

2016-17 CHILD FAMILY SURVEY

NORTH CAROLINA REPORT



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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 North Carolina (NC) 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 | NC | 22% | 78% | 235 |
| | NCI | 20% | 80% | 3,284 |

Table 2. Child's age

| | | Mean | N |
|-------------|-----|-------|-------|
| Child's Age | NC | 14.59 | 239 |
| | NCI | 10.61 | 3,295 |

Table 3. Child's gender

| | | Male | Female | N |
|----------------|-----|------|--------|-------|
| Child's Gender | NC | 72% | 28% | 238 |
| | 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 | NC | 2% | 3% | 23% | 0% | 71% | 2% | 6% |
| | 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 | NC | 60% | 22% | 61% | 18% | 8% | 4% |
| | 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 | NC | 6% | 28% | 0% | 10% | 2% | 0% | 25% |
| | 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 | NC | 8% | 8% | 2% | 7% | 4% |
| | 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 | NC | 14% | 1% | 5% | 18% | 58% |
| | 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 | NC | 68% | 22% | 1% | 5% | 5% | 238 |
| | 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 | NC | 22% | 51% | 28% | 231 |
| | NCI | 26% | 41% | 33% | 3,232 |
| Child's Need for Help With Personal Care Activities | NC | 53% | 40% | 7% | 237 |
| | 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 | NC | 6% | 74% | 19% | 1% | 240 |
| | NCI | 19% | 69% | 12% | 0% | 3,321 |

Table 10. Respondent's health

| | | Excellent | Very good | Fairly good | Poor | N |
|---------------------|-----|-----------|--------------|----------------|------|-------|
| Respondent's Health | NC | 13% | 46% | 36% | 4% | 239 |
| | NCI | 17% | 46% | 33% | 3% | 3,324 |

Table 11. Respondent's relationship to child

| | | Parent | Sibling | Grandparent | Other | N |
|------------------------------------|-----|--------|---------|-------------|-------|-------|
| Respondent's Relationship to Child | NC | 94% | 0% | 5% | 1% | 240 |
| | 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 | NC | 88% |
| | NCI | 74% |
| Respondent Provides Paid Support | NC | 5% |
| | NCI | 12% |
| Other Family Member Provides Paid Support | NC | 7% |
| | NCI | 16% |
| N | NC | 240 |
| | 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) | NC | 21% | 49% | 24% | 5% | 237 |
| | NCI | 18% | 63% | 14% | 5% | 3,295 |
| Number of Children in Household | NC | 45% | 31% | 15% | 9% | 216 |
| | 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 | NC | 3% | 15% | 7% | 21% | 54% | 241 |
| | 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 | NC | 13% | 12% | 19% | 13% | 25% | 8% | 10% | 238 |
| | 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 | NC | 61% | 39% | 234 |
| | 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 | NC | 12% |
| | NCI | 26% |
| In-home Support | NC | 73% |
| | NCI | 56% |
| Out-of-home Respite | NC | 49% |
| | NCI | 34% |
| Early Intervention | NC | 6% |
| | NCI | 20% |
| Transportation | NC | 22% |
| | NCI | 20% |
| Other | NC | 62% |
| | NCI | 71% |
| Self-direction or Fiscal Intermediary Services | NC | 19% |
| | 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) | NC | 47% |
| | NCI | 36% |
| Services or Supports From Other Agencies or Organizations | NC | 66% |
| | NCI | 66% |

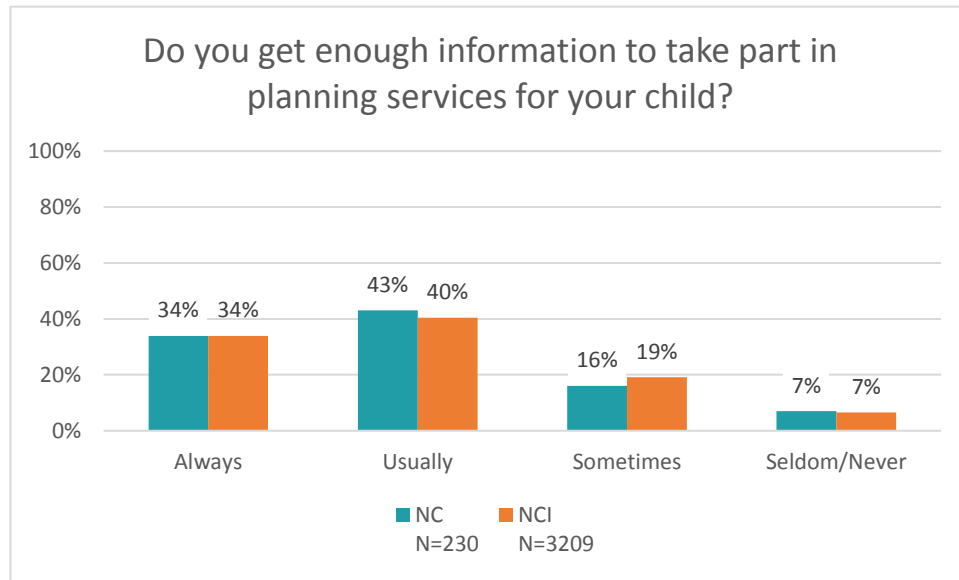
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Information and Planning

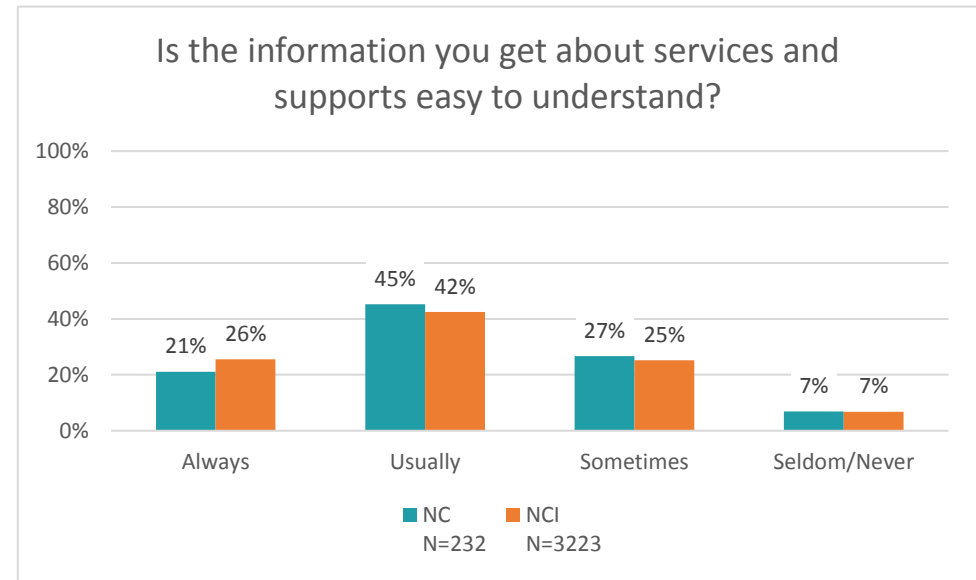
Families and children with disabilities have the information and support necessary to plan for their services and supports.

