
Family/Guardian 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

Ten (10) states submitted a valid sample of the National Core Indicators (NCI) Family/Guardian Survey during the 2011-2012 project year for analysis. The Family/Guardian Survey was administered to families who have an adult family member with disabilities living outside of 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. Family/Guardian 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

Family/Guardian 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 Family/Guardian Survey – Sub-Domains	5
How NCI Data are Used.....	5
Data Limitations	6
 II. Family/Guardian Survey	7
Survey Development	8
Table 2. State Participation in NCI Family/Guardian Survey (adult not living 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. Family/Guardian Survey - state response rates	12
IV. Results	13
Presentation of Data	14
Demographics: Individual	15
Table 1 Residence of Individual.....	16
Table 2 Age of Individual.....	16
Table 3 Gender of Individual.....	17
Table 4 Race of Individual	17
Table 5 Type of Disability Individual.....	18
Table 6 Primary Means of Expression of Individual.....	19
Table 7 Primary Language of Individual.....	20
Table 8 Highest Level of Education of Individual	20
Table 9 Typical Day Activity of Individual	21
Table 10 Frequency of Medical Care Needed for Individual.....	22
Table 11 Amount of Behavioral Support Needed for Individual.....	23
Table 12 Amount of Help Needed for Daily Activities for Individual.....	23
Demographics: Respondents.....	24
Table 13 Age of Respondent.....	25
Table 14 Relationship to Individual.....	26
Table 15 Respondent is Individual's Legal Guardian	27
Table 16 Number of Times Respondent Sees Individual in a Year	27
Table 17 Highest Education Level of Respondent	28
Table 18 Last Year Total Taxable Income	29

Table 19 Last Year Total Out-of-Pocket Expenses.....	29
Services and Supports Received	30
Table 20 Services and Supports Received.....	30
Family/Guardian Survey Results.....	31
Information and Planning.....	32
Q1. Do you get enough information to help you participate in planning services for your family?	33
Table 21 Gets Enough Information To Help Plan Services	33
Q2. Is the information you receive easy to understand?	34
Table 22 Information About Services And Supports Is Easy To Understand	34
Q3. Is the case manager/service coordinator who assists your family with planning generally knowledgeable?	35
Table 23 Case Manager/Service Coordinator Is Generally Knowledgeable	35
Q4. Are you generally kept informed about how your family member is doing?	36
Table 24 Kept Informed About How Family Member Is Doing.....	36
Q5. If your family member has a service plan, did s/he help develop it?.....	37
Table 25 Family Member Helped Make Service Plan	37
Q6. If your family member has a service plan, did you or another family member help develop it?	38
Table 26 Respondent Or Other Family Member Helped Make Service Plan	38
Q7. If your family member has a service plan, does the plan include services and supports that are important to him/her?	39
Table 27 Service Plan Includes Services And Supports Important To Family Member	39
Q8. Does the service plan include all the services and supports your family member needs? ..	40
Table 28 Service Plan Includes Services And Supports Family Member Needs	40
Q9. 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?	41
Table 29 Discussed How To Handle Emergencies At Last Service Planning Meeting	41
Q10. Have you or your family member received information about his/her rights?	42
Table 30 Respondent Or Family Member Received Information About Rights	42

Access and Delivery of Services and Supports	43
Q11. Are you able to contact your family member’s support workers when you need to?	44
Table 31 Respondent Is Able To Contact Support Workers When Needed	44
Q12. Are you able to contact your family member’s case manager/service coordinator when you need to?	45
Table 32 Respondent Is Able To Contact Case Manager/Service Coordinator When Needed ..	45
Q13. Does your family member receive all of the services listed in the service plan?	46
Table 33 Family Member Receives All Services Listed In Service Plan	46
Q14. Are services and supports available within a reasonable distance from your family member’s home?.....	47
Table 34 Services And Supports Are Available Reasonably Close To Family Member's Home .	47
Q15. Do the services and supports change when your family member’s needs change?	48
Table 35 Services And Supports Change When Family Member's Needs Change	48
Q16. 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?.....	49
Table 36 Support Workers Can Communicate With Family Member (If Non-Verbal)	49
Q17. If English is your family member’s first language, do the support workers communicate with him/her effectively in his/her primary language?	50
Table 37 Support Workers Communicate Effectively With Family Member In Primary Language (If English)	50
Q18. If English is not your family member’s first language, are there support workers or translators available to speak with him/her in his/her preferred language?	51
Table 38 Support Workers Or Translators Are Available To Speak With Family Member In Preferred Language (If Not English)	51
Q19. Are services delivered to your family member in a way that is respectful to his/her culture(s)?	52
Table 39 Services Are Delivered In A Way That Is Respectful To Individual’s Culture	52
Q20. Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?	53
Table 40 Family Member Has Access To Special Equipment Or Accommodations Needed.....	53
Q21. Do the support workers have the right training to meet your family member’s needs? ..	54

Table 41 Support Workers Have The Right Training To Meet Family Member's Needs	54
Q22. Do you feel that your family member's residential setting is a healthy and safe environment?	55
Table 42 Family Member's Residential Setting Is Healthy And Safe	55
Q23. Do you feel that your family member's day/ employment setting is a healthy and safe environment?	56
Table 43 Family Member's Day Or Employment Setting Is Healthy And Safe	56
Q24. If your family member transitioned from school services to State funded services during the past year, were you happy with the transition process?	57
Table 44 Happy With Transition From School To State Funded Services (Past Year).....	57
Choice and Control.....	58
Q25. Does the agency providing residential services to your family member involve him/her in important decisions?	59
Table 45 Residential Service Agency Involves Family Member In Important Decisions	59
Q26. Does your family member choose the provider agencies that support him or her?	60
Table 46 Family Member Chooses Provider Agencies.....	60
Q27. If your family member chooses the provider agencies, does s/he have more than one choose from?	61
Table 47 Family Member Chose From More Than One Provider Agency	61
Q28. Does your family member choose the individual support workers who work directly with him/her?.....	62
Table 48 Family Member Chooses Support Workers	62
Q29. If your family member chooses the support workers, is s/he satisfied with the options available?	63
Table 49 Family Member Is Satisfied With Choice Of Support Workers	63
Q30. Did your family member choose his/her case manager/service coordinator?	64
Table 50 Family Member Chose Case Manager/Service Coordinator	64
Q31. Does your family member have control and/or input over the hiring and management of his/her support workers?	65
Table 51 Family Member Has Control Or Input Over Hiring And Management Of Support Workers	65

Q32. Does your family member want to have control and/or input over the hiring and management of his/her support workers?	66
Table 52 Family Member Wants Control Or Input Over Hiring And Management Of Support Workers	66
Q33. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?	67
Table 53 Family Member Knows Money Spent By The ID/DD Agency For Family Member	67
Q34. Does your family member have a say in how this money is spent?	68
Table 54 Family Member Has A Say How ID/DD Agency Money Is Spent.....	68
Q35. If “yes” (to Q34), does your family member have all the information s/he needs to make decisions about how to spend this money?	69
Table 55 Family Member Has All Information Needed To Decide How To Spend ID/DD Agency Money	69
Community Connections	70
Q36. Does your family member participate in community activities?	71
Table 56 Family Member Participates In Community Activities	71
Q37. Does your family member have friends or relationships with persons other than paid staff or other family members?	72
Table 57 Family Member Has Friends Or Relationships With People Other Than Support Workers Or Family	72
Q38. Does your family member have enough support (e.g., support workers, community resources) to work or volunteer in the community?	73
Table 58 Family Member Has Support To Work Or Volunteer	73
Satisfaction with Services and Supports	74
Q39. Overall, are you satisfied with the services and supports your family member currently receives?	75
Table 59 Overall Satisfied With Services And Supports Family Member Receives	75
Q40. Do you know the process for filing a complaint or grievance against your family member’s provider agencies or staff?	76
Table 60 Knows How To File Complaints Or Grievances Against Provider Agencies Or Staff ...	76
Q41. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?	77

Table 61 Satisfied How Complaints Or Grievances Are Handled	77
Q42. Do you know how to report abuse or neglect?	78
Table 62 Knows How To Report Abuse Or Neglect.....	78
Q43. In the past year, did you report abuse or neglect?	79
Table 63 Reported Abuse Or Neglect (Past Year)	79
Q44. If “yes” (to Q43), were the appropriate people responsive to your report?	80
Table 64 Appropriate Parties Were Responsive To Abuse/Neglect Report (If Reported In The Past Year)	80
Outcomes	81
Q45. Do you feel that services and supports have made a positive difference in the life of your family member?	82
Table 65 Services And Supports Made A Positive Difference In Family Member's Life	82
Q46. Do you feel that services and supports have reduced your family’s out-of-pocket expenses related to your family member’s care?	83
Table 66 Services And Supports Reduced Out-Of-Pocket Expenses	83
Q47. Do you feel that the services and supports received address the goals in your family member’s service plan?	84
Table 67 Services And Supports Address Goals In Service Plan	84
Q48. Have the services or supports that your family member received during the past year been either reduced, suspended, or terminated?*	85
Table 68 Services Or Supports Have Been Reduced, Suspended, Or Terminated (Past Year) ...	85
Q49. If “yes” (to Q48), did the reduction/suspension/termination of these services or supports affect your family member’s home, job, relationships, etc.?*	86
Table 69 Service Reduction, Suspension, Or Termination Affected Family Member	86

I. Introduction

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

Overview of National Core Indicators

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

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

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

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

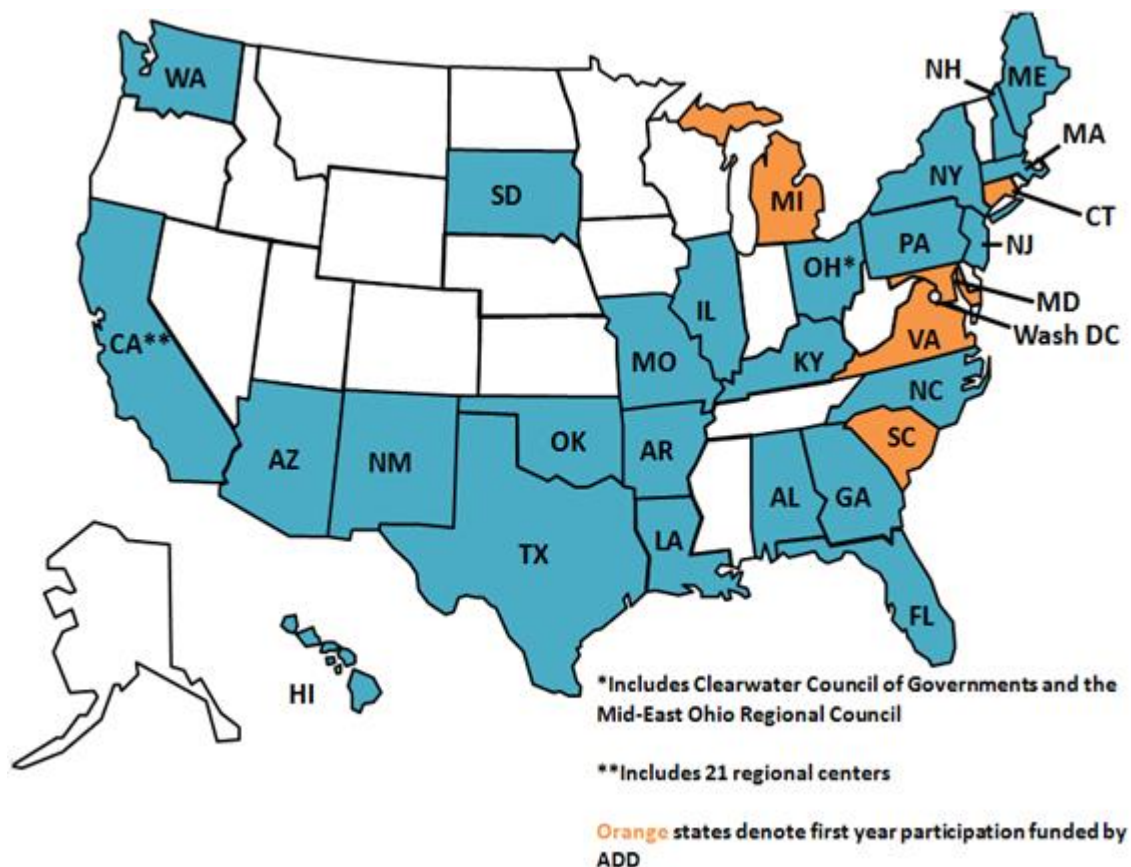
Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI has continued to develop and refine the indicators and expand state participation. For more information about NCI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

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

State Participation

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

Chart 1. NCI State Participation 2011-12



The Core Indicators

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

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

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

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

The data collection tools used to gather indicator data are 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 Family/Guardian Survey indicators.

Table I1. NCI Family/Guardian 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; and the states draw new samples each year rather than following the same group of individuals.

II. Family/Guardian Survey

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

Survey Development

The Family/Guardian Survey was developed and first utilized during Phase II of CIP (1999-2000), in response to various states' interest in determining whether families: were involved in the lives of their family member with a disability, had support to be involved, and were satisfied with the service system that was intended to meet the needs of their family member with disabilities. In this effort, seven states administered the Family/Guardian Survey.

As was mentioned previously, the Family/Guardian 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 Family/Guardian Survey (adult not living with family)

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
CT	AZ	CA-RCOC	AZ	AZ	AZ	CA-RCOC	AZ	CA-RCOC	AZ	GA	AZ	FL
KY	DE	HI	CA-RCOC	CA-RCOC	CA-RCOC	CT	CT	GA	CT	LA	FL	GA
MN	MA	NE	HI	CT	CT	GA	DE	LA	GA	ME	GA	HI
NE	MN	NC	IN	ME	HI	ME	GA	ME	IL	NH	KY	LA
NC	MA	PA	MA	NC	OK	NC	HI	MO	LA	PA	LA	MD
PA	MN	UT	NC	ND	PA	PA	ME	NC	ME	WA	MO	NC
VA	NC	WA	PA	PA	SC	SC	NM	NJ	MO		NC	NH
WA	PA		SC	SC	WY	SD	PA	PA	NC		NJ	PA
	RI		SD	WA		WA	WY	SC	OH		NM	SD
			WY	WY		WY		WA	PA		OH	WA
								WY	SC		PA	
									WY			

Organization of the Family Surveys

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

Demographics

The survey instrument begins with a series of questions relating to characteristics of the *individual* 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 their adult family member with a disability receives.

Questions Regarding Services and Supports

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

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 provides an opportunity for the respondent to make additional open-ended comments concerning the individual'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 Family/Guardian Survey by selecting a random sample of at least 1,000 families who:

1. Had an adult family member with a developmental disability living outside the 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 was asked to enter their survey responses into the Online Data Entry Survey Application (ODESA). A couple of states entered their data into their own data file and sent to HSRI. 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 in 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.

Response Rates

During 2011-2012, 10 states administered the Family/Guardian 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. Family/Guardian Survey - state response rates

State	Surveys Mailed	Surveys Returned	Response Rate (%)	Usable Surveys
FL	1,698	373	22%	360
GA	1,500	530	35%	480
HI	900	157	17%	157
LA	1,500	567	38%	535
MD	538	219	41%	213
NC	889	244	27%	219
NH	1,172	340	29%	279
PA	1,440	328	23%	303
SD	1,500	598	40%	549
WA	1,257	449	36%	435
Overall	12,328	3,805	31%	3,530

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

IV. Results

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

Note:

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

“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 data from the Family/Guardian Survey are presented in this report. Outcome results are presented in six sub-sections corresponding with the sections of the Family/Guardian 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 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 so that all states³ are listed in descending order and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, or 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 percentage of ‘always’ or ‘yes’ responses 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 individual receiving services.

About half (48%) of respondents reported the individual resided in a group home, 15% lived in a specialized institutional facility, 15% lived in their own home or apartment, 12% lived in adult foster care, 5% lived in an agency-owned apartment, 1% lived in a nursing home, and 4% lived in another setting.

Across states, a higher percentage of individuals were male (59%) compared to female (41%) and the average age of individuals was 45 years old. Three-quarters (76%) of respondents indicated the individual was White, 11% were Black/African American, 6% were Asian; 2% of respondents identified the individual as Hispanic/Latino.

The most common disabilities respondents listed the individual as having were: intellectual disability (80%), seizure disorder (25%), and mental illness (18%).

On average across states, two-thirds (67%) of respondents indicated the individual had less than a high school diploma or GED, and 29% reported the individual had a high school diploma or GED.

A majority of individuals required medical care less than once a month (63%), while 24% needed medical care at least once a month, and 14% required care at least once a week. The amount of help needed with daily activities was: 19% none, 22% little, 30% moderate, and 29% complete.

