

Child Family Survey

2020-21 Final Report





Human Services Research Institute (HSRI)

2336 Massachusetts Avenue
Cambridge, MA 02140

NASDDDS

National Association of State Directors of Developmental Disabilities Services

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

301 N Fairfax Street, Suite 101
Alexandria, VA 22314

February 2022

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

Child Family Survey	1
Table of Contents	i
Executive Summary	iv
Important note on Impact of COVID-19	iv
Results	1
Presentation of Data	1
Demographics	1
Child.....	2
Table 1. More Than One Child Living in the Home Has IDD	3
Table 2. Child's Age	3
Table 3. Child's Gender	4
Table 4a. Child's Disabilities	4
Table 4b. Child's Disabilities (continued)	5
Table 5a. Child's Health Conditions	5
Table 5b. Child's Health Conditions (continued)	6
Table 6. Child's Race and Ethnicity	6
Table 7. Child's Preferred Means of Communication.....	7
Table 8. Child's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	7
Table 9. Child's Level of Help Needed with Personal Care Activities.....	8
Respondents.....	9
Table 10. Language usually spoken at home	10
Table 11. Respondent's Age	10
Table 12. Respondent's Health	11
Table 13. Respondent's Relationship to Child.....	11
Table 14. Respondent or Other Family Member Provides Paid Support to Child.....	12
Table 15. Number of Adults in Household	12
Table 16. Number of Children in Household (including child receiving services about whom survey is being completed)	13
Table 17. Respondent's Highest Level of Education	13
Table 18. Total Taxable Household Income of Wage Earners in the Past Year.....	14
Table 19. Residential Designation (Urban, Rural, or Suburban)	14
Services and Supports Received.....	15
Table 20. Services and Supports Received from IDD Agency.....	16
Table 21. Other Services or Supports Received	16
Child Family Survey Results	17
Information and Planning.....	18
Table Q1. Do you get enough information to take part in planning services for your child?	19
Table Q2. Is the information you get about services and supports easy to understand?	20
Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?	21
Table Q4. Do you have enough information about other public services for which your family is eligible?	22
Table Q5. Do you need help planning for your child's future with respect to any of the following?	23
Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?.....	24
Table Q7. Does your child have a service plan?.....	25
Table Q8. Does the plan include all the services and supports your child needs?.....	26
Table Q9. Does your child receive all of the services listed in the plan?	27
Table Q10. Did you or another family member help make the plan?	28

Table Q11. Did your child help make the plan?	29
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?	30
Table Q13. Does your child have a transition plan (as part of an IEP or Section 504 plan through their high school, usually starting at age 14)?	31
Table Q14. If your child has a transition plan, did you help make the plan?	32
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?	33
Access and Delivery of Services and Supports.....	34
Table Q16. Are you able to contact your child's support workers when you want?	35
Table Q17. Are you able to contact your child's case manager/service coordinator when you want?.....	36
Table Q18. Do support workers come and go when they are supposed to?.....	37
Table Q19. Do services and supports change when your family's needs change?.....	38
Table Q20. Do support workers speak to you in a way that you understand?.....	39
Table Q21. Are services delivered in a way that is respectful of your family's culture?.....	40
Table Q22. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with them?	41
Table Q23. Do support workers have the right information and skills to meet your family's needs?.....	42
Table Q24. Does your child have the special equipment or accommodations that they need?	43
Table Q25. Can your child see health professionals when needed?.....	44
Table Q26. Does your child's primary care doctor understand their needs related to their disability?.....	45
Table Q27. Can your child go to the dentist when needed?.....	46
Table Q28. Does your child's dentist understand your child's needs related to their disability?.....	47
Table Q29. If your child takes medications, do you know what they're for?	48
Table Q30. Do you know when your child should take the medication, how much to take, and the potential side effects?	49
Table Q31. If your child uses mental health services, does the mental health professional understand your child's needs related to their disability?.....	50
Table Q32. If you need respite services, how often are you able to use them?	51
Table Q33. If you have used respite services in the past year, were you satisfied with the quality of the respite providers?	52
Table Q34. Does your family get the supports and services it needs?	53
Table Q35. If family does not get the support and services needed, what additional services does your family need?.....	54
Choice, Decision Making and Control.....	55
Table Q36. Can your family choose or change the agency that provides your child's services?	56
Table Q37. Can your family choose or change your child's support workers?.....	57
Table Q38. Does your family manage support workers?	58
Table Q39. Do service providers for your child work together to provide support?	59
Table Q40. Did you, your child, or someone else in your family choose your child's case manager/service coordinator?	60
Involvement in the Community.....	61
Table Q41. Does your child take part in activities in the community?.....	62
Table Q42. For your child, what makes it hard to take part in activities in the community?	63
Table Q43. Does your child spend time with children who do not have developmental disabilities?	64
Table Q44. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?....	65
Table Q45. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?	66
Satisfaction With Services and Supports	67
Table Q46. Overall, are you satisfied with the services and supports your family currently receives?.....	68
Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?	69
Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?	70
Table Q49. Do you know how to report abuse or neglect?	71
Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child?.....	72

Table Q51. If abuse or neglect was reported on behalf of your child in the past year, did the appropriate people respond to the report?	73
Table Q52. If someone outside of your family reported abuse or neglect on behalf of your child in the past year, were you notified of the report in a timely manner?	74
Table Q53. Do you feel that family supports have made a positive difference in the life of your family?	75
Table Q54. Have services and supports reduced your family's out-of-pocket expenses for your child's care?	76
Table Q55. Do you feel that family supports have improved your ability to care for your child?	77
Table Q56. Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?	78
Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change affect your family or your child negatively?.....	79
Table Q58. Have the services or supports that your child received been increased in the past year?.....	80
Table Q59. Are services and supports helping your child to live a good life?.....	81
NCI History and Activities	82
Overview of National Core Indicators	83
State Participation	84
Figure 1. NCI State Participation 2020-21	84
The Core Indicators	84
Sub-Domains and Concern Statements	85
Figure 2. Family Survey Sub-Domains and Concern Statements.....	86
How NCI Data Are Used	86
Caution and Limitations.....	87
Methodology	88
Sampling & Administration.....	89
Weighting	89
Significance Testing.....	90
Technical Details	91
Data Entry and Analysis	91
Response Rates	91
Child Family Survey: State Response Rates	92

Executive Summary

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

The NCI Child Family Survey is administered to families who have a child with a developmental disability who lives in the family's home and receives at least one service other than case management.¹ Not all states that participate in NCI administer the Child Family Survey on an annual basis. Of the 46 states, District of Columbia, and 22 sub-state entities who participated in NCI during the 2020-21 data collection cycle, 10 states submitted a valid sample of Child Family Survey data: Arizona (AZ), Colorado (CO), Minnesota (MN), Missouri (MO), North Carolina (NC), Oregon (OR), South Dakota (SD), Texas (TX), Virginia (VA), and Wisconsin (WI). This Final Report provides a summary of results based on data submitted by June 30, 2021.

Important note on Impact of COVID-19

The 2020-21 NCI Family Survey data collection cycle began July 1, 2020 and ended June 30, 2021. As COVID-19 continued to spread across the United States, states were impacted in various ways throughout the year. Because the family surveys do not collect information on the date of survey completion, these data cannot fully assess what impact the pandemic had on data collected at different times throughout the year. While these data will serve as an important baseline, and meaningful way for states to understand the overall impact of services on families of individuals being served, these data should be read with caution.

To help better understand the overall impact of COVID-19 on families, NCI-IDD added a state-optional COVID-19 Supplement to all NCI Surveys. The COVID-19 Supplement is intended to support the understanding of the experience of people with disabilities and their families at the

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

beginning of the COVID-19 pandemic, and their interactions with services during that time. The NCI Family Survey COVID-19 Supplement can be found [here](#).

Respondents

Family members and/or guardians of children who have IDD and receive at least one public service in addition to case management from the state DD agency. The respondent lives with the child receiving services.

Respondents . . .

15%
are under
age 35



35%
say they or a
family member
provide paid
support to their
child receiving
services



32%
can always get
and use respite
services they
need



30%
reported an annual household
income of \$25K or less



75%
reported services and supports
reduced out-of-pocket expenses
related to care for their child

Child with IDD . . .

67%
male



11
average age



70%
child takes part in
community activities



84%
child spends time with
children without DD



77%
have resources in the
community the family can
use that are not provided
by the IDD agency



20%
take part in family-to-
family networks

2020–21 Child Family Survey (CFS)

4,693 families
participated across
10 states*

NCI-IDD averages:

- Include all participating states
- Data are weighted

*2020–21 CFS

participating states were:
AZ, CO, MN, MO, NC, OR,
SD, TX, VA, and WI



74%
say case manager/service coordinator *always* respects family's choices and opinions



49%
say support workers *always* have the right information and skills to meet family's needs



93%
feel services and supports have made a positive difference for their child



37% *always* get enough information to help plan services



40% say services and supports *always* change when their family's needs change



90% say they or another family member helped make the service plan



18% say their child with IDD helped make the service plan



66%
say their family can *always* choose or change the agency that provides services



65%
say their family can *always* choose or change their child's support workers



80%
say their child's service providers work together to provide support

2020–21 Child Family Survey

Results

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

Presentation of Data

In addition to basic demographic questions and questions on services and supports received, the survey contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes. Each question is constructed so the respondent selects from either four possible responses ("always," "usually," "sometimes," "seldom/never") or two responses ("yes" or "no"). Respondents also have the option to indicate that they don't know the answer to a question or that the question is not applicable.

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

Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI Average range, their 'always' or 'yes' response was not statistically different from the NCI Average.

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

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

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

Note on Texas sample: While the prescribed mode of administration for CFS is mail-in paper surveys or direct entry online, Texas sought to increase the response rate to the CFS surveys by allowing for three modes of administration: paper, web, and phone. Texas mailed out invitation letters to program participants asking them to participate and providing them with a telephone

number and web link so that they could complete the survey by phone or web. Both options were available in both English and Spanish. After a month, Texas sent out paper surveys (available in Spanish and English) to everyone on the sampling frame who had not responded by phone or web.

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

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

Demographics

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

Child

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

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

State	Yes	No	N
AZ	23%	77%	179
CO	27%	73%	248
MN	26%	74%	393
MO	28%	72%	167
NC	20%	80%	170
OR	25%	75%	639
SD	13%	87%	206
TX	25%	75%	1,628
VA	28%	72%	156
WI	23%	77%	792
Weighted NCI-IDD Average	24%	76%	4,578

Table 2. Child's Age

State	Age	N
AZ	9.6	184
CO	10.5	250
MN	13.1	404
MO	11.7	174
NC	15.0	176
OR	11.9	651
SD	10.2	215
TX	11.3	1636
VA	14.0	159
WI	9.3	805
Weighted NCI-IDD Average	11.3	4654

Table 3. Child's Gender

State	Male	Female	N
AZ	66%	34%	185
CO	67%	33%	249
MN	67%	33%	404
MO	78%	22%	174
NC	70%	30%	175
OR	69%	31%	653
SD	61%	39%	215
TX	62%	38%	1,630
VA	69%	31%	159
WI	64%	36%	806
Weighted NCI-IDD Average	67%	33%	4,650

Table 4a. Child's Disabilities

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

State	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
AZ	36%	14%	65%	11%	8%	3%
CO	61%	28%	67%	15%	15%	6%
MN	56%	25%	61%	8%	8%	7%
MO	32%	28%	88%	9%	6%	2%
NC	68%	21%	65%	22%	12%	6%
OR	52%	27%	56%	11%	8%	5%
SD	48%	9%	34%	18%	7%	6%
TX	66%	32%	40%	17%	23%	13%
VA	70%	36%	67%	16%	10%	10%
WI	44%	20%	53%	9%	7%	4%
Weighted NCI-IDD Average	53%	23%	58%	14%	12%	7%

Table 4b. Child's Disabilities (continued)

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

State	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
AZ	4%	15%	0%	15%	0%	3%	21%
CO	10%	36%	0%	5%	0%	3%	34%
MN	8%	28%	0%	13%	0%	3%	31%
MO	5%	17%	0%	1%	0%	1%	16%
NC	9%	24%	1%	9%	1%	3%	27%
OR	9%	17%	1%	11%	1%	6%	26%
SD	13%	27%	0%	21%	0%	1%	27%
TX	16%	37%	6%	8%	0%	1%	43%
VA	10%	32%	1%	8%	1%	2%	29%
WI	7%	19%	0%	14%	1%	1%	32%
Weighted NCI-IDD Average	9%	24%	2%	11%	0%	2%	30%

Table 5a. Child's Health Conditions

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

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	6%	1%	0%	4%	9%
CO	9%	1%	0%	3%	2%
MN	10%	6%	1%	3%	4%
MO	3%	5%	0%	3%	15%
NC	13%	3%	2%	2%	0%
OR	7%	3%	3%	4%	8%
SD	26%	0%	2%	2%	0%
TX	17%	5%	2%	9%	6%
VA	10%	6%	0%	6%	7%
WI	18%	3%	3%	4%	4%
Weighted NCI-IDD Average	13%	4%	2%	6%	5%

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

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

State	Dysphagia	Pressure Ulcers	Oral Health or Dental Problems	Sleep Apnea	Other
AZ	19%	1%	13%	30%	46%
CO	35%	1%	10%	48%	42%
MN	20%	3%	14%	26%	50%
MO	20%	5%	3%	33%	33%
NC	19%	3%	13%	19%	48%
OR	27%	3%	16%	35%	40%
SD	17%	1%	6%	32%	42%
TX	33%	4%	20%	42%	49%
VA	21%	0%	21%	24%	61%
WI	21%	1%	15%	24%	39%
Weighted NCI-IDD Average	25%	3%	16%	33%	46%

Table 6. Child's Race and Ethnicity

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

State	American Indian or Alaska Native	Asian	Black or African American	Hawaiian or Pacific Islander	White	Hispanic or Latino	Other
AZ	6%	6%	10%	3%	58%	40%	2%
CO	1%	8%	7%	0%	80%	19%	3%
MN	4%	7%	16%	0%	74%	7%	2%
MO	3%	5%	9%	1%	86%	9%	1%
NC	2%	2%	24%	1%	68%	8%	3%
OR	6%	6%	5%	1%	79%	18%	2%
SD	8%	3%	4%	0%	86%	3%	1%
TX	1%	3%	17%	0%	46%	56%	2%
VA	2%	10%	21%	1%	71%	6%	4%
WI	3%	6%	9%	0%	83%	9%	1%
Weighted NCI-IDD Average	3%	5%	14%	1%	65%	27%	2%

Table 7. Child's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AZ	68%	14%	4%	8%	5%	187
CO	61%	18%	1%	11%	9%	245
MN	68%	17%	1%	8%	5%	366
MO	79%	11%	1%	6%	4%	170
NC	67%	22%	2%	5%	4%	176
OR	74%	16%	2%	4%	4%	645
SD	65%	22%	5%	6%	2%	213
TX	61%	20%	6%	5%	9%	1,627
VA	55%	19%	1%	9%	16%	155
WI	63%	22%	3%	7%	6%	780
Weighted NCI-IDD Average	66%	18%	4%	6%	6%	4,564

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

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

State	None	Some	Extensive	N
AZ	33%	50%	17%	183
CO	14%	25%	60%	245
MN	16%	41%	42%	394
MO	29%	52%	19%	170
NC	36%	38%	26%	173
OR	26%	49%	25%	649
SD	49%	34%	17%	210
TX	32%	35%	33%	1,631
VA	14%	43%	44%	154
WI	45%	37%	18%	762
Weighted NCI-IDD Average	33%	41%	26%	4,571

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

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

State	None	Some	Extensive	N
AZ	6%	40%	54%	181
CO	1%	21%	78%	247
MN	2%	29%	69%	398
MO	12%	55%	33%	171
NC	7%	39%	54%	176
OR	6%	45%	49%	656
SD	7%	40%	53%	211
TX	6%	31%	63%	1,643
VA	2%	25%	73%	155
WI	8%	41%	51%	780
Weighted NCI-IDD Average	6%	38%	56%	4,618

Respondents

This section provides demographic information about the respondent.

Table 10. Language usually spoken at home

State	English	Spanish	Other	N
AZ	79%	16%	5%	188
CO	93%	2%	4%	250
MN	92%	3%	5%	386
MO	98%	1%	1%	172
NC	96%	2%	2%	175
OR	86%	9%	5%	656
SD	98%	0%	2%	212
TX	74%	20%	6%	1,634
VA	98%	1%	1%	157
WI	95%	4%	2%	784
Weighted NCI-IDD Average	86%	10%	4%	4,614

Table 11. Respondent's Age

State	Under 35	35-54	55-74	75 and older	N
AZ	14%	72%	14%	0%	187
CO	13%	73%	13%	0%	253
MN	10%	76%	14%	1%	396
MO	10%	79%	11%	0%	173
NC	9%	65%	24%	3%	175
OR	10%	72%	17%	1%	659
SD	21%	71%	7%	0%	214
TX	22%	66%	10%	1%	1,642
VA	5%	68%	26%	1%	155
WI	18%	70%	12%	0%	796
Weighted NCI-IDD Average	15%	69%	15%	1%	4,650

Table 12. Respondent's Health

State	Excellent	Very good	Fairly good	Poor	N
AZ	18%	56%	21%	5%	187
CO	19%	49%	29%	3%	254
MN	17%	50%	30%	4%	400
MO	14%	53%	30%	3%	174
NC	18%	43%	33%	6%	175
OR	18%	43%	33%	5%	657
SD	24%	51%	24%	1%	213
TX	14%	36%	40%	9%	1,644
VA	10%	30%	48%	12%	155
WI	16%	52%	30%	2%	793
Weighted NCI-IDD Average	17%	47%	31%	6%	4,652

Table 13. Respondent's Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
AZ	95%	0%	3%	2%	185
CO	96%	0%	3%	1%	253
MN	97%	1%	2%	1%	399
MO	98%	1%	1%	1%	173
NC	89%	0%	10%	2%	175
OR	91%	0%	6%	2%	659
SD	98%	0%	2%	0%	214
TX	91%	0%	6%	2%	1,647
VA	87%	1%	10%	3%	157
WI	94%	0%	5%	1%	795
Weighted NCI-IDD Average	93%	0%	5%	2%	4,657

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

Categories are not mutually exclusive

State	Respondent	Other family member	No	N
AZ	67%	16%	18%	187
CO	37%	53%	16%	254
MN	18%	63%	33%	396
MO	90%	5%	5%	172
NC	64%	21%	18%	174
OR	62%	9%	30%	653
SD	87%	2%	12%	213
TX	73%	5%	23%	1,645
VA	55%	11%	35%	156
WI	80%	6%	14%	795
Weighted NCI-IDD Average	67%	15%	20%	4,645

Table 15. Number of Adults in Household

State	One	Two	Three	Four or more	N
AZ	16%	57%	23%	5%	185
CO	18%	62%	16%	4%	251
MN	19%	53%	21%	8%	399
MO	14%	67%	16%	2%	171
NC	20%	45%	24%	10%	172
OR	18%	57%	16%	8%	655
SD	10%	74%	13%	3%	213
TX	35%	46%	15%	5%	1,641
VA	23%	50%	19%	8%	157
WI	17%	67%	12%	3%	785
Weighted NCI-IDD Average	21%	54%	19%	6%	4,629

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

State	One	Two	Three	Four or More	N
AZ	29%	38%	19%	15%	184
CO	32%	33%	21%	13%	248
MN	33%	31%	22%	14%	377
MO	41%	34%	16%	10%	173
NC	58%	28%	10%	4%	156
OR	37%	38%	16%	9%	651
SD	29%	33%	23%	14%	215
TX	33%	31%	19%	17%	1,608
VA	48%	36%	11%	6%	145
WI	35%	38%	17%	10%	787
Weighted NCI-IDD Average	38%	34%	17%	12%	4,544

Table 17. Respondent's Highest Level of Education

State	No high school diploma or GED	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	11%	9%	6%	24%	50%	185
CO	2%	4%	8%	18%	69%	249
MN	5%	14%	11%	18%	51%	391
MO	3%	9%	6%	17%	65%	172
NC	2%	20%	4%	21%	53%	174
OR	7%	15%	5%	24%	49%	642
SD	4%	12%	10%	15%	58%	213
TX	22%	23%	5%	21%	29%	1,634
VA	5%	16%	6%	23%	49%	158
WI	3%	14%	10%	16%	58%	787
Weighted NCI-IDD Average	9%	16%	6%	21%	48%	4,605

