

Family/Guardian Survey

2019-20 Final Report





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List of Abbreviations Used in This Report

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

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Executive Summary

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

The NCI Family/Guardian Survey is administered to families who have an adult (18 years or older) with a developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI administer the Family/Guardian Survey on an annual basis. Of the 46 states, the District of Columbia, and 22 sub-state entities who participated in NCI during the 2019-20 data collection cycle, 11 states submitted a valid sample of Family/Guardian Survey data: Arizona (AZ), California (CA), Florida (FL), Georgia (GA), Maryland (MD), Minnesota (MN), New Hampshire (NH), North Carolina (NC), Pennsylvania (PA), South Dakota (SD), and Utah (UT). 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 weighted averages for a selection of survey items. Complete breakouts by state for each item in the Family/Guardian Survey can be found in the Results section of this report.

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 *does not live* with the adult receiving services.

Respondents....



24%
are age 75+



65% say they visited their family member with IDD more than 12 times in the past year

Family member with IDD....

Where family member lives...



12% specialized facility for people with ID

59% group home or agency-operated agency

19% own home or apartment

8% adult foster care or host home

1% nursing home

2% other

44%

full guardianship

25%

limited guardianship

4%

Have guardian, but level is unknown



45

average age

60%
are male



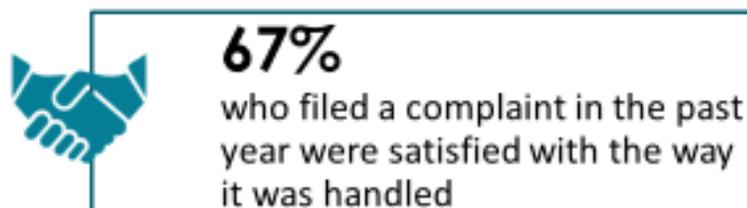
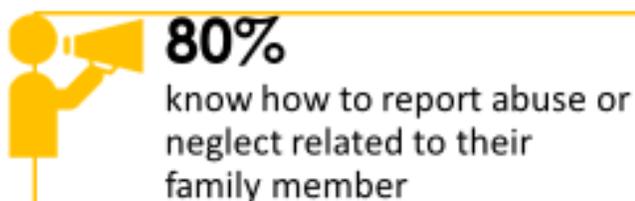
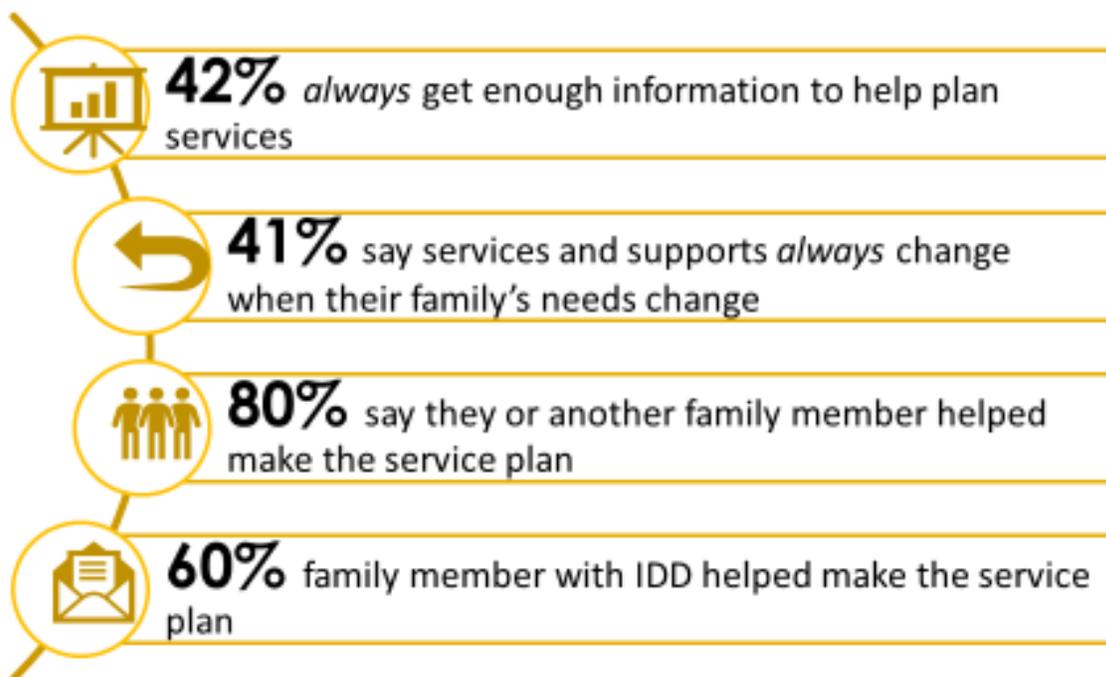
89%

take part in community activities

66%

have friends other than family or paid staff





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 and supports 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. Family Member's Residence

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

| State | Specialized Facility for People With ID ¹ | Group Home or Agency-operated Agency | Independent Home or Apartment | Adult Foster Care or Host Family Home | Nursing Home | Homeless | Other | N |
|-----------------------------|--|--------------------------------------|-------------------------------|---------------------------------------|--------------|-----------|-----------|--------------|
| AZ | 7% | 77% | 4% | 13% | 0% | 0% | 0% | 222 |
| CA | 14% | 43% | 35% | 2% | 1% | 0% | 6% | 5,198 |
| FL | 6% | 63% | 27% | 1% | 0% | 0% | 3% | 364 |
| GA | 10% | 60% | 12% | 17% | 1% | 0% | 0% | 365 |
| MD | 11% | 85% | 1% | 1% | 0% | 0% | 2% | 387 |
| MN | 6% | 65% | 20% | 8% | 1% | 0% | 0% | 547 |
| NH | 5% | 27% | 25% | 41% | 1% | 0% | 1% | 414 |
| NC | 19% | 55% | 3% | 22% | 0% | 0% | 0% | 208 |
| PA | 21% | 71% | 2% | 4% | 1% | 0% | 1% | 651 |
| SD | 0% | 74% | 24% | 1% | 0% | 0% | 0% | 654 |
| UT | 4% | 72% | 14% | 9% | 0% | 0% | 0% | 223 |
| Weighted NCI Average | 12% | 59% | 19% | 8% | 1% | 0% | 2% | 9,233 |

Table 2. Family Member's Residential Designation

| State | Urban or Suburban | Rural | N |
|-----------------------------|-------------------|------------|--------------|
| AZ | 94% | 6% | 220 |
| CA | 94% | 6% | 5,120 |
| FL | 89% | 11% | 359 |
| GA | 84% | 16% | 362 |
| MD | 74% | 26% | 380 |
| MN | 85% | 15% | 544 |
| NH | 54% | 46% | 415 |
| NC | 70% | 30% | 209 |
| PA | 70% | 30% | 641 |
| SD | 97% | 3% | 645 |
| UT | 94% | 6% | 226 |
| Weighted NCI Average | 84% | 16% | 9,121 |

¹ ICF, state-run or other institutional setting

Table 3. Family Member's Age

| State | Age | N |
|-----------------------------|-------------|--------------|
| AZ | 45.8 | 219 |
| CA | 42.8 | 5,146 |
| FL | 46.4 | 347 |
| GA | 46.8 | 371 |
| MD | 47.6 | 380 |
| MN | 44.0 | 528 |
| NH | 46.5 | 412 |
| NC | 47.8 | 210 |
| PA | 48.5 | 659 |
| SD | 45.2 | 667 |
| UT | 42.6 | 224 |
| Weighted NCI Average | 45.4 | 9,163 |

Table 4. Family Member's Gender

| State | Male | Female | N |
|-----------------------------|------------|------------|--------------|
| AZ | 56% | 44% | 224 |
| CA | 61% | 39% | 5,261 |
| FL | 57% | 43% | 363 |
| GA | 60% | 40% | 370 |
| MD | 60% | 40% | 391 |
| MN | 59% | 41% | 551 |
| NH | 60% | 40% | 423 |
| NC | 64% | 36% | 210 |
| PA | 58% | 42% | 666 |
| SD | 55% | 45% | 667 |
| UT | 60% | 40% | 227 |
| Weighted NCI Average | 60% | 40% | 9,353 |

Table 5. 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 Native Alaska | Asian | Black or African American | Hawaiian or Pacific Islander | White | Hispanic or Latino | Other |
|-----------------------------|----------------------------------|-----------|---------------------------|------------------------------|------------|--------------------|-----------|
| AZ | 9% | 2% | 4% | 1% | 77% | 12% | 0% |
| CA | 2% | 8% | 7% | 1% | 76% | 12% | 3% |
| FL | 1% | 1% | 16% | 0% | 74% | 10% | 2% |
| GA | 1% | 2% | 17% | 0% | 80% | 2% | 2% |
| MD | 0% | 3% | 19% | 1% | 78% | 1% | 1% |
| MN | 3% | 2% | 4% | 0% | 91% | 2% | 0% |
| NH | 1% | 1% | 1% | 0% | 97% | 1% | 1% |
| NC | 1% | 0% | 25% | 0% | 73% | 1% | 0% |
| PA | 1% | 1% | 5% | 0% | 92% | 2% | 1% |
| SD | 7% | 1% | 0% | 0% | 92% | 1% | 0% |
| UT | 2% | 2% | 2% | 1% | 91% | 4% | 2% |
| Weighted NCI Average | 2% | 3% | 11% | 0% | 80% | 6% | 2% |

Due to the COVID-19 pandemic and its impact to NCI data collection and sampling processes, we caution against using 2019-20 data to directly compare with past and future NCI data.
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Table 6a. Family Member's Disabilities (not mutually exclusive)

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 | 70% | 36% | 27% | 26% | 9% | 9% |
| CA | 67% | 28% | 33% | 17% | 7% | 6% |
| FL | 77% | 37% | 25% | 20% | 7% | 4% |
| GA | 74% | 32% | 23% | 16% | 9% | 4% |
| MD | 79% | 34% | 28% | 16% | 10% | 9% |
| MN | 78% | 39% | 23% | 13% | 8% | 7% |
| NH | 72% | 42% | 28% | 12% | 7% | 7% |
| NC | 82% | 45% | 26% | 12% | 8% | 6% |
| PA | 84% | 44% | 30% | 18% | 11% | 8% |
| SD | 73% | 37% | 18% | 15% | 9% | 9% |
| UT | 80% | 45% | 28% | 18% | 9% | 4% |
| Weighted NCI Average | 75% | 36% | 28% | 16% | 8% | 6% |

Table 6b. 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 | 13% | 32% | 0% | 10% | 0% | 3% | 10% |
| CA | 10% | 25% | 1% | 8% | 1% | 1% | 13% |
| FL | 8% | 26% | 1% | 9% | 2% | 0% | 13% |
| GA | 13% | 31% | 1% | 13% | 1% | 2% | 18% |
| MD | 8% | 23% | 1% | 8% | 1% | 2% | 7% |
| MN | 6% | 25% | 1% | 13% | 1% | 4% | 12% |
| NH | 19% | 31% | 1% | 8% | 1% | 2% | 15% |
| NC | 9% | 28% | 1% | 10% | 0% | 1% | 16% |
| PA | 11% | 32% | 0% | 11% | 1% | 1% | 10% |
| SD | 11% | 26% | 1% | 13% | 1% | 3% | 9% |
| UT | 19% | 24% | 1% | 8% | 3% | 4% | 12% |
| Weighted NCI Average | 10% | 27% | 1% | 10% | 1% | 2% | 13% |

Table 7a. 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 | 10% | 20% | 7% | 28% | 39% |
| CA | 8% | 18% | 6% | 29% | 28% |
| FL | 9% | 16% | 7% | 40% | 37% |
| GA | 9% | 23% | 8% | 35% | 29% |
| MD | 9% | 22% | 6% | 31% | 37% |
| MN | 11% | 20% | 7% | 25% | 26% |
| NH | 12% | 21% | 8% | 29% | 30% |
| NC | 16% | 19% | 8% | 34% | 30% |
| PA | 10% | 16% | 4% | 25% | 31% |
| SD | 11% | 20% | 5% | 28% | 24% |
| UT | 7% | 22% | 4% | 32% | 22% |
| Weighted NCI Average | 10% | 19% | 6% | 31% | 31% |

Table 7b. 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 Other Dental Problems | Sleep Apnea | Other |
|-----------|------------|-----------------|---------------------------------------|--------------------------------------|-------------|------------|
| AZ | 10% | 2% | 4% | 17% | 6% | 24% |
| CA | 8% | 1% | 3% | 16% | 14% | 27% |
| FL | 9% | 4% | 4% | 15% | 10% | 26% |
| GA | 12% | 1% | 4% | 18% | 14% | 24% |
| MD | 7% | 4% | 7% | 15% | 16% | 15% |
| MN | 6% | 2% | 5% | 12% | 21% | 20% |
| NH | 13% | 3% | 5% | 13% | 16% | 20% |
| NC | 14% | 1% | 8% | 17% | 12% | 22% |
| PA | 23% | 3% | 8% | 16% | 16% | 17% |
| SD | 14% | 3% | 6% | 17% | 20% | 16% |
| UT | 11% | 3% | 2% | 25% | 22% | 28% |
| AZ | 11% | 2% | 5% | 16% | 14% | 23% |

Table 8. Family Member's Preferred Means of Communication

| State | Spoken | Gestures or Body Language | Sign Language or Finger Spelling | Communication Aid or Device | Other | N |
|-----------------------------|------------|---------------------------|----------------------------------|-----------------------------|-----------|--------------|
| AZ | 77% | 17% | 2% | 2% | 3% | 219 |
| CA | 79% | 13% | 2% | 1% | 5% | 5,179 |
| FL | 73% | 17% | 2% | 1% | 7% | 362 |
| GA | 76% | 18% | 1% | 1% | 4% | 363 |
| MD | 74% | 20% | 3% | 1% | 3% | 378 |
| MN | 85% | 11% | 1% | 3% | 1% | 546 |
| NH | 82% | 13% | 1% | 3% | 1% | 425 |
| NC | 76% | 18% | 1% | 1% | 4% | 207 |
| PA | 64% | 25% | 3% | 3% | 6% | 659 |
| SD | 80% | 15% | 2% | 2% | 1% | 657 |
| UT | 78% | 15% | 1% | 1% | 5% | 226 |
| Weighted NCI Average | 77% | 16% | 2% | 2% | 4% | 9,221 |

Table 9. 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 | None | Limited | Full | Has Guardianship but Level is Unknown | N |
|-----------------------------|------------|------------|------------|---------------------------------------|--------------|
| AZ | 7% | 10% | 78% | 4% | 218 |
| CA | 45% | 55% | n/a | n/a | 4,754 |
| FL | 32% | 18% | 46% | 4% | 341 |
| GA | 23% | 12% | 58% | 6% | 346 |
| MD | 43% | 16% | 35% | 7% | 361 |
| MN | 10% | 7% | 77% | 6% | 547 |
| NH | 12% | 12% | 70% | 5% | 427 |
| NC | 2% | 15% | 77% | 6% | 207 |
| PA | 33% | 13% | 46% | 9% | 588 |
| SD | 16% | 17% | 60% | 7% | 645 |
| UT | 19% | 15% | 60% | 6% | 215 |
| Weighted NCI Average | 26% | 25% | 44% | 4% | 8,649 |

Table 10. Guardian or Conservator Relationship to Family Member

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

| State | Family | Friend | State Employee or Guardianship Agency | Other | N |
|-----------------------------|------------|-----------|---------------------------------------|-----------|--------------|
| AZ | 87% | 5% | 5% | 4% | 195 |
| CA | 91% | 1% | 5% | 3% | 2,483 |
| FL | 85% | 2% | 4% | 9% | 223 |
| GA | 87% | 3% | 3% | 7% | 261 |
| MD | 83% | 2% | 10% | 6% | 189 |
| MN | 81% | 1% | 15% | 3% | 482 |
| NH | 90% | 4% | 4% | 2% | 364 |
| NC | 79% | 3% | 15% | 3% | 195 |
| PA | 91% | 0% | 6% | 2% | 376 |
| SD | 93% | 2% | 3% | 3% | 517 |
| UT | 93% | 2% | 4% | 1% | 164 |
| Weighted NCI Average | 86% | 2% | 9% | 4% | 5,449 |

Table 11. Family Member's Highest level of Education

| State | Did Not Complete High School (and Not Currently Enrolled) | Currently Enrolled in High School | High School Certification | High School Diploma or GED | Vocational Training | Some College | College Degree or Higher | N |
|-----------------------------|---|-----------------------------------|---------------------------|----------------------------|---------------------|--------------|--------------------------|--------------|
| AZ | 37% | 1% | 28% | 26% | 1% | 2% | 4% | 202 |
| CA | 28% | 1% | 31% | 21% | 3% | 9% | 7% | 4,913 |
| FL | 34% | 2% | 35% | 16% | 5% | 3% | 5% | 343 |
| GA | 37% | 1% | 39% | 18% | 2% | 1% | 3% | 344 |
| MD | 34% | 1% | 43% | 13% | 5% | 1% | 4% | 367 |
| MN | 18% | 0% | 27% | 45% | 3% | 2% | 4% | 529 |
| NH | 32% | 0% | 28% | 26% | 3% | 4% | 6% | 405 |
| NC | 49% | 0% | 32% | 12% | 1% | 3% | 4% | 186 |
| PA | 37% | 0% | 26% | 28% | 3% | 1% | 4% | 603 |
| SD | 37% | 0% | 26% | 30% | 2% | 1% | 3% | 625 |
| UT | 24% | 0% | 38% | 27% | 1% | 3% | 6% | 205 |
| Weighted NCI Average | 33% | 1% | 32% | 23% | 3% | 4% | 5% | 8,722 |

Table 12. Family Member's Activities in the Past Two Weeks Included *Individual Paid Job in the Community*²

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| AZ | 5% | 95% | 212 |
| CA | 16% | 84% | 4,833 |
| FL | 7% | 93% | 346 |
| GA | 11% | 89% | 347 |
| MD | 6% | 94% | 373 |
| MN | 25% | 75% | 525 |
| NH | 25% | 75% | 410 |
| NC | 6% | 94% | 196 |
| PA | 7% | 93% | 632 |
| SD | 21% | 79% | 623 |
| UT | 17% | 83% | 216 |
| Weighted NCI Average | 12% | 88% | 8,713 |

Table 13. Family Member's Activities in the Past Two Weeks Included *Paid Small Group Job in a Community-based Setting*³

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| AZ | 7% | 93% | 208 |
| CA | 14% | 86% | 4,669 |
| FL | 8% | 92% | 337 |
| GA | 4% | 96% | 338 |
| MD | 6% | 94% | 368 |
| MN | 27% | 73% | 520 |
| NH | 8% | 92% | 396 |
| NC | 10% | 90% | 195 |
| PA | 7% | 93% | 610 |
| SD | 10% | 90% | 620 |
| UT | 17% | 83% | 206 |
| Weighted NCI Average | 12% | 88% | 8,467 |

² 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).

³ 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 14. Family Member's Activities in the Past Two Weeks Included *Paid Work in a Community Job That Primarily Hires People With Disabilities*⁴

| State | Yes | No | N |
|-----------------------------|-----------|------------|--------------|
| AZ | 1% | 99% | 207 |
| CA | 9% | 91% | 4,736 |
| FL | 4% | 96% | 347 |
| GA | 3% | 97% | 346 |
| MD | 3% | 97% | 361 |
| MN | 11% | 89% | 517 |
| NH | 9% | 91% | 393 |
| NC | 4% | 96% | 200 |
| PA | 5% | 95% | 617 |
| SD | 12% | 88% | 634 |
| UT | 7% | 93% | 209 |
| Weighted NCI Average | 6% | 94% | 8,567 |

Table 15. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in the Community*⁵

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| AZ | 16% | 84% | 211 |
| CA | 28% | 72% | 4,554 |
| FL | 23% | 77% | 336 |
| GA | 27% | 73% | 320 |
| MD | 14% | 86% | 355 |
| MN | 23% | 77% | 514 |
| NH | 45% | 55% | 380 |
| NC | 40% | 60% | 189 |
| PA | 24% | 76% | 588 |
| SD | 17% | 83% | 604 |
| UT | 26% | 74% | 196 |
| Weighted NCI Average | 27% | 73% | 8,247 |

⁴ 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.

⁵ Unpaid work in the community includes: volunteering, skills training, and staff-supported community connections.

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

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| AZ | 19% | 81% | 215 |
| CA | 13% | 87% | 4,700 |
| FL | 18% | 82% | 350 |
| GA | 7% | 93% | 340 |
| MD | 12% | 88% | 366 |
| MN | 43% | 57% | 529 |
| NH | 5% | 95% | 390 |
| NC | 25% | 75% | 197 |
| PA | 23% | 77% | 614 |
| SD | 11% | 89% | 627 |
| UT | 27% | 73% | 210 |
| Weighted NCI Average | 21% | 79% | 8,538 |

Table 17. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in a Facility-based Setting*⁷

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| AZ | 61% | 39% | 206 |
| CA | 27% | 73% | 4,542 |
| FL | 35% | 65% | 348 |
| GA | 50% | 50% | 328 |
| MD | 31% | 69% | 342 |
| MN | 23% | 77% | 523 |
| NH | 26% | 74% | 379 |
| NC | 42% | 58% | 189 |
| PA | 31% | 69% | 586 |
| SD | 22% | 78% | 602 |
| UT | 41% | 59% | 206 |
| Weighted NCI Average | 33% | 67% | 8,251 |

⁶ 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.

⁷ An unpaid activity in a facility-based setting includes day habilitation, senior programs, or drop-in centers.

