

Child Family Survey

2019-20 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

January 2021

Reposted 2/14: updated Executive Summary format

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

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	3
Table 4a. Child's Disabilities	4
Table 4b. Child's Disabilities (continued)	4
Table 5a. Child's Health Conditions	4
Table 5b. Child's Health Conditions (continued)	5
Table 6. Child's Race and Ethnicity	5
Table 7. Child's Preferred Means of Communication	5
Table 8. Child's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors.....	6
Table 9. Child's Level of Help Needed With Personal Care Activities.....	6
Respondents	7
Table 10. Language usually spoken at home	8
Table 11. Respondent's Age	8
Table 12. Respondent's Health	8
Table 13. Respondent's Relationship to Child.....	9
Table 14. Respondent or Other Family Member Provides Paid Support to Child.....	9
Table 15. Number of Adults in Household	9
Table 16. Number of Children in Household (including child receiving services about whom survey is being completed)	10
Table 17. Respondent's Highest Level of Education	10
Table 18. Total Taxable Household Income of Wage Earners in the Past Year	10
Table 19. Residential Designation (Urban, Rural, or Suburban)	11
Services and Supports Received.....	12
Table 20. Services and Supports Received From IDD Agency	13
Table 21. Other Services or Supports Received.....	13
Child Family Survey Results	14
Information and Planning.....	15
Table Q1. Do you get enough information to take part in planning services for your child?	16
Table Q2. Is the information you get about services and supports easy to understand?	17
Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?	18
Table Q4. Do you have enough information about other public services for which your family is eligible?.....	19
Table Q5. Do you need help planning for your child's future with respect to any of the following?	20
Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?	21
Table Q7. Does your child have a service plan?	22
Table Q8. Does the plan include all the services and supports your child needs?	23
Table Q9. Does your child receive all of the services listed in the plan?	24
Table Q10. Did you or another family member help make the plan?	25
Table Q11. Did your child help make the plan?	26
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?.....	27
Table Q13. Does your child have a transition plan (as part of an IEP or Section 504 plan through his/her high school, usually starting at age 14)?	28
Table Q14. If your child has a transition plan, did you help make the plan?.....	29
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?	30
Access and Delivery of Services and Supports	31

Table Q16. Are you able to contact your child’s support workers when you want?.....	32
Table Q17. Are you able to contact your child’s case manager/service coordinator when you want?.....	33
Table Q18. Do support workers come and go when they are supposed to?.....	34
Table Q19. Do services and supports change when your family’s needs change?.....	35
Table Q20. Do support workers speak to you in a way that you understand?.....	36
Table Q21. Are services delivered in a way that is respectful of your family’s culture?.....	37
Table Q22. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?.....	38
Table Q23. Do support workers have the right information and skills to meet your family’s needs?.....	39
Table Q24. Does your child have the special equipment or accommodations that s/he needs?.....	40
Table Q25. Can your child see health professionals when needed?.....	41
Table Q26. Does your child’s primary care doctor understand his/her needs related to his/her disability?.....	42
Table Q27. Can your child go to the dentist when needed?.....	43
Table Q28. Does your child’s dentist understand your child’s needs related to his/her disability?.....	44
Table Q29. If your child takes medications, do you know what they’re for?.....	45
Table Q30. Do you know when your child should take the medication, how much to take, and the potential side effects?.....	46
Table Q31. If your child uses mental health services, does the mental health professional understand your child’s needs related to his/her disability?.....	47
Table Q32. If you need respite services, are you able to get them?.....	48
Table Q33. If you have used respite services in the past year, were you satisfied with the quality of the respite providers?.....	49
Table Q34. Does your family get the supports and services it needs?.....	50
Table Q35. If family does not get the support and services needed, what additional services does your family need?.....	51
Choice, Decision Making and Control.....	52
Table Q36. Can your family choose or change the agency that provides your child’s services?.....	53
Table Q37. Can your family choose or change your child’s support workers?.....	54
Table Q38. Does your family manage support workers?.....	55
Table Q39. Do service providers for your child work together to provide support?.....	56
Table Q40. Did you, your child, or someone else in your family choose your child’s case manager/service coordinator?.....	57
Involvement in the Community.....	58
Table Q41. Does your child take part in activities in the community?.....	59
Table Q42. For your child, what makes it hard to take part in activities in the community?.....	60
Table Q43. Does your child spend time with children who do not have developmental disabilities?.....	61
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.)?.....	62
Table Q45. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?.....	63
Satisfaction With Services and Supports.....	64
Table Q46. Overall, are you satisfied with the services and supports your family currently receives?.....	65
Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?.....	66
Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?.....	67
Table Q49. Do you know how to report abuse or neglect?.....	68
Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child?.....	69
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?.....	70
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?.....	71
Table Q53. Do you feel that family supports have made a positive difference in the life of your family?.....	72
Table Q54. Have services and supports reduced your family’s out-of-pocket expenses for your child’s care?.....	73
Table Q55. Do you feel that family supports have improved your ability to care for your child?.....	74
Table Q56. Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?.....	75
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?.....	76
Table Q58. Have the services or supports that your child received been increased in the past year?.....	77
Table Q59. Are services and supports helping your child to live a good life?.....	78
NCI History and Activities.....	79
Overview of National Core Indicators.....	80
State Participation.....	81

Figure 1. NCI State Participation 2018-19	81
The Core Indicators	81
Sub-Domains and Concern Statements	82
Figure 2. Family Survey Sub-Domains and Concern Statements	83
How NCI Data Are Used	83
Caution and Limitations	84
Methodology	85
Sampling & Administration	86
Weighting.....	86
Significance Testing.....	87
Technical Details.....	88
Data Entry and Analysis.....	88
Response Rates.....	88
Child Family Survey: State Response Rates	89

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 2019-20 data collection cycle, eight states submitted a valid sample of Child Family Survey data: Arizona (AZ), Colorado (CO), Louisiana (LA), Missouri (MO), North Carolina (NC), Oregon (OR), Utah (UT), and Wisconsin (WI). This Final Report provides a summary of results based on data submitted by June 30, 2020.

Important note on Impact of COVID-19

The 2019-20 NCI Family Survey data collection cycle began July 1, 2019 and ended June 30, 2020. Midway through data collection, in February 2020, COVID-19 began to spread across the United States. Data collection for the NCI Family Surveys ***continued throughout the pandemic***. States begin data collection at various times throughout the year – some before the pandemic started and some after. Because the family surveys do not collect information on the date of survey completion, we cannot fully assess what impact the pandemic had on data collected at different times throughout the year. Additionally, we cannot determine whether the onset of COVID-19 impacted state samples. For instance, we do not know if certain populations were more or less likely to respond to the survey after February and we do not know whether or how responses were affected for specific questions for those who completed the survey after the pandemic began. While these data will serve as an important baseline, and meaningful way for states to understand

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

the overall impact of services on families of individuals being served, these data should be read with caution.

The following are NCI national averages for a selection of survey items. Complete breakouts by state for each item in the Child Family Survey can be found in the Results section of this report.

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....

12%
are under
age 35



22%
say they or a
family member
provide paid
support to child



28%
always use respite
when the services
are needed



24%
reported an annual household
income of \$25K or less



78%
reported services and
supports reduced out-of-
pocket expenses related to
care for their child

Child with IDD....

67%
are male



12
average age



82%
take part in community
activities



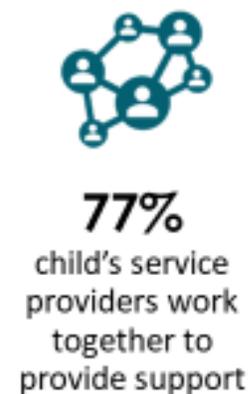
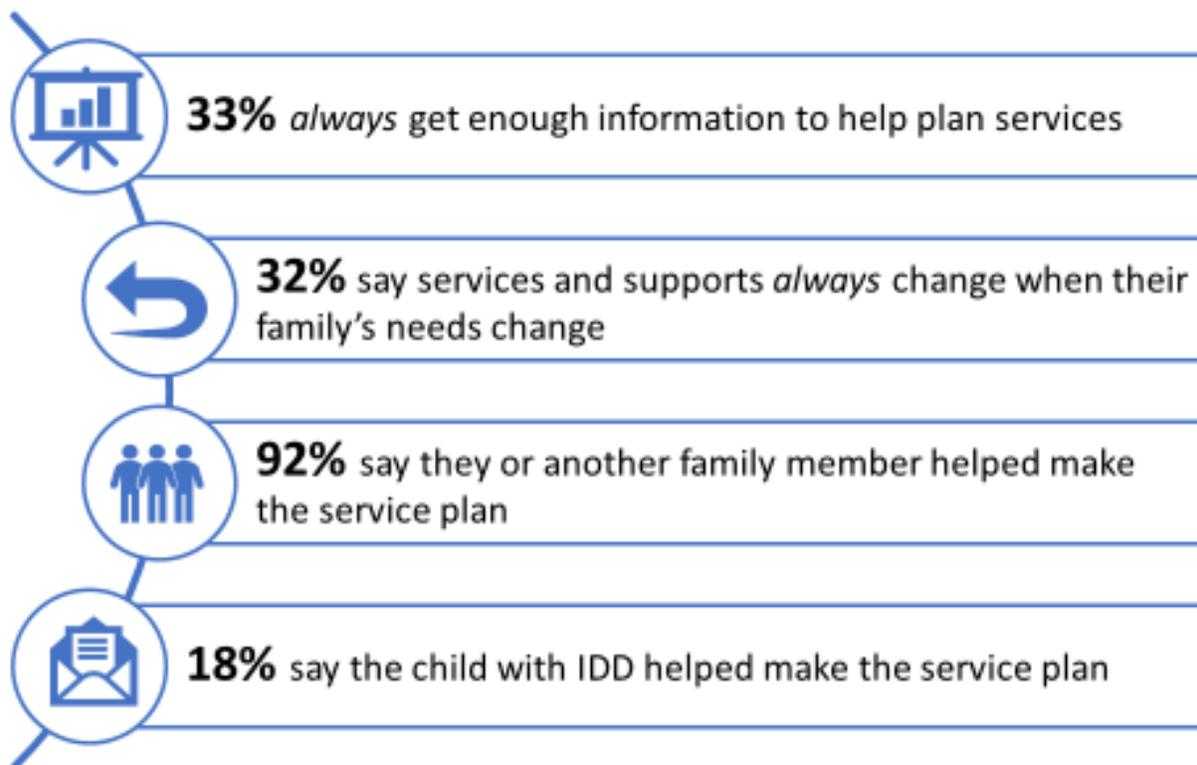
87%
spend time with children
without DD



81%
have resources in the
community the family
can use



20%
take part in family-to-
family networks



Results

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

Presentation of Data

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

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

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

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

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

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

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

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

Demographics

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

Child

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

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

State	Yes	No	N
AZ	18%	82%	159
CO	26%	74%	280
LA	21%	79%	194
MO	27%	73%	223
NC	22%	78%	190
OR	24%	76%	691
UT	27%	73%	196
WI	19%	81%	1,016
Weighted NCI Average	21%	79%	2,949

Table 2. Child's Age

State	Age	N
AZ	11.2	162
CO	11.0	291
LA	9.2	198
MO	11.9	230
NC	15.0	195
OR	11.9	703
UT	13.3	203
WI	10.1	1,053
Weighted NCI Average	12.0	3,035

Table 3. Child's Gender

State	Male	Female	N
AZ	68%	32%	160
CO	63%	37%	291
LA	63%	37%	198
MO	78%	22%	230
NC	66%	34%	194
OR	65%	35%	693
UT	71%	29%	204
WI	65%	35%	1,018
Weighted NCI Average	67%	33%	2,988

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	39%	13%	61%	15%	7%	4%
CO	66%	26%	58%	19%	18%	10%
LA	37%	13%	36%	10%	7%	6%
MO	33%	31%	88%	6%	4%	1%
NC	65%	22%	63%	22%	9%	4%
OR	53%	25%	51%	12%	7%	6%
UT	64%	32%	60%	15%	9%	5%
WI	45%	20%	48%	11%	7%	5%
Weighted NCI Average	49%	19%	58%	15%	8%	5%

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	6%	10%	1%	15%	1%	1%	22%
CO	15%	39%	1%	8%	0%	3%	37%
LA	7%	20%	1%	15%	0%	3%	33%
MO	2%	17%	0%	3%	0%	1%	29%
NC	8%	27%	1%	10%	2%	2%	28%
OR	8%	18%	1%	15%	1%	7%	24%
UT	10%	27%	0%	18%	0%	3%	22%
WI	8%	22%	0%	15%	0%	1%	35%
Weighted NCI Average	7%	20%	0%	13%	1%	2%	28%

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	25%	4%	2%	5%	9%
CO	13%	2%	1%	5%	2%
LA	15%	7%	8%	10%	3%
MO	10%	1%	6%	6%	4%
NC	18%	8%	1%	6%	8%
OR	12%	5%	3%	3%	6%
UT	16%	2%	0%	6%	3%
WI	18%	3%	3%	8%	5%
Weighted NCI Average	18%	5%	3%	6%	7%

Due to the COVID-19 pandemic and its impact to NCI data collection and sampling processes, we caution against using 2019-20 data to directly compare with past and future NCI data.
Child Family Survey Final Report: 2019-20 | 4

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	25%	0%	7%	24%	42%
CO	37%	1%	19%	45%	33%
LA	18%	1%	11%	19%	45%
MO	20%	0%	8%	28%	41%
NC	26%	1%	13%	23%	39%
OR	27%	1%	14%	36%	40%
UT	21%	2%	16%	45%	24%
WI	19%	1%	11%	23%	47%
Weighted NCI Average	24%	1%	11%	25%	41%

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	4%	8%	9%	1%	61%	38%	1%
CO	3%	9%	10%	1%	80%	14%	1%
LA	1%	4%	34%	1%	61%	6%	2%
MO	4%	5%	12%	1%	85%	4%	2%
NC	3%	2%	20%	0%	70%	11%	2%
OR	3%	8%	5%	1%	81%	16%	2%
UT	0%	4%	2%	1%	87%	14%	0%
WI	3%	4%	9%	0%	85%	7%	2%
Weighted NCI Average	3%	5%	13%	0%	72%	18%	1%

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	77%	16%	1%	4%	2%	163
CO	56%	20%	4%	11%	8%	284
LA	61%	26%	5%	3%	5%	191
MO	80%	10%	1%	7%	2%	216
NC	66%	23%	3%	3%	4%	190
OR	69%	18%	2%	7%	4%	699
UT	58%	23%	3%	4%	12%	204
WI	64%	22%	3%	6%	5%	1,036
Weighted NCI Average	69%	20%	3%	5%	4%	2,983

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	39%	44%	17%	162
CO	17%	25%	58%	281
LA	45%	34%	21%	192
MO	32%	50%	18%	223
NC	26%	44%	30%	193
OR	25%	46%	29%	689
UT	17%	40%	42%	201
WI	42%	38%	20%	1,017
Weighted NCI Average	34%	42%	24%	2,958

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	7%	45%	48%	164
CO	1%	14%	85%	287
LA	7%	42%	52%	195
MO	16%	49%	34%	227
NC	5%	37%	58%	193
OR	5%	42%	54%	699
UT	5%	30%	65%	205
WI	6%	44%	50%	1,034
Weighted NCI Average	7%	41%	52%	3,004

Respondents

This section provides demographic information about the respondent.

Table 10. Language usually spoken at home

State	English	Spanish	Other	N
AZ	85%	12%	3%	165
CO	97%	1%	2%	288
LA	97%	1%	2%	197
MO	97%	2%	1%	229
NC	97%	3%	0%	194
OR	88%	7%	6%	704
UT	91%	4%	5%	204
WI	96%	2%	2%	1,042
Weighted NCI Average	92%	6%	2%	3,023

Table 11. Respondent's Age

State	Under 35	35-54	55-74	75 and Older	N
AZ	13%	73%	12%	2%	166
CO	10%	74%	16%	0%	289
LA	25%	56%	16%	3%	197
MO	14%	76%	10%	0%	229
NC	3%	71%	25%	1%	194
OR	8%	73%	18%	1%	705
UT	7%	80%	12%	0%	205
WI	18%	69%	12%	0%	1,049
Weighted NCI Average	12%	71%	16%	1%	3,034

Table 12. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
AZ	23%	46%	27%	3%	166
CO	22%	45%	30%	3%	292
LA	23%	42%	32%	4%	197
MO	17%	49%	29%	5%	230
NC	16%	52%	28%	4%	193
OR	20%	47%	30%	3%	708
UT	25%	40%	29%	5%	204
WI	19%	51%	27%	2%	1,052
Weighted NCI Average	20%	48%	28%	3%	3,042

Table 13. Respondent's Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
AZ	95%	1%	5%	0%	166
CO	97%	0%	3%	0%	291
LA	89%	1%	7%	3%	198
MO	99%	0%	0%	0%	229
NC	90%	0%	7%	3%	194
OR	92%	0%	6%	2%	712
UT	96%	0%	2%	2%	206
WI	95%	0%	4%	1%	1,045
Weighted NCI Average	93%	0%	5%	1%	3,041

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

Responses to this question might have been impacted by the COVID-19 pandemic.

State	Respondent	Other Family Member	No	N
AZ	8%	14%	80%	162
CO	56%	15%	35%	290
LA	9%	14%	77%	195
MO	3%	12%	85%	229
NC	3%	10%	87%	194
OR	6%	28%	66%	703
UT	3%	32%	66%	205
WI	8%	12%	80%	1,034
Weighted NCI Average	8%	14%	79%	3,012

Table 15. Number of Adults in Household

State	One	Two	Three	Four or More	N
AZ	14%	55%	22%	8%	166
CO	15%	65%	17%	3%	289
LA	24%	56%	14%	6%	195
MO	25%	58%	13%	4%	227
NC	23%	57%	15%	5%	192
OR	16%	59%	18%	7%	707
UT	9%	70%	15%	6%	206
WI	16%	65%	13%	6%	1,042
Weighted NCI Average	18%	59%	17%	6%	3,024

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	38%	34%	20%	8%	154
CO	31%	41%	17%	11%	288
LA	41%	37%	15%	7%	189
MO	35%	42%	17%	7%	223
NC	51%	31%	11%	7%	181
OR	37%	39%	15%	9%	686
UT	28%	27%	22%	23%	204
WI	38%	37%	16%	9%	1,004
Weighted NCI Average	40%	35%	16%	8%	2,929

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	8%	15%	7%	19%	52%	165
CO	0%	5%	8%	15%	70%	291
LA	13%	21%	7%	19%	40%	197
MO	4%	13%	8%	19%	57%	227
NC	6%	17%	6%	23%	48%	192
OR	8%	12%	6%	20%	54%	697
UT	3%	12%	4%	26%	55%	205
WI	4%	13%	11%	19%	54%	1,043
Weighted NCI Average	6%	14%	7%	20%	52%	3,017

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	7%	7%	10%	17%	14%	30%	15%	165
CO	1%	3%	5%	13%	21%	39%	17%	288
LA	10%	14%	7%	15%	15%	26%	13%	191
MO	8%	6%	8%	22%	20%	25%	11%	226
NC	10%	9%	9%	17%	12%	28%	15%	193
OR	7%	6%	10%	17%	15%	32%	13%	699
UT	3%	3%	8%	13%	15%	44%	13%	204
WI	5%	7%	7%	17%	18%	36%	10%	1,041
Weighted NCI Average	7%	8%	9%	17%	15%	31%	14%	3,007

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

State	Urban or Suburban	Rural	N
AZ	85%	15%	157
CO	86%	14%	287
LA	56%	44%	181
MO	72%	28%	227
NC	51%	49%	186
OR	76%	24%	688
UT	79%	22%	200
WI	67%	33%	1,018
Weighted NCI Average	69%	31%	2,944

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. Responses to this question might have been impacted by the COVID-19 pandemic.

