40%	7%	237
OR	61%	36%	3%	421
SD†	39%	49%	11%	195
WA	69%	30%	2%	381
WI	55%	39%	6%	937
NCI Average	58%	37%	5%	3301

† In the 2016-17 data cycle, SD used the 2015-16 survey tool. Due to changes made in the 2016-17 survey tool, examinations of SD's data should be made with caution.

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	24%	64%	11%	1%	230
LA	32%	57%	11%	0%	281
MN	11%	77%	13%	0%	456
MO	11%	71%	18%	0%	180
NC	6%	74%	19%	1%	240
OR	14%	71%	15%	0%	421
SD	18%	67%	15%	1%	198
WA	12%	76%	11%	0%	381
WI	23%	69%	8%	0%	934
NCI Average	19%	69%	12%	0%	3,321

Table 11. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
AZ	19%	44%	35%	2%	233
LA	19%	46%	31%	3%	281
MN	15%	46%	36%	4%	456
MO	15%	46%	36%	3%	179
NC	13%	46%	36%	4%	239
OR	16%	48%	32%	4%	422
SD	17%	55%	27%	2%	200
WA	15%	46%	35%	4%	384
WI	18%	52%	28%	2%	930
NCI Average	17%	46%	33%	3%	3,324

Table 12. Respondent's Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
AZ	94%	0%	5%	0%	233
LA	92%	0%	6%	2%	278
MN	98%	0%	2%	1%	456
MO	92%	0%	6%	2%	179
NC	94%	0%	5%	1%	240
OR	94%	0%	4%	1%	423
SD	96%	0%	3%	0%	201
WA	97%	0%	3%	0%	385
WI	96%	0%	3%	1%	932
NCI Average	95%	0%	4%	1%	3,327

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

State	Respondent	Other Family Member	No	N
AZ	5%	14%	81%	231
LA	4%	7%	89%	276
MN	45%	25%	38%	451
MO	3%	15%	82%	177
NC	5%	7%	88%	240
OR	5%	28%	68%	418
SD	6%	9%	86%	200
WA	4%	12%	84%	382
WI	7%	15%	79%	926
NCI Average	12%	16%	74%	3,301

Table 14. Number of Adults in Household

State	One	Two	Three	Four or More	N
AZ	13%	70%	13%	4%	227
LA	32%	53%	11%	5%	276
MN	17%	63%	14%	7%	454
MO	20%	61%	14%	4%	179
NC	21%	49%	24%	5%	237
OR	19%	64%	11%	5%	418
SD†	20%	59%	15%	7%	199
WA	17%	64%	15%	4%	383
WI	15%	67%	14%	4%	922
NCI Average	18%	63%	14%	5%	3,295

† In the 2016-17 data cycle, SD used the 2015-16 survey tool. Due to changes made in the 2016-17 survey tool, examinations of SD's data should be made with caution.

Table 15. Number of Children in Household

State	One	Two	Three	Four or More	N
AZ	31%	37%	19%	13%	227
LA	38%	38%	13%	10%	266
MN	29%	33%	20%	17%	455
MO	43%	33%	13%	10%	174
NC	45%	31%	15%	9%	216
OR	36%	44%	11%	9%	408
SD	38%	34%	20%	7%	181
WA	37%	39%	16%	8%	371
WI	36%	37%	19%	8%	900
NCI Average	35%	36%	17%	11%	3,198

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%	13%	7%	26%	46%	225
LA	10%	21%	7%	17%	46%	278
MN	5%	13%	11%	22%	49%	456
MO	4%	11%	6%	20%	59%	179
NC	3%	15%	7%	21%	54%	241
OR	6%	17%	5%	22%	50%	421
SD	7%	16%	11%	13%	53%	197
WA	0%	10%	8%	24%	58%	378
WI	4%	15%	9%	21%	51%	931
NCI Average	6%	14%	8%	22%	50%	3,306

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	9%	13%	19%	16%	23%	8%	12%	226
LA	18%	11%	12%	13%	22%	13%	12%	274
MN	7%	10%	24%	19%	28%	5%	7%	455
MO	7%	9%	25%	16%	28%	8%	7%	177
NC	13%	12%	19%	13%	25%	8%	10%	238
OR	11%	12%	19%	16%	24%	7%	11%	413
SD†	9%	10%	17%	20%	27%	7%	10%	198
WA	4%	5%	18%	15%	38%	3%	16%	380
WI	8%	9%	18%	19%	33%	4%	9%	924
NCI Average	9%	11%	19%	16%	27%	7%	11%	3,285

†In the 2016-17 data cycle, SD used the 2015-16 survey tool. Due to changes made in the 2016-17 survey tool, examinations of SD's data should be made with caution.

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

State	Urban or Suburban	Rural	N
AZ	84%	16%	226
LA	70%	30%	260
MN	79%	21%	444
MO	63%	37%	175
NC	61%	39%	234
OR	79%	21%	408
SD	67%	33%	201
WA	72%	28%	375
WI	66%	34%	916
NCI Average	75%	25%	3,239

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 ID/DD Agency

State	Financial Support	In-home Support	Out-of-home Respite	Early Intervention	Transportation	Other	Self-direction or Fiscal Intermediary Services
AZ	7%	51%	41%	27%	21%	86%	13%
LA	17%	39%	11%	44%	14%	62%	18%
MN	54%	66%	27%	8%	28%	69%	57%
MO	27%	73%	28%	1%	17%	66%	53%
NC	12%	73%	49%	6%	22%	62%	19%
OR	20%	82%	47%	10%	22%	58%	42%
SD†	59%	12%	44%	14%	16%	67%	35%
WA	32%	52%	34%	7%	14%	66%	21%
WI	37%	46%	39%	25%	15%	71%	20%
NCI Average	26%	56%	34%	20%	20%	71%	28%

Table 20. Other Services or Supports Received

State	Social Security Payments (SSI/SSB)	Services or Supports from Other Agencies or Organizations
AZ	37%	63%
LA	39%	44%
MN	31%	75%
MO	43%	81%
NC	47%	66%
OR	40%	66%
SD†	45%	75%
WA	27%	72%
WI	33%	70%
NCI Average	36%	66%

†In the 2016-17 data cycle, SD used the 2015-16 survey tool. Due to changes made in the 2016-17 survey tool, examinations of SD's data should be made with caution.

Child Family Survey Results

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.

Gets Enough Information to Help Plan Services

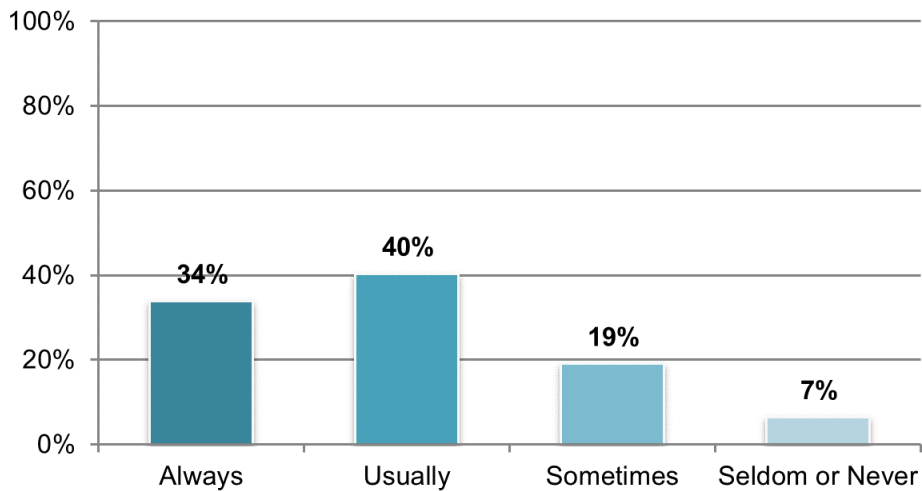


Table Q1. Do you get enough information to help you participate in planning services for your family?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	50%	39%	10%	1%	193
LA	43%	31%	18%	8%	250

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	42%	39%	15%	4%	227
MO	35%	37%	24%	4%	177
NCI Average	34%	40%	19%	7%	3,209
NC	34%	43%	16%	7%	230
WI	32%	43%	20%	5%	916
OR	31%	46%	18%	4%	408

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	26%	44%	23%	7%	438
WA	16%	42%	27%	15%	370

Information About Services and Supports Is Easy to Understand

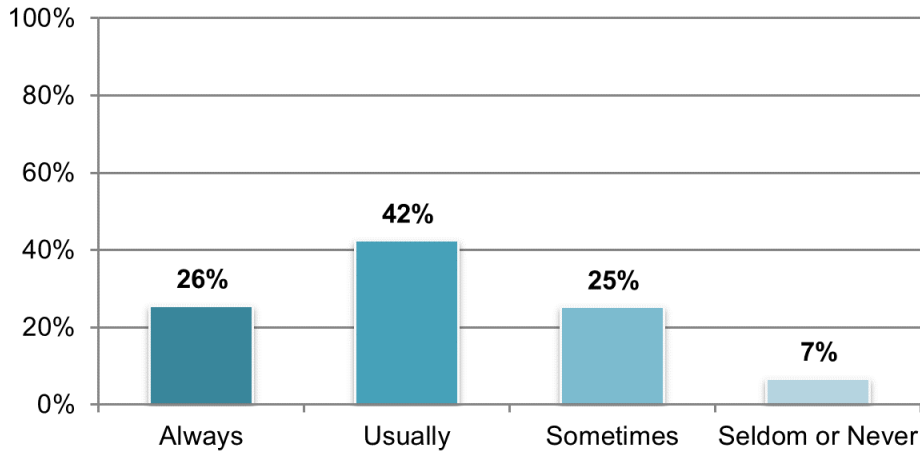


Table Q2. Is the information you receive easy to understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	44%	40%	15%	2%	196
AZ	37%	42%	17%	4%	228

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	28%	40%	26%	6%	252
NCI Average	26%	42%	25%	7%	3,223
WI	25%	43%	27%	5%	911
OR	22%	45%	27%	7%	415
NC	21%	45%	27%	7%	232
MO	20%	55%	20%	5%	176

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	17%	43%	31%	9%	436
WA	11%	37%	37%	15%	377

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

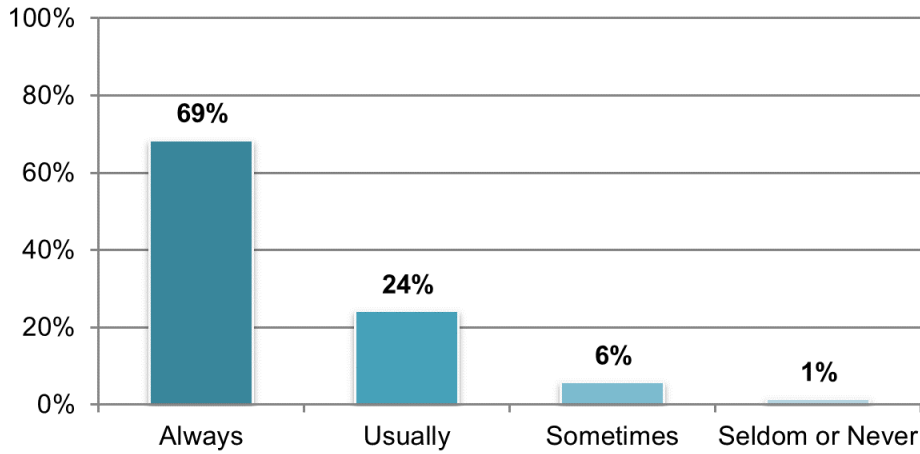


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	79%	19%	2%	0%	194
AZ	77%	19%	3%	1%	229

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MO	71%	23%	5%	1%	175
LA	70%	22%	6%	2%	247
OR	70%	24%	5%	1%	406
NCI Average	69%	24%	6%	1%	3,140
WI	68%	24%	7%	1%	897
WA	62%	29%	8%	1%	353
NC	62%	32%	3%	3%	215

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	58%	29%	10%	2%	424

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

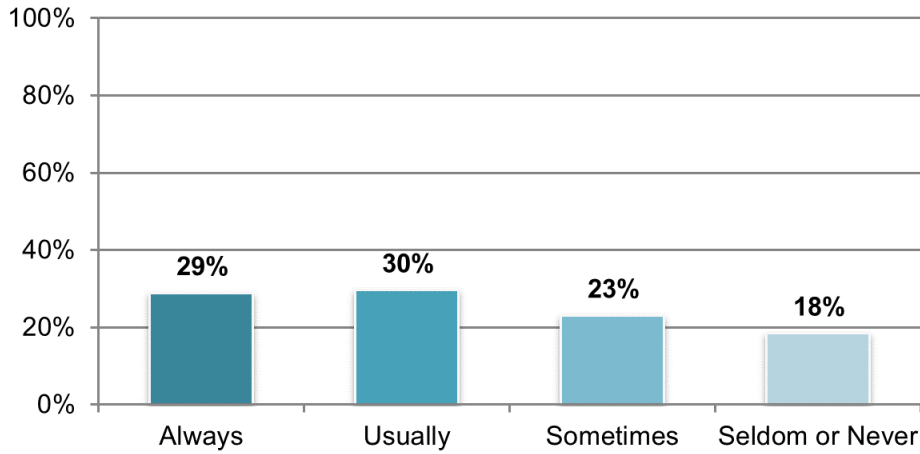


Table Q4. Do you have enough information about other public services for which your family is eligible?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	45%	37%	11%	7%	178

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	38%	24%	21%	17%	198
LA	32%	26%	21%	21%	225
OR	29%	32%	26%	13%	358
NCI Average	29%	30%	23%	18%	2,821
WI	27%	32%	24%	17%	790
NC	24%	31%	26%	19%	205
MO	23%	34%	30%	14%	158

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	22%	33%	22%	23%	390
WA	18%	35%	26%	21%	319

Respondent Needs Help Planning for Child's Future Needs

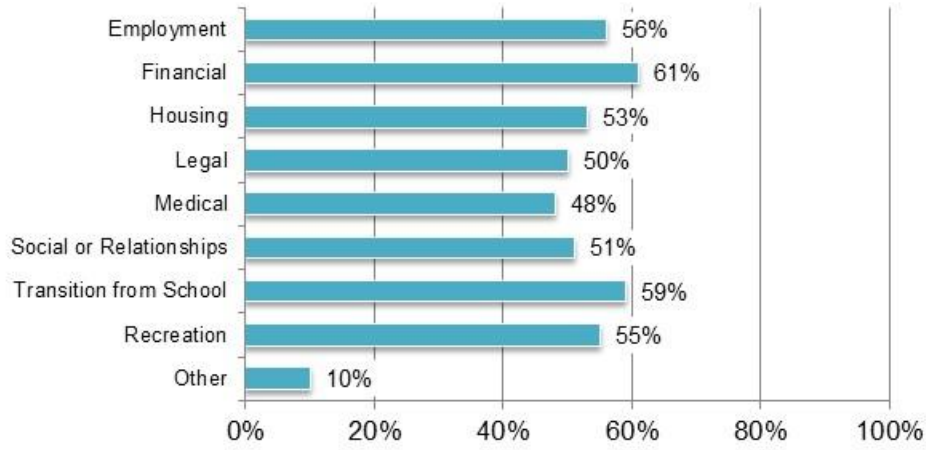


Table Q5. Do you need help planning for your child's future with respect to any of the following?

