

# Family/Guardian Survey

2014-15 Final Report



**NATIONAL CORE  
INDICATORS**

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



Human Services  
Research Institute

**Human Services Research Institute (HSRI)**

2336 Massachusetts Avenue  
Cambridge, MA 02140



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

113 Oronoco Street  
Alexandria, VA 22314

January 21, 2016

**List of Abbreviations Used in This Report**

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

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

**Executive Summary ..... 8**

Demographics and Characteristics of Family Members for Whom the Survey Was Completed .....8

Demographics and Characteristics of Respondents to the Survey .....9

Services and Supports Received.....9

Information and Planning.....9

Access and Delivery of Services and Supports..... 10

Choice and Control..... 10

Community Connections ..... 11

Satisfaction with Services and Supports ..... 11

Family Outcomes ..... 11

**I. Results .....12**

**Survey Development .....13**

Organization of the Family/Guardian Survey ..... 13

    Demographics..... 13

    Services and Supports Received..... 13

    Questions Regarding Services and Supports ..... 14

Presentation of Data..... 14

    Note on Significance: ..... 14

**Demographics.....15**

Family Member ..... 16

    Table 1. Family Member’s Residence ..... 17

Table 2. Family Member’s Age .....	17
Table 3. Family Member’s Gender .....	18
Table 4. Family Member’s Race .....	18
Table 5. Family Member’s Primary Means of Expression.....	19
Table 6. Family Member’s Primary Language.....	19
Table 7. Family Member’s Highest Level of Education .....	20
Table 8. Family Member’s Typical Day Activity .....	21
Table 9. Frequency of Medical Care Needed for Family Member.....	22
Table 10. Amount of Behavioral Support Needed for Family Member.....	22
Table 11. Amount of Help Needed for Family Member’s Daily Activities.....	23
<b>Respondents.....</b>	<b>24</b>
Table 12. Respondent’s Age .....	25
Table 13. Respondent’s Relationship to Family Member .....	25
Table 14. Respondent Is Family Member’s Legal Guardian or Conservator .....	26
Table 15. Number of Times Respondent Sees Family Member in a Year .....	26
Table 16. Respondent’s Highest Level of Education .....	27
Table 17. Total Taxable Family Income of Wage Earners in the Household in the Past Year .....	27
Table 18. Out-of-Pocket Expenses for Family in the Past Year .....	28
<b>Services and Supports Received .....</b>	<b>29</b>
Table 19. Services and Supports Received From ID/DD Agency.....	29
<b>Family/Guardian Survey Results .....</b>	<b>30</b>
<b>Information and Planning.....</b>	<b>31</b>
Table Q1. Do you get enough information to help you participate in planning services for your family member? .....	32
Table Q2. Is the information you receive easy to understand? .....	33
Table Q3. Are you kept informed about how your family member is doing? .....	34
Table Q4. Does your family member have a service plan? .....	35
Table Q5. Did your family member help develop the plan?.....	36

Table Q6. Did you or another family member help develop the plan?.....	37
Table Q7. Does the plan include all the services and supports your family member wants? .....	38
Table Q8. Does the plan include all the services and supports your family member needs? .....	39
Table Q9. Does your family member receive all of the services listed in the plan? .....	40
Table Q10. Did you discuss how to handle emergencies related to your family member at the last service planning meeting? .....	41
Table Q11. Have you or your family member received information about his/her rights?.....	42
<b>Access and Delivery of Services and Supports.....</b>	<b>43</b>
Table Q12. Are you able to contact your family member’s support workers when you need to? .....	44
Table Q13. Are you able to contact your family member’s case manager/service coordinator when you need to? .....	45
Table Q14. Are services and supports available within a reasonable distance from your family member’s home? .....	46
Table Q15. Do the services and supports change when your family member’s needs change? .....	47
Table Q16. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her? .....	48
Table Q17. If English is your family member’s first language, do the support workers speak to him/her effectively? .....	49
Table Q18.19. Are services delivered in a way that is respectful to your family member’s culture?.....	50
Table Q19.20. Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?.....	51
Table Q20.21. Do the support workers have the right training to meet your family member’s needs?.....	52
Table Q21.22. Do you feel that your family member's residential setting is a healthy and safe environment?... 53	
Table Q22.23. Do you feel that your family member’s day/employment setting is a healthy and safe environment?.....	54
<b>Choice and Control.....</b>	<b>55</b>
Table Q25. Does the agency providing residential services to your family member involve him/her in important decisions? .....	56
Table Q26. Does your family member choose the provider agencies that work with him or her? .....	57
Table 27. Can your family member choose a different provider agency if s/he wants to? .....	58
Table Q28. Does your family member choose the individual support workers who work directly with him/her? .....	59

Table Q29. Can your family member choose different support workers if s/he wants to?.....	60
Table Q30. Did your family member choose his/her case manager/service coordinator?.....	61
Table Q31. Does your family member have control and/or input over the hiring and management of his/her support workers?.....	62
Table Q32. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?.....	63
Table Q33. Does your family member have a say in how this money is spent?.....	64
Table 33a. If your family member has a say in how agency money is spent, does s/he have all the information s/he needs to make decisions about how to spend this money?.....	65
<b>Community Connections .....</b>	<b>66</b>
Table Q34. Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?.....	67
Table Q35. Does your family member have friends or relationships with persons other than paid staff or family?.....	68
Table Q36. Does your family member have enough support (support workers, community resources, etc.) to work or volunteer in the community?.....	69
<b>Satisfaction With Services and Supports .....</b>	<b>70</b>
Table Q37. Overall, are you satisfied with the services and supports your family member currently receives?.....	71
Table Q38. Do you know the process for filing a complaint or grievance against provider agencies or staff?.....	72
Table Q39. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?.....	73
Table Q40. Do you know how to report abuse or neglect?.....	74
Table Q41. Within the past year, if abuse or neglect occurred, did you report it? .....	75
Table 41a. If you reported abuse or neglect in the past year, were the appropriate people responsive to your report? .....	76
<b>Family Outcomes .....</b>	<b>77</b>
Table Q42. Do you feel that services and supports have made a positive difference in the life of your family member?.....	78
Table Q43. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care?.....	79
Table Q44. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?.....	80

Table 44a. If services or supports received by your family member were reduced, suspended, or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family member negatively? ..... 81

**II. NCI History and Activities.....82**

**Overview of National Core Indicators .....83**

State Participation ..... 84

The Core Indicators ..... 84

    Sub-Domains and Concern Statements ..... 85

How NCI Data Are Used ..... 86

    Caution and Limitations..... 87

**III. Methodology .....88**

**Sampling & Administration.....89**

Data Entry and Analysis ..... 89

Response Rates ..... 90

## Executive Summary

Direct feedback from families is an important means for states to gauge service and support satisfaction and to pinpoint areas for quality improvement. The National Core Indicators (NCI) project uses standard measures (or indicators) collected across states to assess the outcomes of services provided to individuals with intellectual/developmental disabilities and their families. Indicators address key areas of concern such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that result from NCI surveys are often used to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Many states also share the data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction.

The NCI Family/Guardian Survey is administered to families who have an adult (18 years or older) with a developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Family/Guardian Survey on an annual basis. Of the 41 states, the District of Columbia, and 22 sub-state entities who participated in NCI during the 2014-2015 data collection cycle, fourteen (14) states submitted a valid sample of Family/Guardian Survey data to be included in this report. This Final Report provides a summary of results based on data collected during the 2014-15 data collection cycle.

The following are NCI national averages for a selection of survey items. Complete breakouts by state for each item in the Family/Guardian Survey can be found in the Results section of this report.

### Demographics and Characteristics of Family Members for Whom the Survey Was Completed

By far the most common residential settings in which family members lived were group homes (54%), followed by independent living (14%) and specialized institutional facilities (13%). The average age of the family members was 47 years old; males accounted for a higher percentage of respondents than females (58% versus 42%). Most were white (83%), 11% were black/African-American; 2% were Hispanic.

In terms of level of education achieved, 70% had less than a high school diploma or GED while 26% had a high school diploma or earned a GED. The greatest proportion of family members went

to an out of home day program where they were unpaid (40%), 16% went to an out of home day program where they were paid; 14% are involved in paid community employment.

About two-thirds of family members required moderate or complete help with daily activities (34% and 30%, respectively).

## Demographics and Characteristics of Respondents to the Survey

Across states, the majority of respondents to the survey were older than 55 (61% 55-74 and 21% were 75 or older). Just more than half (56%) were the parent of the individual for whom they were completing the survey, 25% were a sibling. Two-thirds (67%) of respondents had full guardian- or conservatorship over the family member (9% had limited governance).

Most respondents either completed some college or had earned a college degree (23% and 44%, respectively). Nationally, respondents' total taxable family income in the past year was: below \$15,000 (17%); \$15,001-\$25,000 (16%); \$25,001-\$50,000 (25%); \$50,001-\$75,000 (20%); over \$75,000 (22%). Two-thirds 65% spent less than \$100 in out-of-pocket expenses in the past year for their family member's care.

## Services and Supports Received

Among the state funded services and supports (excluding social security benefits) specified in the survey that the family member received, residential supports and social security benefits were the most utilized (both 95%); 92% received transportation services.

## Information and Planning

Around half of all respondents reported \ they always receive enough information to help take part in planning their family member's services (49%) and that the information they get is always easy to understand (51%).

Most respondents and family members were engaged in service planning;67% reported their family member helped develop his or her own plan and 86% of respondents reported that they or another family member helped develop the plan.

The vast majority of respondents indicated that the service plan includes all the services and supports their family member wants (89%) and needs (86%), and that their family member received all service listed in the service plan.

## Access and Delivery of Services and Supports

Around three-fifths of all respondents reported they can always contact support workers (63%) and the case manager/service coordinator (58%) when needed. More than half reported that services and supports always change when their family member's needs change (56%). Three-quarters of all respondents reported that services are always delivered in a manner that is respectful to the family's culture (74%).

Nearly three-quarters of respondents indicated their family member's residential setting is always a healthy and safe environment (71%); 70% felt the same of their family member's day/employment setting.

## Choice and Control

Just over half of all respondents reported that the residential service agency always involves the adult receiving services in important decisions (52%). Thirty-eight percent of respondents reported that their family member always chooses his or her provider agencies; 19% reported that their family member always chooses his/her individual support workers.

Fourteen percent (14%) reported that their family member chose his or her own case manager/service coordinator.

Less than one-fifth reported their family member has control or input over hiring and management of support workers (18%) and fewer indicated their family member knows how much money is spent by the ID/DD agency on his/her behalf (14%). Of the one-third of family members who were reported to have a say in how ID/DD agency money is spent (33%), 87% were reported to have all the information needed to decide how to spend the money.

## Community Connections

The vast majority of respondents reported that their family member participates in community activities (94%) and has friends other than staff or family (77%). Three-quarters of respondents report that their family member has enough support to work or volunteer in the community (75%).

## Satisfaction with Services and Supports

A total of 89% of respondents indicated they are always or usually satisfied with the services and supports their family member receives.

Seventy-two percent (72%) of respondents knew how to file a complaint or grievance against a provider or staff and 82% knew how to report abuse or neglect.

## Family Outcomes

Nearly all respondents reported that services and supports have made a positive difference in their family member's life (97%). Most also indicated that services and supports reduced the family's out-of-pocket expenses for their family member's care (90%).

Of the 17% of respondents who reported that services or supports were reduced, suspended or terminated in the past year, 74% felt that this change had a negative impact on their family member.

# I. Results

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

## Survey Development

The Family/Guardian Survey was developed and first utilized in 1999-2000 in response to various states' interest in determining whether families were involved in the lives of their family member with a developmental disability who did not live at home with them. States were specifically interested in knowing whether these families had the support needed to be involved in their family member's lives and whether families were satisfied with the adequacy of the service system in their family member's needs.

Many questions were drawn from survey instruments already in use in the field; others were developed specifically for NCI. NCI staff routinely refine the instrument based on feedback from families and state staff.

Most participating states use the basic survey tool developed by the project. However, some states opt to incorporate additional survey questions to look more deeply at specific issues. The addition of supplementary questions is typically done after a state participates in NCI for at least a year and establishes baseline results.

### Organization of the Family/Guardian Survey

The Family/Guardian Survey is composed of the three sections described below. Additionally, at the end of the survey, respondents may 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., age, race, type of disability) followed by a series of demographic questions pertaining to the survey respondent (e.g., age, health status, relationship to the individual with the developmental disability).

#### Services and Supports Received

A brief section of the survey asks the respondent to identify the services and supports that they and/or their family member with a developmental disability receive.

## 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" or "no"). Respondents also have the option to indicate that they don't know the answer to a question or that the question is not applicable.

## Presentation of Data

All demographic and individual outcome results from the Family/Guardian Survey are presented in this report. Outcome results are presented in six subsections that correspond with the sections of the Family/Guardian Survey.

For each question, outcome results are first shown in a graph with the NCI Average and then in a table that shows a breakout of each state's percentage.

For all outcome data, tables are formatted so that all states are listed in descending order of percentage 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.

States receive an 'N/A' designation for a survey item if fewer than 20 people responded. The NCI Average is the average of all individual state percentages.

**Note on Significance:** in some cases, a state (let's call it state A) with a lower (or higher) proportion than another state (let's call it state B) may be significantly above (or below) the NCI Average even though the other state that is further away from the NCI Average is not. This may occur because statistical significance depends on both the difference between the average and the state's proportion and the sample size of the state. So, for example, when state A has a larger valid sample for the indicator than state B, state A may be significantly different from the average when state B is not, even though state B's difference from that average is larger than state A's. The larger the sample size of a state, the smaller the difference needs to be to be statistically significant.

# Demographics

**Note:**

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

**“Family Member” refers to the person receiving services who the respondent is answering questions about in this survey.**

## **Family Member**

*This section provides demographic information about the family member receiving services.*

**Table 1. Family Member’s Residence**

State	Specialized Facility for Individuals with ID	Group Home	Agency-Owned Apartment	Own Home or Apartment	Adult Foster Care or Host Home	Nursing Home	Other	N
AZ	5%	75%	1%	2%	12%	2%	3%	245
CO	5%	26%	6%	16%	46%	0%	3%	199
DE	2%	80%	7%	6%	4%	0%	1%	165
FL	9%	60%	1%	25%	1%	1%	2%	370
GA	6%	52%	6%	16%	16%	0%	5%	384
KY	17%	55%	6%	3%	11%	2%	8%	200
LA	24%	41%	4%	29%	1%	0%	2%	311
MD	8%	65%	6%	15%	1%	1%	3%	184
MI	7%	55%	2%	16%	15%	1%	4%	433
NC	29%	52%	0%	2%	11%	1%	5%	284
PA	27%	51%	4%	9%	3%	3%	4%	395
SD	13%	49%	17%	18%	1%	0%	3%	315
VA	21%	64%	1%	3%	8%	3%	1%	307
WI	3%	38%	6%	35%	11%	0%	7%	511
<b>NCI Average</b>	<b>13%</b>	<b>54%</b>	<b>5%</b>	<b>14%</b>	<b>10%</b>	<b>1%</b>	<b>4%</b>	<b>4,303</b>

**Table 2. Family Member’s Age**

State	Age	N
AZ	46	242
CO	47	201
DE	45	163
FL	45	359
GA	45	381
KY	48	197
LA	47	309
MD	47	185
MI	49	426
NC	45	284
PA	51	390
SD	45	325
VA	51	304
WI	48	500
<b>NCI Average</b>	<b>47</b>	<b>4,266</b>

**Table 3. Family Member’s Gender**

State	Male	Female	N
AZ	57%	43%	244
CO	56%	44%	207
DE	60%	40%	163
FL	60%	40%	370
GA	58%	42%	375
KY	60%	40%	202
LA	60%	40%	316
MD	52%	48%	188
MI	57%	43%	437
NC	58%	42%	284
PA	59%	41%	400
SD	52%	48%	333
VA	59%	41%	313
WI	59%	41%	513
<b>NCI Average</b>	<b>58%</b>	<b>42%</b>	<b>4,345</b>

**Table 4. Family Member’s Race**

State	American Indian or Alaska Native	Asian	Black or African-American	Hawaiian or Pacific Islander	White	Other or Unknown	Two or More Races	Hispanic or Latino
AZ	9%	1%	3%	1%	73%	0%	6%	10%
CO	2%	0%	1%	0%	89%	0%	1%	6%
DE	0%	1%	12%	0%	86%	0%	0%	2%
FL	1%	1%	12%	0%	79%	0%	2%	5%
GA	0%	1%	21%	0%	76%	1%	1%	0%
KY	3%	0%	5%	0%	94%	0%	1%	1%
LA	1%	1%	21%	0%	77%	0%	2%	0%
MD	1%	3%	14%	0%	81%	1%	2%	1%
MI	3%	1%	10%	0%	85%	0%	1%	2%
NC	2%	0%	27%	0%	70%	0%	1%	0%
PA	1%	1%	4%	0%	95%	0%	0%	0%
SD	9%	1%	1%	0%	89%	0%	1%	1%
VA	1%	2%	25%	0%	71%	0%	1%	1%
WI	3%	1%	1%	0%	94%	1%	2%	1%
<b>NCI Average</b>	<b>2%</b>	<b>1%</b>	<b>11%</b>	<b>0%</b>	<b>83%</b>	<b>0%</b>	<b>2%</b>	<b>2%</b>

**Table 5. Family Member’s Primary Means of Expression**

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AZ	67%	23%	2%	3%	4%	244
CO	77%	16%	3%	1%	4%	195
DE	72%	22%	1%	1%	3%	167
FL	75%	20%	1%	1%	3%	374
GA	67%	28%	1%	1%	3%	386
KY	69%	25%	1%	2%	2%	201
LA	65%	29%	1%	0%	5%	317
MD	76%	18%	1%	1%	3%	179
MI	66%	29%	2%	1%	2%	439
NC	64%	30%	1%	1%	5%	288
PA	64%	29%	1%	1%	6%	390
SD	75%	17%	3%	2%	3%	315
VA	41%	50%	2%	1%	6%	308
WI	72%	23%	2%	1%	2%	517
<b>NCI Average</b>	<b>68%</b>	<b>26%</b>	<b>2%</b>	<b>1%</b>	<b>4%</b>	<b>4,320</b>

