

NCI Child Family Survey Outcomes

Utah Report

2013-14 Data



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What is NCI?

The National Core Indicators (NCI) program is a voluntary effort by state developmental disability agencies to gauge and track their own performance using a common and nationally validated set of performance measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the Human Services Research Institute (HSRI). NCI has developed a set of more than 100 standard performance measures (or “indicators”) that states use to assess the outcomes of services provided to individuals and their families. These indicators focus on areas such as: employment, rights, service planning, community inclusion, choice, health, and safety. During the 2013-14 data collection cycle, 39 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 a mail-in survey sent to families with children who live in the family home and receive services from the State DD Agency. The NCI Child Family Survey is used to gather data on family outcomes and it is refined and tested to ensure that it is valid and reliable. The survey collects information on the child and respondent’s demographics, services and supports received, and contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes. Respondents also have the option of writing open-ended comments concerning their family’s participation in the service system.

What topics are covered by the survey?

The National Core Indicators are organized by topic or “domain.” Each domain consists of sub-domains, and each sub-domain is associated with a particular area of concern. The NCI Child Family Survey includes items to measure the “Family Outcomes” domain. The table on the following page lists the NCI Family Surveys sub-domains and concerns.

TABLE 1. NCI FAMILY SURVEY – SUB-DOMAINS AND CONCERN STATEMENTS

Sub-Domain	Concern
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 & Control	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
Community Connections	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.
Family 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 Child Family Survey by selecting a random sample of at least 1,000 families who had a child¹ with a developmental disability living at home and received at least one direct service or support other than service coordination.

¹ Some states include child up to age 22 who are receiving services as a child.

All states mailed out a paper survey to families selected in their sample. A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. Both the confidence interval and margin of error used are widely acceptable 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%.

Limitations of Data

The NCI Child Family Survey tool is not intended to be used for monitoring individuals or providers, but rather for assessing system-wide performance. The NCI Statewide Average should not be interpreted as necessarily defining “acceptable” levels of performance or satisfaction, nor does it provide benchmarks for acceptable or unacceptable levels of performance for each indicator. Instead, it describes average levels of performance or satisfaction across the State. It is up to public managers, policy-makers, and other stakeholders to decide what is an acceptable or unacceptable result (i.e., percentage of individuals achieving the indicated outcome).

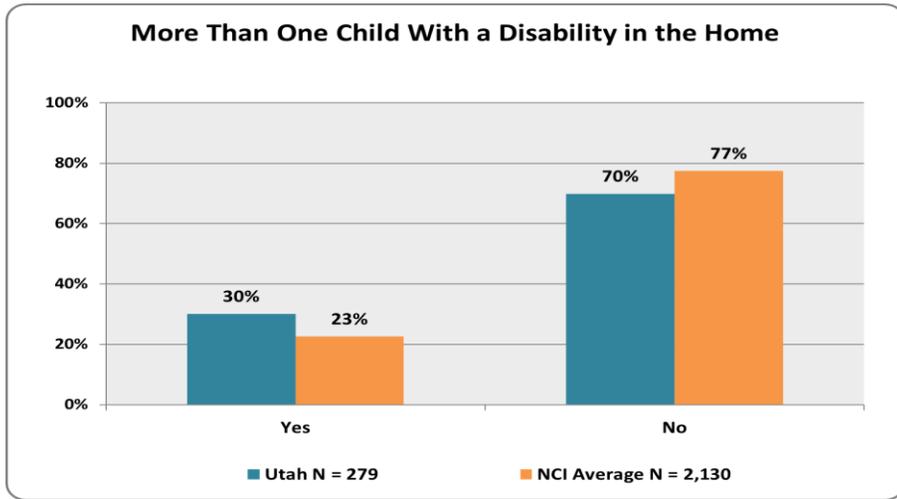
What is contained in this report?

This report illustrates 2013-14 NCI Child Family Survey demographic and outcome results from Utah compared to the NCI Average (the average of all other state averages). In 2013-14, eight states conducted to the Child Family Survey. All results are shown in chart form. Some questions may have a low response rate, particularly questions about knowledge and use of ID/DD money, reporting grievances, and abuse or neglect. States with less than 20 responses to a particular question were excluded from analysis for that question. The number of responses per each question by state and across NCI states are included in each chart. All state and national data results for this survey can be found online at <http://www.nationalcoreindicators.org/resources/reports/>.

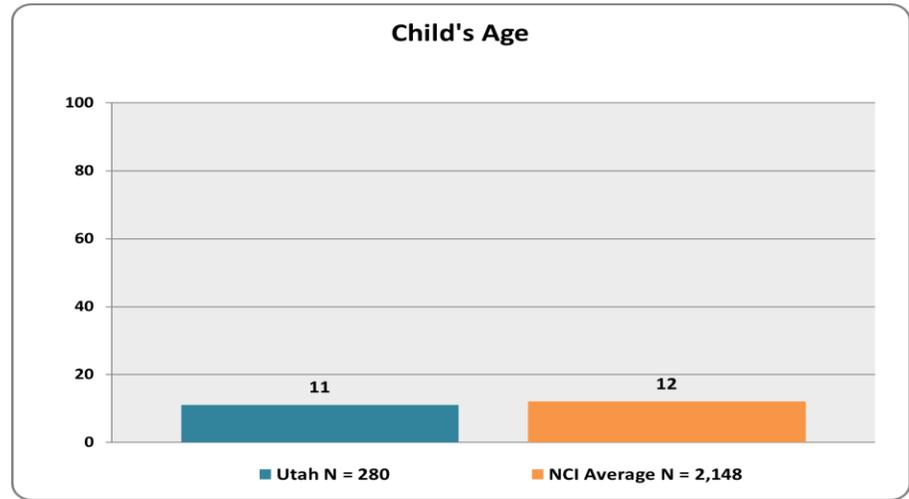
Results: Demographics of Child

ILLUSTRATES THE DEMOGRAPHIC PROFILE OF THE CHILD FOR WHOM THE SURVEY WAS COMPLETED

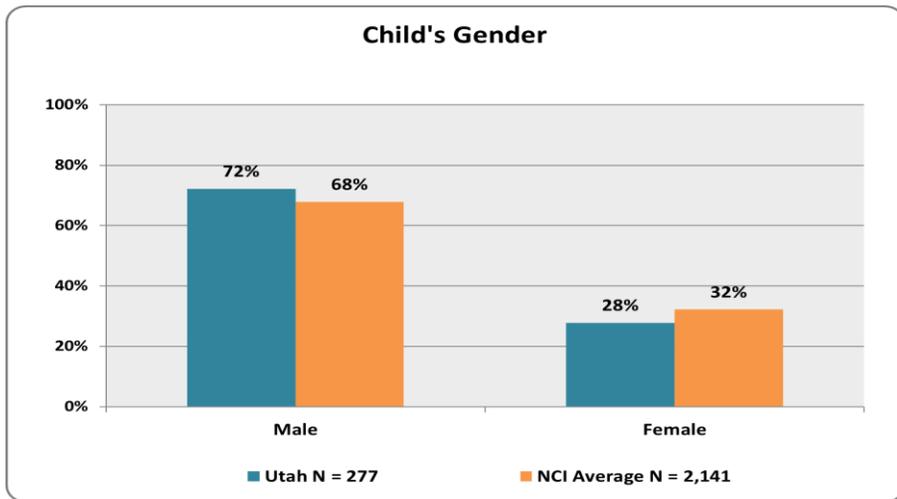
GRAPH 1. MORE THAN ONE CHILD AT HOME WITH ID/DD



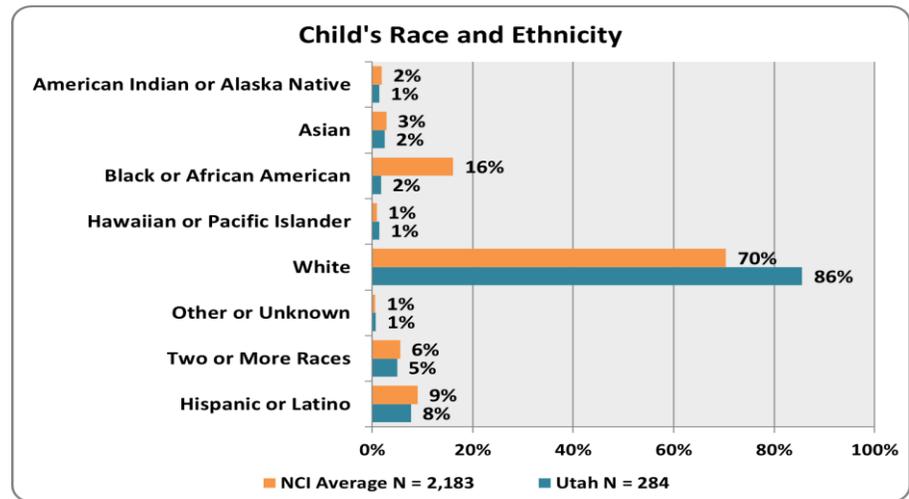
GRAPH 2. CHILD'S AGE



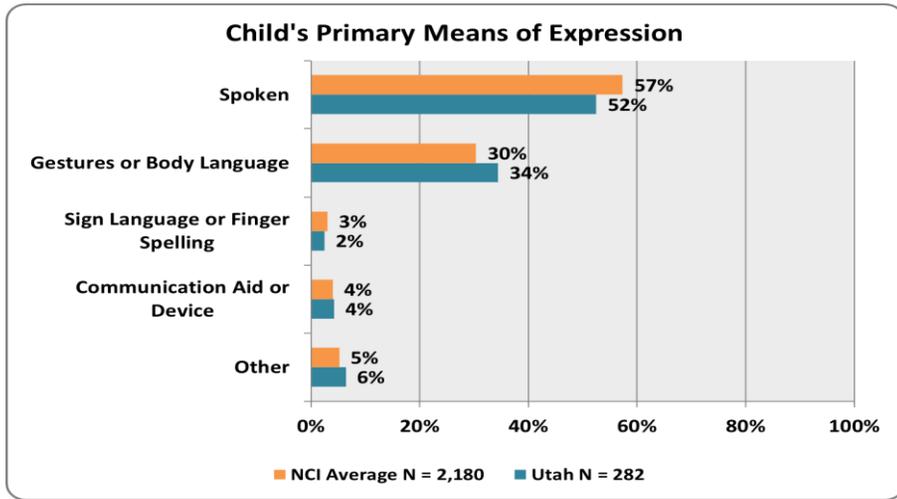
GRAPH 3. CHILD'S GENDER



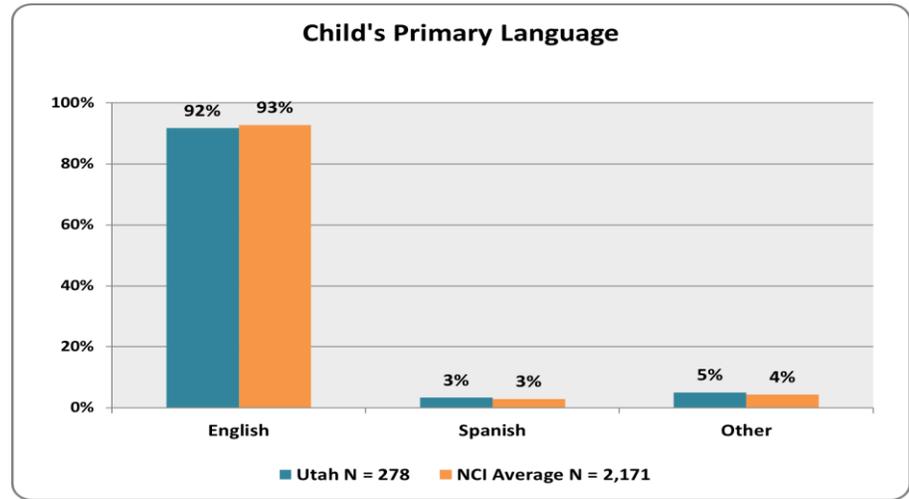
GRAPH 4. CHILD'S RACE AND ETHNICITY



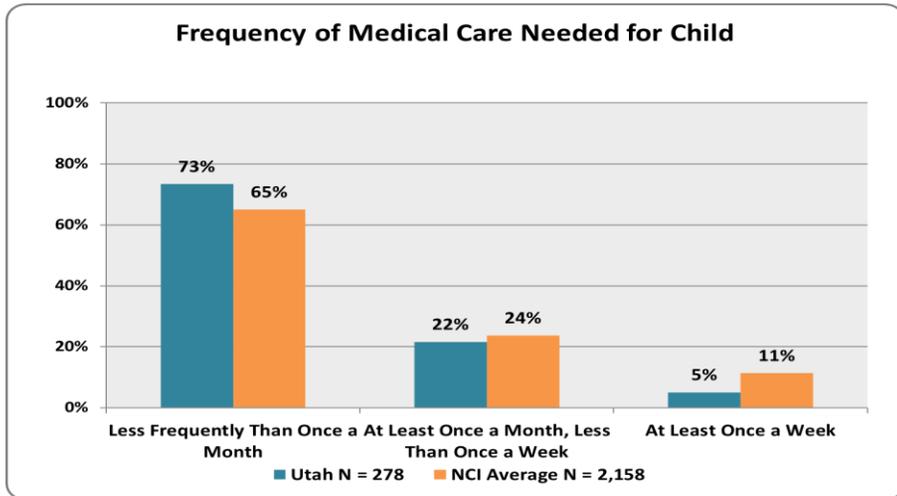
GRAPH 5. CHILD'S PRIMARY MEANS OF EXPRESSION



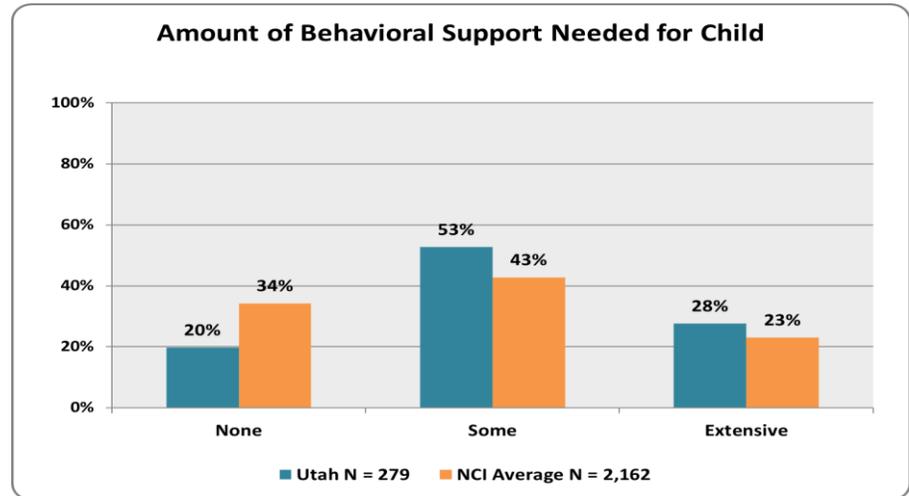
GRAPH 6. CHILD'S PRIMARY LANGUAGE



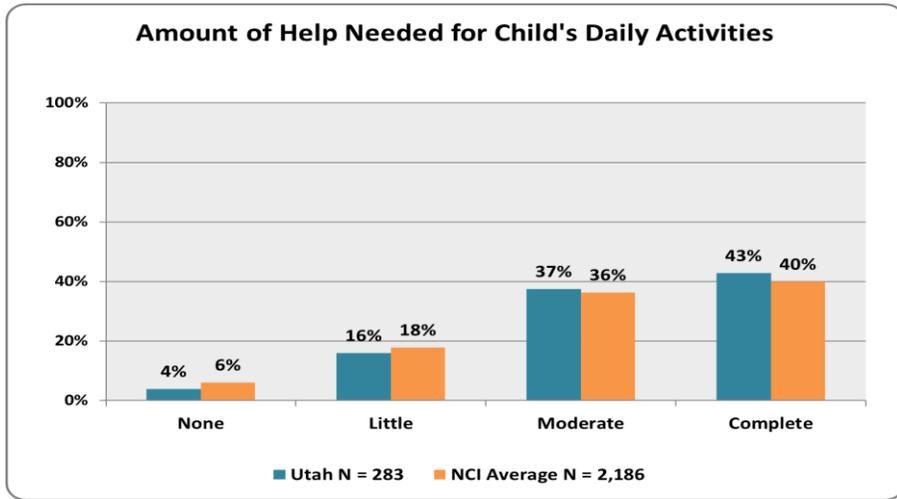
GRAPH 7. FREQUENCY OF MEDICAL CARE NEEDED FOR CHILD



