

Family/Guardian Survey

2016-17 Final Report

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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

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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	1
I. Results	1
Survey Development	2
Organization of the Family/Guardian Survey	2
Demographics.....	2
Services and Supports Received.....	2
Questions Regarding Services and Supports	3
Presentation of Data.....	3
Demographics.....	5
Family Member	6
Table 1. Family Member’s Residence.....	7
Table 2. Family Member’s Residential Designation.....	7
Table 3. Family Member’s Age	8
Table 4. Family Member’s Gender	8
Table 5. Family Member’s Race and Ethnicity	9
Table 6a. Family Member’s Disabilities (not mutually exclusive)	9
Table 6b. Family Member’s Disabilities (continued, not mutually exclusive)	10
Table 7a. Family Member’s Health Conditions	10
Table 7b. Family Member’s Health Conditions (continued)	11
Table 8. Family Member’s Preferred Means of Communication.....	11
Table 9. Family Member Has Legal Court Appointed Guardian or Conservator	12
Table 10. Guardian or Conservator Relationship to Family Member	12
Table 11. Family Member’s Highest level of Education	13
Table 12. Family Member’s Typical Day Activity -- Individual Paid Job in the Community	13

Table 13. Family Member's Typical Day Activity -- Paid Small Group Job in a Community-based Setting	14
Table 14. Family Member's Typical Day Activity -- Unpaid Activity in the Community	14
Table 15. Family Member's Typical Day Activity -- Paid Activity in a Facility-based Setting.....	15
Table 16. Family Member's Typical Day Activity -- Unpaid Activity in a Facility-based Setting.....	15
Table 17. Family Member's Typical Day Activity – School	16
Table 18. Family Member's Typical Day Activity – Stays at Home	16
Table 19. Family Member's Typical Day Activity – Other	17
Table 20. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	17
Table 21. Family Member's Level of Help Needed With Personal Care Activities	18
Table 22. Family Member's Need for Help With Other Daily Activities.....	18
Respondents.....	19
Table 23. Respondent's Age	20
Table 24. Respondent's Health	20
Table 25. Respondent's Relationship to Family Member.....	21
Table 26. Respondent's Frequency of Visits With Family Member	21
Table 27. Respondent's Highest Level of Education	22
Table 28. Total Taxable Household Income of Wage Earners in the Past Year.....	22
Services and Supports Received.....	23
Table 29. Services and Supports Received From ID/DD Agency	24
Table 30. Additional Services and Supports Received	24
Family/Guardian Survey Results	25
Information and Planning.....	26
Table Q1. Do you get enough information to help you participate in planning services for your family?.....	27
Table Q2. Is the information you receive easy to understand?	28
Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?	29
Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?	30
Table Q5. Do you need help planning for your family member's future with respect to any of the following?	31
Table Q6. In the past year, did your family member move out of the family home for the first time?	32

Table Q7. If family member moved out of the home for the first time in the past year, did your family member receive enough information about services available to support him/her?	33
Table Q8. If family member moved out of the home for the first time in the past year, did you have enough choices of service providers to support your family member living outside the family home?	34
Table Q9. Does your family member have a service plan?	35
Table Q10. Does the plan include all the services and supports your family member needs?	36
Table Q11. Does your family member get all of the services listed in the plan?.....	37
Table Q12. Did you or another family member help make the plan?	38
Table Q13. Did your family member help make the plan?	39
Table Q14. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member’s last service planning meeting?	40
Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?	41
Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?	42
Access and Delivery of Services and Supports.....	43
Table Q17. Are you or your family member able to contact his/her support workers when you want to?	44
Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?	45
Table Q19. Do support workers come and leave when they are supposed to?.....	46
Table Q20. Do services and supports change when your family’s needs change?.....	47
Table Q21. Do support workers speak to you in a way that you understand?	48
Table Q22. Are services delivered in a way that is respectful of your family’s culture?	49
Table Q23. 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?	50
Table Q24. Do support workers have the right information and skills to meet your family’s needs?.....	51
Table Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?	52
Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?.....	53
Table Q27. Does your family member’s primary care doctor understand his/her needs related to his/her disability?	54
Table Q28. Do you have access to dental services for your family member?	55

Table Q29. If you have access to dental services for your family member, does your family member’s dentist understand his/her needs related to his/her disability?	56
Table Q30. If your family member takes medications, do you know what they’re for?	57
Table Q31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?	58
Table Q32. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member’s needs related to his/her disability?	59
Table Q33. Does your family get the support and services needed?	60
Table Q34. If family does not get the support and services needed, what additional services are needed?	61
Choice, Decision Making and Control	62
Table Q35. Does the agency providing residential services to your family member involve him/her in important decisions?	63
Table Q36. Can your family choose or change the agency that provides your family member’s services?	64
Table Q37. Can your family choose or change your family member’s support workers?	65
Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)? ..	66
Table Q39. Do service providers for your family member work together to provide support? (For example, does the agency providing transportation work together with the agency providing in-home support if necessary?)	67
Table Q40. Did you, your family member, or someone else in your family choose your family member’s case manager/service coordinator?	68
Involvement in the Community	69
Table Q41. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?	70
Table Q42. For your family member, what are the obstacles or barriers to participation in activities in the community?	71
Table Q43. Does your family member have friends other than paid support workers or family?	72
Table Q44. In your community, are there resources that your family can use that are not provided by the I/DD agency? (For example, recreational programs, community housing, library programs, religious groups, etc.)...	73
Table Q45. Does your family take part in any family-to-family networks in your community? (For example, Parent to Parent, sibling networks, etc.)	74
Satisfaction With Services and Supports	75
Table Q46. Overall, are you satisfied with the services and supports your family currently receives?	76

Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?	77
Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?	78
Table Q49. Do you know how to report abuse or neglect related to your family member?	79
Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your family member?	80
Table Q51. If a report of abuse or neglect was filed in the past year, did the appropriate people respond to the report?	81
Table Q52. If a report of abuse or neglect was filed in the past year by someone other than you or another family, were you notified of the report in a timely manner?	82
Table Q53. Do you feel that services and supports have made a positive difference in the life of your family?... 83	
Table Q54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?	84
Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?	85
Table Q56. Have the services or supports that your family member received been increased in the past year? 86	
Table Q57. Are services and supports helping your family member to live a good life?	87
II. NCI History and Activities.....	88
Overview of National Core Indicators	89
State Participation	90
Figure 1. NCI State Participation 2016-17	90
Sub-Domains and Concern Statements	91
Figure 2. Family Survey Sub-Domains and Concern Statements.....	91
How NCI Data Are Used	91
Caution and Limitations.....	92
III. Methodology	93
Sampling & Administration.....	94

Weighting..... 94

Significance Testing..... 95

Data Entry and Analysis 96

Response Rates 96

 Figure 3. Family/Guardian Survey: State Response Rates 97

Executive Summary

The National Core Indicators (NCI) are standard measures used 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 45 states, the District of Columbia, and 22 sub-state entities who participated in NCI during the 2016-2017 data collection cycle, twelve (12) 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 2016-17 data collection cycle.

The following are NCI national weighted 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.

Note: *All qualified Californians with a developmental disability have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. California law mandates that the intake process begin within 15 days of an individual's or family's request for services and that the Department of Developmental Services begin providing services within 120 days after intake. These statutory requirements make California's service system unique and could impact comparisons between its survey results and the results of other states.*

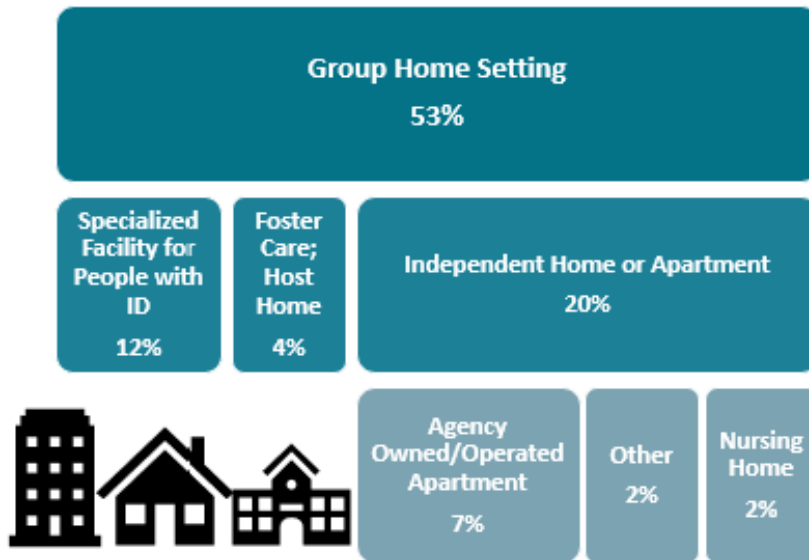
LOOKING AT THE 2016-17 FAMILY/GUARDIAN SURVEY (FGS)

Respondents: families or guardians of adults (18 years or older) with an intellectual/developmental disability. The adult with the disability should not live in the family home (with the respondent) and should receive at least one service funded by the state developmental disability agency in addition to case management.
 12 states*: Total sample: 9,194

Respondents reported the following about their family members:

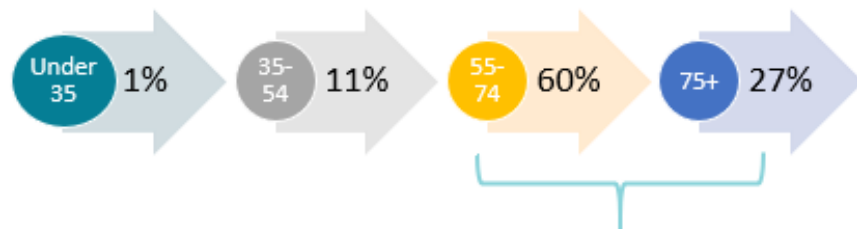


Where do family members with disabilities live?



Respondents reported the following about themselves:

Age of respondents



87% of respondents are over age 55

64% of respondents report seeing their family member 12+ times per year

27%

- Report a total taxable income of less than \$25,000/year

*FGS: AZ, CA, FL, GA, KY, LA, MD, NC, NJ, PA, SD, VA; NCI Average is weighted

Information and Planning

Respondents reported...

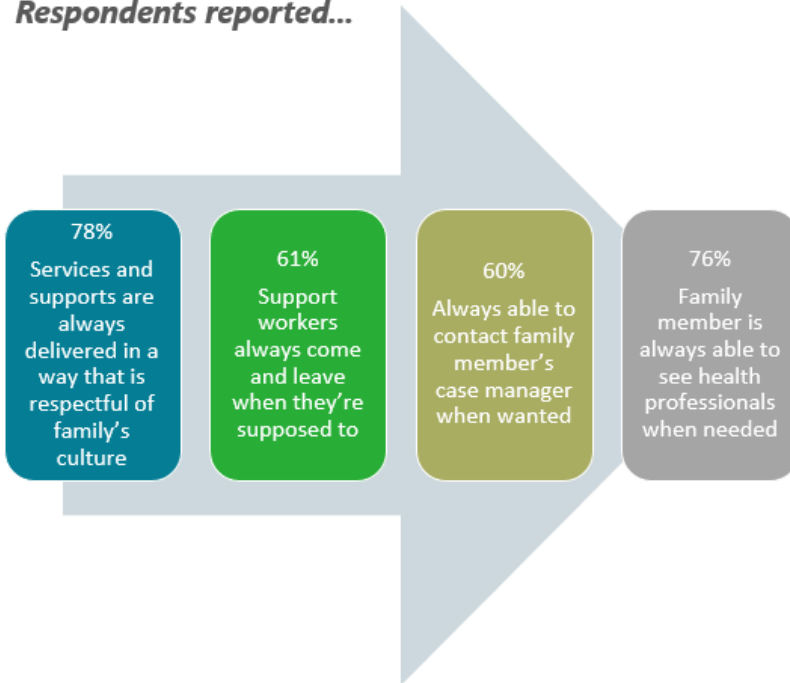
91%

- Family member's service plan includes all services and supports needed

67%

- Family member has enough support to work or volunteer in the community

Respondents reported...



90% of respondents reported that their family gets the support and services needed

Choice, Decision-making and Control

Respondents reported...

Family can always choose or change family member's support workers

35%

Involvement in the Community

Respondents reported...

91%

- Family member with disability takes part in community activities

67%

- Family member with disability has friends other than paid support workers or family

Satisfaction with Services and Supports

Respondent is always satisfied with services and supports family receives

46%

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 an intellectual or developmental disability (who did not live at home with them), whether these families had the support they needed to be involved, and whether they were satisfied with the service system that was intended to meet 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/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

Direct feedback from families is an important means for states to gauge service and support satisfaction and to pinpoint areas for quality improvement. All demographic and individual outcome results from the 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.¹

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

¹ Unlike in previous years, the NCI and state averages were weighted, see note below and "Weighting" in the Methodology section for more information.

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.

Important note on changes to reporting

In previous years, NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). This year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states’ systems. Beginning this year, the NCI averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states, as well as the sample sizes. See more about weighting in the Methodology section.

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.

Demographics

Family Member

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

Table 1. Family Member's Residence

State	Specialized Facility for People With ID ²	Group Home	Agency Operated Apartment	Independent Home or Apartment	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
AZ	6%	65%	3%	4%	22%	1%	0%	0%	316
CA	12%	46%	6%	31%	2%	1%	0%	3%	3,955
FL	0%	66%	6%	23%	2%	1%	1%	2%	213
GA	10%	52%	8%	11%	17%	0%	0%	2%	404
KY	17%	47%	13%	6%	15%	0%	0%	3%	191
LA	29%	35%	0%	34%	0%	0%	0%	1%	397
MD	10%	60%	9%	14%	1%	0%	0%	6%	1,306
NC	10%	64%	14%	8%	2%	1%	0%	1%	188
NJ	17%	57%	4%	0%	20%	0%	0%	2%	553
PA	16%	61%	6%	9%	4%	3%	0%	1%	682
SD†	5%	54%	23%	17%	0%	0%	0%	0%	554
VA	10%	66%	3%	5%	4%	7%	0%	5%	186
NCI Average	12%	53%	7%	20%	4%	2%	0%	2%	8,945

†SD used the previous year's survey; in 2016-17 responses options were clarified, therefore comparisons of SD's should be made with caution.

Table 2. Family Member's Residential Designation

State	Urban or Suburban	Rural	N
AZ	92%	9%	317
CA	94%	6%	3,920
FL	87%	13%	229
GA	83%	17%	393
KY	70%	30%	193
LA	82%	19%	384
MD	77%	23%	1,308
NC	76%	24%	185
NJ	72%	28%	535
PA	71%	29%	676
SD	95%	5%	560
VA	75%	25%	179
NCI Average	85%	15%	8,879

² ICF, state-run or other institutional setting

Table 3. Family Member's Age

State	Age	N
AZ	46.1	319
CA	44.2	3,988
FL	44.3	228
GA	45.3	403
KY	50.0	191
LA	49.4	400
MD	47.1	1,313
NC	48.6	541
NJ	43.3	183
PA	51.3	676
SD	45.0	544
VA	50.1	178
NCI Average	46.3	8,964

Table 4. Family Member's Gender

State	Male	Female	N
AZ	55%	45%	320
CA	60%	41%	4,018
FL	62%	38%	233
GA	61%	39%	408
KY	63%	37%	194
LA	58%	42%	403
MD	59%	41%	1,332
NC	64%	36%	189
NJ	62%	38%	539
PA	55%	45%	687
SD	59%	41%	559
VA	56%	44%	185
NCI Average	59%	41%	9,067

Table 5. Family Member's Race and Ethnicity

State	American Indian or Native Alaska	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	N
AZ	7%	2%	4%	0%	79%	11%	1%	318
CA	2%	8%	6%	1%	76%	14%	2%	3976
FL	1%	1%	11%	1%	80%	10%	2%	235
GA	1%	1%	20%	0%	77%	1%	0%	409
KY	2%	0%	4%	0%	93%	1%	1%	194
LA	1%	0%	23%	0%	74%	0%	1%	405
MD	2%	3%	20%	0%	77%	1%	1%	1328
NC	1%	3%	8%	0%	85%	3%	1%	195
NJ	3%	0%	29%	0%	70%	0%	2%	553
PA	1%	1%	5%	0%	93%	1%	1%	686
SD	11%	1%	1%	0%	89%	1%	0%	567
VA	2%	2%	13%	0%	82%	2%	2%	187
NCI Average	2%	4%	10%	0%	79%	7%	2%	9053

Table 6a. Family Member's Disabilities (not mutually exclusive)

State	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
AZ	77%	36%	22%	20%	9%	9%
CA	68%	28%	28%	17%	8%	6%
FL	79%	39%	28%	15%	8%	9%
GA	77%	33%	24%	14%	12%	7%
KY	79%	32%	24%	16%	6%	5%
LA	77%	35%	18%	16%	13%	8%
MD	72%	29%	23%	18%	10%	7%
NC	77%	33%	33%	12%	6%	5%
NJ	83%	51%	28%	14%	10%	6%
PA	84%	38%	20%	17%	12%	7%
SD†	69%	29%	16%	15%	8%	7%
VA	80%	31%	18%	21%	12%	9%
NCI Average	74%	33%	25%	17%	9%	7%

†SD used the previous year's survey; in 2016-17 responses options for mood illness/psychiatric disorder were clarified, therefore comparisons of SD's should be made with caution.

Table 6b. Family Member's Disabilities (continued, not mutually exclusive)

State	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
AZ	13%	31%	0%	12%	1%	3%	11%
CA	11%	26%	1%	9%	1%	1%	12%
FL	10%	23%	0%	10%	0%	1%	15%
GA	12%	30%	0%	12%	1%	1%	14%
KY	12%	29%	1%	10%	0%	1%	3%
LA	17%	35%	1%	6%	1%	1%	15%
MD	13%	26%	1%	11%	1%	1%	15%
NC	9%	25%	0%	9%	1%	1%	16%
NJ	13%	33%	1%	6%	1%	1%	13%
PA	13%	32%	1%	13%	1%	0%	13%
SD	10%	26%	1%	14%	1%	3%	16%
VA	10%	35%	1%	7%	0%	1%	15%
NCI Average	11%	28%	1%	9%	1%	1%	13%

Table 7a. Family Member's Health Conditions

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	10%	19%	9%	27%	33%
CA	7%	17%	5%	28%	31%
FL	11%	25%	5%	31%	34%
GA	9%	16%	3%	33%	29%
KY	10%	22%	3%	25%	40%
LA	10%	19%	3%	31%	30%
MD	7%	17%	5%	33%	29%
NC	11%	12%	6%	30%	35%
NJ	5%	26%	6%	46%	34%
PA	10%	15%	6%	26%	30%
SD	10%	20%	5%	30%	26%
VA	11%	24%	7%	33%	26%
NCI Average	9%	19%	5%	30%	31%

Table 7b. Family Member's Health Conditions (continued)

State	Dysphagia	Pressure Ulcers	Alzheimer's Disease or other Dementia	Oral Health or Other Dental Problems	Sleep Apnea	Other
AZ	9%	2%	8%	17%	17%	32%
CA	9%	2%	3%	18%	13%	32%
FL	8%	3%	5%	13%	10%	36%
GA	12%	3%	2%	17%	12%	33%
KY	17%	4%	9%	13%	15%	23%
LA	20%	5%	4%	17%	9%	33%
MD	10%	2%	5%	14%	11%	37%
NC	12%	1%	3%	17%	9%	35%
NJ	10%	3%	4%	11%	15%	35%
PA	20%	2%	8%	15%	12%	30%
SD†	12%	3%	8%	1%	2%	36%
VA	11%	2%	7%	16%	8%	34%
NCI Average	12%	2%	5%	16%	12%	33%

†SD used the previous year's survey; in 2016-17 responses options for oral health or other dental problems were clarified, therefore comparisons of SD's should be made with caution.

