Family/Guardian Survey

2015-16 Final Report

A Collaboration of

The National Association of State Directors of Developmental Disabilities Services
and
Human Services Research Institute

Human Services Research Institute (HSRI)

2336 Massachusetts Avenue
Cambridge, MA 02140

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

301 N Fairfax Street, Suite 101
Alexandria, VA 22314

1.27.2016

List of Abbreviations Used in This Report

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

Table of Contents

Family/Guardian Survey Highlights **1**
I. Results **1**
Survey Development **0**
Organization of the Family/Guardian Survey 0
Demographics 0
Services and Supports Received 0
Questions Regarding Services and Supports 0
Presentation of Data 1
Note on Significance: 1
Demographics **3**
Family Member 4
Table 1. Family Member's Residence 5
Table 2. Family Member's Residential Setting 5
Table 3. Family Member's Age 6
Table 4. Family Member's Gender 6
Table 5. Family Member's Race and Ethnicity 7
Table 6. Family Member's Disabilities 8
Table 7. Family Member's Health Conditions 9
Table 8. Family Member's Preferred Means of Communication 10
Table 9. Family Member's Legal Guardianship Arrangement 10
Table 10. Guardian or Conservator Relationship to Family Member 11
Table 11. Family Member's Highest Level of Education 11
Table 12. Family Member's Typical Day Activity – Individual Paid Community Job 12
Table 13. Family Member's Typical Day Activity – Paid Small Group Job in the Community 12
Table 14. Family Member's Typical Day Activity – Unpaid Activity in the Community 13
Table 15. Family Member's Typical Day Activity – Paid Facility-Based Setting 13
Table 16. Family Member's Typical Day Activity – Unpaid Facility-Based Setting 14
Table 17. Family Member's Typical Day Activity – School 14
Table 18. Family Member's Typical Day Activity – Stays at Home 15

Table 19. Family Member's Typical Day Activity – Other 15

Table 20. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors 16

Table 21. Family Member's Level of Help Needed With Personal Care Activities 16

Table 22. Family Member's Need for Help With Other Daily Activities 17

Respondents 18

Table 23. Respondent's Age 19

Table 24. Respondent's Health 19

Table 25. Respondent's Relationship to Family Member 20

Table 26. Respondent's Frequency of Visits Per Year With Family Member 20

Table 27. Respondent's Highest Level of Education 21

Table 28. Total Taxable Household Income of Wage Earners in the Past Year 21

Services and Supports Received 22

Table 29. Services and Supports Received From ID/DD Agency 23

Table 30. Additional Services and Supports Received 23

Family/Guardian Survey Results 24

Information and Planning 25

Table Q1. Do you get enough information to help you participate in planning services for your family? 26

Table Q2. Is the information you receive easy to understand? 27

Table Q3. Do staff or the residential agency keep you informed about how your family member is doing? 28

Table Q4. Does the case manager/service coordinator respect your family's choices and opinions? 29

Table Q5. Do you need help planning for your family member's future with respect to any of the following? 30

Table Q6. In the past year, did your family member move out of the family home for the first time? 31

Table Q7. If yes to Q6, did your family member receive enough information about services available to support him/her? 32

Table Q8. If yes to Q6, did you have enough choices of service providers to support your family member living outside the family home? 33

Table Q9. Does your family member have a service plan? 34

Table Q10. Does the plan include all the services and supports your family member needs? 35

Table Q11. Does your family member receive all of the services listed in the plan? 36

Table Q12. Did you or another family member help develop the plan? 37

Table Q13. Did your family member help develop the plan? 38

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? 39

Table Q15. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster? 40

Table Q16. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community? 41

Access and Delivery of Services and Supports 42

Table Q17. Are you or your family member able to contact his/her support workers when you want to? 43

Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to? 44

Table Q19. Do support workers come and leave when they are supposed to? 45

Table Q20. Do services and supports change when your family's needs change? 46

Table Q21. Do support workers speak to you in a way that you understand? 47

Table Q22. Are services delivered in a way that is respectful of your family's culture? 48

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? 49

Table Q24. Do support workers have the right information and skills to meet your family's needs? 50

Table Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)? 51

Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)? 52

Table Q27. Does your family member's primary care doctor understand your family member's needs related to his/her disability? 53

Table Q28. Do you have access to dental services for your family member? 54

Table Q29. Does your family member's dentist understand your family member's needs related to his/her disability? 55

Table Q30. If your family member takes medications, do you know what they're for? 56

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)? 57

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? 58

Table Q33. Does your family get the support needed? 59

Table Q34. If no to Q33, what additional services are needed? 60

Choice, Decision Making and Control 61
Table Q35. Does the agency providing residential services to your family member involve him/her in important decisions? 62
Table Q36. Can your family choose or change the agency that provides your family member's services? 63
Table Q37. Can your family choose or change your family member's support workers? 64
Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)? 65
Table Q39. Do service providers for your family member work together to provide support? 66
Table Q40. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator? 67
Involvement in the Community 68
Table Q41. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)? 69
Table Q42. If no to Q41, why does your family member not take part in community activities? 70
Table Q43. Does your family member have friends other than paid support workers or family? 71
Table Q44. In your community, are there resources that your family can use that are not provided by the I/DD agency? 72
Table Q45. Does your family take part in any family-to-family networks in your community? 73
Satisfaction With Services and Supports 74
Table Q46. Overall, are you satisfied with the services and supports your family currently receives? 75
Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff? 76
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? 77
Table Q49. Do you know how to report abuse or neglect related to your family member? 78
Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your family member? 79
Table Q51. If yes to Q50, did the appropriate people respond to the report? 80
Table Q52. If Yes to Q50, if someone other than you or another family member reported abuse or neglect in the past year, were you notified of the report in a timely manner? 81
Family Outcomes 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 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

Data Entry and Analysis 94

Response Rates 95

Figure 3. Family/Guardian Survey: State Response Rates 95

IV. Appendix A 96

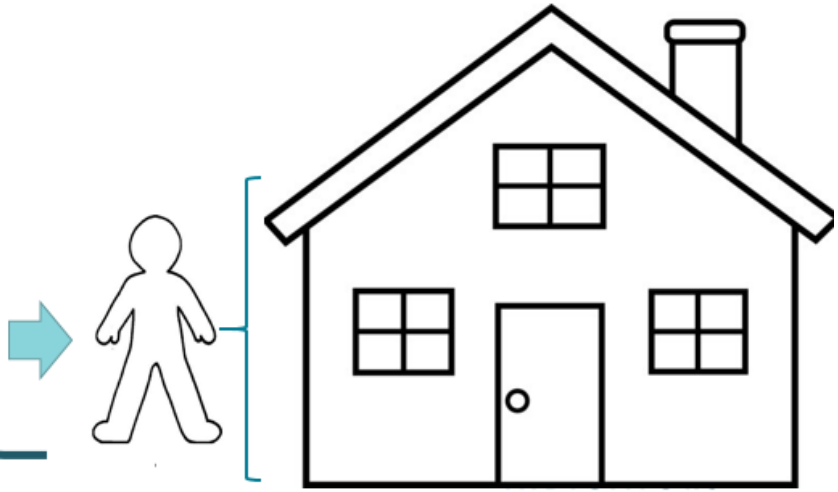
Family/Guardian Survey Highlights

LOOKING AT THE 2015-16 FAMILY/GUARDIAN SURVEY (FGS)

Respondents: families or guardians of an adult (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.
14 states*: Total sample: 6,173

FGS Respondent: Family or guardian of adult with disability

Adult with disability (receiving supports from state) does not live with the family/guardian who responds to FGS survey



*FGS: AK, FL, GA, LA, MD, MI, MN, NC, NH, PA, SD, UT, VA, WA

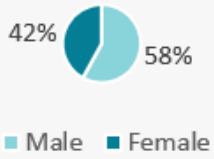
Demographics of sample of family members with disabilities receiving supports from the state

Average Age
of the sample of family members with disabilities receiving supports from the state

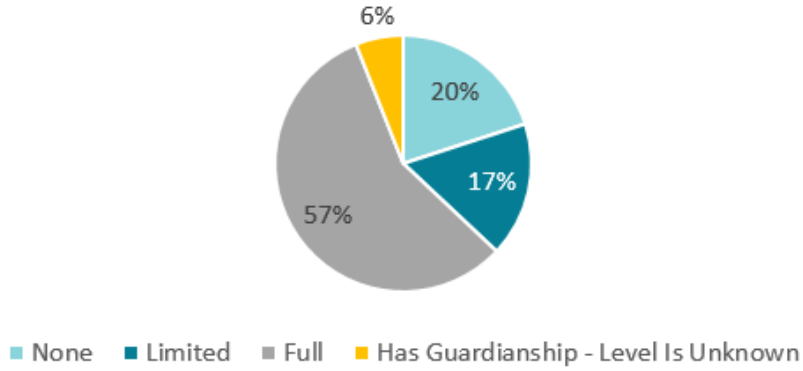
46 years old

****

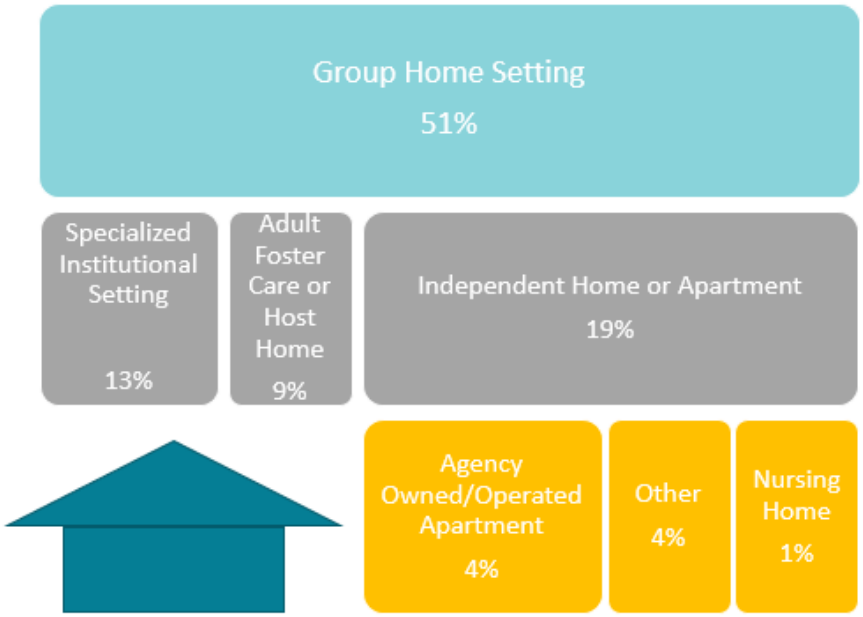
Gender Breakdown
of the sample of family members with disabilities receiving supports from the state



Legal guardianship arrangement for family member with disability

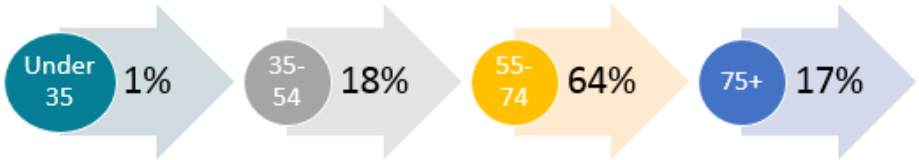


Where do family members with disabilities live?



Characteristics of respondents
(family or guardian of the adult with disability)

Age of respondents



Number of times per year respondent sees family member with disability

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

Information and Planning

Respondents reported…

48%

- Always receive enough information to help plan services for family member with disability

45%

- Information received to help plan services is always easy to understand

Access and Delivery of Supports and Services

Respondents reported…

77% Services and supports are delivered in a way that is respectful of family's culture

52% Services and supports always change when family's needs change

66% Always able to contact family member's case manager when wanted

64% Always able to contact family member's support workers when wanted

Choice, Decision-making and Control

Respondents reported…

Family can always choose or change the agency that provides family member with disability's supports	66%

Involvement in the Community

Respondents reported…

91% – Family member with disability takes part in community activities

72% – 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	49%

I. Results

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

Survey Development

The Family/Guardian Survey was developed and first utilized in 1999-2000 in response to various states' interest in determining whether families were involved in the lives of their family member with a developmental disability (who did not live at home with them), 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 on the characteristics of the family member with a developmental disability (e.g., age, race, type of disability) followed by a series of demographic questions on the survey respondent (e.g., age, health status, relationship to the individual with the developmental disability).

Services and Supports Received

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

Questions Regarding Services and Supports

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

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

***Please note: In the 2015-16 FGS survey tool, the "Seldom" and "Never" response options, which were separate in previous years, were combined into a "Seldom/Never" response option. This may affect comparisons from year to year.**

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.

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 are not included 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 in part on the sample size of the state. So, for example, when state A has a larger valid sample for the indicator than state B, state A may be significantly different from the average when state B is not, even though state B's difference from that average is larger than state A's. The larger the sample size of a state, the smaller the difference needs to be to be statistically significant.

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 Institutional Facility	Group Home	Agency Owned Apartment	Independent Home or Apartment	Adult Foster Care or Host Home	Nursing Home	Other	N
AK	10%	58%	8%	15%	5%	0%	5%	172
FL	7%	64%	2%	25%	1%	0%	2%	330
GA	7%	52%	3%	17%	15%	1%	4%	383
LA	35%	31%	4%	29%	0%	1%	1%	389
MD	8%	64%	5%	16%	2%	1%	4%	1,033
MI	6%	57%	2%	17%	15%	1%	3%	499
MN	8%	60%	3%	12%	11%	3%	3%	411
NC	19%	58%	1%	3%	15%	0%	3%	246
NH	8%	23%	3%	27%	35%	1%	3%	338
PA	29%	48%	3%	14%	2%	2%	1%	416
SD	20%	39%	13%	23%	1%	0%	4%	724
UT	5%	59%	8%	21%	7%	0%	0%	418
VA	11%	70%	2%	4%	9%	5%	0%	228
WA	6%	36%	6%	39%	6%	1%	6%	379
NCI Average	**13%**	**51%**	**4%**	**19%**	**9%**	**1%**	**3%**	**5,966**

Table 2. Family Member's Residential Setting

State	Urban or Suburban	Rural	N
AK	80%	20%	176
FL	85%	15%	324
GA	76%	24%	373
LA	79%	21%	362
MD	73%	27%	1,032
MI	70%	30%	515
MN	88%	12%	415
NC	66%	34%	243
NH	55%	45%	344
PA	64%	36%	406
SD	96%	4%	742
UT	93%	7%	423
VA	71%	29%	226
WA	91%	9%	376
NCI Average	**78%**	**22%**	**5,957**

Table 3. Family Member's Age

State	Age	N
AK	38.0	176
FL	44.2	330
GA	45.3	385
LA	49.8	385
MD	46.9	1,032
MI	49.6	512
MN	46.4	407
NC	45.3	245
NH	45.2	348
PA	50.9	419
SD	45.0	752
UT	43.2	424
VA	46.7	220
WA	46.4	376
NCI Average	**45.9**	**6,011**

Table 4. Family Member's Gender

State	Male	Female	N
AK	64%	36%	177
FL	57%	43%	331
GA	63%	37%	389
LA	58%	42%	388
MD	59%	41%	1,052
MI	58%	43%	520
MN	53%	47%	418
NC	58%	42%	250
NH	62%	38%	351
PA	55%	45%	418
SD	58%	42%	765
UT	60%	40%	429
VA	53%	47%	229
WA	59%	41%	381
NCI Average	**58%**	**42%**	**6,098**

Table 5. Family Member's Race and Ethnicity

State	American Indian or Alaska Native	Asian	Black or African-American	Hawaiian or Pacific Islander	White	Other or Unknown	Two or More Races	Hispanic or Latino
AK	23%	4%	6%	0%	74%	0%	8%	2%
FL	1%	1%	14%	0%	77%	2%	3%	9%
GA	2%	1%	22%	1%	76%	1%	2%	1%
LA	2%	1%	22%	0%	78%	0%	3%	0%
MD	3%	4%	20%	0%	74%	1%	4%	2%
MI	3%	2%	10%	0%	86%	0%	3%	2%
MN	2%	0%	1%	0%	95%	0%	1%	1%
NC	4%	1%	26%	0%	70%	2%	3%	1%
NH	1%	1%	2%	0%	96%	0%	1%	1%
PA	1%	1%	6%	0%	90%	0%	1%	3%
SD	10%	1%	1%	0%	89%	1%	2%	1%
UT	3%	2%	1%	0%	92%	1%	2%	4%
VA	0%	1%	16%	0%	81%	1%	1%	2%
WA	4%	5%	3%	0%	90%	0%	5%	3%
NCI Average	**4%**	**2%**	**11%**	**0%**	**83%**	**1%**	**3%**	**2%**

Table 6. Family Member's Disabilities

State	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
AK	80%	32%	29%	21%	9%	6%	14%	36%	0%	9%	1%	7%	16%
FL	75%	33%	22%	19%	7%	7%	10%	27%	1%	13%	1%	1%	11%
GA	75%	27%	23%	15%	14%	6%	13%	34%	0%	12%	1%	3%	10%
LA	73%	26%	18%	16%	12%	9%	14%	35%	1%	6%	1%	1%	19%
MD	74%	26%	23%	18%	10%	7%	11%	25%	1%	11%	1%	1%	17%
MI	78%	35%	22%	16%	8%	7%	8%	27%	1%	8%	1%	2%	18%
MN	81%	37%	16%	13%	10%	6%	10%	28%	1%	14%	1%	1%	19%
NC	80%	33%	27%	13%	9%	7%	11%	29%	1%	10%	1%	1%	20%
NH	70%	34%	22%	16%	10%	8%	19%	29%	1%	8%	1%	2%	13%
PA	90%	32%	22%	16%	12%	9%	14%	32%	0%	12%	0%	1%	10%
SD	72%	31%	18%	15%	7%	9%	11%	26%	2%	12%	1%	4%	10%
UT	83%	43%	24%	18%	11%	5%	16%	30%	1%	5%	1%	1%	17%
VA	76%	27%	27%	16%	8%	7%	14%	32%	1%	11%	0%	1%	18%
WA	79%	36%	19%	15%	8%	7%	9%	31%	1%	12%	1%	2%	19%
NCI Average	**78%**	**32%**	**22%**	**16%**	**10%**	**7%**	**12%**	**30%**	**1%**	**10%**	**1%**	**2%**	**15%**

Table 7. Family Member's Health Conditions

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Other
AK	4%	12%	6%	31%	33%	11%	0%	4%	49%
FL	12%	18%	6%	31%	37%	8%	3%	6%	36%
GA	9%	20%	8%	38%	32%	13%	3%	5%	29%
LA	11%	13%	5%	38%	27%	24%	6%	5%	30%
MD	8%	21%	6%	36%	33%	12%	3%	5%	35%
MI	13%	20%	7%	34%	31%	13%	4%	8%	36%
MN	11%	17%	5%	25%	30%	13%	1%	5%	38%
NC	11%	22%	8%	33%	35%	16%	3%	9%	37%
NH	11%	20%	8%	26%	37%	16%	3%	6%	27%
PA	13%	15%	6%	25%	33%	24%	2%	7%	34%
SD	10%	23%	6%	31%	27%	21%	5%	8%	26%
UT	7%	23%	6%	32%	29%	11%	3%	4%	37%
VA	15%	23%	6%	35%	29%	14%	4%	6%	40%
WA	13%	18%	6%	31%	32%	14%	1%	6%	44%
NCI Average	**11%**	**19%**	**6%**	**32%**	**32%**	**15%**	**3%**	**6%**	**36%**

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
AK	73%	18%	4%	0%	5%	168
FL	74%	20%	2%	1%	3%	337
GA	70%	23%	3%	1%	3%	383
LA	62%	27%	2%	1%	8%	391
MD	77%	16%	2%	1%	4%	1,014
MI	74%	17%	2%	1%	5%	499
MN	83%	12%	2%	1%	2%	396
NC	71%	23%	2%	0%	3%	250
NH	79%	15%	3%	2%	1%	355
PA	70%	24%	1%	1%	4%	408
SD	80%	14%	2%	1%	2%	701
UT	78%	18%	2%	0%	2%	424
VA	77%	18%	0%	1%	4%	229
WA	79%	15%	3%	0%	3%	394
NCI Average	**75%**	**19%**	**2%**	**1%**	**3%**	**5,949**

Table 9. Family Member's Legal Guardianship Arrangement

State	None	Limited	Full	Has Guardianship but Level Is Unknown	N
AK[1]	1%	4%	93%	2%	177
FL	39%	16%	40%	5%	330
GA	22%	14%	56%	7%	356
LA	28%	23%	37%	12%	367
MD	44%	19%	27%	9%	946
MI	8%	23%	65%	4%	511
MN	7%	11%	75%	6%	411
NC	4%	18%	71%	8%	251
NH	15%	13%	69%	3%	354
PA	35%	18%	40%	7%	381
SD	11%	14%	67%	7%	738
UT	20%	28%	47%	5%	406
VA	26%	18%	50%	6%	222
WA	24%	17%	54%	5%	378
NCI Average	**20%**	**17%**	**57%**	**6%**	**5,828**

[1] AK did not include families of people who were not under guardianship agreements

Table 10. Guardian or Conservator Relationship to Family Member

State	Family	Friend	State Employee or Guardianship Agency	Other	N
AK	78%	7%	15%	1%	168
FL	85%	3%	3%	10%	178
GA	89%	3%	6%	2%	239
LA	92%	0%	6%	2%	212
MD	83%	2%	12%	3%	420
MI	72%	3%	22%	3%	446
MN	76%	2%	17%	4%	369
NC	77%	2%	17%	3%	231
NH	90%	2%	5%	2%	282
PA	90%	2%	8%	1%	220
SD	86%	2%	11%	1%	607
UT	76%	1%	21%	2%	299
VA	88%	3%	4%	5%	145
WA	85%	4%	6%	5%	268
NCI Average	**83%**	**3%**	**11%**	**3%**	**4,084**

Table 11. Family Member's Highest Level of Education

State	Middle or Junior High	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational Training	Some College	College Degree or Higher	N
AK	7%	1%	58%	24%	3%	3%	3%	148
FL	11%	2%	51%	17%	7%	5%	7%	242
GA	13%	1%	49%	26%	3%	4%	5%	257
LA	29%	1%	38%	12%	6%	6%	7%	216
MD	10%	1%	53%	17%	9%	4%	5%	716
MI	22%	2%	36%	15%	17%	5%	4%	288
MN	14%	1%	37%	39%	3%	2%	4%	333
NC	16%	2%	46%	18%	6%	7%	5%	178
NH	12%	1%	39%	31%	5%	4%	7%	262
PA	16%	1%	34%	39%	5%	1%	5%	256
SD	19%	1%	33%	36%	3%	4%	4%	516
UT	7%	0%	50%	31%	4%	3%	6%	306
VA	16%	0%	52%	25%	6%	1%	0%	142
WA	9%	1%	45%	36%	3%	4%	2%	320
NCI Average	**14%**	**1%**	**44%**	**26%**	**6%**	**4%**	**5%**	**4,180**