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition from School	Recreation	Other
AZ	54%	57%	45%	48%	53%	52%	57%	56%	8%
LA	40%	51%	43%	34%	44%	41%	51%	46%	13%
MN	59%	63%	61%	53%	46%	50%	62%	58%	11%
MO	46%	62%	57%	54%	45%	48%	57%	45%	16%
NC	61%	61%	54%	56%	37%	47%	64%	50%	6%
OR	54%	63%	54%	47%	44%	62%	63%	65%	9%
SD	59%	58%	52%	44%	46%	46%	57%	52%	8%
WA	64%	70%	58%	60%	55%	60%	64%	68%	10%
WI	62%	66%	56%	52%	48%	52%	57%	50%	8%
NCI Average	56%	61%	53%	50%	48%	51%	59%	55%	10%

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

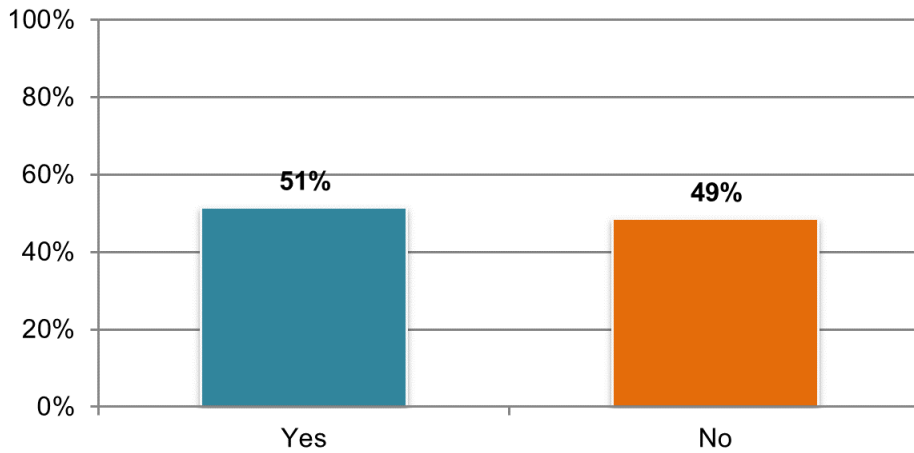


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

Within Average Range

State	Yes	No	N
SD	65%	35%	34
NC	61%	39%	59
WA	57%	43%	67
WI	55%	45%	184
LA	53%	47%	59
NCI Average	51%	49%	660
MO	51%	49%	35
AZ	50%	50%	46
OR	48%	52%	79
MN	44%	56%	97

Child Has a Service Plan

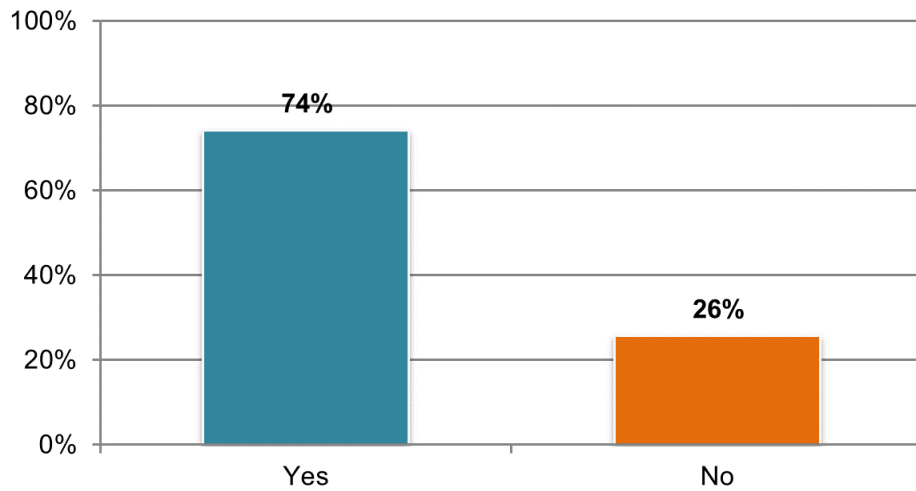


Table Q7. Does your child have a service plan?

Significantly Above Average

State	Yes	No	N
MO	90%	10%	153
OR	87%	13%	389
SD	83%	17%	169
AZ	81%	19%	189

Within Average Range

State	Yes	No	N
NC	81%	19%	215
NCI Average	74%	26%	2,824
MN	73%	27%	374

Significantly Below Average

State	Yes	No	N
WI	70%	30%	825
WA	59%	41%	280
LA	57%	43%	230

Service Plan Includes All the Services and Supports Child Needs

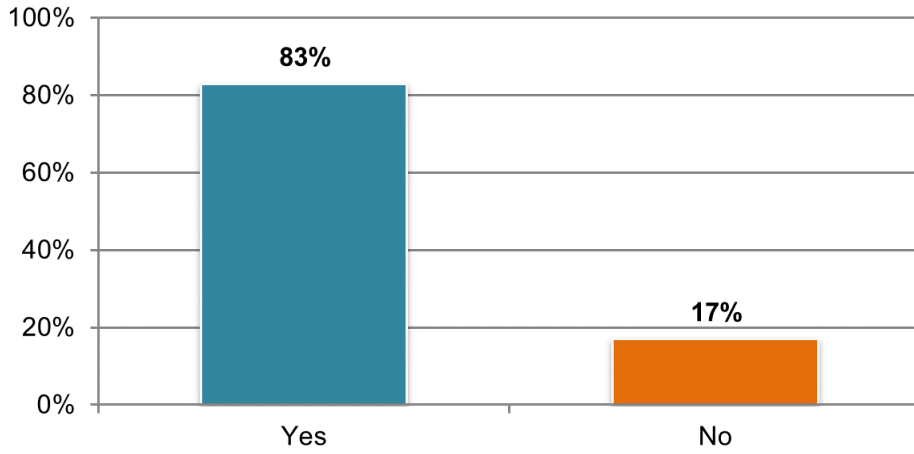


Table Q8. Does the plan include all the services and supports your child needs?

Significantly Above Average

State	Yes	No	N
SD	92%	8%	132

Within Average Range

State	Yes	No	N
LA	88%	13%	112
WI	85%	15%	518
AZ	85%	15%	142
OR	84%	16%	304
NCI Average	83%	17%	1,884
MN	82%	18%	250
NC	79%	21%	158
MO	79%	21%	129

Significantly Below Average

State	Yes	No	N
WA	71%	29%	139

Child Gets All Services Listed in the Service Plan

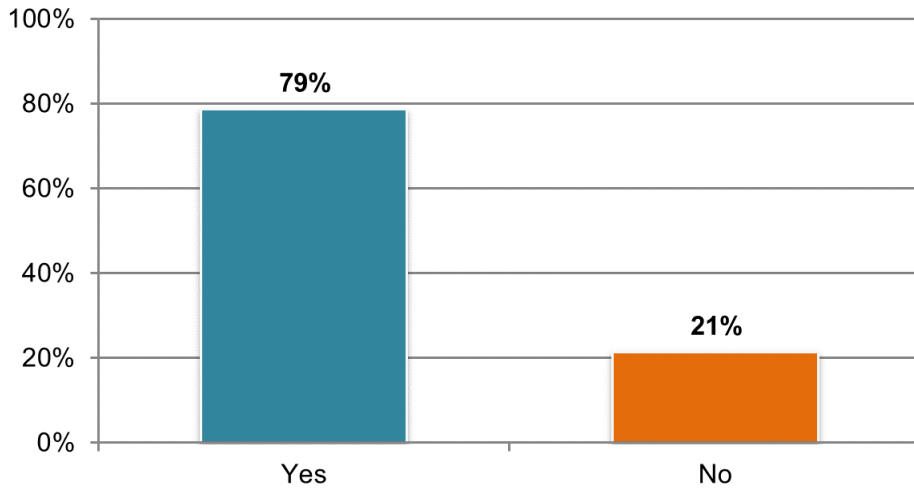


Table Q9. Does your child receive all of the services listed in the plan?

Significantly Above Average

State	Yes	No	N
SD	96%	4%	131
WI	90%	10%	528
NC	87%	13%	163
OR	85%	15%	300

Within Average Range

State	Yes	No	N
LA	85%	15%	116
MO	85%	15%	134
MN	84%	16%	248
NCI Average	79%	21%	1,891

Significantly Below Average

State	Yes	No	N
AZ	65%	35%	138
WA	58%	42%	133

Respondent or Other Family Member Helped Make Service Plan

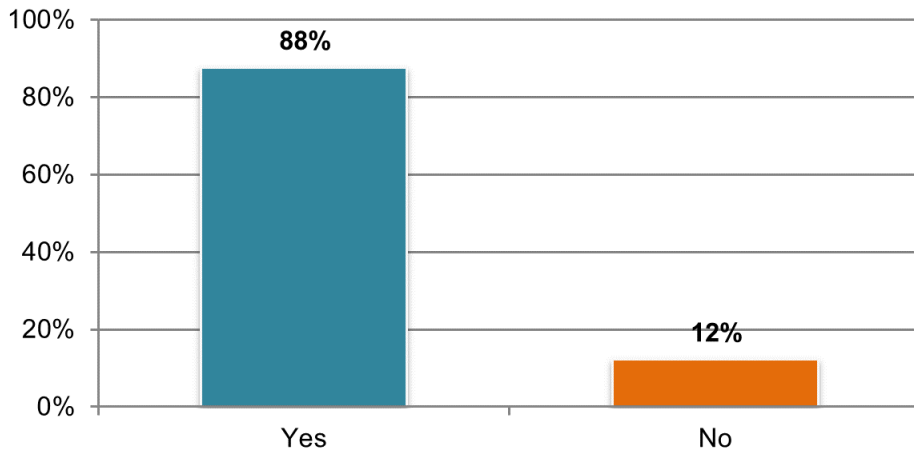


Table Q10. Did you or another family member help develop the plan?

Significantly Above Average

State	Yes	No	N
NC	94%	6%	167

Within Average Range

State	Yes	No	N
MO	93%	7%	135
SD	92%	8%	139
MN	91%	9%	263
OR	91%	9%	319
WI	89%	11%	552
NCI Average	88%	12%	2,000
WA	87%	13%	156
AZ	84%	16%	146
LA	81%	19%	123

Child Helped Make Service Plan

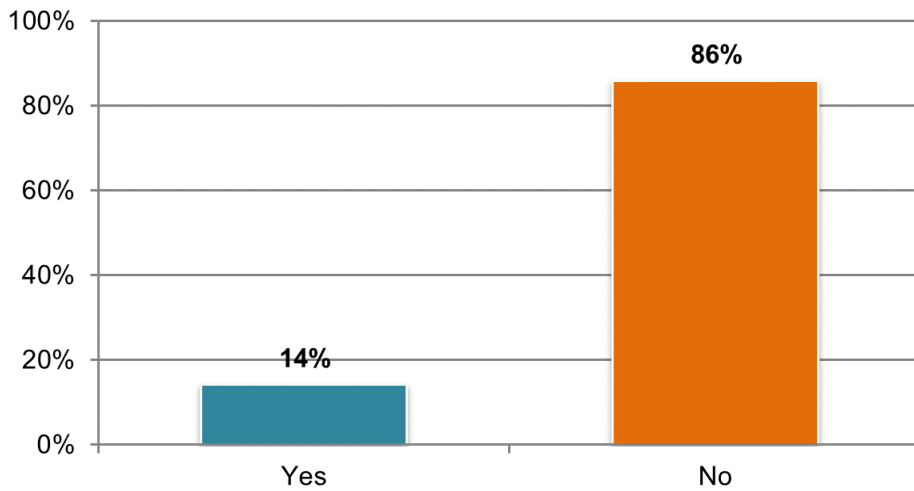


Table Q11. Did your child help develop the plan?

Significantly Above Average

State	Yes	No	N
SD	34%	66%	138

Within Average Range

State	Yes	No	N
NC	22%	78%	168
OR	19%	81%	323
WI	17%	83%	540
NCI Average	14%	86%	2,007
MN	13%	87%	267
MO	13%	87%	133
LA	13%	87%	127
AZ	10%	90%	148
WA	10%	90%	163

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

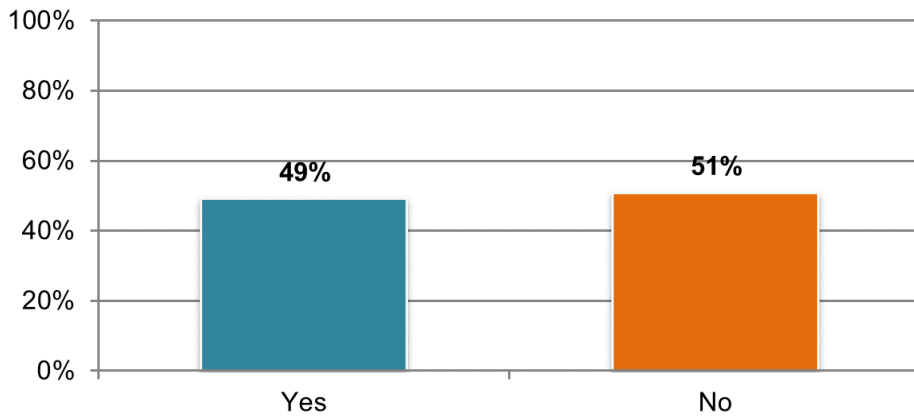


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your child's last service planning meeting?

Significantly Above Average

State	Yes	No	N
LA	70%	30%	123
SD†	69%	31%	129
NC	64%	36%	162
OR	57%	43%	302

Within Average Range

State	Yes	No	N
MO	58%	42%	128
WA	55%	45%	145
MN	51%	49%	249
NCI Average	49%	51%	1,873

Significantly Below Average

State	Yes	No	N
AZ	37%	63%	137
WI	32%	68%	498

† In the 2016-17 data cycle, SD used the 2015-16 survey tool. Due to changes made in the 2016-17 survey tool, examinations of SD's data should be made with caution.

