

Family/Guardian Survey

2015-16 Final Report

Updated: 11/26/19

Data on Table Q42 corrected. Initially reverse coded.



A Collaboration of

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



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List of Abbreviations Used in This Report

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

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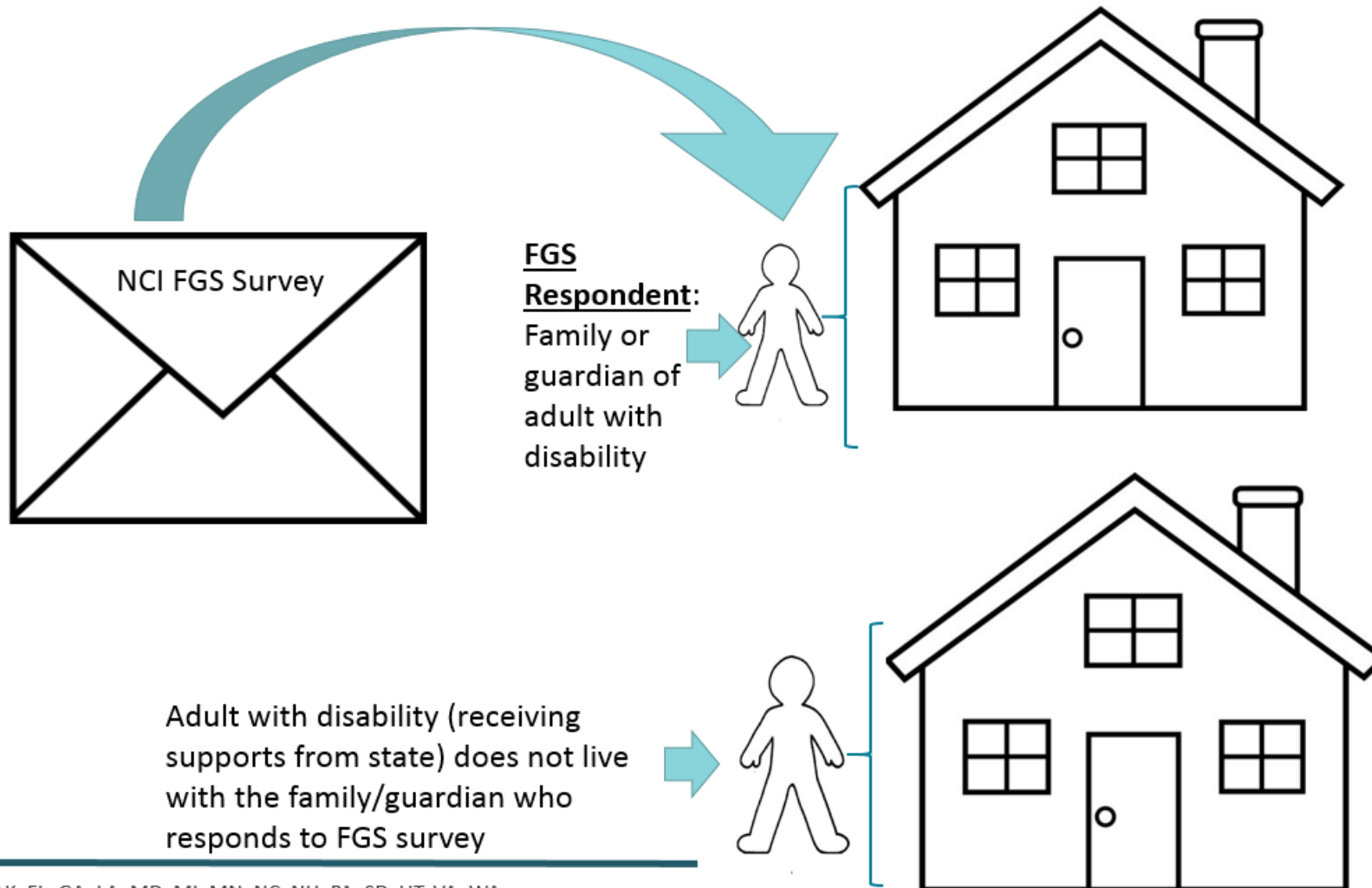
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Family/Guardian Survey Highlights

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

Respondents: families or guardians of an adult (18 years or older) with an intellectual/developmental disability. The adult with the disability should not live in the family home (with the respondent) and should receive at least one service funded by the state developmental disability agency in addition to case management.
14 states*: Total sample: 6,173



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

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

Average Age

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

46 years old

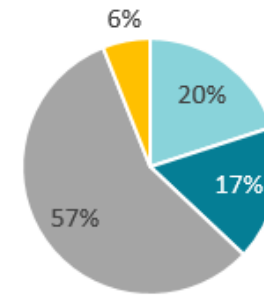
Gender Breakdown

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



■ Male ■ Female

Legal guardianship arrangement for family member with disability



■ None ■ Limited ■ Full ■ Has Guardianship - Level Is Unknown

Where do family members with disabilities live?

Group Home Setting

51%

Specialized Institutional Setting

13%

Adult Foster Care or Host Home

9%

Independent Home or Apartment

19%

Agency Owned/Operated Apartment

4%

Other

4%

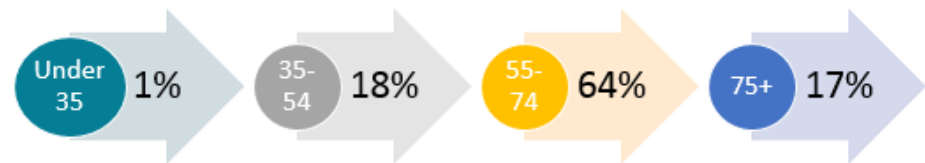
Nursing Home

1%

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



Age of respondents



Number of times per year respondent sees family member with disability

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

Information and Planning



Respondents reported...



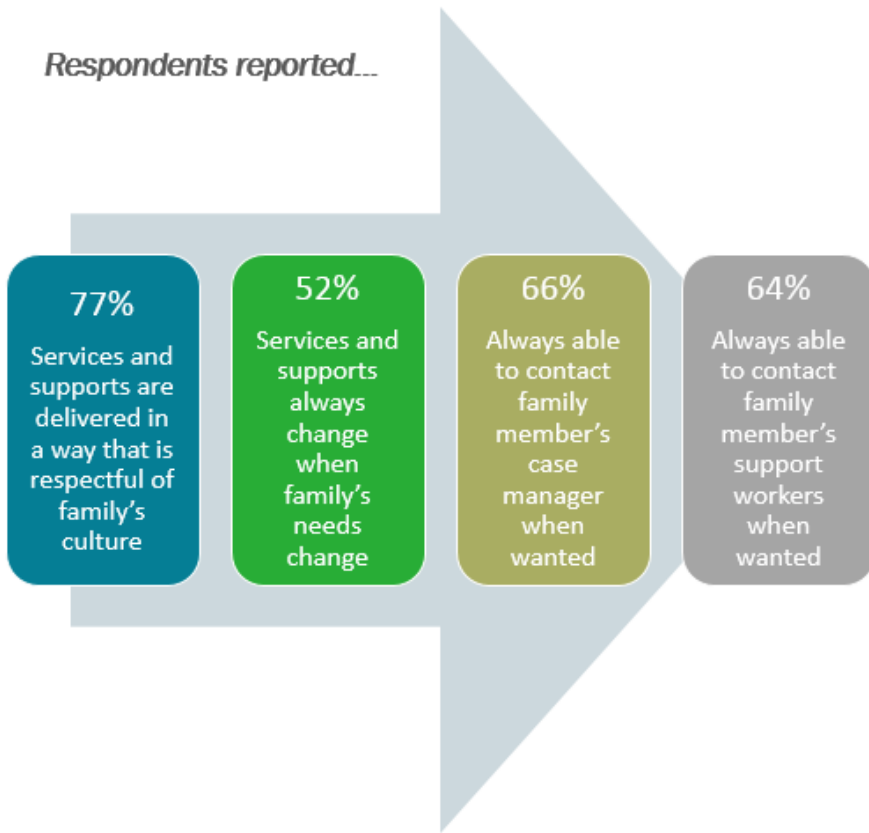
- Always receive enough information to help plan services for family member with disability



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

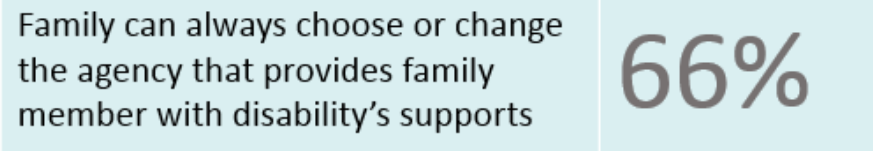
Access and Delivery of Supports and Services

Respondents reported...



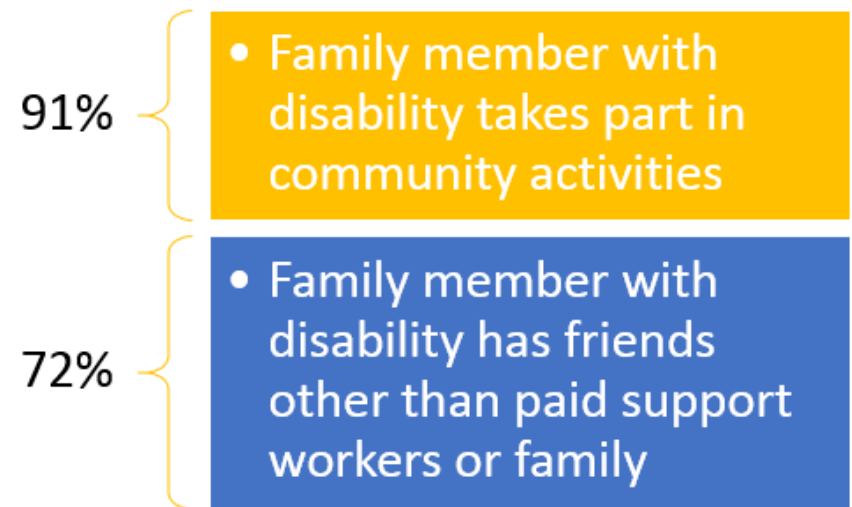
Choice, Decision-making and Control

Respondents reported...

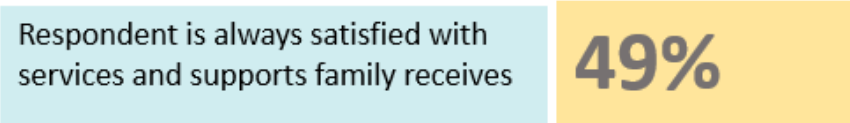


Involvement in the Community

Respondents reported...



Satisfaction with Services and Supports



I. Results

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

Survey Development

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

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

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

Organization of the Family/Guardian Survey

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

Demographics

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

Services and Supports Received

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

Questions Regarding Services and Supports

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

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

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

Presentation of Data

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

For each question, outcome results are first shown in a graph with the NCI Average and then in a table that shows a breakout of each state's percentage.

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the NCI Average, within the range of the NCI Average, and significantly below the NCI Average. Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI Average Range, their 'always' or 'yes' response was not statistically different from the NCI Average.

States are not included for a survey item if fewer than 20 people responded.

The NCI Average is the average of all individual state percentages.

Note on Significance: In some cases, a state (let's call it state A) with a lower (or higher) proportion than another state (let's call it state B) may be significantly above (or below) the NCI Average even though the other state that is further away from the NCI Average is not. This may occur because statistical significance depends in part on the sample size of the state. So, for example, when state A has a larger valid sample for the indicator than state B, state A may be significantly different from the average when state B is not, even though state B's difference from that average is larger than state A's. The larger the sample size of a state, the smaller the difference needs to be to be statistically significant.

Note:

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

“Family Member” refers to the person receiving services who the respondent is answering questions about in this survey.

Demographics

Family Member

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

Table 1. Family Member's Residence

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

Table 2. Family Member's Residential Setting

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

Table 3. Family Member's Age

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

Table 4. Family Member's Gender

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

Table 5. Family Member's Race and Ethnicity

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

Table 6. Family Member's Disabilities

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

Table 7. Family Member's Health Conditions

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

Table 8. Family Member's Preferred Means of Communication

| State | Spoken | Gestures or Body Language | Sign Language or Finger Spelling | Communication Aid or Device | Other | N |
|--------------------|------------|---------------------------|----------------------------------|-----------------------------|-----------|--------------|
| AK | 73% | 18% | 4% | 0% | 5% | 168 |
| FL | 74% | 20% | 2% | 1% | 3% | 337 |
| GA | 70% | 23% | 3% | 1% | 3% | 383 |
| LA | 62% | 27% | 2% | 1% | 8% | 391 |
| MD | 77% | 16% | 2% | 1% | 4% | 1,014 |
| MI | 74% | 17% | 2% | 1% | 5% | 499 |
| MN | 83% | 12% | 2% | 1% | 2% | 396 |
| NC | 71% | 23% | 2% | 0% | 3% | 250 |
| NH | 79% | 15% | 3% | 2% | 1% | 355 |
| PA | 70% | 24% | 1% | 1% | 4% | 408 |
| SD | 80% | 14% | 2% | 1% | 2% | 701 |
| UT | 78% | 18% | 2% | 0% | 2% | 424 |
| VA | 77% | 18% | 0% | 1% | 4% | 229 |
| WA | 79% | 15% | 3% | 0% | 3% | 394 |
| NCI Average | 75% | 19% | 2% | 1% | 3% | 5,949 |

Table 9. Family Member's Legal Guardianship Arrangement

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

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

Table 10. Guardian or Conservator Relationship to Family Member

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

Table 11. Family Member's Highest Level of Education

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Respondents

This section provides demographic information about the respondent.