Residence

Table 1 Residence of Individual

State	Specialized Facility for Individuals with ID	Group Home	Agency-Owned Apartment	Independent Home or Apartment	Adult Foster Care or Host Home	Nursing Home	Other	N
FL	5%	70%	2%	20%	1%	0%	2%	337
GA	7%	54%	5%	17%	12%	0%	4%	475
HI	6%	29%	0%	6%	54%	0%	5%	155
LA	49%	37%	1%	11%	0%	0%	1%	529
MD	10%	76%	9%	3%	0%	0%	2%	211
NC	30%	56%	2%	3%	4%	1%	4%	215
NH	4%	23%	3%	29%	32%	0%	8%	269
PA	17%	54%	6%	13%	3%	4%	2%	298
SD	16%	49%	15%	16%	1%	0%	3%	543
WA	9%	29%	7%	36%	8%	1%	10%	420
NCI Average	15%	48%	5%	15%	12%	1%	4%	3,452

Age

Table 2 Age of Individual

State	Average Age	N
FL	42	332
GA	45	471
HI	48	150
LA	48	513
MD	36	210
NC	47	210
NH	46	273
PA	49	294
SD	45	533
WA	45	413
NCI Average	45	3,399

Gender

Table 3 Gender of Individual

State	Male	Female	N
FL	57%	43%	355
GA	55%	45%	472
HI	61%	39%	154
LA	56%	44%	530
MD	59%	41%	212
NC	66%	34%	218
NH	68%	32%	276
PA	55%	45%	303
SD	51%	49%	543
WA	57%	43%	423
NCI Average	59%	41%	3,486

Race

Table 4 Race of Individual

State	American Indian or Alaska Native	Asian	Black or African American	Native Hawaiian or Other Pacific Islander	White	Other or Unknown	Two or More Races	Hispanic or Latino	N
FL	0%	1%	14%	0%	76%	1%	3%	7%	359
GA	2%	0%	28%	0%	70%	0%	1%	0%	475
HI	2%	56%	1%	19%	25%	0%	21%	3%	156
LA	0%	0%	20%	0%	78%	0%	1%	0%	533
MD	1%	2%	20%	0%	74%	1%	2%	2%	211
NC	2%	0%	19%	0%	77%	1%	1%	1%	218
NH	1%	1%	1%	0%	96%	0%	1%	0%	275
PA	1%	0%	5%	0%	93%	0%	0%	1%	300
SD	10%	0%	1%	0%	89%	0%	1%	1%	547
WA	1%	3%	3%	1%	88%	0%	4%	2%	432
NCI Average	2%	6%	11%	2%	76%	0%	4%	2%	3,506

Type of Disability

Table 5 Type of Disability of Individual

State	ID	Mental Illness	ASD	Cerebral Palsy	Brain Injury	Limited or No Vision	Hearing Loss	Alzheimer's Disease or Other Dementia	Seizure Disorder	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Other
FL	82%	22%	21%	18%	9%	9%	4%	1%	27%	1%	11%	1%	16%
GA	83%	21%	18%	8%	8%	8%	7%	2%	26%	1%	12%	0%	15%
HI	78%	13%	10%	10%	8%	7%	5%	1%	22%	0%	21%	0%	12%
LA	85%	20%	13%	15%	11%	12%	9%	2%	34%	1%	7%	0%	21%
MD	63%	26%	35%	15%	13%	11%	8%	1%	28%	1%	12%	0%	28%
NC	86%	22%	18%	15%	11%	10%	9%	6%	29%	0%	11%	1%	16%
NH	70%	21%	17%	16%	20%	12%	8%	2%	29%	1%	13%	1%	19%
PA	85%	2%	3%	3%	0%	1%	0%	0%	1%	0%	4%	0%	1%
SD	81%	16%	12%	17%	10%	9%	10%	2%	27%	1%	15%	1%	17%
WA	82%	21%	17%	20%	10%	10%	5%	1%	25%	0%	10%	1%	19%
NCI Average	80%	18%	16%	14%	10%	9%	7%	2%	25%	1%	12%	1%	16%

Primary Means of Expression

Table 6 Primary Means of Expression of Individual

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
FL	68%	26%	0%	1%	5%	315
GA	69%	23%	2%	1%	5%	478
HI	61%	28%	3%	0%	8%	137
LA	52%	37%	1%	0%	10%	522
MD	69%	23%	3%	1%	5%	192
NC	66%	27%	0%	0%	7%	218
NH	70%	21%	3%	3%	3%	275
PA	66%	27%	2%	1%	4%	298
SD	67%	26%	1%	2%	4%	544
WA	80%	14%	2%	1%	4%	429
NCI Average	67%	25%	2%	1%	6%	3,408

Primary Language

Table 7 Primary Language of Individual

State	English	Spanish	Other	N
FL	94%	4%	2%	347
GA	97%	0%	3%	471
HI	93%	0%	7%	149
LA	93%	0%	7%	492
MD	95%	0%	4%	208
NC	97%	0%	2%	212
NH	98%	0%	2%	264
PA	97%	0%	2%	292
SD	97%	0%	3%	530
WA	97%	1%	2%	425
NCI Average	96%	1%	3%	3,390

Level of Education

Table 8 Highest Level of Education of Individual

State	Less Than High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree	N
FL	68%	30%	2%	0%	0%	315
GA	70%	26%	3%	0%	0%	423
HI	74%	24%	2%	1%	0%	129
LA	87%	12%	1%	0%	0%	424
MD	55%	38%	4%	2%	2%	194
NC	75%	20%	4%	1%	0%	197
NH	56%	39%	2%	4%	0%	240
PA	66%	31%	3%	0%	0%	277
SD	75%	24%	1%	0%	0%	483
WA	49%	48%	1%	1%	0%	412
NCI Average	67%	29%	2%	1%	0%	3,094

Typical Day Activity

Table 9 Typical Day Activity of Individual

State	Out-of-Home Program - unpaid	Out-of-Home 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
FL	23%	49%	8%	3%	8%	22%	5%	4%	7%	14%
GA	27%	49%	6%	3%	12%	13%	3%	5%	6%	9%
HI	31%	52%	12%	3%	6%	8%	1%	0%	2%	10%
LA	20%	23%	8%	2%	10%	20%	4%	2%	3%	32%
MD	38%	43%	8%	6%	12%	8%	2%	1%	1%	7%
NC	35%	26%	14%	9%	12%	11%	2%	1%	2%	28%
NH	29%	31%	3%	19%	18%	30%	9%	2%	6%	13%
PA	29%	29%	4%	3%	10%	7%	2%	2%	1%	13%
SD	24%	40%	14%	7%	17%	16%	6%	2%	3%	11%
WA	11%	16%	7%	13%	30%	31%	21%	8%	14%	18%
NCI Average	27%	36%	8%	7%	14%	16%	5%	3%	4%	15%

Frequency of Medical Care

Table 10 Frequency of Medical Care Needed for Individual

State	Less than Once a Month	At Least Once a Month, Less than Once a week	At Least Once a Week	N
FL	60%	31%	9%	347
GA	62%	28%	9%	458
HI	74%	21%	5%	145
LA	41%	24%	34%	449
MD	55%	32%	13%	196
NC	59%	20%	20%	211
NH	75%	15%	11%	260
PA	61%	22%	18%	282
SD	70%	19%	12%	528
WA	67%	24%	9%	416
NCI Average	63%	24%	14%	3,292

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

Table 11 Amount of Behavioral Support Needed for Individual

State	No Support Needed	Some Support Needed	Extensive Support Needed	N
FL	29%	44%	26%	352
GA	35%	40%	25%	457
HI	38%	42%	20%	149
LA	26%	33%	41%	510
MD	31%	44%	25%	202
NC	28%	52%	19%	208
NH	39%	44%	17%	267
PA	40%	38%	22%	292
SD	37%	44%	20%	520
WA	39%	44%	17%	421
NCI Average	34%	42%	23%	3,378

Help Needed with Daily Activities

Table 12 Amount of Help Needed for Daily Activities for Individual

State	None	Little	Moderate	Complete	N
FL	16%	21%	35%	27%	349
GA	25%	19%	29%	26%	474
HI	13%	23%	34%	30%	152
LA	15%	15%	24%	46%	525
MD	23%	22%	30%	25%	210
NC	17%	25%	29%	30%	215
NH	19%	24%	29%	28%	276
PA	22%	18%	30%	31%	298
SD	19%	25%	30%	26%	536
WA	18%	25%	35%	22%	419
NCI Average	19%	22%	30%	29%	3,454

Demographics: Respondents

This section provides information about survey respondents. Respondents are the individuals who completed the survey forms, not the individual receiving services.

Across states, the majority of respondents were between 55 and 74 years old (59%); 20% were 35-54 years old, 19% were 75 or older, and 2% were under 35. The majority of respondents were the parent of the individual (58%); the remaining respondents were siblings (27%) and others (16%). Over 60% (62%) were the legal guardian of the individual.

Respondent annual household incomes were: less than \$15,000 (19%), \$15,001 - \$25,000 (18%), \$25,001-\$50,000 (26%), \$50,001 - \$75,000 (16%), and over \$75,000 (21%). While just over half (53%) reported they did not spend out-of-pocket expenses on services and supports for the individual in the previous year, while 12% spent \$1-\$100, 22% spent \$101- \$1,000, 12% spent \$1,001- \$10,000, and 2% spent over \$10,000.

Age of Respondent

Table 13 Age of Respondent

State	Under 35	35-54	55-74	75 or Older	N
FL	4%	22%	59%	14%	345
GA	3%	20%	59%	18%	472
HI	4%	16%	51%	29%	155
LA	2%	19%	56%	24%	529
MD	2%	25%	60%	13%	211
NC	2%	23%	57%	18%	210
NH	1%	20%	61%	18%	276
PA	3%	15%	60%	23%	302
SD	1%	24%	59%	16%	537
WA	2%	15%	67%	16%	427
NCI Average	2%	20%	59%	19%	3,464

Relationship to Individual

Table 14 Relationship to Individual

State	Parent	Sibling	Spouse	Other	N
FL	58%	18%	0%	24%	355
GA	54%	26%	1%	19%	473
HI	53%	34%	0%	13%	154
LA	59%	29%	0%	11%	527
MD	76%	17%	0%	7%	212
NC	49%	25%	0%	26%	209
NH	64%	26%	1%	10%	278
PA	55%	38%	0%	7%	302
SD	51%	31%	0%	19%	544
WA	57%	23%	0%	20%	430
NCI Average	58%	27%	0%	16%	3,484

Respondent is Legal Guardian

Table 15 Respondent is Individual's Legal Guardian

State	Yes, full guardianship/ conservatorship	Yes, limited guardianship/ conservatorship	No	N
FL	63%	13%	24%	347
GA	43%	7%	50%	458
HI	84%	5%	11%	152
LA	58%	9%	33%	510
MD	42%	7%	50%	203
NC	77%	14%	9%	213
NH	78%	8%	14%	275
PA	39%	10%	50%	292
SD	85%	11%	4%	524
WA	49%	15%	37%	426
NCI Average	62%	10%	28%	3,400

Frequency of Visits Each Year

Table 16 Number of Times Respondent Sees Individual in a Year

State	Less than Once	1-3 times	4-6 times	7-12 times	More than 12	N
FL	3%	7%	11%	9%	70%	350
GA	7%	8%	13%	12%	60%	475
HI	8%	22%	14%	10%	46%	154
LA	7%	20%	17%	15%	41%	527
MD	3%	2%	9%	10%	76%	210
NC	3%	6%	12%	18%	61%	215
NH	5%	10%	12%	13%	61%	277
PA	7%	13%	13%	10%	57%	301
SD	4%	15%	10%	14%	57%	547
WA	4%	9%	9%	12%	66%	424
NCI Average	5%	11%	12%	12%	60%	3,480

Highest Education Level

Table 17 Highest Education Level of Respondent

State	Less Than High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree	N
FL	6%	23%	5%	29%	37%	343
GA	11%	25%	9%	23%	32%	469
HI	7%	23%	7%	19%	45%	148
LA	13%	26%	6%	21%	34%	527
MD	4%	22%	4%	23%	47%	209
NC	4%	23%	1%	26%	46%	215
NH	5%	31%	4%	20%	40%	276
PA	6%	32%	6%	18%	38%	299
SD	6%	33%	10%	18%	34%	544
WA	4%	17%	6%	28%	44%	422
NCI Average	7%	25%	6%	23%	40%	3,452

Income Level

Table 18 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
FL	26%	21%	23%	14%	15%	245
GA	34%	23%	22%	10%	11%	431
HI	8%	15%	26%	23%	28%	122
LA	28%	20%	23%	14%	15%	446
MD	13%	10%	22%	14%	42%	166
NC	17%	15%	30%	17%	22%	169
NH	16%	20%	24%	20%	20%	206
PA	21%	20%	26%	13%	21%	239
SD	17%	17%	33%	18%	15%	446
WA	13%	14%	27%	22%	24%	338
NCI Average	19%	18%	26%	16%	21%	2,808

Out-of-Pocket Expenses

Table 19 Last Year Total Out-of-Pocket Expenses

State	Nothing	\$1 - \$100	\$101 - \$1,000	\$1,001 - \$10, 000	Over \$10,000	N
FL	45%	10%	22%	20%	3%	320
GA	54%	12%	22%	11%	1%	460
HI	47%	14%	25%	13%	1%	141
LA	66%	9%	19%	6%	0%	496
MD	37%	13%	22%	22%	7%	197
NC	56%	12%	20%	10%	1%	202
NH	49%	8%	30%	12%	1%	266
PA	61%	9%	22%	8%	1%	287
SD	65%	14%	15%	6%	0%	529
WA	47%	16%	24%	12%	0%	403
NCI Average	53%	12%	22%	12%	2%	3,301

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).

A large majority of respondents indicated that the individual received residential supports (92%) and transportation (90%). Two-thirds (67%) of respondents reported the individual received day/employment supports.

Table 20 Services and Supports Received

State	Residential Supports	Day/Employment Supports	Transportation	Other Services and Supports	Social Security Benefits
FL	94%	70%	91%	59%	95%
GA	89%	71%	89%	46%	90%
HI	95%	80%	97%	53%	95%
LA	87%	49%	83%	65%	84%
MD	96%	87%	98%	65%	91%
NC	96%	65%	92%	67%	87%
NH	92%	57%	88%	58%	90%
PA	89%	64%	88%	62%	93%
SD	97%	79%	96%	70%	95%
WA	86%	53%	77%	42%	87%
NCI Average	92%	67%	90%	59%	91%

Family/Guardian 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 percentages 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 half of respondents reported they or another family member always get enough information to plan services (47%; states ranged between 32%-57%), and of those, 51% reported information is always easy to understand (states ranged between 42%-60%).

Fifty-five percent (55%; states ranged between 37%-66%) reported they are always kept informed about how the individual is doing.

Three-quarters of respondents reported they helped make the individual's service plan (75%) while (57%) reported the individual helped make the service plan. Nearly all reported the service plan includes services and supports important to the individual (96%), and over four-fifths indicated the plan includes all services and supports the individual needs (84%).

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

Gets Enough Information To Help Plan Services

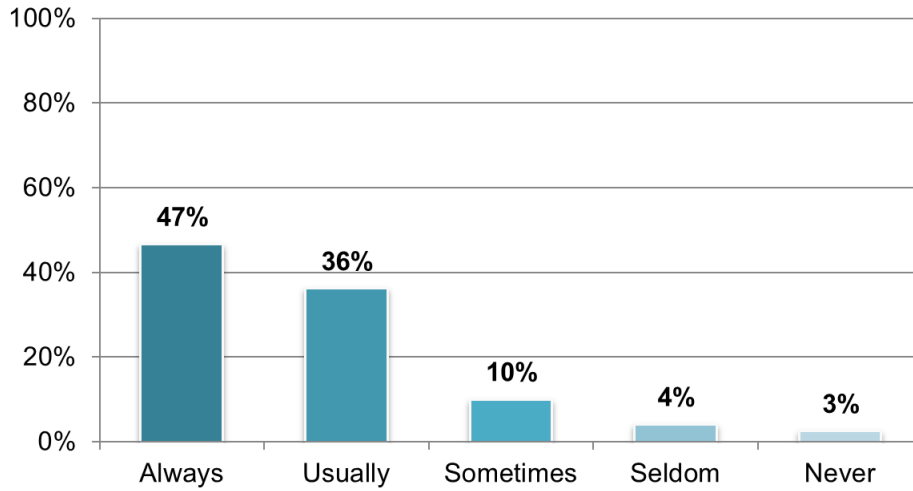


Table 21 Gets Enough Information To Help Plan Services

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	55%	31%	9%	3%	2%	501
SD	55%	37%	7%	2%	0%	533
Within Average Range						
HI	57%	32%	7%	2%	1%	148
NC	54%	37%	4%	4%	1%	217
NH	48%	38%	10%	3%	1%	265
WA	43%	38%	12%	4%	3%	415
FL	43%	39%	11%	5%	2%	341
PA	43%	37%	11%	6%	3%	282
Significantly Below Average						
GA	37%	33%	15%	7%	7%	436
MD	32%	38%	17%	6%	6%	204
NCI Average	47%	36%	10%	4%	3%	3,342

Q2. Is the information you receive easy to understand?

