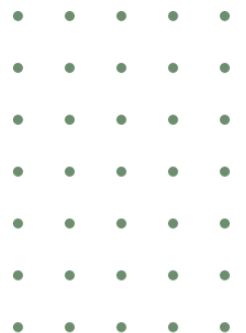


National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)



National Report 2021-22

Adult Family Survey (AFS)





Human Services Research Institute

Human Services Research Institute (HSRI)

2336 Massachusetts Avenue

Cambridge, MA 02140



NASDDDS

National Association of State Directors
of

Developmental Disabilities Services

National Association of State Directors of Developmental Disabilities Services (NASDDDS)

301 N Fairfax Street, Suite 101

Alexandria, VA 22314

May 2023

Questions/Comments: nci@nationalcoreindicators.org

List of Acronyms Used in This Report

AFS	Adult Family Survey
CMS	Centers for Medicare & Medicaid Services
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.

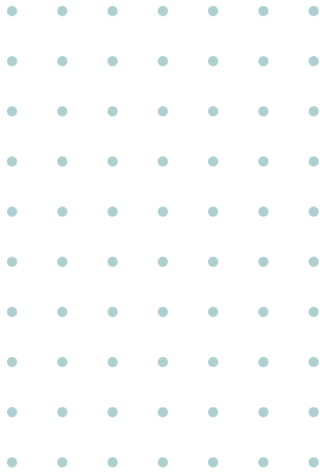
The National Core Indicators (NCI) Adult Family Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who lives in the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Adult Family 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 2021-22 data collection cycle, 12 states submitted a valid sample of Adult Family Survey data: Alaska (AK), Arizona (AZ), California (CA), Georgia (GA), Indiana (IN), Louisiana (LA), Missouri (MO), Montana (MT), New Hampshire (NH), Oklahoma (OK), Pennsylvania (PA), and South Dakota (SD). This Final Report provides a summary of results based on data submitted by June 30, 2022.

Note on the Impact of COVID-19

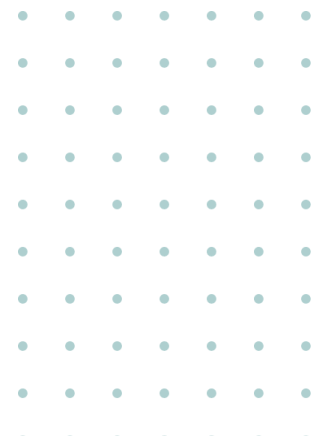
The 2021-22 NCI-IDD Family Survey data collection cycle began July 1, 2021 and ended June 30, 2022. As COVID-19 variants continued to impact communities across the United States, states were impacted in various ways throughout the year. Because the family surveys do not collect information on the date of survey completion, these data cannot fully assess what impact the pandemic had on data collected at different times throughout the year. While these data will serve as an important baseline, and meaningful way for states to understand the overall impact of services on families of individuals being served, these data should be read with caution.

To help better understand the overall impact of COVID-19 on families, NCI-IDD added a state-optional COVID-19 Supplement to all NCI-IDD Surveys. The COVID-19 Supplement is intended to support the understanding of the experience of people with disabilities and their families at the beginning of the COVID-19 pandemic, and their interactions with services during that time. Last year's Family Survey COVID-19 Supplement can be found [here](#).

Note: All Californians with an intellectual or developmental disability as defined by California law have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. As a result of these requirements, all eligible individuals are enrolled in California's service system, and California establishes no waiting list for services. This impacts comparability between California NCI-IDD survey results and the NCI-IDD survey results of other states.



Results



Presentation of Data

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

- Each question is constructed so the respondent selects from either four possible responses ("always," "usually," "sometimes," "seldom/never") or two responses ("yes" or "no"). Respondents also have the option to indicate that they don't know the answer to a question or that the question is not applicable.
- Demographic results are shown in table form with states listed alphabetically. Outcomes are shown first with a chart depicting the NCI-IDD Average. The charts are followed by accessible tables showing state outcomes and the NCI-IDD Average listed in descending order, grouped by level of significance.
- Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI-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.

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.

Note on page orientation: Some pages in this section are in landscape orientation because some table headers cannot be displayed in full in portrait orientation.

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

State	Yes	No	N
AK	16%	84%	146
AZ	17%	83%	238
CA	18%	82%	7752
GA	17%	83%	422
IN	14%	86%	377
LA	15%	85%	605
MO	13%	87%	240
MT	9%	91%	193
NH	10%	90%	550
OK	9%	91%	436
PA	12%	88%	371
SD	16%	84%	191
Weighted NCI-IDD Average	16%	84%	11521

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 2. Family Member's Residential Designation

State	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
AK	66%	34%	134
AZ	85%	15%	236
CA	88%	12%	7094
GA	55%	45%	404
IN	64%	36%	383
LA	51%	49%	599
MO	61%	39%	247
MT	57%	43%	193
NH	51%	49%	563
OK	67%	33%	435
PA	61%	39%	375
SD	70%	30%	190
Weighted NCI-IDD Average	78%	22%	10853

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 3. Family Member's Age

State	Age	N
AK	31.6	173
AZ	32.0	245
CA	34.2	7446
GA	46.2	425
IN	31.8	381
LA	35.4	636
MO	35.0	251
MT	34.7	198
NH	34.5	559
OK	36.7	452
PA	34.9	383
SD	30.3	201
Weighted NCI-IDD Average	34.6	11350

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 4. Family Member's Gender

State	Male	Female	Other	N
AK	60%	40%	0%	140
AZ	54%	46%	0%	247
CA	59%	40%	0%	7692
GA	57%	43%	0%	426
IN	61%	38%	0%	385
LA	59%	41%	0%	613
MO	64%	36%	0%	249
MT	56%	43%	1%	196
NH	59%	41%	0%	561
OK	55%	45%	0%	440
PA	62%	38%	0%	380
SD	61%	39%	0%	201
Weighted NCI-IDD Average	59%	41%	0%	11530

Table note: For "Other", the percentages for CA, IN and Weighted NCI-IDD Average are non-zero even though they are displayed as a rounded-down 0%.

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 5. Family Member's Race and Ethnicity

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
AK	30%	5%	4%	3%	66%	2%	4%	4%
AZ	2%	5%	4%	0%	65%	27%	2%	0%
CA	2%	15%	8%	1%	38%	41%	2%	3%
GA	0%	0%	41%	0%	55%	1%	0%	2%
IN	1%	0%	12%	0%	84%	4%	2%	2%
LA	2%	1%	27%	0%	68%	2%	1%	2%
MO	2%	1%	6%	0%	90%	4%	1%	2%
MT	2%	2%	1%	0%	96%	2%	2%	1%
NH	2%	2%	1%	0%	93%	2%	0%	2%
OK	19%	1%	12%	0%	76%	4%	1%	1%
PA	1%	2%	8%	0%	86%	4%	1%	0%
SD	6%	1%	1%	0%	89%	2%	0%	1%
Weighted NCI-IDD Average	2%	10%	10%	0%	54%	27%	2%	2%

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 6a. Family Member's Conditions

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	Hearing loss (severe or profound)
AK	74%	18%	40%	22%	5%	6%
AZ	64%	21%	40%	18%	9%	6%
CA	61%	21%	38%	16%	8%	5%
GA	73%	24%	25%	22%	13%	6%
IN	69%	31%	44%	15%	8%	7%
LA	62%	29%	36%	22%	16%	8%
MO	63%	22%	40%	17%	6%	5%
MT	70%	18%	30%	17%	10%	6%
NH	69%	28%	36%	10%	9%	8%
OK	79%	23%	25%	27%	12%	7%
PA	88%	33%	40%	15%	9%	8%
SD	67%	22%	31%	13%	7%	4%
Weighted NCI-IDD Average	66%	24%	38%	17%	9%	6%

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 6b. Family Member’s Conditions (Continued)

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

State	Brain Injury	Seizure Or Neurological Disorder	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
AK	14%	29%	0%	11%	2%	7%	29%
AZ	5%	28%	0%	20%	0%	0%	21%
CA	8%	23%	1%	14%	1%	1%	16%
GA	12%	31%	0%	11%	1%	2%	18%
IN	8%	27%	1%	14%	1%	1%	18%
LA	12%	37%	0%	13%	1%	1%	25%
MO	8%	27%	0%	14%	0%	1%	18%
MT	7%	29%	1%	20%	0%	0%	25%
NH	9%	27%	0%	16%	1%	1%	18%
OK	12%	37%	0%	20%	0%	1%	19%
PA	9%	30%	0%	18%	0%	1%	20%
SD	9%	23%	0%	25%	1%	2%	16%
Weighted NCI-IDD Average	8%	26%	0%	15%	1%	1%	18%

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 7a. Family Member’s Health Conditions

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

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AK	13%	17%	7%	26%	18%
AZ	11%	11%	4%	17%	29%
CA	8%	17%	4%	26%	28%
GA	9%	26%	4%	50%	40%
IN	10%	14%	5%	31%	25%
LA	12%	17%	4%	31%	27%
MO	13%	13%	4%	32%	25%
MT	12%	24%	5%	21%	27%
NH	10%	14%	4%	21%	24%
OK	10%	17%	4%	29%	22%
PA	8%	14%	4%	19%	25%
SD	10%	20%	3%	16%	23%
Weighted NCI-IDD Average	9%	16%	4%	26%	28%

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 7b. Family Member’s Health Conditions (continued)

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

State	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Dementia	Oral Health Problems	Sleep Apnea
AK	18%	6%	0%	21%	24%
AZ	8%	2%	3%	15%	20%
CA	6%	1%	2%	12%	17%
GA	7%	3%	4%	14%	16%
IN	11%	3%	2%	11%	23%
LA	13%	4%	3%	10%	17%
MO	8%	4%	0%	13%	20%
MT	15%	0%	1%	13%	23%
NH	12%	3%	3%	8%	20%
OK	16%	3%	2%	12%	20%
PA	10%	0%	1%	12%	18%
SD	7%	1%	1%	5%	30%
Weighted NCI-IDD Average	8%	2%	2%	12%	18%

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 7c. Family Member’s Health Conditions (continued)

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
AK	18%	6%	4%	3%	25%
AZ	25%	8%	5%	3%	25%
CA	18%	5%	3%	1%	26%
GA	10%	7%	3%	1%	14%
IN	23%	4%	4%	0%	21%
LA	13%	11%	6%	1%	29%
MO	19%	2%	3%	0%	25%
MT	22%	4%	4%	1%	29%
NH	20%	5%	5%	1%	26%
OK	15%	5%	3%	3%	19%
PA	15%	6%	1%	0%	35%
SD	14%	2%	7%	0%	26%
Weighted NCI-IDD Average	18%	5%	3%	1%	26%

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 8. Family Member's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AK	80%	10%	3%	2%	4%	138
AZ	75%	15%	3%	3%	5%	246
CA	82%	10%	1%	1%	5%	7859
GA	74%	17%	1%	1%	7%	418
IN	83%	9%	2%	2%	4%	391
LA	72%	18%	1%	1%	8%	623
MO	82%	14%	0%	0%	3%	234
MT	76%	12%	3%	2%	8%	200
NH	89%	7%	1%	1%	1%	569
OK	74%	17%	2%	2%	6%	450
PA	81%	10%	1%	1%	8%	379
SD	89%	8%	1%	2%	1%	194
Weighted NCI-IDD Average	81%	11%	1%	1%	5%	11701

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 9. Family Member's Preferred Language

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AK	92%	1%	0%	0%	0%	2%	5%	140
AZ	93%	6%	0%	0%	0%	1%	0%	252
CA	70%	17%	1%	1%	1%	0%	10%	7930
GA	97%	0%	0%	0%	0%	0%	2%	422
IN	95%	1%	0%	0%	0%	1%	2%	390
LA	98%	0%	0%	0%	0%	1%	2%	630
MO	98%	0%	0%	0%	0%	1%	0%	245
MT	98%	0%	0%	0%	0%	2%	1%	198
NH	98%	1%	0%	0%	0%	1%	1%	567
OK	96%	1%	0%	0%	0%	1%	1%	450
PA	97%	1%	0%	0%	0%	1%	2%	374
SD	98%	1%	0%	0%	0%	1%	1%	199
Weighted NCI-IDD Average	81%	10%	1%	0%	1%	1%	7%	11797

Table note: "Chinese" includes Mandarin, Cantonese, and Hokkien; "Tagalog" includes Filipino.

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 10. Family Member Has Legal Court Appointed Guardian or Conservator

State	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
AK	11%	3%	85%	1%	138
AZ	9%	9%	80%	1%	237
CA	44%	26%	25%	5%	7257
GA	37%	14%	43%	6%	405
IN	21%	5%	71%	3%	383
LA	35%	13%	47%	6%	570
MO	22%	7%	70%	1%	247
MT	18%	11%	68%	3%	198
NH	13%	11%	74%	3%	567
OK	22%	8%	67%	3%	432
PA	22%	20%	53%	5%	307
SD	18%	4%	76%	2%	195
Weighted NCI-IDD Average	35%	20%	41%	4%	10936

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 11. Guardian or Conservator Relationship to Family Member

State	Family	Friend	Employee or State Guardianship Agency	Other	N
AK	98%	0%	0%	2%	123
AZ	96%	1%	0%	2%	202
CA	96%	1%	1%	3%	3732
GA	91%	1%	0%	8%	226
IN	95%	0%	0%	5%	291
LA	92%	1%	0%	7%	351
MO	98%	0%	1%	1%	186
MT	96%	1%	1%	3%	156
NH	98%	1%	0%	1%	478
OK	98%	0%	0%	1%	316
PA	95%	1%	0%	4%	200
SD	97%	1%	0%	2%	155
Weighted NCI-IDD Average	95%	1%	0%	4%	6416

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 12. Family Member's Highest Level of Education

State	Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
AK	15%	4%	45%	23%	3%	8%	3%	136
AZ	16%	8%	26%	42%	2%	5%	2%	249
CA	19%	3%	34%	26%	4%	8%	6%	7410
GA	25%	0%	44%	25%	2%	2%	1%	404
IN	15%	7%	50%	17%	2%	4%	4%	385
LA	27%	6%	44%	15%	2%	3%	3%	613
MO	15%	1%	29%	48%	1%	3%	2%	234
MT	9%	2%	25%	61%	0%	1%	1%	202
NH	10%	0%	44%	37%	2%	4%	3%	563
OK	11%	3%	29%	50%	5%	1%	1%	440
PA	7%	2%	27%	56%	3%	2%	2%	367
SD	10%	9%	38%	34%	3%	3%	4%	199
Weighted NCI-IDD Average	17%	3%	34%	31%	4%	6%	4%	11202

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

State	None	Some	Extensive	N
AK	49%	35%	17%	138
AZ	55%	26%	20%	244
CA	51%	30%	19%	7535
GA	51%	32%	17%	412
IN	53%	34%	13%	384
LA	53%	26%	21%	611
MO	59%	30%	11%	246
MT	59%	26%	15%	195
NH	60%	30%	10%	548
OK	62%	26%	12%	439
PA	55%	31%	15%	370
SD	63%	31%	6%	193
Weighted NCI-IDD Average	53%	30%	17%	11315

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

State	None	Some	Extensive	N
AK	24%	34%	42%	137
AZ	15%	39%	46%	251
CA	27%	36%	37%	7717
GA	26%	32%	42%	423
IN	28%	41%	31%	389
LA	15%	31%	54%	625
MO	27%	37%	36%	249
MT	27%	35%	38%	201
NH	32%	36%	32%	572
OK	22%	35%	43%	444
PA	26%	44%	30%	379
SD	37%	43%	20%	196
Weighted NCI-IDD Average	26%	37%	37%	11583

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

State	None	Some	Extensive	N
AK	2%	24%	74%	137
AZ	2%	14%	84%	251
CA	8%	27%	65%	7719
GA	6%	20%	74%	418
IN	4%	20%	76%	389
LA	5%	13%	82%	622
MO	2%	21%	77%	247
MT	4%	25%	72%	199
NH	4%	26%	70%	566
OK	3%	17%	80%	447
PA	2%	18%	80%	377
SD	6%	31%	63%	197
Weighted NCI-IDD Average	6%	23%	71%	11569

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

Respondents

This section provides information about the survey respondent.

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 16. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AK	96%	1%	0%	1%	0%	1%	1%	139
AZ	92%	7%	0%	0%	0%	0%	0%	252
CA	64%	24%	2%	1%	1%	0%	8%	7945
GA	99%	0%	0%	0%	0%	0%	0%	422
IN	97%	1%	0%	0%	0%	0%	2%	388
LA	99%	0%	0%	0%	0%	0%	0%	625
MO	99%	0%	0%	0%	0%	0%	0%	245
MT	99%	0%	0%	0%	0%	0%	1%	198
NH	98%	2%	0%	0%	0%	0%	0%	567
OK	97%	2%	0%	0%	0%	0%	0%	442
PA	98%	1%	0%	0%	0%	0%	1%	381
SD	98%	1%	0%	0%	0%	0%	1%	199
Weighted NCI-IDD Average	77%	15%	1%	1%	1%	0%	5%	11803

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

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 17. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
AK	5%	14%	69%	12%	139
AZ	4%	30%	57%	10%	252
CA	9%	25%	55%	11%	7933
GA	1%	9%	65%	25%	420
IN	2%	33%	55%	10%	391
LA	3%	22%	62%	13%	627
MO	2%	22%	64%	11%	251
MT	1%	17%	66%	16%	201
NH	2%	17%	71%	10%	568
OK	4%	18%	63%	15%	446
PA	1%	17%	71%	11%	378
SD	5%	31%	56%	7%	197
Weighted NCI-IDD Average	6%	24%	59%	12%	11803

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 18. Respondent's Health

State	Excellent	Very good	Good	Fair	Poor	N
AK	14%	29%	41%	14%	2%	139
AZ	15%	36%	35%	13%	2%	252
CA	11%	30%	37%	18%	3%	7942
GA	6%	26%	40%	23%	4%	423
IN	8%	36%	38%	17%	1%	390
LA	10%	30%	38%	19%	3%	630
MO	12%	33%	40%	15%	1%	248
MT	13%	38%	36%	12%	0%	201
NH	16%	42%	30%	11%	1%	571
OK	12%	31%	39%	17%	1%	448
PA	12%	38%	35%	13%	2%	378
SD	22%	39%	32%	6%	1%	198
Weighted NCI-IDD Average	11%	32%	37%	17%	2%	11820

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 19. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Other	N
AK	86%	2%	0%	5%	7%	138
AZ	87%	6%	0%	3%	3%	251
CA	84%	7%	0%	2%	6%	7799
GA	78%	14%	0%	1%	6%	422
IN	90%	5%	0%	3%	2%	391
LA	86%	6%	0%	4%	4%	631
MO	88%	5%	0%	3%	4%	251
MT	89%	4%	0%	3%	4%	201
NH	86%	7%	0%	2%	4%	570
OK	89%	5%	0%	3%	3%	451
PA	89%	5%	0%	3%	3%	378
SD	93%	4%	0%	1%	2%	196
Weighted NCI-IDD Average	86%	7%	0%	2%	5%	11679

Table note: For "Spouse", the percentages for AZ, CA, GA, IN, MO, NH, and Weighted NCI-IDD Average are non-zero even though they are displayed as a rounded-down 0%.

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

State	No	Yes, Respondent Is	Yes, Another Family Member Is	N
AK	66%	26%	12%	138
AZ	10%	75%	16%	81
CA	49%	39%	16%	7786
GA	88%	6%	5%	420
IN	64%	27%	12%	388
LA	65%	18%	19%	617
MO	78%	10%	13%	251
MT	59%	26%	21%	198
NH	57%	36%	9%	554
OK	47%	42%	12%	445
PA	6%	91%	3%	33
SD	71%	22%	12%	195
Weighted NCI-IDD Average	52%	36%	15%	11106

Table note: Data combined from “select all that apply” questions and therefore might sum over 100%.

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 21. Number of Adults in Household (Not Including Family Member Receiving Supports)

State	One	Two	Three	Four or More	N
AK	10%	25%	42%	23%	137
AZ	8%	29%	42%	20%	251
CA	8%	26%	40%	26%	7777
GA	11%	41%	38%	10%	420
IN	5%	22%	55%	18%	392
LA	9%	34%	45%	12%	618
MO	4%	25%	58%	13%	250
MT	6%	32%	52%	9%	201
NH	8%	24%	49%	18%	565
OK	6%	35%	48%	11%	449
PA	5%	28%	51%	16%	376
SD	11%	23%	53%	13%	196
Weighted NCI-IDD Average	8%	27%	44%	22%	11632

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

State	One	Two	Three	Four or More	None	N
AK	5%	3%	2%	1%	89%	137
AZ	11%	4%	3%	1%	81%	248
CA	12%	4%	2%	1%	81%	7806
GA	5%	1%	1%	0%	92%	424
IN	10%	3%	3%	0%	85%	388
LA	6%	4%	0%	0%	90%	630
MO	5%	2%	1%	0%	92%	249
MT	5%	2%	1%	0%	91%	201
NH	6%	1%	0%	1%	92%	568
OK	6%	2%	1%	0%	90%	448
PA	8%	2%	1%	0%	90%	380
SD	8%	7%	3%	2%	81%	199
Weighted NCI-IDD Average	10%	4%	2%	1%	84%	11678

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 23. 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
AK	1%	20%	9%	25%	44%	138
AZ	9%	17%	6%	27%	41%	247
CA	18%	20%	6%	21%	35%	7762
GA	11%	34%	9%	18%	27%	414
IN	6%	25%	8%	21%	41%	383
LA	11%	31%	7%	23%	29%	622
MO	6%	20%	4%	27%	43%	240
MT	1%	26%	7%	21%	45%	202
NH	2%	24%	5%	22%	47%	565
OK	4%	28%	8%	25%	35%	451
PA	3%	31%	9%	19%	38%	382
SD	3%	20%	16%	16%	46%	197
Weighted NCI-IDD Average	13%	23%	7%	21%	36%	11603

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 24. Total Taxable Household Income of Wage Earners in the Past 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 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	Prefer Not to Say	N
AK	5%	3%	2%	18%	15%	26%	31%	136
AZ	9%	7%	10%	17%	18%	18%	20%	242
CA	14%	8%	9%	17%	12%	17%	23%	7604
GA	25%	9%	11%	19%	9%	8%	19%	407
IN	6%	6%	9%	19%	15%	23%	21%	382
LA	17%	8%	12%	15%	12%	15%	20%	618
MO	6%	6%	11%	22%	16%	19%	20%	236
MT	5%	11%	10%	21%	15%	14%	25%	198
NH	9%	5%	8%	15%	15%	21%	26%	555
OK	10%	9%	12%	17%	14%	15%	23%	429
PA	9%	5%	9%	23%	10%	24%	20%	371
SD	7%	3%	8%	14%	15%	29%	25%	198
Weighted NCI-IDD Average	12%	8%	9%	18%	12%	18%	22%	11376

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

Services and Supports Received

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

Table 25. Services and Supports Received from ID/DD Agency

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

State	Financial Support	In-Home Support	Out of Home Respite Care	Day or Employment Supports	Transportation	Mental/behavioral health care or other treatments or therapies	Self-Direction or Fiscal Intermediary Services
AK	22%	54%	37%	30%	43%	31%	n/a
AZ	13%	48%	43%	48%	52%	47%	43%
CA	17%	35%	23%	44%	36%	22%	21%
GA	18%	39%	17%	53%	59%	22%	31%
IN	7%	29%	22%	39%	39%	43%	43%
LA	12%	69%	15%	22%	44%	24%	46%
MO	16%	37%	28%	56%	56%	25%	43%
MT	20%	38%	24%	53%	58%	23%	52%
NH	37%	27%	35%	49%	61%	29%	59%
OK	11%	47%	12%	34%	50%	24%	37%
PA	15%	45%	25%	49%	59%	27%	53%
SD	28%	13%	26%	41%	41%	25%	68%
Weighted NCI-IDD Average	16%	38%	24%	44%	43%	26%	32%

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

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

State	Social Security Payments (SSI or SSB)	Services or Supports from Other Agencies or Organizations
AK	91%	41%
AZ	92%	34%
CA	82%	26%
GA	98%	22%
IN	90%	42%
LA	94%	27%
MO	97%	36%
MT	97%	48%
NH	94%	24%
OK	97%	14%
PA	96%	48%
SD	94%	42%
Weighted NCI-IDD Average	87%	31%

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

Main Survey Results

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

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

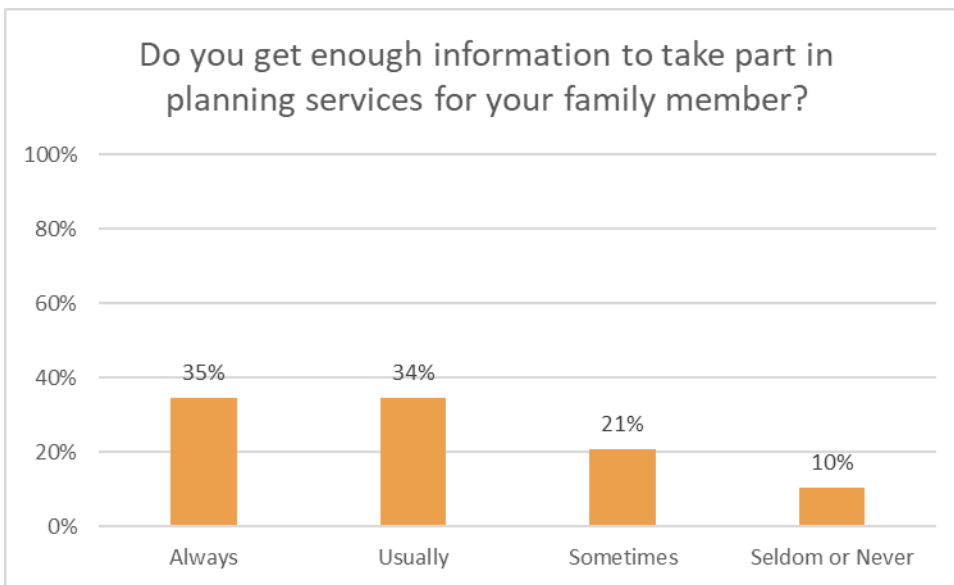


Table 27. Do you get enough information to take part in planning services for your family member? Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AK	52%	34%	11%	4%	171
LA	47%	36%	10%	7%	576
AZ	47%	38%	10%	5%	247
NH	41%	41%	13%	4%	535