Table 8. Family Member's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AZ	74%	19%	3%	2%	2%	313
CA	78%	15%	2%	1%	4%	3,976
FL	76%	18%	2%	0%	3%	235
GA	71%	22%	3%	1%	2%	410
KY	71%	22%	4%	1%	3%	193
LA	60%	29%	1%	1%	9%	403
MD	73%	19%	3%	1%	5%	1,321
NC	72%	18%	2%	1%	7%	194
NJ	76%	19%	3%	0%	3%	555
PA	69%	25%	1%	1%	3%	679
SD	81%	12%	3%	2%	2%	561
VA	63%	33%	0%	1%	4%	187
NCI Average	74%	19%	2%	1%	4%	9,027

Table 9. Family Member Has Legal Court Appointed Guardian or Conservator

State	None	Limited	Full	Has Guardianship but Level Is Unknown	N
AZ	13%	8%	77%	3%	317
CA	44%	0%	0%	56%	3,658
FL	31%	22%	45%	2%	226
GA	24%	9%	61%	6%	393
KY	4%	6%	87%	3%	194
LA	30%	23%	41%	7%	366
MD	45%	18%	29%	9%	1,189
NC	14%	11%	70%	5%	194
NJ	4%	16%	74%	6%	535
PA	29%	17%	44%	10%	610
SD	16%	14%	63%	6%	557
VA	24%	19%	53%	4%	176
NCI Average	32%	10%	32%	26%	8,415

Table 10. Guardian or Conservator Relationship to Family Member

State	Family	Friend	State Employee or Guardianship Agency	Other	N
AZ	87%	3%	9%	2%	259
CA	90%	2%	6%	3%	1,950
FL	75%	4%	9%	13%	142
GA	91%	3%	5%	1%	257
KY	92%	6%	2%	1%	181
LA	87%	1%	10%	2%	205
MD	83%	2%	10%	6%	543
NC	94%	0%	5%	1%	178
NJ	71%	1%	25%	4%	446
PA	87%	2%	7%	3%	368
SD	83%	1%	13%	3%	426
VA	85%	4%	6%	4%	116
NCI Average	86%	2%	8%	4%	5,071

Table 11. Family Member's Highest level of Education

State	Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational Training	Some College	College Degree or Higher	N
AZ	34%	2%	28%	27%	2%	4%	4%	283
CA	35%	1%	26%	20%	3%	9%	6%	3,696
FL	38%	1%	31%	16%	6%	3%	6%	215
GA	35%	0%	39%	17%	1%	3%	4%	363
KY	46%	0%	24%	18%	2%	3%	6%	180
LA	56%	1%	28%	7%	2%	3%	4%	351
MD	36%	0%	36%	15%	5%	3%	5%	1,216
NC	46%	0%	18%	21%	4%	3%	8%	180
NJ	44%	2%	33%	12%	4%	3%	1%	519
PA	44%	0%	23%	26%	3%	1%	2%	578
SD†	22%	0%	33%	34%	3%	3%	5%	417
VA	53%	2%	31%	11%	3%	0%	1%	171
NCI Average	39%	1%	28%	19%	3%	5%	5%	8,169

†SD used the previous year's survey; in 2016-17 responses options were clarified, therefore comparisons of SD's should be made with caution.

Table 12. Family Member's Typical Day Activity -- Individual Paid Job in the Community

State	Usually/Often	Sometimes	Never	N
AZ	9%	2%	89%	208
CA	18%	5%	77%	2619
FL	10%	2%	88%	179
GA	9%	3%	88%	305
KY	15%	5%	80%	149
LA	9%	2%	89%	309
MD	21%	7%	73%	956
NC	9%	6%	85%	145
NJ	11%	5%	84%	446
PA	9%	2%	89%	530
SD†	27%	7%	66%	453
VA	5%	2%	93%	143
NCI Average	14%	4%	82%	6442

†SD used the previous year's survey; in 2016-17 responses options were clarified, therefore comparisons of SD's should be made with caution.

Table 13. Family Member's Typical Day Activity -- Paid Small Group Job in a Community-based Setting

State	Usually/Often	Sometimes	Never	N
AZ	13%	5%	82%	207
CA	18%	6%	76%	2503
FL	10%	2%	88%	178
GA	7%	4%	90%	287
KY	14%	6%	80%	143
LA	14%	6%	81%	303
MD	18%	8%	74%	912
NC	12%	9%	79%	141
NJ	11%	4%	86%	438
PA	9%	2%	89%	521
SD†	19%	8%	73%	429
VA	9%	1%	90%	143
NCI Average	14%	5%	81%	6205

†SD used the previous year's survey; in 2016-17 responses options were clarified, therefore comparisons of SD's should be made with caution.

Table 14. Family Member's Typical Day Activity -- Unpaid Activity in the Community

State	Usually/Often	Sometimes	Never	N
AZ	11%	8%	81%	196
CA	23%	14%	63%	2511
FL	15%	12%	73%	169
GA	16%	15%	69%	293
KY	15%	16%	70%	141
LA	9%	9%	82%	291
MD	19%	18%	63%	918
NC	13%	16%	72%	141
NJ	36%	25%	40%	448
PA	17%	10%	73%	517
SD	13%	24%	63%	418
VA	20%	12%	67%	137
NCI Average	19%	14%	67%	6180

Table 15. Family Member's Typical Day Activity -- Paid Activity in a Facility-based Setting

State	Usually/Often	Sometimes	Never	N
AZ	28%	4%	69%	221
CA	22%	7%	72%	2556
FL	22%	5%	73%	186
GA	14%	7%	79%	293
KY	29%	7%	65%	153
LA	18%	6%	76%	306
MD	28%	9%	63%	967
NC	26%	9%	65%	156
NJ	35%	8%	57%	462
PA	27%	4%	69%	555
SD	39%	11%	50%	460
VA	15%	6%	79%	148
NCI Average	24%	7%	70%	6463

Table 16. Family Member's Typical Day Activity -- Unpaid Activity in a Facility-based Setting

State	Usually/Often	Sometimes	Never	N
AZ	64%	4%	32%	255
CA	36%	7%	57%	2555
FL	39%	4%	57%	184
GA	47%	8%	45%	311
KY	53%	10%	37%	155
LA	23%	7%	70%	314
MD	40%	10%	50%	970
NC	44%	10%	46%	144
NJ	44%	9%	47%	464
PA	36%	6%	57%	534
SD	25%	11%	64%	398
VA	42%	7%	52%	139
NCI Average	39%	7%	54%	6423

Table 17. Family Member's Typical Day Activity – School

State	Usually/Often	Sometimes	Never	N
AZ	7%	0%	93%	162
CA	16%	5%	79%	2009
FL	10%	3%	86%	147
GA	8%	1%	92%	224
KY	3%	1%	97%	117
LA	7%	1%	92%	249
MD	4%	4%	93%	718
NC	4%	2%	94%	122
NJ	12%	7%	80%	396
PA	5%	1%	95%	413
SD	1%	1%	98%	363
VA	3%	1%	96%	110
NCI Average	10%	3%	87%	5030

Table 18. Family Member's Typical Day Activity – Stays at Home

State	Usually/Often	Sometimes	Never	N
AZ	25%	20%	55%	159
CA	37%	19%	44%	1956
FL	34%	23%	43%	150
GA	31%	22%	47%	220
KY	19%	26%	55%	118
LA	38%	12%	50%	250
MD	25%	19%	56%	725
NC	15%	34%	50%	111
NJ	17%	25%	58%	395
PA	30%	21%	49%	395
SD	30%	24%	47%	357
VA	37%	19%	44%	111
NCI Average	31%	21%	48%	4947

Table 19. Family Member's Typical Day Activity – Other

State	Usually/Often	Sometimes	Never	N
AZ	57%	7%	37%	30
CA	62%	9%	29%	571
FL	68%	7%	24%	41
GA	61%	9%	30%	70
LA	62%	7%	32%	76
MD	52%	7%	41%	206
NC	47%	11%	42%	38
NJ	47%	5%	47%	127
PA	76%	10%	14%	72
SD	39%	6%	56%	90
VA	40%	17%	43%	47
NCI Average	58%	9%	32%	1373

*Due to low N (<20) KY is not represented in the table, but their data are included in the NCI Average.

Table 20. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

State	Extensive	Some	None	N
AZ	30%	39%	31%	317
CA	26%	36%	38%	3,790
FL	31%	36%	33%	229
GA	36%	34%	30%	392
KY	31%	43%	26%	192
LA	45%	32%	23%	384
MD	27%	34%	39%	1,286
NC	29%	39%	32%	191
NJ	45%	39%	17%	543
PA	32%	38%	31%	664
SD	21%	42%	37%	544
VA	33%	41%	26%	183
NCI Average	30%	37%	33%	8,715

Table 21. Family Member's Level of Help Needed With Personal Care Activities³

State	Extensive	Some	None	N
AZ	43%	42%	15%	320
CA	34%	35%	31%	3,970
FL	42%	39%	19%	231
GA	41%	40%	19%	406
KY	38%	46%	17%	191
LA	52%	32%	16%	395
MD	38%	36%	26%	1,318
NC	41%	39%	20%	195
NJ	39%	49%	12%	548
PA	48%	36%	17%	669
SD†	29%	39%	31%	555
VA	56%	37%	7%	189
NCI Average	40%	37%	23%	8,987

†SD used the previous year's survey; in 2016-17 responses options were clarified, therefore comparisons of SD's should be made with caution.

Table 22. Family Member's Need for Help With Other Daily Activities⁴

State	Extensive	Some	None	N
AZ	83%	16%	1%	313
CA	68%	28%	5%	3,906
FL	83%	15%	2%	233
GA	84%	14%	2%	408
KY	88%	11%	1%	186
LA	81%	17%	2%	394
MD	76%	22%	2%	1,315
NC	82%	16%	2%	195
NJ	88%	11%	1%	548
PA	84%	14%	2%	658
SD	61%	37%	2%	555
VA	86%	13%	1%	190
NCI Average	76%	21%	3%	8,901

³ For example, bathing, dressing, eating

⁴ For example, scheduling, managing money, or shopping

Respondents

This section provides demographic information about the respondent.

Table 23. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
AZ	4%	20%	56%	20%	320
CA	1%	9%	59%	32%	4,000
FL	3%	20%	59%	19%	231
GA	2%	14%	62%	22%	412
KY	0%	11%	68%	22%	191
LA	1%	15%	58%	27%	405
MD	1%	11%	61%	27%	1,324
NC	1%	9%	62%	29%	193
NJ	4%	22%	63%	11%	548
PA	1%	9%	62%	29%	672
SD	2%	13%	62%	23%	563
VA	1%	12%	62%	25%	189
NCI Average	1%	11%	60%	27%	9,048

Table 24. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
AZ	22%	45%	30%	4%	317
CA	16%	41%	37%	6%	3,994
FL	15%	45%	35%	6%	231
GA	11%	37%	43%	9%	407
KY	8%	42%	44%	6%	190
LA	9%	34%	46%	10%	403
MD	14%	41%	39%	6%	1,322
NC	19%	43%	32%	6%	190
NJ	14%	50%	34%	2%	550
PA	12%	42%	40%	6%	667
SD	17%	45%	36%	2%	556
VA	12%	43%	37%	7%	187
NCI Average	15%	42%	38%	6%	9,014

Table 25. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
AZ	52%	23%	0%	2%	2%	9%	12%	317
CA	84%	11%	0%	1%	0%	1%	3%	4,015
FL	51%	20%	1%	1%	5%	6%	16%	232
GA	57%	25%	1%	2%	1%	3%	11%	412
KY	48%	33%	0%	1%	1%	7%	11%	191
LA	56%	27%	0%	1%	4%	0%	11%	408
MD	57%	25%	0%	3%	2%	1%	12%	1,336
NC	59%	33%	0%	1%	0%	2%	5%	193
NJ	50%	20%	0%	1%	14%	9%	6%	551
PA	57%	38%	0%	1%	0%	2%	2%	675
SD	60%	22%	0%	1%	9%	3%	5%	563
VA	56%	25%	1%	1%	1%	4%	13%	190
NCI Average	67%	21%	0%	1%	2%	3%	7%	9,083

Table 26. Respondent's Frequency of Visits With Family Member

State	Less than once	1-3 times	4-6 times	7-12 times	More Than 12 Times	N
AZ	1%	7%	9%	14%	69%	317
CA	5%	11%	9%	10%	65%	3,999
FL	2%	8%	9%	10%	71%	232
GA	4%	10%	13%	12%	62%	410
KY	2%	8%	12%	15%	63%	190
LA	5%	14%	12%	16%	54%	394
MD	3%	8%	10%	10%	69%	1,330
NC	5%	13%	9%	14%	59%	190
NJ	3%	5%	20%	21%	52%	550
PA	4%	8%	11%	12%	65%	687
SD	5%	10%	9%	12%	63%	564
VA	2%	10%	13%	19%	56%	189
NCI Average	4%	10%	10%	12%	64%	9,052

Table 27. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree or Higher	N
AZ	3%	15%	3%	35%	43%	319
CA	6%	15%	4%	27%	48%	3,958
FL	4%	19%	7%	27%	43%	207
GA	6%	25%	11%	21%	37%	393
KY	3%	27%	5%	28%	38%	189
LA	10%	28%	7%	21%	34%	393
MD	3%	21%	3%	20%	53%	1,320
NC	2%	14%	2%	20%	62%	190
NJ	5%	14%	7%	17%	58%	546
PA	3%	34%	6%	19%	38%	677
SD	5%	23%	11%	21%	40%	556
VA	6%	17%	6%	22%	49%	188
NCI Average	5%	19%	5%	24%	47%	8,936

Table 28. Total Taxable Household Income of Wage Earners in the Past Year

State	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	No Earned Income	Prefer Not to Say	N
AZ	6%	8%	21%	13%	16%	11%	25%	252
CA	5%	11%	16%	12%	21%	11%	25%	3,094
FL	10%	8%	22%	12%	14%	7%	26%	177
GA	8%	12%	17%	8%	13%	11%	31%	310
KY	8%	8%	18%	15%	18%	9%	24%	164
LA	12%	11%	19%	7%	10%	14%	27%	315
MD	5%	9%	15%	12%	23%	9%	26%	1,012
NC	5%	7%	14%	12%	18%	10%	36%	160
NJ	6%	5%	24%	5%	21%	9%	31%	475
PA	5%	10%	18%	9%	12%	14%	32%	529
SD†	8%	11%	22%	15%	14%	5%	26%	487
VA	4%	13%	17%	8%	18%	10%	29%	145
NCI Average	6%	10%	17%	11%	18%	11%	27%	7,120

†SD used the previous year's survey; in 2016-17 responses options were clarified, therefore comparisons of SD's should be made with caution.

Services and Supports Received

This section provides information about the services and supports received by the family.

Table 29. Services and Supports Received From ID/DD Agency

State	Financial Support	In-home Support	Residential Support	Day or Employment Supports	Transportation	Other	Self-direction or Fiscal Intermediary Services
AZ	32%	20%	90%	77%	93%	57%	15%
CA	42%	43%	78%	69%	70%	40%	19%
FL	27%	43%	83%	59%	85%	56%	39%
GA	35%	33%	89%	69%	92%	47%	25%
KY	22%	35%	94%	79%	93%	68%	19%
LA	23%	44%	81%	44%	84%	60%	20%
MD	31%	38%	86%	76%	89%	52%	17%
NC	24%	18%	92%	80%	93%	56%	11%
NJ	30%	25%	95%	74%	95%	65%	17%
PA	23%	30%	88%	67%	89%	63%	19%
SD	27%	31%	87%	66%	88%	61%	36%
VA	33%	25%	91%	60%	90%	61%	13%
NCI Average	33%	36%	84%	68%	82%	52%	20%

Table 30. Additional Services and Supports Received

State	Social Security Payments (SSI/SSB)	Other Agencies or Organizations
AZ	97%	28%
CA	91%	28%
FL	99%	31%
GA	98%	20%
KY	96%	23%
LA	96%	20%
MD	94%	28%
NC	96%	20%
NJ	97%	35%
PA	96%	36%
SD	97%	25%
VA	97%	30%
NCI Average	94%	28%

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: Significance is based on “Always” or “Yes” response.

Gets Enough Information to Help Plan Services

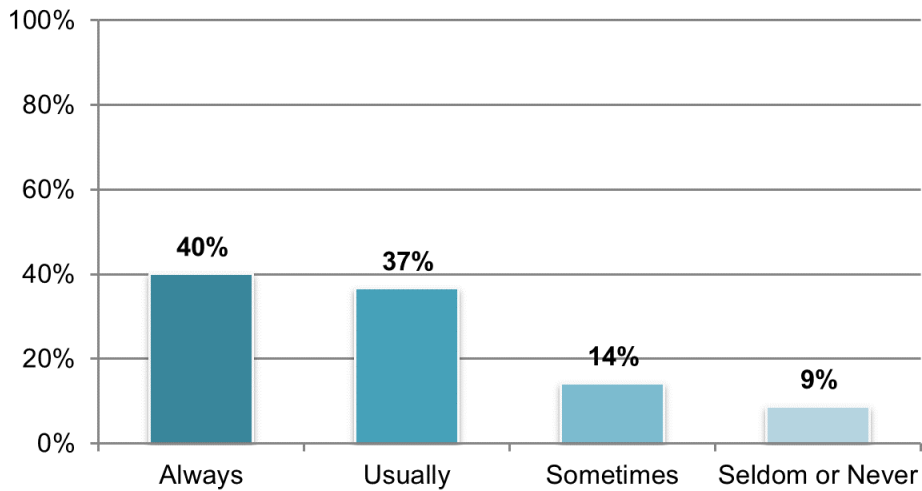


Table Q1. Do you get enough information to help you participate in planning services for your family?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
NC	56%	32%	8%	3%	189
VA	55%	36%	7%	2%	168
AZ	52%	38%	7%	3%	308
PA	46%	38%	13%	4%	606
Within Average Range					
FL	48%	37%	10%	5%	220
LA	43%	34%	13%	10%	352
SD	41%	44%	12%	3%	527
KY	39%	44%	12%	5%	179
GA	37%	36%	18%	8%	367
CA [~]	36%	35%	16%	13%	3,382
Significantly Below Average					
MD	29%	43%	18%	10%	1,154
NJ	25%	41%	21%	13%	512
NCI Average	40%	37%	14%	9%	7,964

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Information About Services and Supports Is Easy to Understand

