

2016-17 CHILD FAMILY SURVEY

OREGON REPORT



Contents

- What is NCI? 1
- What is the NCI Child Family Survey? 1
 - Table A1. NCI Family Survey – Sub-Domains and Concern Statements 2
- How were people selected to participate? 3
- Data Analysis..... 3
- Weighting 4
- Significance testing..... 4
- Limitations of the data 5
- What is contained in this report?..... 5
- Child..... 6
 - Table 1. More than one person living at home has IDD 7
 - Table 2. Child’s age 7
 - Table 3. Child’s gender 7
 - Table 4. Child’s race and ethnicity..... 7
 - Table 5a. Child’s disabilities * 8
 - Table 5b. Child’s disabilities (continued) * 8
 - Table 6a. Child’s health conditions * 8

Table 6b. Child’s health conditions (continued) *	8
Table 7. Child’s preferred means of communication	9
Table 8. Child’s support needs.....	9
Respondents.....	10
Table 9. Respondent’s age	11
Table 10. Respondent’s health.....	11
Table 11. Respondent’s relationship to child.....	11
Table 12. Respondent (or other family member) provides paid support	11
Table 13. Number of individuals in household	12
Table 14. Respondent’s highest level of education.....	12
Table 15. Past year total household taxable income of wage earners	12
Table 16. Family’s residential setting	12
Services and Supports Received.....	13
Table 17. Services and supports received from state *	14
Table 18. Services and supports received (not from IDD agency) *	14
Information and Planning.....	15
Charts for Information and Planning.....	16
Chart 1. Do you get enough information to take part in planning services for your child?	17
Chart 2. Is the information you get about services and supports easy to understand?	17
Chart 3. Does the case manager/service coordinator respect your family’s choices and opinions?	17

Chart 4. Do you have enough information about other public services for which your family is eligible?	17
Chart 5. Respondent needs help with future planning needs	18
Chart 6. If you asked for crisis or emergency services during the past year, were services provided when needed?	18
Chart 7. Does your child have a service plan?.....	18
Chart 8. Does the plan include all the services and supports your child needs?	18
Chart 9. Does your child get all the services listed in the plan?.....	19
Chart 10. Did you or another family member help make the plan?	19
Chart 11. Did your child help make the plan?.....	19
Chart 12. Did you discuss how to handle emergencies at your child’s last service planning meeting?.....	19
Chart 13. Does your child have a transition plan?	20
Chart 14. If your child has a transition plan, did you help make the transition plan?	20
Chart 15. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster?..	20
Tables for Information and Planning.....	21
Table 19. Information and Planning—Always Responses.....	22
Table 20. Respondent Needs Help With Future Planning Needs	23
Table 21. Information and Planning—Yes Responses	24
Access and Delivery of Services and Supports.....	25
Charts for Access and Delivery of Services and Supports.....	26
Chart 16. Are you able to contact your child’s support workers when you want to?	27
Chart 17. Are you able to contact your child’s case manager/service coordinator when you want to?	27

Chart 18. Do support workers come and leave when they are supposed to?	27
Chart 19. Do services and supports change when your family's needs change?	27
Chart 20. Do support workers speak to you in a way that you understand?	28
Chart 21. Are services delivered in a way that is respectful of your family's culture?	28
Chart 22. If your child does not communicate verbally, are there support workers who can communicate with him/her?	28
Chart 23. Do support workers have the right information and skills to meet your family's needs?	28
Chart 24. Does your child have the special equipment or accommodations that s/he needs?	29
Chart 25. Can your child see health professionals when needed?	29
Chart 26. Does your child's primary care doctor understand his/her needs related to his/her disability?	29
Chart 27. Do you have access to dental services for your child?	29
Chart 28. If you have access to dental services for your child, does your child's dentist understand his/her needs related to his/her disability?	30
Chart 29. If your child takes medications, do you know what they're for?	30
Chart 30. If your child takes medications, do you, your child, or someone else in your family know what is needed to take medication safely?	30
Chart 31. If your child uses mental health services, does the mental health professional understand your child's needs related to his/her disability?	30
Chart 32. If you need respite services, do you have access to them?	31
Chart 33. If you have access to respite services, are you satisfied with the quality of the respite providers?	31
Chart 34. Does your family get the supports and services needed?	31
Chart 35. *Additional services needed	31

Tables for Access and Delivery of Services and Supports	32
Table 22. Access and Delivery of Services and Supports—Always Responses	33
Table 23. Access and Delivery of Services and Supports—Always Responses (continued)	34
Table 24. Access and Delivery of Services and Supports—Yes Responses	35
Table 25. Additional Services Needed *	35
Choice, Decision Making and Control	36
Charts for Choice, Decision Making and Control	37
Chart 36. Can your family choose or change the agency that provides your child’s services?	38
Chart 37. Can your family choose or change your child’s support workers?	38
Chart 38. Does your family directly manage support workers?	38
Chart 39. Do service providers for your child work together to provide support?	38
Chart 40. Chose case manager/service coordinator	39
Tables for Choice, Decision Making and Control	40
Table 26. Choice and Control—Always Responses	41
Table 27. Choice and Control—Yes Responses	41
Table 28. Child or someone else in your family chose case manager/service coordinator	41
Involvement in the Community	42
Charts for Involvement in the Community	43
Chart 41. Does your child take part in activities in the community?	44
Chart 42. *Obstacles/Barriers to child’s participation in community activities	44

Chart 43. Does your child spend time with children who do not have developmental disabilities?	44
Chart 44. In your community, are there resources that your family can use that are not provided by the I/DD agency?	44
Chart 45. Does your family take part in any family-to-family networks in your community?.....	45
Tables for Involvement in the Community.....	46
Table 29. Involvement in the Community.....	47
Table 30. Obstacles to Child’s Participation in Community Activities *	47
Table 31. Involvement in the Community—Yes Response	48
Satisfaction With Services and Supports.....	49
Charts for Satisfaction With Services and Supports	50
Chart 46. Overall, are you satisfied with the services and supports your family currently receives?	51
Chart 47. *Do you know how to file a complaint or grievance about provider agencies or staff?	51
Chart 48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?	51
Chart 49. *Do you know how to report abuse or neglect?.....	51
Chart 50. Within the past year, was a report of abuse or neglect filed on behalf of your child?	52
Chart 51. Do you feel that family supports have made a positive difference in the life of your family?.....	52
Chart 52. Have services and supports reduced your family’s out-of-pocket expenses for your child’s care?	52
Chart 53. Do you feel that family supports have improved your ability to care for your child?.....	52
Chart 54. Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?	53

Chart 55. If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family or your child negatively? 53

Chart 56. Have the services or supports that your child received been increased in the past year?..... 53

Chart 57. Are services and supports helping your child to live a good life? 53

Tables for Satisfaction With Services and Supports 54

Table 32. Satisfaction—Always Responses 55

Table 33. Satisfaction—Yes Responses..... 55

Table 34. Satisfaction—Yes Responses (continued)..... 56

What is NCI?

The National Core Indicators (NCI) program 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).

NCI has developed more than 100 standard performance measures (or ‘indicators’) that states use to assess the outcomes of services for individuals and families, including outcomes in the areas of employment, rights, service planning, community inclusion, choice, health, and safety. In 2016-17 a total of 45 states, the District of Columbia and 22 sub-state entities participated in NCI.

What is the NCI Child Family Survey?

The NCI Child Family Survey is used to gather data on family outcomes. It is mailed to families who have a child who lives in the family home and receives services from the state DD agency.¹ The survey collects demographic information on both the child receiving services and the person who fills out the survey (the ‘respondent’) as well as information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

In 2016-17, a total of 16,999 Child Family Surveys were completed across nine states.² The survey contained six groupings of questions (“sub-domains”) that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes (see Table A1 on the following page). Respondents also had the option of writing open-ended comments concerning their family’s participation in the service system.

¹ Some states include families with a child up to age 22 if s/he receives services as a child through the state.

² States that conducted the CFS in 2016-17 were: AZ, LA, MN, MO, NC, OR, SD, WA, and WI.

Table A1. NCI Family Survey – Sub-Domains and Concern Statements

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

How were people selected to participate?

States were asked to administer the survey to a random sample of at least 1,200 families, all of whom have a child with a developmental disability who lives in the family home and receives at least one direct service or support other than service coordination.³

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or both. In previous years, states only had the option to mail paper surveys. A total of six states had at least a portion of surveys completed via direct entry mode.⁴

All states mailed out a paper survey to families selected in their sample. A sample size of 1,200 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. Both the confidence level and margin of error used are widely accepted standards for reviewing results, regardless of population size. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we included in our national reports those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.

Data Analysis

Surveys received from the state were considered valid, based on the following two criteria:

1. The respondent indicated the child with an intellectual or developmental disability receiving services lived in the family home.
2. At least a portion of survey questions were answered aside from demographic information.

³ In some states, up to age 22 if receiving services as a child.

⁴ States that used the direct entry or mail and direct entry options were: LA, MO, NC, SD, WA and WI. For more information on response rates and mode, please see the Methodology section within the national edition of the 2016-17 Child Family Survey Report.

Questions left blank or marked ‘not applicable’ are not included in analysis. For most questions, ‘don’t know’ responses were excluded from analysis. Two questions in the Satisfaction section combine ‘no’ and ‘don’t know’ responses, those questions are denoted with an asterisk in the table. For all items shown, states receive an ‘n/a’ designation in table presentations for a survey item if fewer than 20 people responded; however, their data are included in the NCI Average.

Weighting

In previous years, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). This year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states’ systems. Beginning this year, the NCI averages contained in this report are “weighted” means. Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average—that is, the state’s contribution to the NCI average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.⁵

Significance testing

Starting this survey cycle (2016-17), statistical significance is shown in this report. The state’s percentage was compared to the weighted NCI average (described above), and the differences between the two were tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state’s result depends, in part, on the size of the state’s sample: the larger the sample, the more likely it is that even a small difference will be found *statistically* significant.

⁵ For more information on weighting and significance testing, see the Methodology section of the National Child Family Survey.

The t-test analyses established whether the state's percentage was:

1. Higher than the NCI average, and the difference was statistically significant (denoted in the report with an up arrow ▲);
2. Within the average range (i.e., not statistically different from the NCI Average); or
3. Lower than the NCI average, and the difference was statistically significant (denoted in the report with a down arrow ▼).

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the NCI average; statistical significance was determined at the $p \leq .01$ level.⁶ Demographics data and data on services received were not tested for statistically significant differences.

Limitations of the data

The NCI Child Family Survey is a tool for assessing system-wide performance. It is not intended to be used to monitor individuals or providers. The NCI Statewide Average should not be interpreted as defining or providing a benchmark for "acceptable" levels of performance or satisfaction. Instead, it describes average levels of performance or satisfaction across the State; it is up to public managers, policy-makers, and other stakeholders to use the data to determine programmatic and policy-related priorities.

What is contained in this report?

This report illustrates the 2016-17 NCI Child Family Survey demographic and outcome results from Oregon (OR) compared to the NCI Average. All results are shown first in charts and then in table form, and arrow symbols (▲ and ▼) are used to indicate areas where the state average was statistically higher or lower than the NCI Average. **Please note: items without the ▲ or ▼ arrow symbols indicate that the state was within the NCI Average range.** For most items, the total number of respondents (N) from the state and across NCI states is displayed in charts and tables. States with fewer than 20 responses to a question were excluded from analysis for that question. All state and national data results for this survey can be found online at <http://www.nationalcoreindicators.org/resources/reports/>.

⁶ For more information on weighting and significance testing, see the Methodology section of the National Child Family Survey.

Child

This section provides demographic profiles of the child about whom the survey was completed.

Table 1. More than one person living at home has IDD

		Yes	No	N
More Than One Person Living in the Home Has IDD	OR	21%	79%	416
	NCI	20%	80%	3,284

Table 2. Child's age

		Mean	N
Child's Age	OR	11.14	418
	NCI	10.61	3,295

Table 3. Child's gender

		Male	Female	N
Child's Gender	OR	64%	36%	416
	NCI	67%	33%	3,299

Table 4. Child's race and ethnicity

		American Indian or Alaska Native	Asian	Black or African-American	Hawaiian or Pacific Islander	White	Other or Unknown	Hispanic or Latino
Child's Race and Ethnicity	OR	4%	4%	5%	1%	84%	2%	14%
	NCI	3%	4%	13%	1%	74%	2%	16%

Table 5a. Child's disabilities *

		Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
Child's Disabilities	OR	49%	23%	53%	14%	9%	6%
	NCI	44%	17%	52%	15%	9%	5%

Table 5b. Child's disabilities (continued) *

		Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
Child's Disabilities	OR	8%	24%	1%	11%	0%	8%	31%
	NCI	8%	24%	0%	12%	0%	2%	32%

Table 6a. Child's health conditions *

		Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
Child's Health Conditions	OR	14%	4%	1%	2%	2%
	NCI	11%	4%	2%	6%	5%

Table 6b. Child's health conditions (continued) *

		Dysphagia	Pressure Ulcers	Oral Health or Dental Problems	Sleep Apnea	Other
Child's Health Conditions	OR	30%	1%	15%	27%	54%
	NCI	18%	1%	12%	22%	58%

*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

Table 7. Child's preferred means of communication

		Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
Child's Preferred Means of Communication	OR	63%	22%	2%	8%	5%	418
	NCI	62%	24%	2%	5%	7%	3,248

Table 8. Child's support needs

		Extensive	Some	None	N
Child's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	OR	36%	43%	21%	417
	NCI	26%	41%	33%	3,232
Child's Need for Help With Personal Care Activities	OR	61%	36%	3%	421
	NCI	58%	37%	5%	3,301

Respondents

This section provides demographic information about the respondent.

Table 9. Respondent's age

		Under 35	35-54	55-74	75+	N
Respondent's Age	OR	14%	71%	15%	0%	421
	NCI	19%	69%	12%	0%	3,321

Table 10. Respondent's health

		Excellent	Very good	Fairly good	Poor	N
Respondent's Health	OR	16%	48%	32%	4%	422
	NCI	17%	46%	33%	3%	3,324

Table 11. Respondent's relationship to child

		Parent	Sibling	Grandparent	Other	N
Respondent's Relationship to Child	OR	94%	0%	4%	1%	423
	NCI	95%	0%	4%	1%	3,327

Table 12. Respondent (or other family member) provides paid support

		Family Provides Paid Support to Child
No Family Member Provides Paid Support	OR	68%
	NCI	74%
Respondent Provides Paid Support	OR	5%
	NCI	12%
Other Family Member Provides Paid Support	OR	28%
	NCI	16%
N	OR	418
	NCI	3,301

Table 13. Number of individuals in household

		One	Two	Three	Four or More	N
Number of Adults in Household (Not Including Child Receiving Services)	OR	19%	64%	11%	5%	418
	NCI	18%	63%	14%	5%	3,295
Number of Children in Household	OR	36%	44%	11%	9%	408
	NCI	35%	36%	17%	11%	3,198

Table 14. Respondent's highest level of education

		No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
Respondent's Highest Level of Education	OR	6%	17%	5%	22%	50%	421
	NCI	6%	14%	8%	22%	50%	3,306

Table 15. Past year total household taxable income of wage earners

		Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	No Earned Income	Prefer Not to Say	N
Total Taxable Income of Wage Earners in the Household in Past Year	OR	11%	12%	19%	16%	24%	7%	11%	413
	NCI	9%	11%	19%	16%	27%	7%	11%	3,285

Table 16. Family's residential setting

		Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
Residential Setting	OR	79%	21%	408
	NCI	75%	25%	3,239

Services and Supports Received

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

Table 17. Services and supports received from state *

		Services and Supports Received From State
Financial Support	OR	20%
	NCI	26%
In-home Support	OR	82%
	NCI	56%
Out-of-home Respite	OR	47%
	NCI	34%
Early Intervention	OR	10%
	NCI	20%
Transportation	OR	22%
	NCI	20%
Other	OR	58%
	NCI	71%
Self-direction or Fiscal Intermediary Services	OR	42%
	NCI	28%

Table 18. Services and supports received (not from IDD agency) *

		Additional Services and Supports Received (Not From the IDD Agency)
Social Security Payments (SSI/SSB)	OR	40%
	NCI	36%
Services or Supports From Other Agencies or Organizations	OR	66%
	NCI	66%

