

2021-22 OR Child Family Survey State Report

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Introduction

What is NCI-IDD

The National Core Indicators® – Intellectual and Developmental Disabilities (NCI®-IDD) is a voluntary effort by state developmental disability agencies to track their performance using a standardized set of consumer and family/guardian surveys with nationally validated measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

In 2021-22, a total of 48 states, the District of Columbia and 22 sub-state entities participated in NCI-IDD.

Where are the statistics in this report from?

This report includes findings from the National Core Indicators 2021-22 Child Family Survey (CFS). The NCI-IDD averages data shown are weighted. These data are comprised of 7,902 valid surveys collected across 7 states: Alaska (AK), California (CA), Indiana (IN), Louisiana (LA), Missouri (MO), Oregon (OR) and Wisconsin (WI).

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.

Important note on 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](#).

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 ▼.

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 Adult Family Survey, data analysis and state samples, check out the [National Child Family Survey Report](#).

Demographics

Child

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

State	Yes	No	N
OR	65%	35%	575
Weighted NCI-IDD Average	68%	32%	7615

Table 2. Child's Age

State	Age	N
OR	12.1	619
Weighted NCI-IDD Average	10.6	7741

Table 3. Child's Gender

State	Male	Female	Other	N
OR	67%	33%	0%	624
Weighted NCI-IDD Average	71%	29%	0%	7764

Table 4. Child's Race and Ethnicity

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

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer Not to Say
OR	4%	8%	5%	1%	80%	15%	2%	2%
Weighted NCI-IDD Average	2%	14%	8%	1%	41%	43%	2%	2%

Table 5a. Child's Conditions

All data are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics; 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)
OR	54%	26%	59%	11%	7%	6%
Weighted NCI-IDD Average	34%	12%	71%	8%	5%	3%

Table 5b. Child's Conditions (continued)

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

State	Brain Injury	Seizure Or Neurological Disorder	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
OR	8%	18%	0%	11%	0%	9%	29%
Weighted NCI-IDD Average	4%	14%	0%	9%	0%	1%	21%

Table 6a. Child's Health Conditions

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

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
OR	10%	4%	2%	2%	4%
Weighted NCI-IDD Average	8%	3%	2%	3%	5%

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

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

State	Dysphagia	Pressure Ulcers	Oral Health Problems	Sleep Apnea
OR	25%	2%	16%	27%
Weighted NCI-IDD Average	12%	1%	9%	20%

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

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

State	Other pulmonary diagnosis	Chronic kidney disease	Long-term health problems associated with COVID-19	Other
OR	8%	4%	2%	34%
Weighted NCI-IDD Average	8%	3%	1%	37%

Table 7. Child's Preferred Language

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
OR	88%	3%	0%	0%	0%	1%	8%	631
Weighted NCI-IDD Average	79%	9%	1%	0%	0%	0%	11%	7770

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
OR	65%	14%	2%	6%	13%	630
Weighted NCI-IDD Average	70%	16%	2%	5%	7%	7736

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

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

State	None	Some	Extensive	N
OR	21%	48%	31%	622
Weighted NCI-IDD Average	30%	43%	26%	7621

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

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

State	None	Some	Extensive	N
OR	4%	40%	56%	628
Weighted NCI-IDD Average	9%	42%	49%	7751

Respondents

This section provides demographic information about the respondent.

Table 11. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
OR	87%	7%	0%	0%	1%	0%	5%	629
Weighted NCI-IDD Average	65%	25%	2%	1%	1%	0%	7%	7690

Table 12. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
OR	9%	70%	20%	1%	628
Weighted NCI-IDD Average	13%	75%	12%	0%	7692

Table 13. Respondent's Health

State	Excellent	Very good	Good	Fair	Poor	N
OR	11%	33%	39%	15%	3%	624
Weighted NCI-IDD Average	14%	32%	39%	14%	2%	7698

Table 14. Respondent's Relationship to Child

State	Parent	Sibling	Grandparent	Other	N
OR	92%	0%	5%	3%	629
Weighted NCI-IDD Average	96%	0%	3%	1%	7783

Table 15. Respondent or Other Family Member Provides Paid Support to Child
 Responses are not mutually exclusive, therefore N is not shown.

State	No	Yes, I am	Yes, Another Family Member Is
OR	56%	15%	33%
Weighted NCI-IDD Average	61%	24%	17%

Table 16. Number of Adults in Household

State	One	Two	Three	Four or More	N
OR	18%	58%	15%	9%	628
Weighted NCI-IDD Average	17%	57%	18%	8%	7678

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

State	One	Two	Three	Four or More	N
OR	38%	36%	14%	12%	608
Weighted NCI-IDD Average	36%	38%	17%	9%	7632

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
OR	8%	15%	5%	19%	53%	616
Weighted NCI-IDD Average	16%	19%	7%	16%	42%	7747

Table 19. Total Taxable Household Income of Wage Earners in the Past Year

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	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
OR	8%	6%	8%	21%	15%	32%	9%	622
Weighted NCI-IDD Average	6%	9%	11%	19%	14%	28%	14%	7554

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

State	Urban or Suburban	Rural	N
OR	73%	27%	607
Weighted NCI-IDD Average	84%	16%	6946

Services and Supports Received

This section provides information about the services and supports received by the family from the state.

Table 21a. Services and Supports Received From State

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

State	Financial Support	Out-of-home respite care	Early Intervention
OR	18%	35%	6%
Weighted NCI-IDD Average	15%	29%	8%

Table 21b. Services and Supports Received From State (continued)

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

State	Transportation	Mental/ behavioral health care or other treatments or therapies	Self-Direction or Fiscal Intermediary Services
OR	21%	66%	69%
Weighted NCI-IDD Average	6%	36%	23%

Table 22. Additional Services and Supports Received

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

State	Social Security Payments (SSI or SSB)	Services or Supports from Other Agencies or Organizations
OR	41%	70%
Weighted NCI-IDD Average	33%	63%

Child Family Survey Results

Information and Planning

Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state developmental disabilities system.

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

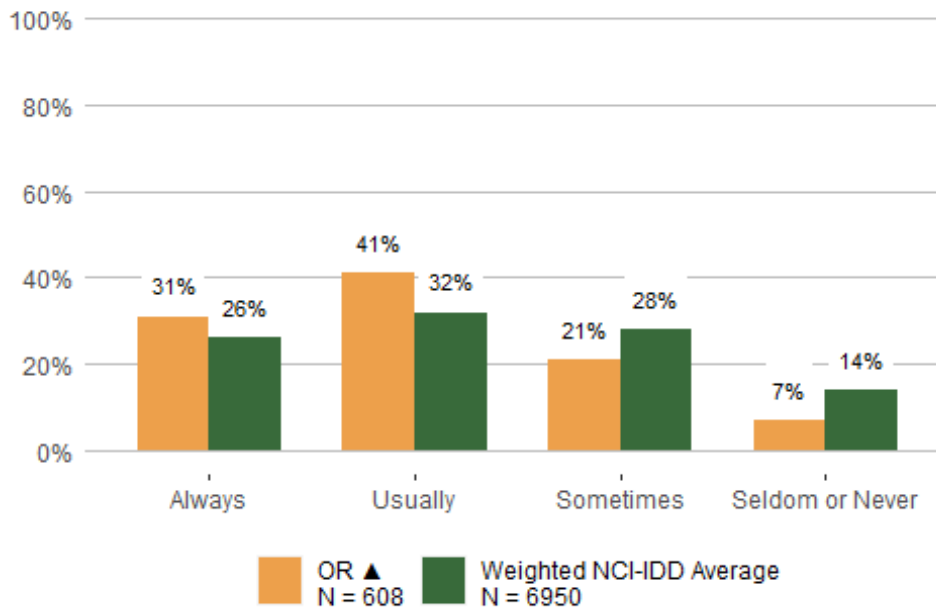


Table 23. Do you get enough information to take part in planning services for your child?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▲	31%	41%	21%	7%	608
Weighted NCI-IDD Average	26%	32%	28%	14%	6950

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

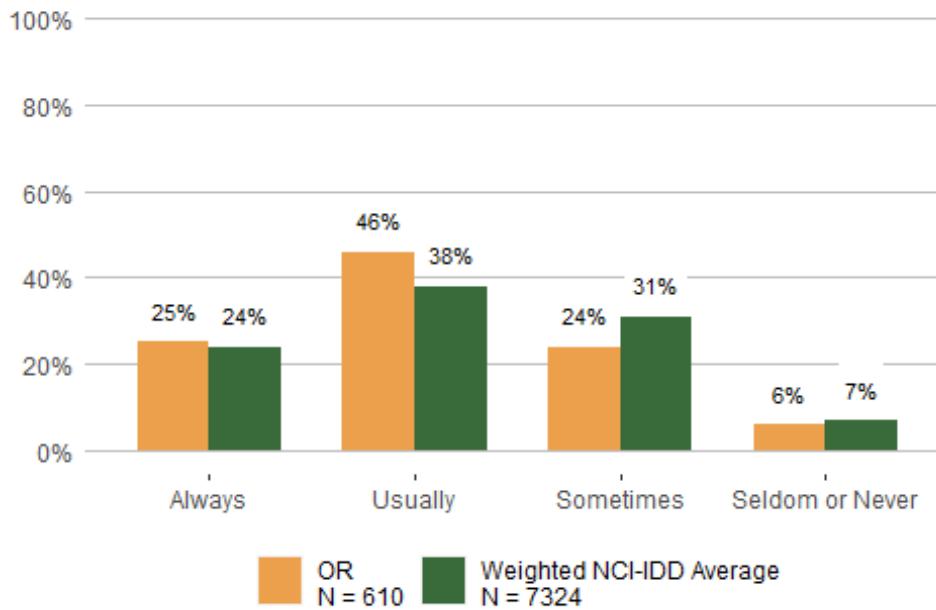


Table 24. Is the information you get about services and supports easy to understand?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	25%	46%	24%	6%	610
Weighted NCI-IDD Average	24%	38%	31%	7%	7324

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

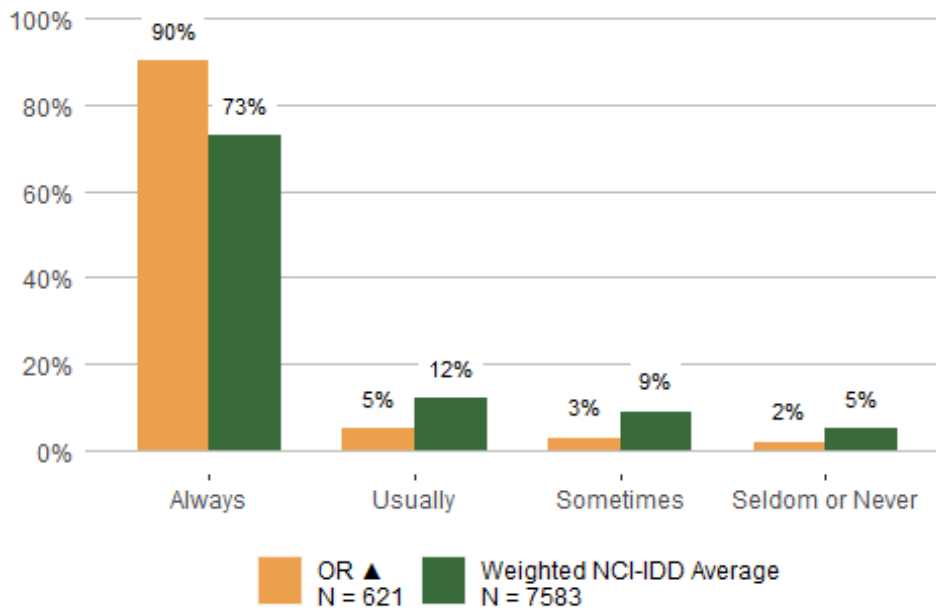


Table 25. Do you get information about services and supports in your preferred language?

New question in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▲	90%	5%	3%	2%	621
Weighted NCI-IDD Average	73%	12%	9%	5%	7583

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

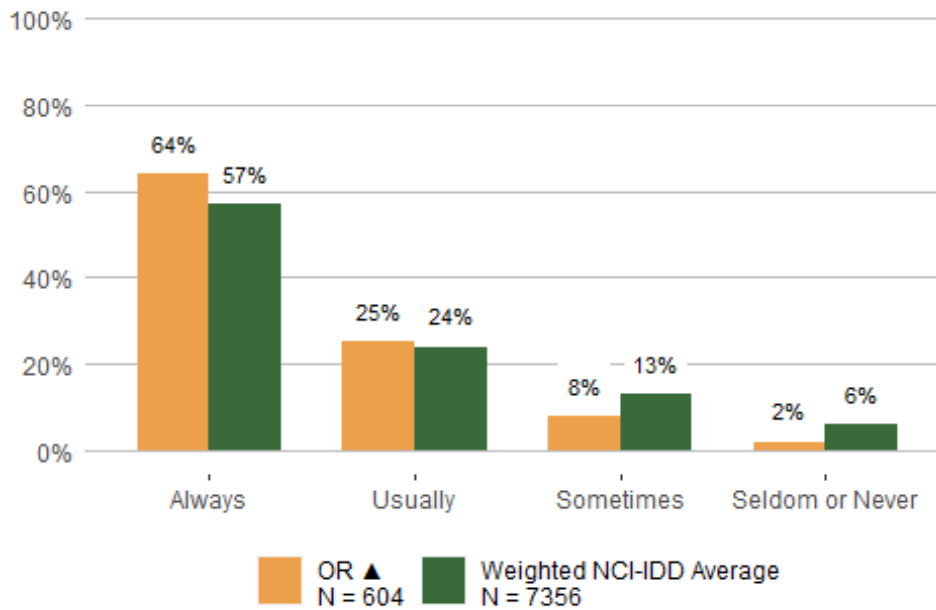


Table 26. Does the case manager/service coordinator listen to your family's choices and opinions?

Question changed in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▲	64%	25%	8%	2%	604
Weighted NCI-IDD Average	57%	24%	13%	6%	7356

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

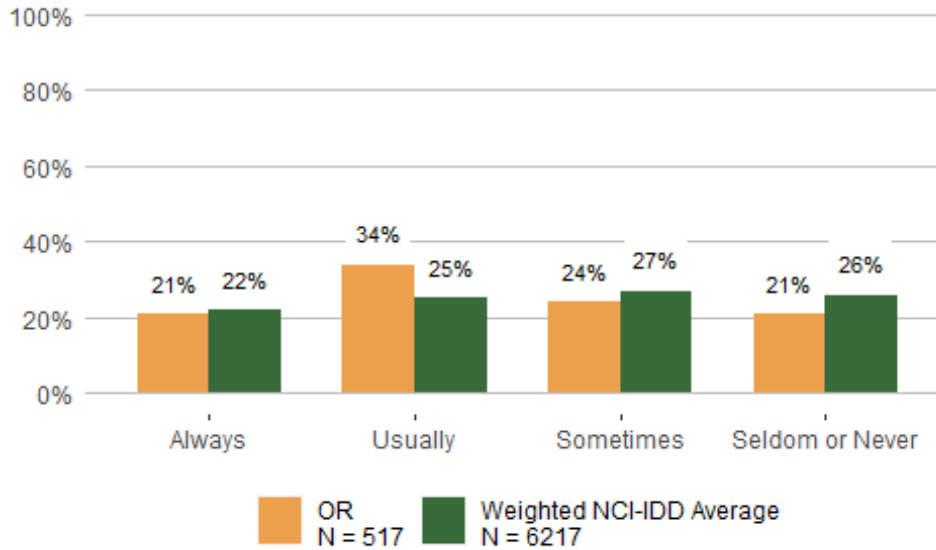


Table 27. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	21%	34%	24%	21%	517
Weighted NCI-IDD Average	22%	25%	27%	26%	6217

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

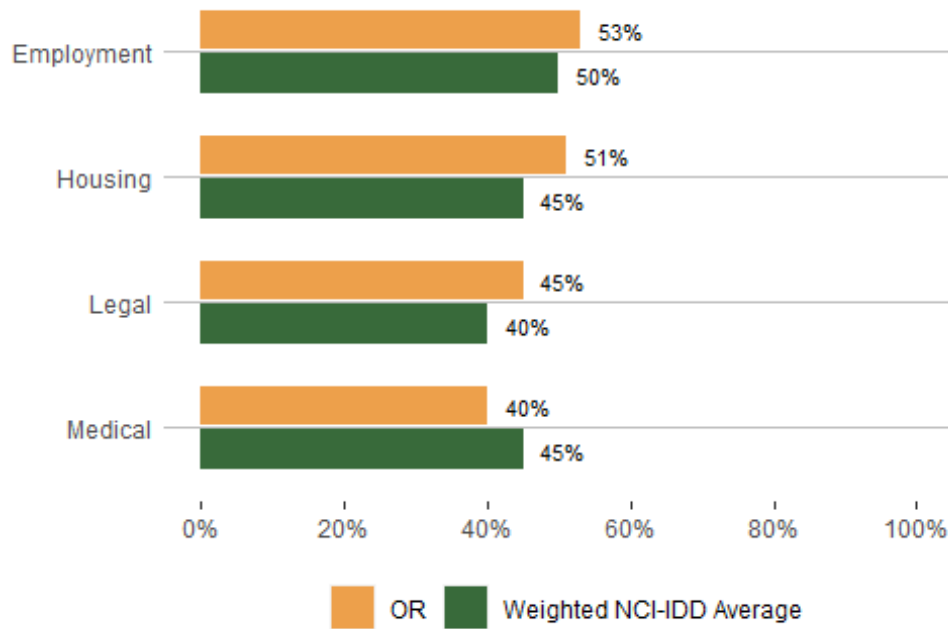


Table 28a. Do you need help planning for your child's future with respect to any of the following?

Categories are not mutually exclusive, therefore N is not shown

State	Employment	Housing	Legal	Medical
OR	53%	51%	45%	40%
Weighted NCI-IDD Average	50%	45%	40%	45%

Do you need help planning for your child's future with respect to any of the following? (continued)

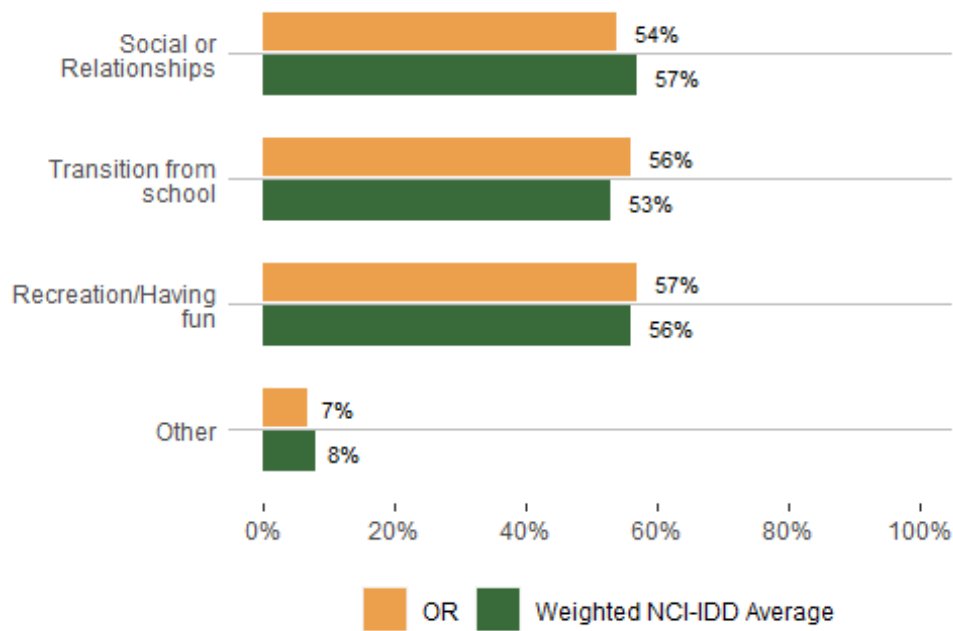


Table 28b. Do you need help planning for your child's future with respect to any of the following? (continued)

Categories are not mutually exclusive, therefore N is not shown

State	Social or Relationships	Transition from school	Recreation/Having fun	Other
OR	54%	56%	57%	7%
Weighted NCI-IDD Average	57%	53%	56%	8%

Has your family learned about alternatives to guardianship?