Charts for Information and Planning

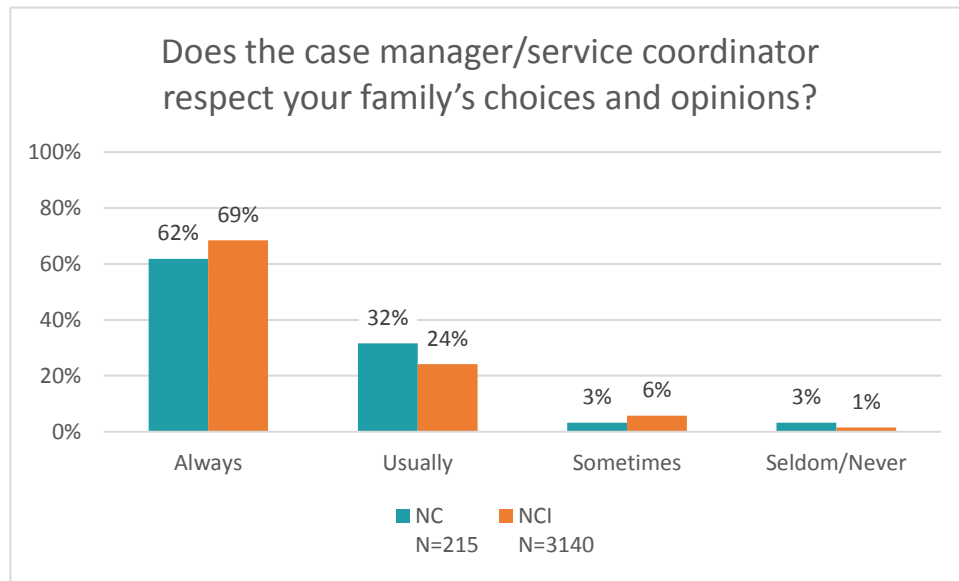
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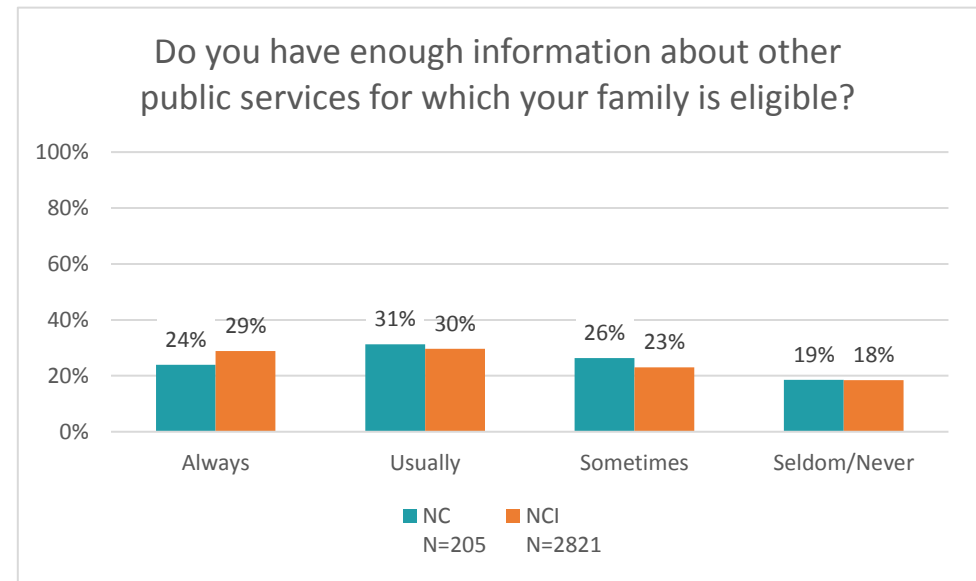
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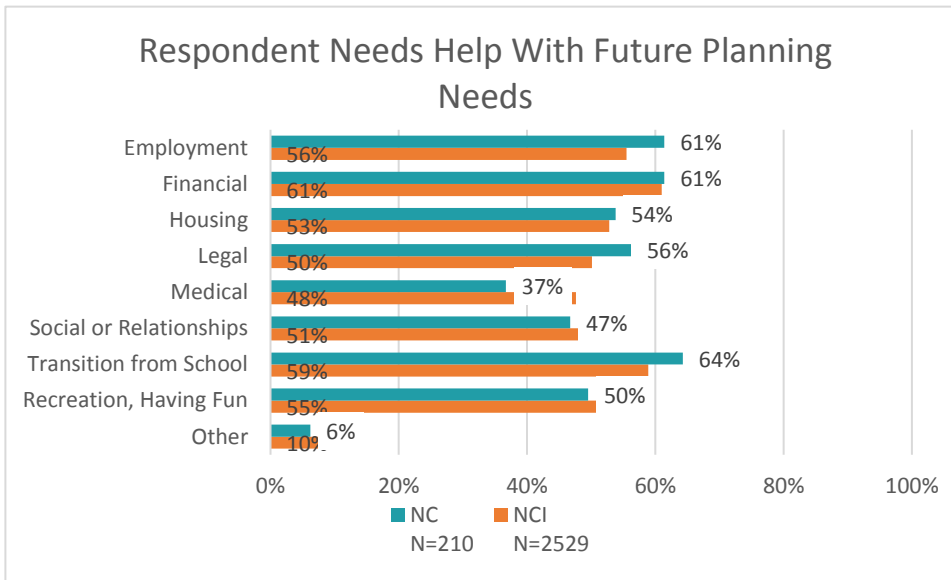
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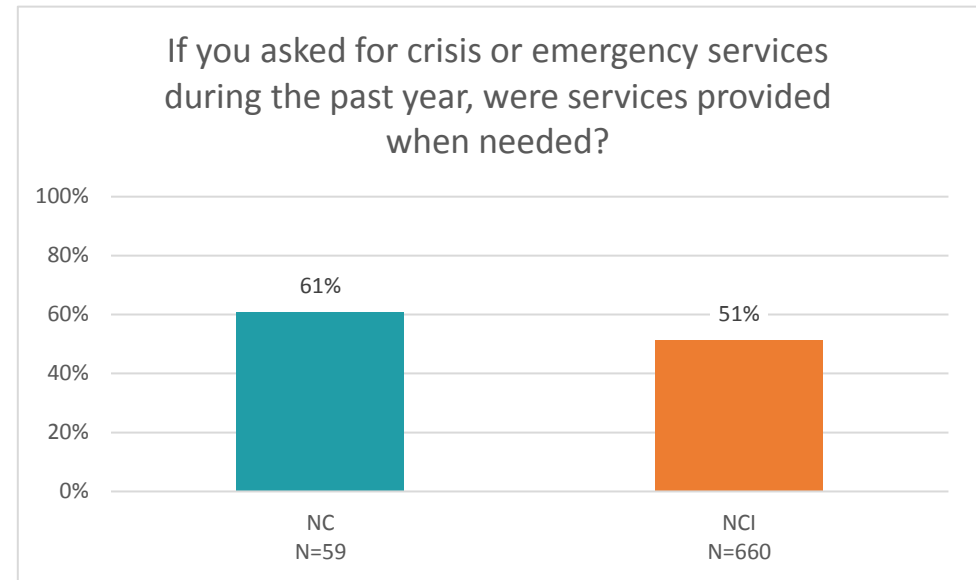
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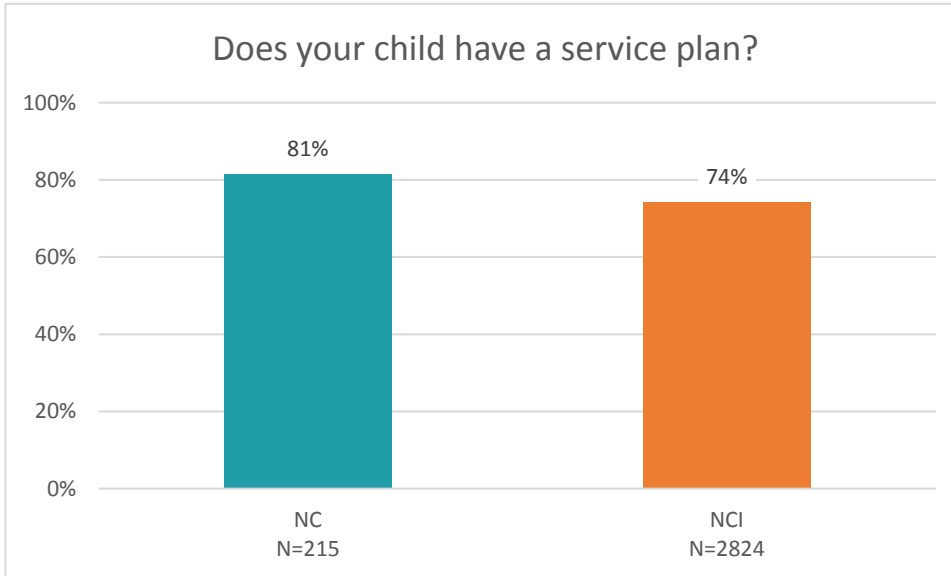
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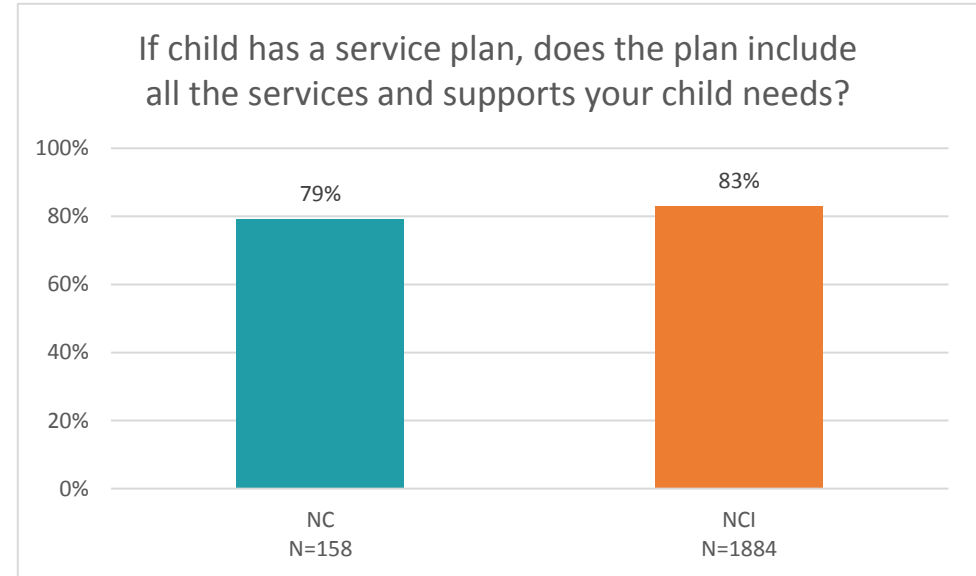
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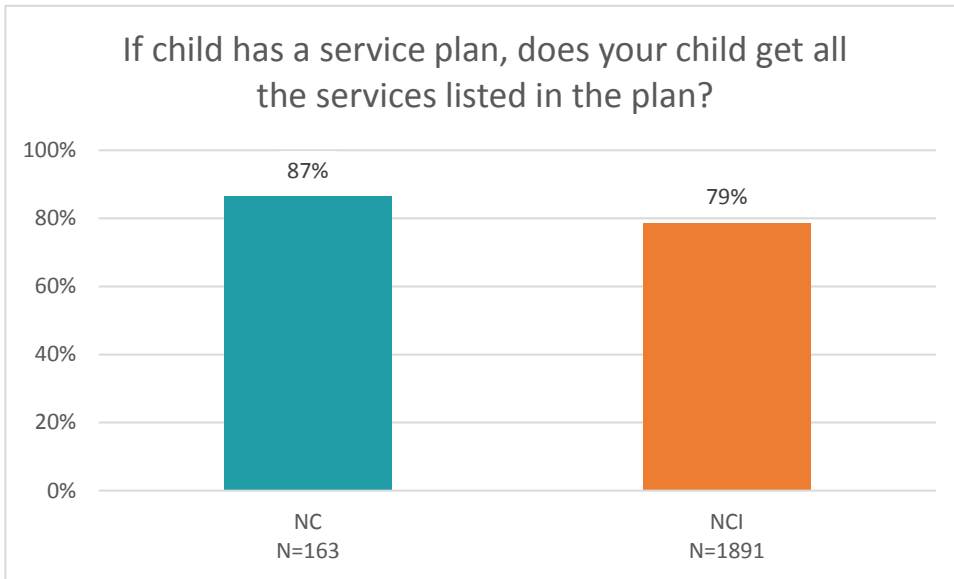
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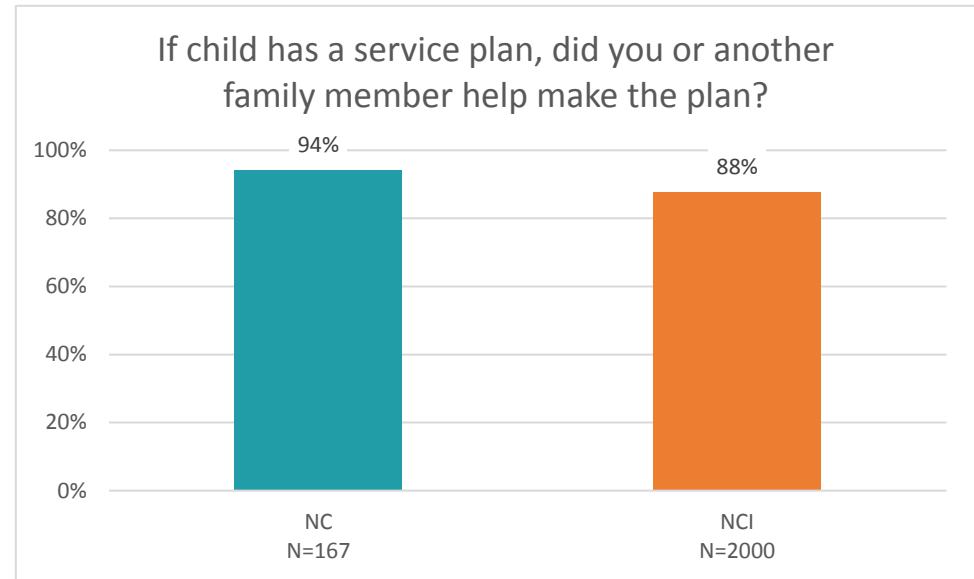
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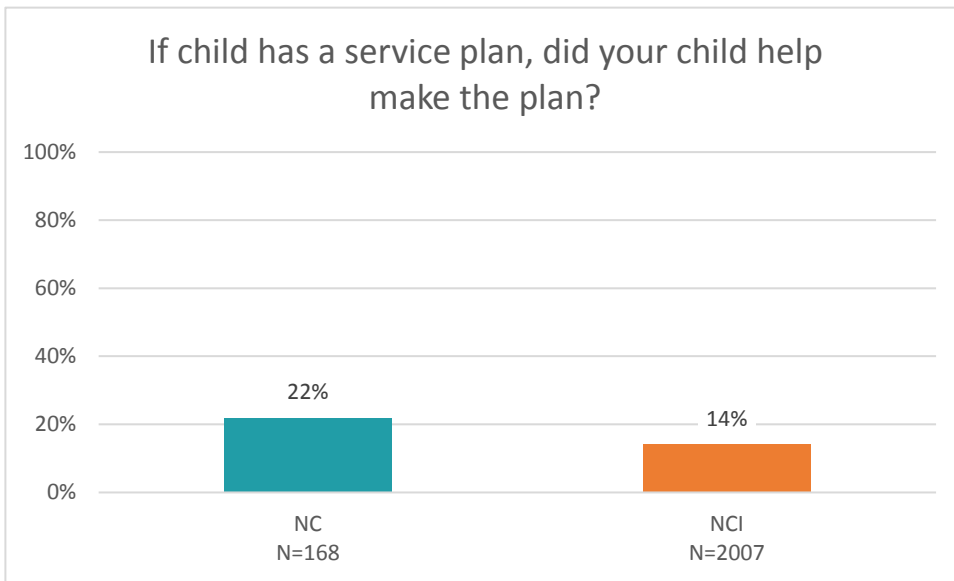
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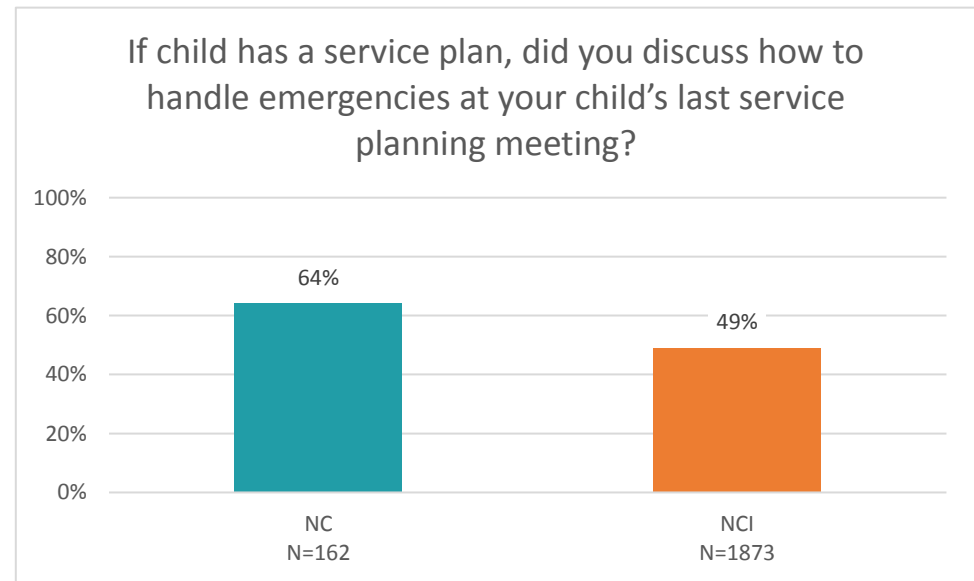
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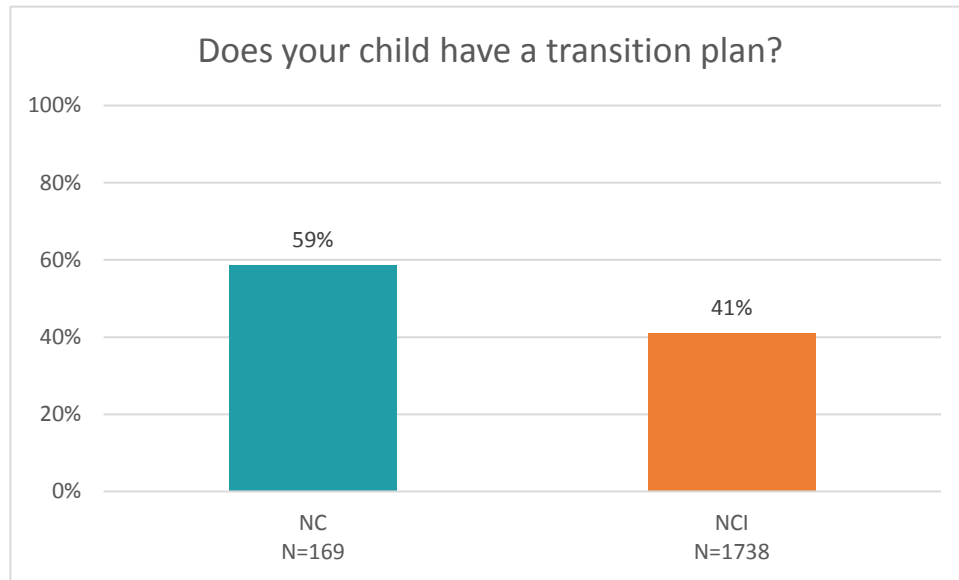
[Chart 11.](#)



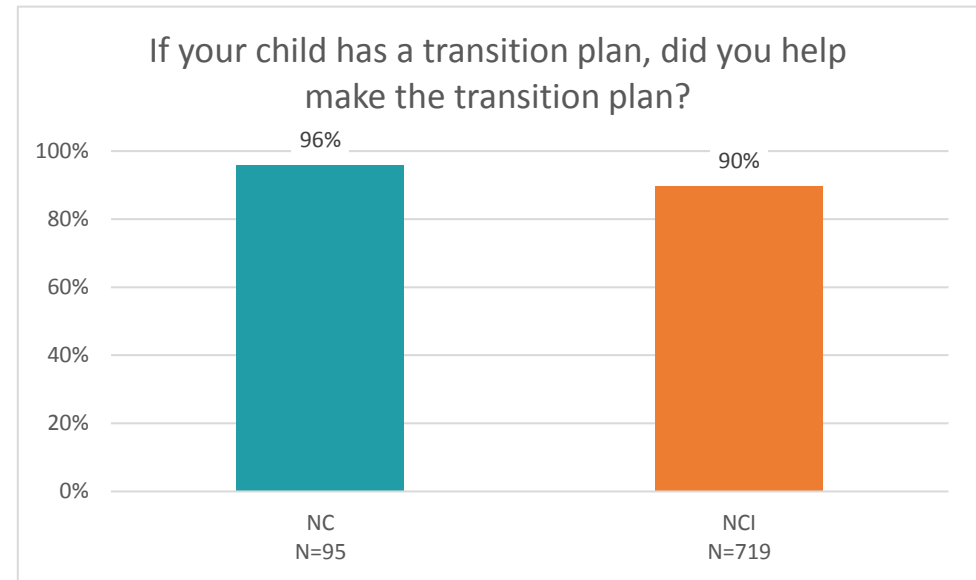
[Chart 12.](#)



