

Adult Family Survey

2019-20 Final Report





Human Services
Research Institute

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January, 2021

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 National Core Indicators (NCI) Adult Family Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who lives in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Adult Family Survey on an annual basis. Of the 46 states, the District of Columbia and 22 sub-state entities that were members of NCI during the 2019-20 data collection cycle, 14 states submitted a valid sample of Adult Family Survey data: Arizona (AZ), California (CA), Delaware (DE), District of Columbia (DC), Florida (FL), Georgia (GA), Maryland (MD), Missouri (MO), New Hampshire (NH), North Carolina (NC), Oklahoma (OK), Pennsylvania (PA), South Dakota (SD), Washington (WA). This Final Report provides a summary of results based on data submitted by June 30, 2020.

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

Important note on Impact of COVID-19

The 2019-20 NCI Family Survey data collection cycle began July 1, 2019 and ended June 30, 2020. Midway through data collection, in February 2020, COVID-19 began to spread across the United States. Data collection for the NCI Family Surveys **continued throughout the pandemic**. States begin data collection at various times throughout the year – some before the pandemic started and some after. Because the family surveys do not collect information on the date of survey completion, we cannot fully assess what impact the pandemic had on data collected at different times throughout the year. Additionally, we cannot determine whether the onset of COVID-19

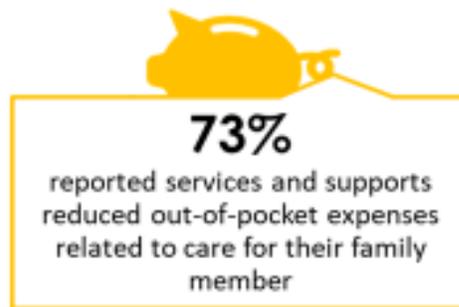
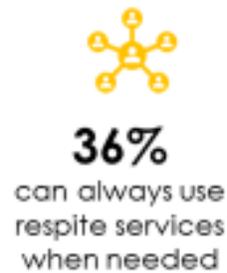
impacted state samples. For instance, we do not know if certain populations were more or less likely to respond to the survey after February and we do not know whether or how responses were affected for specific questions for those who completed the survey after the pandemic began. While these data will serve as an important baseline, and meaningful way for states to understand the overall impact of services on families of individuals being served, these data should be read with caution.

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

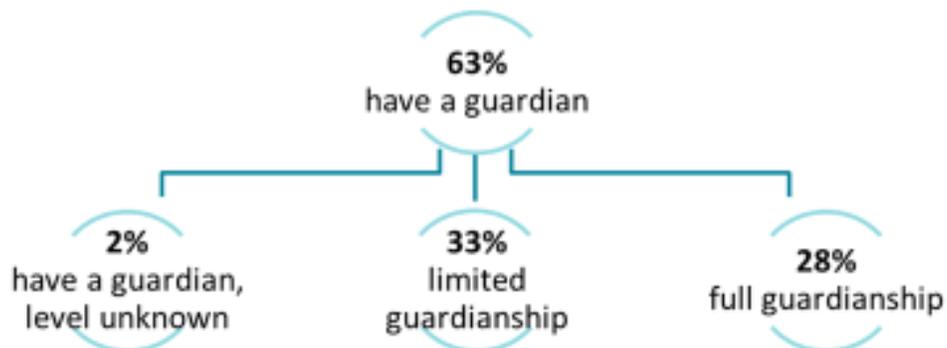
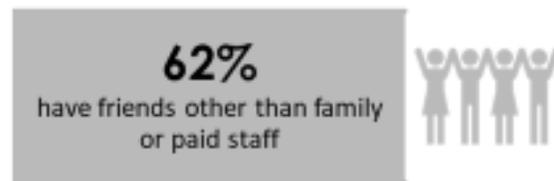
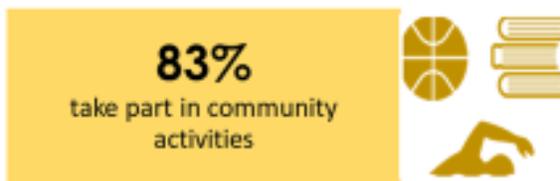
Respondents

Family members and/or guardians of adults who have IDD and receive at least one service in addition to case management from the state DD service system. The respondent lives with the adult receiving services.

Respondents....



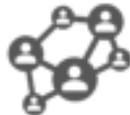
Family member with IDD....





78%

have resources in the community the family can use



19%

take part in family-to-family networks



94%

feel services and supports have made a positive difference for their family member



38% say they *always* get enough information to help plan services



38% say services and supports *always* change when their family's needs change



81% say they or another family member helped make the service plan



65% say their family member with IDD helped make the service plan



74%

family member can *always* see health professionals when needed



65%

family member can *always* go to the dentist when needed



50%

crisis or emergency services were provided in the past year when needed

I. Results

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

Presentation of Data

In addition to basic demographic questions and questions on services received, 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.

Demographic results are shown in table form with states listed alphabetically. Outcomes are shown first with a chart depicting the NCI Average. The charts are followed by accessible tables showing state outcomes and the NCI Average listed in descending order, grouped by level of significance.

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 and 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: "You" and "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.

Note on responses: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

Demographics

Note on responses: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

Family Member

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

Table 1. More Than One Person Living in the Home Has IDD

State	Yes	No	N
AZ	15%	85%	245
CA	16%	84%	14,132
DE	16%	84%	161
DC	19%	81%	153
FL	16%	84%	464
GA	15%	85%	391
MD	10%	90%	395
MO	12%	88%	331
NH	13%	87%	632
NC	13%	87%	204
OK	10%	90%	388
PA	13%	87%	519
SD	14%	86%	255
WA	11%	89%	267
Weighted NCI Average	15%	85%	18,537

Table 2. Family Member's Age

State	Average Age	N
AZ	32.2	254
CA	33.4	14,378
DE	32.7	163
DC	37.3	154
FL	39.2	484
GA	36.0	398
MD	31.2	405
MO	34.3	337
NH	33.1	643
NC	36.1	212
OK	34.8	395
PA	36.4	541
SD	29.8	259
WA	32.7	281
Weighted NCI Average	34.4	18,904

Table 3. Family Member’s Gender

State	Male	Female	N
AZ	54%	46%	256
CA	62%	38%	14,442
DE	65%	35%	163
DC	64%	36%	155
FL	63%	37%	482
GA	58%	42%	401
MD	65%	35%	402
MO	59%	41%	331
NH	55%	45%	643
NC	65%	35%	212
OK	54%	46%	395
PA	56%	44%	533
SD	55%	45%	254
WA	62%	38%	278
Weighted NCI Average	61%	39%	18,947

Table 4. Family Member’s Race and Ethnicity

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other
AZ	4%	2%	4%	0%	71%	28%	0%
CA	2%	16%	9%	1%	43%	37%	2%
DE	3%	4%	20%	1%	74%	4%	2%
DC	0%	0%	89%	1%	8%	3%	2%
FL	1%	2%	22%	0%	60%	20%	2%
GA	1%	3%	35%	0%	59%	3%	3%
MD	3%	7%	28%	0%	65%	3%	0%
MO	3%	2%	8%	0%	90%	2%	1%
NH	2%	2%	0%	0%	96%	2%	1%
NC	0%	4%	30%	0%	65%	4%	1%
OK	17%	2%	11%	0%	76%	5%	0%
PA	2%	1%	9%	0%	89%	3%	0%
SD	6%	1%	2%	0%	89%	3%	0%
WA	4%	8%	6%	2%	86%	5%	3%
Weighted NCI Average	2%	9%	13%	1%	59%	22%	1%

Table 5a. Family Member’s Disabilities

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
AZ	69%	21%	33%	26%	11%	7%
CA	59%	20%	38%	17%	9%	6%
DE	70%	20%	34%	11%	7%	7%
DC	65%	12%	29%	16%	10%	5%
FL	64%	21%	30%	25%	10%	8%
GA	72%	24%	35%	20%	11%	5%
MD	66%	20%	41%	16%	7%	4%
MO	62%	23%	39%	21%	11%	5%
NH	68%	31%	34%	13%	8%	7%
NC	67%	32%	38%	21%	11%	9%
OK	75%	24%	24%	27%	10%	7%
PA	80%	27%	31%	15%	9%	9%
SD	61%	21%	31%	18%	8%	5%
WA	73%	29%	37%	17%	9%	10%
Weighted NCI Average	65%	23%	36%	18%	9%	7%

Table 5b. Family Member’s Disabilities (continued)

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
AZ	11%	33%	0%	16%	1%	2%	19%
CA	10%	22%	1%	15%	1%	1%	14%
DE	5%	11%	0%	21%	1%	0%	15%
DC	5%	19%	1%	13%	0%	5%	14%
FL	10%	32%	1%	18%	1%	1%	19%
GA	8%	27%	0%	15%	2%	2%	20%
MD	9%	21%	0%	17%	0%	0%	14%
MO	10%	32%	1%	16%	0%	1%	19%
NH	8%	29%	0%	16%	0%	0%	20%
NC	10%	34%	1%	16%	1%	0%	26%
OK	17%	38%	1%	20%	1%	2%	13%
PA	8%	27%	1%	20%	1%	1%	16%
SD	7%	27%	0%	20%	0%	1%	17%
WA	10%	31%	0%	15%	1%	5%	23%
Weighted NCI Average	10%	26%	1%	16%	1%	1%	17%

Table 6a. Family Member’s Health Conditions

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	12%	14%	6%	24%	28%
CA	10%	18%	5%	28%	29%
DE	15%	12%	4%	24%	33%
DC	6%	22%	1%	41%	26%
FL	16%	23%	5%	38%	36%
GA	8%	18%	5%	37%	31%
MD	9%	18%	6%	29%	27%
MO	8%	13%	4%	23%	25%
NH	13%	13%	6%	18%	29%
NC	5%	19%	6%	39%	34%
OK	8%	18%	4%	29%	22%
PA	11%	18%	4%	31%	34%
SD	15%	19%	7%	22%	26%
WA	13%	9%	5%	20%	15%
Weighted NCI Average	10%	18%	5%	30%	30%

Table 6b. Family Member’s Health Conditions (continued)

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Dysphagia	Pressure Ulcers	Alzheimer’s Disease or Other Dementia	Oral Health or Dental Problems	Sleep Apnea	Other
AZ	12%	2%	0%	18%	18%	28%
CA	8%	2%	3%	14%	18%	24%
DE	2%	1%	1%	11%	22%	28%
DC	4%	1%	3%	7%	9%	20%
FL	11%	4%	4%	13%	18%	29%
GA	7%	2%	2%	14%	19%	25%
MD	9%	3%	2%	5%	17%	28%
MO	10%	2%	2%	18%	24%	25%
NH	11%	3%	2%	8%	20%	34%
NC	14%	3%	2%	14%	23%	23%
OK	18%	5%	0%	14%	19%	18%
PA	9%	2%	2%	8%	14%	27%
SD	10%	2%	0%	9%	23%	26%
WA	21%	5%	1%	21%	34%	23%
Weighted NCI Average	10%	2%	2%	13%	19%	25%

Table 7. 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	76%	16%	2%	4%	2%	250
CA	81%	11%	2%	1%	5%	14,241
DE	88%	9%	1%	1%	1%	164
DC	75%	15%	4%	3%	2%	150
FL	73%	16%	3%	2%	6%	476
GA	74%	19%	1%	2%	4%	395
MD	78%	13%	3%	3%	3%	401
MO	74%	17%	2%	3%	4%	332
NH	86%	9%	2%	3%	1%	649
NC	71%	22%	3%	2%	1%	208
OK	71%	24%	2%	2%	1%	388
PA	82%	11%	3%	2%	3%	533
SD	82%	11%	2%	2%	4%	256
WA	76%	15%	1%	4%	4%	278
Weighted NCI Average	78%	14%	2%	2%	4%	18,721

Table 8. Family Member Has Legal Court Appointed Guardian or Conservator

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
AZ	18%	11%	69%	2%	251
CA	42%	58%	n/a	n/a	13,477
DE	49%	13%	34%	4%	161
DC	31%	13%	50%	6%	149
FL	29%	19%	47%	4%	448
GA	39%	14%	44%	4%	370
MD	52%	11%	33%	4%	383
MO	22%	10%	65%	2%	330
NH	15%	9%	73%	2%	646
NC	15%	12%	66%	7%	207
OK	23%	7%	67%	3%	377
PA	54%	8%	33%	5%	499
SD	13%	4%	79%	4%	251
WA	28%	10%	59%	2%	263
Weighted NCI Average	37%	33%	28%	2%	17,813

Table 9. Guardian or Conservator Relationship to Family Member

State	Family	Friend	State Employee or Guardianship Agency	Other	N
AZ	96%	1%	0%	2%	201
CA	98%	1%	0%	1%	7,433
DE	92%	4%	0%	4%	78
DC	92%	0%	5%	3%	87
FL	87%	1%	2%	11%	304
GA	88%	0%	0%	12%	218
MD	93%	1%	1%	6%	174
MO	98%	0%	1%	1%	249
NH	98%	1%	1%	1%	526
NC	94%	1%	4%	1%	163
OK	99%	1%	0%	0%	281
PA	98%	0%	1%	1%	220
SD	97%	1%	0%	1%	210
WA	100%	0%	0%	0%	186
Weighted NCI Average	96%	1%	1%	3%	10,330

Table 10. 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 School or Certificate Program	Some College	College Degree or Higher	N
AZ	13%	7%	26%	42%	2%	6%	4%	246
CA	19%	3%	35%	23%	5%	9%	6%	13,541
DE	10%	2%	54%	21%	4%	4%	4%	163
DC	27%	1%	38%	23%	6%	1%	3%	146
FL	19%	2%	38%	26%	5%	5%	5%	464
GA	16%	2%	45%	28%	3%	2%	4%	383
MD	8%	2%	59%	14%	5%	5%	5%	401
MO	17%	0%	27%	42%	3%	4%	6%	322
NH	9%	1%	42%	35%	3%	5%	4%	632
NC	19%	4%	39%	18%	6%	6%	7%	205
OK	12%	9%	24%	46%	2%	3%	4%	378
PA	12%	3%	24%	52%	4%	2%	3%	508
SD	9%	11%	32%	36%	4%	4%	4%	253
WA	9%	3%	33%	40%	1%	8%	7%	281
Weighted NCI Average	16%	3%	35%	29%	4%	7%	5%	17,923

Table 11. Family Member's Activities in the Past Two Weeks Included *Paid Individual Job in the Community*¹

State	Yes	No	N
AZ	10%	90%	252
CA	13%	87%	13,877
DE	27%	73%	154
DC	11%	89%	152
FL	11%	89%	475
GA	12%	88%	389
MD	14%	86%	399
MO	12%	88%	325
NH	39%	61%	635
NC	14%	86%	204
OK	13%	87%	388
PA	22%	78%	524
SD	28%	72%	254
WA	18%	82%	274
Weighted NCI Average	14%	86%	18,302

Table 12. Family Member's Activities in the Past Two Weeks Included *Paid Small Group Job in a Community-based Setting*²

State	Yes	No	N
AZ	9%	91%	248
CA	13%	87%	13,640
DE	11%	89%	155
DC	6%	94%	145
FL	6%	94%	467
GA	7%	93%	384
MD	5%	95%	378
MO	5%	95%	320
NH	8%	92%	611
NC	6%	94%	203
OK	14%	86%	380
PA	14%	86%	511
SD	5%	95%	247
WA	3%	97%	273
Weighted NCI Average	10%	90%	17,962

¹ An individual job is defined as work at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (for example, competitive employment).

² A small group job is defined as work in an integrated setting, as part of a group of not more than 8 people with disabilities (for example, enclave, work crew).

Table 13. Family Member’s Activities in the Past Two Weeks Included *Paid Work in a Community Job That Primarily Hires People With Disabilities*³

State	Yes	No	N
AZ	5%	95%	247
CA	8%	92%	13,538
DE	10%	90%	156
DC	5%	95%	150
FL	6%	94%	460
GA	6%	94%	379
MD	5%	95%	394
MO	3%	97%	323
NH	13%	87%	627
NC	7%	93%	199
OK	8%	92%	381
PA	9%	91%	514
SD	9%	91%	255
WA	5%	95%	272
Weighted NCI Average	7%	93%	17,895

Table 14. Family Member’s Activities in the Past Two Weeks Included *Unpaid Activity in the Community*⁴

State	Yes	No	N
AZ	21%	79%	248
CA	27%	73%	13,697
DE	26%	74%	154
DC	21%	79%	146
FL	18%	82%	468
GA	31%	69%	391
MD	20%	80%	389
MO	34%	66%	328
NH	56%	44%	609
NC	43%	57%	203
OK	26%	74%	377
PA	37%	63%	512
SD	29%	71%	249
WA	14%	86%	267
Weighted NCI Average	28%	72%	18,038

³ Paid work in a community job that primarily hires people with disabilities is defined as work in a setting where the person interacts with the non-disabled population; this is NOT in a traditional sheltered workshop and NOT enclave.

⁴ Unpaid work in the community includes: volunteering, skills training, and staff-supported community connections.

Table 15. Family Member’s Activities in the Past Two Weeks Included *Paid Activity in a Facility-based Setting*⁵

State	Yes	No	N
AZ	15%	85%	247
CA	12%	88%	13,642
DE	10%	90%	154
DC	5%	95%	146
FL	12%	88%	467
GA	11%	89%	391
MD	6%	94%	388
MO	18%	82%	332
NH	3%	97%	615
NC	10%	90%	203
OK	17%	83%	385
PA	25%	75%	507
SD	5%	95%	247
WA	2%	98%	267
Weighted NCI Average	13%	87%	17,991

Table 16. Family Member’s Activities in the Past Two Weeks Included *Unpaid Activity in a Facility-based Setting*⁶

State	Yes	No	N
AZ	37%	63%	243
CA	21%	79%	13,451
DE	24%	76%	156
DC	31%	69%	148
FL	20%	80%	461
GA	34%	66%	388
MD	16%	84%	381
MO	32%	68%	328
NH	18%	82%	613
NC	25%	75%	200
OK	12%	88%	384
PA	23%	77%	501
SD	15%	85%	245
WA	5%	95%	266
Weighted NCI Average	21%	79%	17,765

⁵ Paid work performed in a facility-based setting is defined as work at a location developed specifically to provide work activity exclusively for people with disabilities; may be paid sub-minimum wage. Examples include traditional sheltered workshops or work activity centers.

⁶ An unpaid activity in a facility-based setting includes day habilitation, senior programs, or drop-in centers.

Table 17. Family Member’s Activities in the Past Two Weeks Included *School*

State	Yes	No	N
AZ	11%	89%	245
CA	21%	79%	13,476
DE	6%	94%	158
DC	7%	93%	142
FL	9%	91%	456
GA	8%	92%	390
MD	6%	94%	383
MO	3%	97%	327
NH	5%	95%	624
NC	15%	85%	204
OK	11%	89%	384
PA	6%	94%	510
SD	19%	81%	247
WA	3%	97%	265
Weighted NCI Average	14%	86%	17,811

Table 18. Family Member’s Activities in the Past Two Weeks Included *Stay at Home*

State	Yes	No	N
AZ	47%	53%	237
CA	47%	53%	13,205
DE	50%	50%	153
DC	52%	48%	145
FL	60%	40%	456
GA	49%	51%	374
MD	66%	34%	376
MO	53%	47%	319
NH	42%	58%	592
NC	56%	44%	195
OK	68%	32%	375
PA	43%	57%	477
SD	64%	36%	248
WA	88%	12%	266
Weighted NCI Average	53%	47%	17,418

Table 19. Family Member’s Activities in the Past Two Weeks Included *Other Activities*

State	Yes	No	N
AZ	38%	62%	86
CA	46%	54%	4,949
DE	32%	68%	59
DC	50%	50%	70
FL	39%	61%	174
GA	46%	54%	142
MD	37%	63%	68
MO	32%	68%	128
NH	62%	38%	237
NC	46%	54%	87
OK	31%	69%	110
PA	50%	50%	214
SD	47%	53%	83
WA	35%	65%	92
Weighted NCI Average	44%	56%	6,499

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

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	No Support Needed	Some Support Needed	Extensive Support Needed	N
AZ	56%	31%	13%	245
CA	51%	30%	19%	14,151
DE	71%	25%	4%	163
DC	71%	21%	8%	145
FL	55%	29%	16%	476
GA	55%	29%	17%	398
MD	62%	28%	11%	396
MO	59%	27%	13%	334
NH	64%	27%	9%	635
NC	37%	35%	27%	201
OK	61%	25%	14%	381
PA	60%	28%	12%	518
SD	65%	27%	8%	253
WA	31%	43%	25%	274
Weighted NCI Average	52%	31%	18%	18,570

Table 21. Family Member's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State	No Support Needed	Some Support Needed	Extensive Support Needed	N
AZ	15%	40%	44%	255
CA	29%	35%	36%	14,380
DE	45%	38%	18%	164
DC	45%	31%	24%	154
FL	24%	33%	43%	478
GA	26%	37%	37%	401
MD	34%	34%	32%	403
MO	23%	35%	42%	337
NH	34%	36%	29%	650
NC	17%	33%	50%	210
OK	22%	36%	42%	393
PA	35%	41%	25%	532
SD	37%	39%	24%	256
WA	6%	46%	48%	280
Weighted NCI Average	26%	36%	38%	18,893

Table 22. Family Member's Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State	No Support Needed	Some Support Needed	Extensive Support Needed	N
AZ	3%	10%	86%	251
CA	9%	26%	65%	14,241
DE	9%	34%	56%	163
DC	17%	28%	54%	155
FL	6%	15%	79%	478
GA	5%	17%	78%	397
MD	6%	21%	73%	405
MO	4%	18%	78%	335
NH	5%	27%	69%	647
NC	4%	11%	85%	210
OK	3%	17%	79%	391
PA	4%	23%	73%	529
SD	8%	22%	70%	258
WA	1%	14%	86%	280
Weighted NCI Average	7%	21%	72%	18,740

Respondents

This section provides demographic information about the respondent.