**Table 6. Family Member’s Primary Language**

State	English	Spanish	Other	N
AZ	93%	2%	5%	244
CO	95%	0%	5%	204
DE	98%	1%	2%	167
FL	94%	2%	4%	370
GA	94%	1%	5%	383
KY	96%	0%	4%	203
LA	93%	0%	7%	307
MD	95%	1%	4%	187
MI	94%	0%	6%	440
NC	95%	0%	5%	286
PA	92%	0%	8%	396
SD	99%	0%	1%	317
VA	92%	0%	8%	304
WI	96%	0%	4%	512
<b>NCI Average</b>	<b>95%</b>	<b>1%</b>	<b>5%</b>	<b>4,320</b>

**Table 7. Family Member’s Highest Level of Education**

State	No High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree	N
AZ	62%	34%	2%	3%	0%	220
CO	57%	41%	2%	1%	0%	192
DE	77%	23%	1%	0%	0%	159
FL	63%	32%	2%	1%	1%	346
GA	66%	32%	2%	0%	0%	354
KY	77%	21%	1%	1%	0%	193
LA	78%	17%	2%	1%	1%	287
MD	68%	27%	4%	2%	0%	180
MI	80%	12%	6%	1%	1%	405
NC	77%	18%	4%	0%	0%	267
PA	69%	29%	1%	0%	0%	367
SD	69%	28%	3%	0%	0%	311
VA	84%	13%	2%	0%	0%	268
WI	57%	40%	1%	1%	1%	491
<b>NCI Average</b>	<b>70%</b>	<b>26%</b>	<b>2%</b>	<b>1%</b>	<b>0%</b>	<b>4,040</b>

**Table 8. Family Member’s Typical Day Activity**

State	Out of Home Day Program (Family member is Unpaid)	Out of Home Day Program (Family member is Paid)	Vocational Training	Community Employment (Family Member is Unpaid)	Community Employment (Family Member is Paid)	In-home Day Supports	At Home (by Choice)	At Home (No Services)	At Home (Other)	Other
AZ	56%	13%	4%	2%	11%	6%	4%	1%	7%	16%
CO	62%	24%	7%	6%	16%	13%	5%	2%	4%	6%
DE	36%	26%	6%	3%	25%	4%	2%	0%	1%	11%
FL	43%	12%	7%	2%	4%	14%	4%	1%	2%	17%
GA	52%	13%	5%	5%	9%	14%	6%	3%	3%	16%
KY	55%	16%	7%	4%	8%	6%	2%	1%	1%	19%
LA	19%	12%	13%	2%	8%	18%	5%	2%	5%	29%
MD	45%	21%	10%	4%	20%	7%	2%	3%	3%	10%
MI	28%	14%	19%	4%	9%	22%	8%	5%	5%	13%
NC	35%	14%	16%	8%	10%	12%	2%	3%	0%	32%
PA	36%	17%	5%	4%	9%	14%	4%	4%	2%	25%
SD	24%	19%	16%	5%	25%	12%	6%	1%	2%	17%
VA	38%	9%	5%	3%	9%	20%	5%	1%	5%	23%
WI	25%	19%	14%	8%	27%	23%	11%	5%	7%	16%
<b>NCI Average</b>	<b>40%</b>	<b>16%</b>	<b>10%</b>	<b>4%</b>	<b>13%</b>	<b>13%</b>	<b>5%</b>	<b>2%</b>	<b>3%</b>	<b>18%</b>

**Table 9. 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	69%	25%	6%	236
CO	75%	21%	4%	203
DE	71%	21%	8%	160
FL	62%	31%	7%	363
GA	65%	26%	9%	370
KY	64%	28%	8%	197
LA	52%	26%	22%	295
MD	64%	25%	11%	174
MI	67%	26%	7%	430
NC	59%	23%	18%	271
PA	60%	22%	18%	359
SD	70%	22%	8%	314
VA	49%	27%	23%	299
WI	72%	22%	6%	511
<b>NCI Average</b>	<b>64%</b>	<b>25%</b>	<b>11%</b>	<b>4,182</b>

**Table 10. Amount of Behavioral Support Needed for Family Member**

State	No Support Needed	Some Support Needed	Extensive Support Needed	N
AZ	37%	39%	24%	242
CO	42%	40%	18%	202
DE	42%	40%	18%	164
FL	35%	39%	25%	360
GA	36%	41%	23%	375
KY	28%	53%	18%	197
LA	32%	41%	28%	311
MD	46%	38%	16%	185
MI	35%	42%	23%	431
NC	23%	47%	30%	282
PA	36%	40%	25%	374
SD	40%	47%	13%	322
VA	30%	42%	28%	304
WI	39%	42%	19%	516
<b>NCI Average</b>	<b>36%</b>	<b>42%</b>	<b>22%</b>	<b>4,265</b>

**Table 11. Amount of Help Needed for Family Member’s Daily Activities**

State	None	Little	Moderate	Complete	N
AZ	14%	19%	36%	31%	243
CO	22%	20%	31%	27%	205
DE	25%	23%	30%	22%	166
FL	15%	20%	33%	32%	371
GA	18%	21%	32%	29%	391
KY	14%	19%	39%	28%	203
LA	17%	19%	29%	34%	311
MD	28%	17%	27%	28%	186
MI	13%	19%	35%	33%	441
NC	9%	17%	42%	31%	286
PA	17%	16%	32%	35%	396
SD	27%	24%	29%	21%	330
VA	7%	10%	35%	48%	314
WI	12%	22%	38%	28%	518
<b>NCI Average</b>	<b>17%</b>	<b>19%</b>	<b>34%</b>	<b>30%</b>	<b>4,361</b>

## **Respondents**

*This section provides demographic information about the respondent.*

**Table 12. Respondent's Age**

State	Under 35	35-54	55-74	75 or Older	N
AZ	1%	18%	63%	18%	238
CO	0%	10%	61%	29%	206
DE	0%	10%	60%	30%	168
FL	2%	24%	58%	16%	357
GA	1%	19%	63%	16%	390
KY	2%	13%	66%	21%	200
LA	2%	15%	59%	24%	316
MD	3%	9%	60%	29%	188
MI	1%	19%	64%	16%	436
NC	4%	29%	52%	14%	287
PA	0%	13%	62%	25%	395
SD	1%	16%	63%	19%	329
VA	1%	15%	62%	22%	307
WI	2%	22%	58%	18%	511
<b>NCI Average</b>	<b>2%</b>	<b>17%</b>	<b>61%</b>	<b>21%</b>	<b>4,328</b>

**Table 13. Respondent's Relationship to Family Member**

State	Parent	Sibling	Spouse	Public Guardian	Private Guardian	Other	N
AZ	55%	24%	0%	8%	3%	10%	242
CO	66%	18%	0%	4%	9%	3%	190
DE	79%	14%	0%	0%	4%	3%	168
FL	51%	18%	0%	3%	7%	21%	367
GA	57%	28%	0%	3%	4%	8%	391
KY	55%	30%	1%	2%	4%	8%	203
LA	57%	27%	1%	2%	1%	12%	318
MD	67%	21%	1%	1%	3%	7%	190
MI	44%	27%	0%	18%	7%	4%	443
NC	43%	24%	1%	17%	8%	7%	290
PA	55%	41%	0%	1%	2%	2%	394
SD	59%	27%	0%	5%	7%	3%	307
VA	46%	25%	0%	16%	4%	8%	315
WI	46%	30%	0%	9%	11%	5%	517
<b>NCI Average</b>	<b>56%</b>	<b>25%</b>	<b>0%</b>	<b>6%</b>	<b>5%</b>	<b>7%</b>	<b>4,335</b>

**Table 14. Respondent Is Family Member’s Legal Guardian or Conservator**

State	Yes, Full	Yes, Limited	No	N
AZ	83%	4%	14%	243
CO	74%	4%	21%	205
DE	64%	6%	30%	163
FL	52%	10%	38%	368
GA	68%	5%	27%	387
KY	92%	6%	2%	203
LA	44%	7%	49%	312
MD	32%	12%	56%	177
MI	67%	24%	9%	438
NC	83%	12%	5%	289
PA	45%	14%	41%	359
SD	87%	7%	6%	329
VA	62%	10%	28%	303
WI	92%	6%	2%	518
<b>NCI Average</b>	<b>67%</b>	<b>9%</b>	<b>23%</b>	<b>4,294</b>

**Table 15. Number of Times Respondent Sees Family Member in a Year**

State	Less Than Once	1-3 Times	4-6 Times	7-12 Times	More Than 12 Times	N
AZ	2%	8%	14%	13%	63%	241
CO	4%	10%	11%	12%	63%	207
DE	3%	9%	5%	13%	70%	166
FL	4%	7%	10%	11%	68%	364
GA	5%	8%	11%	11%	66%	390
KY	2%	7%	12%	14%	65%	202
LA	6%	10%	14%	13%	57%	314
MD	4%	4%	9%	13%	70%	187
MI	2%	10%	17%	17%	54%	439
NC	3%	9%	17%	22%	49%	288
PA	8%	13%	14%	13%	52%	395
SD	6%	16%	10%	12%	56%	328
VA	5%	11%	12%	18%	54%	309
WI	1%	8%	13%	12%	65%	515
<b>NCI Average</b>	<b>4%</b>	<b>9%</b>	<b>12%</b>	<b>14%</b>	<b>61%</b>	<b>4,345</b>

**Table 16. Respondent’s Highest Level of Education**

State	No High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree	N
AZ	3%	13%	4%	36%	44%	236
CO	2%	16%	3%	22%	58%	193
DE	4%	21%	1%	25%	50%	165
FL	5%	20%	4%	26%	45%	361
GA	7%	22%	7%	23%	41%	379
KY	9%	27%	2%	24%	37%	201
LA	10%	26%	9%	23%	32%	310
MD	3%	19%	3%	26%	49%	185
MI	3%	24%	4%	21%	48%	437
NC	6%	21%	3%	16%	53%	286
PA	6%	33%	5%	19%	38%	387
SD	5%	30%	12%	19%	34%	319
VA	9%	20%	2%	24%	46%	302
WI	3%	26%	9%	21%	42%	514
<b>NCI Average</b>	<b>5%</b>	<b>23%</b>	<b>5%</b>	<b>23%</b>	<b>44%</b>	<b>4,275</b>

**Table 17. Total Taxable Family Income of Wage Earners in the Household in the Past Year**

State	Below \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	N
AZ	20%	20%	26%	15%	20%	204
CO	9%	12%	24%	24%	30%	169
DE	13%	13%	26%	27%	21%	141
FL	24%	20%	23%	16%	17%	278
GA	21%	18%	22%	19%	21%	290
KY	22%	17%	26%	16%	19%	159
LA	25%	21%	24%	16%	15%	251
MD	12%	12%	23%	21%	32%	147
MI	14%	19%	30%	20%	17%	383
NC	17%	16%	22%	22%	23%	221
PA	17%	18%	26%	19%	20%	284
SD	14%	17%	31%	19%	19%	266
VA	18%	15%	26%	18%	23%	231
WI	11%	14%	27%	22%	26%	443
<b>NCI Average</b>	<b>17%</b>	<b>16%</b>	<b>25%</b>	<b>20%</b>	<b>22%</b>	<b>3,467</b>

**Table 18. Out-of-Pocket Expenses for Family in the Past Year**

State	Nothing	\$1- \$100	\$101- \$1,000	\$1,001- \$10,000	Over \$10,000	N
AZ	43%	9%	29%	17%	2%	221
CO	55%	15%	24%	6%	1%	198
DE	42%	11%	31%	14%	2%	160
FL	46%	13%	22%	19%	1%	323
GA	45%	14%	21%	19%	1%	354
KY	50%	14%	24%	12%	0%	185
LA	57%	12%	22%	9%	1%	293
MD	49%	8%	21%	16%	5%	177
MI	51%	15%	22%	10%	2%	426
NC	59%	12%	21%	6%	2%	258
PA	63%	11%	17%	8%	1%	352
SD	61%	14%	19%	5%	1%	303
VA	67%	7%	17%	9%	0%	282
WI	52%	15%	22%	10%	1%	491
<b>NCI Average</b>	<b>53%</b>	<b>12%</b>	<b>22%</b>	<b>12%</b>	<b>1%</b>	<b>4,023</b>

## Services and Supports Received

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

**Table 19. Services and Supports Received From ID/DD Agency<sup>1</sup>**

State	Residential Supports	Day or Employment Supports	Transportation	Other	Social Security Benefits
AZ	99%	85%	95%	61%	94%
CO	96%	83%	94%	69%	95%
DE	97%	93%	96%	63%	89%
FL	92%	69%	88%	63%	97%
GA	95%	76%	91%	56%	98%
KY	98%	90%	98%	78%	96%
LA	91%	58%	84%	61%	90%
MD	96%	80%	91%	56%	93%
MI	94%	62%	93%	69%	97%
NC	95%	74%	93%	77%	96%
PA	94%	69%	87%	69%	94%
SD	98%	80%	95%	72%	97%
VA	97%	68%	93%	75%	97%
WI	93%	72%	93%	57%	96%
<b>NCI Average</b>	<b>95%</b>	<b>76%</b>	<b>92%</b>	<b>66%</b>	<b>95%</b>

<sup>1</sup> All services provided by the state with the exception on social security benefits.

# Family/Guardian Survey Results

## Information and Planning

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

**Note: State outcomes denoted with an N/A means there were too few cases to report (less than 20 responses).**

### Gets Enough Information to Help Plan Services

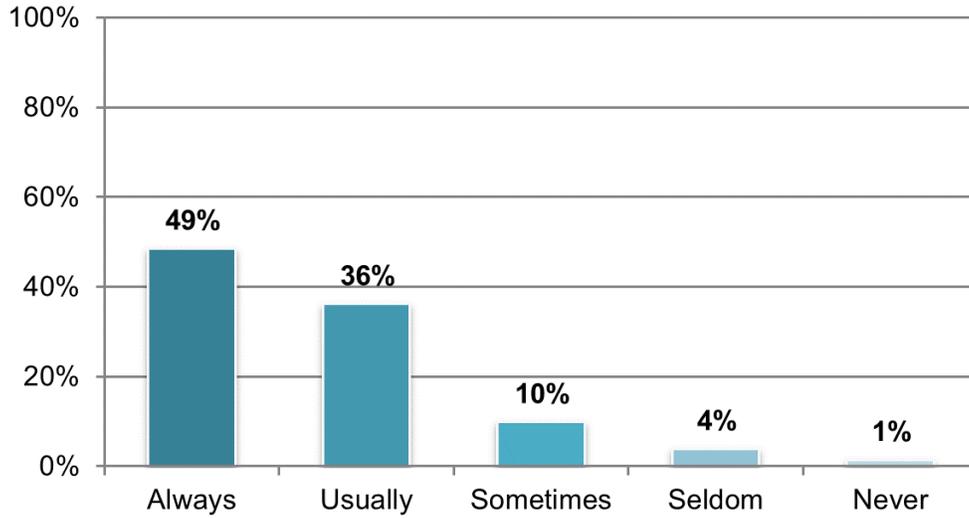


Table Q1. Do you get enough information to help you participate in planning services for your family member?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
NC	64%	28%	6%	1%	1%	281
WI	59%	33%	8%	1%	0%	503
VA	57%	32%	8%	3%	0%	294
MI	56%	32%	9%	3%	1%	429
FL	56%	29%	9%	5%	1%	354
<b>Within Average Range</b>						
AZ	51%	38%	9%	2%	0%	242
SD	50%	38%	10%	1%	1%	330
CO	50%	39%	6%	5%	1%	207
PA	48%	35%	12%	4%	2%	371
KY	45%	37%	13%	4%	1%	196
<b>Significantly Below Average</b>						
GA	40%	38%	14%	3%	4%	370
LA	40%	39%	14%	4%	3%	287
MD	34%	44%	9%	9%	3%	179
DE	30%	45%	13%	10%	3%	159
<b>NCI Average</b>	<b>49%</b>	<b>36%</b>	<b>10%</b>	<b>4%</b>	<b>1%</b>	<b>4,202</b>

### Information About Services and Supports Is Easy to Understand

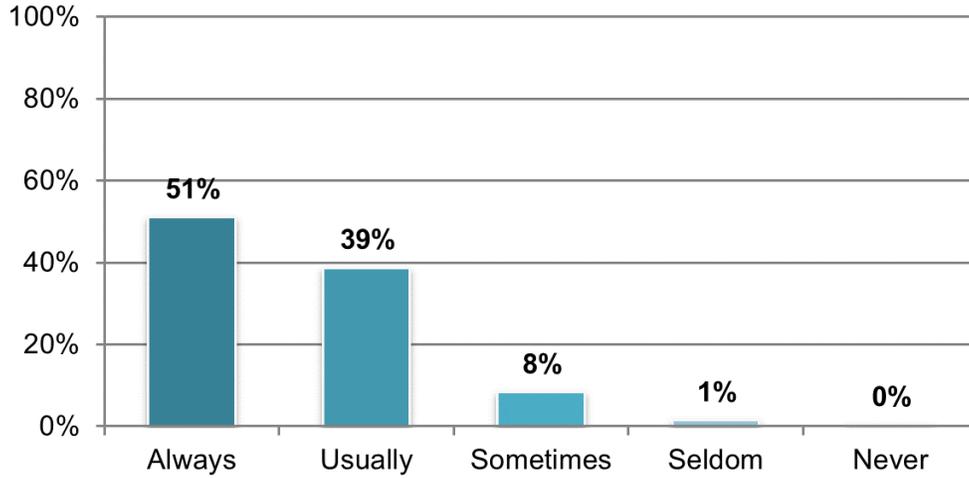


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
VA	59%	32%	9%	0%	0%	298
NC	59%	37%	4%	0%	0%	280
<b>Within Average Range</b>						
MI	57%	36%	7%	1%	0%	428
SD	54%	38%	7%	1%	0%	327
AZ	54%	37%	8%	2%	0%	241
PA	53%	37%	9%	0%	0%	367
FL	53%	37%	9%	2%	0%	350
WI	51%	39%	9%	1%	0%	506
CO	50%	41%	7%	1%	0%	205
LA	48%	39%	12%	1%	0%	281
KY	47%	39%	11%	2%	0%	194
GA	46%	42%	9%	3%	1%	367
MD	45%	42%	6%	3%	3%	175
<b>Significantly Below Average</b>						
DE	38%	48%	10%	4%	0%	157
<b>NCI Average</b>	<b>51%</b>	<b>39%</b>	<b>8%</b>	<b>1%</b>	<b>0%</b>	<b>4,176</b>

