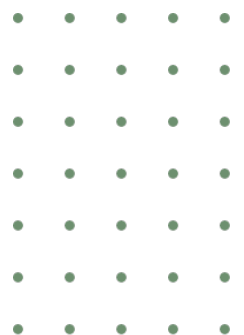


# National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)



National Report 2021-22

**Child Family Survey (CFS)**





# Human Services Research Institute

Human Services Research Institute (HSRI)  
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# NASDDDS

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of  
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## List of Acronyms Used in This Report

CFS	Child Family Survey
CMS	Centers for Medicare & Medicaid Services
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

<b>Executive Summary</b> .....	<b>1</b>
Note on the Impact of COVID-19 .....	1
<b>Results</b> .....	<b>2</b>
<b>Presentation of Data</b> .....	<b>3</b>
<b>Demographics</b> .....	<b>4</b>
<b>Child</b> .....	<b>5</b>
Table 1. More Than One Child Living in the Home Has IDD .....	6
Table 2. Child's Age.....	7
Table 3. Child's Gender .....	8
Table 4. Child's Race and Ethnicity .....	9
Table 5a. Child's Conditions .....	10
Table 5b. Child's Conditions (Continued).....	11
Table 6a. Child's Health Conditions .....	12
Table 6b. Child's Health Conditions (Continued).....	13
Table 7. Family Member's Preferred Language .....	14
Table 8. Child's Preferred Means of Communication.....	15
Table 9. Child's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors.....	16
Table 10. Child's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating) .....	16
<b>Respondents</b> .....	<b>17</b>
Table 11. Language Usually Spoken at Home .....	18
Table 12. Respondent's Age .....	19
Table 13. Respondent's Health .....	19
Table 14. Respondent's Relationship to Child.....	20
Table 15. Respondent or Other Family Member Provides Paid Support to Child .....	20
Table 16. Number of Adults in Household.....	21
Table 17. Number of Children (Under 18 Years Old) in Household (Including the Child Receiving Services) .....	21
Table 18. Respondent's Highest Level of Education .....	22
Table 19. Total Taxable Household Income of Wage Earners in the Past Year .....	23
Table 20. Residential Designation (Urban, Suburban, or Rural) .....	24
<b>Services and Supports Received</b> .....	<b>25</b>
Table 21. Services and Supports Received from ID/DD Agency .....	26
Table 22. Additional Services and Supports Received (not from the IDD Agency) .....	27
<b>Main Survey Results</b> .....	<b>28</b>
<b>Information and Planning</b> .....	<b>29</b>

Table 23. Do you get enough information to take part in planning services for your child? ..... 30

Table 24. Is the information you get about services and supports easy to understand? ..... 31

Table 25. Do you get information about services and supports in your preferred language? ..... 32

Table 26. Does the case manager/service coordinator listen to your family's choices and opinions?..... 33

Table 27. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?..... 34

Table 28. Do you need help planning for your child's future in any of these areas? ..... 35

Table 29. Has your family learned about alternatives to guardianship/conservatorship? ..... 36

Table 30. Does your child have a service plan?..... 37

Table 31. Does the plan include all the services and supports your child needs? ..... 38

Table 32. Did you or someone else in your family (besides your child with a disability) help make the IPP/IFSP?..... 39

Table 33. Did your child help make the plan? ..... 40

Table 34. Do you feel like your family had enough say or input in making the plan?..... 41

Table 35. 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)?..... 42

Table 36. If your child has a transition plan, did you or another family member help make the plan?..... 43

Table 37. If your child has a transition plan, did your child help make the plan?..... 44

**Access and Delivery of Services and Supports ..... 45**

Table 38. Does your child get all the services listed in the plan? ..... 46

Table 39. Does your family get the supports and services it needs? ..... 47

Table 40. What additional services does your family need?..... 48

Table 41. Do services and supports change when your family's needs change?..... 49

Table 42. Does your child have the special equipment or accommodations they need? ..... 50

Table 43. If you need respite services, how often are you able to get them when needed? ..... 51

Table 44. If you have used respite services in the past year, were you satisfied with the quality of the respite providers?..... 52

Table 45. Are you or your family member able to contact their support workers when you want?..... 53

Table 46. Are you or your family member able to contact your child's case manager/service coordinator when you want? ..... 54

Table 47. Do service providers for your child work together to provide support? ..... 55

Table 48. Are services delivered in a way that is respectful of your family's culture? ..... 56

Table 49. Does your child use technology in their everyday life to help them do things on their own?..... 57

Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home? ..... 58

Table 51. How well does the internet work in your home?..... 59

**Workforce ..... 60**

Table 52. Do support workers come and go when they are supposed to? ..... 61

Table 53. Do support workers speak to you in a way you understand? ..... 62

Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child?.....63

Table 55. Do support workers have the right information and skills to meet your family’s needs? .....64

Table 56. Do your child’s support workers change too often? Is there too much “turnover” of support workers? .....65

Table 57. Is there always a staff person available to support your child when support is needed? .....66

**Choice, Decision Making and Control ..... 67**

Table 58. Can someone in your family choose or change the provider agency that provides your child’s services? .....68

Table 59. Can someone in your family choose or change your child’s support workers? .....69

Table 60. Can someone in your family directly manage support staff? .....70

Table 61. Did you, your child, or someone else in your family choose your child’s case manager/service coordinator? .....71

**Involvement in the Community..... 72**

Table 62. Does your child do things in the community? .....73

Table 63. What makes it hard to do things in the community?.....74

Table 64. Does your child spend time with children who do not have developmental disabilities? .....75

Table 65. In your community, are there resources that your family and child can use that are not provided by the I/DD agency? .....76

Table 66. Does your family take part in any family-to-family networks in your community?.....77

**Health, Welfare, and Safety ..... 78**

Table 67. Can your child see a primary care provider (doctor, registered nurse, etc.) when needed? .....79

Table 68. Does your child’s primary care doctor understand your child’s needs related to their disability?.....80

Table 69. Can your child go to the dentist when needed? .....81

Table 70. Does your child’s dentist understand your child’s needs related to their disability?.....82

Table 71. If your child takes prescription medications, do you know what they’re for? .....83

Table 72. Do you, your child, or someone else in your family know what is needed to safely take the prescription medications?.....84

Table 73. Can your child get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling) .....85

Table 74. If your child uses mental health services, does the mental health professional understand your child’s needs related to their disability?.....86

Table 75. If you asked for crisis or emergency services during the past 12 months, were services provided when needed? .....87

Table 76. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or natural disaster?.....88

Table 77. Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child’s case manager/service coordinator? .....89

Table 78. Do you know how to file a complaint or grievance about provider agencies or staff? .....90

Table 79. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled? .....91

Table 80. Do you know how to report abuse or neglect related to your child? ..... 92

Table 81. Within the past 12 months, was a report of abuse or neglect filed on behalf of your child? ..... 93

Table 82. If a report of abuse or neglect was filed on behalf of your child, if someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner? ..... 94

**Satisfaction With Services and Supports ..... 95**

Table 83. Overall, are you satisfied with the services and supports your child currently receives? ..... 96

Table 84. Do you feel that services and supports have made a positive difference in the life of your child? ..... 97

Table 85. Have services and supports reduced your family’s out-of-pocket expenses for your child’s care? ..... 98

Table 86. Do you feel that family supports have improved your ability to care for your child? ..... 99

Table 87. Have the services or supports that your child received during the past 12 months been reduced, suspended, or terminated? ..... 100

Table 88. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family or your child negatively? ..... 101

Table 89. Have the services or supports that your child received been increased in the past year? ..... 102

Table 90. Are services and supports helping your child to live a good life? ..... 103

**COVID-19 Supplement ..... 104**

Table 91. Were your child’s services and supports changed, canceled, or reduced during COVID time? ..... 105

Table 92. If yes, are those changes still in effect (still part of your child’s life)? ..... 106

Table 93. If some or all of your child’s services have reopened or restarted: Did your family get enough information about the services reopening/restarting? ..... 107

Table 94. If some or all of your child’s services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions? ..... 108

Table 95. If staff come into your home to support your child: Do you feel that the staff follow recommendations to keep the household safe and healthy? ..... 109

Table 96. Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community? ..... 110

Table 97. In preparation for the future, have you made or updated an emergency plan with your child’s case manager or with other staff? ..... 111

**NCI-IDD History and Activities..... 112**

**Overview of National Core Indicators ..... 113**

**State Participation ..... 113**

Figure 1. NCI-IDD State Participation 2021-22 ..... 114

**The Core Indicators..... 114**

Sub-Domains and Concern Statements ..... 115

Figure 2. Family Survey Sub-Domains and Concern Statements ..... 115

**How NCI-IDD Data Are Used ..... 115**

Caution and Limitations..... 116

**Methodology ..... 117**

**Sampling & Administration ..... 118**  
    Weighting.....118  
    Significance Testing.....119  
Technical Details ..... 119  
    Data Entry and Analysis ..... 120  
    Response Rates ..... 120  
Figure 3. Child Family Survey: State Response Rates ..... 121



## Executive Summary

The National Core Indicators®-Intellectual and Developmental Disabilities (NCI-IDD) 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-IDD 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 National Core Indicators (NCI) Child Family Survey is administered to families who have a child who lives in the family home and receives at least one service in addition to case management from the state DD agency. A Child Family Survey could be completed for an individual up to 22 years if still receiving “child” services. Not all states that participate in NCI-IDD administer the Child Family Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI-IDD during the 2021-22 data collection cycle, 7 states submitted a valid sample of Child Family Survey data: Alaska (AK), California (CA), Indiana (IN), Louisiana (LA), Missouri (MO), Oregon (OR) and Wisconsin (WI). This Final Report provides a summary of results based on data submitted by June 30, 2022.

### *Note on the Impact of COVID-19*

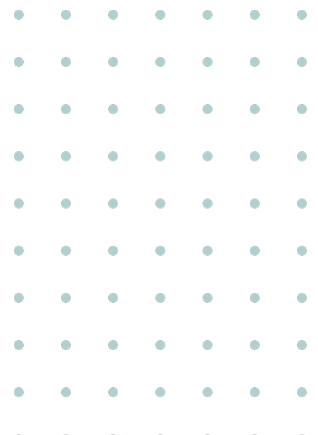
The 2021-22 NCI-IDD Family Survey data collection cycle began July 1, 2021 and ended June 30, 2022. As COVID-19 variants continued to impact communities across the United States, states were impacted in various ways throughout the year. Because the family surveys do not collect information on the date 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-IDD Surveys. The COVID-19 Supplement is intended to support the understanding of the experience of people with disabilities and their families at the beginning of the COVID-19 pandemic, and their interactions with services during that time. Last year’s Family Survey COVID-19 Supplement can be found [here](#).

**Note:** All Californians with an intellectual or developmental disability as defined by California law have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. As a result of these requirements, all eligible individuals are enrolled in California’s service system, and California establishes no waiting list for services. This impacts comparability between California NCI-IDD survey results and the NCI-IDD survey results of other states.



## Results



## Presentation of Data

In addition to basic demographic questions and questions on services 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-IDD Average. The charts are followed by accessible tables showing state outcomes and the NCI-IDD 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-IDD Average range, their 'always' or 'yes' response was not statistically different from the NCI-IDD Average.
- States with 20 or fewer respondents to a question **are not** included in tables; however, their data **are** included in the NCI-IDD 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-IDD Averages:** The NCI-IDD averages contained in this report are "weighted" means; their calculations reflect the relative population sizes of participating states and the states' sample sizes. Prior to 2016-17, NCI-IDD 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 their child's demographics, diagnoses and personal characteristics.

# Demographics

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

**Note on page orientation:** The pages in this section are in landscape orientation because some table headers cannot be displayed in full in portrait orientation.

## *Child*

This section provides demographic information about the child receiving services.

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*

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

State	Yes	No	N
AK	58%	42%	139
CA	68%	32%	5424
CO	74%	26%	216
IN	65%	35%	248
LA	64%	36%	395
MO	69%	31%	186
OR	65%	35%	575
WI	69%	31%	432
<b>Weighted NCI-IDD Average</b>	<b>68%</b>	<b>32%</b>	<b>7615</b>

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*

Table 2. Child's Age

State	Age	N
AK	13.2	163
CA	10.5	5455
CO	11.2	222
IN	11.4	253
LA	8.7	401
MO	11.2	194
OR	12.1	619
WI	10.3	434
<b>Weighted NCI-IDD Average</b>	<b>10.6</b>	<b>7741</b>

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*

**Table 3. Child's Gender**

State	Male	Female	Other	N
AK	69%	31%	0%	162
CA	72%	27%	0%	5480
CO	63%	37%	0%	214
IN	72%	28%	0%	253
LA	63%	37%	0%	401
MO	76%	24%	0%	194
OR	67%	33%	0%	624
WI	65%	35%	0%	436
<b>Weighted NCI-IDD Average</b>	<b>71%</b>	<b>29%</b>	<b>0%</b>	<b>7764</b>

*Table note: For "Other", the percentages for CA, OR and Weighted NCI-IDD Average are non-zero even though they are displayed as a rounded-down 0%.*

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*



**Table 4. Child’s Race and Ethnicity**

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

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer Not to Say
AK	25%	15%	5%	2%	64%	5%	1%	3%
CA	2%	17%	6%	1%	28%	55%	2%	3%
CO	4%	7%	9%	0%	78%	19%	0%	1%
IN	1%	4%	10%	0%	78%	10%	2%	2%
LA	1%	3%	36%	0%	56%	5%	2%	3%
MO	1%	2%	5%	1%	94%	3%	0%	2%
OR	4%	8%	5%	1%	80%	15%	2%	2%
WI	3%	6%	9%	0%	80%	10%	1%	2%
<b>Weighted NCI-IDD Average</b>	<b>2%</b>	<b>14%</b>	<b>8%</b>	<b>1%</b>	<b>41%</b>	<b>43%</b>	<b>2%</b>	<b>2%</b>

*Please note: All data in this section are reported by the respondent based on their understanding of their child’s demographics, diagnoses and personal characteristics*

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

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

State	Intellectual Disability	Mood Illness or psychiatric diagnosis	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Hearing loss (severe or profound)
AK	62%	23%	62%	13%	14%	8%
CA	31%	9%	75%	7%	5%	2%
CO	62%	29%	64%	15%	16%	7%
IN	32%	24%	67%	10%	4%	2%
LA	36%	10%	37%	15%	8%	8%
MO	29%	26%	86%	9%	6%	5%
OR	54%	26%	59%	11%	7%	6%
WI	47%	21%	57%	9%	8%	3%
<b>Weighted NCI-IDD Average</b>	<b>34%</b>	<b>12%</b>	<b>71%</b>	<b>8%</b>	<b>5%</b>	<b>3%</b>

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*

Table 5b. Child's Conditions (Continued)

State	Brain Injury	Seizure Or Neurological Disorder	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
AK	8%	22%	0%	9%	1%	8%	32%
CA	3%	11%	0%	9%	0%	1%	16%
CO	17%	36%	0%	9%	1%	3%	42%
IN	6%	15%	0%	12%	0%	2%	24%
LA	8%	25%	1%	9%	1%	1%	44%
MO	4%	18%	0%	2%	0%	1%	29%
OR	8%	18%	0%	11%	0%	9%	29%
WI	6%	22%	0%	15%	0%	1%	31%
<b>Weighted NCI-IDD Average</b>	<b>4%</b>	<b>14%</b>	<b>0%</b>	<b>9%</b>	<b>0%</b>	<b>1%</b>	<b>21%</b>

Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics

Table 6a. Child's Health Conditions

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol	Dysphagia	Pressure Ulcers
AK	15%	0%	2%	8%	0%	21%	0%
CA	7%	3%	2%	3%	5%	8%	1%
CO	10%	4%	1%	5%	3%	39%	5%
IN	11%	2%	4%	6%	1%	13%	0%
LA	9%	3%	1%	3%	2%	25%	1%
MO	5%	3%	0%	3%	2%	24%	3%
OR	10%	4%	2%	2%	4%	25%	2%
WI	16%	3%	2%	2%	2%	23%	1%
<b>Weighted NCI-IDD Average</b>	<b>8%</b>	<b>3%</b>	<b>2%</b>	<b>3%</b>	<b>5%</b>	<b>12%</b>	<b>1%</b>

Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics

**Table 6b. Child’s Health Conditions (Continued)**

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

State	Oral Health Problems	Sleep Apnea	Other pulmonary diagnosis	Chronic kidney disease	Long-term health problems associated with COVID-19	Other
AK	15%	40%	10%	8%	0%	40%
CA	8%	18%	7%	2%	1%	36%
CO	14%	39%	14%	1%	3%	47%
IN	12%	27%	3%	6%	0%	28%
LA	9%	21%	12%	4%	1%	45%
MO	12%	12%	2%	2%	2%	60%
OR	16%	27%	8%	4%	2%	34%
WI	13%	26%	12%	4%	1%	48%
<b>Weighted NCI-IDD Average</b>	<b>9%</b>	<b>20%</b>	<b>8%</b>	<b>3%</b>	<b>1%</b>	<b>37%</b>

Please note: All data in this section are reported by the respondent based on their understanding of their child’s demographics, diagnoses and personal characteristics

Table 7. Family Member's Preferred Language

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AK	98%	0%	0%	0%	0%	1%	1%	116
CA	73%	12%	1%	0%	0%	0%	14%	5534
CO	96%	0%	0%	0%	0%	2%	1%	222
IN	93%	2%	0%	0%	0%	2%	3%	254
LA	96%	2%	0%	0%	0%	1%	2%	395
MO	100%	0%	0%	0%	0%	0%	0%	189
OR	88%	3%	0%	0%	0%	1%	8%	631
WI	95%	3%	0%	0%	0%	1%	2%	429
<b>Weighted NCI-IDD Average</b>	<b>79%</b>	<b>9%</b>	<b>1%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>11%</b>	<b>7770</b>

Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics

Table 8. Child's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AK	72%	20%	2%	6%	1%	116
CA	70%	15%	2%	4%	8%	5503
CO	63%	15%	1%	11%	9%	222
IN	78%	10%	4%	6%	2%	252
LA	57%	28%	3%	5%	7%	390
MO	78%	11%	2%	6%	3%	185
OR	65%	14%	2%	6%	13%	630
WI	64%	20%	3%	7%	6%	438
<b>Weighted NCI-IDD Average</b>	<b>70%</b>	<b>16%</b>	<b>2%</b>	<b>5%</b>	<b>7%</b>	<b>7736</b>

Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics

**Table 9. Child’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors**

State	None	Some	Extensive	N
AK	25%	37%	38%	115
CA	29%	44%	27%	5400
CO	15%	28%	57%	221
IN	40%	42%	18%	248
LA	46%	31%	23%	388
MO	35%	44%	22%	194
OR	21%	48%	31%	622
WI	35%	44%	21%	433
<b>Weighted NCI-IDD Average</b>	<b>30%</b>	<b>43%</b>	<b>26%</b>	<b>7621</b>

**Table 10. Child’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)**

State	None	Some	Extensive	N
AK	8%	42%	50%	117
CA	10%	42%	48%	5512
CO	0%	20%	79%	221
IN	11%	48%	41%	253
LA	5%	33%	62%	390
MO	9%	52%	39%	193
OR	4%	40%	56%	628
WI	3%	42%	55%	437
<b>Weighted NCI-IDD Average</b>	<b>9%</b>	<b>42%</b>	<b>49%</b>	<b>7751</b>

*Please note: All data in this section are reported by the respondent based on their understanding of their child’s demographics, diagnoses and personal characteristics*



## *Respondents*

This section provides information about the survey respondent.

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*

**Table 11. Language Usually Spoken at Home**

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AK	96%	0%	0%	3%	0%	0%	2%	115
CA	54%	33%	2%	1%	1%	0%	9%	5458
CO	97%	1%	0%	0%	0%	0%	2%	218
IN	91%	6%	0%	0%	0%	0%	3%	252
LA	96%	2%	0%	0%	0%	0%	1%	395
MO	99%	0%	0%	0%	0%	0%	1%	192
OR	87%	7%	0%	0%	1%	0%	5%	629
WI	92%	5%	0%	0%	0%	0%	2%	431
<b>Weighted NCI-IDD Average</b>	<b>65%</b>	<b>25%</b>	<b>2%</b>	<b>1%</b>	<b>1%</b>	<b>0%</b>	<b>7%</b>	<b>7690</b>

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*

Table 12. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
AK	4%	68%	26%	1%	117
CA	14%	75%	10%	0%	5445
CO	9%	72%	19%	0%	222
IN	7%	75%	16%	2%	253
LA	22%	63%	14%	1%	397
MO	13%	79%	7%	1%	194
OR	9%	70%	20%	1%	628
WI	12%	75%	12%	0%	436
<b>Weighted NCI-IDD Average</b>	<b>13%</b>	<b>75%</b>	<b>12%</b>	<b>0%</b>	<b>7692</b>

Table 13. Respondent's Health

State	Excellent	Very good	Good	Fair	Poor	N
AK	10%	26%	39%	21%	3%	117
CA	14%	30%	40%	15%	2%	5458
CO	14%	38%	34%	12%	1%	220
IN	15%	38%	33%	11%	2%	253
LA	16%	34%	36%	13%	2%	396
MO	13%	35%	40%	11%	1%	194
OR	11%	33%	39%	15%	3%	624
WI	12%	42%	37%	8%	1%	436
<b>Weighted NCI-IDD Average</b>	<b>14%</b>	<b>32%</b>	<b>39%</b>	<b>14%</b>	<b>2%</b>	<b>7698</b>

Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics

Table 14. Respondent's Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
AK	86%	0%	9%	5%	117
CA	97%	0%	2%	1%	5539
CO	96%	0%	4%	0%	220
IN	90%	1%	8%	2%	253
LA	89%	0%	8%	3%	394
MO	97%	0%	2%	2%	194
OR	92%	0%	5%	3%	629
WI	95%	0%	3%	2%	437
<b>Weighted NCI-IDD Average</b>	<b>96%</b>	<b>0%</b>	<b>3%</b>	<b>1%</b>	<b>7783</b>

Table 15. Respondent or Other Family Member Provides Paid Support to Child

State	No	Yes, I am	Yes, Another Family Member Is
AK	73%	19%	9%
CA	56%	28%	18%
CO	38%	47%	19%
IN	81%	6%	13%
LA	72%	19%	10%
MO	91%	2%	8%
OR	56%	15%	33%
WI	78%	6%	16%
<b>Weighted NCI-IDD Average</b>	<b>61%</b>	<b>24%</b>	<b>17%</b>

Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics

Table 16. Number of Adults in Household

State	One	Two	Three	Four or More	N
AK	22%	60%	11%	6%	116
CA	16%	55%	19%	10%	5456
CO	16%	64%	16%	5%	217
IN	20%	59%	14%	7%	249
LA	25%	58%	13%	4%	387
MO	20%	66%	12%	2%	194
OR	18%	58%	15%	9%	628
WI	16%	69%	13%	3%	431
<b>Weighted NCI-IDD Average</b>	<b>17%</b>	<b>57%</b>	<b>18%</b>	<b>8%</b>	<b>7678</b>

Table 17. Number of Children (Under 18 Years Old) in Household (Including the Child Receiving Services)

State	One	Two	Three	Four or More	N
AK	49%	29%	17%	5%	113
CA	36%	39%	18%	8%	5427
CO	32%	39%	17%	12%	221
IN	40%	33%	19%	8%	252
LA	37%	37%	16%	10%	388
MO	35%	41%	16%	8%	190
OR	38%	36%	14%	12%	608
WI	34%	39%	14%	13%	433
<b>Weighted NCI-IDD Average</b>	<b>36%</b>	<b>38%</b>	<b>17%</b>	<b>9%</b>	<b>7632</b>

Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics

Table 18. 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
AK	5%	22%	6%	24%	43%	116
CA	20%	21%	7%	15%	37%	5518
CO	1%	4%	5%	18%	71%	222
IN	7%	20%	8%	13%	51%	251
LA	7%	23%	9%	20%	41%	394
MO	2%	12%	4%	22%	60%	194
OR	8%	15%	5%	19%	53%	616
WI	3%	14%	9%	15%	60%	436
<b>Weighted NCI-IDD Average</b>	<b>16%</b>	<b>19%</b>	<b>7%</b>	<b>16%</b>	<b>42%</b>	<b>7747</b>

Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics

Table 19. Total Taxable Household Income of Wage Earners in the Past Year<sup>12</sup>

State	No Earned Income	Up to \$15,000	\$15,001 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	Prefer Not to Say	N
AK	4%	6%	16%	15%	14%	29%	17%	115
CA	6%	10%	12%	20%	13%	26%	14%	5336
CO	3%	4%	4%	10%	18%	45%	17%	222
IN	5%	5%	5%	18%	17%	30%	19%	245
LA	9%	13%	11%	18%	10%	23%	15%	391
MO	9%	4%	8%	16%	17%	34%	12%	190
OR	8%	6%	8%	21%	15%	32%	9%	622
WI	3%	5%	6%	15%	16%	45%	9%	433
<b>Weighted NCI-IDD Average</b>	<b>6%</b>	<b>9%</b>	<b>11%</b>	<b>19%</b>	<b>14%</b>	<b>28%</b>	<b>14%</b>	<b>7554</b>

<sup>1</sup> Respondents did not respond if they were a public guardian/administrator, or if you represent a financial institution or guardianship agency

<sup>2</sup> Does not include state/federal benefits such as SSI, SSDI etc.

Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics

Table 20. Residential Designation (Urban, Suburban, or Rural)

State	Urban or Suburban	Rural	N
AK	68%	32%	114
CA	90%	10%	4788
CO	85%	15%	219
IN	67%	33%	243
LA	60%	40%	362
MO	68%	32%	189
OR	73%	27%	607
WI	70%	30%	424
<b>Weighted NCI-IDD Average</b>	<b>84%</b>	<b>16%</b>	<b>6946</b>

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*



## *Services and Supports Received*

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

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*

**Table 21. Services and Supports Received from ID/DD Agency**

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

State	Financial Support	In-Home Support	Out-of-home respite care	Early Intervention	Transportation	Mental/behavioral health care or other treatments or therapies	Self-Direction or Fiscal Intermediary Services
AK	19%	60%	56%	8%	36%	76%	n/a
CA	11%	32%	30%	1%	2%	21%	15%
CO	36%	55%	43%	7%	16%	86%	n/a
IN	7%	31%	24%	8%	11%	80%	41%
LA	23%	47%	11%	36%	19%	72%	35%
MO	33%	31%	24%	8%	10%	84%	47%
OR	18%	76%	35%	6%	21%	66%	69%
WI	34%	36%	37%	18%	11%	74%	43%
<b>Weighted NCI-IDD Average</b>	<b>15%</b>	<b>35%</b>	<b>29%</b>	<b>8%</b>	<b>6%</b>	<b>36%</b>	<b>23%</b>

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*

**Table 22. Additional Services and Supports Received (not from the IDD Agency)**

State	Social Security Payments (SSI or SSB)	Services or Supports from Other Agencies or Organizations
AK	34%	72%
CA	33%	60%
CO	21%	76%
IN	34%	68%
LA	38%	49%
MO	27%	81%
OR	41%	70%
WI	23%	76%
<b>Weighted NCI-IDD Average</b>	<b>33%</b>	<b>63%</b>

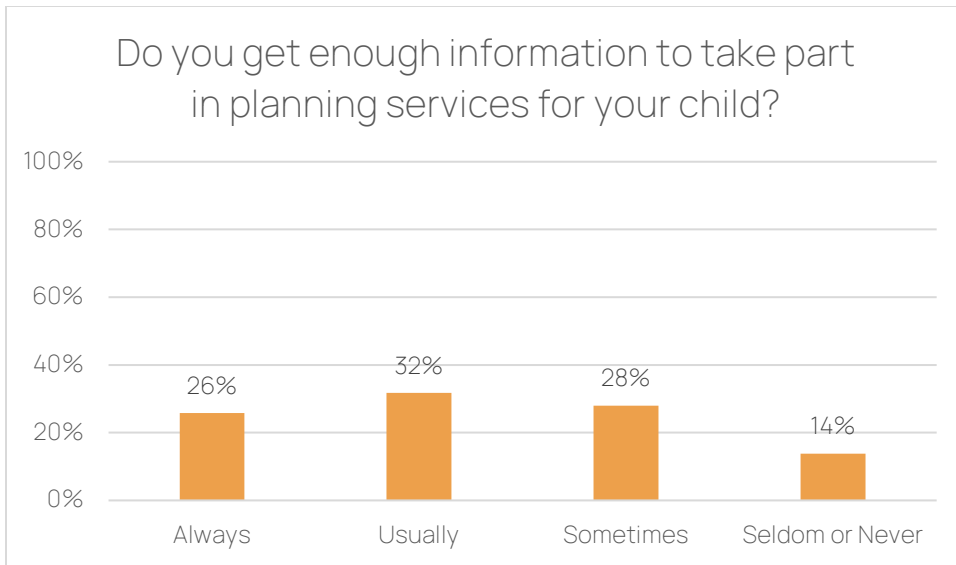
*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics*

## Main 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 family members with disabilities have the information and support necessary to plan for their services and supports.*



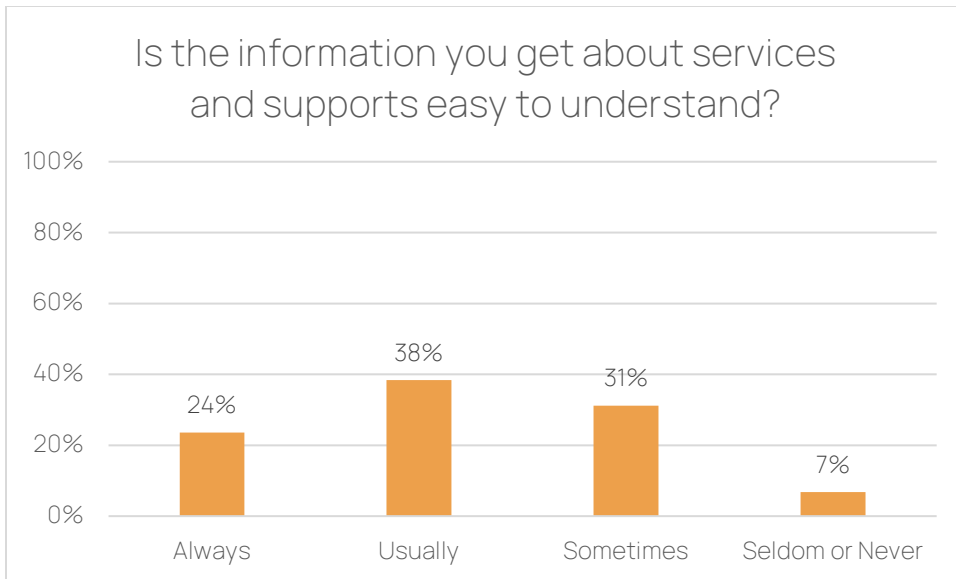
**Table 23. Do you get enough information to take part in planning services for your child?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	44%	33%	19%	4%	160
LA	41%	33%	22%	5%	372
IN	36%	37%	23%	4%	234
OR	31%	41%	21%	7%	608

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
WI	28%	42%	24%	7%	421
<b>Weighted NCI-IDD Average</b>	<b>26%</b>	<b>32%</b>	<b>28%</b>	<b>14%</b>	<b>6950</b>
CO	26%	53%	17%	5%	219
MO	24%	49%	19%	7%	188
CA	23%	29%	31%	17%	4748



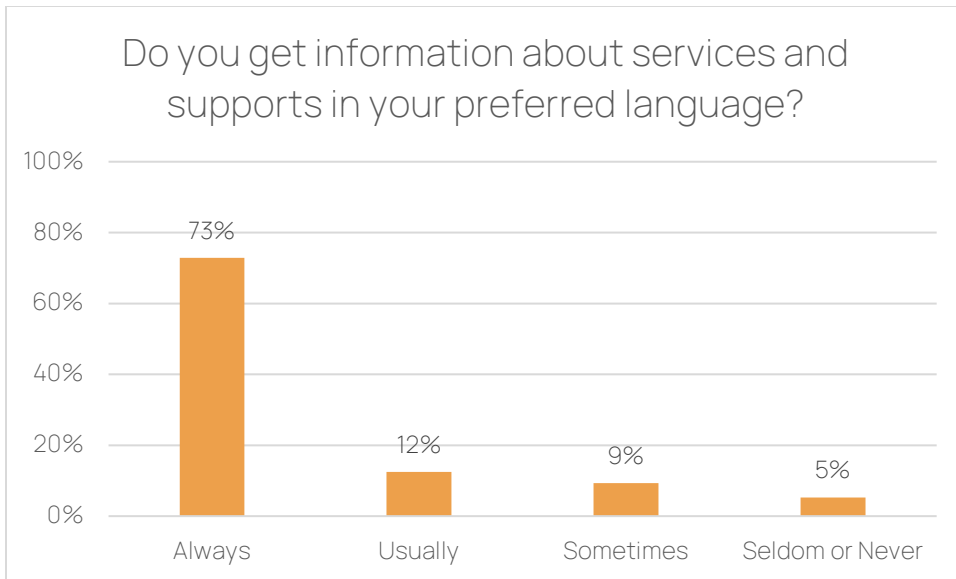
**Table 24. Is the information you get about services and supports easy to understand?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	35%	38%	24%	4%	159

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	27%	43%	27%	3%	376
OR	25%	46%	24%	6%	610
IN	24%	47%	26%	3%	243
CA	24%	36%	33%	7%	5101
<b>Weighted NCI-IDD Average</b>	<b>24%</b>	<b>38%</b>	<b>31%</b>	<b>7%</b>	<b>7324</b>
MO	22%	46%	25%	6%	189
CO	20%	44%	29%	6%	221
WI	19%	47%	26%	8%	425



**Table 25. Do you get information about services and supports in your preferred language?**

New question in 2021-22

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CO	92%	5%	1%	1%	220
MO	92%	5%	1%	2%	188
OR	90%	5%	3%	2%	621
AK	89%	6%	3%	3%	160
LA	88%	5%	3%	3%	389
WI	87%	7%	3%	3%	426
IN	84%	6%	6%	4%	247

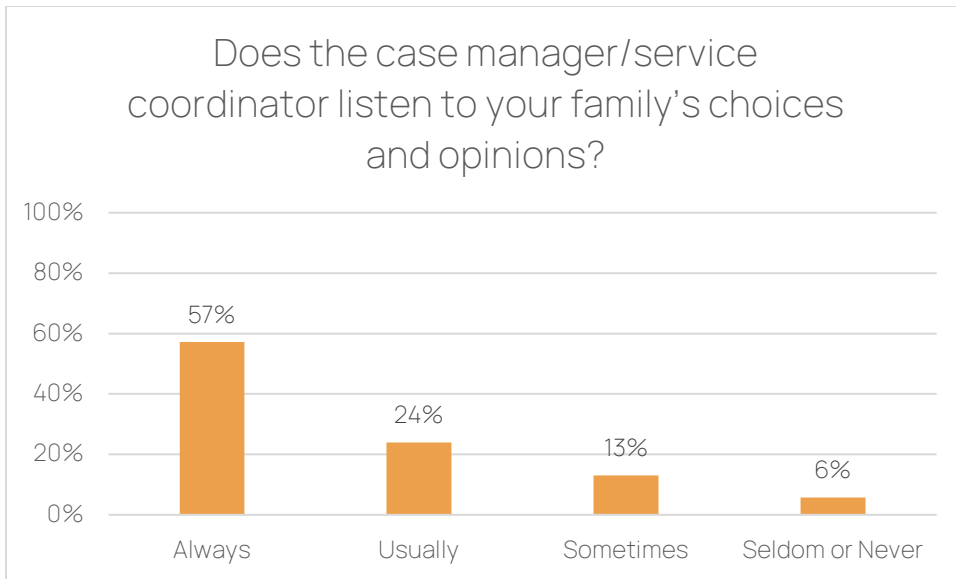
**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
Weighted NCI-IDD Average	73%	12%	9%	5%	7583

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CA	68%	15%	11%	6%	5332





**Table 26. Does the case manager/service coordinator listen to your family's choices and opinions?**

Question changed in 2021-22

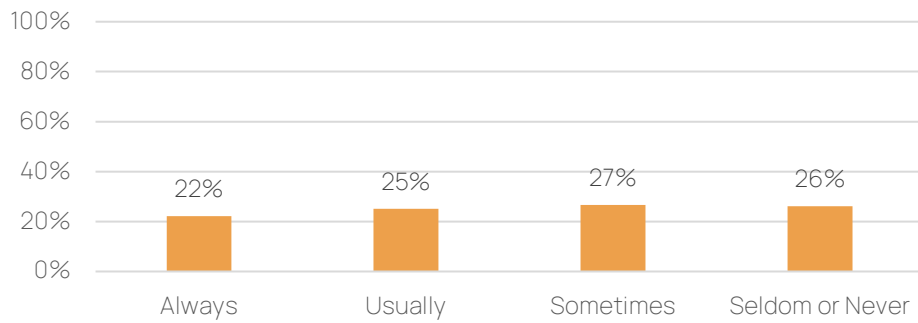
**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	83%	13%	1%	2%	157
IN	77%	18%	3%	2%	242
LA	70%	23%	6%	1%	369
MO	69%	19%	9%	3%	185
OR	64%	25%	8%	2%	604
WI	64%	22%	11%	3%	425
CO	64%	29%	6%	2%	211

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
<b>Weighted NCI-IDD Average</b>	<b>57%</b>	<b>24%</b>	<b>13%</b>	<b>6%</b>	<b>7356</b>
CA	53%	25%	15%	7%	5163

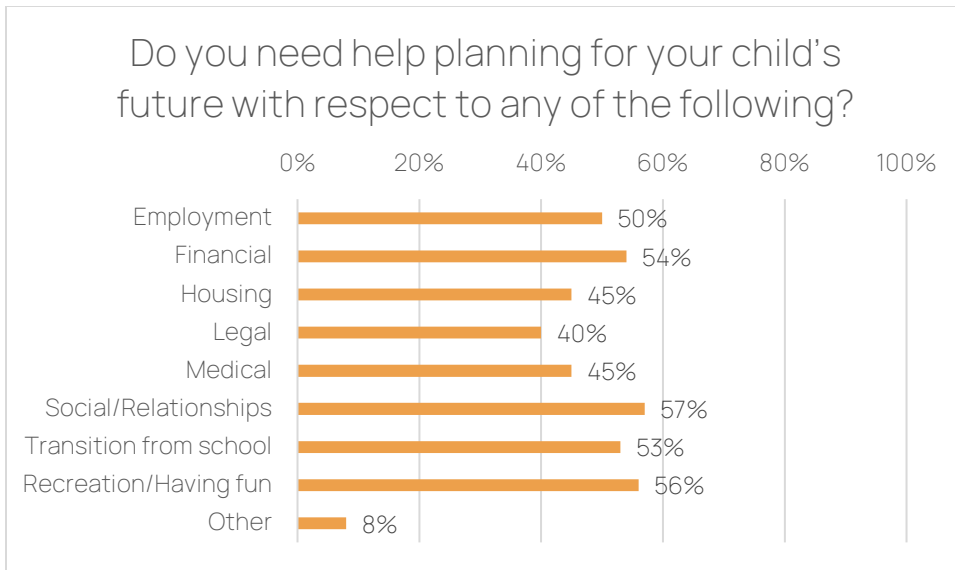
Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?



**Table 27. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?**

**Within Average Range**

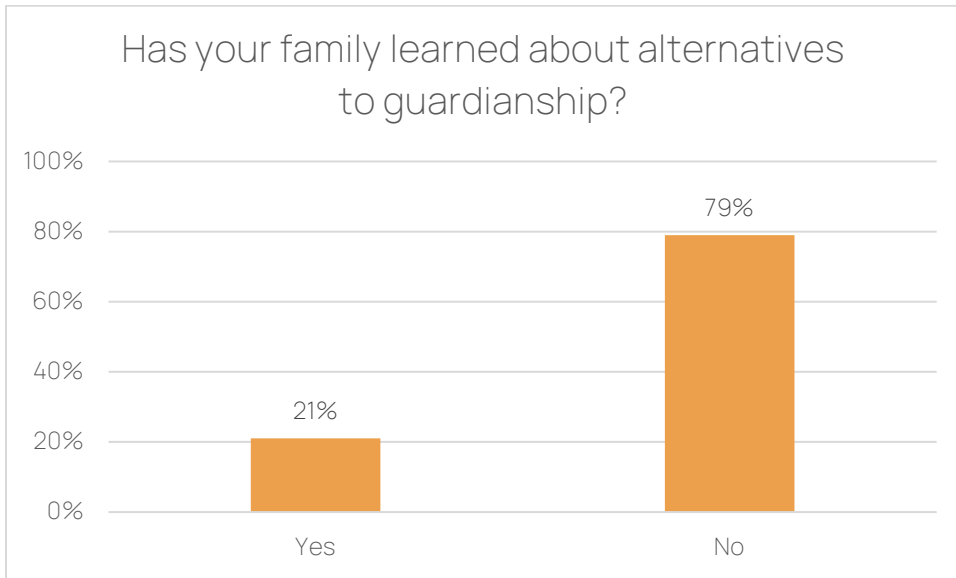
State	Always	Usually	Sometimes	Seldom or Never	N
AK	31%	22%	22%	25%	128
IN	27%	27%	21%	25%	191
LA	24%	25%	26%	25%	303
CA	22%	23%	27%	27%	4405
<b>Weighted NCI-IDD Average</b>	<b>22%</b>	<b>25%</b>	<b>27%</b>	<b>26%</b>	<b>6217</b>
CO	22%	31%	22%	25%	175
OR	21%	34%	24%	21%	517
WI	18%	33%	27%	22%	357
MO	15%	32%	27%	26%	141



**Table 28.** Do you need help planning for your child's future in any of these areas?

Categories are not mutually exclusive, therefore N is not shown

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition from school	Recreation/ Having fun	Other
AK	62%	71%	59%	56%	50%	59%	62%	62%	9%
CA	49%	51%	43%	38%	44%	58%	52%	56%	8%
CO	53%	63%	58%	61%	52%	53%	60%	53%	10%
IN	58%	57%	46%	38%	40%	50%	50%	46%	11%
LA	34%	48%	38%	43%	39%	44%	49%	45%	10%
MO	66%	65%	54%	50%	46%	69%	61%	57%	5%
OR	53%	58%	51%	45%	40%	54%	56%	57%	7%
WI	55%	63%	48%	48%	51%	61%	61%	61%	7%
<b>Weighted NCI-IDD Average</b>	<b>50%</b>	<b>54%</b>	<b>45%</b>	<b>40%</b>	<b>45%</b>	<b>57%</b>	<b>53%</b>	<b>56%</b>	<b>8%</b>



**Table 29. Has your family learned about alternatives to guardianship/conservatorship?**

New question in 2021-22

**Significantly Above Average**

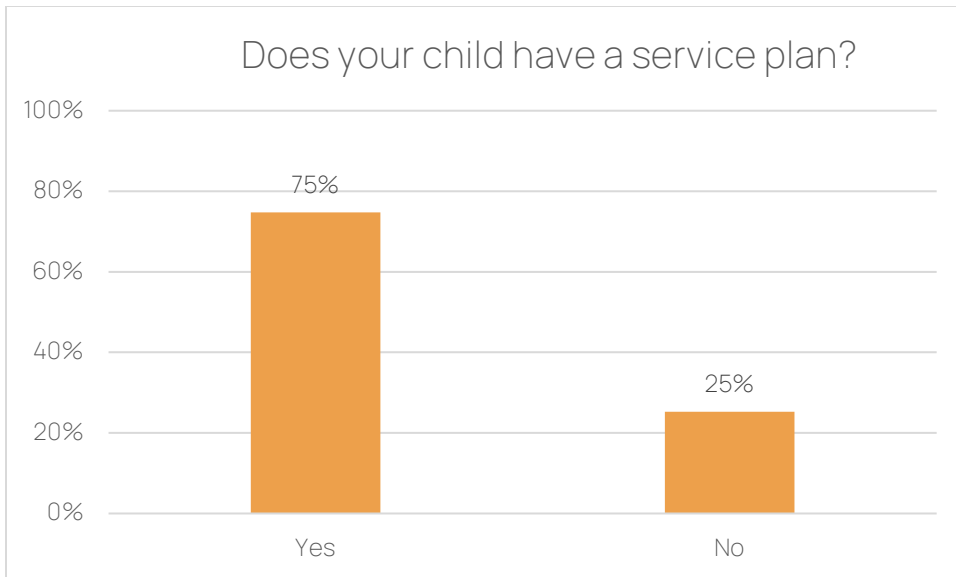
State	Yes	No	N
AK	33%	67%	140
OR	27%	73%	529

**Within Average Range**

State	Yes	No	N
LA	26%	74%	318
WI	24%	76%	384
<b>Weighted NCI-IDD Average</b>	<b>21%</b>	<b>79%</b>	<b>6049</b>
CA	21%	79%	4093
IN	20%	80%	210

**Significantly Below Average**

State	Yes	No	N
CO	15%	85%	204
MO	14%	86%	171



**Table 30. Does your child have a service plan?**

**Significantly Above Average**

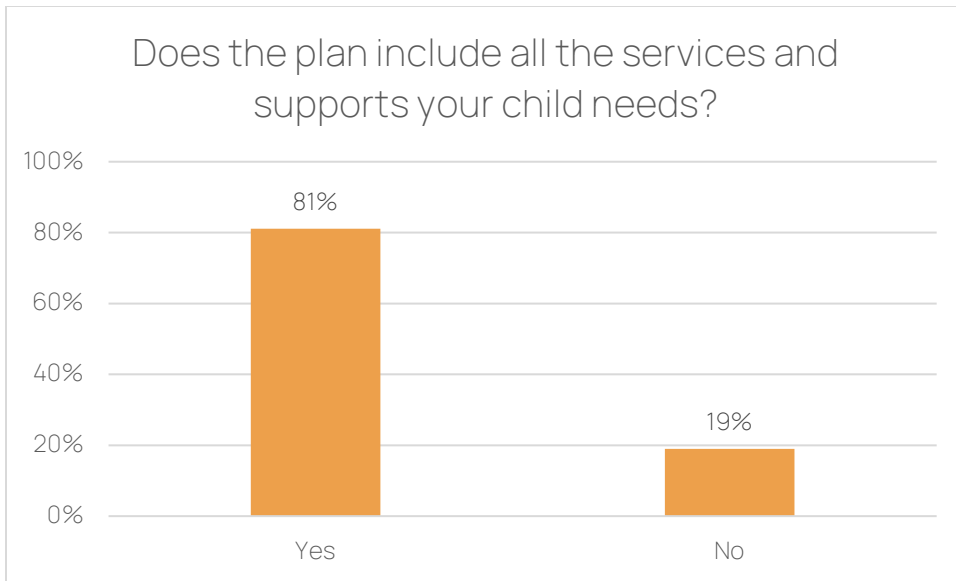
State	Yes	No	N
CO	91%	9%	211
AK	86%	14%	148
OR	85%	15%	547

**Within Average Range**

State	Yes	No	N
WI	78%	22%	365
MO	78%	22%	176
IN	76%	25%	200
<b>Weighted NCI-IDD Average</b>	<b>75%</b>	<b>25%</b>	<b>6334</b>
CA	74%	26%	4366

**Significantly Below Average**

State	Yes	No	N
LA	61%	39%	321



**Table 31. Does the plan include all the services and supports your child needs?**

**Significantly Above Average**

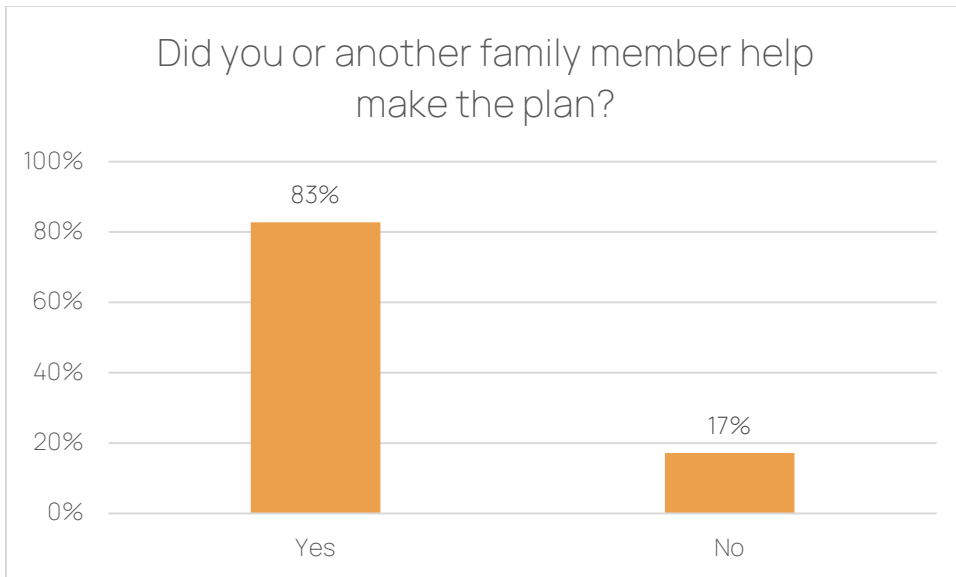
State	Yes	No	N
LA	92%	8%	177

**Within Average Range**

State	Yes	No	N
OR	84%	17%	400
WI	83%	17%	248
IN	82%	18%	130
MO	81%	19%	117
<b>Weighted NCI-IDD Average</b>	<b>81%</b>	<b>19%</b>	<b>3889</b>
CA	80%	20%	2528
AK	80%	20%	114