Child Has a Transition Plan

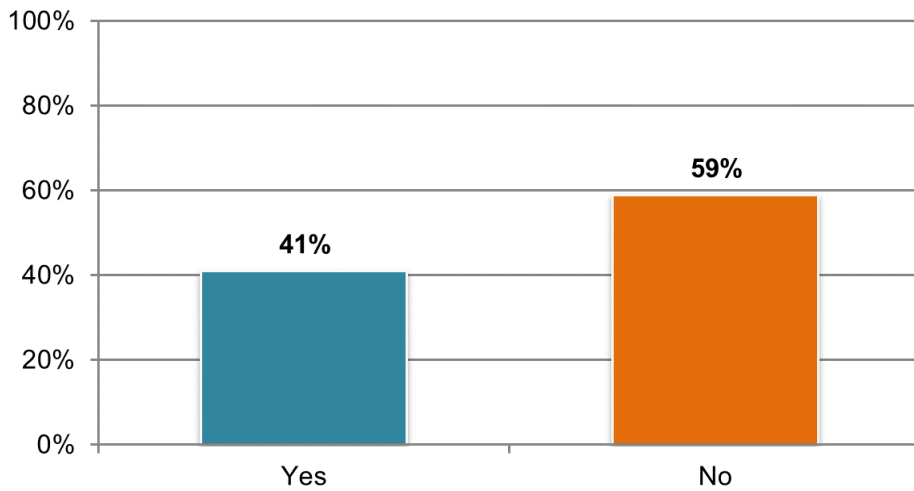


Table Q13. Does your child have a transition plan (as part of an IEP or Section 504 plan through his/her high school, usually starting at age 14)?

Significantly Above Average

State	Yes	No	N
SD	64%	36%	96
NC	59%	41%	169
MN	52%	48%	273

Within Average Range

State	Yes	No	N
MO	46%	54%	105
WI	44%	56%	463
NCI Average	41%	59%	1,738
LA	35%	65%	147
OR	34%	66%	188
WA	33%	67%	200

Significantly Below Average

State	Yes	No	N
AZ	27%	73%	97

Respondent Helped Make Transition Plan

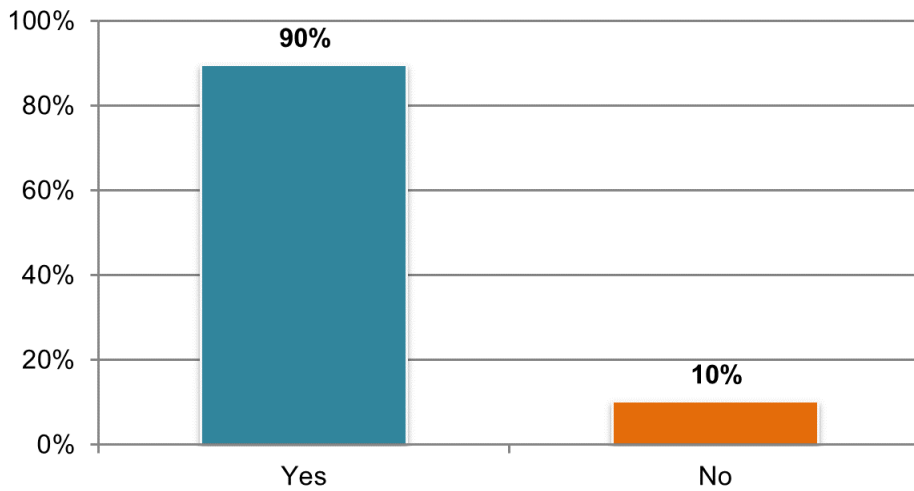


Table Q14. If your child has a service plan, did you help make the transition plan?

Significantly Above Average

State	Yes	No	N
MO	98%	2%	46
NC	96%	4%	95

Within Average Range

State	Yes	No	N
SD	93%	7%	61
WI	93%	7%	192
AZ	90%	10%	21
OR	90%	10%	61
NCI Average	90%	10%	719
WA	89%	11%	61
LA	88%	12%	49
MN	83%	17%	133

Respondent Feels Prepared to Handle the Needs of Child in an Emergency

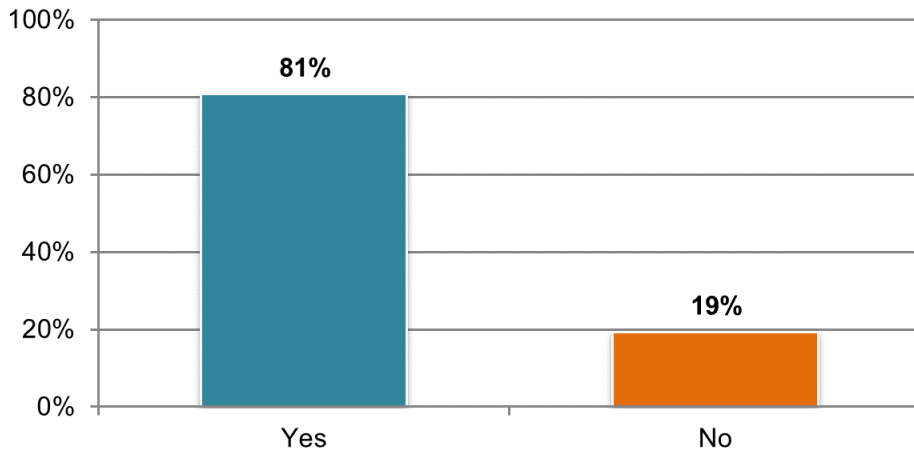


Table Q15. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster?

Significantly Above Average

State	Yes	No	N
LA	92%	8%	251
SD†	92%	8%	156

Within Average Range

State	Yes	No	N
AZ	84%	16%	198
MO	83%	17%	155
NC	82%	18%	214
NCI Average	81%	19%	2,868
WI	79%	21%	792
MN	77%	24%	400

Significantly Below Average

State	Yes	No	N
OR	71%	29%	371
WA	68%	32%	331

† In the 2016-17 data cycle, SD used the 2015-16 survey tool. Due to changes made in the 2016-17 survey tool, examinations of SD's data should be made with caution.

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 or Child Is Able to Contact Support Workers When S/He Wants

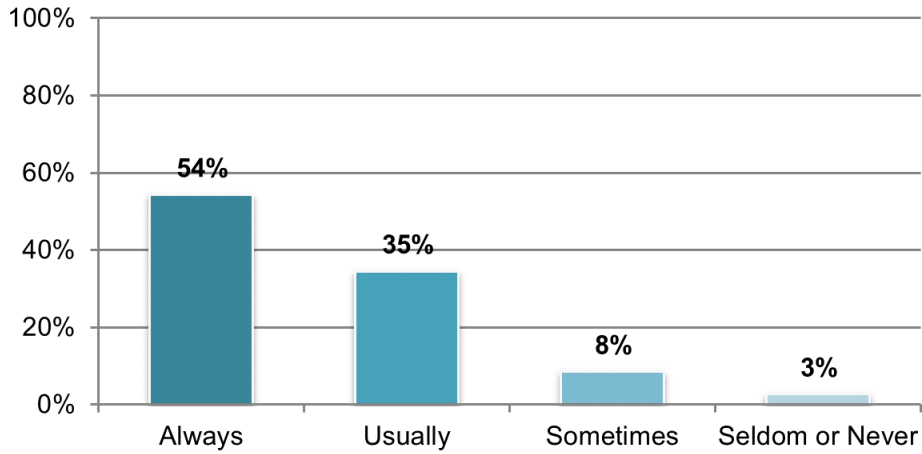


Table Q16. Are you or your child able to contact his/her support workers when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	71%	27%	2%	1%	186

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	60%	30%	8%	1%	218
OR	59%	34%	6%	1%	407
LA	58%	29%	8%	5%	217
WI	58%	31%	8%	3%	859
MO	55%	39%	5%	1%	168
NC	55%	34%	8%	3%	219
NCI Average	54%	35%	8%	3%	2,963

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	43%	44%	10%	3%	409
WA	40%	42%	12%	6%	280

Respondent or Child Is Able to Contact Case Manager or Service Coordinator When S/He Wants

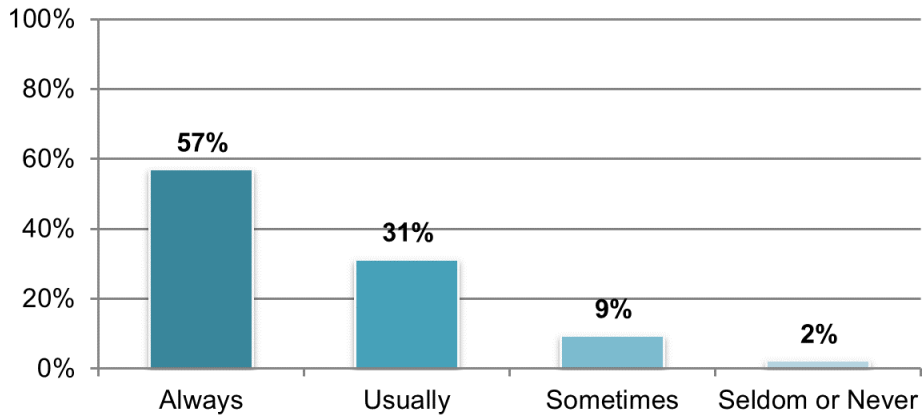


Table Q17. Are you or your child able to contact his/her case manager or service coordinator when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	75%	20%	5%	1%	192
WI	65%	26%	7%	2%	880

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	65%	25%	9%	1%	227
LA	61%	28%	8%	3%	229
NCI Average	57%	31%	9%	2%	3,110
OR	56%	33%	10%	2%	407
MO	55%	36%	8%	1%	173
NC	52%	35%	10%	2%	218

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	46%	40%	9%	4%	423
WA	41%	38%	17%	4%	361

Support Workers Come and Leave When They Are Supposed to

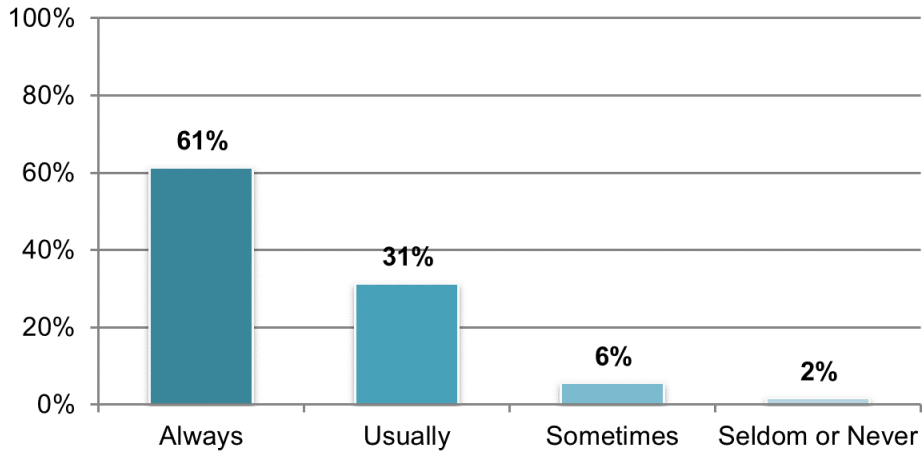


Table Q18. Do support workers come and leave when they are supposed to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	81%	17%	2%	0%	154

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	67%	28%	4%	1%	215
OR	65%	30%	4%	1%	399
WI	65%	29%	5%	1%	802
LA	64%	26%	7%	2%	208
NCI Average	61%	31%	6%	2%	2,770
WA	57%	35%	6%	2%	251
MO	55%	37%	6%	2%	165

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	53%	39%	7%	2%	368
NC	51%	37%	10%	2%	208

Services and Supports Change When Family's Needs Change

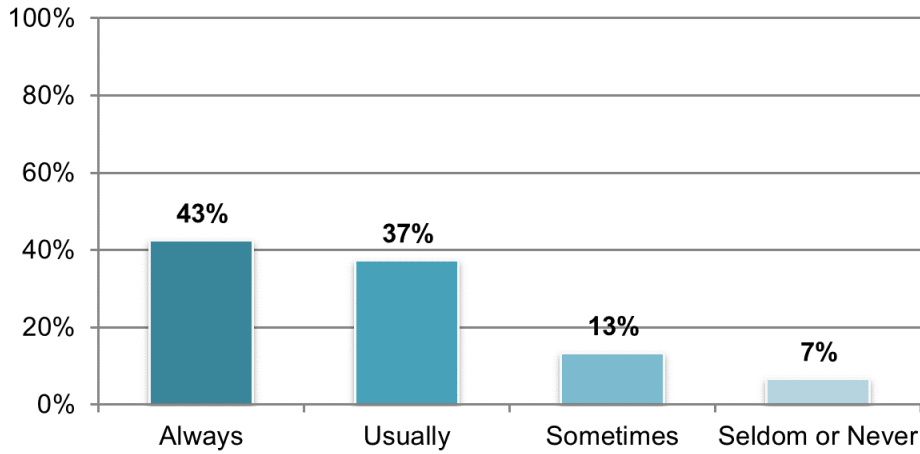


Table Q19. Do services and supports change when your family's needs change?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	67%	23%	10%	0%	164
LA	55%	26%	11%	7%	186

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	51%	38%	7%	4%	189
WI	44%	38%	13%	5%	774
NCI Average	43%	37%	13%	7%	2,613
OR	42%	37%	14%	7%	349
MO	37%	44%	14%	5%	167
NC	34%	48%	11%	7%	203

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	33%	37%	21%	9%	357
WA	18%	40%	24%	19%	224

Support Workers Speak in a Way Respondent Understands

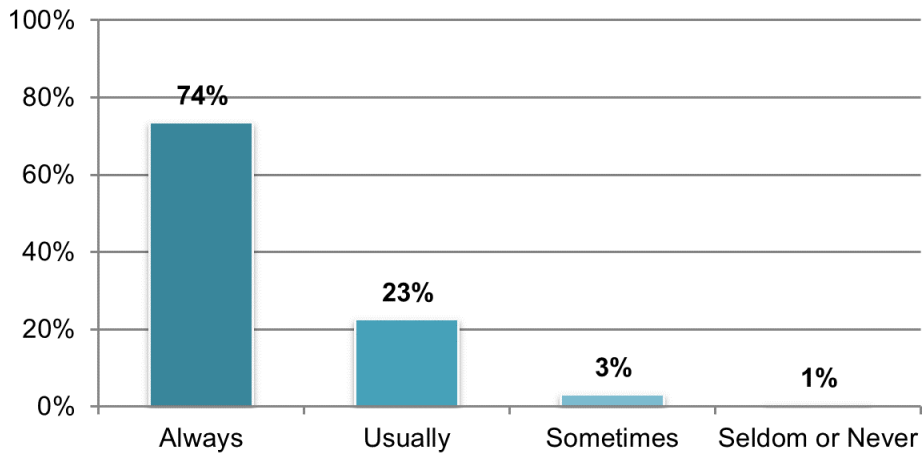


Table Q20. Do support workers speak to you in a way that you understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	83%	15%	1%	1%	165
OR	79%	17%	3%	1%	407

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	78%	21%	1%	0%	215
NC	77%	18%	4%	0%	212
MO	76%	21%	2%	1%	168
LA	75%	20%	5%	0%	214
WI	74%	23%	3%	1%	835
NCI Average	74%	23%	3%	1%	2,868

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	66%	28%	6%	1%	383
WA	61%	32%	6%	2%	269