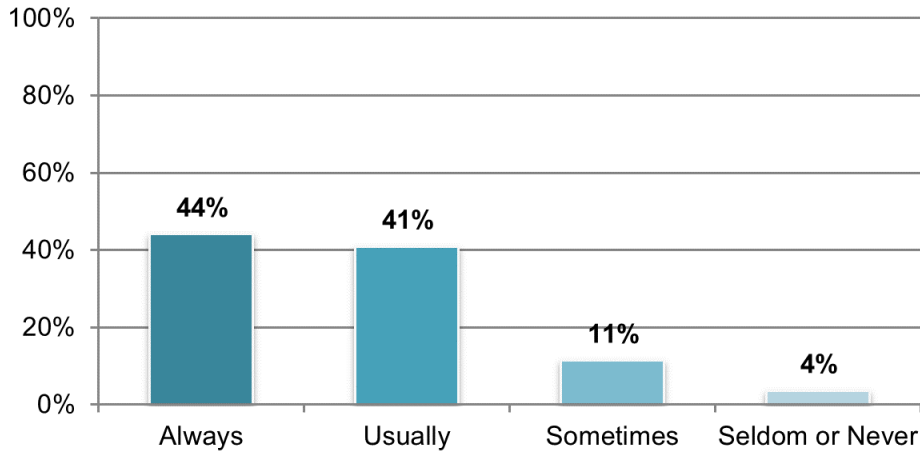


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
AZ	52%	38%	9%	1%	310
Within Average Range					
VA	49%	43%	7%	1%	179
PA	49%	41%	9%	1%	624
NC	47%	41%	11%	2%	192
CA	46%	38%	12%	4%	3,296
LA	45%	42%	10%	3%	352
SD	44%	46%	8%	2%	534
FL	43%	43%	10%	4%	218
KY	37%	44%	14%	5%	180
Significantly Below Average					
MD	37%	45%	13%	5%	1,128
GA	37%	42%	15%	7%	369
NJ	30%	48%	18%	5%	504
NCI Average	44%	41%	11%	4%	7,886

Residential Staff Keep Respondent Informed About Family Member

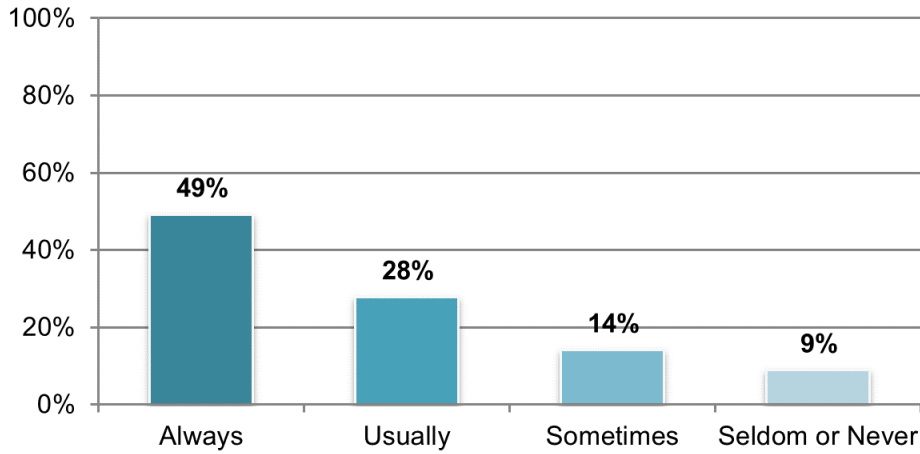


Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
VA	62%	25%	10%	3%	182
AZ	60%	25%	10%	5%	310
PA	55%	29%	13%	4%	654
Within Average Range					
NC	58%	31%	8%	3%	194
FL	57%	28%	10%	4%	225
LA	51%	29%	13%	7%	391
KY	51%	35%	10%	5%	188
GA	49%	24%	16%	10%	402
CA [~]	46%	26%	15%	13%	3,618
SD	42%	36%	16%	6%	547
Significantly Below Average					
NJ	39%	31%	21%	10%	539
MD	38%	29%	20%	12%	1,244
NCI Average	49%	28%	14%	9%	8,494

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Case Manager or Service Coordinator Respects Family's Choices and Opinions

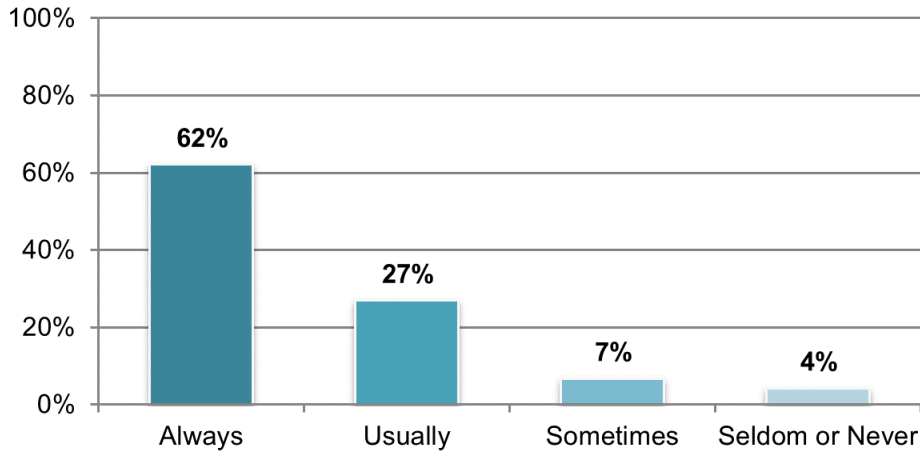


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
NC	73%	21%	5%	2%	191
FL	72%	24%	2%	2%	226
AZ	70%	24%	5%	1%	316
Within Average Range					
VA	68%	24%	6%	2%	181
LA	65%	27%	6%	3%	358
PA	65%	27%	6%	3%	617
KY	61%	31%	6%	2%	188
CA	60%	27%	7%	6%	3,466
GA	59%	28%	8%	5%	381
SD	58%	34%	6%	2%	536
Significantly Below Average					
MD	52%	32%	10%	5%	1,187
NJ	49%	32%	14%	6%	502
NCI Average	62%	27%	7%	4%	8,149

Respondent Needs Help Planning for Family Member's Future Needs

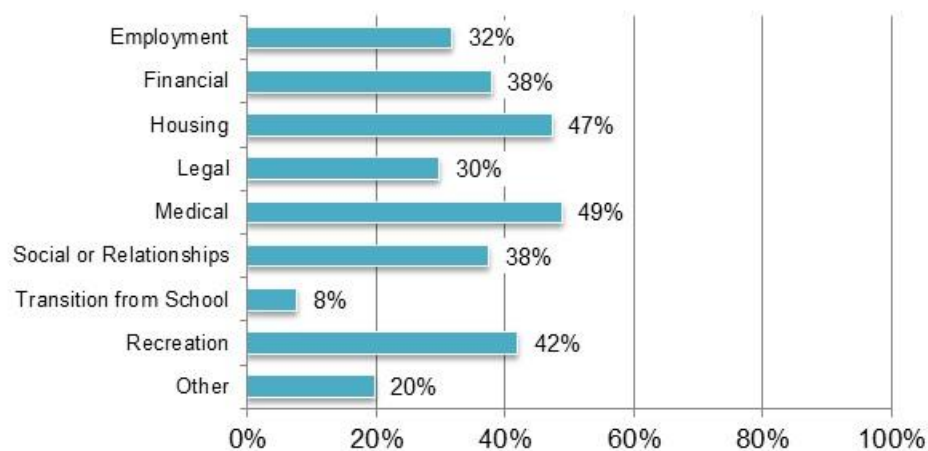


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition from School	Recreation	Other	N
AZ	35%	32%	45%	29%	45%	40%	11%	42%	13%	118
CA	37%	40%	51%	28%	48%	40%	9%	44%	18%	2,006
FL	28%	38%	40%	29%	49%	28%	14%	32%	28%	112
GA	26%	36%	49%	41%	52%	33%	6%	40%	20%	172
KY	24%	36%	57%	34%	52%	43%	3%	37%	7%	67
LA	21%	31%	47%	28%	44%	32%	8%	28%	33%	188
MD	32%	36%	42%	29%	48%	38%	4%	44%	20%	656
NC	31%	37%	48%	33%	51%	37%	5%	46%	24%	324
NJ	39%	37%	40%	33%	39%	37%	7%	40%	20%	82
PA	17%	31%	40%	29%	50%	34%	4%	43%	17%	242
SD	45%	44%	44%	27%	48%	43%	4%	51%	14%	256
VA	22%	41%	51%	39%	61%	42%	10%	46%	19%	83
NCI Average	32%	38%	47%	30%	49%	38%	8%	42%	20%	4,306

Family Member Moved Out of the Family Home For the First Time in the Past Year

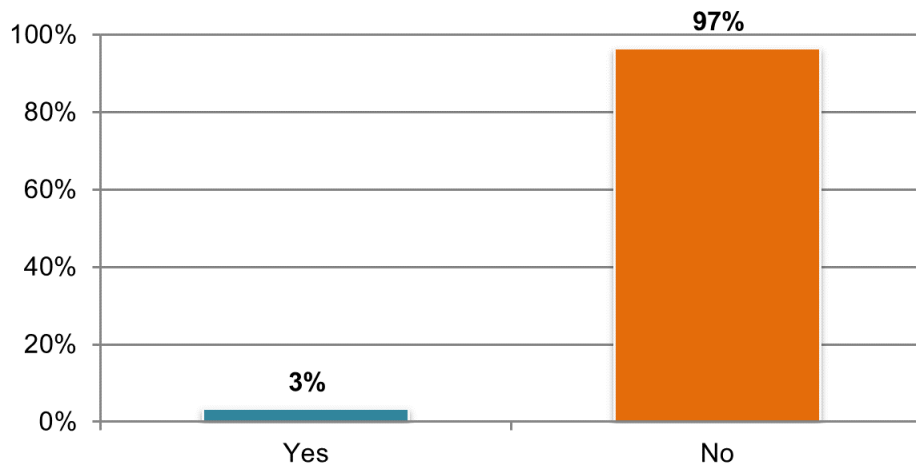


Table Q6. In the past year, did your family member move out of the family home for the first time?

State	Yes	No	N
Within Average Range			
AZ	6%	94%	314
GA	5%	95%	388
FL	5%	95%	228
NC	4%	96%	188
MD	4%	96%	1,275
NJ	4%	96%	534
CA	3%	97%	3,820
VA	3%	97%	173
LA	3%	97%	383
SD	2%	98%	546
KY	2%	98%	192
Significantly Below Average			
PA	2%	98%	658
NCI Average	3%	97%	8,699

Family Member Received Enough Information About Services and Supports If Moved Out of the Family Home in the Past Year

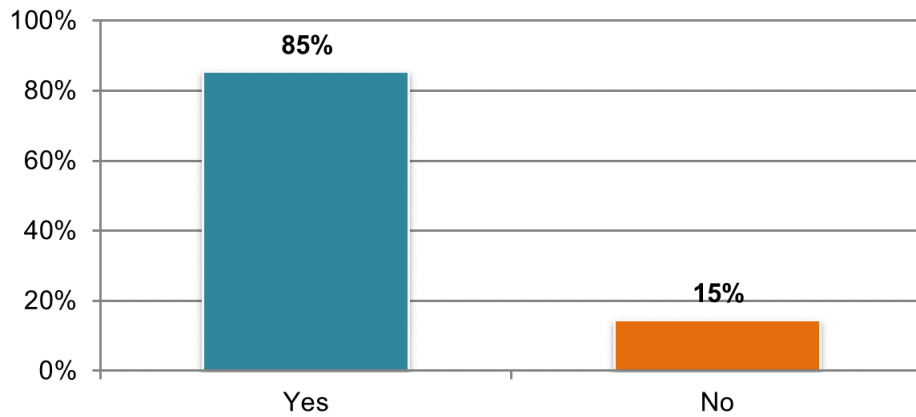


Table Q7. If family member moved out of the home for the first time in the past year, did your family member receive enough information about services available to support him/her?

State	Yes	No	N
Within Average Range			
CA	82%	18%	82
MD	78%	22%	37
GA	67%	33%	21
NCI Average	85%	15%	227

*Due to low N's (<20) the following states are not represented in the table, but their data are included in the NCI Average: AZ, FL, KY, LA, NC, NJ, PA, SD, VA

Respondent Had Enough Choices of Service Providers If Family Member Moved Out of the Family Home in the Past Year

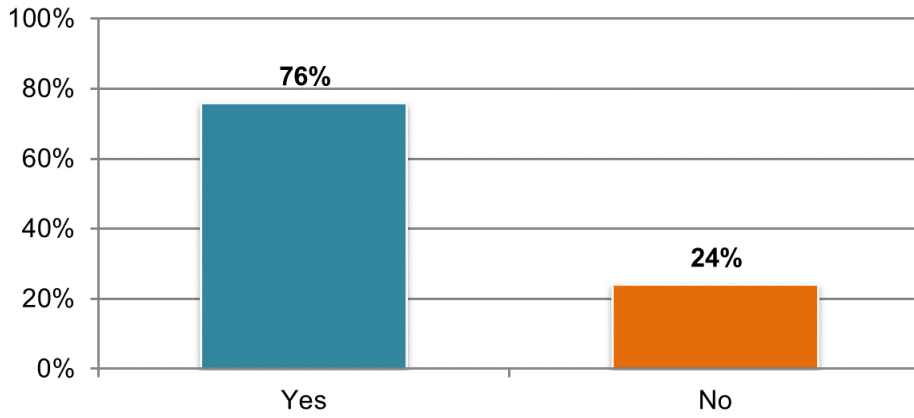


Table Q8. If family member moved out of the home for the first time in the past year, did you have enough choices of service providers to support your family member living outside the family home?

State	Yes	No	N
Within Average Range			
MD	82%	18%	39
CA	73%	28%	80
NCI Average	76%	24%	214

*Due to low N's (<20) the following states are not represented in the table, but their data are included in the NCI Average: AZ, FL, GA, KY, LA, NC, NJ, PA, SD, VA

Family Member Has a Service Plan

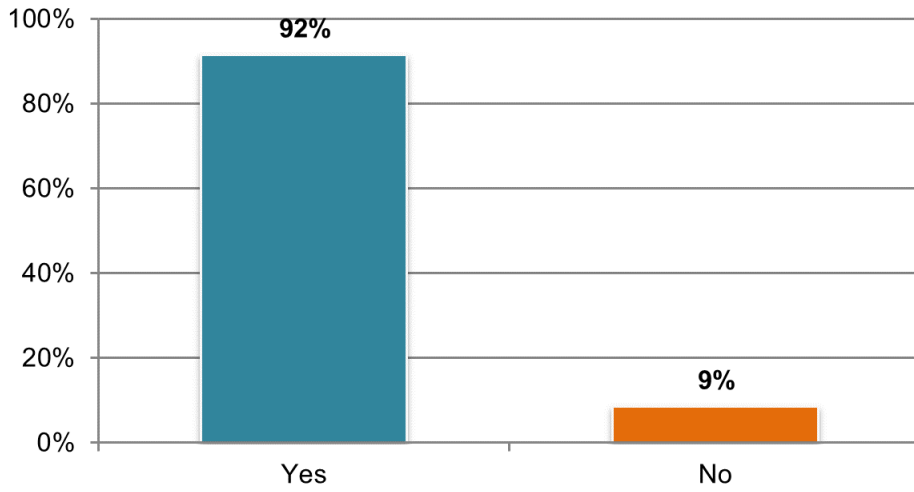


Table Q9. Does your family member have a service plan?

State	Yes	No	N
Significantly Above Average			
FL	98%	2%	208
SD	97%	3%	444
PA	97%	3%	603
Within Average Range			
GA	94%	6%	342
NC	94%	6%	172
AZ	93%	7%	286
CA	92%	8%	3,057
MD	90%	10%	1,047
VA	86%	14%	161
KY	85%	15%	158
Significantly Below Average			
LA	83%	17%	283
NJ	74%	26%	350
NCI Average	92%	9%	7,111

Service Plan Includes All the Services and Supports Family Member Needs

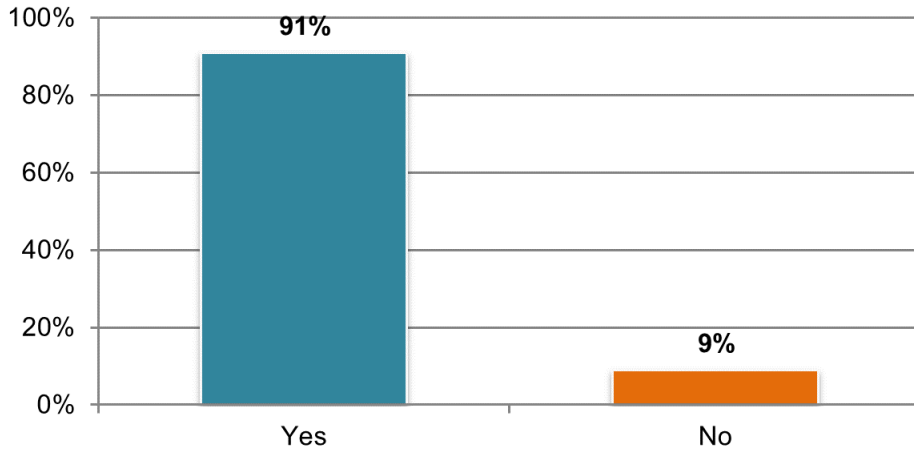


Table Q10. Does the plan include all the services and supports your family member needs?

State	Yes	No	N
Significantly Above Average			
PA	95%	5%	528
LA	95%	5%	222
Within Average Range			
VA	95%	5%	126
AZ	94%	6%	250
SD	94%	6%	404
NC	93%	7%	152
MD	92%	8%	849
KY	92%	8%	125
FL	89%	11%	177
CA [~]	89%	11%	2,377
NJ	88%	12%	227
GA	86%	14%	279
NCI Average	91%	9%	5,716

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Family Member Gets All Services Listed in the Service Plan

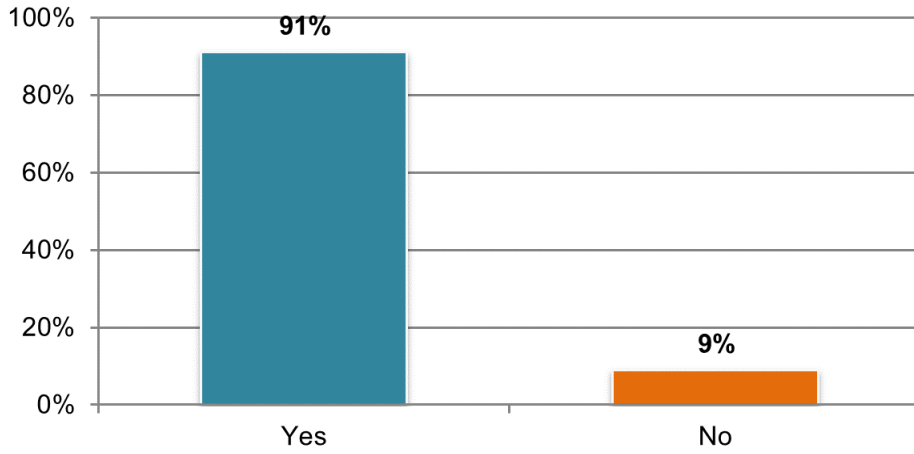


Table Q11. Does your family member get all of the services listed in the plan?

State	Yes	No	N
Significantly Above Average			
NC	97%	3%	148
PA	95%	5%	493
Within Average Range			
AZ	93%	7%	246
VA	93%	7%	120
LA	93%	7%	195
CA	92%	8%	2,218
SD	91%	9%	370
MD [~]	88%	12%	784
KY	88%	12%	115
GA	87%	13%	254
FL	85%	15%	175
Significantly Below Average			
NJ	82%	18%	215
NCI Average	91%	9%	5,333

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent or Other Family Member Helped Make Service Plan

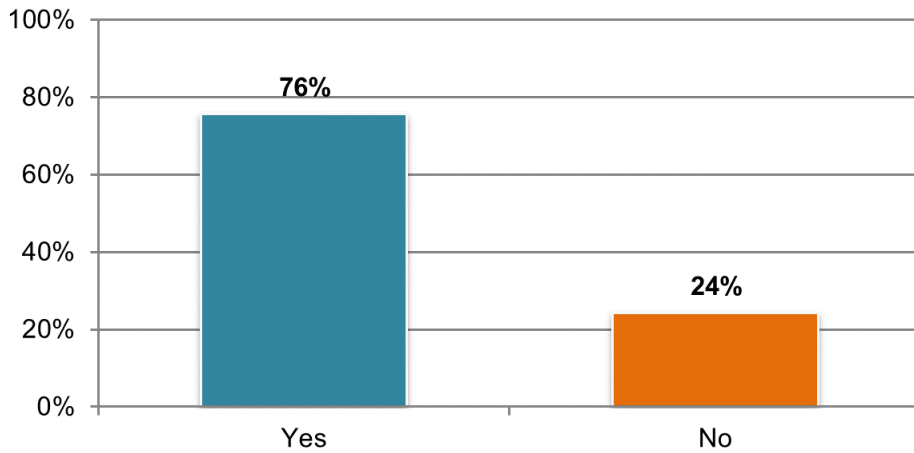


Table Q12. Did you or another family member help make the plan?

