Family/Guardian Survey

2017-18 Final Report

NATIONAL CORE INDICATORS

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

Human Services Research Institute (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

January 24, 2019

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

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Executive Summary

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

The NCI Family/Guardian Survey is administered to families who have an adult (18 years or older) with a developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Family/Guardian Survey on an annual basis. Of the 46states, the District of Columbia, and 22 sub-state entities who participated in NCI during the 2017-18 data collection cycle, ten (10) states submitted a valid sample of Family/Guardian Survey data: Arizona (AZ), Florida (FL), Georgia (GA), Maryland (MD), North Carolina (NC), New Hampshire (NH), Pennsylvania (PA), South Dakota (SD), Utah (UT) and Washington (WA). This Final Report provides a summary of results based on data submitted by June 30, 2018.

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

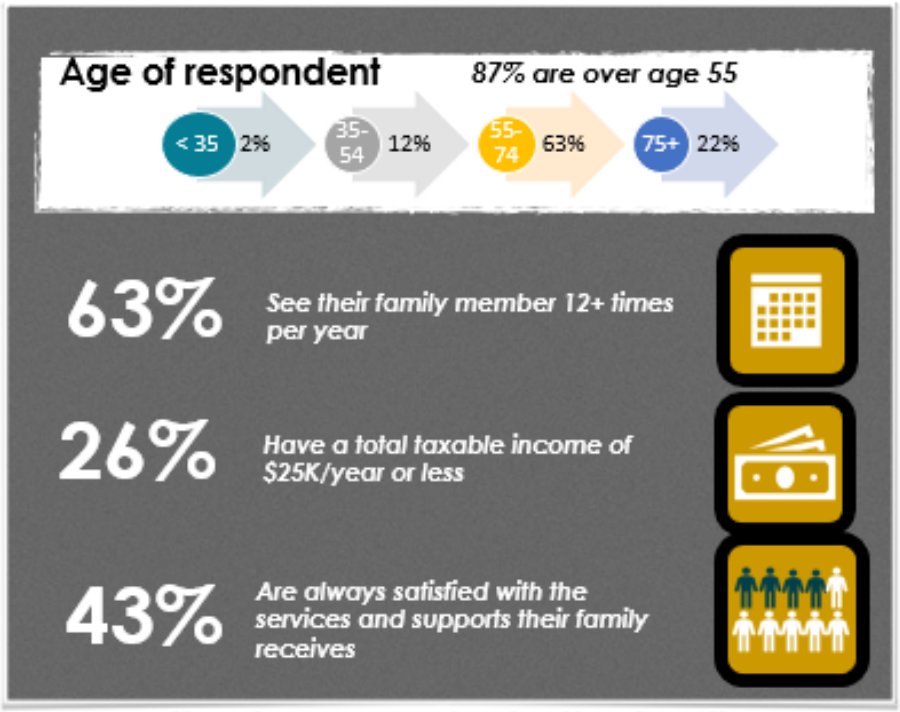
2017-18 Family Guardian Survey

NCI Average Data

- All participating states
- Data are weighted

4,890 families/guardians participated in the 2017-18 Family Guardian Survey in 10 states*

Respondents are families and/or guardians of an adult with I/DD who lives somewhere other than the family home and receives at least one public service in addition to case management from the state DD agency.



According to respondents, the family member with I/DD . . .

Residence

Group Home	57%
Independent Home or Apartment	15%
ICF/ID or Other Specialized Facility for People with ID	11%
Agency Operated Apartment	7%
Adult Foster Care or Host Home	7%
Other (Includes Nursing Home, Homeless or Other)	4%

* AZ, FL, GA, MD, NC, NH, PA, SD, UT, WA; NCI Average is weighted

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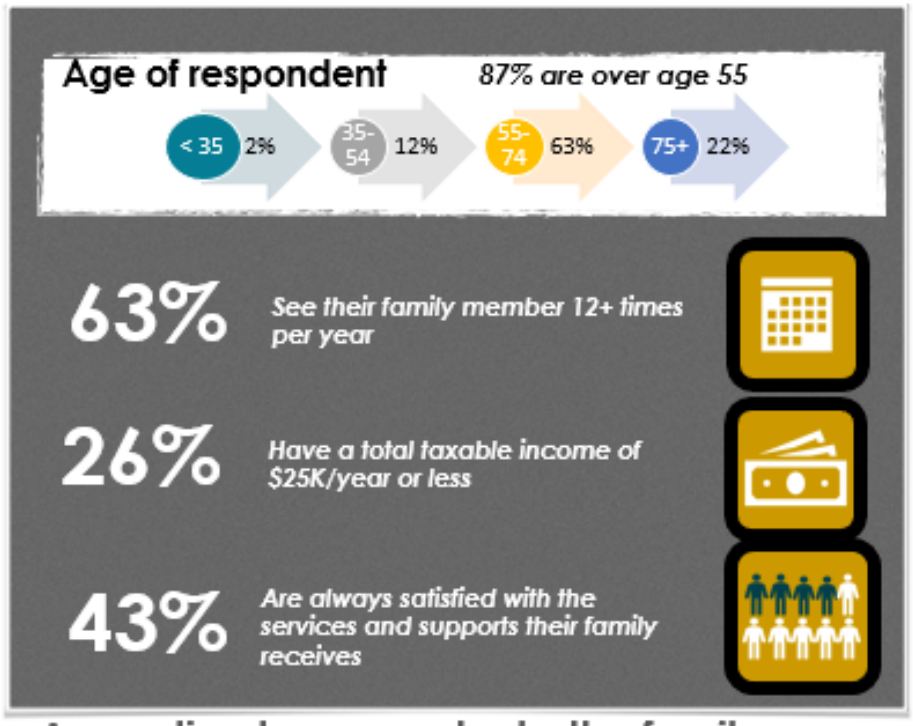

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* AZ, FL, GA, MD, NC, NH, PA, SD, UT, WA; NCI Average is weighted

I. Results

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

Survey Development

The Family/Guardian Survey was developed and first utilized in 1999-2000 in response to various states' interest in determining whether families were involved in the lives of their family member with an intellectual or developmental disability (who did not live at home with them), whether these families had the support they needed to be involved, and whether they were satisfied with the service system that was intended to meet their family member's needs.

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

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

Organization of the Family/Guardian Survey

The Family/Guardian Survey is composed of the three sections described below. Additionally, at the end of the survey, respondents may write open-ended comments concerning their family's participation in the service system.

Demographics

The survey instrument begins with a series of questions relating to characteristics of the family member with a developmental disability (e.g., age, race, type of disability) followed by a series of demographic questions pertaining to the survey respondent (e.g., age, health status, relationship to the individual with the developmental disability).

Services and Supports Received

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

Questions Regarding Services and Supports

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

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

Presentation of Data

Direct feedback from families is an important means for states to gauge service and support satisfaction and to pinpoint areas for quality improvement. All demographic and individual outcome results from the Family/Guardian Survey are presented in this report.

Outcome results are presented in six subsections that correspond with the sections of the survey. For each question, the results are first shown in a graph that depicts the NCI Average and then in a set of tables that break out each state’s percentages. 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, or significantly below the NCI Average. Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI Average range, their ‘always’ or ‘yes’ response was not statistically different from the NCI Average.

States with fewer than 20 respondents to a question ***are not*** included in tables; however, their data ***are*** included in the NCI Average.

Note on Significance: Statistical significance depends on both the amount by which a state differs from the average for a given item and the state’s sample size for that item. So there may be instances where State A’s difference from the average is larger than State B’s, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.

Note on NCI Averages: The NCI averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states, as well as the states’ sample sizes. Prior to 2016-17, NCI averages were calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.

Note on language used in this report: "**Respondent**" refers to the person (usually a parent or guardian) filling out the survey. "**Family Member**" refers to the person receiving services whom the respondent is answering questions about in this survey.

Demographics

Family Member

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

Table 1. Family Member's Residence

State	Specialized Facility for People With ID[1]	Group Home	Agency Operated Apartment	Independent Home or Apartment	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
AZ	7%	74%	2%	3%	12%	1%	0%	1%	272
FL	8%	63%	4%	19%	1%	1%	0%	5%	325
GA	7%	57%	6%	12%	17%	0%	0%	2%	400
MD	10%	63%	8%	17%	1%	1%	0%	0%	1104
NH	7%	22%	6%	22%	36%	1%	0%	5%	445
NC	17%	53%	2%	4%	14%	1%	0%	10%	230
PA	15%	60%	6%	12%	5%	2%	0%	1%	741
SD	18%	45%	23%	13%	0%	0%	0%	1%	487
UT	7%	59%	15%	10%	8%	0%	0%	2%	369
WA	6%	35%	14%	31%	9%	2%	0%	2%	418
NCI Average	**11%**	**57%**	**7%**	**15%**	**7%**	**1%**	**0%**	**3%**	**4,791**

Table 2. Family Member's Residential Designation

State	Urban or Suburban	Rural	N
AZ	91%	9%	276
FL	88%	12%	310
GA	77%	23%	401
MD	76%	24%	1097
NH	57%	43%	442
NC	72%	28%	223
PA	72%	28%	725
SD	97%	3%	484
UT	92%	8%	367
WA	89%	11%	418
NCI Average	**80%**	**20%**	**4743**

Table 3. Family Member's Age

State	Age	N
AZ	43.9	272
FL	46.0	308
GA	44.6	397
MD	47.7	1094
NH	46.5	443
NC	43.9	222
PA	51.9	731
SD	43.9	481
UT	44.8	359
WA	50.7	417
NCI Average	**47.9**	**4,724**

[1] ICF, state-run or other institutional setting

Table 4. Family Member's Gender

State	Male	Female	N
AZ	59%	41%	279
FL	60%	40%	319
GA	57%	43%	409
MD	58%	42%	1119
NH	60%	40%	448
NC	63%	37%	231
PA	57%	43%	747
SD	55%	45%	496
UT	61%	39%	371
WA	52%	48%	419
NCI Average	**58%**	**42%**	**4,838**

Table 5. Family Member's Race and Ethnicity ∞

State	American Indian or Native Alaska	Asian	Black or African American	Hawaiian or Pacific Islander	White	Hispanic or Latino	Other	N
AZ	10%	3%	4%	0%	78%	11%	2%	279
FL	3%	1%	15%	0%	76%	8%	1%	327
GA	1%	1%	17%	0%	81%	1%	0%	404
MD	1%	3%	17%	1%	80%	1%	0%	1117
NH	2%	0%	1%	0%	98%	0%	1%	448
NC	2%	2%	27%	0%	71%	0%	1%	232
PA	2%	1%	5%	0%	93%	1%	0%	737
SD	10%	2%	1%	0%	90%	1%	0%	498
UT	3%	1%	2%	0%	93%	4%	1%	370
WA	5%	3%	1%	0%	90%	2%	1%	422
NCI Average	**3%**	**2%**	**10%**	**0%**	**84%**	**3%**	**1%**	**4,834**

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

State	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
AZ	73%	38%	28%	21%	10%	4%
FL	75%	32%	22%	21%	6%	6%
GA	76%	37%	26%	14%	11%	6%
MD	75%	30%	23%	16%	9%	7%
NH	71%	40%	26%	15%	9%	7%
NC	82%	49%	28%	16%	10%	7%
PA	83%	36%	19%	20%	11%	7%
SD	73%	37%	19%	15%	9%	10%
UT	83%	44%	24%	17%	10%	6%
WA	74%	36%	17%	15%	7%	7%
NCI Average	**78%**	**36%**	**22%**	**18%**	**9%**	**7%**

∞ Categories are not mutually exclusive

Table 6b. Family Member's Disabilities (continued) ∞

State	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
AZ	12%	33%	2%	10%	0%	4%	13%
FL	10%	27%	1%	10%	2%	1%	15%
GA	12%	31%	1%	12%	1%	1%	12%
MD	12%	24%	1%	11%	1%	1%	7%
NH	16%	32%	1%	10%	1%	2%	15%
NC	11%	29%	2%	8%	0%	1%	14%
PA	10%	30%	0%	11%	1%	0%	11%
SD	9%	25%	1%	12%	1%	4%	10%
UT	12%	30%	1%	7%	1%	3%	15%
WA	7%	22%	1%	12%	1%	3%	16%
NCI Average	**10%**	**28%**	**1%**	**11%**	**1%**	**2%**	**12%**

Table 7a. Family Member's Health Conditions ∞

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	8%	17%	4%	29%	31%
FL	9%	19%	8%	32%	35%
GA	7%	20%	5%	35%	34%
MD	9%	21%	7%	37%	33%
NH	11%	15%	9%	25%	26%
NC	7%	20%	8%	41%	36%
PA	10%	16%	7%	27%	30%
SD	10%	22%	4%	25%	17%
UT	10%	25%	6%	25%	24%
WA	13%	22%	7%	36%	30%
NCI Average	**10%**	**19%**	**7%**	**32%**	**32%**

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

State	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Oral Health or Other Dental Problems	Sleep Apnea	Other
AZ	7%	3%	6%	21%	8%	22%
FL	9%	2%	7%	14%	10%	27%
GA	12%	3%	4%	17%	10%	20%
MD	10%	2%	6%	15%	11%	13%
NH	16%	3%	6%	13%	12%	22%
NC	14%	1%	7%	14%	17%	24%
PA	18%	3%	7%	15%	13%	20%
SD	17%	2%	6%	14%	20%	18%
UT	11%	2%	3%	18%	22%	22%
WA	8%	3%	5%	15%	12%	21%
NCI Average	**13%**	**3%**	**6%**	**15%**	**12%**	**21%**

∞ Categories are not mutually exclusive

Table 8. Family Member's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AZ	71%	18%	4%	2%	5%	278
FL	83%	13%	1%	1%	3%	327
GA	70%	22%	2%	1%	5%	400
MD	76%	17%	3%	1%	3%	1107
NH	77%	13%	2%	1%	7%	450
NC	78%	17%	2%	1%	2%	229
PA	70%	21%	2%	1%	6%	741
SD	81%	13%	3%	2%	1%	480
UT	74%	17%	1%	0%	7%	369
WA	82%	11%	2%	1%	4%	425
NCI Average	**76%**	**17%**	**2%**	**1%**	**4%**	**4,806**

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

State	None	Limited	Full	Has Guardianship but Level Is Unknown	N
AZ	1%	5%	89%	5%	280
FL	31%	23%	43%	4%	314
GA	17%	13%	66%	4%	381
MD	47%	18%	29%	7%	985
NH	11%	13%	70%	6%	448
NC	0%	15%	79%	6%	231
PA	30%	19%	42%	8%	662
SD	2%	12%	79%	6%	493
UT	19%	25%	49%	7%	358
WA	29%	16%	51%	4%	407
NCI Average	25%	17%	52%	6%	4559

Table 10. Guardian or Conservator Relationship to Family Member

State	Family	Friend	State Employee or Guardianship Agency	Other	N
AZ	90%	3%	4%	3%	269
FL	82%	5%	5%	8%	206
GA	89%	4%	3%	4%	301
MD	89%	2%	8%	1%	462
NH	90%	4%	6%	0%	371
NC	76%	2%	21%	1%	221
PA	83%	1%	8%	8%	423
SD	89%	3%	6%	1%	476
UT	75%	3%	21%	1%	275
WA	81%	7%	10%	3%	275
NCI Average	**83%**	**3%**	**9%**	**4%**	**3,279**

Table 11. Family Member's Highest level of Education

State	Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational Training	Some College	College Degree or Higher	N
AZ	38%	2%	25%	26%	3%	2%	4%	260
FL	42%	2%	34%	14%	2%	2%	4%	308
GA	37%	0%	43%	13%	2%	1%	4%	359
MD	34%	1%	41%	13%	5%	3%	3%	1044
NH	39%	0%	22%	27%	4%	5%	4%	421
NC	39%	2%	36%	11%	7%	3%	3%	218
PA	45%	0%	22%	26%	4%	1%	1%	681
SD	43%	0%	28%	23%	2%	2%	2%	466
UT	35%	2%	33%	22%	1%	2%	5%	339
WA	32%	0%	34%	28%	2%	1%	2%	407
NCI Average	**39%**	**1%**	**32%**	**20%**	**3%**	**2%**	**3%**	**4,503**

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

State	Usually/Often	Sometimes	Never	N
AZ	7%	2%	91%	255
FL	13%	3%	84%	310
GA	9%	2%	89%	378
MD	19%	5%	76%	1026
NH	23%	5%	72%	425
NC	13%	5%	82%	220
PA	12%	2%	86%	673
SD	22%	6%	72%	472
UT	18%	4%	79%	349
WA	23%	6%	71%	407
NCI Average	**15%**	**4%**	**82%**	**4,515**

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

State	Usually/Often	Sometimes	Never	N
AZ	9%	5%	86%	251
FL	11%	4%	86%	306
GA	7%	2%	91%	374
MD	15%	6%	79%	1014
NH	10%	4%	86%	421
NC	11%	5%	83%	220
PA	8%	3%	89%	658
SD	16%	8%	76%	463
UT	17%	5%	78%	337
WA	8%	4%	88%	392
NCI Average	**10%**	**4%**	**85%**	**4,436**

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

State	Usually/Often	Sometimes	Never	N
AZ	8%	6%	86%	258
FL	13%	13%	74%	308
GA	17%	14%	69%	376
MD	18%	16%	66%	1025
NH	38%	19%	43%	434
NC	36%	16%	48%	222
PA	15%	11%	74%	664
SD	13%	29%	58%	466
UT	13%	17%	70%	342
WA	19%	14%	66%	400
NCI Average	**18%**	**14%**	**68%**	**4,495**

Table 15. Family Member's Typical Day Activities – Paid Work in a Community Job That Primarily Hires People With Disabilities [2]

State	Usually/Often	Sometimes	Never	N
AZ	5%	2%	93%	259
FL	7%	2%	91%	305
GA	4%	2%	94%	376
MD	8%	5%	87%	1005
NH	11%	4%	85%	421
NC	6%	2%	92%	220
PA	6%	2%	93%	665
SD	12%	5%	82%	465
UT	12%	1%	86%	343
WA	10%	4%	86%	400
NCI Average	**7%**	**3%**	**90%**	**4,459**

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

State	Usually/Often	Sometimes	Never	N
AZ	15%	4%	82%	260
FL	20%	4%	75%	309
GA	11%	4%	84%	380
MD	23%	7%	70%	1012
NH	7%	3%	89%	421
NC	20%	6%	73%	226
PA	23%	3%	74%	673
SD	30%	13%	57%	470
UT	30%	4%	66%	348
WA	7%	3%	90%	393
NCI Average	**19%**	**5%**	**76%**	**4,492**

[2] New item added to the survey in 2017-18

Table 17. Family Member's Typical Day Activity -- Unpaid Activity in a Facility-based Setting

State	Usually/Often	Sometimes	Never	N
AZ	55%	5%	40%	265
FL	32%	5%	62%	309
GA	40%	8%	52%	384
MD	39%	8%	53%	1024
NH	17%	13%	71%	424
NC	44%	7%	49%	221
PA	31%	5%	64%	668
SD	24%	10%	66%	463
UT	31%	5%	64%	343
WA	13%	5%	82%	394
NCI Average	**33%**	**6%**	**61%**	**4,495**

Table 18. Family Member's Typical Day Activity – School

State	Usually/Often	Sometimes	Never	N
AZ	5%	2%	93%	257
FL	8%	1%	91%	303
GA	7%	1%	92%	369
MD	3%	3%	94%	1013
NH	3%	2%	95%	425
NC	9%	5%	86%	221
PA	2%	1%	98%	656
SD	2%	1%	97%	469
UT	4%	1%	95%	350
WA	3%	3%	94%	397
NCI Average	**5%**	**2%**	**93%**	**4,460**

Table 19. Family Member's Typical Day Activity – Stays at Home

State	Usually/Often	Sometimes	Never	N
AZ	25%	26%	48%	252
FL	24%	25%	51%	294
GA	25%	27%	48%	344
MD	20%	21%	59%	985
NH	37%	27%	36%	402
NC	17%	28%	54%	213
PA	25%	25%	49%	623
SD	30%	25%	44%	455
UT	26%	29%	45%	326
WA	59%	18%	23%	386
NCI Average	**28%**	**24%**	**47%**	**4,280**

Table 20. Family Member's Typical Day Activity – Other

State	Usually/Often	Sometimes	Never	N
AZ	61%	28%	11%	18
FL	48%	5%	47%	94
GA	40%	14%	47%	131
MD	40%	8%	52%	301
NH	79%	12%	9%	114
NC	49%	12%	39%	76
PA	42%	9%	49%	199
SD	73%	21%	6%	33
UT	54%	9%	37%	92
WA	60%	13%	27%	138
NCI Average	**48%**	**10%**	**42%**	**1,196**

Table 21. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

State	Extensive	Some	None	N
AZ	33%	35%	32%	271
FL	28%	31%	41%	323
GA	32%	32%	36%	392
MD	26%	34%	41%	1086
NH	27%	38%	36%	442
NC	35%	42%	22%	231
PA	28%	36%	35%	722
SD	22%	41%	36%	488
UT	35%	41%	24%	363
WA	24%	42%	35%	411
NCI Average	**29%**	**36%**	**35%**	**4,729**

Table 22. Family Member's Level of Help Needed With Personal Care Activities[3]

State	Extensive	Some	None	N
AZ	45%	42%	13%	277
FL	42%	37%	21%	325
GA	41%	39%	19%	402
MD	37%	37%	26%	1104
NH	39%	37%	24%	447
NC	47%	37%	16%	231
PA	44%	36%	21%	735
SD	32%	40%	27%	496
UT	44%	35%	21%	370
WA	43%	42%	15%	421
NCI Average	**42%**	**38%**	**20%**	**4,808**

[3] For example, bathing, dressing, eating

Table 23. Family Member's Need for Help With Other Daily Activities[4]

State	Extensive	Some	None	N
AZ	90%	10%	0%	277
FL	81%	15%	3%	324
GA	86%	12%	2%	401
MD	76%	21%	3%	1104
NH	75%	23%	2%	450
NC	86%	13%	0%	230
PA	84%	14%	2%	729
SD	72%	26%	2%	496
UT	84%	15%	1%	369
WA	80%	19%	1%	427
NCI Average	**82%**	**16%**	**2%**	**4,807**

[4] For example, scheduling, managing money, or shopping

Respondents

This section provides demographic information about the respondent.