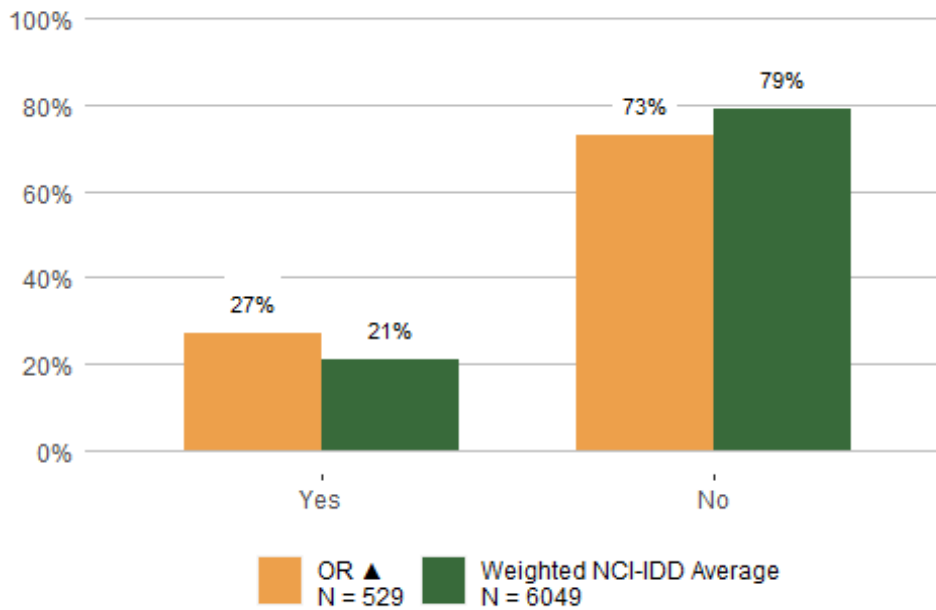


Table 29. Has your family learned about alternatives to guardianship?
New question in 2021-22

State	Yes	No	N
OR ▲	27%	73%	529
Weighted NCI-IDD Average	21%	79%	6049

Does your child have a service plan?

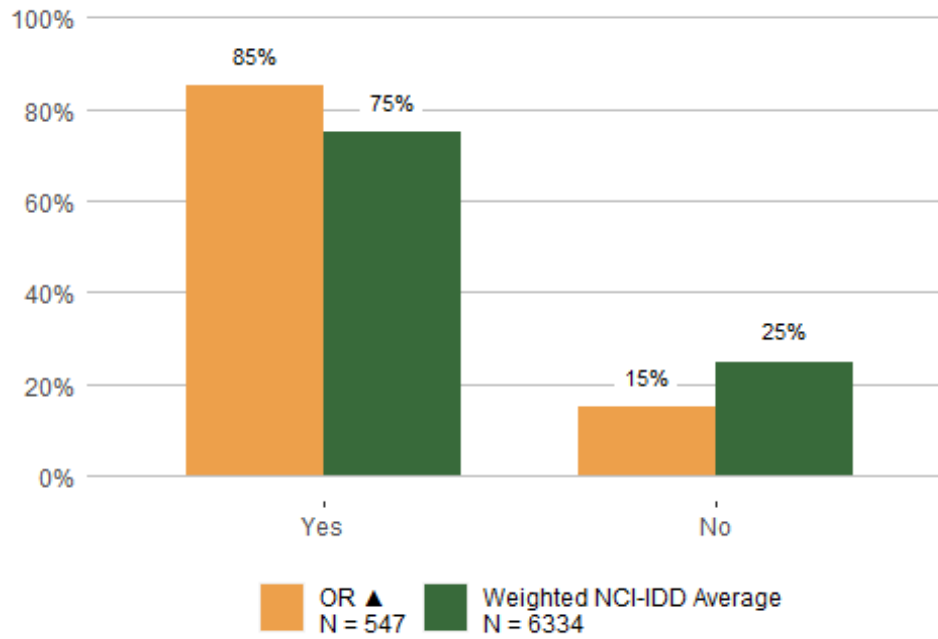


Table 30. Does your child have a service plan?

State	Yes	No	N
OR ▲	85%	15%	547
Weighted NCI-IDD Average	75%	25%	6334

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

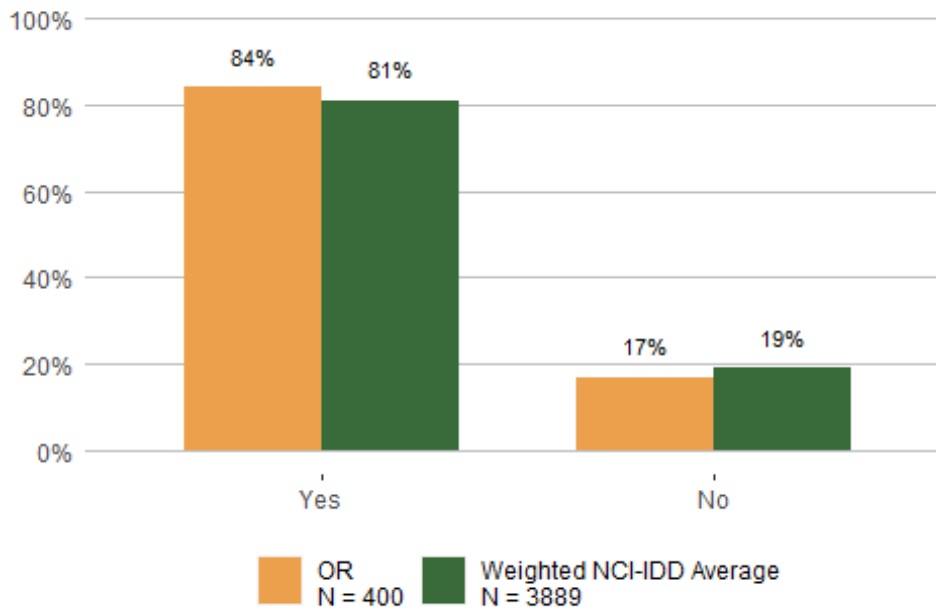


Table 31. Does the service plan include all the services and supports your child needs?

State	Yes	No	N
OR	84%	17%	400
Weighted NCI-IDD Average	81%	19%	3889

Did you or someone else in your family (besides your child with a disability) help make the service plan?

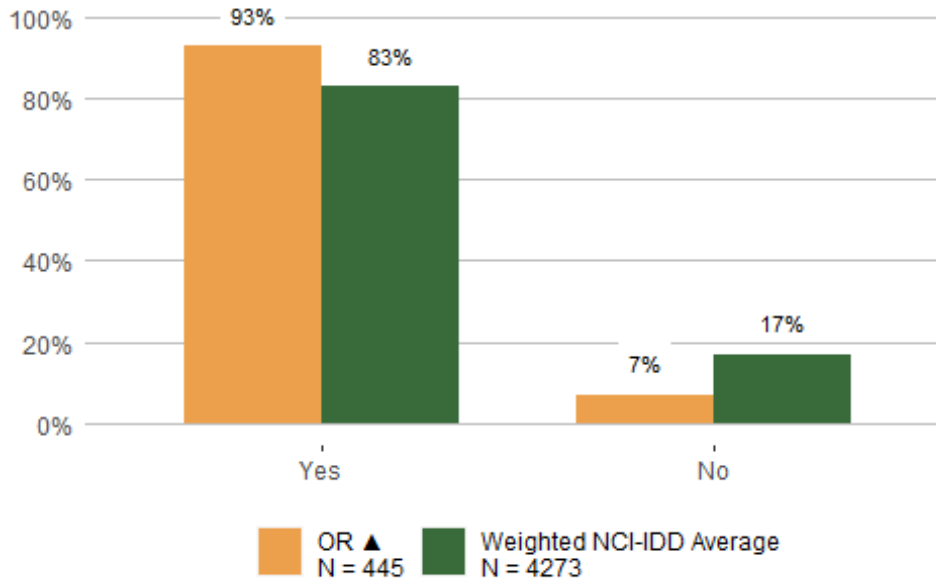


Table 32. Did you or someone else in your family (besides your child with a disability) help make the service plan?

State	Yes	No	N
OR ▲	93%	7%	445
Weighted NCI-IDD Average	83%	17%	4273

Did your child help make the service plan?

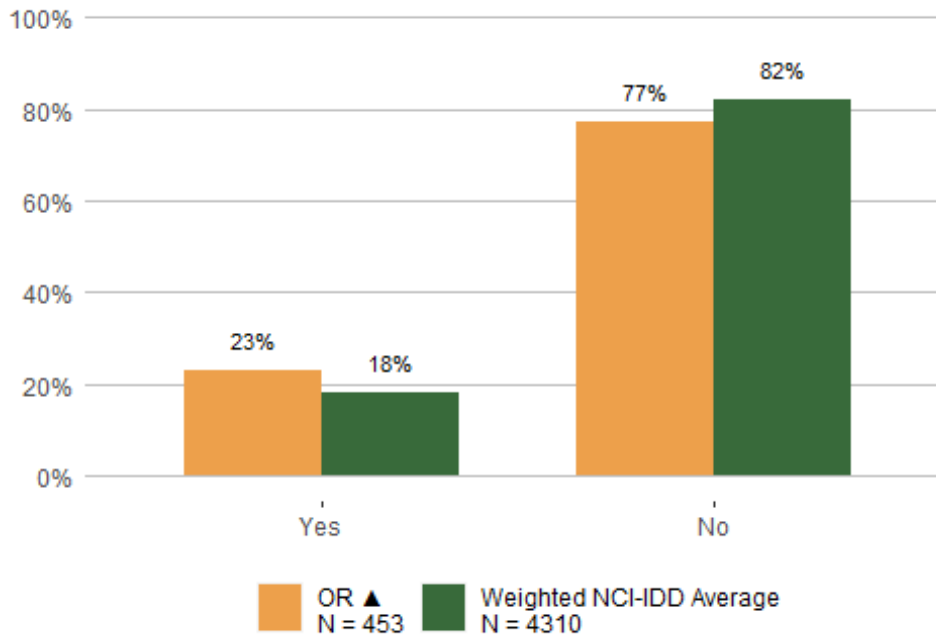


Table 33. Did your child help make the service plan?

State	Yes	No	N
OR ▲	23%	77%	453
Weighted NCI-IDD Average	18%	82%	4310

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

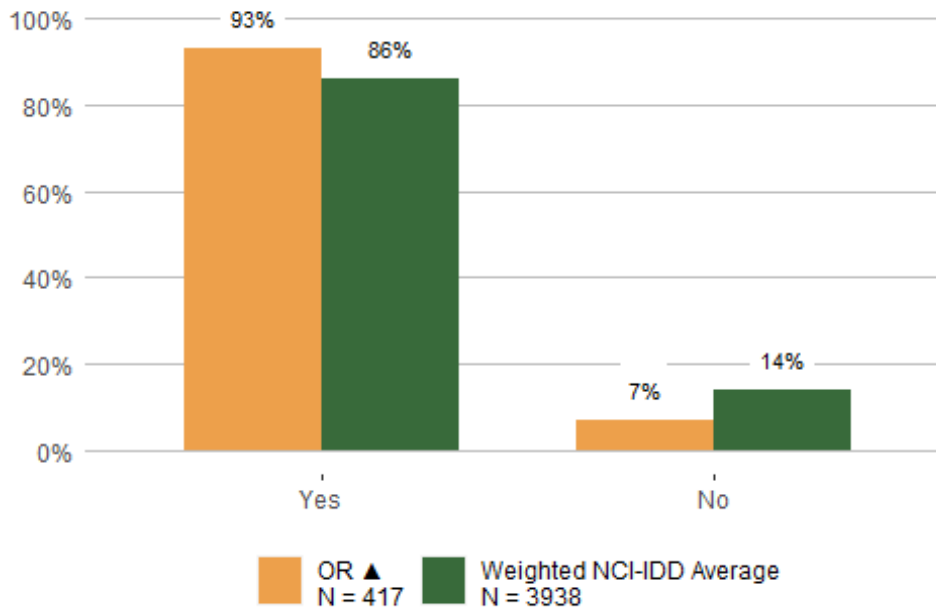


Table 34. Do you feel like your family had enough say or input in making the service plan?

New question in 2021-22

State	Yes	No	N
OR ▲	93%	7%	417
Weighted NCI-IDD Average	86%	14%	3938

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)?

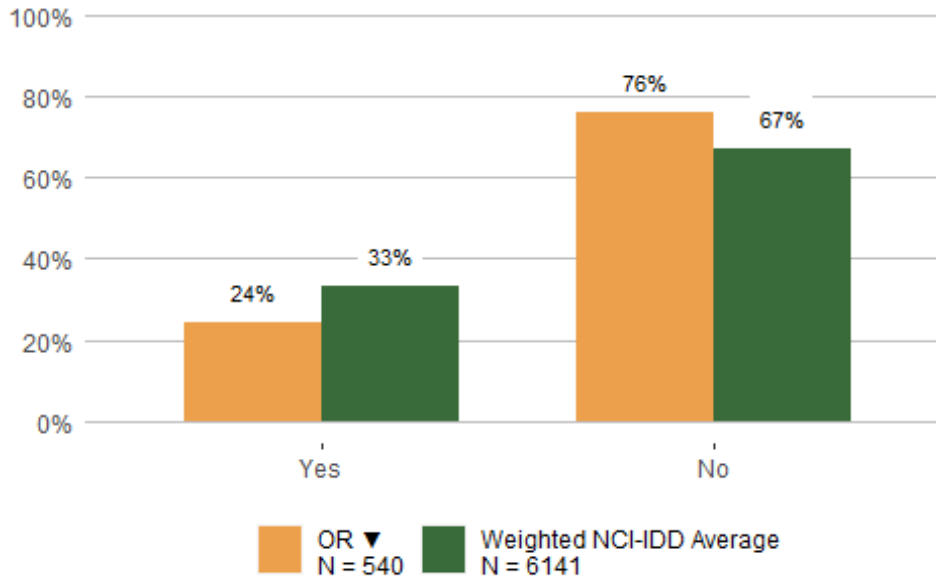


Table 35. Does your child have a transition plan (as part of an IEP or Section 504 plan through their high school, usually starting at age 14)?

State	Yes	No	N
OR ▼	24%	76%	540
Weighted NCI-IDDD Average	33%	67%	6141

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

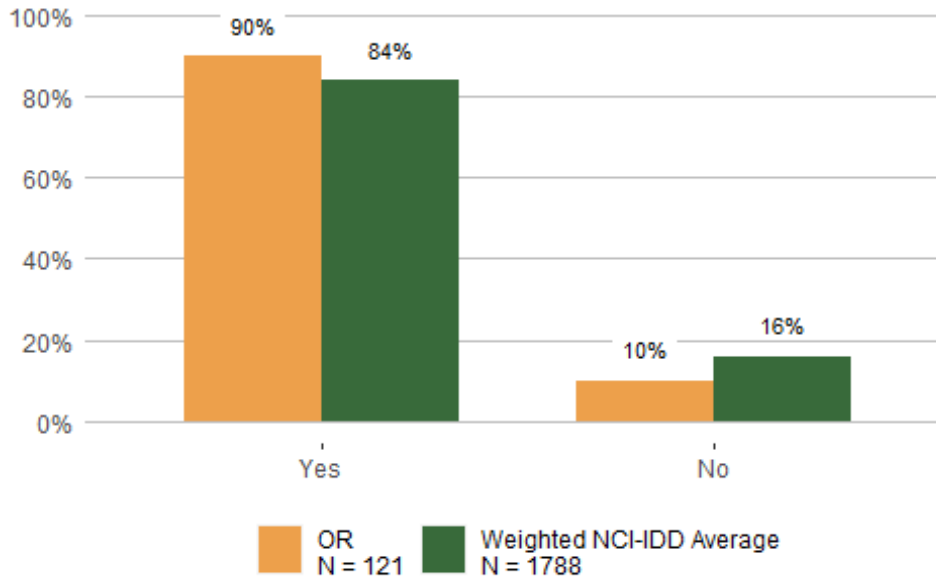


Table 36. If your child has a transition plan, did you or another family member help make the transition plan?

State	Yes	No	N
OR	90%	10%	121
Weighted NCI-IDDD Average	84%	16%	1788

Did your child help make the transition plan?

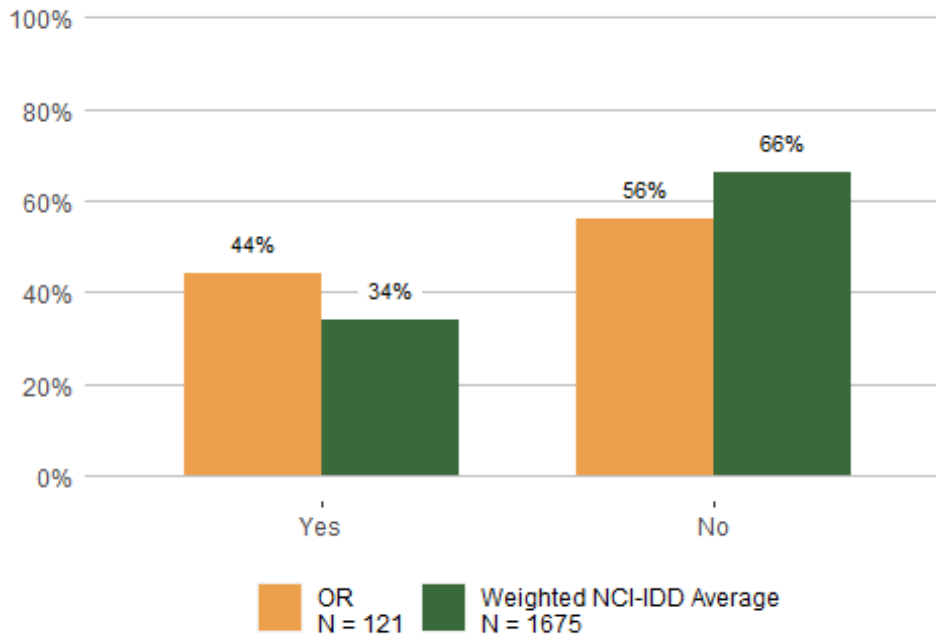


Table 37. If your child has a transition plan, did your child help make the transition plan?

State	Yes	No	N
OR	44%	56%	121
Weighted NCI-IDDD Average	34%	66%	1675

Access and Delivery of Services and Supports

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

Does your child get all the services listed in the ISP?

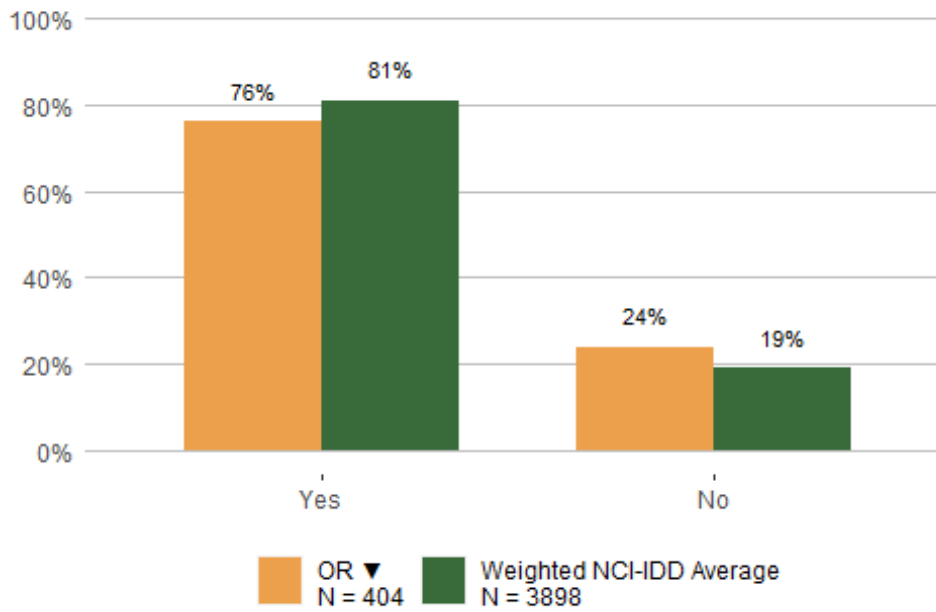


Table 38. Does your child get all the services listed in the ISP?