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	40%	41%	12%	6%	188
OK	38%	42%	15%	6%	413
IN	36%	43%	17%	4%	370
PA	36%	40%	17%	8%	369
MT	35%	44%	15%	6%	191
Weighted NCI-IDD Average	35%	34%	21%	10%	10205

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	34%	45%	14%	6%	242
GA	32%	37%	20%	11%	381
CA	31%	30%	25%	14%	6522

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

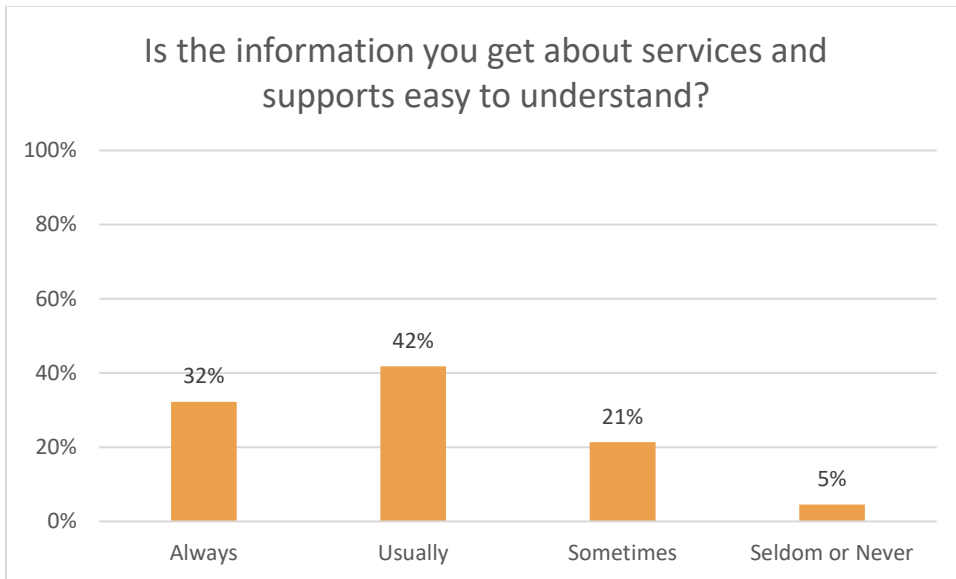


Table 28. Is the information you get about services and supports easy to understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	41%	35%	17%	7%	379
LA	38%	45%	13%	4%	582

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
CA	34%	36%	24%	6%	6883
AK	34%	50%	14%	3%	173
AZ	33%	48%	18%	2%	240
Weighted NCI-IDD Average	32%	42%	21%	5%	10588
NH	31%	54%	13%	2%	551
OK	30%	48%	19%	3%	410
PA	29%	51%	17%	3%	374
SD	27%	56%	13%	3%	193
MT	26%	52%	17%	4%	189

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	24%	56%	15%	5%	243
IN	22%	52%	22%	3%	371

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

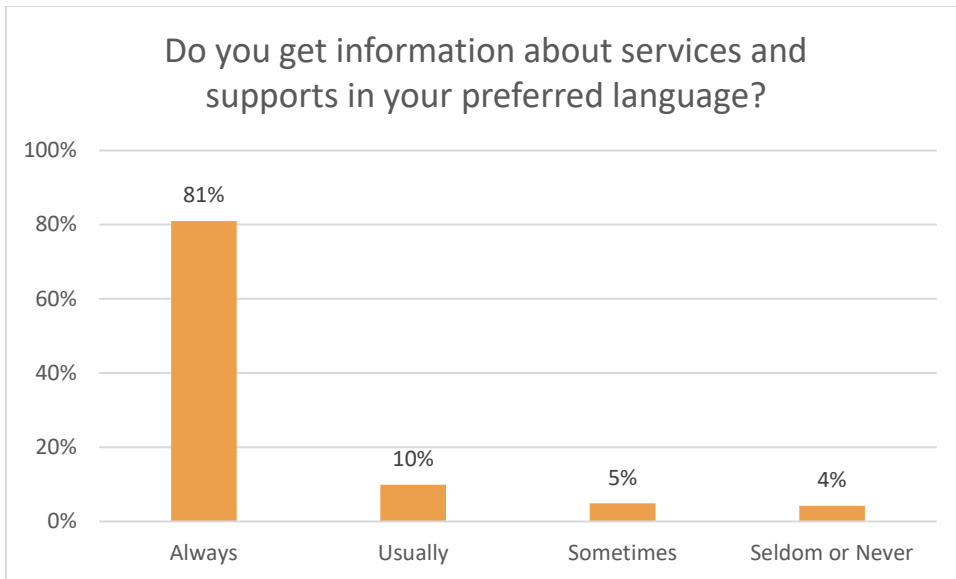


Table 29. Do you get information about services and supports in your preferred language?

New question in 2021-22

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	94%	4%	1%	2%	246
PA	93%	5%	1%	1%	373
SD	93%	3%	1%	4%	197
NH	92%	5%	1%	1%	558
MT	92%	5%	2%	1%	193
IN	92%	6%	1%	1%	380
AK	91%	7%	0%	2%	176
LA	90%	6%	1%	2%	600
OK	88%	8%	1%	3%	431

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	85%	12%	1%	2%	247
Weighted NCI-IDD Average	81%	10%	5%	4%	11152
GA	80%	11%	3%	6%	399

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	74%	12%	8%	6%	7352

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

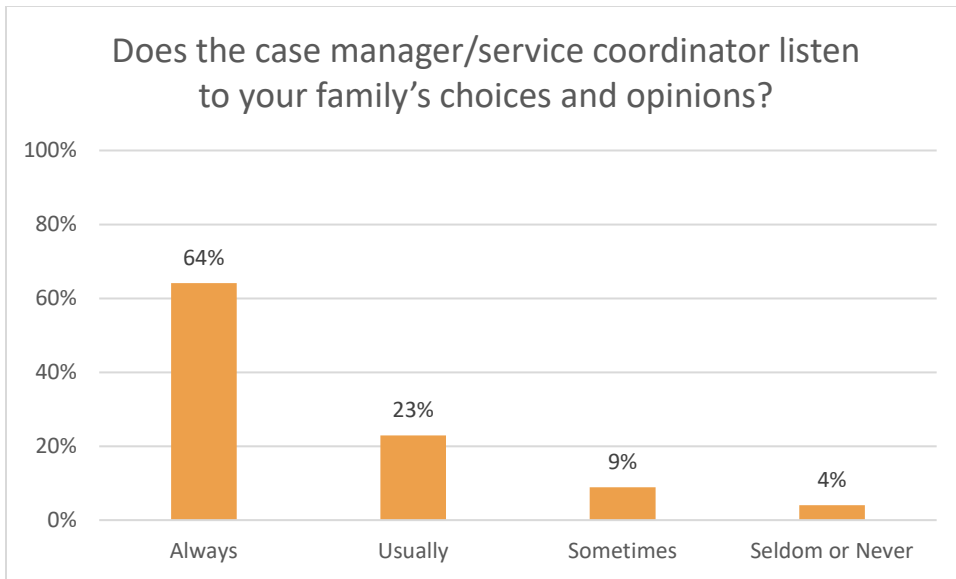


Table 30. Does the case manager/service coordinator listen to your family's choices and opinions?

Question changed in 2021-22

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	84%	14%	2%	0%	376
AK	82%	17%	1%	0%	174
LA	76%	18%	4%	2%	614
AZ	72%	22%	6%	0%	249
NH	72%	22%	5%	1%	560

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	69%	24%	5%	2%	367
SD	69%	26%	3%	2%	193
MO	67%	27%	4%	1%	240
Weighted NCI-IDD Average	64%	23%	9%	4%	11010
OK	62%	28%	8%	3%	434
GA	61%	26%	9%	4%	396
MT	59%	29%	8%	4%	186

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	58%	24%	12%	6%	7221

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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

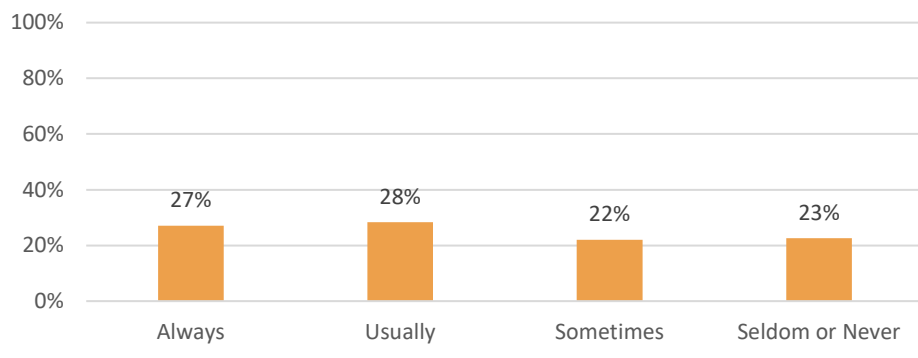


Table 31. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	32%	28%	17%	22%	206
LA	32%	27%	18%	23%	489
SD	31%	39%	15%	15%	175
PA	31%	32%	21%	17%	317
AK	30%	37%	17%	16%	155
IN	27%	35%	19%	19%	313
Weighted NCI-IDD Average	27%	28%	22%	23%	9653
CA	26%	25%	24%	24%	6394
NH	25%	41%	16%	18%	481
OK	25%	38%	17%	20%	415
MT	25%	43%	19%	13%	166
MO	24%	38%	19%	19%	203
GA	22%	32%	17%	29%	339

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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

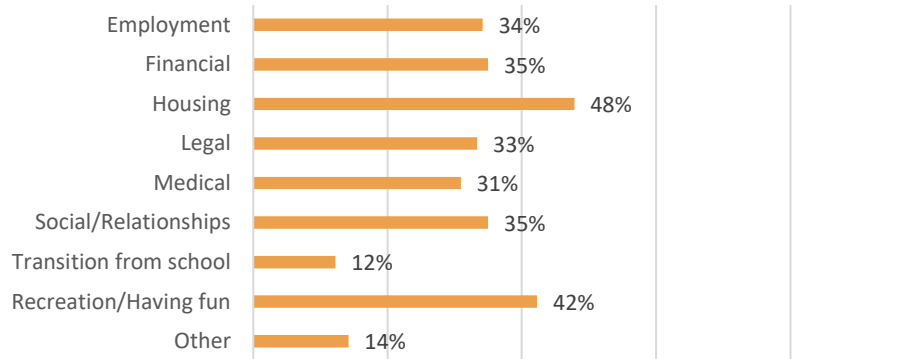


Table 32. Do you need help planning for your family member's future in any of the following areas?

State	Employment	Financial	Housing	Legal	Medical	Social/ Relationships	Transition	Recreation	Other
AK	38%	39%	52%	31%	27%	42%	16%	43%	13%
AZ	37%	40%	53%	35%	34%	33%	14%	48%	9%
CA	37%	35%	45%	33%	32%	36%	14%	43%	14%
GA	12%	25%	47%	37%	31%	25%	2%	26%	16%
IN	37%	39%	53%	36%	27%	35%	14%	40%	15%
LA	17%	28%	31%	28%	27%	21%	11%	28%	13%
MO	18%	29%	50%	35%	20%	27%	4%	33%	17%
MT	37%	35%	51%	30%	21%	38%	5%	44%	24%
NH	39%	35%	60%	30%	21%	45%	1%	44%	10%
OK	30%	29%	48%	38%	32%	28%	7%	35%	15%
PA	30%	35%	61%	35%	30%	36%	4%	45%	19%
SD	39%	43%	55%	27%	26%	46%	19%	36%	11%
Weighted NCI-IDD Average	34%	35%	48%	33%	31%	35%	12%	42%	14%

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

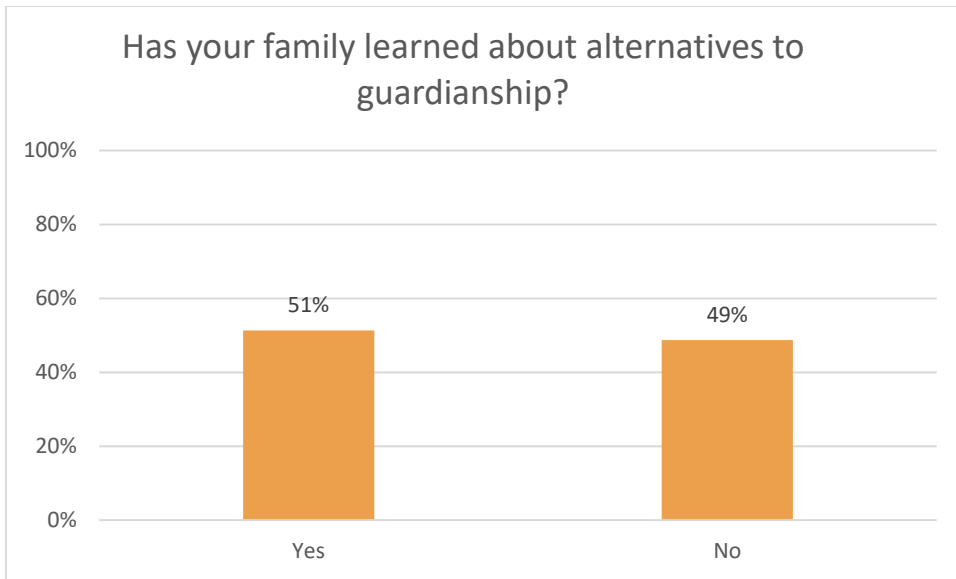


Table 33. Has your family learned about alternatives to guardianship?

New question in 2021-22

Significantly Above Average

State	Yes	No	N
AK	66%	34%	154
AZ	60%	40%	214

Within Average Range

State	Yes	No	N
PA	56%	44%	291
LA	54%	46%	498
SD	54%	46%	159
NH	54%	46%	491
IN	52%	48%	333
Weighted NCI-IDD Average	51%	49%	9334
MO	50%	50%	224
OK	50%	50%	340
CA	49%	51%	6124
MT	47%	53%	169

Significantly Below Average

State	Yes	No	N
GA	42%	58%	337

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

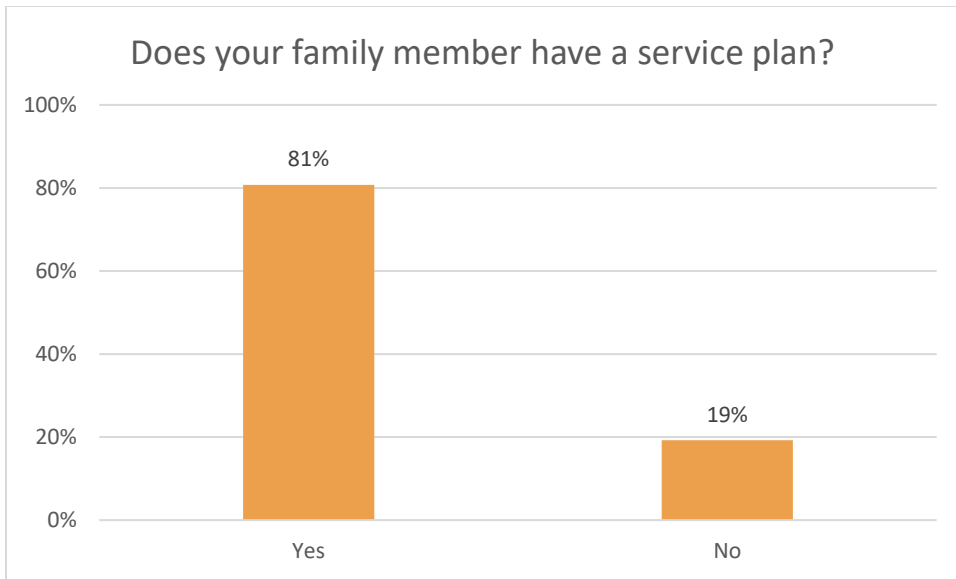


Table 34. Does your family member have a service plan?

Significantly Above Average

State	Yes	No	N
PA	97%	3%	372
MT	94%	6%	188
AK	93%	7%	166
MO	91%	9%	229
NH	85%	15%	513

Within Average Range

State	Yes	No	N
OK	81%	19%	360
Weighted NCI-IDD Average	81%	19%	9739
CA	80%	20%	6444
LA	79%	21%	496
IN	79%	21%	292
SD	76%	24%	168

Significantly Below Average

State	Yes	No	N
AZ	64%	36%	186
GA	60%	40%	325

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

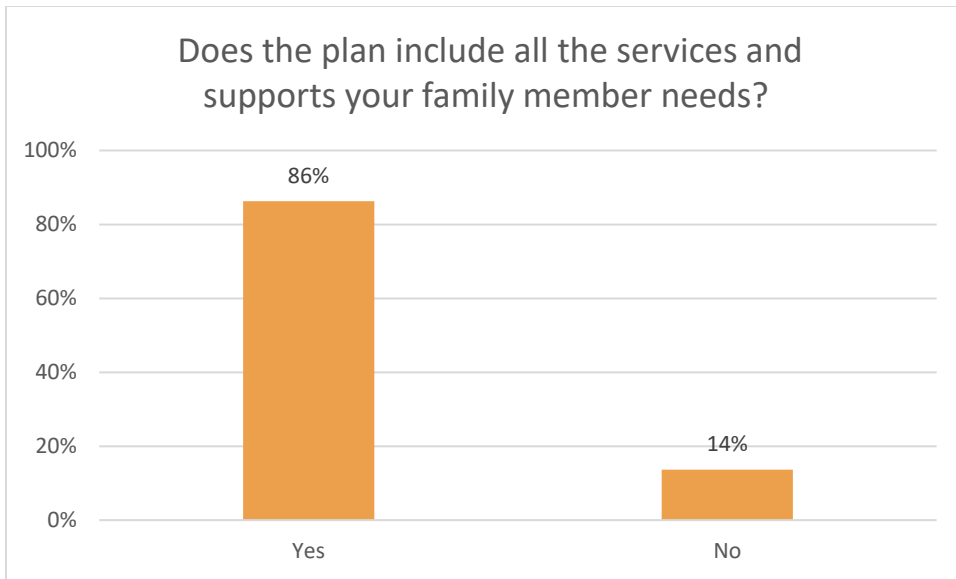


Table 35. Does the plan include all the services and supports your family member needs?

Significantly Above Average

State	Yes	No	N
LA	95%	5%	347
PA	91%	9%	317

Within Average Range

State	Yes	No	N
AZ	91%	9%	110
OK	90%	10%	246
SD	89%	11%	107
IN	87%	13%	190
Weighted NCI-IDD Average	86%	14%	6510
NH	86%	14%	385
GA	85%	15%	169
CA	84%	16%	4150
MO	84%	16%	186
AK	82%	18%	146
MT	79%	21%	157

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

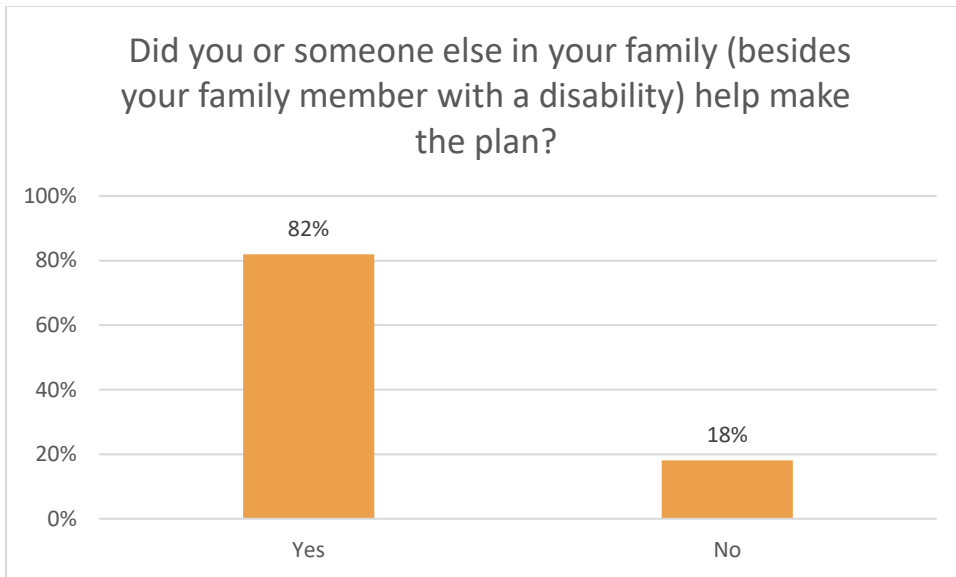


Table 36. Did you or someone else in your family (besides your family member with a disability) help make the plan?

Significantly Above Average

State	Yes	No	N
AK	95%	5%	150
MO	92%	8%	205
SD	91%	9%	119
MT	89%	11%	172

Within Average Range

State	Yes	No	N
AZ	88%	13%	112
OK	87%	13%	263
PA	85%	15%	349
IN	85%	15%	212
NH	85%	15%	419
LA	84%	16%	366
Weighted NCI-IDD Average	82%	18%	7127
GA	82%	18%	184
CA	79%	21%	4576

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

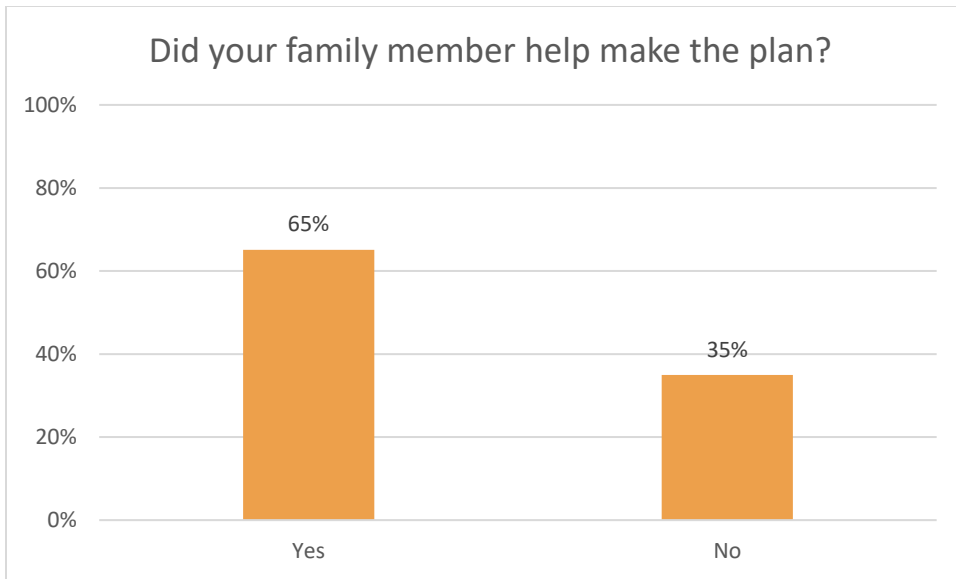


Table 37. Did your family member help make the plan?

Significantly Above Average

State	Yes	No	N
SD	86%	14%	119
MT	76%	24%	170

Within Average Range

State	Yes	No	N
AK	72%	28%	149
NH	71%	29%	420
PA	69%	31%	343
IN	69%	31%	216
Weighted NCI-IDD Average	65%	35%	7078
CA	64%	36%	4537
OK	63%	38%	272
AZ	62%	38%	109
MO	62%	38%	203
GA	60%	40%	181

Significantly Below Average

State	Yes	No	N
LA	53%	47%	359

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

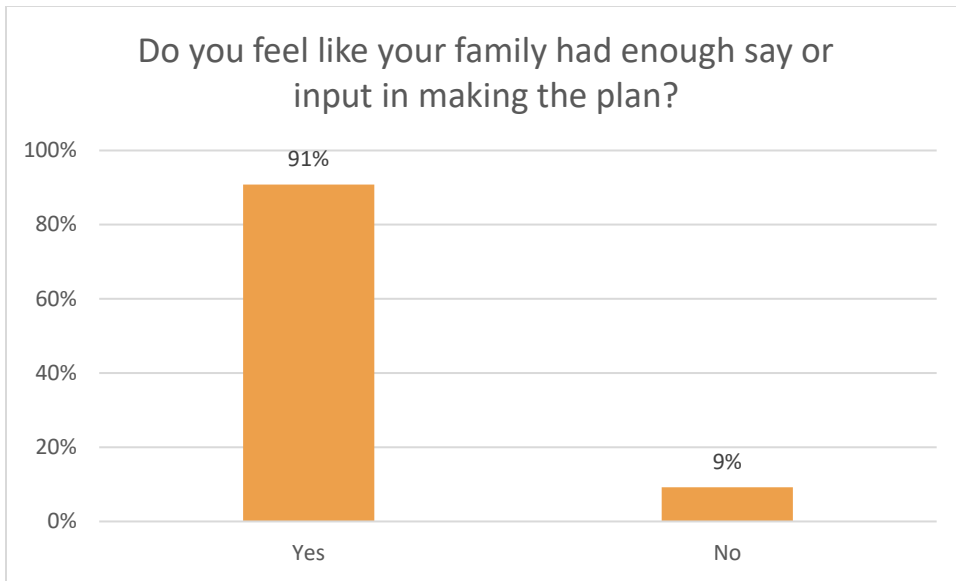


Table 38. Do you feel like your family had enough say or input in making the plan?