Table 18. Family Member's Activities in the Past Two Weeks Included *School*

| State | Yes | No | N |
|-----------------------------|-----------|------------|--------------|
| AZ | 4% | 96% | 209 |
| CA | 10% | 90% | 4,790 |
| FL | 6% | 94% | 345 |
| GA | 7% | 93% | 338 |
| MD | 3% | 97% | 366 |
| MN | 2% | 98% | 529 |
| NH | 2% | 98% | 393 |
| NC | 6% | 94% | 196 |
| PA | 4% | 96% | 616 |
| SD | 2% | 98% | 636 |
| UT | 3% | 97% | 209 |
| Weighted NCI Average | 6% | 94% | 8,627 |

Table 19. Family Member's Activities in the Past Two Weeks Included *Stays at Home*

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| AZ | 25% | 75% | 199 |
| CA | 27% | 73% | 4,646 |
| FL | 28% | 72% | 332 |
| GA | 26% | 74% | 335 |
| MD | 45% | 55% | 357 |
| MN | 27% | 73% | 524 |
| NH | 40% | 60% | 379 |
| NC | 15% | 85% | 199 |
| PA | 32% | 68% | 592 |
| SD | 48% | 52% | 613 |
| UT | 20% | 81% | 200 |
| Weighted NCI Average | 27% | 73% | 8,376 |

Table 20. Family Member's Activities in the Past Two Weeks Included *Other Activities*

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| AZ | 36% | 64% | 76 |
| CA | 48% | 52% | 1,726 |
| FL | 43% | 57% | 139 |
| GA | 38% | 62% | 109 |
| MD | 67% | 33% | 42 |
| MN | 21% | 79% | 195 |
| NH | 62% | 38% | 143 |
| NC | 39% | 61% | 70 |
| PA | 51% | 49% | 237 |
| SD | 44% | 56% | 177 |
| UT | 40% | 60% | 77 |
| Weighted NCI Average | 42% | 58% | 2,991 |

Table 21. 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 | None | Some | Extensive | N |
|-----------------------------|------------|------------|------------|--------------|
| AZ | 32% | 41% | 28% | 218 |
| CA | 40% | 37% | 23% | 5,127 |
| FL | 34% | 35% | 31% | 354 |
| GA | 35% | 33% | 31% | 362 |
| MD | 31% | 40% | 28% | 388 |
| MN | 38% | 41% | 21% | 539 |
| NH | 37% | 39% | 25% | 415 |
| NC | 19% | 46% | 35% | 205 |
| PA | 26% | 38% | 37% | 655 |
| SD | 38% | 44% | 17% | 650 |
| UT | 20% | 43% | 37% | 222 |
| Weighted NCI Average | 33% | 39% | 28% | 9,135 |

Table 22. Family Member's Level of Help Needed With Personal Care Activities (e.g., 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 | None | Some | Extensive | N |
|-----------------------------|------------|------------|------------|--------------|
| AZ | 16% | 43% | 42% | 218 |
| CA | 33% | 35% | 32% | 5,180 |
| FL | 19% | 36% | 45% | 360 |
| GA | 19% | 37% | 43% | 366 |
| MD | 24% | 34% | 42% | 389 |
| MN | 27% | 43% | 30% | 547 |
| NH | 26% | 38% | 36% | 422 |
| NC | 14% | 36% | 50% | 207 |
| PA | 15% | 36% | 49% | 664 |
| SD | 34% | 37% | 29% | 657 |
| UT | 18% | 42% | 40% | 225 |
| Weighted NCI Average | 24% | 37% | 39% | 9,235 |

Table 23. Family Member's Need for Help With Other Daily Activities (e.g., 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 | None | Some | Extensive | N |
|-----------------------------|-----------|------------|------------|--------------|
| AZ | 3% | 10% | 87% | 220 |
| CA | 5% | 30% | 64% | 5,165 |
| FL | 4% | 12% | 83% | 362 |
| GA | 2% | 16% | 83% | 366 |
| MD | 2% | 15% | 84% | 391 |
| MN | 3% | 27% | 70% | 546 |
| NH | 1% | 23% | 75% | 423 |
| NC | 0% | 13% | 86% | 208 |
| PA | 2% | 13% | 84% | 661 |
| SD | 5% | 32% | 63% | 662 |
| UT | 2% | 16% | 82% | 225 |
| Weighted NCI Average | 3% | 21% | 76% | 9,229 |

Respondents

This section provides demographic information about the respondent.

Table 24. Language Spoken at Home

| State | English | Spanish | Other | N |
|-----------------------------|------------|-----------|-----------|--------------|
| AZ | 98% | 1% | 1% | 223 |
| CA | 93% | 3% | 5% | 5,212 |
| FL | 96% | 4% | 1% | 358 |
| GA | 98% | 0% | 2% | 367 |
| MD | 99% | 0% | 1% | 389 |
| MN | 99% | 0% | 1% | 548 |
| NH | 100% | 0% | 0% | 426 |
| NC | 100% | 0% | 0% | 211 |
| PA | 100% | 0% | 0% | 667 |
| SD | 99% | 0% | 0% | 657 |
| UT | 99% | 1% | 0% | 226 |
| Weighted NCI Average | 97% | 1% | 1% | 9,284 |

Table 25. Respondent's Age

| State | Under 35 | 35-54 | 55-74 | 75 and Older | N |
|-----------------------------|-----------|------------|------------|--------------|--------------|
| AZ | 2% | 13% | 59% | 26% | 217 |
| CA | 1% | 8% | 59% | 32% | 5,214 |
| FL | 3% | 17% | 61% | 19% | 357 |
| GA | 1% | 11% | 68% | 20% | 369 |
| MD | 1% | 8% | 61% | 30% | 383 |
| MN | 4% | 19% | 65% | 12% | 549 |
| NH | 1% | 10% | 69% | 21% | 423 |
| NC | 1% | 19% | 62% | 19% | 210 |
| PA | 0% | 9% | 68% | 23% | 663 |
| SD | 1% | 10% | 66% | 23% | 660 |
| UT | 1% | 18% | 60% | 21% | 225 |
| Weighted NCI Average | 2% | 13% | 62% | 24% | 9,270 |

Table 26. Respondent's Health

| State | Excellent | Very Good | Fairly Good | Poor | N |
|-----------------------------|------------|------------|-------------|-----------|--------------|
| AZ | 20% | 50% | 24% | 5% | 222 |
| CA | 18% | 44% | 32% | 6% | 5,213 |
| FL | 17% | 44% | 33% | 6% | 358 |
| GA | 16% | 41% | 37% | 6% | 369 |
| MD | 17% | 42% | 36% | 5% | 389 |
| MN | 22% | 51% | 25% | 1% | 548 |
| NH | 21% | 49% | 26% | 4% | 425 |
| NC | 16% | 47% | 32% | 5% | 211 |
| PA | 12% | 48% | 36% | 4% | 659 |
| SD | 16% | 48% | 34% | 3% | 660 |
| UT | 18% | 44% | 34% | 5% | 226 |
| Weighted NCI Average | 18% | 46% | 32% | 5% | 9,280 |

Due to the COVID-19 pandemic and its impact to NCI data collection and sampling processes, we caution against using 2019-20 data to directly compare with past and future NCI data.
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Table 27. Respondent's Relationship to Family Member

| State | Parent | Sibling | Spouse | Grandparent | Public Guardian | Private Guardian | Other | N |
|-----------------------------|------------|------------|-----------|-------------|-----------------|------------------|-----------|--------------|
| AZ | 62% | 22% | 0% | 1% | 6% | 4% | 5% | 220 |
| CA | 89% | 7% | 0% | 0% | 0% | 0% | 4% | 5,218 |
| FL | 53% | 20% | 0% | 2% | 1% | 4% | 21% | 357 |
| GA | 59% | 27% | 0% | 2% | 1% | 3% | 8% | 365 |
| MD | 61% | 26% | 0% | 3% | 1% | 1% | 8% | 387 |
| MN | 56% | 20% | 0% | 0% | 7% | 6% | 10% | 547 |
| NH | 61% | 26% | 0% | 1% | 0% | 3% | 8% | 424 |
| NC | 50% | 23% | 0% | 1% | 10% | 11% | 4% | 211 |
| PA | 60% | 37% | 0% | 1% | 0% | 0% | 2% | 662 |
| SD | 70% | 22% | 0% | 1% | 1% | 3% | 3% | 662 |
| UT | 72% | 19% | 0% | 2% | 0% | 1% | 5% | 227 |
| Weighted NCI Average | 66% | 19% | 0% | 1% | 3% | 3% | 7% | 9,280 |

Table 28. Respondent's Frequency of Visits With Family Member Last Year

| State | Did not Visit | 1-3 times | 4-6 times | 7-12 times | More Than 12 Times | N |
|-----------------------------|---------------|-----------|------------|------------|--------------------|--------------|
| AZ | 2% | 8% | 11% | 11% | 68% | 222 |
| CA | 5% | 9% | 8% | 10% | 68% | 5,194 |
| FL | 1% | 8% | 8% | 10% | 73% | 357 |
| GA | 1% | 12% | 13% | 17% | 56% | 369 |
| MD | 3% | 13% | 9% | 14% | 61% | 382 |
| MN | 1% | 6% | 9% | 11% | 73% | 548 |
| NH | 4% | 8% | 12% | 12% | 64% | 425 |
| NC | 2% | 10% | 18% | 17% | 53% | 210 |
| PA | 6% | 11% | 12% | 13% | 59% | 658 |
| SD | 3% | 12% | 11% | 13% | 61% | 650 |
| UT | 0% | 6% | 5% | 15% | 74% | 227 |
| Weighted NCI Average | 3% | 9% | 11% | 12% | 65% | 9,242 |

Table 29. Respondent's Highest Level of Education

| State | No High School Diploma or GED | High School Diploma or GED | Vocational School Certificate Program | Some College | College Degree or Higher | N |
|-----------------------------|-------------------------------|----------------------------|---------------------------------------|--------------|--------------------------|--------------|
| AZ | 3% | 15% | 4% | 33% | 45% | 219 |
| CA | 4% | 12% | 4% | 26% | 53% | 5,180 |
| FL | 4% | 22% | 7% | 24% | 43% | 353 |
| GA | 4% | 20% | 6% | 22% | 47% | 367 |
| MD | 4% | 16% | 3% | 19% | 58% | 388 |
| MN | 2% | 17% | 13% | 17% | 52% | 544 |
| NH | 5% | 19% | 4% | 17% | 55% | 424 |
| NC | 3% | 15% | 6% | 20% | 55% | 209 |
| PA | 2% | 29% | 9% | 20% | 40% | 659 |
| SD | 3% | 23% | 14% | 20% | 40% | 652 |
| UT | 1% | 17% | 7% | 29% | 45% | 223 |
| Weighted NCI Average | 4% | 17% | 7% | 23% | 50% | 9,218 |

Table 30. 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 | 7% | 7% | 26% | 9% | 14% | 9% | 29% | 196 |
| CA | 5% | 6% | 14% | 11% | 24% | 10% | 29% | 4,588 |
| FL | 7% | 9% | 19% | 9% | 12% | 11% | 32% | 308 |
| GA | 7% | 10% | 14% | 11% | 15% | 13% | 31% | 330 |
| MD | 3% | 7% | 9% | 13% | 28% | 9% | 31% | 352 |
| MN | 5% | 6% | 17% | 19% | 26% | 5% | 23% | 484 |
| NH | 4% | 7% | 14% | 15% | 18% | 8% | 34% | 382 |
| NC | 7% | 4% | 19% | 15% | 21% | 7% | 28% | 166 |
| PA | 8% | 11% | 16% | 9% | 16% | 11% | 27% | 613 |
| SD | 6% | 9% | 17% | 14% | 19% | 10% | 26% | 607 |
| UT | 5% | 6% | 23% | 16% | 20% | 10% | 19% | 208 |
| Weighted NCI Average | 6% | 7% | 16% | 13% | 21% | 9% | 28% | 8,234 |

Services and Supports Received

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

Table 31. 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 | In-home Support | Residential Support | Day or Employment Supports | Transportation | Other | Self-direction or Fiscal Intermediary Services |
|-----------------------------|-------------------|-----------------|---------------------|----------------------------|----------------|------------|--|
| AZ | 20% | 34% | 95% | 80% | 95% | 52% | 28% |
| CA | 36% | 44% | 79% | 67% | 67% | 41% | 21% |
| FL | 25% | 51% | 88% | 61% | 90% | 56% | 52% |
| GA | 33% | 43% | 94% | 71% | 93% | 47% | 27% |
| MD | 39% | 63% | 96% | 80% | 96% | 64% | 14% |
| MN | 39% | 50% | 87% | 74% | 91% | 50% | 33% |
| NH | 39% | 38% | 90% | 53% | 89% | 53% | 28% |
| NC | 31% | 34% | 92% | 71% | 94% | 62% | 20% |
| PA | 25% | 42% | 96% | 62% | 95% | 74% | 17% |
| SD | 28% | 40% | 87% | 58% | 85% | 54% | 19% |
| UT | 29% | 55% | 95% | 81% | 92% | 60% | 30% |
| Weighted NCI Average | 32% | 45% | 88% | 69% | 86% | 54% | 26% |

Table 32. Additional Services and Supports Received

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) | Other Agencies or Organizations |
|-----------------------------|------------------------------------|---------------------------------|
| AZ | 97% | 21% |
| CA | 91% | 30% |
| FL | 95% | 31% |
| GA | 96% | 22% |
| MD | 95% | 30% |
| MN | 97% | 30% |
| NH | 95% | 27% |
| NC | 96% | 28% |
| PA | 96% | 32% |
| SD | 95% | 25% |
| UT | 98% | 26% |
| Weighted NCI Average | 95% | 29% |

Family/Guardian 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.

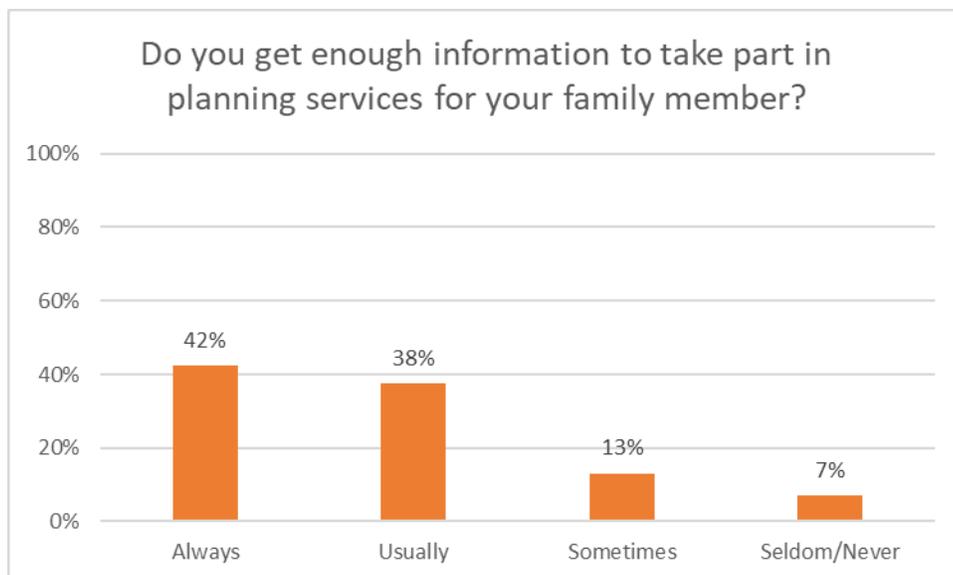


Table Q1. Do you get enough information to take part in planning services for your family member?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| NC | 53% | 36% | 7% | 3% | 204 |
| FL | 50% | 34% | 11% | 4% | 335 |
| MN | 49% | 40% | 9% | 3% | 522 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|------------|-----------------|--------------|
| NH | 47% | 39% | 8% | 5% | 412 |
| AZ | 44% | 44% | 10% | 3% | 216 |
| Weighted NCI Average | 42% | 38% | 13% | 7% | 8,360 |
| PA | 41% | 39% | 15% | 6% | 609 |
| SD | 40% | 45% | 11% | 3% | 628 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| CA | 36% | 36% | 16% | 12% | 4,530 |
| UT | 33% | 41% | 18% | 9% | 209 |
| MD | 31% | 37% | 20% | 13% | 356 |
| GA | 29% | 37% | 24% | 9% | 339 |

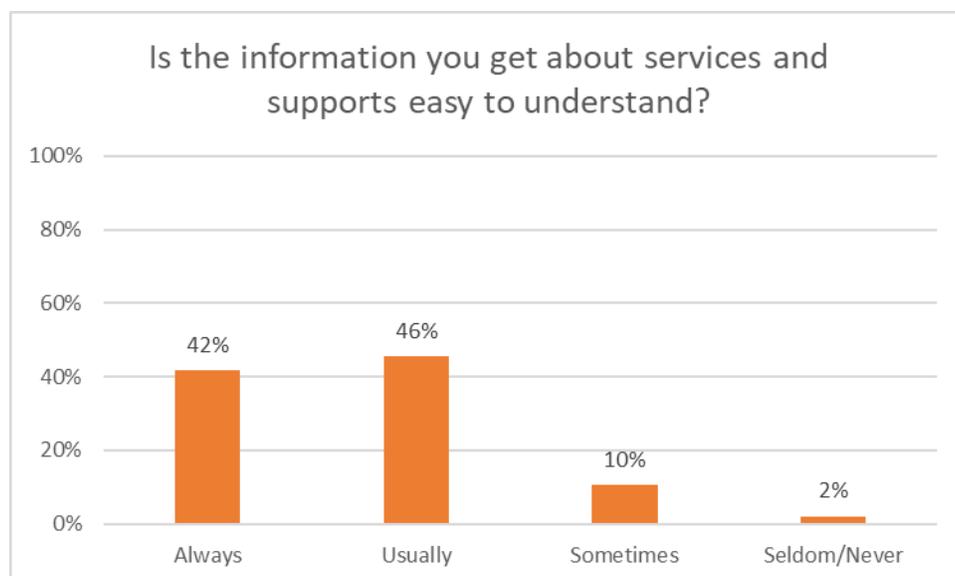


Table Q2. Is the information you get about services and supports easy to understand?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| CA | 49% | 41% | 9% | 2% | 4,517 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|------------|-----------------|--------------|
| NH | 43% | 48% | 8% | 1% | 406 |
| SD | 43% | 48% | 8% | 1% | 636 |
| PA | 42% | 45% | 11% | 2% | 626 |
| NC | 42% | 48% | 8% | 2% | 205 |
| Weighted NCI Average | 42% | 46% | 10% | 2% | 8,377 |
| FL | 41% | 47% | 11% | 1% | 337 |
| AZ | 40% | 51% | 7% | 1% | 216 |
| UT | 38% | 45% | 14% | 3% | 211 |
| MN | 38% | 48% | 14% | 1% | 531 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MD | 31% | 47% | 17% | 5% | 350 |
| GA | 30% | 51% | 14% | 5% | 342 |

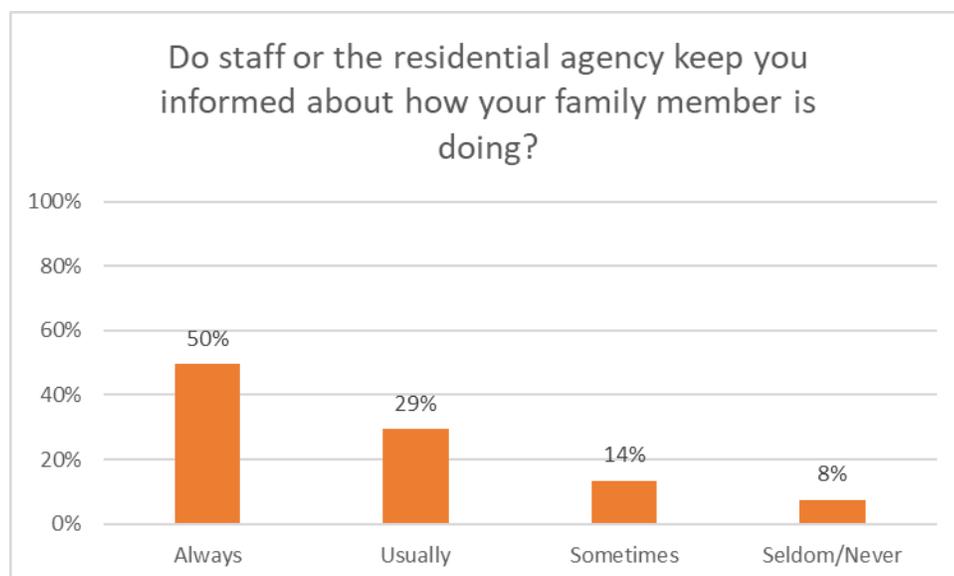


Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 63% | 22% | 12% | 3% | 333 |
| MN | 58% | 29% | 11% | 2% | 520 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|------------|-----------------|--------------|
| NC | 56% | 31% | 10% | 3% | 208 |
| NH | 54% | 30% | 10% | 6% | 404 |
| Weighted NCI Average | 50% | 29% | 14% | 8% | 8,702 |
| PA | 47% | 32% | 16% | 6% | 658 |
| AZ | 46% | 38% | 13% | 4% | 224 |
| GA | 44% | 29% | 16% | 11% | 359 |
| UT | 43% | 33% | 16% | 9% | 221 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| CA | 44% | 28% | 14% | 13% | 4,749 |
| SD | 42% | 37% | 16% | 5% | 638 |
| MD | 34% | 32% | 21% | 13% | 388 |

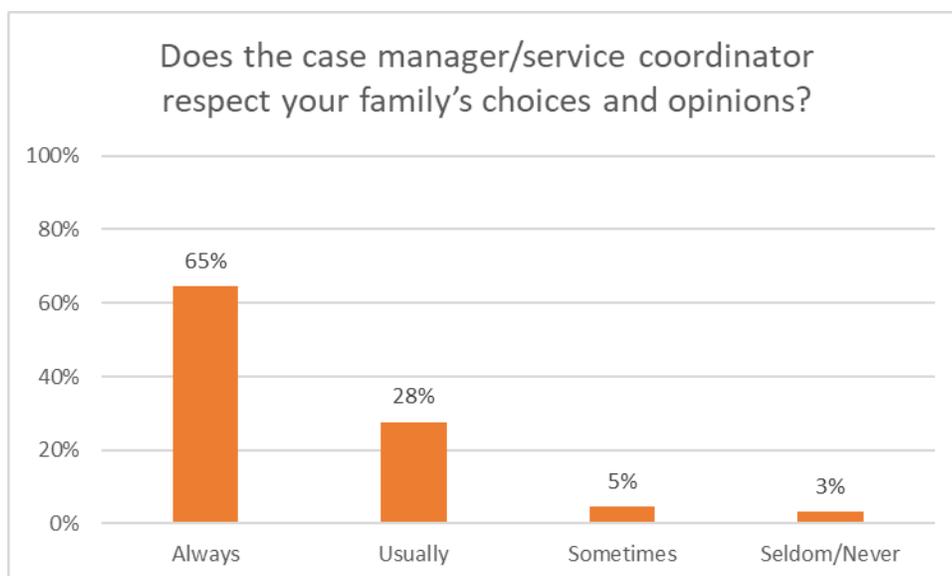


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 77% | 20% | 2% | 1% | 352 |
| MN | 76% | 20% | 2% | 1% | 542 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| UT | 72% | 22% | 3% | 2% | 218 |
| AZ | 69% | 27% | 2% | 2% | 216 |
| NH | 68% | 25% | 5% | 2% | 412 |
| Weighted NCI Average | 65% | 28% | 5% | 3% | 8,557 |
| NC | 63% | 31% | 2% | 3% | 206 |
| PA | 62% | 31% | 5% | 3% | 634 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| CA | 59% | 28% | 7% | 6% | 4,629 |
| SD | 58% | 34% | 6% | 2% | 647 |
| GA | 53% | 37% | 6% | 3% | 337 |
| MD | 49% | 38% | 8% | 5% | 364 |