State	Financial Support	Out-of-home Respite	Early Intervention	Transportation	Other	Self-direction or Fiscal Intermediary Services
AZ	10%	41%	12%	20%	84%	31%
CO	33%	45%	12%	17%	92%	37%
LA	14%	13%	37%	24%	69%	35%
MO	30%	27%	5%	17%	77%	28%
NC	11%	49%	0%	29%	68%	29%
OR	20%	44%	6%	22%	68%	62%
UT	10%	61%	2%	31%	64%	81%
WI	34%	35%	23%	18%	74%	33%
Weighted NCI Average	18%	40%	12%	22%	75%	34%

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. Responses to this question might have been impacted by the COVID-19 pandemic.

State	Social Security Payments (SSI/SSB)	Services or Supports from Other Agencies or Organizations
AZ	39%	68%
CO	24%	75%
LA	39%	44%
MO	35%	79%
NC	47%	66%
OR	35%	72%
UT	27%	76%
WI	31%	70%
Weighted NCI Average	38%	68%

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.

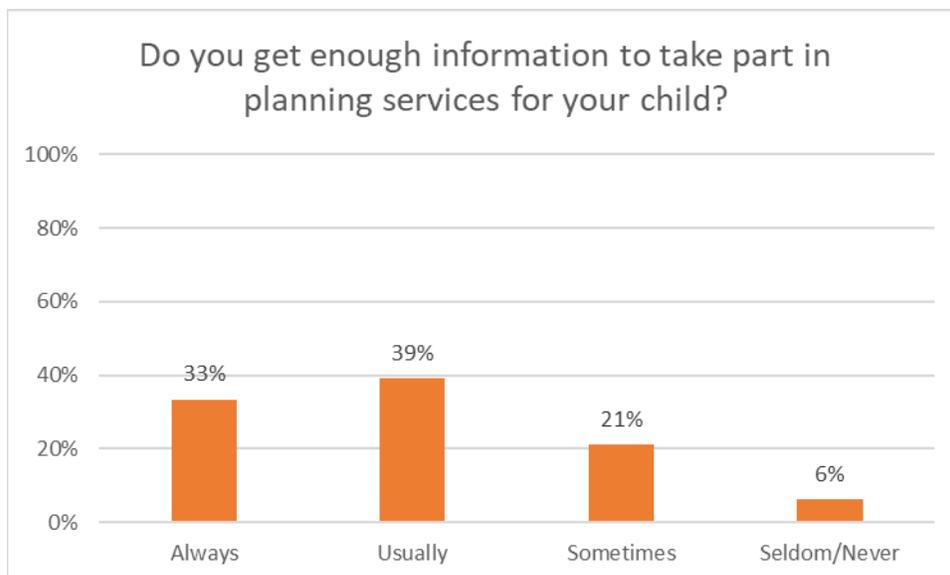


Table Q1. Do you get enough information to take part in planning services for your child?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	38%	29%	23%	10%	170
AZ	36%	36%	23%	5%	160
WI	35%	44%	17%	4%	1,022
Weight NCI Average	33%	39%	21%	6%	2,918
OR	33%	47%	17%	3%	680
UT	32%	47%	16%	5%	198
NC	31%	36%	23%	10%	184
CO	31%	46%	18%	5%	281

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	23%	47%	23%	7%	223

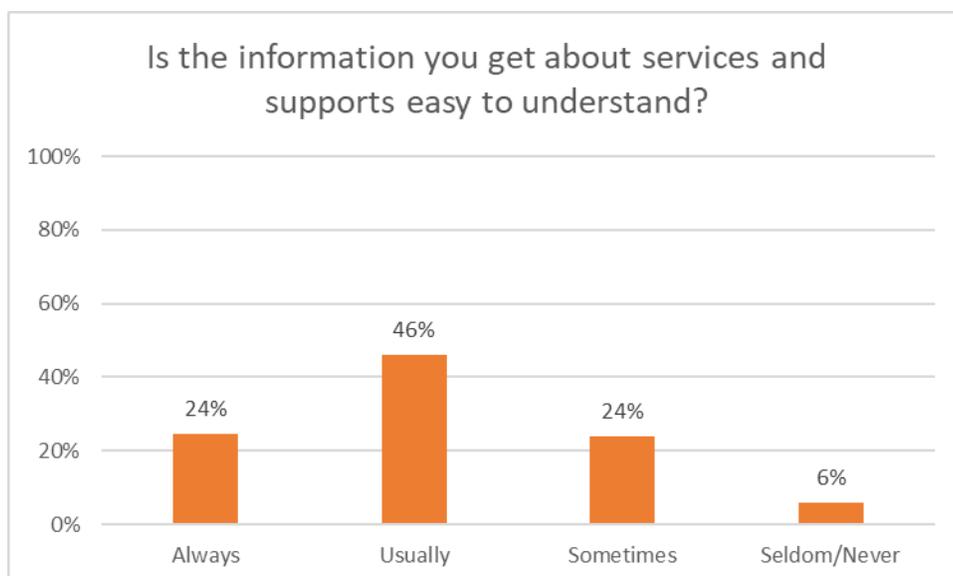


Table Q2. Is the information you get about services and supports easy to understand?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	29%	35%	30%	6%	175
WI	27%	47%	23%	4%	1,026
AZ	26%	50%	20%	4%	163
OR	25%	49%	22%	4%	694
Weight NCI Average	24%	46%	24%	6%	2,940
MO	23%	50%	24%	3%	219
NC	20%	41%	28%	10%	182
CO	19%	46%	28%	6%	279

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	14%	51%	30%	4%	202

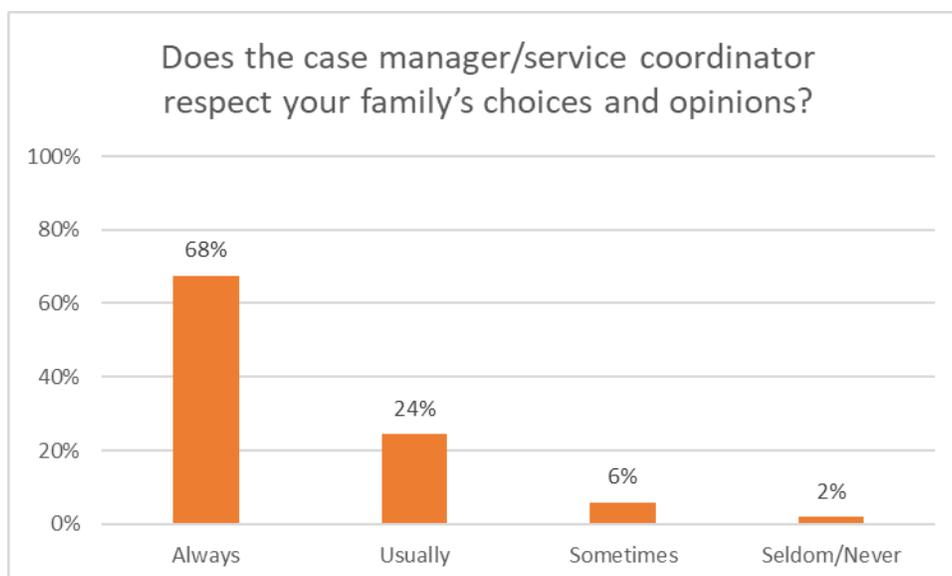


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	87%	11%	1%	0%	202
OR	75%	19%	5%	1%	684
WI	73%	22%	3%	1%	1,009

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	70%	21%	6%	2%	177
AZ	70%	24%	5%	1%	160
Weight NCI Average	68%	24%	6%	2%	2,906
CO	65%	28%	5%	3%	280
MO	64%	29%	5%	2%	217

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	57%	29%	10%	4%	177

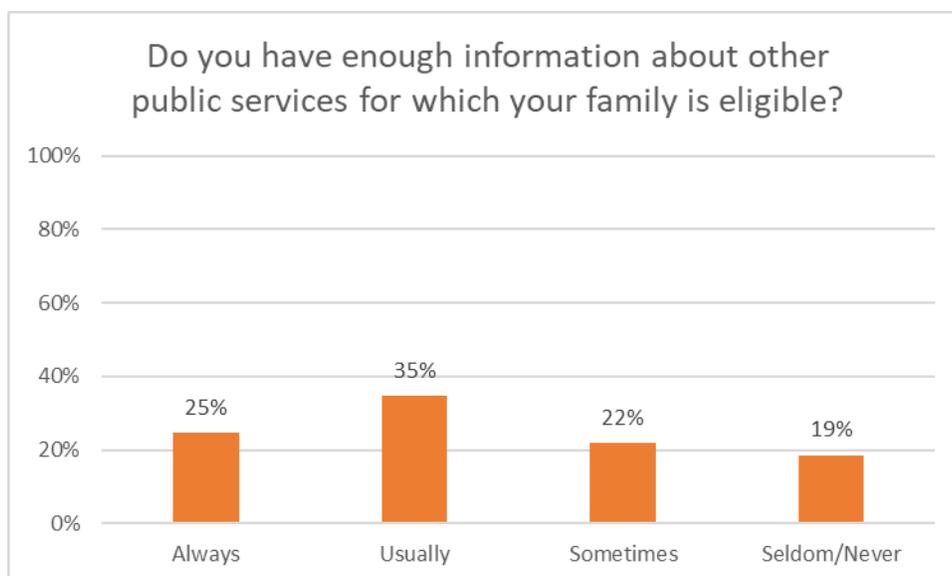


Table Q4. Do you have enough information about other public services for which your family is eligible?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	27%	31%	22%	20%	134
WI	27%	39%	21%	13%	826
OR	26%	40%	22%	12%	579
MO	26%	32%	22%	21%	180
Weight NCI Average	25%	35%	22%	19%	2,426
LA	24%	33%	18%	24%	152
UT	24%	36%	22%	18%	155
NC	21%	35%	23%	22%	158
CO	20%	36%	26%	17%	242

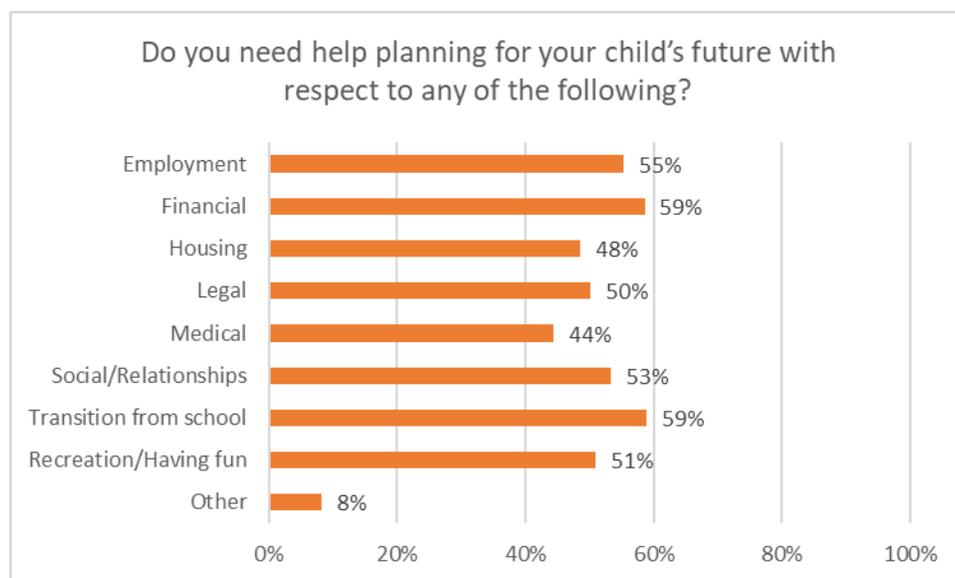


Table Q5. Do you need help planning for your child's future with respect to any of the following?

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	53%	59%	46%	51%	45%	54%	52%	52%	6%
CO	53%	67%	58%	67%	56%	57%	64%	62%	7%
LA	45%	54%	42%	44%	43%	45%	54%	48%	14%
MO	66%	58%	50%	51%	45%	61%	63%	48%	9%
NC	60%	57%	50%	52%	40%	51%	66%	48%	10%
OR	60%	58%	54%	48%	48%	58%	63%	53%	7%
UT	57%	66%	53%	65%	51%	51%	72%	63%	10%
WI	50%	58%	48%	44%	46%	53%	55%	52%	8%
Weight NCI Average	55%	59%	48%	50%	44%	53%	59%	51%	8%

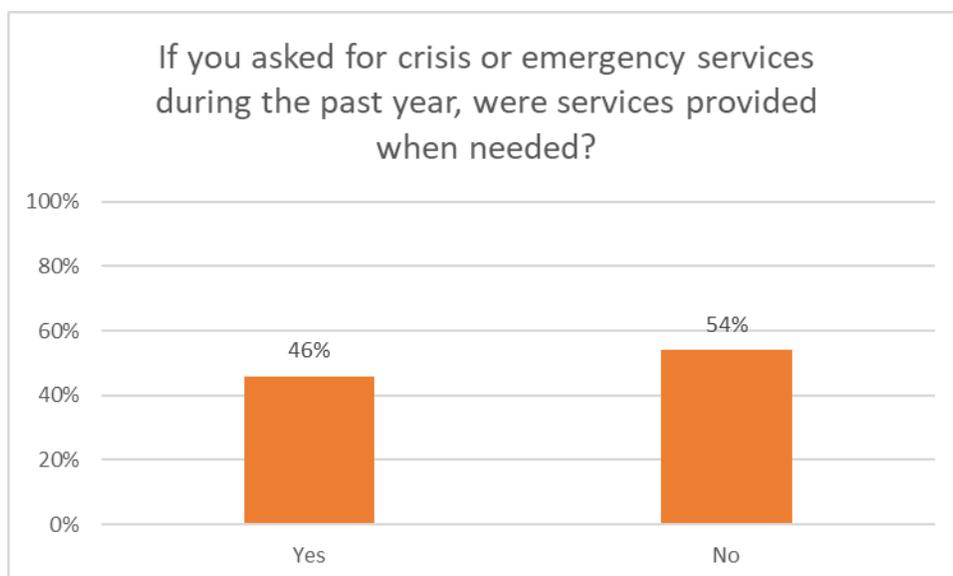


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
UT	72%	28%	39
WI	61%	39%	213

Within Average Range

State	Yes	No	N
MO	66%	34%	35
CO	60%	40%	55
LA	56%	44%	54
OR	54%	46%	155
Weight NCI Average	46%	54%	637
NC	43%	57%	54
AZ	28%	72%	32

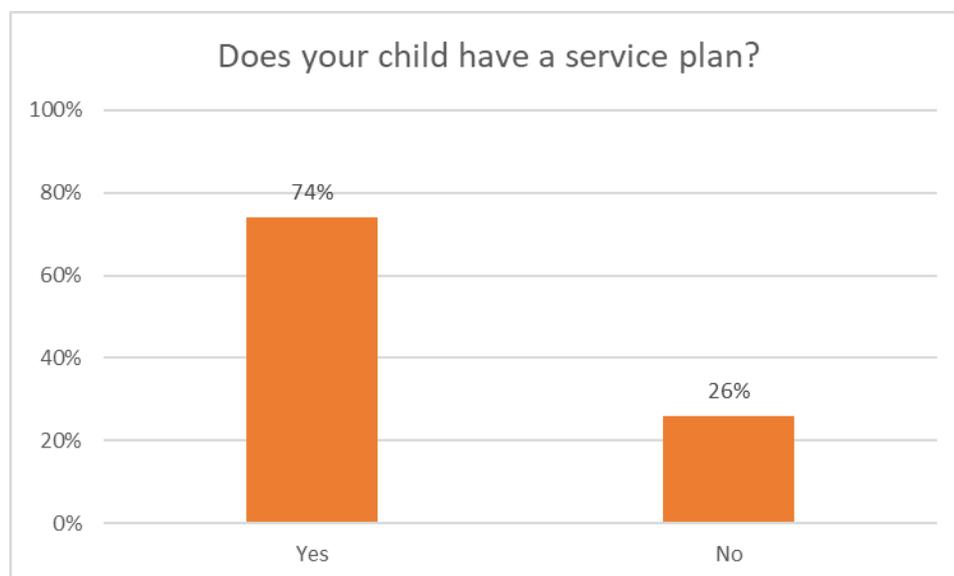


Table Q7. Does your child have a service plan?

Significantly Above Average

State	Yes	No	N
CO	89%	11%	270
OR	89%	11%	593
NC	82%	18%	173

Within Average Range

State	Yes	No	N
WI	77%	23%	885
MO	76%	24%	206
Weight NCI Average	74%	26%	2,553
LA	71%	29%	145
UT	70%	30%	143

Significantly Below Average

State	Yes	No	N
AZ	59%	41%	138

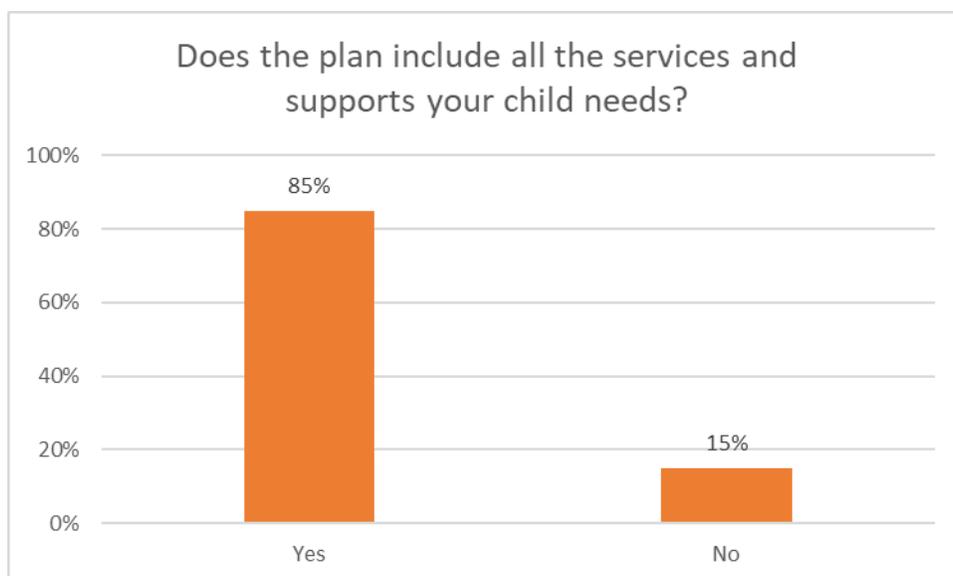


Table Q8. Does the plan include all the services and supports your child needs?

