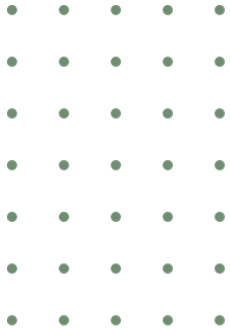


**National Core Indicators[®] - Intellectual and Developmental Disabilities
(NCI[®]-IDD)**



National Report 2023-24

Family/Guardian Survey (FGS)





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of

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April 2025

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List of Acronyms Used in This Report

CMS	Centers for Medicare & Medicaid Services
FGS	Family/Guardian Survey HCBS – Home and Community-Based Services
HSRI	Human Services Research Institute
IDD	Intellectual and developmental disabilities
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NCI	National Core Indicators

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Executive Summary

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

The National Core Indicators (NCI) Family/Guardian Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Family/Guardian Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI-IDD during the 2023-24 data collection cycle, 10 states submitted a valid sample of Family/Guardian Survey data: Arizona (AZ), Delaware (DE), Georgia (GA), Indiana (IN), Maryland (MD), Minnesota (MN), North Dakota (ND), New Jersey (NJ), New Hampshire (NH), and Pennsylvania (PA). This Final Report provides results based on data submitted by June 30, 2024.

Results

Presentation of the Data

In addition to basic demographic questions and questions on services received, the survey contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes.

- Each question is constructed so the respondent selects from either four possible responses (“always”, “usually”, “sometimes”, “seldom/never”) or two responses (“yes” or “no”). Respondents also have the option to indicate that they don’t know the answer to a question or that the question is not applicable.
- Demographic results are shown in table form with states listed alphabetically. Outcomes are shown first with a chart depicting the NCI-IDD Average. The charts are followed by accessible tables showing state outcomes and the NCI-IDD Average. State data were not tested for significance due to the small number of participating states.
- Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI-IDD Average range, their ‘always’ or ‘yes’ response was not statistically different from the NCI-IDD Average.
- States with 20 or fewer respondents to a question are not included in tables; however, their data **are** included in the NCI-IDD Average.
- **Note on Significance:** Statistical significance depends on both the amount by which a state differs from the average for a given item and the state’s sample size for that item. So, there may be instances where State A’s difference from the average is larger than State B’s, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.
- **Note on NCI-IDD Averages:** The NCI-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the states’ sample sizes. Prior to 2016-17, NCI-IDD averages were calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.
- **Note on language used in this report:** “You” and “Respondent” refers to the person (usually a parent or guardian) filling out the survey. “Family Member” refers to the person receiving services whom the respondent is answering questions about in this survey.
- **Note on responses:** All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.
- “N” demonstrates the number of valid responses for each question. “N” can vary between questions. The N does not include missing responses, “don’t know” responses or “not applicable” responses. For information on the total sample from each state, see Figure 3.

Demographics

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

Family Member

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

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics

Table 1a. Family Member’s Residence

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	Specialized facility for people with intellectual disabilities	Group home or agency operated apartment	Independent home or apartment	N
AZ	9%	70%	3%	200
CA	18%	41%	32%	5109
DE	3%	94%	1%	159
GA	11%	52%	25%	200
IN	5%	49%	38%	382
MD	6%	79%	11%	468
MN	5%	79%	9%	407
NH	5%	26%	25%	326
NJ	10%	68%	20%	359
ND	19%	50%	28%	272
PA	8%	81%	7%	537
Weighted NCI-IDD Average	12%	59%	21%	8419

Table 1b. Family Member’s Residence (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	Adult foster care or host family home	Nursing Home	Homeless	Other	N
AZ	10%	0%	0%	9%	200
CA	2%	1%	0%	5%	5109
DE	2%	0%	0%	0%	159
GA	9%	2%	0%	1%	200
IN	1%	0%	0%	8%	382
MD	1%	1%	0%	1%	468
MN	6%	0%	0%	2%	407
NH	38%	1%	0%	4%	326
NJ	1%	0%	0%	0%	359
ND	1%	0%	0%	1%	272
PA	4%	0%	0%	1%	537
Weighted NCI-IDD Average	4%	1%	0%	4%	8419

Table 2. Family Member’s Time Living In Current Residence

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	Less than one year	One to three years	Four to five years	Over five years	N
AZ	14%	26%	16%	44%	196
CA	6%	18%	12%	65%	5113
DE	14%	15%	13%	58%	156
GA	9%	23%	11%	58%	200
IN	13%	27%	9%	50%	390
MD	13%	28%	12%	48%	460
MN	5%	19%	7%	69%	394
NH	12%	28%	14%	47%	330
NJ	8%	24%	11%	57%	357
ND	10%	23%	10%	57%	271
PA	12%	25%	11%	53%	530
Weighted NCI-IDD Average	9%	21%	11%	59%	8397

Table 3. Family Member’s Residential Designation

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
AZ	90%	10%	193
CA	95%	5%	5036
DE	67%	33%	151
GA	79%	21%	195
IN	87%	13%	390
MD	81%	19%	464
MN	90%	10%	401
NH	63%	37%	327
NJ	73%	27%	351
ND	93%	7%	271
PA	70%	30%	523
Weighted NCI-IDD Average	85%	15%	8302

Table 4. Family Member’s Age

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	Age	N
AZ	46.7	196
CA	47.8	5272
DE	47.6	159
GA	46.9	199
IN	45.8	392
MD	42.1	468
MN	50.6	409
NH	47.0	318
NJ	47.2	359
ND	43.6	272
PA	47.8	537
Weighted NCI-IDD Average	47.4	8581

Table 5. Family Member’s Gender

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	Male	Female	Other	N
AZ	59%	41%	0%	198
CA	60%	40%	0%	5274
DE	66%	34%	0%	159
GA	62%	38%	0%	202
IN	57%	42%	1%	393
MD	60%	40%	0%	468
MN	50%	50%	0%	409
NH	60%	39%	0%	316
NJ	64%	36%	0%	359
ND	59%	41%	0%	272
PA	59%	41%	0%	537
Weighted NCI-IDD Average	59%	41%	0%	8587

Table 6. Family Member’s Race/Ethnicity

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer not to say
AZ	4%	2%	6%	0%	76%	15%	1%	3%
CA	3%	8%	6%	0%	74%	12%	2%	2%
DE	1%	1%	13%	0%	80%	3%	1%	3%
GA	3%	2%	22%	0%	69%	1%	1%	2%
IN	1%	1%	7%	0%	90%	1%	1%	2%
MD	1%	4%	17%	0%	72%	3%	2%	3%
MN	1%	1%	1%	0%	95%	1%	0%	1%
NH	1%	0%	1%	1%	94%	1%	1%	3%
NJ	1%	5%	8%	1%	82%	2%	2%	5%
ND	6%	1%	1%	0%	91%	1%	2%	2%
PA	1%	1%	7%	0%	89%	2%	0%	2%
Weighted NCI-IDD Average	2%	4%	7%	0%	81%	6%	1%	2%

Table 7a. Family Member’s Conditions

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State	Intellectual Disability	Mood Illness or psychiatric diagnosis	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision
AZ	80%	45%	31%	16%	7%
CA	73%	28%	34%	16%	7%
DE	75%	29%	43%	13%	8%
GA	82%	39%	32%	20%	8%
IN	74%	46%	33%	17%	9%
MD	79%	38%	42%	15%	8%
MN	81%	41%	14%	16%	8%
NH	76%	37%	31%	14%	10%
NJ	76%	33%	44%	16%	8%
ND	79%	36%	23%	18%	8%
PA	89%	43%	36%	16%	9%
Weighted NCI-IDD Average	78%	36%	33%	16%	8%

Table 7b. Family Member’s Conditions (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State	Hearing loss (severe or profound)	Brain Injury	Seizure or Neurological Disorder	Chemical Dependency
AZ	5%	8%	22%	0%
CA	6%	7%	24%	1%
DE	8%	8%	30%	0%
GA	6%	7%	29%	0%
IN	7%	8%	26%	1%
MD	6%	8%	27%	1%
MN	9%	5%	24%	0%
NH	4%	18%	31%	1%
NJ	6%	8%	27%	0%
ND	4%	10%	32%	0%
PA	6%	8%	27%	0%
Weighted NCI-IDD Average	6%	8%	25%	0%

Table 7c. Family Member’s Conditions (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
AZ	11%	1%	3%	13%
CA	8%	1%	1%	11%
DE	10%	1%	2%	7%
GA	10%	4%	1%	10%
IN	6%	0%	2%	12%
MD	10%	1%	1%	14%
MN	15%	1%	2%	14%
NH	7%	0%	2%	13%
NJ	8%	1%	0%	13%
ND	13%	0%	1%	18%
PA	11%	1%	2%	12%
Weighted NCI-IDD Average	10%	1%	1%	12%

Table 8a. Family Member’s Health Conditions

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	12%	13%	6%	35%	36%
CA	8%	20%	6%	31%	29%
DE	6%	28%	6%	25%	30%
GA	7%	18%	5%	42%	41%
IN	9%	26%	4%	33%	36%
MD	9%	21%	6%	31%	33%
MN	10%	17%	6%	33%	28%
NH	11%	21%	9%	22%	24%
NJ	8%	20%	5%	31%	39%
ND	7%	15%	6%	27%	22%
PA	12%	19%	6%	29%	27%
Weighted NCI-IDD Average	9%	19%	6%	31%	31%

Table 8b. Family Member’s Health Conditions (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Dementia	Oral Health Problems	Sleep Apnea
AZ	5%	3%	7%	16%	15%
CA	9%	2%	3%	17%	14%
DE	16%	3%	7%	13%	25%
GA	10%	2%	4%	18%	15%
IN	15%	3%	4%	17%	22%
MD	10%	3%	5%	12%	13%
MN	7%	1%	7%	13%	22%
NH	14%	3%	4%	13%	17%
NJ	10%	1%	1%	13%	11%
ND	18%	3%	6%	9%	24%
PA	16%	2%	5%	18%	17%
Weighted NCI-IDD Average	11%	2%	4%	16%	16%

Table 8c. Family Member’s Health Conditions (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State	Asthma	Other pulmonary diagnosis (e.g., COPD, bronchitis, emphysema)	Chronic kidney disease	Long-term health problems associated with COVID-19 (also known as Long COVID)	Other
AZ	10%	7%	7%	2%	21%
CA	11%	5%	3%	1%	23%
DE	10%	0%	6%	0%	13%
GA	7%	5%	5%	1%	20%
IN	13%	6%	4%	1%	20%
MD	13%	4%	4%	0%	26%
MN	10%	1%	6%	0%	26%
NH	8%	5%	2%	0%	15%
NJ	8%	3%	2%	0%	27%
ND	10%	3%	6%	0%	23%
PA	11%	3%	4%	1%	22%
Weighted NCI-IDD Average	11%	4%	4%	1%	23%

Table 9. Family Member’s Preferred Means of Communication

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
AZ	81%	13%	3%	1%	3%	198
CA	82%	11%	2%	1%	4%	5173
DE	73%	17%	3%	1%	6%	155
GA	82%	16%	1%	0%	2%	200
IN	86%	11%	1%	1%	2%	380
MD	77%	16%	2%	2%	4%	460
MN	86%	10%	1%	1%	2%	394
NH	84%	12%	1%	3%	1%	333
NJ	79%	11%	2%	2%	6%	357
ND	75%	16%	3%	3%	2%	268
PA	80%	12%	1%	1%	6%	532
Weighted NCI-IDD Average	82%	12%	1%	1%	4%	8450

Table 10. Family Member’s Preferred Language

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AZ	96%	2%	0%	0%	0%	1%	2%	199
CA	94%	1%	0%	0%	0%	1%	3%	5192
DE	96%	0%	0%	0%	0%	1%	3%	158
GA	98%	1%	1%	0%	0%	1%	1%	200
IN	99%	0%	0%	0%	0%	1%	0%	390
MD	97%	0%	0%	0%	0%	1%	1%	459
MN	98%	0%	0%	0%	0%	1%	1%	403
NH	99%	0%	0%	0%	0%	0%	1%	331
NJ	97%	0%	0%	0%	0%	1%	1%	357
ND	97%	0%	0%	0%	0%	2%	1%	268
PA	98%	0%	0%	0%	0%	0%	1%	532
Weighted NCI-IDD Average	96%	1%	0%	0%	0%	1%	2%	8489

Table note: “Chinese” includes Mandarin, Cantonese, and Hokkien. “Tagalog” includes Filipino.

Table 11. Family Member Has Legal Court Appointed Guardian or Conservator

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	No guardianship	Limited guardianship	Full guardianship	Has guardianship but level unknown	N
AZ	11%	9%	74%	6%	196
CA	40%	30%	24%	6%	4857
DE	20%	8%	62%	10%	154
GA	32%	15%	48%	6%	190
IN	14%	10%	72%	4%	390
MD	34%	15%	47%	4%	437
MN	5%	5%	85%	5%	407
NH	10%	12%	74%	3%	331
NJ	20%	11%	65%	4%	350
ND	0%	21%	76%	3%	267
PA	36%	19%	40%	6%	486
Weighted NCI-IDD Average	29%	19%	46%	5%	8065

Table 12. Guardian or Conservator Relationship to Family Member

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

State	Family	Friend	Employee of state or guardianship agency	Other	N
AZ	85%	2%	6%	6%	172
CA	90%	2%	6%	3%	2706
DE	95%	0%	4%	2%	114
GA	92%	2%	3%	3%	120
IN	86%	4%	5%	5%	316
MD	86%	0%	8%	6%	280
MN	77%	2%	17%	4%	375
NH	97%	2%	1%	0%	291
NJ	95%	0%	3%	1%	275
ND	89%	2%	4%	5%	265
PA	86%	1%	11%	2%	271
Weighted NCI-IDD Average	87%	2%	8%	3%	5185

Table 13a. Family Member’s Highest Level of Education

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	Did not complete high school – Not currently in school	Currently enrolled in high school	High school certificate (NOT a high school diploma/GED)	N
AZ	28%	1%	30%	192
CA	33%	1%	30%	4937
DE	40%	2%	44%	151
GA	29%	0%	44%	191
IN	31%	0%	38%	382
MD	21%	1%	48%	453
MN	21%	0%	31%	388
NH	29%	0%	30%	322
NJ	31%	0%	23%	349
ND	17%	0%	31%	258
PA	30%	1%	30%	504
Weighted NCI-IDD Average	30%	0%	32%	8127

Table 13b. Family Member’s Highest Level of Education (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	High school diploma/GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	33%	1%	4%	3%	192
CA	21%	3%	7%	6%	4937
DE	11%	1%	2%	1%	151
GA	23%	1%	2%	2%	191
IN	23%	2%	3%	4%	382
MD	19%	2%	2%	7%	453
MN	40%	2%	1%	5%	388
NH	31%	3%	2%	5%	322
NJ	29%	3%	5%	9%	349
ND	45%	2%	2%	3%	258
PA	36%	2%	1%	0%	504
Weighted NCI-IDD Average	27%	2%	4%	4%	8127

Table 14. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	No support needed; no issues with managing behavior	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
AZ	34%	40%	26%	198
CA	41%	35%	24%	5068
DE	29%	40%	30%	156
GA	32%	41%	27%	196
IN	28%	47%	25%	389
MD	36%	37%	27%	453
MN	39%	39%	22%	399
NH	39%	40%	21%	331
NJ	36%	39%	25%	348
ND	33%	41%	26%	266
PA	31%	40%	28%	523
Weighted NCI-IDD Average	37%	38%	25%	8327

Table 15. Family Member’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	No support needed; no issues with personal care activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
AZ	16%	50%	35%	199
CA	29%	36%	35%	5154
DE	20%	40%	41%	158
GA	23%	39%	39%	200
IN	31%	40%	30%	392
MD	18%	39%	43%	460
MN	20%	42%	39%	407
NH	24%	36%	40%	332
NJ	20%	41%	39%	356
ND	10%	46%	45%	269
PA	22%	39%	39%	530
Weighted NCI-IDD Average	24%	39%	37%	8457

Table 16. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)

Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State	No support needed; no issues with other daily activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
AZ	2%	13%	85%	198
CA	5%	28%	67%	5163
DE	0%	15%	85%	159
GA	4%	19%	77%	201
IN	3%	24%	74%	395
MD	2%	14%	85%	459
MN	1%	18%	81%	409
NH	1%	22%	77%	334
NJ	1%	19%	80%	355
ND	0%	18%	82%	270
PA	2%	15%	83%	532
Weighted NCI-IDD Average	3%	21%	76%	8475

Respondents

This section provides information about the survey respondent.

Table 17. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AZ	99%	1%	0%	0%	0%	0%	1%	200
CA	94%	2%	1%	0%	0%	0%	2%	5177
DE	100%	0%	0%	0%	0%	0%	0%	158
GA	99%	0%	0%	0%	0%	0%	1%	201
IN	99%	0%	0%	0%	0%	0%	0%	391
MD	99%	0%	0%	0%	0%	0%	1%	446
MN	100%	0%	0%	0%	0%	0%	0%	401
NH	100%	0%	0%	0%	0%	0%	0%	333
NJ	98%	1%	0%	0%	0%	0%	1%	343
ND	100%	0%	0%	0%	0%	0%	0%	267
PA	99%	0%	0%	0%	0%	0%	1%	530
Weighted NCI-IDD Average	97%	1%	0%	0%	0%	0%	1%	8447

Table note: “Chinese” includes Mandarin, Cantonese, and Hokkien. “Tagalog” includes Filipino.

Table 18. Respondent's Age

State	18 - 34	35 - 54	55 - 74	75 or older	N
AZ	3%	18%	58%	22%	198
CA	1%	8%	55%	35%	5179
DE	1%	8%	64%	28%	159
GA	0%	9%	65%	26%	201
IN	2%	13%	63%	22%	393
MD	2%	8%	72%	17%	459
MN	2%	13%	65%	19%	396
NH	1%	8%	70%	22%	332
NJ	0%	4%	65%	31%	357
ND	0%	17%	66%	16%	269
PA	1%	9%	65%	25%	530
Weighted NCI-IDD Average	1%	9%	61%	28%	8473

Table 19. Respondent's Health

State	Excellent	Very good	Good	Fair	Poor	N
AZ	15%	37%	34%	12%	3%	197
CA	15%	35%	33%	15%	3%	5220
DE	16%	32%	35%	13%	4%	158
GA	15%	29%	35%	16%	3%	201
IN	14%	33%	38%	15%	1%	393
MD	15%	39%	32%	13%	2%	460
MN	15%	40%	36%	9%	0%	393
NH	21%	36%	30%	11%	2%	330
NJ	14%	38%	34%	12%	1%	356
ND	13%	44%	31%	11%	0%	271
PA	14%	34%	34%	15%	3%	528
Weighted NCI-IDD Average	15%	36%	34%	14%	2%	8507

Table 20. Respondent’s Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public guardian	Private Guardian	Other	N
AZ	55%	23%	0%	2%	7%	6%	9%	200
CA	68%	19%	0%	1%	0%	1%	10%	5193
DE	65%	24%	0%	3%	0%	1%	8%	159
GA	63%	22%	0%	1%	2%	1%	12%	198
IN	59%	20%	0%	3%	2%	6%	10%	387
MD	69%	21%	0%	0%	2%	2%	6%	462
MN	48%	23%	0%	1%	9%	11%	9%	394
NH	62%	26%	1%	2%	0%	3%	7%	333
NJ	71%	27%	0%	0%	0%	0%	1%	354
ND	67%	19%	0%	1%	1%	2%	10%	270
PA	64%	32%	0%	2%	1%	1%	1%	531
Weighted NCI-IDD Average	64%	23%	0%	1%	2%	3%	7%	8481

Table 21. Respondent’s Frequency of Visits with Family Member Past 12 Months

State	Did not visit	1 to 3 times	4 to 6 times	7 to 12 times	More than 12 times	N
AZ	5%	10%	13%	14%	59%	197
CA	7%	11%	10%	11%	61%	5209
DE	3%	9%	16%	11%	60%	158
GA	3%	12%	10%	11%	64%	201
IN	3%	6%	11%	9%	71%	391
MD	2%	7%	8%	11%	72%	458
MN	0%	11%	12%	13%	64%	403
NH	4%	11%	16%	14%	55%	332
NJ	4%	10%	9%	10%	67%	355
ND	3%	8%	11%	7%	70%	271
PA	3%	12%	11%	11%	63%	533
Weighted NCI-IDD Average	4%	11%	11%	11%	63%	8508

Table 22. Respondent's Highest Level of Education

State	No high school diploma or GED	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	5%	15%	5%	25%	50%	194
CA	4%	11%	4%	23%	58%	5160
DE	3%	16%	3%	26%	52%	155
GA	4%	21%	7%	15%	54%	198
IN	3%	25%	7%	19%	47%	378
MD	2%	13%	2%	15%	69%	454
MN	2%	16%	14%	19%	50%	383
NH	2%	20%	3%	15%	61%	328
NJ	1%	10%	2%	17%	71%	350
ND	1%	18%	10%	16%	54%	269
PA	2%	27%	8%	17%	46%	526
Weighted NCI-IDD Average	3%	16%	6%	20%	55%	8395

Table 23. Total Taxable Household Income of Wage Earners in the Last Year

Please note: Respondents did not respond if they were a public guardian/administrator, or if they represent a financial institution or guardianship agency. Does not include state/federal benefits such as SSI, SSDI etc.

State	No earned income	Up to \$15,000	\$15,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	Over \$75,000	Prefer not to say	N
AZ	14%	3%	7%	15%	18%	19%	24%	183
CA	10%	4%	4%	12%	12%	26%	32%	5006
DE	9%	3%	3%	13%	13%	19%	41%	150
GA	8%	4%	9%	12%	12%	20%	35%	195
IN	10%	5%	6%	16%	13%	19%	30%	368
MD	7%	2%	4%	8%	8%	34%	36%	449
MN	5%	6%	6%	13%	14%	21%	36%	354
NH	8%	2%	6%	14%	12%	23%	36%	320
NJ	9%	4%	3%	10%	12%	28%	34%	353
ND	5%	3%	3%	13%	14%	28%	34%	265
PA	10%	4%	5%	12%	10%	20%	40%	512
Weighted NCI-IDD Average	9%	4%	5%	12%	12%	24%	34%	8155

Services and Supports Received

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

Please note: All data in this section are reported by the respondent based on their understanding of their family member's services and supports received.

Table 24a. Services and Supports Received from IDD Agency

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics. Categories are not mutually exclusive; therefore, N is not shown.

State	Financial support	In-home support	Residential supports	Day or employment supports
AZ	22%	27%	91%	68%
CA	38%	47%	67%	64%
DE	30%	36%	98%	59%
GA	32%	47%	77%	65%
IN	34%	68%	68%	53%
MD	26%	41%	87%	68%
MN	44%	39%	91%	67%
NH	46%	33%	76%	45%
NJ	34%	39%	83%	80%
ND	31%	49%	85%	85%
PA	26%	31%	94%	52%
Weighted NCI-IDD Average	34%	42%	79%	63%

Table 24b. Services and Supports Received from IDD Agency (Continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics. Categories are not mutually exclusive; therefore, N is not shown.

State	Transportation	Mental or behavioral health care or other treatments or therapies	Self-direction or fiscal intermediary services
AZ	96%	60%	24%
CA	65%	37%	21%
DE	97%	68%	7%
GA	92%	55%	27%
IN	87%	72%	33%
MD	93%	59%	14%
MN	94%	54%	16%
NH	85%	54%	22%
NJ	90%	59%	28%
ND	97%	61%	18%
PA	94%	67%	11%
Weighted NCI-IDD Average	82%	52%	20%

Table 25. Additional Services and Supports Received (not from the IDD Agency)

Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics. Categories are not mutually exclusive; therefore, N is not shown

State	Social Security (SSI or SSB)	Services or supports from other agencies or organizations
AZ	94%	28%
CA	90%	27%
DE	97%	32%
GA	98%	20%
IN	94%	39%
MD	96%	25%
MN	97%	26%
NH	93%	26%
NJ	98%	28%
ND	97%	39%
PA	97%	33%
Weighted NCI-IDD Average	94%	28%

Main Survey Results

Information and Planning

Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state developmental disabilities system.