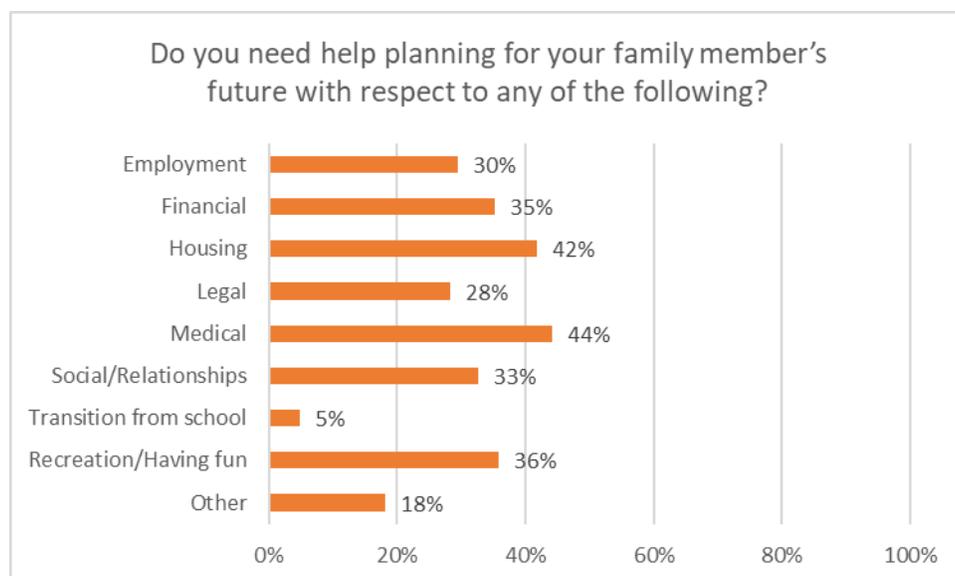


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

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 | 13% | 28% | 38% | 22% | 43% | 25% | 3% | 31% | 17% |
| CA | 36% | 37% | 46% | 30% | 42% | 36% | 7% | 38% | 19% |
| FL | 22% | 39% | 43% | 33% | 49% | 37% | 10% | 42% | 23% |
| GA | 23% | 29% | 37% | 29% | 38% | 27% | 5% | 28% | 26% |
| MD | 34% | 40% | 41% | 30% | 50% | 33% | 3% | 48% | 11% |
| MN | 43% | 40% | 44% | 26% | 44% | 35% | 3% | 38% | 12% |
| NH | 33% | 44% | 45% | 26% | 42% | 38% | 1% | 38% | 17% |
| NC | 18% | 30% | 38% | 29% | 47% | 25% | 3% | 23% | 17% |
| PA | 19% | 23% | 30% | 20% | 40% | 26% | 1% | 31% | 21% |
| SD | 41% | 40% | 44% | 28% | 47% | 37% | 5% | 37% | 10% |
| UT | 35% | 39% | 40% | 28% | 41% | 30% | 2% | 40% | 30% |
| Weighted NCI Average | 30% | 35% | 42% | 28% | 44% | 33% | 5% | 36% | 18% |

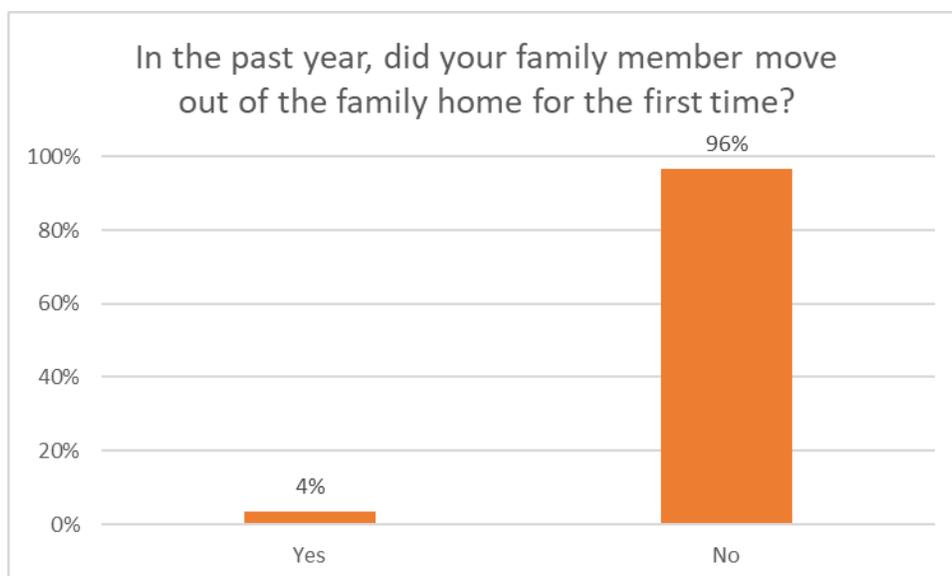


Table Q6. In the past year, did your family member move out of the family home for the first time?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| UT | 9% | 91% | 222 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|-----------|------------|--------------|
| GA | 6% | 94% | 361 |
| NH | 5% | 95% | 419 |
| CA | 4% | 96% | 5,093 |
| MD | 4% | 96% | 367 |
| FL | 4% | 96% | 355 |
| Weighted NCI Average | 4% | 96% | 9,056 |
| NC | 3% | 97% | 203 |
| SD | 3% | 97% | 637 |
| MN | 3% | 97% | 544 |
| PA | 2% | 98% | 639 |
| AZ | 2% | 98% | 216 |

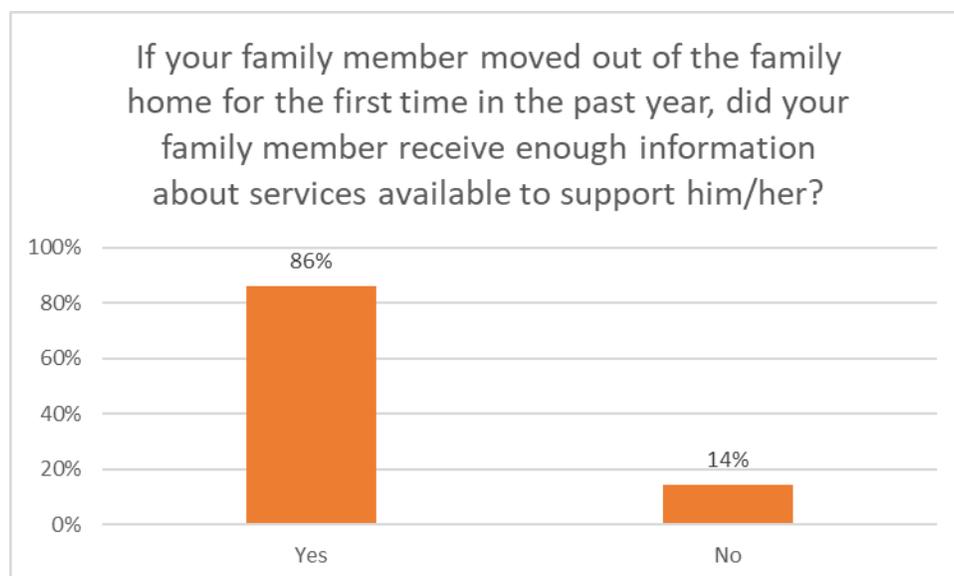


Table Q7. If your family member moved out of the family home for the first time in the past year, did your family member receive enough information about services available to support him/her?⁸

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|------------|
| Weighted NCI Average | 86% | 14% | 282 |
| NH | 85% | 15% | 20 |

Significantly Below Average

| State | Yes | No | N |
|-----------|-----|-----|-----|
| CA | 75% | 25% | 161 |

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, FL, GA, MD, MN, NC, PA, SD, UT

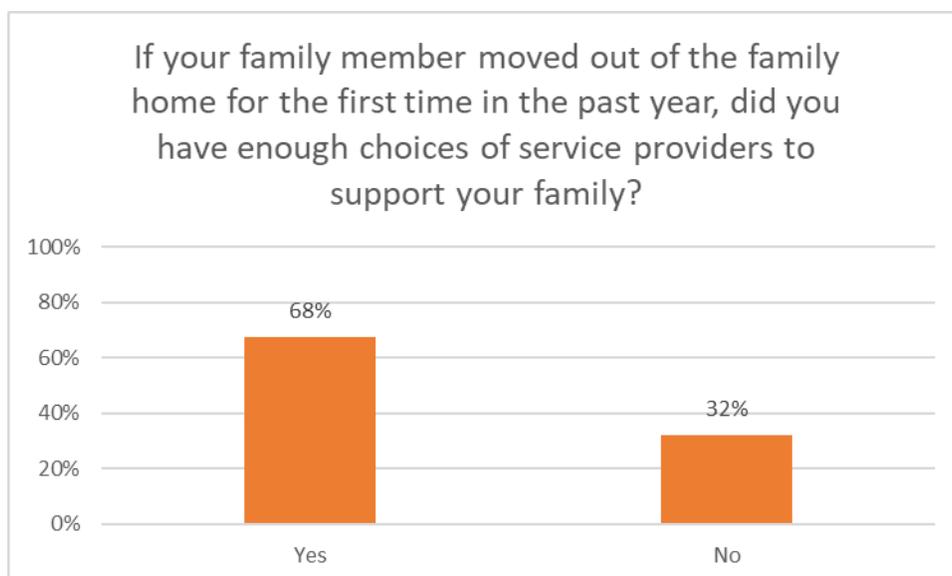


Table Q8. If your family member moved out of the family home for the first time in the past year, did you have enough choices of service providers to support your family?⁹

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|------------|
| NH | 76% | 24% | 21 |
| Weighted NCI Average | 68% | 32% | 293 |
| CA | 66% | 34% | 171 |

⁹ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, FL, GA, MD, MN, NC, PA, SD, UT

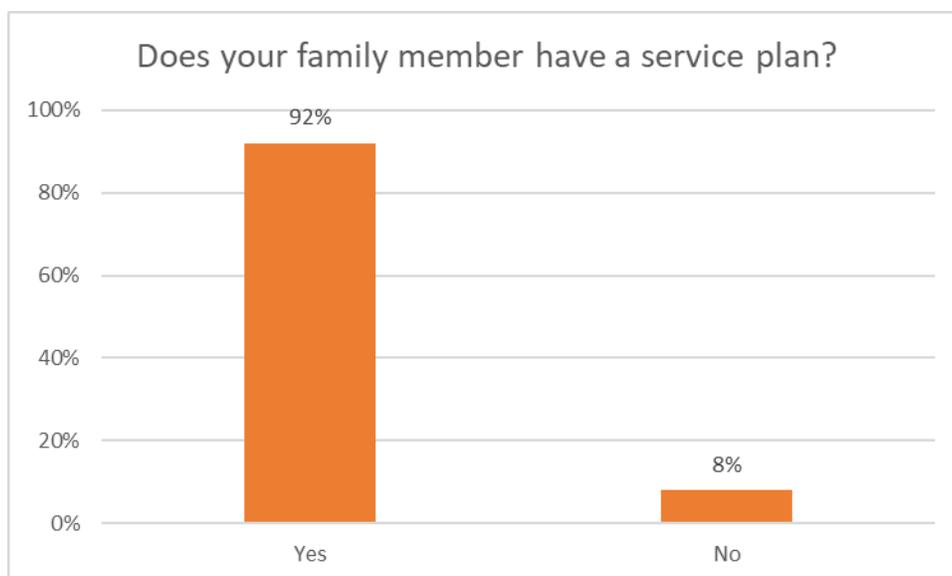


Table Q9. Does your family member have a service plan?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| PA | 98% | 2% | 568 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|-----------|--------------|
| FL | 95% | 5% | 342 |
| NC | 93% | 7% | 180 |
| AZ | 93% | 7% | 212 |
| SD | 92% | 8% | 526 |
| Weighted NCI Average | 92% | 8% | 7,664 |
| NH | 92% | 8% | 387 |
| CA | 91% | 9% | 4,152 |
| MN | 91% | 9% | 514 |
| UT | 89% | 11% | 177 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MD | 85% | 15% | 327 |
| GA | 85% | 15% | 279 |

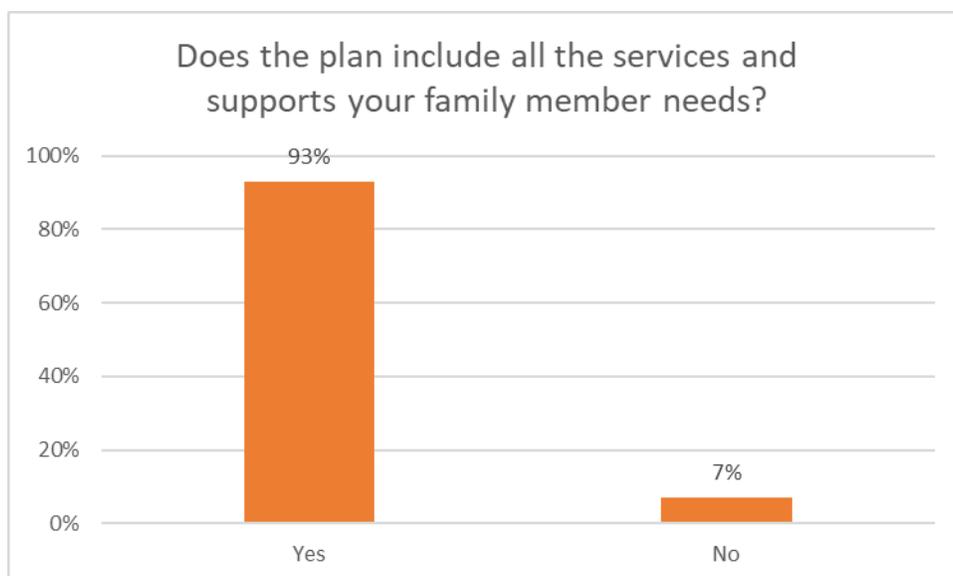


Table Q10. Does the plan include all the services and supports your family member needs?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| PA | 96% | 4% | 515 |
| MN | 96% | 4% | 428 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|-----------|--------------|
| NC | 96% | 4% | 162 |
| AZ | 96% | 4% | 174 |
| SD | 95% | 5% | 446 |
| UT | 95% | 5% | 135 |
| Weighted NCI Average | 93% | 7% | 6,218 |
| FL | 92% | 8% | 308 |
| NH | 91% | 9% | 332 |
| GA | 88% | 12% | 208 |
| MD | 88% | 12% | 233 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-------|
| CA | 90% | 10% | 3,277 |

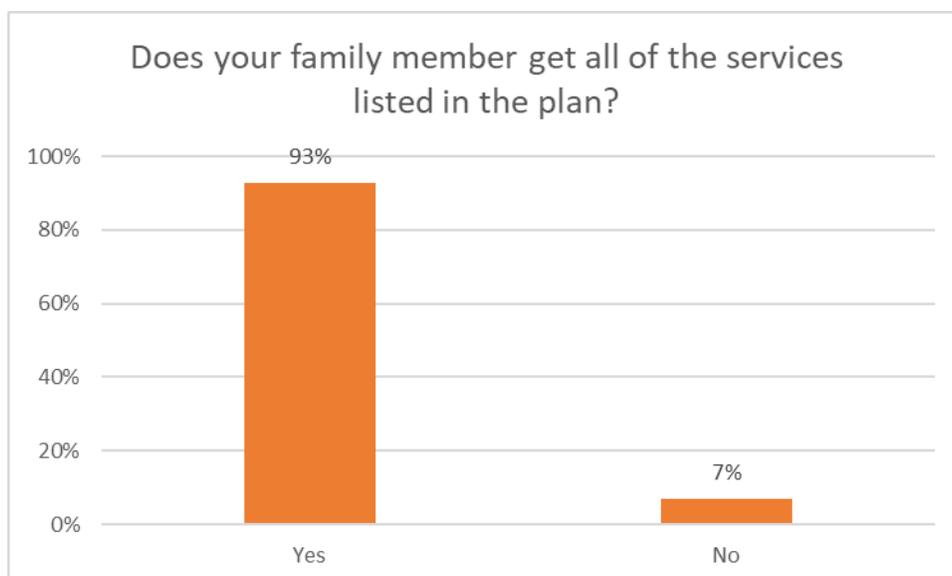


Table Q11. Does your family member get all of the services listed in the plan?

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|-----------|--------------|
| NC | 97% | 3% | 150 |
| FL | 95% | 5% | 293 |
| MN | 95% | 5% | 414 |
| PA | 94% | 6% | 479 |
| Weighted NCI Average | 93% | 7% | 5,869 |
| AZ | 92% | 8% | 167 |
| CA | 91% | 9% | 3,095 |
| NH | 91% | 9% | 322 |
| SD | 90% | 10% | 423 |
| UT | 88% | 12% | 123 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| GA | 86% | 14% | 189 |
| MD | 85% | 15% | 214 |

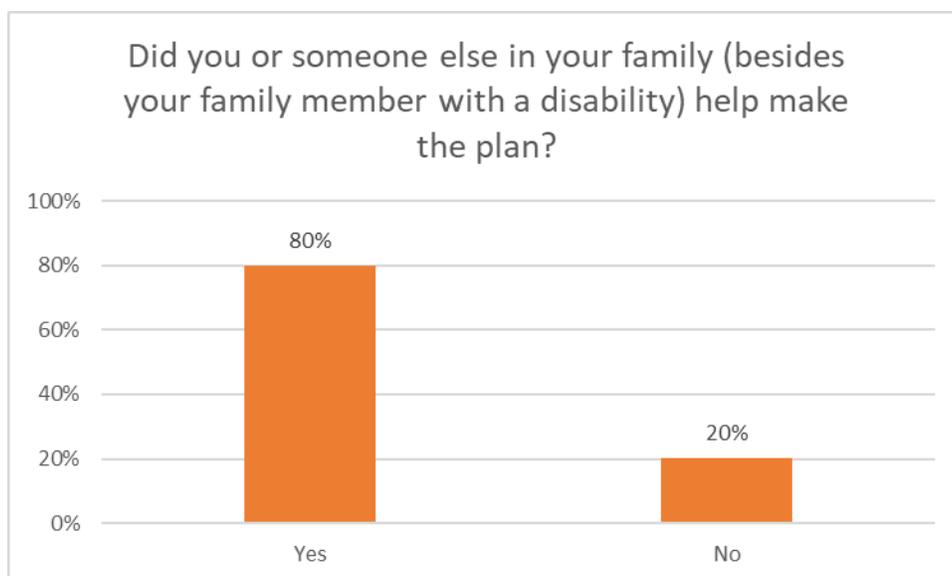


Table Q12. Did you or someone else in your family (besides your family member with a disability) help make the plan?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MN | 88% | 12% | 446 |
| NH | 88% | 12% | 338 |
| NC | 87% | 13% | 166 |
| SD | 86% | 14% | 456 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| UT | 85% | 15% | 142 |
| GA | 83% | 17% | 222 |
| MD | 83% | 17% | 250 |
| AZ | 82% | 18% | 177 |
| Weighted NCI Average | 80% | 20% | 6,540 |
| FL | 78% | 22% | 315 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-------|
| CA | 73% | 27% | 3,501 |
| PA | 70% | 30% | 527 |

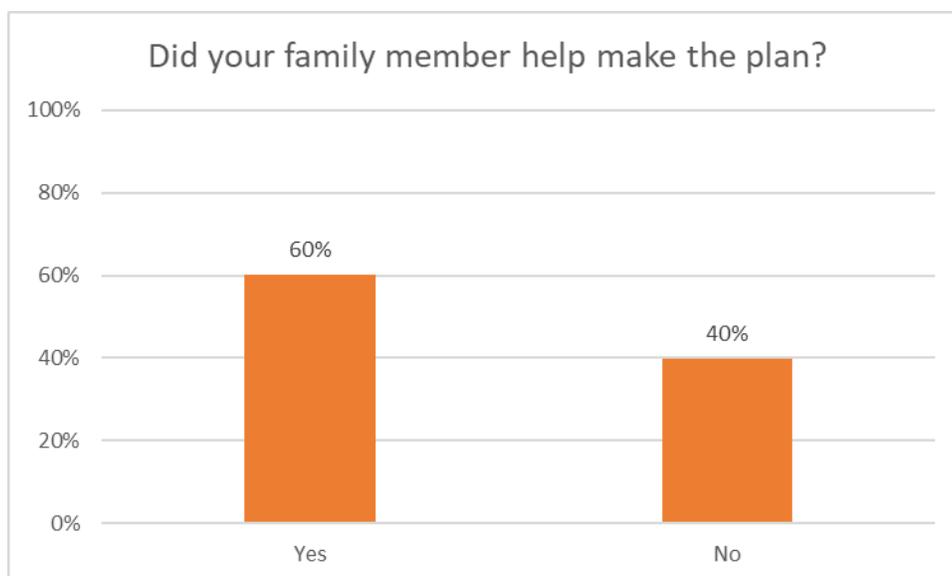


Table Q13. Did your family member help make the plan?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| SD | 81% | 19% | 449 |
| MN | 78% | 22% | 438 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| UT | 66% | 34% | 144 |
| NH | 64% | 36% | 340 |
| MD | 64% | 36% | 250 |
| CA | 62% | 38% | 3,360 |
| GA | 61% | 39% | 221 |
| Weighted NCI Average | 60% | 40% | 6,369 |
| FL | 60% | 40% | 314 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| NC | 49% | 51% | 166 |
| PA | 49% | 51% | 510 |
| AZ | 45% | 55% | 177 |

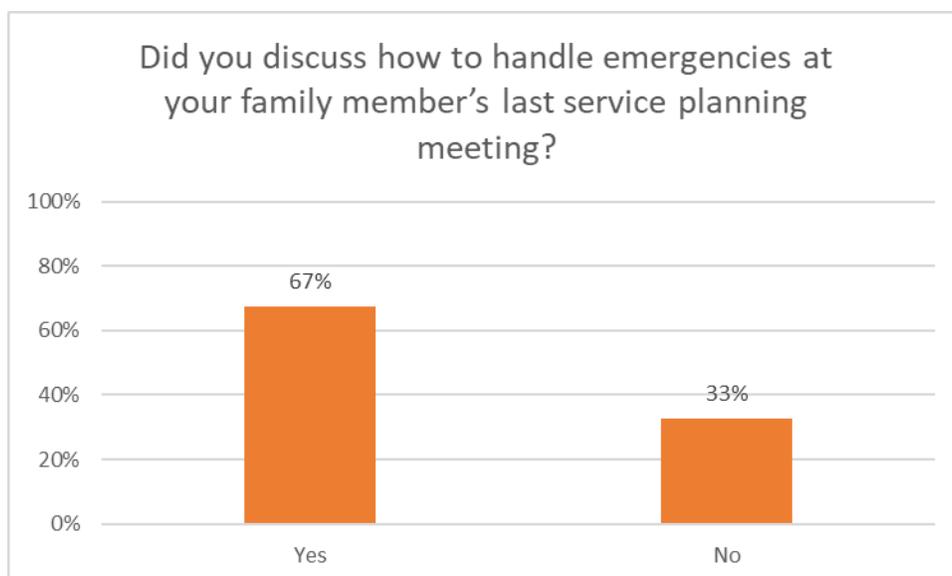


Table Q14. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?

