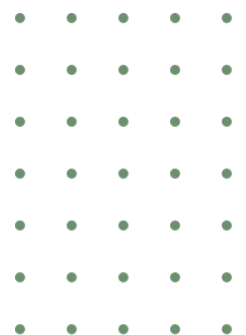


National Core Indicators[®] - Intellectual and
Developmental Disabilities (NCI[®]-IDD)



National Report 2021-22

Family/Guardian Survey (FGS)





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List of Acronyms Used in This Report

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

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Executive Summary

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

The NCI-IDD Family/Guardian Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Family/Guardian Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI-IDD during the 2021-22 data collection cycle, 10 states submitted a valid sample of Family/Guardian Survey data: Arizona (AZ), California (CA), Delaware (DE), Georgia (GA), Indiana (IN), Minnesota (MN), New Hampshire (NH), Pennsylvania (PA), South Dakota (SD), and Washington (WA). This Final Report provides a summary of results based on data submitted by June 30, 2022.

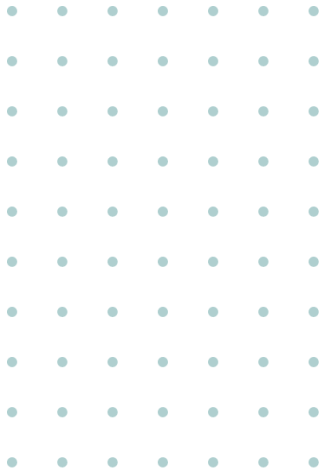
Note on the Impact of COVID-19

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.

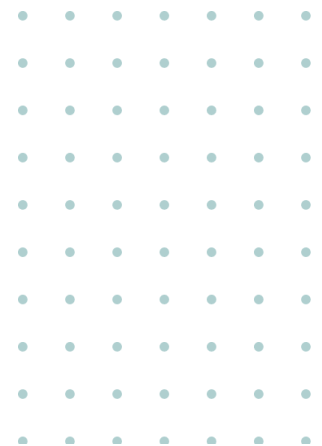
To help better understand the overall impact of COVID-19 on families, NCI-IDD added a state-optional COVID-19 Supplement to all NCI-IDD Surveys. The COVID-19 Supplement is intended to support the understanding of the experience of people with disabilities and their families at the beginning of the COVID-19 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.

[Infographic Executive Summary to be added]



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: The 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. Family Member's Residence

State	Specialized Facility for People with Intellectual Disabilities	Group Home or Agency-Operated Apartment	Independent Home or Apartment	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
AZ	10%	68%	2%	18%	1%	0%	0%	217
CA	17%	40%	38%	2%	1%	0%	1%	4592
DE	5%	87%	1%	4%	0%	0%	2%	182
GA	11%	53%	19%	16%	1%	0%	1%	356
IN	7%	49%	38%	2%	0%	0%	4%	477
MN	7%	65%	19%	5%	0%	0%	3%	411
NH	7%	28%	27%	37%	1%	0%	1%	376
PA	18%	74%	3%	3%	1%	0%	1%	646
SD	0%	72%	27%	1%	0%	0%	0%	495
WA	11%	51%	33%	3%	1%	0%	1%	164
Weighted NCI-IDD Average	14%	52%	27%	4%	1%	0%	1%	7916

Specialized Facility for People With Intellectual Disabilities refers to Intermediate Care Facilities (ICF), state-run or other institutional setting. Independent Home or Apartment refers to housing that is not operated by an agency, and one where the individual may or may not live with a roommate.

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 Time Living in Current Residence

State	Less than one year	One to three years	Four to five years	Over five years	N
AZ	9%	25%	11%	55%	219
CA	8%	21%	12%	60%	4546
DE	9%	21%	11%	59%	182
GA	6%	27%	13%	55%	355
IN	9%	25%	14%	52%	475
MN	8%	22%	9%	61%	414
NH	12%	21%	14%	53%	382
PA	2%	12%	7%	79%	596
SD	7%	18%	13%	63%	488
WA	13%	28%	13%	45%	163
Weighted NCI-IDD Average	7%	21%	11%	61%	7820

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 Residential Designation

State	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
AZ	93%	7%	218
CA	94%	6%	4473
DE	72%	28%	179
GA	77%	23%	344
IN	88%	12%	476
MN	88%	12%	410
NH	59%	41%	383
PA	69%	31%	623
SD	97%	3%	488
WA	91%	9%	161
Weighted NCI-IDD Average	87%	13%	7755

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 Age

State	Age	N
AZ	45.1	218
CA	43.6	4492
DE	45.6	177
GA	47.9	351
IN	47.6	465
MN	44.6	403
NH	46.3	390
PA	49.5	655
SD	47.3	496
WA	38.3	166
Weighted NCI-IDD Average	44.8	7813

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 Gender

State	Male	Female	Other	N
AZ	55%	45%	0%	218
CA	61%	39%	0%	4559
DE	64%	36%	0%	181
GA	62%	38%	0%	357
IN	61%	39%	0%	475
MN	56%	43%	1%	414
NH	66%	34%	1%	390
PA	58%	42%	0%	655
SD	58%	42%	0%	496
WA	62%	37%	1%	166
Weighted NCI-IDD Average	60%	40%	0%	7911

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 6. 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
AZ	9%	2%	5%	0%	71%	16%	4%	0%
CA	2%	9%	6%	0%	73%	13%	2%	2%
DE	1%	3%	17%	0%	77%	1%	2%	0%
GA	3%	2%	21%	0%	73%	2%	1%	1%
IN	1%	1%	6%	0%	91%	1%	1%	1%
MN	1%	2%	2%	0%	91%	1%	1%	2%
NH	2%	1%	1%	0%	96%	0%	0%	1%
PA	1%	1%	6%	0%	91%	2%	1%	0%
SD	8%	0%	1%	0%	89%	2%	0%	1%
WA	6%	3%	3%	1%	87%	7%	0%	2%
Weighted NCI-IDD Average	2%	5%	6%	0%	80%	8%	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 7a. 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)
AZ	75%	37%	29%	15%	9%	9%
CA	68%	28%	36%	17%	8%	5%
DE	76%	35%	38%	14%	4%	8%
GA	79%	32%	25%	13%	10%	5%
IN	75%	38%	34%	15%	8%	6%
MN	79%	39%	27%	15%	6%	8%
NH	70%	39%	33%	12%	9%	6%
PA	86%	39%	30%	15%	11%	7%
SD	69%	28%	17%	17%	7%	6%
WA	76%	34%	45%	13%	7%	5%
Weighted NCI-IDD Average	74%	33%	34%	16%	8%	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 7b. 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
AZ	12%	28%	0%	9%	0%	4%	17%
CA	9%	25%	0%	8%	1%	1%	10%
DE	7%	25%	0%	9%	1%	4%	4%
GA	7%	24%	1%	9%	1%	2%	11%
IN	8%	24%	1%	9%	1%	3%	14%
MN	8%	22%	1%	12%	1%	3%	3%
NH	17%	28%	1%	9%	0%	2%	13%
PA	8%	31%	0%	9%	1%	1%	11%
SD	9%	25%	1%	13%	0%	2%	10%
WA	7%	29%	1%	10%	1%	2%	16%
Weighted NCI-IDD Average	9%	26%	1%	9%	1%	2%	11%

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 8a. 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
AZ	7%	22%	7%	27%	38%
CA	8%	17%	5%	28%	26%
DE	9%	22%	4%	28%	33%
GA	9%	20%	4%	44%	39%
IN	9%	22%	6%	34%	28%
MN	7%	18%	8%	26%	24%
NH	10%	19%	10%	24%	28%
PA	7%	17%	4%	28%	25%
SD	10%	20%	5%	25%	18%
WA	9%	16%	5%	19%	15%
Weighted NCI-IDD Average	8%	18%	5%	28%	27%

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 8b. 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
AZ	6%	2%	3%	19%	8%
CA	8%	2%	2%	14%	15%
DE	16%	0%	4%	13%	20%
GA	9%	2%	7%	15%	13%
IN	10%	3%	5%	13%	22%
MN	13%	3%	6%	9%	21%
NH	17%	4%	4%	14%	17%
PA	24%	2%	5%	13%	16%
SD	16%	4%	5%	16%	25%
WA	15%	0%	4%	15%	22%
Weighted NCI-IDD Average	12%	2%	4%	13%	17%

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 8c. 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
AZ	13%	7%	4%	0%	21%
CA	11%	4%	3%	1%	25%
DE	4%	3%	2%	2%	24%
GA	7%	3%	5%	0%	16%
IN	11%	4%	4%	2%	24%
MN	9%	5%	4%	0%	27%
NH	9%	6%	2%	0%	15%
PA	5%	3%	5%	1%	19%
SD	5%	6%	2%	1%	20%
WA	12%	4%	4%	0%	33%
Weighted NCI-IDD Average	10%	4%	4%	1%	24%

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 Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AZ	80%	15%	1%	1%	3%	220
CA	80%	13%	2%	1%	4%	4467
DE	77%	15%	3%	2%	2%	171
GA	83%	14%	1%	0%	2%	359
IN	82%	12%	2%	1%	3%	471
MN	84%	11%	2%	1%	2%	398
NH	84%	11%	2%	2%	1%	389
PA	71%	18%	1%	2%	8%	648
SD	82%	13%	2%	1%	2%	479
WA	82%	13%	1%	1%	3%	136
Weighted NCI-IDD Average	80%	13%	2%	1%	4%	7738

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's Preferred Language

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AZ	94%	2%	0%	0%	0%	1%	4%	219
CA	93%	2%	1%	0%	0%	1%	3%	4497
DE	97%	0%	0%	1%	0%	2%	0%	177
GA	97%	1%	0%	0%	0%	0%	1%	358
IN	96%	0%	0%	0%	0%	2%	2%	475
MN	98%	0%	0%	0%	0%	2%	0%	408
NH	98%	0%	0%	0%	0%	1%	0%	391
PA	97%	0%	0%	0%	0%	1%	2%	648
SD	97%	0%	0%	0%	0%	2%	0%	488
WA	98%	0%	0%	0%	0%	1%	1%	135
Weighted NCI-IDD Average	95%	1%	0%	0%	0%	1%	2%	7796

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 11. Family Member Has Legal Court Appointed Guardian or Conservator

State	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
AZ	11%	8%	77%	4%	218
CA	42%	28%	24%	6%	4159
DE	22%	14%	56%	8%	166
GA	36%	14%	44%	7%	340
IN	22%	9%	63%	6%	469
MN	10%	8%	80%	3%	410
NH	13%	11%	74%	3%	390
PA	14%	22%	51%	12%	549
SD	18%	17%	58%	7%	479
WA	27%	18%	53%	2%	132
Weighted NCI-IDD Average	29%	21%	44%	6%	7312

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. Guardian or Conservator Relationship to Family Member

State	Family	Friend	Employee or State Guardianship Agency	Other	N
AZ	83%	5%	3%	9%	184
CA	92%	1%	5%	2%	2255
DE	95%	1%	2%	3%	120
GA	88%	3%	4%	5%	191
IN	94%	1%	3%	3%	355
MN	81%	3%	12%	4%	359
NH	94%	2%	2%	2%	331
PA	85%	2%	9%	3%	414
SD	91%	3%	4%	2%	371
WA	86%	5%	3%	5%	96
Weighted NCI-IDD Average	88%	2%	6%	3%	4676

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 Highest level of Education

State	Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
AZ	30%	2%	32%	26%	1%	6%	4%	209
CA	30%	1%	31%	22%	3%	8%	5%	4273
DE	39%	1%	42%	10%	4%	1%	4%	166
GA	33%	1%	41%	18%	2%	1%	4%	339
IN	29%	0%	38%	23%	2%	3%	5%	457
MN	18%	1%	30%	45%	2%	2%	2%	399
NH	32%	0%	30%	27%	4%	3%	5%	376
PA	39%	0%	25%	32%	1%	1%	2%	593
SD	38%	0%	31%	26%	0%	1%	3%	468
WA	15%	1%	40%	33%	1%	4%	5%	135
Weighted NCI-IDD Average	29%	1%	32%	27%	2%	5%	4%	7415

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 Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

State	None	Some	Extensive	N
AZ	37%	38%	25%	212
CA	40%	35%	25%	4348
DE	28%	39%	33%	168
GA	36%	37%	27%	346
IN	32%	42%	26%	460
MN	36%	44%	20%	407
NH	43%	37%	20%	385
PA	27%	38%	34%	622
SD	46%	38%	17%	483
WA	27%	47%	26%	133
Weighted NCI-IDD Average	36%	38%	26%	7564

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 Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)

State	None	Some	Extensive	N
AZ	18%	43%	39%	218
CA	32%	36%	33%	4435
DE	20%	39%	41%	172
GA	24%	38%	38%	348
IN	29%	38%	32%	475
MN	27%	42%	31%	410
NH	27%	38%	35%	387
PA	13%	39%	48%	642
SD	36%	34%	30%	488
WA	14%	45%	41%	133
Weighted NCI-IDD Average	26%	38%	36%	7708

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

State	None	Some	Extensive	N
AZ	3%	20%	77%	217
CA	5%	30%	65%	4486
DE	2%	20%	79%	174
GA	3%	22%	74%	352
IN	1%	25%	74%	470
MN	2%	24%	74%	410
NH	1%	24%	75%	388
PA	1%	13%	87%	643
SD	4%	34%	62%	491
WA	1%	19%	79%	134
Weighted NCI-IDD Average	3%	25%	72%	7765

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.

Table 17. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AZ	97%	1%	0%	0%	0%	0%	1%	220
CA	92%	4%	1%	0%	0%	0%	3%	4513
DE	99%	1%	0%	0%	0%	0%	1%	170
GA	98%	1%	0%	0%	0%	0%	1%	357
IN	99%	1%	0%	0%	0%	0%	0%	473
MN	99%	0%	0%	0%	0%	0%	0%	410
NH	98%	2%	0%	0%	0%	0%	0%	393
PA	99%	0%	0%	0%	0%	0%	1%	650
SD	100%	0%	0%	0%	0%	0%	0%	489
WA	100%	0%	0%	0%	0%	0%	0%	128
Weighted NCI-IDD Average	95%	2%	1%	0%	0%	0%	2%	7803

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

Table 18. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
AZ	2%	15%	62%	20%	221
CA	2%	8%	55%	35%	4505
DE	1%	10%	65%	24%	172
GA	1%	13%	63%	23%	358
IN	1%	11%	64%	24%	470
MN	2%	20%	66%	12%	408
NH	1%	8%	73%	19%	390
PA	1%	8%	64%	27%	646
SD	1%	9%	66%	24%	495
WA	1%	18%	64%	17%	132
Weighted NCI-IDD Average	1%	11%	60%	28%	7797

Table 19. Respondent's Health

State	Excellent	Very good	Good	Fair	Poor	N
AZ	14%	41%	32%	10%	2%	222
CA	15%	34%	32%	16%	3%	4463
DE	16%	34%	32%	15%	4%	171
GA	13%	33%	34%	15%	4%	357
IN	10%	31%	43%	15%	2%	465
MN	17%	41%	34%	7%	1%	400
NH	20%	38%	29%	11%	2%	390
PA	13%	38%	29%	17%	3%	650
SD	15%	38%	36%	9%	1%	494
WA	16%	38%	35%	10%	2%	132
Weighted NCI-IDD Average	15%	36%	33%	14%	3%	7744

Table 20. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
AZ	60%	18%	0%	1%	2%	7%	11%	223
CA	88%	7%	0%	0%	0%	0%	4%	4456
DE	65%	24%	0%	1%	1%	2%	7%	170
GA	55%	24%	1%	3%	4%	1%	14%	353
IN	62%	28%	0%	2%	0%	1%	7%	473
MN	55%	19%	0%	1%	7%	5%	12%	402
NH	66%	25%	1%	1%	1%	4%	3%	390
PA	59%	32%	0%	1%	1%	1%	5%	650
SD	62%	26%	0%	1%	2%	3%	6%	495
WA	68%	13%	0%	2%	3%	1%	14%	133
Weighted NCI-IDD Average	73%	16%	0%	1%	2%	1%	7%	7745

Table 21. Respondent's Frequency of Visits With Family Member In Past 12 Months

State	Did Not Visit	1 to 3 Times	4 to 6 Times	7 to 12 Times	More Than 12 Times	N
AZ	3%	12%	13%	9%	62%	217
CA	7%	11%	9%	10%	63%	4455
DE	8%	16%	10%	9%	57%	171
GA	5%	12%	15%	11%	58%	354
IN	2%	8%	11%	13%	66%	473
MN	1%	8%	7%	17%	67%	406
NH	5%	11%	17%	14%	53%	391
PA	9%	16%	15%	12%	49%	646
SD	7%	12%	15%	14%	53%	490
WA	3%	8%	10%	14%	65%	133
Weighted NCI-IDD Average	6%	11%	11%	12%	61%	7736

Table 22. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
AZ	3%	12%	7%	38%	39%	211
CA	5%	12%	4%	23%	55%	4417
DE	3%	16%	2%	28%	51%	167
GA	6%	21%	5%	22%	47%	356
IN	4%	25%	6%	19%	46%	470
MN	2%	19%	13%	17%	50%	404
NH	3%	17%	4%	15%	60%	388
PA	4%	28%	7%	16%	43%	640
SD	4%	25%	12%	18%	42%	485
WA	0%	8%	3%	27%	62%	131
Weighted NCI-IDD Average	4%	17%	6%	22%	51%	7669

Table 23. 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	Up to \$15,000	\$15,001 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	No Earned Income	Prefer Not to Say	N
AZ	4%	5%	16%	16%	17%	14%	28%	205
CA	5%	6%	11%	11%	23%	13%	32%	4290
DE	3%	5%	9%	16%	27%	7%	34%	165
GA	4%	8%	15%	11%	18%	12%	33%	341
IN	5%	7%	17%	13%	14%	8%	36%	452
MN	6%	5%	12%	14%	29%	3%	31%	356
NH	6%	5%	14%	12%	20%	6%	37%	373
PA	5%	8%	15%	12%	17%	12%	31%	620
SD	5%	8%	17%	13%	21%	7%	29%	455
WA	4%	2%	9%	9%	31%	9%	37%	129
Weighted NCI-IDD Average	5%	6%	12%	12%	22%	11%	32%	7386

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 services and supports received.

Table 24. Services and Supports Received

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

State	Financial Support	In-Home Support	Residential Supports	Day or Employment Supports	Transportation	Mental/behavioral health care or other treatments or therapies	Self-Direction or Fiscal Intermediary Services
AZ	27%	29%	88%	66%	89%	56%	23%
CA	51%	47%	64%	60%	60%	45%	21%
DE	38%	32%	95%	58%	93%	60%	15%
GA	33%	45%	84%	71%	92%	50%	20%
IN	27%	67%	70%	56%	87%	65%	28%
MN	39%	46%	82%	65%	87%	54%	22%
NH	38%	33%	76%	47%	86%	52%	16%
PA	26%	32%	94%	52%	93%	68%	8%
SD	27%	34%	77%	64%	89%	53%	24%
WA	39%	59%	73%	47%	86%	46%	16%
Weighted NCI-IDD Average	40%	45%	75%	59%	76%	52%	19%

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

Table 25. 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
AZ	98%	24%
CA	90%	24%
DE	98%	20%
GA	99%	21%
IN	96%	34%
MN	97%	33%
NH	94%	28%
PA	97%	25%
SD	97%	31%
WA	94%	35%
Weighted NCI-IDD Average	93%	27%

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

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](#)

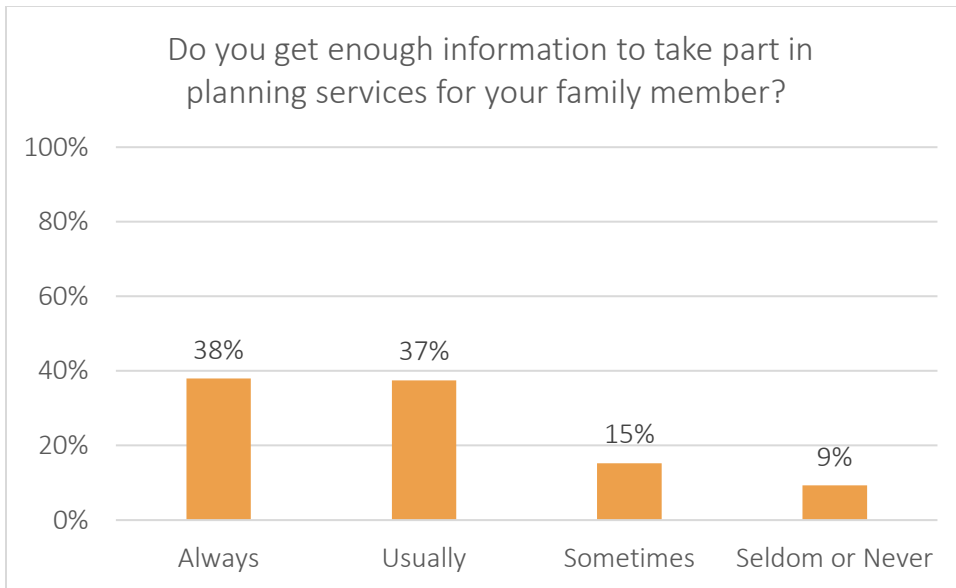


Table 26. Do you get enough information to take part in planning services for your family member?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	52%	39%	8%	1%	398
AZ	51%	32%	11%	6%	215
NH	47%	38%	11%	4%	374

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	41%	36%	16%	8%	594
SD	40%	44%	13%	4%	462
Weighted NCI-IDD Average	38%	37%	15%	9%	6940
IN	37%	44%	13%	6%	449
CA	35%	35%	17%	13%	3844
GA	31%	37%	21%	10%	315

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
DE	27%	47%	18%	9%	164
WA	25%	49%	16%	10%	127