Within Average Range

State	Yes	No	N
OR	88%	12%	470
WI	88%	12%	586
AZ	87%	13%	70
UT	86%	14%	79
Weight NCI Average	85%	15%	1,781
NC	84%	16%	123
LA	83%	17%	87
MO	80%	20%	141

Significantly Below Average

State	Yes	No	N
CO	75%	25%	225

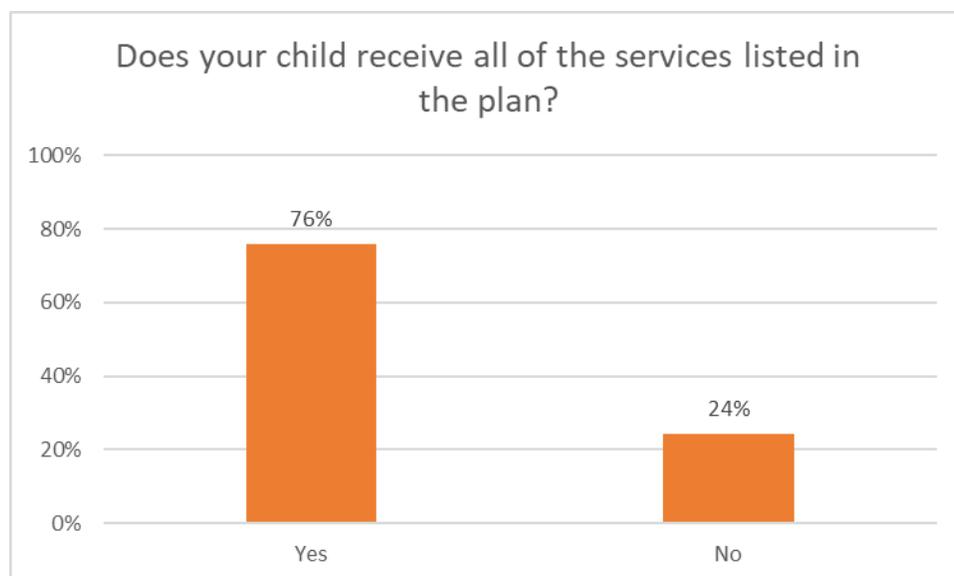


Table Q9. Does your child receive all of the services listed in the plan?

Significantly Above Average

State	Yes	No	N
UT	89%	11%	81
WI	84%	16%	611
OR	84%	16%	457

Within Average Range

State	Yes	No	N
LA	80%	20%	81
MO	79%	21%	146
NC	77%	23%	125
Weight NCI Average	76%	24%	1,809
CO	68%	32%	230
AZ	64%	36%	78

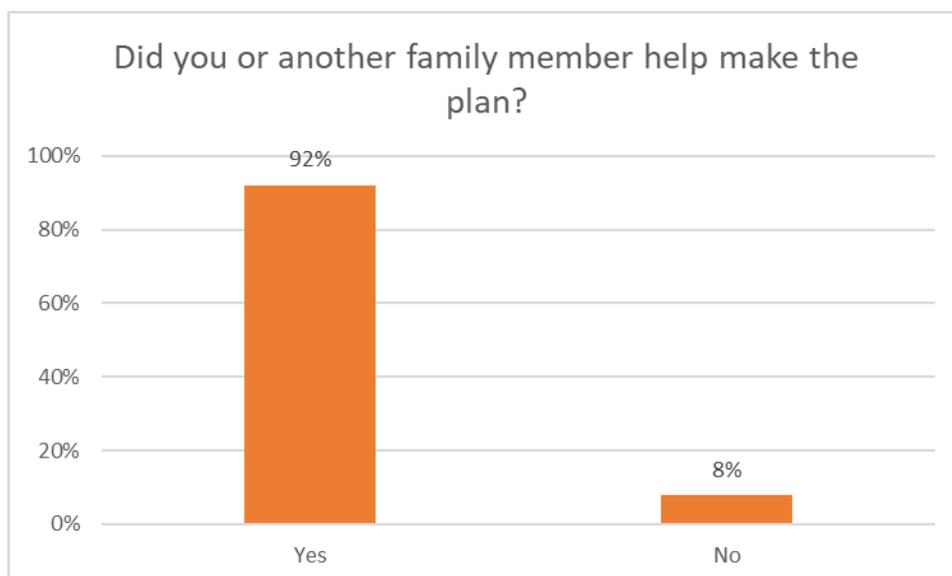


Table Q10. Did you or another family member help make the plan?

Significantly Above Average

State	Yes	No	N
OR	95%	5%	510

Within Average Range

State	Yes	No	N
MO	94%	6%	155
NC	94%	6%	137
CO	94%	6%	238
Weight NCI Average	92%	8%	1,946
WI	91%	9%	646
AZ	91%	9%	76
UT	89%	11%	90

Significantly Below Average

State	Yes	No	N
LA	80%	20%	94

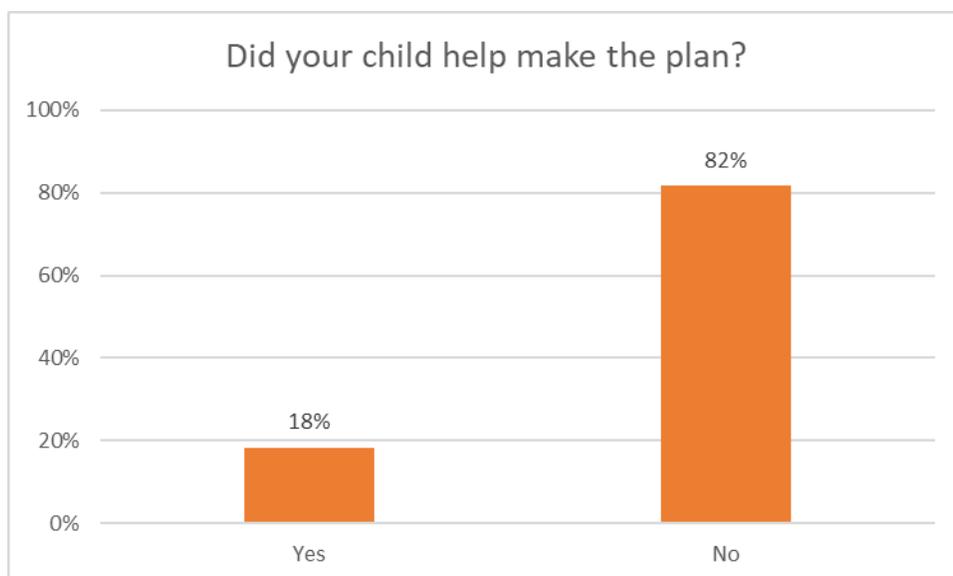


Table Q11. Did your child help make the plan?

Significantly Above Average

State	Yes	No	N
MO	32%	68%	152
OR	25%	75%	508

Within Average Range

State	Yes	No	N
UT	23%	77%	92
Weight NCI Average	18%	82%	1,965
WI	18%	82%	660
AZ	16%	84%	80
NC	16%	84%	139
CO	15%	85%	240
LA	13%	87%	94

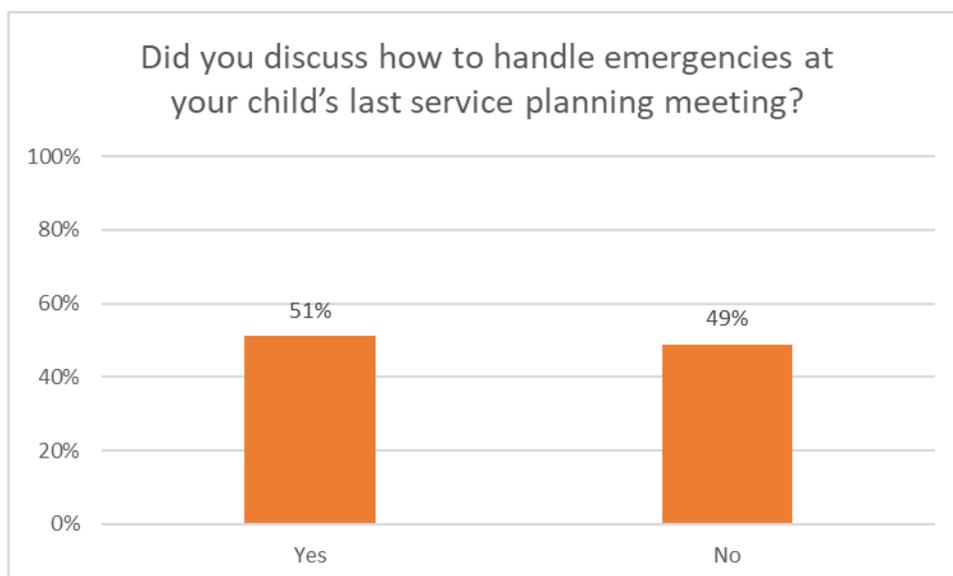


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your child's last service planning meeting?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
LA	75%	25%	89
NC	63%	37%	131
OR	63%	37%	446
CO	62%	38%	226

Within Average Range

State	Yes	No	N
MO	53%	47%	142
Weight NCI Average	51%	49%	1,770
UT	47%	53%	83

Significantly Below Average

State	Yes	No	N
WI	38%	62%	578
AZ	33%	67%	75

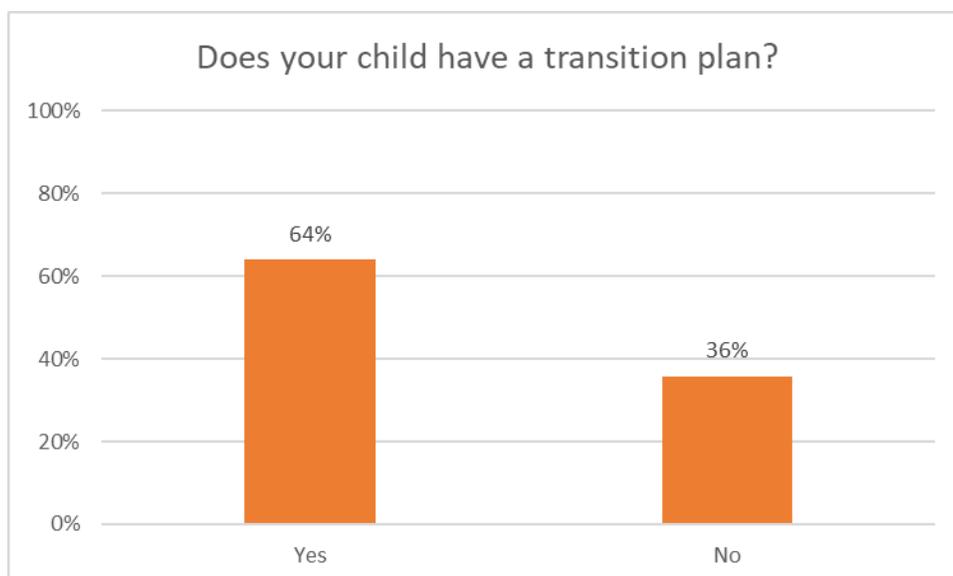


Table Q13. Does your child have a transition plan (as part of an IEP or Section 504 plan through his/her high school, usually starting at age 14)?

Within Average Range

State	Yes	No	N
LA	72%	28%	54
UT	72%	28%	90
WI	67%	33%	291
Weight NCI Average	64%	36%	1,013
NC	64%	36%	128
OR	64%	36%	244
AZ	63%	37%	49
MO	58%	42%	77
CO	51%	49%	80

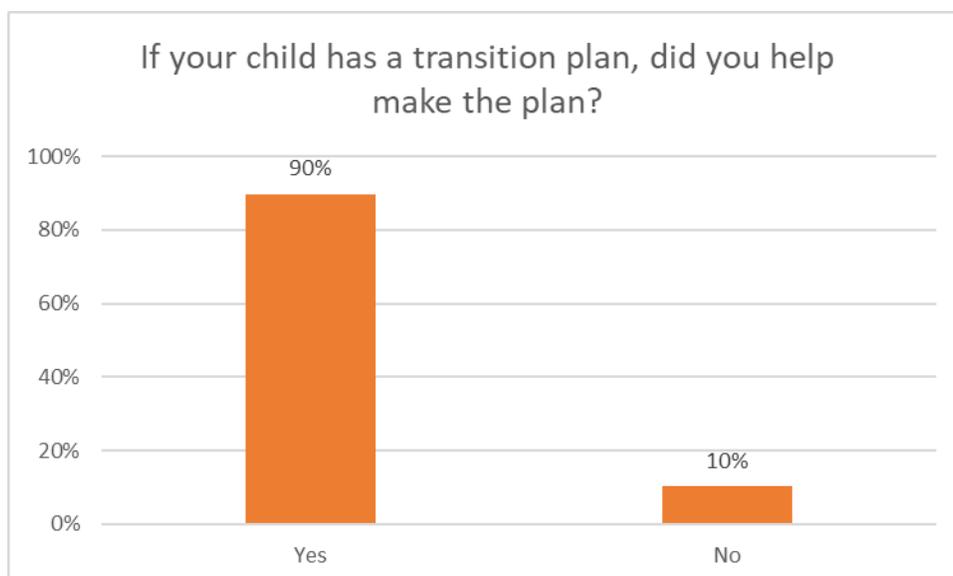


Table Q14. If your child has a transition plan, did you help make the plan?

Within Average Range

State	Yes	No	N
CO	95%	5%	37
WI	93%	7%	174
MO	93%	7%	42
UT	92%	8%	61
LA	91%	9%	35
Weight NCI Average	90%	10%	596
OR	90%	10%	143
AZ	89%	11%	27
NC	88%	12%	77

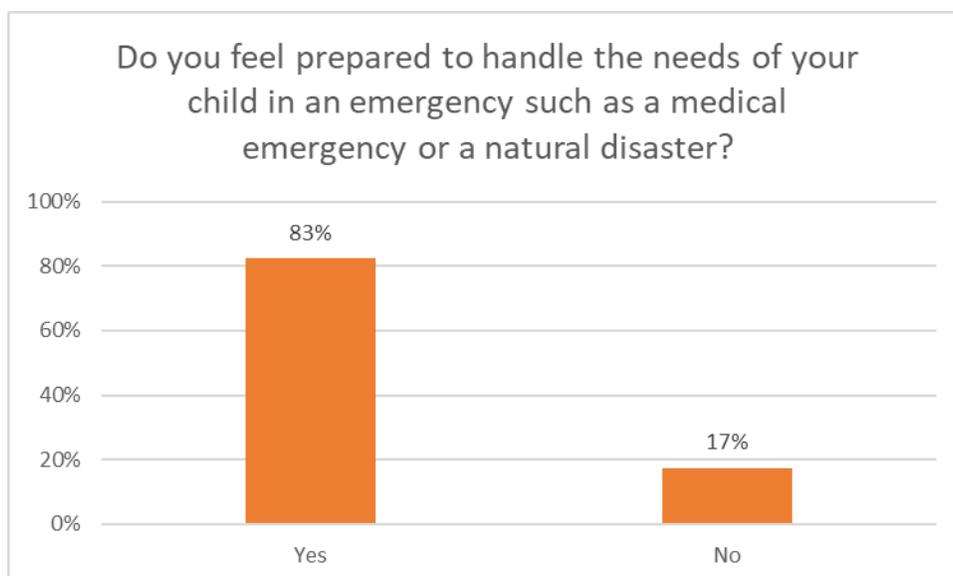


Table Q15. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
LA	92%	8%	181

Within Average Range

State	Yes	No	N
WI	84%	16%	915
CO	84%	16%	254
AZ	84%	16%	147
Weight NCI Average	83%	17%	2,679
NC	81%	19%	183
OR	80%	20%	609
MO	76%	24%	209

Significantly Below Average

State	Yes	No	N
UT	66%	34%	181

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.

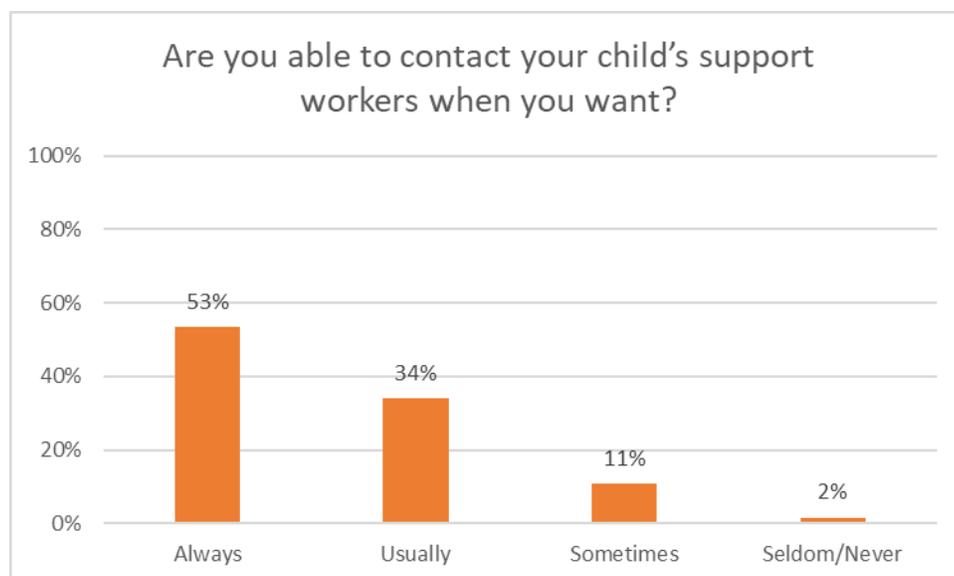


Table Q16. Are you able to contact your child's support workers when you want?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	65%	29%	3%	3%	197

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	63%	28%	6%	3%	156
OR	57%	34%	7%	1%	669
WI	57%	35%	7%	1%	941
NC	55%	33%	11%	1%	171
Weight NCI Average	53%	34%	11%	2%	2,757
AZ	49%	32%	16%	2%	158
CO	46%	44%	8%	2%	273
MO	44%	46%	7%	3%	192

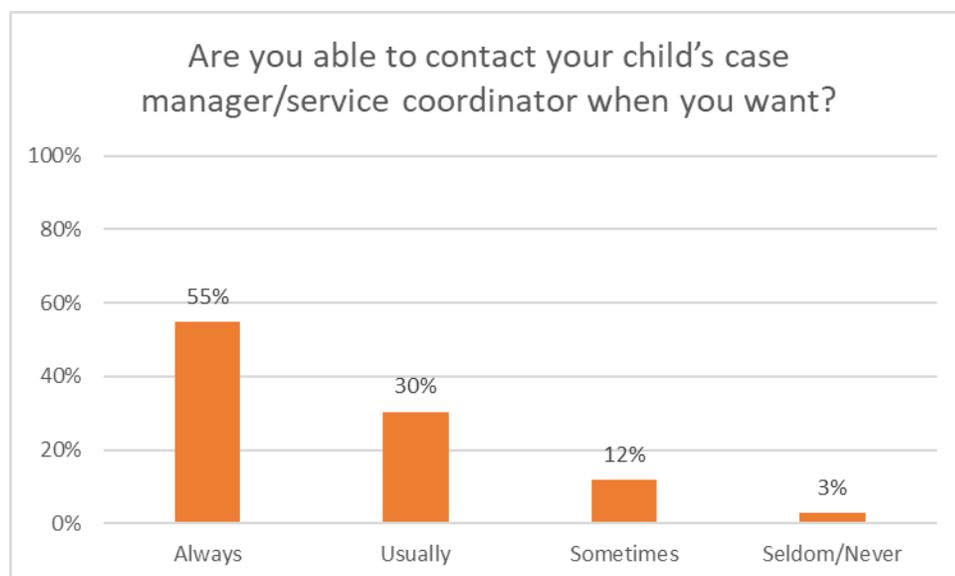


Table Q17. Are you able to contact your child's case manager/service coordinator when you want?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	73%	24%	2%	1%	201
WI	65%	28%	6%	1%	992

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	60%	30%	8%	2%	165
Weight NCI Average	55%	30%	12%	3%	2,876
NC	54%	29%	13%	4%	168
OR	54%	36%	9%	1%	695
CO	51%	38%	8%	3%	281
MO	49%	38%	9%	4%	217
AZ	48%	29%	19%	3%	157

