
Adult 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

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

113 Oronoco Street
Alexandria, VA 22314

Organization of Report

Fourteen (14) states submitted a valid sample of the National Core Indicators (NCI) Adult Family Survey during the 2011-2012 project year for analysis. The Adult Family Survey was administered to families who have an adult (18 year or older) with disabilities living in the family 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. Adult 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

CIP – Core Indicators Project

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

Adult Family Survey	1
2011-12 Final Report.....	1
.....	1
Table of Contents.....	v
I. Introduction	1
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 I1. NCI Adult Family Survey – Sub-Domains	5
How NCI Data are Used.....	5
Data Limitations	6
II. Adult Family Survey	7
Survey Development	8
Table 2. State participation in NCI Adult Family Survey (adult living at home with family)	8
Organization of the Family Surveys.....	9
III. Methodology	10
Sampling & Administration.....	11

Data Entry and Analysis	11
Response Rates	12
Table 3. Adult Family Survey - state response rates	12
IV. Results	13
Presentation of Data	14
Demographics: Individual	15
Table 4 Age of Family Member	16
Table 5 Gender of Family Member	16
Table 6 Race of Individual	17
Table 7 More Than One Person Living in the Home Has ID/DD	18
Table 8 Type of Disability Family Member (not mutually exclusive)	19
Table 9 Primary Means of Expression of Family Member	20
Table 10 Primary Language of Family Member	20
Table 11 Highest Level of Education of Family Member	21
Table 12 Typical Day Activity of Family Member	22
Table 13 Frequency of Medical Care Needed for Family Member	23
Table 14 Amount of Behavioral Support Needed for Family Member	24
Table 15 Amount of Help Needed for Daily Activities for Family Member	24
Demographics: Respondents	25
Table 16 Age of Respondent	26
Table 17 Health of Respondent	26
Table 18 Relationship to Family Member	27
Table 19 Respondent is Primary Caregiver	27
Table 20 Number of Adults in Household	28
Table 21 Respondent is Family Member's Legal Guardian	28
Table 22 Highest Education Level of Respondents	29
Table 23 Last Year Total Taxable Income	29

Table 24 Last Year Out-of-Pocket Expenses.....	30
Services and Supports Received	31
Table 25 Services and Supports Received.....	31
Adult Family Survey Results.....	32
Information and Planning.....	33
Q1. Do you get enough information to help you participate in planning services for your family?	34
Table 26 Gets enough information to help plan services	34
Q2. Is the information you receive easy to understand?	35
Table 27 Information about services and supports is easy to understand	35
Q3. Does the information you receive primarily come from your family member’s case manager/service coordinator (as opposed to family, friends, and others outside state services)?	36
Table 28 Information about services and supports comes from case manager/service coordinator	36
Q4. Does your family member’s case manager/service coordinator tell you about public services that you are eligible for (e.g., food stamps, Supplemental Security Income [SSI], housing subsidies, etc.)?	37
Table 29 Case manager/service coordinator tells family about eligible public services.....	37
Q5. Does the case manager/service coordinator who assists your family with planning respect your family’s choices and opinions?	38
Table 30 Case manager/service coordinator respects choices and opinions	38
Q6. Is the case manager/service coordinator who assists your family with planning generally knowledgeable?	39
Table 31 Case manager/service coordinator is generally knowledgeable.....	39
Q7. If your family member has a service plan, does the plan include services and supports that are important to your family?.....	40
Table 32 Service plan includes services and supports important to the family	40
Q8. If your family member has a service plan, did s/he help develop it?.....	41
Table 33 Family member helped make service plan	41
Q9. If your family member has a service plan, did you or another family member help develop it?	42

Table 34 Family helped make service plan.....	42
Q10. Does the service plan include all the services and supports your family member needs?"	43
Table 35 Service plan includes services and supports family member needs	43
Q11. If your family member has a service plan, did you discuss how to handle emergencies related to your family member at the last service planning meeting?	44
Table 36 Discussed how to handle emergencies at last service planning meeting	44
Q12. Have you or your family member received information about his/her rights?	45
Table 37 Respondent or family member received information about rights	45
Access and Delivery of Services and Supports	46
Q13. Are you or your family member able to contact his/her support workers when you need to?	47
Table 38 Family member or respondent is able to contact support workers when needed.....	47
Q14. Are you or your family member able to contact his/her case manager/service coordinator when you need to?	48
Table 39 Family member or respondent is able to contact case manager/service coordinator when needed	48
Q15. Does your family member receive all of the services listed in the service plan?	49
Table 40 Family member receives all services listed in service plan	49
Q16. Does your family member get the services and supports that s/he needs?	50
Table 41 Family member gets services and supports needed	50
Q17. Does your family get the services and supports you need?	51
Table 42 Family gets services and supports needed	51
Q18. Are services and supports available at the times that your family member needs them? ..	52
Table 43 Services and supports are available when needed	52
Q19. Are services and supports, received outside the family home, available within a reasonable distance from your family home?	53
Table 44 Services and supports are available in a reasonable distance from home	53
Q20. Do the services and supports change when your family member's needs change?	54
Table 45 Services and supports change when family member's needs change	54

Q21. If English is not your first language, are there support workers or translators available to speak with you in your preferred language?	55
Table 46 Support workers or translators are available to speak in primary language (if not english)	55
Q22. If English is your first language, do the support workers communicate with you effectively in your primary language?	56
Table 47 Support workers communicate effectively in primary language (if English)	56
Q23. If your family member does not verbally communicate (for example, uses gestures or sign language), are there enough support workers available who can communicate with him/her?	57
Table 48 Support workers can communicate with family member (if non-verbal)	57
Q24. Are services delivered to your family in a way that is respectful to your family's culture(s)?	58
Table 49 Services are delivered in a respectful manner to family's culture	58
Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?	59
Table 50 Family member has access to special equipment or accommodations needed	59
Q26. Do you feel that your family member's day/employment setting is a healthy and safe environment?	60
Table 51 Family member's day or employment setting is healthy and safe	60
Q27. Do the support workers have the right training to meet your family's needs?	61
Table 52 Support workers have the right training to meet family's needs	61
Q28. Do the support workers who come to your home arrive on time and when scheduled? ..	62
Table 53 Support workers arrive on time	62
Q29. If your family member transitioned from school services to state funded services during the past year, were you happy with the transition process?	63
Table 54 Happy with transition from school to state funded services (past year)	63
Q30. If you asked for crisis/emergency services during the past year, were services provided when needed?	64
Table 55 Crisis or emergency services were provided when needed	64
Q31. Do you have access to health services for your family member?	65
Table 56 Respondent has access to health services for family member	65

Q32. If “yes” (to Q31), are you satisfied with the quality of these providers?	66
Table 57 Satisfied with family member's health providers.....	66
Q33. Do you have access to dental services for your family member?.....	67
Table 58 Respondent has access to dental services for family member	67
Q34. If “yes” (to Q33), are you satisfied with the quality of these providers?	68
Table 59 Satisfied with family member's dental providers	68
Q35. Do you have access to necessary medications for your family member?	69
Table 60 Respondent has access to needed medications for family member.....	69
Q36. If “yes” (to Q35), are you satisfied with how your family member’s medication needs are monitored?	70
Table 61 Satisfied with how medication needs are monitored	70
Q37. If applicable, do you have access to mental health services for your family member?.....	71
Table 62 Respondent has access to mental health services for family member.....	71
Q38. If “yes” (Q37), are you satisfied with the quality of these providers?.....	72
Table 63 Satisfied with family member's mental health providers.....	72
Q39. If applicable, do you have access to quality respite services for your family?	73
Table 64 Respondent has access to respite services for family member.....	73
Q40. If “yes” (to Q39), are you satisfied with the quality of these providers?	74
Table 65 Satisfied with family member's respite providers	74
Q41. Are there other services that your family member needs that are not currently offered or available?*	75
Table 66 There are other services needed not currently offered	75
Choice and Control.....	76
Q42. Do you choose the provider agencies who work with your family?	77
Table 67 Respondent chooses provider agencies.....	77
Q43. Does your family member choose the provider agencies who work with your family?	78
Table 68 Family member chooses provider agencies.....	78
Q44. If you or your family member choose the provider agencies, do you have more than one to choose from?	79
Table 69 Respondent or family member choose from more than one provider agency	79

Q45. Do you choose the individual support workers who work directly with your family?.....	80
Table 70 Respondent chooses support workers	80
Q46. Does your family member choose the individual support workers who work directly with your family?	81
Table 71 Family member chooses support workers	81
Q47. If you or your family member chose the individual support workers, are you satisfied with the options available?	82
Table 72 Satisfied with choice of support workers.....	82
Q48. Did you choose your family member's case manager/service coordinator?.....	83
Table 73 Respondent chose case manager/service coordinator	83
Q49. Did your family member choose his/her case manager/service coordinator?	84
Table 74 Family member chose case manager/service coordinator	84
Q50. Do you have control and/or input over the hiring and management of your family member's support workers?	85
Table 75 Respondent has control or input over hiring and management of support workers .	85
Q51. Does your family member have control and/or input over the hiring and management of his/her support workers?	86
Table 76 Family member has control or input over hiring and management of support workers.....	86
Q52. Do you want to have control and/or input over the hiring and management of your family member's support workers?	87
Table 77 Respondent wants control or input over hiring and management of support workers	87
Q53. Does your family member want to have control and/or input over the hiring and management of your family member's support workers?.....	88
Table 78 Family member wants control or input over hiring and management of support workers.....	88
Q54. Do you know how much money is spent by the ID/DD agency on behalf of your family member with a developmental disability?.....	89
Table 79 Respondent knows money spent by the ID/DD agency for family member	89
Q55. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?	90

Table 80 Family member knows money spent by the ID/DD agency for family member	90
Q56. Do you have a say in how this money is spent?	91
Table 81 Respondent has a say how ID/DD agency money is spent.....	91
Q57. Does your family member have a say in how this money is spent?	92
Table 82 Family member has a say how ID/DD agency money is spent	92
Q58. If “yes” (to Q56), do you have all the information you need to make decisions about how to spend this money?	93
Table 83 Respondent has all information needed to decide how to spend id/dd agency money	93
Q59. If “yes” (to Q57), does your family member have all the information s/he needs to make decisions about how to spend this money?	94
Table 84 Family member has all information needed to decide how to spend ID/DD agency money	94
Community Connections	95
Q60. Does your family member participate in community activities?	96
Table 85 Family member participates in community activities	96
Q61. Does your family member have friends or relationships with persons other than paid support workers or family?	97
Table 86 Family member has friends or relationships with people other than support workers or family	97
Q62. Does your family member have enough supports (e.g., support workers, community resources) to work or volunteer in the community?	98
Table 87 Family member has support to work or volunteer	98
Satisfaction with Services and Supports	99
Q63. Overall, are you satisfied with the services and supports your family and family member currently receive?	100
Table 88 Overall satisfied with services and supports family member and family receives ...	100
Q64. Do you know the process for filing a complaint or grievance against provider agencies or staff?	101
Table 89 Knows how to file complaints or grievances against provider agencies or staff	101
Q65. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?	102

Table 90 Satisfied how complaints or grievances are handled	102
Q66. Do you know how to report abuse or neglect?	103
Table 91 Knows how to report abuse or neglect	103
Q67. In the past year, did you report abuse or neglect?	104
Table 92 Reported abuse or neglect (in past year)	104
Q68. If “yes” (to Q67), were the appropriate people responsive to your report?	105
Table 93 Appropriate parties were responsive to abuse/neglect report (if reported in the past year)	105
Outcomes	106
Q69. Do you feel that services and supports have made a positive difference in the life of your family?	107
Table 94 Services and supports made a positive difference for family	107
Q70. Do you feel that services and supports have reduced your family’s out-of-pocket expenses related to your family member’s care?	108
Table 95 Services and supports reduced out-of-pocket expenses	108
Q71. Do you feel that services and supports address the goals in your family member’s service plan?	109
Table 96 Services and supports address goals in service plan	109
Q72. Have services made a difference in helping keep your family member at home?	110
Table 97 Family supports have helped keep family member at home	110
Q73. Have the services or supports that you or your family member received during the past year been either reduced, suspended, or terminated?*	111
Table 98 Services or supports have been reduced, suspended or terminated (past year)	111
Q74. If “yes” (to Q73), did the reduction/suspension/termination of these services or supports affect your family or your family member’s home, job, relationships, etc.?*	112
Table 99 Service reduction, suspension, or termination affected family	112

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.

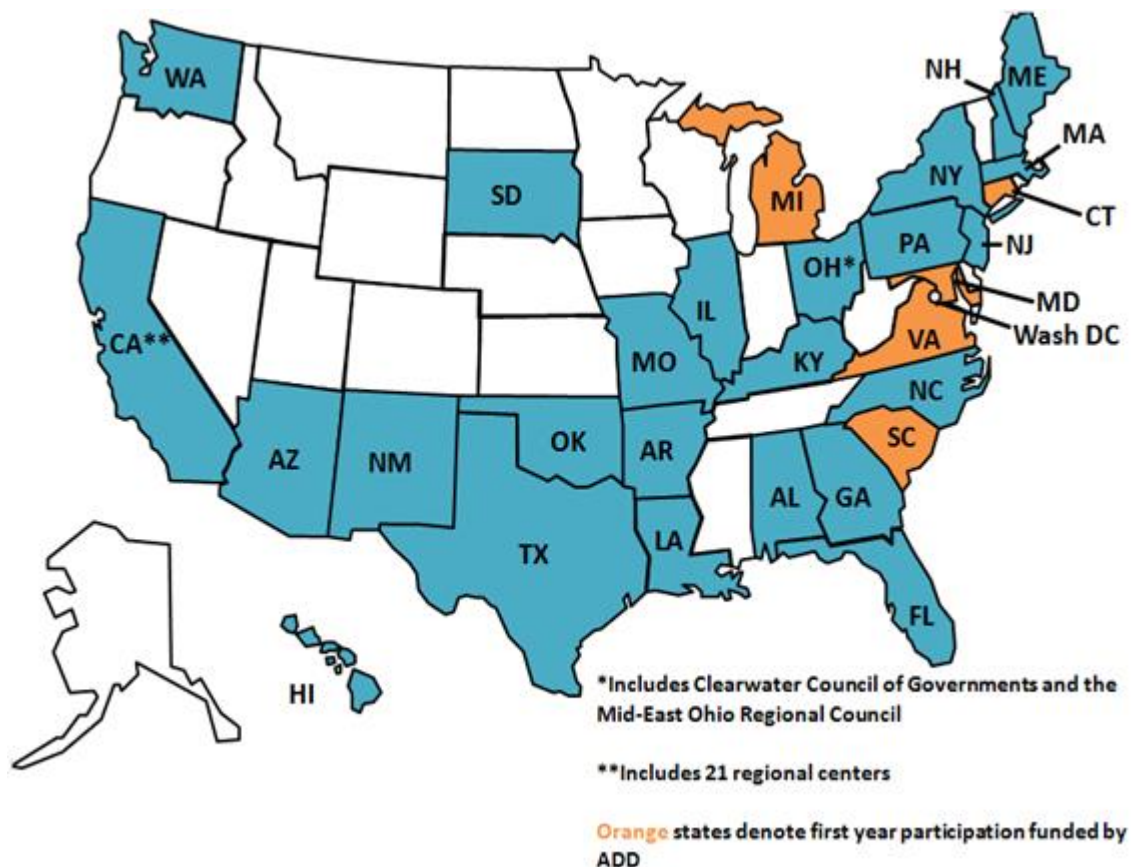
Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI has continued to develop and refine the indicators and expand state participation. For more information about NCI 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 disabilities¹.

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.

¹ 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 domains and sub-domains covered by the NCI Adult Family Survey indicators.

Table I1. NCI Adult Family Survey – Sub-Domains

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

How 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. Adult Family Survey

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

Survey Development

The Adult Family Survey was developed and first utilized during Phase I of CIP (2000-2001) by a technical advisory group for the purpose of measuring the experiences of families who had an adult family member with a disability living at home. Results and feedback from Phase I demonstrated that the survey was relatively straightforward to administer, yielded good response rates, and provided sound feedback to the participating state DD agencies.

As mentioned previously, the Adult Family Survey was significantly revised during the 2009-2010 data collection cycle to better align the NCI indicators with CMS waiver assurances.

Table 2. State participation in NCI Adult Family Survey (adult living at home with family)

Field Test	1999-2000	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	AZ	CT	AZ	CA-RCOC	AZ	CA-RCOC	AZ	CT	AZ	GA	AZ	FL	AZ
CT	CT	DE	CA-RCOC	CT	CA-RCOC	CT	CA-RCOC	DE	CA-RCOC	HI	DC	GA	CT
MO	KY	IA	HI	DE	CT	HI	CT	GA	CT	IL	GA	LA	FL
NE	NE	KY	IL	HI	ME	OK	GA	HI	GA	LA	LA	NC	GA
PA	NC	MA	IA	IN	NC	PA	KY	ME	LA	ME	ME	NJ	HI
VT	PA	MN	NE	IA	ND	SC	ME	NM	ME	MO	NH	NM	LA
VA	VT	MO	NC	ME	OK	WV	NC	OK	MO	NM	NY	OH	MD
	WA	NE	OK	MA	PA	WY	OK	PA	NC	OH	OK	OK	MI
		NC	PA	NC	SC		PA	VT	NJ	OK	PA	PA	NC
		PA	UT	OK	WA		SC	WV	OK	PA	WA		NH
		RI	VT	PA	WV		SD	WY	PA	SC			OK
		UT	WA	SC	WY		WA		SC				PA
			WV	SD			WV		WA				SD
			WY	WV			WY		WV				WA
				WY					WY				

Organization of the Family Surveys

The Adult Family Survey is composed of three 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 *family member* with a developmental disability (e.g., individual's age, race, type of disability) followed by a series of demographic questions pertaining 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 the respondent to identify the services and supports they and/or their family member 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 they don't know the answer to a question, or the question is not applicable.

Additional Comments

The end of each section also provides an opportunity for the respondent 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 Adult Family Survey by selecting a random sample of at least 1,000 families who:

1. Had an adult individual with a developmental disability living at home; and
2. Received at least one direct service or support other than 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 Online Data Entry Survey Application (ODESA). 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 the individual lived outside the family home.
2. The respondent indicated the individual was under the age of 18.
3. Demographic information was entered into the file, but no survey questions were answered.

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the NCI average²; 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.

² The "NCI Average" is the average of each state's percentages.

Response Rates

During 2011-2012, 14 states administered the Adult 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. Adult Family Survey - state response rates

State	Surveys Mailed	Surveys Returned	Response Rate (%)	Usable Surveys
AZ	1,000	351	35%	312
CT	1,200	380	32%	342
FL	1,700	384	23%	373
GA	1,499	602	40%	548
HI	900	638	71%	632
LA	1,500	453	30%	408
MD	1,011	483	48%	473
MI	1,100	303	28%	301
NC	1,667	298	18%	295
NH	1,349	397	29%	360
OK	1,517	729	48%	713
PA	1,440	343	24%	322
SD	286	135	47%	120
WA	1,250	373	30%	368
Overall	17,419	5,869	34%	5,567

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.

“Individual” or **“Family Member”** refers to the person (most likely a family member) receiving services who the respondent is answering questions about in this 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 states³ 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.

³ For some items, data are not shown due to an insufficient number of survey responses (fewer than 20).

Demographics: Individual

This section provides information about the adult receiving services and living in the household.

Across states, a higher percentage of family members were male (56%) compared to female (44%) and the average age of family members was 34 years old. On average across states, 71% of respondents indicated their family member was white, 14% were Black/African American, 5% were Asian; 5% of respondents identified their family member as Hispanic/Latino.

The most common disabilities respondents listed their family member as having were: intellectual disability (73%), seizure disorder (26%), autism spectrum disorder (19%), and cerebral palsy (18%).

Nearly all respondents indicated the highest level of education their family member was either a high school diploma or GED (48%) or less than a high school diploma or GED (46%)

Just over four-fifths of family members required medical care less than once a month (81%), while 15% needed medical care at least once a month, and 5% required care at least once a week. The amount of help needed with daily activities was: 23% none, 24% little, 27% moderate, and 26% complete.

More than half of respondents indicated their family member typically attends either a paid or unpaid day program during the day (35% and 22%, respectively). Others day activities included paid community employment (16%) and in-home day supports (17%).

Age

Table 4 Age of Family Member

State	Age	N
AZ	31	309
CT	35	340
FL	35	367
GA	38	538
HI	34	613
LA	36	396
MD	28	469
MI	33	289
NC	34	290
NH	34	357
OK	33	690
PA	36	319
SD	33	120
WA	32	358
NCI Average	34	5,455

Gender

Table 5 Gender of Family Member

State	Male	Female	N
AZ	52%	48%	310
CT	55%	45%	321
FL	55%	45%	366
GA	56%	44%	534
HI	57%	43%	620
LA	48%	52%	402
MD	61%	39%	471
MI	57%	43%	298
NC	61%	39%	291
NH	53%	47%	358
OK	57%	43%	704
PA	54%	46%	319
SD	55%	45%	116
WA	59%	41%	357
NCI Average	56%	44%	5,467

Race

Table 6 Race of Individual

State	American Indian/Alaska Native	Asian	Black/African American	Hawaiian/ Pacific Islander	White	Other/ Unknown	Mixed- Two or more	Hispanic/ Latino	N
AZ	3%	2%	5%	1%	66%	1%	4%	25%	309
CT	1%	3%	13%	0%	82%	0%	1%	4%	334
FL	1%	2%	15%	0%	62%	0%	2%	20%	368
GA	1%	0%	42%	0%	54%	0%	3%	1%	545
HI	3%	47%	2%	29%	24%	3%	25%	5%	620
LA	2%	0%	27%	0%	69%	0%	2%	1%	406
MD	1%	3%	26%	0%	65%	1%	3%	2%	469
MI	3%	2%	19%	0%	77%	0%	1%	3%	298
NC	2%	1%	28%	1%	68%	0%	3%	2%	291
NH	2%	2%	1%	0%	95%	1%	2%	1%	358
OK	11%	2%	10%	0%	77%	1%	5%	2%	703
PA	0%	1%	6%	0%	89%	0%	1%	2%	320
SD	6%	0%	1%	1%	93%	0%	3%	2%	120
WA	3%	7%	3%	1%	77%	1%	8%	6%	358
NCI Average	3%	5%	14%	2%	71%	1%	5%	5%	5,4499

More than One Person with ID/DD in the Home

Table 7 More Than One Person Living in the Home Has ID/DD

State	Yes	No	N
AZ	13%	87%	303
CT	10%	90%	305
FL	8%	92%	358
GA	18%	82%	537
HI	12%	88%	598
LA	15%	85%	395
MD	10%	90%	462
MI	16%	84%	295
NC	11%	89%	282
NH	8%	92%	346
OK	8%	92%	669
PA	18%	82%	309
SD	15%	85%	116
WA	10%	90%	347
NCI Average	12%	88%	5,322

Type of Disability

Table 8 Type of Disability Family Member (not mutually exclusive)

State	Intellectual Disability	Mental Illness	Autism Spectrum Disorder	Cerebral Palsy	Brain Injury	Seizure/ Neurological Disorder	Chemical Dependency	Limited or No Vision	Hearing Loss	Alzheimer's Disease/ Other Dementia	Down Syndrome	Prader-Willi Syndrome	Other Disability	Don't Know
AZ	70%	14%	22%	21%	8%	27%	0%	7%	7%	1%	23%	0%	21%	3%
CT	81%	10%	20%	11%	7%	19%	1%	4%	2%	1%	17%	1%	11%	3%
FL	75%	11%	15%	28%	11%	32%	2%	13%	8%	0%	20%	0%	17%	2%
GA	81%	16%	17%	17%	9%	27%	1%	10%	6%	2%	15%	1%	19%	3%
HI	74%	12%	21%	19%	8%	32%	1%	9%	8%	1%	17%	0%	17%	2%
LA	70%	13%	15%	25%	9%	29%	1%	13%	7%	2%	17%	1%	26%	2%
MD	56%	15%	30%	16%	9%	22%	1%	7%	7%	1%	14%	1%	28%	2%
MI	63%	16%	24%	19%	8%	30%	1%	12%	7%	1%	16%	0%	27%	2%
NC	79%	15%	26%	15%	11%	26%	2%	9%	7%	1%	13%	1%	20%	3%
NH	68%	12%	21%	16%	9%	26%	1%	9%	8%	1%	21%	1%	27%	1%
OK	82%	12%	16%	31%	13%	37%	1%	11%	8%	0%	17%	1%	21%	1%
PA	86%	1%	2%	1%	1%	1%	0%	0%	0%	0%	7%	0%	2%	1%
SD	67%	8%	21%	16%	10%	23%	0%	7%	2%	3%	15%	0%	20%	1%
WA	69%	18%	21%	19%	13%	33%	2%	10%	6%	1%	17%	1%	21%	2%
NCI Average	73%	12%	19%	18%	9%	26%	1%	9%	6%	1%	16%	1%	20%	2%

Primary Means of Expression

Table 9 Primary Means of Expression of Family Member

State	Spoken	Gestures/Body Language	Sign Language/Finger Spelling	Communication Aid/Device	Other	N
AZ	69%	20%	4%	4%	3%	308
CT	78%	17%	2%	1%	1%	327
FL	71%	21%	1%	1%	6%	334
GA	70%	21%	4%	1%	4%	537
HI	69%	21%	2%	1%	7%	611
LA	73%	20%	1%	1%	5%	377
MD	81%	14%	2%	1%	1%	417
MI	78%	17%	1%	1%	3%	272
NC	75%	18%	2%	2%	3%	290
NH	80%	13%	2%	2%	3%	355
OK	66%	28%	1%	2%	3%	707
PA	77%	17%	3%	1%	2%	321
SD	89%	8%	0%	1%	3%	118
WA	70%	18%	4%	3%	4%	363
NCI Average	75%	18%	2%	1%	3%	5,337

Primary Language

Table 10 Primary Language of Family Member

State	English	Spanish	Other	N
AZ	85%	11%	4%	307
CT	96%	2%	1%	313
FL	87%	10%	3%	351
GA	98%	1%	1%	536
HI	91%	0%	9%	612
LA	98%	0%	2%	390
MD	96%	1%	3%	462
MI	98%	0%	2%	292
NC	99%	0%	1%	291
NH	97%	1%	2%	357
OK	97%	1%	2%	694
PA	97%	2%	2%	318
SD	99%	0%	1%	117
WA	90%	3%	7%	359
NCI Average	95%	2%	3%	5,399