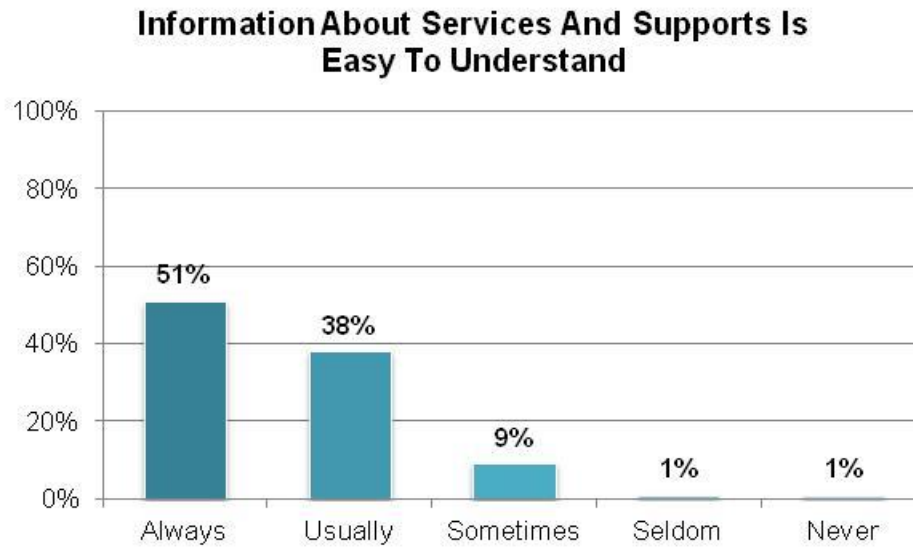


Table 22 Information About Services And Supports Is Easy To Understand

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	60%	29%	9%	1%	0%	499
SD	59%	37%	5%	0%	0%	533
Within Average Range						
HI	55%	31%	11%	2%	1%	147
NC	54%	41%	5%	0%	0%	214
NH	51%	41%	7%	0%	0%	264
PA	49%	44%	7%	1%	0%	280
MD	46%	39%	11%	2%	2%	196
FL	45%	42%	10%	2%	1%	340
WA	45%	39%	14%	1%	1%	414
Significantly Below Average						
GA	42%	41%	11%	4%	2%	424
NCI Average	51%	38%	9%	1%	1%	3,311

Q3. Is the case manager/service coordinator who assists your family with planning generally knowledgeable?

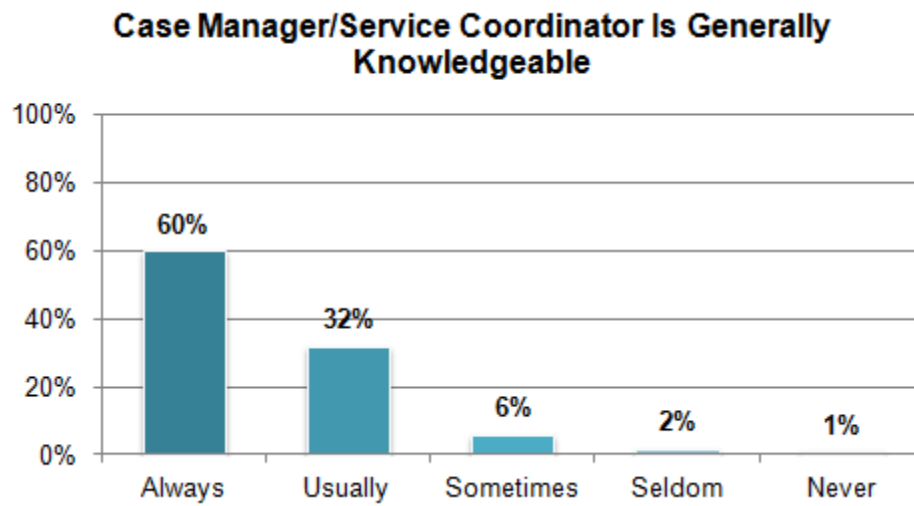


Table 23 Case Manager/Service Coordinator Is Generally Knowledgeable

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
SD	66%	29%	4%	1%	0%	529
Within Average Range						
HI	67%	28%	3%	1%	0%	148
NC	65%	28%	4%	1%	1%	209
WA	63%	29%	6%	1%	0%	404
NH	63%	29%	8%	1%	0%	263
LA	61%	31%	6%	1%	1%	490
FL	61%	31%	6%	1%	1%	341
PA	54%	35%	8%	3%	1%	270
Significantly Below Average						
GA	50%	35%	10%	2%	2%	422
MD	47%	41%	9%	2%	1%	192
NCI Average	60%	32%	6%	2%	1%	3,268

Q4. Are you generally kept informed about how your family member is doing?

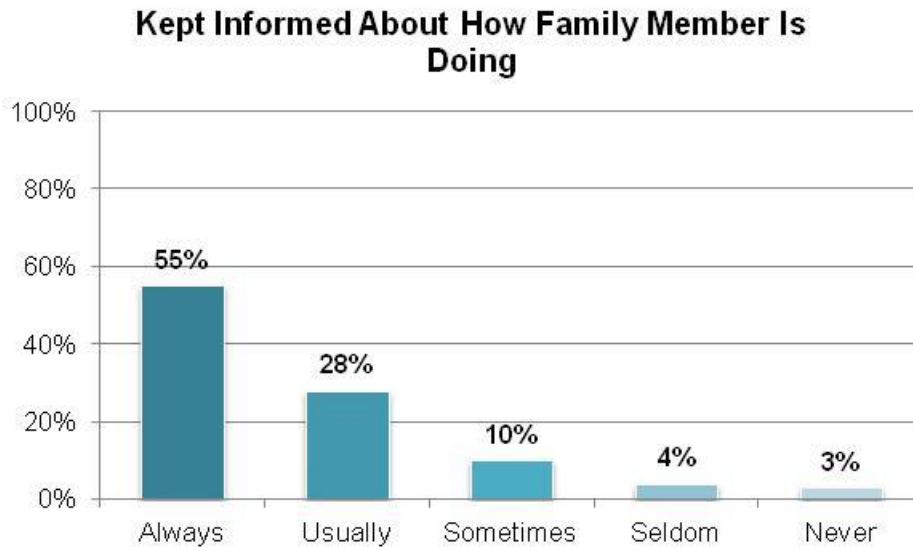


Table 24 Kept Informed About How Family Member Is Doing

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NC	66%	24%	6%	3%	1%	216
LA	62%	26%	7%	3%	2%	519
Within Average Range						
HI	63%	21%	9%	4%	2%	149
NH	60%	25%	8%	5%	2%	271
FL	57%	28%	9%	3%	2%	350
SD	54%	31%	10%	3%	1%	543
WA	52%	31%	11%	5%	2%	412
GA	50%	26%	13%	6%	5%	456
Significantly Below Average						
PA	46%	34%	13%	4%	2%	293
MD	37%	32%	15%	9%	7%	210
NCI Average	55%	28%	10%	4%	3%	3,419

Q5. If your family member has a service plan, did s/he help develop it?

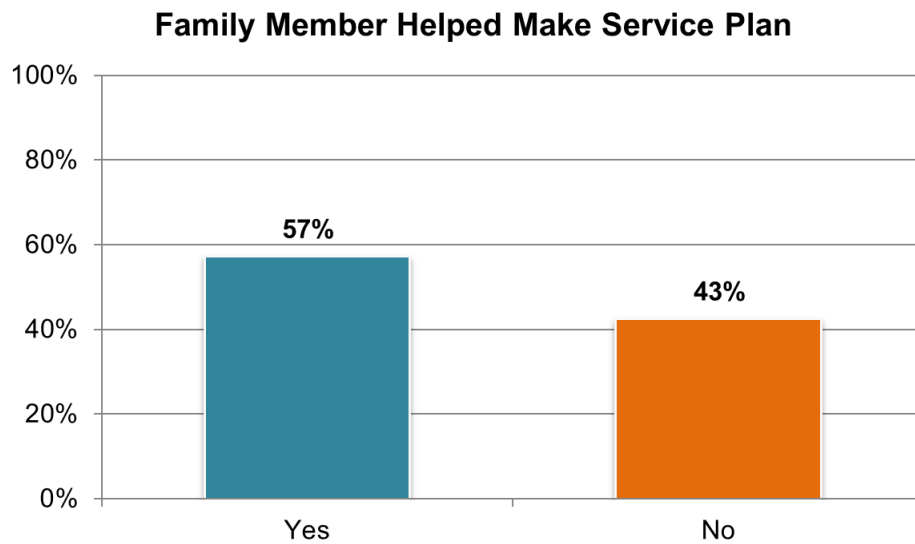


Table 25 Family Member Helped Make Service Plan

State	Yes	No	N
Significantly Above Average			
SD	73%	27%	463
WA	66%	34%	334
Within Average Range			
FL	64%	36%	307
GA	63%	37%	341
HI	63%	37%	126
PA	53%	47%	204
NH	53%	47%	232
MD	52%	48%	166
NC	52%	48%	168
Significantly Below Average			
LA	34%	66%	351
NCI Average	57%	43%	2,692

Q6. If your family member has a service plan, did you or another family member help develop it?

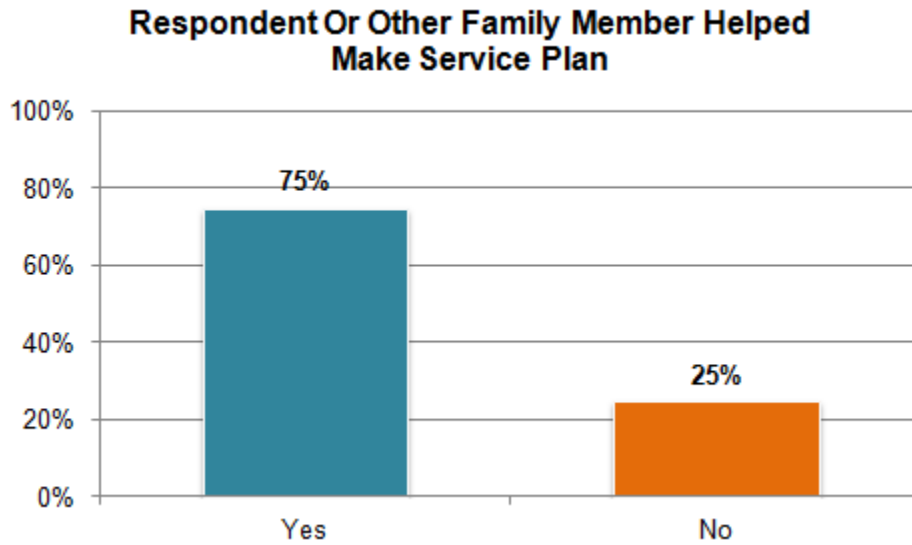


Table 26 Respondent Or Other Family Member Helped Make Service Plan

State	Yes	No	N
Significantly Above Average			
NH	85%	15%	260
SD	85%	15%	501
Within Average Range			
WA	79%	21%	359
HI	77%	23%	133
MD	77%	23%	185
NC	77%	23%	200
FL	77%	23%	335
GA	71%	29%	397
Significantly Below Average			
PA	61%	39%	245
LA	59%	41%	408
NCI Average	75%	25%	3,023

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

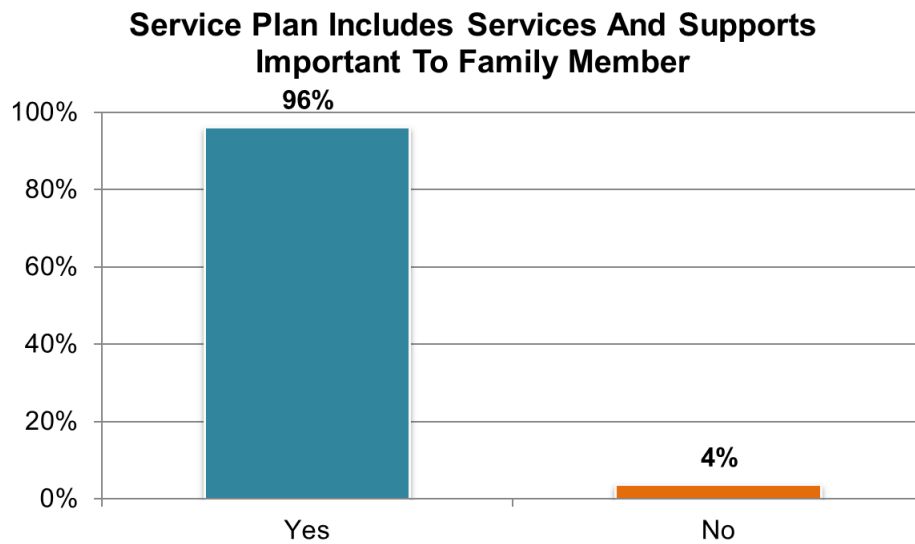


Table 27 Service Plan Includes Services And Supports Important To Family Member

State	Yes	No	N
Significantly Above Average			
SD	99%	1%	492
Within Average Range			
HI	98%	2%	141
NH	97%	3%	255
WA	97%	3%	348
PA	97%	3%	234
FL	97%	3%	319
MD	95%	5%	171
LA	95%	5%	379
GA	94%	6%	359
NC	93%	7%	198
NCI Average	96%	4%	2,896

Q8. Does the service plan include all the services and supports your family member needs?

Service Plan Includes Services And Supports Family Member Needs

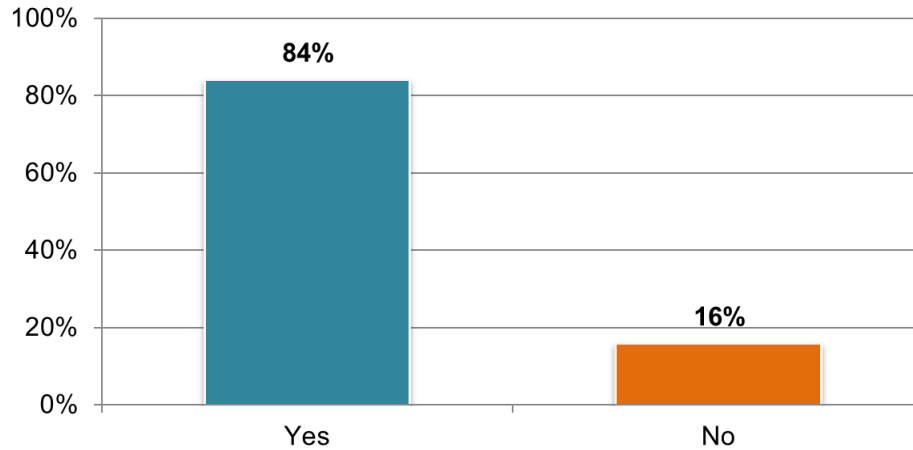


Table 28 Service Plan Includes Services And Supports Family Member Needs

State	Yes	No	N
Significantly Above Average			
HI	91%	9%	137
SD	89%	11%	485
Within Average Range			
LA	88%	12%	383
NC	88%	13%	184
PA	86%	14%	220
NH	85%	15%	248
GA	85%	15%	349
WA	82%	18%	326
MD	77%	23%	164
Significantly Below Average			
FL	71%	29%	306
NCI Average	84%	16%	2,802

Q9. 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?

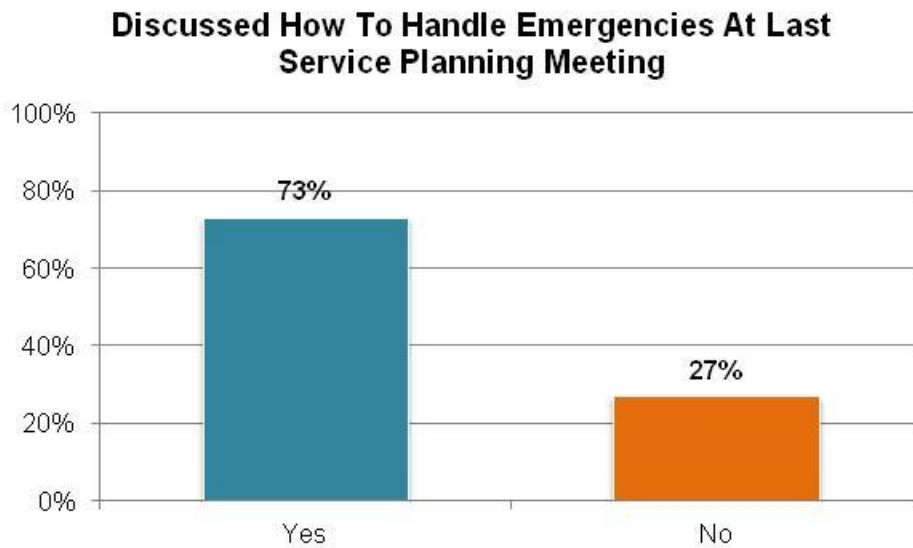


Table 29 Discussed How To Handle Emergencies At Last Service Planning Meeting

State	Yes	No	N
Significantly Above Average			
HI	86%	14%	132
NC	83%	17%	186
SD	81%	19%	474
Within Average Range			
FL	77%	23%	314
WA	76%	24%	345
NH	76%	24%	240
LA	72%	28%	402
Significantly Below Average			
PA	65%	35%	222
GA	64%	36%	374
MD	53%	47%	175
NCI Average	73%	27%	2,864

Q10. Have you or your family member received information about his/her rights?