**Significantly Above Average**

State	Yes	No	N
CO	63%	37%	175



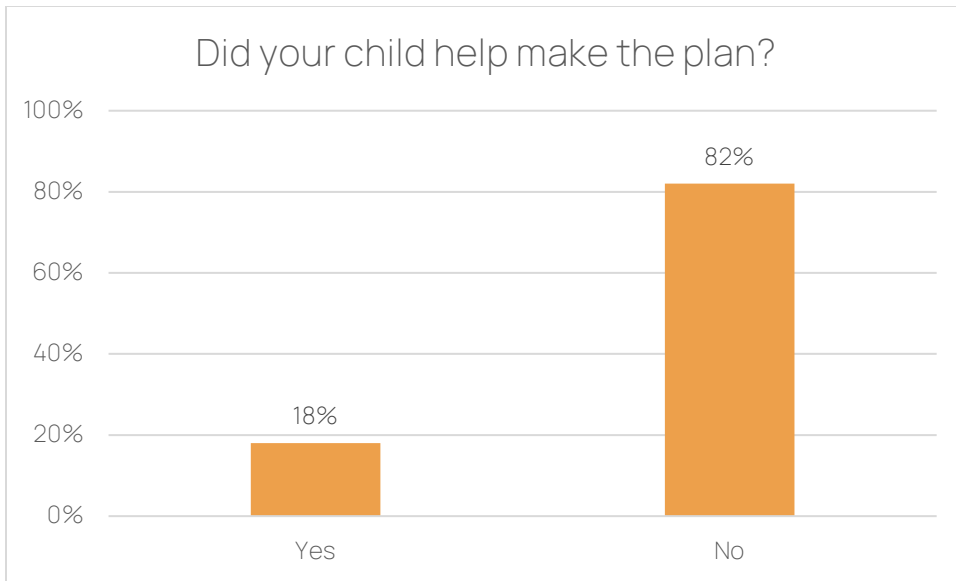
**Table 32. Did you or someone else in your family (besides your child with a disability) help make the IPP/IFSP?**

**Significantly Above Average**

State	Yes	No	N
AK	98%	2%	126
MO	95%	5%	134
CO	94%	6%	186
OR	93%	7%	445
WI	90%	10%	276

**Within Average Range**

State	Yes	No	N
LA	88%	12%	181
IN	86%	14%	143
<b>Weighted NCI-IDD Average</b>	<b>83%</b>	<b>17%</b>	<b>4273</b>
CA	80%	20%	2782



**Table 33. Did your child help make the plan?**

**Significantly Above Average**

State	Yes	No	N
OR	23%	77%	453

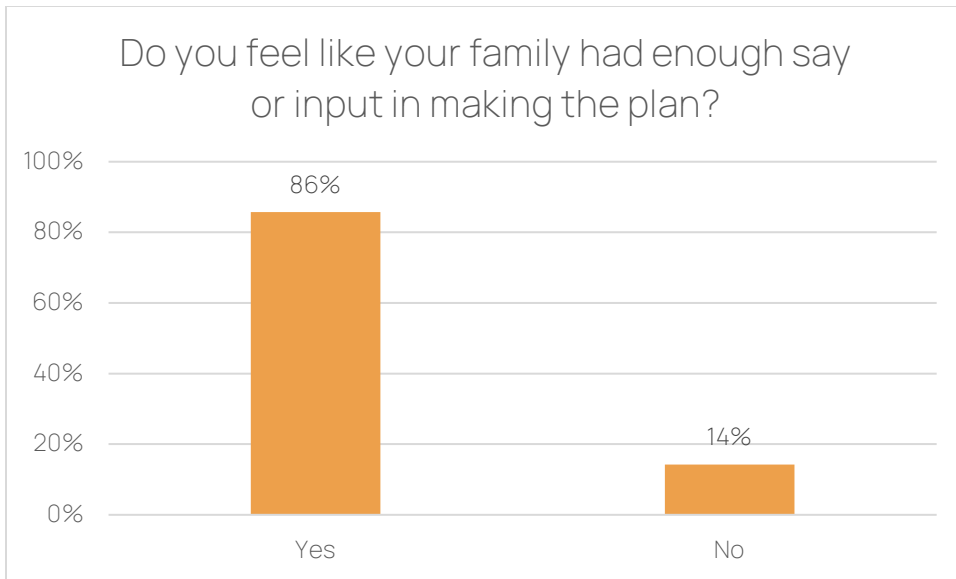
**Within Average Range**

State	Yes	No	N
MO	27%	73%	135
AK	25%	75%	124
IN	24%	76%	143
WI	20%	80%	281
CO	19%	81%	188
<b>Weighted NCI-IDD Average</b>	<b>18%</b>	<b>82%</b>	<b>4310</b>
CA	17%	83%	2798

**Significantly Below Average**

State	Yes	No	N
LA	11%	89%	188





**Table 34. Do you feel like your family had enough say or input in making the plan?**

New question in 2021-22

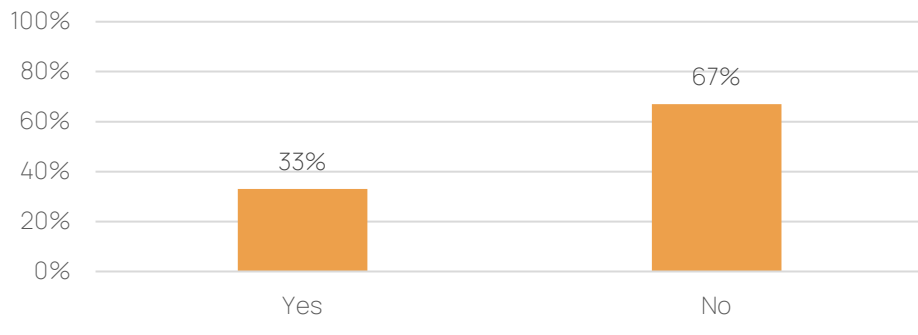
**Significantly Above Average**

State	Yes	No	N
AK	97%	3%	121
IN	93%	7%	135
CO	93%	7%	183
OR	93%	7%	417

**Within Average Range**

State	Yes	No	N
MO	91%	9%	125
WI	90%	10%	261
LA	89%	11%	174
<b>Weighted NCI-IDD Average</b>	<b>86%</b>	<b>14%</b>	<b>3938</b>
CA	83%	17%	2522

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)?



**Table 35. 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)?**

**Within Average Range**

State	Yes	No	N
CA	37%	63%	4238
AK	35%	65%	128
<b>Weighted NCI-IDD Average</b>	<b>33%</b>	<b>67%</b>	<b>6141</b>

**Significantly Below Average**

State	Yes	No	N
OR	24%	76%	540
WI	23%	77%	344
IN	22%	78%	194
CO	20%	80%	202
LA	20%	80%	336
MO	18%	82%	159

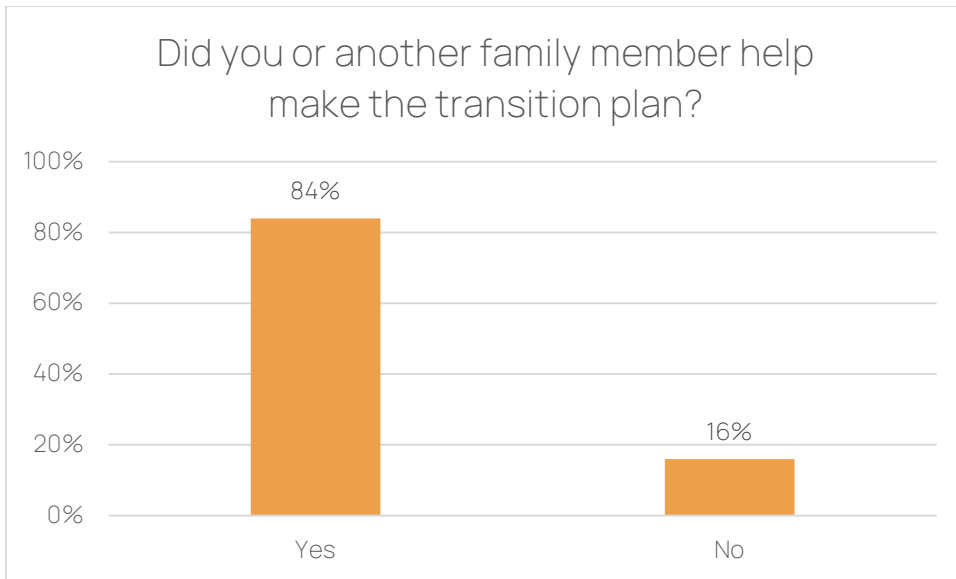


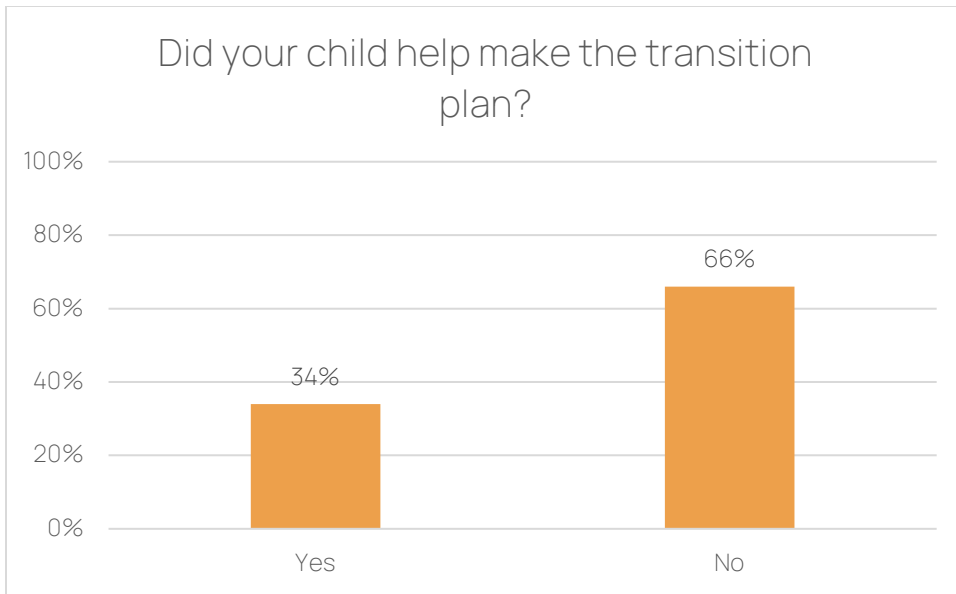
Table 36. If your child has a transition plan, did you or another family member help make the plan?

**Within Average Range**

State	Yes	No	N
CO	94%	6%	36

**Within Average Range**

State	Yes	No	N
OR	90%	10%	121
WI	88%	12%	77
IN	88%	12%	42
AK	87%	13%	38
<b>Weighted NCI-IDD Average</b>	<b>84%</b>	<b>16%</b>	<b>1788</b>
CA	83%	17%	1387
MO	82%	18%	28
LA	78%	22%	59



**Table 37. If your child has a transition plan, did your child help make the plan?**

**Within Average Range**

State	Yes	No	N
MO	54%	46%	28
IN	51%	49%	37
OR	44%	56%	121
AK	39%	61%	38
WI	38%	62%	74
<b>Weighted NCI-IDD Average</b>	<b>34%</b>	<b>66%</b>	<b>1675</b>
CA	32%	68%	1283
CO	28%	72%	39
LA	22%	78%	55

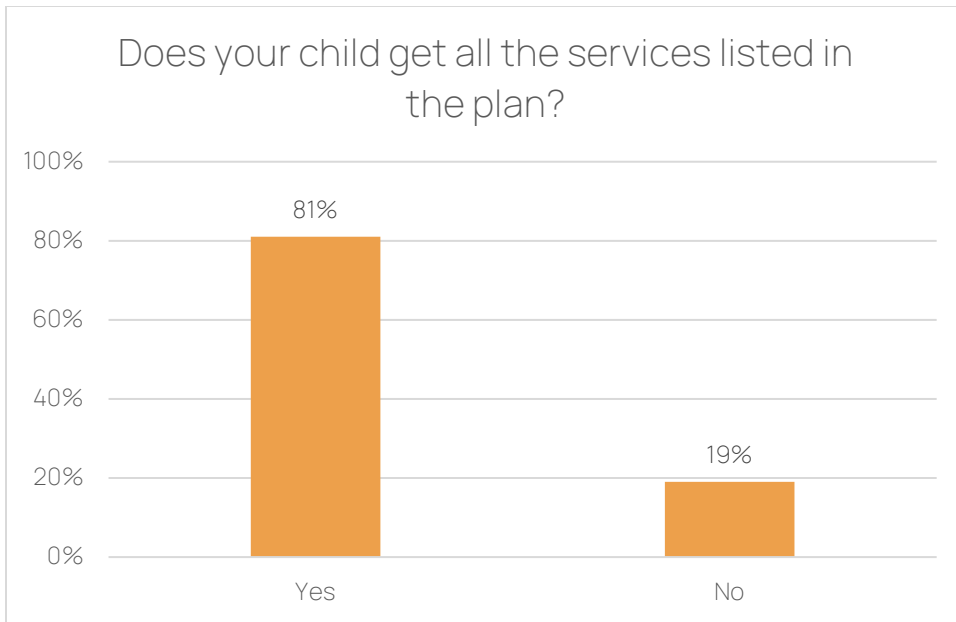
## *Access and Delivery of Services and Supports*

*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 38. Does your child get all the services listed in the plan?**

**Significantly Above Average**

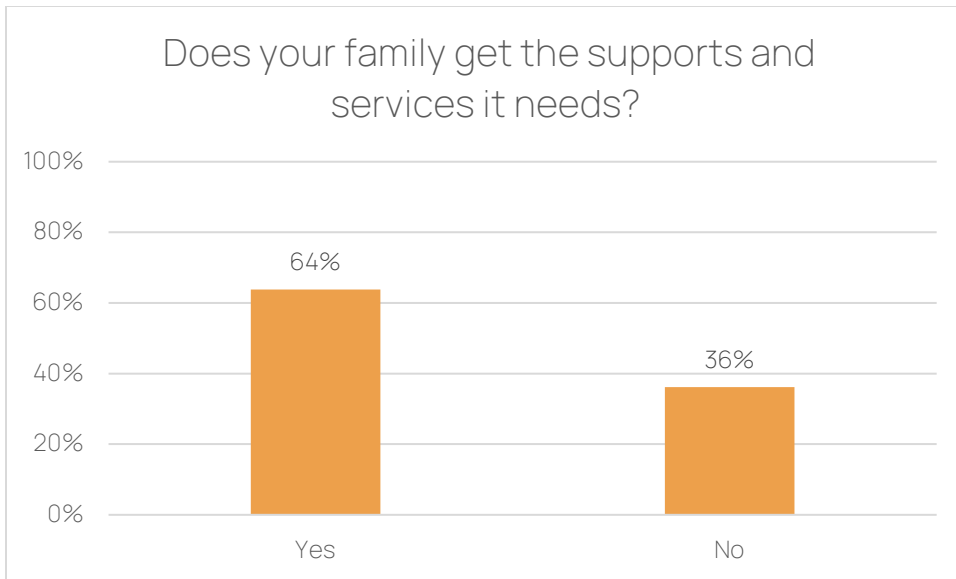
State	Yes	No	N
LA	92%	8%	165

**Within Average Range**

State	Yes	No	N
WI	83%	17%	258
CA	83%	17%	2512
<b>Weighted NCI-IDD Average</b>	<b>81%</b>	<b>19%</b>	<b>3898</b>
MO	80%	20%	123
IN	74%	26%	138

**Significantly Below Average**

State	Yes	No	N
OR	76%	24%	404
CO	70%	30%	179
AK	62%	38%	119



**Table 39. Does your family get the supports and services it needs?**

**Significantly Above Average**

State	Yes	No	N
LA	73%	27%	321

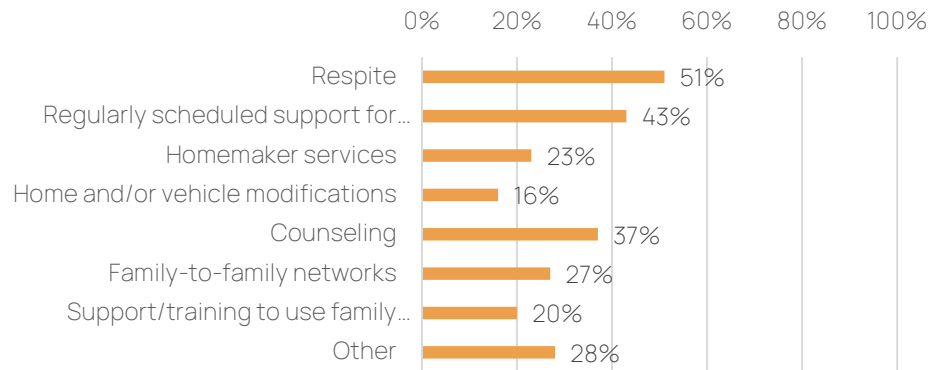
**Within Average Range**

State	Yes	No	N
IN	68%	32%	223
WI	67%	33%	368
<b>Weighted NCI-IDD Average</b>	<b>64%</b>	<b>36%</b>	<b>6145</b>
MO	63%	37%	166
CA	63%	37%	4155
OR	59%	41%	566
AK	57%	43%	143

**Significantly Above Average**

State	Yes	No	N
CO	54%	46%	203

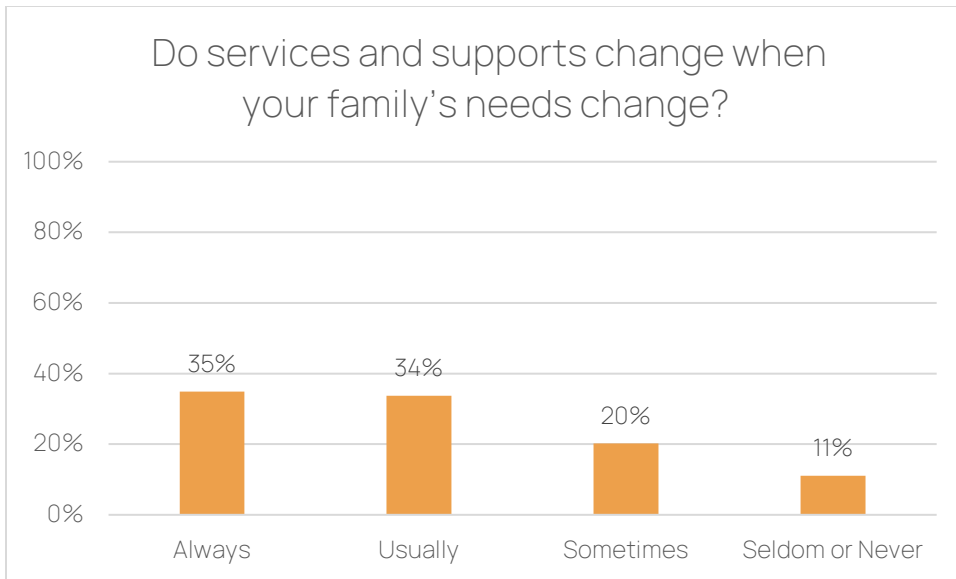
If your family does not get the supports and services it needs, what additional services does your family need?:



**Table 40. What additional services does your family need?**

State	Respite	Regularly scheduled support for child	Homemaker services	Home and/or vehicle modifications	Counseling	Family-to-family networks	Support/training to use family member's assistive technology	Other
AK	73%	54%	19%	25%	32%	27%	10%	29%
CA	46%	42%	22%	13%	39%	27%	21%	28%
CO	78%	32%	45%	21%	34%	27%	17%	21%
IN	55%	37%	15%	22%	28%	19%	10%	39%
LA	55%	45%	19%	27%	32%	20%	11%	19%
MO	68%	51%	20%	19%	46%	36%	19%	22%
OR	69%	52%	26%	28%	35%	30%	18%	26%
WI	65%	50%	28%	24%	28%	34%	27%	26%
<b>Weighted NCI-IDD Average</b>	<b>51%</b>	<b>43%</b>	<b>23%</b>	<b>16%</b>	<b>37%</b>	<b>27%</b>	<b>20%</b>	<b>28%</b>





**Table 41. Do services and supports change when your family's needs change?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	49%	32%	14%	5%	192
LA	46%	33%	15%	6%	284

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
MO	35%	38%	18%	9%	141
<b>Weighted NCI-IDD Average</b>	<b>35%</b>	<b>34%</b>	<b>20%</b>	<b>11%</b>	<b>5509</b>
WI	34%	44%	16%	6%	338
CA	34%	32%	22%	13%	3697
AK	31%	30%	27%	12%	134
CO	26%	49%	15%	10%	185

**Significantly Below Average**

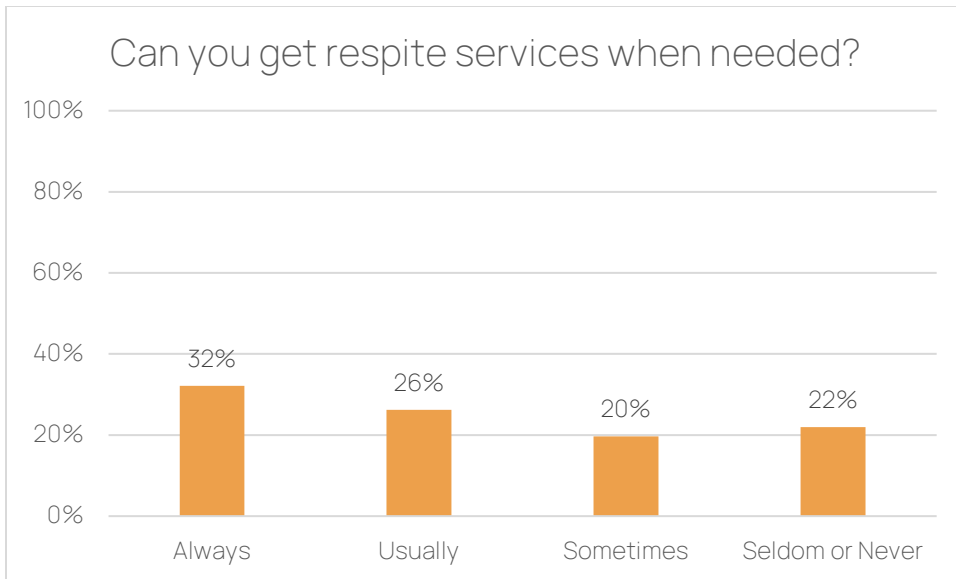
State	Always	Usually	Sometimes	Seldom or Never	N
OR	26%	46%	20%	8%	538



**Table 42. Does your child have the special equipment or accommodations they need?**

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	47%	28%	13%	12%	100
IN	45%	29%	13%	13%	120
LA	43%	29%	18%	9%	206
CA	42%	26%	15%	16%	1987
<b>Weighted NCI-IDD Average</b>	<b>40%</b>	<b>30%</b>	<b>16%</b>	<b>14%</b>	<b>3302</b>
OR	35%	37%	17%	11%	385
WI	33%	41%	20%	6%	251
MO	33%	44%	13%	10%	89
CO	32%	44%	21%	3%	164



**Table 43. If you need respite services, how often are you able to get them when needed?**

**Significantly Above Average**

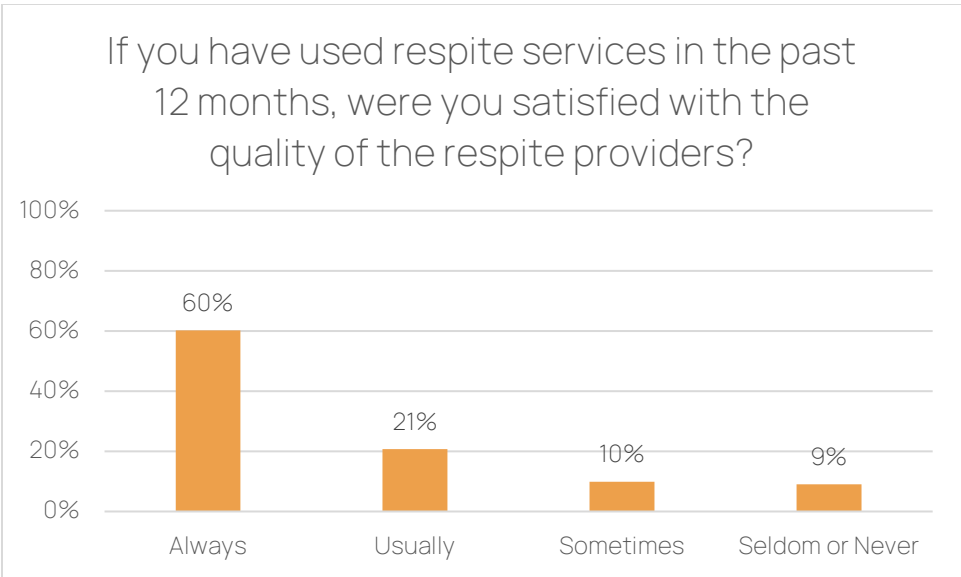
State	Always	Usually	Sometimes	Seldom or Never	N
CA	37%	26%	19%	18%	3680