Level of Education

Table 11 Highest Level of Education of Family Member

State	Less than High School Diploma/GED	High School Diploma/GED	Vocational School	Some College	College Degree	N
AZ	39%	56%	1%	1%	2%	290
CT	53%	44%	1%	0%	1%	271
FL	55%	40%	4%	0%	0%	317
GA	54%	43%	3%	0%	0%	494
HI	48%	49%	2%	1%	0%	574
LA	66%	27%	4%	1%	2%	367
MD	45%	45%	2%	5%	1%	447
MI	56%	29%	11%	2%	2%	263
NC	52%	41%	3%	3%	0%	265
NH	36%	57%	3%	4%	0%	333
OK	29%	66%	3%	1%	0%	680
PA	38%	55%	6%	1%	0%	303
SD	37%	62%	0%	1%	0%	111
WA	33%	60%	4%	2%	0%	342
NCI Average	46%	48%	3%	2%	1%	5,057

Typical Day Activity

Table 12 Typical Day Activity of Family Member

State	Out of home day program unpaid	Out of home day program paid	Vocational training	Community employment unpaid	Community employment paid	In-home day supports	At home by choice	At home no services	At home other	Other	N
AZ	25%	36%	5%	3%	10%	14%	13%	9%	9%	16%	306
CT	19%	54%	6%	6%	25%	9%	4%	6%	3%	5%	325
FL	14%	39%	4%	4%	11%	21%	14%	8%	13%	14%	367
GA	35%	43%	4%	3%	11%	12%	7%	7%	6%	6%	544
HI	33%	38%	6%	8%	8%	15%	15%	7%	11%	18%	617
LA	15%	30%	4%	3%	9%	34%	15%	6%	9%	14%	398
MD	32%	37%	6%	13%	22%	5%	6%	8%	6%	9%	466
MI	33%	24%	10%	9%	13%	12%	11%	8%	10%	21%	294
NC	23%	29%	9%	11%	15%	21%	16%	9%	10%	14%	290
NH	28%	47%	6%	24%	24%	22%	13%	6%	10%	7%	358
OK	5%	26%	8%	5%	17%	35%	24%	6%	10%	12%	702
PA	14%	40%	4%	3%	11%	6%	7%	5%	4%	6%	316
SD	25%	39%	11%	10%	24%	5%	10%	7%	5%	8%	119
WA	10%	12%	8%	12%	22%	20%	30%	15%	20%	18%	362
NCI Average	22%	35%	6%	8%	16%	17%	13%	8%	9%	12%	5,464

Frequency of Medical Care

Table 13 Frequency of Medical Care Needed for Family Member

State	Less frequently than once/month	At least once/month, but not once/week	At least once/week, or more frequently	N
AZ	82%	14%	5%	298
CT	84%	11%	5%	308
FL	76%	16%	8%	348
GA	82%	15%	3%	514
HI	74%	21%	5%	583
LA	73%	20%	8%	386
MD	84%	13%	4%	445
MI	80%	15%	5%	284
NC	81%	17%	2%	280
NH	85%	11%	4%	348
OK	82%	14%	4%	702
PA	85%	9%	6%	310
SD	90%	10%	0%	116
WA	78%	18%	5%	353
NCI Average	81%	15%	5%	5,275

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

Table 14 Amount of Behavioral Support Needed for Family Member

State	No support needed	Some support needed	Extensive support needed	N
AZ	58%	29%	13%	304
CT	65%	26%	9%	316
FL	58%	31%	11%	363
GA	53%	37%	10%	540
HI	55%	32%	13%	608
LA	54%	32%	14%	389
MD	70%	23%	7%	454
MI	56%	36%	8%	291
NC	58%	32%	11%	288
NH	64%	28%	8%	352
OK	60%	29%	12%	704
PA	68%	25%	7%	314
SD	65%	30%	4%	115
WA	39%	42%	19%	362
NCI Average	59%	31%	10%	5,400

Help Needed with Daily Activities

Table 15 Amount of Help Needed for Daily Activities for Family Member

State	None	Little	Moderate	Complete	N
AZ	11%	24%	31%	34%	306
CT	28%	26%	26%	20%	327
FL	21%	19%	25%	35%	366
GA	29%	24%	24%	23%	543
HI	25%	21%	27%	27%	624
LA	17%	19%	23%	41%	404
MD	35%	25%	22%	18%	468
MI	18%	25%	32%	25%	297
NC	29%	20%	26%	25%	294
NH	23%	30%	26%	20%	358
OK	19%	22%	27%	32%	705
PA	28%	29%	24%	20%	321
SD	33%	33%	20%	14%	120
WA	6%	19%	45%	30%	366
NCI Average	23%	24%	27%	26%	5,499

Demographics: Respondents

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

Across states, the majority of respondents were between 55 and 74 years old (54%); 31% were 35-54 years old, 10% were 75 or older, and 6% were under 35. The majority of respondents were the parent of the family member (86%); the remaining respondents were siblings (7%), and others (6%). Almost 70% had either full or limited guardianship/conservatorship of their family member (64% and 5%, respectively).

Respondent's household incomes were: less than \$15,000 (23%), \$15,001 - \$25,000 (17%), \$25,001-\$50,000 (28%), \$50,001 - \$75,000 (16%), and over \$75,000 (16%). Twenty-one percent (21%) reported they did not spend out-of-pocket expenses on services and supports for their family member in the previous year, while 16% spent \$1-\$100, 36% spent \$101- \$1,000, 25% spent \$1,001- \$10,000, and 2% spent over \$10,000.

Age of Respondent

Table 16 Age of Respondent

State	Under 35	35-54	55-74	75 Plus	N
AZ	4%	38%	52%	6%	309
CT	5%	21%	61%	13%	321
FL	7%	27%	56%	10%	365
GA	6%	26%	58%	10%	542
HI	9%	33%	50%	8%	618
LA	6%	26%	54%	13%	402
MD	7%	39%	50%	4%	465
MI	7%	30%	51%	13%	296
NC	6%	36%	49%	9%	285
NH	4%	32%	57%	7%	355
OK	5%	25%	60%	9%	699
PA	4%	27%	58%	12%	320
SD	6%	36%	49%	9%	120
WA	5%	32%	53%	10%	365
NCI Average	6%	31%	54%	10%	5,462

Respondent Health

Table 17 Health of Respondent

State	Excellent	Good	Fair	Poor	N
AZ	16%	59%	21%	4%	309
CT	17%	53%	26%	4%	322
FL	12%	55%	28%	5%	362
GA	10%	52%	34%	4%	535
HI	16%	57%	24%	3%	615
LA	11%	45%	35%	9%	396
MD	23%	53%	21%	3%	459
MI	16%	57%	26%	1%	291
NC	16%	57%	23%	3%	286
NH	19%	66%	14%	1%	354
OK	15%	60%	20%	5%	699
PA	15%	60%	22%	3%	316
SD	29%	53%	17%	2%	118
WA	15%	55%	26%	3%	363
NCI Average	16%	56%	24%	4%	5,425

Relationship to Family Member

Table 18 Relationship to Family Member

State	Parent	Sibling	Spouse	Other	N
AZ	85%	6%	0%	9%	309
CT	88%	8%	0%	4%	326
FL	86%	8%	0%	6%	367
GA	80%	10%	1%	9%	534
HI	80%	11%	0%	8%	610
LA	86%	6%	1%	7%	397
MD	95%	2%	1%	2%	464
MI	83%	9%	1%	7%	296
NC	83%	8%	0%	8%	285
NH	86%	9%	1%	4%	358
OK	87%	5%	0%	7%	708
PA	85%	11%	1%	4%	321
SD	92%	5%	1%	3%	119
WA	91%	4%	0%	5%	364
NCI Average	86%	7%	0%	6%	5,458

Primary Caregiver

Table 19 Respondent is Primary Caregiver

State	Yes	No	N
AZ	95%	5%	307
CT	96%	4%	318
FL	96%	4%	363
GA	97%	3%	533
HI	92%	8%	602
LA	94%	6%	398
MD	96%	4%	467
MI	96%	4%	295
NC	96%	4%	285
NH	97%	3%	357
OK	95%	5%	706
PA	95%	5%	320
SD	97%	3%	118
WA	96%	4%	361
NCI Average	96%	4%	5,430

Number of Adults in the Household (not including family member)

Table 20 Number of Adults in Household

State	One	Two	Three	Four or more	N
AZ	26%	52%	16%	7%	300
CT	32%	46%	17%	5%	323
FL	36%	51%	8%	5%	364
GA	35%	47%	13%	4%	526
HI	30%	38%	20%	12%	610
LA	39%	46%	12%	4%	393
MD	23%	48%	20%	9%	464
MI	32%	46%	16%	7%	294
NC	28%	52%	14%	6%	276
NH	23%	55%	17%	5%	354
OK	33%	52%	12%	3%	703
PA	25%	51%	19%	5%	317
SD	30%	53%	13%	4%	117
WA	27%	54%	15%	4%	359
NCI Average	30%	49%	15%	6%	5,400

Respondent is Legal Guardian

Table 21 Respondent is Family Member's Legal Guardian

State	Yes, full guardianship/conservatorship	Yes, limited guardianship/conservatorship	No	N
AZ	62%	3%	35%	309
CT	81%	5%	14%	318
FL	50%	9%	42%	361
GA	55%	5%	40%	513
HI	74%	4%	23%	605
LA	68%	5%	27%	370
MD	44%	4%	52%	448
MI	65%	10%	25%	291
NC	70%	6%	24%	282
NH	78%	4%	18%	357
OK	63%	6%	30%	702
PA	49%	3%	48%	303
SD	73%	4%	22%	116
WA	57%	5%	38%	360
NCI Average	64%	5%	31%	5,335

Highest Education Level

Table 22 Highest Education Level of Respondents

State	Less than High School Diploma/GED	High School Diploma/GED	Vocational School	Some College	College Degree	N
AZ	14%	25%	5%	30%	26%	307
CT	10%	31%	3%	20%	37%	314
FL	14%	28%	6%	25%	27%	362
GA	19%	30%	9%	20%	22%	538
HI	13%	29%	5%	26%	27%	605
LA	17%	36%	6%	19%	22%	377
MD	5%	22%	3%	24%	45%	467
MI	8%	31%	3%	26%	31%	293
NC	11%	25%	4%	19%	41%	285
NH	7%	26%	3%	22%	42%	352
OK	8%	28%	7%	26%	31%	707
PA	9%	42%	5%	17%	27%	316
SD	5%	34%	6%	16%	38%	117
WA	9%	24%	5%	36%	26%	356
NCI Average	11%	29%	5%	23%	32%	5,396

Income Level

Table 23 Last Year Total Taxable Income

State	Below \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	N
AZ	28%	15%	27%	18%	11%	268
CT	17%	8%	29%	21%	25%	290
FL	30%	22%	28%	11%	8%	314
GA	38%	22%	20%	13%	7%	468
HI	21%	16%	26%	19%	18%	548
LA	32%	19%	25%	8%	15%	343
MD	15%	11%	25%	18%	31%	420
MI	27%	17%	29%	12%	15%	257
NC	23%	17%	28%	19%	13%	253
NH	15%	17%	32%	14%	23%	284
OK	21%	19%	32%	14%	14%	626
PA	21%	22%	29%	15%	13%	267
SD	21%	17%	26%	19%	17%	106
WA	15%	21%	33%	20%	12%	331
NCI Average	23%	17%	28%	16%	16%	4,775

Out-of-Pocket Expenses

Table 24 Last Year Out-of-Pocket Expenses

State	Nothing	\$1- \$100	\$101- \$1,000	\$1,001- \$10,000	Over \$10,000	N
AZ	24%	11%	33%	31%	2%	289
CT	17%	15%	34%	32%	2%	308
FL	17%	15%	40%	24%	3%	345
GA	17%	21%	42%	18%	2%	509
HI	25%	16%	37%	20%	2%	583
LA	20%	15%	34%	28%	3%	382
MD	17%	14%	36%	30%	4%	450
MI	20%	19%	35%	23%	3%	284
NC	16%	13%	43%	26%	2%	277
NH	19%	12%	32%	33%	3%	324
OK	19%	17%	40%	22%	2%	683
PA	29%	20%	32%	17%	2%	293
SD	29%	21%	30%	18%	2%	115
WA	19%	13%	36%	30%	1%	348
NCI Average	21%	16%	36%	25%	2%	5,190

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).

The majority of respondents indicated their family member receives day employment supports (62%) and transportation (60%); 38% receive in-home support and 29% receive out-of-home respite care.

Table 25 Services and Supports Received

State	Financial support	In-home support	Out-of-home respite care	Day/Employment supports	Transportation	Other services/supports	Social security benefits
AZ	5%	51%	53%	64%	63%	36%	91%
CT	26%	26%	28%	82%	72%	15%	91%
FL	12%	52%	31%	53%	55%	28%	89%
GA	10%	24%	18%	70%	71%	18%	92%
HI	14%	31%	35%	55%	66%	22%	90%
LA	8%	66%	25%	47%	54%	17%	94%
MD	6%	16%	16%	79%	74%	20%	87%
MI	15%	42%	34%	58%	61%	28%	90%
NC	9%	52%	37%	54%	49%	20%	88%
NH	40%	36%	42%	70%	74%	27%	91%
OK	16%	59%	16%	42%	50%	30%	93%
PA	14%	29%	29%	63%	60%	23%	90%
SD	4%	8%	19%	89%	55%	27%	91%
WA	25%	36%	27%	40%	34%	19%	92%
NCI Average	15%	38%	29%	62%	60%	24%	91%

Adult 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

About a third of respondents reported they always get enough information to plan services (32%; states ranged between 24%-42%), and of those, 32% reported information is always easy to understand (states ranged between 26%-40%). Thirty-eight percent (38%; states ranged between 29%-45%) reported information about services and supports always comes from the case manager/service coordinator

The majority of respondents reported they or their family member helped make the service plan (87% and 58%, respectively). Nearly all reported their family member's service plan includes services and supports important to the family (93%) and almost three-quarters of respondents (73%) indicated the plan includes services and supports their family member needs.

Q1. Do you get enough information to help you participate in planning services for your family?

Gets Enough Information To Help Plan Services

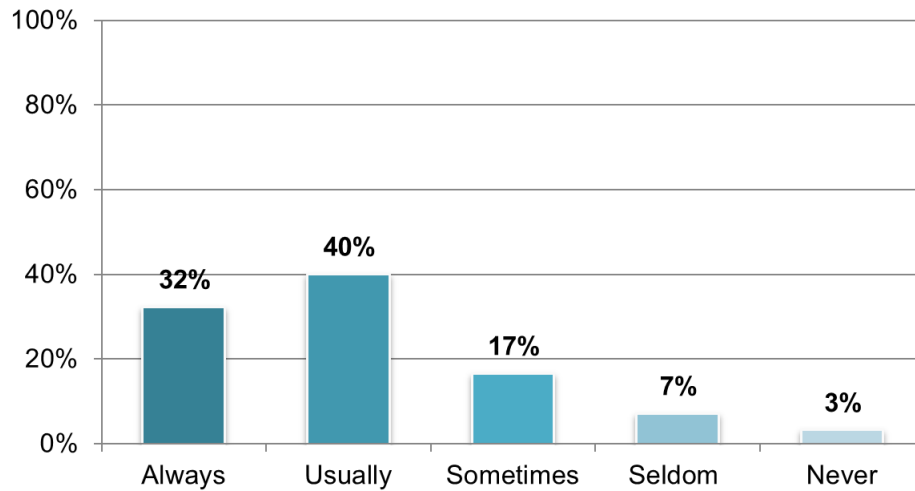


Table 26 Gets enough information to help plan services

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NH	42%	41%	12%	4%	1%	347
HI	39%	40%	16%	3%	2%	600
Within Average Range						
OK	37%	43%	13%	4%	3%	667
LA	37%	38%	16%	6%	4%	380
WA	32%	42%	15%	7%	4%	338
FL	32%	41%	15%	8%	4%	346
CT	32%	33%	19%	11%	5%	313
AZ	32%	40%	16%	9%	3%	282
MI	31%	43%	17%	8%	1%	276
PA	30%	41%	16%	8%	4%	299
NC	29%	39%	18%	8%	5%	275
SD	28%	47%	18%	5%	1%	114
GA	27%	36%	21%	11%	5%	506
Significantly Below Average						
MD	24%	38%	22%	11%	5%	445
NCI Average	32%	40%	17%	7%	3%	5,188

Q2. Is the information you receive easy to understand?

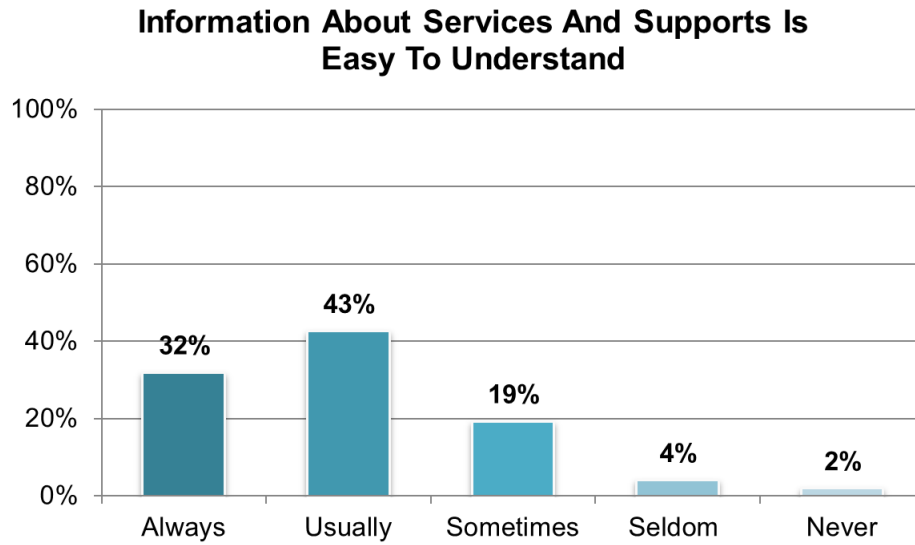


Table 27 Information about services and supports is easy to understand

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NH	40%	45%	13%	3%	0%	346
HI	38%	43%	16%	2%	1%	595
Within Average Range						
LA	35%	39%	21%	3%	2%	375
OK	34%	46%	13%	5%	2%	661
MI	33%	41%	20%	4%	2%	281
SD	33%	46%	20%	1%	1%	112
AZ	33%	43%	19%	3%	2%	285
CT	31%	41%	19%	7%	2%	298
GA	31%	35%	27%	5%	2%	488
PA	29%	46%	18%	5%	2%	288
FL	29%	42%	21%	6%	3%	347
WA	27%	45%	21%	4%	3%	341
NC	27%	42%	22%	4%	4%	269
MD	26%	44%	21%	6%	2%	436
NCI Average	32%	43%	19%	4%	2%	5,122

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

Information About Services And Supports Comes From Case Manager/Service Coordinator

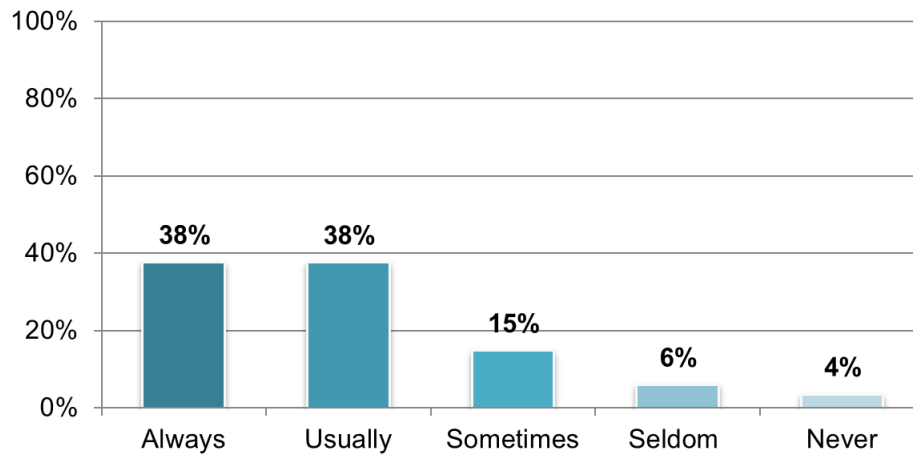


Table 28 Information about services and supports comes from case manager/service coordinator

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
FL	45%	39%	10%	3%	2%	349
WA	43%	34%	15%	5%	3%	341
NH	43%	40%	12%	3%	1%	347
HI	43%	37%	13%	5%	2%	581
LA	43%	37%	13%	4%	3%	369
CT	41%	32%	15%	8%	4%	310
NC	39%	36%	12%	6%	7%	260
PA	37%	39%	14%	7%	4%	292
MI	36%	38%	18%	6%	3%	269
AZ	34%	37%	19%	6%	4%	279
SD	32%	44%	19%	4%	1%	109
Significantly Below Average						
OK	32%	34%	16%	11%	7%	605
MD	31%	42%	15%	8%	4%	440
GA	29%	39%	17%	9%	7%	484
NCI Average	38%	38%	15%	6%	4%	5,035

Q4. Does your family member's case manager/service coordinator tell you about public services that you are eligible for (e.g., food stamps, Supplemental Security Income [SSI], housing subsidies, etc.)?

Case Manager/Service Coordinator Tells Family About Eligible Public Services

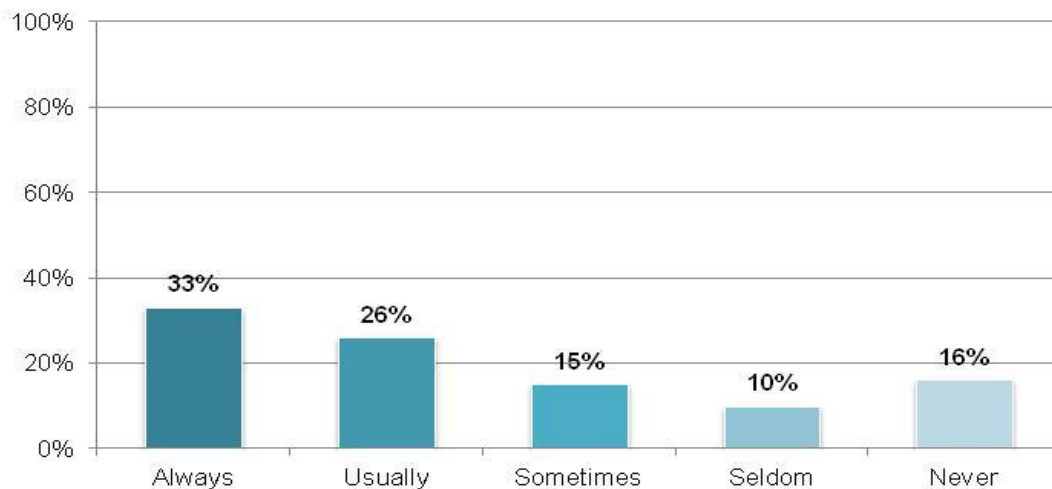


Table 29 Case manager/service coordinator tells family about eligible public services

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
WA	46%	25%	11%	10%	7%	337
CT	43%	24%	14%	7%	13%	301
HI	39%	28%	12%	7%	13%	578
Within Average Range						
FL	40%	28%	12%	8%	11%	345
NH	38%	25%	13%	10%	13%	322
MI	31%	28%	18%	9%	14%	274
LA	30%	24%	14%	10%	22%	351
PA	30%	34%	14%	10%	12%	283
MD	29%	28%	16%	10%	16%	434
OK	29%	27%	14%	14%	16%	603
NC	29%	27%	12%	9%	23%	257
AZ	26%	23%	17%	13%	20%	281
SD	26%	21%	22%	17%	13%	103
Significantly Below Average						
GA	24%	23%	16%	10%	27%	486
NCI Average	33%	26%	15%	10%	16%	4,955

Q5. Does the case manager/service coordinator who assists your family with planning respect your family's choices and opinions?

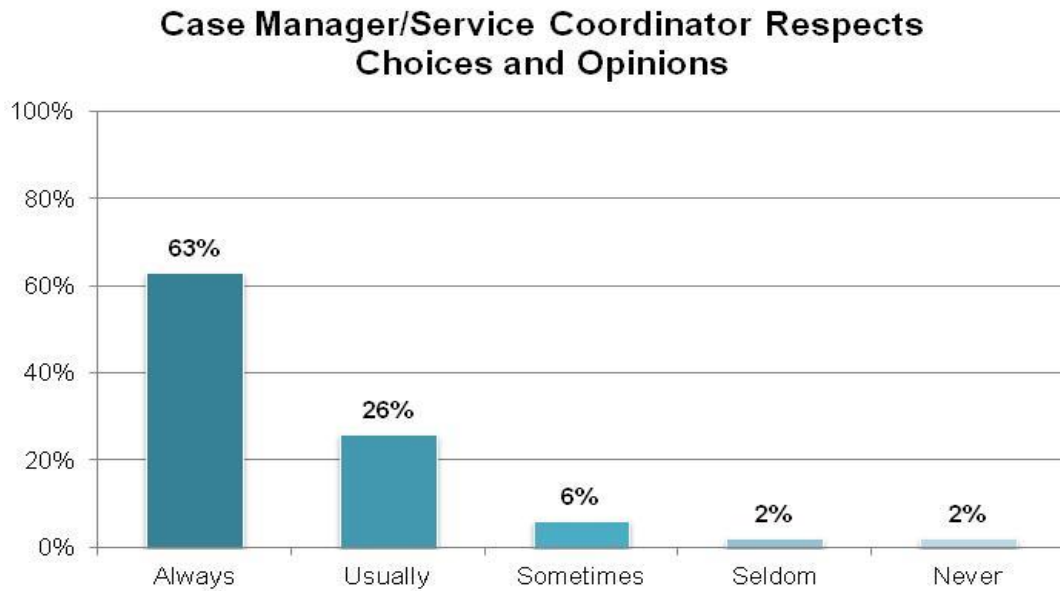


Table 30 Case manager/service coordinator respects choices and opinions

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	71%	23%	3%	0%	3%	350
Within Average Range						
HI	68%	24%	6%	1%	2%	593
NH	67%	24%	5%	2%	1%	352
WA	67%	24%	5%	2%	3%	341
MI	66%	26%	4%	3%	0%	271
NC	65%	21%	6%	3%	5%	259
CT	64%	22%	7%	3%	4%	295
LA	63%	28%	4%	2%	3%	370
AZ	62%	26%	7%	3%	2%	290
PA	62%	28%	6%	3%	2%	294
GA	58%	28%	8%	3%	5%	483
MD	57%	28%	10%	2%	3%	435
SD	50%	35%	13%	2%	0%	111
Significantly Below Average						
OK	56%	34%	7%	2%	2%	634
NCI Average	63%	26%	6%	2%	2%	5,078

Q6. Is the case manager/service coordinator who assists your family with planning generally knowledgeable?

