

# **Child Family Survey**

## **2011-12 Final Report**



**NATIONAL CORE  
INDICATORS**

A Collaboration of  
the National Association of State Directors of  
Developmental Disabilities Services  
and the Human Services Research Institute



Human Services  
Research Institute

**Human Services Research Institute (HSRI)**

2336 Massachusetts Avenue  
Cambridge, MA 02140



**National Association of State Directors Of  
Developmental Disabilities Services  
(NASDDDS)**

113 Oronoco Street  
Alexandria, VA 22314

August 12, 2013

---

## Organization of Report

Five states submitted a valid sample of the National Core Indicators (NCI) Child Family Survey during the 2011-2012 project year for analysis. The Child Family Survey was administered to families who have a child with disabilities living in the family's home and receive at least one service other than case management. This Final Report provides a summary of results based on data submitted by June 30, 2012.

This report is organized as follows:

### **I. Introduction**

This section gives a brief overview of NCI history and activities, and presents the core indicators measured with the Family Surveys.

### **II. Child Family Survey**

This section briefly describes the structure of the survey instrument.

### **III. Methodology**

This section describes the protocol used by states to select families to participate in the survey, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by NCI Program staff to aggregate and analyze the data.

### **IV. Results**

This section provides state-by-state and national results for demographic and survey outcomes data.

---

## List of Abbreviations

AFS – Adult Family Survey

CFS – Child Family Survey

CMS – Centers for Medicare and Medicaid

FGS – Family/Guardian Survey

HCBS – Home and Community Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

---

# Table of Contents

<b>Child Family Survey .....</b>	<b>1</b>
<b>2011-12 Final Report.....</b>	<b>1</b>
<b>Table of Contents.....</b>	<b>v</b>
 <b>I. Introduction .....</b>	<b>1</b>
Overview of National Core Indicators.....	2
State Participation .....	3
Chart 1. NCI State Participation 2011-12 .....	3
The Core Indicators.....	3
The Indicators.....	5
Table 1. NCI Child Family Survey – Sub-Domains.....	5
How NCI Data are Used.....	5
Data Limitations .....	6
 <b>II. Child Family Survey .....</b>	<b>7</b>
Survey Development .....	8
Table 2. State Participation in NCI Child Family Survey (Children Living at Home with Family).....	8
Organization of the Family Surveys.....	9
 <b>III. Methodology.....</b>	<b>10</b>
Sampling & Administration.....	11
Data Entry and Analysis .....	11
Response Rates .....	12

---

Table 3. Child Family Survey - State Response Rates.....	12
<b>IV. Results .....</b>	<b>13</b>
Presentation of Data .....	14
Demographics: Children.....	15
Table 4 Age of Child.....	16
Table 5 Gender of Child .....	16
Table 6 Race of Child.....	17
Table 7 Type of Disability- Child .....	17
Table 8 Primary Means of Expression of Child .....	18
Table 9 Primary Language of Child .....	18
Table 10 Frequency of Medical Care Needed for Child .....	19
Table 11 Amount of Behavioral Support Needed for Child .....	19
Table 12 Amount of Help Needed for Daily Activities for Child .....	20
Demographics: Respondents.....	21
Table 13 Age of Respondent.....	22
Table 14 Health of Respondent.....	22
Table 15 Relationship to Child .....	23
Table 16 Respondent is Primary Caregiver.....	23
Table 17 Number of Adults in Household .....	24
Table 18 Highest Education Level of Respondent.....	24
Table 19 Last Year Total Taxable Income .....	25
Table 20 Last Year Out-of-Pocket Expenses.....	25
Services and Supports Received .....	26
Table 21 Services and Supports Received.....	26
Child Family Survey Results .....	27
Information and Planning.....	28

---

---

Q1. Do you receive information about the services and supports that are available to your child and family? .....	29
Table 22 Do you receive information about the services and supports that are available to your child and family? .....	29
Q2. Is the information you receive easy to understand? .....	30
Table 23 Is the information you receive easy to understand? .....	30
Q3. Does the information you receive primarily come from your case manager/service coordinator (as opposed to family, friends, and others outside State services)? .....	31
Table 24 Does the information you receive primarily come from your case manager/service coordinator (as opposed to family, friends, and others outside State services)? .....	31
Q4. Do you receive information about the status of your child's development? .....	32
Table 25 Do you receive information about the status of your child's development? .....	32
Q5. Is the information you receive easy to understand? .....	33
Table 26 Is the information you receive easy to understand? .....	33
Q6. Do you get enough information to help you participate in planning services for your family? .....	34
Table 27 Do you get enough information to help you participate in planning services for your family? .....	34
Q7. Does the case manager/service coordinator who assists you with planning help you figure out what you need as a family to support your child? .....	35
Table 28 Does the case manager/service coordinator who assists you with planning help you figure out what you need as a family to support your child? .....	35
Q8. Does the case manager/service coordinator who assists you with planning respect your choices and opinions? .....	36
Table 29 Does the case manager/service coordinator who assists you with planning respect your choices and opinions? .....	36
Q9. Does your case manager/service coordinator tell you about public services that you are eligible for? (e.g., food stamps, Early Period Screening Diagnosis and Treatment [EPSDT], Supplemental Security Income [SSI], housing subsidies, etc.) .....	37
Table 30 Does your case manager/service coordinator tell you about public services that you are eligible for? (e.g., food stamps, Early Period Screening Diagnosis and Treatment [EPSDT], Supplemental Security Income [SSI], housing subsidies, etc.) .....	37
Q10. Is the case manager/service coordinator who assists you with planning generally knowledgeable? .....	38

---

---

Table 31 Is the case manager/service coordinator who assists you with planning generally knowledgeable? .....	38
Q11. If your child has a service plan, did you help develop it? .....	39
Table 32 If your child has a service plan, did you help develop it? .....	39
Q12. If your child has a service plan, does it include services and supports that are important to you? .....	40
Table 33 If your child has a service plan, does it include services and supports that are important to you? .....	40
Q13. Does the service plan include all the services and supports your family needs? .....	41
Table 34 Does the service plan include all the services and supports your family needs? .....	41
Q14. If your child has a service plan, did you discuss how to handle emergencies related to your child at the last service planning meeting? .....	42
Table 35 If your child has a service plan, did you discuss how to handle emergencies related to your child at the last service planning meeting? .....	42
Q15. Have you received information about your family's rights? .....	43
Table 36 Have you received information about your family's rights? .....	43
Access and Delivery of Services and Supports .....	44
Q16. Are you able to contact your support workers when you need to? .....	45
Table 37 Are you able to contact your support workers when you need to? .....	45
Q17. Are you able to contact your case manager/service coordinator when you need to? .....	46
Table 38 Are you able to contact your case manager/service coordinator when you need to? .....	46
Q18. Does your child receive all of the services listed in the service plan? .....	47
Table 39 Does your child receive all of the services listed in the service plan? .....	47
Q19. Does your child get the services and supports that s/he needs? .....	48
Table 40 Does your child get the services and supports that s/he needs? .....	48
Q20. Does your family get the services and supports you need? .....	49
Table 41 Does your family get the services and supports you need? .....	49
Q21. Are services and supports available at the times that you need them? .....	50
Table 42 Are services and supports available at the times that you need them? .....	50
Q22. Are services and supports, received outside the family home, available within a reasonable distance from your family home? .....	51

---



---

Table 43 Are services and supports, received outside the family home, available within a reasonable distance from your family home? .....	51
Q23. Do the services and supports change when your child's needs change? .....	52
Table 44 Do the services and supports change when your child's needs change? .....	52
Q25. If English is your first language, do the support workers communicate with you effectively in your primary language? .....	53
Table 45 If English is your first language, do the support workers communicate with you effectively in your primary language? .....	53
Q26. If your child does not verbally communicate (for example, uses gestures or sign language), are there enough support workers available who can communicate with him/her? .....	54
Table 46 If your child does not verbally communicate (for example, uses gestures or sign language), are there enough support workers available who can communicate with him/her? .....	54
Q27. Are services delivered to your family in a way that is respectful to your family's culture(s)? .....	55
Table 47 Are services delivered to your family in a way that is respectful to your family's culture(s)? .....	55
Q28. Does your child have access to the special equipment or accommodations that s/he needs (e.g., wheelchair, ramp, communication board)? .....	56
Table 48 Does your child have access to the special equipment or accommodations that s/he needs (e.g., wheelchair, ramp, communication board)? .....	56
Q29. Do the support workers have the right training to meet your child's needs? .....	57
Table 49 Do the support workers have the right training to meet your child's needs? .....	57
Q30. Do the support workers who come to your home arrive on time and when scheduled? ..	58
Table 50 Do the support workers who come to your home arrive on time and when scheduled? .....	58
Q31. If you asked for crisis/emergency services during the past year, were services provided when needed? .....	59
Table 51 If you asked for crisis/emergency services during the past year, were services provided when needed? .....	59
Q32. Do you have access to health services for your child? .....	60
Table 52 Do you have access to health services for your child? .....	60
Q33. If "yes" (to Q32), are you satisfied with the quality of these providers? .....	61

---

---

Table 53 If “yes” (to Q32), are you satisfied with the quality of these providers? .....	61
Q34. Do you have access to dental services for your child? .....	62
Table 54 Do you have access to dental services for your child?.....	62
Q35. If “yes” (to Q34), are you satisfied with the quality of these providers? .....	63
Table 55 If “yes” (to Q34), are you satisfied with the quality of these providers? .....	63
Q36. Do you have access to necessary medications for your child? .....	64
Table 56 Do you have access to necessary medications for your child?.....	64
Q37. If “yes” (to Q36), are you satisfied with how your child’s medication needs are monitored? .....	65
Table 57 If “yes” (to Q36), are you satisfied with how your child’s medication needs are monitored? .....	65
Q38. If applicable, do you have access to mental health services for your child? .....	66
Table 58 If applicable, do you have access to mental health services for your child? .....	66
Q39. If “yes” (Q38), are you satisfied with the quality of these providers? .....	67
Table 59 If “yes” (Q38), are you satisfied with the quality of these providers? .....	67
Q40. If applicable, do you have access to quality respite services for your family? .....	68
Table 60 If applicable, do you have access to quality respite services for your family? .....	68
Q41. If “yes” (to Q40), are you satisfied with the quality of these providers? .....	69
Table 61 If “yes” (to Q40), are you satisfied with the quality of these providers? .....	69
Q42. Are there other services that your family member needs that are not currently offered or available? .....	70
Table 62 Are there other services that your family member needs that are not currently offered or available? .....	70
Choice and Control.....	71
Q43. Do you choose the provider agencies who work with your family? .....	72
Table 63 Do you choose the provider agencies who work with your family? .....	72
Q44. If you choose the provider agencies, do you have more than one to choose from? .....	73
Table 64 If you choose the provider agencies, do you have more than one to choose from? .....	73
Q45. Do you choose the individual support workers who work directly with your family? .....	74

---

---

Table 65 Do you choose the individual support workers who work directly with your family? .....	74
Q46. If you choose the individual support workers, are you satisfied with the options available? .....	75
Table 66 If you choose the individual support workers, are you satisfied with the options available? .....	75
Q47. Did you choose your case manager/service coordinator? .....	76
Table 67 Did you choose your case manager/service coordinator? .....	76
Q48. Do you have control and/or input over the hiring and management of your family's support workers? .....	77
Table 68 Do you have control and/or input over the hiring and management of your family's support workers? .....	77
Q49. Do you want to have control and/or input over the hiring and management of your family's support workers? .....	78
Table 69 Do you want to have control and/or input over the hiring and management of your family's support workers? .....	78
Q50. Do you know how much money is spent by the ID/DD agency on behalf of your child?*.79	
Table 70 Do you know how much money is spent by the ID/DD agency on behalf of your child?*. .....	79
Q51. Do you have a say in how this money is spent? .....	80
Table 71 Do you have a say in how this money is spent? .....	80
Q52. If "yes" (to Q51), do you have all the information you need to make decisions about how to spend this money? .....	81
Table 72 If "yes" (to Q51), do you have all the information you need to make decisions about how to spend this money? .....	81
Community Connections .....	82
Q53. Does your child participate in community activities? .....	83
Table 73 Does your child participate in community activities? .....	83
Q54. Does your child spend time with children who do not have developmental disabilities? .....	84
Table 74 Does your child spend time with children who do not have developmental disabilities? .....	84
Satisfaction with Services and Supports .....	85

---

---

Q55. Overall, are you satisfied with the services and supports your child and family currently receive? .....	86
Table 75 Overall, are you satisfied with the services and supports your child and family currently receive? .....	86
Q56. Do you know the process for filing a complaint or grievance against provider agencies or staff?*	87
Table 76 Do you know the process for filing a complaint or grievance against provider agencies or staff?*	87
Q57. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved? .....	88
Table 77 Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved? .....	88
Q58. Do you know how to report abuse or neglect?*	89
Table 78 Do you know how to report abuse or neglect?*	89
Q59. In the past year, did you report abuse or neglect? .....	90
Table 79 In the past year, did you report abuse or neglect? .....	90
Outcomes .....	91
Q61. Do you feel that family supports have made a positive difference in the life of your family? .....	92
Table 80 Do you feel that family supports have made a positive difference in the life of your family? .....	92
Q62. Do you feel that services and supports have reduced your family's out-of-pocket expenses related to your child's care? .....	93
Table 81 Do you feel that services and supports have reduced your family's out-of-pocket expenses related to your child's care? .....	93
Q63. Do you feel that services and supports address the goals in your child's service plan? .....	94
Table 82 Do you feel that services and supports address the goals in your child's service plan? .....	94
Q64. Do you feel that family supports have improved your ability to care for your child? .....	95
Table 83 Do you feel that family supports have improved your ability to care for your child? .....	95
Q65. Do you feel that family supports have helped you to keep your child at home? .....	96
Table 84 Do you feel that family supports have helped you to keep your child at home? .....	96

---

---

Q66. Have the services or supports that your child/family received during the past year been either reduced, suspended, or terminated? .....	97
--	----

Table 85 Have the services or supports that your child/family received during the past year been either reduced, suspended, or terminated? .....	97
--	----

Q67. If “yes” (to Q66), did the reduction/suspension/termination of these services or supports affect your family or your child’s relationships, health, welfare, etc.? .....	98
---	----

Table 85 If “yes” (to Q66), did the reduction/suspension/termination of these services or supports affect your family or your child’s relationships, health, welfare, etc.? .....	98
---	----

---

# I. Introduction

*This section gives a brief overview of the history of NCI, its current activities, and the Core Indicators.*

---

## Overview of National Core Indicators

In December 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with Human Services Research Institute (HSRI), launched the Core Indicators Project (CIP). The aim of CIP was to support state developmental disabilities authorities in developing and implementing performance and outcome indicators as well as related data collection strategies that would enable them to measure service delivery system performance. This effort, now called National Core Indicators (NCI), strives to provide states with sound tools to use in support of their efforts to improve system performance and thereby to better serve people with intellectual and developmental disabilities and their families. NASDDDS' active sponsorship of NCI facilitates states pooling their knowledge, expertise and resources in this endeavor.

In 1997, 15 states convened to discuss the scope and content of a potential performance measurement framework that could be shared across states. Directors and staff from these 15 states worked to identify the major domains and sub-domains of performance, indicators, measures, and data sources. The original 61 indicators, developed through a consensus process, were intended to provide a system-level “snapshot” of how well each state was performing. The states were guided by a set of criteria designed to select indicators that were:

1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of disability or residential setting

During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states volunteered to pilot test the indicators. Eight additional states served on the Steering Committee.

Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI has continued to develop and refine the indicators and expand state participation. For more information about NCI states, technical reports, and other resources, visit the program's website:

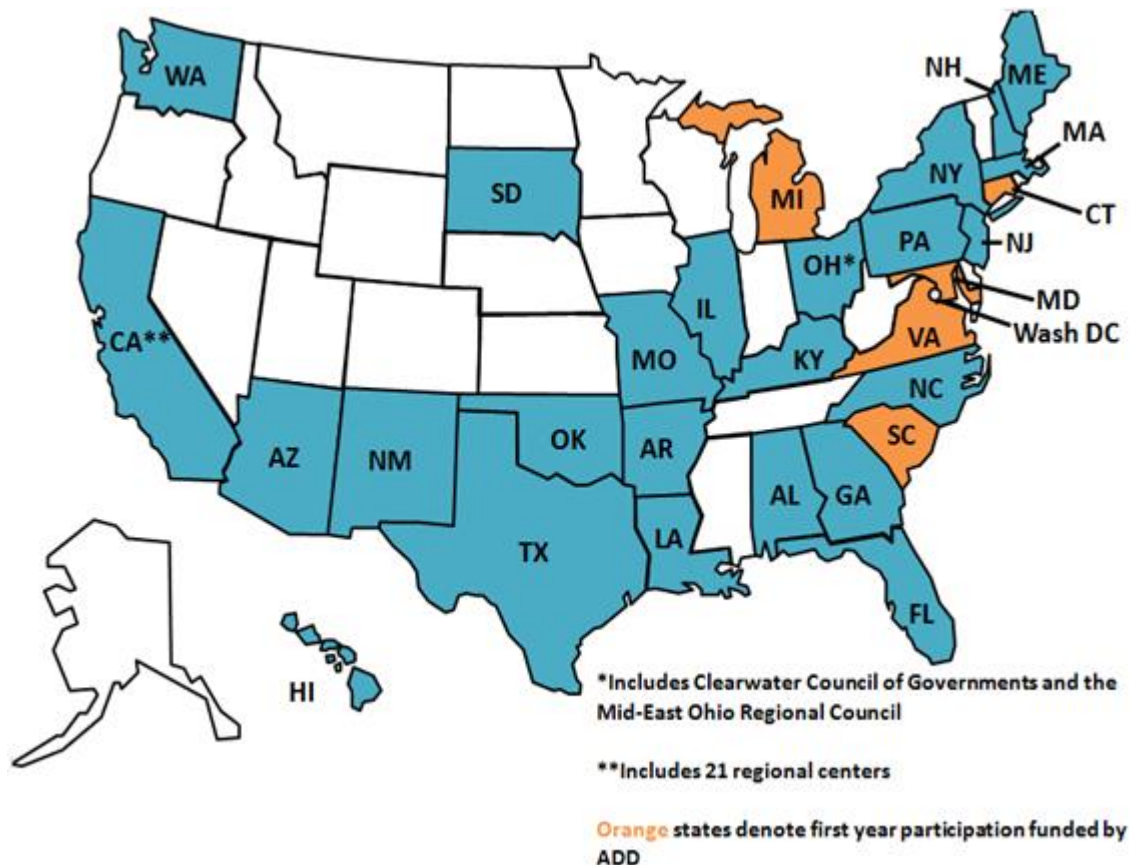
<http://www.nationalcoreindicators.org>.

---

## State Participation

As of the 2011-2012 data collection cycle, NCI was composed of 29 states and 23 sub-state entities. State participation in NCI is entirely voluntary. The chart below details all states that participated in NCI data collection in 2011-12.

Chart 1. NCI State Participation 2011-12



## The Core Indicators

The Core Indicators are the foundation of the effort. They are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, respect/rights, service planning, community inclusion, choice, and health and safety.

The current set of performance indicators include approximately 100 consumer, family, system, and health and safety outcomes –outcomes that are important to understanding the overall health of public developmental disabilities agencies. Indicators are organized across five broad domains: Individual Outcomes, Health Welfare & Rights, Staff Stability & Competency, Family Outcomes, and



---

System Performance. Each domain is broken down into sub-domains through which the indicator outcome can be discerned. Four data sources are used to assess outcomes: the Adult Consumer Survey, three Family Surveys, a Provider Survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates).

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI program is a dynamic effort that allows for measures to be added, dropped, or changed in order to reflect the current and future priorities of participating states. Most recently, the indicator set was revised to include enhanced information about health and wellness, employment status, and experience of self-direction among people with intellectual and developmental disabilities<sup>1</sup>.

The data collection tools used to gather indicator data are regularly refined and tested to ensure they remain valid, reliable, and applicable to current issues within the field. Details on the design and testing of this tool are provided in the next section.

---

<sup>1</sup> For a complete list of Core Indicators, visit the Indicators Page on the NCI website at: <http://nationalcoreindicators.org/indicators/>.

---

## The Indicators

The survey instrument is designed specifically to measure certain Core Indicators. Most indicators correspond to single survey items. However, a few indicators refer to clusters of related survey items. The following table lists the sub-domains covered by the NCI Child Family Survey indicators.

Table 1. NCI Child Family Survey – Sub-Domains

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

## How NCI Data are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI as a data source for supplemental performance measures in their HCBS waiver quality management systems and include the information in support of evidentiary reports to CMS. Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

---

## Data Limitations

This report does not provide benchmarks for acceptable or unacceptable levels of performance for each indicator. Rather, it is up to each state to decide whether its score or percentage is an acceptable performance level. States that fall into the “below average” tier on any scale or indicator are not necessarily underperforming on that scale or indicator. Instead, falling into the “below average” tier indicates the state’s scale score or indicator percentage is significantly lower than the average, where “significantly” means “not due to chance.” The tables display states’ scores relative to one another and show which states tend to have similar results. The difference between a “below average” state and the average across the other states may be very small. Again, it is up to public managers, policy-makers, and other stakeholders to decide whether the differences in results suggest state-level changes or further investigation are necessary.

The average of states’ proportions should not be interpreted as defining “acceptable” levels of performance or satisfaction. Instead, it is a multi-state “norm” that describes present average levels of performance or satisfaction across the participating states. Instances in which there are few significant differences among states denote the majority of states are performing similarly. Instances in which several states’ results are especially high (considerably above the average level) indicate the levels of performance or satisfaction achieved in those states might define a level of performance that may serve as a guidepost for other states.

Data from previous years are not presented in this report. Comparisons of results from year to year should be made with caution for several reasons: even slight changes in wording or response options of certain questions may affect comparability of results from one year to the next; the mix of participating states differs slightly each year and may affect the NCI Averages. States draw new samples each year rather than following the same group of individuals.

---

## II. Child Family Survey

*This section briefly describes the development and organization of the survey instrument.*

## Survey Development

The Child Family Survey was developed and first utilized during Phase III of the Core Indicators Project (2000-2001), in response to state interest in determining the level of satisfaction with services and supports among families of children with disabilities living at home. In this effort, five states administered the Child Family Survey.

Below is a figure indicating state participation in the Child Family Survey since its inception.