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
Weighted NCI-IDD Average	32%	26%	20%	22%	5283

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	22%	22%	19%	37%	142
AK	20%	25%	29%	26%	141
OR	20%	23%	23%	35%	527
LA	19%	23%	16%	42%	162
WI	18%	32%	25%	25%	309
MO	13%	25%	21%	42%	125
CO	10%	21%	31%	38%	197



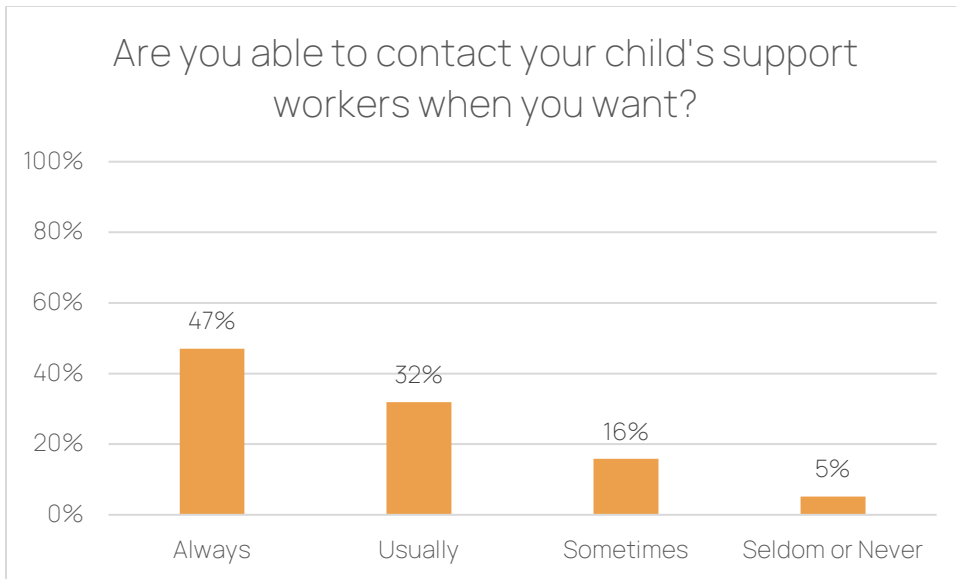
**Table 44. If you have used respite services in the past year, were you satisfied with the quality of the respite providers?**

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
CA	61%	19%	10%	9%	2794
<b>Weighted NCI-IDD Average</b>	<b>60%</b>	<b>21%</b>	<b>10%</b>	<b>9%</b>	<b>3827</b>
IN	59%	22%	7%	12%	83
WI	58%	25%	8%	9%	237
OR	57%	24%	10%	9%	333
AK	56%	26%	9%	9%	99
MO	55%	25%	6%	14%	71

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CO	45%	33%	12%	10%	138
LA	40%	39%	10%	11%	72



**Table 45. Are you or your family member able to contact their support workers when you want?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	70%	25%	4%	1%	224
LA	67%	25%	6%	2%	341
AK	62%	30%	7%	1%	138

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	52%	39%	8%	1%	581
MO	51%	38%	9%	3%	157
WI	50%	36%	12%	2%	363
<b>Weighted NCI-IDD Average</b>	<b>47%</b>	<b>32%</b>	<b>16%</b>	<b>5%</b>	<b>6559</b>
CA	43%	32%	19%	6%	4547
CO	41%	44%	11%	4%	208



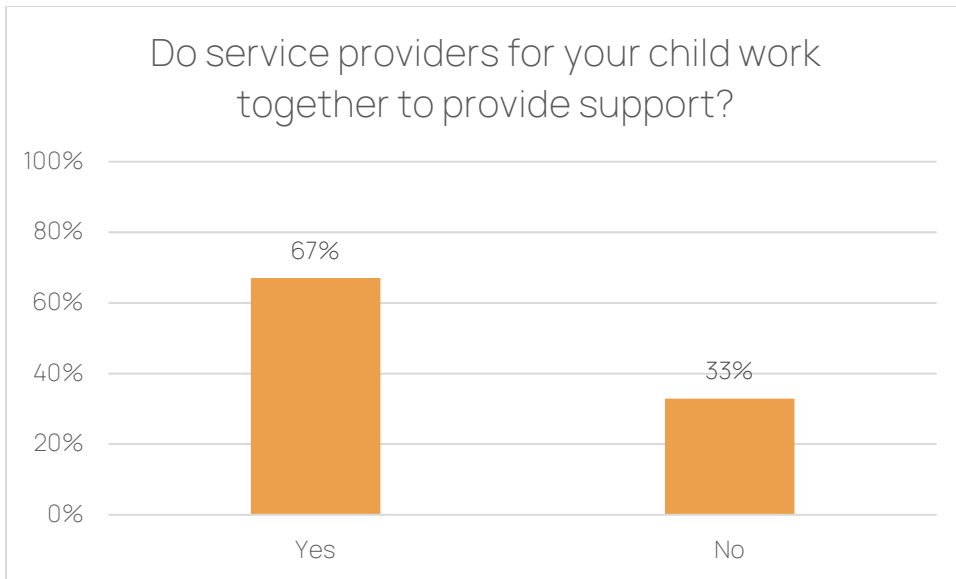
**Table 46. Are you or your family member able to contact your child's case manager/service coordinator when you want?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	79%	17%	3%	1%	152
IN	77%	18%	3%	2%	243
LA	64%	29%	6%	1%	354
WI	56%	31%	10%	3%	409

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
MO	56%	33%	8%	3%	177
CO	53%	34%	12%	1%	209
OR	51%	38%	10%	1%	608
<b>Weighted NCI-IDD Average</b>	<b>50%</b>	<b>31%</b>	<b>15%</b>	<b>5%</b>	<b>7109</b>
CA	45%	31%	17%	6%	4957



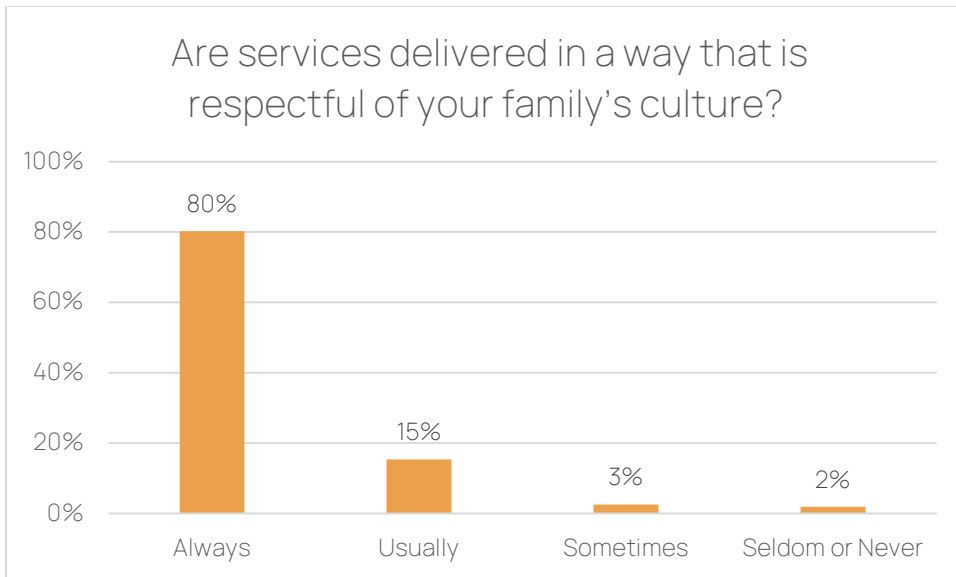
**Table 47. Do service providers for your child work together to provide support?**

**Significantly Above Average**

State	Yes	No	N
IN	81%	19%	129
LA	80%	20%	181

**Within Average Range**

State	Yes	No	N
WI	75%	25%	194
CO	71%	29%	127
AK	69%	31%	96
OR	69%	31%	326
<b>Weighted NCI-IDD Average</b>	<b>67%</b>	<b>33%</b>	<b>3400</b>
CA	64%	36%	2284
MO	59%	41%	63



**Table 48. Are services delivered in a way that is respectful of your family's culture?**

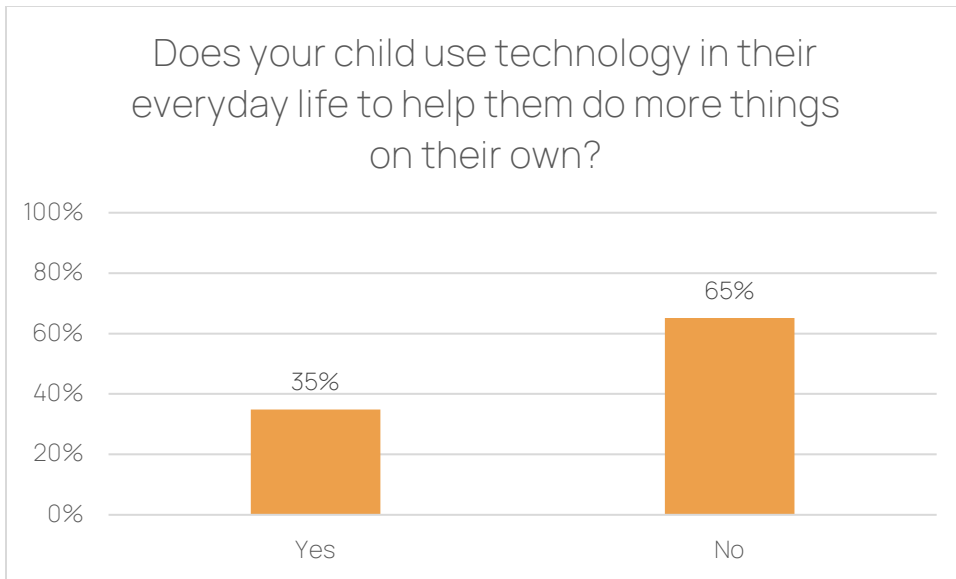
**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	87%	10%	1%	2%	234

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	83%	15%	2%	0%	591
LA	83%	14%	2%	1%	353
<b>Weighted NCI-IDD Average</b>	<b>80%</b>	<b>15%</b>	<b>2%</b>	<b>2%</b>	<b>6836</b>
CA	80%	16%	3%	2%	4753
MO	79%	18%	2%	1%	164
CO	79%	20%	1%	0%	208
WI	78%	17%	3%	2%	389
AK	76%	18%	2%	4%	144





**Table 49. Does your child use technology in their everyday life to help them do things on their own?**

New question in 2021-22

**Significantly Above Average**

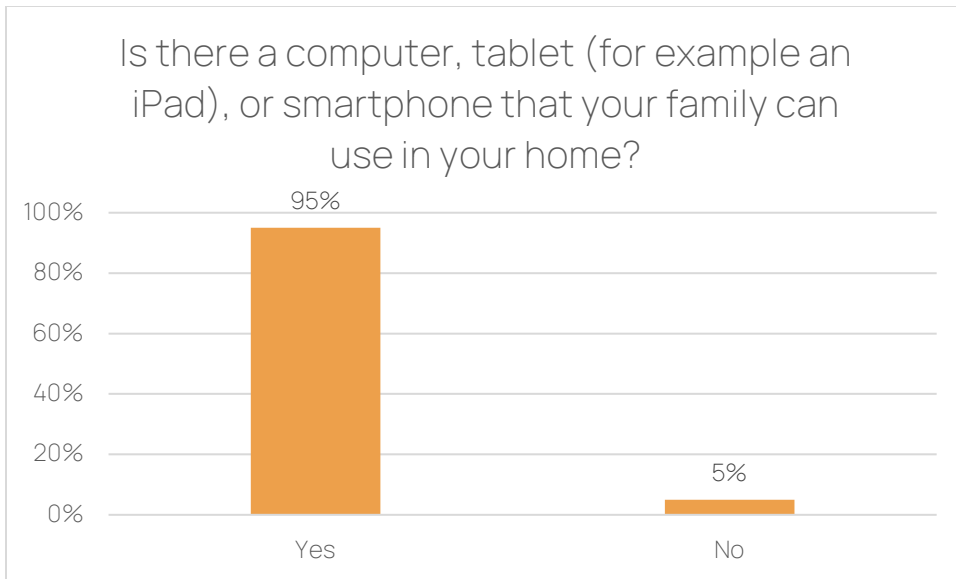
State	Yes	No	N
CO	55%	45%	218
AK	50%	50%	157
WI	47%	53%	394
OR	43%	57%	609

**Within Average Range**

State	Yes	No	N
<b>Weighted NCI-IDD Average</b>	<b>35%</b>	<b>65%</b>	<b>7196</b>
CA	34%	66%	5011
IN	33%	67%	245
MO	30%	70%	181

**Significantly Below Average**

State	Yes	No	N
LA	27%	73%	381



**Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home?**

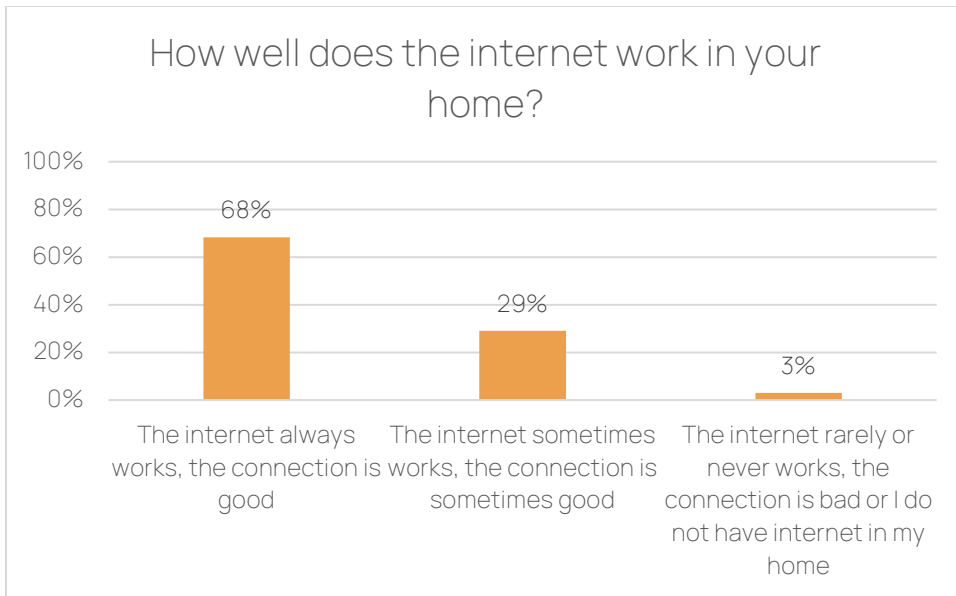
New question in 2021-22

**Significantly Above Average**

State	Yes	No	N
MO	98%	2%	188

**Within Average Range**

State	Yes	No	N
IN	97%	3%	250
OR	96%	4%	625
CO	96%	4%	217
WI	96%	4%	404
AK	96%	4%	159
<b>Weighted NCI-IDD Average</b>	<b>95%</b>	<b>5%</b>	<b>7597</b>
CA	95%	5%	5361
LA	93%	7%	393



**Table 51. How well does the internet work in your home?**

New question in 2021-22

**Significantly Above Average**

State	The internet always works	The internet sometimes works	The internet rarely or never works, or I do not have internet in my home	N
IN	78%	20%	2%	252

**Within Average Range**

State	The internet always works	The internet sometimes works	The internet rarely or never works, or I do not have internet in my home	N
MO	74%	24%	2%	190
WI	72%	26%	2%	410
OR	71%	27%	2%	619
CO	68%	31%	0%	219
<b>Weighted NCI-IDD Average</b>	<b>68%</b>	<b>29%</b>	<b>3%</b>	<b>7622</b>
CA	67%	30%	3%	5385
LA	66%	29%	4%	391
AK	65%	30%	4%	156

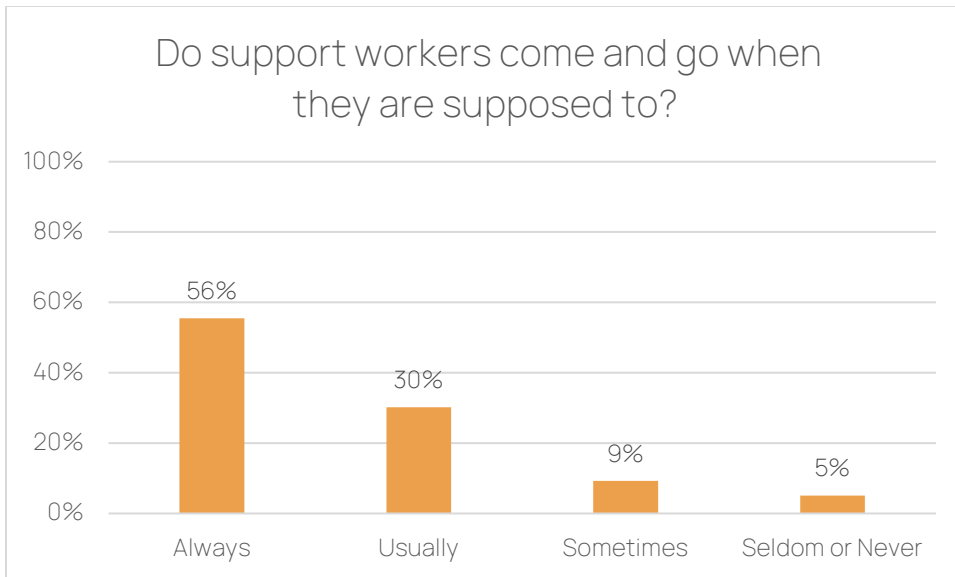
## Workforce

*There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.*

**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.



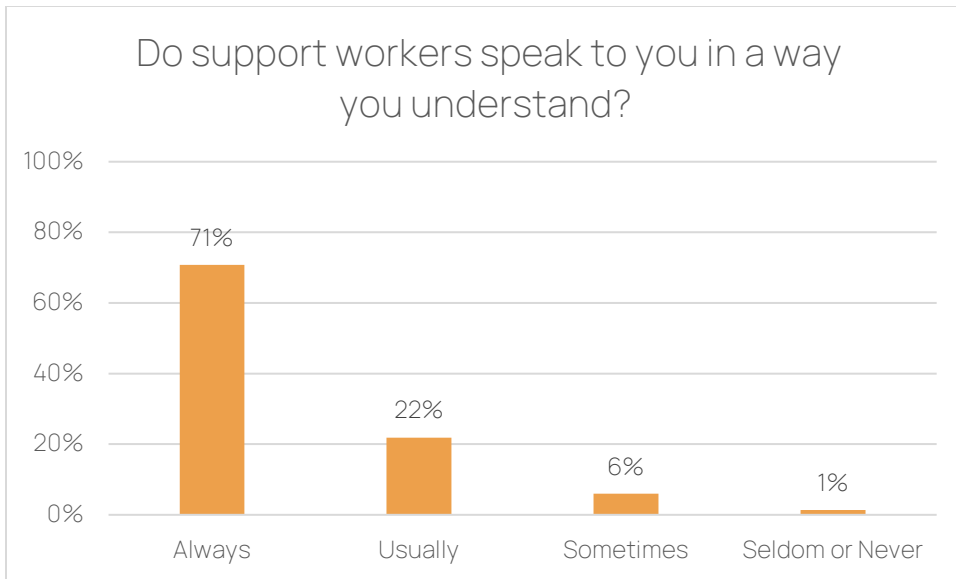
**Table 52. Do support workers come and go when they are supposed to?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	70%	24%	5%	1%	210
LA	66%	26%	5%	4%	310

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	59%	28%	11%	2%	120
<b>Weighted NCI-IDD Average</b>	<b>55%</b>	<b>30%</b>	<b>9%</b>	<b>5%</b>	<b>5558</b>
MO	55%	41%	3%	2%	128
WI	54%	34%	7%	4%	317
CA	54%	30%	10%	6%	3744
OR	53%	34%	11%	3%	551
CO	48%	44%	5%	3%	178



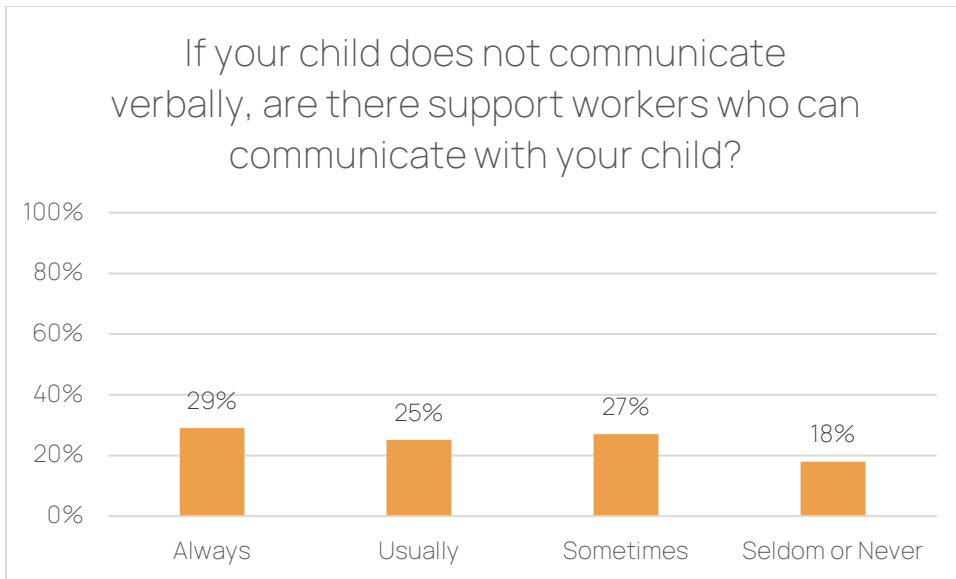
**Table 53. Do support workers speak to you in a way you understand?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CO	82%	16%	2%	1%	192
LA	81%	16%	2%	1%	334
IN	80%	16%	3%	0%	215
OR	78%	20%	2%	0%	581

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	76%	17%	6%	1%	131
MO	73%	24%	2%	1%	151
<b>Weighted NCI-IDD Average</b>	<b>71%</b>	<b>22%</b>	<b>6%</b>	<b>1%</b>	<b>6365</b>
CA	69%	22%	7%	2%	4421
WI	67%	30%	3%	1%	340



**Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child?**

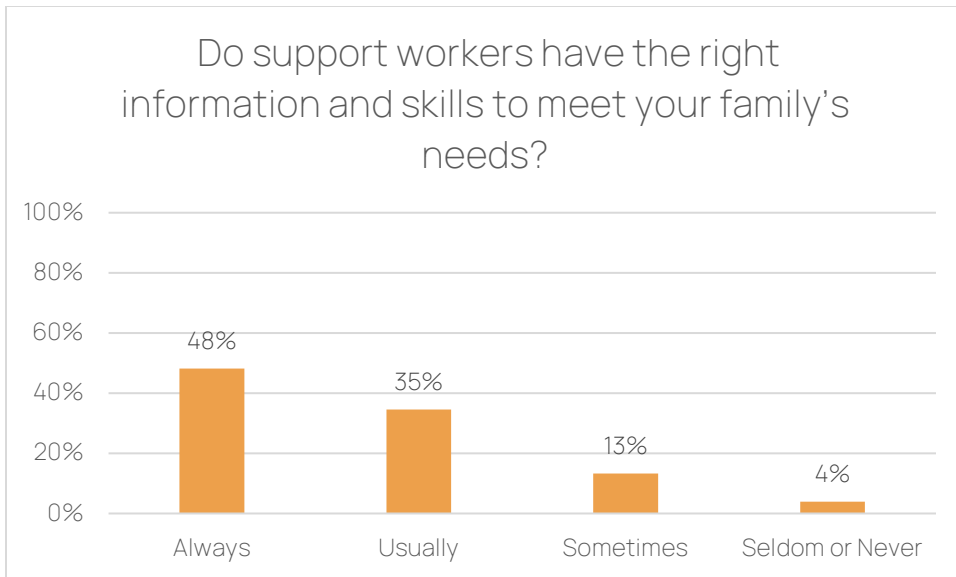
**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
CA	31%	20%	28%	21%	301
OR	30%	48%	14%	7%	69
LA	30%	35%	20%	15%	40
<b>Weighted NCI-IDD Average</b>	<b>29%</b>	<b>25%</b>	<b>27%</b>	<b>18%</b>	<b>500</b>

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
WI	11%	36%	32%	21%	28
CO	9%	36%	50%	5%	22

Table note: AK, IN, and MO not reported due to low sample size.