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

State	No earned income	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	Prefer not to say	N
AZ	5%	5%	12%	14%	22%	26%	15%	182
CO	2%	7%	5%	16%	13%	41%	16%	246
MN	2%	5%	6%	24%	16%	35%	13%	394
MO	5%	6%	6%	23%	15%	37%	8%	171
NC	7%	9%	13%	16%	15%	29%	12%	171
OR	8%	6%	11%	18%	17%	30%	10%	646
SD	2%	5%	4%	17%	21%	38%	13%	215
TX	16%	26%	14%	15%	8%	12%	9%	1,626
VA	5%	14%	10%	20%	10%	28%	14%	155
WI	4%	7%	6%	18%	19%	39%	7%	782
Weighted NCI-IDD Average	8%	11%	11%	17%	15%	27%	11%	4,588

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

State	Urban or suburban	Rural	N
AZ	85%	15%	180
CO	89%	11%	245
MN	73%	27%	384
MO	68%	32%	171
NC	56%	44%	173
OR	75%	25%	635
SD	69%	31%	211
TX	75%	25%	1,612
VA	64%	36%	150
WI	66%	34%	771
Weighted NCI-IDD Average	72%	28%	4,532

Services and Supports Received

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

Table 20. Services and Supports Received from IDD Agency

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

State	Financial support	In-home support	Out-of-home respite care	Early intervention	Transportation	Other	Self-direction or fiscal intermediary services
AZ	8%	56%	34%	18%	12%	89%	21%
CO	36%	55%	46%	8%	15%	94%	46%
MN	59%	55%	29%	3%	29%	71%	79%
MO	28%	28%	18%	4%	8%	67%	30%
NC	19%	73%	46%	1%	17%	67%	31%
OR	16%	77%	38%	6%	14%	67%	60%
SD	67%	18%	42%	12%	14%	82%	93%
TX	10%	66%	20%	14%	18%	66%	38%
VA	12%	85%	32%	0%	21%	74%	54%
WI	33%	36%	33%	27%	16%	73%	27%
Weighted NCI-IDD Average	19%	59%	33%	13%	16%	74%	36%

Table 21. Other Services or Supports Received

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

State	Social Security Payments (SSI/SSB)	Services or supports from other agencies or organizations
AZ	30%	71%
CO	24%	76%
MN	36%	78%
MO	28%	76%
NC	52%	66%
OR	38%	75%
SD	24%	73%
TX	74%	50%
VA	45%	67%
WI	24%	66%
Weighted NCI-IDD Average	44%	65%

Child Family Survey Results

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

Information and Planning

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

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

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

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

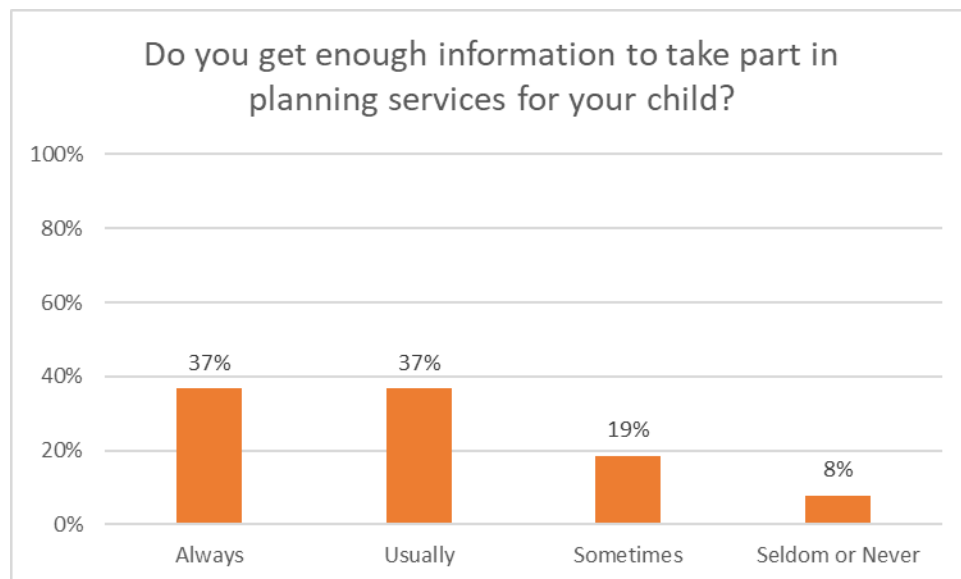


Table Q1. Do you get enough information to take part in planning services for your child?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	48%	40%	10%	2%	210
TX	45%	17%	24%	15%	1,564

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
Weighted NCI-IDD Average	37%	37%	19%	8%	4,502
AZ	36%	41%	15%	7%	181
WI	36%	43%	18%	3%	779
VA	35%	41%	21%	3%	157
NC	35%	42%	17%	7%	166
OR	35%	44%	17%	4%	637
MN	31%	46%	18%	5%	395
CO	31%	47%	17%	6%	249

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	23%	40%	23%	14%	164

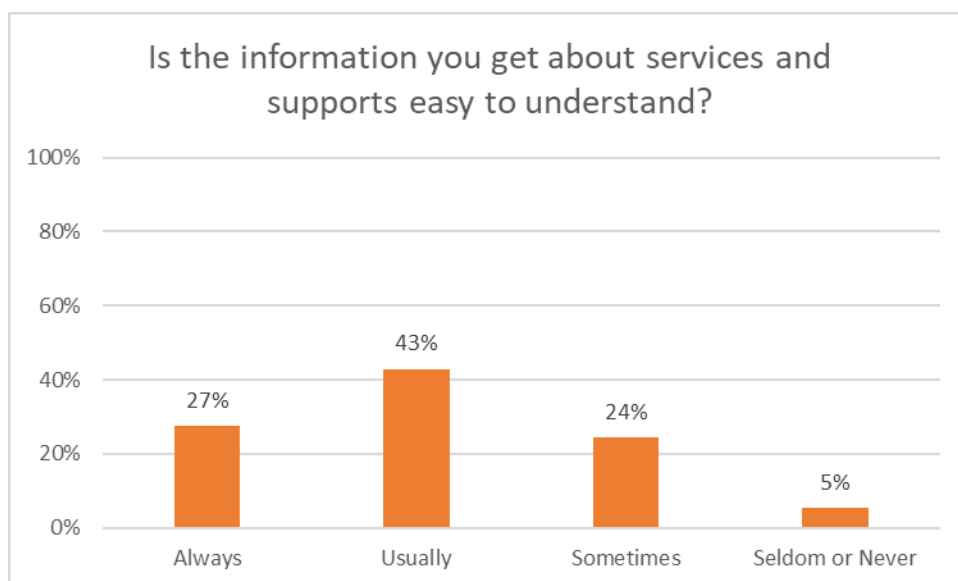


Table Q2. Is the information you get about services and supports easy to understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	41%	24%	28%	8%	1,533

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	35%	55%	9%	2%	210
AZ	28%	45%	23%	4%	182
WI	28%	47%	23%	3%	774
Weighted NCI-IDD Average	27%	43%	24%	5%	4,477
OR	23%	52%	21%	3%	644
NC	20%	52%	23%	5%	168
MO	20%	52%	21%	8%	164

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CO	18%	44%	32%	6%	248
VA	17%	45%	32%	6%	159
MN	15%	49%	30%	6%	395

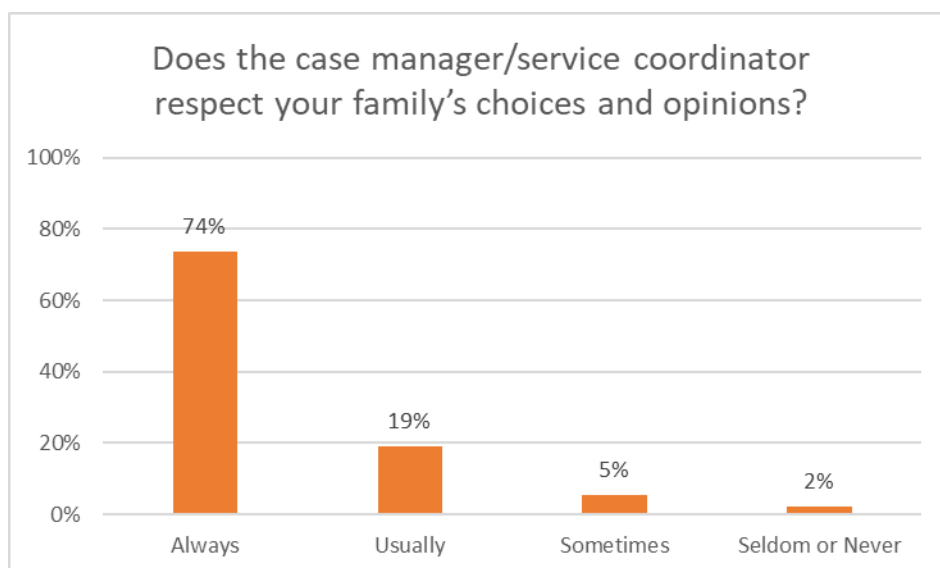


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	82%	15%	1%	1%	208
TX	79%	11%	8%	3%	1,555

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MN	76%	19%	5%	1%	396
AZ	76%	17%	4%	2%	181
WI	75%	21%	3%	1%	772
OR	74%	21%	4%	1%	643
Weighted NCI-IDD Average	74%	19%	5%	2%	4,479
CO	73%	21%	2%	3%	241
MO	67%	24%	6%	3%	161
NC	64%	28%	6%	2%	163
VA	64%	28%	8%	1%	159

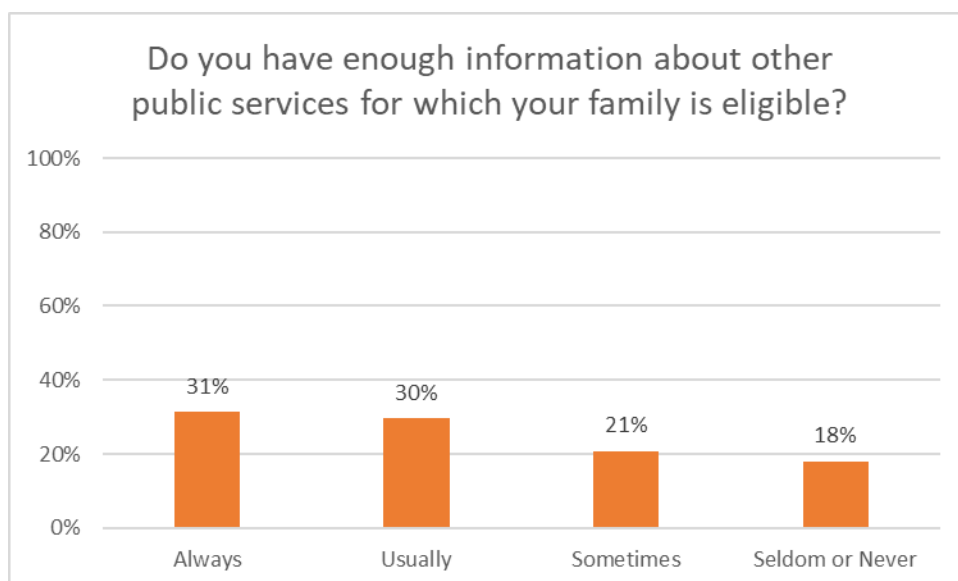


Table Q4. Do you have enough information about other public services for which your family is eligible?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	46%	17%	21%	16%	1,484
SD	42%	37%	16%	6%	180

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	32%	31%	20%	17%	143
Weighted NCI-IDD Average	31%	30%	21%	18%	3,996
OR	30%	38%	21%	11%	558
AZ	30%	30%	18%	22%	148
WI	28%	33%	23%	16%	652
MO	27%	30%	24%	19%	138
MN	26%	32%	28%	15%	333

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	21%	39%	19%	21%	150
CO	19%	37%	29%	16%	210

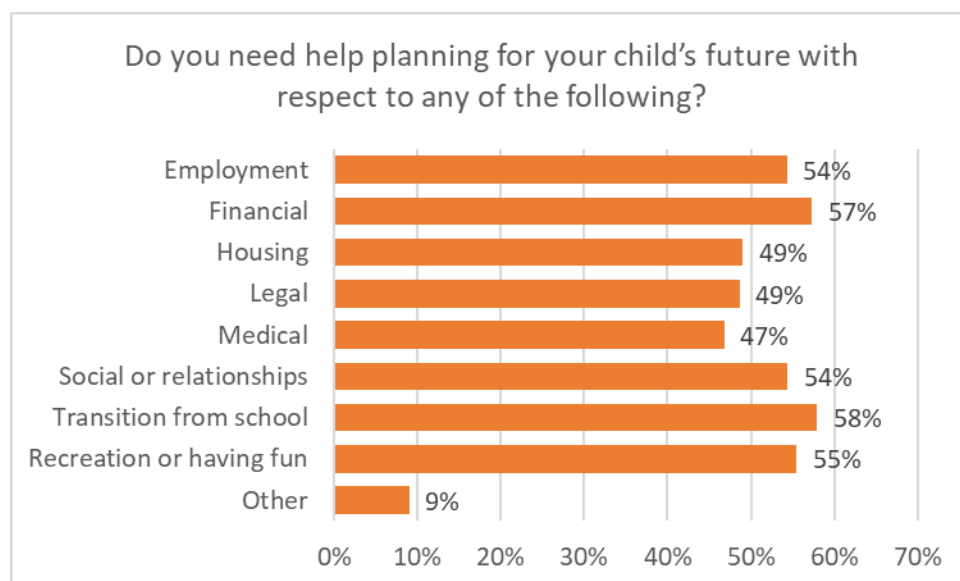


Table Q5. Do you need help planning for your child's future with respect to any of the following?

Categories are not mutually exclusive, therefore N is not shown

State	Employment	Financial	Housing	Legal	Medical	Social or relationships	Transition From School	Recreation or Having Fun	Other
AZ	47%	50%	38%	43%	42%	54%	50%	51%	7%
CO	52%	64%	59%	62%	52%	58%	60%	60%	11%
MN	60%	55%	51%	46%	35%	45%	58%	52%	11%
MO	68%	62%	53%	51%	49%	62%	62%	54%	4%
NC	56%	54%	51%	50%	36%	48%	61%	52%	12%
OR	56%	56%	47%	42%	42%	56%	57%	53%	11%
SD	51%	51%	43%	47%	40%	52%	52%	51%	4%
TX	60%	67%	59%	55%	69%	59%	67%	63%	8%
VA	55%	59%	59%	57%	49%	63%	66%	56%	5%
WI	47%	57%	44%	44%	41%	56%	51%	57%	9%
Weighted NCI-IDD Average	54%	57%	49%	49%	47%	54%	58%	55%	9%

Note, some state outcomes appear out of order due to sample and effect size. Learn more about sample and effect size [here](#).

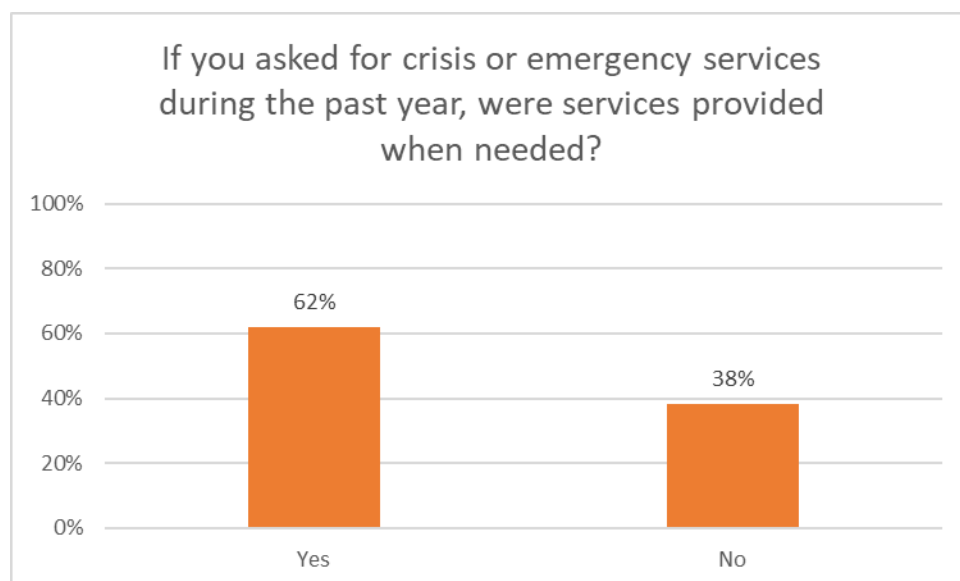


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

Significantly Above Average

State	Yes	No	N
AZ	68%	32%	44

Within Average Range

State	Yes	No	N
TX	68%	32%	667
VA	64%	36%	58
Weighted NCI-IDD Average	62%	38%	1,328
WI	61%	39%	161
MN	55%	45%	92
SD	55%	45%	29
NC	55%	45%	51
CO	47%	53%	58
MO	45%	55%	31

Significantly Below Average

State	Yes	No	N
OR	48%	52%	137

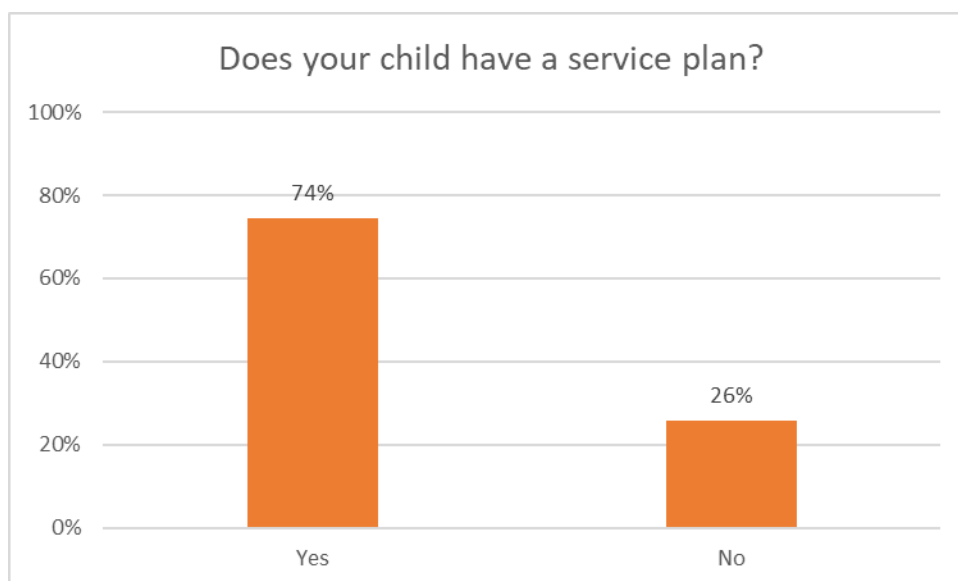


Table Q7. Does your child have a service plan?

Significantly Above Average

State	Yes	No	N
CO	91%	9%	242
VA	91%	9%	135
OR	86%	14%	557
MN	83%	17%	333
NC	83%	17%	158
WI	80%	20%	675

Within Average Range

State	Yes	No	N
MO	80%	20%	154
Weighted NCI-IDD Average	74%	26%	4,000
SD	74%	26%	172

Significantly Below Average

State	Yes	No	N
TX	64%	36%	1,431
AZ	63%	37%	143

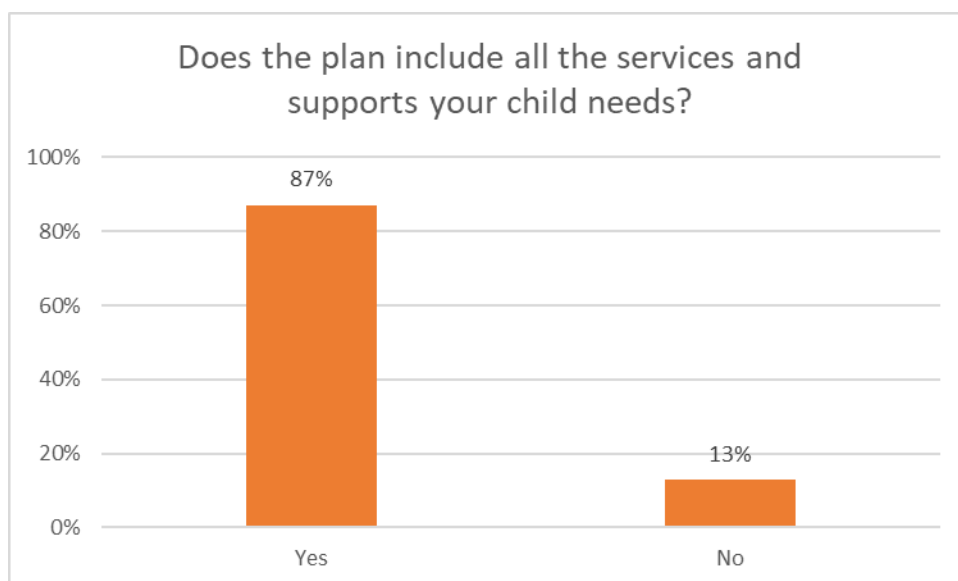


Table Q8. Does the plan include all the services and supports your child needs?