Table 23. Respondent's Age

| State | Under 35 | 35-54 | 55-74 | 75 or Older | N |
|--------------------|-----------|------------|------------|-------------|--------------|
| AK | 0% | 22% | 71% | 7% | 177 |
| FL | 3% | 23% | 58% | 17% | 334 |
| GA | 0% | 18% | 62% | 20% | 391 |
| LA | 1% | 14% | 62% | 23% | 394 |
| MD | 2% | 11% | 61% | 26% | 1,044 |
| MI | 2% | 17% | 67% | 15% | 503 |
| MN | 3% | 23% | 63% | 11% | 411 |
| NC | 3% | 25% | 59% | 13% | 251 |
| NH | 2% | 17% | 64% | 18% | 355 |
| PA | 0% | 9% | 67% | 24% | 413 |
| SD | 1% | 16% | 64% | 19% | 758 |
| UT | 0% | 25% | 60% | 14% | 424 |
| VA | 1% | 15% | 68% | 16% | 231 |
| WA | 1% | 13% | 68% | 18% | 394 |
| NCI Average | 1% | 18% | 64% | 17% | 6,080 |

Table 24. Respondent's Health

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

Table 25. Respondent's Relationship to Family Member

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

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

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

Table 27. Respondent's Highest Level of Education

| State | No High School Diploma or GED | High School Diploma or GED | Vocational School | Some College | College Degree or Higher | N |
|--------------------|-------------------------------|----------------------------|-------------------|--------------|--------------------------|--------------|
| AK | 0% | 13% | 2% | 19% | 66% | 165 |
| FL | 4% | 22% | 6% | 26% | 42% | 326 |
| GA | 9% | 22% | 8% | 21% | 41% | 368 |
| LA | 9% | 28% | 10% | 22% | 32% | 376 |
| MD | 5% | 19% | 3% | 23% | 50% | 1,033 |
| MI | 3% | 22% | 3% | 26% | 47% | 493 |
| MN | 3% | 20% | 12% | 18% | 48% | 399 |
| NC | 4% | 13% | 6% | 20% | 56% | 250 |
| NH | 6% | 20% | 5% | 14% | 55% | 346 |
| PA | 3% | 35% | 5% | 14% | 43% | 408 |
| SD | 5% | 27% | 12% | 19% | 37% | 731 |
| UT | 2% | 20% | 7% | 22% | 49% | 421 |
| VA | 5% | 26% | 4% | 23% | 42% | 226 |
| WA | 3% | 14% | 6% | 30% | 47% | 391 |
| NCI Average | 4% | 22% | 6% | 21% | 47% | 5,933 |

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

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

Services and Supports Received

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

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

| State | Financial Support | In-home Support | Residential Support | Day or Employment Supports | Transportation | Other | Self-direction or Fiscal Intermediary Services |
|--------------------|-------------------|-----------------|---------------------|----------------------------|----------------|------------|--|
| AK | 47% | 50% | 89% | 53% | 86% | 56% | 23% |
| FL | 33% | 49% | 85% | 64% | 85% | 59% | 42% |
| GA | 35% | 38% | 92% | 73% | 93% | 47% | 26% |
| LA | 21% | 36% | 74% | 44% | 78% | 48% | 17% |
| MD | 32% | 32% | 83% | 81% | 89% | 50% | 18% |
| MI | 22% | 51% | 89% | 56% | 88% | 64% | 23% |
| MN | 44% | 37% | 88% | 79% | 92% | 55% | 24% |
| NC | 34% | 35% | 93% | 71% | 88% | 61% | 20% |
| NH | 42% | 36% | 85% | 56% | 82% | 53% | 24% |
| PA | 26% | 28% | 87% | 55% | 81% | 60% | 11% |
| SD | 30% | 32% | 87% | 69% | 91% | 64% | 28% |
| UT | 31% | 44% | 94% | 85% | 94% | 61% | 25% |
| VA | 21% | 26% | 94% | 72% | 94% | 66% | 23% |
| WA | 38% | 57% | 83% | 52% | 83% | 46% | 26% |
| NCI Average | 33% | 39% | 88% | 65% | 87% | 56% | 24% |

Table 30. Additional Services and Supports Received

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

Family/Guardian Survey Results

Information and Planning

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

Gets Enough Information to Help Plan Services

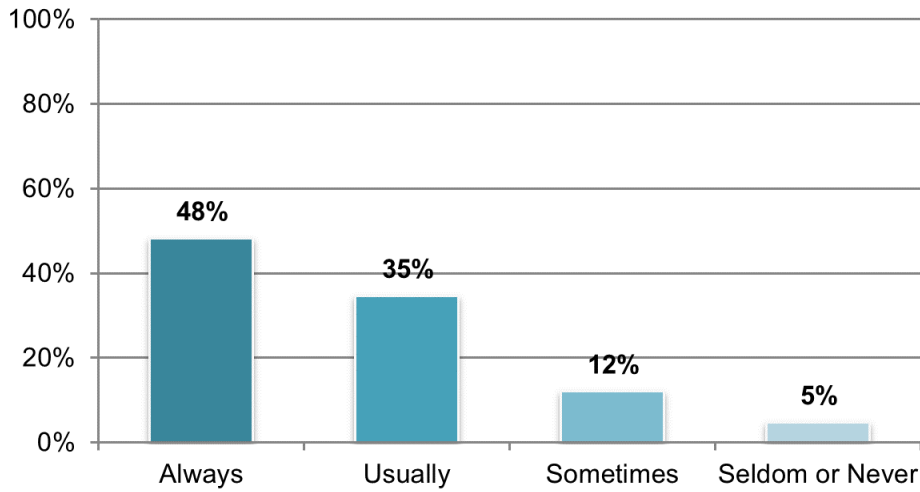


Table Q1. Do you get enough information to help you participate in planning services for your family?

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

Information About Services and Supports Is Easy to Understand

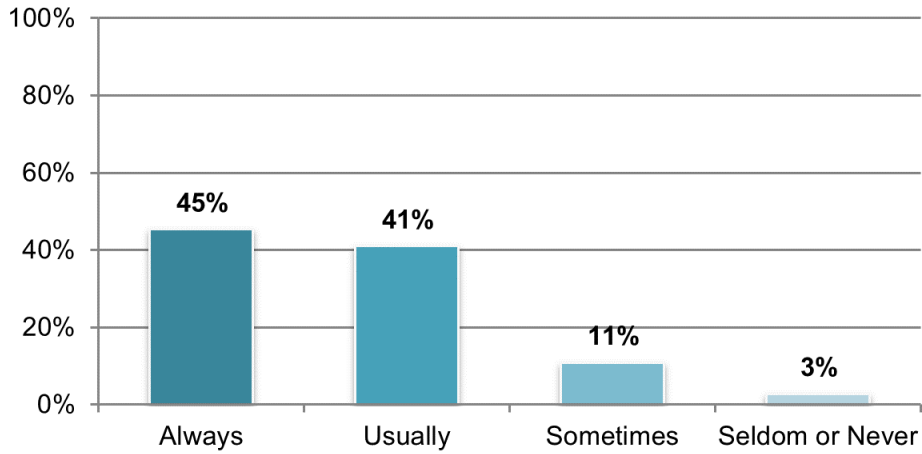


Table Q2. Is the information you receive easy to understand?

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

Residential Staff Keep Respondent Informed About Family Member

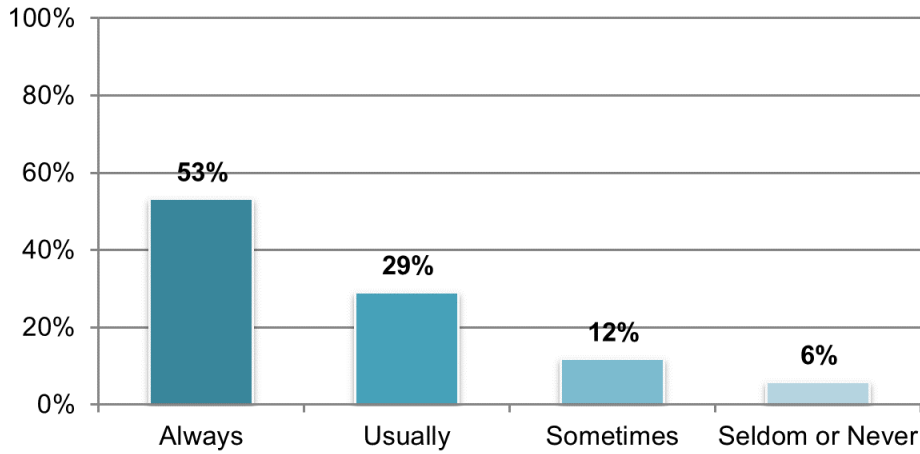


Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?

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

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

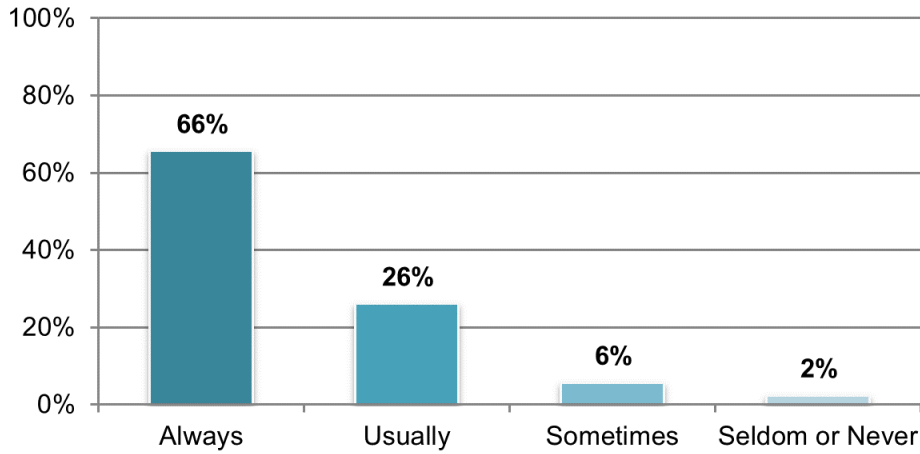


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

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

Respondent Needs Help Planning for Family Member's Future Needs

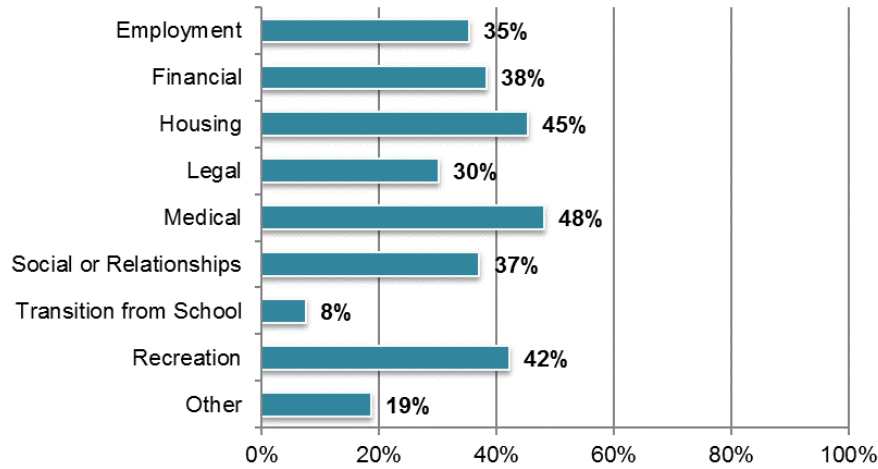


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

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

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

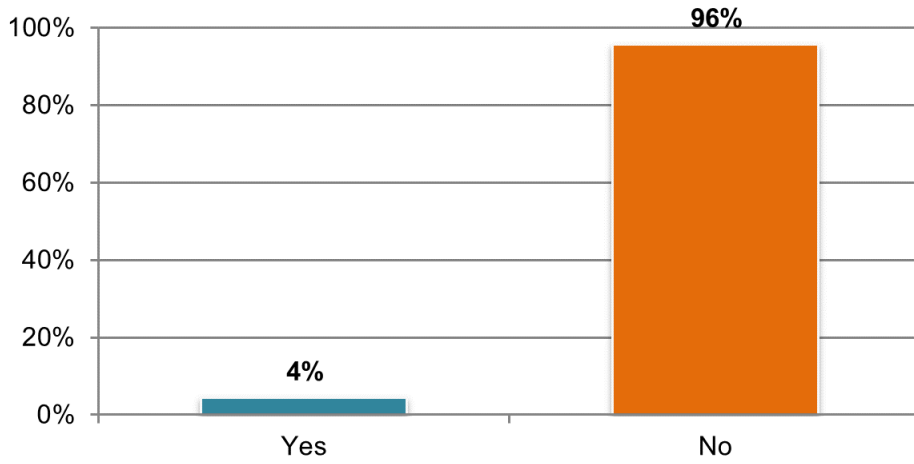


Table Q6. In the past year, did your family member move out of the family home for the first time?