New question in 2021-22

Significantly Above Average

State	Yes	No	N
NH	98%	2%	408
MO	97%	3%	197
IN	97%	3%	205
SD	97%	3%	118
LA	95%	5%	344

Within Average Range

State	Yes	No	N
AZ	95%	5%	109
MT	95%	5%	160
AK	95%	5%	150
GA	94%	6%	165
PA	94%	6%	325
OK	94%	6%	258
Weighted NCI-IDD Average	91%	9%	6692

Significantly Below Average

State	Yes	No	N
CA	87%	13%	4253

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

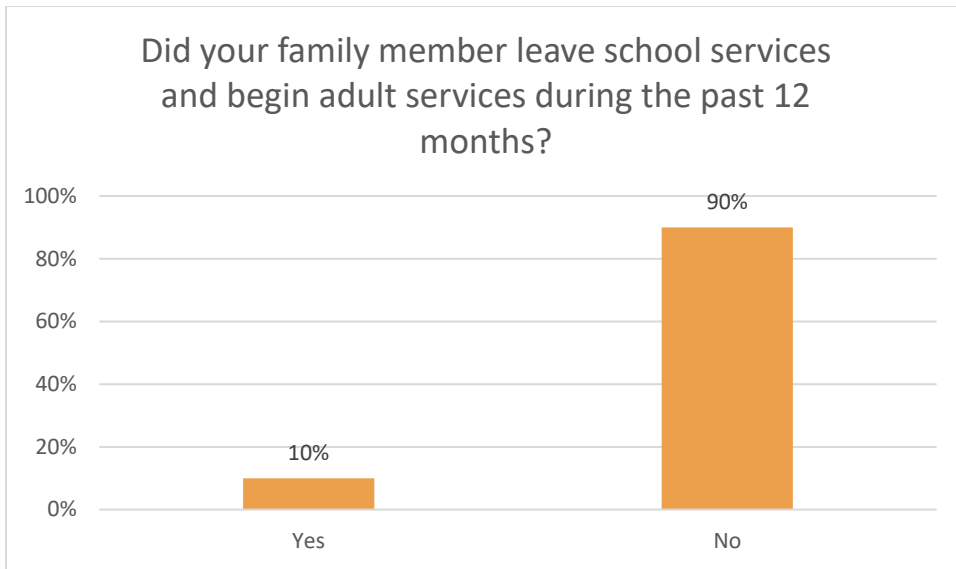


Table 39. Did your family member leave school services and begin adult services during the past 12 months?

State	Yes	No	N
AK	4%	96%	165
AZ	10%	90%	232
CA	14%	86%	6998
GA	1%	99%	380
IN	7%	93%	374
LA	5%	95%	587
MO	3%	97%	239
MT	2%	98%	193
NH	5%	95%	553
OK	3%	97%	427
PA	4%	96%	372
SD	10%	90%	193
Weighted NCI-IDD Average	10%	90%	10713

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

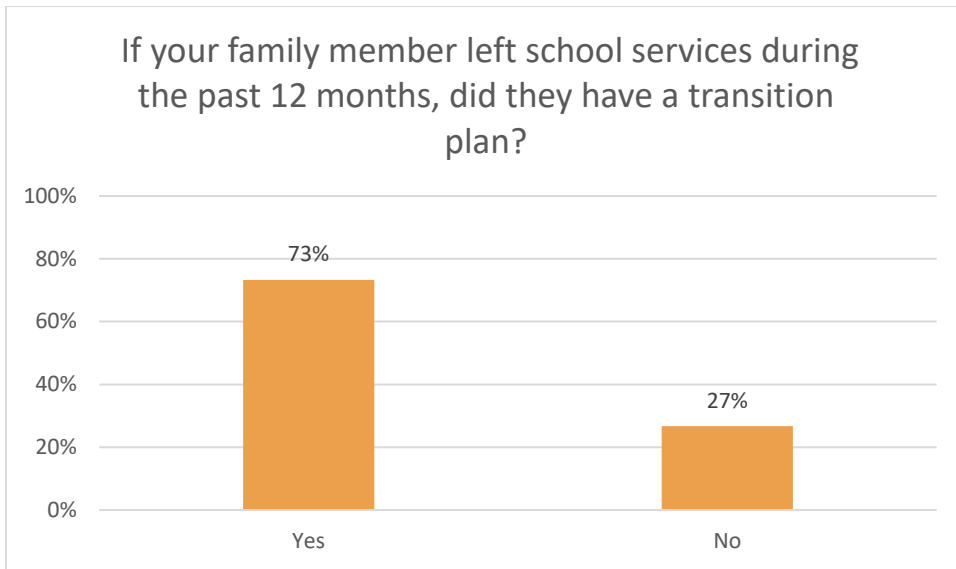


Table 40. If your family member left school services during the past 12 months, did they have a transition plan?

Within Average Range

State	Yes	No	N
NH	79%	21%	24
AZ	77%	23%	22
Weighted NCI-IDD Average	73%	27%	867
CA	73%	27%	730
LA	65%	35%	20

Table note: AK, GA, IN, MO, MT, OK, PA, and SD are not included in the above list due to low counts.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

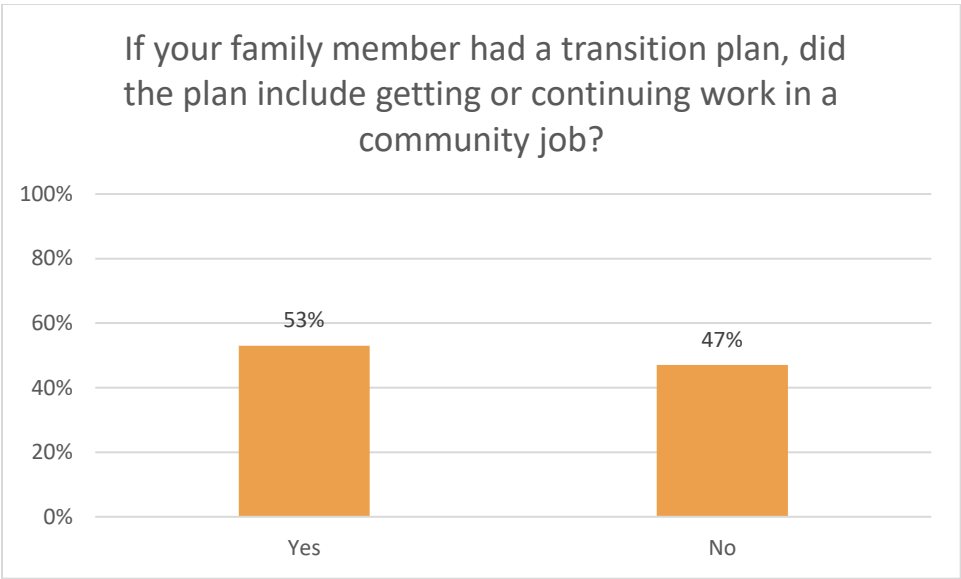


Table 41. If your family member had a transition plan, did the plan include getting or continuing work in a community job?

Within Average Range

State	Yes	No	N
Weighted NCI-IDD Average	53%	47%	555
CA	51%	49%	459

Table note: AK, AZ, GA, IN, LA, MO, MT, NH, OK, PA, and SD are not included in the above table due to low counts.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

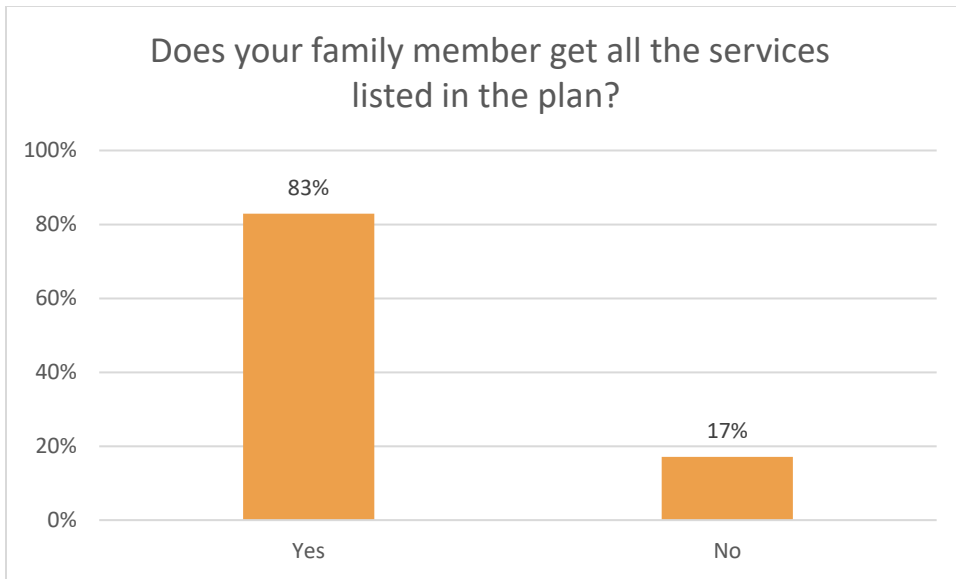


Table 42. Does your family member get all the services listed in the plan?

Significantly Above Average

State	Yes	No	N
SD	93%	7%	112
LA	91%	9%	339

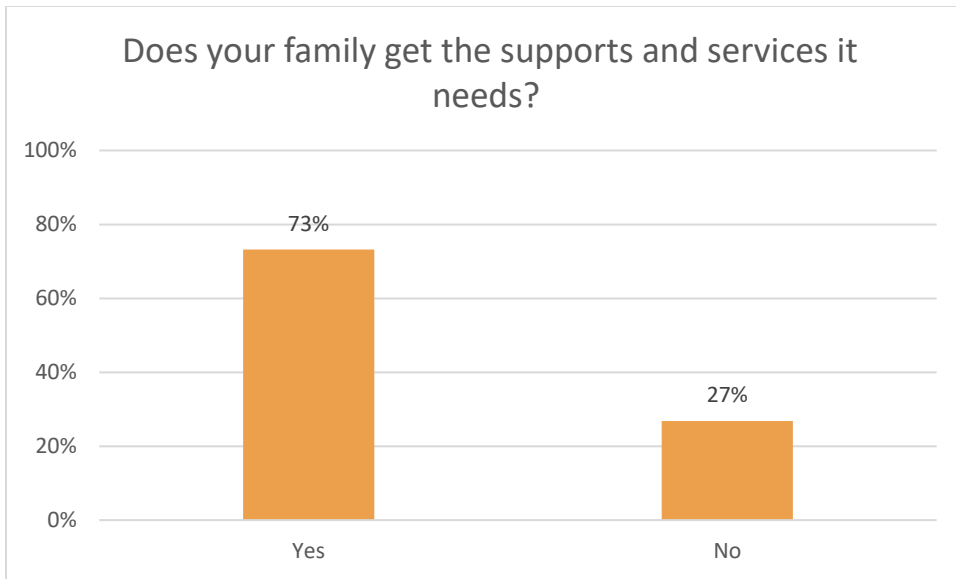
Within Average Range

State	Yes	No	N
AZ	87%	13%	109
OK	86%	14%	243
NH	86%	14%	402
PA	83%	17%	321
CA	83%	17%	4171
Weighted NCI-IDD Average	83%	17%	6555
MT	81%	19%	160
GA	79%	21%	169
MO	79%	21%	192
IN	77%	23%	191

Significantly Below Average

State	Yes	No	N
AK	66%	34%	146

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)



**Table 43. Does your family get the supports and services it needs?
Significantly Above Average**

State	Yes	No	N
LA	81%	19%	539
AZ	81%	19%	232

Within Average Range

State	Yes	No	N
NH	77%	23%	509
OK	74%	26%	361
Weighted NCI-IDD Average	73%	27%	9576
IN	73%	27%	304
CA	73%	27%	6235
SD	72%	28%	176
PA	72%	28%	338
MT	68%	32%	166
AK	66%	34%	128
MO	66%	34%	214

Significantly Below Average

State	Yes	No	N
GA	66%	34%	342

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

If your family does not get the supports and services it needs, what additional services does your family need?:

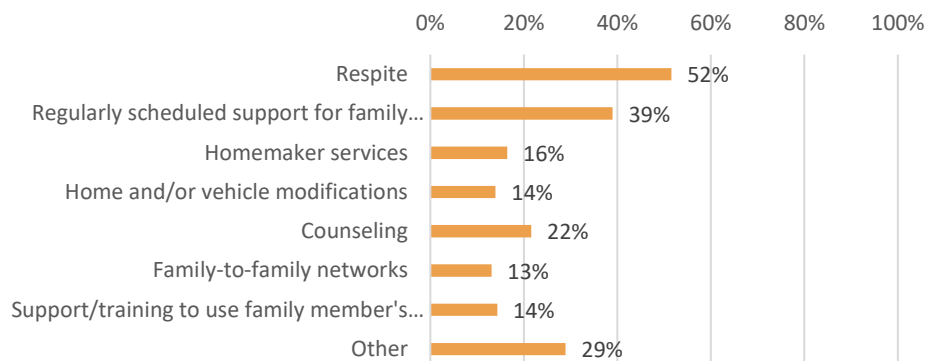


Table 44. What additional services are needed?

State	Respite	Regularly scheduled support for family member	Homemaker services	Home and/or vehicle modifications	Counseling	Family-to-family networks	Assistive technology training and support	Other
AK	63%	51%	12%	19%	14%	16%	7%	37%
AZ	53%	35%	12%	9%	23%	14%	12%	40%
CA	45%	36%	18%	15%	27%	15%	18%	34%
GA	64%	40%	25%	17%	13%	11%	15%	18%
IN	66%	52%	13%	13%	14%	12%	6%	23%
LA	48%	40%	22%	28%	28%	13%	18%	26%
MO	59%	33%	16%	14%	11%	11%	14%	33%
MT	69%	38%	21%	6%	12%	17%	6%	25%
NH	57%	43%	8%	7%	17%	14%	6%	29%
OK	63%	30%	23%	23%	18%	13%	9%	42%
PA	59%	49%	13%	11%	10%	6%	7%	12%
SD	58%	38%	18%	11%	11%	13%	9%	29%
Weighted NCI-IDD Average	52%	39%	16%	14%	22%	13%	14%	29%

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

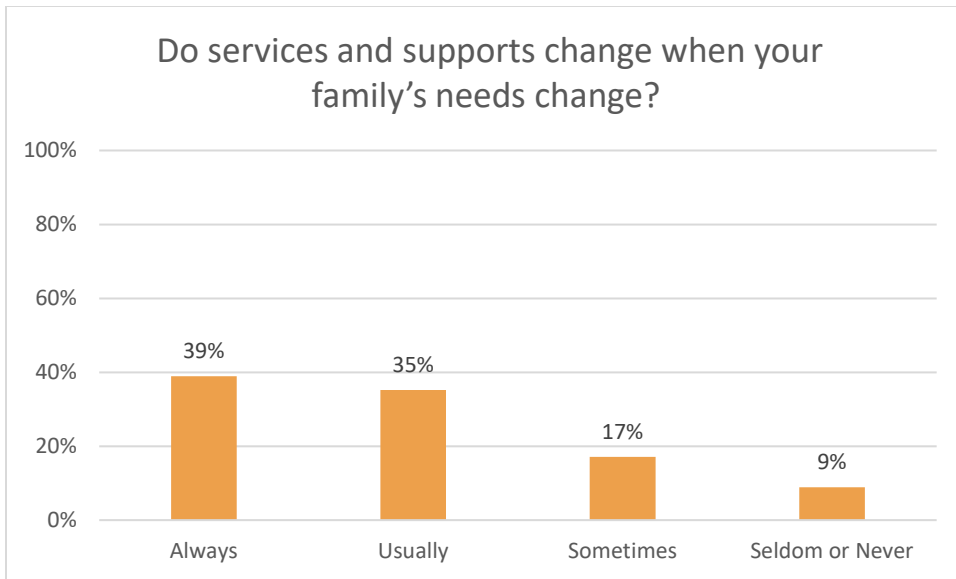


Table 45. Do services and supports change when your family's needs change?

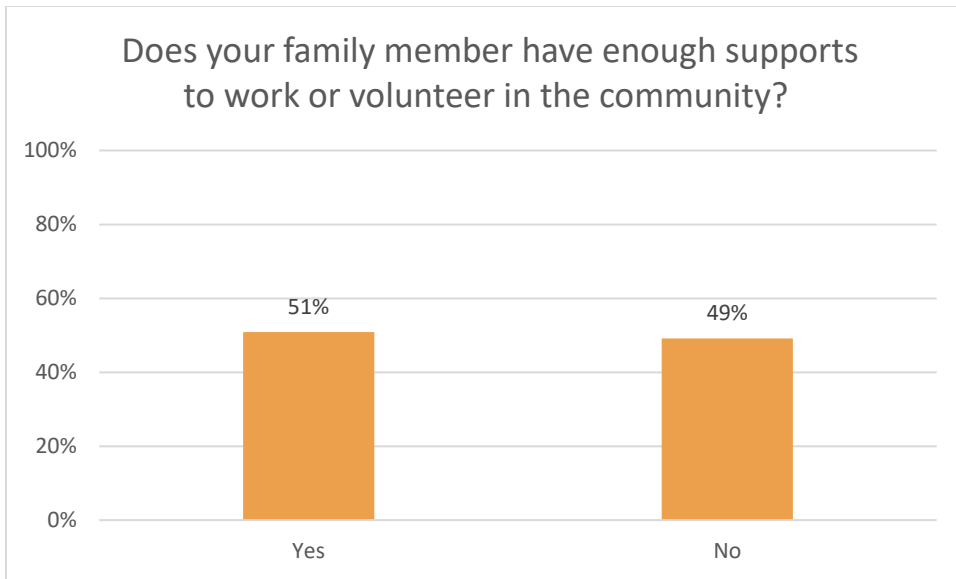
Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	50%	35%	9%	6%	505

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	45%	37%	14%	5%	303
AZ	43%	39%	14%	3%	208
SD	43%	38%	14%	5%	149
IN	41%	36%	17%	6%	278
OK	40%	38%	17%	5%	341
Weighted NCI-IDD Average	39%	35%	17%	9%	7996
MO	37%	38%	18%	7%	181
NH	36%	40%	14%	10%	428
CA	36%	33%	19%	12%	5052
GA	33%	42%	15%	10%	272
AK	33%	40%	15%	13%	141
MT	31%	38%	14%	16%	138

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)



**Table 46. Does your family member have enough supports to work or volunteer in the community?
Significantly Above Average**

State	Yes	No	N
NH	69%	31%	451
SD	67%	33%	156
MO	63%	38%	176
OK	62%	38%	284
MT	61%	39%	158
PA	59%	41%	278

Within Average Range

State	Yes	No	N
IN	57%	43%	253
AK	51%	49%	125
Weighted NCI-IDD Average	51%	49%	7691
AZ	50%	50%	159
LA	49%	51%	352
CA	47%	53%	5045
GA	45%	55%	254

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

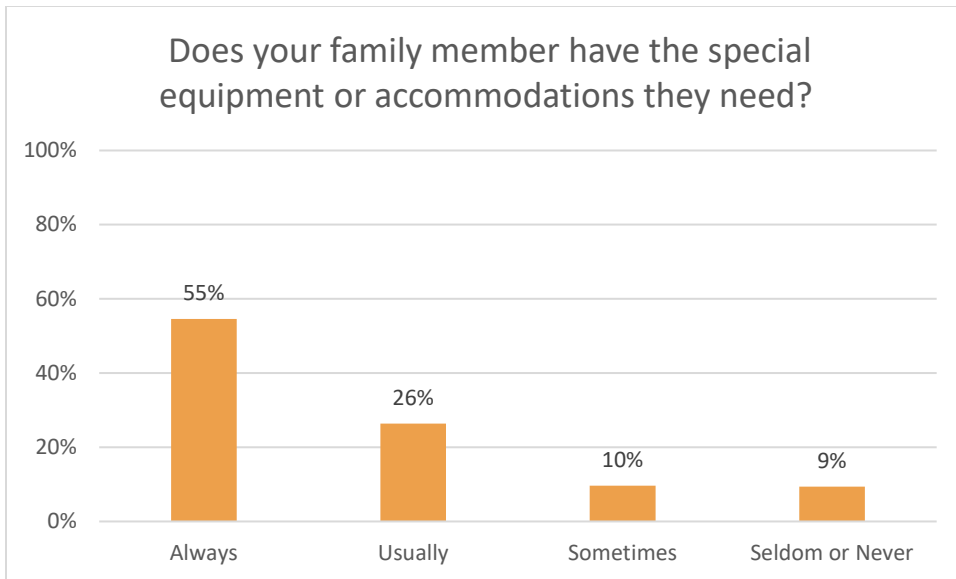


Table 47. Does your family member have the special equipment or accommodations they need?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AK	62%	20%	10%	8%	89
PA	60%	26%	4%	11%	136
NH	56%	32%	7%	5%	218
IN	56%	32%	9%	3%	147
CA	55%	23%	11%	11%	2912
Weighted NCI-IDD Average	55%	26%	10%	9%	4656
LA	54%	32%	8%	6%	357
MT	53%	34%	12%	1%	98
MO	53%	32%	11%	5%	95
SD	52%	29%	12%	8%	77
AZ	50%	34%	7%	9%	125
OK	46%	32%	13%	9%	206
GA	46%	28%	15%	11%	196

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

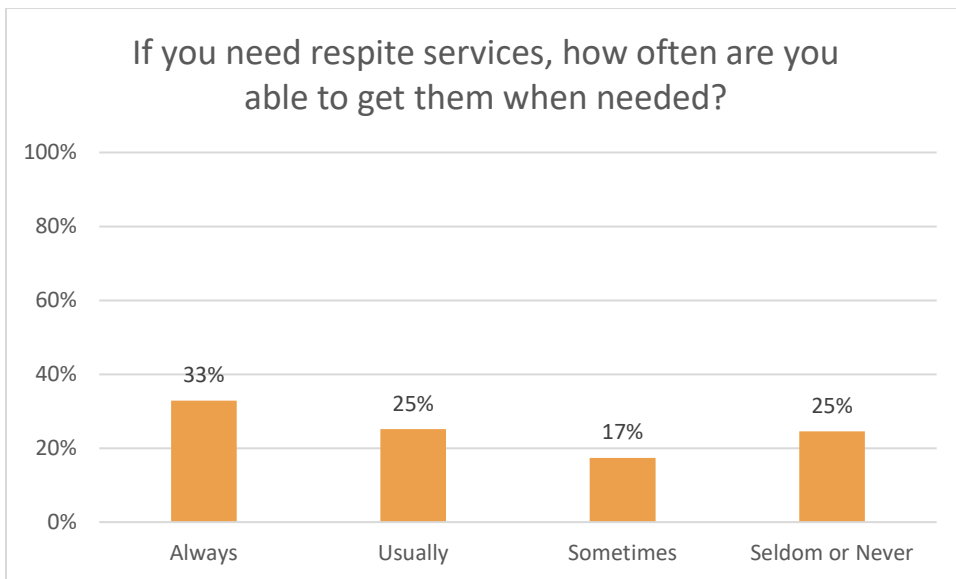


Table 48. If you need respite services, how often are you able to get them when needed?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	38%	24%	17%	21%	4459

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	39%	30%	16%	15%	211
LA	34%	27%	11%	28%	338
Weighted NCI-IDD Average	33%	25%	17%	25%	6778
IN	25%	24%	23%	28%	205

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	23%	33%	21%	22%	396
AK	21%	21%	24%	35%	139
OK	19%	21%	12%	48%	203
PA	19%	23%	21%	37%	214
SD	19%	28%	28%	25%	107
MO	18%	25%	21%	35%	154
GA	18%	30%	9%	43%	235
MT	17%	27%	19%	37%	117