Significantly Above Average

State	Yes	No	N
TX	91%	9%	883

Within Average Range

State	Yes	No	N
AZ	94%	6%	83
OR	90%	10%	422
Weighted NCI-IDD Average	87%	13%	2,774
MN	87%	13%	250
WI	86%	14%	477
SD	84%	16%	117
NC	83%	17%	117
VA	81%	19%	111
MO	77%	23%	107

Significantly Below Average

State	Yes	No	N
CO	77%	23%	207

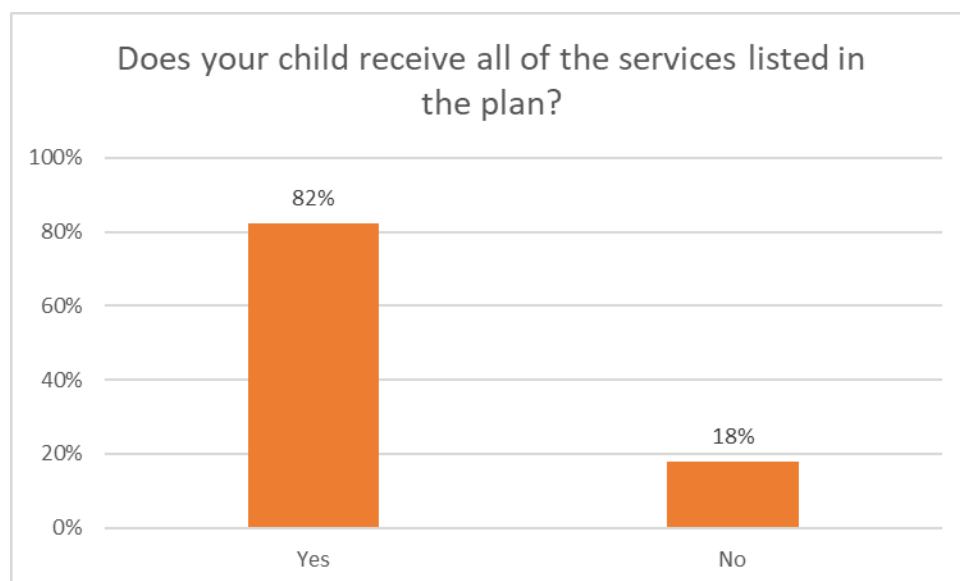


Table Q9. Does your child receive all of the services listed in the plan?

Significantly Above Average

State	Yes	No	N
MN	88%	12%	251
WI	87%	13%	488

Within Average Range

State	Yes	No	N
SD	88%	12%	120
OR	85%	15%	412
TX	84%	16%	870
AZ	84%	16%	85
Weighted NCI-IDD Average	82%	18%	2,772
NC	78%	22%	122
MO	76%	24%	105
VA	73%	27%	112

Significantly Below Average

State	Yes	No	N
CO	71%	29%	207

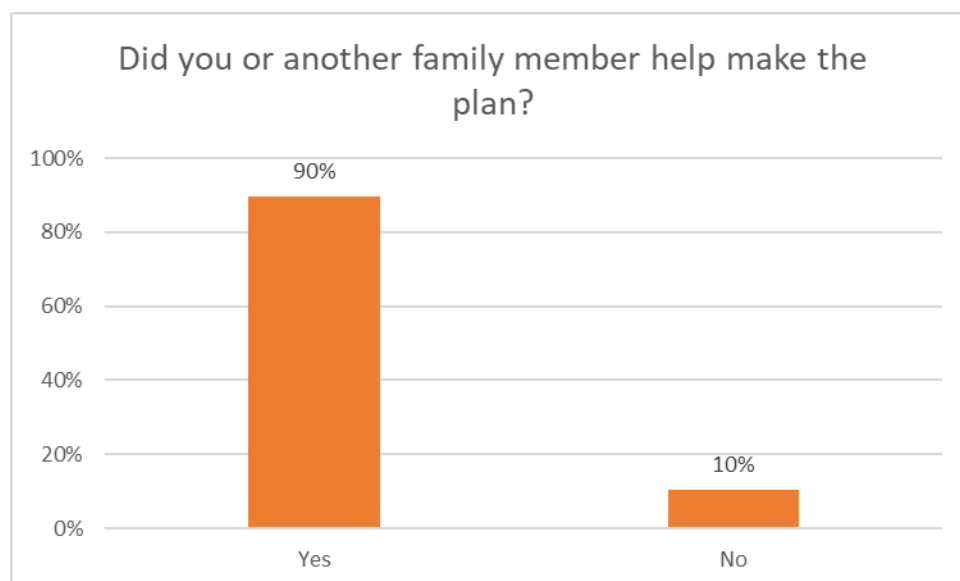


Table Q10. Did you or another family member help make the plan?

Significantly Above Average

State	Yes	No	N
MO	97%	3%	121
CO	94%	6%	214

Within Average Range

State	Yes	No	N
SD	94%	6%	124
NC	93%	7%	131
WI	91%	9%	521
Weighted NCI-IDD Average	90%	10%	2,948
AZ	90%	10%	86
OR	89%	11%	457
VA	88%	12%	118
MN	88%	12%	268

Significantly Below Average

State	Yes	No	N
TX	82%	18%	908

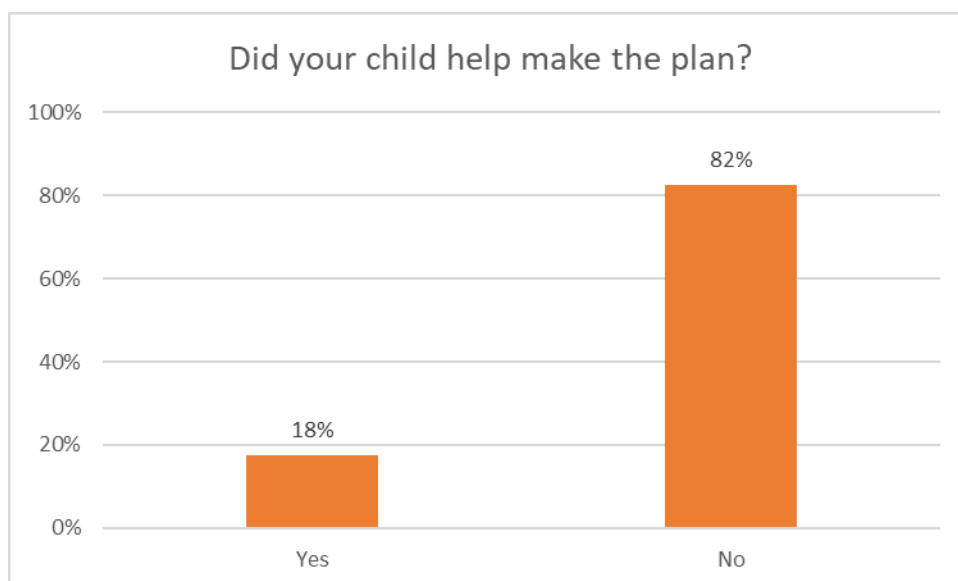


Table Q11. Did your child help make the plan?

Within Average Range

State	Yes	No	N
SD	27%	73%	123
MO	22%	78%	121
OR	21%	79%	453
NC	21%	79%	130
VA	20%	80%	117
Weighted NCI-IDD Average	18%	82%	2,943
TX	18%	82%	905
MN	17%	83%	269
WI	17%	83%	521
AZ	11%	89%	85

Significantly Below Average

State	Yes	No	N
CO	11%	89%	219

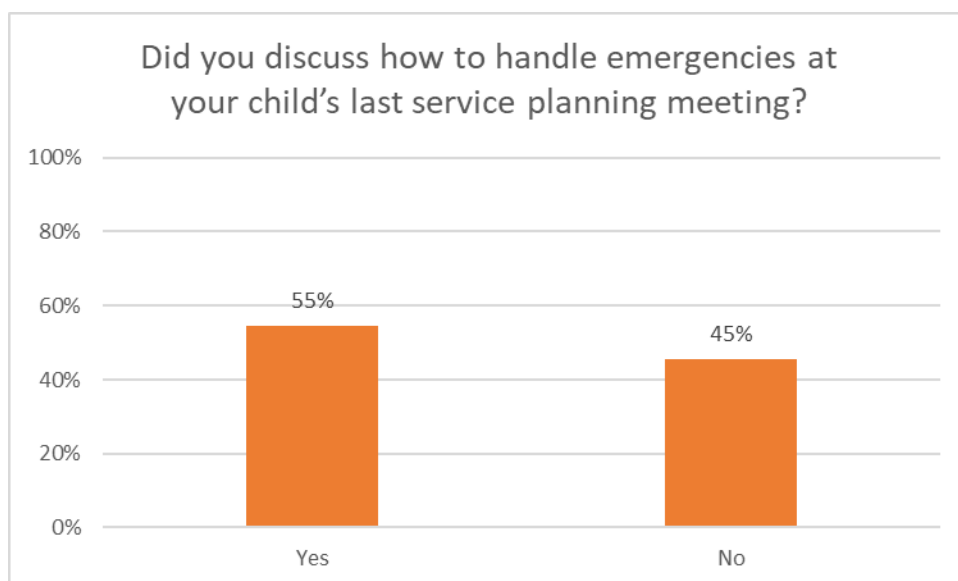


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your child's last service planning meeting?

Significantly Above Average

State	Yes	No	N
TX	73%	27%	852
OR	61%	39%	403

Within Average Range

State	Yes	No	N
CO	62%	38%	205
SD	59%	41%	106
NC	59%	41%	119
MO	55%	45%	101
Weighted NCI-IDD Average	55%	45%	2,681
VA	47%	53%	115
MN	47%	53%	230
AZ	42%	58%	85

Significantly Below Average

State	Yes	No	N
WI	35%	65%	465

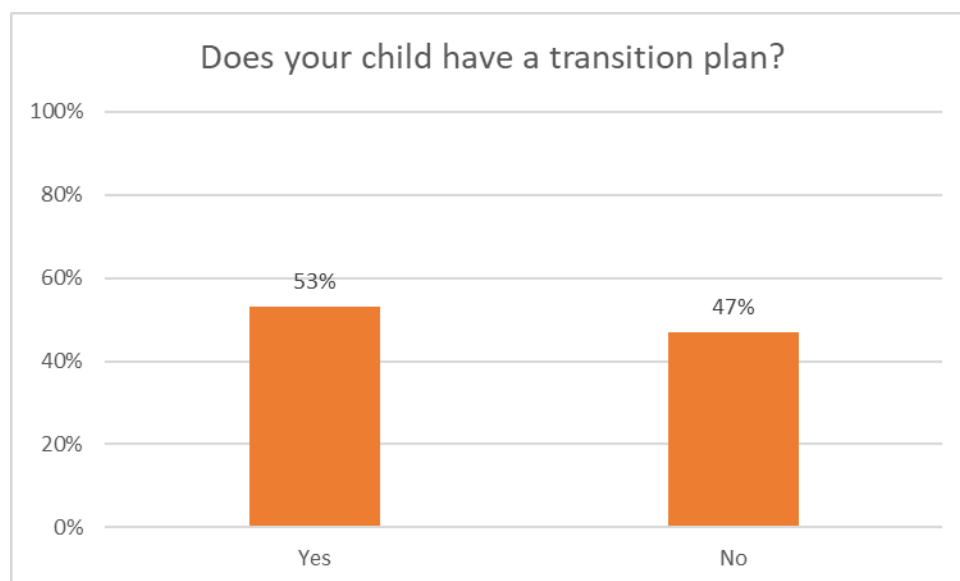


Table Q13. Does your child have a transition plan (as part of an IEP or Section 504 plan through their high school, usually starting at age 14)?

Significantly Above Average

State	Yes	No	N
CO	75%	25%	55
VA	70%	30%	91
MN	69%	31%	177
WI	63%	37%	180

Within Average Range

State	Yes	No	N
SD	64%	36%	50
NC	61%	39%	108
OR	60%	40%	232
Weighted NCI-IDD Average	53%	47%	1,999
AZ	47%	53%	30
MO	39%	61%	49

Significantly Below Average

State	Yes	No	N
TX	42%	58%	1,027

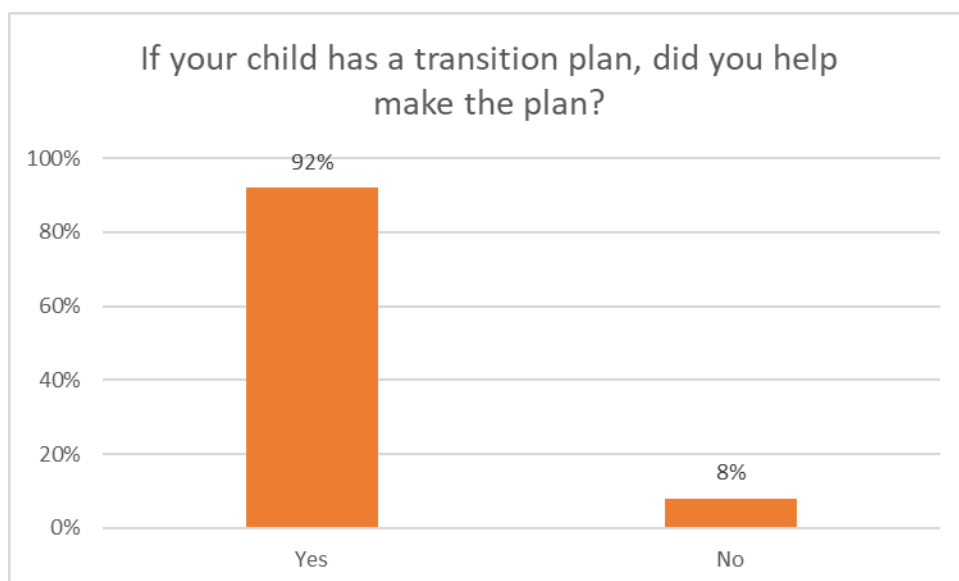


Table Q14. If your child has a transition plan, did you help make the plan? ²

Within Average Range

State	Yes	No	N
CO	97%	3%	37
VA	97%	3%	61
SD	97%	3%	29
OR	94%	6%	118
MN	94%	6%	113
WI	94%	6%	111
Weighted NCI-IDD Average	92%	8%	971
TX	91%	9%	407
NC	91%	9%	65

² The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: AZ, MO.

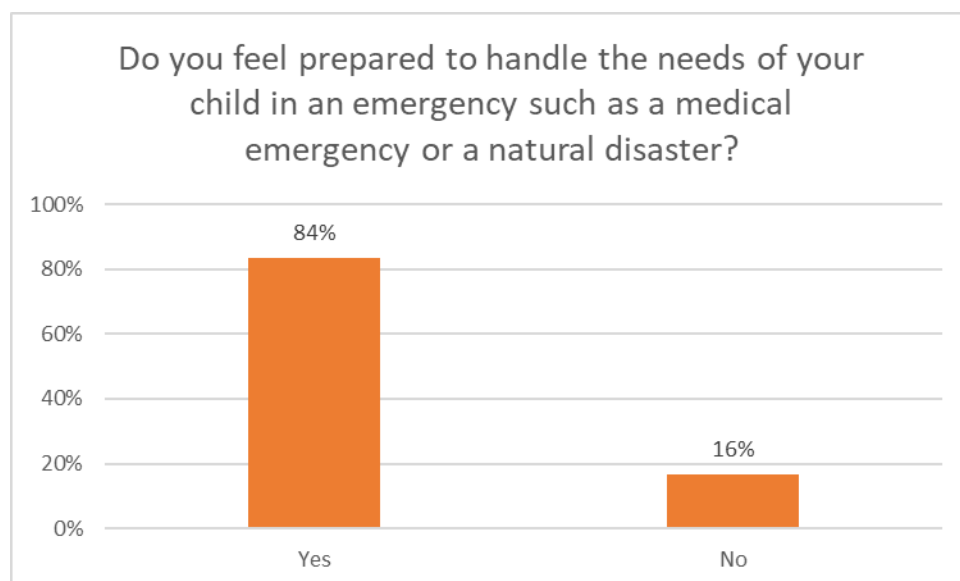


Table Q15. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster?

Significantly Above Average

State	Yes	No	N
SD	92%	8%	196
TX	87%	13%	1,547

Within Average Range

State	Yes	No	N
MN	86%	14%	352
Weighted NCI-IDD Average	84%	16%	4,200
AZ	83%	17%	166
WI	83%	17%	695
CO	82%	18%	234
NC	81%	19%	151
MO	80%	20%	150
OR	79%	21%	565
VA	74%	26%	144

Access and Delivery of Services and Supports

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

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

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

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

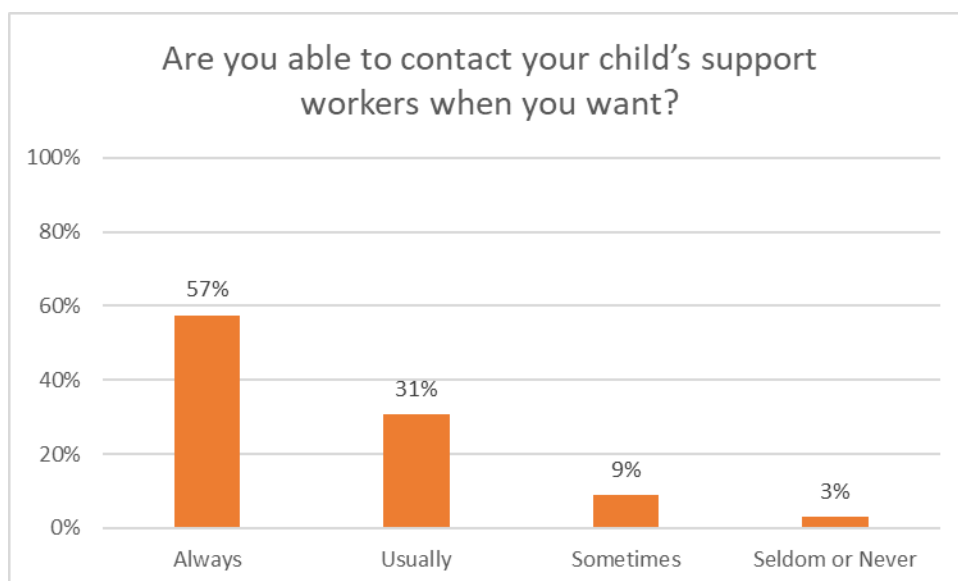


Table Q16. Are you able to contact your child's support workers when you want?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	69%	26%	4%	0%	200
TX	65%	16%	14%	4%	1,523

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	59%	32%	6%	3%	180
WI	58%	34%	7%	2%	703
Weighted NCI-IDD Average	57%	31%	9%	3%	4,281
OR	56%	36%	7%	1%	618
VA	54%	37%	6%	3%	155
NC	53%	35%	8%	4%	161
MN	52%	39%	8%	2%	359

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CO	46%	41%	10%	3%	236
MO	42%	43%	10%	5%	146