Services and Supports Are Delivered in a Way Respectful of Family's Culture

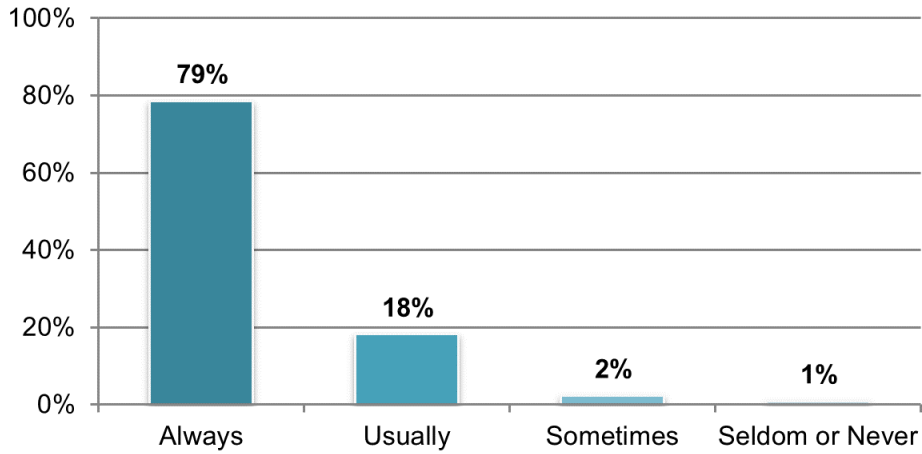


Table Q21. Are services delivered in a way that is respectful of your family's culture?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	88%	11%	1%	1%	188

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	83%	15%	1%	0%	228
OR	82%	16%	2%	0%	416
MO	81%	17%	1%	1%	176
WI	80%	17%	2%	1%	884
LA	80%	14%	4%	2%	242
NCI Average	79%	18%	2%	1%	3,091
NC	74%	21%	4%	1%	224

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	72%	25%	3%	1%	423
WA	71%	25%	4%	1%	310

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

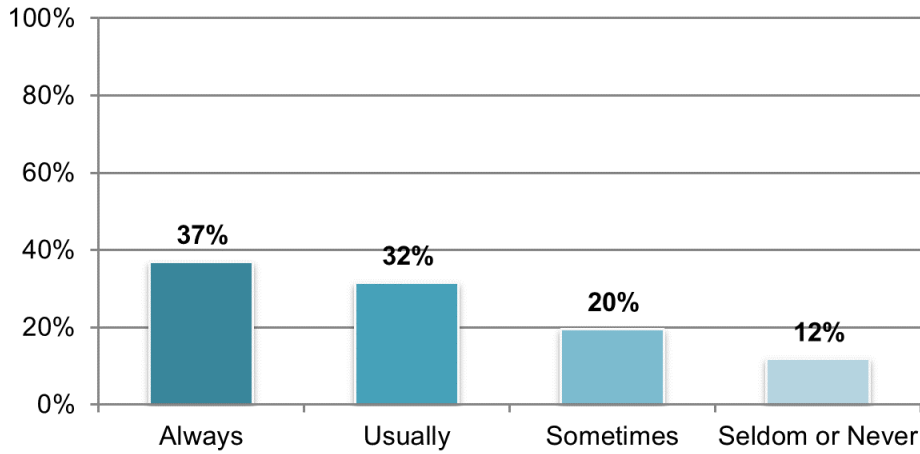


Table Q22. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	50%	30%	17%	3%	30
OR	48%	25%	10%	17%	52
MO	42%	27%	18%	13%	45
MN	39%	26%	20%	15%	54
NCI Average	37%	32%	20%	12%	418
NC	35%	47%	16%	2%	49
WI	30%	21%	30%	18%	109

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	14%	41%	27%	18%	49

*Due to low N's (<20) the following states are not represented in the table, but their data are included in the NCI Average: AZ, SD

Support Workers Have the Right Information and Skills to Meet Family's Needs

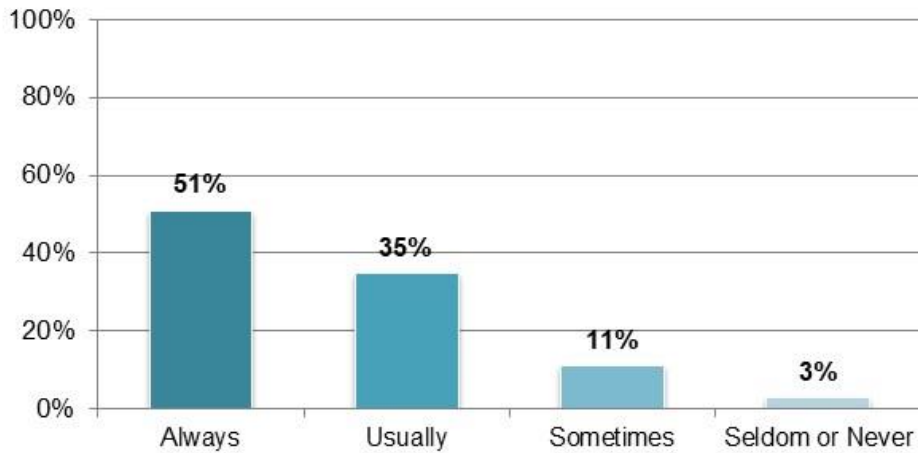


Table Q23. Do support workers have the right information and skills to meet your family's needs?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	69%	17%	12%	1%	205
SD	68%	27%	5%	1%	162

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	57%	33%	7%	2%	218
OR	52%	33%	13%	3%	399
NCI Average	51%	35%	11%	3%	2,803
WI	48%	38%	12%	2%	819
MO	48%	43%	8%	1%	165
NC	43%	40%	14%	3%	214

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	42%	41%	14%	3%	367
WA	35%	43%	16%	7%	254

Child Has Access to Special Equipment or Accommodations Needed

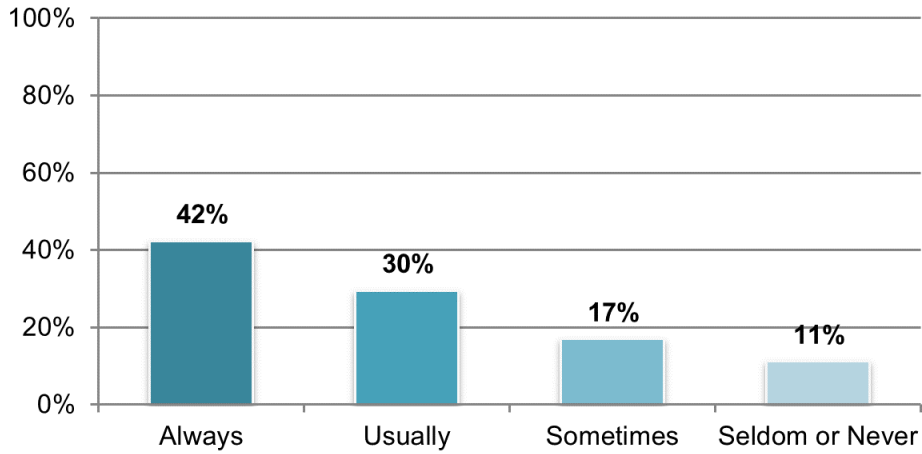


Table Q24. Does your child have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	66%	24%	6%	4%	112

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	47%	25%	14%	14%	110
LA	47%	23%	11%	19%	120
MO	45%	30%	19%	6%	131
MN	44%	29%	18%	8%	255
NCI Average	42%	30%	17%	11%	1,838
OR	42%	27%	21%	10%	265
NC	41%	39%	12%	8%	118
WI	38%	34%	20%	8%	512

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	24%	37%	25%	14%	215

Child Can See Health Professionals When Needed

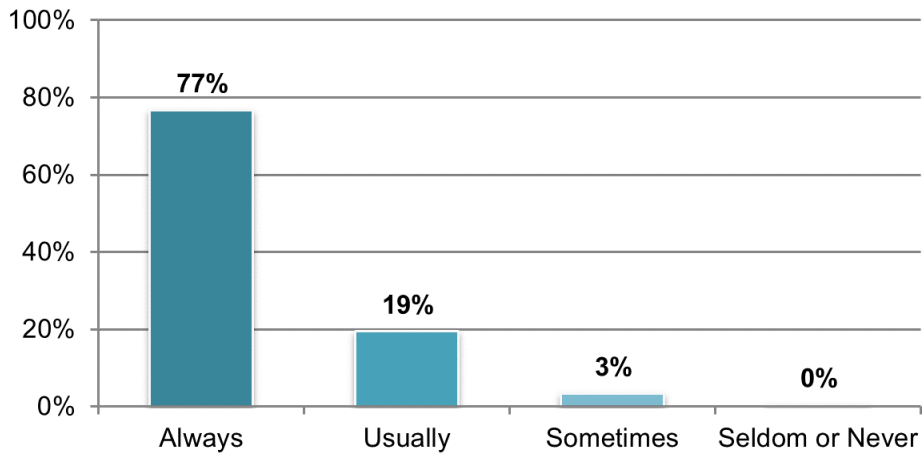


Table Q25. Can your child see health professionals when needed (for example, doctor, dentist, psychologist)?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MO	82%	15%	3%	0%	177
AZ	82%	15%	4%	0%	227
LA	80%	16%	4%	1%	275
NC	78%	19%	2%	0%	239
WI	77%	19%	3%	1%	927
NCI Average	77%	19%	3%	0%	3,081
OR	75%	20%	5%	0%	420
MN	71%	25%	3%	1%	455

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	64%	31%	4%	1%	361

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

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

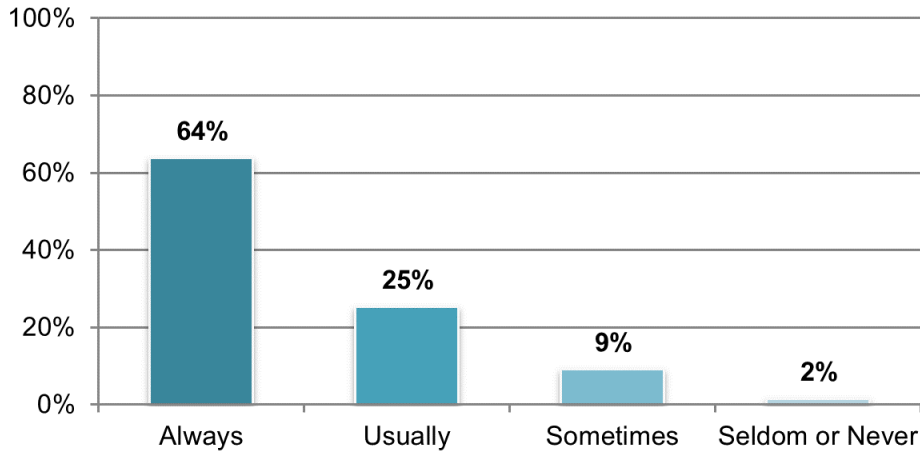


Table Q26. Does your child's primary care doctor understand his/her needs related to his/her disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	70%	21%	9%	1%	230
LA	69%	21%	8%	2%	265
MO	65%	28%	6%	0%	179
NCI Average	64%	25%	9%	2%	3,050
WI	64%	26%	9%	2%	916
OR	63%	24%	11%	2%	415
MN	61%	28%	11%	1%	449
NC	57%	34%	8%	1%	236

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	51%	34%	12%	3%	360

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

Respondent Has Access to Dental Services for Child

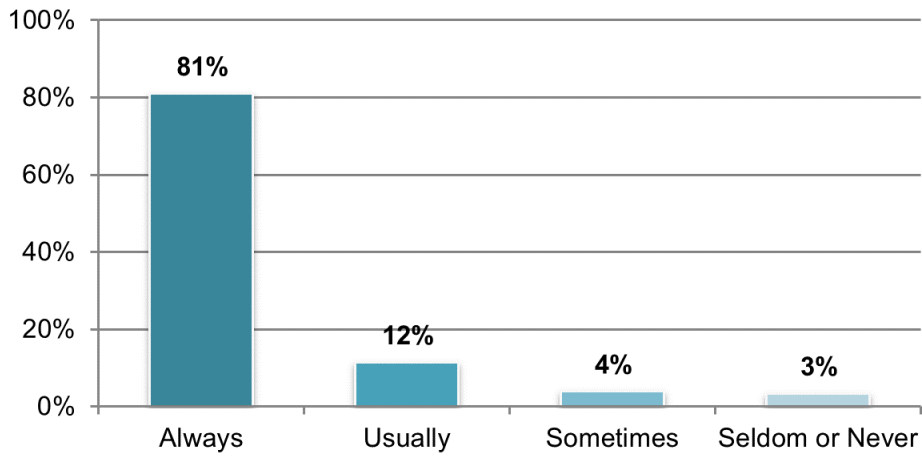


Table Q27. Do you have access to dental services for your child?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	86%	8%	3%	3%	221
OR	84%	11%	2%	2%	412
NC	84%	9%	4%	3%	239
LA	82%	12%	2%	4%	265
NCI Average	81%	12%	4%	3%	3,017
WA	80%	15%	3%	3%	354
WI	79%	12%	4%	5%	900

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	75%	15%	6%	3%	450
MO	72%	16%	7%	5%	176

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

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

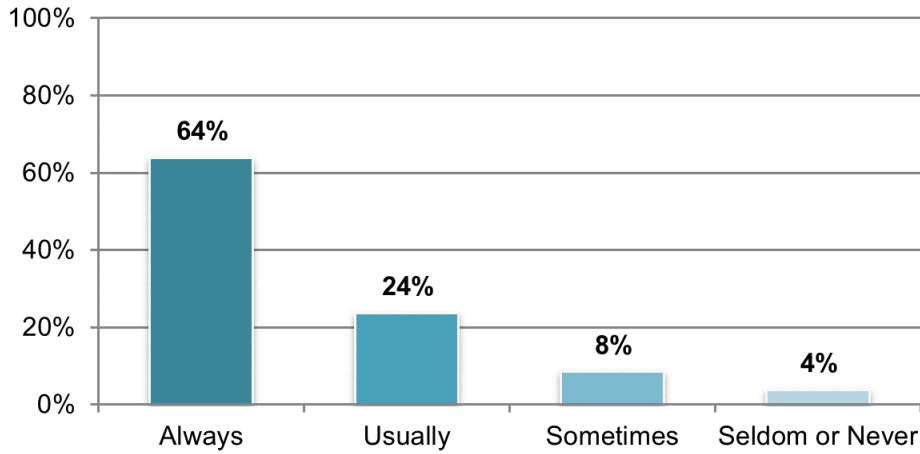


Table Q28. If respondent has access to dental services for the child, does your child's dentist understand his/her needs related to his/her disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	72%	22%	4%	3%	226
AZ	70%	19%	7%	3%	204
NC	69%	21%	7%	3%	230
WI	67%	23%	7%	3%	802
NCI Average	64%	24%	8%	4%	2,788
OR	58%	32%	7%	3%	383
MO	55%	27%	14%	4%	168

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	57%	25%	12%	6%	428
WA	53%	33%	11%	4%	347