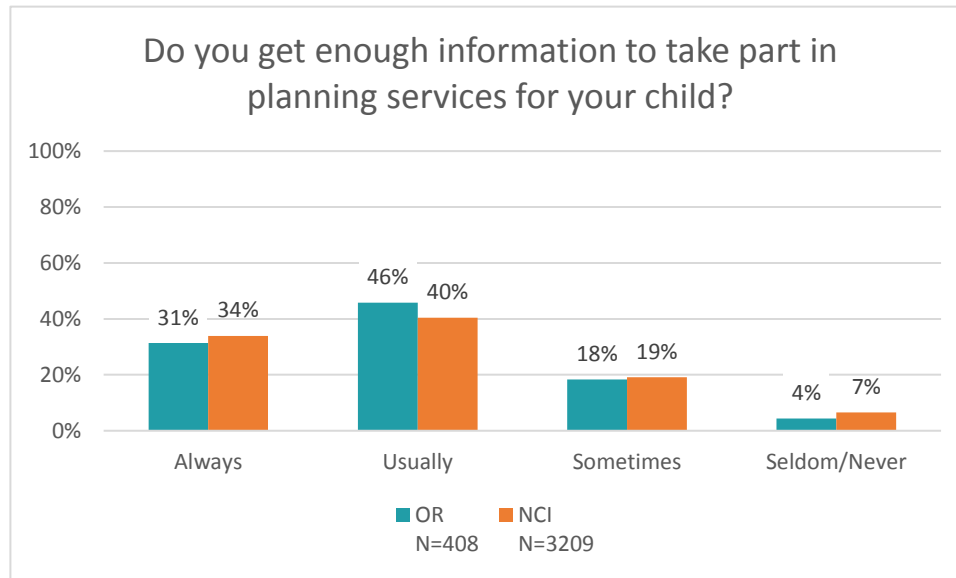
*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

Information and Planning

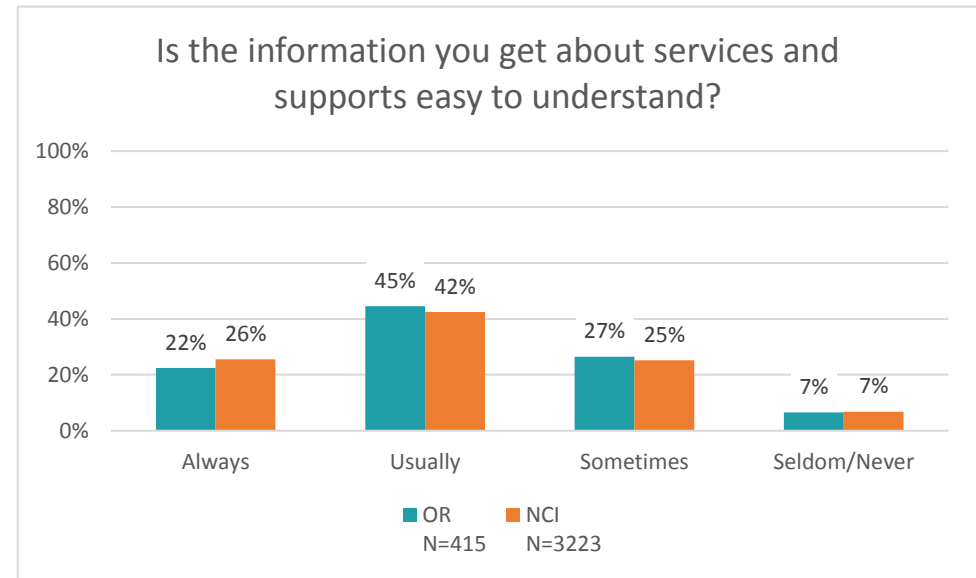
Families and children with disabilities have the information and support necessary to plan for their services and supports.

Charts for Information and Planning

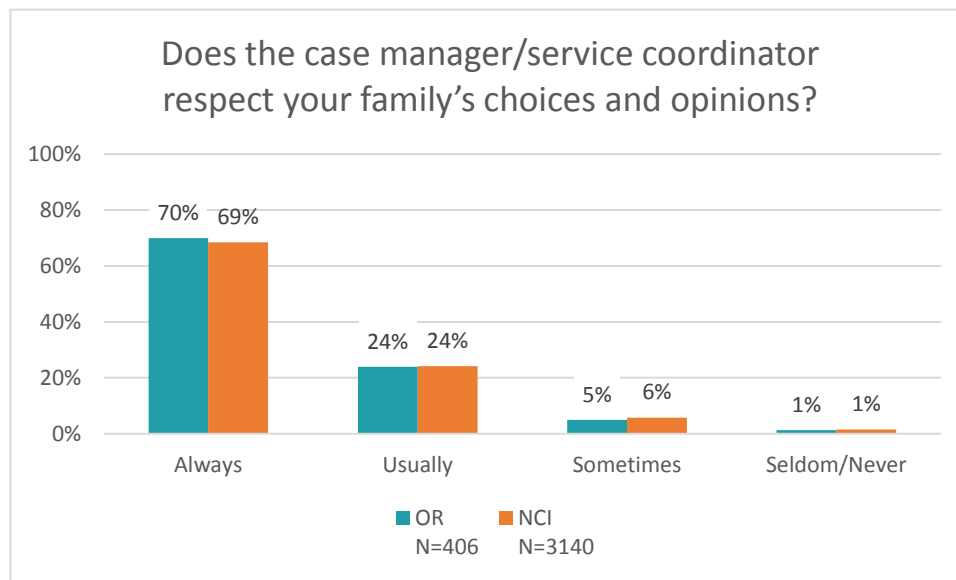
[Chart 1.](#)



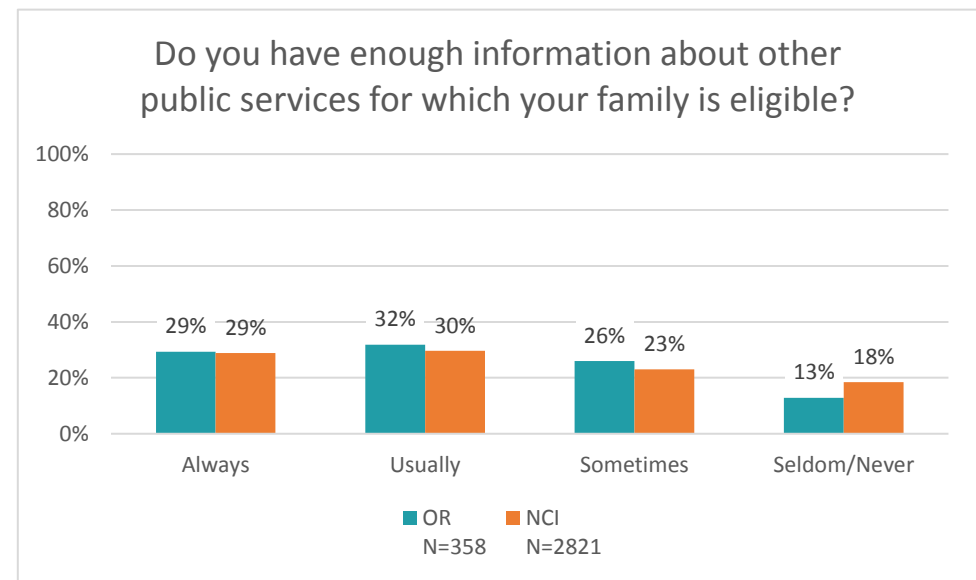
[Chart 2.](#)



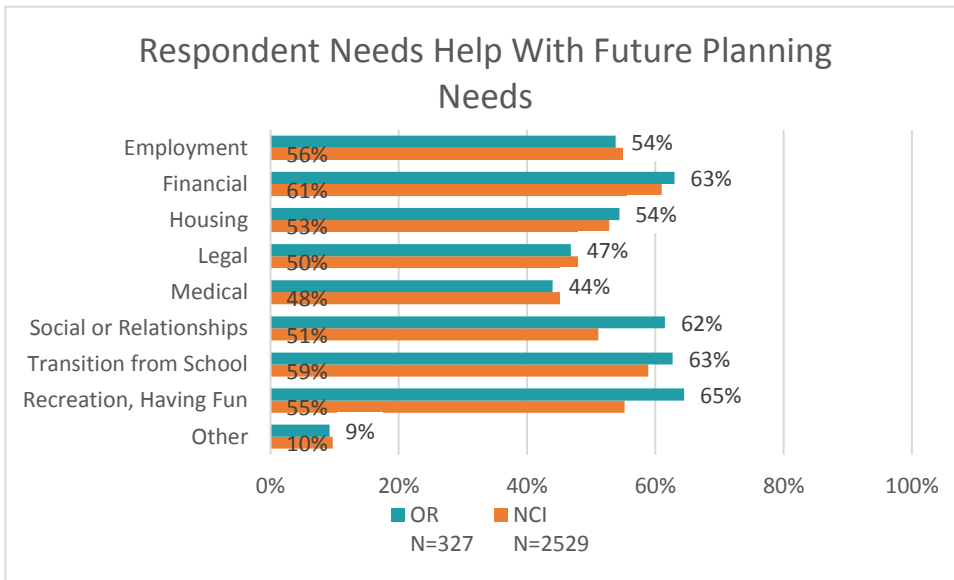
[Chart 3.](#)



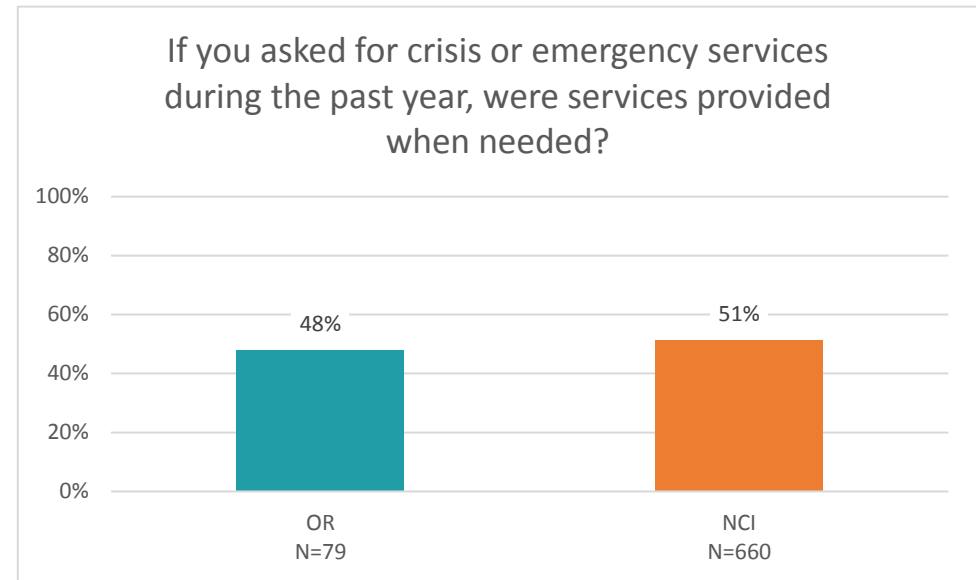
[Chart 4.](#)



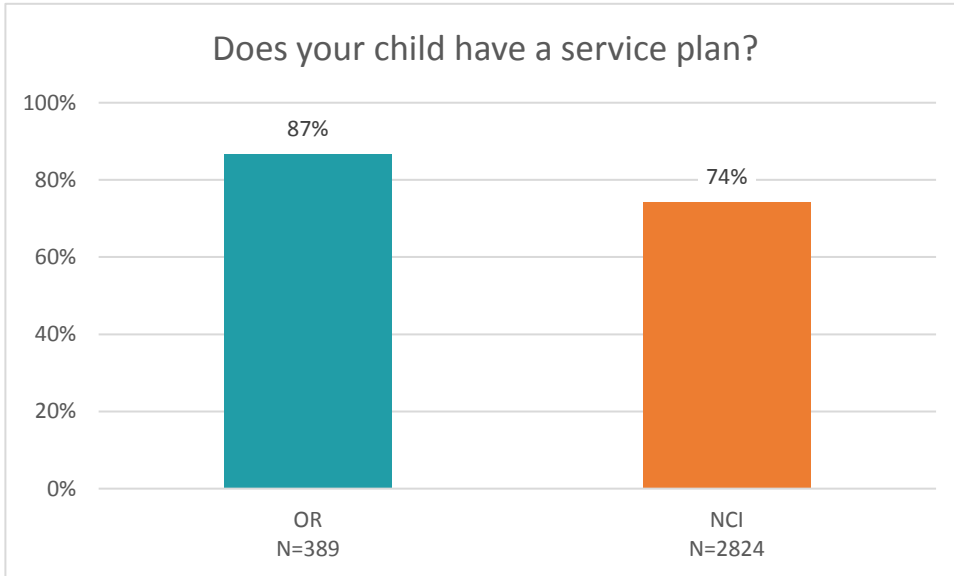
[Chart 5.](#)



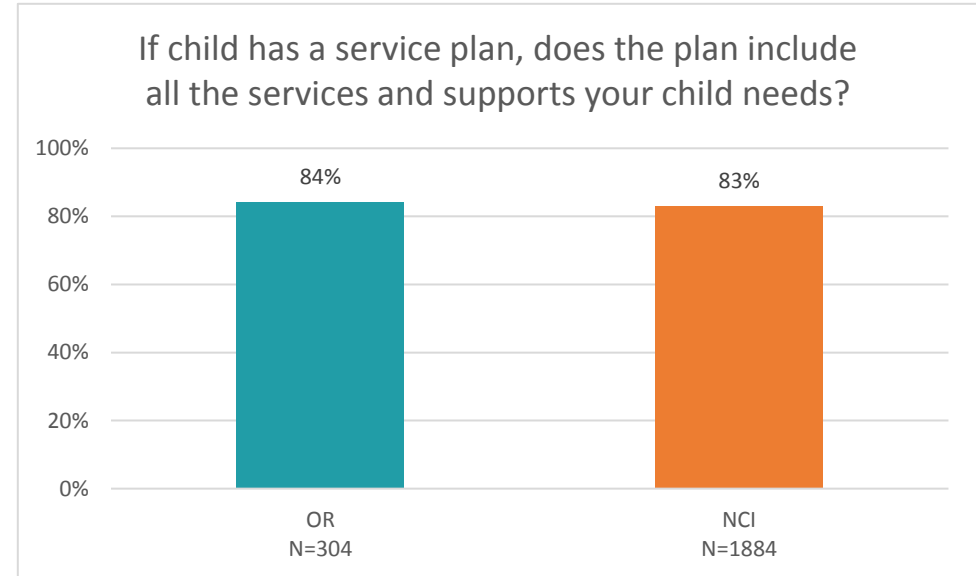
[Chart 6.](#)



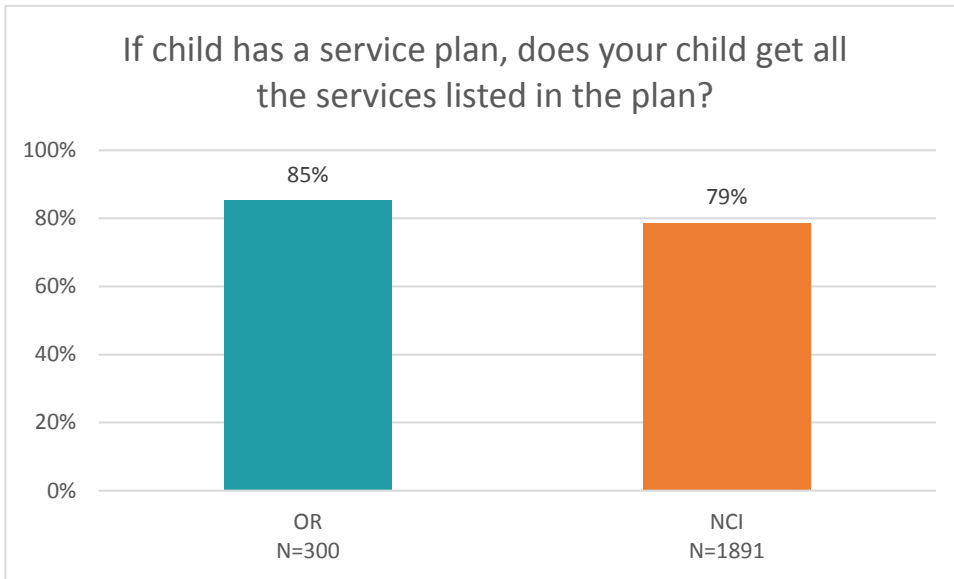
[Chart 7.](#)