State	Yes	No	N
OR ▼	76%	24%	404
Weighted NCI-IDD Average	81%	19%	3898

Does your family get the supports and services it needs?

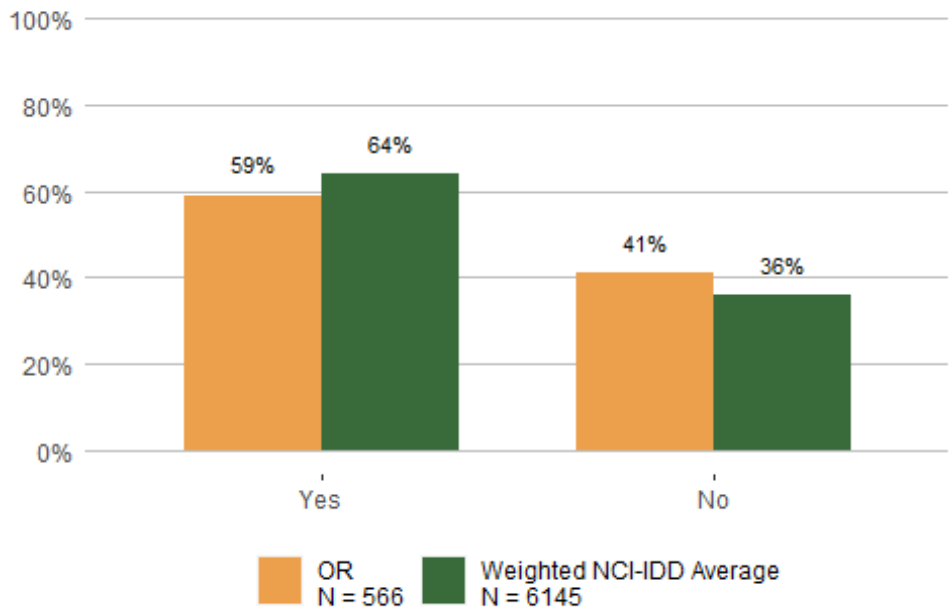


Table 39. Does your family get the supports and services it needs?

State	Yes	No	N
OR	59%	41%	566
Weighted NCI-IDD Average	64%	36%	6145

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

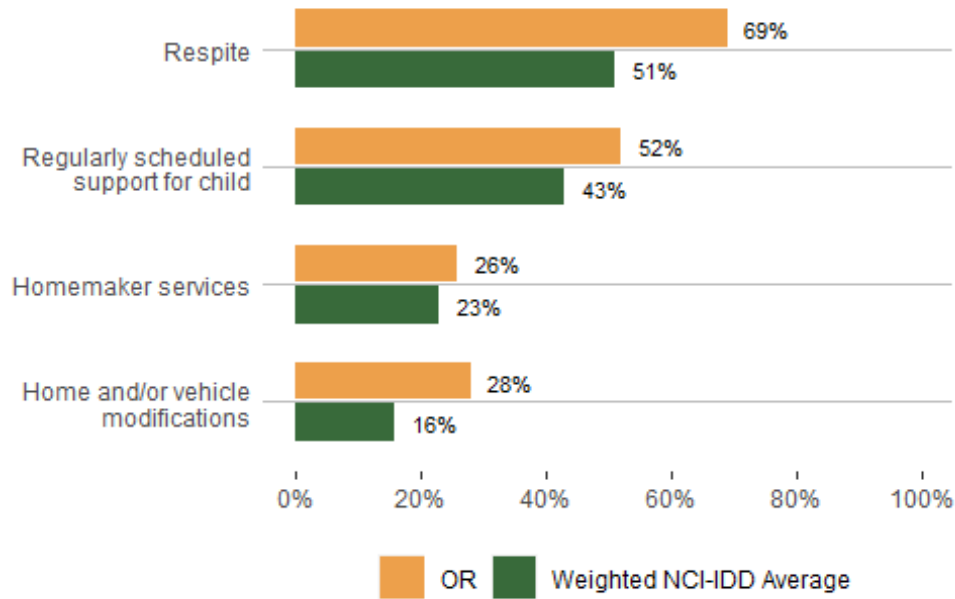


Table 40a. If your family does not get the supports and services it needs, what additional services does your family need?

Categories are not mutually exclusive, therefore N is not shown

State	Respite	Regularly scheduled support for child	Homemaker services	Home and/or vehicle modifications
OR	69%	52%	26%	28%
Weighted NCI-IDD Average	51%	43%	23%	16%

If your family does not get the supports and services it needs, Wwhat additional services does your family need? (continued)

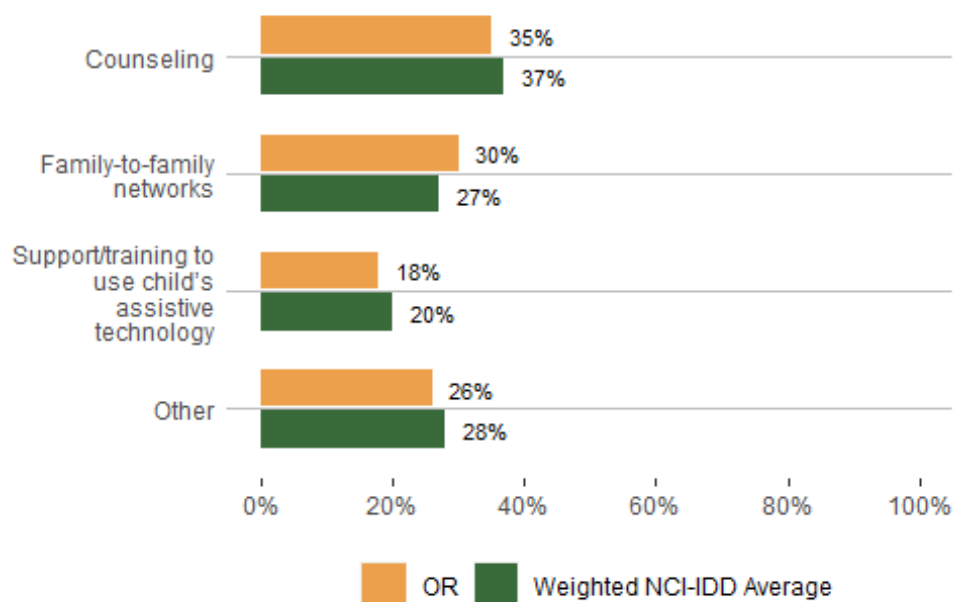


Table 40b. If your family does not get the supports and services it needs, Wwhat additional services does your family need? (continued)

Categories are not mutually exclusive, therefore N is not shown

State	Counseling	Family-to-family networks	Support/training to use child's assistive technology	Other
OR	35%	30%	18%	26%
Weighted NCI-IDD Average	37%	27%	20%	28%

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

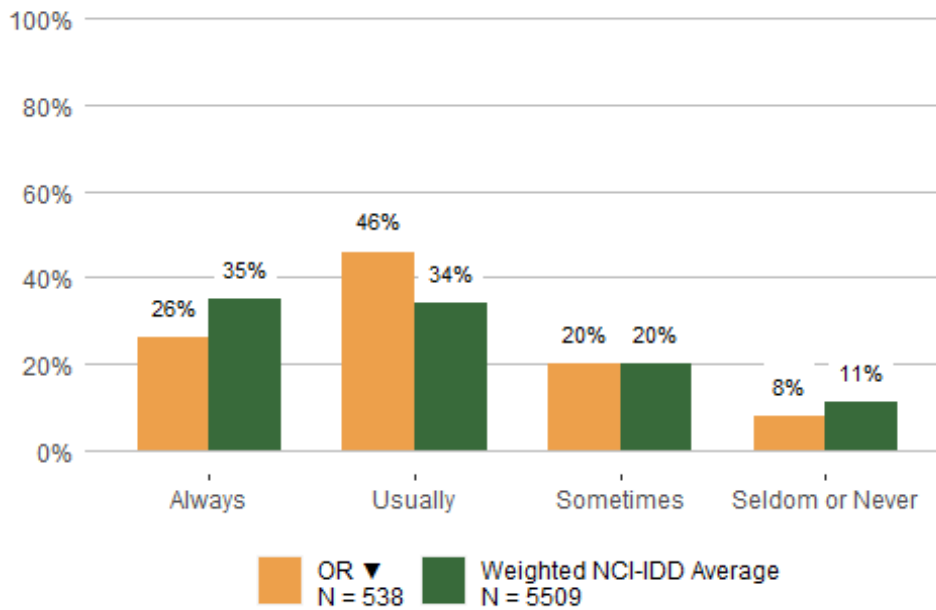


Table 41. Do services and supports change when your family's needs change?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▼	26%	46%	20%	8%	538
Weighted NCI-IDD Average	35%	34%	20%	11%	5509

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

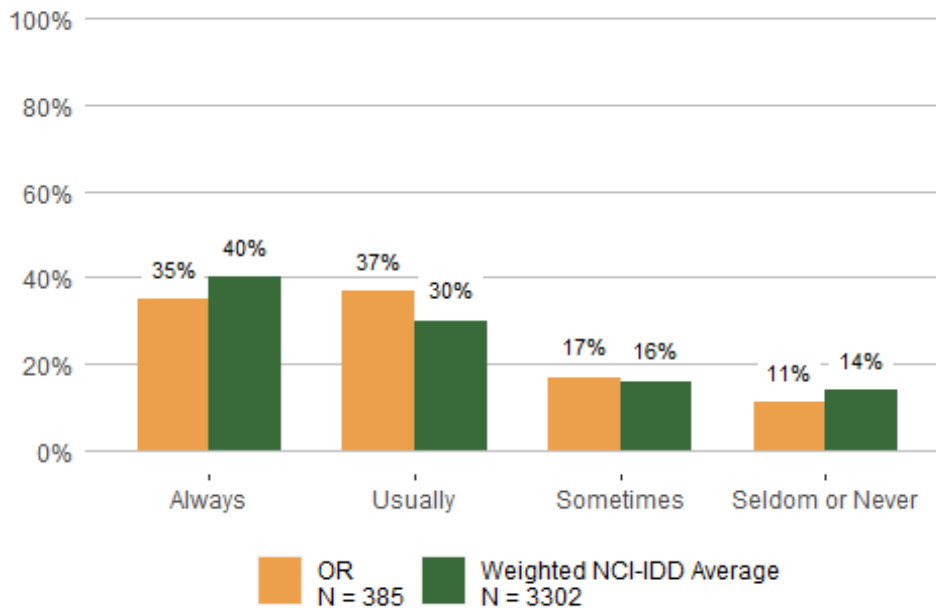


Table 42. Does your child have the special equipment or accommodations they need?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	35%	37%	17%	11%	385
Weighted NCI-IDD Average	40%	30%	16%	14%	3302

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

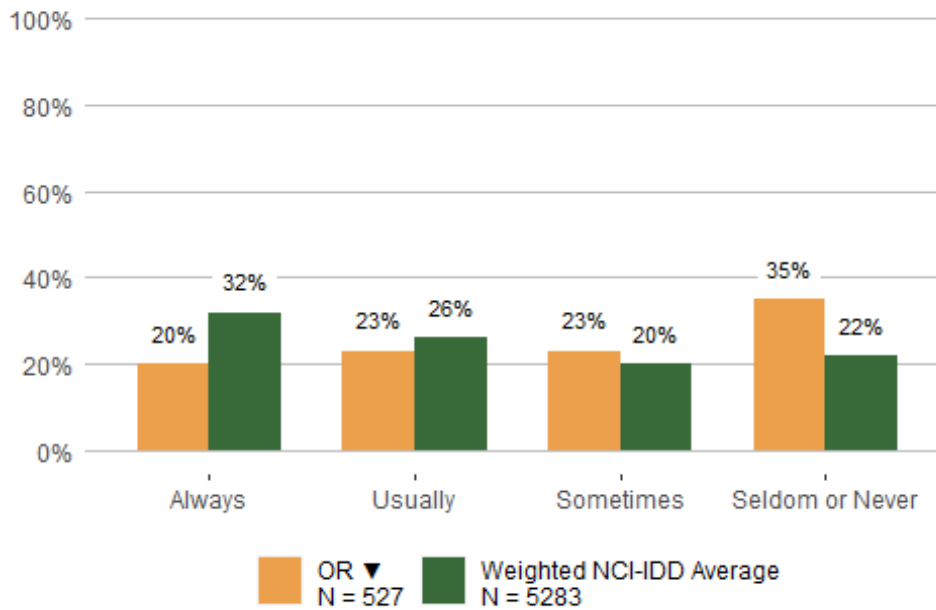


Table 43. If you need respite services, how often are you able to get them when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▼	20%	23%	23%	35%	527
Weighted NCI-IDD Average	32%	26%	20%	22%	5283

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

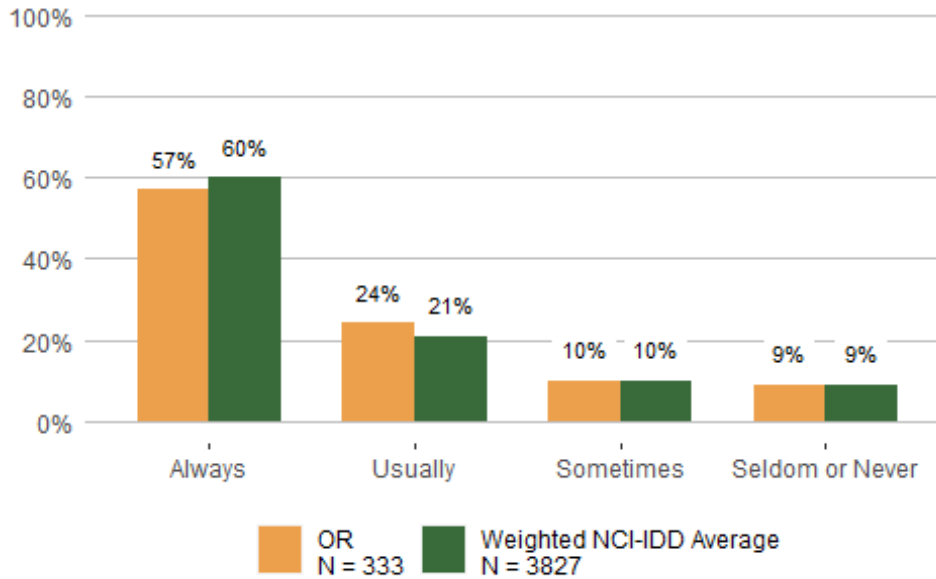


Table 44. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite providers?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	57%	24%	10%	9%	333
Weighted NCI-IDD Average	60%	21%	10%	9%	3827

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

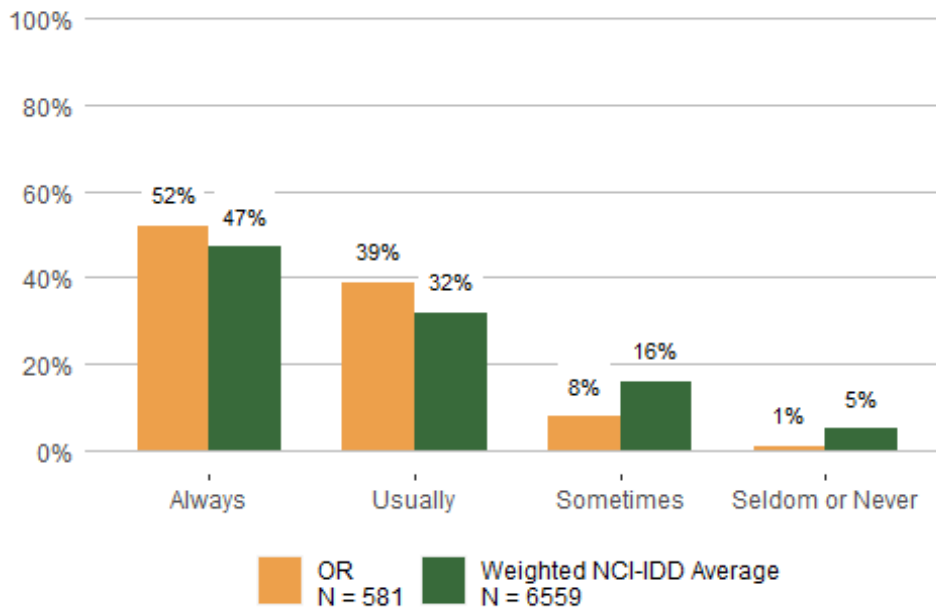


Table 45. Are you able to contact your child's support workers when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	52%	39%	8%	1%	581
Weighted NCI-IDD Average	47%	32%	16%	5%	6559

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

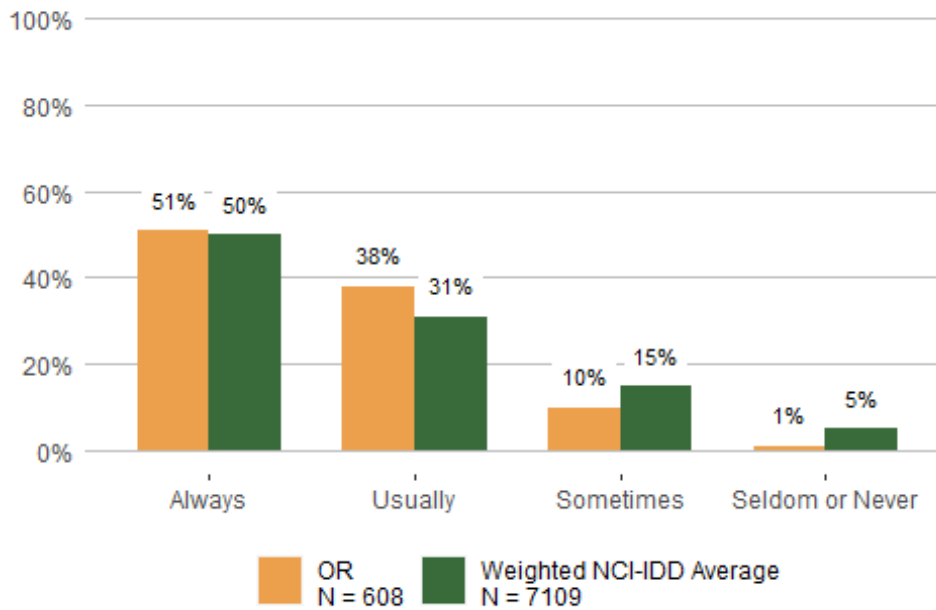


Table 46. Are you able to contact your child's case manager /service coordinator when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	51%	38%	10%	1%	608
Weighted NCI-IDD Average	50%	31%	15%	5%	7109

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

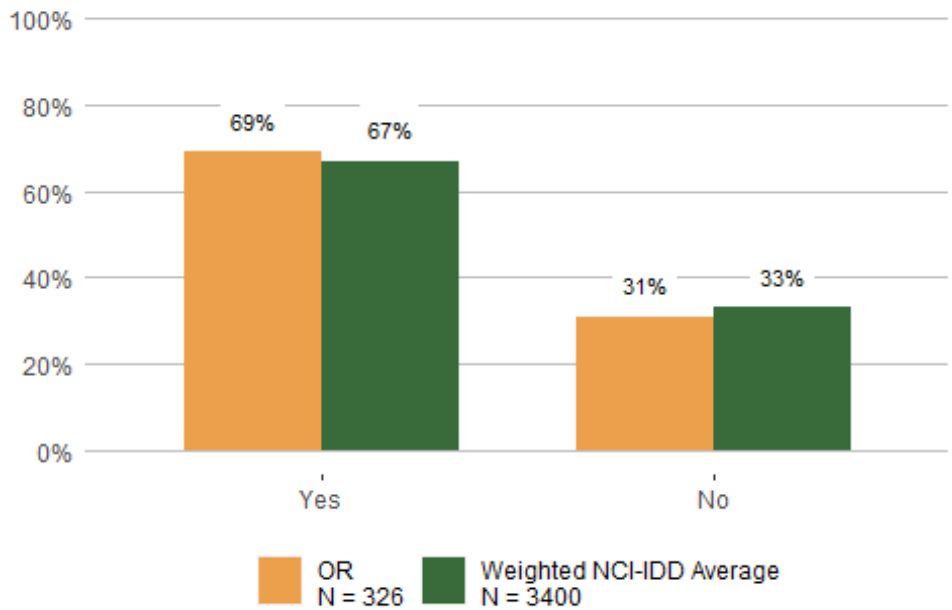


Table 47. Do service providers for your child work together to provide support?