### Kept Informed About How Family Member Is Doing

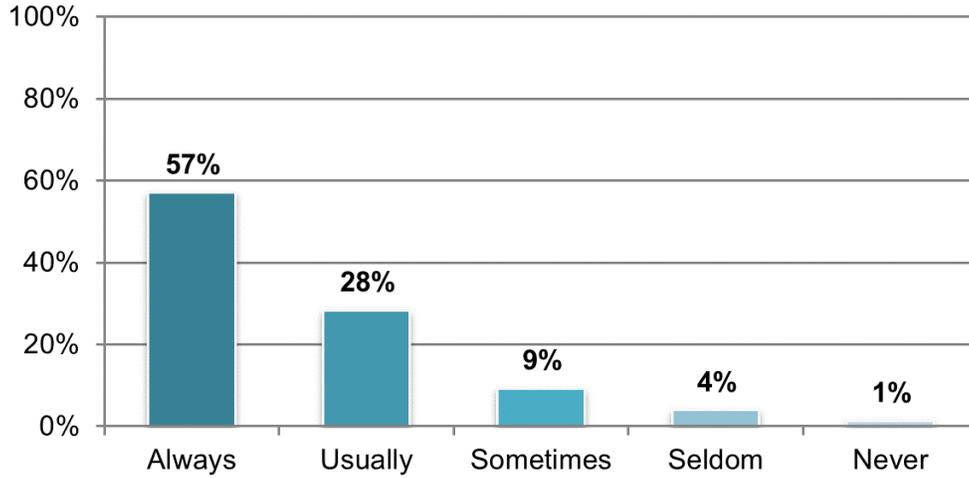
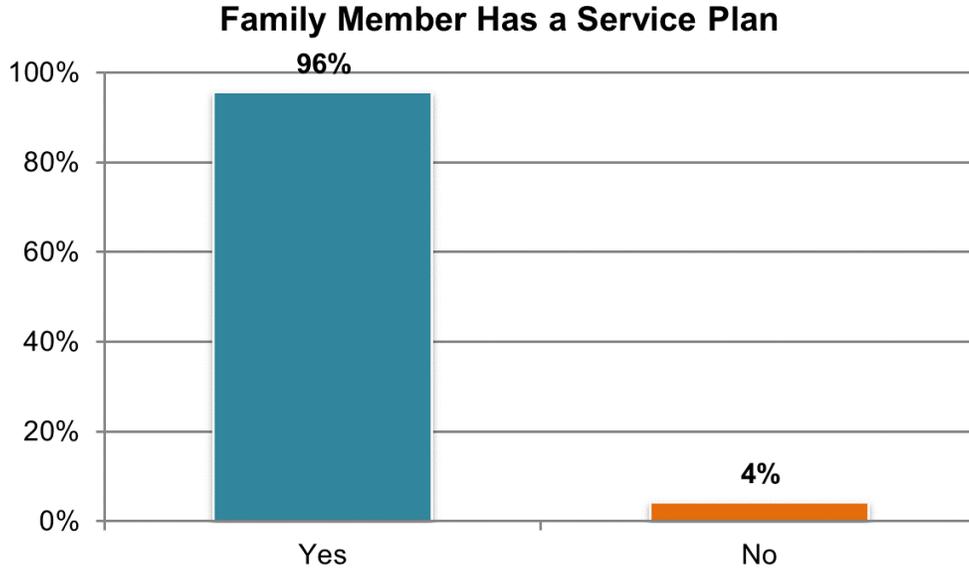


Table Q3. Are you kept informed about how your family member is doing?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
WI	71%	24%	4%	1%	0%	494
VA	66%	23%	8%	2%	0%	309
NC	66%	29%	2%	2%	1%	286
FL	65%	21%	10%	3%	1%	356
<b>Within Average Range</b>						
MI	63%	26%	7%	3%	1%	434
AZ	59%	32%	6%	3%	0%	239
PA	57%	27%	11%	4%	1%	379
CO	56%	29%	9%	5%	0%	206
KY	56%	26%	14%	3%	0%	201
GA	55%	27%	11%	3%	3%	382
LA	53%	30%	10%	4%	2%	303
SD	53%	33%	9%	5%	1%	331
<b>Significantly Below Average</b>						
MD	42%	34%	13%	7%	4%	184
DE	36%	37%	16%	8%	4%	167
<b>NCI Average</b>	<b>57%</b>	<b>28%</b>	<b>9%</b>	<b>4%</b>	<b>1%</b>	<b>4,271</b>



**Table Q4. Does your family member have a service plan?**

State	Yes	No	N
<b>Significantly Above Average</b>			
FL	99%	1%	351
NC	98%	2%	252
<b>Within Average Range</b>			
MI	97%	3%	390
CO	97%	3%	187
SD	97%	3%	287
WI	96%	4%	466
GA	96%	4%	325
DE	96%	4%	135
PA	96%	4%	295
AZ	95%	5%	215
MD	95%	5%	164
VA	95%	5%	246
KY	93%	7%	171
<b>Significantly Below Average</b>			
LA	88%	12%	223
<b>NCI Average</b>	<b>96%</b>	<b>4%</b>	<b>3,707</b>

### Family Member Helped Develop Service Plan

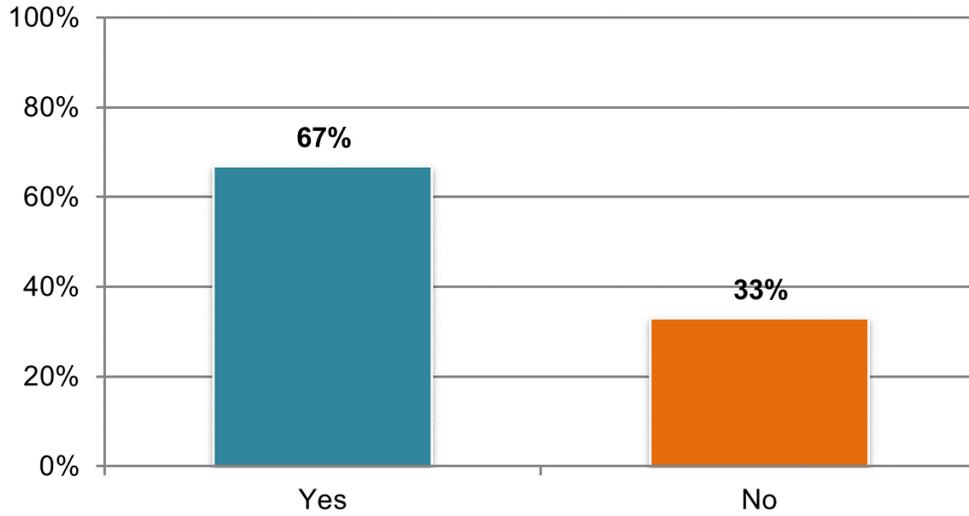


Table Q5. Did your family member help develop the plan?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	81%	19%	247
<b>Within Average Range</b>			
MD	74%	26%	136
CO	73%	27%	164
FL	73%	27%	309
MI	72%	28%	351
DE	70%	30%	114
GA	70%	30%	279
WI	66%	34%	404
KY	65%	35%	139
AZ	61%	39%	174
PA	61%	39%	238
LA	61%	39%	157
<b>Significantly Below Average</b>			
NC	59%	41%	212
VA	52%	48%	190
<b>NCI Average</b>	<b>67%</b>	<b>33%</b>	<b>3,114</b>

### Respondent or Another Family Member Helped Develop Service Plan

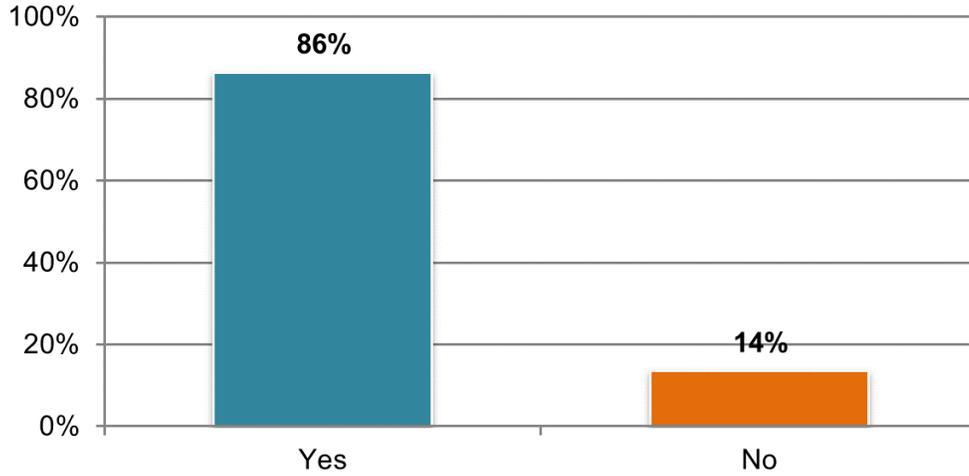


Table Q6. Did you or another family member help develop the plan?

State	Yes	No	N
<b>Significantly Above Average</b>			
AZ	92%	8%	197
MI	92%	8%	370
<b>Within Average Range</b>			
CO	90%	10%	172
KY	90%	10%	153
MD	89%	11%	150
WI	89%	11%	429
SD	89%	11%	263
GA	89%	11%	297
NC	88%	12%	235
DE	87%	13%	126
FL	84%	16%	329
VA	82%	18%	220
<b>Significantly Below Average</b>			
LA	78%	22%	182
PA	72%	28%	261
<b>NCI Average</b>	<b>86%</b>	<b>14%</b>	<b>3,384</b>

### Service Plan Includes All the Services and Supports Family Member Wants

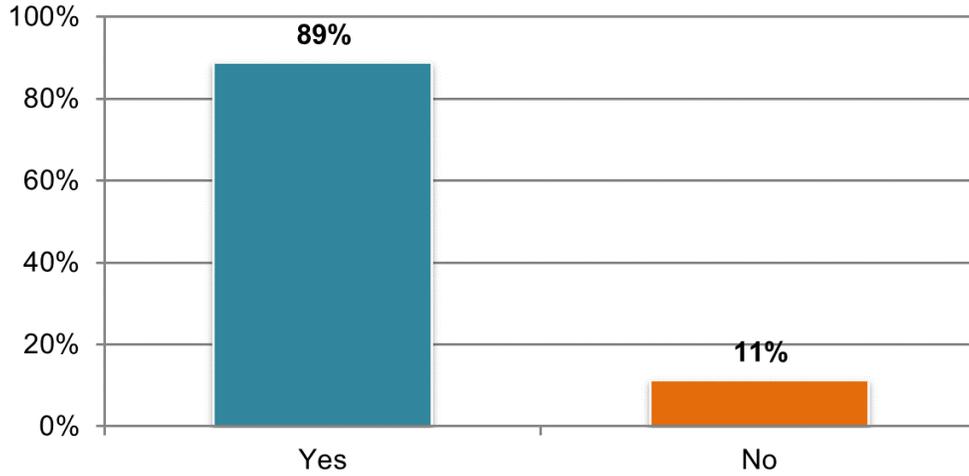


Table Q7. Does the plan include all the services and supports your family member wants?

State	Yes	No	N
<b>Within Average Range</b>			
VA	93%	7%	193
MD	92%	8%	131
CO	91%	9%	154
WI	91%	9%	409
SD	90%	10%	251
PA	90%	10%	236
MI	90%	10%	344
NC	89%	11%	218
KY	89%	11%	141
AZ	89%	11%	180
FL	87%	13%	313
LA	87%	13%	164
GA	84%	16%	269
DE	81%	19%	111
<b>NCI Average</b>	<b>89%</b>	<b>11%</b>	<b>3,114</b>

### Service Plan Includes All the Services and Supports Family Member Needs

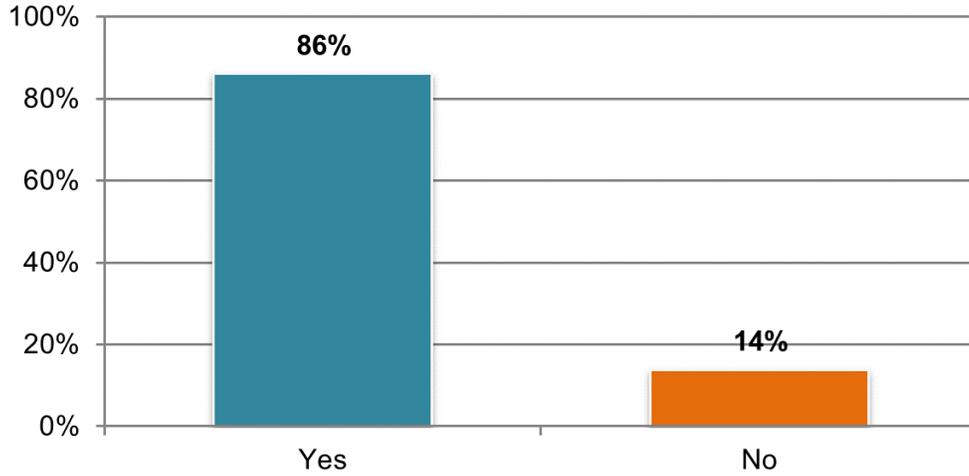


Table Q8. Does the plan include all the services and supports your family member needs?

State	Yes	No	N
<b>Significantly Above Average</b>			
VA	93%	7%	215
NC	90%	10%	231
<b>Within Average Range</b>			
WI	90%	10%	422
CO	89%	11%	168
SD	89%	11%	254
MD	88%	12%	139
MI	88%	12%	353
PA	88%	12%	252
LA	87%	13%	166
AZ	86%	14%	188
KY	84%	16%	143
FL	81%	19%	313
GA	80%	20%	274
<b>Significantly Below Average</b>			
DE	72%	28%	110
<b>NCI Average</b>	<b>86%</b>	<b>14%</b>	<b>3,228</b>

### Family Member Receives All Services Listed in Service Plan

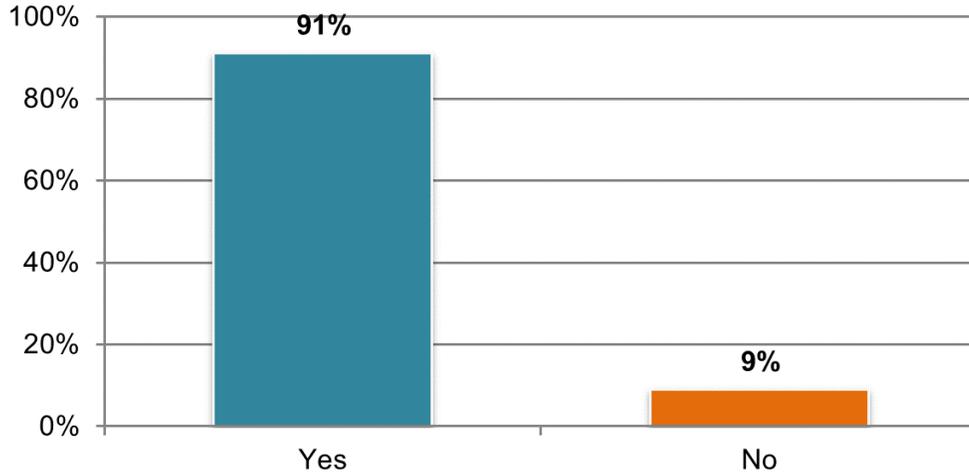
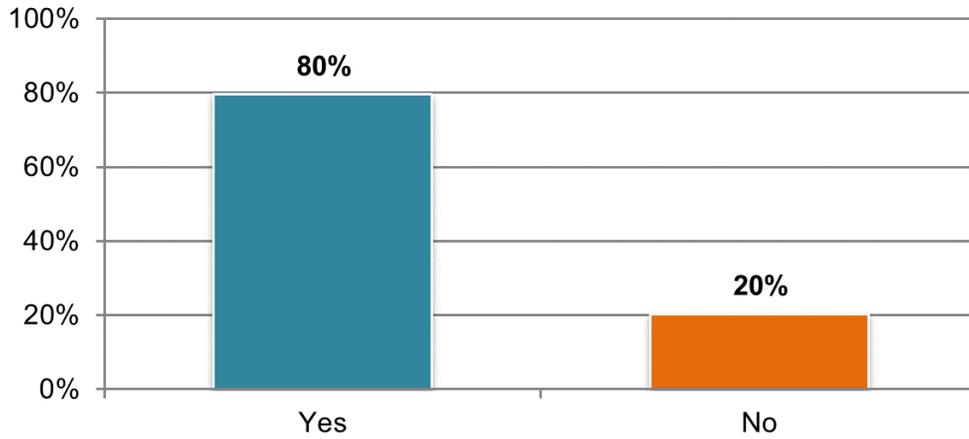


Table Q9. Does your family member receive all of the services listed in the plan?