Table 12. Family Member's Typical Day Activity – Individual Paid Community Job

State	Never	Usually/Often	Sometimes	N
AK	73%	23%	4%	143
FL	82%	14%	4%	242
GA	87%	11%	2%	285
LA	91%	6%	2%	294
MD	73%	21%	5%	743
MI	90%	8%	3%	397
MN	75%	23%	2%	334
NC	85%	11%	4%	191
NH	71%	24%	4%	291
PA	85%	11%	4%	290
SD	71%	24%	6%	596
UT	77%	17%	6%	314
VA	92%	5%	3%	178
WA	66%	26%	7%	312
NCI Average	**80%**	**16%**	**4%**	**4,610**

Table 13. Family Member's Typical Day Activity – Paid Small Group Job in the Community

State	Never	Usually/Often	Sometimes	N
AK	87%	9%	4%	142
FL	87%	10%	3%	230
GA	90%	6%	4%	269
LA	85%	11%	4%	297
MD	74%	19%	7%	699
MI	86%	10%	5%	388
MN	70%	25%	6%	332
NC	85%	12%	4%	190
NH	83%	11%	7%	274
PA	89%	8%	3%	273
SD	72%	21%	8%	568
UT	78%	13%	9%	304
VA	90%	7%	3%	176
WA	83%	12%	4%	291
NCI Average	**83%**	**12%**	**5%**	**4,433**

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

State	Never	Usually/Often	Sometimes	N
AK	51%	27%	22%	143
FL	75%	14%	11%	235
GA	65%	19%	16%	277
LA	85%	6%	9%	290
MD	69%	16%	15%	699
MI	61%	25%	14%	405
MN	68%	16%	16%	322
NC	46%	34%	20%	189
NH	34%	41%	24%	295
PA	71%	17%	12%	280
SD	64%	12%	24%	557
UT	67%	14%	19%	302
VA	59%	28%	13%	180
WA	58%	27%	15%	305
NCI Average	**62%**	**21%**	**16%**	**4,479**

Table 15. Family Member's Typical Day Activity – Paid Facility-Based Setting

State	Never	Usually/Often	Sometimes	N
AK	79%	15%	6%	142
FL	66%	28%	6%	253
GA	79%	16%	5%	279
LA	72%	22%	5%	309
MD	55%	33%	12%	756
MI	69%	24%	7%	419
MN	45%	47%	8%	362
NC	62%	30%	8%	204
NH	84%	10%	6%	269
PA	61%	32%	6%	305
SD	45%	41%	14%	615
UT	59%	35%	6%	337
VA	73%	20%	7%	187
WA	77%	16%	7%	286
NCI Average	**66%**	**26%**	**7%**	**4,723**

Table 16. Family Member's Typical Day Activity – Unpaid Facility-Based Setting

State	Never	Usually/Often	Sometimes	N
AK	37%	49%	14%	142
FL	54%	41%	5%	242
GA	48%	46%	6%	287
LA	63%	30%	7%	282
MD	46%	45%	8%	725
MI	65%	23%	12%	391
MN	63%	30%	7%	321
NC	39%	52%	9%	187
NH	63%	25%	12%	259
PA	55%	36%	9%	300
SD	64%	22%	13%	551
UT	48%	43%	9%	322
VA	47%	46%	7%	187
WA	79%	11%	10%	275
NCI Average	**55%**	**36%**	**9%**	**4,471**

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

State	Never	Usually/Often	Sometimes	N
AK	93%	3%	4%	125
FL	87%	12%	1%	194
GA	88%	12%	0%	228
LA	93%	6%	1%	238
MD	91%	6%	3%	533
MI	88%	11%	1%	324
MN	95%	4%	1%	280
NC	81%	13%	6%	156
NH	90%	6%	4%	230
PA	96%	3%	1%	231
SD	94%	4%	2%	467
UT	93%	5%	2%	261
VA	95%	4%	1%	150
WA	93%	5%	2%	256
NCI Average	**91%**	**7%**	**2%**	**3,673**

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

State	Never	Usually/Often	Sometimes	N
AK	24%	52%	25%	126
FL	40%	32%	28%	198
GA	43%	30%	26%	212
LA	50%	36%	14%	232
MD	66%	20%	14%	516
MI	28%	51%	21%	349
MN	54%	22%	24%	280
NC	55%	18%	27%	149
NH	38%	41%	20%	232
PA	49%	36%	16%	225
SD	49%	32%	19%	463
UT	47%	27%	26%	257
VA	50%	28%	22%	144
WA	19%	66%	15%	294
NCI Average	**44%**	**35%**	**21%**	**3,677**

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

State	Never	Usually/Often	Sometimes	N
AK	19%	66%	16%	32
FL	28%	63%	8%	71
GA	29%	64%	7%	45
LA	61%	31%	8%	62
MD	34%	58%	9%	151
MI	27%	54%	19%	95
MN	76%	21%	3%	72
NC	39%	45%	16%	49
NH	21%	67%	12%	58
PA	27%	63%	10%	30
SD	50%	39%	11%	90
UT	36%	54%	10%	70
VA	39%	47%	14%	36
WA	17%	70%	13%	77
NCI Average	**36%**	**53%**	**11%**	**938**

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

State	None	Some	Extensive	N
AK	34%	37%	29%	172
FL	31%	40%	29%	322
GA	32%	35%	33%	374
LA	24%	31%	45%	380
MD	41%	33%	26%	997
MI	25%	40%	35%	504
MN	37%	38%	25%	417
NC	23%	37%	40%	239
NH	34%	35%	31%	346
PA	34%	34%	32%	396
SD	31%	43%	25%	727
UT	24%	37%	39%	413
VA	22%	42%	37%	226
WA	27%	46%	27%	392
NCI Average	**30%**	**38%**	**32%**	**5,905**

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

State	None	Some	Extensive	N
AK	16%	42%	42%	178
FL	18%	42%	40%	335
GA	20%	37%	43%	382
LA	16%	30%	53%	388
MD	25%	36%	39%	1,036
MI	17%	38%	46%	523
MN	23%	44%	33%	419
NC	11%	45%	44%	251
NH	26%	37%	37%	354
PA	20%	35%	45%	416
SD	29%	42%	30%	751
UT	17%	41%	43%	425
VA	11%	38%	51%	230
WA	18%	46%	36%	388
NCI Average	**19%**	**39%**	**42%**	**6,076**

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

State	None	Some	Extensive	N
AK	0%	25%	75%	177
FL	4%	16%	80%	331
GA	3%	16%	80%	382
LA	3%	14%	82%	391
MD	4%	20%	77%	1,027
MI	2%	16%	82%	519
MN	2%	22%	76%	411
NC	2%	15%	83%	249
NH	2%	28%	70%	353
PA	2%	16%	82%	414
SD	2%	29%	69%	746
UT	1%	18%	80%	420
VA	1%	14%	85%	233
WA	1%	15%	84%	392
NCI Average	**2%**	**19%**	**79%**	**6,045**

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
AK	0%	22%	71%	7%	177
FL	3%	23%	58%	17%	334
GA	0%	18%	62%	20%	391
LA	1%	14%	62%	23%	394
MD	2%	11%	61%	26%	1,044
MI	2%	17%	67%	15%	503
MN	3%	23%	63%	11%	411
NC	3%	25%	59%	13%	251
NH	2%	17%	64%	18%	355
PA	0%	9%	67%	24%	413
SD	1%	16%	64%	19%	758
UT	0%	25%	60%	14%	424
VA	1%	15%	68%	16%	231
WA	1%	13%	68%	18%	394
NCI Average	**1%**	**18%**	**64%**	**17%**	**6,080**

Table 24. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
AK	30%	39%	29%	2%	178
FL	17%	40%	38%	5%	336
GA	13%	38%	42%	7%	389
LA	7%	33%	50%	10%	397
MD	14%	42%	38%	6%	1,036
MI	14%	53%	31%	2%	507
MN	18%	51%	29%	2%	407
NC	14%	47%	35%	4%	250
NH	19%	48%	30%	4%	353
PA	12%	43%	38%	7%	414
SD	14%	49%	34%	3%	759
UT	21%	42%	33%	4%	420
VA	12%	44%	37%	6%	232
WA	20%	43%	34%	4%	394
NCI Average	**16%**	**44%**	**36%**	**5%**	**6,072**

Table 25. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
AK	63%	13%	0%	1%	14%	5%	4%	164
FL	52%	15%	0%	2%	2%	6%	22%	334
GA	56%	28%	1%	2%	3%	4%	7%	386
LA	55%	31%	1%	2%	2%	2%	9%	395
MD	58%	25%	1%	2%	3%	1%	9%	1,043
MI	39%	29%	0%	0%	17%	8%	7%	511
MN	46%	20%	0%	1%	6%	8%	20%	396
NC	45%	22%	0%	1%	14%	9%	9%	250
NH	63%	23%	2%	1%	3%	4%	4%	354
PA	53%	41%	0%	1%	1%	2%	2%	418
SD	61%	23%	0%	2%	8%	3%	3%	730
UT	64%	18%	0%	1%	11%	2%	4%	423
VA	55%	30%	0%	0%	3%	3%	8%	233
WA	58%	23%	0%	1%	1%	6%	11%	396
NCI Average	**55%**	**24%**	**0%**	**1%**	**6%**	**4%**	**9%**	**6,033**

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

State	Less than once	1-3 times	4-6 times	7-12 times	12+ times	N
AK	3%	15%	13%	6%	63%	172
FL	3%	8%	9%	8%	72%	329
GA	4%	9%	13%	13%	61%	381
LA	7%	13%	15%	12%	53%	390
MD	3%	8%	9%	12%	69%	1,033
MI	3%	7%	15%	14%	61%	511
MN	0%	4%	7%	9%	79%	408
NC	3%	9%	15%	18%	55%	251
NH	5%	10%	10%	10%	65%	345
PA	6%	12%	9%	11%	61%	415
SD	4%	11%	12%	16%	58%	753
UT	2%	3%	12%	14%	69%	421
VA	5%	9%	14%	14%	58%	228
WA	5%	8%	8%	13%	67%	393
NCI Average	**4%**	**9%**	**11%**	**12%**	**64%**	**6,030**

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
AK	0%	13%	2%	19%	66%	165
FL	4%	22%	6%	26%	42%	326
GA	9%	22%	8%	21%	41%	368
LA	9%	28%	10%	22%	32%	376
MD	5%	19%	3%	23%	50%	1,033
MI	3%	22%	3%	26%	47%	493
MN	3%	20%	12%	18%	48%	399
NC	4%	13%	6%	20%	56%	250
NH	6%	20%	5%	14%	55%	346
PA	3%	35%	5%	14%	43%	408
SD	5%	27%	12%	19%	37%	731
UT	2%	20%	7%	22%	49%	421
VA	5%	26%	4%	23%	42%	226
WA	3%	14%	6%	30%	47%	391
NCI Average	**4%**	**22%**	**6%**	**21%**	**47%**	**5,933**

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

State	Below $15,000	$15,00-$25,000	$25,001-$50,000	$50,001-$75,000	Over $75,000	No Earned Income	N
AK	8%	6%	17%	20%	42%	6%	109
FL	14%	14%	28%	21%	10%	13%	174
GA	16%	19%	23%	13%	19%	10%	219
LA	18%	17%	26%	14%	10%	15%	259
MD	12%	13%	20%	18%	27%	10%	603
MI	11%	15%	33%	18%	17%	6%	327
MN	9%	8%	25%	23%	32%	3%	244
NC	8%	18%	27%	17%	23%	7%	154
NH	11%	13%	19%	17%	26%	14%	208
PA	13%	19%	20%	14%	22%	13%	240
SD	13%	17%	30%	17%	17%	8%	522
UT	10%	12%	25%	22%	22%	8%	255
VA	11%	13%	22%	17%	30%	7%	139
WA	9%	11%	27%	16%	28%	9%	256
NCI Average	**12%**	**14%**	**24%**	**18%**	**23%**	**9%**	**3,709**

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
AK	47%	50%	89%	53%	86%	56%	23%
FL	33%	49%	85%	64%	85%	59%	42%
GA	35%	38%	92%	73%	93%	47%	26%
LA	21%	36%	74%	44%	78%	48%	17%
MD	32%	32%	83%	81%	89%	50%	18%
MI	22%	51%	89%	56%	88%	64%	23%
MN	44%	37%	88%	79%	92%	55%	24%
NC	34%	35%	93%	71%	88%	61%	20%
NH	42%	36%	85%	56%	82%	53%	24%
PA	26%	28%	87%	55%	81%	60%	11%
SD	30%	32%	87%	69%	91%	64%	28%
UT	31%	44%	94%	85%	94%	61%	25%
VA	21%	26%	94%	72%	94%	66%	23%
WA	38%	57%	83%	52%	83%	46%	26%
NCI Average	**33%**	**39%**	**88%**	**65%**	**87%**	**56%**	**24%**

Table 30. Additional Services and Supports Received

State	SSI/SSB	Other Agencies or Organizations
AK	95%	46%
FL	97%	27%
GA	98%	25%
LA	95%	19%
MD	93%	28%
MI	98%	42%
MN	96%	32%
NC	96%	38%
NH	96%	29%
PA	95%	33%
SD	97%	27%
UT	96%	21%
VA	98%	22%
WA	96%	36%
NCI Average	**96%**	**30%**

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.

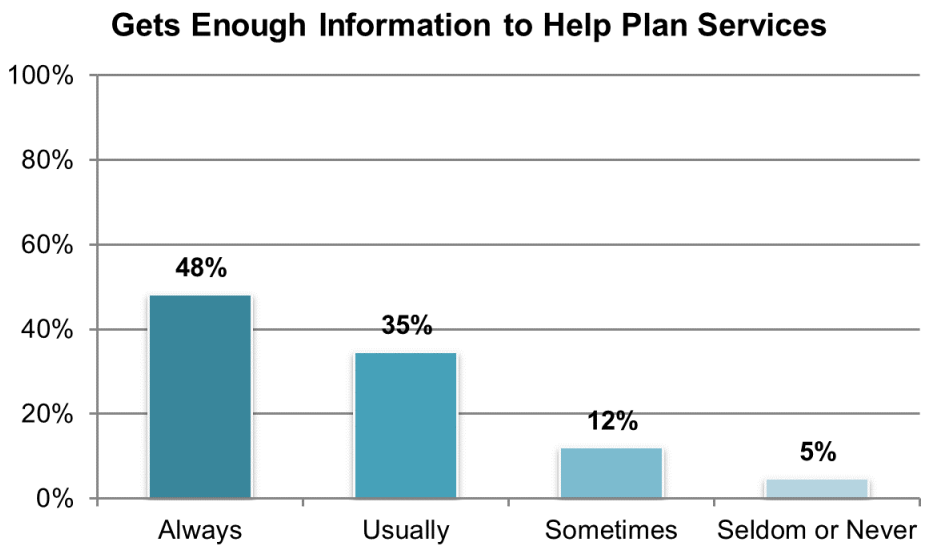


Table Q1. Do you get enough information to help you participate in planning services for your family?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
NC	61%	29%	8%	2%	241
MN	58%	33%	7%	2%	399
FL	56%	30%	9%	4%	309
Within Average Range					
AK	55%	37%	6%	2%	173
VA	54%	31%	11%	4%	220
MI	53%	35%	7%	4%	490
NH	51%	35%	9%	5%	339
UT	48%	32%	14%	5%	400
WA	45%	37%	13%	6%	356
Significantly Below Average					
SD	43%	42%	13%	3%	712
PA	40%	39%	16%	5%	371
GA	39%	32%	21%	9%	347
LA	39%	38%	17%	7%	340
MD	35%	36%	19%	10%	932
NCI Average	**48%**	**35%**	**12%**	**5%**	**5,629**

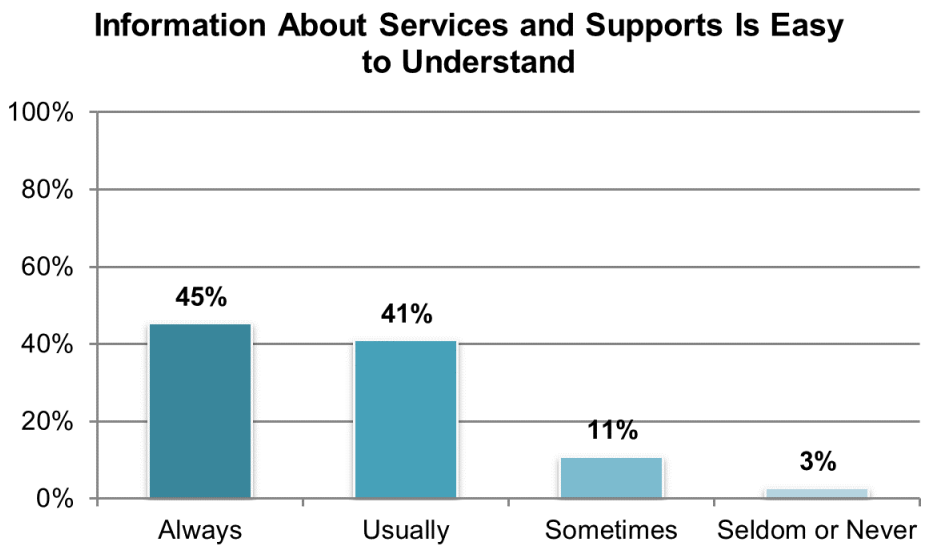


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
MI	51%	40%	5%	4%	498
Within Average Range					
VA	53%	37%	8%	1%	227
NC	52%	37%	9%	1%	246
FL	52%	36%	11%	2%	318
NH	50%	36%	11%	3%	339
UT	46%	44%	8%	3%	400
SD	45%	44%	9%	2%	725
PA	44%	42%	10%	3%	381
LA	44%	38%	14%	4%	356
MN	43%	41%	14%	2%	398
AK	41%	49%	9%	1%	172
Significantly Below Average					
MD	38%	40%	17%	6%	921
WA	38%	46%	13%	4%	368
GA	37%	44%	14%	5%	343
NCI Average	**45%**	**41%**	**11%**	**3%**	**5,692**

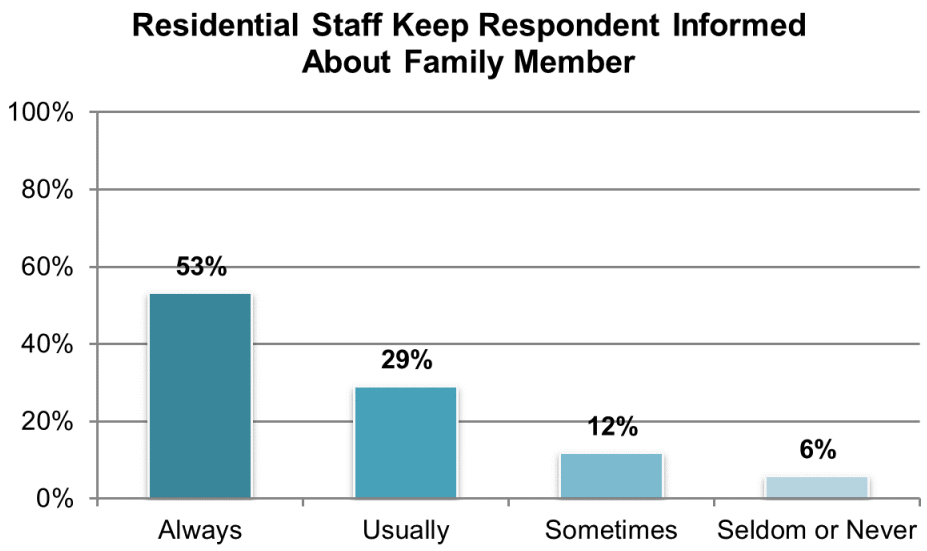


Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
MN	66%	26%	6%	2%	396
NC	64%	27%	6%	3%	250
FL	64%	23%	9%	5%	323
Within Average Range					
MI	59%	30%	7%	4%	510
VA	58%	29%	10%	3%	228
NH	56%	28%	11%	5%	341
LA	54%	26%	12%	7%	374
AK	52%	28%	14%	7%	169
GA	51%	27%	14%	8%	372
PA	49%	31%	15%	6%	390
Significantly Below Average					
SD	47%	32%	16%	5%	744
WA	45%	33%	11%	11%	343
UT	41%	37%	18%	5%	416
MD	40%	31%	17%	11%	982
NCI Average	**53%**	**29%**	**12%**	**6%**	**5,838**

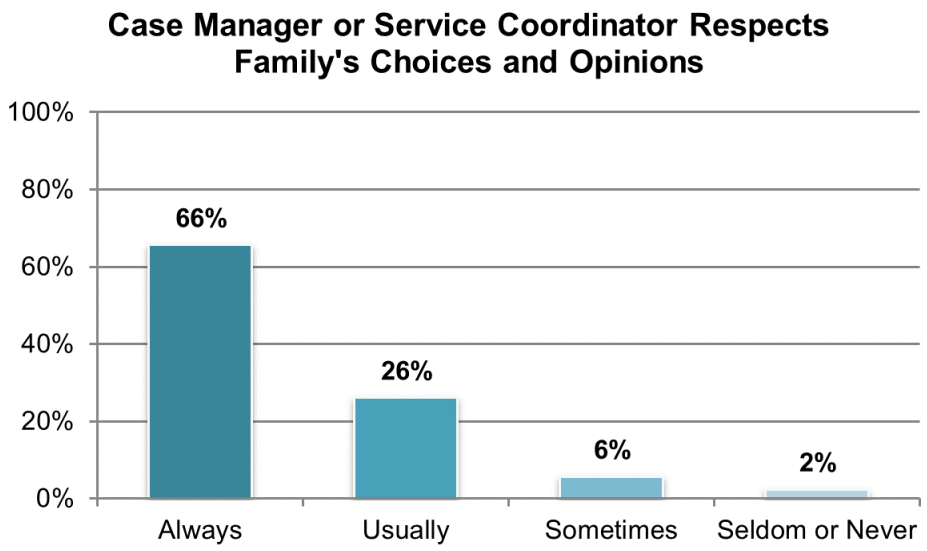


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	79%	17%	3%	1%	324
MN	73%	23%	2%	2%	403
Within Average Range					
NC	71%	25%	3%	0%	241
VA	68%	26%	5%	1%	225
NH	68%	25%	5%	3%	342
MI	68%	26%	5%	2%	511
UT	67%	24%	6%	2%	406
WA	63%	27%	6%	3%	375
LA	63%	26%	7%	4%	353
AK	62%	32%	2%	3%	173
SD	61%	28%	8%	2%	740
GA	61%	27%	8%	5%	358
PA	61%	29%	8%	2%	378
Significantly Below Average					
MD	54%	31%	10%	5%	945
NCI Average	**66%**	**26%**	**6%**	**2%**	**5,774**