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

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| FL | 90% | 10% | 298 |
| NC | 80% | 20% | 155 |
| MN | 80% | 20% | 424 |
| SD | 75% | 25% | 436 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| Weighted NCI Average | 67% | 33% | 5,721 |
| PA | 62% | 38% | 450 |
| GA | 60% | 40% | 198 |
| UT | 60% | 40% | 130 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-------|
| NH | 57% | 43% | 296 |
| MD | 56% | 44% | 228 |
| AZ | 50% | 50% | 165 |
| CA | 48% | 52% | 2,941 |

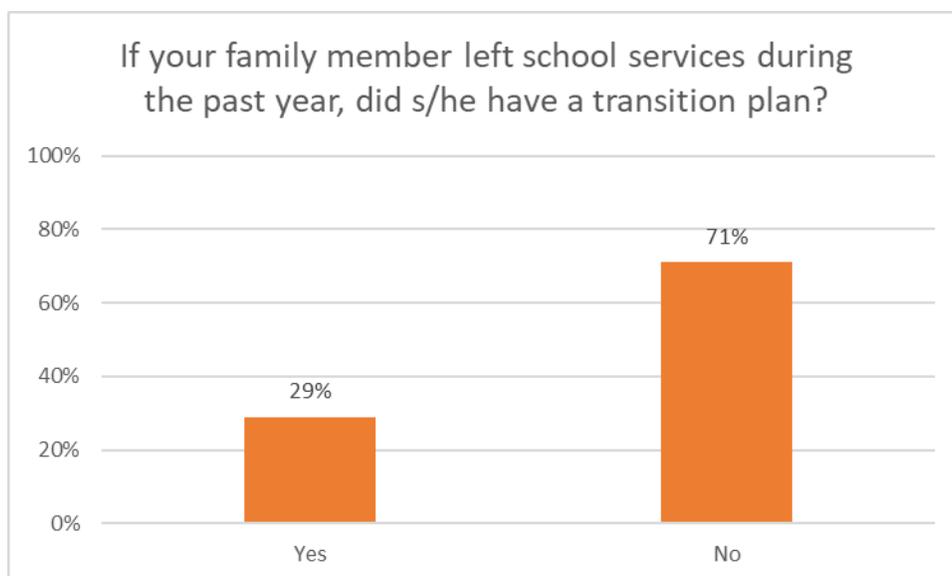


Table Q15. If your family member left school services during the past year, did s/he have a transition plan?¹⁰

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

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|------------|
| UT | 38% | 63% | 24 |
| MN | 33% | 67% | 30 |
| CA | 30% | 70% | 167 |
| Weighted NCI Average | 29% | 71% | 352 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|----|
| NH | 15% | 85% | 52 |

¹⁰ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, FL, GA, MD, NC, PA, SD

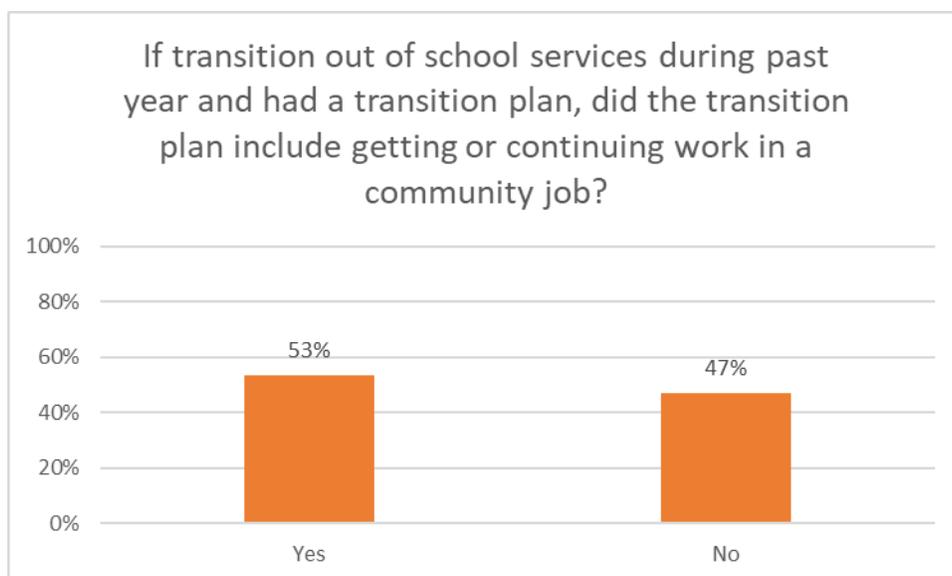


Table Q16. If transition out of school services during past year and had a transition plan, did the transition plan include getting or continuing work in a community job?¹¹

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|-----------|
| Weighted NCI Average | 53% | 47% | 91 |
| CA | 40% | 60% | 47 |

¹¹ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average:
AZ, FL, GA, MD, MN, NC, NH, PA, SD, UT

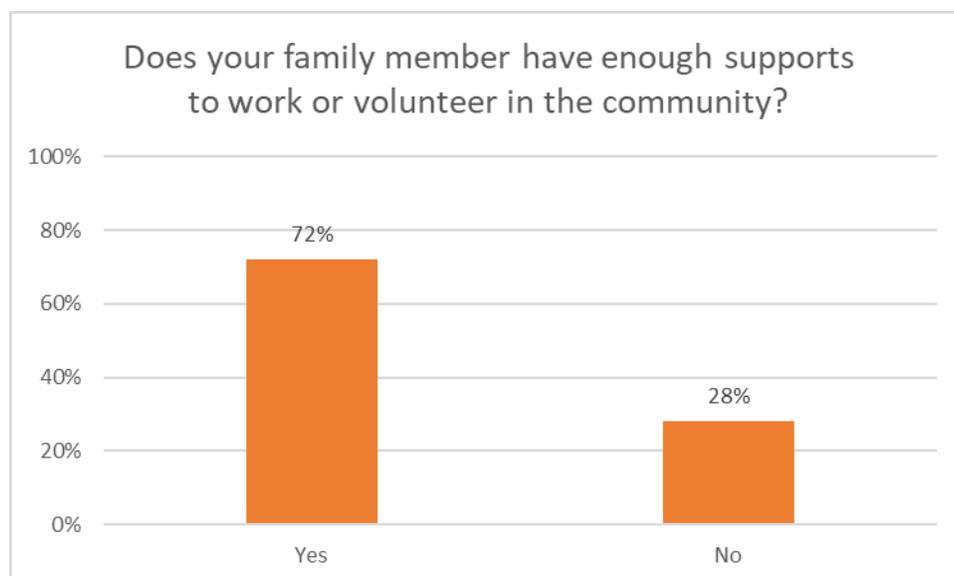


Table Q17. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

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

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MN | 84% | 16% | 443 |
| NH | 79% | 21% | 312 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| PA | 77% | 23% | 387 |
| SD | 75% | 25% | 474 |
| NC | 73% | 27% | 141 |
| Weighted NCI Average | 72% | 28% | 5,902 |
| CA | 69% | 31% | 3,195 |
| UT | 67% | 33% | 152 |
| AZ | 67% | 33% | 127 |
| FL | 66% | 34% | 211 |
| MD | 64% | 36% | 223 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| GA | 56% | 44% | 237 |

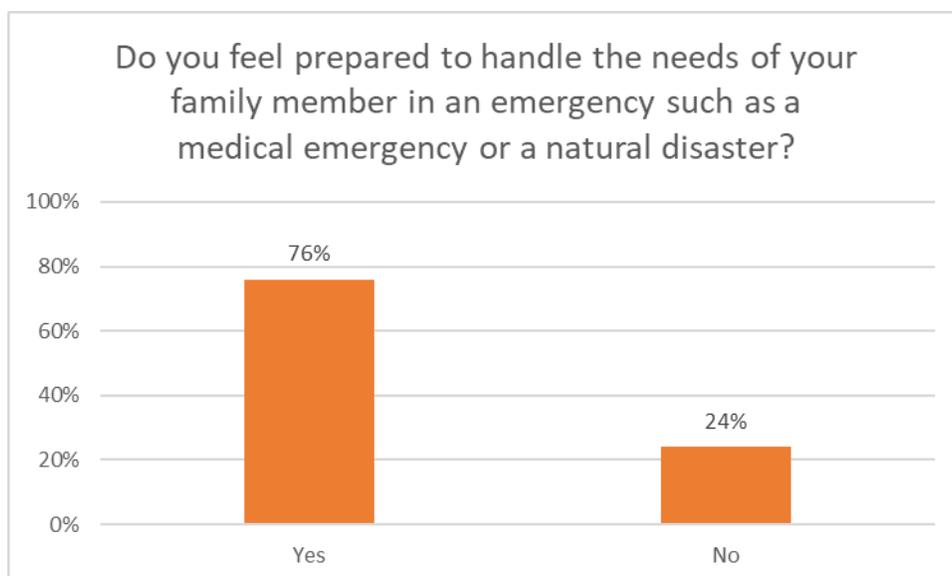


Table Q18. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

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

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| MN | 90% | 10% | 496 |
| FL | 86% | 14% | 328 |
| SD | 84% | 16% | 562 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| NH | 77% | 23% | 370 |
| AZ | 77% | 23% | 197 |
| NC | 76% | 24% | 184 |
| Weighted NCI Average | 76% | 24% | 7,685 |
| GA | 75% | 25% | 316 |
| UT | 67% | 33% | 192 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-------|
| CA | 71% | 29% | 4,224 |
| PA | 69% | 31% | 514 |
| MD | 60% | 40% | 302 |

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.

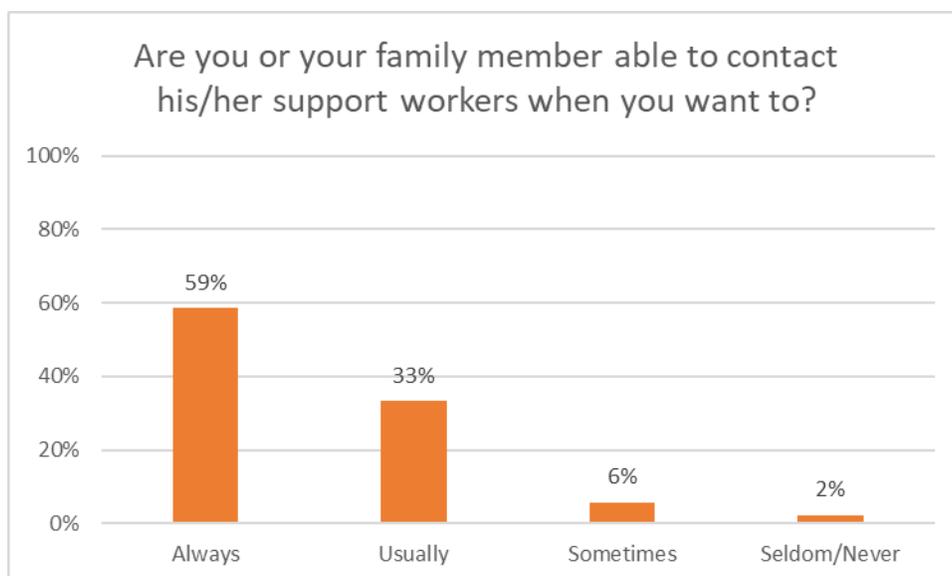


Table Q19. Are you or your family member able to contact his/her support workers when you want to?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 76% | 21% | 2% | 1% | 351 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| NH | 63% | 30% | 4% | 2% | 410 |
| NC | 62% | 33% | 5% | 0% | 196 |
| MN | 61% | 34% | 4% | 1% | 534 |
| PA | 60% | 34% | 5% | 2% | 643 |
| Weighted NCI Average | 59% | 33% | 6% | 2% | 8,505 |
| SD | 57% | 37% | 5% | 1% | 636 |
| UT | 57% | 36% | 4% | 3% | 217 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| CA | 53% | 34% | 8% | 5% | 4,580 |
| GA | 51% | 37% | 9% | 3% | 358 |
| AZ | 49% | 41% | 9% | 1% | 219 |
| MD | 48% | 39% | 8% | 5% | 361 |

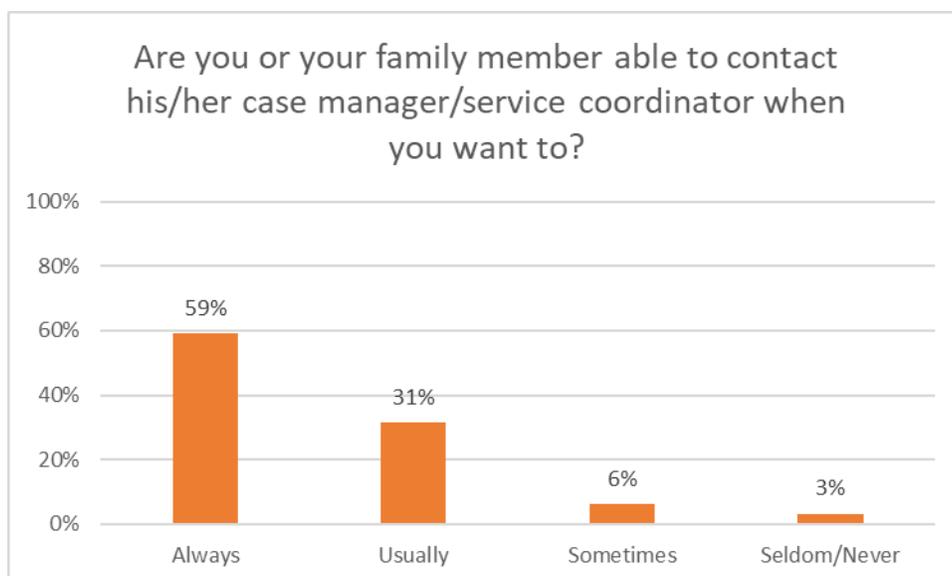


Table Q20. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 77% | 20% | 2% | 1% | 348 |
| MN | 68% | 26% | 4% | 2% | 545 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| UT | 66% | 26% | 6% | 2% | 216 |
| NC | 62% | 34% | 3% | 0% | 204 |
| NH | 61% | 33% | 4% | 2% | 413 |
| SD | 60% | 34% | 5% | 1% | 637 |
| PA | 60% | 33% | 5% | 3% | 639 |
| Weighted NCI Average | 59% | 31% | 6% | 3% | 8,635 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| GA | 52% | 35% | 8% | 5% | 347 |
| CA | 51% | 34% | 9% | 6% | 4,704 |
| AZ | 49% | 37% | 11% | 3% | 222 |
| MD | 46% | 38% | 11% | 6% | 360 |

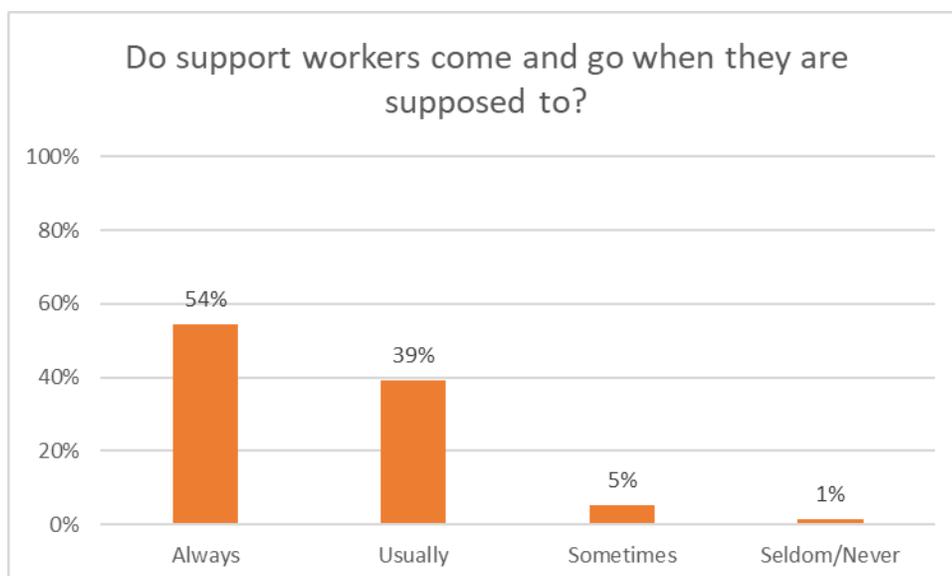


Table Q21. Do support workers come and go when they are supposed to?

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

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 69% | 29% | 2% | 0% | 288 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| MN | 56% | 39% | 4% | 0% | 418 |
| Weighted NCI Average | 54% | 39% | 5% | 1% | 5,830 |
| PA | 54% | 39% | 6% | 1% | 363 |
| NH | 54% | 40% | 4% | 2% | 290 |
| UT | 52% | 42% | 6% | 0% | 155 |
| NC | 52% | 43% | 5% | 1% | 128 |
| CA | 51% | 40% | 6% | 2% | 3,223 |
| SD | 51% | 41% | 7% | 2% | 398 |
| MD | 50% | 38% | 7% | 5% | 189 |
| GA | 46% | 45% | 8% | 2% | 221 |
| AZ | 45% | 45% | 8% | 2% | 157 |

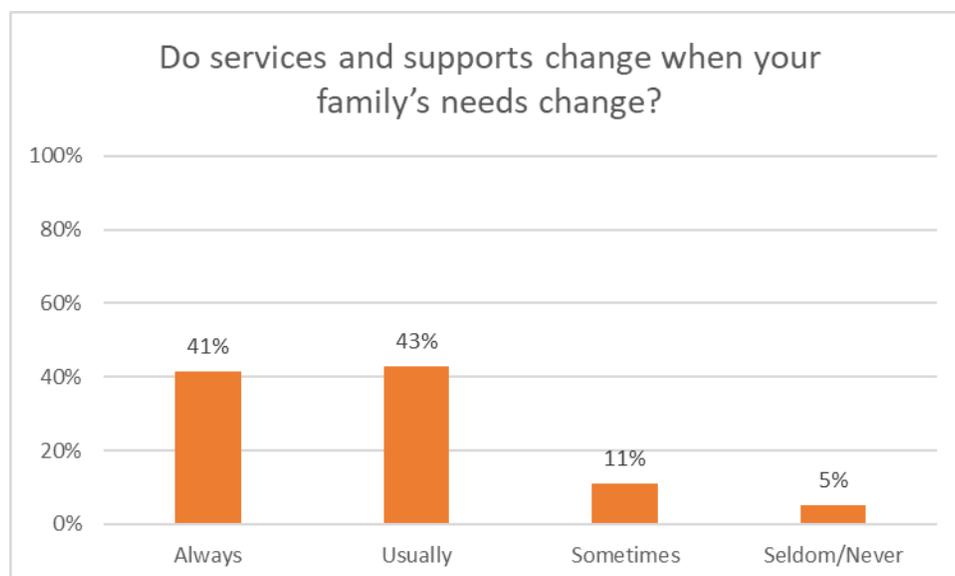


Table Q22. Do services and supports change when your family's needs change?

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 | 52% | 35% | 10% | 2% | 269 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|------------|-----------------|--------------|
| MN | 47% | 40% | 11% | 3% | 415 |
| NC | 42% | 48% | 6% | 4% | 158 |
| NH | 41% | 41% | 13% | 5% | 302 |
| Weighted NCI Average | 41% | 43% | 11% | 5% | 5,836 |
| PA | 41% | 45% | 10% | 4% | 412 |
| SD | 40% | 45% | 10% | 5% | 473 |
| UT | 38% | 46% | 12% | 4% | 164 |
| CA | 37% | 43% | 13% | 7% | 3,056 |
| MD | 35% | 38% | 16% | 12% | 208 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| GA | 31% | 46% | 16% | 7% | 232 |
| AZ | 31% | 49% | 14% | 7% | 147 |

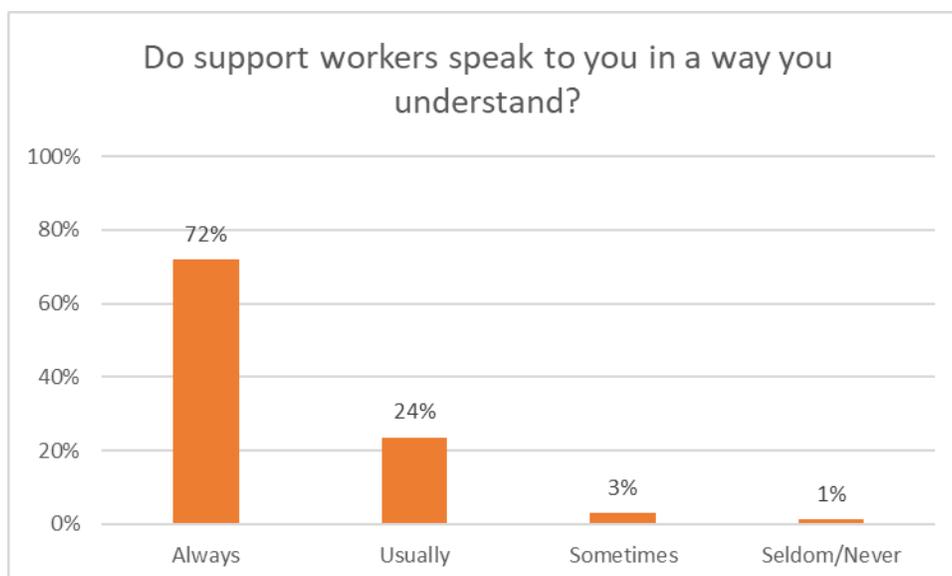


Table Q23. Do support workers speak to you in a way you understand?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 80% | 17% | 2% | 1% | 341 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| NC | 75% | 22% | 2% | 1% | 197 |
| MN | 73% | 23% | 4% | 0% | 511 |
| CA | 73% | 22% | 3% | 2% | 4,439 |
| NH | 73% | 23% | 4% | 1% | 383 |
| Weighted NCI Average | 72% | 24% | 3% | 1% | 8,201 |
| UT | 72% | 25% | 3% | 0% | 212 |
| PA | 70% | 27% | 3% | 0% | 611 |
| SD | 68% | 29% | 2% | 1% | 620 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| GA | 65% | 31% | 3% | 1% | 345 |
| AZ | 62% | 34% | 3% | 1% | 202 |
| MD | 57% | 30% | 8% | 5% | 340 |

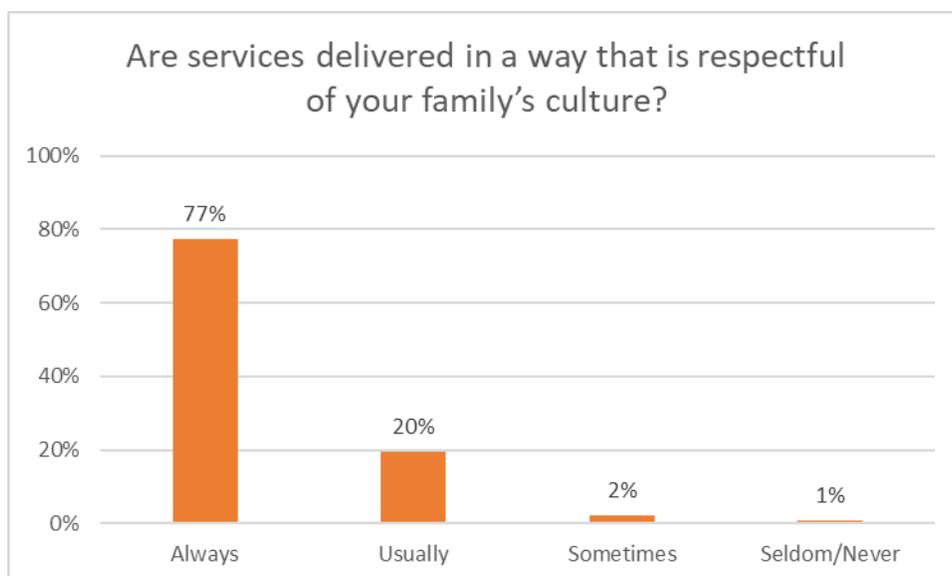


Table Q24. Are services delivered in a way that is respectful of your family's culture?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 83% | 15% | 2% | 0% | 341 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| CA | 81% | 16% | 2% | 1% | 4,548 |
| MN | 81% | 16% | 3% | 0% | 524 |
| NH | 78% | 18% | 3% | 1% | 401 |
| Weighted NCI Average | 77% | 20% | 2% | 1% | 8,336 |
| NC | 77% | 21% | 2% | 1% | 199 |
| UT | 77% | 20% | 3% | 0% | 215 |
| PA | 74% | 22% | 3% | 0% | 605 |
| SD | 73% | 24% | 2% | 1% | 619 |
| AZ | 70% | 27% | 3% | 0% | 206 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| GA | 64% | 32% | 3% | 1% | 340 |
| MD | 64% | 28% | 5% | 3% | 338 |

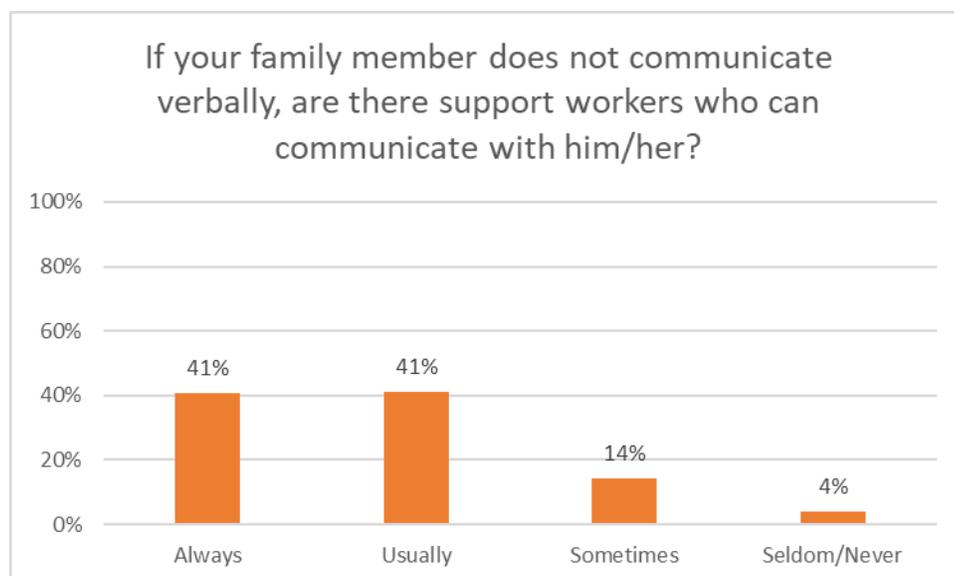


Table Q25. If your family member does not communicate verbally (for example, uses gestures or sign language, or a communication aid), are there support workers who can communicate with him/her?

