

# **Child Family Survey (CFS) State Report**

2022-23 Oregon Report

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## **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 2022-23 data collection cycle, 9 states submitted a valid sample of Child Family Survey data: Florida (FL), Indiana (IN), Missouri (MO), North Dakota (ND), Oregon (OR), South Dakota (SD), Tennessee (TN), Texas (TX), and Wisconsin (WI). This Final Report provides a summary of results based on data submitted by June 30, 2023.

### What is the NCI-IDD Child Family Survey?

The NCI-IDD Child Family Survey is used to gather data on family outcomes. It is mailed to families who have a child who lives with the respondent and receives at least one service in addition to case management from the state DD agency. Some states survey respondents who have a "child" up to 22 years old who receive child services. The survey collects demographic information on both the individual receiving services ('family member') as well as the person who fills out the survey (the 'respondent') and information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable. Please note that while the term "case manager" is used throughout this report, the same role may also be referred to as "service coordinator" or "supports coordinator" depending on the state. Important note on responses: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses, and personal characteristics. What is included in this report?

### What is included in this report?

This report includes this state's Child Family Survey data compared to the NCI-IDD Average. State outcomes that are significantly higher or lower than the NCI-IDD Average are indicated with an arrow:

- Outcomes where the state is significantly above the NCI-IDD average are denoted with an up arrow †;
- Outcomes where the state is significantly below the NCI-IDD average are denoted with a down arrow \( \psi. \)

Significance is based on "Always" or "Yes" response.

The charts in this document, grouped by subdomain, display the state results alongside the average across states (NCI-IDD average). The charts are followed by accessible tables containing the same information.

To find out more about the development of the Child Family Survey, data analysis and state samples, check out the National Child Family Survey Report.

# Results

#### **Presentation of the 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.
- 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 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.

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

State (names abbreviated)	Yes	No	N
OR	63%	37%	603
Weighted NCI-IDD Average	66%	34%	2751

Table 2. Child's Age

State (names abbreviated)	Age	N
OR	11.7	620
Weighted NCI-IDD Average	11.1	2844

Table 3. Child's Gender

State (names abbreviated)	Male	Female	Other	N
OR	64%	35%	0%	621
Weighted NCI-IDD Average	64%	36%	0%	2840

Table 4a. Child's Race and Ethnicity

State (names abbreviated)	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander
OR	5%	7%	5%	2%
Weighted NCI-IDD Average	2%	4%	9%	0%

Table 4b. Child's Race and Ethnicity (continued)

State (names abbreviated)	White	Hispanic or Latino	Other	Prefer not to say
OR	78%	17%	2%	3%
Weighted NCI-IDD Average	70%	23%	2%	2%

Table 5a. Child's Conditions

State (names abbreviated)	Intellectual developmental disability	Mood illness/psychiatric diagnosis	Autism spectrum disorder	Cerebral palsy
OR	53%	24%	59%	10%
Weighted NCI- IDD Average	46%	22%	55%	15%

Table 5b. Child's Conditions (Continued)

State (names abbreviated)	Limited or no vision – legally blind	Hearing loss (severe or profound)	Brain injury	Seizure disorder or neurological problem	Chemical dependency
OR	6%	6%	6%	16%	0%
Weighted NCI- IDD Average	10%	5%	9%	25%	0%

### Table 5c. Child's Conditions (Continued)

State (names abbreviated)	Down syndrome	Prader-Willi syndrome	Fetal alcohol spectrum disorder (FASD)	Other
OR	11%	0%	7%	32%
Weighted NCI-IDD Average	11%	0%	2%	34%

Table 6a. Child's Health Conditions

State (names abbreviated)	Cardiovascular disease	Diabetes	Cancer	High blood pressure	High cholesterol
OR	10%	3%	2%	2%	4%
Weighted NCI- IDD Average	13%	3%	3%	5%	6%

Table 6b. Child's Health Conditions (continued)

State (names abbreviated)	Dysphagia	Pressure ulcers	Oral health or dental problems	Sleep apnea	Other pulmonary diagnosis (e.g., COPD, bronchitis, emphysema)
OR	22%	1%	13%	23%	8%
Weighted NCI- IDD Average	22%	2%	10%	29%	13%

### Table 6c. Child's Health Conditions (continued)

State (names abbreviated)	Asthma	Chronic kidney disease	Long-term health problems associated with COVID-19	Other
OR	29%	1%	2%	34%
Weighted NCI-IDD Average	29%	3%	2%	36%

Table 7a. Family Member's Preferred Language

State (names abbreviated)	English	Spanish	Chinese	N
OR	91%	3%	0%	593
Weighted NCI-IDD Average	93%	5%	0%	2807

Table note: "Chinese" includes Mandarin, Cantonese, and Hokkien".

Table 7b. Family Member's Preferred Language (continued)

State (names abbreviated)	Tagalog	Vietnamese	American Sign Language	Other	N
OR	0%	1%	1%	5%	593
Weighted NCI-IDD Average	0%	0%	1%	2%	2807

Table note: "Tagalog" includes Filipino.

Table 8. Child's Preferred Means of Communication

State (names abbreviated)	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
OR	73%	14%	1%	6%	5%	571
Weighted NCI-IDD Average	68%	18%	2%	6%	5%	2782

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

State (names abbreviated)	No support needed; no issues with managing behavior	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
OR	19%	50%	31%	618
Weighted NCI- IDD Average	34%	42%	24%	2805

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

State (names abbreviated)	No support needed; no issues with personal care activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed	N
OR	4%	40%	56%	618
Weighted NCI- IDD Average	6%	41%	53%	2841

Res	pon	dents
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This section provides information about the survey respondent.

Table 11a. Language Usually Spoken at Home

State (names abbreviated)	English	Spanish	Chinese	N
OR	88%	8%	1%	599
Weighted NCI-IDD Average	89%	9%	0%	2815

Table note: "Chinese" includes Mandarin, Cantonese, and Hokkien".

Table 11b. Language Usually Spoken at Home (continued)

State (names abbreviated)	Tagalog	Vietnamese	American Sign Language	Other	N
OR	0%	1%	0%	3%	599
Weighted NCI-IDD Average	0%	0%	0%	2%	2815

Table note: "Tagalog" includes Filipino.

Table 12. Respondent's Age

State (names abbreviated)	Under 34	35 – 54	55 – 74	75 or older	N
OR	10%	71%	18%	1%	621
Weighted NCI-IDD Average	12%	73%	14%	1%	2848

Table 13. Respondent's Health

State (names abbreviated)	Excellent	Very good	Good	Fair	Poor	N
OR	10%	33%	40%	16%	2%	623
Weighted NCI-IDD Average	13%	37%	36%	12%	2%	2851

Table 14. Respondent's Relationship to Child

State (names abbreviated)	Parent (biological, adoptive, or foster)	Sibling	Grandparent	Other	N
OR	90%	0%	8%	2%	619
Weighted NCI-IDD Average	92%	0%	6%	2%	2849

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

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

State (names abbreviated)	No	Yes, I am	Yes, another family member is
OR	61%	12%	29%
Weighted NCI-IDD Average	77%	5%	18%

Table 16. Number of Adults in Household

State (names abbreviated)	One	Two	Three	Four or more	N
OR	22%	52%	20%	6%	618
Weighted NCI-IDD Average	21%	61%	14%	5%	2835

Table 17. Number of Children (Under 18 years old) in Household (including the child receiving services)

State (names abbreviated)	One	Two	Three	Four or more	N
OR	39%	38%	14%	9%	607
Weighted NCI-IDD Average	35%	37%	18%	10%	2800

Table 18a. Respondent's Highest Level of Education

State (names abbreviated)	No high school diploma/GED	High school diploma/GED	Vocational school or certificate program	N
OR	8%	18%	6%	599
Weighted NCI- IDD Average	7%	13%	8%	2816

Table 18b. Respondent's Highest Level of Education

State (names abbreviated)	Some college	College degree or higher	N
OR	19%	48%	599
Weighted NCI-IDD Average	17%	55%	2816

Table 19a. Total Taxable Household Income of Wage Earners in the Past 12 Months

Please note: Respondents did not respond if they were a public guardian/administrator, or if they represent a financial institution or guardianship agency. Does not include state/federal benefits such as SSI, SSDI etc.

State (names abbreviated)	No earned income	Up to \$15,000	\$15,001 <b>–</b> \$25,000	\$25,001 <b>–</b> \$50,000	N
OR	7%	7%	10%	18%	613
Weighted NCI-IDD Average	6%	8%	8%	15%	2825

Table 19b. Total Taxable Household Income of Wage Earners in the Past 12 Months (continued)

Please note: Respondents did not respond if they were a public guardian/administrator, or if they represent a financial institution or guardianship agency. Does not include state/federal benefits such as SSI, SSDI etc.

State (names abbreviated)	\$50,001–\$75,000	Over \$75,000	Prefer not to say	N
OR	15%	33%	11%	613
Weighted NCI-IDD Average	16%	36%	12%	2825

Table 20. Residential Designation

State (names abbreviated)	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
OR	75%	25%	605
Weighted NCI-IDD Average	73%	27%	2773

Services and	Supports	Received
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This section provides information about the services and supports received by the child from the state ID/DD agency.

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

State (names abbreviated)	Financial support	In-home support	Out-of-home respite care	Early intervention
OR	17%	76%	33%	9%
Weighted NCI-IDD Average	20%	48%	25%	17%

Table 21b. Services and Supports Received from ID/DD Agency (continued)

State (names abbreviated)	Transportation	Mental or behavioral health care or other treatments or therapies	Self-direction or fiscal intermediary services
OR	23%	74%	67%
Weighted NCI- IDD Average	15%	77%	48%

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

State (names abbreviated)	Social Security (SSI or SSB)	Services or supports from other agencies or organizations
OR	37%	72%
Weighted NCI-IDD Average	35%	70%

#### **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 have the information and support needed to take part in planning supports and services for their child receiving services and supports from the state developmental disabilities 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.