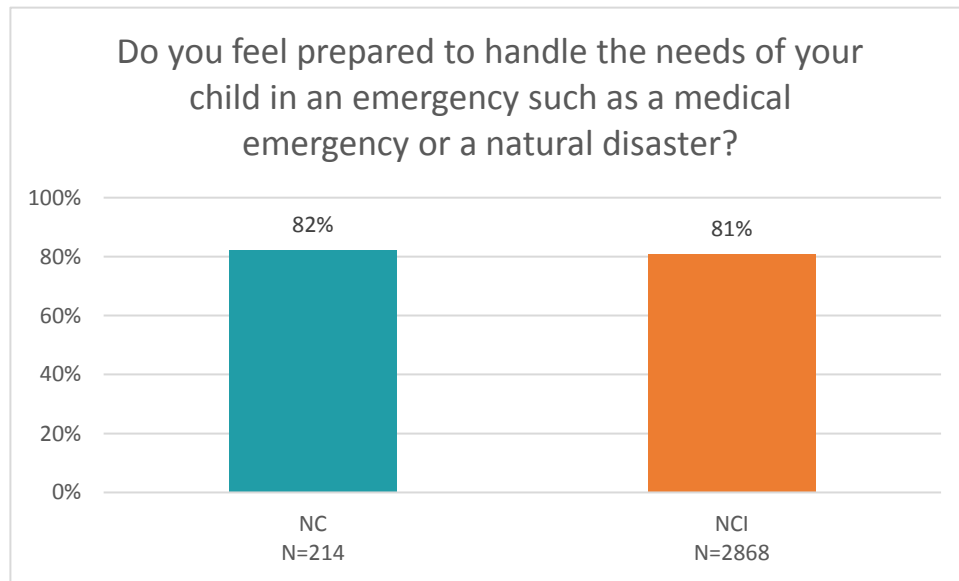
[Chart 13.](#)



[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? | NC | 34% | 43% | 16% | 7% | 230 |
| | NCI | 34% | 40% | 19% | 7% | 3,209 |
| Is the information you get about services and supports easy to understand? | NC | 21% | 45% | 27% | 7% | 232 |
| | NCI | 26% | 42% | 25% | 7% | 3,223 |
| Does the case manager/service coordinator respect your family's choices and opinions? | NC | 62% | 32% | 3% | 3% | 215 |
| | NCI | 69% | 24% | 6% | 1% | 3,140 |
| Do you have enough information about other public services for which your family is eligible? | NC | 24% | 31% | 26% | 19% | 205 |
| | NCI | 29% | 30% | 23% | 18% | 2,821 |

Table 20. Respondent Needs Help With Future Planning Needs

| | | Yes |
|-------------------------|-----|-------|
| Employment | NC | 61% |
| | NCI | 56% |
| Financial | NC | 61% |
| | NCI | 61% |
| Housing | NC | 54% |
| | NCI | 53% |
| Legal | NC | 56% |
| | NCI | 50% |
| Medical | NC | 37% |
| | NCI | 48% |
| Social or Relationships | NC | 47% |
| | NCI | 51% |
| Transition from School | NC | 64% |
| | NCI | 59% |
| Recreation, Having Fun | NC | 50% |
| | NCI | 55% |
| Other | NC | 6% |
| | NCI | 10% |
| N | NC | 210 |
| | 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? | NC | 61% | 39% | 59 |
| | NCI | 51% | 49% | 660 |
| Does your child have a service plan? | NC | 81% | 19% | 215 |
| | 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? | NC | 79% | 21% | 158 |
| | NCI | 83% | 17% | 1,884 |
| Does your child get all the services listed in the plan? | NC▲ | 87% | 13% | 163 |
| | NCI | 79% | 21% | 1,891 |
| Did you or another family member help make the plan? | NC▲ | 94% | 6% | 167 |
| | NCI | 88% | 12% | 2,000 |
| Did your child help make the plan? | NC | 22% | 78% | 168 |
| | NCI | 14% | 86% | 2,007 |
| Did you discuss how to handle emergencies at your child's last service planning meeting? | NC▲ | 64% | 36% | 162 |
| | NCI | 49% | 51% | 1,873 |
| Does your child have a transition plan? | NC▲ | 59% | 41% | 169 |
| | NCI | 41% | 59% | 1,738 |
| If your child has a transition plan, did you help make the transition plan? | NC▲ | 96% | 4% | 95 |
| | 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? | NC | 82% | 18% | 214 |
| | 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.

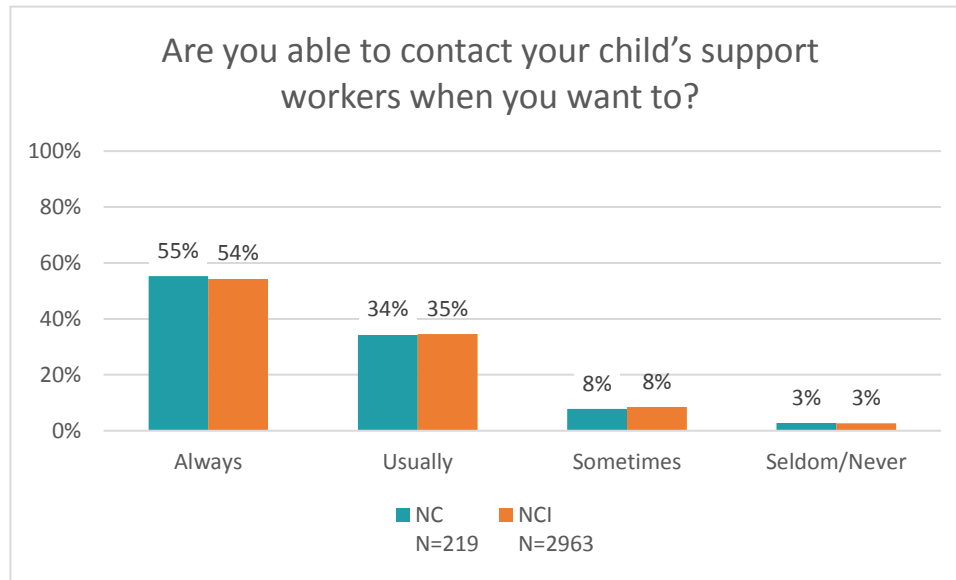


Chart 17.

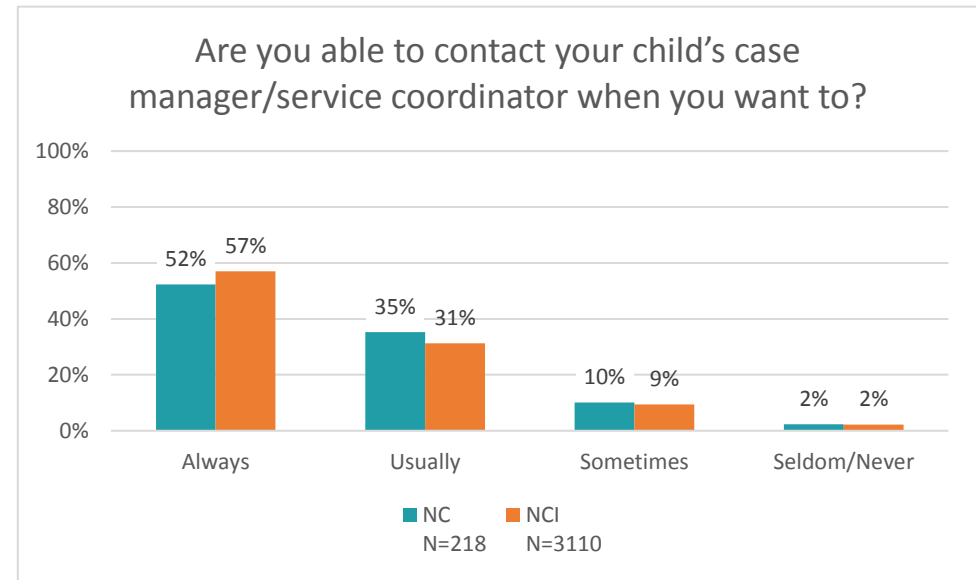


Chart 18.

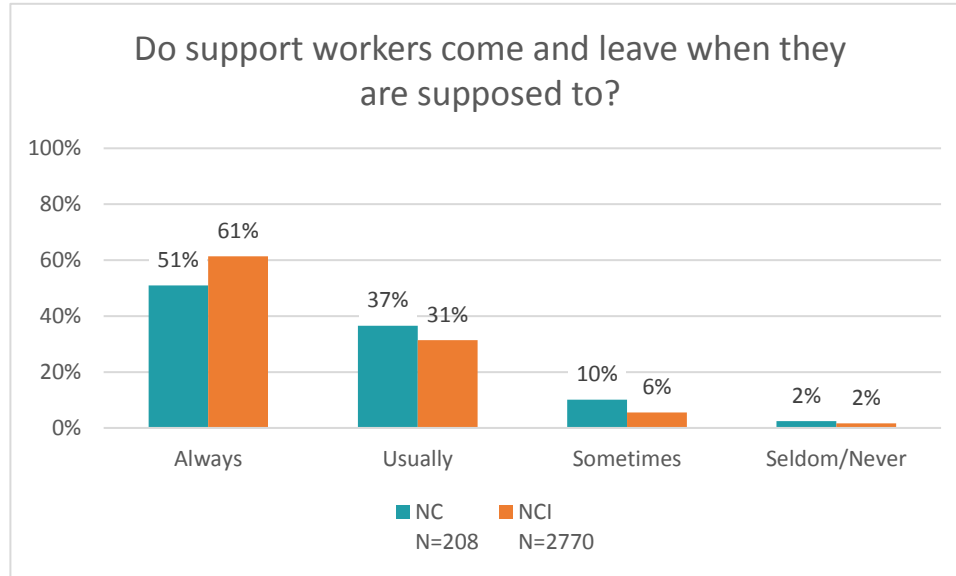
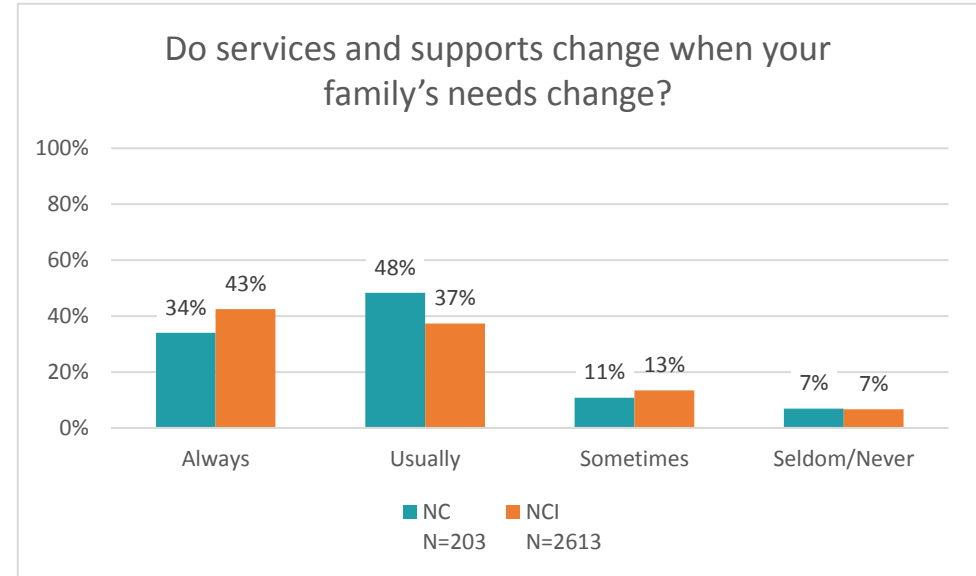
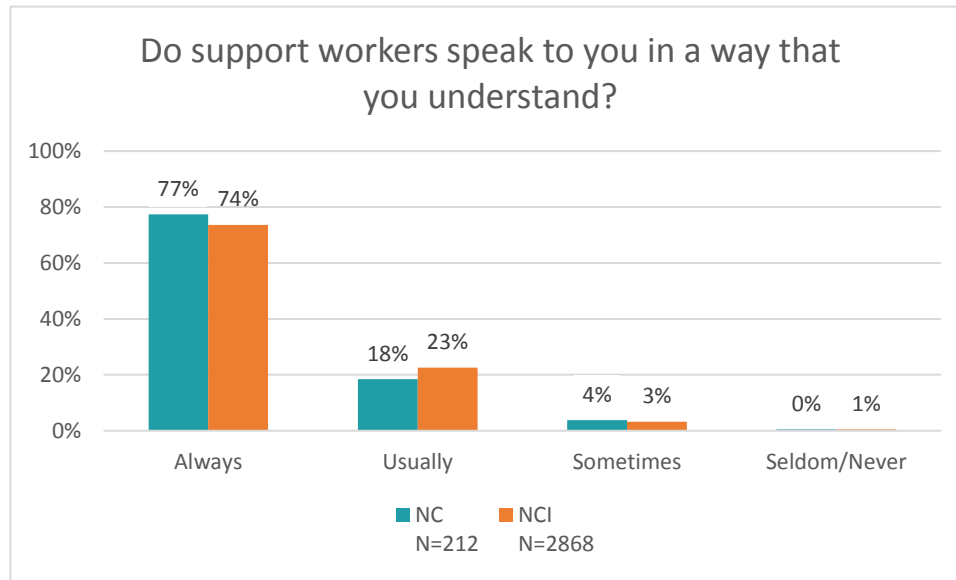


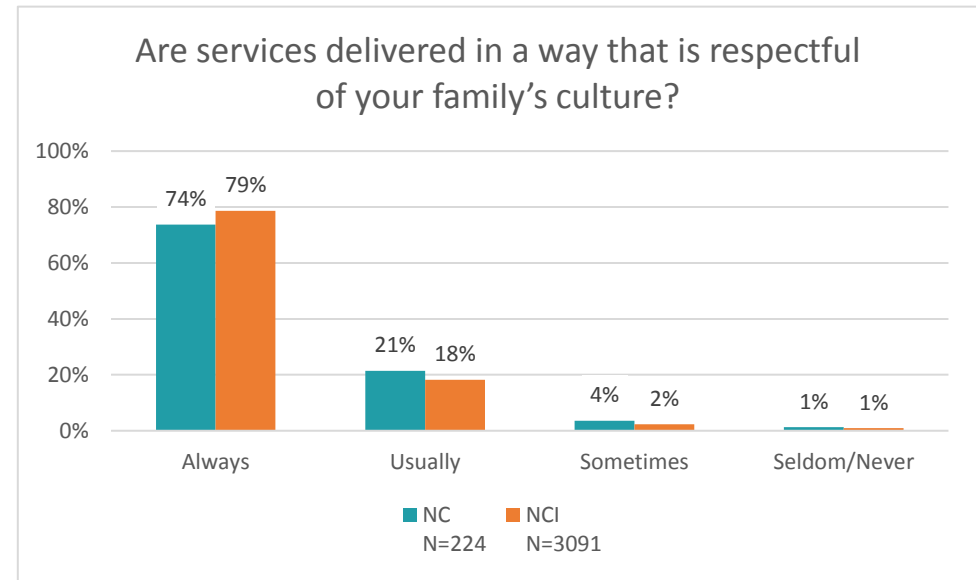
Chart 19.