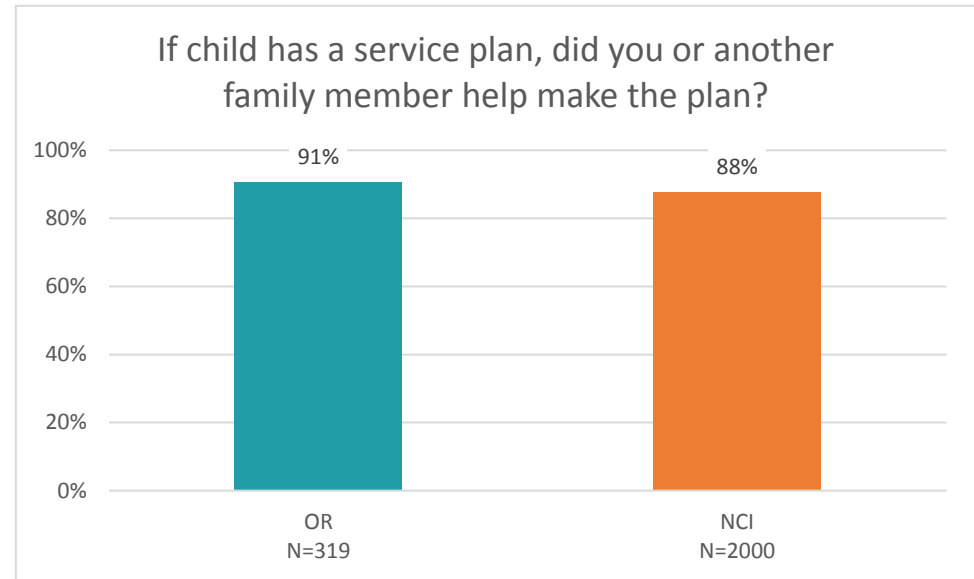
[Chart 8.](#)



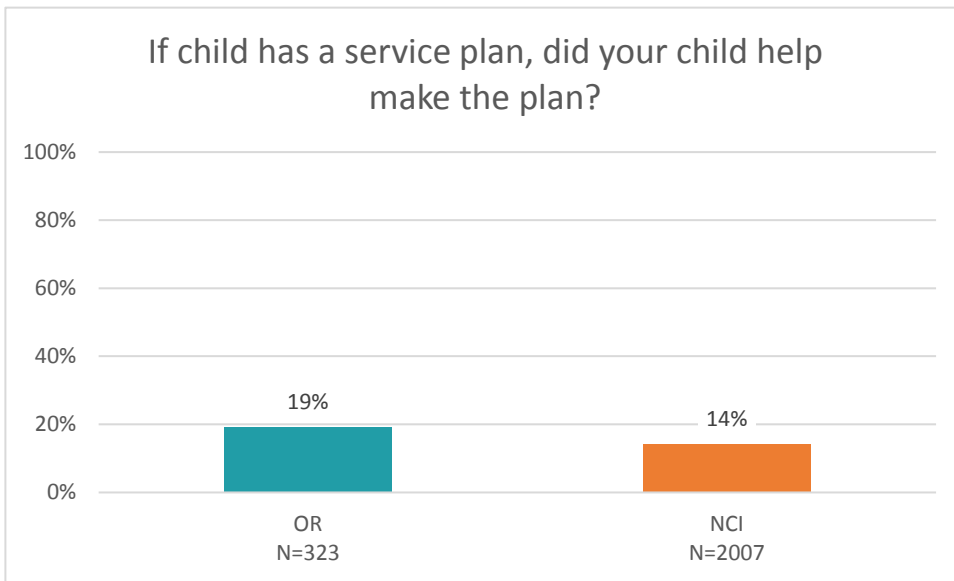
[Chart 9.](#)



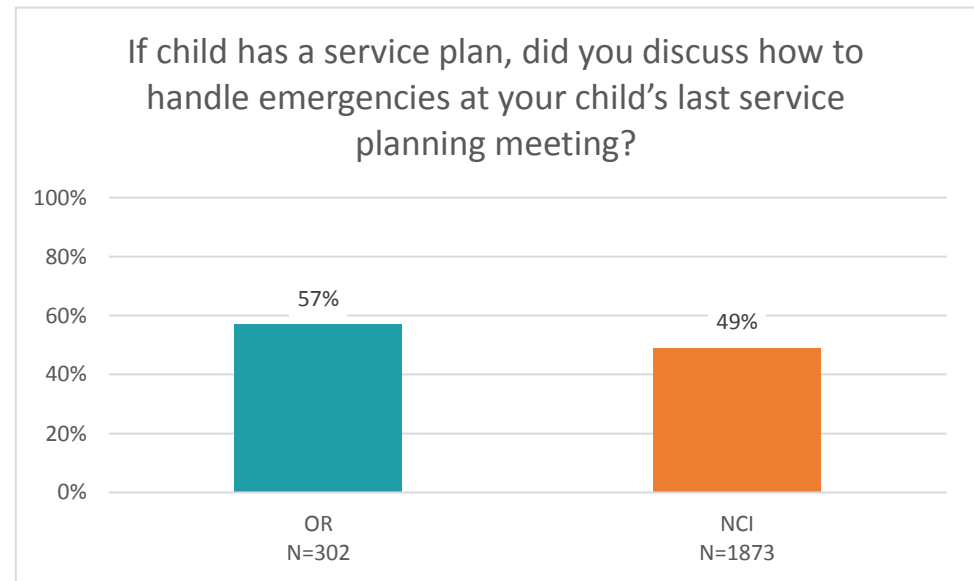
[Chart 10.](#)



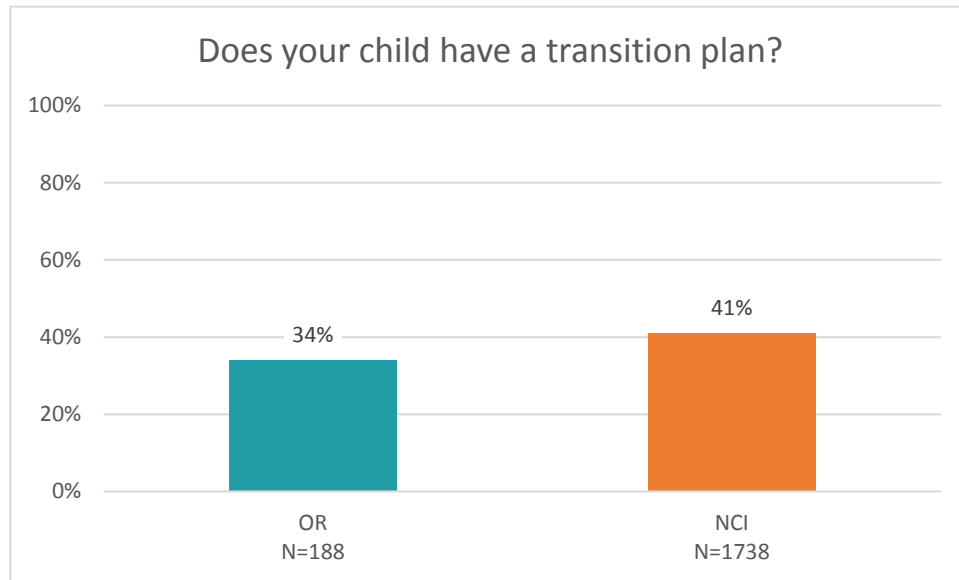
[Chart 11.](#)



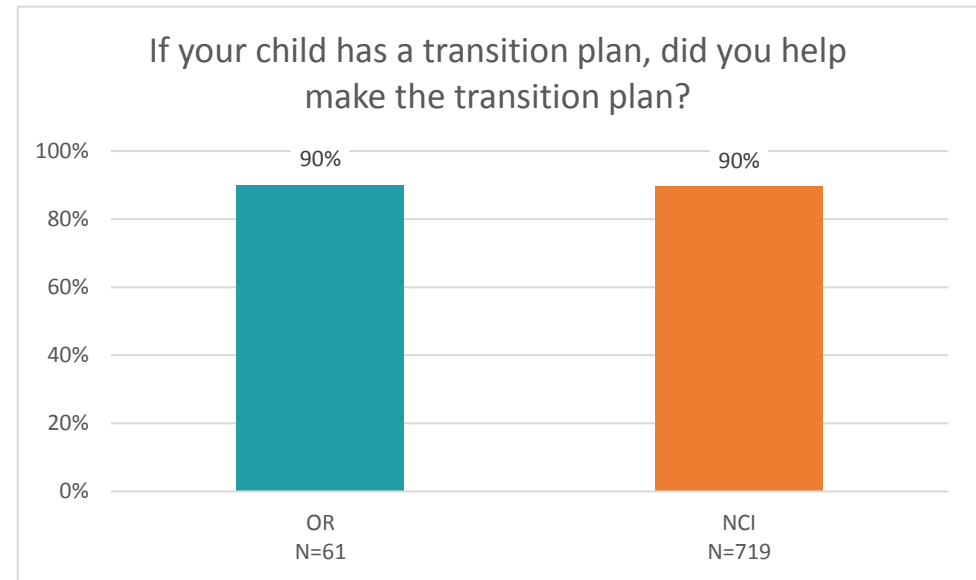
[Chart 12.](#)



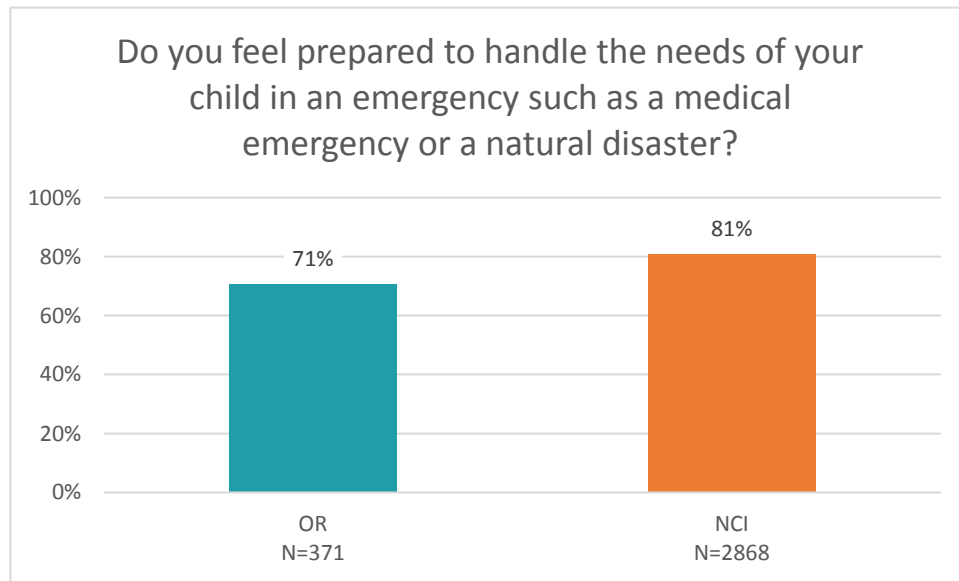
[Chart 13.](#)



[Chart 14.](#)



[Chart 15.](#)



Tables for Information and Planning

Table 19. Information and Planning—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Do you get enough information to take part in planning services for your child?	OR	31%	46%	18%	4%	408
	NCI	34%	40%	19%	7%	3,209
Is the information you get about services and supports easy to understand?	OR	22%	45%	27%	7%	415
	NCI	26%	42%	25%	7%	3,223
Does the case manager/service coordinator respect your family's choices and opinions?	OR	70%	24%	5%	1%	406
	NCI	69%	24%	6%	1%	3,140
Do you have enough information about other public services for which your family is eligible?	OR	29%	32%	26%	13%	358
	NCI	29%	30%	23%	18%	2,821

Table 20. Respondent Needs Help With Future Planning Needs

		Yes
Employment	OR	54%
	NCI	56%
Financial	OR	63%
	NCI	61%
Housing	OR	54%
	NCI	53%
Legal	OR	47%
	NCI	50%
Medical	OR	44%
	NCI	48%
Social or Relationships	OR	62%
	NCI	51%
Transition from School	OR	63%
	NCI	59%
Recreation, Having Fun	OR	65%
	NCI	55%
Other	OR	9%
	NCI	10%
N	OR	327
	NCI	2,529

Table 21. Information and Planning—Yes Responses

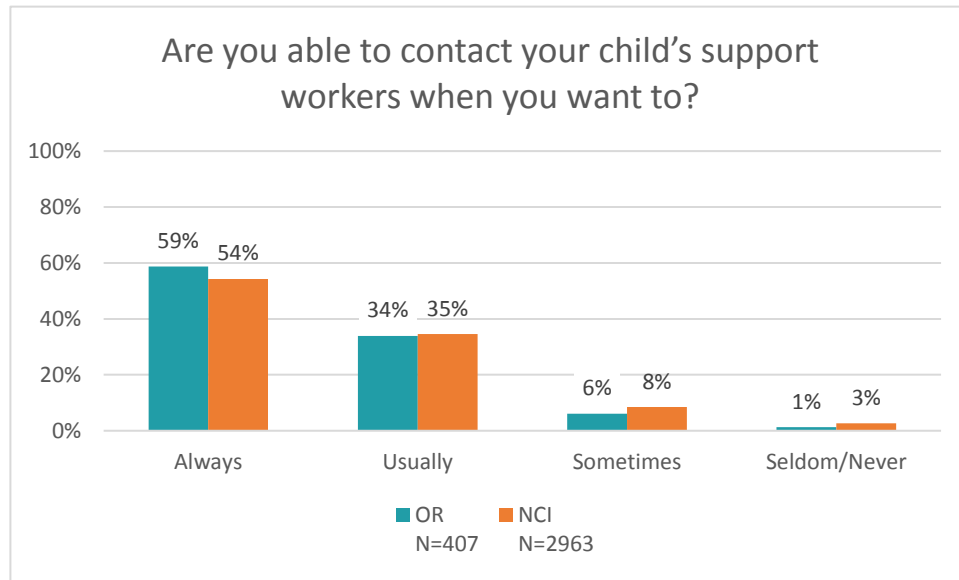
		Yes	No	N
If you asked for crisis or emergency services during the past year, were services provided when needed?	OR	48%	52%	79
	NCI	51%	49%	660
Does your child have a service plan?	OR ▲	87%	13%	389
	NCI	74%	26%	2,824
<i>If your child has a service plan...</i>				
Does the plan include all the services and supports your child needs?	OR	84%	16%	304
	NCI	83%	17%	1,884
Does your child get all the services listed in the plan?	OR ▲	85%	15%	300
	NCI	79%	21%	1,891
Did you or another family member help make the plan?	OR	91%	9%	319
	NCI	88%	12%	2,000
Did your child help make the plan?	OR	19%	81%	323
	NCI	14%	86%	2,007
Did you discuss how to handle emergencies at your child's last service planning meeting?	OR ▲	57%	43%	302
	NCI	49%	51%	1,873
Does your child have a transition plan?	OR	34%	66%	188
	NCI	41%	59%	1,738
If your child has a transition plan, did you help make the transition plan?	OR	90%	10%	61
	NCI	90%	10%	719
Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or a natural disaster?	OR ▼	71%	29%	371
	NCI	81%	19%	2,868

Access and Delivery of Services and Supports

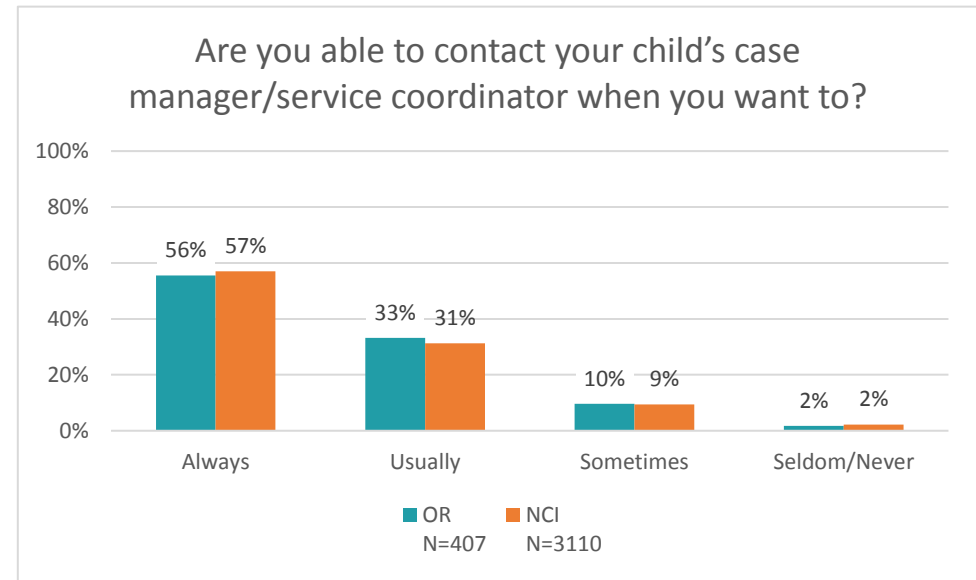
Families and children with disabilities get the services and supports they need.