**Table 2. State Participation in NCI Child Family Survey (Children Living at Home with Family)**

2000-2001	2001-2002	2002-2003	2003-2004	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011	2011-2012
AZ	CA-RCOC	AZ	CA-RCOC	AZ	CA-RCOC	AZ	CA-RCOC	AZ	LA	AZ	LA
MN	NE	CA-RCOC	CT	CA-RCOC	CT	CT	HI	LA	MO	HI	MEORC
NC	NC	MA	HI	CT	HI	OK	LA	MO	NC	LA	NC
UT	UT	SC	ND	WA	SC	TX	NJ	SC	NH	MEORC	SD
WA	VT	SD	SC	WY	SD	WA	OK	TX	OH-MEORC	NC	NJ
		WA	WY		TX	WV	SC	WA	TX	OH	
		WY			WY	WY	WV			WA	
							WY				

---

## Organization of the Family Surveys

The Child Family Survey is composed of three main sections described below. There is also an opportunity for families to write open-ended comments concerning their family's participation in the service system.

### Demographics

The survey instrument begins with a series of questions relating to characteristics of the *child* with a developmental disability (e.g., individual's age, race, type of disability) followed by a series of demographic questions that pertain to the *respondent* (e.g., respondent's age, health status, relationship to the individual with the disability).

### Services and Supports Received

A brief section of the survey asks respondents to identify the services and supports that they and/or their child with a disability receive.

### Questions Regarding Services and Supports

The survey contains six groupings of questions that probe specific areas of quality service provision, which are: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes.

Each question is constructed so the respondent selects from either five possible responses ("always", "usually", "sometimes", "seldom", or "never") or two responses ("yes", "no"). Respondents also have the option to indicate that they don't know the answer to a question, or that the question is not applicable.

### Additional Comments

The end of each section also provides an opportunity for respondents to make additional open-ended comments concerning their family's participation in the service system.

---

## III. Methodology

*This section describes the protocol used by states to select families to participate in the survey, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by NCI Program staff to aggregate and analyze the data.*

---

## Sampling & Administration

States were asked to administer the Child Family Survey by selecting a random sample of at least 1,000 families who:

1. Have an child<sup>2</sup> with developmental disabilities living at home; and
2. Receive at least one direct service or support besides service coordination.

All states mailed out a paper survey to families selected in their sample. A sample size of 1,000 was recommended in anticipation that states would obtain at least a 40% return rate, yielding 400 or more usable responses per state. However, most states decided to sample more than 1,000 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. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. Because of lower than expected response rates, we did include states in this report that submitted less than 400 surveys up to a margin of error no greater than +/- 7% (see pg. 12)

## Data Entry and Analysis

Each state entered their survey responses into the ODESA (Online Data Entry Survey Application). All raw data files were reviewed for completeness, invalid responses were eliminated, and quality checks were performed. The data files were then cleaned and merged to create the national dataset.

Data were considered invalid, and therefore excluded, based on the following three criteria:

1. The respondent indicated that their child with disabilities lived outside the family home.
2. The respondent indicated their child with disabilities was over the age of 22.
3. If demographic information was entered into the file, but no survey questions were answered.

---

<sup>2</sup> Children were defined as individuals with disabilities age 18 or younger; however, a Child Family Survey could be completed for an individual up to 22 years if still receiving “child” services.



---

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the NCI average<sup>3</sup>; significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

## Response Rates

During 2011-2012, five states administered the Child Family Survey and submitted a valid sample size for comparison -- a sample that would yield a 95% confidence rating with +/- 7% margin of error; their data are included in this report. Table 3 shows the number of surveys each state mailed, surveys returned, response rates, and the number of valid surveys accepted for inclusion in data analysis.

**Table 3. Child Family Survey - State Response Rates**

State	Surveys Mailed	Surveys Returned	Response Rate (%)	Usable Surveys
LA	1,900	360	19%	335
MEORC	1,382	326	24%	309
NC	1,574	271	17%	264
SD	800	289	36%	280
NJ	1,300	300	23%	293
Overall	6,956	1,546	22%	1,481

---

<sup>3</sup> The "NCI Average" is the average of the state percentages.

---

## IV. Results

*This section provides state-by-state and national results for demographic, service utilization, service planning, access and delivery, choice and control, community connections, satisfaction and outcome data.*

### **Note:**

**“Respondent” refers to the person (usually a parent or guardian) filling out the survey.**

---

## Presentation of Data

Direct feedback from families is an important means for states to gauge service and support satisfaction and to pinpoint areas for quality improvement. All demographic and individual outcome results from the Adult Family Survey are presented in this report. Outcome results are presented in six sub-sections corresponding with the sections of the Adult Family Survey. The beginning of each subsection provides an overall synopsis of findings across states, displaying the NCI Average for “yes” or “always” responses for all questions within that section. The NCI Average is the average of all individual state percentages.

For each question, outcomes are first shown in a graph with the NCI Average for response categories, followed by a table which shows a breakdown of each state’s percentage.

Tables are formatted whereby all states<sup>4</sup> are listed in descending order and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, and significantly below the NCI Average. Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI Average Range, their ‘always’ or ‘yes’ response was not statistically different from the NCI average.

---

<sup>4</sup> For some items, data are not shown due to an insufficient number of survey responses (fewer than 20).

---

## Demographics: Children

**This section provides information about the child with disabilities living in the household.**

Across states, the average age of children was 11. About two-thirds (66%) of children were male compared to 34% female. Most children were white (74%), while 16% were Black/African American, 3% were American Indian or Alaska Native and 3% were Asian; 5% of respondents identified their child as Hispanic/Latino.

The most common disabilities respondents listed their child as having were: autism spectrum disorder (43%), intellectual disability (34%), and seizure/neurological disorder (21%).

While most children's primary means of expression was spoken language (65%), one-quarter (25%) used gestures or body language, 3% used a communication aid or device, 2% used sign language or finger spelling, and 5% used other means to communicate. The primary language for the majority of children was English (97%).

Most children required medical care less than once a month (71%), while 20% needed medical care at least once a month, and 9% required care at least once a week. The amount of behavioral support needed for children was reported as follows: 50% did not need support, 37% required some support, and 14% needed extensive support. The amount of help indicated the child needed for daily activities was: 11% none, 23% little, 34% moderate and 32% complete.

---

## Age

**Table 4 Age of Child**

State	Average Age
LA	9
MEORC	8
NC	13
NJ	15
SD	11
<b>NCI Average</b>	<b>11</b>

## Gender

**Table 5 Gender of Child**

State	Male	Female
LA	68%	32%
MEORC	62%	38%
NC	69%	31%
NJ	68%	32%
SD	63%	37%
<b>NCI Average</b>	<b>66%</b>	<b>34%</b>

## Race

Table 6 Race of Child

State	American Indian or Alaska Native	Asian	Black or African American	Native Hawaiian or Other Pacific Islander	White	Other or Unknown	Two or More Races	Hispanic or Latino
LA	1%	2%	34%	0%	62%	0%	2%	2%
MEORC	1%	1%	1%	1%	93%	0%	3%	2%
NC	2%	1%	23%	0%	69%	0%	3%	3%
NJ	1%	7%	16%	0%	59%	0%	4%	16%
SD	8%	3%	4%	0%	88%	0%	1%	3%
<b>NCI Average</b>	<b>3%</b>	<b>3%</b>	<b>16%</b>	<b>0%</b>	<b>74%</b>	<b>0%</b>	<b>3%</b>	<b>5%</b>

## Type of Disability

Table 7 Type of Disability- Child

State	ID	Mental Illness	ASD	Cerebral Palsy	Brain Injury	Limited or No Vision	Hearing Loss	Seizure/ Neurological Disorder	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Other	No Other	Don't Know
LA	23%	17%	38%	19%	5%	9%	6%	27%	1%	8%	1%	37%	9%	6%
MEORC	24%	20%	26%	13%	5%	4%	5%	14%	0%	8%	0%	41%	8%	6%
NC	52%	11%	51%	17%	5%	9%	4%	25%	1%	9%	2%	34%	2%	2%
NJ	34%	25%	57%	11%	8%	6%	2%	18%	1%	10%	2%	24%	2%	2%
SD	36%	17%	41%	15%	8%	6%	3%	21%	0%	22%	1%	21%	3%	1%
<b>NCI Average</b>	<b>34%</b>	<b>18%</b>	<b>43%</b>	<b>15%</b>	<b>6%</b>	<b>7%</b>	<b>4%</b>	<b>21%</b>	<b>1%</b>	<b>11%</b>	<b>1%</b>	<b>31%</b>	<b>5%</b>	<b>3%</b>

## Primary Means of Expression

Table 8 Primary Means of Expression of Child

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other
LA	56%	31%	3%	1%	9%
MEORC	64%	30%	3%	1%	1%
NC	67%	25%	1%	3%	4%
NJ	69%	16%	1%	6%	8%
SD	68%	24%	2%	3%	4%
<b>NCI Average</b>	<b>65%</b>	<b>25%</b>	<b>2%</b>	<b>3%</b>	<b>5%</b>

## Primary Language

Table 9 Primary Language of Child

State	English	Spanish	Other
LA	98%	1%	2%
MEORC	96%	1%	3%
NC	98%	1%	0%
NJ	94%	4%	2%
SD	97%	1%	2%
<b>NCI Average</b>	<b>97%</b>	<b>1%</b>	<b>2%</b>

---

## Frequency of Medical Care

Table 10 Frequency of Medical Care Needed for Child

State	Less than Once a Month	At Least Once a Month, Less than Once a week	At Least Once a Week
LA	58%	24%	18%
MEORC	76%	18%	6%
NC	67%	23%	10%
NJ	76%	16%	8%
SD	75%	19%	5%
<b>NCI Average</b>	<b>71%</b>	<b>20%</b>	<b>9%</b>

## Behavioral Support Needed for Self-Injurious, Disruptive, or Destructive Behavior

Table 11 Amount of Behavioral Support Needed for Child

State	No Support Needed	Some Support Needed	Extensive Support Needed
LA	52%	31%	17%
MEORC	61%	32%	7%
NC	38%	42%	19%
NJ	46%	37%	17%
SD	51%	40%	8%
<b>NCI Average</b>	<b>50%</b>	<b>37%</b>	<b>14%</b>



---

## Help Needed with Daily Activities

**Table 12 Amount of Help Needed for Daily Activities for Child**

State	None	Little	Moderate	Complete
LA	7%	17%	33%	43%
MEORC	12%	27%	37%	24%
NC	10%	20%	37%	34%
NJ	21%	23%	27%	29%
SD	7%	28%	36%	30%
<b>NCI Average</b>	<b>11%</b>	<b>23%</b>	<b>34%</b>	<b>32%</b>

---

## Demographics: Respondents

This section provides information about survey respondents. Respondents are the individuals who completed the survey forms, not the child with disabilities living in the household.

Across states, the majority of respondents were between 35 and 54 years old (65%); 24% were under 35, and 10% were 55-74. Over four-fifths rated their overall health as either good (55%) or excellent (26%).

The vast majority respondents were the child's parent (95%), 4% were grandparents, and 1% had a relationship not listed. Nearly all were the child's primary caregiver (99%).

Just over two-thirds of respondents indicated there were two adults living in the home (68%) while 20% reported there was one adult. While 42% of respondents had a college degree, 20% had some college experience (but no degree), 21% had a high school diploma or GED, 8% attended vocational school, and 8% had less than a high school diploma.

Respondent's household incomes were: less than \$15,000 (22%), \$15,001 - \$25,000 (13%), \$25,001-\$50,000 (25%), \$50,001 - \$75,000 (19%), and over \$75,000 (22%). Twenty-three percent (23%) reported they did not spend out-of-pocket expenses on services and supports on their child in the previous year, while 12% spent \$1-\$100, 34% spent \$101- \$1,000, 28% spent \$1,001- \$10,000, and 4% spent over \$10,000.

---

## Age of Respondent

**Table 13 Age of Respondent**

State	Under 35	35-54	55-74	75 or Older
LA	36%	57%	6%	1%
MEORC	40%	51%	8%	0%
NC	16%	73%	11%	0%
NJ	9%	78%	14%	0%
SD	22%	68%	10%	0%
<b>NCI Average</b>	<b>24%</b>	<b>65%</b>	<b>10%</b>	<b>0%</b>

## Respondent's Health

**Table 14 Health of Respondent**

State	Excellent	Good	Fair	Poor
LA	30%	47%	17%	5%
MEORC	25%	62%	12%	1%
NC	23%	56%	19%	2%
NJ	20%	56%	19%	4%
SD	34%	52%	13%	1%
<b>NCI Average</b>	<b>26%</b>	<b>55%</b>	<b>16%</b>	<b>3%</b>

---

## Relationship to Child

Table 15 Relationship to Child

State	Parent	Sibling	Grandparent	Other
LA	94%	1%	5%	1%
MEORC	94%	0%	5%	1%
NC	92%	0%	5%	4%
NJ	97%	0%	1%	1%
SD	98%	0%	2%	0%
<b>NCI Average</b>	<b>95%</b>	<b>0%</b>	<b>4%</b>	<b>1%</b>

## Primary Caregiver

Table 16 Respondent is Primary Caregiver

State	Yes	No
LA	99%	1%
MEORC	99%	1%
NC	98%	2%
NJ	100%	0%
SD	99%	1%
<b>NCI Average</b>	<b>99%</b>	<b>1%</b>

---

## Number of Adults in the Household

Table 17 Number of Adults in Household

State	One	Two	Three	Four or More
LA	28%	62%	8%	2%
MEORC	12%	78%	6%	4%
NC	23%	64%	12%	2%
NJ	21%	58%	13%	9%
SD	15%	79%	4%	1%
<b>NCI Average</b>	<b>20%</b>	<b>68%</b>	<b>8%</b>	<b>3%</b>

## Highest Education Level

Table 18 Highest Education Level of Respondent

State	Less Than High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree
LA	10%	26%	11%	19%	34%
MEORC	13%	30%	5%	17%	36%
NC	8%	17%	6%	22%	48%
NJ	7%	16%	3%	25%	48%
SD	3%	18%	16%	18%	46%
<b>NCI Average</b>	<b>8%</b>	<b>21%</b>	<b>8%</b>	<b>20%</b>	<b>42%</b>

---

## Income Level

**Table 19 Last Year Total Taxable Income**

State	Below \$15,000	\$15,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	Over \$75,000
LA	35%	12%	19%	13%	22%
MEORC	24%	15%	30%	18%	12%
NC	25%	14%	23%	16%	23%
NJ	14%	9%	19%	21%	36%
SD	11%	16%	32%	24%	16%
<b>NCI Average</b>	<b>22%</b>	<b>13%</b>	<b>25%</b>	<b>19%</b>	<b>22%</b>

## Out-of-Pocket Expense

**Table 20 Last Year Out-of-Pocket Expenses**

State	Nothing	\$1 - \$100	\$101 - \$1,000	\$1,001 - \$10,000	Over \$10,000
LA	28%	10%	30%	28%	4%
MEORC	31%	12%	34%	22%	1%
NC	21%	11%	35%	28%	4%
NJ	12%	8%	29%	41%	9%
SD	20%	19%	40%	19%	3%
<b>NCI Average</b>	<b>23%</b>	<b>12%</b>	<b>34%</b>	<b>28%</b>	<b>4%</b>

---

## Services and Supports Received

This section provides information about the services and supports received by the family from the state ID/DD agency (social security benefits being the exception).

Respondents indicated their child received in-home support (39%), financial support (33%), and 25% received out-of-home respite supports. Forty-one (41%) received social security benefits.

**Table 21 Services and Supports Received**

State	Financial Support	In-Home Support	Out-of-Home Respite	Early Intervention	Transportation	Other Services and Supports	Social Security Benefits
LA	35%	54%	13%	35%	13%	63%	42%
MEORC	34%	14%	15%	41%	18%	64%	32%
NC	17%	67%	38%	3%	22%	65%	50%
NJ	21%	22%	14%	2%	23%	31%	44%
SD	59%	37%	44%	12%	20%	69%	40%
<b>NCI Average</b>	<b>33%</b>	<b>39%</b>	<b>25%</b>	<b>18%</b>	<b>19%</b>	<b>58%</b>	<b>41%</b>

---

## Child Family Survey Results

This section of the report presents outcomes at the state and national level for all questions. It is divided into six subsections:

- Information and Planning
- Access and Delivery of Services and Supports
- Choice and Control
- Community Connections
- Satisfaction with Services and Supports
- Outcomes

Results are presented first in graph form and then in table form showing each state's percentage for all response options. Within the tables, states are listed in descending order: significantly above the NCI Average, within the NCI Average, and significantly below the NCI Average. Significance is taken to be at or below the .01 level, and is based on the 'always' or 'yes' responses.



---

## Information and Planning

Thirty percent (30%) of respondents reported they always get enough information to plan services (states ranged between 12%-62%); 34% reported the information they receive is always easy to understand (states ranged between 15%-53%). One-third (33%) reported the information they receive about services and supports always comes from the case manager/service coordinator (states ranged between 16%-54%).

Across states, 37% reported they received information about their child's development, and 43% reported information for their child's development was easy to understand.

A majority of respondents reported the case manager respects their choices and opinions (62%, states ranged between 33%-87%). Just under half (47%) reported the case manager/service coordinator is generally knowledgeable (states ranged between 28%-78%).

The vast majority of respondents reported they helped make their child's service plan (94%), and most reported the service plan includes services and supports that are important to them (94%). Almost three-quarters of respondents (73%) indicated the plan includes all services and supports their family needs.

Q1. Do you receive information about the services and supports that are available to your child and family?

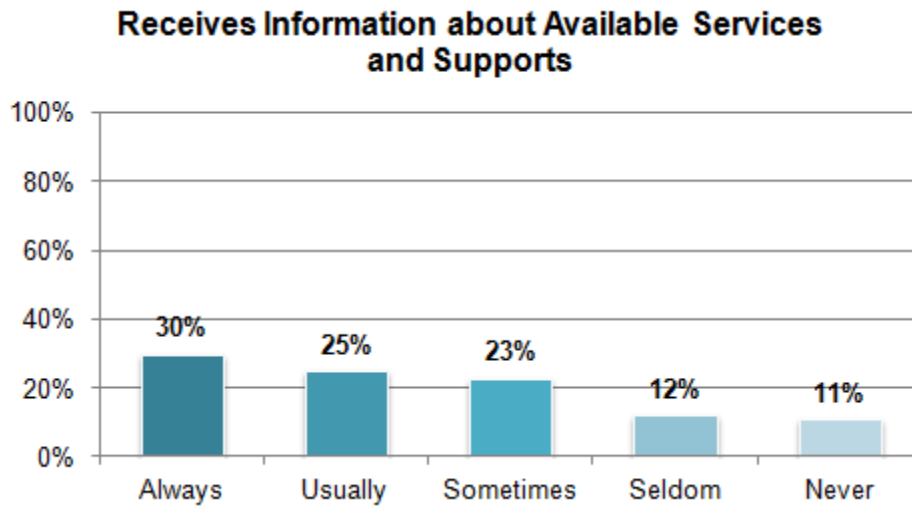


Table 22 Do you receive information about the services and supports that are available to your child and family?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	62%	27%	9%	1%	1%	277
MEORC	40%	29%	18%	7%	6%	298
<b>Significantly Below Average</b>						
LA	23%	28%	27%	10%	12%	316
NJ	12%	14%	31%	18%	24%	283
NC	12%	28%	29%	21%	10%	257
<b>NCI Average</b>	<b>30%</b>	<b>25%</b>	<b>23%</b>	<b>12%</b>	<b>11%</b>	<b>1,431</b>

Q2. Is the information you receive easy to understand?

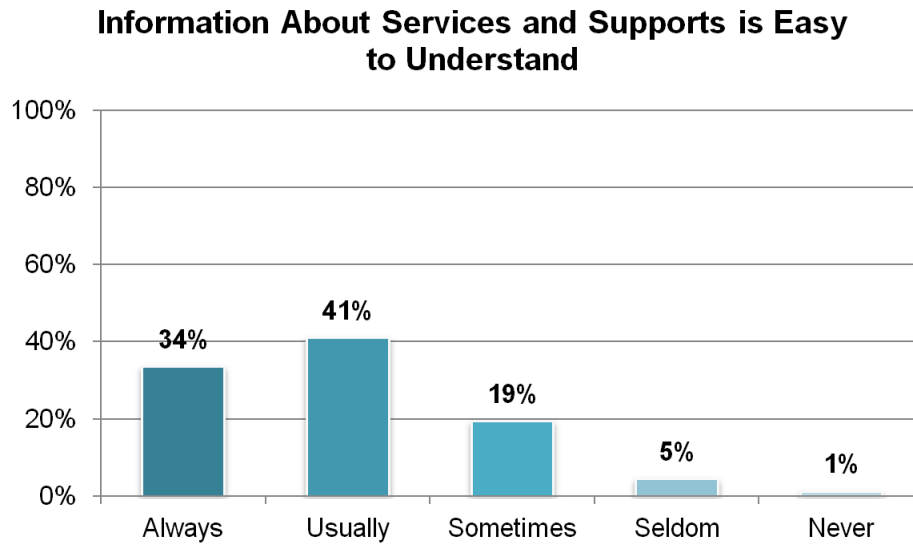
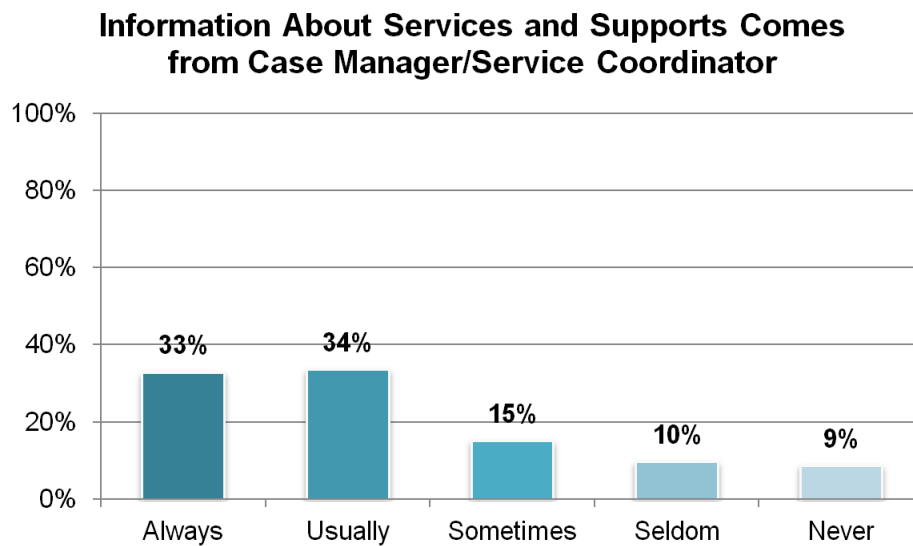


Table 23 Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	53%	40%	6%	1%	0%	272
MEORC	48%	38%	12%	1%	1%	276
<b>Within Average Range</b>						
LA	30%	38%	25%	5%	2%	273
<b>Significantly Below Average</b>						
NJ	22%	46%	23%	7%	2%	204
NC	15%	44%	31%	9%	1%	226
<b>NCI Average</b>	<b>34%</b>	<b>41%</b>	<b>19%</b>	<b>5%</b>	<b>1%</b>	<b>1,251</b>

**Q3. Does the information you receive primarily come from your case manager/service coordinator (as opposed to family, friends, and others outside State services)?**



**Table 24 Does the information you receive primarily come from your case manager/service coordinator (as opposed to family, friends, and others outside State services)?**

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	54%	38%	6%	2%	0%	272
<b>Within Average Range</b>						
MEORC	40%	39%	13%	6%	3%	269
LA	31%	33%	18%	11%	7%	297
<b>Significantly Below Average</b>						
NC	24%	37%	23%	10%	7%	243
NJ	16%	22%	16%	19%	27%	245
<b>NCI Average</b>	<b>33%</b>	<b>34%</b>	<b>15%</b>	<b>10%</b>	<b>9%</b>	<b>1,326</b>

Q4. Do you receive information about the status of your child's development?