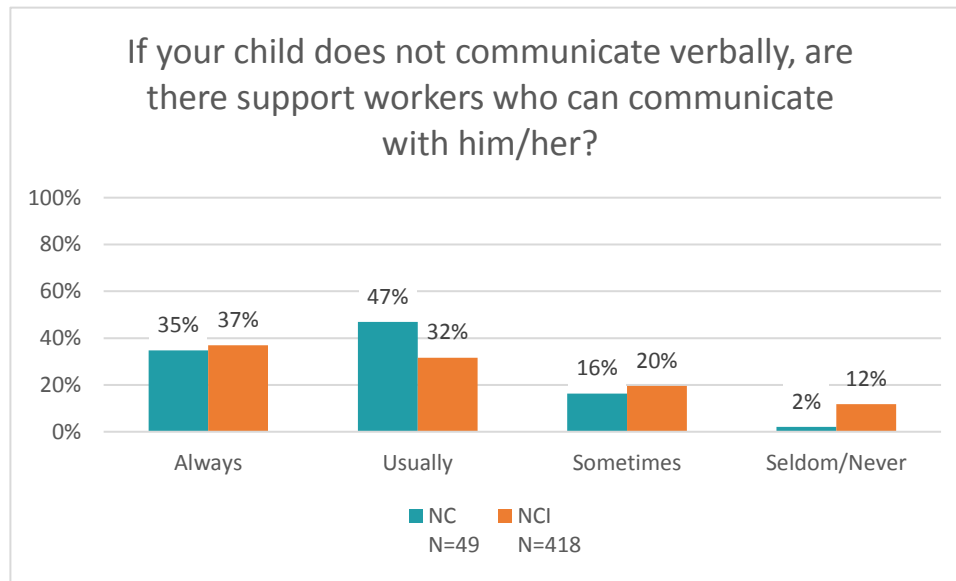
[Chart 20.](#)



[Chart 21.](#)



[Chart 22.](#)



[Chart 23.](#)

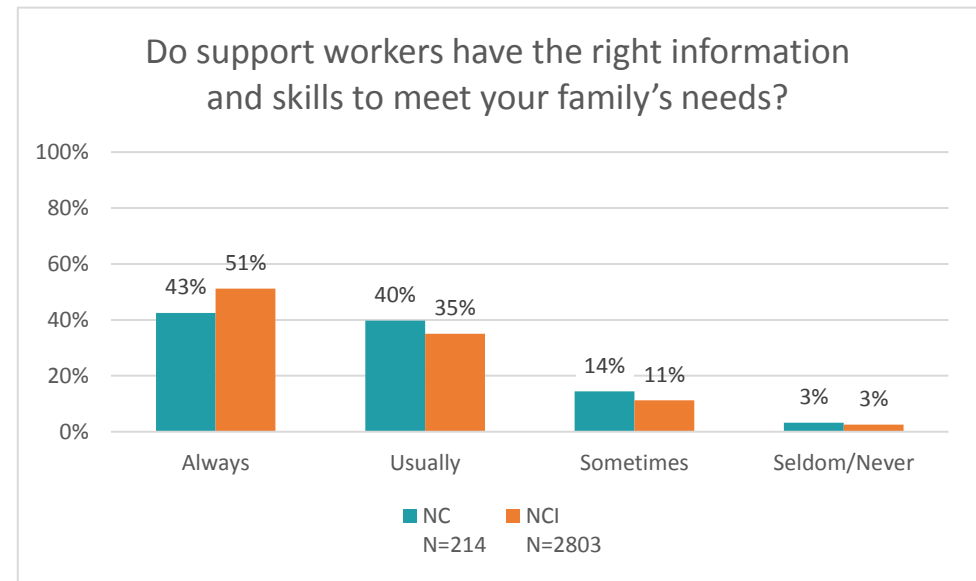


Chart 24.

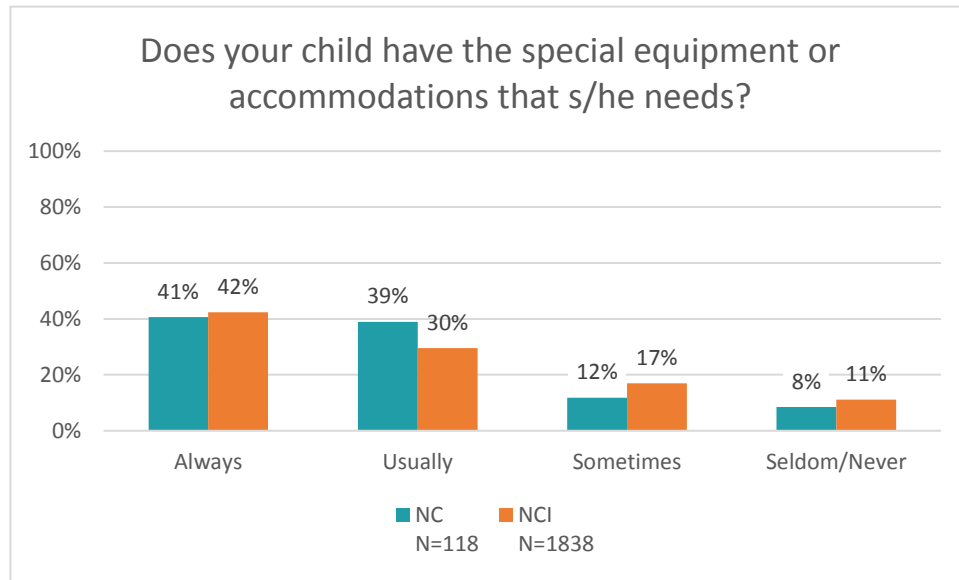


Chart 25.

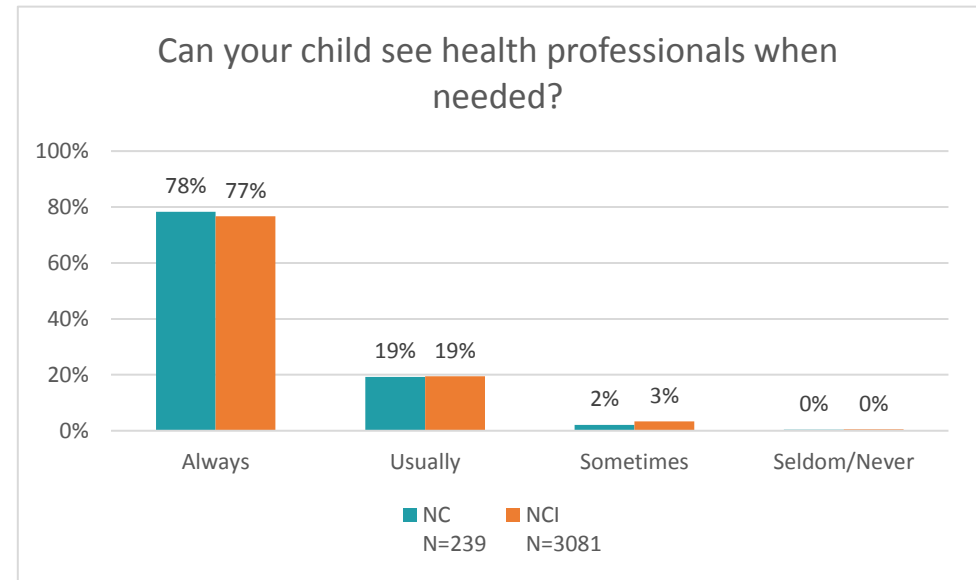


Chart 26.

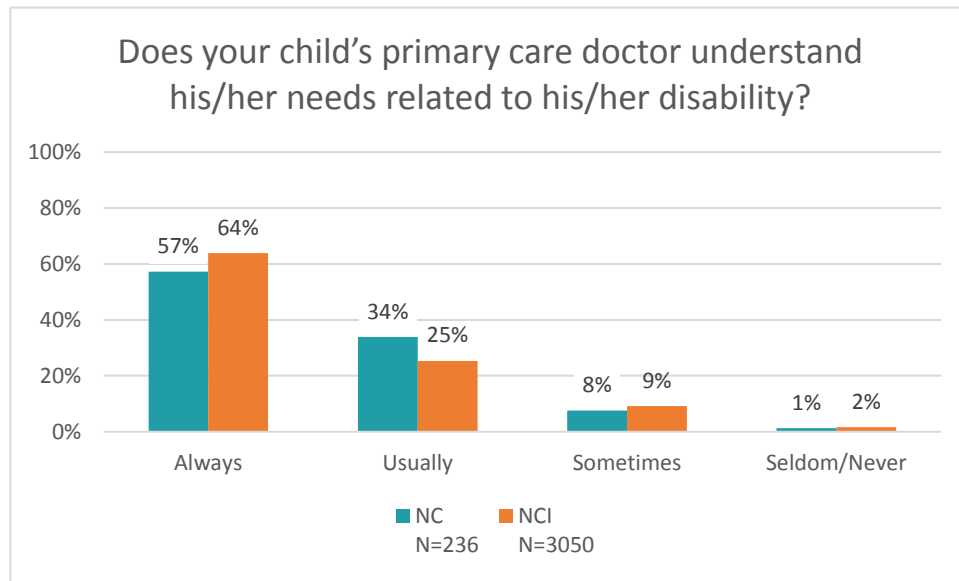


Chart 27.

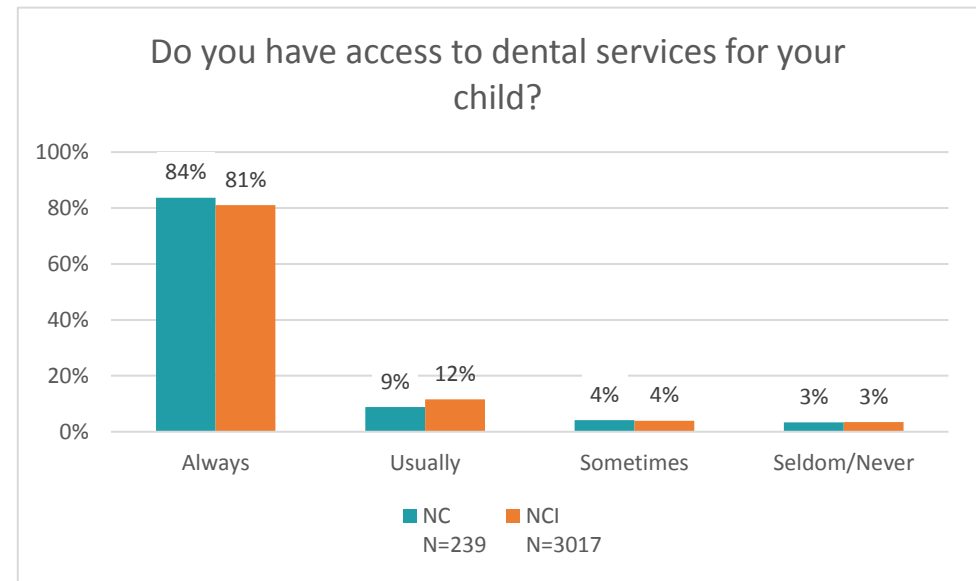


Chart 28.

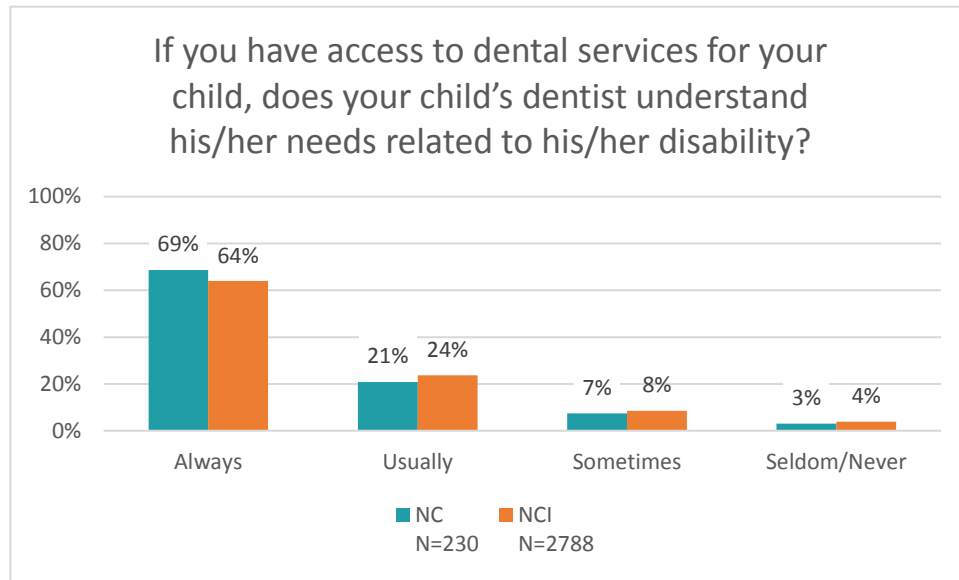


Chart 29.

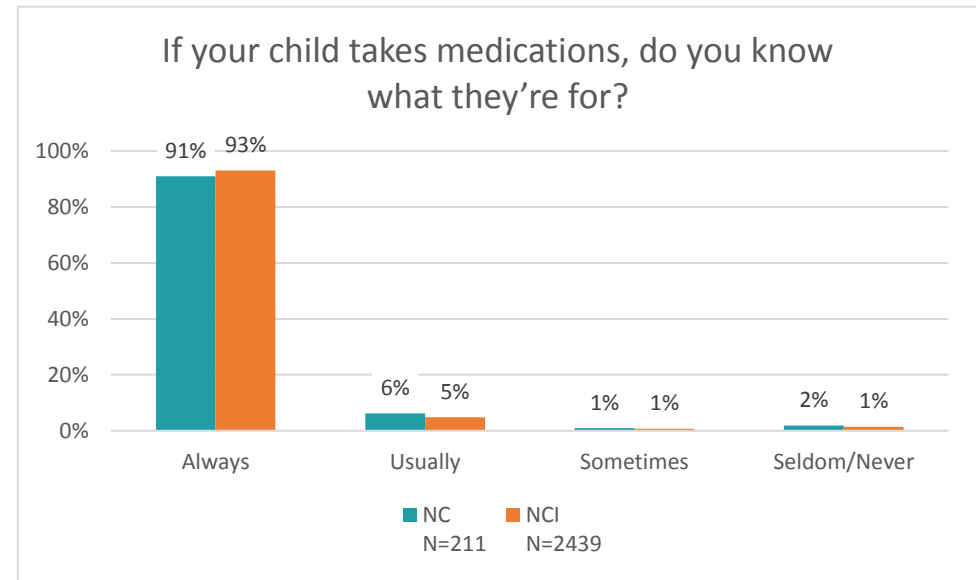


Chart 30.