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

### Do you get enough information to take part in planning services for your child?

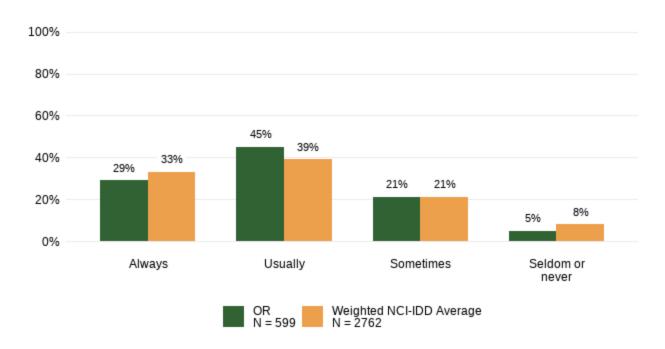


Table 23. Do you have enough information to take part in planning services for your child?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	29%	45%	21%	5%	599
Weighted NCI-IDD Average	33%	39%	21%	8%	2762

### Is the information you get about services and supports easy to understand?

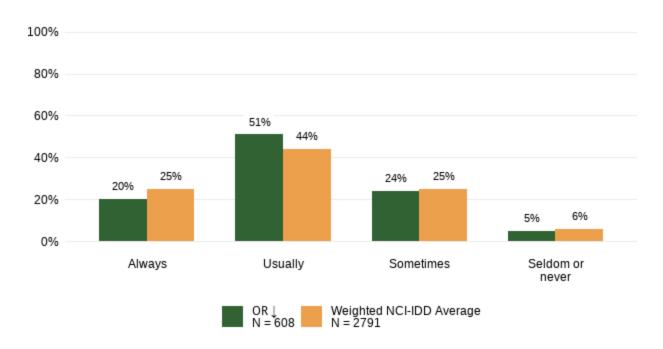


Table 24. Is the information you get about services and supports easy to understand?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	20%	51%	24%	5%	608
Weighted NCI-IDD Average	25%	44%	25%	6%	2791

### Do you get information about services and supports in your preferred language?

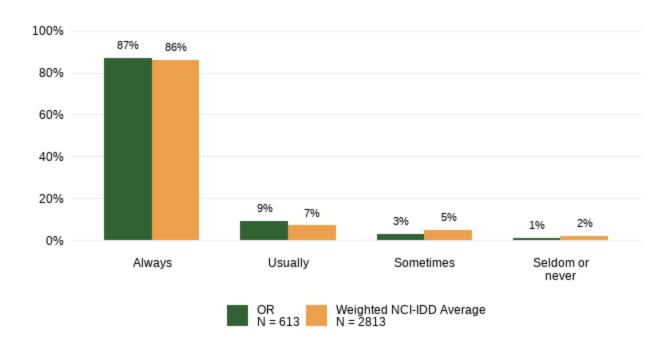


Table 25. Do you get information about services and supports in your preferred language?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	87%	9%	3%	1%	613
Weighted NCI-IDD Average	86%	7%	5%	2%	2813

### Does the case manager/service coordinator listen to your family's choices and opinions?

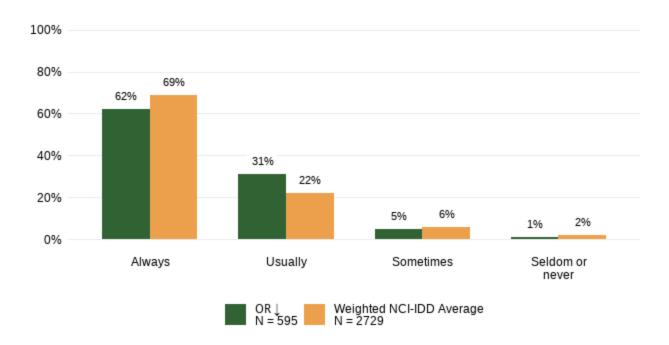


Table 26. Does the case manager/service coordinator listen to your family's choices and opinions?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR↓	62%	31%	5%	1%	595
Weighted NCI-IDD Average	69%	22%	6%	2%	2729

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

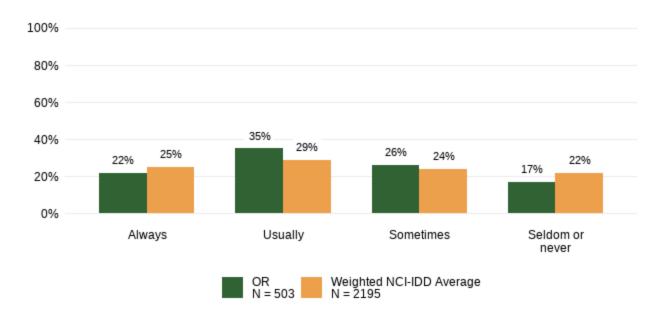


Table 27. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	22%	35%	26%	17%	503
Weighted NCI-IDD Average	25%	29%	24%	22%	2195

# Do you need help planning for your child's future in any of these areas?

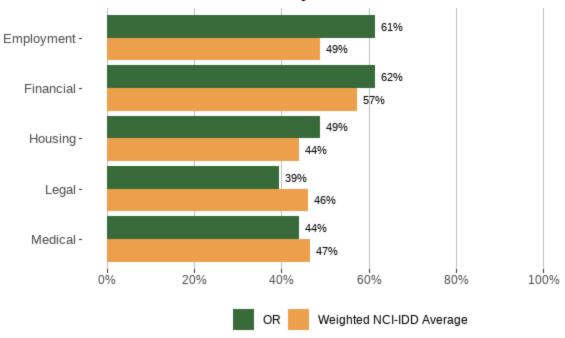
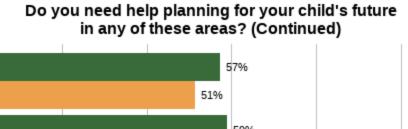


Table 28a. Do you need help planning for your child's future in any of these areas?

State (names abbreviated)	Employment	Financial	Housing	Legal	Medical
OR	61%	62%	49%	39%	44%
Weighted NCI-IDD Average	49%	57%	44%	46%	47%



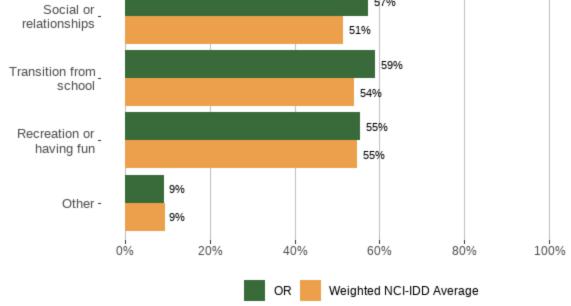


Table 28b. Do you need help planning for your child's future in any of these areas? (Continued)

State (names abbreviated)	Social or relationships	Transition from school	Recreation or having fun	Other
OR	57%	59%	55%	9%
Weighted NCI-IDD Average	51%	54%	55%	9%

### Has your family learned about alternatives to guardianship?

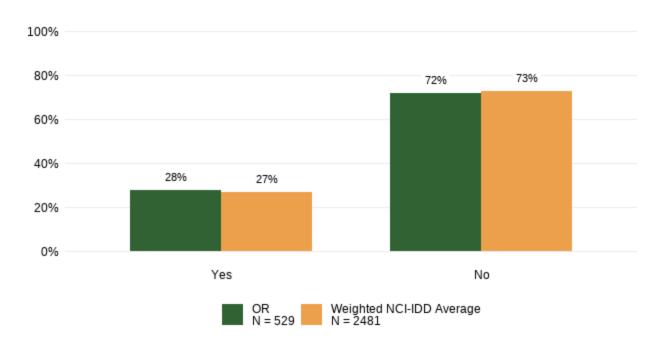


Table 29. Has your family learned about alternatives to guardianship?

If arrows are present, Key: Up Arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
OR	28%	72%	529
Weighted NCI-IDD Average	27%	73%	2481

Table note: Alternatives to guardianship let a family member make more decisions for themselves, with or without the help of others. This might include "Supported Decision Making (SDM)", allows a person with a disability to make their own decisions with the help of people they trust. "Other decision-making supports", like health-care proxies, advance directives, powers of attorney, notarized statements, representation agreements, etc.

#### Does your child have a service plan?

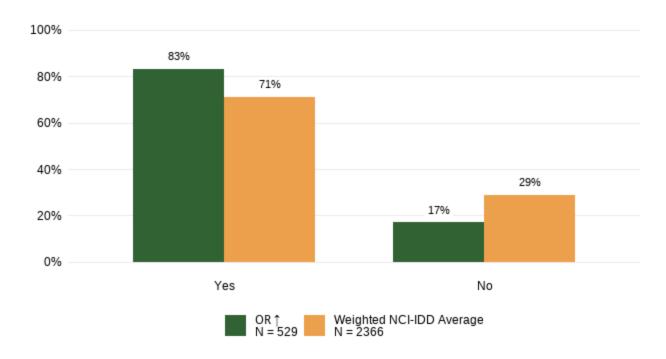


Table 30. Does your child have a service plan?

State (names abbreviated)	Yes	No	N
OR ↑	83%	17%	529
Weighted NCI-IDD Average	71%	29%	2366

#### Does the plan include all the services and supports your child needs?

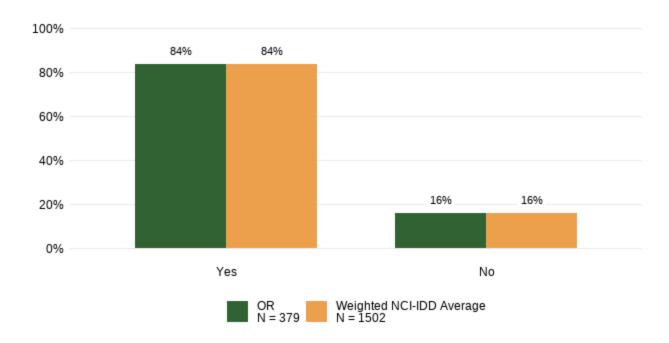


Table 31. Does the plan include all the services and supports your child needs?