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

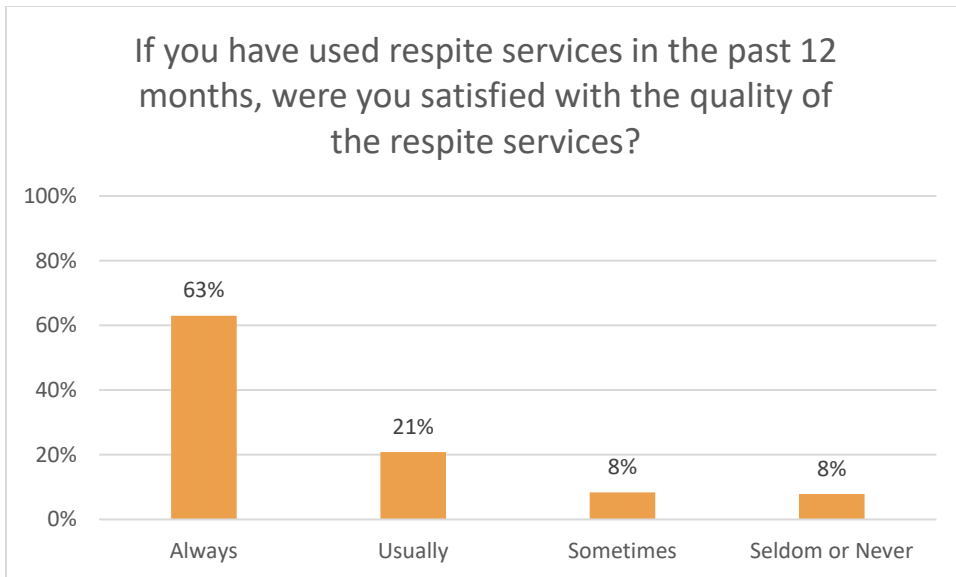


Table 49. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MT	68%	20%	2%	11%	65
AZ	67%	19%	8%	6%	156
NH	65%	25%	6%	3%	269
CA	65%	19%	8%	8%	2920
LA	64%	19%	5%	12%	162
Weighted NCI-IDD Average	63%	21%	8%	8%	4157
SD	63%	26%	9%	3%	70
MO	61%	22%	7%	10%	72
IN	57%	23%	14%	5%	115
AK	55%	26%	5%	14%	85
PA	55%	32%	7%	6%	82

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	47%	25%	9%	18%	87
OK	36%	36%	4%	23%	74

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

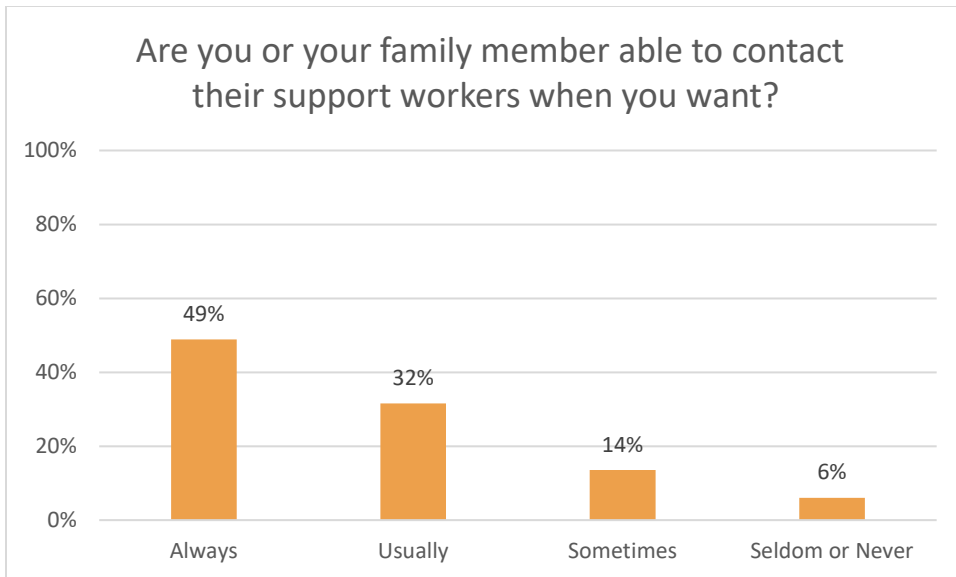


Table 50. Are you or your family member able to contact their support workers when you want?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	66%	26%	5%	3%	576
PA	61%	29%	8%	2%	347

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	56%	37%	4%	2%	167
NH	54%	34%	8%	5%	498
OK	53%	34%	8%	5%	369
AZ	52%	36%	10%	2%	231
AK	51%	28%	13%	8%	152
IN	50%	35%	11%	3%	315
Weighted NCI-IDD Average	4%	32%	14%	6%	9687
GA	48%	36%	12%	4%	362
MO	47%	40%	10%	3%	214
CA	44%	30%	17%	8%	6280
MT	40%	44%	10%	6%	176

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

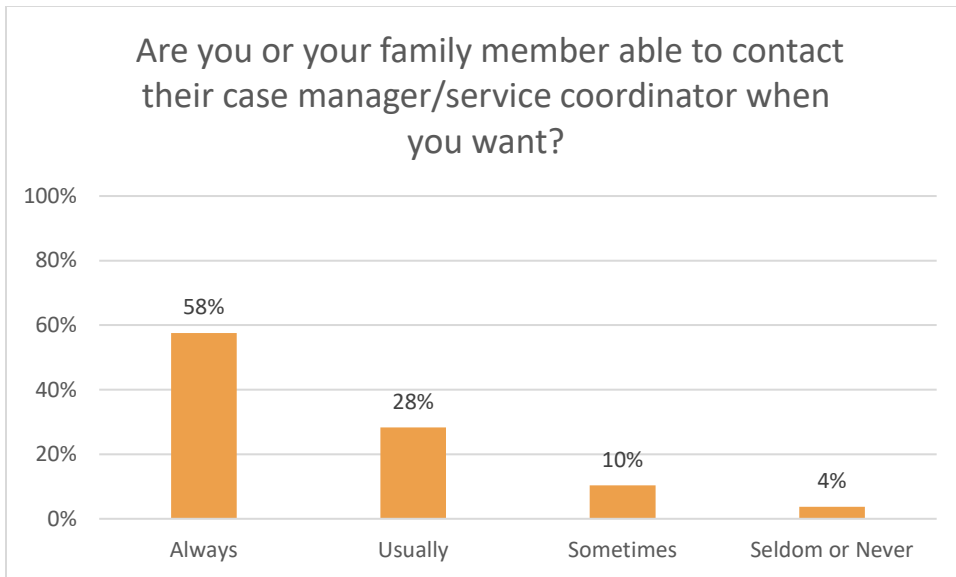


Table 51. Are you or your family member able to contact their case manager/service coordinator when you want?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	78%	20%	2%	1%	373
AK	77%	18%	3%	1%	173
LA	69%	24%	5%	1%	609
SD	68%	26%	6%	1%	190
PA	68%	28%	3%	1%	374

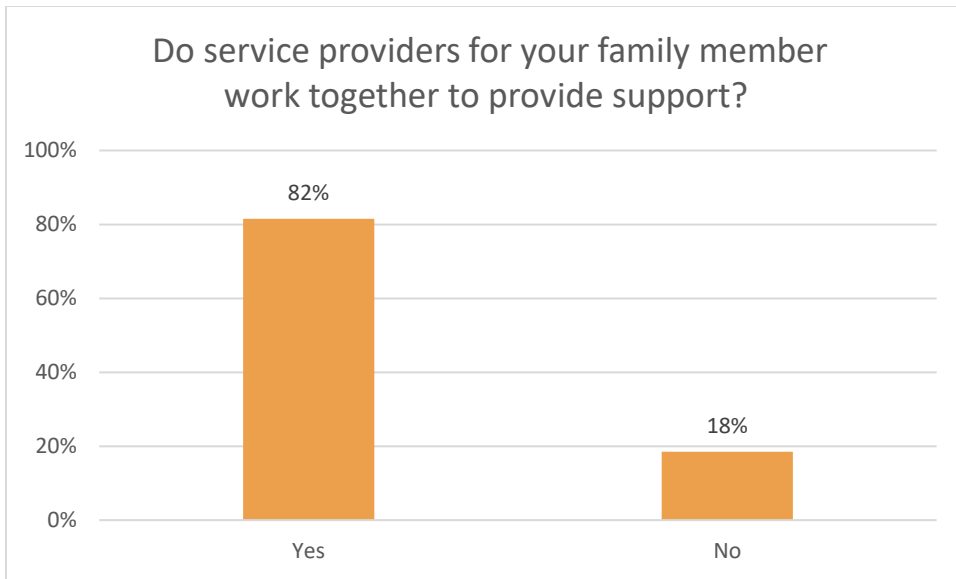
Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MO	62%	33%	4%	1%	230
NH	62%	31%	6%	1%	557
AZ	60%	33%	7%	1%	243
OK	59%	30%	8%	3%	435
Weighted NCI-IDD Average	58%	28%	10%	4%	11057
GA	52%	35%	10%	2%	386
MT	49%	35%	11%	4%	192

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	51%	29%	14%	6%	7295

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)



**Table 52. Do service providers for your family member work together to provide support?
Significantly Above Average**

State	Yes	No	N
LA	90%	10%	325
PA	89%	11%	205
IN	88%	12%	207
NH	88%	13%	264

Within Average Range

State	Yes	No	N
MT	86%	14%	105
OK	83%	17%	202
SD	82%	18%	74
AZ	82%	18%	142
Weighted NCI-IDD Average	82%	18%	5876
MO	81%	19%	124
CA	79%	21%	3933
AK	75%	25%	102
GA	74%	26%	193

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)



Table 53. Are services delivered in a way that is respectful of your family's culture?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	86%	13%	1%	1%	350

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
IN	85%	14%	1%	0%	347
AK	83%	13%	3%	1%	156
LA	83%	14%	1%	2%	572
NH	82%	15%	2%	1%	516
MO	80%	19%	0%	0%	223
Weighted NCI-IDD Average	80%	16%	2%	2%	10274
CA	79%	16%	3%	2%	6780
MT	78%	21%	0%	1%	181
SD	77%	21%	1%	1%	175
AZ	77%	20%	3%	0%	233
OK	76%	21%	1%	1%	392

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	71%	24%	3%	3%	349

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

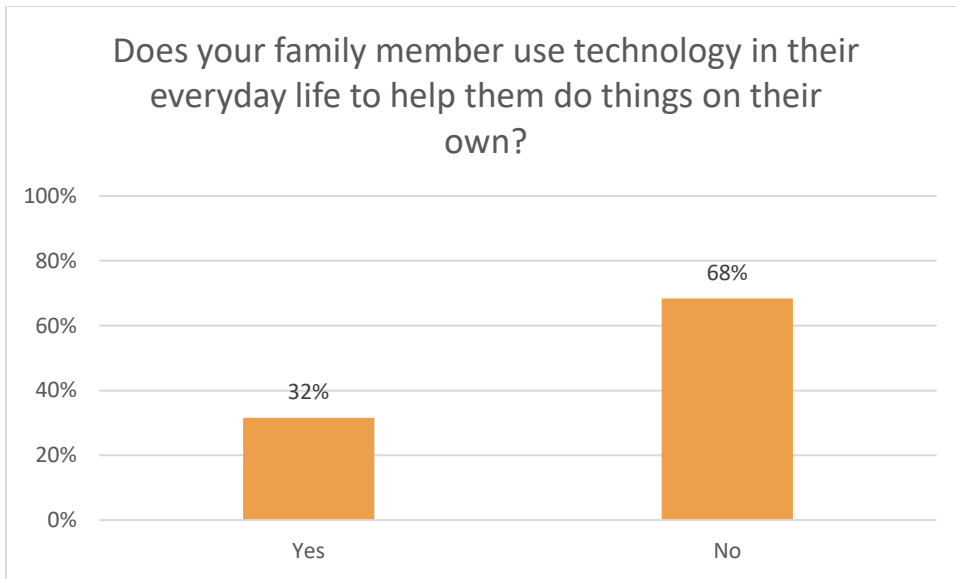


Table 54. Does your family member use technology in their everyday life to help them do things on their own?

New question in 2021-22

Within Average Range

State	Yes	No	N
AZ	38%	62%	240
CA	35%	65%	7199
NH	34%	66%	553
SD	34%	66%	190
Weighted NCI-IDD Average	32%	68%	10976
AK	31%	69%	169
IN	29%	71%	377
MT	29%	71%	195
OK	27%	73%	424

Significantly Below Average

State	Yes	No	N
LA	24%	76%	613
PA	23%	77%	361
MO	18%	82%	244
GA	17%	83%	411

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

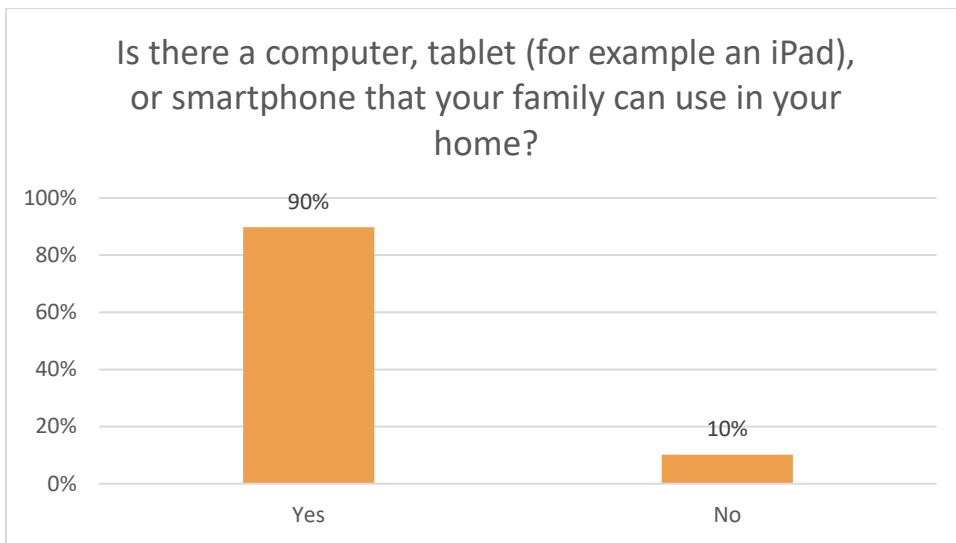


Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?

New question in 2021-22

Significantly Above Average

State	Yes	No	N
PA	94%	6%	381

Within Average Range

State	Yes	No	N
SD	93%	7%	199
IN	92%	8%	382
NH	92%	8%	567
AK	92%	8%	170
AZ	91%	9%	248
CA	90%	10%	7732
Weighted NCI-IDD Average	90%	10%	11600
MO	90%	10%	241
MT	87%	13%	198
OK	86%	14%	445

Significantly Below Average

State	Yes	No	N
LA	83%	17%	617
GA	75%	25%	420

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

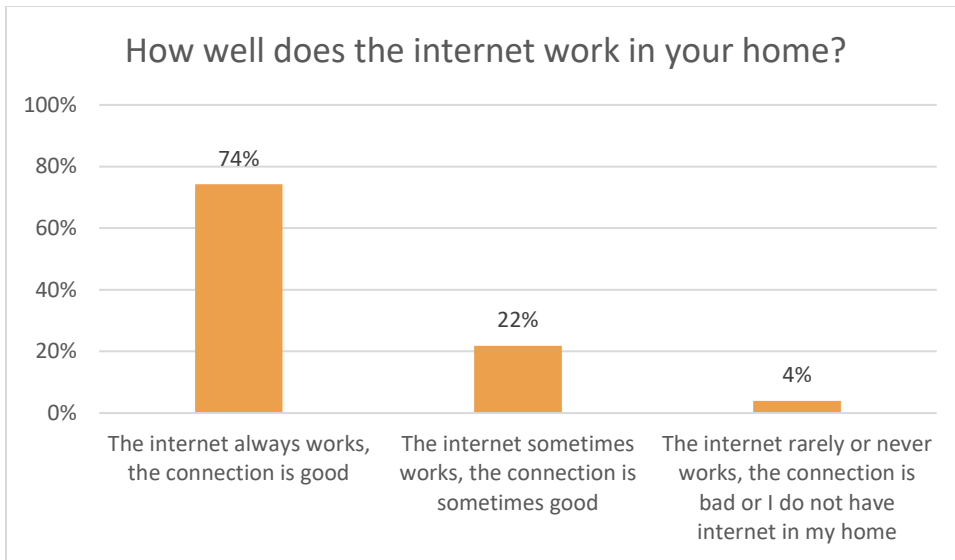


Table 56. How well does the internet work in your home?

New question in 2021-22

Significantly Above Average

State	The internet always works	The internet sometimes works	The internet rarely or never works or I do not have internet in my home	N
NH	84%	14%	2%	560
SD	83%	12%	5%	195
PA	83%	15%	3%	374

Within Average Range

State	The internet always works	The internet sometimes works	The internet rarely or never works or I do not have internet in my home	N
IN	77%	20%	3%	379
MO	76%	17%	7%	243
MT	75%	19%	6%	195
Weighted NCI-IDD Average	74%	22%	4%	11318
OK	74%	22%	5%	423
CA	73%	23%	4%	7537
AK	72%	24%	4%	169
AZ	72%	27%	2%	244

Significantly Below Average

State	The internet always works	The internet sometimes works	The internet rarely or never works or I do not have internet in my home	N
GA	67%	22%	11%	395
LA	63%	29%	8%	604

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

Workforce (New in 2021-22)

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.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

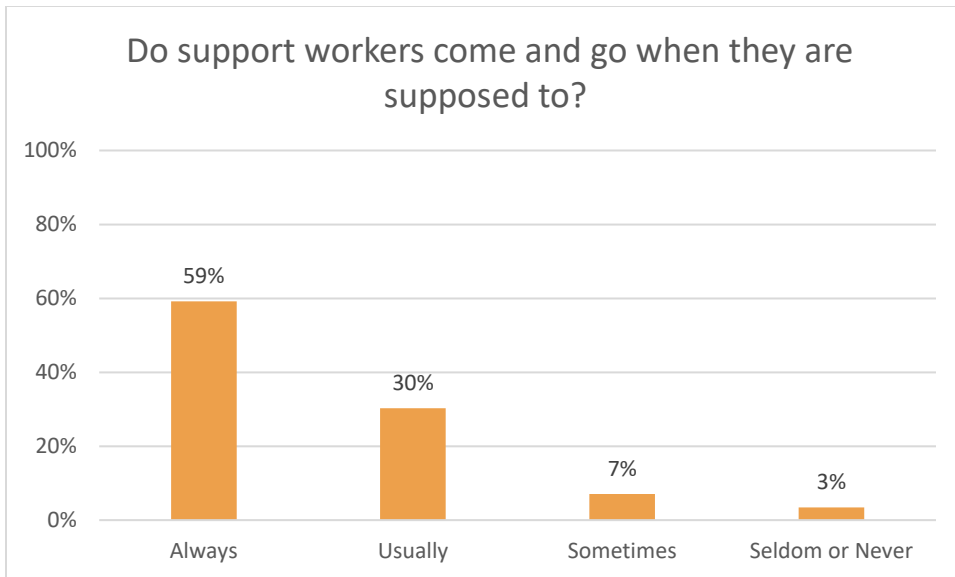


Table 57. Do support workers come and go when they are supposed to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	69%	24%	3%	3%	545
PA	66%	29%	3%	2%	327

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	64%	31%	4%	1%	223
Weighted NCI-IDD Average	59%	30%	7%	3%	8470
CA	58%	29%	9%	5%	5442
SD	57%	37%	3%	3%	134
IN	57%	33%	9%	1%	281
NH	57%	34%	6%	3%	424
OK	55%	36%	8%	2%	318
MO	52%	44%	4%	0%	183
AK	51%	40%	7%	1%	139

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	50%	39%	7%	4%	304
MT	47%	41%	6%	5%	150

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

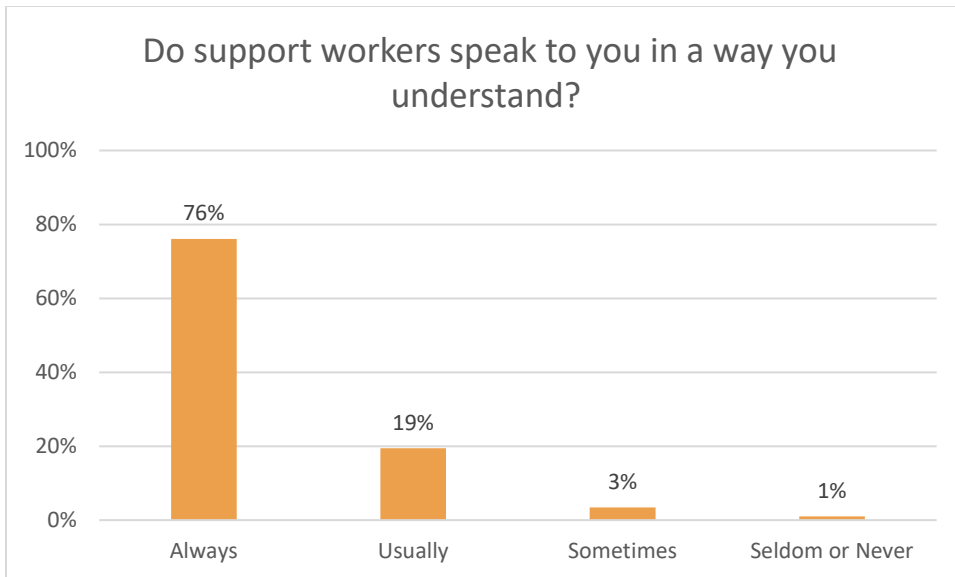


Table 58. Do support workers speak to you in a way you understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	83%	14%	2%	1%	568
PA	83%	16%	0%	1%	346

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AK	83%	15%	1%	1%	144
IN	81%	16%	2%	0%	310
NH	81%	17%	2%	0%	464
MO	78%	21%	0%	1%	205
AZ	77%	22%	2%	0%	227
SD	76%	24%	0%	0%	156
Weighted NCI-IDD Average	76%	19%	3%	1%	9438
OK	75%	20%	5%	0%	352
CA	73%	20%	5%	2%	6144
GA	72%	26%	2%	1%	359
MT	70%	28%	2%	0%	163

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

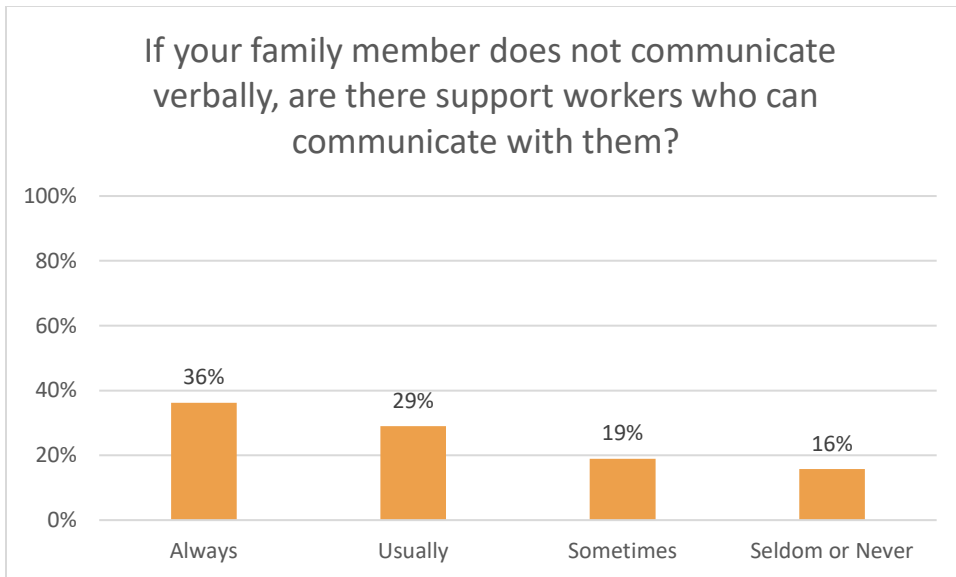


Table 59. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
LA	44%	36%	11%	9%	150
GA	41%	35%	13%	11%	92
OK	40%	34%	17%	9%	104
CA	39%	23%	17%	20%	1036
NH	39%	30%	23%	9%	44
IN	38%	34%	22%	6%	50
Weighted NCI-IDD Average	36%	29%	19%	16%	1791
AK	34%	45%	8%	13%	76
AZ	32%	25%	26%	18%	57
PA	26%	40%	26%	9%	58
MO	25%	43%	17%	15%	53
SD	24%	48%	16%	12%	25
MT	22%	50%	11%	17%	46

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

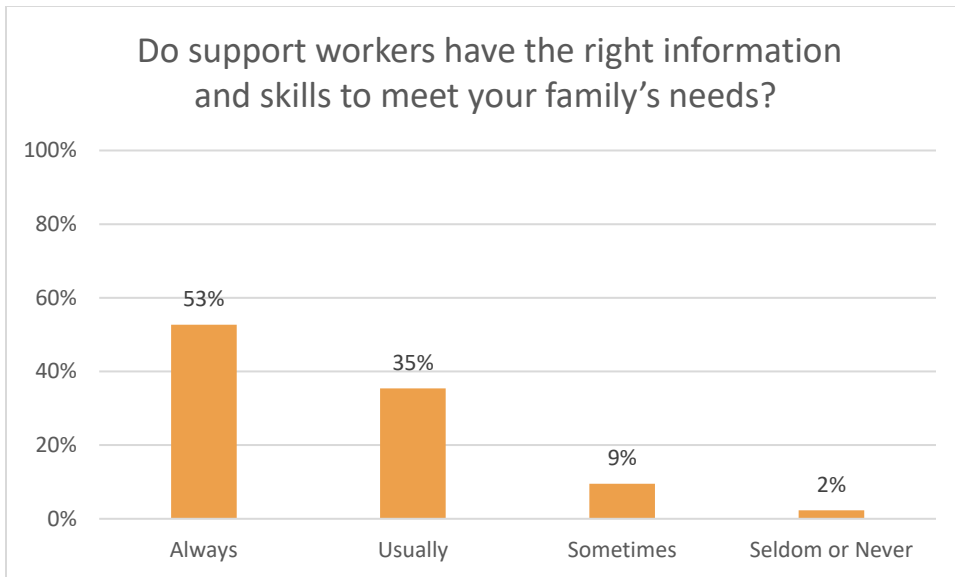


Table 60. Do support workers have the right information and skills to meet your family's needs?
Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	64%	27%	7%	2%	552