State	Yes	No	N
OR	69%	31%	326
Weighted NCI-IDD Average	67%	33%	3400

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

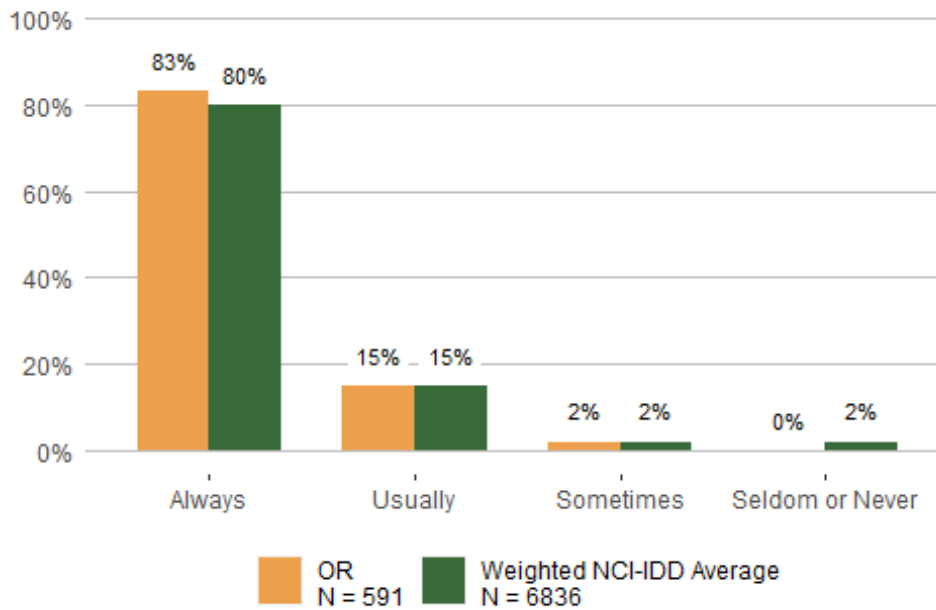


Table 48. Are services delivered in a way that is respectful of your family's culture?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	83%	15%	2%	0%	591
Weighted NCI-IDD Average	80%	15%	2%	2%	6836

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

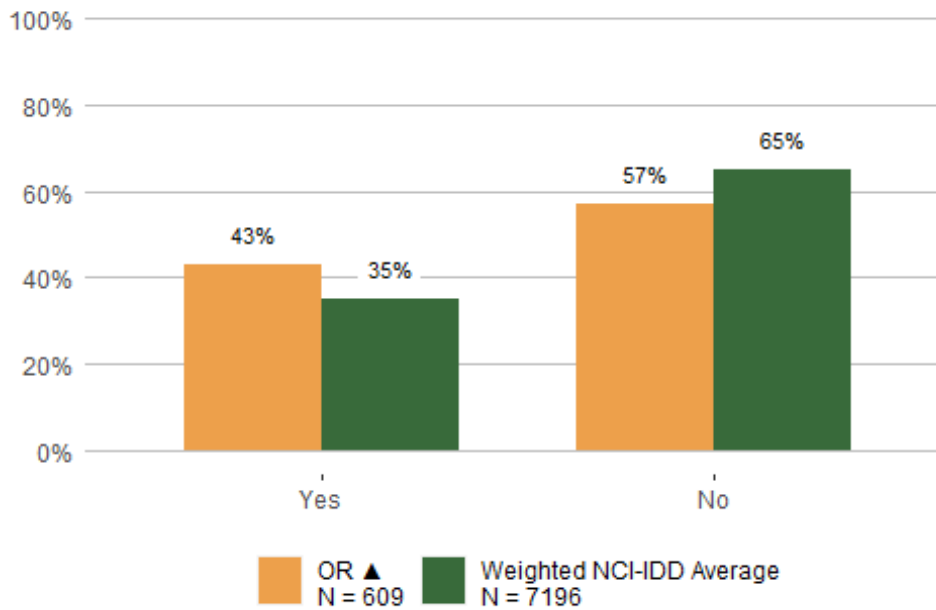


Table 49. Does your child use technology in their everyday life to help them do things on their own?

State	Yes	No	N
OR ▲	43%	57%	609
Weighted NCI-IDD Average	35%	65%	7196

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

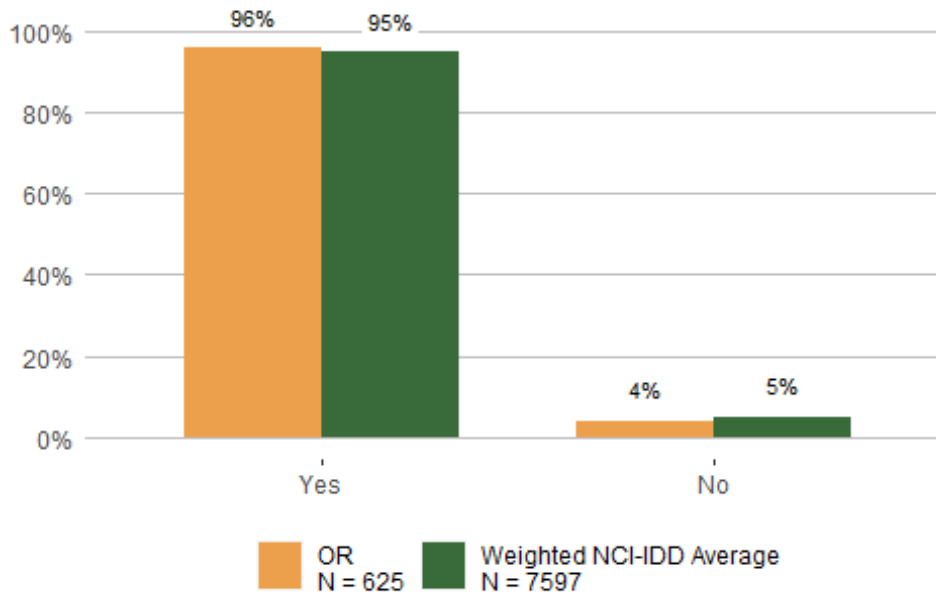


Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?

State	Yes	No	N
OR	96%	4%	625
Weighted NCI-IDD Average	95%	5%	7597

How well does the internet work in your home?

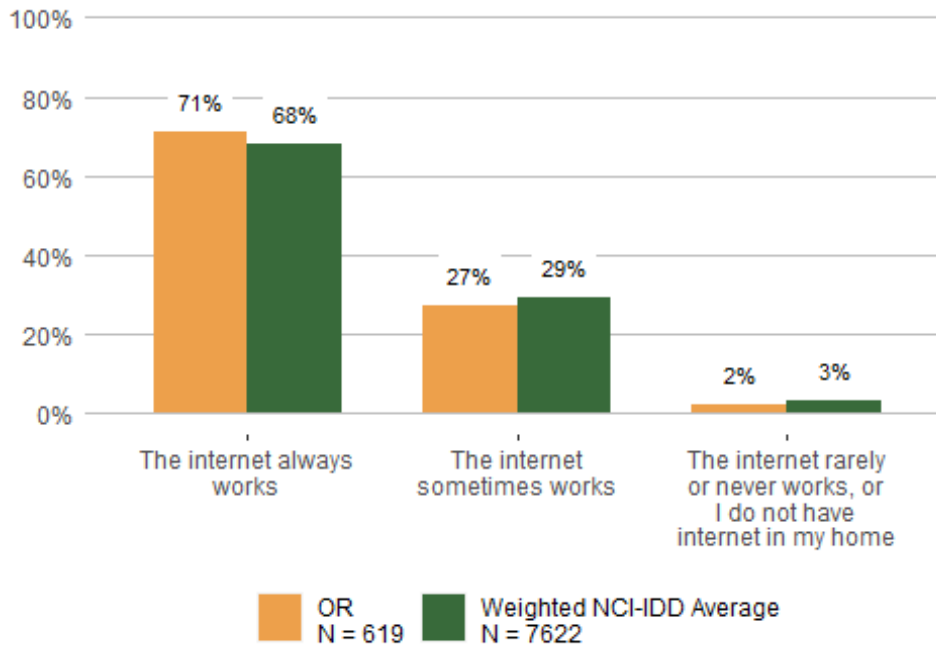


Table 51. How well does the internet work in your home?

New question in 2021-22

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
OR	71%	27%	2%	619
Weighted NCI-IDD Average	68%	29%	3%	7622

Workforce (New in 2021-22)

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.

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

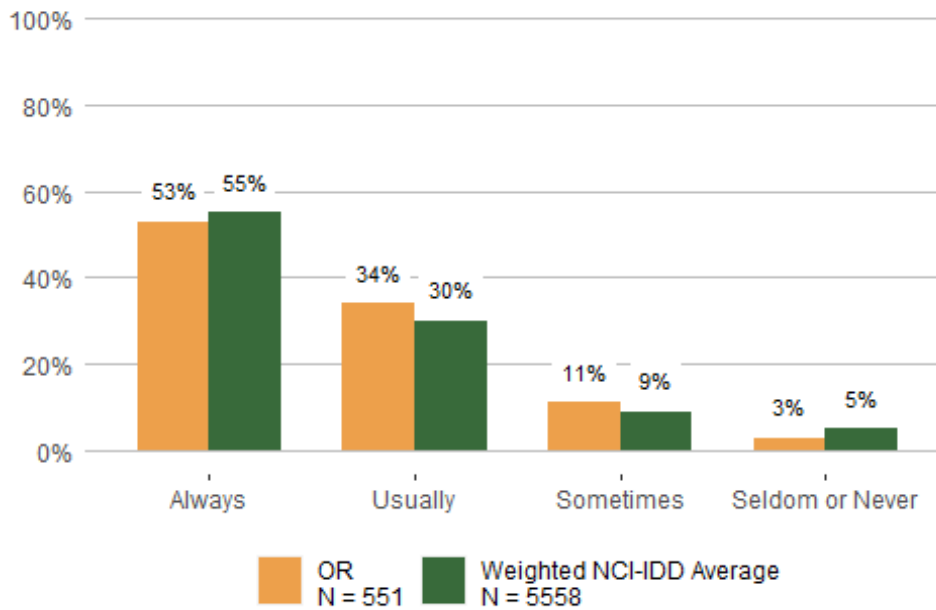


Table 52. Do support workers come and go when they are supposed to?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	53%	34%	11%	3%	551
Weighted NCI-IDD Average	55%	30%	9%	5%	5558

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

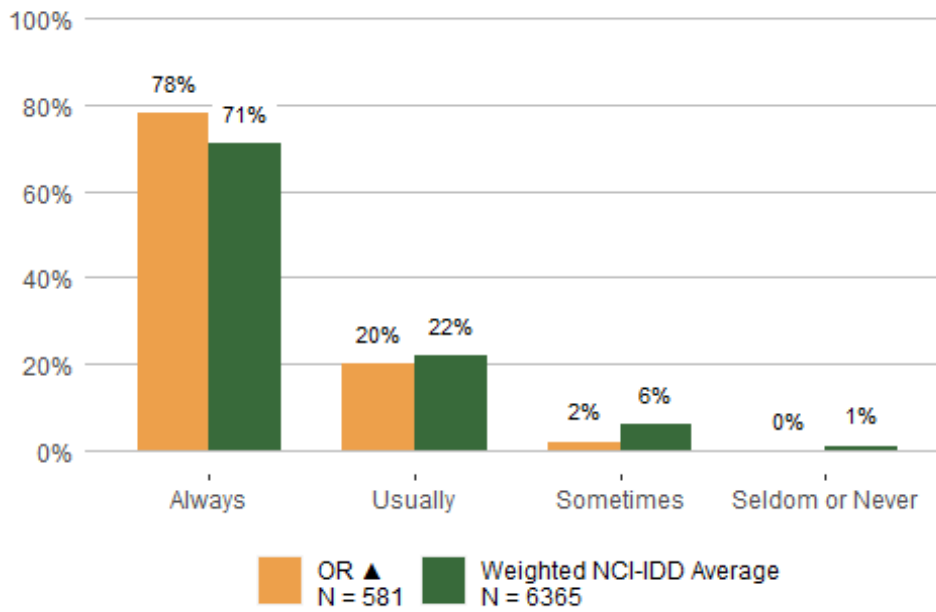


Table 53. Do support workers speak to you in a way you understand?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▲	78%	20%	2%	0%	581
Weighted NCI-IDD Average	71%	22%	6%	1%	6365

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

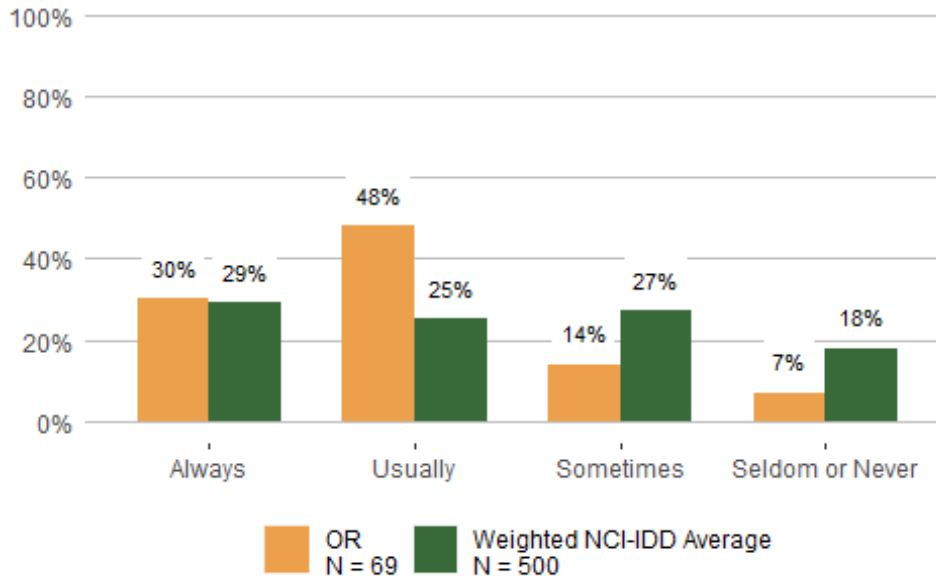


Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	30%	48%	14%	7%	69
Weighted NCI-IDD Average	29%	25%	27%	18%	500

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

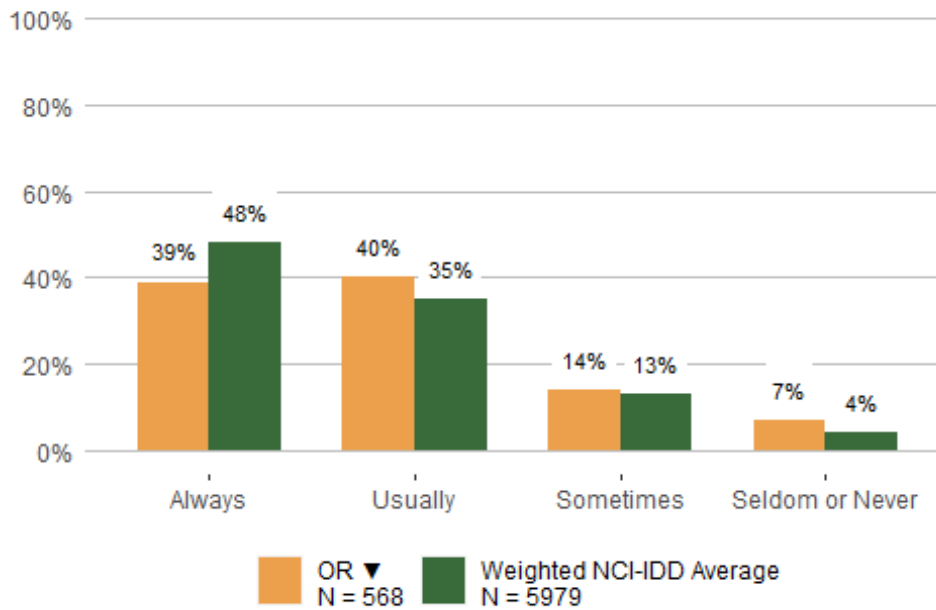


Table 55. Do support workers have the right information and skills to meet your family's needs?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▼	39%	40%	14%	7%	568
Weighted NCI-IDD Average	48%	35%	13%	4%	5979

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

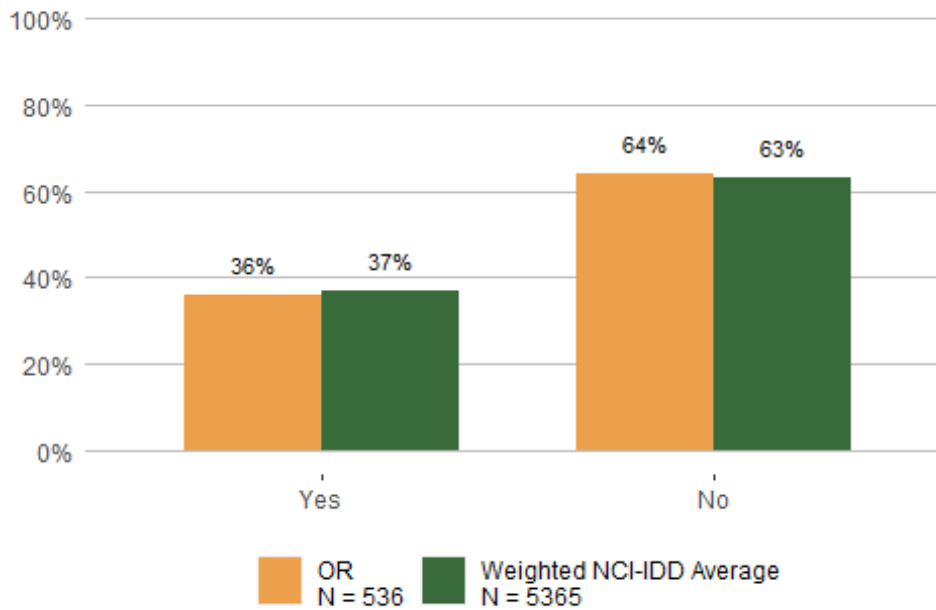


Table 56. Do your child's support workers change too often? Is there too much "turnover" of support workers?

New question in 2021-22

State	Yes	No	N
OR	36%	64%	536
Weighted NCI-IDD Average	37%	63%	5365

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

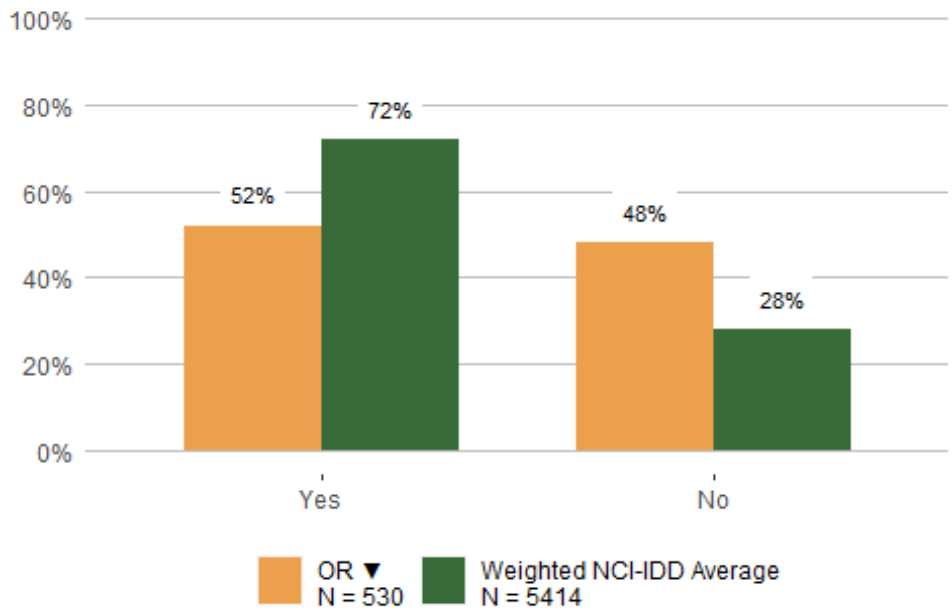


Table 57. Is there always a staff person available to support your child when support is needed?