Charts for Access and Delivery of Services and Supports

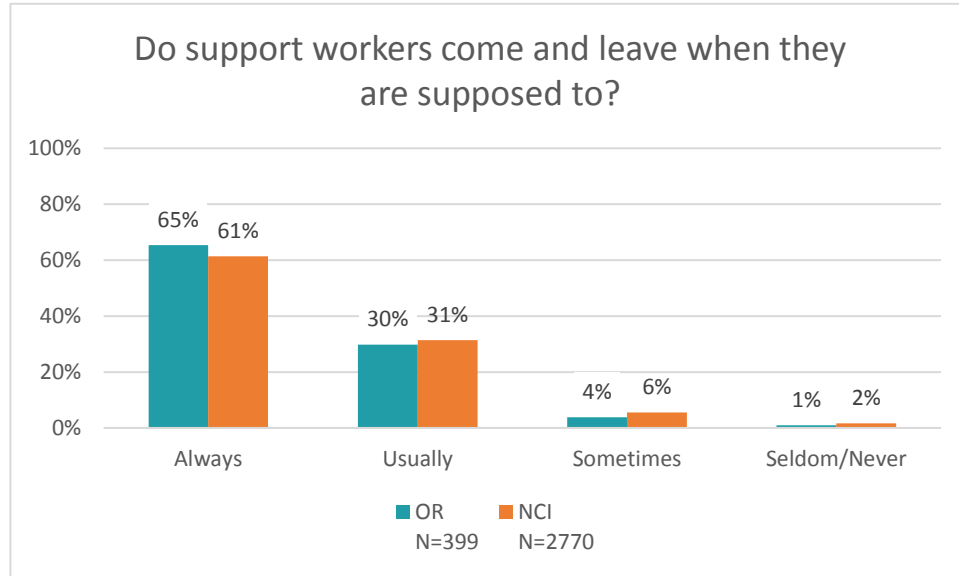
[Chart 16.](#)



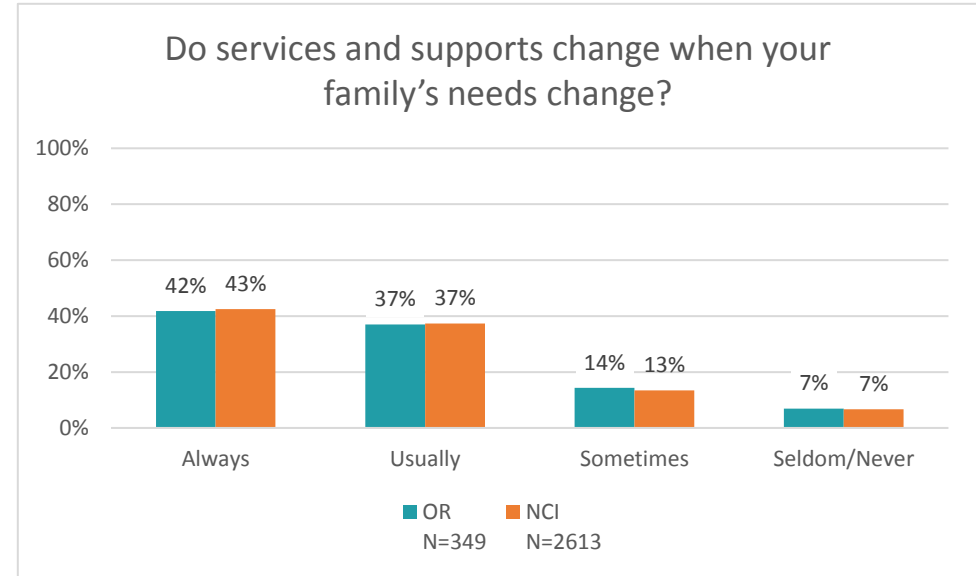
[Chart 17.](#)



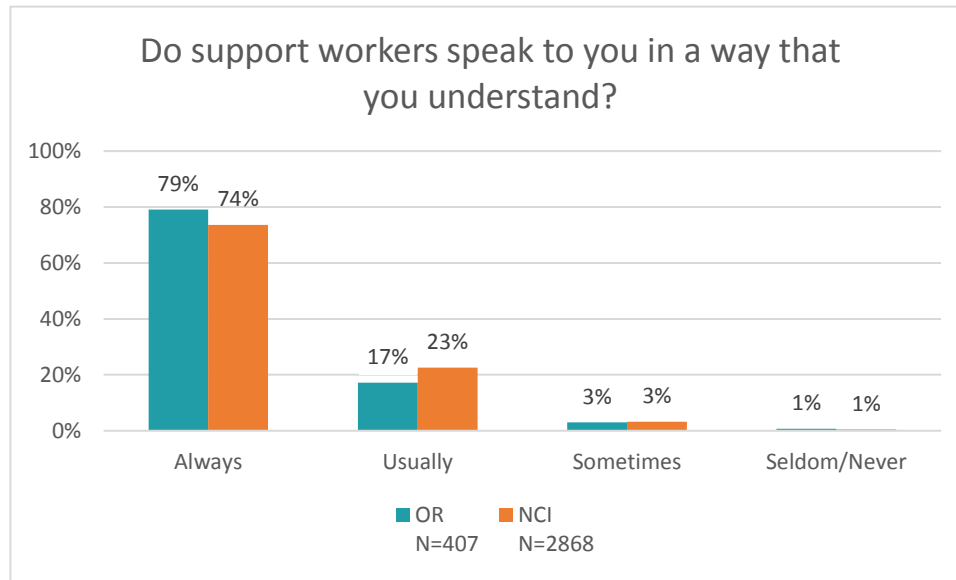
[Chart 18.](#)



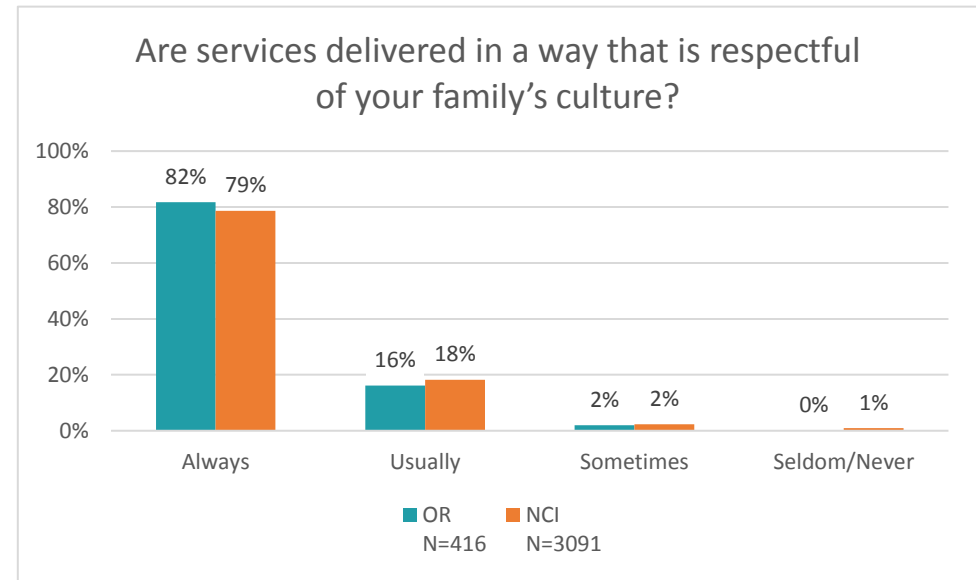
[Chart 19.](#)



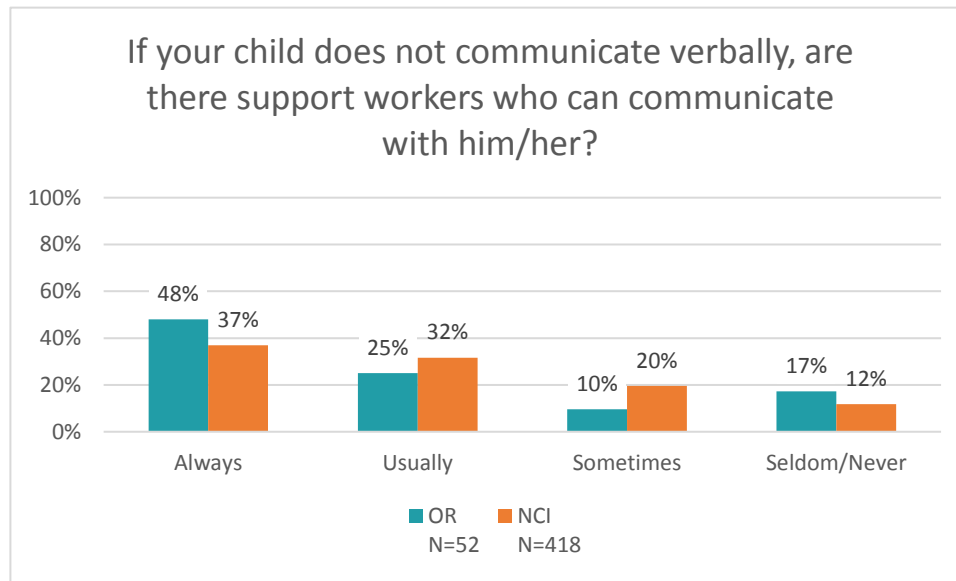
[Chart 20.](#)



[Chart 21.](#)



[Chart 22.](#)



[Chart 23.](#)

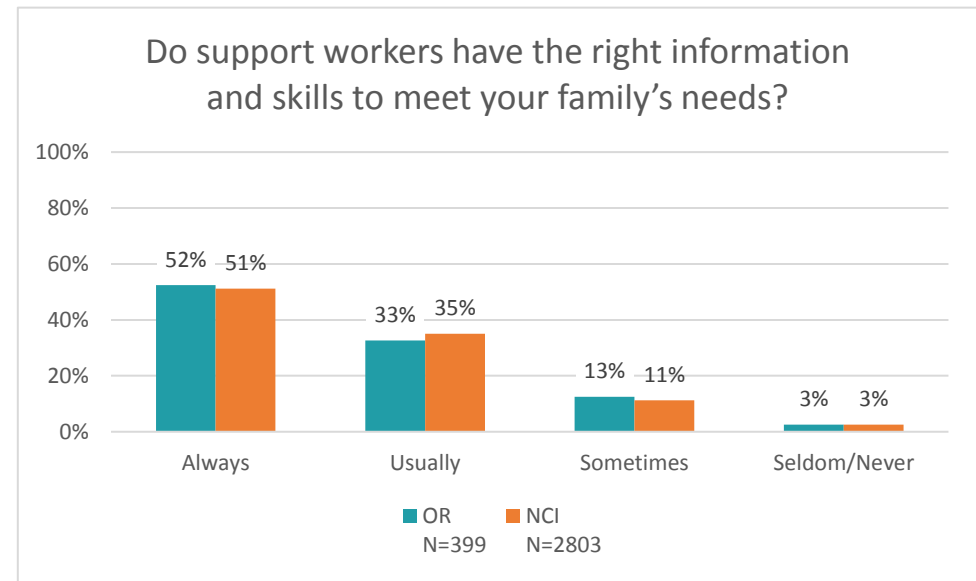


Chart 24.

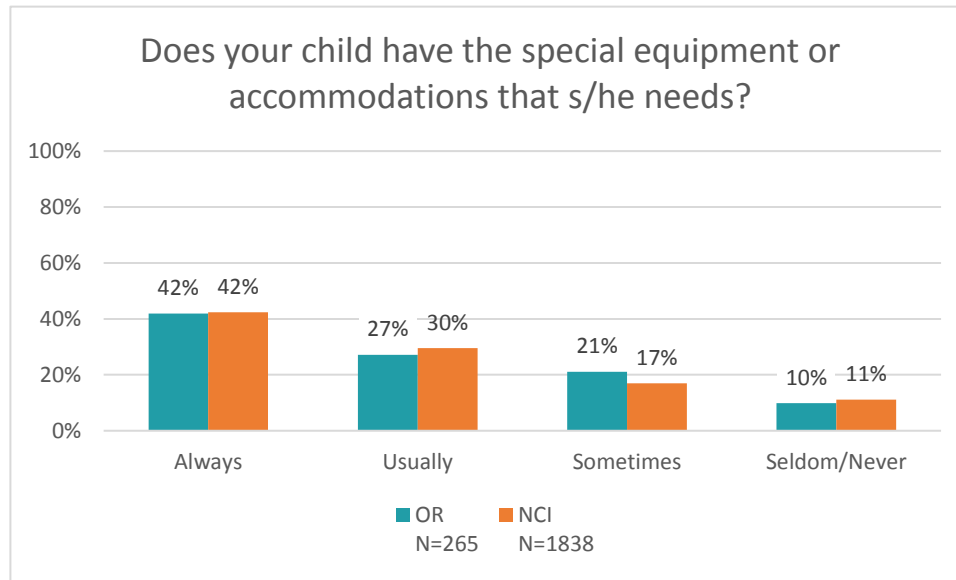


Chart 25.

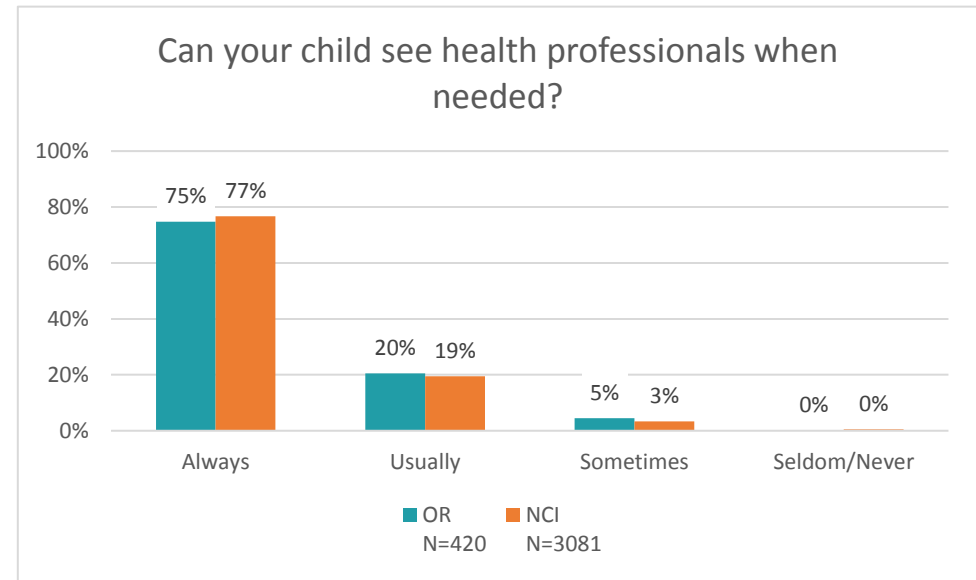


Chart 26.