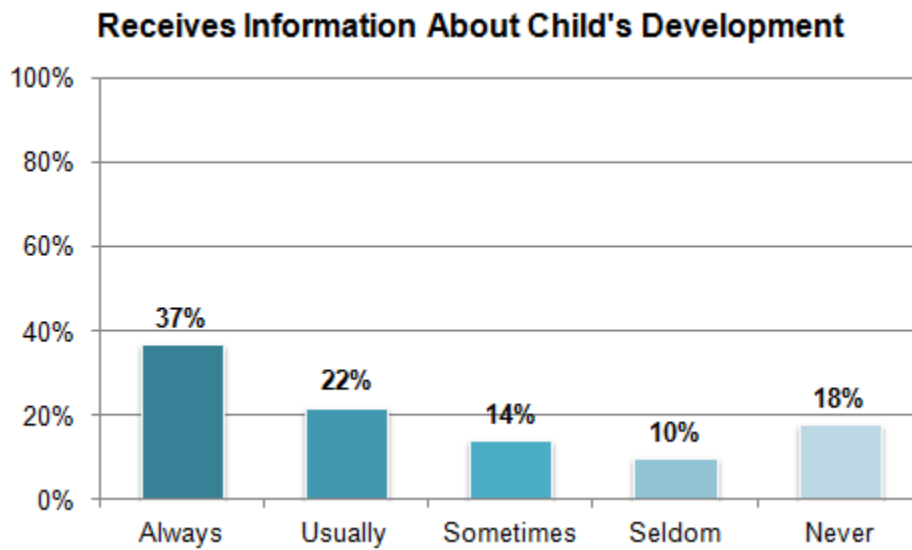


Table 25 Do you receive information about the status of your child's development?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
MEORC	54%	21%	11%	8%	6%	270
SD	44%	29%	15%	7%	6%	248
<b>Within Average Range</b>						
LA	42%	21%	14%	9%	14%	305
<b>Significantly Below Average</b>						
NC	27%	28%	16%	16%	13%	249
NJ	18%	13%	11%	9%	49%	245
<b>NCI Average</b>	<b>37%</b>	<b>22%</b>	<b>14%</b>	<b>10%</b>	<b>18%</b>	<b>1,317</b>

Q5. Is the information you receive easy to understand?

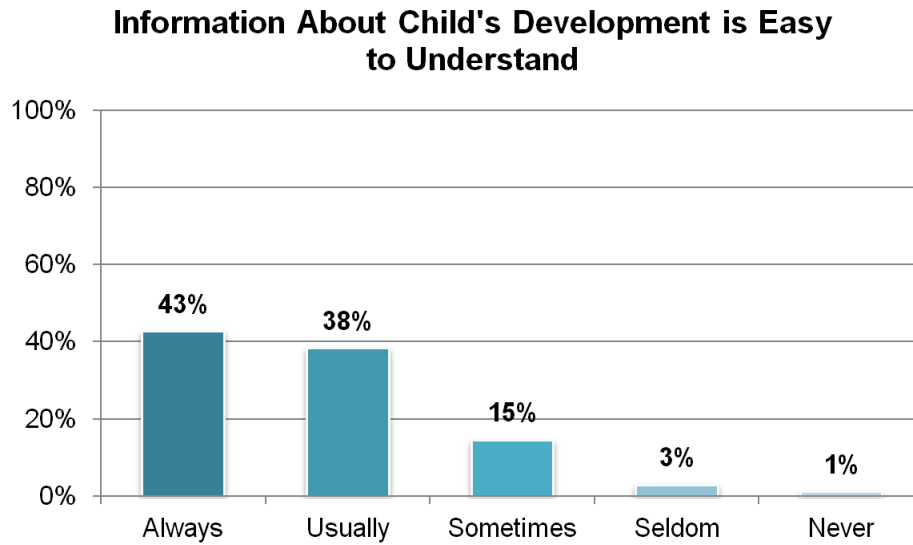


Table 26 Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
MEORC	56%	35%	8%	1%	1%	250
<b>Within Average Range</b>						
SD	48%	40%	10%	2%	0%	232
LA	44%	38%	14%	4%	1%	257
NJ	42%	33%	22%	0%	3%	119
<b>Significantly Below Average</b>						
NC	25%	47%	20%	8%	1%	214
<b>NCI Average</b>	<b>43%</b>	<b>38%</b>	<b>15%</b>	<b>3%</b>	<b>1%</b>	<b>1,072</b>

Q6. Do you get enough information to help you participate in planning services for your family?

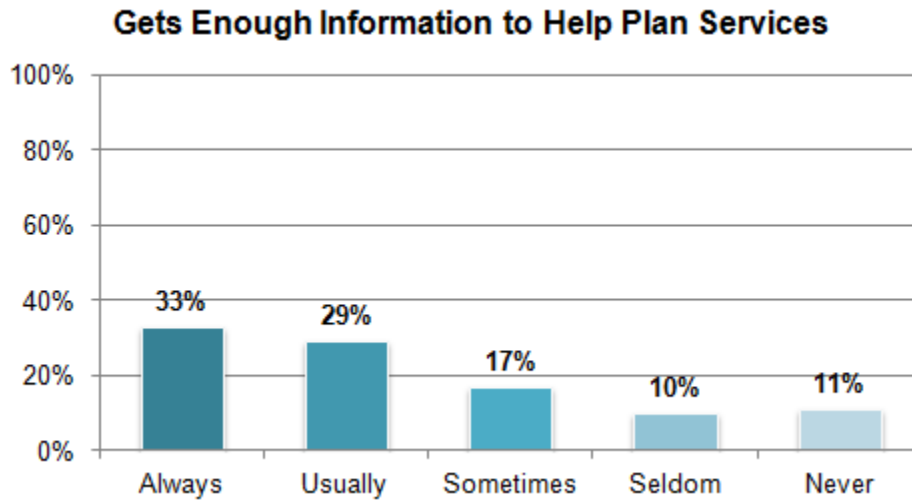
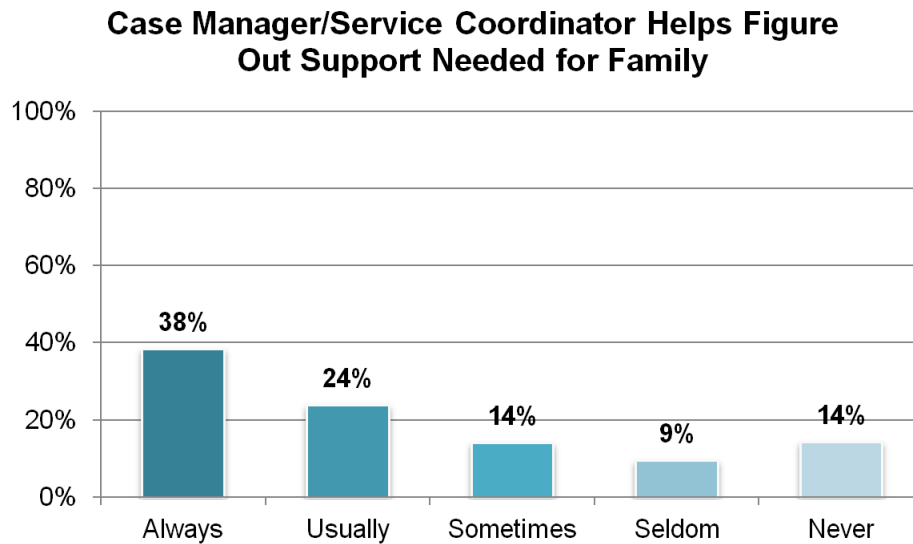


Table 27 Do you get enough information to help you participate in planning services for your family?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	56%	31%	9%	3%	1%	273
MEORC	48%	31%	11%	7%	4%	275
<b>Within Average Range</b>						
LA	34%	27%	21%	8%	11%	304
<b>Significantly Below Average</b>						
NC	18%	36%	22%	15%	9%	248
NJ	10%	19%	22%	16%	33%	259
<b>NCI Average</b>	<b>33%</b>	<b>29%</b>	<b>17%</b>	<b>10%</b>	<b>11%</b>	<b>1,359</b>

**Q7. Does the case manager/service coordinator who assists you with planning help you figure out what you need as a family to support your child?**

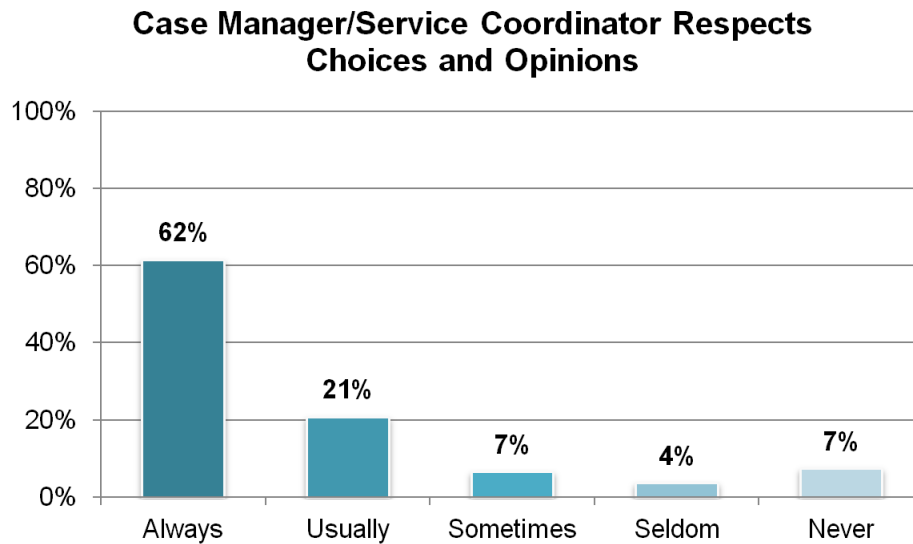


**Table 28 Does the case manager/service coordinator who assists you with planning help you figure out what you need as a family to support your child?**

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	67%	22%	6%	3%	1%	268
MEORC	45%	29%	14%	6%	6%	267
<b>Within Average Range</b>						
LA	36%	23%	18%	9%	13%	300
<b>Significantly Below Average</b>						
NC	29%	31%	19%	10%	11%	249
NJ	14%	14%	13%	18%	40%	259
<b>NCI Average</b>	<b>38%</b>	<b>24%</b>	<b>14%</b>	<b>9%</b>	<b>14%</b>	<b>1,343</b>



**Q8. Does the case manager/service coordinator who assists you with planning respect your choices and opinions?**



**Table 29 Does the case manager/service coordinator who assists you with planning respect your choices and opinions?**

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	87%	11%	2%	0%	0%	275
<b>Within Average Range</b>						
MEORC	68%	21%	6%	2%	2%	264
LA	65%	23%	5%	2%	5%	278
NC	56%	29%	10%	3%	3%	240
<b>Significantly Below Average</b>						
NJ	33%	20%	10%	12%	26%	203
<b>NCI Average</b>	<b>62%</b>	<b>21%</b>	<b>7%</b>	<b>4%</b>	<b>7%</b>	<b>1,260</b>

Q9. Does your case manager/service coordinator tell you about public services that you are eligible for? (e.g., food stamps, Early Period Screening Diagnosis and Treatment [EPSDT], Supplemental Security Income [SSI], housing subsidies, etc.)

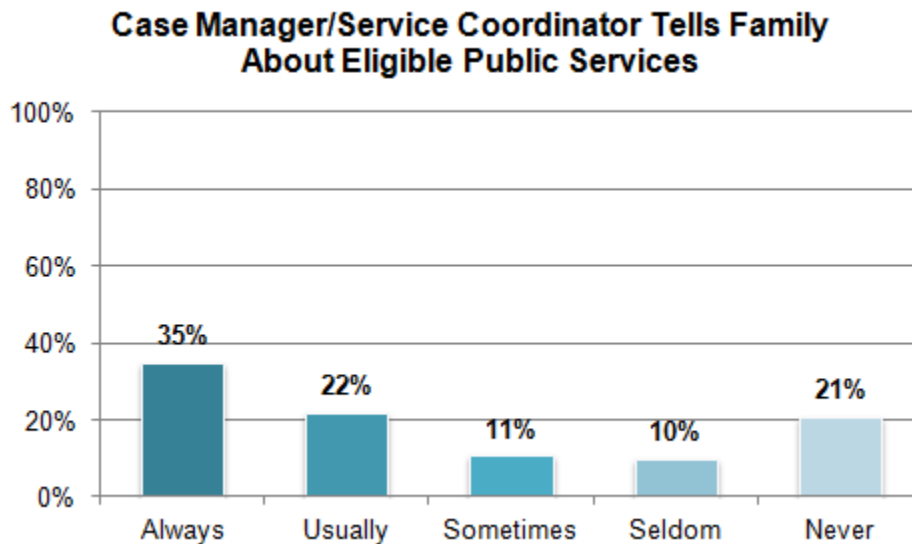


Table 30 Does your case manager/service coordinator tell you about public services that you are eligible for? (e.g., food stamps, Early Period Screening Diagnosis and Treatment [EPSDT], Supplemental Security Income [SSI], housing subsidies, etc.)

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	63%	25%	8%	2%	2%	262
MEORC	45%	26%	11%	7%	11%	251
<b>Within Average Range</b>						
LA	32%	20%	15%	11%	22%	292
<b>Significantly Below Average</b>						
NC	19%	27%	14%	15%	24%	239
NJ	15%	13%	8%	16%	49%	235
<b>NCI Average</b>	<b>35%</b>	<b>22%</b>	<b>11%</b>	<b>10%</b>	<b>21%</b>	<b>1,279</b>

Q10. Is the case manager/service coordinator who assists you with planning generally knowledgeable?

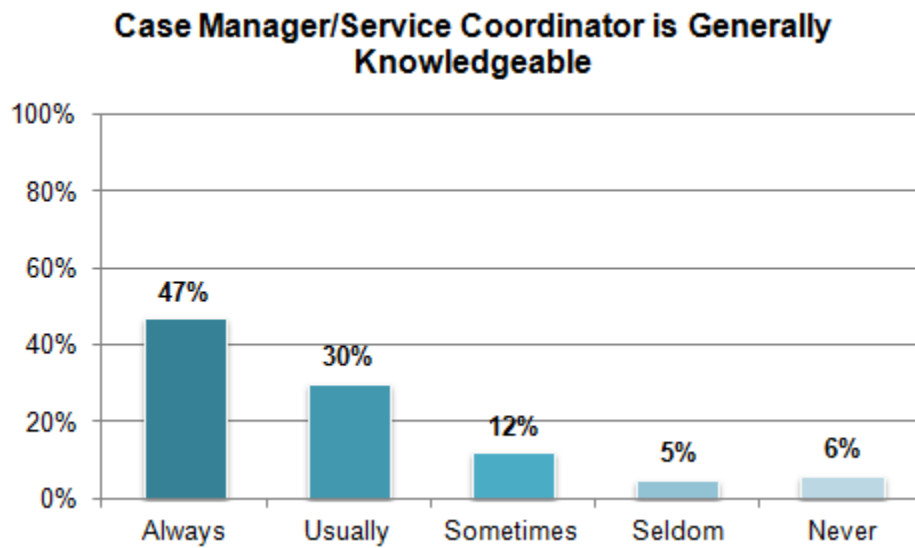


Table 31 Is the case manager/service coordinator who assists you with planning generally knowledgeable?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	78%	18%	2%	1%	1%	272
MEORC	57%	32%	7%	3%	2%	265
<b>Within Average Range</b>						
LA	42%	33%	15%	6%	5%	283
<b>Significantly Below Average</b>						
NC	32%	40%	18%	7%	3%	238
NJ	28%	28%	17%	10%	17%	198
<b>NCI Average</b>	<b>47%</b>	<b>30%</b>	<b>12%</b>	<b>5%</b>	<b>6%</b>	<b>1,256</b>

Q11. If your child has a service plan, did you help develop it?

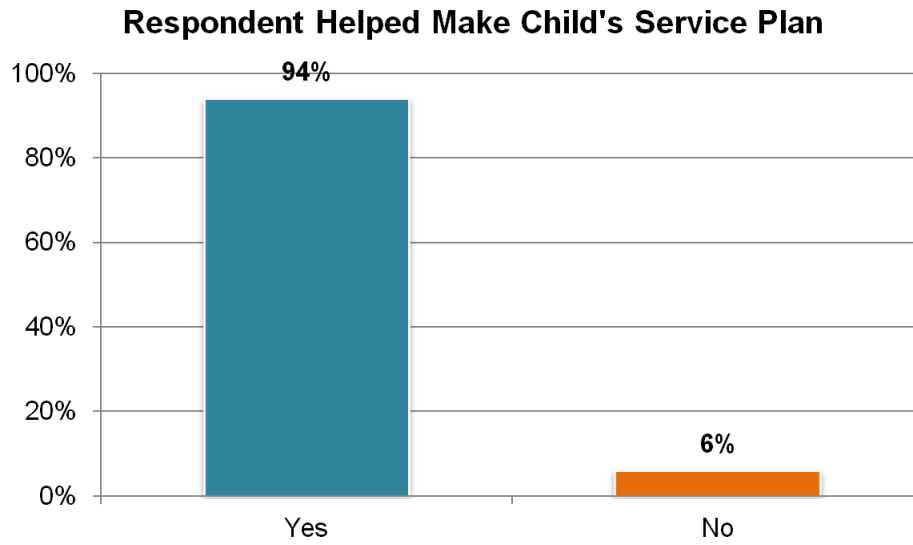
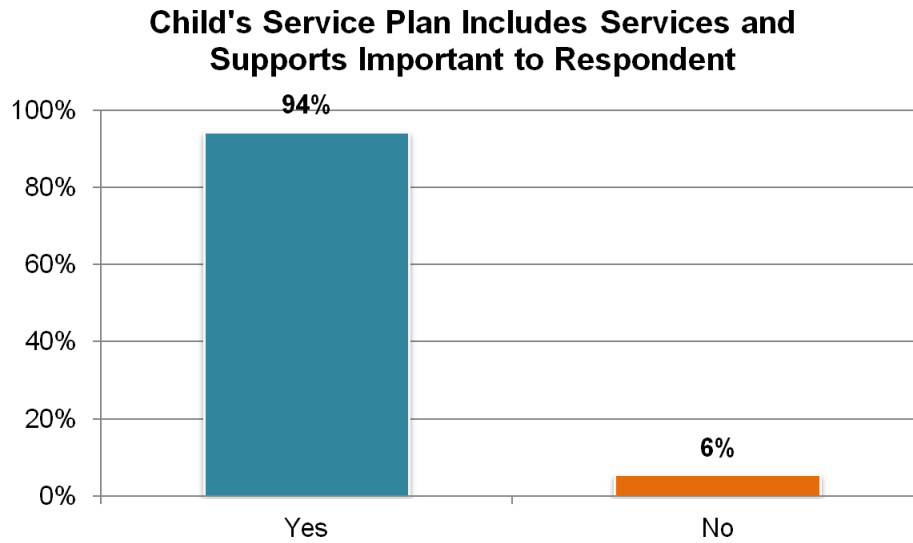


Table 32 If your child has a service plan, did you help develop it?

State	Yes	No	N
<b>Significantly Above Average</b>			
NC	99%	1%	227
<b>Within Average Range</b>			
SD	97%	3%	257
MEORC	97%	3%	213
NJ	89%	11%	236
LA	88%	12%	247
<b>NCI Average</b>	<b>94%</b>	<b>6%</b>	<b>1,180</b>

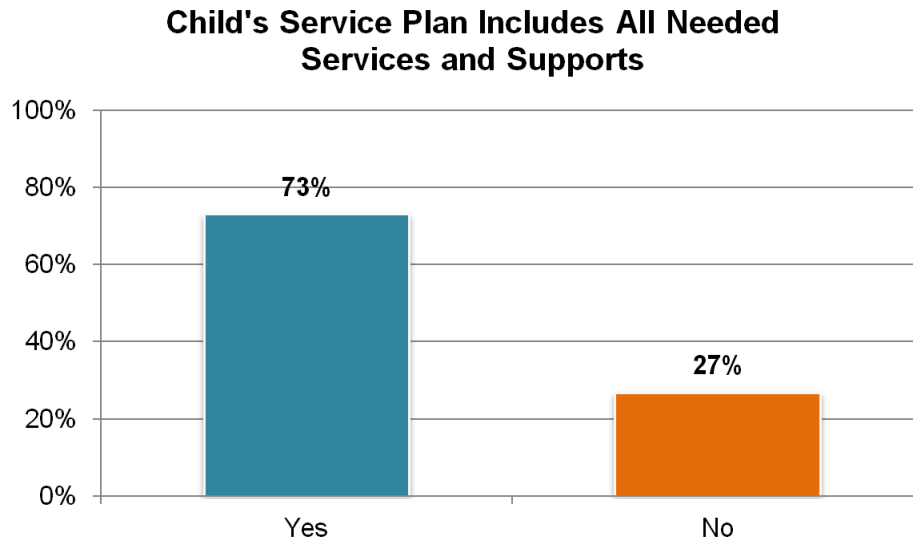
Q12. If your child has a service plan, does it include services and supports that are important to you?