Table 24. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
AZ	1%	13%	66%	20%	275
FL	5%	19%	58%	18%	329
GA	0%	15%	67%	17%	402
MD	1%	10%	60%	29%	1115
NH	1%	15%	63%	21%	450
NC	4%	19%	61%	17%	229
PA	1%	8%	63%	28%	723
SD	1%	17%	65%	18%	482
UT	1%	10%	73%	16%	364
WA	1%	8%	69%	22%	419
NCI Average	**2%**	**12%**	**63%**	**22%**	**4,788**

Table 25. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
AZ	19%	50%	27%	4%	274
FL	19%	43%	33%	5%	329
GA	16%	39%	37%	8%	402
MD	17%	42%	34%	7%	1113
NH	23%	48%	26%	3%	449
NC	15%	44%	35%	6%	232
PA	17%	45%	32%	5%	719
SD	18%	48%	33%	1%	483
UT	27%	37%	33%	3%	363
WA	17%	48%	32%	4%	426
NCI Average	**18%**	**45%**	**33%**	**5%**	**4,790**

Table 26. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
AZ	57%	18%	0%	4%	7%	8%	6%	277
FL	50%	24%	0%	1%	3%	6%	16%	325
GA	58%	21%	0%	2%	3%	4%	11%	405
MD	58%	27%	0%	2%	1%	1%	12%	1105
NH	62%	26%	1%	1%	1%	4%	6%	451
NC	51%	18%	0%	0%	17%	10%	4%	233
PA	56%	38%	0%	0%	2%	2%	2%	731
SD	61%	22%	0%	2%	5%	3%	6%	486
UT	59%	20%	0%	1%	1%	13%	7%	364
WA	52%	28%	0%	1%	1%	8%	10%	427
NCI Average	**54%**	**27%**	**0%**	**1%**	**4%**	**5%**	**8%**	**4,804**

Table 27. Respondent's Frequency of Visits With Family Member Last Year

State	Less than Once	1-3 times	4-6 times	7-12 times	More Than 12 Times	N
AZ	1%	8%	11%	11%	69%	280
FL	2%	11%	7%	9%	70%	324
GA	2%	11%	12%	14%	62%	403
MD	4%	8%	10%	12%	66%	1100
NH	2%	9%	12%	14%	63%	450
NC	3%	8%	20%	18%	50%	234
PA	5%	9%	11%	14%	60%	726
SD	4%	10%	12%	15%	58%	488
UT	3%	6%	16%	12%	63%	363
WA	5%	8%	11%	11%	65%	426
NCI Average	**4%**	**9%**	**11%**	**13%**	**63%**	**4,794**

Table 28. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School	Some College	College Degree or Higher	N
AZ	2%	14%	6%	34%	44%	278
FL	4%	21%	5%	27%	42%	323
GA	7%	22%	9%	21%	42%	399
MD	3%	19%	4%	22%	53%	1101
NH	4%	21%	7%	17%	51%	446
NC	3%	20%	6%	15%	56%	228
PA	4%	29%	8%	19%	40%	719
SD	4%	25%	11%	23%	37%	482
UT	1%	13%	8%	31%	46%	364
WA	5%	20%	5%	26%	44%	422
NCI Average	**4%**	**22%**	**6%**	**23%**	**45%**	**4,762**

Table 29. Total Taxable Household Income of Wage Earners in the Past Year

State	No Earned Income	Up to $15,000	$15,001-$25,000	$25,001-$50,000	$50,001-$75,000	Over $75,000	Prefer Not to Say	N
AZ	10%	3%	7%	19%	17%	16%	28%	269
FL	13%	6%	12%	18%	13%	11%	27%	313
GA	14%	5%	10%	17%	9%	15%	30%	379
MD	9%	4%	8%	14%	12%	24%	30%	1036
NH	11%	5%	6%	15%	16%	19%	28%	416
NC	8%	4%	9%	18%	12%	21%	28%	226
PA	10%	7%	11%	15%	10%	15%	32%	664
SD	8%	5%	9%	23%	17%	12%	27%	467
UT	9%	5%	6%	22%	14%	24%	19%	355
WA	11%	6%	8%	19%	15%	18%	23%	410
NCI Average	**11%**	**5%**	**10%**	**17%**	**13%**	**17%**	**28%**	**4,535**

Services and Supports Received

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

Table 30. Services and Supports Received From ID/DD Agency ∞

State	Financial Support	In-home Support	Residential Support	Day or Employment Supports	Transportation	Other	Self-direction or Fiscal Intermediary Services
AZ	25%	27%	96%	75%	95%	65%	27%
FL	31%	48%	89%	64%	88%	59%	48%
GA	34%	44%	91%	68%	94%	49%	28%
MD	34%	48%	87%	75%	91%	55%	21%
NH	45%	41%	87%	50%	86%	55%	30%
NC	33%	36%	92%	72%	92%	73%	20%
PA	31%	43%	90%	67%	92%	64%	24%
SD	25%	32%	94%	65%	92%	63%	32%
UT	30%	57%	95%	78%	94%	67%	45%
WA	32%	63%	87%	44%	89%	46%	34%
NCI Average	**31%**	**46%**	**90%**	**65%**	**91%**	**60%**	**30%**

Table 31. Additional Services and Supports Received ∞

State	Social Security Payments (SSI/SSB)	Other Agencies or Organizations
AZ	97%	31%
FL	96%	35%
GA	98%	24%
MD	92%	31%
NH	95%	29%
NC	97%	40%
PA	93%	30%
SD	97%	26%
UT	97%	25%
WA	97%	31%
NCI Average	**95%**	**32%**

∞ Categories are not mutually exclusive

Family/Guardian Survey Results

Please Note:

Note on Significance: Statistical significance depends on both the amount by which a state differs from the average for a given item and the state's sample size for that item. There may be instances where State A's difference from the average is larger than State B's, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.

Information and Planning

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

Note: Significance is based on "Always" or "Yes" response.

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

"**Family Member**" refers to the person receiving services whom the respondent is answering questions about in this survey.

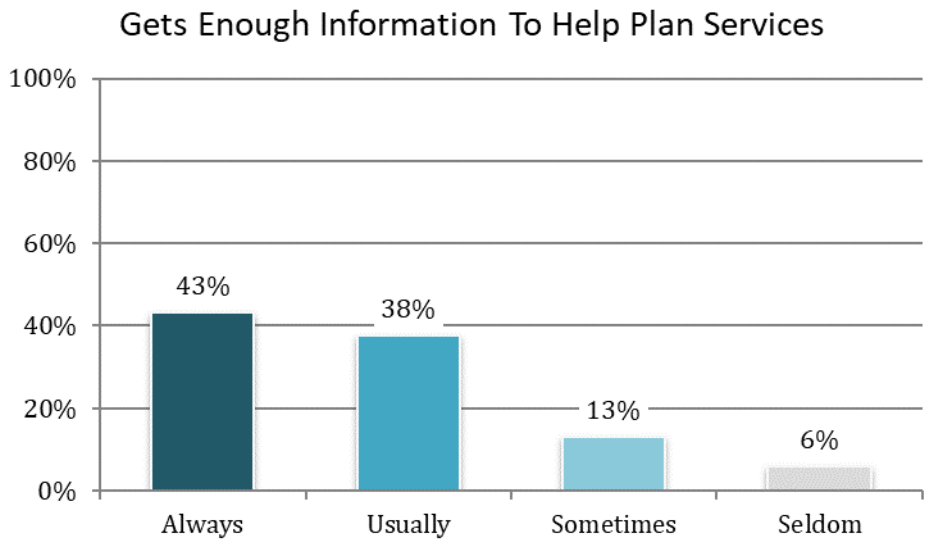


Table Q1. Do you get enough information to help you participate in planning services for your family?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	57%	33%	9%	1%	221

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
FL	48%	32%	14%	7%	307
NH	45%	40%	12%	3%	425
WA	45%	41%	9%	5%	394
UT	45%	36%	12%	8%	346
NCI Average	**43%**	**38%**	**13%**	**6%**	**4,475**
SD	43%	41%	12%	4%	476
AZ	43%	40%	13%	4%	264
PA	42%	40%	12%	6%	682

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	33%	37%	21%	10%	364
MD	30%	40%	20%	10%	996

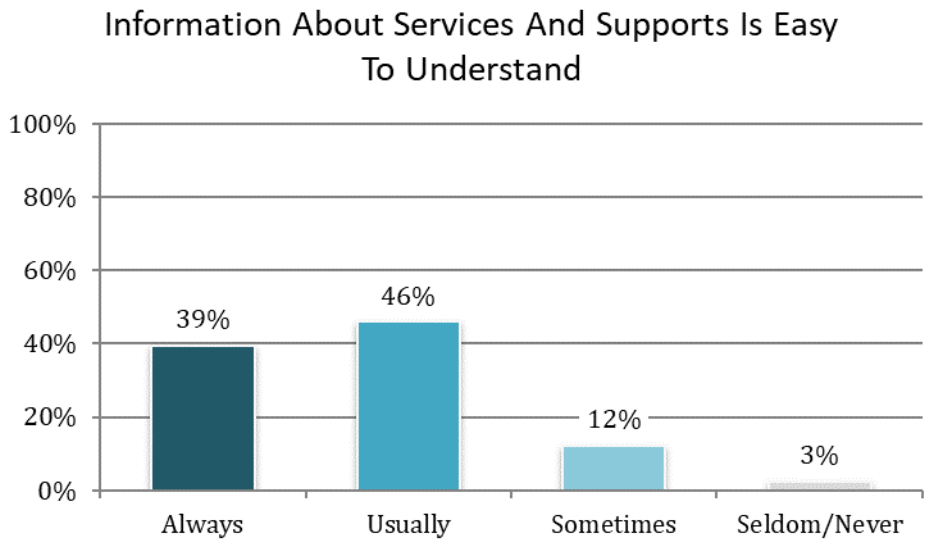


Table Q2. Is the information you receive easy to understand?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	43%	42%	15%	0%	226
FL	43%	43%	11%	3%	311
PA	42%	48%	9%	1%	688
NH	41%	46%	11%	2%	431
UT	41%	45%	11%	3%	352
SD	40%	48%	10%	2%	481
NCI Average	**39%**	**46%**	**12%**	**3%**	**4,521**
AZ	37%	48%	12%	3%	269
WA	36%	48%	13%	3%	405

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	34%	45%	17%	5%	991
GA	30%	49%	16%	5%	367

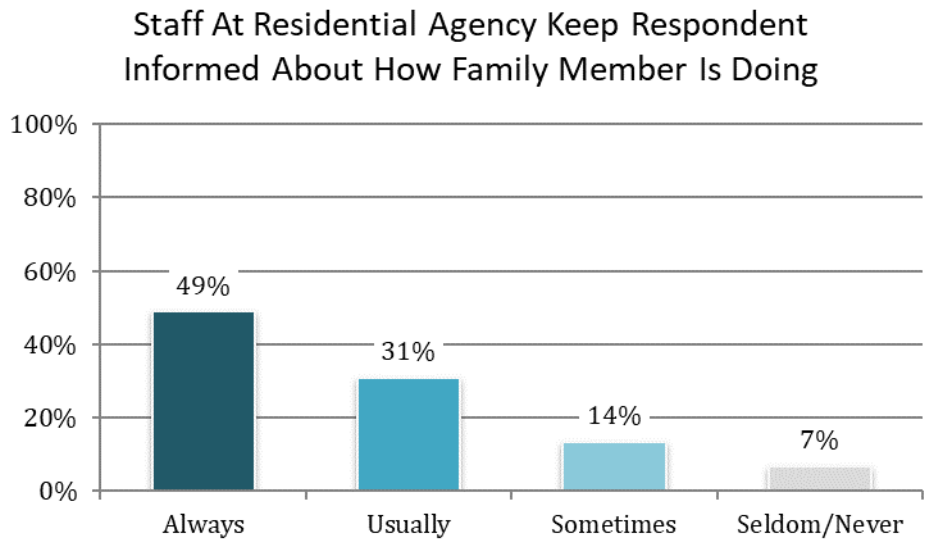


Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	57%	29%	9%	6%	314

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	57%	30%	10%	3%	231
AZ	51%	28%	14%	7%	274
NH	51%	32%	11%	6%	437
WA	49%	30%	12%	9%	395
NCI Average	**49%**	**31%**	**14%**	**7%**	**4,672**
PA	48%	32%	15%	5%	724
UT	47%	31%	13%	8%	365

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	42%	32%	17%	9%	392
SD	40%	39%	13%	9%	488
MD	35%	33%	21%	10%	1,052

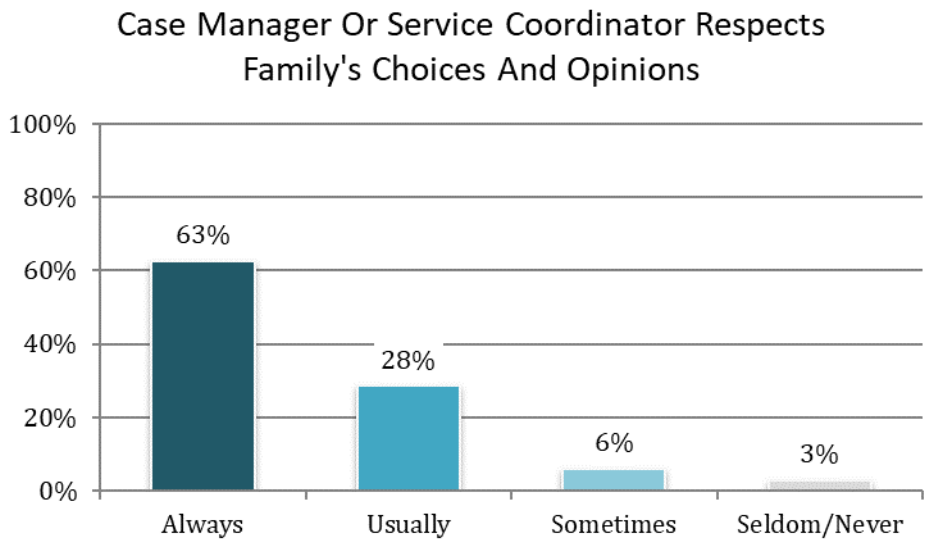


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	72%	21%	4%	3%	321

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	69%	24%	5%	1%	226
UT	65%	27%	4%	3%	358
WA	65%	28%	4%	3%	399
NH	64%	28%	7%	2%	430
AZ	63%	30%	7%	1%	271
NCI Average	**63%**	**28%**	**6%**	**3%**	**4,588**
PA	60%	31%	7%	2%	701

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	57%	33%	7%	2%	488
GA	53%	35%	9%	4%	376
MD	49%	36%	10%	6%	1,018

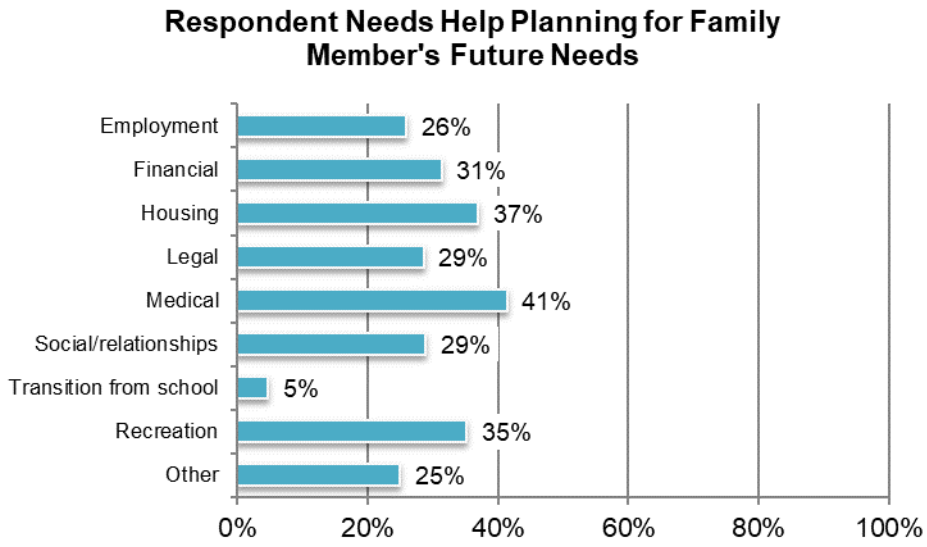


Table Q5. Do you need help planning for your family member's future with respect to any of the following? ∞

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition from School	Recreation	Other	N
AZ	25%	31%	45%	29%	49%	32%	8%	39%	12%	118
FL	27%	35%	46%	32%	49%	31%	8%	35%	19%	86
GA	20%	35%	38%	28%	41%	29%	5%	36%	27%	198
MD	31%	36%	36%	33%	41%	30%	3%	39%	20%	574
NH	38%	35%	51%	29%	50%	42%	3%	45%	13%	33
NC	34%	37%	44%	34%	45%	41%	8%	43%	25%	104
PA	15%	20%	23%	22%	30%	18%	2%	27%	37%	325
SD	43%	41%	49%	29%	44%	47%	5%	50%	13%	218
UT	36%	39%	35%	33%	42%	36%	6%	39%	27%	165
WA	28%	31%	36%	28%	40%	29%	3%	33%	27%	257
NCI Average	**26%**	**31%**	**37%**	**29%**	**41%**	**29%**	**5%**	**35%**	**25%**	**2,378**

∞ Categories are not mutually exclusive

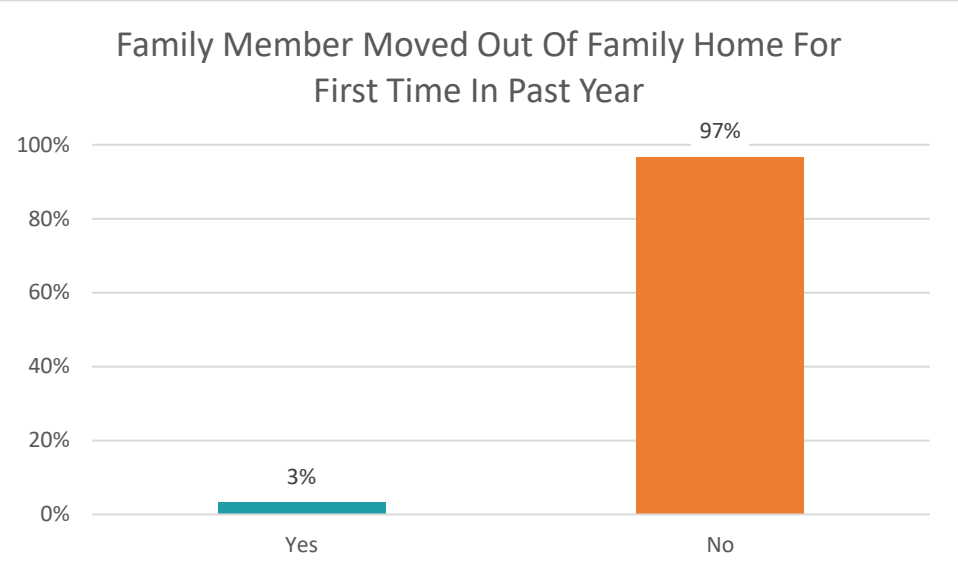


Table Q6. In the past year, did your family member move out of the family home for the first time?