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

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

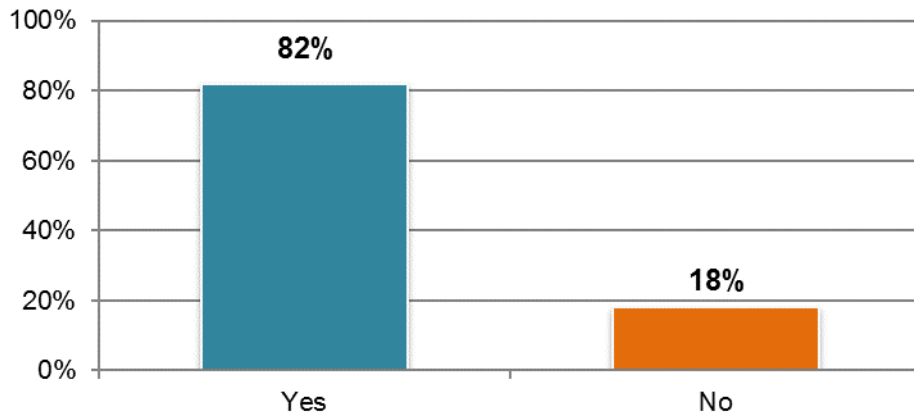


Table Q7. If yes to Q6, did your family member receive enough information about services available to support him/her?

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

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

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

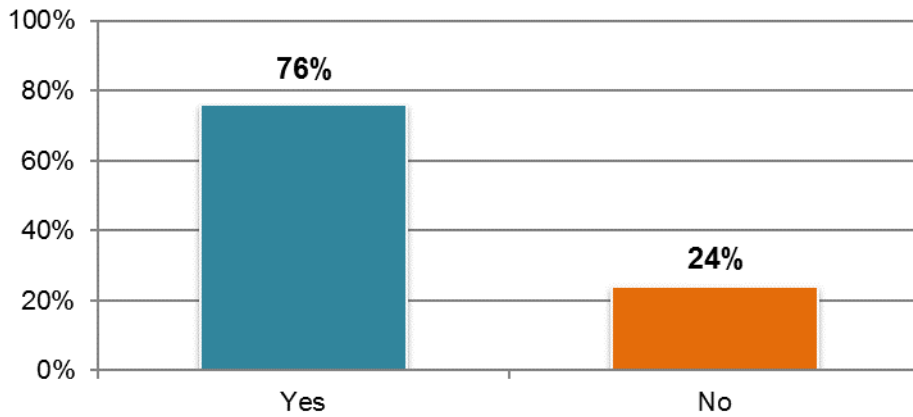


Table Q8. If yes to Q6, did you have enough choices of service providers to support your family member living outside the family home?

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

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

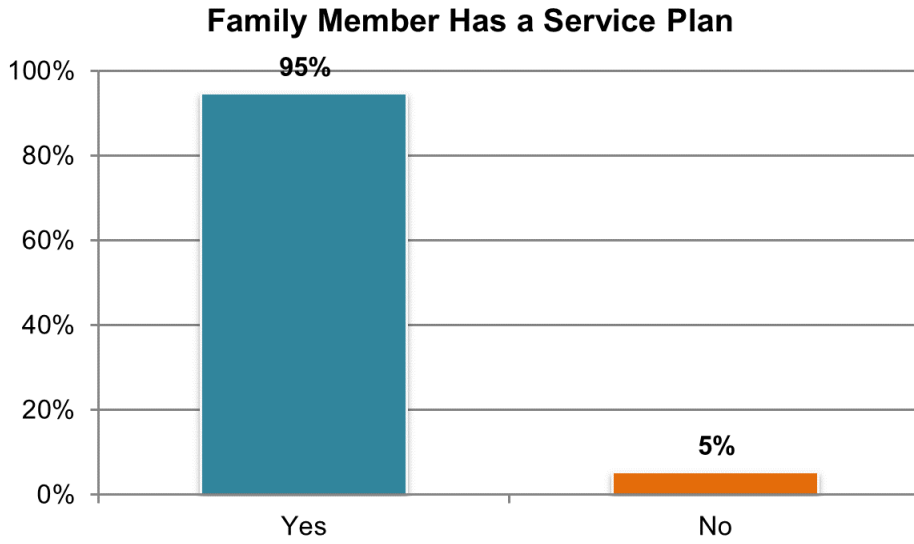


Table Q9. Does your family member have a service plan?

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

Service Plan Includes All the Services and Supports Family Member Needs

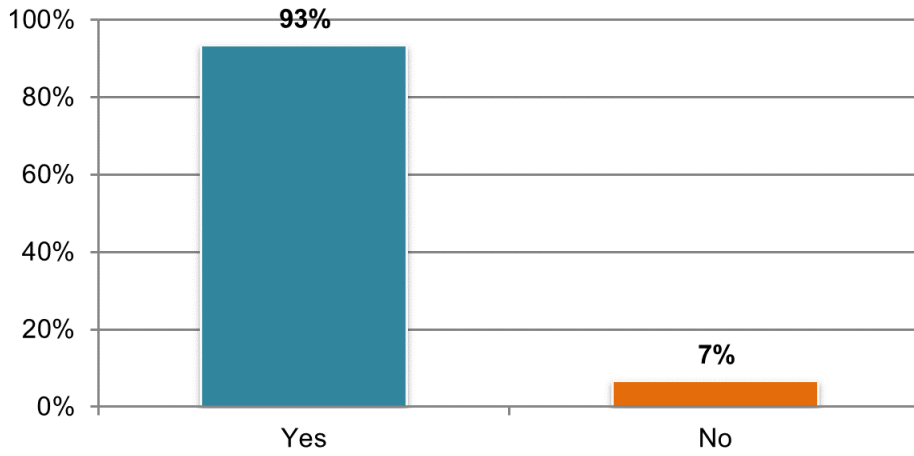


Table Q10. Does the plan include all the services and supports your family member needs?

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

Family Member Receives All Services Listed in the Service Plan

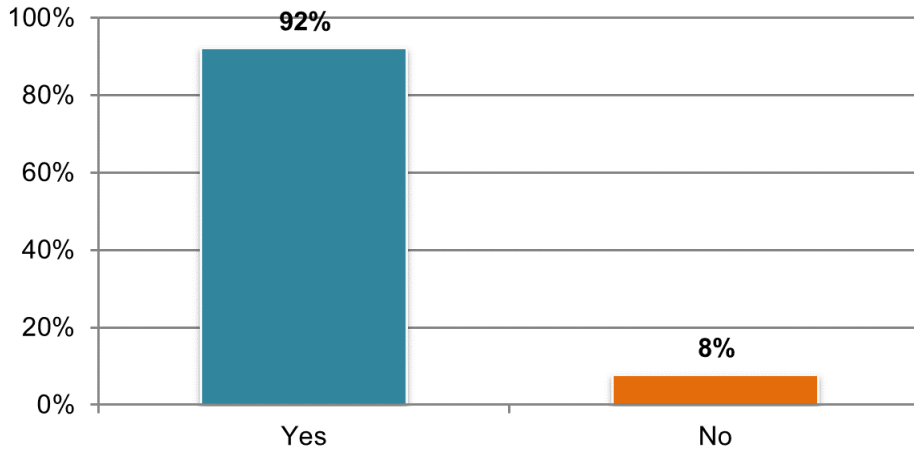


Table Q11. Does your family member receive all of the services listed in the plan?

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

Respondent or Other Family Member Helped Develop Service Plan

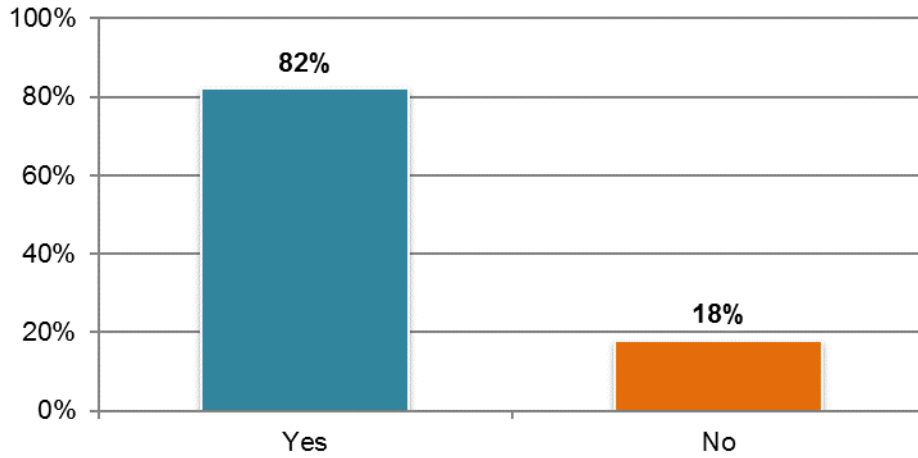


Table Q12. Did you or another family member help develop the plan?

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

Family Member Helped Develop Service Plan

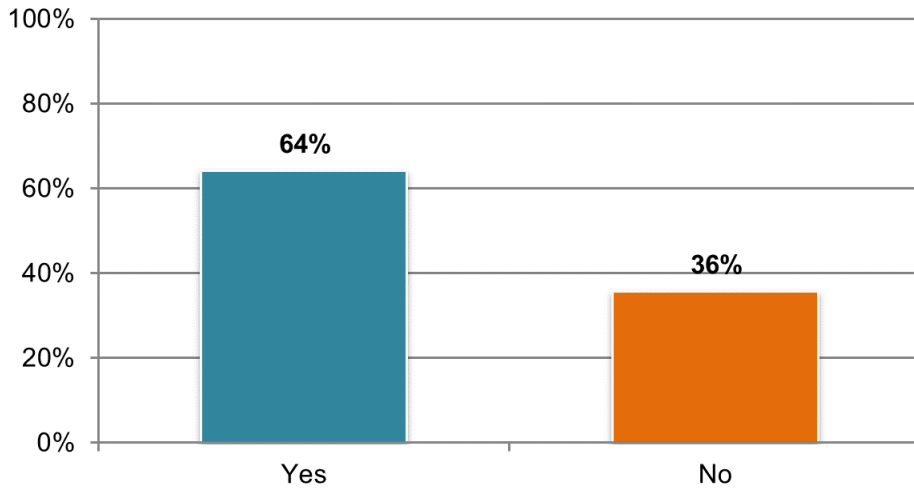


Table Q13. Did your family member help develop the plan?

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

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

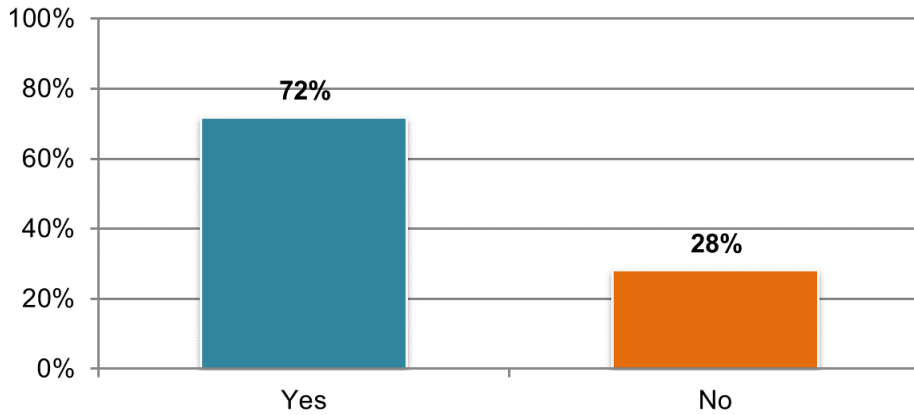


Table Q14. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?