Note: Significance is based on “Always” or “Yes” response.

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

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

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

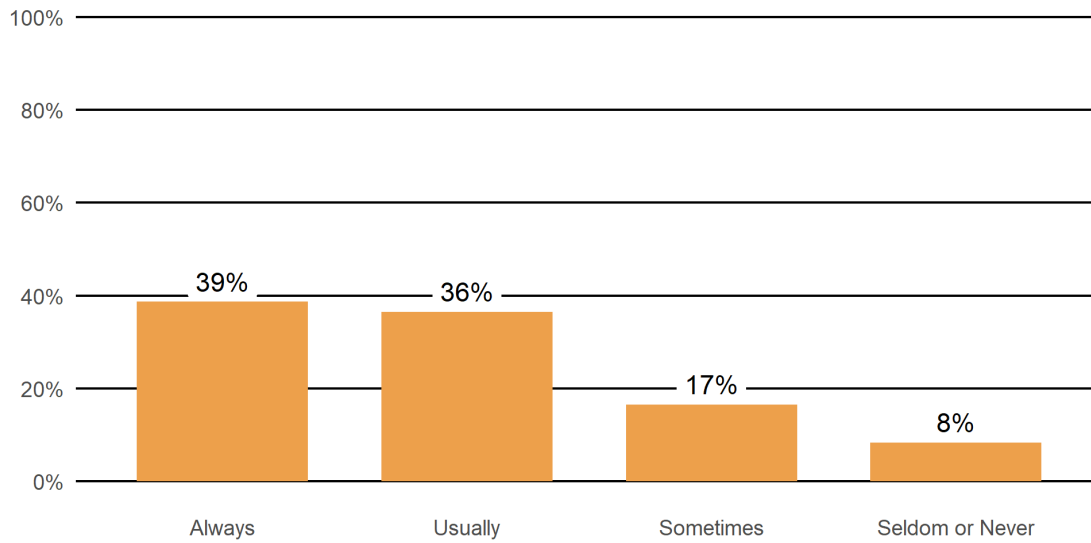


Table 26. Do you get enough information to take part in planning services for your family member?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	56%	35%	8%	1%	394
ND ↑	51%	41%	6%	2%	261
NH ↑	49%	39%	10%	2%	324
AZ	48%	35%	14%	4%	192
Weighted NCI-IDD Average	39%	36%	17%	8%	7769
PA	37%	39%	17%	7%	479
NJ	36%	34%	20%	10%	340
CA	35%	35%	17%	12%	4636
IN	34%	39%	20%	6%	365
GA	34%	38%	18%	11%	186
MD ↓	33%	38%	20%	9%	440
DE ↓	29%	43%	23%	5%	152

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

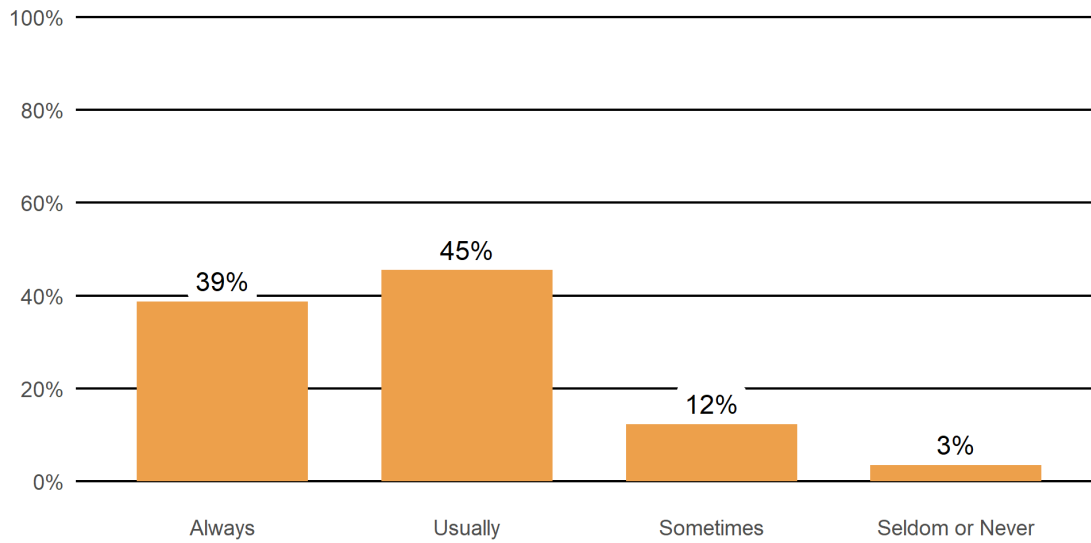


Table 27. Is the information you get about services and supports easy to understand?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
ND ↑	51%	42%	6%	0%	265
MN	44%	44%	10%	2%	397
NH	43%	47%	9%	1%	326
CA	41%	43%	11%	4%	4499
PA	40%	47%	10%	3%	480
Weighted NCI-IDD Average	39%	45%	12%	3%	7636
GA	38%	46%	12%	3%	185
AZ	35%	49%	15%	2%	195
NJ	34%	46%	15%	5%	331
MD ↓	29%	47%	18%	6%	440
IN ↓	29%	47%	20%	4%	367
DE ↓	25%	60%	15%	1%	151

Do you get information about services and supports in your preferred language?

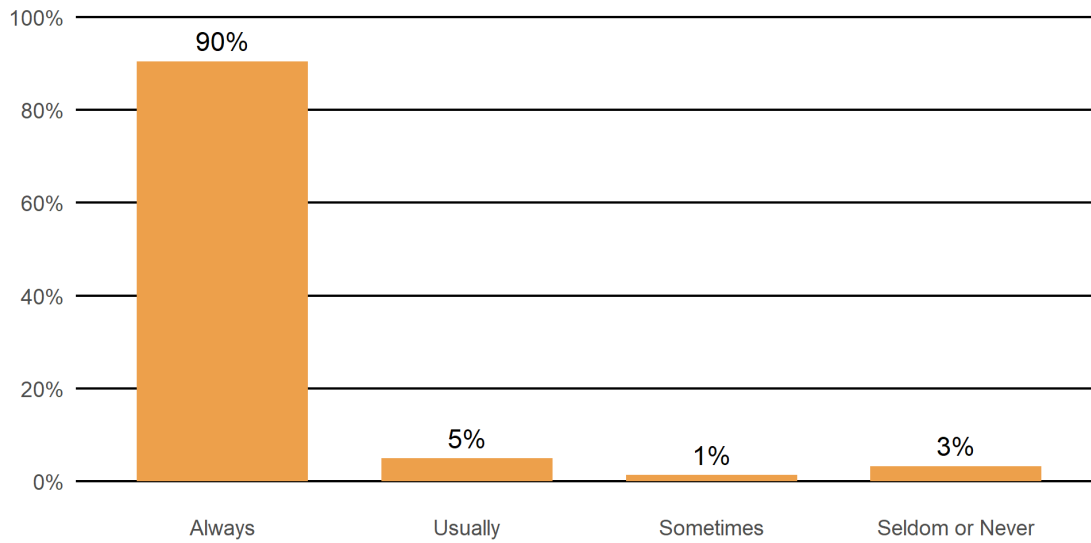


Table 28. Do you get information about services and supports in your preferred language?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
ND ↑	98%	2%	0%	0%	268
MN ↑	97%	3%	0%	0%	402
NH ↑	96%	3%	0%	1%	330
DE	94%	3%	2%	1%	157
PA	93%	4%	1%	3%	517
NJ	92%	3%	1%	4%	347
AZ	91%	7%	1%	1%	196
GA	91%	5%	1%	3%	194
IN	91%	6%	2%	2%	379
Weighted NCI-IDD Average	90%	5%	1%	3%	8086
MD	90%	7%	1%	3%	450
CA ↓	87%	6%	2%	5%	4846

Does the case manager or service coordinator listen to your family's choices and opinions?

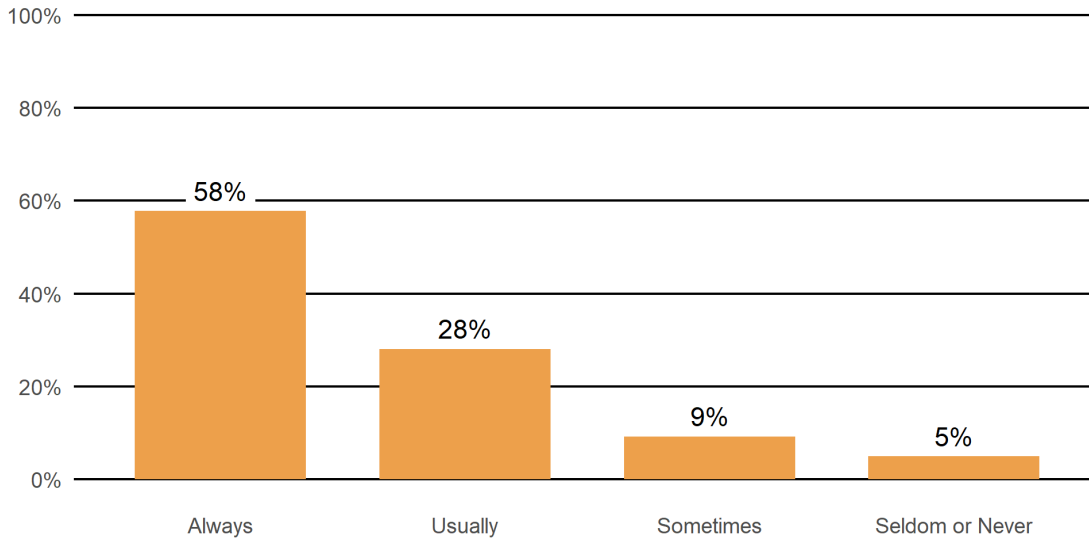


Table 29. Does the case manager or service coordinator listen to your family's choices and opinions?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	71%	24%	5%	1%	400
IN ↑	69%	22%	7%	2%	369
NH ↑	66%	24%	7%	2%	322
NJ	64%	24%	9%	2%	341
AZ	60%	28%	9%	3%	192
ND	58%	33%	7%	1%	267
Weighted NCI-IDD Average	58%	28%	9%	5%	7751
PA	55%	31%	10%	4%	506
CA	54%	28%	10%	8%	4581
MD	52%	30%	13%	6%	436
GA ↓	44%	37%	12%	6%	187
DE ↓	43%	37%	14%	6%	150

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

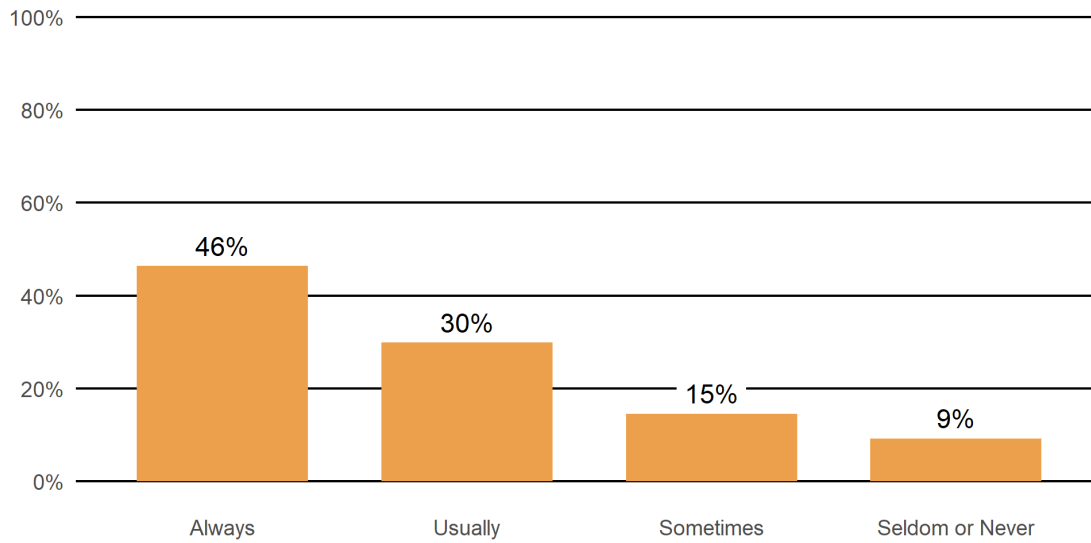


Table 30. Do staff or the residential agency keep you informed about how your family member is doing?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	58%	31%	9%	2%	396
NH ↑	57%	26%	12%	5%	320
AZ	52%	29%	13%	7%	195
ND	49%	38%	10%	3%	265
CA	47%	26%	14%	12%	4701
GA	47%	26%	18%	10%	188
Weighted NCI-IDD Average	46%	30%	15%	9%	7871
PA	45%	34%	14%	7%	516
NJ	42%	26%	20%	12%	328
DE	38%	35%	20%	8%	159
IN ↓	39%	37%	18%	6%	365
MD ↓	31%	36%	19%	14%	438

Do you need help planning for your family member's future in any of these areas?

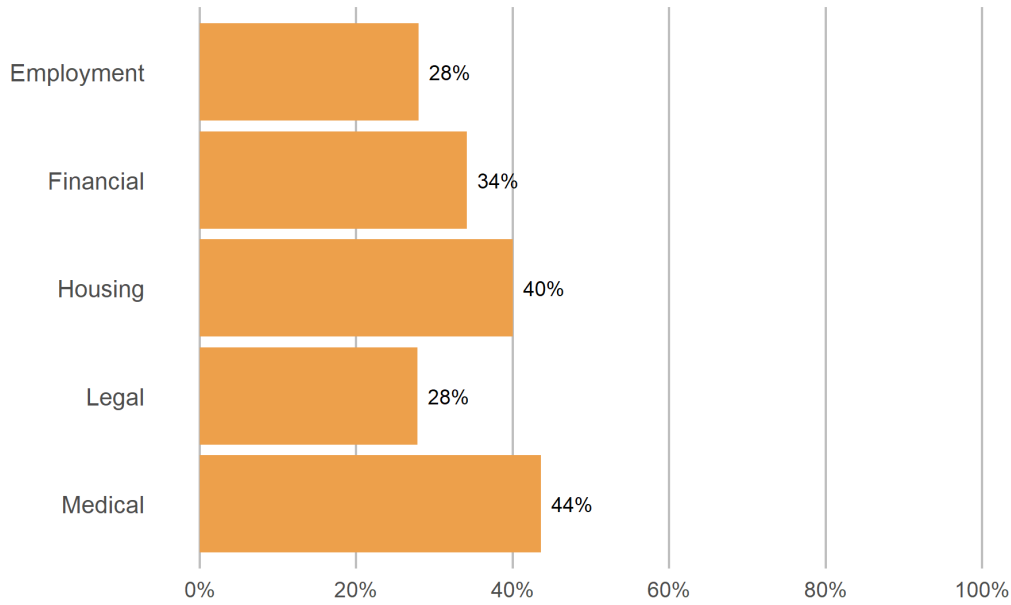


Table 31a. Do you need help planning for your family member's future in any of these areas?

Categories are not mutually exclusive, therefore N is not shown.

State	Employment	Financial	Housing	Legal	Medical
AZ	21%	20%	35%	22%	36%
CA	28%	35%	41%	25%	45%
DE	26%	34%	34%	30%	41%
GA	20%	32%	50%	33%	47%
IN	32%	41%	44%	28%	42%
MD	38%	36%	41%	34%	42%
MN	30%	29%	33%	22%	42%
NH	33%	49%	48%	32%	48%
NJ	23%	37%	43%	35%	46%
ND	34%	42%	41%	25%	42%
PA	25%	33%	36%	33%	43%
Weighted NCI-IDD Average	28%	34%	40%	28%	44%

Do you need help planning for your family member's future in any of these areas? (Continued)

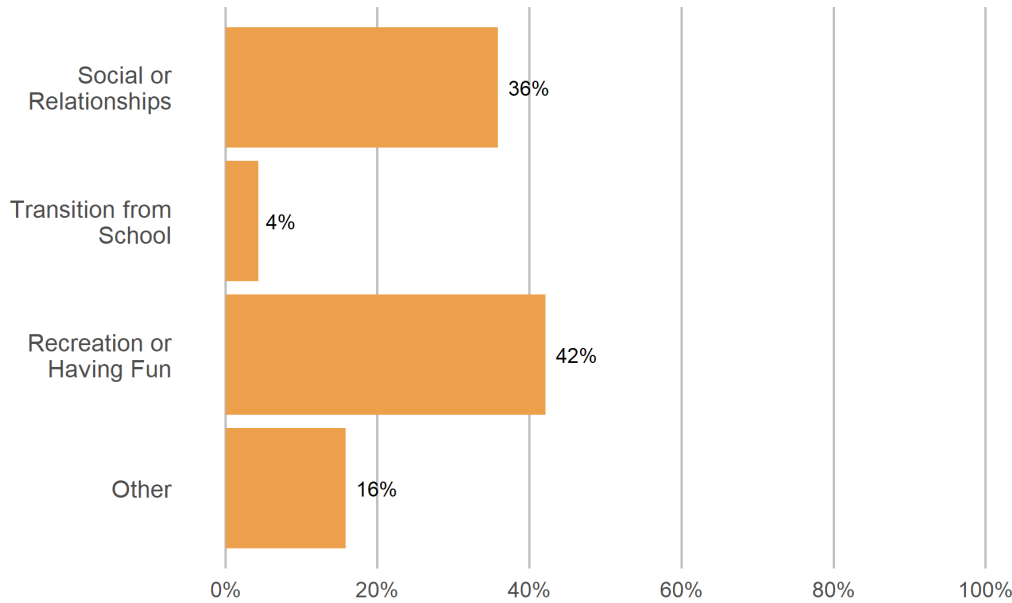


Table 31b. Do you need help planning for your family member's future in any of these areas? (Continued)

Categories are not mutually exclusive, therefore N is not shown.

State	Social or Relationships	Transition from School	Recreation or Having Fun	Other
AZ	24%	2%	32%	17%
CA	38%	6%	41%	14%
DE	34%	5%	37%	19%
GA	41%	1%	43%	16%
IN	37%	3%	43%	20%
MD	38%	2%	47%	16%
MN	25%	1%	49%	25%
NH	39%	4%	43%	11%
NJ	36%	2%	44%	16%
ND	37%	4%	36%	19%
PA	37%	5%	43%	14%
Weighted NCI-IDD Average	36%	4%	42%	16%

Has your family learned about alternatives to guardianship?

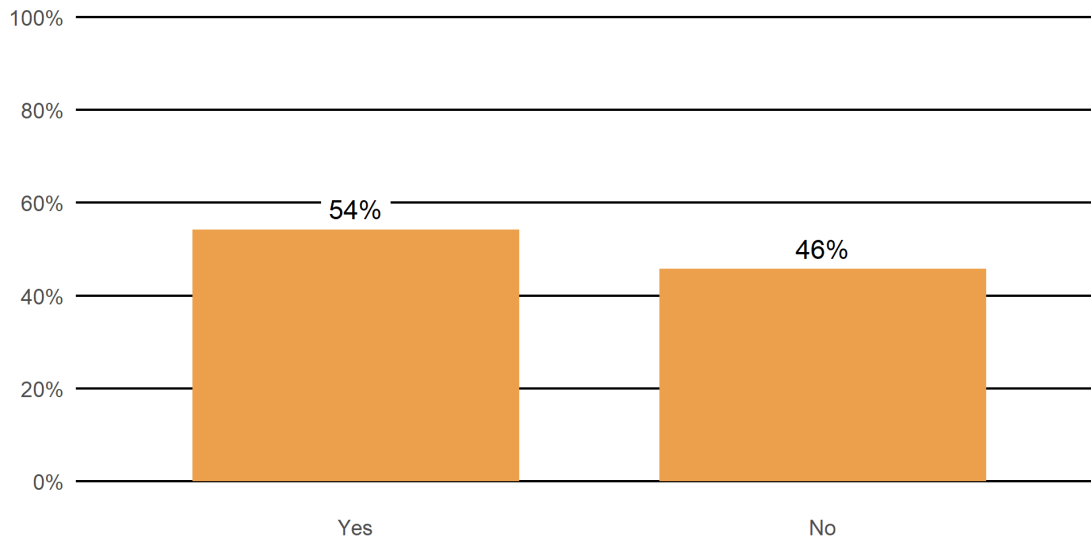


Table 32. Has your family learned about alternatives to guardianship?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND ↑	73%	27%	241
MN ↑	70%	30%	334
NH	61%	39%	277
IN	58%	42%	306
AZ	57%	43%	162
Weighted NCI-IDD Average	54%	46%	6560
MD	53%	47%	388
PA	51%	49%	374
CA	51%	49%	3914
NJ	50%	50%	299
GA	47%	53%	144
DE	43%	57%	121

Table note: Alternatives to guardianship let a family member make more decisions for themselves, with or without the help of others. This might include: **“Supported Decision Making (SDM)”**, allows a person with a disability to make their own decisions with the help of people they trust. **“Other decision-making supports”**, like health-care proxies, advance directives, powers of attorney, notarized statements, representation agreements, etc.

Does your family member have a service plan?