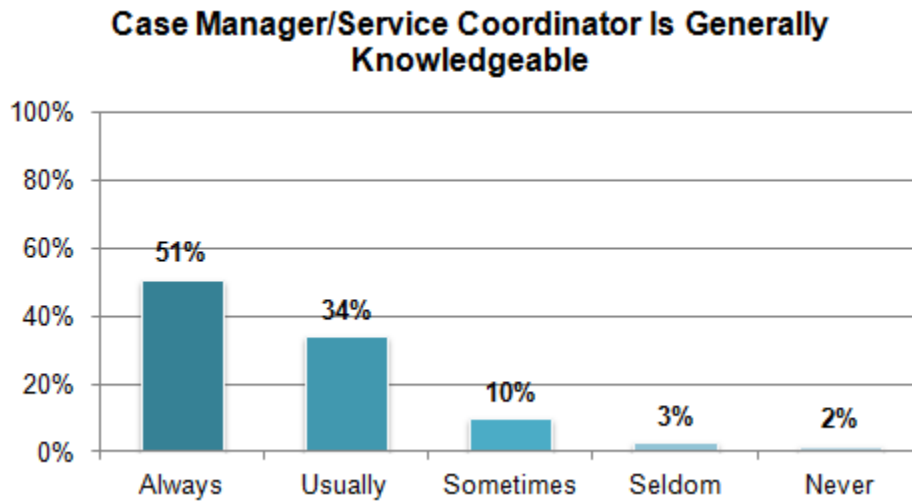


Table 31 Case manager/service coordinator is generally knowledgeable

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
WA	63%	30%	4%	2%	2%	336
CT	61%	25%	9%	3%	3%	302
FL	59%	30%	7%	1%	2%	353
HI	59%	29%	10%	2%	1%	590
Within Average Range						
NH	54%	33%	11%	1%	1%	349
NC	50%	33%	9%	4%	4%	252
MI	49%	35%	12%	4%	1%	275
MD	49%	33%	13%	3%	2%	423
PA	49%	36%	11%	3%	1%	292
OK	48%	37%	10%	3%	2%	629
AZ	47%	36%	12%	2%	2%	290
GA	46%	36%	11%	2%	5%	471
LA	46%	35%	13%	5%	2%	375
SD	41%	45%	11%	3%	1%	113
NCI Average	51%	34%	10%	3%	2%	5,050

Q7. If your family member has a service plan, does the plan include services and supports that are important to your family?

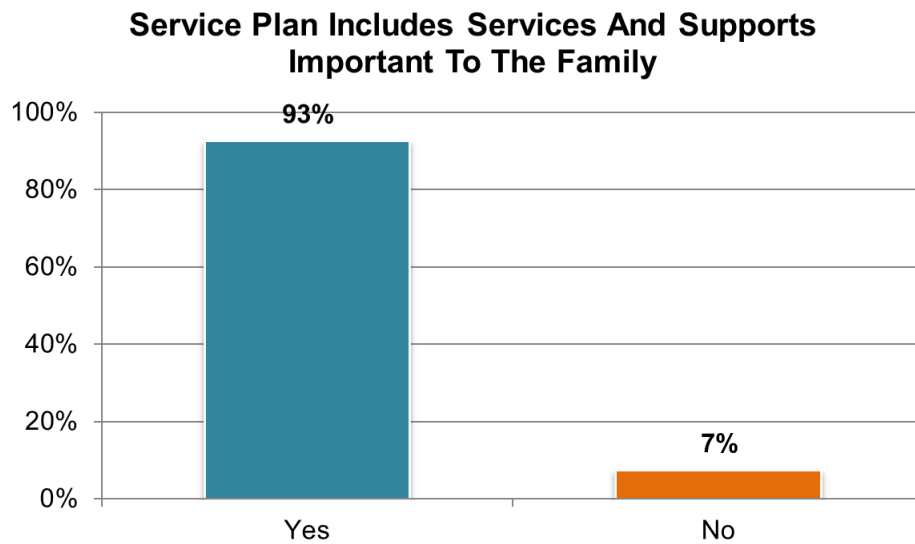


Table 32 Service plan includes services and supports important to the family

State	Yes	No	N
Significantly Above Average			
HI	96%	4%	571
Within Average Range			
NH	96%	4%	324
LA	95%	5%	311
OK	95%	5%	539
FL	95%	5%	320
MI	94%	6%	246
PA	93%	7%	255
SD	93%	7%	97
WA	92%	8%	271
AZ	92%	8%	240
NC	92%	8%	233
MD	88%	12%	378
Significantly Below Average			
GA	88%	12%	441
CT	86%	14%	246
NCI Average	93%	7%	4,472

Q8. If your family member has a service plan, did s/he help develop it?

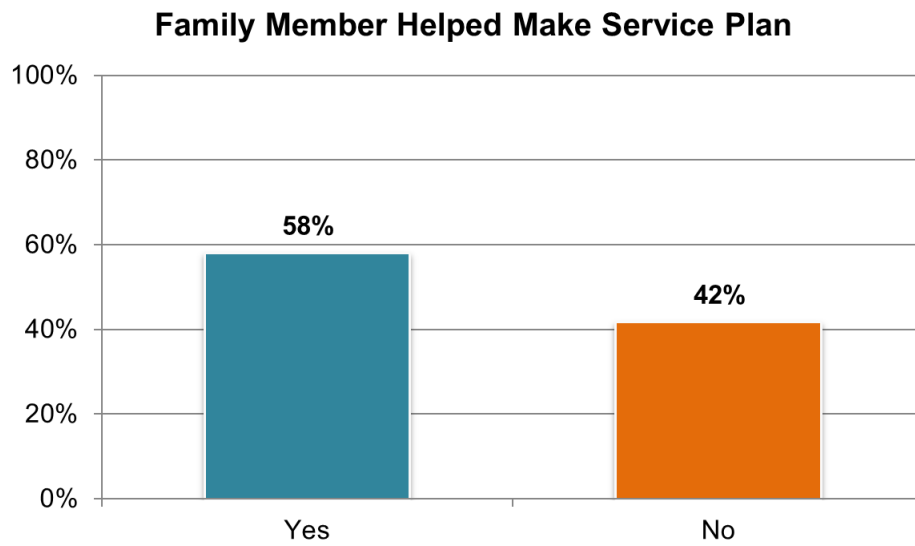


Table 33 Family member helped make service plan

State	Yes	No	N
Significantly Above Average			
SD	74%	26%	93
HI	71%	29%	539
NH	68%	32%	318
MD	66%	34%	376
Within Average Range			
MI	64%	36%	236
FL	64%	36%	313
PA	61%	39%	251
GA	60%	40%	421
NC	53%	47%	227
CT	52%	48%	244
WA	50%	50%	267
Significantly Below Average			
OK	49%	51%	513
LA	48%	52%	301
AZ	35%	65%	236
NCI Average	58%	42%	4,335

Q9. If your family member has a service plan, did you or another family member help develop it?

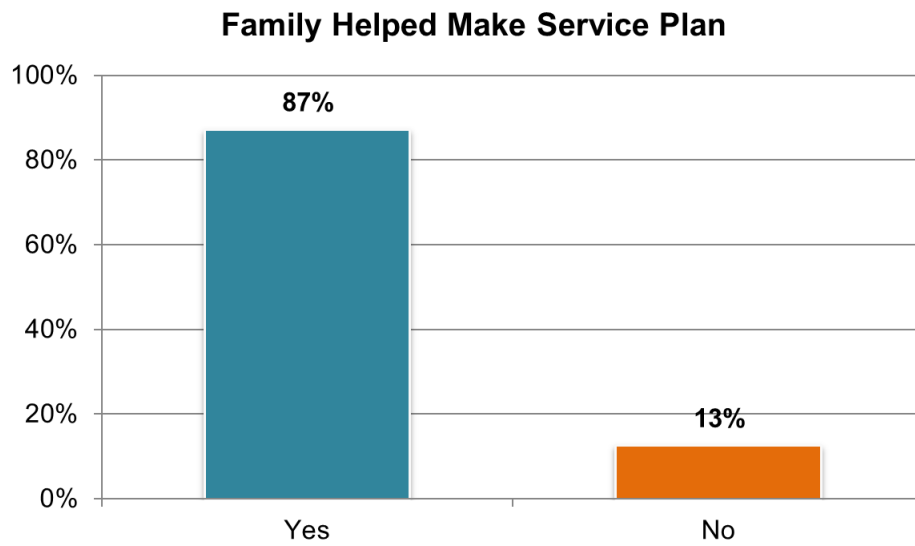


Table 34 Family helped make service plan

State	Yes	No	N
Significantly Above Average			
NH	94%	6%	322
HI	93%	7%	558
Within Average Range			
OK	89%	11%	528
PA	89%	11%	264
AZ	88%	12%	250
MI	87%	13%	246
NC	87%	13%	244
FL	86%	14%	326
MD	86%	14%	390
SD	86%	14%	99
WA	86%	14%	275
LA	85%	15%	319
CT	84%	16%	252
GA	83%	17%	420
NCI Average	87%	13%	4,493

Q10. Does the service plan include all the services and supports your family member needs?

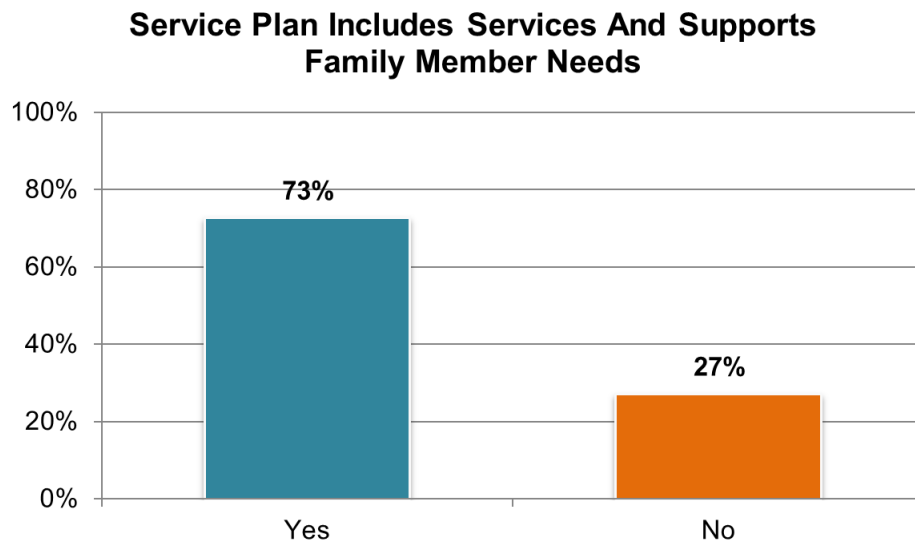


Table 35 Service plan includes services and supports family member needs

State	Yes	No	N
Significantly Above Average			
HI	84%	16%	529
Within Average Range			
PA	79%	21%	244
NH	78%	22%	306
LA	77%	23%	297
AZ	77%	23%	239
OK	76%	24%	532
MI	74%	26%	231
GA	72%	28%	416
SD	71%	29%	90
WA	69%	31%	244
CT	66%	34%	231
NC	66%	34%	229
Significantly Below Average			
MD	65%	35%	346
FL	65%	35%	316
NCI Average	73%	27%	4,250

Q11. If your family member has a service plan, did you discuss how to handle emergencies related to your family member at the last service planning meeting?

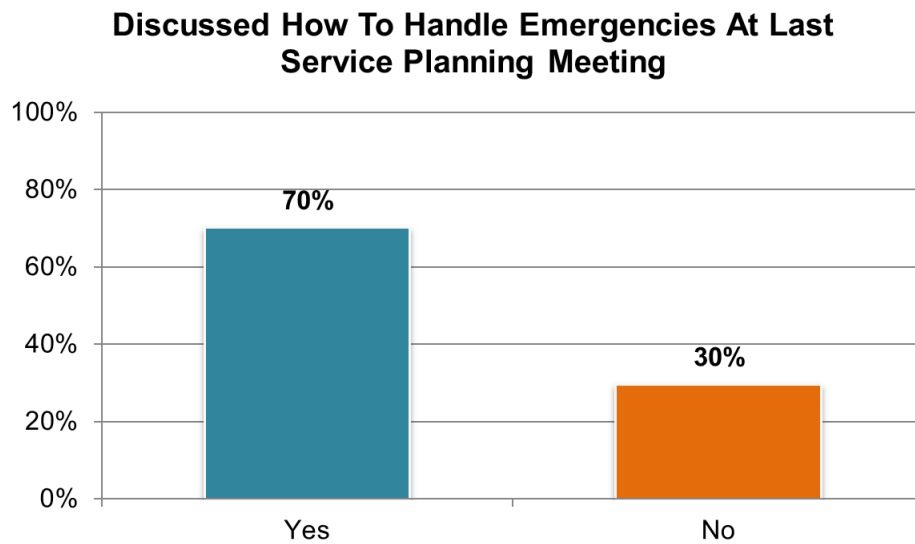


Table 36 Discussed how to handle emergencies at last service planning meeting

State	Yes	No	N
Significantly Above Average			
LA	83%	17%	321
HI	82%	18%	542
OK	80%	20%	535
WA	79%	21%	254
NC	78%	22%	231
Within Average Range			
FL	75%	25%	306
SD	68%	32%	95
AZ	67%	33%	249
GA	65%	35%	420
MI	64%	36%	251
NH	62%	38%	292
Significantly Below Average			
PA	61%	39%	248
CT	60%	40%	239
MD	58%	42%	358
NCI Average	70%	30%	4,341

Q12. Have you or your family member received information about his/her rights?

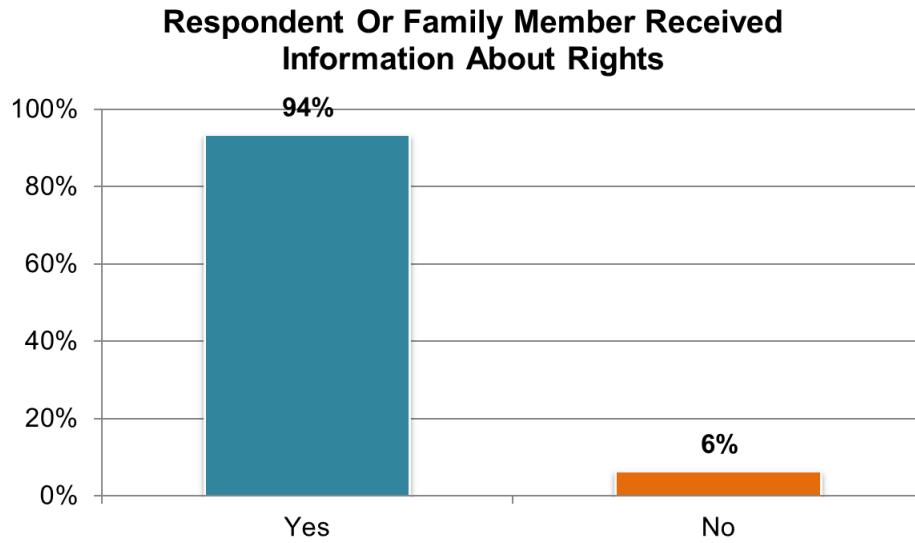


Table 37 Respondent or family member received information about rights

State	Yes	No	N
Significantly Above Average			
OK	98%	2%	641
HI	97%	3%	555
NH	97%	3%	345
Within Average Range			
SD	97%	3%	110
MI	96%	4%	271
FL	95%	5%	344
WA	95%	5%	305
AZ	94%	6%	266
LA	93%	7%	365
PA	91%	9%	268
NC	91%	9%	249
GA	90%	10%	483
Significantly Below Average			
MD	89%	11%	394
CT	86%	14%	261
NCI Average	94%	6%	4,857

Access and Delivery of Services and Supports

The majority of respondents reported they are always able to contact supports workers and the case manager/service coordinator when needed (54% and 53%, respectively). Fifty-four percent (54%) reported their family member always receives all services listed in the service plan; 43% reported their family member and 39% reported the family always receives all the services and supports needed.

Just over one-third of respondents reported services are always available when needed (35%; states ranged between 24%-45%). Almost 40% of respondents reported services and supports are always located reasonably close to their home (39%). Thirty-one percent (31%) reported supports always change when their family member's needs change.

Of respondents whose family member is non-verbal, 39% reported support workers are always able to communicate effectively with their family member. Those whose primary language is English reported support workers always communicate effectively in English (80%) and 52% whose primary language is not English reported support workers are always able to communicate with them.

About half (49%) reported their family member always has access to special accommodations or equipment needed. Almost two-thirds reported their family member's day or employment setting is always healthy and safe (63%).

Three-quarters (75%) of respondents reported crisis or emergency services were provided when needed. The majority reported their family member has access to: health services (98%), dental services (80%), needed medication (97%), mental health services (84%), and respite services (72%). Just less than half (45%) of respondents reported there are other services needed that are not currently offered.

Q13. Are you or your family member able to contact his/her support workers when you need to?

Family Member Or Respondent Is Able To Contact Support Workers When Needed

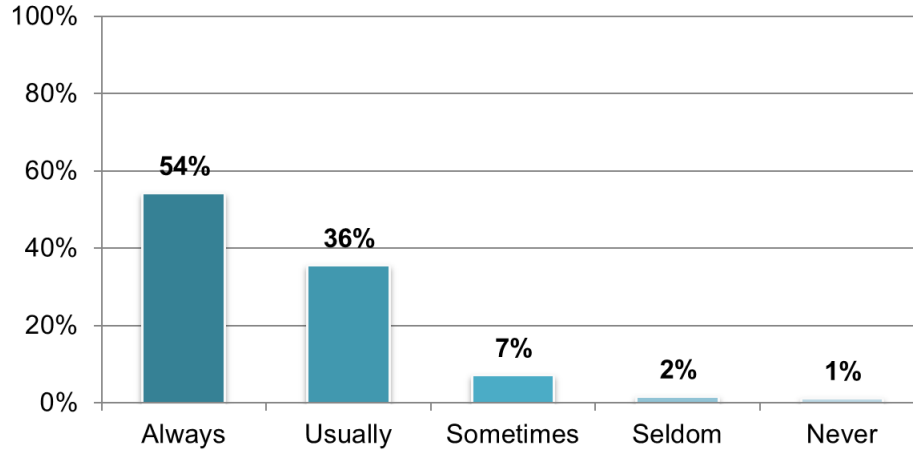


Table 38 Family member or respondent is able to contact support workers when needed

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	66%	25%	6%	1%	1%	360
LA	62%	31%	5%	1%	1%	381
Within Average Range						
NH	60%	35%	4%	0%	0%	342
HI	57%	34%	8%	1%	1%	596
PA	56%	37%	5%	2%	1%	299
NC	54%	32%	11%	2%	1%	262
SD	54%	43%	3%	0%	0%	113
MD	51%	37%	8%	2%	1%	445
OK	51%	40%	7%	2%	0%	677
CT	51%	33%	10%	2%	3%	291
GA	51%	35%	8%	3%	3%	501
MI	50%	37%	10%	2%	1%	284
AZ	49%	38%	9%	2%	1%	297
WA	47%	41%	7%	2%	3%	329
NCI Average	54%	36%	7%	2%	1%	5,177

Q14. Are you or your family member able to contact his/her case manager/service coordinator when you need to?

**Family Member Or Respondent Is Able To
Contact Case Manager/Service Coordinator
When Needed**

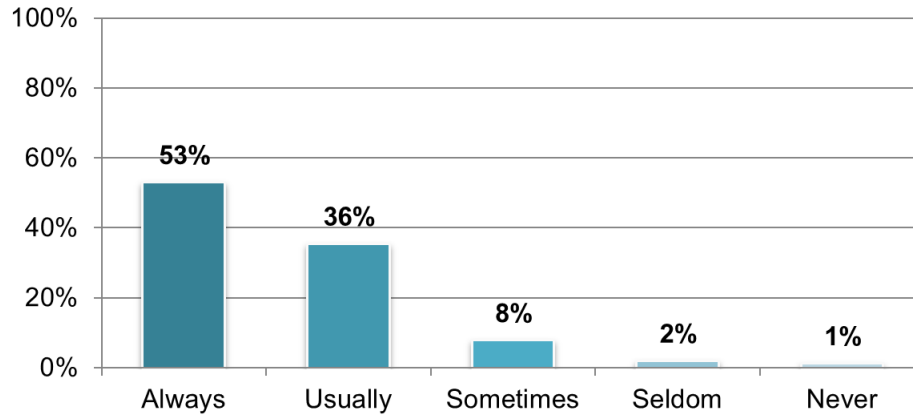


Table 39 Family member or respondent is able to contact case manager/service coordinator when needed

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	65%	25%	7%	1%	1%	362
Within Average Range						
LA	58%	32%	8%	1%	2%	379
NH	58%	36%	5%	1%	0%	351
PA	57%	34%	5%	2%	2%	298
OK	53%	38%	7%	2%	0%	600
SD	53%	41%	6%	0%	0%	117
HI	52%	34%	8%	3%	2%	486
CT	52%	35%	9%	2%	2%	307
WA	50%	40%	5%	2%	2%	351
GA	49%	35%	9%	4%	2%	497
MD	49%	35%	11%	3%	1%	447
MI	49%	39%	8%	4%	0%	284
NC	48%	36%	11%	4%	2%	253
AZ	47%	38%	13%	1%	1%	299
NCI Average	53%	36%	8%	2%	1%	5,031

Q15. Does your family member receive all of the services listed in the service plan?

Family Member Receives All Services Listed In Service Plan

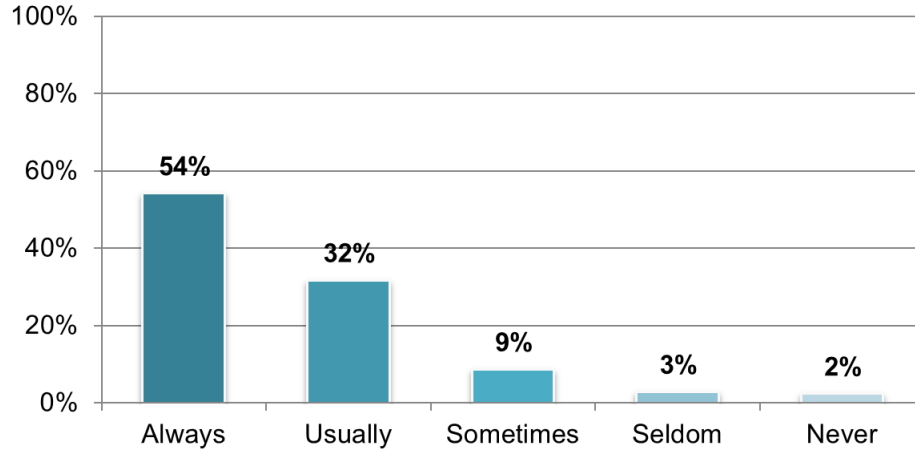


Table 40 Family member receives all services listed in service plan

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	62%	23%	8%	4%	3%	315
HI	62%	31%	6%	1%	1%	556
Within Average Range						
WA	62%	27%	6%	1%	3%	278
FL	60%	25%	9%	4%	2%	326
NH	60%	33%	5%	2%	0%	329
AZ	58%	26%	9%	4%	3%	257
OK	58%	34%	5%	2%	1%	539
NC	57%	29%	10%	2%	3%	223
MI	51%	36%	9%	4%	1%	247
PA	51%	31%	10%	4%	4%	252
CT	49%	36%	8%	4%	3%	235
GA	48%	33%	13%	2%	4%	412
Significantly Below Average						
MD	44%	35%	14%	5%	3%	384
SD	39%	46%	12%	2%	1%	98
NCI Average	54%	32%	9%	3%	2%	4,451

Q16. Does your family member get the services and supports that s/he needs?

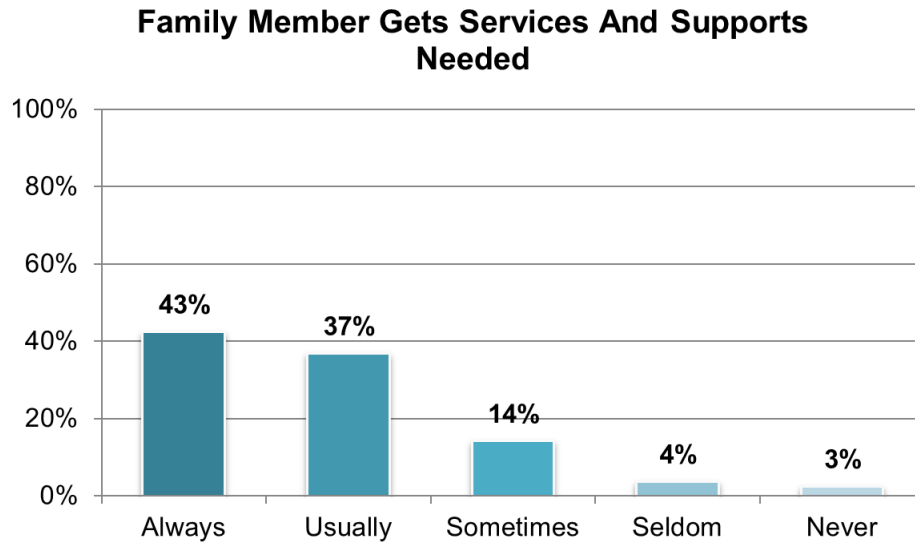


Table 41 Family member gets services and supports needed

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	52%	28%	14%	3%	2%	364
HI	52%	36%	9%	2%	1%	586
Within Average Range						
NH	50%	39%	8%	2%	1%	347
OK	45%	37%	14%	3%	2%	656
PA	43%	34%	15%	5%	3%	283
WA	43%	34%	16%	3%	4%	325
AZ	43%	38%	14%	3%	2%	290
GA	42%	34%	16%	3%	5%	467
MI	42%	38%	14%	5%	1%	277
FL	41%	35%	16%	5%	3%	347
NC	40%	35%	14%	5%	5%	257
CT	37%	40%	15%	4%	4%	282
SD	32%	50%	14%	2%	2%	113
Significantly Below Average						
MD	34%	39%	17%	7%	3%	432
NCI Average	43%	37%	14%	4%	3%	5,026

Q17. Does your family get the services and supports you need?