State (names abbreviated)	Yes	No	N
OR	84%	16%	379
Weighted NCI-IDD Average	84%	16%	1502

### Did you or another family member help make the plan?

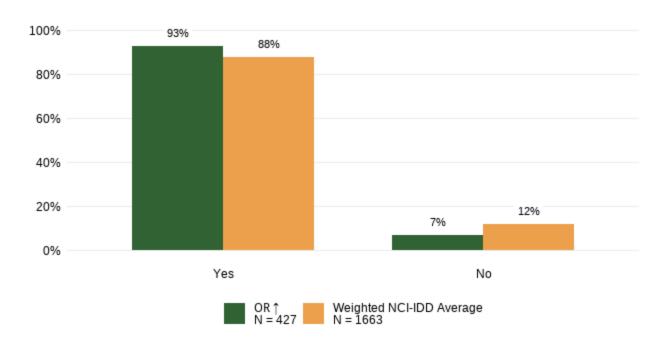


Table 32. Did you or another family member help make the plan?

State (names abbreviated)	Yes	No	N
OR ↑	93%	7%	427
Weighted NCI-IDD Average	88%	12%	1663

#### Did your child help make the plan?

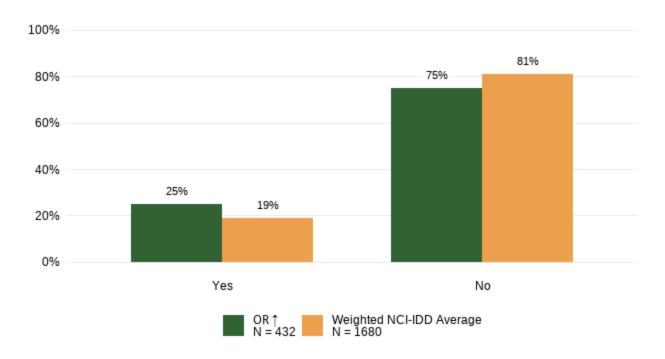


Table 33. Did your child help make the plan?

State (names abbreviated)	Yes	No	N
OR ↑	25%	75%	432
Weighted NCI-IDD Average	19%	81%	1680

### Do you feel like your family had enough say or input in making the plan?

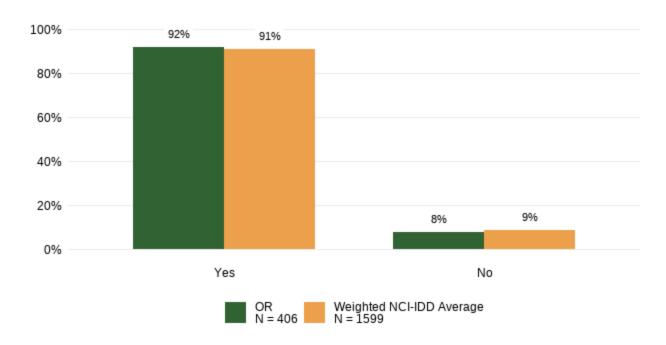


Table 34. Do you feel like your family had enough say or input in making the plan?

State (names abbreviated)	Yes	No	N
OR	92%	8%	406
Weighted NCI-IDD Average	91%	9%	1599

# 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)?

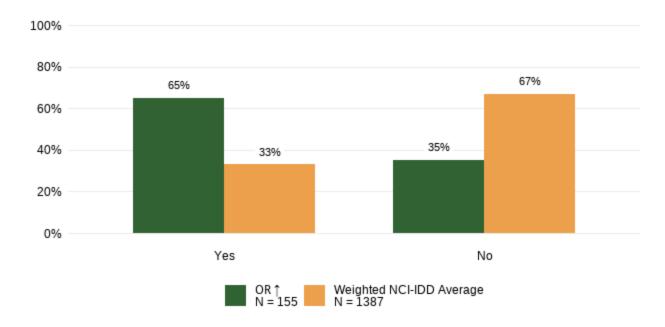


Table 35. Does your child have a transition plan (as part of an IEP or Section 504 plan through their high school, usually starting at age 14)?

State (names abbreviated)	Yes	No	N
OR ↑	65%	35%	155
Weighted NCI-IDD Average	33%	67%	1387

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

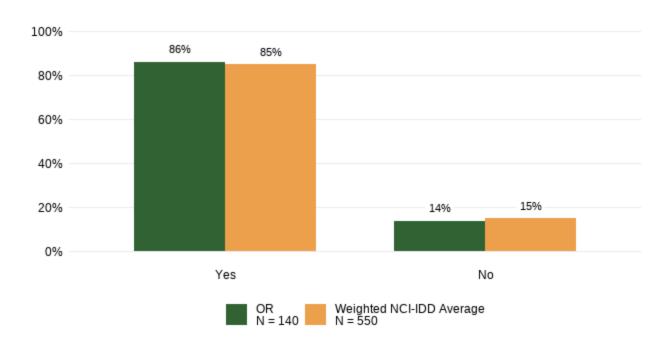


Table 36. If your child has a transition plan, did you or another family member help make the plan?

State (names abbreviated)	Yes	No	N
OR	86%	14%	140
Weighted NCI-IDD Average	85%	15%	550

### If your child has a transition plan, did your child help make the plan?

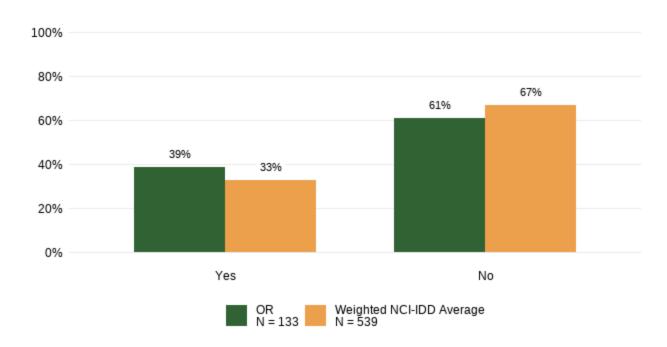


Table 37. If your child has a transition plan, did your child help make the plan?

State (names abbreviated)	Yes	No	N
OR	39%	61%	133
Weighted NCI-IDD Average	33%	67%	539

#### **Access and Delivery of Services and Supports**

Families receive services and supports that are appropriate to the needs of the family and the child receiving services and supports from the state developmental disabilities 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.

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

### Does your child get all the services listed in the plan?

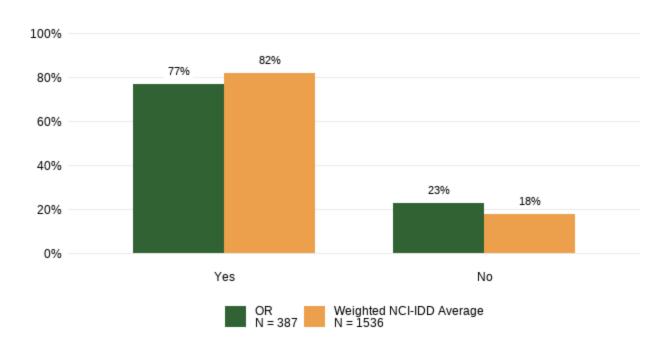


Table 38. Does your child get all the services listed in the plan?

State (names abbreviated)	Yes	No	N
OR	77%	23%	387
Weighted NCI-IDD Average	82%	18%	1536

### Does your family get the supports and services it needs?

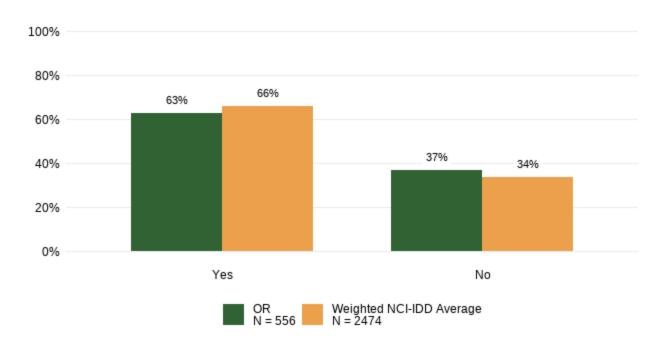


Table 39. Does your family get the supports and services it needs?

State (names abbreviated)	Yes	No	N
OR	63%	37%	556
Weighted NCI-IDD Average	66%	34%	2474

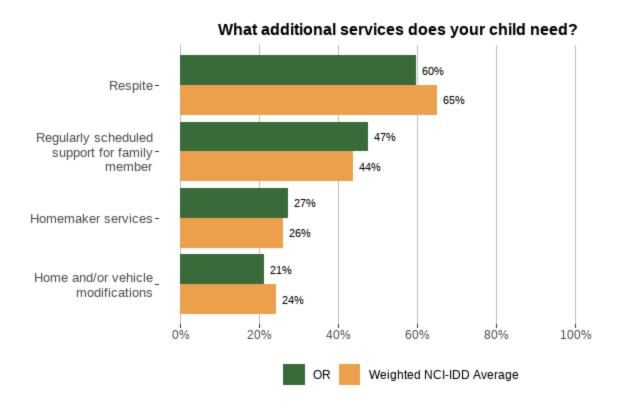


Table 40a. What additional services does your child need?