GRAPH 8. AMOUNT OF BEHAVIORAL SUPPORT NEEDED FOR CHILD



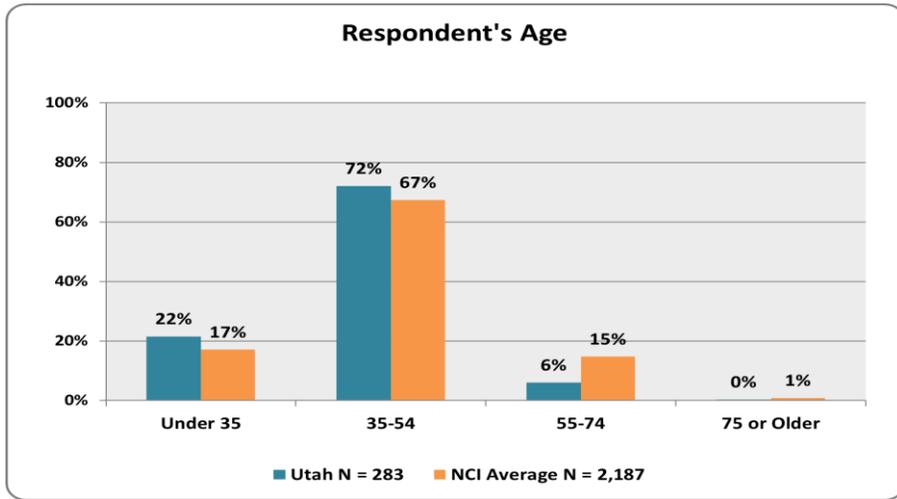
GRAPH 9. AMOUNT OF HELP NEEDED FOR CHILD'S DAILY ACTIVITIES



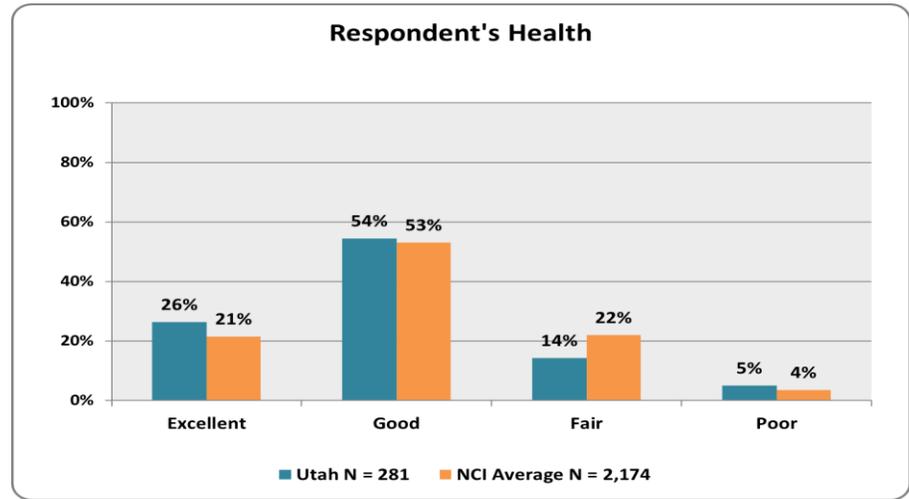
Results: Demographics of Respondent

ILLUSTRATES THE DEMOGRAPHIC PROFILE OF THE SURVEY RESPONDENTS

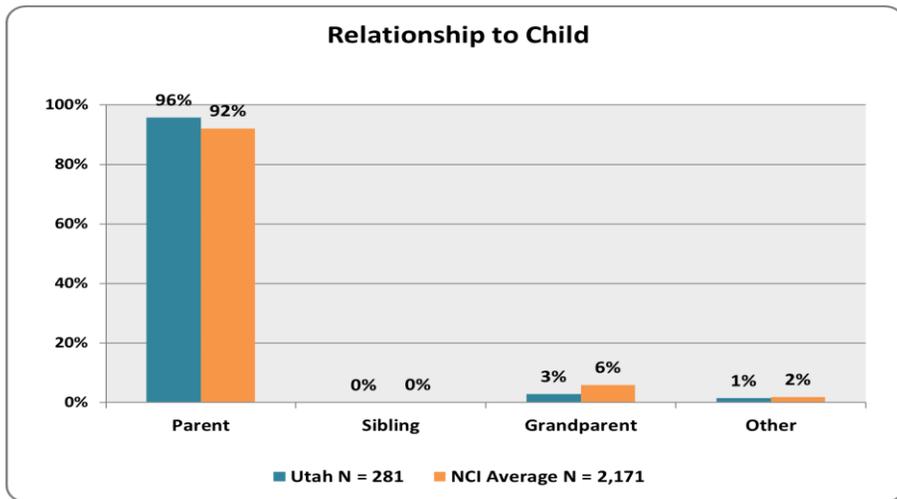
GRAPH 10. RESPONDENT'S AGE



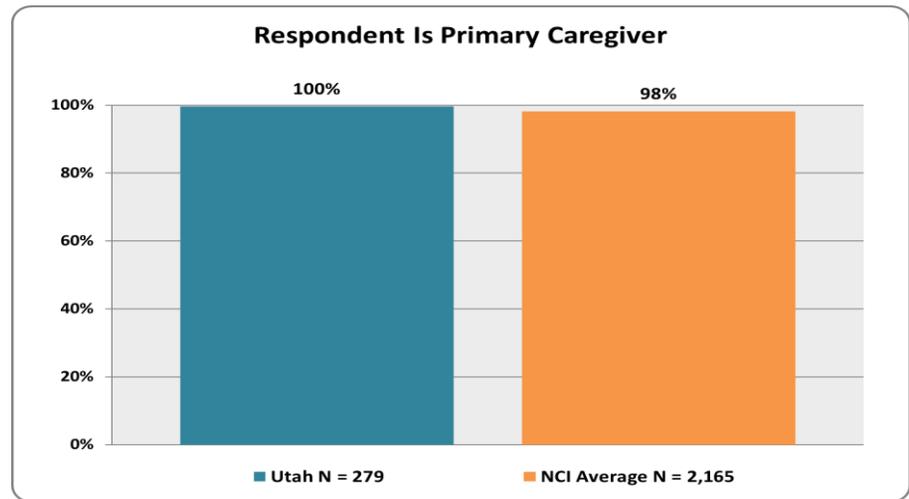
GRAPH 11. RESPONDENT'S HEALTH



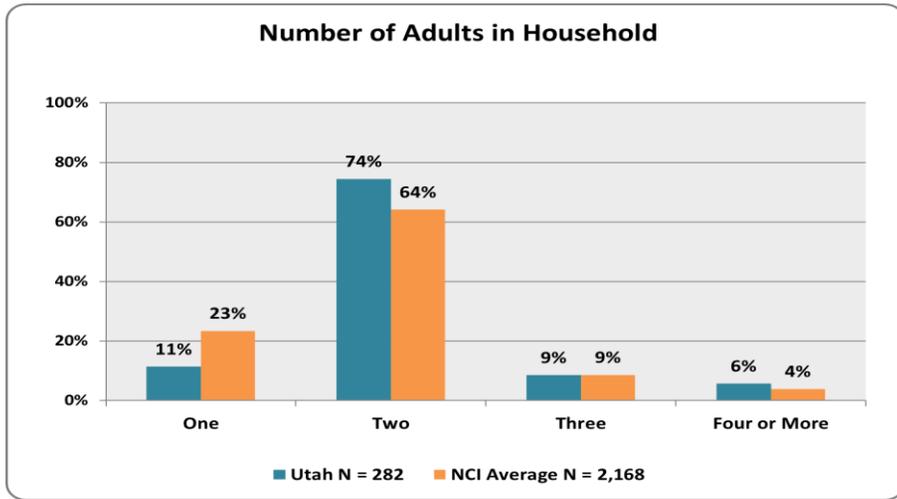
GRAPH 12. RELATIONSHIP TO CHILD



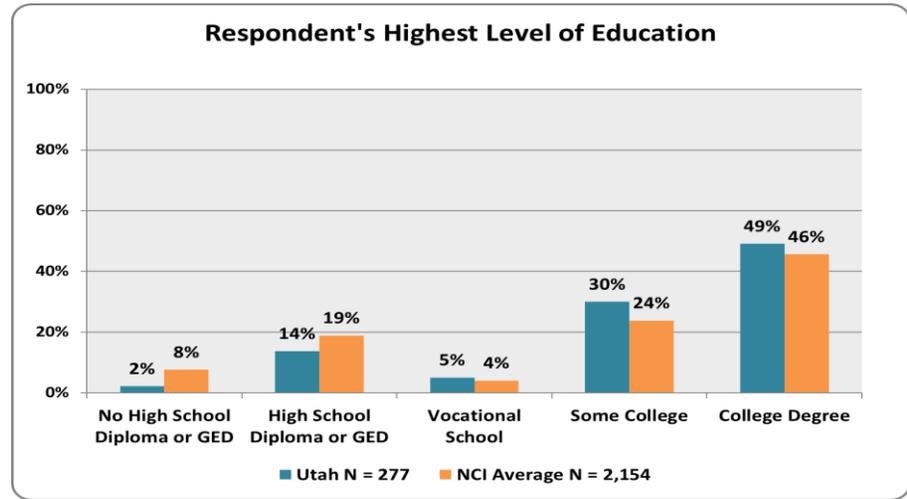
GRAPH 13. RESPONDENT IS PRIMARY CAREGIVER



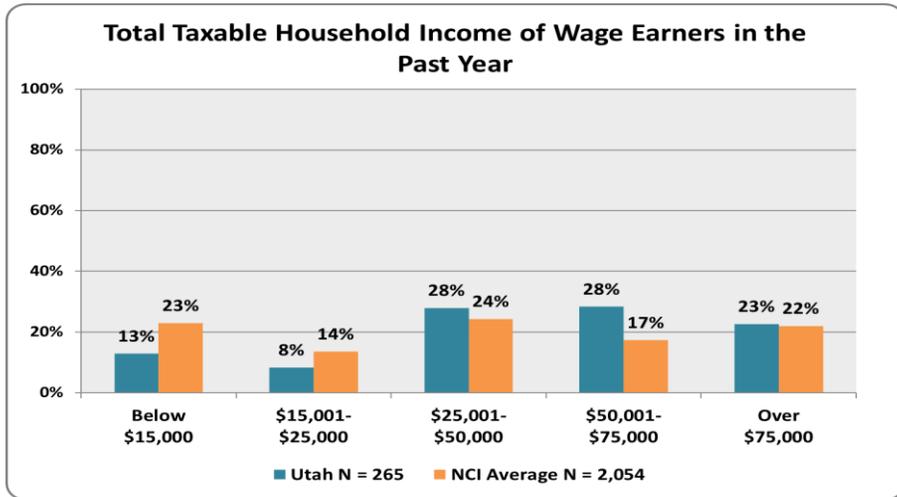
GRAPH 14. NUMBER OF ADULTS IN HOUSEHOLD



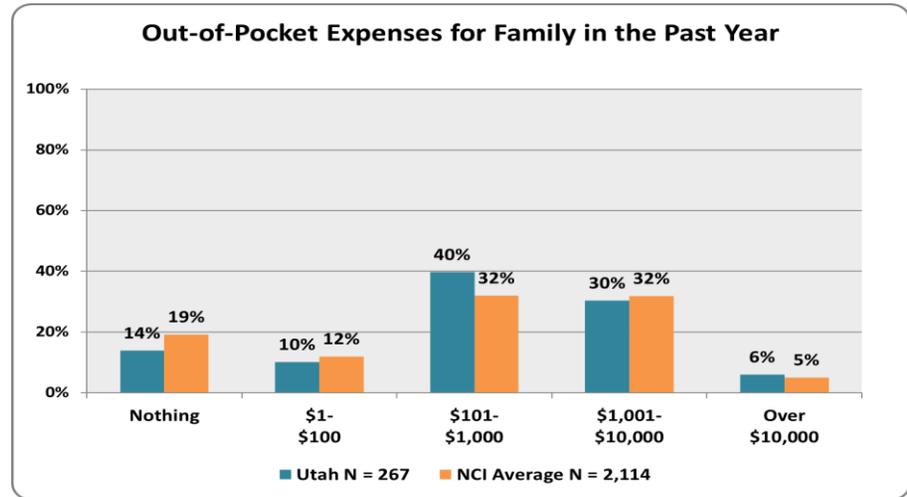
GRAPH 15. RESPONDENT'S HIGHEST LEVEL OF EDUCATION