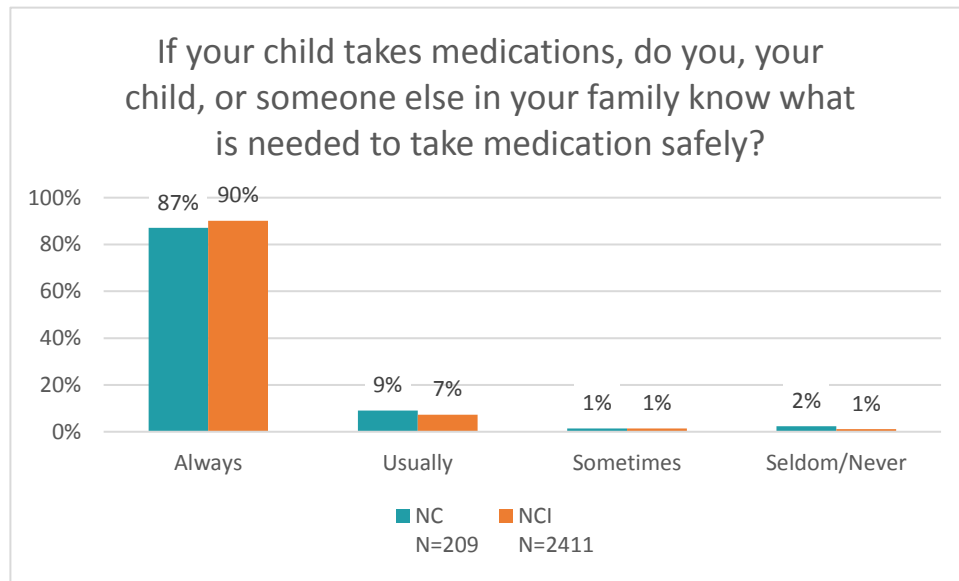


Chart 31.

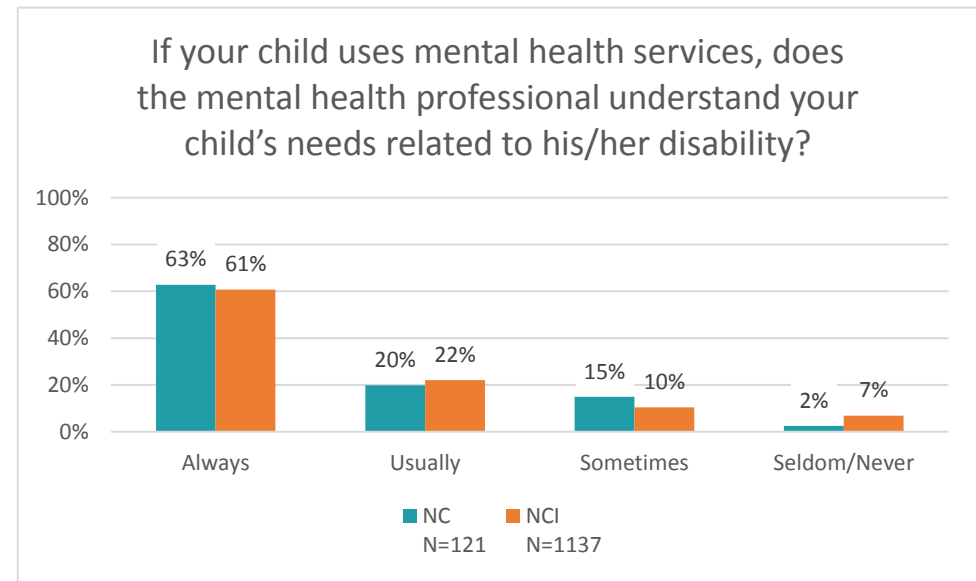


Chart 32.

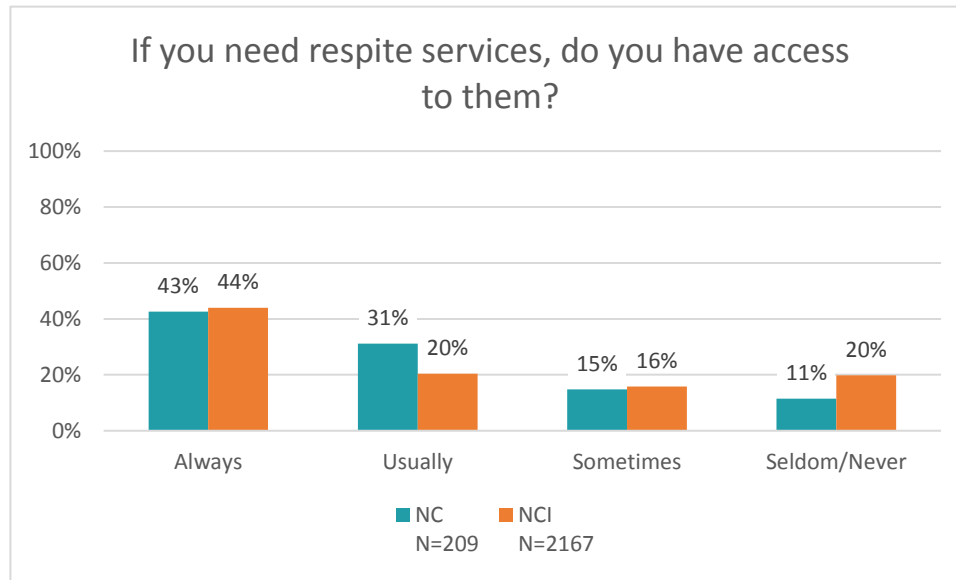


Chart 33.

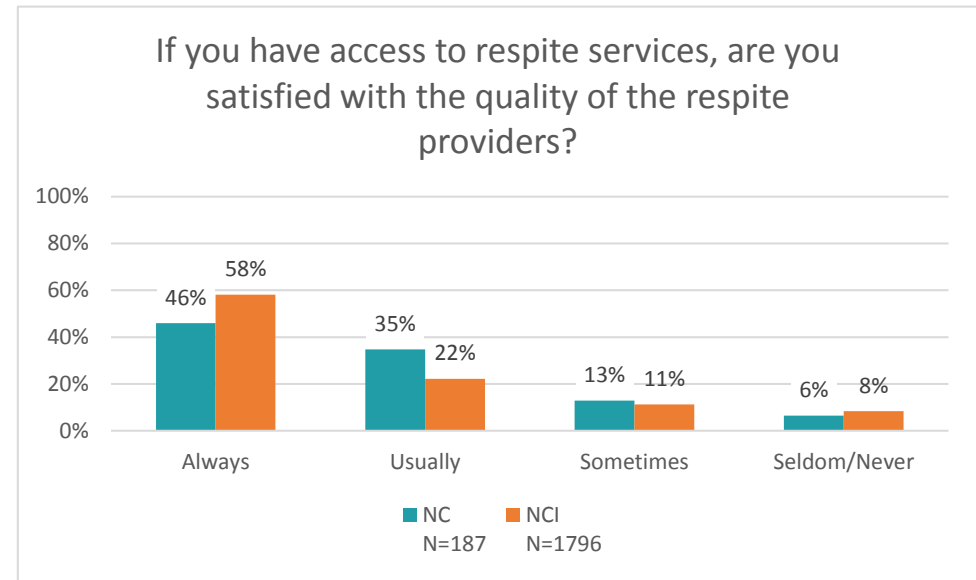


Chart 34.

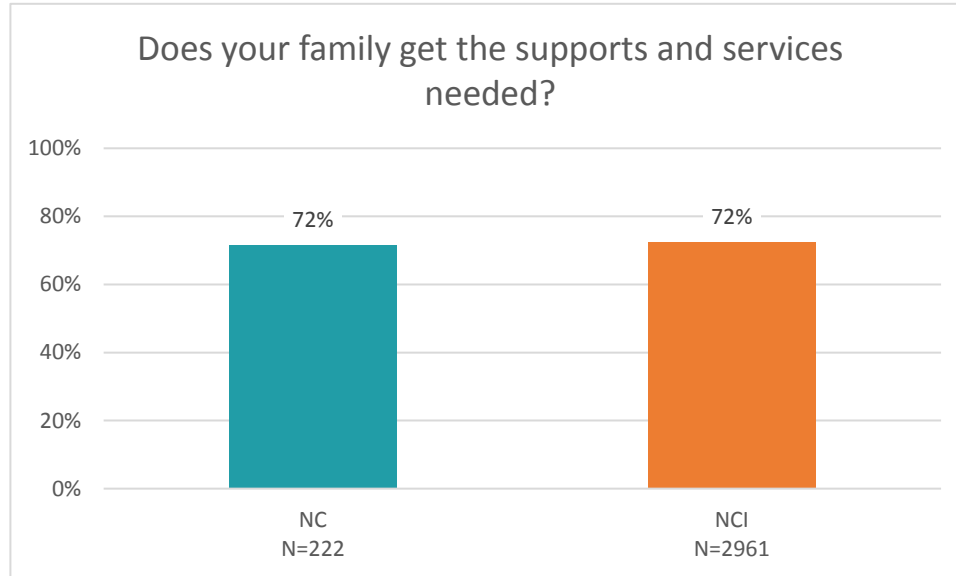
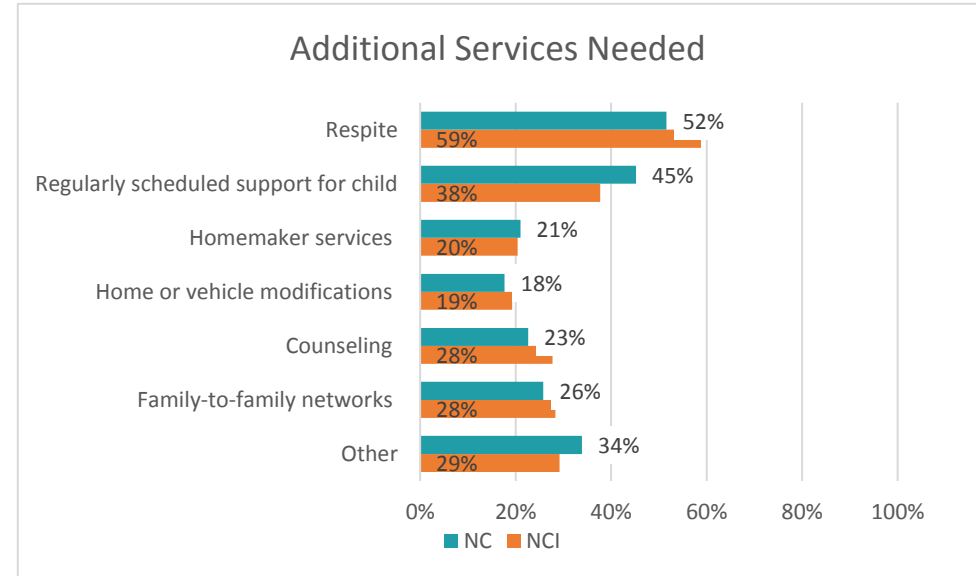


Chart 35. *



*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? | NC | 55% | 34% | 8% | 3% | 219 |
| | NCI | 54% | 35% | 8% | 3% | 2,963 |
| Are you able to contact your child’s case manager/service coordinator when you want to? | NC | 52% | 35% | 10% | 2% | 218 |
| | NCI | 57% | 31% | 9% | 2% | 3,110 |
| Do support workers come and leave when they are supposed to? | NC▼ | 51% | 37% | 10% | 2% | 208 |
| | NCI | 61% | 31% | 6% | 2% | 2,770 |
| Do services and supports change when your family’s needs change? | NC | 34% | 48% | 11% | 7% | 203 |
| | NCI | 43% | 37% | 13% | 7% | 2,613 |
| Do support workers speak to you in a way that you understand? | NC | 77% | 18% | 4% | 0% | 212 |
| | NCI | 74% | 23% | 3% | 1% | 2,868 |
| Are services delivered in a way that is respectful of your family’s culture? | NC | 74% | 21% | 4% | 1% | 224 |
| | NCI | 79% | 18% | 2% | 1% | 3,091 |
| If your child does not communicate verbally, are there support workers who can communicate with him/her? | NC | 35% | 47% | 16% | 2% | 49 |
| | NCI | 37% | 32% | 20% | 12% | 418 |
| Do support workers have the right information and skills to meet your family’s needs? | NC | 43% | 40% | 14% | 3% | 214 |
| | NCI | 51% | 35% | 11% | 3% | 2,803 |
| Does your child have the special equipment or accommodations that s/he needs? | NC | 41% | 39% | 12% | 8% | 118 |
| | 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? | NC | 78% | 19% | 2% | 0% | 239 |
| | NCI | 77% | 19% | 3% | 0% | 3,081 |
| Does your child's primary care doctor understand his/her needs related to his/her disability? | NC | 57% | 34% | 8% | 1% | 236 |
| | NCI | 64% | 25% | 9% | 2% | 3,050 |
| Do you have access to dental services for your child? | NC | 84% | 9% | 4% | 3% | 239 |
| | 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? | NC | 69% | 21% | 7% | 3% | 230 |
| | NCI | 64% | 24% | 8% | 4% | 2,788 |
| If your child takes medications, do you know what they're for? | NC | 91% | 6% | 1% | 2% | 211 |
| | 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? | NC | 87% | 9% | 1% | 2% | 209 |
| | 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? | NC | 63% | 20% | 15% | 2% | 121 |
| | NCI | 61% | 22% | 10% | 7% | 1,137 |
| If you need respite services, do you have access to them? | NC | 43% | 31% | 15% | 11% | 209 |
| | NCI | 44% | 20% | 16% | 20% | 2,167 |
| If you have access to respite services, are you satisfied with the quality of the respite providers? | NC▼ | 46% | 35% | 13% | 6% | 187 |
| | 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? | NC | 72% | 28% | 222 |
| | NCI | 72% | 28% | 2,961 |

Table 25. Additional Services Needed *

| | | Needs Service |
|---------------------------------------|-----|---------------|
| Respite | NC | 52% |
| | NCI | 59% |
| Regularly scheduled support for child | NC | 45% |
| | NCI | 38% |
| Homemaker services | NC | 21% |
| | NCI | 20% |
| Home or vehicle modifications | NC | 18% |
| | NCI | 19% |
| Counseling | NC | 23% |
| | NCI | 28% |
| Family-to-family networks | NC | 26% |
| | NCI | 28% |
| Other | NC | 34% |
| | 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.