Significantly Above Average

State	Yes	No	N
AZ	9%	91%	274

Within Average Range

State	Yes	No	N
UT	5%	95%	365
MD	4%	96%	1,080
NC	4%	96%	228
GA	4%	96%	391
NH	3%	97%	447
NCI Average	**3%**	**97%**	**4,720**
SD	3%	97%	494
FL	3%	97%	322
WA	3%	97%	409

Significantly Below Average

State	Yes	No	N
PA	2%	98%	710

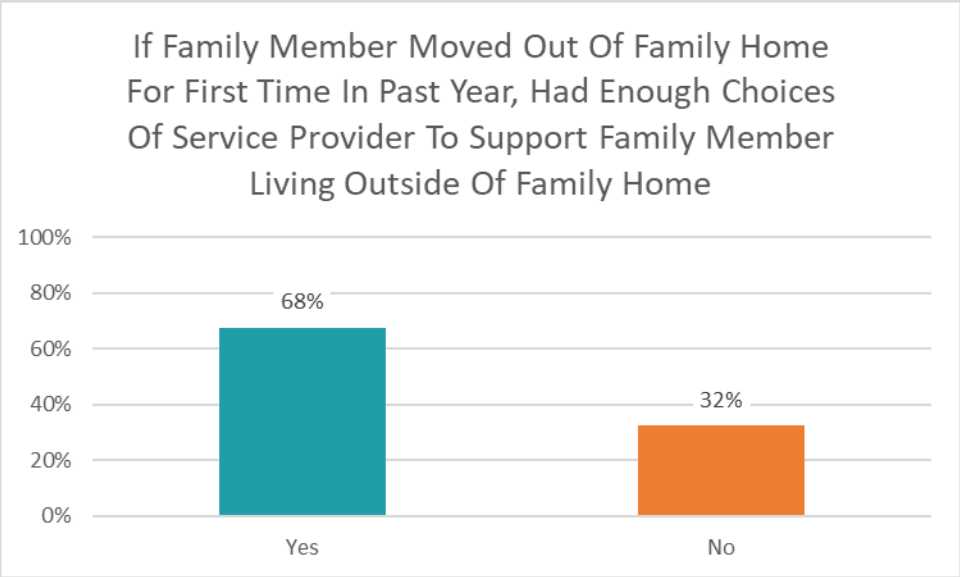


Table Q7. If family member moved out of the home for the first time in the past year, did you have enough choices of service providers to support your family member living outside the family home?

Within Average Range

State	Yes	No	N
NCI Average	**68%**	**32%**	**148**
MD	66%	34%	38
AZ	55%	45%	20

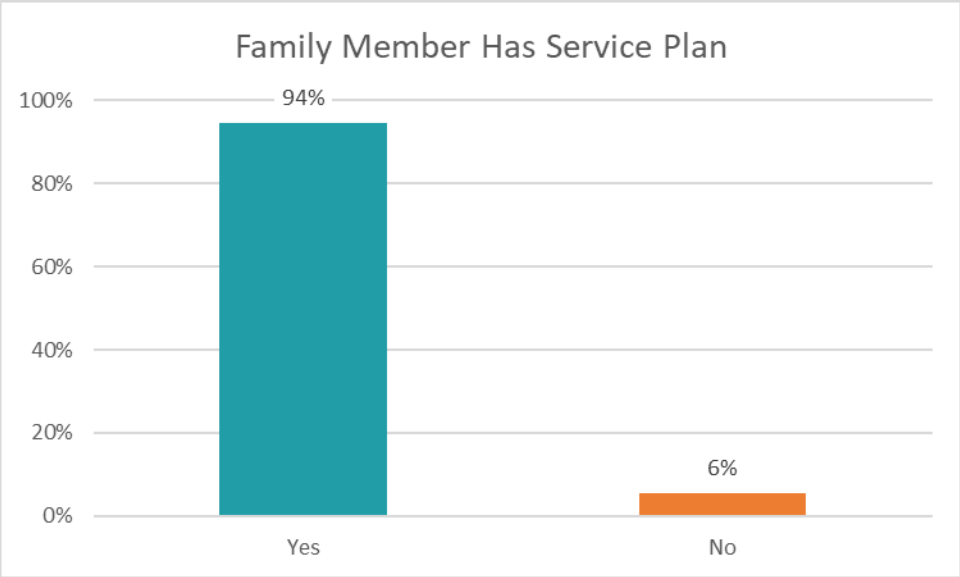


Table Q8. Does your family member have a service plan?

Significantly Above Average

State	Yes	No	N
FL	97%	3%	307

Within Average Range

State	Yes	No	N
NH	96%	4%	400
PA	96%	4%	621
NCI Average	**94%**	**6%**	**3,976**
NC	94%	6%	207
UT	93%	7%	298
WA	93%	7%	342
AZ	93%	7%	248
GA	92%	8%	302
SD	92%	8%	398

Significantly Below Average

State	Yes	No	N
MD	91%	9%	853

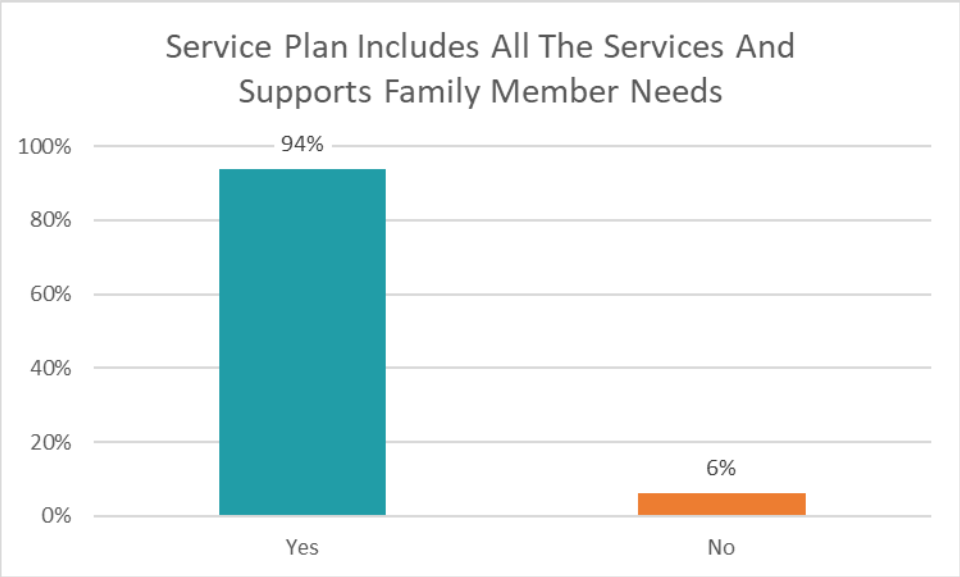


Table Q9. Does the plan include all the services and supports your family member needs?

Significantly Above Average

State	Yes	No	N
PA	97%	3%	549

Within Average Range

State	Yes	No	N
FL	95%	5%	277
SD	94%	6%	340
NCI Average	**94%**	**6%**	**3,393**
AZ	94%	6%	216
NC	94%	6%	185
UT	93%	7%	241
NH	92%	8%	363
WA	90%	10%	294

Significantly Below Average

State	Yes	No	N
MD	90%	10%	683
GA	88%	12%	245

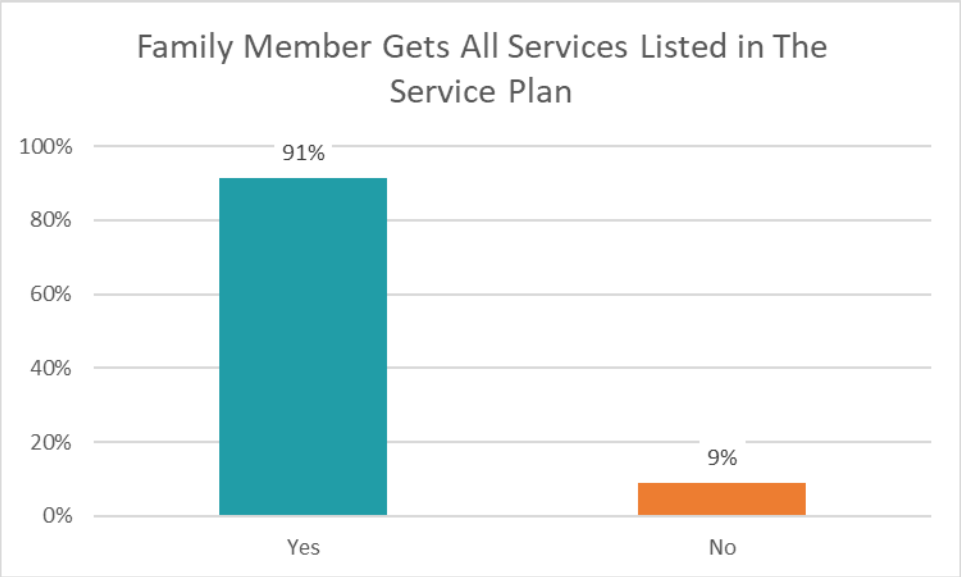


Table Q10. Does your family member get all of the services listed in the plan?

Significantly Above Average

State	Yes	No	N
PA	94%	6%	510

Within Average Range

State	Yes	No	N
NC	95%	5%	178
UT	92%	8%	224
FL	91%	9%	255
NCI Average	**91%**	**9%**	**3,149**
NH	90%	10%	341
GA	89%	11%	217
WA	89%	11%	270
AZ	88%	12%	208

Significantly Below Average

State	Yes	No	N
MD	86%	14%	630
SD	85%	15%	316

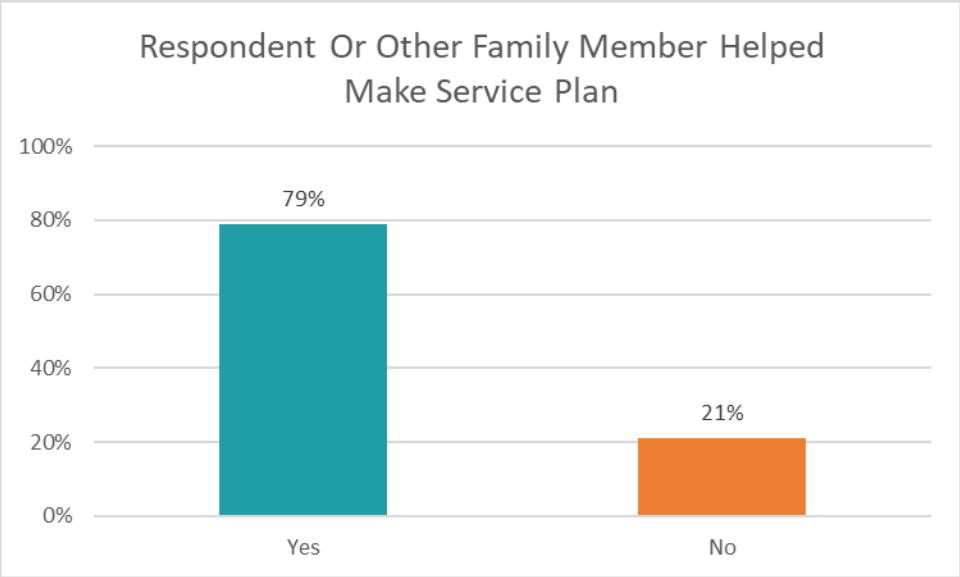


Table Q11. Did you or another family member help make the plan?

Significantly Above Average

State	Yes	No	N
NH	89%	11%	365
UT	89%	11%	253
NC	86%	14%	181

Within Average Range

State	Yes	No	N
SD	86%	14%	335
AZ	83%	17%	220
MD	82%	18%	720
GA	80%	20%	260
NCI Average	**79%**	**21%**	**3,477**
FL	77%	23%	286
WA	76%	24%	294
SD	86%	14%	335

Significantly Below Average

State	Yes	No	N
PA	74%	26%	563

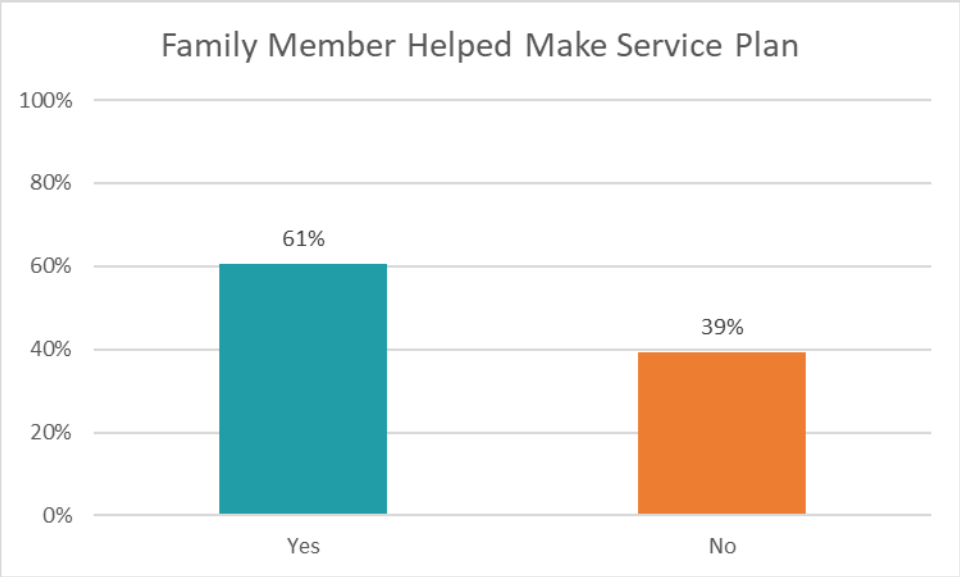


Table Q12. Did your family member help make the plan?

Significantly Above Average

State	Yes	No	N
SD	75%	25%	343
WA	70%	30%	289
MD	68%	32%	699

Within Average Range

State	Yes	No	N
UT	68%	32%	246
FL	64%	36%	280
NCI Average	**61%**	**39%**	**3,398**
NH	60%	40%	359
GA	60%	40%	254
NC	58%	42%	180

Significantly Below Average

State	Yes	No	N
PA	54%	46%	532
AZ	45%	55%	216

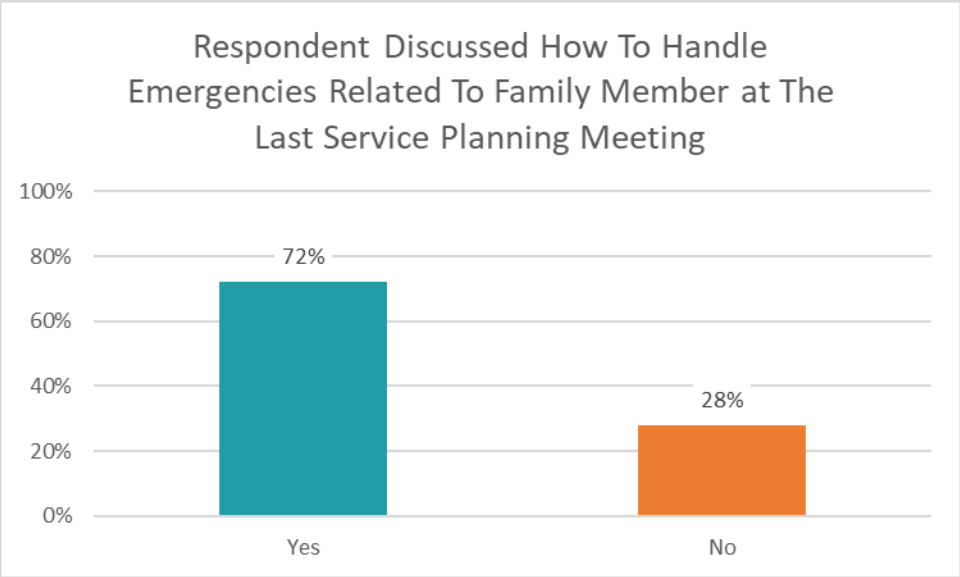


Table Q13. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?

Significantly Above Average

State	Yes	No	N
FL	84%	16%	257

Within Average Range

State	Yes	No	N
NC	77%	23%	177
WA	76%	24%	248
NCI Average	**72%**	**28%**	**3,091**
PA	71%	29%	459
SD	69%	31%	308
UT	66%	34%	235
NH	61%	39%	323

Significantly Below Average

State	Yes	No	N
GA	60%	40%	235
AZ	57%	43%	203
MD	57%	43%	646

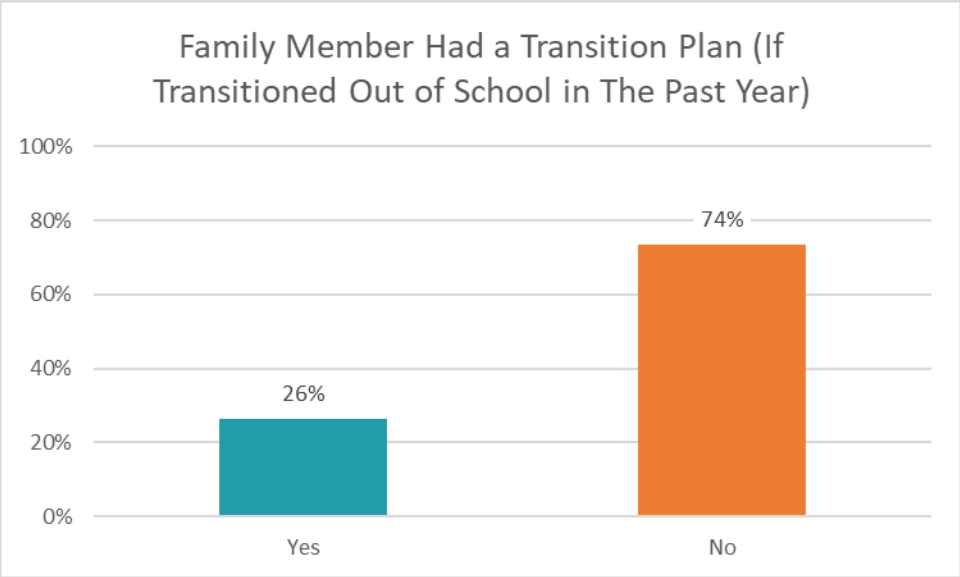


Table Q14. If your family member transitioned out of school services during the past year, did s/he have a transition plan?