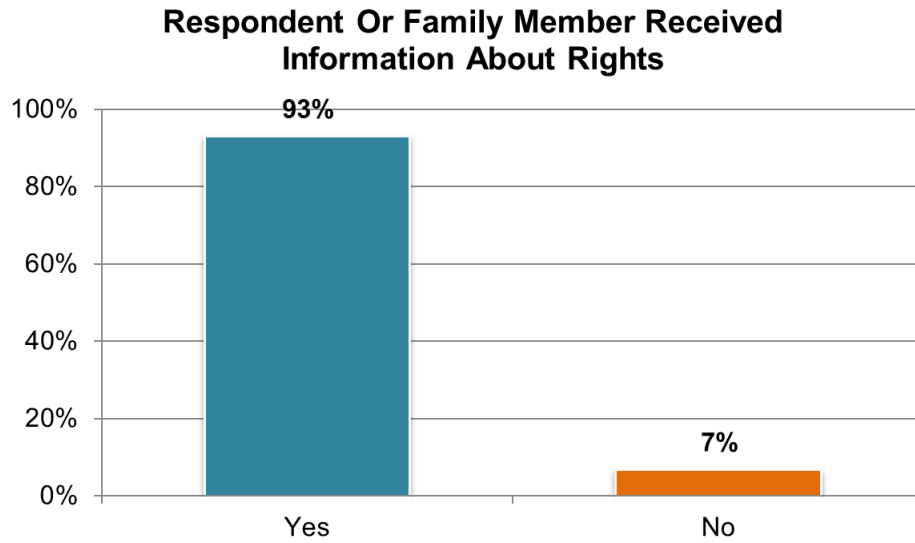


Table 30 Respondent Or Family Member Received Information About Rights

State	Yes	No	N
Significantly Above Average			
NH	99%	1%	261
SD	98%	2%	524
NC	97%	3%	212
Within Average Range			
FL	95%	5%	333
WA	94%	6%	375
HI	93%	7%	137
LA	92%	8%	465
PA	89%	11%	251
Significantly Below Average			
GA	87%	13%	416
MD	85%	15%	184
NCI Average	93%	7%	3,158

Access and Delivery of Services and Supports

The majority of respondents reported they are always able to contact support workers and the case manager/service coordinator when needed (63% and 57%, respectively). Sixty percent (60%) reported the individual always receives all services listed in the service plan (states ranged between 50%-69%).

The majority of respondents reported services and supports are always located within a reasonable distance from the individual's home (63%; states ranged between 57%-71%). Just over half reported services and supports always change when the individual's needs change (53%).

Just over half of respondents whose individual is non-verbal reported support workers are always able to communicate effectively with the individual (53%). Three-quarters (74%) whose individual's primary language is English reported support workers always communicate effectively in English and 59% reported support workers are always able to communicate with the individual whose primary language is not English.

Two-thirds (67%; states ranged between 58%-77%) reported the individual always has access to special accommodations or equipment needed. The majority reported the individual's residential setting is always healthy and safe (70%) and the day or employment setting is always healthy and safe (69%).

Q11. Are you able to contact your family member's support workers when you need to?

Respondent Is Able To Contact Support Workers When Needed

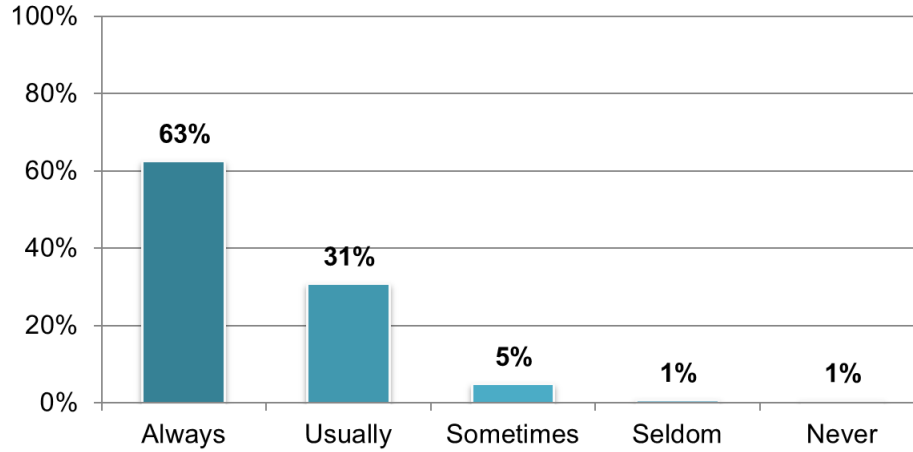


Table 31 Respondent Is Able To Contact Support Workers When Needed

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
HI	69%	27%	3%	1%	1%	148
LA	68%	26%	5%	0%	0%	530
NC	68%	28%	3%	1%	0%	216
FL	65%	29%	6%	0%	0%	350
SD	63%	34%	2%	0%	0%	543
NH	63%	31%	4%	1%	1%	268
WA	58%	33%	7%	1%	1%	415
MD	57%	35%	7%	1%	0%	211
GA	57%	32%	8%	2%	2%	457
PA	56%	37%	6%	0%	1%	282
NCI Average	63%	31%	5%	1%	1%	3,420

Q12. Are you able to contact your family member's case manager/service coordinator when you need to?

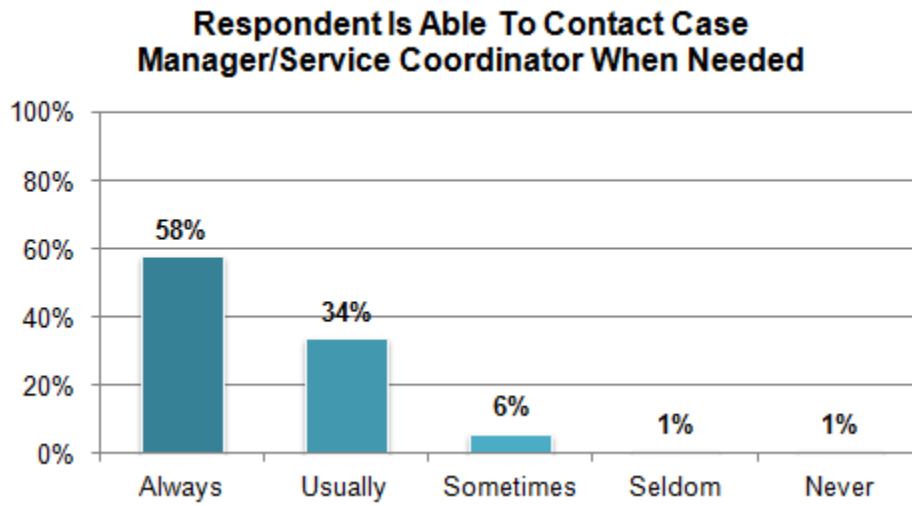


Table 32 Respondent Is Able To Contact Case Manager/Service Coordinator When Needed

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
NC	64%	29%	4%	1%	1%	213
LA	63%	31%	5%	1%	0%	520
HI	63%	32%	4%	1%	1%	126
FL	61%	30%	7%	1%	1%	343
SD	60%	36%	4%	0%	0%	537
NH	60%	33%	6%	0%	1%	269
Significantly Below Average						
WA	51%	39%	6%	3%	1%	406
GA	50%	36%	10%	2%	2%	449
PA	48%	40%	8%	2%	3%	275
NCI Average	58%	34%	6%	1%	1%	3,138

Q13. Does your family member receive all of the services listed in the service plan?

Family Member Receives All Services Listed In Service Plan

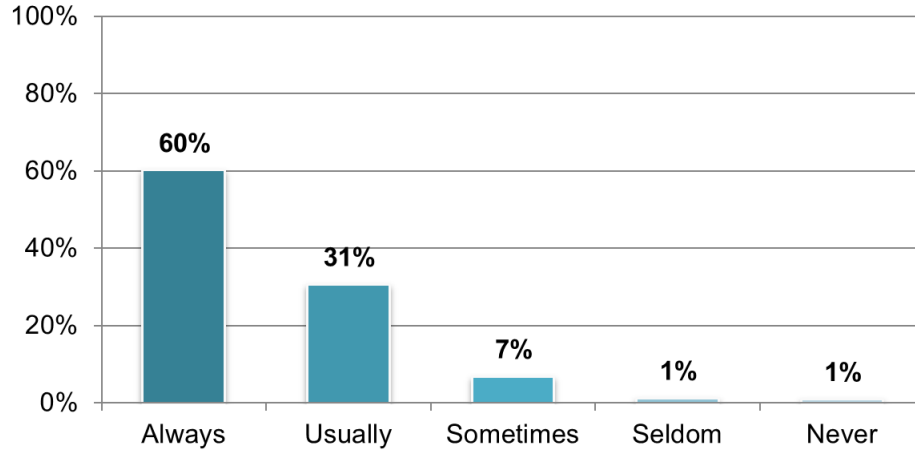


Table 33 Family Member Receives All Services Listed In Service Plan

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
HI	69%	27%	4%	0%	0%	135
LA	66%	29%	4%	0%	1%	403
WA	62%	30%	6%	1%	1%	348
PA	62%	32%	5%	1%	0%	203
NC	61%	31%	6%	2%	1%	189
SD	59%	34%	7%	0%	0%	504
NH	59%	33%	6%	1%	1%	245
FL	56%	33%	9%	1%	1%	304
GA	55%	30%	10%	3%	1%	343
MD	50%	31%	13%	2%	3%	167
NCI Average	60%	31%	7%	1%	1%	2,841

Q14. Are services and supports available within a reasonable distance from your family member's home?

Services And Supports Are Available Reasonably Close To Family Member's Home

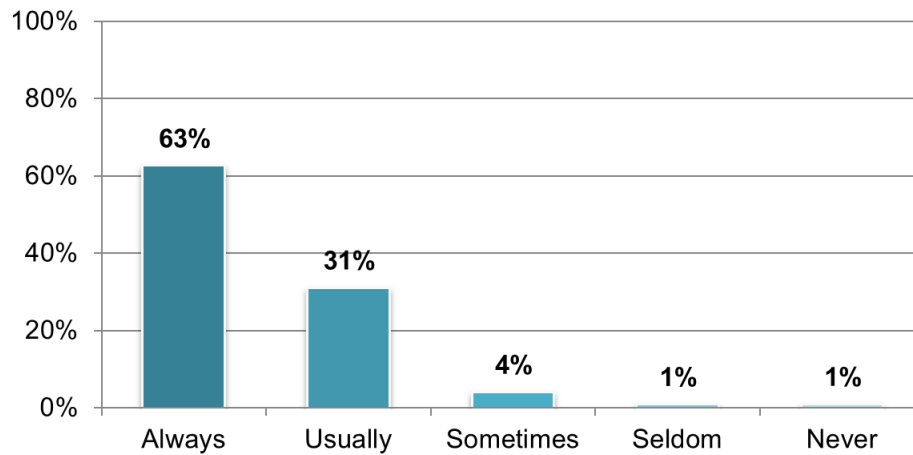


Table 34 Services And Supports Are Available Reasonably Close To Family Member's Home

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
SD	71%	25%	3%	0%	0%	514
LA	70%	26%	2%	1%	1%	442
Within Average Range						
NH	64%	31%	3%	1%	1%	268
HI	62%	32%	4%	1%	1%	136
WA	61%	31%	6%	1%	1%	370
PA	61%	32%	4%	2%	1%	246
MD	61%	33%	4%	1%	2%	182
NC	60%	36%	4%	1%	0%	193
GA	58%	31%	6%	3%	2%	405
FL	57%	37%	5%	0%	1%	315
NCI Average	63%	31%	4%	1%	1%	3,071

Q15. Do the services and supports change when your family member's needs change?

Services And Supports Change When Family Member's Needs Change

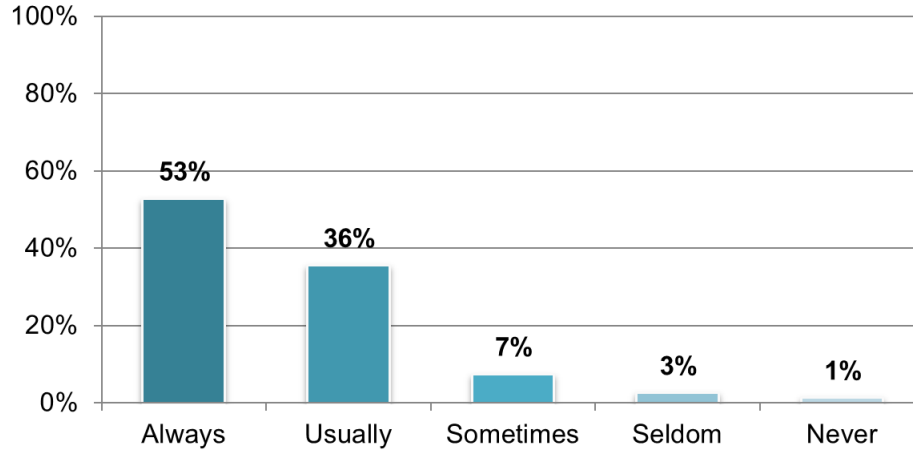


Table 35 Services And Supports Change When Family Member's Needs Change

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
LA	59%	33%	6%	1%	1%	432
SD	59%	32%	8%	0%	0%	508
HI	57%	32%	8%	2%	1%	126
NH	56%	33%	9%	2%	0%	248
PA	52%	36%	6%	4%	2%	244
WA	51%	36%	8%	3%	2%	354
GA	51%	34%	9%	4%	3%	357
NC	50%	43%	4%	3%	2%	200
FL	48%	37%	8%	3%	3%	311
MD	45%	40%	9%	5%	1%	167
NCI Average	53%	36%	7%	3%	1%	2,947

Q16. 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)

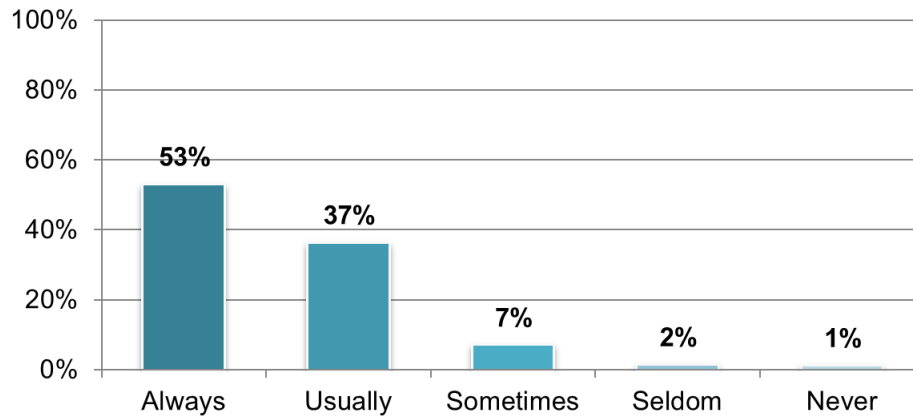


Table 36 Support Workers Can Communicate With Family Member (If Non-Verbal)

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	62%	31%	4%	1%	1%	335
Within Average Range						
SD	61%	33%	5%	1%	0%	307
FL	60%	29%	7%	1%	3%	181
HI	57%	35%	5%	2%	0%	96
WA	55%	37%	5%	1%	2%	185
NH	53%	41%	5%	1%	0%	76
NC	50%	38%	13%	0%	0%	72
GA	49%	36%	9%	3%	2%	253
PA	47%	40%	7%	3%	3%	96
Significantly Below Average						
MD	35%	49%	10%	3%	2%	96
NCI Average	53%	37%	7%	2%	1%	1,697

Q17. If English is your family member's first language, do the support workers communicate with him/her effectively in his/her primary language?

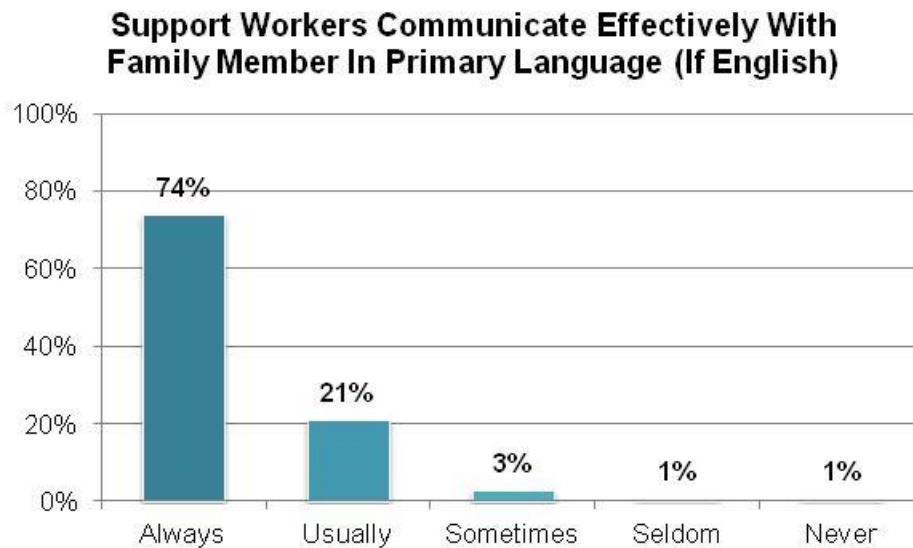


Table 37 Support Workers Communicate Effectively With Family Member In Primary Language (If English)

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
SD	87%	10%	2%	1%	0%	146
NC	83%	16%	0%	1%	1%	197
Within Average Range						
NH	80%	18%	2%	0%	0%	241
LA	79%	18%	2%	1%	1%	193
PA	78%	19%	2%	1%	0%	253
FL	77%	20%	2%	1%	1%	122
GA	73%	24%	3%	0%	1%	106
WA	69%	24%	4%	1%	1%	67
HI	66%	29%	2%	2%	2%	56
Significantly Below Average						
MD	52%	38%	7%	2%	2%	61
NCI Average	74%	21%	3%	1%	1%	1,442

Q18. If English is not your family member's first language, are there support workers or translators available to speak with him/her in his/her preferred language?