GRAPH 16. TOTAL TAXABLE HOUSEHOLD INCOME OF WAGE EARNERS IN THE PAST YEAR



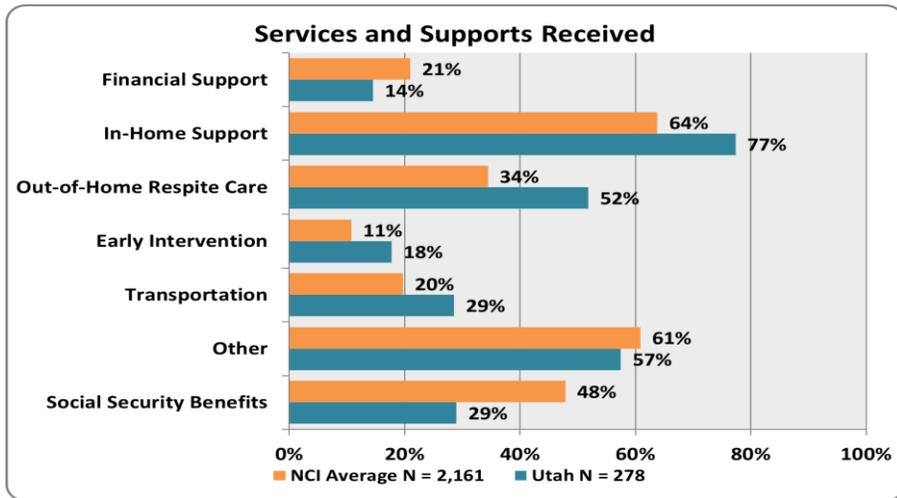
GRAPH 17. OUT-OF-POCKET EXPENSES FOR FAMILY IN THE PAST YEAR



Services and Supports Received

ILLUSTRATES THE SERVICES AND SUPPORTS RECEIVED BY CHILDREN AND FAMILIES

GRAPH 18. SERVICES AND SUPPORTS RECEIVED²

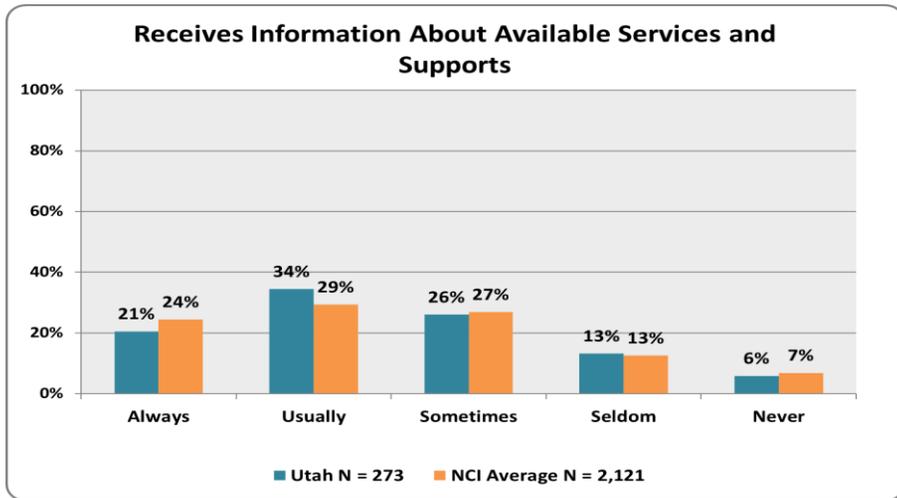


² All services and supports are received from the ID/DD Agency except social security benefits.

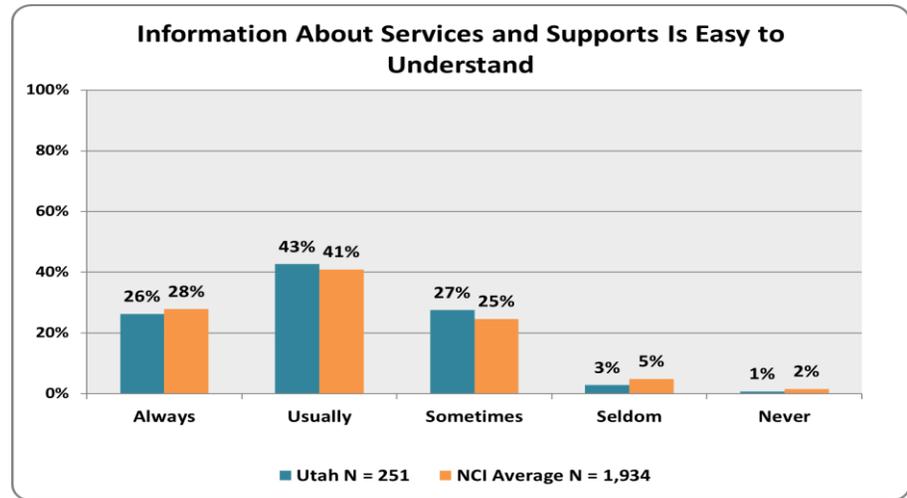
Information and Planning

FAMILIES AND CHILDREN WITH DISABILITIES HAVE THE INFORMATION AND SUPPORT NECESSARY TO PLAN FOR THEIR SERVICES AND SUPPORTS

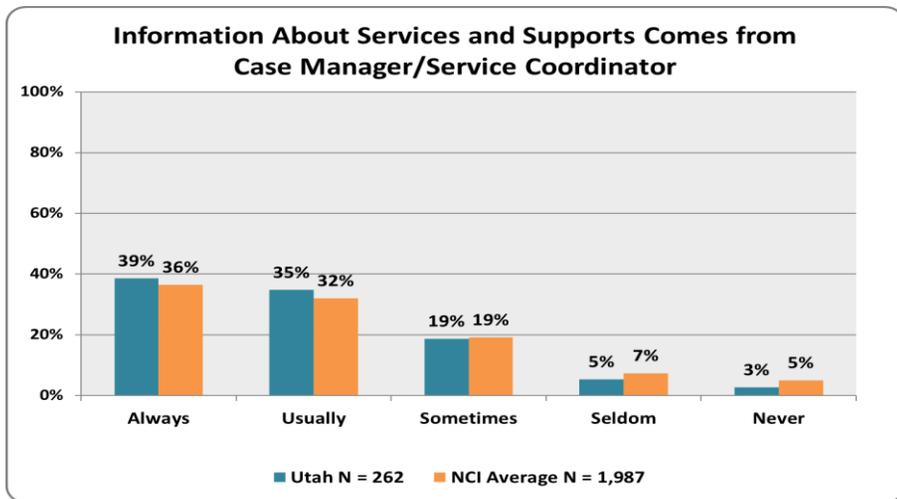
GRAPH 19. DO YOU RECEIVE INFORMATION ABOUT THE SERVICES AND SUPPORTS THAT ARE AVAILABLE TO YOUR CHILD AND FAMILY?



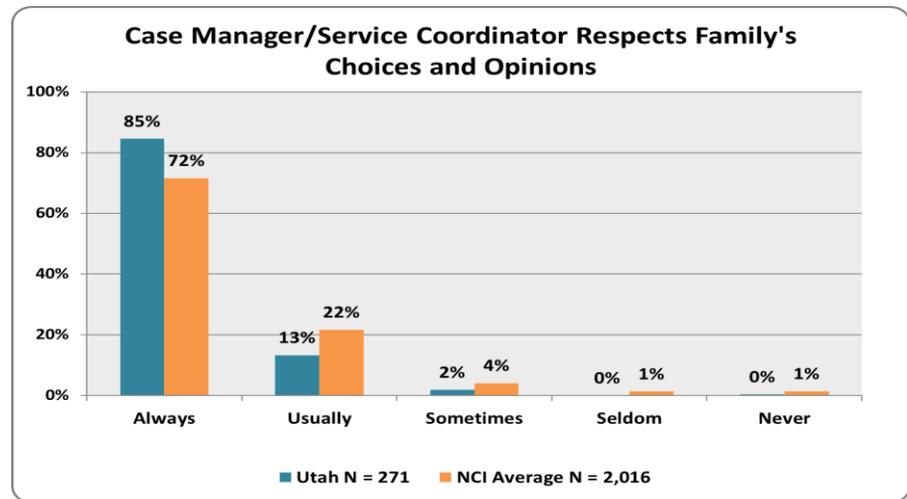
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GRAPH 21. DOES THE INFORMATION YOU RECEIVE COME FROM YOUR CASE MANAGER/SERVICE COORDINATOR?

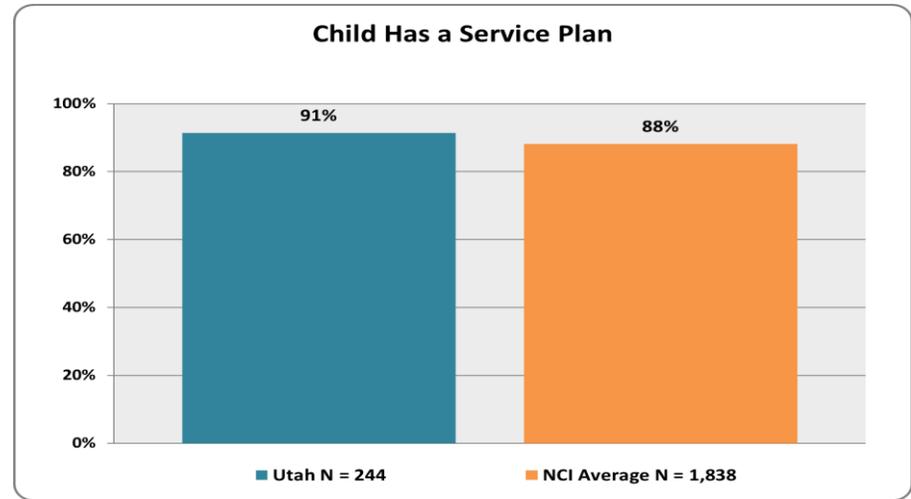
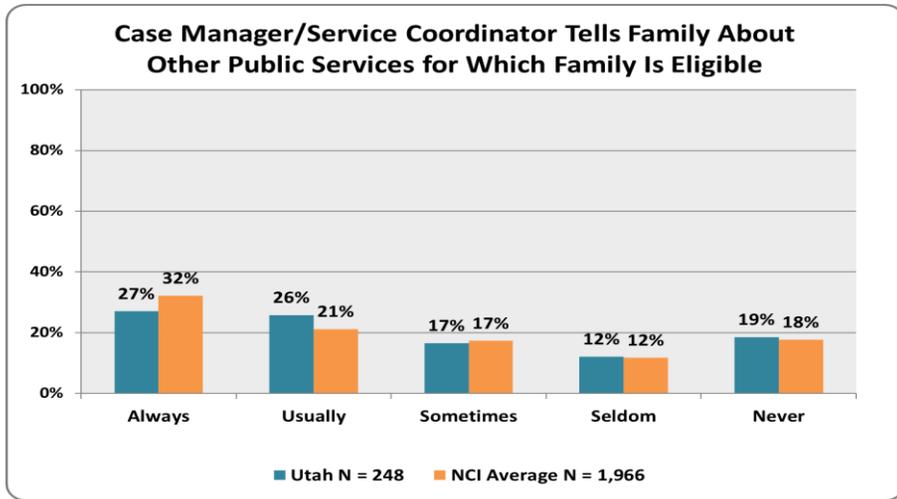


GRAPH 22. DOES THE CASE MANAGER/SERVICE COORDINATOR RESPECT YOUR FAMILY'S CHOICES AND OPINIONS?



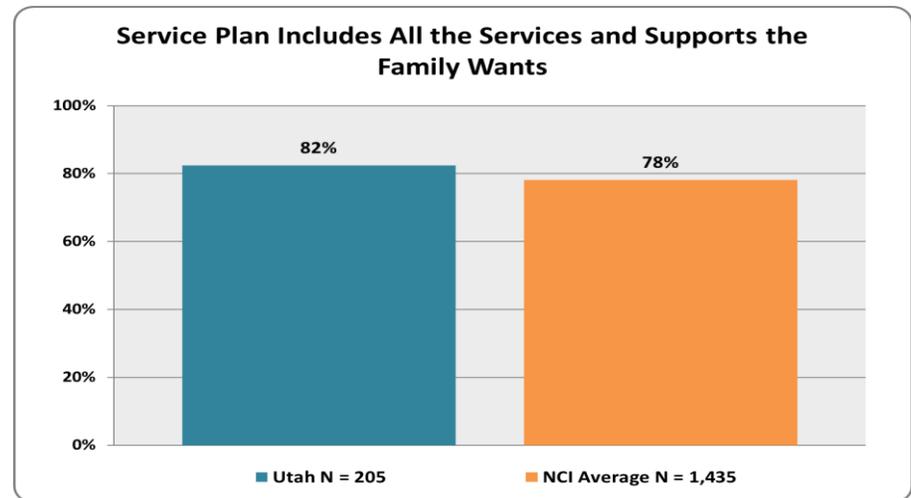
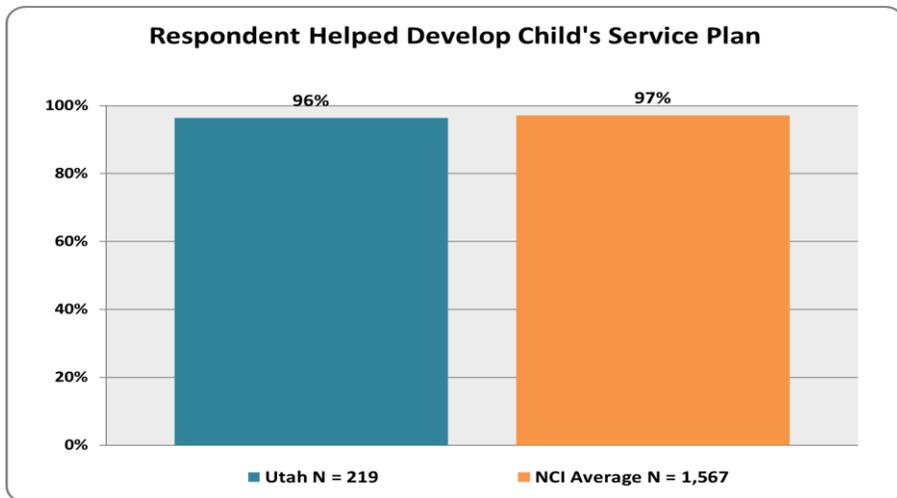
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GRAPH 24. DOES YOUR CHILD HAVE A SERVICE PLAN?

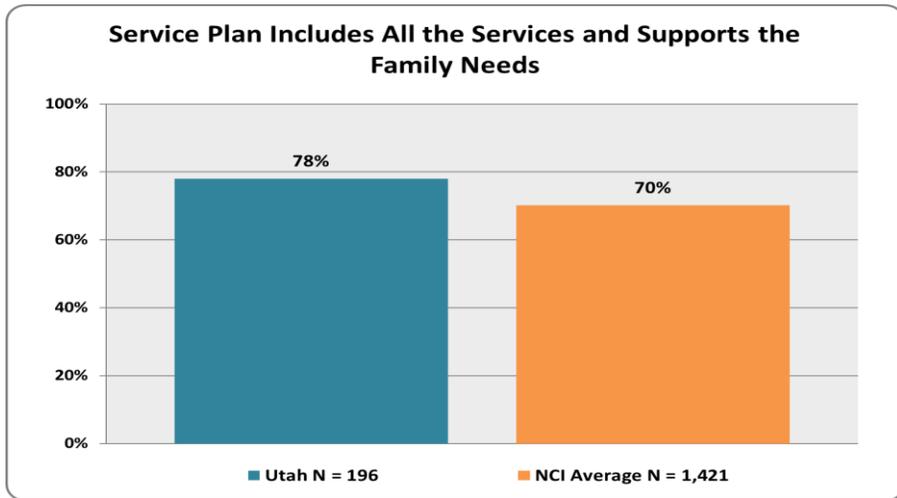


GRAPH 25. DID YOU HELP DEVELOP THE SERVICE PLAN?