Within Average Range

State	Yes	No	N
SD	38%	62%	21
MD	35%	65%	20
NCI Average	**26%**	**74%**	**143**

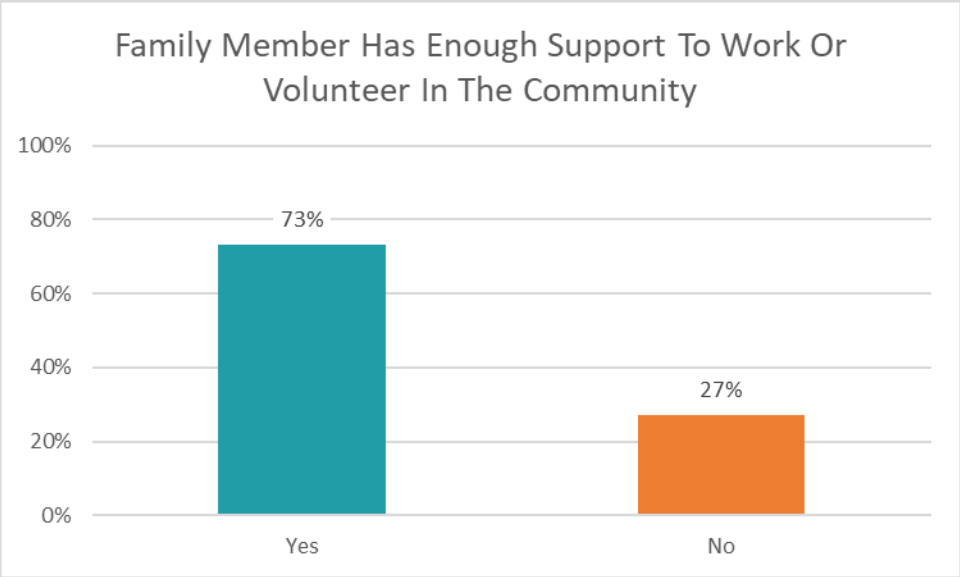


Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

Significantly Above Average

State	Yes	No	N
PA	80%	20%	373

Within Average Range

State	Yes	No	N
UT	80%	20%	233
NH	79%	21%	311
WA	76%	24%	279
SD	73%	27%	347
NCI Average	**73%**	**27%**	**2,910**
NC	73%	27%	170
FL	69%	31%	167
GA	67%	33%	218
AZ	63%	37%	142

Significantly Below Average

State	Yes	No	N
MD	66%	34%	670

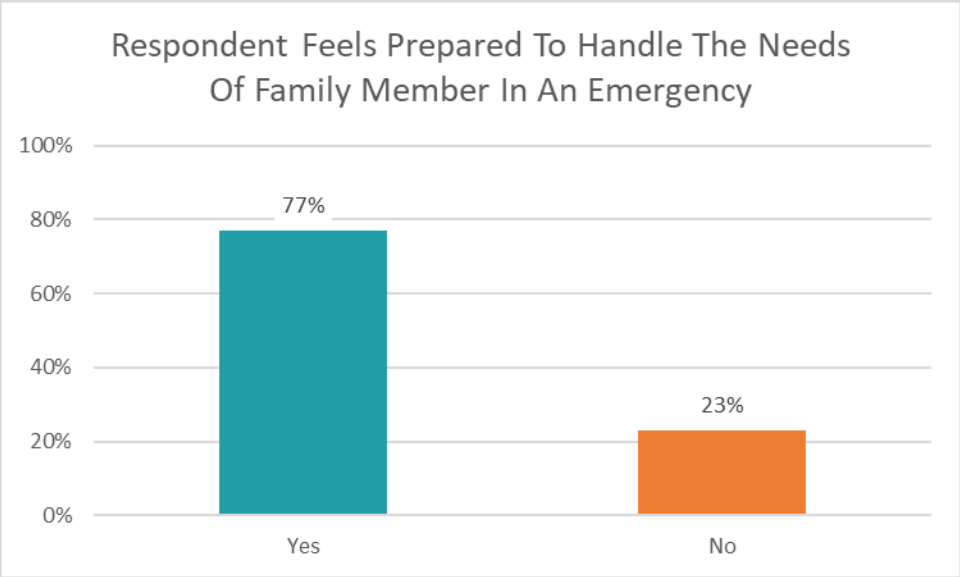


Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

Significantly Above Average

State	Yes	No	N
SD	84%	16%	408
FL	83%	17%	293

Within Average Range

State	Yes	No	N
WA	81%	19%	331
NC	80%	20%	199
AZ	79%	21%	242
NCI Average	**77%**	**23%**	**3,953**
GA	75%	25%	343
PA	74%	26%	568
NH	74%	26%	367

Significantly Below Average

State	Yes	No	N
UT	69%	31%	316
MD	66%	34%	886

Access and Delivery of Services and Supports

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

Note: Significance is based on "Always" or "Yes" response.

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

"**Family Member**" refers to the person receiving services whom the respondent is answering questions about in this survey.

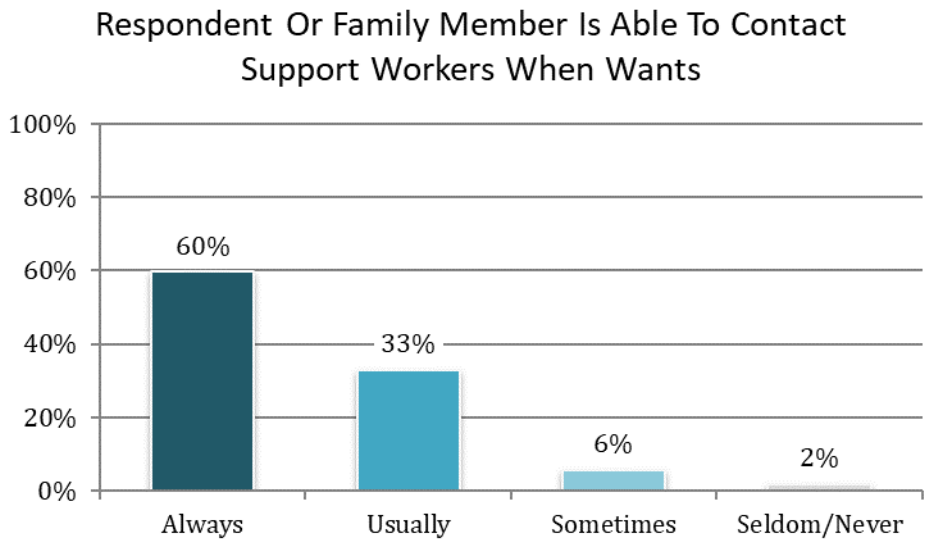


Table Q17. Are you or your family member able to contact his/her support workers when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	73%	21%	4%	2%	316

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	62%	35%	2%	1%	221
PA	61%	33%	5%	1%	686
UT	60%	33%	5%	2%	361
NH	60%	31%	5%	3%	426
NCI Average	**60%**	**33%**	**6%**	**2%**	**4,567**
WA	56%	37%	6%	2%	396

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	53%	38%	8%	1%	483
GA	51%	38%	7%	4%	390
AZ	50%	40%	8%	2%	263
MD	47%	40%	10%	3%	1,025

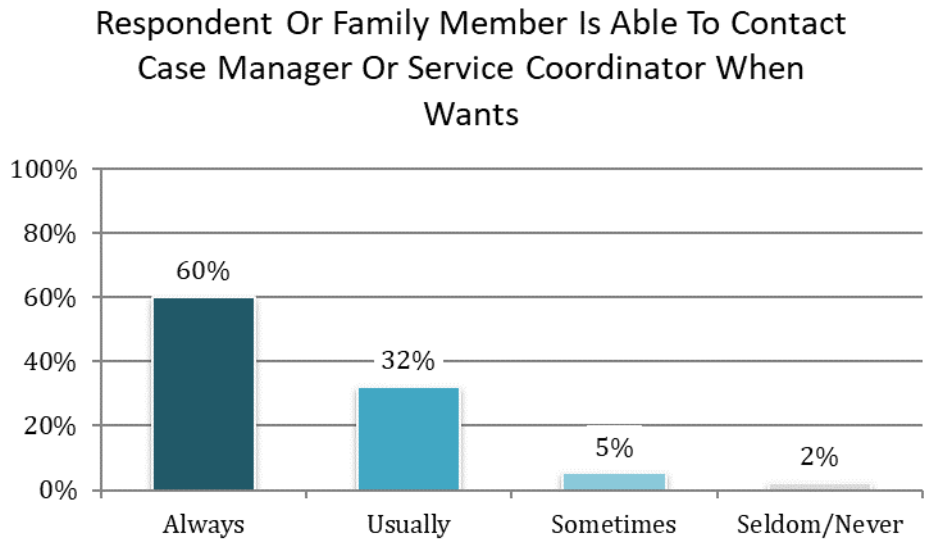


Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	72%	22%	3%	2%	318

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	67%	28%	4%	2%	222
UT	66%	28%	5%	1%	363
NCI Average	**60%**	**32%**	**5%**	**2%**	**4,600**
PA	60%	34%	4%	1%	687
NH	60%	32%	6%	2%	441
WA	57%	34%	7%	2%	397
SD	57%	35%	7%	1%	487

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	50%	37%	8%	4%	384
AZ	49%	41%	7%	3%	274
MD	49%	39%	8%	4%	1,027

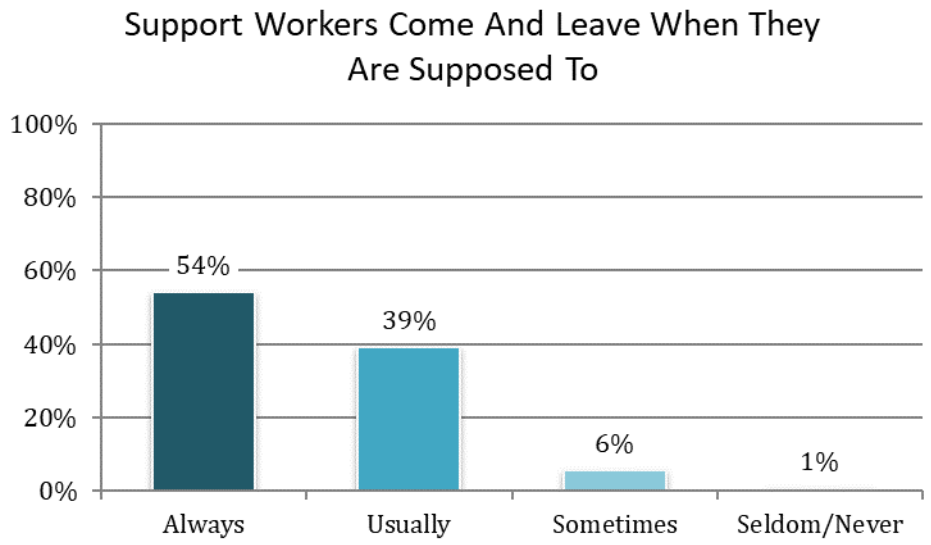


Table Q19. Do support workers come and leave when they are supposed to?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
FL	62%	32%	5%	1%	267
UT	62%	34%	2%	2%	271
NC	57%	36%	7%	0%	168
PA	56%	40%	4%	0%	417
WA	55%	41%	4%	0%	310
NCI Average	**54%**	**39%**	**6%**	**1%**	**3,228**
NH	53%	43%	4%	1%	329
SD	49%	44%	6%	1%	320
GA	48%	45%	5%	2%	255

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	44%	44%	10%	3%	197
MD	42%	48%	9%	1%	694

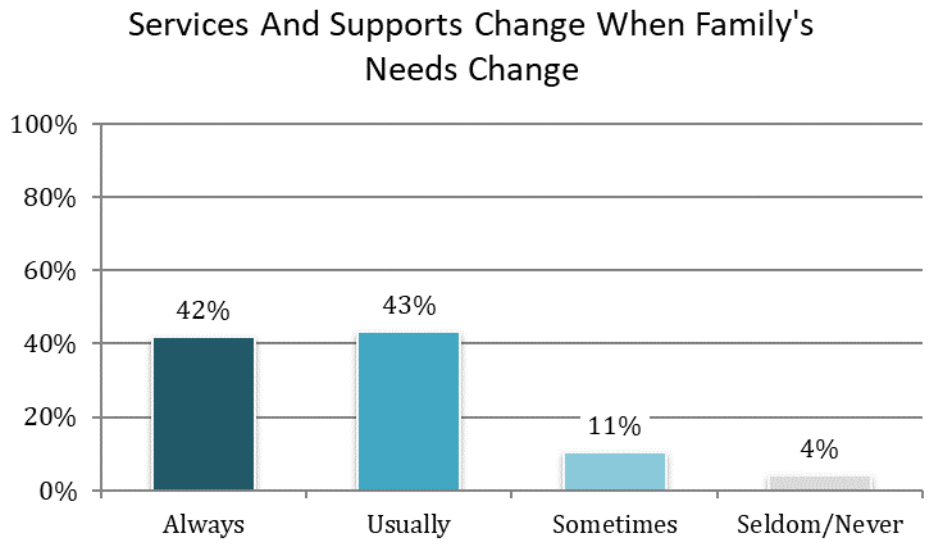


Table Q20. Do services and supports change when your family's needs change?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	50%	35%	12%	3%	255

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
UT	49%	39%	9%	3%	261
PA	43%	46%	7%	3%	458
NH	42%	42%	11%	5%	322
NCI Average	**42%**	**43%**	**11%**	**4%**	**3,268**
NC	42%	44%	10%	4%	180
SD	39%	42%	15%	3%	379
WA	39%	47%	9%	5%	296

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	34%	48%	12%	6%	264
MD	33%	46%	15%	6%	666
AZ	33%	48%	13%	6%	187

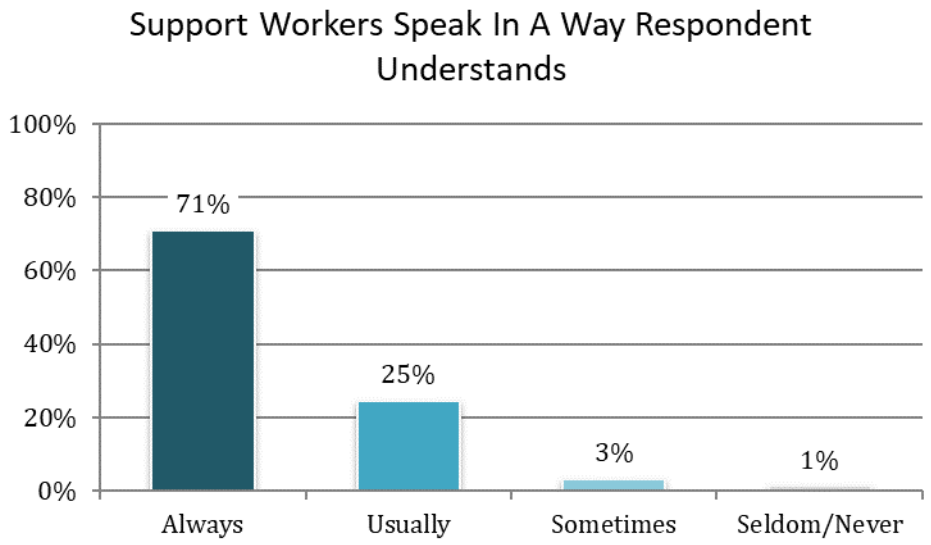


Table Q21. Do support workers speak to you in a way that you understand?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
UT	76%	21%	1%	1%	353
FL	76%	19%	3%	2%	315
NH	75%	23%	1%	1%	406
PA	74%	23%	2%	1%	665
WA	72%	24%	3%	1%	398
NCI Average	**71%**	**25%**	**3%**	**1%**	**4,431**
NC	70%	25%	4%	0%	210
AZ	64%	28%	6%	2%	258

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	65%	31%	4%	1%	477
MD	62%	31%	5%	2%	979
GA	62%	33%	3%	2%	370

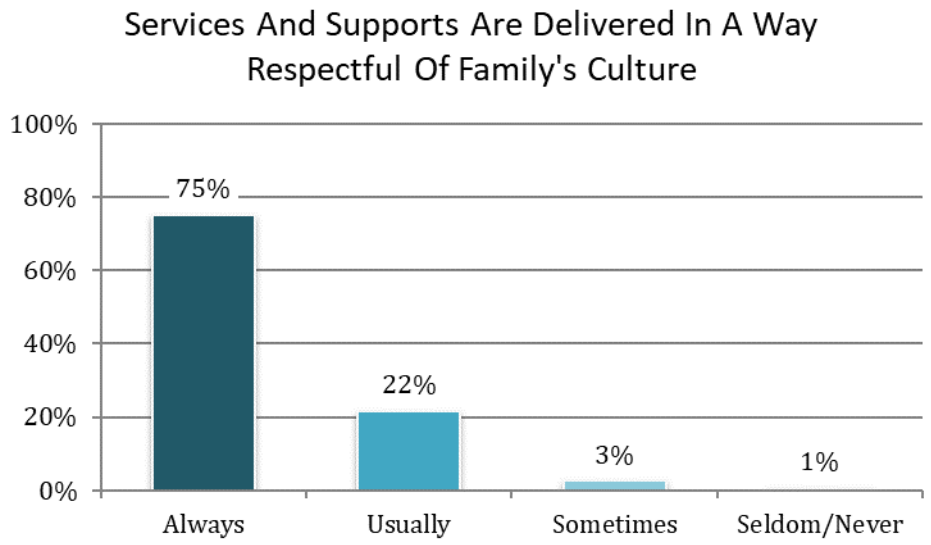


Table Q22. Are services delivered in a way that is respectful of your family's culture?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	81%	17%	2%	0%	315

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	78%	19%	2%	1%	650
NH	77%	19%	3%	1%	417
WA	76%	21%	2%	1%	388
UT	76%	22%	1%	1%	346
NCI Average	**75%**	**22%**	**3%**	**1%**	**4,405**
AZ	75%	21%	3%	1%	256
NC	72%	25%	2%	0%	216
SD	71%	26%	2%	1%	461

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	67%	28%	4%	1%	362
MD	65%	28%	5%	2%	994

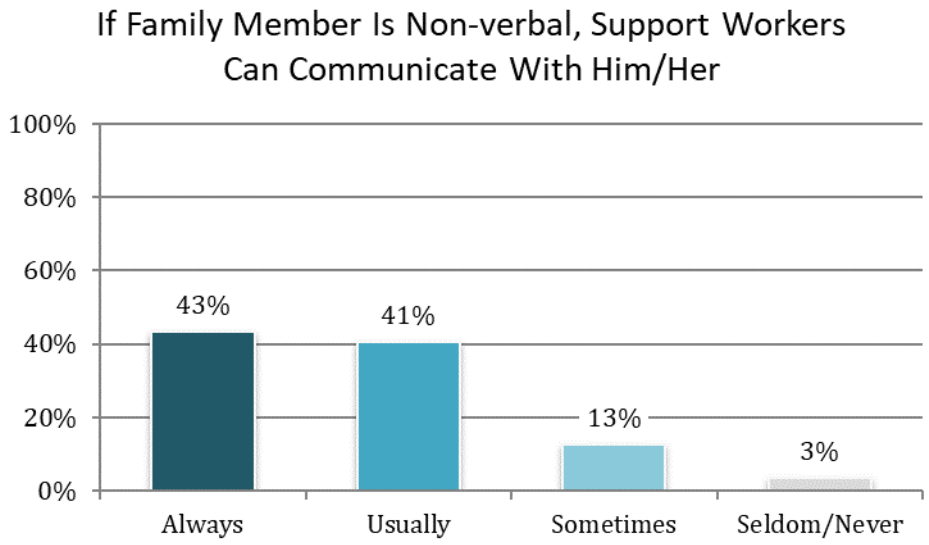


Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	54%	30%	14%	2%	50
PA	48%	39%	10%	4%	193
UT	47%	33%	12%	8%	91
NCI Average	**43%**	**41%**	**13%**	**3%**	**1,062**
WA	42%	42%	15%	1%	67
GA	41%	43%	13%	3%	111
FL	40%	44%	12%	4%	52
MD	38%	43%	15%	3%	229
NH	36%	50%	12%	2%	101
AZ	31%	41%	20%	7%	70

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	31%	56%	11%	2%	98

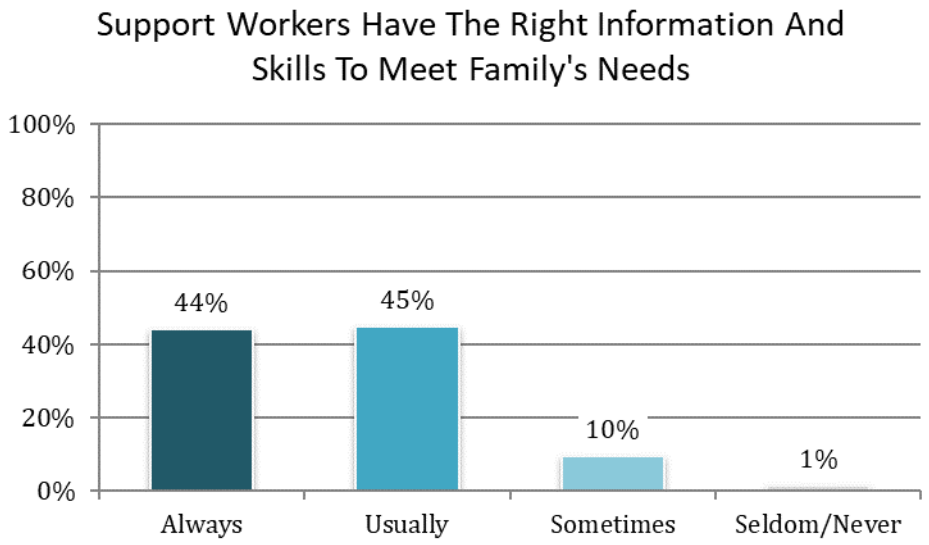


Table Q24. Do support workers have the right information and skills to meet your family's needs?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	55%	37%	7%	2%	303