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

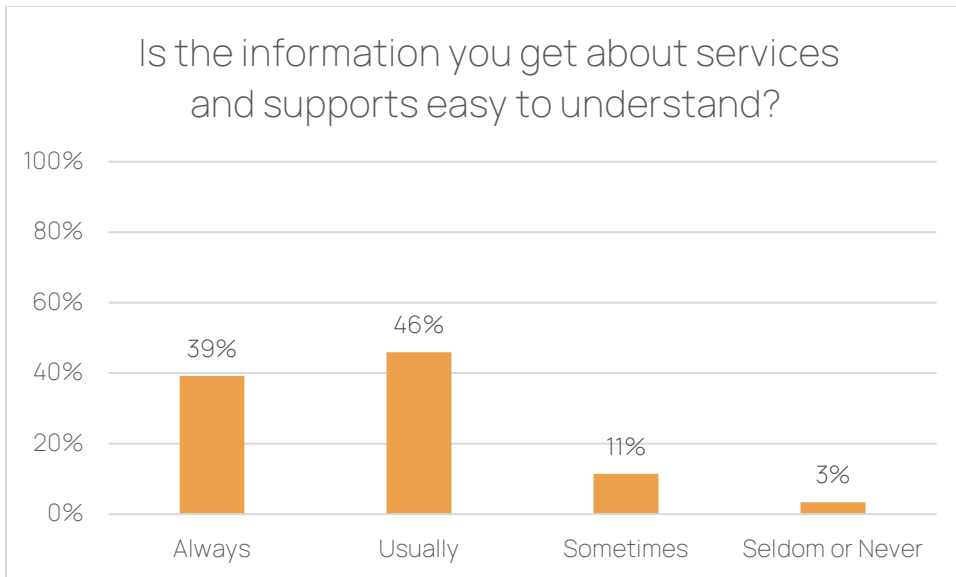


Table 27. Is the information you get about services and supports easy to understand?
Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	44%	44%	9%	3%	596
NH	43%	47%	7%	3%	375
AZ	43%	46%	10%	1%	212
MN	42%	48%	9%	1%	398
SD	40%	48%	10%	1%	474
CA	40%	44%	12%	4%	3779
Weighted NCI-IDD Average	39%	46%	11%	3%	6868
GA	36%	45%	17%	3%	311
IN	34%	49%	15%	3%	440
DE	31%	55%	11%	3%	159

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	22%	60%	11%	7%	124

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

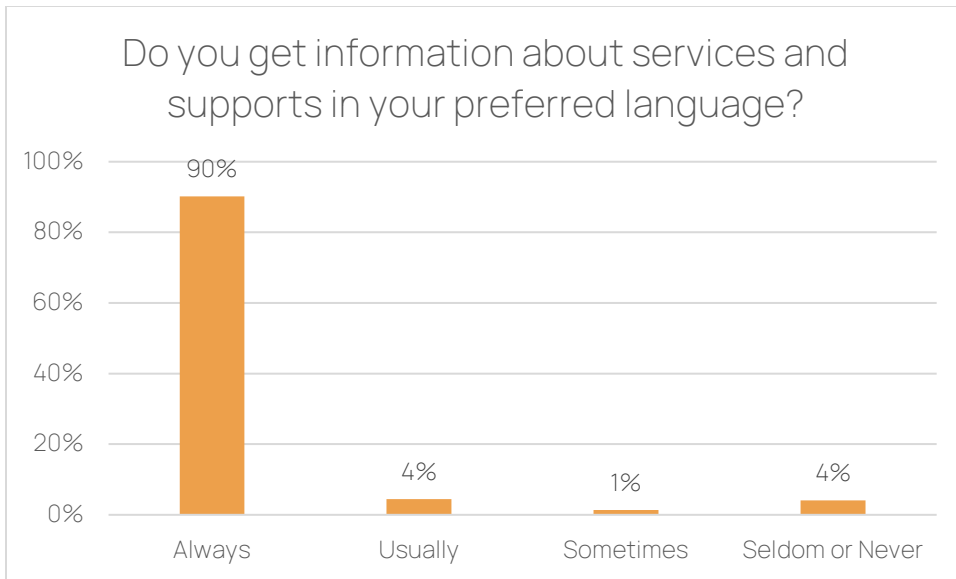


Table 28. Do you get information about services and supports in your preferred language?

New question in 2021-22

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	97%	2%	1%	1%	382
MN	97%	2%	0%	0%	407
WA	96%	1%	0%	3%	123
IN	93%	4%	0%	2%	456

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	93%	5%	0%	2%	486
DE	92%	3%	1%	5%	166
PA	91%	4%	1%	4%	634
AZ	91%	7%	1%	1%	207
Weighted NCI-IDD Average	90%	4%	1%	4%	7256
GA	90%	5%	3%	2%	334

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	87%	5%	2%	6%	4061

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

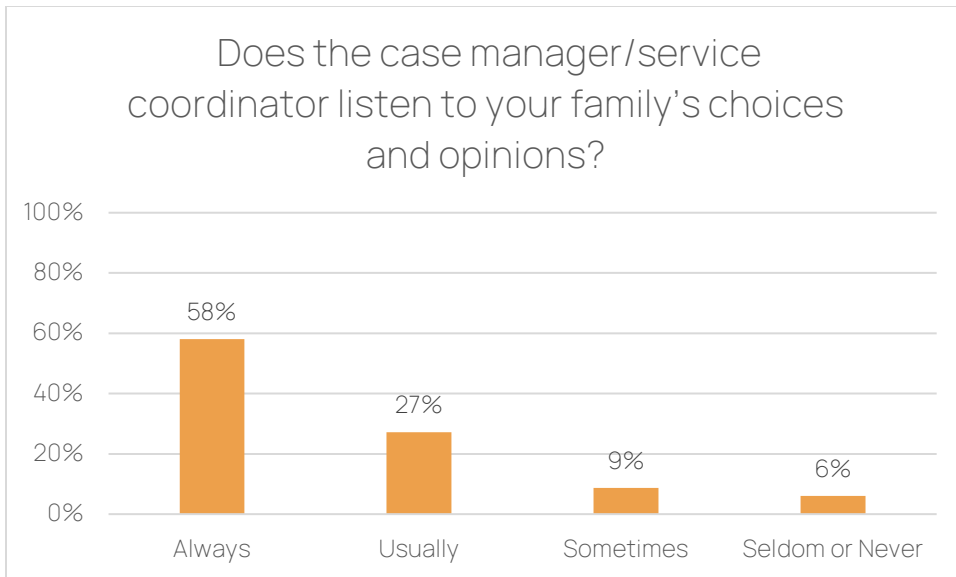


Table 29. Does the case manager/service coordinator listen to your family's choices and opinions?

Question changed in 2021-22

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	74%	22%	3%	1%	402
IN	69%	22%	6%	3%	451
NH	64%	28%	4%	3%	369

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	62%	27%	7%	4%	215
PA	60%	29%	7%	4%	612
SD	59%	32%	6%	2%	473
Weighted NCI-IDD Average	58%	27%	9%	6%	7104
CA	54%	27%	10%	9%	3971

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	49%	31%	14%	5%	325
WA	44%	36%	12%	8%	121
DE	43%	38%	12%	7%	165

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

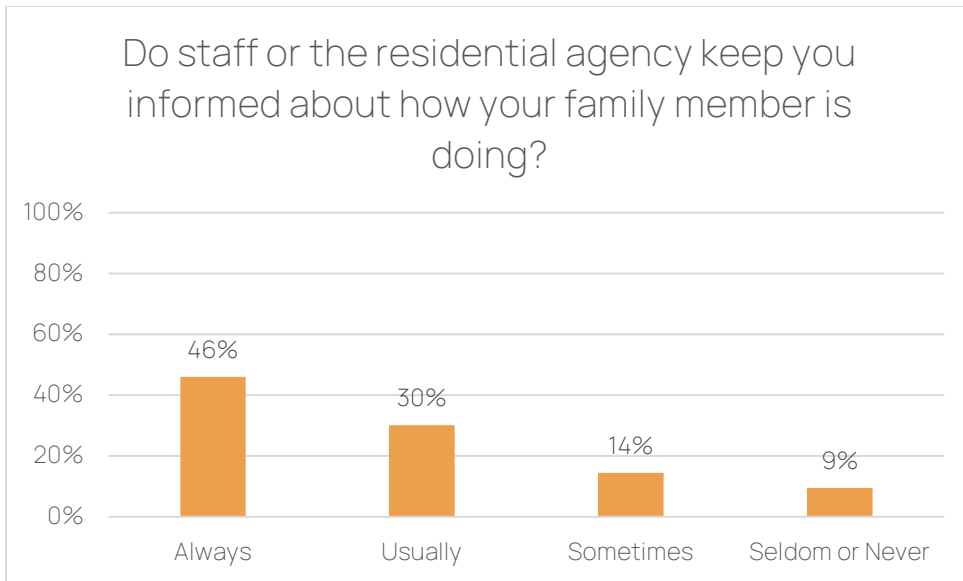


Table 30. Do staff or the residential agency keep you informed about how your family member is doing?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	56%	27%	12%	5%	211
MN	56%	33%	10%	2%	387
NH	55%	28%	10%	6%	368

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
GA	52%	21%	19%	9%	325
PA	47%	32%	15%	6%	643
Weighted NCI-IDD Average	46%	30%	14%	9%	7056
CA	44%	28%	15%	13%	3937
IN	43%	34%	14%	9%	435
SD	42%	39%	15%	5%	463

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
DE	35%	37%	19%	9%	171
WA	31%	34%	16%	18%	116

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 in any of these areas?

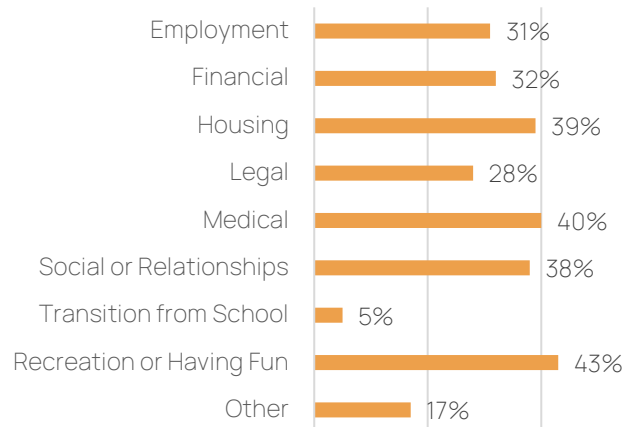


Table 31. Do you need help planning for your family member's future in any of these areas?

Categories are not mutually exclusive, therefore N is not shown

State	Employment	Financial	Housing	Legal	Medical	Social or Relationships	Transition from School	Recreation or Having Fun	Other
AZ	19%	20%	32%	27%	40%	32%	10%	42%	24%
CA	33%	33%	41%	28%	41%	40%	7%	43%	17%
DE	33%	30%	22%	22%	45%	31%	2%	46%	19%
GA	21%	29%	35%	28%	40%	31%	2%	33%	19%
IN	26%	33%	35%	25%	38%	39%	1%	45%	18%
MN	34%	32%	38%	24%	32%	28%	4%	36%	23%
NH	41%	38%	43%	23%	35%	37%	1%	42%	22%
PA	22%	27%	36%	29%	42%	35%	4%	49%	16%
SD	37%	43%	44%	27%	50%	41%	4%	46%	13%
WA	41%	39%	45%	33%	38%	40%	2%	46%	12%
Weighted NCI-IDD Average	31%	32%	39%	28%	40%	38%	5%	43%	17%

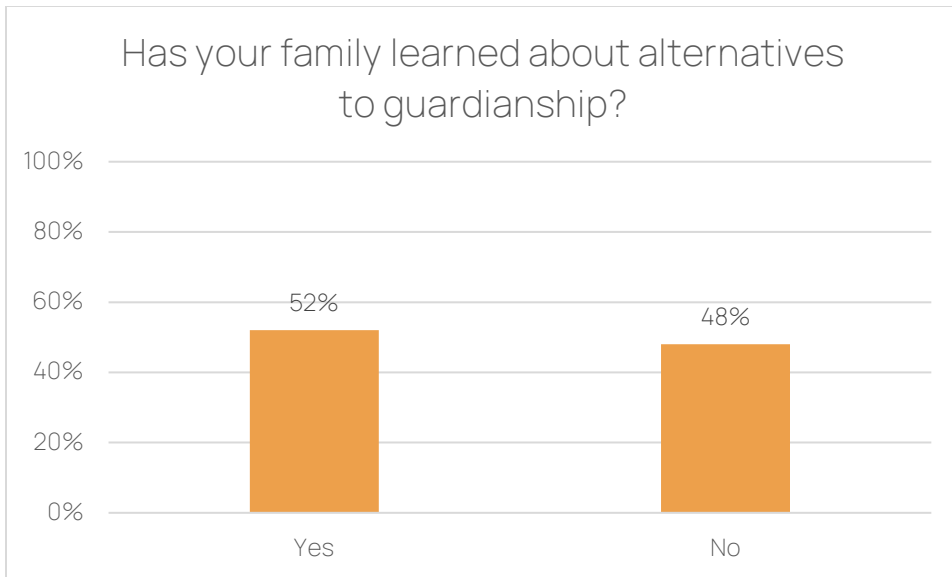


Table 32. Has your family learned about alternatives to guardianship?

Significantly Above Average

State	Yes	No	N
MN	67%	33%	341
SD	64%	36%	374

Within Average Range

State	Yes	No	N
NH	58%	42%	318
AZ	53%	47%	180
PA	53%	47%	448
WA	52%	48%	108
IN	52%	48%	367
Weighted NCI-IDD Average	51%	49%	6016
GA	47%	53%	299
CA	46%	54%	3447
DE	44%	56%	136

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

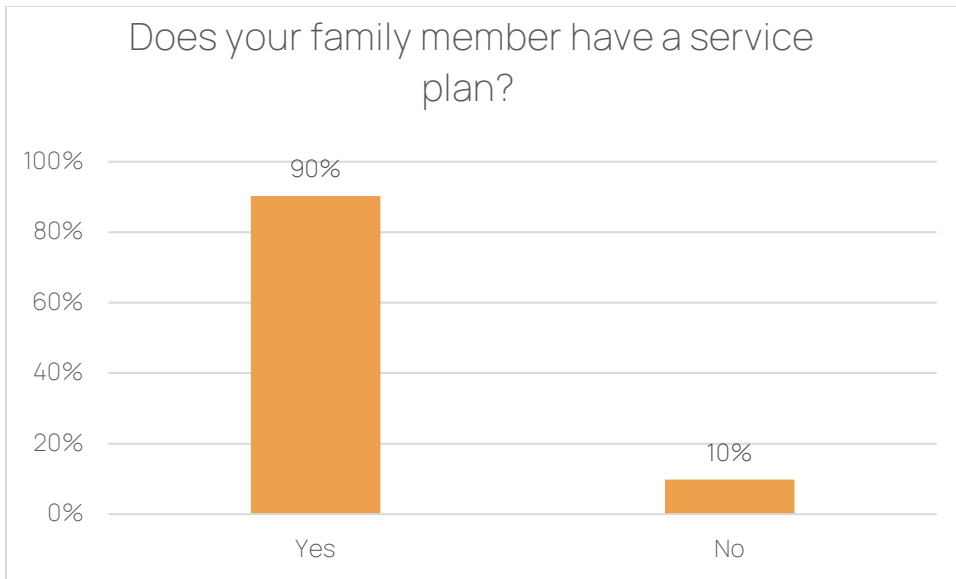


Table 33. Does your family member have a service plan?

Significantly Above Average

State	Yes	No	N
PA	96%	4%	597
NH	94%	6%	347

Within Average Range

State	Yes	No	N
WA	93%	7%	112
SD	90%	10%	375
Weighted NCI-IDD Average	90%	10%	6197
CA	90%	10%	3517
MN	89%	11%	350
IN	89%	11%	354
GA	87%	13%	263

Significantly Below Average

State	Yes	No	N
DE	71%	29%	116
AZ	70%	30%	168

Please note: Data for this question are reported by the respondent based on their understanding of their family member’s services and supports.

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

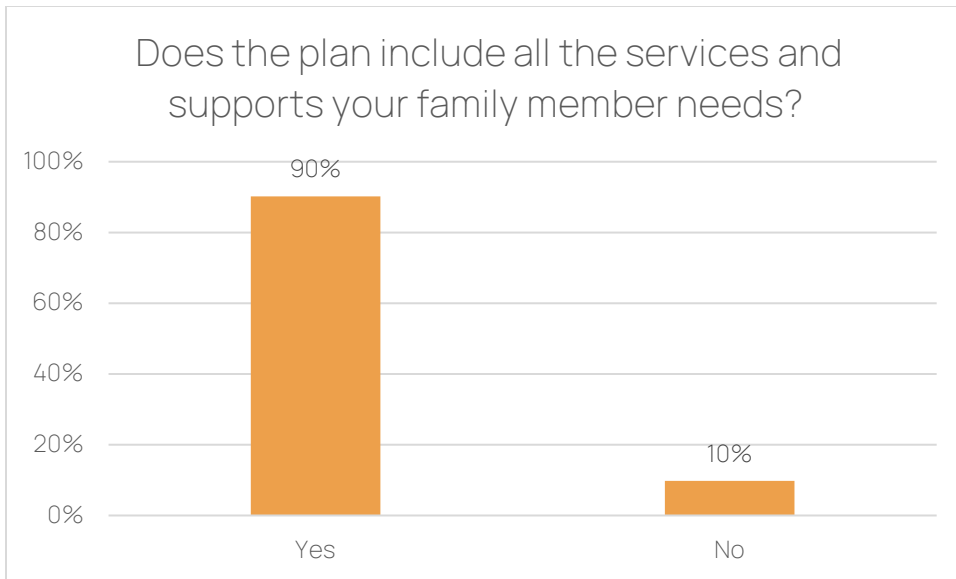


Table 34. Does the plan include all the services and supports your family member needs?

Significantly Above Average

State	Yes	No	N
AZ	97%	3%	107
MN	96%	4%	294
PA	96%	4%	528
SD	95%	5%	309

Within Average Range

State	Yes	No	N
DE	90%	10%	73
Weighted NCI-IDD Average	90%	10%	4896
IN	89%	11%	287
GA	88%	12%	195
NH	88%	12%	303
CA	87%	13%	2712
WA	80%	20%	88

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

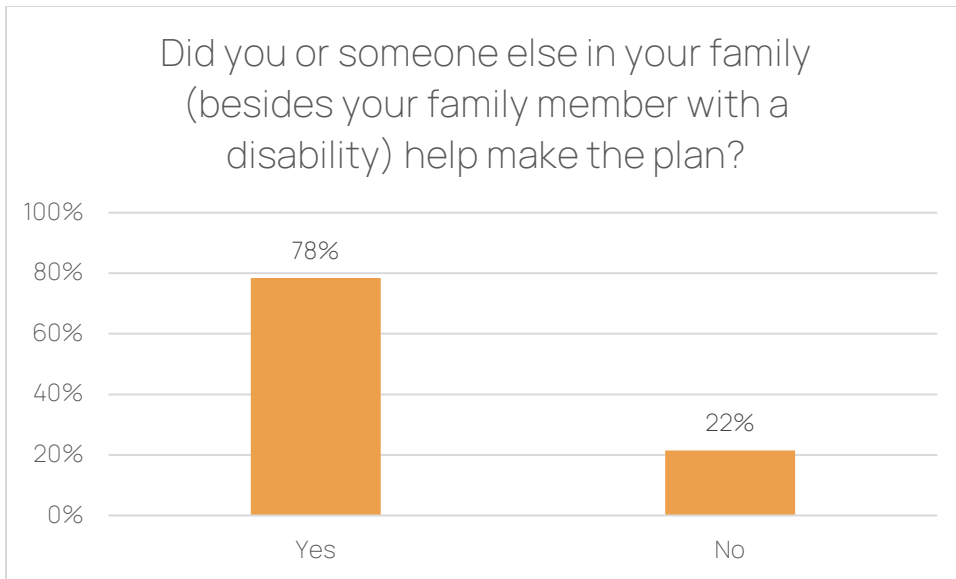


Table 35. Did you or someone else in your family (besides your family member with a disability) help make the plan?

Significantly Above Average

State	Yes	No	N
DE	91%	9%	76
MN	89%	11%	297
AZ	89%	11%	107
NH	88%	12%	313
SD	87%	13%	323
IN	87%	13%	295
GA	85%	15%	212

Within Average Range

State	Yes	No	N
WA	84%	16%	99
Weighted NCI-IDD Average	78%	22%	5204
CA	75%	25%	2944

Significantly Below Average

State	Yes	No	N
PA	72%	28%	538

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

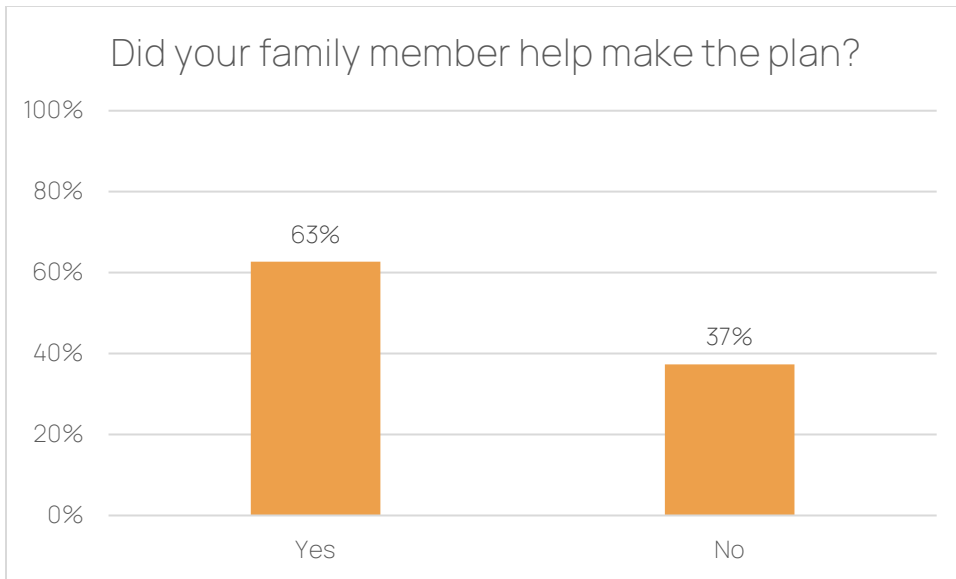


Table 36. Did your family member help make the plan?