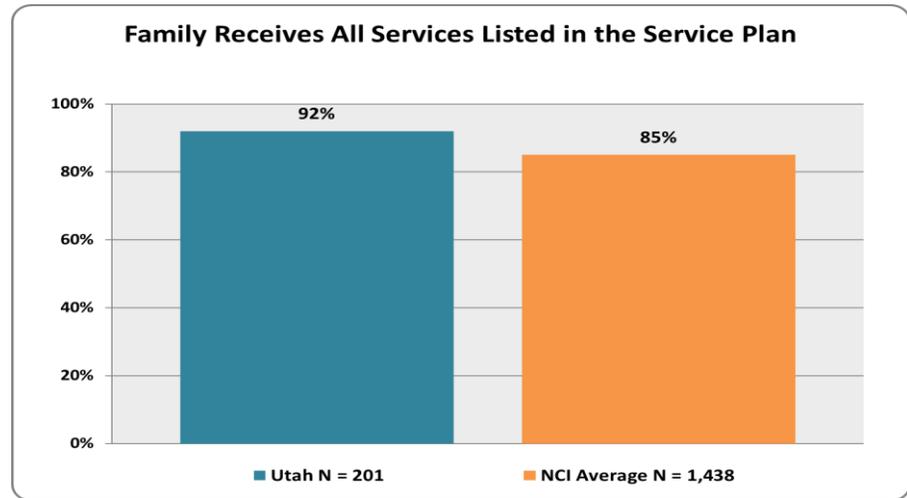
GRAPH 26. DOES THE SERVICE PLAN INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY WANTS?



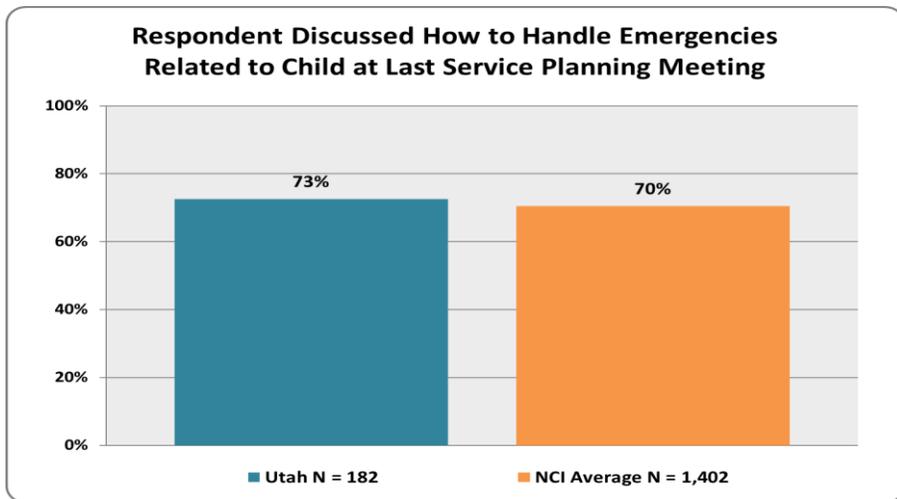
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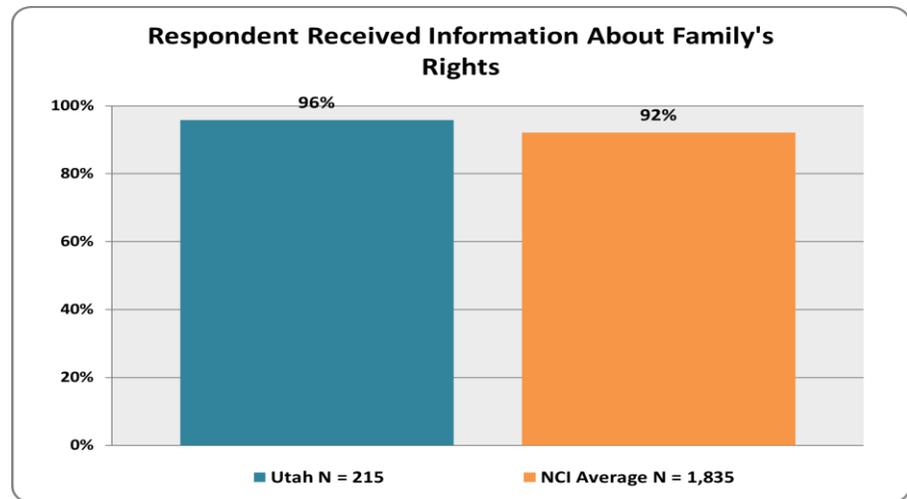
GRAPH 28. DOES YOUR FAMILY RECEIVE ALL THE SERVICES LISTED IN THE SERVICE PLAN?



GRAPH 29. DID YOU DISCUSS HOW TO HANDLE EMERGENCIES RELATED TO YOUR CHILD AT THE LAST SERVICE PLANNING MEETING?



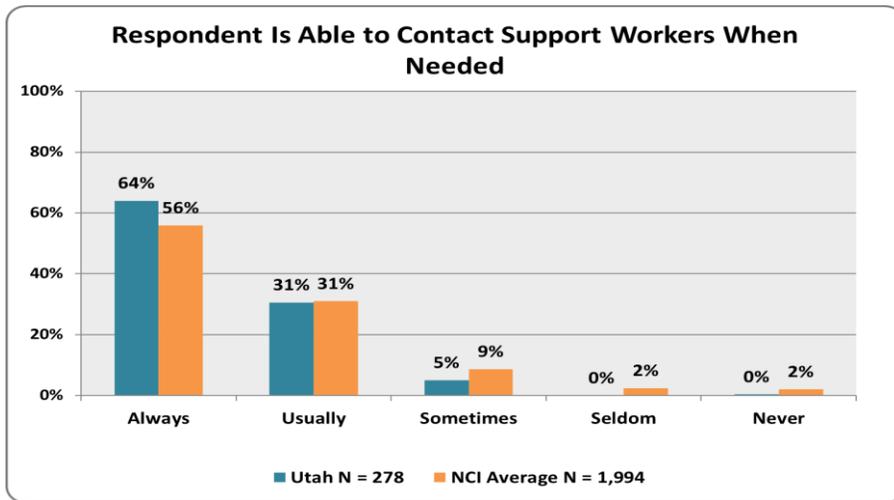
GRAPH 30. HAVE YOU RECEIVED INFORMATION ABOUT YOUR FAMILY'S RIGHTS?



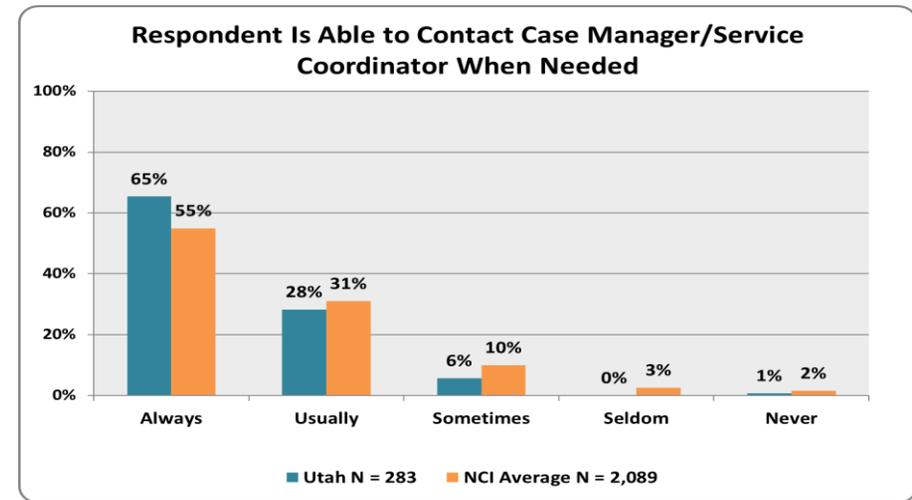
Access and Delivery

FAMILIES AND CHILDREN WITH DISABILITIES GET THE SERVICES AND SUPPORTS THEY NEED

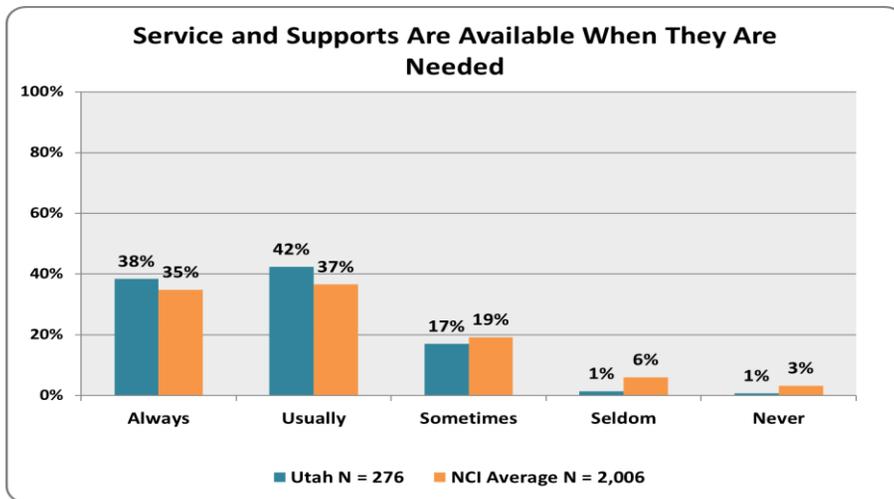
GRAPH 31. ARE YOU ABLE TO CONTACT YOUR SUPPORT WORKERS WHEN YOU NEED TO?



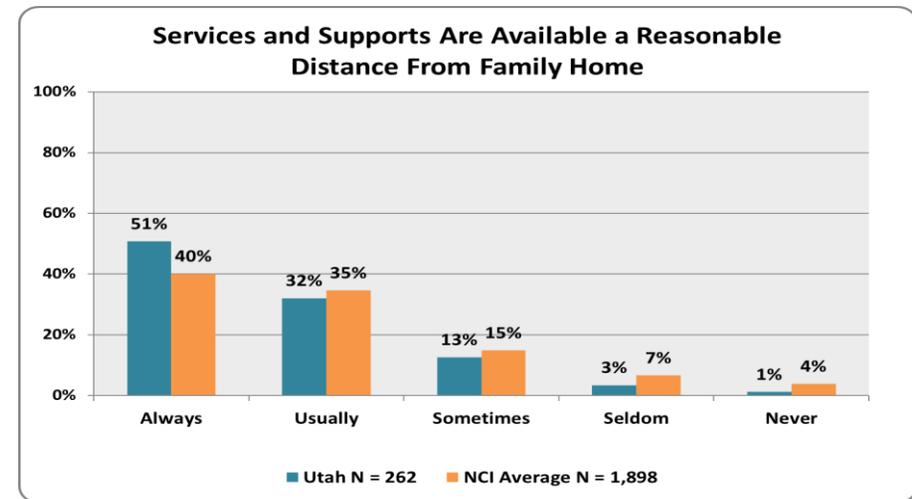
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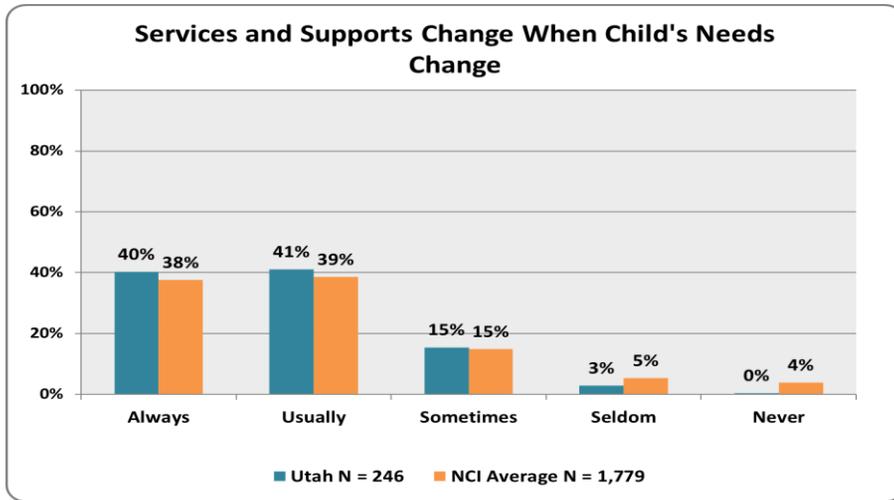
GRAPH 33. ARE SERVICES AND SUPPORTS AVAILABLE WHEN YOU NEED THEM?



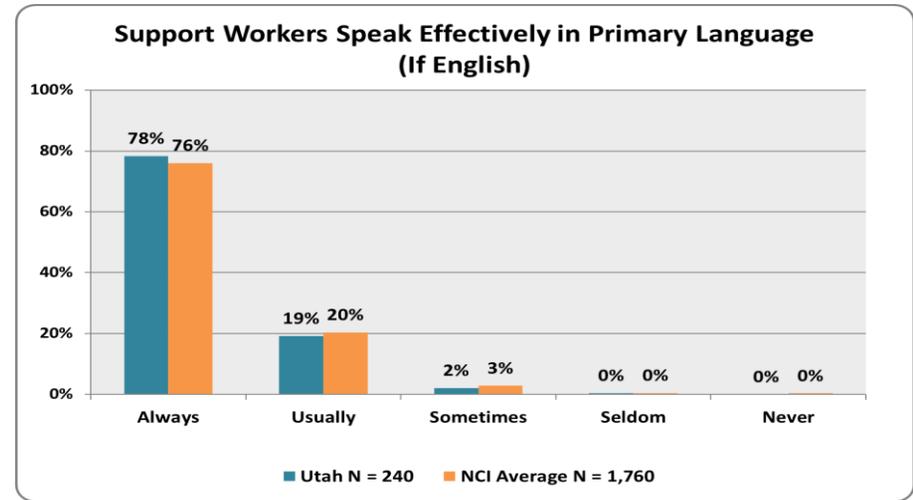
GRAPH 34. ARE SERVICES AND SUPPORTS AVAILABLE WITHIN A REASONABLE DISTANCE FROM YOUR HOME?