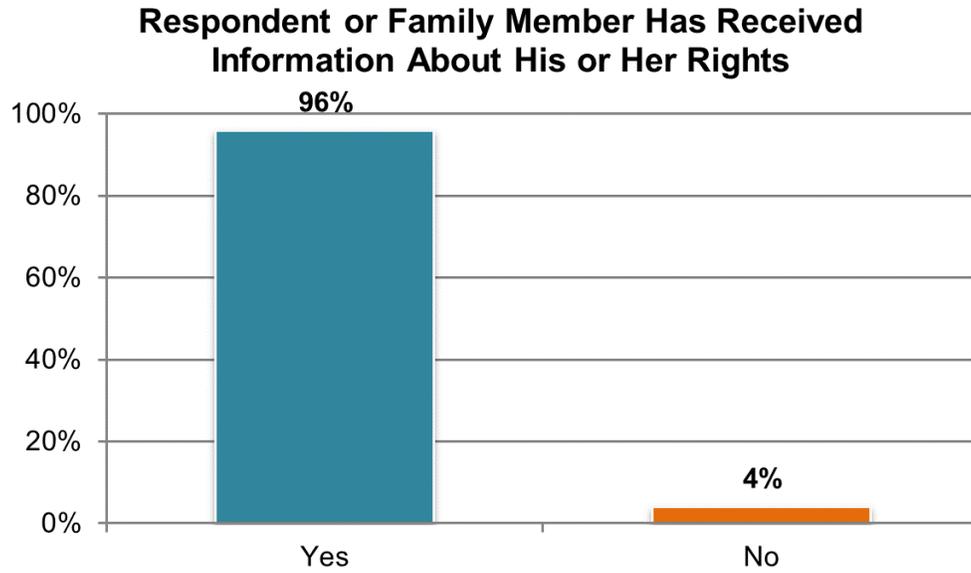
State	Yes	No	N
<b>Significantly Above Average</b>			
WI	97%	3%	418
NC	96%	4%	223
VA	96%	4%	203
<b>Within Average Range</b>			
AZ	94%	6%	179
PA	94%	6%	225
FL	94%	6%	308
CO	94%	6%	160
LA	93%	7%	154
MI	93%	7%	343
MD	90%	10%	135
SD	89%	11%	240
GA	88%	12%	255
KY	86%	14%	131
<b>Significantly Below Average</b>			
DE	71%	29%	98
<b>NCI Average</b>	<b>91%</b>	<b>9%</b>	<b>3,072</b>

### Respondent Discussed How to Handle Emergencies Related to Family Member at Last Service Planning Meeting



**Table Q10. Did you discuss how to handle emergencies related to your family member at the last service planning meeting?**

State	Yes	No	N
<b>Significantly Above Average</b>			
NC	91%	9%	236
KY	88%	12%	153
LA	87%	13%	172
MI	86%	14%	352
<b>Within Average Range</b>			
WI	83%	17%	403
FL	82%	18%	317
SD	82%	18%	244
AZ	80%	20%	178
VA	79%	21%	211
CO	76%	24%	162
GA	76%	24%	279
PA	74%	26%	246
MD	72%	28%	141
<b>Significantly Below Average</b>			
DE	61%	39%	114
<b>NCI Average</b>	<b>80%</b>	<b>20%</b>	<b>3,208</b>



**Table Q11. Have you or your family member received information about his/her rights?**

State	Yes	No	N
<b>Significantly Above Average</b>			
NC	99%	1%	272
VA	99%	1%	286
MI	99%	1%	411
WI	99%	1%	475
KY	98%	2%	191
FL	98%	2%	351
<b>Within Average Range</b>			
SD	98%	2%	302
CO	97%	3%	196
AZ	96%	4%	233
PA	96%	4%	316
GA	93%	7%	353
LA	93%	7%	259
DE	90%	10%	139
<b>Significantly Below Average</b>			
MD	88%	12%	164
<b>NCI Average</b>	<b>96%</b>	<b>4%</b>	<b>3,948</b>

## Access and Delivery of Services and Supports

*Families and family members with disabilities get the services and supports they need.*

**Note: State outcomes denoted with an N/A means there were too few cases to report (less than 20 responses).**

### Respondent Is Able to Contact Support Workers When Needed

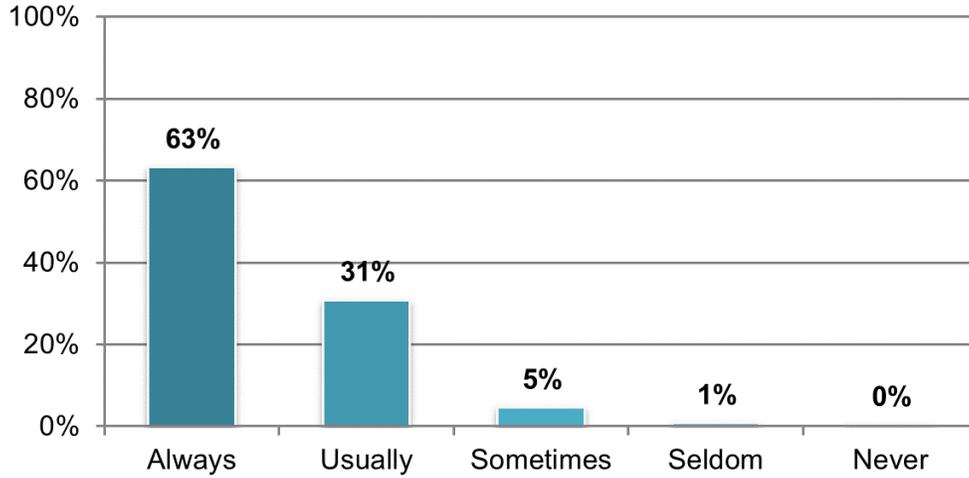


Table Q12. Are you able to contact your family member’s support workers when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
WI	74%	23%	2%	0%	0%	514
FL	73%	21%	5%	1%	1%	363
VA	72%	26%	2%	1%	0%	313
<b>Within Average Range</b>						
CO	67%	29%	4%	0%	0%	202
NC	67%	30%	2%	1%	0%	288
MI	65%	30%	5%	0%	0%	437
PA	64%	29%	6%	1%	0%	395
GA	62%	32%	4%	1%	1%	385
SD	61%	34%	4%	1%	0%	324
LA	61%	31%	5%	1%	1%	305
AZ	59%	35%	4%	2%	0%	245
KY	59%	37%	4%	0%	0%	198
<b>Significantly Below Average</b>						
MD	52%	36%	8%	2%	2%	184
DE	49%	37%	11%	1%	1%	166
<b>NCI Average</b>	<b>63%</b>	<b>31%</b>	<b>5%</b>	<b>1%</b>	<b>0%</b>	<b>4,319</b>

### Respondent Is Able to Contact Case Manager/Service Coordinator When Needed

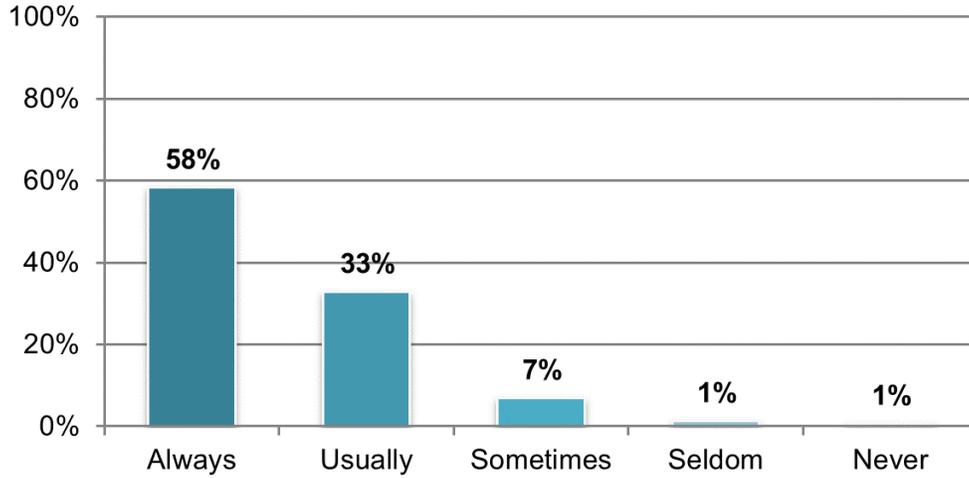


Table Q13. Are you able to contact your family member’s case manager/service coordinator when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
FL	72%	21%	6%	1%	1%	357
VA	70%	26%	4%	0%	0%	308
WI	69%	28%	2%	0%	0%	509
<b>Within Average Range</b>						
NC	63%	32%	3%	1%	0%	282
KY	61%	31%	7%	0%	0%	197
MI	59%	34%	6%	1%	0%	438
PA	58%	33%	7%	1%	0%	378
SD	57%	37%	5%	1%	0%	330
GA	56%	35%	6%	1%	1%	379
CO	56%	36%	7%	0%	0%	201
LA	54%	37%	7%	1%	1%	303
AZ	52%	39%	7%	2%	0%	242
<b>Significantly Below Average</b>						
MD	46%	37%	10%	5%	2%	175
DE	42%	33%	19%	3%	3%	161
<b>NCI Average</b>	<b>58%</b>	<b>33%</b>	<b>7%</b>	<b>1%</b>	<b>1%</b>	<b>4,260</b>

### Services and Supports Are Available a Reasonable Distance from Family Member's Home

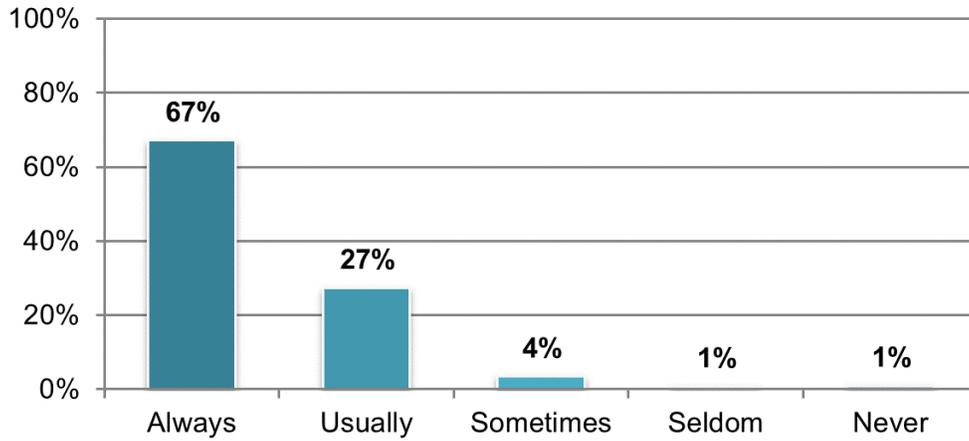


Table Q14. Are services and supports available within a reasonable distance from your family member’s home?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
WI	74%	23%	2%	0%	1%	501
<b>Within Average Range</b>						
SD	73%	23%	2%	1%	2%	317
FL	70%	25%	3%	0%	1%	345
PA	70%	24%	4%	0%	2%	350
CO	70%	28%	2%	0%	0%	197
NC	69%	24%	4%	2%	1%	272
MI	69%	28%	2%	0%	0%	414
LA	68%	23%	5%	3%	1%	282
KY	67%	28%	4%	0%	1%	188
AZ	65%	29%	3%	2%	0%	231
VA	65%	31%	3%	0%	1%	288
GA	64%	29%	5%	1%	2%	370
MD	63%	30%	4%	1%	2%	166
<b>Significantly Below Average</b>						
DE	55%	39%	4%	0%	1%	152
<b>NCI Average</b>	<b>67%</b>	<b>27%</b>	<b>4%</b>	<b>1%</b>	<b>1%</b>	<b>4,073</b>

### Services and Supports Change When Family Member's Needs Change

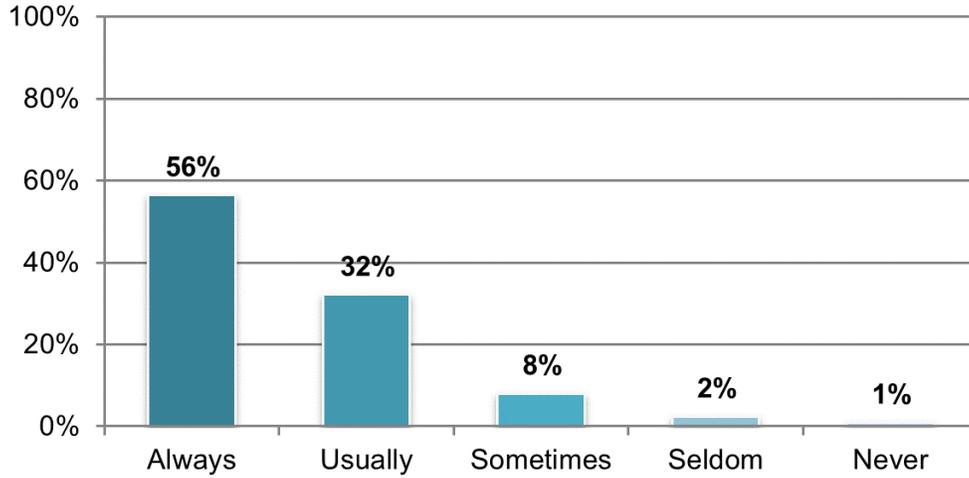


Table Q15. Do the services and supports change when your family member’s needs change?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
WI	63%	28%	6%	2%	1%	485
<b>Within Average Range</b>						
CO	61%	32%	7%	0%	0%	190
NC	61%	30%	6%	2%	1%	264
VA	60%	35%	3%	1%	0%	272
MI	60%	32%	7%	1%	1%	389
SD	58%	31%	9%	2%	0%	313
FL	58%	30%	9%	2%	1%	325
AZ	58%	30%	10%	2%	0%	222
PA	57%	30%	7%	4%	1%	324
LA	57%	32%	6%	4%	2%	260
KY	56%	32%	7%	3%	1%	174
GA	51%	35%	10%	3%	1%	340
<b>Significantly Below Average</b>						
MD	45%	34%	16%	4%	1%	148
DE	44%	39%	9%	5%	3%	139
<b>NCI Average</b>	<b>56%</b>	<b>32%</b>	<b>8%</b>	<b>2%</b>	<b>1%</b>	<b>3,845</b>

### Support Workers Can Communicate with Family Member (If Non-Verbal)

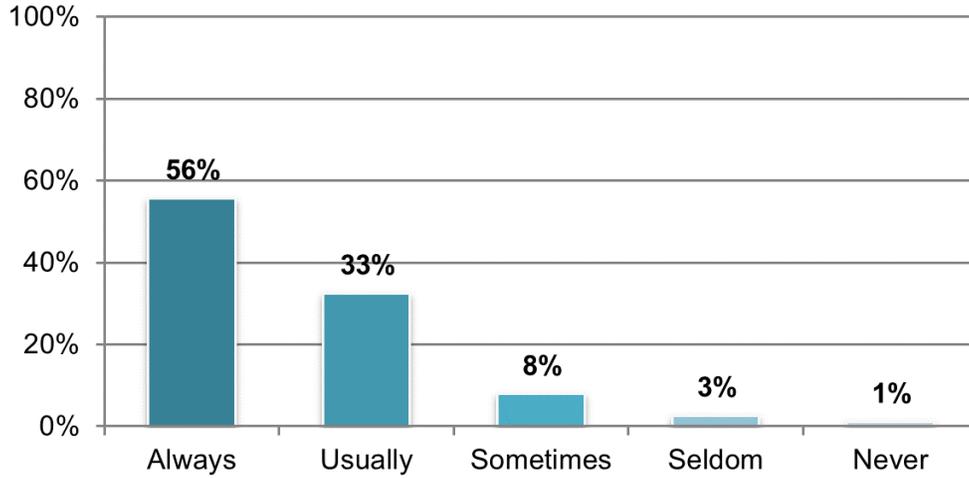


Table Q16. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
WI	67%	22%	9%	1%	0%	137
FL	67%	20%	8%	2%	2%	86
<b>Within Average Range</b>						
NC	66%	28%	5%	0%	0%	95
MI	63%	28%	6%	1%	1%	144
PA	61%	30%	6%	1%	2%	129
SD	57%	35%	5%	2%	1%	84
LA	55%	32%	10%	1%	2%	98
VA	55%	35%	8%	1%	1%	174
AZ	53%	34%	7%	3%	3%	73
KY	53%	34%	10%	3%	0%	59
GA	50%	40%	6%	3%	2%	121
CO	46%	42%	10%	2%	0%	48
MD	44%	36%	13%	4%	2%	45
DE	42%	40%	7%	11%	0%	45
<b>NCI Average</b>	<b>56%</b>	<b>33%</b>	<b>8%</b>	<b>3%</b>	<b>1%</b>	<b>1,338</b>

### Support Workers Speak Effectively with Family Member in Primary Language (If English)

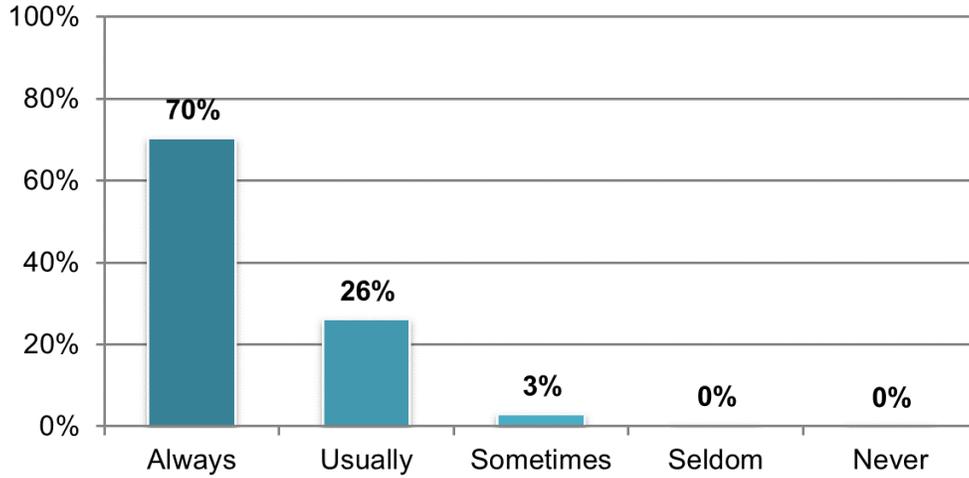


Table Q17. If English is your family member’s first language, do the support workers speak to him/her effectively?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
FL	79%	18%	2%	1%	0%	326
NC	77%	23%	1%	0%	0%	261
<b>Within Average Range</b>						
MI	76%	20%	3%	1%	0%	386
VA	75%	23%	2%	0%	0%	258
WI	74%	23%	3%	0%	0%	471
GA	73%	25%	2%	0%	0%	342
SD	72%	27%	1%	0%	0%	308
LA	72%	26%	2%	0%	0%	265
CO	71%	27%	2%	1%	0%	181
PA	71%	25%	4%	0%	0%	335
KY	70%	24%	4%	2%	0%	184
AZ	68%	29%	2%	0%	0%	214
<b>Significantly Below Average</b>						
MD	59%	34%	7%	1%	0%	162
DE	50%	40%	8%	1%	1%	151
<b>NCI Average</b>	<b>70%</b>	<b>26%</b>	<b>3%</b>	<b>0%</b>	<b>0%</b>	<b>3,844</b>