**Table 33** If your child has a service plan, does it include services and supports that are important to you?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	98%	2%	254
<b>Within Average Range</b>			
MEORC	97%	3%	216
NC	95%	5%	226
LA	94%	6%	240
NJ	88%	12%	225
<b>NCI Average</b>	<b>94%</b>	<b>6%</b>	<b>1,161</b>

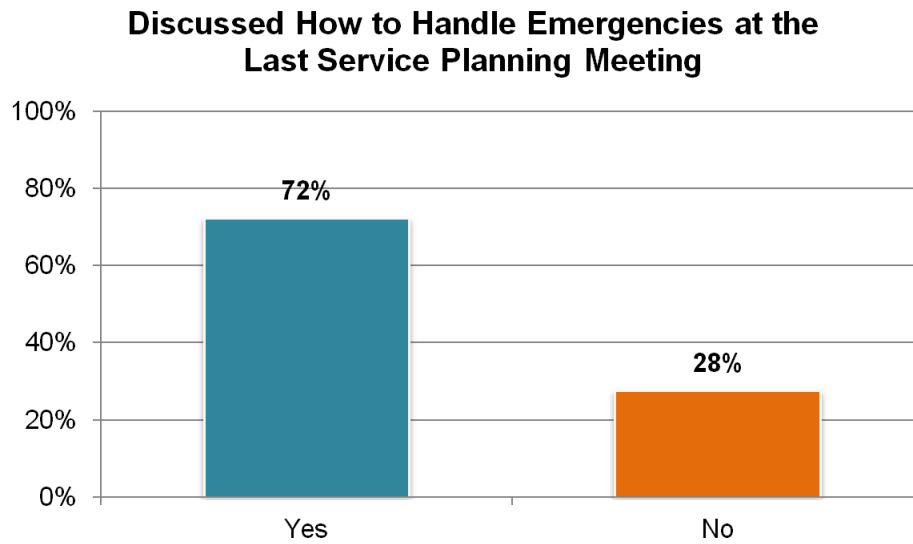
**Q13. Does the service plan include all the services and supports your family needs?**



**Table 34 Does the service plan include all the services and supports your family needs?**

State	Yes	No	N
<b>Significantly Above Average</b>			
MEORC	91%	9%	200
SD	87%	13%	242
<b>Within Average Range</b>			
LA	78%	22%	231
<b>Significantly Below Average</b>			
NC	61%	39%	211
NJ	49%	51%	204
<b>NCI Average</b>	<b>73%</b>	<b>27%</b>	<b>1,088</b>

**Q14. If your child has a service plan, did you discuss how to handle emergencies related to your child at the last service planning meeting?**



**Table 35 If your child has a service plan, did you discuss how to handle emergencies related to your child at the last service planning meeting?**

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	82%	18%	219
<b>Within Average Range</b>			
NC	79%	21%	209
LA	77%	23%	231
MEORC	72%	28%	172
<b>Significantly Below Average</b>			
NJ	52%	48%	216
<b>NCI Average</b>	<b>72%</b>	<b>28%</b>	<b>1,047</b>

Q15. Have you received information about your family's rights?

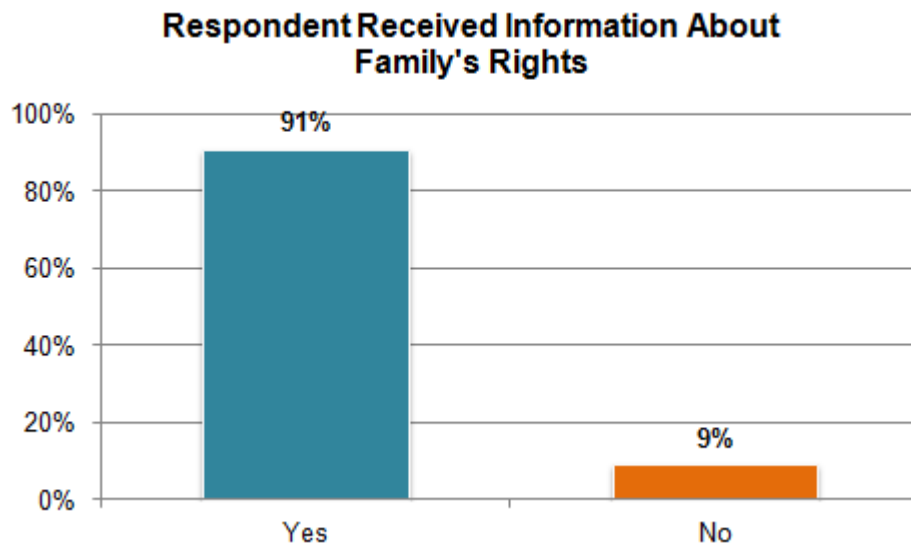


Table 36 Have you received information about your family's rights?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	99%	1%	264
MEORC	97%	3%	265
<b>Within Average Range</b>			
NC	90%	10%	232
LA	89%	11%	263
<b>Significantly Below Average</b>			
NJ	82%	18%	232
<b>NCI Average</b>	<b>91%</b>	<b>9%</b>	<b>1,256</b>



---

## Access and Delivery of Services and Supports

Just over half of the respondents reported they are always able to contact supports workers and the case manager/service coordinator when needed (52% and 53%, respectively). The majority reported their child always receives all services listed in the service plan (60%). While 43% reported their child always gets the services and supports needed, 37% report the family always gets the services and supports needed.

One-third of respondents reported services are always available when needed (33%; states ranged between 14%-47%) and 34% reported services and supports are always located reasonably close to the family home (states ranged between 15%-45%). Just over one-third (34%) reported services and supports always change when their child's needs change (states ranged between 13%-51%).

Four-fifths of respondents whose primary language is English reported support workers always communicate effectively in English (80%, states ranged between 60%-92%). Just under half (45%) reported there are enough support workers who can always communicate with their child who is non-verbal (states ranged between 19%-52%)

About three-quarters (74%) of respondents reported services are always delivered in a respectful manner towards the family's culture (states ranged between 61%-88%). Just over half (51%) reported support workers always have the right training to meet their child's needs (states ranged between 32%-67%).

Almost two-thirds of respondents reported crisis or emergency services were provided when needed (65%, states ranged between 37%-86%). The majority reported their child has access to: health services (97%), dental services (91%), needed medications (97%), mental health services (81%), and respite services (70%). Forty-four percent (44%) of respondents reported there are other services needed that are not currently offered.

**\*Results for question 24 are not included in this report. All state N's were too low to report.**

Q16. Are you able to contact your support workers when you need to?

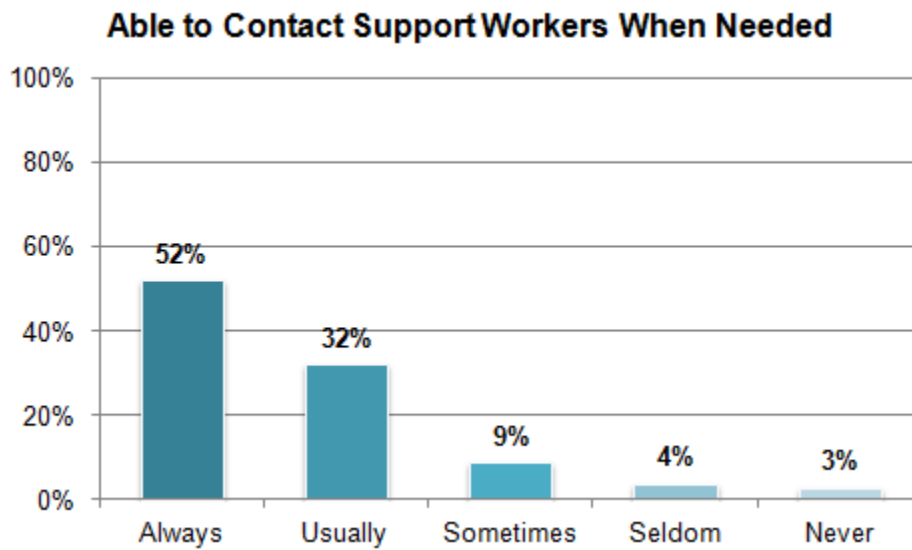


Table 37 Are you able to contact your support workers when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	71%	24%	3%	0%	0%	266
LA	64%	24%	10%	1%	1%	294
<b>Within Average Range</b>						
MEORC	57%	37%	5%	1%	0%	259
NC	44%	41%	9%	3%	2%	243
<b>Significantly Below Average</b>						
NJ	23%	32%	19%	14%	12%	236
<b>NCI Average</b>	<b>52%</b>	<b>32%</b>	<b>9%</b>	<b>4%</b>	<b>3%</b>	<b>1,298</b>

Q17. Are you able to contact your case manager/service coordinator when you need to?

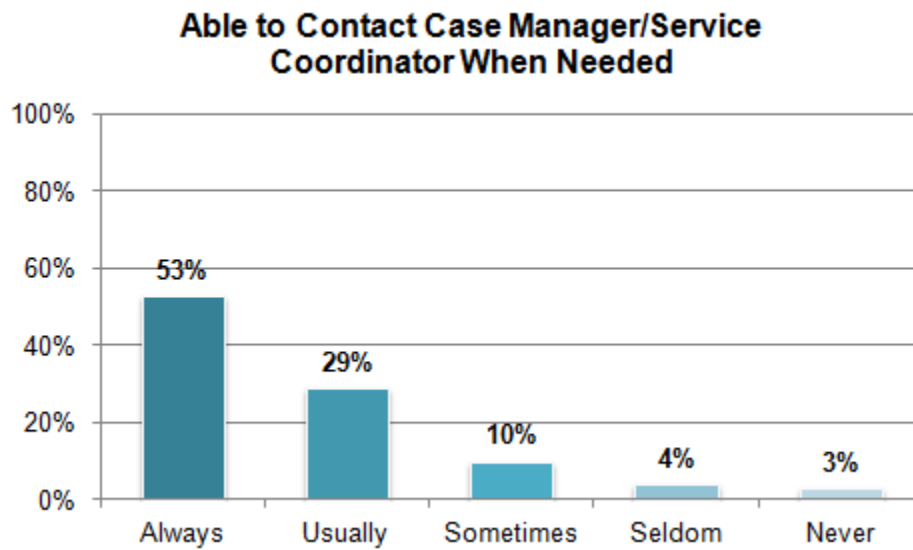


Table 38 Are you able to contact your case manager/service coordinator when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	74%	23%	1%	1%	0%	278
MEORC	63%	31%	4%	2%	1%	268
LA	62%	24%	11%	2%	1%	305
<b>Significantly Below Average</b>						
NC	42%	39%	13%	4%	2%	248
NJ	26%	27%	22%	13%	13%	254
<b>NCI Average</b>	<b>53%</b>	<b>29%</b>	<b>10%</b>	<b>4%</b>	<b>3%</b>	<b>1,353</b>

Q18. Does your child receive all of the services listed in the service plan?

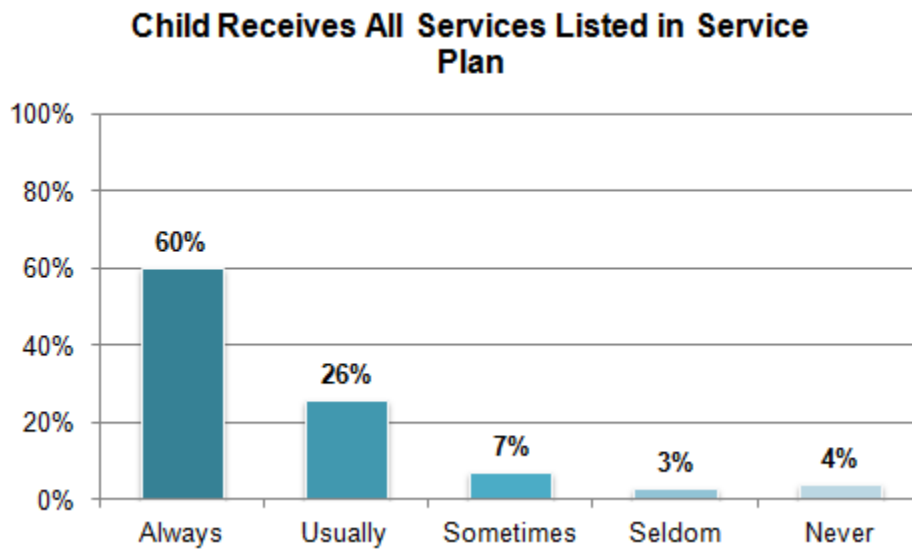


Table 39 Does your child receive all of the services listed in the service plan?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	75%	19%	3%	1%	1%	260
MEORC	70%	24%	4%	0%	1%	213
LA	68%	20%	7%	2%	3%	247
<b>Significantly Below Average</b>						
NC	46%	31%	10%	7%	5%	231
NJ	41%	34%	12%	4%	8%	215
<b>NCI Average</b>	<b>60%</b>	<b>26%</b>	<b>7%</b>	<b>3%</b>	<b>4%</b>	<b>1,166</b>

Q19. Does your child get the services and supports that s/he needs?

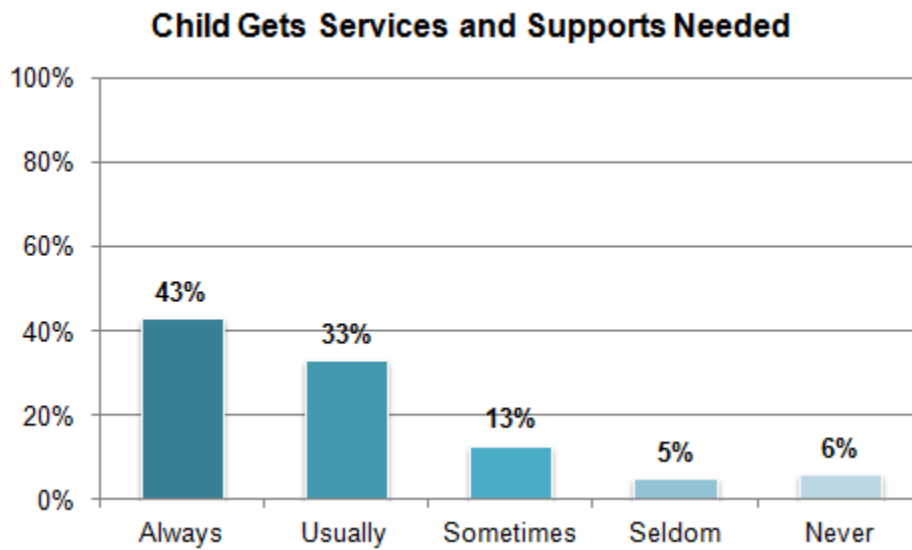


Table 40 Does your child get the services and supports that s/he needs?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
MEORC	62%	28%	8%	1%	1%	276
SD	55%	36%	7%	2%	0%	274
<b>Within Average Range</b>						
LA	49%	33%	12%	4%	3%	304
<b>Significantly Below Average</b>						
NC	30%	37%	18%	7%	9%	245
NJ	20%	31%	23%	11%	15%	257
<b>NCI Average</b>	<b>43%</b>	<b>33%</b>	<b>13%</b>	<b>5%</b>	<b>6%</b>	<b>1,356</b>

Q20. Does your family get the services and supports you need?

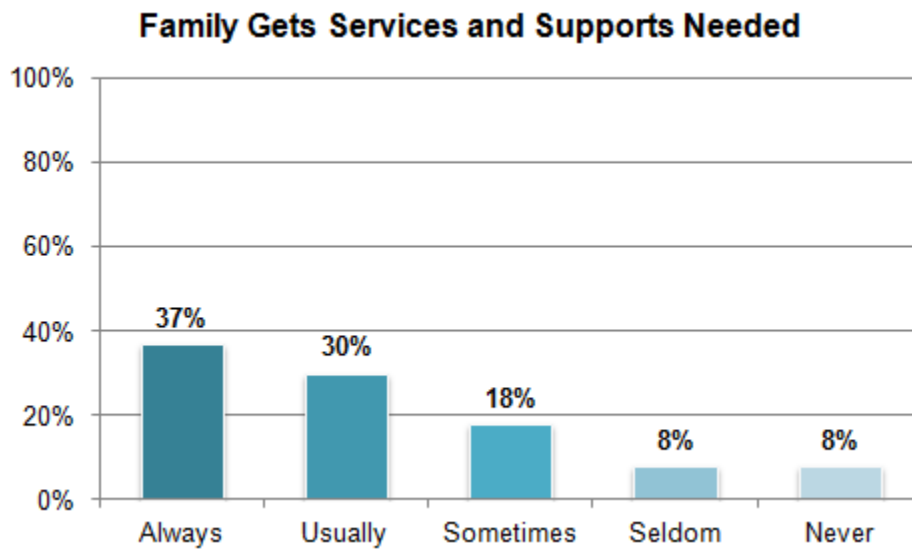


Table 41 Does your family get the services and supports you need?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
MEORC	56%	30%	9%	5%	1%	261
SD	50%	36%	11%	1%	2%	275
<b>Within Average Range</b>						
LA	39%	33%	18%	6%	4%	291
<b>Significantly Below Average</b>						
NC	25%	31%	24%	10%	10%	242
NJ	14%	19%	26%	20%	22%	250
<b>NCI Average</b>	<b>37%</b>	<b>30%</b>	<b>18%</b>	<b>8%</b>	<b>8%</b>	<b>1,319</b>

Q21. Are services and supports available at the times that you need them?

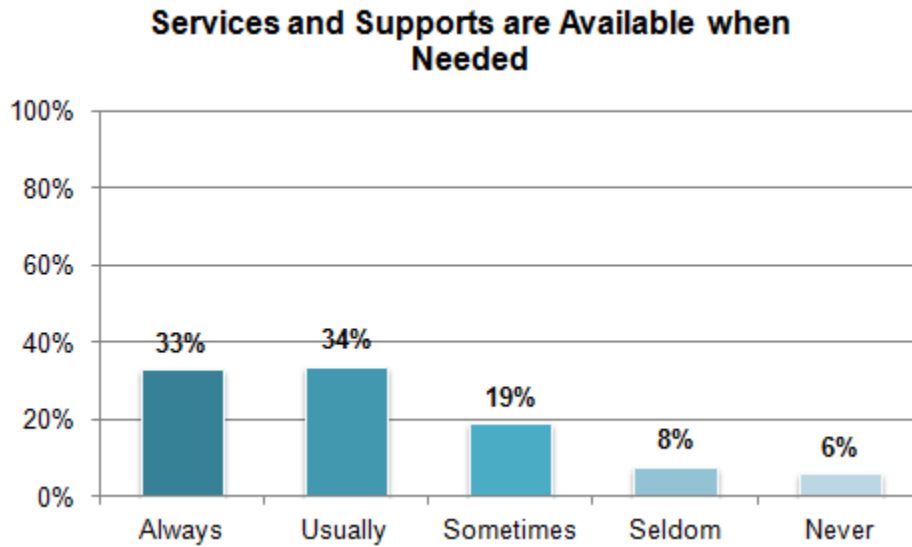


Table 42 Are services and supports available at the times that you need them?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
MEORC	47%	34%	15%	4%	0%	261
SD	47%	38%	13%	1%	1%	273
<b>Within Average Range</b>						
LA	39%	32%	20%	5%	3%	292
<b>Significantly Below Average</b>						
NC	20%	42%	21%	9%	9%	246
NJ	14%	24%	25%	19%	18%	223
<b>NCI Average</b>	<b>33%</b>	<b>34%</b>	<b>19%</b>	<b>8%</b>	<b>6%</b>	<b>1,295</b>

Q22. Are services and supports, received outside the family home, available within a reasonable distance from your family home?

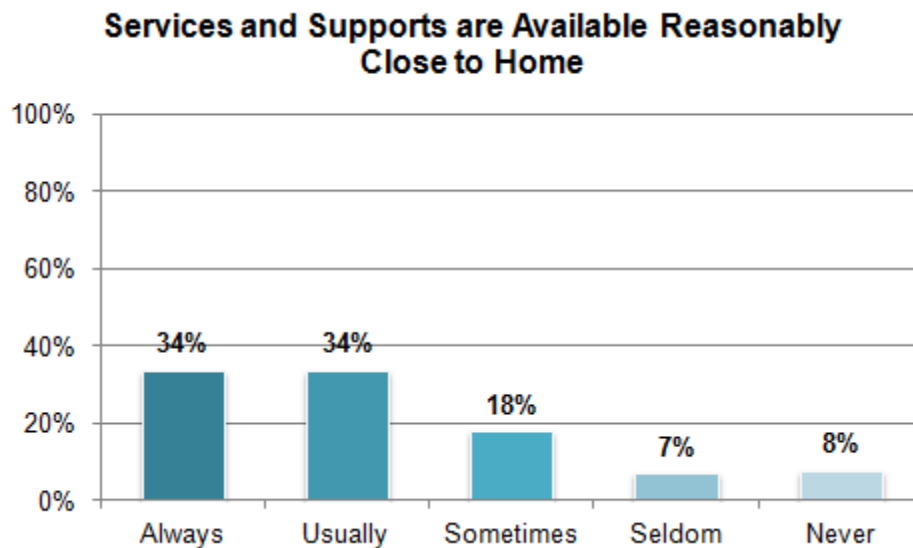


Table 43 Are services and supports, received outside the family home, available within a reasonable distance from your family home?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
MEORC	45%	33%	16%	4%	2%	227
SD	44%	35%	17%	3%	1%	240
<b>Within Average Range</b>						
LA	38%	34%	13%	8%	8%	213
NC	28%	40%	18%	5%	10%	215
<b>Significantly Below Average</b>						
NJ	15%	26%	26%	15%	19%	186
<b>NCI Average</b>	<b>34%</b>	<b>34%</b>	<b>18%</b>	<b>7%</b>	<b>8%</b>	<b>1,081</b>



Q23. Do the services and supports change when your child's needs change?

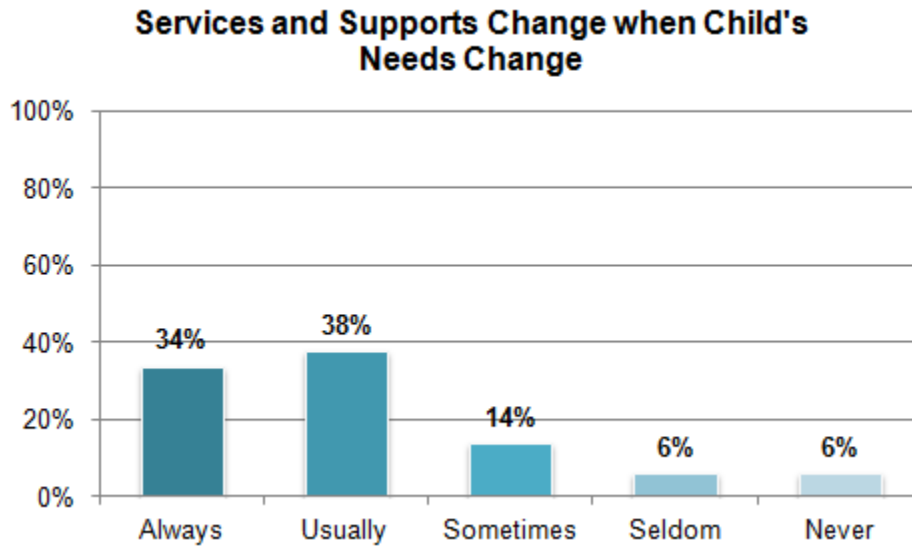


Table 44 Do the services and supports change when your child's needs change?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	51%	38%	9%	2%	1%	258
MEORC	47%	37%	10%	2%	3%	230
<b>Within Average Range</b>						
LA	40%	36%	16%	5%	3%	257
<b>Significantly Below Average</b>						
NC	21%	52%	14%	8%	6%	229
NJ	13%	29%	24%	15%	19%	182
<b>NCI Average</b>	<b>34%</b>	<b>38%</b>	<b>14%</b>	<b>6%</b>	<b>6%</b>	<b>1,156</b>

Q25. If English is your first language, do the support workers communicate with you effectively in your primary language?