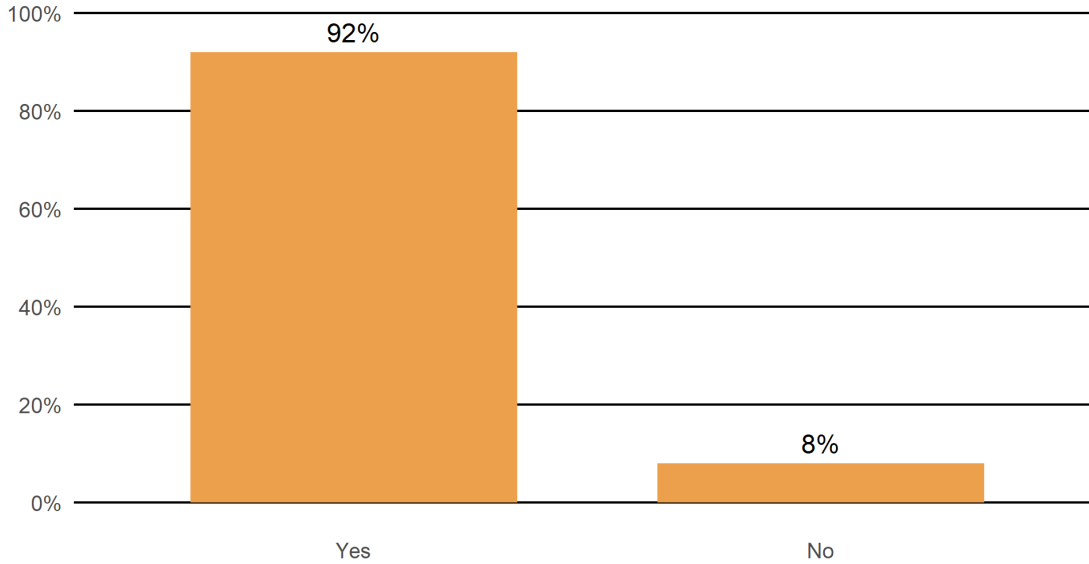


Table 33. Does your family member have a service plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
PA ↑	98%	2%	487
NH ↑	97%	3%	306
ND ↑	96%	4%	236
MD ↑	96%	4%	409
MN	93%	7%	337
NJ	93%	7%	290
Weighted NCI-IDD Average	92%	8%	6930
CA	90%	10%	4165
IN	88%	12%	296
GA	87%	13%	138
DE ↓	80%	20%	111
AZ ↓	77%	23%	155

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

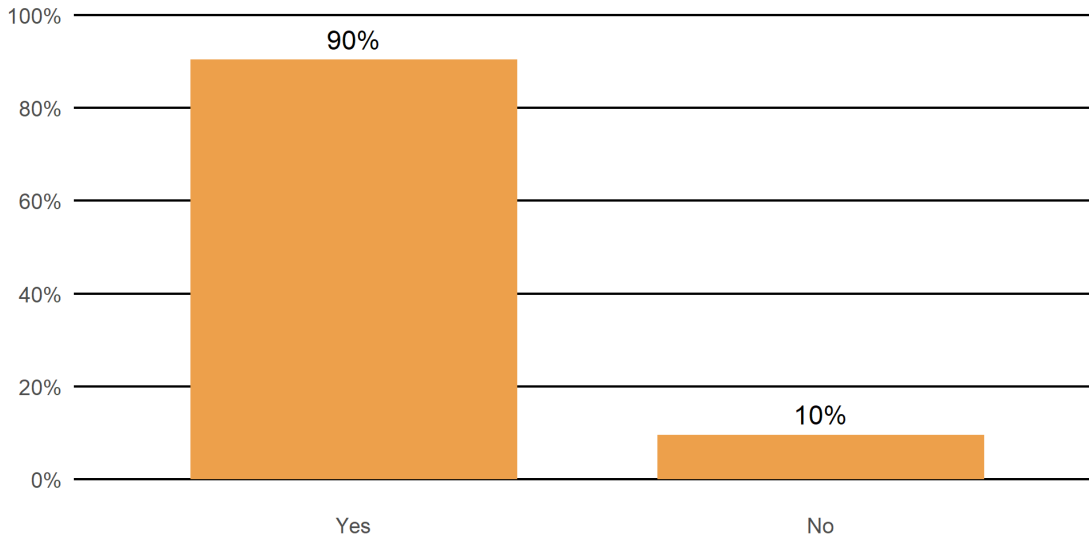


Table 34. Does the plan include all the services and supports your family member needs?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
MN ↑	96%	4%	302
ND ↑	95%	5%	214
PA ↑	94%	6%	436
AZ	95%	5%	110
DE	91%	9%	82
Weighted NCI-IDD Average	90%	10%	5633
NH	89%	11%	277
CA	89%	11%	3268
MD	88%	12%	359
IN	86%	14%	235
GA	83%	17%	104
NJ ↓	84%	16%	246

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

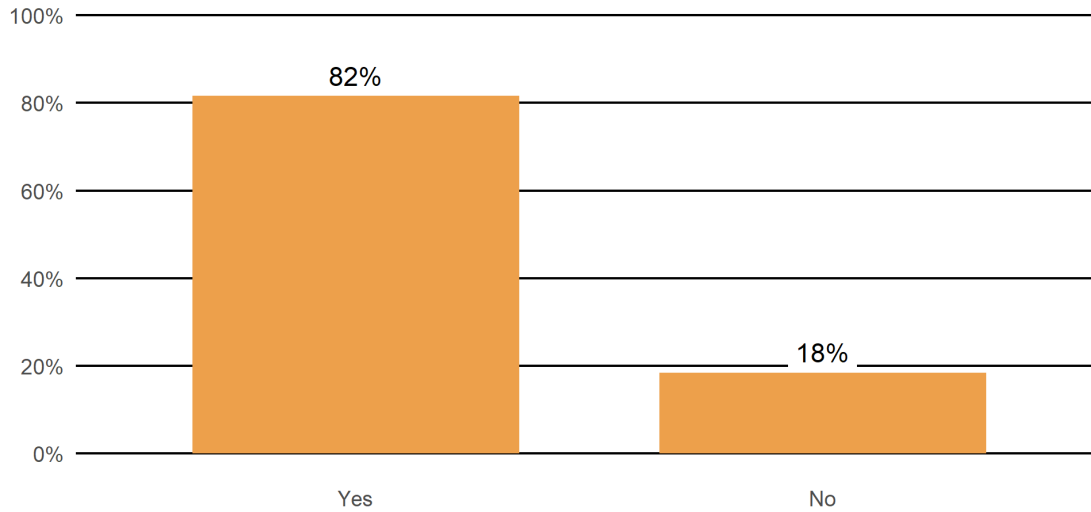


Table 35. Did you or someone else in your family (besides your family member with a disability) help make the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
NH ↑	91%	9%	282
ND ↑	90%	10%	219
MN ↑	89%	11%	302
NJ ↑	88%	12%	260
MD ↑	88%	12%	384
AZ	88%	12%	112
GA	87%	13%	111
DE	86%	14%	83
IN	86%	14%	242
Weighted NCI-IDD Average	82%	18%	5948
PA	79%	21%	447
CA ↓	76%	24%	3506

Did your family member help make the plan?

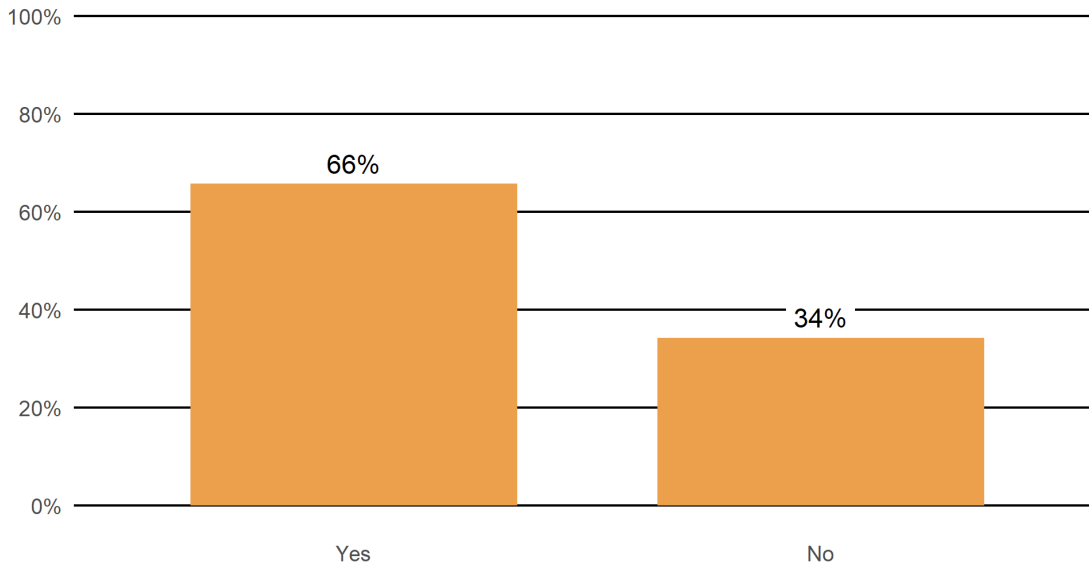


Table 36. Did your family member help make the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND ↑	81%	19%	217
MN ↑	77%	23%	299
MD	71%	29%	380
IN	71%	29%	237
GA	67%	33%	109
Weighted NCI-IDD Average	66%	34%	5804
CA	65%	35%	3409
NH	64%	36%	280
PA	63%	37%	426
AZ	56%	44%	108
DE	52%	48%	83
NJ ↓	52%	48%	256

Do you feel like your family had enough say or input in making the plan?

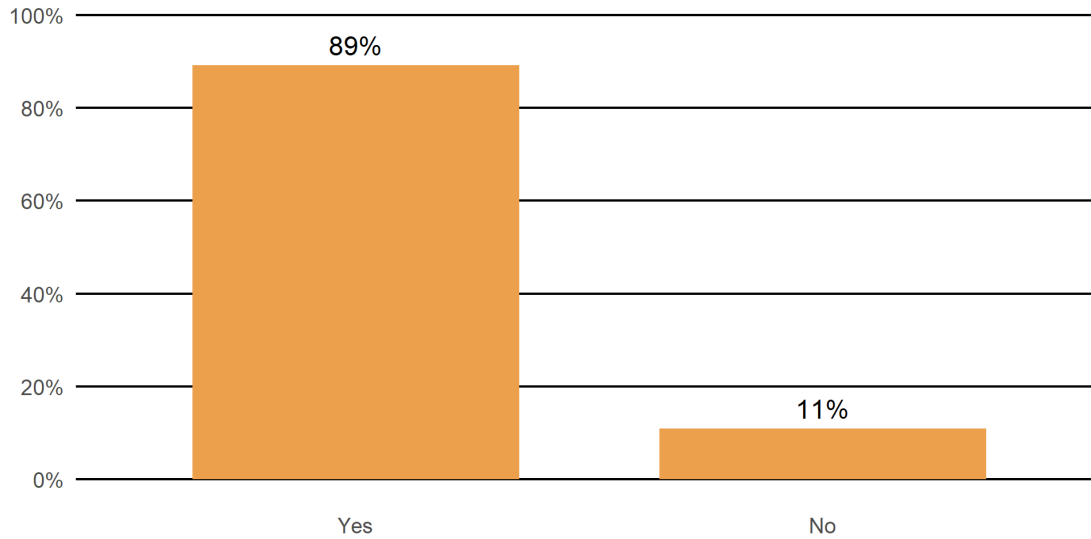


Table 37. Do you feel like your family had enough say or input in making the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
MN ↑	97%	3%	295
NH ↑	94%	6%	276
IN ↑	94%	6%	240
ND	93%	7%	213
AZ	92%	8%	108
DE	89%	11%	76
Weighted NCI-IDD Average	89%	11%	5651
PA	89%	11%	431
NJ	88%	12%	247
MD	88%	12%	364
CA	86%	14%	3301
GA	85%	15%	100

Did your family member leave school services and begin adult services during the past 12 months?

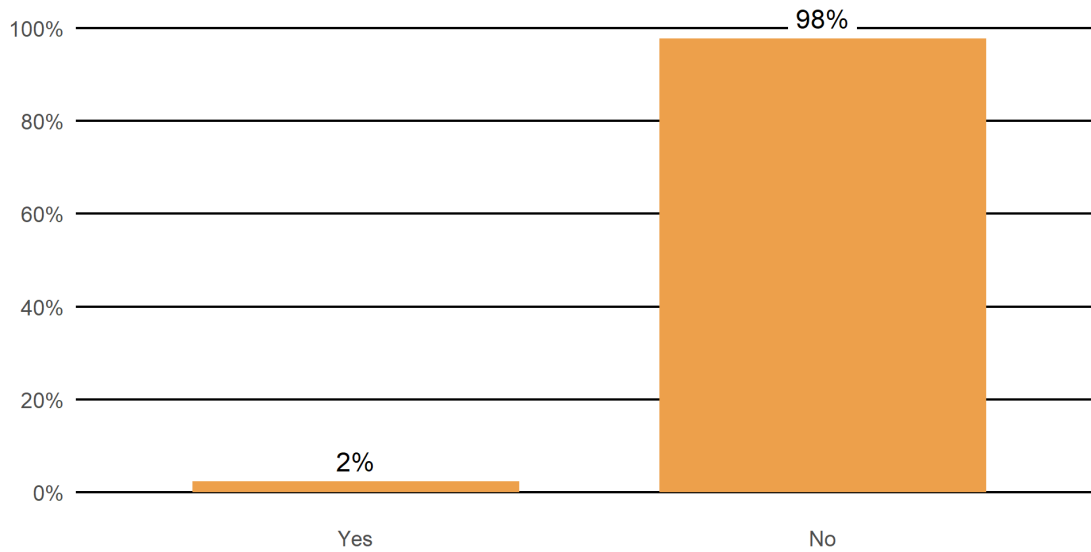


Table 38. Did your family member leave school services and begin adult services during the past 12 months?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND	3%	97%	262
CA	3%	97%	4753
MD	3%	97%	444
Weighted NCI-IDD Average	2%	98%	7915
AZ	2%	98%	187
PA	2%	98%	515
NJ	1%	99%	338
IN	1%	99%	370
NH ↓	1%	99%	317
GA ↓	1%	99%	180
MN ↓	1%	99%	396
DE ↓	0%	100%	153

If your family member left school services during the past 12 months, did your family member have a transition plan?

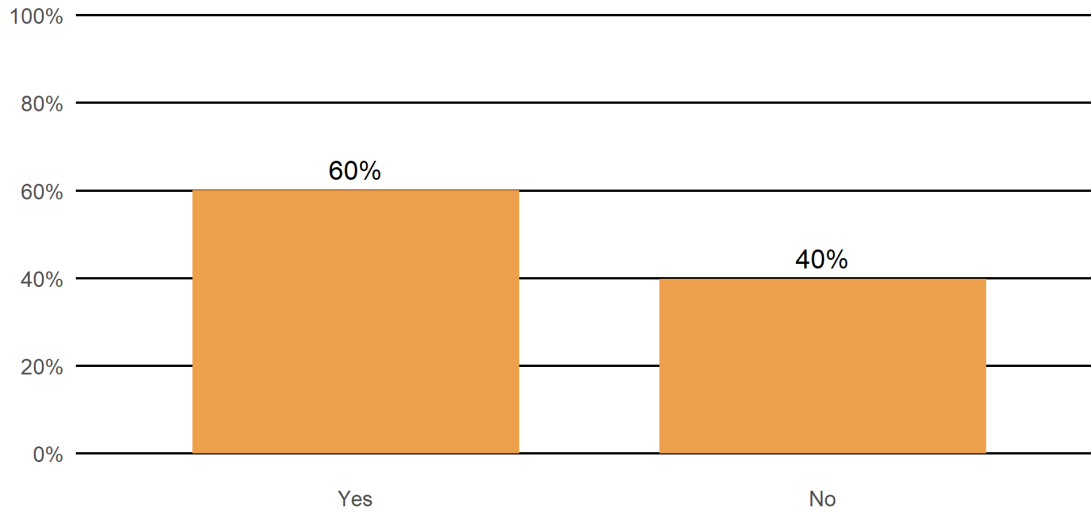


Table 39. If your family member left school services during the past 12 months, did your family member have a transition plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
Weighted NCI-IDD Average	60%	40%	135
CA ↓	43%	57%	101

Table note: The following states had an N of less than 20 and were not shown: AZ, DE, GA, IN, MD, MN, ND, NH, NJ, PA

If your family member had a transition plan, did the transition plan include getting or continuing work in a community job?

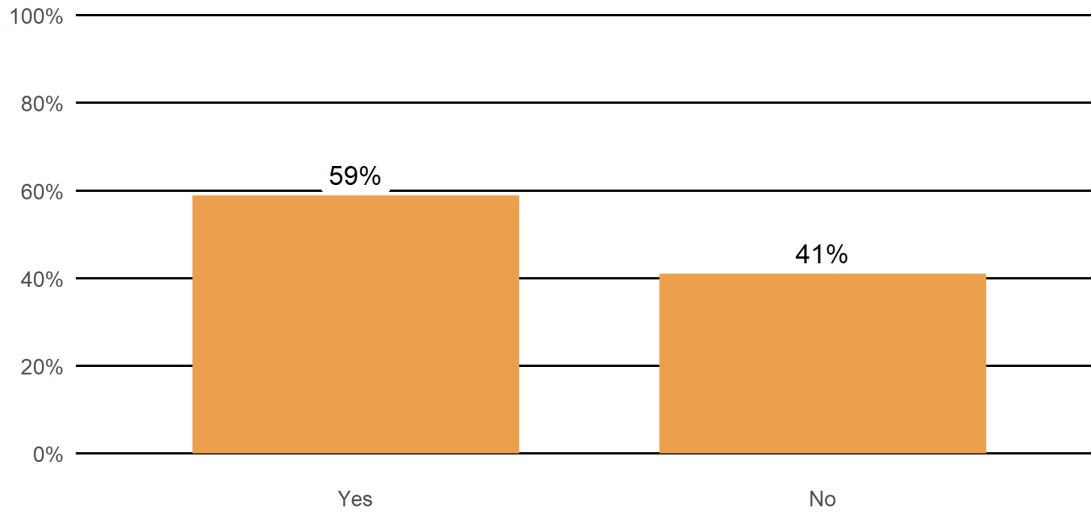


Table 40. If your family member had a transition plan, did the transition plan include getting or continuing work in a community job?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
Weighted NCI-IDD Average	59%	41%	60
CA	41%	59%	37

Table note: The following states had an N of less than 20 and were not shown: AZ, IN, DE, GA, MD, MN, ND, NH, NJ, PA

Access and Delivery of Services and Supports

Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state developmental disabilities system.

Note: Significance is based on “Always” or “Yes” response.

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

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

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

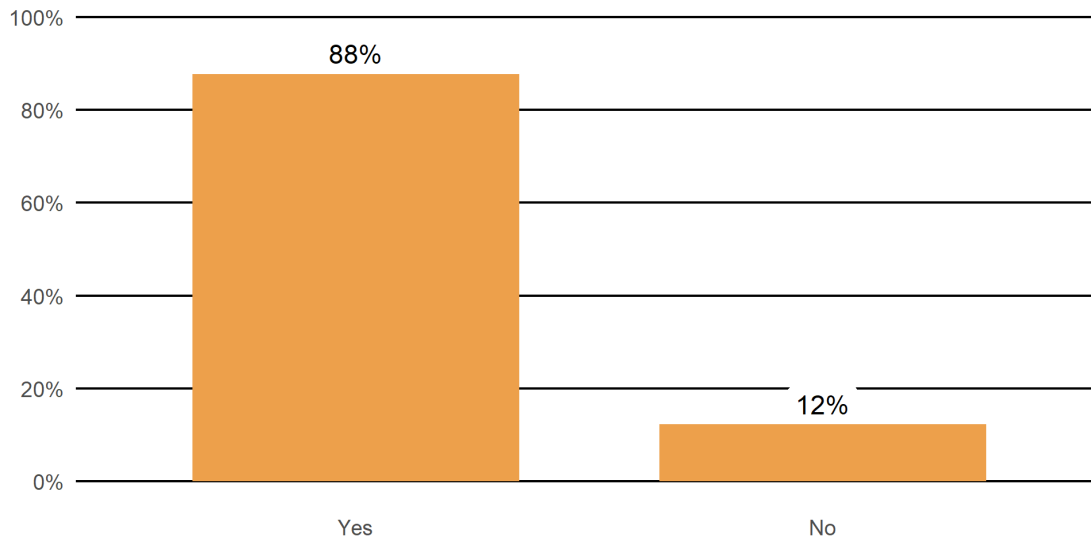


Table 41. Does your family member get all the services listed in the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
MN ↑	94%	6%	286
ND	92%	8%	208
NH	90%	10%	270
CA	89%	11%	3129
PA	89%	11%	405
Weighted NCI-IDD Average	88%	12%	5360
AZ	86%	14%	108
DE	85%	15%	75
NJ	85%	15%	236
GA	82%	18%	94
IN ↓	80%	20%	228
MD ↓	79%	21%	321

Does your family get the supports and services it needs?

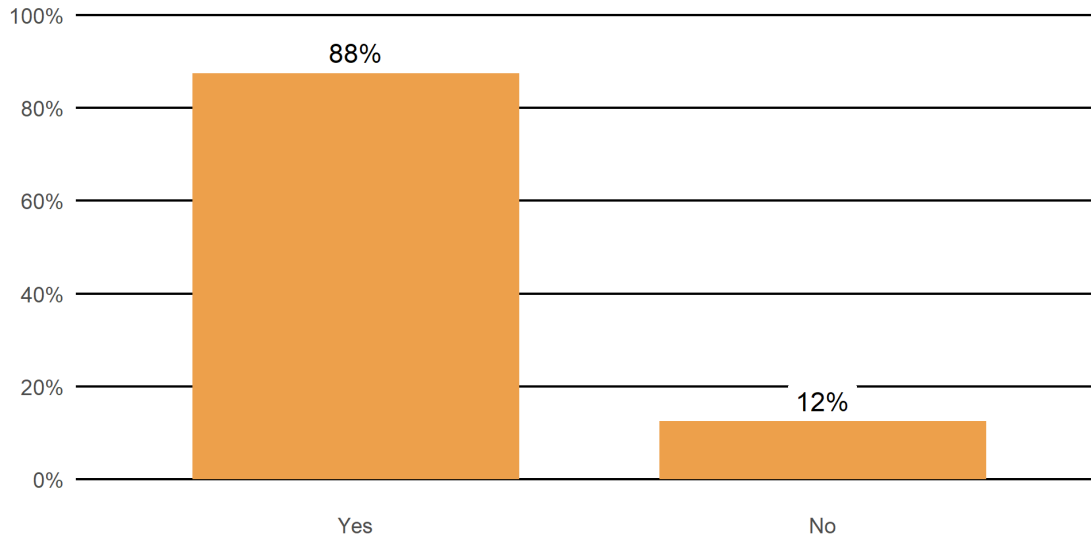


Table 42. Does your family get the supports and services it needs?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
MN ↑	92%	8%	380
ND	91%	9%	254
PA	90%	10%	471
AZ	88%	12%	173
Weighted NCI-IDD Average	88%	12%	7254
IN	87%	13%	336
CA	86%	14%	4326
NJ	85%	15%	301
NH	84%	16%	307
DE	83%	17%	138
MD	83%	17%	398
GA	83%	17%	170

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

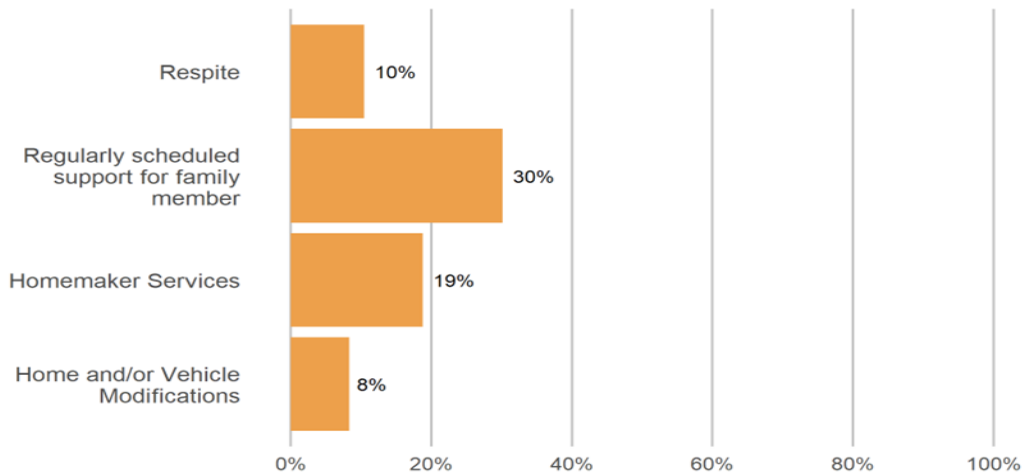


Table 43a. If your family does not get the support and services needed, what additional services does your family need?

Categories are not mutually exclusive, therefore N is not shown.

State	Respite	Regularly scheduled support for family member	Homemaker Services	Home or Vehicle Modifications
CA	9%	33%	20%	6%
DE	19%	19%	10%	5%
GA	15%	30%	11%	15%
IN	21%	46%	26%	13%
MD	20%	31%	14%	15%
MN	4%	26%	37%	4%
NH	33%	39%	14%	2%
NJ	11%	18%	18%	5%
ND	0%	14%	5%	10%
PA	3%	28%	15%	10%
Weighted NCI-IDD Average	10%	30%	19%	8%

Table note: The following states had an N of less than 20 and were not shown: AZ

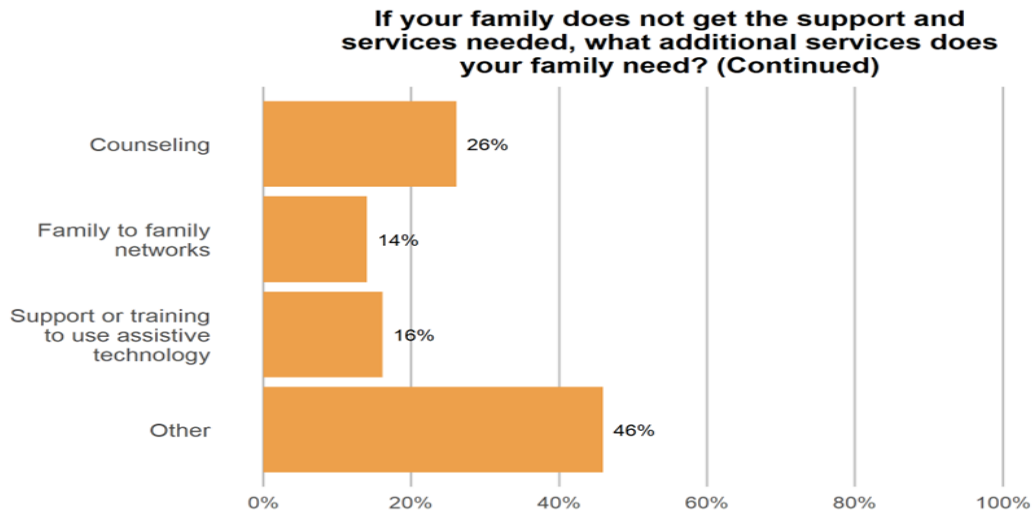


Table 43b If your family does not get the support and services needed, what additional services does your family need? (Continued)

Categories are not mutually exclusive, therefore N is not shown.