State	Yes	No	N
Significantly Above Average			
AZ	88%	12%	253
NC	87%	13%	150
KY	87%	13%	128
SD	86%	14%	404
MD	82%	18%	887
Within Average Range			
VA	84%	16%	126
GA	78%	22%	296
NJ	77%	23%	244
FL	77%	23%	181
LA	75%	25%	228
PA	73%	27%	536
Significantly Below Average			
CA	70%	30%	2,554
NCI Average	76%	24%	5,987

Family Member Helped Make Service Plan

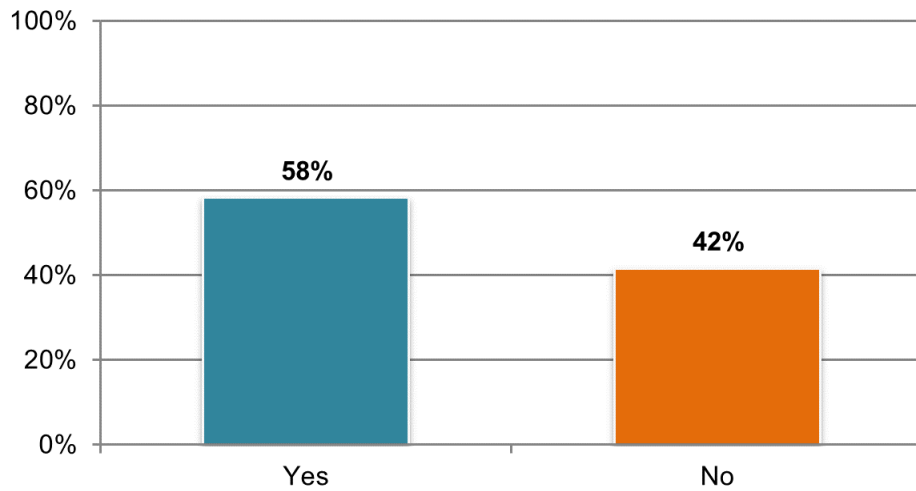


Table Q13. Did your family member help make the plan?

State	Yes	No	N
Significantly Above Average			
SD	80%	20%	387
MD	67%	33%	860
Within Average Range			
KY	62%	38%	122
FL	60%	40%	182
CA	59%	41%	2,429
AZ	59%	41%	248
NC	59%	41%	152
GA	58%	42%	295
VA	58%	42%	128
LA	53%	47%	213
Significantly Below Average			
PA	51%	49%	518
NJ	47%	53%	239
NCI Average	58%	42%	5,773

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

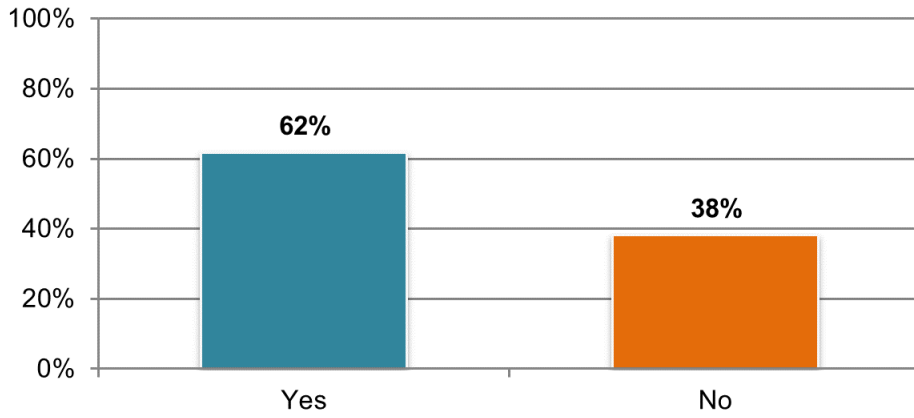


Table Q14. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?

State	Yes	No	N
Significantly Above Average			
FL	82%	18%	179
LA	82%	18%	220
NC	77%	23%	151
KY	73%	27%	120
SD	70%	30%	383
Within Average Range			
PA	65%	35%	479
VA	64%	36%	115
AZ	62%	38%	243
MD	59%	41%	823
NJ	59%	41%	232
GA	56%	44%	266
Significantly Below Average			
CA	50%	50%	2,222
NCI Average	62%	38%	5,433

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

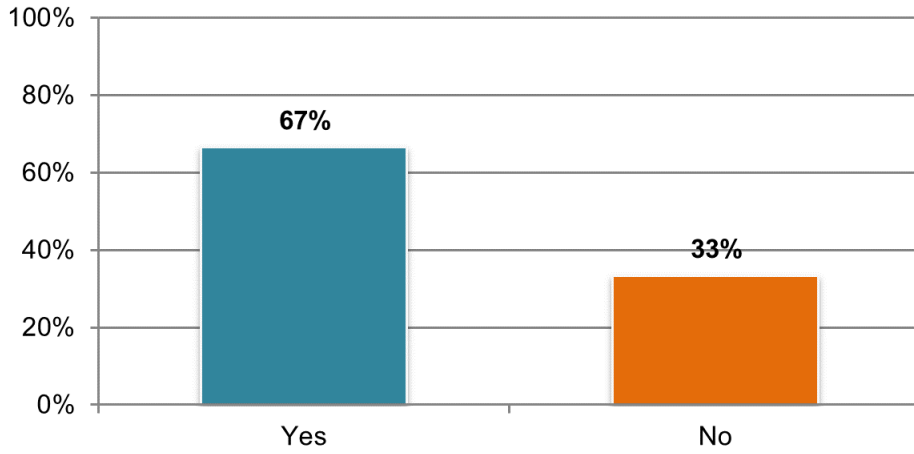


Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

State	Yes	No	N
Significantly Above Average			
SD	75%	25%	389
Within Average Range			
NC	71%	29%	140
PA	69%	31%	335
CA [~]	69%	31%	2,162
AZ	66%	34%	198
FL	65%	35%	144
MD	65%	35%	734
LA	64%	36%	180
VA	63%	37%	100
KY	61%	39%	101
GA	61%	39%	229
Significantly Below Average			
NJ	52%	48%	285
NCI Average	67%	33%	4,997

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent Feels Prepared to Handle the Needs of Family Member in an Emergency

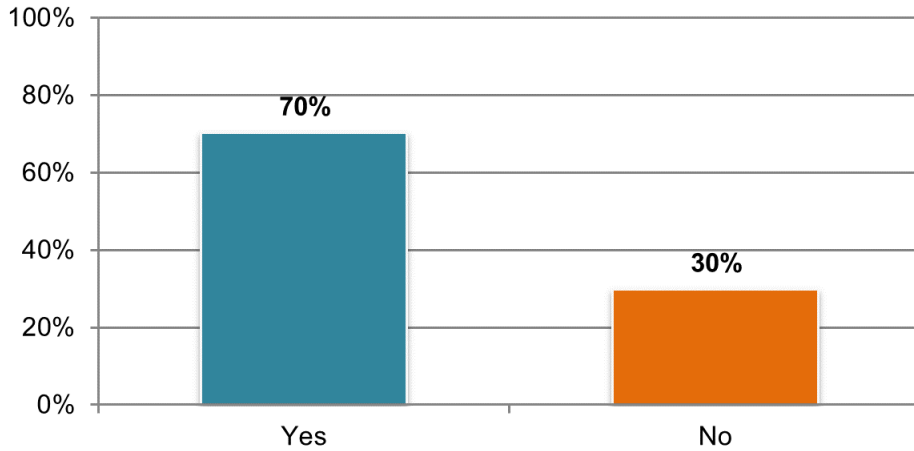


Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

State	Yes	No	N
Significantly Above Average			
SD†	83%	17%	435
FL	82%	18%	198
AZ	82%	18%	275
Within Average Range			
NC	75%	25%	165
KY	71%	29%	163
GA	70%	30%	344
VA	70%	30%	147
PA	69%	31%	490
CA	68%	32%	2,909
LA	68%	32%	334
Significantly Below Average			
MD	64%	36%	1,037
NJ	61%	39%	427
NCI Average	70%	30%	6,924

†SD used the previous year's survey; in 2016-17 responses options were changed, therefore comparisons of SD's should be made with caution.

Access and Delivery of Services and Supports

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

Respondent or Family Member Is Able to Contact Support Workers When Wants

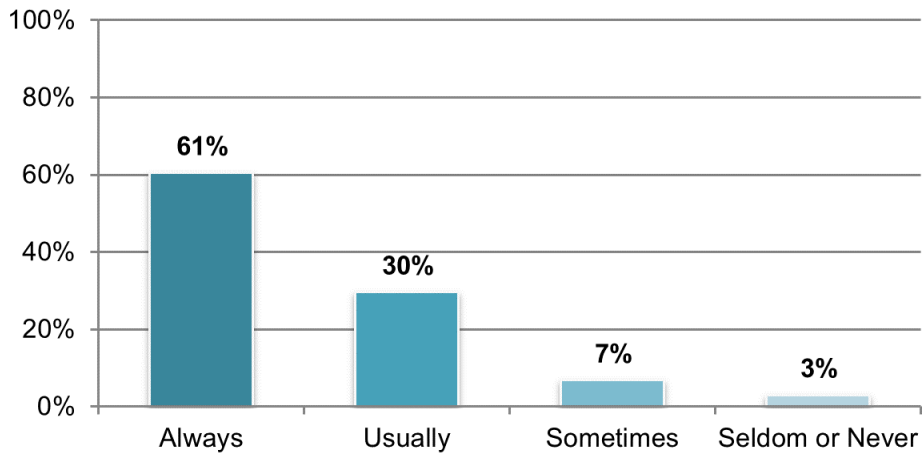


Table Q17. Are you or your family member able to contact his/her support workers when you want to?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	78%	18%	2%	2%	224
PA	70%	25%	4%	1%	642
Within Average Range					
NC	68%	25%	5%	2%	190
VA	67%	27%	4%	2%	181
AZ	65%	30%	4%	1%	307
LA	62%	31%	6%	1%	373
SD	60%	32%	6%	2%	541
KY	57%	36%	6%	1%	188
CA [~]	56%	31%	9%	5%	3,498
GA	55%	35%	8%	2%	385
Significantly Below Average					
NJ	51%	35%	12%	3%	493
MD	50%	39%	9%	3%	1,234
NCI Average	61%	30%	7%	3%	8,256

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent or Family Member Is Able to Contact Case Manager or Service Coordinator When Wants

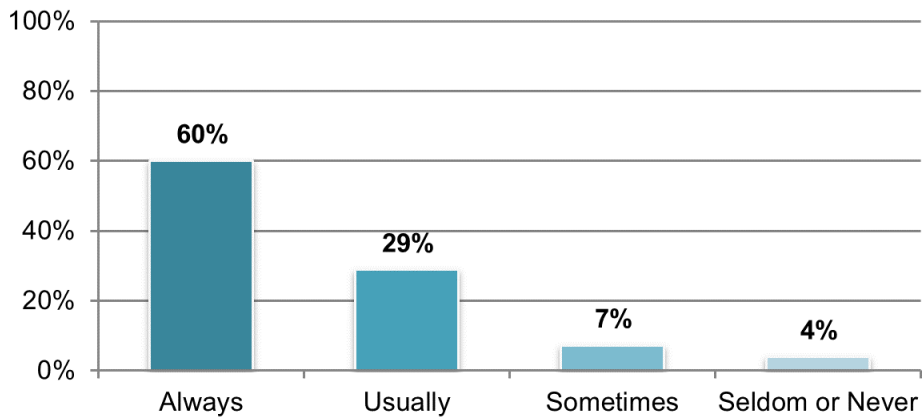


Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	77%	19%	3%	1%	223
NC	71%	24%	3%	2%	190
PA	70%	24%	4%	1%	646
Within Average Range					
VA	66%	30%	2%	2%	181
KY	65%	27%	6%	2%	188
AZ	64%	28%	7%	2%	313
LA	61%	28%	8%	3%	367
SD	61%	31%	6%	2%	542
Significantly Below Average					
CA	55%	31%	9%	6%	3,595
MD	52%	33%	11%	3%	1,232
GA	52%	35%	10%	3%	380
NJ	43%	36%	12%	9%	502
NCI Average	60%	29%	7%	4%	8,359

Support Workers Come and Leave When They Are Supposed to

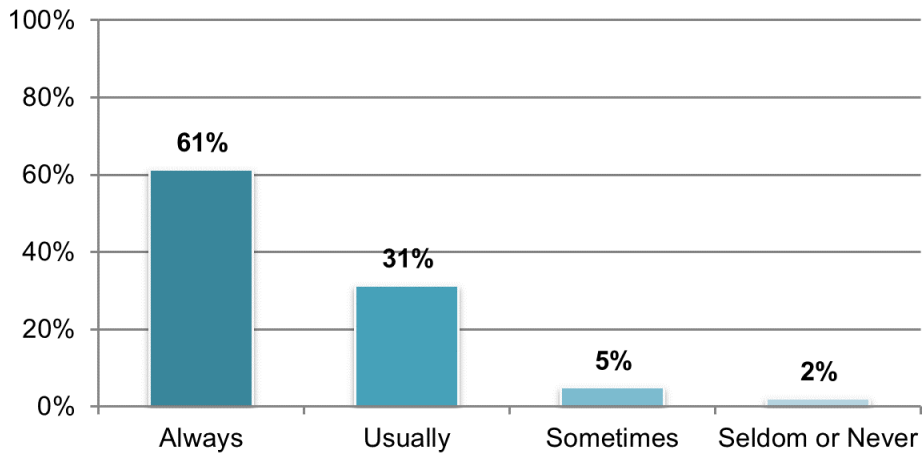


Table Q19. Do support workers come and leave when they are supposed to?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	75%	21%	3%	1%	182
Within Average Range					
PA	67%	28%	3%	2%	404
NC	65%	29%	4%	2%	133
AZ	64%	30%	5%	1%	246
SD	62%	33%	5%	0%	345
VA	61%	33%	5%	0%	111
LA	61%	34%	4%	1%	224
CA	60%	32%	6%	3%	2,398
GA	59%	32%	6%	3%	243
KY	56%	39%	3%	2%	132
Significantly Below Average					
MD	53%	38%	6%	3%	818
NJ	47%	41%	11%	2%	266
NCI Average	61%	31%	5%	2%	5,502

Services and Supports Change When Family Member's Needs Change

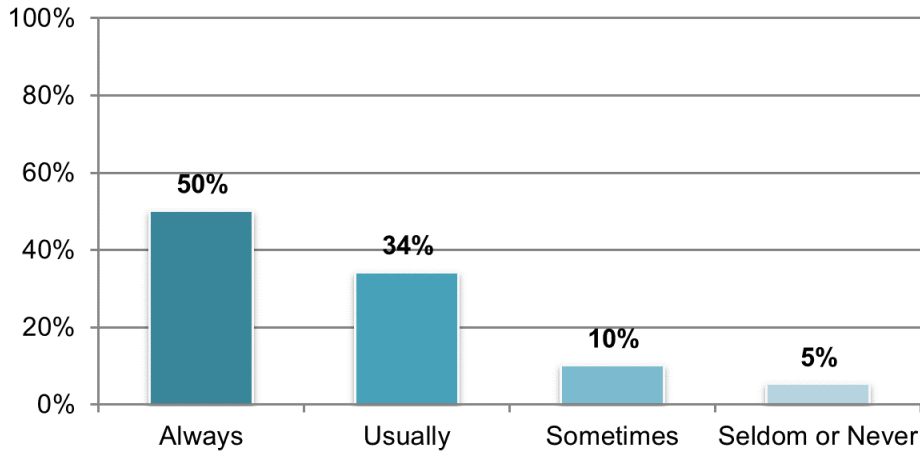


Table Q20. Do services and supports change when your family's needs change?

State	Always	Usually	Sometimes	Seldom or Never	N
Within Average Range					
VA	59%	34%	5%	2%	136
FL	58%	28%	9%	4%	170
AZ	57%	31%	8%	3%	225
LA	55%	33%	7%	6%	249
NC	54%	36%	7%	3%	149
PA	53%	34%	10%	3%	425
CA	49%	34%	10%	7%	2,192
GA	49%	31%	12%	7%	268
SD	47%	37%	12%	4%	401
KY	42%	41%	16%	1%	134
Significantly Below Average					
MD	41%	37%	12%	9%	759
NJ	32%	43%	18%	8%	277
NCI Average	50%	34%	10%	5%	5,385

Support Workers Speak in a Way Respondent Understands

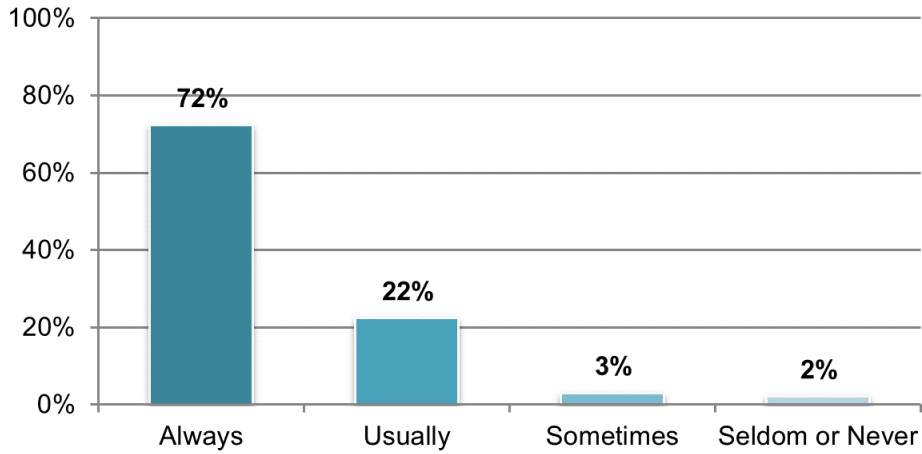


Table Q21. Do support workers speak to you in a way that you understand?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	80%	17%	1%	2%	225
Within Average Range					
NC	78%	20%	1%	1%	178
AZ	75%	21%	3%	0%	296
PA	75%	22%	2%	1%	630
SD	73%	23%	3%	1%	529
CA	72%	21%	4%	3%	3,261
VA	72%	28%	1%		172
LA	72%	25%	2%	1%	344
KY	72%	25%	2%	1%	179
GA	69%	25%	4%	2%	363
MD [~]	68%	26%	4%	2%	1,153
Significantly Below Average					
NJ	60%	32%	6%	2%	446
NCI Average	72%	22%	3%	2%	7,776

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Services and Supports Are Delivered in a Way Respectful of Family's Culture

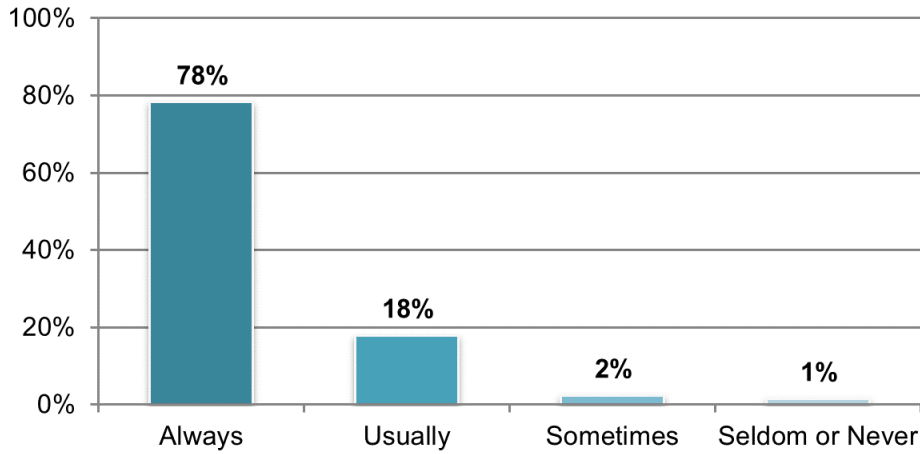


Table Q22. Are services delivered in a way that is respectful of your family's culture?