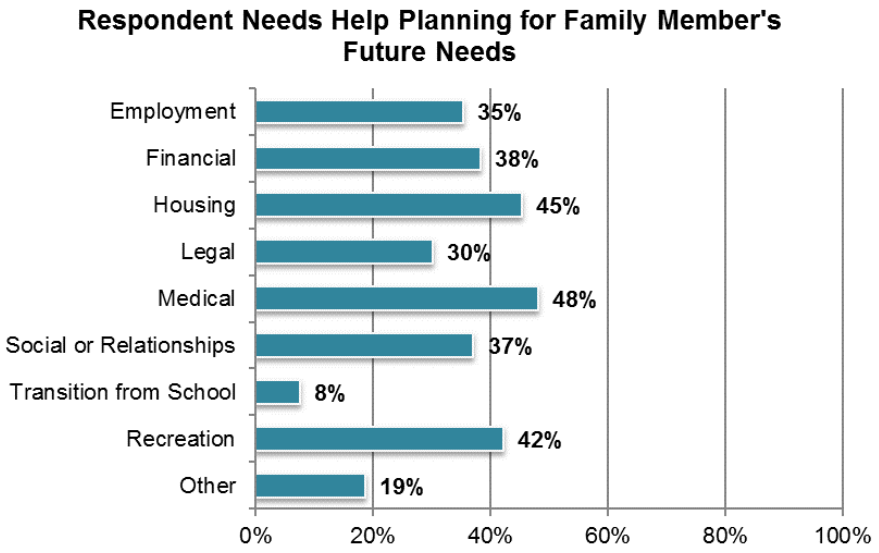


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition from School	Recreation	Other	N
AK	46%	43%	49%	29%	46%	47%	13%	45%	20%	83
FL	29%	40%	41%	30%	53%	36%	7%	45%	23%	143
GA	25%	39%	43%	32%	47%	35%	7%	35%	16%	155
LA	21%	28%	45%	23%	49%	26%	7%	32%	26%	193
MD	36%	42%	47%	35%	47%	36%	6%	48%	17%	477
MI	33%	32%	41%	28%	47%	38%	11%	48%	26%	184
MN	48%	52%	52%	38%	44%	38%	11%	45%	21%	151
NC	38%	39%	41%	32%	45%	41%	13%	42%	18%	104
NH	39%	41%	50%	22%	53%	34%	4%	40%	17%	183
PA	24%	29%	41%	32%	51%	32%	2%	42%	9%	129
SD	47%	45%	54%	31%	56%	47%	7%	53%	11%	359
UT	37%	44%	46%	34%	53%	43%	9%	49%	22%	166
VA	27%	27%	39%	28%	35%	32%	3%	28%	17%	71
WA	46%	36%	43%	28%	47%	35%	6%	40%	18%	205
NCI Average	**35%**	**38%**	**45%**	**30%**	**48%**	**37%**	**8%**	**42%**	**19%**	**2,603**

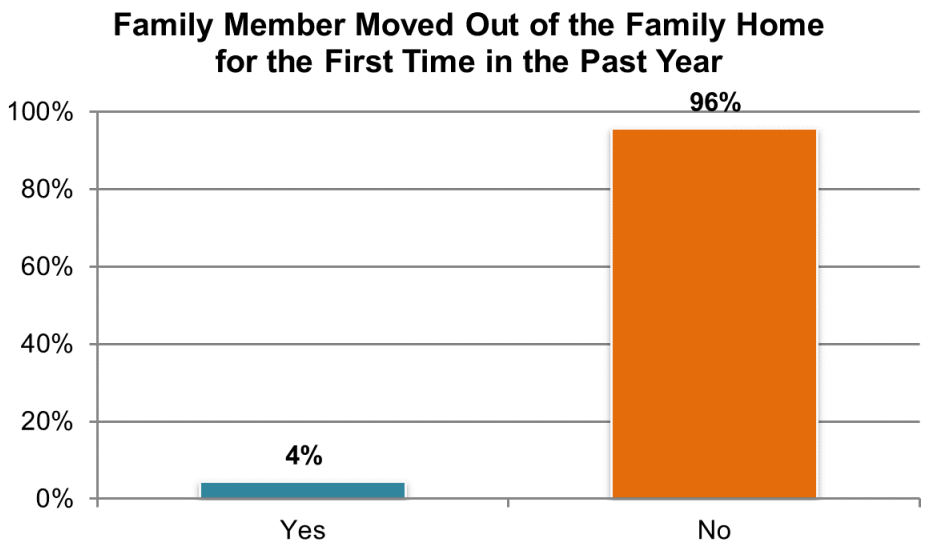


Table Q6. In the past year, did your family member move out of the family home for the first time?

State	Yes	No	N
Within Average Range			
NH	7%	93%	349
UT	7%	93%	420
LA	7%	93%	368
FL	6%	94%	320
MD	5%	95%	1,002
AK	4%	96%	170
PA	4%	96%	406
MN	4%	96%	411
GA	3%	97%	376
MI	3%	97%	502
WA	3%	97%	392
SD	3%	97%	737
VA	2%	98%	222
Significantly Below Average			
NC	1%	99%	247
NCI Average	**4%**	**96%**	**5,922**

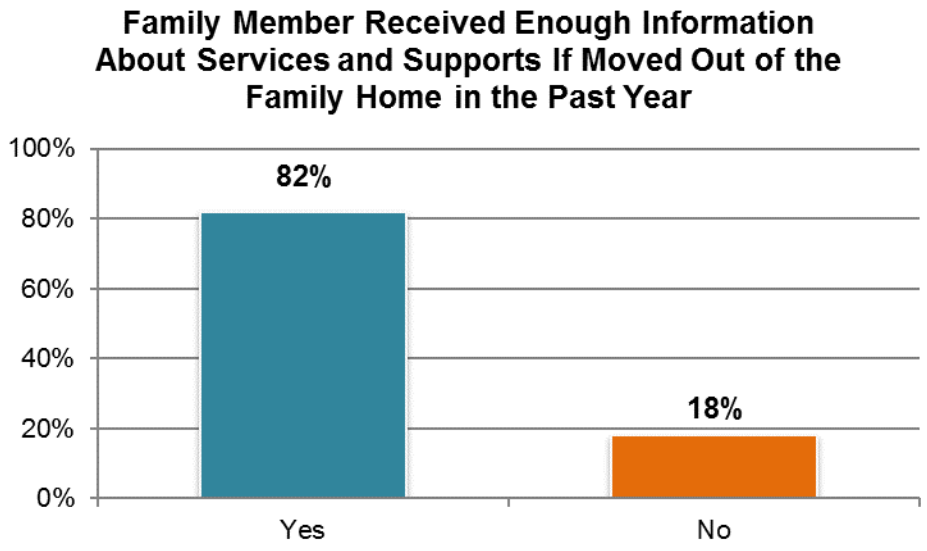


Table Q7. If yes to Q6, did your family member receive enough information about services available to support him/her?

State	Yes	No	N
Within Average Range			
UT	88%	12%	26
NH	85%	15%	20
MD	74%	26%	38
NCI Average	**82%**	**18%**	**84**

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: AK, FL, GA, LA, MI, MN, NC, PA, SD, VA, WA.

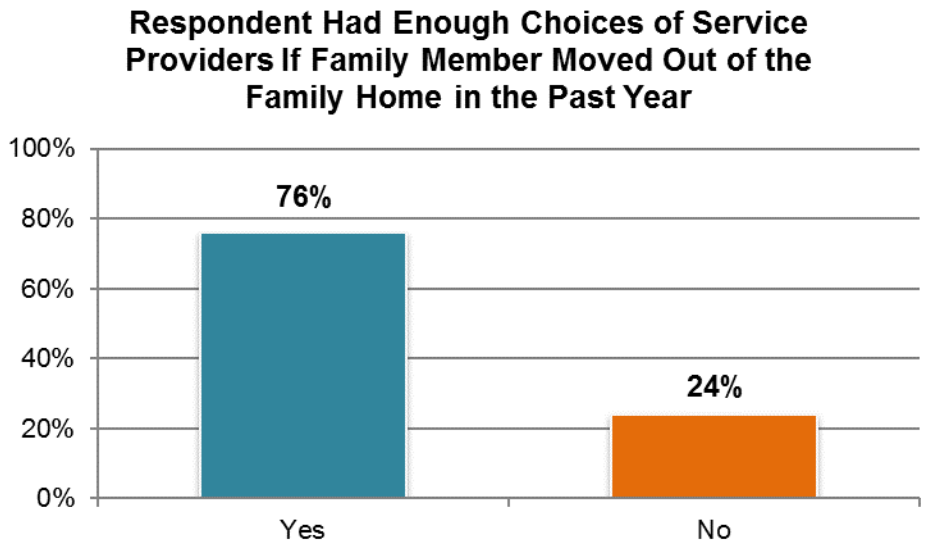


Table Q8. If yes to Q6, did you have enough choices of service providers to support your family member living outside the family home?

State	Yes	No	N
Within Average Range			
UT	81%	19%	27
MD	76%	24%	34
NH	70%	30%	20
NCI Average	**76%**	**24%**	**81**

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: AK, FL, GA, LA, MI, MN, NC, PA, SD, VA, WA.

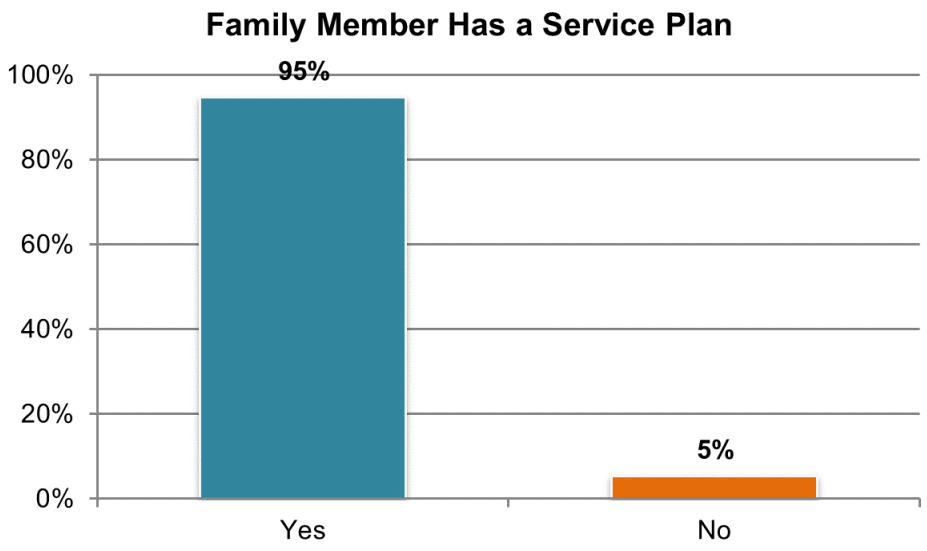


Table Q9. Does your family member have a service plan?

State	Yes	No	N
Significantly Above Average			
AK	99%	1%	163
PA	98%	2%	362
Within Average Range			
MN	97%	3%	373
UT	96%	4%	375
SD	96%	4%	592
MI	96%	4%	485
NH	96%	4%	316
FL	95%	5%	304
NC	95%	5%	225
WA	95%	5%	328
VA	93%	7%	197
GA	92%	8%	259
Significantly Below Average			
MD	91%	9%	801
LA	88%	12%	263
NCI Average	**95%**	**5%**	**5,043**

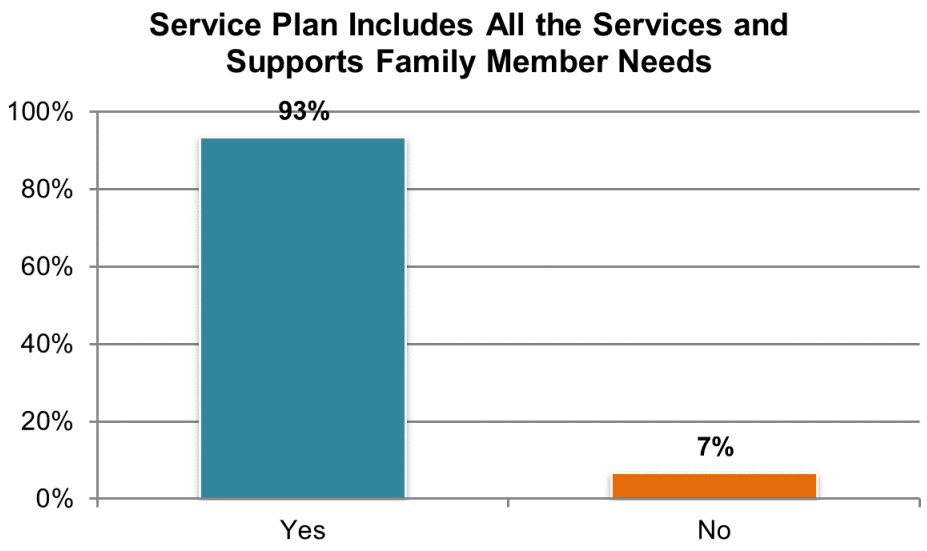


Table Q10. Does the plan include all the services and supports your family member needs?

State	Yes	No	N
Significantly Above Average			
MN	98%	2%	346
NC	97%	3%	207
Within Average Range			
UT	95%	5%	316
LA	95%	5%	201
SD	94%	6%	526
NH	94%	6%	281
GA	93%	7%	214
AK	93%	7%	151
PA	92%	8%	333
MI	92%	8%	437
VA	92%	8%	169
FL	91%	9%	272
WA	90%	10%	288
Significantly Below Average			
MD	89%	11%	659
NCI Average	**93%**	**7%**	**4,400**

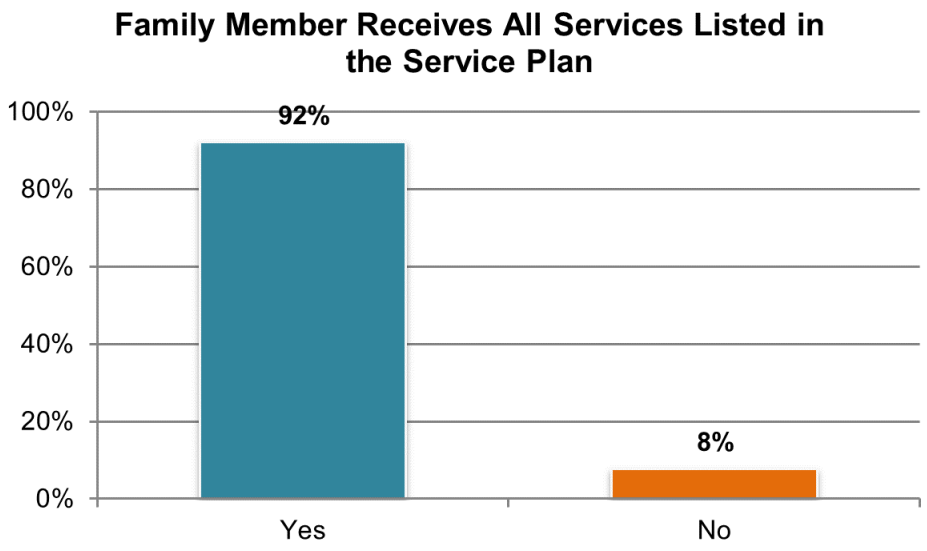


Table Q11. Does your family member receive all of the services listed in the plan?

State	Yes	No	N
Significantly Above Average			
FL	97%	3%	263
MN	96%	4%	334
Within Average Range			
NC	95%	5%	193
NH	94%	6%	270
VA	93%	7%	147
MI	93%	7%	415
PA	93%	7%	308
GA	92%	8%	198
UT	92%	8%	288
LA	91%	9%	194
WA	91%	9%	271
AK	90%	10%	150
SD	89%	11%	482
Significantly Below Average			
MD	86%	14%	608
NCI Average	**92%**	**8%**	**4,121**

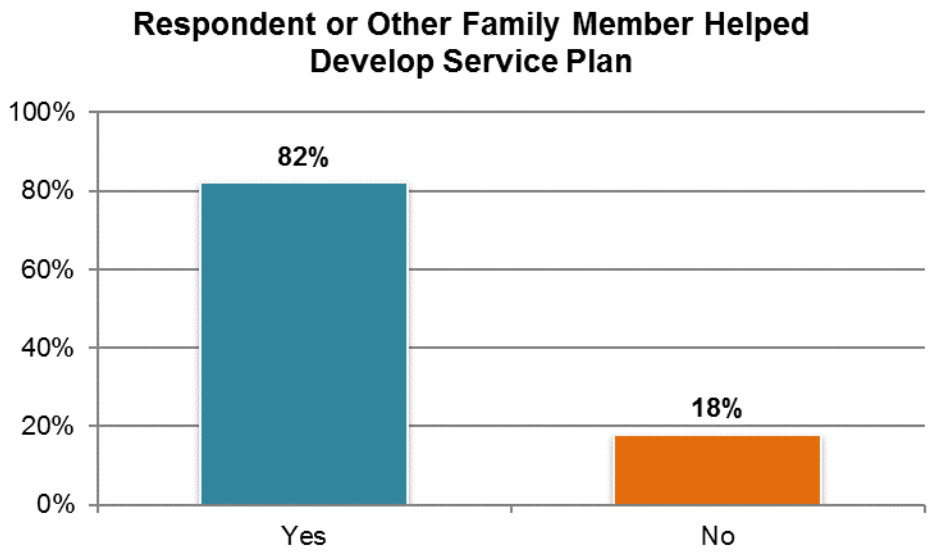


Table Q12. Did you or another family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
AK	93%	7%	159
MN	91%	9%	347
NH	87%	13%	291
UT	87%	13%	338
Within Average Range			
SD	83%	17%	540
MI	83%	17%	435
NC	82%	18%	212
MD	82%	18%	681
FL	81%	19%	274
GA	80%	20%	229
WA	79%	21%	296
VA	78%	22%	166
Significantly Below Average			
LA	74%	26%	217
PA	67%	33%	338
NCI Average	**82%**	**18%**	**4,523**

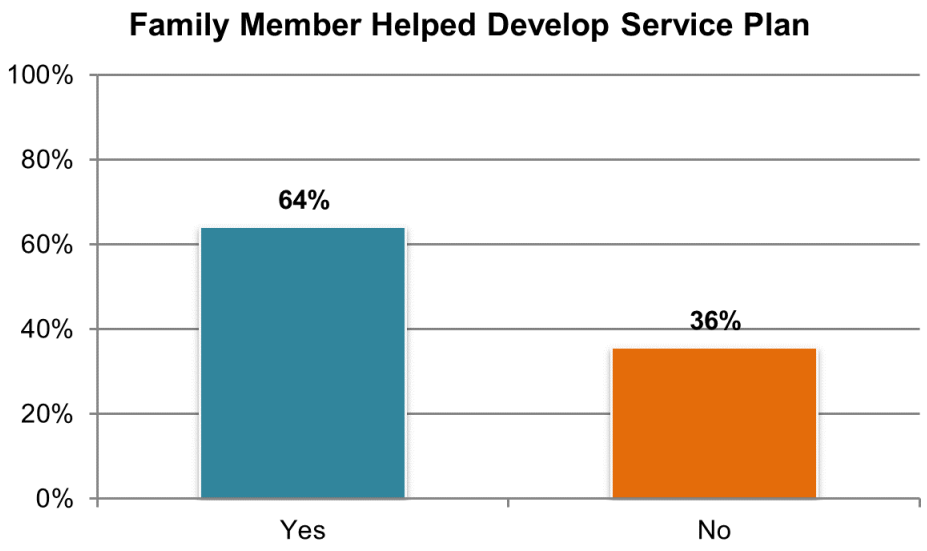


Table Q13. Did your family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
SD	77%	23%	520
MN	73%	27%	341
Within Average Range			
AK	69%	31%	156
UT	67%	33%	330
MD	67%	33%	660
FL	66%	34%	275
MI	66%	34%	439
WA	66%	34%	282
NH	65%	35%	284
NC	64%	36%	204
GA	59%	41%	219
VA	56%	44%	160
Significantly Below Average			
LA	55%	45%	210
PA	51%	49%	317
NCI Average	**64%**	**36%**	**4,397**

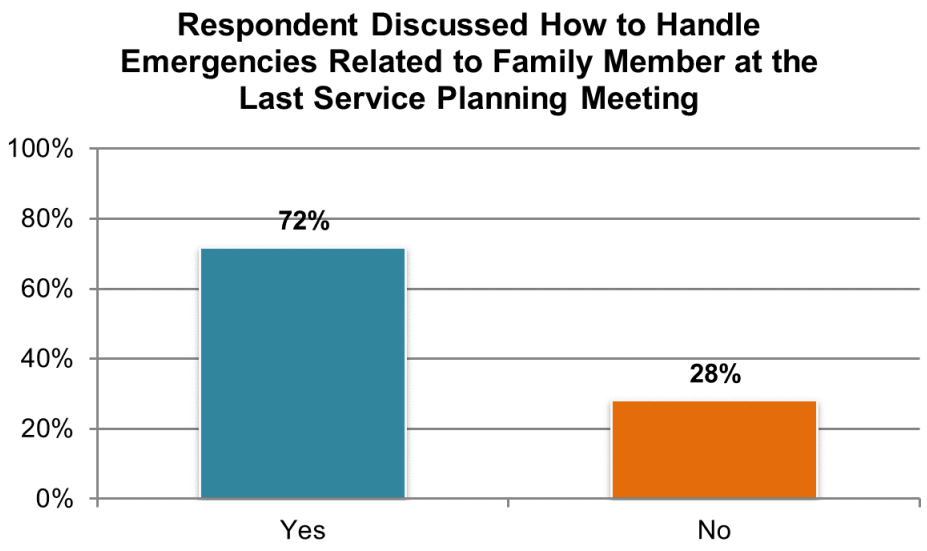


Table Q14. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?