**Table 55. Do support workers have the right information and skills to meet your family's needs?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	61%	30%	7%	3%	320

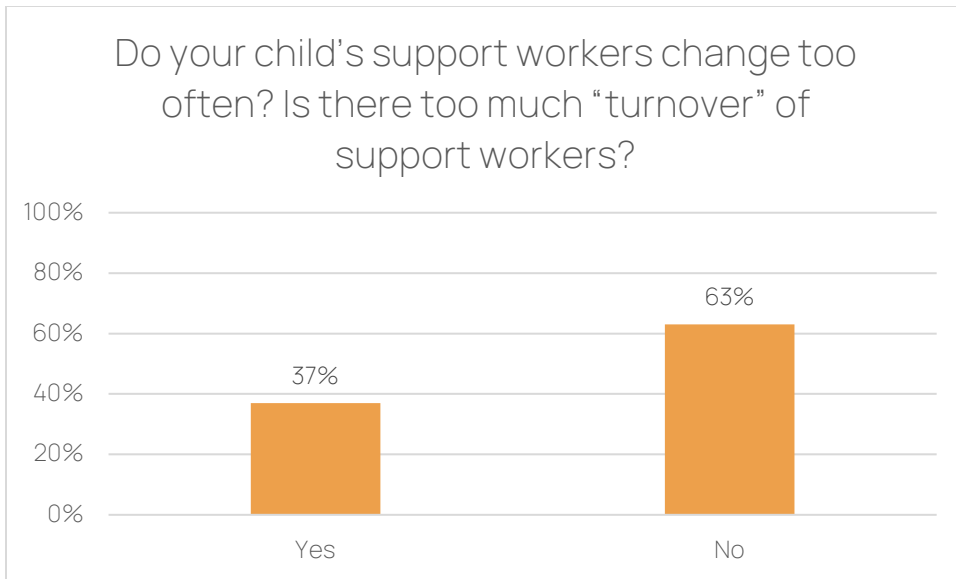
**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	56%	36%	8%	1%	208
CA	49%	33%	14%	4%	4092
AK	48%	32%	14%	5%	130
<b>Weighted NCI-IDD Average</b>	<b>48%</b>	<b>35%</b>	<b>13%</b>	<b>4%</b>	<b>5979</b>

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	39%	40%	14%	7%	568
WI	37%	47%	12%	5%	328
MO	36%	48%	15%	1%	138
CO	30%	53%	12%	5%	195





**Table 56. Do your child's support workers change too often? Is there too much "turnover" of support workers?**

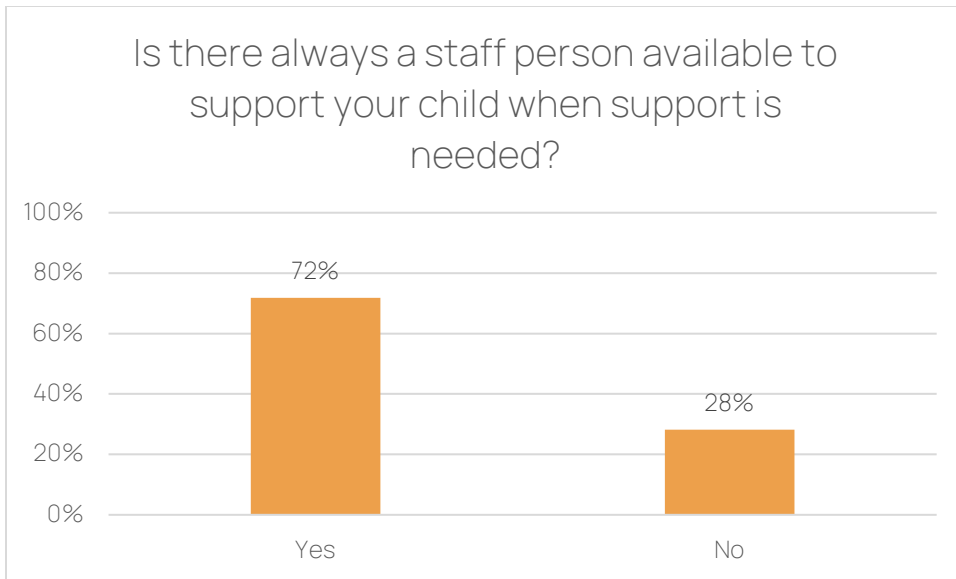
New question in 2021-22

**Within Average Range**

State	Yes	No	N
AK	49%	51%	121
CO	47%	53%	182
CA	40%	60%	3586
<b>Weighted NCI-IDD Average</b>	<b>37%</b>	<b>63%</b>	<b>5365</b>
OR	36%	64%	536
MO	35%	65%	127
WI	35%	65%	310

**Significantly Below Average**

State	Yes	No	N
LA	25%	75%	302
IN	23%	77%	201



**Table 57. Is there always a staff person available to support your child when support is needed?**

New question in 2021-22

**Within Average Range**

State	Yes	No	N
CA	75%	25%	3662
LA	74%	26%	294
IN	74%	26%	193
<b>Weighted NCI-IDD Average</b>	<b>72%</b>	<b>28%</b>	<b>5414</b>

**Significantly Below Average**

State	Yes	No	N
WI	62%	38%	301
CO	60%	40%	177
MO	58%	42%	127
OR	52%	48%	530
AK	42%	58%	130

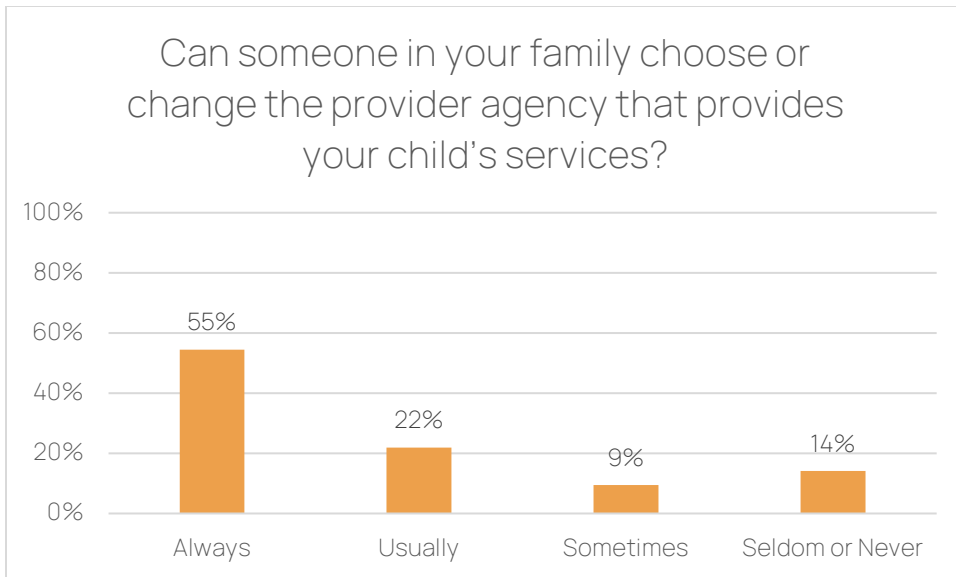
## *Choice, Decision Making and Control*

*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 58. Can someone in your family choose or change the provider agency that provides your child's services?**

**Significantly Above Average**

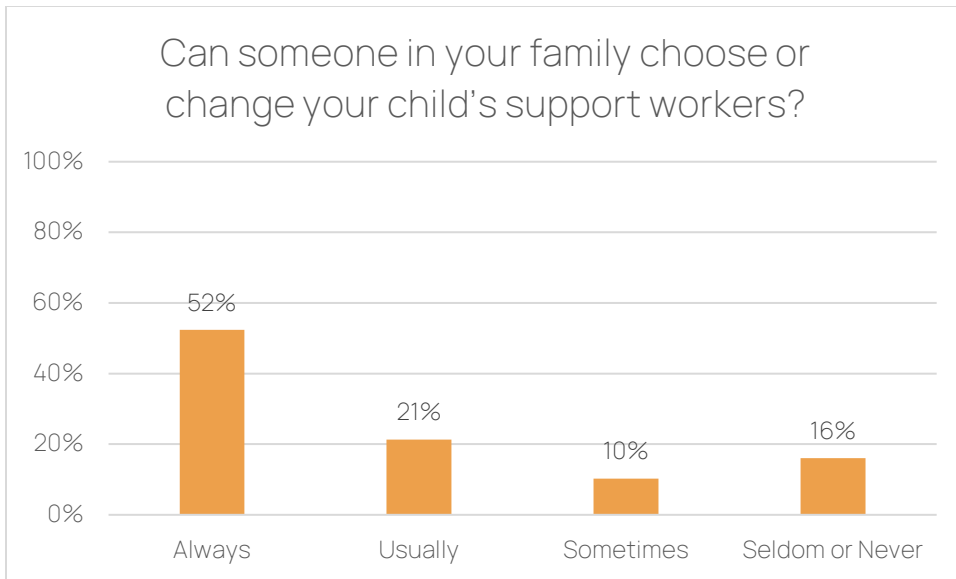
State	Always	Usually	Sometimes	Seldom or Never	N
IN	76%	17%	1%	6%	213
AK	68%	14%	6%	13%	133
LA	67%	16%	4%	12%	273
OR	67%	22%	6%	5%	422

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
MO	58%	28%	2%	12%	101
WI	55%	24%	8%	12%	189
<b>Weighted NCI-IDD Average</b>	<b>55%</b>	<b>22%</b>	<b>9%</b>	<b>14%</b>	<b>4324</b>
CO	54%	31%	9%	6%	177

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CA	49%	23%	12%	16%	2816



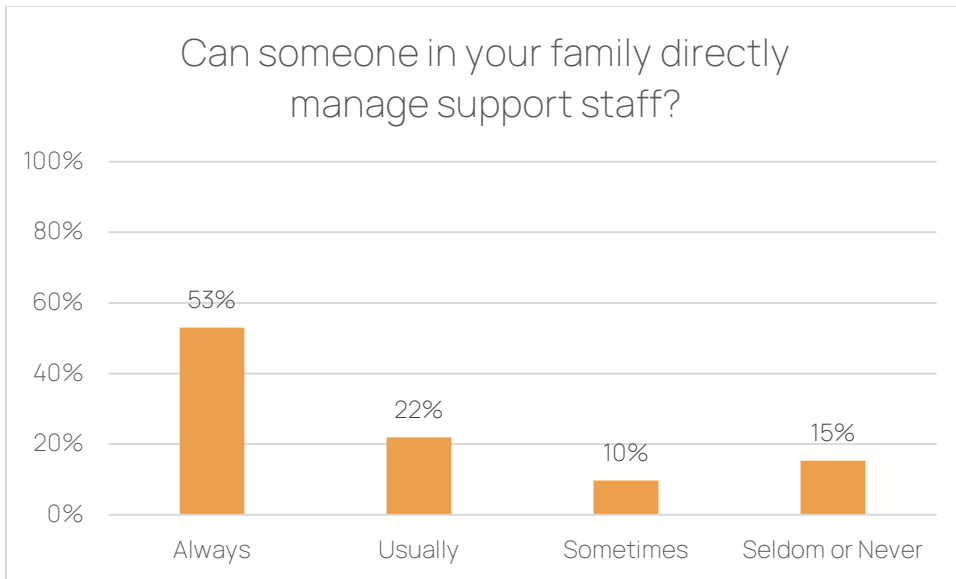
**Table 59. Can someone in your family choose or change your child's support workers?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	71%	17%	5%	7%	191
OR	69%	17%	6%	8%	519
LA	65%	15%	5%	16%	247
AK	64%	16%	5%	15%	132

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
MO	57%	22%	11%	10%	82
<b>Weighted NCI-IDD Average</b>	<b>52%</b>	<b>22%</b>	<b>10%</b>	<b>16%</b>	<b>4217</b>
CA	48%	22%	12%	19%	2655
WI	47%	29%	11%	12%	204
CO	43%	32%	14%	11%	187



**Table 60. Can someone in your family directly manage support staff?**

Question changed in 2021-22

**Significantly Above Average**

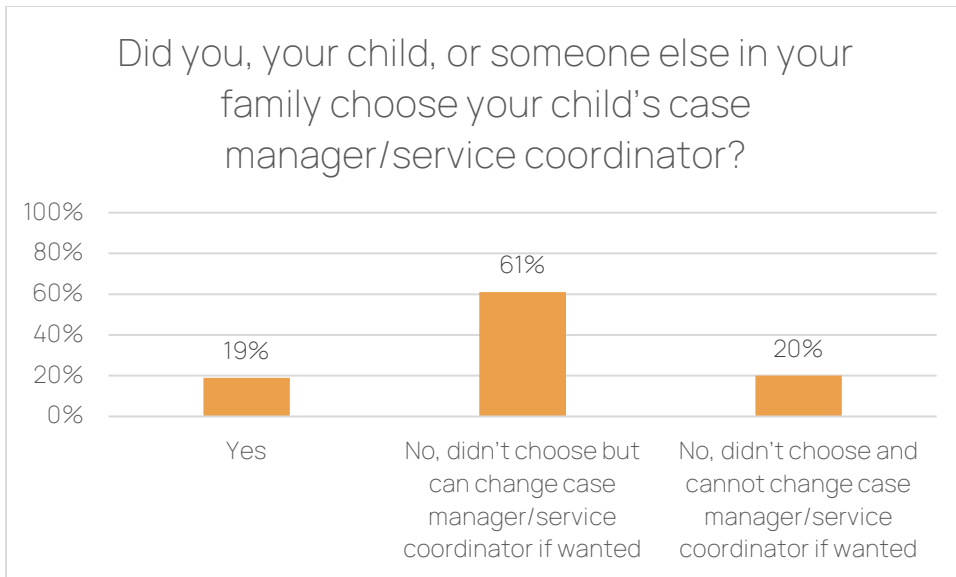
State	Always	Usually	Sometimes	Seldom or Never	N
OR	71%	19%	5%	5%	533
LA	62%	17%	7%	14%	242

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
MO	65%	16%	6%	13%	77
IN	61%	22%	6%	11%	177
<b>Weighted NCI-IDD Average</b>	<b>53%</b>	<b>22%</b>	<b>10%</b>	<b>15%</b>	<b>4167</b>
WI	52%	32%	5%	11%	215
AK	50%	13%	10%	26%	127
CA	50%	22%	11%	17%	2639

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
CO	39%	38%	13%	10%	157



**Table 61. Did you, your child, or someone else in your family choose your child's case manager/service coordinator?**

**Significantly Above Average**

State	Yes	Didn't choose but can change case manager/service coordinator	Didn't choose and cannot change case manager/service coordinator	N
AK	84%	12%	4%	146
IN	49%	48%	3%	231
LA	45%	43%	12%	329
OR	30%	55%	15%	508

**Within Average Range**

State	Yes	Didn't choose but can change case manager/service coordinator	Didn't choose and cannot change case manager/service coordinator	N
<b>Weighted NCI-IDD Average</b>	<b>19%</b>	<b>61%</b>	<b>20%</b>	<b>5440</b>
MO	17%	59%	23%	128

**Significantly Below Average**

State	Yes	Didn't choose but can change case manager/service coordinator	Didn't choose and cannot change case manager/service coordinator	N
CA	15%	63%	22%	3605
WI	7%	65%	28%	305
CO	4%	69%	27%	188

## *Involvement in the Community*

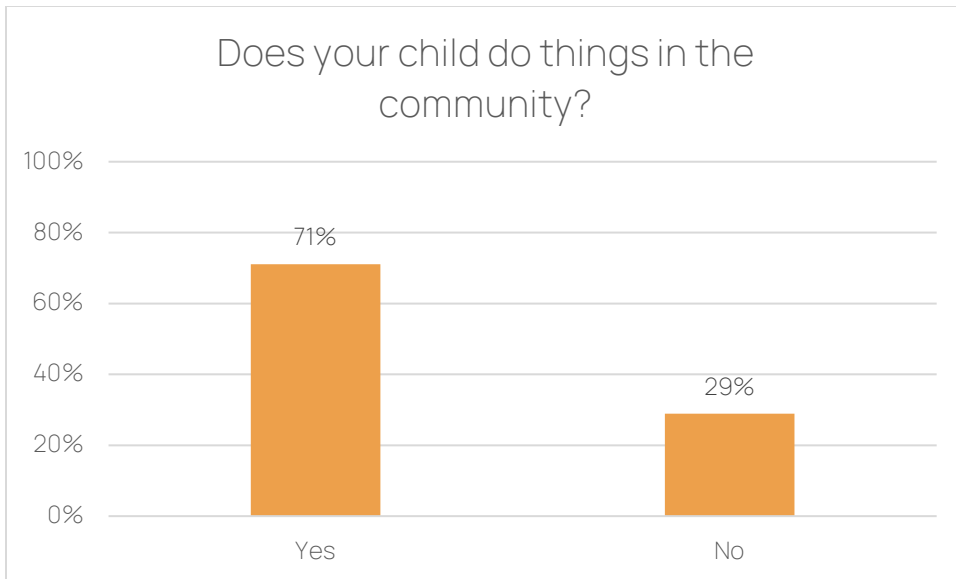
*Family members with disabilities use integrated community services and participate in everyday community activities.*

**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.

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





**Table 62. Does your child do things in the community?**

Question changed in 2021-22

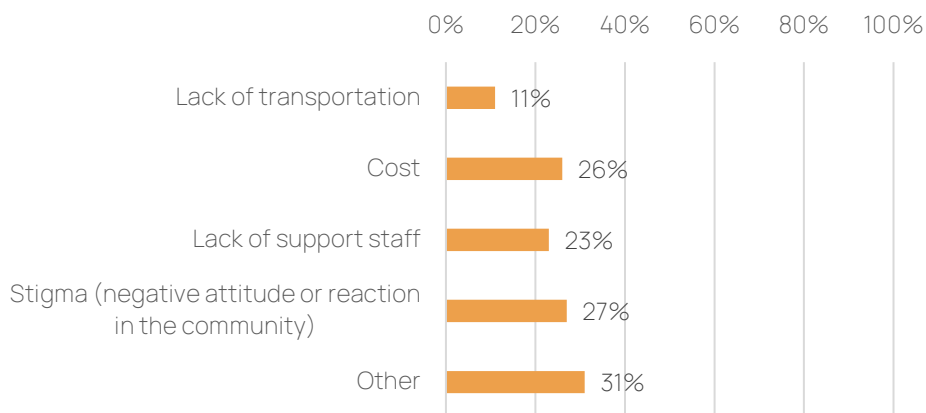
**Significantly Above Average**

State	Yes	No	N
MO	84%	16%	187
WI	82%	18%	393
IN	81%	19%	250
CO	80%	20%	210
OR	79%	21%	620

**Within Average Range**

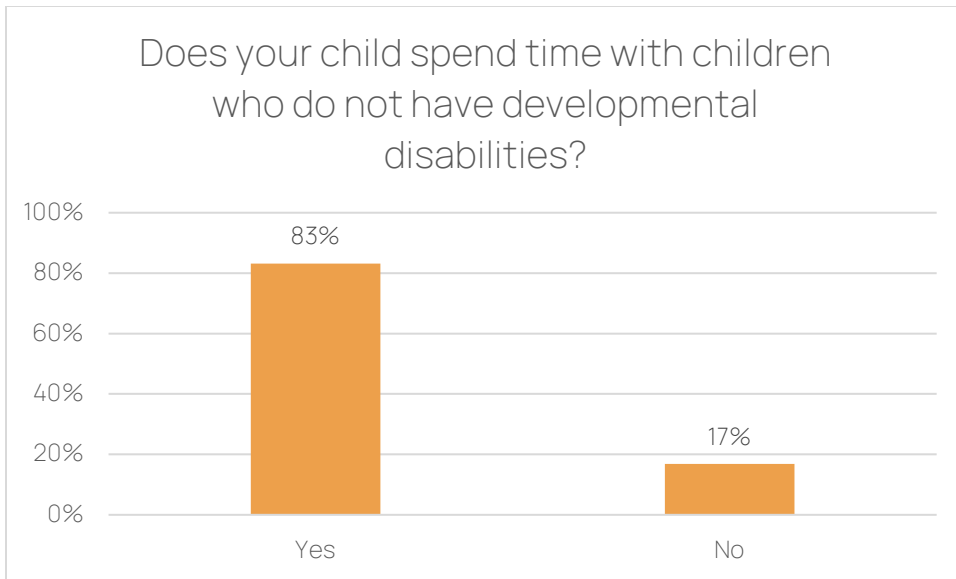
State	Yes	No	N
AK	79%	21%	156
LA	75%	25%	389
<b>Weighted NCI-IDD Average</b>	<b>71%</b>	<b>29%</b>	<b>7372</b>
CA	68%	32%	5167

### What makes it hard to take part in activities in the community?



**Table 63. What makes it hard to do things in the community?**

State	Lack of transportation	Cost	Lack of support staff	Stigma	Other
AK	10%	25%	29%	21%	47%
CA	11%	26%	22%	26%	28%
CO	17%	33%	42%	34%	49%
IN	8%	21%	19%	24%	38%
LA	9%	20%	15%	18%	37%
MO	10%	32%	24%	38%	44%
OR	13%	32%	33%	33%	41%
WI	11%	27%	31%	36%	41%
<b>Weighted NCI-IDD Average</b>	<b>11%</b>	<b>26%</b>	<b>23%</b>	<b>27%</b>	<b>31%</b>



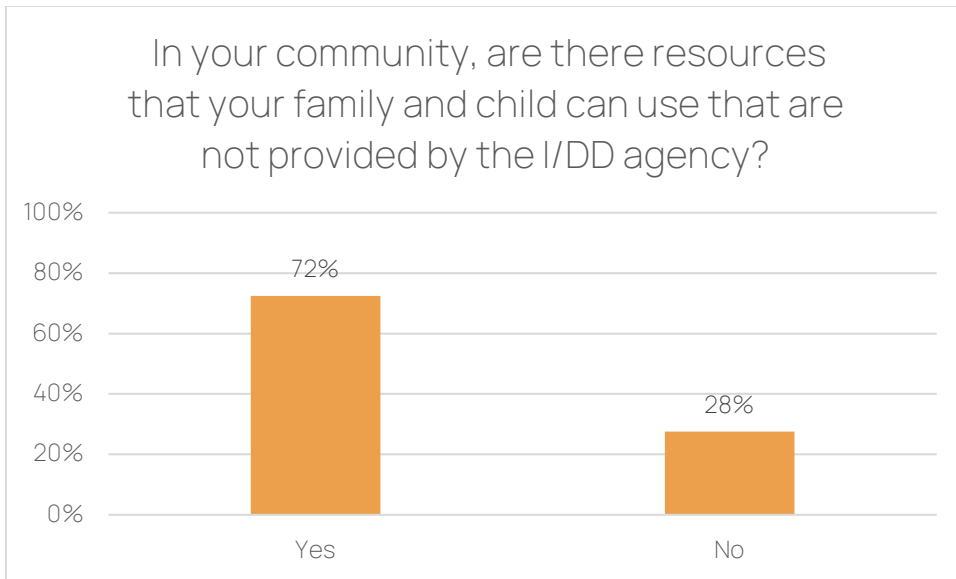
**Table 64. Does your child spend time with children who do not have developmental disabilities?**

**Significantly Above Average**

State	Yes	No	N
MO	90%	10%	186
IN	89%	11%	247

**Within Average Range**

State	Yes	No	N
LA	87%	13%	384
WI	85%	15%	392
OR	85%	15%	622
AK	84%	16%	156
<b>Weighted NCI-IDD Average</b>	<b>83%</b>	<b>17%</b>	<b>7367</b>
CA	82%	18%	5167
CO	80%	20%	213



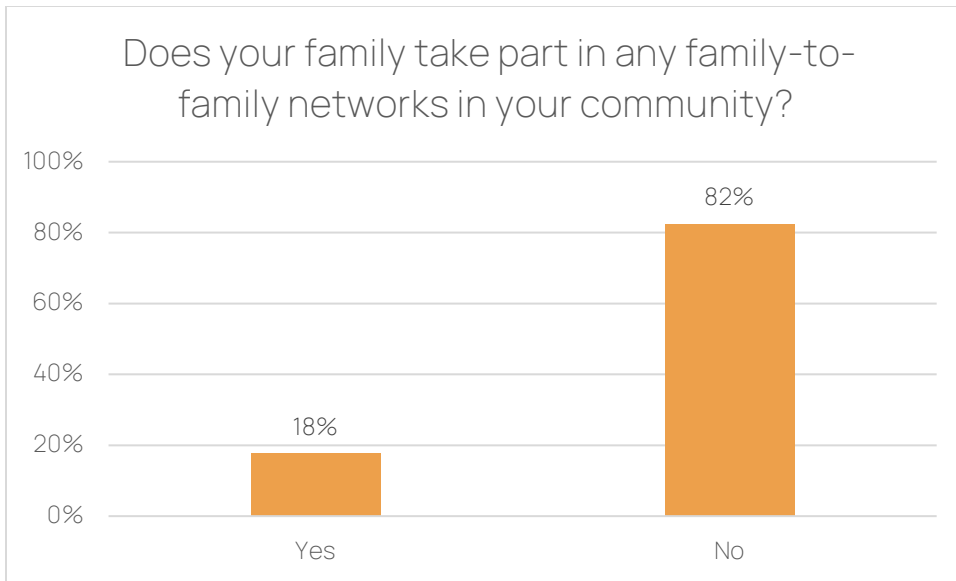
**Table 65. In your community, are there resources that your family and child can use that are not provided by the I/DD agency?**