State	Counseling	Family to family networks	Support or training to use assistive technology	Other
CA	35%	13%	13%	46%
DE	14%	43%	19%	38%
GA	19%	11%	19%	44%
IN	26%	8%	13%	26%
MD	20%	20%	25%	46%
MN	11%	19%	26%	41%
NH	22%	12%	4%	51%
NJ	30%	11%	16%	57%
ND	10%	14%	10%	81%
PA	13%	15%	20%	55%
Weighted NCI-IDD Average	26%	14%	16%	46%

Table note: The following states had an N of less than 20 and were not shown: AZ

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

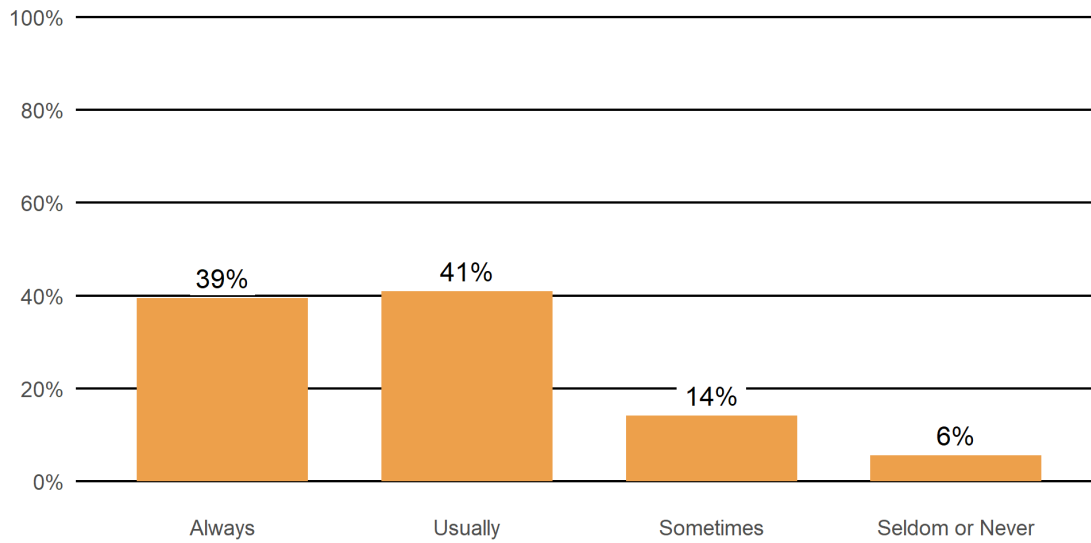


Table 44. Do services and supports change when your family's needs change?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	49%	38%	10%	3%	312
ND	44%	43%	10%	3%	213
PA	43%	38%	14%	5%	342
Weighted NCI-IDD Average	39%	41%	14%	6%	5563
CA	39%	42%	13%	6%	3258
NH	39%	37%	16%	8%	237
AZ	37%	41%	20%	2%	138
IN	35%	45%	16%	4%	293
DE	34%	48%	12%	5%	91
NJ	34%	39%	18%	9%	232
GA ↓	29%	43%	20%	8%	136
MD ↓	28%	44%	18%	11%	311

Does your family member have enough supports to work or volunteer in the community?

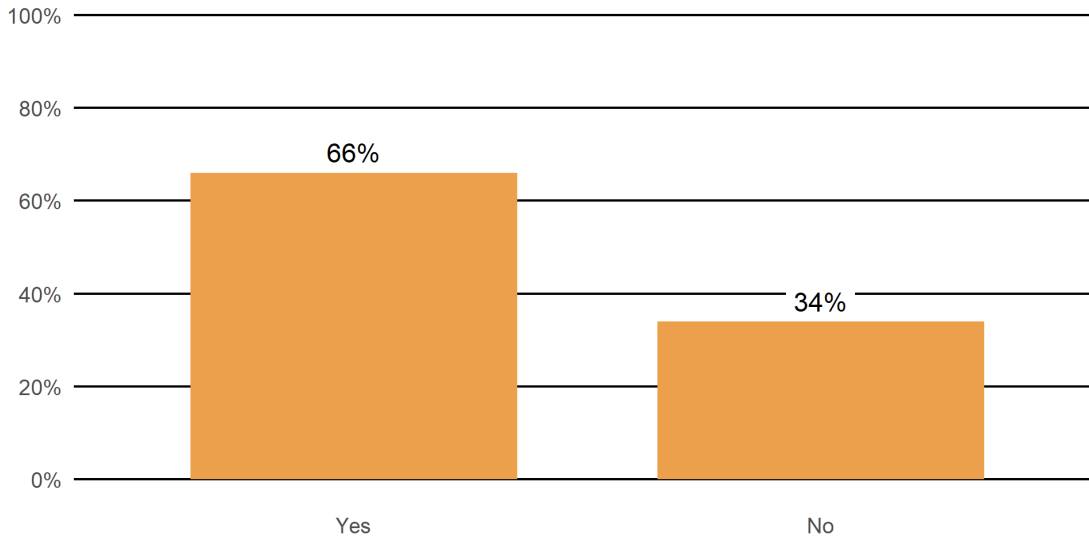


Table 45. Does your family member have enough supports to work or volunteer in the community? (These types of supports might include support workers, community resources, transportation)

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
MN ↑	81%	19%	275
ND ↑	81%	19%	209
PA	68%	32%	294
NH	68%	32%	206
IN	67%	33%	235
Weighted NCI-IDD Average	66%	34%	4937
DE	66%	34%	93
NJ	63%	37%	189
MD	63%	38%	288
CA	62%	38%	2928
AZ	57%	43%	108
GA	57%	43%	112

Does your family member have the special equipment or accommodations that they need?

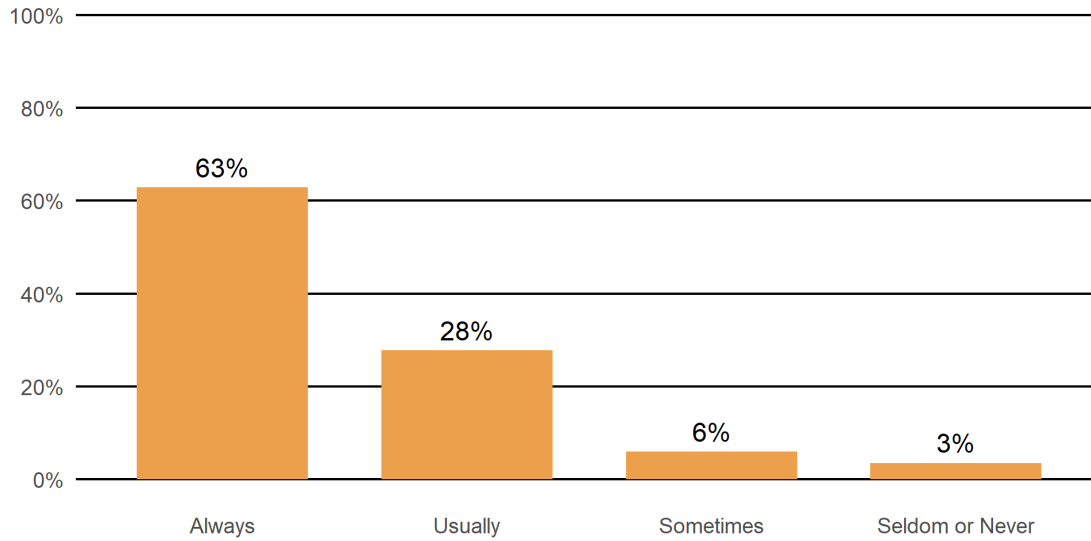


Table 46. Does your family member have the special equipment or accommodations that they need?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	69%	25%	4%	2%	230
PA	69%	26%	3%	2%	303
DE	65%	29%	4%	2%	84
AZ	65%	22%	12%	1%	114
ND	65%	29%	4%	2%	164
NH	64%	25%	8%	4%	170
Weighted NCI-IDD Average	63%	28%	6%	3%	4261
CA	61%	28%	6%	5%	2447
NJ	60%	28%	7%	5%	167
IN	59%	31%	8%	2%	228
GA	53%	36%	7%	4%	115
MD ↓	49%	33%	12%	6%	239

Are you or your family member able to contact support workers when you want?

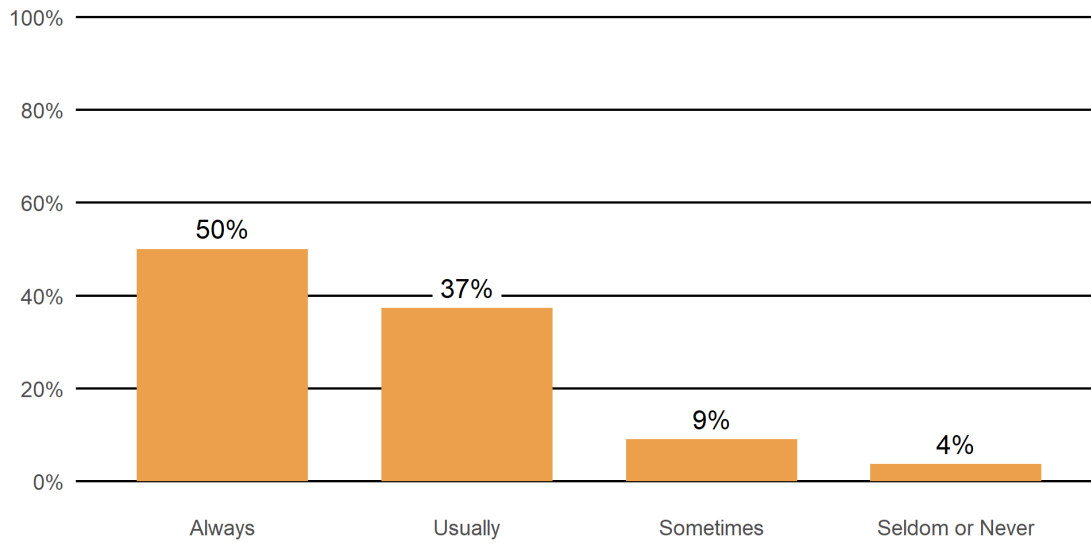


Table 47. Are you or your family member able to contact support workers when you want?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	60%	34%	6%	1%	381
NH	56%	36%	7%	2%	299
ND	55%	36%	6%	2%	265
PA	52%	37%	8%	3%	494
NJ	51%	36%	11%	2%	314
IN	50%	37%	10%	3%	370
Weighted NCI-IDD Average	50%	37%	9%	4%	7511
CA	48%	38%	9%	6%	4451
GA	47%	38%	10%	4%	192
AZ	47%	41%	10%	2%	189
DE	42%	45%	12%	1%	139
MD ↓	40%	40%	15%	5%	417

Are you or your family member able to contact the case manager or service coordinator when you want?

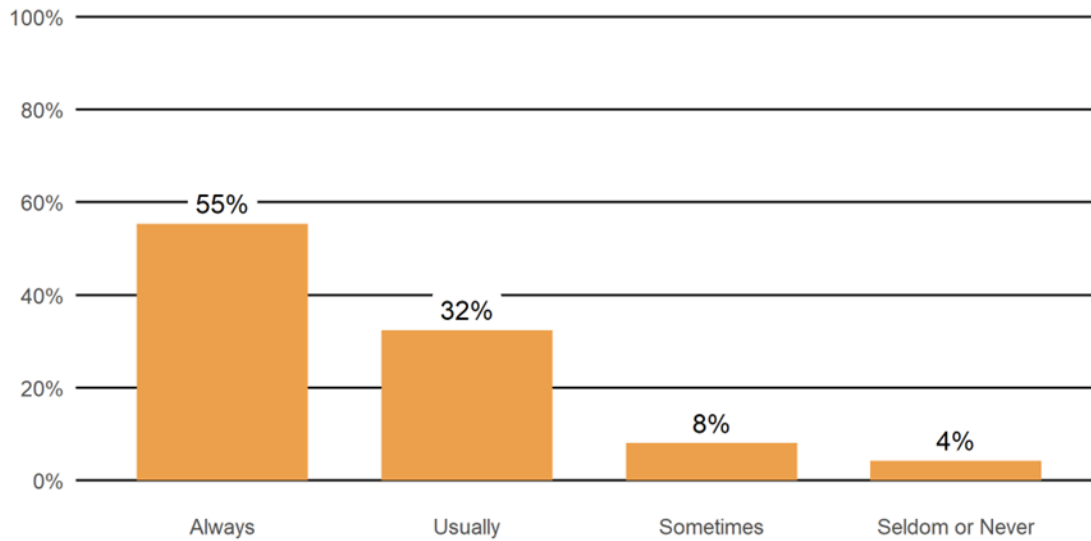


Table 48. Are you or your family member able to contact the case manager or service coordinator when you want?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN ↑	69%	25%	4%	1%	381
NJ ↑	67%	27%	5%	2%	326
MN ↑	64%	31%	4%	1%	399
NH ↑	64%	28%	6%	2%	327
ND	60%	35%	3%	1%	267
PA	57%	33%	7%	3%	499
Weighted NCI-IDD Average	55%	32%	8%	4%	7879
AZ	52%	36%	9%	3%	194
GA	51%	38%	8%	3%	189
MD	51%	36%	8%	5%	426
DE	48%	39%	9%	4%	137
CA ↓	49%	33%	10%	7%	4734

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

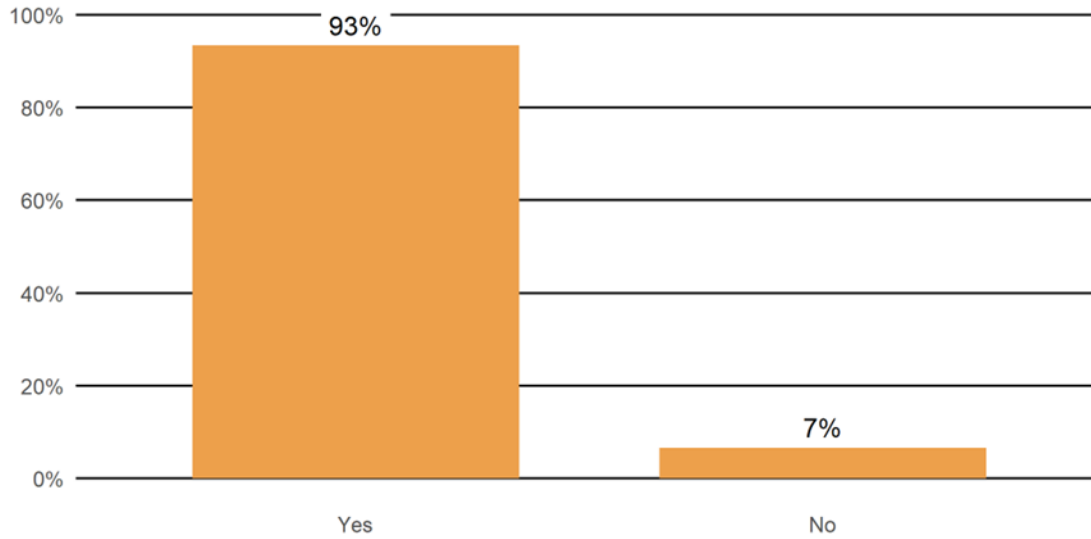


Table 49. Do service providers for your family member work together to provide support?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND ↑	98%	2%	210
PA ↑	96%	4%	370
DE	96%	4%	102
NH	95%	5%	206
MN	95%	5%	328
AZ	94%	6%	146
Weighted NCI-IDD Average	93%	7%	5546
GA	93%	7%	132
NJ	93%	7%	219
IN	93%	7%	301
CA	92%	8%	3225
MD	90%	10%	307

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

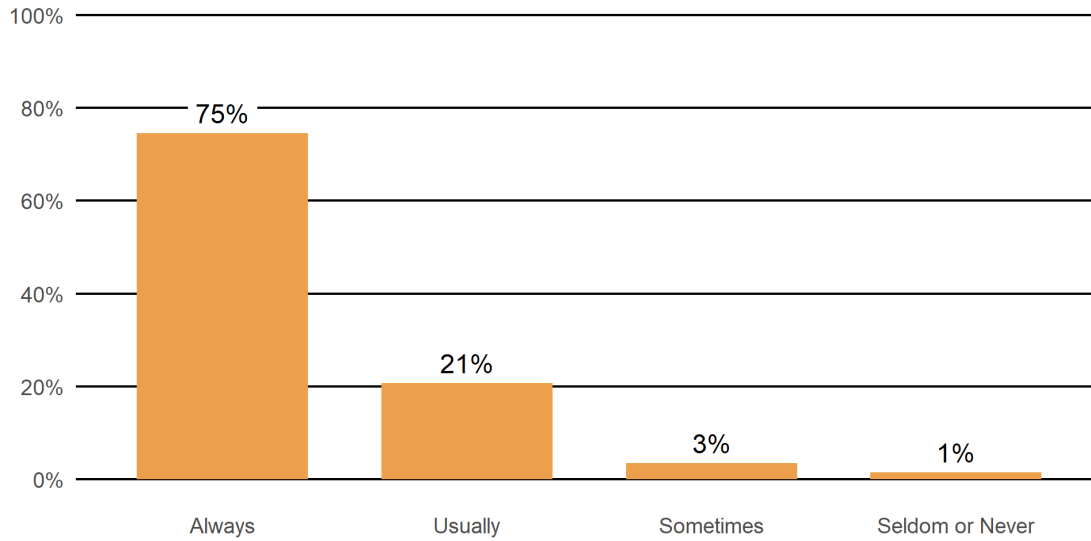


Table 50. Are services delivered in a way that is respectful of your family's culture?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	79%	18%	3%	1%	312
ND	78%	18%	4%	0%	263
CA	77%	19%	2%	2%	4423
MN	76%	21%	1%	2%	397
PA	75%	21%	3%	1%	502
NJ	75%	19%	5%	1%	316
Weighted NCI-IDD Average	75%	21%	3%	1%	7523
IN	72%	22%	5%	1%	361
AZ	71%	22%	6%	1%	189
GA	71%	22%	5%	2%	192
DE	66%	28%	6%	0%	144
MD ↓	63%	27%	8%	2%	424

Does your family member use technology in their everyday life to help them do things on their own?

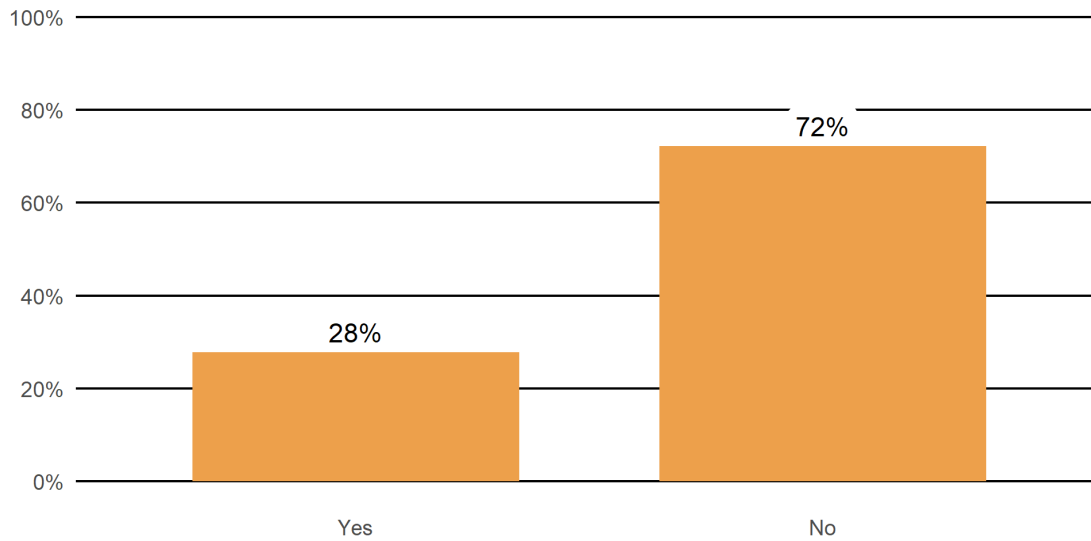


Table 51. Does your family member use technology in their everyday life to help them do things on their own?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND	34%	66%	253
NJ	32%	68%	314
CA	31%	69%	4679
IN	30%	70%	356
MN	29%	71%	396
MD	28%	72%	424
Weighted NCI-IDD Average	28%	72%	7724
NH	28%	72%	325
AZ	24%	76%	178
PA ↓	20%	80%	476
GA ↓	18%	82%	181
DE ↓	18%	82%	142

Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?

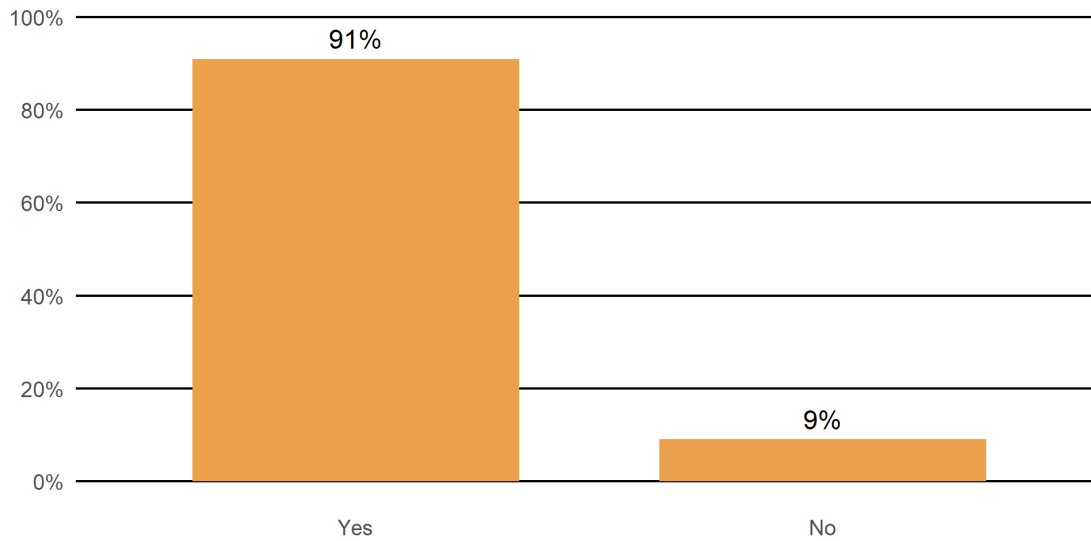


Table 52. Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
NJ ↑	96%	4%	335
MD ↑	95%	5%	444
ND	94%	6%	258
NH	94%	6%	322
CA	92%	8%	5006
Weighted NCI-IDD Average	91%	9%	8183
DE	91%	9%	154
AZ	90%	10%	188
PA	90%	10%	511
IN	89%	11%	380
MN	87%	13%	389
GA	85%	15%	196

How well does the internet work in your home?