State	Yes	No	N
Significantly Above Average			
MN	86%	14%	339
LA	82%	18%	212
FL	81%	19%	262
NC	80%	20%	196
MI	78%	22%	416
Within Average Range			
SD	77%	23%	512
AK	75%	25%	154
WA	70%	30%	265
UT	67%	33%	319
NH	64%	36%	266
VA	64%	36%	152
Significantly Below Average			
PA	61%	39%	275
GA	61%	39%	212
MD	60%	40%	641
NCI Average	**72%**	**28%**	**4,221**

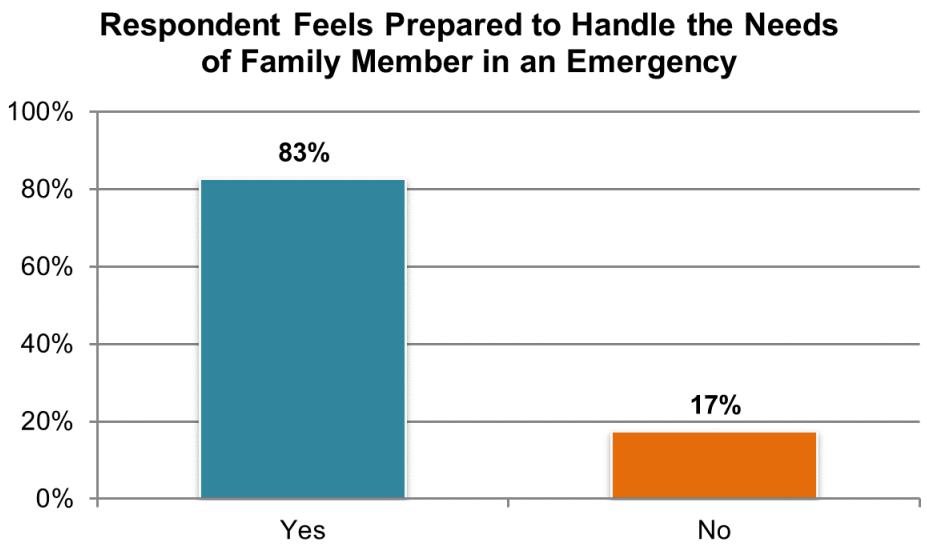


Table Q15. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

State	Yes	No	N
Significantly Above Average			
MN	94%	6%	336
FL	88%	12%	267
MI	88%	12%	405
Within Average Range			
SD	86%	14%	481
NC	86%	14%	187
AK	84%	16%	147
WA	82%	18%	257
VA	81%	19%	144
NH	81%	19%	241
GA	79%	21%	203
UT	79%	21%	317
PA	77%	23%	269
LA	76%	24%	204
Significantly Below Average			
MD	74%	26%	606
NCI Average	**83%**	**17%**	**4,064**

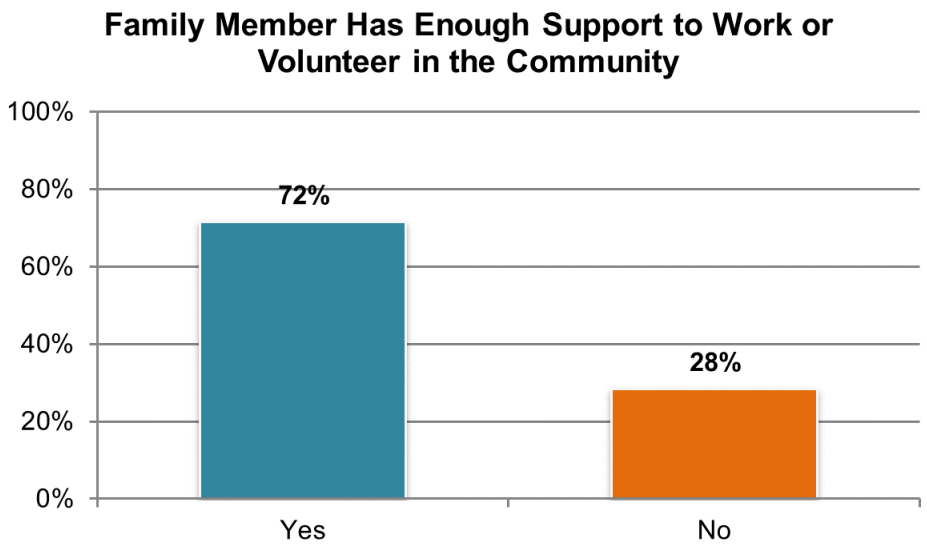


Table Q16. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

State	Yes	No	N
Significantly Above Average			
MN	88%	12%	292
WA	80%	20%	266
NH	80%	20%	234
Within Average Range			
MI	75%	25%	322
NC	75%	25%	175
UT	74%	26%	243
AK	74%	26%	115
SD	73%	27%	508
FL	71%	30%	200
VA	66%	34%	125
GA	64%	36%	209
Significantly Below Average			
MD	64%	36%	606
PA	61%	39%	197
LA	56%	44%	181
NCI Average	**72%**	**28%**	**3,673**

Access and Delivery of Services and Supports

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

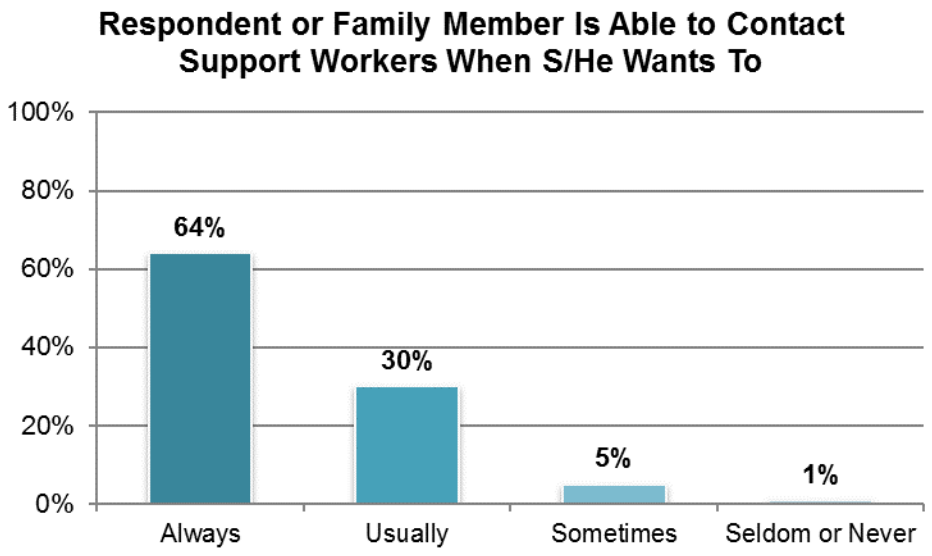


Table Q17. Are you or your family member able to contact his/her support workers when you want to?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	80%	16%	4%	1%	327
MN	71%	26%	2%	1%	397
Within Average Range					
MI	67%	28%	4%	2%	494
NH	67%	28%	4%	1%	338
UT	67%	27%	5%	2%	409
NC	64%	31%	5%	0%	234
VA	63%	30%	6%	0%	219
GA	62%	30%	5%	3%	361
LA	62%	27%	8%	2%	366
PA	61%	32%	6%	1%	385
WA	60%	32%	6%	2%	366
SD	60%	34%	5%	1%	735
AK	56%	38%	5%	1%	164
Significantly Below Average					
MD	55%	34%	8%	4%	959
NCI Average	**64%**	**30%**	**5%**	**1%**	**5,754**

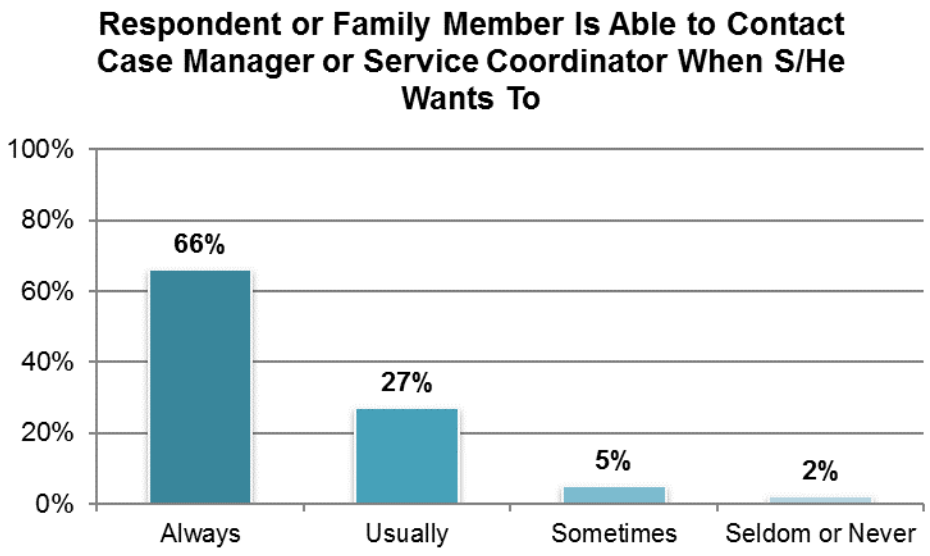


Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	81%	13%	3%	2%	326
UT	73%	21%	4%	2%	414
Within Average Range					
MN	72%	24%	3%	1%	405
NH	69%	26%	4%	1%	351
MI	68%	25%	5%	2%	509
NC	67%	28%	4%	1%	239
VA	65%	29%	5%	1%	220
SD	65%	29%	5%	1%	739
AK	64%	28%	7%	1%	171
WA	63%	29%	6%	2%	367
PA	63%	29%	6%	2%	386
LA	62%	28%	7%	3%	351
GA	62%	29%	5%	4%	362
Significantly Below Average					
MD	53%	34%	8%	4%	982
NCI Average	**66%**	**27%**	**5%**	**2%**	**5,822**

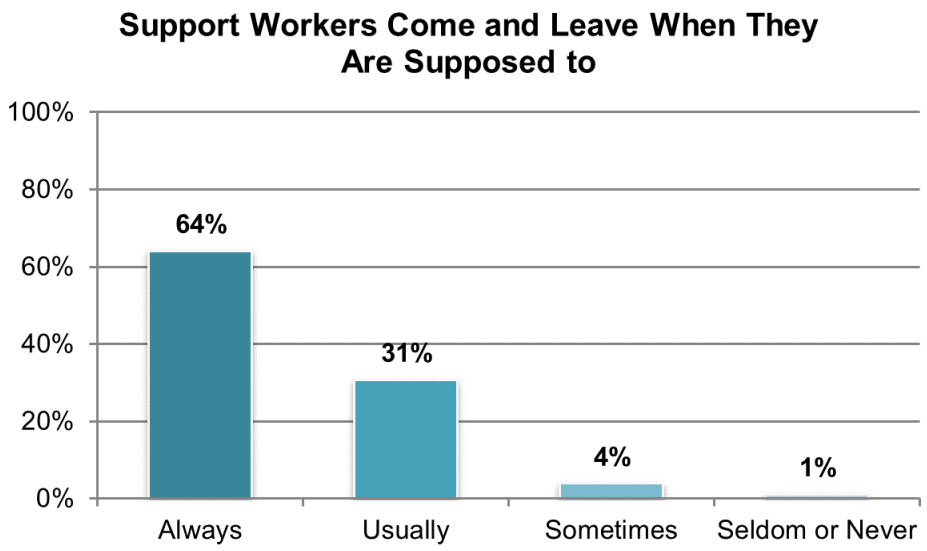


Table Q19. Do support workers come and leave when they are supposed to?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	78%	19%	3%	0%	265
Within Average Range					
VA	70%	28%	2%	0%	130
MN	70%	28%	2%	1%	322
LA	68%	25%	5%	3%	219
NH	67%	26%	6%	1%	248
MI	64%	31%	3%	2%	383
WA	64%	35%	1%	0%	265
UT	63%	32%	3%	1%	290
PA	63%	29%	6%	1%	232
SD	63%	32%	4%	1%	453
NC	63%	33%	5%	0%	163
GA	59%	35%	4%	2%	232
Significantly Below Average					
AK	54%	42%	5%	0%	130
MD	54%	37%	6%	3%	632
NCI Average	**64%**	**31%**	**4%**	**1%**	**3,964**

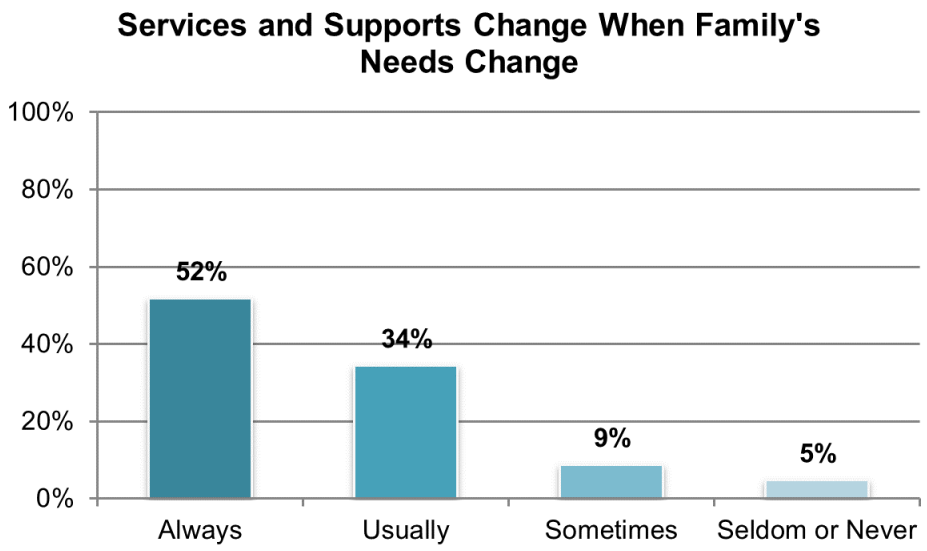


Table Q20. Do services and supports change when your family's needs change?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
MN	62%	29%	7%	2%	302
Within Average Range					
FL	59%	30%	8%	3%	259
NC	56%	36%	5%	2%	176
VA	55%	39%	5%	1%	149
UT	55%	36%	7%	3%	312
NH	53%	30%	13%	4%	255
MI	52%	36%	6%	6%	375
PA	52%	34%	9%	5%	250
LA	51%	31%	10%	7%	241
WA	48%	40%	9%	2%	254
GA	48%	34%	9%	10%	230
AK	47%	35%	12%	7%	144
Significantly Below Average					
SD	45%	38%	12%	5%	556
MD	43%	34%	13%	10%	585
NCI Average	**52%**	**34%**	**9%**	**5%**	**4,088**

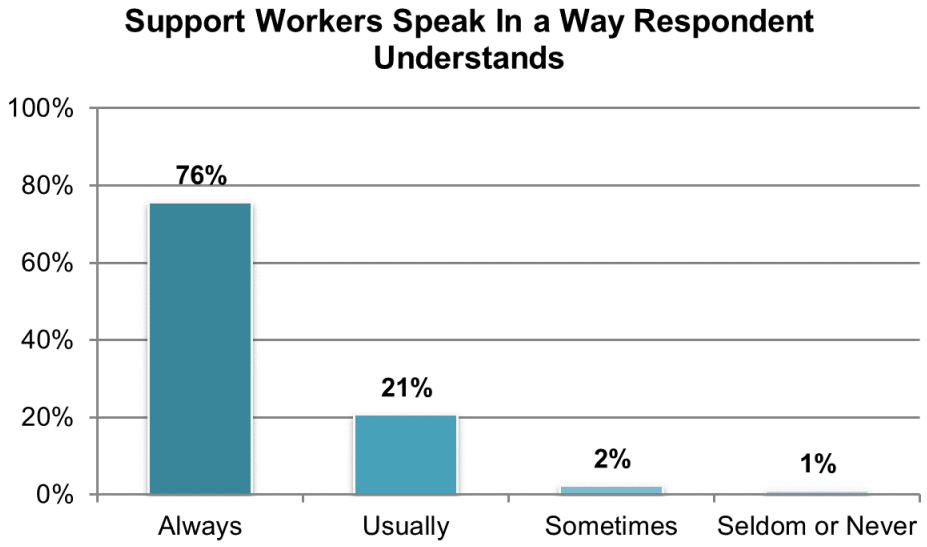


Table Q21. Do support workers speak to you in a way that you understand?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	83%	13%	3%	1%	320
MI	82%	16%	1%	1%	490
Within Average Range					
MN	81%	18%	1%	0%	388
NH	78%	18%	3%	1%	316
NC	77%	21%	2%	0%	229
UT	77%	20%	2%	1%	406
WA	76%	21%	1%	2%	357
PA	75%	21%	3%	1%	364
SD	75%	22%	3%	0%	707
VA	75%	23%	2%	0%	212
LA	73%	22%	2%	2%	339
GA	71%	22%	4%	3%	350
AK	70%	27%	2%	1%	164
Significantly Below Average					
MD	67%	26%	4%	2%	901
NCI Average	**76%**	**21%**	**2%**	**1%**	**5,543**

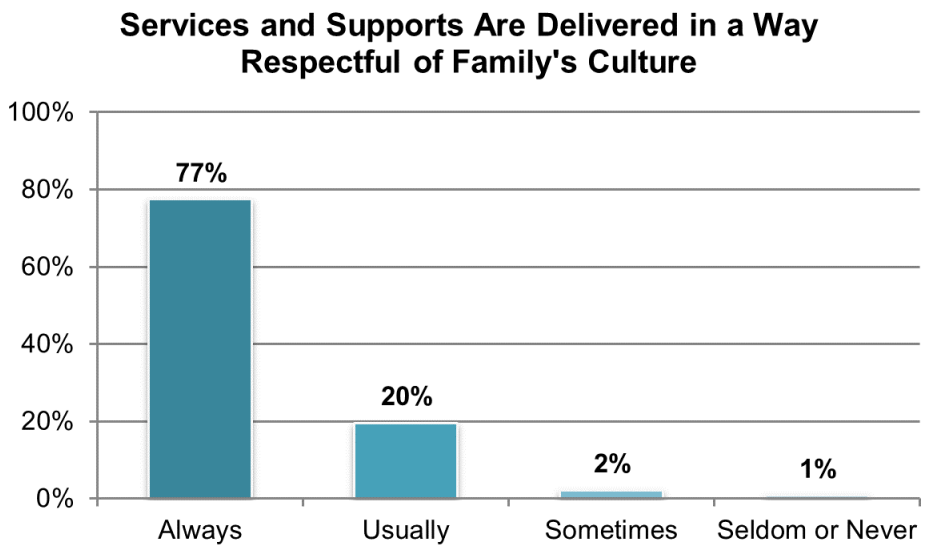


Table Q22. Are services delivered in a way that is respectful of your family's culture?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	85%	12%	2%	0%	316
MN	85%	14%	1%	0%	395
MI	84%	14%	1%	1%	483
Within Average Range					
WA	83%	15%	2%	1%	360
NH	79%	19%	1%	1%	328
PA	78%	18%	3%	1%	365
UT	78%	20%	1%	0%	406
NC	77%	21%	2%	0%	234
VA	77%	20%	3%	0%	213
SD	77%	21%	2%	1%	704
GA	73%	23%	3%	1%	350
LA	72%	24%	2%	2%	339
Significantly Below Average					
MD	69%	25%	4%	2%	931
AK	67%	29%	2%	1%	168
NCI Average	**77%**	**20%**	**2%**	**1%**	**5,592**

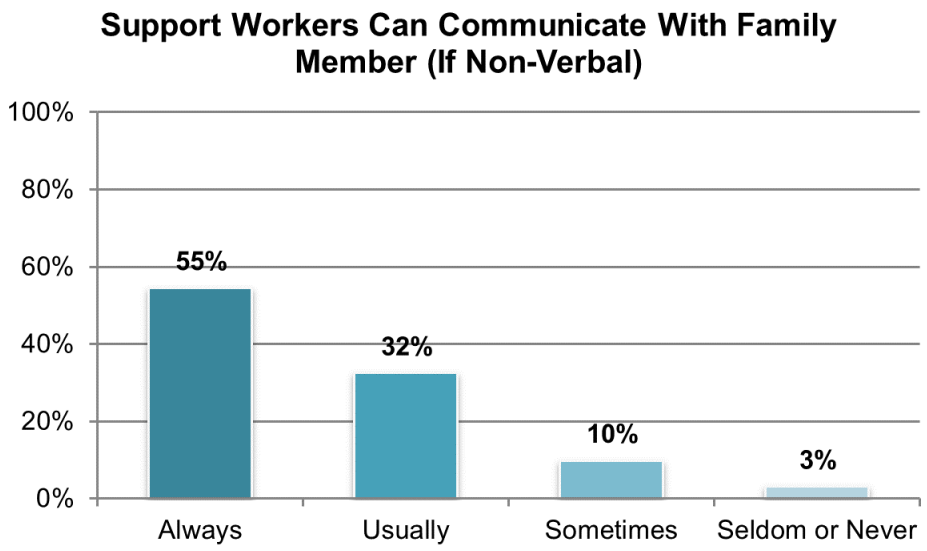


Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	75%	13%	9%	3%	77
Within Average Range					
NC	63%	24%	13%	0%	63
MN	61%	31%	6%	2%	87
SD	58%	33%	7%	2%	176
MI	58%	32%	8%	2%	126
NH	58%	32%	6%	4%	71
WA	57%	28%	13%	3%	76
LA	53%	34%	8%	4%	120
AK	50%	39%	9%	2%	46
GA	50%	35%	10%	5%	105
UT	48%	42%	8%	2%	114
PA	48%	36%	11%	5%	102
VA	42%	38%	16%	4%	55
Significantly Below Average					
MD	43%	37%	14%	6%	230
NCI Average	**55%**	**32%**	**10%**	**3%**	**1,448**

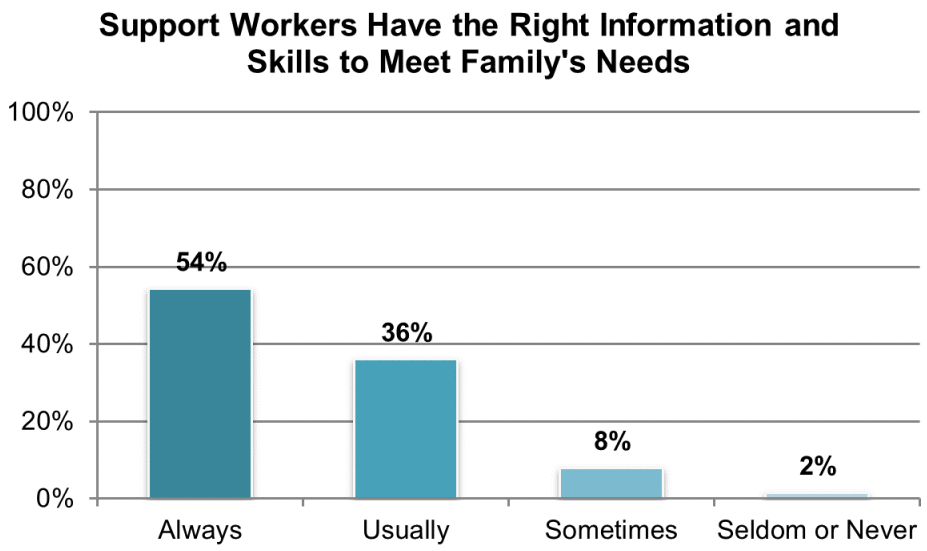


Table Q24. Do support workers have the right information and skills to meet your family's needs?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	70%	25%	5%	0%	310
MN	62%	32%	4%	1%	380
Within Average Range					
MI	59%	36%	4%	1%	478
NC	59%	38%	3%	0%	220
NH	57%	33%	7%	2%	303
GA	55%	33%	9%	3%	331
LA	53%	34%	10%	2%	322
UT	53%	41%	6%	1%	394
WA	52%	38%	8%	2%	345
PA	51%	39%	8%	2%	350
SD	51%	37%	11%	1%	675
VA	51%	39%	9%	1%	201
Significantly Below Average					
MD	47%	37%	13%	3%	871
AK	41%	42%	14%	2%	163
NCI Average	**54%**	**36%**	**8%**	**2%**	**5,343**