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

Respondent Knows What Child's Medications Are for

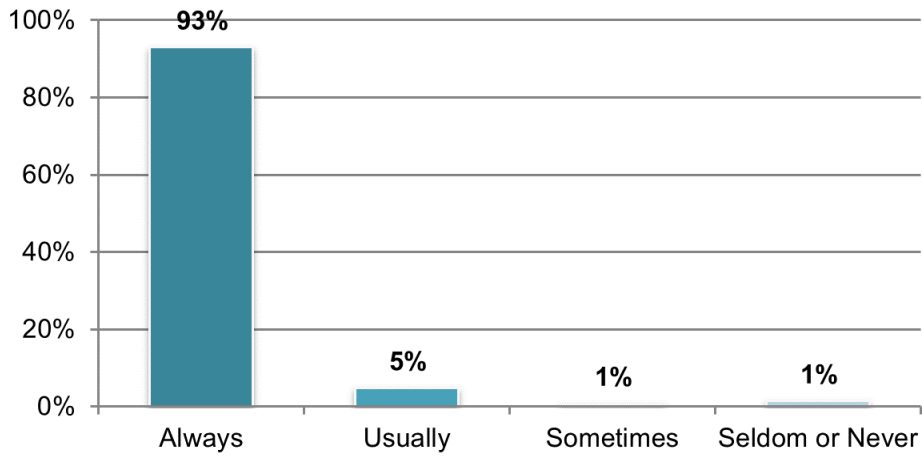


Table Q29. If your child takes medications, do you know what they're for?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	94%	5%	1%	1%	148
LA	94%	3%	1%	2%	196
WA	94%	4%	0%	1%	299
WI	94%	3%	1%	1%	713
MO	93%	5%	1%	1%	166
OR	93%	4%	1%	2%	328
NCI Average	93%	5%	1%	1%	2,439
MN	90%	7%	1%	2%	378
NC	91%	6%	1%	2%	211

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

Respondent, Child, or Other Family Member Knows What Is Needed for Child to Take Medication Safely

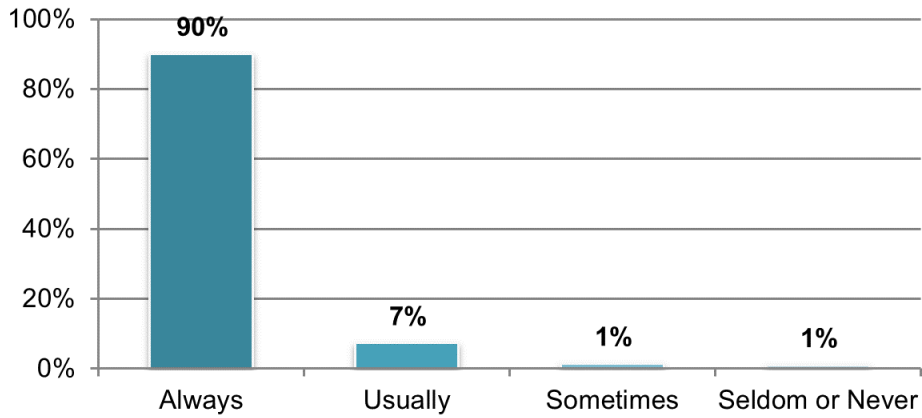


Table Q30. If your child takes medications, do you, your child, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MO	95%	4%	1%	1%	165
WI	92%	7%	0%	1%	701
LA	91%	6%	2%	1%	194
OR	91%	7%	1%	2%	328
NCI Average	90%	7%	1%	1%	2,411
AZ	90%	6%	3%	1%	146
WA	90%	9%	1%	0%	297
MN	89%	9%	1%	1%	371
NC	87%	9%	1%	2%	209

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

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

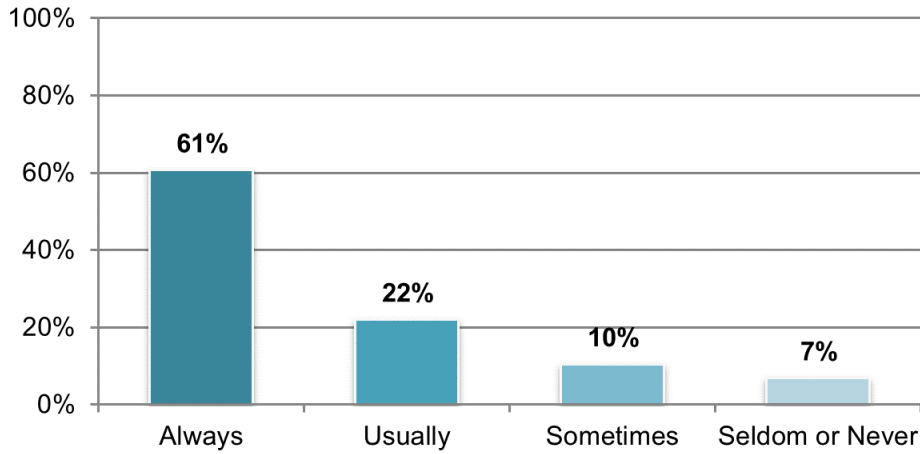


Table Q31. If your child uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your child's needs related to his/her disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	71%	18%	6%	5%	79
MO	65%	29%	3%	4%	77
NC	63%	20%	15%	2%	121
WI	61%	26%	8%	5%	290
AZ	61%	10%	16%	13%	79
NCI Average	61%	22%	10%	7%	1,137
OR	60%	24%	12%	4%	162
MN	60%	26%	7%	7%	206

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	45%	43%	10%	2%	123

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

Respondent Has Access to Respite Services

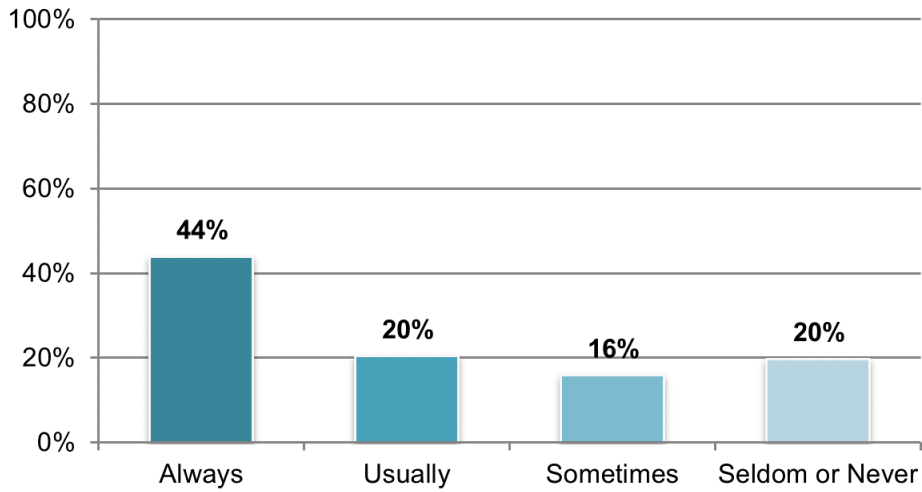


Table Q32. If you need respite services, do you have access to them?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	63%	16%	12%	9%	181
OR	51%	28%	14%	8%	353

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NCI Average	44%	20%	16%	20%	2,167
NC	43%	31%	15%	11%	209
WI	41%	28%	18%	14%	659
LA	35%	19%	14%	32%	100
MO	35%	18%	18%	29%	133

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	27%	17%	19%	36%	264
WA	20%	15%	25%	41%	268

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

Respondent Is Satisfied With the Quality of Child's Respite Services

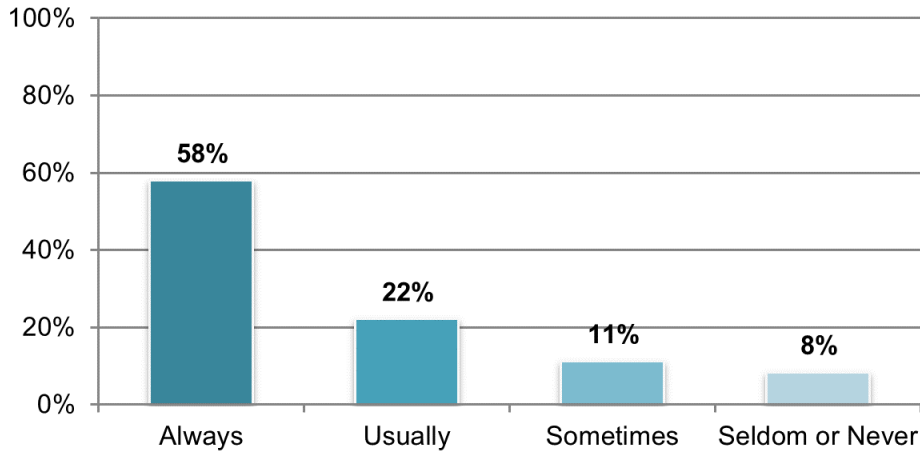


Table Q33. If respondent has access to respite services, are you satisfied with the quality of the respite services?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	72%	12%	8%	7%	161

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OR	64%	24%	8%	4%	324
NCI Average	58%	22%	11%	8%	1,796
WI	55%	29%	11%	5%	586
LA	53%	20%	16%	11%	64
MO	52%	23%	14%	12%	95

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	48%	26%	14%	12%	180
NC	46%	35%	13%	6%	187
WA	36%	28%	19%	17%	199

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

Family Gets Supports and Services Needed

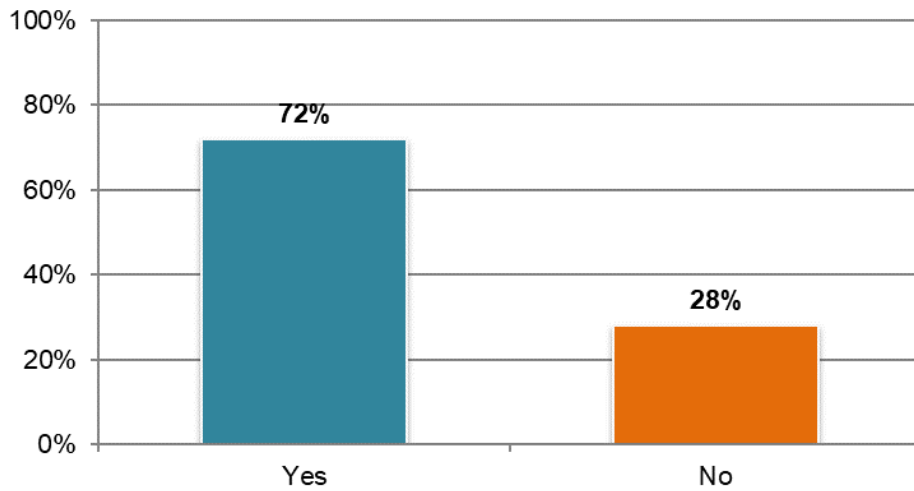


Table Q34. Does your family get the support and services needed?

Significantly Above Average

State	Yes	No	N
SD	86%	14%	186
AZ	81%	19%	211
LA	80%	20%	225

Within Average Range

State	Yes	No	N
OR	73%	27%	373
NCI Average	72%	28%	2,961
NC	72%	28%	222
WI	71%	29%	856
MO	67%	33%	162
MN	67%	33%	412

Significantly Below Average

State	Yes	No	N
WA	51%	49%	314

Additional Services Needed

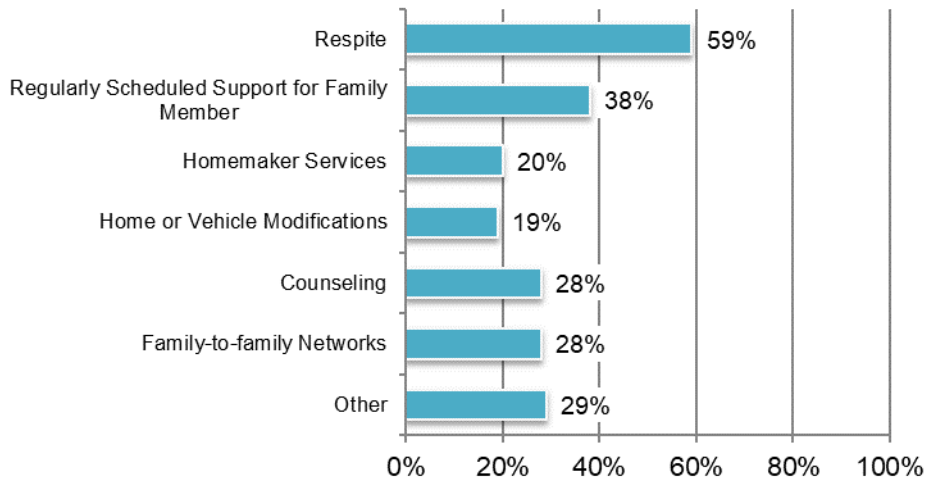


Table Q35. If family does not get the support and services needed, what additional services are needed?

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Other	N
AZ	45%	33%	13%	10%	30%	23%	28%	40
LA	47%	45%	16%	21%	40%	21%	24%	38
MN	71%	39%	29%	15%	29%	35%	26%	130
MO	62%	27%	15%	25%	15%	14%	33%	52
NC	52%	45%	21%	18%	23%	26%	34%	62
OR	50%	36%	30%	44%	30%	24%	19%	93
SD	56%	32%	20%	36%	20%	32%	44%	25
WA	74%	45%	22%	22%	26%	33%	39%	153
WI	56%	34%	17%	22%	26%	33%	29%	241
NCI Average	59%	38%	20%	19%	28%	28%	29%	834

† In the 2016-17 data cycle, SD used the 2015-16 survey tool. Due to changes made in the 2016-17 survey tool, examinations of SD's data should be made with caution

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.