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
CA	54%	32%	11%	3%	5824
PA	54%	37%	7%	2%	326
Weighted NCI-IDD Average	53%	35%	9%	2%	8984
OK	53%	37%	7%	3%	331
SD	52%	36%	10%	1%	148
IN	51%	40%	8%	1%	302
GA	48%	43%	7%	2%	329
MO	47%	45%	6%	2%	199
AZ	46%	44%	8%	3%	222
AK	43%	45%	10%	2%	147

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	46%	45%	7%	1%	445
MT	38%	48%	11%	3%	159

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

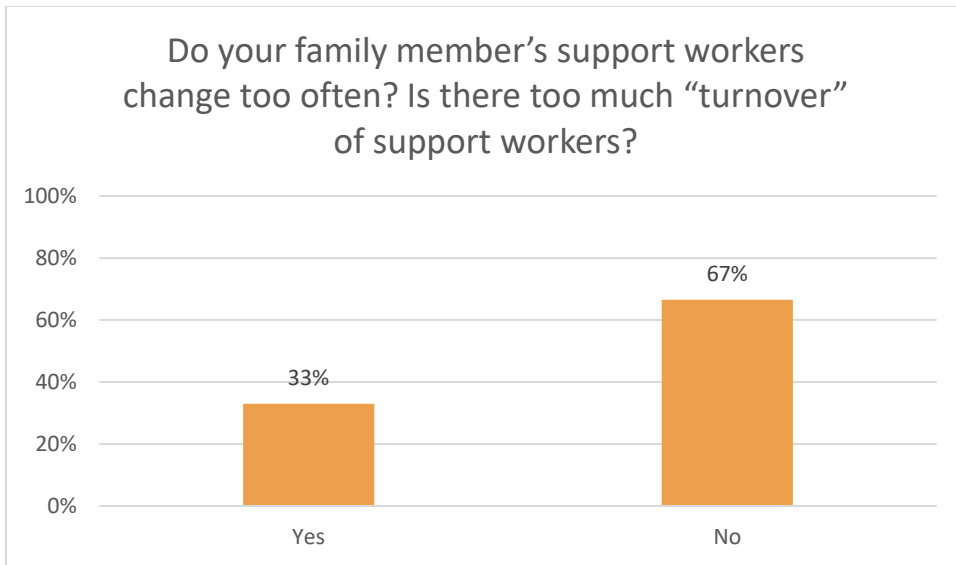


Table 61. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

New question in 2021-22

Significantly Above Average

State	Yes	No	N
MT	45%	55%	152

Within Average Range

State	Yes	No	N
AZ	41%	59%	216
NH	40%	60%	410
MO	34%	66%	190
PA	34%	66%	320
Weighted NCI-IDD Average	33%	67%	8265
CA	33%	67%	5251
AK	32%	68%	142
GA	31%	69%	309
IN	31%	69%	282

Significantly Below Average

State	Yes	No	N
OK	26%	74%	333
SD	23%	77%	129
LA	23%	77%	531

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

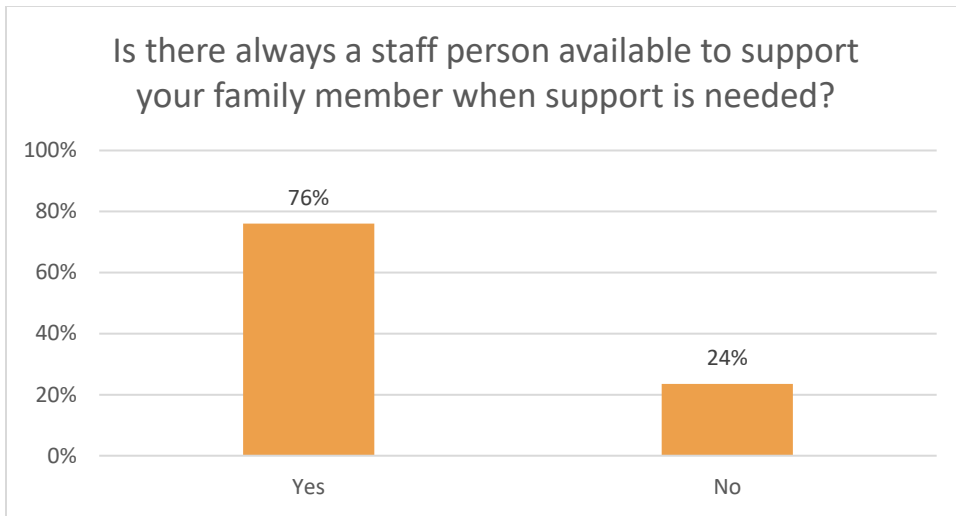


Table 62. Is there always a staff person available to support your family member when support is needed?

New question in 2021-22

Within Average Range

State	Yes	No	N
LA	80%	20%	551
CA	79%	21%	5413
Weighted NCI-IDD Average	76%	24%	8424
AZ	76%	24%	204
SD	76%	24%	127
GA	75%	25%	325
PA	75%	25%	303
OK	74%	26%	302
MO	69%	31%	182

Significantly Below Average

State	Yes	No	N
IN	68%	32%	288
NH	68%	32%	437
MT	64%	36%	140
AK	51%	49%	152

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

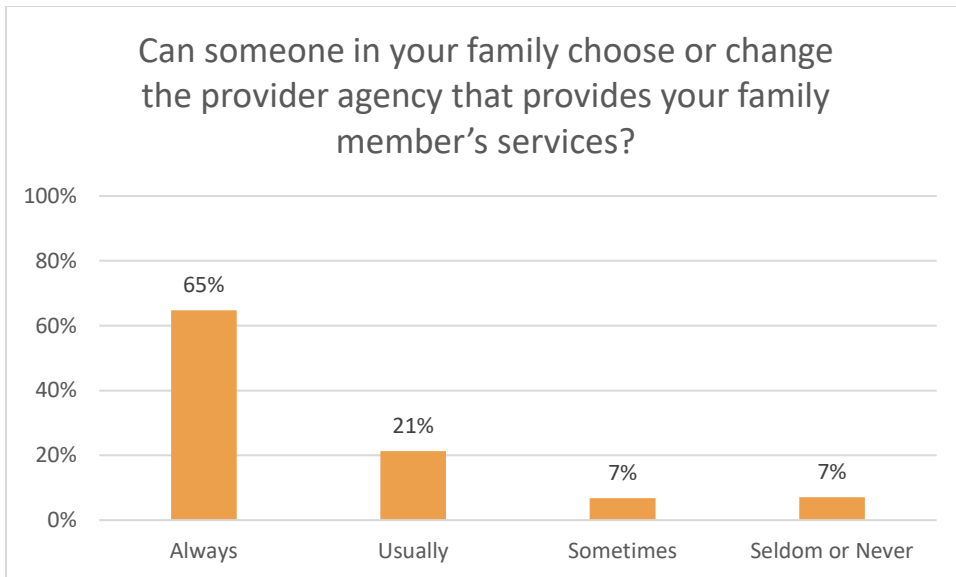


Table 63. Can someone in your family choose or change the agency that provides your family member's services?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	82%	14%	2%	1%	338
AK	77%	15%	5%	3%	151
LA	77%	16%	3%	5%	519
NH	73%	19%	5%	3%	344
OK	72%	19%	5%	5%	307

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	71%	22%	5%	2%	274
SD	70%	25%	2%	3%	124
AZ	66%	24%	3%	7%	201
Weighted NCI-IDD Average	65%	21%	7%	7%	6709
MT	64%	19%	5%	11%	115
MO	64%	24%	4%	8%	157
GA	61%	25%	8%	6%	248

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	57%	22%	10%	11%	3931

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

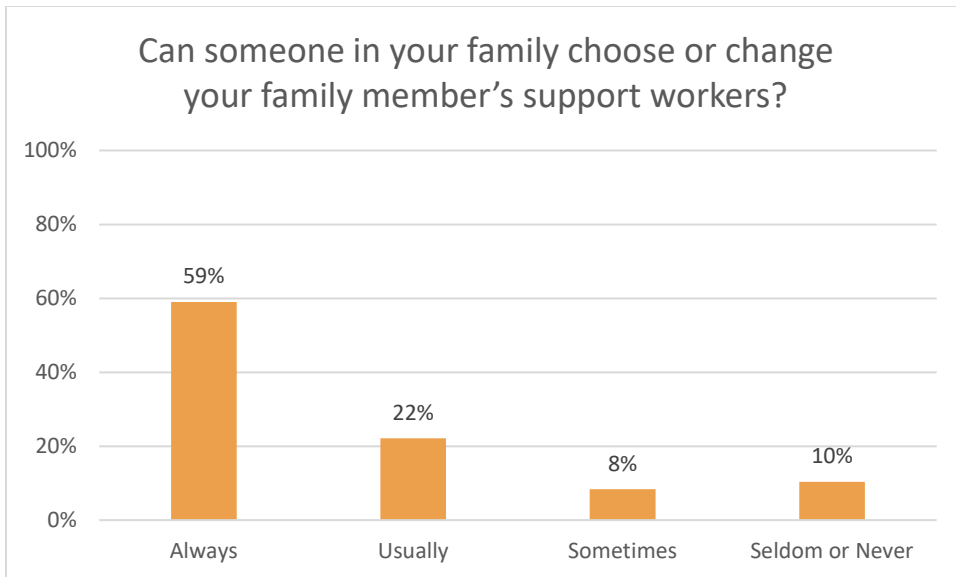


Table 64. Can someone in your family choose or change your family member's support workers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	73%	18%	4%	4%	287
LA	73%	18%	4%	5%	509

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AK	67%	17%	8%	8%	146
OK	66%	22%	5%	8%	280
PA	63%	25%	7%	5%	272
NH	62%	22%	8%	8%	371
MO	61%	23%	6%	9%	148
Weighted NCI-IDD Average	59%	22%	8%	10%	6429
AZ	58%	23%	10%	9%	184
MT	57%	18%	12%	13%	120
GA	57%	25%	6%	13%	233
SD	55%	26%	9%	11%	94

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	53%	22%	10%	14%	3785

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

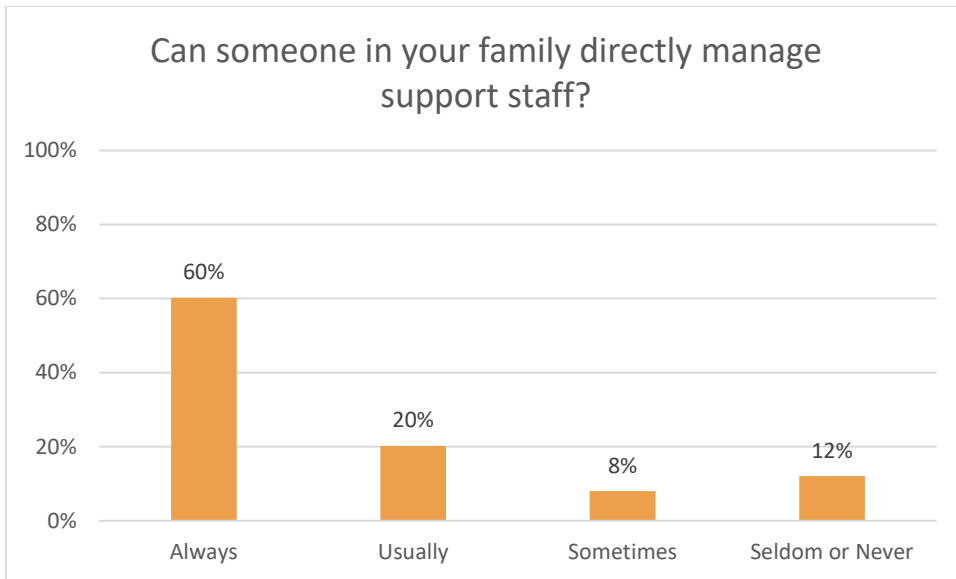


Table 65. Can someone in your family directly manage support staff?

Question changed in 2021-22

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	70%	16%	5%	9%	465
IN	69%	17%	5%	9%	247

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	65%	18%	6%	11%	347
OK	64%	19%	5%	12%	257
MO	63%	17%	6%	15%	139
PA	62%	22%	6%	10%	255
Weighted NCI-IDD Average	60%	20%	8%	12%	6140
GA	59%	17%	7%	16%	226
AZ	58%	25%	6%	11%	176
CA	58%	21%	9%	13%	3689
AK	57%	15%	10%	19%	134
MT	51%	22%	9%	17%	121
SD	49%	24%	10%	18%	84

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

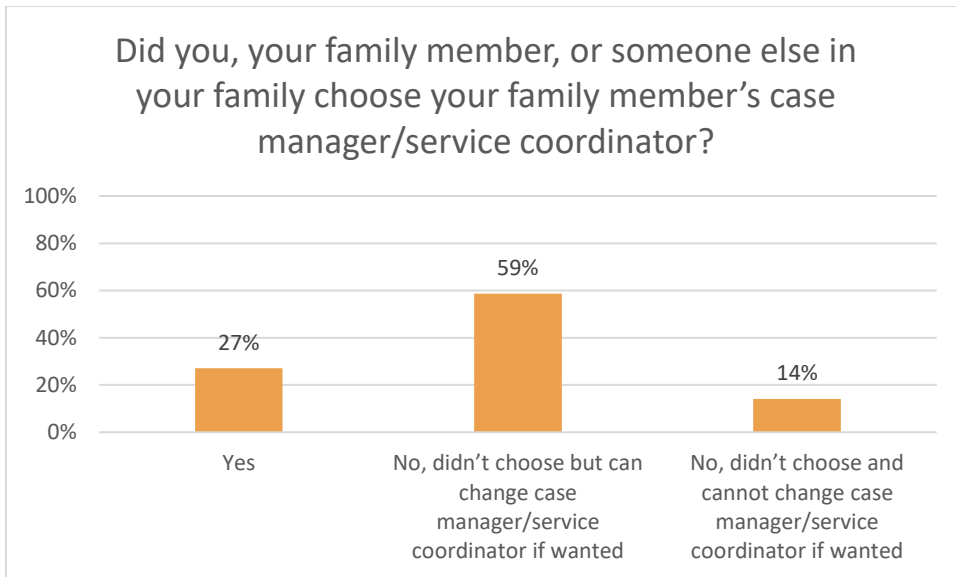


Table 66. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

Significantly Above Average

State	Yes	Didn't choose but can change CM/SC	Didn't choose and cannot change CM/SC	N
AK	85%	15%	0%	161
IN	65%	34%	1%	361
LA	50%	43%	7%	533

Within Average Range

State	Yes	Didn't choose but can change CM/SC	Didn't choose and cannot change CM/SC	N
SD	35%	55%	10%	159
MO	31%	55%	14%	191
Weighted NCI-IDD Average	27%	59%	14%	8585
PA	26%	67%	7%	324
AZ	24%	66%	11%	219
GA	23%	55%	22%	307
NH	22%	69%	9%	458

Significantly Below Average

State	Yes	Didn't choose but can change CM/SC	Didn't choose and cannot change CM/SC	N
CA	19%	62%	19%	5342
MT	16%	55%	28%	164
OK	16%	61%	24%	366

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

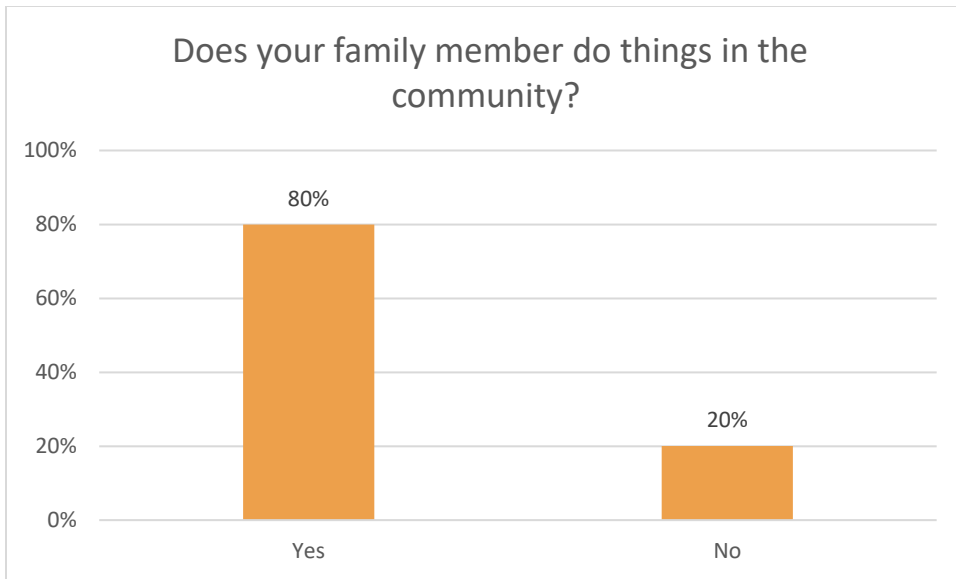


Table 67. Does your family member do things in the community?

Question changed in 2021-22

Significantly Above Average

State	Yes	No	N
SD	92%	8%	197
PA	90%	10%	376
MT	89%	11%	199
NH	88%	12%	557
AZ	86%	14%	244
MO	86%	14%	240
IN	86%	14%	381
OK	85%	15%	441

Within Average Range

State	Yes	No	N
AK	86%	14%	169
LA	82%	18%	615
Weighted NCI-IDD Average	80%	20%	11338
GA	76%	24%	417

Significantly Below Average

State	Yes	No	N
CA	75%	25%	7502

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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

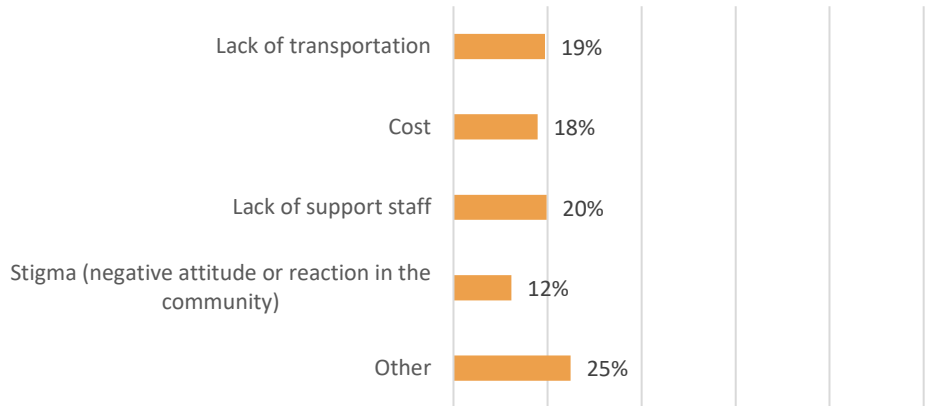
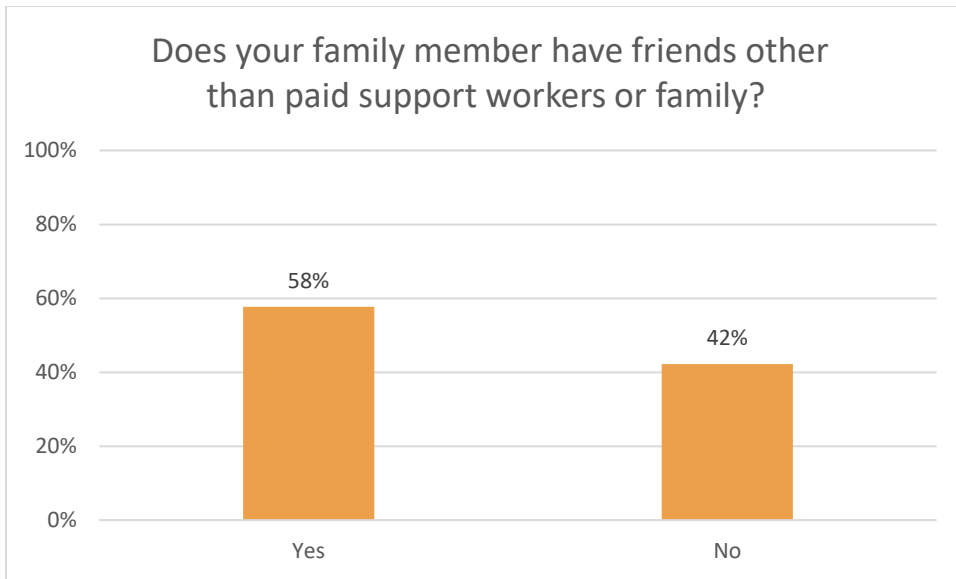


Table 68. For your family member, what makes it hard to do things in the community?

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

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AK	16%	13%	30%	10%	38%
AZ	22%	26%	28%	14%	51%
CA	20%	18%	18%	13%	24%
GA	15%	15%	17%	9%	22%
IN	18%	15%	21%	14%	30%
LA	10%	16%	12%	10%	29%
MO	21%	16%	24%	8%	34%
MT	19%	16%	25%	9%	20%
NH	21%	15%	28%	5%	34%
OK	11%	12%	13%	9%	35%
PA	21%	18%	25%	12%	7%
SD	24%	18%	22%	13%	19%
Weighted NCI-IDD Average	19%	18%	20%	12%	25%

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)



**Table 69. Does your family member have friends other than paid support workers or family?
Significantly Above Average**

State	Yes	No	N
OK	73%	27%	436
SD	73%	27%	188
GA	68%	32%	404
NH	66%	34%	544
LA	64%	36%	605

Within Average Range

State	Yes	No	N
MT	66%	34%	191
MO	65%	35%	242
PA	62%	38%	372
AK	62%	38%	167
IN	60%	40%	374
Weighted NCI-IDD Average	58%	42%	10893
AZ	56%	44%	235
CA	54%	46%	7135

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

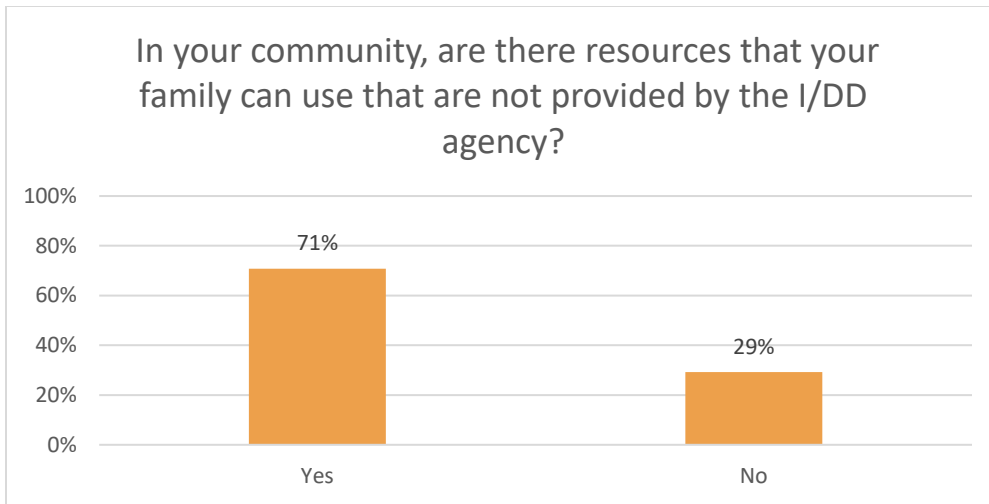


Table 70. In your community, are there resources that your family can use that are not provided by the I/DD agency?

Significantly Above Average

State	Yes	No	N
MO	83%	17%	185
AK	80%	20%	136
IN	80%	20%	254
OK	77%	23%	337

Within Average Range

State	Yes	No	N
SD	79%	21%	151
PA	75%	25%	275
NH	74%	26%	415
Weighted NCI-IDD Average	71%	29%	7949
GA	71%	29%	312
AZ	69%	31%	174
CA	68%	32%	5127
MT	67%	33%	135

Significantly Below Average

State	Yes	No	N
LA	64%	36%	448

Those who used direct entry saw the question "In the community, are there resources or support that your family can use that are not provided by the I/DD agency?" Those who used the paper tool saw the question "In the community, are there resources or support that your family member can use that are not provided by the I/DD agency?"

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

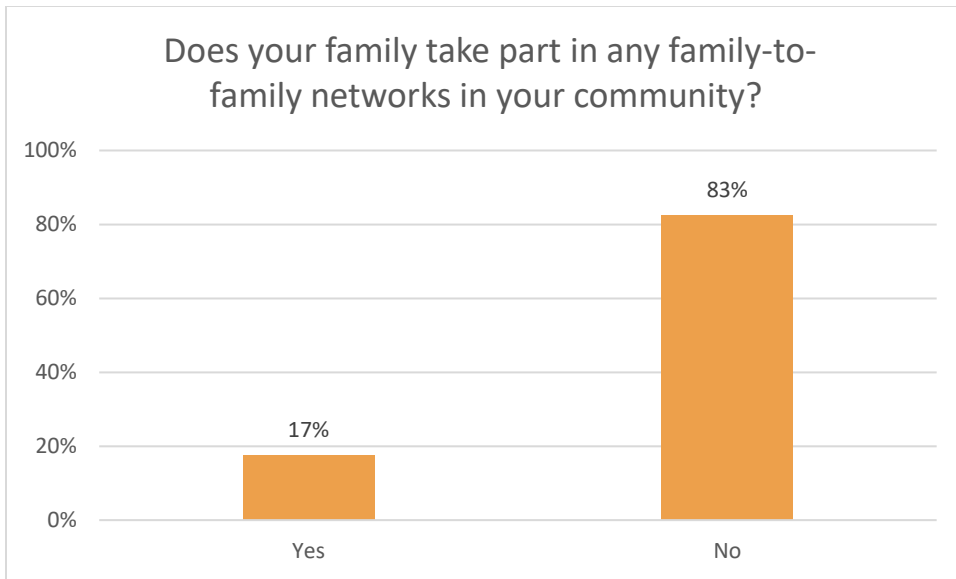


Table 71. Does your family take part in any family-to-family networks in your community?