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

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

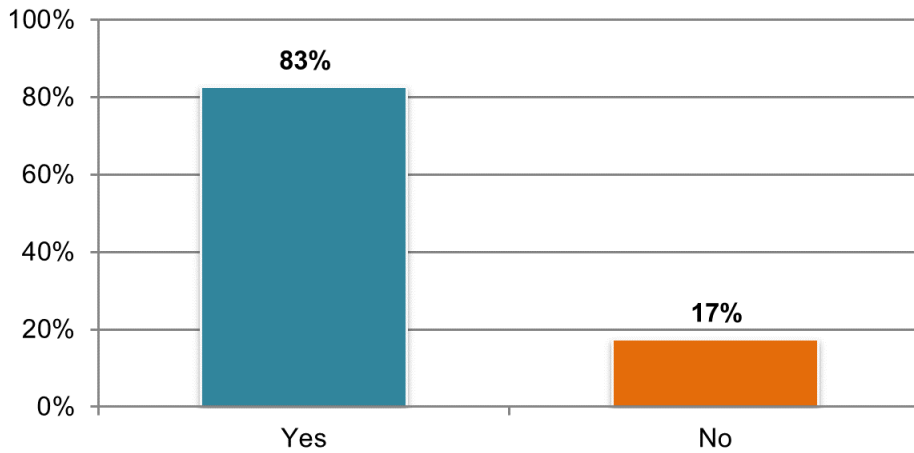


Table Q15. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

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

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

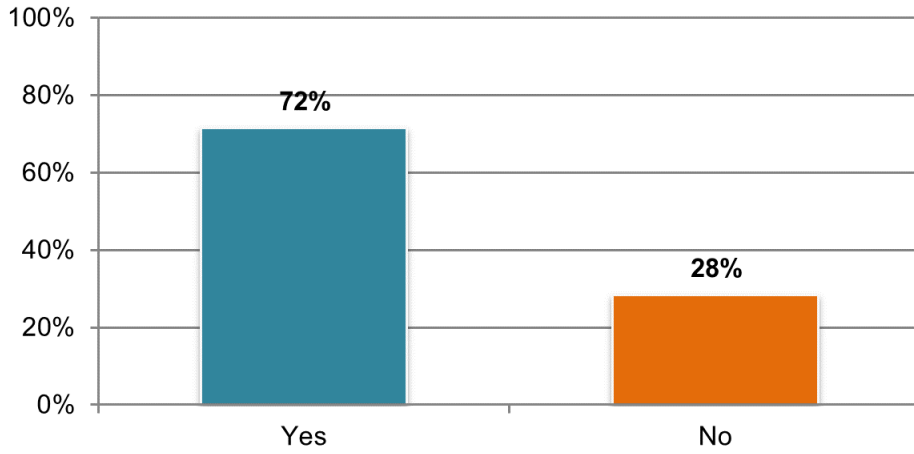


Table Q16. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

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

Access and Delivery of Services and Supports

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

Respondent or Family Member Is Able to Contact Support Workers When S/He Wants To

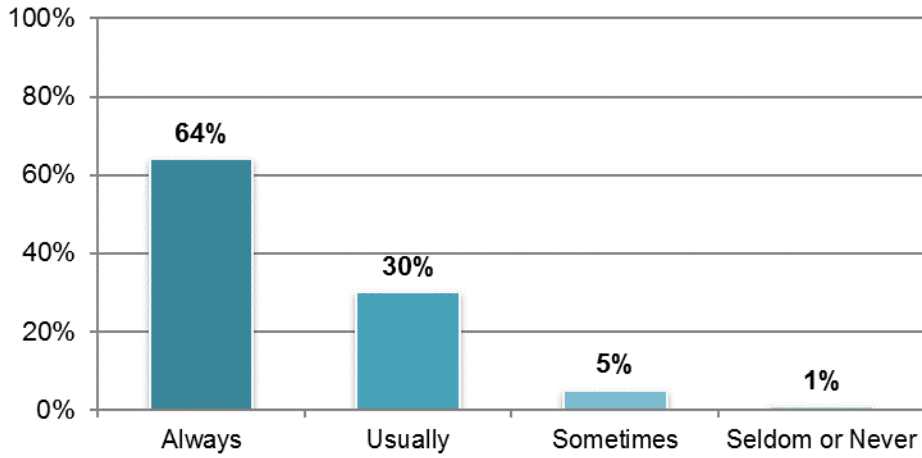


Table Q17. Are you or your family member able to contact his/her support workers when you want to?

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

Respondent or Family Member Is Able to Contact Case Manager or Service Coordinator When S/He Wants To

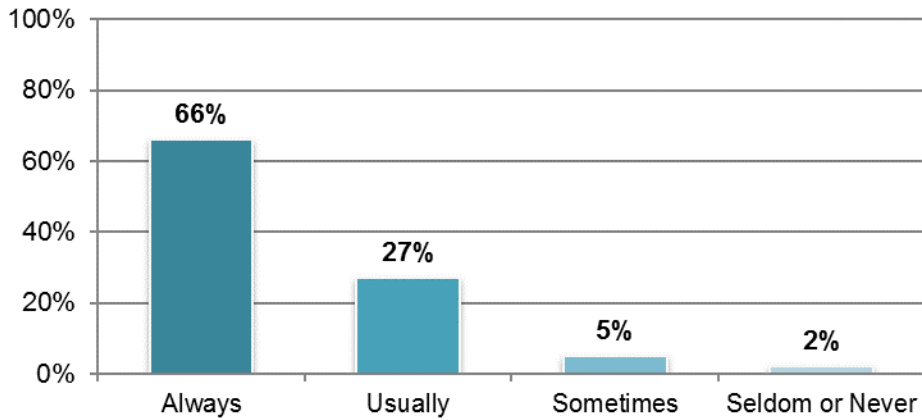


Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

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

Support Workers Come and Leave When They Are Supposed to

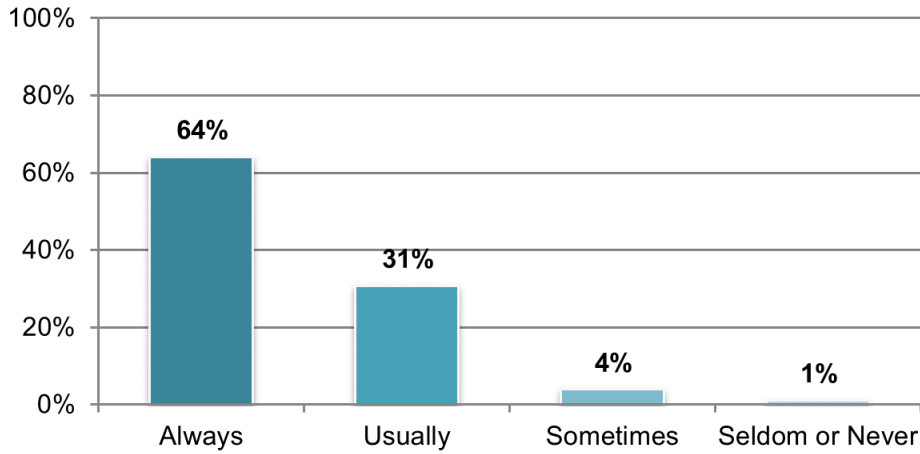


Table Q19. Do support workers come and leave when they are supposed to?

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

Services and Supports Change When Family's Needs Change

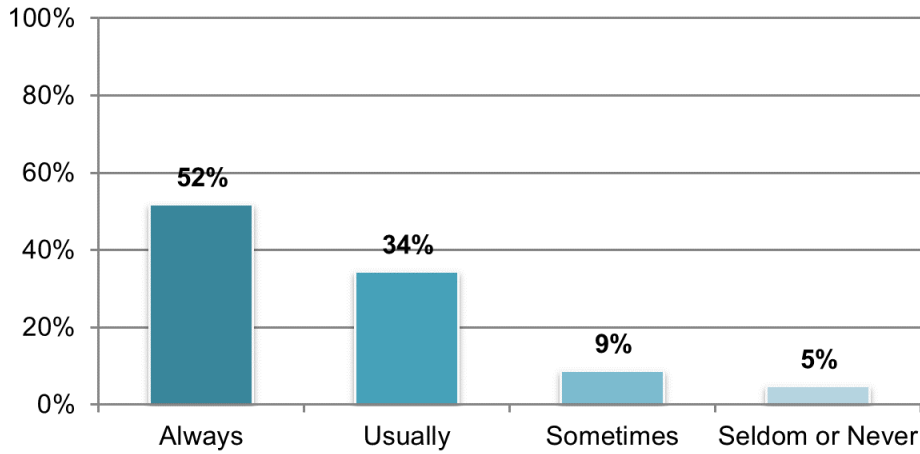


Table Q20. Do services and supports change when your family's needs change?

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

Support Workers Speak In a Way Respondent Understands

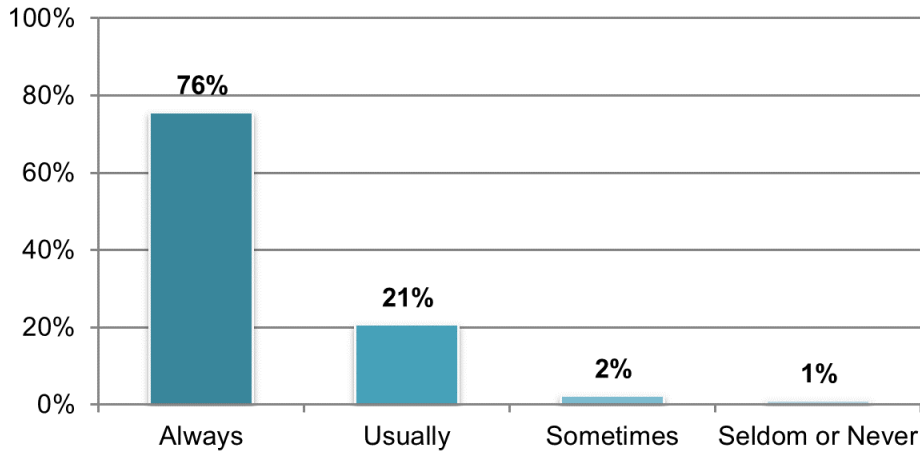


Table Q21. Do support workers speak to you in a way that you understand?

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

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

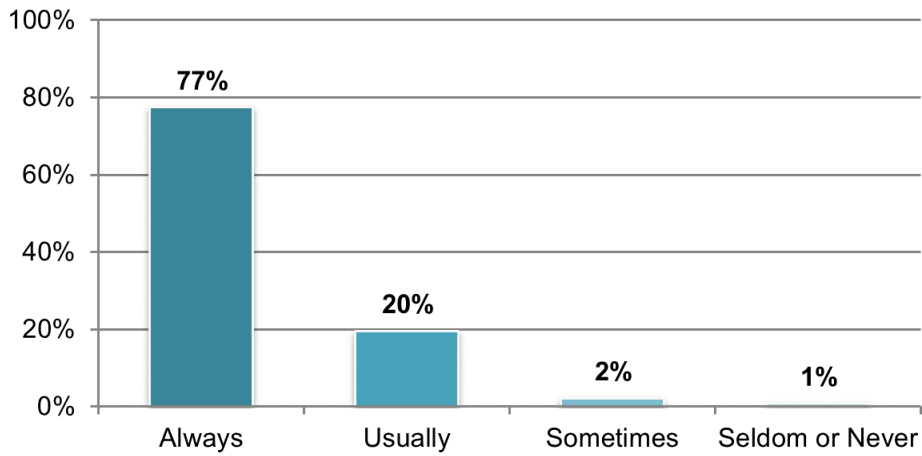


Table Q22. Are services delivered in a way that is respectful of your family's culture?

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

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

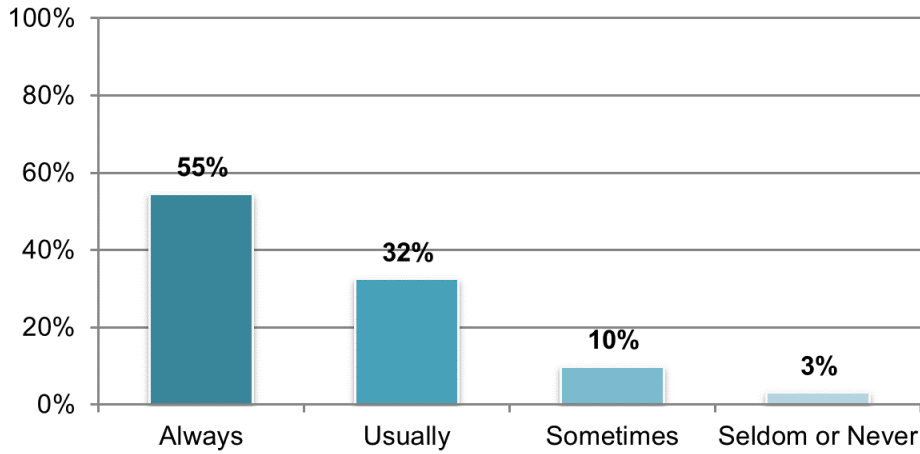


Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

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

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

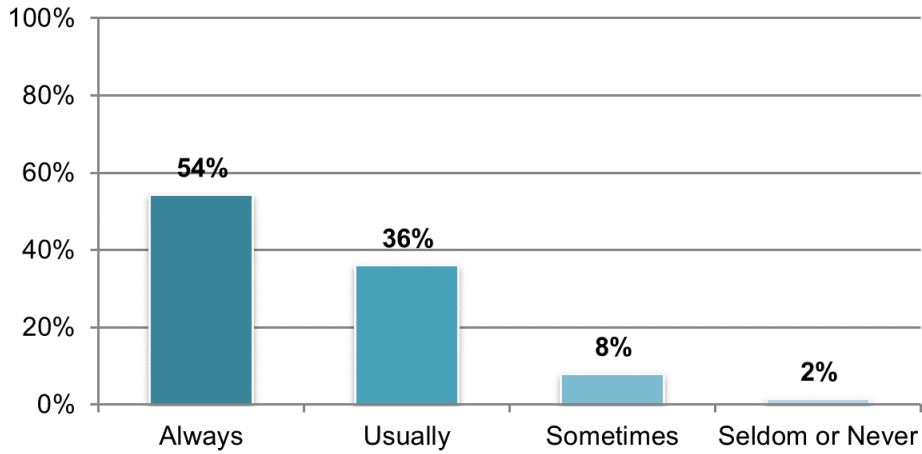


Table Q24. Do support workers have the right information and skills to meet your family's needs?