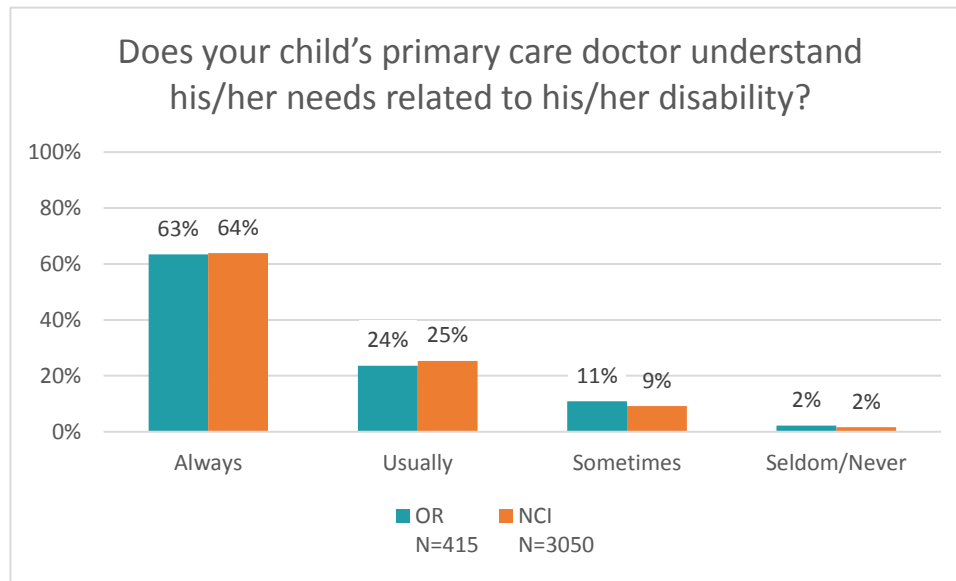
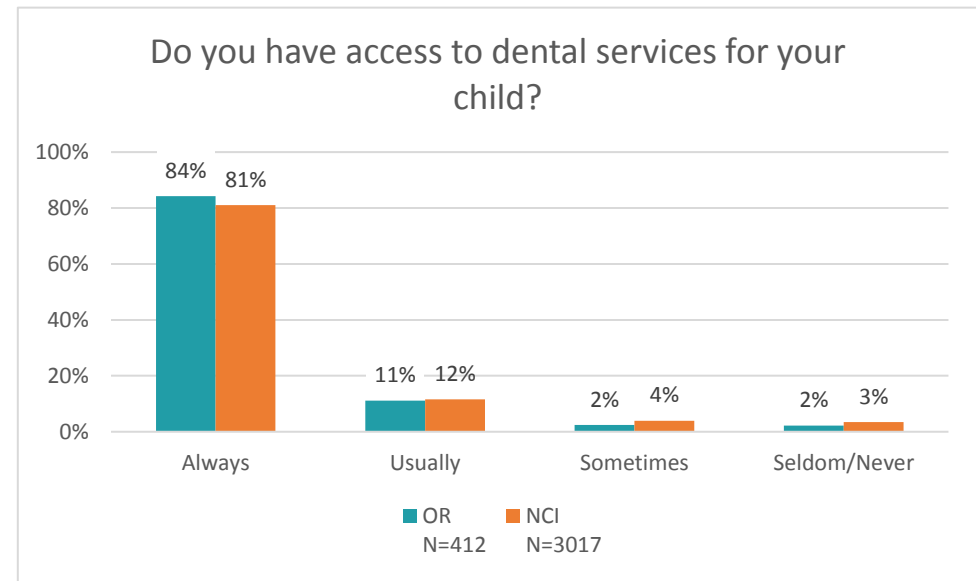
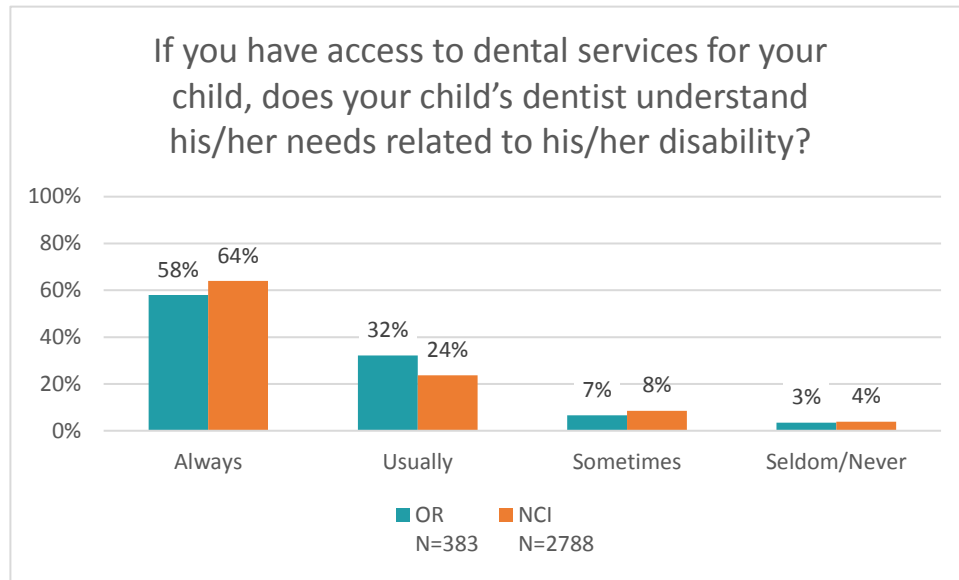


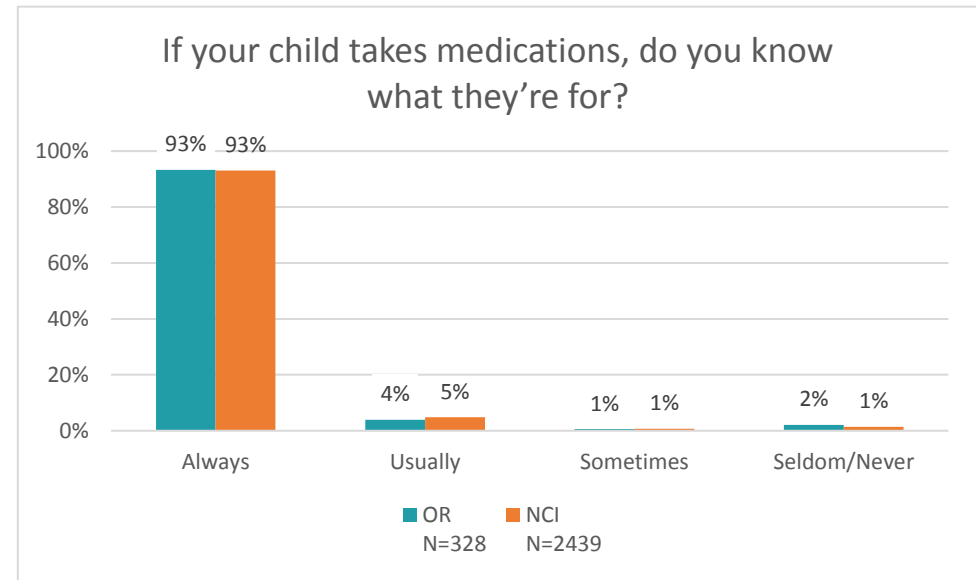
Chart 27.



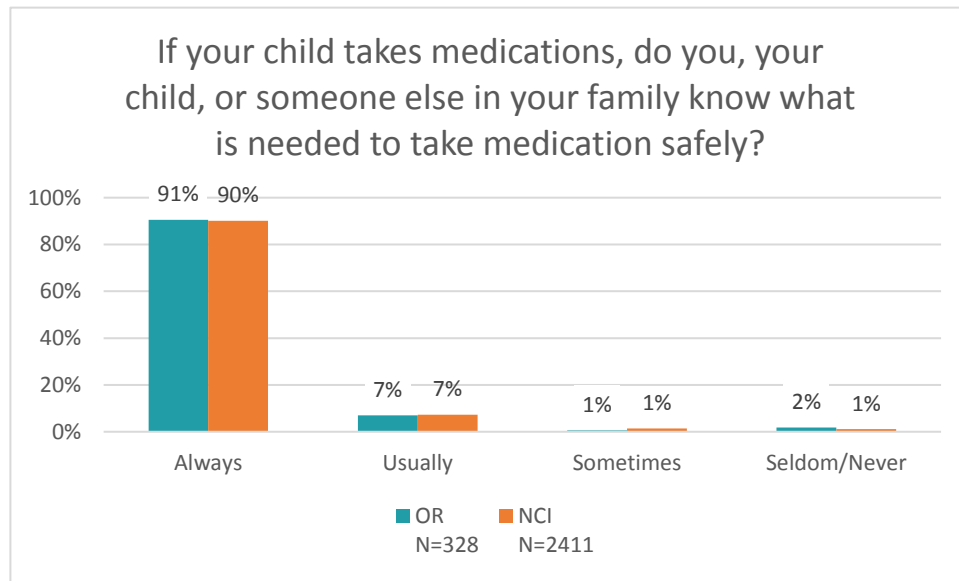
[Chart 28.](#)



[Chart 29.](#)



[Chart 30.](#)



[Chart 31.](#)

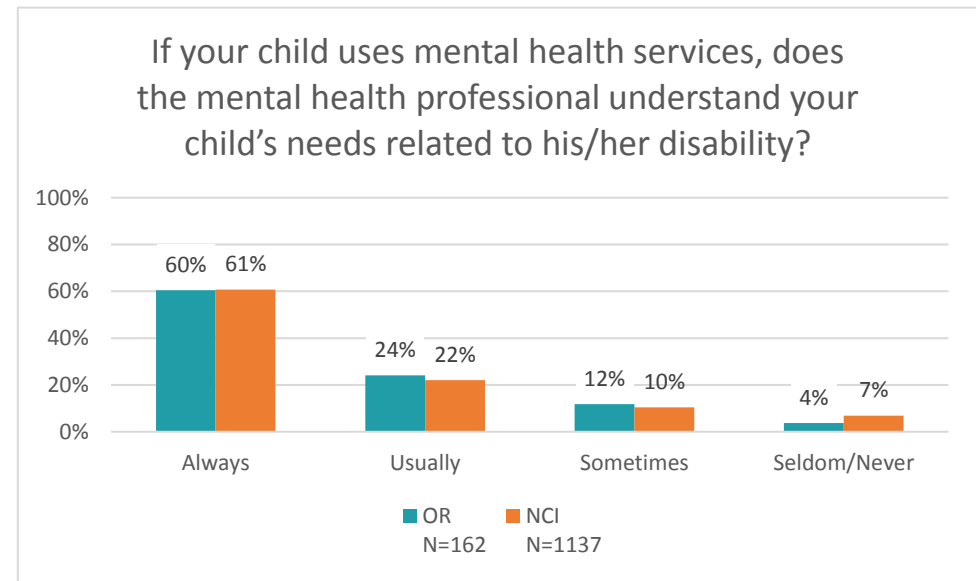


Chart 32.

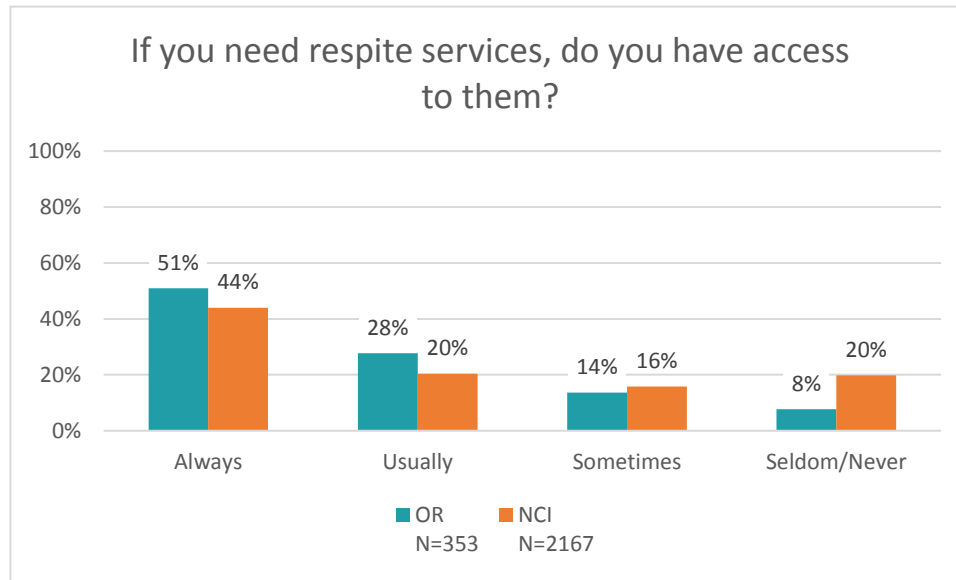


Chart 33.

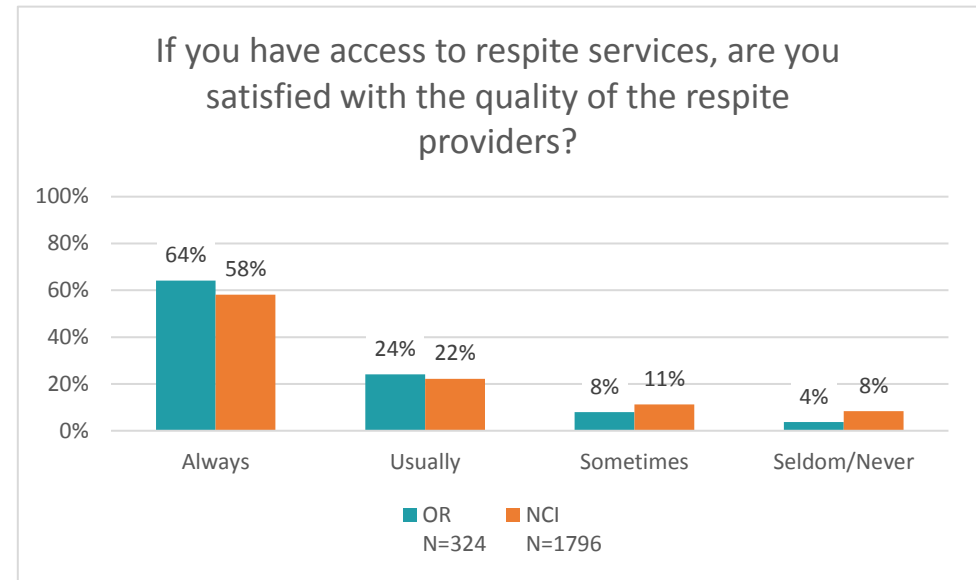


Chart 34.