**Significantly Above Average**

State	Yes	No	N
MO	86%	14%	149

**Within Average Range**

State	Yes	No	N
WI	78%	22%	292
IN	76%	24%	167
AK	74%	26%	127
OR	73%	27%	439
<b>Weighted NCI-IDD Average</b>	<b>72%</b>	<b>28%</b>	<b>5154</b>
LA	72%	28%	259
CA	71%	29%	3561
CO	68%	32%	160



**Table 66. Does your family take part in any family-to-family networks in your community?**

**Within Average Range**

State	Yes	No	N
CO	26%	74%	192
LA	24%	76%	308
WI	19%	81%	343
CA	18%	82%	4611
<b>Weighted NCI-IDD Average</b>	<b>18%</b>	<b>82%</b>	<b>6518</b>
OR	15%	85%	551
IN	14%	86%	218
AK	13%	87%	141

**Significantly Below Average**

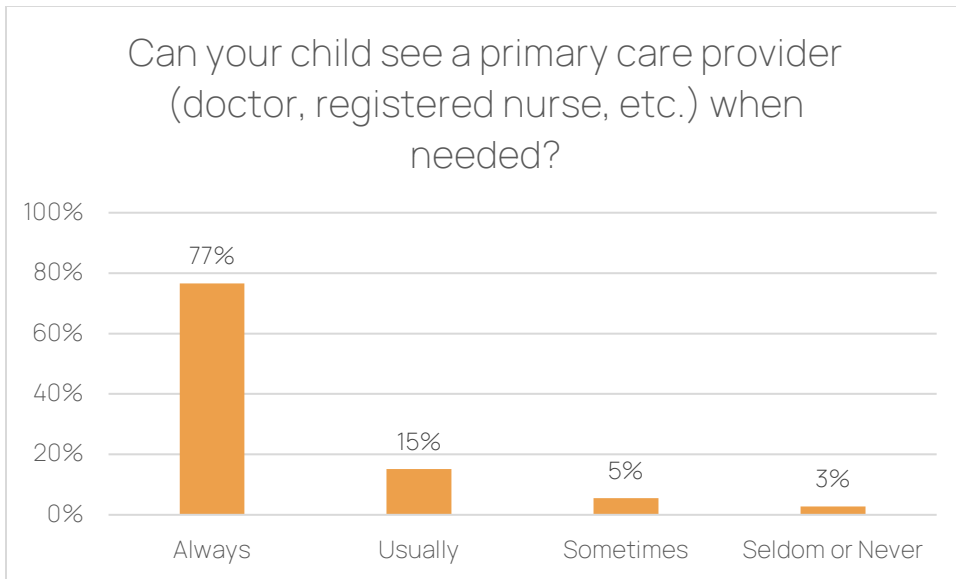
State	Yes	No	N
MO	11%	89%	154

## *Health, Welfare, and Safety*

*Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state DD system.*

**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.**



**Table 67. Can your child see a primary care provider (doctor, registered nurse, etc.) when needed?**

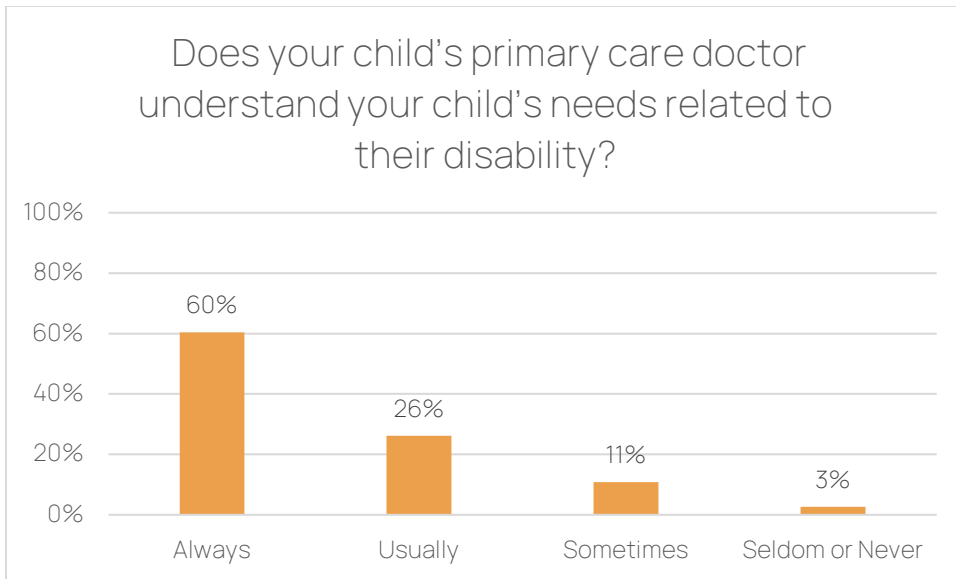
New question in 2021-22

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	88%	10%	1%	1%	390
IN	88%	9%	2%	1%	251
MO	87%	11%	2%	0%	189

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	81%	16%	1%	2%	156
<b>Weighted NCI-IDD Average</b>	<b>77%</b>	<b>15%</b>	<b>5%</b>	<b>3%</b>	<b>7369</b>
CO	77%	20%	1%	2%	209
OR	76%	19%	3%	2%	615
WI	75%	22%	2%	1%	390
CA	75%	15%	7%	3%	5169



**Table 68. Does your child's primary care doctor understand your child's needs related to their disability?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	74%	20%	5%	1%	384

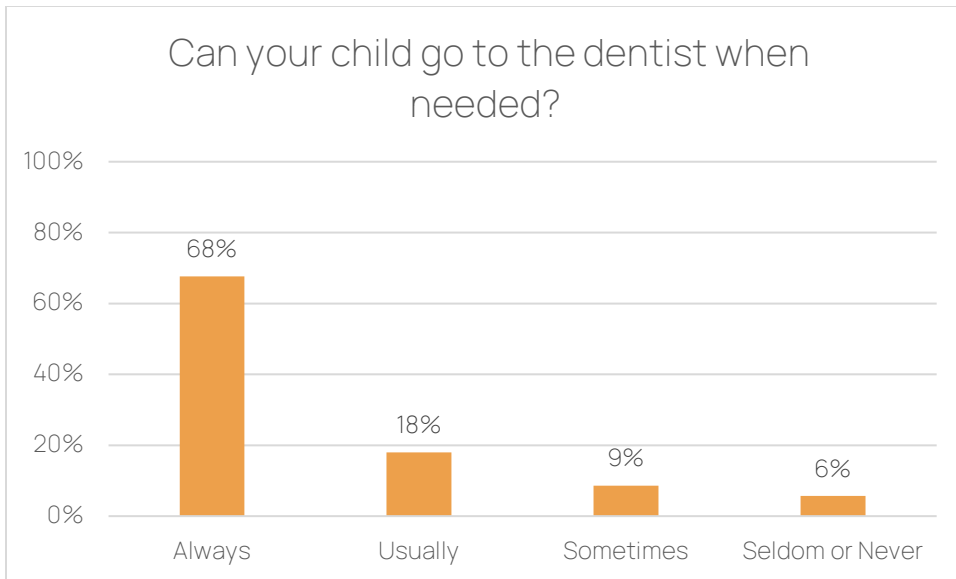
**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	68%	24%	7%	2%	250
CA	61%	25%	12%	3%	5206
<b>Weighted NCI-IDD Average</b>	<b>60%</b>	<b>26%</b>	<b>11%</b>	<b>3%</b>	<b>7390</b>
AK	60%	31%	6%	3%	157

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
WI	52%	36%	11%	1%	388
CO	50%	37%	9%	4%	213
MO	50%	39%	10%	2%	187
OR	49%	38%	10%	3%	605





**Table 69. Can your child go to the dentist when needed?**

**Significantly Above Average**

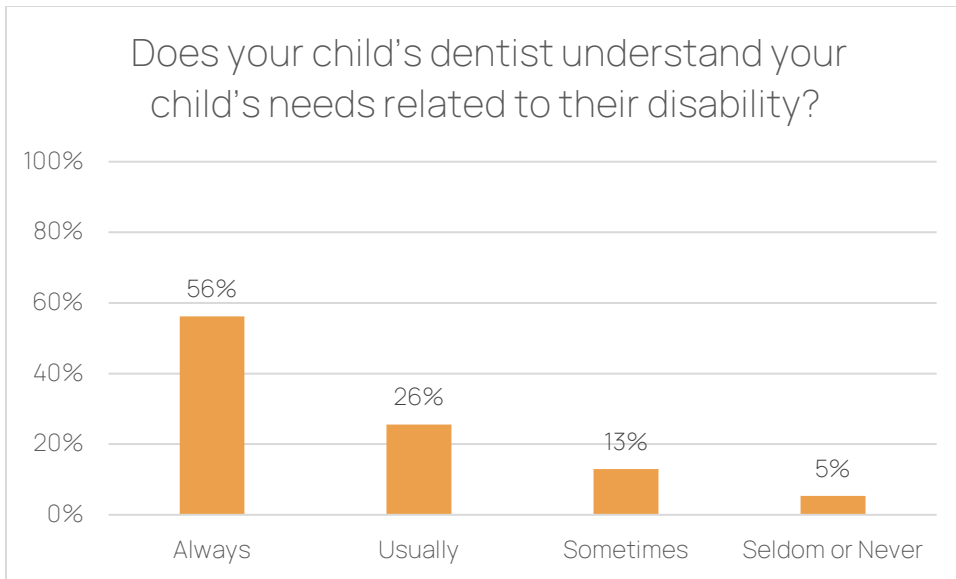
State	Always	Usually	Sometimes	Seldom or Never	N
IN	78%	15%	4%	4%	250
LA	76%	16%	5%	3%	383

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	72%	18%	6%	4%	154
<b>Weighted NCI-IDD Average</b>	<b>68%</b>	<b>18%</b>	<b>9%</b>	<b>6%</b>	<b>7448</b>
CA	68%	17%	9%	6%	5255
CO	67%	25%	5%	3%	216
MO	64%	21%	9%	6%	187

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
WI	60%	24%	9%	7%	387
OR	58%	27%	9%	7%	616



**Table 70. Does your child's dentist understand your child's needs related to their disability?**

**Significantly Above Average**

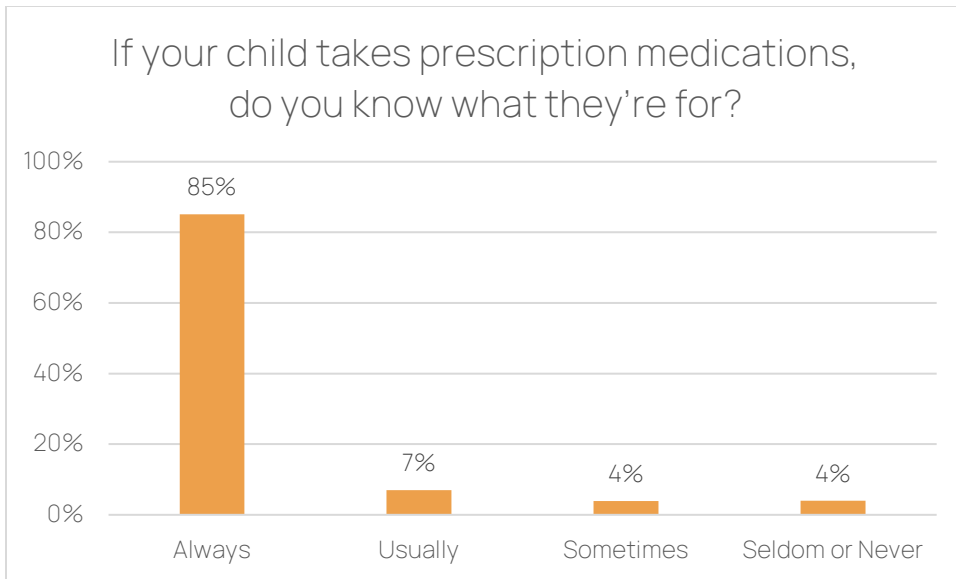
State	Always	Usually	Sometimes	Seldom or Never	N
LA	68%	23%	6%	3%	331
IN	66%	21%	8%	4%	237

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	62%	27%	10%	1%	148
<b>Weighted NCI-IDD Average</b>	<b>56%</b>	<b>26%</b>	<b>13%</b>	<b>5%</b>	<b>6917</b>
CA	56%	25%	13%	5%	4881
CO	53%	28%	15%	4%	211
WI	52%	27%	14%	6%	355

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	46%	32%	15%	7%	593
MO	43%	32%	17%	8%	161



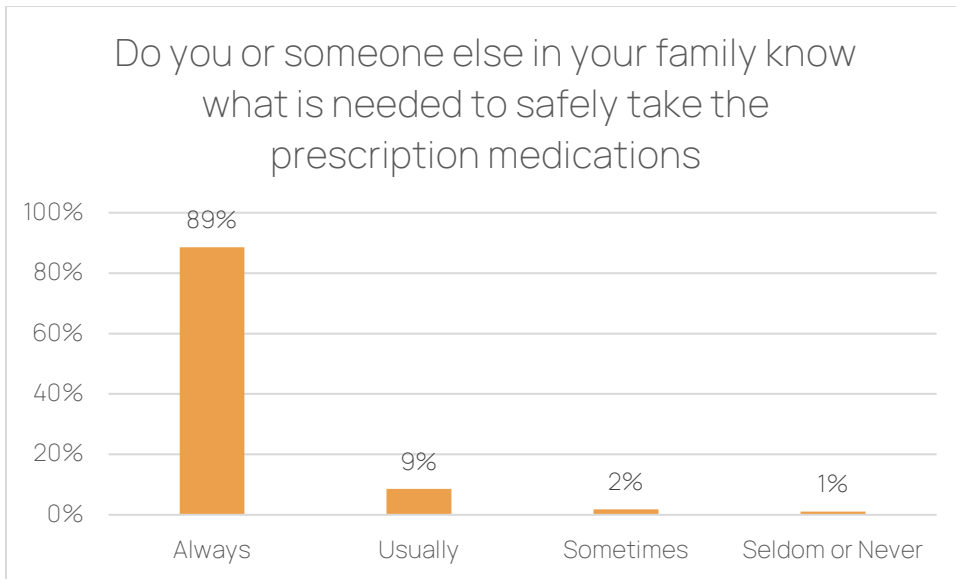
**Table 71. If your child takes prescription medications, do you know what they're for?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	94%	2%	3%	1%	282
OR	93%	5%	2%	0%	466
MO	93%	6%	1%	1%	137
CO	92%	5%	2%	1%	182
AK	92%	6%	2%		117

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	91%	6%	2%	1%	180
WI	89%	8%	2%	1%	293
<b>Weighted NCI-IDD Average</b>	<b>85%</b>	<b>7%</b>	<b>4%</b>	<b>4%</b>	<b>4469</b>
CA	82%	7%	5%	6%	2812



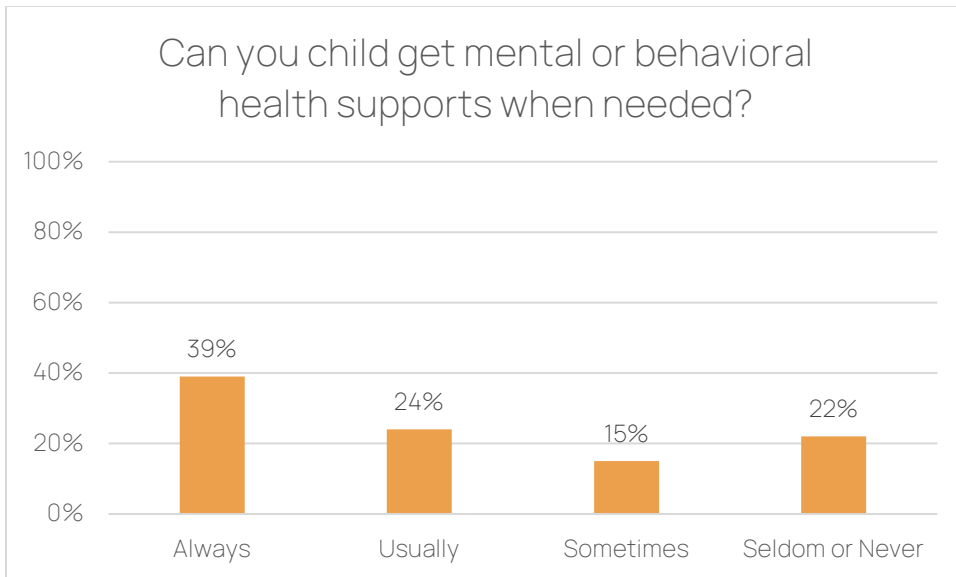
**Table 72. Do you, your child, or someone else in your family know what is needed to safely take the prescription medications?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	93%	4%	1%	1%	286

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
CO	93%	6%	1%	1%	182
IN	92%	6%	1%	1%	177
OR	92%	7%	1%	0%	464
MO	91%	6%	1%	1%	134
AK	91%	8%	1%	1%	120
WI	90%	8%	1%	0%	290
<b>Weighted NCI-IDD Average</b>	<b>89%</b>	<b>9%</b>	<b>2%</b>	<b>1%</b>	<b>4452</b>
CA	87%	10%	2%	1%	2799



**Table 73. Can your child get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)**

New question in 2021-22.

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	59%	22%	8%	10%	187
LA	51%	19%	8%	23%	296

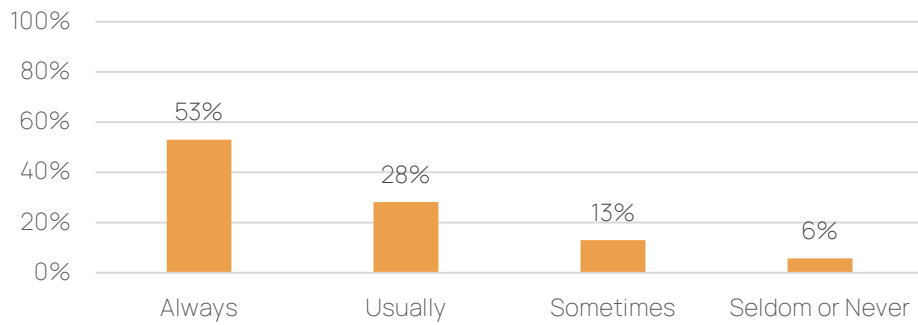
**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
AK	43%	23%	11%	23%	115
WI	40%	27%	16%	17%	289
MO	40%	26%	12%	21%	137
<b>Weighted NCI-IDD Average</b>	<b>39%</b>	<b>24%</b>	<b>15%</b>	<b>22%</b>	<b>5569</b>
CA	37%	23%	16%	24%	3906

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	44%	38%	15%	4%	360
CO	28%	33%	21%	18%	164

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



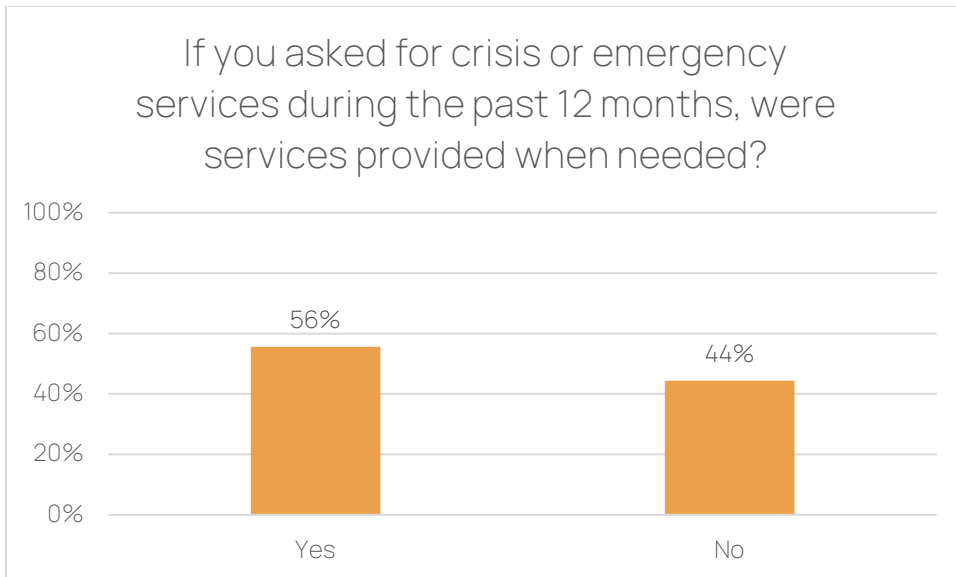
**Table 74. If your child uses mental health services, does the mental health professional understand your child's needs related to their disability?**

**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	61%	26%	9%	4%	192
IN	61%	31%	6%	2%	166
MO	54%	34%	12%	0%	111
<b>Weighted NCI-IDD Average</b>	<b>53%</b>	<b>28%</b>	<b>13%</b>	<b>6%</b>	<b>4402</b>
AK	53%	32%	13%	3%	95
CA	53%	27%	14%	6%	3124
WI	50%	28%	11%	11%	212
CO	42%	35%	17%	6%	142

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	44%	38%	15%	4%	360



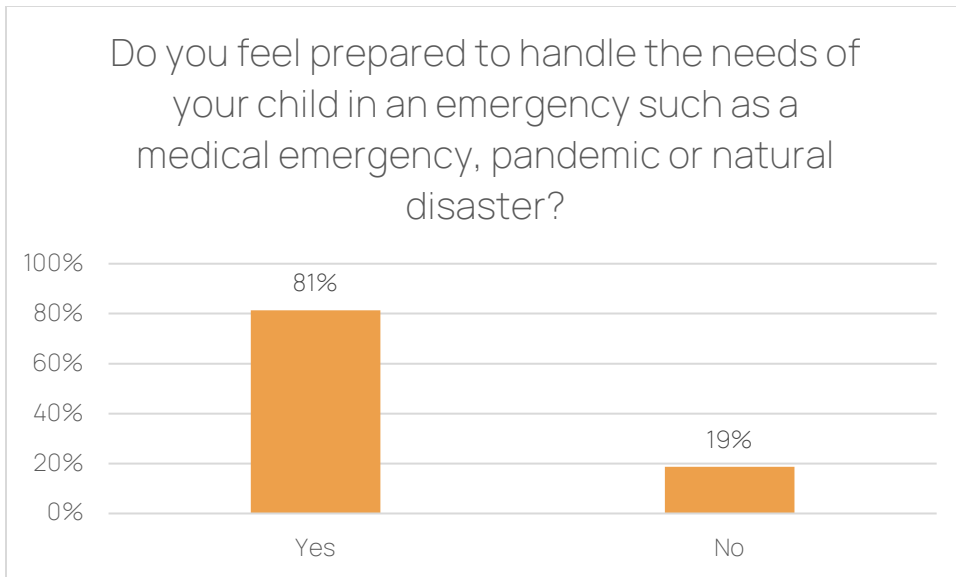
**Table 75. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?**

**Significantly Above Average**

State	Yes	No	N
LA	78%	22%	100

**Within Average Range**

State	Yes	No	N
MO	74%	26%	38
IN	67%	33%	46
AK	64%	36%	50
WI	59%	41%	69
OR	57%	43%	134
CO	56%	44%	52
<b>Weighted NCI-IDD Average</b>	<b>56%</b>	<b>44%</b>	<b>1991</b>
CA	53%	47%	1502



**Table 76. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or natural disaster?**

**Significantly Above Average**

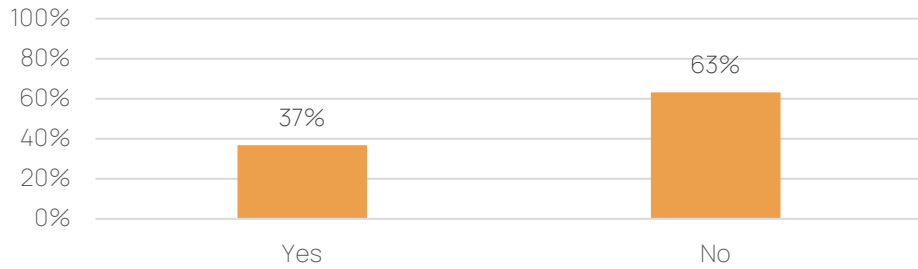
State	Yes	No	N
IN	95%	5%	236
LA	94%	6%	356

**Within Average Range**

State	Yes	No	N
AK	87%	13%	147
MO	84%	16%	174
CO	83%	17%	199
OR	83%	17%	560
WI	83%	17%	356
<b>Weighted NCI-IDD Average</b>	<b>81%</b>	<b>19%</b>	<b>6600</b>
CA	79%	21%	4572



Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child's case manager/service coordinator?