Significantly Above Average

State	Yes	No	N
SD	82%	18%	307
MN	75%	25%	294

Within Average Range

State	Yes	No	N
GA	70%	30%	207
IN	68%	32%	292
WA	63%	37%	5030
NH	64%	36%	302
CA	63%	37%	2829
Weighted NCI-IDD Average	63%	37%	5030
DE	59%	41%	75
AZ	57%	43%	108

Significantly Below Average

State	Yes	No	N
PA	48%	52%	520

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

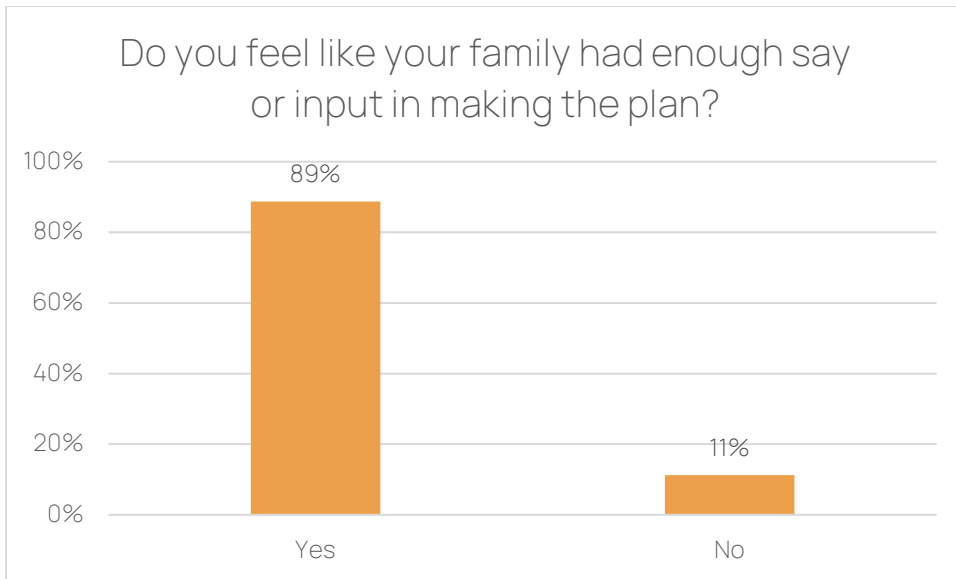


Table 37. Do you feel like your family had enough say or input in making the plan?

New question in 2021-22

Significantly Above Average

State	Yes	No	N
MN	97%	3%	300
SD	96%	4%	305
NH	94%	6%	297
IN	94%	6%	286

Within Average Range

State	Yes	No	N
DE	92%	8%	71
AZ	91%	9%	105
Weighted NCI-IDD Average	89%	11%	4900
GA	89%	11%	203
PA	88%	12%	509
CA	86%	14%	2728
WA	84%	16%	96

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

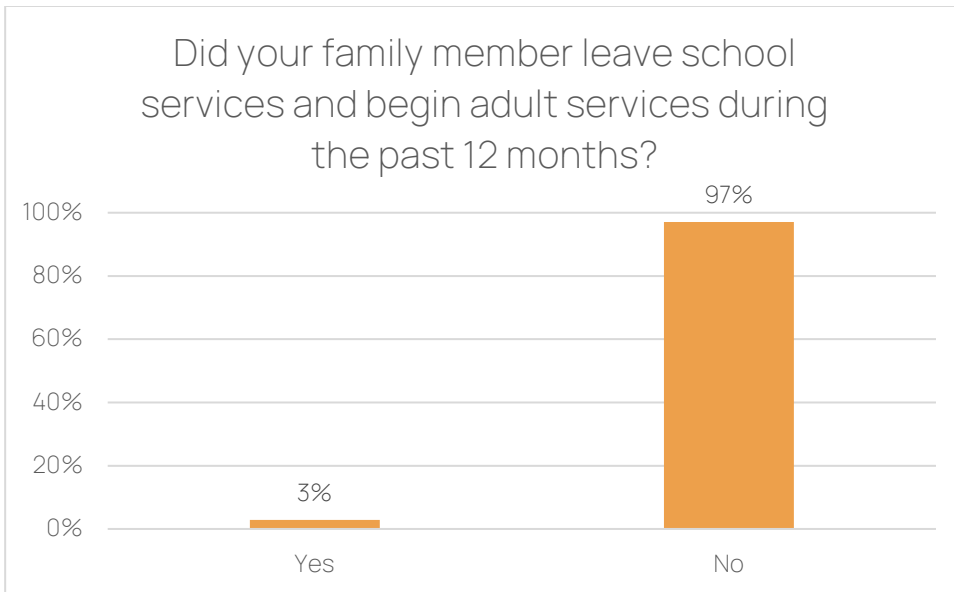


Table 38. Did your family member leave school services and begin adult services during the past 12 months?

Within Average Range

State	Yes	No	N
CA	4%	96%	4040
WA	3%	97%	115
Weighted NCI-IDD Average	3%	97%	7142
AZ	2%	98%	208
NH	1%	99%	375
DE	1%	99%	162

Significantly Below Average

State	Yes	No	N
PA	1%	99%	616
SD	1%	99%	459
IN	1%	99%	443
MN	1%	99%	395
GA	0%	100%	329

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

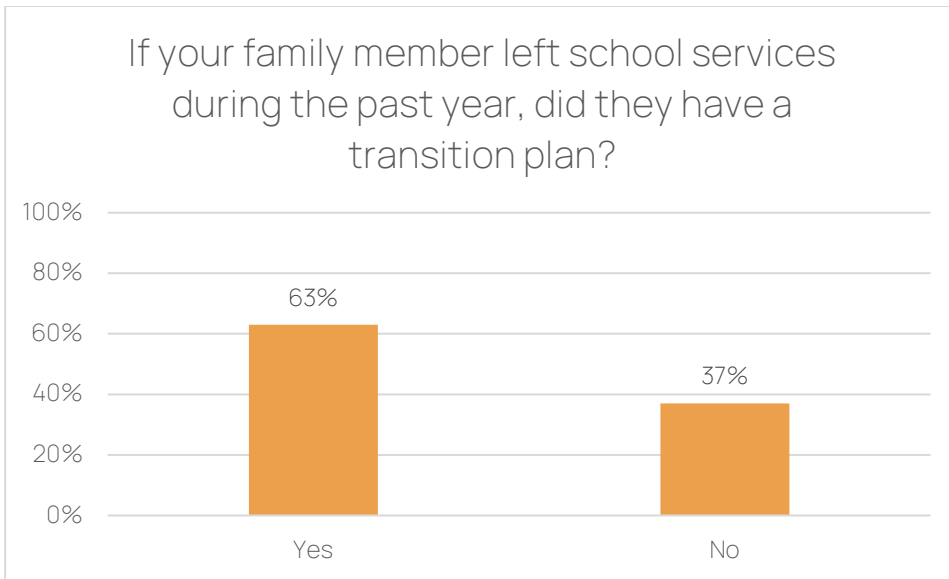


Table 39. If your family member left school services during the past 12 months, did your family member have a transition plan?

Within Average Range

State	Yes	No	N
Weighted NCI-IDD Average	63%	37%	112
CA	59%	41%	94

Table note: States not displayed due to low counts: AZ, DE, GA, IN, MN, NH, PA, SD, WA

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

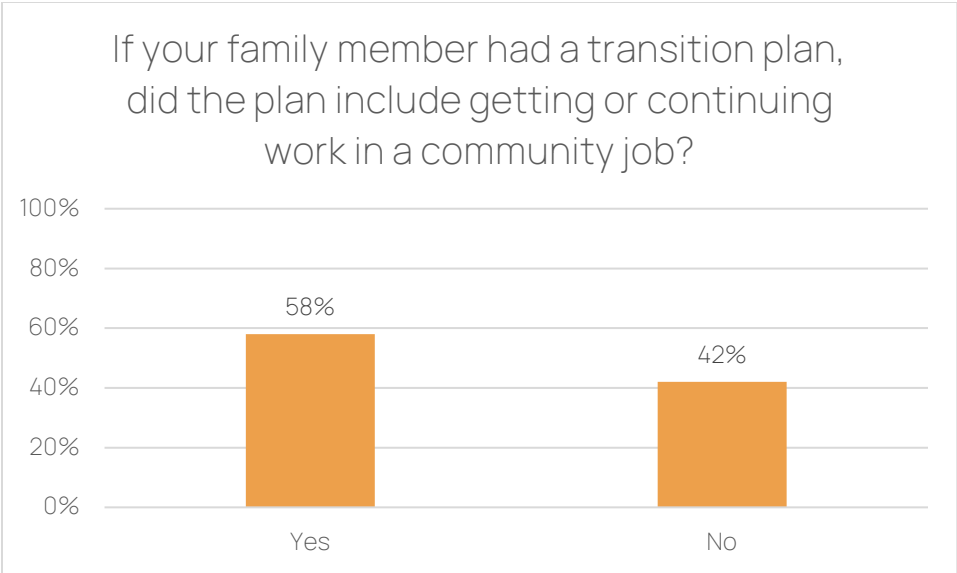


Table 40. If your family member had a transition plan, did the transition plan include getting or continuing work in a community job?

Within Average Range

State	Yes	No	N
Weighted NCI-IDD Average	58%	42%	54
CA	55%	45%	42

Table note: States not displayed due to low counts: AZ, DE, GA, IN, MN, NH, PA, SD, WA

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](#)

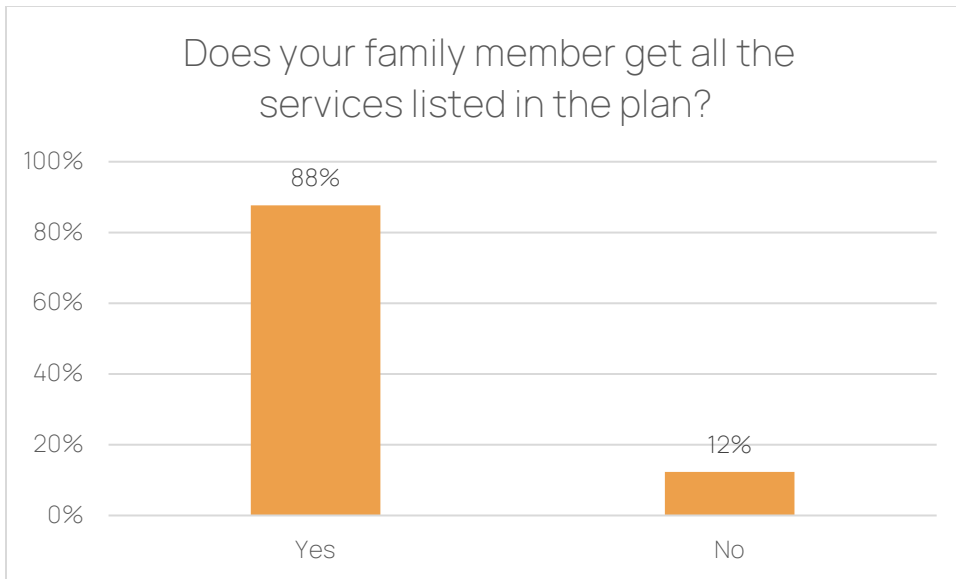


Table 41. Does your family member get all the services listed in the plan?

Significantly Above Average

State	Yes	No	N
AZ	94%	6%	104
MN	92%	8%	288
PA	92%	8%	484

Within Average Range

State	Yes	No	N
SD	91%	9%	295
CA	88%	12%	2547
Weighted NCI-IDD Average	88%	12%	4623
NH	87%	13%	296
DE	80%	20%	65
GA	80%	20%	180

Significantly Below Average

State	Yes	No	N
IN	79%	21%	276
WA	73%	27%	88

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

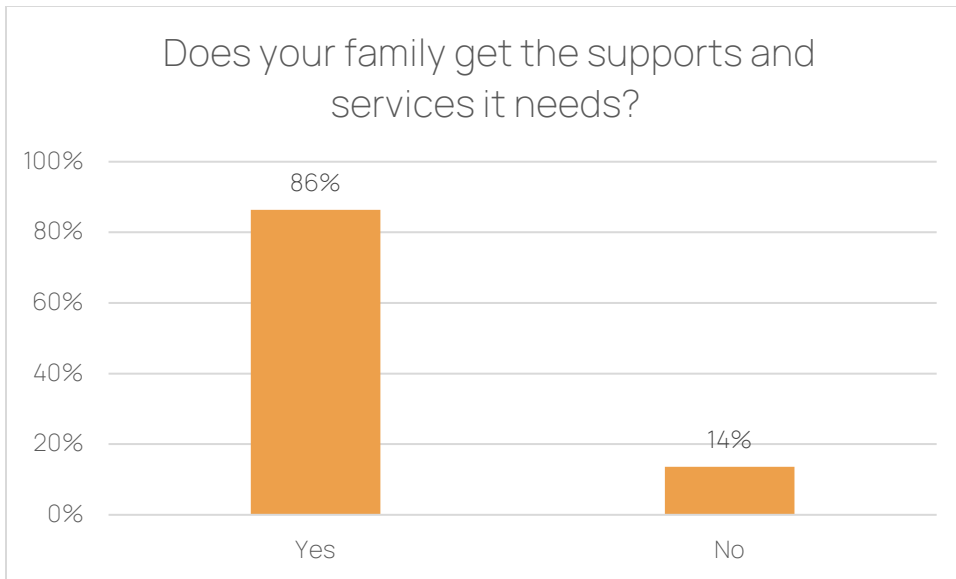


Table 42. Does your family get the supports and services it needs?
Significantly Above Average

State	Yes	No	N
SD	95%	5%	439
DE	93%	7%	147
PA	92%	8%	572

Within Average Range

State	Yes	No	N
MN	90%	10%	383
AZ	89%	11%	199
GA	87%	13%	292
Weighted NCI-IDD Average	86%	14%	6592
NH	86%	14%	359
CA	85%	15%	3675
IN	84%	16%	419

Significantly Below Average

State	Yes	No	N
WA	74%	26%	110

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

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

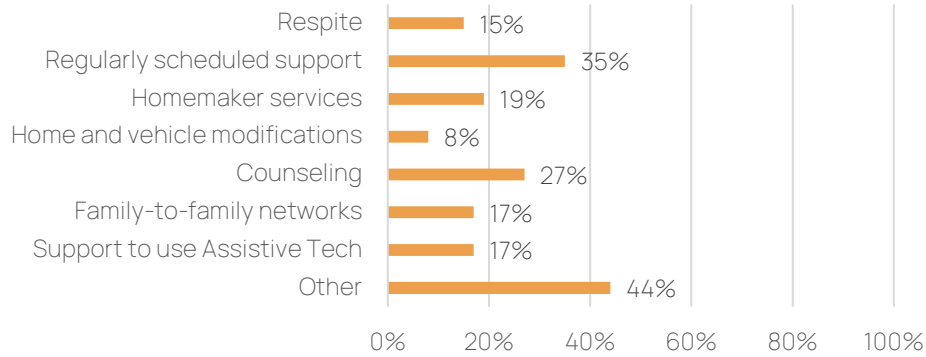


Table 43. If family does not get the support and services needed, what additional services does your family need?

Categories are not mutually exclusive, therefore N is not shown

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-Family Networks	Support or Training to Use Assistive Technology	Other
CA	10%	30%	19%	7%	34%	14%	17%	44%
GA	17%	20%	17%	7%	20%	10%	10%	60%
IN	15%	42%	20%	7%	15%	12%	24%	41%
MN	15%	44%	9%	9%	18%	9%	9%	41%
NH	24%	27%	13%	7%	13%	16%	9%	53%
PA	15%	40%	5%	5%	25%	33%	13%	40%
WA	29%	46%	39%	7%	18%	25%	21%	46%
AZ	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
DE	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
SD	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Weighted NCI-IDD Average	15%	35%	19%	8%	27%	17%	17%	44%

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

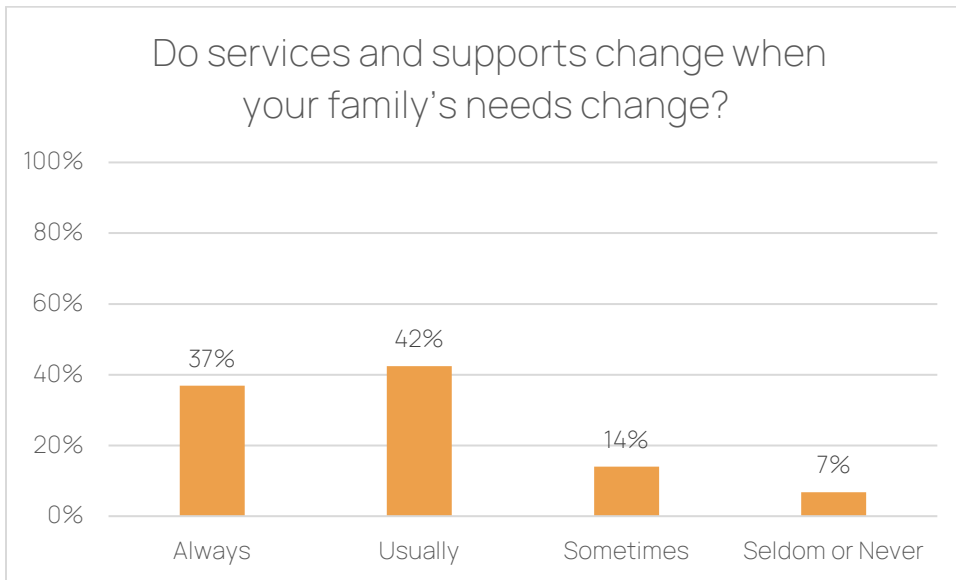


Table 44. Do services and supports change when your family's needs change?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MN	42%	45%	9%	4%	312
NH	42%	43%	11%	4%	265
PA	40%	42%	13%	4%	413
SD	40%	46%	12%	2%	341
CA	37%	40%	15%	7%	2684
Weighted NCI-IDD Average	37%	42%	14%	7%	4954
IN	35%	43%	15%	6%	352
AZ	35%	46%	13%	6%	156
GA	33%	47%	13%	7%	233
DE	29%	54%	13%	4%	112

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	19%	43%	20%	18%	86

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

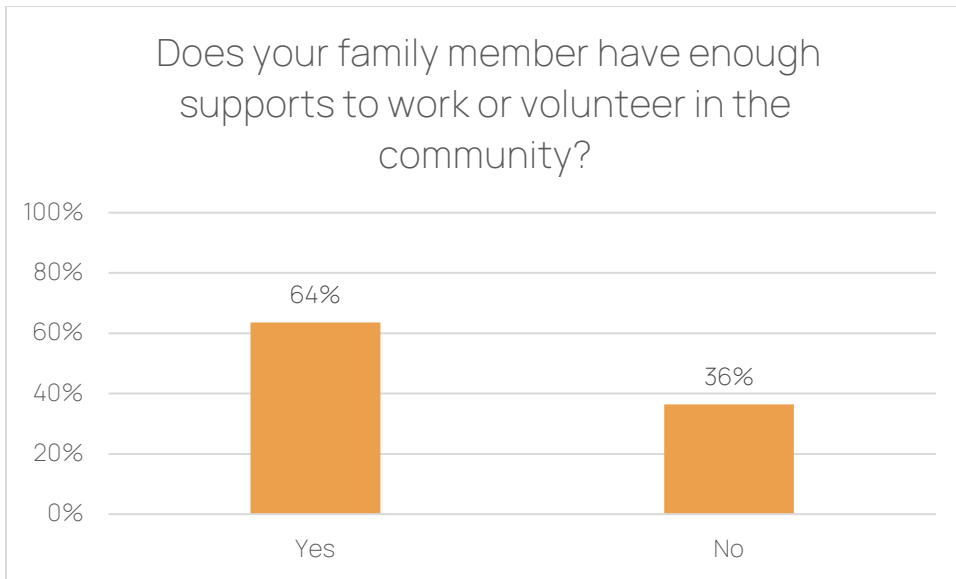


Table 45. Does your family member have enough supports to work or volunteer in the community? (These types of supports might include support workers, community resources, transportation)

Significantly Above Average

State	Yes	No	N
SD	80%	20%	330
MN	71%	29%	310

Within Average Range

State	Yes	No	N
NH	67%	33%	258
PA	66%	34%	342
AZ	65%	35%	118
Weighted NCI-IDD Average	64%	36%	4713
CA	62%	38%	2653
IN	61%	39%	294
WA	61%	39%	89
DE	56%	44%	104
GA	55%	45%	215

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

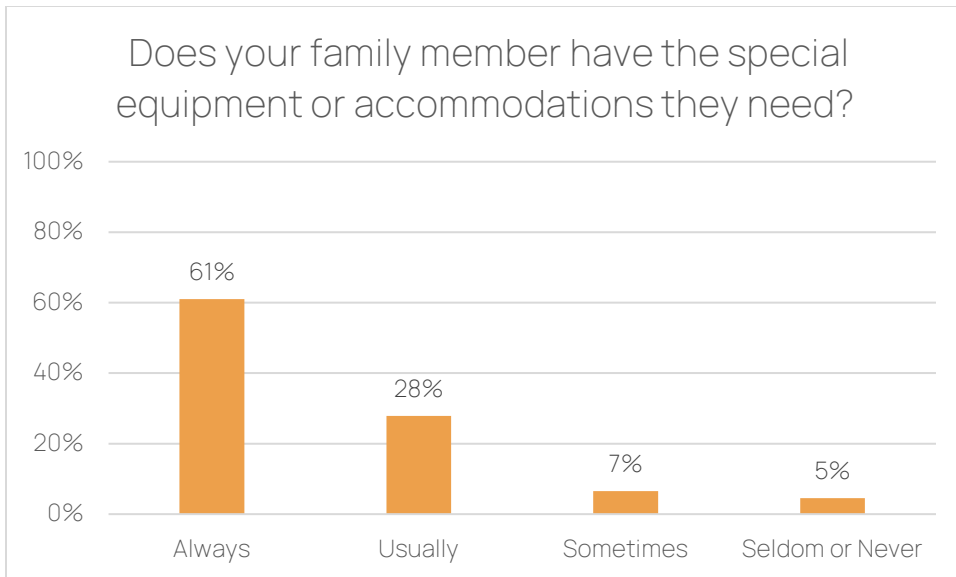


Table 46. Does your family member have the special equipment or accommodations that they need?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	68%	25%	5%	2%	405