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

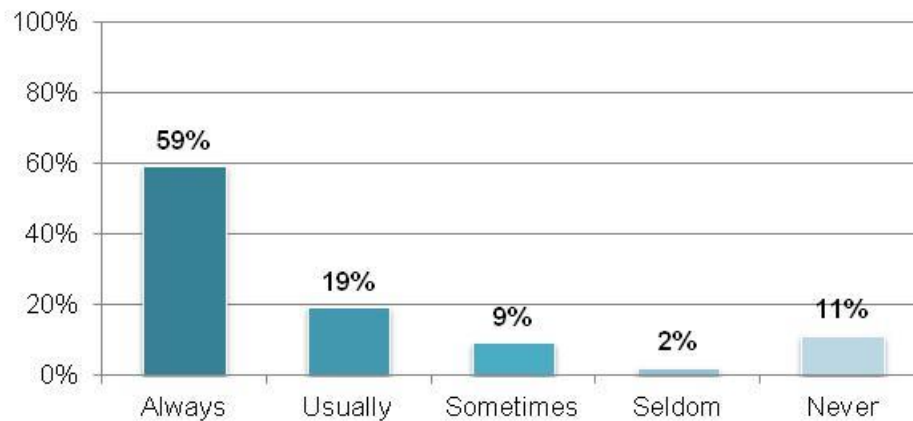


Table 38 Support Workers Or Translators Are Available To Speak With Family Member In Preferred Language (If Not English)

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
LA	68%	10%	3%	3%	18%	40
GA	63%	15%	14%	3%	5%	86
FL	59%	27%	7%	0%	7%	41
SD	57%	25%	7%	0%	11%	28
WA	48%	16%	16%	4%	16%	25
NCI Average	59%	19%	9%	2%	11%	220

Q19. Are services delivered to your family member in a way that is respectful to his/her culture(s)?

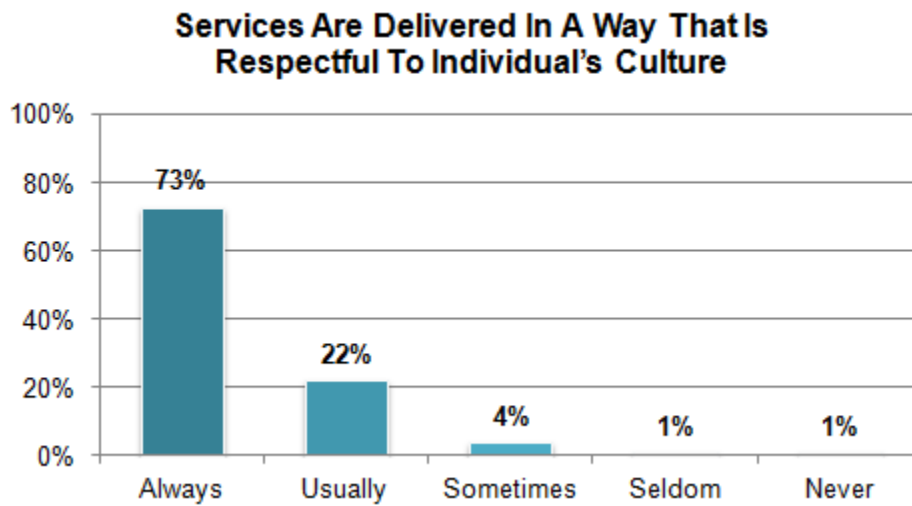


Table 39 Services Are Delivered In A Way That Is Respectful To Individual's Culture

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
HI	77%	18%	5%	0%	0%	128
NC	77%	21%	2%	0%	0%	197
NH	77%	21%	2%	0%	0%	232
LA	77%	20%	2%	0%	0%	468
WA	76%	22%	2%	0%	0%	353
FL	75%	21%	3%	0%	1%	323
SD	75%	23%	2%	0%	0%	511
PA	73%	23%	2%	1%	0%	245
MD	66%	27%	6%	1%	0%	177
Significantly Below Average						
GA	53%	23%	10%	3%	11%	299
NCI Average	73%	22%	4%	1%	1%	2,933

Q20. Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?

Member Has Access To Special Equipment Or Accommodations Needed

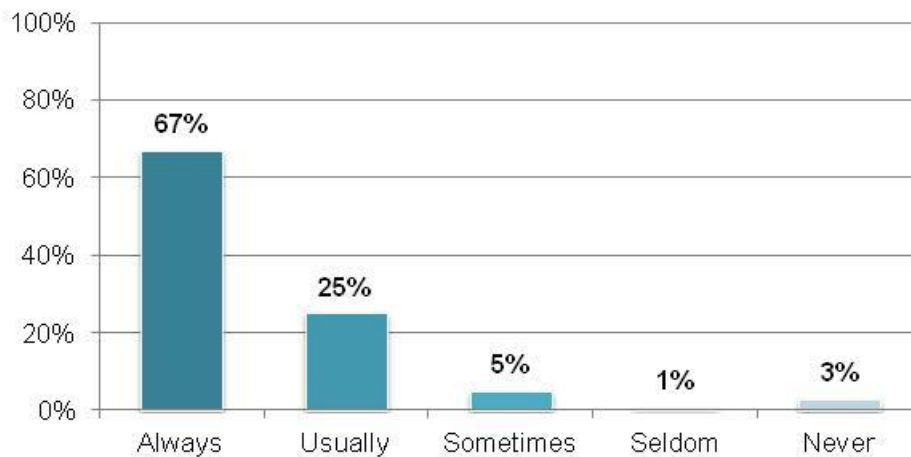


Table 40 Family Member Has Access To Special Equipment Or Accommodations Needed

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	77%	19%	2%	1%	2%	371
SD	75%	22%	2%	0%	1%	383
Within Average Range						
NH	71%	21%	5%	1%	2%	143
NC	70%	28%	1%	1%	1%	148
PA	69%	23%	2%	1%	5%	176
HI	64%	24%	4%	1%	6%	70
GA	62%	24%	5%	2%	7%	249
WA	59%	32%	4%	1%	3%	230
FL	59%	29%	8%	1%	2%	180
MD	58%	26%	12%	0%	4%	101
NCI Average	67%	25%	5%	1%	3%	2,051

Q21. Do the support workers have the right training to meet your family member's needs?

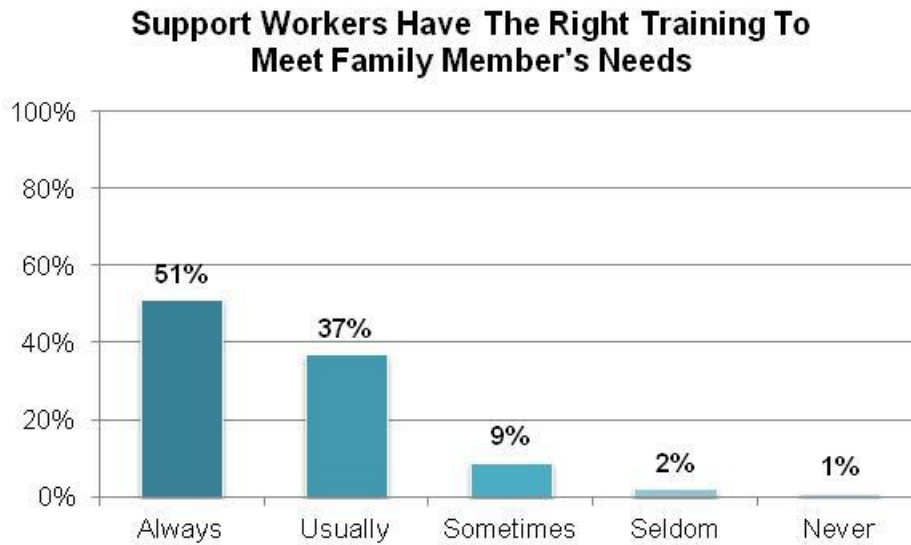


Table 41 Support Workers Have The Right Training To Meet Family Member's Needs

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
HI	58%	38%	4%	0%	0%	127
NC	57%	35%	7%	0%	0%	202
LA	56%	35%	6%	2%	0%	458
FL	54%	36%	7%	1%	1%	312
SD	53%	36%	10%	2%	0%	498
WA	52%	35%	11%	2%	0%	368
GA	50%	35%	10%	3%	2%	390
PA	48%	38%	10%	2%	2%	247
NH	47%	42%	9%	1%	1%	242
Significantly Below Average						
MD	38%	37%	16%	7%	2%	195
NCI Average	51%	37%	9%	2%	1%	3,039

Q22. Do you feel that your family member's residential setting is a healthy and safe environment?

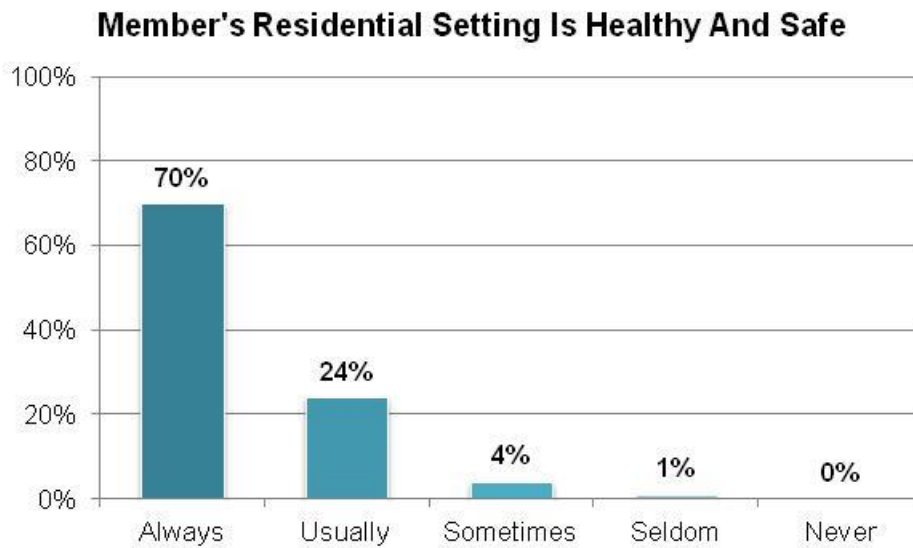


Table 42 Family Member's Residential Setting Is Healthy And Safe

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
NC	77%	21%	2%	0%	0%	214
HI	76%	23%	1%	0%	0%	148
FL	76%	20%	3%	1%	1%	349
LA	74%	21%	3%	1%	0%	517
NH	73%	23%	3%	1%	0%	263
GA	70%	22%	6%	1%	1%	445
PA	69%	24%	6%	1%	0%	289
SD	67%	28%	5%	0%	0%	540
WA	66%	27%	4%	1%	1%	424
Significantly Below Average						
MD	56%	32%	9%	2%	1%	206
NCI Average	70%	24%	4%	1%	0%	3,395

Q23. Do you feel that your family member's day/ employment setting is a healthy and safe environment?

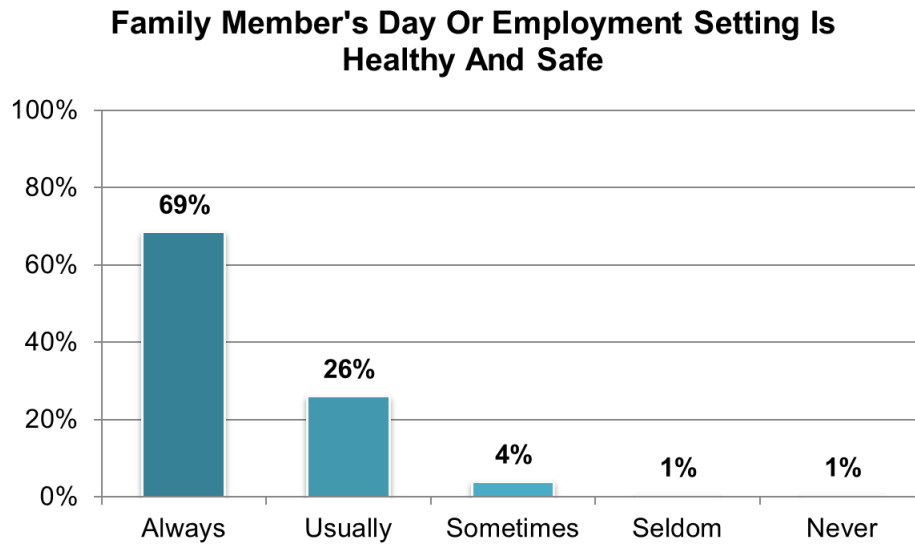


Table 43 Family Member's Day Or Employment Setting Is Healthy And Safe

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
NC	76%	21%	3%	0%	0%	178
HI	73%	22%	3%	0%	1%	116
LA	73%	22%	4%	1%	0%	381
FL	70%	25%	4%	0%	0%	281
SD	70%	27%	3%	0%	0%	473
NH	68%	29%	2%	1%	0%	224
WA	66%	28%	5%	1%	1%	312
GA	66%	24%	6%	2%	1%	392
PA	65%	30%	3%	0%	2%	240
Significantly Below Average						
MD	57%	33%	6%	1%	2%	185
NCI Average	69%	26%	4%	1%	1%	2,782

Q24. 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)**

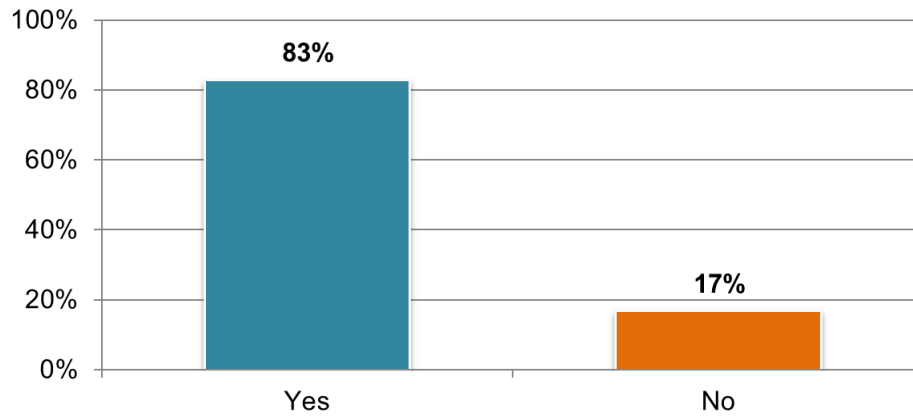


Table 44 Happy With Transition From School To State Funded Services (Past Year)

State	Yes	No	N
Within Average Range			
MD	85%	15%	27
FL	81%	19%	21
NCI Average	83%	17%	48

Choice and Control

Just over half of respondents reported the residential service agency always involve the individual in decisions (55%; states ranged between 40%-64%). Twenty-nine percent (29%) reported the individual always chooses their provider agency and 15% of individuals always choose their support workers.

Fourteen percent (14%; states ranged between 4%-38%) of respondents reported the individual has control or input in hiring their support workers and 25% reported the individual wants to have this control or input. Of the 11% of respondents who reported the individual knows how much money is spent by the ID/DD agency on his/her behalf, 26% reported the individual has a say in how the money is spent; the majority reported the individual has all the information needed to decide how to spend the money (88%).

Q25. Does the agency providing residential services to your family member involve him/her in important decisions?

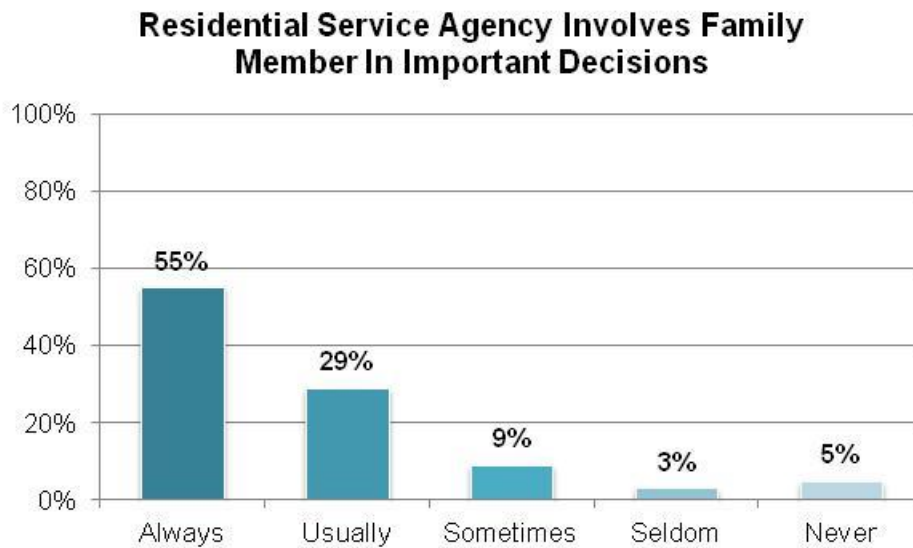


Table 45 Residential Service Agency Involves Family Member In Important Decisions

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	64%	25%	6%	2%	4%	400
Within Average Range						
SD	60%	32%	5%	1%	2%	477
NC	60%	24%	9%	3%	4%	172
FL	59%	26%	6%	4%	5%	301
WA	58%	27%	9%	3%	3%	346
HI	56%	29%	5%	3%	7%	116
NH	56%	32%	7%	1%	4%	228
GA	49%	26%	12%	5%	8%	371
PA	48%	33%	11%	4%	4%	232
Significantly Below Average						
MD	40%	32%	18%	3%	7%	174
NCI Average	55%	29%	9%	3%	5%	2,817

Q26. Does your family member choose the provider agencies that support him or her?