Significantly Above Average

State	Yes	No	N
GA	24%	76%	348

Within Average Range

State	Yes	No	N
LA	22%	78%	524
AK	20%	80%	152
OK	19%	81%	349
CA	18%	82%	6361
Weighted NCI-IDD Average	17%	83%	9617
IN	17%	83%	310
MT	16%	84%	164
AZ	15%	85%	221
SD	15%	85%	158
PA	15%	85%	322
MO	13%	87%	200

Significantly Below Average

State	Yes	No	N
NH	12%	88%	508

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

Health, Welfare, and Safety (New in 2021-22)

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.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

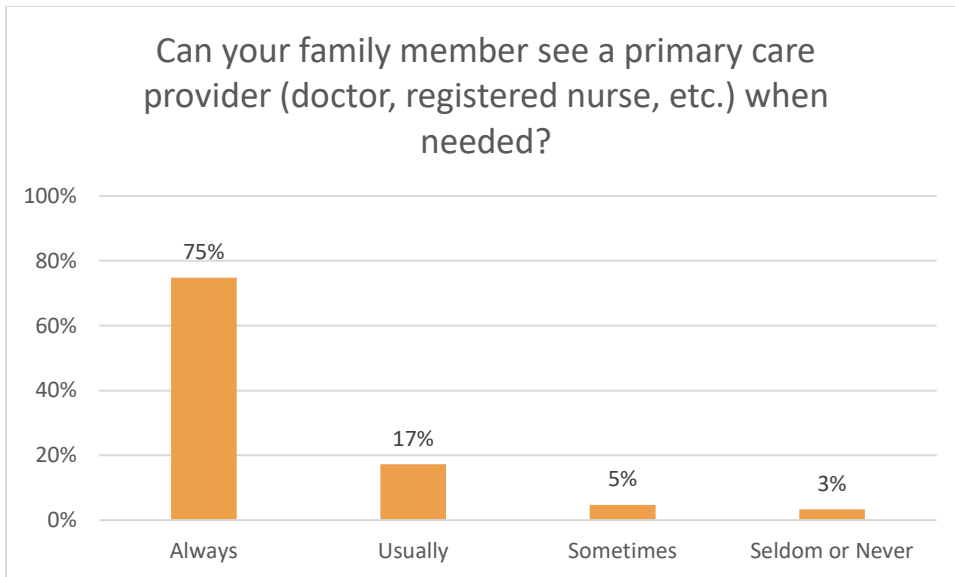


Table 72. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

New question in 2021-22

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	86%	11%	1%	1%	567
SD	83%	11%	4%	2%	197
LA	81%	15%	2%	3%	619
IN	80%	17%	1%	2%	380
PA	80%	15%	2%	3%	378

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
OK	78%	19%	2%	1%	447
AK	78%	19%	2%	1%	169
MO	78%	18%	3%	2%	243
Weighted NCI-IDD Average	75%	17%	5%	3%	11294
MT	75%	21%	1%	3%	194
GA	75%	17%	5%	3%	410
AZ	73%	21%	4%	3%	242
CA	72%	17%	6%	4%	7448

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

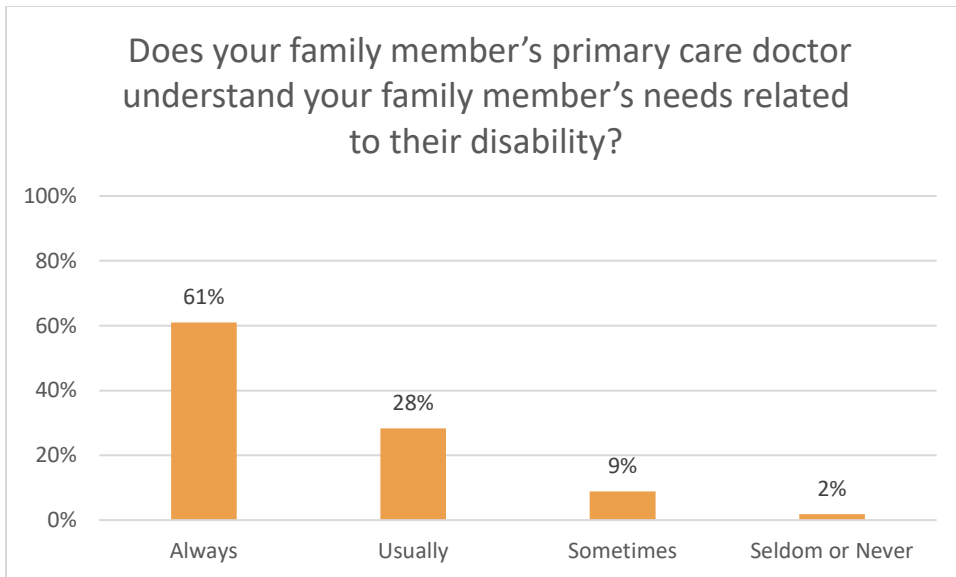


Table 73. Does your family member's primary care doctor understand your family member's needs related to their disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	72%	24%	4%	1%	627

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	66%	29%	4%	0%	367
OK	64%	29%	6%	1%	446
GA	62%	30%	6%	2%	407
Weighted NCI-IDD Average	61%	28%	9%	2%	11144
IN	61%	31%	7%	1%	374
CA	60%	26%	11%	3%	7344
SD	60%	33%	7%	0%	193
AZ	56%	33%	10%	0%	242
AK	55%	32%	10%	2%	164
MO	53%	40%	6%	1%	232

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	55%	36%	8%	1%	552
MT	51%	39%	9%	2%	196

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

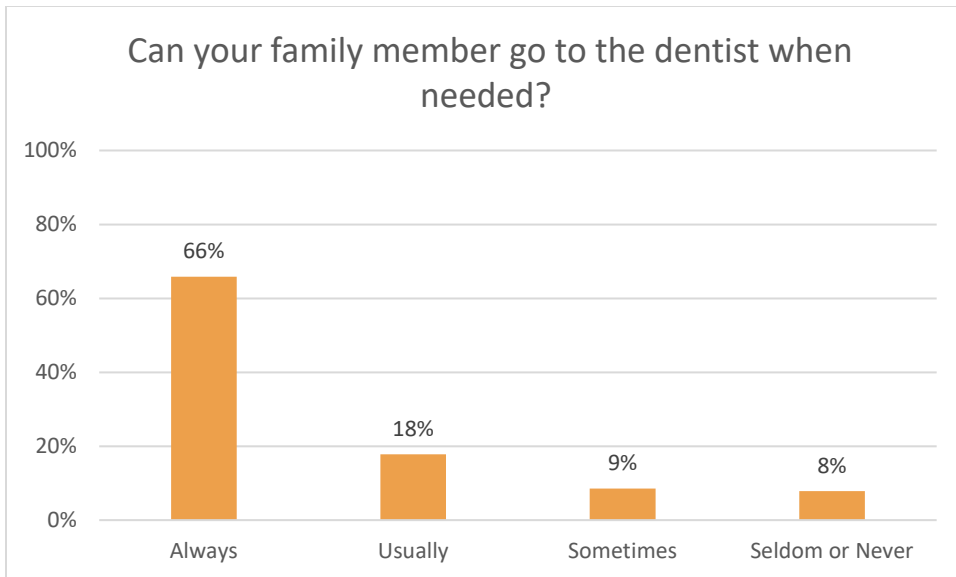


Table 74. Can your family member go to the dentist when needed?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	81%	13%	3%	3%	197
PA	77%	14%	6%	4%	371
NH	71%	15%	6%	8%	558

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
IN	72%	18%	6%	4%	380
MT	69%	23%	3%	5%	197
AK	66%	24%	5%	5%	170
Weighted NCI-IDD Average	66%	18%	9%	8%	11355
LA	66%	18%	5%	12%	607
CA	64%	18%	10%	9%	7532
OK	62%	22%	7%	9%	448
MO	62%	17%	10%	10%	239
AZ	62%	22%	9%	7%	246

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	59%	20%	8%	13%	410

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

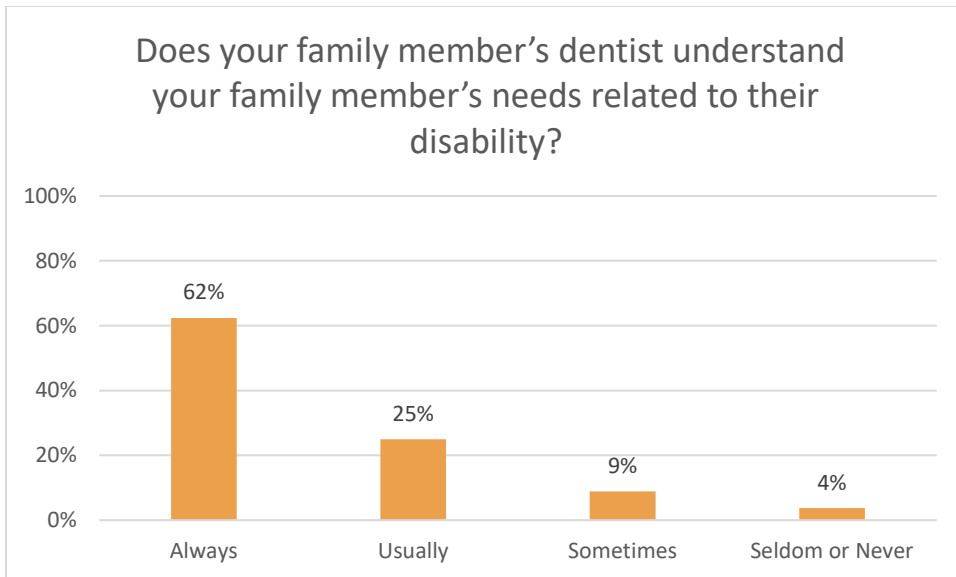


Table 75. Does your family member's dentist understand your family member's needs related to their disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	69%	22%	6%	3%	521

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MT	66%	28%	3%	3%	185
NH	65%	27%	6%	2%	492
IN	64%	26%	7%	2%	334
AK	64%	27%	8%	1%	157
GA	63%	27%	7%	3%	342
SD	63%	32%	5%	0%	190
PA	63%	27%	8%	2%	339
Weighted NCI-IDD Average	62%	25%	9%	4%	10129
CA	62%	24%	10%	5%	6744
OK	61%	30%	6%	3%	398
AZ	61%	27%	9%	4%	227

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MO	51%	34%	11%	5%	200

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

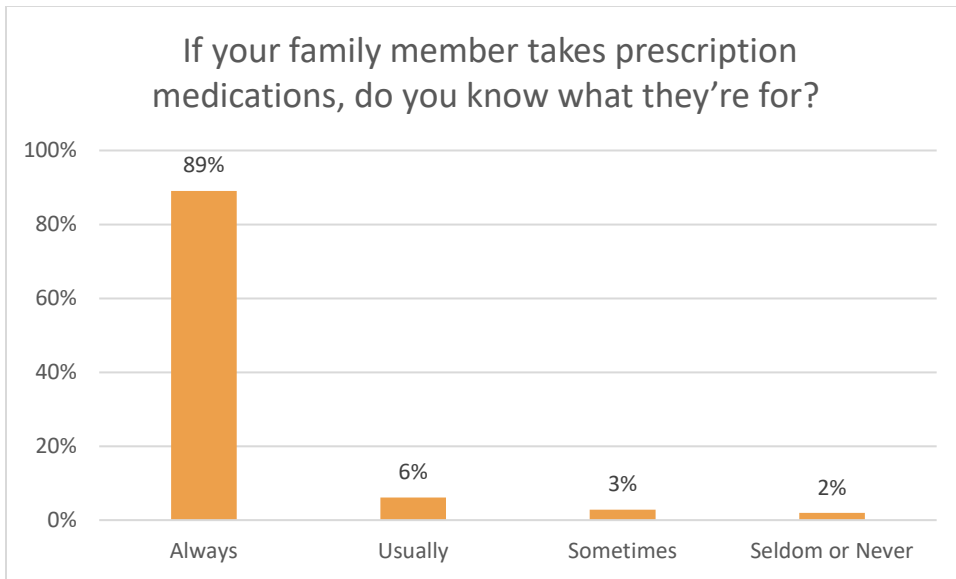


Table 76. If your family member takes prescription medications, do you know what they're for?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
MT	96%	2%	2%	0%	164
AK	96%	1%	2%	1%	138
AZ	95%	1%	2%	1%	222
PA	95%	4%	1%	1%	337
NH	92%	5%	1%	1%	498

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MO	93%	6%	1%	0%	215
OK	92%	6%	1%	0%	404
LA	91%	7%	1%	1%	563
IN	90%	5%	3%	2%	337
Weighted NCI-IDD Average	89%	6%	3%	2%	9417
GA	88%	8%	2%	1%	396
SD	87%	10%	1%	2%	164
CA	86%	7%	4%	3%	5979

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

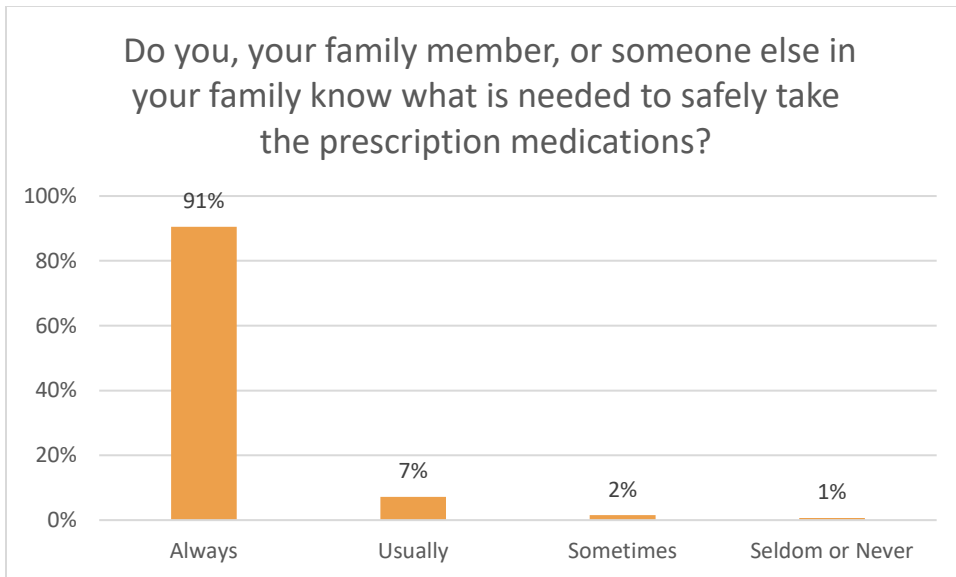


Table 77. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AK	98%	1%	1%	1%	138
PA	95%	4%	0%	1%	336
OK	94%	6%	1%	0%	400
NH	94%	6%	0%	1%	493

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	94%	6%	0%	0%	220
MO	93%	6%	0%	1%	213
IN	93%	5%	2%	0%	332
MT	92%	6%	2%	0%	159
Weighted NCI-IDD Average	91%	7%	2%	1%	9347
LA	90%	8%	1%	1%	563
GA	90%	7%	2%	2%	390
CA	88%	9%	2%	1%	5944
SD	87%	11%	2%	0%	159

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

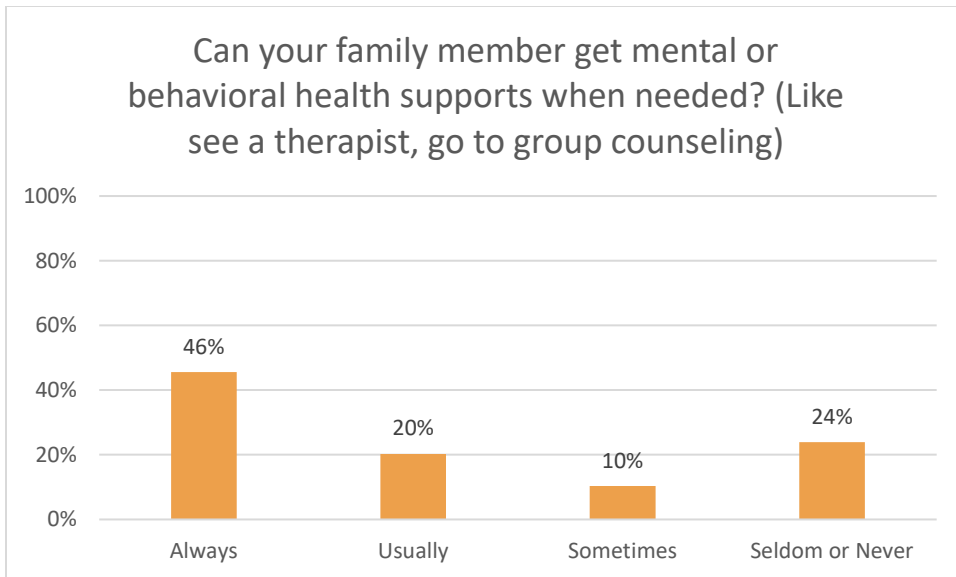


Table 78. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling).

New question in 2021-22

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
IN	53%	22%	10%	16%	273
SD	52%	27%	7%	14%	135
MO	51%	19%	8%	23%	160
PA	50%	21%	9%	20%	273
NH	50%	20%	10%	20%	412
AK	49%	20%	10%	21%	112
AZ	48%	19%	12%	21%	175
LA	47%	19%	6%	28%	434
MT	46%	16%	8%	31%	131
Weighted NCI-IDD Average	46%	20%	10%	24%	8232
GA	43%	20%	6%	30%	299
CA	43%	20%	11%	26%	5497
OK	41%	21%	8%	30%	331

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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

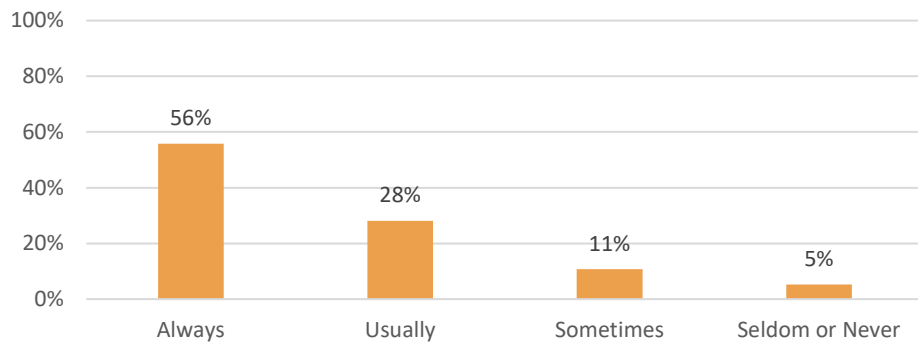


Table 79. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	64%	24%	7%	5%	301

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AK	62%	21%	12%	5%	73
OK	61%	31%	6%	2%	183
IN	59%	29%	8%	3%	201
PA	58%	31%	9%	3%	199
Weighted NCI-IDD Average	56%	28%	11%	5%	6095
NH	55%	35%	5%	4%	258
CA	55%	26%	12%	6%	4231
AZ	54%	29%	11%	6%	120
SD	52%	35%	8%	5%	97
MT	51%	29%	16%	4%	80
MO	51%	39%	5%	5%	110
GA	48%	37%	10%	5%	242

Table note: Mental health services can include using the phone or computer to do a videoconference visit with a mental or behavioral health care provider.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

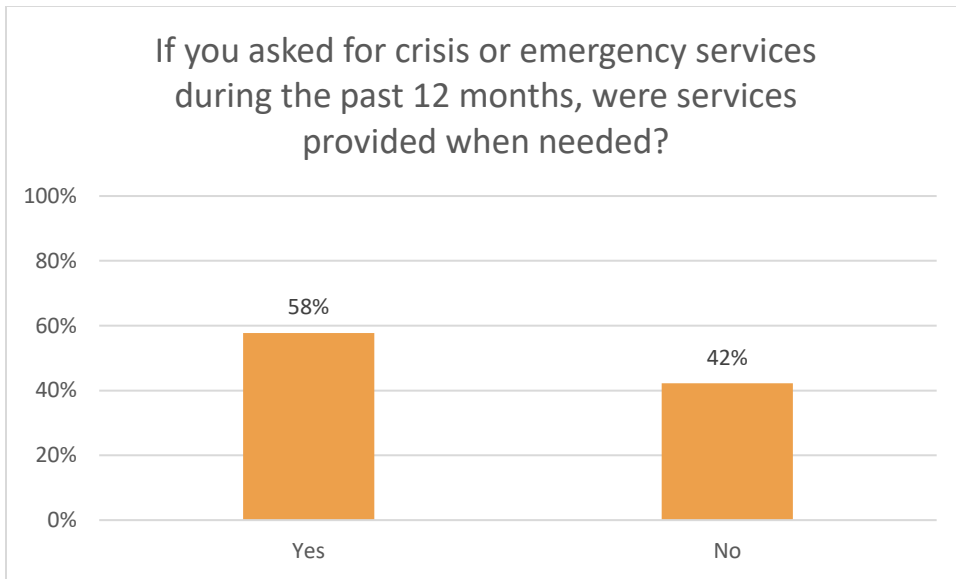


Table 80. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

Within Average Range

State	Yes	No	N
MT	79%	21%	28
IN	68%	32%	53
MO	68%	32%	34
OK	67%	33%	79
NH	65%	35%	83
LA	64%	36%	160
AK	61%	39%	33
SD	59%	41%	32
Weighted NCI-IDD Average	58%	42%	2975
GA	57%	43%	105
AZ	57%	43%	65
CA	57%	43%	2255
PA	54%	46%	48

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

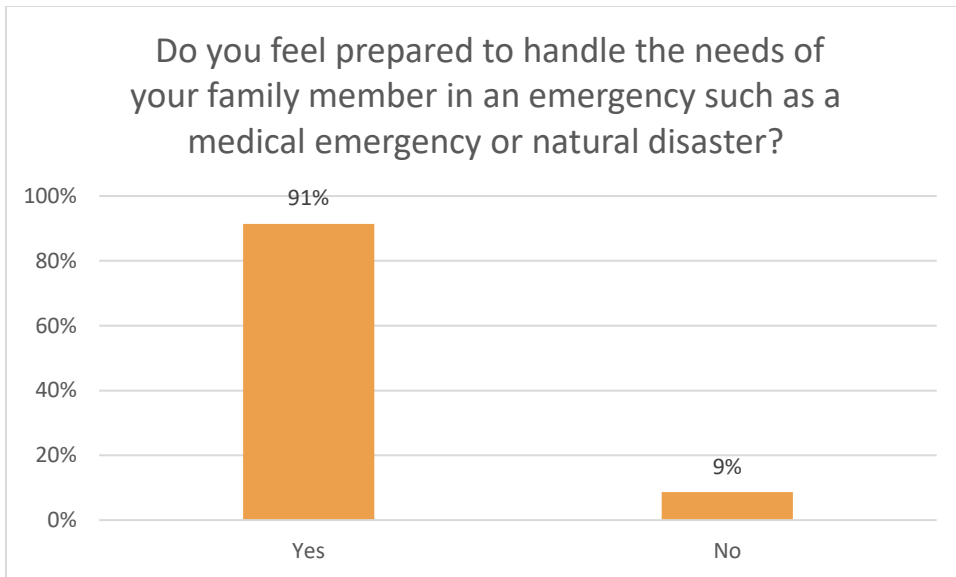


Table 81. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?

Significantly Above Average

State	Yes	No	N
LA	97%	3%	598
IN	96%	4%	347
SD	96%	4%	184
AK	96%	4%	164
OK	95%	5%	422

Within Average Range

State	Yes	No	N
MT	95%	5%	184
AZ	94%	6%	234
NH	94%	6%	528
MO	94%	6%	228
PA	94%	6%	339
GA	93%	7%	394
Weighted NCI-IDD Average	91%	9%	10523
CA	89%	11%	6901

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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

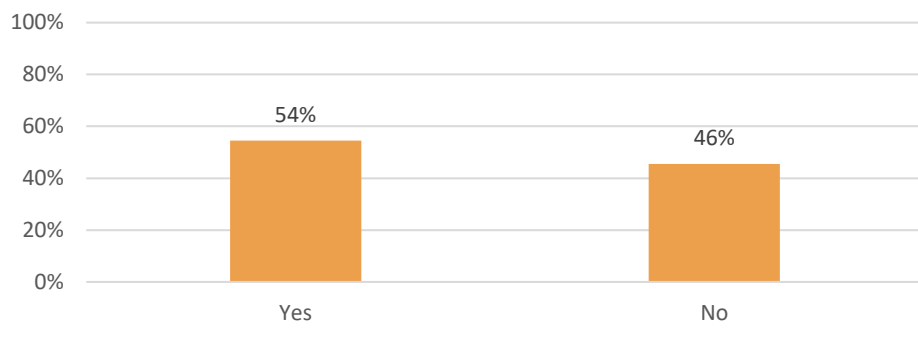


Table 82. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/service coordinator?