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	49%	41%	10%	0%	212
UT	47%	43%	10%	0%	335
WA	44%	45%	9%	1%	374
NCI Average	**44%**	**45%**	**10%**	**1%**	**4,194**
PA	43%	49%	8%	0%	610
NH	42%	46%	11%	2%	386
GA	41%	47%	10%	2%	355

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	37%	48%	12%	2%	443
MD	34%	49%	14%	3%	928
AZ	33%	51%	13%	3%	248

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

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	67%	28%	4%	2%	436

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	60%	31%	4%	5%	124
NCI Average	**60%**	**32%**	**5%**	**3%**	**2,786**
UT	59%	33%	7%	2%	243
FL	59%	35%	4%	2%	182
GA	59%	34%	5%	3%	228
NH	58%	33%	6%	2%	257
SD	58%	35%	6%	2%	295
WA	58%	34%	5%	3%	238
AZ	56%	36%	6%	3%	169

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	52%	34%	9%	4%	614

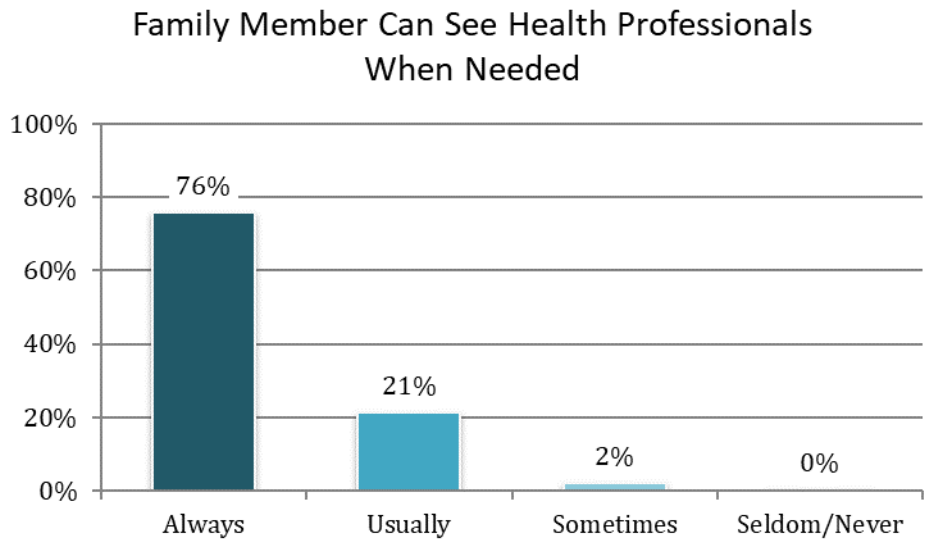


Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	80%	19%	1%	0%	697

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	80%	18%	2%	0%	445
FL	80%	17%	2%	1%	324
NCI Average	**76%**	**21%**	**2%**	**0%**	**4,686**
GA	75%	22%	3%	1%	396
NC	75%	23%	2%	0%	231
SD	75%	24%	2%	0%	489
AZ	73%	24%	2%	1%	275
WA	72%	24%	4%	0%	407
UT	71%	25%	3%	1%	360

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	68%	27%	4%	1%	1,062

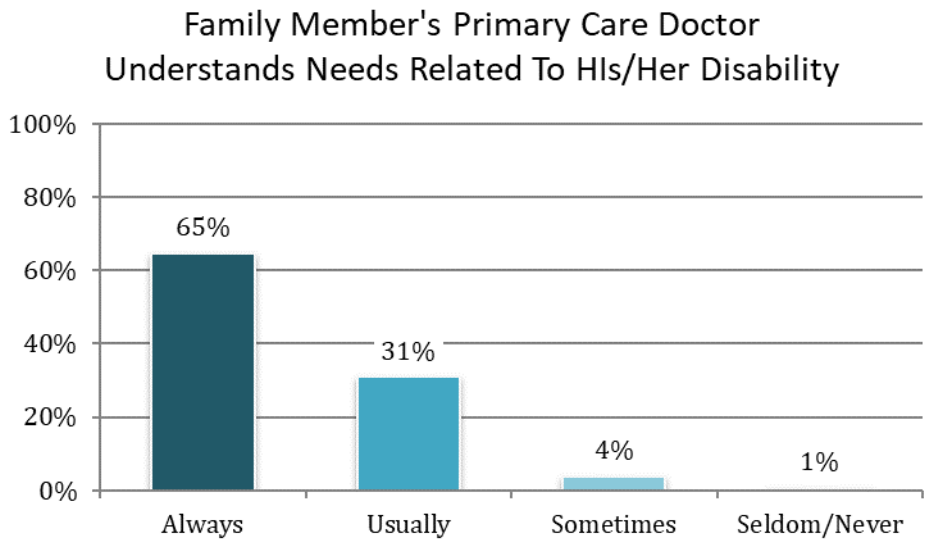


Table Q27. Does your family member's primary care doctor understand his/her needs related to his/her disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	71%	26%	3%	1%	625

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
FL	66%	30%	3%	1%	302
UT	66%	28%	5%	2%	319
NCI Average	**65%**	**31%**	**4%**	**1%**	**4,276**
NC	64%	32%	4%	0%	216
NH	62%	32%	5%	1%	410
MD	62%	31%	6%	1%	947
GA	61%	34%	4%	1%	352
SD	60%	37%	3%	0%	462
WA	60%	36%	3%	1%	379
AZ	59%	36%	5%	0%	264

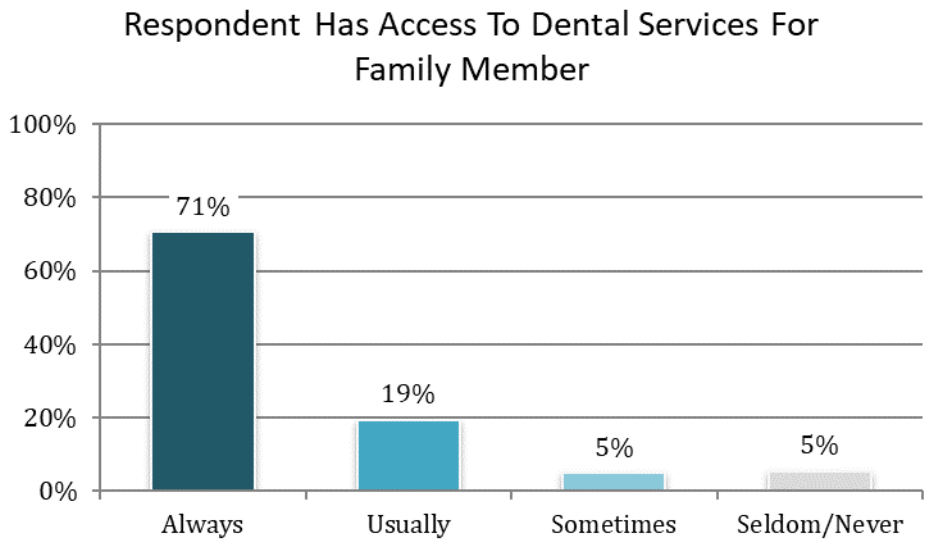


Table Q28. Do you have access to dental services for your family member?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	80%	17%	0%	2%	470
PA	78%	16%	3%	3%	661

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	74%	19%	3%	4%	219
NCI Average	**71%**	**19%**	**5%**	**5%**	**4,423**
NH	68%	17%	7%	8%	422
FL	67%	22%	5%	5%	313
MD	66%	22%	5%	7%	987
WA	66%	19%	7%	7%	389
UT	65%	18%	8%	9%	334
GA	65%	20%	7%	8%	363
AZ	65%	23%	5%	7%	265

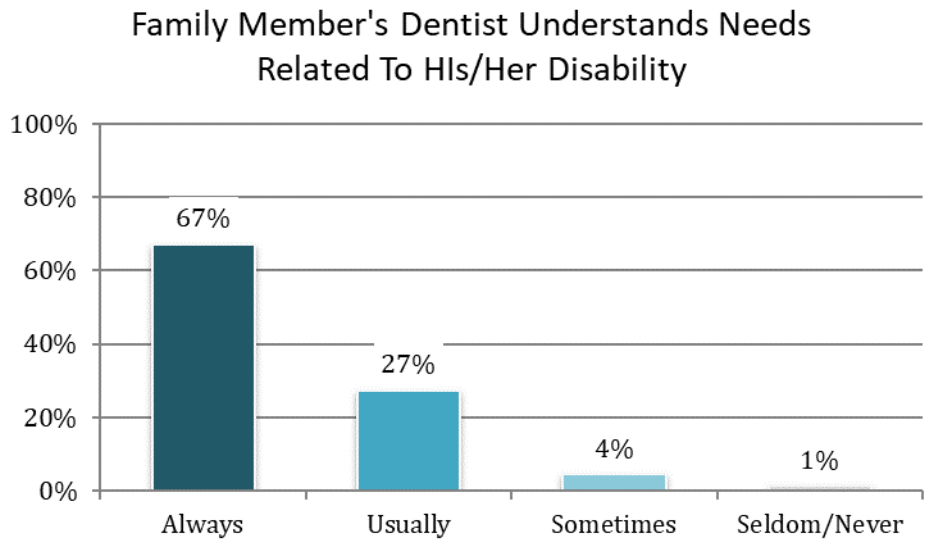


Table Q29. If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	75%	22%	3%	1%	268

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	71%	26%	3%	0%	421
PA	70%	26%	4%	1%	568
UT	67%	24%	7%	2%	284
NCI Average	**67%**	**27%**	**4%**	**1%**	**3,779**
NH	64%	29%	6%	1%	364
MD	64%	30%	5%	2%	837
GA	63%	29%	5%	3%	299
NC	62%	33%	4%	1%	190
WA	62%	30%	7%	1%	323
AZ	60%	32%	8%	1%	225

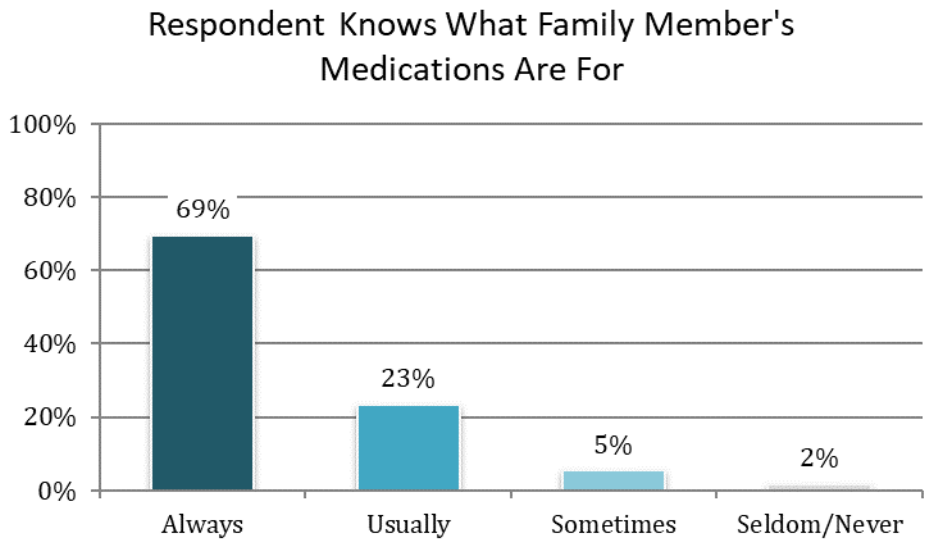


Table Q30. If your family member takes medications, do you know what they're for?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	78%	20%	2%	0%	253
NH	77%	18%	4%	1%	406

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
FL	73%	22%	4%	1%	310
NC	72%	21%	5%	1%	225
WA	72%	19%	7%	2%	380
NCI Average	**69%**	**23%**	**5%**	**2%**	**4,373**
GA	68%	24%	6%	2%	363
UT	67%	24%	6%	2%	335
PA	66%	27%	5%	2%	659

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	63%	27%	8%	2%	984
SD	59%	29%	9%	2%	458

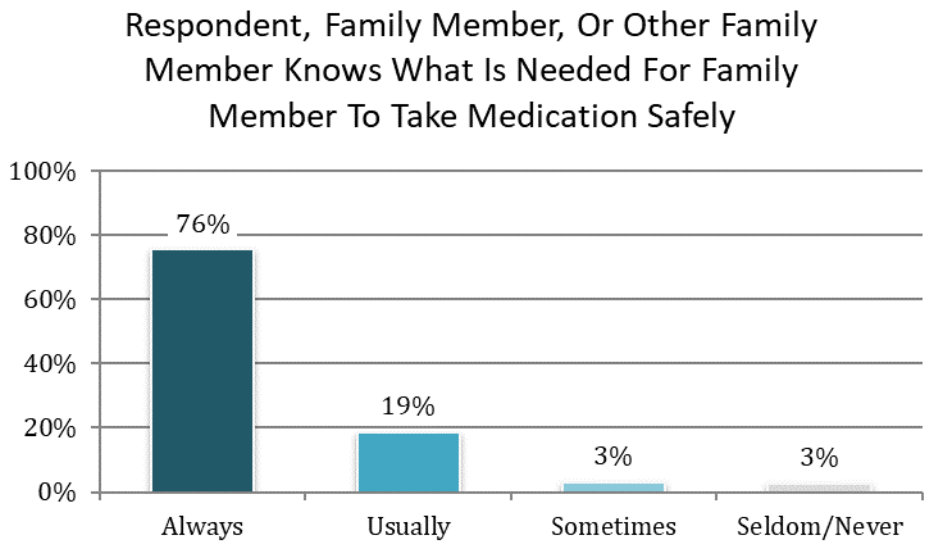


Table Q31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	82%	15%	2%	1%	300

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	82%	14%	1%	3%	217
AZ	82%	15%	1%	2%	244
NH	80%	16%	1%	3%	384
GA	76%	18%	2%	4%	346
NCI Average	**76%**	**19%**	**3%**	**3%**	**4,084**
WA	75%	18%	4%	3%	365
PA	71%	22%	4%	4%	586
UT	69%	22%	5%	3%	318

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	67%	24%	6%	4%	900
SD	66%	25%	7%	3%	424

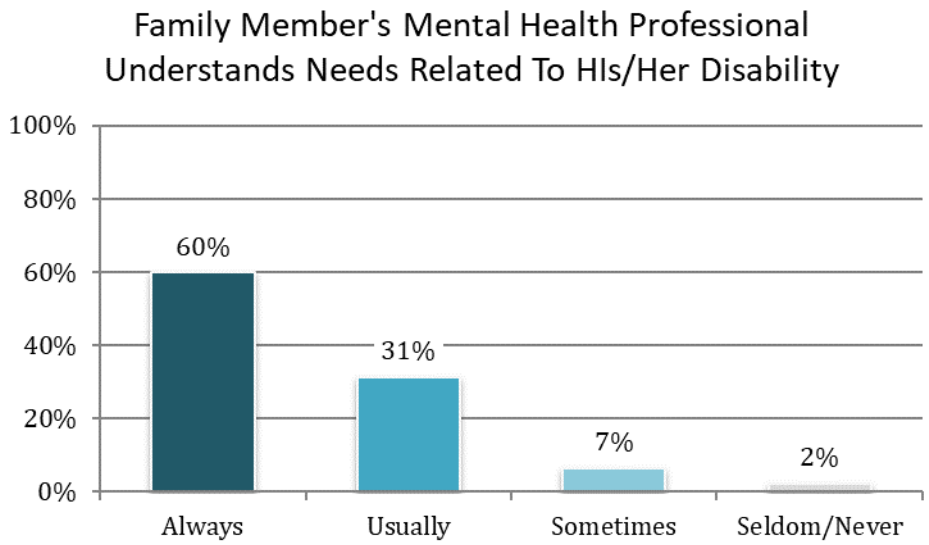


Table Q32. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
FL	68%	27%	3%	2%	180
UT	62%	26%	7%	5%	196
NCI Average	**60%**	**31%**	**7%**	**2%**	**2,557**
NC	60%	36%	3%	2%	169
SD	60%	29%	8%	3%	283
PA	60%	31%	8%	1%	411
AZ	59%	31%	8%	2%	147
NH	57%	32%	8%	4%	222
GA	57%	37%	4%	2%	217
WA	55%	29%	9%	7%	170

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	54%	34%	9%	3%	562

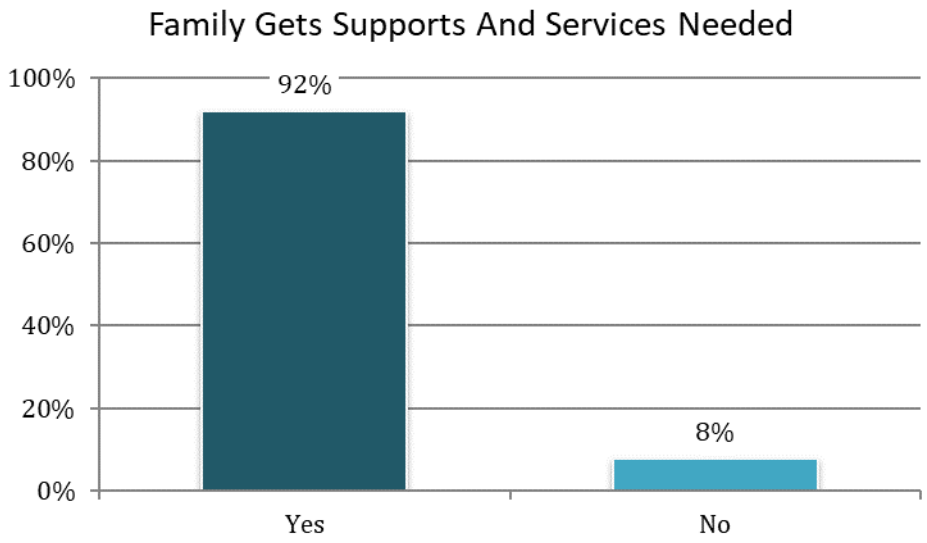


Table Q33. Does your family get the support and services needed?

Significantly Above Average

State	Yes	No	N
PA	95%	5%	636

Within Average Range

State	Yes	No	N
FL	94%	6%	294
SD	93%	7%	437
AZ	93%	7%	252
NCI Average	**92%**	**8%**	**4,191**
NC	91%	9%	222
GA	90%	10%	347
UT	90%	10%	319
WA	89%	11%	359
NH	89%	11%	409

Significantly Below Average

State	Yes	No	N
MD	86%	14%	916

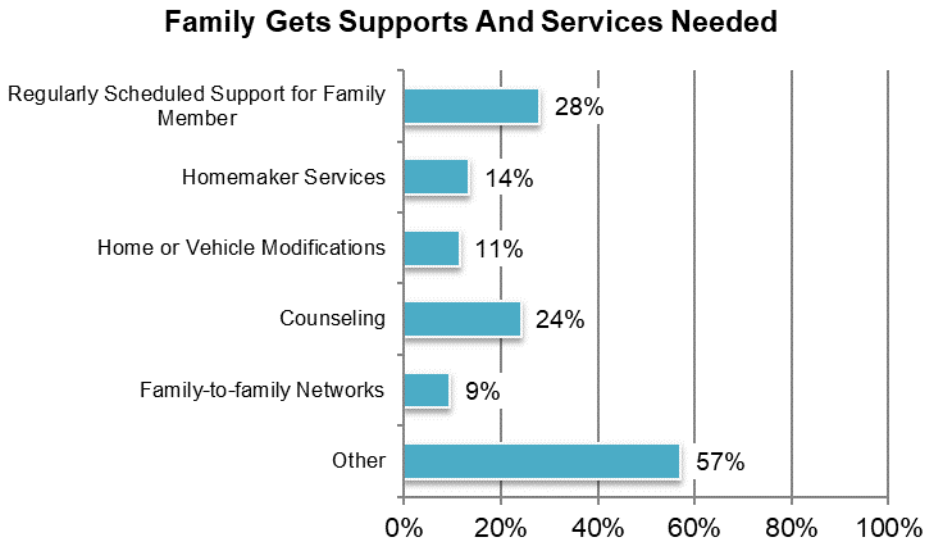


Table Q34. What additional services and supports are needed?