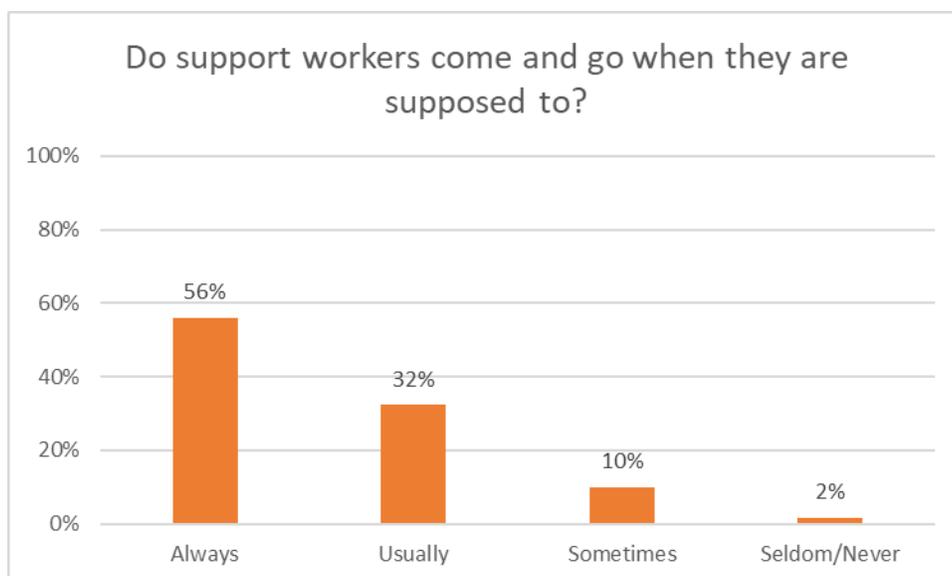


Table Q18. Do support workers come and go when they are supposed to?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	65%	30%	4%	1%	834

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	66%	25%	8%	1%	148
UT	60%	31%	8%	1%	195
OR	60%	31%	7%	2%	651
MO	59%	30%	8%	4%	171
Weight NCI Average	56%	32%	10%	2%	2,571
AZ	56%	29%	14%	1%	157
CO	51%	42%	5%	2%	251

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	46%	39%	12%	3%	164

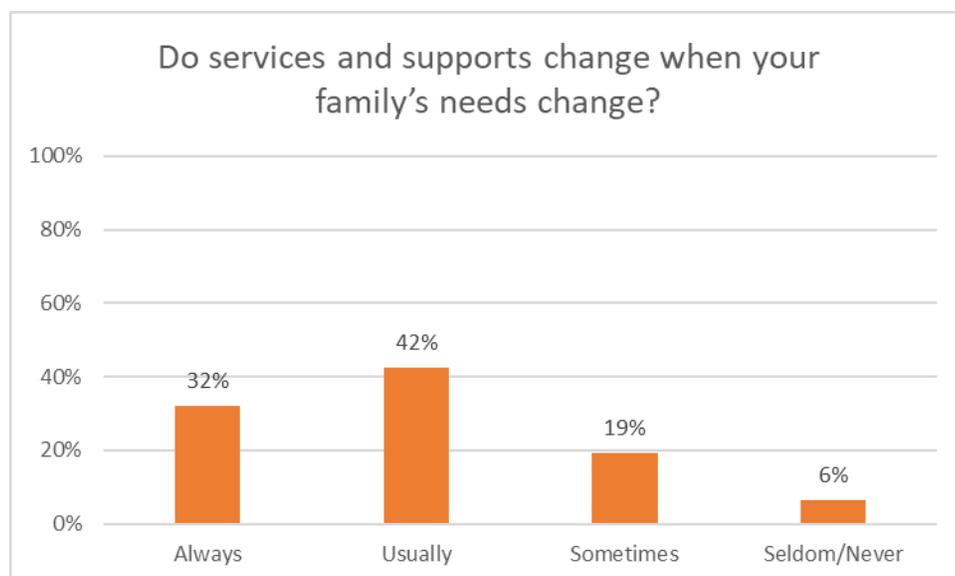


Table Q19. Do services and supports change when your family's needs change?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	44%	32%	17%	7%	126
WI	39%	41%	16%	4%	842

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
Weight NCI Average	32%	42%	19%	6%	2,439
UT	31%	50%	12%	7%	162
AZ	31%	43%	22%	4%	143
CO	30%	44%	16%	9%	246
MO	30%	43%	16%	11%	171
OR	29%	47%	19%	5%	587
NC	28%	43%	20%	9%	162

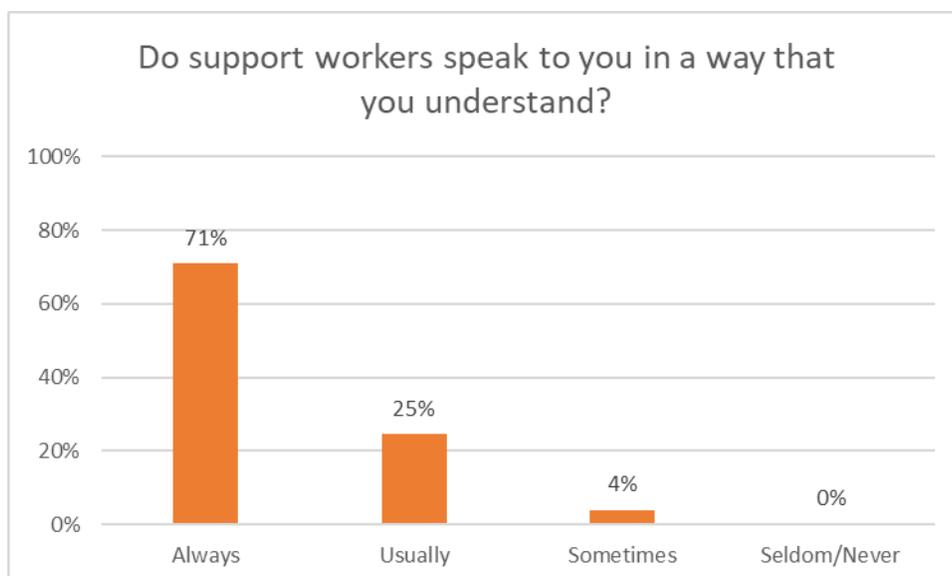


Table Q20. Do support workers speak to you in a way that you understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	81%	16%	2%	2%	193
OR	76%	20%	3%	0%	669

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	77%	21%	1%	1%	156
WI	73%	23%	3%	1%	902
Weight NCI Average	71%	25%	4%	0%	2,692
CO	69%	27%	3%	1%	258
NC	69%	25%	5%	1%	173
AZ	68%	27%	5%	0%	158
MO	68%	27%	5%	0%	183

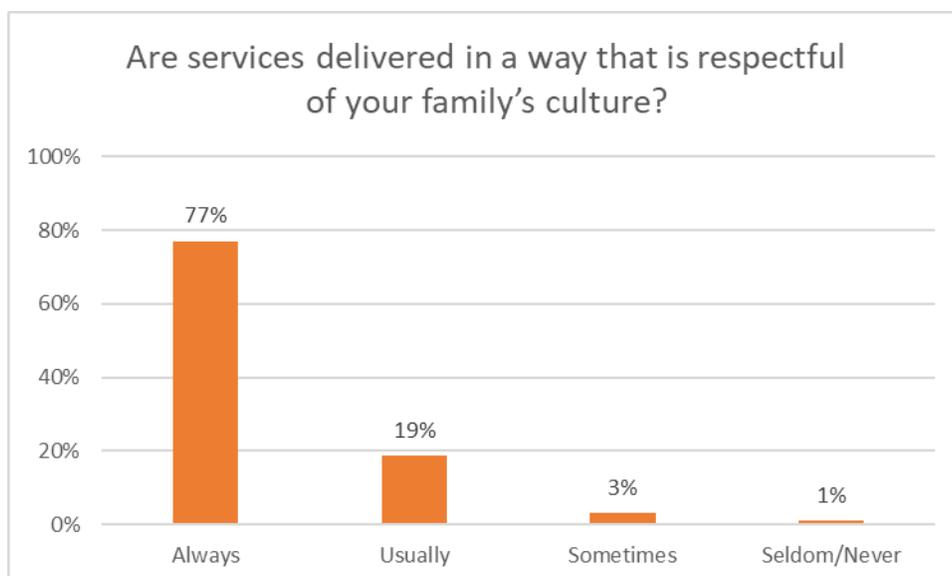


Table Q21. Are services delivered in a way that is respectful of your family's culture?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	85%	14%	1%	1%	198
OR	81%	16%	2%	1%	693

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	83%	13%	2%	2%	168
WI	79%	18%	2%	1%	991
Weight NCI Average	77%	19%	3%	1%	2,880
MO	76%	20%	3%	1%	210
AZ	75%	20%	4%	0%	159
NC	75%	19%	4%	2%	182
CO	74%	23%	2%	1%	279

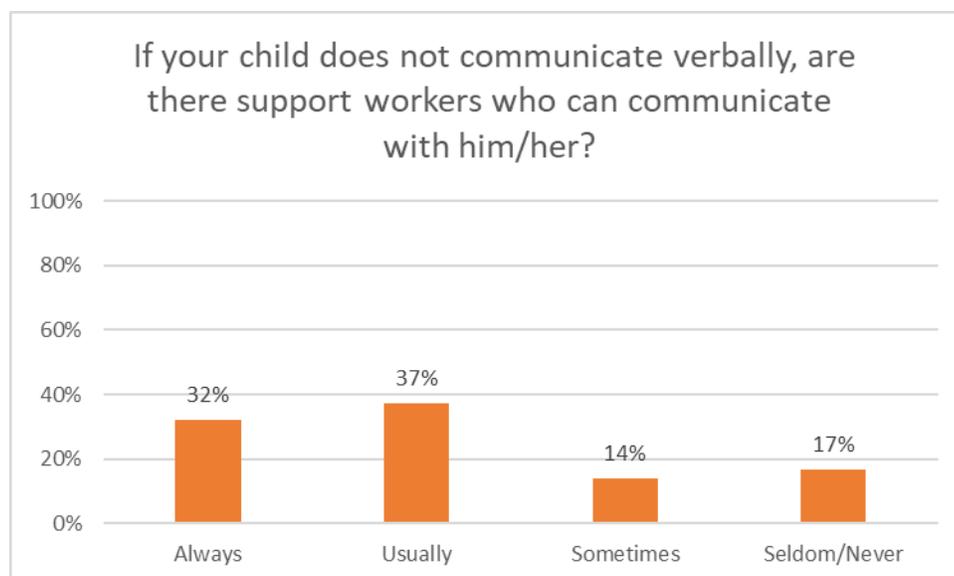


Table Q22. If your child does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?²

Responses to this question might have been impacted by the COVID-19 pandemic.

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	42%	46%	6%	6%	48
MO	35%	30%	0%	35%	20
OR	34%	36%	18%	12%	89
Weight NCI Average	32%	37%	14%	17%	349
UT	20%	44%	29%	7%	41
CO	19%	30%	30%	22%	37

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	20%	32%	30%	19%	81

² The following states are not included in the table due to low N (<20), but their responses are included in the NCI Average: AZ, LA

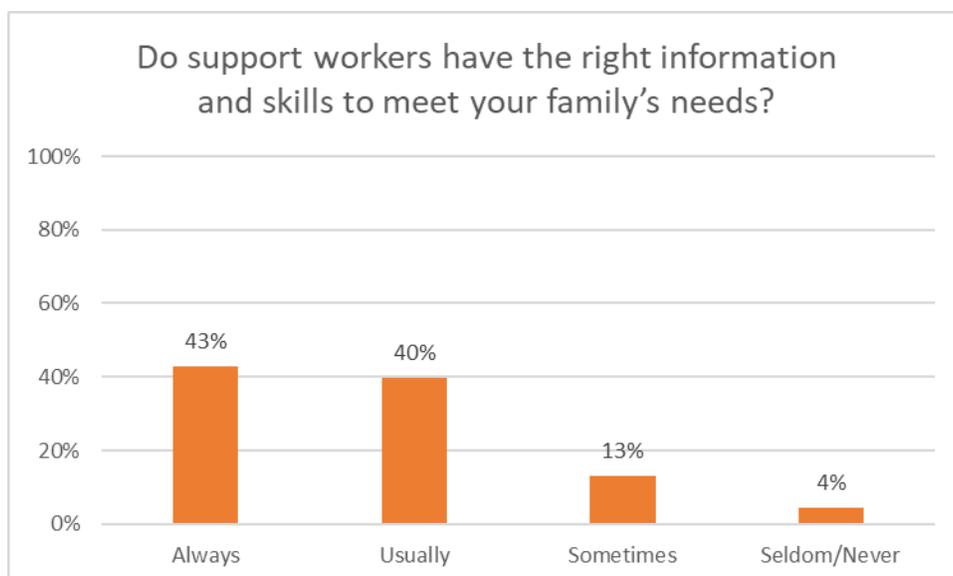


Table Q23. Do support workers have the right information and skills to meet your family's needs?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	57%	28%	12%	3%	152

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
UT	49%	41%	9%	1%	193
OR	46%	37%	14%	3%	659
WI	45%	44%	9%	2%	889
AZ	44%	38%	14%	5%	154
Weight NCI Average	43%	40%	13%	4%	2,656
NC	38%	39%	15%	8%	169
MO	37%	45%	17%	1%	178

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CO	34%	51%	11%	5%	262



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

Responses to this question might have been impacted by the COVID-19 pandemic.

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
WI	38%	40%	17%	5%	609
AZ	38%	34%	18%	10%	88
LA	36%	28%	13%	22%	89
MO	35%	46%	10%	9%	105
Weight NCI Average	34%	39%	17%	10%	1,765
CO	32%	48%	16%	3%	234
UT	31%	36%	23%	11%	120
OR	31%	44%	18%	7%	412
NC	30%	40%	18%	13%	108

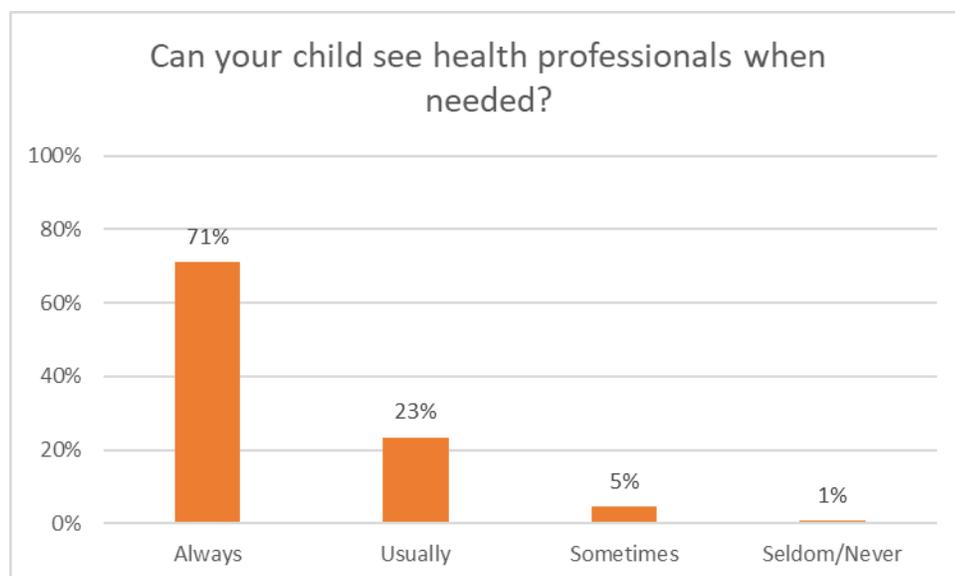


Table Q25. Can your child see health professionals when needed?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	83%	14%	3%	1%	192

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	76%	19%	4%	1%	195
AZ	73%	21%	6%	1%	160
Weight NCI Average	71%	23%	5%	1%	3,006
MO	67%	26%	5%	2%	229
UT	66%	30%	3%	0%	204

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	65%	30%	3%	1%	704
WI	63%	30%	5%	1%	1,034
CO	63%	33%	3%	1%	288

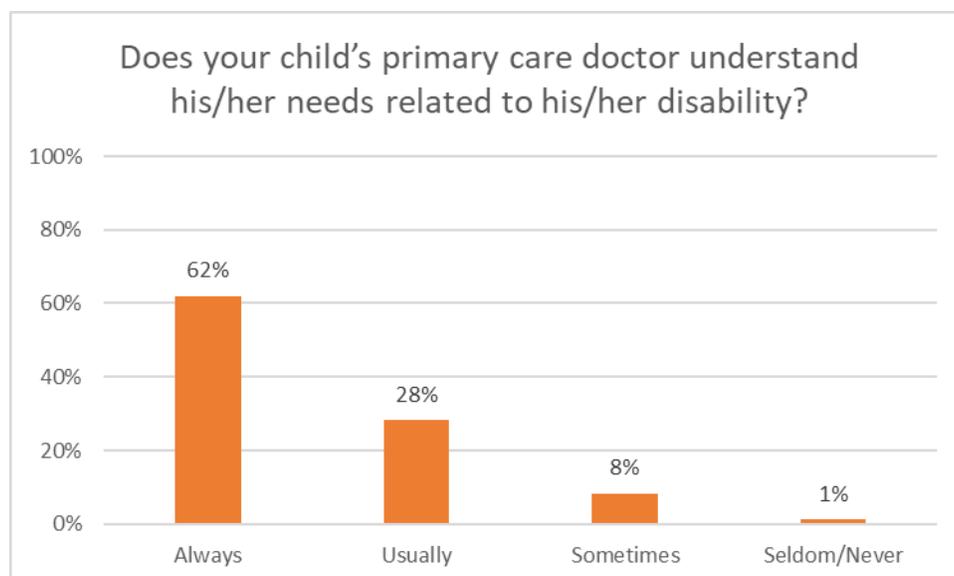


Table Q26. Does your child's primary care doctor understand his/her needs related to his/her disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	68%	26%	5%	1%	190
AZ	67%	25%	8%	1%	163
NC	62%	29%	8%	1%	191
Weight NCI Average	62%	28%	8%	1%	2,968
WI	60%	29%	8%	3%	1,021
CO	60%	32%	8%	1%	288
UT	57%	32%	9%	3%	203

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	57%	34%	8%	2%	693
MO	47%	35%	14%	3%	219

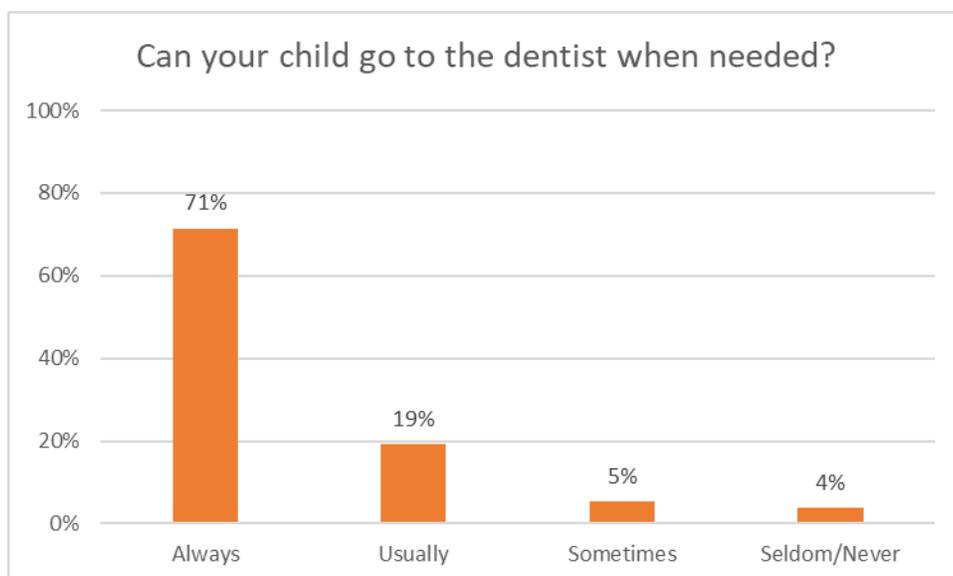


Table Q27. Can your child go to the dentist when needed?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	81%	13%	4%	2%	162