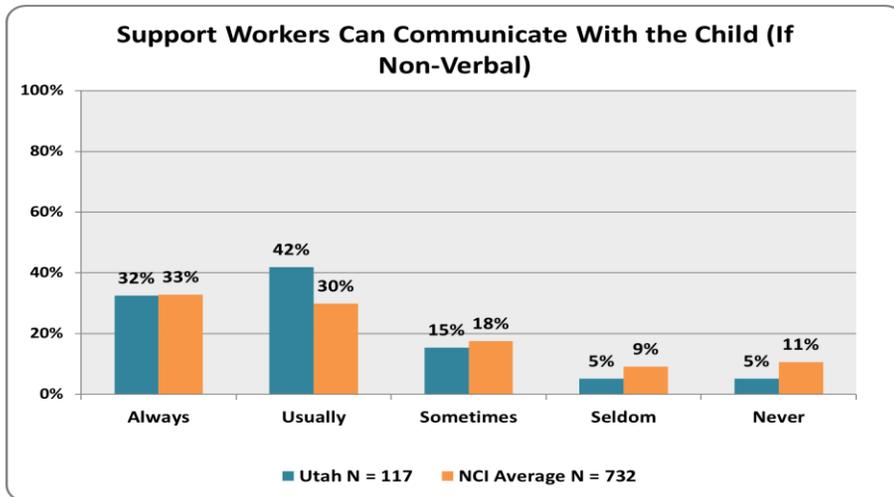
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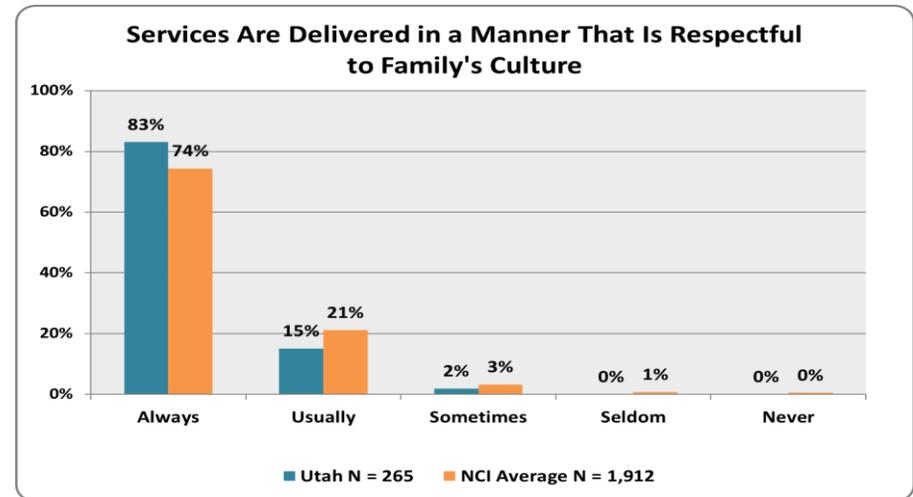
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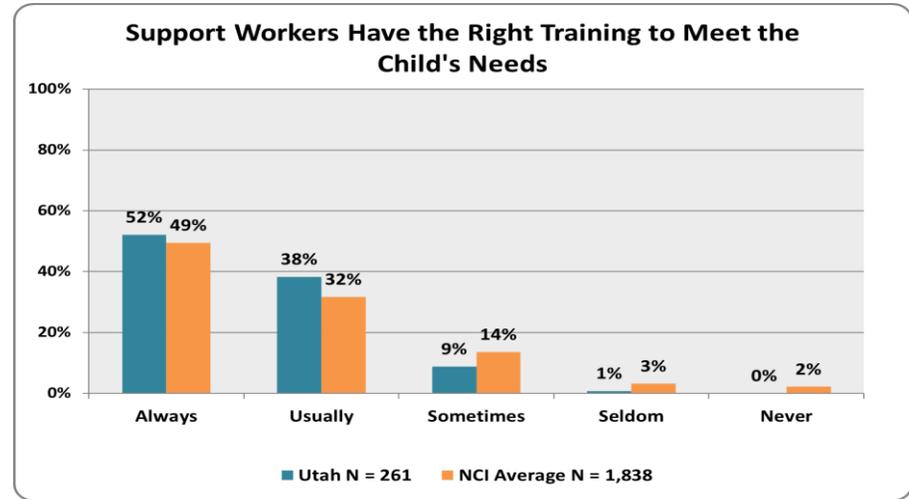
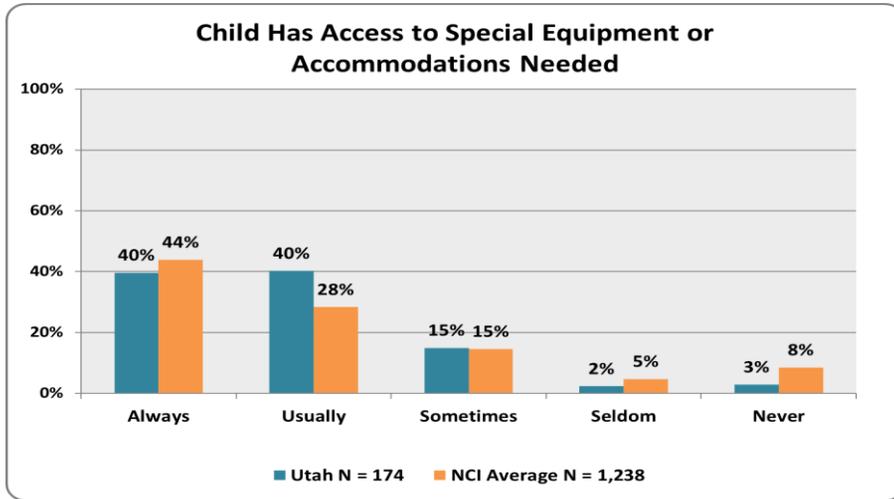


GRAPH 38. ARE SERVICES DELIVERED IN A WAY THAT IS RESPECTFUL TO YOUR FAMILY'S CULTURE?



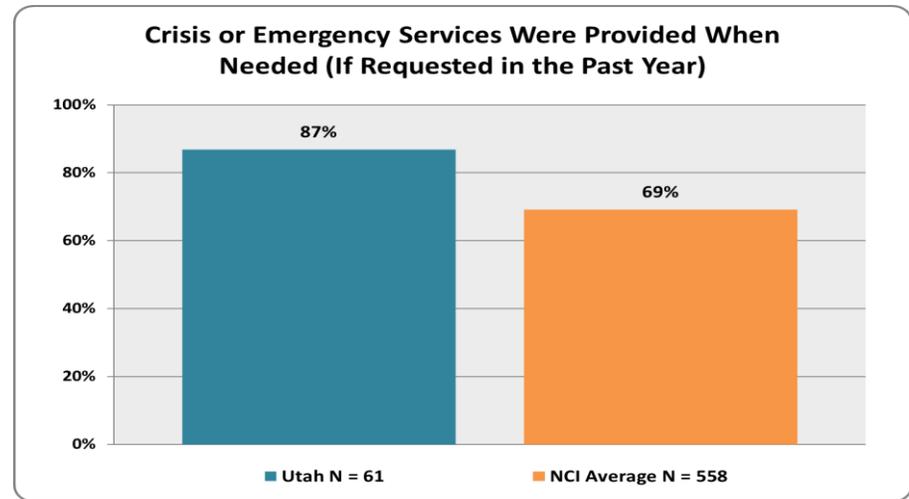
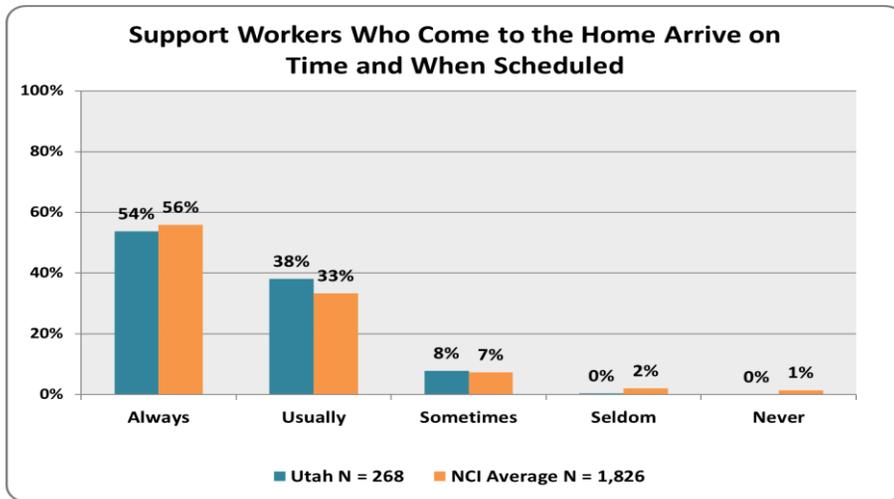
GRAPH 39. DOES YOUR CHILD HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT S/HE NEEDS (E.G., WHEELCHAIR, RAMP, COMMUNICATION BOARD)?

GRAPH 40. DO THE SUPPORT WORKERS HAVE THE RIGHT TRAINING TO MEET YOUR CHILD'S NEEDS?

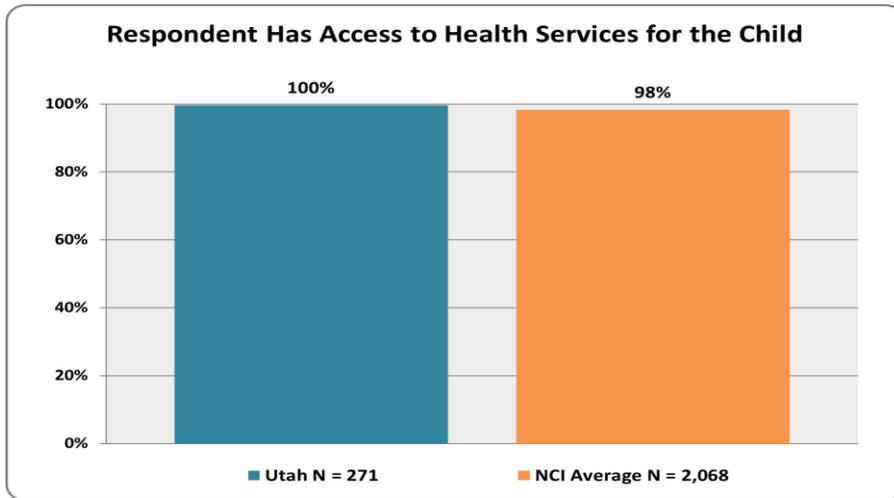


GRAPH 41. DO THE SUPPORT WORKERS WHO COME TO YOUR HOME ARRIVE ON TIME AND WHEN SCHEDULED?

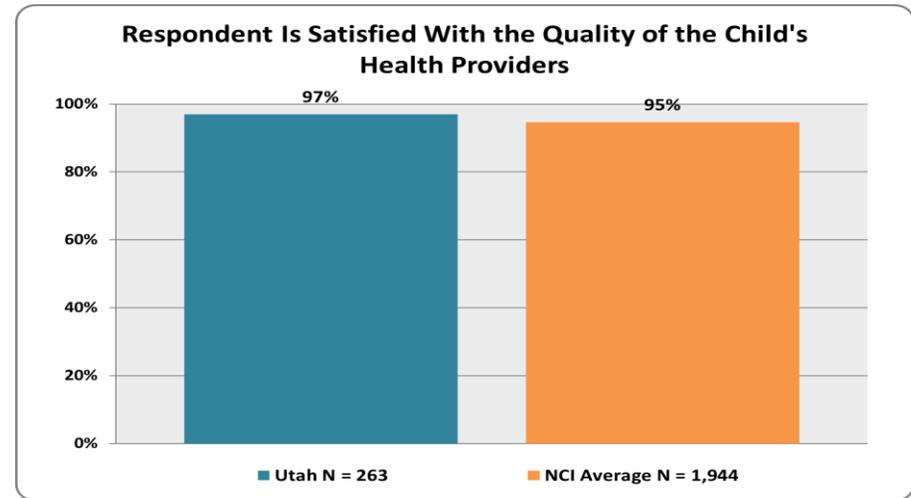
GRAPH 42. IF YOU ASKED FOR CRISIS/EMERGENCY SERVICES DURING THE PAST YEAR, WERE SERVICES PROVIDED WHEN NEEDED?



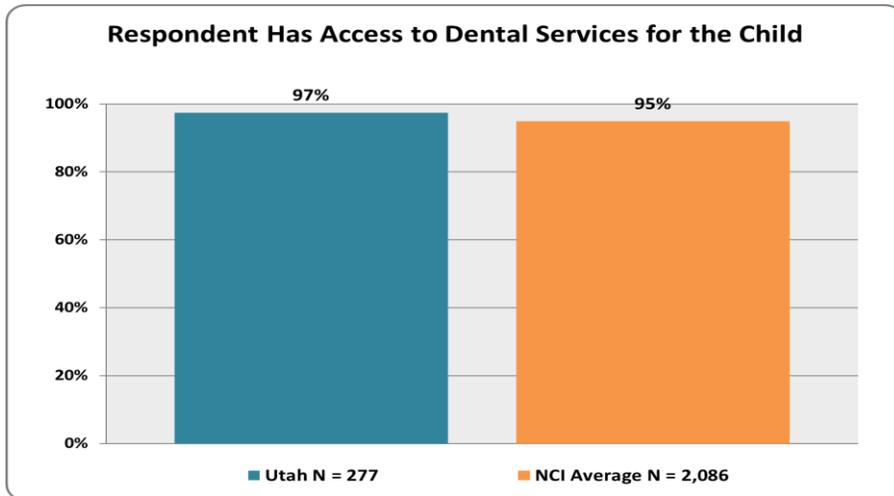
GRAPH 43. DO YOU HAVE ACCESS TO HEALTH SERVICES FOR YOUR CHILD?



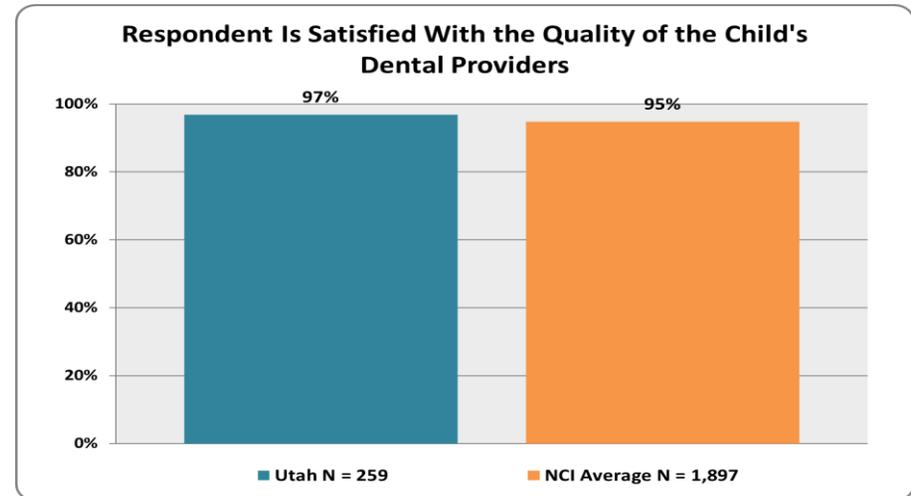
GRAPH 44. IF YOU HAVE ACCESS TO HEALTH SERVICES FOR YOUR CHILD, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



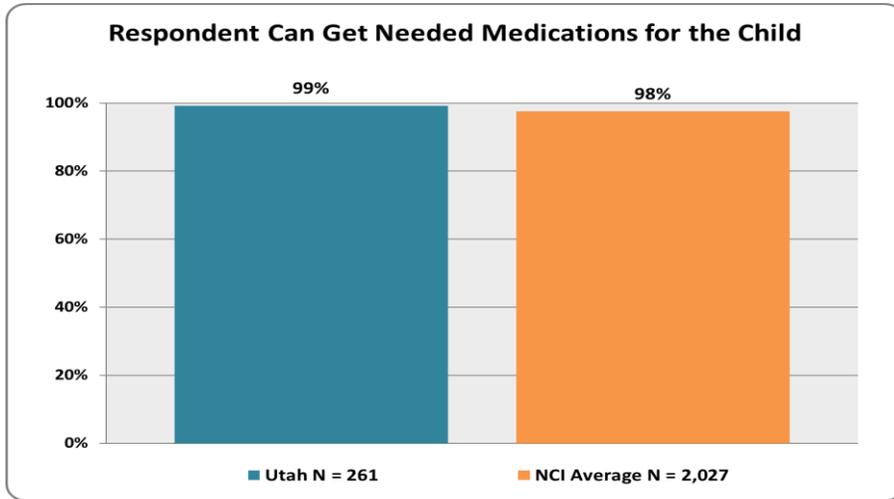
GRAPH 45. DO YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR CHILD?