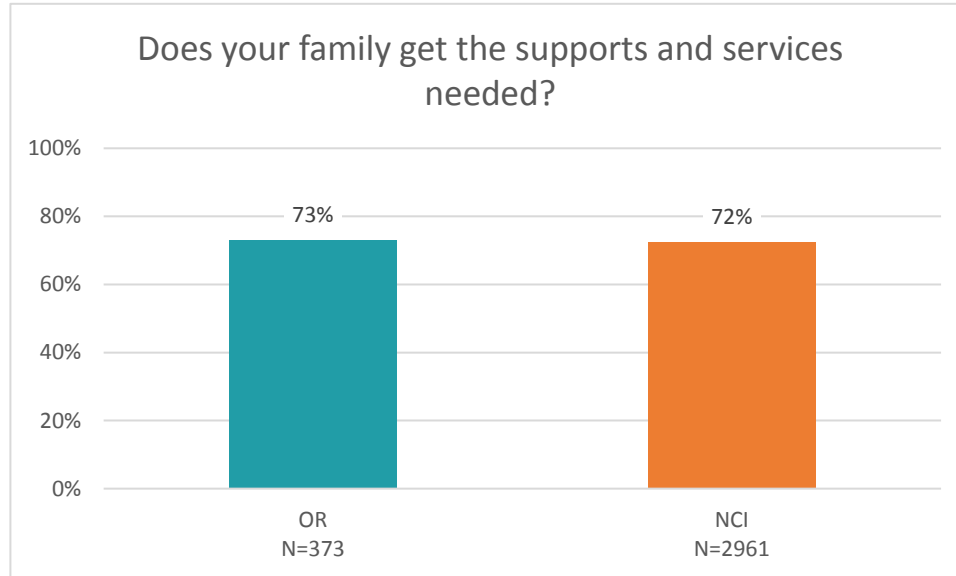
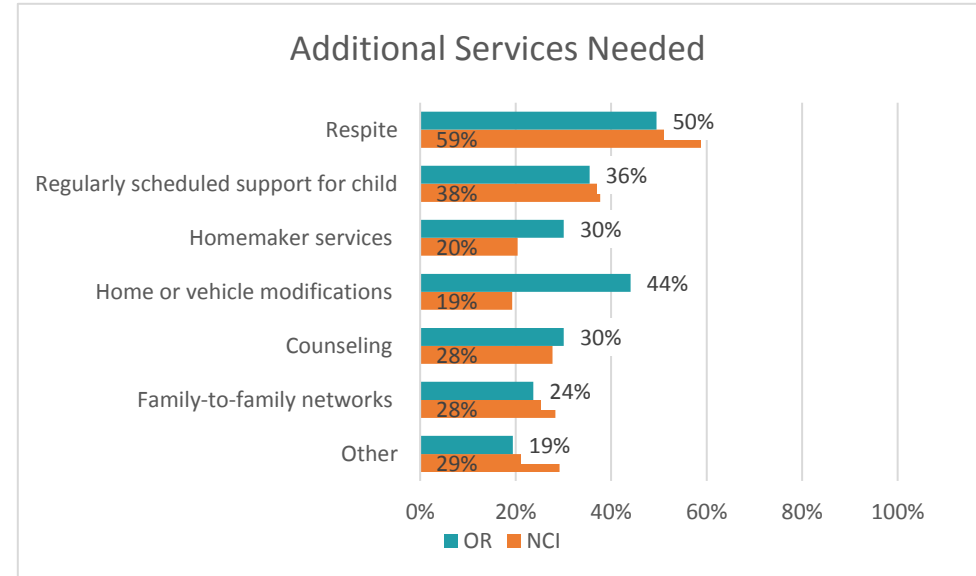


Chart 35. *



*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

Tables for Access and Delivery of Services and Supports

Table 22. Access and Delivery of Services and Supports—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Are you able to contact your child's support workers when you want to?	OR	59%	34%	6%	1%	407
	NCI	54%	35%	8%	3%	2,963
Are you able to contact your child's case manager/service coordinator when you want to?	OR	56%	33%	10%	2%	407
	NCI	57%	31%	9%	2%	3,110
Do support workers come and leave when they are supposed to?	OR	65%	30%	4%	1%	399
	NCI	61%	31%	6%	2%	2,770
Do services and supports change when your family's needs change?	OR	42%	37%	14%	7%	349
	NCI	43%	37%	13%	7%	2,613
Do support workers speak to you in a way that you understand?	OR▲	79%	17%	3%	1%	407
	NCI	74%	23%	3%	1%	2,868
Are services delivered in a way that is respectful of your family's culture?	OR	82%	16%	2%	0%	416
	NCI	79%	18%	2%	1%	3,091
If your child does not communicate verbally, are there support workers who can communicate with him/her?	OR	48%	25%	10%	17%	52
	NCI	37%	32%	20%	12%	418
Do support workers have the right information and skills to meet your family's needs?	OR	52%	33%	13%	3%	399
	NCI	51%	35%	11%	3%	2,803
Does your child have the special equipment or accommodations that s/he needs?	OR	42%	27%	21%	10%	265
	NCI	42%	30%	17%	11%	1,838

Table 23. Access and Delivery of Services and Supports—Always Responses (continued)

		Always	Usually	Sometimes	Seldom/Never	N
Can your child see health professionals when needed?	OR	75%	20%	5%	0%	420
	NCI	77%	19%	3%	0%	3,081
Does your child's primary care doctor understand his/her needs related to his/her disability?	OR	63%	24%	11%	2%	415
	NCI	64%	25%	9%	2%	3,050
Do you have access to dental services for your child?	OR	84%	11%	2%	2%	412
	NCI	81%	12%	4%	3%	3,017
If you have access to dental services for your child, does your child's dentist understand his/her needs related to his/her disability?	OR	58%	32%	7%	3%	383
	NCI	64%	24%	8%	4%	2,788
If your child takes medications, do you know what they're for?	OR	93%	4%	1%	2%	328
	NCI	93%	5%	1%	1%	2,439
If your child takes medications, do you, your child, or someone else in your family know what is needed to take medication safely?	OR	91%	7%	1%	2%	328
	NCI	90%	7%	1%	1%	2,411
If your child uses mental health services, does the mental health professional understand your child's needs related to his/her disability?	OR	60%	24%	12%	4%	162
	NCI	61%	22%	10%	7%	1,137
If you need respite services, do you have access to them?	OR▲	51%	28%	14%	8%	353
	NCI	44%	20%	16%	20%	2,167
If you have access to respite services, are you satisfied with the quality of the respite providers?	OR	64%	24%	8%	4%	324
	NCI	58%	22%	11%	8%	1,796

Table 24. Access and Delivery of Services and Supports—Yes Responses

		Yes	No	N
Does your family get the supports and services needed?	OR	73%	27%	373
	NCI	72%	28%	2,961

Table 25. Additional Services Needed *

		Needs Service
Respite	OR	50%
	NCI	59%
Regularly scheduled support for child	OR	36%
	NCI	38%
Homemaker services	OR	30%
	NCI	20%
Home or vehicle modifications	OR	44%
	NCI	19%
Counseling	OR	30%
	NCI	28%
Family-to-family networks	OR	24%
	NCI	28%
Other	OR	19%
	NCI	29%

*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

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.

Charts for Choice, Decision Making and Control

Chart 36.

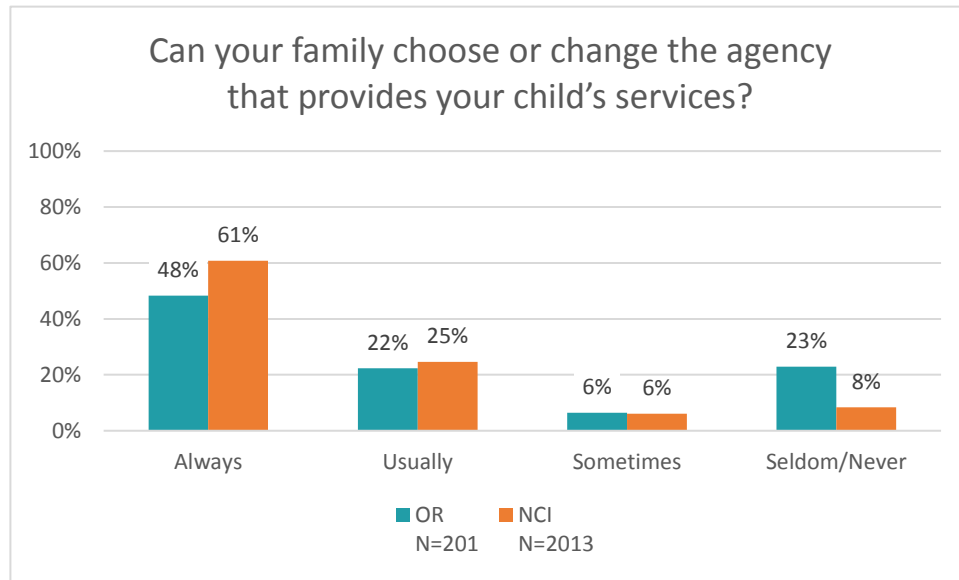


Chart 37.

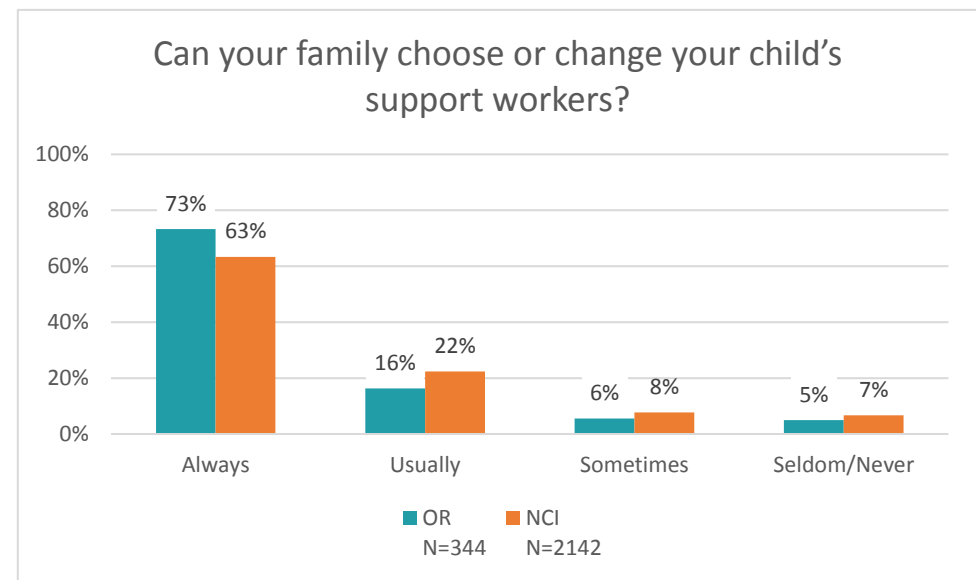


Chart 38.

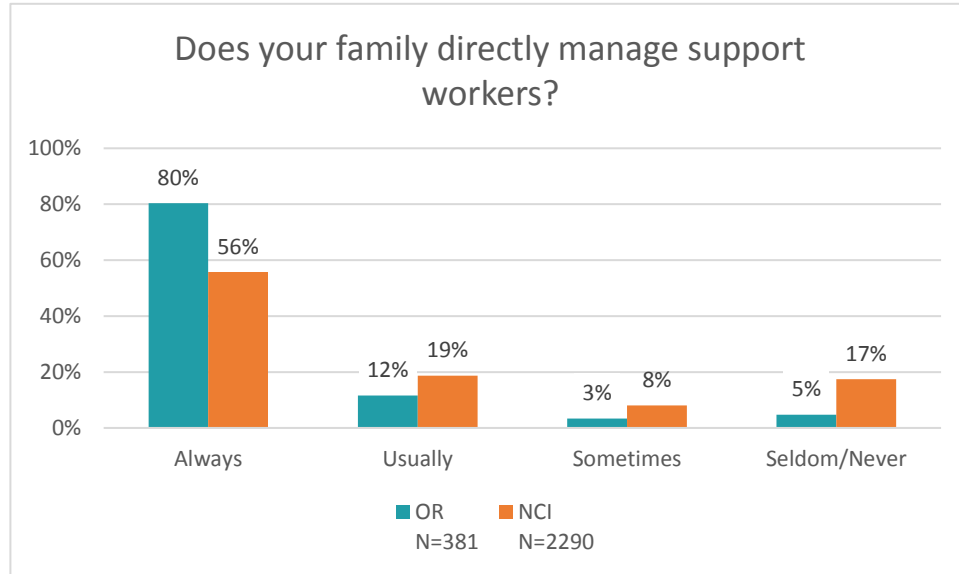


Chart 39.

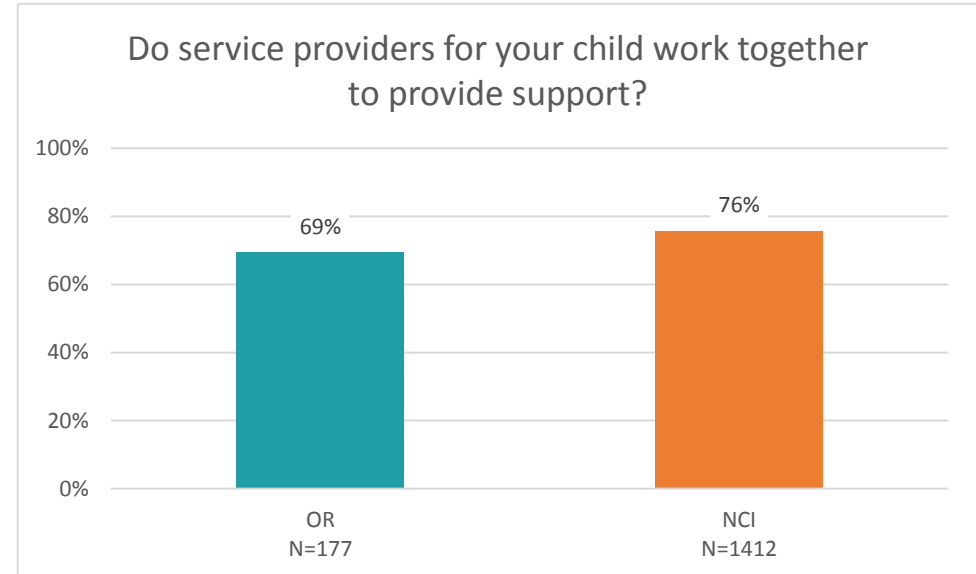
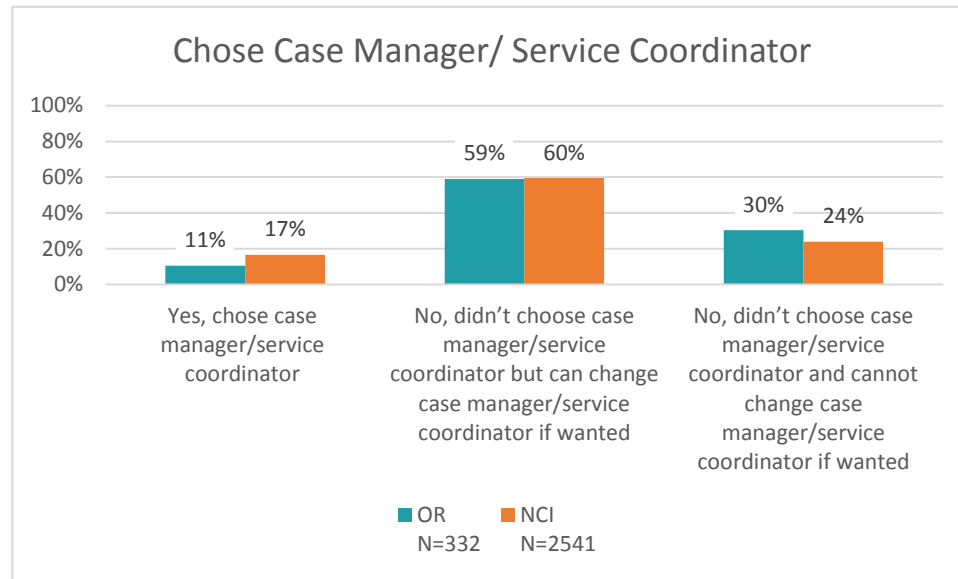


Chart 40.



Tables for Choice, Decision Making and Control

Table 26. Choice and Control—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Can your family choose or change the agency that provides your child's services?	OR ▼	48%	22%	6%	23%	201
	NCI	61%	25%	6%	8%	2,013
Can your family choose or change your child's support workers?	OR ▲	73%	16%	6%	5%	344
	NCI	63%	22%	8%	7%	2,142
Does your family directly manage support workers?	OR ▲	80%	12%	3%	5%	381
	NCI	56%	19%	8%	17%	2,290

Table 27. Choice and Control—Yes Responses

		Yes	No	N
Do service providers for your child work together to provide support?	OR	69%	31%	177
	NCI	76%	24%	1,412

Table 28. Child or someone else in your family chose case manager/service coordinator

		Chose Case Manager/ Service Coordinator
Yes, chose case manager/service coordinator	OR ▼	11%
	NCI	17%
No, didn't choose case manager/service coordinator but can change case manager/service coordinator if wanted	OR ▼	59%
	NCI	60%
No, didn't choose case manager/service coordinator and cannot change case manager/service coordinator if wanted	OR ▼	30%
	NCI	24%
N	OR ▼	332
	NCI	2,541

Involvement in the Community

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

Charts for Involvement in the Community

Chart 41.