New question in 2021-22

Significantly Above Average

State	Yes	No	N
LA	92%	8%	603
AK	69%	31%	166
OK	64%	36%	423

Within Average Range

State	Yes	No	N
SD	58%	42%	183
AZ	57%	43%	229
MO	56%	44%	232
IN	56%	44%	351
PA	55%	45%	357
Weighted NCI-IDD Average	54%	46%	10624
CA	52%	48%	6966

Significantly Below Average

State	Yes	No	N
GA	46%	54%	395
NH	46%	54%	532
MT	39%	61%	187

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

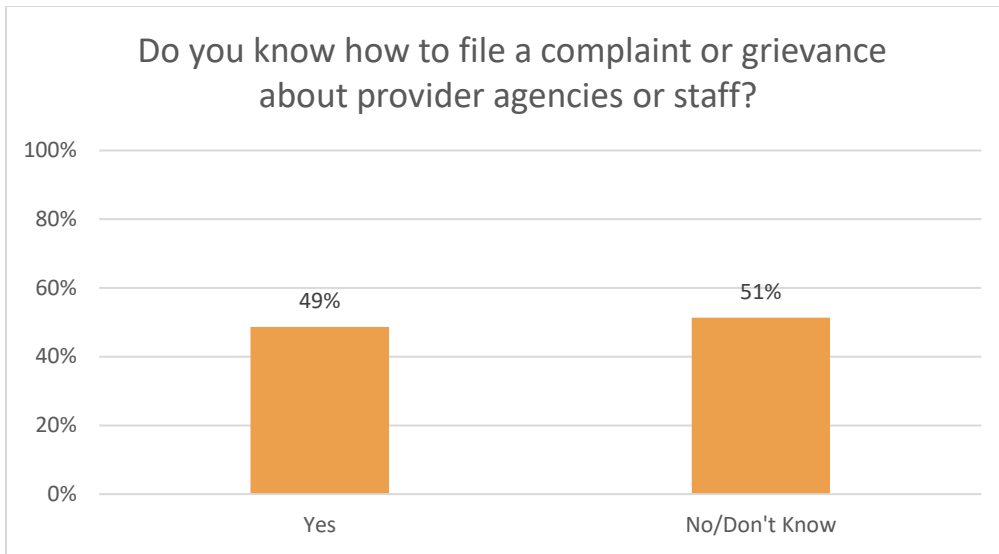


Table 83. Do you know how to file a complaint or grievance about provider agencies or staff?

Significantly Above Average

State	Yes	No or Don't Know	N
LA	75%	25%	611
OK	72%	28%	446
SD	70%	30%	199
PA	69%	31%	376
NH	65%	35%	568
AK	63%	37%	167
AZ	61%	39%	248
IN	61%	39%	380
MT	61%	39%	196
MO	59%	41%	244

Within Average Range

State	Yes	No or Don't Know	N
GA	50%	50%	417
Weighted NCI-IDD Average	49%	51%	11481

Significantly Below Average

State	Yes	No or Don't Know	N
CA	38%	62%	7629

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

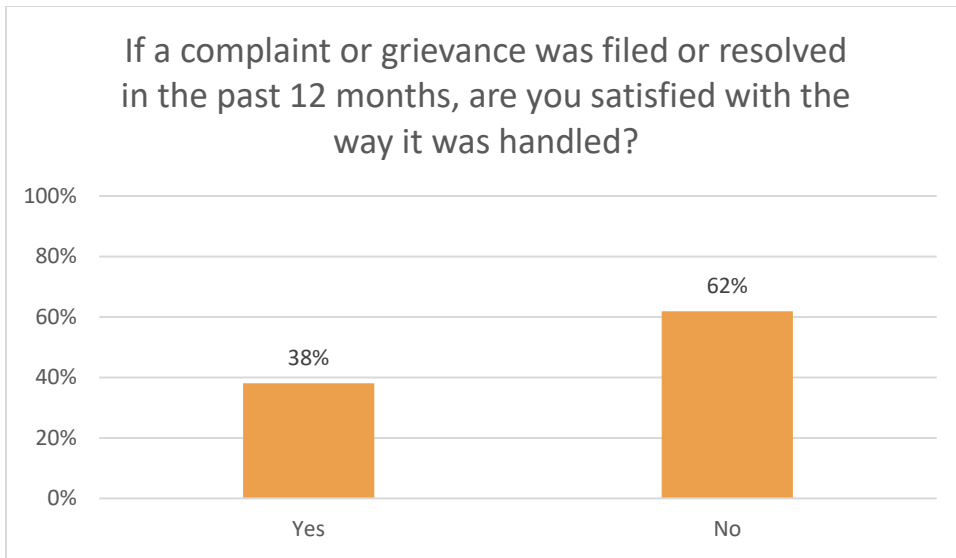


Table 84. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

Significantly Above Average

State	Yes	No	N
LA	59%	41%	51

Within Average Range

State	Yes	No	N
NH	57%	43%	35
GA	39%	61%	44
Weighted NCI-IDD Average	38%	62%	1100
CA	35%	65%	843
OK	25%	75%	24
AK	19%	81%	26

Table note: AZ, IN, MO, MT, PA, SD not included due to low counts.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

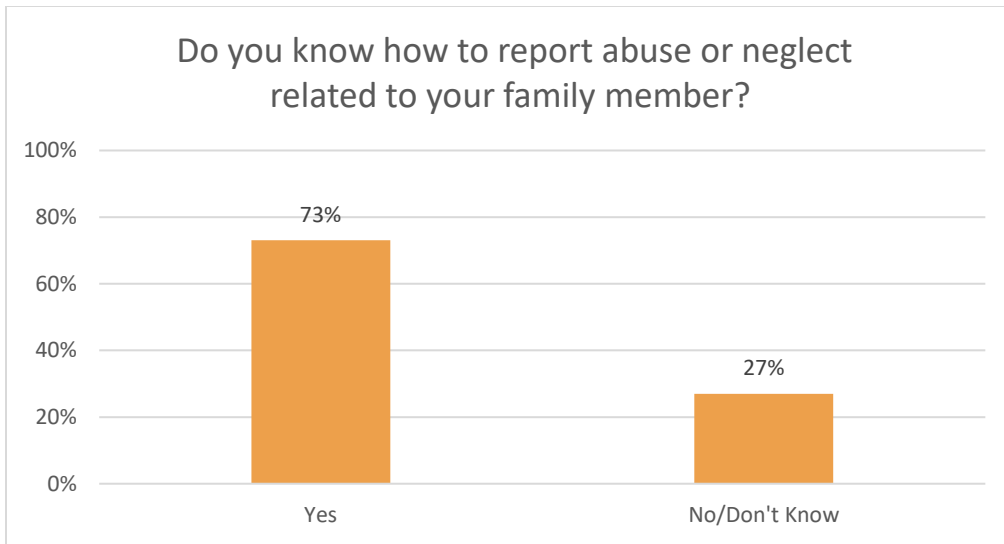


Table 85. Do you know how to report abuse or neglect related to your family member?

Significantly Above Average

State	Yes	No or Don't Know	N
AK	89%	11%	171
SD	88%	12%	199
LA	88%	12%	613
PA	86%	14%	379
OK	85%	15%	445
MT	84%	16%	197
MO	83%	17%	244
AZ	81%	19%	249
IN	81%	19%	383
NH	79%	21%	561

Within Average Range

State	Yes	No or Don't Know	N
GA	76%	24%	416
Weighted NCI-IDD Average	73%	27%	11400

Significantly Below Average

State	Yes	No or Don't Know	N
CA	66%	34%	7543

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

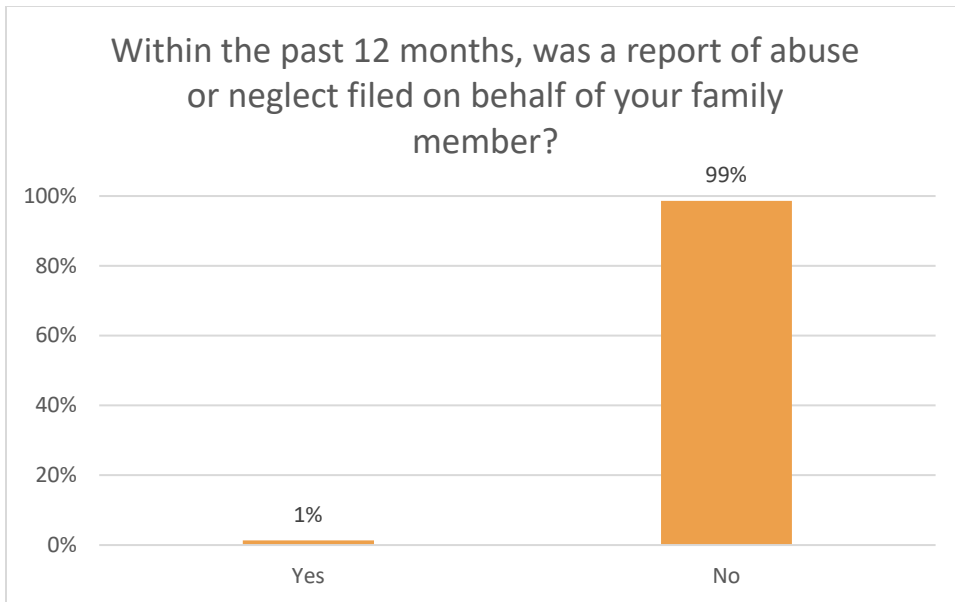


Table 86. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

Within Average Range

State	Yes	No	N
PA	3%	97%	378
NH	2%	98%	543
AK	2%	98%	164
GA	2%	98%	402
Weighted NCI-IDD Average	1%	99%	11037
CA	1%	99%	7264
AZ	1%	99%	238
MT	1%	99%	199
LA	1%	99%	602
SD	1%	99%	195
MO	0%	100%	242

Significantly Below Average

State	Yes	No	N
OK	0%	100%	432
IN	0%	100%	379

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

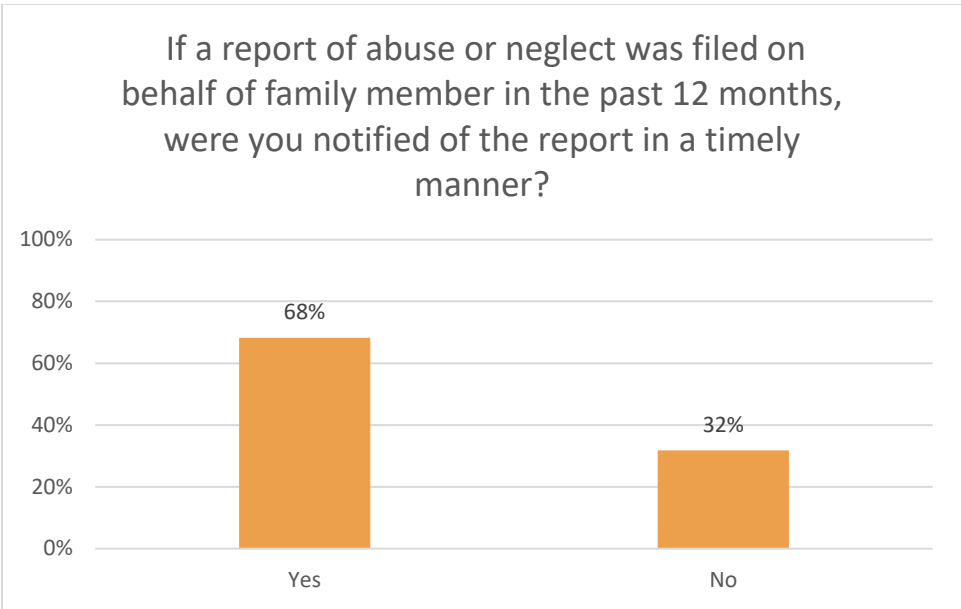


Table 87. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

Within Average Range

State	Yes	No	N
Weighted NCI-IDD Average	68%	32%	90
CA	67%	33%	64

Table note: AK, AZ, GA, IN, LA, MO, MT, NH, OK, PA, SD not included due to low counts.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

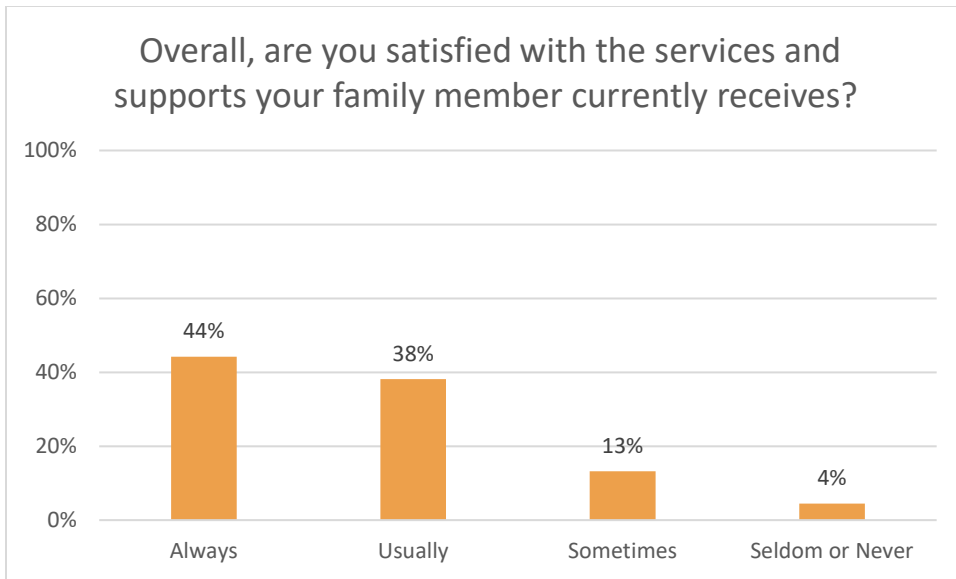


Table 88. Overall, are you satisfied with the services and supports your family member currently receives?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
LA	55%	34%	8%	3%	613

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	47%	42%	8%	4%	249
CA	46%	34%	15%	5%	7410
OK	44%	38%	13%	5%	432
Weighted NCI-IDD Average	44%	38%	13%	4%	11222
NH	42%	39%	15%	3%	558
GA	41%	40%	13%	5%	400
IN	40%	46%	11%	3%	375
MO	38%	49%	12%	2%	245
SD	37%	48%	11%	3%	198

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	38%	47%	11%	4%	376
MT	34%	47%	17%	3%	197
AK	34%	42%	17%	7%	169

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

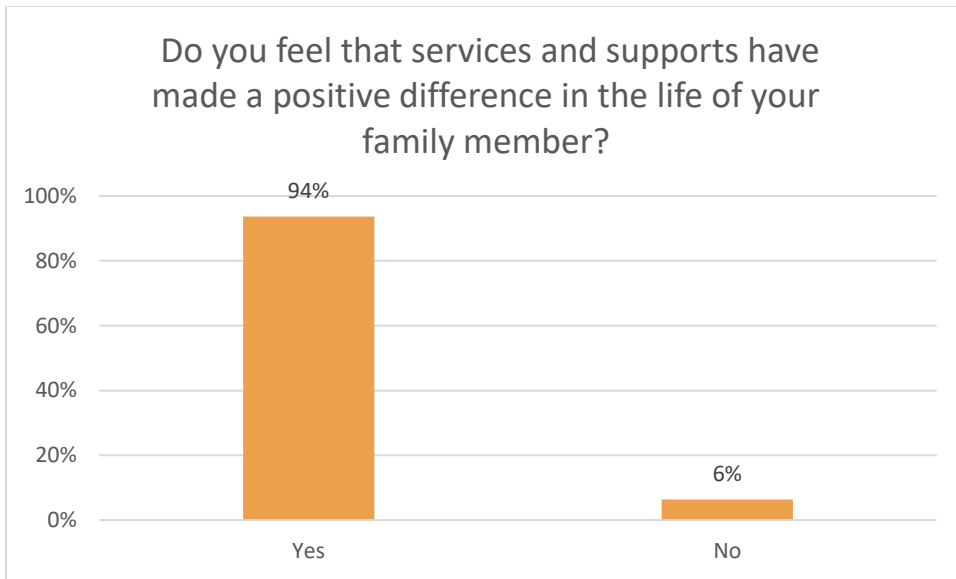


Table 89. Do you feel that services and supports have made a positive difference in the life of your family member?

Significantly Above Average

State	Yes	No	N
MO	97%	3%	231

Within Average Range

State	Yes	No	N
SD	96%	4%	186
IN	96%	4%	346
OK	96%	4%	417
AZ	96%	4%	239
MT	96%	4%	191
AK	96%	4%	160
NH	95%	5%	540
PA	95%	5%	366
LA	95%	5%	585
Weighted NCI-IDD Average	94%	6%	10531
CA	93%	7%	6890
GA	91%	9%	380

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

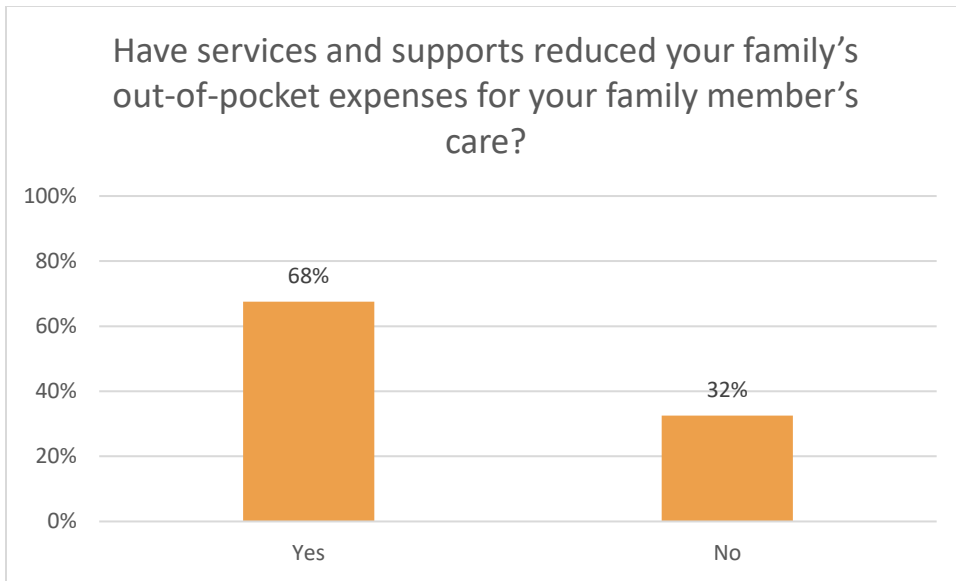


Table 90. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

Significantly Above Average

State	Yes	No	N
OK	83%	17%	408
AZ	77%	23%	226

Within Average Range

State	Yes	No	N
NH	72%	28%	502
IN	72%	28%	316
LA	71%	29%	543
MO	71%	29%	221
SD	70%	30%	171
Weighted NCI-IDD Average	68%	32%	9839
PA	67%	33%	342
MT	66%	34%	180
CA	66%	34%	6421
AK	59%	41%	156

Significantly Below Average

State	Yes	No	N
GA	61%	39%	353

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

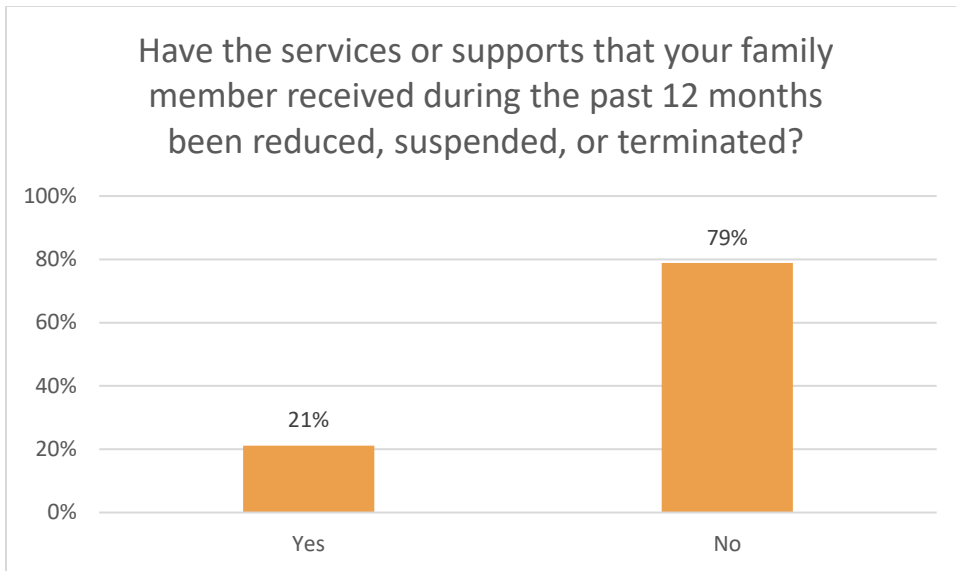


Table 91. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

Significantly Above Average

State	Yes	No	N
AK	38%	62%	162

Within Average Range

State	Yes	No	N
PA	26%	74%	360
NH	25%	75%	536
CA	22%	78%	6685
Weighted NCI-IDD Average	21%	79%	10269
IN	21%	79%	360
MT	20%	80%	183
GA	20%	80%	368
MO	19%	81%	229
SD	17%	83%	178
AZ	16%	84%	235

Significantly Below Average

State	Yes	No	N
LA	13%	87%	566
OK	8%	92%	408

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

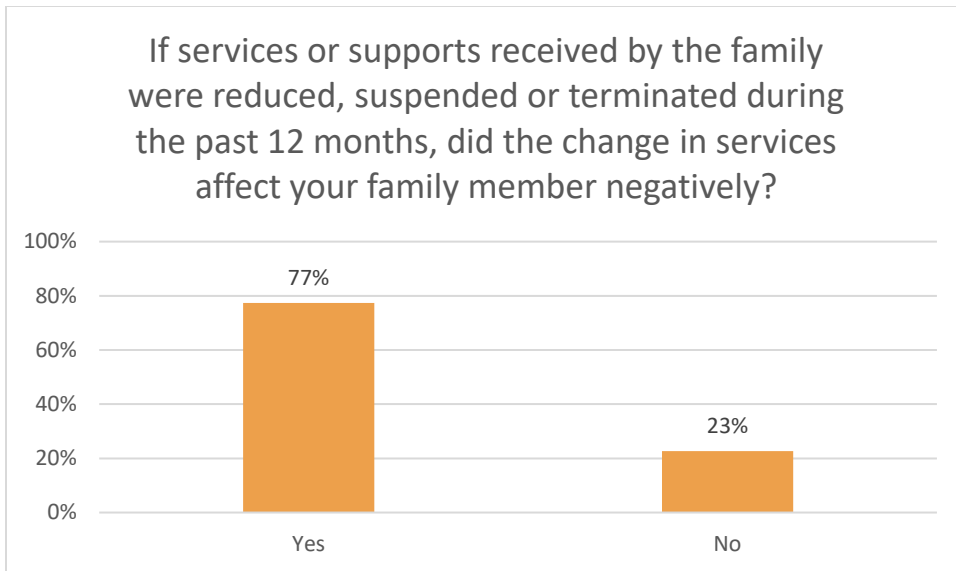


Table 92. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?

Within Average Range

State	Yes	No	N
MO	89%	11%	38
PA	84%	16%	80
GA	80%	20%	59
OK	79%	21%	28
CA	77%	23%	1266
Weighted NCI-IDD Average	77%	23%	1872
AK	75%	25%	57
AZ	74%	26%	31
NH	72%	28%	121
LA	71%	29%	59
IN	69%	31%	70
SD	66%	34%	29
MT	59%	41%	34

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

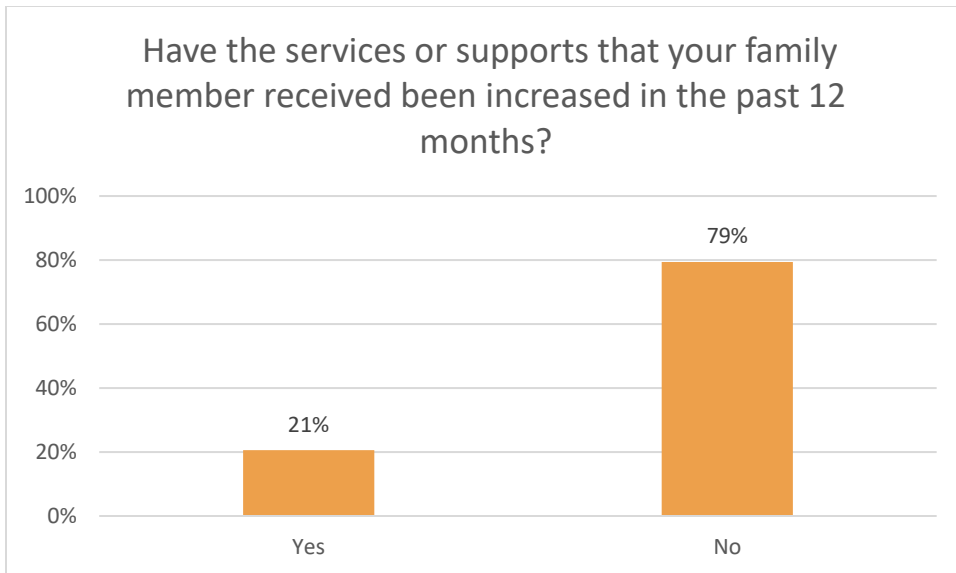


Table 93. Have the services or supports that your family member received been increased in the past 12 months?