Family Can Choose or Change Child's Provider Agency

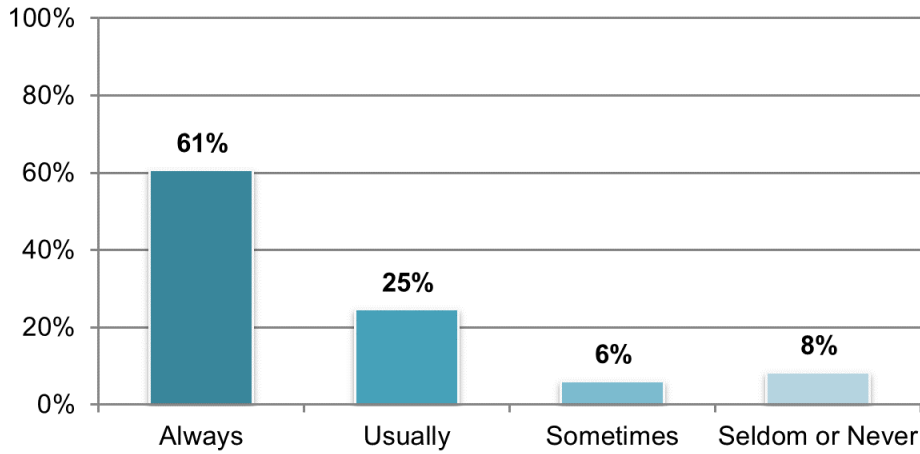


Table Q36. Can your family choose or change the agency that provides your child's services?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	77%	16%	4%	3%	115
NC	74%	19%	3%	4%	209
LA	72%	18%	3%	7%	173

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	64%	25%	4%	6%	181
NCI Average	61%	25%	6%	8%	2,013
MN	59%	31%	6%	4%	326
MO	58%	23%	9%	9%	120

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	48%	22%	6%	23%	201
WI	47%	25%	9%	18%	499
WA	43%	25%	15%	16%	189

Family Can Choose or Change Child's Support Workers

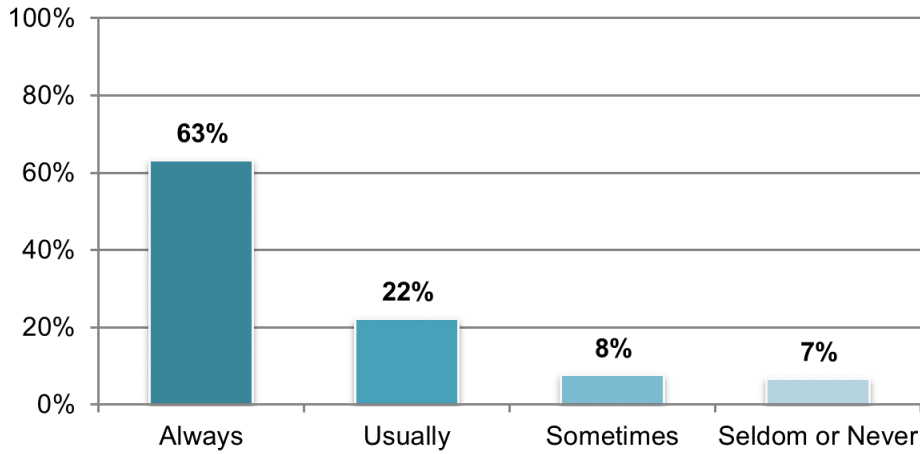


Table Q37. Can your family choose or change your child's support workers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	80%	12%	3%	5%	118
OR	73%	16%	6%	5%	344
NC	72%	18%	6%	3%	206

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	72%	18%	5%	5%	170
AZ	67%	22%	6%	5%	174
NCI Average	63%	22%	8%	7%	2,142
MO	62%	22%	7%	9%	138

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	55%	27%	9%	9%	286
WI	52%	26%	11%	11%	515
WA	45%	29%	15%	11%	191

Family Directly Manages Support Workers

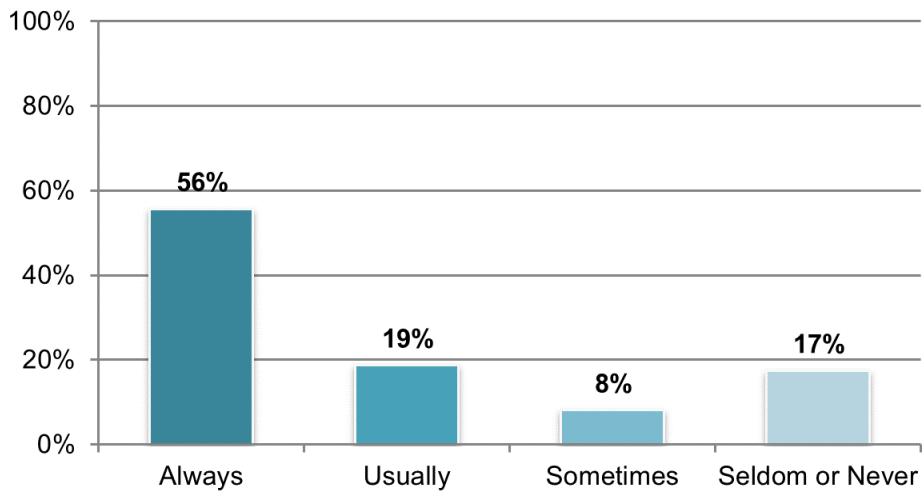


Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	80%	12%	3%	5%	381
MN	64%	19%	5%	12%	335

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	58%	20%	7%	15%	103
NCI Average	56%	19%	8%	17%	2,290
AZ	54%	22%	9%	15%	171
WA	54%	25%	10%	11%	211
LA	53%	9%	9%	30%	151
MO	47%	18%	9%	25%	142

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	44%	19%	10%	27%	196
WI	42%	21%	12%	25%	600

Child's Service Providers Work Together to Provide Support

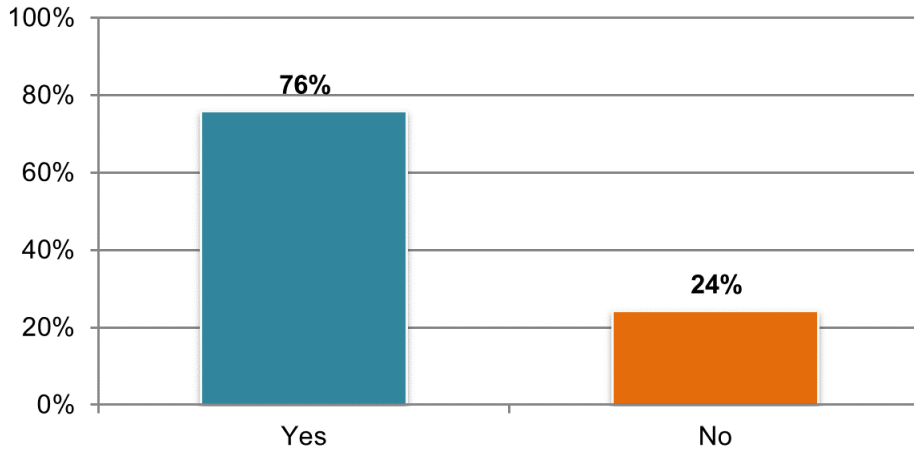


Table Q39. Do service providers for your child work together to provide support?

Significantly Above Average

State	Yes	No	N
SD	88%	12%	74

Within Average Range

State	Yes	No	N
MO	84%	16%	88
NC	83%	17%	110
LA	79%	21%	121
WI	78%	22%	396
AZ	78%	23%	120
NCI Average	76%	24%	1,412
OR	69%	31%	177
WA	69%	31%	125
MN	69%	31%	201

**Respondent, Child, or Other Family Member
Chose or Did Not Choose But Can Request to
Change Case Manager or Service Coordinator**

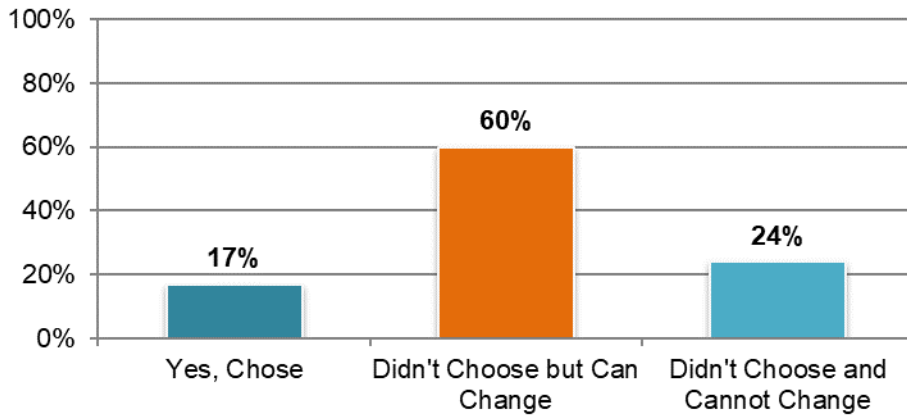


Table Q40. Did you, your child, or someone else in your family choose your child's case manager/service coordinator?

Significantly Above Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
LA	48%	41%	10%	203
NC	29%	55%	16%	185

Within Average Range

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
SD	22%	69%	10%	157
MN	17%	51%	32%	351
NCI Average	17%	60%	24%	2,541
MO	12%	65%	23%	157

Significantly Below Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
OR	11%	59%	30%	332
AZ	9%	76%	15%	195
WA	8%	50%	42%	272
WI	8%	56%	36%	689

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.

Child Takes Part in Activities in Community

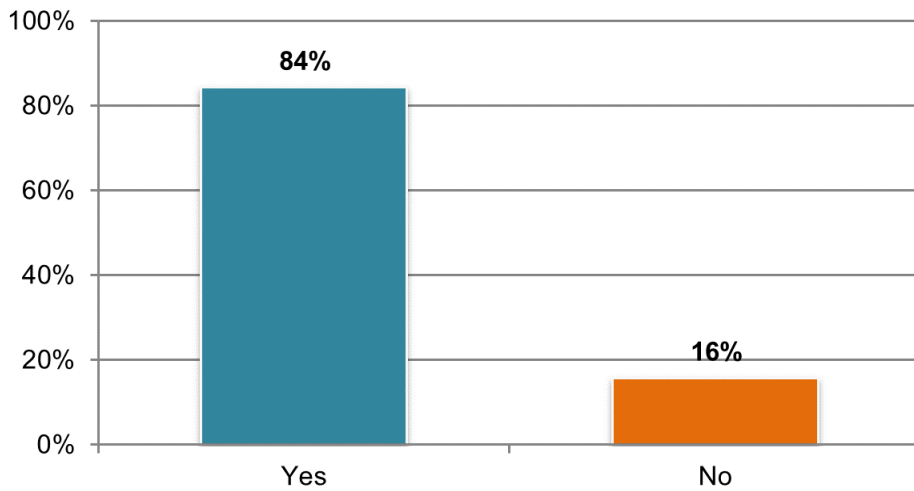


Table Q41. Does your child take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

Significantly Above Average

State	Yes	No	N
NC	91%	9%	237

Within Average Range

State	Yes	No	N
SD	89%	11%	202
OR	86%	14%	416
WA	85%	15%	355
NCI Average	84%	16%	3,250
WI	84%	16%	916
MN	84%	16%	448
AZ	83%	17%	229
LA	82%	18%	274
MO	82%	18%	173

Obstacles/Barriers to Child's Participation in Community

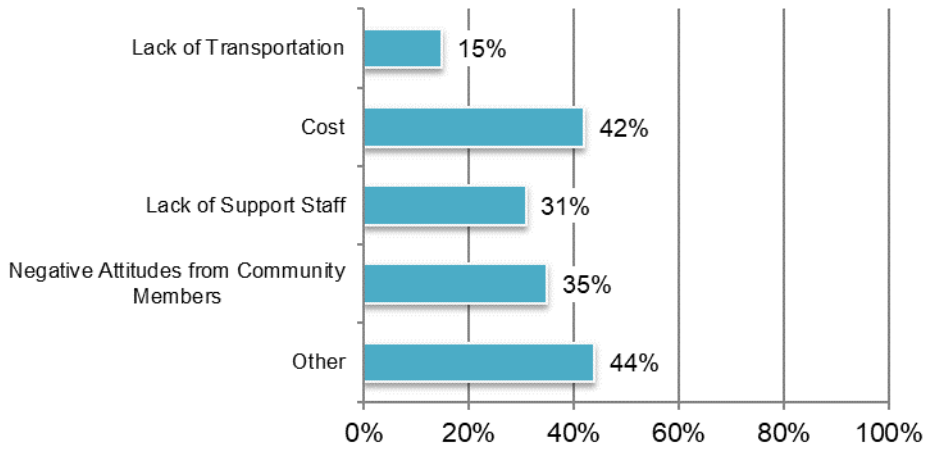


Table Q42. For your child, what are the obstacles or barriers to participation in activities in the community?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes from Community Members	Other	N
AZ	18%	44%	22%	36%	38%	157
LA	18%	39%	16%	28%	46%	194
MN	13%	46%	37%	42%	42%	378
MO	14%	33%	40%	31%	47%	148
NC	12%	48%	32%	35%	46%	193
OR	12%	46%	34%	43%	49%	349
SD	21%	48%	38%	31%	45%	29
WA	11%	41%	45%	35%	46%	322
WI	13%	37%	37%	30%	47%	762
NCI Average	15%	42%	31%	35%	44%	2,532

Child Spends Time With Children Without DD

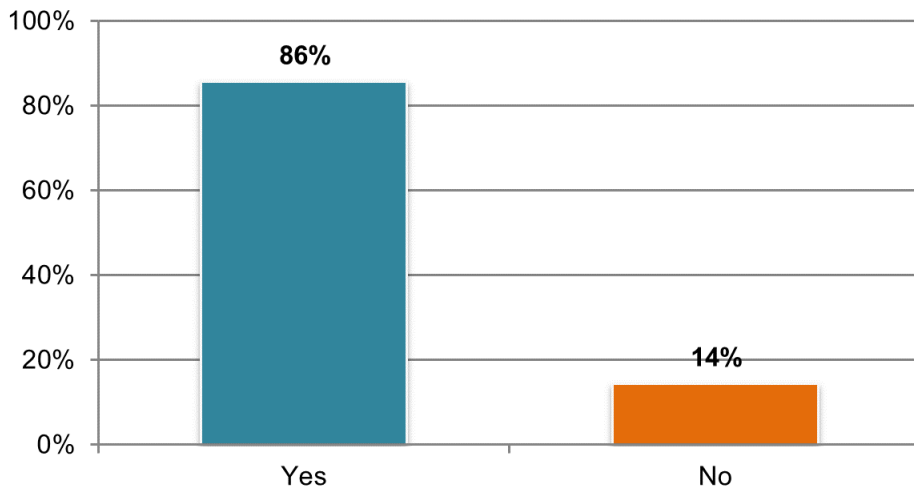


Table Q43. Does your child spend time with children who do not have developmental disabilities?

Significantly Above Average

State	Yes	No	N
SD	93%	7%	201
LA	91%	9%	268

Within Average Range

State	Yes	No	N
AZ	90%	10%	223
WI*	89%	11%	913
NCI Average	86%	14%	3,227
OR	85%	15%	410
MN	81%	19%	448
MO	81%	19%	178

Significantly Below Average

State	Yes	No	N
WA	78%	22%	353
NC	76%	24%	233

*The state is "within" the NCI average range due to small effect sizes. For more details, please see the Methodology section.

**There Are Resources in the Community the Child
Can Use That Are Not Provided by the IDD
Agency**

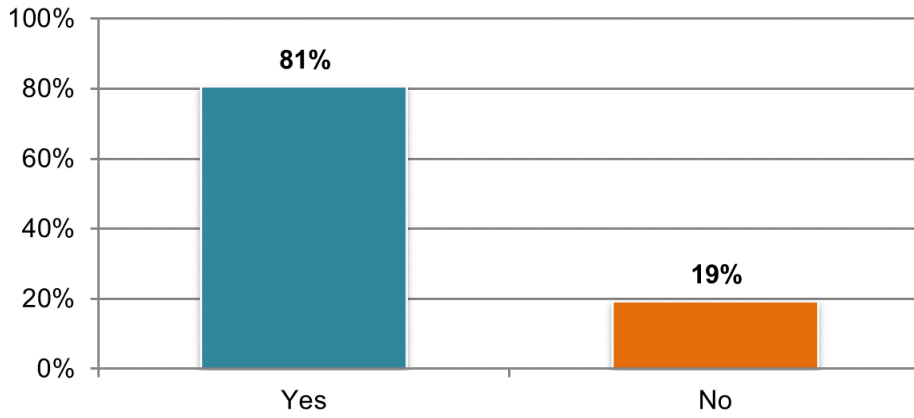


Table Q44. In your community, are there resources that your family can use that are not provided by the I/DD agency?