Table 23. Language Usually Spoken at Home

State	English	Spanish	Other	N
AZ	89%	9%	2%	251
CA	68%	19%	13%	14,428
DE	97%	2%	1%	164
DC	97%	2%	1%	153
FL	90%	9%	1%	475
GA	98%	1%	2%	399
MD	96%	1%	3%	404
MO	99%	0%	1%	328
NH	99%	0%	1%	649
NC	97%	1%	2%	210
OK	97%	2%	0%	394
PA	98%	1%	1%	531
SD	98%	0%	2%	256
WA	99%	1%	1%	277
Weighted NCI Average	83%	11%	7%	18,919

Table 24. Respondent's Age

State	Under 35	35-54	55-74	75 and Older	N
AZ	5%	29%	59%	7%	255
CA	6%	24%	60%	10%	14,371
DE	3%	23%	66%	8%	166
DC	7%	18%	59%	17%	157
FL	3%	18%	57%	21%	476
GA	2%	23%	65%	10%	400
MD	4%	16%	74%	6%	402
MO	1%	19%	72%	8%	337
NH	2%	20%	69%	9%	647
NC	4%	22%	64%	10%	211
OK	1%	21%	66%	12%	393
PA	3%	16%	66%	14%	534
SD	2%	36%	56%	7%	256
WA	2%	22%	68%	8%	277
Weighted NCI Average	4%	22%	62%	11%	18,882

Table 25. Respondent's Health

State	Excellent	Very Good	Fairly Good	Poor	N
AZ	23%	43%	31%	4%	255
CA	17%	45%	32%	6%	14,336
DE	16%	47%	35%	2%	165
DC	12%	54%	32%	2%	155
FL	11%	42%	40%	6%	483
GA	14%	43%	38%	5%	399
MD	18%	48%	32%	2%	405
MO	13%	45%	39%	3%	338
NH	18%	53%	26%	4%	647
NC	17%	42%	38%	3%	212
OK	13%	46%	37%	4%	394
PA	14%	47%	36%	3%	535
SD	20%	49%	31%	0%	258
WA	15%	45%	36%	4%	277
Weighted NCI Average	16%	45%	34%	5%	18,859

Table 26. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Other	N
AZ	85%	9%	1%	2%	2%	252
CA	86%	8%	0%	2%	4%	14,365
DE	81%	6%	1%	5%	7%	166
DC	74%	10%	0%	8%	9%	156
FL	84%	10%	0%	1%	4%	480
GA	86%	7%	1%	1%	5%	401
MD	93%	4%	0%	1%	2%	405
MO	88%	5%	0%	2%	4%	333
NH	90%	6%	1%	2%	2%	649
NC	77%	8%	0%	2%	12%	212
OK	87%	6%	0%	4%	3%	390
PA	89%	7%	0%	2%	2%	531
SD	94%	3%	0%	1%	2%	258
WA	89%	5%	0%	3%	4%	278
Weighted NCI Average	86%	7%	0%	2%	4%	18,876

Table 27. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services

Responses to this question might have been impacted by the COVID-19 pandemic.

State	Respondent Provides Paid Support	Other Family Member Provides Paid Support	No	N
AZ	38%	17%	48%	249
CA	40%	13%	49%	14,183
DE	6%	2%	93%	163
DC	19%	10%	71%	152
FL	14%	9%	78%	479
GA	5%	6%	89%	395
MD	9%	7%	84%	399
MO	9%	14%	78%	329
NH	29%	9%	63%	636
NC	35%	17%	54%	209
OK	39%	11%	51%	388
PA	14%	12%	75%	527
SD	12%	12%	78%	252
WA	68%	20%	21%	277
Weighted NCI Average	32%	13%	58%	18,638

Table 28. Number of Adults in Household (Not Including Family Member Receiving Services)

State	One	Two	Three	Four or More	N
AZ	8%	28%	44%	20%	252
CA	8%	27%	42%	24%	14,286
DE	8%	21%	45%	25%	165
DC	15%	43%	30%	12%	152
FL	11%	31%	41%	17%	474
GA	8%	32%	42%	18%	396
MD	6%	23%	47%	24%	400
MO	7%	28%	46%	19%	334
NH	5%	29%	48%	19%	651
NC	11%	33%	45%	11%	210
OK	6%	36%	50%	8%	392
PA	8%	29%	46%	17%	530
SD	4%	29%	53%	14%	255
WA	4%	34%	47%	15%	274
Weighted NCI Average	8%	29%	43%	20%	18,771

Table 29. Number of Children (Under 18 Years Old) in Household

State	None	One	Two	Three	Four or More	N
AZ	77%	14%	6%	2%	0%	251
CA	82%	11%	5%	2%	1%	14,309
DE	82%	15%	1%	2%	1%	164
DC	86%	5%	5%	3%	2%	155
FL	89%	7%	3%	0%	1%	482
GA	89%	6%	4%	2%	0%	398
MD	87%	8%	3%	1%	0%	400
MO	88%	7%	3%	1%	1%	332
NH	90%	7%	2%	0%	0%	651
NC	88%	7%	4%	1%	0%	209
OK	84%	8%	5%	3%	1%	394
PA	90%	7%	3%	0%	0%	531
SD	80%	10%	5%	2%	2%	256
WA	88%	7%	4%	0%	1%	275
Weighted NCI Average	85%	9%	4%	1%	1%	18,807

Table 30. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
AZ	11%	16%	6%	29%	37%	252
CA	16%	19%	6%	23%	35%	14,224
DE	5%	21%	6%	27%	40%	165
DC	13%	36%	9%	19%	23%	156
FL	9%	29%	7%	22%	33%	475
GA	7%	19%	10%	22%	42%	395
MD	2%	14%	4%	21%	60%	403
MO	5%	22%	7%	27%	41%	333
NH	2%	23%	6%	21%	48%	648
NC	7%	19%	9%	23%	42%	210
OK	5%	25%	7%	29%	34%	391
PA	6%	38%	6%	15%	35%	527
SD	5%	21%	15%	14%	45%	257
WA	2%	12%	7%	31%	49%	278
Weighted NCI Average	11%	22%	7%	23%	38%	18,714

Table 31. 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	6%	9%	14%	21%	11%	23%	16%	241
CA	10%	8%	11%	19%	11%	19%	22%	13,362
DE	10%	7%	9%	12%	14%	28%	20%	163
DC	17%	8%	14%	18%	9%	12%	21%	145
FL	20%	9%	13%	20%	9%	10%	19%	458
GA	15%	8%	10%	18%	15%	19%	16%	381
MD	4%	7%	4%	13%	11%	38%	23%	398
MO	14%	4%	11%	18%	16%	17%	20%	322
NH	7%	8%	7%	16%	13%	22%	28%	629
NC	11%	7%	10%	18%	16%	19%	18%	202
OK	9%	13%	13%	14%	12%	18%	20%	374
PA	10%	7%	9%	19%	10%	19%	26%	505
SD	8%	5%	9%	24%	15%	25%	14%	244
WA	3%	2%	6%	21%	18%	23%	27%	273
Weighted NCI Average	10%	7%	10%	19%	12%	20%	22%	17,697

Table 32. Residential Designation (Urban, Suburban, or Rural)

State	Urban or Suburban	Rural	N
AZ	87%	13%	241
CA	90%	10%	13,188
DE	52%	48%	163
DC	96%	4%	135
FL	80%	20%	460
GA	64%	36%	393
MD	68%	32%	394
MO	59%	41%	323
NH	53%	47%	636
NC	59%	41%	206
OK	71%	29%	392
PA	60%	40%	517
SD	72%	28%	247
WA	72%	28%	272
Weighted NCI Average	78%	22%	17,567

Services and Supports Received

This section provides information about the services and supports received by the family from the state ID/DD agency.

Table 33. Services and Supports Received From ID/DD Agency

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

State	Financial support	Out-of-home respite care	Day/Employment supports	Transportation	Other services/ supports	Self-direction/fiscal intermediary services
AZ	13%	47%	55%	61%	44%	42%
CA	12%	25%	54%	49%	20%	20%
DE	6%	18%	63%	65%	16%	16%
DC	15%	35%	66%	84%	47%	43%
FL	21%	26%	44%	56%	27%	54%
GA	24%	24%	59%	61%	22%	49%
MD	10%	22%	66%	64%	25%	28%
MO	14%	25%	47%	60%	23%	41%
NH	37%	38%	56%	63%	29%	57%
NC	17%	46%	51%	61%	36%	30%
OK	21%	15%	31%	42%	29%	50%
PA	14%	32%	58%	65%	25%	46%
SD	34%	27%	40%	45%	22%	37%
WA	27%	35%	38%	47%	22%	44%
Weighted NCI Average	15%	29%	53%	55%	25%	33%

Table 34. Additional Services and Supports Received (not from the IDD Agency)

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

State	Social Security Payments (SSI/SSB)	Services or Supports from Other Agencies or Organizations
AZ	92%	26%
CA	85%	27%
DE	84%	43%
DC	92%	41%
FL	97%	26%
GA	96%	22%
MD	92%	37%
MO	95%	31%
NH	94%	23%
NC	97%	35%
OK	92%	17%
PA	95%	37%
SD	91%	42%
WA	95%	29%
Weighted NCI Average	90%	29%

Adult Family Survey Results

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.

“You” and **“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.

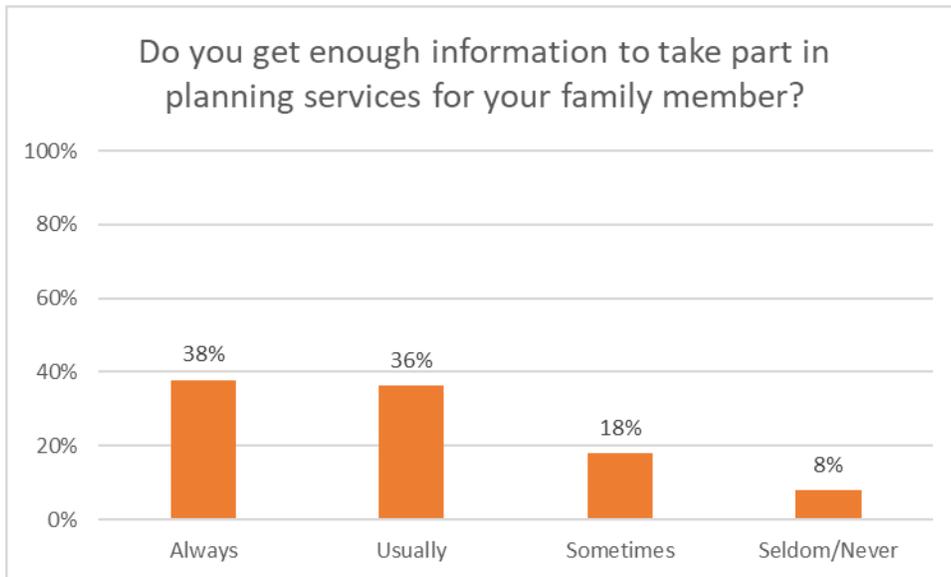


Table Q1. Do you get enough information to take part in planning services for your family member?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	54%	32%	11%	3%	202
DC	51%	30%	16%	3%	145
FL	45%	33%	15%	6%	430

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	43%	39%	14%	4%	504
SD	43%	41%	11%	6%	238
AZ	43%	40%	14%	4%	244
NH	39%	39%	17%	4%	624
OK	39%	40%	13%	8%	373
Weighted NCI Average	38%	36%	18%	8%	16,723
WA	36%	43%	16%	5%	268

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	33%	34%	22%	11%	12,472
MD	31%	44%	15%	10%	383
GA	29%	39%	22%	10%	375
MO	28%	48%	17%	7%	312
DE	17%	41%	29%	12%	153

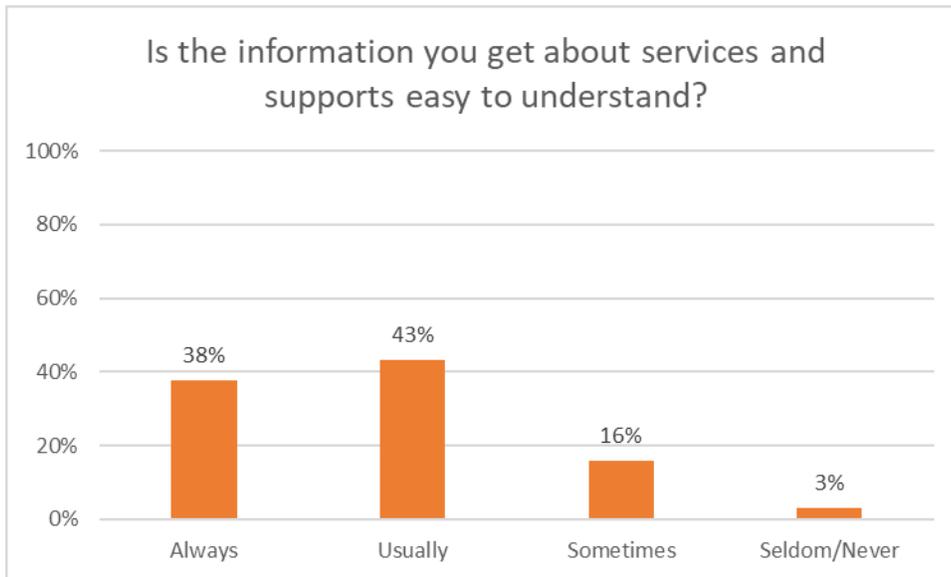


Table Q2. Is the information you get about services and supports easy to understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
DC	50%	34%	15%	1%	151
CA	46%	39%	13%	2%	13,605

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
Weighted NCI Average	38%	43%	16%	3%	17,904
AZ	36%	44%	17%	3%	243
FL	36%	43%	19%	3%	448
PA	33%	46%	18%	3%	507
NC	33%	51%	13%	3%	203
SD	32%	48%	17%	2%	244

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	32%	49%	15%	4%	629
OK	29%	47%	18%	6%	375
MD	24%	49%	22%	5%	387
GA	24%	44%	25%	7%	367
WA	23%	51%	23%	4%	272
MO	23%	54%	19%	4%	316
DE	20%	43%	25%	12%	157

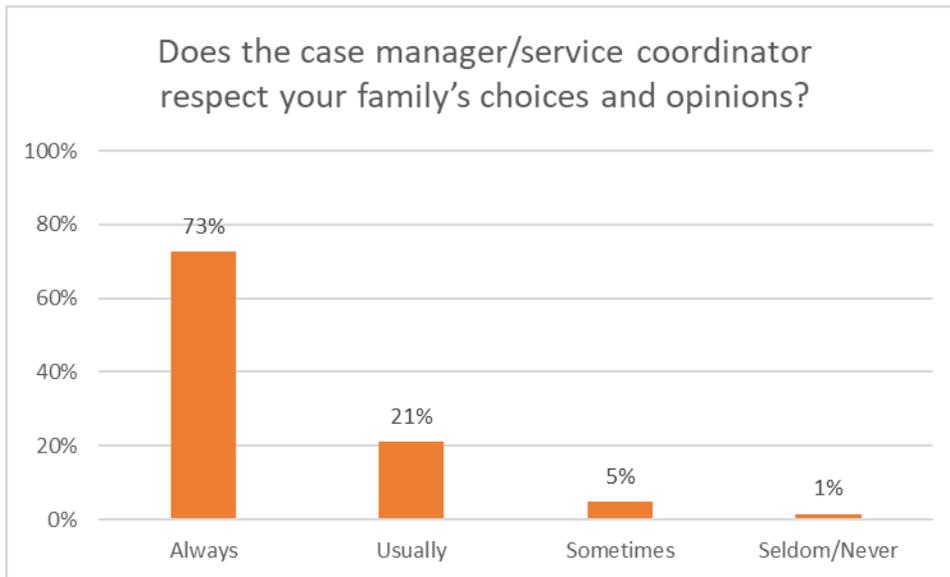


Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	81%	13%	5%	1%	470
WA	81%	17%	2%	0%	268

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	78%	16%	5%	0%	249
PA	77%	19%	3%	1%	523
DC	77%	18%	5%	1%	150
NC	77%	20%	4%		200
Weighted NCI Average	73%	21%	5%	1%	18,025
NH	70%	24%	4%	2%	618
SD	70%	26%	4%	1%	246
CA	69%	22%	6%	2%	13,705
MO	67%	27%	4%	2%	319

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
OK	66%	28%	4%	2%	377
MD	64%	28%	5%	2%	390
GA	57%	35%	6%	2%	364
DE	54%	35%	8%	3%	146

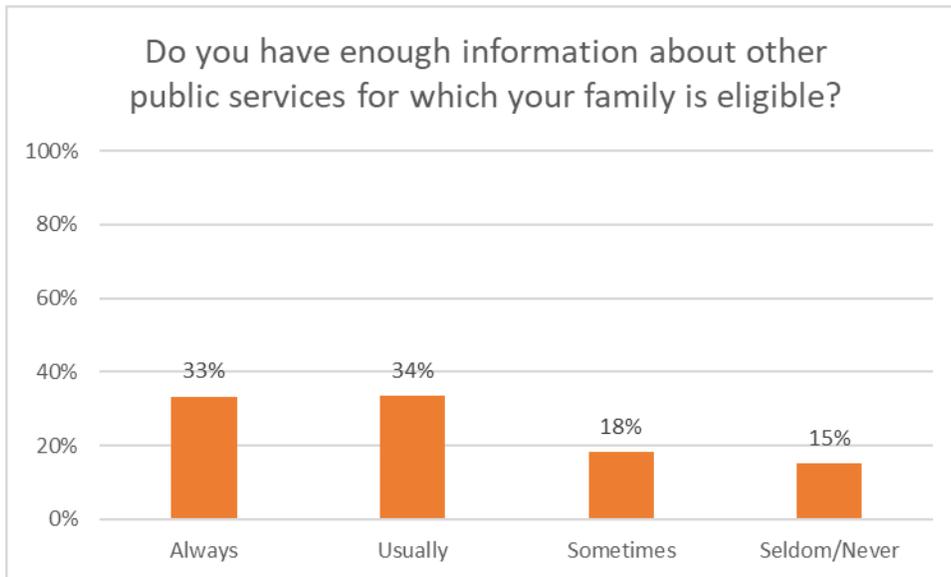


Table Q4. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
DC	53%	28%	13%	6%	139
FL	42%	30%	16%	13%	416

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	42%	36%	14%	9%	216
AZ	37%	31%	14%	17%	225
OK	37%	37%	14%	13%	343
PA	36%	39%	13%	12%	454
NH	34%	38%	17%	11%	569
Weighted NCI Average	33%	34%	18%	15%	15,950
NC	33%	36%	20%	11%	179
CA	32%	31%	19%	17%	12,070
WA	31%	41%	21%	8%	255
MO	28%	40%	17%	15%	280

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	25%	37%	23%	15%	350
DE	23%	32%	25%	20%	138
GA	20%	27%	24%	28%	316

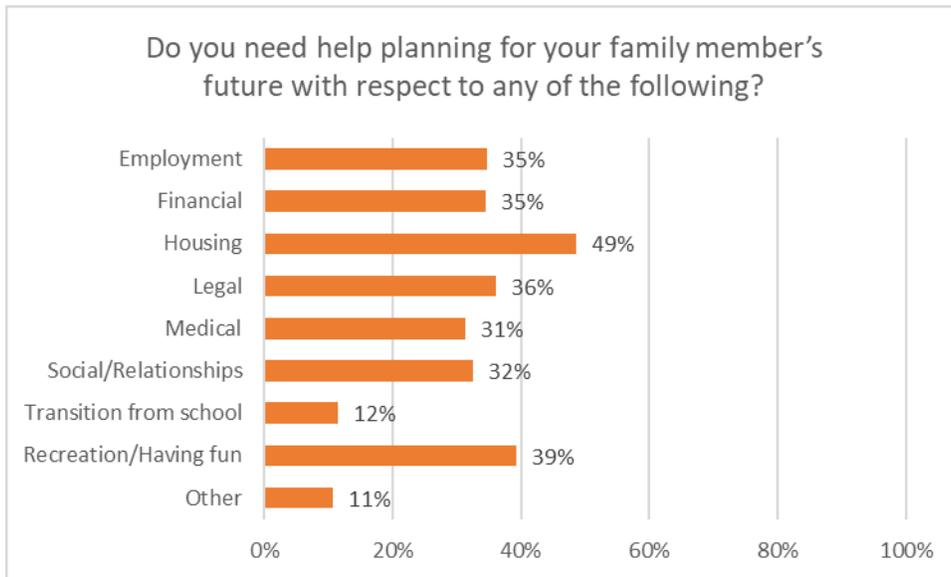


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

Categories are not mutually exclusive, therefore N is not shown

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition From School	Recreation or Having Fun	Other
AZ	35%	31%	44%	35%	25%	31%	14%	41%	7%
CA	39%	36%	48%	35%	34%	35%	15%	40%	9%
DE	38%	38%	53%	38%	32%	32%	7%	26%	10%
DC	26%	13%	30%	24%	12%	19%	4%	25%	7%
FL	21%	31%	39%	37%	34%	27%	6%	34%	21%
GA	25%	35%	51%	42%	33%	25%	8%	32%	16%
MD	44%	40%	60%	43%	28%	37%	9%	46%	8%
MO	24%	33%	52%	32%	27%	27%	3%	31%	12%
NH	40%	40%	59%	29%	27%	40%	4%	37%	13%
NC	30%	38%	46%	43%	29%	29%	13%	41%	10%
OK	32%	33%	46%	39%	39%	31%	15%	34%	8%
PA	27%	31%	50%	33%	25%	26%	7%	34%	11%
SD	50%	35%	51%	18%	25%	39%	19%	43%	11%
WA	38%	27%	54%	36%	29%	35%	8%	44%	11%
Weighted NCI Average	35%	35%	49%	36%	31%	32%	12%	39%	11%

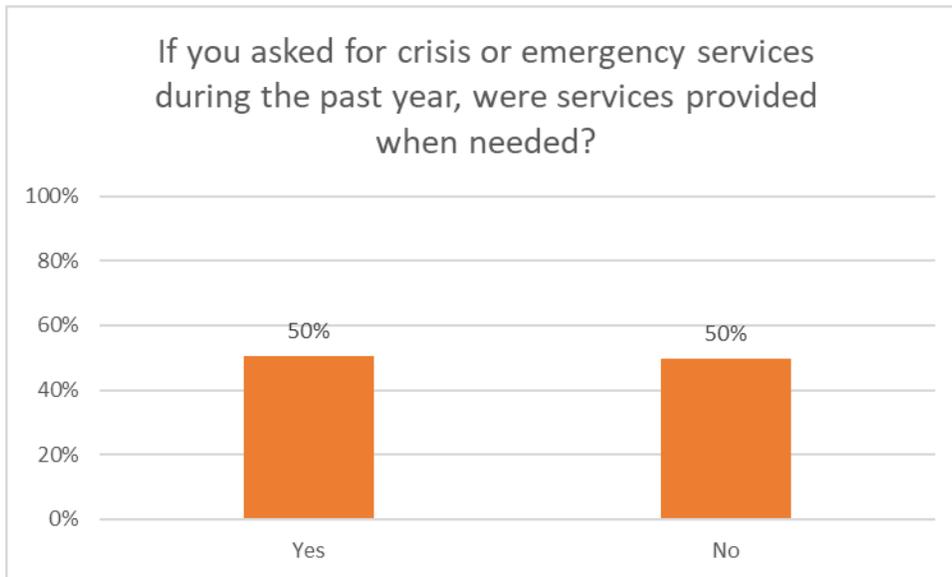


Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

Responses to this question might have been impacted by the COVID-19 pandemic.