New question in 2021-22

State	Yes	No	N
OR ▼	52%	48%	530
Weighted NCI-IDD Average	72%	28%	5414

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.

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

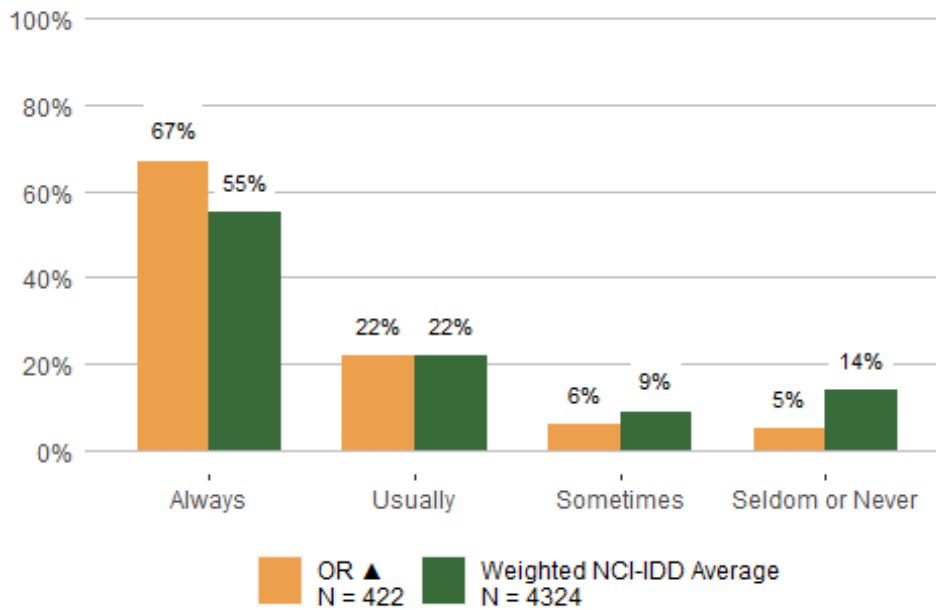


Table 58. Can someone in your family choose or change the agency that provides your child's services?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▲	67%	22%	6%	5%	422
Weighted NCI-IDD Average	55%	22%	9%	14%	4324

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

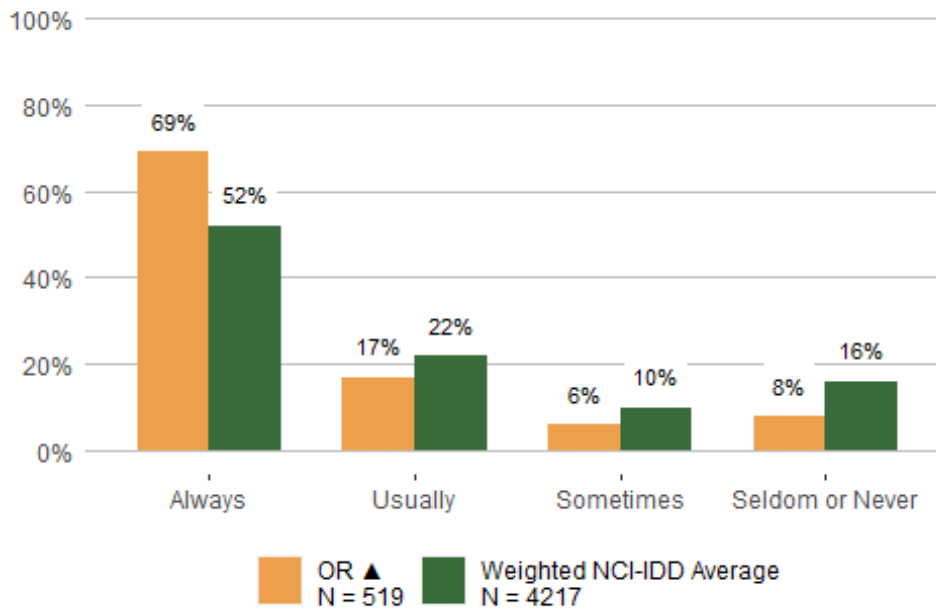


Table 59. Can someone in your family choose or change your child's support workers?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▲	69%	17%	6%	8%	519
Weighted NCI-IDD Average	52%	22%	10%	16%	4217

Can someone in your family directly manage support staff?

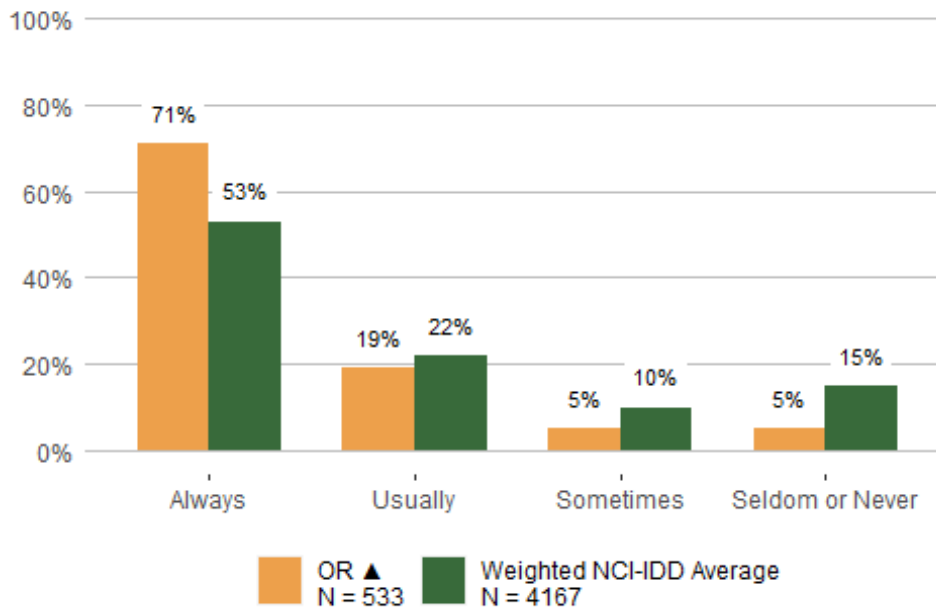


Table 60. Can someone in your family directly manage support staff?
Question changed in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▲	71%	19%	5%	5%	533
Weighted NCI-IDD Average	53%	22%	10%	15%	4167

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

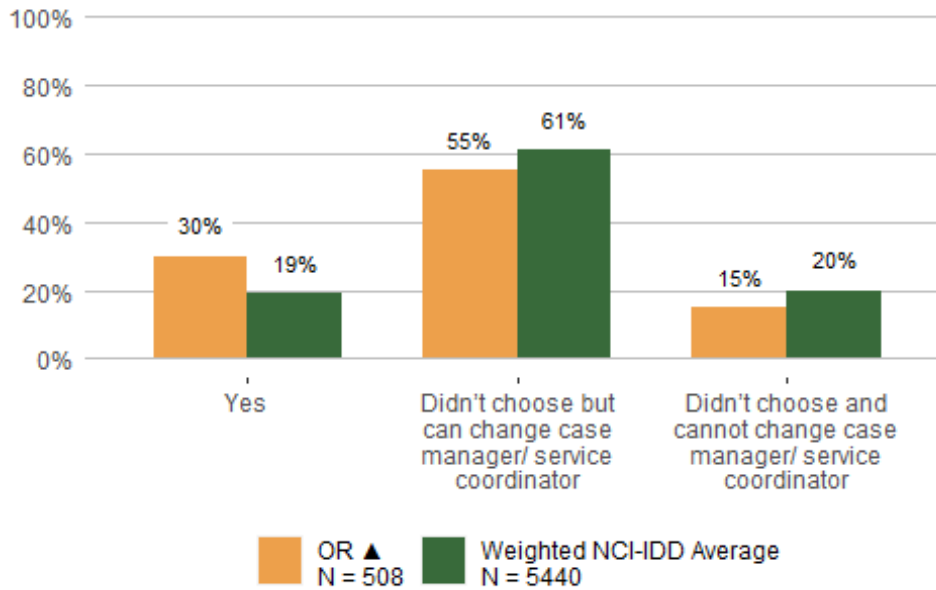


Table 61. Did you, your child, or someone else in your family choose your child's case manager/service coordinator?

State	Yes	Didn't choose but can change case manager/ service coordinator	Didn't choose and cannot change case manager/ service coordinator	N
OR ▲	30%	55%	15%	508
Weighted NCI-IDD Average	19%	61%	20%	5440

Involvement in the Community

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

Does your child do things in the community?

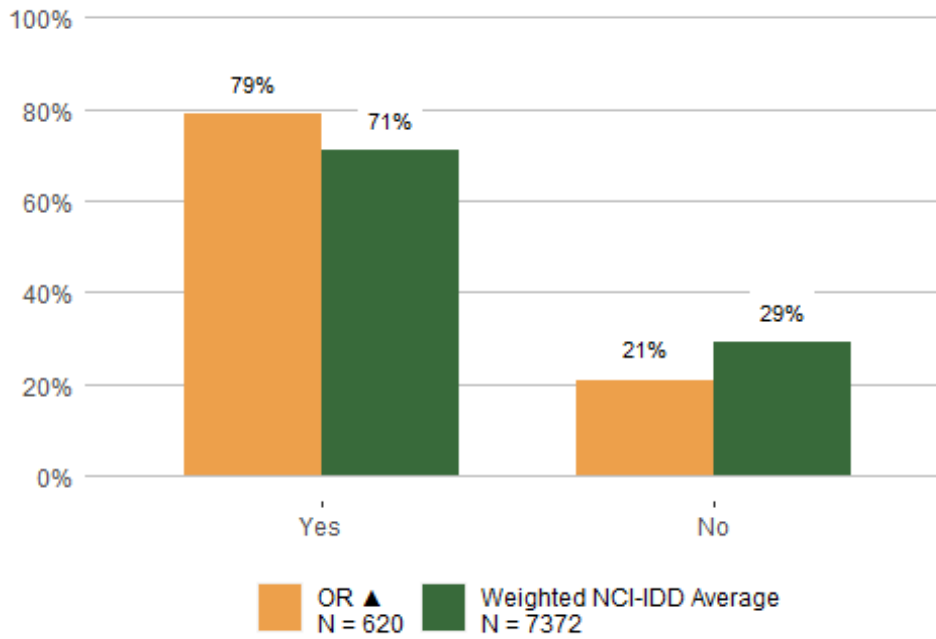


Table 62. Does your child do things in the community?

Question changed in 2021-22

State	Yes	No	N
OR ▲	79%	21%	620
Weighted NCI-IDD Average	71%	29%	7372

What makes it hard to do things in the community?

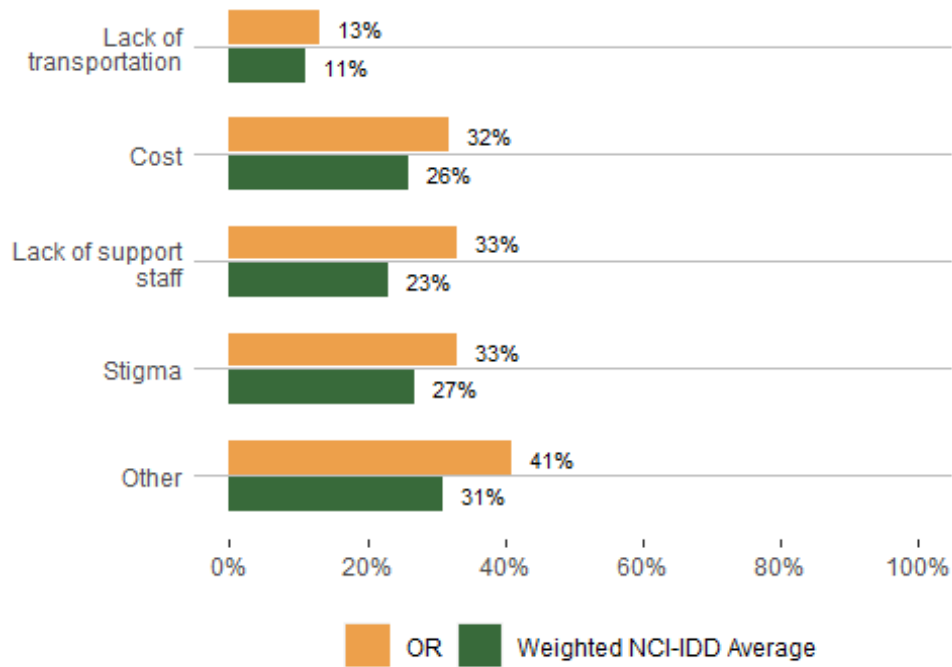


Table 63. What makes it hard to do things in the community?
 Categories are not mutually exclusive, therefore N is not shown.

State	Lack of transportation	Cost	Lack of support staff	Stigma	Other
OR	13%	32%	33%	33%	41%
Weighted NCI-IDD Average	11%	26%	23%	27%	31%

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

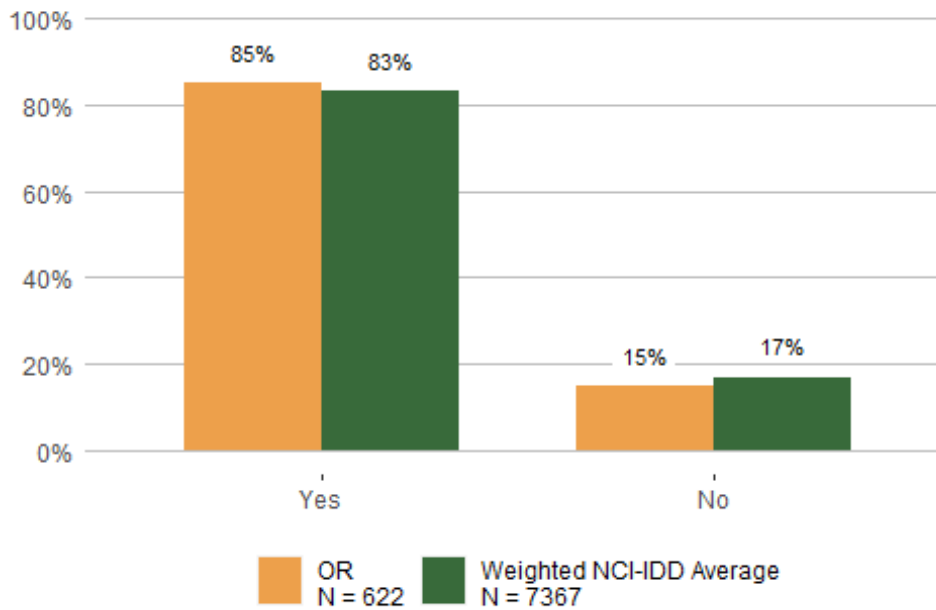


Table 64. Does your child spend time with children who do not have developmental disabilities?

State	Yes	No	N
OR	85%	15%	622
Weighted NCI-IDD Average	83%	17%	7367

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

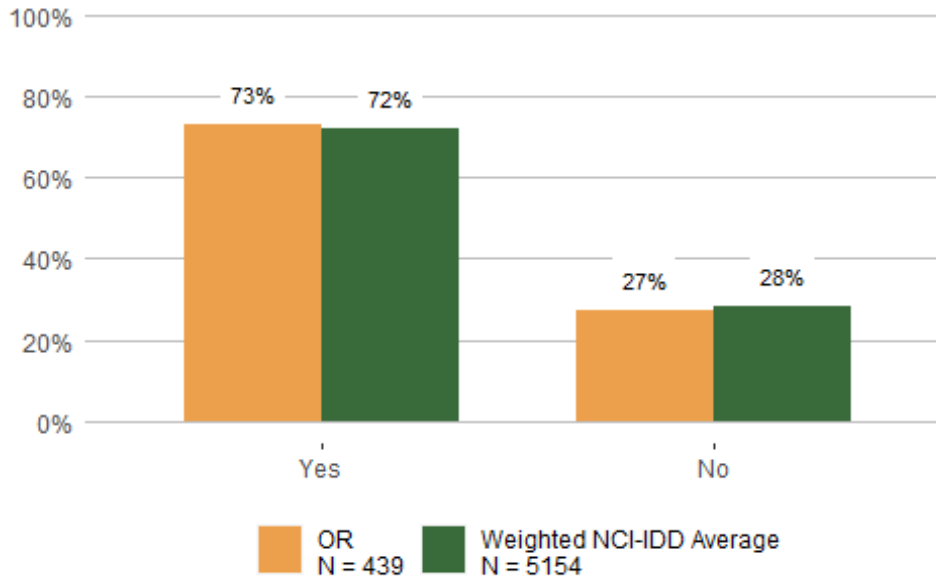


Table 65. In your community, are there resources that your family can use that are not provided by the I/DD agency?

State	Yes	No	N
OR	73%	27%	439
Weighted NCI-IDD Average	72%	28%	5154

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

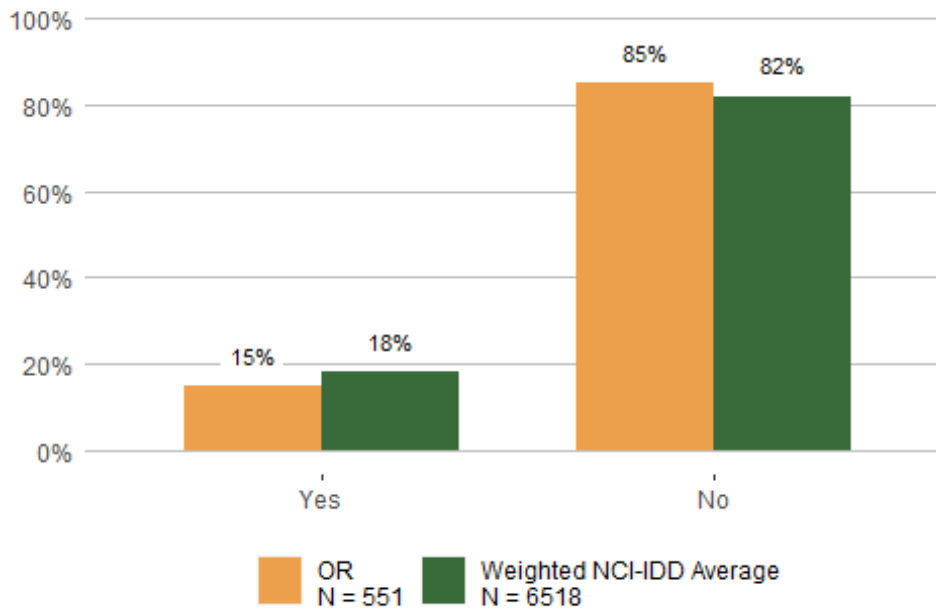


Table 66. Does your family take part in any family-to-family networks in your community?

State	Yes	No	N
OR	15%	85%	551
Weighted NCI-IDD Average	18%	82%	6518

Health, Welfare, and Safety (New in 2021-22)

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

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

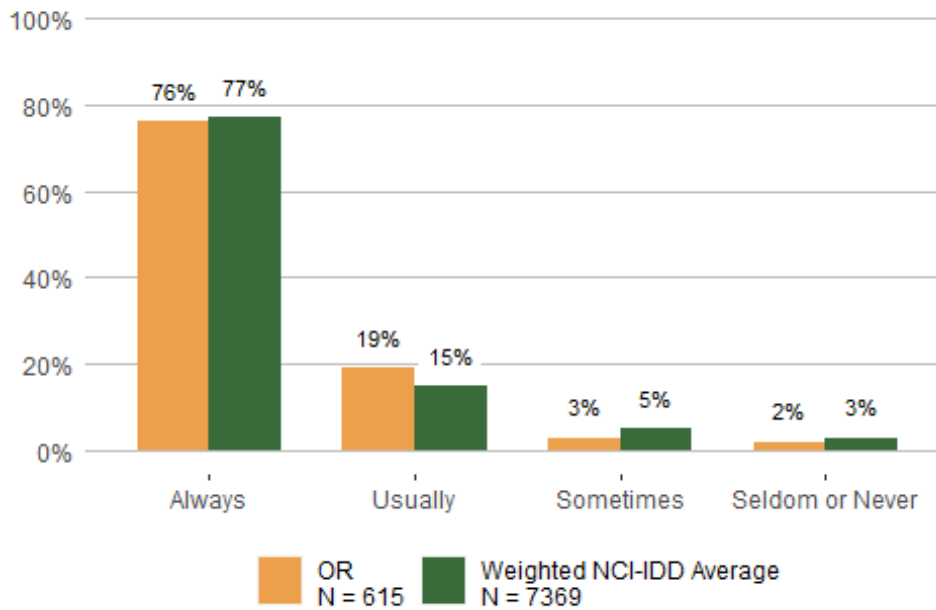


Table 67. Can your child see a primary care provider (doctor, registered nurse, etc.) when needed?