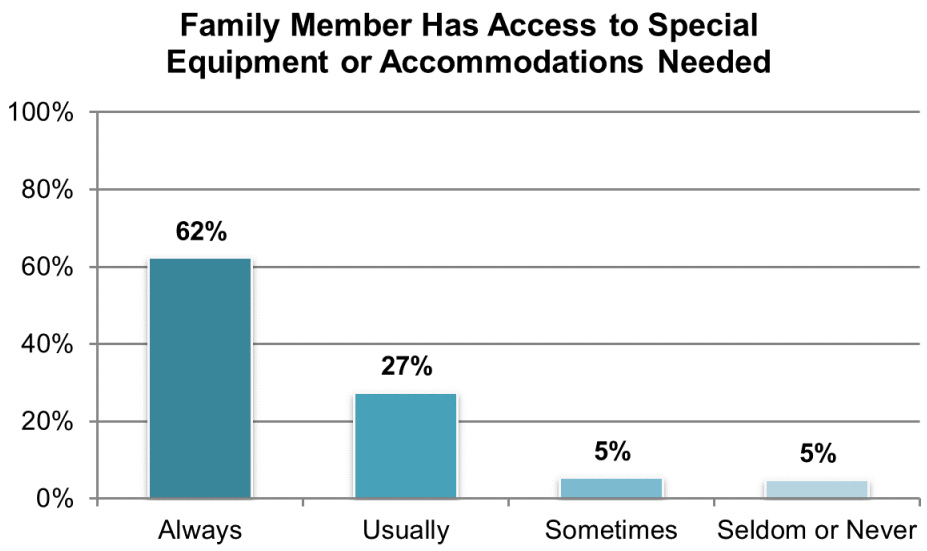


Table Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
MN	72%	22%	3%	3%	216
Within Average Range					
LA	68%	22%	7%	3%	213
PA	68%	24%	4%	4%	228
MI	68%	22%	4%	5%	289
SD	66%	26%	4%	3%	403
GA	62%	24%	5%	8%	189
VA	62%	29%	5%	4%	133
NH	62%	27%	7%	4%	176
WA	61%	26%	6%	7%	201
FL	60%	30%	6%	4%	162
NC	57%	31%	7%	5%	122
AK	57%	31%	5%	7%	84
Significantly Below Average					
MD	55%	31%	5%	9%	541
UT	52%	39%	7%	2%	227
NCI Average	**62%**	**27%**	**5%**	**5%**	**3,184**

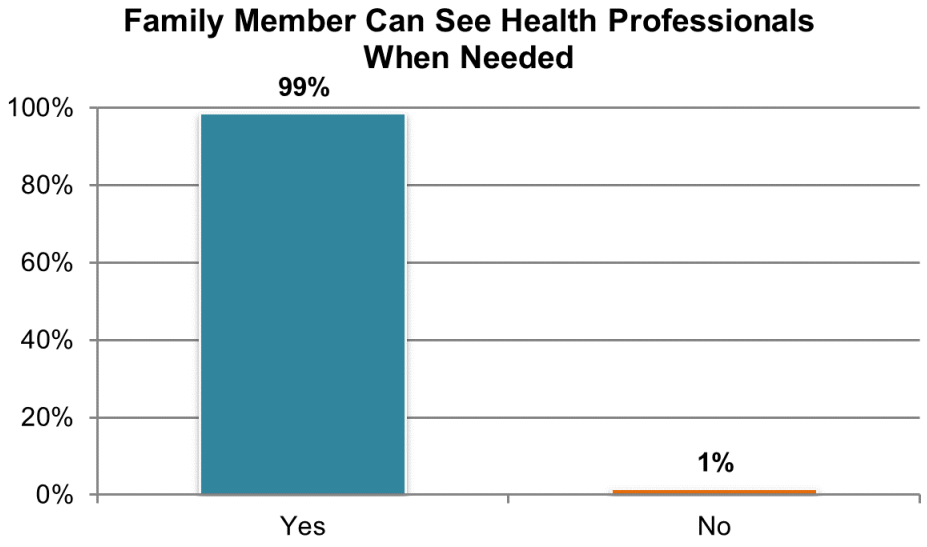


Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

State	Yes	No	N
Significantly Above Average			
SD	99%	1%	741
Within Average Range			
PA	99%	1%	396
MI	99%	1%	502
MN	99%	1%	414
GA	99%	1%	366
AK	99%	1%	174
NH	99%	1%	343
NC	99%	1%	243
VA	99%	1%	222
MD	98%	2%	993
UT	98%	2%	417
LA	98%	2%	369
WA	98%	2%	380
FL	97%	3%	318
NCI Average	**99%**	**1%**	**5,878**

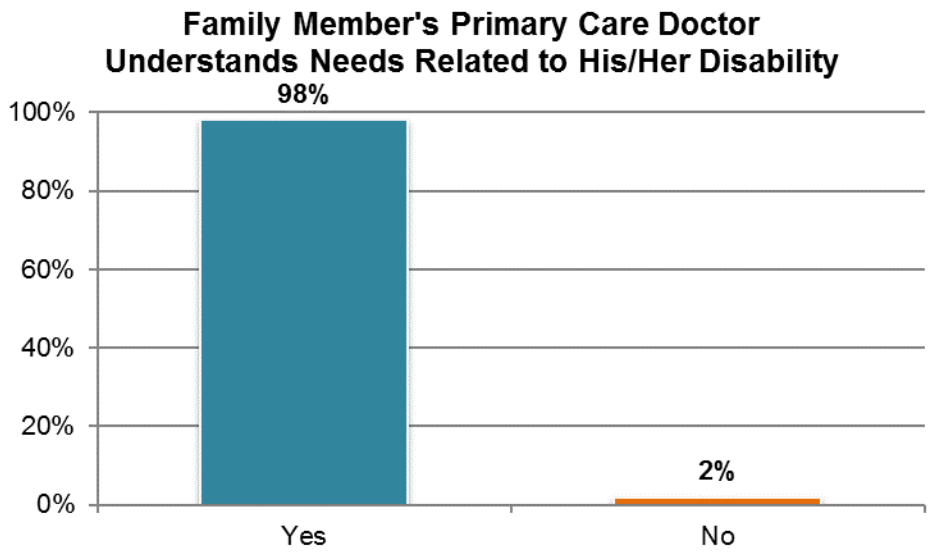


Table Q27. Does your family member's primary care doctor understand your family member's needs related to his/her disability?

State	Yes	No	N
Significantly Above Average			
NC	100%	0%	231
Within Average Range			
FL	99%	1%	295
MN	99%	1%	400
MI	99%	1%	468
LA	98%	2%	326
SD	98%	2%	676
UT	98%	2%	377
PA	98%	2%	351
GA	98%	2%	325
MD	98%	2%	899
VA	98%	2%	203
NH	98%	2%	323
WA	97%	3%	343
AK	97%	3%	166
NCI Average	**98%**	**2%**	**5,383**

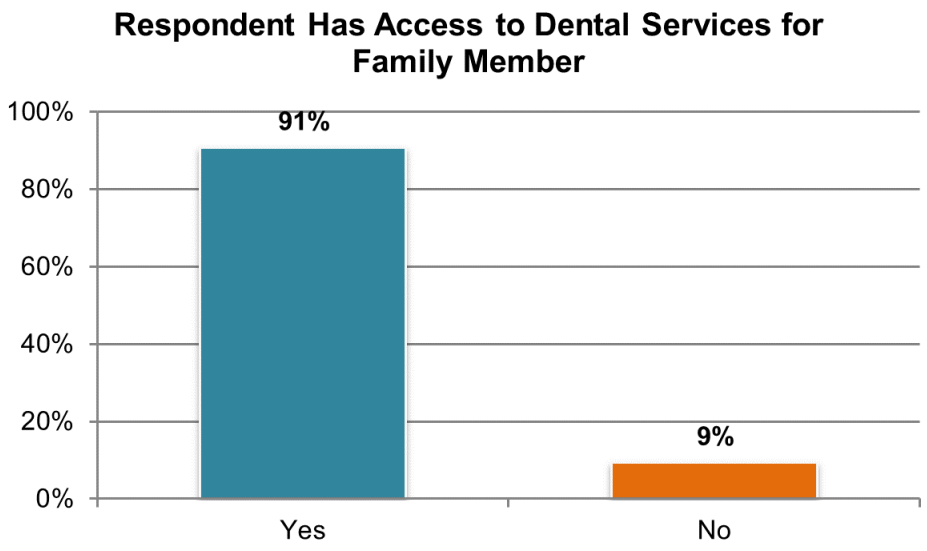


Table Q28. Do you have access to dental services for your family member?

State	Yes	No	N
Significantly Above Average			
AK	97%	3%	172
MN	97%	3%	406
NC	95%	5%	231
PA	95%	5%	377
SD	95%	5%	712
Within Average Range			
WA	91%	9%	364
MI	91%	9%	467
MD	91%	9%	945
NH	90%	10%	325
FL	90%	10%	311
UT	89%	11%	382
GA	87%	13%	337
Significantly Below Average			
VA	84%	16%	204
LA	79%	21%	341
NCI Average	**91%**	**9%**	**5,574**

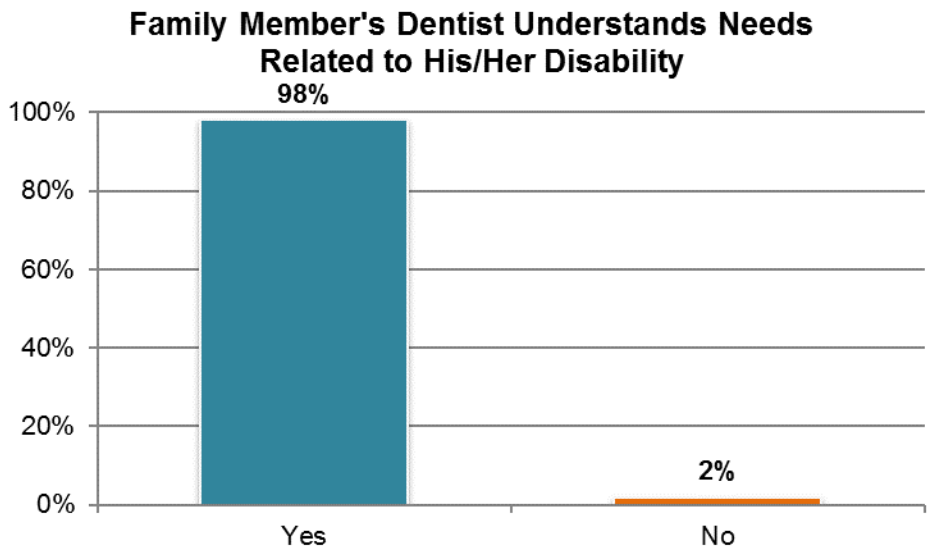


Table Q29. Does your family member's dentist understand your family member's needs related to his/her disability?

State	Yes	No	N
Within Average Range			
GA	99%	1%	259
LA	99%	1%	221
UT	99%	1%	300
MN	99%	1%	368
SD	99%	1%	605
NC	99%	1%	209
NH	99%	1%	267
FL	98%	2%	252
MI	98%	2%	369
WA	98%	2%	296
MD	98%	2%	759
PA	97%	3%	318
AK	97%	3%	155
VA	97%	3%	150
NCI Average	**98%**	**2%**	**4,528**

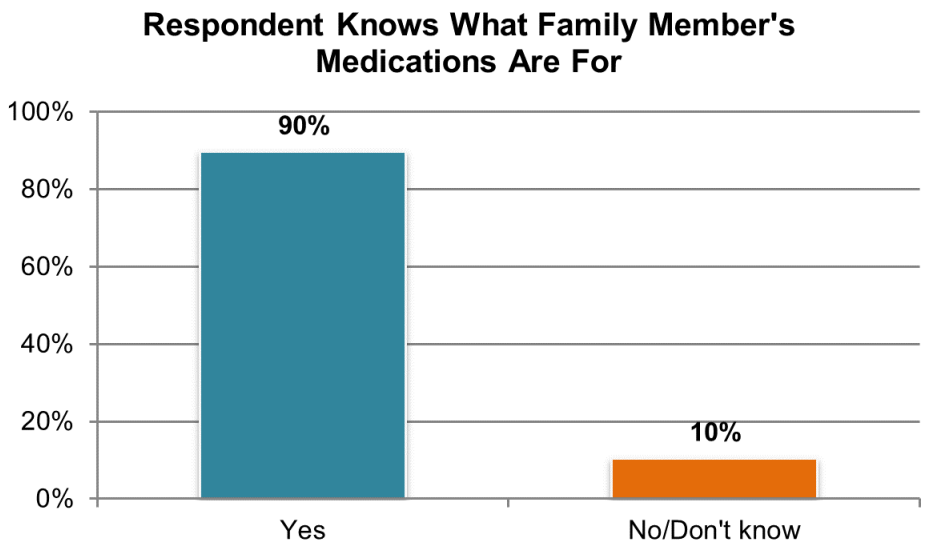


Table Q30. If your family member takes medications, do you know what they're for?[2]

State	Yes	No/Don't Know	N
Significantly Above Average			
AK	99%	1%	162
MN	94%	6%	405
NH	94%	6%	324
Within Average Range			
NC	93%	7%	241
FL	92%	8%	323
MI	91%	9%	480
VA	90%	10%	222
UT	89%	11%	408
WA	88%	12%	364
GA	86%	14%	359
PA	85%	15%	395
Significantly Below Average			
SD	86%	14%	718
MD	85%	15%	975
LA	83%	17%	367
NCI Average	**90%**	**10%**	**5,743**

[2] For this question, 'no' and 'don't know' responses were combined.

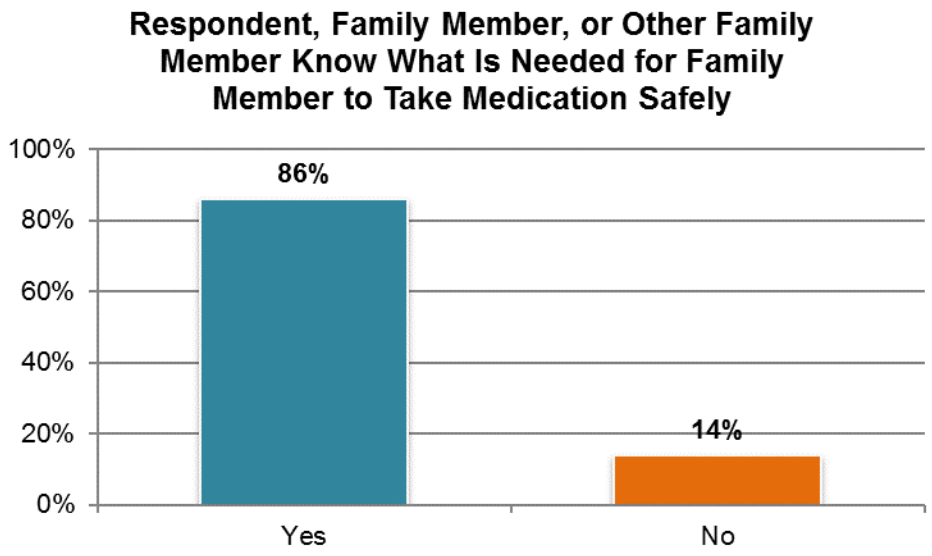


Table Q31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?[3]

State	Yes	No/Don't Know	N
Significantly Above Average			
AK	94%	6%	163
NC	92%	8%	235
MN	92%	8%	407
NH	90%	10%	326
Within Average Range			
MI	89%	11%	484
FL	88%	12%	319
UT	85%	15%	404
WA	84%	16%	368
SD	83%	17%	717
VA	83%	17%	216
GA	83%	17%	361
Significantly Below Average			
MD	82%	18%	945
LA	77%	23%	360
PA	77%	23%	381
NCI Average	**86%**	**14%**	**5,686**

[3] For this question, 'no' and 'don't know' responses were combined.

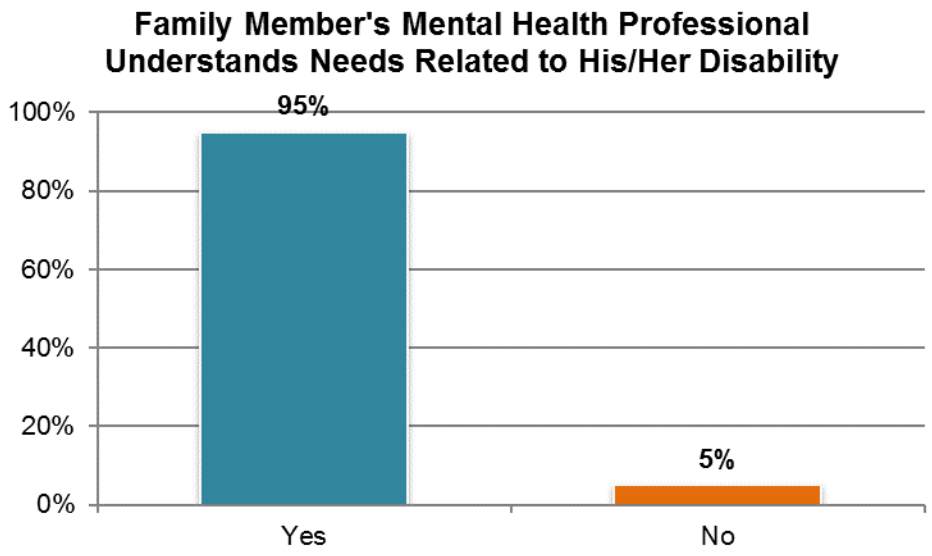


Table Q32. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability?

State	Yes	No	N
Significantly Above Average			
MN	99%	1%	245
Within Average Range			
VA	98%	2%	146
NC	97%	3%	177
AK	97%	3%	103
MI	97%	3%	373
FL	95%	5%	173
GA	95%	5%	211
PA	94%	6%	234
UT	94%	6%	227
SD	94%	6%	427
WA	94%	6%	139
NH	93%	7%	193
LA	93%	7%	217
Significantly Below Average			
MD	92%	8%	531
NCI Average	**95%**	**5%**	**3,396**

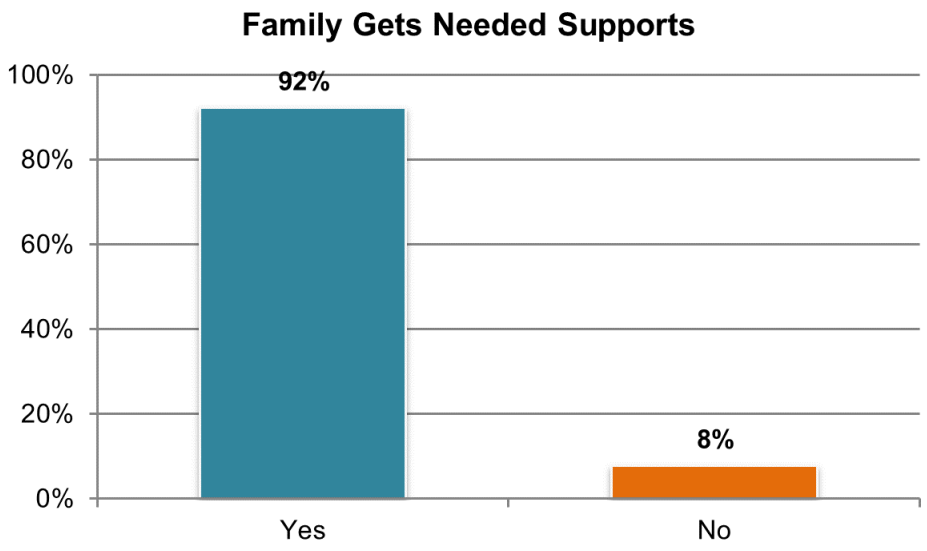


Table Q33. Does your family get the support needed?

State	Yes	No	N
Significantly Above Average			
MN	97%	3%	393
SD	95%	5%	688
Within Average Range			
MI	93%	7%	482
AK	93%	7%	167
VA	92%	8%	211
NH	92%	8%	326
NC	92%	8%	240
GA	92%	8%	324
FL	92%	8%	311
LA	92%	8%	329
UT	91%	9%	402
PA	90%	10%	364
MD	90%	10%	874
WA	88%	12%	356
NCI Average	**92%**	**8%**	**5,467**

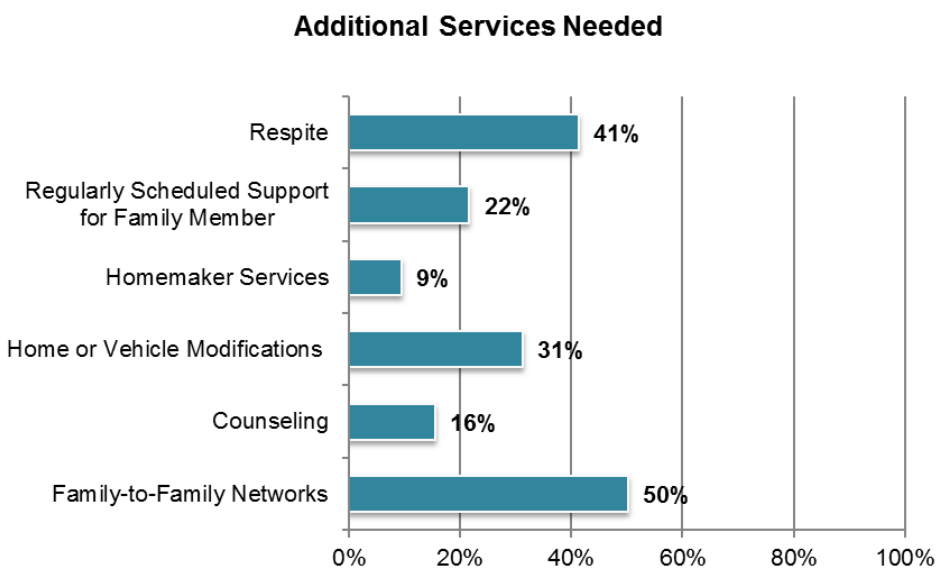


Table Q34. If no to Q33, what additional services are needed?

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-Family Networks	N
FL	24%	10%	0%	38%	5%	67%	21
GA	38%	19%	14%	29%	10%	57%	21
LA	36%	16%	16%	36%	20%	56%	25
MD	44%	14%	10%	27%	21%	46%	71
MI	50%	19%	4%	31%	31%	50%	26
NH	45%	27%	14%	41%	9%	32%	22
PA	53%	17%	7%	20%	13%	37%	30
SD	46%	42%	8%	38%	23%	35%	26
UT	39%	26%	6%	26%	16%	55%	31
WA	38%	27%	16%	27%	8%	68%	37
NCI Average	**41%**	**22%**	**9%**	**31%**	**16%**	**50%**	**310**

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: AK, MN, NC, AND VA.

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.