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	78%	15%	2%	4%	182
UT	75%	18%	4%	2%	203
Weight NCI Average	71%	19%	5%	4%	2,942
NC	71%	20%	5%	5%	194
CO	67%	25%	6%	2%	286
MO	67%	23%	6%	4%	220

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OR	63%	25%	7%	4%	698
WI	60%	25%	9%	6%	997

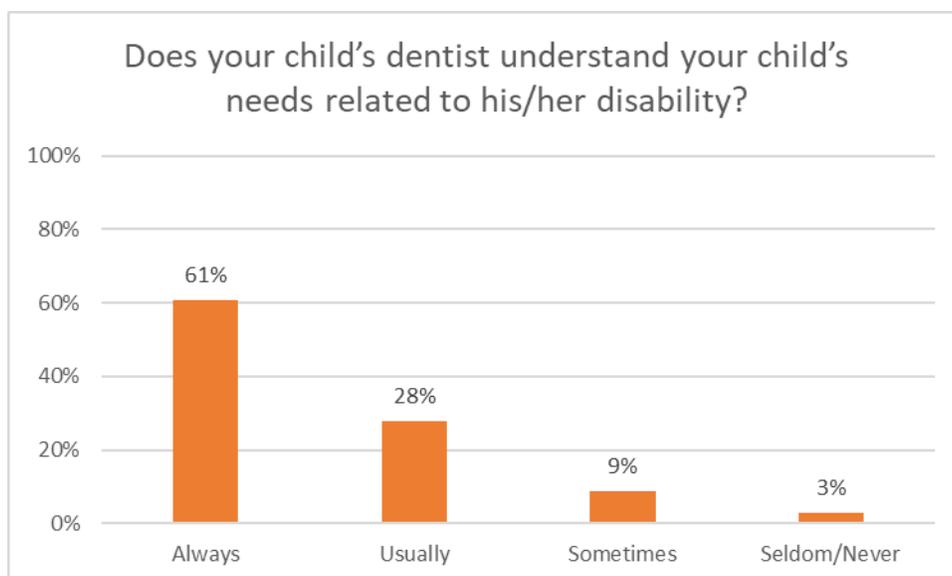


Table Q28. Does your child's dentist understand your child's needs related to his/her disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	72%	20%	6%	1%	157

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	68%	25%	5%	3%	154
Weight NCI Average	61%	28%	9%	3%	2,719
UT	59%	32%	8%	1%	197
NC	59%	30%	9%	2%	183
CO	53%	31%	12%	4%	277

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	55%	28%	12%	4%	889
OR	55%	32%	9%	4%	656
MO	51%	33%	14%	2%	206

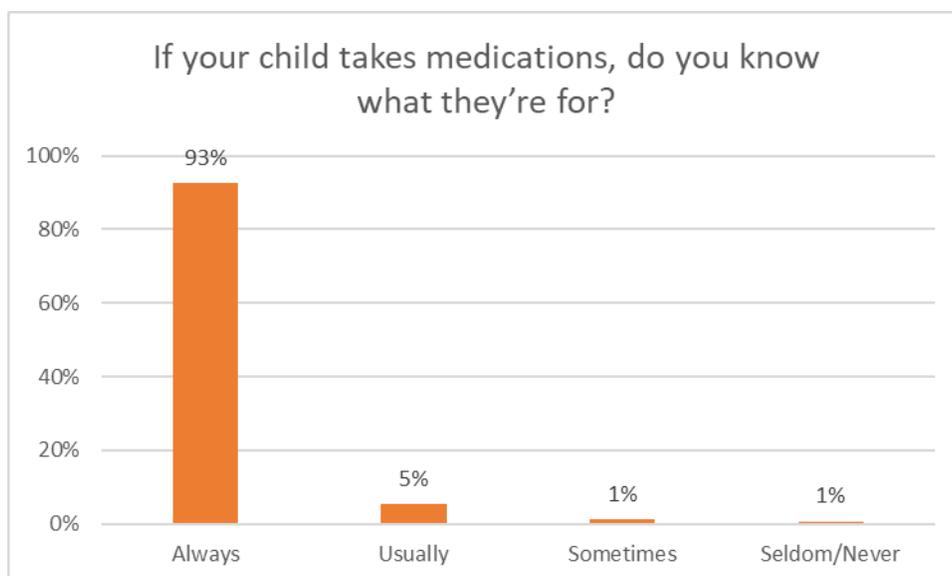


Table Q29. If your child takes medications, do you know what they're for?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	97%	1%	1%	1%	147

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	95%	4%	0%	1%	104
CO	95%	4%	1%	0%	247
OR	93%	6%	1%	1%	535
WI	93%	5%	1%	1%	763
Weight NCI Average	93%	5%	1%	1%	2,330
MO	92%	8%	1%	0%	178
UT	92%	7%	1%	1%	178
NC	89%	7%	3%	1%	178

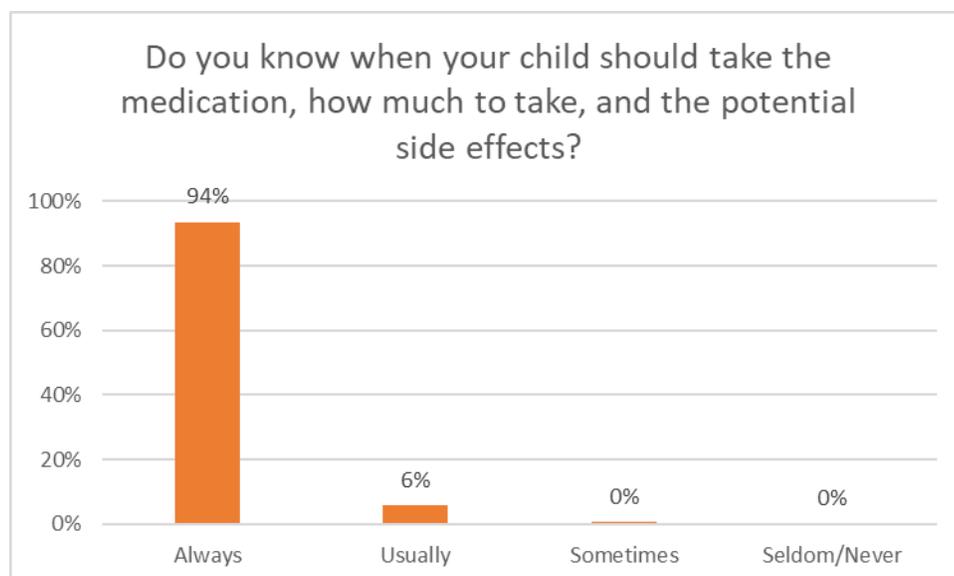


Table Q30. Do you know when your child should take the medication, how much to take, and the potential side effects?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	95%	4%	1%	1%	146
OR	94%	5%	0%	0%	535
MO	94%	6%	0%	0%	178
AZ	94%	6%	0%	0%	103
Weight NCI Average	94%	6%	0%	0%	2,325
CO	94%	6%	0%	0%	248
NC	93%	5%	1%	1%	179
WI	93%	7%	0%	0%	758
UT	89%	10%	0%	1%	178

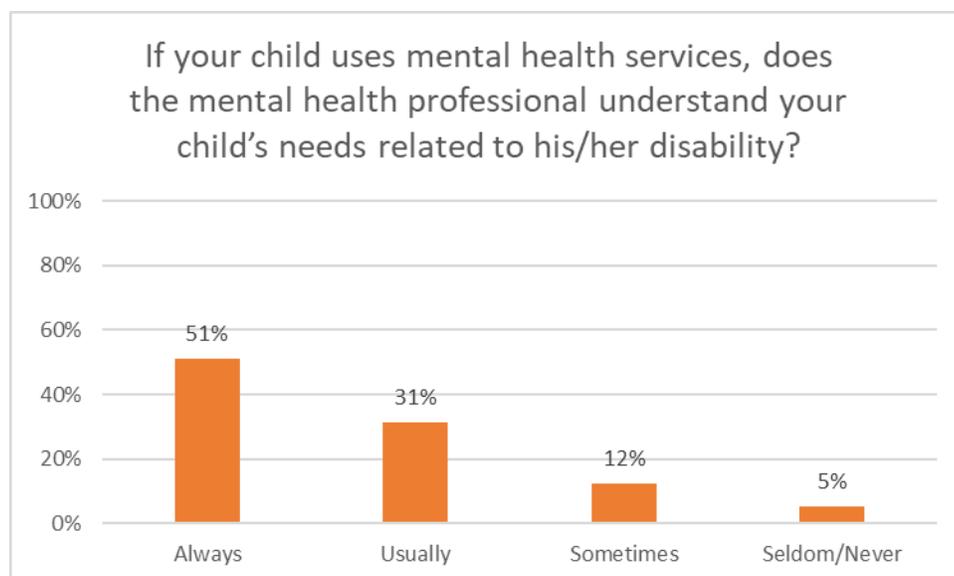


Table Q31. If your child uses mental health services, does the mental health professional understand your child's needs related to his/her disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	71%	14%	9%	7%	58
WI	58%	30%	9%	3%	376

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
UT	59%	31%	7%	3%	94
MO	54%	38%	8%	1%	114
OR	51%	36%	7%	6%	271
Weight NCI Average	51%	31%	12%	5%	1,198
NC	50%	31%	16%	4%	101
AZ	45%	32%	15%	8%	62
CO	45%	37%	11%	7%	122

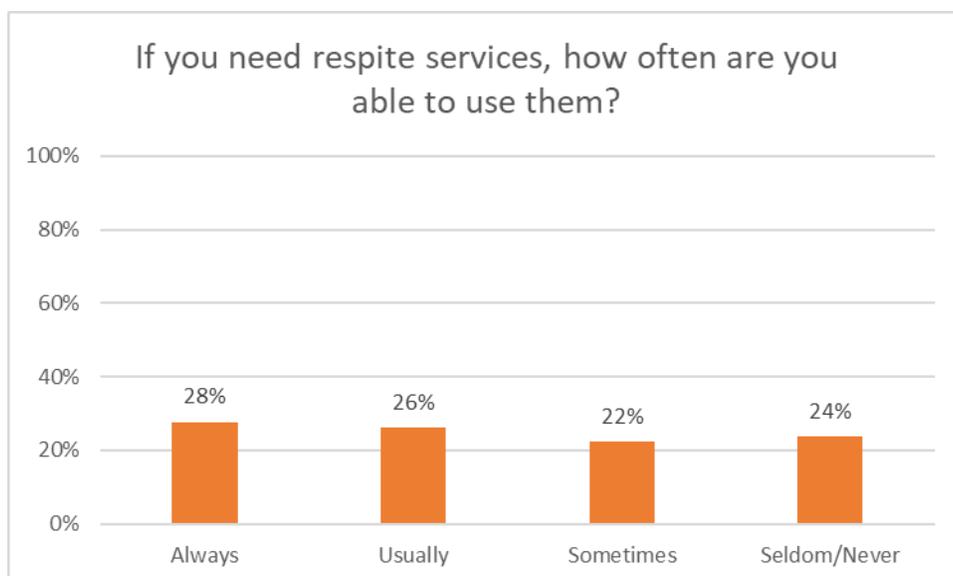


Table Q32. If you need respite services, how often are you able to use them?

Responses to this question might have been impacted by the COVID-19 pandemic.

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	38%	27%	21%	14%	130
UT	33%	40%	20%	7%	193
Weight NCI Average	28%	26%	22%	24%	2,135
LA	26%	13%	15%	46%	72
OR	25%	26%	21%	27%	553
WI	25%	28%	23%	24%	665
CO	24%	25%	25%	25%	233
NC	21%	25%	23%	30%	159

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	12%	28%	26%	35%	130

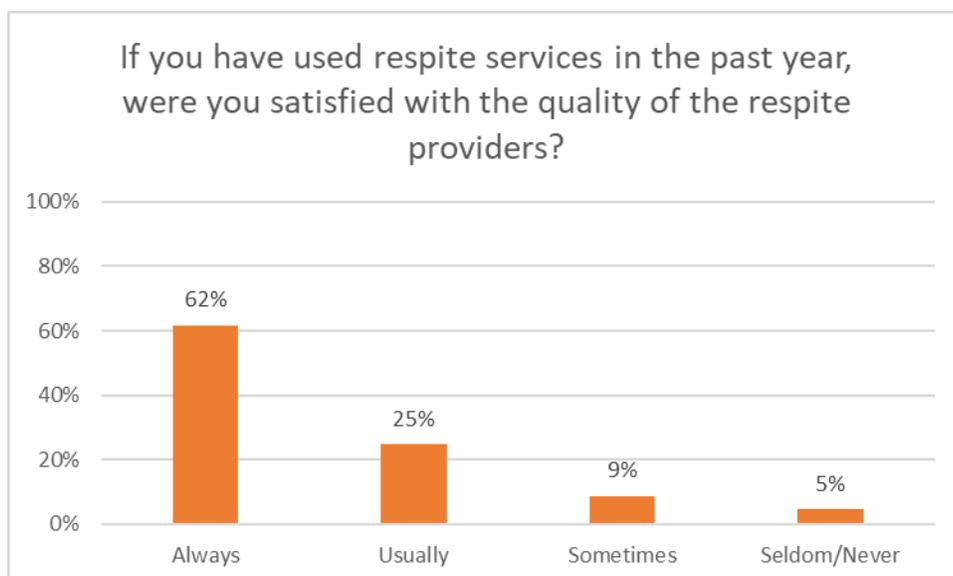


Table Q33. If you have used respite services in the past year, were you satisfied with the quality of the respite providers?

Responses to this question might have been impacted by the COVID-19 pandemic.

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	65%	22%	9%	4%	117
WI	64%	24%	9%	2%	549
OR	62%	28%	6%	4%	430
LA	62%	18%	6%	15%	34
Weight NCI Average	62%	25%	9%	5%	1,727
NC	59%	27%	9%	6%	126
MO	57%	28%	10%	4%	89
UT	54%	31%	12%	2%	185

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CO	51%	27%	14%	8%	197

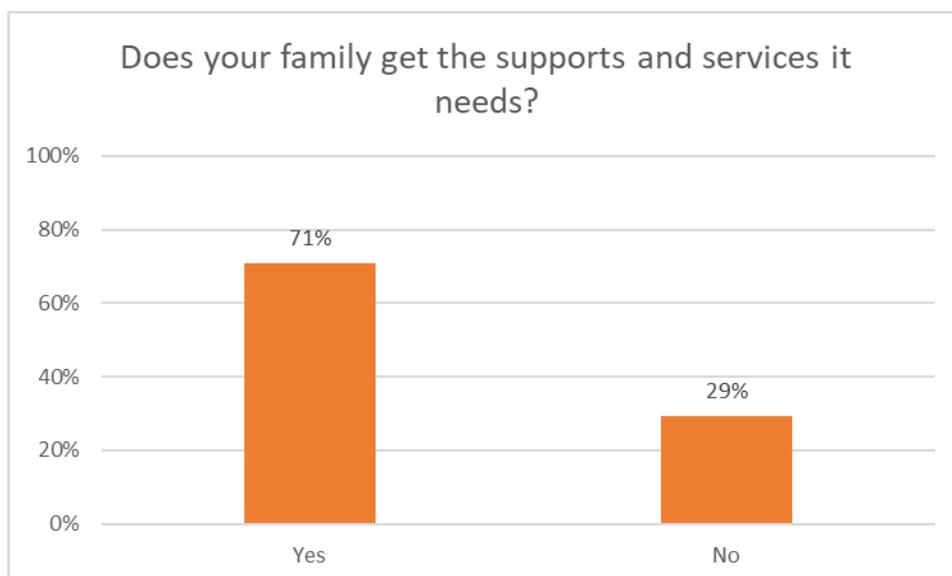


Table Q34. Does your family get the supports and services it needs?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
WI	78%	22%	922
OR	76%	24%	650

Within Average Range

State	Yes	No	N
UT	78%	22%	188
AZ	74%	26%	153
Weight NCI Average	71%	29%	2,732
LA	68%	32%	166
MO	66%	34%	204
NC	63%	37%	176

Significantly Below Average

State	Yes	No	N
CO	63%	37%	273

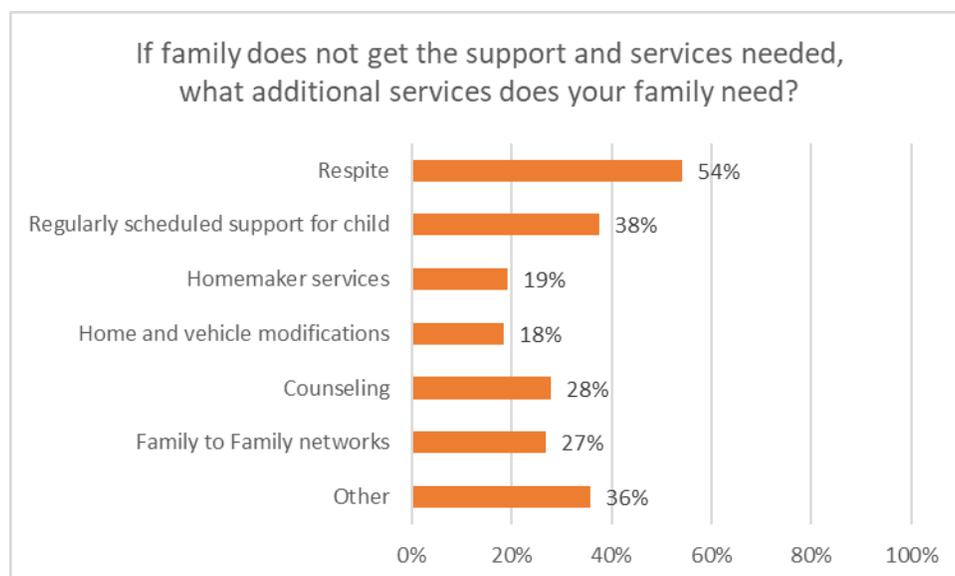


Table Q35. If family does not get the support and services needed, what additional services does your family need?

Categories are not mutually exclusive, therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Other
AZ	49%	27%	19%	14%	27%	22%	41%
CO	71%	29%	46%	21%	31%	22%	23%
LA	48%	41%	13%	17%	26%	20%	30%
MO	63%	37%	17%	11%	27%	27%	23%
NC	54%	44%	13%	21%	32%	32%	40%
OR	50%	40%	24%	24%	24%	24%	31%
UT	46%	29%	39%	24%	37%	34%	24%
WI	60%	43%	26%	22%	22%	31%	35%
Weight NCI Average	54%	38%	19%	18%	28%	27%	36%

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.