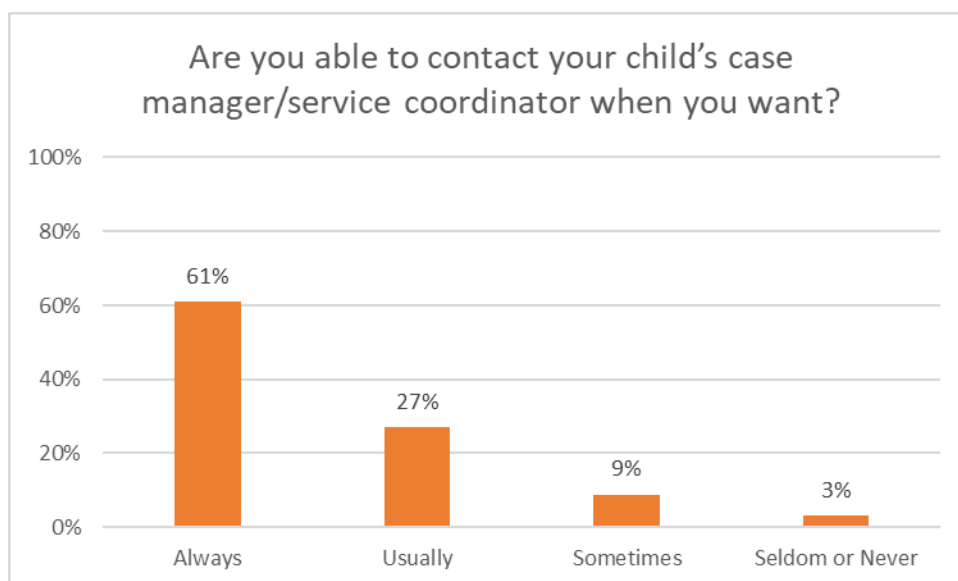


Table Q17. Are you able to contact your child's case manager/service coordinator when you want?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	78%	16%	5%	0%	210

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	66%	25%	6%	3%	183
WI	64%	27%	7%	2%	756
TX	63%	18%	14%	5%	1,547
Weighted NCI-IDD Average	61%	27%	9%	3%	4,460
VA	59%	32%	8%	1%	158
NC	58%	32%	7%	3%	161

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	56%	33%	10%	2%	649
MN	53%	37%	9%	1%	391
CO	52%	36%	10%	2%	241
MO	49%	38%	10%	4%	164

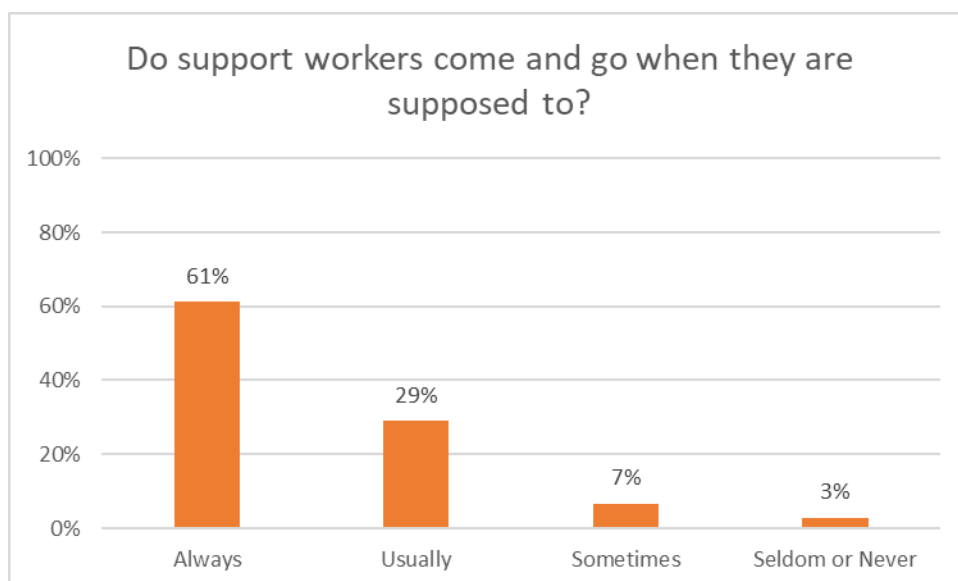


Table Q18. Do support workers come and go when they are supposed to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	81%	17%	2%	1%	149
TX	70%	16%	9%	4%	1,465

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
WI	65%	29%	5%	1%	608
VA	63%	29%	6%	2%	154
AZ	61%	32%	5%	2%	168
Weighted NCI-IDD Average	61%	29%	7%	3%	3,925
OR	59%	32%	7%	1%	584
MN	58%	36%	6%	0%	320
CO	56%	35%	8%	2%	205
MO	54%	36%	7%	4%	121

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	50%	38%	8%	4%	151

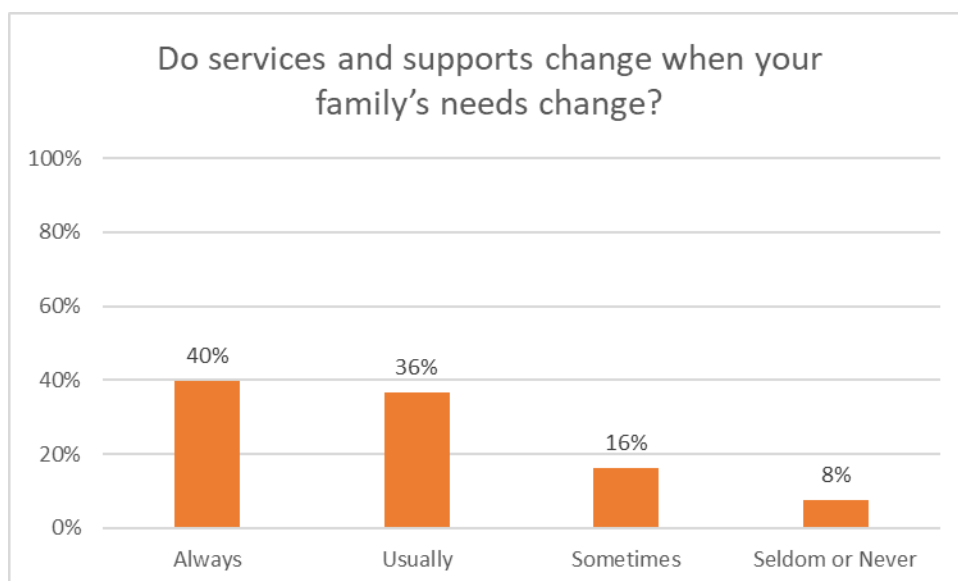


Table Q19. Do services and supports change when your family's needs change?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	53%	34%	11%	2%	167
TX	51%	20%	19%	10%	1,398

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	44%	35%	12%	9%	137
WI	42%	38%	15%	5%	636
Weighted NCI-IDD Average	40%	36%	16%	8%	3,878
AZ	40%	39%	15%	6%	159
OR	35%	44%	15%	6%	544
NC	34%	44%	13%	9%	161

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CO	30%	43%	21%	6%	209
MN	27%	45%	21%	7%	340
MO	27%	46%	17%	10%	127

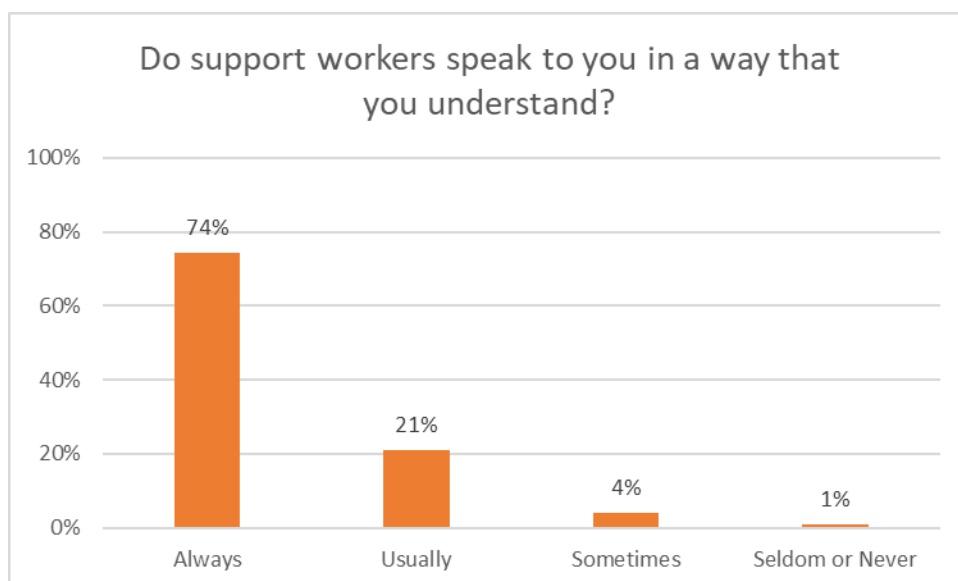


Table Q20. Do support workers speak to you in a way that you understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	79%	12%	7%	1%	1,518

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	80%	17%	3%	0%	172
OR	78%	18%	3%	0%	613
MO	75%	21%	3%	1%	136
WI	75%	23%	2%	0%	660
Weighted NCI-IDD Average	74%	21%	4%	1%	4,160
NC	73%	25%	2%	1%	159
AZ	72%	25%	3%	1%	179
VA	70%	28%	1%	1%	152
CO	70%	24%	4%	1%	219

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	67%	29%	4%	0%	352

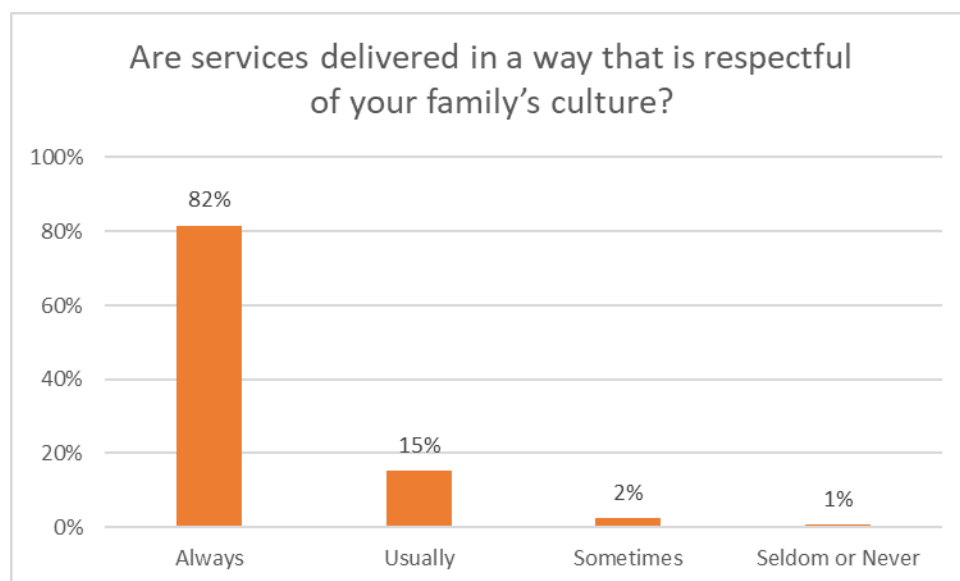


Table Q21. Are services delivered in a way that is respectful of your family's culture?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	88%	11%	1%	0%	640
TX	85%	8%	5%	1%	1,556

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	84%	13%	3%	0%	206
AZ	83%	16%	2%	0%	184
Weighted NCI-IDD Average	82%	15%	2%	1%	4,448
WI	81%	17%	1%	0%	756
CO	80%	18%	2%	0%	239
MN	80%	17%	3%	1%	388
MO	77%	21%	1%	1%	156
NC	77%	20%	2%	1%	167
VA	73%	24%	3%	0%	156

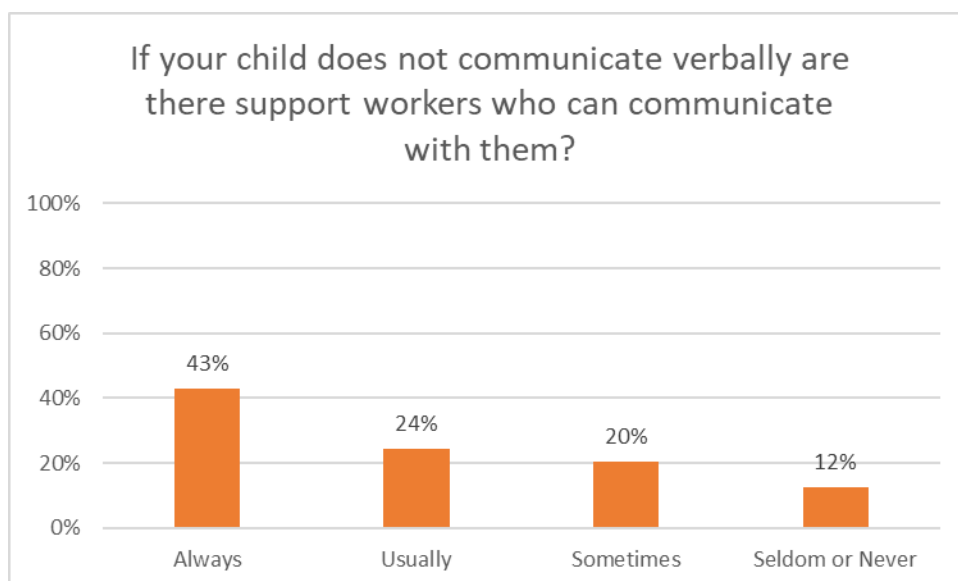


Table Q22. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with them? ³

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	48%	20%	21%	10%	89
Weighted NCI-IDD Average	43%	24%	20%	12%	579
NC	43%	30%	15%	11%	46
TX	41%	21%	19%	20%	183
OR	33%	28%	28%	12%	58
VA	29%	29%	23%	19%	48
WI	27%	25%	31%	16%	55
MN	20%	36%	27%	18%	56

³ The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: CO, MO, SD.

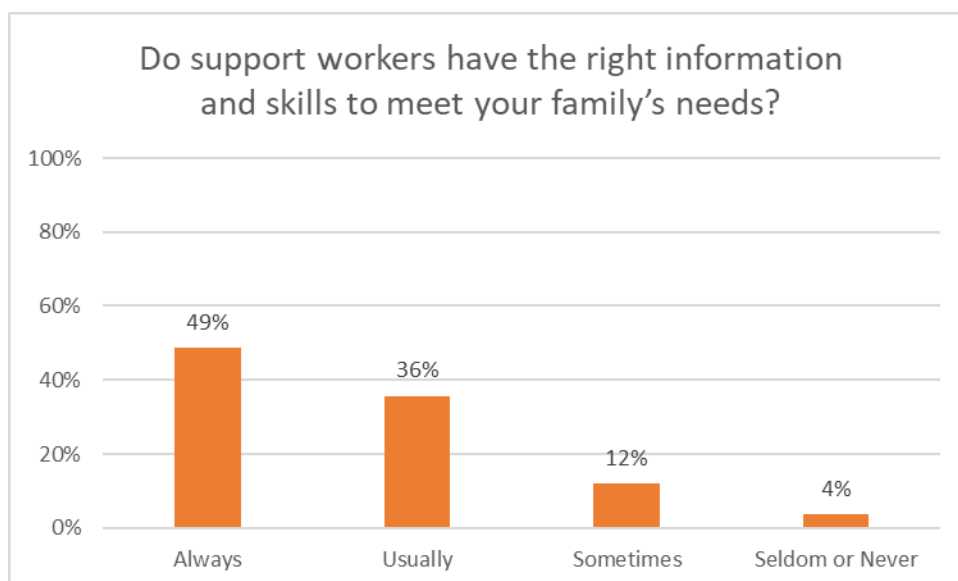


Table Q23. Do support workers have the right information and skills to meet your family's needs?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	65%	19%	12%	4%	1,503

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	53%	39%	7%	1%	174
OR	49%	37%	12%	2%	603
Weighted NCI-IDD Average	49%	36%	12%	4%	4,105
AZ	46%	42%	8%	4%	180
WI	46%	41%	11%	2%	650
VA	44%	37%	16%	3%	153
MN	44%	43%	13%	1%	331
MO	43%	39%	12%	6%	125
NC	39%	40%	17%	5%	162

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CO	36%	51%	10%	3%	224



Table Q24. Does your child have the special equipment or accommodations that they need?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	57%	17%	15%	12%	1,203

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	48%	35%	14%	4%	155
Weighted NCI-IDD Average	42%	32%	17%	9%	3,006
VA	41%	25%	16%	17%	104
AZ	40%	35%	15%	10%	100
NC	37%	34%	19%	10%	93
MO	32%	46%	12%	10%	68

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	36%	39%	19%	6%	462
MN	34%	43%	19%	4%	253
OR	33%	44%	18%	5%	387
CO	27%	50%	18%	6%	181

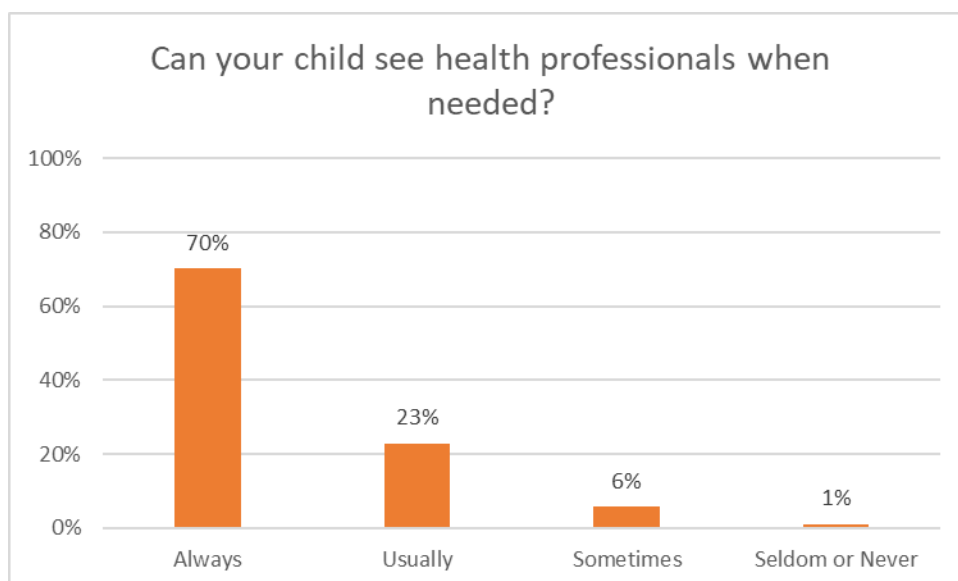


Table Q25. Can your child see health professionals when needed?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	81%	16%	3%	0%	215

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	75%	20%	4%	1%	158
AZ	74%	22%	4%	0%	186
NC	72%	21%	5%	2%	176
TX	70%	18%	9%	2%	1,582
Weighted NCI-IDD Average	70%	23%	6%	1%	4,552
MO	70%	25%	4%	1%	169
WI	67%	27%	5%	0%	774
CO	62%	31%	6%	1%	248

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	64%	30%	6%	0%	391
OR	63%	31%	6%	1%	653

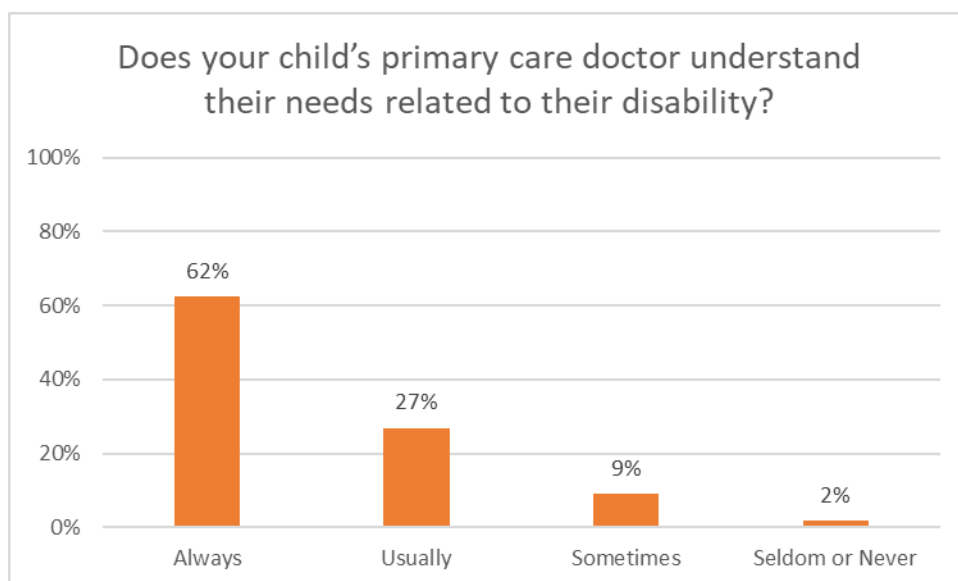


Table Q26. Does your child's primary care doctor understand their needs related to their disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	75%	14%	9%	3%	1,567

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	70%	18%	10%	1%	157
AZ	64%	28%	8%	0%	185
SD	64%	27%	7%	3%	211
Weighted NCI-IDD Average	62%	27%	9%	2%	4,504
MN	59%	33%	6%	1%	383
NC	59%	30%	9%	2%	174
CO	54%	34%	10%	2%	246