State (names abbreviated)	Respite	Regularly scheduled support for family member	Homemaker services	Home and/or vehicle modifications
OR	60%	47%	27%	21%
Weighted NCI- IDD Average	65%	44%	26%	24%

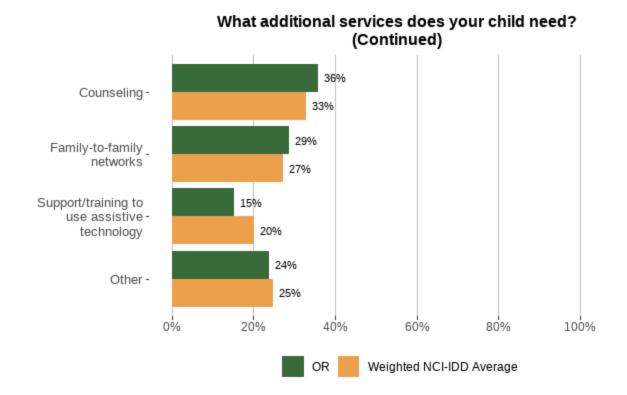


Table 40b. What additional services does your child need? (Continued)

State (names abbreviated)	Counseling	Family-to- family networks	Support/training to use assistive technology	Other
OR	36%	29%	15%	24%
Weighted NCI-IDD Average	33%	27%	20%	25%

### Do services and supports change when your family's needs change?

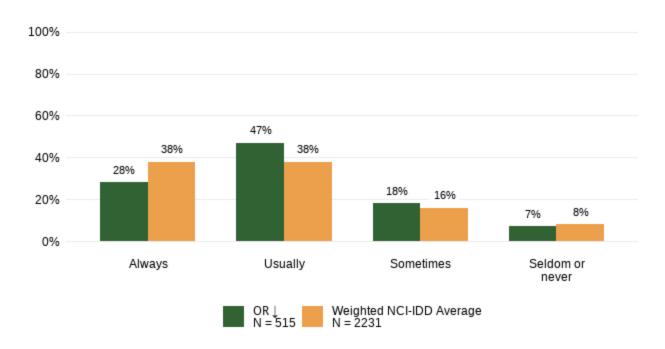


Table 41. Do services and supports change when your family's needs change?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	28%	47%	18%	7%	515
Weighted NCI-IDD Average	38%	38%	16%	8%	2231

### Does your child have the special equipment or accommodations they need?

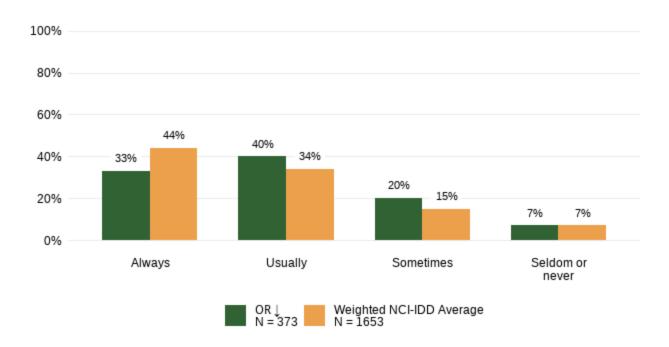


Table 42. Does your child have the special equipment or accommodations they need?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	33%	40%	20%	7%	373
Weighted NCI-IDD Average	44%	34%	15%	7%	1653

### If you need respite services, how often are you able to get them when needed?

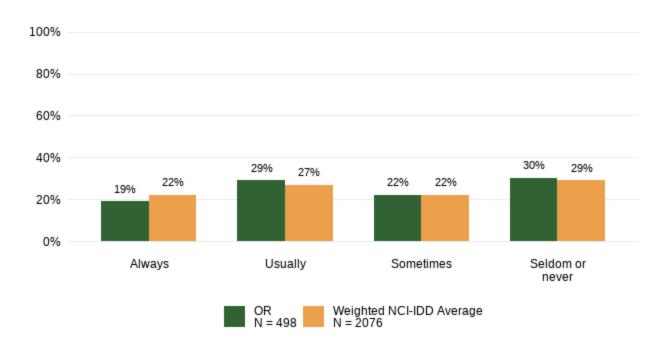


Table 43. If you need respite services, how often are you able to get them when needed?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	19%	29%	22%	30%	498
Weighted NCI-IDD Average	22%	27%	22%	29%	2076

# If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

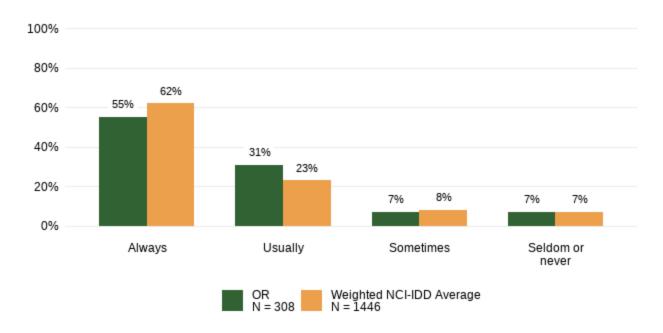


Table 44. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	55%	31%	7%	7%	308
Weighted NCI-IDD Average	62%	23%	8%	7%	1446

## Are you able to contact your child's support workers when you want?

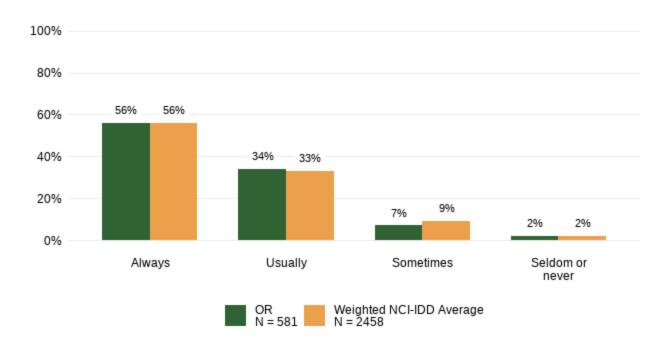


Table 45. Are you able to contact your child's support workers when you want?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	56%	34%	7%	2%	581
Weighted NCI-IDD Average	56%	33%	9%	2%	2458

#### Are you able to contact your child's case manager or service coordinator when you want?

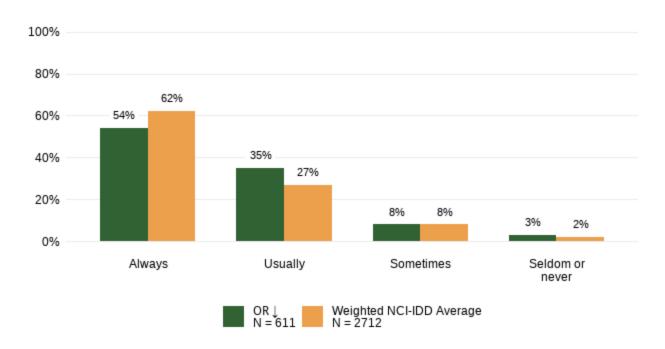


Table 46. Are you able to contact your child's case manager or service coordinator when you want?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	54%	35%	8%	3%	611
Weighted NCI-IDD Average	62%	27%	8%	2%	2712

### Do service providers for your child work together to provide support?

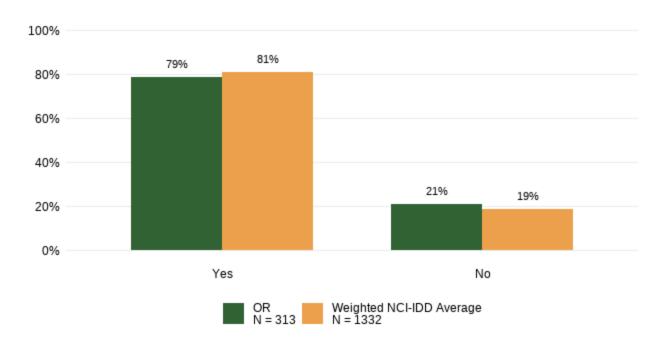


Table 47. Do service providers for your child work together to provide support?

State (names abbreviated)	Yes	No	N
OR	79%	21%	313
Weighted NCI-IDD Average	81%	19%	1332

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

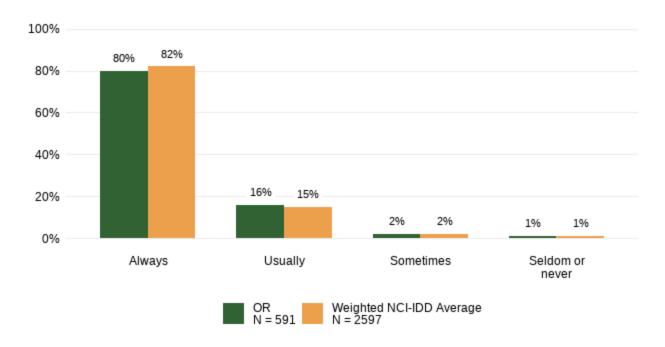


Table 48. Are services delivered in a way that is respectful of your family's culture?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	80%	16%	2%	1%	591
Weighted NCI-IDD Average	82%	15%	2%	1%	2597

### Does your child use technology in their everyday life to help them do more things on their own?

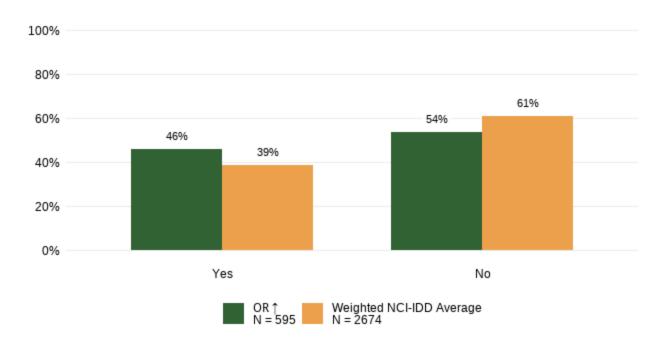


Table 49. Does your child use technology in their everyday life to help them do more things on their own?

State (names abbreviated)	Yes	No	N
OR↑	46%	54%	595
Weighted NCI-IDD Average	39%	61%	2674

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

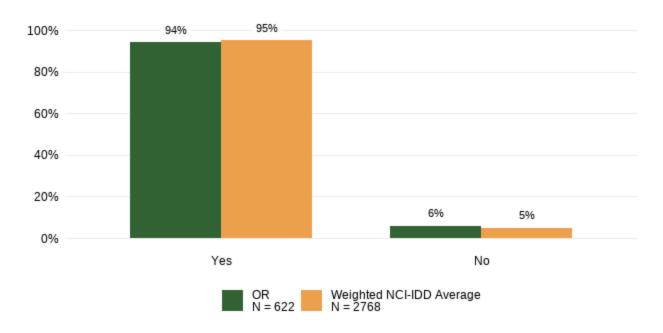


Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home?