Family Member Chooses Provider Agencies

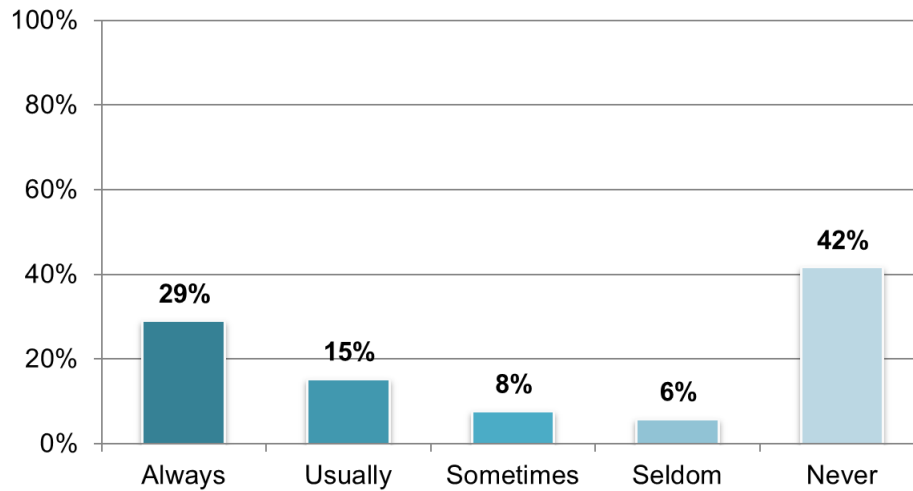


Table 46 Family Member Chooses Provider Agencies

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	39%	16%	10%	9%	26%	270
Within Average Range						
HI	34%	16%	5%	9%	35%	85
SD	34%	21%	7%	8%	30%	277
LA	32%	14%	6%	3%	45%	262
GA	31%	14%	7%	6%	41%	310
WA	29%	16%	13%	8%	34%	293
NH	28%	17%	6%	2%	47%	177
NC	24%	16%	9%	4%	47%	141
MD	24%	10%	8%	7%	52%	135
Significantly Below Average						
PA	17%	13%	8%	5%	57%	161
NCI Average	29%	15%	8%	6%	42%	2,111

Q27. If your family member chooses the provider agencies, does s/he have more than one choose from?

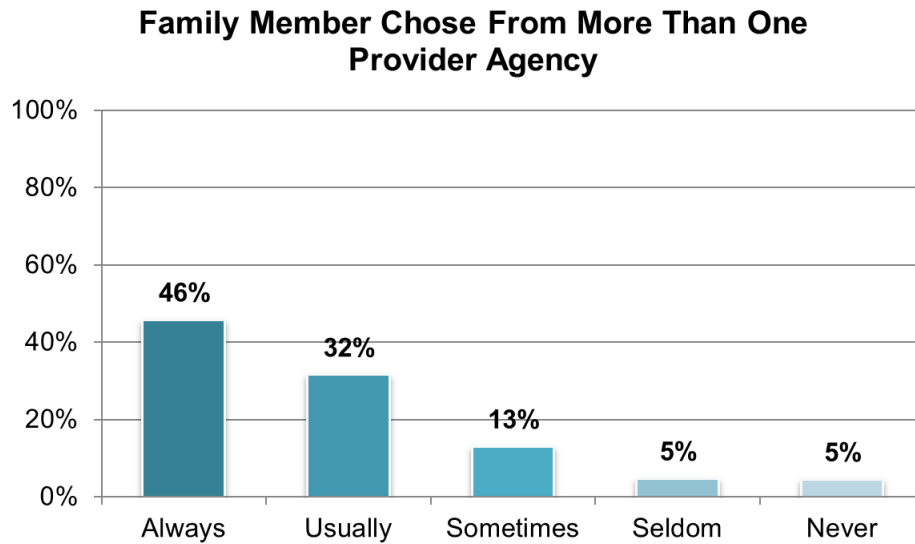


Table 47 Family Member Chose From More Than One Provider Agency

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	62%	28%	6%	1%	3%	100
Within Average Range						
FL	51%	32%	10%	4%	3%	159
HI	49%	33%	8%	8%	3%	39
MD	49%	24%	14%	5%	8%	37
NH	45%	32%	18%	2%	4%	56
SD	44%	35%	11%	2%	9%	113
GA	41%	30%	14%	8%	7%	132
PA	41%	30%	20%	5%	5%	44
NC	41%	41%	7%	9%	2%	54
WA	38%	30%	23%	4%	4%	128
NCI Average	46%	32%	13%	5%	5%	862

Q28. Does your family member choose the individual support workers who work directly with him/her?

Family Member Chooses Support Workers

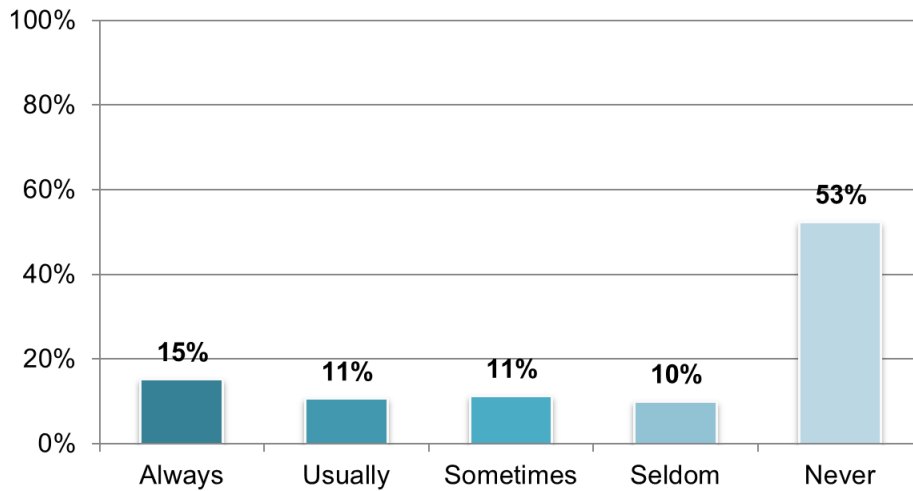


Table 48 Family Member Chooses Support Workers

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	33%	13%	16%	10%	28%	250
Within Average Range						
WA	19%	12%	14%	11%	45%	276
HI	18%	14%	13%	14%	42%	79
NH	17%	10%	11%	11%	50%	174
SD	16%	16%	13%	13%	42%	285
LA	14%	11%	7%	6%	62%	247
GA	14%	15%	9%	8%	55%	278
NC	10%	9%	14%	7%	60%	142
Significantly Below Average						
PA	7%	6%	9%	13%	66%	162
MD	4%	3%	8%	7%	78%	140
NCI Average	15%	11%	11%	10%	53%	2,033

Q29. If your family member chooses the support workers, is s/he satisfied with the options available?

Family Member Is Satisfied With Choice Of Support Workers

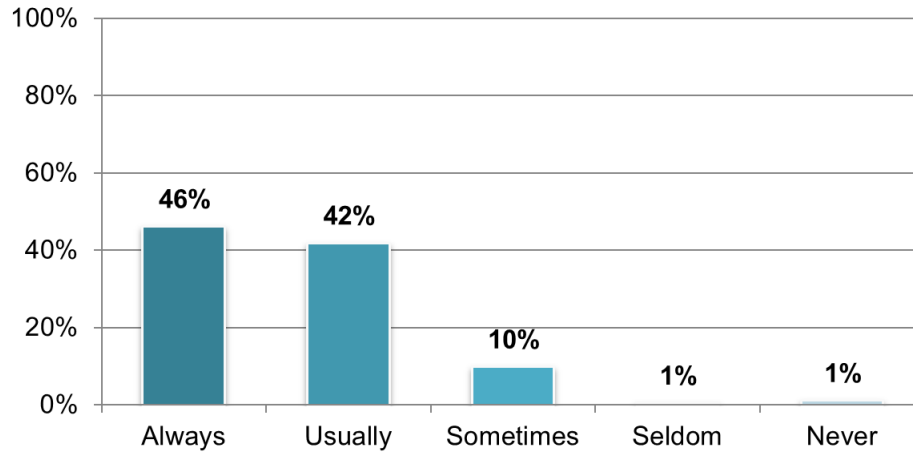


Table 49 Family Member Is Satisfied With Choice Of Support Workers

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	58%	30%	10%	1%	0%	142
Within Average Range						
PA	50%	29%	18%	0%	3%	34
LA	48%	41%	11%	0%	0%	73
WA	45%	45%	9%	1%	0%	115
HI	45%	48%	6%	0%	0%	33
SD	45%	45%	9%	1%	0%	119
NH	42%	42%	13%	0%	3%	64
GA	42%	45%	6%	2%	5%	102
NC	38%	53%	10%	0%	0%	40
NCI Average	46%	42%	10%	1%	1%	722

Q30. Did your family member choose his/her case manager/service coordinator?

Family Member Chose Case Manager/Service Coordinator

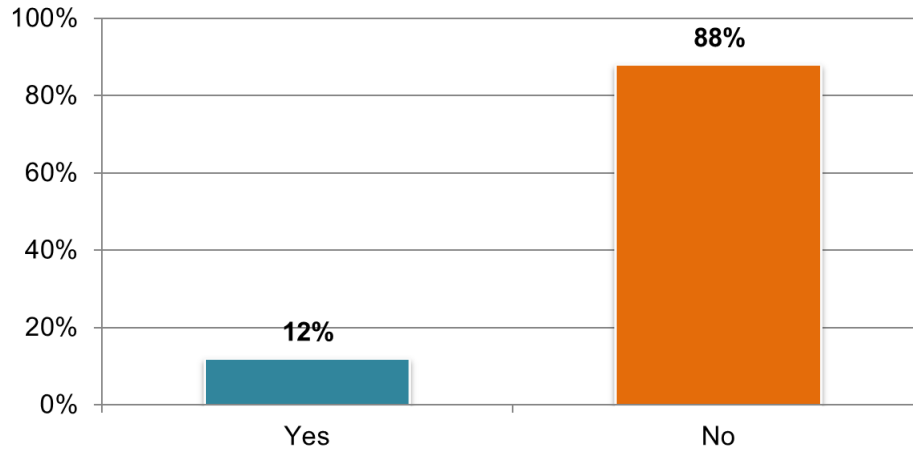


Table 50 Family Member Chose Case Manager/Service Coordinator

State	Yes	No	N
Significantly Above Average			
FL	43%	57%	288
Within Average Range			
GA	14%	86%	354
NH	13%	87%	219
NC	12%	88%	166
LA	11%	89%	316
MD	9%	91%	168
Significantly Below Average			
SD	6%	94%	386
WA	6%	94%	327
PA	3%	97%	205
HI	2%	98%	103
NCI Average	12%	88%	2,532

Q31. Does your family member have control and/or input over the hiring and management of his/her support workers?

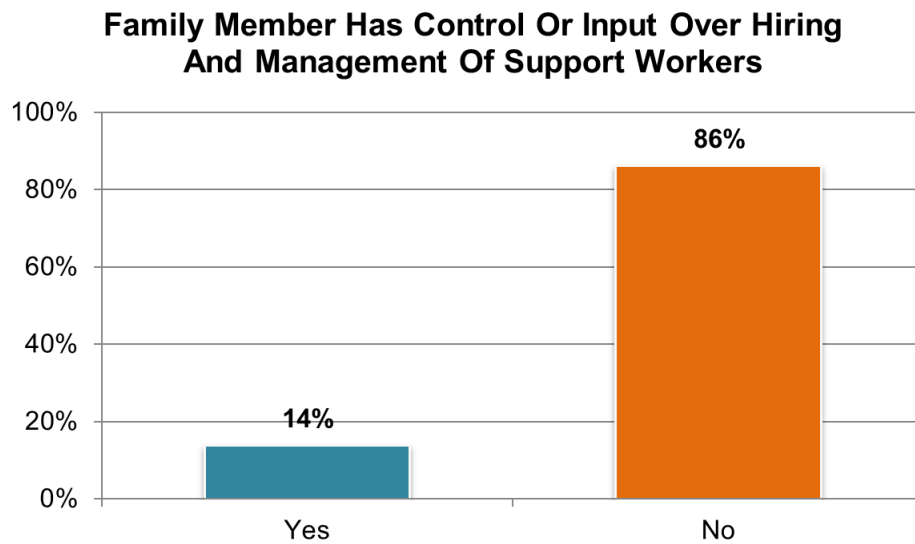


Table 51 Family Member Has Control Or Input Over Hiring And Management Of Support Workers

State	Yes	No	N
Significantly Above Average			
FL	38%	62%	267
WA	23%	77%	301
Within Average Range			
NH	21%	79%	199
GA	14%	86%	352
NC	10%	90%	160
LA	10%	90%	325
HI	8%	92%	100
Significantly Below Average			
PA	6%	94%	212
SD	6%	94%	358
MD	4%	96%	172
NCI Average	14%	86%	2,446

Q32. Does your family member want to have control and/or input over the hiring and management of his/her support workers?

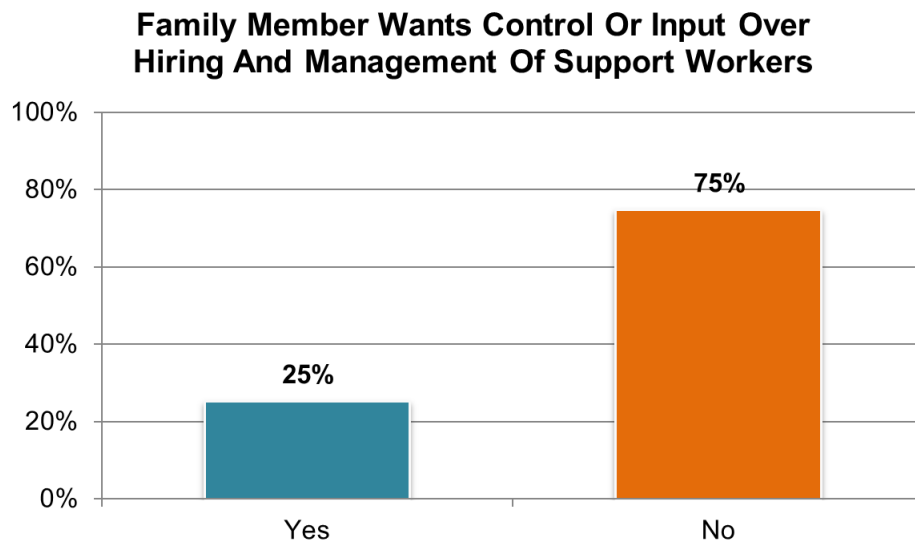


Table 52 Family Member Wants Control Or Input Over Hiring And Management Of Support Workers

State	Yes	No	N
Significantly Above Average			
FL	46%	54%	217
NH	34%	66%	157
Within Average Range			
WA	33%	67%	251
MD	26%	74%	112
GA	25%	75%	277
HI	20%	80%	83
NC	19%	81%	131
Significantly Below Average			
SD	17%	83%	289
LA	17%	83%	281
PA	16%	84%	157
NCI Average	25%	75%	1,955

Q33. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?