State	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Other
FL	29%	10%	6%	23%	6%	53%
GA	13%	0%	0%	8%	0%	42%
MD	32%	11%	7%	26%	6%	60%
PA	35%	15%	16%	26%	14%	64%
SD	36%	24%	18%	33%	16%	68%
UT	33%	12%	9%	26%	10%	64%
WA	17%	8%	4%	12%	0%	48%
NCI Average	**28%**	**14%**	**11%**	**24%**	**9%**	**57%**

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.

Note: Significance is based on "Always" or "Yes" response.

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

"**Family Member**" refers to the person receiving services whom the respondent is answering questions about in this survey.

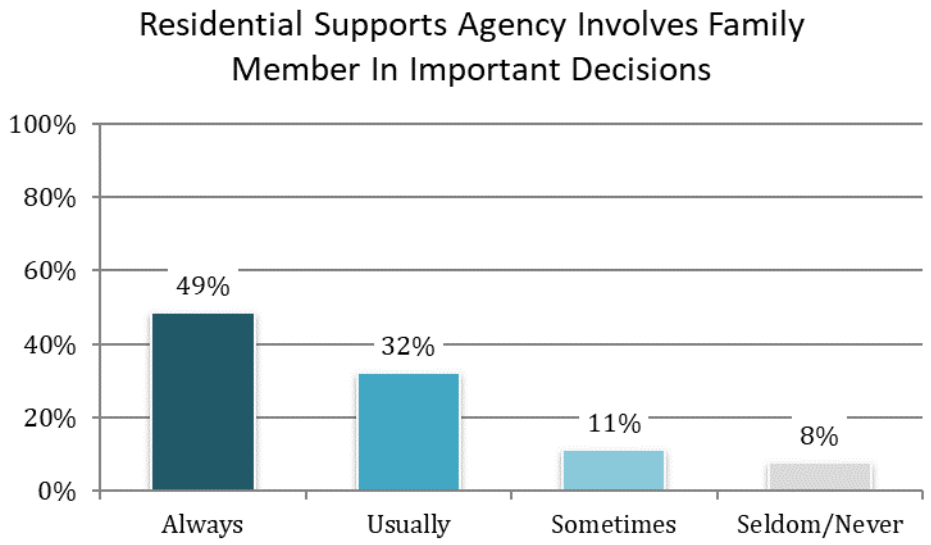


Table Q35. Does the agency providing residential services to your family member involve him/her in important decisions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	58%	27%	7%	8%	283

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	52%	28%	13%	7%	373
NCI Average	**49%**	**32%**	**11%**	**8%**	**3,891**
PA	49%	33%	10%	7%	568
WA	49%	35%	11%	5%	332
NC	48%	33%	11%	7%	201
UT	47%	31%	14%	8%	312
SD	46%	40%	12%	2%	440
GA	43%	30%	15%	12%	310

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	40%	36%	16%	8%	838
AZ	36%	34%	19%	11%	234

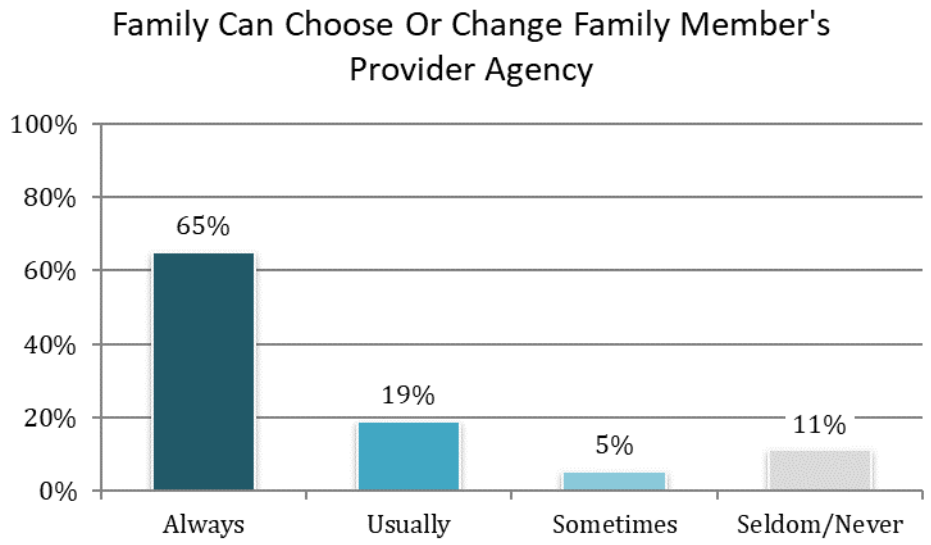


Table Q36. Can your family choose or change the agency that provides your family member's services?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	75%	15%	2%	7%	254
UT	73%	17%	4%	6%	271

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	67%	20%	5%	8%	177
NH	66%	16%	5%	13%	267
NCI Average	**65%**	**19%**	**5%**	**11%**	**2,974**
PA	63%	16%	5%	16%	370
GA	62%	23%	5%	10%	270
WA	60%	23%	8%	9%	240
AZ	57%	21%	9%	13%	206

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	57%	21%	5%	17%	326
MD	55%	24%	7%	14%	593

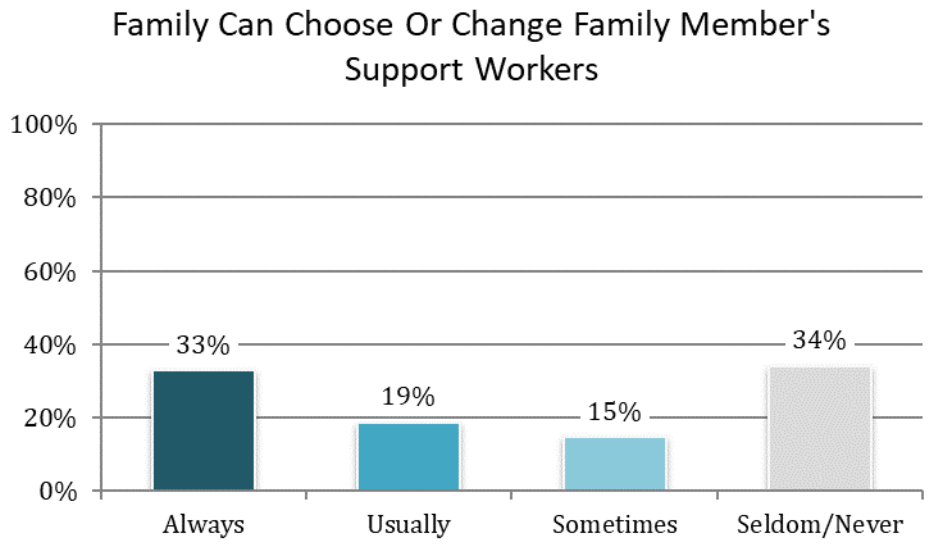


Table Q37. Can your family choose or change your family member's support workers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	49%	18%	13%	21%	236

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	40%	18%	13%	29%	168
NH	38%	23%	13%	26%	315
GA	36%	15%	13%	36%	256
NCI Average	**33%**	**19%**	**15%**	**34%**	**3,058**
WA	33%	24%	14%	29%	252
UT	31%	18%	11%	40%	267
AZ	27%	20%	13%	40%	198

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	23%	17%	18%	43%	417
SD	21%	21%	11%	47%	307
MD	19%	17%	17%	46%	642

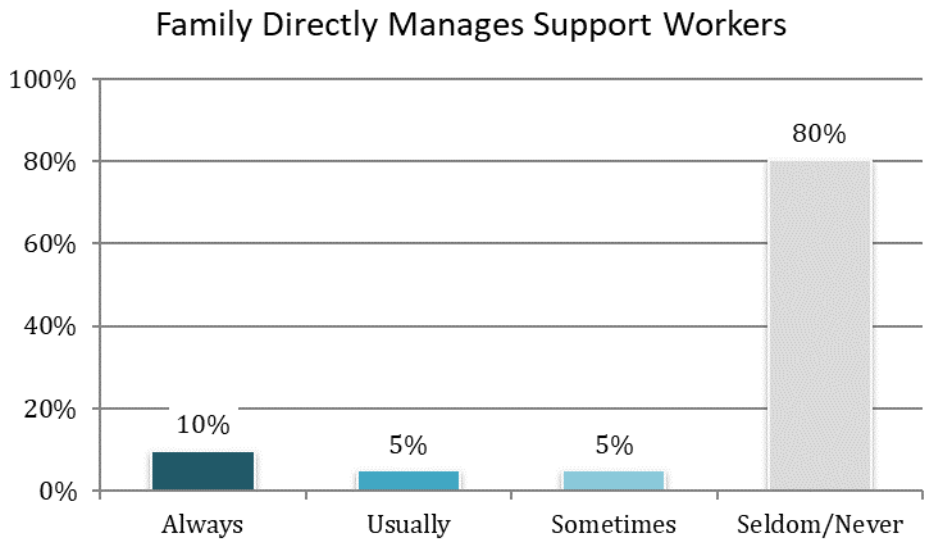


Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	24%	8%	4%	64%	228

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
GA	10%	6%	5%	78%	275
NCI Average	**10%**	**5%**	**5%**	**80%**	**3,447**
NC	10%	7%	6%	78%	166
WA	9%	7%	8%	77%	288
NH	9%	6%	6%	80%	324
UT	7%	3%	2%	88%	291
AZ	6%	2%	4%	87%	178

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	4%	4%	6%	87%	809
PA	4%	3%	4%	89%	521
SD	3%	2%	3%	92%	367

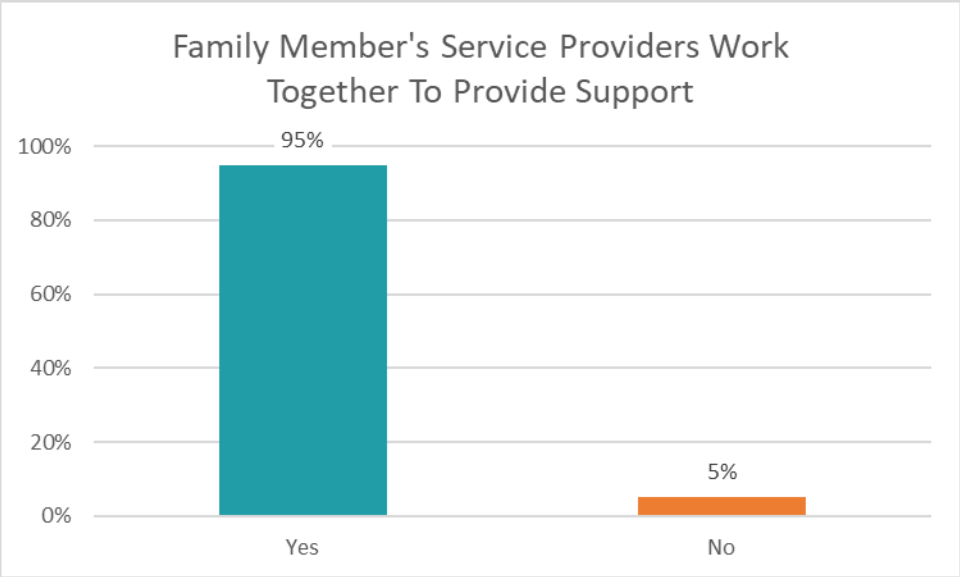


Table Q39. Do service providers for your family member work together to provide support? (For example, does the agency providing transportation work together with the agency providing in-home support if necessary?)

Significantly Above Average

State	Yes	No	N
UT	98%	2%	291

Within Average Range

State	Yes	No	N
FL	97%	3%	247
PA	96%	4%	456
GA	96%	4%	263
NH	95%	5%	305
NCI Average	**95%**	**5%**	**3,341**
SD	95%	5%	355
AZ	94%	6%	198
NC	94%	6%	175
WA	92%	8%	288

Significantly Below Average

State	Yes	No	N
MD	92%	8%	763

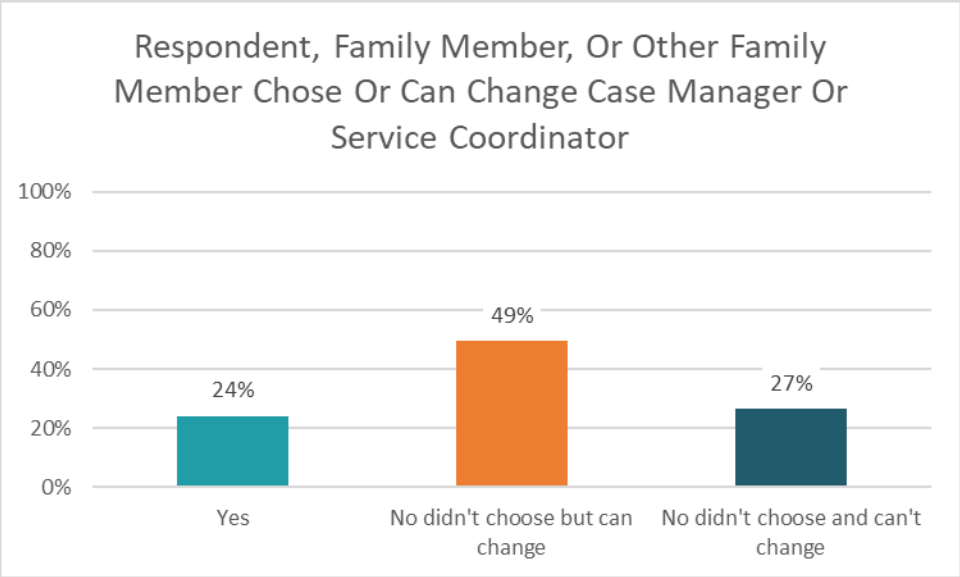


Table Q40. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

Significantly Above Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
FL	60%	33%	7%	291

Within Average Range

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
NCI Average	**24%**	**49%**	**27%**	**3,937**
NC	18%	48%	35%	185

Significantly Below Average

State	Yes, Chose	Didn't Choose but Can Change	Didn't Choose and Cannot Change	N
GA	17%	51%	33%	338
NH	15%	65%	21%	382
MD	13%	53%	34%	869
PA	11%	52%	37%	569
AZ	10%	69%	21%	248
WA	7%	62%	31%	310

Involvement in the Community

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

Note: Significance is based on "Always" or "Yes" response.

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

"**Family Member**" refers to the person receiving services whom the respondent is answering questions about in this survey.

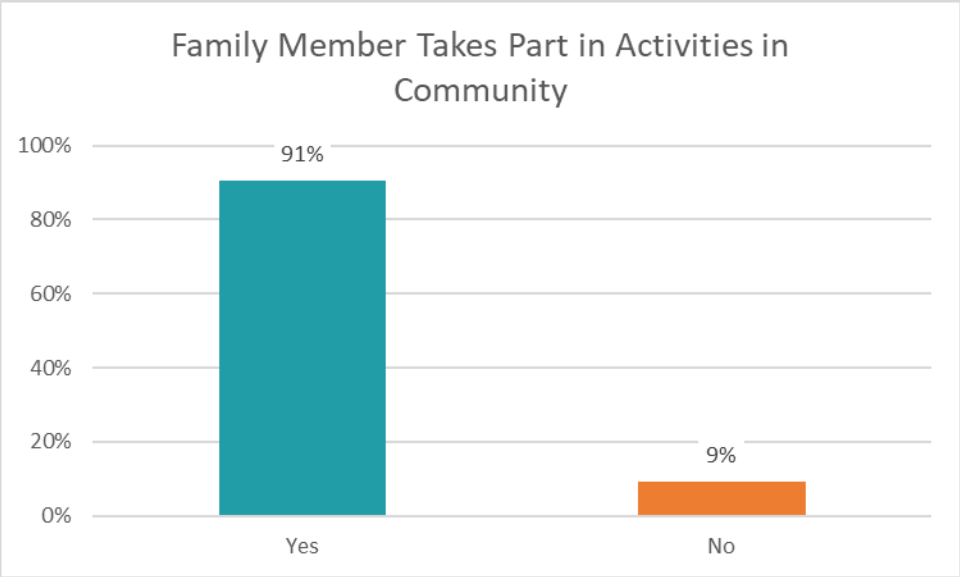


Table Q41. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

Within Average Range

State	Yes	No	N
GA	94%	6%	372
UT	93%	7%	352
NH	93%	7%	438
NC	92%	8%	224
FL	92%	8%	310
PA	92%	8%	697
SD	92%	8%	474
NCI Average	**91%**	**9%**	**4,566**
AZ	89%	11%	264
MD	89%	11%	1,031
WA	86%	14%	404

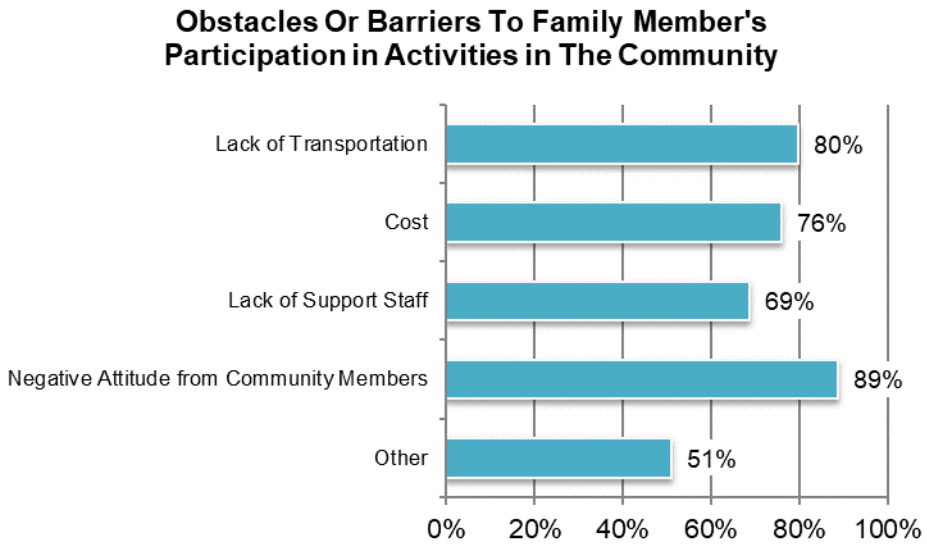


Table Q42. For your family member, what are the obstacles or barriers to participation in activities in the community?

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitude from Community Members	Other	N
AZ	84%	80%	62%	87%	50%	196
FL	82%	74%	76%	91%	51%	225
GA	84%	75%	74%	87%	51%	294
MD	75%	75%	59%	88%	59%	761
NH	71%	68%	65%	86%	60%	295
NC	80%	65%	66%	84%	56%	151
PA	86%	86%	72%	91%	41%	519
SD	69%	65%	48%	91%	71%	355
UT	71%	67%	60%	90%	51%	260
WA	71%	72%	70%	88%	54%	356
NCI Average	**80%**	**76%**	**69%**	**89%**	**51%**	**3,412**

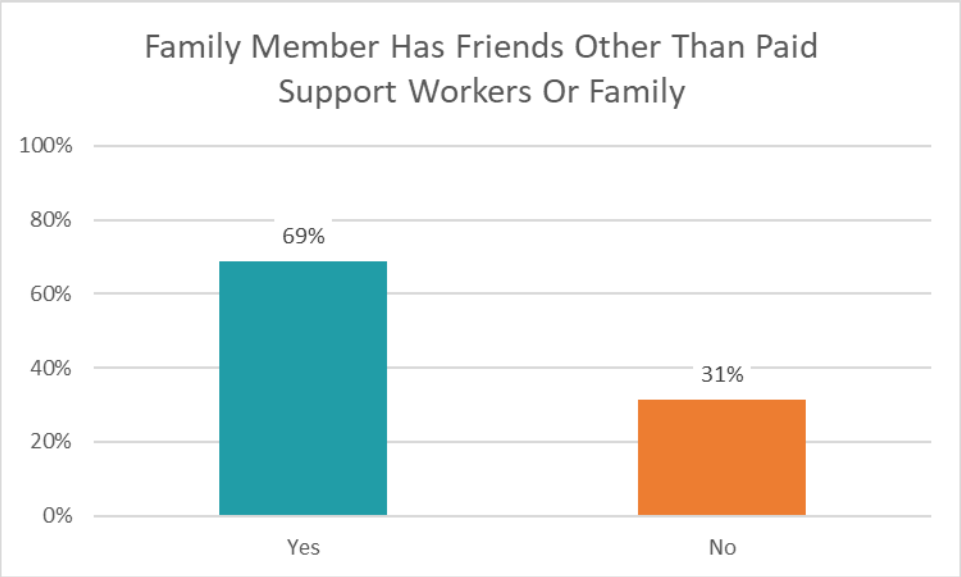


Table Q43. Does your family member have friends other than paid support workers or family?