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

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|------------|-----------------|--------------|
| PA | 48% | 37% | 14% | 1% | 210 |
| NH | 47% | 43% | 7% | 3% | 76 |
| SD | 43% | 47% | 9% | 1% | 131 |
| UT | 42% | 36% | 18% | 4% | 45 |
| FL | 41% | 40% | 16% | 2% | 82 |
| MN | 41% | 43% | 9% | 7% | 76 |
| CA | 41% | 38% | 14% | 8% | 844 |
| Weighted NCI Average | 41% | 41% | 14% | 4% | 1,745 |
| MD | 40% | 40% | 12% | 7% | 97 |
| NC | 40% | 44% | 17% | 0% | 48 |
| GA | 34% | 51% | 13% | 2% | 83 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|----|
| AZ | 25% | 51% | 19% | 6% | 53 |

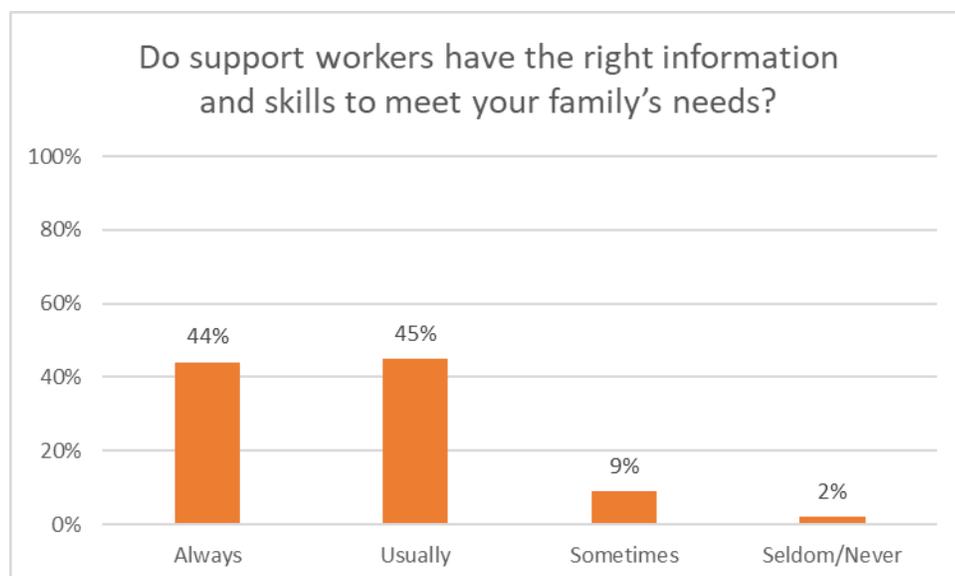


Table Q26. Do support workers have the right information and skills to meet your family's needs?

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

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 59% | 36% | 4% | 1% | 331 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| MN | 46% | 45% | 8% | 1% | 501 |
| NH | 45% | 47% | 7% | 1% | 372 |
| Weighted NCI Average | 44% | 45% | 9% | 2% | 7,740 |
| CA | 44% | 44% | 10% | 3% | 4,152 |
| NC | 43% | 48% | 7% | 2% | 189 |
| PA | 42% | 43% | 13% | 2% | 574 |
| SD | 39% | 49% | 10% | 2% | 585 |
| UT | 38% | 46% | 15% | 1% | 202 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| GA | 35% | 50% | 10% | 5% | 317 |
| AZ | 34% | 51% | 11% | 4% | 199 |
| MD | 33% | 51% | 13% | 3% | 318 |

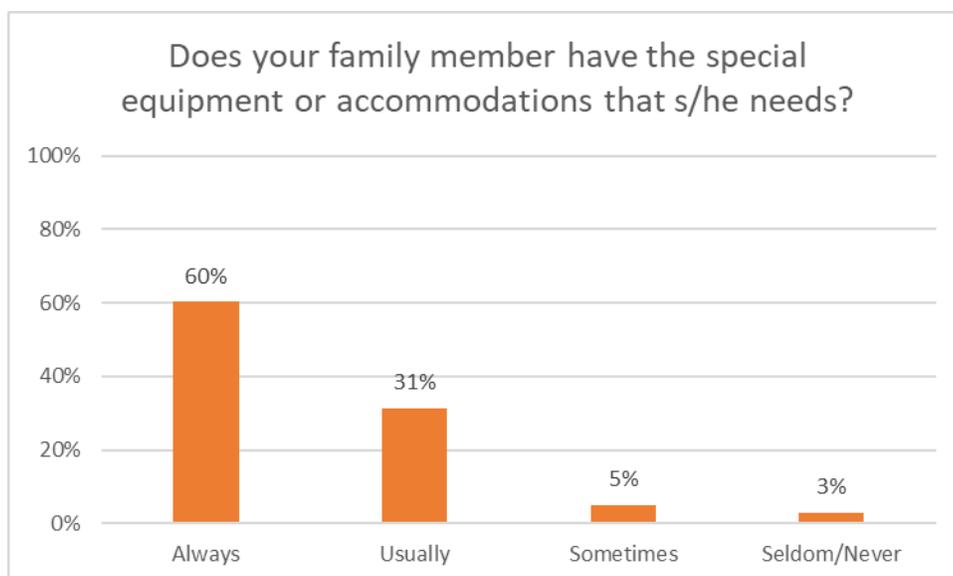


Table Q27. Does your family member have the special equipment or accommodations that s/he needs?

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

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| FL | 67% | 27% | 3% | 3% | 181 |
| PA | 65% | 29% | 4% | 2% | 387 |
| MN | 64% | 28% | 5% | 3% | 264 |
| NC | 62% | 35% | 2% | 2% | 113 |
| SD | 61% | 32% | 5% | 2% | 363 |
| Weighted NCI Average | 60% | 31% | 5% | 3% | 4,242 |
| NH | 59% | 31% | 7% | 3% | 206 |
| CA | 58% | 31% | 6% | 5% | 2,084 |
| GA | 55% | 36% | 8% | 1% | 189 |
| UT | 54% | 34% | 9% | 2% | 125 |
| MD | 54% | 34% | 8% | 3% | 206 |
| AZ | 49% | 40% | 8% | 2% | 124 |

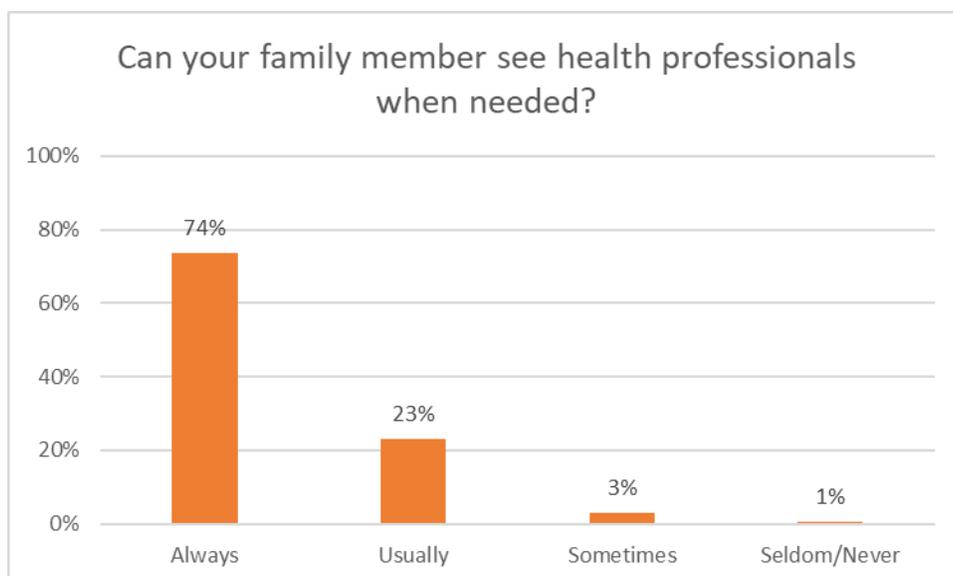


Table Q28. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

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

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 82% | 16% | 2% | 1% | 352 |
| NH | 81% | 18% | 1% | 0% | 423 |
| PA | 78% | 20% | 1% | 0% | 646 |
| MN | 78% | 19% | 3% | 0% | 542 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| NC | 77% | 21% | 2% | 0% | 207 |
| Weighted NCI Average | 74% | 23% | 3% | 1% | 8,940 |
| SD | 72% | 26% | 2% | 0% | 646 |
| GA | 72% | 24% | 2% | 1% | 353 |
| AZ | 70% | 29% | 1% | 0% | 220 |
| MD | 67% | 28% | 4% | 1% | 365 |
| UT | 66% | 32% | 2% | 0% | 221 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| CA | 67% | 27% | 5% | 1% | 4,965 |

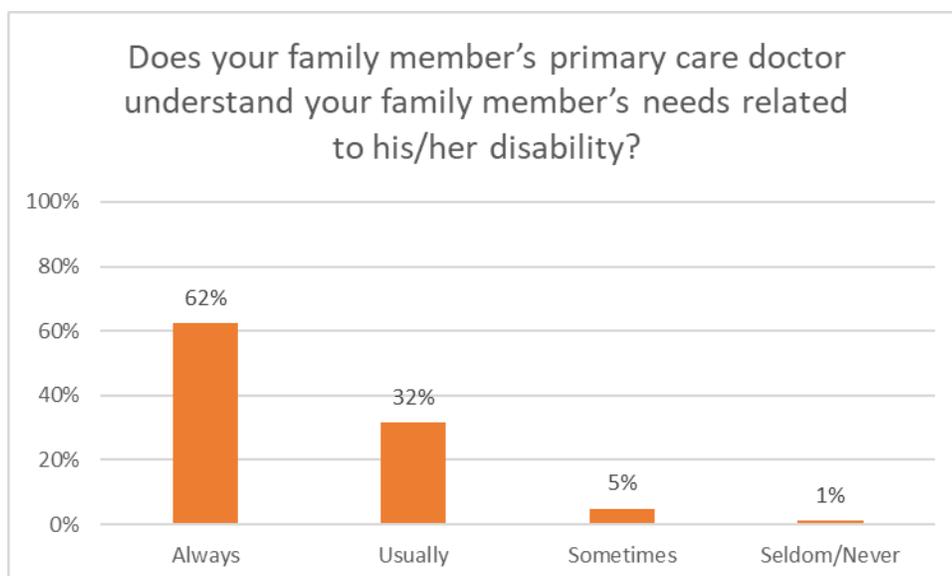


Table Q29. Does your family member's primary care doctor understand your family member's needs related to his/her disability?

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| PA | 67% | 30% | 3% | 0% | 559 |
| FL | 67% | 28% | 5% | 0% | 331 |
| NC | 66% | 27% | 5% | 2% | 196 |
| MD | 66% | 29% | 4% | 1% | 318 |
| MN | 65% | 31% | 4% | 0% | 525 |
| SD | 63% | 34% | 3% | 1% | 585 |
| Weighted NCI Average | 62% | 32% | 5% | 1% | 7,899 |
| NH | 62% | 33% | 4% | 1% | 399 |
| GA | 58% | 37% | 3% | 2% | 319 |
| UT | 55% | 38% | 6% | 2% | 197 |
| AZ | 54% | 39% | 5% | 1% | 213 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| CA | 56% | 35% | 7% | 2% | 4,257 |

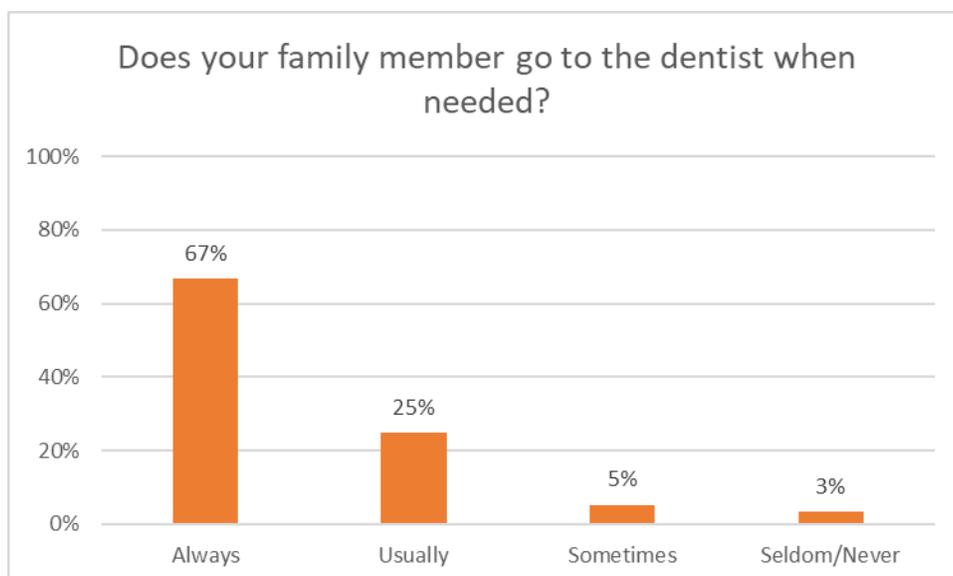


Table Q30. Does your family member go to the dentist when needed?

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

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| PA | 77% | 19% | 3% | 1% | 624 |
| MN | 72% | 21% | 6% | 2% | 537 |
| SD | 71% | 25% | 2% | 1% | 637 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| NC | 72% | 26% | 1% | 2% | 200 |
| NH | 67% | 20% | 5% | 8% | 411 |
| Weighted NCI Average | 67% | 25% | 5% | 3% | 8,638 |
| MD | 65% | 27% | 6% | 3% | 349 |
| AZ | 64% | 27% | 5% | 4% | 220 |
| GA | 63% | 25% | 7% | 6% | 338 |
| FL | 62% | 27% | 7% | 4% | 348 |
| UT | 60% | 31% | 6% | 3% | 217 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| CA | 61% | 26% | 8% | 5% | 4,757 |

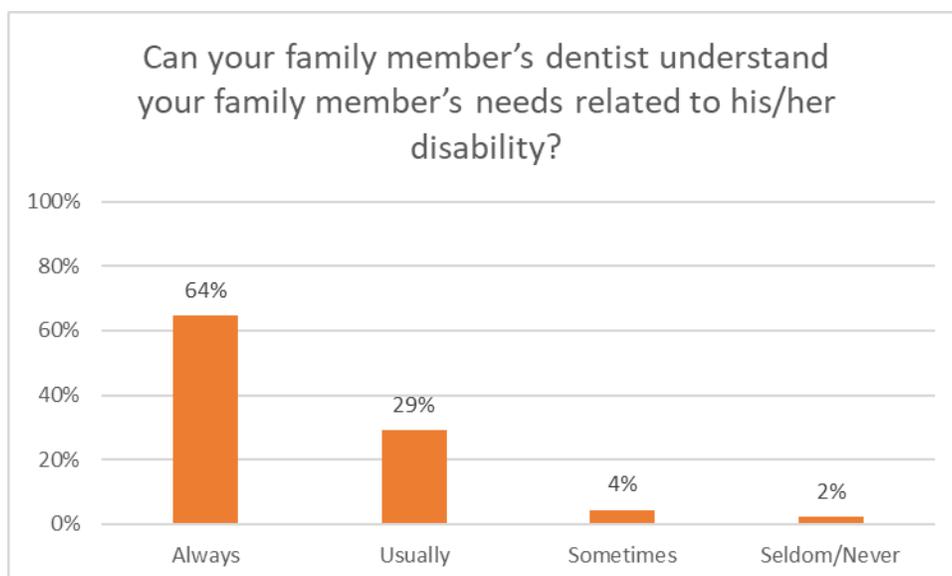


Table Q31. Can your family member's dentist understand your family member's needs related to his/her disability?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| PA | 70% | 26% | 3% | 1% | 515 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| MD | 68% | 27% | 3% | 2% | 290 |
| SD | 67% | 29% | 3% | 1% | 549 |
| FL | 67% | 24% | 7% | 2% | 308 |
| MN | 65% | 28% | 5% | 2% | 485 |
| GA | 65% | 29% | 4% | 2% | 287 |
| Weighted NCI Average | 64% | 29% | 4% | 2% | 7,270 |
| NC | 63% | 33% | 2% | 2% | 178 |
| CA | 63% | 29% | 5% | 3% | 3,940 |
| NH | 62% | 32% | 6% | 1% | 336 |
| AZ | 59% | 37% | 4% | 2% | 200 |
| UT | 56% | 34% | 6% | 4% | 182 |

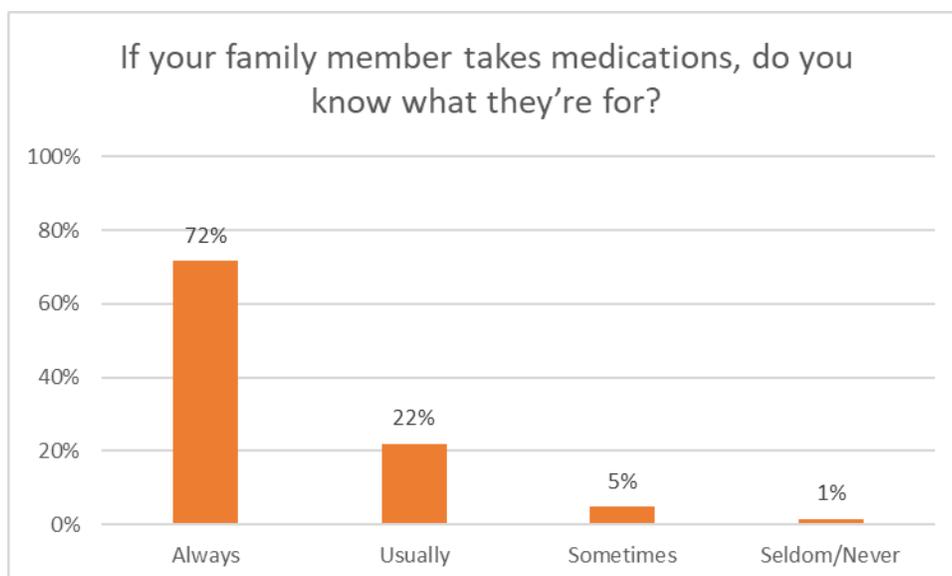


Table Q32. If your family member takes medications, do you know what they're for?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| MN | 79% | 17% | 3% | 1% | 513 |
| FL | 78% | 18% | 4% | 1% | 341 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| NH | 75% | 21% | 3% | 1% | 395 |
| AZ | 73% | 20% | 6% | 1% | 202 |
| Weighted NCI Average | 72% | 22% | 5% | 1% | 8,098 |
| CA | 71% | 21% | 6% | 2% | 4,353 |
| NC | 71% | 24% | 3% | 1% | 202 |
| GA | 69% | 26% | 3% | 2% | 339 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| PA | 66% | 27% | 6% | 1% | 606 |
| SD | 65% | 28% | 7% | 1% | 600 |
| MD | 61% | 29% | 8% | 2% | 342 |
| UT | 60% | 29% | 6% | 4% | 205 |

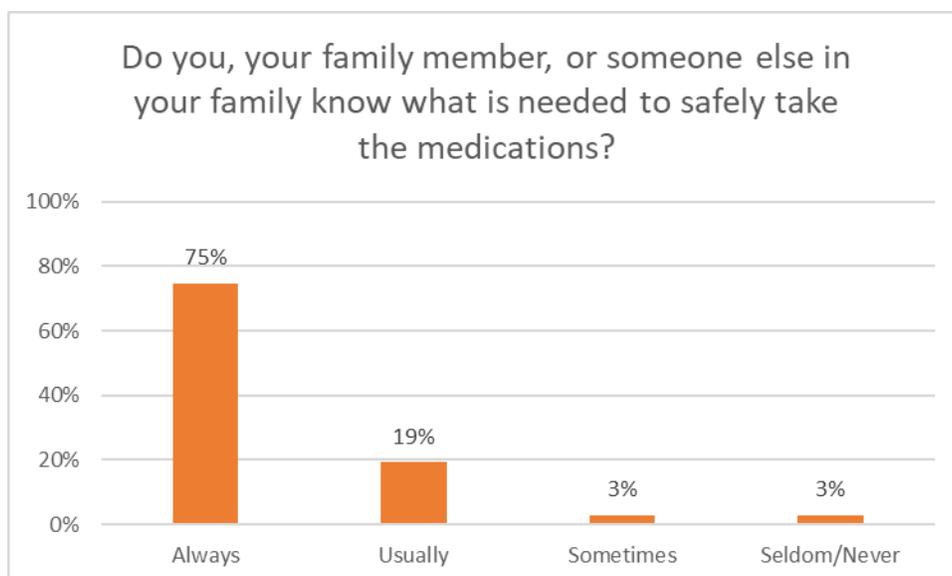


Table Q33. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 81% | 15% | 1% | 3% | 329 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| MN | 78% | 17% | 3% | 2% | 502 |
| NH | 78% | 17% | 2% | 3% | 372 |
| NC | 77% | 21% | 1% | 2% | 190 |
| GA | 75% | 19% | 3% | 3% | 318 |
| Weighted NCI Average | 75% | 19% | 3% | 3% | 7,590 |
| CA | 74% | 19% | 4% | 3% | 4,061 |
| AZ | 72% | 20% | 5% | 3% | 197 |
| PA | 71% | 21% | 4% | 4% | 547 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| SD | 69% | 25% | 3% | 3% | 571 |
| MD | 68% | 23% | 6% | 4% | 308 |
| UT | 62% | 29% | 6% | 4% | 195 |