State (names abbreviated)	Yes	No	N
OR	94%	6%	622
Weighted NCI-IDD Average	95%	5%	2768

#### How well does the internet work in your home?

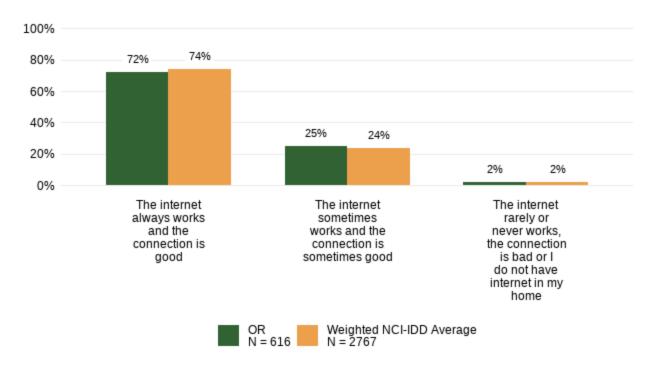


Table 51. How well does the internet work in your home?

State (names abbreviated)	The internet always works and the connection is good	The internet sometimes works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
OR	72%	25%	2%	616
Weighted NCI- IDD Average	74%	24%	2%	2767

#### Workforce

There is stable and sufficient workforce to meet demand. Children 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 the children.

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.

### Do support workers come and go when they are supposed to?

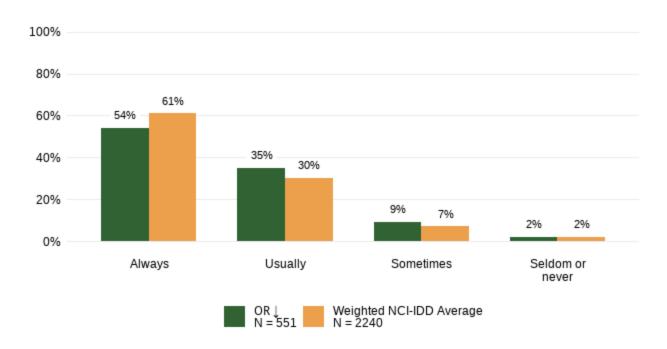


Table 52. Do support workers come and go when they are supposed to?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	54%	35%	9%	2%	551
Weighted NCI-IDD Average	61%	30%	7%	2%	2240

## Do support workers speak to you in a way you understand?

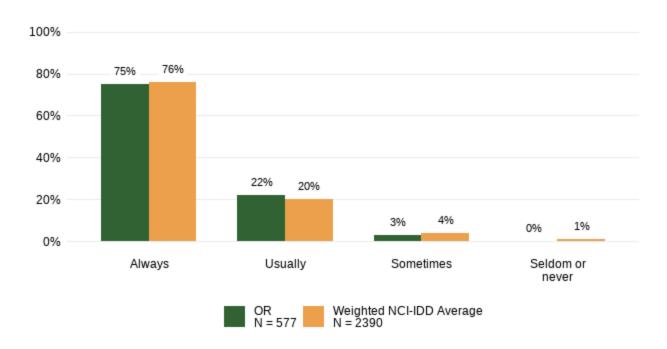


Table 53. Do support workers speak to you in a way you understand?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	75%	22%	3%	0%	577
Weighted NCI-IDD Average	76%	20%	4%	1%	2390

# If your child does not communicate verbally, are there support workers who can communicate with your child?

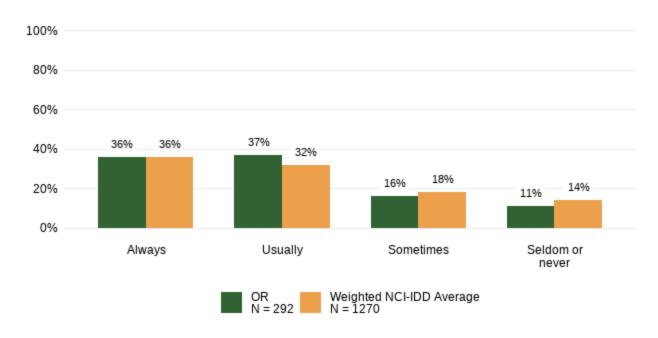


Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	36%	37%	16%	11%	292
Weighted NCI-IDD Average	36%	32%	18%	14%	1270

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

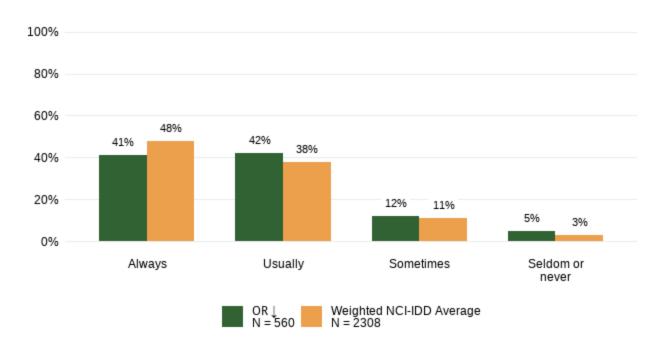


Table 55. Do support workers have the right information and skills to meet your family's needs?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	41%	42%	12%	5%	560
Weighted NCI-IDD Average	48%	38%	11%	3%	2308

## Do your child's support workers change too often? Is there too much "turnover" of support workers?

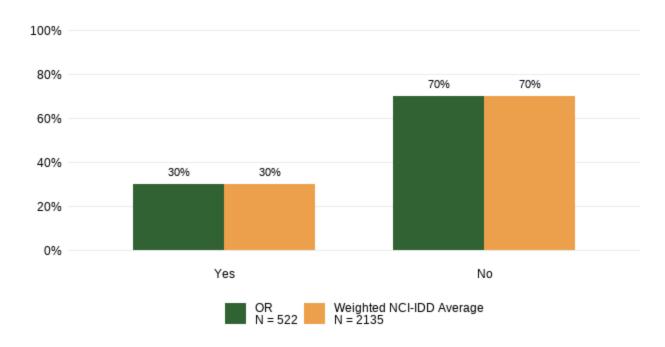


Table 56. Do your child's support workers change too often? Is there too much "turnover" of support workers?

State (names abbreviated)	Yes	No	N
OR	30%	70%	522
Weighted NCI-IDD Average	30%	70%	2135

### Is there always a staff person available to support your child when support is needed?

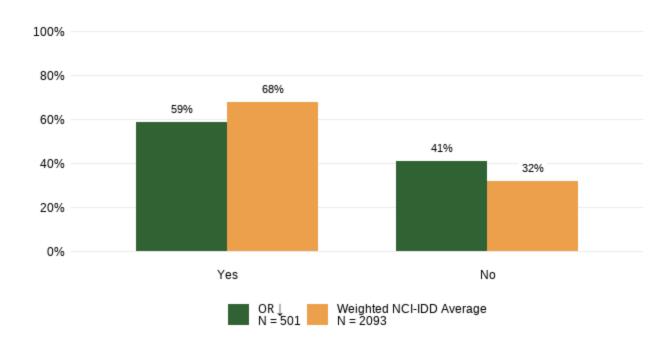


Table 57. Is there always a staff person available to support your child when support is needed?

State (names abbreviated)	Yes	No	N
OR ↓	59%	41%	501
Weighted NCI-IDD Average	68%	32%	2093

#### **Choice, Decision Making and Control**

Families and children 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.

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

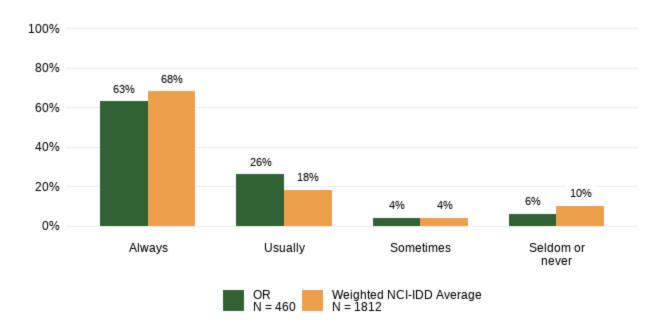


Table 58. Can someone in your family choose or change the provider agency that provides your child's services?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	63%	26%	4%	6%	460
Weighted NCI-IDD Average	68%	18%	4%	10%	1812

### Can someone in your family choose or change your child's support workers?

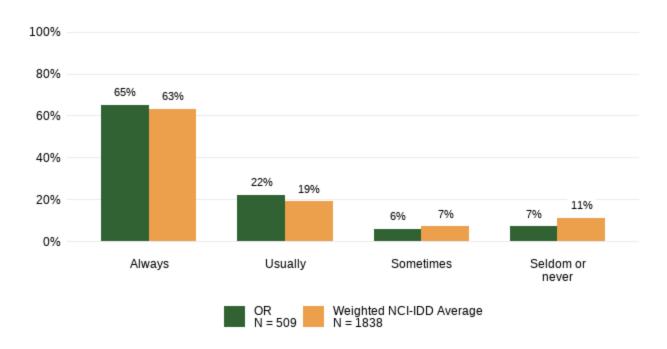


Table 59. Can someone in your family choose or change your child's support workers?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	65%	22%	6%	7%	509
Weighted NCI-IDD Average	63%	19%	7%	11%	1838

#### Can someone in your family directly manage support staff?

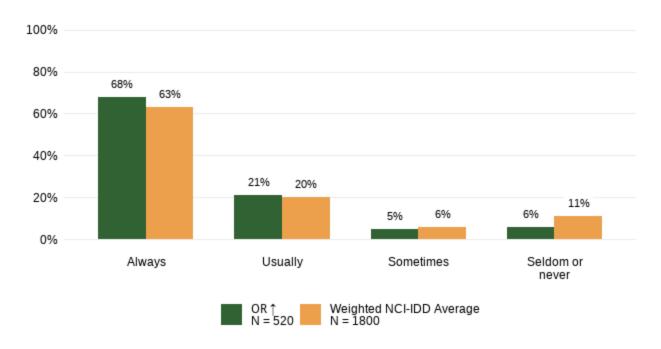


Table 60. Can someone in your family directly manage support staff?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↑	68%	21%	5%	6%	520
Weighted NCI-IDD Average	63%	20%	6%	11%	1800

#### Did you, your family member, or someone else in your family choose your child's case manager or service coordinator?