Within Average Range

State	Yes	No	N
NC	66%	34%	53
FL	60%	40%	115
DC	60%	40%	50
AZ	57%	43%	53
MO	56%	44%	64
PA	52%	48%	99
Weighted NCI Average	50%	50%	4,716
WA	50%	50%	44
CA	47%	53%	3,820
OK	45%	55%	75
NH	45%	55%	91
SD	44%	56%	48
GA	43%	57%	89
MD	39%	61%	95
DE	30%	70%	20

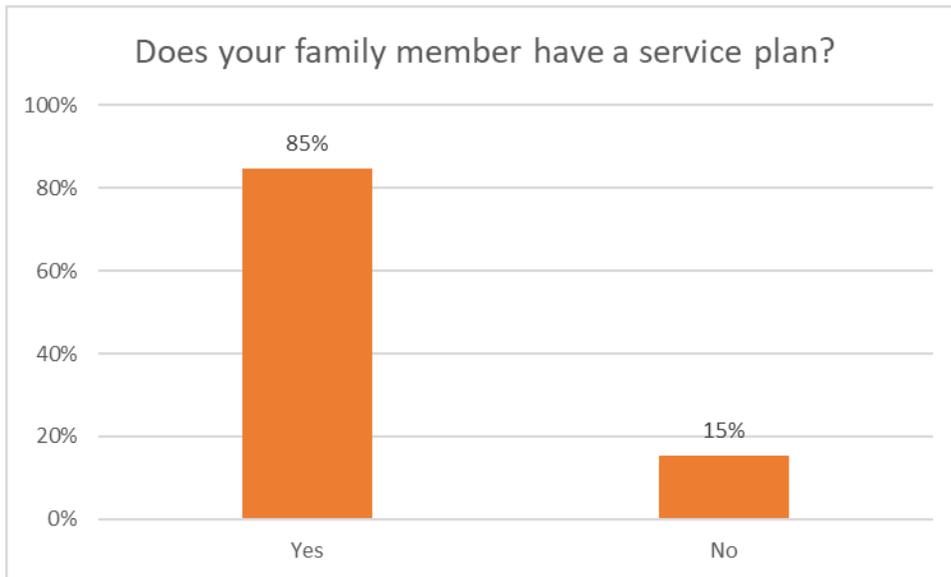


Table Q7. Does your family member have a service plan?

Significantly Above Average

State	Yes	No	N
PA	97%	3%	516
FL	90%	10%	445

Within Average Range

State	Yes	No	N
NC	89%	11%	192
MO	88%	12%	295
AZ	86%	14%	217
WA	86%	14%	228
MD	85%	15%	349
Weighted NCI Average	85%	15%	15,610
SD	84%	16%	201
NH	82%	18%	576
OK	80%	20%	329

Significantly Below Average

State	Yes	No	N
CA	80%	20%	11,702
DC	75%	25%	142
GA	65%	35%	299
DE	50%	50%	119

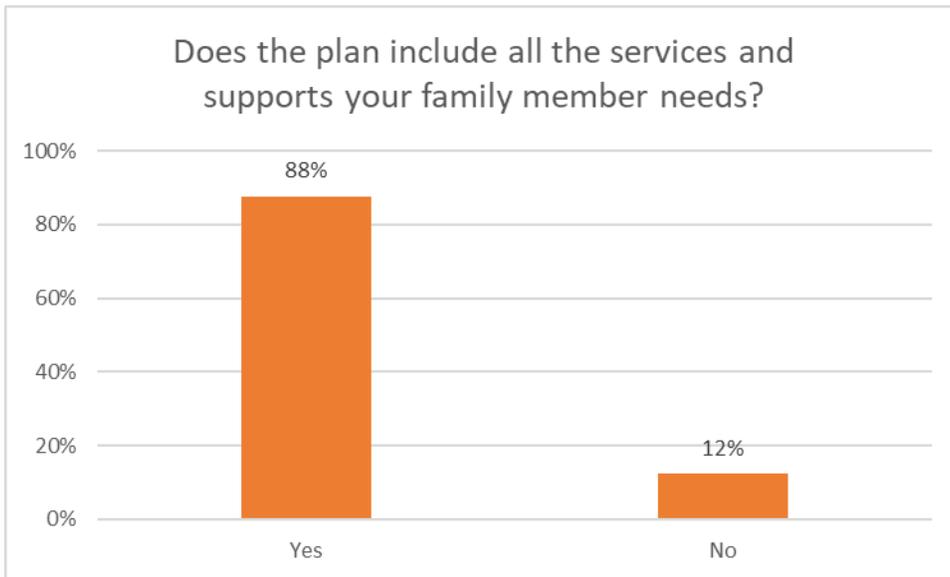


Table Q8. Does the plan include all the services and supports your family member needs?

Significantly Above Average

State	Yes	No	N
PA	94%	6%	452

Within Average Range

State	Yes	No	N
DC	93%	7%	96
FL	90%	10%	353
AZ	89%	11%	171
MD	89%	11%	261
Weighted NCI Average	88%	12%	10,725
SD	87%	13%	151
MO	87%	13%	227
NC	87%	13%	157
OK	86%	14%	236
NH	86%	14%	418
DE	86%	14%	49
CA	86%	14%	7,822
WA	83%	17%	173

Significantly Below Average

State	Yes	No	N
GA	78%	22%	159

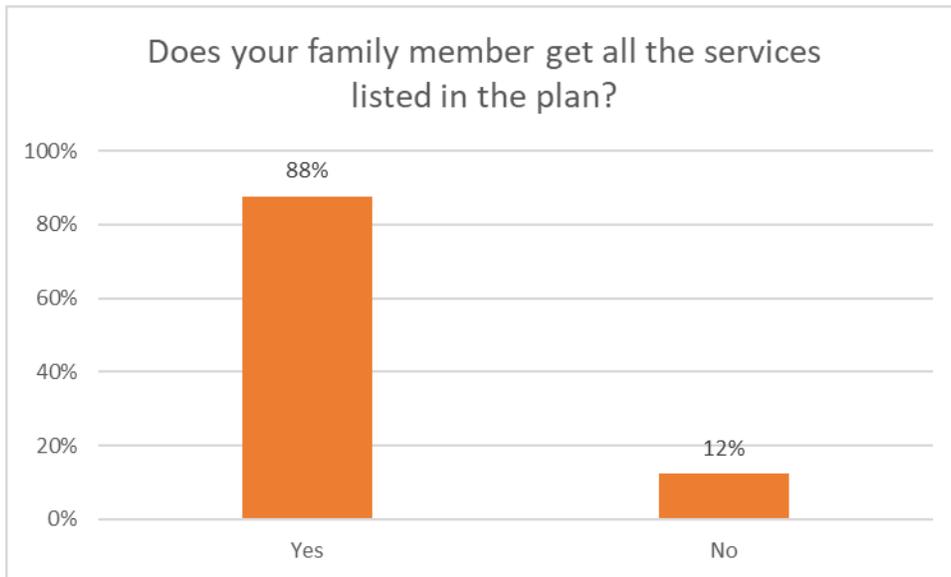


Table Q9. Does your family member get all the services listed in the plan?

Significantly Above Average

State	Yes	No	N
PA	94%	6%	446

Within Average Range

State	Yes	No	N
NH	91%	9%	429
DC	89%	11%	88
OK	88%	12%	230
CA	88%	12%	7,846
FL	88%	12%	341
SD	88%	12%	155
Weighted NCI Average	88%	12%	10,722
NC	87%	13%	159
MO	85%	15%	223
WA	84%	16%	172
AZ	83%	17%	172
GA	81%	19%	162

Significantly Below Average

State	Yes	No	N
MD	80%	20%	255
DE	68%	32%	44

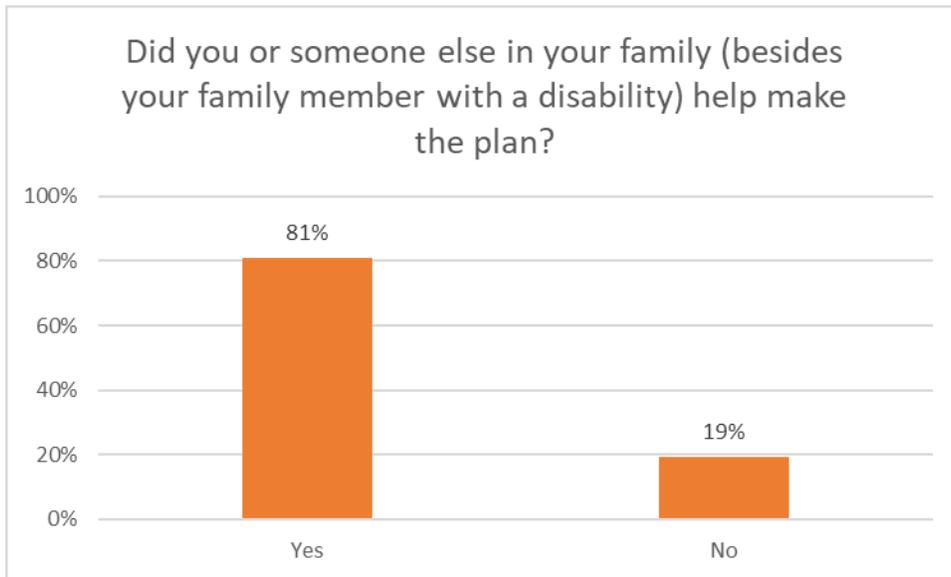


Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the plan?

Significantly Above Average

State	Yes	No	N
MD	92%	8%	283
NC	90%	10%	165
MO	90%	10%	249
NH	89%	11%	454

Within Average Range

State	Yes	No	N
WA	87%	13%	187
OK	86%	14%	245
DE	85%	15%	53
GA	84%	16%	180
SD	83%	17%	158
FL	82%	18%	374
PA	81%	19%	473
Weighted NCI Average	81%	19%	11,715
AZ	75%	25%	174
DC	74%	26%	96

Significantly Below Average

State	Yes	No	N
CA	76%	24%	8,624

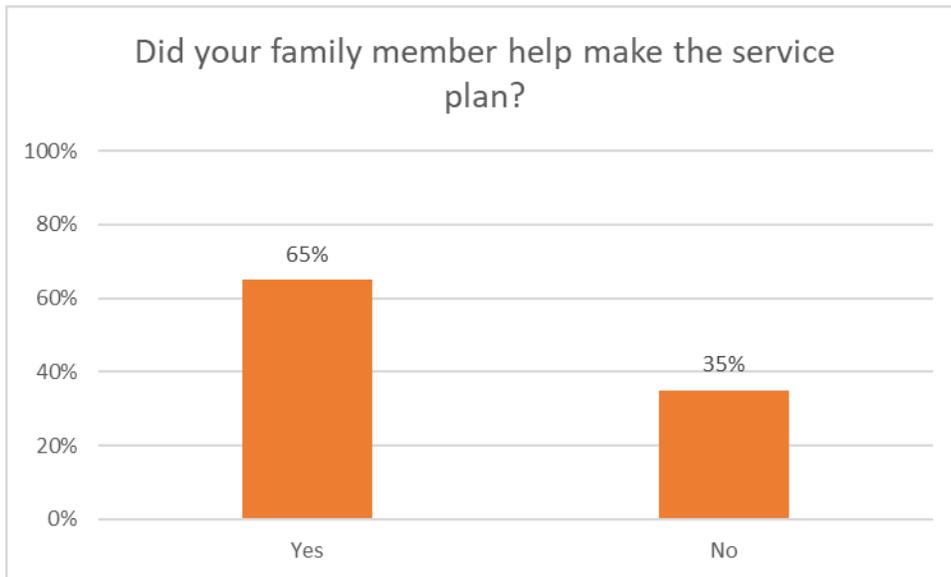


Table Q11. Did your family member help make the service plan?

Significantly Above Average

State	Yes	No	N
DE	80%	20%	55
MD	77%	23%	288
SD	77%	23%	158
WA	74%	26%	184
NH	74%	26%	463

Within Average Range

State	Yes	No	N
DC	68%	32%	93
PA	67%	33%	464
CA	65%	35%	8,672
Weighted NCI Average	65%	35%	11,749
FL	64%	36%	364
GA	63%	38%	176
MO	62%	38%	247
OK	62%	38%	246
NC	58%	42%	166

Significantly Below Average

State	Yes	No	N
AZ	51%	49%	173

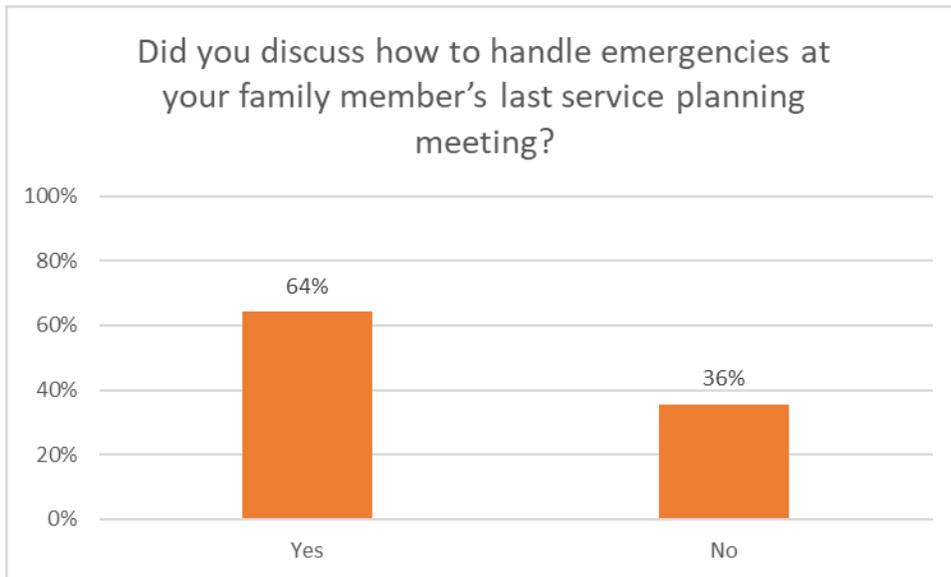


Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or natural disaster) at your family member's last service planning meeting?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
FL	89%	11%	370
NC	84%	16%	165
OK	81%	19%	238
WA	80%	20%	179

Within Average Range

State	Yes	No	N
SD	71%	29%	146
DC	70%	30%	98
Weighted NCI Average	64%	36%	10,683
PA	60%	40%	421
MD	59%	41%	256
MO	57%	43%	232
GA	55%	45%	171

Significantly Below Average

State	Yes	No	N
CA	55%	45%	7,767
AZ	52%	48%	166
NH	43%	57%	422
DE	40%	60%	52

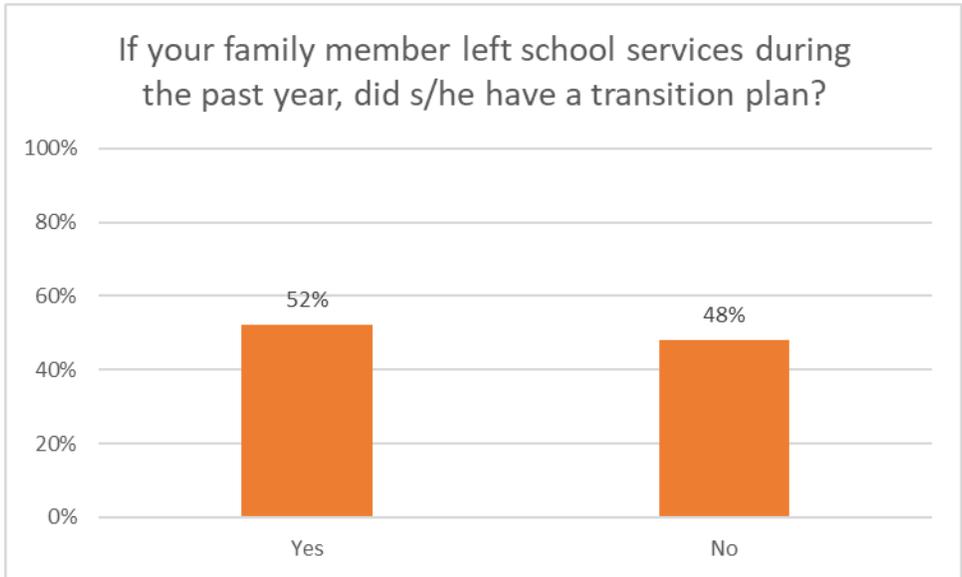


Table Q13. If your family member left school services during the past year, did s/he have a transition plan?⁷

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
MD	77%	23%	39

Within Average Range

State	Yes	No	N
SD	61%	39%	33
WA	54%	46%	24
PA	53%	47%	30
Weighted NCI Average	52%	48%	1,999
GA	50%	50%	24
CA	48%	52%	1,619
AZ	47%	53%	36
FL	45%	55%	20
NH	39%	61%	92
OK	26%	74%	23

⁷ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: DE, DC, MO, NC.

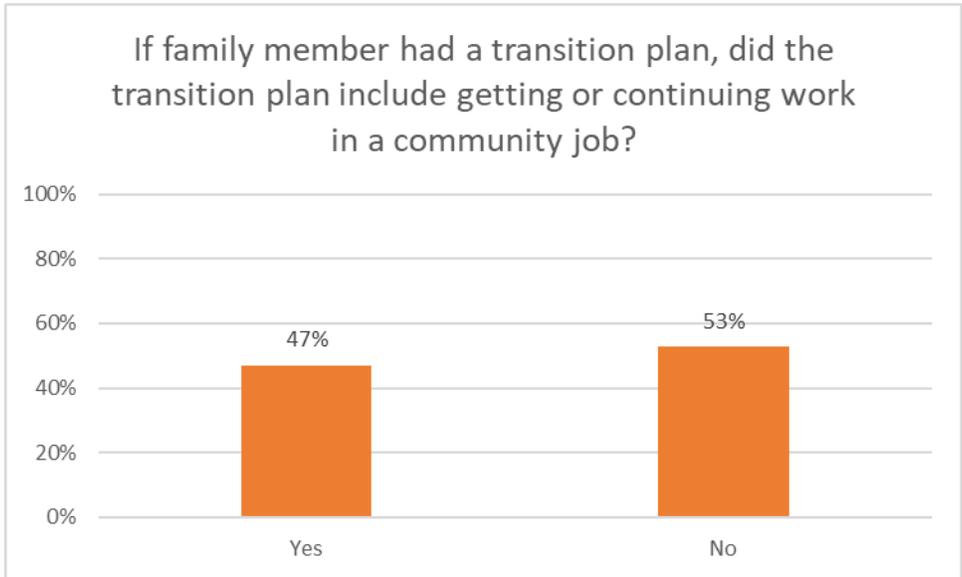


Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?⁸

Within Average Range

State	Yes	No	N
NH	57%	43%	30
MD	54%	46%	26
CA	50%	50%	679
Weighted NCI Average	47%	53%	851

⁸ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, DE, DC, FL, GA, MO, NC, OK, PA, SD, WA.