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	57%	31%	10%	2%	765
MO	50%	36%	13%	1%	171
OR	49%	36%	12%	2%	645

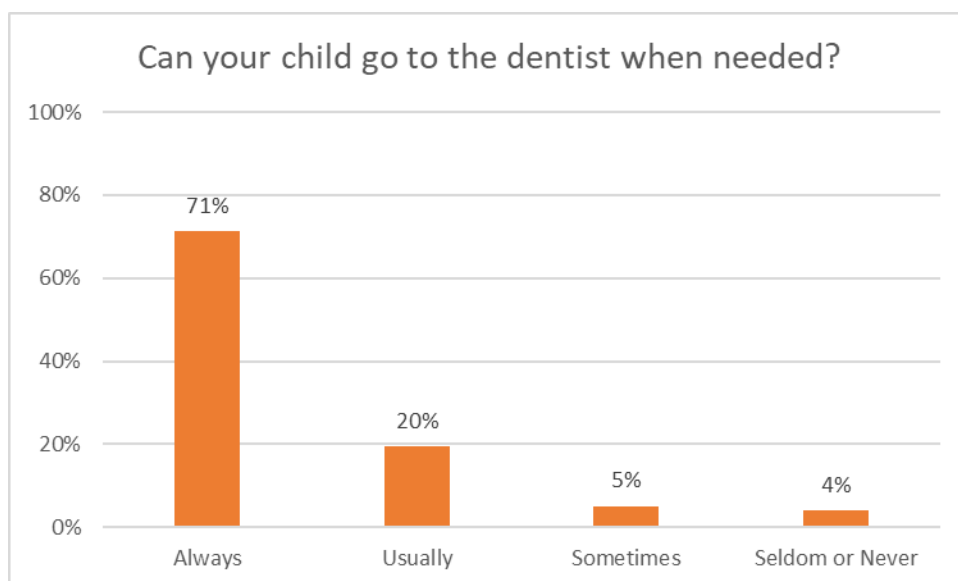


Table Q27. Can your child go to the dentist when needed?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	81%	13%	3%	3%	212
TX	75%	13%	7%	4%	1,574

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	76%	19%	3%	2%	176
AZ	73%	21%	3%	3%	187
Weighted NCI-IDD Average	71%	20%	5%	4%	4,504
VA	70%	18%	8%	4%	158
CO	70%	23%	5%	3%	246
MO	69%	20%	6%	5%	170

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	66%	21%	6%	6%	739
OR	59%	26%	9%	6%	654
MN	55%	30%	8%	6%	388

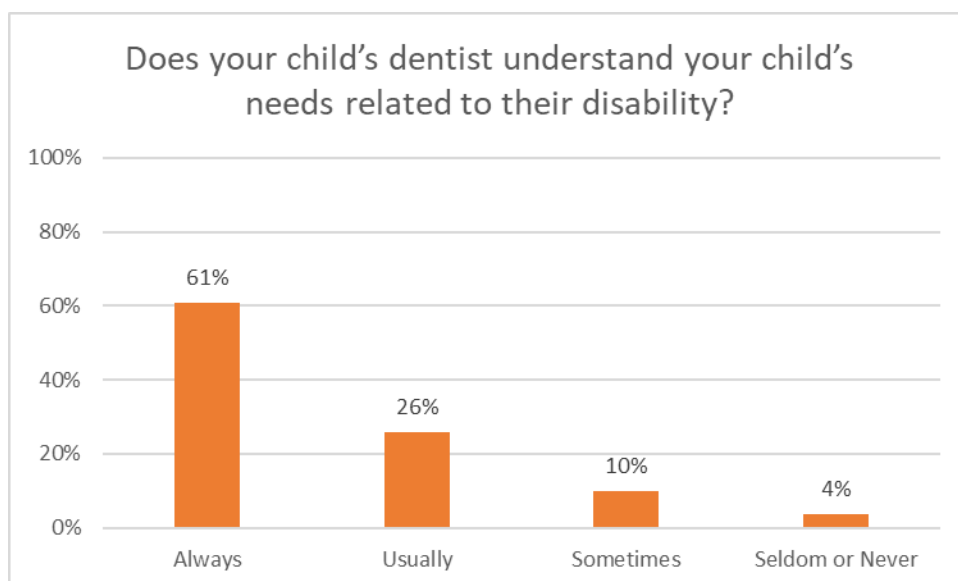


Table Q28. Does your child's dentist understand your child's needs related to their disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	72%	12%	11%	5%	1,523

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	66%	25%	7%	2%	149
AZ	61%	26%	9%	4%	170
Weighted NCI-IDD Average	61%	26%	10%	4%	4,217
NC	60%	31%	7%	1%	164
WI	58%	26%	11%	5%	642
SD	55%	32%	10%	3%	201
CO	54%	35%	8%	3%	237

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	50%	33%	11%	6%	609
MN	49%	35%	13%	3%	364
MO	46%	39%	13%	3%	158

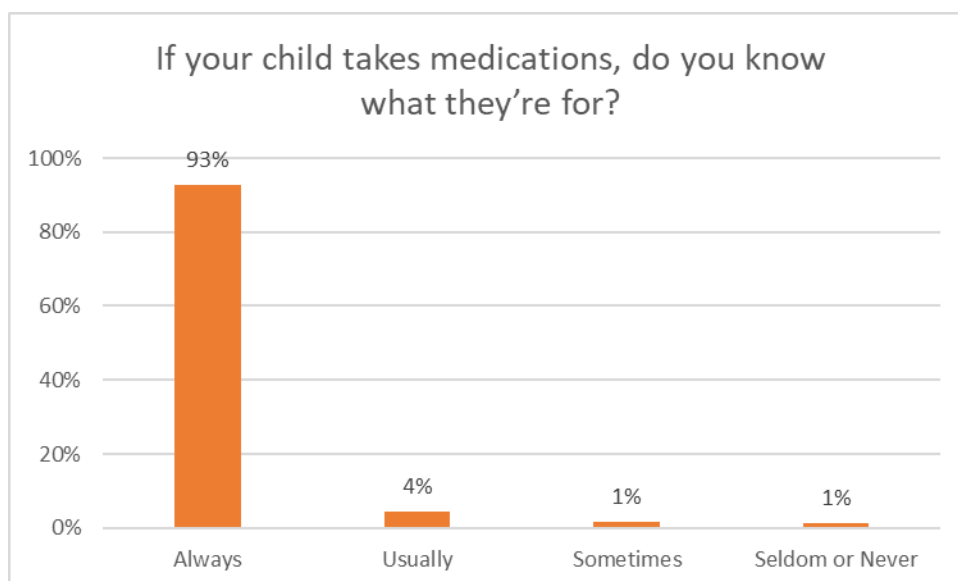


Table Q29. If your child takes medications, do you know what they're for?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	97%	1%	0%	2%	132

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OR	94%	3%	1%	1%	489
CO	94%	4%	0%	2%	206
TX	94%	3%	2%	1%	1,507
Weighted NCI-IDD Average	93%	4%	1%	1%	3,827
WI	91%	6%	2%	1%	560
SD	91%	7%	1%	2%	168
MN	91%	6%	2%	1%	336
MO	91%	5%	4%	0%	134
VA	91%	6%	1%	1%	144
NC	89%	8%	2%	1%	151

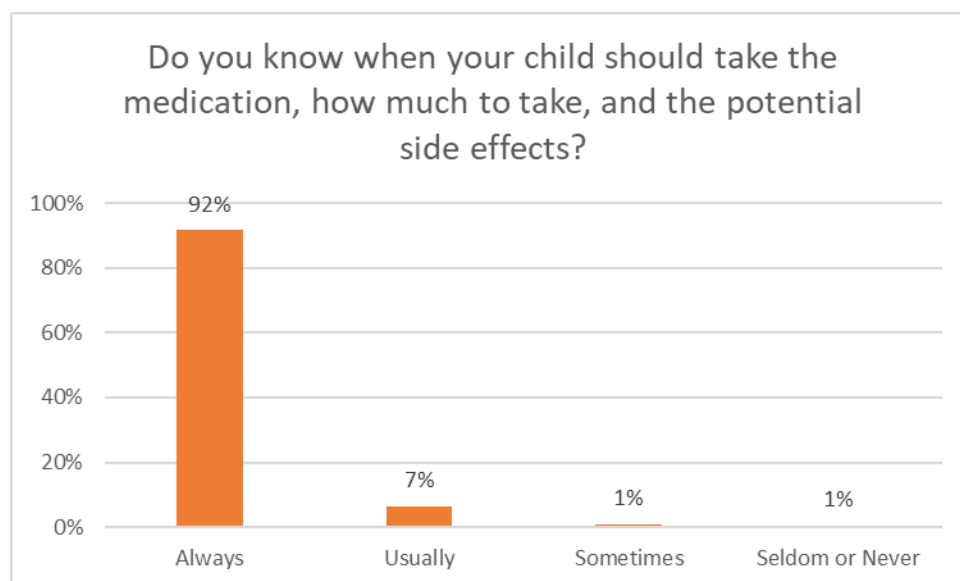


Table Q30. Do you know when your child should take the medication, how much to take, and the potential side effects?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	95%	4%	1%	0%	481

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	95%	4%	1%	0%	140
CO	93%	6%	1%	0%	205
TX	93%	5%	2%	1%	1,505
AZ	92%	6%	1%	1%	131
SD	92%	8%	0%	0%	167
Weighted NCI-IDD Average	92%	7%	1%	1%	3,793
WI	91%	7%	0%	1%	549
MO	91%	8%	2%	0%	133
NC	90%	9%	1%	0%	149
MN	89%	7%	1%	2%	333

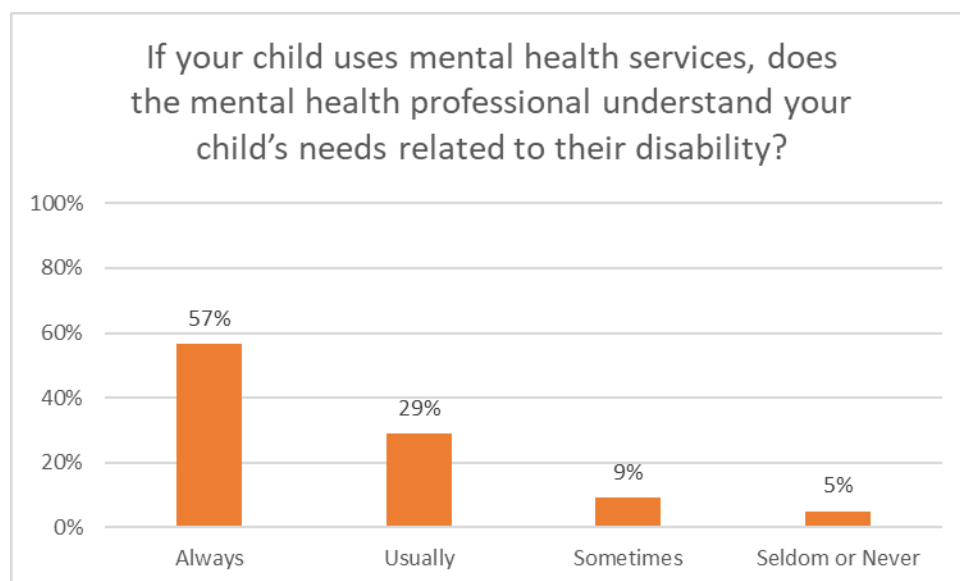


Table Q31. If your child uses mental health services, does the mental health professional understand your child's needs related to their disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	72%	18%	7%	3%	68
TX	68%	13%	13%	6%	814

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
VA	68%	18%	9%	5%	87
AZ	58%	30%	7%	5%	76
Weighted NCI-IDD Average	57%	29%	9%	5%	2,064
WI	53%	33%	10%	4%	273
NC	51%	37%	8%	5%	87
OR	51%	34%	8%	7%	271
MO	49%	39%	10%	2%	90
CO	47%	35%	13%	5%	96

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	45%	43%	8%	4%	202

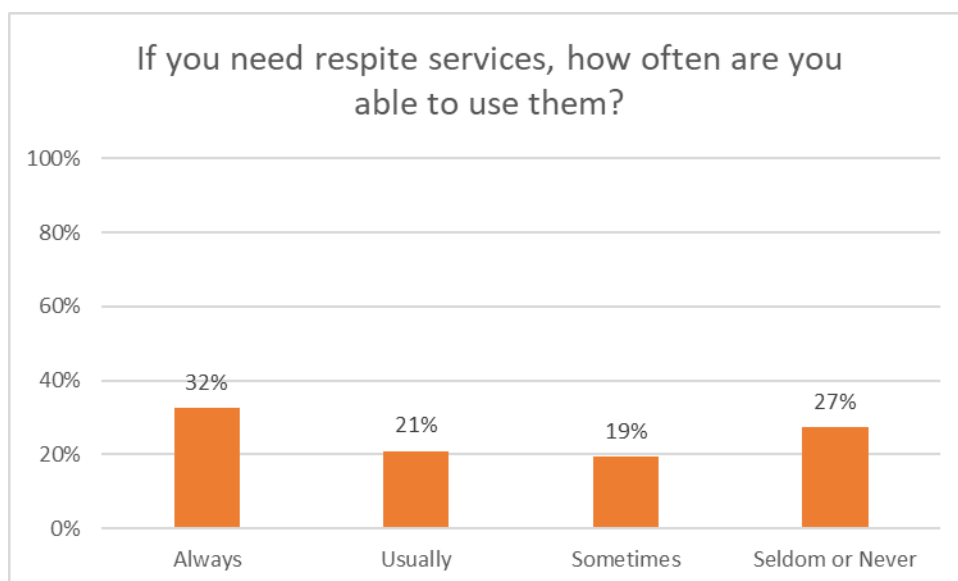


Table Q32. If you need respite services, how often are you able to use them?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	44%	14%	16%	26%	1,067
AZ	44%	22%	17%	17%	144

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
Weighted NCI-IDD Average	32%	21%	19%	27%	3,226
VA	30%	25%	17%	28%	141
SD	27%	20%	32%	21%	169

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	27%	26%	26%	21%	505
OR	27%	23%	20%	30%	506
CO	24%	26%	20%	30%	206
NC	22%	24%	18%	36%	152
MN	18%	19%	23%	40%	237
MO	12%	13%	24%	51%	99

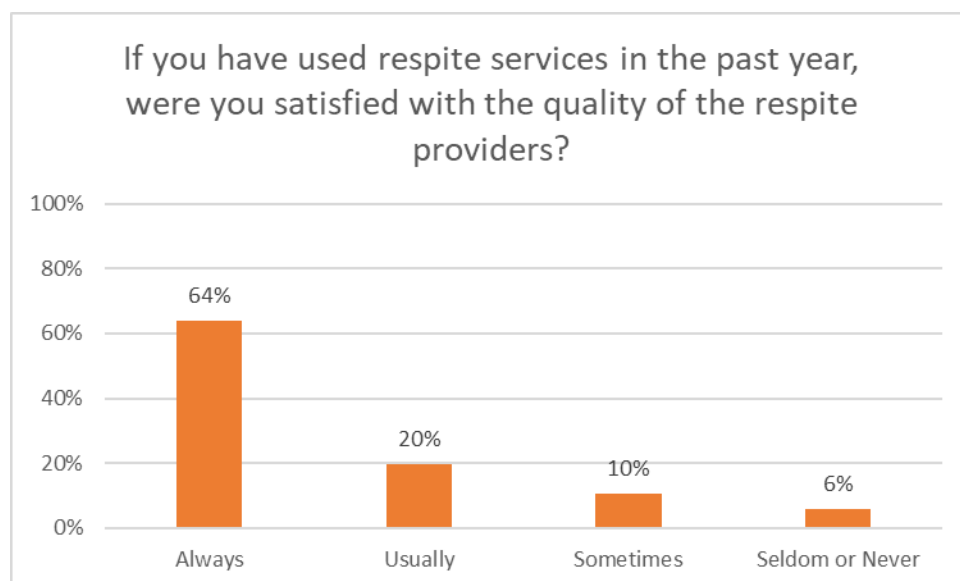


Table Q33. If you have used respite services in the past year, were you satisfied with the quality of the respite providers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	78%	17%	3%	3%	144
TX	70%	13%	11%	7%	754

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OR	66%	22%	7%	5%	361
VA	65%	20%	7%	9%	102
AZ	64%	18%	14%	4%	120
Weighted NCI-IDD Average	64%	20%	10%	6%	2,341
WI	64%	22%	9%	5%	404
MN	61%	25%	6%	8%	147
NC	60%	25%	8%	7%	109
CO	59%	25%	12%	5%	147
MO	57%	21%	15%	8%	53

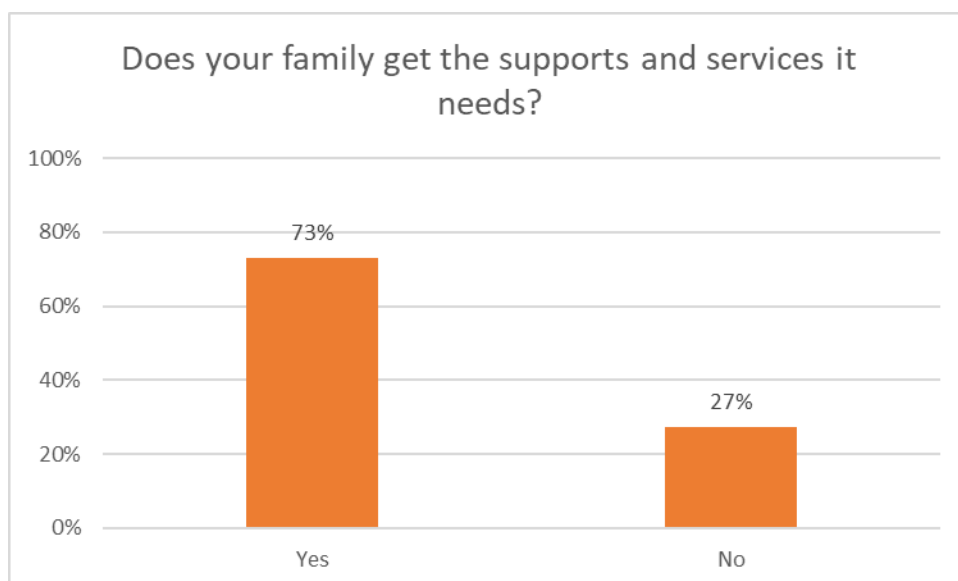


Table Q34. Does your family get the supports and services it needs?

Significantly Above Average

State	Yes	No	N
TX	80%	20%	1,491

Within Average Range

State	Yes	No	N
SD	79%	21%	197
AZ	76%	24%	174
WI	75%	25%	699
OR	74%	26%	567
Weighted NCI-IDD Average	73%	27%	4,180
MN	69%	31%	357
NC	65%	35%	161

Significantly Below Average

State	Yes	No	N
VA	62%	38%	142
MO	61%	39%	156
CO	55%	45%	236

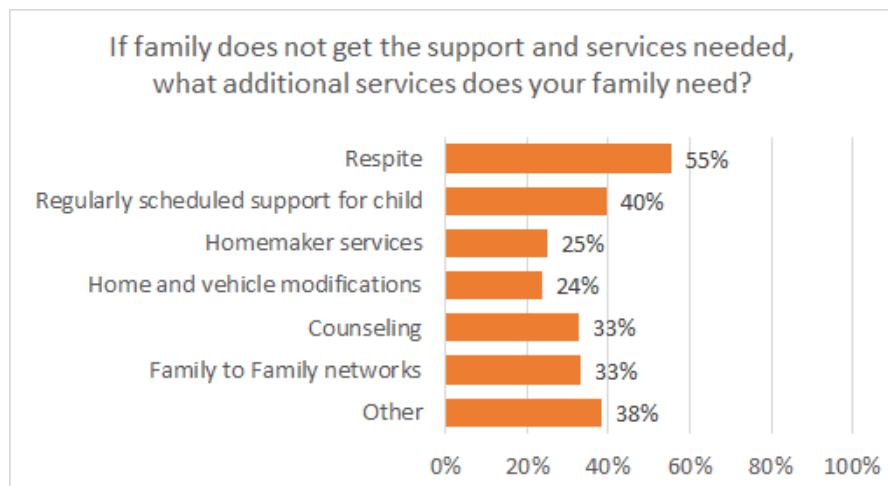


Table Q35. If family does not get the support and services needed, what additional services does your family need?