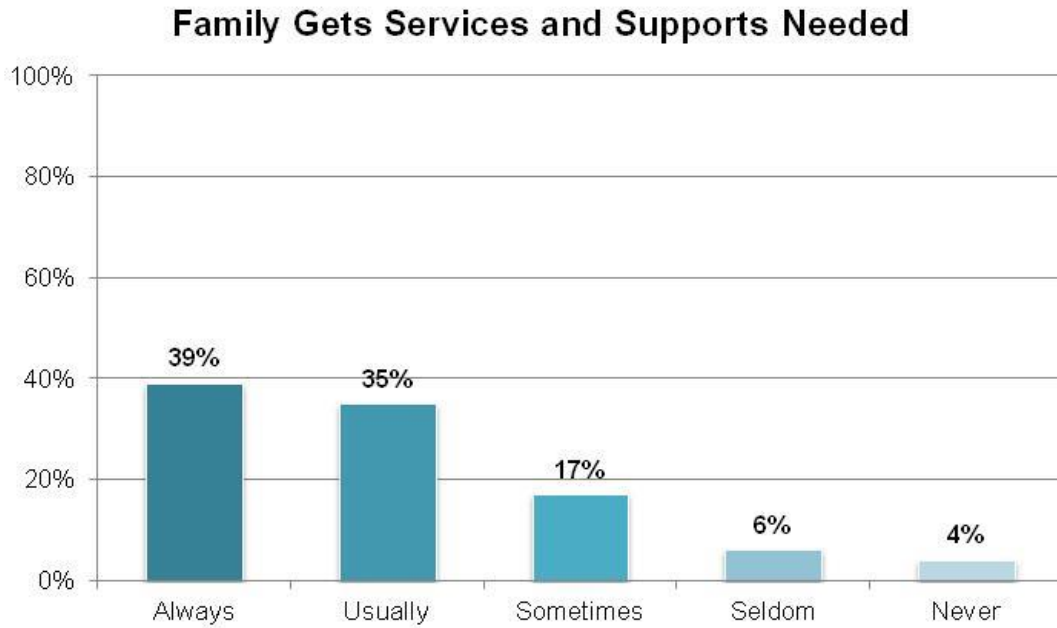


Table 42 Family gets services and supports needed

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	47%	27%	17%	6%	3%	365
HI	47%	35%	11%	4%	3%	571
Within Average Range						
NH	46%	38%	11%	3%	2%	336
AZ	41%	35%	17%	4%	2%	280
OK	41%	37%	16%	4%	2%	654
WA	39%	35%	15%	6%	5%	319
GA	39%	32%	18%	4%	6%	476
PA	39%	33%	18%	6%	4%	272
MI	38%	36%	18%	5%	3%	273
FL	35%	34%	19%	8%	5%	332
NC	34%	36%	16%	8%	5%	260
SD	33%	37%	22%	6%	2%	109
Significantly Below Average						
MD	31%	36%	19%	8%	6%	405
CT	30%	33%	24%	8%	5%	279
NCI Average	39%	35%	17%	6%	4%	4,931

Q18. Are services and supports available at the times that your family member needs them?

Services And Supports Are Available When Needed

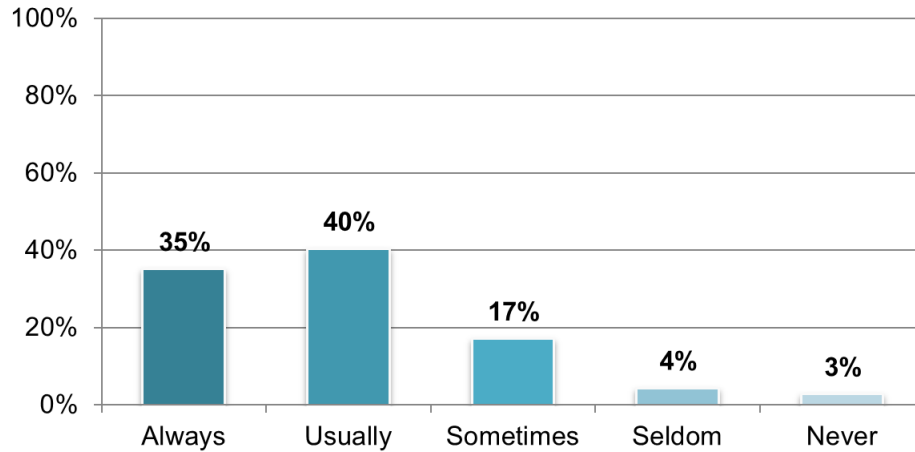


Table 43 Services and supports are available when needed

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	45%	33%	14%	4%	4%	374
NH	43%	42%	11%	2%	1%	342
HI	42%	42%	11%	4%	1%	575
Within Average Range						
WA	37%	36%	19%	5%	3%	311
AZ	37%	42%	16%	3%	2%	280
OK	37%	43%	15%	3%	2%	661
GA	36%	36%	20%	4%	4%	469
FL	36%	39%	14%	6%	5%	352
PA	36%	38%	16%	5%	5%	269
MI	31%	44%	19%	5%	1%	271
MD	30%	38%	21%	7%	4%	413
NC	29%	44%	18%	5%	3%	261
SD	29%	47%	23%	1%	1%	111
Significantly Below Average						
CT	24%	42%	23%	7%	4%	269
NCI Average	35%	40%	17%	4%	3%	4,958

Q19. Are services and supports, received outside the family home, available within a reasonable distance from your family home?

Services And Supports Are Available In A Reasonable Distance From Home

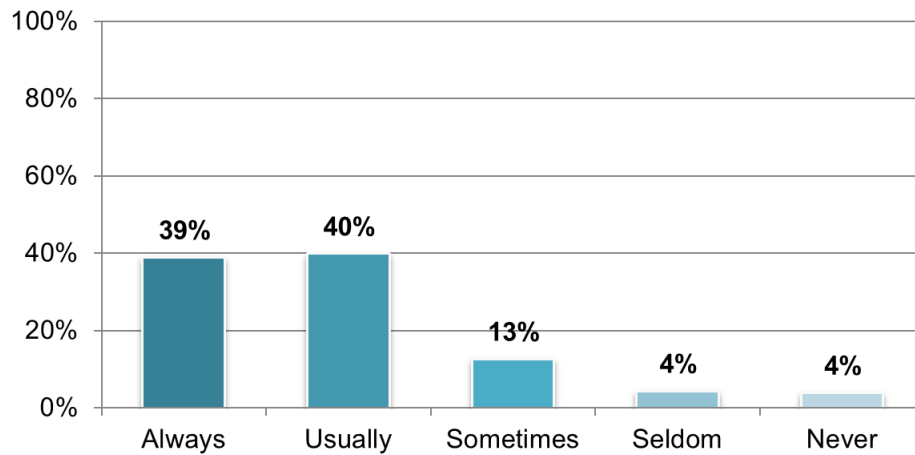


Table 44 Services and supports are available in a reasonable distance from home

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NH	49%	38%	8%	4%	1%	304
LA	48%	31%	12%	4%	5%	318
Within Average Range						
HI	43%	38%	12%	4%	3%	526
AZ	40%	40%	11%	3%	5%	262
MI	40%	39%	12%	7%	3%	244
GA	38%	36%	15%	5%	6%	437
FL	38%	39%	14%	4%	4%	293
MD	37%	39%	15%	5%	4%	377
CT	37%	42%	12%	5%	3%	245
SD	36%	49%	12%	1%	2%	106
PA	36%	45%	10%	5%	5%	250
OK	36%	44%	14%	4%	3%	580
WA	34%	38%	16%	6%	5%	279
NC	33%	41%	14%	6%	6%	228
NCI Average	39%	40%	13%	4%	4%	4,449

Q20. Do the services and supports change when your family member's needs change?

Services And Supports Change When Family Member's Needs Change

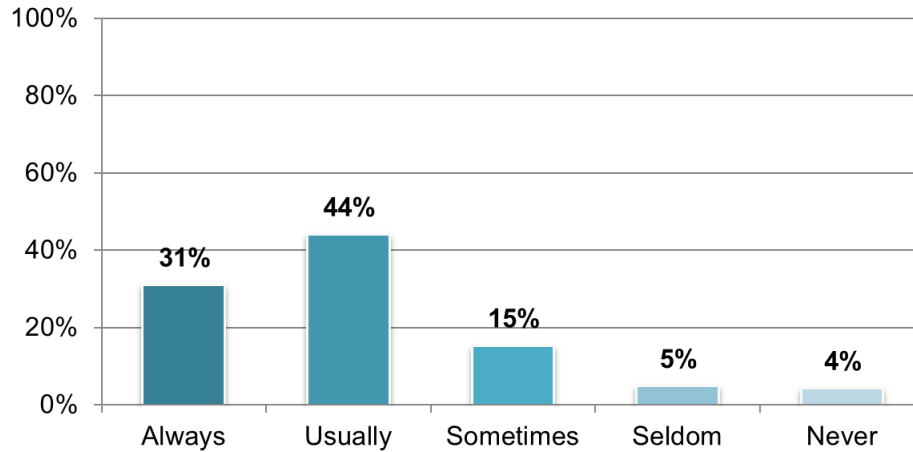


Table 45 Services and supports change when family member's needs change

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
NH	38%	46%	11%	4%	1%	311
LA	38%	42%	10%	6%	4%	319
HI	36%	45%	13%	3%	4%	514
GA	35%	39%	16%	4%	6%	421
NC	34%	42%	14%	6%	4%	228
AZ	32%	43%	19%	3%	3%	252
PA	32%	44%	18%	3%	3%	243
WA	30%	41%	15%	8%	6%	266
FL	29%	44%	16%	5%	6%	314
OK	29%	50%	13%	6%	3%	595
MI	29%	48%	16%	4%	3%	237
SD	27%	43%	22%	4%	4%	104
CT	23%	46%	16%	9%	6%	221
Significantly Below Average						
MD	24%	48%	16%	5%	7%	333
NCI Average	31%	44%	15%	5%	4%	4,358

Q21. If English is not your first language, are there support workers or translators available to speak with you in your preferred language?

Support Workers Or Translators Are Available To Speak In Preferred Language (If Not English)

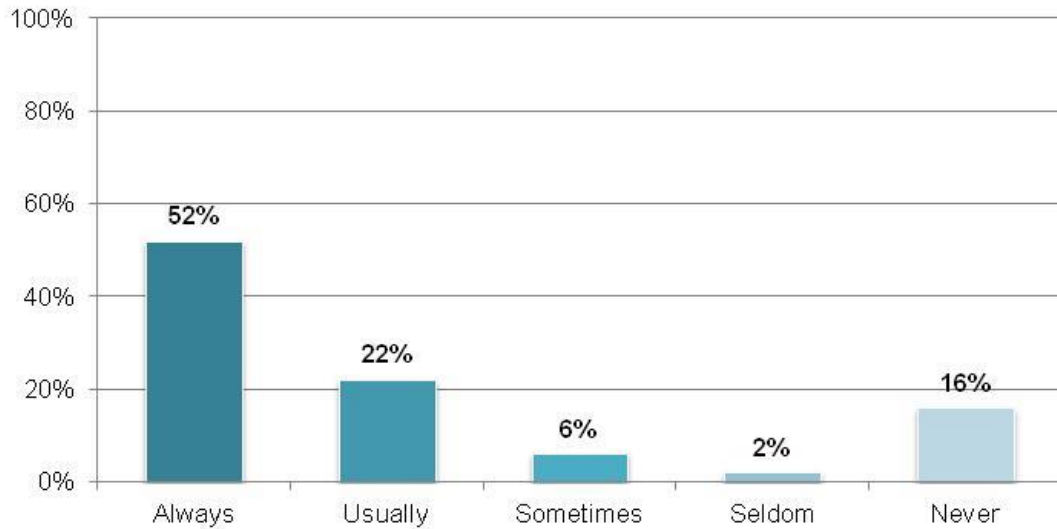


Table 46 Support workers or translators are available to speak in primary language (if not English)

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
LA	68%	5%	0%	0%	27%	22
FL	61%	29%	2%	0%	7%	41
GA	58%	17%	1%	4%	20%	76
HI	56%	19%	12%	5%	8%	85
OK	54%	31%	0%	0%	14%	35
AZ	40%	24%	12%	4%	20%	25
WA	29%	32%	18%	4%	18%	28
NCI Average	52%	22%	6%	2%	16%	312

Q22. If English is your first language, do the support workers communicate with you effectively in your primary language?

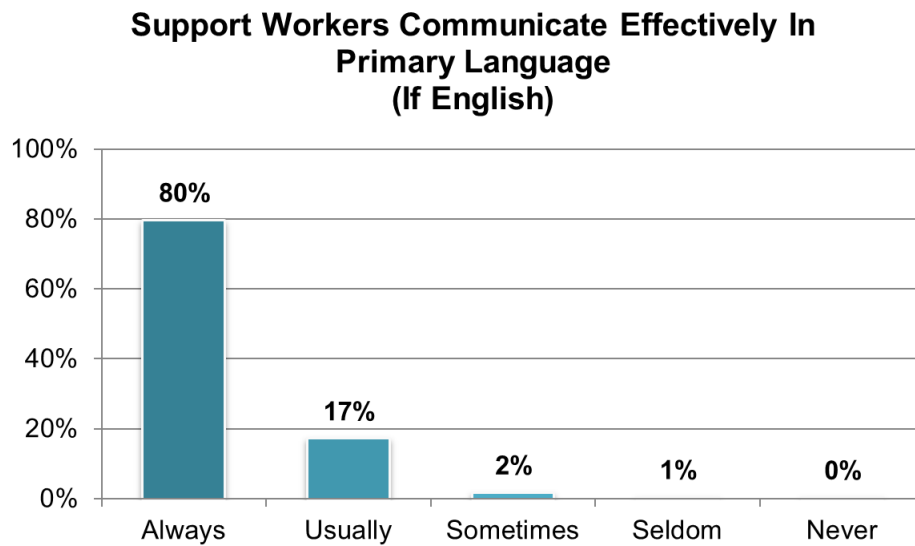


Table 47 Support workers communicate effectively in primary language (if English)

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NH	88%	11%	1%	0%	0%	291
Within Average Range						
WA	89%	9%	1%	0%	0%	74
GA	84%	11%	2%	1%	2%	95
LA	84%	14%	2%	0%	0%	92
PA	84%	15%	1%	0%	0%	237
CT	81%	16%	2%	0%	1%	258
MI	80%	17%	1%	0%	1%	70
NC	79%	17%	2%	1%	0%	203
FL	78%	18%	1%	2%	0%	92
OK	77%	22%	1%	1%	0%	185
AZ	76%	24%	0%	0%	0%	59
HI	74%	20%	5%	1%	0%	124
MD	70%	26%	4%	0%	0%	104
NCI Average	80%	17%	2%	1%	0%	1,593

Q23. If your family member does not verbally communicate (for example, uses gestures or sign language), are there enough support workers available who can communicate with him/her?

**Support Workers Can Communicate With Family Member
(If Non-Verbal)**

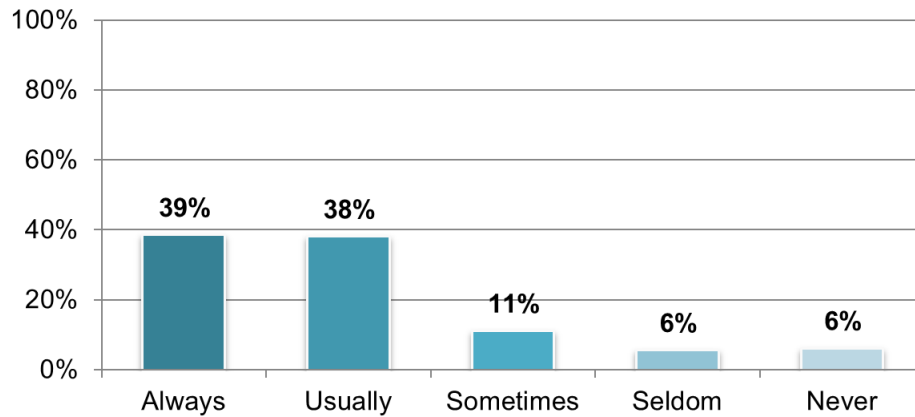


Table 48 Support workers can communicate with family member (if non-verbal)

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
LA	48%	35%	7%	4%	6%	158
FL	46%	30%	12%	6%	5%	156
GA	43%	33%	11%	4%	9%	258
WA	42%	35%	14%	7%	1%	147
HI	42%	42%	9%	2%	5%	292
OK	40%	38%	11%	5%	6%	311
SD	39%	44%	14%	0%	3%	36
MI	36%	42%	11%	5%	6%	114
AZ	35%	34%	15%	5%	12%	137
CT	33%	41%	15%	3%	8%	66
MD	31%	45%	11%	9%	5%	148
NC	27%	42%	5%	16%	10%	62
NCI Average	39%	38%	11%	6%	6%	1,885

Q24. Are services delivered to your family in a way that is respectful to your family's culture?

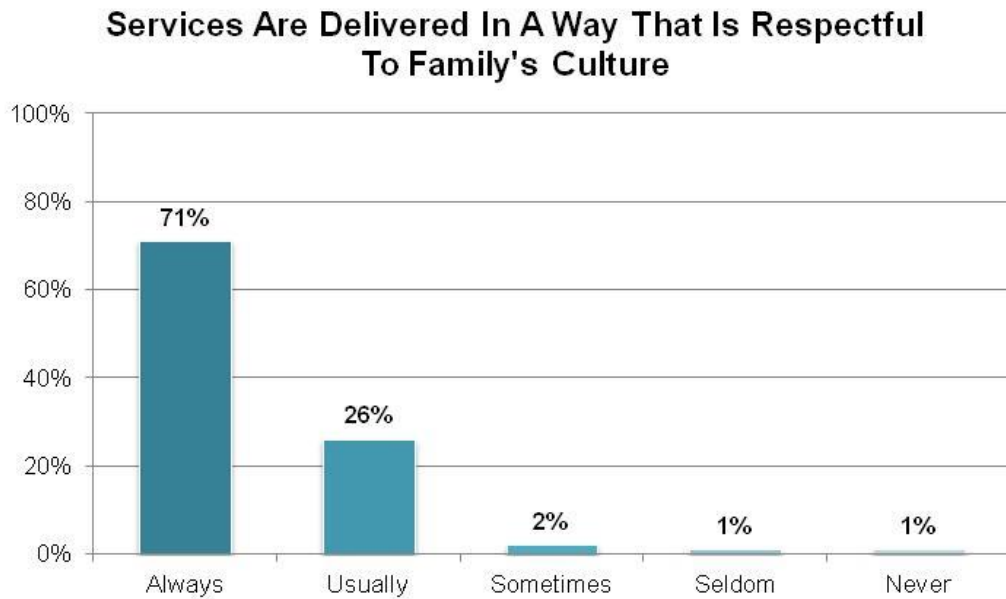


Table 49 Services are delivered in a respectful manner to family's culture

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NH	84%	15%	1%	0%	0%	311
Within Average Range						
FL	74%	22%	3%	0%	1%	326
PA	74%	21%	1%	2%	2%	255
MI	73%	26%	1%	0%	0%	246
WA	73%	24%	2%	0%	1%	295
LA	70%	25%	2%	1%	1%	350
AZ	70%	28%	2%	0%	0%	276
MD	70%	25%	3%	1%	0%	383
OK	69%	28%	2%	1%	0%	613
CT	69%	27%	2%	0%	1%	241
HI	68%	27%	3%	1%	1%	524
NC	68%	25%	5%	1%	2%	235
GA	64%	26%	5%	2%	3%	431
SD	59%	40%	0%	0%	1%	86
NCI Average	71%	26%	2%	1%	1%	4,572

Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

Family Member Has Access To Special Equipment Or Accomodations Needed

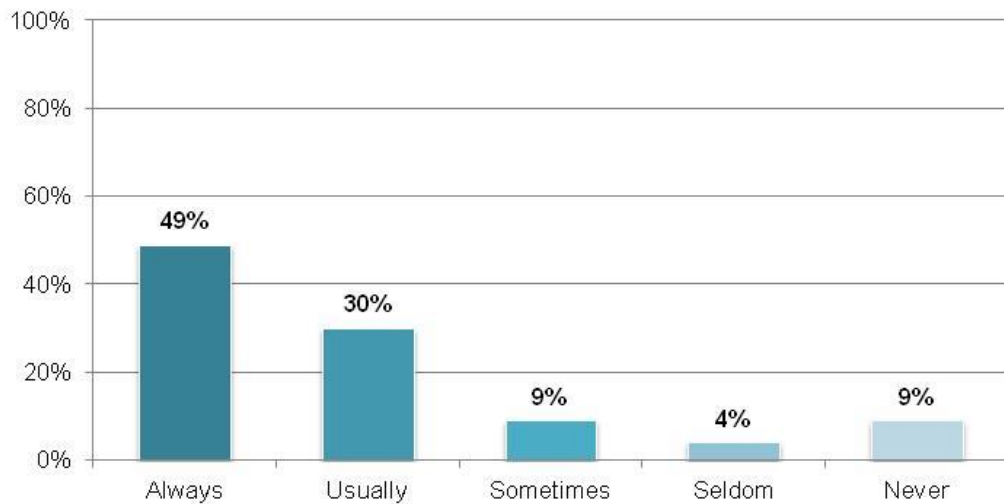


Table 50 Family member has access to special equipment or accommodations needed

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
NH	58%	36%	5%	1%	1%	142
LA	56%	23%	10%	5%	6%	205
GA	53%	24%	7%	2%	14%	268
PA	51%	27%	12%	2%	8%	115
HI	51%	24%	9%	4%	11%	286
OK	50%	32%	9%	4%	5%	376
SD	50%	37%	4%	4%	4%	46
FL	49%	25%	10%	7%	9%	175
WA	48%	30%	9%	4%	9%	162
CT	47%	25%	4%	5%	19%	79
MI	45%	34%	8%	4%	9%	115
NC	44%	35%	8%	4%	9%	138
AZ	44%	34%	15%	2%	5%	157
Significantly Below Average						
MD	36%	31%	17%	6%	10%	146
NCI Average	49%	30%	9%	4%	9%	2,410

Q26. Do you feel that your family member's day/employment setting is a healthy and safe environment?

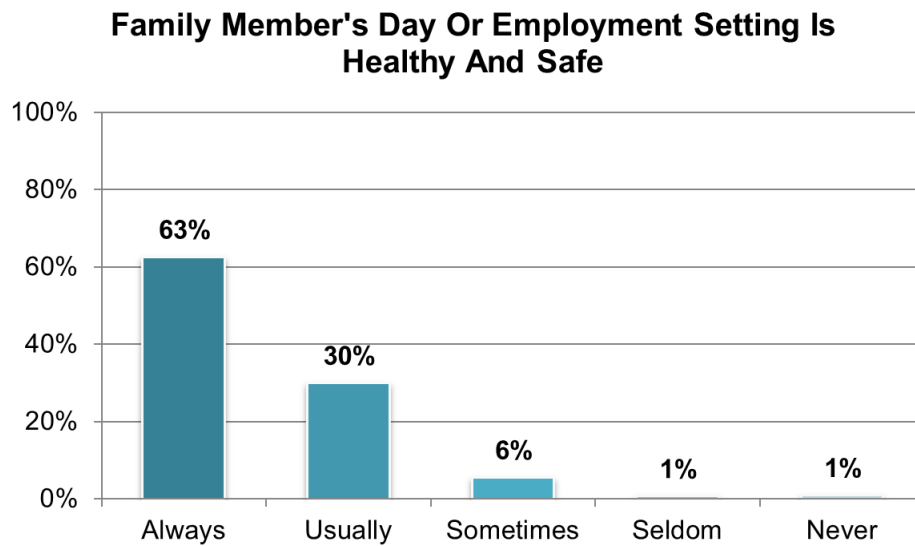


Table 51 Family member's day or employment setting is healthy and safe

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	73%	21%	4%	0%	1%	294
Within Average Range						
NH	70%	26%	4%	0%	0%	304
NC	68%	26%	4%	1%	0%	213
FL	67%	27%	5%	1%	0%	275
HI	65%	29%	4%	0%	1%	475
OK	65%	27%	7%	1%	0%	485
PA	64%	29%	6%	0%	0%	243
CT	61%	32%	5%	1%	1%	290
MI	61%	33%	5%	0%	1%	217
WA	60%	30%	6%	1%	2%	248
GA	58%	30%	7%	2%	2%	440
AZ	58%	32%	8%	0%	1%	251
SD	54%	42%	5%	0%	0%	110
Significantly Below Average						
MD	53%	38%	6%	2%	2%	421
NCI Average	63%	30%	6%	1%	1%	4,266

Q27. Do the support workers have the right training to meet your family's needs?

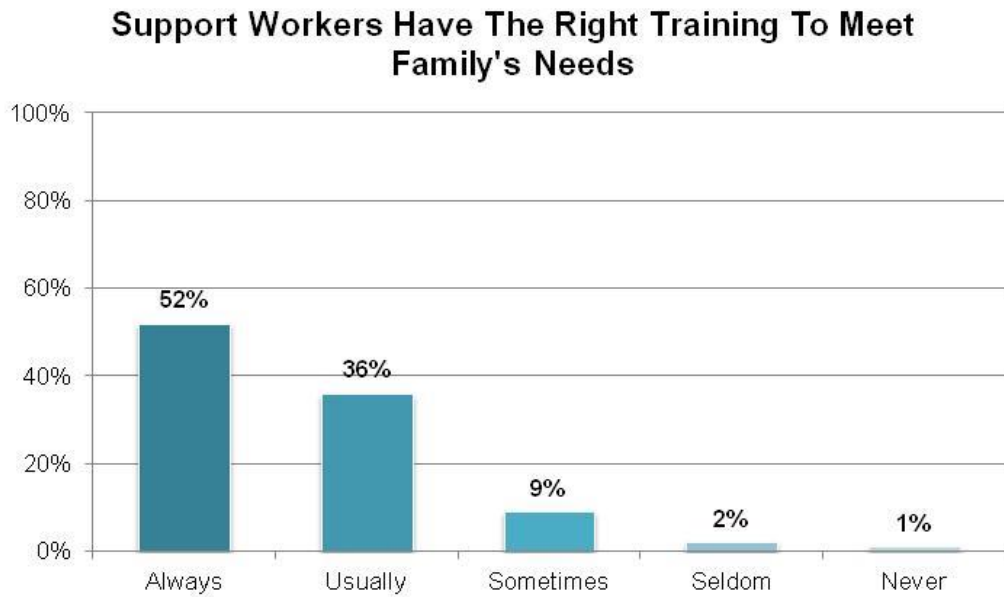


Table 52 Support workers have the right training to meet family's needs

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	63%	26%	8%	2%	1%	351
OK	60%	32%	6%	2%	0%	601
Within Average Range						
PA	57%	33%	6%	3%	1%	266
FL	57%	32%	8%	2%	1%	332
HI	55%	34%	9%	2%	0%	513
MI	54%	35%	9%	1%	1%	241
NC	54%	33%	8%	3%	2%	247
GA	54%	31%	10%	2%	3%	443
NH	52%	38%	8%	2%	0%	314
WA	51%	35%	10%	3%	2%	261
CT	49%	37%	11%	1%	1%	270
AZ	46%	40%	11%	2%	1%	274
Significantly Below Average						
MD	42%	41%	11%	4%	2%	395
SD	38%	49%	11%	2%	0%	106
NCI Average	52%	36%	9%	2%	1%	4,614

Q28. Do the support workers who come to your home arrive on time and when scheduled?