**Table 77. Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child's case manager/service coordinator?**

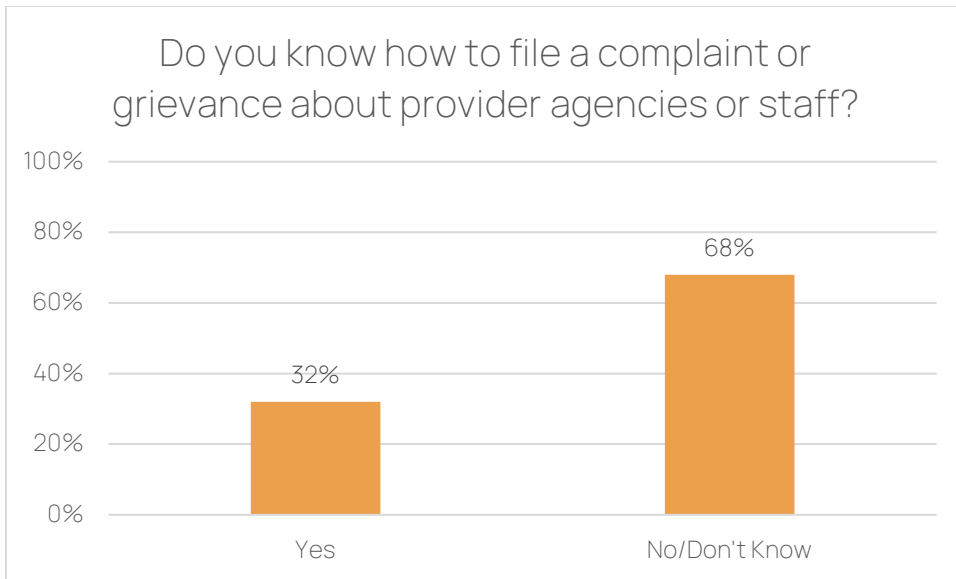
New question in 2021-22

**Significantly Above Average**

State	Yes	No	N
LA	72%	28%	359
AK	55%	45%	146
OR	45%	55%	584

**Within Average Range**

State	Yes	No	N
CO	44%	56%	204
IN	44%	56%	233
MO	40%	60%	170
<b>Weighted NCI-IDD Average</b>	<b>37%</b>	<b>63%</b>	<b>6830</b>
CA	34%	66%	4769
WI	31%	69%	365



**Table 78. Do you know how to file a complaint or grievance about provider agencies or staff?**

**Significantly Above Average**

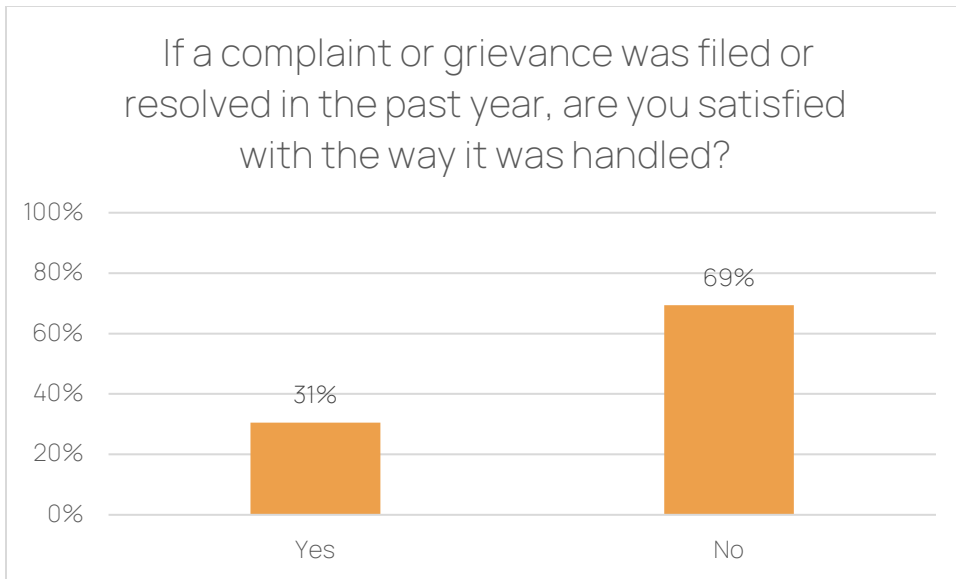
State	Yes	No or Don't Know	N
CO	62%	38%	214
WI	56%	44%	392
LA	54%	46%	390
AK	52%	48%	157
OR	52%	48%	624
IN	46%	54%	251

**Within Average Range**

State	Yes	No or Don't Know	N
MO	38%	62%	190
<b>Weighted NCI-IDD Average</b>	<b>32%</b>	<b>68%</b>	<b>7476</b>

**Significantly Below Average**

State	Yes	No or Don't Know	N
CA	25%	75%	5258



**Table 79. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?**

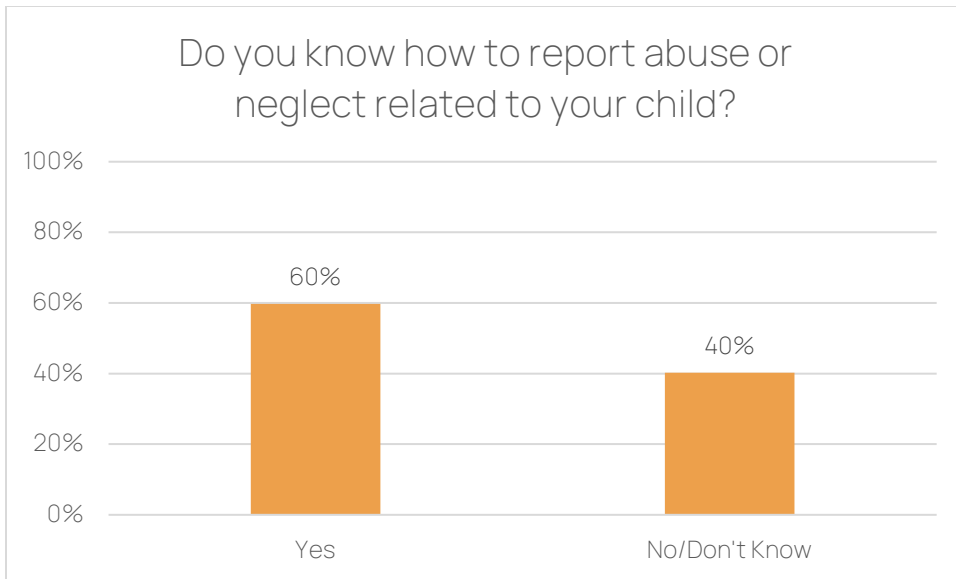
**Significantly Above Average**

State	Yes	No	N
LA	57%	43%	44

**Within Average Range**

State	Yes	No	N
OR	38%	62%	34
<b>Weighted NCI-IDD Average</b>	<b>31%</b>	<b>69%</b>	<b>704</b>
WI	30%	70%	23
CA	27%	73%	550

Table note: AK, CO, IN, and MO not shown due to low sample size.



**Table 80. Do you know how to report abuse or neglect related to your child?**

**Significantly Above Average**

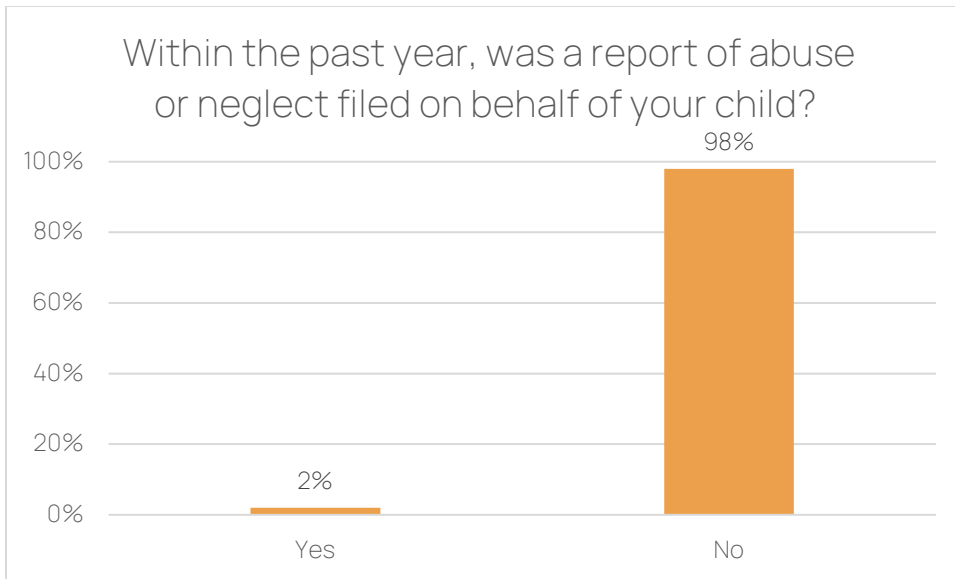
State	Yes	No or Don't Know	N
LA	83%	17%	361
OR	83%	17%	629
AK	82%	18%	155
CO	80%	20%	210
WI	75%	25%	387
IN	74%	26%	250
MO	73%	27%	190

**Within Average Range**

State	Yes	No or Don't Know	N
Weighted NCI-IDD Average	60%	40%	7448

**Significantly Below Average**

State	Yes	No or Don't Know	N
CA	54%	46%	5266



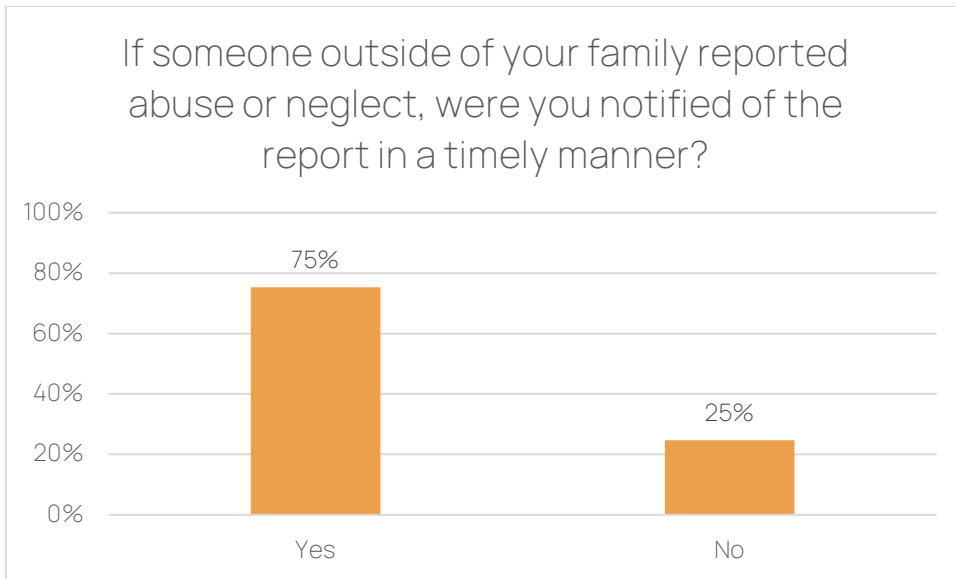
**Table 81. Within the past 12 months, was a report of abuse or neglect filed on behalf of your child?**

**Significantly Above Average**

State	Yes	No	N
OR	5%	95%	612

**Within Average Range**

State	Yes	No	N
AK	7%	93%	147
MO	4%	96%	182
LA	3%	97%	356
CO	3%	97%	209
WI	3%	97%	380
IN	3%	97%	247
<b>Weighted NCI-IDD Average</b>	<b>2%</b>	<b>98%</b>	<b>7186</b>
CA	1%	99%	5053



**Table 82. If a report of abuse or neglect was filed on behalf of your child, if someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?**

**Within Average Range**

State	Yes	No	N
OR	88%	12%	26
<b>Weighted NCI-IDD Average</b>	<b>75%</b>	<b>25%</b>	<b>118</b>
CA	72%	28%	50

Table note: AK, CO, IN, LA, MO and WI not shown due to low sample size.

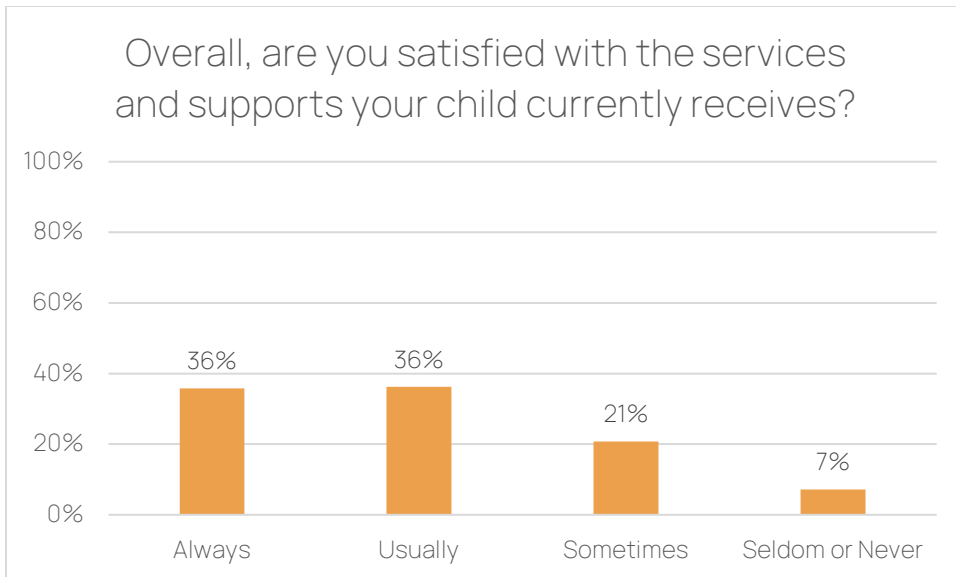
## *Satisfaction With Services and Supports*

*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.**

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



**Table 83. Overall, are you satisfied with the services and supports your child currently receives?**

**Significantly Above Average**

State	Always	Usually	Sometimes	Seldom or Never	N
LA	52%	34%	11%	3%	385

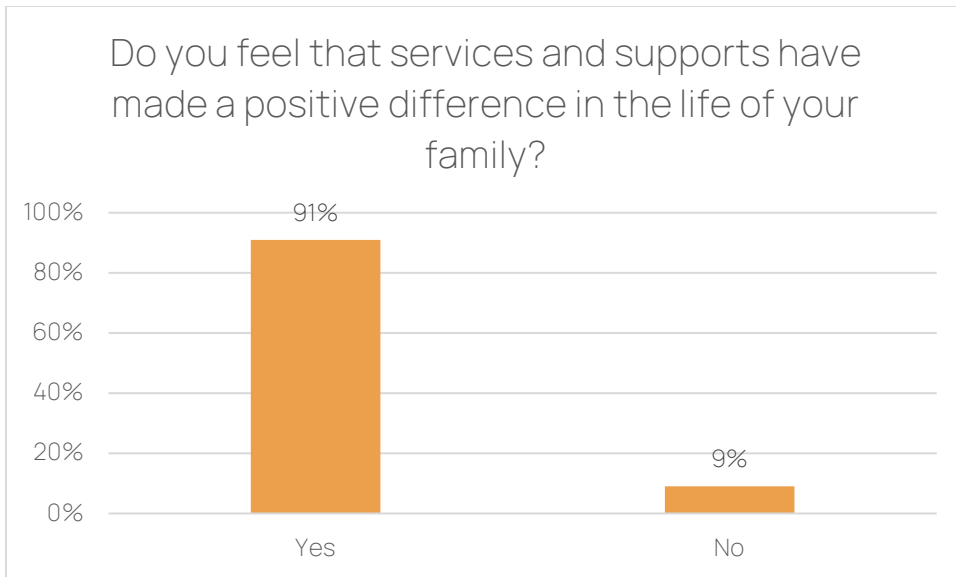
**Within Average Range**

State	Always	Usually	Sometimes	Seldom or Never	N
IN	42%	40%	13%	5%	249
AK	36%	37%	18%	9%	154
<b>Weighted NCI-IDD Average</b>	<b>36%</b>	<b>37%</b>	<b>21%</b>	<b>7%</b>	<b>7373</b>
CA	36%	34%	22%	8%	5170
WI	32%	42%	20%	5%	394
CO	29%	49%	17%	6%	214
MO	27%	46%	19%	8%	184

**Significantly Below Average**

State	Always	Usually	Sometimes	Seldom or Never	N
OR	28%	49%	18%	5%	623





**Table 84. Do you feel that services and supports have made a positive difference in the life of your child<sup>3</sup>?**

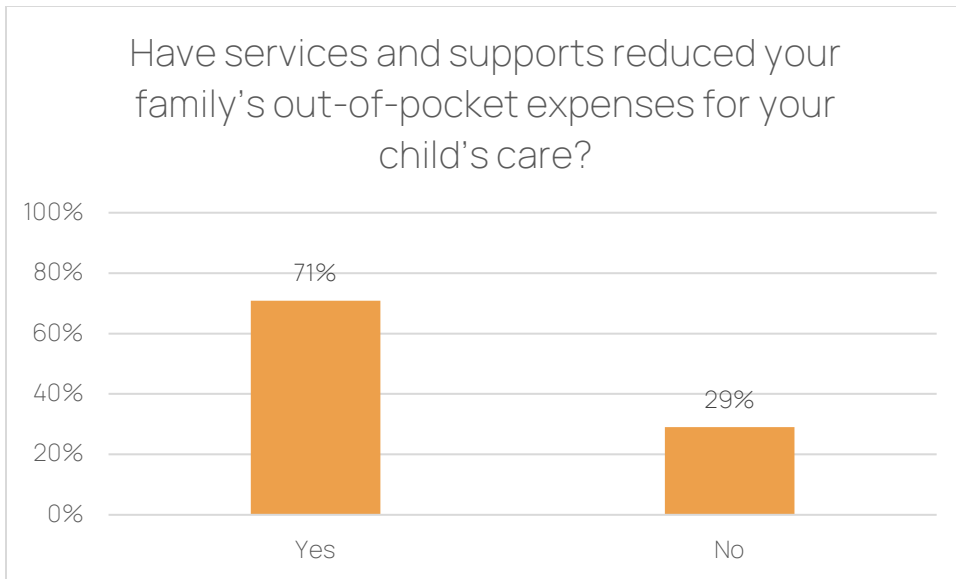
**Significantly Above Average**

State	Yes	No	N
CO	96%	4%	204

**Within Average Range**

State	Yes	No	N
AK	95%	5%	145
LA	94%	6%	357
WI	94%	6%	369
IN	94%	6%	223
OR	93%	7%	593
<b>Weighted NCI-IDD Average</b>	<b>91%</b>	<b>9%</b>	<b>6807</b>
MO	91%	9%	182
CA	90%	10%	4734

<sup>3</sup> Those who completed the survey using the Direct Entry mode saw: “Do you feel that services and supports have made a positive difference in the life of your *family*?” while those who completed the survey on paper saw “Do you feel that services and supports have made a positive difference in the life of your *child*?”



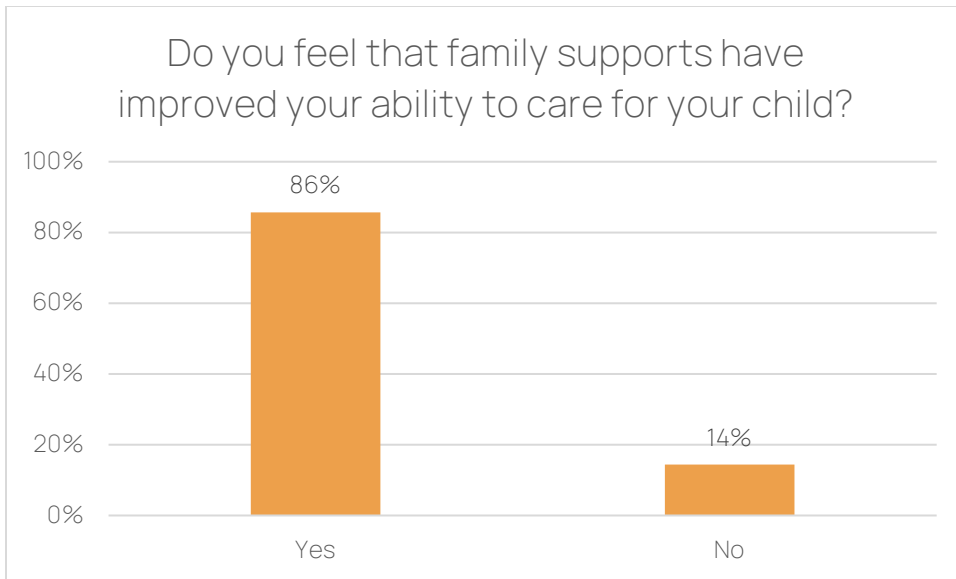
**Table 85. Have services and supports reduced your family's out-of-pocket expenses for your child's care?**

**Significantly Above Average**

State	Yes	No	N
WI	87%	13%	369
CO	84%	16%	205
OR	78%	22%	583

**Within Average Range**

State	Yes	No	N
AK	75%	25%	138
LA	72%	28%	348
IN	71%	29%	227
<b>Weighted NCI-IDD Average</b>	<b>71%</b>	<b>29%</b>	<b>6564</b>
MO	71%	29%	173
CA	69%	31%	4521



**Table 86. Do you feel that family supports have improved your ability to care for your child<sup>4</sup>?**

**Significantly Above Average**

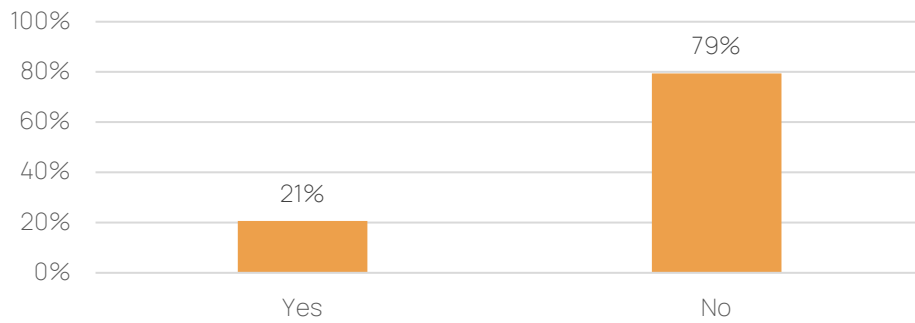
State	Yes	No	N
AK	92%	8%	145
OR	90%	10%	578

**Within Average Range**

State	Yes	No	N
CO	90%	10%	201
LA	89%	11%	348
WI	87%	13%	361
IN	87%	13%	213
<b>Weighted NCI-IDD Average</b>	<b>86%</b>	<b>14%</b>	<b>6463</b>
MO	86%	14%	174
CA	85%	15%	4443

<sup>4</sup> Those who completed the survey using the Direct Entry mode saw: “Do you feel that family supports have improved your ability to care for your child?” while those who completed the survey on paper saw “Do you feel that services and supports have improved your ability to care for your child?”

Have services or supports that your child/family received during the past 12 months been reduced, suspended, or terminated?