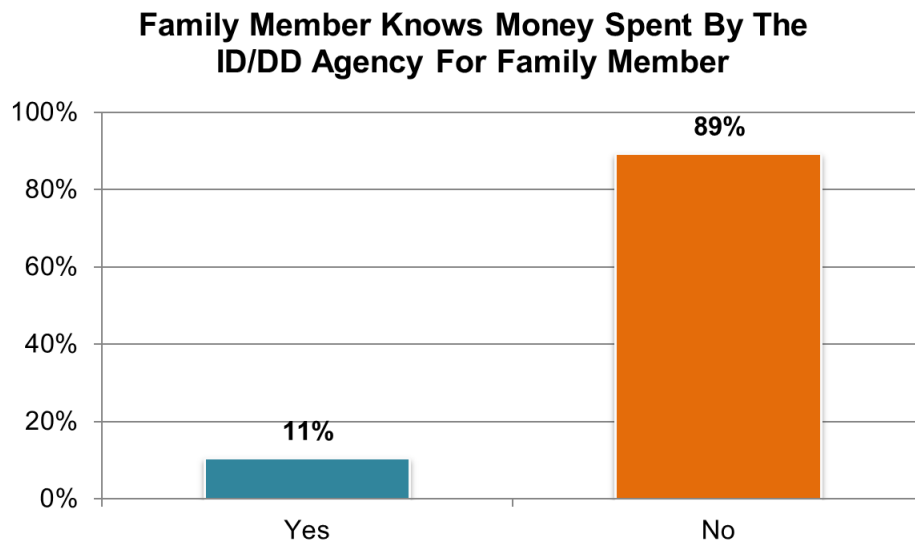


Table 53 Family Member Knows Money Spent By The ID/DD Agency For Family Member

State	Yes	No ⁴	N
Significantly Above Average			
FL	25%	75%	301
Within Average Range			
SD	15%	85%	461
GA	14%	86%	412
NH	9%	91%	234
NC	9%	91%	184
HI	9%	91%	117
WA	8%	92%	384
Significantly Below Average			
LA	6%	94%	407
PA	5%	95%	258
MD	5%	95%	180
NCI Average	11%	89%	2,938

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

Q34. 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

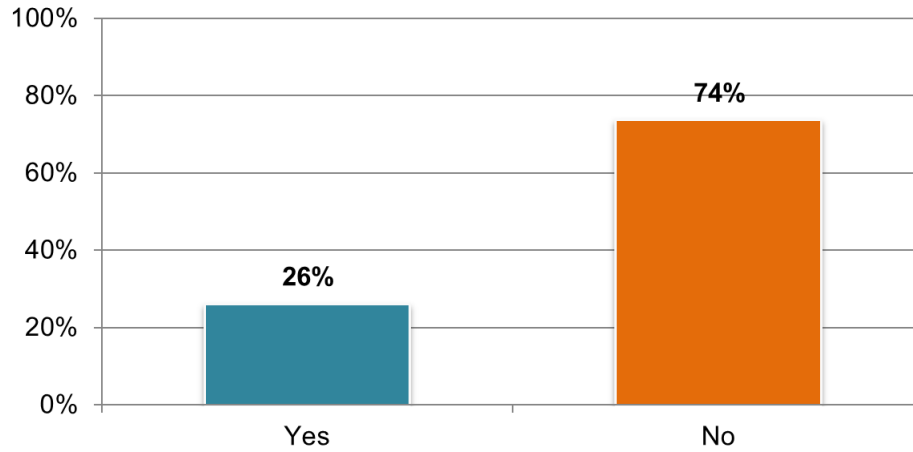


Table 54 Family Member Has A Say How ID/DD Agency Money Is Spent

State	Yes	No	N
Significantly Above Average			
SD	42%	58%	359
FL	41%	59%	250
Within Average Range			
GA	30%	70%	313
WA	29%	71%	287
NC	25%	75%	158
NH	23%	78%	200
PA	21%	79%	192
Significantly Below Average			
LA	20%	80%	320
MD	17%	83%	149
HI	15%	85%	92
NCI Average	26%	74%	2,320

Q35. If “yes” (to Q34), does your family member have all the information s/he needs to make decisions about how to spend this money?

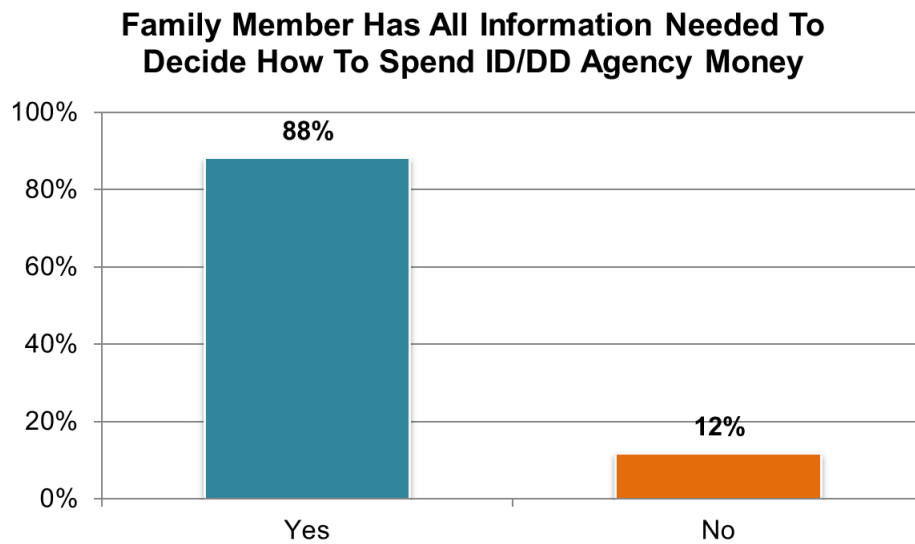


Table 55 Family Member Has All Information Needed To Decide How To Spend ID/DD Agency Money

State	Yes	No	N
Within Average Range			
LA	96%	4%	50
SD	92%	8%	116
GA	90%	10%	79
FL	90%	10%	88
PA	88%	13%	32
WA	86%	14%	65
NC	86%	14%	36
NH	76%	24%	37
NCI Average	88%	12%	503

Community Connections

Over four-fifths of respondents reported the individual participates in community activities (85%). Just over three-quarters (76%) reported the individual has friends with people other than support workers or family. A majority reported the individual has support needed to work or volunteer in the community (69%).

Q36. Does your family member participate in community activities?

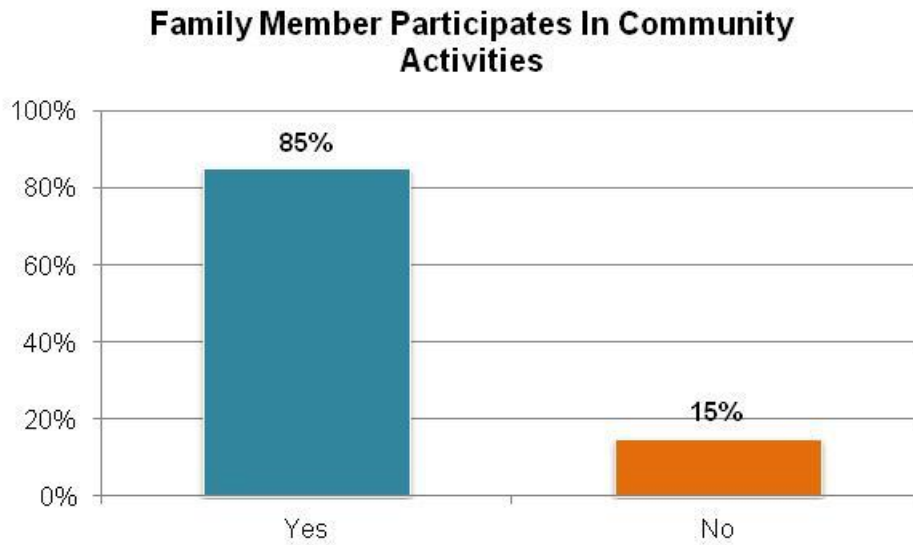


Table 56 Family Member Participates In Community Activities

State	Yes	No	N
Significantly Above Average			
NH	92%	8%	247
SD	91%	9%	478
Within Average Range			
NC	89%	11%	200
FL	85%	15%	324
LA	84%	16%	424
GA	83%	17%	381
PA	83%	17%	254
MD	82%	18%	179
HI	78%	22%	120
Significantly Below Average			
WA	78%	22%	389
NCI Average	85%	15%	2,996

Q37. Does your family member have friends or relationships with persons other than paid staff or other family members?

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

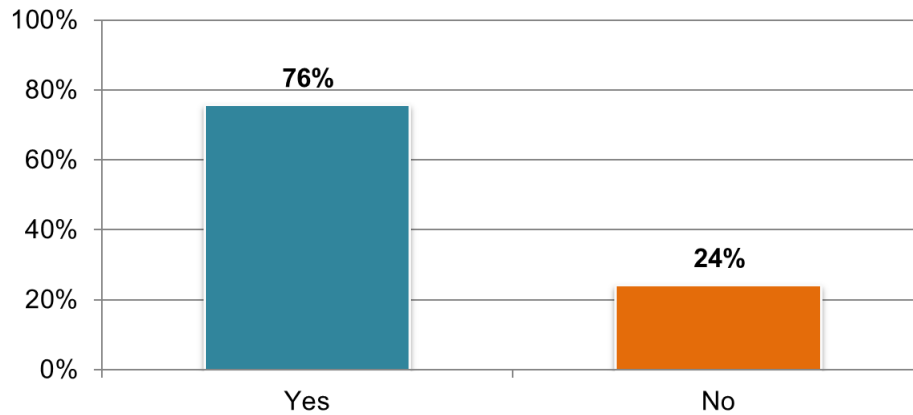


Table 57 Family Member Has Friends Or Relationships With People Other Than Support Workers Or Family

State	Yes	No	N
Within Average Range			
NH	81%	19%	244
SD	81%	19%	478
GA	80%	20%	398
WA	77%	23%	386
NC	77%	23%	197
HI	75%	25%	117
FL	75%	25%	320
PA	74%	26%	250
MD	72%	28%	185
Significantly Below Average			
LA	64%	36%	403
NCI Average	76%	24%	2,978

Q38. Does your family member have enough support (e.g., support workers, community resources) to work or volunteer in the community?

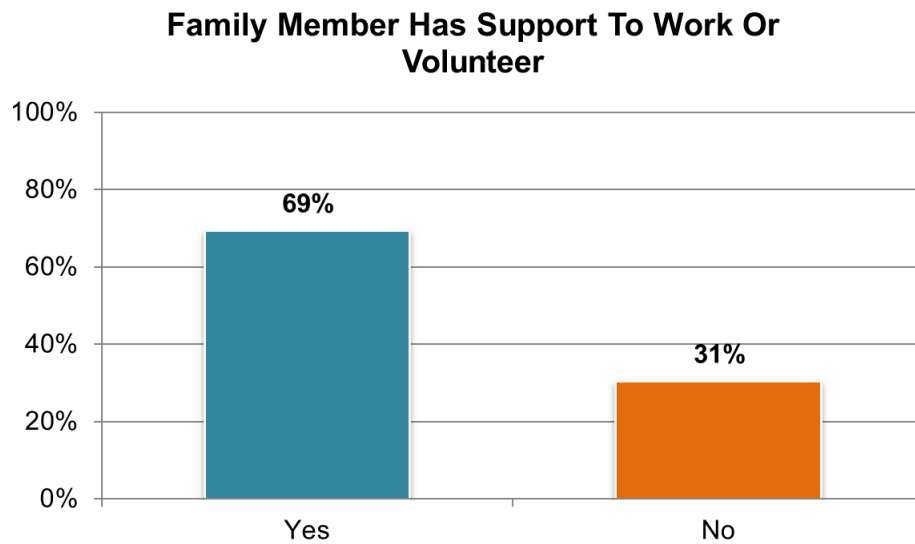


Table 58 Family Member Has Support To Work Or Volunteer

State	Yes	No	N
Within Average Range			
NH	77%	23%	185
WA	73%	27%	306
SD	72%	28%	358
NC	71%	29%	143
GA	71%	29%	291
HI	70%	30%	91
PA	69%	31%	170
LA	64%	36%	283
MD	63%	37%	139
FL	60%	40%	225
NCI Average	69%	31%	2,191

Satisfaction with Services and Supports

Nearly half of respondents reported they are always satisfied with the services and supports the individual receives (47%; states ranged between 36%-60%). About two-thirds (65%; states ranged between 41%-82%) reported they know how to file a complaint or grievance against the provider agency or staff, and 85% reported they are satisfied how complaints or grievances are handled. Just over three-fourths reported they know how to report abuse or neglect (76%), and 7% did so in the past year. Of those who reported abuse or neglect the past year, 74% indicated the appropriate parties were responsive.

Q39. Overall, are you satisfied with the services and supports your family member currently receives?

Overall Satisfied With Services And Supports Family Member Receives

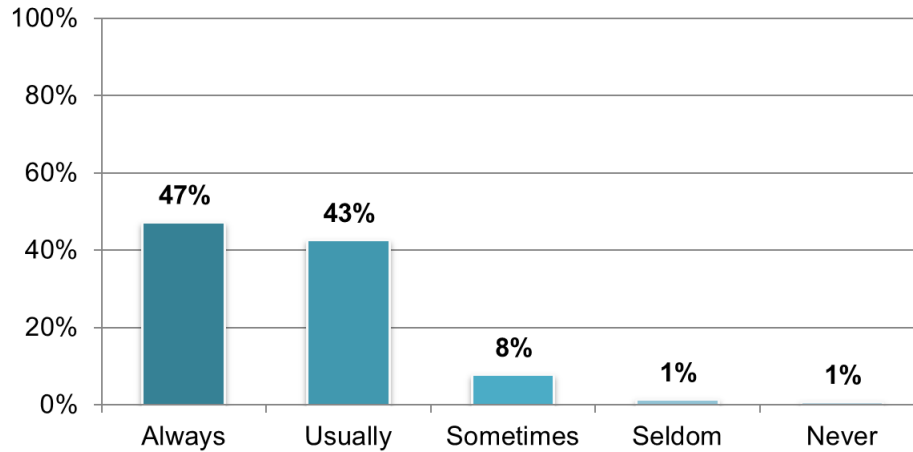


Table 59 Overall Satisfied With Services And Supports Family Member Receives

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
LA	60%	32%	6%	1%	0%	516
HI	60%	34%	5%	0%	1%	146
Within Average Range						
NC	53%	37%	8%	1%	0%	212
GA	46%	40%	9%	2%	3%	443
SD	46%	48%	5%	0%	0%	538
NH	44%	49%	6%	1%	0%	263
FL	43%	44%	10%	2%	1%	338
WA	42%	48%	7%	2%	1%	414
PA	42%	50%	7%	1%	0%	288
Significantly Below Average						
MD	36%	44%	15%	4%	1%	200
NCI Average	47%	43%	8%	1%	1%	3,358

Q40. Do you know the process for filing a complaint or grievance against your family member’s provider agencies or staff?

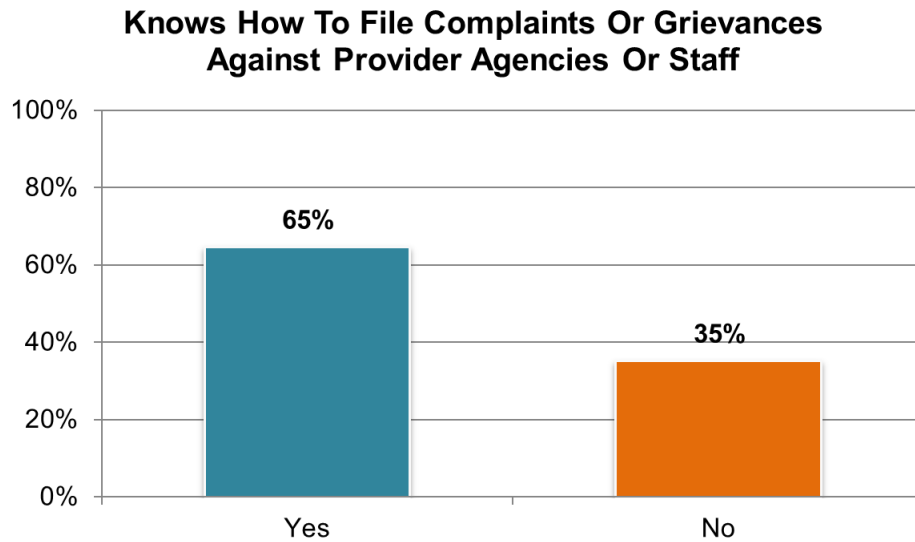


Table 60 Knows How To File Complaints Or Grievances Against Provider Agencies Or Staff

State	Yes	No ⁵	N
Significantly Above Average			
NH	82%	18%	268
FL	81%	19%	335
NC	77%	23%	210
SD	73%	27%	519
Within Average Range			
LA	68%	32%	496
WA	62%	38%	403
HI	58%	42%	137
Significantly Below Average			
PA	56%	44%	279
GA	49%	51%	439
MD	41%	60%	200
NCI Average	65%	35%	3,286

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

Q41. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

Satisfied How Complaints Or Grievances Are Handled

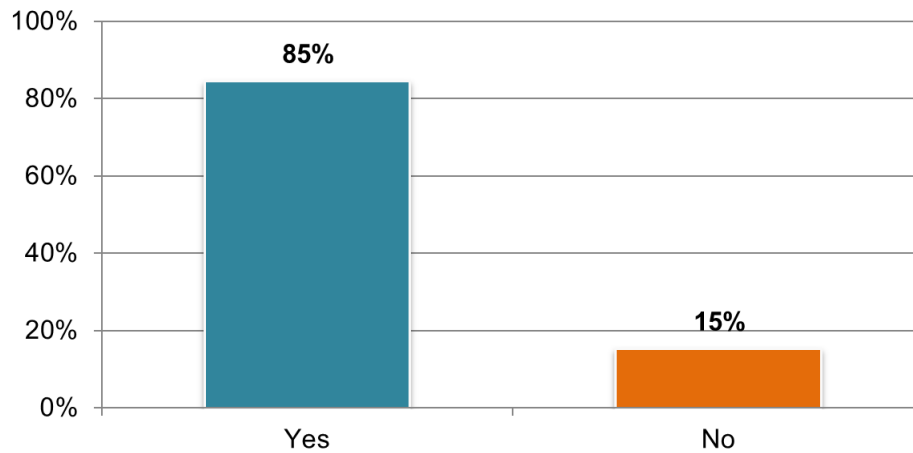


Table 61 Satisfied How Complaints Or Grievances Are Handled

State	Yes	No	N
Significantly Above Average			
LA	92%	8%	299
SD	91%	9%	276
Within Average Range			
HI	90%	10%	58
NC	87%	13%	136
NH	87%	13%	163
WA	86%	14%	166
FL	84%	16%	231
PA	83%	17%	118
GA	78%	22%	251
Significantly Below Average			
MD	69%	31%	100
NCI Average	85%	15%	1,798

Q42. Do you know how to report abuse or neglect?