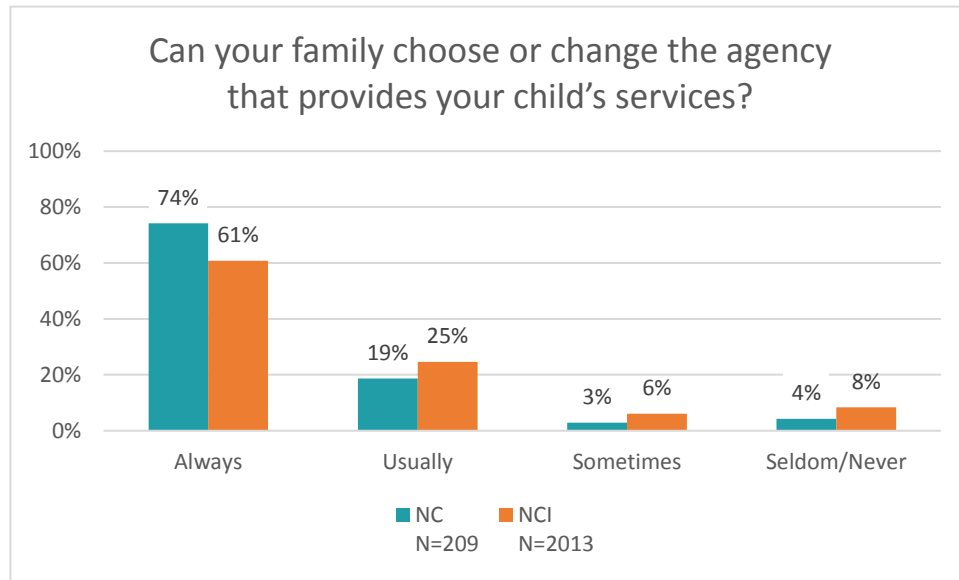


Chart 37.

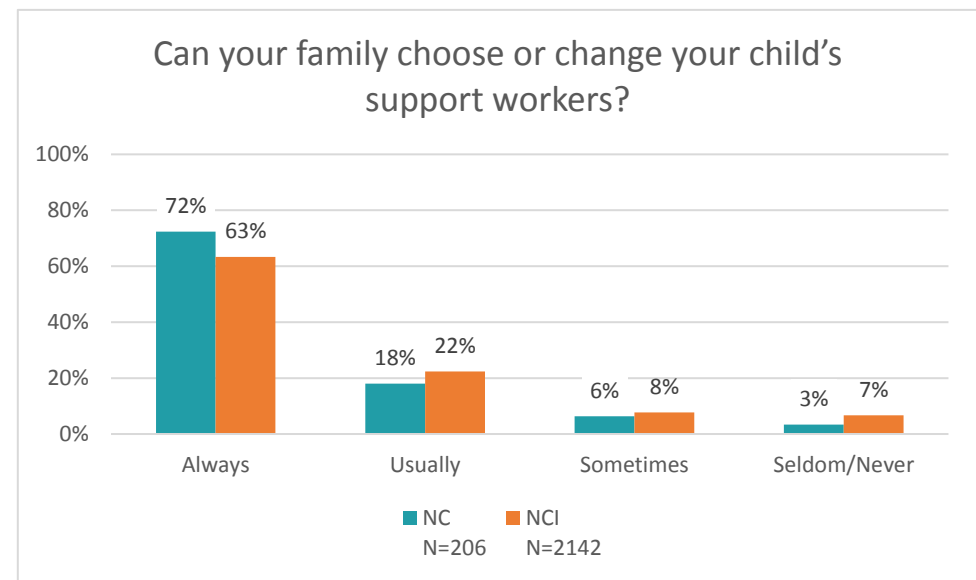


Chart 38.

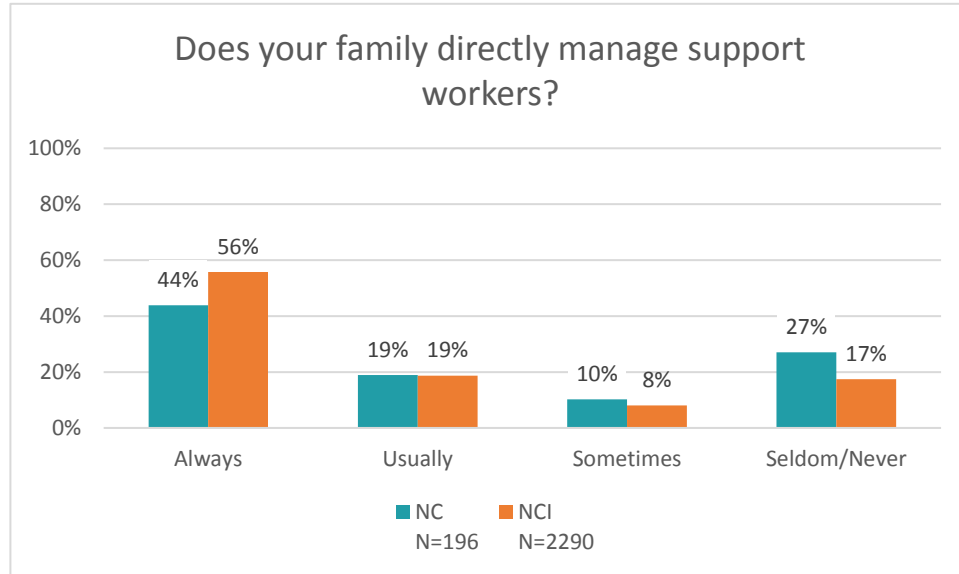


Chart 39.

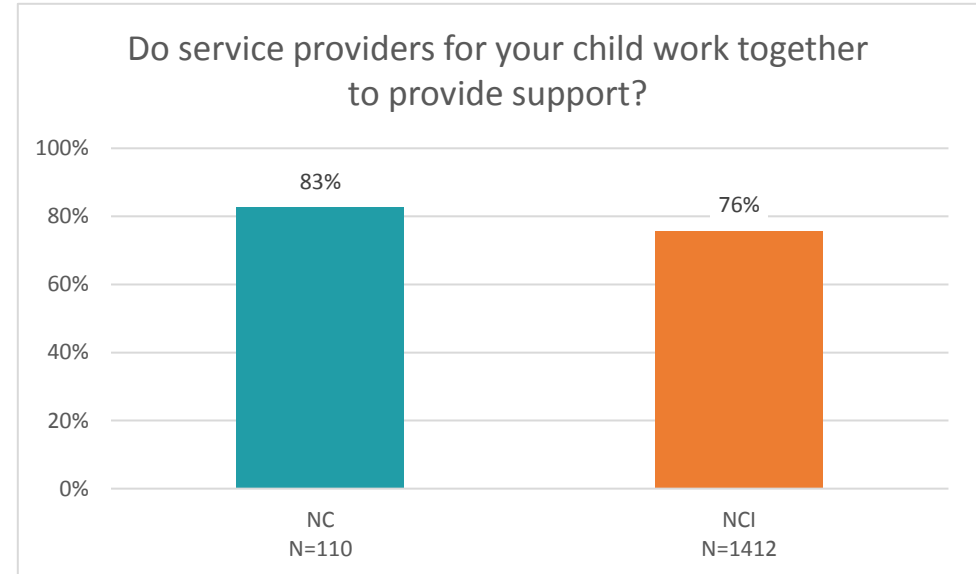
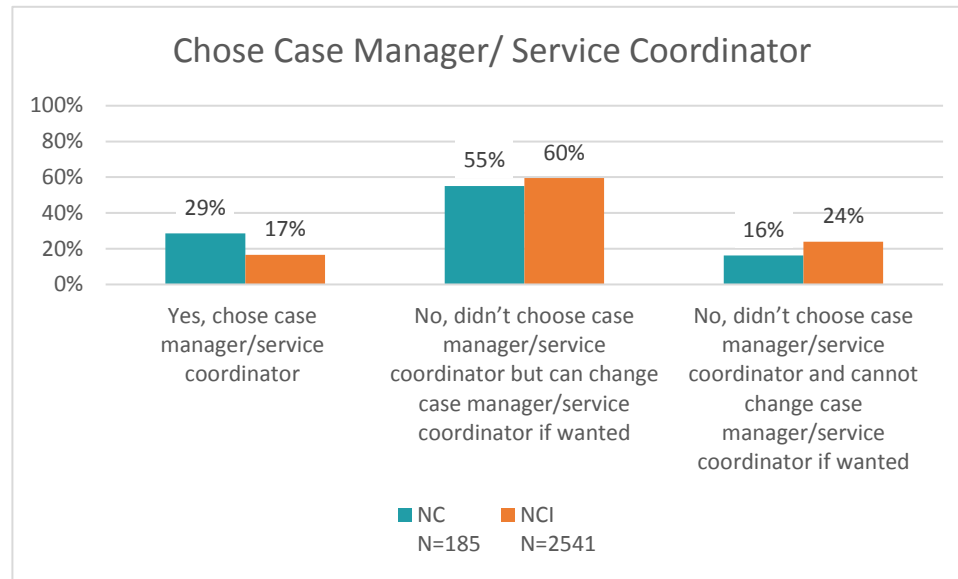


Chart 40.



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? | NC▲ | 74% | 19% | 3% | 4% | 209 |
| | NCI | 61% | 25% | 6% | 8% | 2,013 |
| Can your family choose or change your child's support workers? | NC▲ | 72% | 18% | 6% | 3% | 206 |
| | NCI | 63% | 22% | 8% | 7% | 2,142 |
| Does your family directly manage support workers? | NC▼ | 44% | 19% | 10% | 27% | 196 |
| | 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? | NC | 83% | 17% | 110 |
| | NCI | 76% | 24% | 1,412 |

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

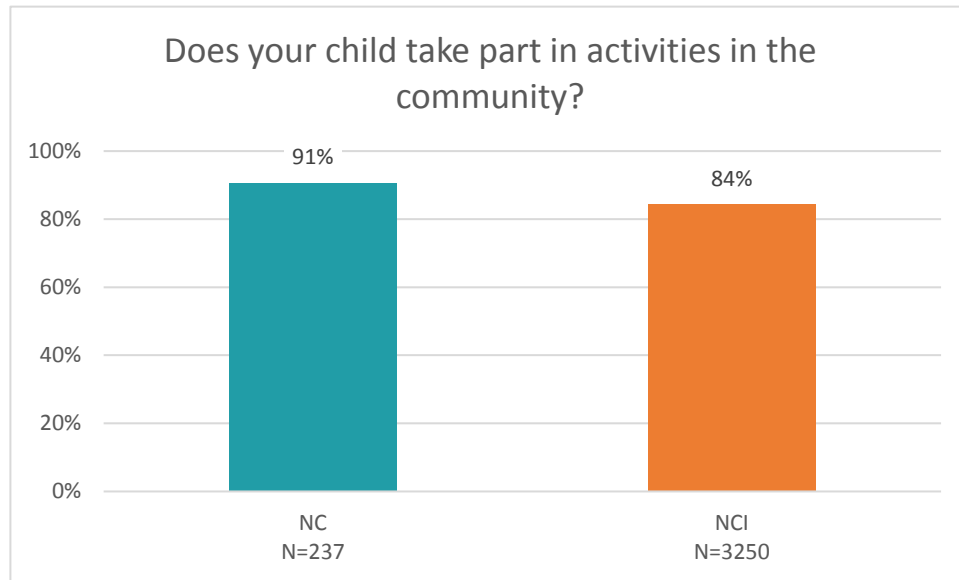
| | | Chose Case Manager/ Service Coordinator |
|---|-----|--|
| Yes, chose case manager/service coordinator | NC▲ | 29% |
| | NCI | 17% |
| No, didn't choose case manager/service coordinator but can change case manager/service coordinator if wanted | NC▲ | 55% |
| | NCI | 60% |
| No, didn't choose case manager/service coordinator and cannot change case manager/service coordinator if wanted | NC▲ | 16% |
| | NCI | 24% |
| N | NC▲ | 185 |
| | NCI | 2,541 |

Involvement in the Community

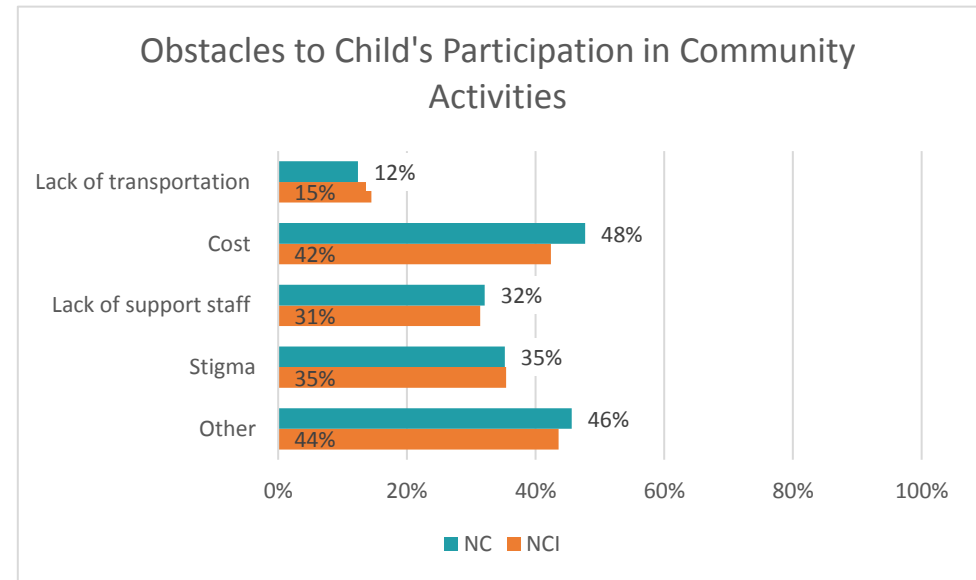
Children with disabilities use integrated community services and participate in everyday community activities.