**Table 87. Have the services or supports that your child received during the past 12 months been reduced, suspended, or terminated?**

**Significantly Above Average**

State	Yes	No	N
AK	37%	63%	146
MO	35%	65%	173

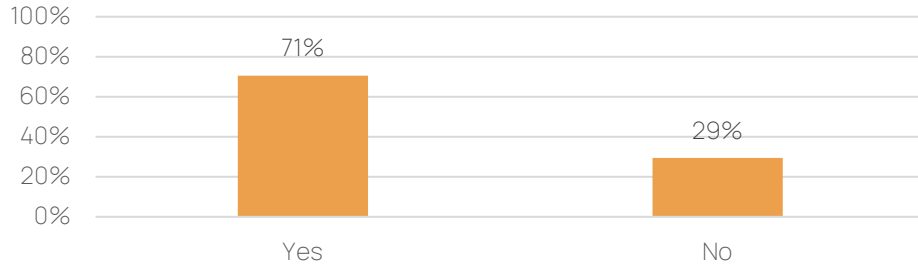
**Within Average Range**

State	Yes	No	N
CO	29%	71%	208
CA	21%	79%	4474
<b>Weighted NCI-IDD Average</b>	<b>21%</b>	<b>79%</b>	<b>6553</b>
OR	18%	82%	579
LA	16%	84%	363
IN	16%	84%	243

**Significantly Below Average**

State	Yes	No	N
WI	15%	85%	367

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



**Table 88. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family or your child negatively?**

**Significantly Above Average**

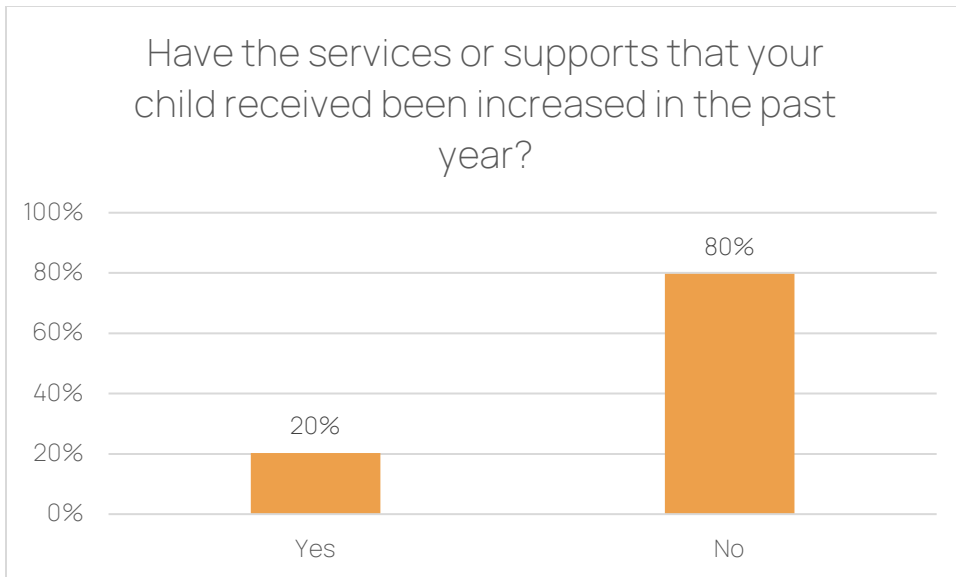
State	Yes	No	N
CO	90%	10%	49
OR	83%	17%	90

**Within Average Range**

State	Yes	No	N
WI	84%	16%	51
AK	74%	26%	47
<b>Weighted NCI-IDD Average</b>	<b>71%</b>	<b>29%</b>	<b>1136</b>
CA	70%	30%	775
MO	69%	31%	51
IN	65%	35%	31

**Significantly Below Average**

State	Yes	No	N
LA	50%	50%	42



**Table 89. Have the services or supports that your child received been increased in the past year?**

**Significantly Above Average**

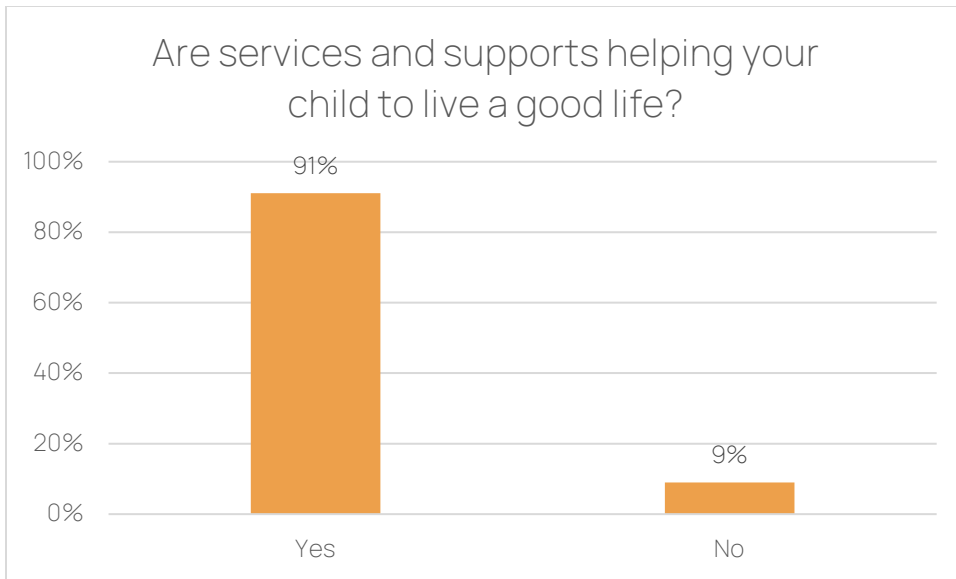
State	Yes	No	N
OR	26%	74%	559

**Within Average Range**

State	Yes	No	N
WI	25%	75%	356
LA	23%	77%	347
<b>Weighted NCI-IDD Average</b>	<b>20%</b>	<b>80%</b>	<b>6518</b>
CA	20%	80%	4505
CO	18%	82%	204
IN	15%	85%	229
MO	14%	86%	175

**Significantly Below Average**

State	Yes	No	N
AK	10%	90%	143



**Table 90. Are services and supports helping your child to live a good life?**

**Significantly Above Average**

State	Yes	No	N
AK	98%	2%	141
CO	97%	3%	195
OR	95%	5%	567
LA	95%	5%	350

**Within Average Range**

State	Yes	No	N
WI	93%	7%	358
IN	92%	8%	215
MO	92%	8%	170
<b>Weighted NCI-IDD Average</b>	<b>91%</b>	<b>9%</b>	<b>6371</b>
CA	90%	10%	4375

## *COVID-19 Supplement*

*The COVID-19 Supplement is intended to support an ongoing understanding of the continuing effects of the pandemic on people's lives and services.*

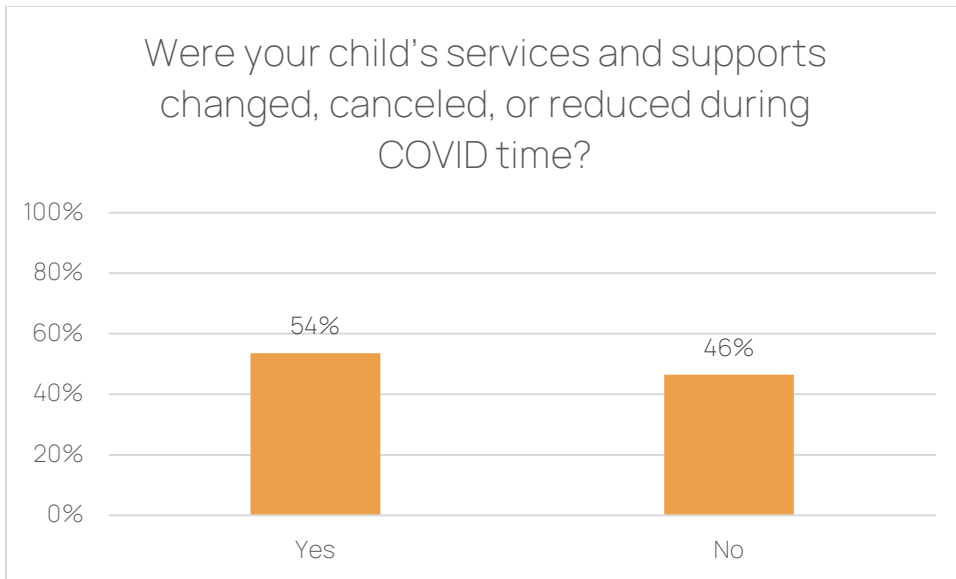
*Please note that for the state of LA, the COVID supplement was only completed by those who used the Direct Entry mode.*

**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 91. Were your child's services and supports changed, canceled, or reduced during COVID time?**

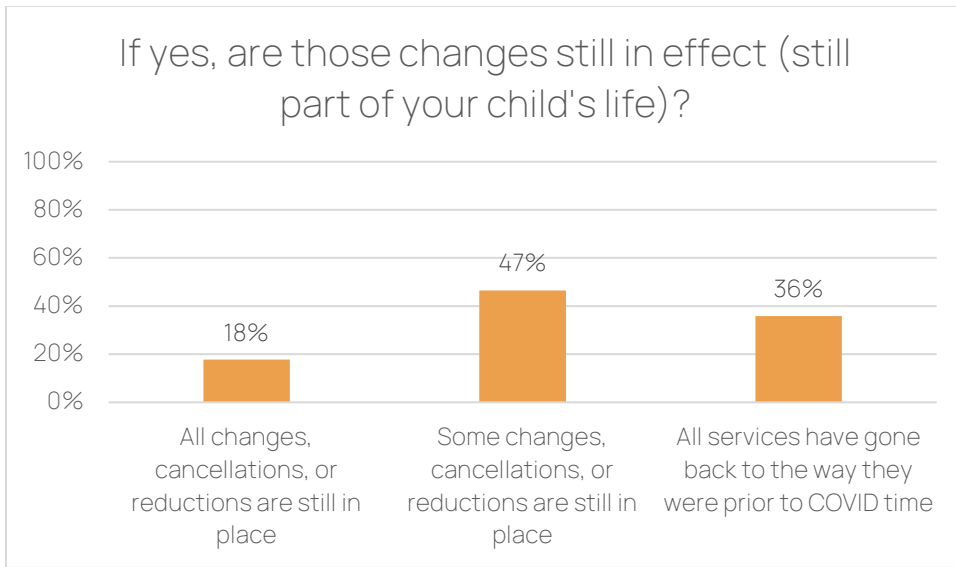
**Significantly Above Average**

State	Yes	No	N
MO	75%	25%	167
CO	74%	26%	197
WI	65%	35%	368
IN	63%	37%	225

**Within Average Range**

State	Yes	No	N
<b>Weighted NCI-IDD Average</b>	<b>54%</b>	<b>46%</b>	<b>5689</b>
CA	51%	49%	4646
LA	45%	55%	86

Table note: AK and OR did not administer the COVID 19 Supplemental Questions.



**Table 92. If yes, are those changes still in effect (still part of your child's life)?**

**Within Average Range**

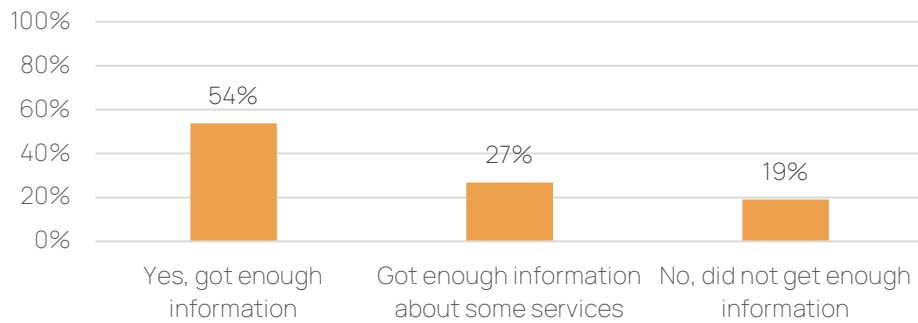
State	All changes still in place	Some changes still in place	All services have gone back to the way they were prior to COVID	N
CA	20%	47%	33%	2089
LA	20%	34%	46%	35
<b>Weighted NCI-IDD Average</b>	<b>17%</b>	<b>47%</b>	<b>36%</b>	<b>2755</b>
MO	13%	64%	22%	121
IN	12%	37%	51%	134

**Significantly Below Average**

State	All changes still in place	Some changes still in place	All services have gone back to the way they were prior to COVID	N
WI	9%	46%	45%	234
CO	6%	64%	30%	142

Table note: AK and OR did not administer the COVID 19 Supplemental Questions.

If some or all of your child's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?



**Table 93. If some or all of your child's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?**

**Significantly Above Average**

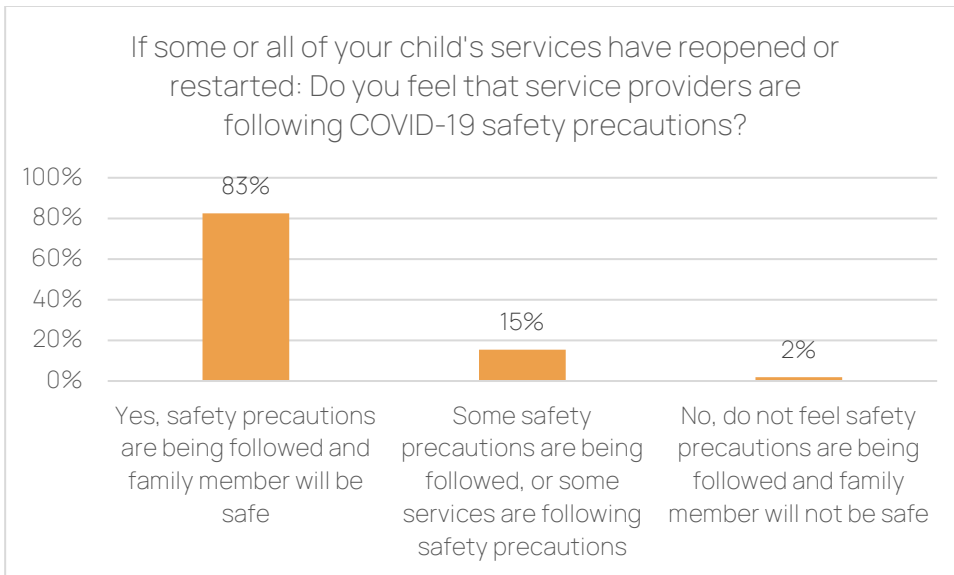
State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
LA	82%	14%	4%	28
IN	81%	15%	4%	112
WI	69%	23%	8%	197

**Within Average Range**

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
MO	65%	15%	19%	98
CO	64%	27%	9%	123
<b>Weighted NCI-IDD Average</b>	<b>54%</b>	<b>27%</b>	<b>19%</b>	<b>2066</b>

**Significantly Below Average**

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
CA	46%	30%	24%	1508



**Table 94. If some or all of your child's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?**

**Significantly Above Average**

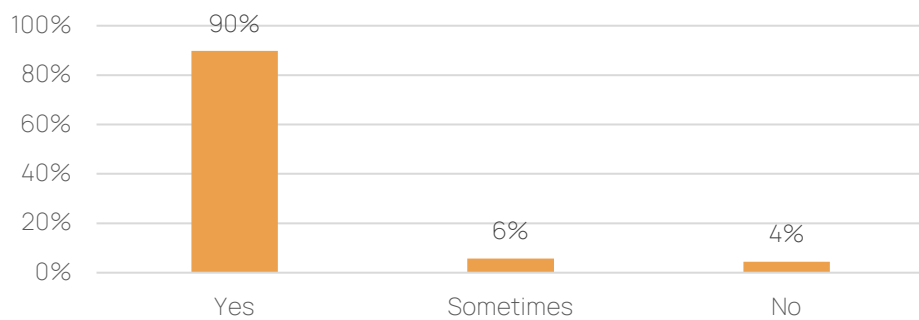
State	Yes	Some precautions being followed	No	N
IN	95%	5%	0%	110

**Within Average Range**

State	Yes	Some precautions being followed	No	N
LA	89%	11%	0%	28
MO	87%	13%	0%	95
CO	85%	13%	2%	124
<b>Weighted NCI-IDD Average</b>	<b>83%</b>	<b>15%</b>	<b>2%</b>	<b>2009</b>
CA	81%	16%	2%	1446
WI	77%	20%	3%	206

Table note: AK and OR did not administer the COVID 19 Supplemental Questions.

If staff come into your home to support your child: Do you feel that the staff follow recommendations to keep the household safe and healthy?



**Table 95. If staff come into your home to support your child: Do you feel that the staff follow recommendations to keep the household safe and healthy?**

**Significantly Above Average**

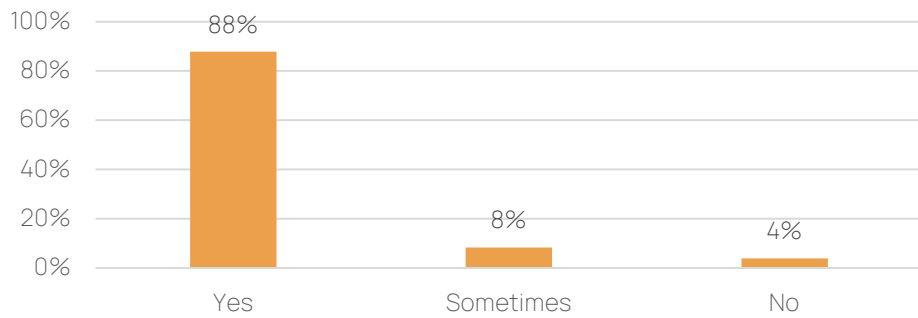
State	Yes	Sometimes	No	N
LA	99%	1%	0%	78
IN	98%	1%	1%	200

**Within Average Range**

State	Yes	Sometimes	No	N
CO	92%	5%	3%	185
WI	91%	7%	1%	327
MO	91%	6%	4%	140
<b>Weighted NCI-IDD Average</b>	<b>90%</b>	<b>6%</b>	<b>4%</b>	<b>4687</b>
CA	89%	6%	5%	3757

Table note: AK and OR did not administer the COVID 19 Supplemental Questions.

Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community?



**Table 96. Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community?**

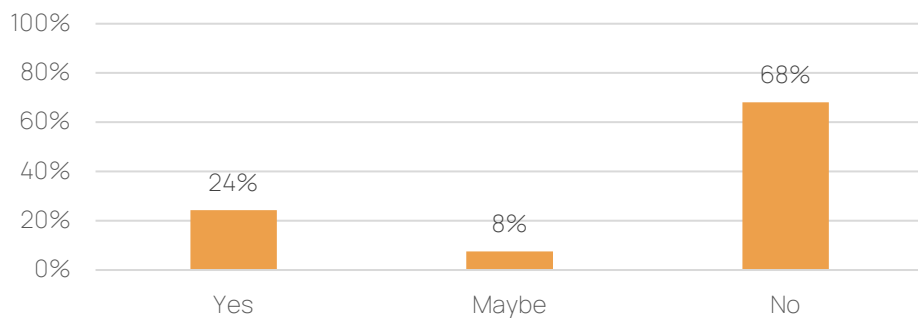
**Significantly Above Average**

State	Yes	Sometimes	No	N
CO	95%	2%	3%	192
IN	94%	5%	0%	223

**Within Average Range**

State	Yes	Sometimes	No	N
LA	92%	6%	2%	86
WI	91%	7%	2%	371
MO	88%	8%	4%	169
<b>Weighted NCI-IDD Average</b>	<b>88%</b>	<b>8%</b>	<b>4%</b>	<b>5785</b>
CA	87%	9%	4%	4744

In preparation for the future, have you made or updated an emergency plan with your child's case manager or with other staff?



**Table 97. In preparation for the future, have you made or updated an emergency plan with your child's case manager or with other staff?**

**Significantly Above Average**

State	Yes	Maybe	No	N
LA	62%	5%	33%	85
IN	36%	5%	59%	203
CO	34%	4%	62%	181

**Within Average Range**

State	Yes	Maybe	No	N
MO	28%	8%	64%	149
WI	25%	7%	68%	346
<b>Weighted NCI-IDD Average</b>	<b>24%</b>	<b>8%</b>	<b>68%</b>	<b>5302</b>
CA	22%	8%	70%	4338

## **NCI-IDD History and Activities**

*This section briefly describes the history of the National Core Indicators and NCI-IDD 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-Intellectual and Developmental Disabilities (NCI-IDD), 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-IDD 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

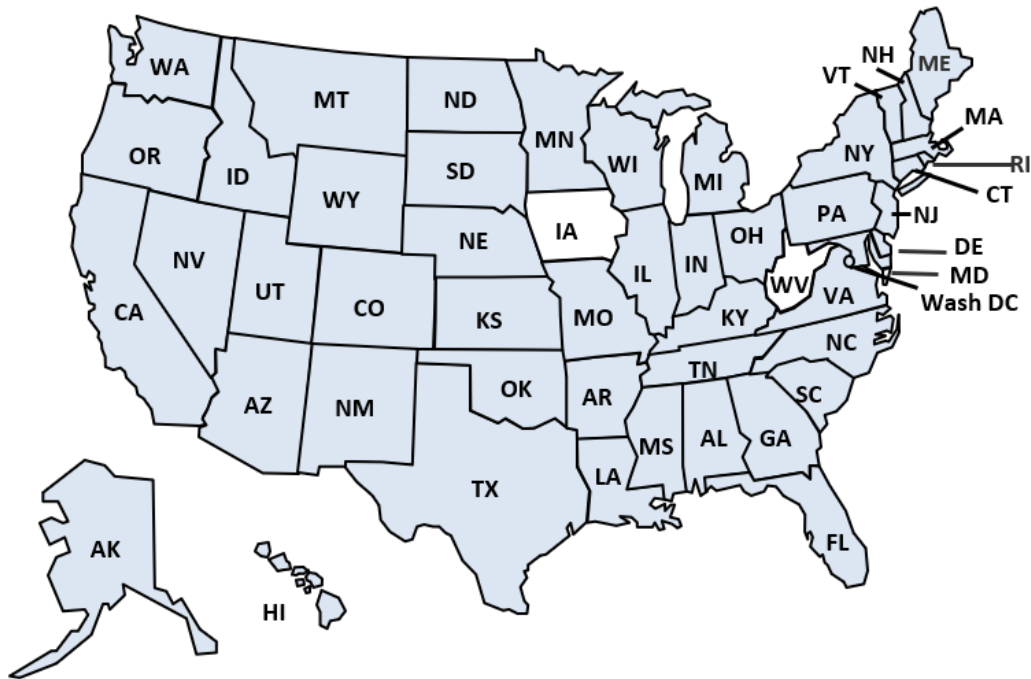
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

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

### *State Participation*

During the 2021-22 data collection cycle, State participation is entirely voluntary, and participating states are highlighted on the map below. Not all states participate in all surveys each year.

Figure 1. NCI-IDD State Participation 2021-22



### *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 entire list of Core Indicators, please visit the Indicators page on the NCI-IDD 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 In-Person Survey, three Family Surveys, and a State of the Workforce Survey.

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

### *How NCI-IDD 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-IDD as a data source for supplemental performance measures in their home and community-based services (HCBS) waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate

individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

For more information on how to use these data for quality improvement, please see this handbook: [Using National Core Indicators for Quality Improvement Initiatives](#).<sup>5</sup>

### 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-IDD Average suggests that changes or further investigation are necessary.

Moreover, the NCI-IDD 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-IDD Averages; and states draw new samples each year rather than following the same group of individuals.

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<sup>5</sup> Located on the National Core Indicators website: <https://idd.nationalcoreindicators.org/> →How it Works →How to Use the Data

## 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-IDD staff to aggregate and analyze the data.

## Sampling & Administration

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

1. Had a child under age 18 living in the home; and
2. The child living in the home received at least one direct service or support in addition to 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 sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.<sup>6</sup>

### *Weighting*

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI-IDD reports, we use “NCI-IDD average” to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI-IDD 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-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the sample sizes.

Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI-IDD average—that is, the state’s contribution to the NCI-IDD 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.

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<sup>6</sup> See “Response Rates” for information on total surveys mailed and received by states as well as each state’s margin of error.

## Significance Testing

For each of the items in the report, each state's percentage was compared to the weighted NCI-IDD 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-IDD average**, where the difference between the state's percentage and the weighted NCI-IDD 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-IDD average range**, where the difference between the state's percentage and the weighted NCI-IDD 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-IDD average**, where the difference between the state's percentage and the weighted NCI-IDD average: a) was in favor of the NCI-IDD 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-IDD Average, within the range of the NCI-IDD Average, and significantly below the NCI-IDD Average.

### Technical Details

The comparisons were done through one sample t-tests using the weighted NCI-IDD 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 individual with an intellectual or developmental disability receiving services lived outside of the family home.
2. Demographic information was entered into the file but no survey questions were answered.

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the NCI-IDD average<sup>7</sup>; significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

## *Response Rates*

During 2020-21, 7 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% (7.49% or less) margin of error; their data are included in this report. The following table shows the number of individuals receiving services who were eligible to be drawn into the sample ("total population"), the number of surveys each state sent, complete surveys, response rates, margins of error, and survey submission modes.

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<sup>7</sup> The NCI-IDD Average is a weighted average. Please see the section "Weighting" for more details.



Figure 3. Child Family Survey: State Response Rates <sup>8</sup>

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AK	669	669	163	24.4%	6.68%	86%	14%
CA	93,889	39,967	5,589	14.0%	1.27%	72%	28%
CO	2,500	2,466	222	9.0%	1.27%	62%	38%
IN	8,634	1,500	255	17.0%	6.05%	67%	33%
LA	4,838	-	401	-	4.69%	76%	24%
MO	3,588	1,500	194	12.9%	6.84%	75%	25%
OR	4,550	4,500	637	14.2%	3.60%	89%	11%
WI	10,456	-	441	-	4.57%	0%	100%
<b>Total</b>	<b>126,624</b>		<b>7,902</b>	<b>15.2%</b>		<b>66%</b>	<b>34%</b>

<sup>8</sup> Please note: The family surveys are mail 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.