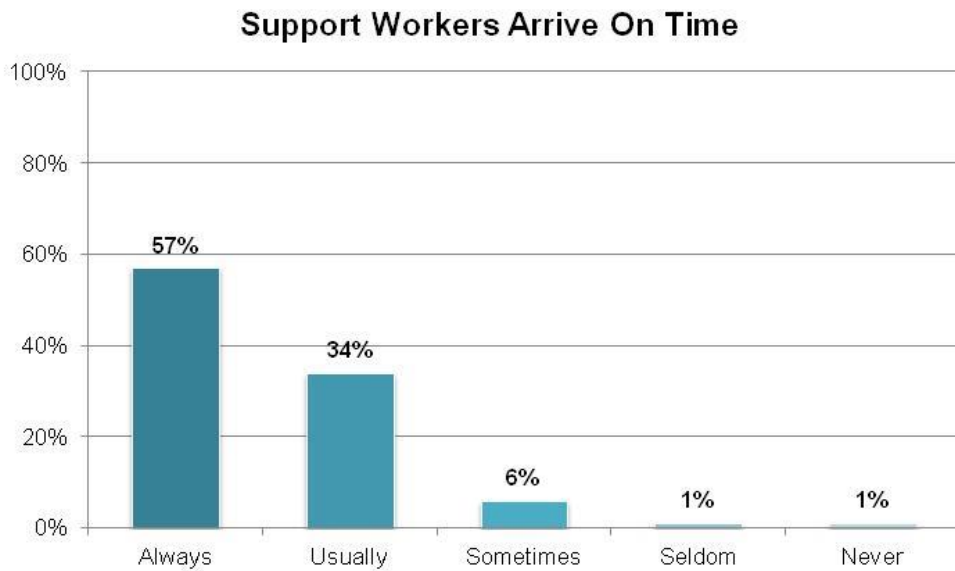


Table 53 Support workers arrive on time

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
FL	64%	29%	5%	1%	1%	336
LA	62%	28%	7%	1%	1%	343
PA	62%	33%	2%	0%	2%	242
OK	61%	30%	8%	1%	0%	559
WA	60%	34%	4%	1%	1%	249
MI	60%	29%	7%	3%	0%	224
AZ	59%	32%	8%	0%	1%	253
HI	58%	34%	6%	1%	1%	439
CT	57%	34%	6%	1%	2%	208
NH	56%	40%	3%	1%	0%	296
SD	52%	40%	9%	0%	0%	58
NC	51%	34%	10%	2%	2%	220
GA	51%	36%	7%	3%	3%	354
Significantly Below Average						
MD	49%	42%	4%	2%	3%	283
NCI Average	57%	34%	6%	1%	1%	4,064

Q29. If your family member transitioned from school services to state funded services during the past year, were you happy with the transition process?

Happy With Transition From School To State Funded Services (Past Year)

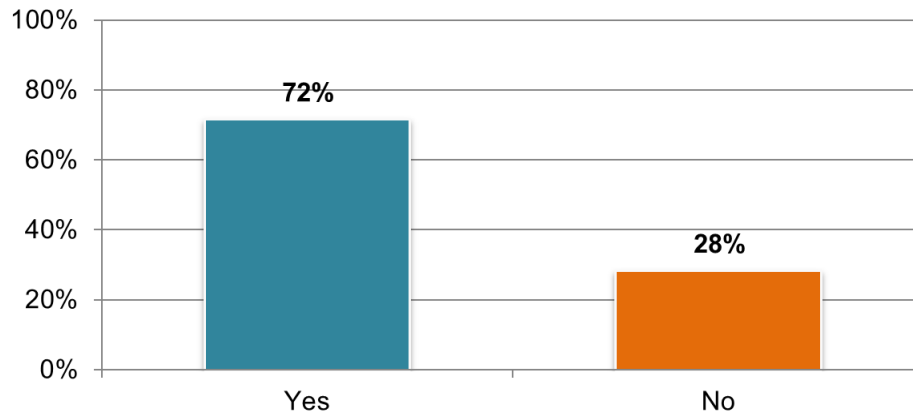


Table 54 Happy with transition from school to state funded services (past year)

State	Yes	No	N
Significantly Above Average			
OK	89%	11%	35
Within Average Range			
CT	84%	16%	31
HI	80%	20%	61
MD	77%	23%	110
NH	77%	23%	44
MI	76%	24%	33
LA	73%	27%	30
WA	71%	29%	31
AZ	70%	30%	37
PA	63%	37%	30
NC	61%	39%	28
GA	60%	40%	30
FL	50%	50%	22
NCI Average	72%	28%	522

Q30. If you asked for crisis/emergency services during the past year, were services provided when needed?

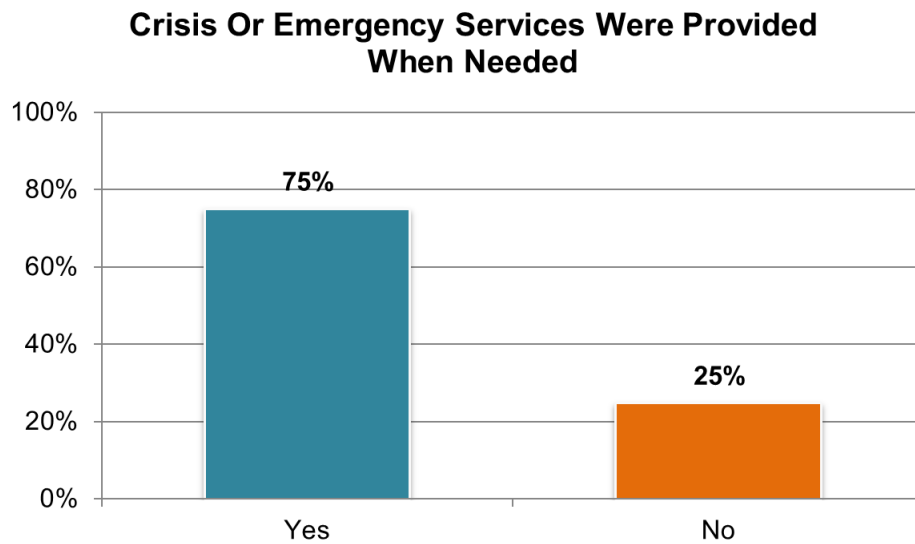


Table 55 Crisis or emergency services were provided when needed

State	Yes	No	N
Significantly Above Average			
NH	88%	13%	64
HI	87%	13%	225
GA	85%	15%	322
Within Average Range			
WA	81%	19%	95
OK	76%	24%	136
LA	74%	26%	124
MI	73%	27%	70
FL	73%	27%	91
AZ	72%	28%	72
PA	70%	30%	56
CT	68%	32%	53
MD	67%	33%	105
NC	64%	36%	56
NCI Average	75%	25%	1,469

Q31. Do you have access to health services for your family member?

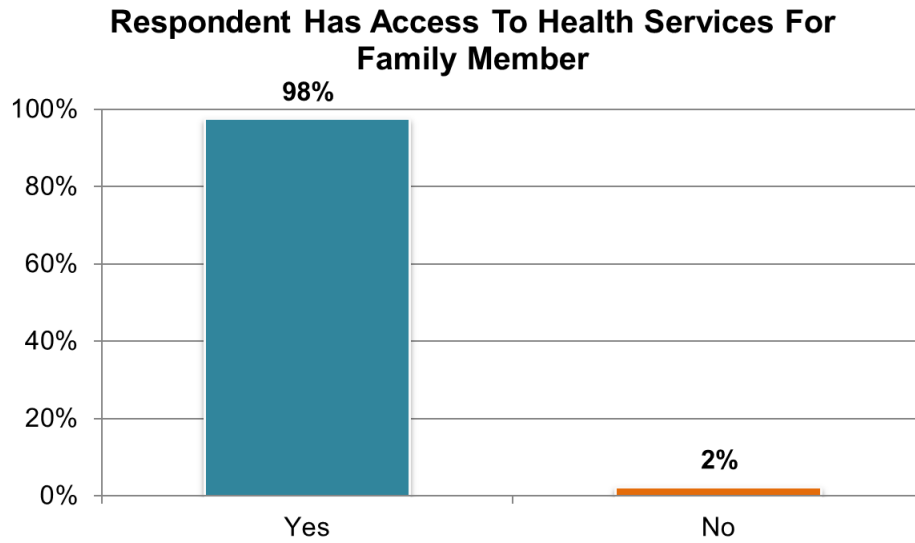


Table 56 Respondent has access to health services for family member

State	Yes	No	N
Within Average Range			
SD	100%	0%	112
NH	99%	1%	331
AZ	99%	1%	298
PA	99%	1%	296
WA	98%	2%	328
OK	98%	2%	677
FL	98%	2%	346
MD	97%	3%	442
MI	97%	3%	278
CT	97%	3%	306
HI	97%	3%	564
NC	96%	4%	270
LA	96%	4%	373
Significantly Below Average			
GA	94%	6%	493
NCI Average	98%	2%	5,114

Q32. If “yes” (to Q31), are you satisfied with the quality of these providers?

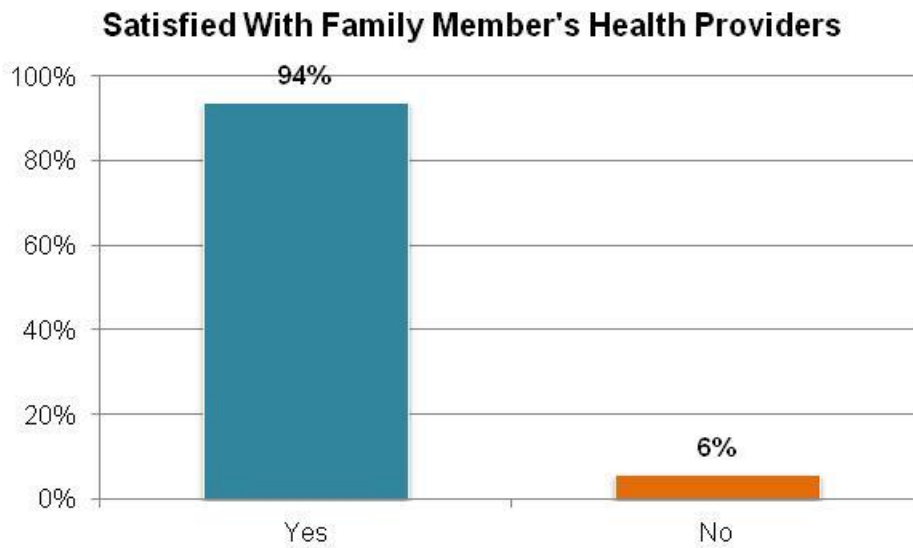


Table 57 Satisfied with family member's health providers

State	Yes	No	N
Within Average Range			
PA	98%	2%	284
SD	98%	2%	110
OK	97%	3%	632
CT	96%	4%	287
MI	95%	5%	261
HI	95%	5%	513
LA	95%	5%	336
FL	95%	5%	314
MD	94%	6%	406
NH	94%	6%	319
NC	94%	6%	251
WA	93%	7%	304
AZ	92%	8%	278
Significantly Below Average			
GA	89%	11%	439
NCI Average	94%	6%	4,734

Q33. Do you have access to dental services for your family member?

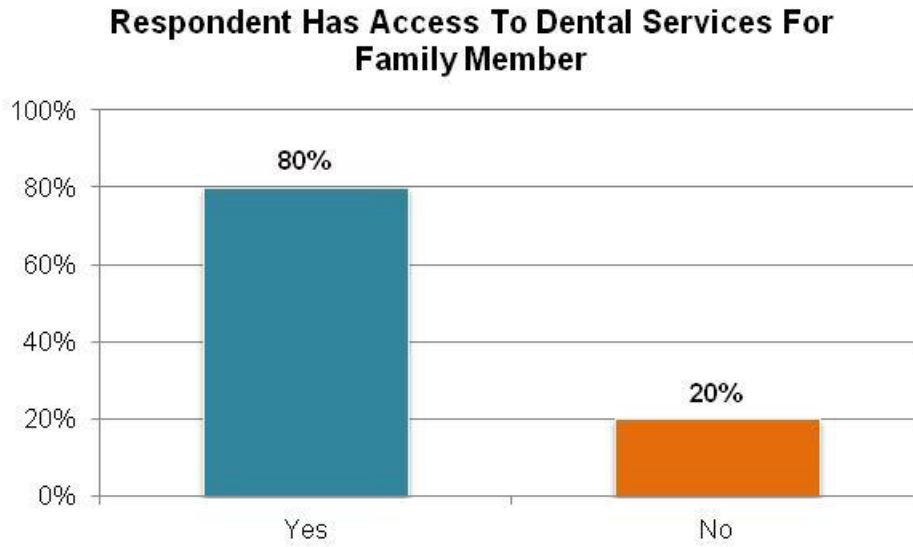


Table 58 Respondent has access to dental services for family member

State	Yes	No	N
Significantly Above Average			
SD	98%	2%	114
PA	90%	10%	287
CT	88%	12%	298
Within Average Range			
NH	86%	14%	318
NC	86%	14%	268
HI	84%	16%	553
OK	82%	18%	641
MD	81%	19%	427
WA	80%	20%	322
MI	79%	21%	270
GA	78%	22%	480
Significantly Below Average			
FL	69%	31%	323
LA	67%	33%	347
AZ	59%	41%	271
NCI Average	80%	20%	4,919

Q34. If “yes” (to Q33), are you satisfied with the quality of these providers?

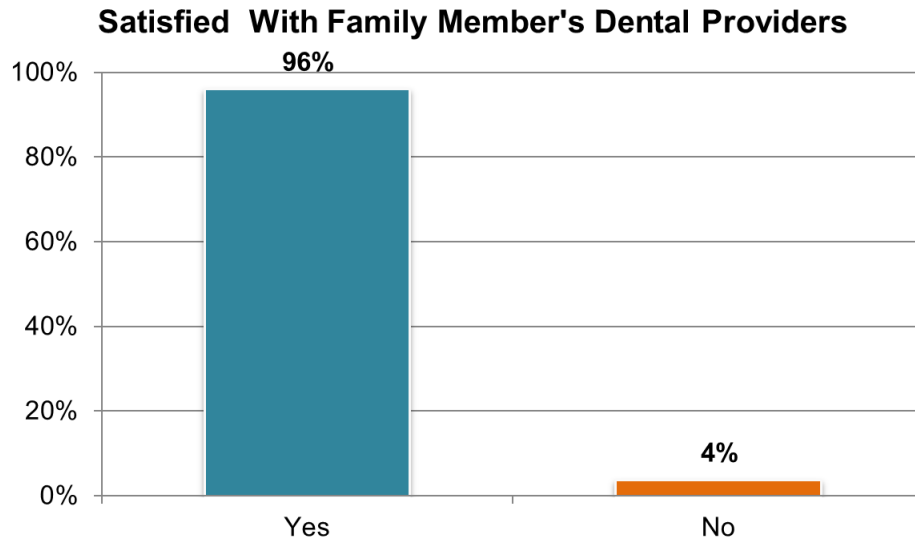


Table 59 Satisfied with family member's dental providers

State	Yes	No	N
Significantly Above Average			
SD	100%	0%	110
Within Average Range			
NH	98%	2%	266
NC	97%	3%	222
OK	97%	3%	504
HI	97%	3%	426
LA	97%	3%	218
FL	96%	4%	206
PA	96%	4%	248
MI	96%	4%	204
WA	95%	5%	242
MD	94%	6%	320
AZ	94%	6%	152
GA	94%	6%	348
CT	93%	7%	244
NCI Average	96%	4%	3,710

Q35. Do you have access to necessary medications for your family member?

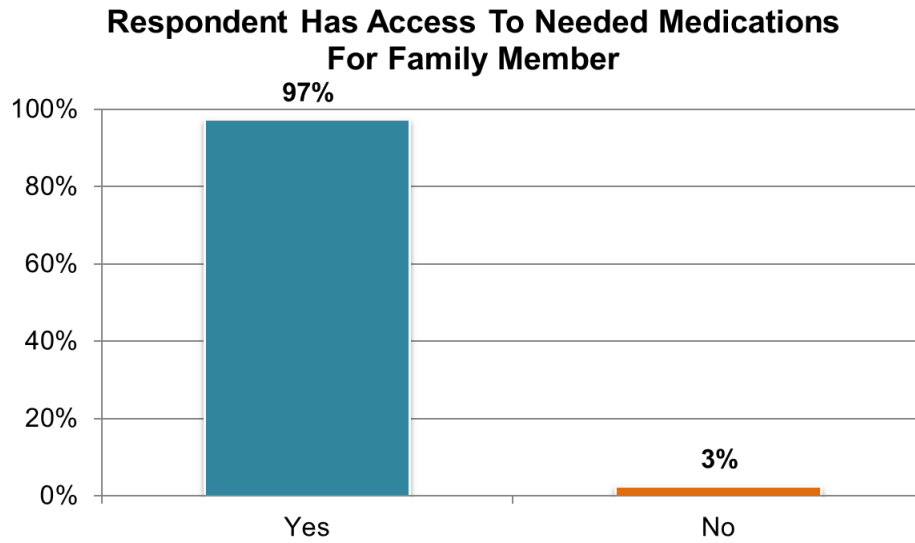


Table 60 Respondent has access to needed medications for family member

State	Yes	No	N
Significantly Above Average			
SD	100%	0%	107
NH	99%	1%	308
PA	99%	1%	287
OK	99%	1%	668
AZ	99%	1%	274
Within Average Range			
WA	98%	2%	324
NC	98%	2%	259
HI	98%	2%	556
FL	98%	2%	336
LA	98%	2%	370
CT	98%	2%	282
MD	97%	3%	410
MI	97%	3%	273
Significantly Below Average			
GA	88%	12%	452
NCI Average	97%	3%	4,906

Q36. If “yes” (to Q35), are you satisfied with how your family member’s medication needs are monitored?

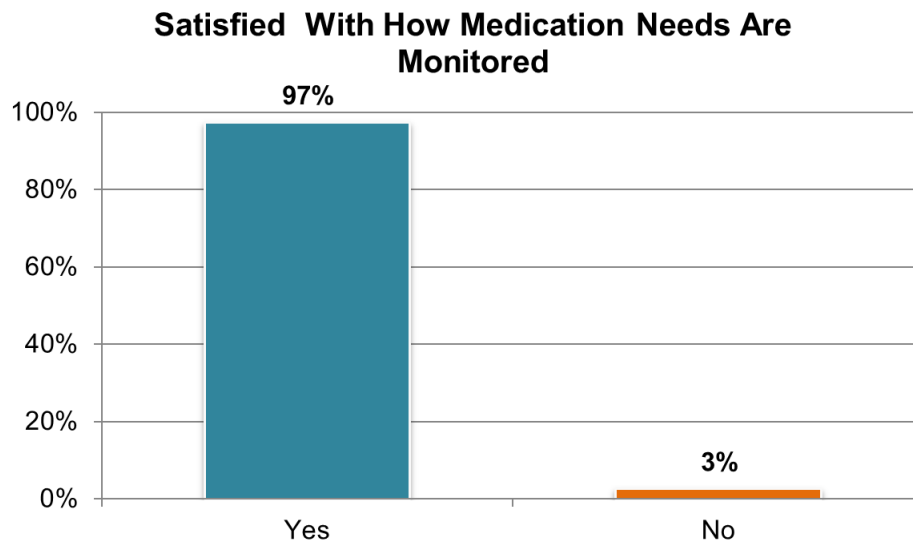


Table 61 Satisfied with how medication needs are monitored

State	Yes	No	N
Significantly Above Average			
PA	99%	1%	264
NH	99%	1%	286
LA	99%	1%	339
Within Average Range			
OK	99%	1%	635
MI	98%	2%	251
SD	98%	2%	100
NC	98%	2%	232
CT	98%	2%	244
WA	97%	3%	297
HI	97%	3%	495
MD	97%	3%	352
FL	97%	3%	304
AZ	95%	5%	249
Significantly Below Average			
GA	91%	9%	339
NCI Average	97%	3%	4,387

Q37. If applicable, do you have access to mental health services for your family member?

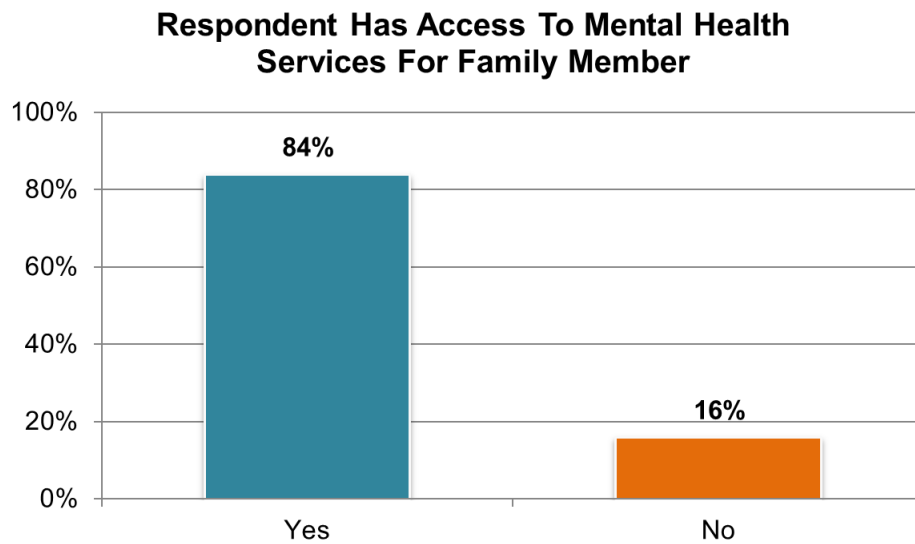


Table 62 Respondent has access to mental health services for family member

State	Yes	No	N
Significantly Above Average			
SD	95%	5%	58
MI	94%	6%	194
NH	93%	7%	137
Within Average Range			
PA	89%	11%	147
AZ	86%	14%	136
OK	85%	15%	284
MD	83%	17%	221
NC	83%	17%	144
CT	82%	18%	129
WA	81%	19%	142
HI	79%	21%	310
LA	77%	23%	167
FL	76%	24%	148
Significantly Below Average			
GA	72%	28%	330
NCI Average	84%	16%	2,547

Q38. If “yes” (Q37), are you satisfied with the quality of these providers?

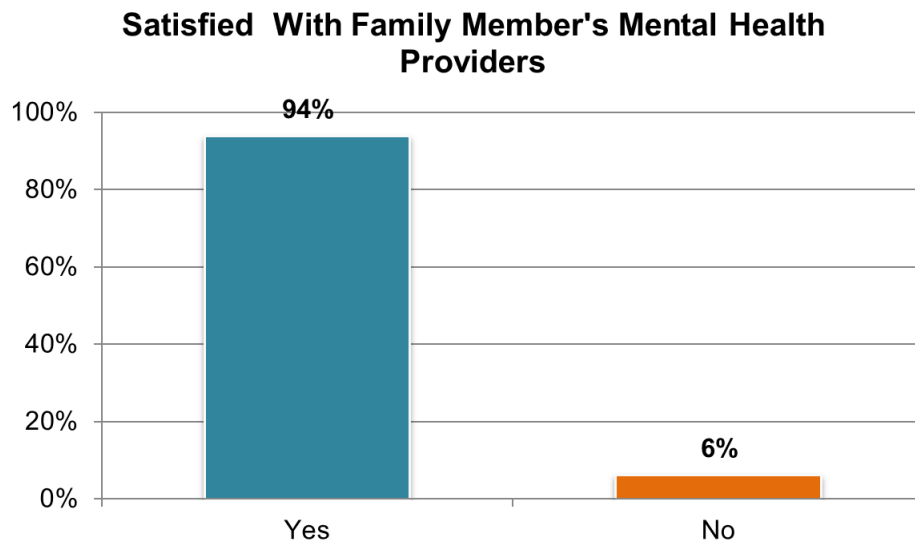


Table 63 Satisfied with family member's mental health providers

State	Yes	No	N
Significantly Above Average			
NC	98%	2%	108
MI	98%	2%	161
Within Average Range			
OK	97%	3%	208
FL	96%	4%	97
HI	96%	4%	210
PA	95%	5%	119
MD	95%	5%	150
SD	94%	6%	49
NH	94%	6%	111
CT	93%	7%	98
LA	92%	8%	119
AZ	90%	10%	103
GA	90%	10%	212
WA	87%	13%	95
NCI Average	94%	6%	1,840

Q39. If applicable, do you have access to quality respite services for your family?

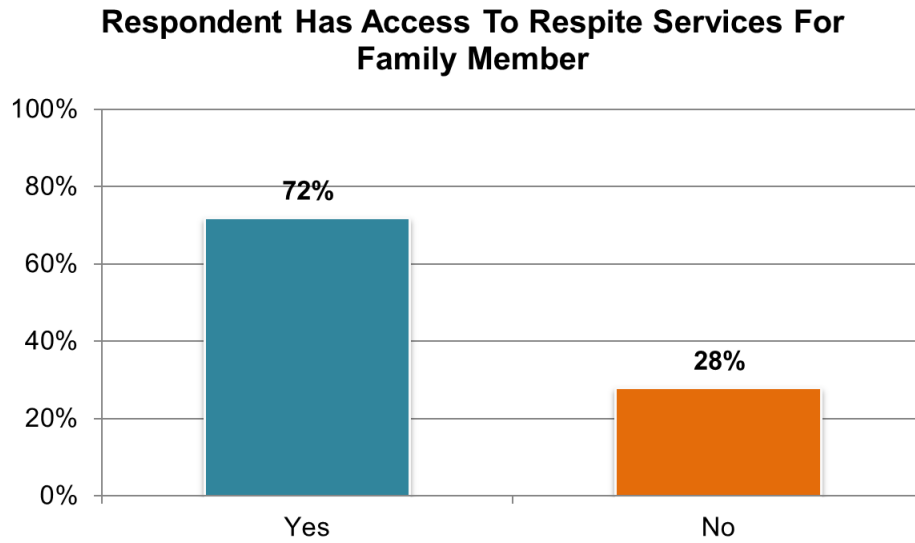


Table 64 Respondent has access to respite services for family member

State	Yes	No	N
Significantly Above Average			
AZ	95%	5%	255
NH	83%	17%	229
MI	81%	19%	190
Within Average Range			
LA	78%	22%	226
WA	77%	23%	227
FL	76%	24%	236
NC	73%	27%	193
HI	73%	27%	335
CT	72%	28%	177
PA	68%	32%	164
SD	64%	36%	56
Significantly Below Average			
GA	58%	42%	295
MD	57%	43%	215
OK	53%	47%	286
NCI Average	72%	28%	3,084

Q40. If “yes” (to Q39), are you satisfied with the quality of these providers?