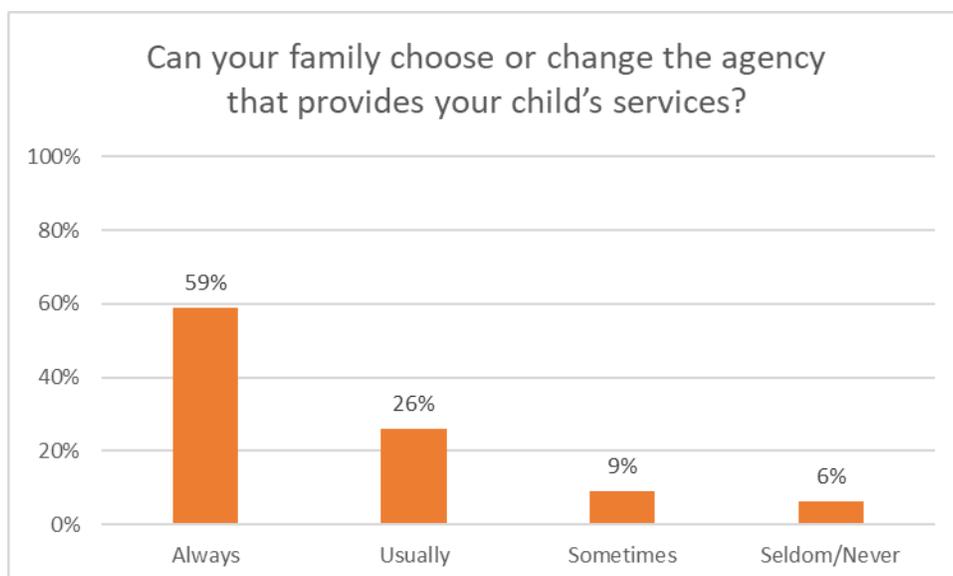


Table Q36. Can your family choose or change the agency that provides your child's services?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	72%	17%	4%	7%	125
NC	69%	21%	8%	2%	155

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
UT	67%	25%	6%	2%	155
Weight NCI Average	59%	26%	9%	6%	1,865
OR	59%	25%	7%	9%	429
AZ	57%	30%	9%	4%	138
CO	56%	27%	8%	9%	231

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	45%	28%	13%	15%	501
MO	40%	27%	15%	18%	131

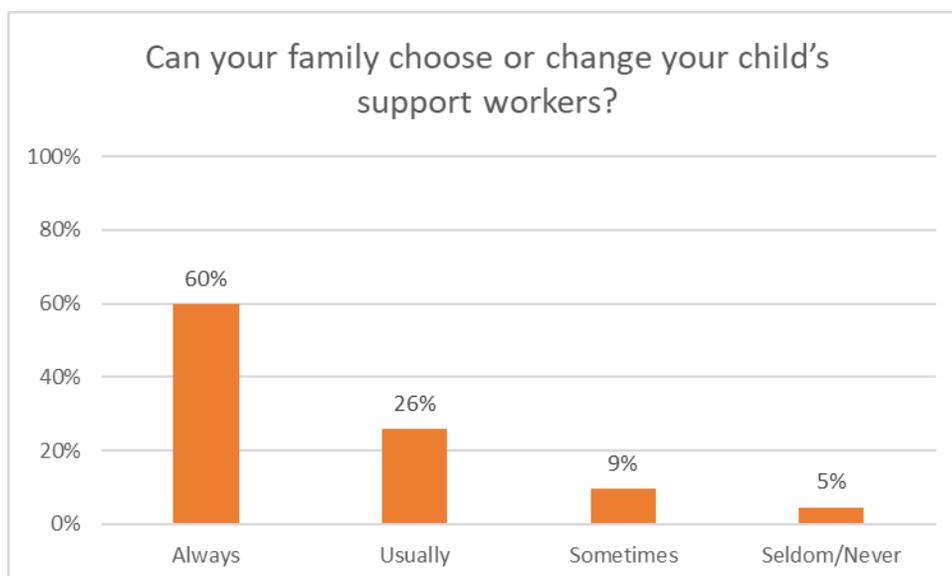


Table Q37. Can your family choose or change your child's support workers?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	73%	18%	6%	2%	175
OR	70%	20%	6%	4%	584

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	69%	16%	9%	6%	125
NC	61%	24%	12%	2%	161
Weight NCI Average	60%	26%	9%	5%	2,031
AZ	60%	31%	7%	3%	121

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WI	54%	28%	10%	8%	513
CO	51%	30%	12%	7%	231
MO	44%	28%	15%	13%	121

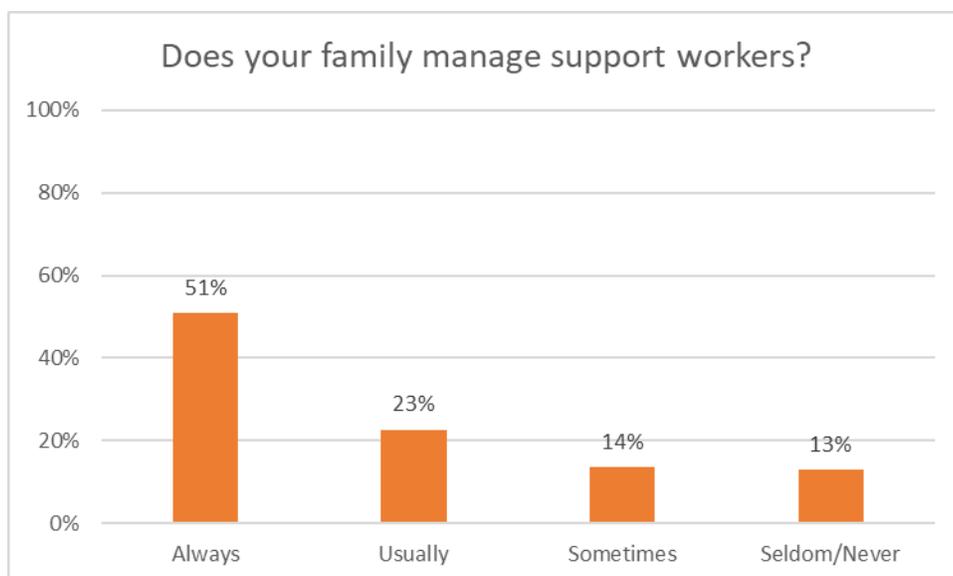


Table Q38. Does your family manage support workers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
UT	74%	12%	9%	5%	180
OR	74%	15%	6%	5%	612

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	57%	18%	12%	14%	113
AZ	53%	23%	14%	10%	118
Weight NCI Average	51%	23%	14%	13%	2,122
WI	48%	23%	12%	17%	590
NC	42%	26%	16%	15%	153

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CO	40%	28%	22%	10%	231
MO	38%	22%	14%	26%	125

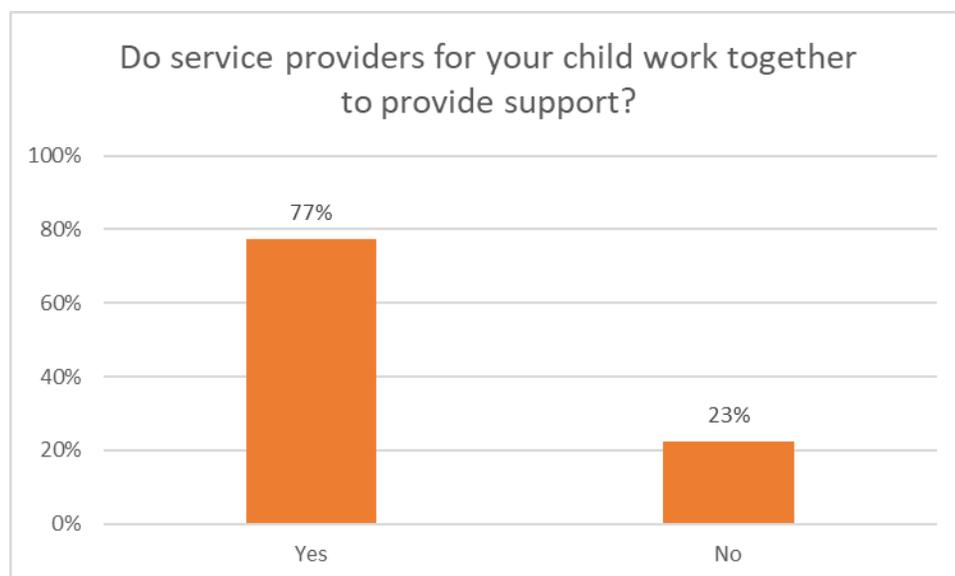


Table Q39. Do service providers for your child work together to provide support?

Responses to this question might have been impacted by the COVID-19 pandemic.

Within Average Range

State	Yes	No	N
WI	81%	19%	448
NC	79%	21%	103
OR	79%	21%	312
Weight NCI Average	77%	23%	1,398
LA	77%	23%	83
AZ	77%	23%	86
CO	76%	24%	172
UT	73%	27%	94
MO	68%	32%	100

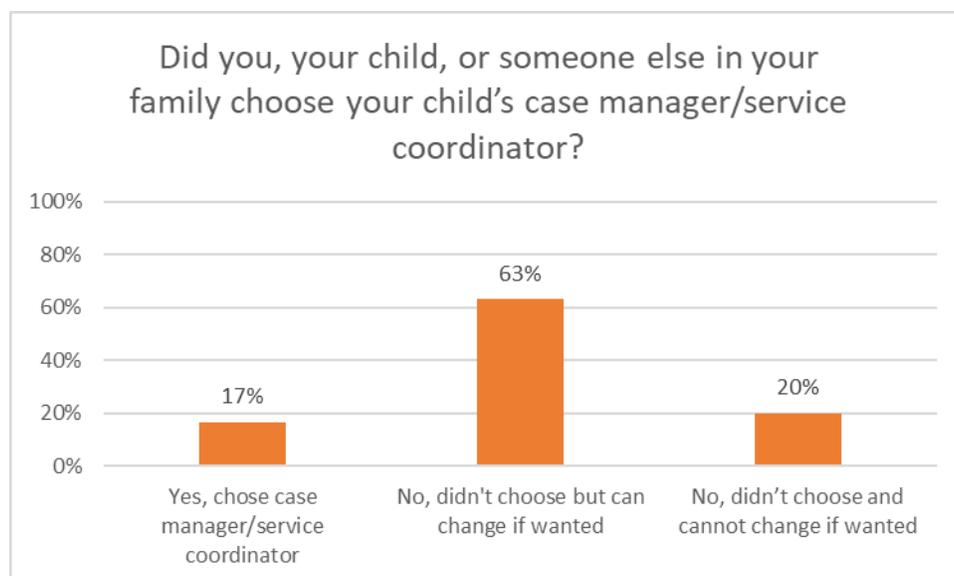


Table Q40. Did you, your child, or someone else in your family choose your child's case manager/service coordinator?

Significantly Above Average

State	Yes, chose case manager/service coordinator	No, didn't choose but can change if wanted	No, didn't choose and cannot change if wanted	N
UT	89%	10%	1%	194
LA	47%	43%	11%	150

Within Average Range

State	Yes, chose case manager/service coordinator	No, didn't choose but can change if wanted	No, didn't choose and cannot change if wanted	N
NC	20%	54%	26%	159
Weight NCI Average	17%	63%	20%	2,457
OR	16%	65%	19%	586
AZ	10%	76%	14%	146

Significantly Below Average

State	Yes, chose case manager/service coordinator	No, didn't choose but can change if wanted	No, didn't choose and cannot change if wanted	N
WI	11%	64%	25%	769
MO	9%	59%	32%	193
CO	8%	77%	15%	260

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.

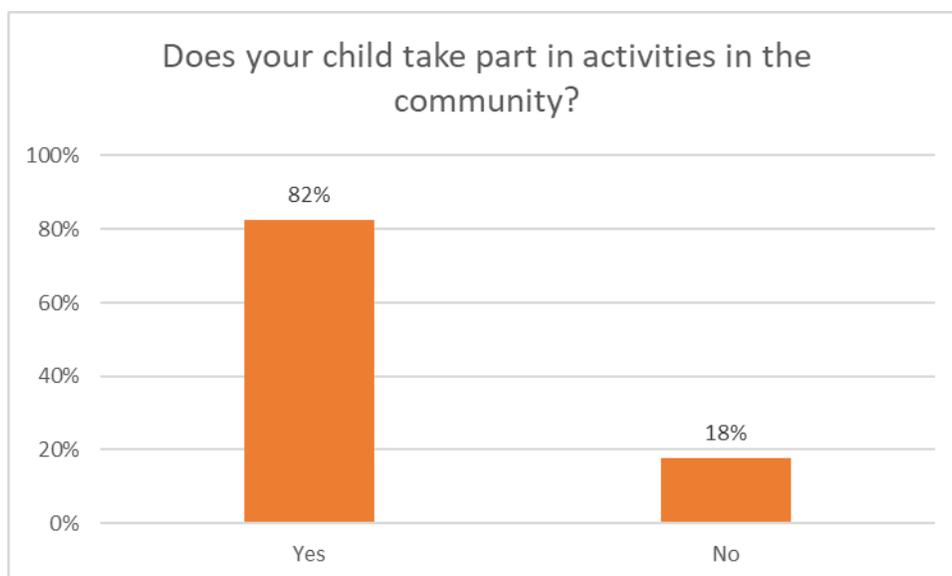


Table Q41. Does your child take part in activities in the community?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
NC	87%	13%	192

Within Average Range

State	Yes	No	N
UT	84%	16%	202
MO	83%	17%	230
Weight NCI Average	82%	18%	2,950
AZ	82%	18%	160
WI	81%	19%	1,012
OR	80%	20%	680
CO	78%	22%	283
LA	74%	26%	191

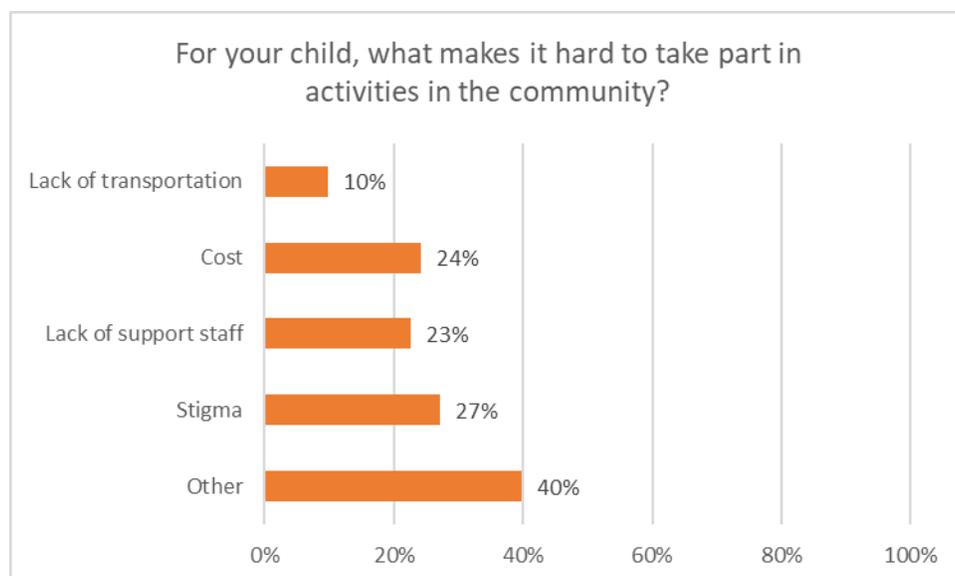


Table Q42. For your child, what makes it hard to take part in activities in the community?

Responses to this question might have been impacted by the COVID-19 pandemic.

Categories are not mutually exclusive, therefore N is not shown

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	11%	24%	18%	26%	38%
CO	11%	28%	40%	36%	51%
LA	8%	15%	10%	16%	35%
MO	5%	25%	21%	33%	39%
NC	12%	26%	26%	30%	41%
OR	7%	26%	25%	27%	44%
UT	13%	28%	33%	32%	45%
WI	8%	24%	26%	26%	40%
Weight NCI Average	10%	24%	23%	27%	40%

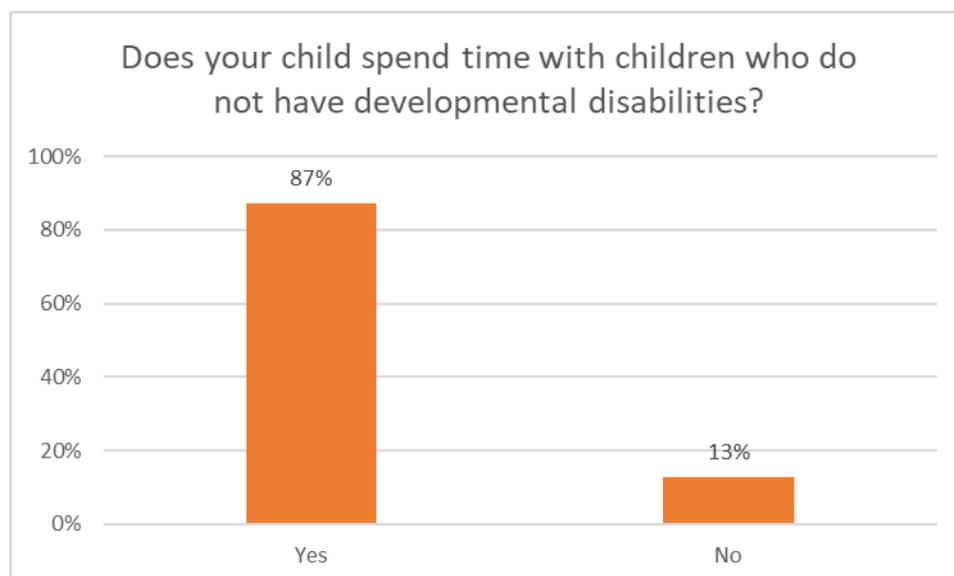


Table Q43. Does your child spend time with children who do not have developmental disabilities?