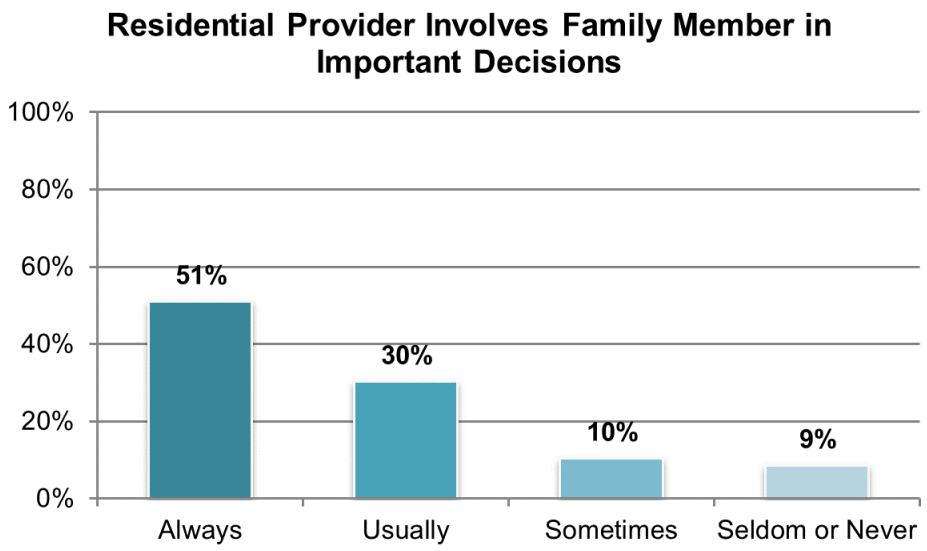


Table Q35. Does the agency providing residential services to your family member involve him/her in important decisions?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	64%	19%	9%	8%	276
MN	60%	29%	7%	4%	367
Within Average Range					
NH	56%	27%	10%	7%	296
SD	54%	34%	9%	3%	668
NC	53%	28%	11%	9%	218
LA	52%	28%	7%	13%	287
UT	51%	34%	9%	6%	375
PA	51%	25%	12%	12%	301
MI	49%	31%	12%	8%	448
GA	49%	32%	7%	12%	278
VA	47%	29%	14%	10%	180
WA	45%	37%	12%	5%	299
Significantly Below Average					
MD	46%	33%	12%	9%	768
AK	37%	38%	13%	13%	152
NCI Average	**51%**	**30%**	**10%**	**9%**	**4,913**

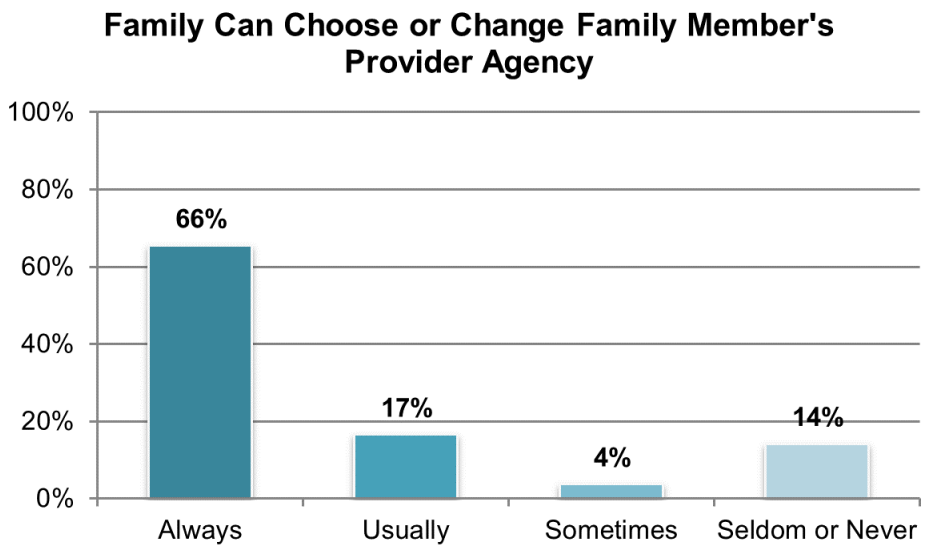


Table Q36. Can your family choose or change the agency that provides your family member's services?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
UT	79%	14%	3%	4%	333
MN	77%	14%	2%	7%	308
FL	76%	13%	3%	7%	268
Within Average Range					
LA	68%	15%	2%	14%	241
GA	65%	20%	3%	13%	246
AK	65%	24%	3%	8%	151
PA	65%	11%	7%	18%	198
NH	63%	15%	2%	21%	198
MI	62%	17%	3%	17%	323
NC	61%	19%	6%	14%	175
WA	60%	21%	3%	16%	226
VA	59%	15%	4%	22%	128
Significantly Below Average					
MD	60%	16%	6%	18%	587
SD	56%	18%	7%	19%	436
NCI Average	**66%**	**17%**	**4%**	**14%**	**3,818**

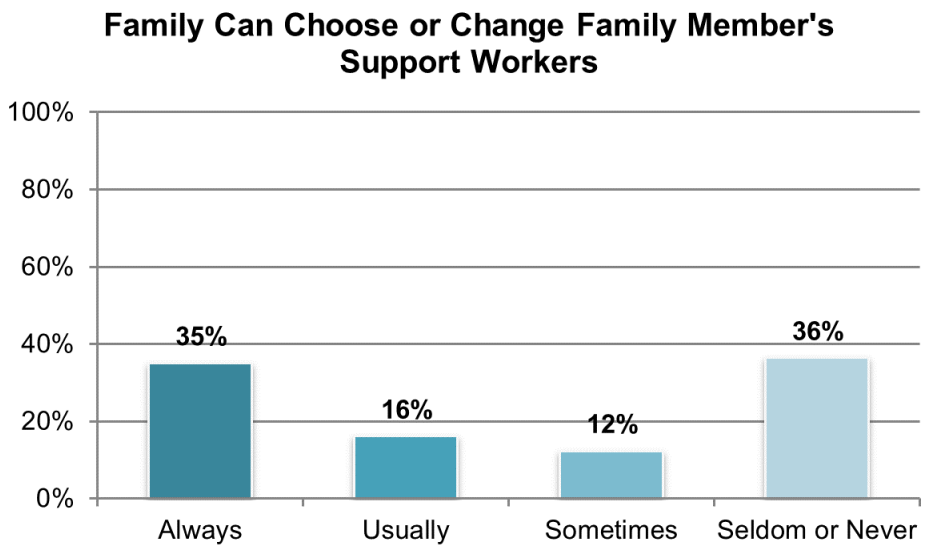


Table Q37. Can your family choose or change your family member's support workers?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	55%	10%	9%	25%	260
NH	48%	19%	10%	23%	234
Within Average Range					
NC	39%	18%	12%	31%	175
GA	39%	14%	10%	36%	231
LA	39%	16%	10%	35%	232
MI	37%	23%	8%	32%	341
MN	36%	16%	13%	36%	296
UT	36%	22%	13%	30%	300
WA	31%	19%	12%	37%	233
AK	29%	21%	21%	29%	145
Significantly Below Average					
PA	27%	9%	16%	48%	223
MD	26%	13%	13%	48%	616
VA	25%	7%	10%	58%	129
SD	24%	18%	16%	41%	422
NCI Average	**35%**	**16%**	**12%**	**36%**	**3,837**

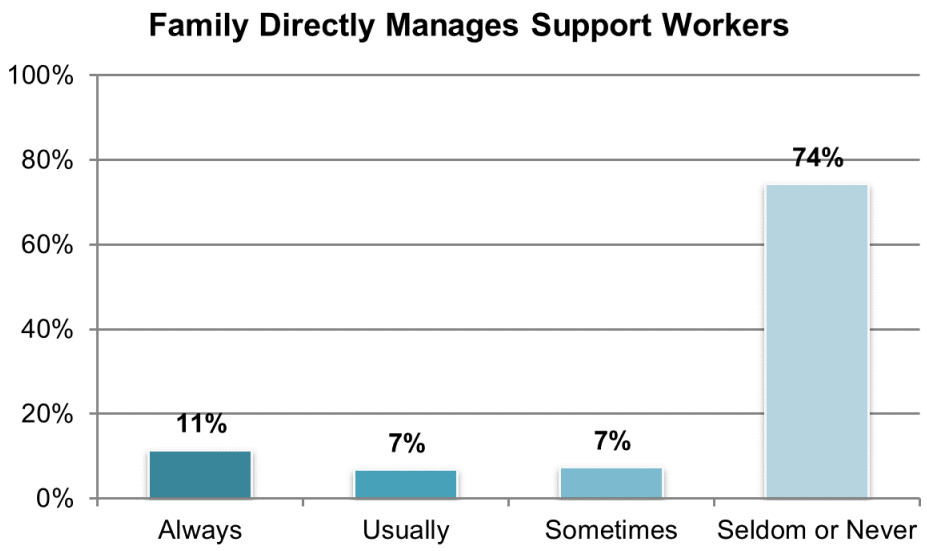


Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	25%	8%	9%	57%	281
Within Average Range					
NH	15%	11%	8%	66%	264
MN	14%	5%	8%	73%	331
WA	14%	7%	6%	74%	296
NC	13%	7%	9%	71%	195
GA	11%	5%	5%	80%	298
LA	11%	7%	6%	76%	272
MI	10%	8%	8%	73%	402
AK	9%	12%	9%	70%	162
VA	9%	4%	6%	80%	164
MD	9%	6%	6%	79%	781
Significantly Below Average					
UT	7%	6%	9%	78%	360
SD	7%	6%	7%	80%	569
PA	7%	4%	5%	84%	293
NCI Average	**11%**	**7%**	**7%**	**74%**	**4,668**

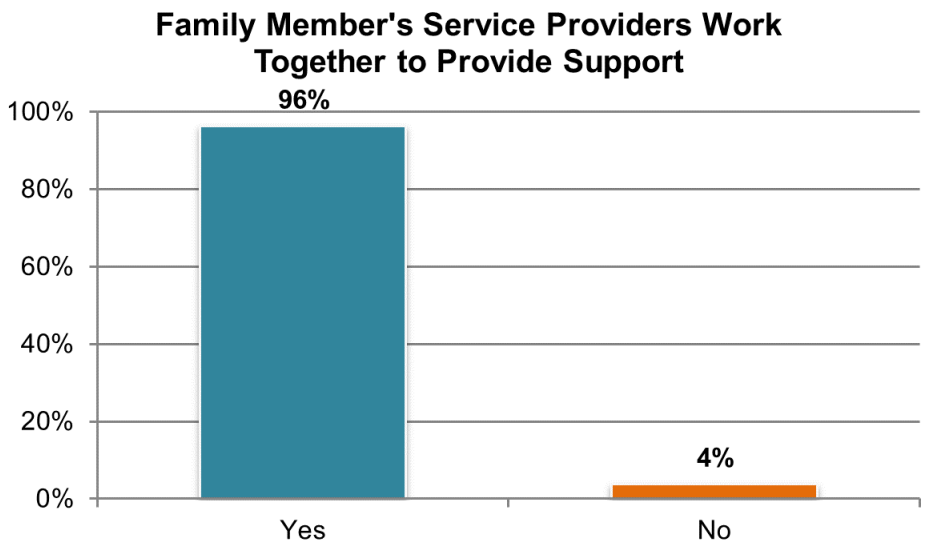


Table Q39. Do service providers for your family member work together to provide support?

State	Yes	No	N
Significantly Above Average			
NC	100%	0%	179
MN	99%	1%	340
Within Average Range			
VA	98%	2%	163
SD	97%	3%	555
AK	97%	3%	136
MI	97%	3%	362
FL	97%	3%	255
UT	97%	3%	343
PA	96%	4%	255
LA	95%	5%	222
NH	95%	5%	244
GA	94%	6%	269
WA	94%	6%	255
Significantly Below Average			
MD	92%	8%	682
NCI Average	**96%**	**4%**	**4,260**

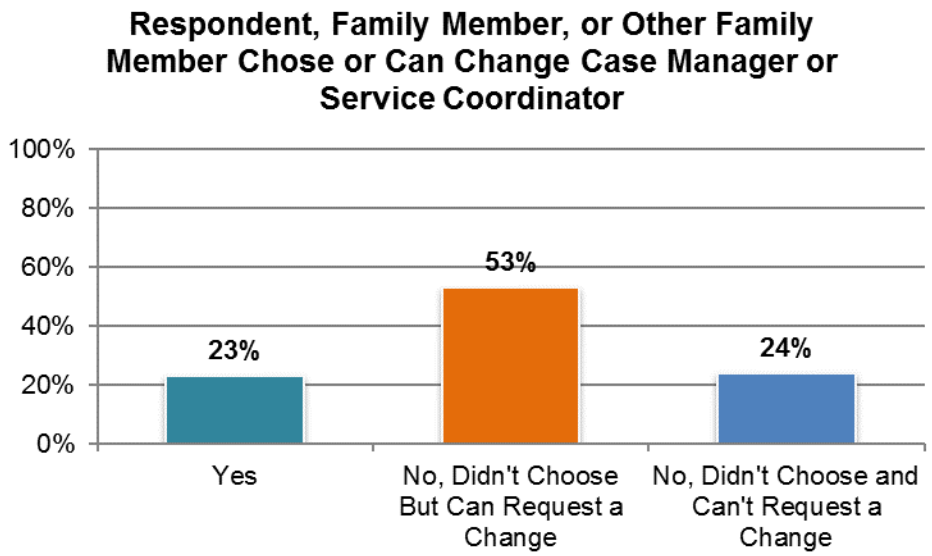


Table Q40. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

State	Yes, chose	No, did not choose but can change	No, did not choose and cannot change	N
Significantly Above Average				
AK	70%	23%	7%	167
FL	69%	27%	4%	301
UT	60%	30%	10%	363
Within Average Range				
LA	23%	40%	37%	252
Significantly Below Average				
MD	18%	53%	29%	792
NH	16%	67%	17%	303
MI	11%	62%	27%	416
PA	11%	64%	25%	281
GA	10%	59%	31%	286
NC	9%	62%	29%	196
MN	8%	68%	23%	342
VA	7%	60%	33%	180
WA	6%	58%	37%	289
SD	5%	62%	33%	592
NCI Average	**23%**	**53%**	**24%**	**4,760**

Involvement in the Community

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

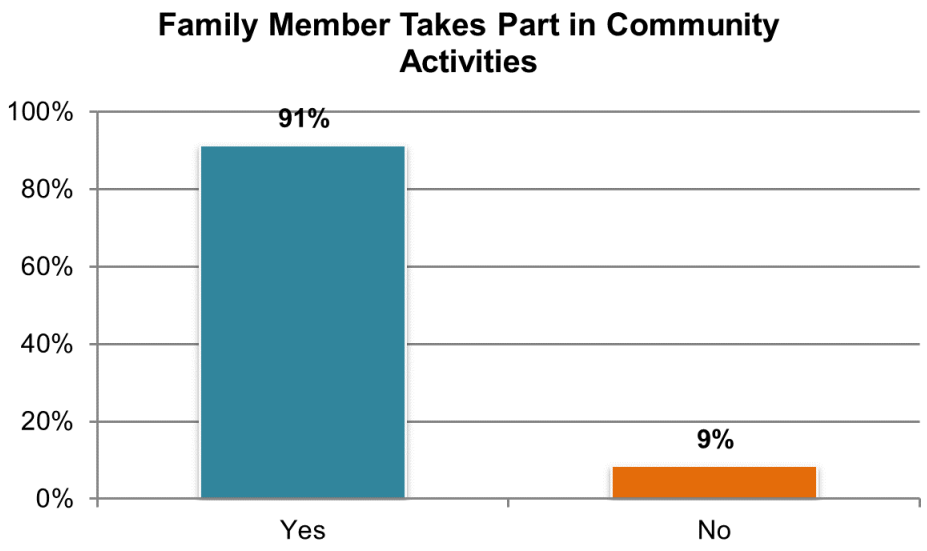


Table Q41. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

State	Yes	No	N
Significantly Above Average			
MN	96%	4%	413
GA	95%	5%	351
Within Average Range			
NC	95%	5%	244
SD	94%	6%	726
FL	94%	6%	319
MI	92%	8%	503
PA	92%	8%	391
VA	91%	9%	220
NH	91%	9%	345
UT	91%	9%	414
AK	90%	10%	168
MD	90%	10%	974
WA	87%	13%	380
Significantly Below Average			
LA	84%	16%	341
NCI Average	**91%**	**9%**	**5,789**

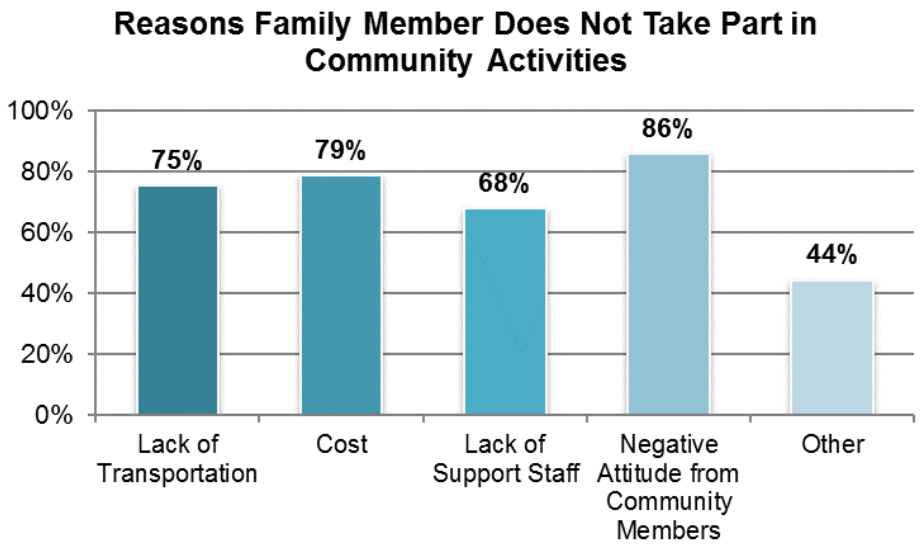


Table Q42. If no to Q41, why does your family member not take part in community activities?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitude from Community Members	Other	N
LA	82%	80%	84%	92%	43%	49
MD	78%	81%	68%	86%	51%	77
MI	85%	85%	61%	88%	42%	33
NH	70%	74%	65%	87%	52%	23
PA	89%	93%	93%	86%	18%	28
SD	71%	71%	66%	79%	61%	38
UT	58%	69%	39%	81%	61%	36
WA	70%	80%	68%	91%	27%	44
NCI Average	**75%**	**79%**	**68%**	**86%**	**44%**	**328**

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: AK, FL, GA, MN, NC, AND VA.

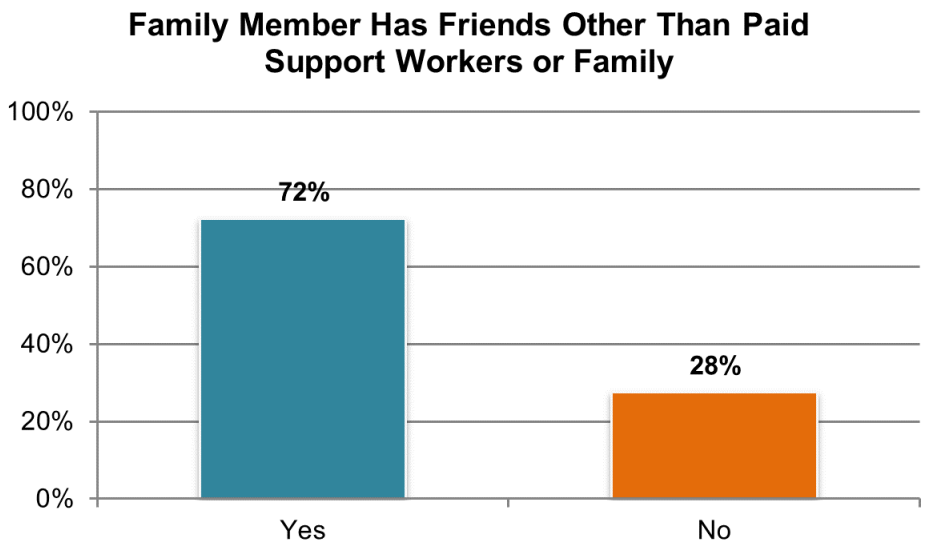


Table Q43. Does your family member have friends other than paid support workers or family?

State	Yes	No	N
Significantly Above Average			
SD	83%	17%	674
MN	83%	17%	394
Within Average Range			
GA	77%	23%	324
NH	76%	24%	322
FL	75%	25%	308
NC	73%	27%	218
AK	73%	27%	161
VA	72%	28%	206
WA	71%	29%	357
MD	69%	31%	929
UT	66%	34%	383
Significantly Below Average			
MI	66%	34%	463
PA	66%	34%	348
LA	64%	36%	340
NCI Average	**72%**	**28%**	**5,427**

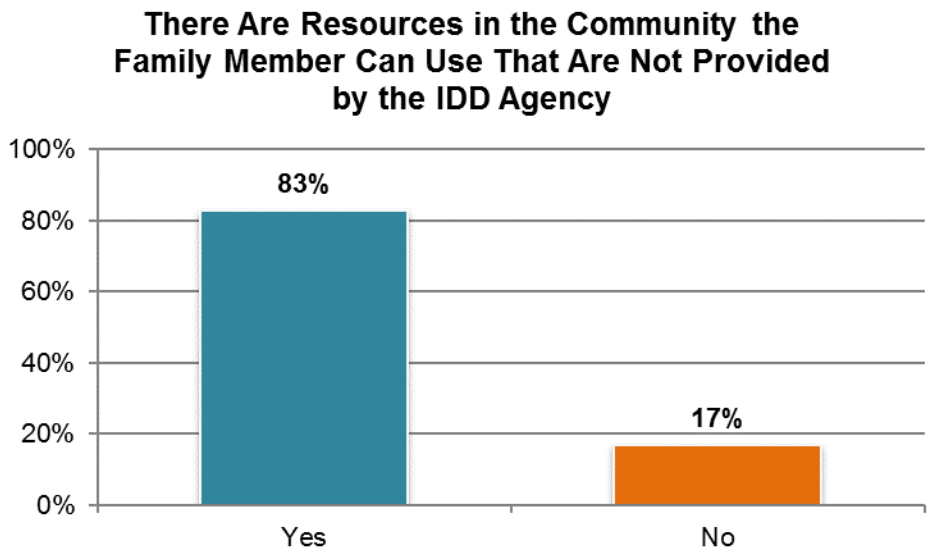


Table Q44. In your community, are there resources that your family can use that are not provided by the I/DD agency?

State	Yes	No	N
Significantly Above Average			
MN	95%	5%	354
WA	95%	5%	267
Within Average Range			
FL	87%	13%	241
NH	86%	14%	250
SD	85%	15%	541
GA	84%	16%	228
UT	84%	16%	318
MI	82%	18%	375
NC	82%	18%	186
AK	81%	19%	143
PA	80%	20%	237
VA	77%	23%	142
Significantly Below Average			
MD	75%	25%	720
LA	66%	34%	226
NCI Average	**83%**	**17%**	**4,228**

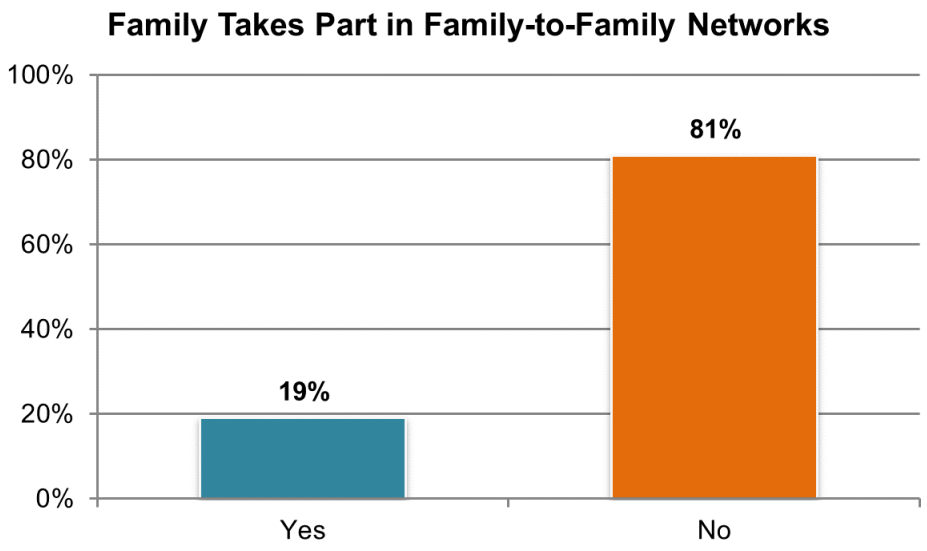


Table Q45. Does your family take part in any family-to-family networks in your community?