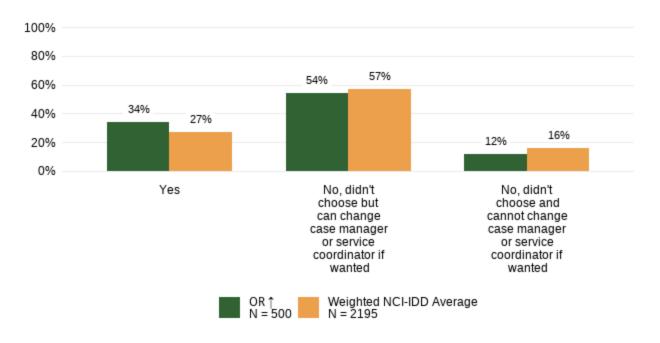


Table 61. Did you, your child, or someone else in your family choose your child's case manager or service coordinator?

State (names abbreviated)	Yes	No, didn't choose but can change case manager or service coordinator if wanted	No, didn't choose and cannot change case manager or service coordinator if wanted	N
OR ↑	34%	54%	12%	500
Weighted NCI- IDD Average	27%	57%	16%	2195

#### **Involvement in the Community**

Children receiving services and supports from the state Developmental disabilities system are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.

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.

#### Does your child do things in the community?

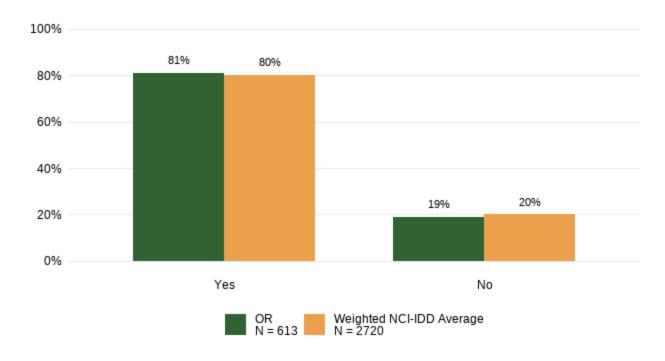


Table 62. Does your child do things in the community?

State (names abbreviated)	Yes	No	N
OR	81%	19%	613
Weighted NCI-IDD Average	80%	20%	2720

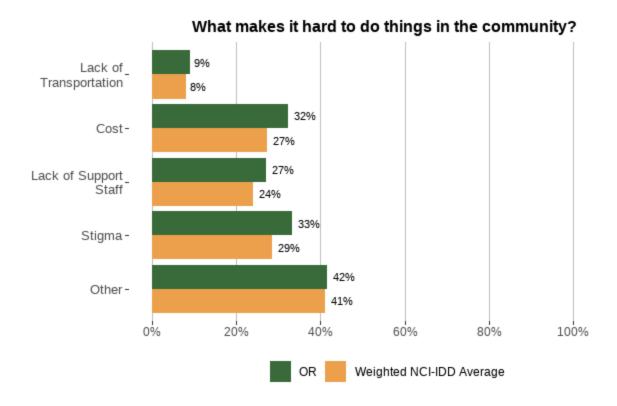


Table 63. What makes it hard to do things in the community?

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

State (names abbreviated)	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
OR	9%	32%	27%	33%	42%
Weighted NCI-IDD Average	8%	27%	24%	29%	41%

### Does your child spend time with children who do not have developmental disabilities?

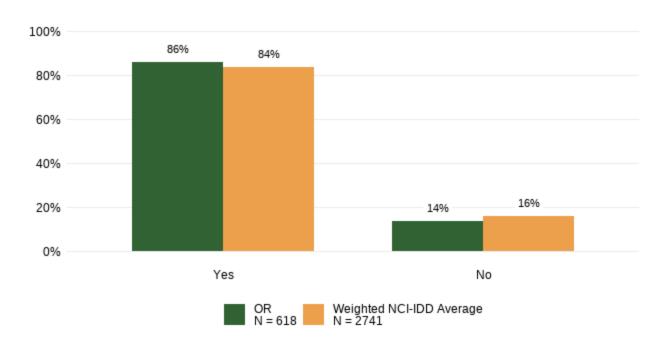


Table 64. Does your child spend time with children who do not have developmental disabilities?

State (names abbreviated)	Yes	No	N
OR	86%	14%	618
Weighted NCI-IDD Average	84%	16%	2741

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

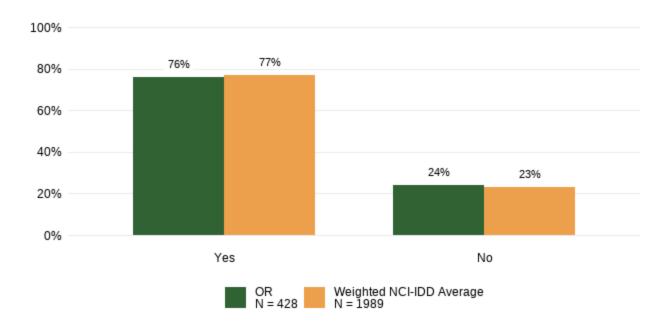


Table 65. In your community, are there resources that your family and child can use that are not provided by the I/DD agency?

State (names abbreviated)	Yes	No	N
OR	76%	24%	428
Weighted NCI-IDD Average	77%	23%	1989

### Does your family take part in any family-to-family networks in your community?

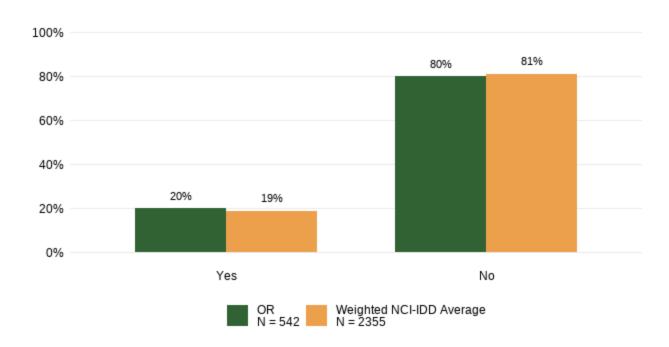


Table 66. Does your family take part in any family-to-family networks in your community?

State (names abbreviated)	Yes	No	N
OR	20%	80%	542
Weighted NCI-IDD Average	19%	81%	2355

#### Health, Welfare, and Safety

Families are supported to ensure the health, welfare, and safety of their child receiving services and supports from the state developmental disabilities 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.

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

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

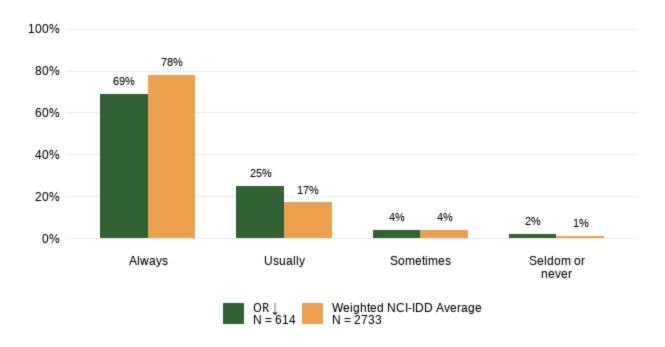


Table 67. Can your child see a primary care provider (doctor, registered nurse, etc.) when needed?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR↓	69%	25%	4%	2%	614
Weighted NCI-IDD Average	78%	17%	4%	1%	2733

### Does your child's primary care doctor understand your child's needs related to their disability?

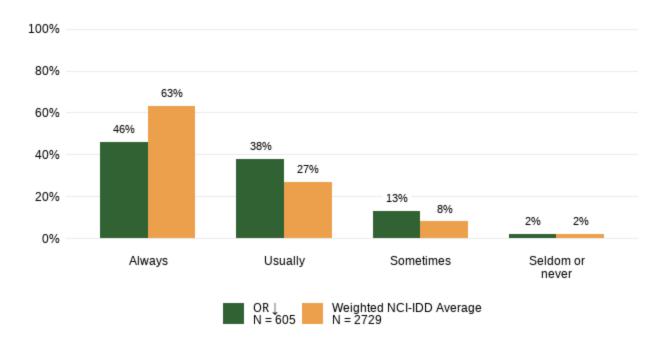


Table 68. Does your child's primary care doctor understand your child's needs related to their disability?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	46%	38%	13%	2%	605
Weighted NCI-IDD Average	63%	27%	8%	2%	2729

#### Can your child go to the dentist when needed?

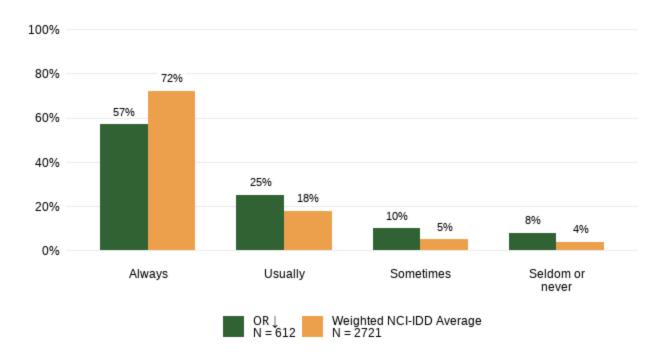


Table 69. Can your child go to the dentist when needed?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	57%	25%	10%	8%	612
Weighted NCI-IDD Average	72%	18%	5%	4%	2721