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

Family Member Has Access to Special Equipment or Accommodations Needed

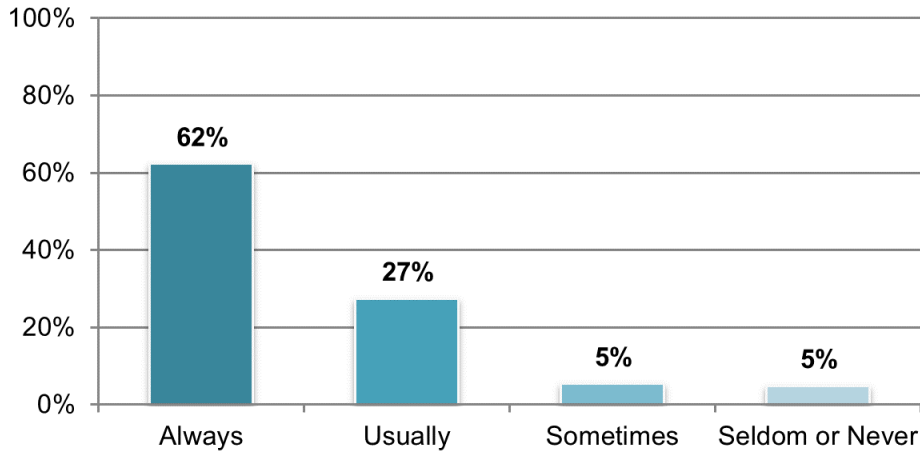


Table Q25. Does your family member have access to the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

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

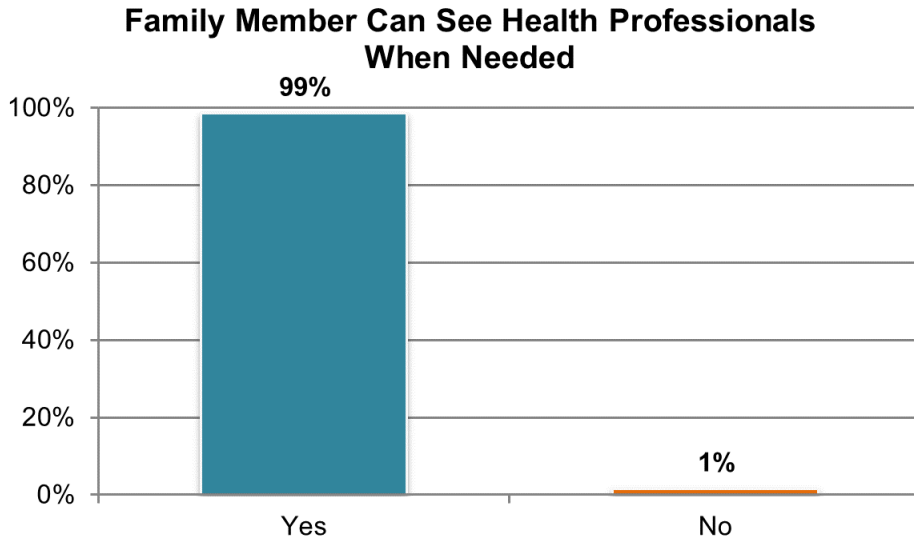


Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

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

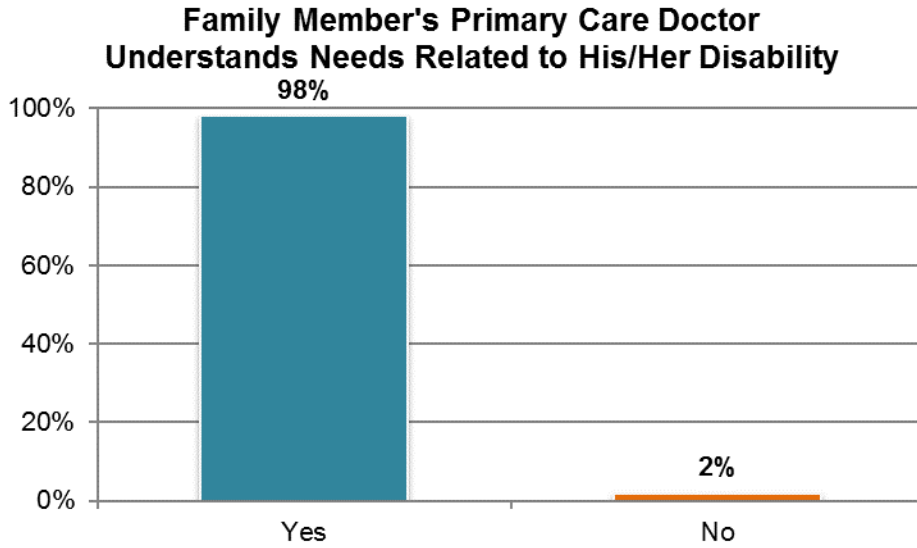


Table Q27. Does your family member's primary care doctor understand your family member's needs related to his/her disability?

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

Respondent Has Access to Dental Services for Family Member

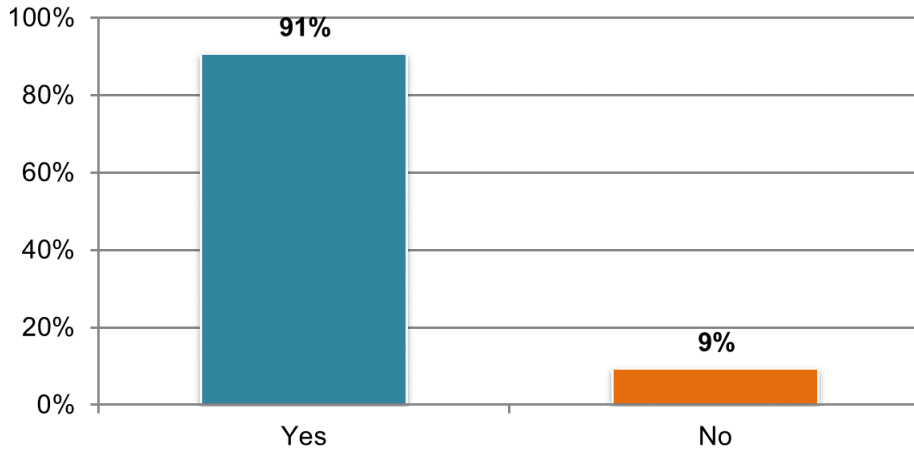


Table Q28. Do you have access to dental services for your family member?

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

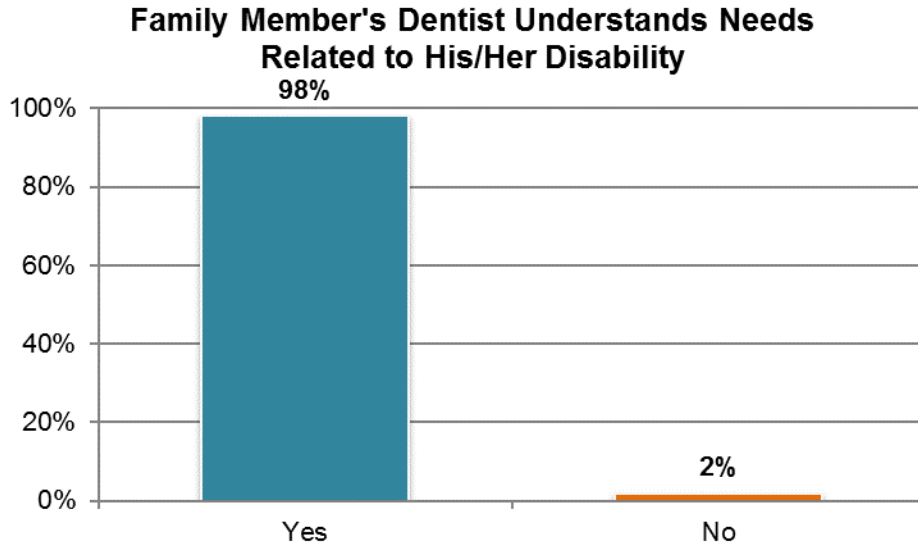


Table Q29. Does your family member's dentist understand your family member's needs related to his/her disability?

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

Respondent Knows What Family Member's Medications Are For

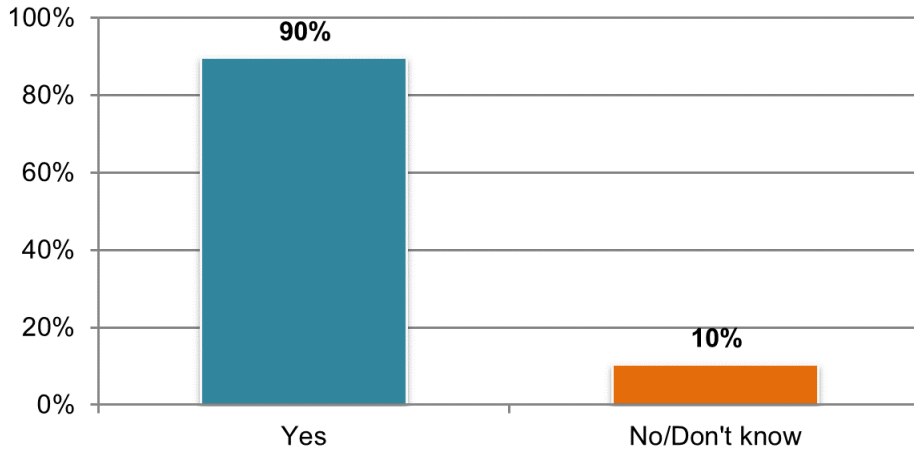


Table Q30. If your family member takes medications, do you know what they're for?²

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

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

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

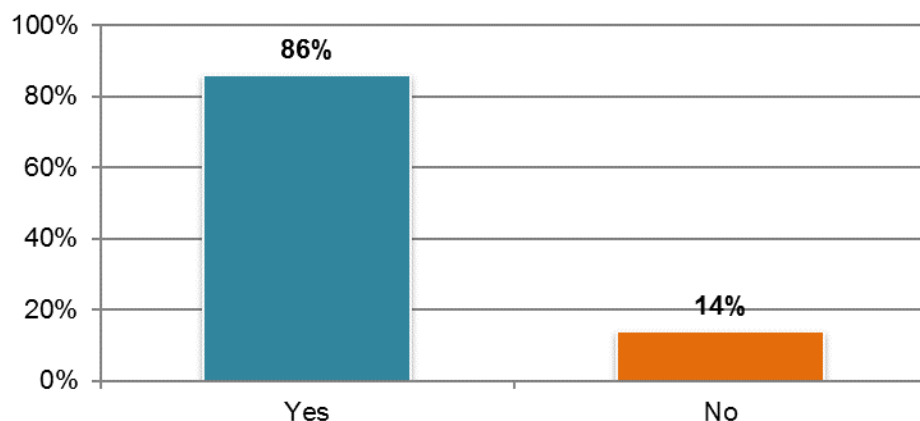


Table Q31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, potential side effects)?³

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

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

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

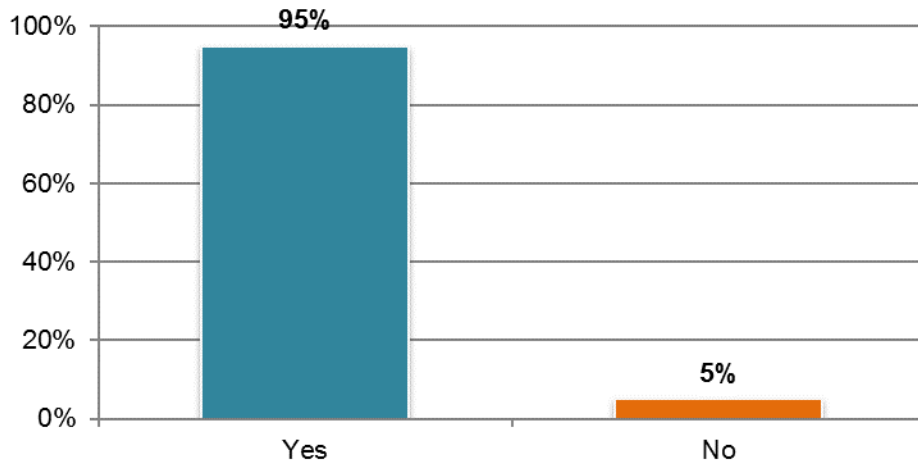


Table Q32. If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability?

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

Family Gets Needed Supports

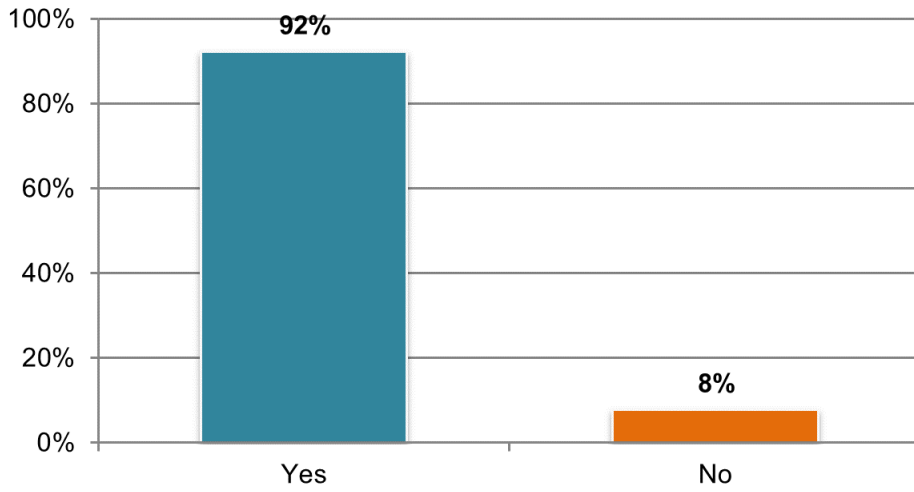


Table Q33. Does your family get the support needed?