State	Yes	No	N
Significantly Above Average			
FL	26%	74%	274
LA	26%	74%	291
Within Average Range			
MD	22%	78%	846
NC	21%	79%	190
SD	21%	79%	575
GA	20%	80%	282
MN	19%	81%	344
VA	19%	81%	180
NH	17%	83%	288
AK	16%	84%	140
WA	16%	84%	320
PA	16%	84%	317
Significantly Below Average			
MI	14%	86%	411
UT	13%	87%	343
NCI Average	**19%**	**81%**	**4,801**

Satisfaction With Services and Supports

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

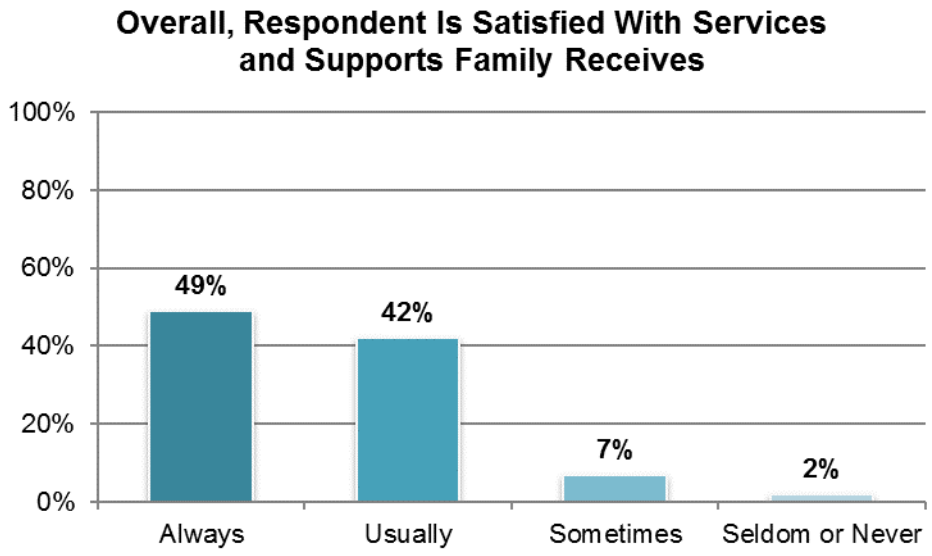


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
FL	57%	36%	6%	1%	326
Within Average Range					
NC	55%	38%	6%	0%	247
MN	53%	42%	4%	1%	412
VA	53%	41%	5%	1%	227
PA	52%	39%	6%	3%	400
NH	51%	39%	7%	3%	354
UT	50%	46%	3%	1%	415
LA	49%	40%	9%	2%	382
MI	49%	43%	6%	2%	516
SD	49%	41%	9%	1%	752
GA	46%	41%	11%	2%	370
WA	44%	47%	8%	1%	379
Significantly Below Average					
MD	38%	48%	11%	4%	997
AK	35%	55%	8%	2%	169
NCI Average	**49%**	**42%**	**7%**	**2%**	**5,946**

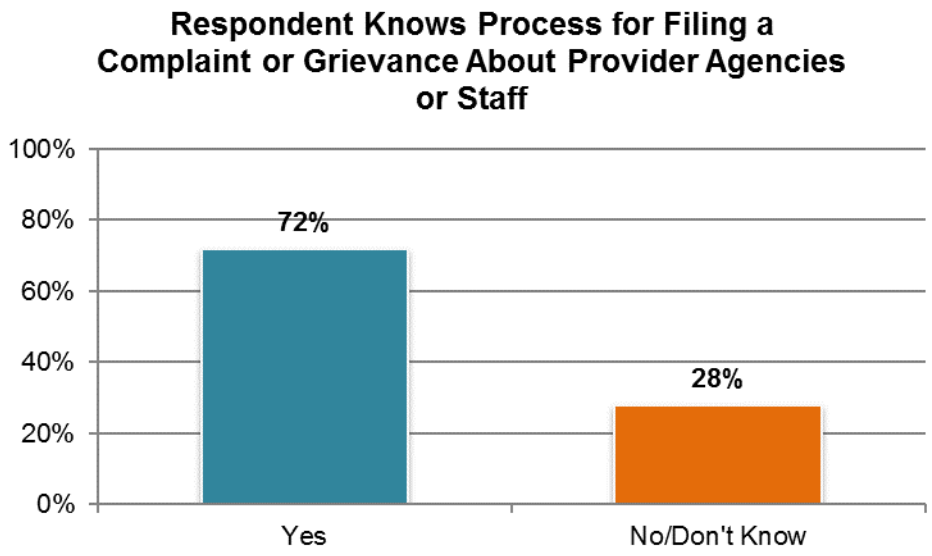


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?[4]

State	Yes	No/Don't Know	N
Significantly Above Average			
MI	86%	14%	513
MN	83%	17%	412
AK	81%	19%	168
FL	81%	19%	330
NH	78%	22%	349
Within Average Range			
NC	78%	22%	245
SD	76%	24%	735
LA	70%	30%	383
VA	69%	31%	227
WA	68%	32%	384
UT	67%	33%	416
Significantly Below Average			
PA	61%	39%	402
GA	60%	40%	374
MD	49%	51%	1,016
NCI Average	**72%**	**28%**	**5,954**

[4] For this question, 'no' and 'don't know' responses were combined.

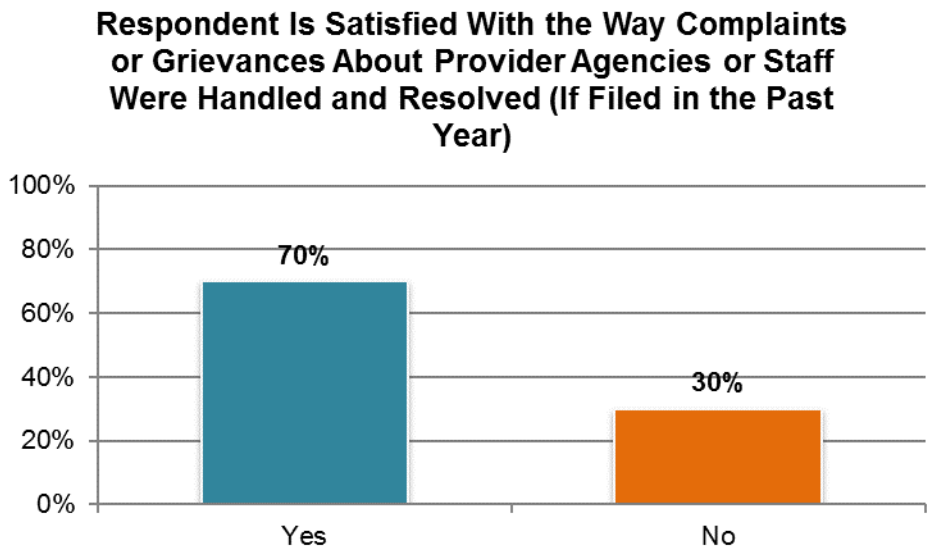


Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

State	Yes	No	N
Significantly Above Average			
NC	86%	14%	43
SD	81%	19%	91
Within Average Range			
VA	81%	19%	32
LA	74%	26%	89
MN	73%	27%	52
FL	73%	27%	44
UT	72%	28%	43
MI	71%	29%	120
NH	70%	30%	53
PA	65%	35%	54
GA	62%	38%	71
AK	60%	40%	25
WA	57%	43%	30
Significantly Below Average			
MD	59%	41%	173
NCI Average	**70%**	**30%**	**920**

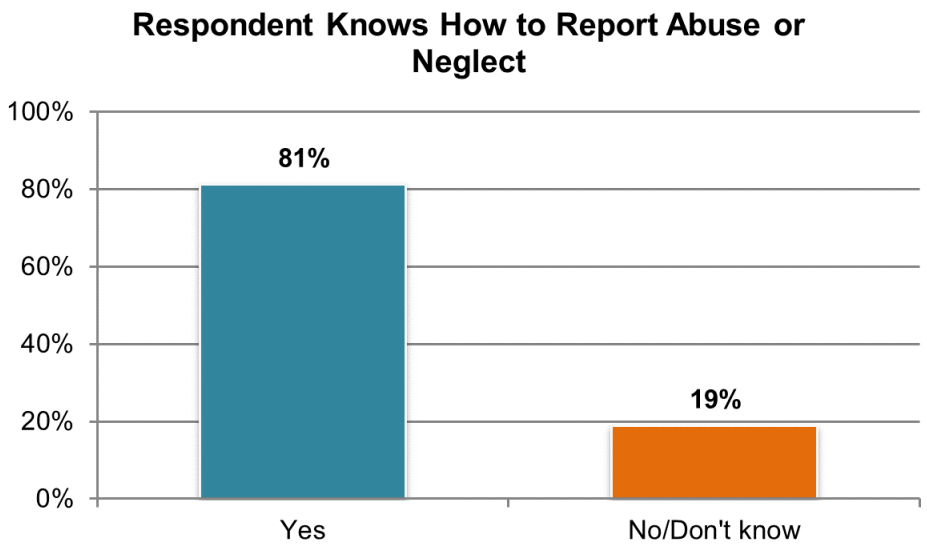


Table Q49. Do you know how to report abuse or neglect related to your family member?[5]

State	Yes	No/Don't Know	N
Significantly Above Average			
AK	91%	9%	168
MN	90%	10%	415
MI	89%	11%	512
FL	88%	12%	334
SD	85%	15%	744
Within Average Range			
NC	85%	15%	246
LA	82%	18%	382
NH	81%	19%	351
VA	81%	19%	222
WA	78%	22%	387
UT	78%	22%	414
Significantly Below Average			
GA	72%	28%	375
PA	71%	29%	407
MD	65%	35%	1,031
NCI Average	**81%**	**19%**	**5,988**

[5] For this question, 'no' and 'don't know' responses were combined.

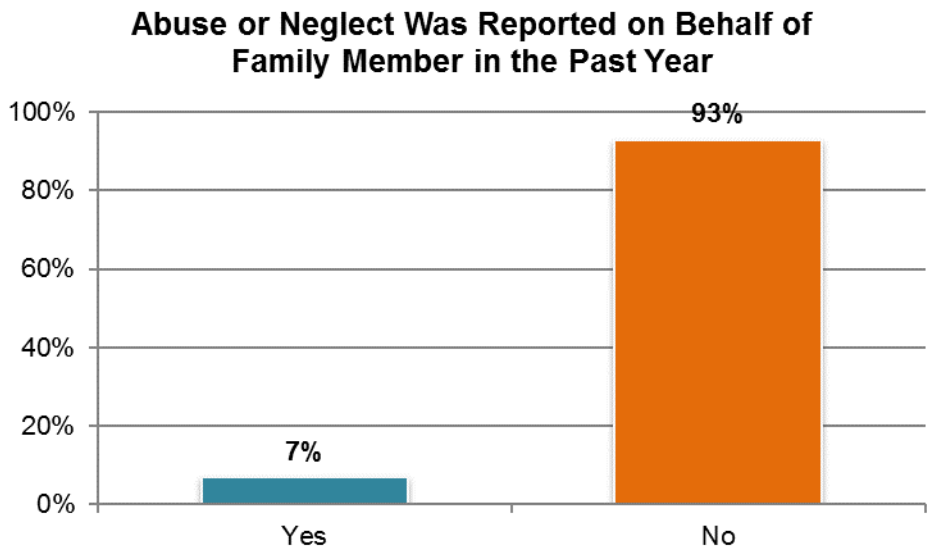


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

State	Yes	No	N
Within Average Range			
MI	10%	90%	482
NH	10%	90%	325
LA	9%	91%	354
MD	9%	91%	928
VA	8%	92%	214
AK	8%	93%	160
PA	7%	93%	363
MN	7%	93%	393
NC	7%	93%	230
FL	6%	94%	294
GA	6%	94%	360
UT	6%	94%	377
WA	5%	95%	353
Significantly Below Average			
SD	4%	96%	707
NCI Average	**7%**	**93%**	**5,540**

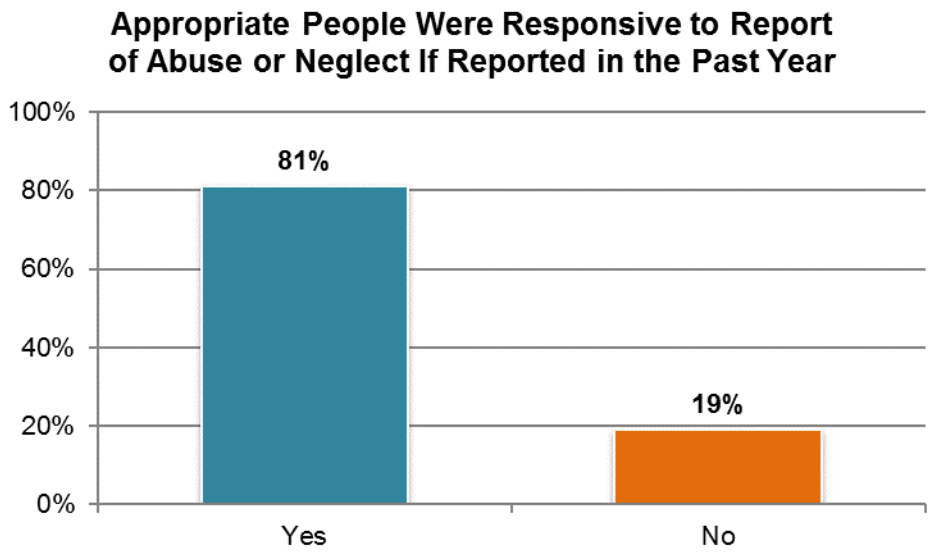


Table Q51. If yes to Q50, did the appropriate people respond to the report?

State	Yes	No	N
Within Average Range			
MN	90%	10%	20
MI	86%	14%	37
PA	80%	20%	20
NH	79%	21%	28
MD	69%	31%	58
NCI Average	**81%**	**19%**	**163**

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: AK, FL, GA, LA, NC, SD, UT, VA, AND WA.

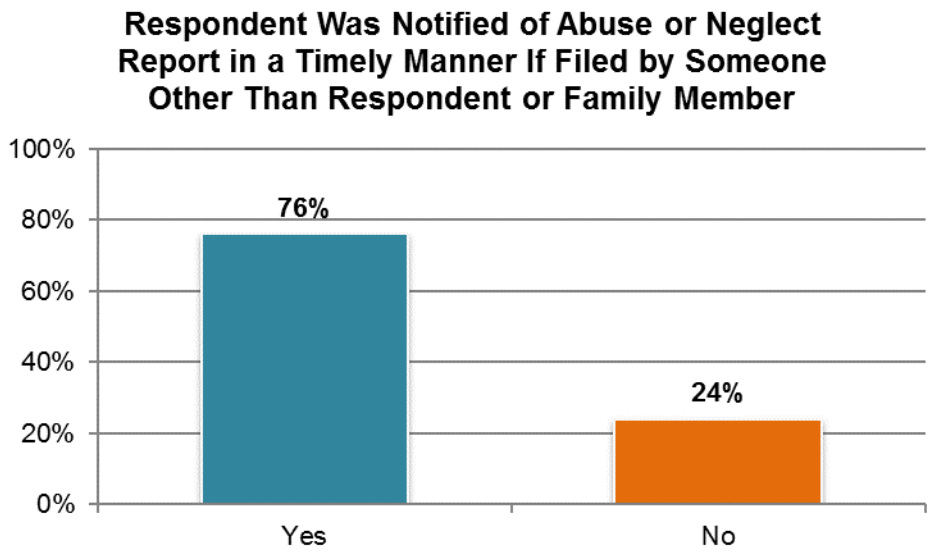


Table Q52. If Yes to Q50, if someone other than you or another family member reported abuse or neglect in the past year, were you notified of the report in a timely manner?

State	Yes	No	N
Within Average Range			
NH	87%	13%	23
MI	84%	16%	32
MD	69%	31%	45
LA	65%	35%	20
NCI Average	**76%**	**24%**	**120**

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATES WERE NOT INCLUDED IN THIS ANALYSIS: AK, FL, GA, MN, NC, PA, SD, UT, VA, AND WA.

Family Outcomes

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

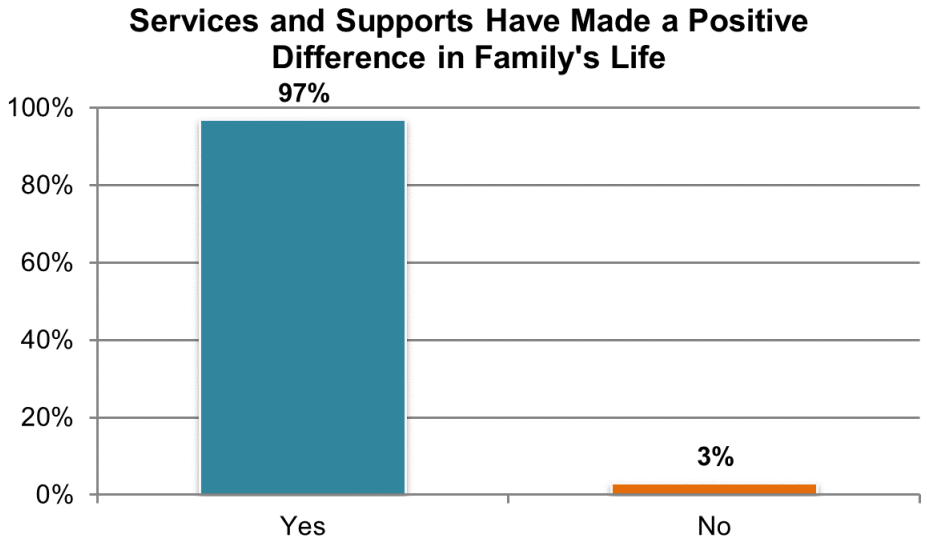


Table Q53. Do you feel that services and supports have made a positive difference in the life of your family?

State	Yes	No	N
Significantly Above Average			
UT	99%	1%	414
MN	99%	1%	403
WA	99%	1%	367
Within Average Range			
NC	98%	2%	236
AK	98%	2%	165
NH	97%	3%	344
FL	97%	3%	317
GA	97%	3%	342
MI	97%	3%	487
PA	96%	4%	370
SD	96%	4%	714
VA	95%	5%	222
LA	94%	6%	358
Significantly Below Average			
MD	94%	6%	931
NCI Average	**97%**	**3%**	**5,670**

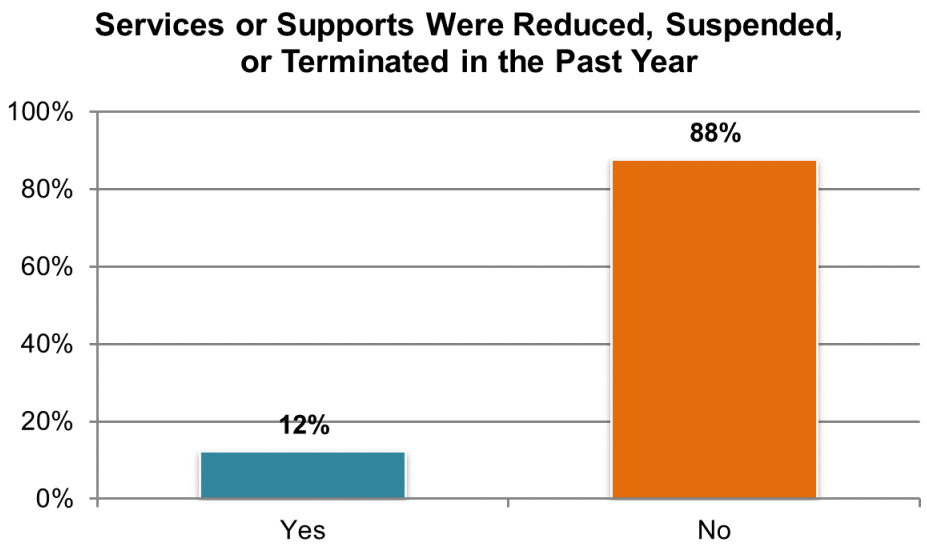


Table Q54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?

State	Yes	No	N
Significantly Above Average			
FL	18%	82%	288
MI	18%	82%	449
Within Average Range			
AK	19%	81%	165
NC	16%	84%	219
LA	15%	85%	316
NH	13%	87%	327
MD	12%	88%	858
PA	11%	89%	348
WA	10%	90%	340
GA	9%	91%	310
Significantly Below Average			
SD	8%	92%	631
UT	8%	92%	367
MN	8%	92%	389
VA	5%	95%	203
NCI Average	**12%**	**88%**	**5,210**

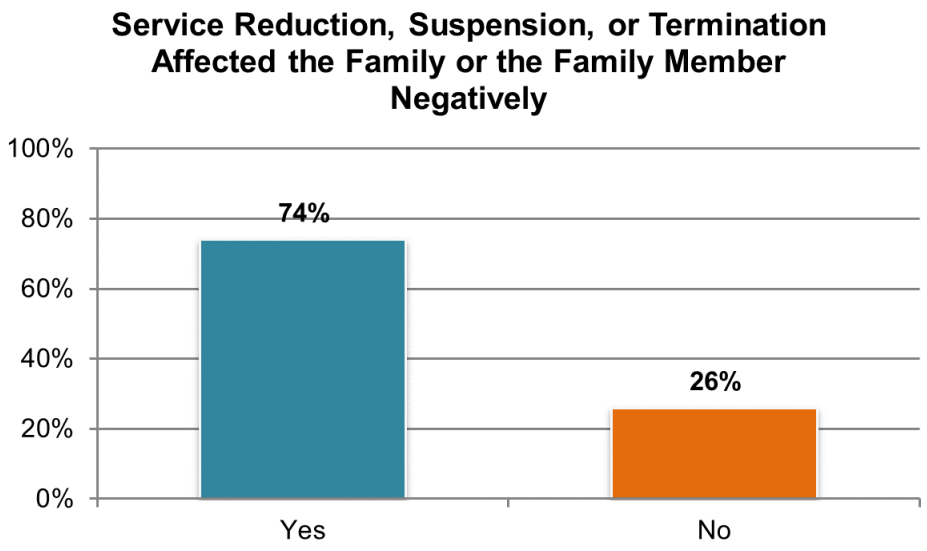


Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?

State	Yes	No	N
Within Average Range			
MD	83%	18%	80
LA	78%	22%	37
GA	78%	22%	23
NC	77%	23%	31
UT	76%	24%	25
AK	75%	25%	28
NH	75%	25%	36
FL	74%	26%	43
WA	74%	26%	31
SD	72%	28%	43
PA	69%	31%	29
MI	67%	33%	72
MN	64%	36%	22
NCI Average	**74%**	**26%**	**500**

DUE TO LOW RESPONSE RATE (<20), THE FOLLOWING STATE WAS NOT INCLUDED IN THIS ANALYSIS: VA.