### Services Are Delivered in a Manner That Is Respectful to Family Member's Culture

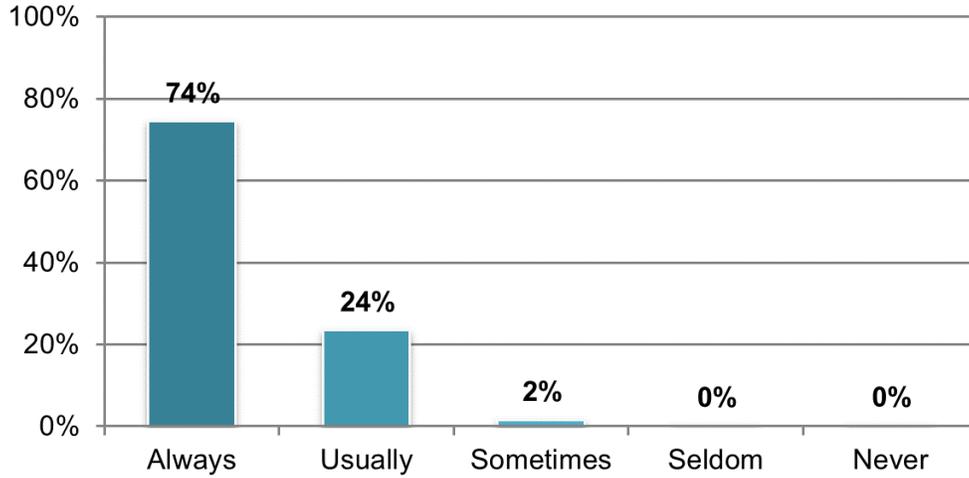
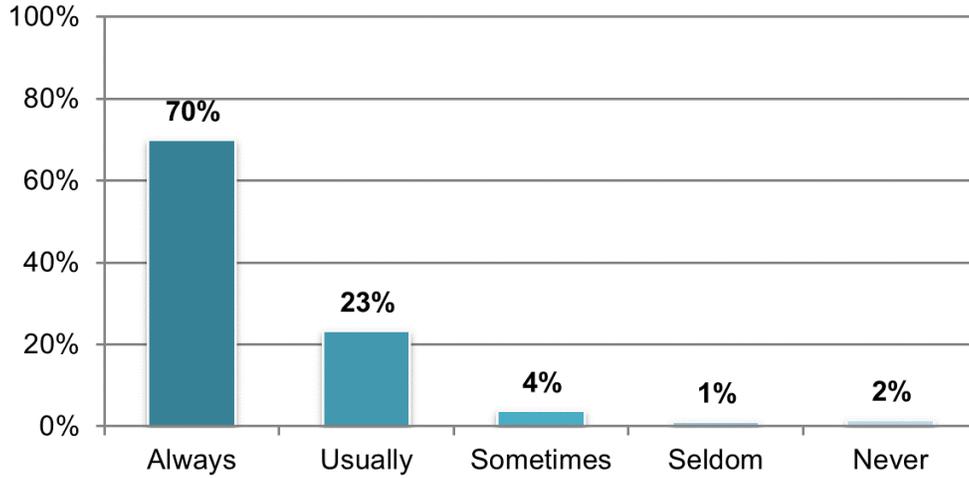


Table Q18–19. Are services delivered in a way that is respectful to your family member’s culture?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
FL	84%	14%	1%	1%	0%	339
WI	80%	19%	1%	0%	0%	468
NC	79%	19%	1%	0%	0%	267
<b>Within Average Range</b>						
MI	77%	22%	1%	0%	0%	404
PA	76%	22%	1%	0%	0%	338
SD	76%	23%	1%	0%	0%	297
VA	76%	23%	1%	0%	0%	284
CO	74%	24%	1%	0%	1%	182
GA	74%	24%	2%	0%	1%	348
AZ	73%	25%	1%	0%	0%	221
MD	72%	25%	3%	0%	1%	158
KY	72%	25%	3%	1%	0%	179
LA	70%	27%	3%	0%	0%	273
<b>Significantly Below Average</b>						
DE	61%	36%	2%	0%	1%	150
<b>NCI Average</b>	<b>74%</b>	<b>24%</b>	<b>2%</b>	<b>0%</b>	<b>0%</b>	<b>3,908</b>

### Family Member Has Access to Special Equipment or Accommodations Needed



**Table Q19–20.** Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
VA	81%	16%	2%	0%	1%	245
PA	78%	18%	3%	0%	1%	254
MI	78%	19%	2%	1%	1%	270
<b>Within Average Range</b>						
NC	75%	19%	3%	2%	1%	156
WI	74%	22%	3%	0%	1%	299
SD	74%	23%	2%	1%	1%	189
FL	72%	23%	2%	1%	2%	184
MD	70%	22%	5%	1%	1%	94
AZ	66%	27%	5%	1%	0%	146
GA	66%	24%	5%	1%	4%	216
CO	65%	28%	4%	3%	0%	109
LA	64%	22%	5%	2%	6%	178
DE	62%	31%	3%	1%	2%	87
<b>Significantly Below Average</b>						
KY	55%	33%	8%	2%	2%	121
<b>NCI Average</b>	<b>70%</b>	<b>23%</b>	<b>4%</b>	<b>1%</b>	<b>2%</b>	<b>2,548</b>

### Support Workers Have the Right Training to Meet Family Member's Needs

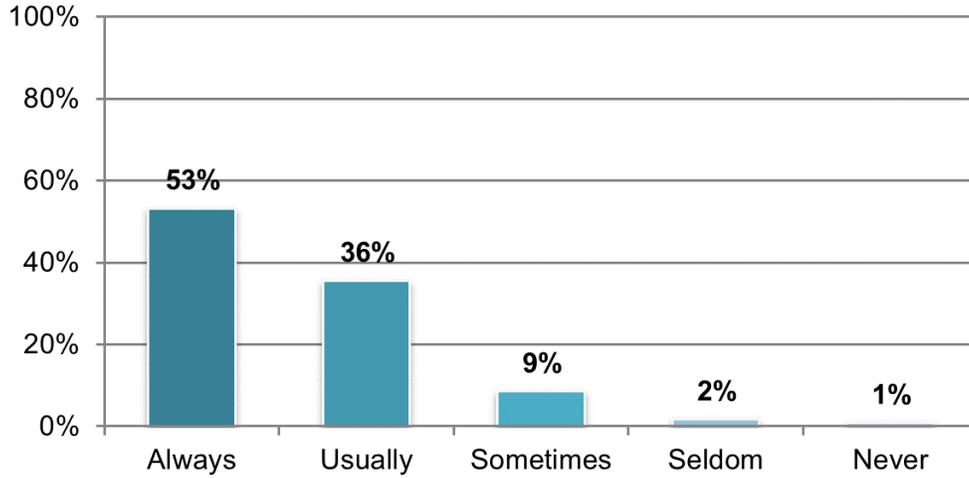


Table Q20–21. Do the support workers have the right training to meet your family member’s needs?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
FL	67%	25%	5%	1%	1%	321
VA	66%	29%	4%	1%	0%	290
MI	60%	31%	7%	1%	0%	410
<b>Within Average Range</b>						
WI	58%	34%	8%	1%	0%	485
CO	57%	37%	5%	1%	1%	188
NC	56%	37%	6%	2%	0%	270
PA	56%	34%	8%	1%	1%	347
LA	53%	34%	10%	2%	2%	265
GA	51%	36%	9%	2%	2%	350
AZ	49%	37%	12%	2%	0%	223
SD	48%	39%	12%	2%	0%	305
KY	47%	39%	11%	3%	1%	187
<b>Significantly Below Average</b>						
MD	39%	45%	13%	2%	0%	150
DE	39%	43%	11%	4%	4%	134
<b>NCI Average</b>	<b>53%</b>	<b>36%</b>	<b>9%</b>	<b>2%</b>	<b>1%</b>	<b>3,925</b>

### Family Member's Residential Setting Is a Healthy and Safe Environment

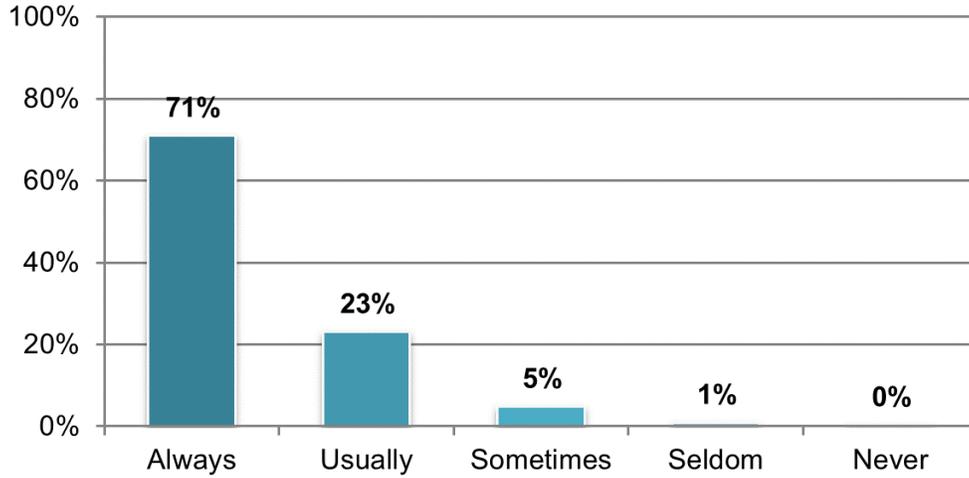


Table Q21–22. Do you feel that your family member's residential setting is a healthy and safe environment?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
VA	79%	16%	4%	0%	0%	309
FL	79%	16%	4%	1%	1%	358
WI	77%	21%	1%	0%	0%	510
MI	77%	18%	5%	0%	0%	433
<b>Within Average Range</b>						
CO	76%	22%	2%	0%	0%	203
NC	76%	19%	4%	1%	0%	279
PA	71%	23%	5%	1%	1%	388
GA	70%	22%	6%	1%	1%	372
AZ	69%	24%	5%	1%	0%	242
LA	68%	24%	6%	2%	0%	300
MD	66%	26%	7%	1%	1%	183
KY	65%	26%	8%	2%	0%	200
<b>Significantly Below Average</b>						
SD	62%	33%	4%	1%	0%	327
DE	57%	35%	6%	1%	1%	161
<b>NCI Average</b>	<b>71%</b>	<b>23%</b>	<b>5%</b>	<b>1%</b>	<b>0%</b>	<b>4,265</b>

### Family Member's Day/Employment Setting Is a Healthy and Safe Environment

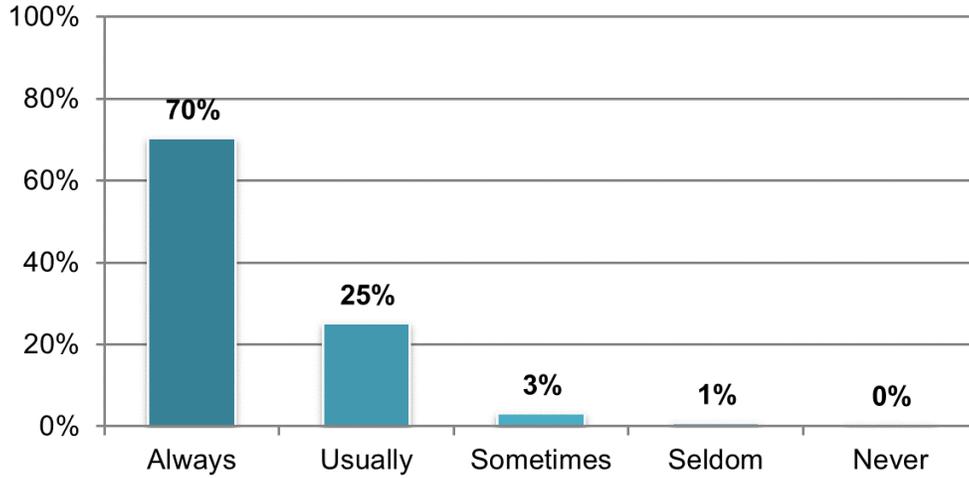


Table Q22–23. Do you feel that your family member’s day/employment setting is a healthy and safe environment?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
WI	80%	18%	2%	0%	0%	437
VA	78%	18%	3%	0%	0%	245
PA	77%	19%	3%	0%	1%	308
<b>Within Average Range</b>						
NC	76%	21%	3%	0%	0%	245
FL	75%	21%	3%	0%	0%	296
MI	75%	21%	3%	1%	0%	336
GA	69%	26%	3%	1%	1%	299
AZ	69%	27%	4%	0%	0%	220
SD	67%	29%	3%	0%	0%	292
MD	66%	27%	3%	3%	2%	154
CO	65%	33%	2%	1%	0%	185
LA	64%	29%	5%	2%	0%	223
KY	62%	31%	5%	1%	1%	169
DE	62%	33%	3%	2%	1%	152
<b>NCI Average</b>	<b>70%</b>	<b>25%</b>	<b>3%</b>	<b>1%</b>	<b>0%</b>	<b>3,561</b>

## Choice and Control

*Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.*

**Note: State outcomes denoted with an N/A means there were too few cases to report (less than 20 responses).**

### Residential Service Agency Involves Family Member in Important Decisions

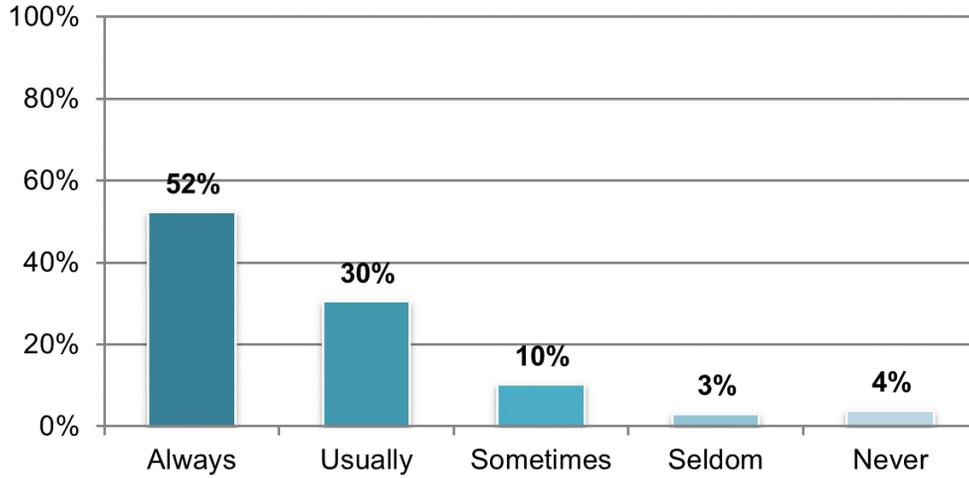


Table Q25. Does the agency providing residential services to your family member involve him/her in important decisions?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
FL	68%	18%	7%	3%	4%	278
<b>Within Average Range</b>						
WI	57%	30%	8%	2%	3%	391
SD	55%	33%	10%	2%	0%	266
MI	54%	31%	8%	2%	5%	337
MD	54%	27%	15%	0%	5%	108
AZ	53%	28%	11%	4%	3%	174
CO	52%	33%	9%	2%	3%	170
NC	51%	34%	9%	2%	4%	204
VA	51%	29%	10%	4%	6%	217
PA	50%	34%	9%	4%	4%	254
KY	50%	29%	14%	5%	3%	145
LA	50%	29%	13%	3%	5%	212
GA	45%	34%	11%	3%	7%	272
DE	42%	37%	10%	7%	3%	126
<b>NCI Average</b>	<b>52%</b>	<b>30%</b>	<b>10%</b>	<b>3%</b>	<b>4%</b>	<b>3,154</b>

### Family Member Chooses Provider Agencies

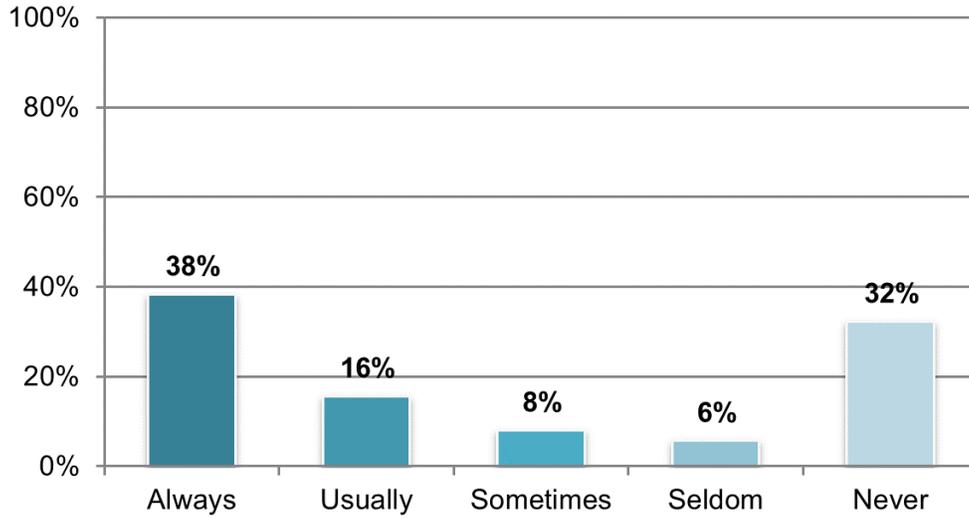


Table Q26. Does your family member choose the provider agencies that work with him or her?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
FL	53%	12%	5%	6%	24%	272
<b>Within Average Range</b>						
LA	48%	15%	4%	5%	29%	164
WI	45%	17%	11%	2%	25%	340
CO	44%	12%	8%	6%	30%	131
MD	41%	17%	4%	6%	32%	108
GA	38%	15%	6%	4%	37%	234
SD	38%	15%	14%	9%	24%	173
KY	37%	21%	9%	6%	27%	122
MI	37%	14%	9%	7%	33%	258
NC	36%	16%	10%	5%	34%	166
AZ	33%	18%	11%	5%	33%	132
VA	31%	12%	8%	5%	44%	153
DE	30%	23%	8%	7%	33%	92
<b>Significantly Below Average</b>						
PA	27%	13%	6%	7%	47%	173
<b>NCI Average</b>	<b>38%</b>	<b>16%</b>	<b>8%</b>	<b>6%</b>	<b>32%</b>	<b>2,518</b>