Categories are not mutually exclusive, therefore N is not shown.

State	Respite	Regularly scheduled support for child	Homemaker services	Home or vehicle modifications	Counseling	Family-to-family networks	Other
AZ	36%	26%	10%	13%	28%	31%	46%
CO	57%	21%	37%	19%	31%	28%	25%
MN	76%	35%	30%	22%	31%	22%	32%
MO	69%	31%	22%	14%	31%	36%	29%
NC	52%	41%	16%	21%	29%	30%	41%
OR	58%	42%	26%	20%	28%	28%	36%
SD	55%	35%	20%	35%	15%	28%	30%
TX	70%	65%	52%	45%	53%	48%	40%
VA	69%	37%	20%	35%	28%	26%	35%
WI	53%	39%	26%	23%	27%	32%	34%
Weighted NCI-IDD Average	55%	40%	25%	24%	33%	33%	38%

Choice, Decision Making and Control

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

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

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

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

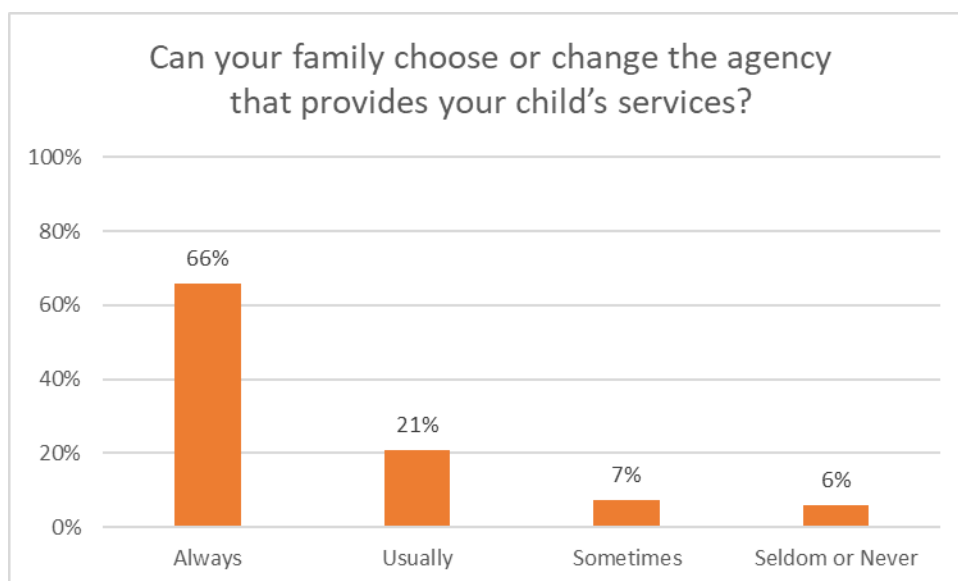


Table Q36. Can your family choose or change the agency that provides your child's services?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	72%	20%	5%	3%	150
TX	71%	12%	7%	9%	1,454
SD	68%	18%	6%	8%	117
AZ	66%	24%	7%	3%	148
MN	66%	26%	5%	4%	311
Weighted NCI-IDD Average	66%	21%	7%	6%	3,368
OR	61%	24%	8%	6%	404
CO	61%	21%	11%	8%	200
VA	58%	29%	8%	6%	120

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	48%	32%	12%	9%	383
MO	41%	27%	16%	16%	81

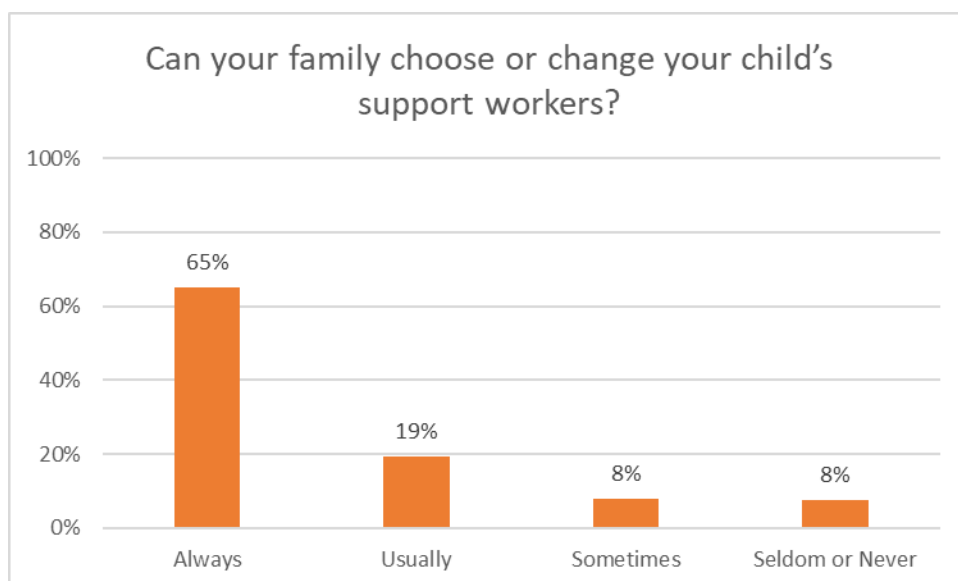


Table Q37. Can your family choose or change your child's support workers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	72%	17%	7%	3%	546

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
TX	69%	11%	8%	11%	1,395
SD	69%	19%	8%	4%	137
AZ	67%	17%	8%	8%	143
Weighted NCI-IDD Average	65%	19%	8%	8%	3,409
NC	64%	25%	5%	6%	150
MN	59%	29%	7%	5%	269
VA	59%	27%	7%	7%	124
CO	58%	24%	13%	5%	196

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	57%	24%	13%	5%	369
MO	44%	29%	15%	13%	80

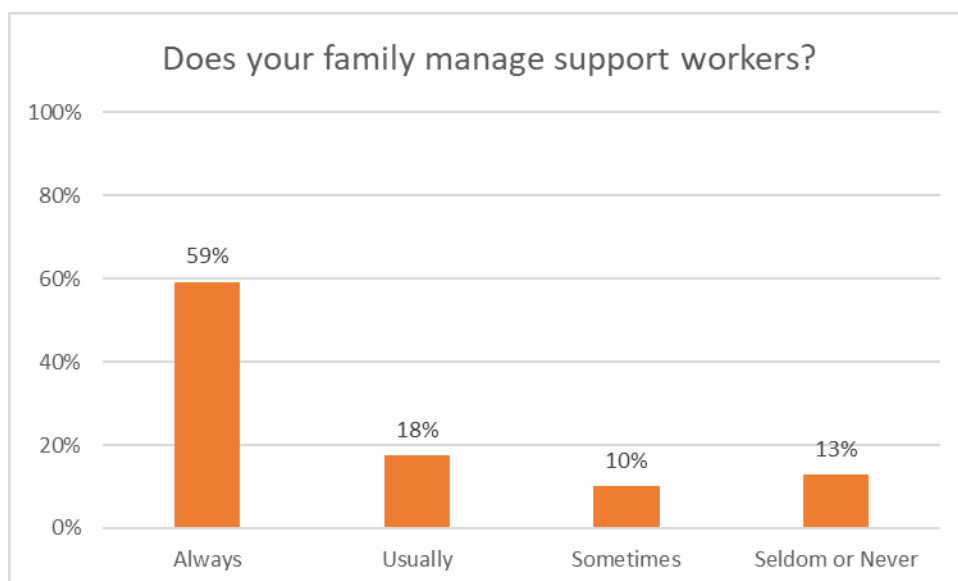


Table Q38. Does your family manage support workers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	73%	18%	4%	6%	296
OR	73%	17%	7%	4%	569

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	67%	20%	8%	5%	132
SD	66%	21%	3%	10%	119
TX	63%	10%	10%	17%	1,418
Weighted NCI-IDD Average	59%	18%	10%	13%	3,500
VA	58%	19%	8%	15%	134
CO	50%	27%	14%	10%	185

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	51%	22%	12%	15%	423
NC	47%	20%	14%	18%	153
MO	42%	23%	7%	28%	71

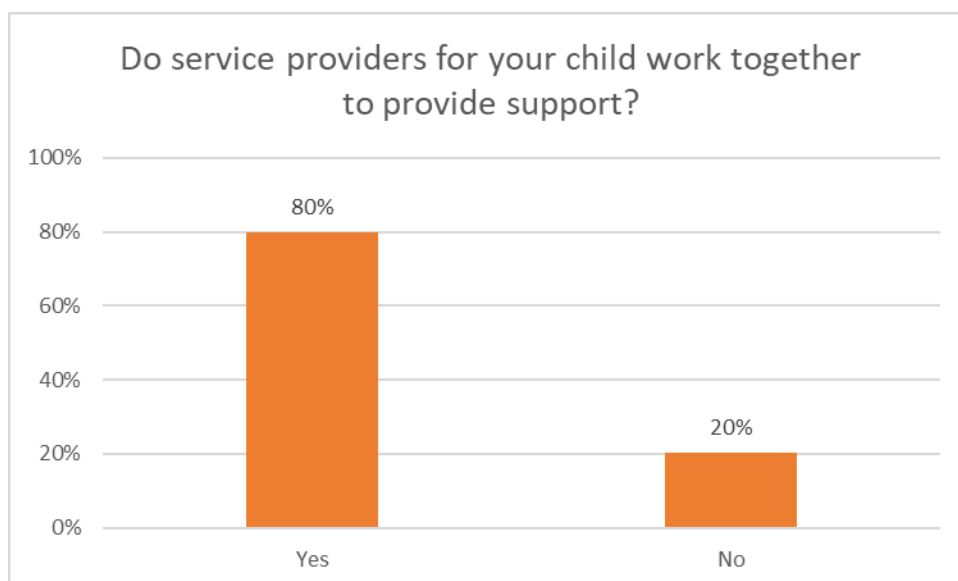


Table Q39. Do service providers for your child work together to provide support?

Significantly Above Average

State	Yes	No	N
TX	86%	14%	1,174

Within Average Range

State	Yes	No	N
VA	82%	18%	99
SD	81%	19%	75
WI	80%	20%	369
OR	80%	20%	307
Weighted NCI-IDD Average	80%	20%	2,635
NC	78%	22%	91
CO	77%	23%	163
AZ	77%	23%	91
MO	67%	33%	75

Significantly Below Average

State	Yes	No	N
MN	70%	30%	191

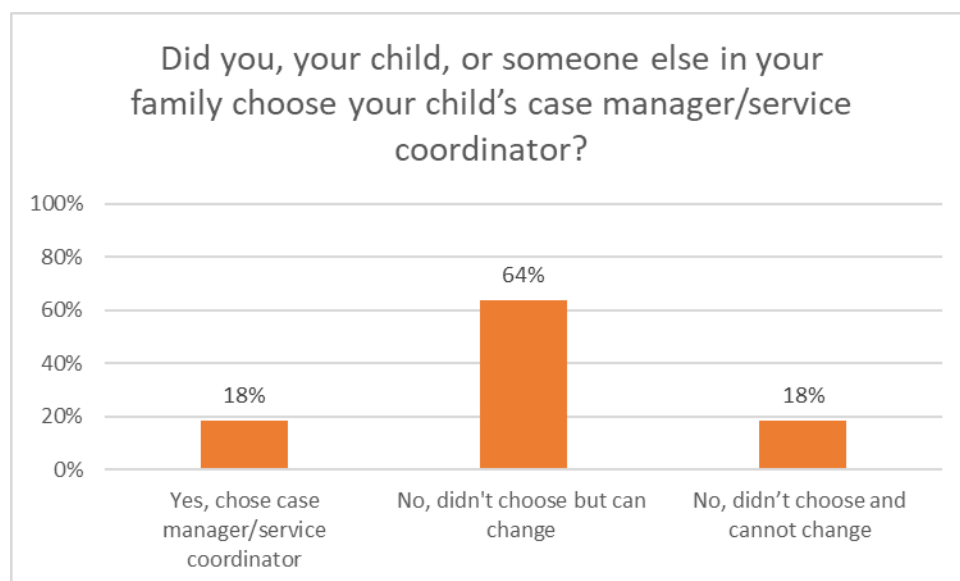


Table Q40. Did you, your child, or someone else in your family choose your child's case manager/service coordinator?

Significantly Above Average

State	Yes, chose case manager/service coordinator	No, didn't choose but can change	No, didn't choose and cannot change	N
TX	28%	55%	17%	1,253

Within Average Range

State	Yes, chose case manager/service coordinator	No, didn't choose but can change	No, didn't choose and cannot change	N
NC	22%	55%	23%	145
OR	20%	61%	19%	532
Weighted NCI-IDD Average	18%	64%	18%	3,655
VA	17%	64%	19%	136
SD	15%	77%	8%	177
AZ	14%	76%	10%	162

Significantly Below Average

State	Yes, chose case manager/service coordinator	No, didn't choose but can change	No, didn't choose and cannot change	N
WI	12%	63%	24%	596
MN	11%	63%	25%	315
CO	7%	76%	17%	205
MO	7%	66%	28%	134

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.

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

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

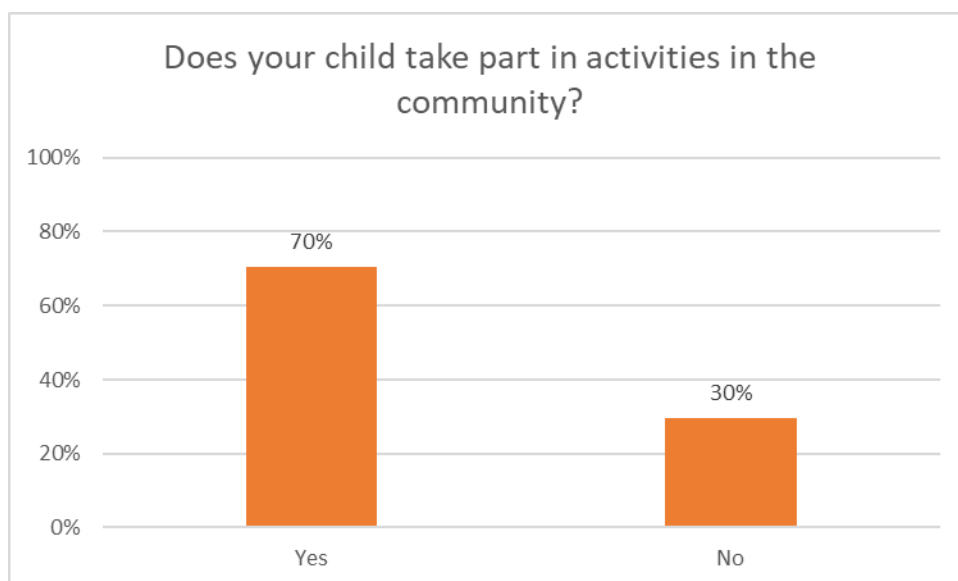


Table Q41. Does your child take part in activities in the community?

Significantly Above Average

State	Yes	No	N
SD	81%	19%	210
WI	78%	22%	769

Within Average Range

State	Yes	No	N
NC	76%	24%	174
MN	76%	24%	384
CO	74%	26%	241
MO	73%	27%	171
AZ	72%	28%	181
VA	72%	28%	158
OR	71%	29%	635
Weighted NCI-IDD Average	70%	30%	4,476

Significantly Below Average

State	Yes	No	N
TX	57%	43%	1,553

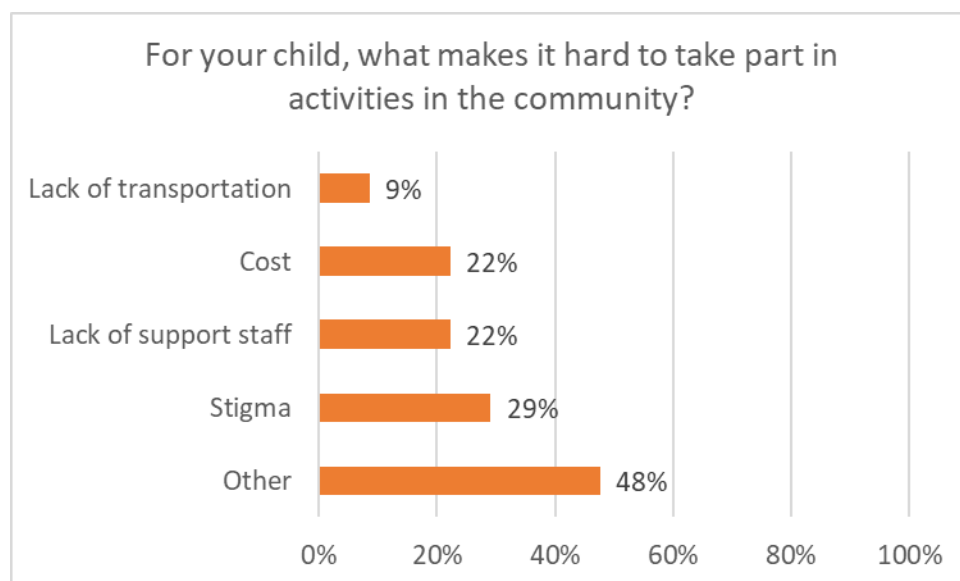


Table Q42. For your child, what makes it hard to take part in activities in the community?

Categories are not mutually exclusive, therefore N is not shown

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	4%	20%	10%	32%	46%
CO	8%	23%	33%	33%	52%
MN	9%	20%	33%	36%	42%
MO	4%	23%	21%	34%	41%
NC	6%	18%	20%	24%	53%
OR	7%	22%	24%	30%	43%
SD	4%	21%	17%	17%	41%
TX	17%	29%	29%	29%	52%
VA	11%	27%	36%	28%	56%
WI	8%	22%	28%	28%	42%
Weighted NCI-IDD Average	9%	22%	22%	29%	48%

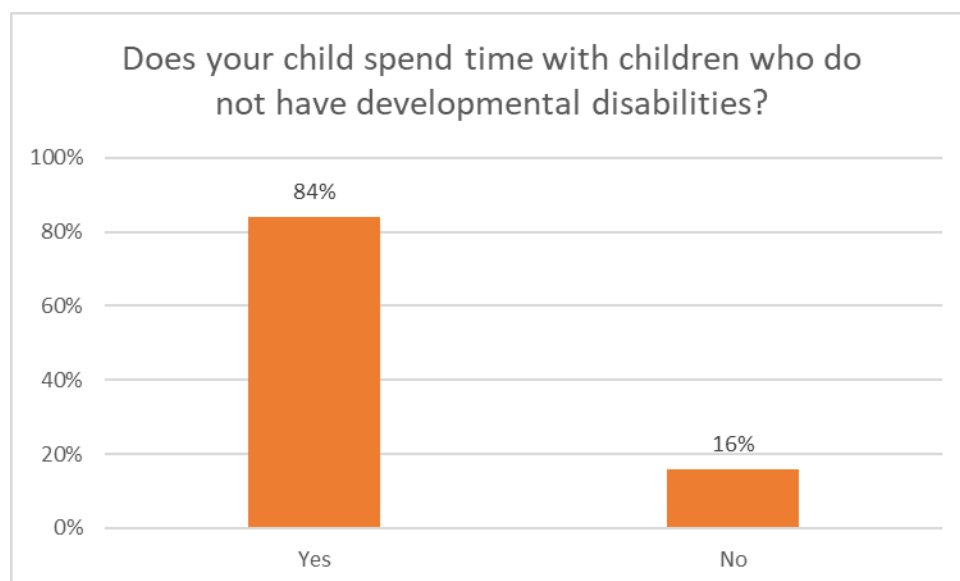


Table Q43. Does your child spend time with children who do not have developmental disabilities?