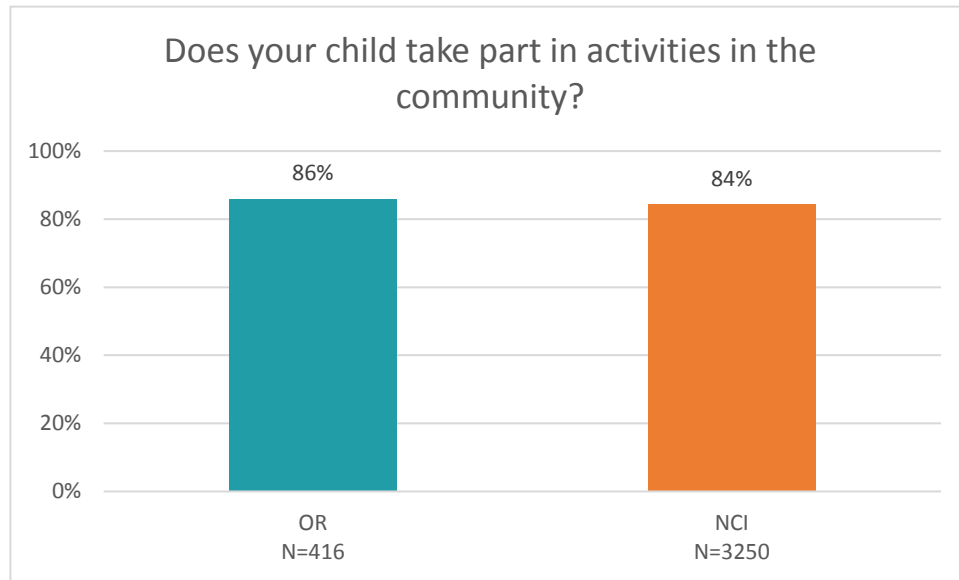


Chart 42. *

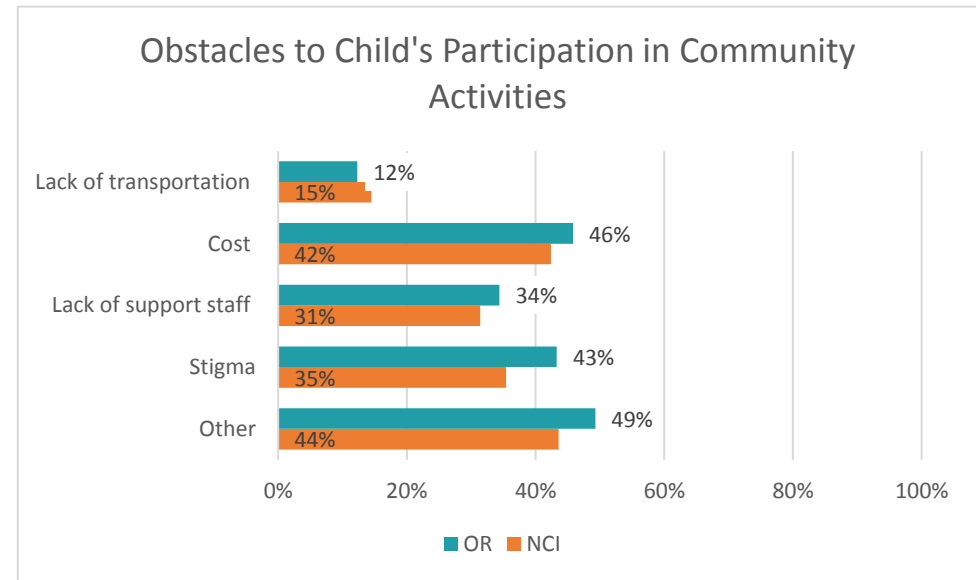


Chart 43.

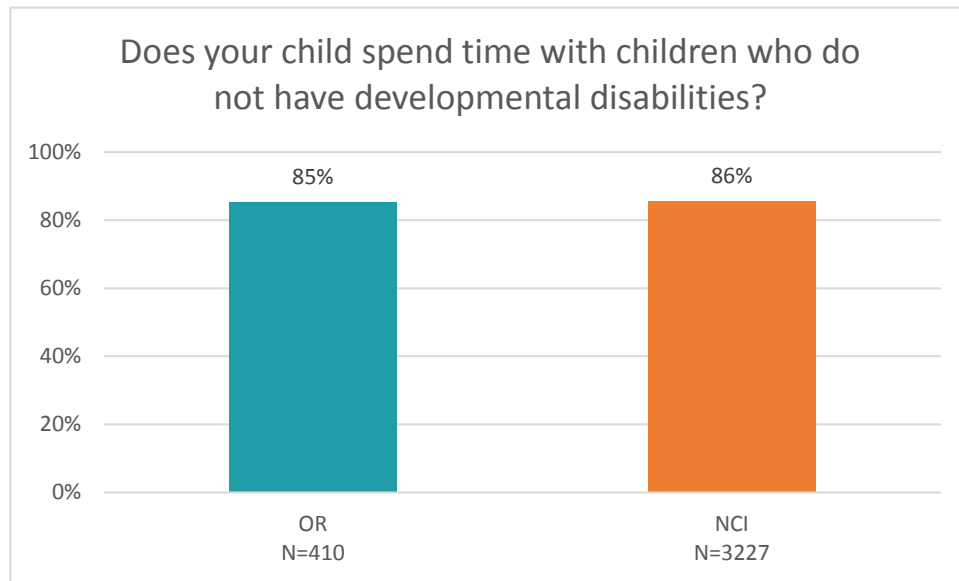
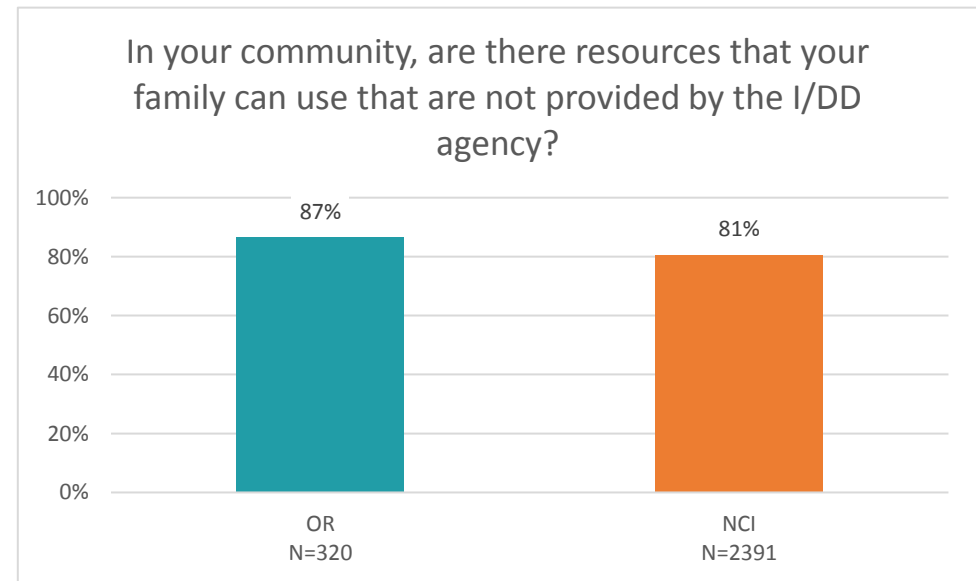
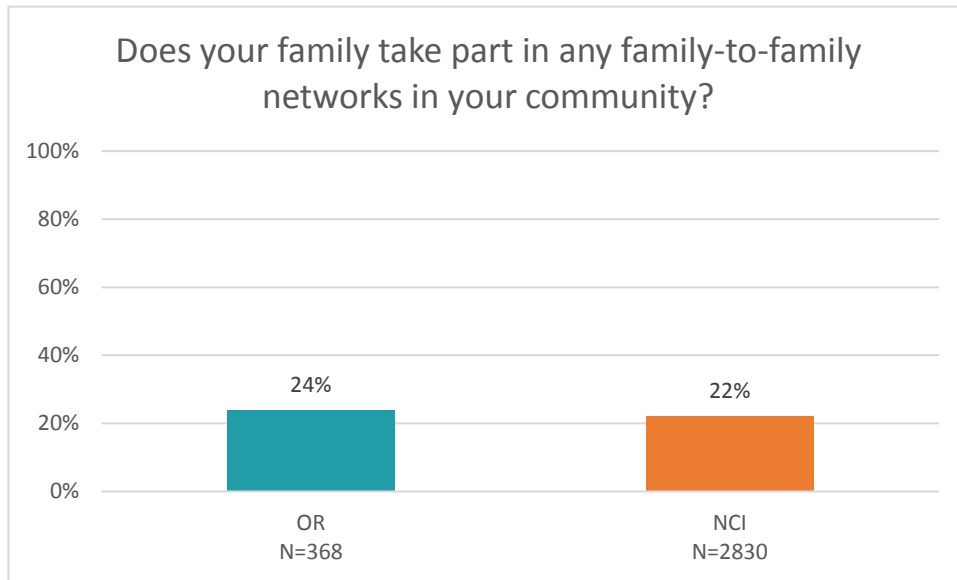


Chart 44.



*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

[Chart 45.](#)



Tables for Involvement in the Community

Table 29. Involvement in the Community

		Yes	No	N
Does your child take part in activities in the community?	OR	86%	14%	416
	NCI	84%	16%	3,250

Table 30. Obstacles to Child's Participation in Community Activities *

		Obstacles/Barriers
Lack of transportation	OR	12%
	NCI	15%
Cost	OR	46%
	NCI	42%
Lack of support staff	OR	34%
	NCI	31%
Stigma	OR	43%
	NCI	35%
Other	OR	49%
	NCI	44%

*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

Table 31. Involvement in the Community—Yes Response

		Yes	No	N
Does your child spend time with children who do not have developmental disabilities?	OR	85%	15%	410
	NCI	86%	14%	3,227
In your community, are there resources that your family can use that are not provided by the I/DD agency?	OR▲	87%	13%	320
	NCI	81%	19%	2,391
Does your family take part in any family-to-family networks in your community?	OR	24%	76%	368
	NCI	22%	78%	2,830

Satisfaction With Services and Supports

Families and children with disabilities receive adequate and satisfactory supports.

Charts for Satisfaction With Services and Supports

Chart 46.

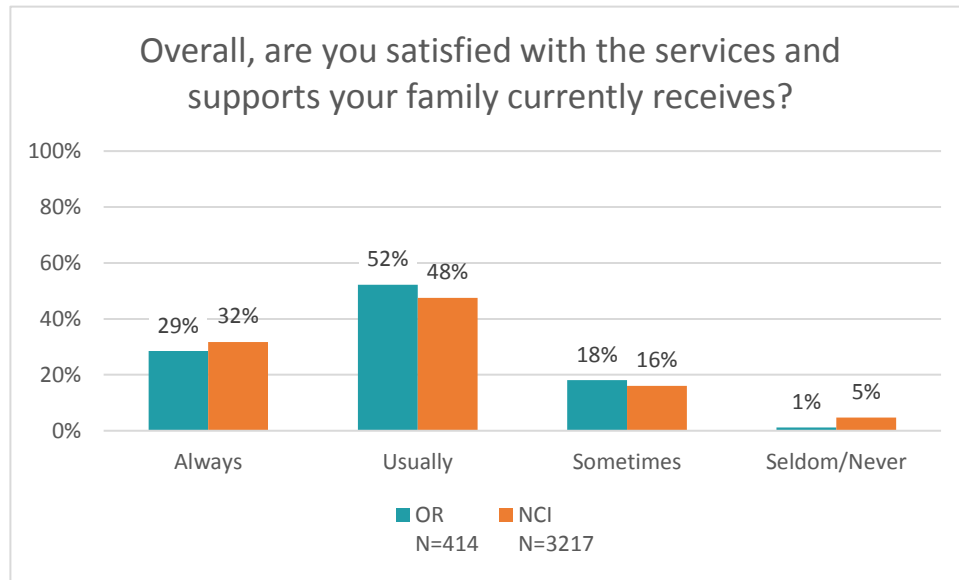


Chart 47. *

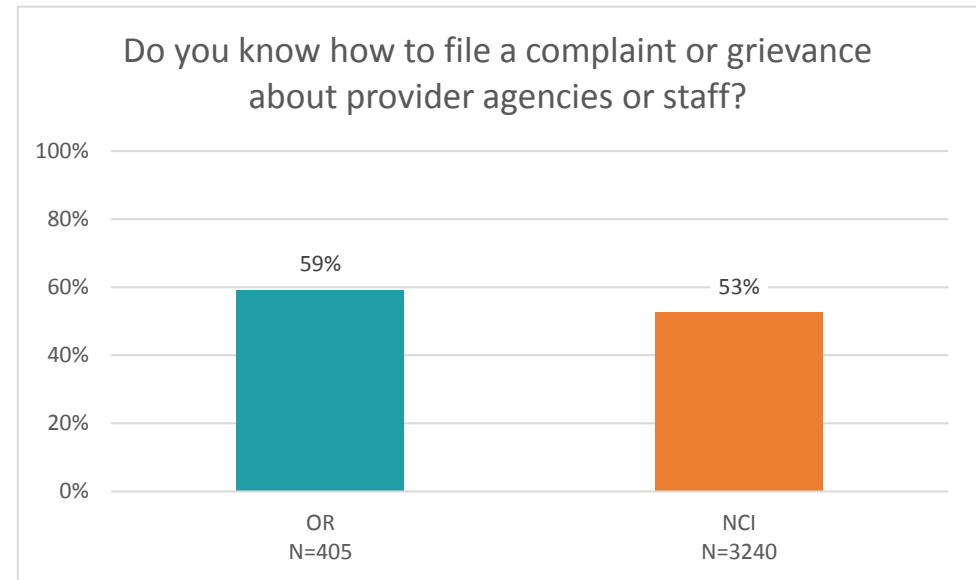


Chart 48.

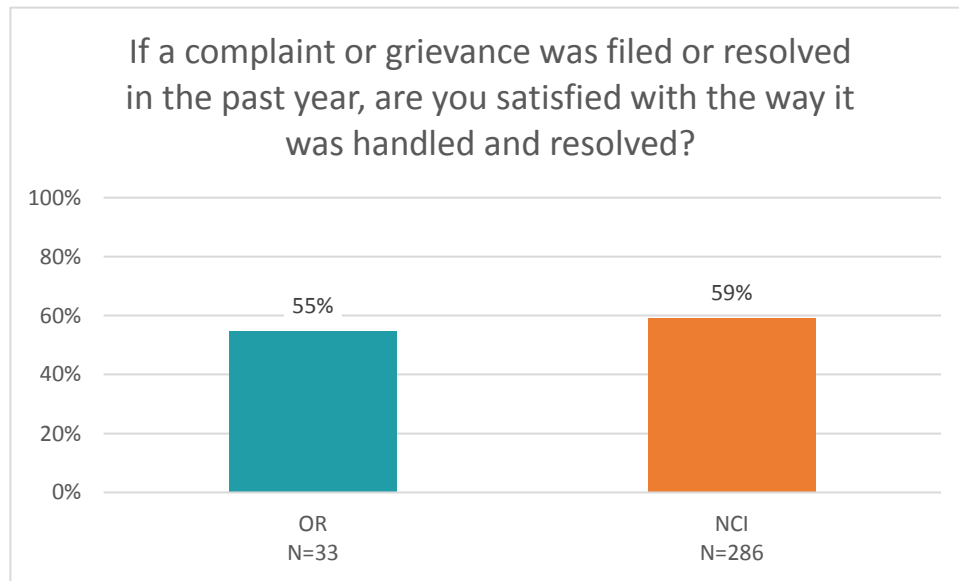
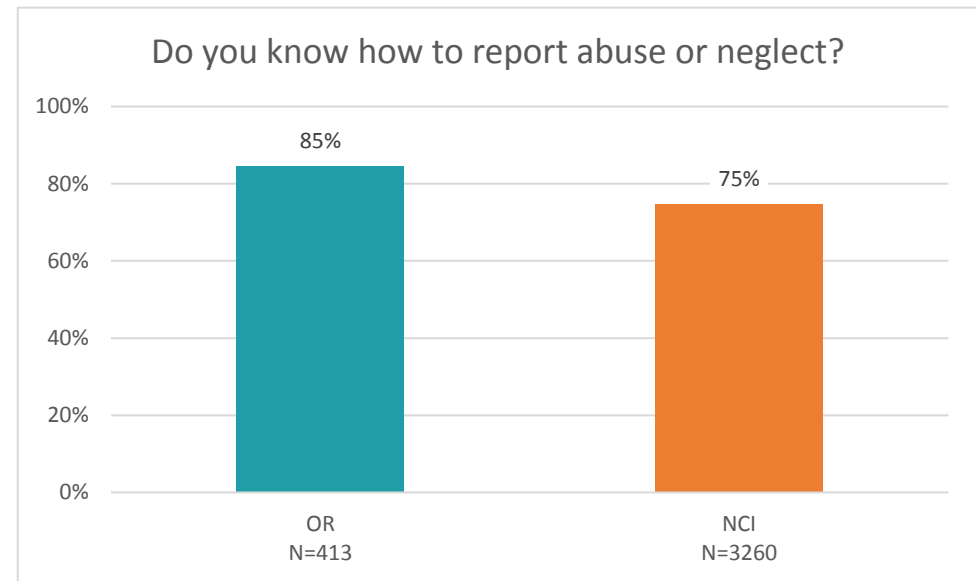
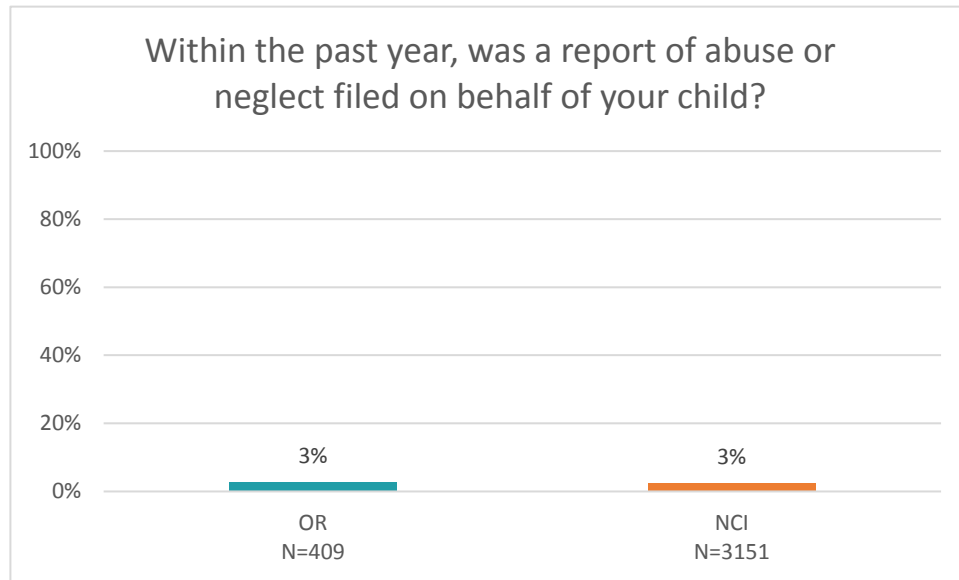