### Family Member Can Choose a Different Provider Agency If Desired

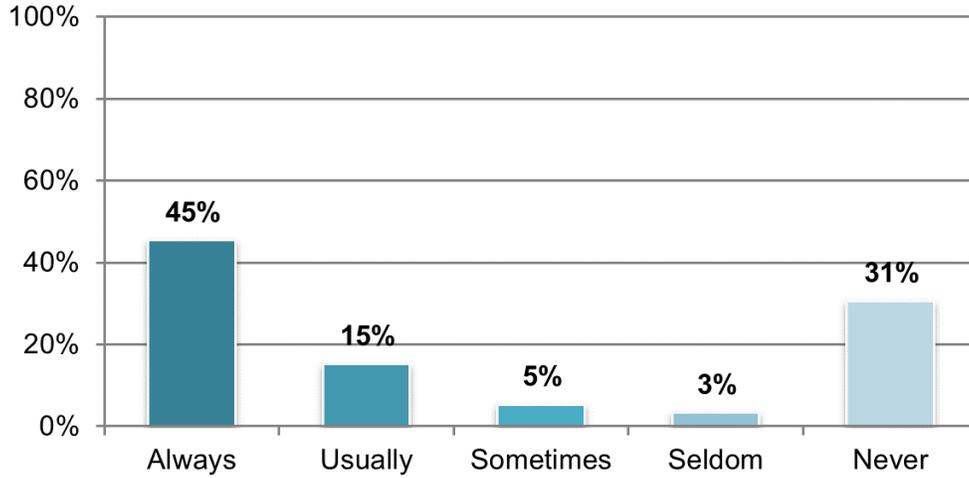


Table 27. Can your family member choose a different provider agency if s/he wants to?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
FL	66%	11%	3%	5%	14%	263
<b>Within Average Range</b>						
CO	55%	17%	4%	4%	20%	109
LA	55%	12%	3%	4%	27%	163
MD	50%	18%	4%	0%	28%	74
AZ	48%	17%	8%	3%	25%	109
KY	48%	17%	2%	2%	31%	122
WI	47%	19%	6%	3%	25%	320
GA	43%	15%	5%	4%	33%	219
NC	40%	12%	10%	5%	32%	154
SD	39%	19%	7%	7%	29%	123
MI	39%	15%	6%	6%	34%	222
PA	36%	12%	4%	1%	47%	139
VA	35%	14%	6%	1%	43%	141
DE	35%	16%	6%	4%	39%	77
<b>NCI Average</b>	<b>45%</b>	<b>15%</b>	<b>5%</b>	<b>3%</b>	<b>31%</b>	<b>2,235</b>

### Family Member Chooses Individual Support Workers That Work Directly With Him/Her

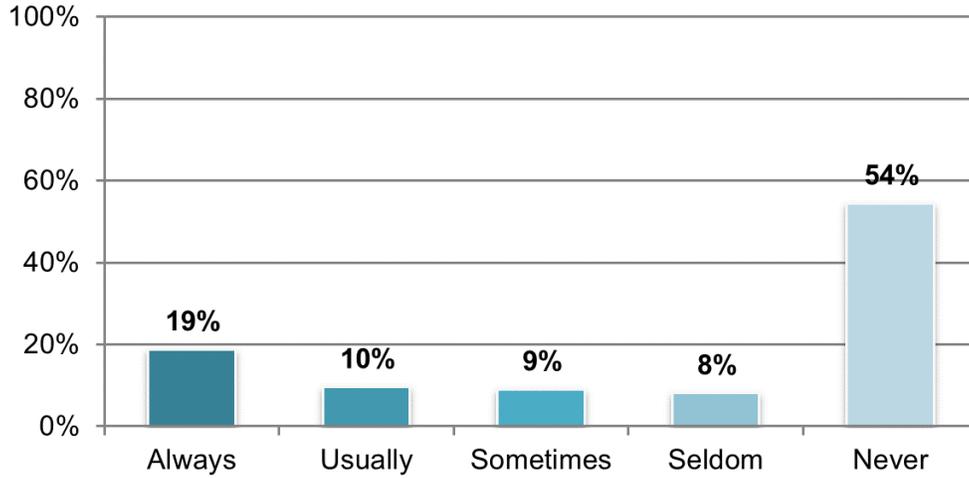


Table Q28. Does your family member choose the individual support workers who work directly with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
FL	51%	11%	4%	5%	28%	272
<b>Within Average Range</b>						
LA	26%	7%	8%	6%	53%	175
WI	24%	13%	15%	8%	40%	353
NC	22%	9%	10%	11%	47%	169
GA	20%	9%	9%	9%	53%	247
VA	19%	6%	5%	4%	66%	163
CO	18%	19%	13%	8%	42%	130
MI	18%	14%	8%	12%	48%	273
AZ	15%	5%	11%	7%	63%	130
KY	13%	14%	11%	10%	51%	127
<b>Significantly Below Average</b>						
SD	10%	8%	12%	11%	59%	182
PA	10%	8%	4%	8%	70%	204
MD	9%	10%	7%	4%	70%	106
DE	7%	1%	9%	9%	73%	107
<b>NCI Average</b>	<b>19%</b>	<b>10%</b>	<b>9%</b>	<b>8%</b>	<b>54%</b>	<b>2,638</b>

### Family Member Can Choose Different Support Workers If Desired

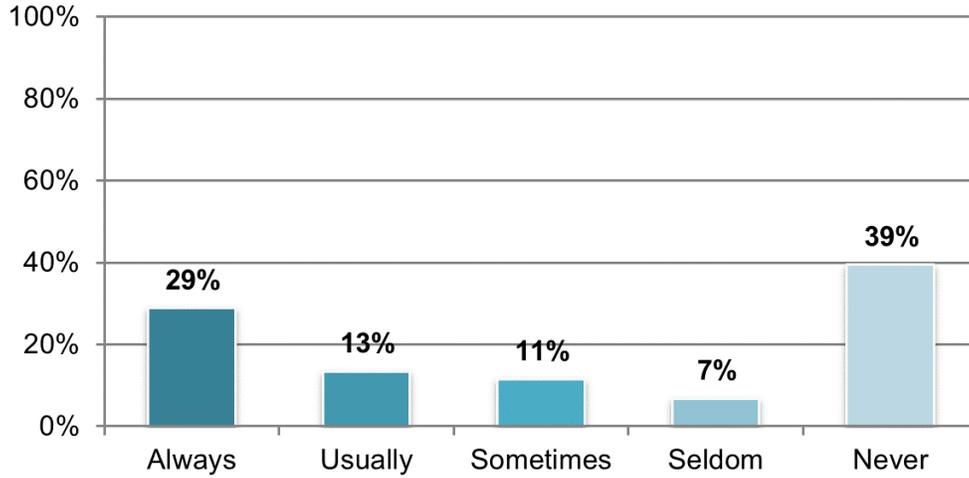


Table Q29. Can your family member choose different support workers if s/he wants to?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
FL	61%	10%	6%	5%	17%	264
<b>Within Average Range</b>						
LA	39%	10%	10%	6%	35%	155
WI	31%	17%	15%	6%	30%	311
MI	31%	18%	8%	11%	32%	234
GA	30%	12%	13%	5%	40%	216
CO	30%	27%	11%	5%	28%	111
NC	29%	13%	13%	11%	33%	156
VA	26%	11%	12%	4%	46%	140
AZ	25%	11%	20%	4%	39%	115
KY	24%	14%	13%	7%	43%	119
SD	23%	14%	12%	12%	40%	146
PA	21%	11%	6%	6%	57%	159
MD	20%	14%	11%	8%	47%	76
<b>Significantly Below Average</b>						
DE	15%	5%	13%	5%	64%	88
<b>NCI Average</b>	<b>29%</b>	<b>13%</b>	<b>11%</b>	<b>7%</b>	<b>39%</b>	<b>2,290</b>

### Family Member Chose Case Manager/Service Coordinator

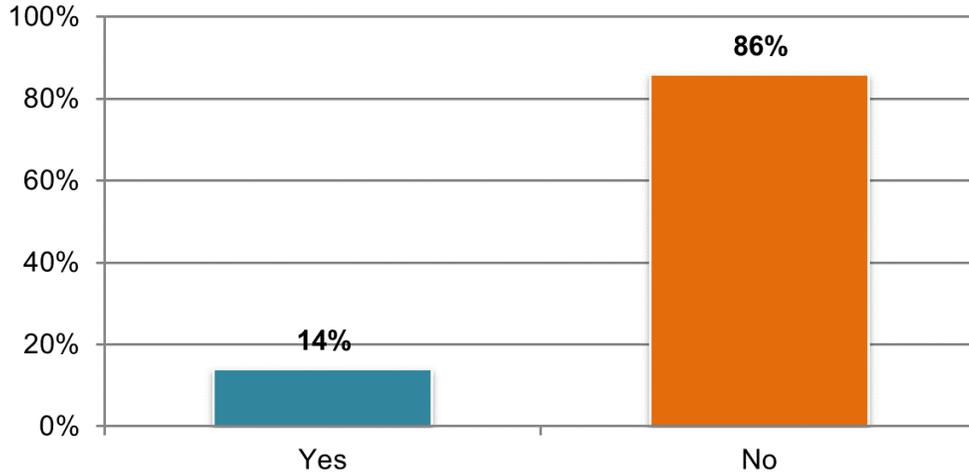
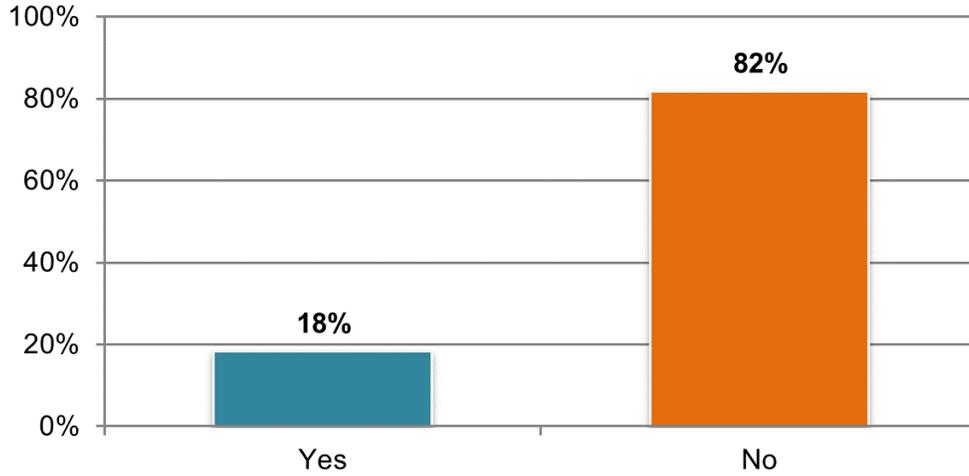


Table Q30. Did your family member choose his/her case manager/service coordinator?

State	Yes	No	N
<b>Significantly Above Average</b>			
FL	52%	48%	295
WI	24%	76%	400
<b>Within Average Range</b>			
LA	19%	81%	196
MD	18%	82%	129
KY	18%	82%	169
GA	13%	87%	295
MI	10%	90%	353
<b>Significantly Below Average</b>			
SD	9%	91%	244
PA	8%	92%	259
AZ	7%	93%	183
NC	7%	93%	203
VA	5%	95%	220
CO	4%	96%	158
DE	3%	97%	142
<b>NCI Average</b>	<b>14%</b>	<b>86%</b>	<b>3,246</b>

### Family Member Has Control or Input Over Hiring and Management of Support Workers



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

State	Yes	No	N
<b>Significantly Above Average</b>			
FL	54%	46%	282
WI	33%	67%	403
LA	27%	73%	191
<b>Within Average Range</b>			
CO	24%	76%	147
MI	20%	80%	329
GA	16%	84%	271
NC	15%	85%	203
KY	14%	86%	153
MD	11%	89%	114
<b>Significantly Below Average</b>			
AZ	12%	88%	171
PA	11%	89%	251
SD	7%	93%	233
VA	7%	93%	214
DE	5%	95%	131
<b>NCI Average</b>	<b>18%</b>	<b>82%</b>	<b>3,093</b>

### Family Member Knows How Much Money Is Spent by ID/DD Agency on His/Her Behalf

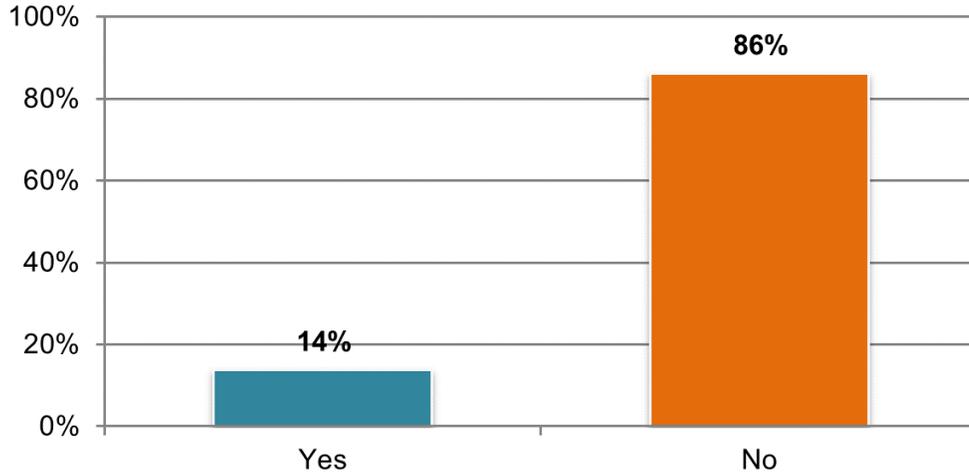


Table Q32. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?

State	Yes	No	N
<b>Significantly Above Average</b>			
FL	34%	66%	310
WI	25%	75%	445
<b>Within Average Range</b>			
AZ	16%	84%	197
MI	16%	84%	389
GA	15%	85%	329
SD	14%	86%	279
NC	12%	88%	223
VA	11%	89%	247
LA	11%	89%	257
KY	10%	90%	166
MD	10%	90%	156
<b>Significantly Below Average</b>			
CO	8%	92%	179
DE	7%	93%	150
PA	5%	95%	314
<b>NCI Average</b>	<b>14%</b>	<b>86%</b>	<b>3,641</b>

### Family Member Has a Say in How ID/DD Agency Money Is Spent

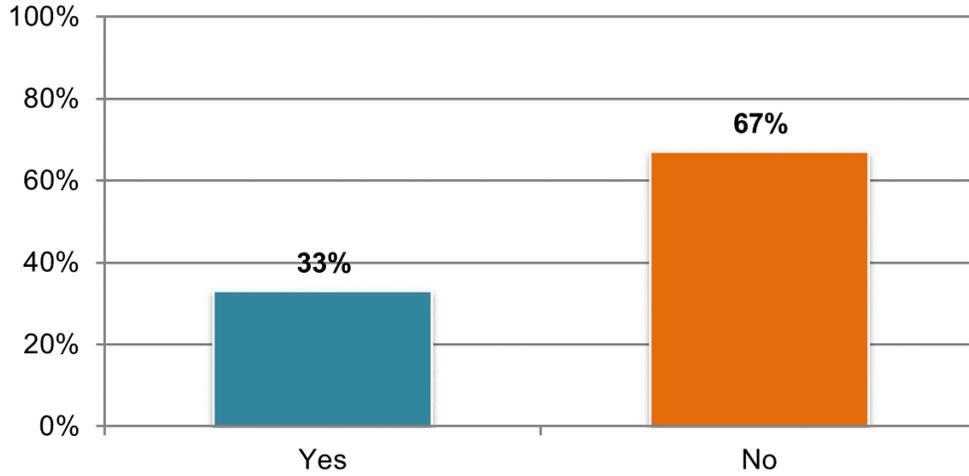
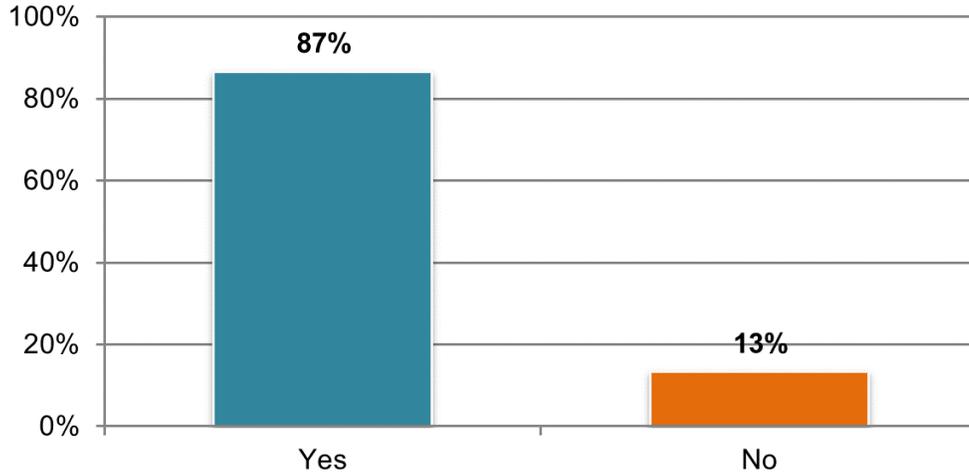


Table Q33. Does your family member have a say in how this money is spent?

State	Yes	No	N
<b>Significantly Above Average</b>			
FL	54%	46%	290
SD	46%	54%	235
WI	42%	58%	394
<b>Within Average Range</b>			
CO	34%	66%	136
AZ	34%	66%	176
KY	32%	68%	145
MD	31%	69%	112
VA	30%	70%	189
GA	30%	70%	277
PA	29%	71%	239
MI	29%	71%	319
LA	27%	73%	187
<b>Significantly Below Average</b>			
NC	25%	75%	190
DE	20%	80%	118
<b>NCI Average</b>	<b>33%</b>	<b>67%</b>	<b>3,007</b>

### Family Member Has All Information Needed to Decide How to Spend ID/DD Agency Money



**Table 33a.** If your family member has a say in how agency money is spent, does s/he have all the information s/he needs to make decisions about how to spend this money?