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

Additional Services Needed

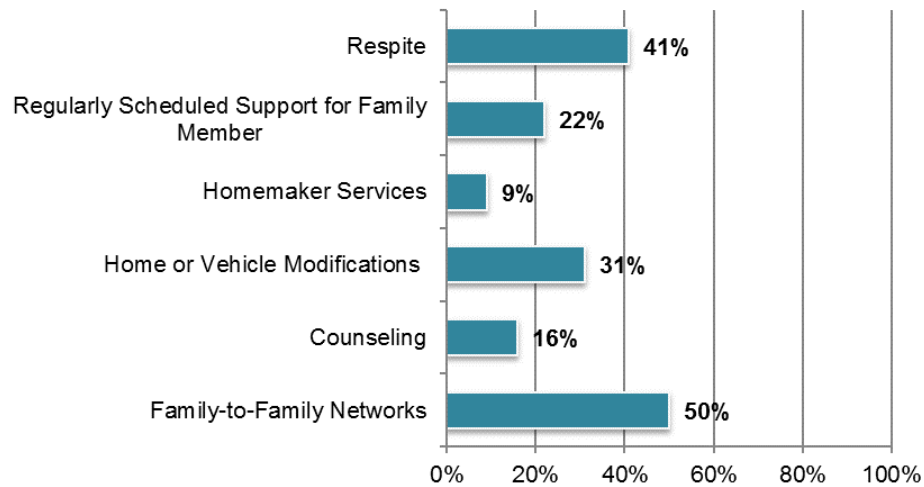


Table Q34. If no to Q33, what additional services are needed?

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

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

Choice, Decision Making and Control

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

Residential Provider Involves Family Member in Important Decisions

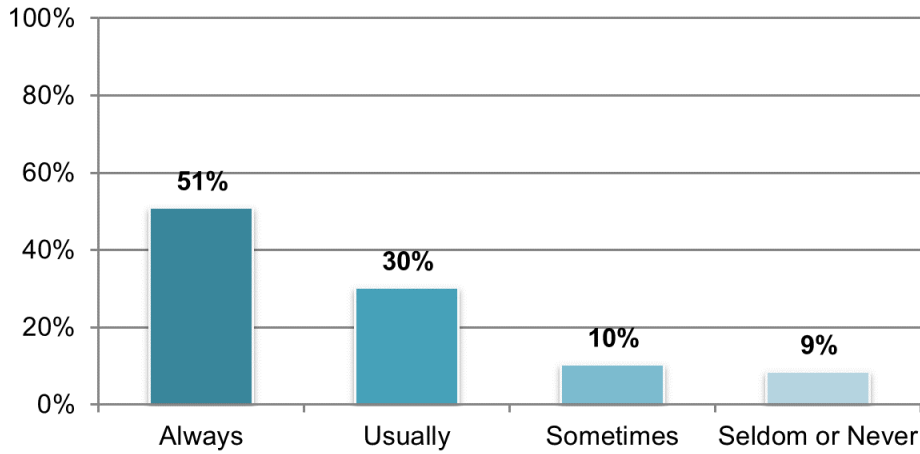


Table Q35. Does the agency providing residential services to your family member involve him/her in important decisions?

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

Family Can Choose or Change Family Member's Provider Agency

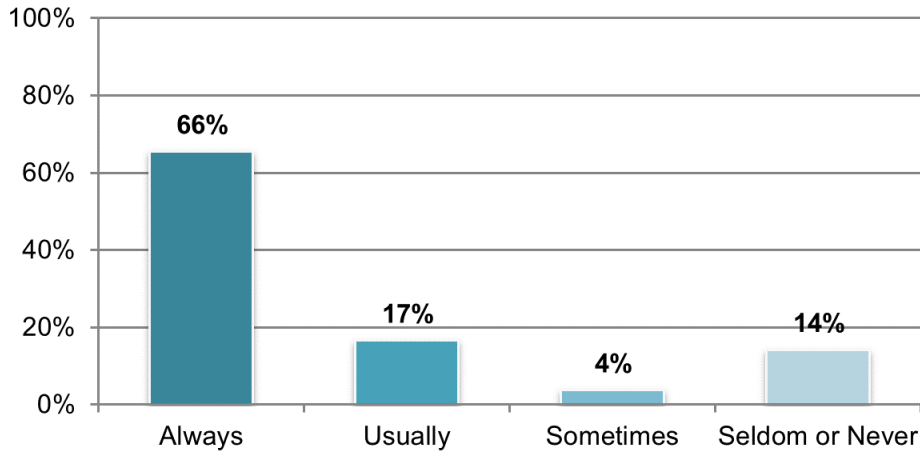


Table Q36. Can your family choose or change the agency that provides your family member's services?

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

Family Can Choose or Change Family Member's Support Workers

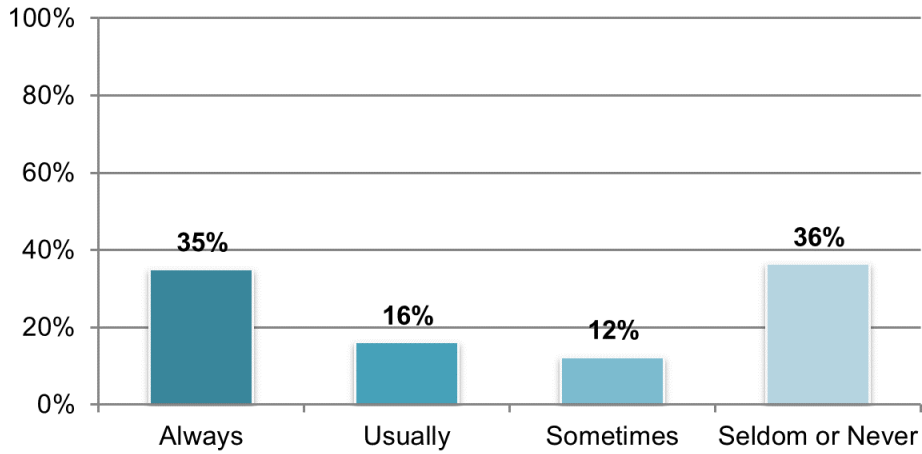


Table Q37. Can your family choose or change your family member's support workers?

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

Family Directly Manages Support Workers

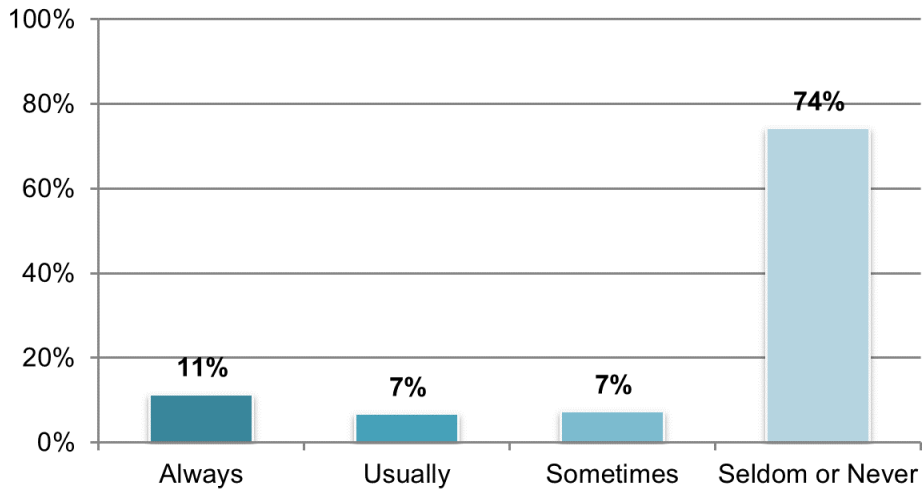


Table Q38. Does your family directly manage support workers (for example, hiring and deciding schedule)?

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

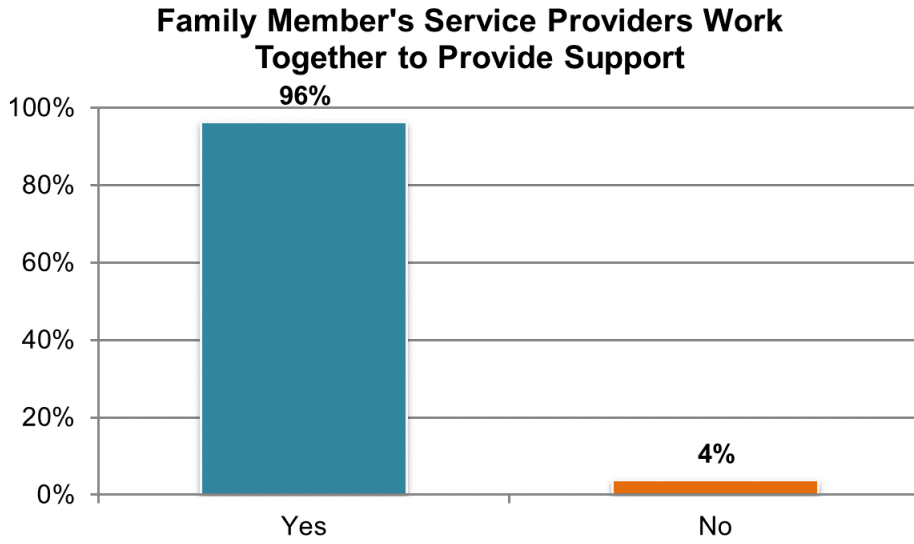


Table Q39. Do service providers for your family member work together to provide support?

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

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

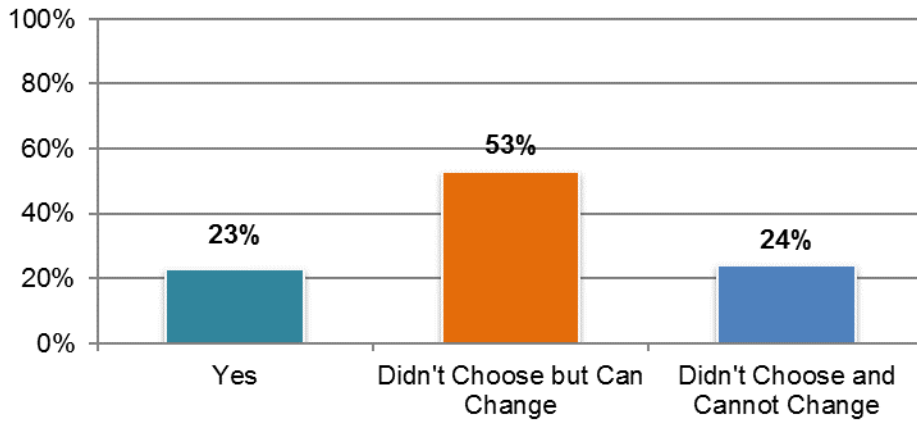


Table Q40. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

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

Involvement in the Community

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

Family Member Takes Part in Community Activities

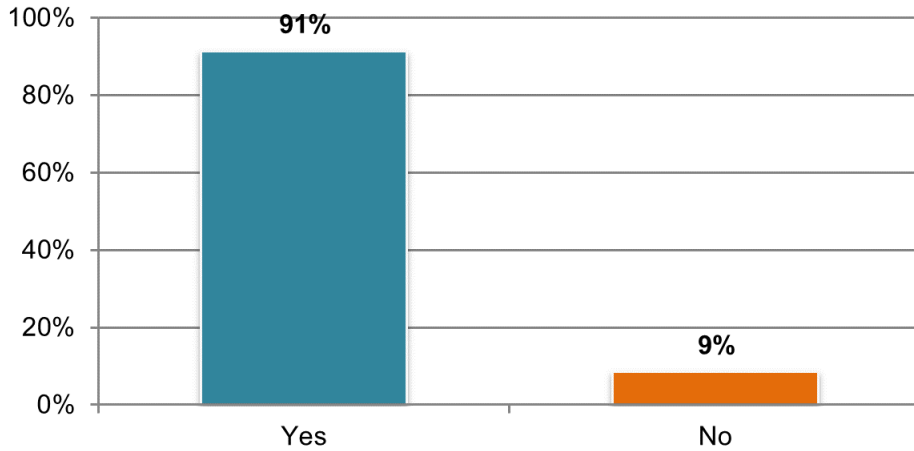


Table Q41. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?

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

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

| State | Lack of Transportation | Cost | Lack of Support Staff | Negative Attitude from Community Members | Other | N |
|--------------------|------------------------|------------|-----------------------|--|------------|------------|
| LA | 18% | 20% | 16% | 8% | 57% | 49 |
| MD | 22% | 19% | 32% | 14% | 49% | 77 |
| MI | 15% | 15% | 39% | 12% | 58% | 33 |
| NH | 30% | 26% | 35% | 13% | 48% | 23 |
| PA | 11% | 7% | 7% | 14% | 82% | 28 |
| SD | 29% | 29% | 34% | 21% | 39% | 38 |
| UT | 42% | 31% | 61% | 19% | 39% | 36 |
| WA | 30% | 20% | 32% | 9% | 73% | 44 |
| NCI Average | 25% | 21% | 32% | 14% | 56% | 328 |

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

Family Member Has Friends Other Than Paid Support Workers or Family

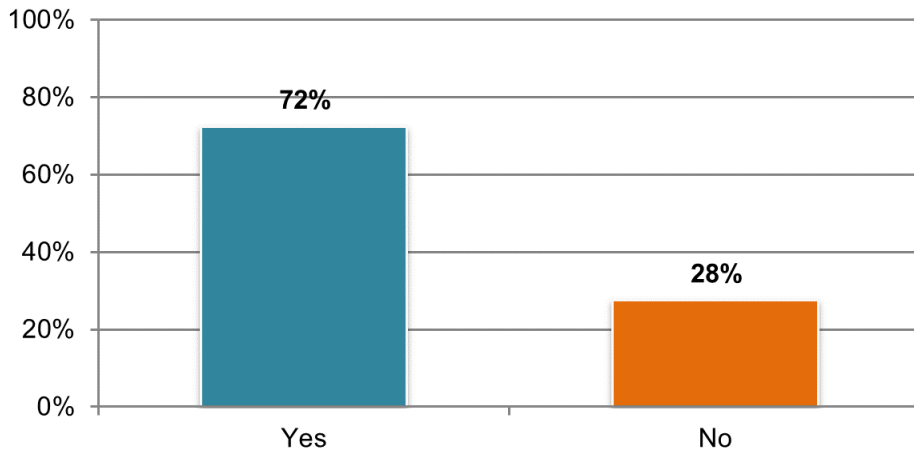


Table Q43. Does your family member have friends other than paid support workers or family?