### Does your child's dentist understand your child's needs related to their disability?

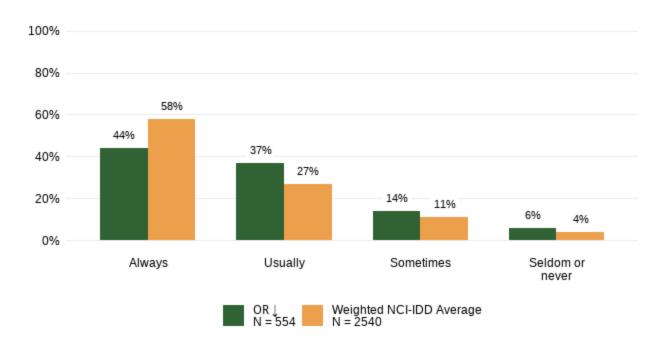


Table 70. Does your child's dentist understand your child's needs related to their disability?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR↓	44%	37%	14%	6%	554
Weighted NCI-IDD Average	58%	27%	11%	4%	2540

### If your child takes prescription medications, do you know what they're for?

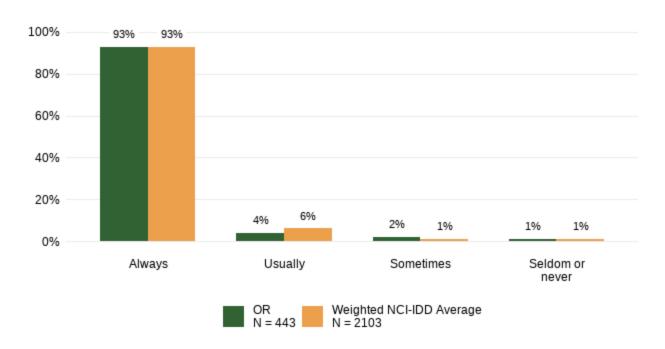


Table 71. If your child takes prescription medications, do you know what they're for?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	93%	4%	2%	1%	443
Weighted NCI-IDD Average	93%	6%	1%	1%	2103

#### Do you or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

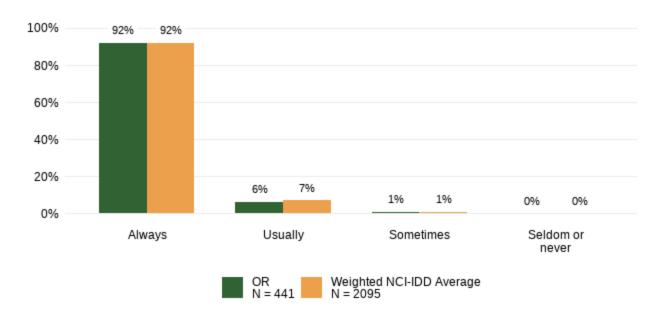


Table 72. Do you or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR	92%	6%	1%	0%	441
Weighted NCI-IDD Average	92%	7%	1%	0%	2095

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

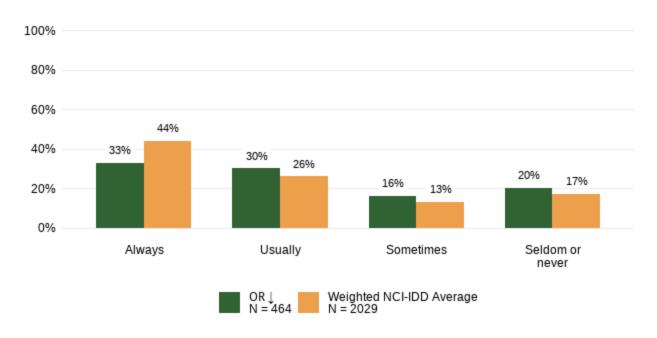


Table 73. Can your child get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	33%	30%	16%	20%	464
Weighted NCI-IDD Average	44%	26%	13%	17%	2029

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

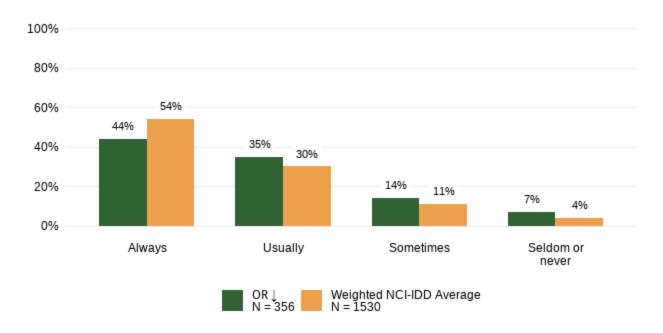


Table 74. If your child uses mental health services, does the mental health professional understand your child's needs related to their disability?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	44%	35%	14%	7%	356
Weighted NCI-IDD Average	54%	30%	11%	4%	1530

## If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

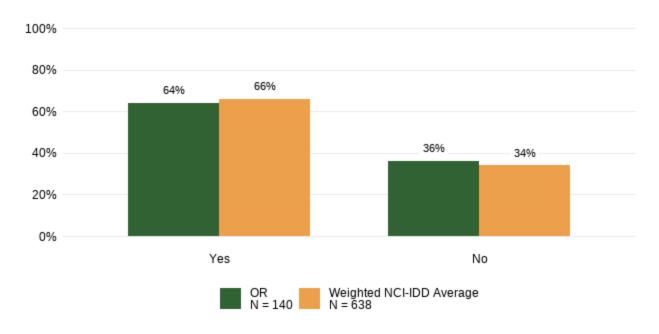


Table 75. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

State (names abbreviated)	Yes	No	N
OR	64%	36%	140
Weighted NCI-IDD Average	66%	34%	638

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

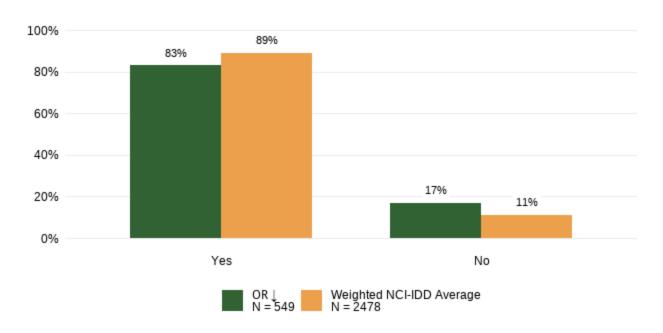


Table 76. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or natural disaster?

State (names abbreviated)	Yes	No	N
OR ↓	83%	17%	549
Weighted NCI-IDD Average	89%	11%	2478

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

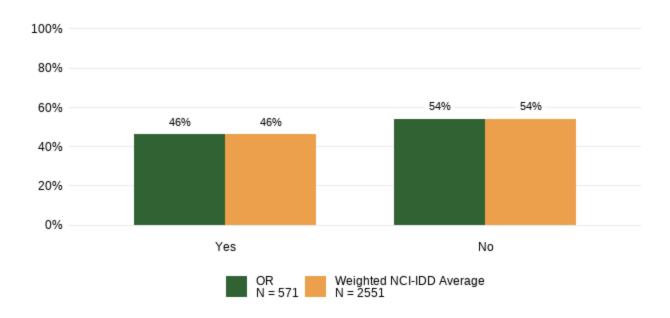


Table 77. Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child's case manager/service coordinator?

State (names abbreviated)	Yes	No	N
OR	46%	54%	571
Weighted NCI-IDD Average	46%	54%	2551

#### Do you know how to file a complaint or grievance about provider agencies or staff?

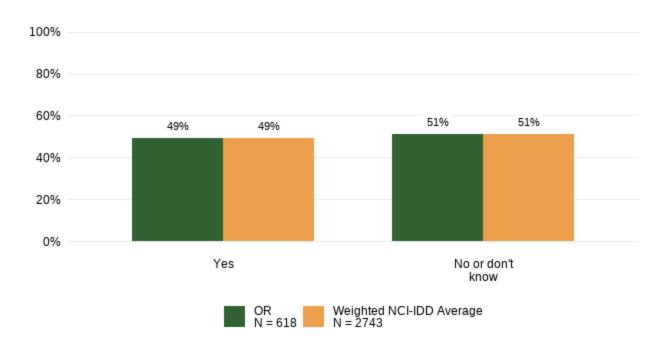


Table 78. Do you know how to file a complaint or grievance about provider agencies or staff?

State (names abbreviated)	Yes	No or don't know	N
OR	49%	51%	618
Weighted NCI-IDD Average	49%	51%	2743

#### If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

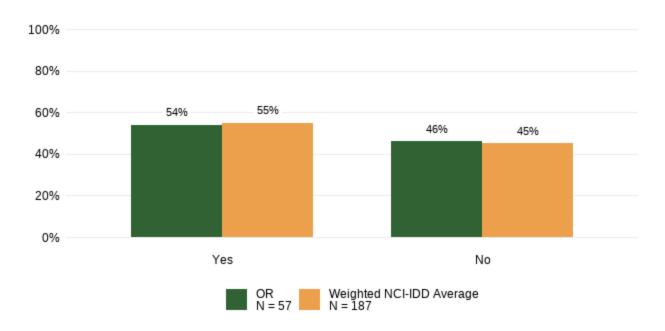


Table 79. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

State (names abbreviated)	Yes	No	N
OR	54%	46%	57
Weighted NCI-IDD Average	55%	45%	187

### Do you know how to report abuse or neglect related to your child?

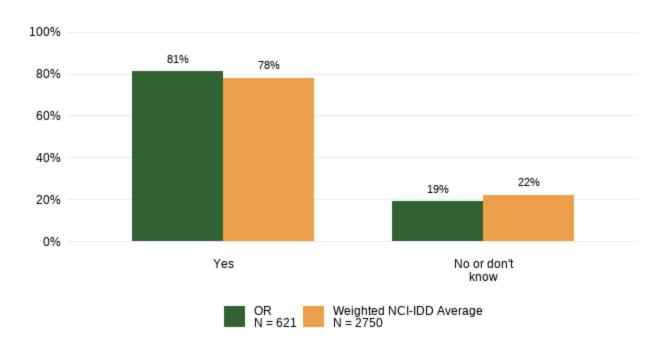


Table 80. Do you know how to report abuse or neglect related to your child?