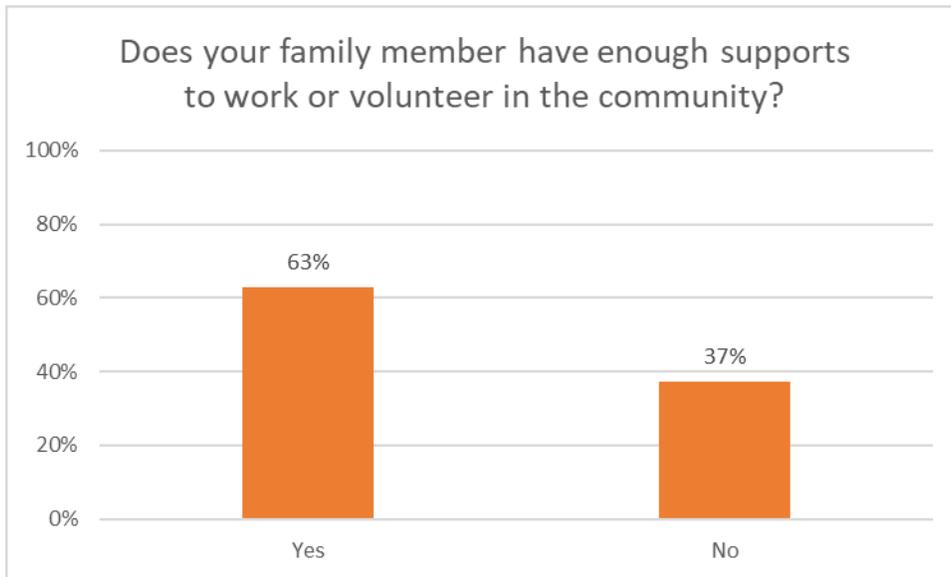


Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
PA	77%	23%	380
NH	73%	27%	513

Within Average Range

State	Yes	No	N
DC	71%	29%	105
DE	71%	29%	112
NC	70%	30%	148
MO	67%	33%	215
OK	63%	37%	256
WA	63%	37%	202
Weighted NCI Average	63%	37%	12,371
SD	63%	37%	198
MD	61%	39%	291
FL	61%	39%	303
AZ	59%	41%	155
CA	59%	41%	9,221

Significantly Below Average

State	Yes	No	N
GA	51%	49%	272

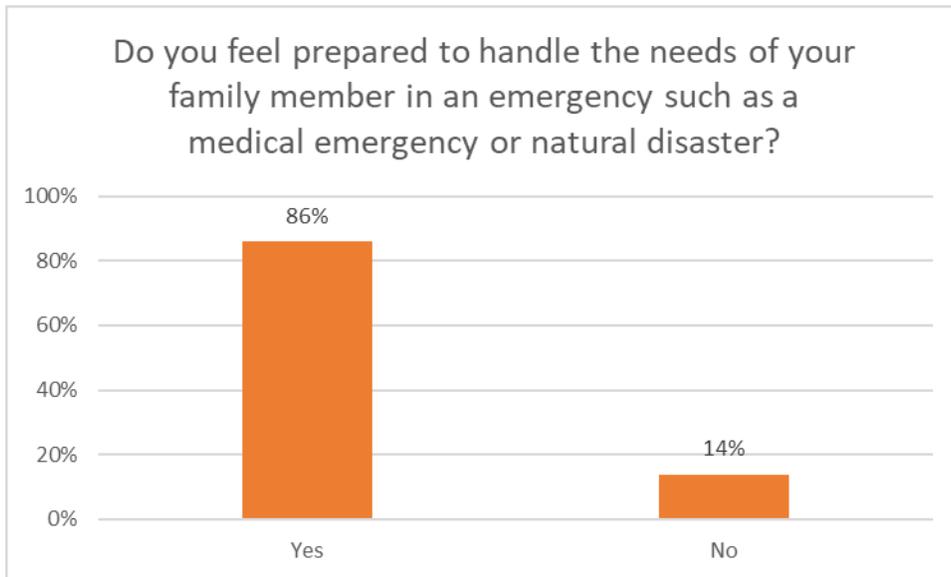


Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
DC	94%	6%	143
SD	93%	7%	234
FL	93%	7%	457
OK	91%	9%	363
NH	89%	11%	570

Within Average Range

State	Yes	No	N
WA	91%	9%	235
AZ	88%	12%	233
PA	88%	12%	482
NC	87%	14%	200
Weighted NCI Average	86%	14%	16,407
MD	86%	14%	355
GA	85%	15%	360
MO	84%	16%	298
CA	83%	17%	12,330
DE	82%	18%	147

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.

“You” and **“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.

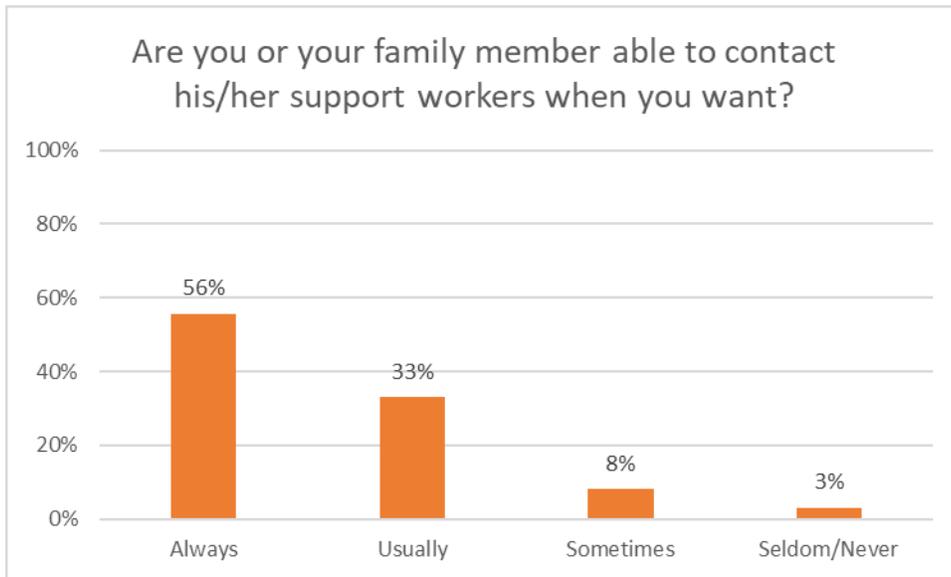


Table Q17. Are you or your family member able to contact his/her support workers when you want?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	69%	25%	4%	2%	449
PA	67%	29%	4%	0%	519

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	62%	32%	5%	1%	147
SD	59%	33%	6%	2%	224
AZ	59%	29%	10%	3%	240
NH	58%	34%	6%	2%	572
NC	57%	38%	5%	1%	196
Weighted NCI Average	56%	33%	8%	3%	16,274
WA	53%	40%	5%	2%	213
OK	51%	37%	9%	4%	357
CA	51%	33%	11%	5%	12,223
MO	49%	40%	7%	3%	298
GA	49%	36%	10%	5%	347

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	48%	41%	7%	4%	347
DE	40%	39%	11%	9%	142

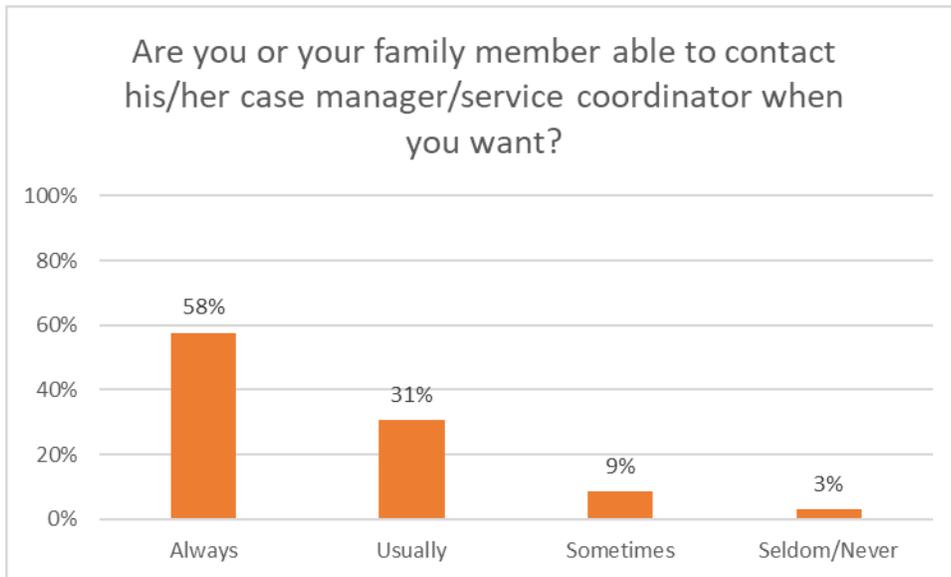


Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	72%	23%	4%	0%	529
FL	70%	23%	5%	2%	470

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	65%	28%	5%	2%	243
DC	64%	27%	6%	3%	150
NH	61%	31%	7%	1%	622
WA	61%	32%	6%	1%	266
NC	58%	34%	6%	1%	201
Weighted NCI Average	58%	31%	9%	3%	17,765
AZ	57%	30%	11%	2%	249
MD	53%	37%	6%	3%	378
OK	52%	35%	8%	6%	386

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	52%	32%	11%	5%	13,436
GA	49%	36%	10%	5%	361
MO	49%	41%	9%	2%	323
DE	40%	37%	14%	9%	151

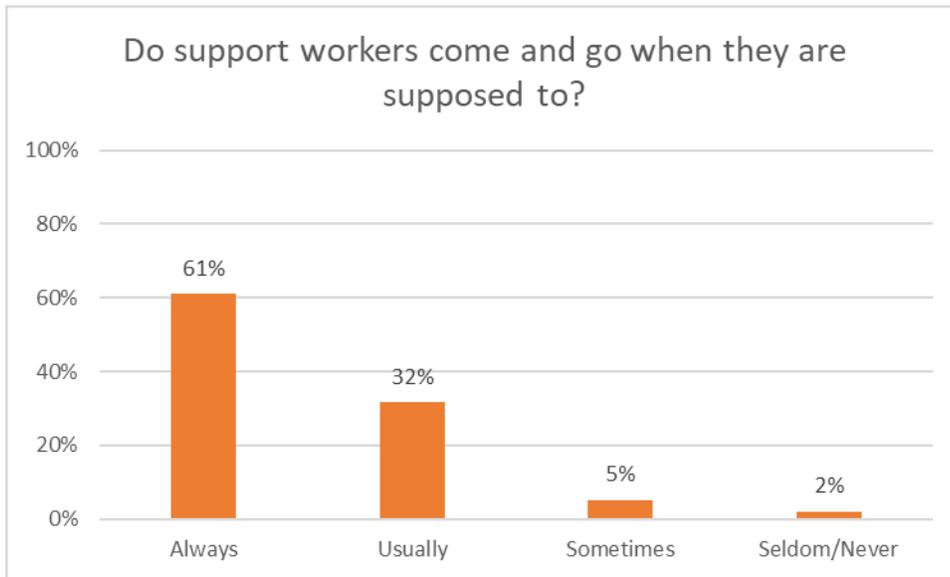


Table Q19. Do support workers come and go when they are supposed to?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	72%	26%	2%	0%	494
FL	68%	25%	4%	2%	423

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	67%	25%	6%	1%	224
WA	64%	32%	3%	1%	173
OK	61%	31%	6%	2%	302
Weighted NCI Average	61%	32%	5%	2%	14,481
SD	60%	34%	5%	1%	161
CA	60%	31%	6%	3%	10,942
MO	57%	34%	8%	1%	248
NH	57%	36%	6%	2%	496
DC	53%	38%	7%	2%	138

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	51%	43%	4%	2%	188
GA	50%	38%	9%	3%	287
MD	47%	43%	7%	3%	296
DE	41%	42%	9%	7%	109

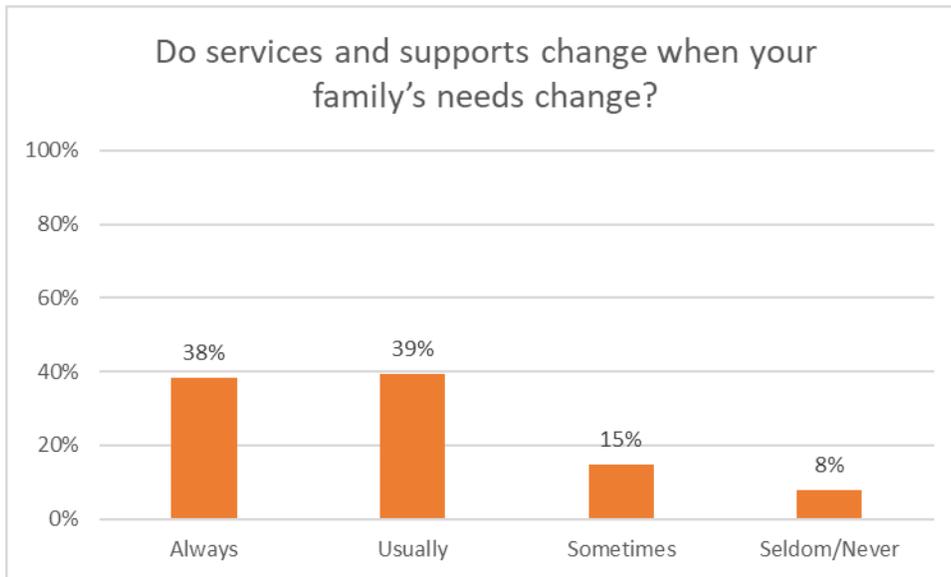


Table Q20. Do services and supports change when your family's needs change?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	46%	36%	13%	5%	348

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	49%	38%	7%	7%	117
PA	44%	39%	12%	4%	395
OK	43%	41%	10%	6%	259
AZ	41%	43%	11%	5%	192
NC	41%	39%	14%	6%	180
NH	39%	38%	13%	10%	438
Weighted NCI Average	38%	39%	15%	8%	12,436
SD	37%	46%	10%	7%	182
MO	36%	41%	18%	4%	223
WA	36%	36%	17%	10%	172
CA	35%	39%	16%	9%	9,359
MD	33%	43%	15%	9%	254
DE	29%	37%	14%	20%	76

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	28%	42%	17%	13%	241

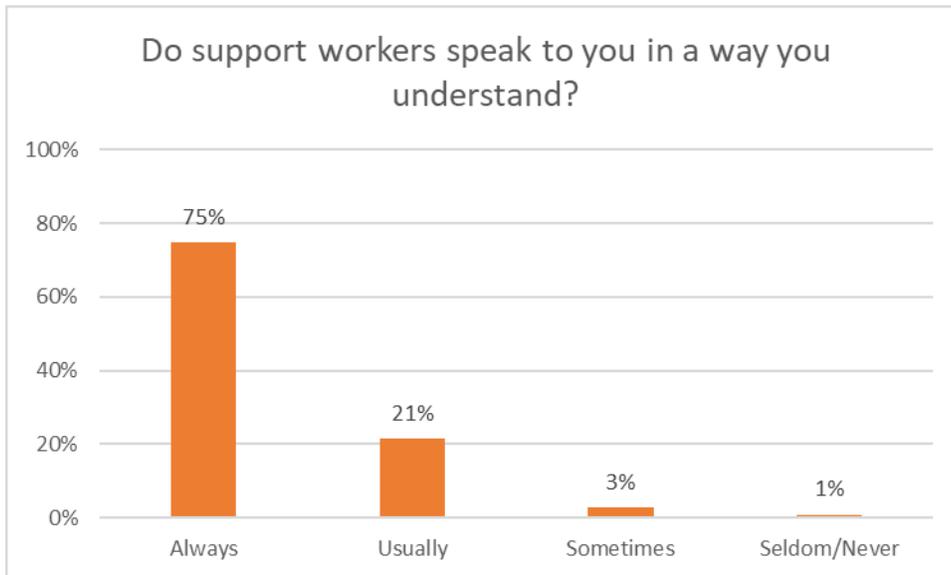


Table Q21. Do support workers speak to you in a way you understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	82%	15%	3%	1%	439
PA	80%	17%	2%	0%	496

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	80%	18%	2%	0%	233
DC	79%	19%	1%	1%	143
NC	79%	18%	2%	1%	195
NH	78%	19%	3%	0%	550
Weighted NCI Average	75%	21%	3%	1%	15,960
OK	74%	22%	2%	2%	329
MO	72%	25%	1%	1%	268
WA	72%	26%	1%	1%	193
CA	72%	23%	4%	1%	12,127
SD	71%	25%	4%	0%	198

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	67%	27%	3%	2%	335
GA	65%	30%	3%	2%	325
DE	58%	35%	5%	2%	129

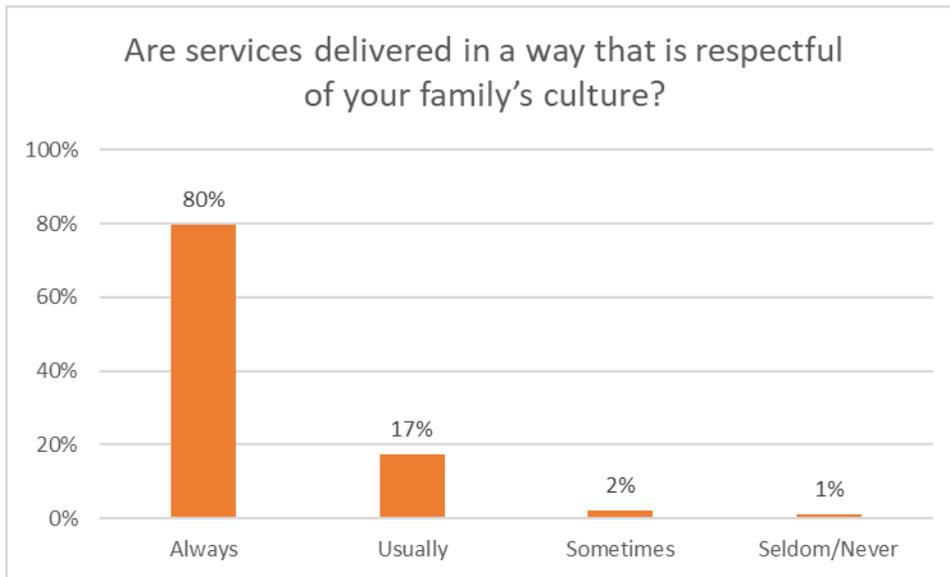


Table Q22. Are services delivered in a way that is respectful of your family's culture?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	85%	13%	1%	1%	511

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
WA	85%	14%	1%	0%	225
FL	83%	15%	1%	1%	444
AZ	83%	14%	3%	0%	246
NH	80%	16%	3%	1%	598
NC	80%	18%	2%	1%	199
Weighted NCI Average	80%	17%	2%	1%	17,286
SD	79%	19%	1%	1%	237
CA	78%	19%	3%	1%	13,171
OK	77%	20%	2%	1%	354
MO	76%	22%	1%	1%	302
DC	70%	24%	3%	2%	149

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	73%	21%	3%	2%	363
GA	69%	27%	3%	1%	347
DE	65%	29%	3%	3%	140

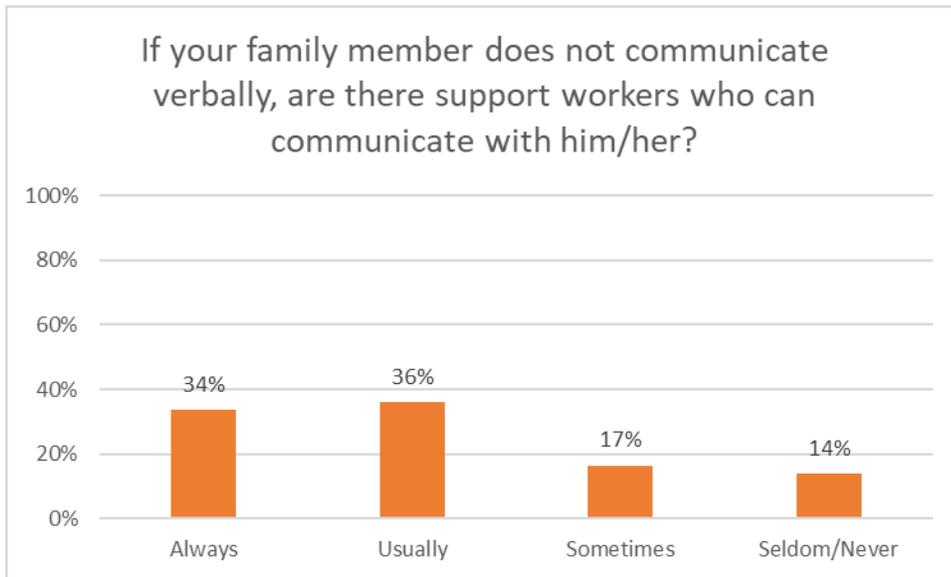


Table Q23. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with him/her? ⁹

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
DC	58%	25%	14%	3%	36

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	45%	31%	15%	9%	55
PA	40%	34%	16%	10%	93
FL	39%	31%	17%	14%	109
CA	34%	31%	16%	19%	2,053
Weighted NCI Average	34%	36%	17%	14%	2,933
NH	33%	46%	14%	8%	80
GA	31%	44%	17%	8%	90
OK	29%	40%	22%	9%	103
MD	29%	40%	25%	6%	77
SD	28%	44%	15%	13%	39
WA	28%	35%	26%	11%	54
NC	24%	56%	9%	11%	55

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	20%	40%	28%	12%	75

⁹ DE not included in the table due to low N (>20), but their responses are included in the NCI Average.