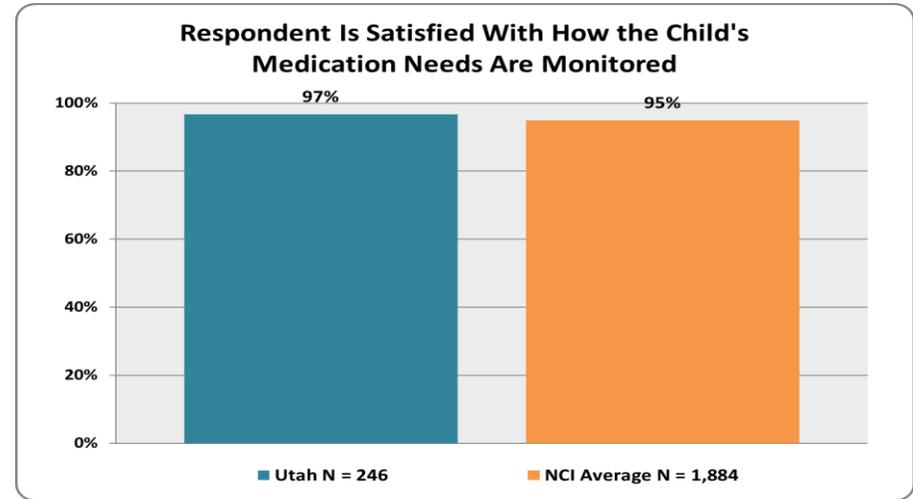
GRAPH 46. IF YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR CHILD, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



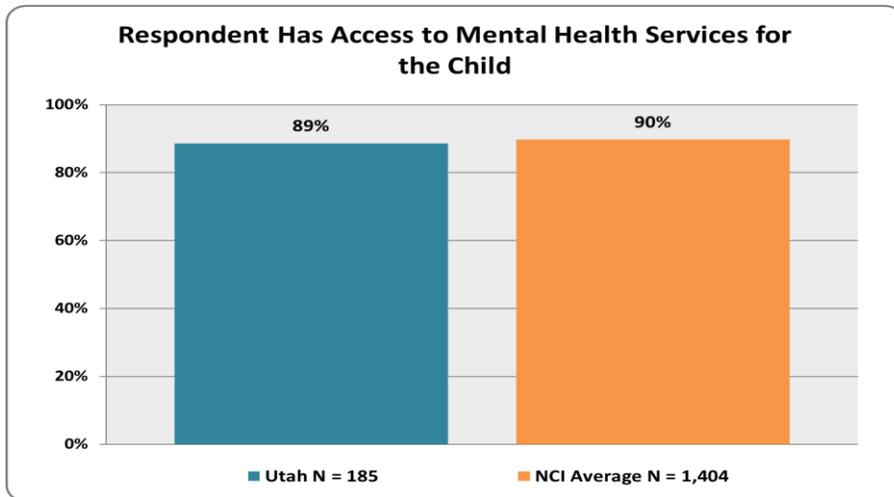
GRAPH 47. ARE YOU ABLE TO GET MEDICATIONS NEEDED FOR YOUR CHILD?



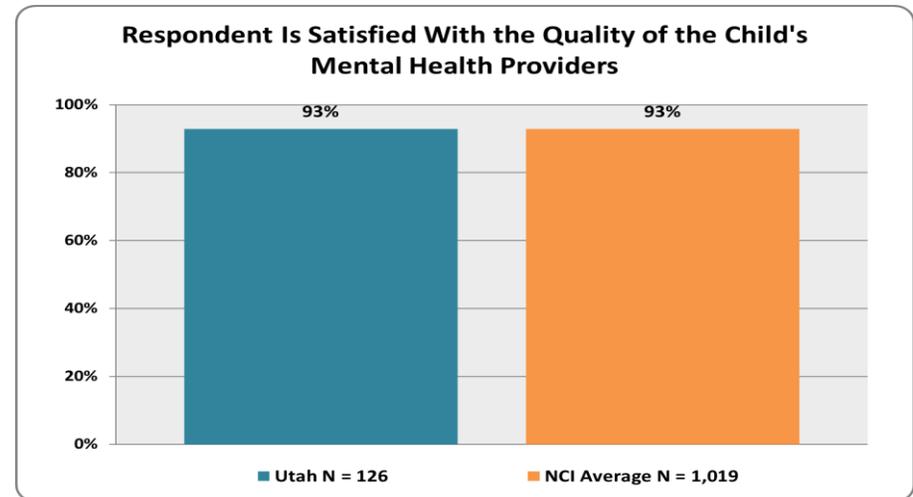
GRAPH 48. IF YOU HAVE ACCESS TO NEEDED MEDICATIONS FOR YOUR CHILD, ARE YOU SATISFIED WITH HOW YOUR CHILD'S MEDICATION NEEDS ARE MONITORED?



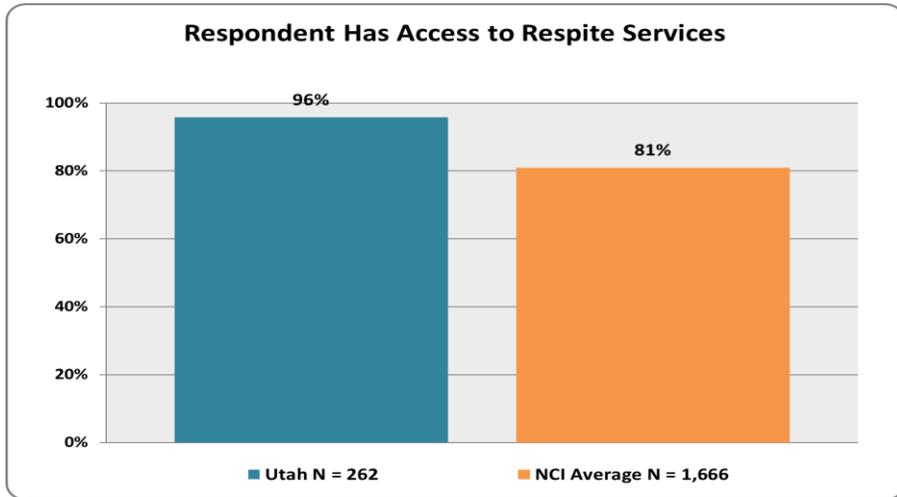
GRAPH 49. IF NEEDED, DO YOU HAVE ACCESS TO MENTAL HEALTH SERVICES FOR YOUR CHILD?



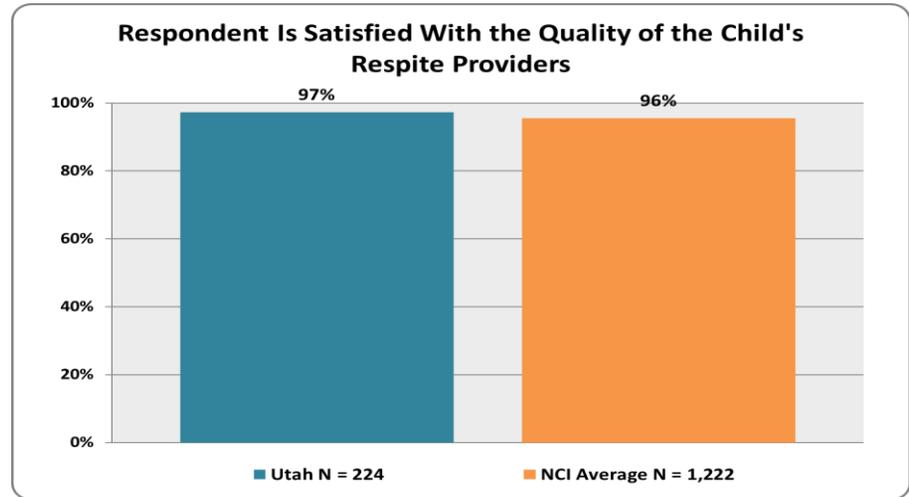
GRAPH 50. IF YOU HAVE ACCESS TO MENTAL HEALTH SERVICES FOR YOUR CHILD, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



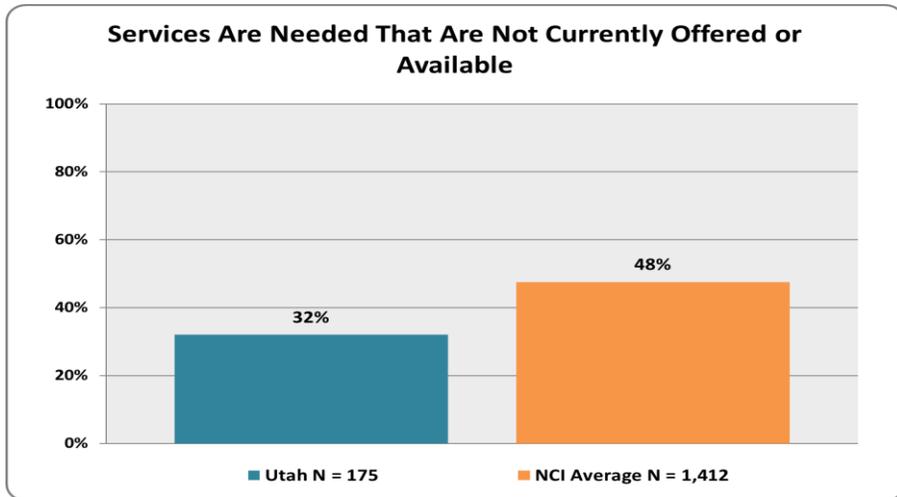
GRAPH 51. IF YOU NEED RESPITE SERVICES, DO YOU HAVE ACCESS TO THEM?



GRAPH 52. IF YOU HAVE ACCESS TO RESPITE SERVICES, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



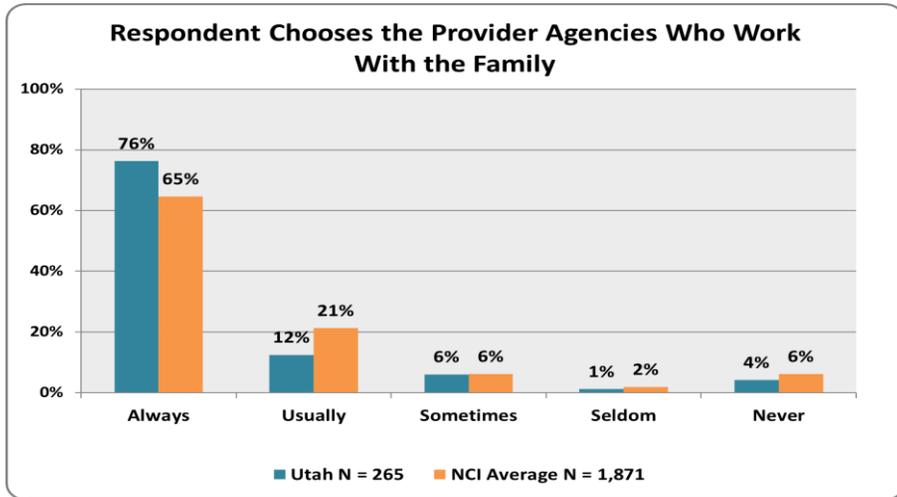
GRAPH 53. ARE THERE SERVICES THAT YOUR FAMILY NEEDS THAT ARE NOT CURRENTLY OFFERED OR AVAILABLE?



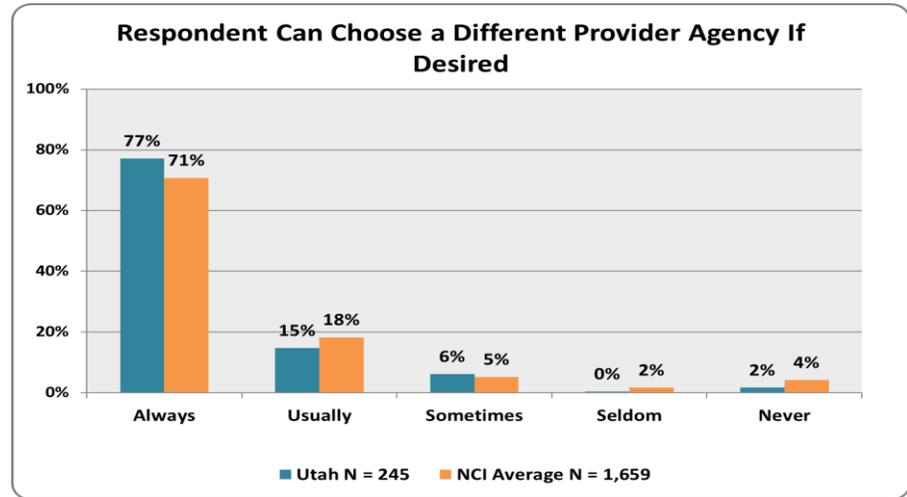
Choice and Control

FAMILIES DETERMINE THE SERVICES AND SUPPORTS THEY AND THEIR CHILDREN RECEIVE AND THE INDIVIDUALS OR AGENCIES WHO PROVIDE THEM

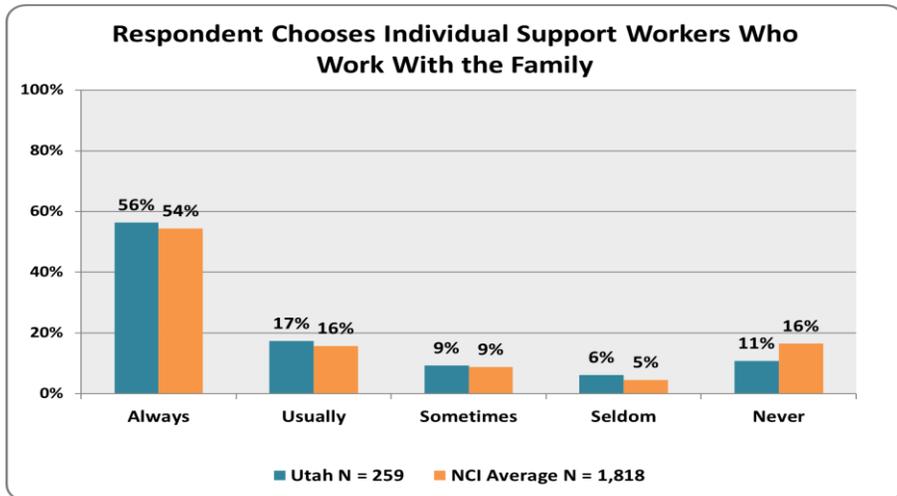
GRAPH 54. DO YOU CHOOSE THE PROVIDER AGENCIES WHO WORK WITH YOUR FAMILY?