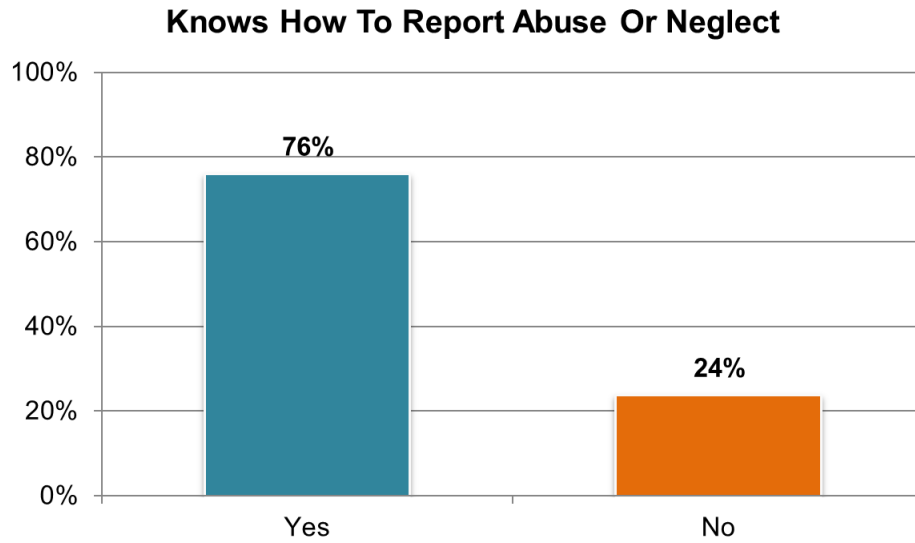


Table 62 Knows How To Report Abuse Or Neglect

State	Yes	No ⁶	N
Significantly Above Average			
FL	88%	12%	337
NH	88%	12%	263
NC	84%	16%	209
SD	82%	18%	518
Within Average Range			
WA	77%	23%	407
LA	77%	23%	498
PA	73%	27%	277
HI	65%	35%	141
Significantly Below Average			
GA	67%	33%	452
MD	59%	41%	196
NCI Average	76%	24%	3,298

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

Q43. In the past year, did you report abuse or neglect?

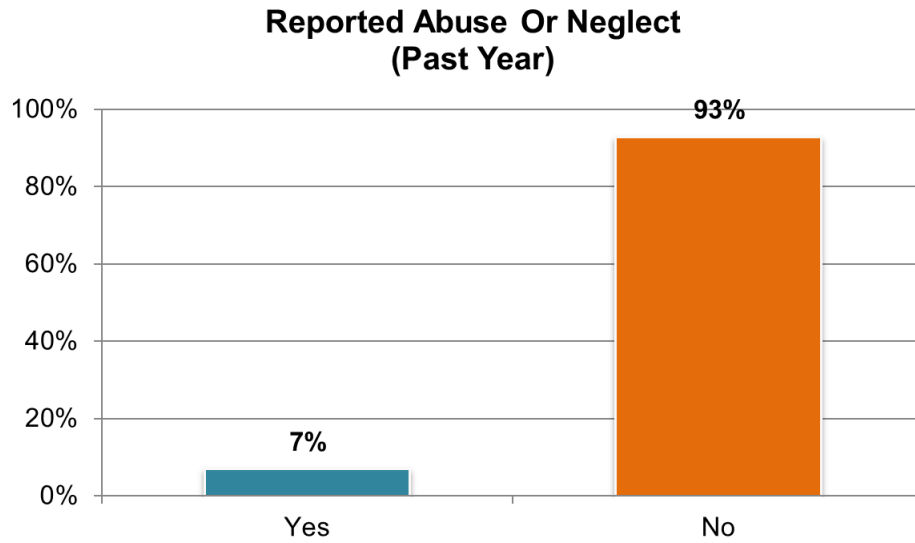


Table 63 Reported Abuse Or Neglect (Past Year)

State	Yes	No	N
Within Average Range			
GA	10%	90%	421
FL	10%	90%	315
MD	9%	91%	195
WA	8%	92%	401
LA	8%	92%	488
NH	7%	93%	258
NC	5%	95%	164
PA	5%	95%	278
HI	5%	95%	132
Significantly Below Average			
SD	3%	97%	515
NCI Average	7%	93%	3,167

Q44. If “yes” (to Q43), were the appropriate people responsive to your report?

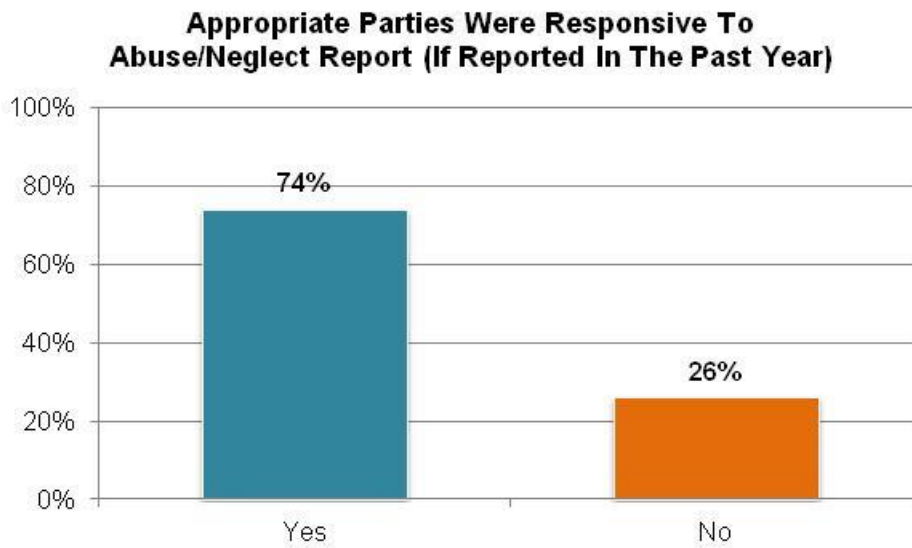


Table 64 Appropriate Parties Were Responsive To Abuse/Neglect Report (If Reported In The Past Year)

State	Yes	No	N
Within Average Range			
LA	90%	10%	31
FL	73%	27%	22
GA	69%	31%	39
WA	64%	36%	22
NCI Average	74%	26%	114

Outcomes

Nearly all respondents reported services and supports made a positive difference in the life of the individual (97%). Almost 90% reported services and supports reduced out-of pocket expenses (88%). Twenty-eight percent (28%; states ranged between 10%-62%) reported services or supports were reduced, suspended, or terminated in the past year. Of those, 62% reported service reduction negatively affected the individual.

Q45. Do you feel that services and supports have made a positive difference in the life of your family member?

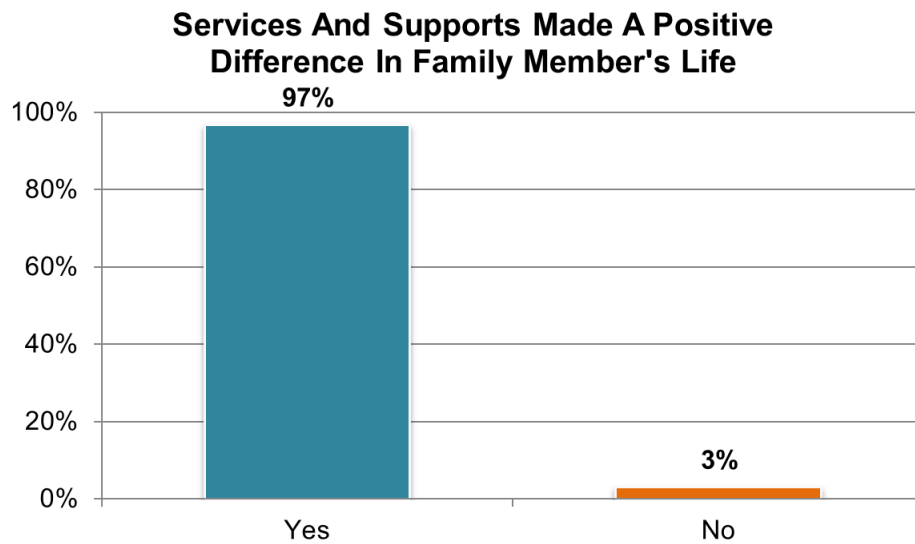


Table 65 Services And Supports Made A Positive Difference In Family Member's Life

State	Yes	No	N
Significantly Above Average			
SD	99%	1%	513
Within Average Range			
NH	98%	2%	259
WA	98%	2%	398
FL	98%	2%	332
NC	98%	2%	205
LA	98%	2%	482
HI	97%	3%	133
PA	96%	4%	266
GA	96%	4%	425
MD	92%	8%	195
NCI Average	97%	3%	3,208

Q46. 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

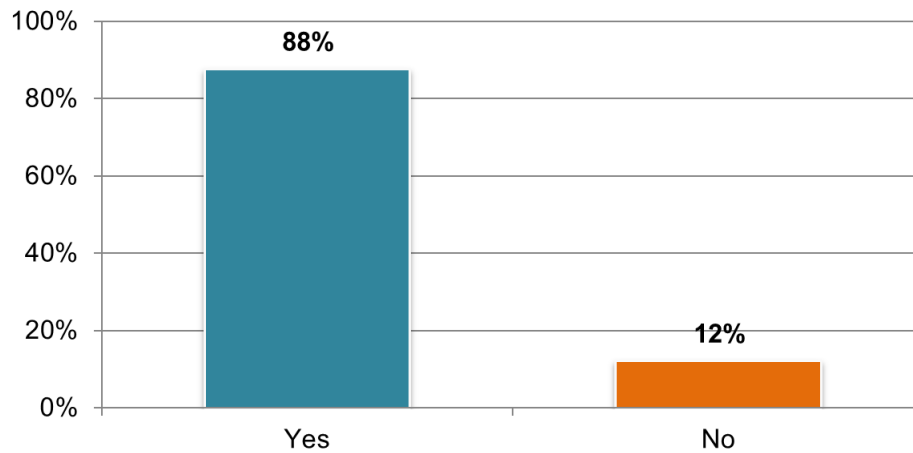


Table 66 Services And Supports Reduced Out-Of-Pocket Expenses

State	Yes	No	N
Within Average Range			
SD	90%	10%	393
LA	90%	10%	386
WA	89%	11%	330
NC	88%	12%	160
MD	88%	12%	180
HI	88%	13%	112
PA	87%	13%	218
NH	86%	14%	214
GA	85%	15%	354
FL	85%	15%	283
NCI Average	88%	12%	2,630

Q47. Do you feel that the services and supports received address the goals in your family member's service plan?

Services And Supports Address Goals In Service Plan

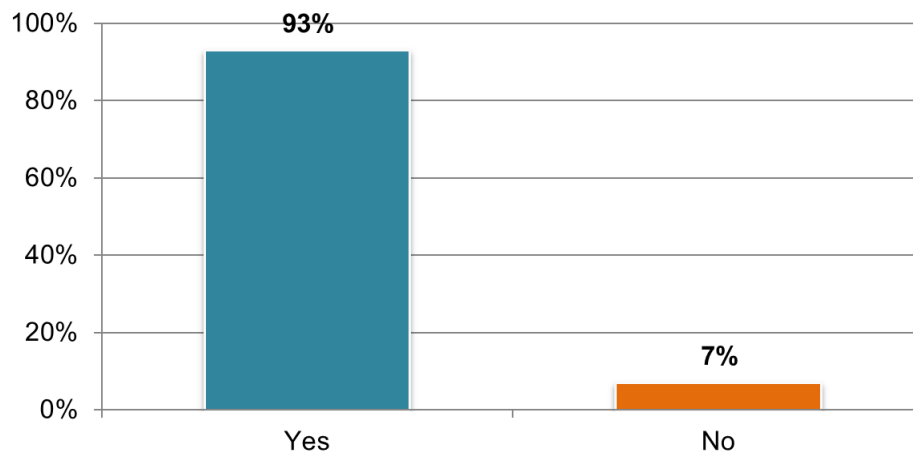


Table 67 Services And Supports Address Goals In Service Plan

State	Yes	No	N
Significantly Above Average			
LA	97%	3%	414
SD	97%	3%	481
Within Average Range			
NC	95%	5%	191
NH	94%	6%	252
PA	94%	6%	246
HI	94%	6%	122
WA	93%	7%	352
GA	92%	8%	370
FL	90%	10%	308
Significantly Below Average			
MD	82%	18%	154
NCI Average	93%	7%	2,890

Q48. Have the services or supports that 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)**

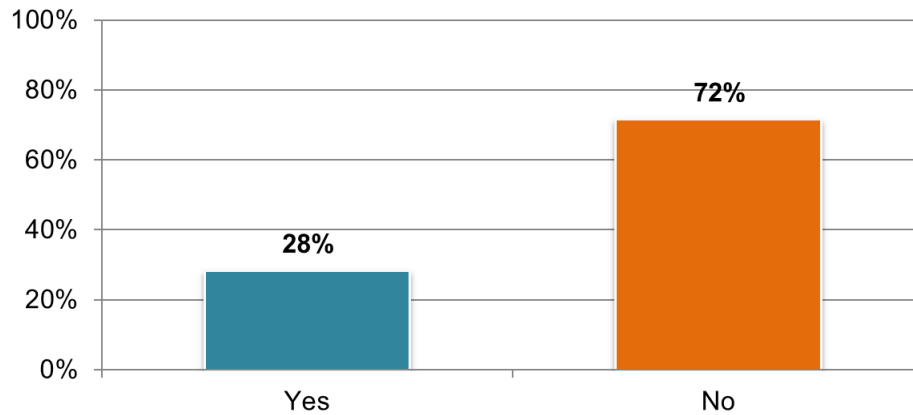


Table 68 Services Or Supports Have Been Reduced, Suspended, Or Terminated (Past Year)

State	Yes	No	N
Significantly Above Average			
FL	62%	38%	288
WA	39%	61%	320
Within Average Range			
HI	37%	63%	101
NC	33%	67%	178
GA	26%	74%	330
NH	21%	79%	217
Significantly Below Average			
PA	20%	80%	206
LA	19%	81%	347
MD	18%	82%	176
SD	10%	90%	420
NCI Average	28%	72%	2,583

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

Q49. If “yes” (to Q48), did the reduction/suspension/termination of these services or supports affect your family member’s home, job, relationships, etc.?*

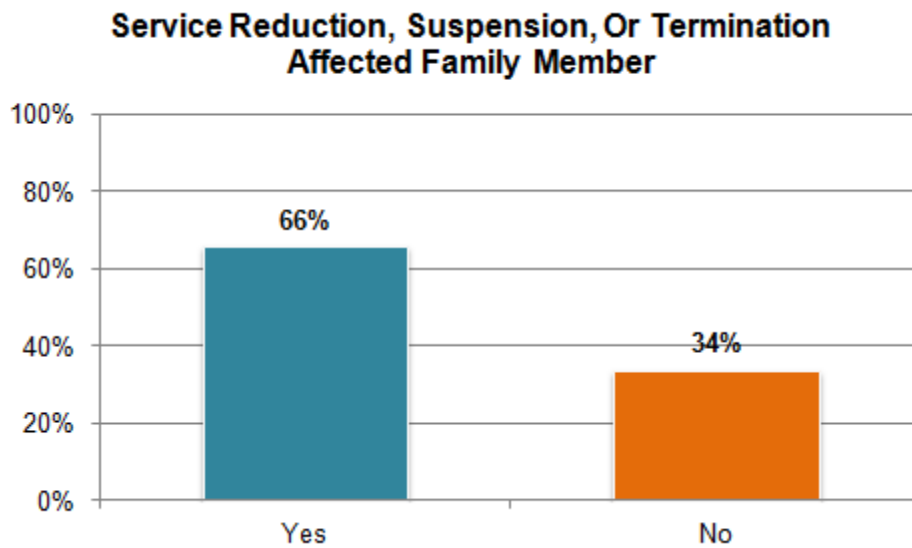


Table 69 Service Reduction, Suspension, Or Termination Affected Family Member

State	Yes	No	N
Within Average Range			
SD	79%	21%	34
GA	77%	23%	73
LA	76%	24%	51
FL	76%	24%	149
MD	67%	33%	27
NC	64%	36%	33
WA	61%	39%	96
PA	56%	44%	25
HI	40%	60%	30
NCI Average	66%	34%	518

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