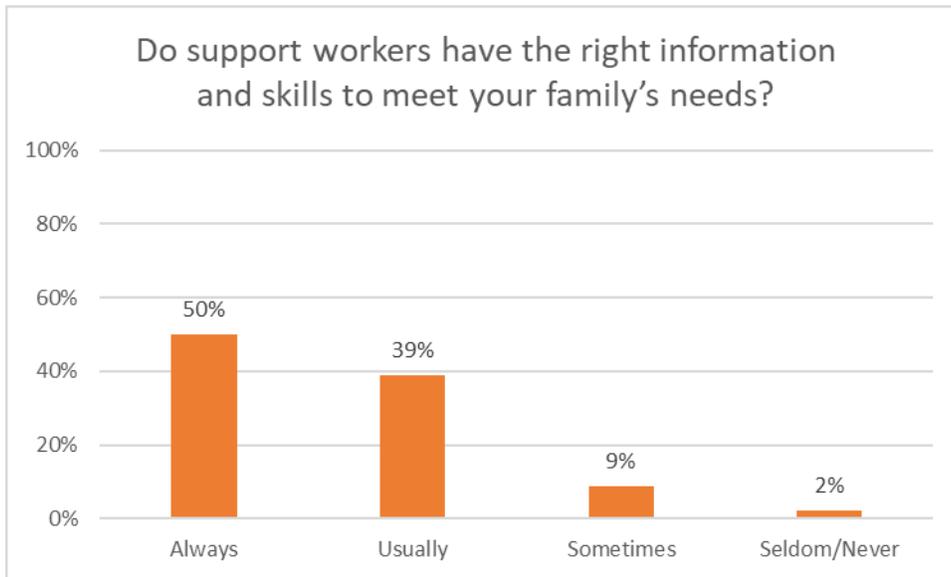


Table Q24. Do support workers have the right information and skills to meet your family's needs?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	63%	30%	6%	1%	424
PA	58%	36%	6%	0%	481

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	55%	36%	6%	2%	141
Weighted NCI Average	50%	39%	9%	2%	15,149
CA	49%	38%	10%	3%	11,456
OK	49%	41%	8%	2%	319
MO	47%	42%	9%	2%	266
NC	46%	44%	7%	3%	196
AZ	46%	43%	9%	2%	229
WA	42%	49%	7%	2%	181
SD	41%	49%	9%	2%	187

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	43%	45%	10%	3%	519
GA	43%	46%	8%	3%	310
MD	37%	46%	14%	3%	317
DE	36%	47%	11%	6%	123

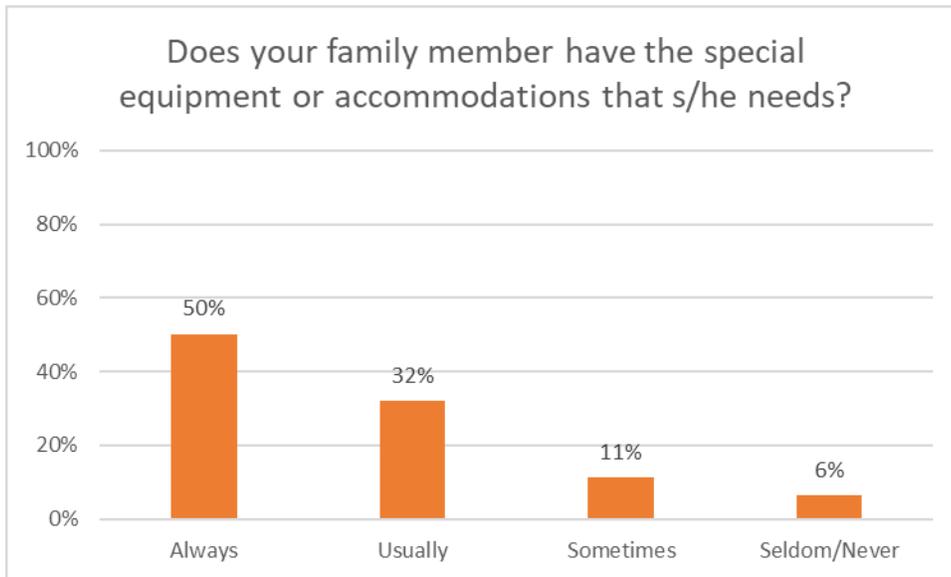


Table Q25. Does your family member have the special equipment or accommodations that s/he needs?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	60%	25%	10%	5%	226

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	64%	24%	5%	7%	58
AZ	55%	31%	11%	3%	149
PA	52%	32%	10%	6%	190
CA	52%	30%	10%	8%	5,107
NC	50%	32%	12%	5%	117
Weighted NCI Average	50%	32%	11%	6%	7,016
DE	50%	32%	5%	13%	38
FL	50%	33%	10%	7%	231
MO	48%	40%	11%	2%	151
OK	46%	35%	12%	7%	208
SD	46%	43%	8%	3%	116
MD	44%	35%	14%	6%	140
WA	39%	38%	17%	6%	117

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	38%	35%	17%	10%	168

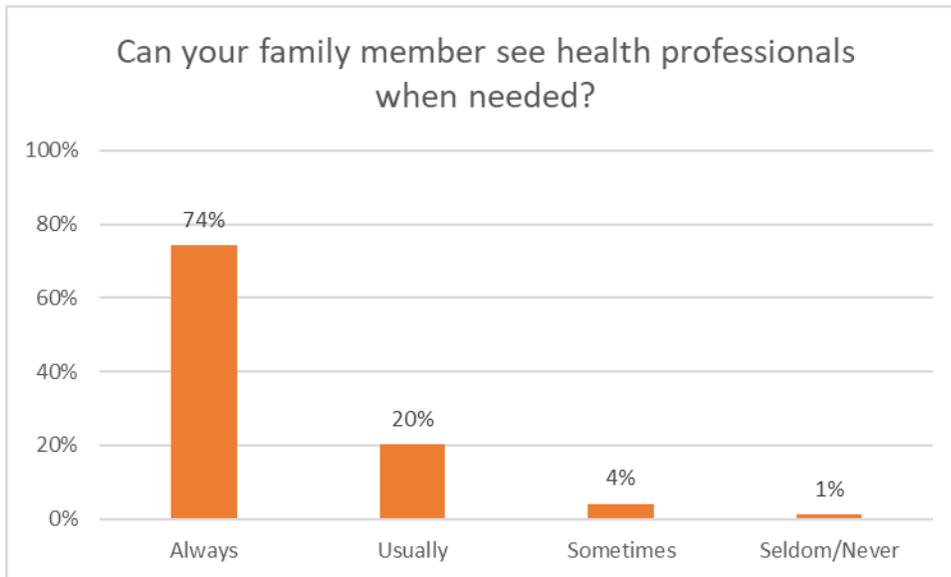


Table Q26. Can your family member see health professionals when needed?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	82%	16%	2%	0%	212
NH	80%	16%	2%	1%	645
PA	80%	17%	2%	1%	535

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MD	79%	18%	2%	1%	395
OK	79%	18%	2%	1%	390
FL	78%	18%	3%	1%	478
DE	77%	13%	5%	4%	164
SD	77%	21%	1%	1%	253
AZ	76%	20%	4%	0%	251
DC	76%	21%	3%	0%	152
MO	74%	19%	5%	1%	331
Weighted NCI Average	74%	20%	4%	1%	18,542
GA	74%	22%	4%	1%	393
CA	70%	23%	5%	2%	14,080
WA	67%	25%	6%	2%	263

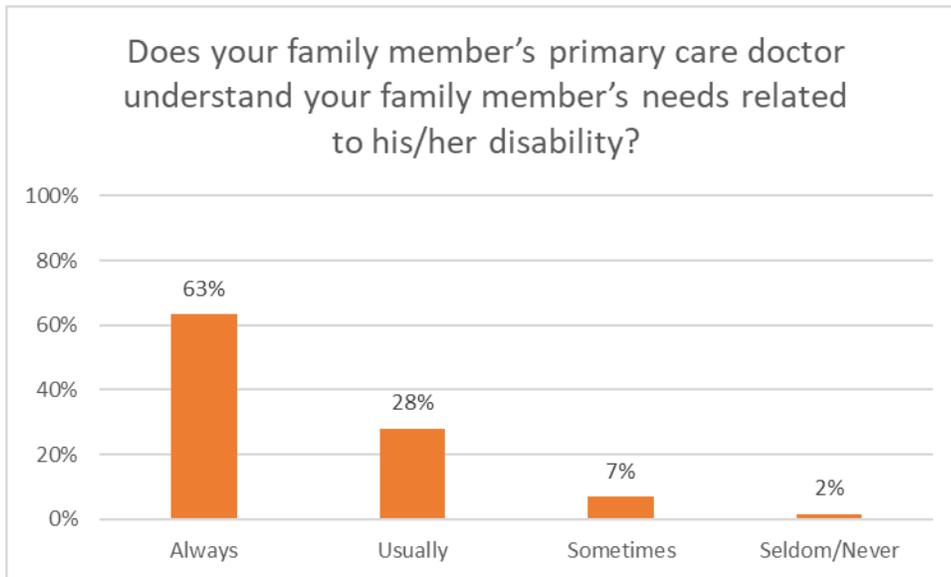


Table Q27. Does your family member's primary care doctor understand your family member's needs related to his/her disability?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
DC	82%	16%	1%	0%	152
FL	71%	24%	4%	1%	460
OK	70%	26%	4%	0%	388
PA	70%	26%	4%	1%	527

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DE	67%	25%	8%	0%	159
NC	67%	26%	7%	0%	209
AZ	66%	28%	4%	3%	251
SD	66%	28%	5%	2%	247
GA	65%	27%	7%	2%	387
Weighted NCI Average	63%	28%	7%	2%	18,020
CA	61%	29%	8%	2%	13,634
MD	60%	34%	5%	1%	392
NH	59%	30%	9%	1%	631

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	54%	39%	5%	1%	323
WA	53%	32%	12%	3%	260

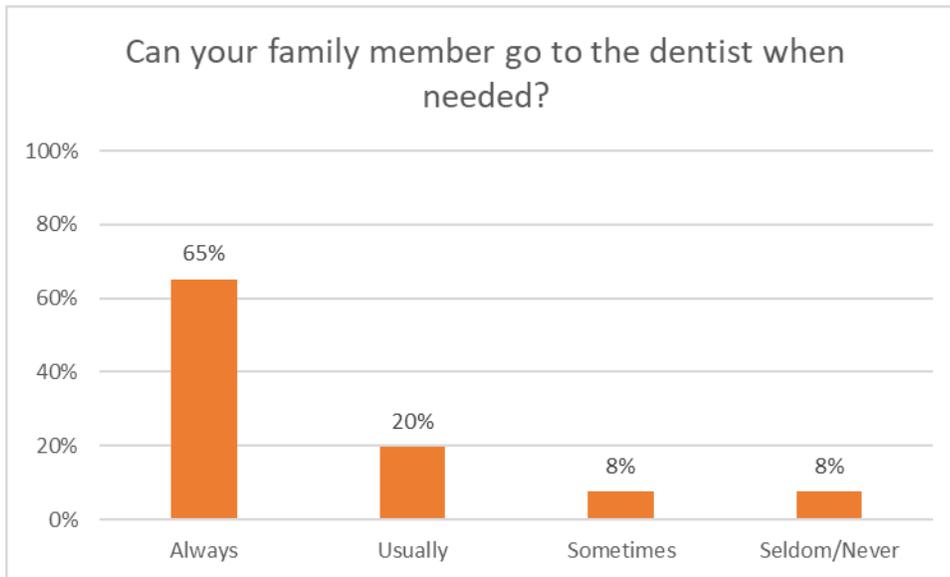


Table Q28. Can your family member go to the dentist when needed?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	74%	16%	6%	5%	521
SD	74%	17%	4%	5%	255
NH	73%	14%	4%	8%	633
MD	72%	18%	5%	4%	389

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	73%	15%	4%	8%	209
DC	72%	20%	5%	3%	151
AZ	70%	15%	6%	9%	250
DE	68%	15%	7%	10%	155
Weighted NCI Average	65%	20%	8%	8%	18,325
OK	63%	24%	6%	6%	385
CA	62%	22%	8%	7%	13,923
FL	60%	20%	11%	9%	470
MO	59%	24%	5%	12%	330
WA	58%	22%	7%	13%	268

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	57%	20%	11%	12%	386

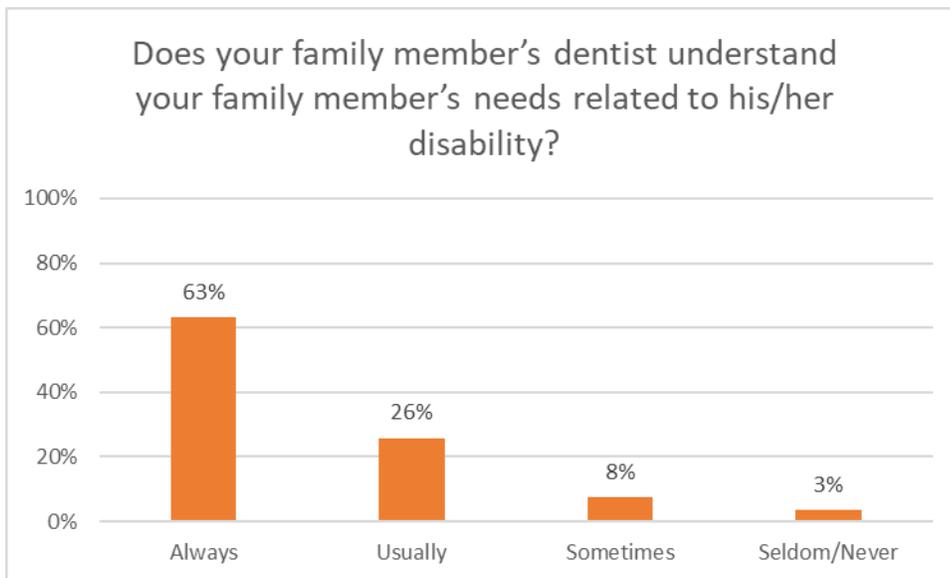


Table Q29. Does your family member's dentist understand your family member's needs related to his/her disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
DC	77%	17%	4%	2%	145

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	69%	23%	7%	2%	188
PA	68%	24%	5%	2%	480
NH	68%	23%	5%	3%	569
MD	67%	23%	7%	4%	366
SD	65%	27%	8%	1%	234
AZ	63%	25%	8%	3%	226
Weighted NCI Average	63%	26%	8%	3%	16,519
FL	63%	28%	6%	3%	397
OK	63%	28%	6%	3%	343
CA	62%	26%	8%	4%	12,579
DE	62%	31%	6%	2%	133
GA	58%	31%	8%	3%	337
WA	58%	28%	9%	5%	234

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	54%	33%	9%	4%	288

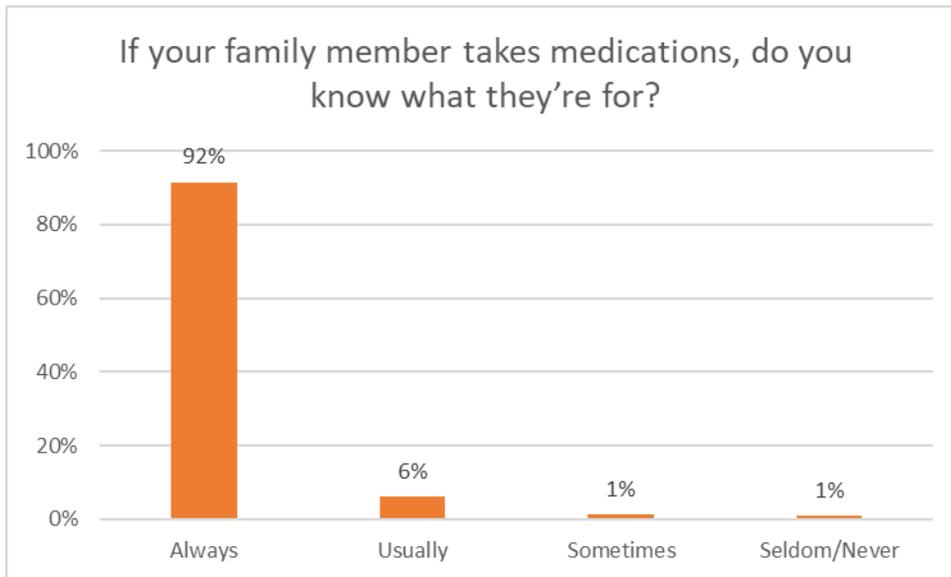


Table Q30. If your family member takes medications, do you know what they're for?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	97%	3%	0%	0%	240
AZ	96%	4%	0%	0%	220
NH	95%	3%	1%	0%	568
MD	95%	4%	1%	0%	317

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NC	93%	6%	0%	1%	194
SD	93%	6%	1%	0%	218
GA	92%	6%	2%	1%	359
PA	92%	6%	1%	1%	472
Weighted NCI Average	92%	6%	1%	1%	15,327
FL	91%	6%	1%	1%	433
OK	91%	7%	1%	1%	350
CA	89%	7%	2%	1%	11,421
MO	89%	8%	1%	2%	287
DE	89%	6%	2%	2%	129
DC	89%	8%	3%	0%	119

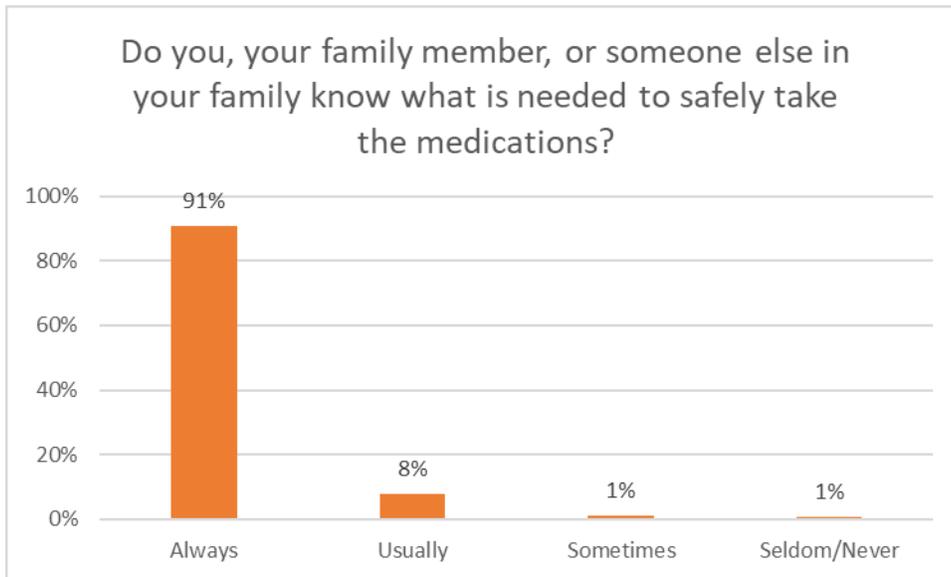


Table Q31. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	96%	3%	0%	0%	568
WA	95%	5%	0%	0%	233
PA	94%	6%	0%	1%	469

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	94%	5%	1%	0%	219
MD	93%	6%	1%	0%	314
OK	93%	6%	1%	1%	348
NC	92%	6%	2%	0%	192
SD	92%	8%	0%	0%	219
DC	92%	8%	1%	0%	119
DE	91%	8%	1%	0%	127
FL	91%	8%	1%	1%	432
GA	91%	7%	1%	1%	356
Weighted NCI Average	91%	8%	1%	1%	15,127
MO	90%	8%	1%	1%	287
CA	88%	10%	1%	1%	11,244

If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?

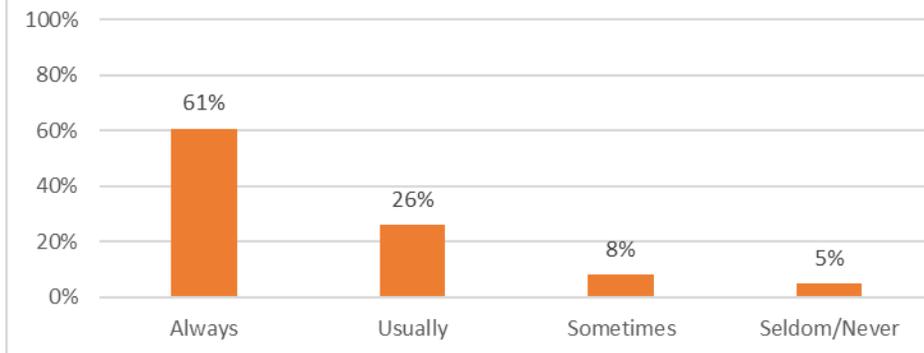


Table Q32. If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
DC	76%	24%	0%	0%	67

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	66%	26%	6%	2%	189
FL	66%	23%	8%	3%	156
GA	64%	23%	10%	4%	142
NC	63%	27%	8%	2%	112
MD	63%	21%	10%	6%	136
AZ	62%	25%	7%	6%	112
OK	61%	26%	8%	5%	97
Weighted NCI Average	61%	26%	8%	5%	6,728
NH	60%	29%	9%	2%	187
SD	59%	28%	11%	2%	93
MO	59%	26%	10%	5%	105
CA	58%	27%	9%	7%	5,229
DE	52%	29%	14%	5%	42
WA	51%	33%	11%	5%	61

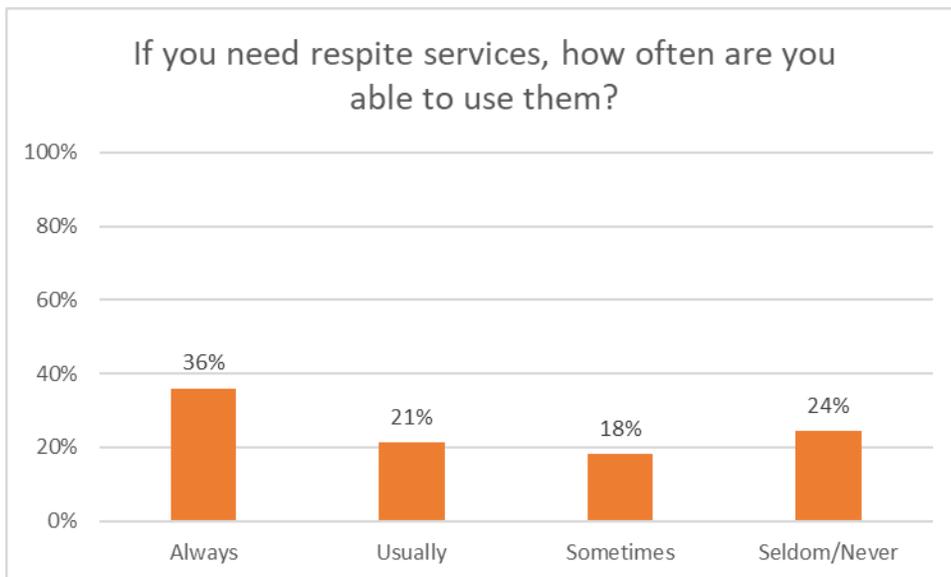


Table Q33. If you need respite services, how often are you able to use them?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	50%	21%	17%	13%	204
CA	42%	22%	17%	20%	7,532

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	47%	20%	17%	16%	83
Weighted NCI Average	36%	21%	18%	24%	9,921
NC	36%	21%	22%	22%	157
PA	32%	22%	17%	29%	255

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	29%	22%	24%	26%	418
FL	27%	21%	19%	33%	242
WA	27%	24%	20%	29%	185
OK	22%	14%	13%	52%	143
MO	19%	19%	22%	40%	159
SD	19%	29%	27%	24%	131
GA	17%	17%	24%	42%	185
MD	17%	19%	20%	44%	163
DE	14%	13%	16%	58%	64