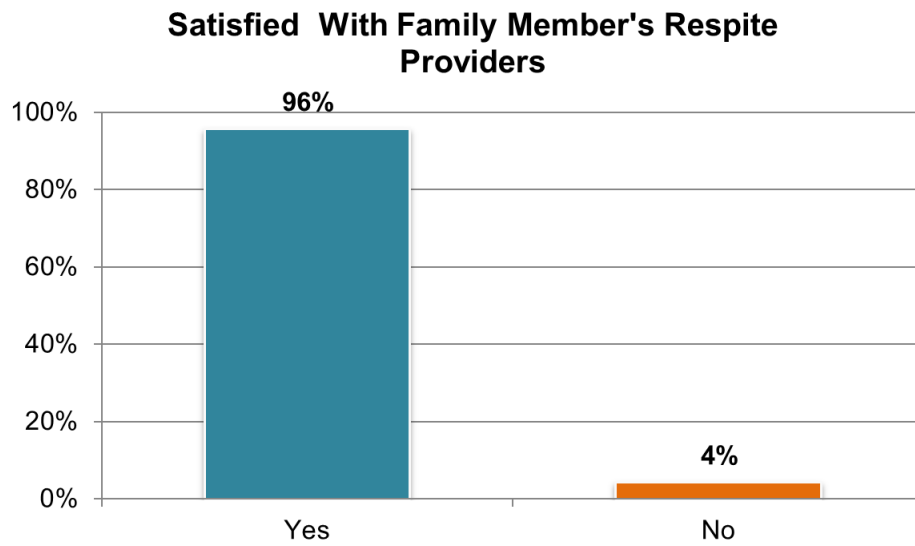


Table 65 Satisfied with family member's respite providers

State	Yes	No	N
Significantly Above Average			
OK	99%	1%	139
Within Average Range			
NC	98%	2%	121
MD	97%	3%	32
LA	97%	3%	158
HI	97%	3%	210
WA	96%	4%	151
FL	96%	4%	164
PA	96%	4%	103
GA	95%	5%	147
AZ	94%	6%	230
MI	94%	6%	65
CT	93%	7%	107
SD	93%	7%	30
NH	93%	7%	174
NCI Average	96%	4%	1,831

Q41. Are there other services that your family member needs that are not currently offered or available?*

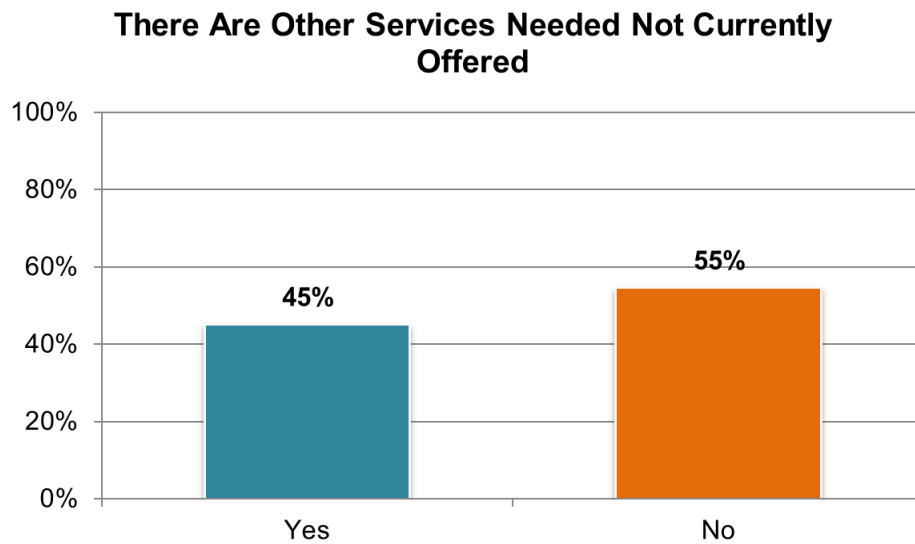


Table 66 There are other services needed not currently offered

State	Yes	No	N
Significantly Above Average			
FL	56%	44%	241
Within Average Range			
NC	54%	46%	185
MD	52%	48%	302
CT	51%	49%	182
MI	46%	54%	173
GA	46%	54%	351
SD	46%	54%	65
LA	46%	54%	244
HI	43%	57%	307
WA	42%	58%	206
AZ	42%	58%	185
PA	40%	60%	180
Significantly Below Average			
OK	38%	62%	426
NH	31%	69%	219
NCI Average	45%	55%	3,266

*The yes response is the less desired response meaning there **are** other services needed.

Choice and Control

Just over half of respondents reported they always choose the family's provider agencies (54%; states ranged between 27%-79%) and 29% reported their family member made this choice (states ranged between 21%-46%). Thirty-seven percent (37%) reported they always choose the family's support workers (states ranged between 13%-58%) and 22% reported their family member made this choice (states ranged between 6%-35%). Twenty-one percent (21%) of respondents and 12% of family members chose their case manager/service coordinator.

Just under half (46%) of respondents reported they have input in hiring their support workers and 67% reported they want to have this control or input; 30% reported their family member has control or input in hiring their support workers and 44% reported their family member wants to have this control or input.

Of the 27% of respondents who reported they know how much money is spent by the ID/DD agency on their behalf of their family member, 38% have a say in how money is spent.

Twelve percent (12%) reported their family member knows how much money is spent by the ID/DD agency on their behalf, and of those, 25% reported their family member has a say in how the money is spent. The majority of respondents who reported they or their family member decide how ID/DD agency money is spent, reported they and their family member receive enough information to make this decision (86% and 87%, respectively).

Q42. Do you choose the provider agencies who work with your family?

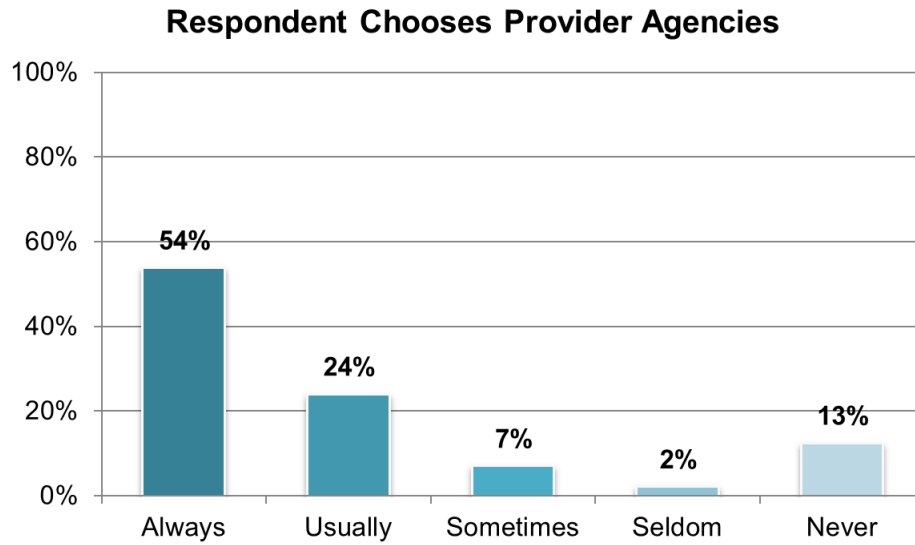


Table 67 Respondent chooses provider agencies

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	79%	12%	3%	1%	4%	369
NH	67%	22%	3%	1%	7%	293
OK	66%	18%	5%	2%	9%	573
Within Average Range						
NC	60%	24%	6%	2%	8%	248
HI	58%	27%	6%	2%	7%	509
AZ	57%	23%	10%	1%	10%	273
FL	55%	22%	9%	2%	12%	344
MD	54%	29%	7%	1%	9%	406
WA	52%	31%	5%	2%	10%	279
PA	47%	31%	11%	1%	10%	245
MI	45%	26%	10%	2%	16%	260
Significantly Below Average						
CT	43%	32%	7%	2%	15%	257
GA	42%	20%	9%	5%	24%	445
SD	27%	22%	9%	5%	36%	74
NCI Average	54%	24%	7%	2%	13%	4,575

Q43. Does your family member choose the provider agencies who work with your family?

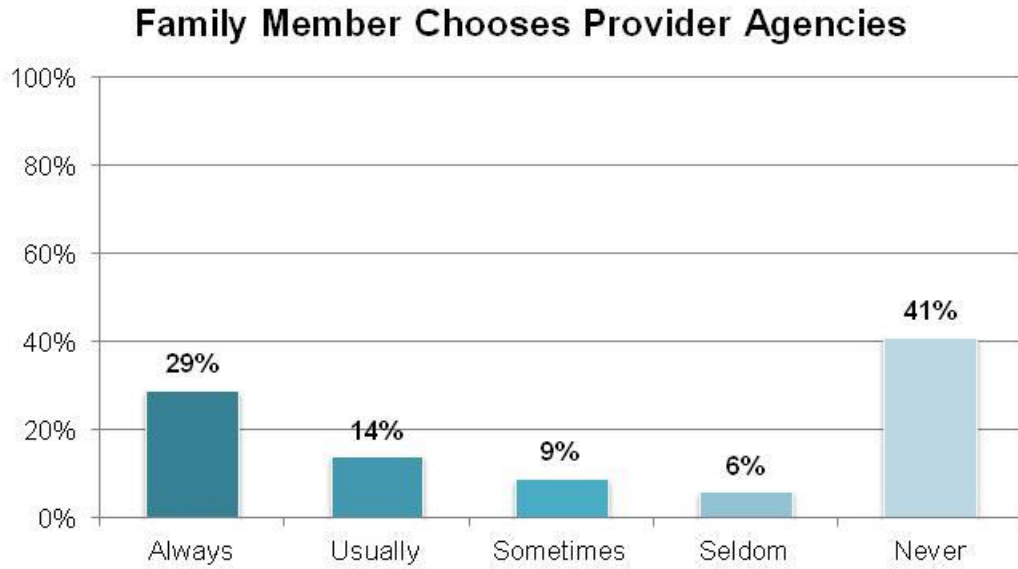


Table 68 Family member chooses provider agencies

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	46%	9%	4%	4%	38%	312
OK	39%	15%	8%	7%	32%	522
HI	38%	18%	9%	6%	29%	455
Within Average Range						
FL	33%	15%	10%	6%	36%	306
MD	30%	16%	10%	5%	38%	374
NH	30%	15%	12%	6%	38%	263
AZ	29%	15%	10%	6%	40%	251
CT	25%	16%	7%	5%	47%	218
MI	24%	13%	10%	10%	43%	240
WA	23%	16%	12%	5%	45%	256
PA	22%	16%	11%	5%	46%	241
NC	22%	12%	7%	6%	52%	219
SD	20%	11%	13%	12%	45%	76
Significantly Below Average						
GA	21%	12%	9%	7%	51%	420
NCI Average	29%	14%	9%	6%	41%	4,153

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

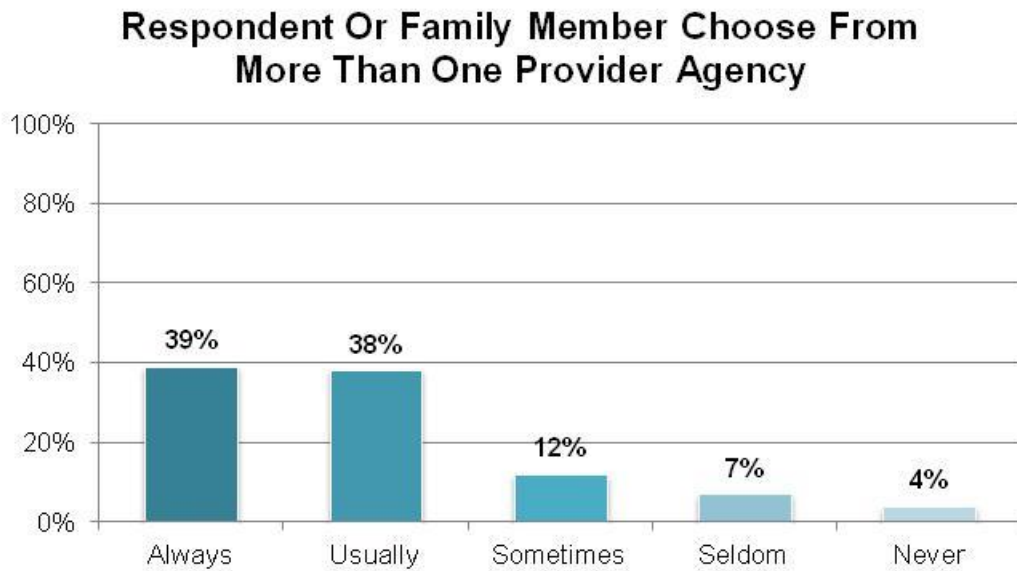


Table 69 Respondent or family member choose from more than one provider agency

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	71%	23%	3%	1%	3%	174
Within Average Range						
NH	47%	35%	8%	8%	3%	118
OK	45%	39%	8%	4%	5%	273
HI	44%	39%	9%	4%	4%	256
FL	42%	33%	16%	6%	3%	171
AZ	40%	41%	14%	3%	2%	119
NC	40%	36%	15%	3%	6%	86
MD	35%	40%	14%	8%	3%	191
MI	34%	43%	10%	10%	2%	90
SD	32%	43%	14%	7%	4%	28
WA	32%	40%	15%	8%	6%	123
GA	30%	34%	14%	9%	13%	143
PA	29%	45%	16%	4%	6%	89
CT	29%	41%	9%	17%	3%	86
NCI Average	39%	38%	12%	7%	4%	1,947

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

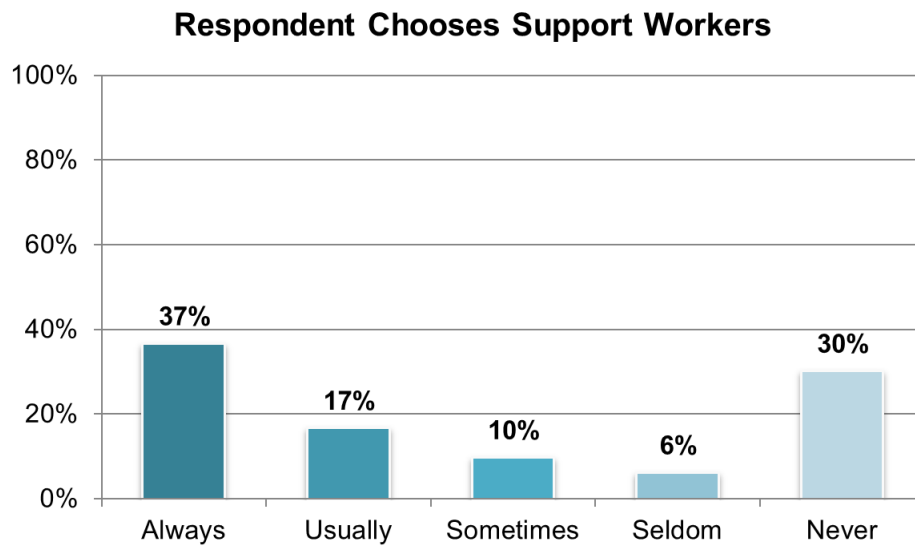


Table 70 Respondent chooses support workers

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	58%	16%	5%	4%	17%	344
OK	57%	17%	6%	4%	16%	587
FL	50%	20%	8%	3%	19%	315
Within Average Range						
WA	43%	22%	9%	5%	22%	253
NC	41%	25%	11%	6%	18%	234
HI	41%	22%	9%	7%	21%	460
AZ	41%	20%	11%	6%	22%	258
NH	39%	13%	13%	8%	27%	285
MI	33%	21%	8%	7%	31%	237
Significantly Below Average						
GA	27%	11%	8%	8%	46%	400
CT	27%	15%	10%	9%	38%	224
PA	26%	15%	14%	6%	39%	248
MD	17%	11%	12%	8%	52%	393
SD	13%	9%	14%	8%	58%	80
NCI Average	37%	17%	10%	6%	30%	4,318

Q46. Does your family member choose the individual support workers who work directly with your family?

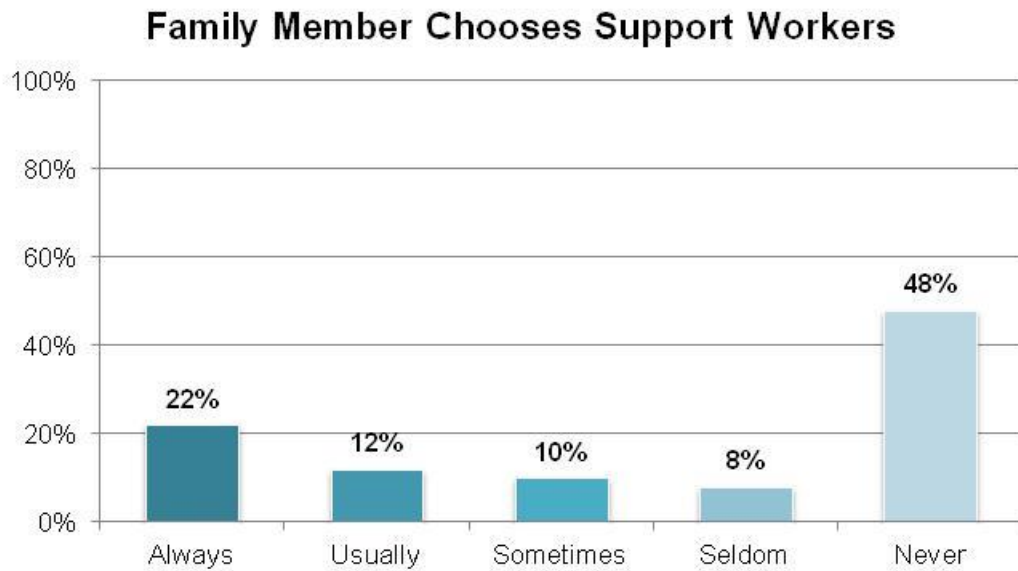


Table 71 Family member chooses support workers

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	35%	10%	7%	6%	42%	309
OK	33%	16%	9%	8%	34%	536
HI	32%	15%	10%	9%	34%	431
FL	32%	13%	10%	4%	42%	283
Within Average Range						
NH	25%	10%	15%	7%	44%	267
WA	24%	14%	15%	6%	41%	243
AZ	24%	13%	11%	7%	46%	245
MI	22%	14%	8%	8%	48%	225
NC	19%	17%	12%	10%	41%	211
GA	17%	10%	7%	9%	58%	387
Significantly Below Average						
PA	15%	10%	11%	8%	56%	236
CT	14%	14%	5%	9%	58%	211
MD	13%	8%	9%	7%	63%	380
SD	6%	10%	12%	10%	61%	77
NCI Average	22%	12%	10%	8%	48%	4,041

Q47. If you or your family member chose the individual support workers, are you satisfied with the options available?

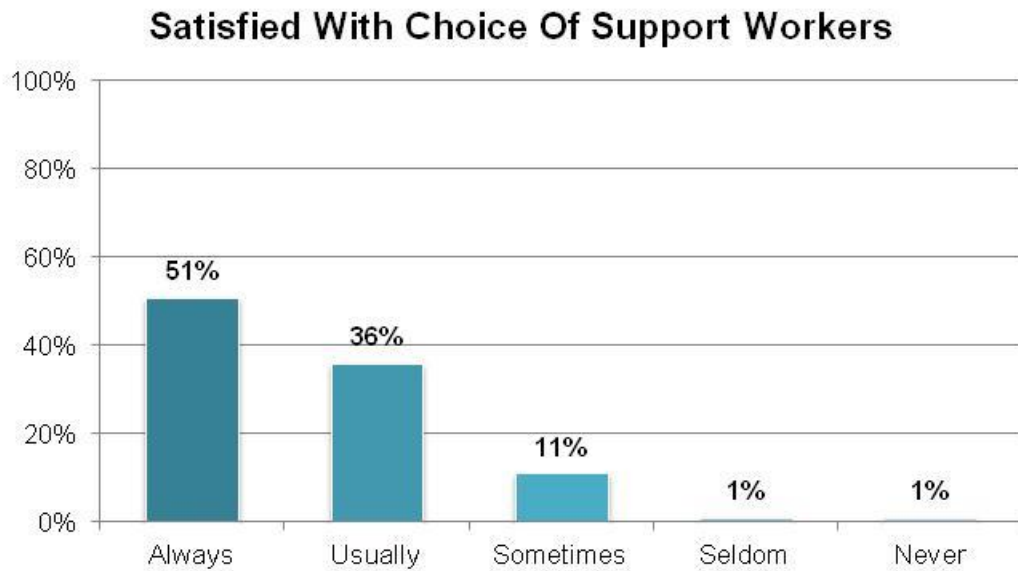


Table 72 Satisfied with choice of support workers

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	71%	18%	10%	1%	0%	164
OK	60%	28%	9%	3%	0%	318
Within Average Range						
AZ	56%	34%	7%	1%	2%	114
FL	56%	33%	7%	2%	2%	162
GA	55%	31%	11%	0%	2%	123
MI	55%	30%	13%	1%	1%	97
NH	54%	36%	8%	2%	0%	133
HI	53%	36%	10%	1%	1%	241
CT	49%	41%	7%	1%	3%	74
MD	43%	42%	13%	1%	1%	115
NC	43%	39%	14%	3%	1%	106
WA	41%	44%	12%	2%	2%	121
PA	40%	43%	18%	0%	0%	80
SD	40%	45%	15%	0%	0%	20
NCI Average	51%	36%	11%	1%	1%	1,868

Q48. Did you choose your family member's case manager/service coordinator?

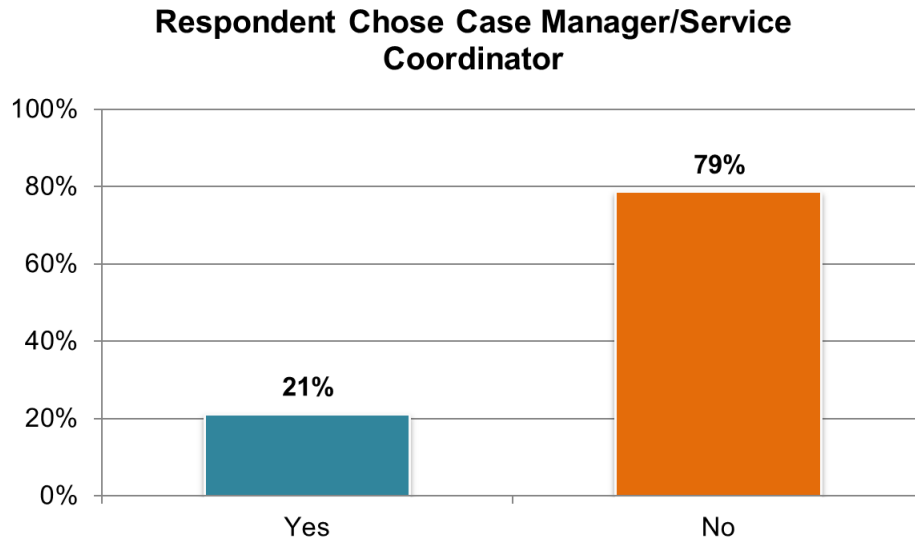


Table 73 Respondent chose case manager/service coordinator

State	Yes	No	N
Significantly Above Average			
FL	59%	41%	345
LA	47%	53%	362
NC	39%	61%	257
OK	29%	71%	487
Within Average Range			
MI	21%	79%	255
MD	16%	84%	441
Significantly Below Average			
PA	14%	86%	280
NH	14%	86%	336
GA	13%	87%	469
AZ	13%	87%	289
SD	11%	89%	101
HI	9%	91%	569
WA	8%	92%	341
CT	4%	96%	313
NCI Average	21%	79%	4,845

Q49. Did your family member choose his/her case manager/service coordinator?

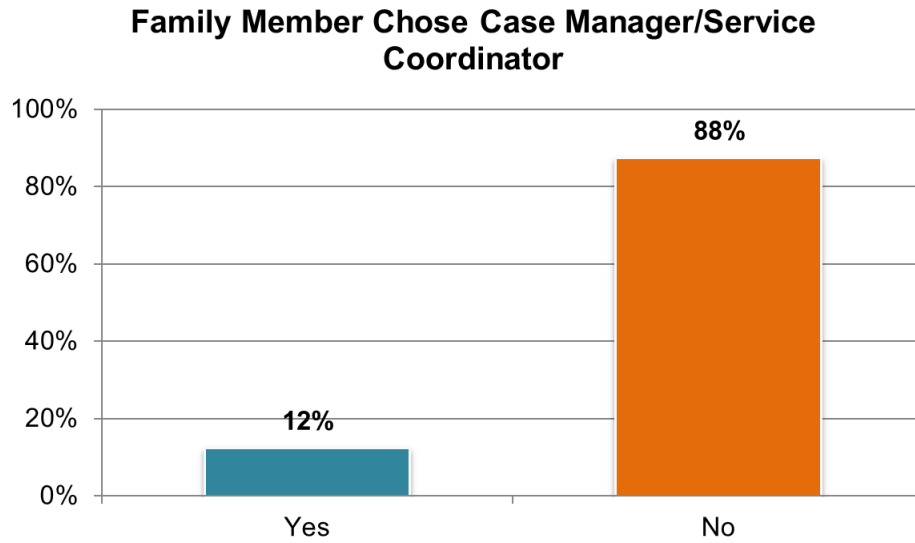


Table 74 Family member chose case manager/service coordinator

State	Yes	No	N
Significantly Above Average			
FL	33%	67%	326
LA	25%	75%	346
OK	21%	79%	455
Within Average Range			
NC	19%	81%	243
MI	13%	88%	248
MD	12%	88%	436
PA	10%	90%	270
GA	10%	90%	463
NH	8%	92%	333
SD	6%	94%	96
Significantly Below Average			
HI	7%	93%	552
AZ	6%	94%	270
WA	6%	94%	333
CT	1%	99%	302
NCI Average	12%	88%	4,673

Q50. Do you have control and/or input over the hiring and management of your family member's support workers?

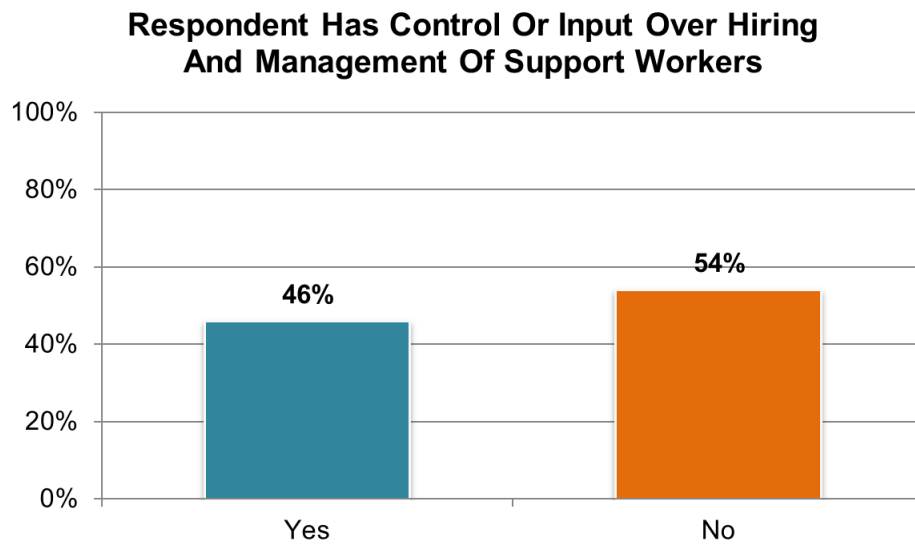


Table 75 Respondent has control or input over hiring and management of support workers

State	Yes	No	N
Significantly Above Average			
LA	69%	31%	328
OK	68%	32%	564
FL	65%	35%	313
NC	64%	36%	237
Within Average Range			
WA	53%	47%	260
NH	48%	52%	301
MI	46%	54%	214
AZ	44%	56%	248
HI	44%	56%	478
CT	38%	62%	259
Significantly Below Average			
PA	34%	66%	236
GA	27%	73%	430
MD	27%	73%	370
SD	15%	85%	86
NCI Average	46%	54%	4,324

Q51. Does your family member have control and/or input over the hiring and management of his/her support workers?