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	63%	31%	4%	2%	118
NH	62%	30%	5%	3%	196
IN	62%	27%	6%	4%	247
CA	61%	26%	7%	6%	1986
Weighted NCI-IDD Average	61%	28%	7%	5%	3781
SD	60%	32%	4%	4%	278
MN	59%	30%	7%	4%	222
DE	57%	32%	8%	3%	95
WA	46%	33%	10%	11%	61

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	49%	40%	10%	1%	173

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

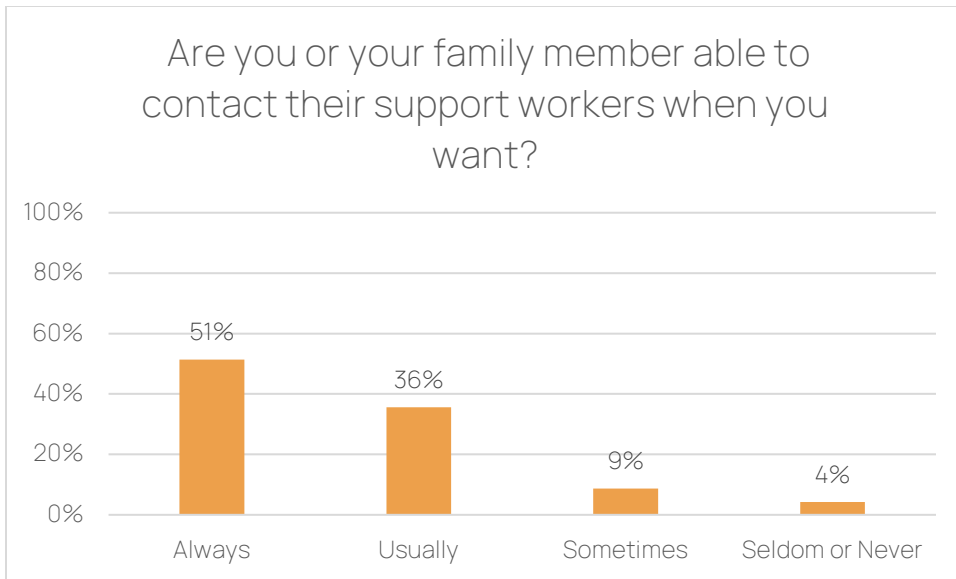


Table 47. Are you or your family member able to contact support workers when you want?
Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	62%	31%	4%	3%	383
PA	60%	34%	5%	1%	590

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	54%	36%	7%	3%	363
SD	53%	42%	5%	0%	465
AZ	52%	37%	7%	3%	203
Weighted NCI-IDD Average	51%	36%	9%	4%	6755
GA	50%	37%	9%	3%	310
CA	48%	36%	10%	6%	3744
IN	46%	38%	11%	5%	431
DE	43%	40%	14%	3%	162
WA	40%	40%	13%	7%	104

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

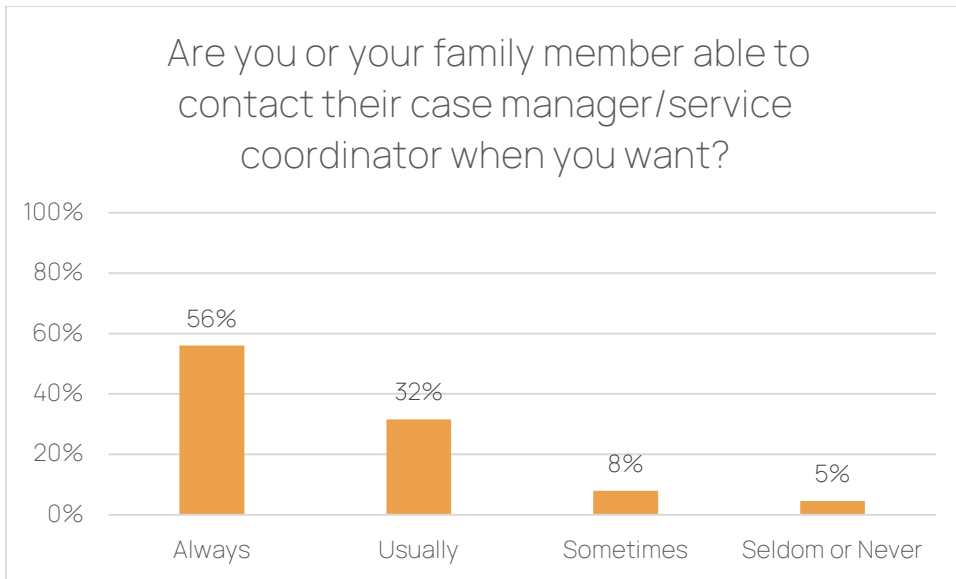


Table 48. Are you or your family member able to contact the case manager/service coordinator when you want?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	71%	26%	2%	1%	403
IN	67%	26%	6%	1%	453
SD	64%	32%	3%	0%	478
PA	63%	30%	6%	1%	604

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	62%	31%	5%	2%	378
AZ	59%	32%	5%	4%	207
Weighted NCI-IDD Average	56%	32%	8%	5%	7139
GA	51%	34%	11%	4%	337

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	50%	33%	10%	7%	4001
WA	41%	41%	9%	9%	114
DE	41%	46%	9%	4%	164

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

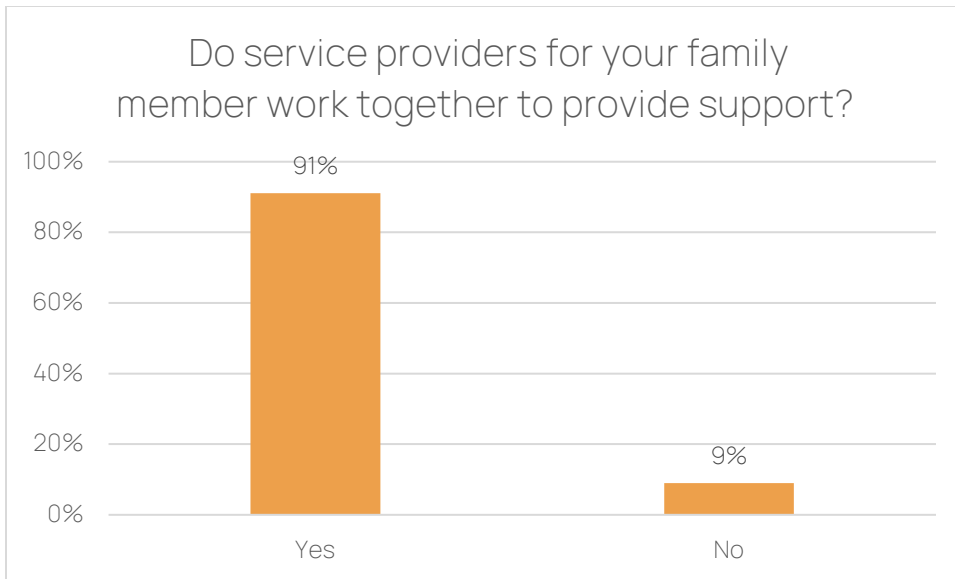


Table 49. Do service providers for your family member work together to provide support?
Significantly Above Average

State	Yes	No	N
SD	97%	3%	357
NH	96%	4%	265
PA	95%	5%	402

Within Average Range

State	Yes	No	N
AZ	94%	6%	154
DE	93%	7%	124
MN	93%	7%	296
GA	93%	7%	228
IN	92%	8%	336
Weighted NCI-IDD Average	91%	9%	4951
CA	90%	10%	2721
WA	79%	21%	68

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

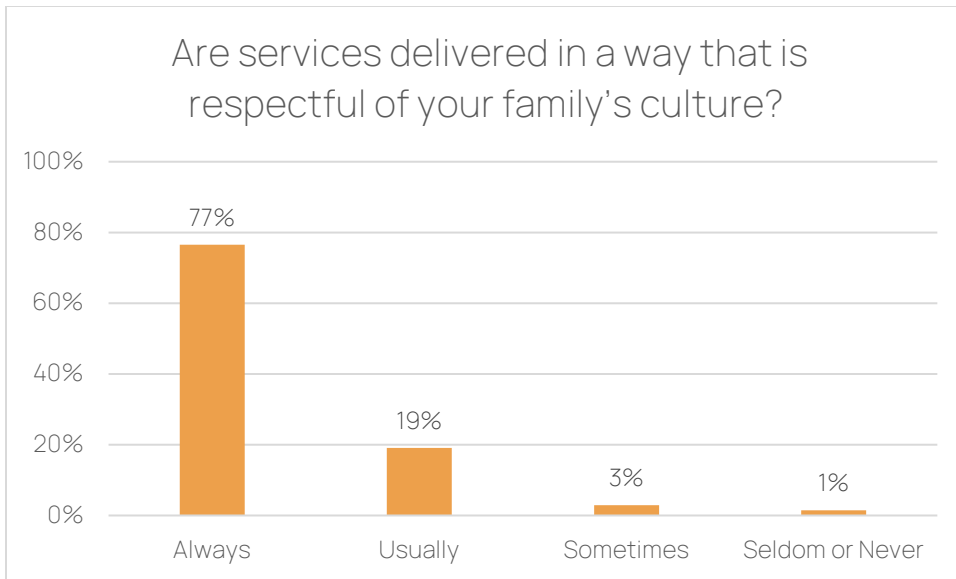


Table 50. Are services delivered in a way that is respectful of your family's culture?
Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	82%	16%	2%	0%	392

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	81%	16%	3%	1%	357
CA	79%	17%	2%	2%	3785
SD	78%	21%	1%	0%	467
PA	77%	19%	3%	1%	593
Weighted NCI-IDD Average	77%	19%	3%	1%	6836
AZ	71%	21%	6%	1%	202
DE	69%	26%	4%	2%	162
WA	67%	25%	6%	2%	109

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	70%	23%	6%	1%	440
GA	68%	27%	4%	1%	329

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

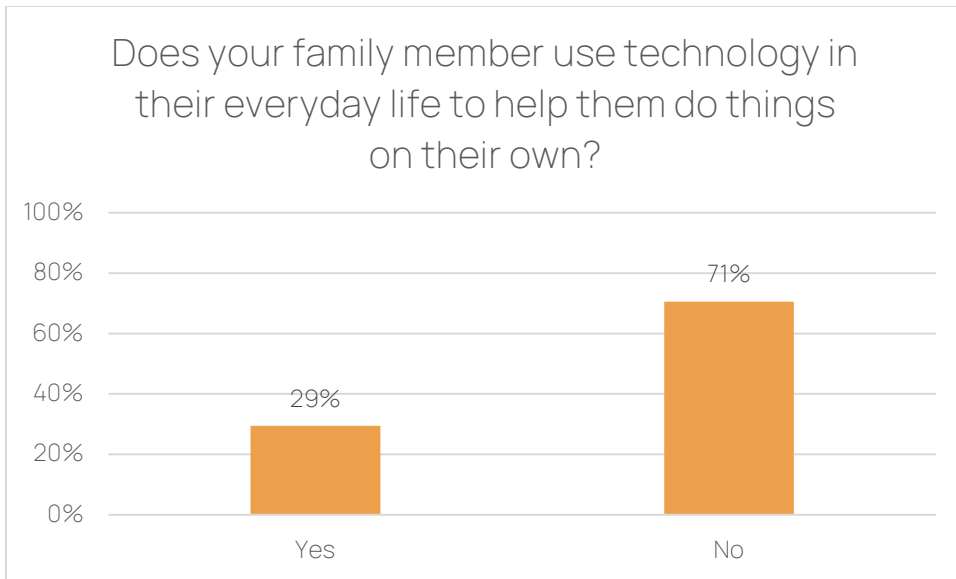


Table 51. Does your family member use technology in their everyday life to help them do things on their own?

New question in 2021-22

Significantly Above Average

State	Yes	No	N
CA	36%	64%	3874

Within Average Range

State	Yes	No	N
WA	31%	69%	110
SD	30%	70%	439
MN	30%	70%	392
Weighted NCI-IDD Average	29%	71%	6872
IN	27%	73%	433
NH	26%	74%	353
AZ	23%	77%	207

Significantly Below Average

State	Yes	No	N
GA	18%	82%	322
PA	18%	82%	579
DE	17%	83%	163

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

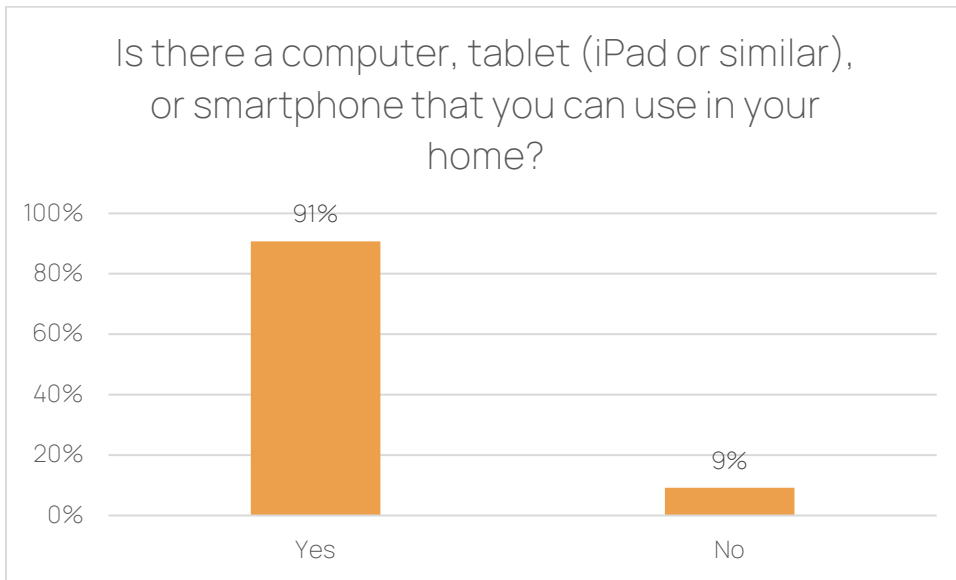


Table 52. Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?

New question in 2021-22

Significantly Above Average

State	Yes	No	N
DE	96%	4%	164

Within Average Range

State	Yes	No	N
WA	93%	7%	115
MN	92%	8%	393
NH	92%	8%	378
CA	91%	9%	4251
Weighted NCI-IDD Average	91%	9%	7421
IN	90%	10%	461
GA	90%	10%	350
PA	90%	10%	616
AZ	89%	11%	215
SD	88%	12%	478

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

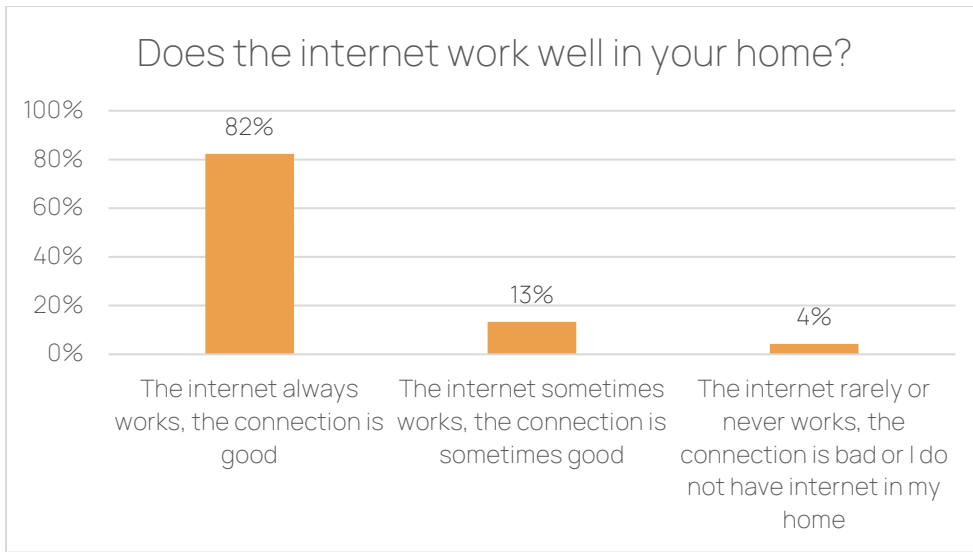


Table 53. Does the internet work well in your home?

New question in 2021-22

Within Average Range

State	The internet always works, the connection is good	The internet sometimes works, the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
DE	86%	11%	3%	163
SD	84%	10%	6%	460
CA	84%	13%	4%	4032
NH	84%	12%	4%	366
PA	84%	11%	5%	595
MN	83%	13%	4%	385
Weighted NCI-IDD Average	82%	13%	4%	7080
AZ	80%	16%	3%	209
GA	79%	15%	6%	326
WA	77%	21%	3%	111

Significantly Below Average

State	The internet always works, the connection is good	The internet sometimes works, the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
IN	75%	18%	7%	433

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](#)

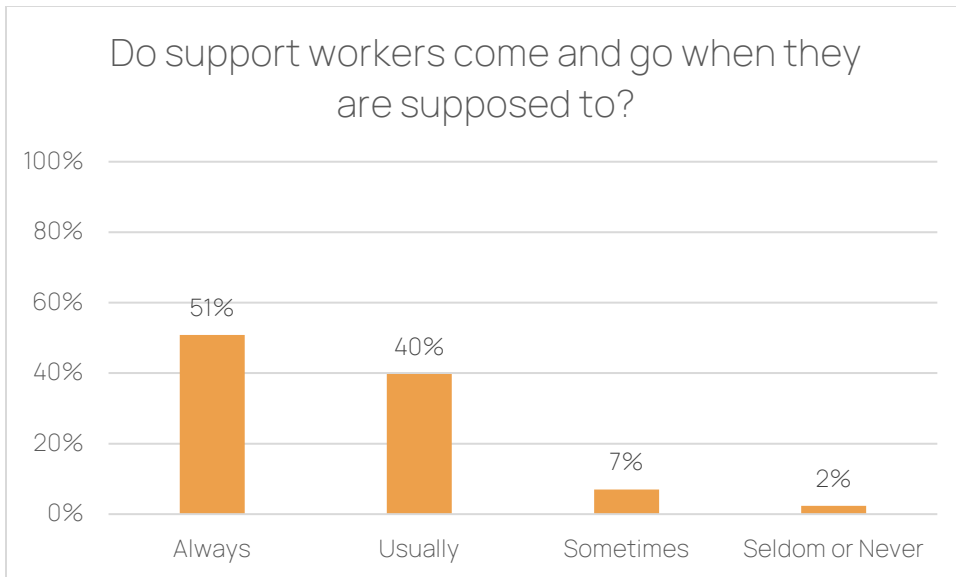


Table 54. Do support workers come and go when they are supposed to?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	57%	38%	4%	1%	341
AZ	56%	33%	7%	4%	159
NH	56%	38%	6%	1%	247
MN	55%	38%	6%	1%	304
GA	51%	38%	10%	1%	207
Weighted NCI-IDD Average	51%	40%	7%	2%	4689
CA	51%	39%	7%	3%	2603
SD	50%	45%	6%	0%	327
DE	39%	53%	7%	1%	85
WA	37%	44%	13%	5%	72

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	40%	48%	10%	2%	344

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

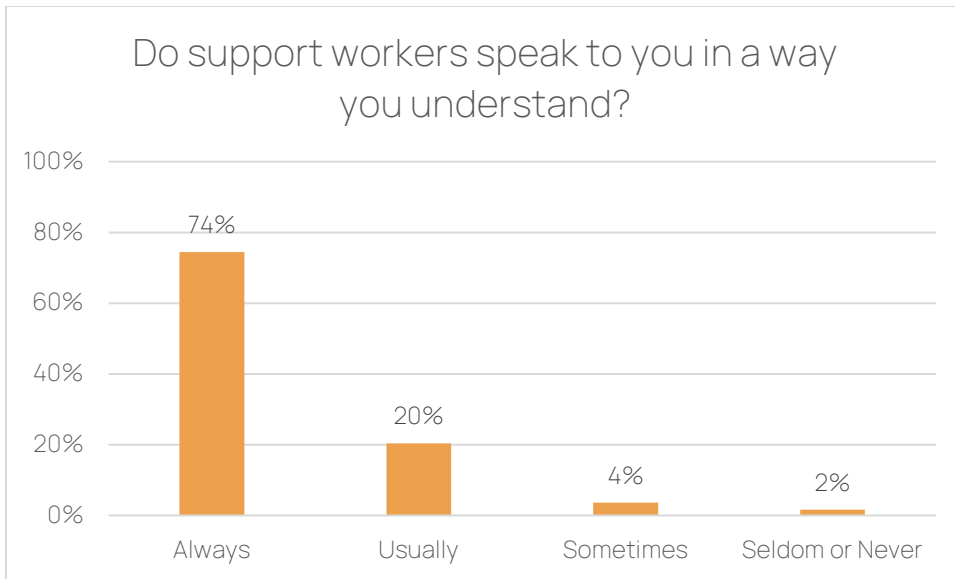


Table 55. Do support workers speak to you in a way you understand?
Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	79%	17%	3%	1%	600

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	78%	20%	3%	0%	352
MN	77%	21%	3%	0%	383
CA	75%	19%	4%	3%	3750
Weighted NCI-IDD Average	74%	20%	4%	2%	6763
SD	73%	24%	2%	1%	466
GA	70%	23%	5%	1%	313
IN	70%	24%	5%	1%	438
AZ	70%	26%	3%	2%	197
WA	68%	24%	6%	2%	104

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
DE	63%	32%	4%	1%	160

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

If your family member does not communicate verbally, are there support workers who can communicate with them?