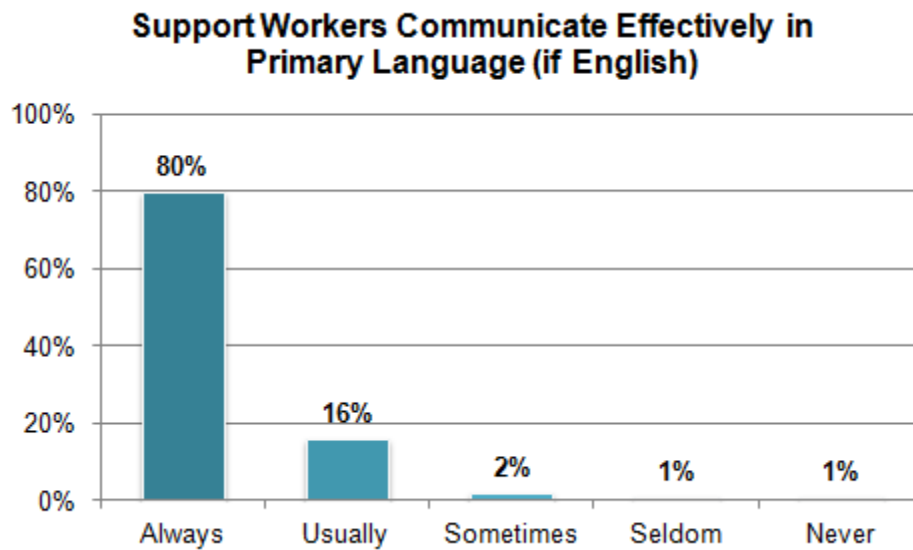


Table 45 If English is your first language, do the support workers communicate with you effectively in your primary language?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	92%	7%	1%	0%	0%	226
MEORC	87%	12%	1%	0%	0%	233
<b>Within Average Range</b>						
LA	84%	13%	1%	1%	1%	211
NC	80%	18%	2%	0%	0%	201
<b>Significantly Below Average</b>						
NJ	60%	30%	5%	3%	2%	149
<b>NCI Average</b>	<b>80%</b>	<b>16%</b>	<b>2%</b>	<b>1%</b>	<b>1%</b>	<b>1,020</b>

Q26. If your child does not verbally communicate (for example, uses gestures or sign language), are there enough support workers available who can communicate with him/her?

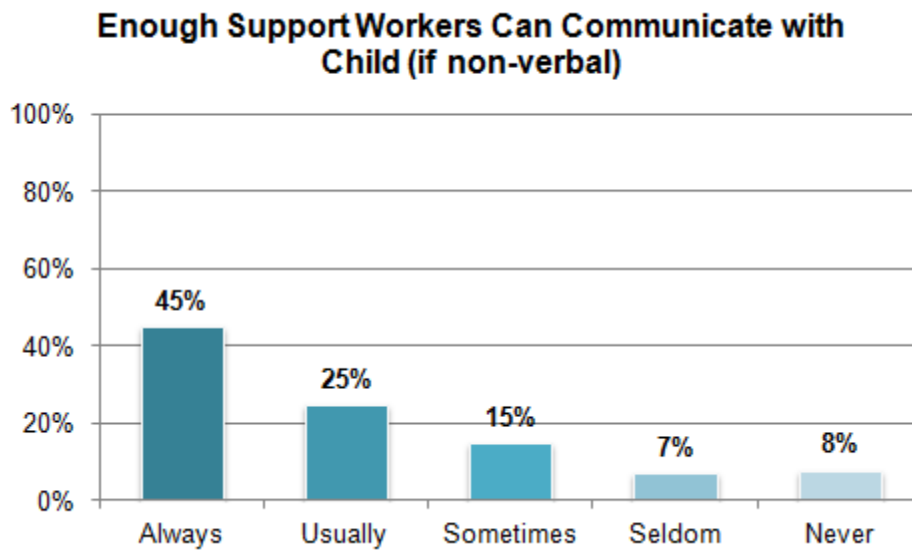


Table 46 If your child does not verbally communicate (for example, uses gestures or sign language), are there enough support workers available who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
MEORC	52%	30%	10%	4%	3%	90
<b>Within Average Range</b>						
LA	40%	28%	13%	10%	10%	136
SD	31%	28%	28%	4%	10%	83
<b>Significantly Below Average</b>						
NJ	19%	26%	24%	16%	16%	58
NCI Average	45%	25%	15%	7%	8%	1,387

Q27. Are services delivered to your family in a way that is respectful to your family's culture(s)?

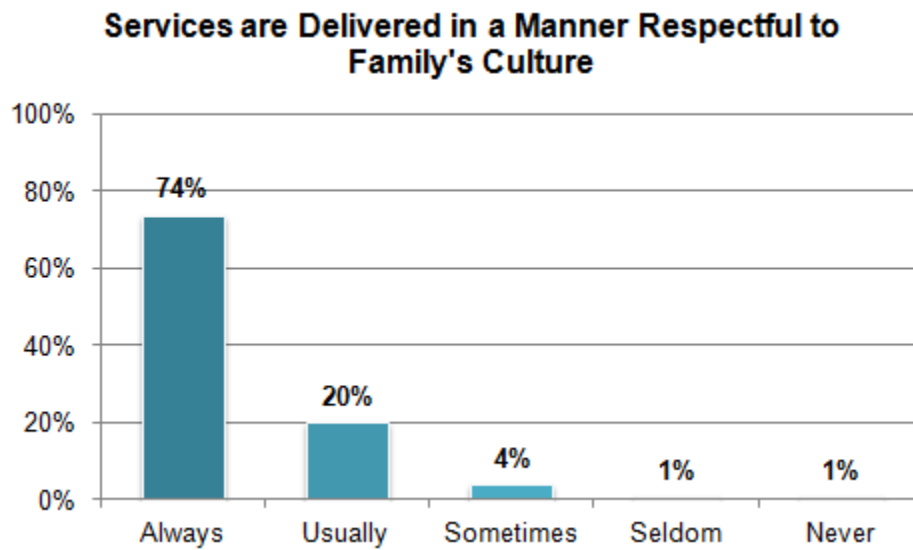


Table 47 Are services delivered to your family in a way that is respectful to your family's culture(s)?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	88%	10%	1%	0%	1%	248
MEORC	81%	17%	2%	0%	0%	237
<b>Within Average Range</b>						
LA	76%	18%	4%	0%	2%	274
<b>Significantly Below Average</b>						
NC	64%	32%	3%	0%	1%	228
NJ	61%	25%	8%	5%	2%	165
<b>NCI Average</b>	<b>74%</b>	<b>20%</b>	<b>4%</b>	<b>1%</b>	<b>1%</b>	<b>1,152</b>

Q28. Does your child have access to the special equipment or accommodations that s/he needs (e.g., wheelchair, ramp, communication board)?

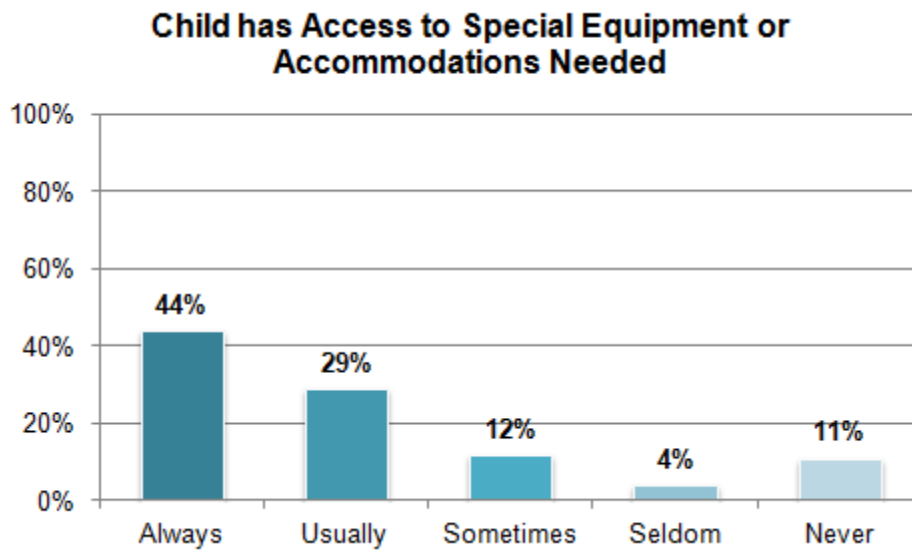


Table 48 Does your child have access to the special equipment or accommodations that s/he needs (e.g., wheelchair, ramp, communication board)?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
MEORC	60%	30%	7%	1%	3%	144
SD	59%	30%	6%	3%	2%	178
<b>Within Average Range</b>						
LA	46%	22%	12%	4%	16%	180
<b>Significantly Below Average</b>						
NC	31%	36%	18%	3%	12%	152
NJ	25%	27%	17%	8%	23%	112
<b>NCI Average</b>	<b>44%</b>	<b>29%</b>	<b>12%</b>	<b>4%</b>	<b>11%</b>	<b>766</b>

Q29. Do the support workers have the right training to meet your child's needs?

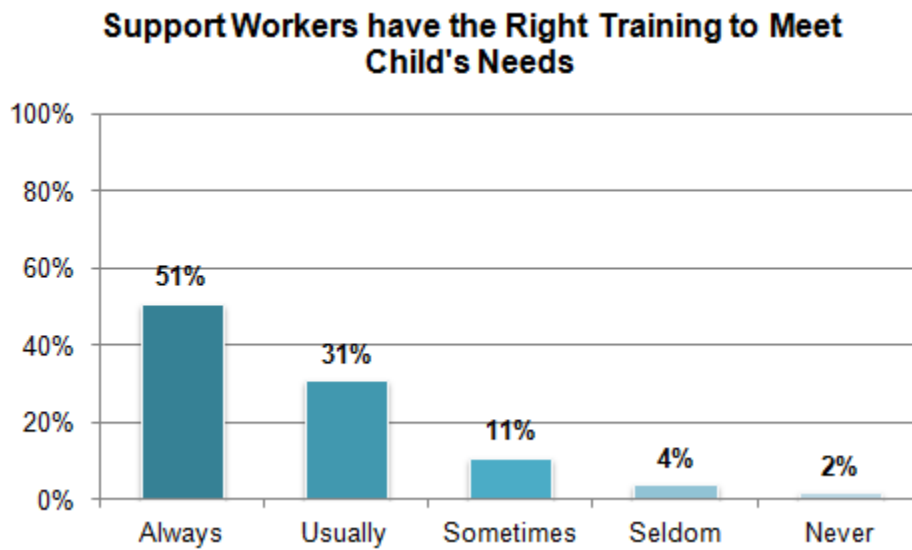


Table 49 Do the support workers have the right training to meet your child's needs?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	67%	24%	6%	1%	2%	245
MEORC	63%	29%	6%	2%	0%	246
LA	59%	29%	6%	4%	2%	274
<b>Significantly Below Average</b>						
NC	35%	38%	17%	5%	5%	231
NJ	32%	38%	18%	9%	3%	152
<b>NCI Average</b>	<b>51%</b>	<b>31%</b>	<b>11%</b>	<b>4%</b>	<b>2%</b>	<b>1,148</b>

Q30. Do the support workers who come to your home arrive on time and when scheduled?

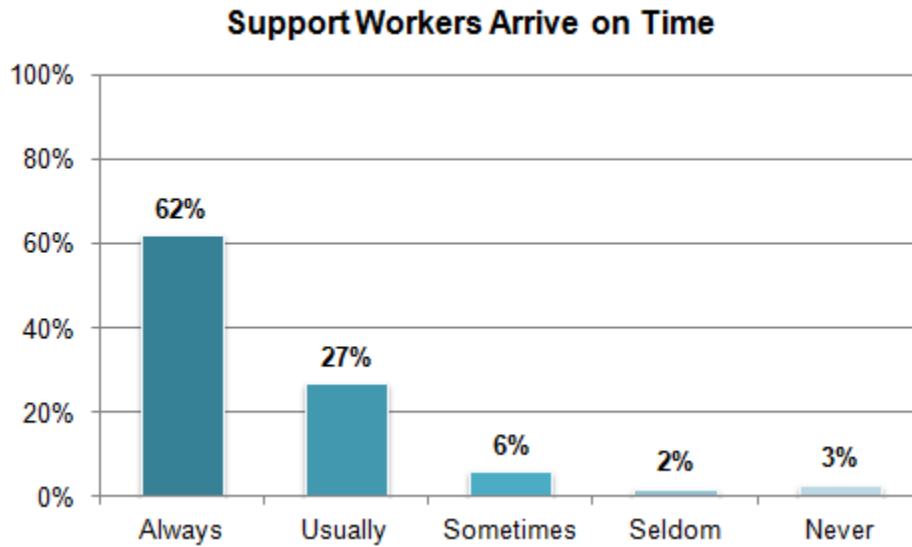
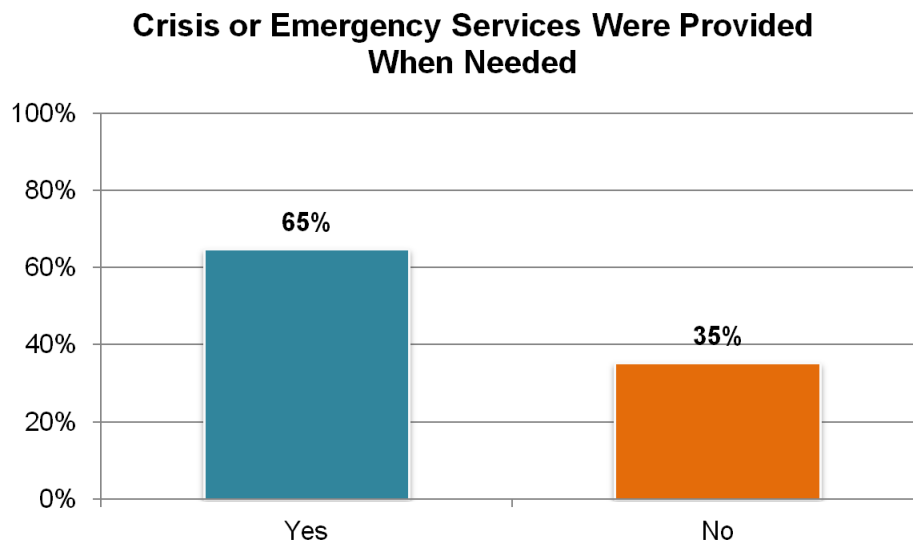


Table 50 Do the support workers who come to your home arrive on time and when scheduled?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	80%	18%	1%	0%	0%	210
MEORC	72%	23%	4%	1%	1%	194
<b>Within Average Range</b>						
LA	65%	23%	9%	0%	2%	265
NJ	53%	28%	6%	3%	10%	97
<b>Significantly Below Average</b>						
NC	40%	46%	10%	3%	1%	232
<b>NCI Average</b>	<b>62%</b>	<b>27%</b>	<b>6%</b>	<b>2%</b>	<b>3%</b>	<b>998</b>

**Q31. If you asked for crisis/emergency services during the past year, were services provided when needed?**



**Table 51 If you asked for crisis/emergency services during the past year, were services provided when needed?**

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	86%	14%	57
<b>Within Average Range</b>			
MEORC	78%	22%	49
LA	74%	26%	82
NC	49%	51%	70
<b>Significantly Below Average</b>			
NJ	37%	63%	67
<b>NCI Average</b>	<b>65%</b>	<b>35%</b>	<b>325</b>



Q32. Do you have access to health services for your child?

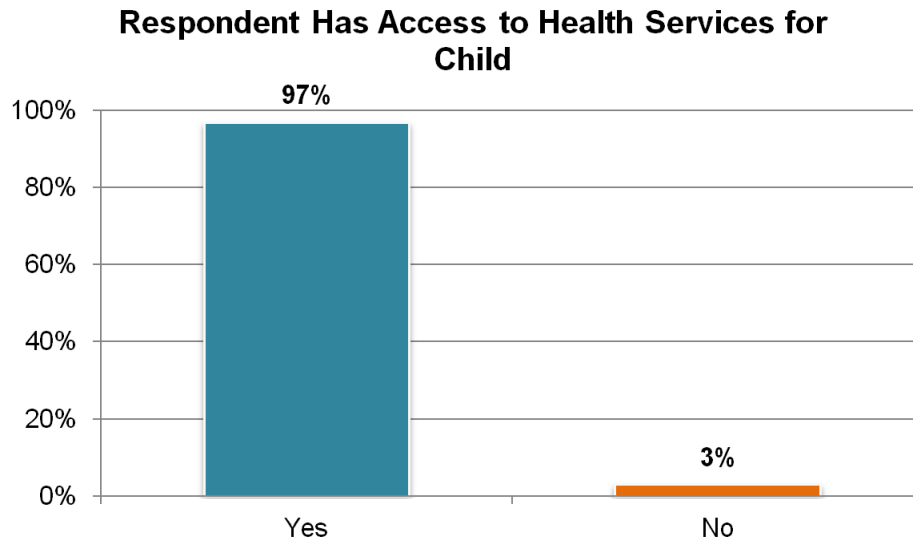


Table 52 Do you have access to health services for your child?

State	Yes	No	N
Significantly Above Average			
SD	99%	1%	268
Within Average Range			
MEORC	99%	1%	289
LA	98%	2%	308
NC	95%	5%	250
NJ	93%	7%	270
NCI Average	97%	3%	1,385

Q33. If “yes” (to Q32), are you satisfied with the quality of these providers?

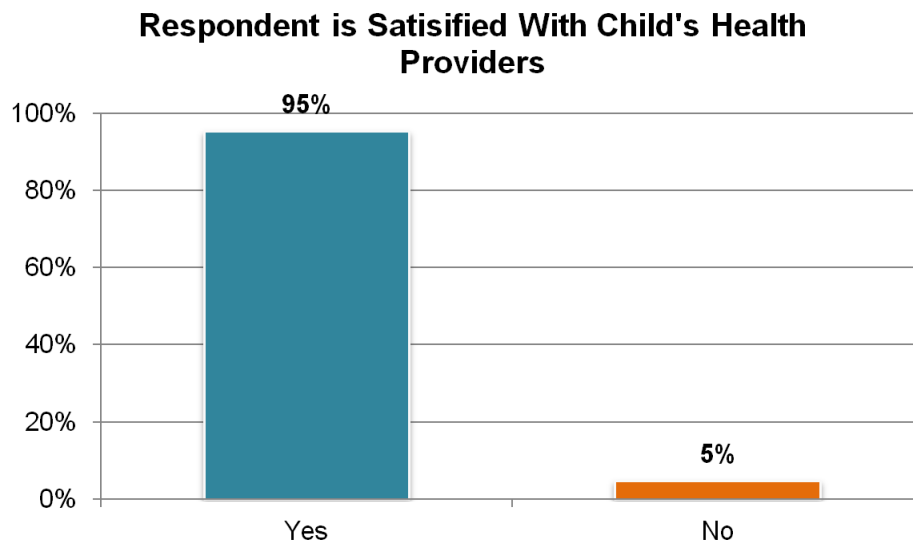


Table 53 If “yes” (to Q32), are you satisfied with the quality of these providers?

State	Yes	No	N
<b>Significantly Above Average</b>			
MEORC	99%	1%	278
SD	98%	2%	257
<b>Within Average Range</b>			
LA	97%	3%	289
NC	94%	6%	235
NJ	90%	10%	229
<b>NCI Average</b>	<b>95%</b>	<b>5%</b>	<b>1,288</b>

Q34. Do you have access to dental services for your child?

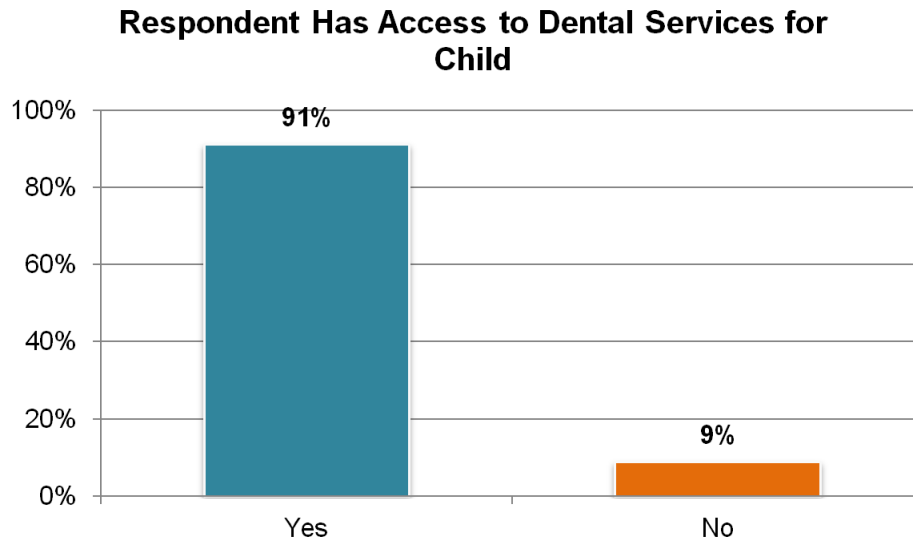


Table 54 Do you have access to dental services for your child?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	95%	5%	267
<b>Within Average Range</b>			
MEORC	95%	5%	273
NC	92%	8%	250
LA	90%	10%	294
<b>Significantly Below Average</b>			
NJ	84%	16%	263
<b>NCI Average</b>	<b>91%</b>	<b>9%</b>	<b>1,347</b>

Q35. If “yes” (to Q34), are you satisfied with the quality of these providers?