New question in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
OR	76%	19%	3%	2%	615
Weighted NCI-IDD Average	77%	15%	5%	3%	7369

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

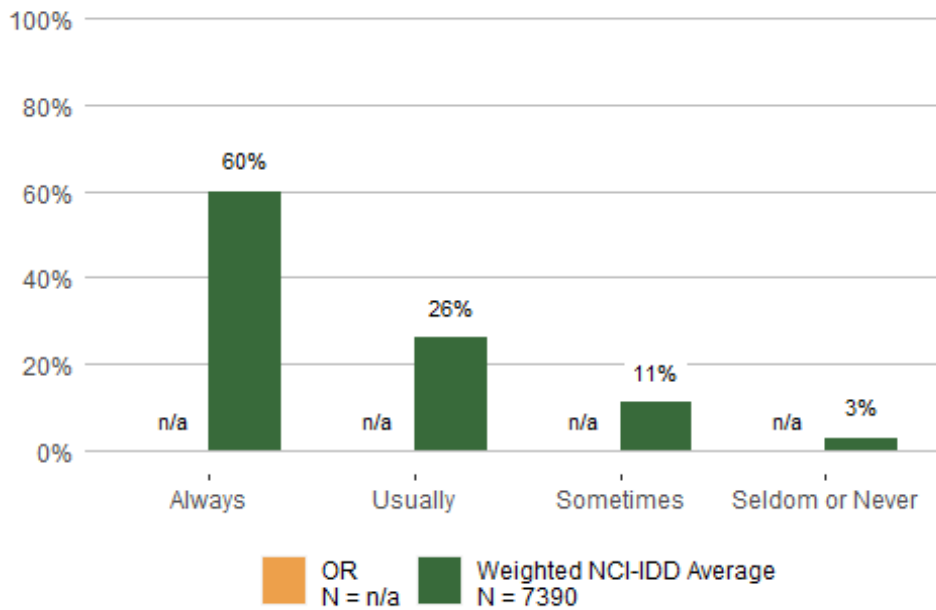


Table 68. Does your child's primary care doctor understand your child's needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▼	49%	38%	10%	3%	605
Weighted NCI-IDD Average	60%	26%	11%	3%	7390

Can your child go to the dentist when needed?

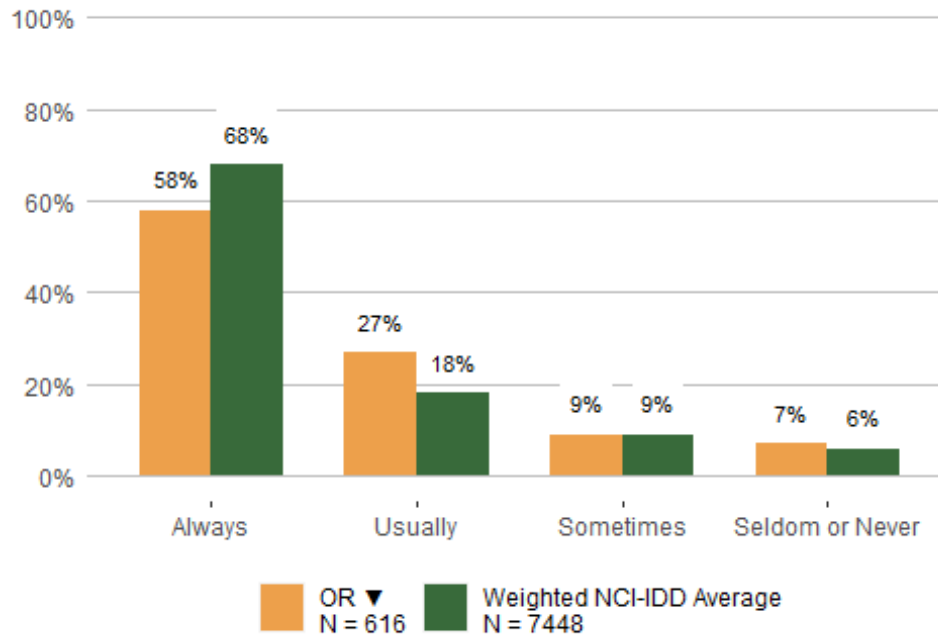


Table 69. Can your child go to the dentist when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▼	58%	27%	9%	7%	616
Weighted NCI-IDD Average	68%	18%	9%	6%	7448

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

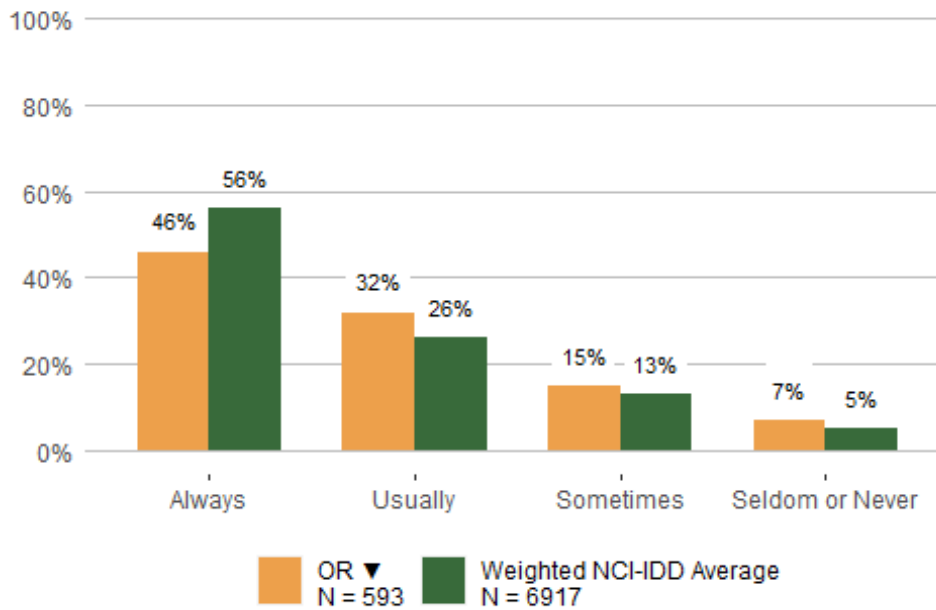


Table 70. Does your child's dentist understand your child's needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▼	46%	32%	15%	7%	593
Weighted NCI-IDD Average	56%	26%	13%	5%	6917

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

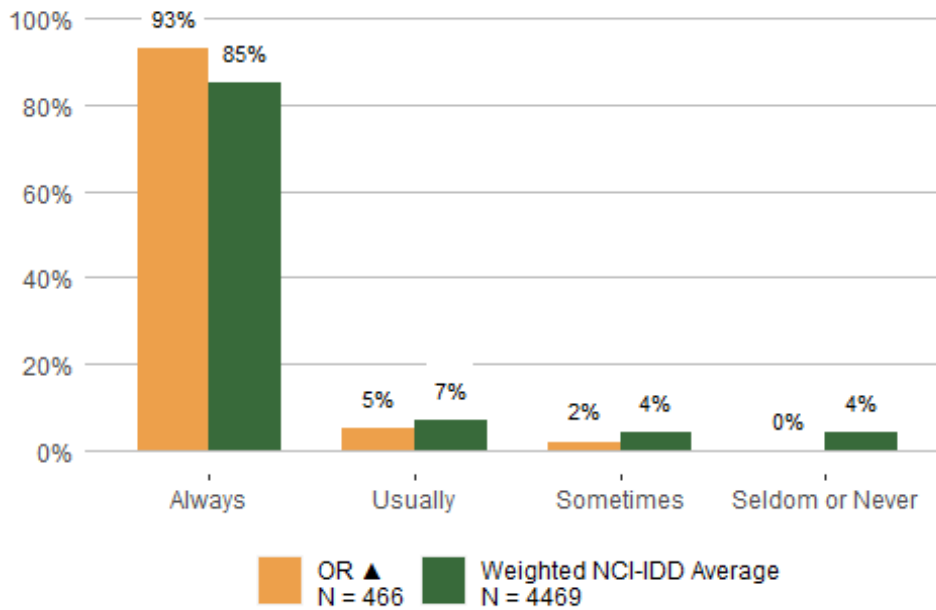


Table 71. If your child takes prescription medications, do you know what they're for?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▲	93%	5%	2%	0%	466
Weighted NCI-IDD Average	85%	7%	4%	4%	4469

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

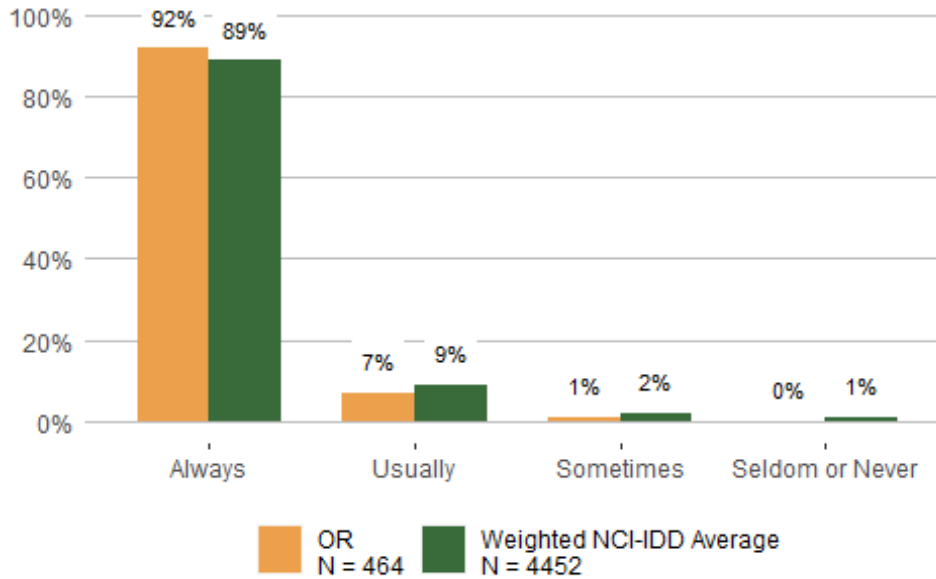


Table 72. Do you, or someone else in your family know what is needed to safely take the prescription medications?

State	Always	Usually	Sometimes	Seldom or Never	N
OR	92%	7%	1%	0%	464
Weighted NCI-IDD Average	89%	9%	2%	1%	4452

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

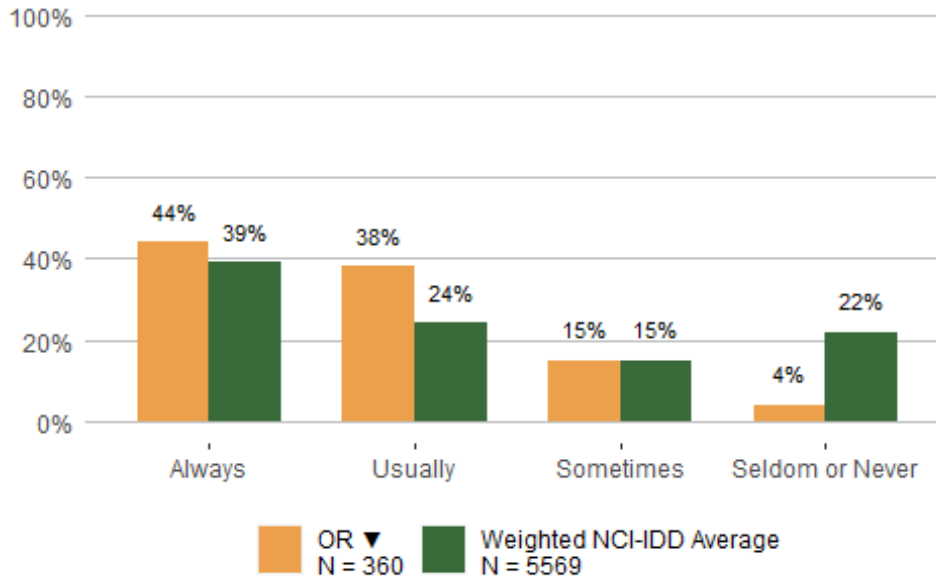


Table 73. Can your child get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling).

New question in 2021-22.

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▼	44%	38%	15%	4%	360
Weighted NCI-IDD Average	39%	24%	15%	22%	5569

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

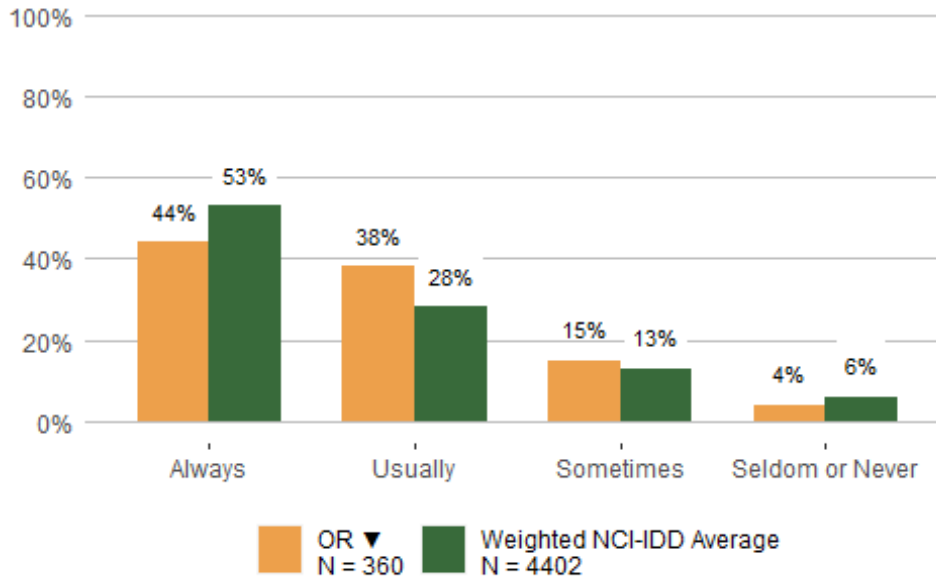


Table 74. If your child uses mental health services, does the mental health professional understand your child's needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▼	44%	38%	15%	4%	360
Weighted NCI-IDD Average	53%	28%	13%	6%	4402

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

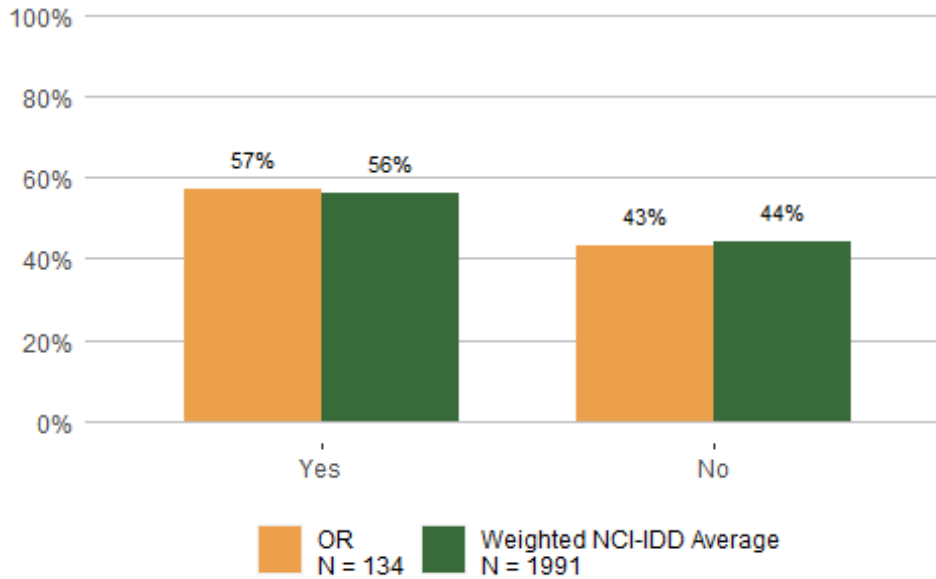


Table 75. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

State	Yes	No	N
OR	57%	43%	134
Weighted NCI-IDD Average	56%	44%	1991

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

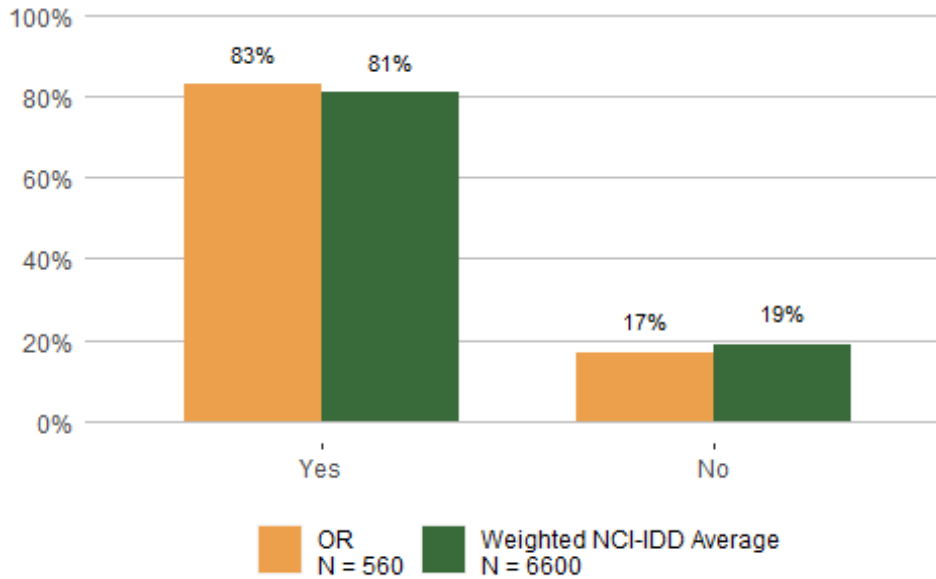


Table 76. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency, pandemic or natural disaster?

State	Yes	No	N
OR	83%	17%	560
Weighted NCI-IDD Average	81%	19%	6600

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

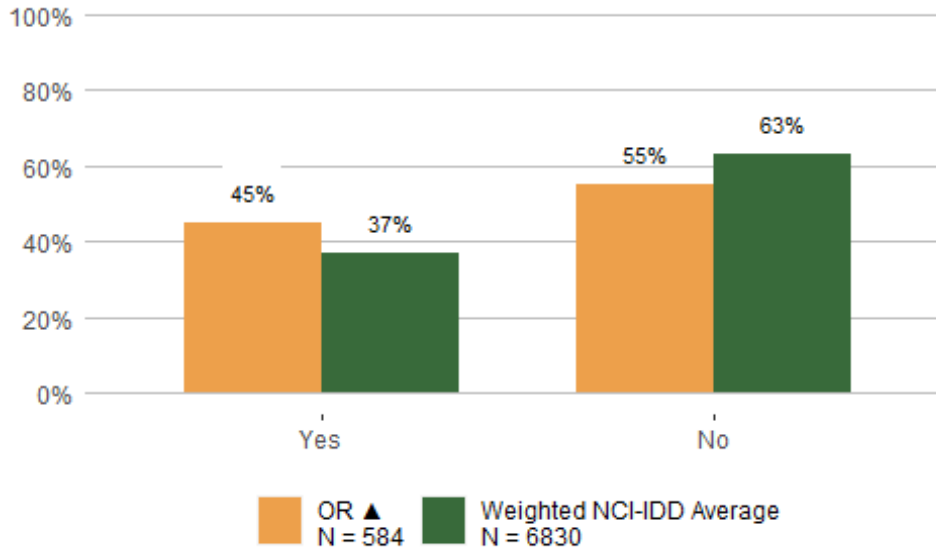


Table 77. Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child's case manager/service coordinator?