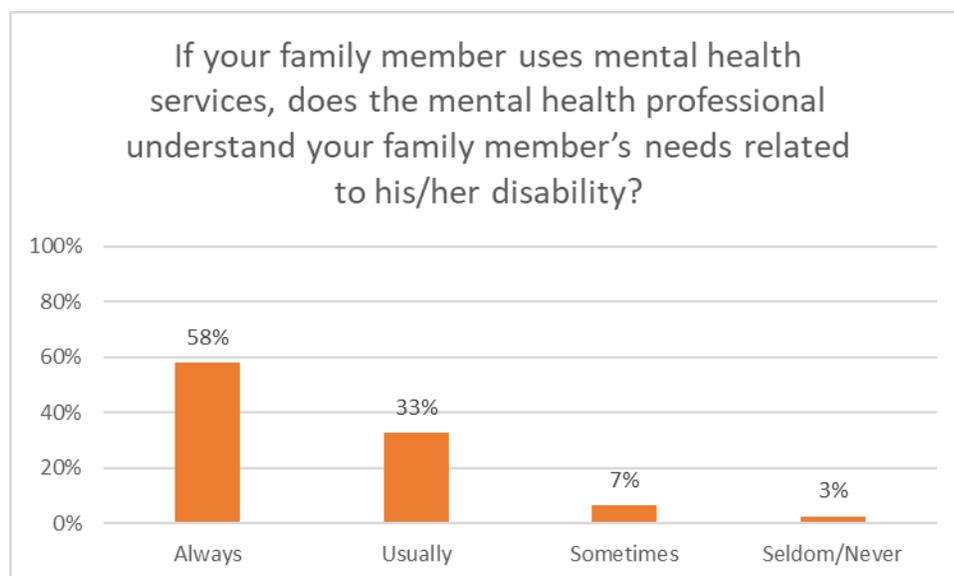


Table Q34. If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 72% | 25% | 2% | 1% | 209 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| MN | 62% | 32% | 5% | 2% | 299 |
| SD | 58% | 32% | 7% | 2% | 336 |
| Weighted NCI Average | 58% | 33% | 7% | 3% | 4,592 |
| MD | 58% | 30% | 10% | 2% | 206 |
| PA | 58% | 33% | 7% | 2% | 416 |
| GA | 57% | 34% | 5% | 3% | 206 |
| AZ | 56% | 34% | 7% | 2% | 122 |
| NC | 54% | 37% | 6% | 3% | 144 |
| UT | 54% | 34% | 7% | 5% | 109 |
| CA | 53% | 33% | 9% | 4% | 2,342 |
| NH | 51% | 40% | 6% | 2% | 203 |

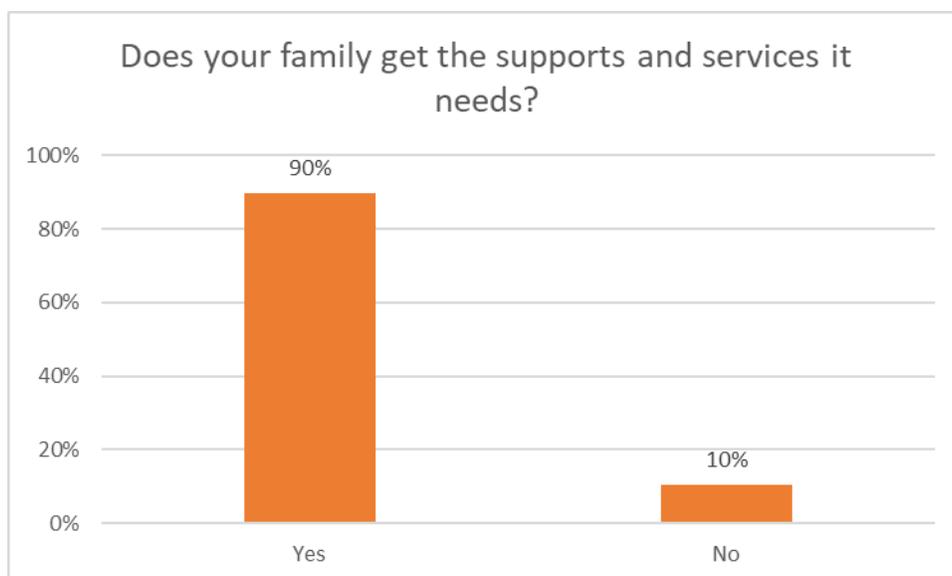


Table Q35. Does your family get the supports and services it needs?

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

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| PA | 94% | 6% | 569 |
| MN | 93% | 7% | 506 |
| SD | 93% | 7% | 593 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| MD | 93% | 7% | 310 |
| AZ | 91% | 9% | 213 |
| NC | 91% | 9% | 194 |
| FL | 90% | 10% | 332 |
| Weighted NCI Average | 90% | 10% | 7,754 |
| NH | 88% | 12% | 372 |
| UT | 87% | 13% | 197 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-------|
| CA | 86% | 14% | 4,156 |
| GA | 83% | 17% | 312 |

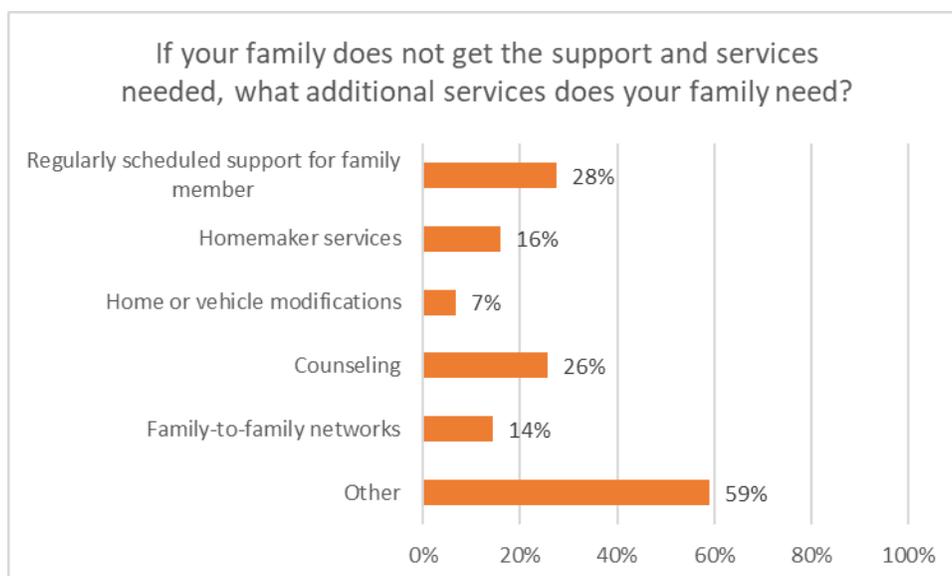


Table Q36. If your family does not get the support and services needed, what additional services does your family need?

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

| State | Regularly Scheduled Support for Family Member | Homemaker Services | Home or Vehicle Modifications | Counseling | Family-to-family Networks | Other |
|-----------------------------|---|--------------------|-------------------------------|------------|---------------------------|------------|
| AZ | n/a | n/a | n/a | n/a | n/a | n/a |
| CA | 31% | 20% | 8% | 36% | 15% | 56% |
| FL | 19% | 15% | 12% | 0% | 0% | 81% |
| GA | 29% | 7% | 7% | 31% | 13% | 64% |
| MD | n/a | n/a | n/a | n/a | n/a | n/a |
| MN | 19% | 19% | 0% | 19% | 6% | 66% |
| NH | 46% | 8% | 3% | 22% | 5% | 62% |
| NC | n/a | n/a | n/a | n/a | n/a | n/a |
| PA | 9% | 18% | 14% | 32% | 18% | 55% |
| SD | 32% | 32% | 0% | 32% | 13% | 42% |
| UT | 31% | 12% | 12% | 42% | 27% | 35% |
| Weighted NCI Average | 28% | 16% | 7% | 26% | 14% | 59% |

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.

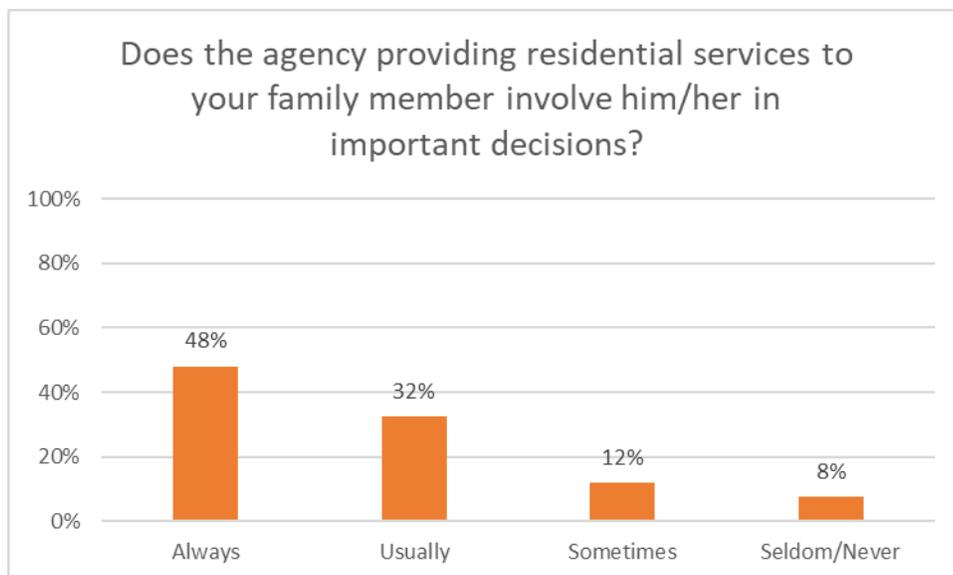


Table Q37. Does the agency providing residential services to your family member involve him/her in important decisions?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 60% | 21% | 12% | 8% | 305 |
| MN | 57% | 33% | 7% | 3% | 492 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|------------|-----------------|--------------|
| CA | 49% | 32% | 10% | 9% | 3,606 |
| NH | 49% | 36% | 10% | 5% | 351 |
| Weighted NCI Average | 48% | 32% | 12% | 8% | 6,937 |
| SD | 48% | 41% | 7% | 4% | 510 |
| MD | 46% | 33% | 12% | 9% | 307 |
| UT | 45% | 38% | 10% | 7% | 193 |
| NC | 40% | 37% | 16% | 6% | 178 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| PA | 41% | 36% | 13% | 10% | 521 |
| GA | 38% | 32% | 17% | 12% | 285 |
| AZ | 36% | 35% | 15% | 14% | 189 |

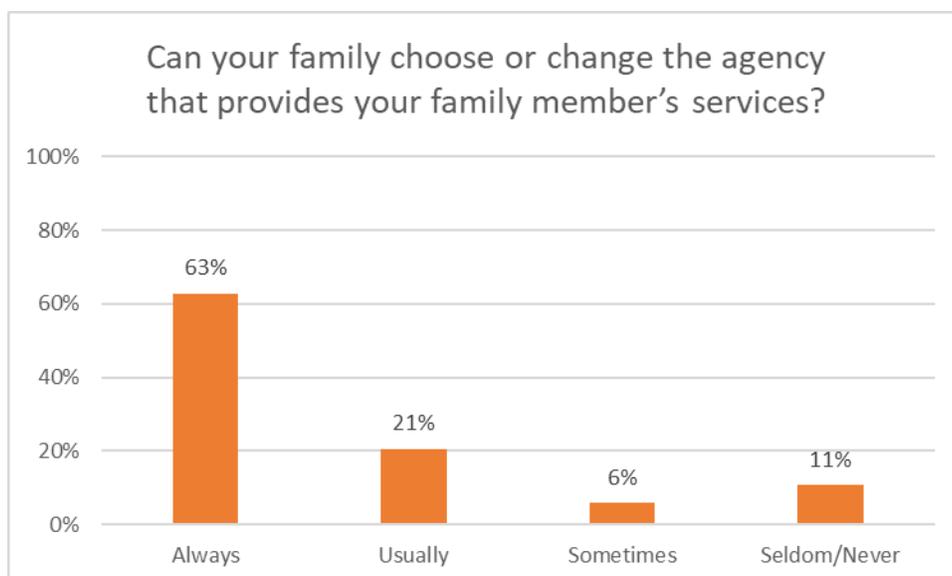


Table Q38. Can your family choose or change the agency that provides your family member's services?

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

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 76% | 12% | 5% | 7% | 282 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| UT | 70% | 20% | 7% | 3% | 183 |
| MN | 67% | 22% | 4% | 7% | 410 |
| NH | 67% | 20% | 4% | 10% | 273 |
| NC | 64% | 20% | 6% | 9% | 149 |
| SD | 63% | 21% | 4% | 12% | 430 |
| Weighted NCI Average | 63% | 21% | 6% | 11% | 5,145 |
| PA | 60% | 21% | 7% | 12% | 329 |
| GA | 59% | 24% | 6% | 10% | 249 |
| MD | 59% | 20% | 7% | 15% | 217 |
| AZ | 54% | 28% | 6% | 12% | 154 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-------|
| CA | 53% | 23% | 7% | 16% | 2,469 |

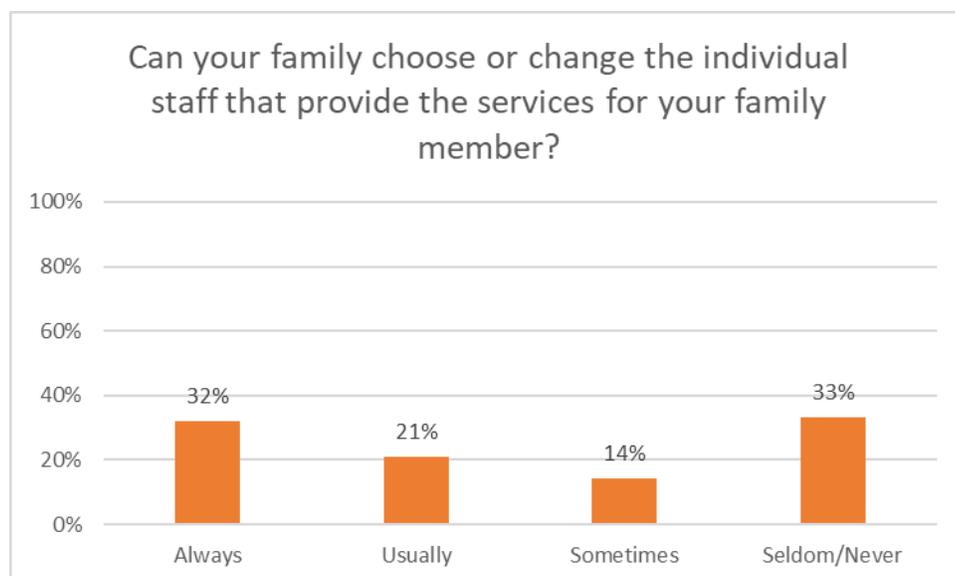


Table Q39. Can your family choose or change the individual staff that provide the services for your family member?

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 | 54% | 17% | 9% | 19% | 272 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|------------|-----------------|--------------|
| NH | 39% | 26% | 12% | 23% | 287 |
| CA | 33% | 24% | 14% | 29% | 2,722 |
| Weighted NCI Average | 32% | 21% | 14% | 33% | 5,303 |
| SD | 31% | 19% | 11% | 39% | 390 |
| NC | 29% | 25% | 14% | 32% | 142 |
| AZ | 27% | 22% | 14% | 37% | 153 |
| MN | 26% | 21% | 16% | 36% | 403 |
| GA | 25% | 19% | 18% | 38% | 229 |
| UT | 24% | 22% | 15% | 38% | 156 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| PA | 22% | 16% | 18% | 45% | 341 |
| MD | 16% | 13% | 16% | 55% | 208 |

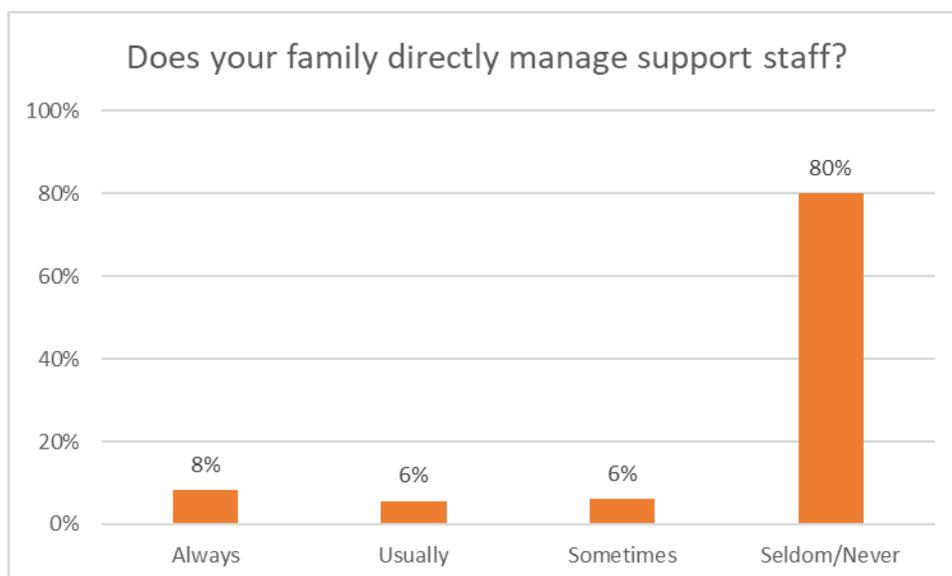


Table Q40. Does your family directly manage support staff?

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 23% | 10% | 10% | 57% | 257 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|-----------|-----------|-----------|-----------------|--------------|
| NH | 11% | 4% | 6% | 79% | 316 |
| MN | 9% | 4% | 6% | 81% | 398 |
| CA | 9% | 7% | 9% | 76% | 3,139 |
| Weighted NCI Average | 8% | 6% | 6% | 80% | 6,109 |
| GA | 7% | 5% | 3% | 85% | 259 |
| SD | 7% | 5% | 4% | 85% | 447 |
| NC | 5% | 6% | 4% | 85% | 143 |

Significantly Below Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| AZ | 4% | 3% | 7% | 86% | 155 |
| UT | 3% | 5% | 3% | 89% | 169 |
| PA | 2% | 2% | 2% | 94% | 544 |
| MD | 2% | 2% | 4% | 92% | 282 |

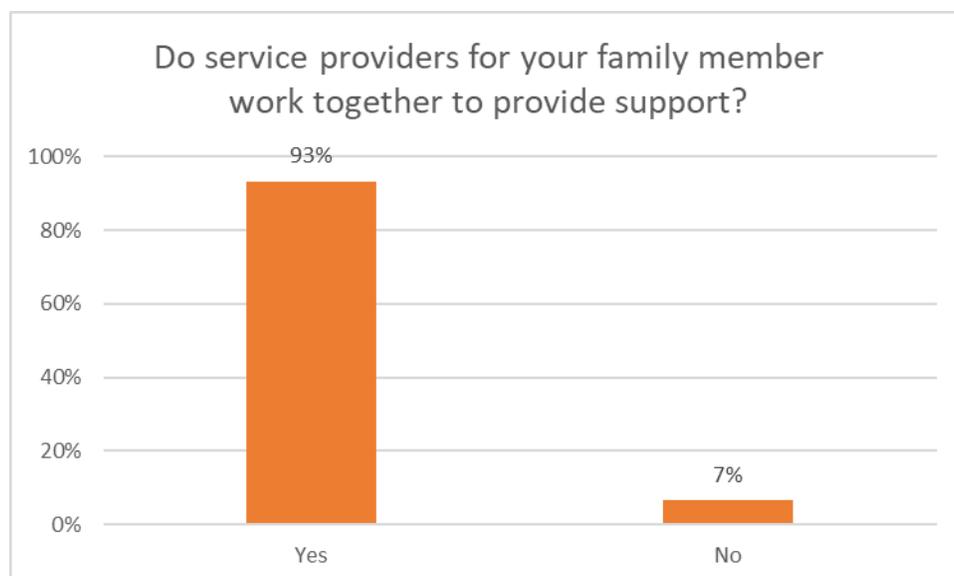


Table Q41. Do service providers for your family member work together to provide support?

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

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| UT | 97% | 3% | 171 |
| PA | 96% | 4% | 449 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|-----------|--------------|
| SD | 96% | 4% | 466 |
| NH | 95% | 5% | 297 |
| GA | 95% | 5% | 253 |
| FL | 95% | 5% | 282 |
| MN | 94% | 6% | 443 |
| Weighted NCI Average | 93% | 7% | 6,225 |
| AZ | 93% | 7% | 159 |
| NC | 93% | 7% | 149 |
| MD | 92% | 8% | 258 |
| CA | 91% | 9% | 3,298 |

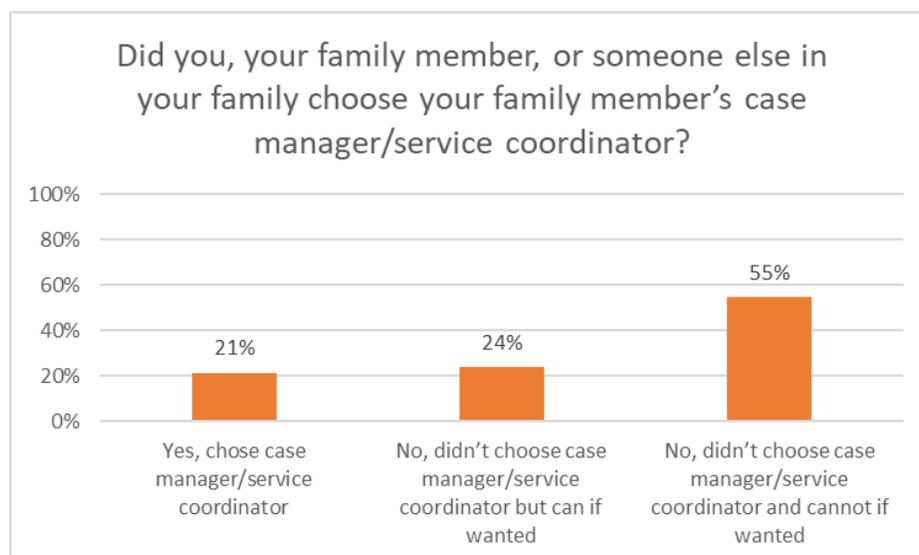


Table Q42. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

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 | 71% | 23% | 6% | 337 |
| UT | 58% | 35% | 8% | 193 |
| SD | 40% | 45% | 15% | 571 |
| NH | 28% | 59% | 13% | 359 |

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 |
|-----------------------------|---|---|--|--------------|
| Weighted NCI Average | 21% | 55% | 24% | 7,198 |
| MD | 17% | 49% | 34% | 302 |

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 |
|-------|---|---|--|-------|
| GA | 15% | 52% | 32% | 305 |
| PA | 14% | 54% | 32% | 501 |
| AZ | 11% | 71% | 18% | 202 |
| CA | 9% | 65% | 25% | 3,802 |
| MN | 9% | 65% | 26% | 460 |
| NC | 8% | 58% | 33% | 166 |

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.