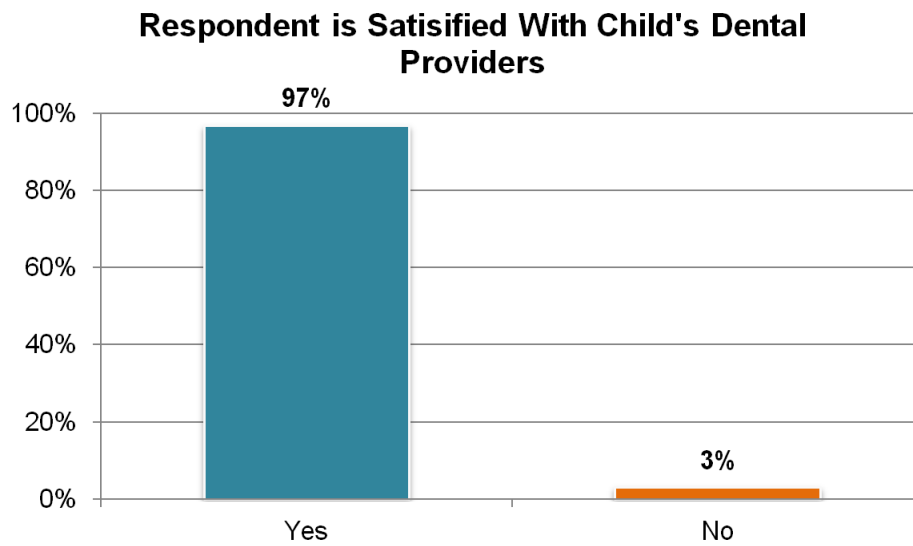


Table 55 If “yes” (to Q34), are you satisfied with the quality of these providers?

State	Yes	No	N
<b>Within Average Range</b>			
MEORC	98%	2%	247
SD	98%	2%	247
NJ	97%	3%	207
NC	96%	4%	224
LA	96%	4%	251
<b>NCI Average</b>	<b>97%</b>	<b>3%</b>	<b>1,176</b>

Q36. Do you have access to necessary medications for your child?

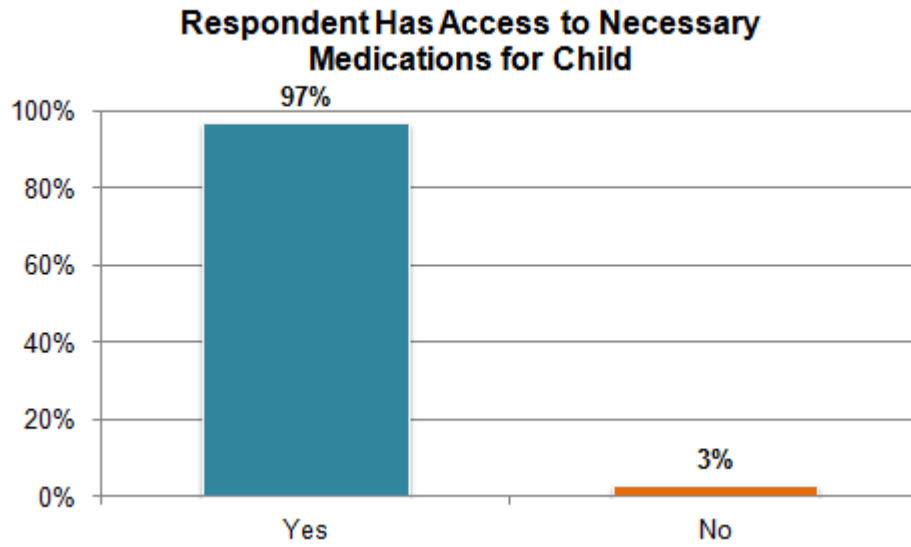


Table 56 Do you have access to necessary medications for your child?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	99%	1%	258
<b>Within Average Range</b>			
MEORC	99%	1%	251
LA	99%	1%	299
NC	95%	5%	238
<b>Significantly Below Average</b>			
NJ	92%	8%	243
<b>NCI Average</b>	<b>97%</b>	<b>3%</b>	<b>1,289</b>

Q37. If “yes” (to Q36), are you satisfied with how your child’s medication needs are monitored?

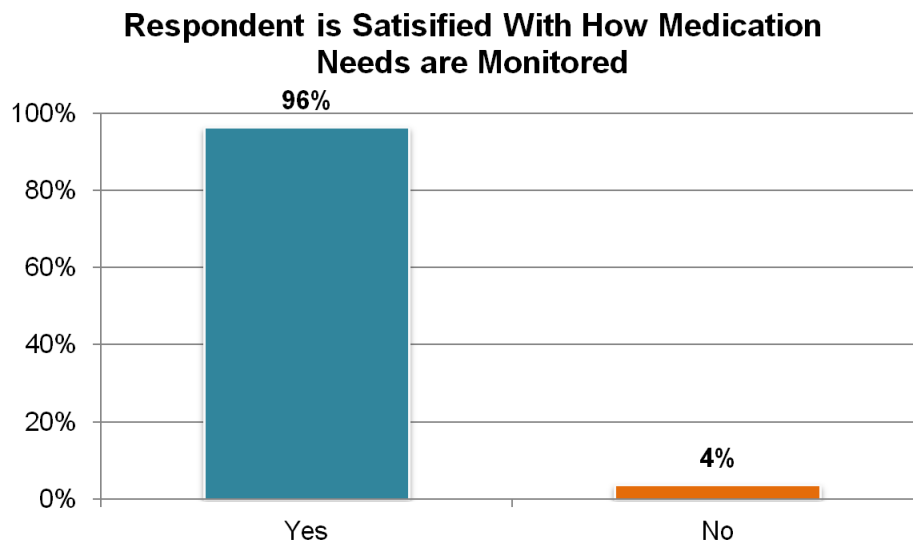


Table 57 If “yes” (to Q36), are you satisfied with how your child’s medication needs are monitored?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	98%	2%	245
<b>Within Average Range</b>			
MEORC	98%	2%	236
LA	98%	3%	280
NC	96%	4%	217
NJ	92%	8%	203
<b>NCI Average</b>	<b>96%</b>	<b>4%</b>	<b>1,181</b>

Q38. If applicable, do you have access to mental health services for your child?

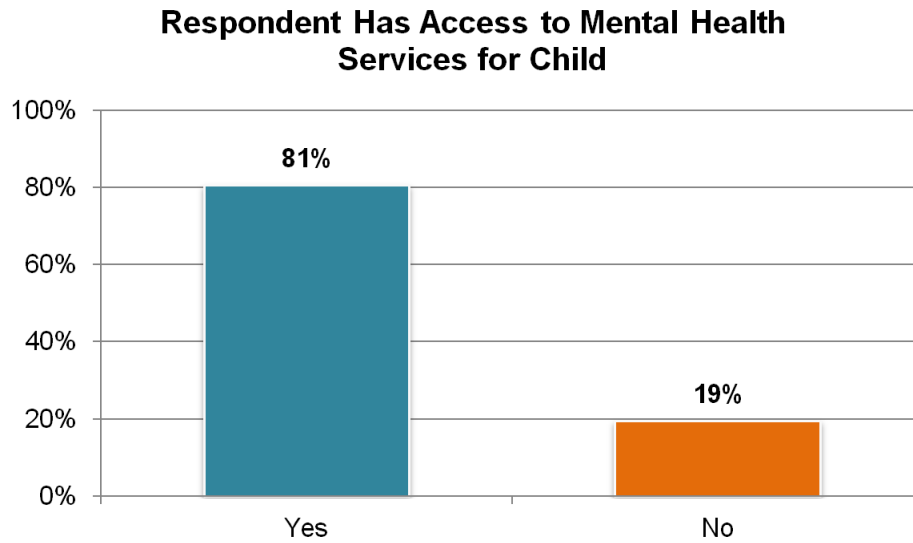


Table 58 If applicable, do you have access to mental health services for your child?

State	Yes	No	N
<b>Significantly Above Average</b>			
MEORC	91%	9%	127
SD	90%	10%	127
<b>Within Average Range</b>			
NC	76%	24%	147
LA	75%	25%	143
NJ	71%	29%	153
<b>NCI Average</b>	<b>81%</b>	<b>19%</b>	<b>697</b>

Q39. If “yes” (Q38), are you satisfied with the quality of these providers?

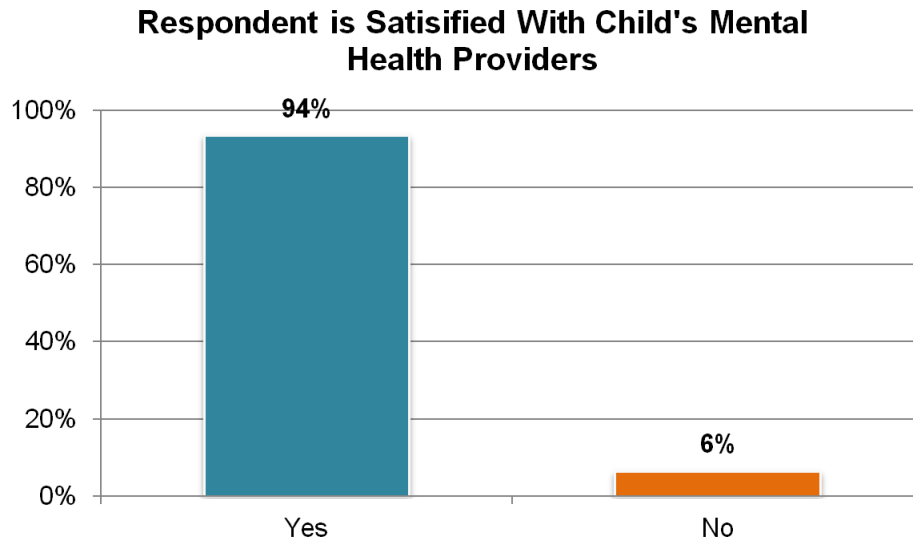
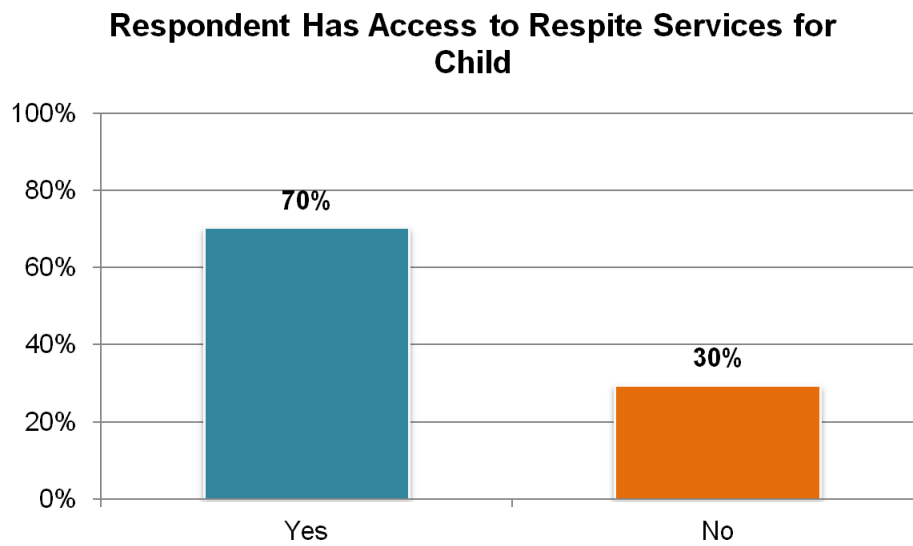


Table 59 If “yes” (Q38), are you satisfied with the quality of these providers?

State	Yes	No	N
<b>Within Average Range</b>			
MEORC	97%	3%	102
SD	95%	5%	101
LA	94%	6%	90
NJ	93%	7%	86
NC	88%	12%	100
<b>NCI Average</b>	<b>94%</b>	<b>6%</b>	<b>479</b>



**Q40. If applicable, do you have access to quality respite services for your family?**



**Table 60 If applicable, do you have access to quality respite services for your family?**

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	85%	15%	233
MEORC	80%	20%	123
<b>Within Average Range</b>			
NC	70%	30%	204
LA	67%	33%	163
<b>Significantly Below Average</b>			
NJ	49%	51%	177
<b>NCI Average</b>	<b>70%</b>	<b>30%</b>	<b>900</b>

Q41. If “yes” (to Q40), are you satisfied with the quality of these providers?

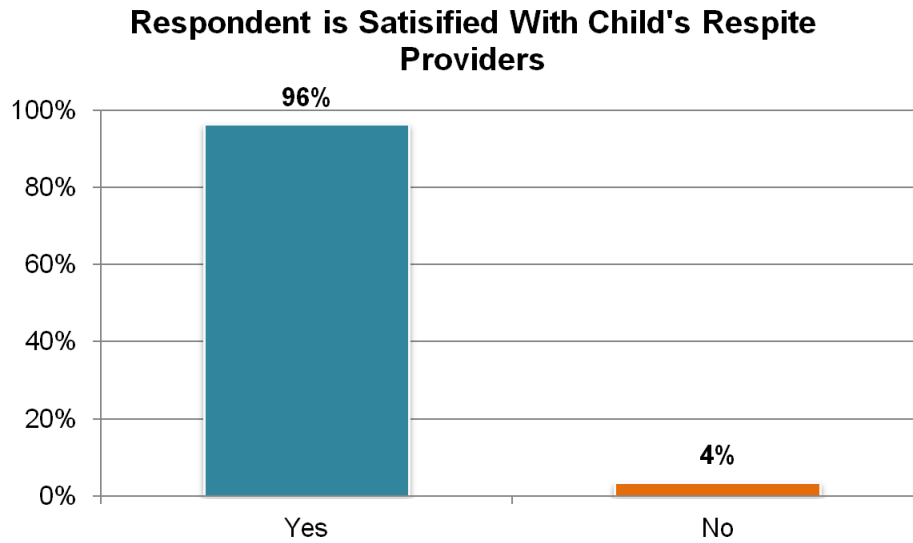
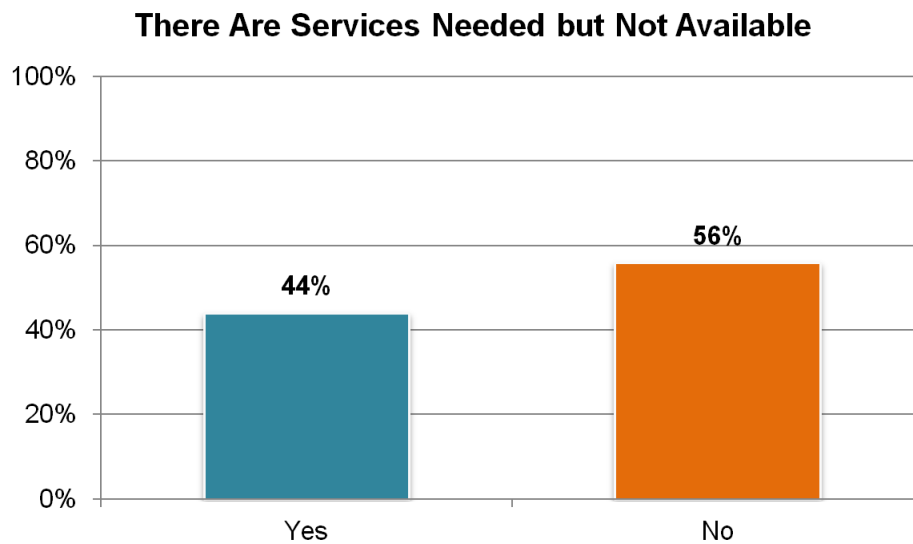


Table 61 If “yes” (to Q40), are you satisfied with the quality of these providers?

State	Yes	No	N
<b>Within Average Range</b>			
MEORC	99%	1%	88
SD	98%	2%	185
LA	98%	2%	102
NJ	96%	4%	77
NC	91%	9%	130
<b>NCI Average</b>	<b>96%</b>	<b>4%</b>	<b>582</b>

**Q42. Are there other services that your family member needs that are not currently offered or available?**



**Table 62 Are there other services that your family member needs that are not currently offered or available?**

State	Yes	No	N
<b>Significantly Above Average</b>			
NJ	67%	33%	174
NC	62%	38%	148
<b>Within Average Range</b>			
LA	39%	61%	171
<b>Significantly Below Average</b>			
MEORC	27%	73%	162
SD	26%	74%	179
<b>NCI Average</b>	<b>44%</b>	<b>56%</b>	<b>834</b>

---

## Choice and Control

Just over half of respondents reported they always choose the family's provider agencies (53%; states ranged between 28%-68%) and 50% reported they always had more than one agency to choose from (states ranged between 27%-70%). About half (49%) reported they always choose the individual support workers who work with the family (states ranged from 32%-66%); 51% reported they were satisfied with the choice of support workers (states ranged from 32%-66%). Twenty-six percent (26%) reported they chose the case manager/service coordinator (states ranged from 3%-46%).

Just under half (49%) reported they have input in hiring their support workers and 68% reported they want to have this input. Thirty percent (30%) of respondents reported they know how much money is spent by the ID/DD agency on their behalf of their child. Of the 41% have a say in how this money is spent, 88% report they have enough information to make this decision.

Q43. Do you choose the provider agencies who work with your family?

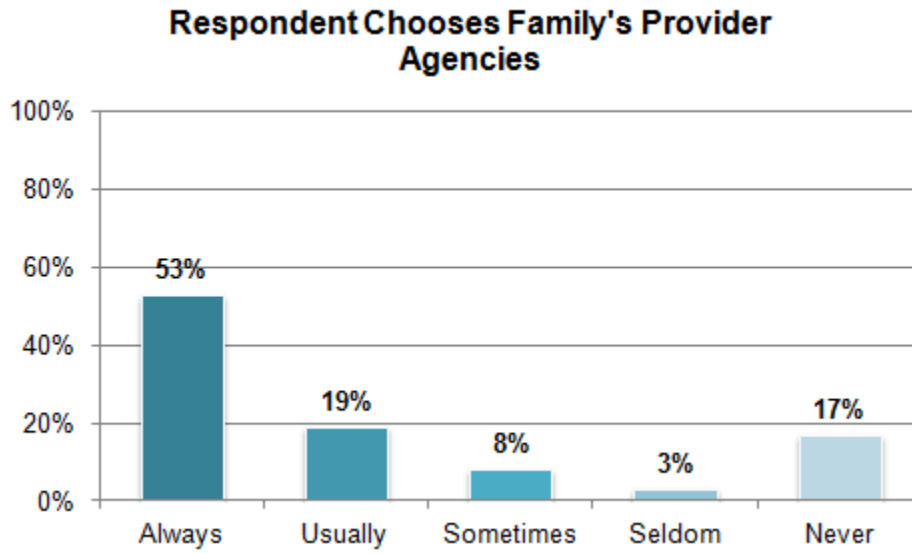


Table 63 Do you choose the provider agencies who work with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
LA	68%	18%	6%	2%	6%	288
NC	66%	21%	7%	2%	4%	246
<b>Within Average Range</b>						
SD	55%	12%	4%	3%	26%	159
MEORC	46%	24%	13%	3%	14%	236
<b>Significantly Below Average</b>						
NJ	28%	22%	12%	6%	32%	163
<b>NCI Average</b>	<b>53%</b>	<b>19%</b>	<b>8%</b>	<b>3%</b>	<b>17%</b>	<b>1,092</b>

Q44. If you choose the provider agencies, do you have more than one to choose from?

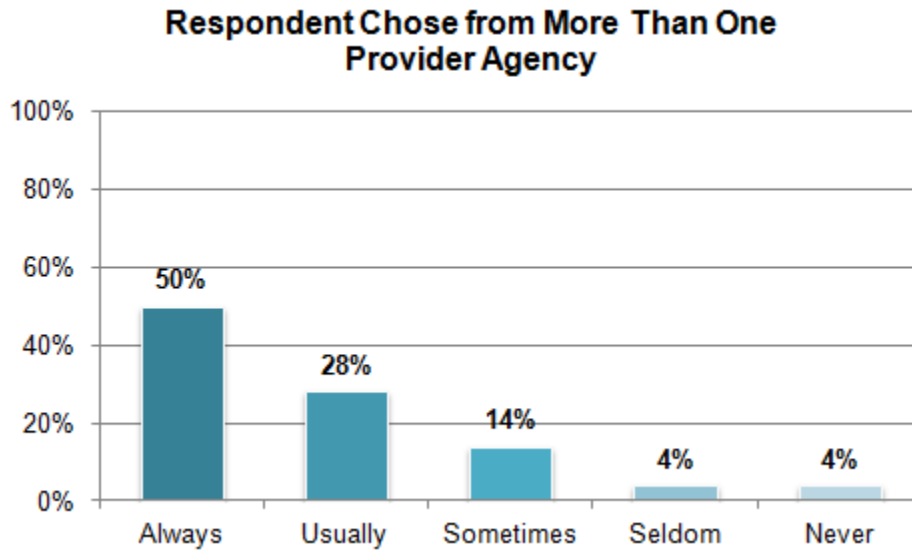


Table 64 If you choose the provider agencies, do you have more than one to choose from?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
LA	70%	21%	6%	2%	1%	254
<b>Within Average Range</b>						
SD	60%	25%	8%	2%	5%	87
NC	56%	29%	8%	4%	3%	216
<b>Significantly Below Average</b>						
MEORC	37%	34%	20%	7%	2%	180
NJ	27%	28%	28%	5%	12%	78
<b>NCI Average</b>	<b>50%</b>	<b>28%</b>	<b>14%</b>	<b>4%</b>	<b>4%</b>	<b>815</b>

Q45. Do you choose the individual support workers who work directly with your family?

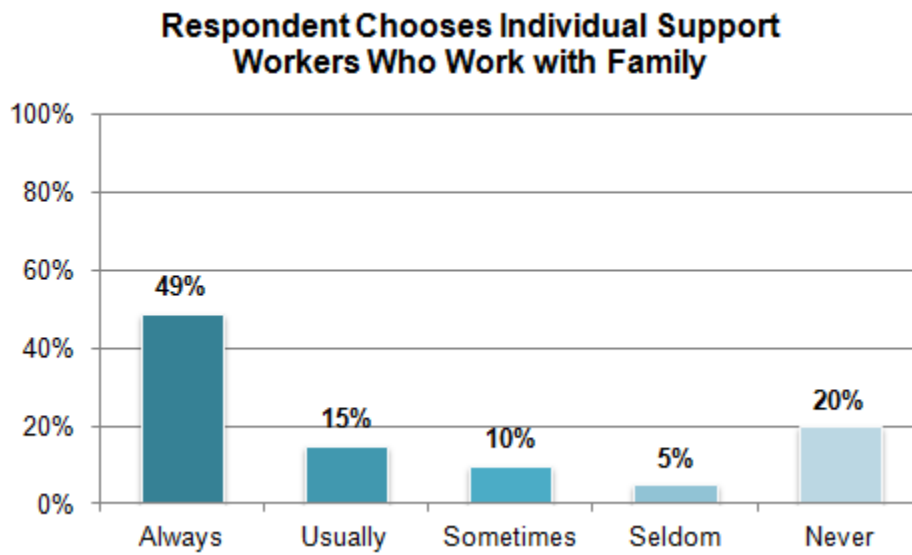


Table 65 Do you choose the individual support workers who work directly with your family?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
LA	66%	16%	7%	1%	10%	271
<b>Within Average Range</b>						
SD	58%	12%	5%	4%	20%	161
NC	57%	18%	12%	4%	10%	242
<b>Significantly Below Average</b>						
MEORC	33%	18%	14%	9%	26%	192
NJ	32%	13%	13%	6%	36%	136
<b>NCI Average</b>	<b>49%</b>	<b>15%</b>	<b>10%</b>	<b>5%</b>	<b>20%</b>	<b>1,002</b>

Q46. If you choose the individual support workers, are you satisfied with the options available?