Significantly Above Average

State	Yes	No	N
SD	81%	19%	431
WA	76%	24%	390

Within Average Range

State	Yes	No	N
FL	72%	28%	298
GA	72%	28%	368
NH	71%	29%	408
NCI Average	**69%**	**31%**	**4,304**
NC	68%	32%	216
MD	66%	34%	986
PA	65%	35%	632
UT	62%	38%	319

Significantly Below Average

State	Yes	No	N
AZ	57%	43%	256

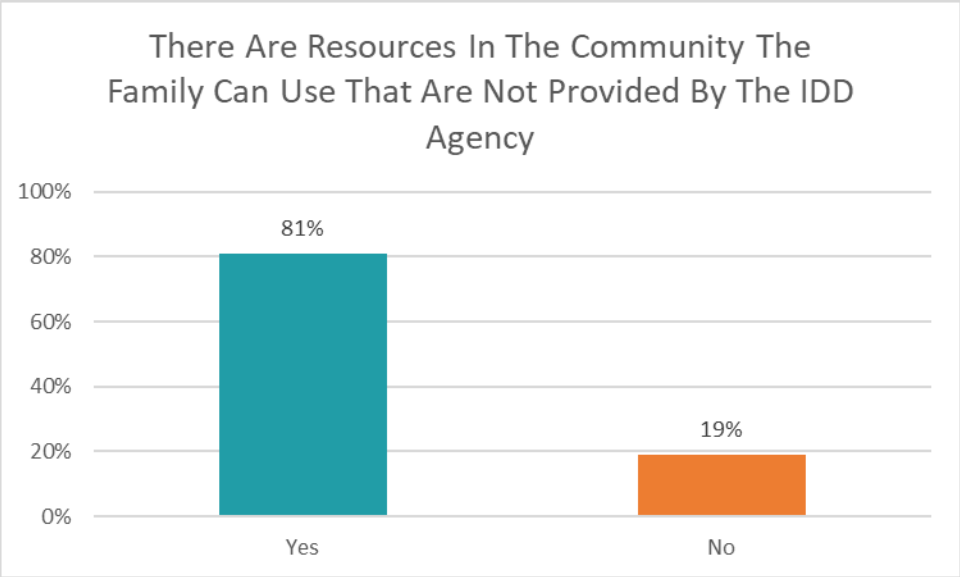


Table Q44. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

Significantly Above Average

State	Yes	No	N
WA	89%	11%	293

Within Average Range

State	Yes	No	N
SD	83%	17%	341
FL	83%	17%	212
UT	82%	18%	262
NC	82%	18%	176
NCI Average	**81%**	**19%**	**3,158**
MD	81%	19%	698
PA	78%	22%	403
GA	78%	22%	277
NH	77%	23%	299
AZ	77%	23%	197

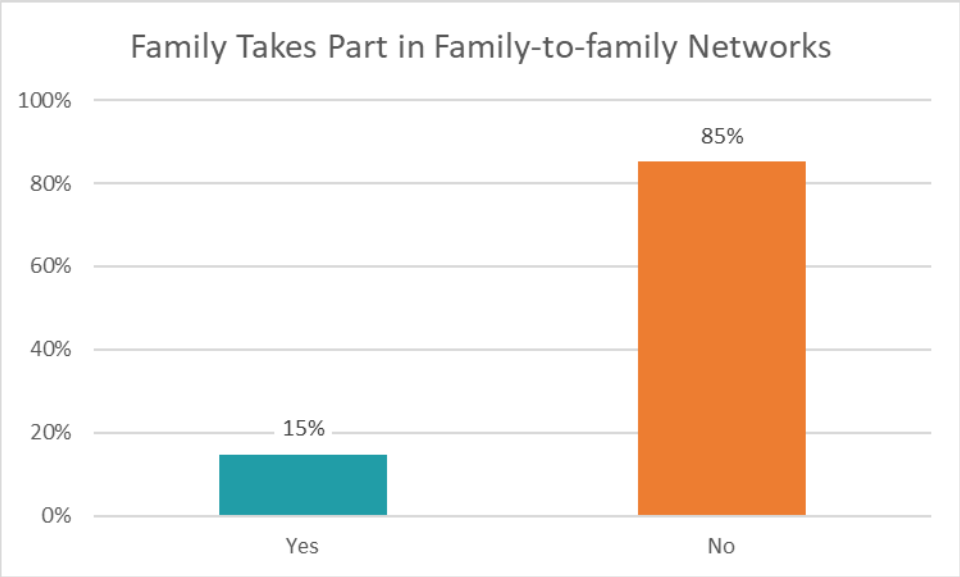


Table Q45. Does your family take part in any family-to-family networks in your community? (For example, Parent to Parent, sibling networks, etc.)

Within Average Range

State	Yes	No	N
FL	19%	81%	260
GA	17%	83%	322
MD	16%	84%	897
SD	16%	84%	395
NC	15%	85%	188
NCI Average	**15%**	**85%**	**3,836**
WA	14%	86%	345
PA	13%	87%	550
UT	10%	90%	270
AZ	9%	91%	239
NH	5%	95%	370

Satisfaction With Services and Supports

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

Note: Significance is based on "Always" or "Yes" response.

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

"**Family Member**" refers to the person receiving services whom the respondent is answering questions about in this survey.

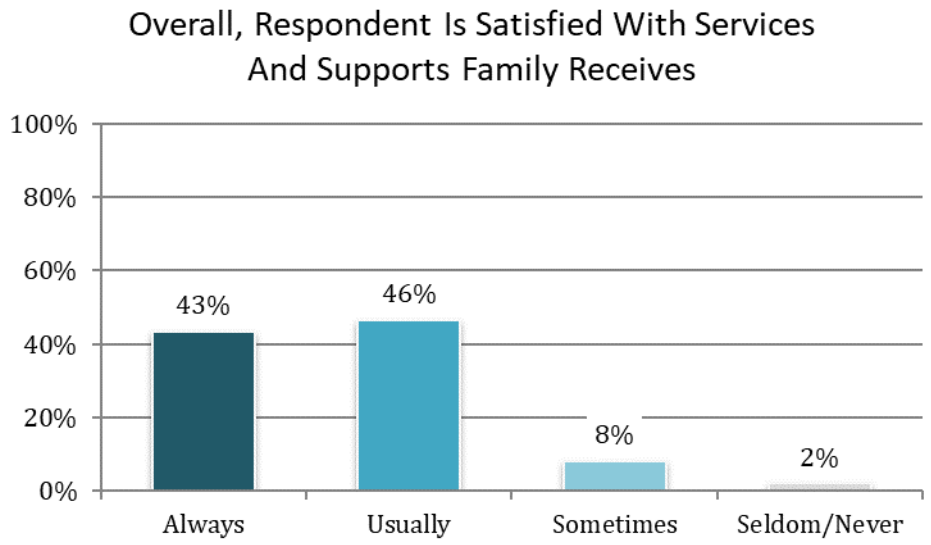


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	55%	37%	6%	2%	328

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
UT	45%	45%	8%	2%	360
NC	45%	47%	6%	2%	230
PA	44%	48%	6%	1%	710
NCI Average	**43%**	**46%**	**8%**	**2%**	**4,703**
NH	41%	46%	10%	3%	441
WA	41%	50%	8%	1%	416
GA	40%	47%	10%	3%	394
AZ	38%	50%	9%	2%	265

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	36%	51%	11%	2%	483
MD	32%	52%	13%	3%	1076

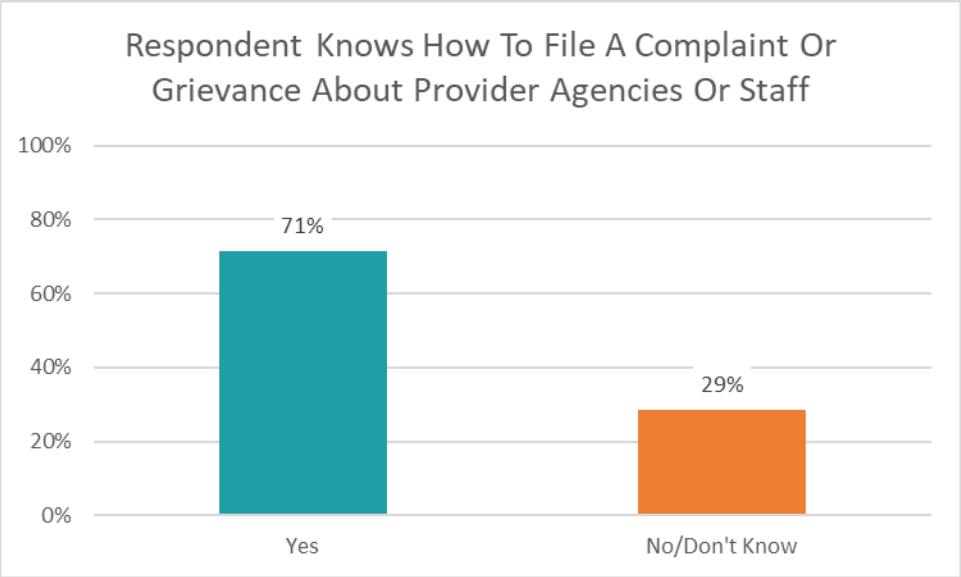


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?[5]

Significantly Above Average

State	Yes	No/Don't Know	N
NC	83%	17%	227
FL	83%	17%	331
SD	79%	21%	483

Within Average Range

State	Yes	No/Don't Know	N
NH	76%	24%	448
WA	73%	27%	417
AZ	73%	27%	274
NCI Average	**71%**	**29%**	**4,750**
UT	68%	32%	364
PA	67%	33%	709
GA	67%	33%	400
NH	76%	24%	448

Significantly Below Average

State	Yes	No/Don't Know	N
MD	50%	50%	1,097

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

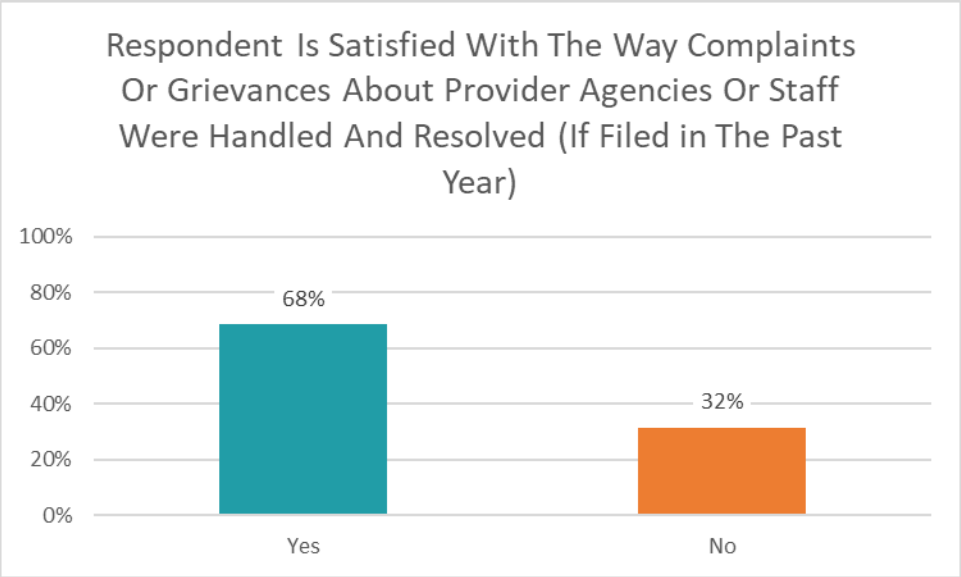


Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

Significantly Above Average

State	Yes	No	N
NH	83%	17%	53

Within Average Range

State	Yes	No	N
SD	76%	24%	83
FL	72%	28%	43
NC	71%	29%	41
PA	70%	30%	100
NCI Average	68%	32%	673
WA	68%	32%	53
AZ	67%	33%	49
UT	66%	34%	35
GA	60%	40%	58
MD	59%	41%	158

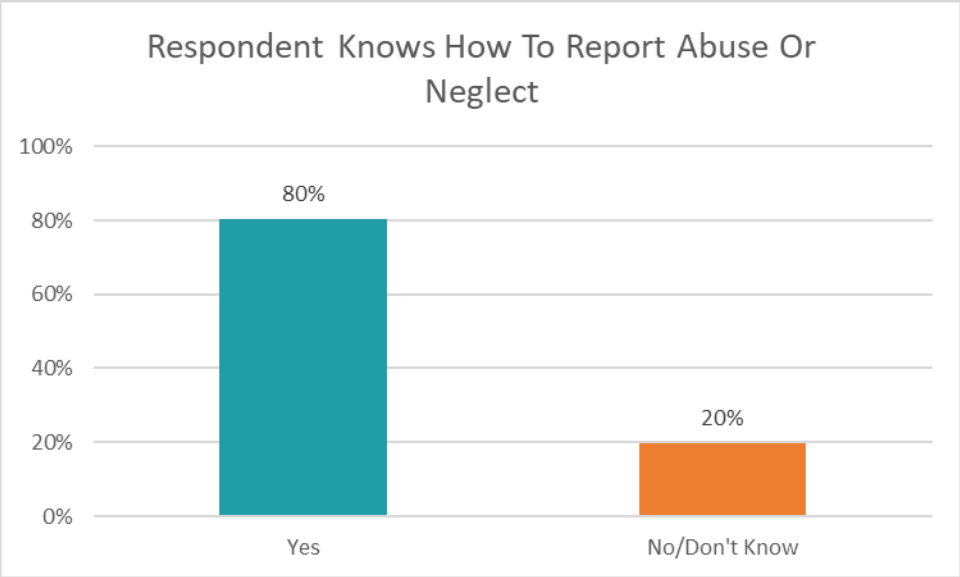


Table Q49. Do you know how to report abuse or neglect related to your family member?[6]

Significantly Above Average

State	Yes	No/Don't Know	N
NC	90%	10%	226
FL	89%	11%	326

Within Average Range

State	Yes	No/Don't Know	N
NH	85%	15%	445
SD	84%	16%	494
WA	83%	17%	416
UT	81%	19%	367
NCI Average	**80%**	**20%**	**4,776**
AZ	78%	22%	278
GA	78%	22%	400

Significantly Below Average

State	Yes	No/Don't Know	N
PA	75%	25%	726
MD	67%	33%	1,098

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

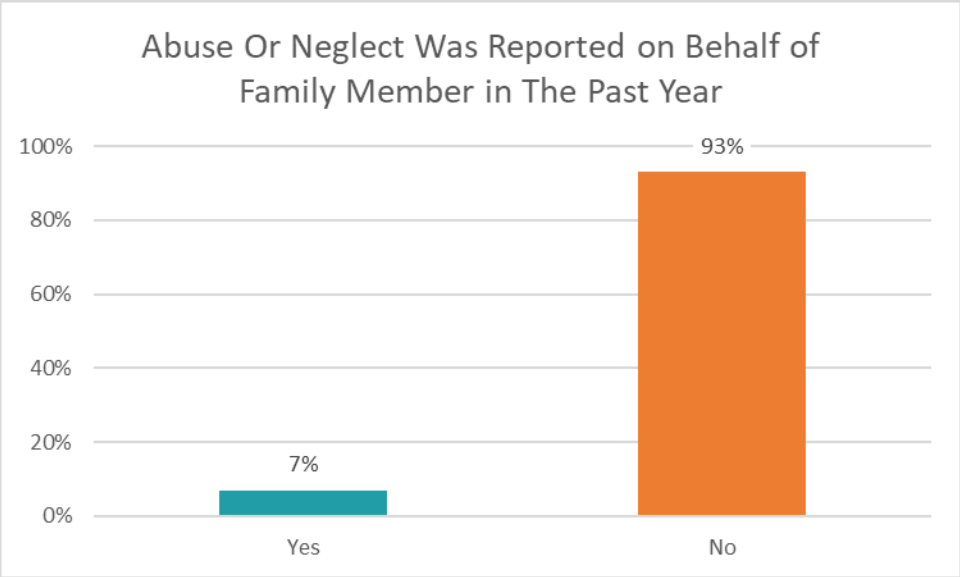


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

Within Average Range

State	Yes	No	N
AZ	10%	90%	261
PA	9%	91%	690
WA	8%	92%	408
NC	7%	93%	224
NCI Average	**7%**	**93%**	**4,552**
GA	6%	94%	380
SD	6%	94%	467
NH	6%	94%	429
MD	5%	95%	1,023
UT	5%	95%	352
FL	5%	95%	318

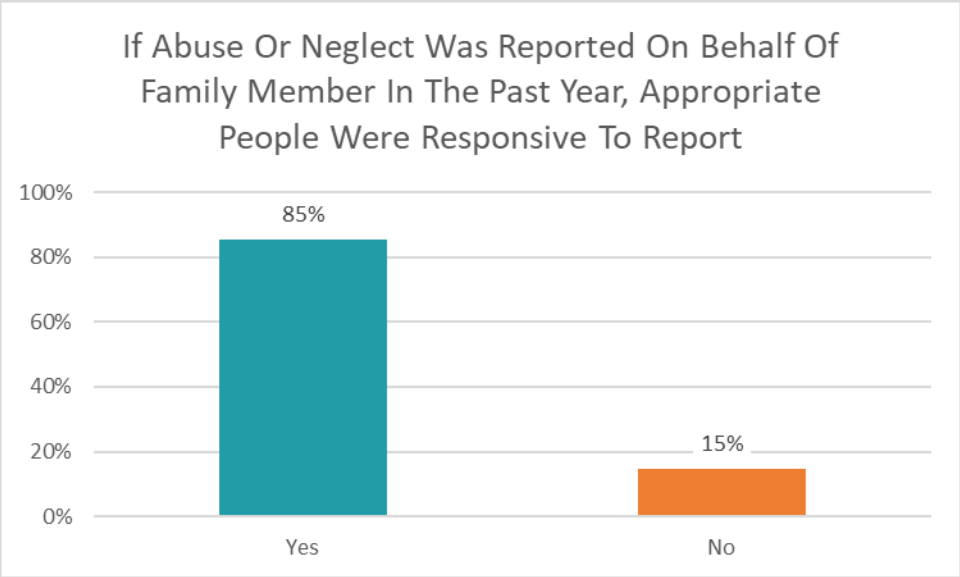


Table Q51. If a report of abuse or neglect was filed in the past year, did the appropriate people respond to the report?

Significantly Above Average

State	Yes	No	N
PA	95%	5%	43

Within Average Range

State	Yes	No	N
WA	92%	8%	24
SD	87%	13%	23
NCI Average	**85%**	**15%**	**236**
MD	85%	15%	41
NH	81%	19%	21

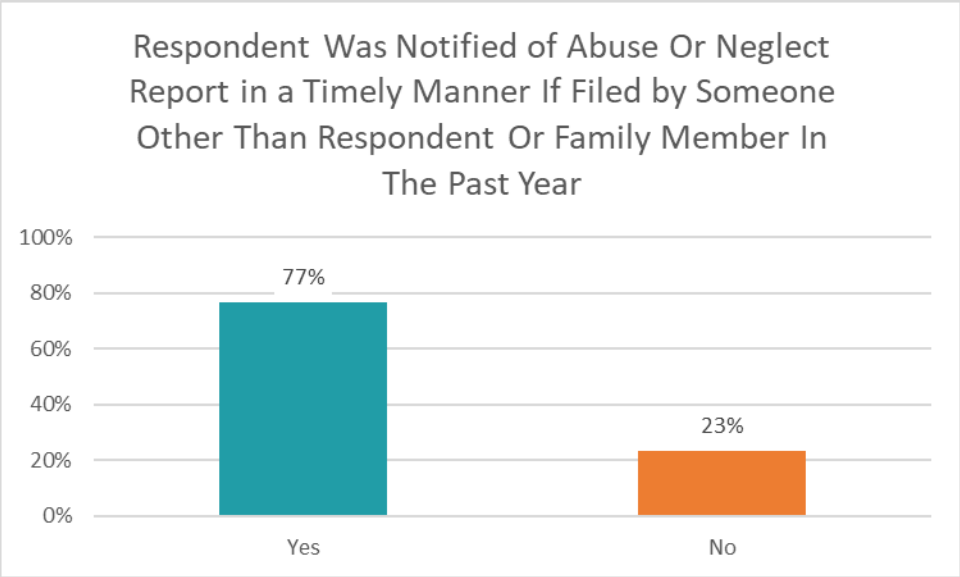


Table Q52. If a report of abuse or neglect was filed in the past year by someone other than you or another family, were you notified of the report in a timely manner?