Significantly Above Average

State	Yes	No	N
SD	93%	7%	213
WI	88%	12%	772

Within Average Range

State	Yes	No	N
MN	86%	14%	388
AZ	85%	15%	185
OR	85%	15%	648
Weighted NCI-IDD Average	84%	16%	4,514
MO	84%	16%	166
TX	84%	16%	1,561
NC	81%	19%	176
CO	80%	20%	248
VA	77%	23%	157

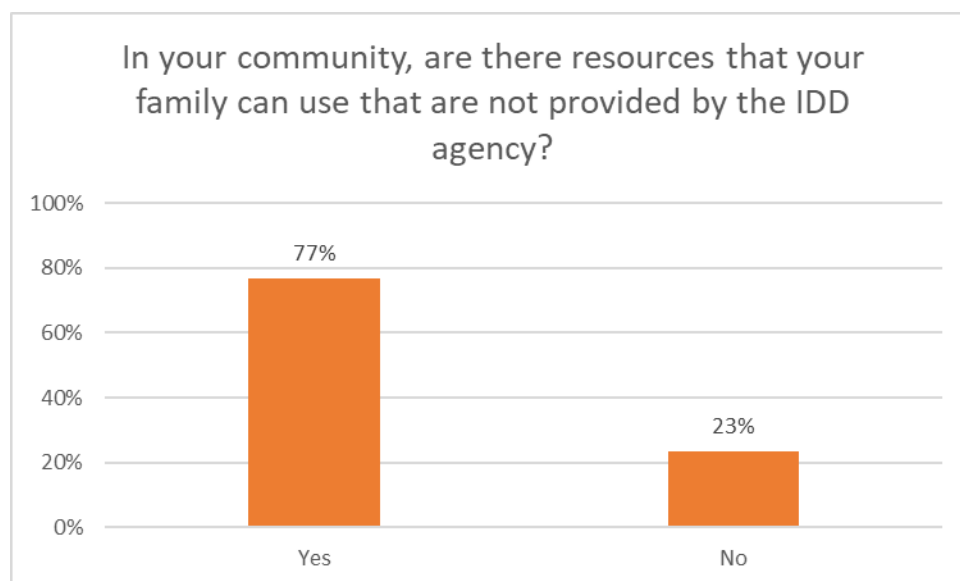


Table Q44. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

Significantly Above Average

State	Yes	No	N
WI	82%	18%	558

Within Average Range

State	Yes	No	N
MO	84%	16%	129
AZ	83%	17%	127
CO	80%	20%	169
SD	80%	20%	165
OR	77%	23%	454
Weighted NCI-IDD Average	77%	23%	3,429
MN	77%	23%	291
NC	76%	24%	140
VA	76%	24%	127

Significantly Below Average

State	Yes	No	N
TX	66%	34%	1,269

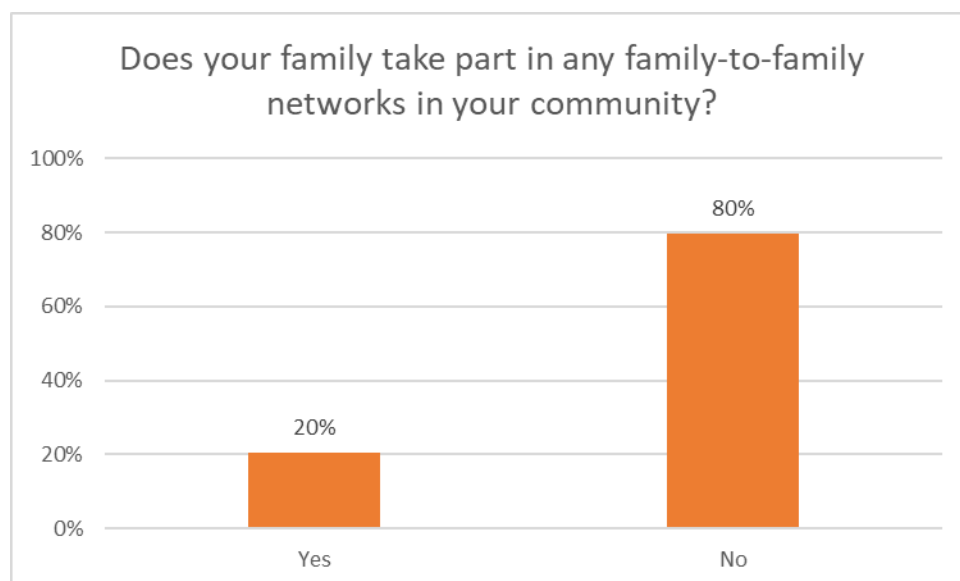


Table Q45. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?

Within Average Range

State	Yes	No	N
MN	24%	76%	325
TX	23%	77%	1,389
CO	23%	77%	226
OR	22%	78%	564
NC	21%	79%	154
Weighted NCI-IDD Average	20%	80%	3,940
WI	19%	81%	650
AZ	18%	82%	161
VA	18%	82%	140
SD	15%	85%	181
MO	13%	87%	150

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.

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

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

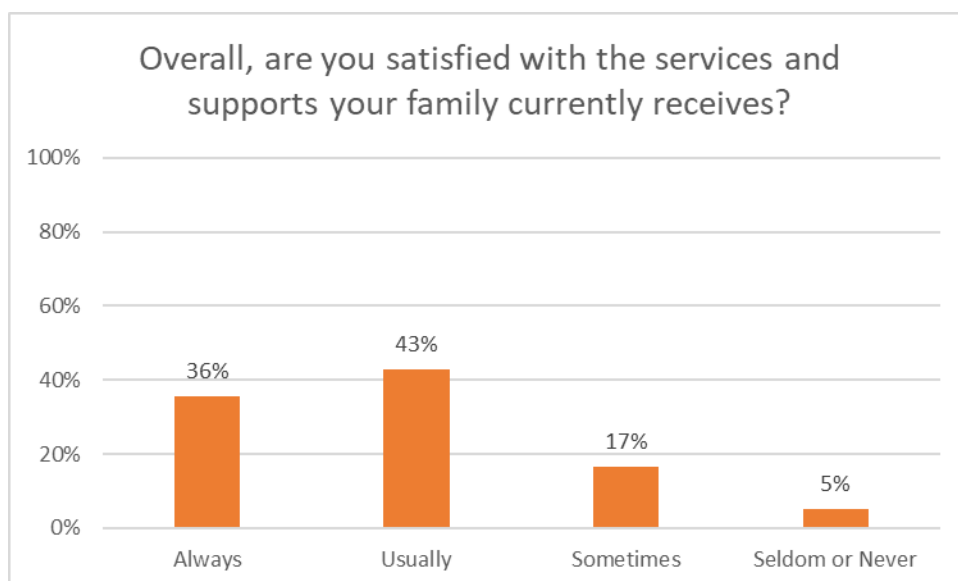


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
TX	50%	27%	18%	5%	1,551
SD	45%	41%	12%	1%	214

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	39%	46%	13%	2%	186
Weighted NCI-IDD Average	36%	43%	17%	5%	4,492
WI	34%	46%	16%	4%	776
NC	27%	46%	17%	9%	169

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	27%	49%	19%	4%	386
OR	27%	55%	15%	4%	644
VA	25%	49%	19%	8%	158
CO	24%	56%	15%	5%	241
MO	22%	47%	23%	9%	167

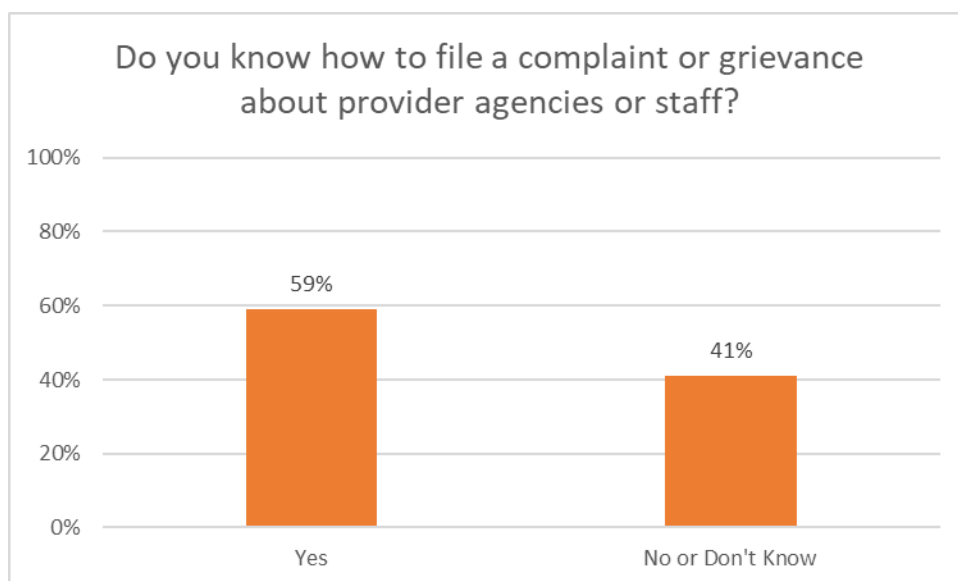


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff? ⁴

Significantly Above Average

State	Yes	No or Don't Know	N
TX	66%	34%	1,565

Within Average Range

State	Yes	No or Don't Know	N
CO	67%	33%	245
SD	65%	35%	213
NC	60%	40%	174
OR	59%	41%	656
Weighted NCI-IDD Average	59%	41%	4,540
WI	58%	42%	780
AZ	55%	45%	186
VA	54%	46%	158

Significantly Below Average

State	Yes	No or Don't Know	N
MN	52%	48%	392
MO	46%	54%	171

⁴ Don't Know' responses were included in 'No' responses for this question.



Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled? ⁵

Significantly Above Average

State	Yes	No	N
TX	71%	29%	403

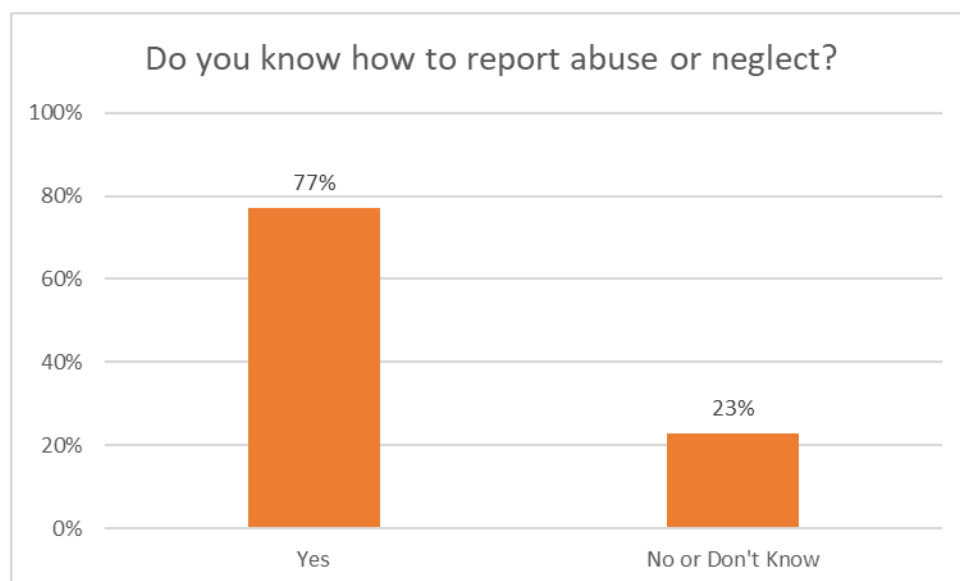
Within Average Range

State	Yes	No	N
WI	64%	36%	33
NC	60%	40%	30
Weighted NCI-IDD Average	60%	40%	629
OR	59%	41%	37
MN	53%	47%	32
VA	50%	50%	26
AZ	36%	64%	22

Significantly Below Average

State	Yes	No	N
CO	22%	78%	23

⁵ The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: MO, SD.

Table Q49. Do you know how to report abuse or neglect? ⁶**Significantly Above Average**

State	Yes	No or Don't Know	N
SD	91%	9%	213
OR	86%	14%	649

Within Average Range

State	Yes	No or Don't Know	N
WI	81%	19%	774
CO	81%	19%	246
TX	80%	20%	1,555
MN	79%	21%	389
NC	78%	22%	172
MO	77%	23%	171
Weighted NCI-IDD Average	77%	23%	4,511
VA	76%	24%	157

Significantly Below Average

State	Yes	No or Don't Know	N
AZ	68%	32%	185

⁶ Don't Know' responses were included in 'No' responses for this question.

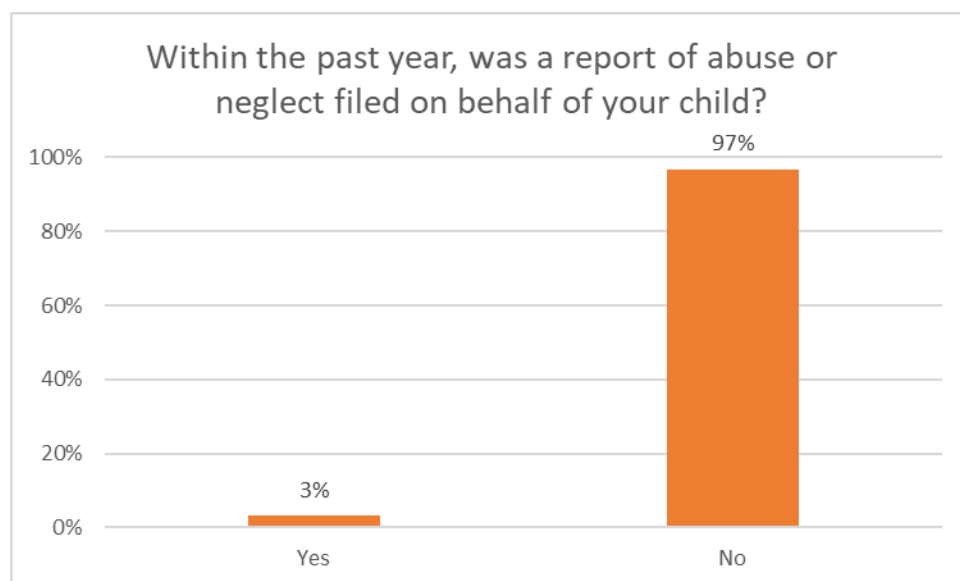


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child?

Within Average Range

State	Yes	No	N
TX	5%	95%	1,532
OR	4%	96%	636
CO	4%	96%	243
MO	4%	96%	168
VA	4%	96%	141
Weighted NCI-IDD Average	3%	97%	4,435
WI	3%	97%	765
NC	2%	98%	172
AZ	2%	98%	185
MN	2%	98%	387

Significantly Below Average

State	Yes	No	N
SD	0%	100%	206

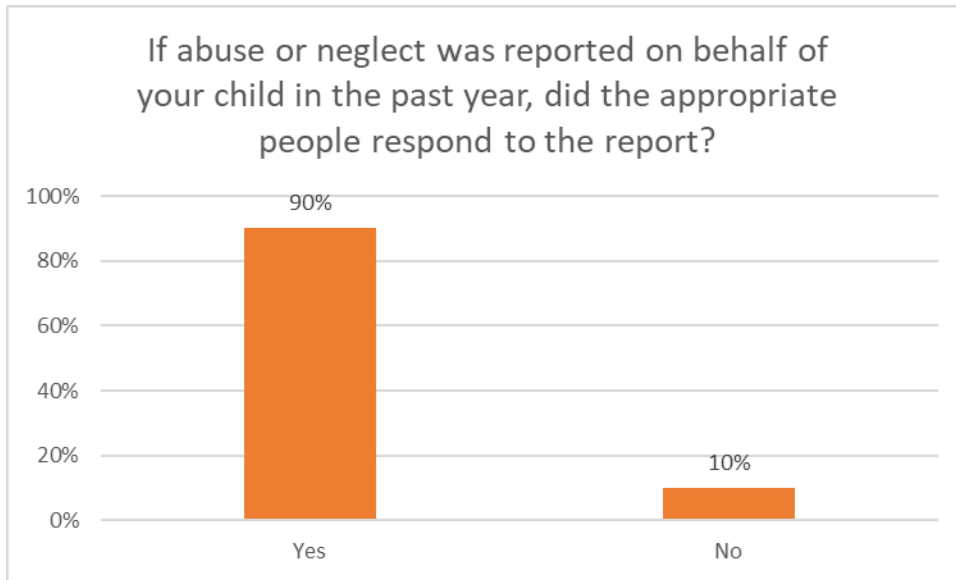


Table Q51. If abuse or neglect was reported on behalf of your child in the past year, did the appropriate people respond to the report? ⁷

Within Average Range

State	Yes	No	N
Weighted NCI-IDD Average	90%	10%	153
OR	88%	12%	26
WI	87%	13%	23
TX	85%	15%	72

⁷ The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: AZ, CO, MN, MO, NC, SD, VA.

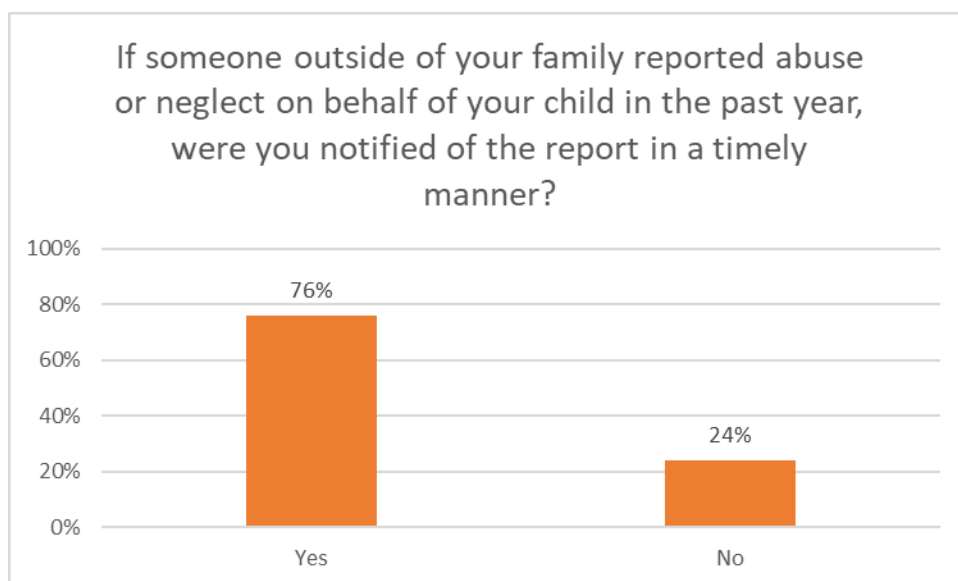


Table Q52. If someone outside of your family reported abuse or neglect on behalf of your child in the past year, were you notified of the report in a timely manner?⁸

Within Average Range

State	Yes	No	N
Weighted NCI-IDD Average	76%	24%	112
OR	74%	26%	23
TX	71%	29%	48

⁸ The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: AZ, CO, MN, MO, NC, SD, VA, WI.

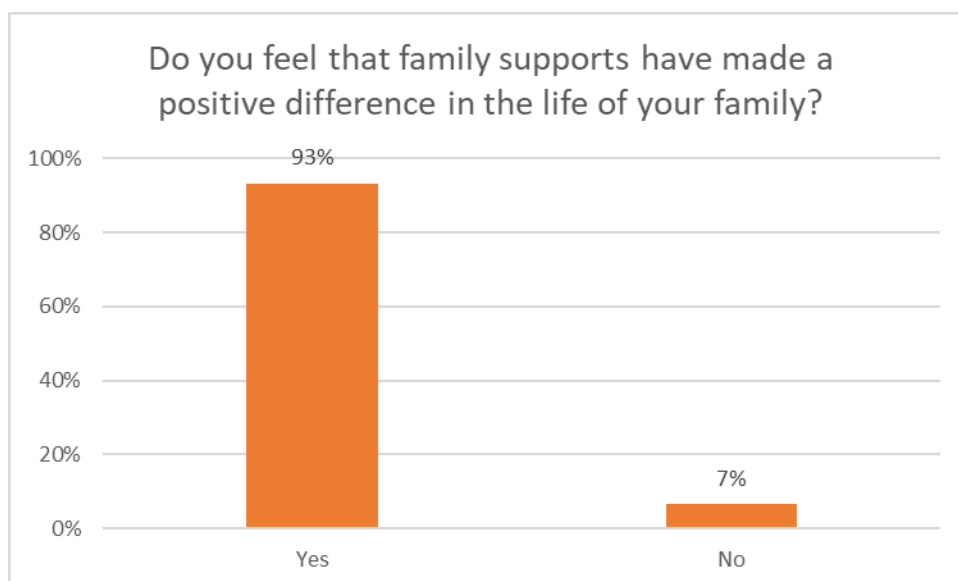


Table Q53. Do you feel that family supports have made a positive difference in the life of your family?