Within Average Range

State	Yes	No	N
CA	23%	77%	6489
MO	22%	78%	224
PA	21%	79%	343
Weighted NCI-IDD Average	21%	79%	9927
GA	19%	81%	352
NH	17%	83%	517
AZ	17%	83%	233
SD	15%	85%	170

Significantly Below Average

State	Yes	No	N
LA	14%	86%	543
OK	13%	87%	390
IN	13%	87%	334
MT	12%	88%	177
AK	10%	90%	155

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

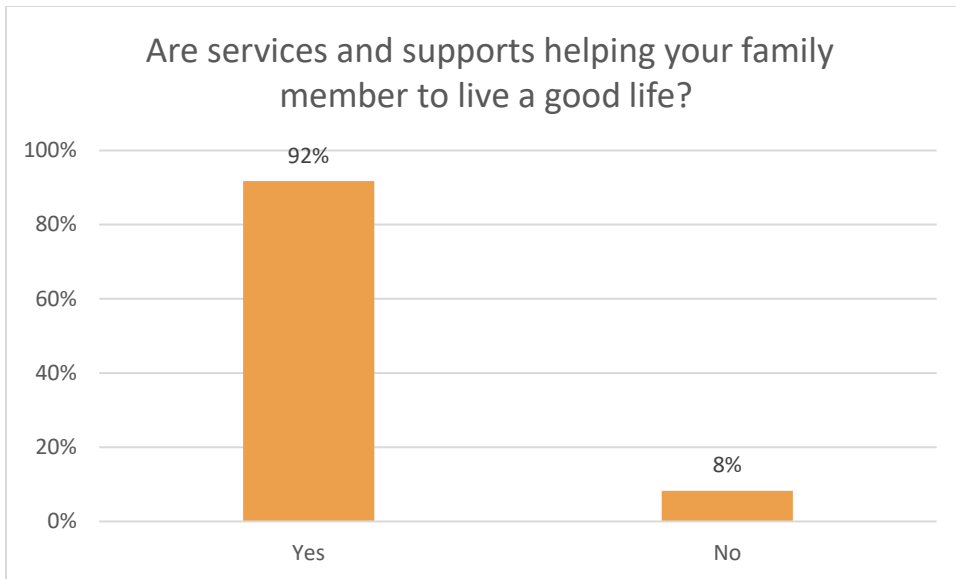


Table 94. Are services and supports helping your family member to live a good life?

Significantly Above Average

State	Yes	No	N
MO	98%	2%	226
SD	97%	3%	183
OK	96%	4%	406
LA	96%	4%	580
NH	95%	5%	522

Within Average Range

State	Yes	No	N
AK	95%	5%	154
PA	94%	6%	341
MT	94%	6%	179
IN	94%	6%	335
AZ	94%	6%	239
Weighted NCI-IDD Average	92%	8%	10119
GA	92%	8%	360
CA	90%	10%	6594

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

COVID-19 Supplement

The COVID-19 Supplement is intended to support an ongoing understanding of the continuing effects of the pandemic on people's lives and services.

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.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

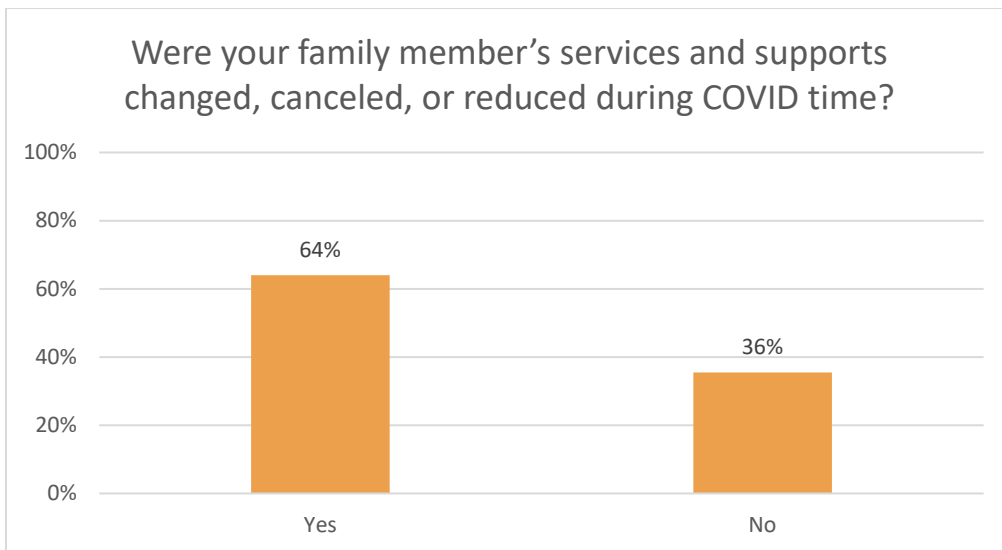


Table 95. Were your family member's services and supports changed, canceled, or reduced during COVID time?

Significantly Above Average

State	Yes	No	N
PA	79%	21%	340
NH	76%	24%	483
MO	75%	25%	219
GA	72%	28%	377

Within Average Range

State	Yes	No	N
IN	73%	27%	114
AZ	70%	30%	211
MT	70%	30%	184
Weighted NCI-IDD Average	64%	36%	8559
SD	56%	44%	191
LA	50%	50%	28

Significantly Below Average

State	Yes	No	N
CA	59%	41%	6020
OK	48%	52%	393

Table note: AK did not elect to administer the COVID-19 Supplemental Questions and is not included in the above tables.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

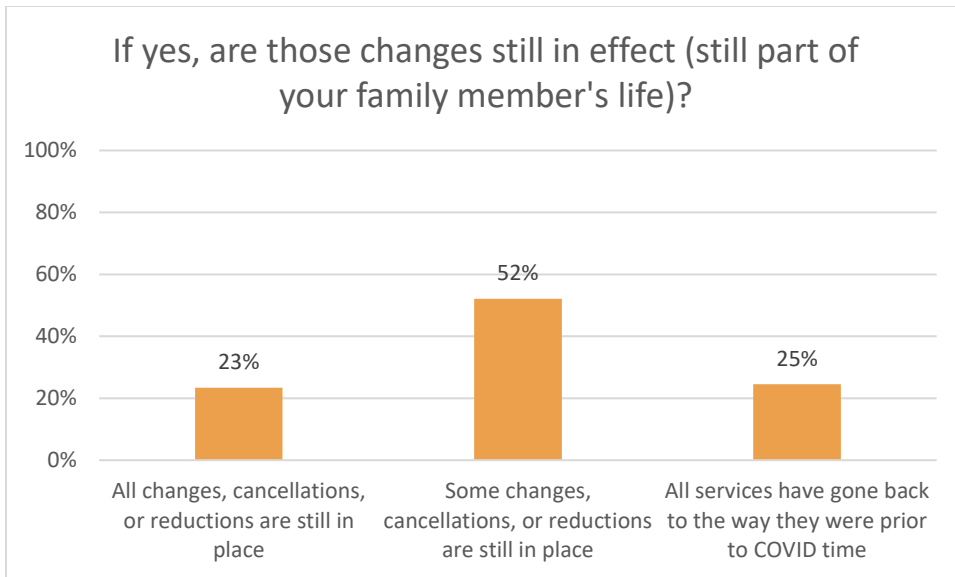


Table 96. If yes, are those changes still in effect (still part of your family member's life)?

Within Average Range

State	All changes still in place	Some changes still in place	All services have gone back to the way they were prior to COVID	N
NH	29%	54%	17%	357
CA	27%	54%	19%	3218
Weighted NCI-IDD Average	23%	52%	25%	4893
GA	23%	42%	35%	257
PA	21%	48%	31%	260
IN	19%	47%	35%	81
AZ	16%	58%	26%	141

Significantly Below Average

State	All changes still in place	Some changes still in place	All services have gone back to the way they were prior to COVID	N
MO	14%	56%	30%	160
MT	14%	49%	37%	124
OK	14%	45%	42%	177
SD	5%	37%	59%	104

Table note: AK did not elect to administer the COVID-19 Supplemental Questions and is not included in the above tables. LA is not included due to low counts.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

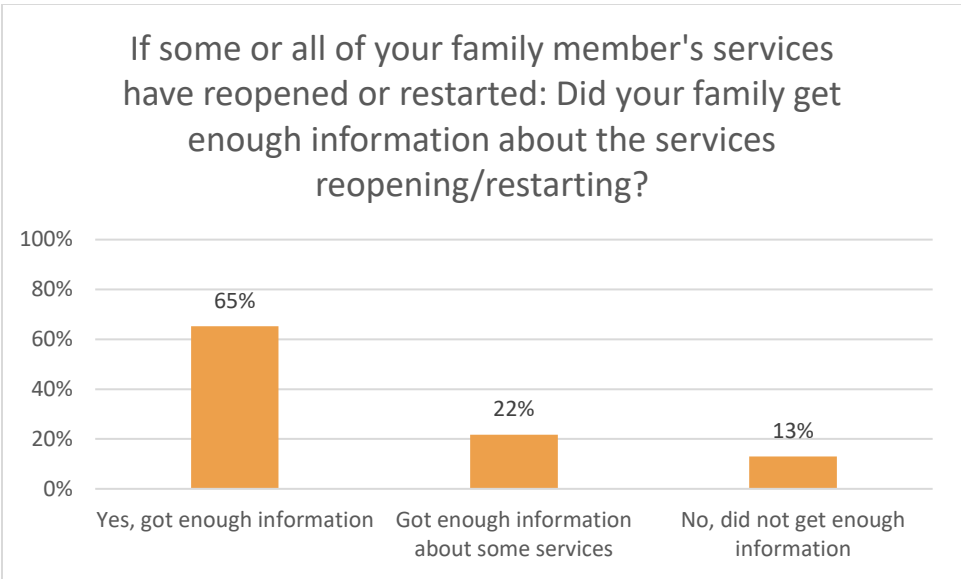


Table 97. If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?

Significantly Above Average

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
IN	84%	11%	5%	62
MO	80%	17%	4%	127

Within Average Range

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
SD	76%	19%	5%	91
MT	76%	13%	12%	94
OK	72%	13%	15%	143
PA	72%	23%	6%	193
GA	71%	18%	10%	182
AZ	70%	22%	8%	106
NH	68%	24%	8%	222
Weighted NCI-IDD Average	65%	22%	13%	3341

Significantly Below Average

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
CA	58%	23%	19%	2109

Table note: AK did not elect to administer the COVID-19 Supplemental Questions and is not included in the above tables. LA is not included due to low counts.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

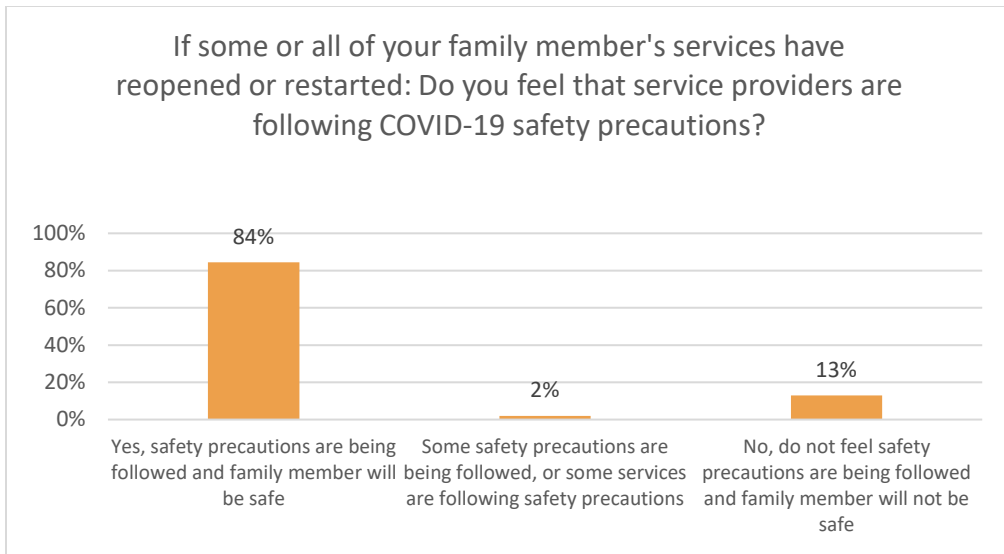


Table 98. If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?

Significantly Above Average

State	Yes	Some precautions being followed	No	N
IN	94%	5%	2%	64

Within Average Range

State	Yes	Some precautions being followed	No	N
MO	91%	5%	5%	127
PA	88%	1%	11%	187
GA	87%	4%	9%	179
OK	85%	2%	13%	136
NH	84%	1%	14%	232
Weighted NCI-IDD Average	84%	2%	13%	3253
CA	84%	14%	2%	2028
SD	82%	18%	0%	92
MT	81%	19%	0%	94

Significantly Below Average

State	Yes	Some precautions being followed	No	N
AZ	72%	24%	4%	104

Table note: AK did not elect to administer the COVID-19 Supplemental Questions and is not included in the above tables. LA is not included due to low counts.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

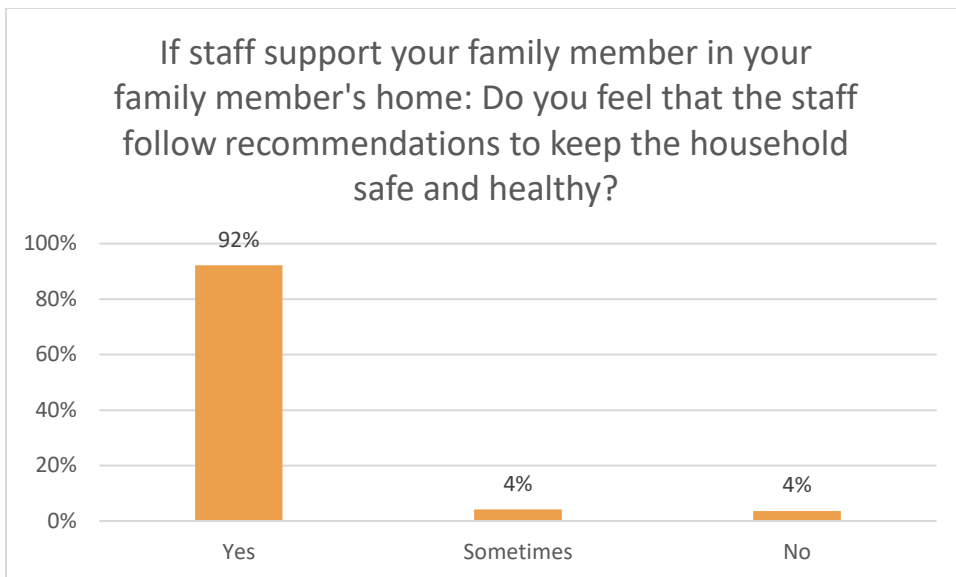


Table 99. If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?

Within Average Range

State	Yes	Sometimes	No	N
SD	95%	3%	3%	119
MT	94%	4%	2%	125
PA	94%	3%	2%	281
AZ	94%	4%	2%	165
NH	93%	5%	2%	343
LA	92%	8%	0%	26
Weighted NCI-IDD Average	92%	4%	4%	7069
IN	92%	5%	3%	100
CA	92%	4%	4%	5153
OK	91%	5%	4%	283
GA	89%	5%	5%	301
MO	88%	5%	7%	173

Table note: AK did not elect to administer the COVID-19 Supplemental Questions and is not included in the above tables.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

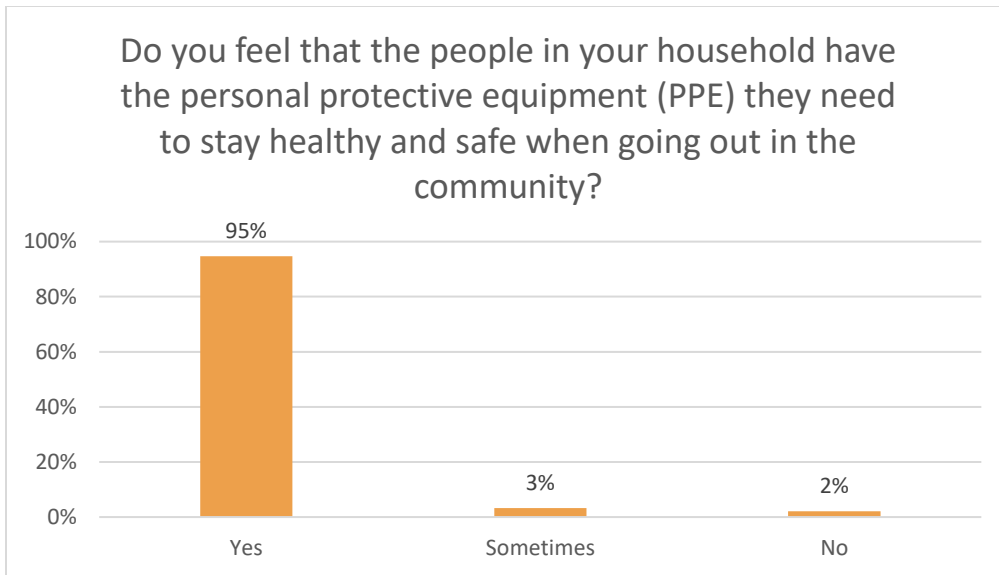


Table 100. Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community?

Significantly Above Average

State	Yes	Sometimes	No	N
SD	98%	1%	1%	188
PA	97%	1%	1%	347

Within Average Range

State	Yes	Sometimes	No	N
AZ	96%	2%	2%	210
OK	95%	3%	2%	373
NH	95%	2%	2%	457
Weighted NCI-IDD Average	95%	3%	2%	9092
IN	95%	5%	0%	111
CA	94%	4%	2%	6585
MO	94%	4%	2%	216
GA	93%	3%	4%	397
LA	93%	7%	0%	28
MT	92%	5%	3%	180

Table note: AK did not elect to administer the COVID-19 Supplemental Questions and is not included in the above tables.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

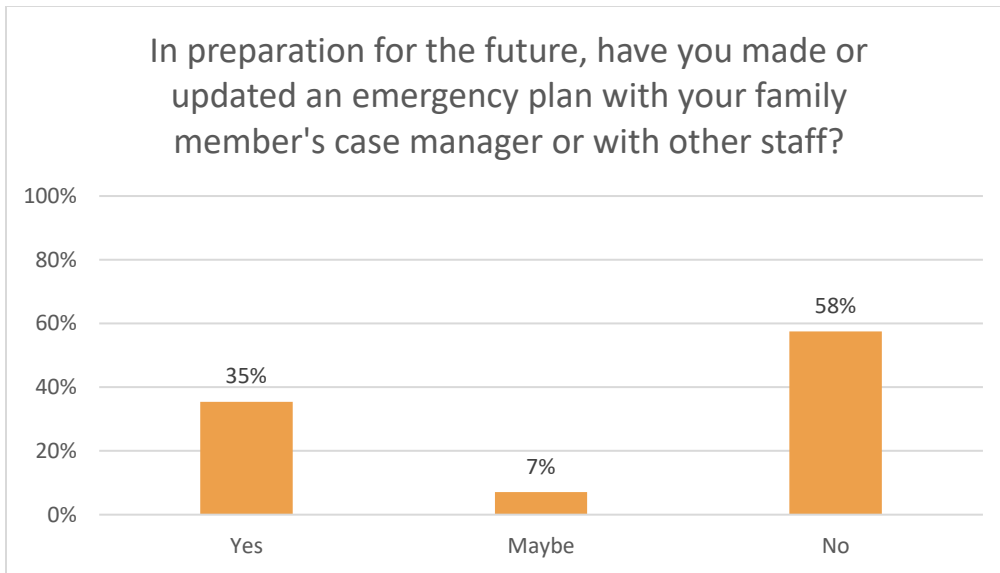


Table 101. In preparation for the future, have you made or updated an emergency plan with your family member's case manager or with other staff?

Significantly Above Average

State	Yes	Maybe	No	N
LA	74%	4%	22%	27
OK	55%	5%	41%	364
AZ	51%	9%	41%	199
MO	47%	7%	46%	208

Within Average Range

State	Yes	Maybe	No	N
IN	38%	3%	59%	100
Weighted NCI-IDD Average	35%	7%	58%	8454
PA	35%	7%	58%	308
SD	34%	5%	61%	160
NH	33%	7%	60%	420
GA	33%	7%	60%	363
MT	33%	4%	63%	171
CA	33%	7%	60%	6134

Table note: AK did not elect to administer the COVID-19 Supplemental Questions and is not included in the above tables.

Please note: some state outcomes may appear out of order due to sample size differences. [Learn more.](#)

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 (NCI), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI-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.

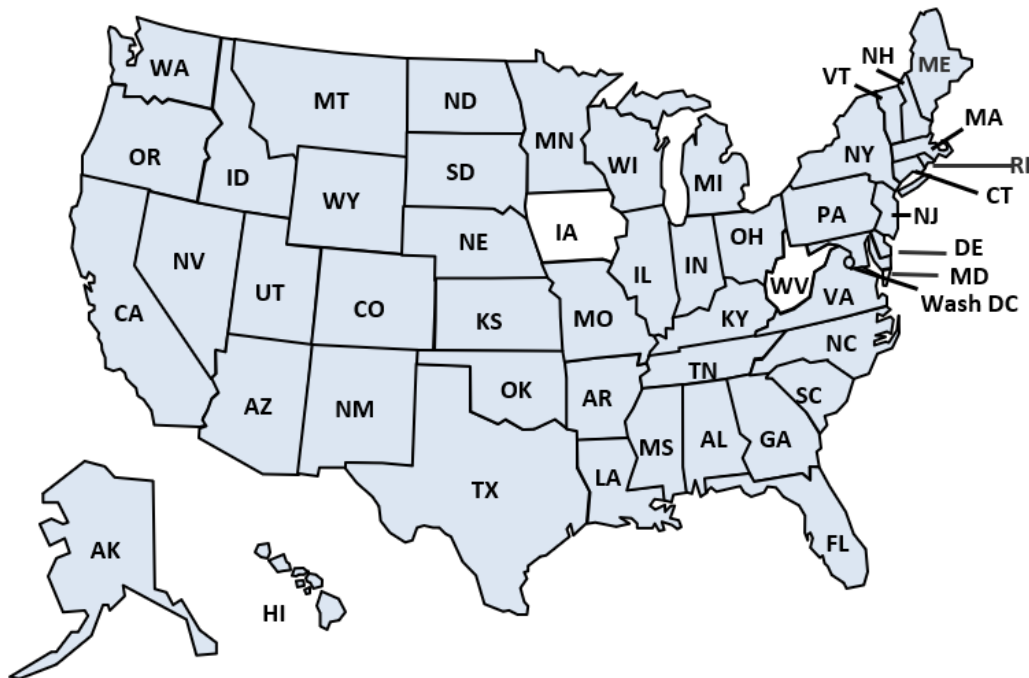
Since the initial field test, NCI-IDD has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI-IDD continues to develop and refine the indicators and expand state participation. For more information about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

<https://idd.nationalcoreindicators.org/>.

State Participation

State participation is entirely voluntary. As of the 2021-22 data collection cycle, the participating states are highlighted on the map below. Not all states participate in all surveys each year.

Figure 1. NCI-IDD State Participation 2021-22



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://idd.nationalcoreindicators.org/how-it-works/>.

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 In-Person Survey, three Family Surveys, and State of the Workforce in IDD survey.

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI-IDD initiative is a dynamic effort that allows

for measures to be added, dropped, or changed to reflect current and future priorities of participating states.

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

Sub-Domains and Concern Statements

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

Family Survey Sub-Domains and Concern 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 (New in 2021-22)	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 (New in 2021-22)	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-IDD 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-IDD 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; and states draw new samples each year rather than following the same group of individuals.

Methodology

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

Sampling & Administration

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

1. Had an adult individual (aged 18 or over) with an intellectual or developmental disability living in the home; and
2. The adult individual with an intellectual or developmental disability living in the home received at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys. A total of five states (CA, IN, LA, MO, MT) had at least a portion of surveys completed via direct entry for the 2021-22 data collection cycle.

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 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 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 NCI-IDD average**, where the difference between the state's percentage and the weighted NCI-IDD average: a) was in favor of the 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 NCI-IDD Average, within the range of the NCI-IDD Average, and significantly below the 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 outside of the family home.
2. Demographic information was entered into the file but no survey questions were answered.

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the NCI-IDD average. The 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 2020-21, 12 states administered the Adult Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The following table shows the number of individuals receiving services who were eligible to be drawn into the sample ("total population"), the number of surveys each state sent, complete surveys, response rates, margins of error, and survey submission modes.

Adult Family Survey: State Response Rates

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AK	855	855	176	20.6%	7.5%	81%	19%
AZ	11,791	1,400	253	18.1%	6.1%	100%	0%
CA	92,941	40,416	8032	19.9%	1.0%	79%	21%
GA	6,955	1,700	431	25.4%	4.6%	100%	0%
IN	13,516	1,500	393	26.2%	4.9%	37%	63%
LA	4,837	NOT AVAILABLE	636	NOT AVAILABLE	3.6%	95%	5%
MO	3,655	1,500	251	16.7%	6.0%	85%	15%
MT	745	748	202	27.0%	5.9%	92%	8%
NH	2,066	NOT AVAILABLE	578	NOT AVAILABLE	3.5%	100%	0%
OK	2,006	NOT AVAILABLE	453	NOT AVAILABLE	4.0%	100%	0%
PA	18,982	2,050	383	18.7%	5.0%	100%	0%
SD	900	900	201	22.3%	6.1%	100%	0%
Total	159,249		11989		-	83%	17%

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