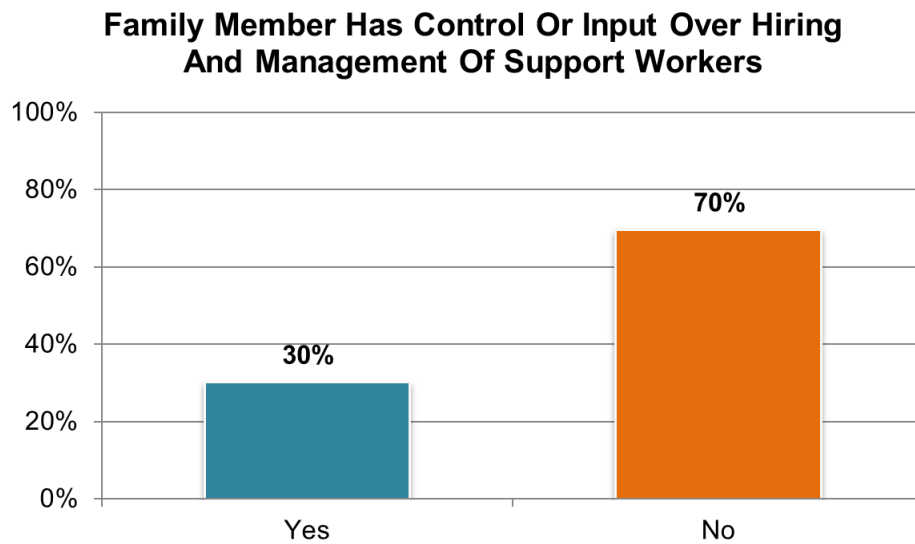


Table 76 Family member has control or input over hiring and management of support workers

State	Yes	No	N
Significantly Above Average			
OK	47%	53%	517
FL	44%	56%	295
LA	40%	60%	315
Within Average Range			
NH	37%	63%	288
NC	36%	64%	228
WA	35%	65%	255
HI	32%	68%	448
MI	27%	73%	211
AZ	27%	73%	243
CT	24%	76%	246
PA	22%	78%	224
Significantly Below Average			
GA	21%	79%	418
MD	20%	80%	353
SD	11%	89%	84
NCI Average	30%	70%	4,125

Q52. Do you want to have control and/or input over the hiring and management of your family member's support workers?

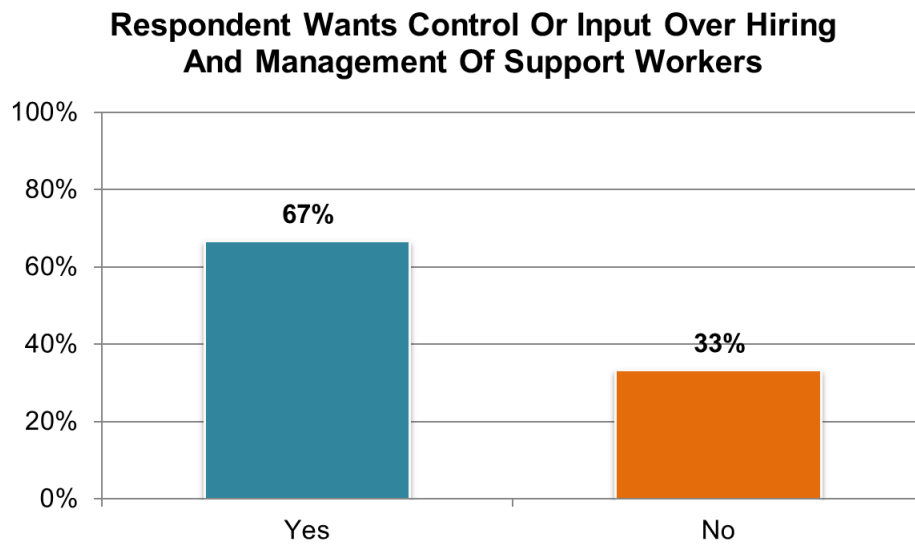


Table 77 Respondent wants control or input over hiring and management of support workers

State	Yes	No	N
Significantly Above Average			
NC	80%	20%	225
OK	80%	20%	538
LA	77%	23%	307
FL	75%	25%	283
Within Average Range			
WA	74%	26%	241
AZ	69%	31%	235
CT	68%	32%	222
HI	66%	34%	421
MI	65%	35%	196
NH	64%	36%	273
MD	64%	36%	333
PA	61%	39%	197
Significantly Below Average			
GA	47%	53%	382
SD	44%	56%	71
NCI Average	67%	33%	3,924

Q53. Does your family member want to have control and/or input over the hiring and management of your family member's support workers?

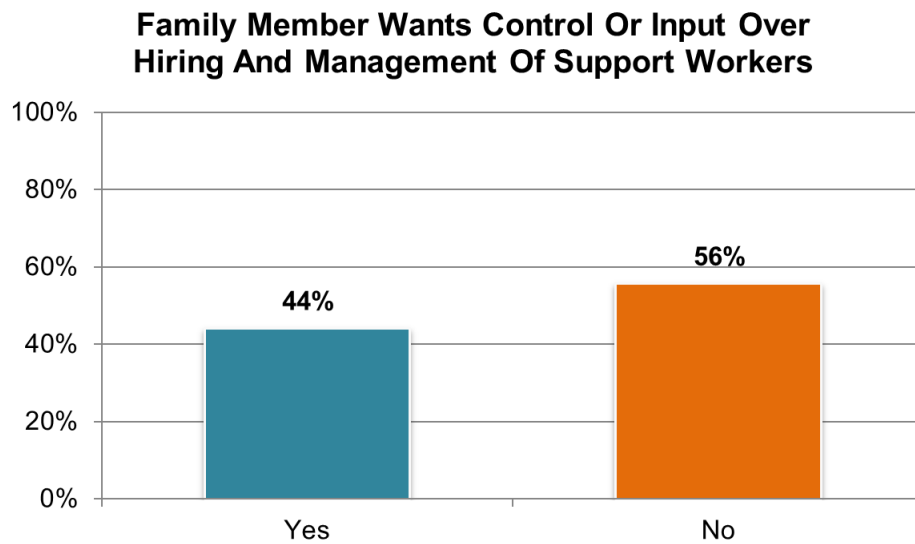


Table 78 Family member wants control or input over hiring and management of support workers

State	Yes	No	N
Significantly Above Average			
FL	54%	46%	256
HI	52%	48%	387
Within Average Range			
OK	50%	50%	471
LA	47%	53%	269
CT	47%	53%	197
NH	45%	55%	242
NC	45%	55%	198
MD	45%	55%	319
MI	43%	57%	180
WA	42%	58%	218
AZ	41%	59%	218
PA	41%	59%	180
Significantly Below Average			
GA	36%	64%	349
SD	30%	70%	63
NCI Average	44%	56%	3,547

Q54. Do you know how much money is spent by the ID/DD agency on behalf of your family member with a developmental disability?

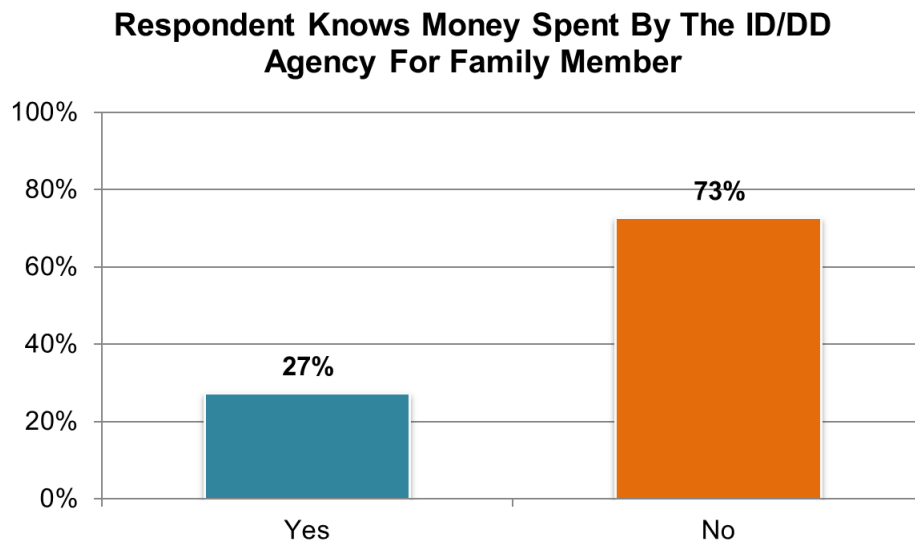


Table 79 Respondent knows money spent by the ID/DD agency for family member

State	Yes	No ⁴	N
Significantly Above Average			
FL	54%	46%	353
OK	52%	48%	676
NH	45%	55%	342
CT	39%	61%	310
Within Average Range			
PA	29%	71%	290
GA	28%	72%	485
MI	22%	78%	268
Significantly Below Average			
MD	20%	80%	450
LA	20%	80%	363
WA	19%	81%	356
HI	18%	82%	572
NC	18%	82%	262
AZ	11%	89%	295
SD	8%	92%	106
NCI Average	27%	73%	5,128

⁴ For this question, “don’t know” responses were included with the “no” responses.

Q55. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?

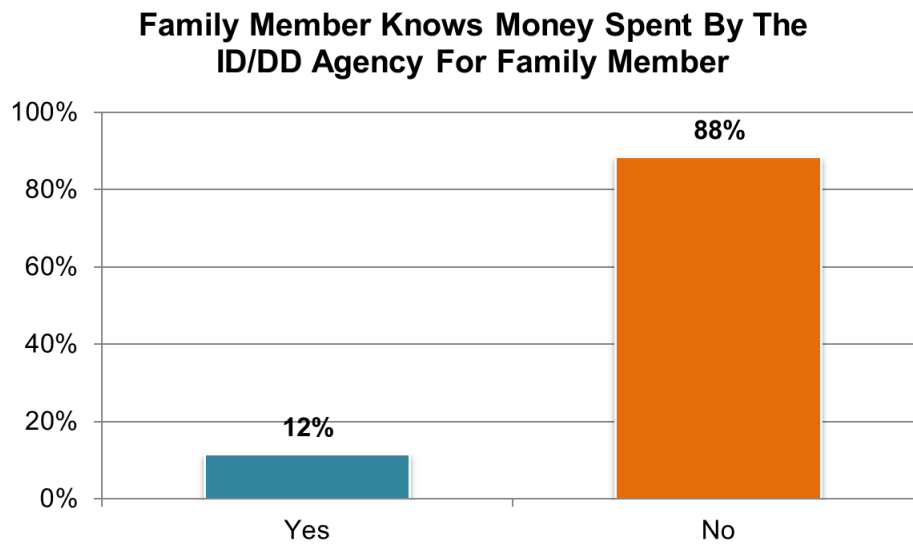


Table 80 Family member knows money spent by the ID/DD agency for family member

State	Yes	No ⁵	N
Significantly Above Average			
FL	26%	74%	317
OK	20%	80%	602
NH	20%	80%	317
Within Average Range			
GA	17%	83%	484
PA	13%	87%	278
CT	13%	87%	279
LA	10%	90%	342
HI	9%	91%	561
MI	8%	92%	261
Significantly Below Average			
MD	8%	92%	422
WA	7%	93%	329
AZ	4%	96%	283
NC	4%	96%	246
SD	2%	98%	102
NCI Average	12%	88%	4,823

⁵ For this question, “don’t know” responses were included with the “no” responses.

Q56. Do you have a say in how this money is spent?

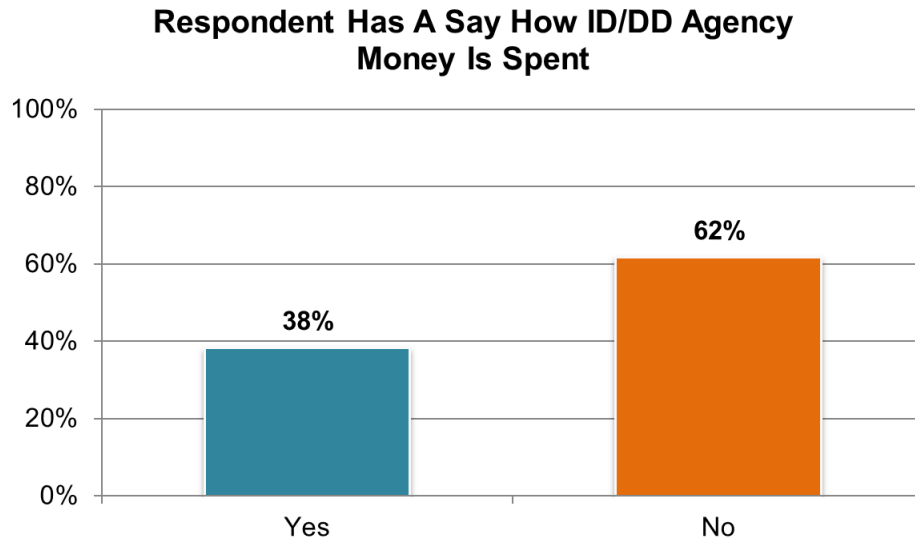


Table 81 Respondent has a say how ID/DD agency money is spent

State	Yes	No	N
Significantly Above Average			
OK	70%	30%	557
NH	57%	43%	301
FL	54%	46%	296
PA	52%	48%	211
WA	52%	48%	231
CT	49%	51%	247
Within Average Range			
GA	33%	67%	414
Significantly Below Average			
MI	29%	71%	198
NC	26%	74%	220
MD	25%	75%	365
HI	25%	75%	401
SD	23%	77%	78
AZ	21%	79%	220
LA	21%	79%	267
NCI Average	38%	62%	4,006

Q57. Does your family member have a say in how this money is spent?

Family Member Has A Say How ID/DD Agency Money Is Spent

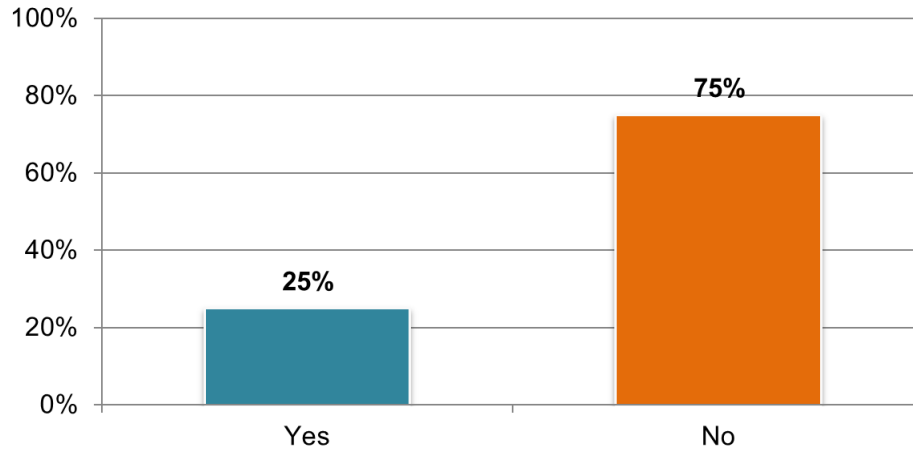


Table 82 Family member has a say how ID/DD agency money is spent

State	Yes	No	N
Significantly Above Average			
OK	43%	57%	509
NH	39%	61%	278
FL	37%	63%	276
Within Average Range			
WA	32%	68%	225
PA	30%	70%	215
CT	27%	73%	236
GA	24%	76%	404
MI	19%	81%	201
Significantly Below Average			
MD	19%	81%	355
HI	18%	82%	390
AZ	17%	83%	224
SD	16%	84%	81
LA	16%	84%	264
NC	12%	88%	206
NCI Average	25%	75%	3,864

Q58. If “yes” (to Q56), do you have all the information you need to make decisions about how to spend this money?

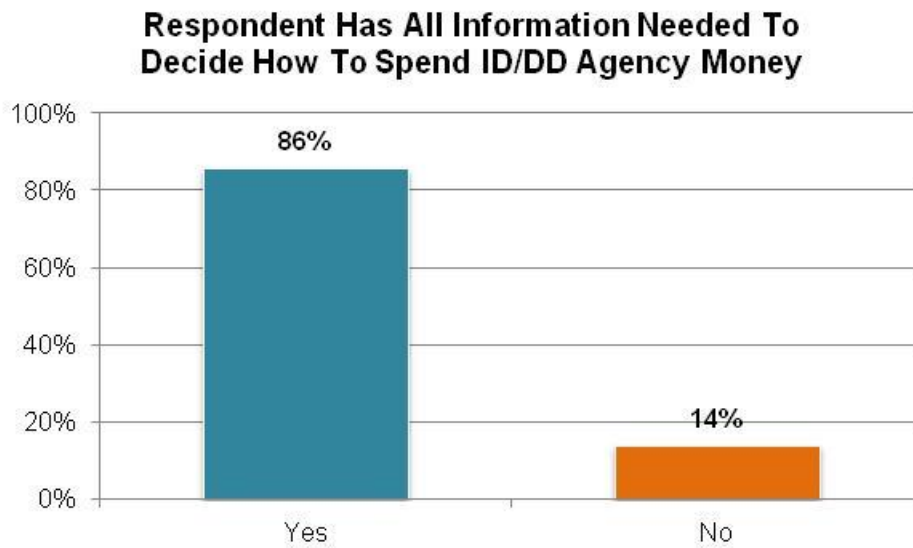


Table 83 Respondent has all information needed to decide how to spend ID/DD agency money

State	Yes	No	N
Within Average Range			
WA	94%	6%	88
OK	93%	7%	305
CT	91%	9%	91
FL	91%	9%	135
NH	90%	10%	148
HI	89%	11%	72
LA	89%	11%	45
PA	87%	13%	91
NC	82%	18%	44
AZ	82%	18%	38
MD	69%	31%	26
Significantly Below Average			
GA	70%	30%	91
NCI Average	86%	14%	1,174

Q59. If “yes” (to Q57), does your family member have all the information s/he needs to make decisions about how to spend this money?

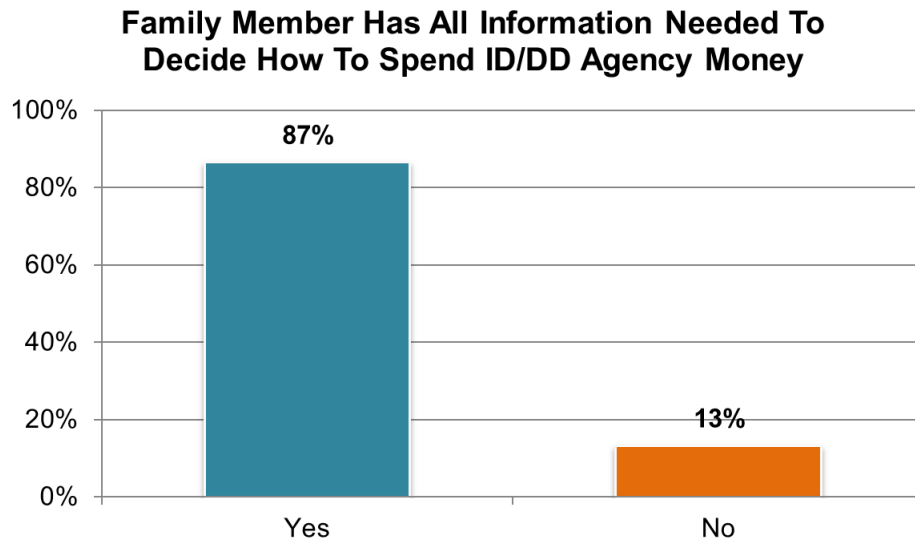


Table 84 Family member has all information needed to decide how to spend ID/DD agency money

State	Yes	No	N
Significantly Above Average			
OK	96%	4%	159
Within Average Range			
MI	95%	5%	21
FL	93%	7%	74
WA	91%	9%	56
LA	90%	10%	30
MD	89%	11%	36
HI	87%	13%	52
CT	83%	17%	60
NH	82%	18%	88
AZ	81%	19%	27
PA	79%	21%	52
GA	75%	25%	57
NCI Average	87%	13%	712

Community Connections

About three-quarters of respondents (74%) reported their family member participates in community activities. About four-fifths reported their family member has friends with people other than support workers or family (79%) and 63% reported their family member has support needed to work or volunteer in the community (states ranged between 55%-76%).

Q60. Does your family member participate in community activities?

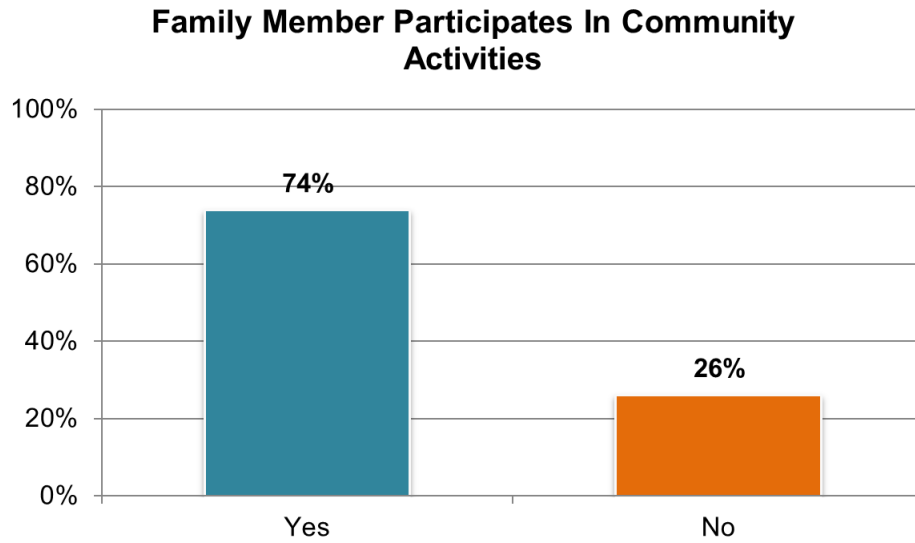


Table 85 Family member participates in community activities

State	Yes	No	N
Significantly Above Average			
NH	85%	15%	344
Within Average Range			
SD	82%	18%	107
GA	79%	21%	508
OK	78%	22%	670
NC	77%	23%	273
MI	77%	23%	275
HI	74%	26%	549
AZ	74%	26%	289
LA	72%	28%	383
PA	71%	29%	298
FL	69%	31%	343
WA	68%	32%	339
Significantly Below Average			
MD	66%	34%	436
CT	62%	38%	296
NCI Average	74%	26%	5,110

Q61. Does your family member have friends or relationships with persons other than paid support workers or family?

**Family Member Has Friends Or Relationships
With People Other Than Support Workers Or
Family**

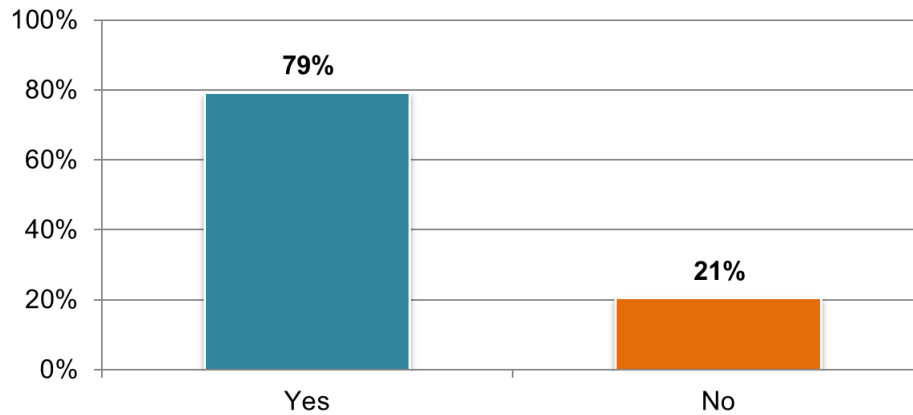


Table 86 Family member has friends or relationships with people other than support workers or family

State	Yes	No	N
Significantly Above Average			
OK	88%	12%	667
GA	84%	16%	500
Within Average Range			
SD	84%	16%	111
NH	83%	17%	344
NC	82%	18%	279
PA	80%	20%	293
MI	80%	20%	282
HI	79%	21%	549
LA	77%	23%	385
FL	77%	23%	344
WA	76%	24%	333
MD	74%	26%	444
AZ	74%	26%	292
CT	72%	28%	298
NCI Average	79%	21%	5,121

Q62. Does your family member have enough supports (e.g., support workers, community resources) to work or volunteer in the community?

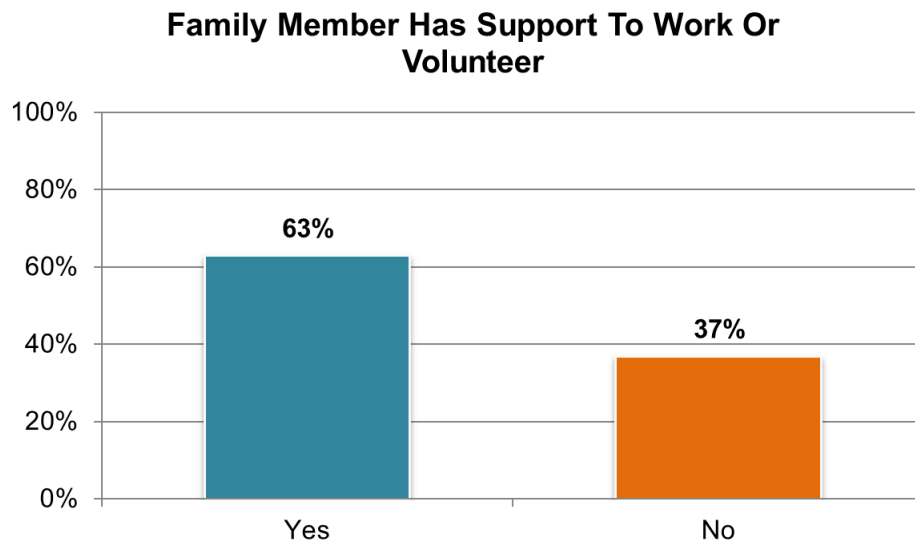


Table 87 Family member has support to work or volunteer

State	Yes	No	N
Significantly Above Average			
NH	76%	24%	283
Within Average Range			
OK	68%	32%	513
HI	68%	32%	440
MI	67%	33%	218
SD	66%	34%	88
PA	64%	36%	219
LA	61%	39%	275
NC	60%	40%	224
CT	60%	40%	239
MD	60%	40%	372
GA	60%	40%	392
WA	59%	41%	270
FL	56%	44%	250
AZ	55%	45%	220
NCI Average	63%	37%	4,003

Satisfaction with Services and Supports

Just over one-third of respondents reported they are always satisfied with the services and supports their family member receives (34%). Sixty percent (60%; states ranged between 34%-83%) reported they know how to file a complaint or grievance against their provider agency or staff and 81% reported they are satisfied how complaints or grievances are handled. Just over three-fourths reported they know how to report abuse or neglect (77%), and 5% did so in the past year. Of those who reported abuse or neglect in the past year, 78% reported the appropriate parties were responsive.