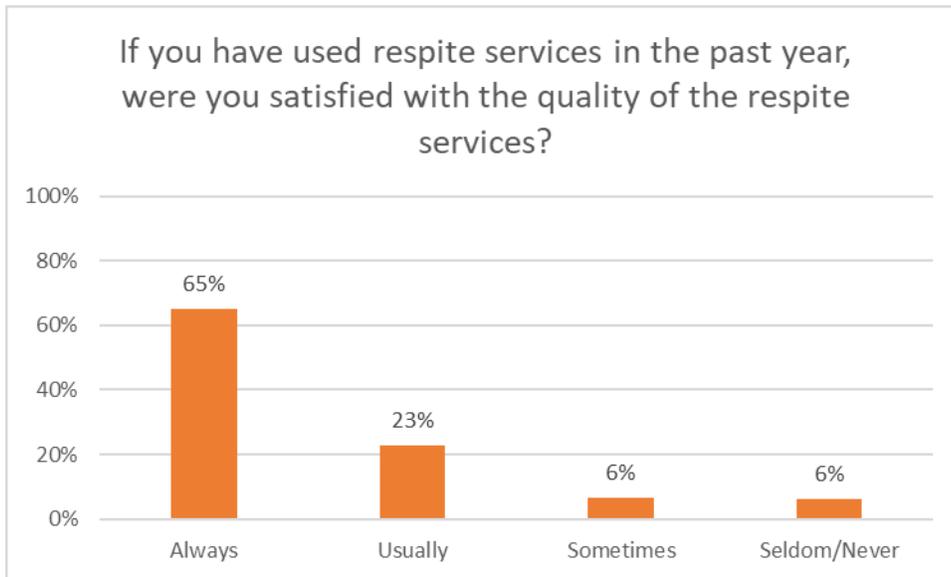


Table Q34. If you have used respite services in the past year, were you satisfied with the quality of the respite services?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	76%	19%	3%	2%	326

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	72%	18%	3%	7%	164
SD	71%	19%	3%	7%	100
AZ	70%	23%	4%	3%	182
Weighted NCI Average	65%	23%	6%	6%	7,402
CA	65%	22%	7%	6%	5,771
NC	65%	24%	7%	4%	127
DC	62%	19%	6%	13%	53
WA	62%	24%	10%	4%	135
FL	62%	23%	7%	9%	151
MD	54%	29%	4%	13%	96
OK	54%	28%	6%	13%	69
GA	53%	33%	9%	5%	101
DE	53%	30%	13%	3%	30
MO	53%	33%	7%	7%	97

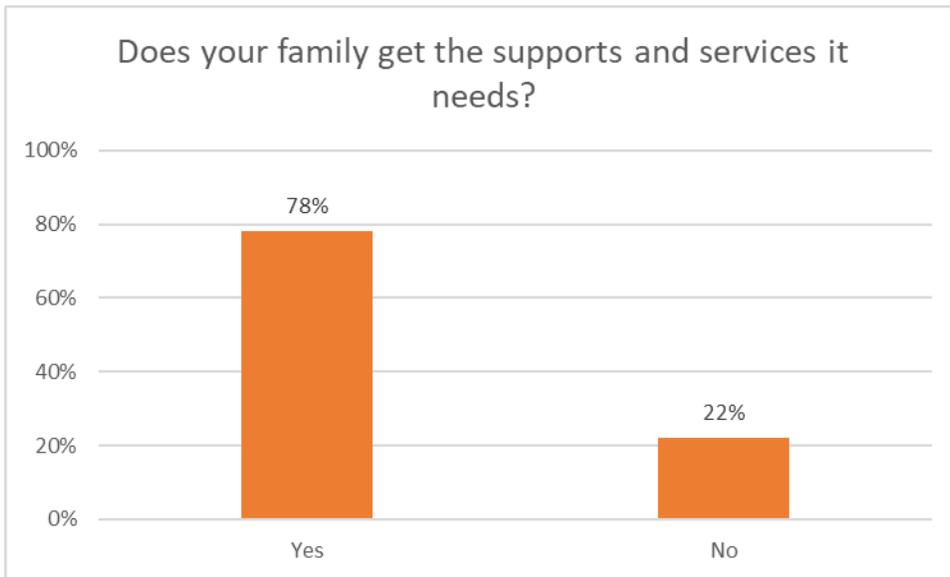


Table Q35. Does your family get the supports and services it needs?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
DC	89%	11%	137
PA	83%	17%	483

Within Average Range

State	Yes	No	N
AZ	84%	16%	234
NC	83%	17%	191
FL	80%	20%	425
WA	78%	22%	232
Weighted NCI Average	78%	22%	15,405
SD	78%	22%	221
CA	77%	23%	11,481
NH	76%	24%	568
OK	74%	26%	350
MO	74%	26%	288
DE	68%	32%	126

Significantly Below Average

State	Yes	No	N
MD	69%	31%	356
GA	61%	39%	313

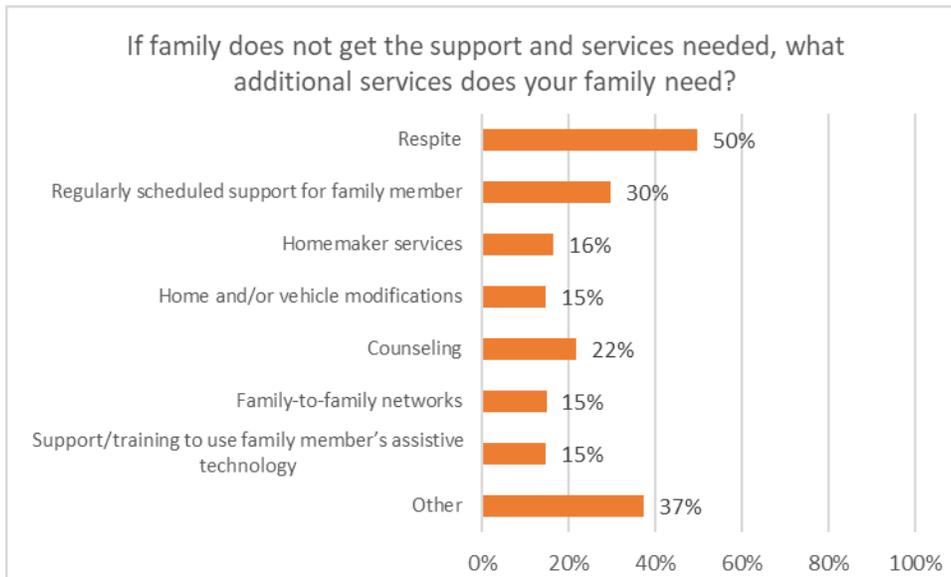


Table Q36. If family does not get the support and services needed, what additional services does your family need?

Categories are not mutually exclusive, therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Support or Training to Use Assistive Technology	Other
AZ	31%	22%	11%	11%	14%	11%	11%	0%
CA	43%	28%	18%	12%	26%	15%	16%	39%
DE	50%	25%	6%	8%	17%	14%	0%	53%
DC	54%	23%	8%	0%	8%	8%	0%	62%
FL	65%	28%	24%	19%	19%	12%	17%	35%
GA	61%	24%	17%	14%	18%	18%	7%	42%
MD	60%	40%	15%	18%	20%	22%	12%	32%
MO	47%	21%	10%	19%	15%	12%	12%	38%
NH	47%	32%	12%	9%	18%	12%	3%	47%
NC	56%	34%	16%	25%	22%	13%	19%	34%
OK	67%	30%	18%	20%	10%	12%	12%	19%
PA	46%	27%	10%	8%	13%	9%	13%	47%
SD	59%	41%	16%	14%	8%	12%	14%	41%
WA	64%	36%	16%	22%	26%	26%	18%	46%
Weighted NCI Average	50%	30%	16%	15%	22%	15%	15%	37%

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.

“You” and **“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.

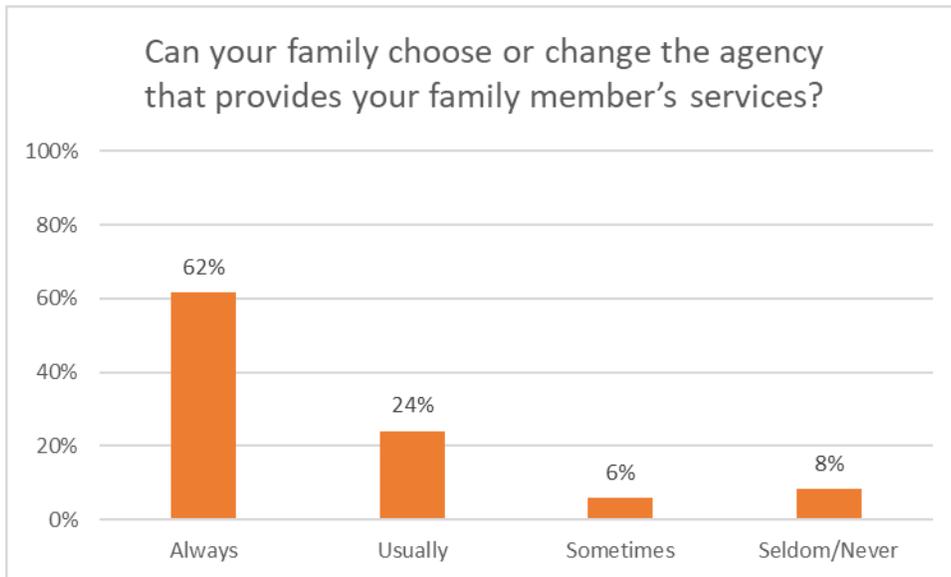


Table Q37. Can your family choose or change the agency that provides your family member's services?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	79%	14%	4%	4%	170
AZ	72%	20%	3%	4%	203
FL	70%	20%	3%	6%	348
OK	70%	16%	5%	9%	282
PA	69%	24%	4%	3%	382
NH	69%	19%	2%	10%	374

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	70%	23%	4%	3%	122
SD	64%	27%	3%	6%	157
Weighted NCI Average	62%	24%	6%	8%	9,846
MO	62%	22%	8%	8%	203
WA	61%	27%	5%	8%	143
DE	60%	27%	4%	9%	90
GA	59%	27%	5%	10%	238
MD	57%	28%	7%	8%	254

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	49%	29%	9%	13%	6,880

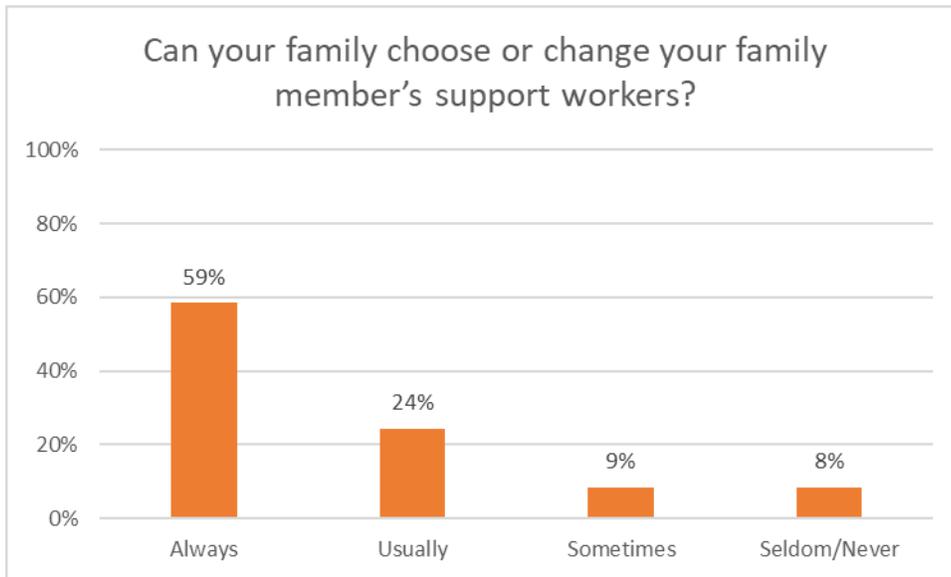


Table Q38. Can your family choose or change your family member's support workers?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	73%	18%	4%	5%	363
AZ	69%	17%	7%	7%	183
OK	68%	18%	7%	7%	285
PA	65%	24%	4%	7%	368

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DC	68%	22%	4%	6%	119
NC	67%	18%	9%	6%	175
SD	60%	19%	9%	12%	139
GA	60%	24%	7%	9%	225
Weighted NCI Average	59%	24%	9%	8%	9,986
MO	58%	25%	10%	8%	199
WA	55%	27%	13%	5%	149
NH	53%	22%	14%	11%	438
DE	46%	32%	6%	15%	65

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	50%	28%	10%	12%	7,034
MD	40%	37%	15%	8%	244

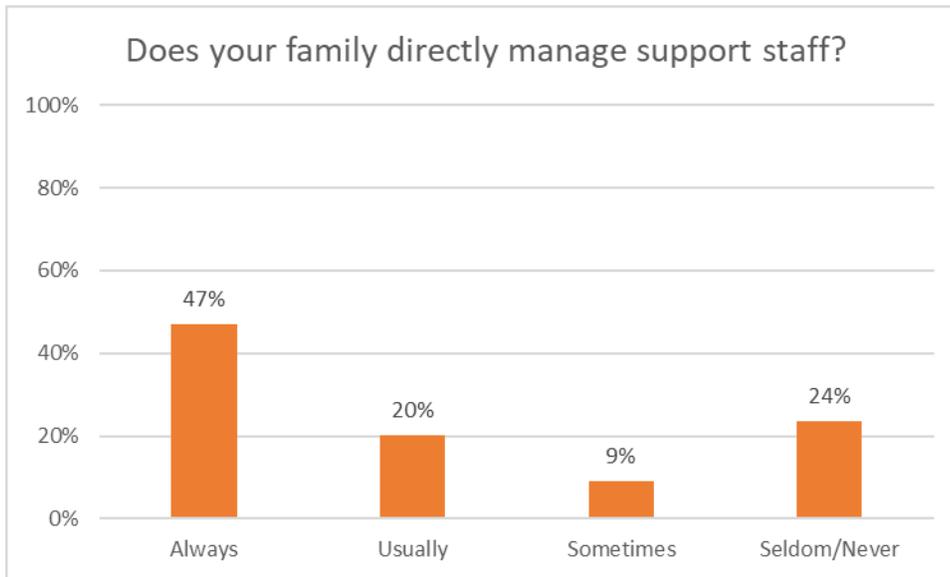


Table Q39. Does your family directly manage support staff?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
FL	58%	18%	7%	17%	332
AZ	57%	21%	6%	16%	173
OK	56%	20%	6%	18%	249

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
WA	56%	19%	6%	19%	139
PA	51%	18%	8%	23%	336
GA	50%	12%	7%	30%	225
NH	48%	15%	8%	29%	430
Weighted NCI Average	47%	20%	9%	24%	9,516
CA	46%	21%	10%	23%	6,754
MO	45%	11%	7%	38%	215
DC	43%	28%	8%	21%	109
SD	40%	17%	4%	40%	124

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NC	32%	26%	12%	30%	165
MD	30%	18%	15%	38%	209
DE	23%	18%	7%	52%	56

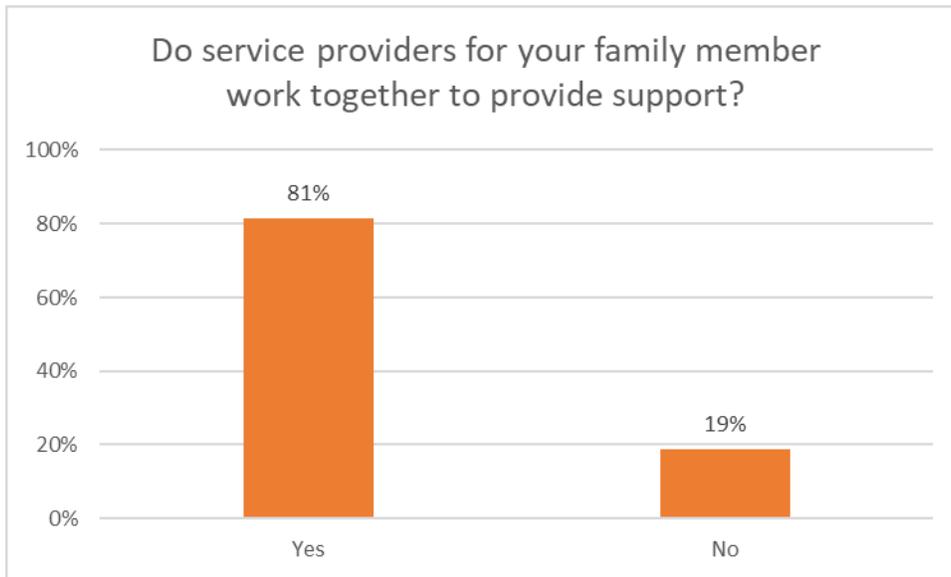


Table Q40. Do service providers for your family member work together to provide support?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
PA	88%	12%	292

Within Average Range

State	Yes	No	N
NC	88%	12%	145
OK	85%	15%	179
DC	85%	15%	110
NH	84%	16%	297
AZ	84%	16%	153
FL	82%	18%	274
Weighted NCI Average	81%	19%	9,278
MD	81%	19%	213
SD	79%	21%	114
CA	79%	21%	6,954
MO	78%	22%	176
DE	75%	25%	67
GA	74%	26%	189
WA	72%	28%	115

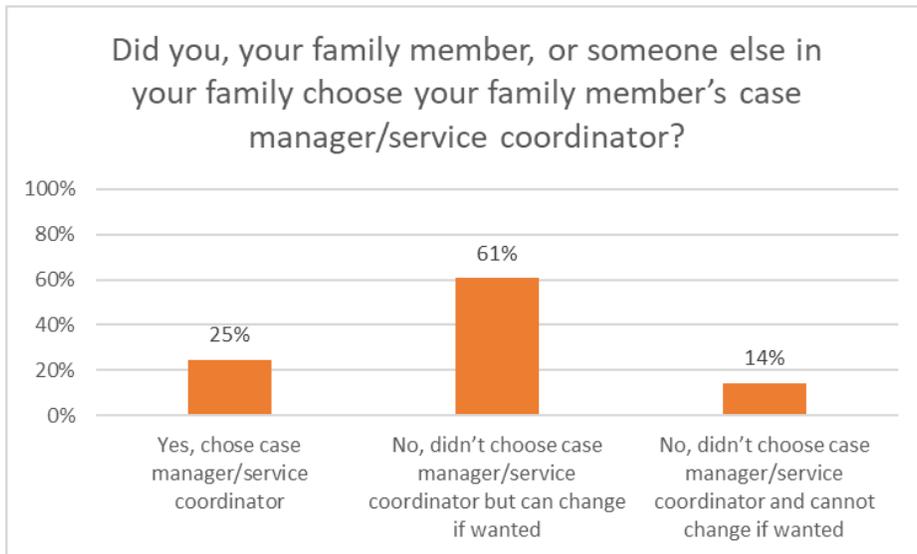


Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

Significantly Above Average

State	Yes, chose case manager/ service coordinator	No, didn't choose case manager/ service coordinator but can change if wanted	No, didn't choose case manager/ service coordinator and cannot change if wanted	N
FL	68%	29%	2%	434
SD	34%	56%	10%	212

Within Average Range

State	Yes, chose case manager/ service coordinator	No, didn't choose case manager/ service coordinator but can change if wanted	No, didn't choose case manager/ service coordinator and cannot change if wanted	N
NC	29%	56%	14%	174
DC	26%	65%	9%	129
MD	26%	57%	17%	325
PA	25%	64%	11%	451
Weighted NCI Average	25%	61%	14%	13,666
NH	23%	65%	12%	534
GA	20%	57%	23%	292
MO	19%	58%	23%	283

Significantly Below Average

State	Yes, chose case manager/ service coordinator	No, didn't choose case manager/ service coordinator but can change if wanted	No, didn't choose case manager/ service coordinator and cannot change if wanted	N
OK	18%	57%	25%	324
CA	17%	67%	16%	9,937
DE	13%	52%	35%	117
AZ	11%	77%	12%	230
WA	4%	69%	27%	224

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.

“You” and **“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.