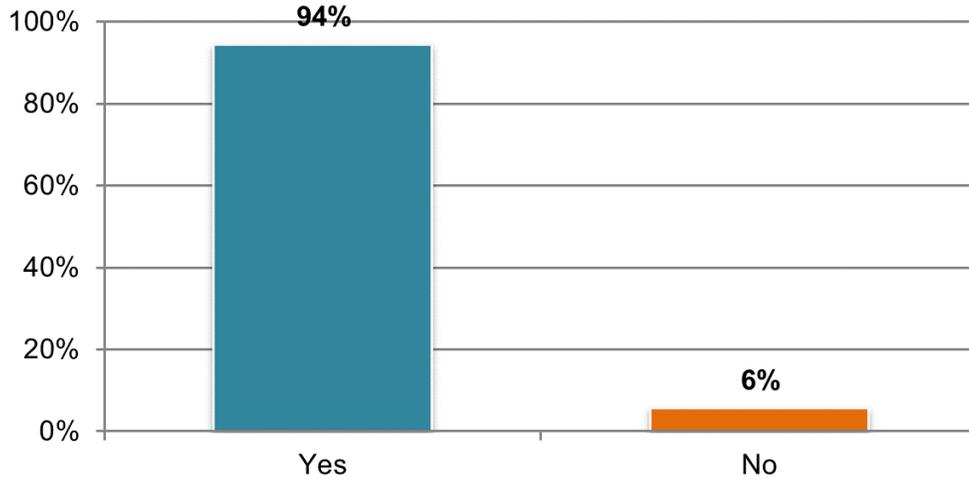
State	Yes	No	N
<b>Significantly Above Average</b>			
LA	98%	2%	46
SD	95%	5%	85
FL	94%	6%	131
<b>NCI Average</b>	<b>87%</b>	<b>13%</b>	<b>822</b>
<b>Within Average Range</b>			
WI	92%	8%	137
MI	91%	9%	70
AZ	87%	13%	53
NC	84%	16%	38
PA	84%	16%	49
VA	82%	18%	39
KY	81%	19%	37
MD	81%	19%	26
GA	81%	19%	72
CO	77%	23%	39
<b>N &lt; 20</b>			
DE	N/A	N/A	N/A

## Community Connections

*Family members with disabilities use integrated community services and participate in everyday community activities.*

**Note: State outcomes denoted with an N/A means there were too few cases to report (less than 20 responses).**

### Family Member Participates in Community Activities



**Table Q34. Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?**

State	Yes	No	N
<b>Within Average Range</b>			
PA	97%	3%	360
WI	96%	4%	496
GA	96%	4%	352
MI	96%	4%	423
NC	95%	5%	266
SD	95%	5%	313
KY	95%	5%	193
AZ	94%	6%	233
DE	94%	6%	159
FL	94%	6%	341
CO	94%	6%	201
VA	93%	7%	298
MD	92%	8%	178
LA	90%	10%	277
<b>NCI Average</b>	<b>94%</b>	<b>6%</b>	<b>4,090</b>

### Family Member Has Friends or Relationships With People Other Than Paid Staff or Family

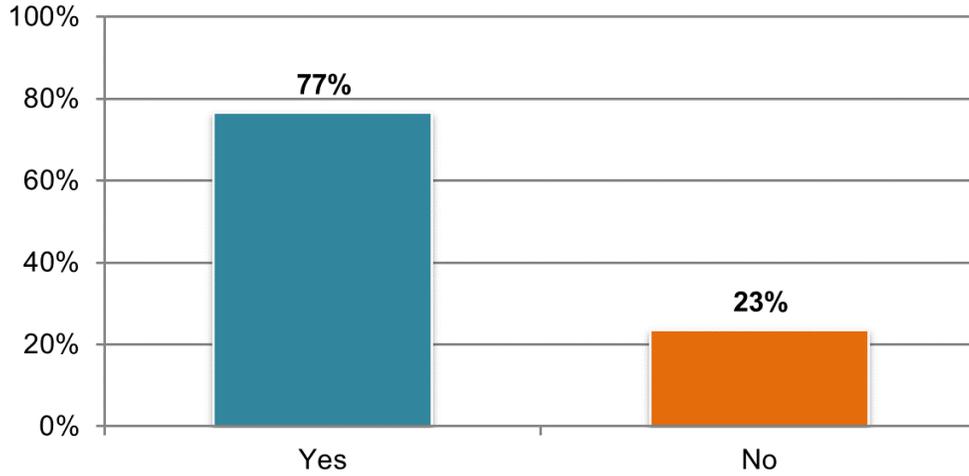
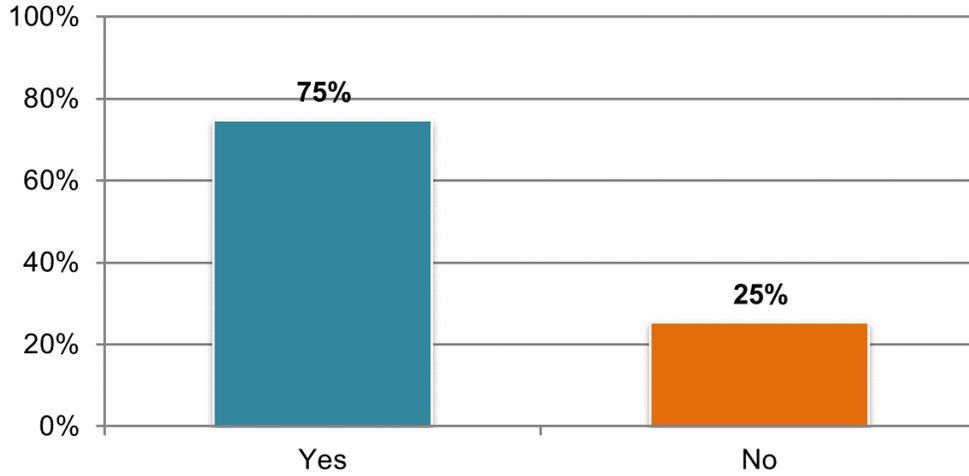


Table Q35. Does your family member have friends or relationships with persons other than paid staff or family?

State	Yes	No	N
<b>Significantly Above Average</b>			
SD	86%	14%	291
MI	83%	17%	408
WI	82%	18%	459
<b>Within Average Range</b>			
FL	81%	19%	326
GA	81%	19%	337
CO	80%	20%	187
NC	77%	23%	248
KY	76%	24%	177
MD	75%	25%	167
PA	74%	26%	329
LA	72%	28%	270
DE	72%	28%	144
<b>Significantly Below Average</b>			
AZ	67%	33%	212
VA	66%	34%	264
<b>NCI Average</b>	<b>77%</b>	<b>23%</b>	<b>3,819</b>

### Family Member Has Enough Support to Work or Volunteer in the Community



**Table Q36. Does your family member have enough support (support workers, community resources, etc.) to work or volunteer in the community?**

State	Yes	No	N
<b>Significantly Above Average</b>			
NC	84%	17%	200
WI	80%	20%	406
<b>Within Average Range</b>			
CO	81%	19%	153
SD	79%	21%	239
FL	78%	22%	264
MI	77%	23%	292
PA	76%	24%	244
KY	75%	25%	141
AZ	74%	26%	168
LA	71%	29%	200
GA	70%	30%	268
VA	69%	31%	199
MD	66%	34%	122
DE	65%	35%	110
<b>NCI Average</b>	<b>75%</b>	<b>25%</b>	<b>3,006</b>

## Satisfaction With Services and Supports

*Families and family members with disabilities receive adequate and satisfactory supports.*

**Note: State outcomes denoted with an N/A means there were too few cases to report (less than 20 responses).**

### Respondent Is Overall Satisfied With Services and Supports Family Member Receives

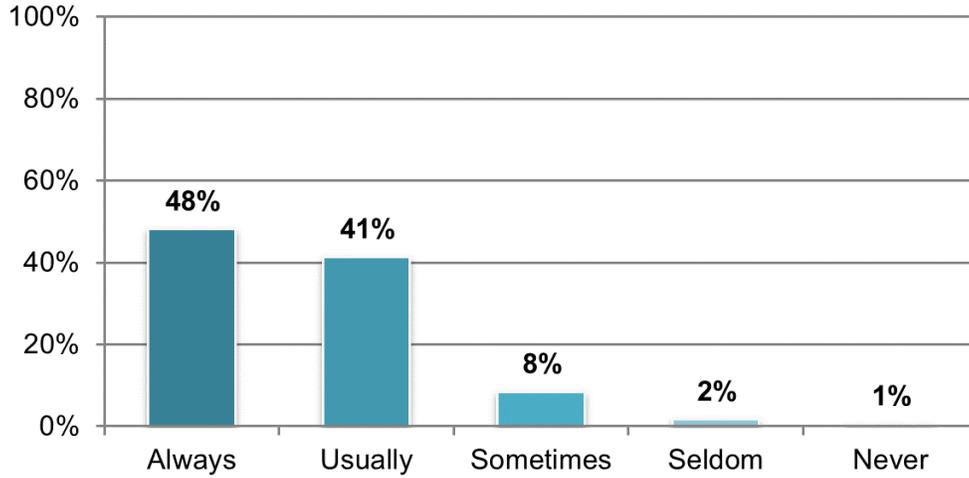


Table Q37. Overall, are you satisfied with the services and supports your family member currently receives?

State	Always	Usually	Sometimes	Seldom	Never	N
<b>Significantly Above Average</b>						
VA	61%	33%	4%	1%	1%	309
FL	56%	33%	8%	3%	0%	350
WI	54%	41%	4%	0%	0%	505
<b>Within Average Range</b>						
PA	52%	37%	9%	1%	1%	392
CO	51%	43%	5%	0%	0%	203
AZ	50%	41%	8%	1%	0%	239
NC	50%	43%	6%	1%	0%	275
MI	50%	41%	8%	1%	0%	433
SD	47%	43%	8%	2%	0%	331
KY	46%	42%	10%	2%	1%	199
GA	45%	43%	9%	3%	1%	368
LA	44%	43%	9%	2%	1%	303
<b>Significantly Below Average</b>						
DE	35%	46%	16%	3%	1%	159
MD	33%	49%	14%	4%	1%	183
<b>NCI Average</b>	<b>48%</b>	<b>41%</b>	<b>8%</b>	<b>2%</b>	<b>1%</b>	<b>4,249</b>

### Respondent Knows How to File a Complaint or Grievance Against Provider Agencies or Staff

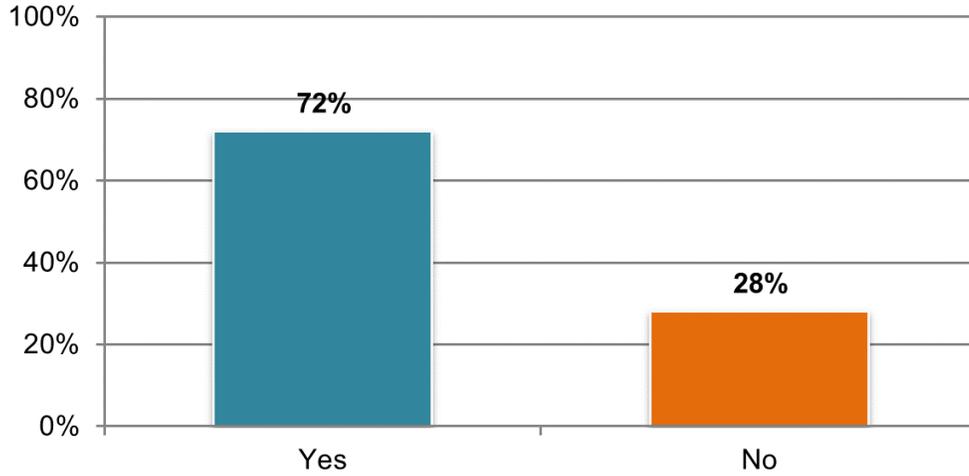
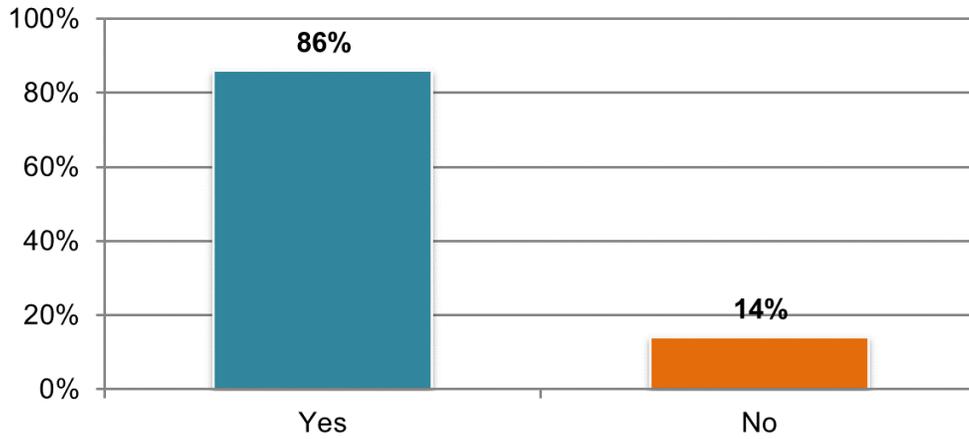


Table Q38. Do you know the process for filing a complaint or grievance against provider agencies or staff?<sup>2</sup>

State	Yes	No	N
<b>Significantly Above Average</b>			
CO	85%	15%	202
NC	85%	15%	269
FL	85%	15%	347
MI	84%	16%	434
KY	83%	17%	196
WI	82%	18%	514
<b>Within Average Range</b>			
SD	78%	22%	316
AZ	75%	25%	234
VA	72%	28%	300
<b>Significantly Below Average</b>			
PA	64%	36%	379
GA	64%	36%	365
LA	63%	37%	299
DE	50%	50%	156
MD	39%	61%	181
<b>NCI Average</b>	<b>72%</b>	<b>28%</b>	<b>4,192</b>

<sup>2</sup> Don't know' responses are included with 'no' responses.

### Respondent Is Satisfied With How Complaints or Grievances Against Provider Agencies or Staff Are Handled and Resolved



**Table Q39.** Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

State	Yes	No	N
<b>Significantly Above Average</b>			
CO	96%	4%	105
VA	93%	7%	164
SD	92%	8%	180
NC	91%	9%	188
<b>Within Average Range</b>			
WI	89%	11%	282
MI	89%	11%	281
FL	88%	12%	228
LA	87%	13%	187
AZ	85%	15%	131
GA	84%	16%	202
KY	83%	17%	133
PA	83%	17%	202
<b>Significantly Below Average</b>			
MD	71%	29%	70
DE	70%	30%	93
<b>NCI Average</b>	<b>86%</b>	<b>14%</b>	<b>2,446</b>

### Respondent Knows How to Report Abuse or Neglect

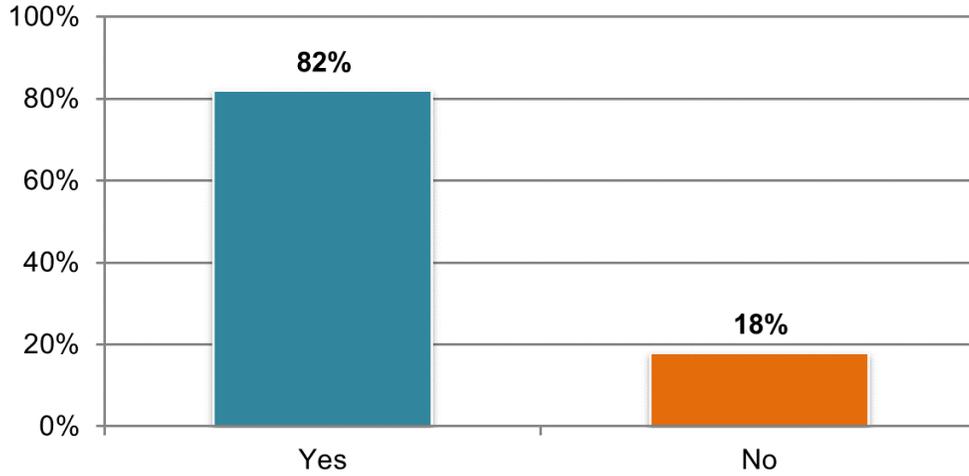


Table Q40. Do you know how to report abuse or neglect?<sup>3</sup>

State	Yes	No	N
<b>Significantly Above Average</b>			
FL	94%	6%	344
NC	91%	9%	270
MI	89%	11%	428
CO	89%	11%	193
WI	88%	12%	499
<b>Within Average Range</b>			
KY	88%	12%	195
SD	85%	15%	317
VA	84%	16%	298
AZ	82%	18%	232
LA	81%	19%	295
<b>Significantly Below Average</b>			
PA	76%	24%	368
GA	73%	27%	361
DE	68%	32%	155
MD	61%	39%	178
<b>NCI Average</b>	<b>82%</b>	<b>18%</b>	<b>4,133</b>

<sup>3</sup> Don't know' responses are included with 'no' responses.

### Respondent Reported Abuse or Neglect If it Occurred in the Past Year

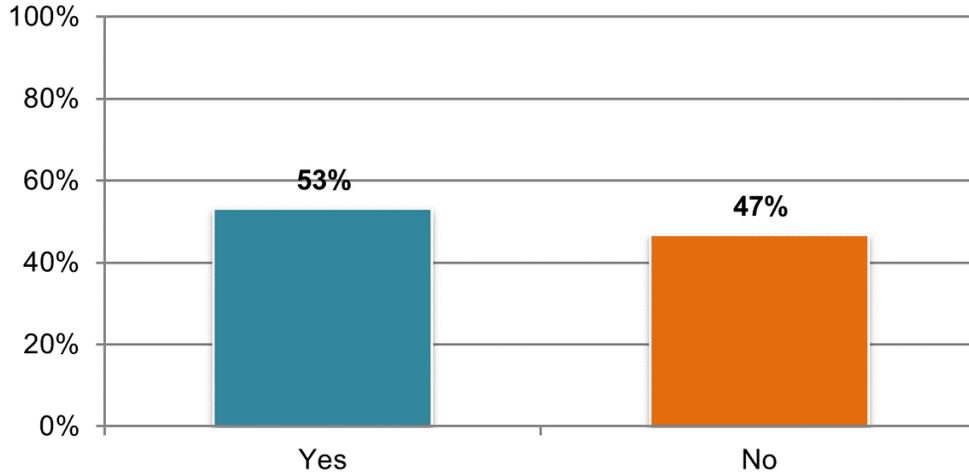
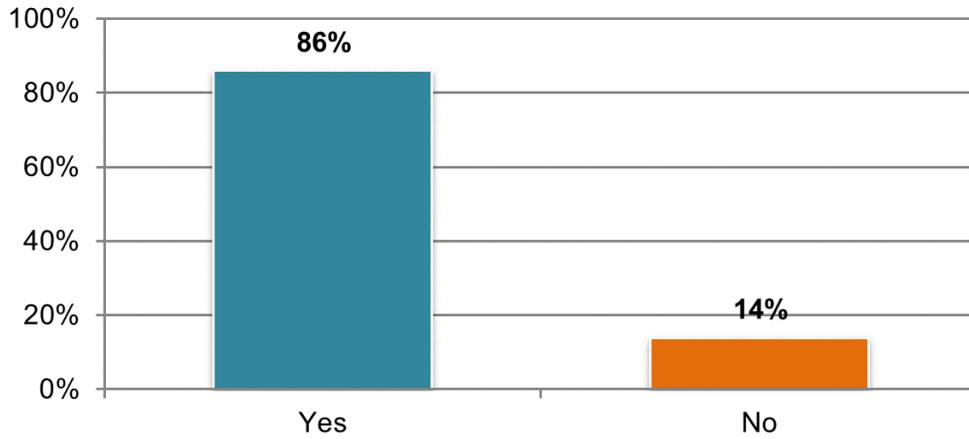


Table Q41. Within the past year, if abuse or neglect occurred, did you report it?