New question in 2021-22

State	Yes	No	N
OR ▲	45%	55%	584
Weighted NCI-IDD Average	37%	63%	6830

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

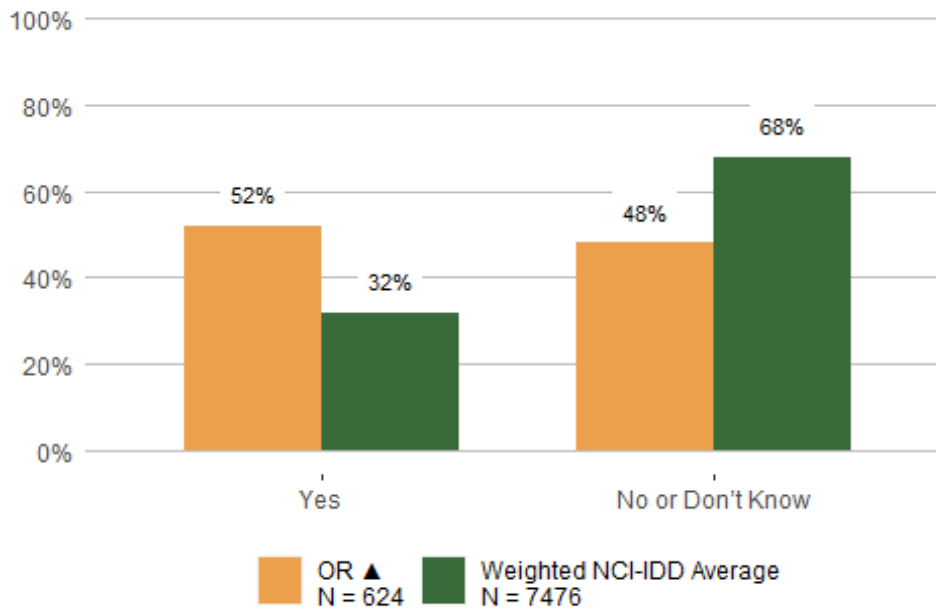


Table 78. Do you know how to file a complaint or grievance about provider agencies or staff?

State	Yes	No or Don't Know	N
OR ▲	52%	48%	624
Weighted NCI-IDD Average	32%	68%	7476

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

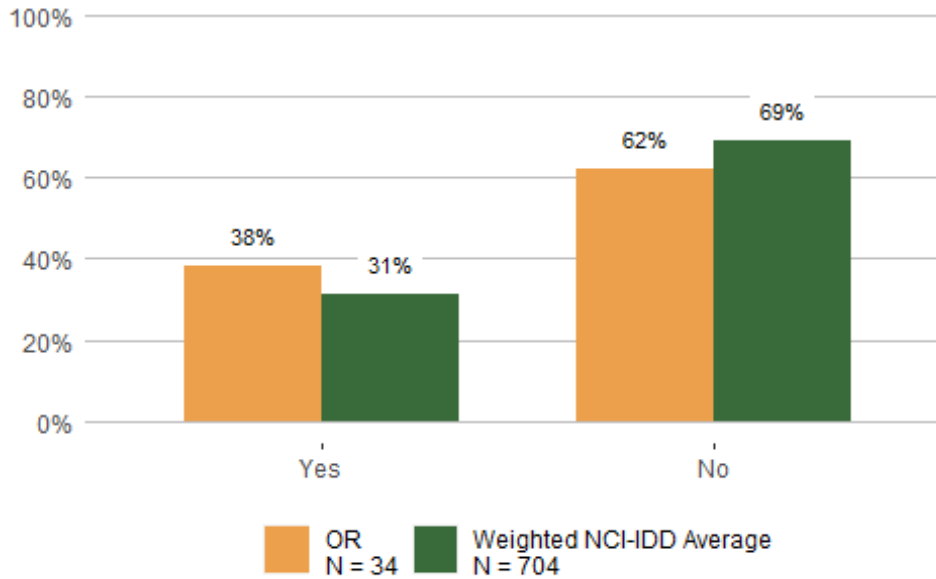


Table 79. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

State	Yes	No	N
OR	38%	62%	34
Weighted NCI-IDD Average	31%	69%	704

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

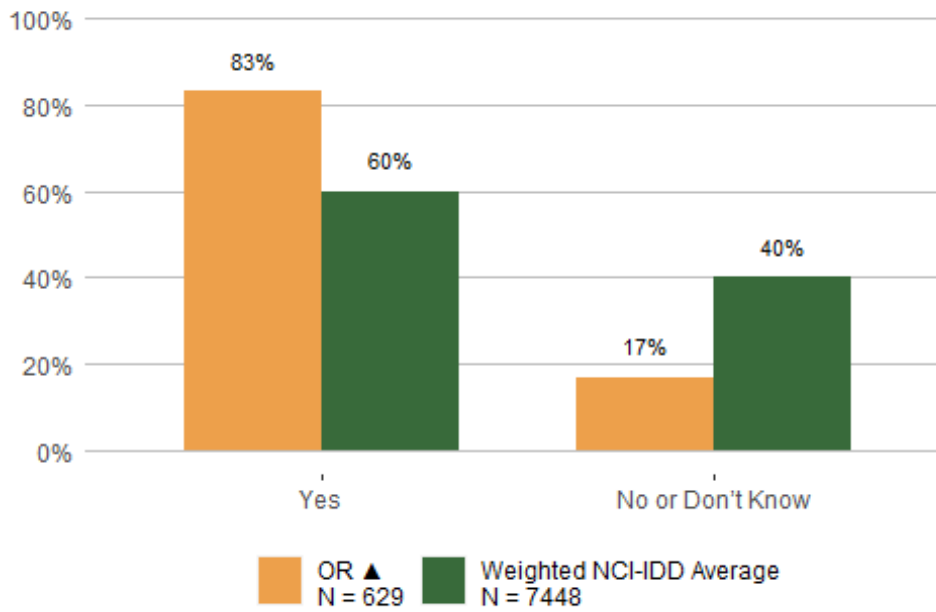


Table 80. Do you know how to report abuse or neglect related to your child?

State	Yes	No or Don't Know	N
OR ▲	83%	17%	629
Weighted NCI-IDD Average	60%	40%	7448

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

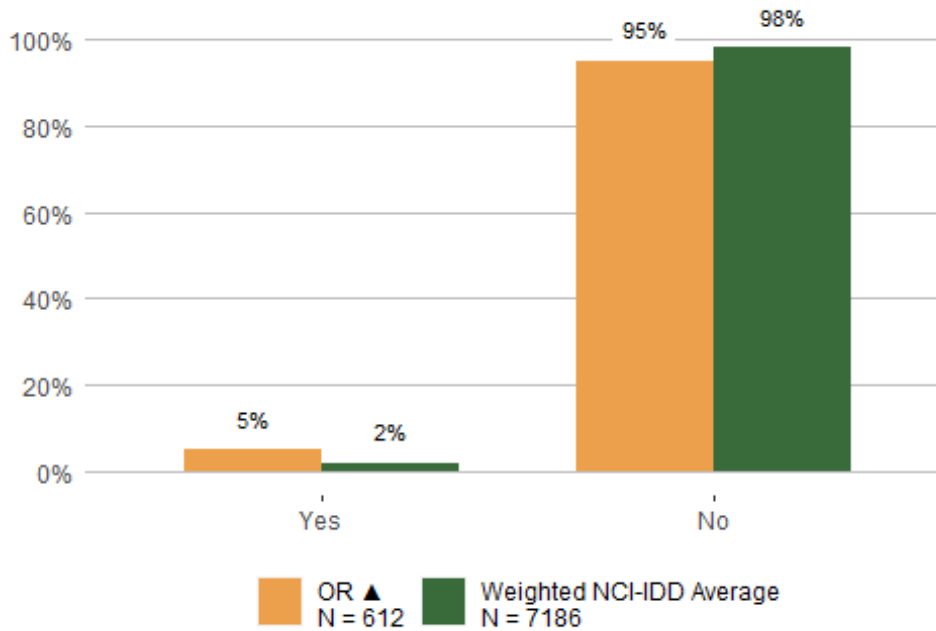


Table 81. Within the past 12 months, was a report of abuse or neglect filed on behalf of your child?

State	Yes	No	N
OR ▲	5%	95%	612
Weighted NCI-IDD Average	2%	98%	7186

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

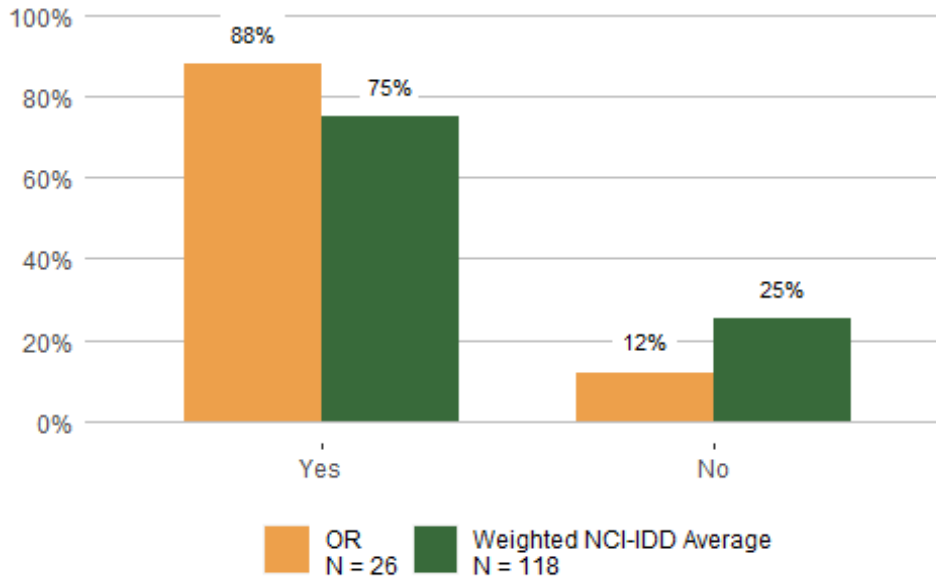


Table 82. If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?

State	Yes	No	N
OR	88%	12%	26
Weighted NCI-IDD Average	75%	25%	118

Family Satisfaction

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

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

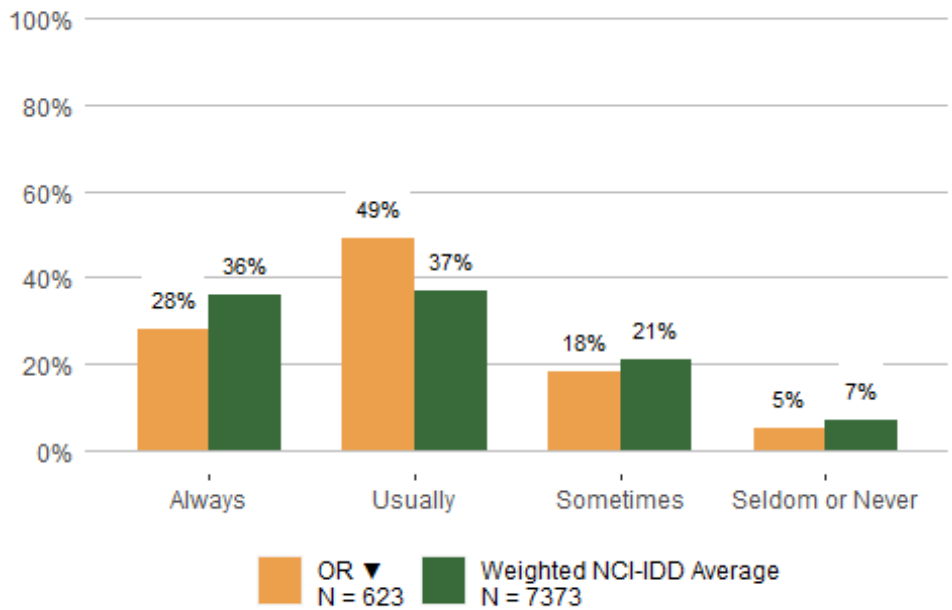


Table 83. Overall, are you satisfied with the services and supports your child currently receives?

State	Always	Usually	Sometimes	Seldom or Never	N
OR ▼	28%	49%	18%	5%	623
Weighted NCI-IDD Average	36%	37%	21%	7%	7373

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

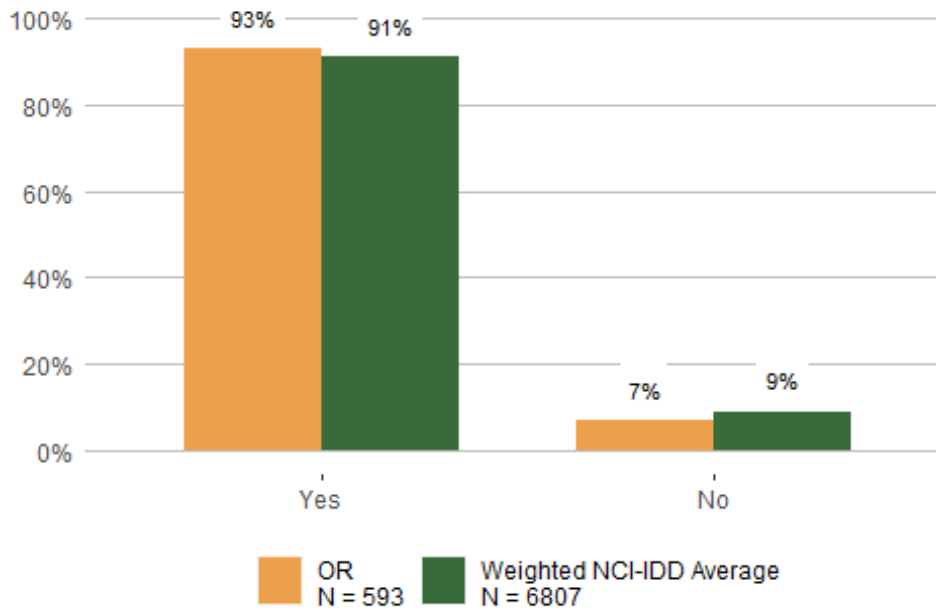


Table 84. Do you feel that services and supports have made a positive difference in the life of your family?

State	Yes	No	N
OR	93%	7%	593
Weighted NCI-IDD Average	91%	9%	6807

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

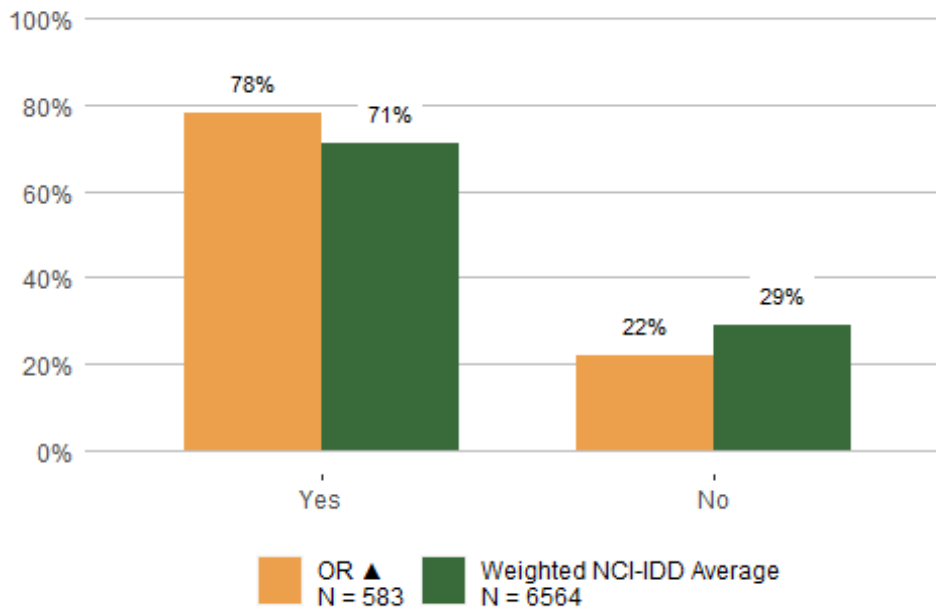


Table 85. Have services and supports reduced your family's out-of-pocket expenses for your child's care?

State	Yes	No	N
OR ▲	78%	22%	583
Weighted NCI-IDD Average	71%	29%	6564

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

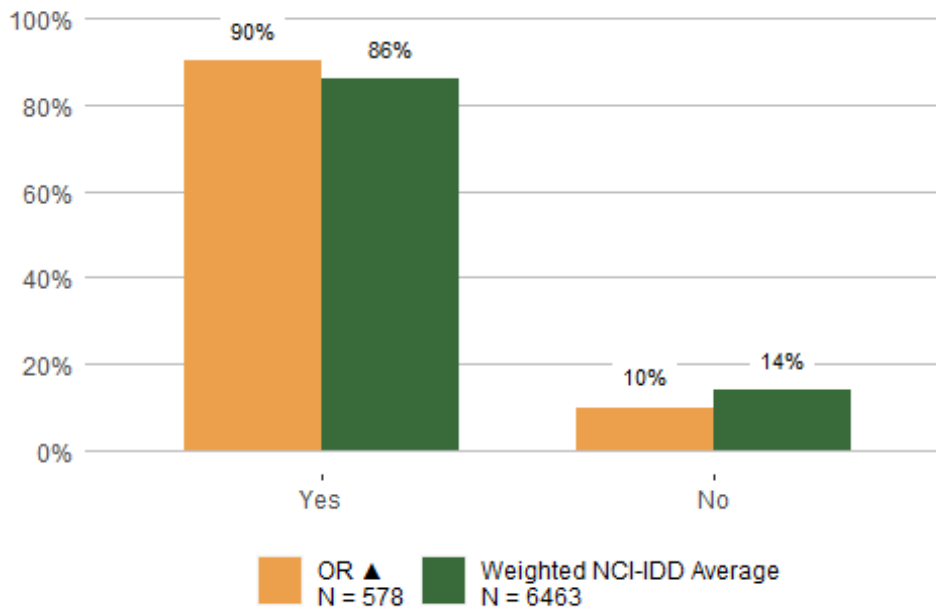


Table 86. Do you feel that family supports have improved your ability to care for your child?

State	Yes	No	N
OR ▲	90%	10%	578
Weighted NCI-IDD Average	86%	14%	6463

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

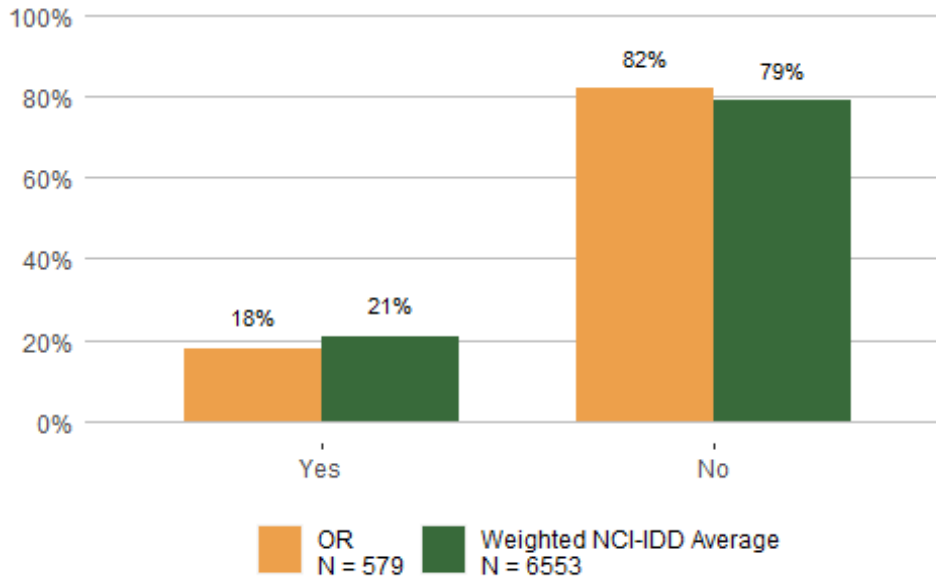


Table 87. Have services or supports that your child/family received during the past 12 months been reduced, suspended, or terminated?