Within Average Range

State	Yes	No	N
SD	90%	10%	20
PA	78%	23%	40
NCI Average	**77%**	**23%**	**205**
WA	76%	24%	21
MD	63%	38%	32

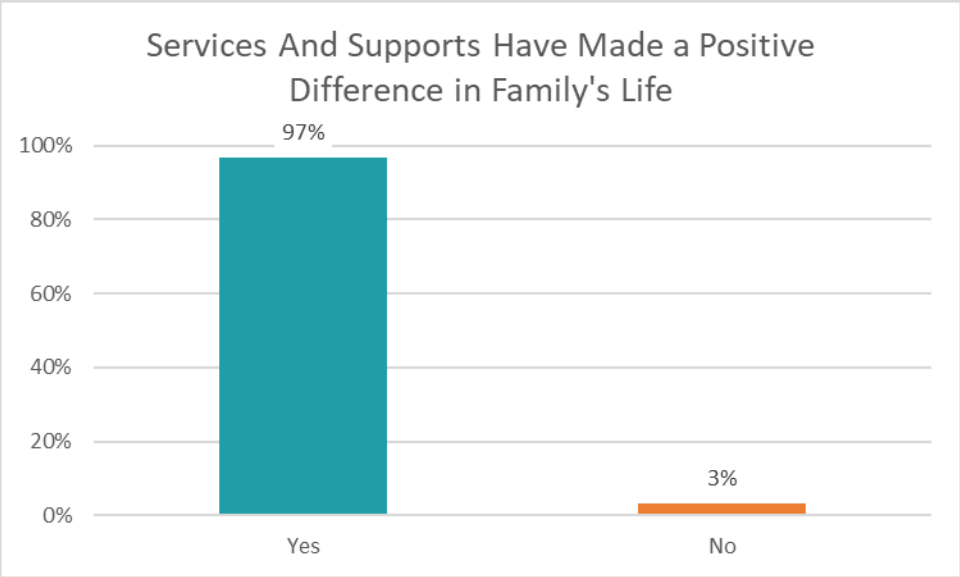


Table Q53. Do you feel that services and supports have made a positive difference in the life of your family?

Within Average Range

State	Yes	No	N
UT	98%	2%	347
NC	98%	2%	219
GA	97%	3%	375
WA	97%	3%	397
PA	97%	3%	682
FL	97%	3%	315
NCI Average	**97%**	**3%**	**4,484**
SD	97%	3%	456
NH	96%	4%	422
AZ	95%	5%	253

Significantly Below Average

State	Yes	No	N
MD	94%	6%	1,018

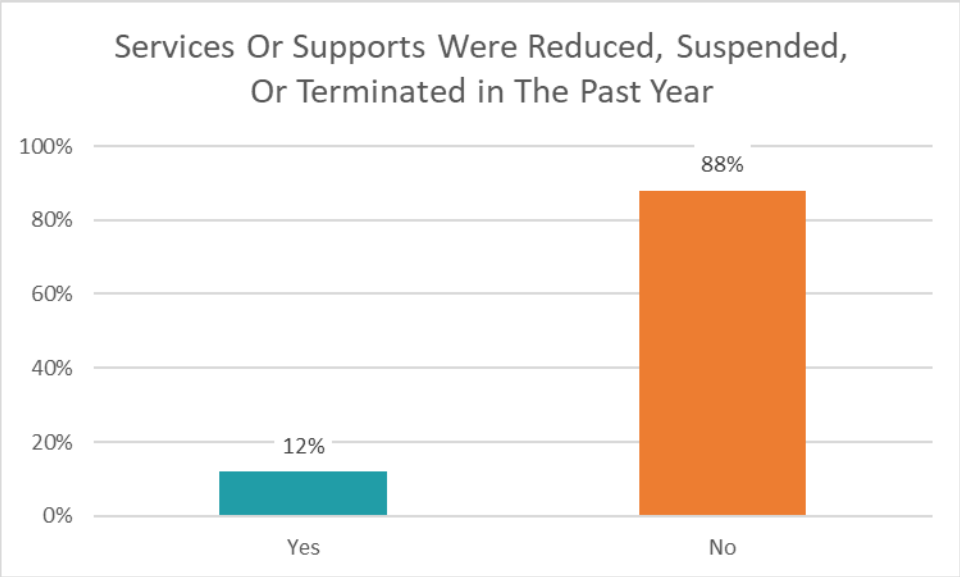


Table Q54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?

Within Average Range

State	Yes	No	N
NC	15%	85%	208
FL	13%	87%	271
WA	13%	87%	370
MD	13%	87%	919
SD	12%	88%	442
NCI Average	**12%**	**88%**	**4,136**
UT	12%	88%	316
GA	11%	89%	333
PA	11%	89%	625
NH	10%	90%	405
AZ	8%	92%	247

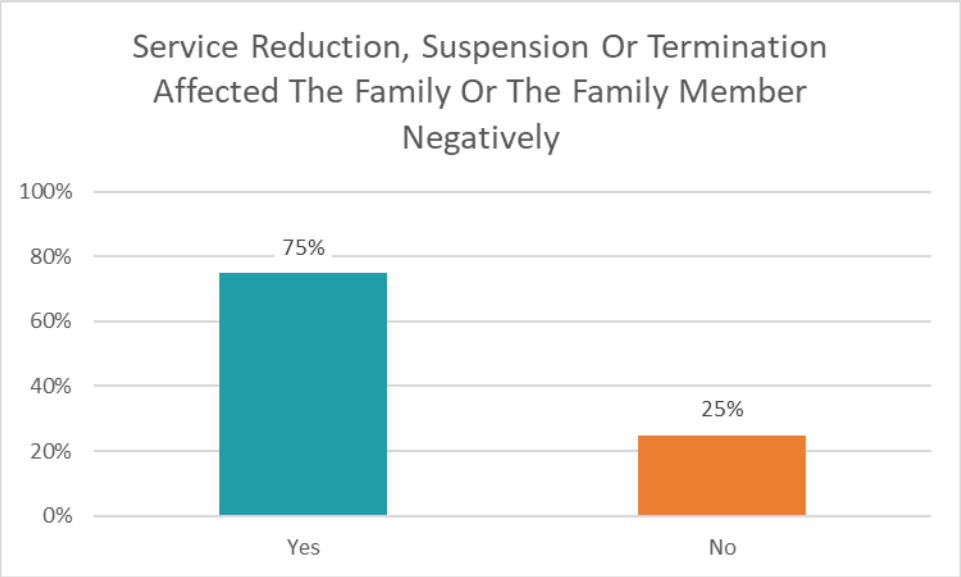


Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?

Within Average Range

State	Yes	No	N
UT	87%	13%	30
GA	82%	18%	33
PA	77%	23%	44
MD	76%	24%	100
FL	76%	24%	29
SD	76%	24%	45
NCI Average	**75%**	**25%**	**400**
NC	71%	29%	28
NH	71%	29%	35
WA	71%	29%	38

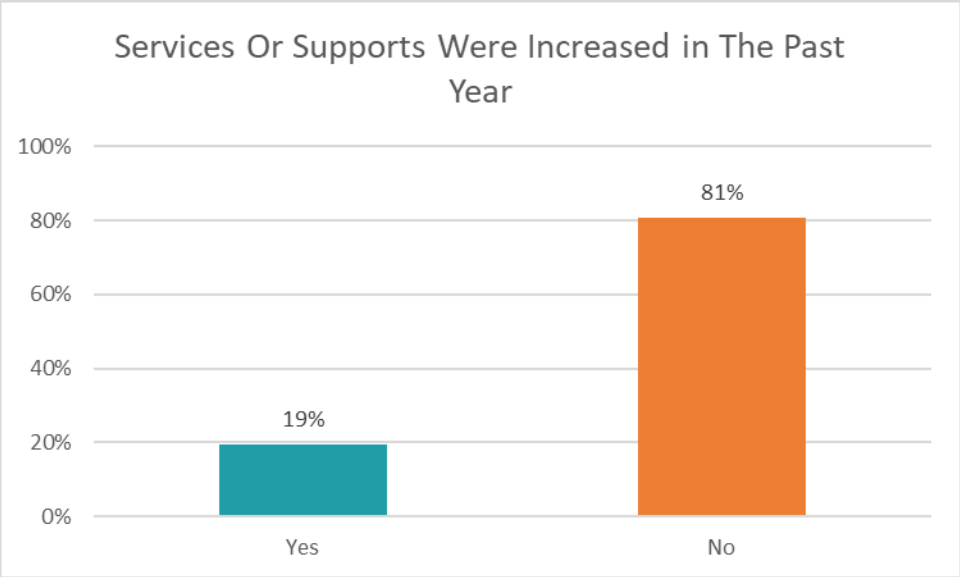


Table Q56. Have the services or supports that your family member received been increased in the past year?

Within Average Range

State	Yes	No	N
WA	23%	77%	326
PA	22%	78%	501
NC	20%	80%	191
UT	20%	80%	264
NCI Average	**19%**	**81%**	**3,544**
GA	18%	82%	275
SD	17%	83%	370
FL	17%	83%	240
MD	16%	84%	787
AZ	16%	84%	228

Significantly Below Average

State	Yes	No	N
NH	14%	86%	362

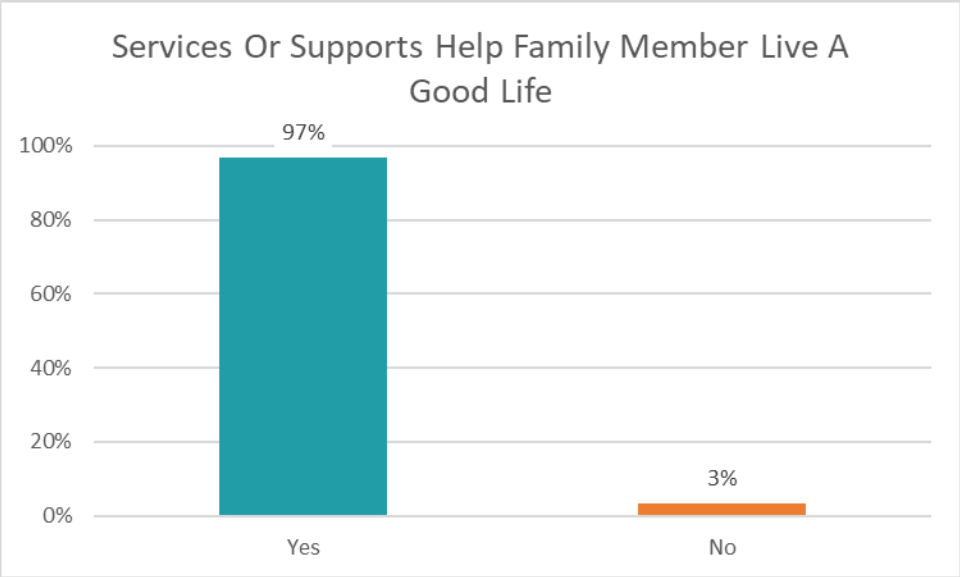


Table Q57. Are services and supports helping your family member to live a good life?

Within Average Range

State	Yes	No	N
UT	98%	2%	342
NC	98%	2%	222
WA	98%	2%	394
FL	97%	3%	319
GA	97%	3%	368
NH	97%	3%	425
NCI Average	97%	3%	4,477
PA	97%	3%	679
SD	96%	4%	458
AZ	95%	5%	261
MD	94%	6%	1,009

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

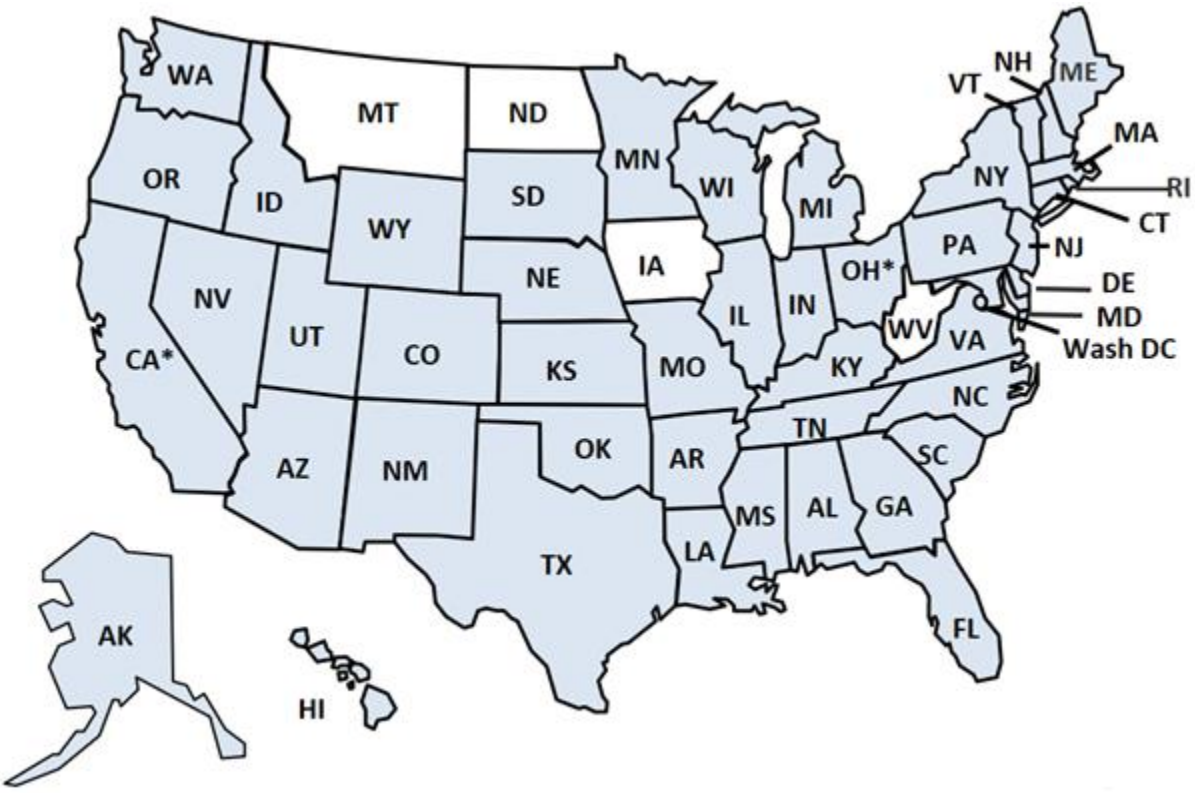
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven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

Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI continues to develop and refine the indicators and expand state participation. For more information about NCI states, technical reports, and other resources, please visit http://www.nationalcoreindicators.org.

State Participation

During the 2017-18 data collection cycle, 46 states, the District of Columbia and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and participating states are highlighted on the map below. Not all states participate in all surveys each year.

Figure 1. NCI State Participation 2017-18



The Core Indicators

The Core Indicators are the standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern, including employment, respect/rights, service planning, community inclusion, choice, and health and safety. An example of a Core Indicator would be, "The proportion of people who have a paid job in the community." To see the complete list of Core Indicators, please visit the Indicators page on the NCI website at http://www.nationalcoreindicators.org/indicators.

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly

participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

The current set of performance indicators includes approximately 100 consumer, family, system, and health and safety outcomes—outcomes that are important to understanding the overall health of public developmental disabilities agencies. Indicators are organized across five broad domains: Individual Outcomes; Health, Welfare and Rights; Staff Stability and Competency; Family Outcomes; and System Performance. Each domain is broken down into sub-domains, as shown in the following table. Four data sources are used to assess outcomes: the Adult In-Person Survey, three Family Surveys, a Provider Survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates).

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI program is a dynamic effort that allows for measures to be added, dropped, or changed to reflect current and future priorities of participating states.

The data collection tools used to gather indicator data are regularly refined and tested to ensure they remain valid, reliable, and applicable to current issues within the field. Details on the design and testing of this tool are provided in the next section of this report.

Sub-Domains and Concern Statements

The following table lists the sub-domains under 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 (HCBS) waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

For more information on how to use these data for quality improvement, please see this handbook: Using National Core Indicators for Quality Improvement Initiatives.[7]

[7] Located on the National Core Indicators website: www.nationalcoreindicators.org →Resources →Technical Reports

Caution and Limitations

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

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

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

III. Methodology

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

Sampling & Administration

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

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

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as "direct entry"), or a combination of both modes. Prior to that, states only had the option to mail paper surveys. A total of three states had at least a portion of surveys completed via the new direct entry mode for the 2017-18 data collection cycle.[8]

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%.[9]

Weighting

Statistically, the term "average" refers to a calculated central or middle value of a set of numbers. In NCI reports, we use "NCI average" to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as "average of averages"). Last year, the approach was enhanced to consider the relative numbers of people receiving services through participating states' systems. The NCI averages contained in this report are "weighted"

[8] States that used the direct entry or mail and direct entry options were: FL, NC and WA.

[9] See "Response Rates" section for information on total surveys mailed and received by states as well as each state's margin of error.

means; their calculations reflect the relative population sizes of participating states, as well as the sample sizes.

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

Significance Testing

For each of the items in the report, each state's percentage was compared to the weighted NCI average (described above), and the differences between the two were tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state's result depends in part on the size of the state's sample—the larger the sample, the more likely it is that even a small difference will be found *statistically* significant. A statistically significant difference for a state with a large sample size, in and by itself, does not necessarily mean there is a *practically* significant difference. The inclusion of effect sizes allows us to present "meaningfully significant" results, which take the magnitude or size of the differences into account.

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

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

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, and significantly below the NCI Average. No symbol was used for the

state's percentage being "within" the NCI average range due to lack of statistical significance (i.e., $p \geq .01$).

Technical Details

The comparisons were done through one sample t-tests using the weighted NCI average as the benchmark. A conservative cut-off point (alpha) of $p < .01$ was used to detect statistically significant differences. Effect sizes are calculated using the formula: Cohen's $d = \frac{2t}{\sqrt{df}}$. A cutoff point of Cohen's $d = 0.2$ was chosen for the effect size to be considered "meaningfully significant," following the standard interpretation offered by Cohen (1988) that Cohen's d of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

Data Entry and Analysis

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

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

1. The respondent indicated the individual with an intellectual or developmental disability receiving services lived outside of 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[10]; significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

Response Rates

During 2017-18, 10 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.

[10] The NCI Average is the sum of all state averages divided by the total number of states.

Figure 3. Family/Guardian Survey: State Response Rates[11]

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	4,287	1,400	280	20%	5.66%	n/a	n/a
FL	13,315	2,000	333	17%	5.30%	93.7%	6.3%
GA	3,509	1,700	410	24%	4.55%	n/a	n/a
MD	8,536[12]	8,523	1,127	13%	2.72%	n/a	n/a
NH	1,451	1,451	455	31%	3.81%	n/a	n/a
NC	~7,000 *	900	234	26%	6.30% *	91.0%	9.0%
PA	~18,200 *	~1,800-2,000 *	751	~40% *	3.50% *	n/a	n/a
SD	1,776	1,501	500	33%	3.72%	n/a	n/a
UT	~1,500 *	1,000	371	37%	4.42% *	n/a	n/a
WA	9,022	2,000	429	21%	4.62%	73.0%	27.0%
Overall			4,890			94.3%	5.7%

*Estimates

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

[12] This is the number of families with valid contact info.