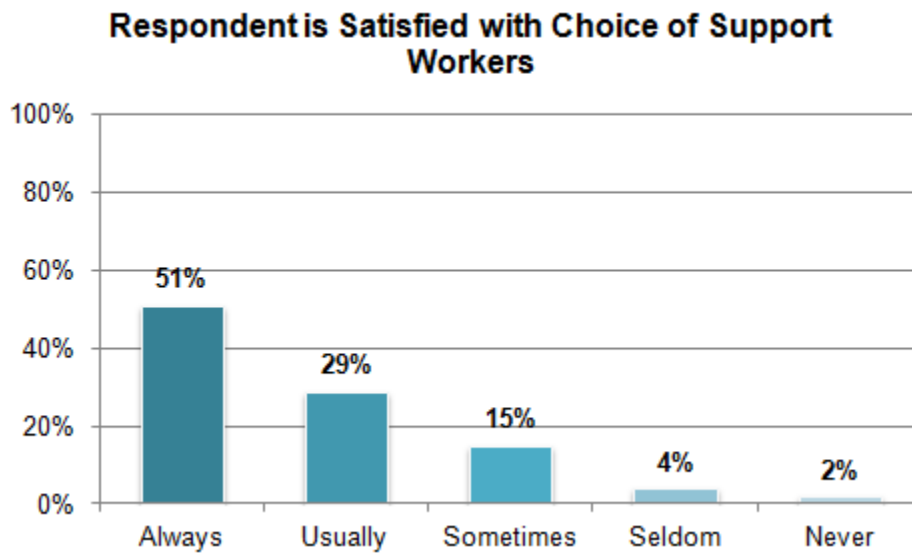


Table 66 If you choose the individual support workers, are you satisfied with the options available?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
LA	66%	20%	9%	5%	0%	244
<b>Within Average Range</b>						
SD	63%	26%	8%	0%	3%	119
MEORC	54%	31%	12%	3%	1%	118
NJ	38%	30%	25%	4%	3%	73
<b>Significantly Below Average</b>						
NC	32%	37%	19%	9%	4%	230
<b>NCI Average</b>	<b>51%</b>	<b>29%</b>	<b>15%</b>	<b>4%</b>	<b>2%</b>	<b>784</b>



Q47. Did you choose your case manager/service coordinator?

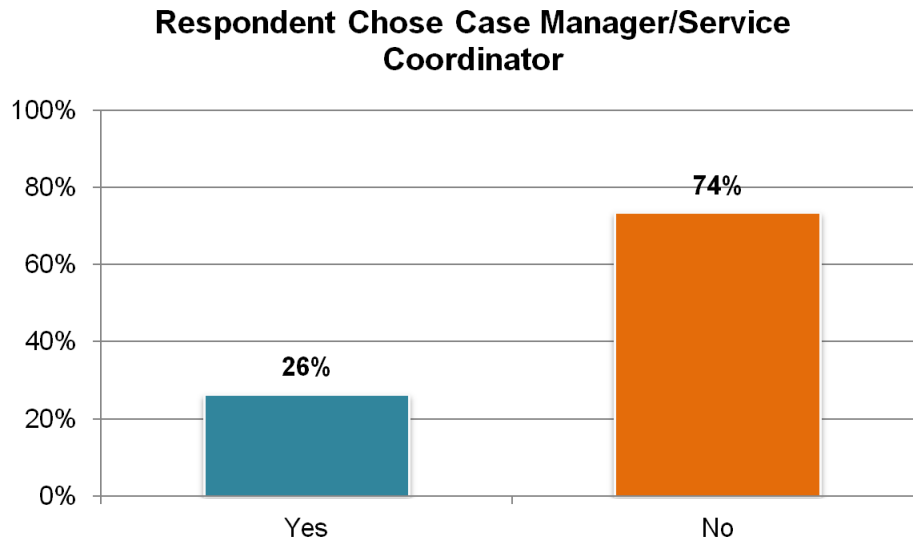


Table 67 Did you choose your case manager/service coordinator?

State	Yes	No	N
<b>Significantly Above Average</b>			
LA	46%	54%	285
NC	41%	59%	247
<b>Within Average Range</b>			
SD	23%	77%	261
<b>Significantly Below Average</b>			
MEORC	18%	82%	246
NJ	3%	97%	246
<b>NCI Average</b>	<b>26%</b>	<b>74%</b>	<b>1,285</b>

Q48. Do you have control and/or input over the hiring and management of your family's support workers?

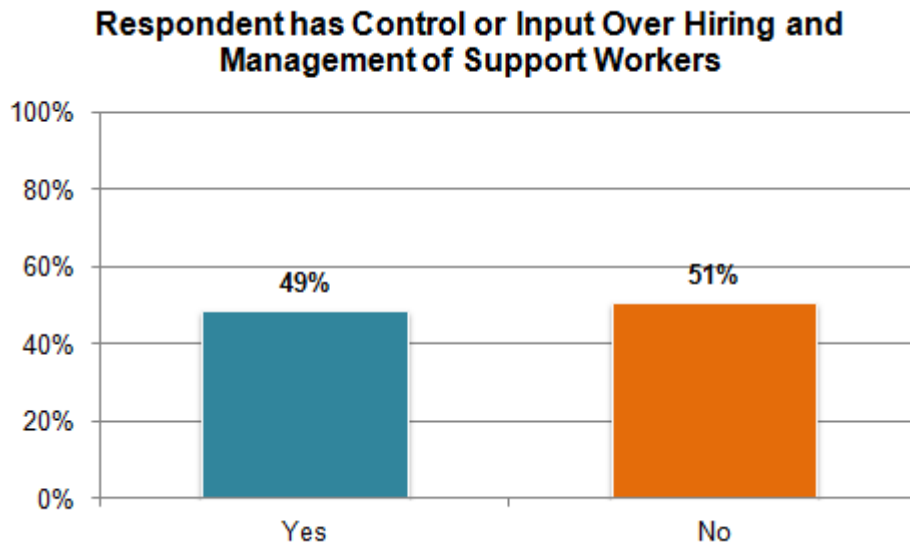


Table 68 Do you have control and/or input over the hiring and management of your family's support workers?

State	Yes	No	N
<b>Significantly Above Average</b>			
NC	73%	27%	226
LA	64%	36%	235
<b>Within Average Range</b>			
SD	54%	46%	173
<b>Significantly Below Average</b>			
MEORC	28%	72%	134
NJ	26%	74%	174
<b>NCI Average</b>	<b>49%</b>	<b>51%</b>	<b>942</b>

Q49. Do you want to have control and/or input over the hiring and management of your family's support workers?

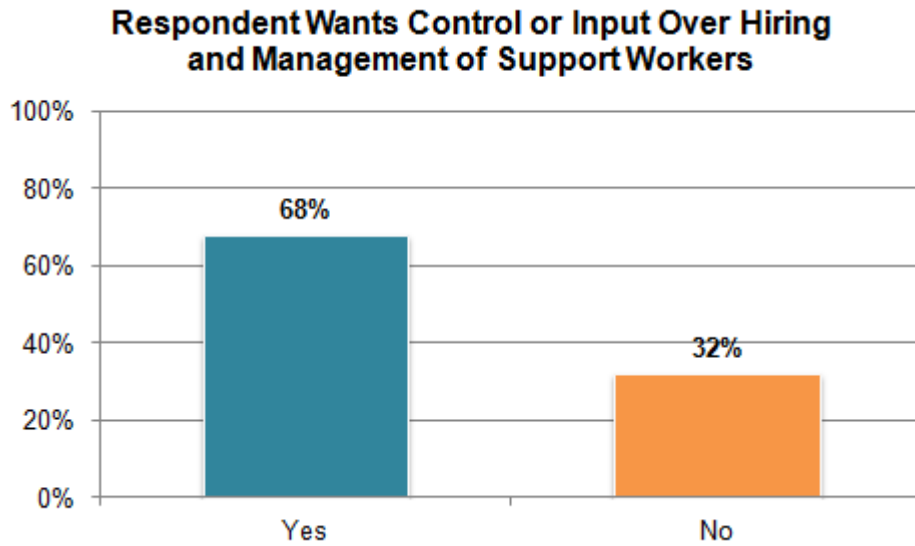


Table 69 Do you want to have control and/or input over the hiring and management of your family's support workers?

State	Yes	No	N
<b>Significantly Above Average</b>			
NC	91%	9%	220
NJ	78%	22%	178
<b>Within Average Range</b>			
LA	73%	27%	229
<b>Significantly Below Average</b>			
SD	53%	47%	197
MEORC	46%	54%	142
<b>NCI Average</b>	<b>68%</b>	<b>32%</b>	<b>966</b>

Q50. Do you know how much money is spent by the ID/DD agency on behalf of your child?\*

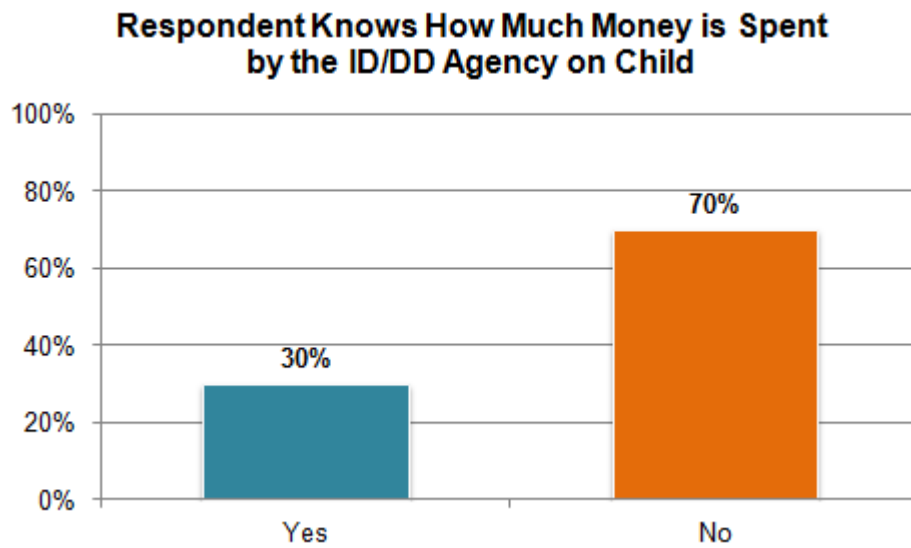


Table 70 Do you know how much money is spent by the ID/DD agency on behalf of your child?\*

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	72%	28%	262
<b>Within Average Range</b>			
LA	35%	65%	303
<b>Significantly Below Average</b>			
NC	21%	79%	249
MEORC	14%	86%	278
NJ	9%	91%	252
<b>NCI Average</b>	<b>30%</b>	<b>70%</b>	<b>1,344</b>

\*Don't know responses are included with 'No' responses.

Q51. Do you have a say in how this money is spent?

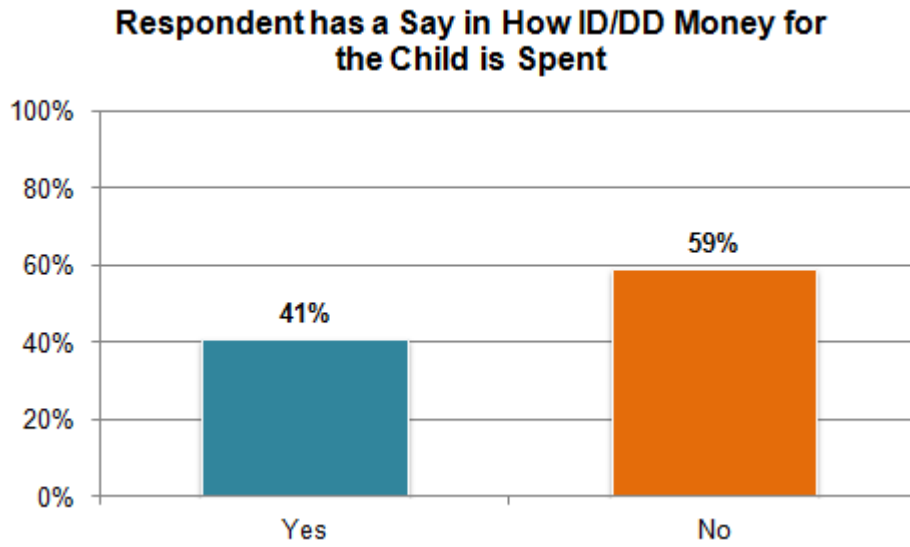


Table 701 Do you have a say in how this money is spent?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	87%	13%	220
<b>Within Average Range</b>			
MEORC	43%	57%	159
LA	33%	67%	200
<b>Significantly Below Average</b>			
NC	23%	77%	184
NJ	17%	83%	172
<b>NCI Average</b>	<b>41%</b>	<b>59%</b>	<b>935</b>

Q52. If “yes” (to Q51), do you have all the information you need to make decisions about how to spend this money?

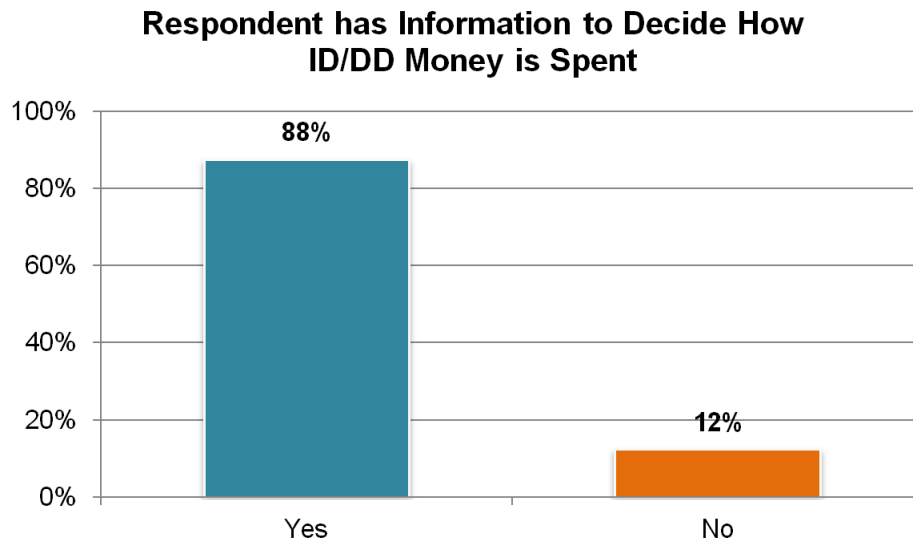


Table 72 If “yes” (to Q51), do you have all the information you need to make decisions about how to spend this money?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	94%	6%	173
<b>Within Average Range</b>			
MEORC	93%	7%	57
LA	91%	9%	57
NJ	83%	17%	24
NC	77%	23%	30
<b>NCI Average</b>	<b>88%</b>	<b>12%</b>	<b>341</b>

---

## Community Connections

The majority of respondents indicated their child participates in community activities (62%, states ranged between 46%-72%) and 86% reported their child spends time with children who not have developmental disabilities (states ranged between 70%-93%).

Q53. Does your child participate in community activities?

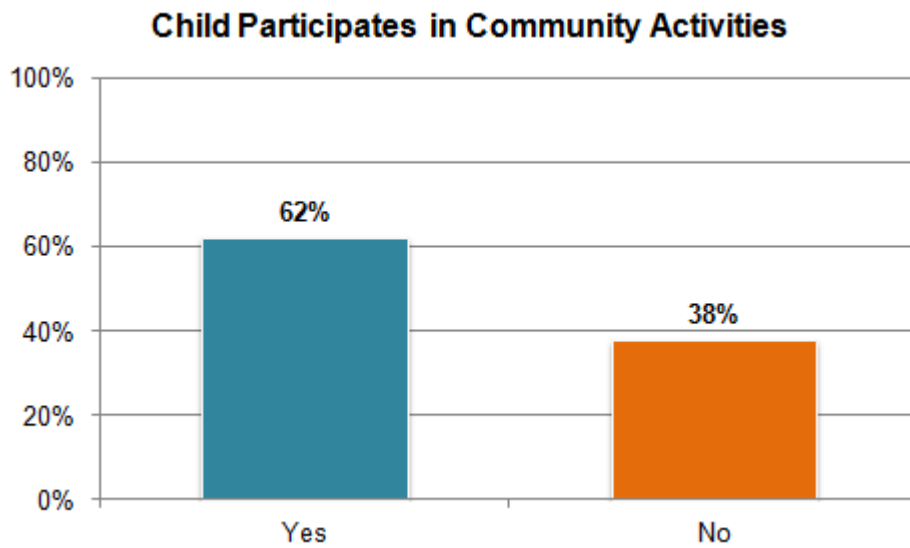


Table 73 Does your child participate in community activities?

State	Yes	No	N
<b>Significantly Above Average</b>			
NC	72%	28%	253
<b>Within Average Range</b>			
SD	69%	31%	267
MEORC	65%	35%	274
LA	57%	43%	303
<b>Significantly Below Average</b>			
NJ	46%	54%	274
<b>NCI Average</b>	<b>62%</b>	<b>38%</b>	<b>1,371</b>



Q54. Does your child spend time with children who do not have developmental disabilities?

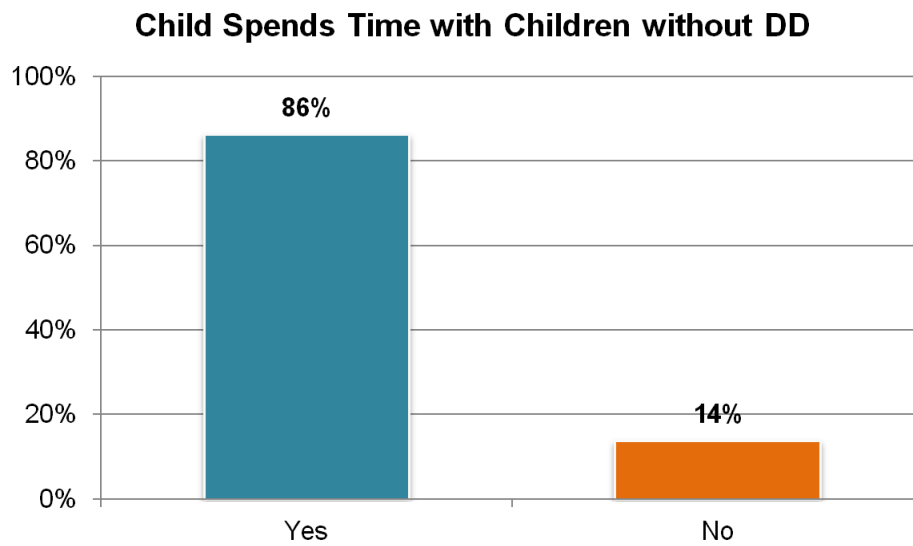


Table 74 Does your child spend time with children who do not have developmental disabilities?

State	Yes	No	N
<b>Significantly Above Average</b>			
LA	93%	7%	319
MEORC	93%	7%	296
SD	91%	9%	263
<b>Within Average Range</b>			
NC	84%	16%	259
<b>Significantly Below Average</b>			
NJ	70%	30%	269
<b>NCI Average</b>	<b>86%</b>	<b>14%</b>	<b>1,406</b>

---

## Satisfaction with Services and Supports

Thirty-nine percent (39%) of respondents reported they are always satisfied with the services and supports their child and family receives (states ranged between 12%-63%).

Just over half (55%) indicated they know how to file a complaint or grievance against provider agencies or staff and 77% reported they are satisfied with the way complaints or grievances are handled. Three-quarters (75%) know how to report abuse or neglect; 4% did so in the past year.

**\*Results for question 60 are not included in this report. All state N's were too low to report.**

Q55. Overall, are you satisfied with the services and supports your child and family currently receive?