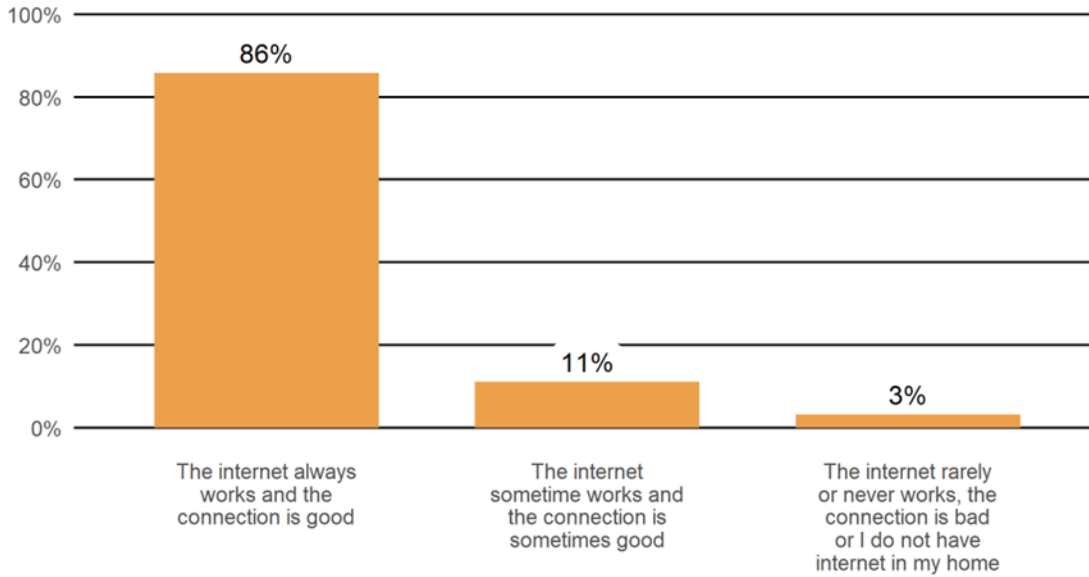


Table 53. How well does the internet work in your home?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	The internet always works and the connection is good	The internet sometime works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
MD ↑	90%	9%	1%	435
NJ	89%	10%	1%	334
MN	88%	9%	2%	365
NH	88%	10%	2%	306
ND	87%	10%	2%	245
CA	86%	11%	3%	4863
Weighted NCI-IDD Average	86%	11%	3%	7907
AZ	84%	12%	3%	180
PA	83%	12%	5%	486
IN	83%	13%	4%	361
DE	82%	14%	4%	146
GA	81%	16%	3%	186

Workforce

There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.

Note: Significance is based on “Always” or “Yes” response.

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

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

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

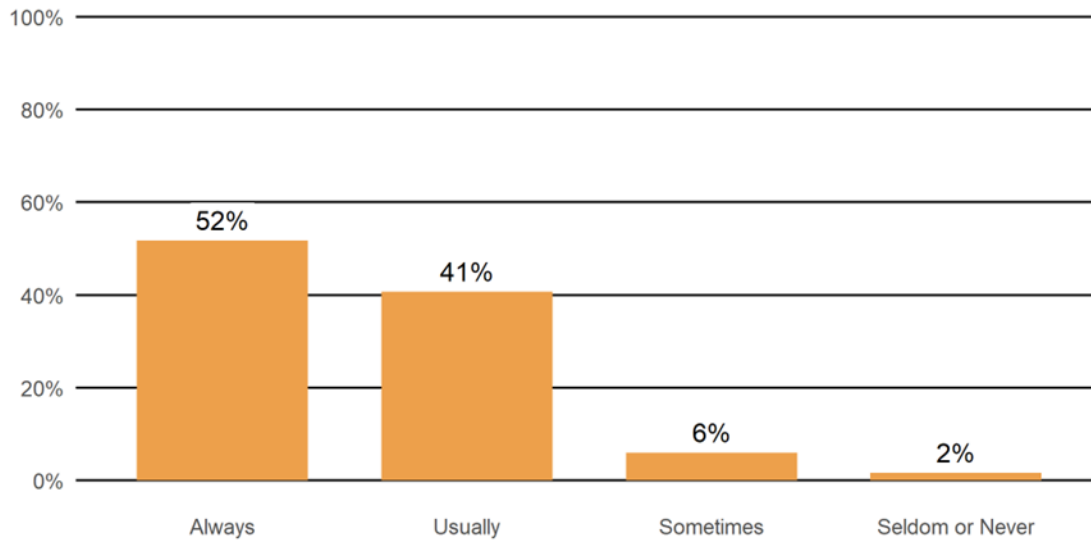


Table 54. Do support workers come and go when they are supposed to?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	61%	33%	5%	1%	150
PA	56%	38%	5%	1%	323
NH	56%	38%	6%	0%	195
MN	55%	41%	4%	0%	303
NJ	53%	39%	7%	1%	222
ND	52%	42%	6%	1%	197
Weighted NCI-IDD Average	52%	41%	6%	2%	5363
CA	51%	40%	6%	2%	3160
GA	50%	40%	8%	3%	129
DE	49%	41%	11%	0%	76
IN ↓	41%	48%	9%	1%	302
MD ↓	37%	53%	8%	2%	306

Do support workers speak to you in a way you understand?

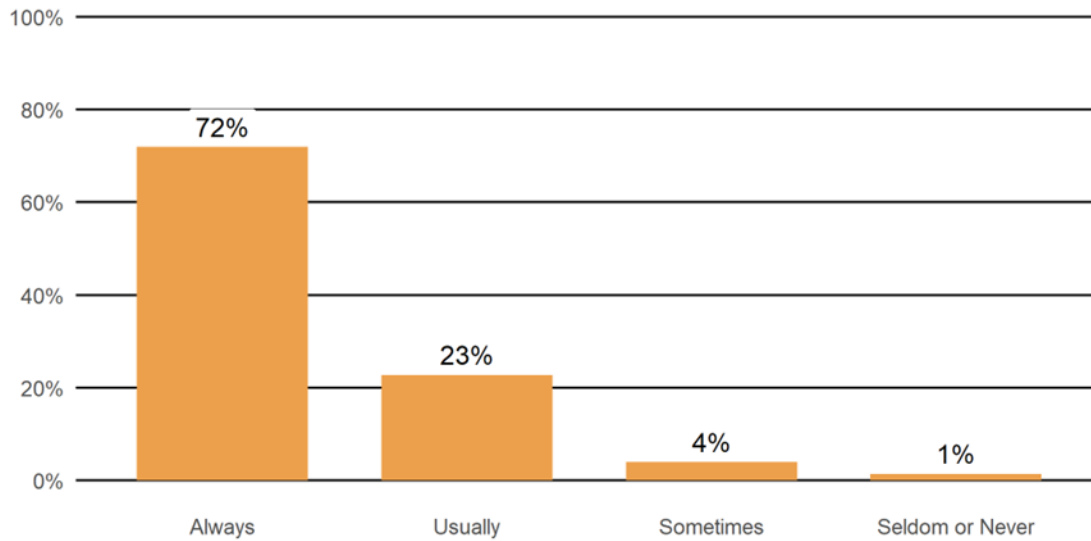


Table 55. Do support workers speak to you in a way you understand?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	77%	20%	3%	0%	500
MN	74%	22%	3%	1%	375
GA	74%	22%	4%	0%	187
ND	74%	24%	2%	0%	263
NH	74%	24%	2%	1%	283
NJ	73%	21%	4%	2%	309
Weighted NCI-IDD Average	72%	23%	4%	1%	7400
CA	72%	23%	4%	2%	4361
DE	71%	24%	5%	1%	147
IN	68%	27%	4%	1%	369
AZ	68%	25%	6%	2%	182
MD ↓	59%	30%	9%	1%	424

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

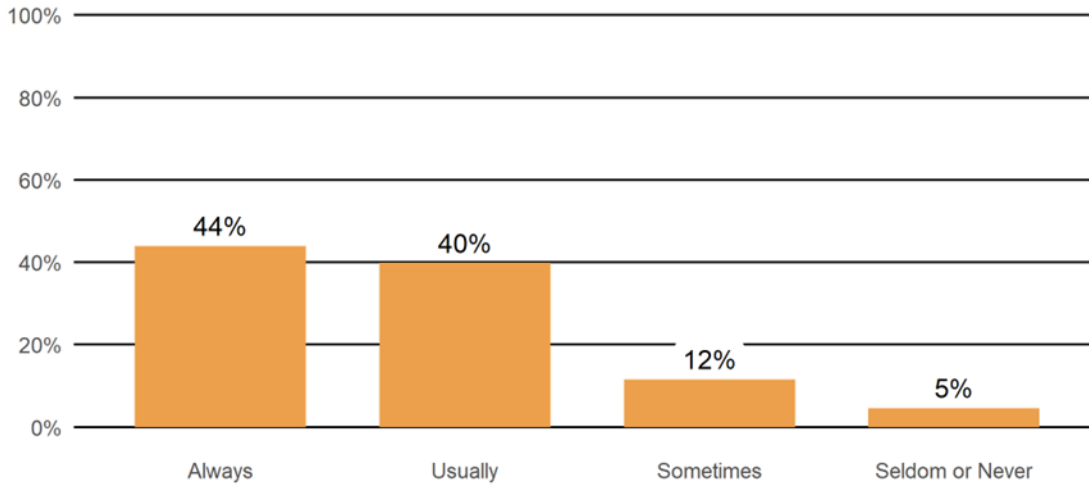


Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH ↑	58%	36%	5%	2%	132
CA	49%	36%	11%	4%	1737
MN	44%	42%	9%	4%	158
AZ	44%	35%	16%	5%	75
Weighted NCI-IDD Average	44%	40%	12%	5%	3041
PA	44%	45%	8%	3%	213
ND	42%	43%	13%	1%	134
NJ	40%	34%	16%	9%	128
IN	39%	41%	16%	4%	134
GA	38%	40%	16%	5%	73
DE	31%	50%	13%	6%	68
MD ↓	29%	49%	17%	5%	189

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

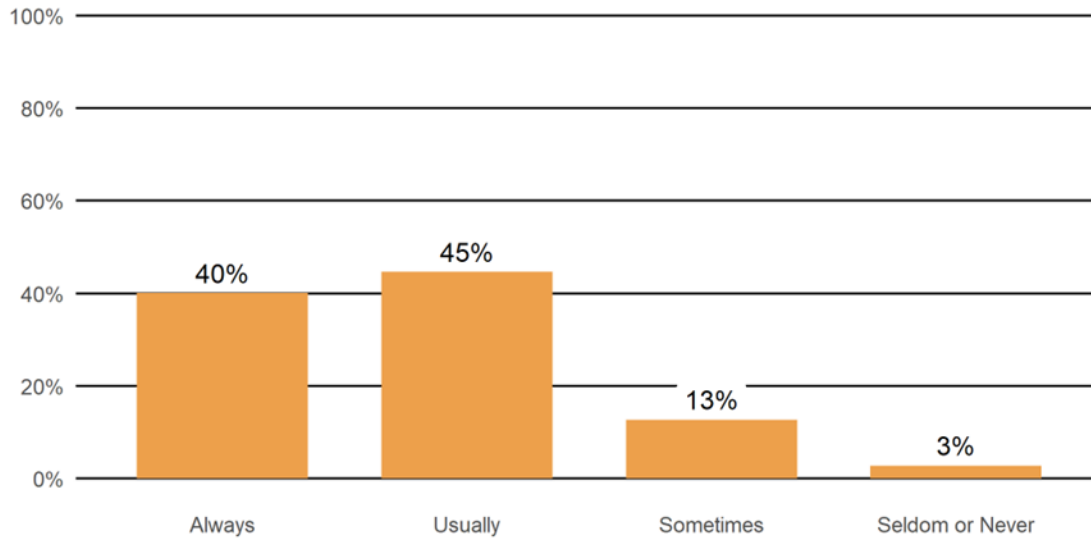


Table 57. Do support workers have the right information and skills to meet your family's needs?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	47%	43%	9%	1%	370
NH	43%	45%	10%	2%	271
PA	42%	45%	11%	2%	471
CA	41%	45%	11%	3%	4124
Weighted NCI-IDD Average	40%	45%	13%	3%	7050
NJ	39%	40%	16%	5%	304
GA	39%	43%	16%	2%	180
AZ	39%	44%	14%	3%	181
ND	36%	50%	13%	1%	253
DE	31%	54%	11%	4%	140
IN ↓	33%	46%	19%	3%	352
MD ↓	25%	48%	20%	6%	404

Do your family member's support workers change too often? Is there too much "turnover" of support workers?

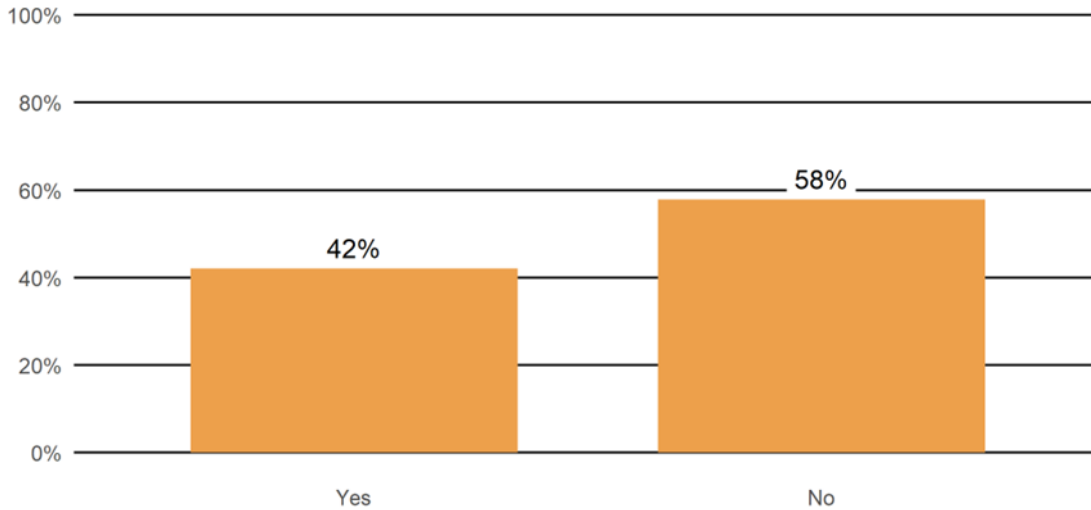


Table 58. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
AZ ↑	53%	47%	167
MD ↑	52%	48%	379
IN ↑	52%	48%	339
GA	50%	50%	145
ND	50%	50%	228
NJ	49%	51%	281
MN	48%	52%	338
DE	47%	53%	114
PA	44%	56%	424
Weighted NCI-IDD Average	42%	58%	6372
NH	40%	60%	256
CA ↓	32%	68%	3701

Is there always a staff person available to support your family member when support is needed?

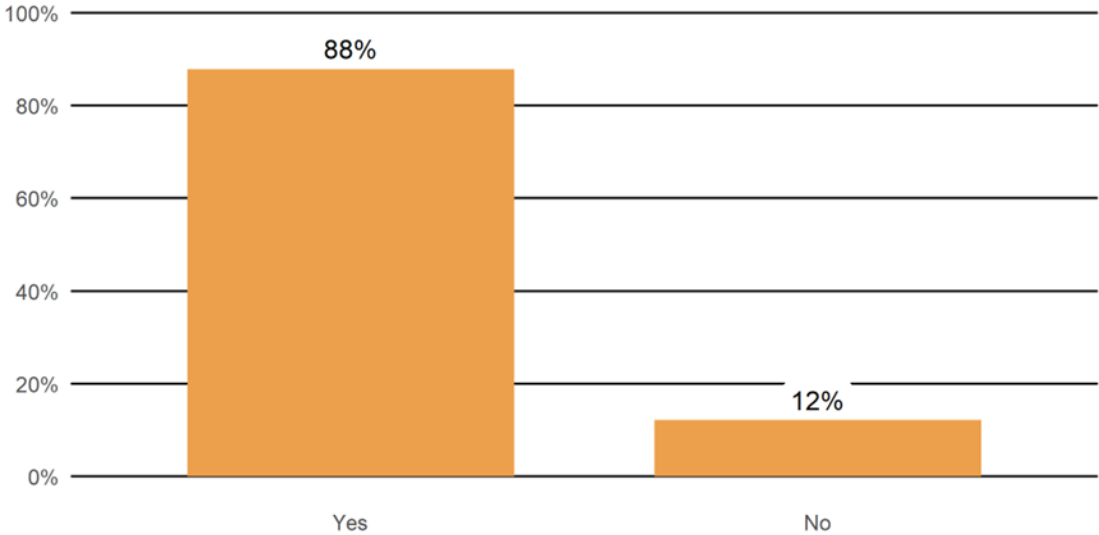


Table 59. Is there always a staff person available to support your family member when support is needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
PA ↑	94%	6%	489
MN	90%	10%	382
AZ	89%	11%	170
GA	88%	12%	169
CA	88%	12%	4184
Weighted NCI-IDD Average	88%	12%	7079
NH	87%	13%	281
ND	84%	16%	231
NJ	84%	16%	286
IN	83%	17%	345
MD	83%	17%	396
DE ↓	33%	67%	146

Choice, Decision Making and Control

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

Note: Significance is based on “Always” or “Yes” response.

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

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

Can someone in your family choose or change the provider agency that provides your family member's services?

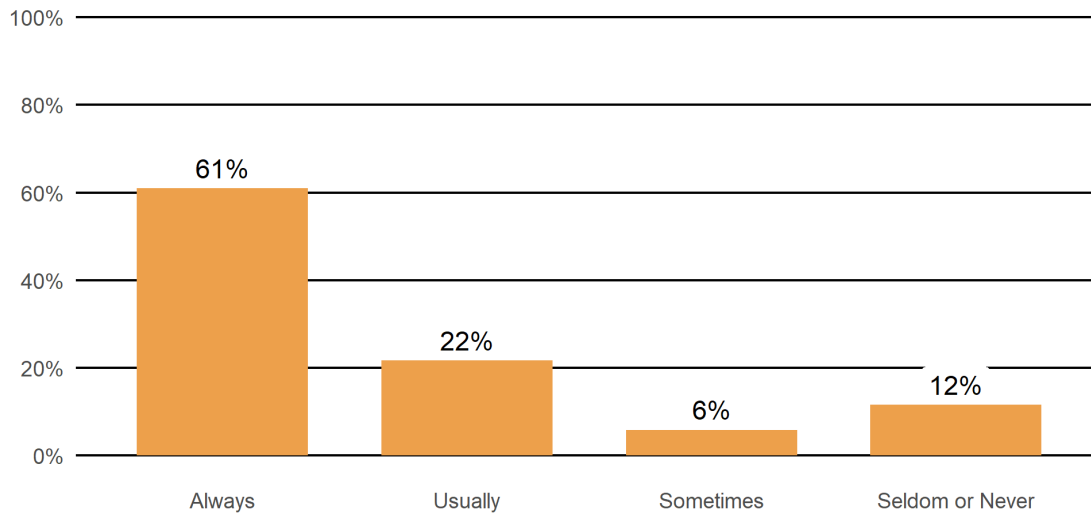


Table 60. Can someone in your family choose or change the provider agency that provides your family member's services?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN ↑	76%	15%	3%	5%	330
NH ↑	71%	20%	2%	7%	219
MN ↑	69%	19%	3%	8%	298
GA	63%	21%	7%	8%	123
DE	62%	17%	8%	13%	92
PA	61%	24%	5%	10%	292
Weighted NCI-IDD Average	61%	22%	6%	12%	4855
ND	61%	26%	2%	12%	197
MD	61%	22%	5%	12%	307
AZ	59%	21%	6%	14%	143
NJ	55%	19%	13%	13%	206
CA ↓	54%	24%	7%	15%	2648

Can someone in your family choose or change your family member's support workers?

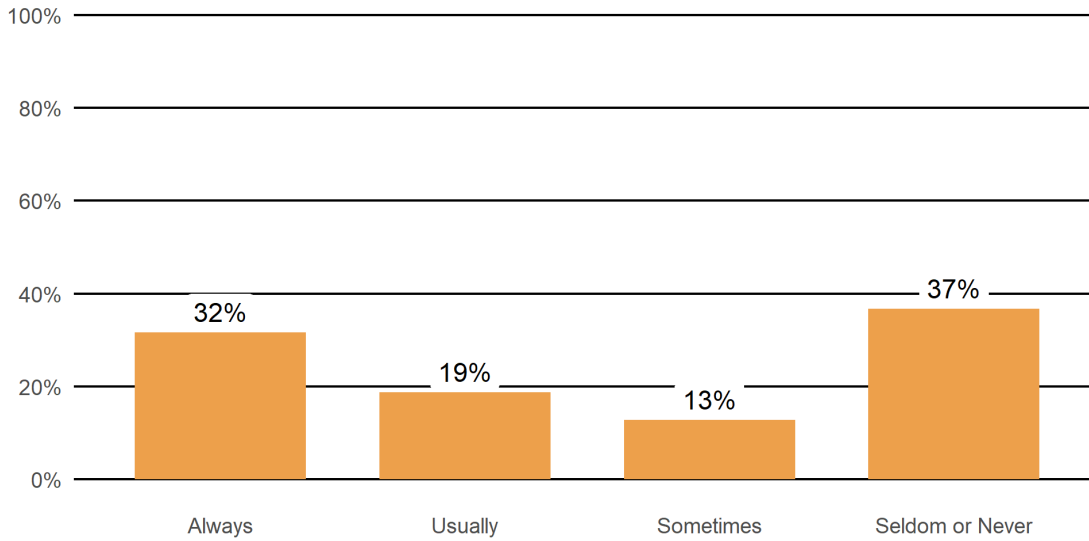


Table 61. Can someone in your family choose or change your family member's support workers?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH ↑	52%	20%	10%	18%	191
AZ	39%	15%	9%	38%	116
IN	36%	21%	17%	26%	289
CA	35%	21%	13%	31%	2573
GA	33%	20%	10%	37%	117
Weighted NCI-IDD Average	32%	19%	13%	37%	4519
MN	31%	18%	13%	38%	250
NJ	29%	12%	12%	47%	201
PA	26%	20%	12%	43%	267
MD ↓	21%	13%	14%	52%	271
ND ↓	19%	20%	11%	49%	176
DE ↓	13%	16%	13%	57%	68

Can someone in your family directly manage support staff?

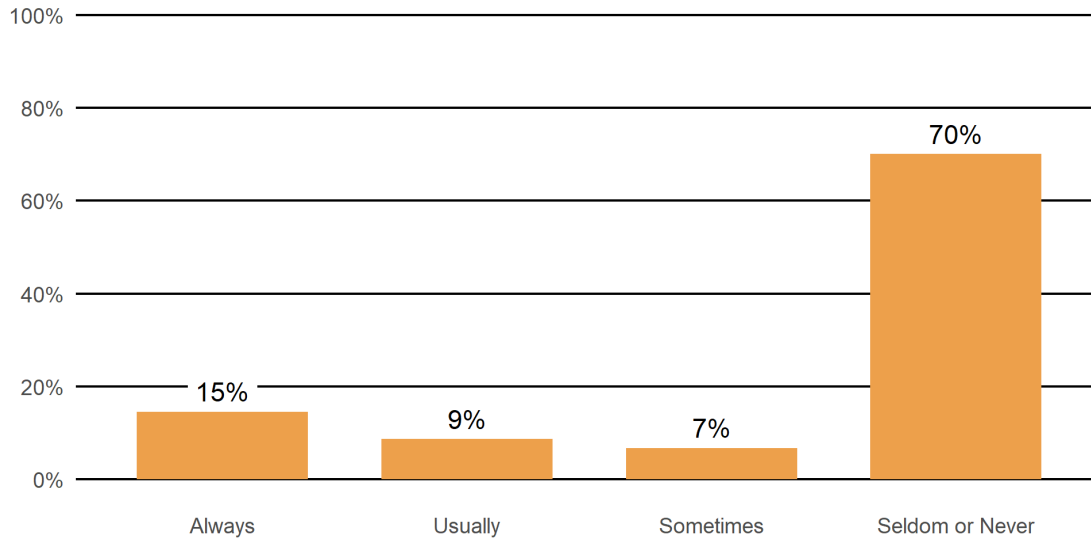


Table 62. Can someone in your family directly manage support staff?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA ↑	26%	8%	4%	62%	111
NH ↑	25%	13%	8%	54%	177
AZ	19%	4%	5%	72%	103
CA	18%	11%	9%	62%	2611
IN	18%	8%	7%	68%	255
NJ	16%	11%	6%	67%	198
Weighted NCI-IDD Average	15%	9%	7%	70%	4538
MN	10%	6%	7%	77%	242
MD ↓	9%	7%	5%	79%	286
PA ↓	8%	7%	4%	82%	304
ND ↓	3%	5%	8%	84%	173
DE ↓	1%	3%	5%	91%	78

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

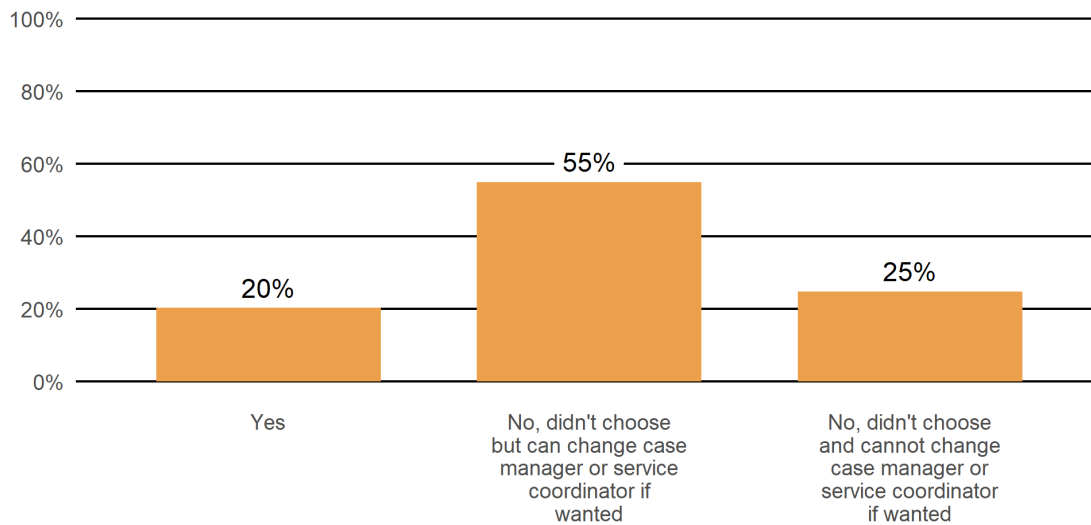


Table 63. Did you, your family member, or someone else in your family choose your family member's case manager or service coordinator?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No, didn't choose but can change case manager or service coordinator if wanted	No, didn't choose and cannot change case manager or service coordinator if wanted	N
IN ↑	57%	35%	8%	343
NJ ↑	47%	37%	17%	292
ND ↑	36%	38%	26%	210
MD ↑	33%	50%	17%	363
NH	27%	61%	12%	293
PA	23%	50%	27%	402
Weighted NCI-IDD Average	20%	55%	25%	6569
DE	18%	28%	54%	101
GA	15%	54%	31%	158
AZ ↓	13%	69%	18%	161
CA ↓	11%	60%	29%	3897
MN ↓	7%	68%	25%	349

Community Connections

Family members receiving services and supports from the state Developmental Disabilities system are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.