State	Yes	No	N
OR	18%	82%	579
Weighted NCI-IDD Average	21%	79%	6553

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?

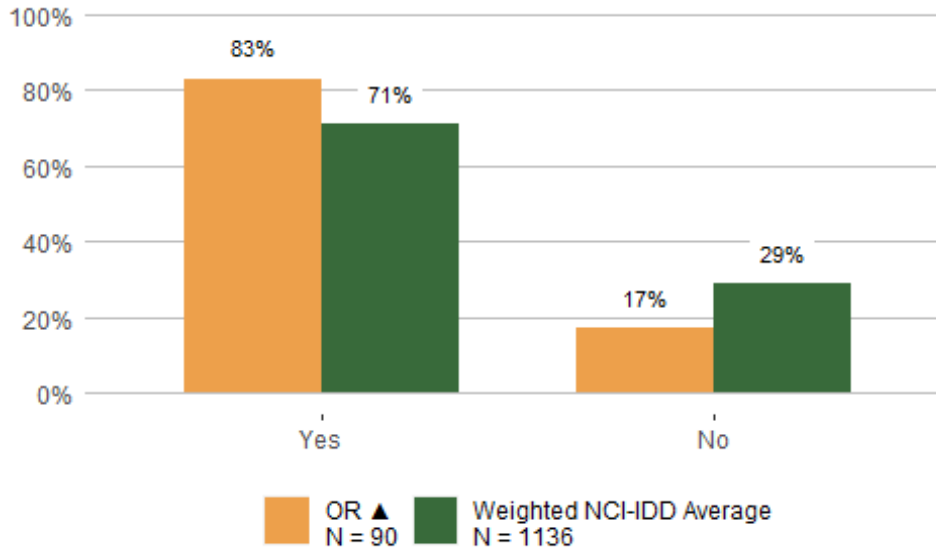


Table 88. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family or your child negatively?

State	Yes	No	N
OR ▲	83%	17%	90
Weighted NCI-IDD Average	71%	29%	1136

Have the services or supports that your child is receiving been increased in the past 12 months?

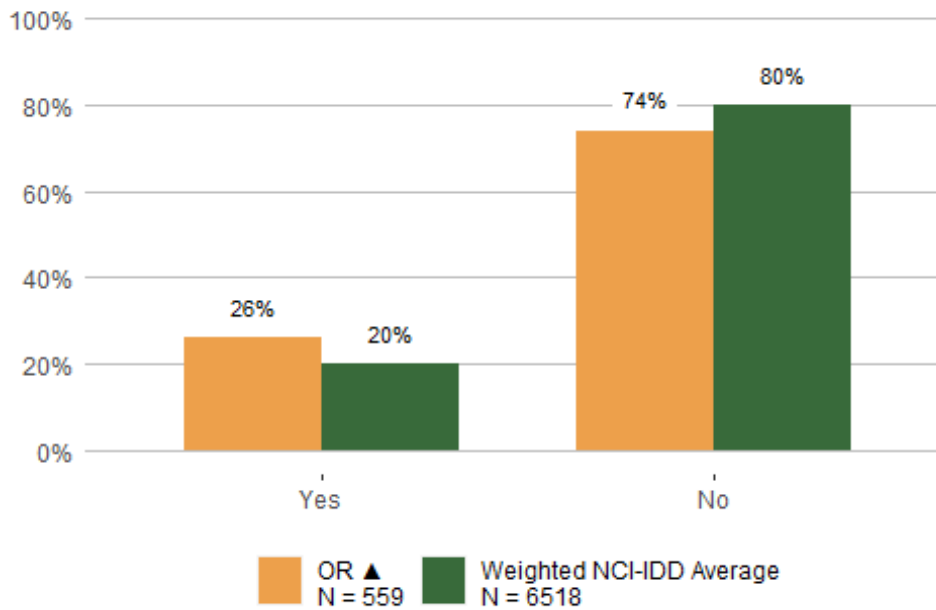


Table 89. Have the services or supports that your child is receiving been increased in the past 12 months?

State	Yes	No	N
OR ▲	26%	74%	559
Weighted NCI-IDD Average	20%	80%	6518

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

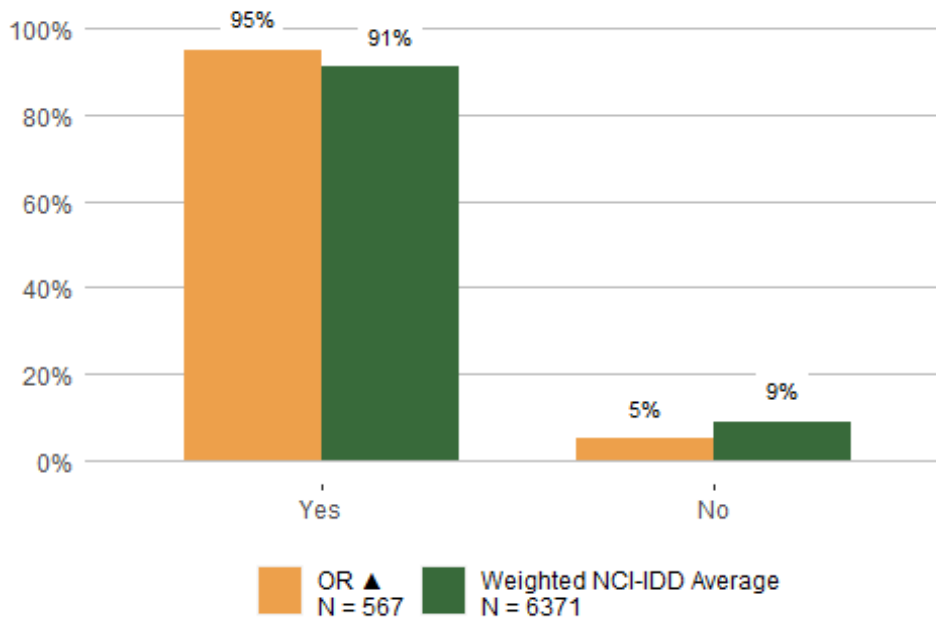


Table 90. Are services and supports helping your child to live a good life?

State	Yes	No	N
OR ▲	95%	5%	567
Weighted NCI-IDD Average	91%	9%	6371

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. Note: the COVID-19 Supplement was state optional, one state chose not to administer the Supplement.

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

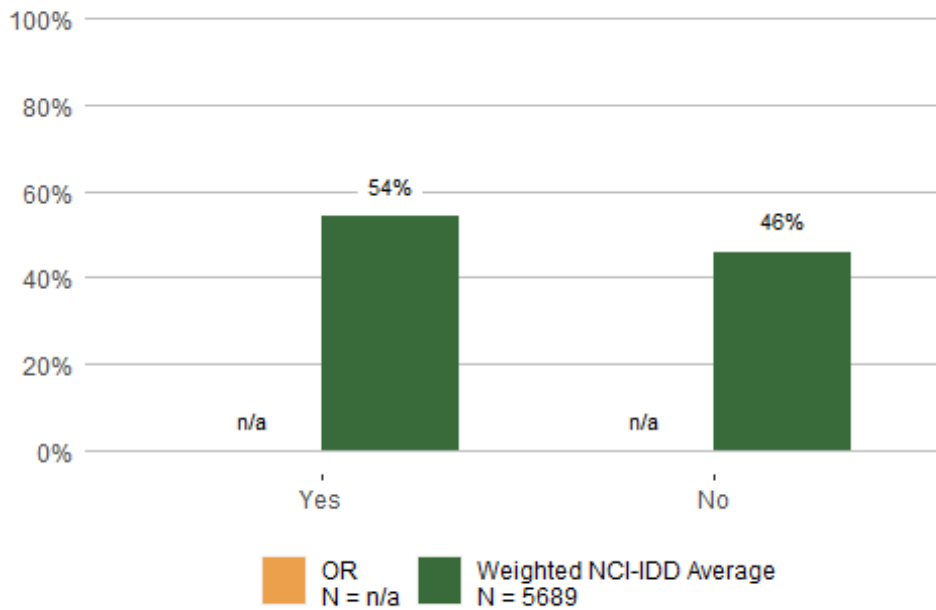


Table 91. Were your child's services and supports changed, canceled, or reduced during COVID time?

State	Yes	No	N
OR	n/a	n/a	n/a
Weighted NCI-IDD Average	54%	46%	5689

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

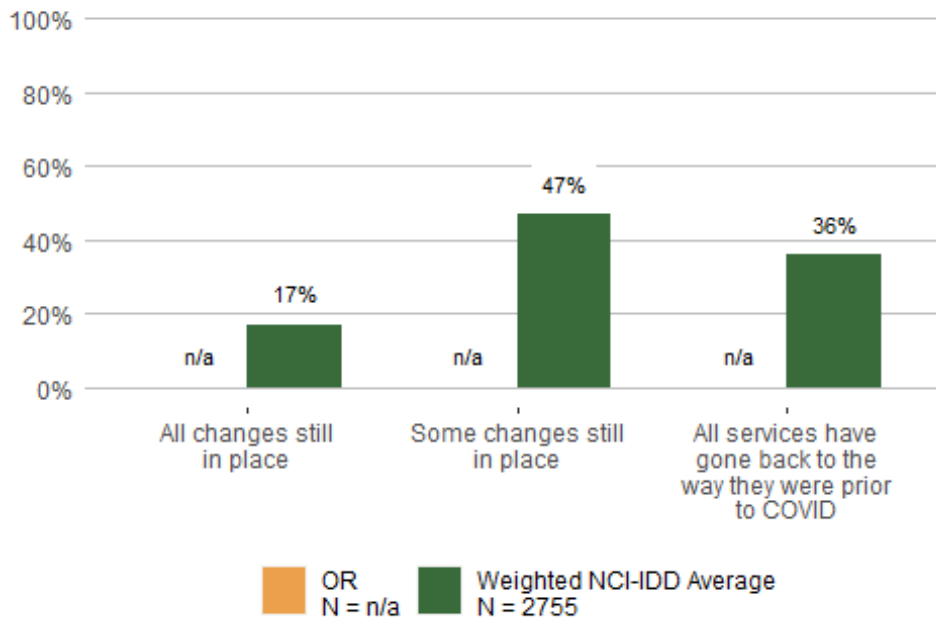


Table 92. If yes, are those changes still in effect (still part of your child's life)?

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
OR	n/a	n/a	n/a	n/a
Weighted NCI-IDD Average	17%	47%	36%	2755

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

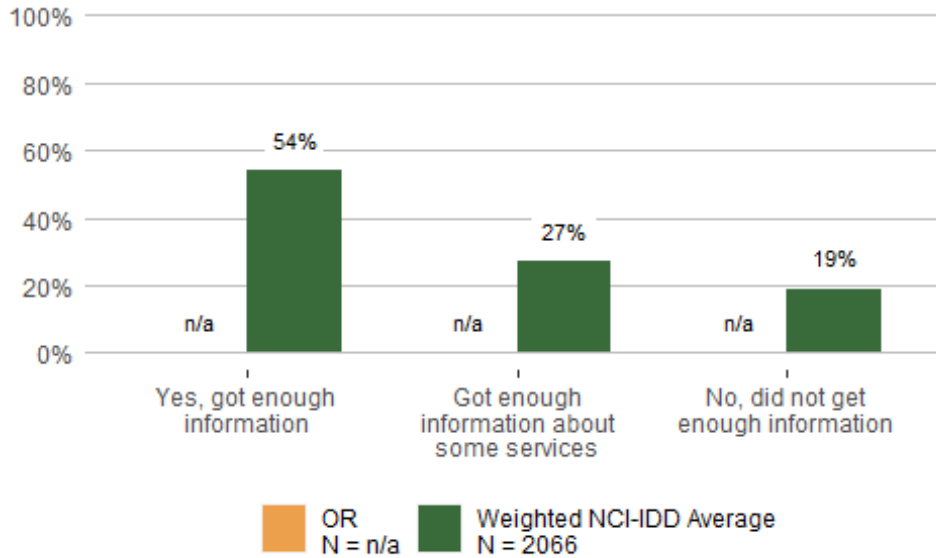


Table 93. If some or all of your child's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
OR	n/a	n/a	n/a	n/a
Weighted NCI-IDD Average	54%	27%	19%	2066

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?

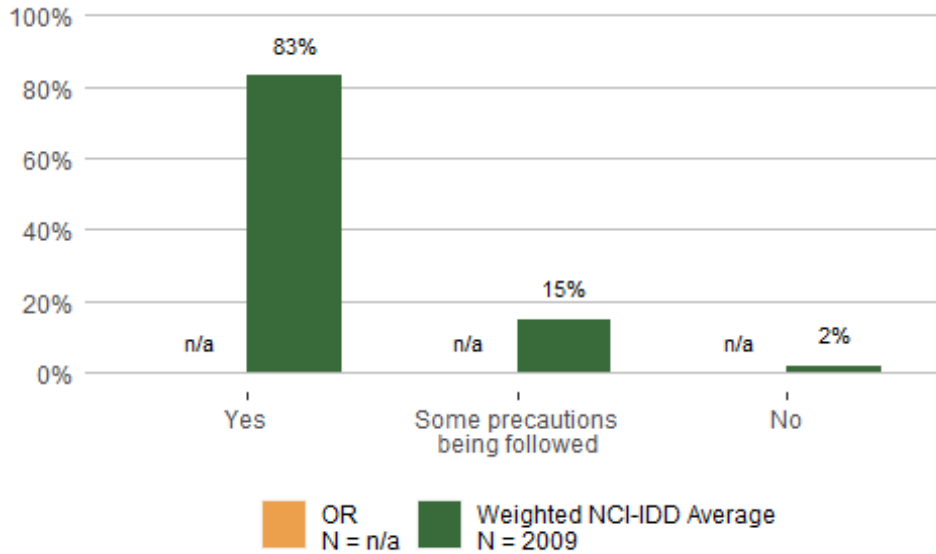


Table 94. If some or all of your child's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?

State	Yes	Some precautions being followed	No	N
OR	n/a	n/a	n/a	n/a
Weighted NCI-IDD Average	83%	15%	2%	2009

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?

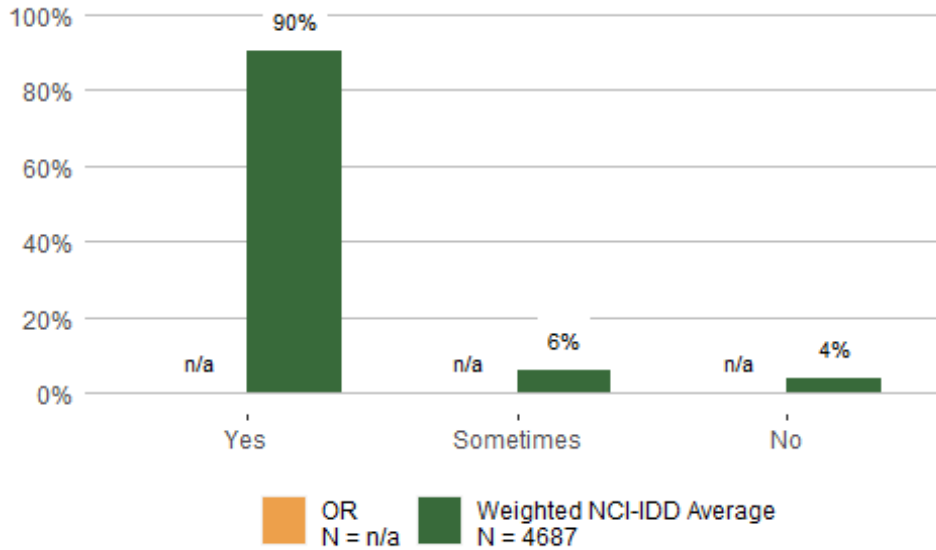


Table 95. If staff come into your home to support your child: Do you feel that the staff follow recommendations to keep the household safe and healthy?

State	Yes	Sometimes	No	N
OR	n/a	n/a	n/a	n/a
Weighted NCI-IDD Average	90%	6%	4%	4687

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?

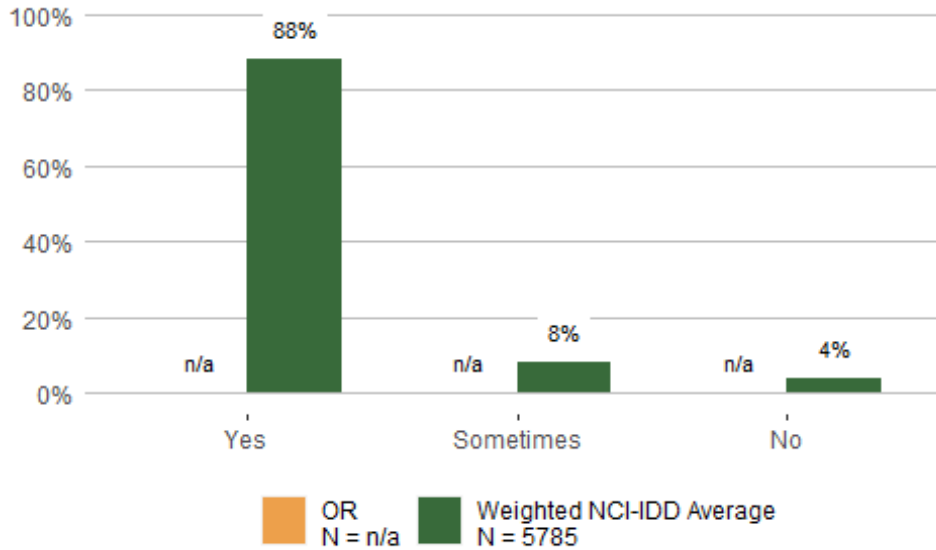


Table 96. Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community?

State	Yes	Sometimes	No	N
OR	n/a	n/a	n/a	n/a
Weighted NCI-IDD Average	88%	8%	4%	5785

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

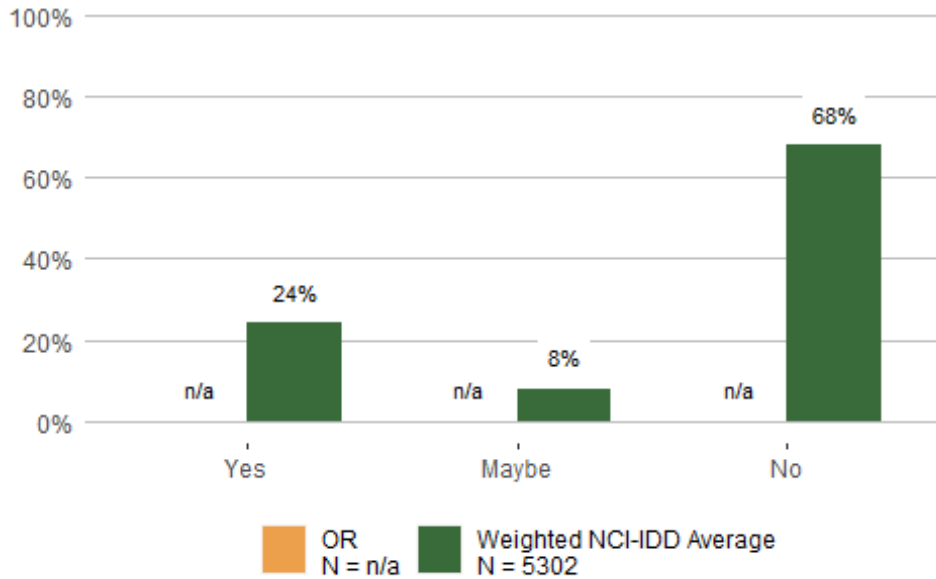


Table 97. In preparation for the future, have you made or updated an emergency plan with your child's case manager or with other staff?

State	Yes	Maybe	No	N
OR	n/a	n/a	n/a	n/a
Weighted NCI-IDD Average	24%	8%	68%	5302