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

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

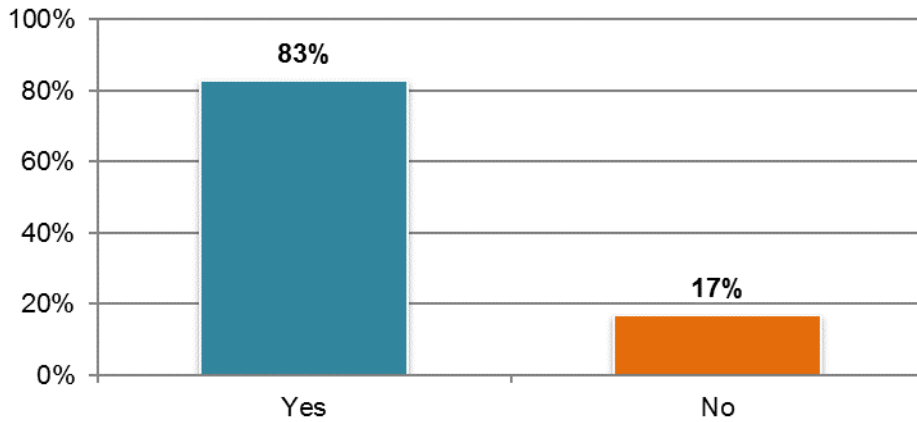


Table Q44. In your community, are there resources that your family can use that are not provided by the IDD agency?

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

Family Takes Part in Family-to-family Networks

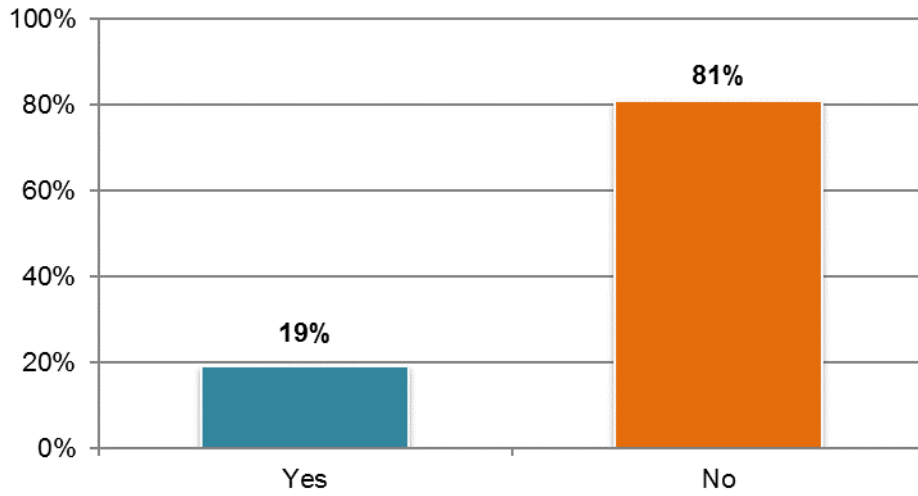


Table Q45. Does your family take part in any family-to-family networks in your community?

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

Satisfaction With Services and Supports

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

Overall, Respondent Is Satisfied With Services and Supports Family Receives

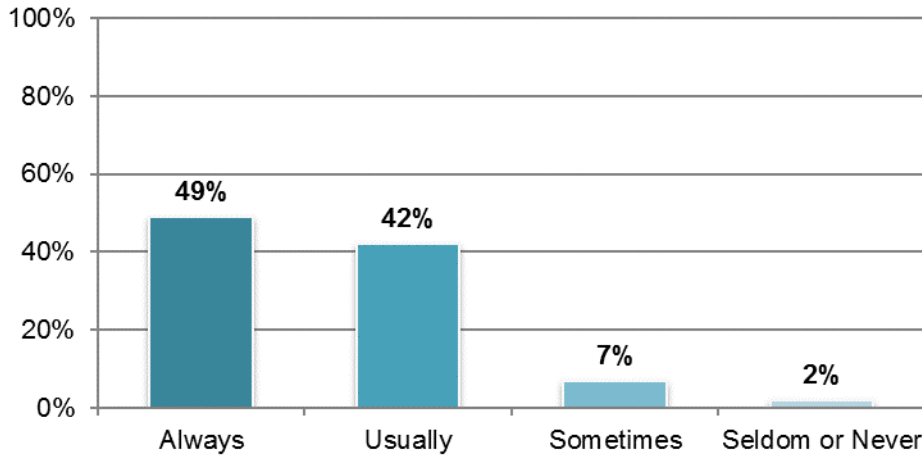


Table Q46. Overall, are you satisfied with the services and supports your family currently receives?

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

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

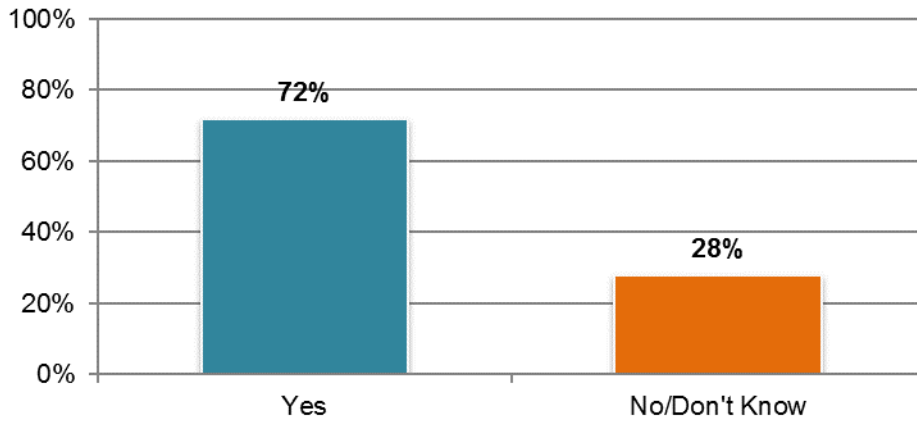


Table Q47. Do you know how to file a complaint or grievance about provider agencies or staff?⁴

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

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

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

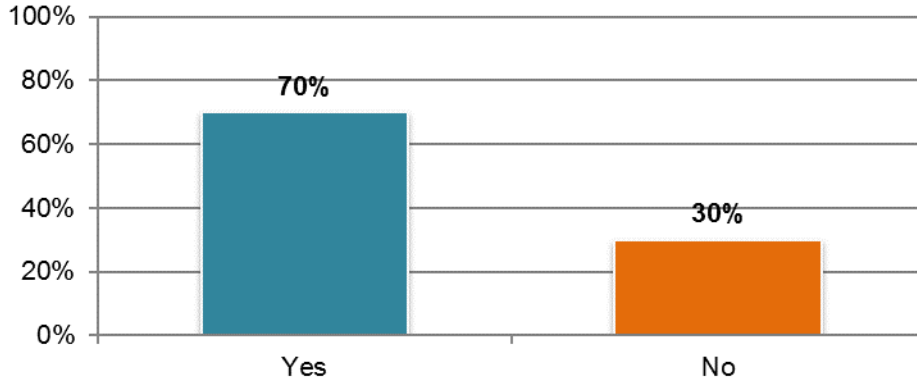


Table Q48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

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

Respondent Knows How to Report Abuse or Neglect

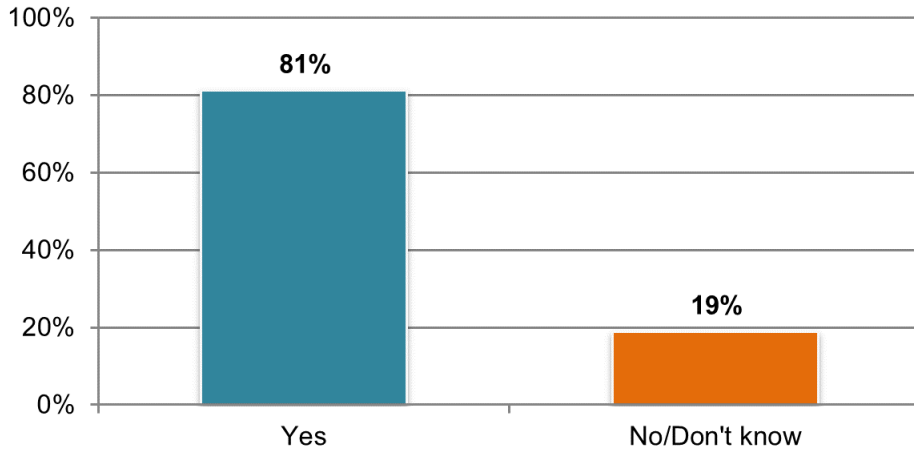


Table Q49. Do you know how to report abuse or neglect related to your family member?⁵

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

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

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

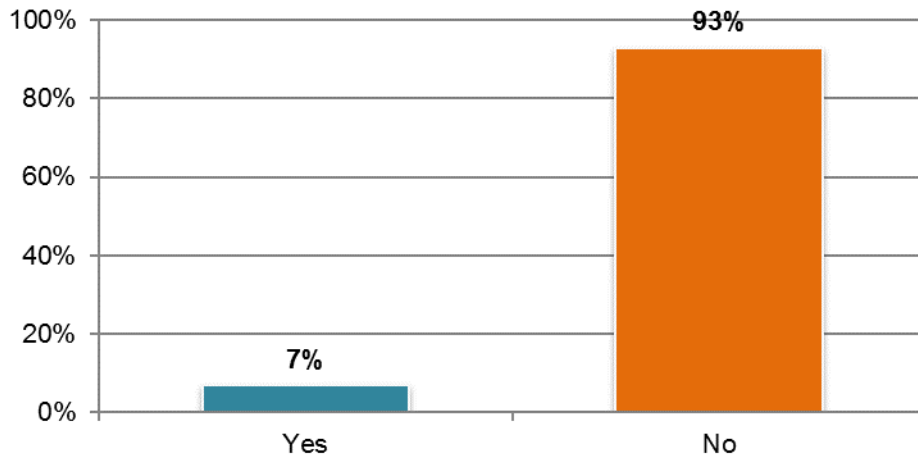


Table Q50. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

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

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

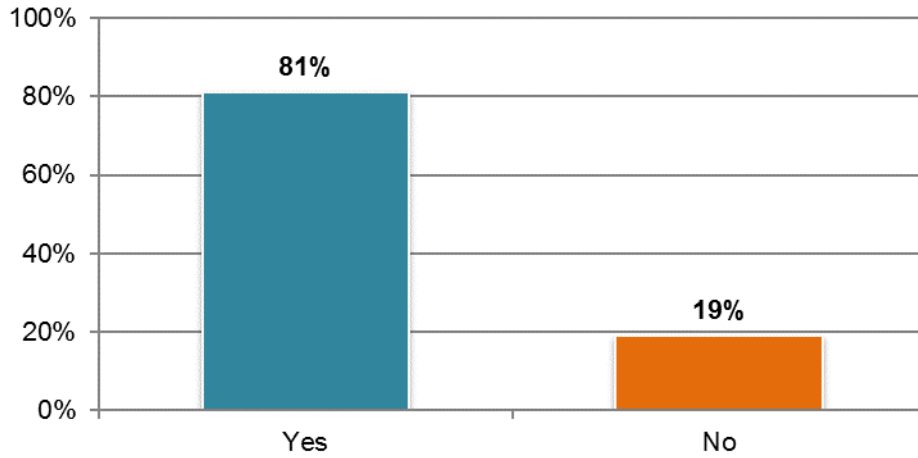


Table Q51. If yes to Q50, did the appropriate people respond to the report?

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

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

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

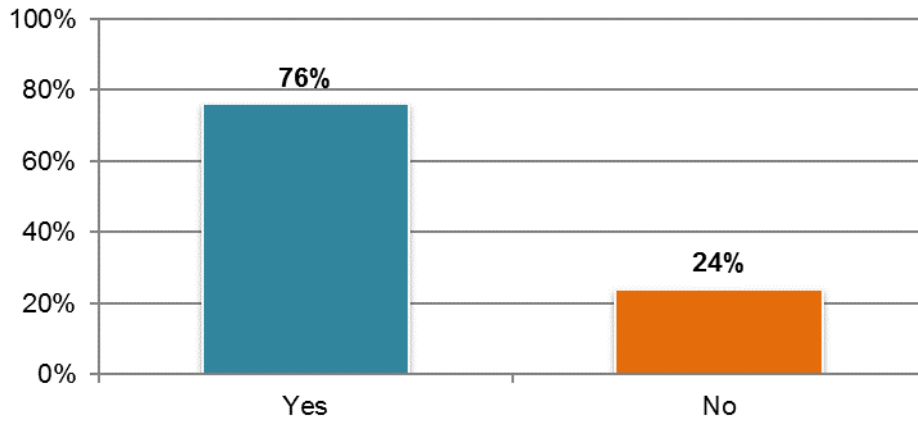


Table Q52. If Yes to Q50, if someone other than you or another family member reported abuse or neglect in the past year, were you notified of the report in a timely manner?