Note: Significance is based on “Always” or “Yes” response.

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

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

Does your family member do things in the community?

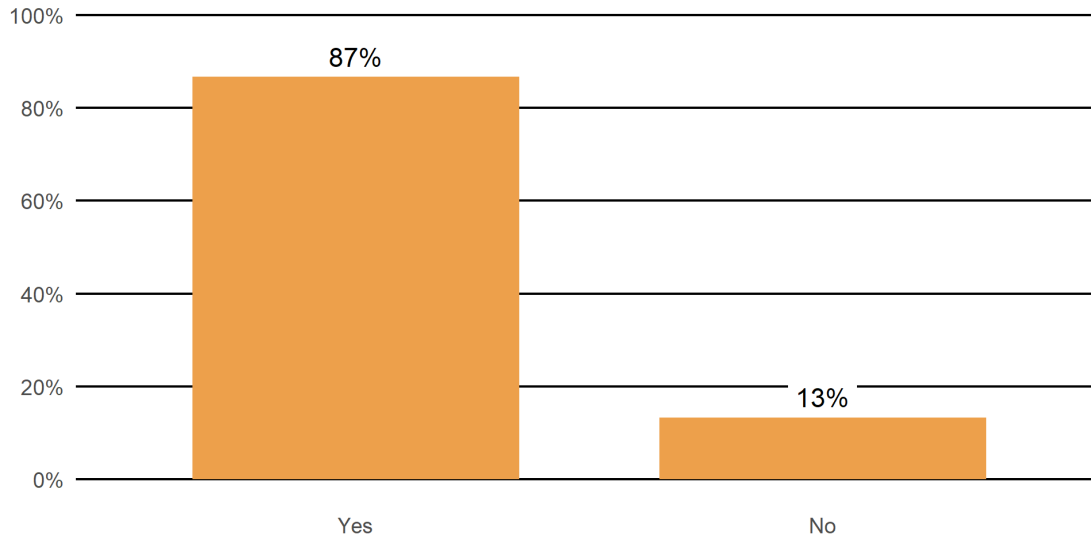


Table 64. Does your family member do things in the community?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND ↑	94%	6%	266
MN ↑	94%	6%	398
PA ↑	91%	9%	501
MD	89%	11%	417
NH	89%	11%	322
DE	88%	12%	146
IN	87%	13%	374
Weighted NCI-IDD Average	87%	13%	7943
NJ	85%	15%	318
GA	84%	16%	188
CA	83%	17%	4824
AZ	81%	19%	189

For your family member, what makes it hard to do things in the community?

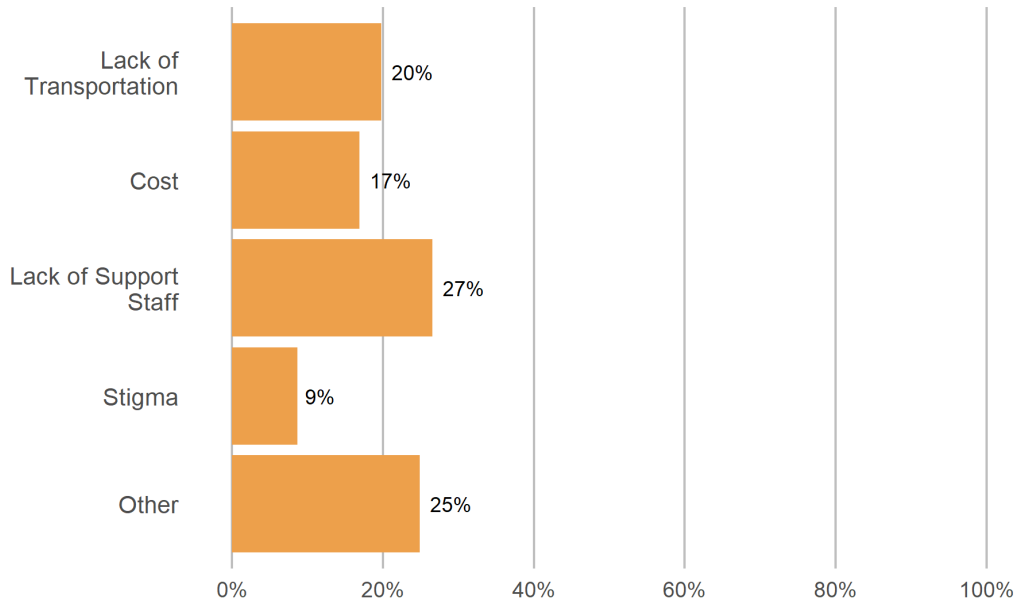


Table 65. For your family member, what makes it hard to do things in the community?

Categories are not mutually exclusive, therefore N is not shown.

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	21%	19%	24%	9%	30%
CA	22%	19%	19%	10%	25%
DE	10%	12%	25%	9%	33%
GA	20%	17%	27%	11%	26%
IN	26%	23%	39%	8%	20%
MD	24%	16%	34%	8%	28%
MN	17%	16%	41%	3%	17%
NH	23%	20%	30%	9%	33%
NJ	23%	14%	38%	8%	24%
ND	17%	16%	36%	7%	30%
PA	11%	11%	25%	11%	27%
Weighted NCI-IDD Average	20%	17%	27%	9%	25%

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

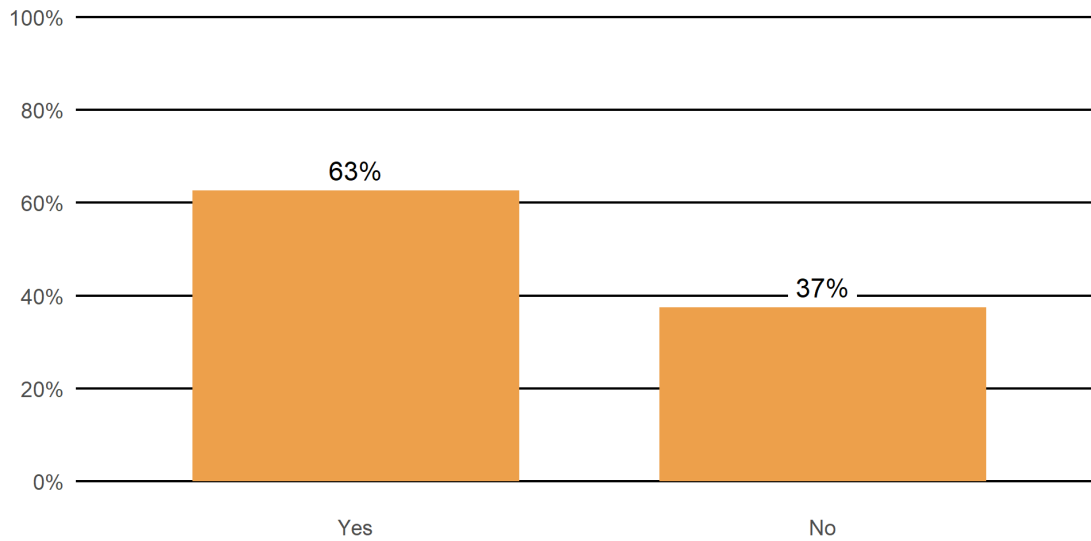


Table 66. Does your family member have friends other than paid support workers or family?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
MN ↑	77%	23%	386
ND ↑	75%	25%	247
GA	67%	33%	175
NH	64%	36%	299
IN	64%	36%	369
Weighted NCI-IDD Average	63%	37%	7578
PA	61%	39%	466
AZ	60%	40%	184
CA	60%	40%	4600
NJ	59%	41%	306
MD	59%	41%	413
DE ↓	48%	52%	133

In your community, are there resources or support that your family member can use that are not provided by the I/DD agency?

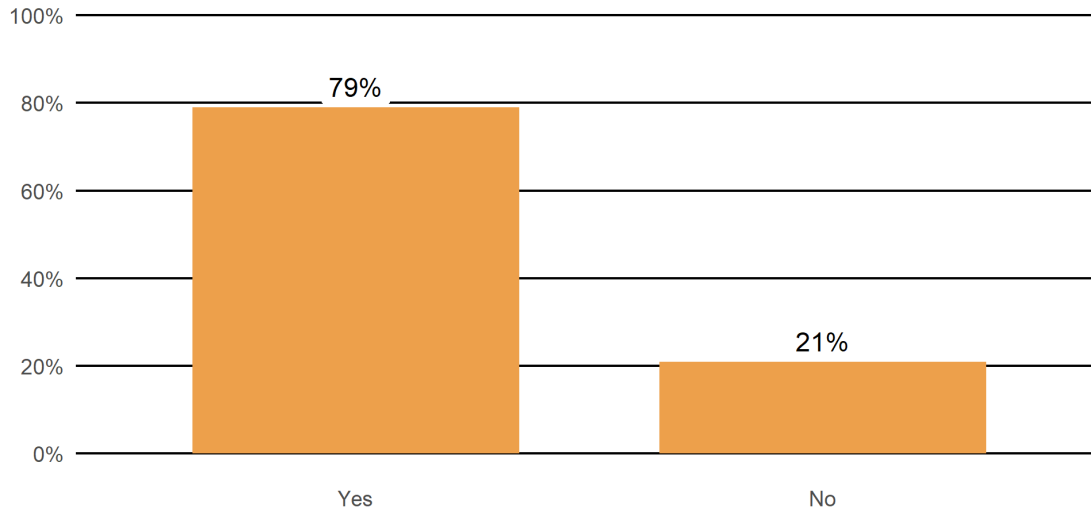


Table 67. In your community, are there resources or support that your family member can use that are not provided by the I/DD agency?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
IN ↑	89%	11%	253
MN ↑	87%	13%	317
ND	84%	16%	199
PA	84%	16%	301
MD	81%	19%	314
NH	79%	21%	237
Weighted NCI-IDD Average	79%	21%	5511
DE	76%	24%	94
CA	75%	25%	3299
AZ	75%	25%	139
GA	70%	30%	139
NJ ↓	68%	32%	219

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

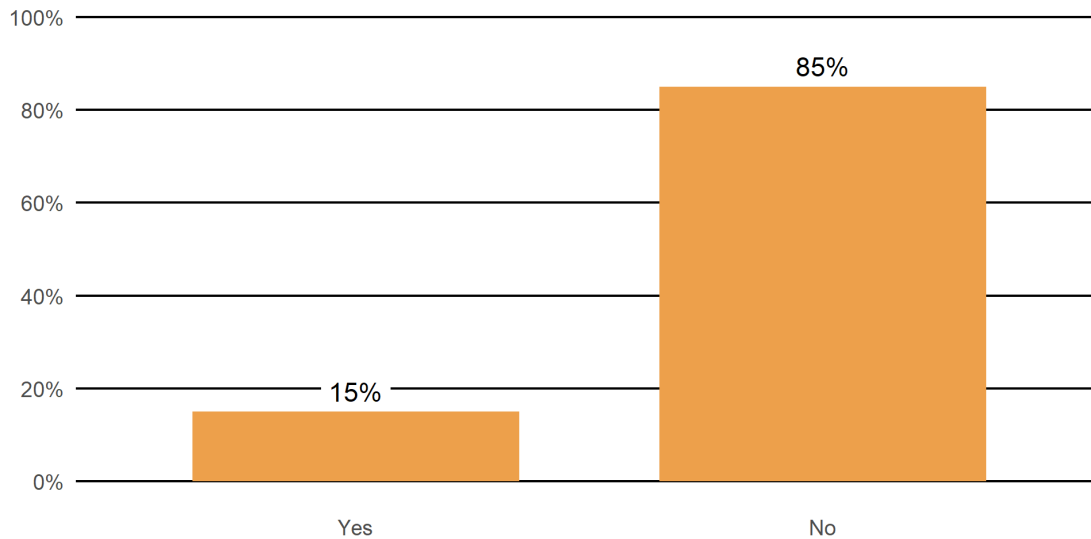


Table 68. Does your family take part in any family-to-family networks in your community?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND ↑	23%	77%	226
DE	21%	79%	127
GA	18%	82%	155
PA	16%	84%	426
MN	15%	85%	329
Weighted NCI-IDD Average	15%	85%	7009
CA	15%	85%	4342
NJ	14%	86%	280
IN	14%	86%	318
NH	13%	87%	275
MD	13%	87%	369
AZ	12%	88%	162

Health, Welfare and Safety

Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state developmental disabilities system.

Note: Significance is based on “Always” or “Yes” response.

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

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

Can your family member see a primary care provider when needed?

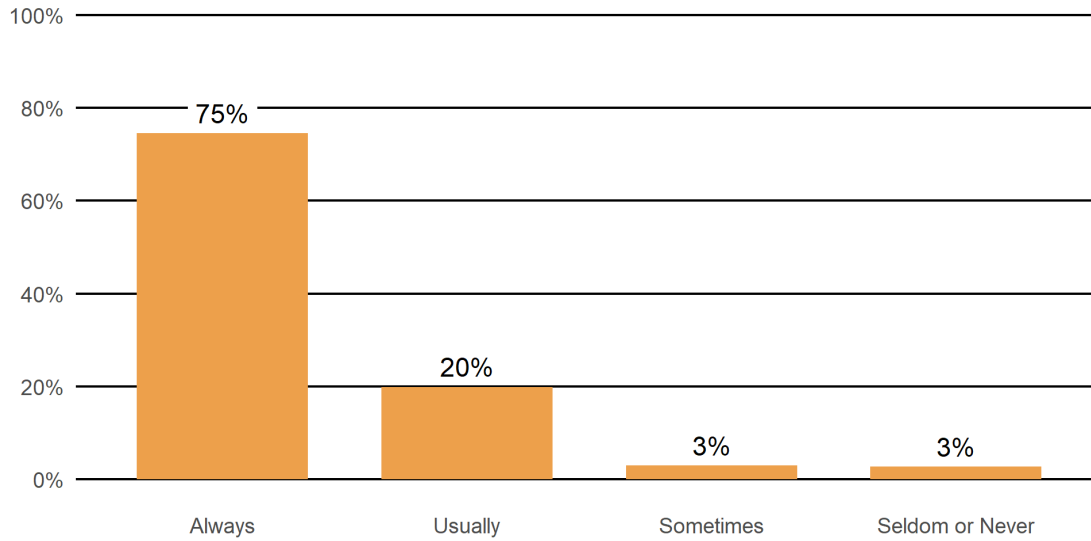


Table 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	82%	16%	1%	2%	400
PA ↑	79%	16%	2%	3%	504
NH	77%	18%	2%	3%	324
NJ	76%	20%	2%	1%	323
ND	76%	20%	3%	2%	259
Weighted NCI-IDD Average	75%	20%	3%	3%	7999
MD	74%	22%	4%	0%	430
DE	73%	22%	3%	2%	152
AZ	73%	20%	4%	3%	192
IN	72%	21%	4%	3%	380
CA	71%	22%	4%	3%	4843
GA	70%	24%	3%	3%	192

Does your family member's primary care provider understand your family member's needs related to their disability?

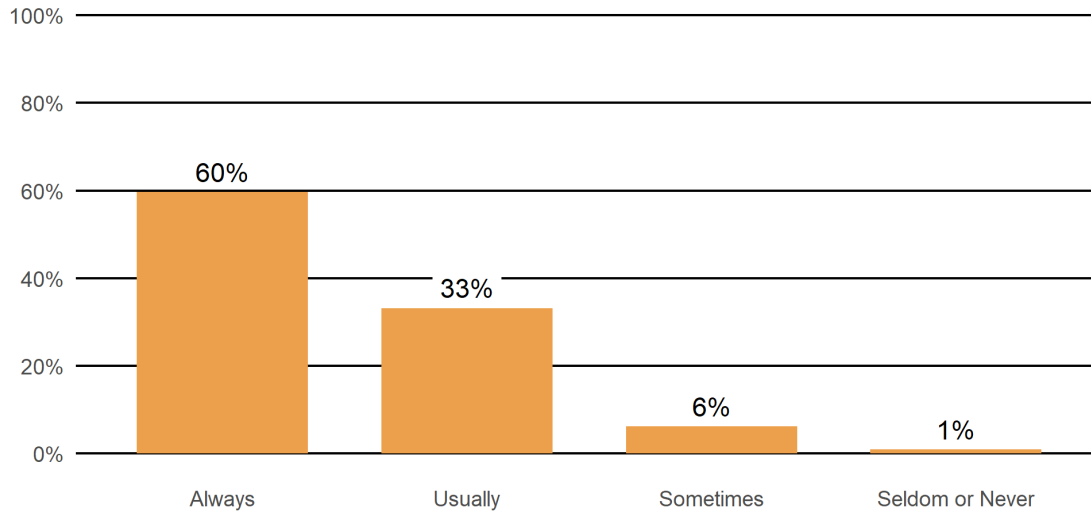


Table 70. Does your family member's primary care provider (doctor, registered nurse, etc.) understand your family member's needs related to their disability?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	70%	28%	2%	1%	399
NJ	65%	29%	6%	1%	315
DE	64%	32%	4%	0%	146
PA	61%	34%	5%	0%	479
Weighted NCI-IDD Average	60%	33%	6%	1%	7564
IN	59%	37%	4%	1%	353
GA	59%	34%	7%	0%	180
NH	59%	35%	5%	1%	318
MD	57%	34%	9%	0%	405
AZ	57%	34%	9%	1%	185
CA	56%	34%	8%	2%	4526
ND	56%	40%	4%	0%	258

Can your family member go to the dentist when needed?

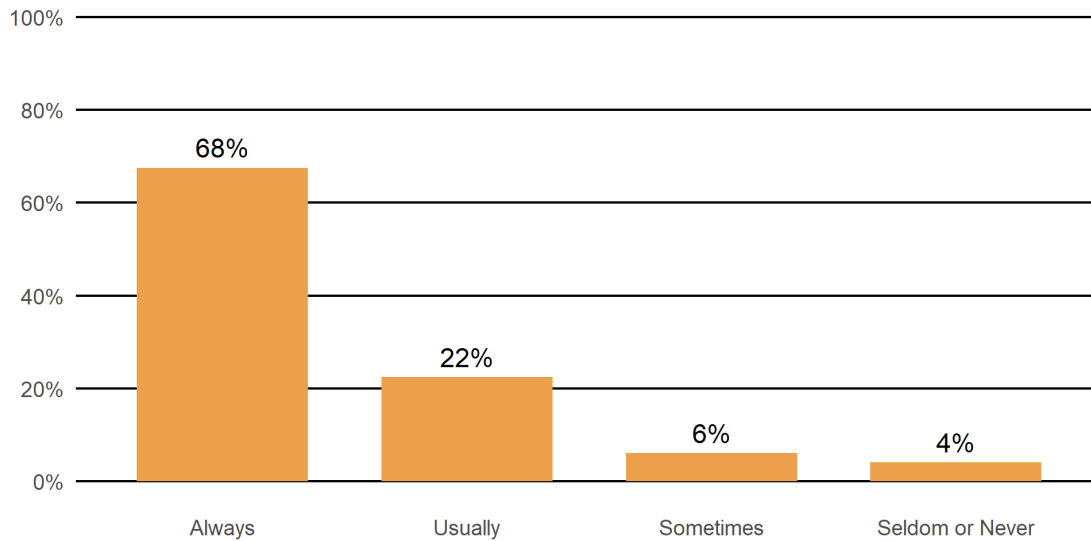


Table 71. Can your family member go to the dentist when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	77%	17%	4%	2%	504
MN	71%	22%	4%	3%	399
NJ	69%	24%	5%	2%	328
Weighted NCI-IDD Average	68%	22%	6%	4%	8016
ND	67%	26%	4%	3%	267
MD	67%	23%	6%	3%	431
IN	66%	25%	6%	4%	381
AZ	65%	27%	5%	3%	191
NH	65%	22%	7%	6%	325
CA	64%	23%	8%	6%	4855
DE	61%	27%	7%	4%	147
GA	60%	25%	7%	8%	188

Does your family member's dentist understand your family member's needs related to their disability

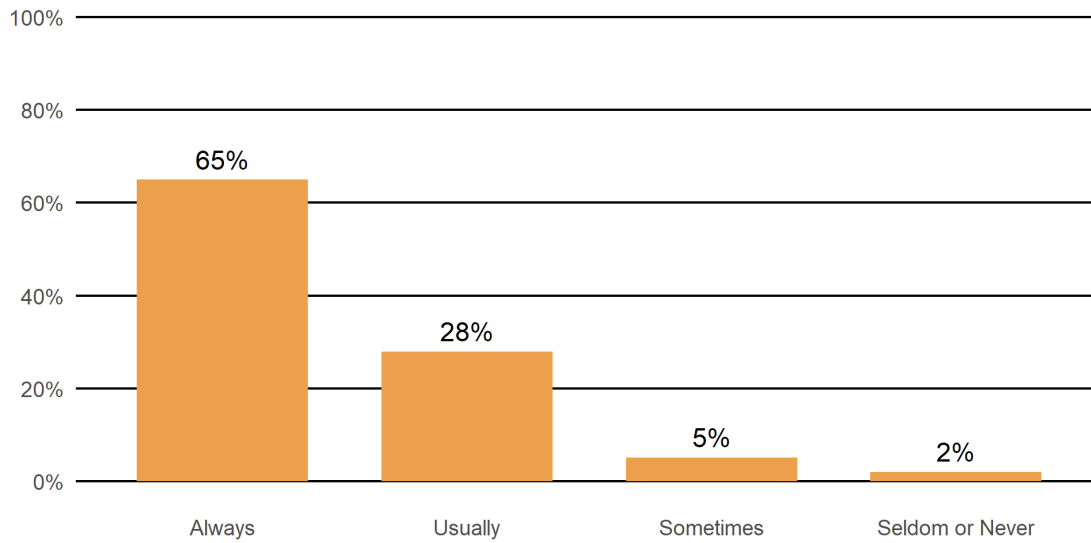


Table 72. Does your family member's dentist understand your family member's needs related to their disability?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	71%	25%	3%	1%	375
NJ	70%	24%	5%	2%	293
PA	68%	28%	3%	1%	446
AZ	66%	29%	4%	1%	171
ND	65%	31%	3%	1%	249
Weighted NCI-IDD Average	65%	28%	5%	2%	6799
CA	63%	29%	6%	3%	4015
GA	62%	27%	8%	3%	155
MD	62%	27%	10%	2%	363
NH	62%	31%	6%	1%	271
DE	60%	32%	6%	2%	126
IN	60%	32%	6%	2%	335