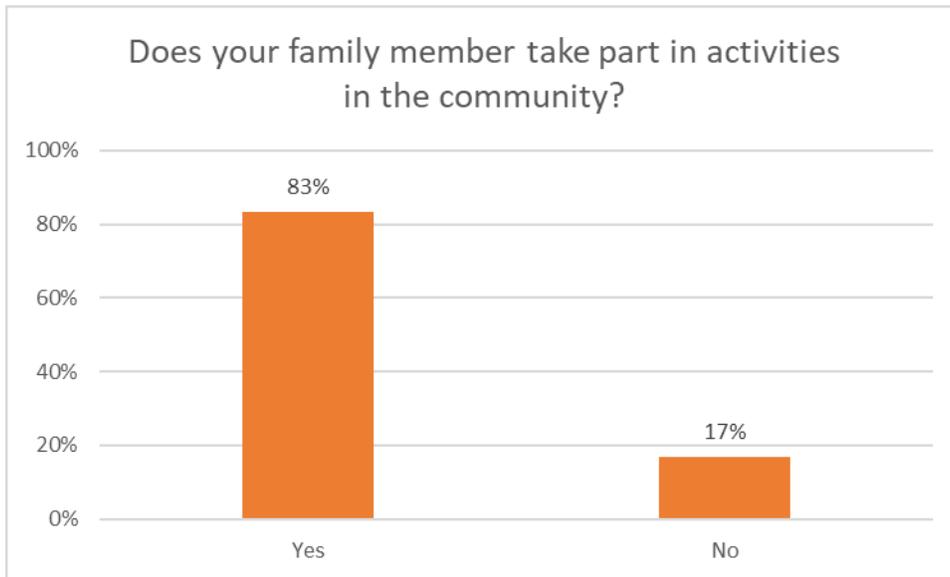


Table Q42. Does your family member take part in activities in the community?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
NC	91%	9%	208
NH	89%	11%	633
SD	89%	11%	254
GA	88%	12%	395

Within Average Range

State	Yes	No	N
DC	90%	10%	146
AZ	88%	12%	252
MD	87%	13%	390
MO	87%	13%	334
PA	87%	13%	525
OK	86%	14%	392
DE	83%	17%	157
Weighted NCI Average	83%	17%	18,206
FL	83%	17%	468
WA	80%	20%	256
CA	79%	21%	13,796

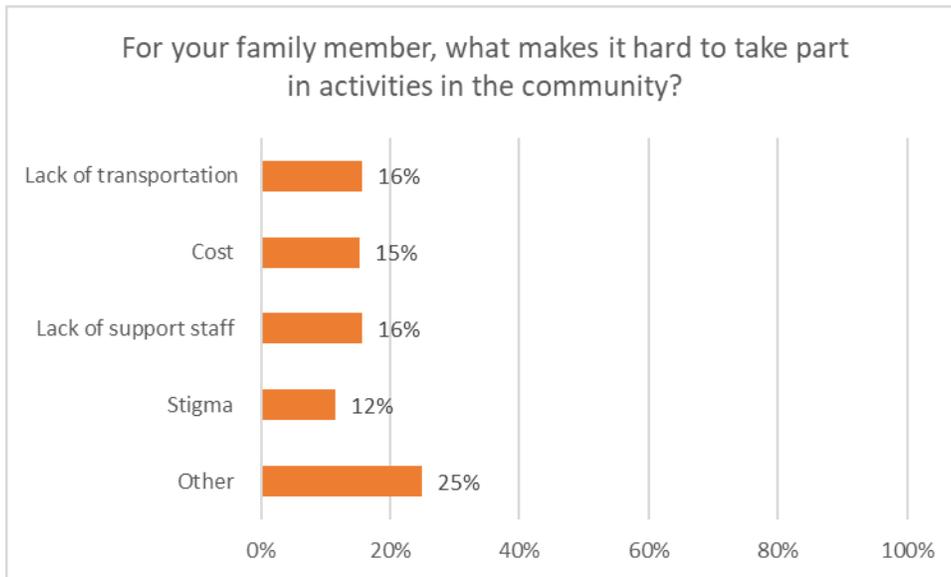


Table Q43. For your family member, what makes it hard to take part in activities in the community?

Categories are not mutually exclusive, therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	15%	19%	15%	11%	26%
CA	17%	16%	15%	13%	23%
DE	23%	19%	8%	7%	23%
DC	11%	12%	8%	4%	16%
FL	12%	17%	10%	11%	26%
GA	16%	16%	18%	11%	26%
MD	19%	11%	25%	11%	24%
MO	19%	17%	16%	9%	31%
NH	22%	18%	21%	10%	27%
NC	12%	10%	20%	11%	27%
OK	12%	13%	14%	11%	22%
PA	16%	12%	14%	8%	24%
SD	25%	16%	20%	11%	25%
WA	14%	18%	19%	12%	38%
Weighted NCI Average	16%	15%	16%	12%	25%

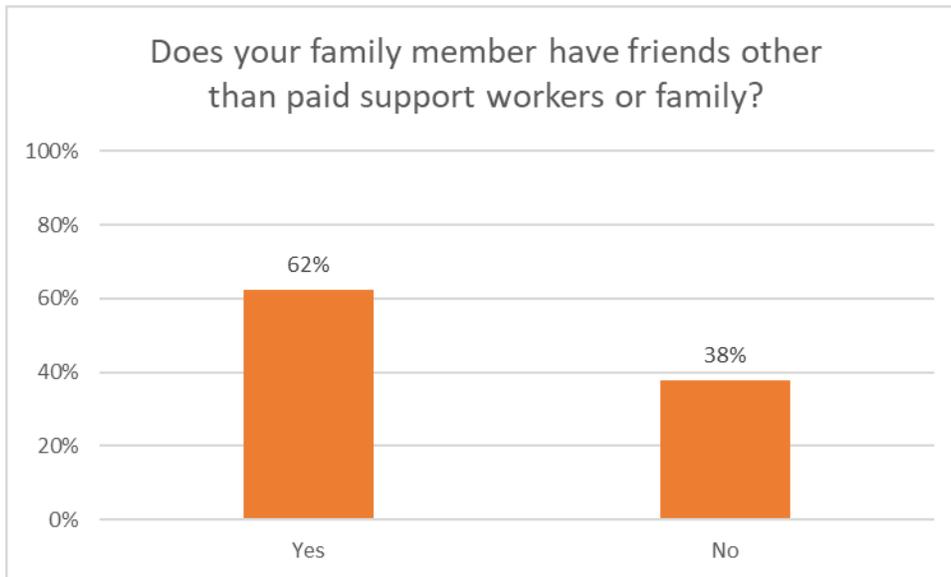


Table Q44. Does your family member have friends other than paid support workers or family?

Significantly Above Average

State	Yes	No	N
SD	75%	25%	246
DE	73%	27%	153
OK	72%	28%	385

Within Average Range

State	Yes	No	N
DC	70%	30%	147
NC	69%	31%	210
MO	68%	32%	327
PA	68%	32%	511
NH	66%	34%	629
FL	66%	34%	471
GA	66%	34%	385
AZ	63%	37%	248
WA	63%	37%	255
Weighted NCI Average	62%	38%	17,749
MD	62%	38%	393
CA	58%	42%	13,389

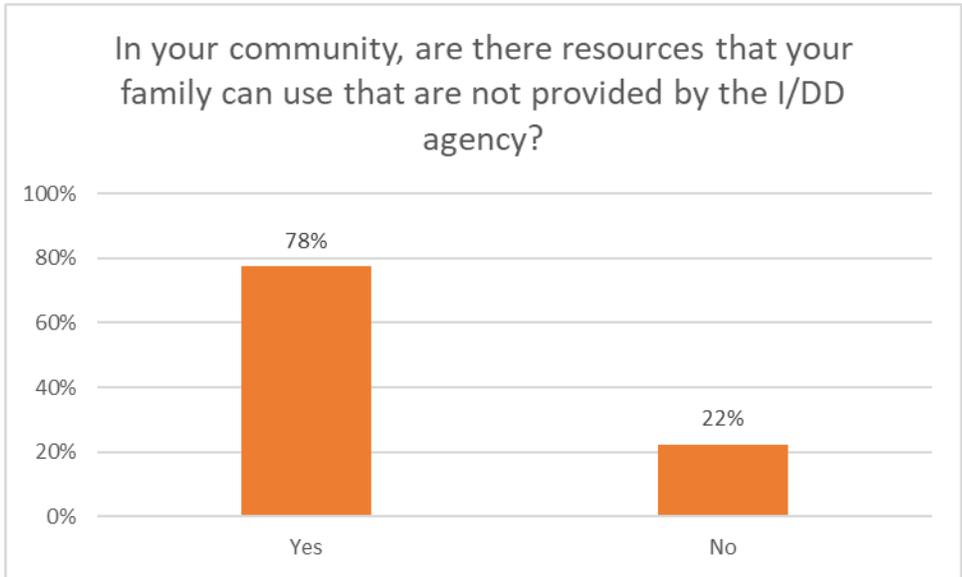


Table Q45. In your community, are there resources that your family can use that are not provided by the I/DD agency?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
WA	86%	14%	190
MD	83%	17%	303

Within Average Range

State	Yes	No	N
DC	82%	18%	124
MO	80%	20%	240
NH	80%	20%	488
NC	80%	20%	172
PA	80%	20%	365
GA	78%	22%	264
Weighted NCI Average	78%	22%	12,719
DE	77%	23%	111
SD	77%	23%	185
OK	77%	23%	307
AZ	77%	23%	184
FL	76%	24%	345
CA	75%	25%	9,441

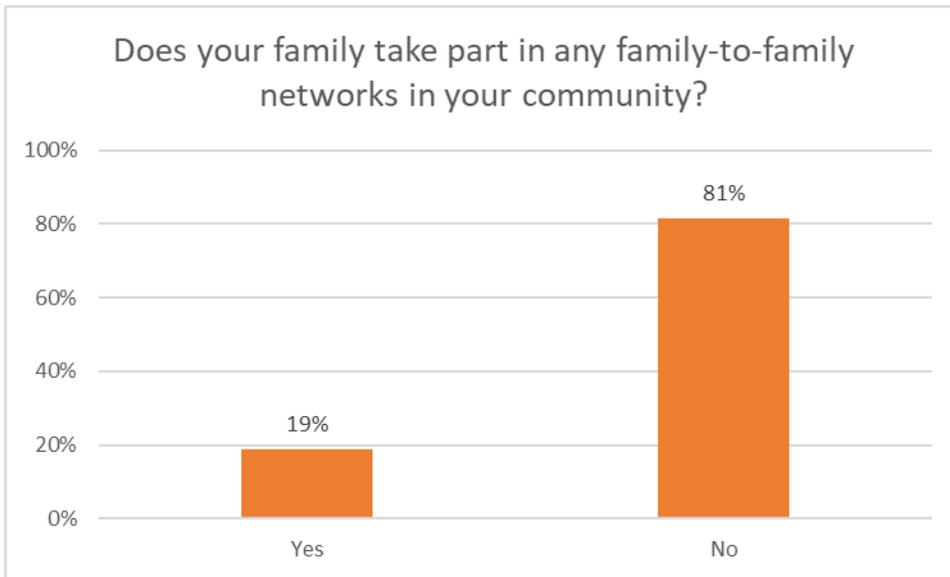


Table Q46. Does your family take part in any family-to-family networks in your community?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
DC	31%	69%	118

Within Average Range

State	Yes	No	N
NC	26%	74%	170
MD	22%	78%	348
SD	21%	79%	200
DE	20%	80%	137
OK	19%	81%	334
WA	19%	81%	228
CA	19%	81%	12,036
Weighted NCI Average	19%	81%	15,859
AZ	18%	82%	216
FL	17%	83%	423
GA	17%	83%	329
PA	15%	85%	462

Significantly Below Average

State	Yes	No	N
MO	9%	91%	275
NH	8%	92%	583

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.

“You” and **“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.

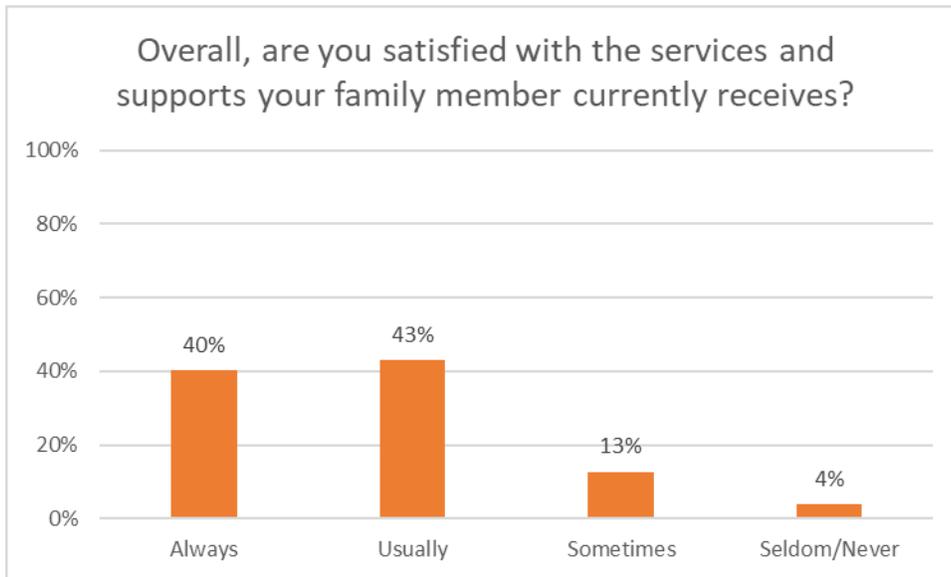


Table Q47. Overall, are you satisfied with the services and supports your family member currently receives?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
DC	52%	38%	8%	2%	149

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
FL	44%	41%	9%	5%	470
NC	44%	41%	12%	2%	210
AZ	44%	45%	8%	3%	254
PA	43%	47%	9%	1%	537
CA	41%	40%	14%	4%	13,780
OK	40%	42%	11%	7%	387
Weighted NCI Average	40%	43%	13%	4%	18,166
SD	37%	46%	14%	3%	251
WA	36%	49%	12%	2%	251

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	32%	50%	13%	5%	632
MO	30%	55%	12%	3%	326
GA	28%	48%	19%	6%	378
MD	24%	51%	18%	7%	386
DE	23%	42%	25%	10%	155

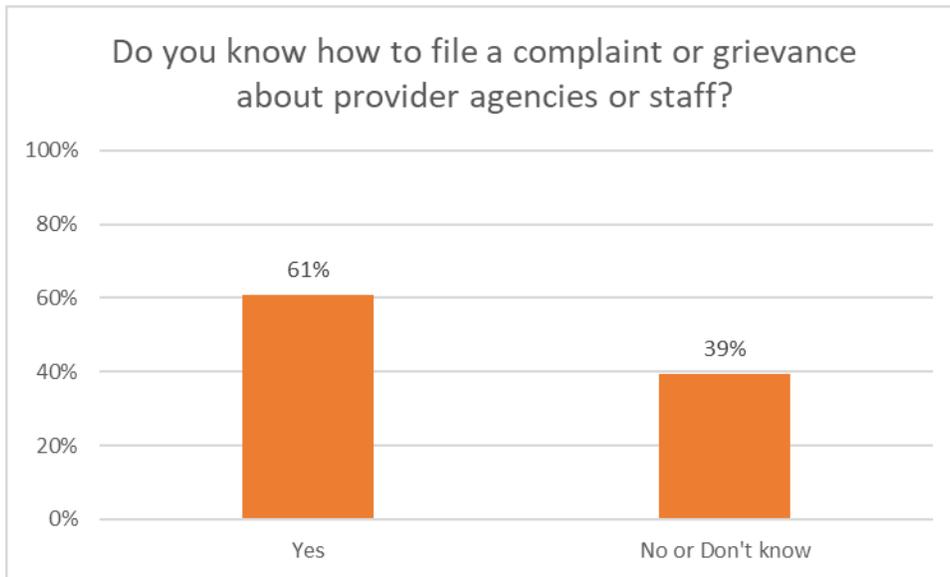


Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff?¹⁰

Significantly Above Average

State	Yes	No or Don't Know	N
DC	77%	23%	154
OK	77%	23%	389
SD	77%	23%	253
PA	75%	25%	533
NH	74%	26%	637
FL	73%	27%	470
NC	72%	28%	211
WA	71%	29%	256

Within Average Range

State	Yes	No or Don't Know	N
AZ	68%	32%	254
MO	64%	36%	328
Weighted NCI Average	61%	39%	18,465

Significantly Below Average

State	Yes	No or Don't Know	N
CA	51%	49%	14,045
MD	48%	52%	395
GA	48%	52%	382
DE	39%	61%	158

¹⁰ 'Don't Know' responses were included in 'No' responses for this question.



Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled? ¹¹

Within Average Range

State	Yes	No	N
NC	71%	29%	28
FL	70%	30%	56
AZ	68%	32%	28
DC	67%	33%	36
GA	61%	39%	28
NH	60%	40%	52
Weighted NCI Average	58%	42%	2,176
PA	57%	43%	42
CA	54%	46%	1795
MD	49%	51%	39

¹¹ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: DE, MO, OK, SD, WA.

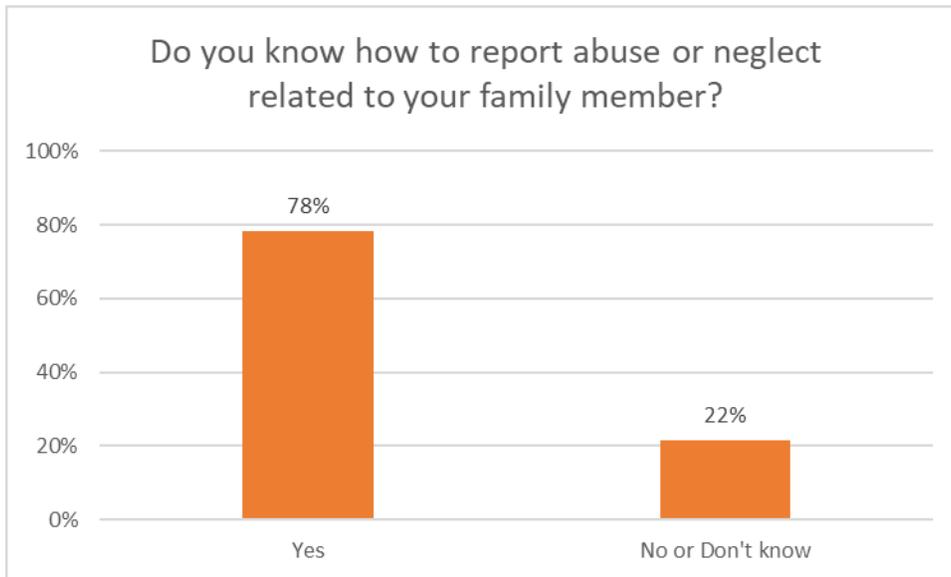


Table Q50. Do you know how to report abuse or neglect related to your family member?¹²

Significantly Above Average

State	Yes	No or Don't Know	N
DC	91%	9%	144
SD	91%	9%	253
OK	91%	9%	390
PA	89%	11%	531
WA	89%	11%	253
FL	89%	11%	479
NH	84%	16%	634
MO	84%	16%	330

Within Average Range

State	Yes	No or Don't Know	N
NC	84%	16%	209
AZ	82%	18%	256
Weighted NCI Average	78%	22%	18,428

Significantly Below Average

State	Yes	No or Don't Know	N
CA	72%	28%	14,014
GA	71%	29%	386
MD	66%	34%	392
DE	64%	36%	157

¹² 'Don't Know' responses were included in 'No' responses for this question.

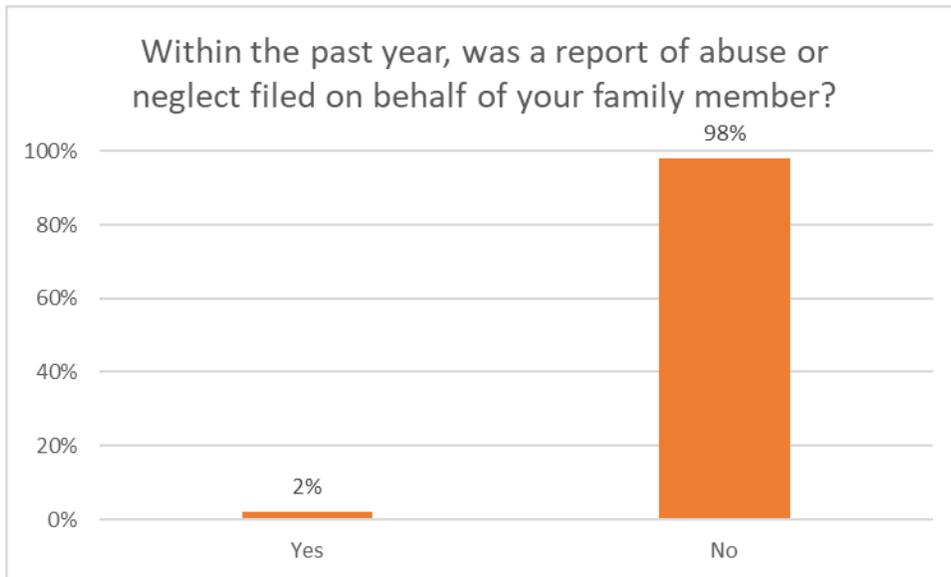


Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

Within Average Range

State	Yes	No	N
DC	4%	96%	150
WA	4%	96%	253
NH	3%	97%	631
NC	2%	98%	209
FL	2%	98%	467
CA	2%	98%	13,455
DE	2%	98%	152
Weighted NCI Average	2%	98%	17,812
AZ	2%	98%	252
MO	2%	98%	326
PA	2%	98%	529
GA	1%	99%	375

Significantly Below Average

State	Yes	No	N
OK	1%	99%	380
SD	0%	100%	248
MD	0%	100%	385

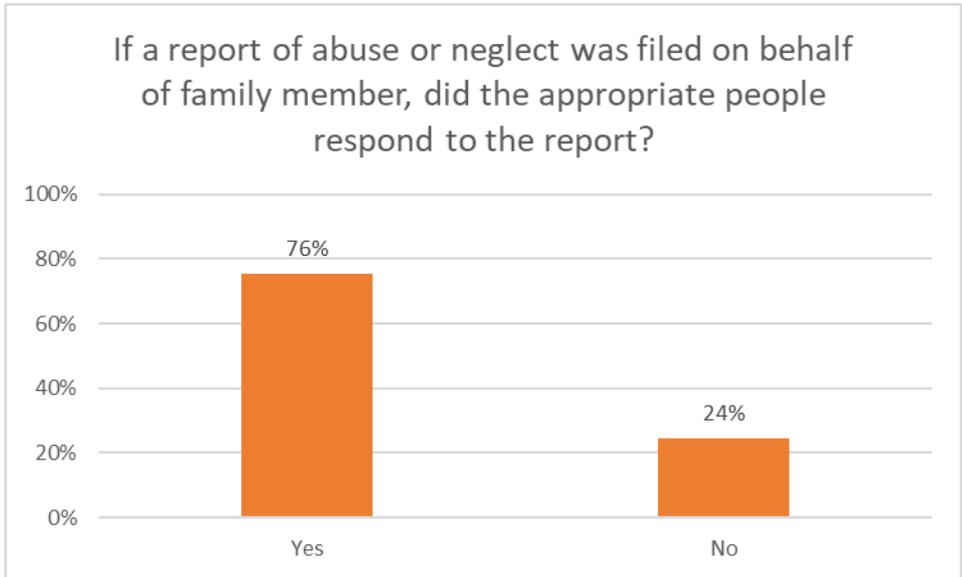


Table Q52. If a report of abuse or neglect was filed on behalf of family member, did the appropriate people respond to the report? ¹³

Within Average Range

State	Yes	No	N
Weighted NCI Average	76%	24%	267
CA	74%	26%	197

¹³ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, DE, DC, FL, GA, MD, MO, NH, NC, OK, PA, SD, WA.