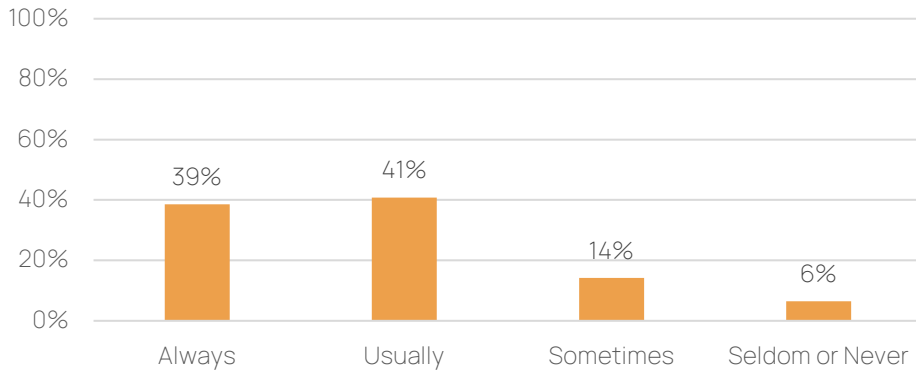


Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	51%	36%	11%	2%	61
SD	51%	40%	8%	1%	87
DE	44%	41%	15%	0%	41
CA	43%	38%	13%	6%	684
Weighted NCI-IDD Average	39%	41%	14%	6%	1295
PA	38%	42%	15%	6%	163
AZ	37%	34%	21%	8%	38
IN	32%	41%	17%	10%	81
GA	31%	37%	31%	0%	51
MN	30%	57%	9%	4%	70
WA	n/a	n/a	n/a	n/a	n/a

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

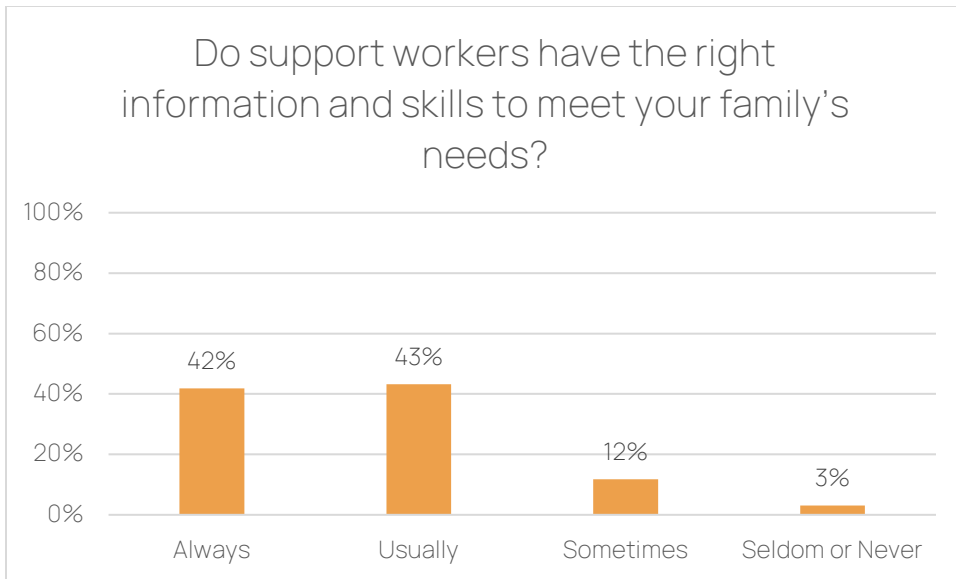


Table 57. Do support workers have the right information and skills to meet your family's needs?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	45%	46%	7%	1%	340
PA	45%	41%	11%	3%	566
CA	45%	42%	10%	3%	3499
AZ	42%	43%	11%	4%	198
Weighted NCI-IDD Average	42%	43%	12%	3%	6382
SD	41%	50%	8%	1%	440
MN	41%	46%	11%	2%	371
GA	40%	42%	16%	1%	299

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	35%	46%	17%	2%	418
DE	29%	47%	21%	3%	156
WA	22%	47%	21%	11%	95

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

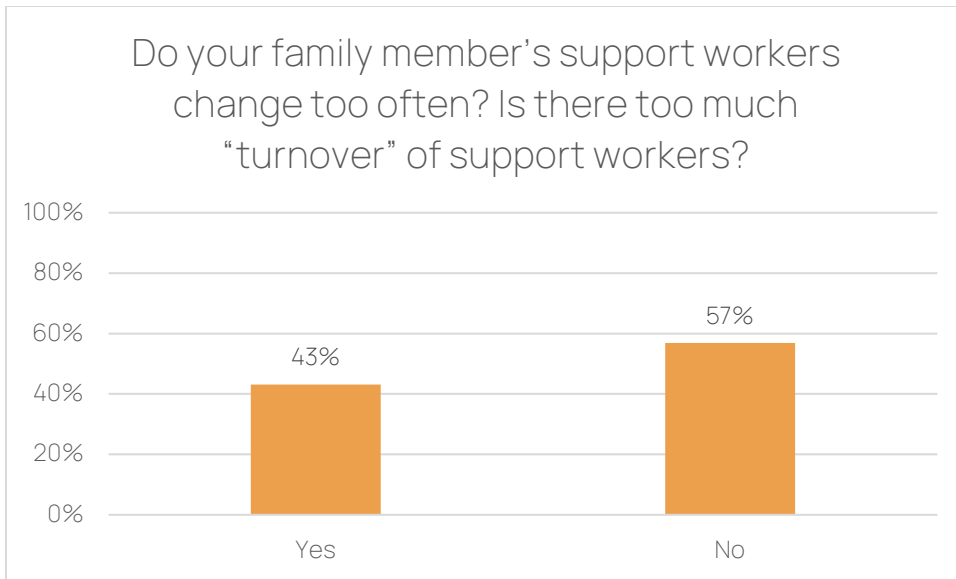


Table 58. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

New question in 2021-22

Significantly Above Average

State	Yes	No	N
IN	51%	49%	399
PA	49%	51%	481

Within Average Range

State	Yes	No	N
WA	54%	46%	94
MN	49%	51%	348
SD	47%	53%	358
DE	45%	55%	139
AZ	44%	56%	178
GA	44%	56%	283
Weighted NCI-IDD Average	43%	57%	5781

Significantly Below Average

State	Yes	No	N
CA	37%	63%	3195
NH	34%	66%	306

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



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

New question in 2021-22

Significantly Above Average

State	Yes	No	N
PA	93%	7%	578
AZ	90%	10%	194
GA	90%	10%	288
SD	88%	12%	415
CA	86%	14%	3577
NH	86%	14%	330

Within Average Range

State	Yes	No	N
Weighted NCI-IDD Average	79%	21%	6418
IN	78%	22%	421
WA	72%	28%	95

Significantly Below Average

State	Yes	No	N
DE	40%	60%	151
MN	27%	73%	369

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](#)

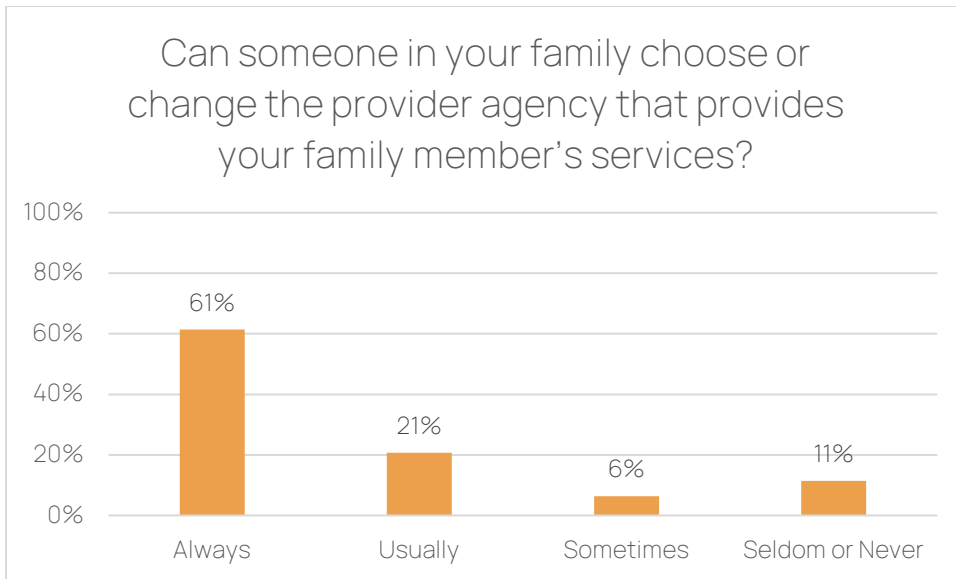


Table 60. Can someone in your family choose or change the provider agency that provides your family member's services?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	73%	18%	4%	5%	377

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NH	68%	21%	2%	9%	255
MN	67%	21%	4%	8%	291
GA	65%	19%	6%	10%	243
PA	64%	19%	6%	10%	359
AZ	62%	19%	6%	13%	154
Weighted NCI-IDD Average	61%	21%	6%	12%	4348
SD	61%	22%	3%	14%	295
DE	57%	24%	3%	16%	100
CA	57%	22%	8%	14%	2198
WA	49%	24%	11%	17%	76

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

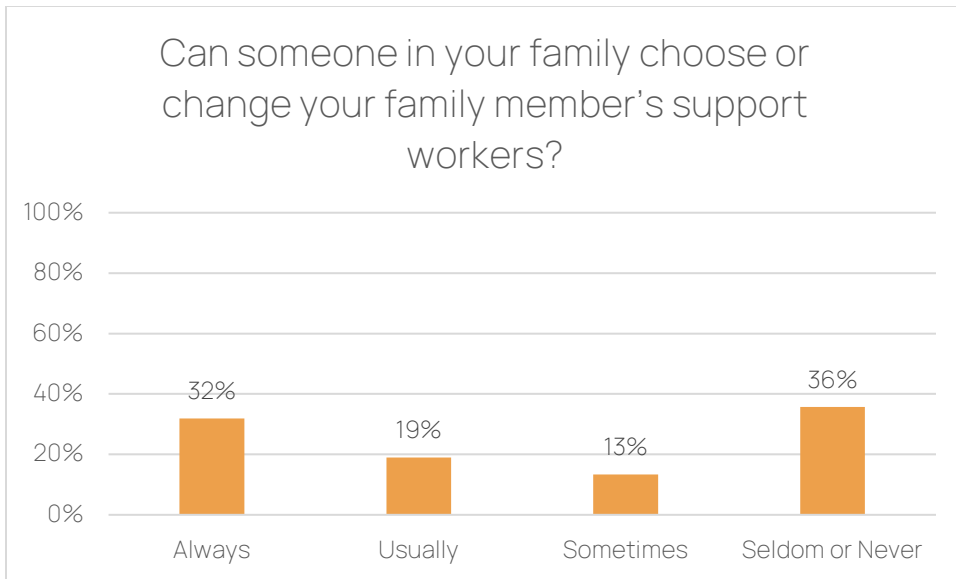


Table 61. Can someone in your family choose or change your family member's support workers?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	44%	22%	14%	21%	234
GA	43%	15%	10%	32%	212

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
IN	38%	19%	16%	26%	313
CA	36%	21%	13%	29%	2126
MN	33%	15%	10%	42%	261
Weighted NCI-IDD Average	32%	19%	13%	36%	3972
AZ	31%	23%	11%	35%	127
SD	27%	16%	13%	44%	244

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	20%	13%	14%	53%	305
DE	18%	15%	12%	55%	78
WA	15%	22%	19%	43%	72

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

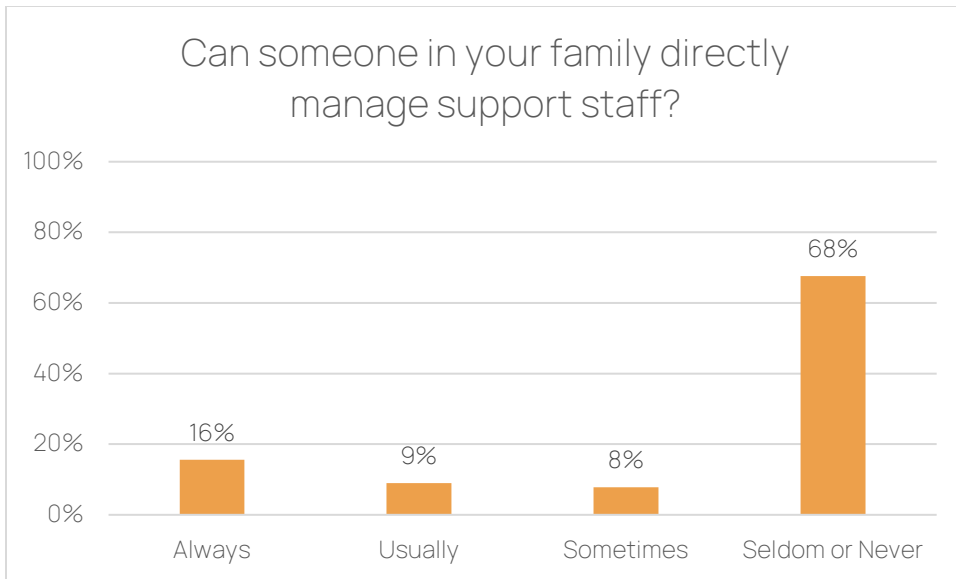


Table 62. Can someone in your family directly manage support staff?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	26%	10%	5%	59%	194

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
GA	20%	11%	7%	62%	206
CA	19%	11%	10%	59%	2113
MN	17%	9%	7%	68%	252
Weighted NCI-IDD Average	15%	9%	8%	68%	3911
IN	15%	11%	10%	64%	292
WA	11%	9%	7%	73%	82
AZ	12%	5%	4%	79%	112

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
DE	7%	2%	6%	84%	81
SD	7%	6%	5%	81%	247
PA	7%	2%	3%	88%	332

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

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

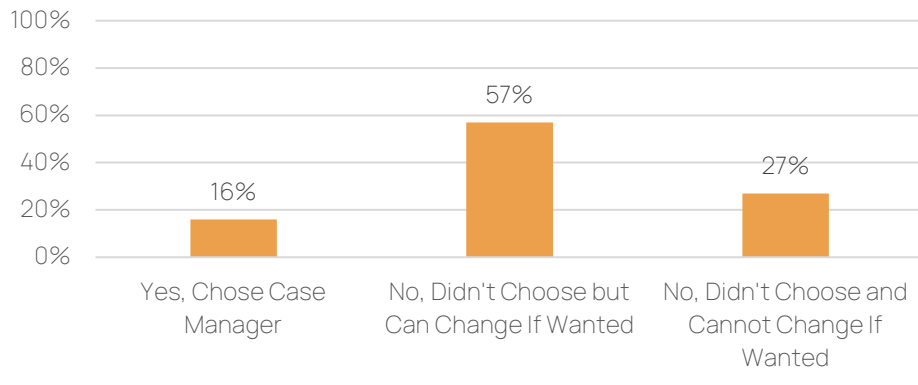


Table 63. Did you, your family member, or someone else in your family choose your family member's case manager?

Significantly Above Average

State	Yes, Chose Case Manager	No, Didn't Choose but Can Change If Wanted	No, Didn't Choose and Cannot Change If Wanted	N
IN	63%	30%	7%	417
SD	43%	42%	15%	380
NH	24%	67%	9%	332

Within Average Range

State	Yes, Chose Case Manager	No, Didn't Choose but Can Change If Wanted	No, Didn't Choose and Cannot Change If Wanted	N
PA	19%	48%	33%	457
GA	18%	51%	31%	272
Weighted NCI-IDD Average	16%	57%	27%	5788
AZ	12%	67%	21%	187
DE	11%	31%	58%	117

Significantly Below Average

State	Yes, Chose Case Manager	No, Didn't Choose but Can Change If Wanted	No, Didn't Choose and Cannot Change If Wanted	N
CA	11%	63%	27%	3195
MN	7%	67%	25%	329
WA	2%	53%	45%	102

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](#)

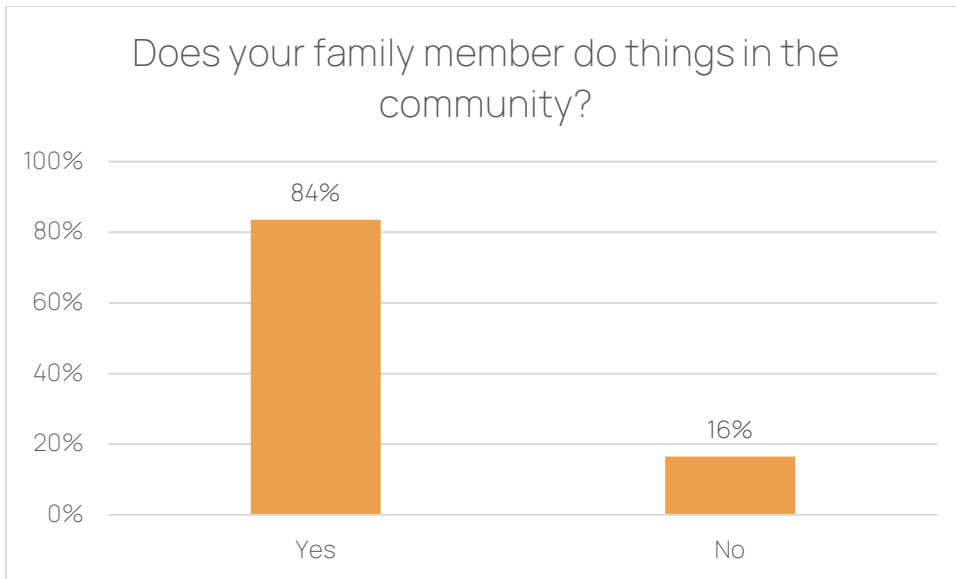


Table 64. Does your family member do things in the community?

Question changed in 2021-22

Significantly Above Average

State	Yes	No	N
MN	94%	6%	394
SD	94%	6%	472

Within Average Range

State	Yes	No	N
DE	88%	12%	161
NH	87%	13%	372
IN	85%	15%	445
PA	84%	16%	594
Weighted NCI-IDD Average	83%	17%	7037
GA	82%	18%	330
WA	81%	19%	106
CA	81%	19%	3960
AZ	76%	24%	203

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

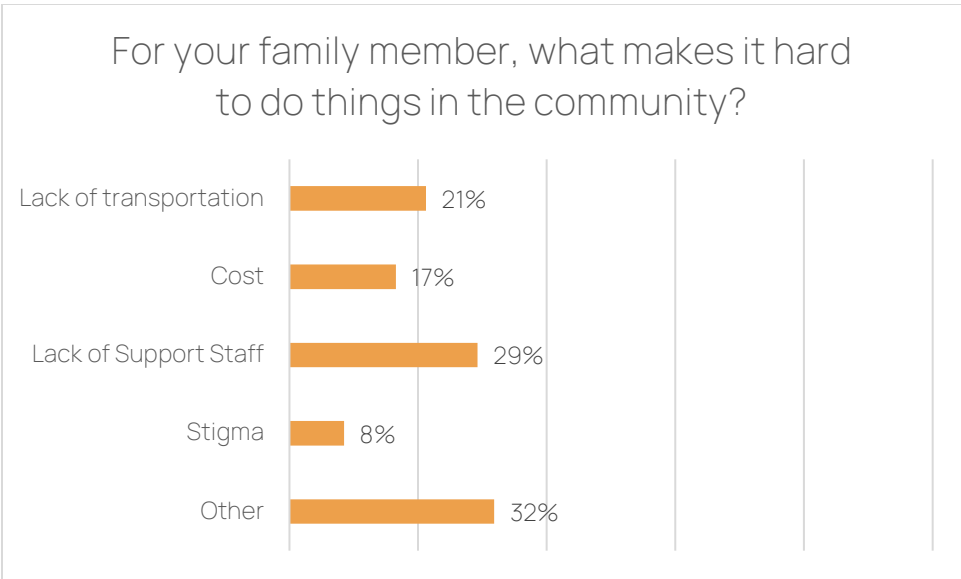


Table 65. For your family member, what makes it hard to do things in the community?

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

State	Lack of transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	20%	16%	26%	9%	51%
CA	24%	18%	21%	10%	29%
DE	10%	10%	24%	8%	31%
GA	14%	16%	24%	5%	25%
IN	23%	16%	42%	6%	26%
MN	22%	16%	40%	4%	23%
NH	18%	14%	22%	5%	36%
PA	12%	11%	39%	11%	49%
SD	23%	18%	33%	5%	18%
WA	27%	23%	43%	9%	35%
Weighted NCI-IDD Average	21%	17%	29%	8%	32%

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

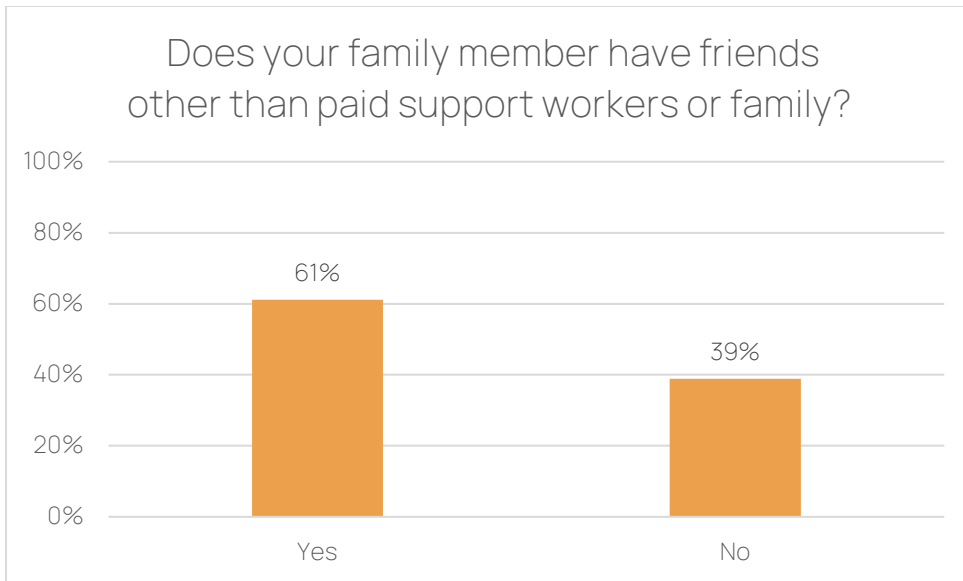


Table 66. Does your family member have friends other than paid support workers or family?
Significantly Above Average

State	Yes	No	N
SD	81%	19%	442
MN	72%	28%	377
GA	69%	31%	321

Within Average Range

State	Yes	No	N
IN	65%	35%	433
Weighted NCI-IDD Average	61%	39%	6762
NH	61%	39%	356
CA	58%	42%	3802
WA	59%	41%	110
PA	58%	42%	561
AZ	58%	42%	205
DE	57%	43%	155

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

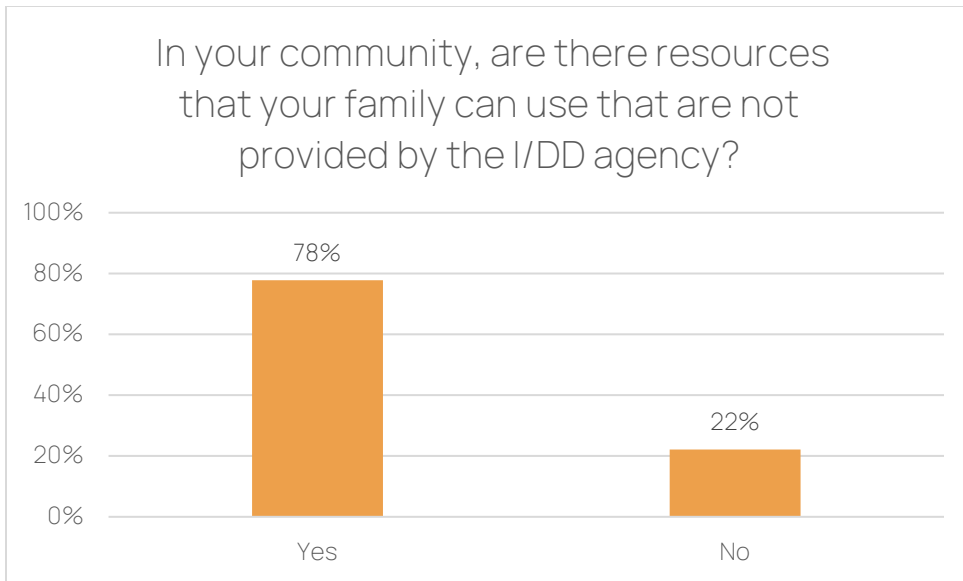


Table 67. In your community, are there resources or support that your family member can use that are not provided by the I/DD agency?