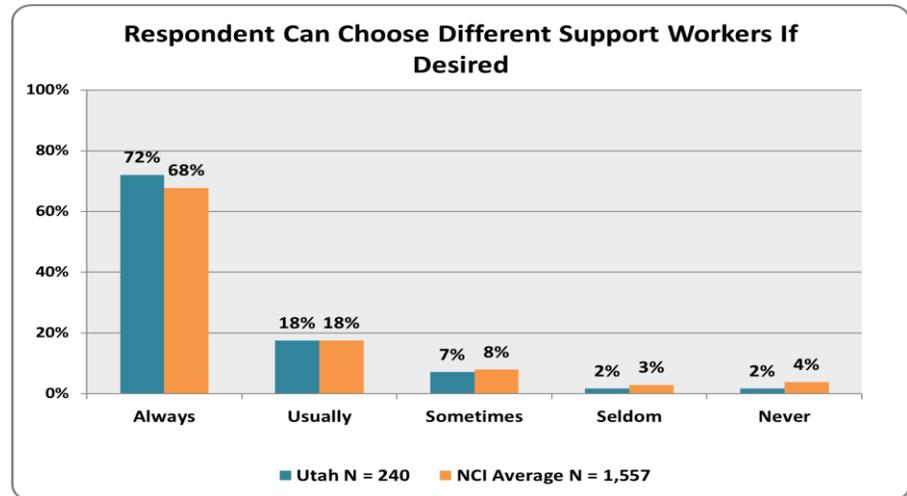
GRAPH 55. CAN YOU CHOOSE A DIFFERENT PROVIDER AGENCY IF YOU WANT TO?



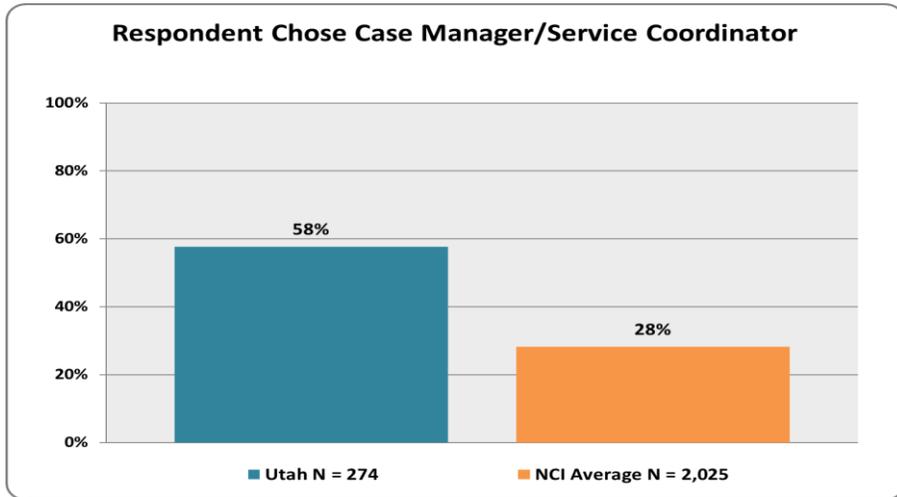
GRAPH 56. DO YOU CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH YOUR FAMILY?



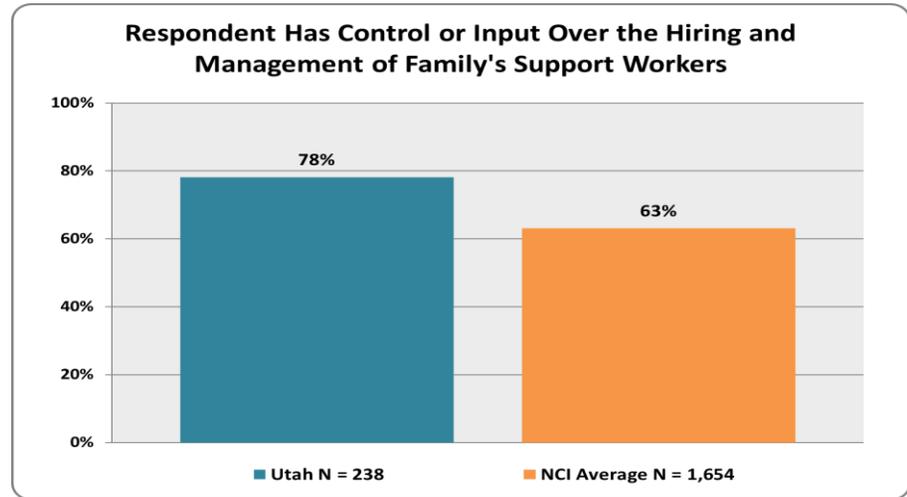
GRAPH 57. CAN YOU CHOOSE DIFFERENT SUPPORT WORKERS IF YOU WANT TO?



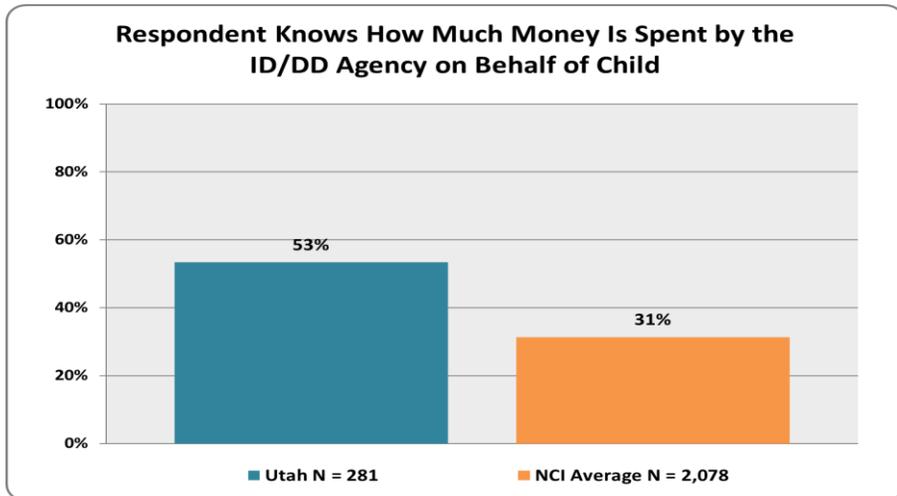
GRAPH 58. DID YOU CHOOSE YOUR CASE MANAGER/SERVICE COORDINATOR?



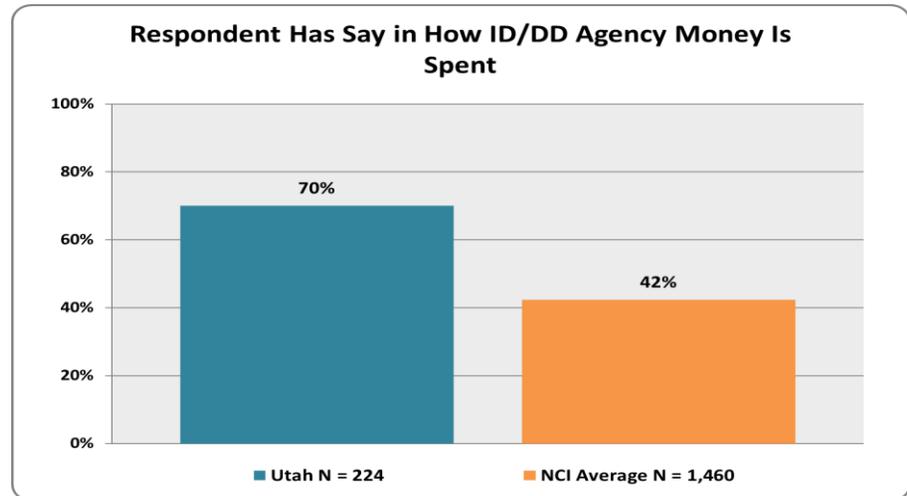
GRAPH 59. DO YOU HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF YOUR FAMILY'S SUPPORT WORKERS?



GRAPH 60. DO YOU KNOW HOW MUCH MONEY IS SPENT BY THE ID/DD AGENCY ON BEHALF OF YOUR CHILD?*

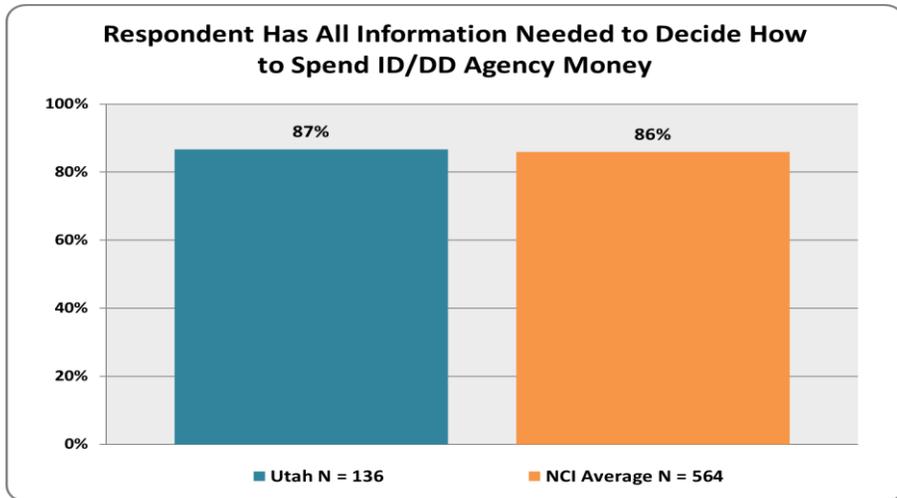


GRAPH 61. DO YOU HAVE A SAY IN HOW ID/DD AGENCY MONEY IS SPENT ON BEHALF OF YOUR CHILD?



*'Don't Know' responses were included in 'No' responses for this question.

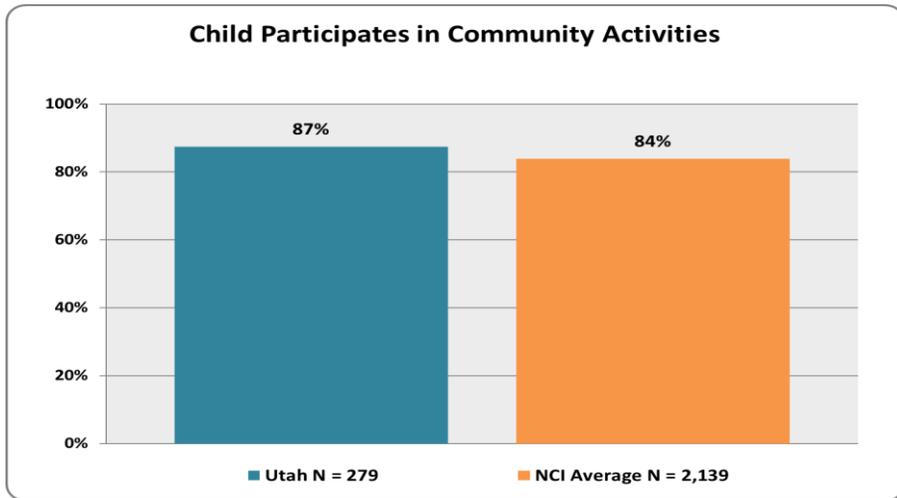
GRAPH 62. IF YOU HAVE A SAY IN HOW ID/DD AGENCY MONEY IS SPENT, DO YOU HAVE ALL THE INFORMATION YOU NEED TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?



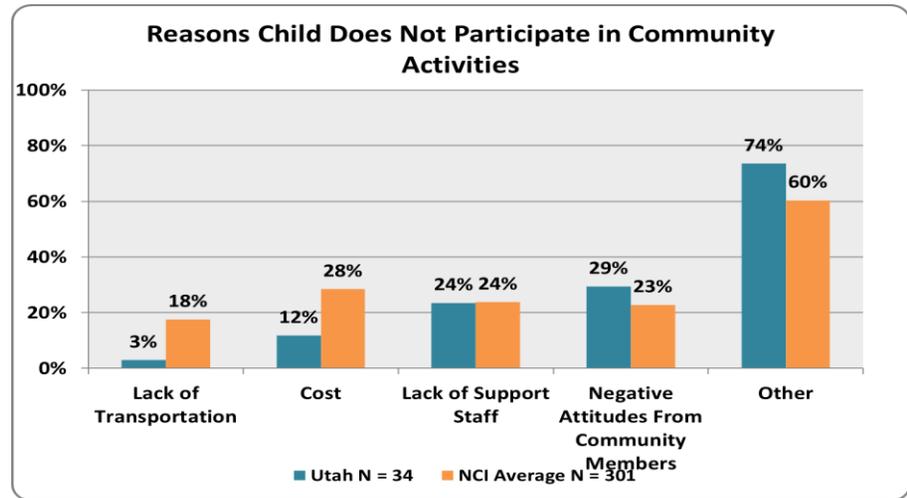
Community Connections

CHILDREN WITH DISABILITIES USE INTEGRATED COMMUNITY SERVICES AND PARTICIPATE IN EVERYDAY COMMUNITY ACTIVITIES

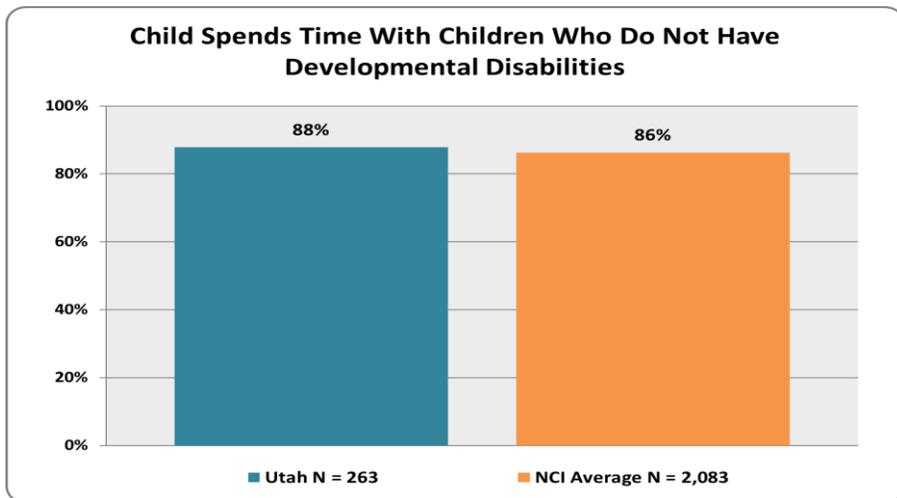
GRAPH 63. DOES YOUR CHILD PARTICIPATE IN COMMUNITY ACTIVITIES (SUCH AS GOING OUT TO A RESTAURANT, MOVIE, OR SPORTING EVENT)?



GRAPH 64. IF YOUR CHILD DOESN'T PARTICIPATE IN COMMUNITY ACTIVITIES, WHY NOT?