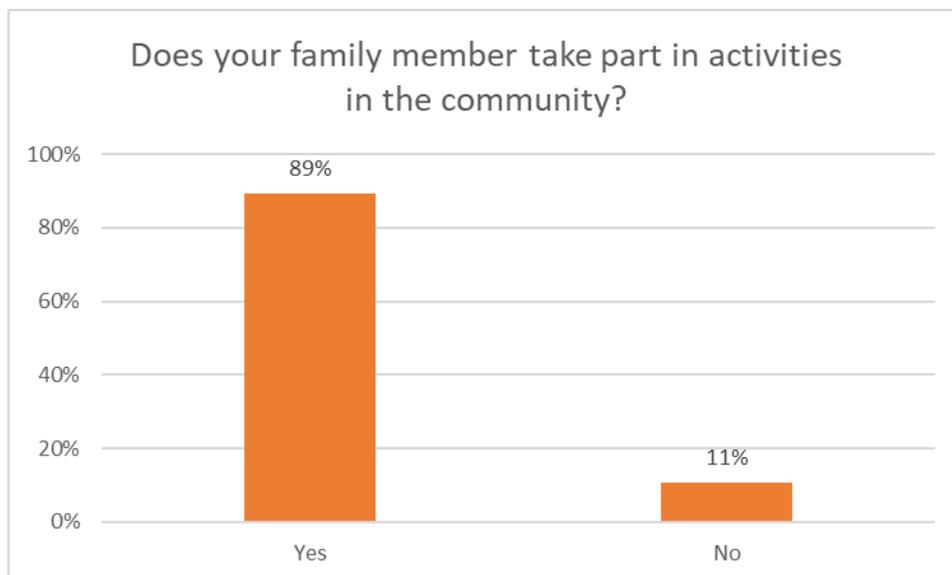


Table Q43. Does your family member take part in activities in the community?

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

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| MN | 94% | 6% | 538 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| NC | 93% | 7% | 205 |
| UT | 92% | 8% | 219 |
| SD | 92% | 8% | 626 |
| PA | 92% | 8% | 637 |
| GA | 90% | 10% | 354 |
| FL | 89% | 11% | 340 |
| NH | 89% | 11% | 403 |
| Weighted NCI Average | 89% | 11% | 8,618 |
| MD | 87% | 13% | 359 |
| AZ | 86% | 14% | 220 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-------|
| CA | 85% | 15% | 4,717 |

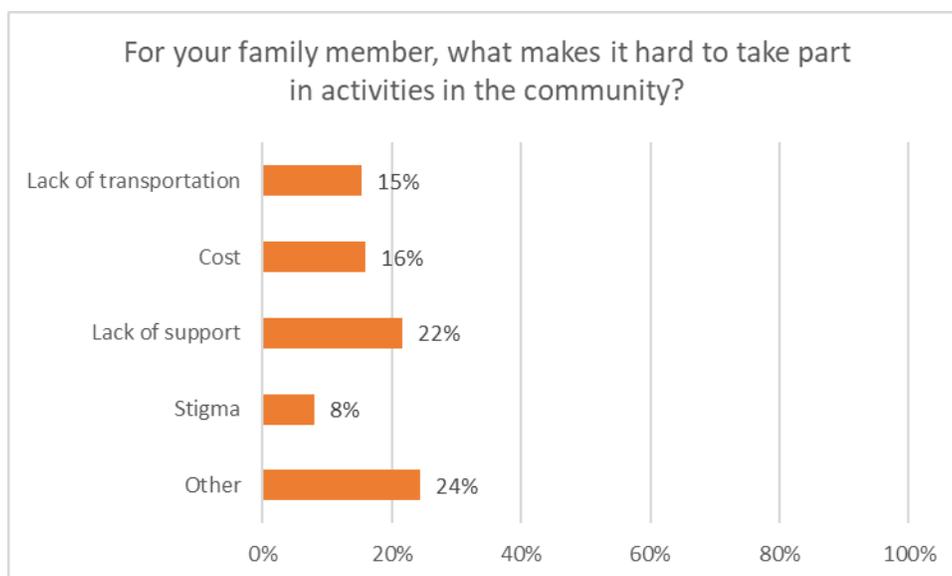


Table Q44. For your family member, what makes it hard to take part in activities in the community?

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 | 14% | 13% | 22% | 11% | 27% |
| CA | 21% | 20% | 17% | 10% | 25% |
| FL | 11% | 15% | 15% | 6% | 25% |
| GA | 13% | 16% | 23% | 9% | 22% |
| MD | 15% | 11% | 31% | 7% | 26% |
| MN | 21% | 17% | 35% | 7% | 18% |
| NH | 18% | 22% | 20% | 6% | 25% |
| NC | 8% | 14% | 20% | 7% | 23% |
| PA | 8% | 7% | 17% | 7% | 29% |
| SD | 21% | 20% | 33% | 5% | 21% |
| UT | 21% | 19% | 32% | 9% | 27% |
| Weighted NCI Average | 15% | 16% | 22% | 8% | 24% |

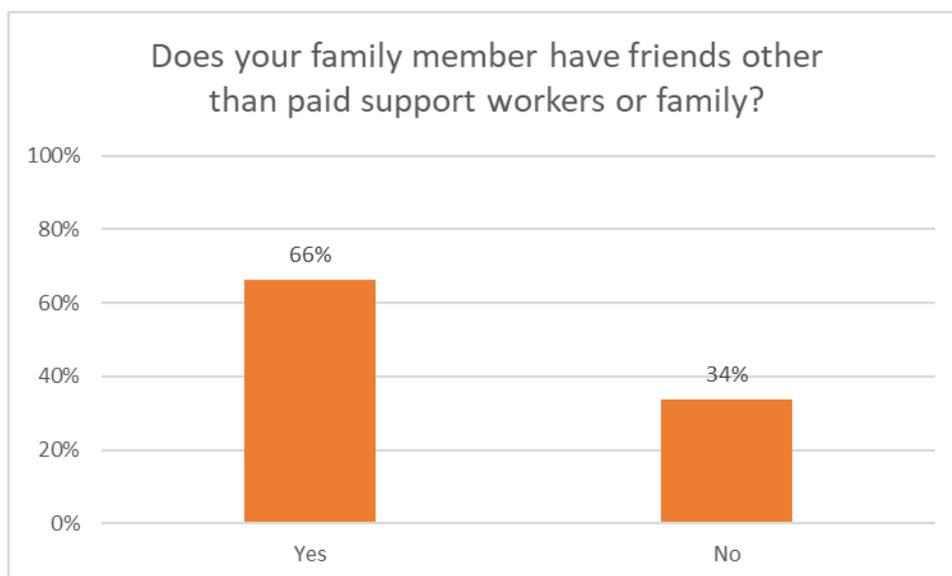


Table Q45. Does your family member have friends other than paid support workers or family?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| SD | 77% | 23% | 588 |
| MN | 77% | 23% | 518 |
| GA | 75% | 25% | 333 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| NH | 69% | 31% | 391 |
| FL | 69% | 31% | 337 |
| UT | 67% | 33% | 207 |
| MD | 67% | 33% | 335 |
| Weighted NCI Average | 66% | 34% | 8,189 |
| CA | 65% | 35% | 4,509 |
| PA | 61% | 39% | 582 |
| NC | 59% | 41% | 192 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| AZ | 57% | 43% | 197 |

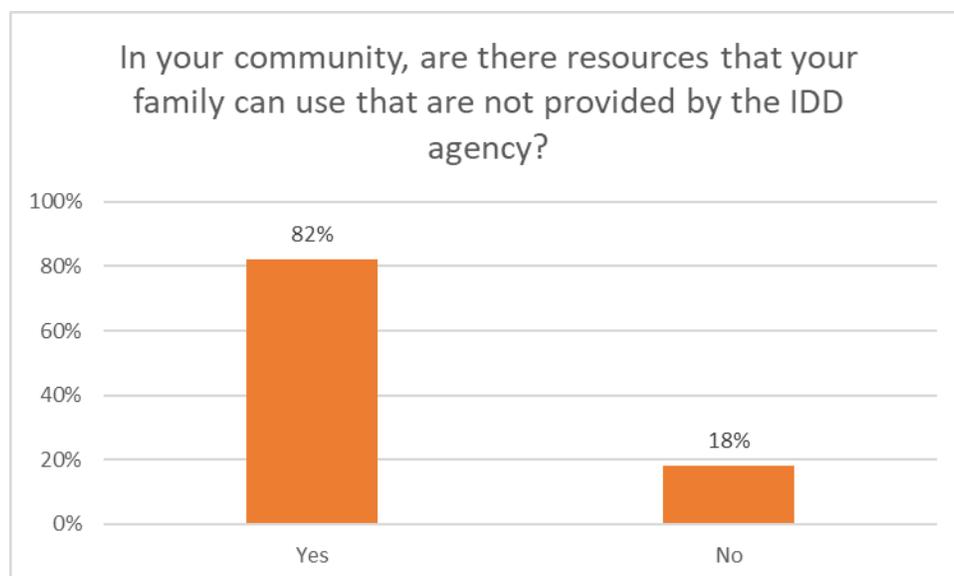


Table Q46. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

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

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| MN | 91% | 9% | 464 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| UT | 86% | 14% | 161 |
| MD | 86% | 14% | 238 |
| SD | 84% | 16% | 451 |
| FL | 84% | 16% | 255 |
| Weighted NCI Average | 82% | 18% | 5,925 |
| CA | 82% | 18% | 3,195 |
| GA | 82% | 18% | 224 |
| NH | 81% | 19% | 292 |
| PA | 79% | 21% | 356 |
| AZ | 78% | 22% | 143 |
| NC | 73% | 27% | 146 |

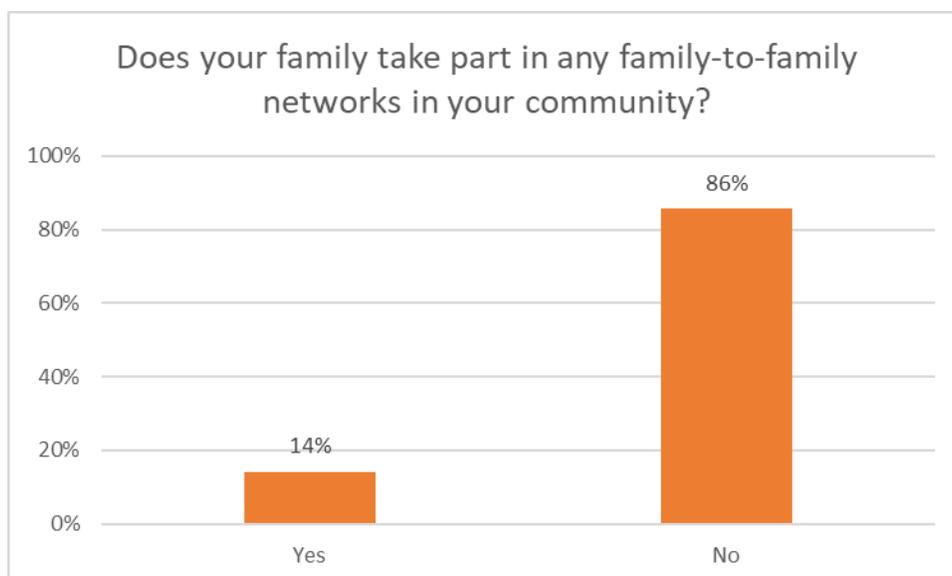


Table Q47. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?

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

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| SD | 18% | 82% | 521 |
| MD | 18% | 82% | 311 |
| GA | 17% | 83% | 291 |
| FL | 16% | 84% | 297 |
| NC | 15% | 85% | 173 |
| Weighted NCI Average | 14% | 86% | 7,680 |
| CA | 14% | 86% | 4,354 |
| MN | 14% | 86% | 465 |
| PA | 12% | 88% | 532 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| NH | 9% | 91% | 356 |
| AZ | 9% | 91% | 194 |
| UT | 9% | 91% | 186 |

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.

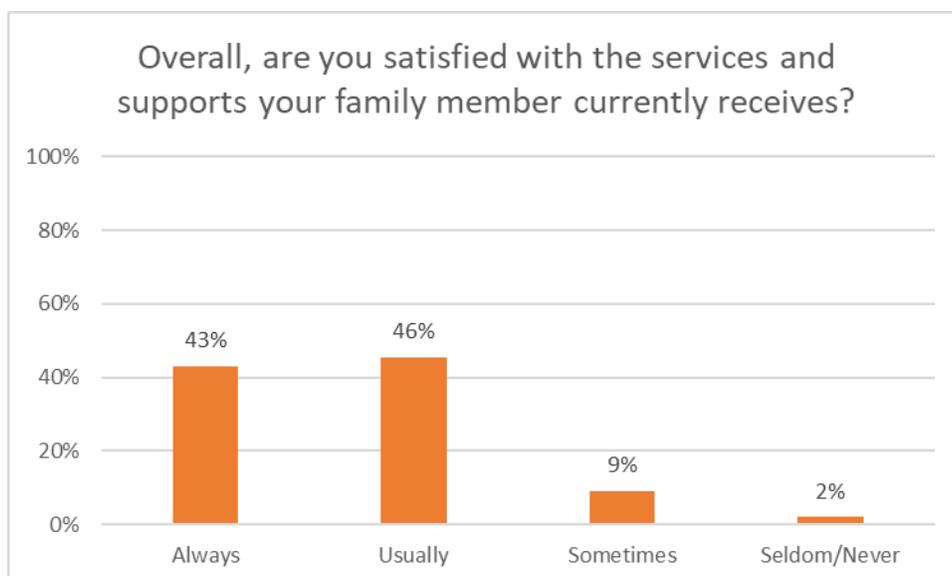


Table Q48. Overall, are you satisfied with the services and supports your family member currently receives?

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

Significantly Above Average

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-------|--------|---------|-----------|-----------------|-----|
| FL | 57% | 34% | 8% | 1% | 355 |

Within Average Range

| State | Always | Usually | Sometimes | Seldom or Never | N |
|-----------------------------|------------|------------|-----------|-----------------|--------------|
| NH | 44% | 43% | 10% | 3% | 421 |
| PA | 44% | 46% | 9% | 1% | 646 |
| MN | 43% | 48% | 8% | 1% | 547 |
| Weighted NCI Average | 43% | 46% | 9% | 2% | 8,994 |
| NC | 42% | 48% | 7% | 2% | 206 |
| SD | 41% | 50% | 7% | 2% | 648 |
| CA | 41% | 46% | 10% | 3% | 4,994 |
| GA | 38% | 47% | 11% | 4% | 358 |
| AZ | 37% | 51% | 11% | 1% | 223 |
| MD | 37% | 47% | 13% | 3% | 371 |
| UT | 37% | 54% | 8% | 1% | 225 |

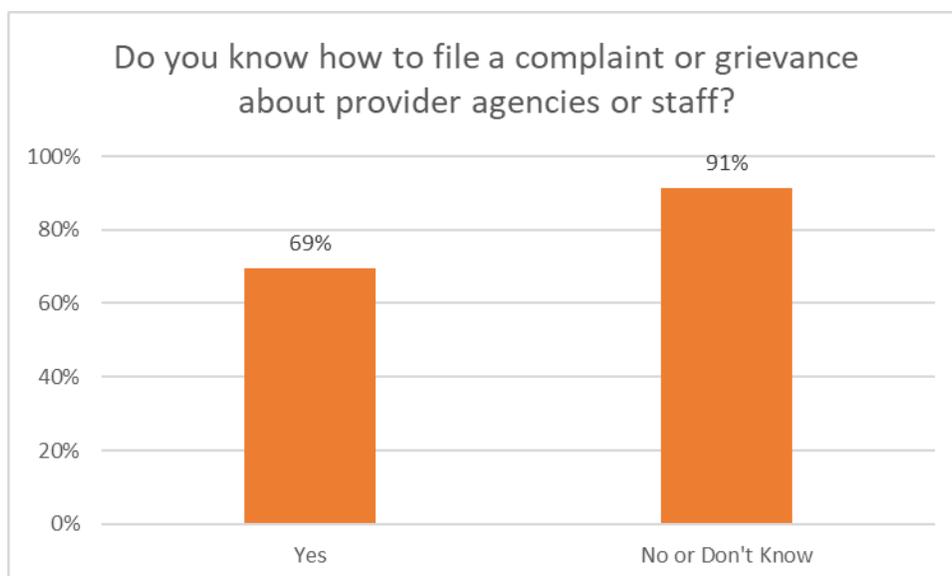


Table Q49. Do you know how to file a complaint or grievance about provider agencies or staff?¹²

Significantly Above Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-----|
| NC | 84% | 16% | 206 |
| FL | 82% | 18% | 357 |
| MN | 79% | 21% | 549 |
| NH | 78% | 22% | 420 |
| SD | 77% | 23% | 650 |

Within Average Range

| State | Yes | No or Don't Know | N |
|-----------------------------|------------|------------------|--------------|
| AZ | 71% | 29% | 222 |
| Weighted NCI Average | 69% | 31% | 9,106 |
| PA | 68% | 32% | 657 |
| UT | 68% | 32% | 222 |
| GA | 63% | 37% | 365 |

Significantly Below Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-------|
| MD | 58% | 42% | 368 |
| CA | 54% | 46% | 5,090 |

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

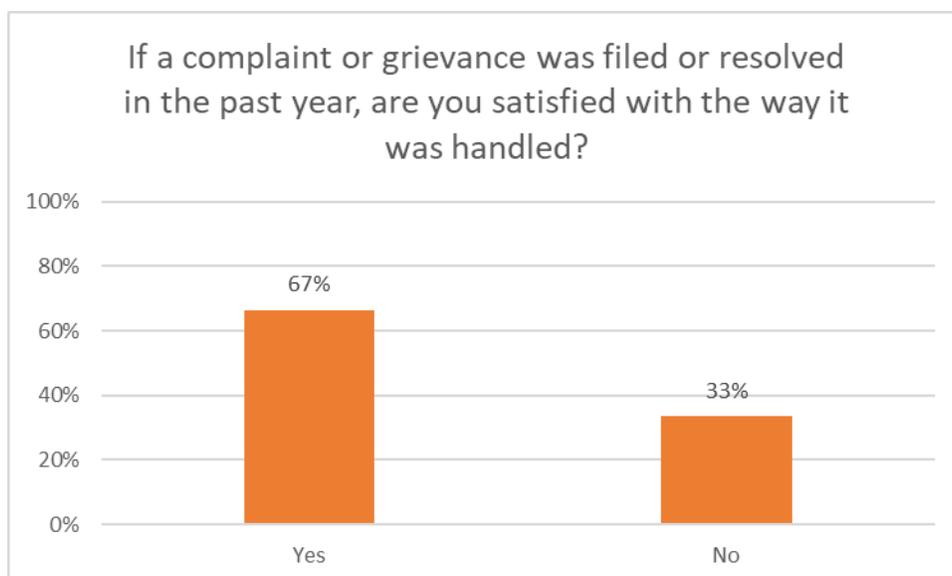


Table Q50. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| UT | 85% | 15% | 27 |
| NC | 83% | 17% | 29 |
| NH | 76% | 24% | 62 |
| FL | 70% | 30% | 40 |
| AZ | 68% | 32% | 22 |
| Weighted NCI Average | 67% | 33% | 1,027 |
| SD | 65% | 35% | 92 |
| MN | 63% | 37% | 60 |
| MD | 63% | 37% | 57 |
| PA | 62% | 38% | 102 |
| GA | 60% | 40% | 47 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| CA | 56% | 44% | 489 |

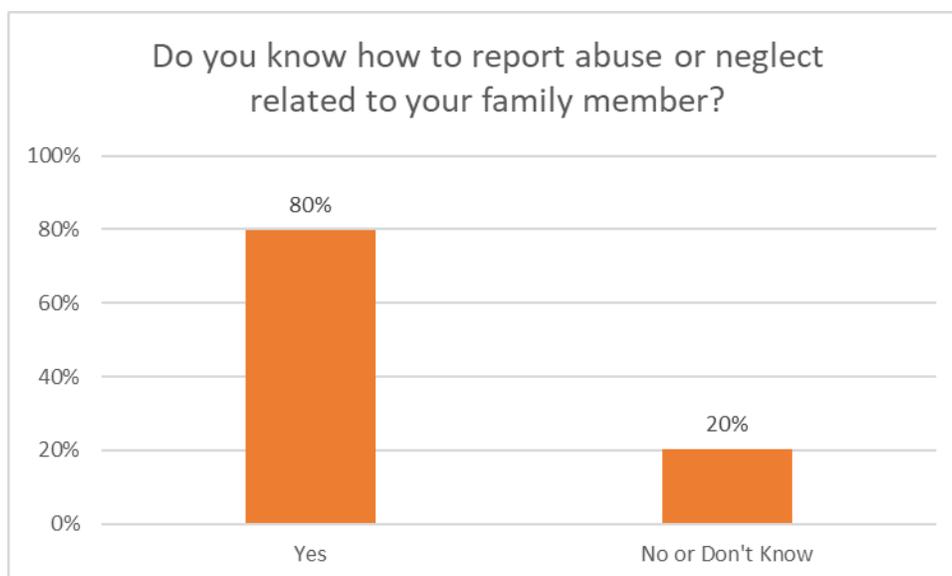


Table Q51. Do you know how to report abuse or neglect related to your family member?¹³

Significantly Above Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-----|
| NC | 93% | 7% | 207 |
| MN | 91% | 9% | 549 |
| FL | 90% | 10% | 363 |
| SD | 87% | 13% | 640 |

Within Average Range

| State | Yes | No or Don't Know | N |
|-----------------------------|------------|------------------|--------------|
| NH | 84% | 16% | 419 |
| Weighted NCI Average | 80% | 20% | 9,130 |
| AZ | 79% | 21% | 221 |
| UT | 78% | 22% | 223 |

Significantly Below Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-------|
| PA | 75% | 25% | 656 |
| GA | 72% | 28% | 363 |
| CA | 69% | 31% | 5,110 |
| MD | 69% | 31% | 379 |

¹³ 'Don't Know' responses were included in 'No' responses for this question.