Significantly Above Average

State	Yes	No	N
OR	87%	13%	320

Within Average Range

State	Yes	No	N
SD	84%	16%	177
AZ	82%	18%	166
MN	81%	19%	340
WA	81%	19%	264
NCI Average	81%	19%	2,391
MO	80%	20%	128
LA	79%	21%	194
WI	78%	22%	612
NC	74%	26%	190

Family Takes Part in Family-to-family Networks

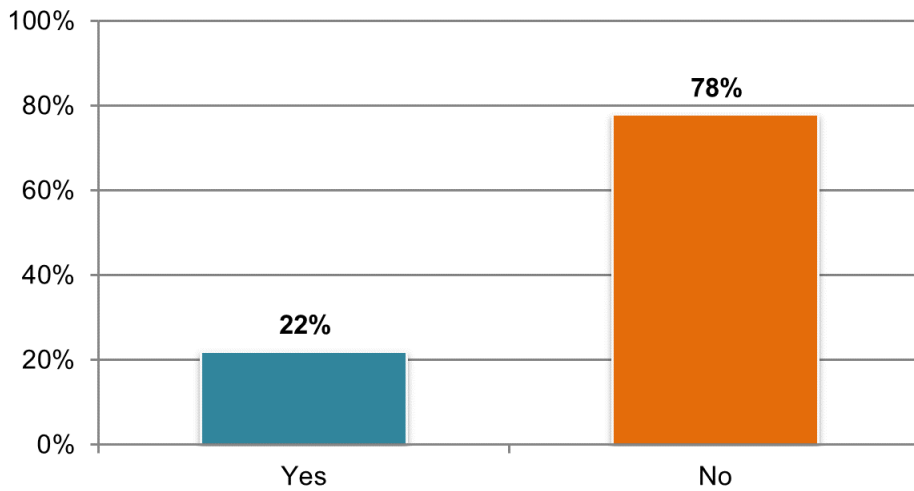


Table Q45. Does your family take part in any family-to-family networks in your community?

Significantly Above Average

State	Yes	No	N
WA	31%	69%	338

Within Average Range

State	Yes	No	N
NC	25%	75%	207
OR	24%	76%	368
LA	23%	77%	226
AZ	23%	77%	204
NCI Average	22%	78%	2,830
MN	20%	80%	368
WI	18%	82%	785

Significantly Below Average

State	Yes	No	N
SD	18%	82%	174
MO	11%	89%	160

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.

Overall, Respondent Is Satisfied With Services and Supports Family Receives

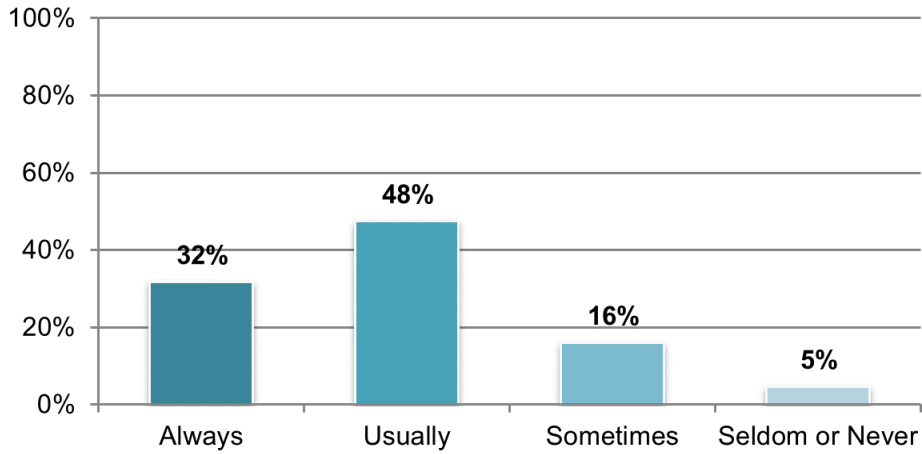


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	55%	36%	8%	2%	198
AZ	43%	45%	10%	2%	228
LA	43%	35%	16%	6%	267

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NCI Average	32%	48%	16%	5%	3,217
WI	31%	46%	18%	5%	914
OR	29%	52%	18%	1%	414

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	24%	50%	20%	7%	229
MO	23%	63%	13%	1%	174
MN	22%	55%	18%	6%	449
WA	12%	47%	28%	13%	344

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

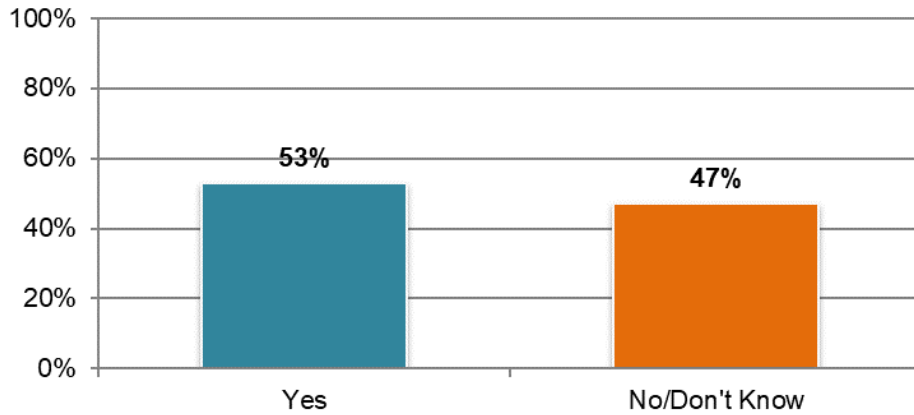


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?²

Significantly Above Average

State	Yes	No/Don't Know	N
SD	78%	22%	197
WI	60%	40%	926
NC	59%	41%	234

Within Average Range

State	Yes	No/Don't Know	N
OR	59%	41%	405
MO	55%	45%	173
LA	53%	47%	271
NCI Average	53%	47%	3240
MN	50%	50%	452
AZ	49%	51%	232

Significantly Below Average

State	Yes	No/Don't Know	N
WA	41%	59%	350

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

**Respondent Is Satisfied With the Way
Complaints or Grievances About Provider
Agencies or Staff Were Handled and Resolved (If
Filed in the Past Year)**

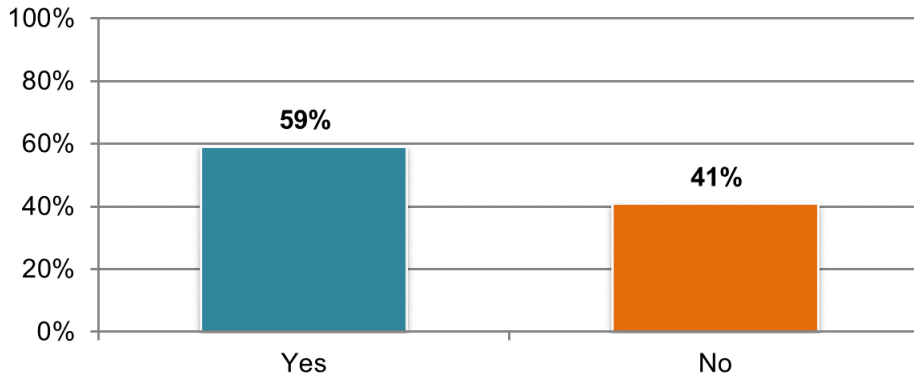


Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

Within Average Range

State	Yes	No	N
LA	72%	28%	36
NC	69%	31%	36
NCI Average	59%	41%	286
AZ	58%	42%	26
WI	57%	43%	70
OR	55%	45%	33
MN	49%	51%	35

*Due to low N's (<20) the following states are not represented in table, but their data are included in the NCI Average: MO, SD, WA

Respondent Knows How to Report Abuse or Neglect

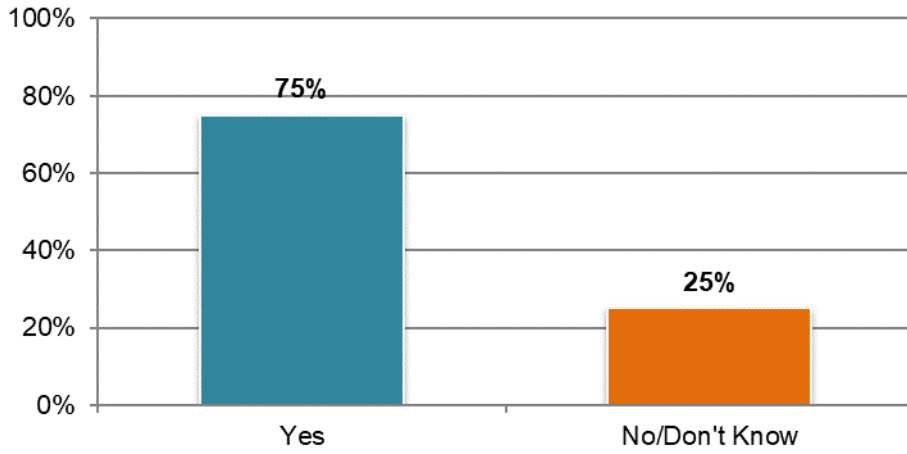


Table Q49. Do you know how to report abuse or neglect related to your child?³

Significantly Above Average

State	Yes	No/Don't Know	N
SD	92%	8%	199
MO	86%	14%	179
OR	85%	15%	413
NC	81%	19%	237

Within Average Range

State	Yes	No/Don't Know	N
MN	79%	21%	450
WI	78%	22%	930
LA	76%	24%	274
NCI Average	75%	25%	3,260
WA	71%	29%	348

Significantly Below Average

State	Yes	No/Don't Know	N
AZ	63%	37%	230

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

Abuse or Neglect Was Reported on Behalf of Child in the Past Year

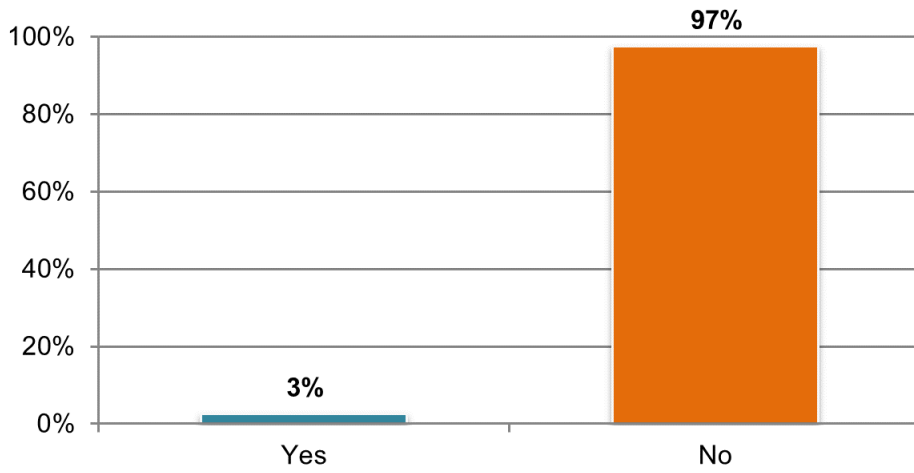


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child?

Within Average Range

State	Yes	No	N
MO	5%	95%	165
SD	5%	95%	196
NC	4%	96%	224
WA	4%	96%	344
OR	3%	97%	409
NCI Average	3%	97%	3,151
MN	2%	98%	433
LA	2%	98%	264
AZ	2%	98%	219
WI	2%	98%	897

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

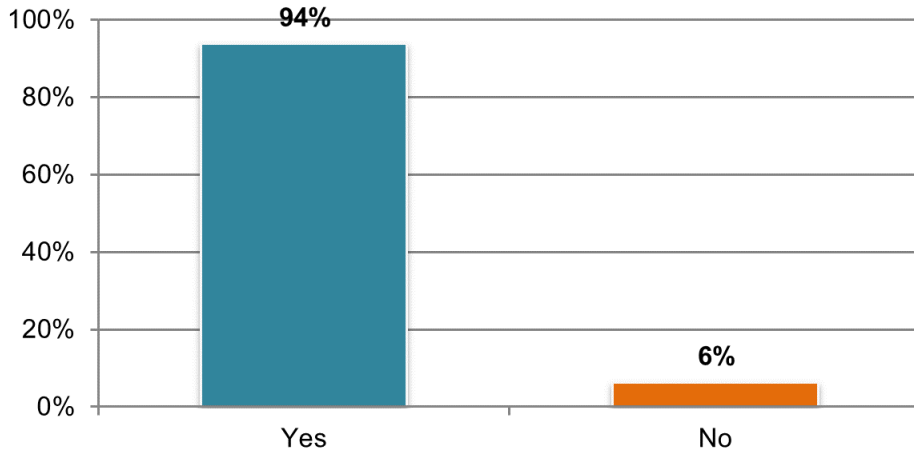


Table Q51. Do you feel that services and supports have made a positive difference in the life of your family?

Significantly Above Average

State	Yes	No	N
SD	99%	1%	196
OR	97%	3%	379

Within Average Range

State	Yes	No	N
MO	97%	3%	165
NC	96%	4%	212
MN	95%	5%	392
WI	94%	6%	839
NCI Average	94%	6%	2,907
AZ	94%	6%	204
LA	93%	7%	228

Significantly Below Average

State	Yes	No	N
WA	84%	16%	292

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

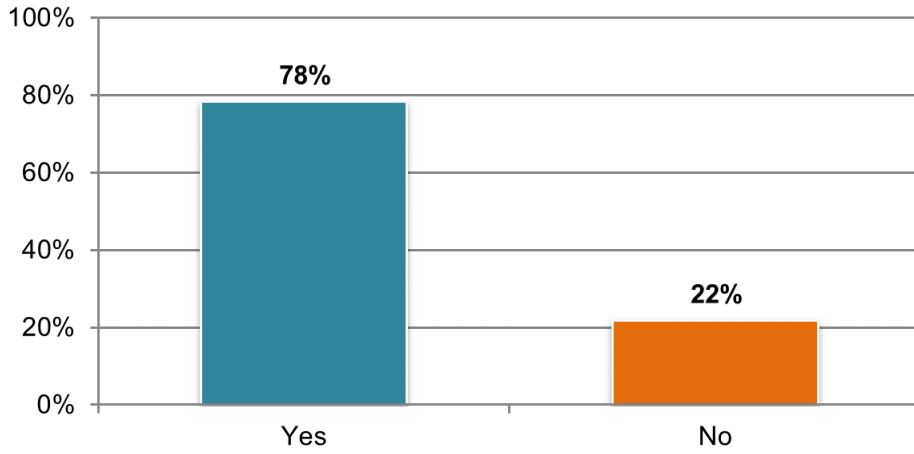


Table Q52. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your child's care?