Q63. Overall, are you satisfied with the services and supports your family and family member currently receive?

Overall Satisfied With Services And Supports Family Member And Family Receives

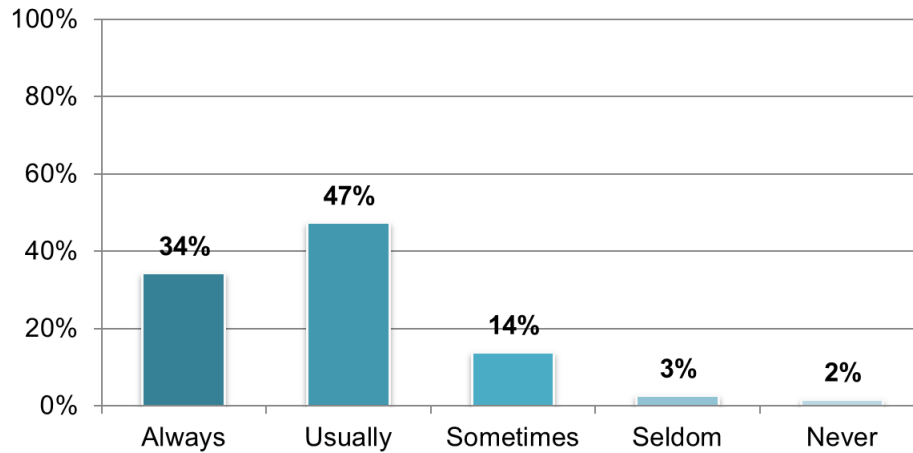


Table 88 Overall satisfied with services and supports family member and family receives

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	43%	42%	12%	2%	1%	379
HI	42%	45%	11%	2%	0%	577
Within Average Range						
NH	41%	48%	8%	2%	0%	345
OK	38%	50%	10%	1%	1%	678
FL	38%	46%	12%	3%	2%	352
AZ	36%	46%	17%	0%	1%	295
GA	36%	43%	16%	2%	3%	504
MI	34%	45%	15%	5%	1%	284
SD	31%	50%	18%	0%	1%	110
PA	30%	53%	11%	4%	1%	287
NC	29%	48%	15%	5%	3%	272
WA	28%	50%	16%	3%	3%	338
CT	27%	52%	15%	4%	2%	306
Significantly Below Average						
MD	28%	46%	18%	5%	3%	446
NCI Average	34%	47%	14%	3%	2%	5,173

Q64. Do you know the process for filing a complaint or grievance against provider agencies or staff?

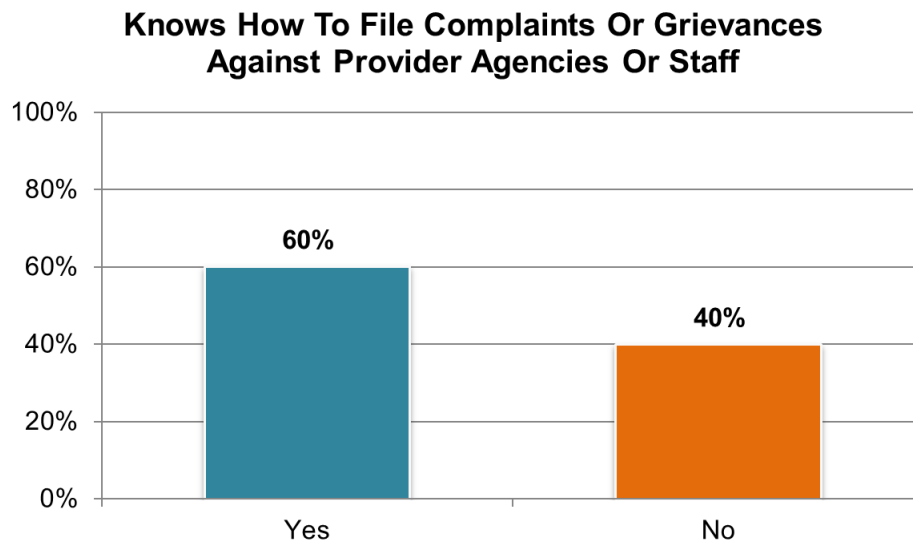


Table 89 Knows how to file complaints or grievances against provider agencies or staff

State	Yes	No ⁶	N
Significantly Above Average			
OK	83%	17%	672
LA	74%	26%	379
MI	72%	28%	279
SD	72%	28%	114
NH	71%	29%	337
FL	69%	31%	354
Within Average Range			
PA	62%	38%	291
WA	60%	40%	339
NC	59%	41%	272
AZ	52%	48%	291
Significantly Below Average			
HI	53%	47%	558
GA	41%	59%	504
CT	38%	62%	306
MD	34%	66%	444
NCI Average	60%	40%	5,140

⁶ For this question, “don’t know” responses were included with the “no” responses.

Q65. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

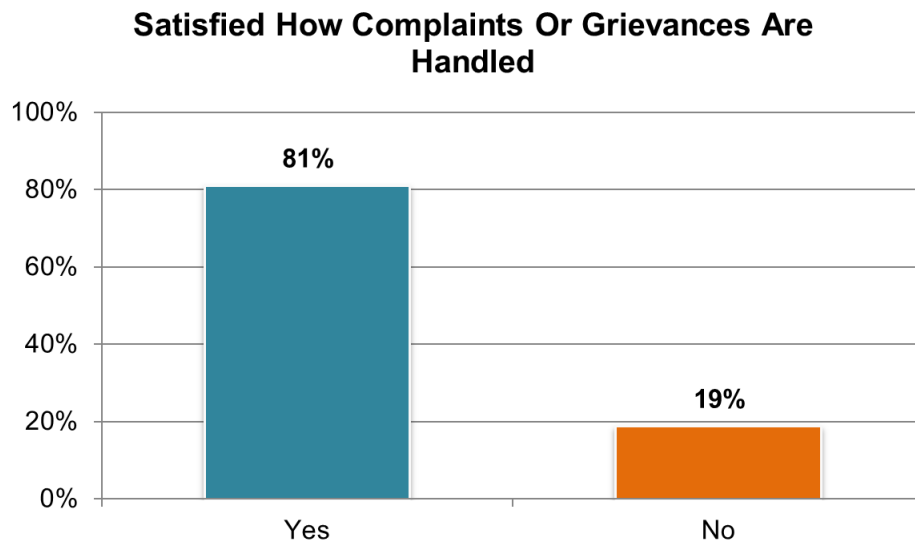


Table 90 Satisfied how complaints or grievances are handled

State	Yes	No	N
Significantly Above Average			
LA	92%	8%	179
FL	89%	11%	151
OK	88%	13%	328
Within Average Range			
SD	85%	15%	47
NH	85%	15%	138
PA	84%	16%	87
MI	83%	17%	114
HI	83%	17%	230
NC	79%	21%	116
AZ	78%	22%	112
WA	77%	23%	124
GA	75%	25%	233
MD	69%	31%	123
CT	67%	33%	85
NCI Average	81%	19%	2,067

Q66. Do you know how to report abuse or neglect?

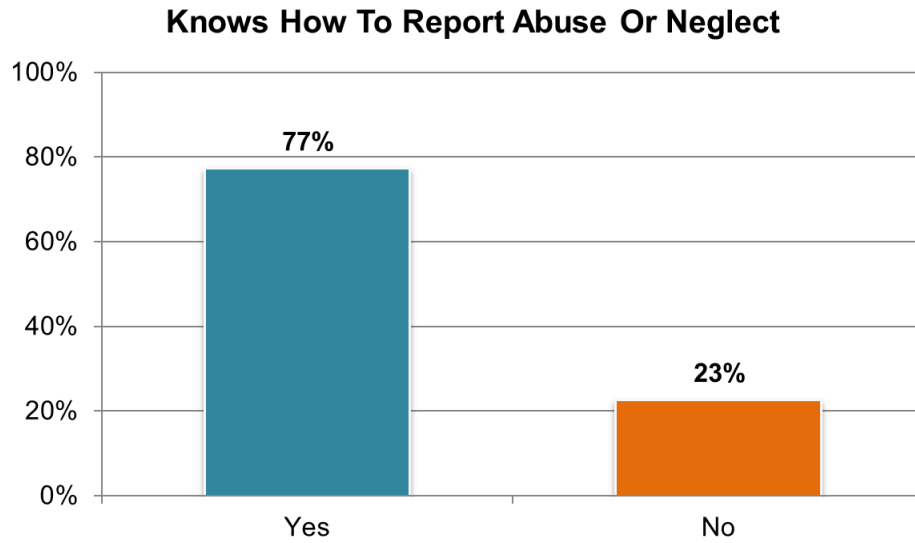


Table 91 Knows how to report abuse or neglect

State	Yes	No ⁷	N
Significantly Above Average			
OK	92%	8%	675
FL	86%	14%	354
NH	86%	14%	338
SD	86%	14%	112
LA	86%	14%	380
Within Average Range			
MI	83%	17%	270
WA	80%	20%	339
NC	77%	23%	272
PA	76%	24%	285
AZ	72%	28%	290
Significantly Below Average			
HI	70%	30%	555
GA	67%	33%	506
CT	64%	36%	294
MD	57%	43%	442
NCI Average	77%	23%	5,112

⁷ For this question, “don’t know” responses were included with the “no” responses.

Q67. In the past year, did you report abuse or neglect?

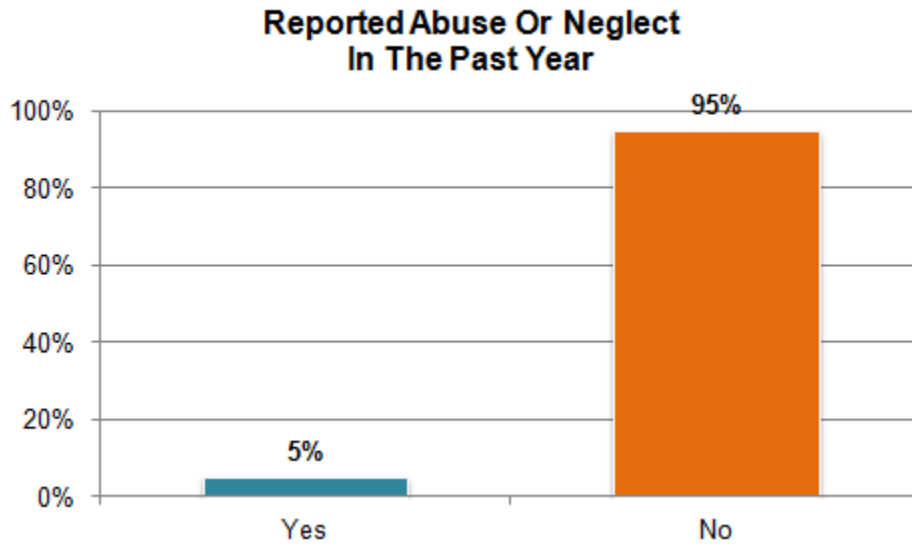


Table 92 Reported abuse or neglect (in past year)

State	Yes	No	N
Within Average Range			
HI	7%	93%	527
GA	6%	94%	489
NC	6%	94%	255
NH	5%	95%	327
MI	5%	95%	271
AZ	5%	95%	281
WA	5%	95%	321
LA	5%	95%	355
MD	4%	96%	425
OK	4%	96%	655
SD	4%	96%	103
CT	4%	96%	289
FL	3%	97%	337
Significantly Below Average			
PA	2%	98%	276
NCI Average	5%	95%	4,911

Q68. If “yes” (to Q67), were the appropriate people responsive to your report?

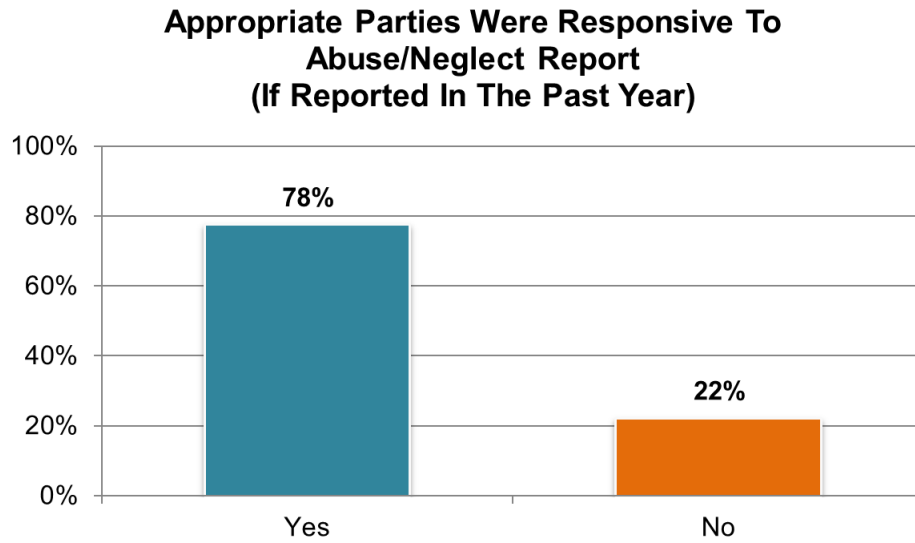


Table 93 Appropriate parties were responsive to abuse/neglect report (if reported in the past year)

State	Yes	No	N
Within Average Range			
OK	82%	18%	22
GA	76%	24%	21
HI	75%	25%	24
NCI Average	78%	22%	67

Outcomes

Most respondents reported services and supports made a positive difference in the life of their family (94%). A majority reported services and supports reduced out-of-pocket expenses (82%; states ranged between 75%-90%). One-third (33%) of respondents indicated services or supports were reduced, suspended, or terminated in the past year; of those, 68% reported service reduction affected their family member.

Q69. Do you feel that services and supports have made a positive difference in the life of your family?

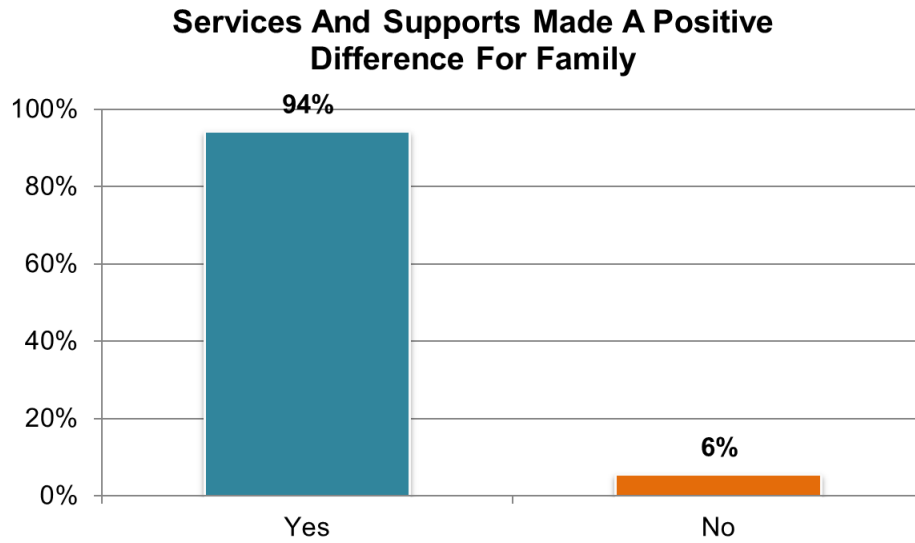


Table 94 Services and supports made a positive difference for family

State	Yes	No	N
Significantly Above Average			
NH	98%	2%	338
OK	98%	2%	658
HI	97%	3%	552
LA	97%	3%	370
Within Average Range			
AZ	96%	4%	281
SD	96%	4%	102
GA	94%	6%	488
FL	94%	6%	342
NC	93%	7%	243
PA	92%	8%	264
MI	92%	8%	263
MD	92%	8%	403
CT	91%	9%	279
WA	91%	9%	317
NCI Average	94%	6%	4,900

Q70. Do you feel that services and supports have reduced your family's out-of-pocket expenses related to your family member's care?

Services And Supports Reduced Out-Of-Pocket Expenses

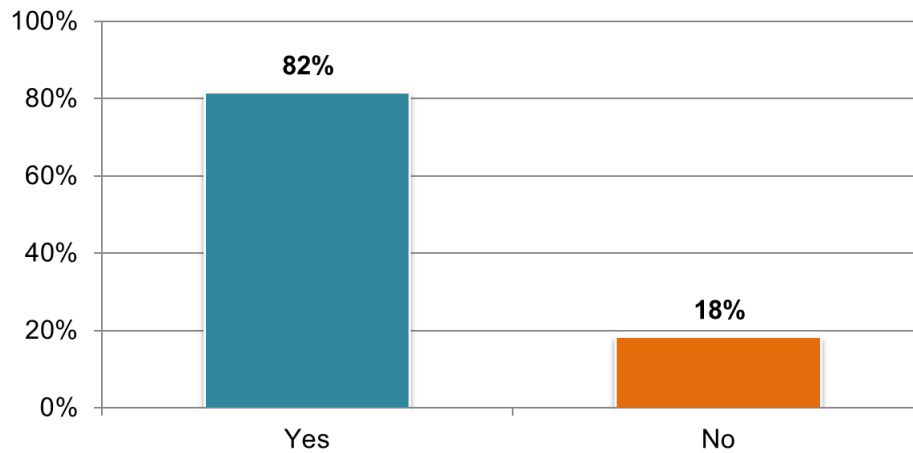


Table 95 Services and supports reduced out-of-pocket expenses

State	Yes	No	N
Significantly Above Average			
OK	90%	10%	646
AZ	88%	12%	260
Within Average Range			
NH	87%	13%	322
FL	85%	15%	328
HI	84%	16%	516
WA	82%	18%	303
LA	81%	19%	340
CT	81%	19%	286
MI	80%	20%	245
SD	79%	21%	86
GA	79%	21%	446
NC	78%	22%	249
PA	78%	22%	249
Significantly Below Average			
MD	75%	25%	401
NCI Average	82%	18%	4,677

Q71. Do you feel that services and supports address the goals in your family member's service plan?

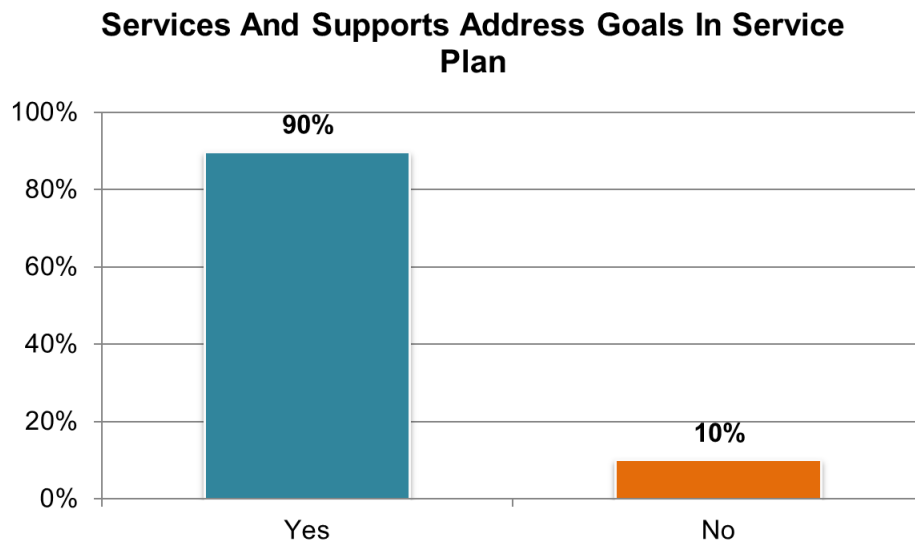


Table 96 Services and supports address goals in service plan

State	Yes	No	N
Significantly Above Average			
NH	95%	5%	327
HI	95%	5%	527
OK	94%	6%	636
Within Average Range			
AZ	93%	7%	267
LA	92%	8%	345
SD	92%	8%	89
MI	90%	10%	251
FL	88%	12%	330
GA	88%	12%	443
PA	87%	13%	247
WA	87%	13%	269
NC	86%	14%	229
CT	86%	14%	255
MD	85%	15%	372
NCI Average	90%	10%	4,587

Q72. Have services made a difference in helping keep your family member at home?

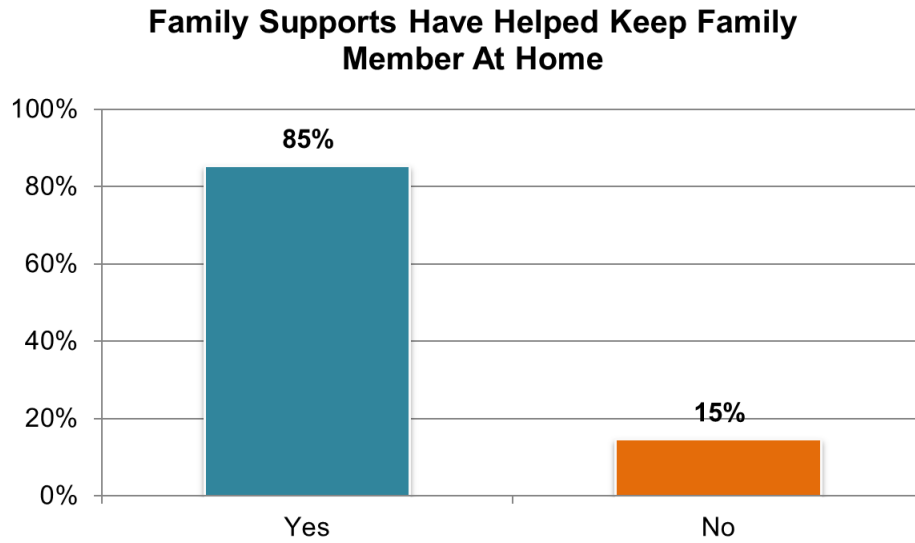


Table 97 Family supports have helped keep family member at home

State	Yes	No	N
Significantly Above Average			
OK	93%	8%	640
HI	92%	8%	484
LA	90%	10%	342
Within Average Range			
NH	89%	11%	305
FL	88%	12%	312
NC	87%	13%	230
WA	87%	13%	313
MI	86%	14%	252
GA	85%	15%	427
AZ	84%	16%	267
CT	82%	18%	257
PA	79%	21%	247
SD	76%	24%	91
Significantly Below Average			
MD	78%	22%	354
NCI Average	85%	15%	4,521

Q73. Have the services or supports that you or your family member received during the past year been either reduced, suspended, or terminated?*

**Services Or Supports Have Been Reduced,
Suspended Or Terminated
(Past Year)**

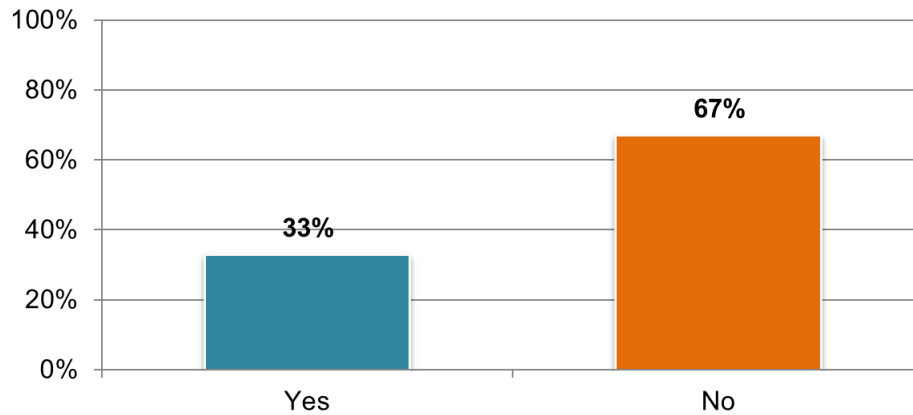


Table 98 Services or supports have been reduced, suspended or terminated (past year)

State	Yes	No	N
Significantly Above Average			
FL	70%	30%	316
AZ	61%	39%	286
WA	59%	41%	320
NC	45%	55%	234
Within Average Range			
LA	32%	68%	347
HI	31%	69%	505
CT	26%	74%	263
Significantly Below Average			
GA	25%	75%	440
PA	23%	77%	246
NH	21%	79%	321
MI	20%	80%	261
OK	20%	80%	621
MD	13%	87%	389
SD	13%	88%	96
NCI Average	33%	67%	4,645

*The yes response is the less desired response meaning there **has been** a reduction in services.

Q74. If “yes” (to Q73), did the reduction/suspension/termination of these services or supports affect your family or your family member’s home, job, relationships, etc.?*

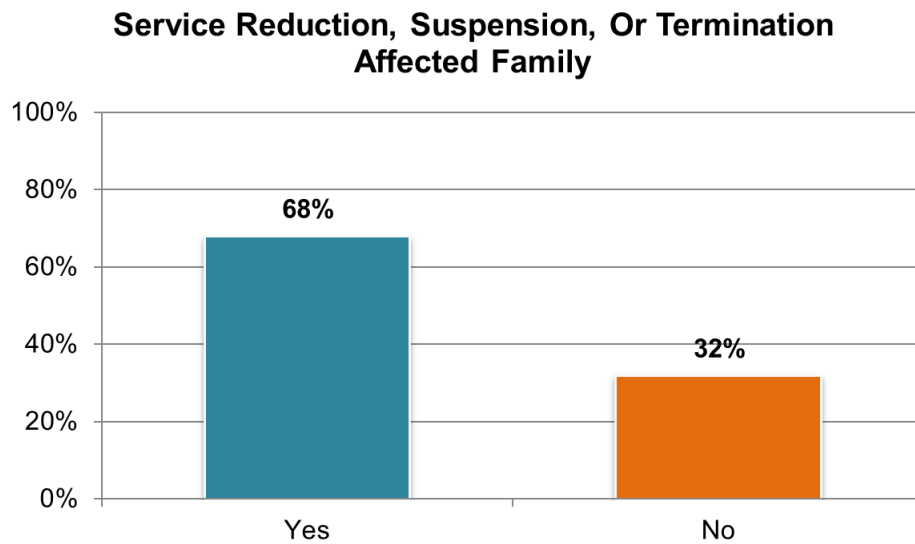


Table 99 Service reduction, suspension, or termination affected family

State	Yes	No	N
Within Average Range			
OK	74%	26%	107
WA	73%	27%	162
NC	72%	28%	83
FL	72%	28%	194
HI	71%	29%	136
LA	70%	30%	96
CT	69%	31%	49
MI	67%	33%	46
AZ	66%	34%	149
MD	64%	36%	42
GA	59%	41%	94
PA	58%	42%	38
NCI Average	68%	32%	1,196

*The yes response is the less desired response meaning reduction in services has affected the family.