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

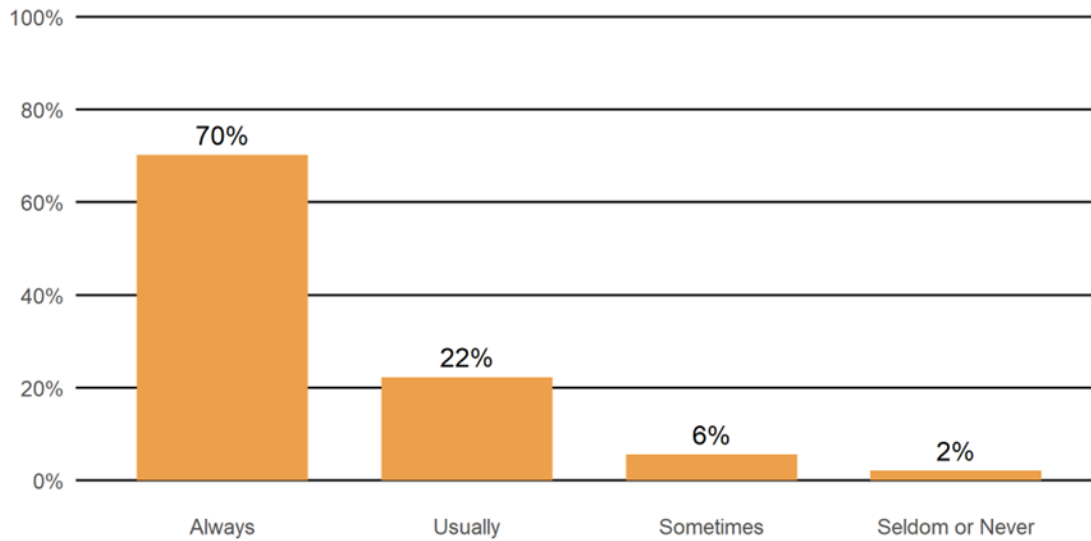


Table 73. If your family member takes prescription medications, do you know what they're for?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH ↑	79%	16%	4%	1%	305
NJ ↑	77%	19%	4%	0%	306
AZ	77%	17%	4%	1%	180
ND	74%	21%	4%	1%	251
MN	73%	22%	4%	2%	387
CA	71%	21%	6%	2%	4328
MD	71%	20%	6%	2%	411
Weighted NCI-IDD Average	70%	22%	6%	2%	7335
PA	66%	25%	7%	2%	475
GA	61%	30%	6%	2%	179
DE	61%	29%	7%	3%	146
IN ↓	63%	28%	5%	3%	367

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

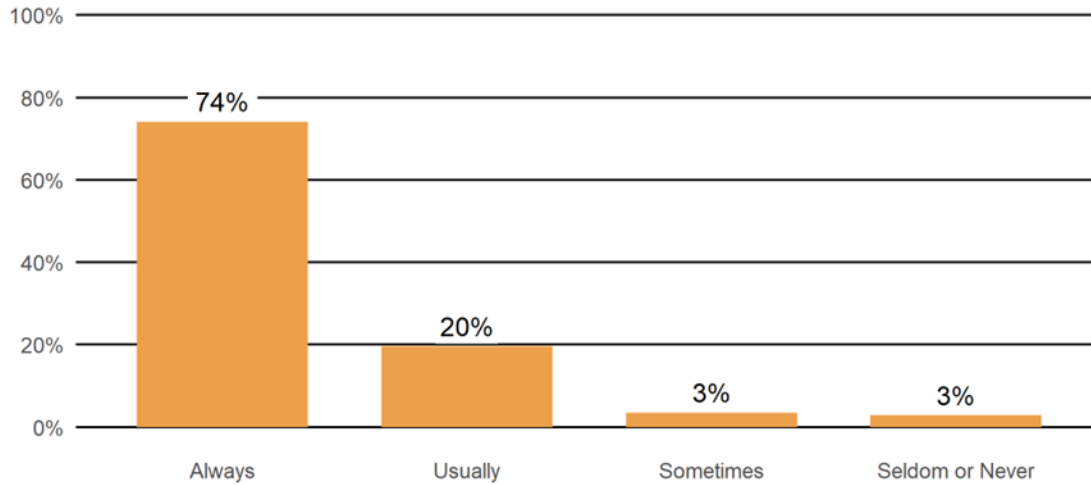


Table 74. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH ↑	83%	12%	3%	2%	297
MN	79%	17%	2%	2%	375
NJ	77%	19%	3%	2%	297
ND	77%	18%	3%	2%	244
AZ	76%	18%	5%	2%	176
CA	75%	18%	4%	3%	4107
DE	74%	18%	4%	4%	136
Weighted NCI-IDD Average	74%	20%	3%	3%	7003
MD	74%	21%	3%	3%	400
GA	71%	22%	3%	4%	178
IN	70%	23%	5%	2%	355
PA ↓	68%	25%	4%	3%	438

Can your family member get mental or behavioral health supports when needed?

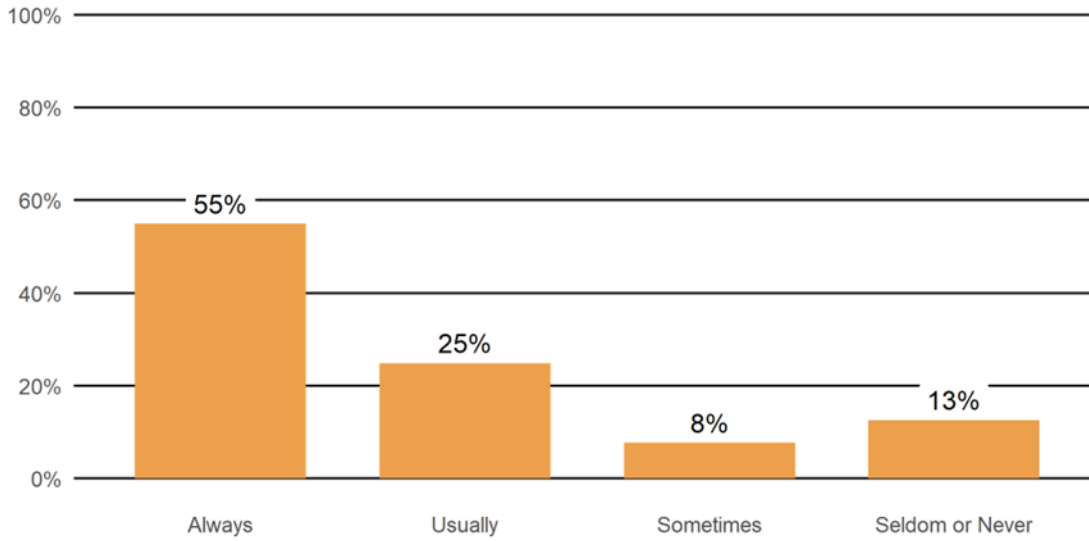


Table 75. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling.)

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	66%	21%	5%	8%	335
PA ↑	62%	22%	7%	9%	412
AZ	61%	21%	5%	13%	160
IN	60%	28%	6%	6%	338
ND	57%	30%	6%	8%	218
DE	57%	26%	6%	11%	118
Weighted NCI-IDD Average	55%	25%	8%	13%	6310
MD	52%	29%	10%	9%	359
NJ	51%	28%	11%	10%	265
GA	51%	29%	5%	15%	157
CA ↓	48%	25%	9%	18%	3676
NH ↓	46%	31%	7%	17%	272

Does your family member's mental or behavioral health professional understand your family member's needs related to their disability?

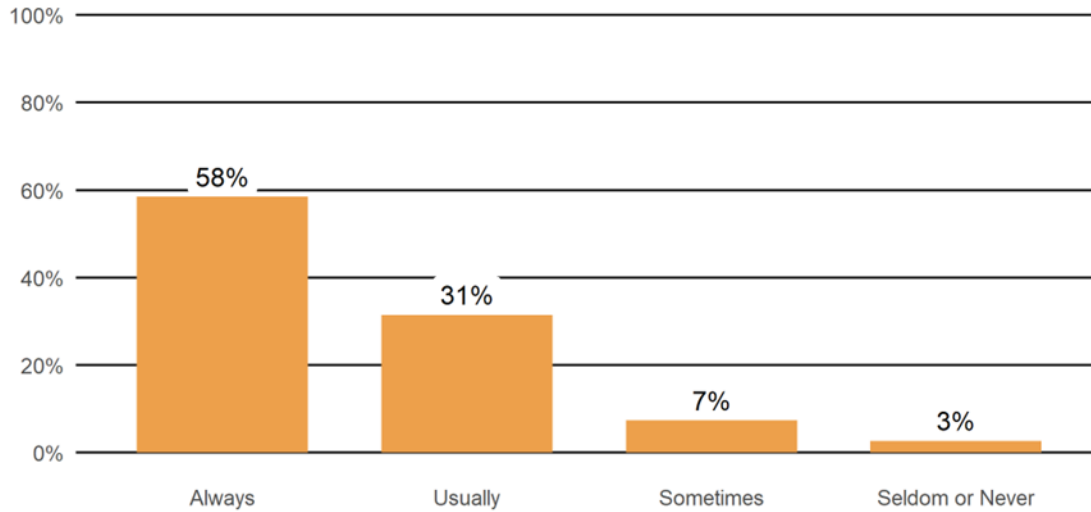


Table 76. Does your family member's mental or behavioral health professional understand your family member's needs related to their disability?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	69%	26%	4%	1%	291
IN	61%	31%	5%	2%	315
PA	59%	32%	9%	1%	380
Weighted NCI-IDD Average	58%	31%	7%	3%	5363
AZ	58%	33%	6%	2%	139
DE	58%	32%	8%	2%	109
ND	56%	37%	4%	3%	188
CA	56%	32%	8%	4%	3085
NH	56%	34%	7%	3%	208
NJ	56%	31%	11%	3%	225
MD	54%	34%	8%	4%	290
GA	51%	38%	6%	5%	133

If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

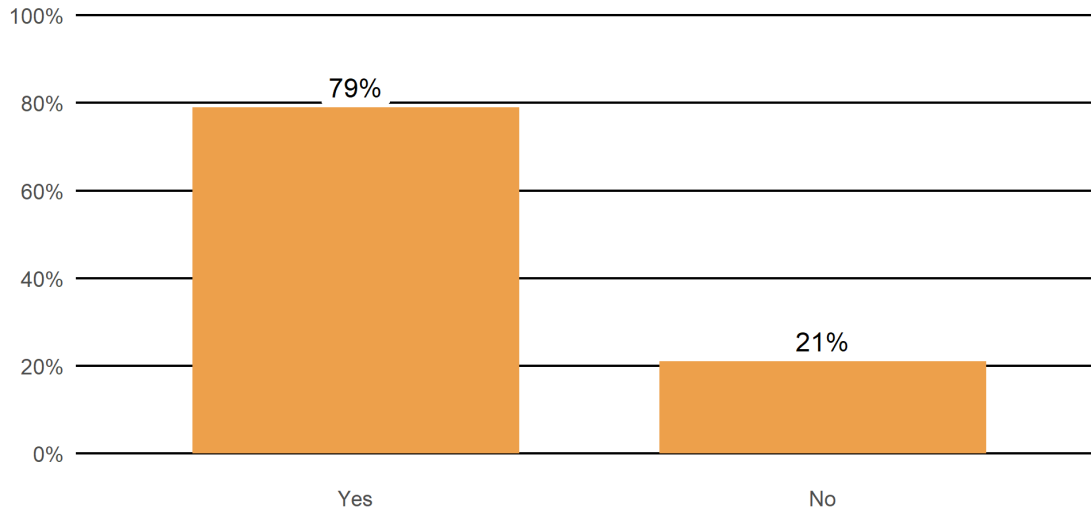


Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND	89%	11%	65
GA	85%	15%	48
IN	84%	16%	113
AZ	81%	19%	64
CA	80%	20%	1321
Weighted NCI-IDD Average	79%	21%	2161
PA	78%	22%	110
MN	77%	23%	115
MD	74%	26%	130
NJ	74%	26%	76
DE	73%	27%	41
NH	68%	32%	78

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

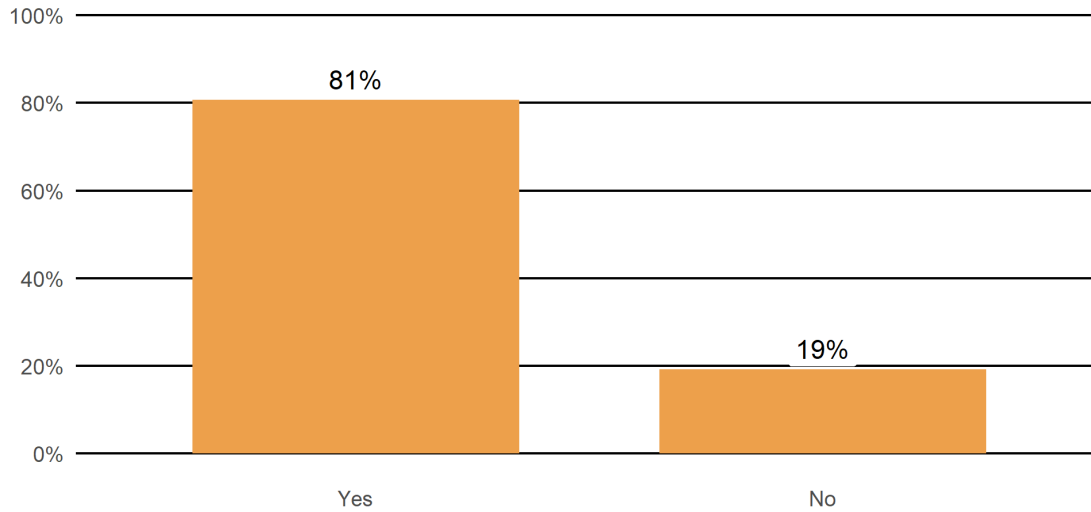


Table 78. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency, pandemic or natural disaster?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND ↑	92%	8%	242
MN ↑	90%	10%	366
IN ↑	88%	12%	343
NH	84%	16%	285
GA	82%	18%	160
Weighted NCI-IDD Average	81%	19%	7078
PA	80%	20%	422
AZ	79%	21%	169
MD	79%	21%	371
CA	78%	22%	4304
NJ	77%	23%	281
DE ↓	70%	30%	135

Have you talked about how to handle emergencies with your family member’s case manager or service coordinator?

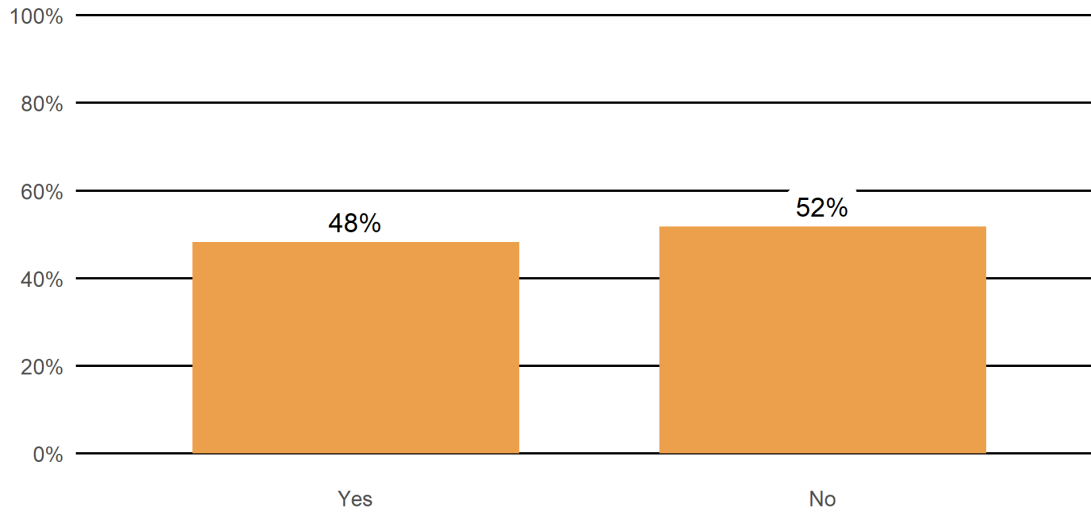


Table 79. Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member’s case manager or service coordinator?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
ND ↑	72%	28%	250
MN ↑	64%	36%	384
IN ↑	58%	42%	371
AZ	53%	47%	183
NH	51%	49%	313
Weighted NCI-IDD Average	48%	52%	7788
GA	48%	52%	190
PA	46%	54%	492
CA	44%	56%	4732
MD	43%	57%	409
NJ	41%	59%	319
DE	38%	62%	145

Do you know how to file a complaint or grievance about provider agencies or staff?

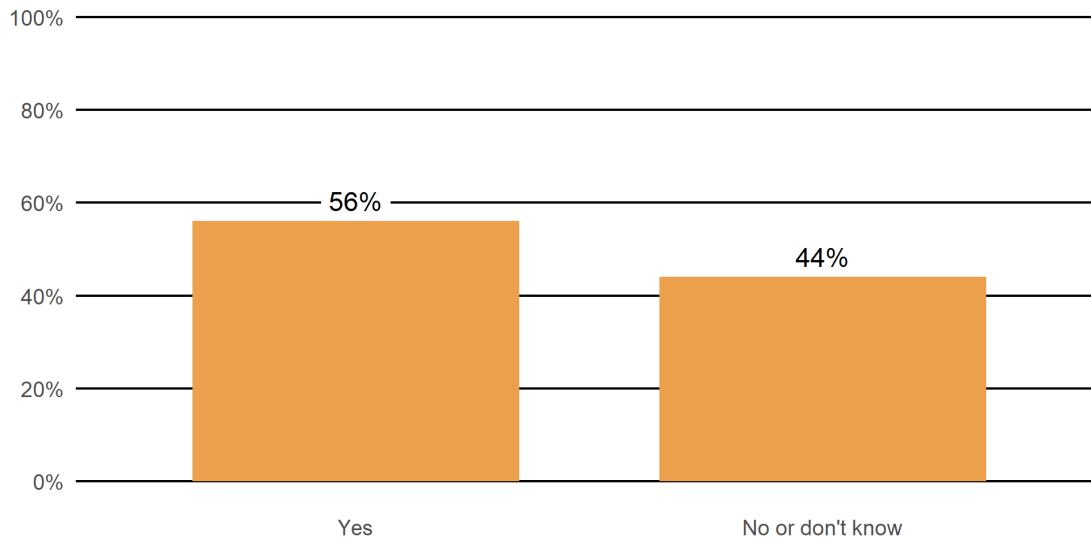


Table 80. Do you know how to file a complaint or grievance about provider agencies or staff?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No or don't know	N
MN ↑	80%	20%	397
NH ↑	73%	27%	331
ND ↑	72%	28%	265
IN ↑	63%	37%	387
AZ	62%	38%	197
PA	60%	40%	525
DE	59%	41%	153
Weighted NCI-IDD Average	56%	44%	8333
GA	55%	46%	200
NJ ↓	48%	52%	325
CA ↓	48%	52%	5113
MD ↓	46%	54%	440

If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

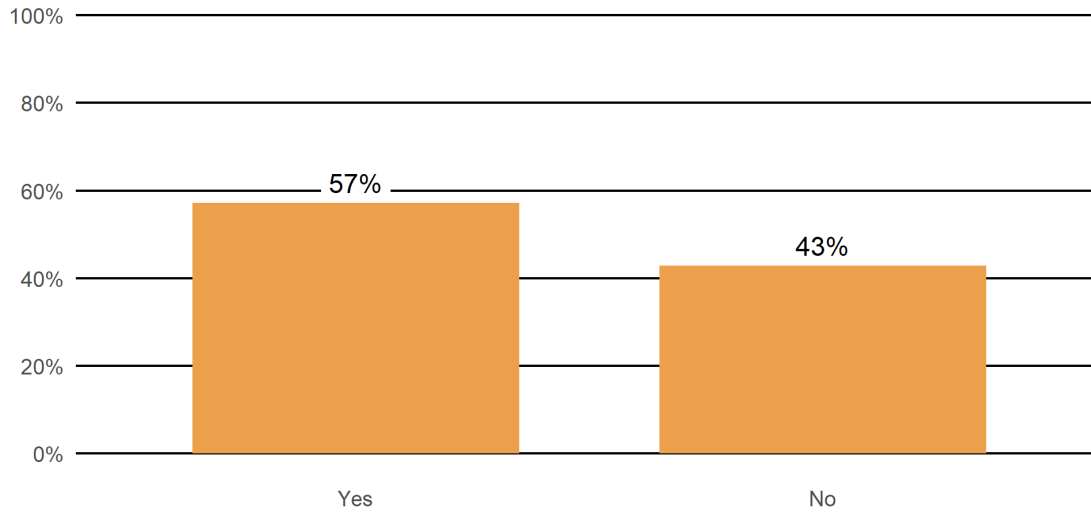


Table 81. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
MN	71%	29%	35
ND	71%	29%	51
AZ	67%	33%	33
NH	63%	38%	32
GA	62%	38%	21
PA	60%	40%	58
DE	59%	41%	32
IN	58%	42%	67
Weighted NCI-IDD Average	57%	43%	883
CA	56%	44%	433
MD	45%	55%	73
NJ ↓	35%	65%	48

Do you know how to report abuse or neglect related to your family member?