Significantly Above Average

State	Yes	No	N
SD	96%	4%	194
WI	82%	18%	851

Within Average Range

State	Yes	No	N
MO	84%	16%	168
MN	83%	17%	414
NC	83%	17%	213
OR	81%	19%	395
AZ	79%	21%	206
NCI Average	78%	22%	2,992

Significantly Below Average

State	Yes	No	N
WA	69%	31%	319
LA	63%	37%	232

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

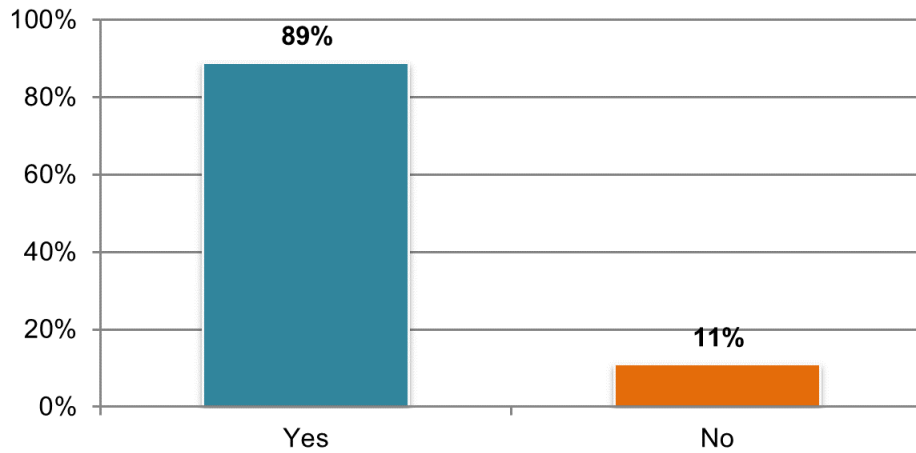


Table Q53. Do you feel that family supports have improved your ability to care for your child?

Significantly Above Average

State	Yes	No	N
SD	94%	6%	187
OR	93%	7%	391

Within Average Range

State	Yes	No	N
NC	93%	7%	210
MO	93%	7%	162
MN	91%	9%	418
AZ	90%	10%	211
WI	89%	11%	849
NCI Average	89%	11%	2,973
LA	85%	15%	238

Significantly Below Average

State	Yes	No	N
WA	77%	23%	307

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

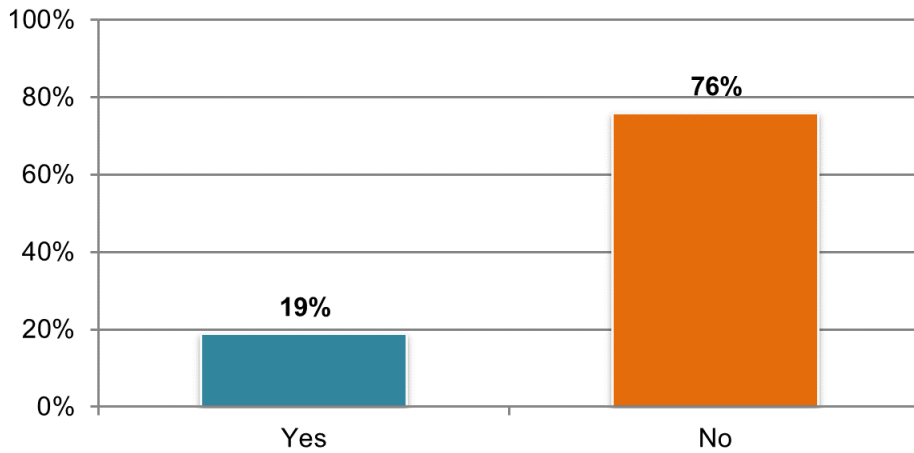


Table Q54. Have the services or supports that you or your child received during the past year been reduced, suspended, or terminated?

Significantly Above Average

State	Yes	No	N
OR	44%	52%	416

Within Average Range

State	Yes	No	N
NC	25%	68%	236
LA	22%	73%	266
NCI Average	19%	76%	3,224
MN	18%	76%	447
WI	18%	77%	916
MO	15%	83%	169
WA	15%	76%	346
AZ	13%	84%	227
SD	12%	81%	201

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

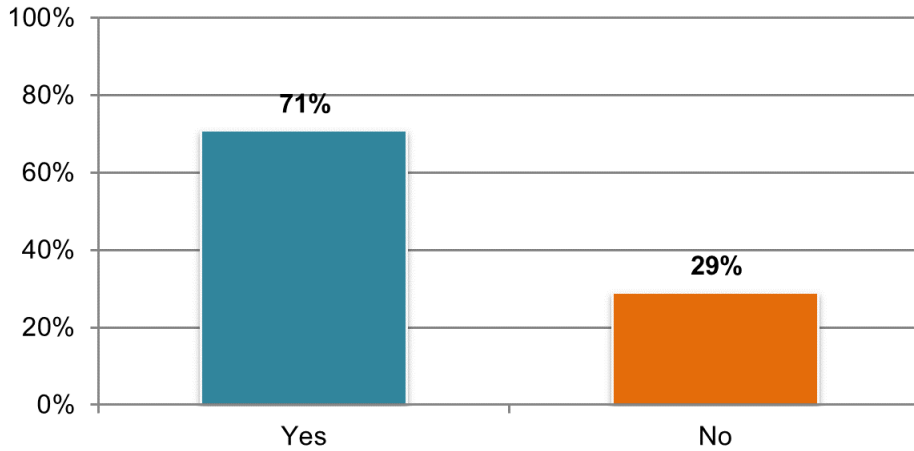


Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your child negatively?

Significantly Above Average

State	Yes	No	N
OR	79%	21%	168

Within Average Range

State	Yes	No	N
WA	84%	16%	45
MN	79%	21%	73
MO	76%	24%	25
NC	75%	25%	55
WI	72%	28%	149
NCI Average	71%	29%	615
AZ	60%	40%	25
LA	55%	45%	53
SD	55%	45%	22

Services or Supports Were Increased in the Past Year

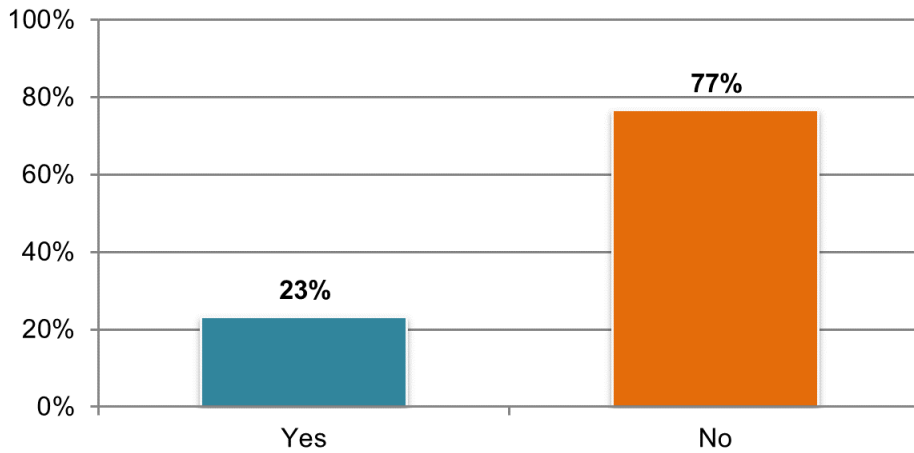


Table Q56. Have the services or supports that your child received been increased in the past year?

Significantly Above Average

State	Yes	No	N
WA	31%	69%	319
OR	30%	70%	389

Within Average Range

State	Yes	No	N
MO	33%	67%	157
WI	25%	75%	834
NCI Average	23%	77%	2,955
AZ	22%	78%	209
MN	22%	78%	415
NC	19%	81%	218
LA	18%	82%	247

Significantly Below Average

State	Yes	No	N
SD	12%	88%	167

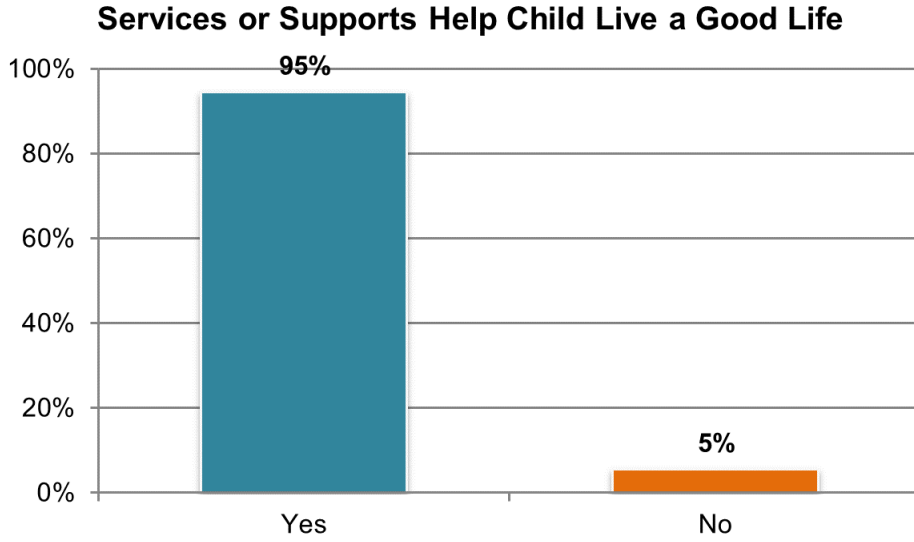


Table Q57. Are services and supports helping your child to live a good life?

Significantly Above Average

State	Yes	No	N
OR	98%	2%	403
MO	98%	2%	162

Significantly Below Average

State	Yes	No	N
SD	97%	3%	191
AZ	97%	3%	215
NC	95%	5%	214
MN	95%	5%	402
NCI Average	95%	5%	2,958
WI	94%	6%	848
LA	90%	10%	237

Significantly Below Average

State	Yes	No	N
WA	84%	16%	286

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 Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states volunteered to pilot test the indicators. Eight additional states served on the Steering Committee.

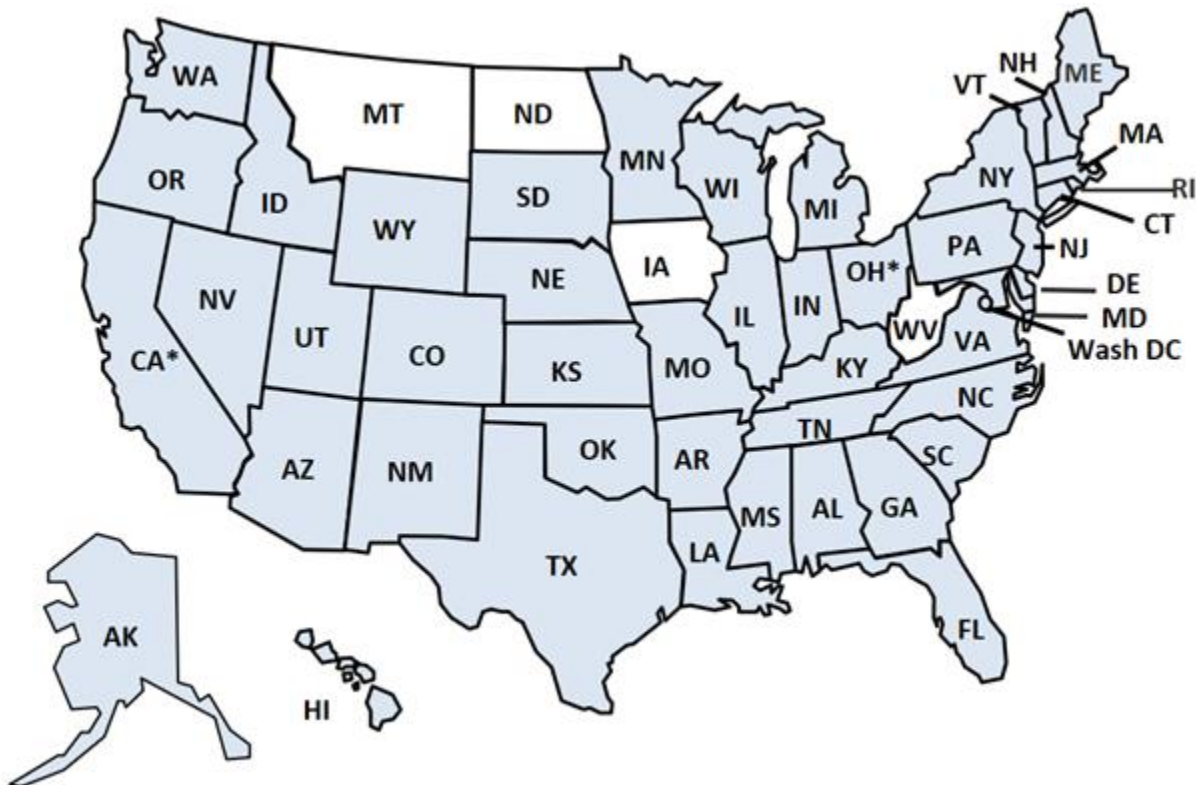
Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI continues to develop and refine the indicators and expand state participation. For more information about NCI states,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

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

State Participation

During the 2016-17 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 2016-17



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 Consumer Survey, three Family Surveys, a Provider Survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates).

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

The data collection tools used to gather indicator data are regularly refined and tested to ensure they remain valid, reliable, and applicable to current issues within the field. Details on the design and 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. In previous years states only had the option to mail paper surveys. A total of seven states had at least a portion of surveys completed via the new direct entry mode.⁶

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

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. In previous years, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). This year, the approach has been enhanced to consider the relative numbers of people receiving services through participating states’ systems. Beginning this year, the NCI averages contained in this report are

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: SD, WA, NC, WI, MO, MN.

⁷ See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

“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

Starting this survey cycle (2016-17), for each of the non-adjusted items, each state’s percentage will be compared to the weighted NCI average (described above), and the differences between the two will be 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 as a new criterion allows us to present “meaningfully significant” results, which take consideration of the magnitude or size of the differences into account.

The state percentages in this report are categorized into one of the 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 $d \leq 0.2$);
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. A state that falls “within” the NCI average range due to the difference not meeting the effect size criterion are denoted with a Caron symbol (̂). 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 child lived outside 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; 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 2016-17, nine 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 ⁸

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	15,419	1,400	233	17%	6.37%	n/a	n/a
LA	7,171*	2,300	282	12%	5.72%	n/a	n/a
MN	10,500	1,147	457	40%	4.48%	80.40%	19.60%
MO	2,518	1,000	180	18%	7.04%	1.30%	98.70%
NC	4,000	1,200	242	20%	6.11%	95.50%	4.50%
OR	2,793	2,793	423	15%	4.39%	n/a	n/a
SD	889	889	203	23%	6.05%	89.40%	10.60%
WA	5,200*	2,000	386	19%	4.80%	91.70%	8.30%
WI	7,568	7,568	946	13%	2.98%	99.00%	1.00%
Total			3,352			81.40%	18.60%

*Estimate

⁸ 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.