Significantly Above Average

State	Yes	No	N
UT	93%	7%	199

Within Average Range

State	Yes	No	N
MO	91%	9%	227
NC	88%	12%	191
OR	88%	12%	697
Weight NCI Average	87%	13%	2,968
WI	87%	13%	1,018
LA	87%	13%	193
AZ	86%	14%	165
CO	85%	15%	278

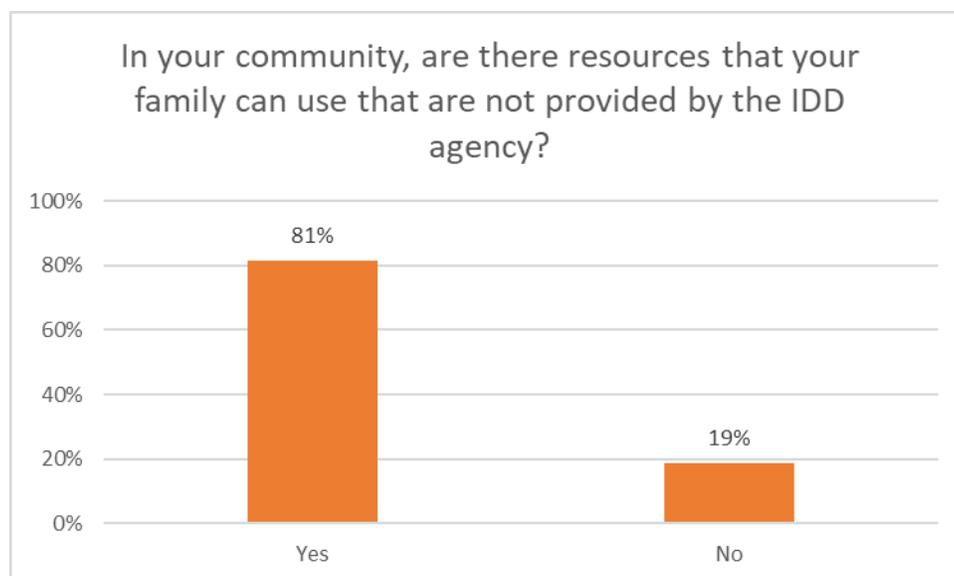


Table Q44. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
OR	87%	13%	565

Within Average Range

State	Yes	No	N
MO	86%	14%	176
UT	85%	15%	171
WI	82%	18%	726
Weight NCI Average	81%	19%	2,292
NC	81%	19%	159
CO	81%	19%	214
AZ	81%	19%	129

Significantly Below Average

State	Yes	No	N
LA	72%	28%	152

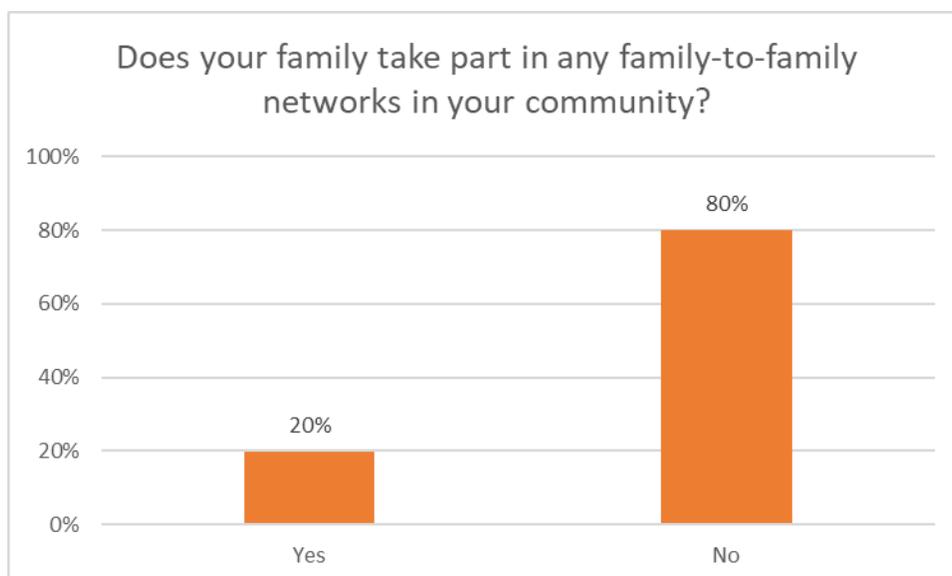


Table Q45. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
OR	24%	76%	609

Within Average Range

State	Yes	No	N
LA	26%	74%	151
CO	26%	74%	266
UT	23%	77%	183
NC	22%	78%	171
Weight NCI Average	20%	80%	2,584
WI	18%	82%	859
AZ	17%	83%	143

Significantly Below Average

State	Yes	No	N
MO	13%	87%	202

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.

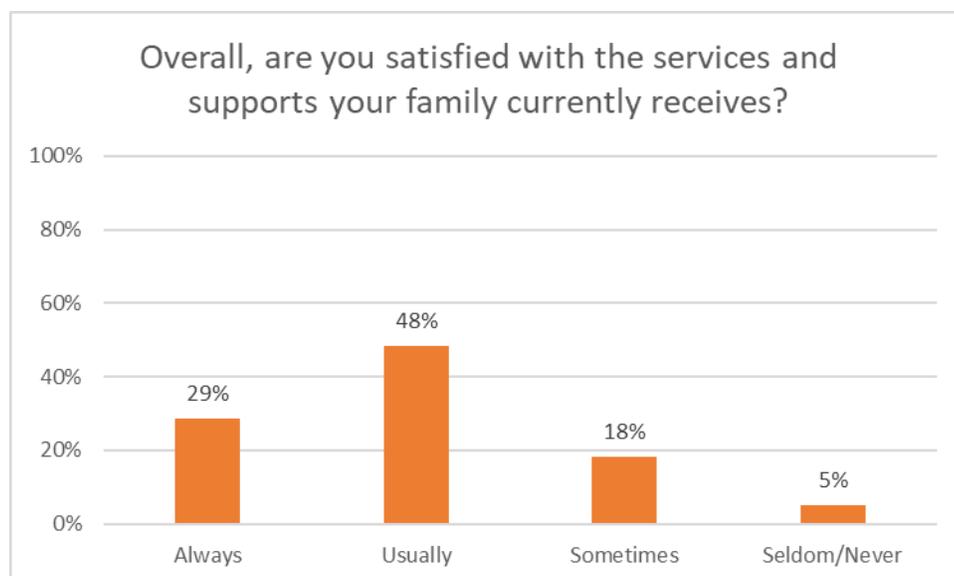


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	42%	35%	18%	5%	179

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
WI	32%	49%	16%	3%	1,018
UT	31%	56%	11%	1%	204
OR	31%	51%	16%	2%	699
AZ	31%	47%	19%	3%	163
Weight NCI Average	29%	48%	18%	5%	2,952
CO	24%	56%	16%	4%	280
MO	23%	45%	24%	8%	224
NC	21%	50%	19%	10%	185

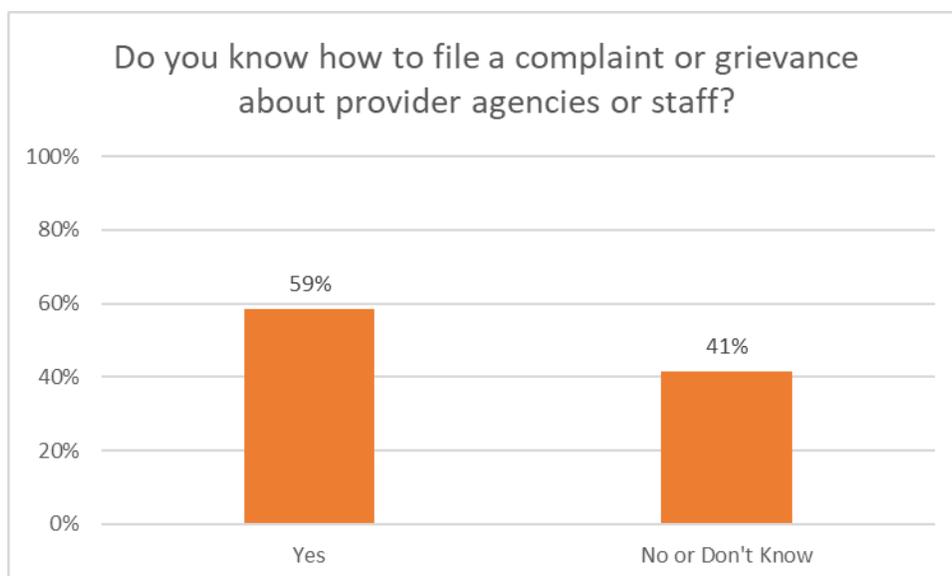


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?³

Significantly Above Average

State	Yes	No or Don't Know	N
CO	80%	20%	285

Within Average Range

State	Yes	No or Don't Know	N
OR	60%	40%	707
WI	60%	40%	1,031
UT	60%	40%	205
NC	59%	41%	192
Weight NCI Average	59%	41%	3,004
LA	59%	41%	193
AZ	56%	44%	165

Significantly Below Average

State	Yes	No or Don't Know	N
MO	50%	50%	226

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

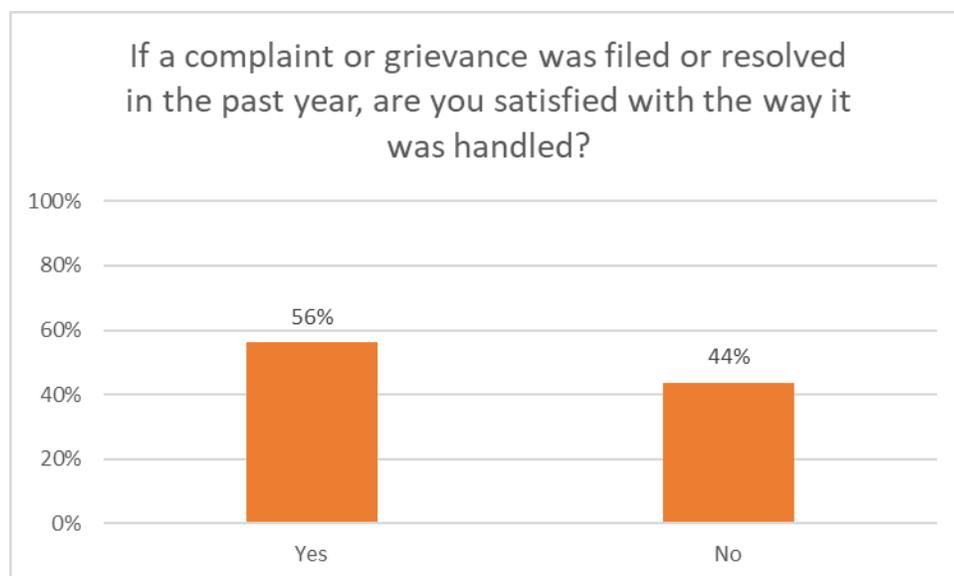
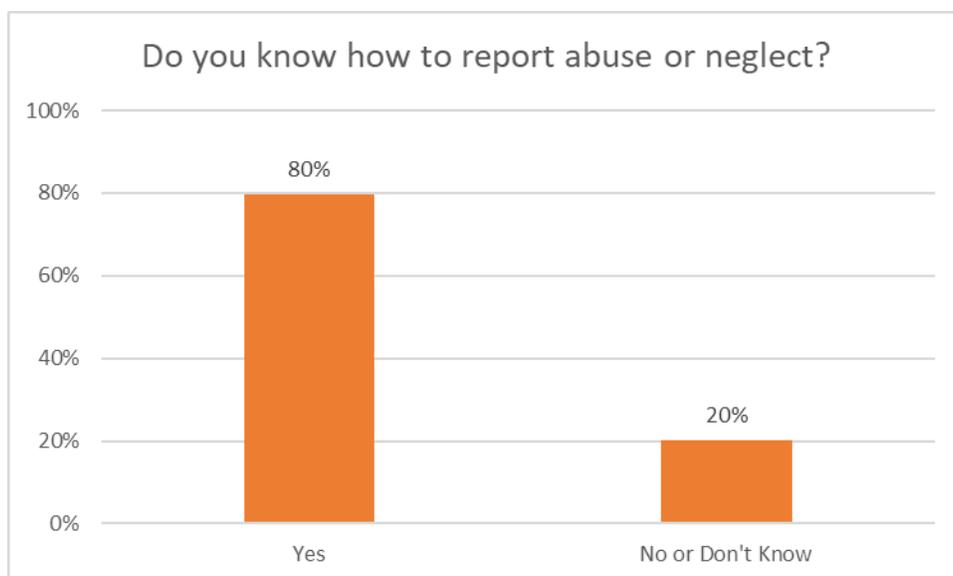


Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?⁴

Within Average Range

State	Yes	No	N
LA	66%	34%	29
CO	60%	40%	25
NC	59%	41%	27
Weight NCI Average	56%	44%	227
AZ	55%	45%	20
OR	46%	54%	41
WI	46%	54%	61

⁴ The following states are not included in the table due to low N (<20), but their responses are included in the NCI Average: MO, UT

Table Q49. Do you know how to report abuse or neglect?⁵**Significantly Above Average**

State	Yes	No or Don't Know	N
CO	91%	9%	285
OR	85%	15%	705

Within Average Range

State	Yes	No or Don't Know	N
NC	83%	17%	191
MO	83%	17%	230
WI	81%	19%	1,018
Weight NCI Average	80%	20%	2,988
UT	79%	21%	204
LA	78%	22%	190
AZ	73%	27%	165

⁵ Don't Know' responses were included in 'No' responses for this question.

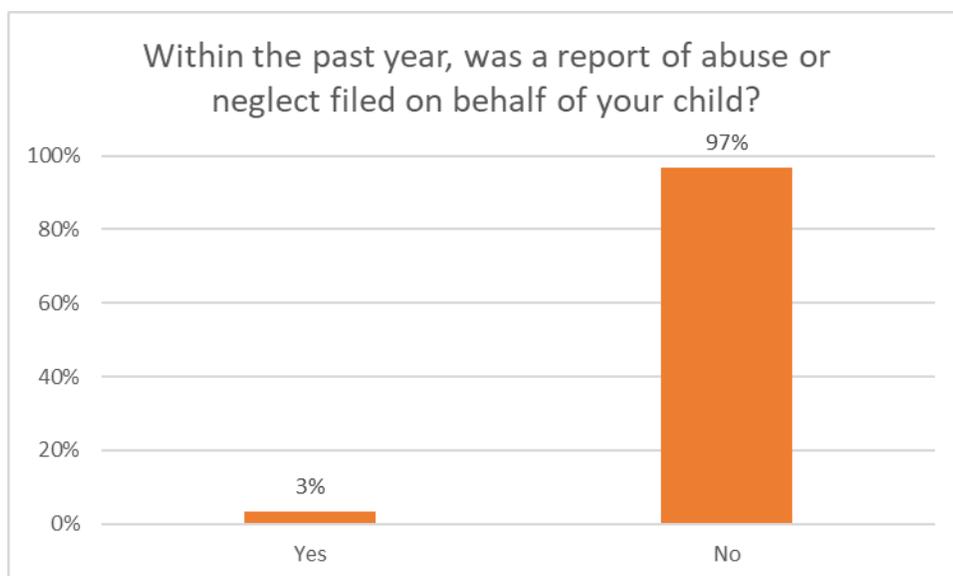


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your child?

Within Average Range

State	Yes	No	N
CO	6%	94%	283
MO	5%	95%	226
OR	5%	95%	682
NC	4%	96%	188
Weight NCI Average	3%	97%	2,935
WI	3%	97%	1,011
UT	2%	98%	199
AZ	2%	98%	161
LA	2%	98%	185

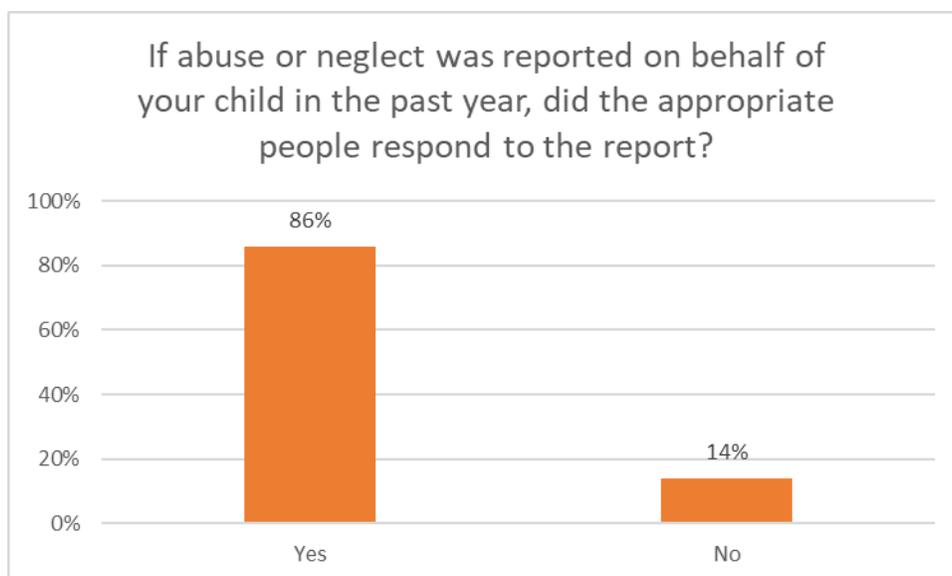


Table Q51. If abuse or neglect was reported on behalf of your child in the past year, did the appropriate people respond to the report?⁶

Within Average Range

State	Yes	No	N
OR	93%	7%	30
Weight NCI Average	86%	14%	95
WI	85%	15%	20

⁶ The following states are not included in the table due to low N (<20), but their responses are included in the NCI Average: AZ, CO, LA, MO, NC, UT

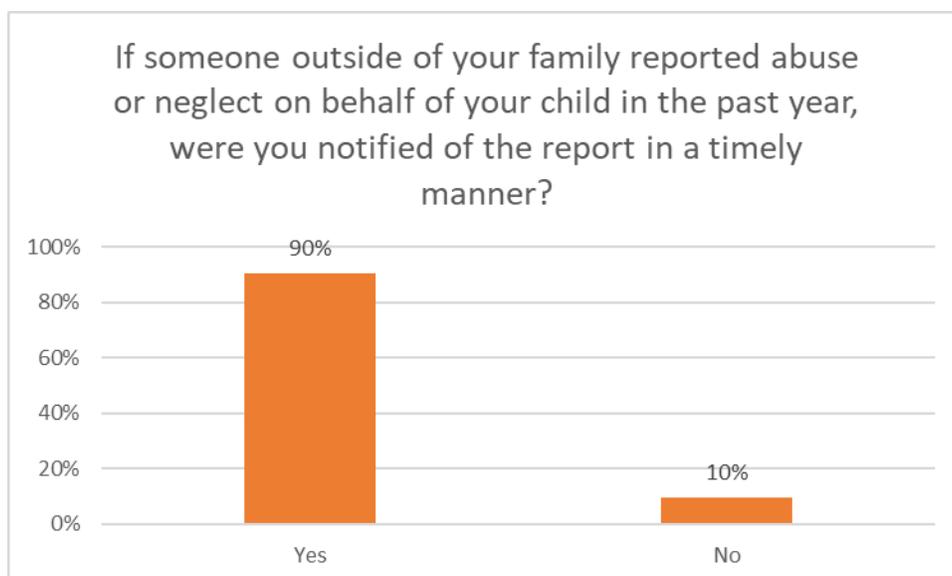


Table Q52. If someone outside of your family reported abuse or neglect on behalf of your child in the past year, were you notified of the report in a timely manner? ⁷

Within Average Range

State	Yes	No	N
Weight NCI Average	90%	10%	73
OR	88%	13%	24

⁷ The following states are not included in the table due to low N (<20), but their responses are included in the NCI Average: AZ, CO, LA, MO, NC, UT, WI

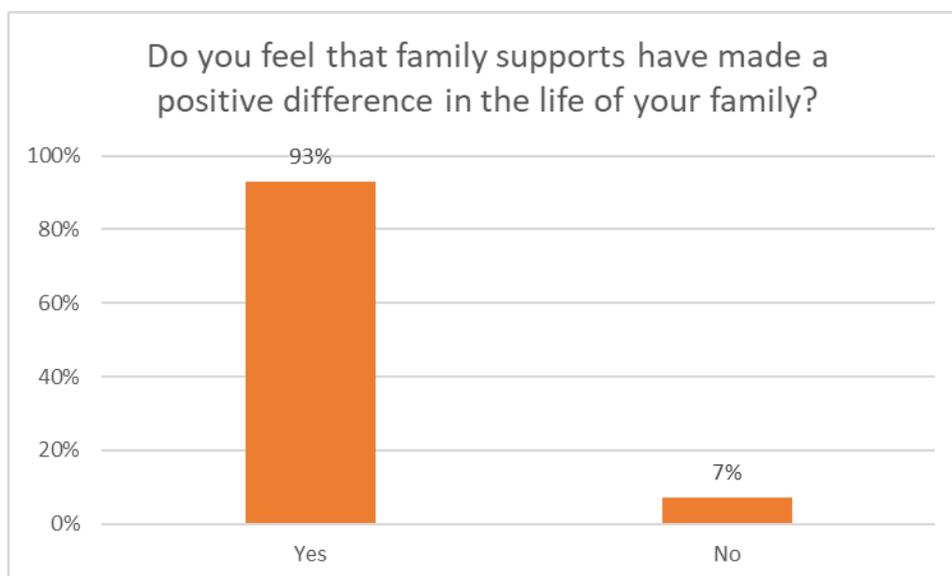


Table Q53. Do you feel that family supports have made a positive difference in the life of your family?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
UT	98%	2%	191
CO	97%	3%	266
OR	96%	4%	648