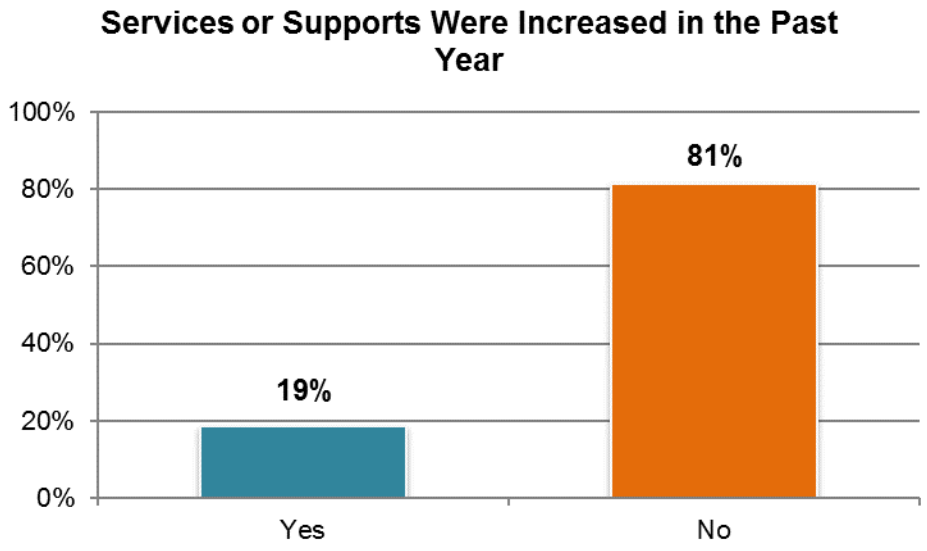


Table Q56. Have the services or supports that your family member received been increased in the past year?

State	Yes	No	N
Significantly Above Average			
FL	26%	74%	269
Within Average Range			
VA	27%	73%	166
SD	22%	78%	538
WA	21%	79%	284
PA	21%	79%	266
LA	20%	80%	273
GA	18%	82%	249
UT	17%	83%	309
MI	17%	83%	426
NH	16%	84%	291
MD	15%	85%	746
AK	14%	86%	158
NC	14%	86%	192
Significantly Below Average			
MN	13%	87%	365
NCI Average	**19%**	**81%**	**4,532**

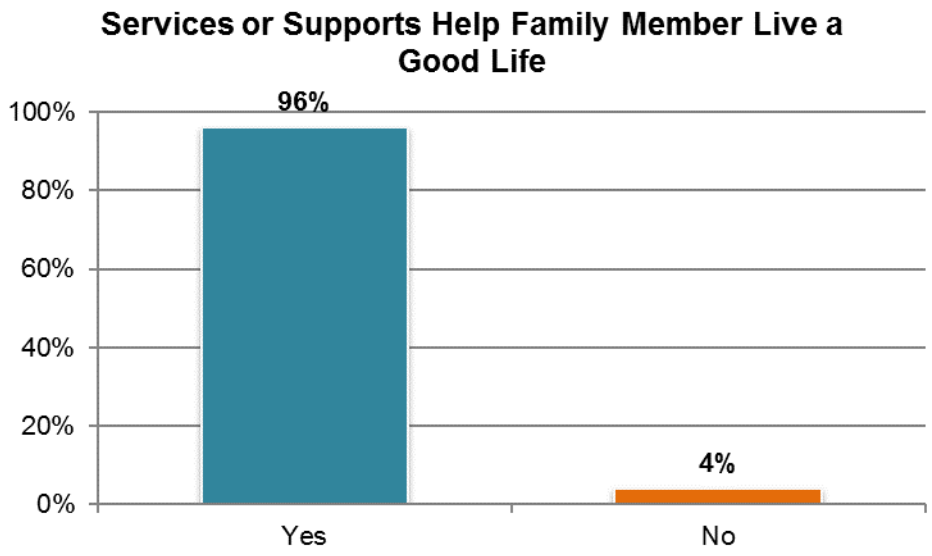


Table Q57. Are services and supports helping your family member to live a good life?

State	Yes	No	N
Within Average Range			
NC	98%	2%	231
WA	98%	2%	361
UT	98%	2%	402
MI	97%	3%	479
SD	97%	3%	689
VA	97%	3%	212
AK	97%	3%	164
MN	97%	3%	398
FL	97%	3%	326
GA	96%	4%	341
PA	96%	4%	361
LA	95%	5%	350
NH	94%	6%	337
Significantly Below Average			
MD	93%	7%	910
NCI Average	**96%**	**4%**	**5,561**

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

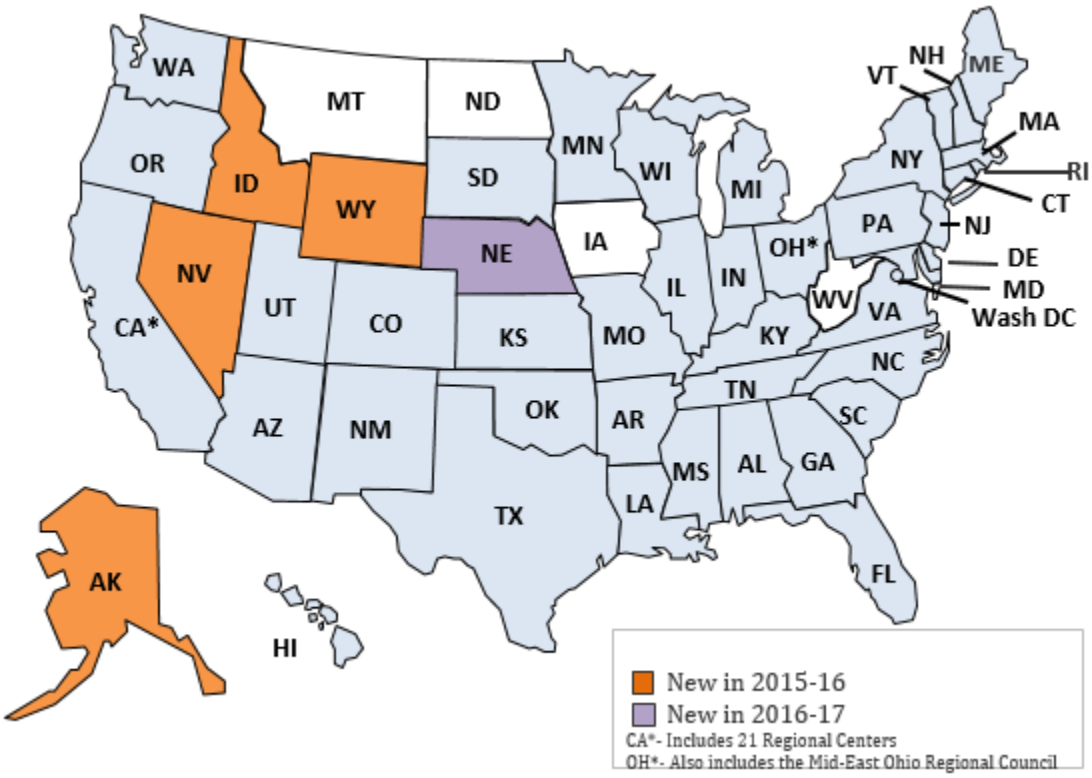
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

Since the initial field test, NCI 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 2015-16 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.

Figure 1. NCI State Participation



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

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

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

III. Methodology

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

Sampling & Administration

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

1. Had an adult individual with a developmental disability NOT living in the family home; and
2. Received at least one direct service or support other than service coordination.

All states mailed out a paper survey to families selected in their sample. A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.

Data Entry and Analysis

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

Data were considered invalid, and therefore excluded, on the following two bases:

1. The respondent indicated the individual with a developmental disability lived in the family home.
2. Demographic information was entered into the file but no survey questions were answered.

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

Response Rates

In 2015-16, 14 states administered the Family/Guardian Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The table below shows the number of surveys each state mailed, usable surveys returned, and the response rates.

Figure 3. Family/Guardian Survey: State Response Rates

State	Number Eligible to Be Drawn Into the Sample	Surveys Mailed	Usable Surveys Returned	Response Rate	Margin of Error
AK	852	852	178	21%	6.54%
FL	13676	1700	340	20%	5.25%
GA	5477	2500	396	16%	4.74%
LA	7058	2000	397	20%	4.78%
MD	7971	7800	1057	14%	2.81%
MI	34509	2000	525	26%	4.24%
MN	29000	2000	421	21%	4.74%
NC	5750	920	252	27%	6.04%
NH	1852	1852	360	19%	4.64%
PA	4732	1285	419	33%	4.57%
SD	2082	2082	767	37%	2.81%
UT	2200	1000	429	43%	4.25%
VA	982	726	235	32%	5.58%
WA	9000	1450	397	27%	4.81%
Total			**6,173**		

IV. Appendix A

Family Guardian Survey Changes from 2014-15 to 2015-16

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
Information About Family Member								
A	Does your family member with a disability live at home with you?	A	Does this person live at home with you?	No change	NA	x	x	x
B	Where does your family member live?	B	Where does this person live?	Modified Added/changed response categories: Added text: "state run or other institution" for specialized facility Added “homeless” Now include open text field for “other”	NA	-	x	-
C	Does your family member live in an urban or rural area?			New question This could be important for states to drill down by outcomes based on the person's setting	NA	x	x	x
D	How old is your family member with a disability?	C	How old is your family member with a disability?	No change	NA	x	x	x
E	What is the gender of your family member?	D	What is the gender of this person?	No change	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
F	Has your family member been diagnosed with any of the conditions listed below?	E	Has this person been diagnosed with any of the following disabilities listed below?	Modified Changed response options from "yes", "no", "don't know" to check all that apply Added vision and hearing response options Added fetal alcohol syndrome Added explanations to some response options	Beginning 2015-16, conditions can be compared to years prior to 2013-14.	x	x	x
G	Has your family member with a disability been diagnosed with any of the health conditions listed below?	E2	Has this person been diagnosed with any of the following health conditions listed below?	Modified Changed response options from "yes", "no", "don't know" to check all that apply Deleted vision and hearing response options Added explanations to some response options	NA	x	x	x
H	What is your family member's race and ethnicity?	F	What is this person's race?	Modified Added "and ethnicity"	NA (question always captured race and ethnicity)	x	x	x
I	What is your family member's preferred means of communication?	G	What is this persons' primary means of expression?	Modified Added open text for "other" response	NA	x	x	x
J	Does your family member have a legal/court-appointed guardian or conservator?			New question Replaces former question P	Parallel comparisons cannot be made from previous years' data.	x	x	-

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
K	If your family member has a legal/court-appointed guardian, what's the guardian's relationship to your family member?			New question Distinguish who conserves individuals	NA	x	x	-
L	What is your family member's highest completed level of education?	I	What is this person's highest education level?	Modified Added/changed response options: Added response- "middle school" and "currently enrolled in HS" "Certificate program" Changed responses: "High school certificate **(NOT a high school diploma/GED)**" and added "college **or higher**"	Comparisons to previous years' data should be made with caution.	x	x	-
M	What does your family member do during the day?	J	What does this person typically do during the day?	Modified Changed response options Changed response categories to reflect frequency of each activity	Comparisons to previous years' data should be made with caution.	x	x	-
N	If your family member needs support to manage self-injurious, disruptive, or destructive behavior, how much support is needed?	L	Does this person need support to manage any of the following behaviors: self-injurious behavior, disruptive behavior, destructive behavior?	Modified Added explanation to response options	Comparisons to previous years' data should be made with caution.	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
O	If your family member needs help (support) with personal care activities (for example, bathing, dressing, eating), please indicate how much.	M	About how much help does this person need with daily activities (such as bathing, dressing, eating)?	Modified Changed response options	Comparisons to previous years' data should be made with caution.	x	x	x
P	If your family member needs help (support) with other daily activities (for example, scheduling, managing money, or shopping), please indicate how much.			New question	NA	x	x	-
Deleted or Rephrased Questions- Information About Family Member **H. What is this person's primary language? (*this question will be re-added in future years)** **K. How often does this person require medical care by a trained medical provider (e.g., nurse or physician)?**								

Information About Respondent								
Q	What is your age?	N	What is your age?	No change	NA	x	x	x
R	How would you describe your health?			New question Aligns with questions in AFS and CFS	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
S	How are you related to this person?	O	How are you related to this person?	Modified Added "grandparent" to responses	NA	x	x	x
T	Typically, how often do you see this person each year?	Q	Typically, how often do you see this person each year?	No change	NA	-	x	-
U	What is <u>your</u> highest education level?	R	What is your highest education level?	Modified Added response options: "Vocational school to "vocational school **or certificate program"** "College degree" to "college degree ***or higher***"	Comparisons to previous years' data should be made with caution.	x	x	x
V	If you are the person's family and/or guardian: What was the total income last year of all wage earners in your household? Do <u>not</u> include state/federal benefits such as SSI, SSDI, etc.	S	What was the total taxable income last year of the wage earner(s) in your household?	Modified Now only applicable to respondents who are family or guardians Deleted "taxable" Added additional explanatory text Added response option "prefer not to say"	Comparisons to previous years' data should be made with caution.	x	x	x
W	What County do you currently live in (do not write in Country- "USA")?	U	What County do you currently live in	No change	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
Deleted or Rephrased Questions- Information About Family Member **P. Are you a legal guardian (e.g., you have been appointed by the court) or conservator for this person?** **T. Approximately how much out-of-pocket money did you spend last year on this person's medical services, equipment, supplies, therapies, and other supports/services?**								
Services and Supports Received								
i-vii	Services received	i-iv	Services received	Added response categories: financial support, in-home support, self-directed support	NA- other responses remain unchanged from previous years	x	x	x
viii	Does your family member receive Social Security payments (SSI or SSDI, survivor benefits, etc.)?	v	Does your family member receive Social Security payments (SSI or SSDI, survivor benefits, etc.)?	No change	NA	x	x	x
ix	Does your family member receive services or supports from other agencies or organizations (school services, vocational rehab, etc.)	NA	NA	New question Determine additional non-state funded supports the person receives	NA	x	x	x
Part 2: Questions About Services and Supports **Overall changes:** **Combined Seldom and Never responses** **Included explanatory text for NA responses where applicable**								
Information and Planning								

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
1	Do you get enough information to take part in planning services for your family member?	1	Do you get enough information to help you participate in planning services for your family member?	No change	NA	x	x	x
2	Is the information you get about services and supports easy to understand?	2	Is the information you receive easy to understand?	Modified	Comparisons to previous years' data should be made with caution.	x	x	x
3	Do staff or does the residential agency keep you informed about how your family member is doing?	3	Are you kept informed about how your family member is doing?	Modified	Parallel comparisons to previous years' data cannot be made.	-	x	-
4	Does the case manager/service coordinator respect your family's choices and opinions?			New question Aligns with question in AFS and CFS	NA	x	x	x
5	Do you need help planning for your family member's future with respect to any of the following?			New question Adds information about future planning; all other questions are about current services/needs	NA	x	x	x
6	In the past year, did your family member move out of the family home for the first time?			New question Determine is out-of-home service placement occurred recently; prompts next questions	NA	-	x	-
7	If yes to Q6, did your family member receive enough information about services available to support him/her?			New question Provides information about recent transition experience process for families	NA	-	x	-

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
8	If yes to Q6, did you have enough choices of service providers to support your family member living outside the family home?			New question Provides information about recent transition experience process for families	NA	-	x	-
9	Does your family member have a service plan? *(Does your family member have a list of services his/her case manager/service coordinator will help get?)*	4	Does your family member have a service plan?	Modified Added additional explanatory text	Comparisons to previous years' data should be made with caution.	x	x	x
10	Does the plan include all the services and supports your family member needs?	8	Does the plan include all the services and supports your family member needs?	Changed order of questions	NA	x	x	x
11	Does your family member get all the services listed in the plan?	9	Does your family member receive all of the services listed in the plan?	Changed order of questions	NA	x	x	x
12	Did you or another family member (beside your family member with a disability) help make the plan?	6	Did you or another family member help develop the plan?	Changed order of questions	NA	x	x	x
13	Did your family member help make the plan?	5	Did your family member help develop the plan?	Changed order of questions	NA	x	x	x
14	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?	10	Did you discuss how to handle emergencies related to your family member at the last service planning meeting?	Modified Rephrased with additional explanatory text	Comparisons to previous years' data should be made with caution.	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
15	Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?			New question Builds on emergency preparedness and adequacy of ER plans from Q14	NA	x	x	x

Deleted or Rephrased Questions- Information and Planning

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

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

Access and Delivery of Services and Supports								
19	Are you or your family member able to contact his/her support workers when you want to?	12	Are you able to contact your family member's support workers when you need to?	Modified Changed "need" to "want"	Comparisons to previous years' data should be made with caution.	x	x	x
20	Are you or your family member able to contact his/her case manager/service coordinator when you want to? *(If you call or email do they get back to you?)*	13	Are you able to contact your family member's case manager/service coordinator when you need to?	Modified Added additional explanatory text	NA	x	x	x
21	Do support workers come and leave when they are supposed to? *(Do they show up on time? Do they show up when they say they will?)*			New question Aligns with question in AFS and CFS	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
22	Do services and supports change when your family's needs change?	15	Do the services and supports change when your family member's needs change?	Modified	Comparisons to previous years' data should be made with caution.	x	x	x
23	Do support workers speak to you in a way that you understand? (*Do they use words you understand? Do they talk to you in the language you prefer?*)			New question Replaces former Q16 and Q17	In future years, this question will be able to be analyzed by primary language.	x	x	x
24	Are services delivered in a way that is respectful of your family's culture?	19	Are services delivered in a way that is respectful to your family member's culture?	Changed order of questions	NA	x	x	x
25	If your family member does not communicate verbally (for example, uses gestures or sign language, uses communication aid), are there support workers who can communicate with him/her?	16	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?	Changed order of questions	NA	x	x	x
26	Do support workers have the right information and skills to meet your family's needs?			New question Replaces former Q21	Replaces former Q21	x	x	x
27	Does your family member have the special equipment or accommodations that s/he needs (*some examples include wheelchair, ramp, communication board*)?	20	Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchair, ramp, communication board)?	No change	NA	x	x	x

2015-2016		2014-2015	Change Made	Note	AFS	FGS	CFS
28	Can your family member see health professionals (for example, his/her doctor, dentist, psychologist) when needed?		New question Gets at health access	NA	x	x	x
29	Does your family member's primary care doctor understand his/her needs related to his/her disability?		New question Gets at quality of care	NA	x	x	x
30	Do you have access to dental services for your family member?		New question Gets at health access	NA	x	x	x
31	If yes to Q30, does your family member's dentist understand his/her needs related to his/her disability?		New question Gets at quality of care	NA	x	x	x
32	If your family member takes medications, do you know what they're for?		New question Gets at family understanding of medication use	NA	x	x	x
33	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*)?		New question Better get at family understanding of using medication safely	NA	x	x	x

2015-2016		2014-2015	Change Made	Note	AFS	FGS	CFS
34	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?		New question Gets at quality of care	NA	x	x	x
35	Does your family get the support needed?		New question Aligns with question in AFS and CFS	NA	x	x	x
36	If no to Q35, what additional services are needed?		New question Aligns with question in AFS and CFS	NA	x	x	x

Deleted or Rephrased Questions- Access and Delivery of Services and Supports

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

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

18. If English is not your family member's first language, are there support workers or translators who can speak with him/her in the preferred language?

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

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

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

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

Choice, Decision-Making, and Control

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
37	Does the agency providing residential services to your family member involve him/her in important decisions?	25	Does the agency providing residential services to your family member involve him/her in important decisions?	No change	NA	-	x	-
38	Can your family choose or change the agency that provides your family member's services?			New question Replaces former Q26-Q27, now includes all family and whether family chose or can change agencies.	Parallel comparisons to previous years' data cannot be made.	x	x	x
39	Can your family choose or change the individual staff that provide the services for your family member?			New question Replaces former Q28-Q29, now includes all family and whether family chose or can change workers.	Parallel comparisons to previous years' data cannot be made.	x	x	x
40	Does your family directly manage support workers (for example, hiring and deciding schedule)?			New question Replaces former Q31	NA	x	x	x
41	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?)			New question Determines whether multiple providers work together to support families	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
42	Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?			New question Replaces former Q30, now includes all family and whether family chose or can request a change to case manager.	Parallel comparisons to previous years' data cannot be made.	x	x	x
Deleted or Modified- Choice and Decision-Making **26. Did your family member choose the provider agencies that work with him or her?** **27. Can your family member choose a different provider agency if s/he wants to?** **28. Did your family member choose the individual support workers who work directly with him/her?** **29. Can your family member choose different support workers if s/he wants to?** **30. Did your family member choose his/her case manager/service coordinator?** **31. Does your family member have control and/or input over the hiring and management of his/her support workers?** **32. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?** **33. Does your family member have a say in how this money is spent?** **33a. If Yes to Q33, does your family member have all the information s/he needs to make decisions about how to spend this money?**								
Involvement in the Community								
43	Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?	34	Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?	No change	NA	x	x	x
44	If no to Q43, why not?	34a	If No to Q34, why?	No change	NA	x	x	x
45	Does your family member have friends other than paid support workers or family?	35	Does your family member have friends or relationships with persons other than paid staff or family?	Modified Deleted "or relationships"	NA	x	x	-

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
46	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.)			New question Determines whether families have access to non-traditional supports	NA	x	x	x
47	Does your family take part in any family-to-family networks in your community? (For example, Parent to Parent, sibling networks, etc.)			New question Determines whether families have access to support networks	NA	x	x	x
Satisfaction								
48	Overall, are you satisfied with the services and supports your family member currently receives?	37	Overall, are you satisfied with the services and supports your family member currently receives?	No change	NA	x	x	x
49	Do you know how to file a complaint or grievance about provider agencies or staff?	38	Do you know the process for filing a complaint or grievance against provider agencies or staff?	Modified	NA	x	x	x
50	If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?			Replaces former Q39	Parallel comparisons to previous years' data cannot be made.	x	x	x
51	Do you know how to report abuse or neglect related to your family member?	40	Do you know how to report abuse or neglect?	Modified	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
52	Within the past year, was a report of abuse or neglect filed on behalf of your family member?	41	Within the past year, if abuse or neglect occurred, did you report it?	Modified	Parallel comparisons to previous years' data cannot be made.	x	x	x
53	If yes to Q52, did the appropriate people respond to the report?	41a	If Yes to Q41, were the appropriate people responsive to your report?	Modified	Due to rephrasing of Q51 and Q52, parallel comparisons to previous years' data cannot be made.	x	x	x
54	If yes to Q52, if someone other than you or another family member reported abuse or neglect in the past year, were you notified of the report in a timely manner?			New question Follow-up to assess whether family is kept apprised of abuse/neglect reports	NA	x	x	x
Deleted or Rephrased Questions- Satisfaction **39. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?**								

Outcomes								
55	Do you feel that services and supports have made a positive difference in the life of your family member?	42	Do you feel that services and supports have made a positive difference in the life of your family member?	No change	NA	x	x	x

2015-2016		2014-2015		Change Made	Note	AFS	FGS	CFS
56	Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?	44	Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?	No change	NA	x	x	x
57	If yes to Q56, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?	44a	If Yes to Q44, did the reduction, suspension, or termination of these services or supports affect your family member negatively?	No change	NA	x	x	x
58	Have the services or supports that your family member received been increased in the past year?			New question This gets at the reverse of previous question (whether services were reduced); may give some insight to other outcomes	NA	x	x	x
59	Are services and supports helping your family member to live a good life?			New question Helps determine overall satisfaction with service delivery	NA	x	x	x

Deleted or Rephrased Questions- Outcomes

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