State	Always	Usually	Sometimes	Seldom or Never	N
Within Average Range					
FL	84%	14%	1%	0%	218
CA [~]	81%	14%	3%	2%	3,332
NC	80%	18%	1%	1%	183
PA	80%	17%	2%	1%	619
AZ	80%	19%	1%	1%	309
KY	78%	19%	2%	1%	186
SD	77%	21%	1%	1%	515
VA	76%	23%	1%	1%	176
Significantly Below Average					
MD	71%	24%	3%	2%	1,155
LA	70%	26%	3%	1%	341
GA	70%	25%	3%	2%	365
NJ	67%	26%	4%	2%	477
NCI Average	78%	18%	2%	1%	7,876

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

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

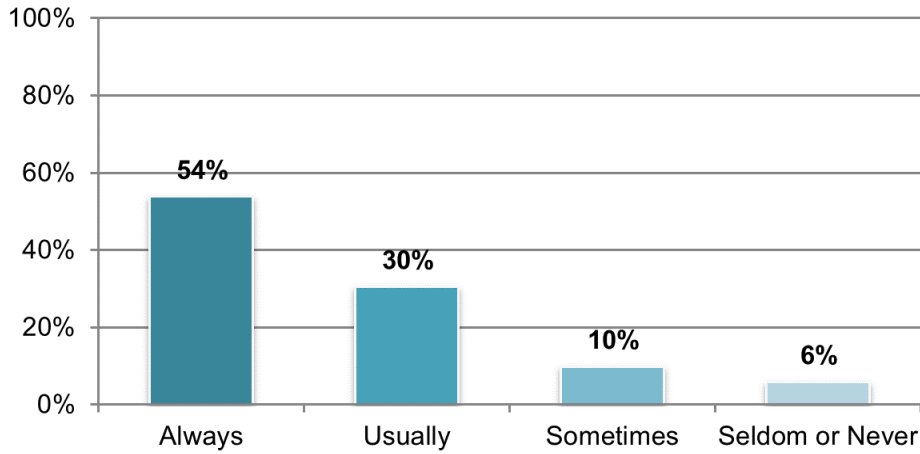


Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom or Never	N
Within Average Range					
VA	61%	28%	9%	2%	64
AZ	60%	27%	8%	5%	75
FL	58%	31%	2%	8%	48
LA	56%	35%	4%	5%	128
NC	56%	29%	8%	6%	48
GA	56%	29%	10%	6%	104
CA	55%	26%	11%	7%	682
PA	55%	35%	8%	3%	194
MD	47%	36%	12%	5%	315
KY	44%	38%	13%	4%	52
Significantly Below Average					
NJ	34%	32%	24%	10%	135
NCI Average	54%	30%	10%	6%	1,852

*Due to low N's (<20) SD is not represented in the table, but their data are included in the NCI Average.

Support Workers Have the Right Information and Skills to Meet Family's Needs

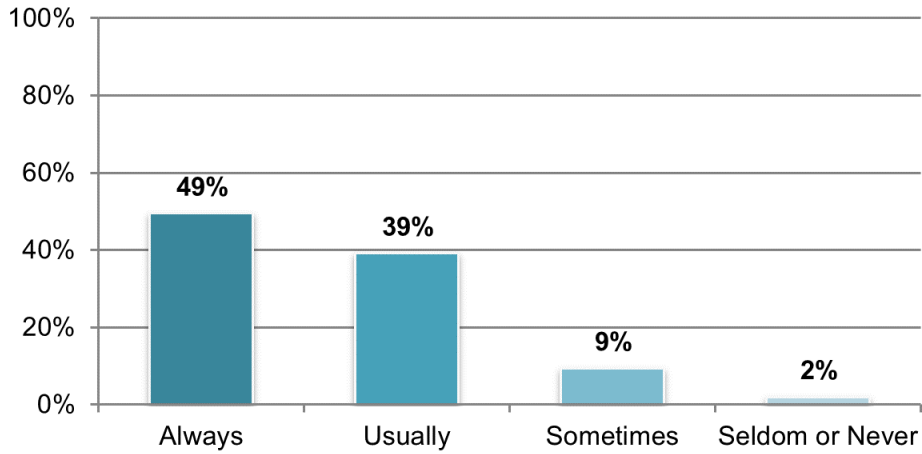


Table Q24. Do support workers have the right information and skills to meet your family's needs?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	63%	30%	6%	1%	215
NC	58%	33%	8%	1%	178
Within Average Range					
GA	54%	32%	12%	2%	358
PA	54%	38%	7%	1%	608
LA	54%	38%	6%	2%	329
VA	52%	44%	4%	1%	170
KY	51%	39%	10%	1%	170
AZ	50%	41%	8%	1%	285
SD	46%	35%	15%	4%	26
CA [~]	46%	42%	10%	2%	3,057
Significantly Below Average					
MD	44%	41%	13%	3%	1,114
NJ	32%	43%	20%	5%	450
NCI Average	49%	39%	9%	2%	6,960

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Family Member Has Access to Special Equipment or Accommodations Needed

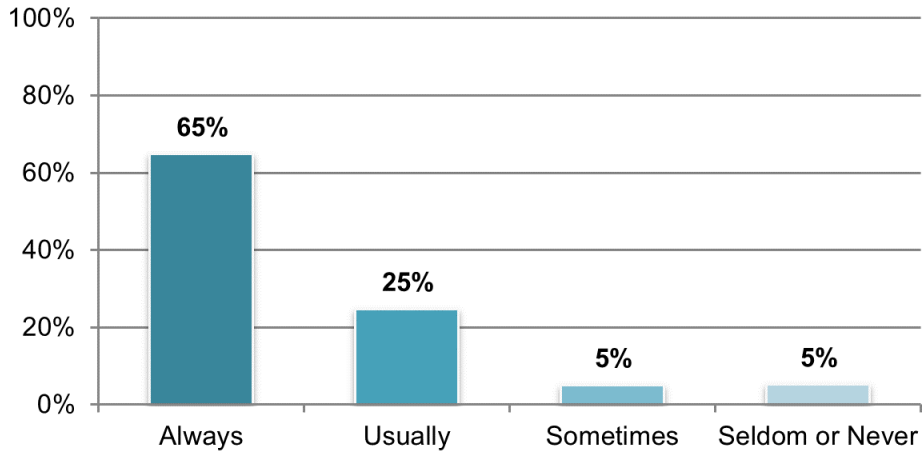


Table Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
AZ	79%	14%	4%	3%	174
PA	73%	21%	3%	2%	406
Within Average Range					
FL	71%	24%	3%	2%	107
NC	69%	21%	4%	6%	89
LA	67%	26%	5%	2%	231
VA	63%	29%	6%	2%	132
CA	63%	24%	6%	8%	1,718
GA	62%	26%	4%	7%	214
MD	60%	25%	7%	8%	648
Significantly Below Average					
NJ	56%	29%	8%	6%	252
KY	52%	41%	4%	4%	108
NCI Average	65%	25%	5%	5%	4,091

*Due to low N's (<20) SD is not represented in the table, but their data are included in the NCI Average.

Family Member Can See Health Professionals When Needed

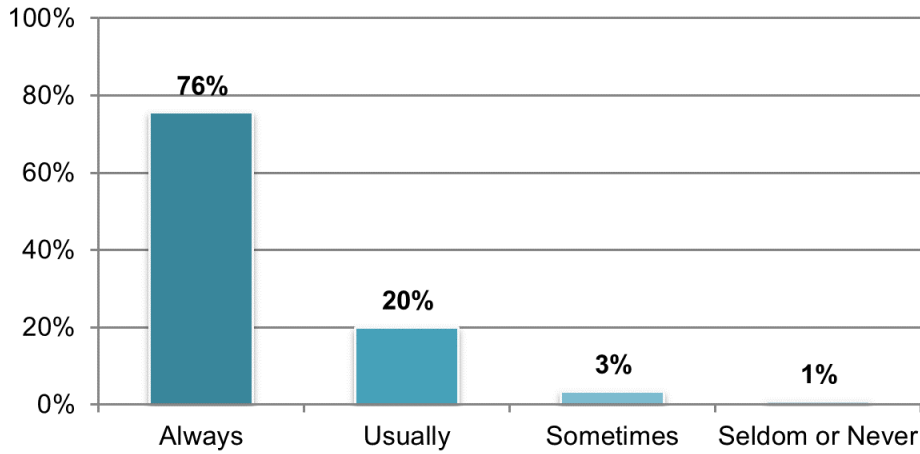


Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
AZ	86%	13%	1%	0%	314
PA	85%	14%	1%	0%	663
FL	83%	12%	4%	1%	230
NC	83%	16%	2%	0%	193
Within Average Range					
LA	77%	20%	3%	0%	379
GA	77%	20%	3%	1%	394
KY	77%	21%	3%	0%	189
VA	74%	22%	3%	2%	185
MD	74%	23%	3%	1%	1,266
Significantly Below Average					
CA	71%	23%	5%	2%	3,684
NJ	70%	26%	3%	1%	523
NCI Average	76%	20%	3%	1%	8,020

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

Family Member's Primary Care Doctor Understands Needs Related to His/Her Disability

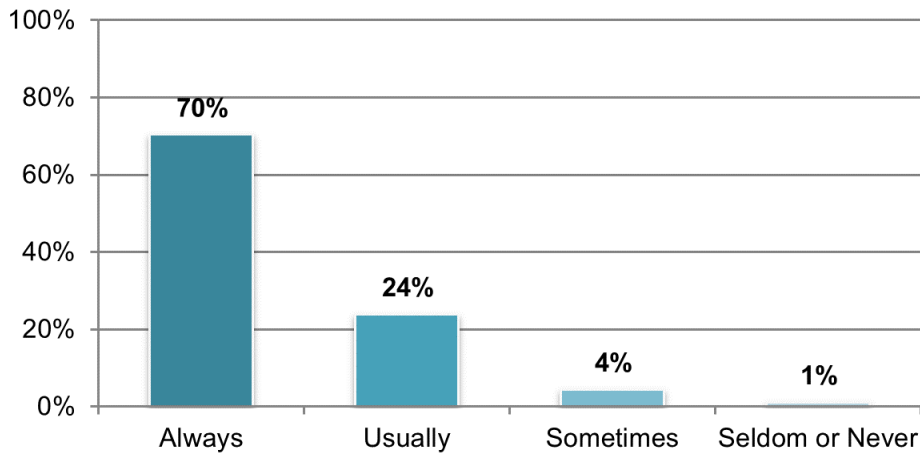


Table Q27. Does your family member's primary care doctor understand his/her needs related to his/her disability?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	80%	16%	3%	1%	223
NC	79%	17%	3%	1%	185
AZ	79%	17%	3%	1%	311
Within Average Range					
LA	76%	21%	3%	1%	349
VA	75%	20%	5%	0%	166
PA	74%	21%	4%	0%	619
GA	70%	25%	4%	1%	370
MD	69%	25%	5%	1%	1,145
KY	67%	31%	2%	1%	185
CA [~]	66%	27%	6%	2%	3,256
Significantly Below Average					
NJ	60%	33%	5%	2%	457
NCI Average	70%	24%	4%	1%	7,266

[†]SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent Has Access to Dental Services for Family Member

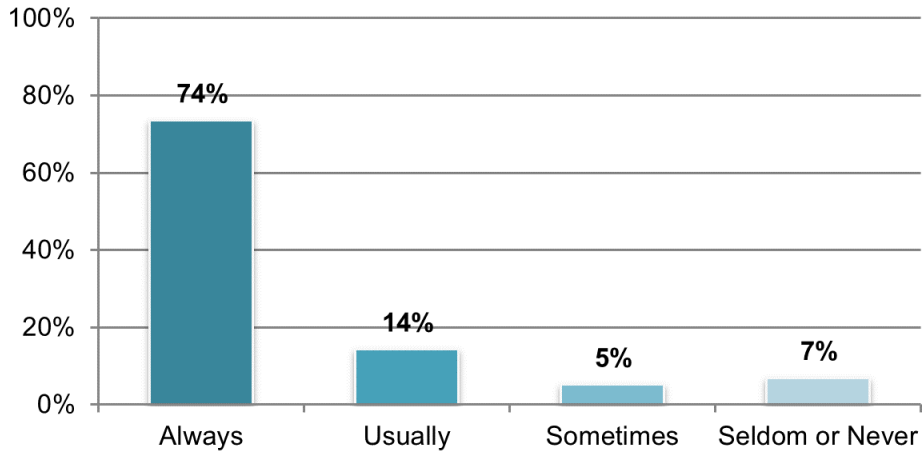


Table Q28. Do you have access to dental services for your family member?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
PA	84%	11%	2%	4%	628
AZ	83%	10%	4%	3%	306
NC	82%	13%	1%	4%	184
Within Average Range					
KY	77%	16%	3%	4%	182
MD	76%	15%	3%	6%	1,178
VA	74%	9%	12%	6%	160
FL	73%	13%	6%	8%	213
GA	72%	15%	3%	9%	355
LA	70%	14%	5%	11%	341
NJ	69%	21%	3%	6%	481
CA [~]	69%	15%	7%	9%	3,336
NCI Average	74%	14%	5%	7%	7,364

[†]SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Family Member's Dentist Understands Needs Related to His/Her Disability

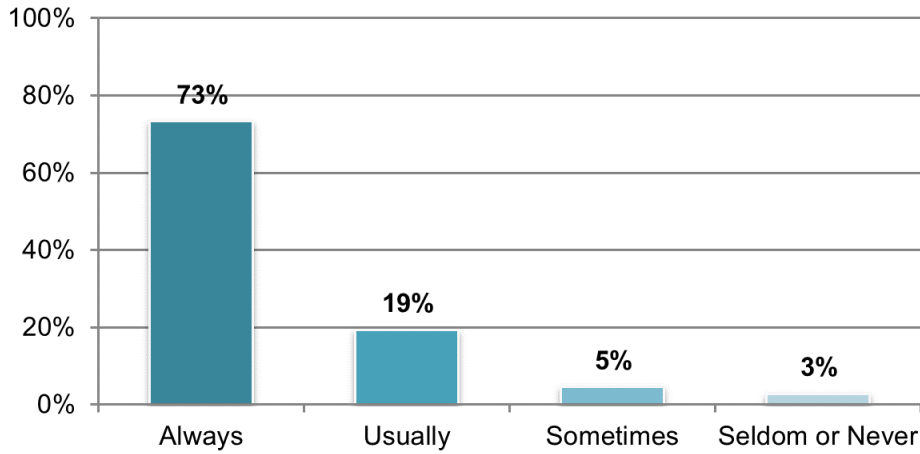


Table Q29. If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
AZ	82%	12%	4%	2%	292
PA	79%	17%	3%	1%	574
Within Average Range					
KY	79%	19%	2%		173
NC	79%	17%	2%	2%	168
FL	78%	16%	5%	2%	193
VA	75%	18%	5%	1%	146
MD	75%	21%	2%	2%	1,027
GA	73%	21%	3%	3%	317
LA	73%	19%	2%	6%	283
CA [~]	69%	21%	6%	4%	2,819
Significantly Below Average					
NJ	66%	27%	6%	2%	413
NCI Average	73%	19%	5%	3%	6,405

[†]SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent Knows What Family Member's Medications Are For

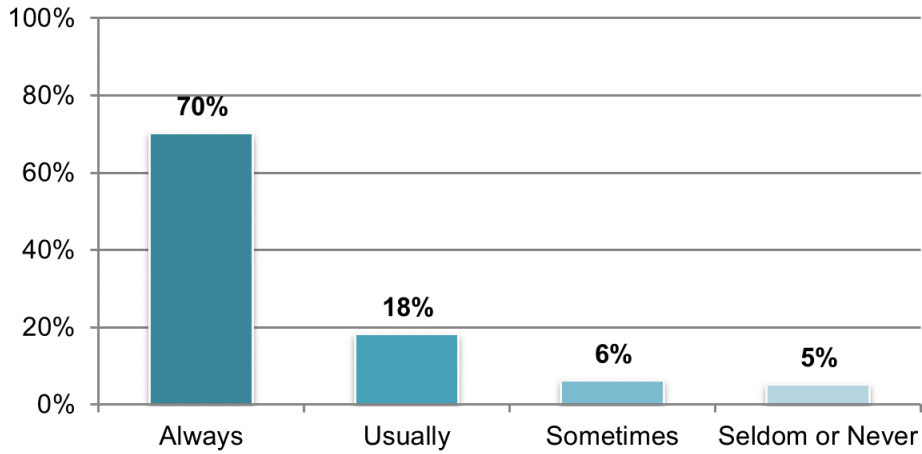


Table Q30. If your family member takes medications, do you know what they're for?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
AZ	84%	12%	3%	1%	300
FL	81%	11%	6%	2%	219
Within Average Range					
VA	75%	21%	2%	2%	175
NC	71%	21%	5%	3%	193
PA	70%	19%	7%	4%	641
CA	69%	17%	7%	7%	3,492
LA	69%	20%	5%	6%	367
KY	68%	23%	5%	5%	185
GA	67%	21%	7%	5%	381
Significantly Below Average					
MD	64%	22%	7%	7%	1,229
NJ	63%	23%	7%	7%	520
NCI Average	70%	18%	6%	5%	7,702

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

Respondent, Family Member, or Other Family Member Knows What Is Needed for Family Member to Take Medication Safely

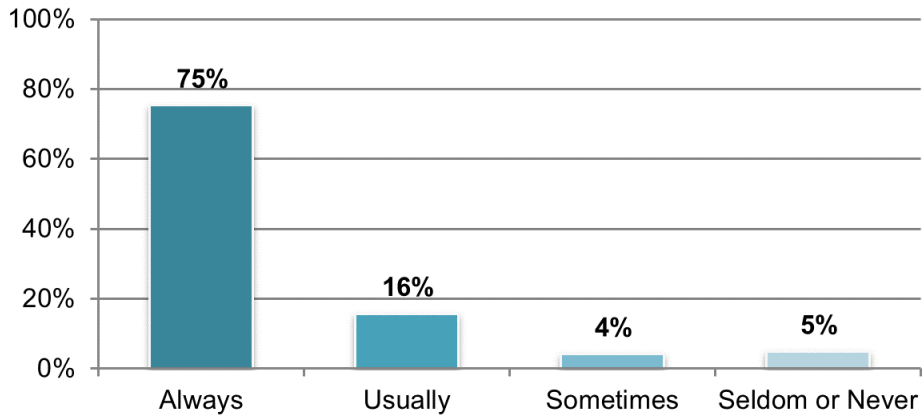


Table Q31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	86%	7%	5%	2%	216
AZ	84%	11%	2%	3%	291
Within Average Range					
NC	79%	18%	1%	2%	177
LA	78%	14%	2%	6%	339
KY	76%	16%	3%	5%	173
GA	75%	17%	4%	3%	356
PA	75%	14%	5%	5%	584
CA	74%	16%	4%	6%	3,135
MD	72%	18%	5%	5%	1,129
VA	70%	22%	4%	4%	166
Significantly Below Average					
NJ	69%	21%	5%	5%	471
NCI Average	75%	16%	4%	5%	7,037

†SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

Family Member's Mental Health Professional Understands Needs Related to His/Her Disability

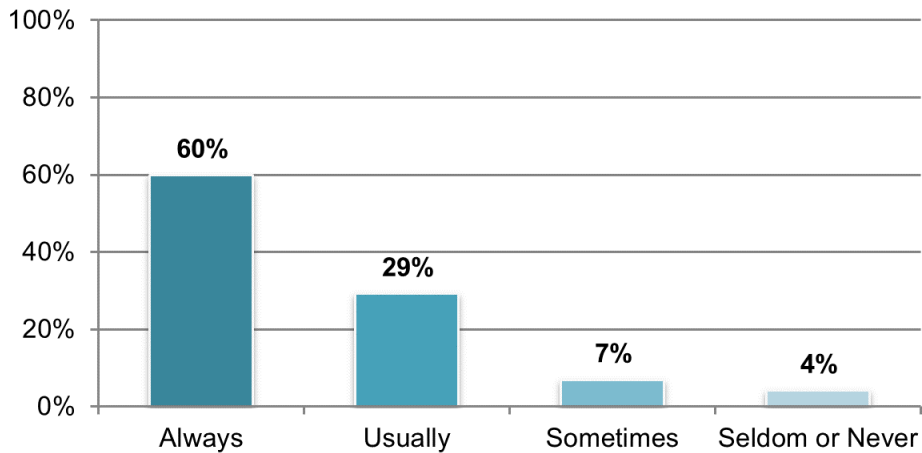


Table Q32. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
AZ	73%	16%	7%	3%	187
VA	72%	20%	5%	3%	105
FL	71%	16%	7%	6%	143
Within Average Range					
LA	65%	26%	3%	6%	240
PA	59%	34%	6%	2%	390
GA	58%	29%	6%	6%	234
NC	58%	34%	5%	3%	146
MD	57%	32%	6%	4%	689
CA [~]	56%	31%	9%	5%	1,764
KY	54%	39%	6%	2%	114
NJ	53%	35%	9%	3%	308
NCI Average	60%	29%	7%	4%	4,320

[†]SD used the previous year's survey; in 2016-17 this question changed, therefore SD was excluded from analysis.