Within Average Range

State	Yes	No	N
WI	94%	6%	943
Weight NCI Average	93%	7%	2,740
AZ	93%	7%	150
NC	92%	8%	179
LA	91%	9%	164
MO	88%	12%	199

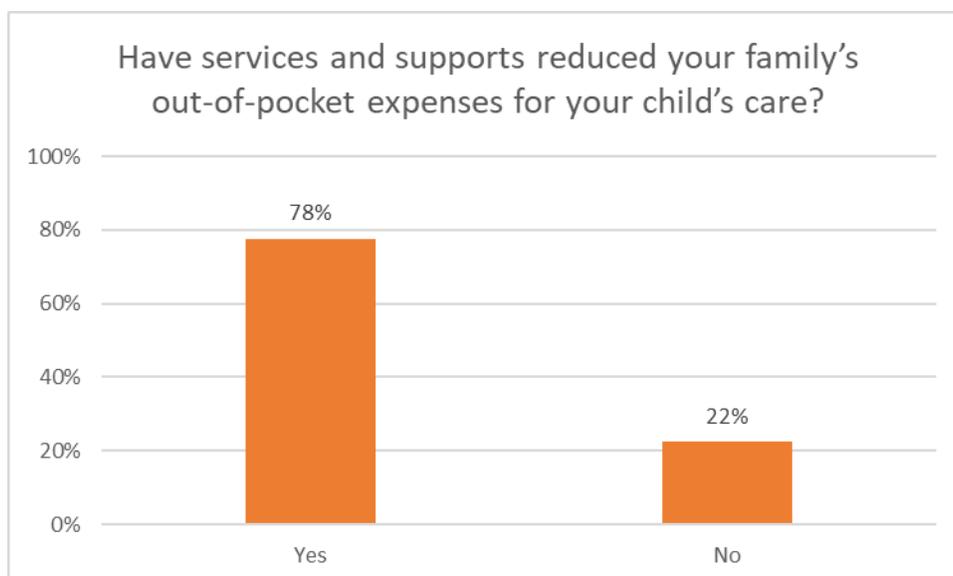


Table Q54. Have services and supports reduced your family's out-of-pocket expenses for your child's care?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
CO	91%	9%	277
UT	85%	15%	196
WI	82%	18%	944

Within Average Range

State	Yes	No	N
AZ	84%	16%	148
OR	80%	20%	653
Weight NCI Average	78%	22%	2,771
NC	72%	28%	175

Significantly Below Average

State	Yes	No	N
LA	63%	37%	169
MO	61%	39%	209

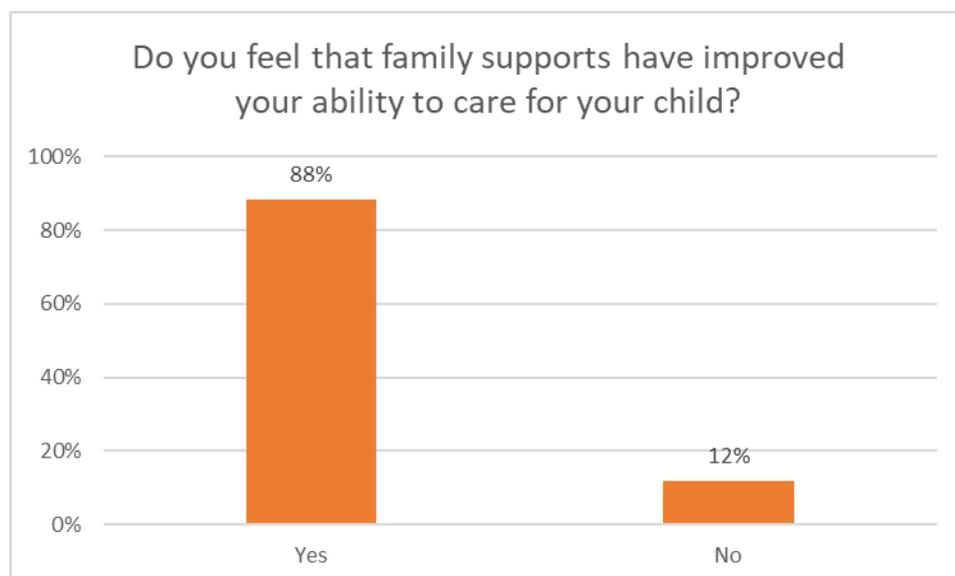


Table Q55. Do you feel that family supports have improved your ability to care for your child?

Significantly Above Average

State	Yes	No	N
UT	96%	4%	194
CO	94%	6%	273
OR	91%	9%	659

Within Average Range

State	Yes	No	N
AZ	92%	8%	154
WI	89%	11%	943
Weight NCI Average	88%	12%	2,770
NC	85%	15%	185
LA	82%	18%	170
MO	81%	19%	192

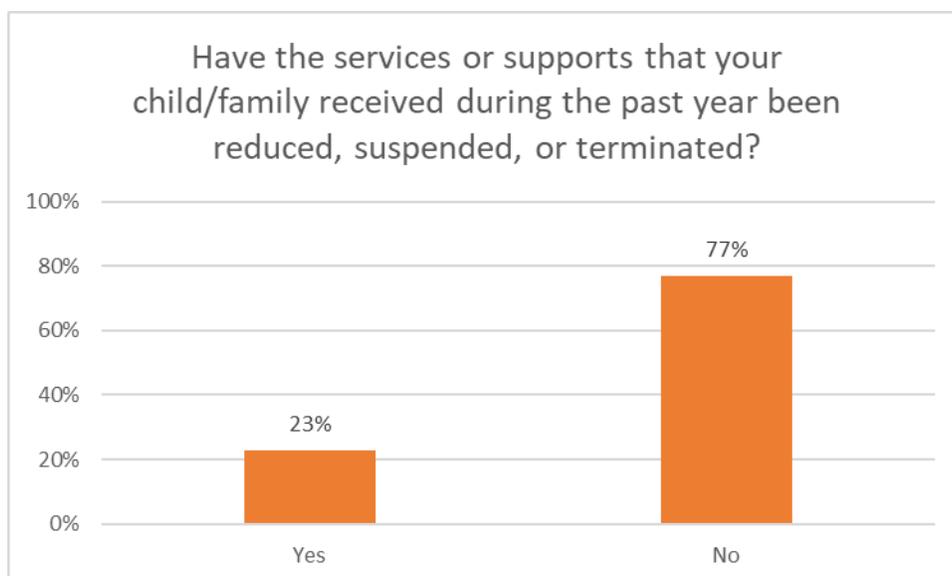


Table Q56. Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
CO	33%	67%	276

Within Average Range

State	Yes	No	N
MO	31%	69%	206
LA	30%	70%	175
AZ	26%	74%	155
Weight NCI Average	23%	77%	2,810
WI	21%	79%	959
NC	21%	79%	180

Significantly Below Average

State	Yes	No	N
OR	10%	90%	667
UT	7%	93%	192

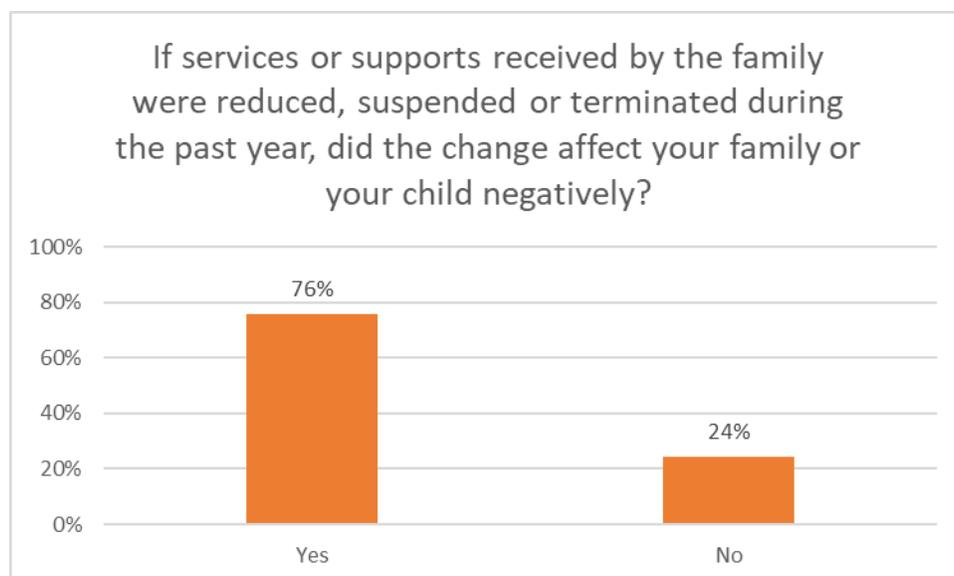


Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change affect your family or your child negatively?⁸

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
NC	91%	9%	34
CO	87%	13%	90

Within Average Range

State	Yes	No	N
OR	79%	21%	57
WI	78%	22%	176
Weight NCI Average	76%	24%	507
MO	75%	25%	59
AZ	65%	35%	34
LA	60%	40%	43

⁸ UT is not included in the table due to low N (<20), but their responses are included in the NCI Average

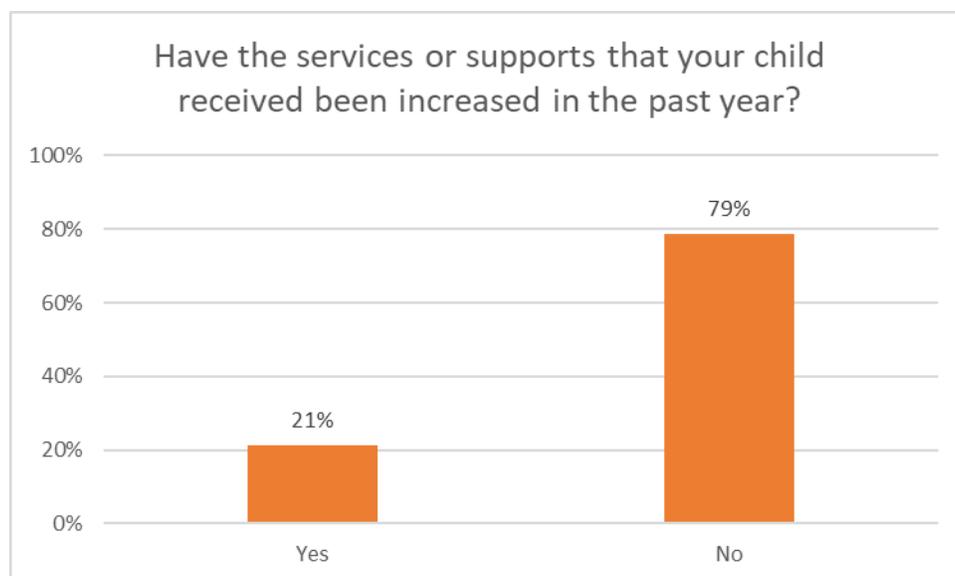


Table Q58. Have the services or supports that your child received been increased in the past year?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
OR	35%	65%	623
WI	28%	72%	930

Within Average Range

State	Yes	No	N
Weight NCI Average	21%	79%	2,693
UT	21%	79%	169
LA	20%	80%	170
NC	20%	80%	176
AZ	18%	82%	154
CO	17%	83%	262

Significantly Below Average

State	Yes	No	N
MO	11%	89%	209

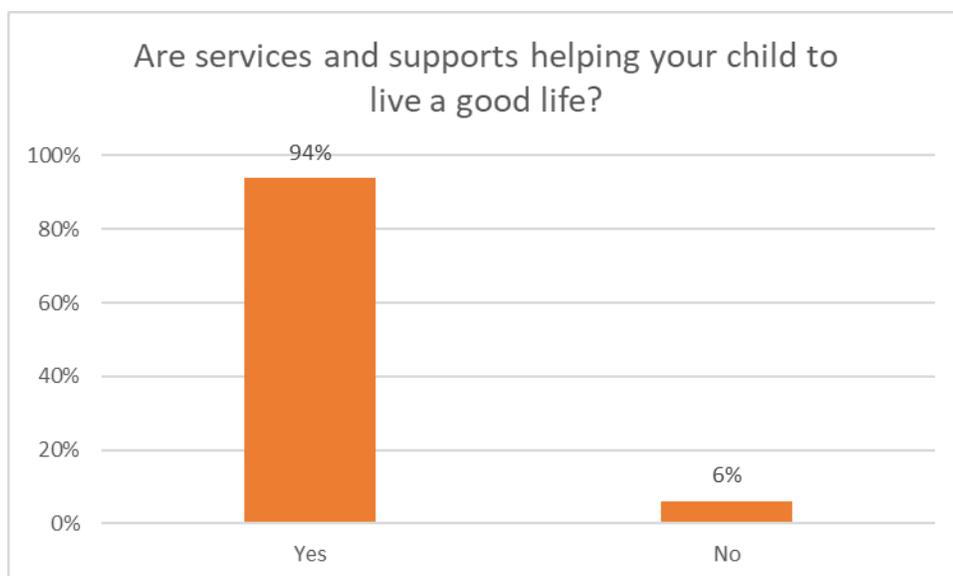


Table Q59. Are services and supports helping your child to live a good life?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
UT	99%	1%	193
AZ	97%	3%	152
OR	96%	4%	656

Within Average Range

State	Yes	No	N
CO	96%	4%	264
WI	96%	4%	943
Weight NCI Average	94%	6%	2,739
LA	91%	9%	163
MO	90%	10%	189
NC	89%	11%	179

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

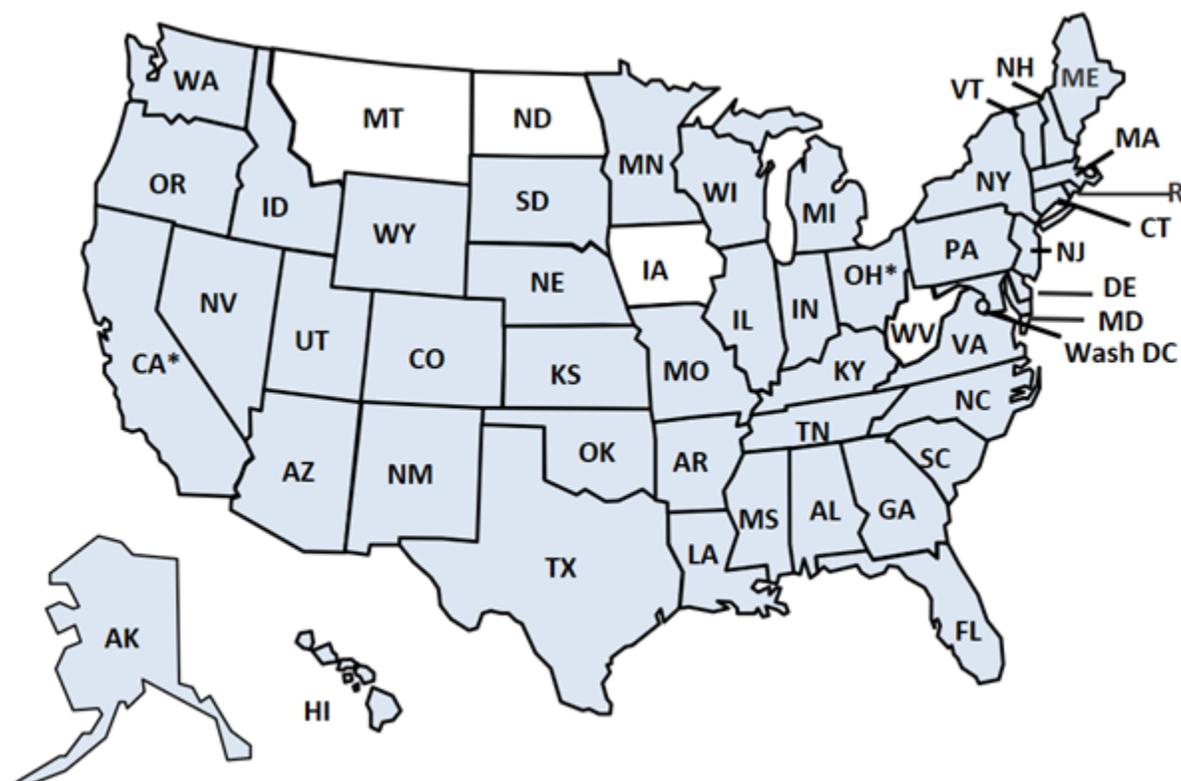
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven 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 2019-20 data collection cycle, 46 states, the District of Columbia, and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and the participating states are shown on the map below.

Figure 1. NCI State Participation 2018-19



The Core Indicators

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

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

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

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

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

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

Sub-Domains and Concern Statements

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

Figure 2. Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

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

For more information on how to use these data for quality improvement, please see this handbook: [Using National Core Indicators for Quality Improvement Initiatives](#).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: CA, CO, LA, NC, OH, OR, WA and WI.

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 $d = \frac{2t}{\sqrt{df}}$. A cutoff point of Cohen's $d = 0.2$ was chosen for the effect size to be considered “meaningfully significant,” following the standard interpretation offered by Cohen (1988) that Cohen's d of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

Data Entry and Analysis

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

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

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

Statistical significance testing was conducted on each state's “yes” or “always” response compared to the NCI 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 2019-20, eight states administered the Child Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% margin of error; their data are included in this report. The following table shows the number of surveys each state sent, surveys returned, response rates, and the number of valid surveys accepted for inclusion in data analysis.

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	Complete Surveys	Response Rate ¹⁵	Margin of Error	Paper Submission	Direct Entry Submission
AZ	17,434	1,400	166	11.9%	7.57%	100%	0.0%
CO	2,084	2,084	292	14.0%	5.32%	64%	36%
LA	3,927	2,000	198	9.9%	6.79%	95%	5%
MO	3,859	1,500	230	15.3%	6.27%	84%	16%
NC	14,945	1,200	195	16.3%	6.97%	89%	11%
OR	4,661	4,661	715	15.3%	3.37%	90%	10%
UT	825	825	206	25.0%	5.92%	76%	24%
WI	11,487	11,024	1054	9.6%	2.88%	62%	38%
Overall ¹⁶	59,222	1,400	3,056	14.7%	5.64%	77%	23%

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.

¹⁵ State response rates were calculated as following: the number of complete surveys divided by total surveys sent in that state (type "RR1" as defined by the American Association for Public Opinion Research). For more details on the definition, please see the AAPOR report: https://www.aapor.org/AAPOR_Main/media/publications/Standard-Definitions20169theditionfinal.pdf

¹⁶ Consistent with past years, the "overall" response rates and margins of error were calculated as the average of state averages, and the overall paper submission and direct entry submission rates were calculated as averages weighted by state total service population sizes (column 2 of this table).