Significantly Above Average

State	Yes	No	N
MN	89%	11%	298
SD	84%	16%	301

Within Average Range

State	Yes	No	N
WA	81%	19%	86
IN	80%	20%	303
NH	79%	21%	273
Weighted NCI-IDD Average	78%	22%	4803
GA	76%	24%	225
PA	76%	24%	381
CA	75%	25%	2689
DE	71%	29%	98
AZ	70%	30%	149

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

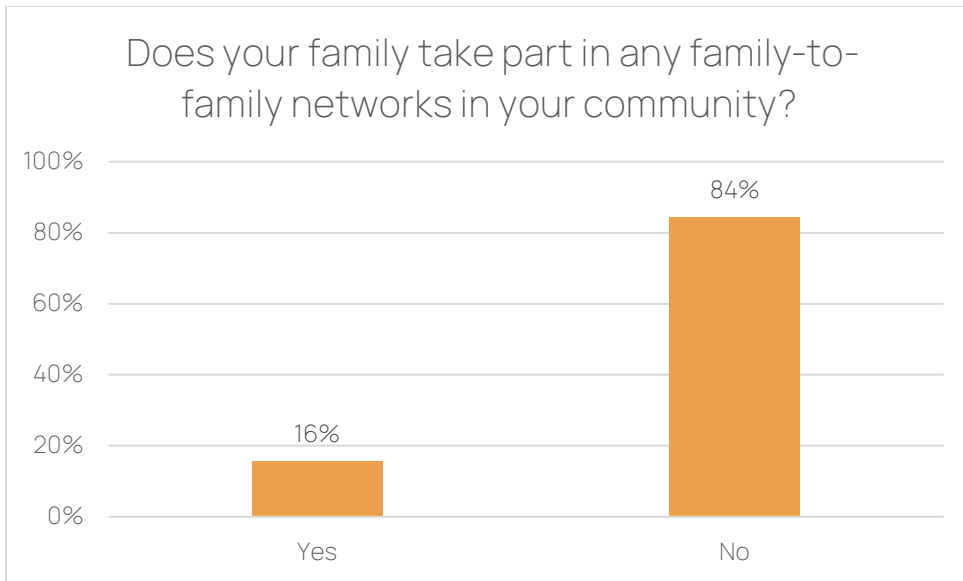


Table 68. Does your family take part in any family-to-family networks in your community?
Within Average Range

State	Yes	No	N
GA	18%	82%	264
IN	18%	82%	369
DE	17%	83%	150
PA	17%	83%	510
SD	16%	84%	376
AZ	16%	84%	189
Weighted NCI-IDD Average	16%	84%	6278
CA	15%	85%	3659
WA	14%	86%	106
MN	13%	87%	326
NH	12%	88%	329

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](#)

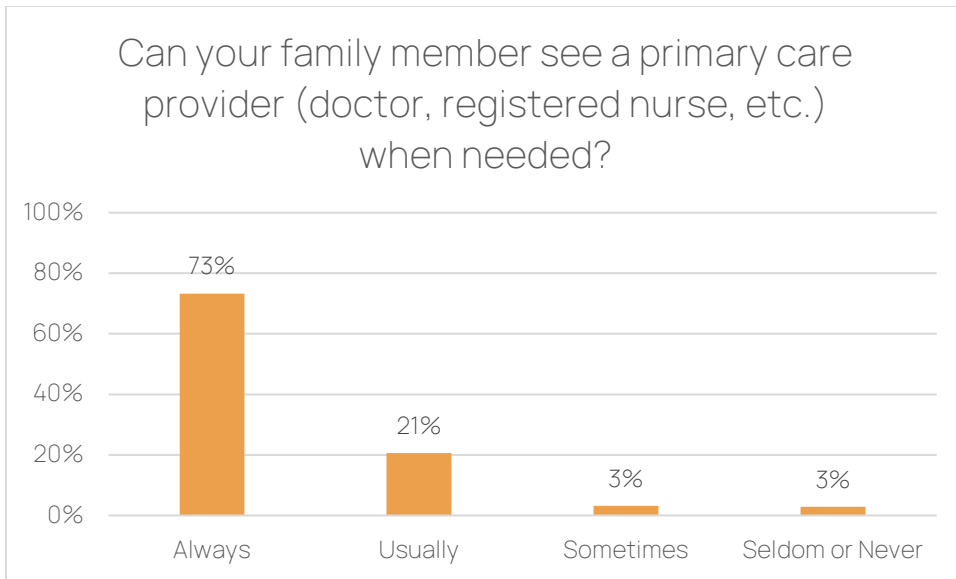


Table 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

New question in 2021-22

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
MN	82%	14%	2%	2%	397
NH	81%	16%	2%	1%	378
PA	81%	16%	1%	2%	610

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DE	77%	21%	1%	1%	164
SD	77%	22%	1%	0%	474
AZ	75%	16%	3%	6%	216
GA	74%	20%	3%	4%	338
Weighted NCI-IDD Average	73%	21%	3%	3%	7183
CA	70%	22%	5%	4%	4049
IN	70%	25%	3%	3%	445

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	61%	36%	3%	1%	112

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

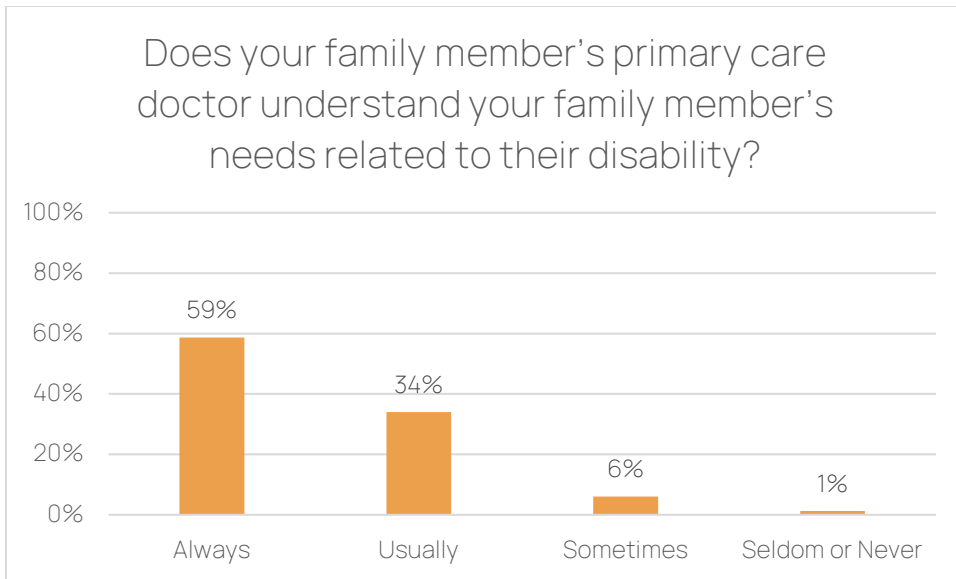


Table 70. Does your family member's primary care provider (doctor, registered nurse, etc.) understand your family member's needs related to their disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DE	66%	29%	4%	1%	153
GA	64%	27%	8%	0%	326
MN	62%	34%	3%	1%	393
PA	62%	33%	4%	1%	569
NH	61%	33%	6%	0%	366
AZ	59%	38%	3%	0%	209
Weighted NCI-IDD Average	59%	34%	6%	1%	6783
IN	58%	36%	5%	0%	423
CA	57%	34%	8%	2%	3795
SD	55%	39%	5%	0%	445
WA	54%	38%	7%	1%	104

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

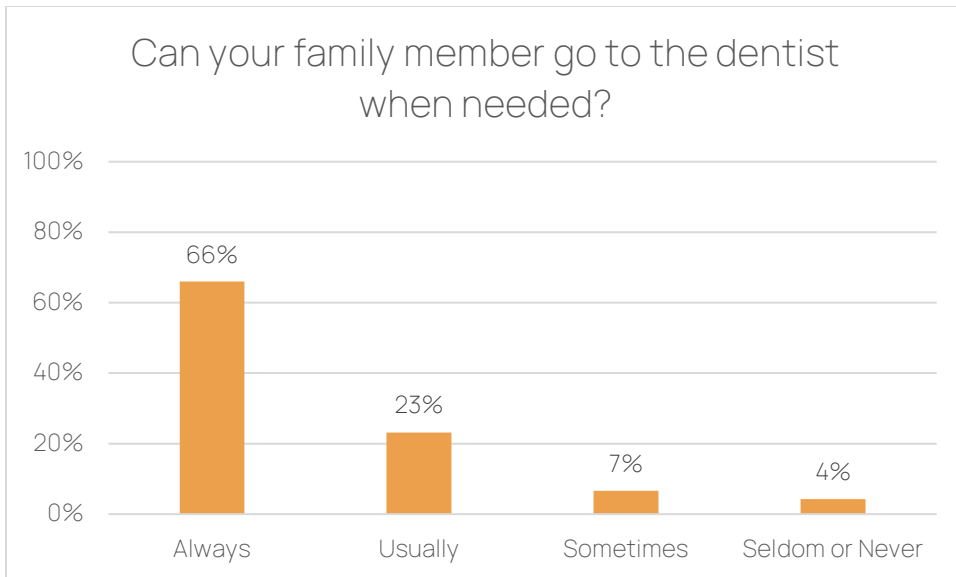


Table 71. Can your family member go to the dentist when needed?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
SD	77%	20%	3%	1%	469
PA	75%	19%	4%	2%	613

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MN	71%	19%	6%	3%	398
IN	70%	22%	4%	4%	446
NH	66%	21%	6%	7%	377
Weighted NCI-IDD Average	66%	23%	7%	4%	7233
DE	65%	29%	3%	3%	160
GA	63%	21%	8%	8%	336
CA	63%	24%	8%	5%	4106
AZ	62%	27%	7%	4%	215
WA	54%	33%	8%	5%	113

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

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

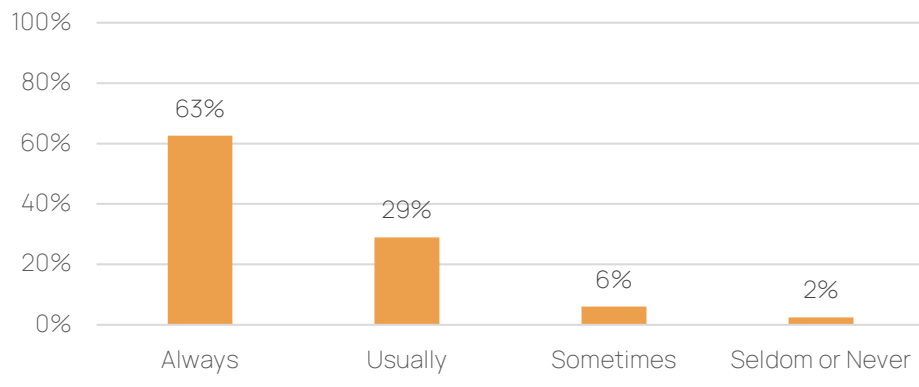


Table 72. Does your family member's dentist understand your family member's needs related to their disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	70%	27%	3%	1%	537

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	66%	30%	3%	0%	408
MN	65%	29%	4%	2%	364
NH	65%	29%	4%	2%	320
DE	64%	31%	3%	1%	138
GA	64%	26%	7%	2%	287
IN	64%	29%	5%	1%	388
AZ	64%	28%	7%	1%	196
Weighted NCI-IDD Average	63%	29%	6%	2%	6138
CA	60%	30%	7%	3%	3406
WA	52%	31%	12%	5%	94

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

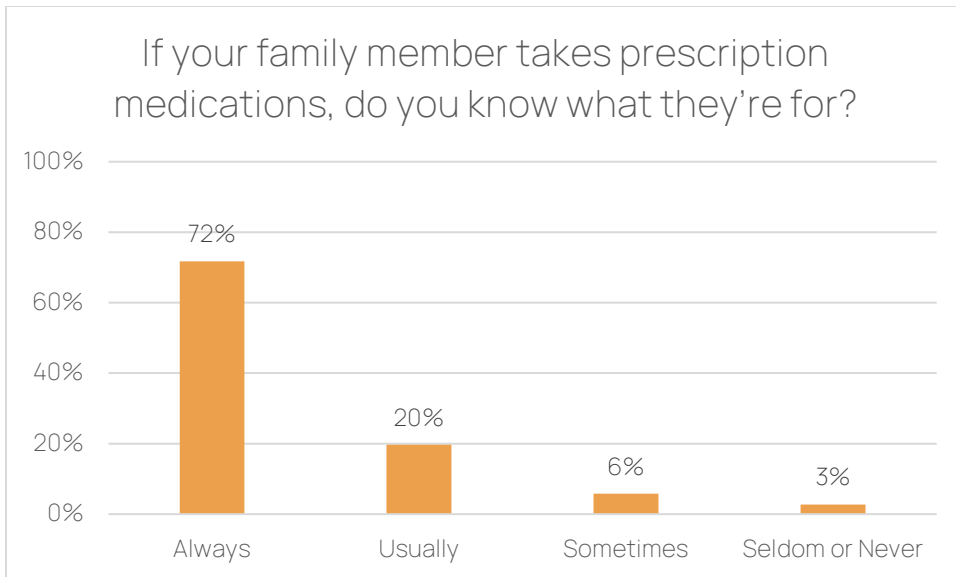


Table 73. If your family member takes prescription medications, do you know what they're for?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	80%	16%	3%	1%	349
MN	79%	16%	3%	2%	383

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	78%	17%	4%	2%	197
WA	74%	18%	6%	2%	104
CA	72%	19%	6%	3%	3624
Weighted NCI-IDD Average	72%	20%	6%	3%	6558
GA	69%	21%	7%	3%	318
PA	67%	23%	6%	4%	576

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	64%	25%	8%	3%	425
SD	62%	30%	6%	2%	426
DE	58%	28%	10%	4%	156

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

Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications?

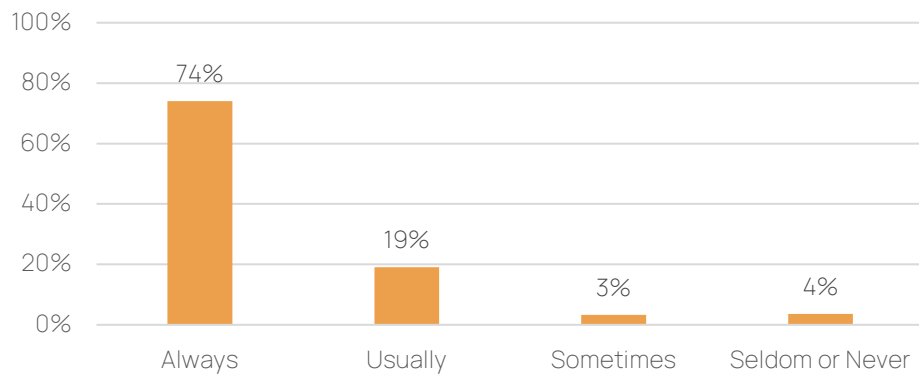


Table 74. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	81%	13%	2%	4%	335

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MN	77%	19%	2%	2%	379
GA	76%	17%	3%	4%	305
AZ	76%	20%	2%	3%	197
CA	75%	17%	4%	4%	3436
Weighted NCI-IDD Average	74%	19%	3%	4%	6234
DE	72%	18%	5%	5%	148
PA	72%	20%	4%	4%	515
WA	70%	22%	3%	5%	103

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	67%	25%	3%	4%	408
SD	66%	27%	4%	3%	409

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

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

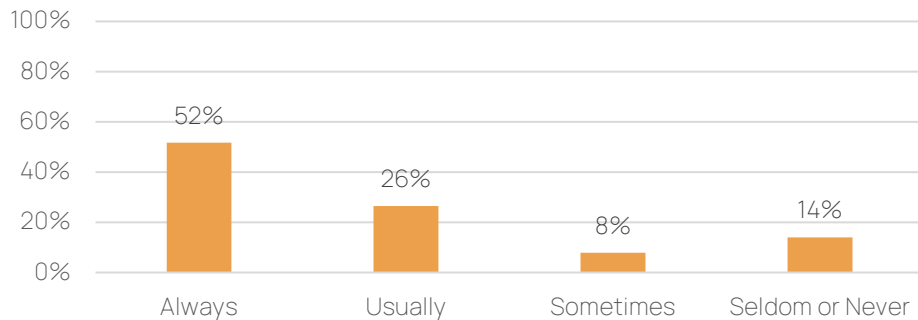


Table 75. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling.)

New question in 2021-22

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	63%	24%	4%	9%	503
MN	63%	25%	5%	7%	346
SD	59%	31%	4%	7%	362

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
GA	55%	22%	8%	14%	264
IN	54%	29%	6%	10%	386
NH	54%	25%	8%	13%	292
AZ	54%	24%	8%	14%	183
Weighted NCI-IDD Average	52%	26%	8%	14%	5599
DE	50%	33%	8%	9%	142

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
CA	46%	26%	11%	18%	3025
WA	30%	42%	7%	21%	96

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

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

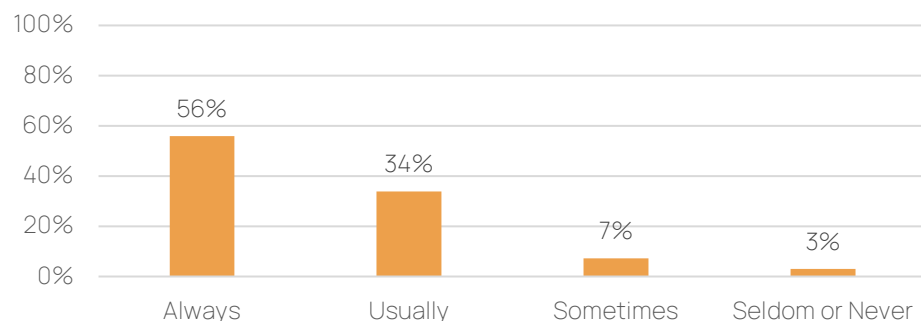


Table 76. Does your family member's mental or behavioral health professional understand your family member's needs related to their disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
MN	62%	33%	4%	1%	283
PA	61%	32%	4%	2%	466
IN	60%	32%	7%	1%	354
SD	59%	36%	5%	0%	315
GA	57%	33%	8%	2%	238
NH	56%	35%	5%	4%	244
Weighted NCI-IDD Average	56%	34%	7%	3%	4830
CA	54%	34%	9%	4%	2596
AZ	53%	34%	10%	3%	143
DE	47%	44%	6%	3%	131

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
WA	36%	47%	12%	7%	60

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

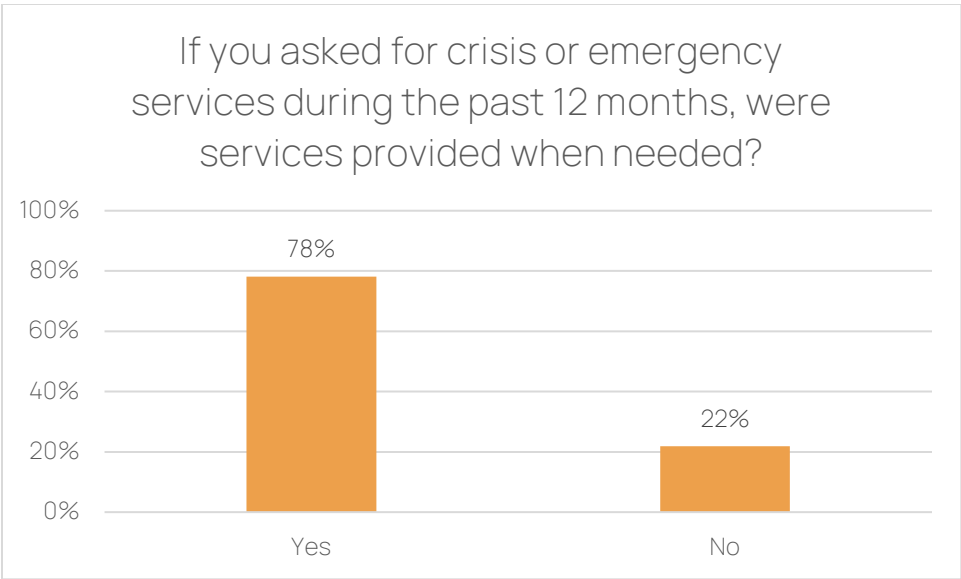


Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

Significantly Above Average

State	Yes	No	N
SD	89%	11%	128
PA	87%	13%	141

Within Average Range

State	Yes	No	N
AZ	88%	12%	67
NH	84%	16%	85
WA	83%	17%	23
Weighted NCI-IDD Average	78%	22%	1872
IN	77%	23%	139
GA	77%	23%	81
MN	76%	24%	100
CA	75%	25%	1067
DE	71%	29%	41

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

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

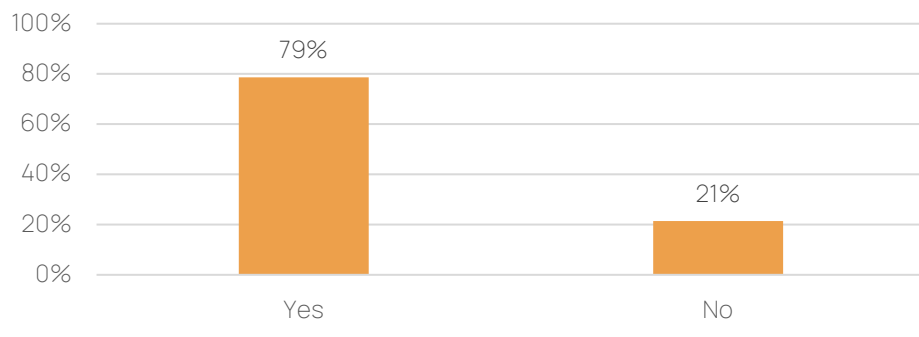


Table 78. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency, pandemic or natural disaster?