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Family Gets Supports and Services Needed

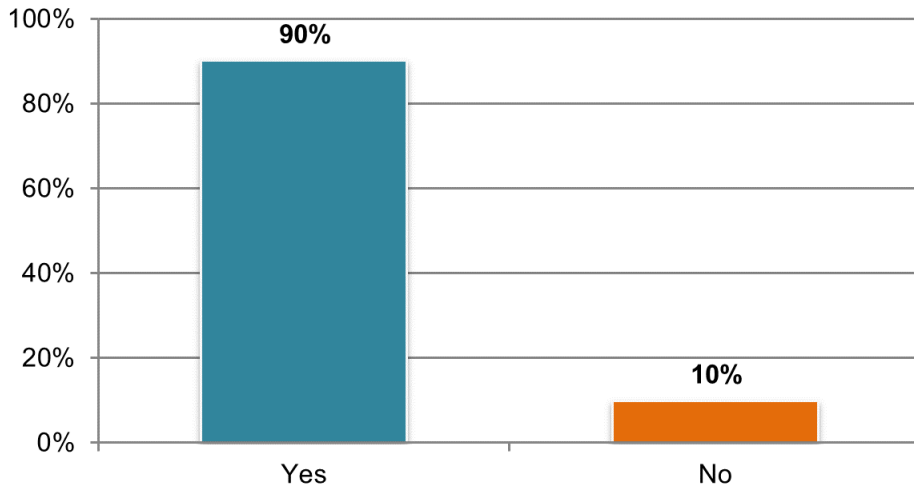


Table Q33. Does your family get the support and services needed?

State	Yes	No	N
Significantly Above Average			
AZ	95%	5%	305
SD	94%	6%	511
Within Average Range			
LA	94%	6%	340
FL	93%	7%	209
PA	93%	7%	616
NC	92%	8%	183
VA	92%	8%	171
KY	91%	9%	179
GA	90%	10%	347
MD	89%	11%	1,132
NJ	89%	11%	458
CA	88%	12%	3,234
NCI Average	90%	10%	7,685

Additional Services Needed

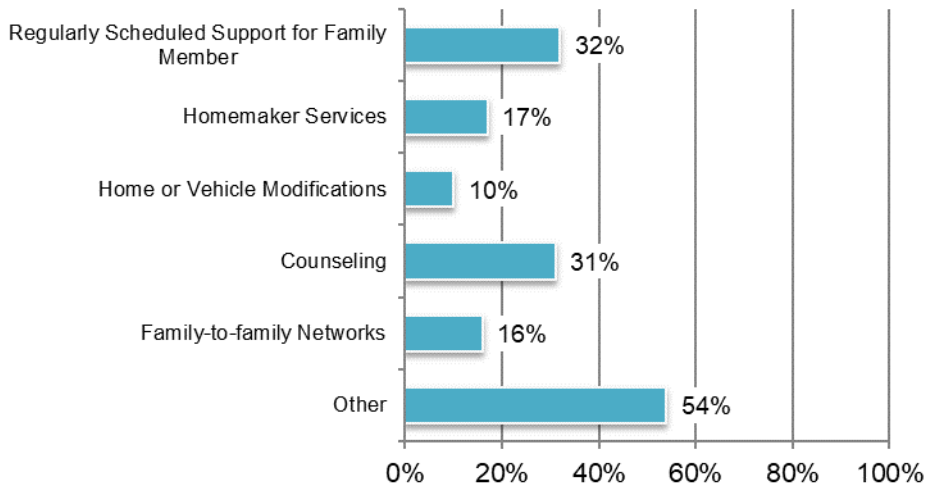


Table Q34. If family does not get the support and services needed, what additional services are needed?

State	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Other
CA	33%	18%	9%	36%	16%	54%
GA	47%	13%	10%	40%	30%	43%
MD	39%	18%	13%	27%	27%	50%
NJ	8%	0%	0%	8%	0%	83%
PA	31%	15%	10%	28%	13%	51%
SD†	27%	32%	5%	23%	9%	64%
NCI Average	32%	17%	10%	31%	16%	54%

*Due to low N's (<20) the following states are not represented in the table, but their data are included in the NCI Average: AZ, FL, KY, LA, NC, VA

†SD used the previous year's survey; in 2016-17 responses options were clarified, therefore comparisons of SD's should be made with caution.

Choice, Decision Making and Control

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

Residential Provider Involves Family Member in Important Decisions

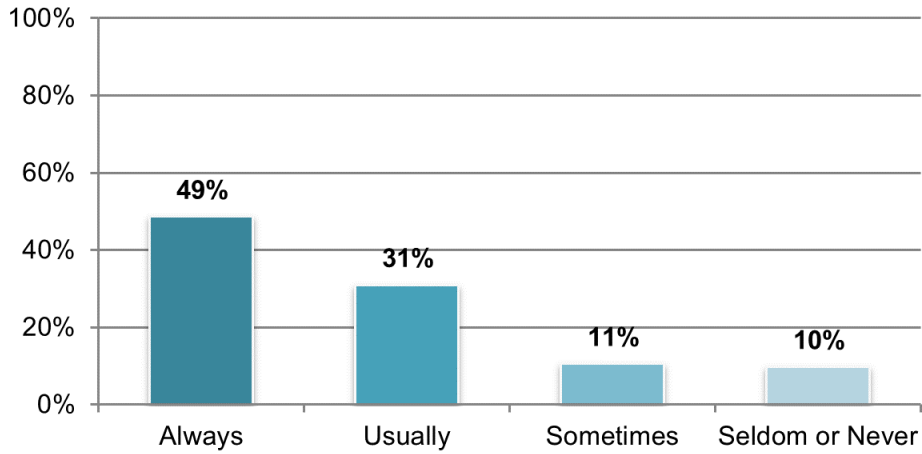


Table Q35. Does the agency providing residential services to your family member involve him/her in important decisions?

State	Always	Usually	Sometimes	Seldom or Never	N
Within Average Range					
LA	56%	24%	9%	11%	286
FL	54%	27%	11%	8%	191
SD	52%	37%	7%	4%	491
CA	50%	30%	9%	10%	2,735
NC	50%	30%	13%	8%	167
PA	49%	32%	10%	9%	550
AZ	48%	30%	13%	8%	279
MD	45%	34%	12%	9%	990
KY	45%	35%	10%	10%	164
GA	44%	32%	12%	13%	310
VA	43%	42%	9%	6%	157
Significantly Below Average					
NJ	35%	29%	18%	18%	440
NCI Average	49%	31%	11%	10%	6,760

Family Can Choose or Change Family Member's Provider Agency

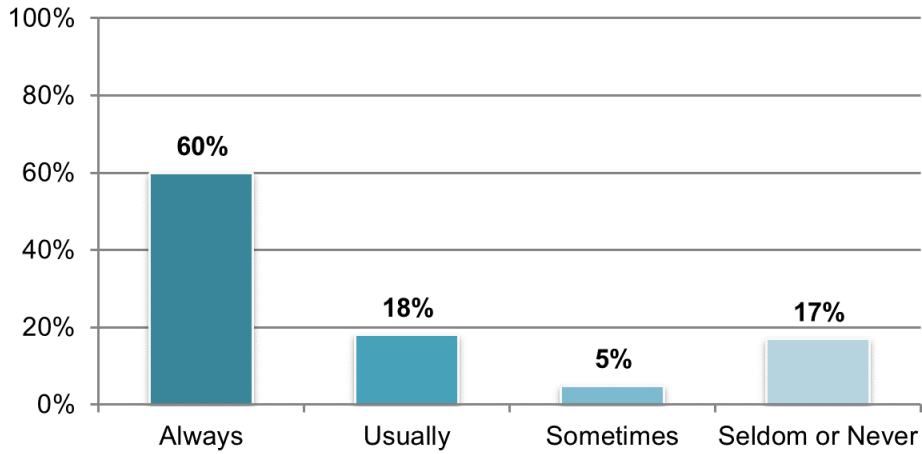


Table Q36. Can your family choose or change the agency that provides your family member's services?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	77%	15%	3%	5%	186
KY	73%	15%	1%	10%	154
LA	69%	13%	2%	16%	231
Within Average Range					
VA	67%	20%	4%	9%	129
GA	66%	15%	3%	16%	291
AZ	64%	19%	5%	13%	232
NC	64%	19%	5%	13%	151
SD	59%	20%	5%	16%	353
MD	59%	20%	4%	16%	747
PA	57%	17%	4%	21%	355
Significantly Below Average					
CA	53%	20%	6%	21%	1,923
NJ	28%	17%	12%	43%	231
NCI Average	60%	18%	5%	17%	4,983

Family Can Choose or Change Family Member's Support Workers

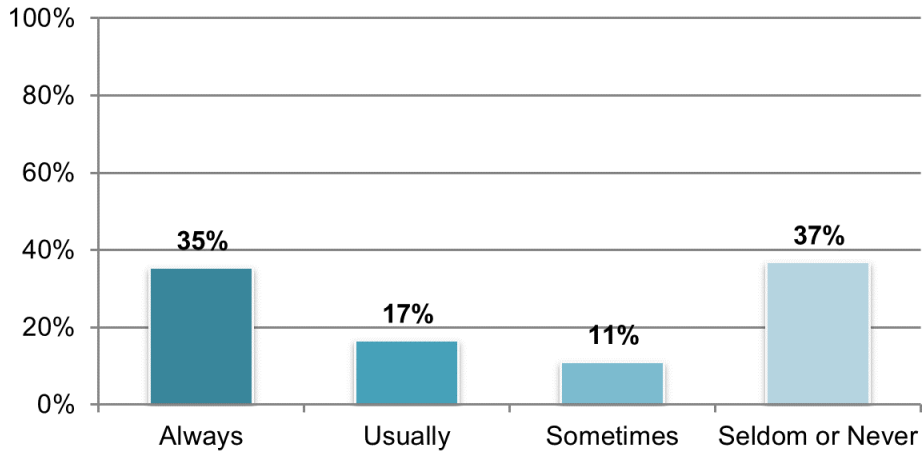


Table Q37. Can your family choose or change your family member's support workers?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	58%	13%	9%	19%	178
NC	47%	22%	6%	26%	148
Within Average Range					
LA	42%	14%	12%	31%	236
GA	39%	12%	9%	40%	265
CA	35%	19%	12%	34%	2,076
SD	35%	17%	11%	37%	348
KY	35%	17%	11%	36%	140
AZ	33%	14%	14%	39%	227
VA	33%	20%	11%	36%	132
Significantly Below Average					
PA	27%	12%	12%	49%	378
MD	23%	17%	14%	46%	774
NJ	9%	11%	10%	71%	302
NCI Average	35%	17%	11%	37%	5,204

Family Directly Manages Support Workers

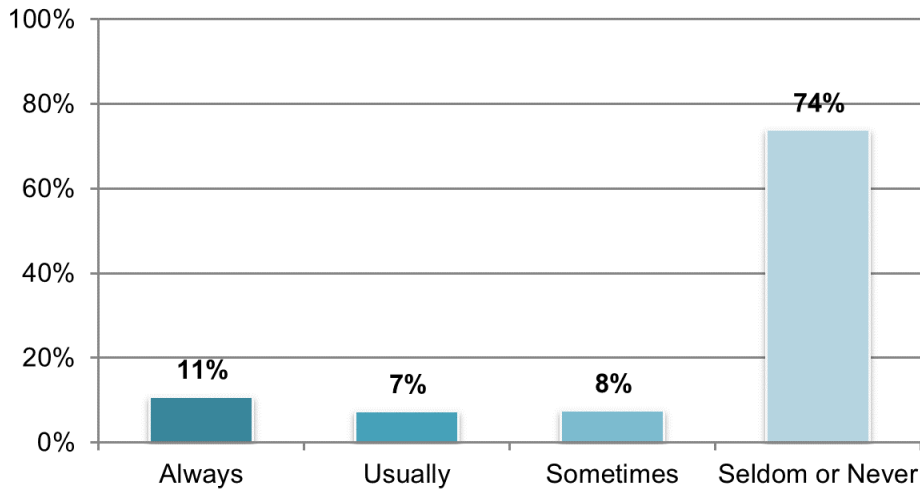


Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	26%	11%	11%	53%	188
Within Average Range					
GA	15%	3%	8%	74%	312
NC	14%	8%	11%	67%	146
LA	13%	7%	5%	75%	284
VA	11%	15%	5%	68%	136
KY	10%	6%	7%	77%	148
AZ	10%	8%	7%	75%	241
CA	10%	9%	9%	73%	2,639
SD	10%	6%	7%	77%	432
MD [~]	9%	4%	6%	82%	992
Significantly Below Average					
PA	5%	4%	5%	86%	513
NJ	1%	3%	5%	90%	406
NCI Average	11%	7%	8%	74%	6,437

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Family Member's Service Providers Work Together to Provide Support

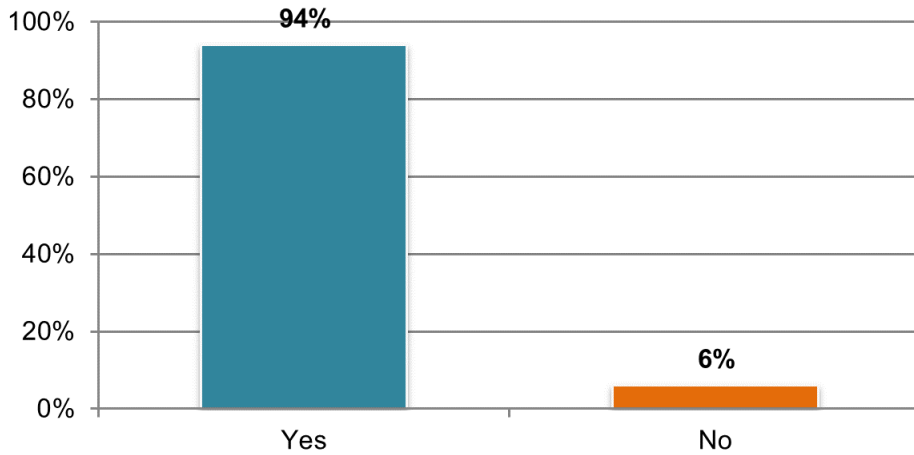


Table Q39. Do service providers for your family member work together to provide support? (For example, does the agency providing transportation work together with the agency providing in-home support if necessary?)