Chart 49. *

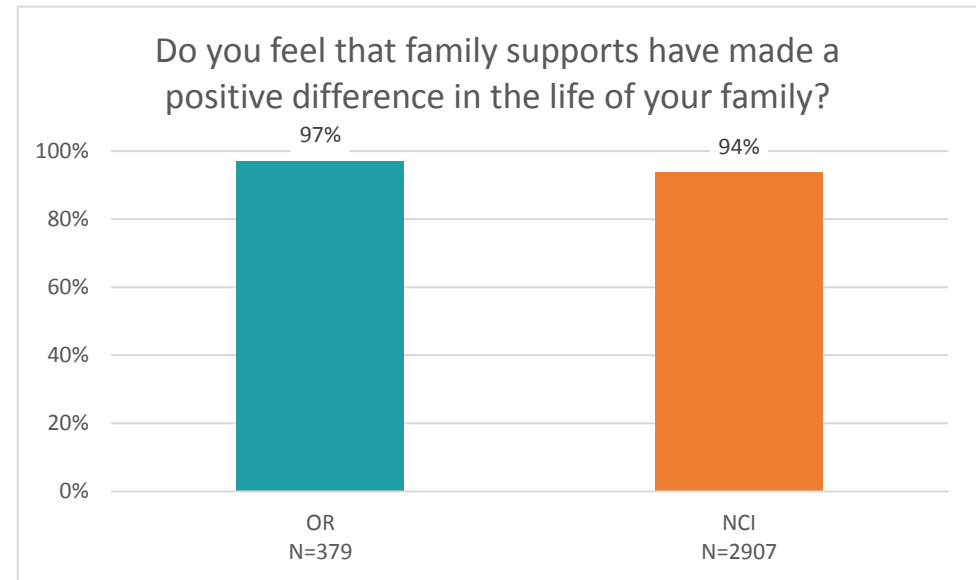


*For this question, 'No' and 'Don't know' responses were combined.

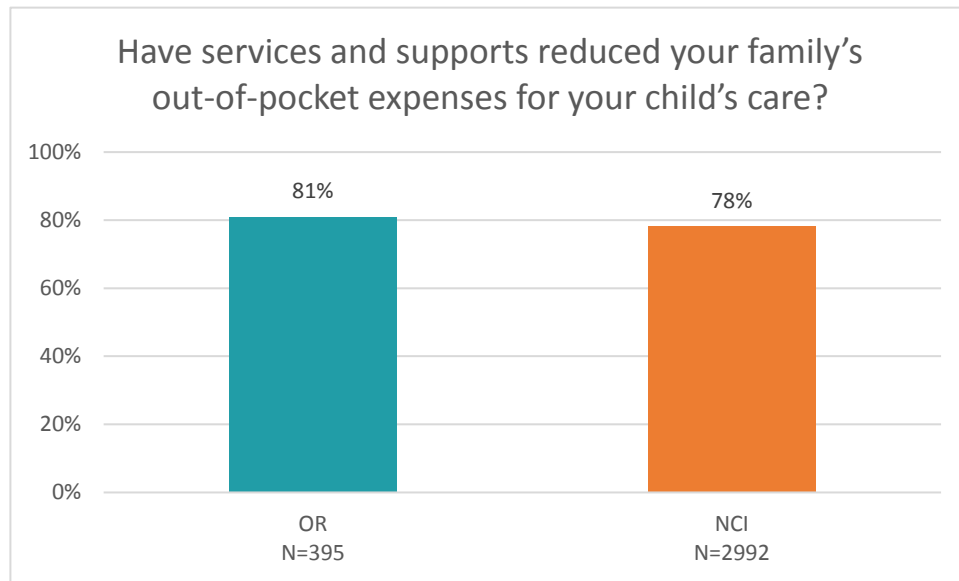
[Chart 50.](#)



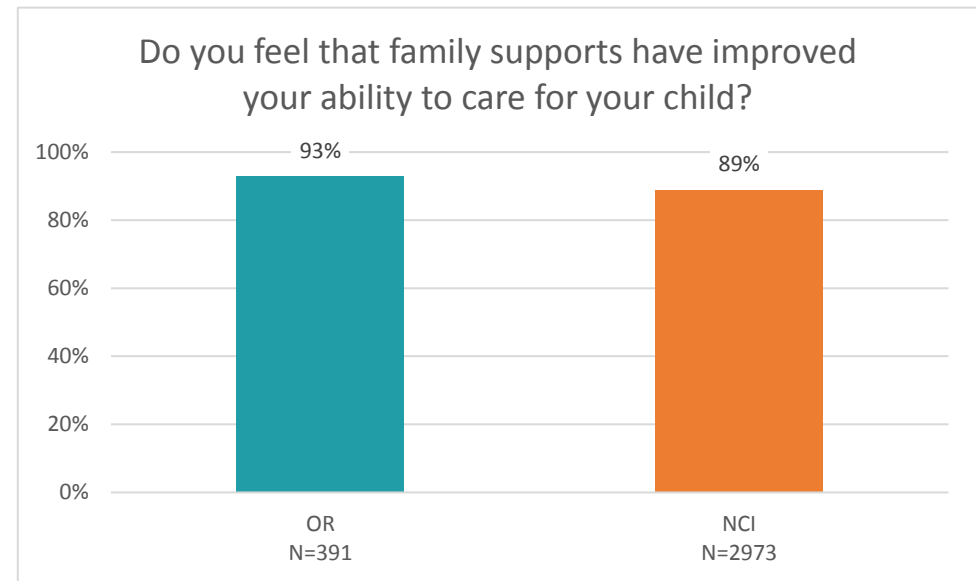
[Chart 51.](#)



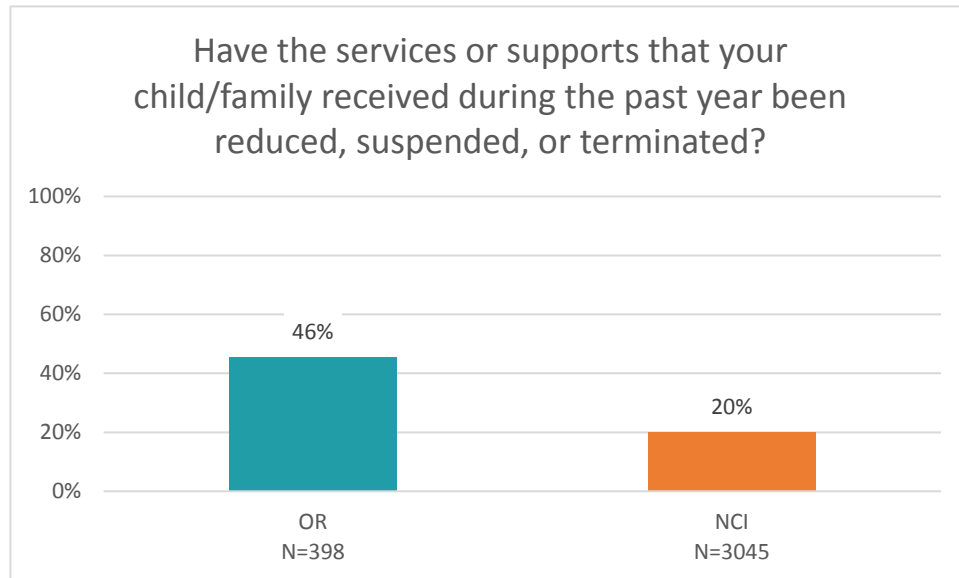
[Chart 52.](#)



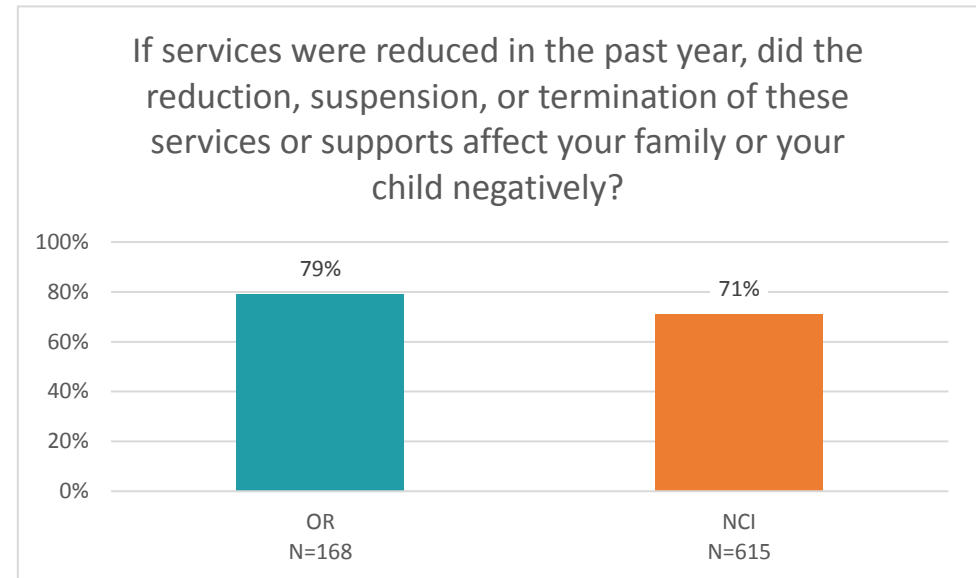
[Chart 53.](#)



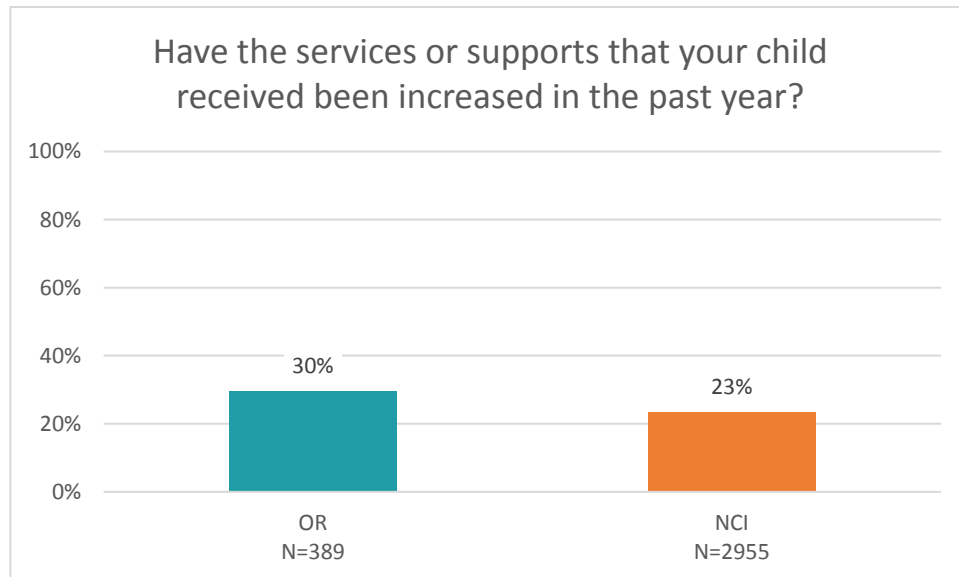
[Chart 54.](#)



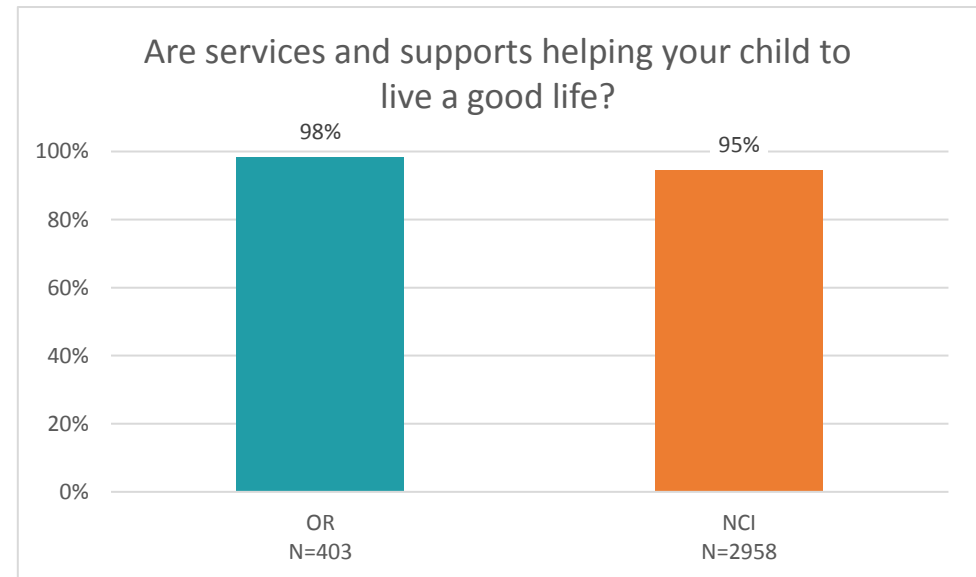
[Chart 55.](#)



[Chart 56.](#)



[Chart 57.](#)



Tables for Satisfaction With Services and Supports

Table 32. Satisfaction—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Overall, are you satisfied with the services and supports your family currently receives?	OR	29%	52%	18%	1%	414
	NCI	32%	48%	16%	5%	3,217

Table 33. Satisfaction—Yes Responses

		Yes	No	N
Do you know how to file a complaint or grievance about provider agencies or staff?*	OR	59%	41%	405
	NCI	53%	47%	3,240
If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?	OR	55%	45%	33
	NCI	59%	41%	286
Do you know how to report abuse or neglect?*	OR▲	85%	15%	413
	NCI	75%	25%	3,260
Within the past year, was a report of abuse or neglect filed on behalf of your child?	OR	3%	97%	409
	NCI	3%	97%	3,151

*For this question, 'No' and 'Don't know' responses were combined.

Table 34. Satisfaction—Yes Responses (continued)

		Yes	No	N
Do you feel that family supports have made a positive difference in the life of your family?	OR ▲	97%	3%	379
	NCI	94%	6%	2,907
Have services and supports reduced your family's out-of-pocket expenses for your child's care?	OR	81%	19%	395
	NCI	78%	22%	2,992
Do you feel that family supports have improved your ability to care for your child?	OR ▲	93%	7%	391
	NCI	89%	11%	2,973
Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated?	OR ▲	46%	55%	398
	NCI	20%	80%	3,045
If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?	OR ▼	79%	21%	168
	NCI	71%	29%	615
Have the services or supports that your child received been increased in the past year?	OR ▲	30%	70%	389
	NCI	23%	77%	2,955
Are services and supports helping your child to live a good life?	OR ▲	98%	2%	403
	NCI	95%	5%	2,958