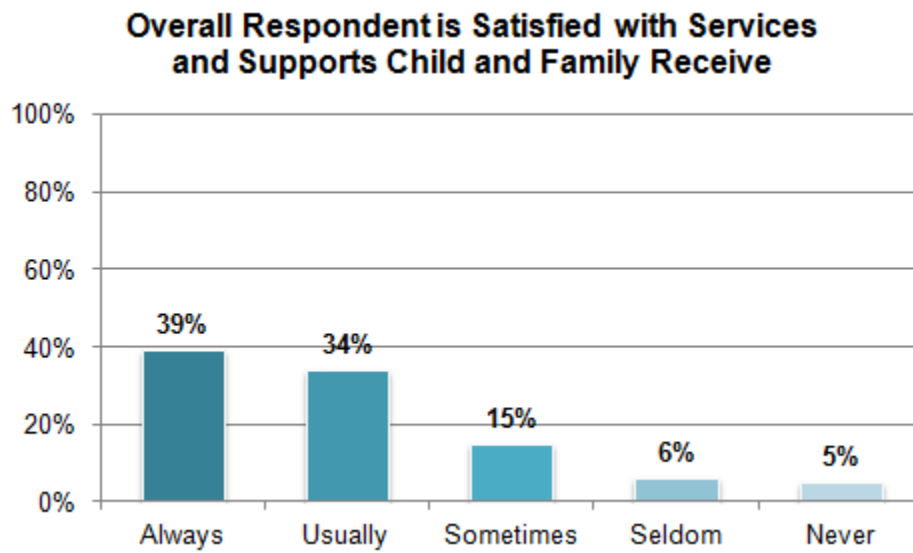
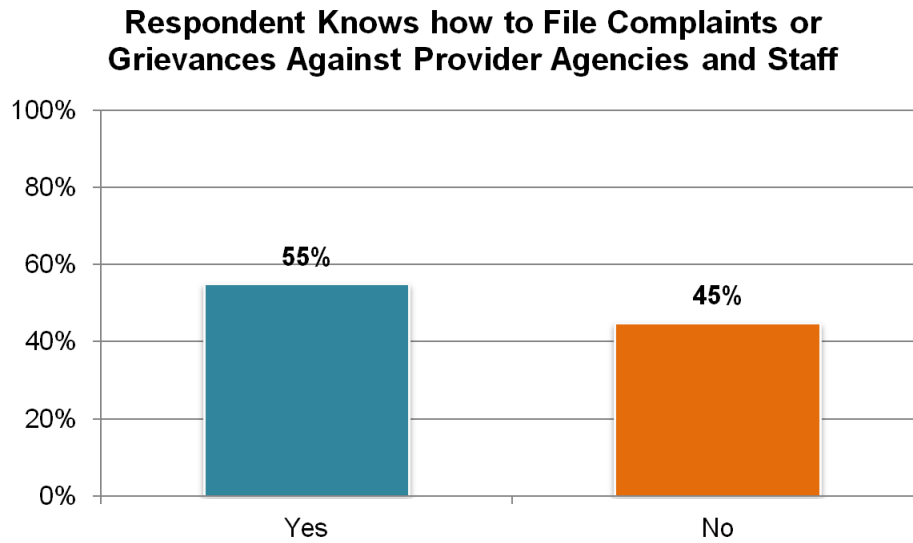


Table 75 Overall, are you satisfied with the services and supports your child and family currently receive?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
SD	63%	30%	5%	1%	1%	271
MEORC	52%	33%	13%	2%	1%	292
LA	48%	32%	14%	4%	2%	313
<b>Significantly Below Average</b>						
NC	22%	46%	18%	7%	7%	251
NJ	12%	30%	25%	17%	17%	247
<b>NCI Average</b>	<b>39%</b>	<b>34%</b>	<b>15%</b>	<b>6%</b>	<b>5%</b>	<b>1,374</b>

Q56. Do you know the process for filing a complaint or grievance against provider agencies or staff?\*

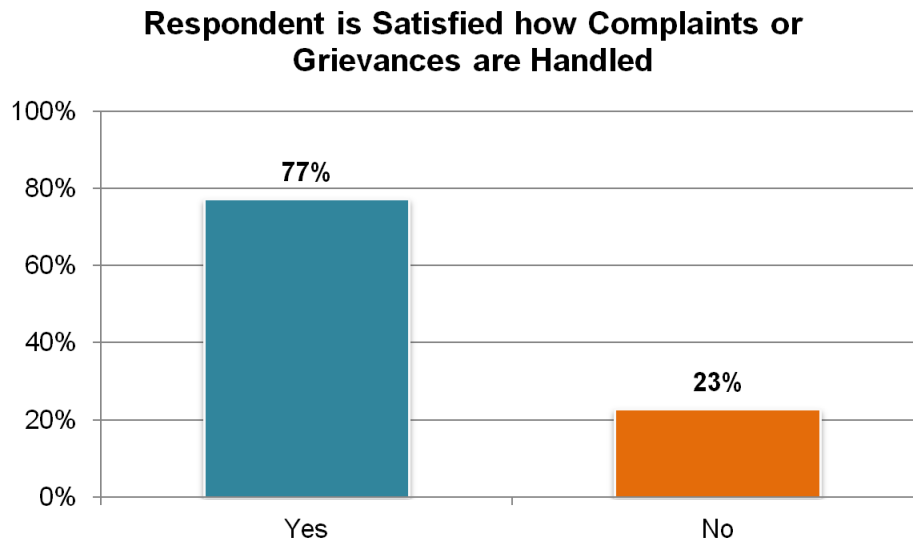


**Table 76** Do you know the process for filing a complaint or grievance against provider agencies or staff?\*

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	82%	18%	266
<b>Within Average Range</b>			
MEORC	62%	38%	288
LA	61%	39%	316
NC	54%	46%	251
<b>Significantly Below Average</b>			
NJ	17%	83%	252
<b>NCI Average</b>	<b>55%</b>	<b>45%</b>	<b>1,373</b>

\*Don't know responses are included with 'No' responses.

**Q57. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?**



**Table 77 Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?**

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	96%	4%	102
MEORC	91%	9%	91
<b>Within Average Range</b>			
LA	83%	17%	131
NC	69%	31%	108
<b>Significantly Below Average</b>			
NJ	47%	53%	53
<b>NCI Average</b>	<b>77%</b>	<b>23%</b>	<b>485</b>

Q58. Do you know how to report abuse or neglect?\*

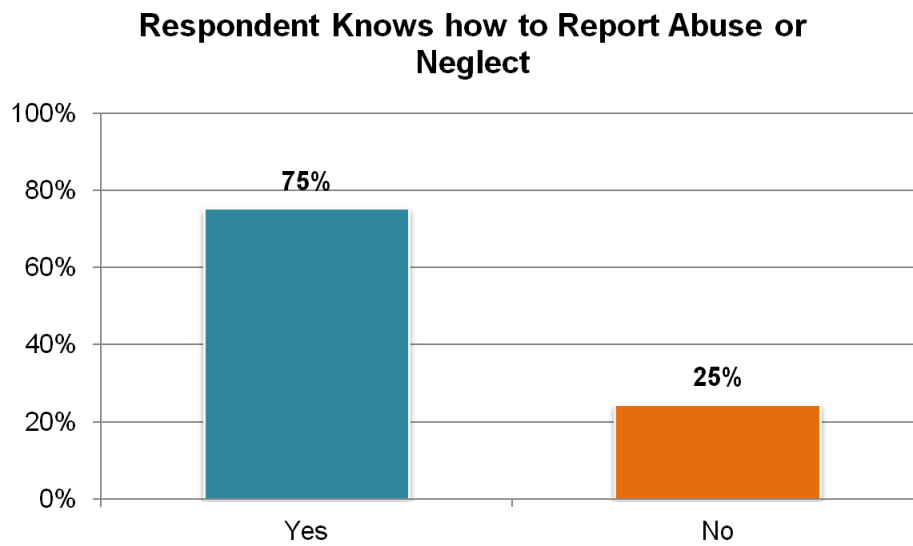


Table 78 Do you know how to report abuse or neglect?\*

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	93%	7%	270
MEORC	83%	18%	280
<b>Within Average Range</b>			
LA	78%	22%	316
NC	75%	25%	248
<b>Significantly Below Average</b>			
NJ	49%	51%	254
<b>NCI Average</b>	<b>75%</b>	<b>25%</b>	<b>1,368</b>

\*Don't know responses are included with 'No' responses.

Q59. In the past year, did you report abuse or neglect?

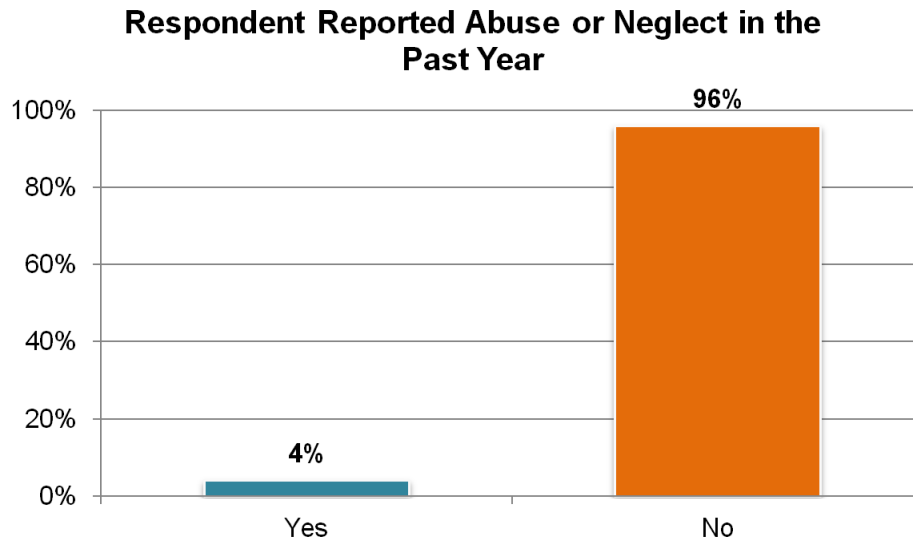


Table 79 In the past year, did you report abuse or neglect?

State	Yes	No	N
Within Average Range			
NC	6%	94%	221
NJ	4%	96%	238
SD	4%	96%	264
LA	3%	97%	302
MEORC	3%	97%	269
NCI Average	4%	96%	1,294

---

## Outcomes

Ninety percent (90%) of respondents reported they always feel services and supports made a positive difference in the life of their family (states ranged between 70%-100%).

Just over four-fifths of respondents reported services and supports reduced out-of-pocket expenses related to their child's care (81%, states ranged between 55%-99%). Most respondents felt supports services and supports: address the goals in their child's service plan (85%), improved their ability to care for their child (85%) and helped keep their child at home (81%).

Of the 29% who reported services were reduced, suspended, or terminated in the past year, 62% reported the reduction affected the life of the family or child.



Q61. Do you feel that family supports have made a positive difference in the life of your family?

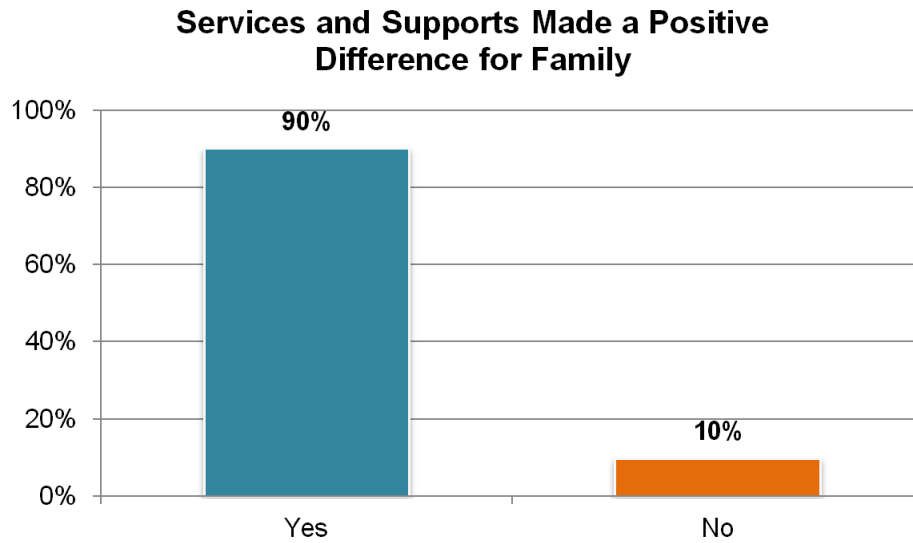


Table 80 Do you feel that family supports have made a positive difference in the life of your family?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	100%	0%	270
MEORC	96%	4%	250
LA	94%	6%	285
<b>Within Average Range</b>			
NC	91%	9%	227
<b>Significantly Below Average</b>			
NJ	70%	30%	191
<b>NCI Average</b>	<b>90%</b>	<b>10%</b>	<b>1,223</b>

Q62. Do you feel that services and supports have reduced your family's out-of-pocket expenses related to your child's care?

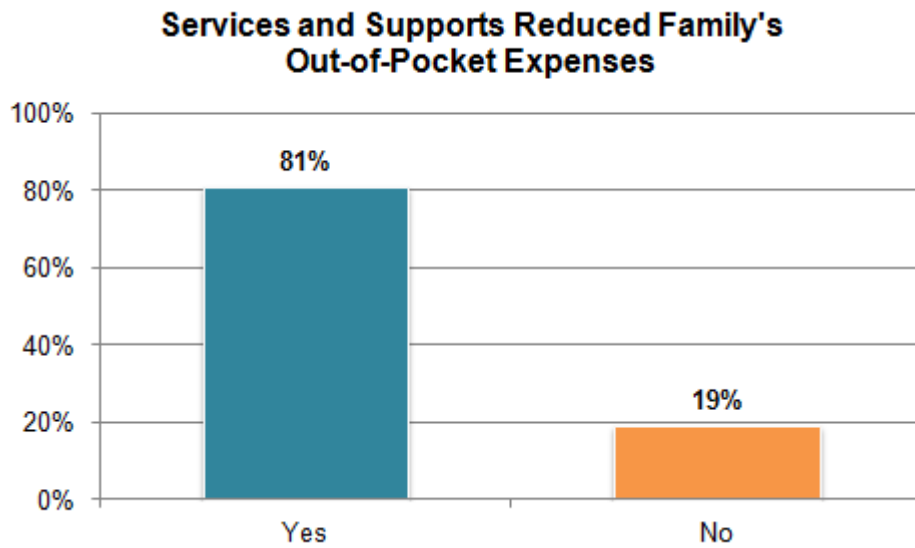


Table 81 Do you feel that services and supports have reduced your family's out-of-pocket expenses related to your child's care?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	99%	1%	276
MEORC	88%	12%	228
<b>Within Average Range</b>			
LA	86%	14%	291
NC	78%	22%	218
<b>Significantly Below Average</b>			
NJ	55%	45%	214
<b>NCI Average</b>	<b>81%</b>	<b>19%</b>	<b>1,227</b>

Q63. Do you feel that services and supports address the goals in your child's service plan?

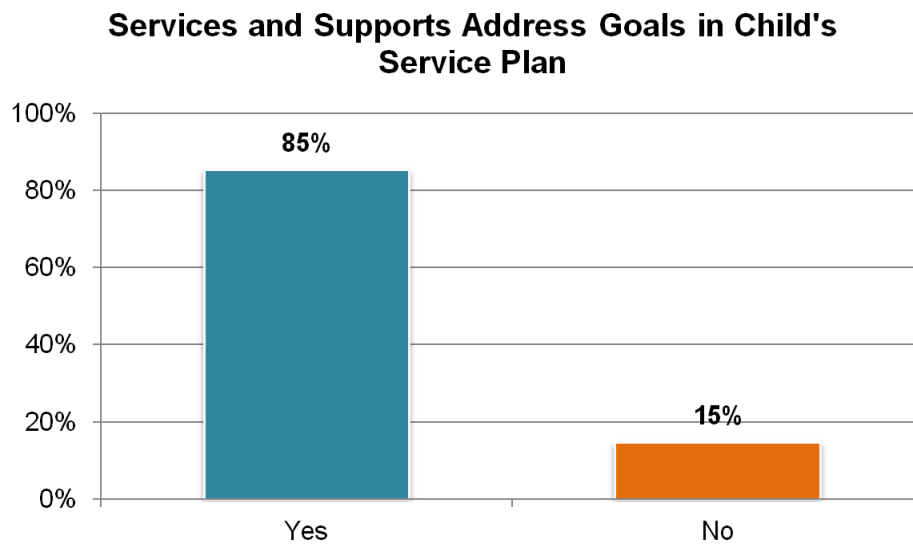


Table 82 Do you feel that services and supports address the goals in your child's service plan?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	98%	2%	269
MEORC	95%	5%	244
LA	92%	8%	272
<b>Within Average Range</b>			
NC	85%	15%	226
<b>Significantly Below Average</b>			
NJ	56%	44%	166
<b>NCI Average</b>	<b>85%</b>	<b>15%</b>	<b>1,177</b>

Q64. Do you feel that family supports have improved your ability to care for your child?

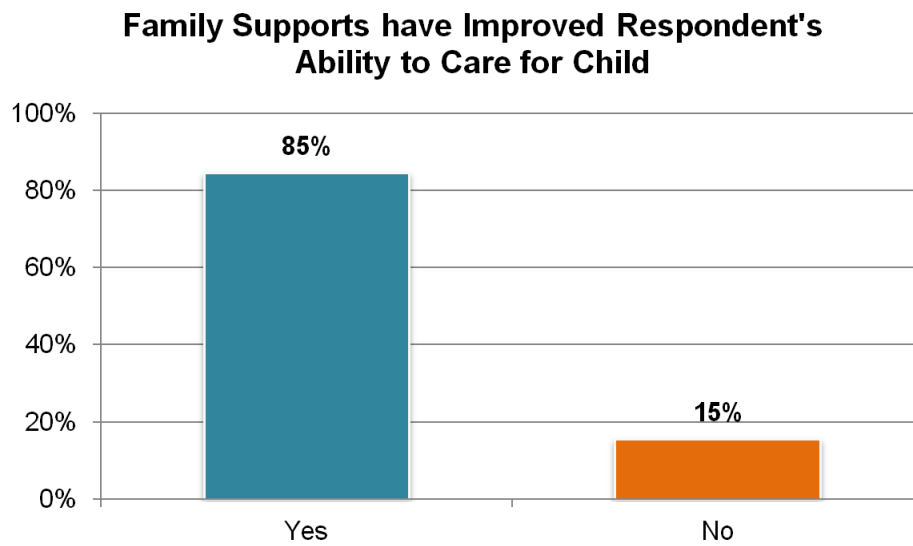


Table 83 Do you feel that family supports have improved your ability to care for your child?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	95%	5%	266
MEORC	93%	7%	229
<b>Within Average Range</b>			
LA	89%	11%	281
NC	83%	17%	232
<b>Significantly Below Average</b>			
NJ	62%	38%	191
<b>NCI Average</b>	<b>85%</b>	<b>15%</b>	<b>1,199</b>

Q65. Do you feel that family supports have helped you to keep your child at home?

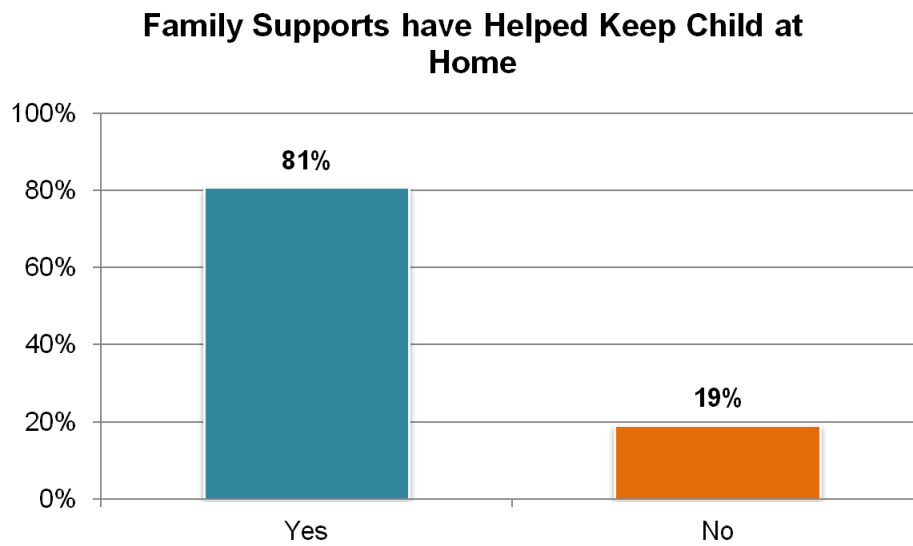
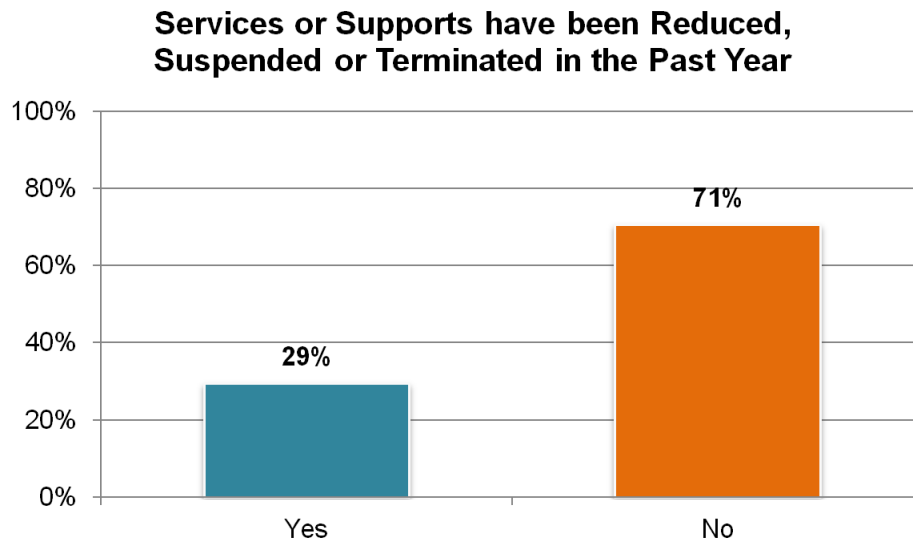


Table 84 Do you feel that family supports have helped you to keep your child at home?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	94%	6%	235
LA	87%	13%	241
<b>Within Average Range</b>			
NC	86%	14%	218
MEORC	82%	18%	168
<b>Significantly Below Average</b>			
NJ	56%	44%	153
<b>NCI Average</b>	<b>81%</b>	<b>19%</b>	<b>1,015</b>

**Q66. Have the services or supports that your child/family received during the past year been either reduced, suspended, or terminated?**



**Table 85 Have the services or supports that your child/family received during the past year been either reduced, suspended, or terminated?**

State	Yes	No	N
<b>Significantly Above Average</b>			
NC	50%	50%	231
NJ	43%	57%	167
<b>Significantly Below Average</b>			
LA	21%	79%	273
SD	19%	81%	243
MEORC	15%	85%	230
<b>NCI Average</b>	<b>29%</b>	<b>71%</b>	<b>1,144</b>

Q67. If “yes” (to Q66), did the reduction/suspension/termination of these services or supports affect your family or your child’s relationships, health, welfare, etc.?

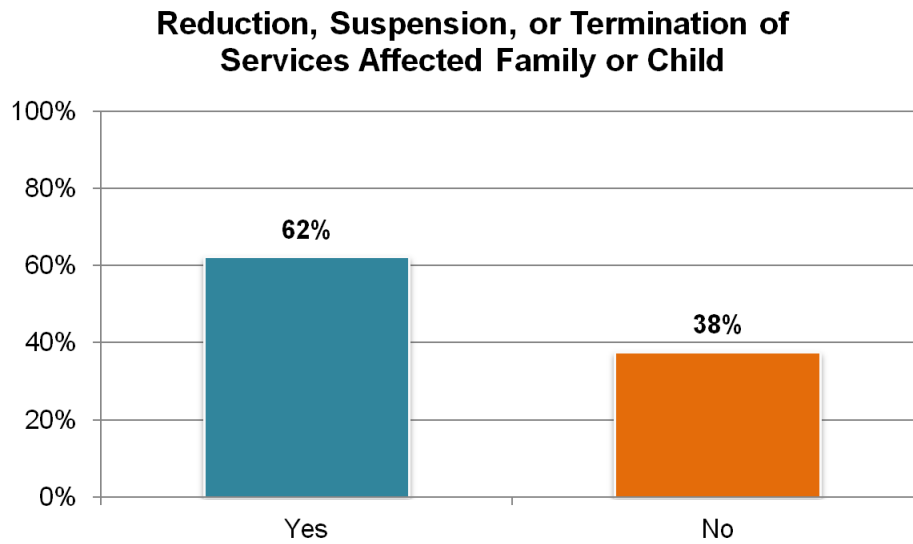


Table 71 If “yes” (to Q66), did the reduction/suspension/termination of these services or supports affect your family or your child’s relationships, health, welfare, etc.?

State	Yes	No	N
<b>Significantly Above Average</b>			
NJ	86%	14%	56
<b>Within Average Range</b>			
NC	74%	26%	97
LA	65%	35%	52
MEORC	46%	54%	28
<b>Significantly Below Average</b>			
SD	40%	60%	35
<b>NCI Average</b>	<b>62%</b>	<b>38%</b>	<b>268</b>