State (names abbreviated)	Yes	No or don't know	N
OR	81%	19%	621
Weighted NCI-IDD Average	78%	22%	2750

#### Within the past 12 months, was a report of abuse or neglect filed on behalf of your child?

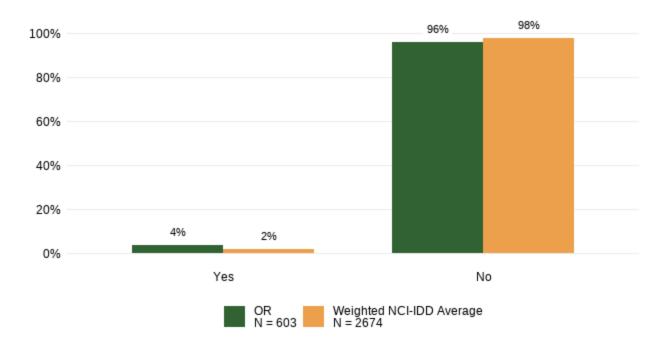


Table 81. Within the past 12 months, was a report of abuse or neglect filed on behalf of your child?

State (names abbreviated)	Yes	No	N
OR	4%	96%	603
Weighted NCI-IDD Average	2%	98%	2674

### If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?

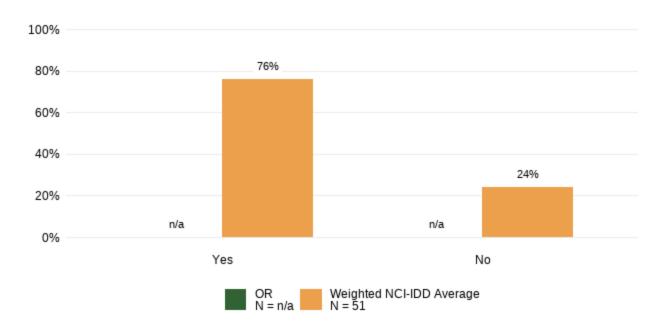


Table 82. If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?

State (names abbreviated)	Yes	No	N
OR	n/a	n/a	n/a
Weighted NCI-IDD Average	76%	24%	51

#### **Satisfaction With Services and Supports**

Services and supports lead to better lives for children with disabilities and their families.

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.

#### Overall, are you satisfied with the services and supports your child currently receives?

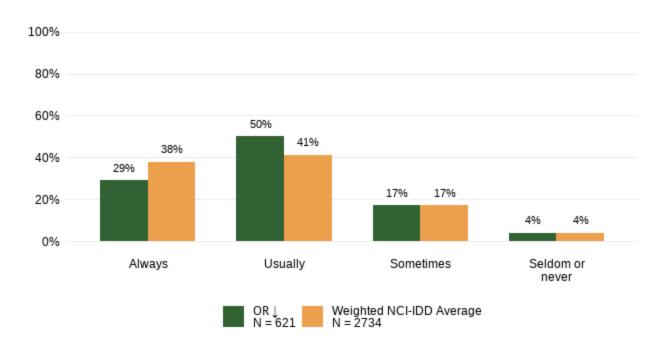


Table 83. Overall, are you satisfied with the services and supports your child currently receives?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↓	29%	50%	17%	4%	621
Weighted NCI-IDD Average	38%	41%	17%	4%	2734

#### Do you feel that services and supports have made a positive difference in the life of your child?

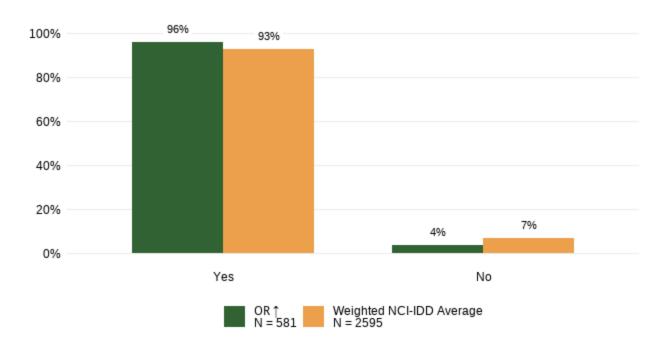


Table 84. Do you feel that services and supports have made a positive difference in the life of your child?

State (names abbreviated)	Yes	No	N
OR ↑	96%	4%	581
Weighted NCI-IDD Average	93%	7%	2595

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

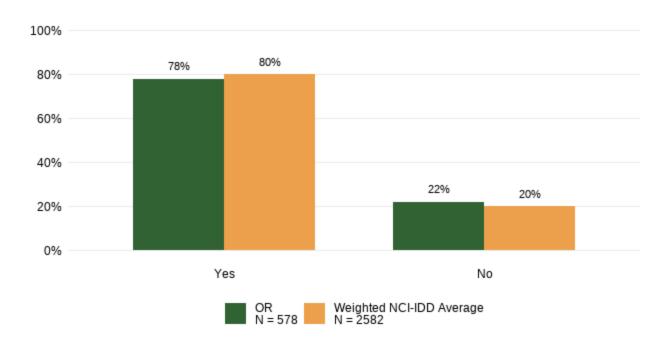


Table 85. Have services and supports reduced your family's out-of-pocket expenses for your child's care?

State (names abbreviated)	Yes	No	N
OR	78%	22%	578
Weighted NCI-IDD Average	80%	20%	2582

#### Do you feel that family supports have improved your ability to care for your child?

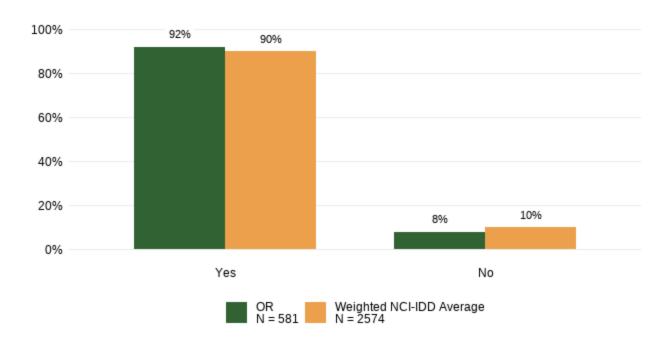


Table 86. Do you feel that family supports have improved your ability to care for your child?

State (names abbreviated)	Yes	No	N
OR	92%	8%	581
Weighted NCI-IDD Average	90%	10%	2574

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

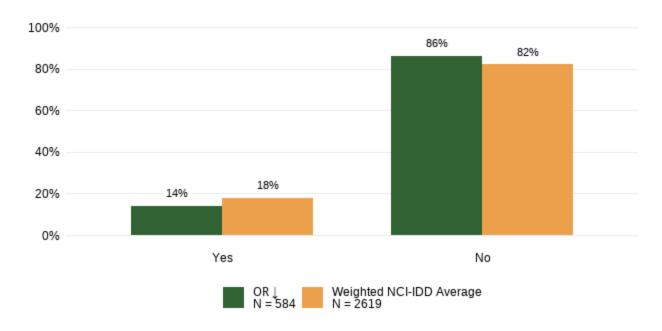


Table 87. Have the services or supports that your child received during the past 12 months been reduced, suspended, or terminated?

State (names abbreviated)	Yes	No	N
OR ↓	14%	86%	584
Weighted NCI-IDD Average	18%	82%	2619

# If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family or your child negatively?

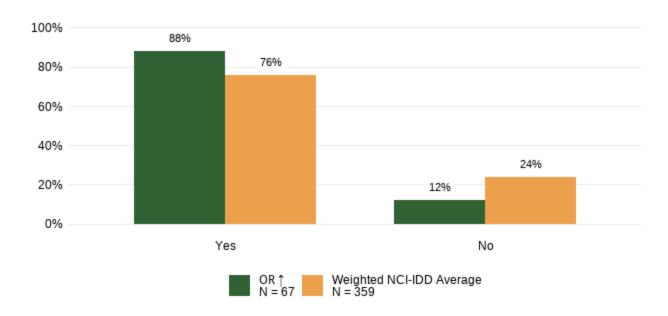


Table 88. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family or your child negatively?

State (names abbreviated)	Yes	No	N
OR ↑	88%	12%	67
Weighted NCI-IDD Average	76%	24%	359

### Have the services or supports that your child received been increased in the past 12 months?

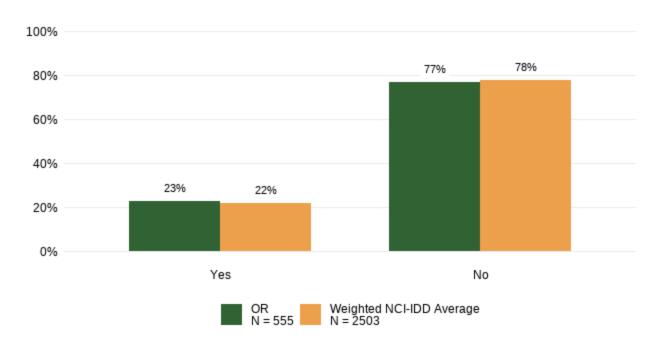


Table 89. Have the services or supports that your child received been increased in the past 12 months?

State (names abbreviated)	Yes	No	N
OR	23%	77%	555
Weighted NCI-IDD Average	22%	78%	2503

### Are services and supports helping your child to live a good life?

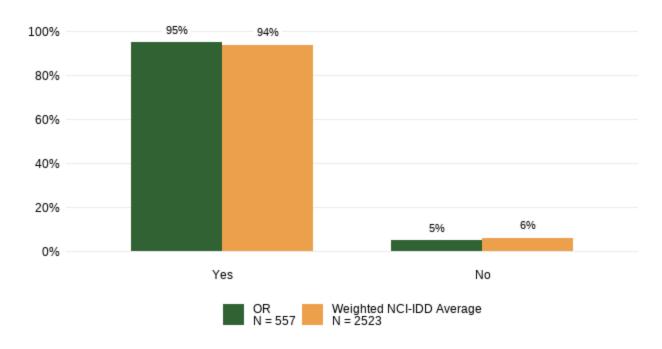


Table 90. Are services and supports helping your child to live a good life?

State (names abbreviated)	Yes	No	N
OR	95%	5%	557
Weighted NCI-IDD Average	94%	6%	2523