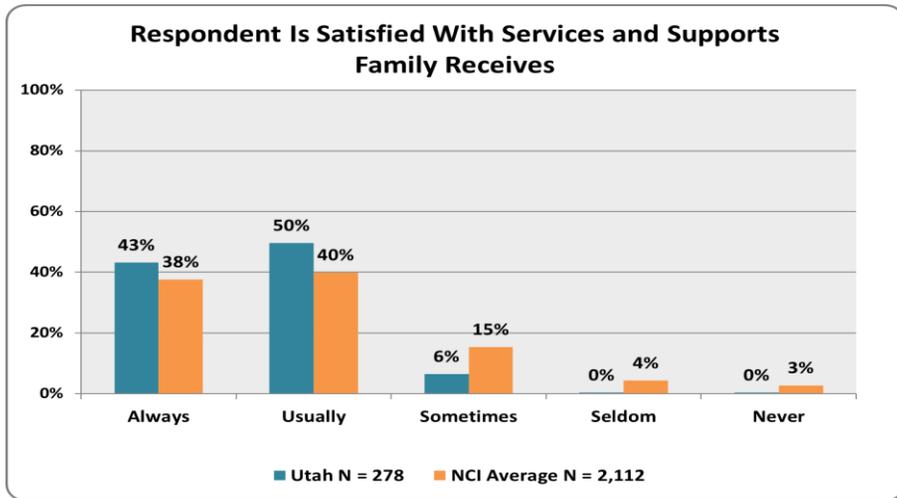
GRAPH 65. DOES YOUR CHILD SPEND TIME WITH CHILDREN WHO DO NOT HAVE DEVELOPMENTAL DISABILITIES?



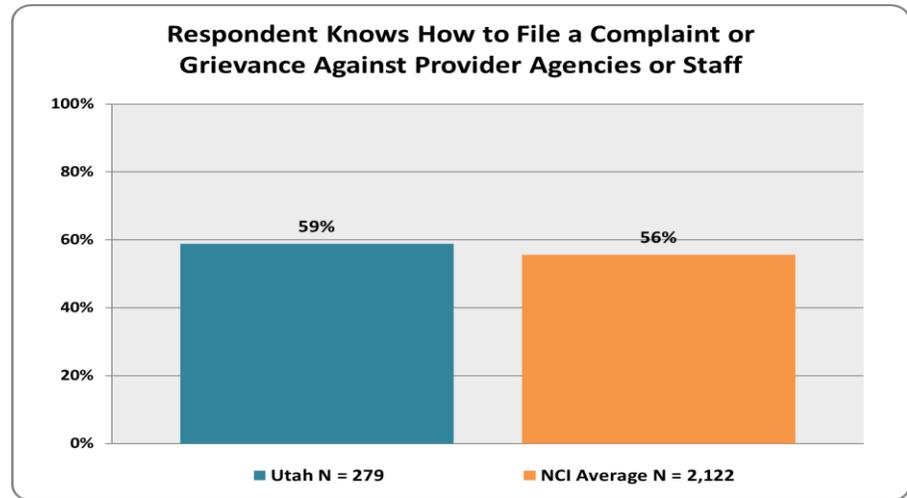
Satisfaction

FAMILIES AND CHILDREN WITH DISABILITIES RECEIVE ADEQUATE AND SATISFACTORY SUPPORTS

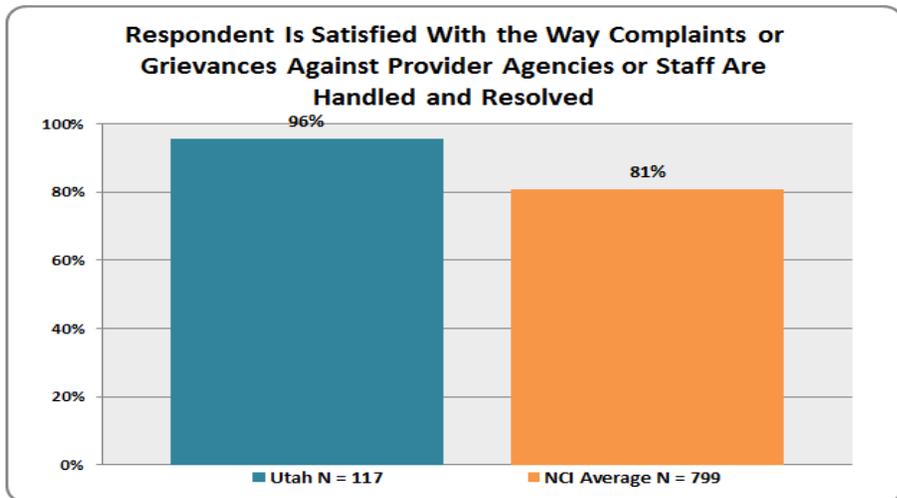
GRAPH 66. OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS YOUR FAMILY CURRENTLY RECEIVES?



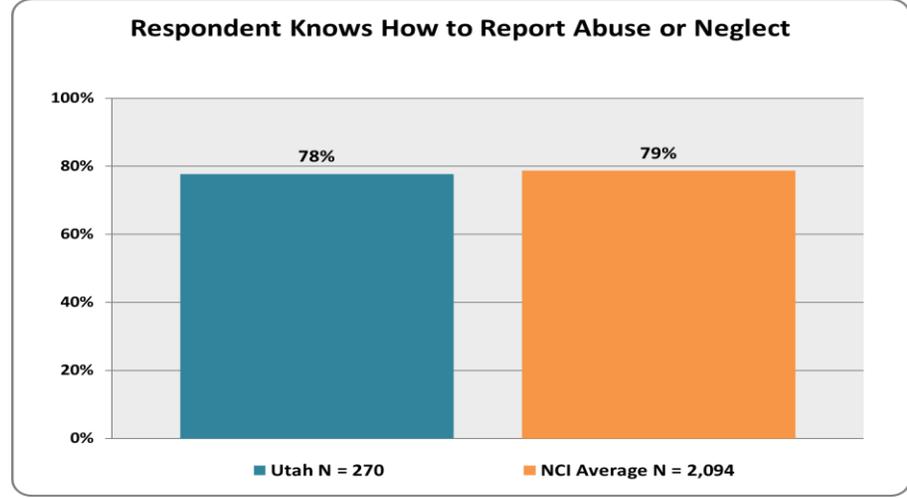
GRAPH 67. DO YOU KNOW THE PROCESS FOR FILING A COMPLAINT OR GRIEVANCE AGAINST PROVIDER AGENCIES OR STAFF?*



GRAPH 68. ARE YOU SATISFIED WITH THE WAY COMPLAINTS OR GRIEVANCES AGAINST PROVIDER AGENCIES OR STAFF ARE HANDLED AND RESOLVED?

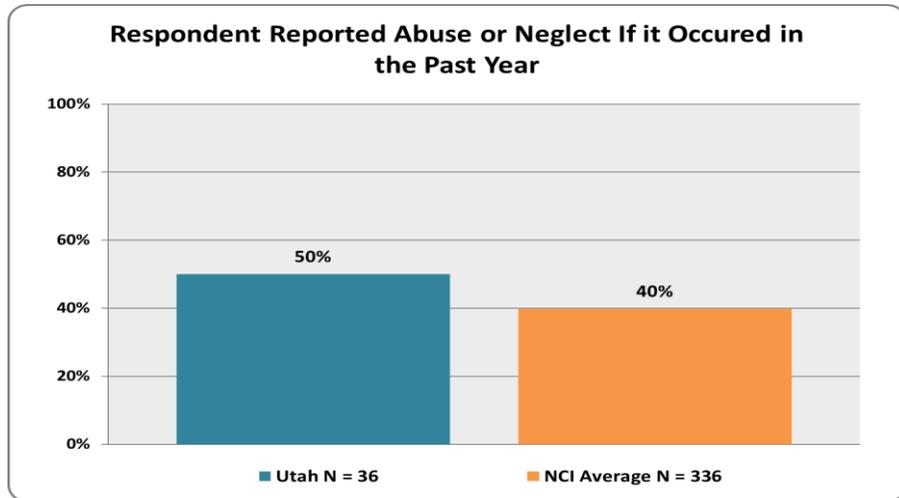


GRAPH 69. DO YOU KNOW HOW TO REPORT ABUSE OR NEGLECT?*



*'Don't Know' responses were included in 'No' responses for this question.

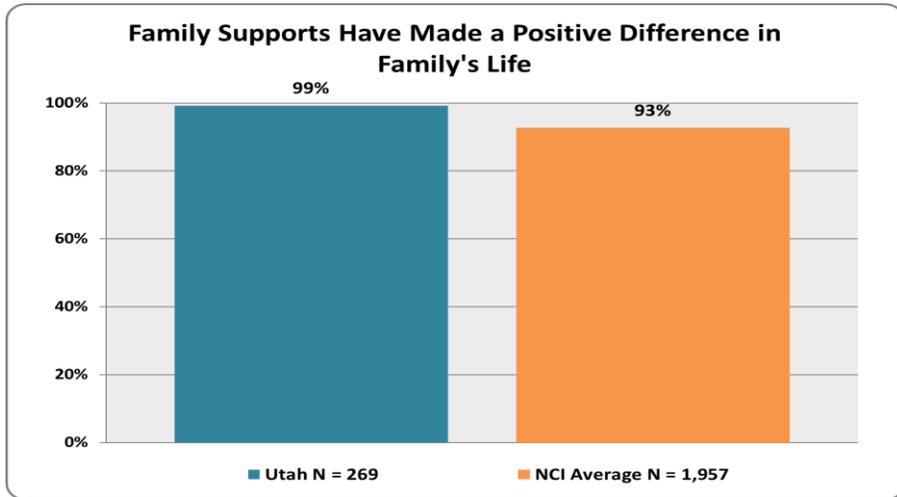
GRAPH 70. WITHIN THE PAST YEAR, IF ABUSE OR NEGLECT OCCURRED, DID YOU REPORT IT?



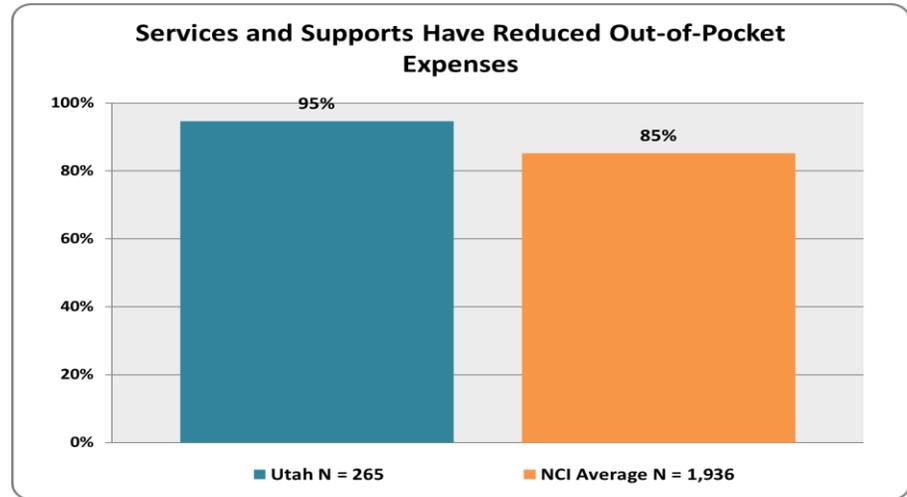
Family Outcomes

INDIVIDUAL AND FAMILY SUPPORTS MAKE A POSITIVE DIFFERENCE IN THE LIVES OF FAMILIES

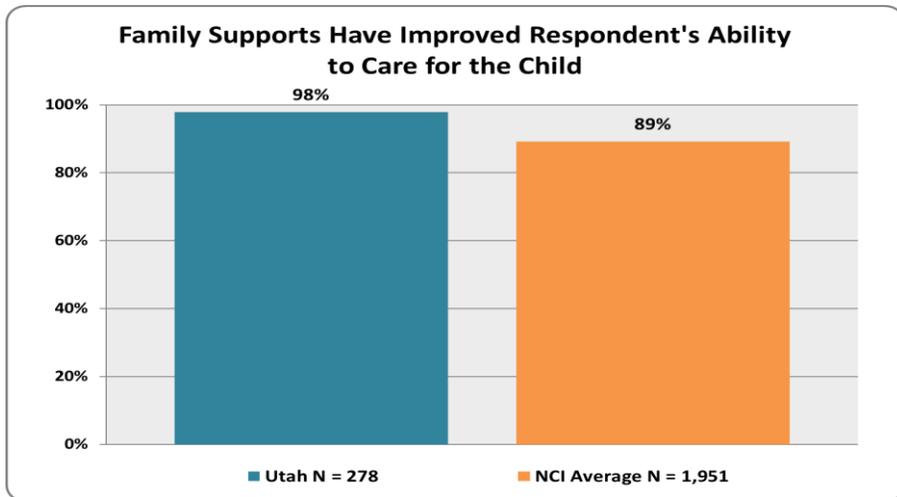
GRAPH 71. DO YOU FEEL THAT FAMILY SUPPORTS HAVE MADE A POSITIVE DIFFERENCE IN THE LIFE OF YOUR FAMILY?



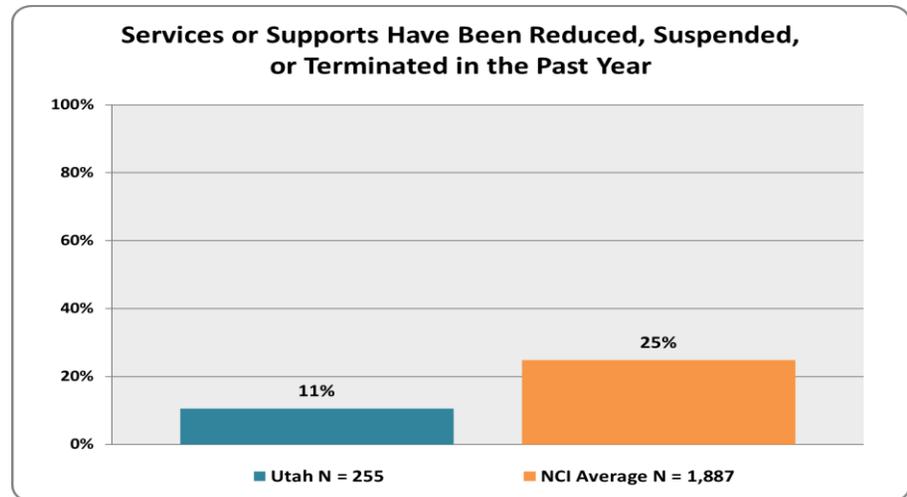
GRAPH 72. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE REDUCED YOUR FAMILY'S OUT-OF-POCKET EXPENSES FOR YOUR CHILD'S CARE?



GRAPH 73. DO YOU FEEL THAT FAMILY SUPPORTS HAVE IMPROVED YOUR ABILITY TO CARE FOR YOUR CHILD?



GRAPH 74. HAVE THE SERVICES OR SUPPORTS THAT YOUR CHILD/FAMILY RECEIVES BEEN REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR?



GRAPH 75. IF SERVICES OR SUPPORTS RECEIVED BY FAMILY WERE REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR, DID THIS CHANGE AFFECT YOUR FAMILY NEGATIVELY?