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

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

Family Outcomes

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

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

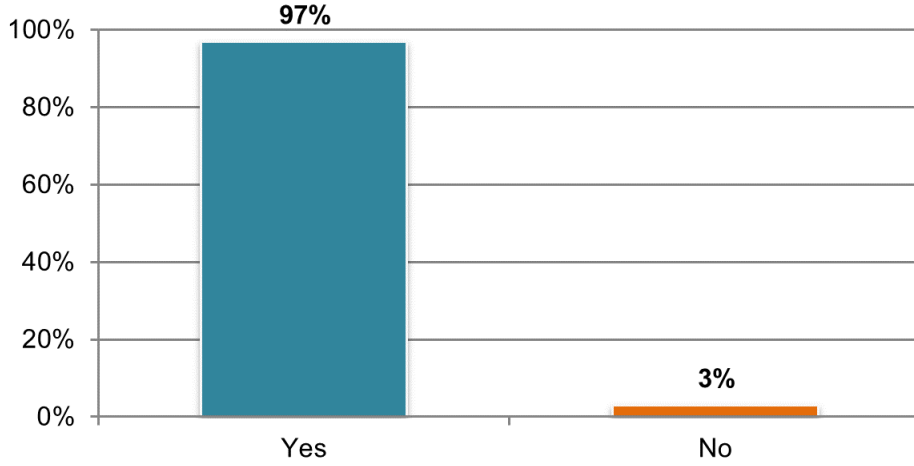


Table Q53. Do you feel that services and supports have made a positive difference in the life of your family?

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

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

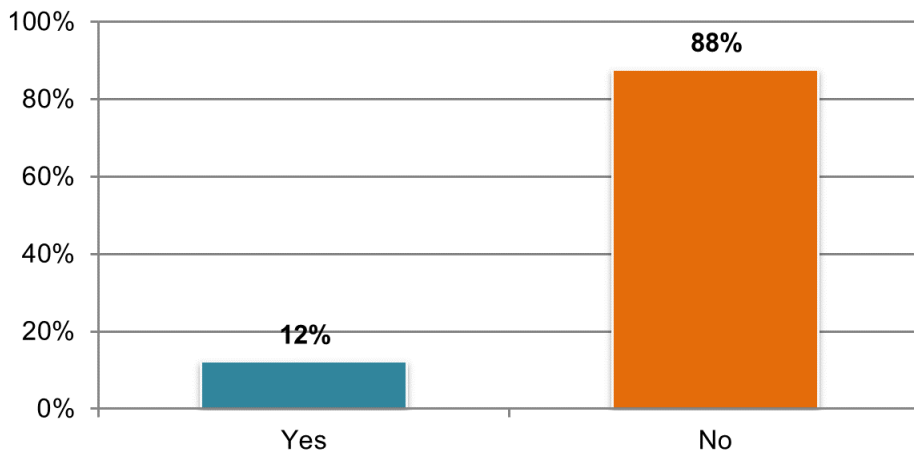


Table Q54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?

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

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

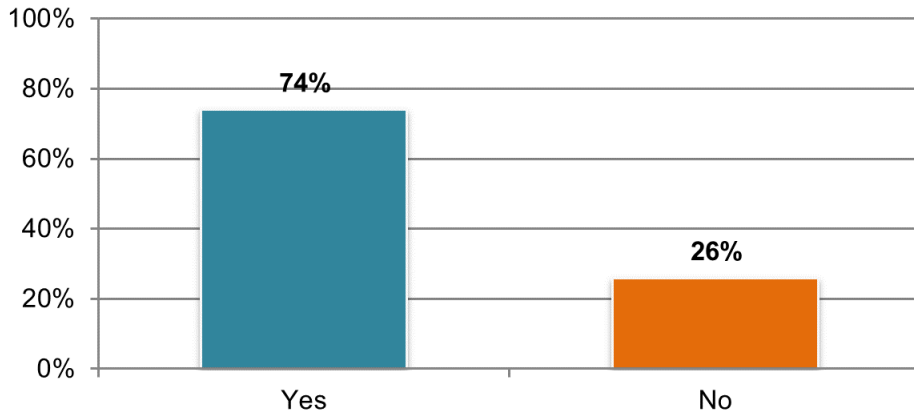


Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?

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

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

Services or Supports Were Increased in the Past Year

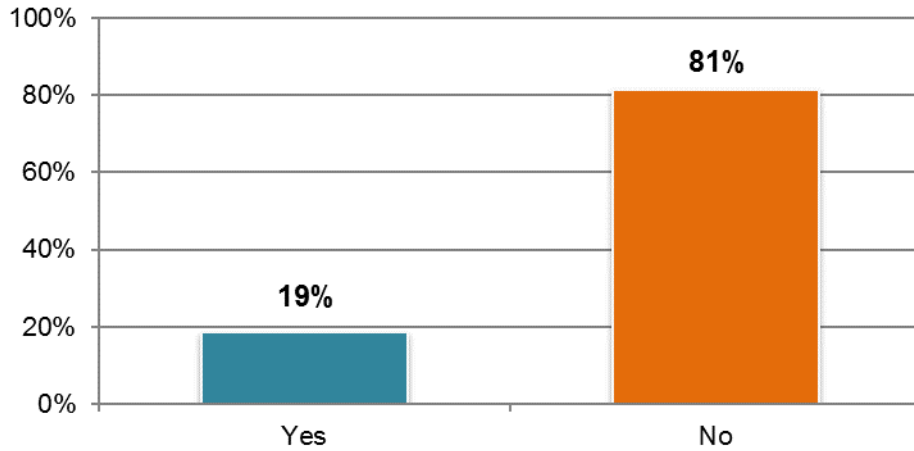


Table Q56. Have the services or supports that your family member received been increased in the past year?

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

Services or Supports Help Family Member Live a Good Life

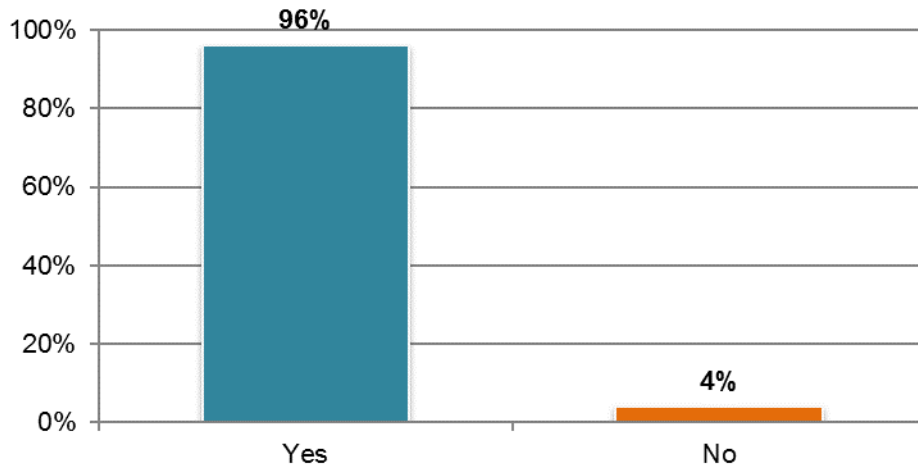


Table Q57. Are services and supports helping your family member to live a good life?

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

II. NCI History and Activities

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

Overview of National Core Indicators

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

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

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

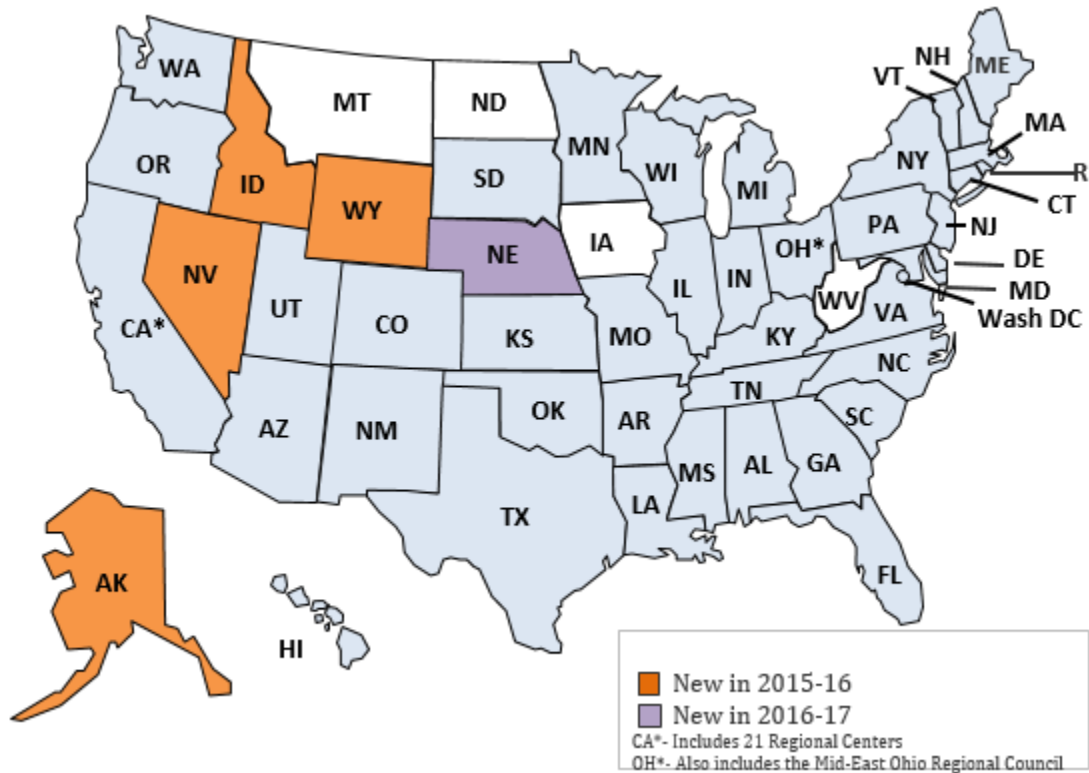
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

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

State Participation

During the 2015-16 data collection cycle, 45 states, the District of Columbia and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and participating states are highlighted on the map below.

Figure 1. NCI State Participation



Sub-Domains and Concern Statements

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

Figure 2. Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

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

Caution and Limitations

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

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

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

III. Methodology

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

Sampling & Administration

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

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

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

Data Entry and Analysis

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

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

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

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

Response Rates

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

Figure 3. Family/Guardian Survey: State Response Rates

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

IV. Appendix A

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

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

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

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

| 2015-2016 | | 2014-2015 | | Change Made | Note | AFS | FGS | CFS |
|-----------|--|-----------|--|--------------------------------------|--|-----|-----|-----|
| O | If your family member needs help (support) with personal care activities (for example, bathing, dressing, eating), please indicate how much. | M | About how much help does this person need with daily activities (such as bathing, dressing, eating)? | Modified Changed response options | Comparisons to previous years' data should be made with caution. | X | X | X |
| P | If your family member needs help (support) with other daily activities (for example, scheduling, managing money, or shopping), please indicate how much. | | | New question | NA | X | X | - |

Deleted or Rephrased Questions- Information About Family Member

H. What is this person's primary language? (*this question will be re-added in future years)

K. How often does this person require medical care by a trained medical provider (e.g., nurse or physician)?

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

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

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

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

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

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

Deleted or Rephrased Questions- Information and Planning

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

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

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

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

| 2015-2016 | | 2014-2015 | Change Made | Note | AFS | FGS | CFS |
|-----------|---|-----------|---|------|-----|-----|-----|
| 28 | Can your family member see health professionals (for example, his/her doctor, dentist, psychologist) when needed? | | New question Gets at health access | NA | X | X | X |
| 29 | Does your family member's primary care doctor understand his/her needs related to his/her disability? | | New question Gets at quality of care | NA | X | X | X |
| 30 | Do you have access to dental services for your family member? | | New question Gets at health access | NA | X | X | X |
| 31 | If yes to Q30, does your family member's dentist understand his/her needs related to his/her disability? | | New question Gets at quality of care | NA | X | X | X |
| 32 | If your family member takes medications, do you know what they're for? | | New question Gets at family understanding of medication use | NA | X | X | X |
| 33 | If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications (<i>when it should be taken, how much to take, potential side effects</i>)? | | New question Better get at family understanding of using medication safely | NA | X | X | X |

| 2015-2016 | | 2014-2015 | Change Made | Note | AFS | FGS | CFS |
|-----------|--|-----------|---|------|-----|-----|-----|
| 34 | If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability? | | New question Gets at quality of care | NA | X | X | X |
| 35 | Does your family get the support needed? | | New question Aligns with question in AFS and CFS | NA | X | X | X |
| 36 | If no to Q35, what additional services are needed? | | New question Aligns with question in AFS and CFS | NA | X | X | X |

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

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

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

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

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

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

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

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

Choice, Decision-Making, and Control

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

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

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

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

Deleted or Rephrased Questions- Satisfaction

39. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

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

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

Deleted or Rephrased Questions- Outcomes

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