Charts for Involvement in the Community

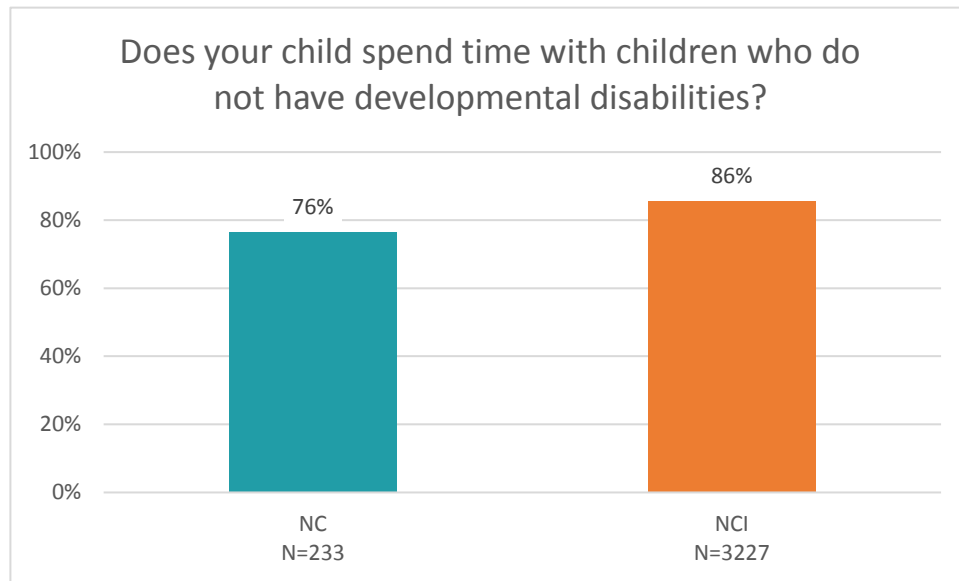
[Chart 41.](#)



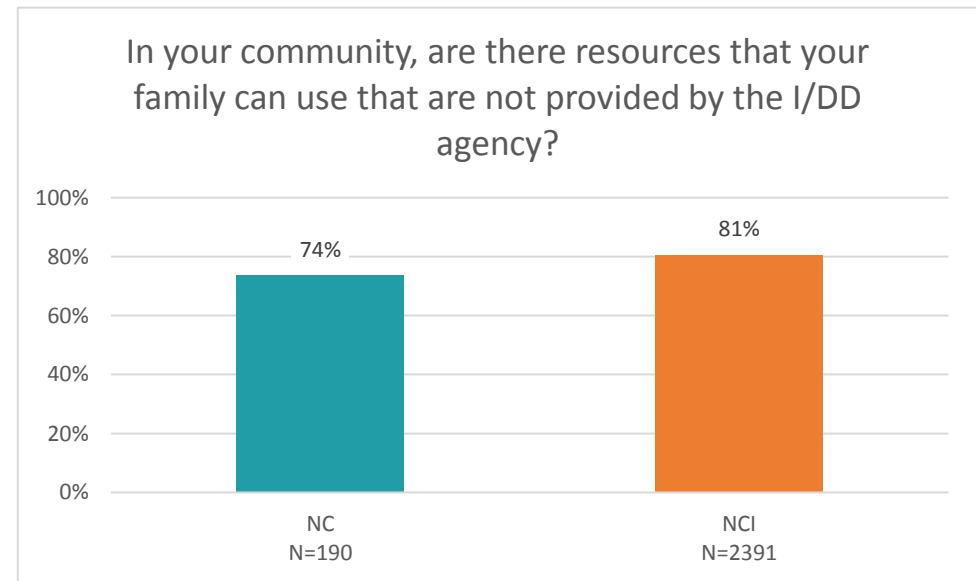
[Chart 42.](#) *



[Chart 43.](#)

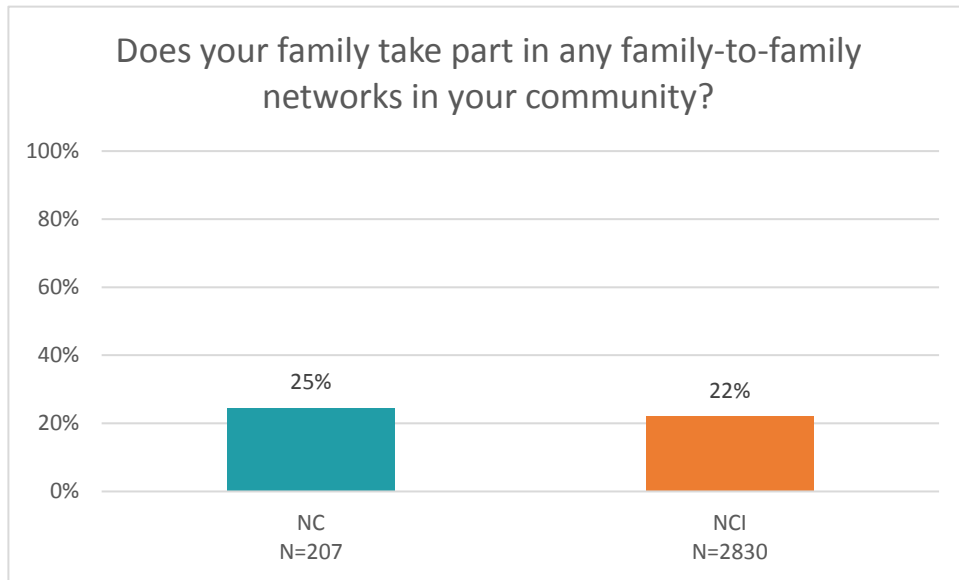


[Chart 44.](#)



*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? | NC▲ | 91% | 9% | 237 |
| | NCI | 84% | 16% | 3,250 |

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

| | | Obstacles/Barriers |
|------------------------|-----|--------------------|
| Lack of transportation | NC | 12% |
| | NCI | 15% |
| Cost | NC | 48% |
| | NCI | 42% |
| Lack of support staff | NC | 32% |
| | NCI | 31% |
| Stigma | NC | 35% |
| | NCI | 35% |
| Other | NC | 46% |
| | 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? | NC ▼ | 76% | 24% | 233 |
| | 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? | NC | 74% | 26% | 190 |
| | NCI | 81% | 19% | 2,391 |
| Does your family take part in any family-to-family networks in your community? | NC | 25% | 75% | 207 |
| | 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.

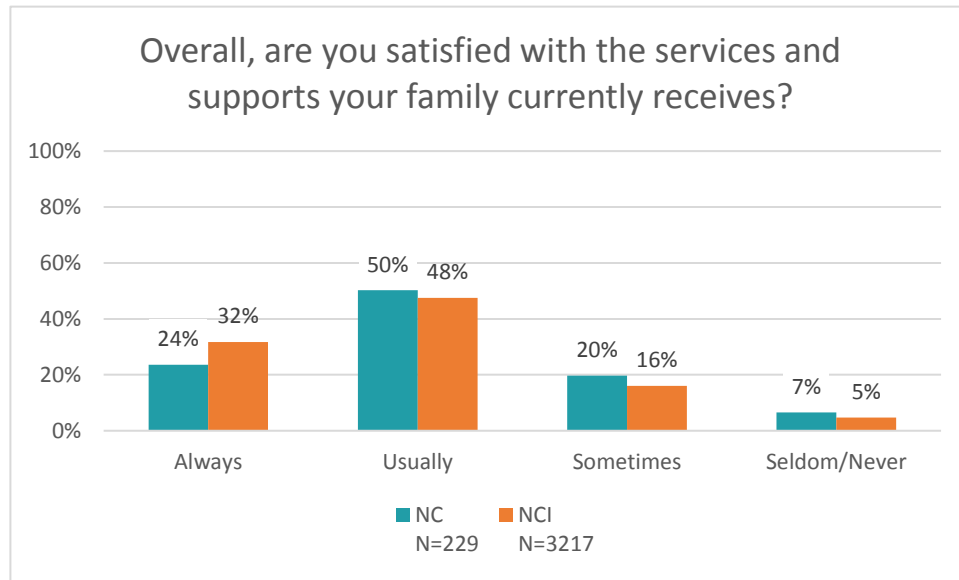


Chart 47. *

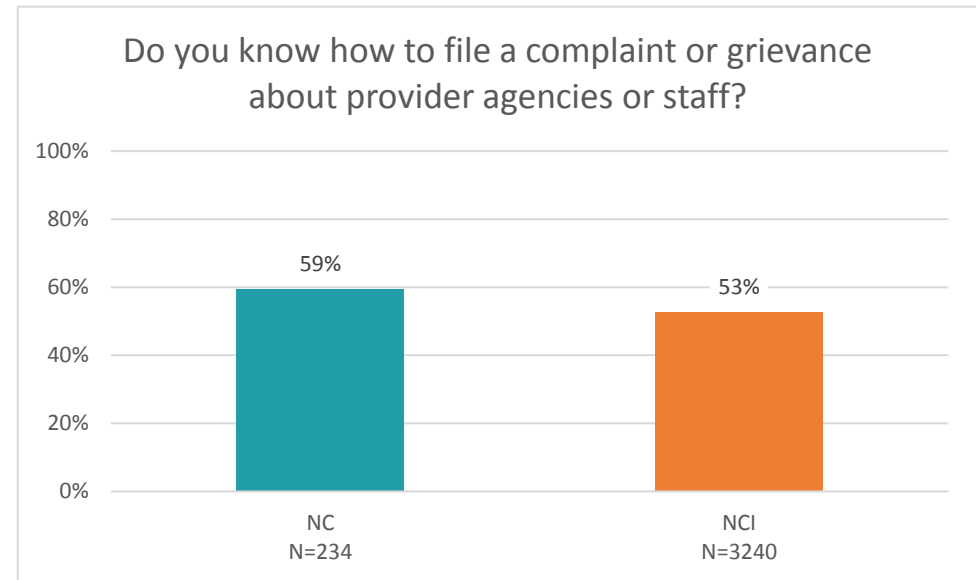


Chart 48.

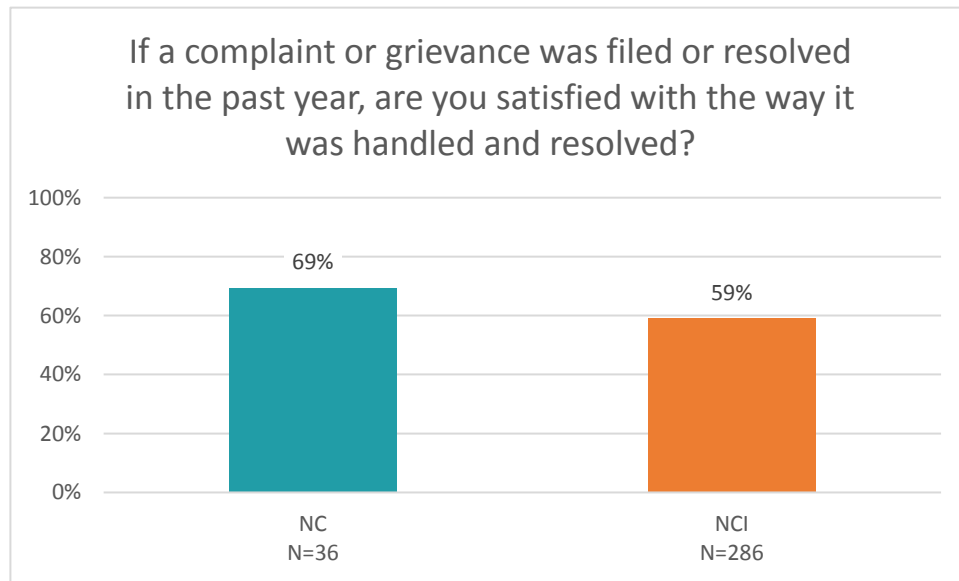
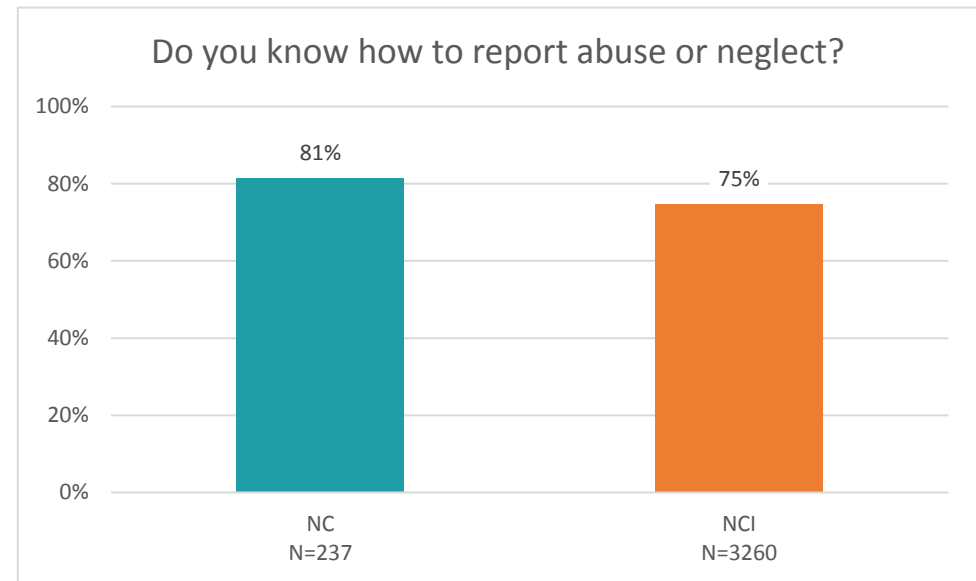
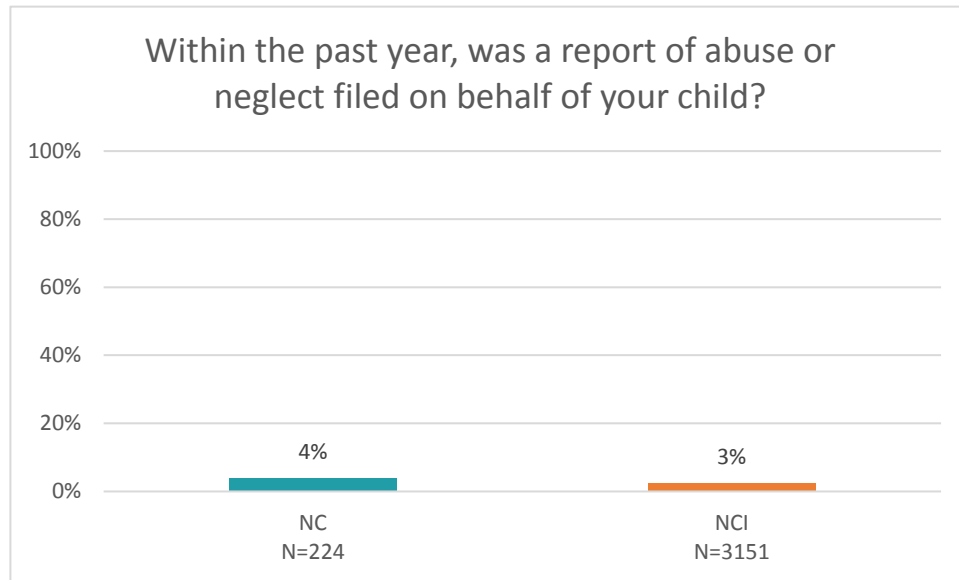


Chart 49. *

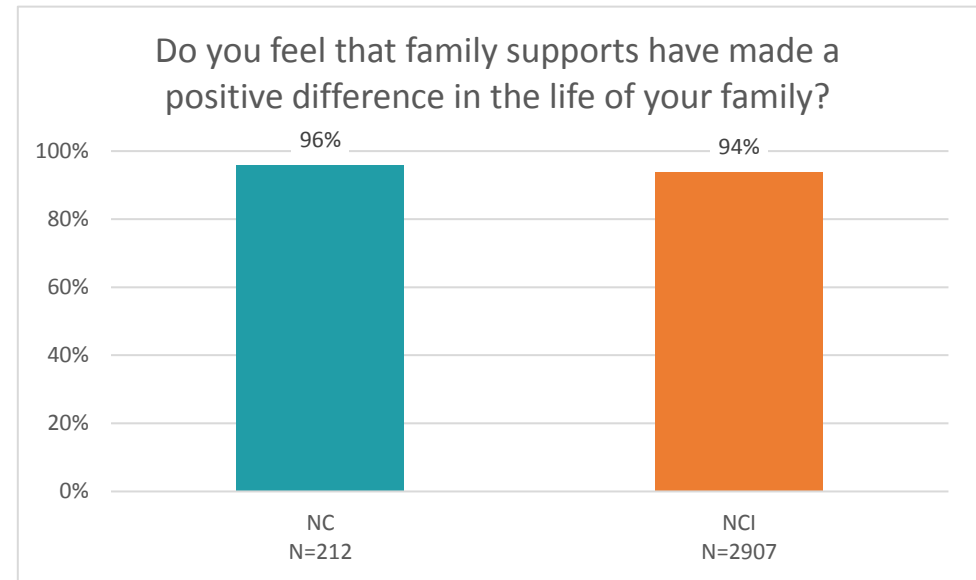


*For this question, 'No' and 'Don't know' responses were combined.