State	Yes	No	N
Significantly Above Average			
NC	98%	2%	148
SD	97%	3%	408
PA	96%	4%	439
Within Average Range			
KY	97%	3%	144
FL	97%	3%	179
VA	97%	3%	144
AZ	96%	4%	232
GA	93%	7%	283
MD	93%	7%	855
LA	92%	8%	249
CA [~]	92%	8%	2,337
NJ	90%	10%	332
NCI Average	94%	6%	5,750

[~]The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Respondent, Family Member, or Other Family Member Chose or Can Change Case Manager or Service Coordinator

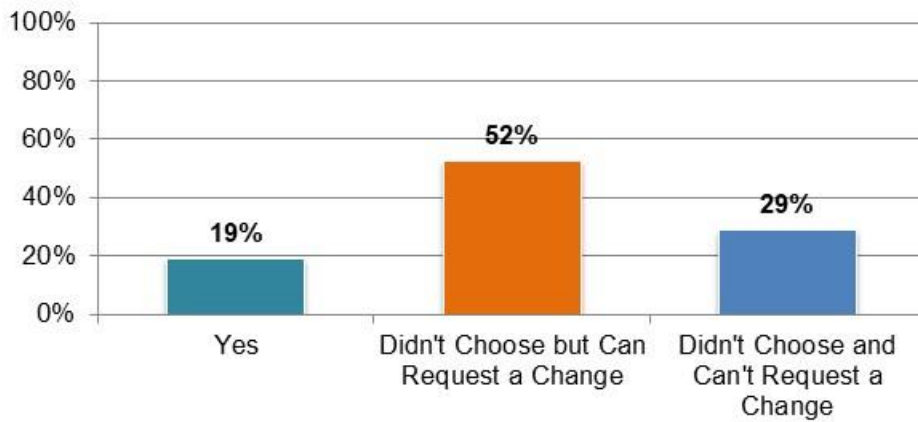


Table Q40. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

State	Yes	Didn't Choose but Can Request a Change	Didn't Choose and Can't Request a Change	N
Significantly Above Average				
FL	64%	29%	7%	219
SD	50%	38%	12%	485
KY	49%	39%	12%	168
LA	29%	37%	34%	295
Within Average Range				
PA	15%	49%	35%	460
GA	15%	51%	35%	315
NC	14%	61%	25%	165
Significantly Below Average				
MD	15%	50%	35%	1,001
VA	12%	59%	30%	145
AZ	9%	69%	21%	278
CA	8%	63%	29%	2,858
NJ	4%	32%	63%	425
NCI Average	19%	52%	29%	6,814

Involvement in the Community

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

Family Member Takes Part in Activities in Community

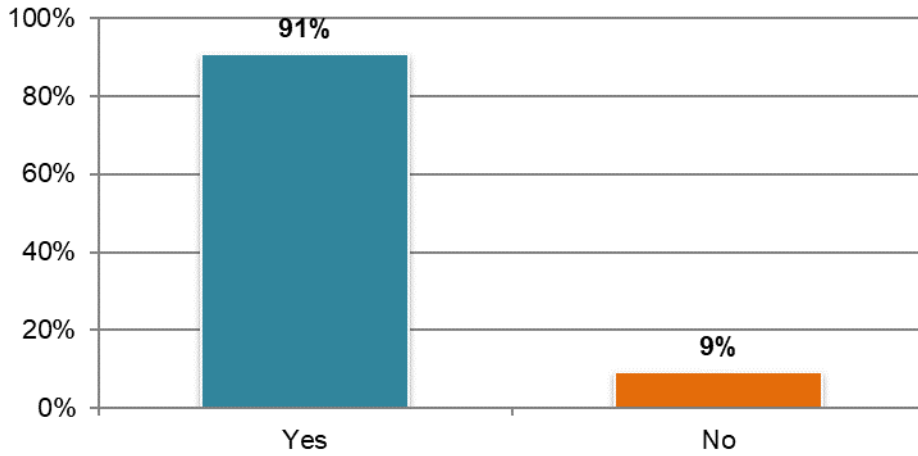


Table Q41. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

State	Yes	No	N
Significantly Above Average			
NC	98%	2%	187
PA	94%	6%	634
SD	94%	6%	537
Within Average Range			
KY	95%	5%	182
GA	94%	6%	371
FL	93%	7%	219
NJ	92%	8%	508
MD	91%	9%	1,230
AZ	91%	9%	309
CA [~]	88%	12%	3,555
VA	88%	12%	179
Significantly Below Average			
LA	85%	15%	349
NCI Average	91%	9%	8,260

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Table Q42. For your family member, what are the obstacles or barriers to participation in activities in the community?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitude from Community Members	Other	N
AZ	20%	26%	38%	17%	35%	158
CA	33%	36%	28%	15%	40%	2238
FL	21%	29%	21%	8%	47%	158
GA	19%	25%	24%	12%	46%	215
KY	26%	26%	43%	13%	35%	107
LA	21%	21%	21%	12%	51%	241
MD	27%	27%	41%	12%	42%	791
NJ	25%	29%	45%	10%	44%	394
NC	13%	30%	36%	22%	38%	112
PA	18%	24%	34%	12%	46%	353
SD	38%	23%	54%	8%	43%	56
VA	24%	20%	35%	15%	45%	102
NCI Average	24%	26%	35%	13%	43%	4925

Family Member Has Friends Other Than Paid Support Workers or Family

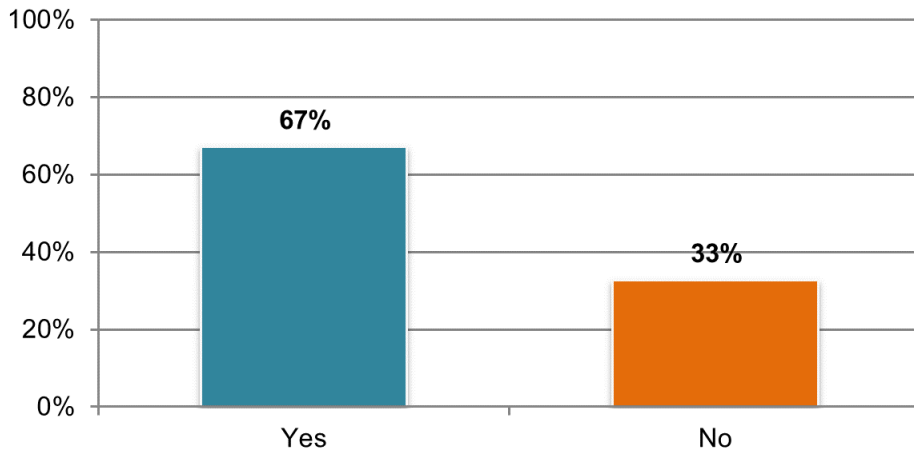


Table Q43. Does your family member have friends other than paid support workers or family?

State	Yes	No	N
Significantly Above Average			
SD	82%	18%	505
PA	72%	28%	585
FL	73%	27%	212
Within Average Range			
GA	73%	27%	359
KY	71%	29%	174
MD	70%	30%	1,154
NC	69%	31%	177
AZ	65%	35%	298
VA	65%	35%	162
CA*	65%	35%	3,317
Significantly Below Average			
LA	60%	40%	333
NJ	57%	43%	473
NCI Average	67%	33%	7,749

*The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

**There Are Resources in the Community the
Family Member Can Use That Are Not Provided
by the IDD Agency**

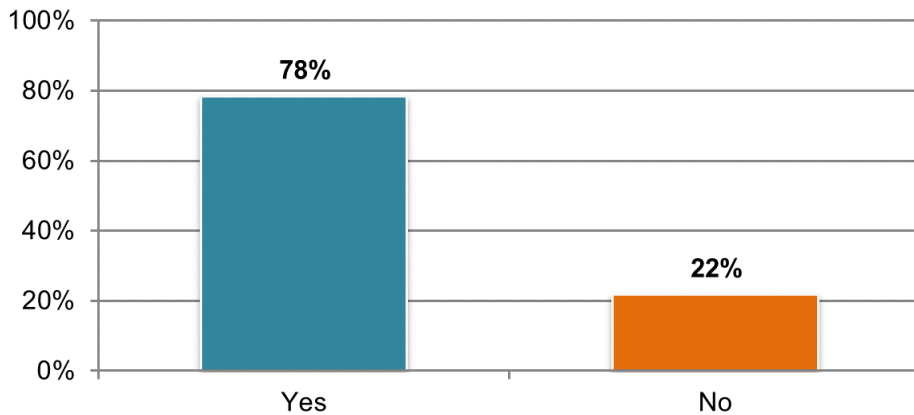


Table Q44. In your community, are there resources that your family can use that are not provided by the I/DD agency? (For example, recreational programs, community housing, library programs, religious groups, etc.)

State	Yes	No	N
Significantly Above Average			
SD	86%	14%	402
MD	83%	17%	856
Within Average Range			
FL	85%	15%	166
PA	82%	18%	378
KY	81%	19%	121
GA	80%	20%	259
AZ	78%	22%	235
CA	78%	22%	2,299
VA	78%	22%	121
NC	76%	24%	149
Significantly Below Average			
LA	67%	33%	246
NJ	63%	37%	276
NCI Average	78%	22%	5,508

Family Takes Part in Family-to-Family Networks

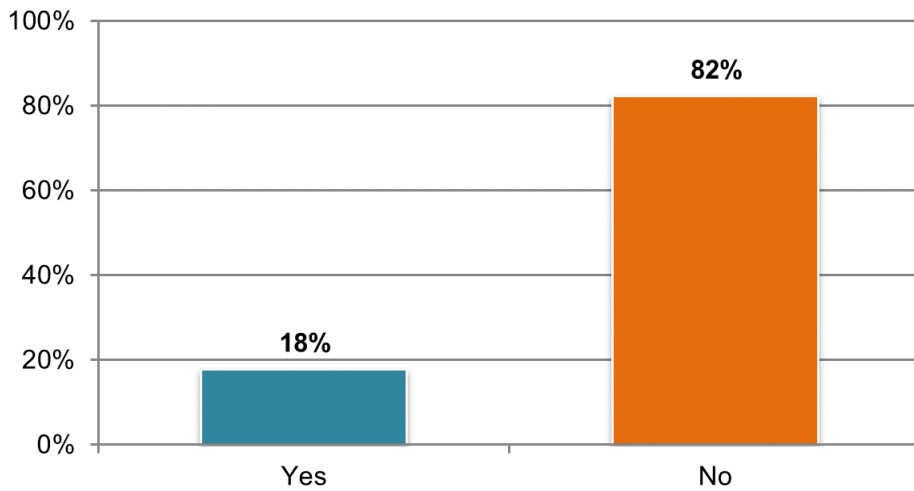


Table Q45. Does your family take part in any family-to-family networks in your community? (For example, Parent to Parent, sibling networks, etc.)

State	Yes	No	N
Significantly Above Average			
LA	25%	75%	297
Within Average Range			
FL	24%	76%	191
KY	22%	78%	144
GA	20%	80%	303
MD	20%	80%	1,015
SD	19%	81%	429
VA	18%	82%	145
PA	17%	83%	514
CA	17%	83%	3,105
AZ	15%	85%	271
NJ	14%	86%	428
Significantly Below Average			
NC	10%	90%	156
NCI Average	18%	82%	6,998

Satisfaction With Services and Supports

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

Overall, Respondent Is Satisfied With Services and Supports Family Receives

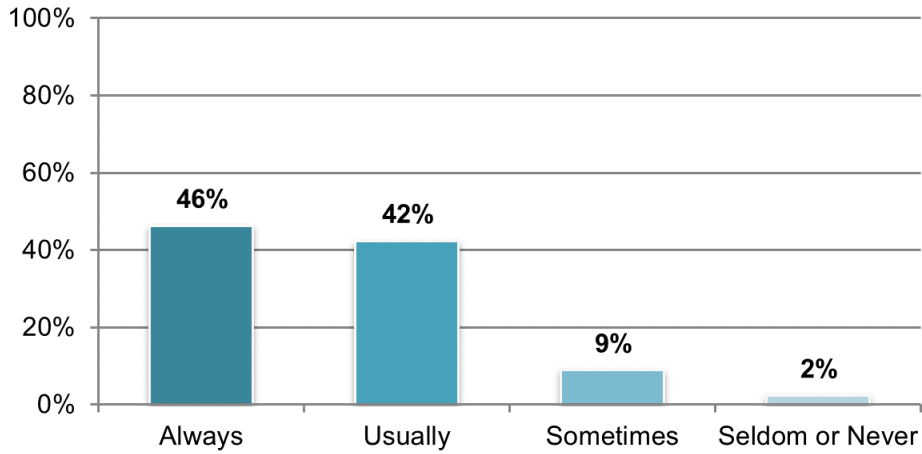


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
LA	55%	37%	7%	2%	391
Within Average Range					
FL	54%	38%	8%	0%	226
PA	51%	43%	6%	1%	675
NC	49%	44%	5%	2%	194
VA	49%	42%	7%	2%	187
AZ	47%	45%	7%	2%	318
CA	46%	42%	9%	3%	3,768
SD	45%	46%	6%	2%	556
GA	45%	41%	10%	4%	400
KY	45%	47%	6%	2%	191
Significantly Below Average					
MD	37%	47%	13%	3%	1,271
NJ	34%	46%	17%	3%	528
NCI Average	46%	42%	9%	2%	8,705

Respondent Knows Process for Filing a Complaint or Grievance About Provider Agencies or Staff

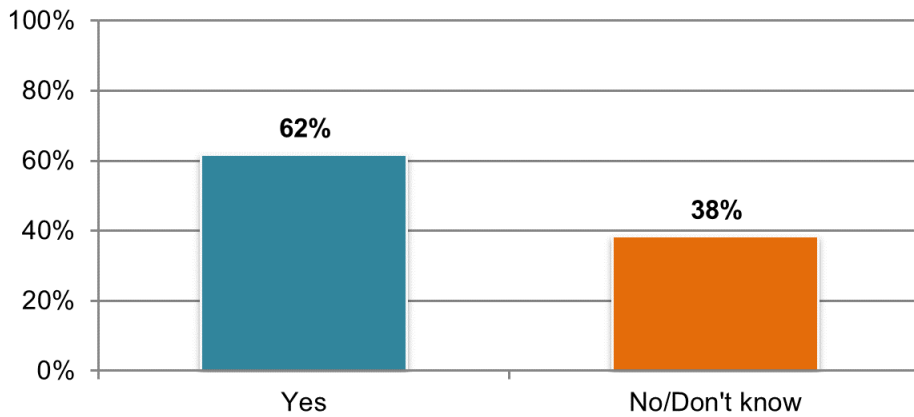


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?⁵

State	Yes	No/Don't know	N
Significantly Above Average			
NC	81%	19%	190
FL	78%	22%	229
KY	78%	22%	188
SD	75%	25%	549
LA	72%	28%	384
AZ	72%	28%	315
PA	70%	30%	642
Within Average Range			
VA	70%	30%	178
GA	63%	37%	396
Significantly Below Average			
MD	52%	48%	1,251
NJ	52%	48%	528
CA	52%	48%	3,773
NCI Average	62%	38%	8,623

⁵ 'Don't Know' responses were included in 'No' responses for this question.

**Respondent Is Satisfied With the Way
Complaints or Grievances About Provider
Agencies or Staff Were Handled and Resolved (If
Filed in the Past Year)**

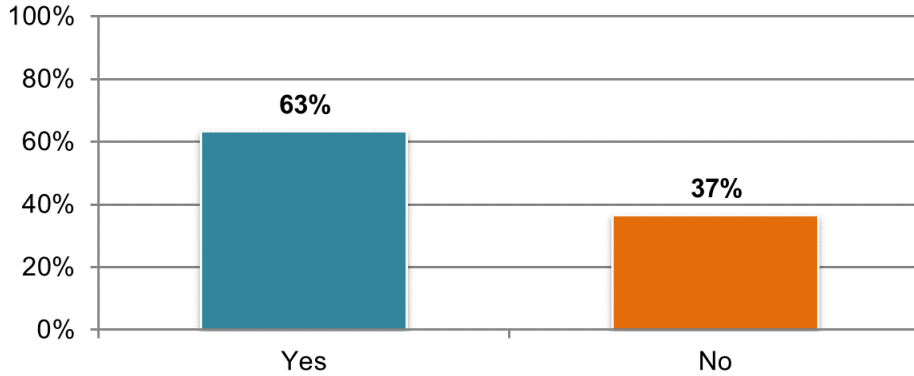


Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

State	Yes	No	N
Significantly Above Average			
SD	78%	22%	69
Within Average Range			
VA	76%	24%	45
NC	74%	26%	43
FL	66%	34%	35
KY	65%	35%	23
PA	65%	35%	97
AZ	63%	38%	48
CA	62%	38%	471
MD	60%	40%	198
LA	58%	42%	71
GA	54%	46%	70
NJ	51%	49%	94
NCI Average	63%	37%	1,264

Respondent Knows How to Report Abuse or Neglect

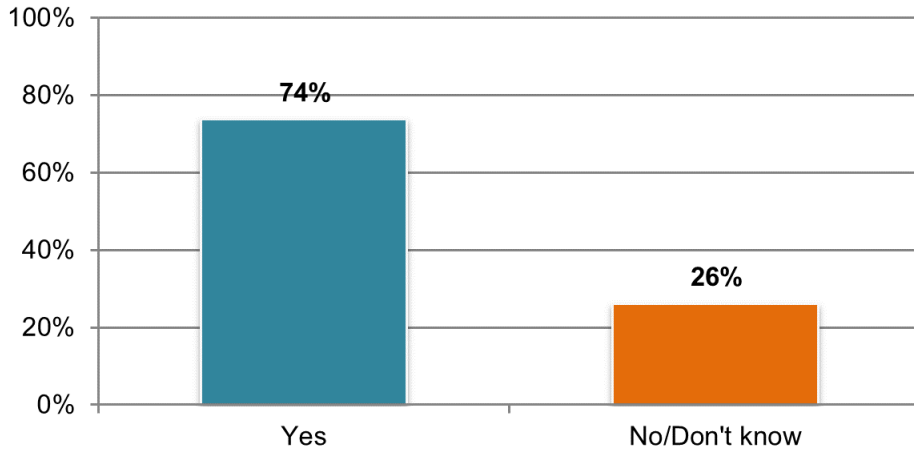


Table Q49. Do you know how to report abuse or neglect related to your family member?⁶

State	Yes	No/Don't know	N
Significantly Above Average			
NC	87%	13%	191
FL	87%	13%	232
VA	84%	16%	179
KY	84%	16%	188
AZ	83%	17%	312
SD	82%	18%	549
PA	79%	21%	648
Within Average Range			
LA	78%	22%	389
GA	74%	26%	401
Significantly Below Average			
MD	68%	32%	1,259
CA	67%	33%	3,803
NJ	64%	36%	534
NCI Average	74%	26%	8,685

⁶ 'Don't Know' responses were included in 'No' responses for this question.

Abuse or Neglect Was Reported on Behalf of Family Member in the Past Year

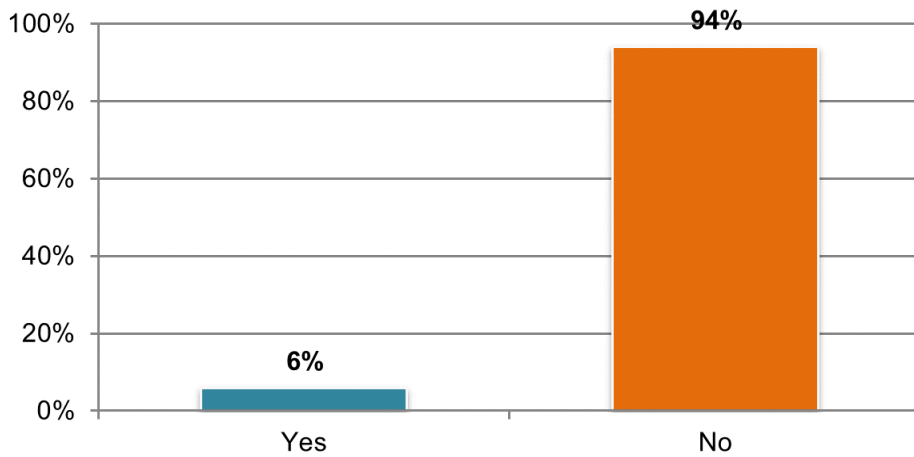


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

State	Yes	No	N
Significantly Above Average			
NJ	11%	89%	509
Within Average Range			
VA	8%	92%	173
FL	7%	93%	215
NC	7%	93%	187
GA	7%	93%	375
AZ	7%	93%	302
LA	7%	93%	369
SD	6%	94%	520
PA	6%	94%	618
MD	5%	95%	1,196
KY	5%	95%	181
CA~	5%	95%	3,520
NCI Average	6%	94%	8,165

~The state is "within" the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

Appropriate People Were Responsive to Report of Abuse or Neglect If Reported in the Past Year

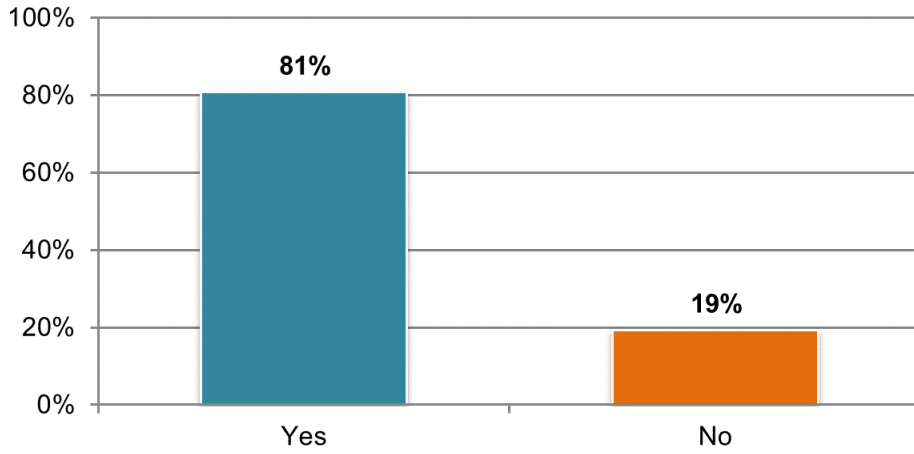


Table Q51. If a report of abuse or neglect was filed in the past year, did the appropriate people respond to the report?