State	Yes	No	N
<b>Within Average Range</b>			
KY	68%	32%	37
DE	63%	37%	41
NC	63%	38%	40
LA	59%	41%	68
GA	55%	45%	65
FL	55%	45%	67
MI	54%	46%	85
VA	51%	49%	59
AZ	48%	52%	52
PA	48%	52%	69
MD	43%	57%	30
WI	42%	58%	59
SD	42%	58%	45
<b>NCI Average</b>	<b>53%</b>	<b>47%</b>	<b>717</b>
<b>Within Average Range</b>			
CO	N/A	N/A	N/A

### Appropriate People Were Responsive to Abuse/Neglect Report if Reported in the Past Year



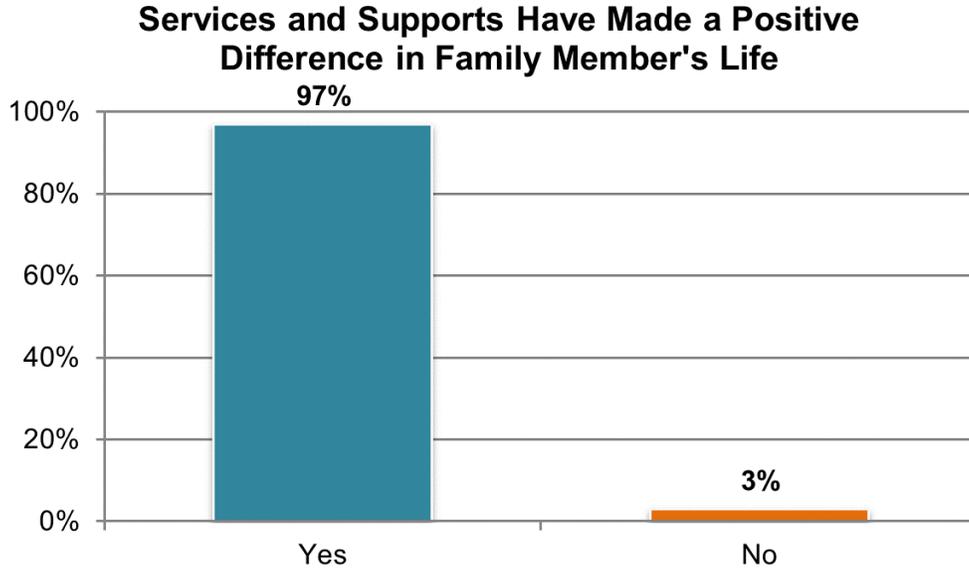
**Table 41a. If you reported abuse or neglect in the past year, were the appropriate people responsive to your report?**

State	Yes	No	N
<b>Significantly Above Average</b>			
LA	96%	4%	27
<b>Within Average Range</b>			
FL	94%	6%	33
WI	90%	10%	20
VA	88%	12%	25
NC	87%	13%	23
MI	84%	16%	38
GA	77%	23%	26
AZ	72%	28%	25
<b>NCI Average</b>	<b>86%</b>	<b>14%</b>	<b>217</b>
<b>N &lt; 20</b>			
CO	N/A	N/A	N/A
DE	N/A	N/A	N/A
KY	N/A	N/A	N/A
MD	N/A	N/A	N/A
PA	N/A	N/A	N/A
SD	N/A	N/A	N/A

## Family Outcomes

*Individual and family supports make a positive difference in the lives of families.*

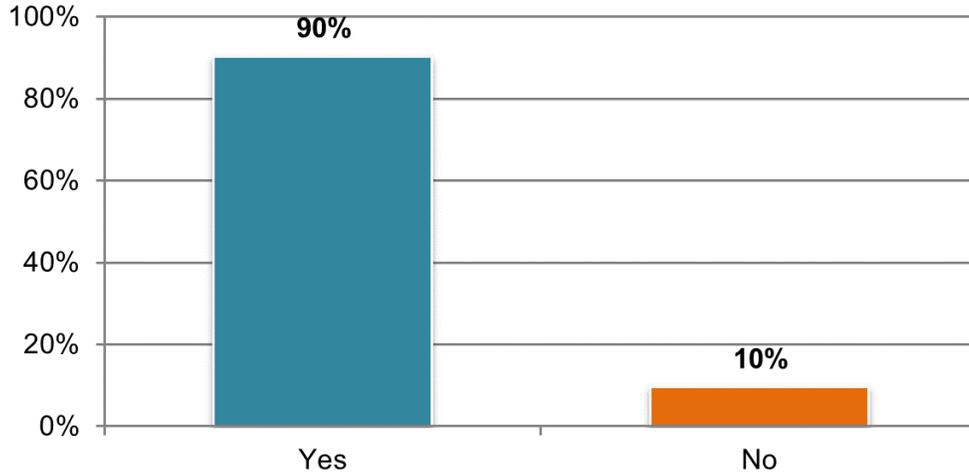
**Note: State outcomes denoted with an N/A means there were too few cases to report (less than 20 responses).**



**Table Q42. Do you feel that services and supports have made a positive difference in the life of your family member?**

State	Yes	No	N
<b>Significantly Above Average</b>			
WI	99%	1%	500
NC	99%	1%	271
<b>Within Average Range</b>			
FL	99%	1%	338
MI	98%	2%	411
SD	98%	2%	317
CO	98%	2%	196
PA	98%	2%	363
VA	98%	2%	297
GA	97%	3%	352
AZ	96%	4%	224
LA	96%	4%	296
KY	95%	5%	191
DE	95%	5%	148
MD	94%	6%	171
<b>NCI Average</b>	<b>97%</b>	<b>3%</b>	<b>4,075</b>

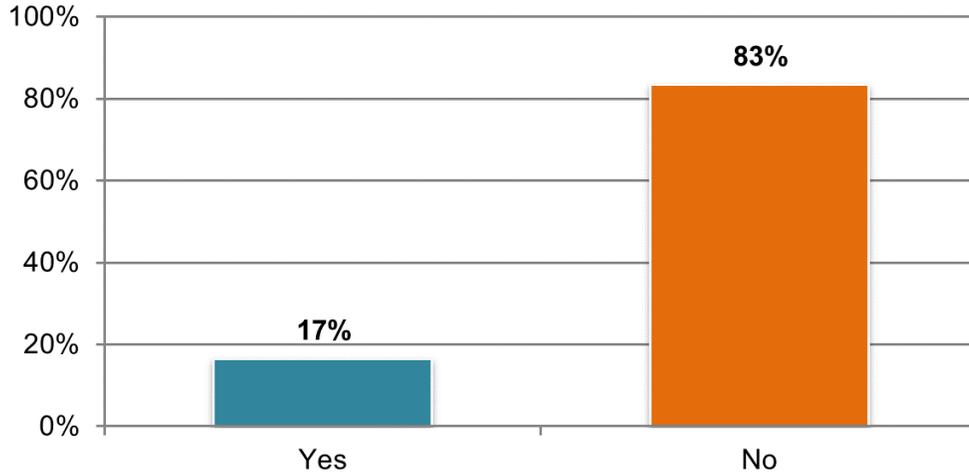
### Services and Supports Have Reduced Out-of-Pocket Expenses



**Table Q43. Do you feel that services and supports have reduced your family’s out-of-pocket expenses for your family member’s care?**

State	Yes	No	N
<b>Significantly Above Average</b>			
CO	96%	4%	160
NC	94%	6%	201
<b>Within Average Range</b>			
LA	93%	7%	248
GA	93%	7%	309
DE	92%	8%	132
WI	92%	8%	391
PA	91%	9%	291
KY	91%	9%	160
VA	89%	11%	190
AZ	88%	12%	186
SD	88%	12%	268
FL	88%	12%	285
MD	87%	13%	156
<b>Significantly Below Average</b>			
MI	84%	16%	303
<b>NCI Average</b>	<b>90%</b>	<b>10%</b>	<b>3,280</b>

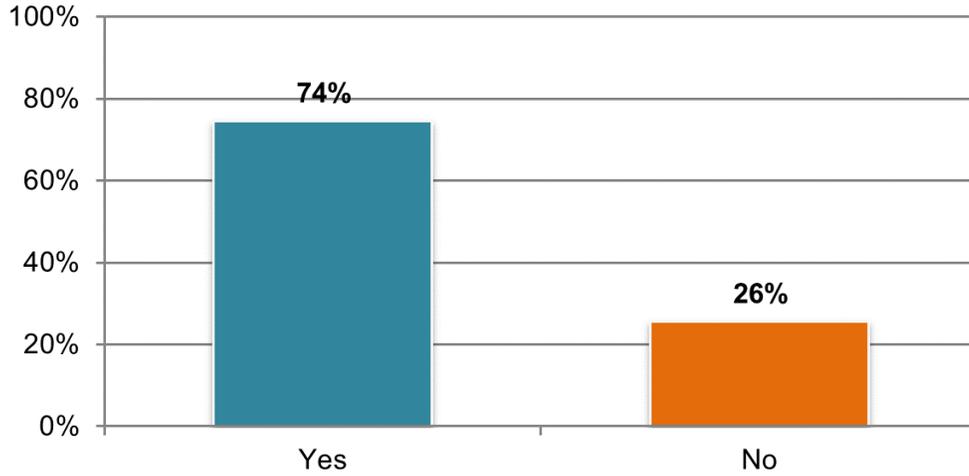
### Services or Supports Have Been Reduced, Suspended, or Terminated in the Past Year



**Table Q44. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?**

State	Yes	No	N
<b>Significantly Above Average</b>			
FL	28%	72%	288
MI	24%	76%	330
<b>Within Average Range</b>			
NC	21%	79%	227
WI	21%	79%	451
LA	19%	81%	222
CO	19%	81%	171
DE	16%	84%	128
KY	15%	85%	155
GA	12%	88%	309
SD	12%	88%	281
MD	11%	89%	140
<b>Significantly Below Average</b>			
PA	12%	88%	295
VA	11%	89%	229
AZ	11%	89%	199
<b>NCI Average</b>	<b>17%</b>	<b>83%</b>	<b>3,425</b>

### Service Reduction, Suspension, or Termination Affected the Family Member Negatively



**Table 44a. If services or supports received by your family member were reduced, suspended, or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family member negatively?**

State	Yes	No	N
<b>Within Average Range</b>			
GA	86%	14%	28
LA	84%	16%	32
NC	81%	19%	37
FL	81%	19%	63
SD	72%	28%	25
WI	72%	28%	74
KY	70%	30%	20
CO	68%	32%	22
PA	68%	32%	22
MI	63%	37%	51
<b>NCI Average</b>	<b>74%</b>	<b>26%</b>	<b>374</b>
<b>N &lt; 20</b>			
VA	N/A	N/A	N/A
AZ	N/A	N/A	N/A
DE	N/A	N/A	N/A
MD	N/A	N/A	N/A

## II. NCI History and Activities

*This section briefly describes the history of the National Core Indicators and NCI surveys.*

## Overview of National Core Indicators

In December 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI), launched the Core Indicators Project. The aim of the project was to support state developmental disabilities authorities in the development and implementation of performance and outcome indicators—and related data collection strategies—so that they could measure service delivery system performance. This effort, now called National Core Indicators (NCI), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI facilitates pooled knowledge, expertise, and resources among the states.

In 1997, 15 states convened to discuss the scope and content of a potential performance measurement framework. 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 that was 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

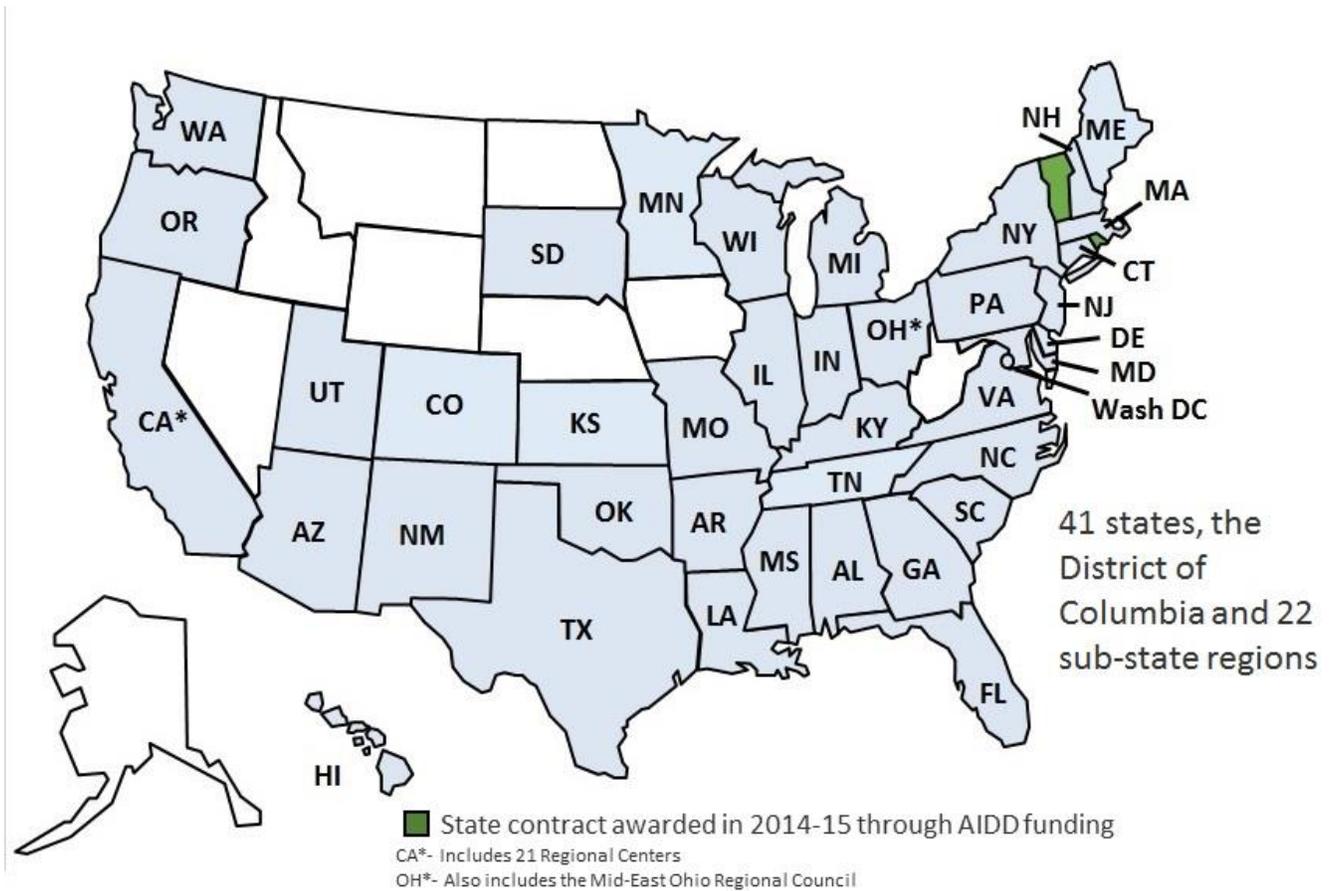
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states 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 continues to develop and refine the indicators and expand state participation. For more information about NCI states, technical reports, and other resources, please visit <http://www.nationalcoreindicators.org>.

## State Participation

During the 2014-15 data collection cycle, 41 states, the District of Columbia and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and participating states are highlighted on the map below.

### NCI State Participation 2014-15



## The Core Indicators

The Core Indicators are the 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. An example of a Core Indicator would be, “The proportion of people who have a paid job in the community.” To see the entire list of Core Indicators, please visit

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

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

The current set of performance indicators includes 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 and Rights; Staff Stability and Competency; Family Outcomes; and System Performance. Each domain is broken down into sub-domains (please see Table 1 on the following page). 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 to reflect current and future priorities of participating states.

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 methodology of this tool are provided in the next section of this report.

### **Sub-Domains and Concern Statements**

The following table lists the sub-domains and concern statements that compose the “Family Outcomes” domain.

## Family Survey Sub-Domains and Concern Statements

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

## How NCI Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI as a data source for supplemental performance measures in their home and community-based services waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services. 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.

NCI data are not intended to be used at the provider level. 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).

## Caution and Limitations

This report does not provide benchmarks for acceptable or unacceptable levels of performance. Rather, it is up to each state to decide whether its score or percentage is acceptable. States that fall into the “below average” tier on any scale or indicator are not necessarily underperforming; instead, this placement indicates only that the state’s scale score or indicator percentage is significantly lower than the average of all states—where “significantly” means “not due to chance.” The results tables throughout this report display states’ scores relative to one another and show which states tend to have similar results. Notably, the difference between a “below average” state and the average across the other states may be very small, and it is up to public managers, policymakers, and other stakeholders to decide whether a state’s result relative to the NCI Average suggests that changes or further investigation are necessary.

Moreover, the NCI Average should not be interpreted as defining “acceptable” levels of performance or satisfaction. Instead, it represents a multi-state “norm” that describes average levels of performance or satisfaction across the participating states. In some instances there are few significant differences among states; this denotes that the majority of states are performing similarly. Instances where several states’ results are especially high (considerably above the average level) may indicate that some states are attaining a level of performance that could serve as a guidepost for others.

Data from previous years are not presented in this report. Comparisons of results from year to year should be made with caution: 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 states draw new samples each year rather than following the same group of individuals.

## 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 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 individual with a developmental disability not living in the family 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 with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.

## Data Entry and Analysis

Each state entered its 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, on the following two bases:

1. The respondent indicated the individual with a developmental disability lived in the family home.
2. 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 average; 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 2014-2015, 14 states administered the Family/Guardian Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The table below shows the number of surveys each state mailed, usable surveys returned, and the response rates.

### Family/Guardian Survey: State Response Rates<sup>4</sup>

State	Usable Surveys Returned	Surveys Mailed	Response Rate
AZ	247	1300	19.0%
CO	208	639	32.6%
DE	168	960	17.5%
FL	375	1700	22.1%
GA	395	1500	26.3%
KY	203	1367	14.9%
LA	319	2000	16.0%
MD	190	1200	15.8%
MI	446	1800	24.8%
NC	292	920	31.7%
PA	405	1400	28.9%
SD	336	911	36.9%
VA	318	1180	26.9%
WI	521	1200	43.4%
<b>NCI Average</b>	<b>4715</b>	<b>18077</b>	<b>26.1%</b>

<sup>4</sup> Some numbers may be approximates.