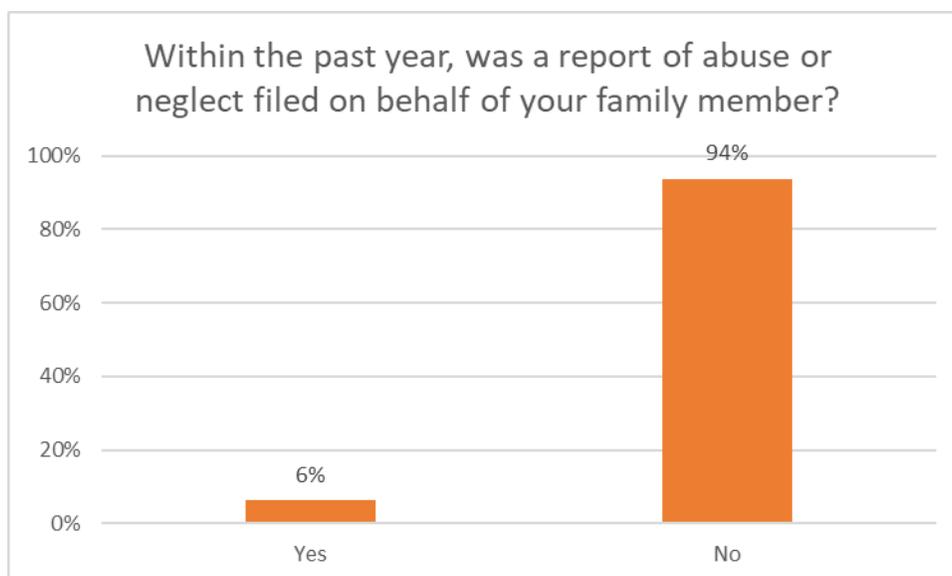


Table Q52. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| PA | 11% | 89% | 615 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|-----------|------------|--------------|
| GA | 10% | 90% | 352 |
| MN | 8% | 92% | 536 |
| MD | 7% | 93% | 358 |
| AZ | 7% | 93% | 219 |
| NH | 7% | 93% | 410 |
| Weighted NCI Average | 6% | 94% | 8,724 |
| NC | 6% | 94% | 198 |
| FL | 6% | 94% | 348 |
| SD | 6% | 94% | 629 |
| UT | 5% | 95% | 218 |

Significantly Below Average

| State | Yes | No or Don't Know | N |
|-------|-----|------------------|-------|
| CA | 4% | 96% | 4,841 |

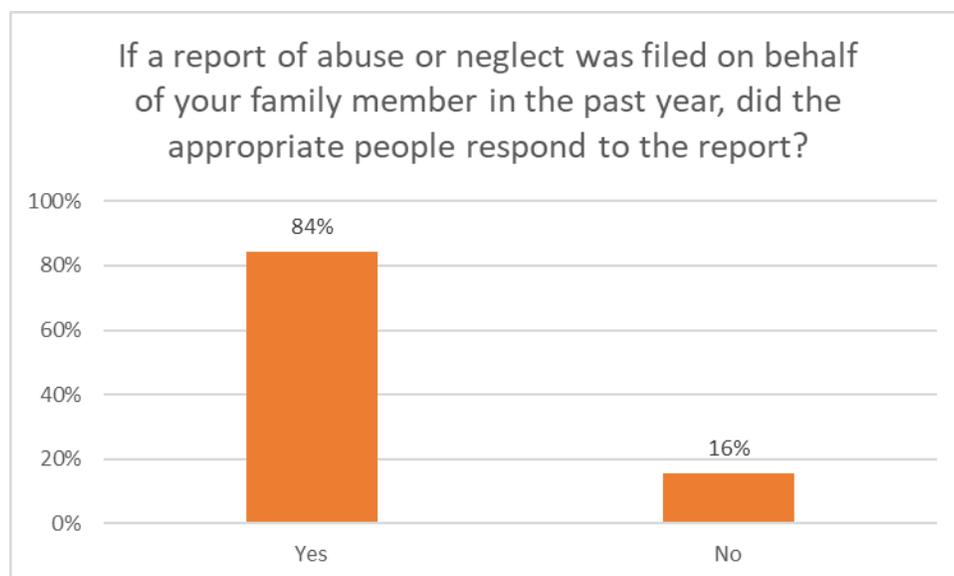


Table Q53. If a report of abuse or neglect was filed on behalf of your family member in the past year, did the appropriate people respond to the report?¹⁴

Within Average Range

| State | Yes | No | N |
|-------|-----|----|----|
| NH | 96% | 4% | 24 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|------------|
| CA | 86% | 14% | 134 |
| GA | 86% | 14% | 28 |
| Weighted NCI Average | 84% | 16% | 365 |
| MN | 84% | 16% | 37 |
| PA | 83% | 17% | 48 |
| SD | 82% | 18% | 28 |

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, FL, MD, NC, UT

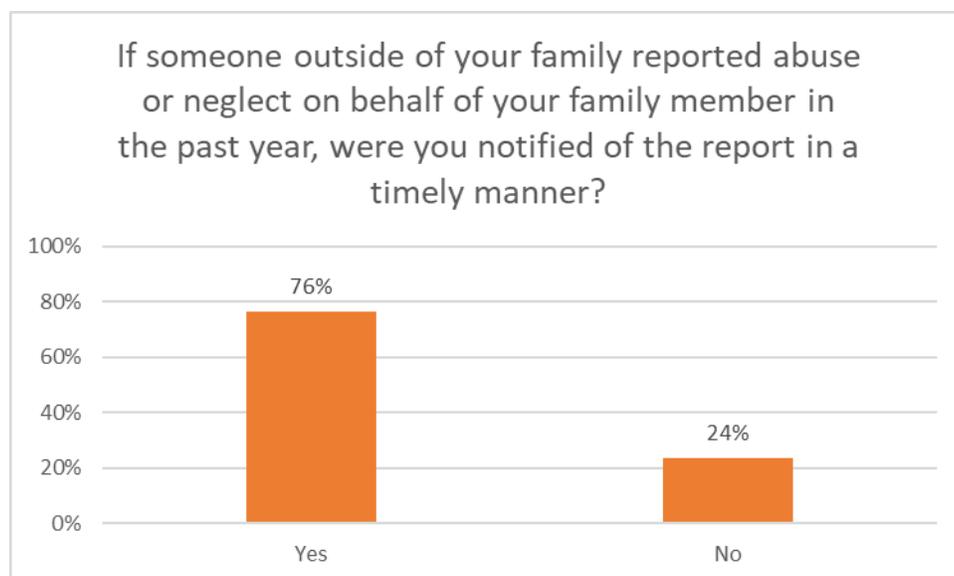


Table Q54. If someone outside of your family reported abuse or neglect on behalf of your family member in the past year, were you notified of the report in a timely manner? ¹⁵

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|------------|
| NH | 91% | 9% | 23 |
| PA | 83% | 17% | 48 |
| MN | 82% | 18% | 33 |
| SD | 77% | 23% | 26 |
| Weighted NCI Average | 76% | 24% | 337 |
| GA | 75% | 25% | 28 |

Significantly Below Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| CA | 64% | 36% | 118 |

¹⁵ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, FL, MD, NC, UT

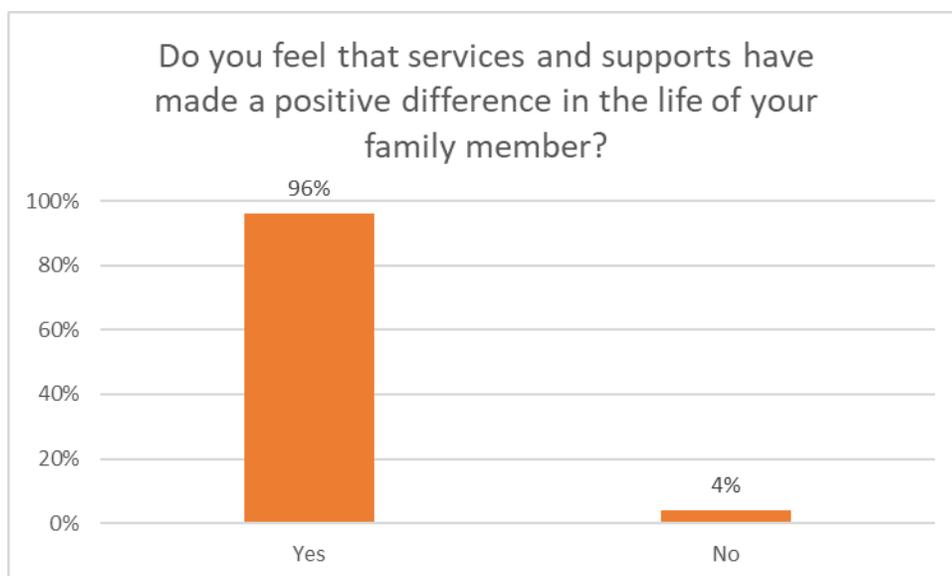


Table Q55. Do you feel that services and supports have made a positive difference in the life of your family member?

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

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|-----------|--------------|
| AZ | 98% | 2% | 211 |
| FL | 97% | 3% | 329 |
| MN | 97% | 3% | 524 |
| NC | 97% | 3% | 201 |
| UT | 96% | 4% | 217 |
| Weighted NCI Average | 96% | 4% | 8,500 |
| GA | 96% | 4% | 339 |
| PA | 95% | 5% | 620 |
| CA | 95% | 5% | 4,693 |
| SD | 95% | 5% | 608 |
| NH | 95% | 5% | 406 |
| MD | 93% | 7% | 352 |

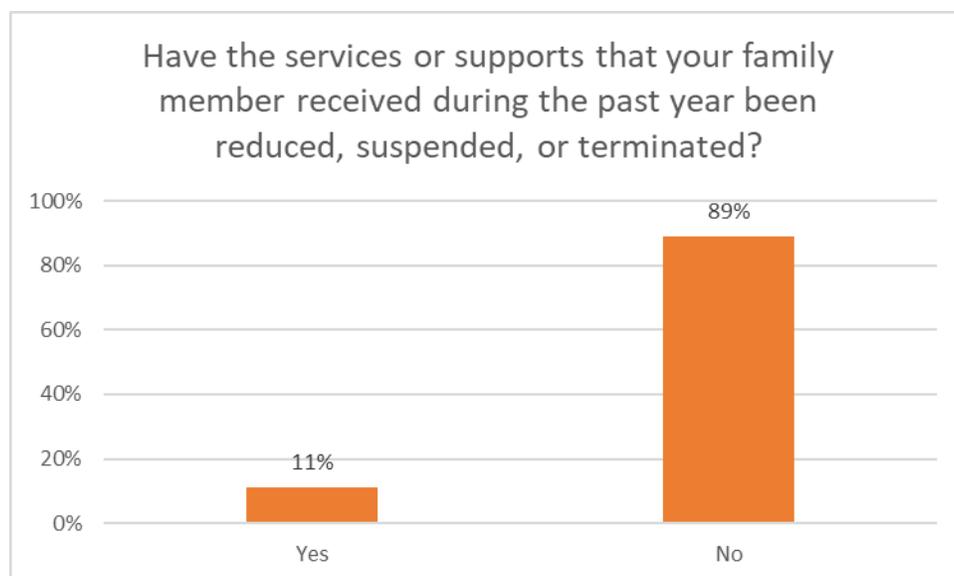


Table Q56. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

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

Significantly Above Average

| State | Yes | No | N |
|-------|-----|-----|-----|
| SD | 21% | 79% | 570 |
| FL | 17% | 83% | 318 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| MD | 14% | 86% | 333 |
| GA | 12% | 88% | 314 |
| CA | 11% | 89% | 4,280 |
| Weighted NCI Average | 11% | 89% | 7,891 |
| PA | 9% | 91% | 572 |
| NC | 9% | 91% | 187 |
| NH | 9% | 91% | 390 |
| MN | 9% | 91% | 522 |
| AZ | 8% | 92% | 206 |
| UT | 7% | 93% | 199 |

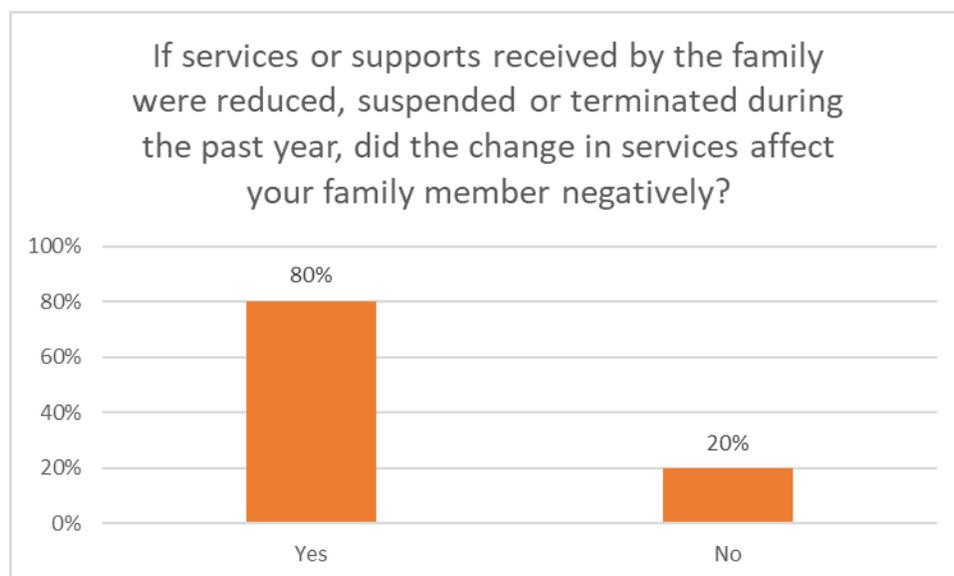


Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?¹⁶

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

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|------------|
| FL | 84% | 16% | 45 |
| Weighted NCI Average | 80% | 20% | 758 |
| MD | 79% | 21% | 38 |
| CA | 79% | 21% | 403 |
| SD | 78% | 22% | 95 |
| GA | 78% | 22% | 27 |
| NH | 78% | 22% | 27 |
| MN | 72% | 28% | 39 |
| PA | 64% | 36% | 42 |

¹⁶ The following states are not included in the table due to low N (>20), but their responses are included in the NCI Average: AZ, NC, UT

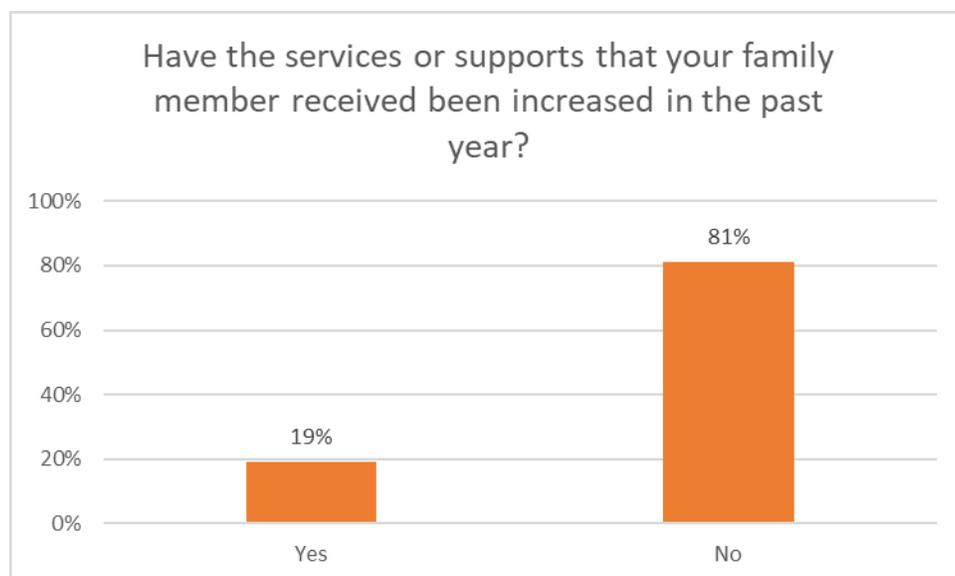


Table Q58. Have the services or supports that your family member received been increased in the past year?

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

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|------------|--------------|
| NC | 23% | 77% | 170 |
| PA | 21% | 79% | 433 |
| UT | 20% | 80% | 152 |
| NH | 20% | 80% | 350 |
| CA | 20% | 80% | 3,550 |
| MD | 19% | 81% | 275 |
| Weighted NCI Average | 19% | 81% | 6,631 |
| GA | 18% | 82% | 257 |
| SD | 17% | 83% | 497 |
| MN | 16% | 84% | 479 |
| FL | 15% | 85% | 282 |
| AZ | 15% | 85% | 186 |

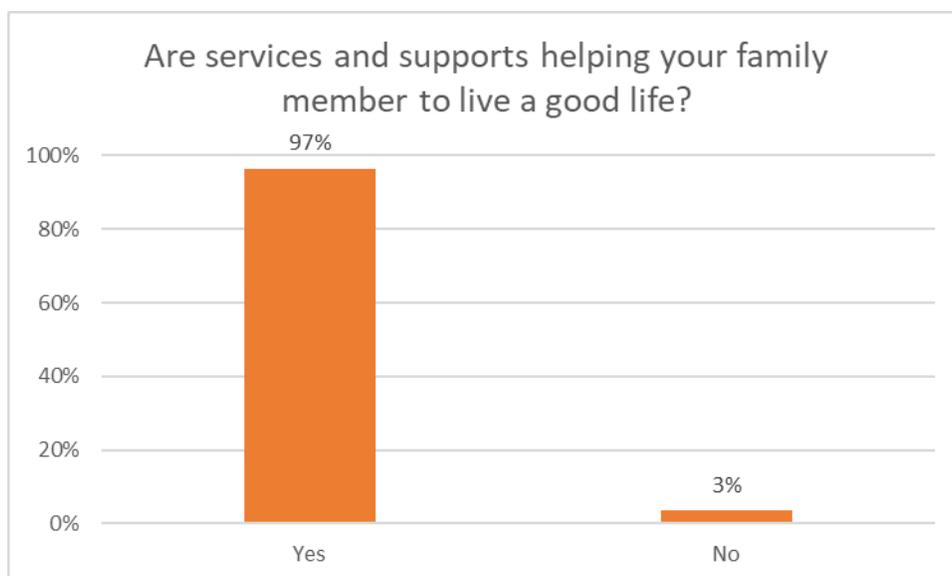


Table Q59. Are services and supports helping your family member to live a good life?

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

Significantly Above Average

| State | Yes | No | N |
|-------|-----|----|-----|
| UT | 99% | 1% | 214 |
| MN | 98% | 2% | 526 |

Within Average Range

| State | Yes | No | N |
|-----------------------------|------------|-----------|--------------|
| AZ | 98% | 2% | 200 |
| FL | 98% | 2% | 344 |
| PA | 97% | 3% | 599 |
| NC | 97% | 3% | 202 |
| Weighted NCI Average | 97% | 3% | 8,377 |
| CA | 96% | 4% | 4,612 |
| NH | 95% | 5% | 404 |
| SD | 95% | 5% | 601 |
| GA | 95% | 5% | 340 |
| MD | 95% | 5% | 335 |

NCI History and Activities

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

Overview of National Core Indicators

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

In 1997, 15 states convened to discuss the scope and content of a potential performance measurement framework. Directors and staff from these 15 states worked to identify the major domains and sub-domains of performance, indicators, measures, and data sources. The original 61 indicators, developed through a consensus process, were intended to provide a system-level “snapshot” of how well each state was performing. The states were guided by a set of criteria that was designed to select indicators that were:

1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of disability or residential setting

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

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

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

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

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

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

Sub-Domains and Concern Statements

The following table lists the sub-domains under the “Family Outcomes” domain.

Figure 2. Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI as a data source for supplemental performance measures in their home and community-based services (HCBS) waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

For more information on how to use these data for quality improvement, please see this handbook: [Using National Core Indicators for Quality Improvement Initiatives](#).¹⁷

¹⁷ Located on the National Core Indicators website: <https://www.nationalcoreindicators.org> → Resources → Technical Reports

Caution and Limitations

This report does not provide benchmarks for acceptable or unacceptable levels of performance. Rather, it is up to each state to decide whether its score or percentage is an acceptable performance level. States that fall into the “below average” tier on any scale or indicator are not necessarily underperforming; instead, this placement indicates only that the state’s scale score or indicator percentage is significantly lower than the average of all states—where “significantly” means “not due to chance.” The results tables throughout this report display states’ scores relative to one another and show which states tend to have similar results. Notably, the difference between a “below average” state and the average across the other states may be very small, and it is up to public managers, 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 where several states’ results are especially high (considerably above the average level) may indicate that some states are attaining a level of performance that could serve as a guidepost for others.

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

Methodology

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

Sampling & Administration

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

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

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys. A total of three states had at least a portion of surveys completed via direct entry for the 2019-20 data collection cycle.¹⁸

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%.¹⁹

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”

¹⁸ States that used the direct entry or mail and direct entry options were: CA, MD, NC.

¹⁹ See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

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

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

Significance Testing

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

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

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

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, and significantly below the NCI Average.

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 “always” or “yes” response compared to the NCI average²⁰; 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, 11 states administered the Family/Guardian Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The 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.

²⁰ The NCI Average is a weighted average. Please see the section “Weighting” for more details.

Figure 3. Family/Guardian Survey: State Response Rates²¹

| State | Total Population | Surveys Sent | Complete Surveys | Response Rate ²² | Margin of Error | Paper Submission | Direct Entry Submission |
|------------------------------|------------------|---------------|------------------|-----------------------------|-----------------|------------------|-------------------------|
| AZ | 4,395 | 1,400 | 225 | 16.1% | 6.36% | 100% | 0% |
| CA | 28,754 | 28,754 | 5317 | 18.5% | 1.21% | 74% | 26% |
| FL | 11,789 | 1,800 | 366 | 20.3% | 5.04% | 100% | 0% |
| GA | 3,659 | 1,700 | 374 | 22.0% | 4.80% | 100% | 0% |
| MD | 6,819 | 6,819 | 397 | 5.8% | 4.77% | 82% | 18% |
| MN | 12,091 | 1,200 | 551 | 45.9% | 4.08% | 100% | 0% |
| NH | 1,810 | 1,810 | 431 | 23.8% | 4.12% | 100% | 0% |
| NC | 14,945 | 900 | 211 | 23.4% | 6.70% | 90% | 10% |
| PA | 9,050 | 2,000 | 669 | 33.5% | 3.65% | 100% | 0% |
| SD | 1,816 | 1,800 | 667 | 37.1% | 3.02% | 100% | 0% |
| UT | 2,400 | 1,000 | 227 | 22.7% | 6.19% | 100% | 0% |
| Overall ²³ | 97,528 | 49,183 | 9,435 | 24.5% | 4.54% | 90% | 10% |

²¹ Please note: The family surveys are mail out surveys or completed online by respondents who choose to take part in the survey. As such, the final sample is a sample of convenience and cannot be considered representative of the entire service population in the state.

²² 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

²³ 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).