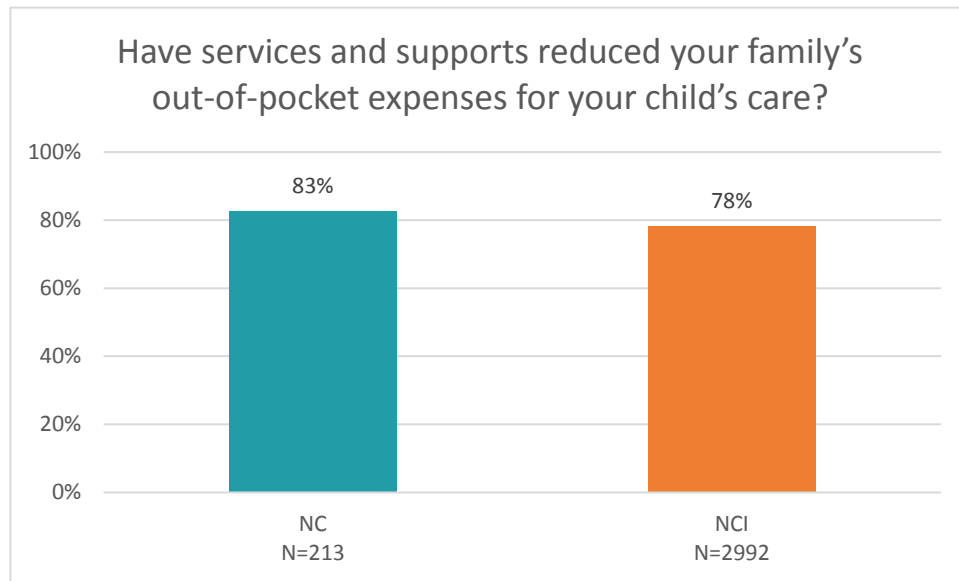
[Chart 50.](#)



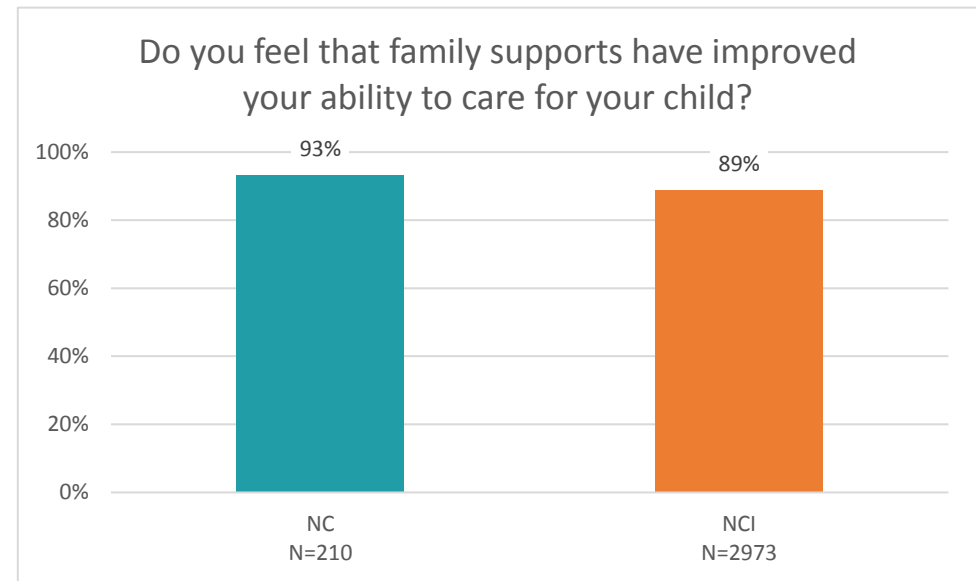
[Chart 51.](#)



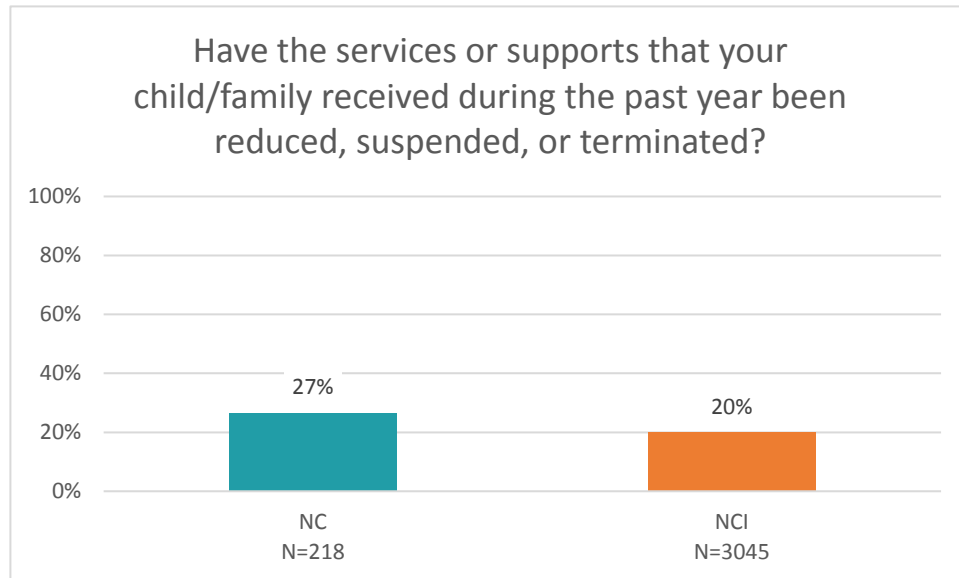
[Chart 52.](#)



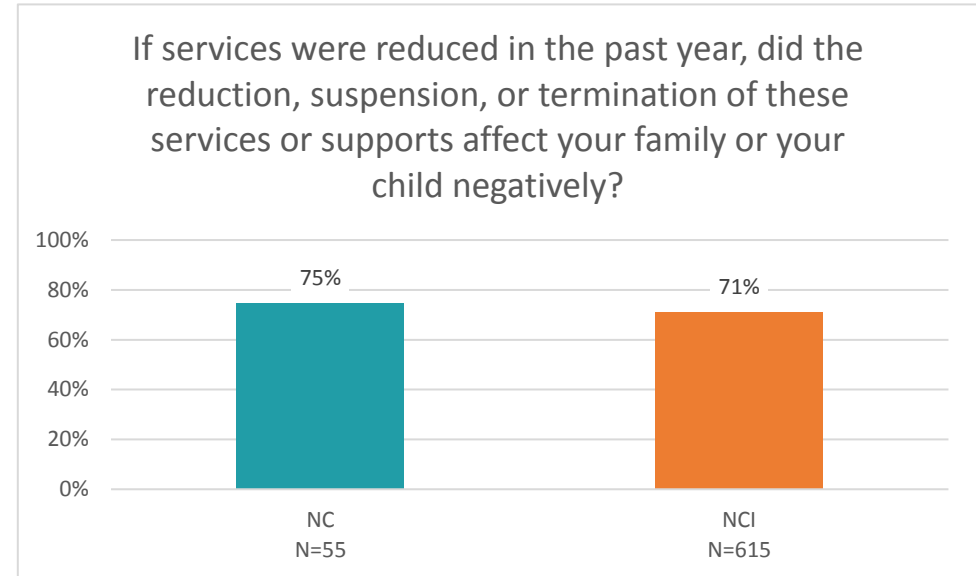
[Chart 53.](#)



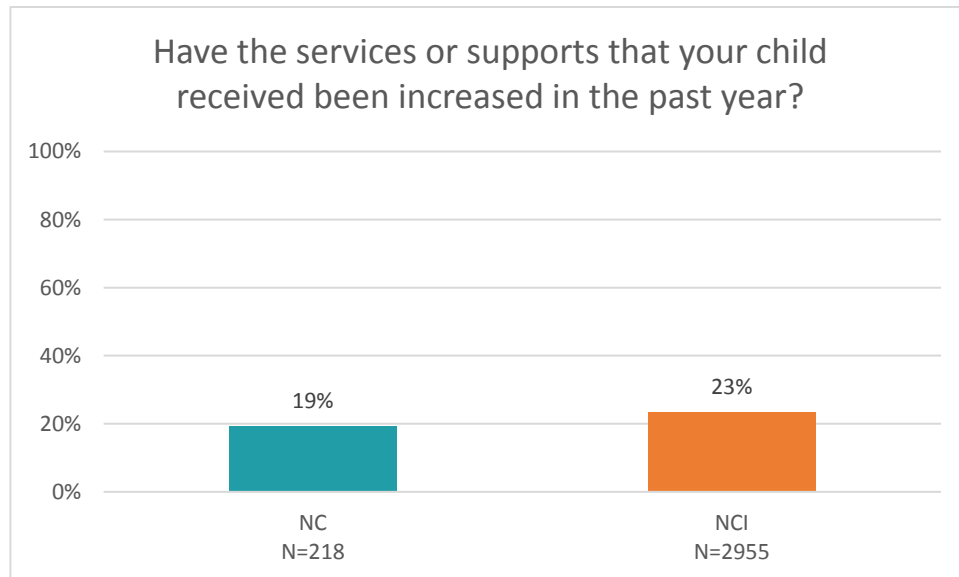
[Chart 54.](#)



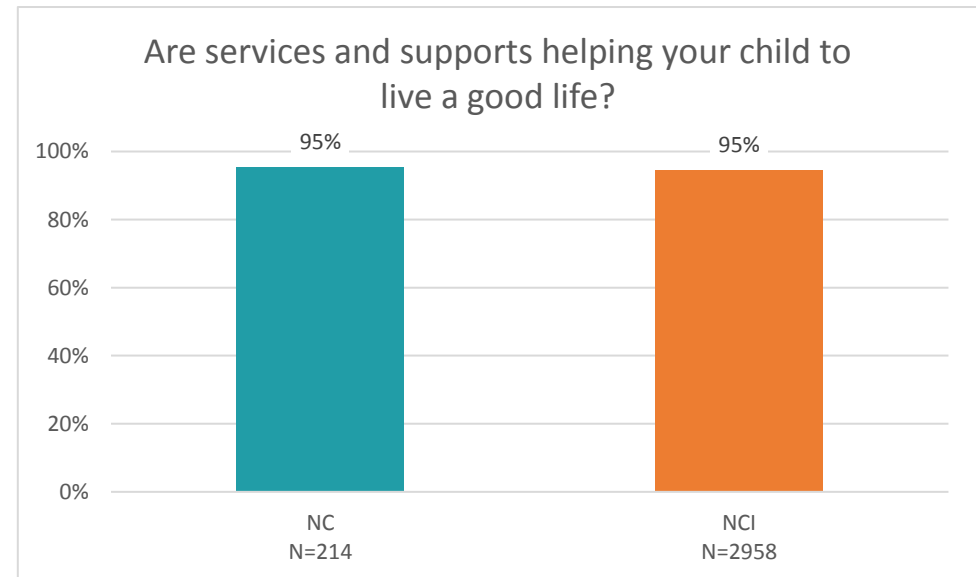
[Chart 55.](#)



[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? | NC ▼ | 24% | 50% | 20% | 7% | 229 |
| | 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?* | NC ▲ | 59% | 41% | 234 |
| | 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? | NC | 69% | 31% | 36 |
| | NCI | 59% | 41% | 286 |
| Do you know how to report abuse or neglect?* | NC ▲ | 81% | 19% | 237 |
| | NCI | 75% | 25% | 3,260 |
| Within the past year, was a report of abuse or neglect filed on behalf of your child? | NC | 4% | 96% | 224 |
| | 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? | NC | 96% | 4% | 212 |
| | NCI | 94% | 6% | 2,907 |
| Have services and supports reduced your family's out-of-pocket expenses for your child's care? | NC | 83% | 17% | 213 |
| | NCI | 78% | 22% | 2,992 |
| Do you feel that family supports have improved your ability to care for your child? | NC | 93% | 7% | 210 |
| | NCI | 89% | 11% | 2,973 |
| Have the services or supports that your child/family received during the past year been reduced, suspended, or terminated? | NC | 27% | 73% | 218 |
| | 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? | NC | 75% | 25% | 55 |
| | NCI | 71% | 29% | 615 |
| Have the services or supports that your child received been increased in the past year? | NC | 19% | 81% | 218 |
| | NCI | 23% | 77% | 2,955 |
| Are services and supports helping your child to live a good life? | NC | 95% | 5% | 214 |
| | NCI | 95% | 5% | 2,958 |