If a report of abuse or neglect was filed on behalf of family member, 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?

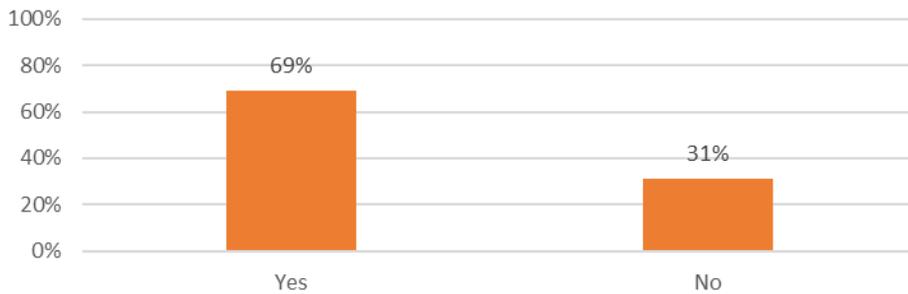


Table Q53. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past year, were you notified of the report in a timely manner? ¹⁴

Within Average Range

State	Yes	No	N
Weighted NCI Average	69%	31%	198
CA	62%	38%	149

¹⁴ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, DE, DC, FL, GA, MD, MO, NH, NC, OK, PA, SD, WA.

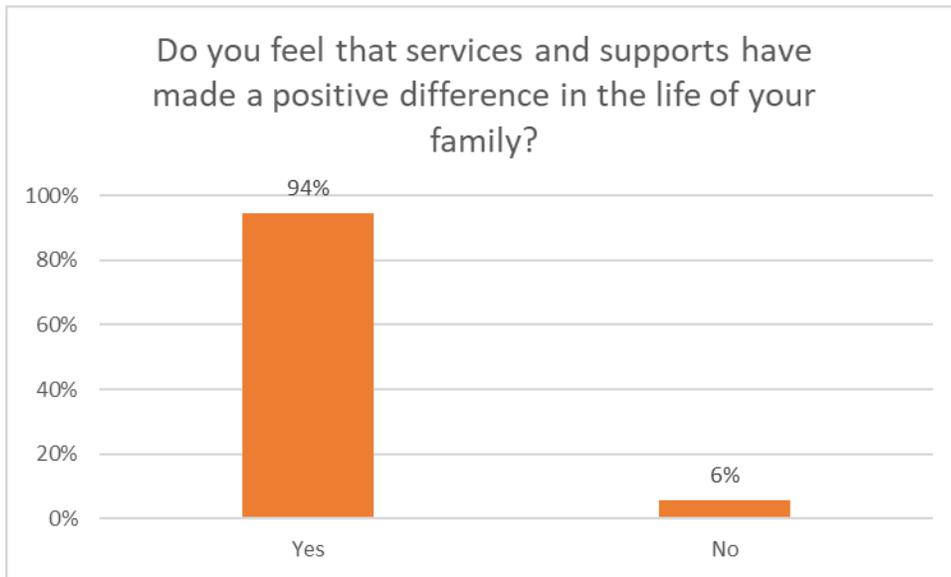


Table Q54. Do you feel that services and supports have made a positive difference in the life of your family member?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
MO	97%	3%	313
PA	97%	3%	500

Within Average Range

State	Yes	No	N
AZ	96%	4%	241
WA	96%	4%	224
OK	95%	5%	367
NC	95%	5%	204
GA	95%	5%	340
NH	95%	5%	598
SD	95%	5%	238
Weighted NCI Average	94%	6%	16,722
FL	94%	6%	435
CA	93%	7%	12,628
MD	93%	7%	357
DC	92%	8%	138

Significantly Below Average

State	Yes	No	N
DE	86%	14%	139

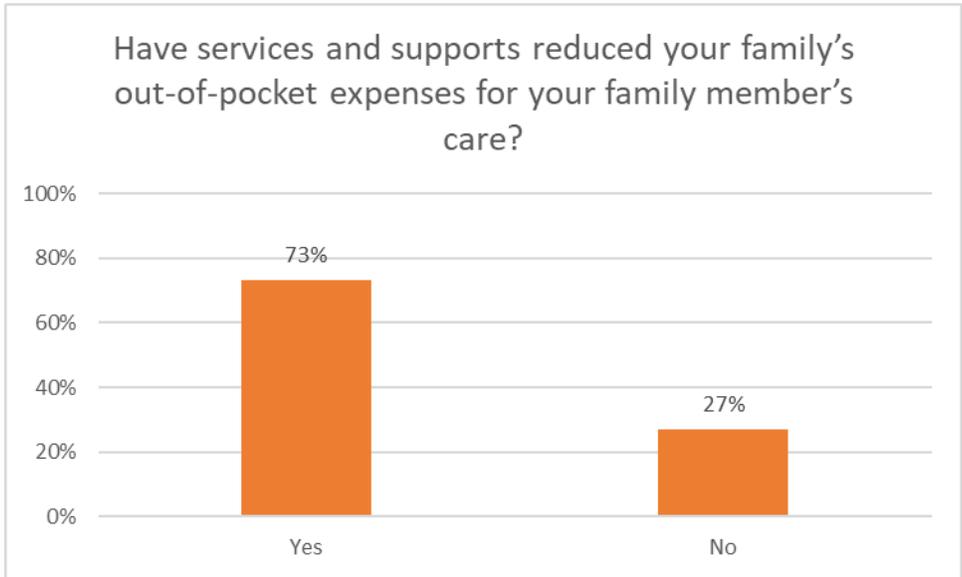


Table Q55. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

Responses to this question might have been impacted by the COVID-19 pandemic.

Within Average Range

State	Yes	No	N
WA	80%	20%	235
AZ	79%	21%	238
NC	79%	21%	192
OK	78%	22%	357
FL	77%	23%	425
MO	77%	23%	296
SD	75%	25%	212
Weighted NCI Average	73%	27%	15,785
CA	72%	28%	11,821
NH	70%	30%	574
GA	69%	31%	350

Significantly Below Average

State	Yes	No	N
PA	67%	33%	469
MD	64%	36%	340
DC	58%	42%	139
DE	50%	50%	137

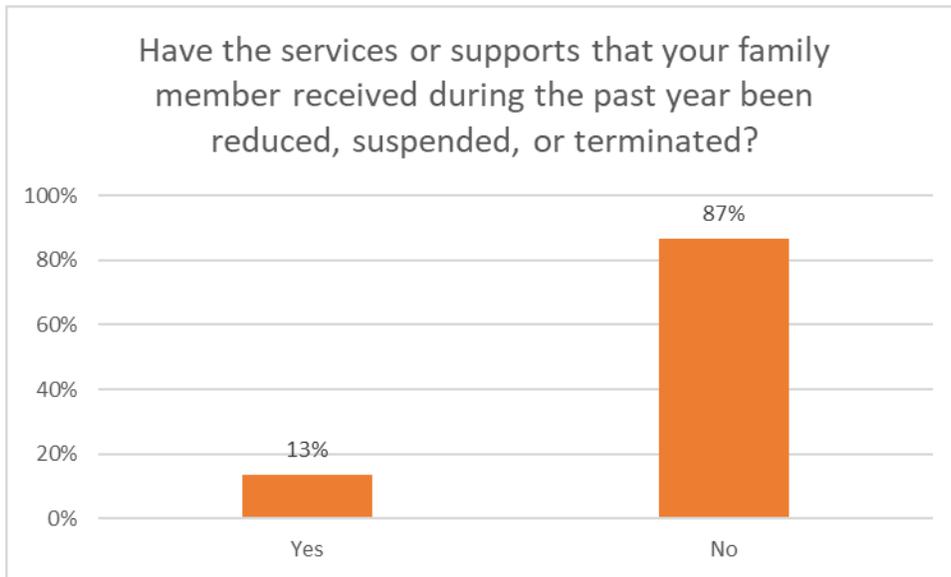


Table Q56. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

Significantly Above Average

State	Yes	No	N
MD	29%	71%	356
SD	23%	77%	236

Within Average Range

State	Yes	No	N
DE	20%	80%	135
WA	20%	80%	230
MO	17%	83%	320
FL	16%	84%	422
DC	16%	84%	146
NH	14%	86%	600
NC	14%	86%	191
Weighted NCI Average	13%	87%	16,499
OK	12%	88%	353
CA	12%	88%	12,419
AZ	11%	89%	242
GA	10%	90%	353

Significantly Below Average

State	Yes	No	N
PA	9%	91%	496

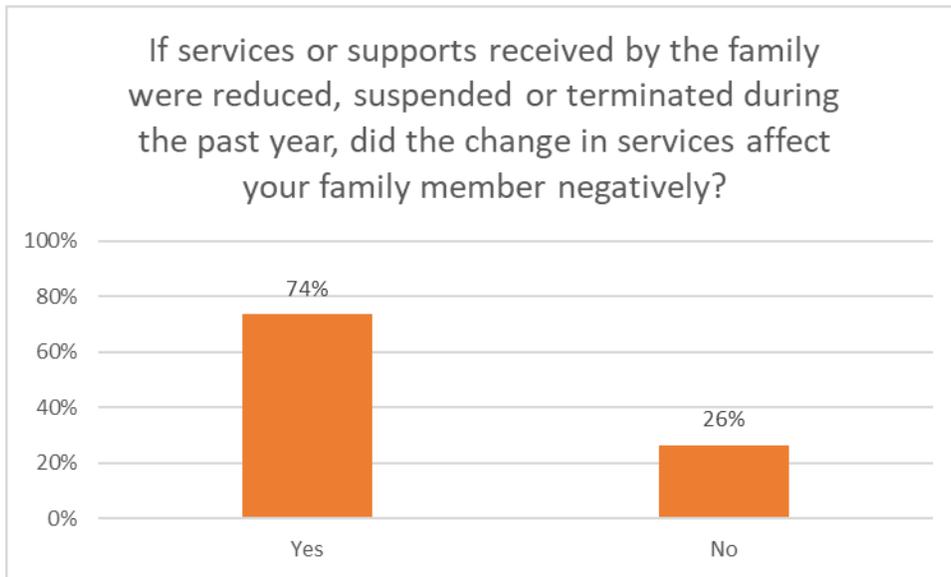


Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
GA	93%	7%	29

Within Average Range

State	Yes	No	N
DE	91%	9%	22
AZ	83%	17%	23
MO	81%	19%	52
MD	79%	21%	91
WA	78%	22%	41
OK	74%	26%	39
CA	74%	26%	1,199
Weighted NCI Average	74%	26%	1,763
NH	73%	27%	73
FL	72%	28%	61
PA	72%	28%	39
SD	71%	29%	49
DC	59%	41%	22
NC	52%	48%	23

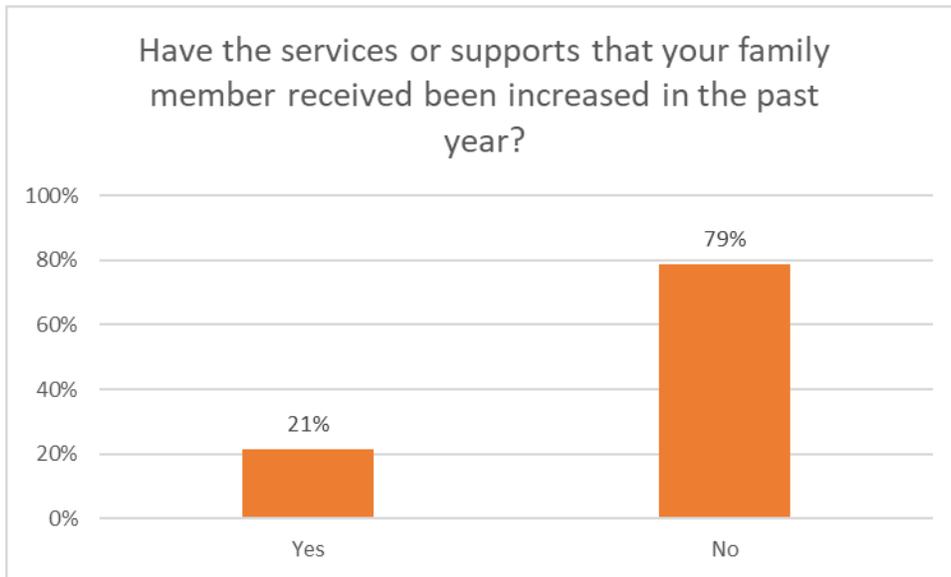


Table Q58. Have the services or supports that your family member received been increased in the past year?

Responses to this question might have been impacted by the COVID-19 pandemic.

Within Average Range

State	Yes	No	N
NC	27%	73%	182
CA	23%	77%	11,859
PA	22%	78%	461
Weighted NCI Average	21%	79%	15,802
DC	21%	79%	134
MO	20%	80%	311
FL	20%	80%	409
AZ	19%	81%	238
MD	18%	82%	340
SD	17%	83%	230
OK	17%	83%	337

Significantly Below Average

State	Yes	No	N
GA	15%	85%	337
NH	14%	86%	604
WA	14%	86%	227
DE	10%	90%	133

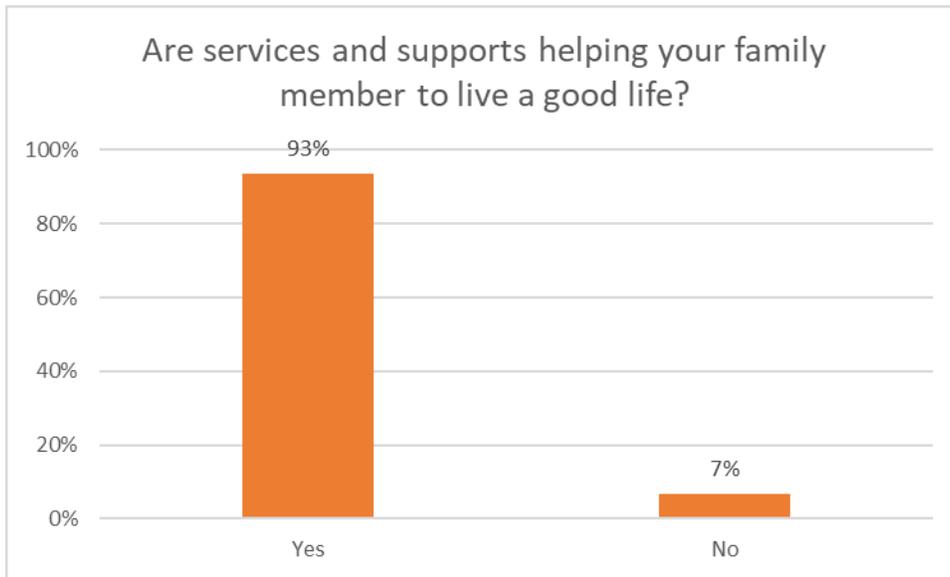


Table Q59. Are services and supports helping your family member to live a good life?

Responses to this question might have been impacted by the COVID-19 pandemic.

Significantly Above Average

State	Yes	No	N
AZ	98%	2%	241
PA	96%	4%	503

Within Average Range

State	Yes	No	N
MO	95%	5%	309
NC	95%	5%	201
WA	95%	5%	224
OK	94%	6%	363
SD	94%	6%	231
FL	94%	6%	432
Weighted NCI Average	93%	7%	16,379
CA	92%	8%	12,318
GA	92%	8%	339
DC	90%	10%	142

Significantly Below Average

State	Yes	No	N
NH	90%	10%	600
MD	88%	12%	343
DE	84%	16%	133

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 (CIP). 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

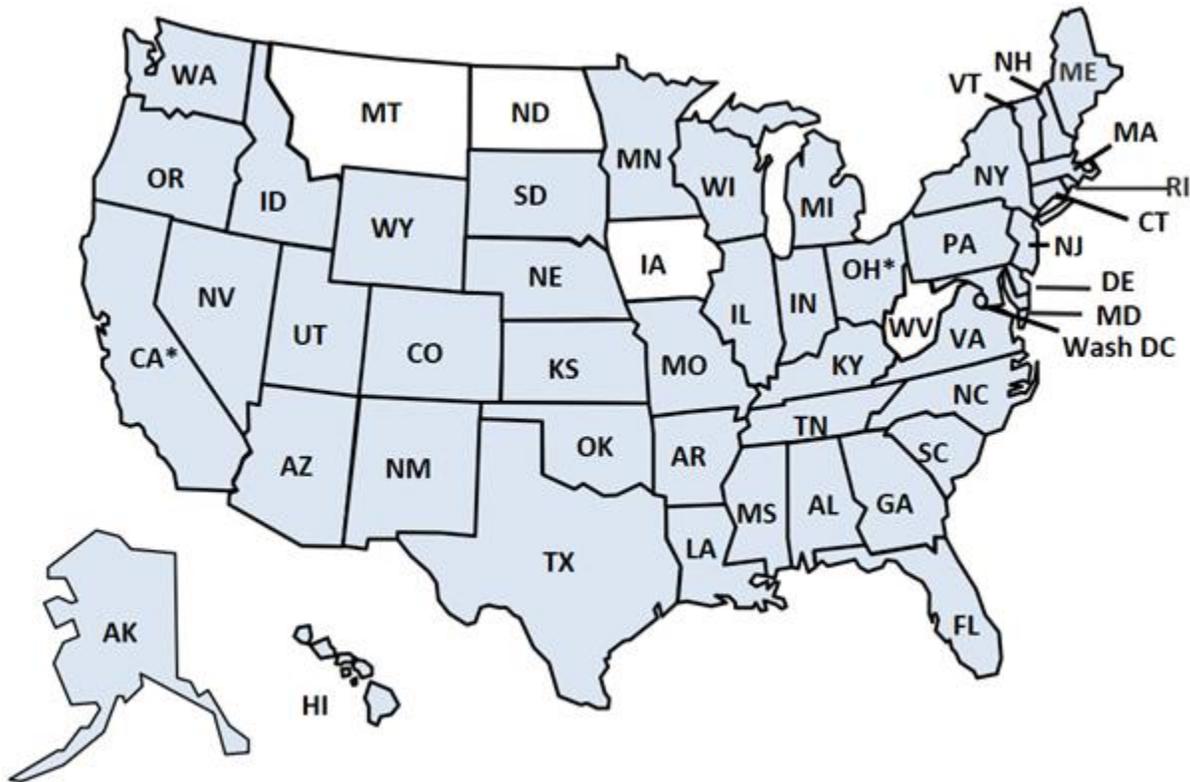
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven 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 the NCI website at <https://www.nationalcoreindicators.org/>.

State Participation

During the 2019-20 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 2019-20



The Core Indicators

The Core Indicators are the standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern, including employment, respect/rights, service planning, community inclusion, choice, and health and safety. An example of a Core Indicator would be, “The proportion of people who have a paid job in the community.” To see the entire list of Core Indicators, please visit the Indicators page on the NCI website at <https://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 Staff Stability 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](#).¹⁵

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

¹⁵ Located on the National Core Indicators website: www.nationalcoreindicators.org →Resources →Technical Reports

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, policy-makers, 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 in which several states’ results are especially high (considerably above the average level) indicate the levels of performance or satisfaction achieved in those states might define a level of performance that may serve as a guidepost for other states.

Data from previous years are not presented in this report. Comparisons of results from year to year should be made with caution: 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 Adult Family Survey by selecting a random sample of at least 1,000 families who:

1. Had an adult individual (aged 18 or over) with an intellectual or developmental disability living in the home; and
2. The adult individual with an intellectual or developmental disability living in the home 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 six states had at least a portion of surveys completed via direct entry for the 2019-20 data collection cycle.¹⁶

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%.¹⁷

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”). The approach has since been enhanced to consider the relative numbers of people receiving services through participating states’ systems. The NCI averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the sample sizes.

¹⁶ States that used the direct entry or mail and direct entry options were: CA, DE, MD, MO, NC, WA.

¹⁷ See “Response Rates” for information on total surveys mailed and received by states as well as each state’s margin of error.

Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average—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.

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 average¹⁸; 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 2019-20, 14 states administered the Adult Family 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 following table shows the number of individuals receiving services who were eligible to be drawn into the sample ("total population"), the number of surveys each state sent, complete surveys, response rates, margins of error, and survey submission modes.

¹⁸ The NCI Average is a weighted average. Please see the section "Weighting" for more details.

Figure 3. Adult Family Survey: State Response Rates ¹⁹

State	Total Population	Surveys Sent	Complete Surveys	Response Rate ²⁰	Margin of Error	Paper Submission	Direct Entry Submission
AZ	10,641	1,400	257	18.4%	6.04%	100%	0%
CA	81,718	81,718	14,621	17.9%	0.73%	82%	18%
DE	1,142	1,142	166	14.5%	7.03%	17%	83%
DC	675	675	157	23.3%	6.86%	100%	0%
FL	17,624	1,700	488	28.7%	4.37%	100%	0%
GA	4,018	1,700	403	23.7%	4.63%	100%	0%
MD	9,570	8,820	409	4.6%	4.74%	59%	41%
MO	3,041	1,500	338	22.5%	5.03%	92%	8%
NH	2189	2,189	653	29.8%	3.21%	100%	0%
NC	14,945	1,200	212	17.7%	6.68%	92%	8%
OK	1900	1,900	397	20.9%	4.38%	100%	0%
PA	20,500	2,000	541	27.1%	4.16%	100%	0%
SD	934	934	259	27.7%	5.18%	100%	0%
WA	10,741	2,500	282	11.3%	5.76%	0%	100%
Overall ²¹	179,638	109,378	19,183	20.6%	4.91%	82%	18%

¹⁹ Please note: The family surveys are mail 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.

²⁰ State response rates are calculated as following: the number of complete surveys divided by total surveys sent in that state (type “RR1” as defined by the American Association for Public Opinion Research). For more details on the definition, please see the AAPOR report: https://www.aapor.org/AAPOR_Main/media/publications/Standard-Definitions20169theditionfinal.pdf

²¹ Consistent with past years, the overall response rate and margin of error were calculated as the average of state averages, and the overall paper submission and direct entry submission rates were calculated as averages weighted by state total service population sizes (column 2 of this table).