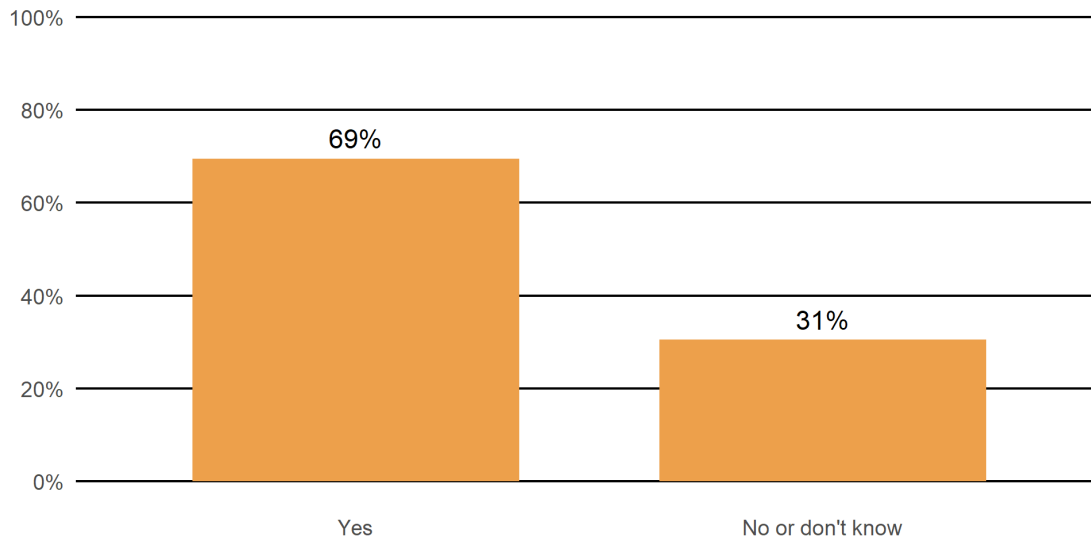


Table 82. Do you know how to report abuse or neglect related to your family member?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No or don't know	N
MN ↑	90%	10%	404
ND ↑	85%	15%	265
NH ↑	85%	15%	328
IN ↑	76%	24%	389
AZ	77%	23%	197
PA	71%	29%	514
DE	70%	30%	154
Weighted NCI-IDD Average	69%	31%	8325
GA	65%	35%	199
CA ↓	63%	37%	5104
NJ ↓	62%	38%	330
MD ↓	59%	41%	441

Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

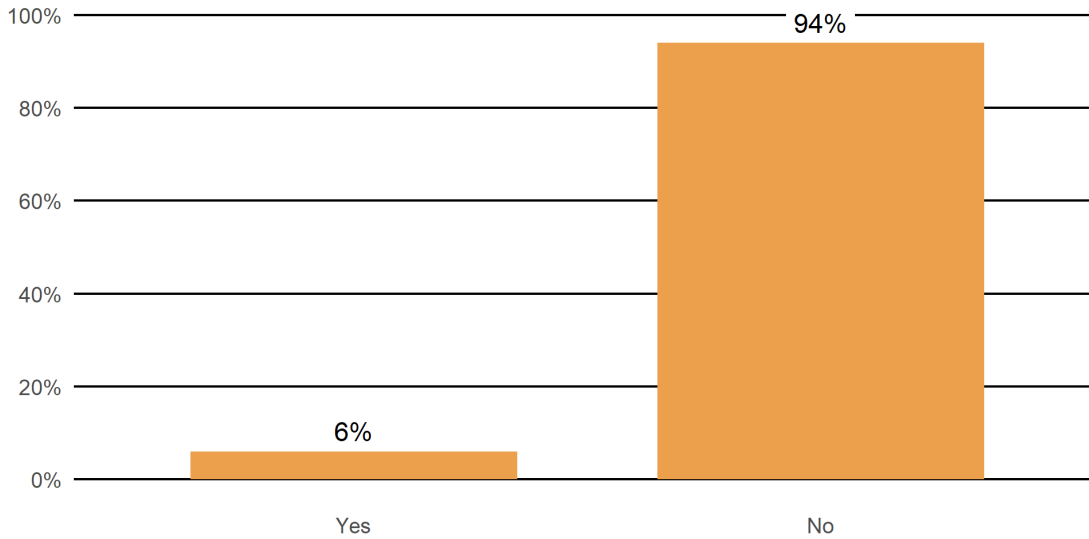


Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
DE ↑	17%	83%	148
NJ ↑	12%	88%	317
ND	10%	90%	253
PA	9%	91%	494
AZ	9%	91%	187
MD	9%	91%	408
IN	8%	92%	365
NH	7%	93%	323
Weighted NCI-IDD Average	6%	94%	7842
GA	5%	95%	186
MN	4%	96%	391
CA ↓	3%	97%	4770

If a report of abuse or neglect in the past 12 months was filed on behalf of a family member, or if someone other than you or another family member reported abuse or neglect in the 12 months, were you notified of the report in a timely manner?

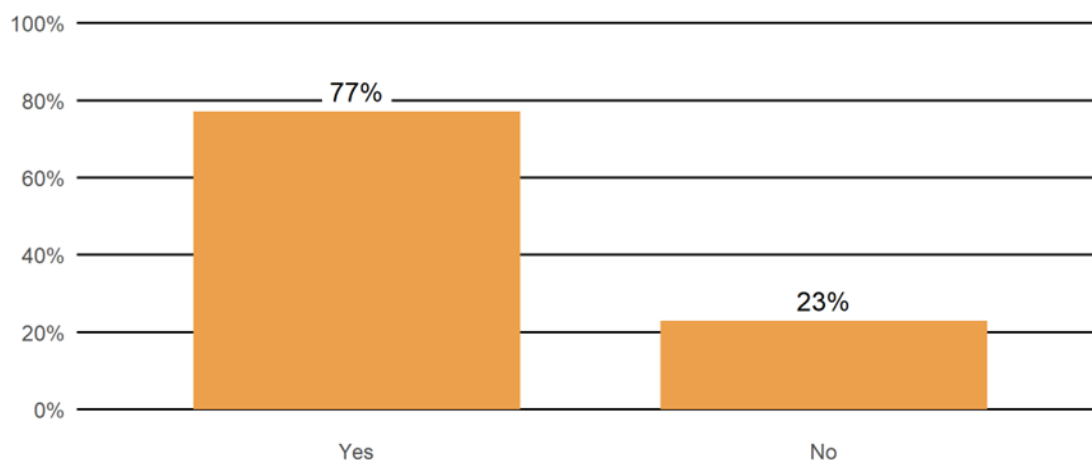


Table 84. If a report of abuse or neglect was filed on behalf of a family member, or if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
NH	86%	14%	21
IN	85%	15%	27
PA	81%	19%	42
Weighted NCI-IDD Average	77%	23%	309
NJ	76%	24%	29
MD	68%	32%	28
CA	66%	34%	88
DE	65%	35%	23
ND	57%	43%	23

Table note: The following states had an N of less than 20 and were not shown: AZ, GA, MN

Family Satisfaction

Services and supports lead to better lives for people with disabilities and their families.

Note: Significance is based on “Always” or “Yes” response.

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

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

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

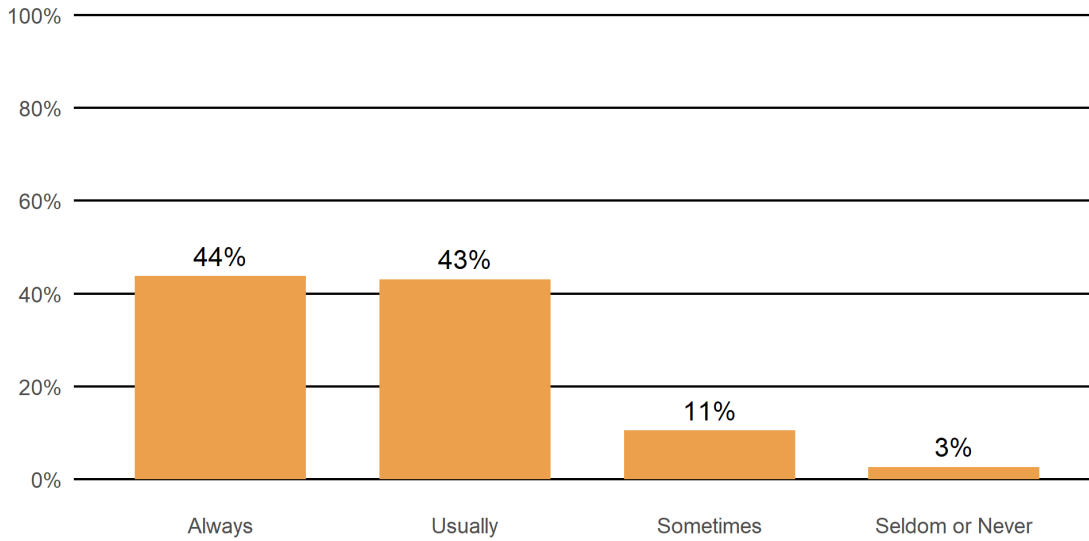


Table 85. Overall, are you satisfied with the services and supports your family member currently receives?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	52%	41%	6%	1%	403
NH	50%	38%	10%	2%	333
AZ	47%	41%	10%	2%	197
CA	46%	41%	9%	3%	4996
PA	44%	45%	10%	1%	526
Weighted NCI-IDD Average	44%	43%	11%	3%	8223
ND	43%	48%	8%	1%	264
GA	41%	44%	12%	3%	198
NJ	41%	39%	16%	4%	324
DE	35%	52%	10%	3%	157
IN ↓	34%	47%	15%	4%	388
MD ↓	26%	53%	15%	6%	437

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

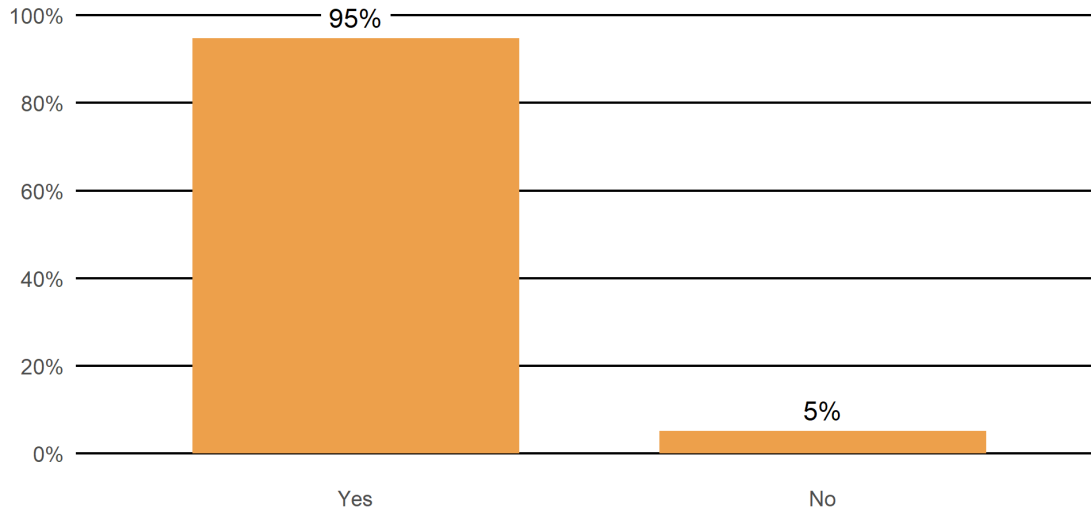


Table 86. Do you feel that services and supports have made a positive difference in the life of your family member?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
PA ↑	97%	3%	488
ND	97%	3%	259
MN	97%	3%	394
DE	96%	4%	142
NH	96%	4%	321
Weighted NCI-IDD Average	95%	5%	7827
CA	95%	5%	4766
GA	94%	6%	180
AZ	94%	6%	185
IN	92%	8%	374
NJ	91%	9%	308
MD ↓	90%	10%	410

Does the agency providing residential services to your family member involve them in important decisions?

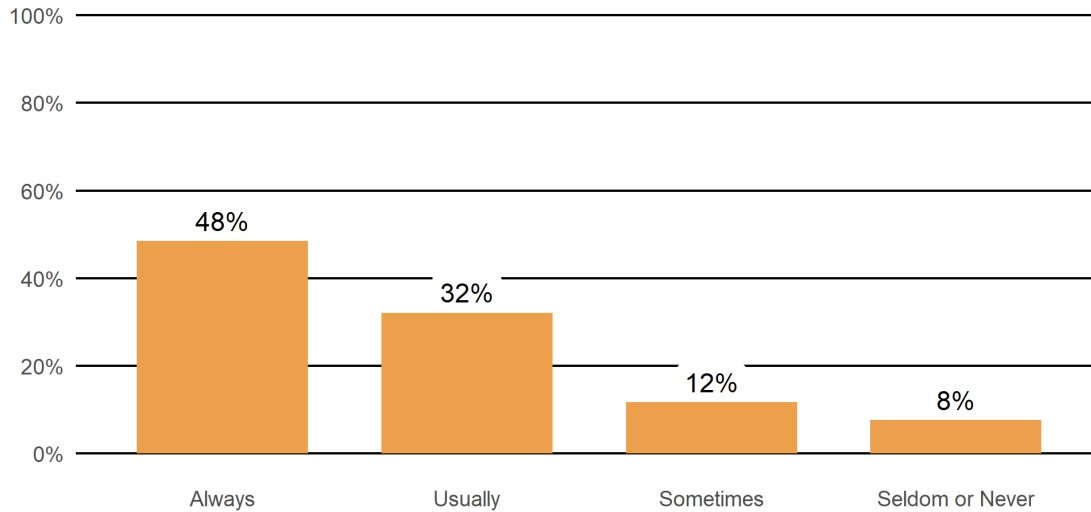


Table 87. Does the agency providing residential services to your family member involve them in important decisions?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN ↑	55%	30%	9%	5%	371
NH	56%	30%	9%	5%	282
ND	55%	32%	10%	3%	252
CA	51%	30%	10%	8%	3713
Weighted NCI-IDD Average	48%	32%	12%	8%	6437
AZ	46%	30%	20%	4%	168
GA	46%	29%	18%	8%	147
IN	45%	36%	12%	7%	318
PA	45%	37%	13%	5%	428
NJ	42%	25%	13%	19%	257
DE	38%	39%	15%	8%	125
MD ↓	40%	35%	13%	12%	376

Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

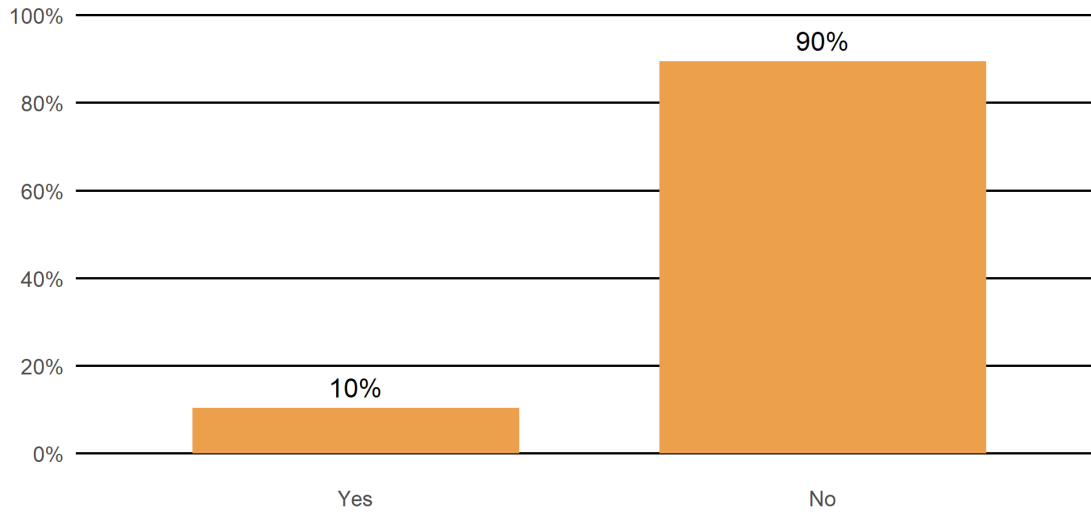


Table 88. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
NH	15%	85%	313
GA	15%	85%	169
IN	15%	85%	350
MD	13%	87%	408
AZ	12%	88%	187
NJ	12%	88%	303
CA	11%	89%	4314
Weighted NCI-IDD Average	10%	90%	7298
ND	10%	90%	247
MN	8%	92%	399
PA ↓	7%	93%	472
DE ↓	5%	95%	136

If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?

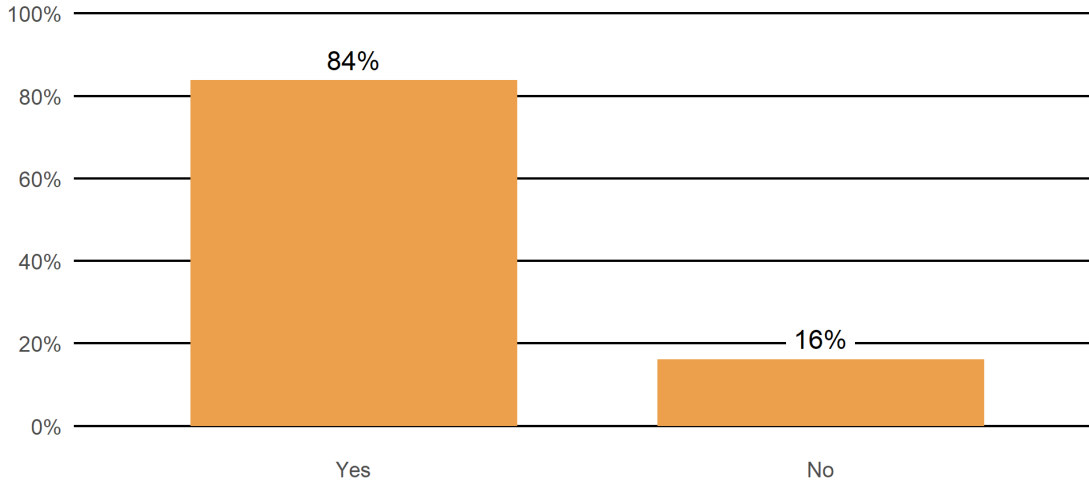


Table 89. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
NJ ↑	97%	3%	30
MN	92%	8%	24
MD	91%	9%	47
Weighted NCI-IDD Average	84%	16%	667
PA	83%	17%	24
GA	83%	17%	23
IN	82%	18%	45
ND	82%	18%	22
CA	81%	19%	389
NH	79%	21%	38

Table note: The following states had a low count of responses (N<20) and were not shown: AZ, DE

Have the services or supports that your family member received been increased in the past 12 months?

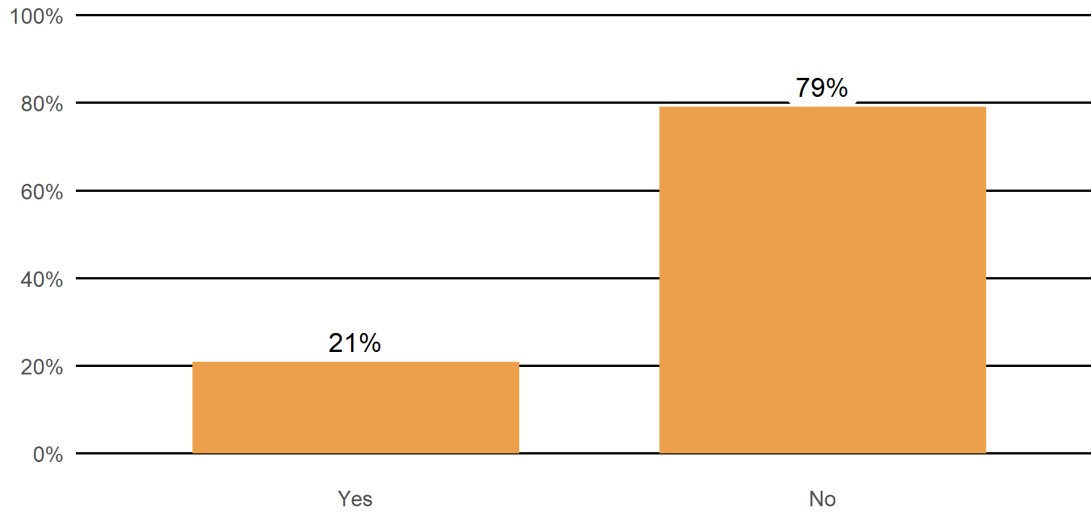


Table 90. Have the services or supports that your family member received been increased in the past 12 months?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
MD	27%	73%	360
IN	24%	76%	321
NH	23%	77%	279
PA	21%	79%	399
CA	21%	79%	3597
AZ	21%	79%	172
Weighted NCI-IDD Average	21%	79%	6228
NJ	20%	80%	268
DE	18%	82%	114
GA	18%	82%	142
ND	17%	83%	217
MN	16%	84%	359

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

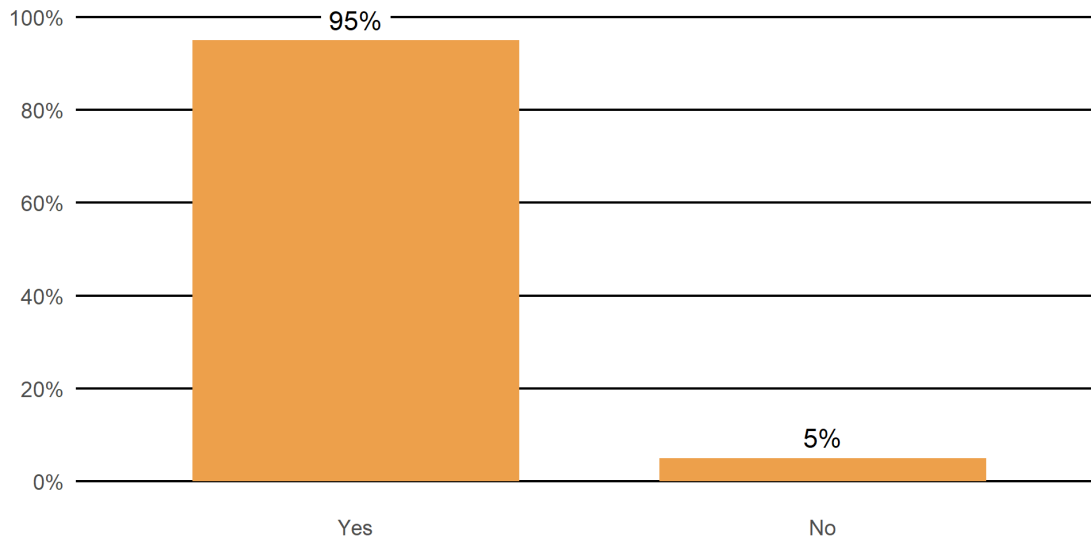


Table 91. Are services and supports helping your family member to live a good life?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State	Yes	No	N
PA ↑	98%	2%	475
DE	98%	2%	143
ND	97%	3%	251
MN	97%	3%	386
NH	96%	4%	313
Weighted NCI-IDD Average	95%	5%	7617
CA	95%	5%	4628
AZ	93%	7%	181
GA	93%	7%	179
IN	93%	7%	366
MD	92%	8%	390
NJ ↓	90%	10%	305

NCI-IDD History and Activities

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

Overview of National Core Indicators

In December 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI), launched the Core Indicators Project (CIP). The aim of the project was to support state developmental disabilities authorities in the development and implementation of performance and outcome indicators—and related data collection strategies—so that they could measure service delivery system performance. This effort, now called National Core Indicators-Intellectual and Developmental Disabilities (NCI-IDD), 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-IDD facilitates pooled knowledge, expertise, and resources among the states.

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

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

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

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

The Core Indicators

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

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

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

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

The NCI-IDD program is a dynamic effort that allows for measures to be added, dropped, or changed to reflect current and future priorities of participating states.

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

Sub-Domains and Value Statements

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

Family Survey Sub-Domains and Value Statements

Sub-Domain	Value Statement
Information and Planning	Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state Developmental disabilities system.
Choice and Decision Making	Families and their family members receiving services and supports from the state Developmental disabilities system are involved in making choices about supports, services, and providers.
Access & Support Delivery	Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state Developmental disabilities system.
Workforce	There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.
Community Connections	Family members receiving services and supports from the state Developmental disabilities system are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.
Health, Welfare, and Safety	Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state Developmental disabilities system.
Family Satisfaction	Services and supports lead to better lives for people with disabilities and their families.

How NCI Data Are Used

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

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

Caution and Limitations

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

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

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

Methodology

This section describes the protocol used by states to select families to participate in the survey, administer the survey, and convey the resulting data for analysis. It also includes information on the statistical methods used by NCI-IDD 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 (aged 18 or over) with an intellectual or developmental disability living outside of the home; and
2. The adult individual with an intellectual or developmental disability living outside of the home received at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys.

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

Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI-IDD reports, we use “NCI-IDD average” to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI-IDD average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). The approach has since been enhanced to consider the relative numbers of people receiving services through participating states’ systems. The NCI-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the sample sizes.

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

Significance Testing

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

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

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

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

Technical Details

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

Data Entry and Analysis

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

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

1. The respondent indicated the individual with an intellectual or developmental disability receiving services lived 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 Weighted NCI-IDD Average. The Weighted NCI-IDD Average is a weighted average. Please see the section “Weighting” for more details. Statistical significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

Response Rates

During 2023-24, eleven states administered the Family/Guardian Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The following table shows the number of individuals receiving services who were eligible to be drawn into the sample (total population), the number of surveys each state sent, complete surveys, response rates, margins of error, and survey submission modes.

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

Family Guardian Survey: State Response Rates

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	4975	1400	201	14%	6.3%	88%	12%
CA	41792	84000	5274	6%	1.2%	81%	19%
DE	1138	549	159	29%	7.1%	72%	28%
GA	3610	-	203	-	6.3%	100%	0%
IN	6634	1500	398	27%	4.5%	67%	33%
MD	6179	4658	468	10%	4.2%	25%	75%
MN	11104	1600	409	26%	4.4%	86%	14%
ND	1061	1061	272	26%	5.4%	75%	25%
NH	1527	1527	334	22%	4.9%	100%	0%
NJ	6410	6410	359	6%	4.7%	0%	100%
PA	18872	2000	537	27%	3.9%	87%	13%
Total	103302	104705	8614	8%	1.0%	76%	24%

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