Significantly Above Average

State	Yes	No	N
CO	98%	2%	228
AZ	97%	3%	167
WI	96%	4%	690

Within Average Range

State	Yes	No	N
SD	96%	4%	194
MN	95%	5%	352
NC	95%	5%	147
OR	94%	6%	594
Weighted NCI-IDD Average	93%	7%	4,126
VA	92%	8%	146
MO	88%	12%	138

Significantly Below Average

State	Yes	No	N
TX	86%	14%	1,470

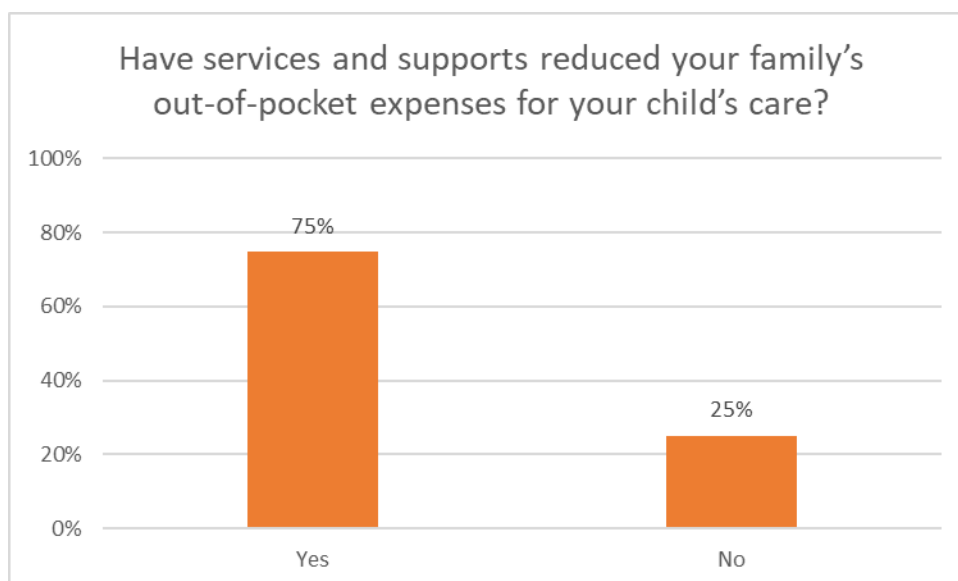


Table Q54. Have services and supports reduced your family's out-of-pocket expenses for your child's care?

Significantly Above Average

State	Yes	No	N
SD	91%	9%	203
CO	90%	10%	230
MN	85%	15%	362
VA	83%	17%	148

Within Average Range

State	Yes	No	N
AZ	82%	18%	173
WI	79%	21%	713
OR	77%	23%	593
Weighted NCI-IDD Average	75%	25%	4,231
TX	69%	31%	1,480
NC	66%	34%	169

Significantly Below Average

State	Yes	No	N
MO	63%	37%	160

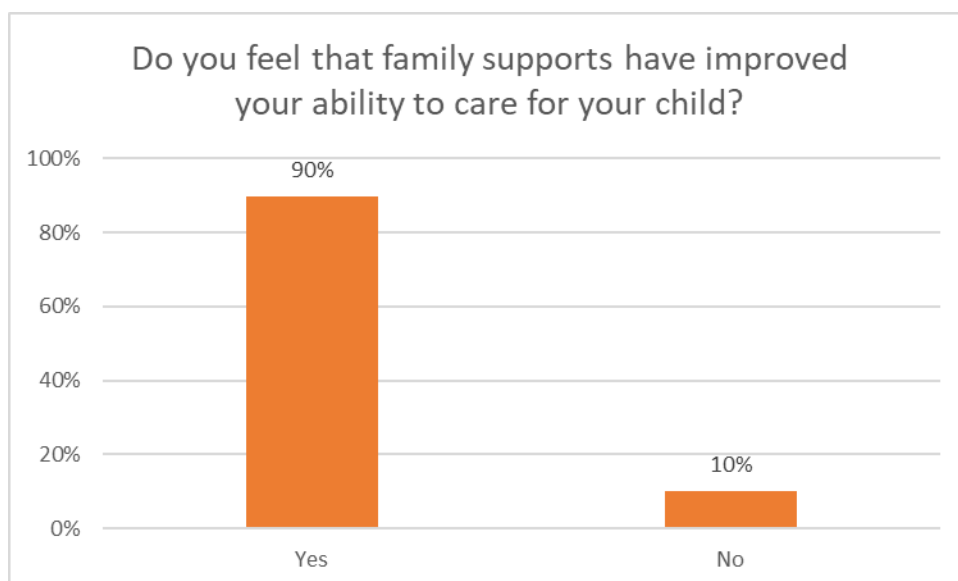


Table Q55. Do you feel that family supports have improved your ability to care for your child?

Significantly Above Average

State	Yes	No	N
CO	97%	3%	228
MN	95%	5%	349

Within Average Range

State	Yes	No	N
AZ	94%	6%	171
OR	92%	8%	591
VA	92%	8%	144
SD	92%	8%	204
WI	91%	9%	693
Weighted NCI-IDD Average	90%	10%	4,184
NC	87%	13%	160
TX	87%	13%	1,491

Significantly Below Average

State	Yes	No	N
MO	78%	22%	153

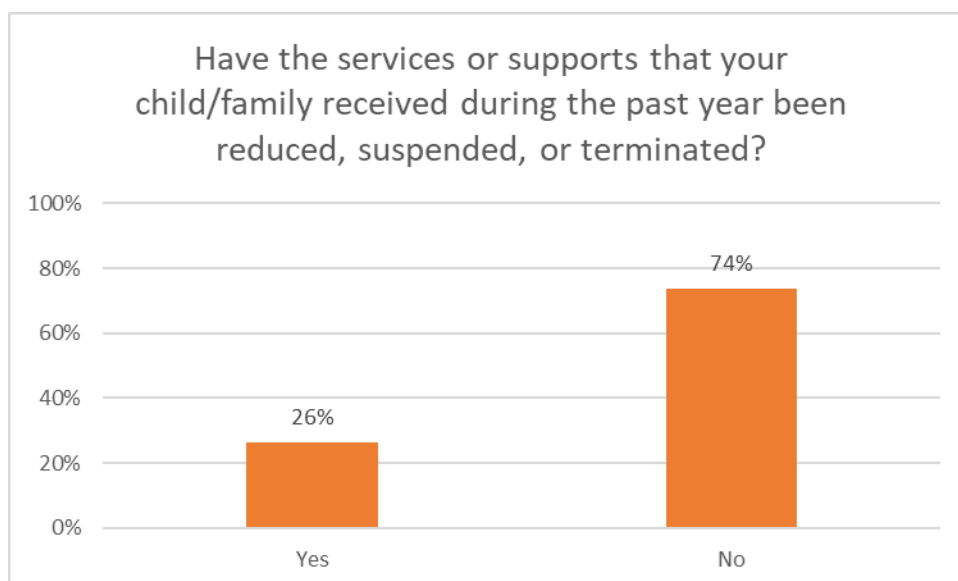


Table Q56. Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?

Significantly Above Average

State	Yes	No	N
CO	37%	63%	233

Within Average Range

State	Yes	No	N
MO	35%	65%	158
VA	28%	72%	147
AZ	27%	73%	176
NC	27%	73%	166
Weighted NCI-IDD Average	26%	74%	4,293
TX	26%	74%	1,502
WI	25%	75%	733
SD	22%	78%	200
MN	21%	79%	374

Significantly Below Average

State	Yes	No	N
OR	20%	80%	604

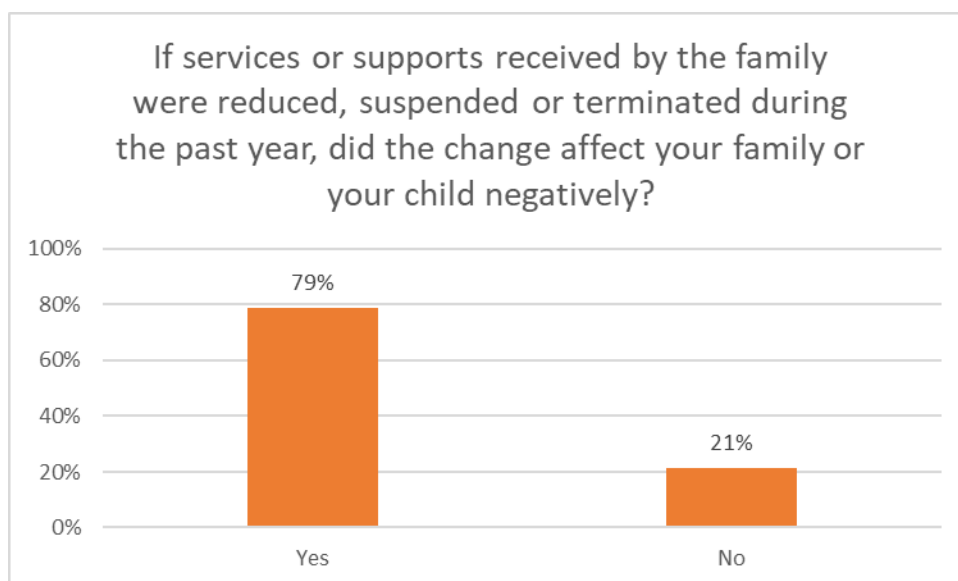


Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change affect your family or your child negatively?

Significantly Above Average

State	Yes	No	N
CO	89%	11%	82

Within Average Range

State	Yes	No	N
OR	86%	14%	106
NC	86%	14%	35
SD	81%	19%	31
VA	80%	20%	35
Weighted NCI-IDD Average	79%	21%	993
TX	77%	23%	376
AZ	77%	23%	43
WI	75%	25%	161
MN	74%	26%	72
MO	73%	27%	52

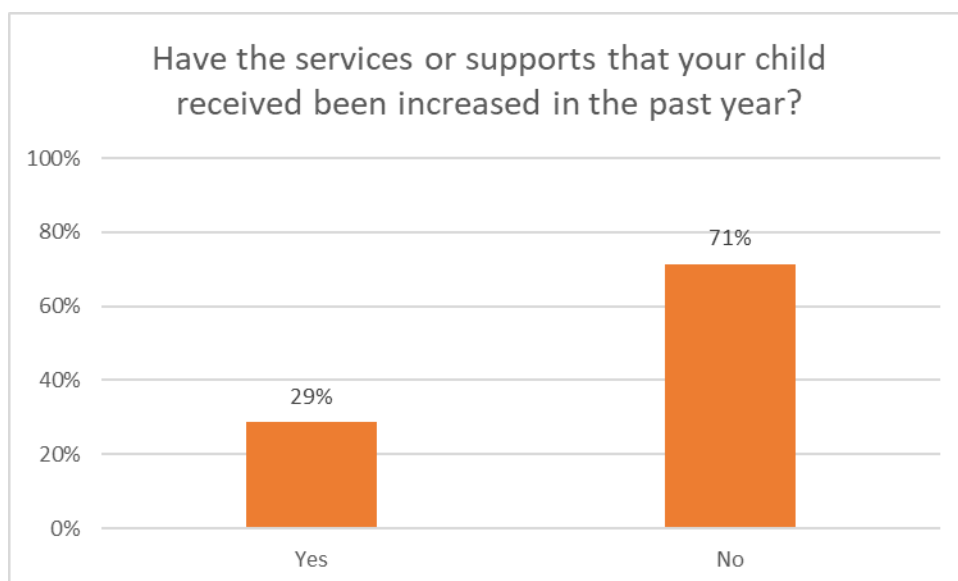


Table Q58. Have the services or supports that your child received been increased in the past year?

Significantly Above Average

State	Yes	No	N
OR	39%	61%	585

Within Average Range

State	Yes	No	N
NC	34%	66%	163
VA	33%	67%	141
WI	32%	68%	706
AZ	29%	71%	167
Weighted NCI-IDD Average	29%	71%	4,178
MN	27%	73%	351
CO	25%	75%	226

Significantly Below Average

State	Yes	No	N
TX	22%	78%	1,499
SD	15%	85%	187
MO	14%	86%	153

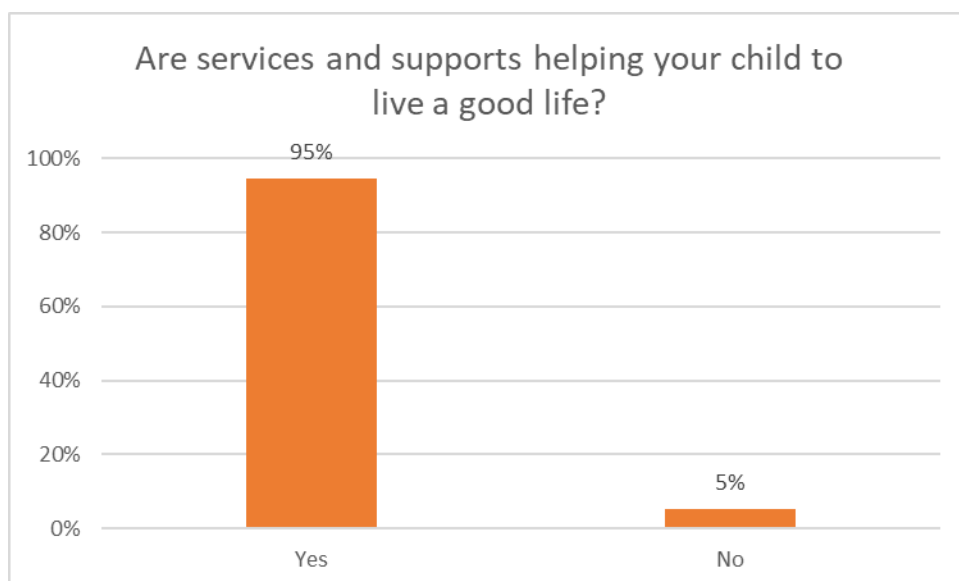


Table Q59. Are services and supports helping your child to live a good life?

Within Average Range

State	Yes	No	N
MN	97%	3%	371
CO	96%	4%	226
WI	96%	4%	710
AZ	95%	5%	177
OR	95%	5%	607
SD	95%	5%	202
Weighted NCI-IDD Average	95%	5%	4,252
TX	94%	6%	1,519
NC	93%	7%	153
VA	91%	9%	142
MO	90%	10%	145

NCI History and Activities

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

Overview of National Core Indicators

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

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

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

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

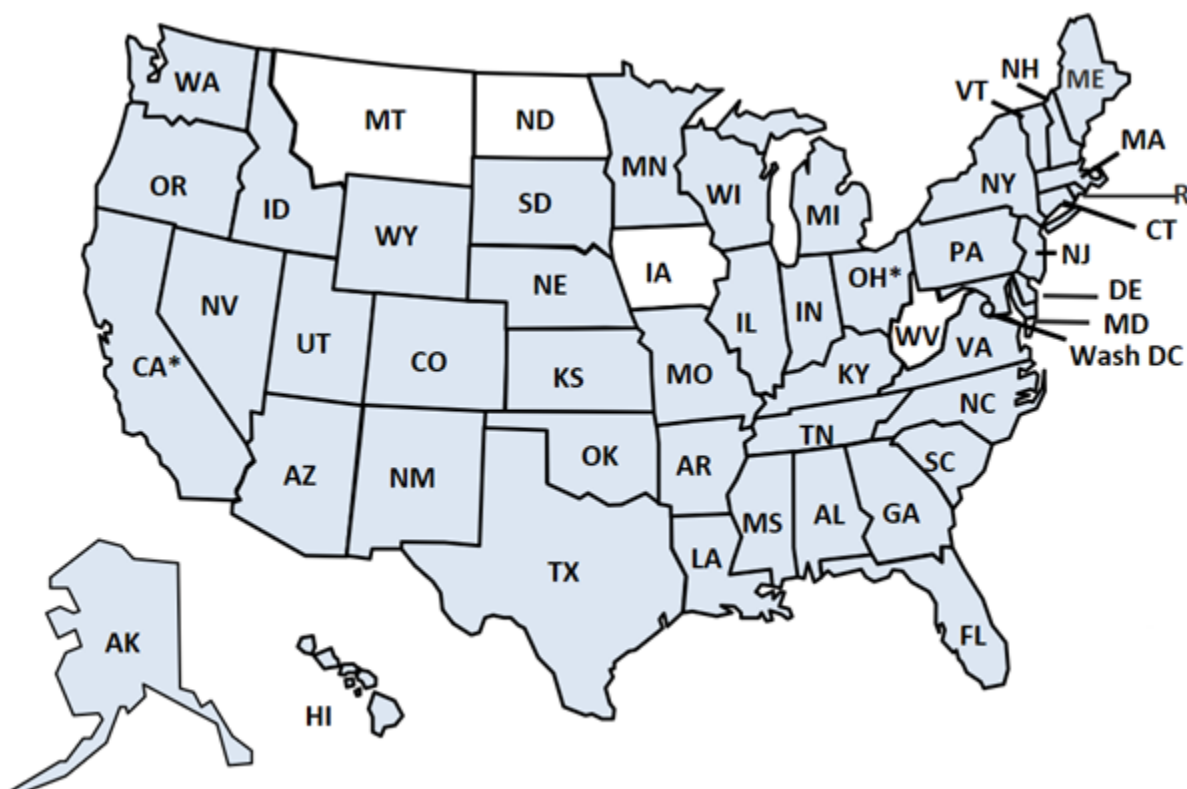
Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI continues to develop and refine the indicators and expand state participation. For more information about NCI states,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

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

State Participation

During the 2020-21 data collection cycle, 46 states, the District of Columbia, and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and the participating states are shown on the map below.

Figure 1. NCI State Participation 2020-21



The Core Indicators

The Core Indicators are the standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern, including employment, respect/rights, service planning, community inclusion, choice, and health and safety. An example of a Core Indicator would be, “The proportion of people who have a paid job in the community.” To see the complete list of Core Indicators, please visit the Indicators page on the NCI website at <https://www.nationalcoreindicators.org/indicators>.

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

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

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

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

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

Sub-Domains and Concern Statements

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

Figure 2. Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

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

For more information on how to use these data for quality improvement, please see this handbook: [Using National Core Indicators for Quality Improvement Initiatives](#).⁹

⁹ Located on the National Core Indicators website: www.nationalcoreindicators.org → Resources → Technical Reports

Caution and Limitations

This report does not provide benchmarks for acceptable or unacceptable levels of performance. Rather, it is up to each state to decide whether its score or percentage is an acceptable performance level. States that fall into the “below average” tier on any scale or indicator are not necessarily underperforming; instead, this placement indicates only that the state’s scale score or indicator percentage is significantly lower than the average of all states—where “significantly” means “not due to chance.” The results tables throughout this report display states’ scores relative to one another and show which states tend to have similar results. Notably, the difference between a “below average” state and the average across the other states may be very small, and it is up to public managers, policy-makers, and other stakeholders to decide whether a state’s result relative to the NCI Average suggests that changes or further investigation are necessary.

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

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

Methodology

This section describes the protocol used by states to select families to participate in the survey, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by NCI Program staff to aggregate and analyze the data.

Sampling & Administration

States were asked to administer the Child Family Survey by selecting a random sample of at least 1,000 families who:

1. Had a child¹⁰ with a developmental disability living at home; and
2. Received at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys. A total of eight states had at least a portion of surveys completed via direct entry for the 2019-20 data collection cycle.¹¹

A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.¹²

Weighting

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

¹⁰ A Child Family Survey could be completed for an individual up to 22 years if still receiving “child” services.

¹¹ States that used the direct entry or mail and direct entry options were:

¹² See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

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

Significance Testing

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

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

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

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, and significantly below the NCI Average.

Technical Details

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

Data Entry and Analysis

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

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

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

Statistical significance testing was conducted on each state's “yes” or “always” response compared to the NCI average¹³; 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 2020-21, ten states administered the Child Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% margin of error; their data are included in this report. The following table shows the number of surveys each state sent, surveys returned, response rates, and the number of valid surveys accepted for inclusion in data analysis.

¹³ The NCI Average is a weighted average. Please see the section “Weighting” for more details.

Child Family Survey: State Response Rates ¹⁴

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	17,268	1,400	188	13.4%	7.11%	100%	0%
CO	2,255	2,195	254	11.6%	5.79%	59%	41%
MN	3,928	1,600	404	25.3%	4.62%	76%	24%
MO	3,546	1,500	174	11.6%	7.25%	77%	23%
NC	14,638	1,200	176	14.7%	7.34%	84%	16%
OR	4,809	4,809	667	13.9%	3.52%	89%	11%
SD	811	811	215	26.5%	5.73%	100%	0%
TX	17,349	11,830	1650	13.9%	2.30%	95%	5%
VA	942	942	159	16.9%	7.09%	100%	0%
WI	11,004	10,927	806	7.4%	3.32%	62%	38%
Total	76,550	37,214	4,693	15.5%	5.41%	84%	16%

¹⁴ 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.