Significantly Above Average

State	Yes	No	N
MN	87%	13%	362
NH	86%	14%	328
SD	86%	14%	411

Within Average Range

State	Yes	No	N
AZ	83%	17%	199
GA	83%	17%	303
IN	82%	18%	401
Weighted NCI-IDD Average	79%	21%	6380
WA	77%	23%	100
CA	76%	24%	3615
PA	76%	24%	517
DE	74%	26%	144

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?

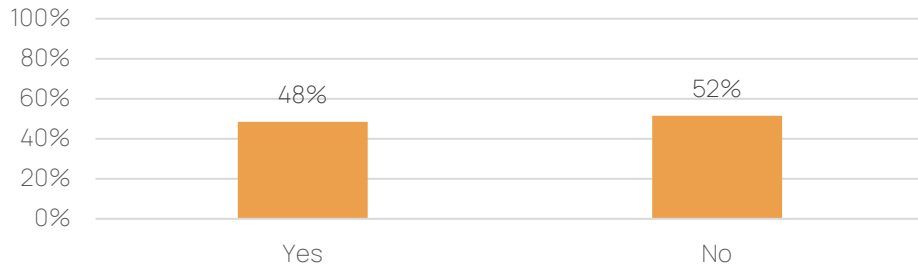


Table 79. Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member's case manager/service coordinator?

Significantly Above Average

State	Yes	No	N
SD	62%	38%	463
MN	61%	39%	385
IN	58%	42%	443

Within Average Range

State	Yes	No	N
GA	54%	46%	332
AZ	53%	47%	208
WA	50%	50%	110
NH	50%	50%	352
PA	49%	51%	589
Weighted NCI-IDD Average	48%	52%	7023
DE	39%	61%	160

Significantly Below Average

State	Yes	No	N
CA	42%	58%	3981

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

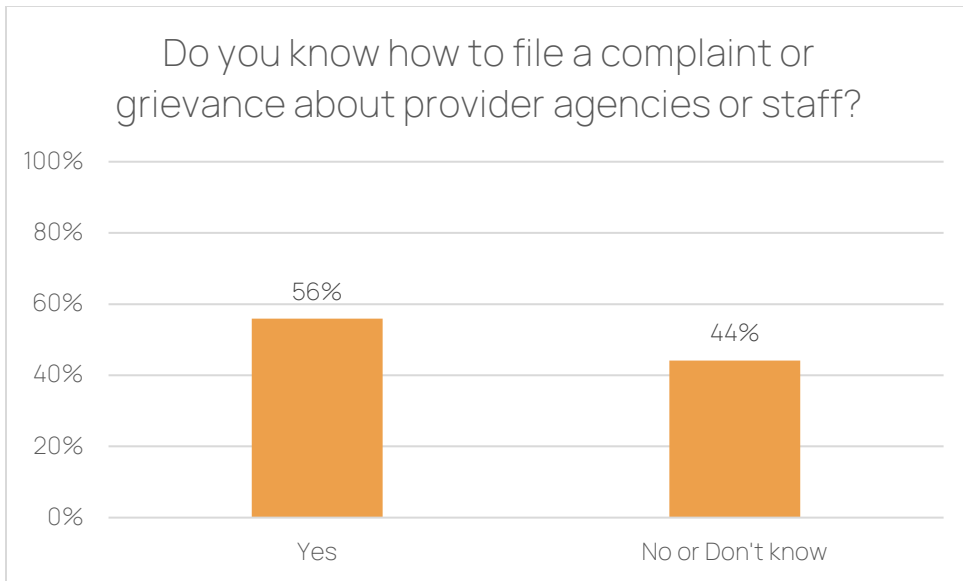


Table 80. Do you know how to file a complaint or grievance about provider agencies or staff?
Significantly Above Average

State	Yes	No or Don't Know	N
MN	76%	24%	392
NH	75%	25%	380
WA	71%	29%	112
SD	71%	29%	482
IN	62%	38%	463
PA	61%	39%	635

Within Average Range

State	Yes	No or Don't Know	N
AZ	62%	38%	220
GA	57%	43%	348
Weighted NCI-IDD Average	56%	44%	7438
DE	47%	53%	169

Significantly Below Average

State	Yes	No or Don't Know	N
CA	45%	55%	4237

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

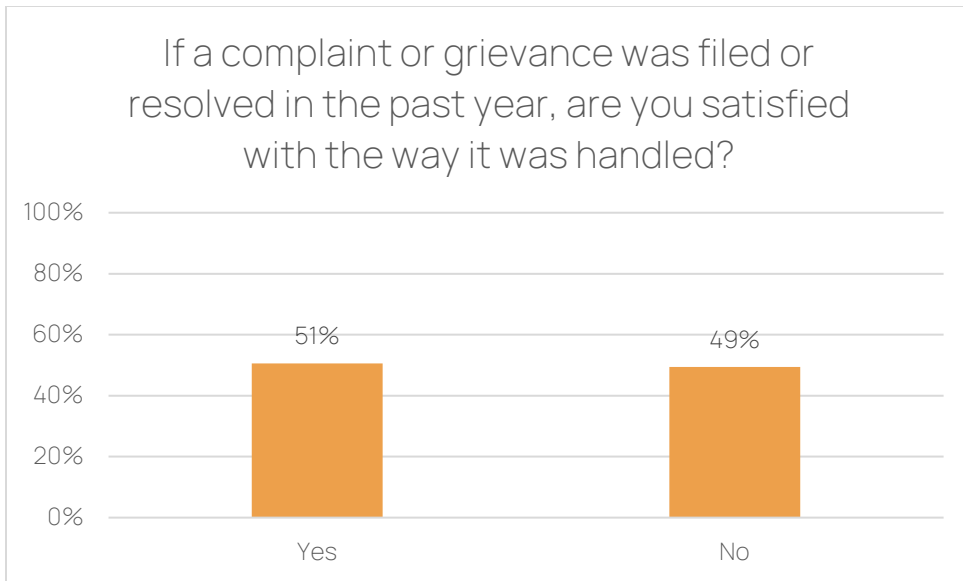


Table 81. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

Significantly Above Average

State	Yes	No	N
SD	73%	27%	60

Within Average Range

State	Yes	No	N
PA	59%	41%	83
MN	58%	42%	31
DE	57%	43%	21
NH	56%	44%	32
AZ	55%	45%	31
IN	55%	45%	66
Weighted NCI-IDD Average	51%	49%	711
GA	48%	52%	42
WA	n/a	n/a	n/a

Significantly Below Average

State	Yes	No	N
CA	43%	57%	331

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

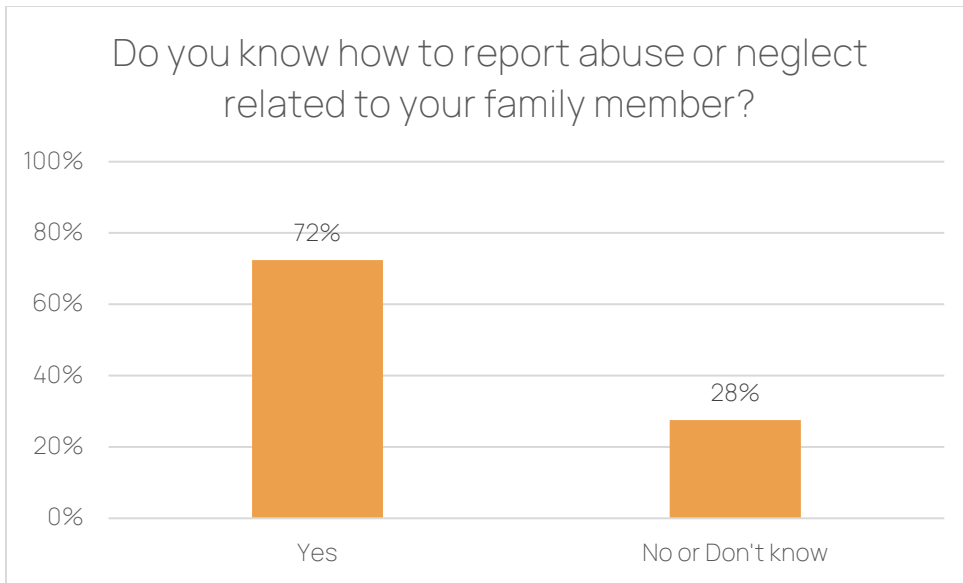


Table 82. Do you know how to report abuse or neglect related to your family member?
Significantly Above Average

State	Yes	No or Don't Know	N
MN	98%	2%	411
SD	84%	16%	487
WA	84%	16%	114

Within Average Range

State	Yes	No or Don't Know	N
NH	82%	18%	375
IN	77%	23%	462
AZ	75%	25%	216
PA	73%	27%	624
GA	73%	27%	346
Weighted NCI-IDD Average	72%	28%	7433
DE	68%	32%	171

Significantly Below Average

State	Yes	No or Don't Know	N
CA	63%	37%	4227

"No" and "Don't Know" responses were combined.

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

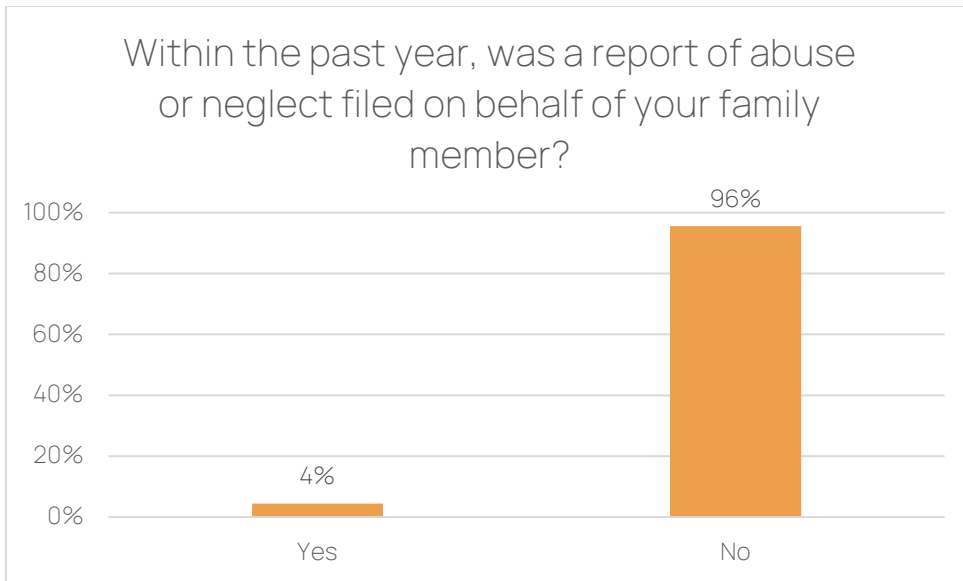


Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

Significantly Above Average

State	Yes	No	N
IN	8%	92%	439

Within Average Range

State	Yes	No	N
DE	10%	90%	156
SD	7%	93%	468
PA	6%	94%	588
AZ	6%	94%	200
WA	5%	95%	108
MN	5%	95%	388
Weighted NCI-IDD Average	4%	96%	7184
GA	4%	96%	326
NH	3%	97%	375
CA	3%	97%	4136

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

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

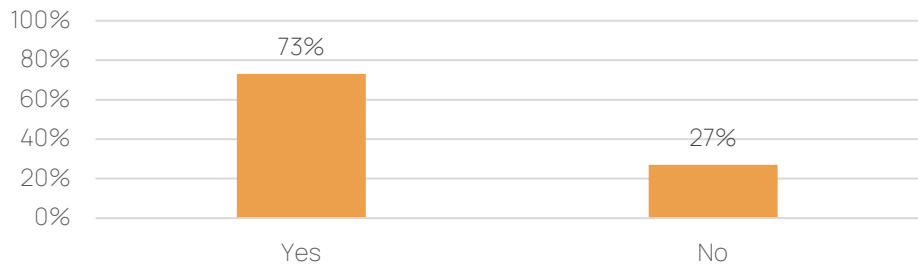


Table 84. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past year, were you notified of the report in a timely manner?

Within Average Range

State	Yes	No	N
PA	79%	21%	29
IN	77%	23%	26
Weighted NCI-IDD Average	73%	27%	222
CA	66%	34%	89

Table note: States not displayed due to low counts: AZ, DE, GA, MN, NH, SD, WA

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](#)

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

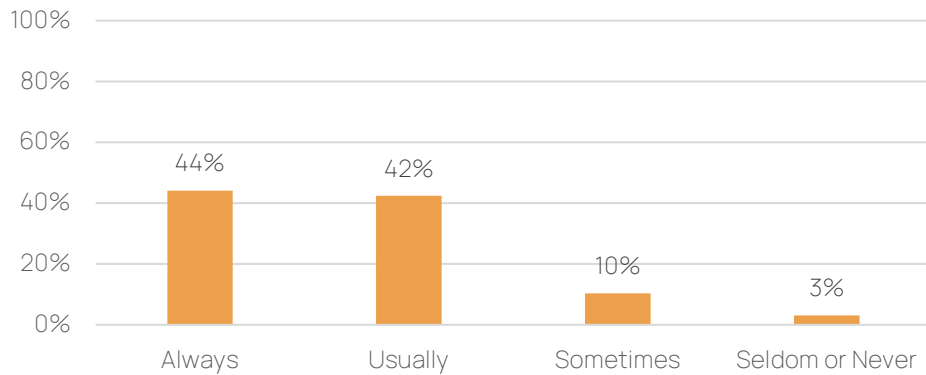


Table 85. Overall, are you satisfied with the services and supports your family member currently receives?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	51%	38%	8%	3%	627

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	48%	41%	9%	2%	218
NH	47%	42%	8%	3%	384
MN	45%	46%	8%	1%	401
SD	45%	48%	6%	1%	485
CA	45%	42%	10%	3%	4214
GA	44%	40%	14%	2%	337
Weighted NCI-IDD Average	44%	42%	10%	3%	7411
DE	40%	48%	7%	5%	171

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	34%	48%	14%	4%	464
WA	23%	49%	20%	8%	110

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

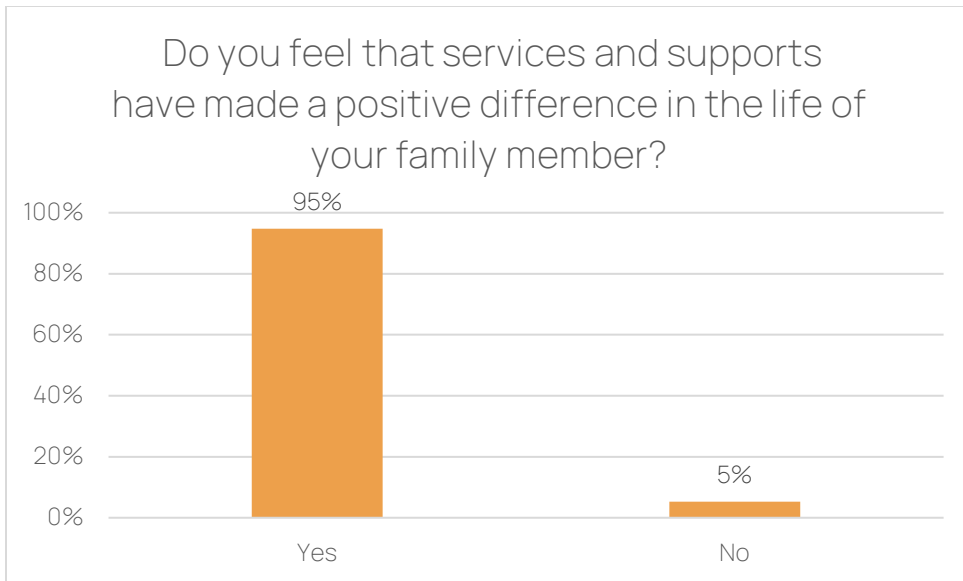


Table 86. Do you feel that services and supports have made a positive difference in the life of your family member?

Significantly Above Average

State	Yes	No	N
MN	98%	2%	390
NH	98%	2%	370
SD	97%	3%	464

Within Average Range

State	Yes	No	N
AZ	97%	3%	205
CA	95%	5%	4014
Weighted NCI-IDD Average	95%	5%	7045
PA	94%	6%	587
IN	94%	6%	440
GA	94%	6%	320
DE	94%	6%	156
WA	87%	13%	99

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

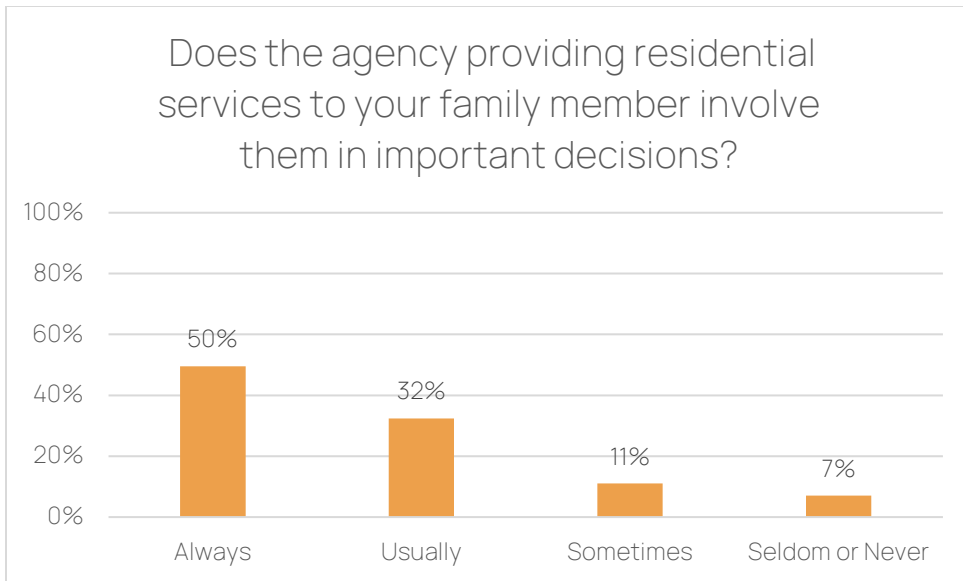


Table 87. Does the agency providing residential services to your family members involve them in important decisions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NH	58%	30%	8%	5%	332

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
SD	54%	39%	6%	2%	431
MN	54%	33%	10%	3%	359
CA	52%	30%	10%	8%	3063
AZ	52%	29%	13%	6%	190
Weighted NCI-IDD Average	50%	32%	11%	7%	5741
PA	48%	36%	10%	6%	483
GA	45%	31%	15%	9%	262
DE	41%	35%	17%	7%	148

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	41%	36%	13%	11%	382
WA	36%	37%	18%	9%	91

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

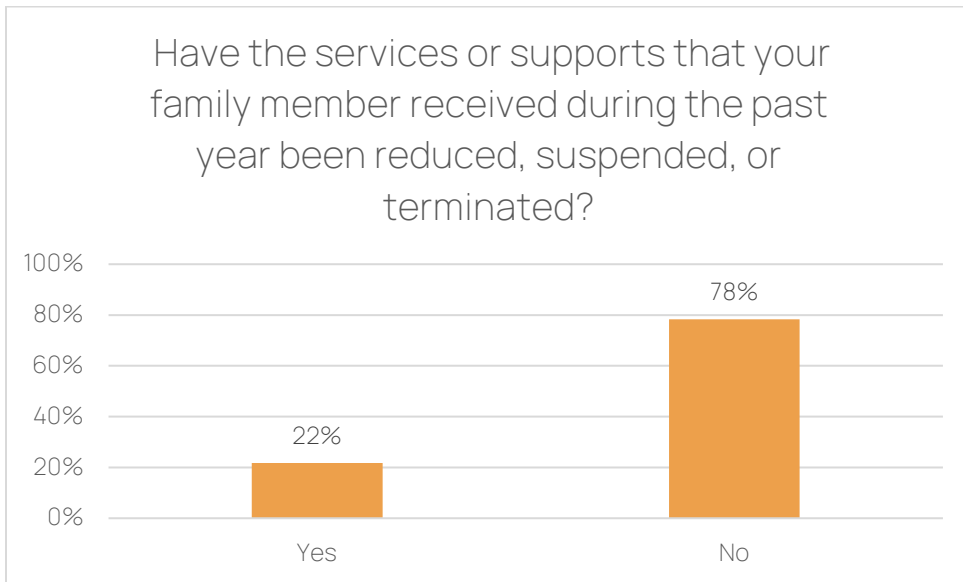


Table 88. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

Within Average Range

State	Yes	No	N
NH	25%	75%	361
IN	23%	77%	404
PA	23%	77%	554
CA	23%	77%	3750
Weighted NCI-IDD Average	22%	78%	6660
GA	21%	79%	308
WA	20%	80%	98
MN	21%	79%	386
DE	18%	82%	155
AZ	16%	84%	205

Significantly Below Average

State	Yes	No	N
SD	13%	87%	439

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

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

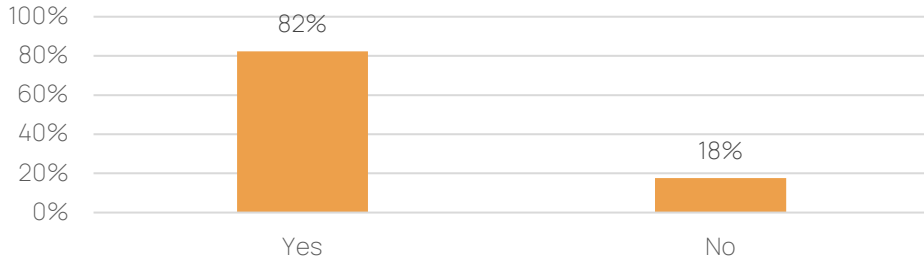


Table 89. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?