State	Yes	No	N
Significantly Above Average			
SD	95%	5%	21
Within Average Range			
PA	92%	8%	26
VA	91%	9%	n/a
GA	90%	10%	21
AZ	89%	11%	n/a
CA	82%	18%	128
VA	91%	9%	n/a
VA	91%	9%	n/a
MD	74%	26%	46
NJ	72%	28%	46
FL	69%	31%	n/a
KY	57%	43%	n/a
NCI Average	81%	19%	362

Respondent Was Notified of Abuse or Neglect Report in a Timely Manner If Filed by Someone Other Than Respondent or Family Member

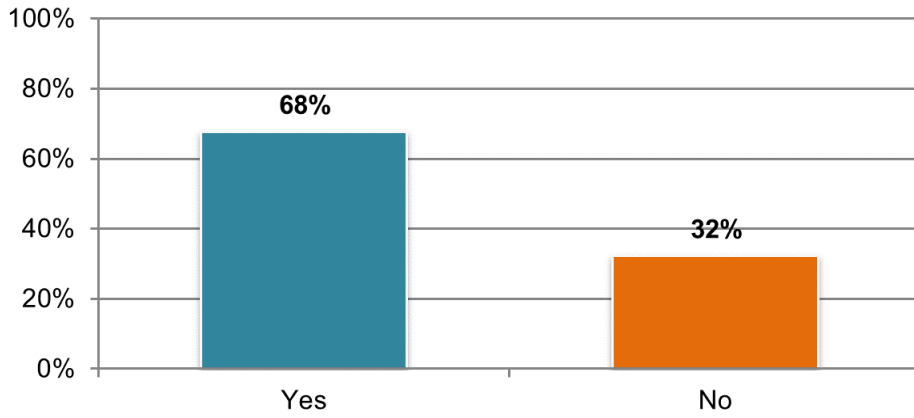


Table Q52. If a report of abuse or neglect was filed in the past year by someone other than you or another family, were you notified of the report in a timely manner?

State	Yes	No	N
Within Average Range			
PA	83%	17%	35
CA	63%	37%	123
SD	61%	39%	23
MD	55%	45%	40
NJ	53%	47%	43
NCI Average	68%	32%	350

*Due to low N's (<20) the following states are not represented in the table, but their data are included in the NCI Average: AZ, FL, GA, KY, LA, NC, VA

Services and Supports Have Made a Positive Difference in Family Member's Life

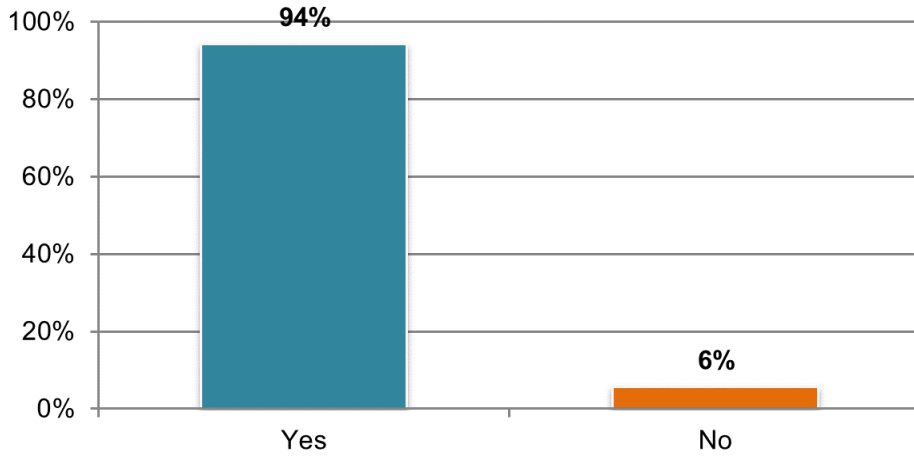


Table Q53. Do you feel that services and supports have made a positive difference in the life of your family?

State	Yes	No	N
Significantly Above Average			
FL	99%	1%	225
PA	98%	2%	615
NC	98%	2%	184
VA	98%	2%	171
SD	97%	3%	524
Within Average Range			
KY	96%	4%	181
LA	96%	4%	360
AZ	95%	5%	305
MD	95%	5%	1,189
GA	94%	6%	364
NJ	93%	7%	494
Significantly Below Average			
CA	91%	9%	3,512
NCI Average	94%	6%	8,124

Services or Supports Were Reduced, Suspended, or Terminated in the Past Year

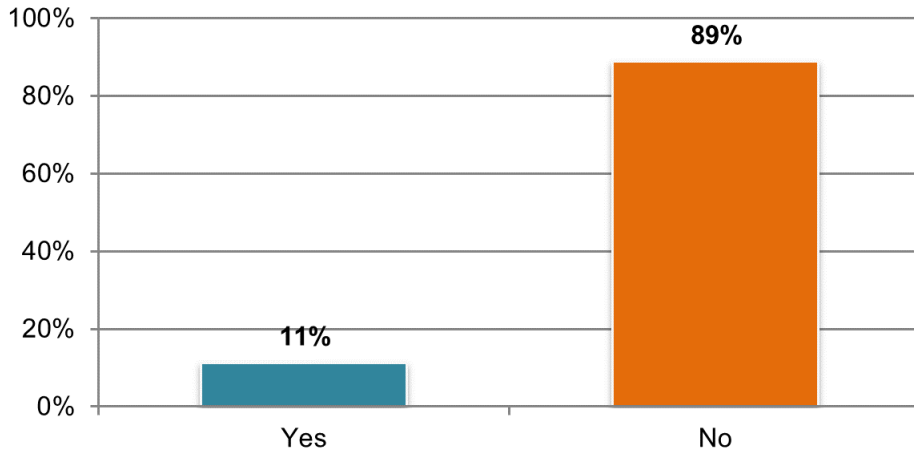


Table Q54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?

State	Yes	No	N
Within Average Range			
LA	16%	84%	333
NJ	15%	85%	450
FL	14%	86%	207
NC	13%	87%	175
VA	13%	87%	156
GA	12%	88%	334
CA	11%	89%	3,074
SD	10%	90%	487
MD	9%	91%	1,091
KY	9%	91%	170
AZ	9%	91%	304
Significantly Below Average			
PA	7%	93%	580
NCI Average	11%	89%	7,361

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

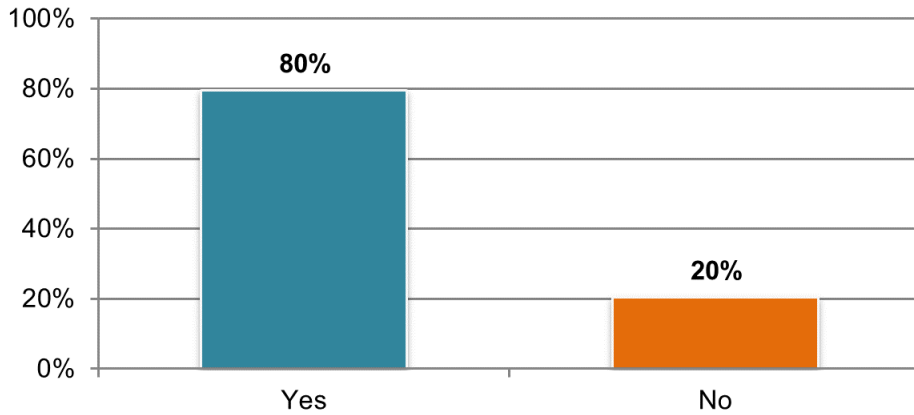


Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?

State	Yes	No	N
Significantly Above Average			
NJ	94%	6%	54
Within Average Range			
GA	88%	13%	32
MD	83%	17%	88
AZ	83%	17%	23
CA	79%	21%	277
FL	79%	21%	24
PA	76%	24%	33
SD	76%	24%	37
LA	75%	25%	40
NCI Average	80%	20%	654

*Due to low N's (<20) the following states are not represented in the table, but their data are included in the NCI Average: KY, NC, VA

Services or Supports Were Increased in the Past Year

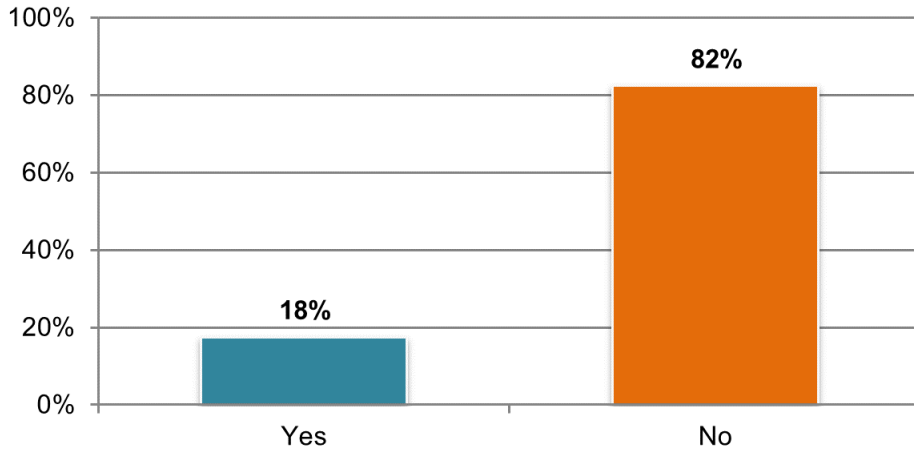


Table Q56. Have the services or supports that your family member received been increased in the past year?

State	Yes	No	N
Within Average Range			
GA	22%	78%	270
PA	22%	78%	449
VA	21%	79%	139
KY	18%	82%	143
NJ	18%	82%	375
NC	17%	83%	161
LA	17%	83%	257
MD	17%	83%	944
AZ	17%	83%	278
SD	17%	83%	416
FL	16%	84%	181
CA	16%	84%	2,566
NCI Average	18%	82%	6,179

Services or Supports Help Family Member Live a Good Life

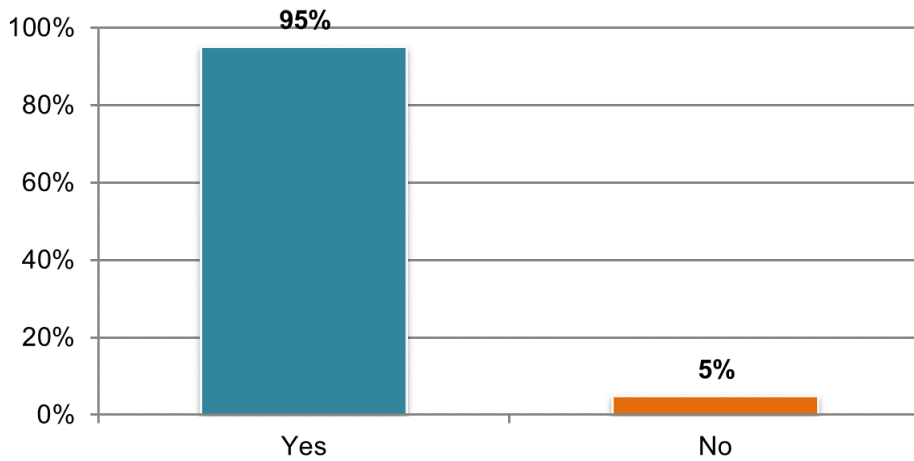


Table Q57. Are services and supports helping your family member to live a good life?

State	Yes	No	N
Significantly Above Average			
FL	98%	2%	222
SD	97%	3%	505
Within Average Range			
NC	98%	2%	184
VA	98%	2%	168
KY	97%	3%	183
AZ	97%	3%	308
PA	97%	3%	614
LA	96%	4%	348
GA	95%	5%	368
MD	95%	5%	1,181
NJ	94%	6%	484
CA [~]	93%	7%	3,387
NCI Average	95%	5%	7,952

[~]The state is “within” the NCI average range due to small effect sizes. For more detail, please see the Methodology section.

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

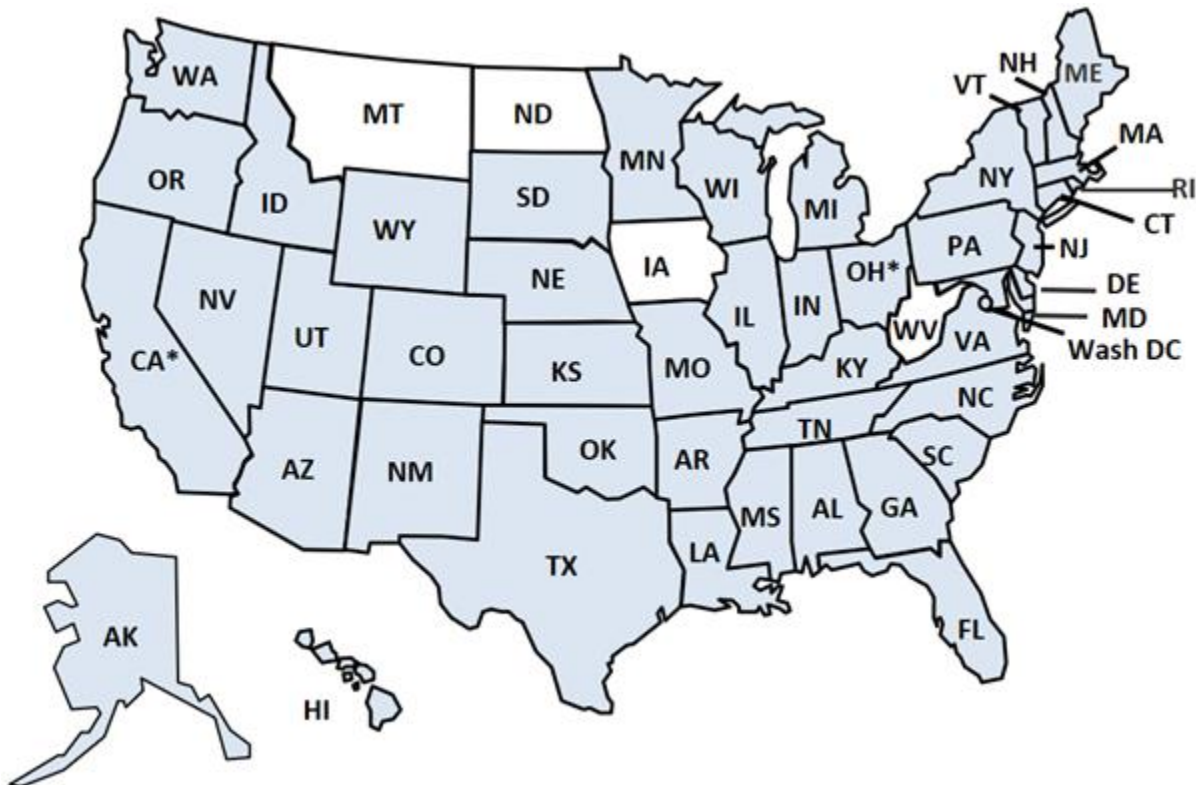
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states 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 2016-17 data collection cycle, 45 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. Not all states participate in all surveys each year.

Figure 1. NCI State Participation 2016-17



Sub-Domains and Concern Statements

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

Figure 2. Family Survey Sub-Domains and Concern Statements

Sub-Domain	Concern Statement
Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
Choice, Decision Making & 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.
Involvement in the Community	Family members with disabilities use integrated community services and participate in everyday community activities.
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.
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 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. 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 an acceptable performance level. 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.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. In previous years states would only have the option to mail paper surveys. A total of five states had at least a portion of surveys completed via direct entry mode.⁷

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%.⁸

Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI reports, we use “NCI average” to demonstrate the typical performance of all the states which conducted the survey. In previous years, NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). This year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states’ systems. Beginning this year, the NCI averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states, as well as the sample sizes.

⁷ States that used the direct entry or mail and direct entry options were: KY, LA, NC, NJ, and SD.

⁸ See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average – i.e. the state’s contribution to the NCI average is proportional to its’ service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.

Significance Testing

Starting this survey cycle (2016-17), for each of the non-adjusted items, each state’s percentage will be compared to the weighted NCI average (described above), and the differences between the two will be tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state’s result depends, in part, on the size of the state’s sample – the larger the sample, the more likely it is that even a small difference will be found *statistically* significant. A statistically significant difference for a state with a large sample size, in and by itself, does not necessarily mean there is a *practically* significant difference. The inclusion of effect sizes as a new criterion allows us to present “meaningfully significant” results, which take consideration of the magnitude or size of the differences into account.

The state percentages in this report are categorized into one of the three classes:

1. **Significantly above the NCI average**, where the difference between the state’s percentage and the weighted NCI average a) was in favor of the state, b) was statistically significant (i.e. $p < .01$), **and** c) met the effect size criterion (i.e. Cohen’s $d > 0.2$, see below for details);
2. **Within the NCI average range**, where the difference between the state’s percentage and the weighted NCI average was a) not statistically significant (i.e. $p \geq .01$), **or** b) did not meet the effect size criterion (i.e. Cohen’s $d \leq 0.2$);
3. **Significantly below the NCI average**, where the difference between the state’s percentage and the weighted NCI average a) was in favor of the NCI average, b) was statistically significant (i.e. $p < .01$), **and** c) met the effect size criterion (i.e. Cohen’s $d > 0.2$);

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. A state that falls “within” the NCI average range due to the difference not meeting the effect size criterion are denoted with a

Caron symbol (°). No symbol was used for the state's percentage being "within" the NCI average range due to lack of statistical significance (i.e. $p \geq .01$).

Technical Details

The comparisons were done through one sample T-tests using the weighted NCI average as the benchmark. A conservative cut-off point (alpha) of $p < 0.01$ was used to detect statistically significant differences. Effect sizes are calculated using the formula: Cohen's $d = \frac{2t}{\sqrt{df}}$. A cutoff point of Cohen's $d = 0.2$ was chosen for the effect size to be considered "meaningfully significant", following the standard interpretation offered by Cohen (1988) that Cohen's d of 0.8 = large, 0.5 = moderate, and 0.2 being at least a small effect.

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 2016-17, 12 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.

Figure 3. Family/Guardian Survey: State Response Rates⁹

State	Total Population	Surveys Sent	Useable Surveys	Response Rate	Margin of Error	Mode	
						Paper	Direct Entry
AZ	4,128	1,400	322	23%	5.24%	n/a	n/a
CA	5,7475	19,799	4,062	21%	1.48%	n/a	n/a
FL	11,105	1,200-1,500	238		6.28%	n/a	n/a
GA	5,481	1,500-1,800	415		4.63%	n/a	n/a
KY	4,351*	945	194	21%	6.88%	97.9%	2.1%
LA	7,058	2,300	411	18%	4.69%	94.9%	5.1%
MD	9,951	9,951	1,341	13%	2.49%	n/a	n/a
NC	6,400*	850	195	23%	6.91%	96.4%	3.60%
NJ	7440	7,440	562	8%	3.97%	32.9%	67.10%
PA	Up to 15,700	1,600	693	43%	3.64%	n/a	n/a
SD	2,082	2,082	570	27%	3.50%	99.5%	0.5%
VA	7,000*	706	191	27%	6.99%	n/a	n/a
NCI Average			9194			95.5%	4.50%

*Estimate

⁹ Please note: The family surveys are mail out surveys or completed online by respondents who choose to take part in the survey. As such, the final sample is a sample of convenience and cannot be considered representative of the entire service population in the state.