Within Average Range

State	Yes	No	N
AZ	87%	13%	30
PA	84%	16%	110
CA	83%	17%	714
Weighted NCI-IDD Average	82%	18%	1218
IN	82%	18%	71
DE	79%	21%	24
GA	79%	21%	52
NH	75%	25%	77
MN	73%	27%	75
SD	67%	33%	48

Table note: State not displayed due to low counts: WA

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

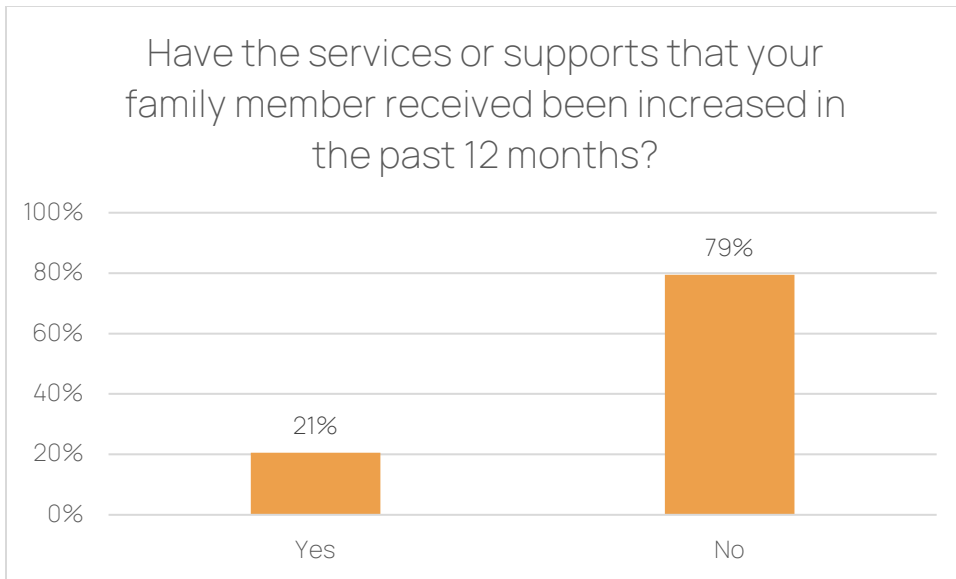


Table 90. Have the services or supports that your family member received been increased in the past 12 months?

Within Average Range

State	Yes	No	N
GA	23%	77%	275
PA	22%	78%	441
WA	21%	79%	91
CA	21%	79%	3103
Weighted NCI-IDD Average	21%	79%	5653
IN	20%	80%	359
AZ	18%	82%	182
MN	18%	82%	369
SD	17%	83%	368
DE	17%	83%	129
NH	17%	83%	336

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

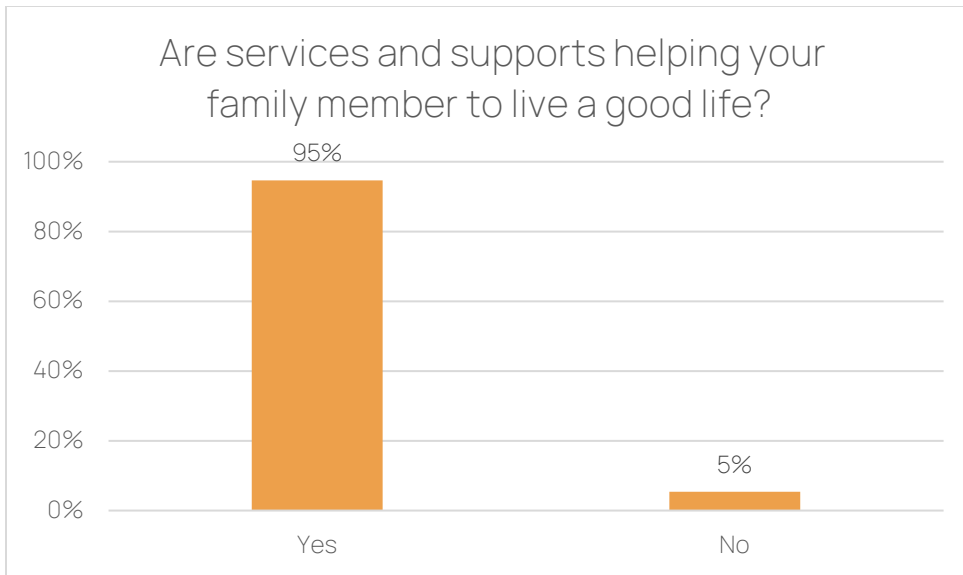


Table 91. Are services and supports helping your family member to live a good life?
Significantly Above Average

State	Yes	No	N
SD	98%	2%	462
MN	97%	3%	388

Within Average Range

State	Yes	No	N
NH	96%	4%	367
AZ	96%	4%	194
CA	95%	5%	3833
Weighted NCI-IDD Average	95%	5%	6851
PA	94%	6%	597
IN	94%	6%	429
GA	94%	6%	326
DE	94%	6%	154
WA	86%	14%	101

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.

Despite being optional, this module was used by all FGS-participating states this year.

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](#)

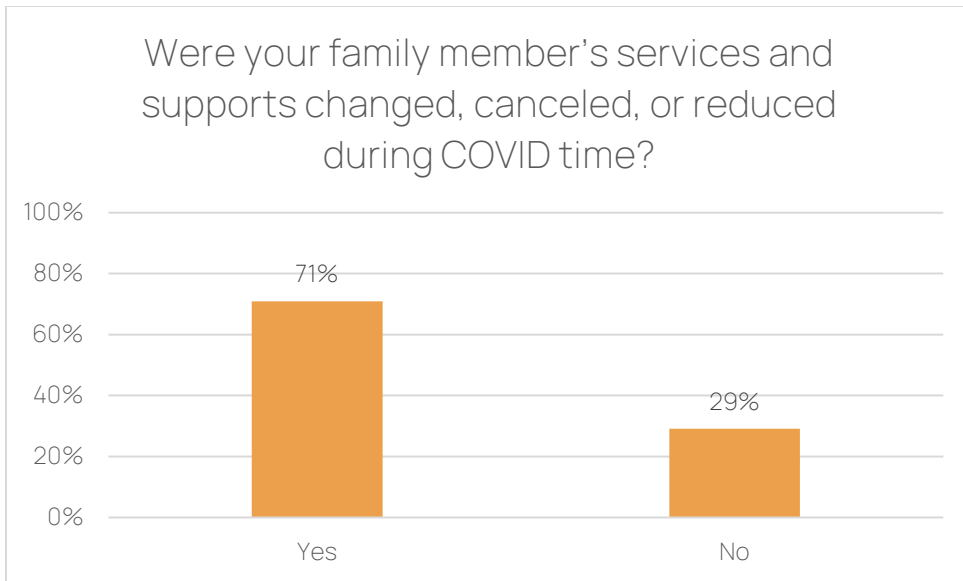


Table 92. Were your family member's services and supports changed, canceled, or reduced during COVID time?

Significantly Above Average

State	Yes	No	N
NH	77%	23%	325

Within Average Range

State	Yes	No	N
DE	78%	22%	157
PA	75%	25%	564
SD	72%	28%	443
MN	72%	28%	396
AZ	72%	28%	169
GA	72%	28%	291
Weighted NCI-IDD Average	71%	29%	6116
CA	69%	31%	3599
WA	69%	31%	107
IN	60%	40%	65

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

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

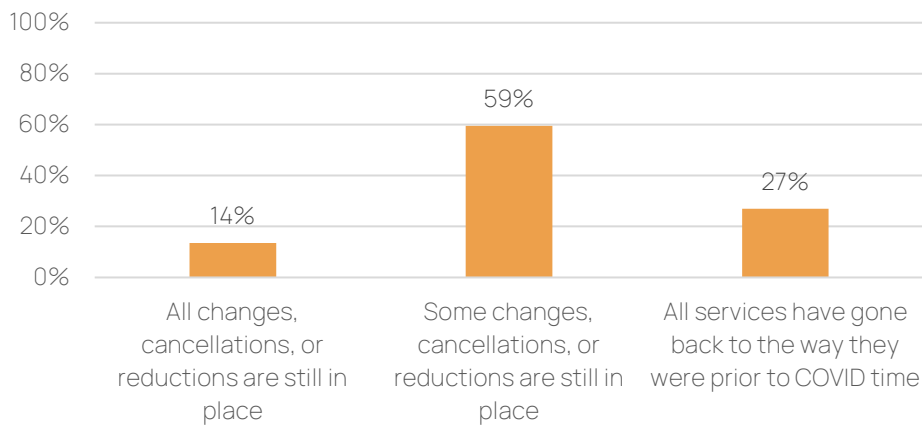


Table 93. If yes, are those changes still in effect (still part of your family member's life)?
Significantly Above Average

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
NH	28%	56%	16%	234

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
DE	19%	58%	23%	112
CA	17%	59%	24%	2296
AZ	15%	50%	35%	117
Weighted NCI-IDD Average	14%	59%	27%	4003
PA	13%	62%	26%	388
GA	11%	49%	39%	190
WA	6%	71%	23%	66
IN	6%	37%	57%	35

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
MN	8%	62%	31%	274
SD	2%	40%	58%	291

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

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?

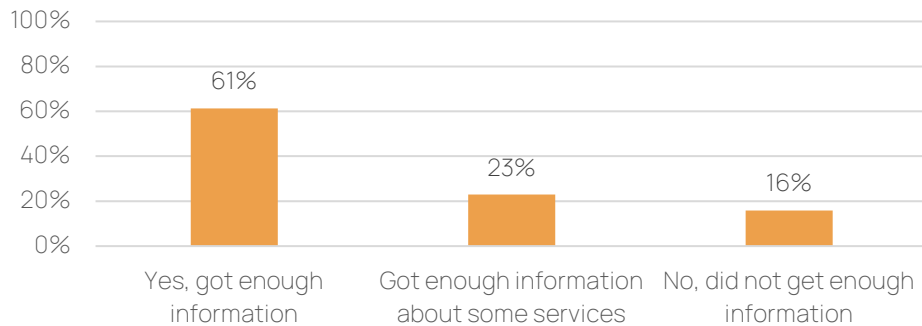


Table 94. If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?

Significantly Above Average

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
SD	72%	20%	9%	268

Within Average Range

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
MN	69%	23%	8%	235
IN	68%	19%	13%	31
NH	65%	21%	14%	145
AZ	63%	21%	16%	90
GA	62%	20%	19%	151
Weighted NCI-IDD Average	61%	23%	16%	3014
PA	60%	24%	16%	304
CA	60%	22%	18%	1653
DE	54%	30%	16%	82
WA	53%	27%	20%	56

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

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?

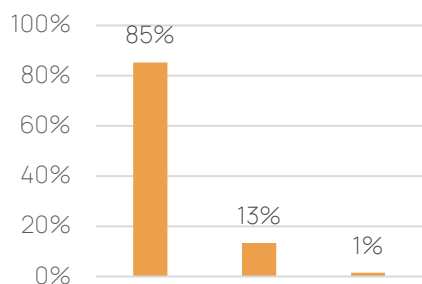


Table 95. If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?

Significantly Above Average

State	Yes	Some precautions being followed	No	N
SD	91%	9%	0%	266

Within Average Range

State	Yes	Some precautions being followed	No	N
PA	89%	10%	1%	294
GA	88%	9%	3%	146
CA	88%	12%	1%	1627
DE	87%	12%	1%	76
NH	87%	13%	1%	151
Weighted NCI-IDD Average	85%	13%	1%	2973
MN	85%	14%	1%	237
IN	85%	11%	4%	27
AZ	77%	17%	5%	92

Significantly Below Average

State	Yes	Some precautions being followed	No	N
WA	61%	33%	5%	57

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

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?

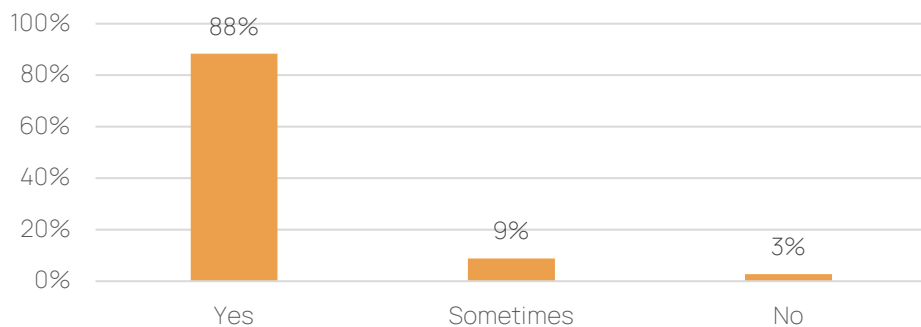


Table 96. If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?

Significantly Above Average

State	Yes	Sometimes	No	N
SD	93%	6%	2%	347

Within Average Range

State	Yes	Sometimes	No	N
GA	90%	8%	2%	257
CA	90%	8%	2%	2938
NH	90%	5%	5%	254
PA	89%	7%	4%	432
Weighted NCI-IDD Average	88%	9%	3%	4982
MN	88%	10%	2%	347
DE	87%	9%	4%	115
AZ	83%	10%	7%	148
WA	82%	15%	3%	89
IN	78%	20%	2%	55

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

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

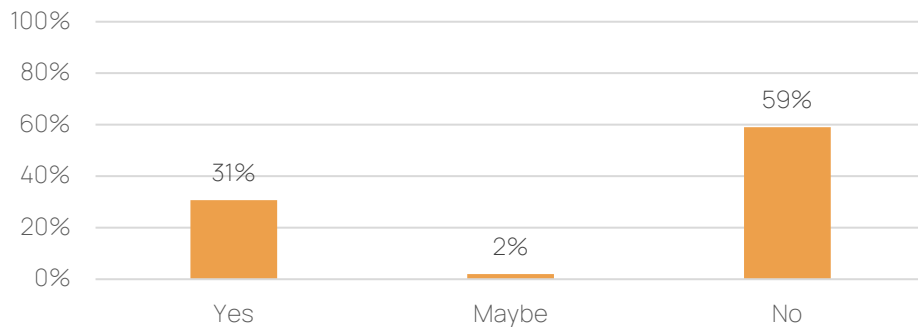


Table 97. In preparation for the future, have you made or updated an emergency plan with your family member's case manager/service coordinator or with other staff?

Significantly Above Average

State	Yes	Maybe	No	N
MN	40%	4%	56%	352

Within Average Range

State	Yes	Maybe	No	N
IN	43%	2%	59%	58
AZ	39%	5%	60%	157
SD	35%	4%	63%	409
PA	34%	6%	61%	473
GA	33%	9%	59%	291
WA	33%	7%	60%	102
NH	32%	5%	64%	280
Weighted NCI-IDD Average	31%	5%	64%	5626
DE	25%	3%	71%	147

Significantly Below Average

State	Yes	Maybe	No	N
CA	26%	5%	69%	3357

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-Intellectual and Developmental Disabilities (NCI-IDD), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI-IDD facilitates pooled knowledge, expertise, and resources among the states. In 1997, 15 states convened to discuss the scope and content of a potential performance measurement framework. Directors and staff from these 15 states worked to identify the major domains and sub-domains of performance, indicators, measures, and data sources. The original 61 indicators, developed through a consensus process, were intended to provide a system-level “snapshot” of how well each state was performing. The states were guided by a set of criteria that was designed to select indicators that were:

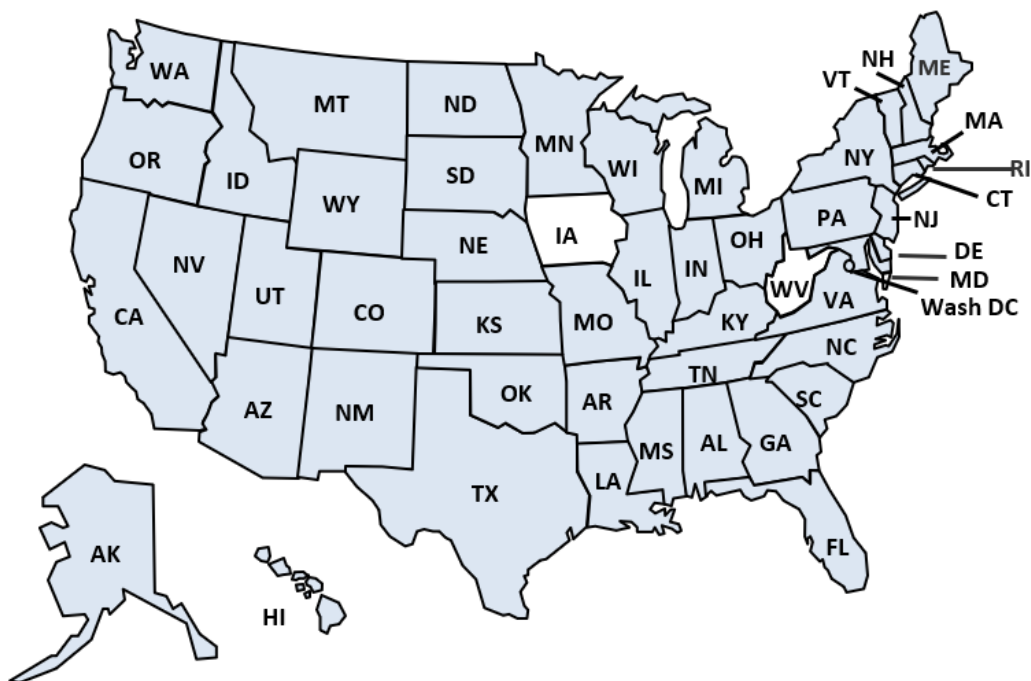
1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of disability or residential setting

During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states volunteered to pilot test the indicators. Eight additional states served on the Steering Committee. Since the initial field test, NCI-IDD has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI-IDD continues to develop and refine the indicators and expand state participation. For more information about NCI-IDD states, technical reports, and other resources please visit the NCI-IDD website at <https://idd.nationalcoreindicators.org/>.

State Participation

State participation is entirely voluntary, and participating states are highlighted on the map below. Not all states participate in all surveys each year.

Figure 1. NCI-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://legacy.nationalcoreindicators.org/about/indicators/>.

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

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

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

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

Sub-Domains and Value Statements

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

Family Survey Sub-Domains and Value Statements

Sub-Domain	Value Statement
Information and Planning	Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state Developmental disabilities system.
Choice and Decision Making	Families and their family members receiving services and supports from the state Developmental disabilities system are involved in making choices about supports, services, and providers.
Access & Support Delivery	Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state Developmental disabilities system.
Workforce (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 Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI as a data source for supplemental performance measures in their home and community-based services (HCBS) waiver quality management systems and include the information in support of

evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

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

Caution and Limitations

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

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

Data from previous years are not presented in this report. Comparisons of results from year to year should be made with caution: even slight changes in wording or response options of certain questions may affect comparability of results from one year to the next; the mix of participating states differs slightly each year and may affect the NCI-IDD Averages; 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 Family/Guardian Survey by selecting a random sample of at least 1,000 families who:

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

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys. A total of five states (CA, DE, IN, MN, WA) 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 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 average as the benchmark. A conservative cut-off point (alpha) of $p < .01$ was used to detect statistically significant differences. Effect sizes are calculated using the formula: Cohen's $d = \frac{2t}{\sqrt{df}}$. A cutoff point of Cohen's $d = 0.2$ was chosen for the effect size to be considered “meaningfully significant,” following the standard interpretation offered by Cohen (1988) that Cohen's d of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

Data Entry and Analysis

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

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

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

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the NCI-IDD average. The NCI-IDD Average is a weighted average. Please see the section "Weighting" for more details. Significance is shown at the $p < .01$ level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

Response Rates

During 2021-22, ten states administered the Family/Guardian Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The following table shows the number of individuals receiving services who were eligible to be drawn into the sample ("total population"), the number of surveys each state sent, complete surveys, response rates, margins of error, and survey submission modes.

Family/Guardian Survey: State Response Rates

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	4,717	1,400	223	15.9%	6.39%	100%	0%
CA	57,504	33,877	4,670	13.8%	1.37%	73%	27%
DE	1,131	500	184	36.8%	6.61%	60%	40%
GA	4,936	1,700	361	21.2%	4.97%	100%	0%
IN	7,686	1,500	481	32.1%	4.33%	84%	16%
MN	12,626	1,600	417	26.1%	4.72%	81%	19%
NH	1,483	1,483	397	26.8%	4.20%	100%	0%
PA	18,723	2,050	655	32.0%	3.76%	100%	0%
SD	1,800	1,800	496	27.6%	3.75%	100%	0%
WA	9,157	2,500	166	6.6%	7.45%	0%	100%
Total	119,763	47,927	8,050	23.9%	-	80%	20%

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.