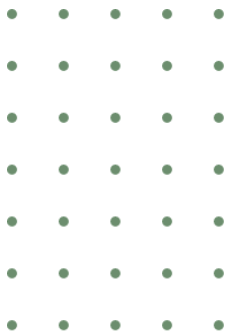


# National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)



National Report 2022-23

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 National Core Indicators (NCI) Family/Guardian Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Family/Guardian Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI-IDD during the 2022-23 data collection cycle, five states submitted a valid sample of Family/Guardian Survey data: Arizona (AZ), Georgia (GA), Maryland (MD), New Jersey (NJ), and Pennsylvania (PA). This Final Report provides a summary of results based on data submitted by June 30, 2023.

# Results

## Presentation of the Data

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

- Each question is constructed so the respondent selects from either four possible responses (“always”, “usually”, “sometimes”, “seldom/never”) or two responses (“yes” or “no”). Respondents also have the option to indicate that they don’t know the answer to a question or that the question is not applicable.
- Demographic results are shown in table form with states listed alphabetically. Outcomes are shown first with a chart depicting the NCI-IDD Average. The charts are followed by accessible tables showing state outcomes and the NCI-IDD Average. State data were not tested for significance due to the small number of participating states.
- 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 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 responses:** Some pages in this section are in landscape orientation because some table headers cannot be displayed in full in portrait orientation

## **Family Member**

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

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

Table 1a. Family Member's Residence

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

State (names abbreviated)	Specialized facility for people with intellectual disabilities	Group home or agency-operated apartment	Independent home or apartment	N
AZ	14%	73%	4%	162
GA	12%	53%	22%	322
MD	7%	74%	18%	411
NJ	8%	69%	20%	591
PA	11%	82%	2%	649
<b>Weighted NCI-IDD Average</b>	10%	74%	10%	2,135

Table note: 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.

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

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

State (names abbreviated)	Adult foster care or host family home	Nursing Home	Homeless	Other	N
AZ	7%	0%	0%	2%	162
GA	10%	2%	1%	0%	322
MD	1%	0%	0%	0%	411
NJ	0%	0%	0%	3%	591
PA	3%	0%	0%	1%	649
<b>Weighted NCI-IDD Average</b>	<b>3%</b>	<b>0%</b>	<b>0%</b>	<b>1%</b>	<b>2,135</b>

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

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

State (names abbreviated)	Less than one year	One to three years	Four to five years	Over five years	N
<b>AZ</b>	14%	29%	9%	48%	161
<b>GA</b>	9%	25%	14%	53%	320
<b>MD</b>	14%	28%	14%	44%	400
<b>NJ</b>	8%	23%	13%	56%	590
<b>PA</b>	4%	20%	12%	64%	640
<b>Weighted NCI-IDD Average</b>	<b>8%</b>	<b>24%</b>	<b>13%</b>	<b>55%</b>	<b>2,111</b>



Table 3. Family Member’s Residential Designation

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

State (names abbreviated)	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
AZ	89%	11%	159
GA	83%	17%	308
MD	79%	21%	394
NJ	79%	21%	584
PA	71%	29%	638
<b>Weighted NCI-IDD Average</b>	<b>78%</b>	<b>22%</b>	<b>2,083</b>

Table 4. Family Member's Age

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

State (names abbreviated)	Age	N
AZ	45.6	157
GA	47.1	316
MD	41.3	411
NJ	46.3	598
PA	44.8	650
<b>Weighted NCI-IDD Average</b>	<b>44.6</b>	<b>2,132</b>

Table 5. Family Member's Gender

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

State (names abbreviated)	Male	Female	Other	N
<b>AZ</b>	54%	46%	0%	160
<b>GA</b>	56%	44%	0%	320
<b>MD</b>	61%	39%	0%	411
<b>NJ</b>	65%	35%	0%	598
<b>PA</b>	61%	39%	0%	650
<b>Weighted NCI-IDD Average</b>	<b>60%</b>	<b>39%</b>	<b>0%</b>	<b>2,139</b>

Table 6. Family Member’s Race/Ethnicity

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

State (names abbreviated)	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer not to say
<b>AZ</b>	4%	2%	6%	1%	78%	11%	1%	4%
<b>GA</b>	2%	2%	25%	1%	67%	2%	3%	2%
<b>MD</b>	1%	3%	17%	0%	73%	3%	3%	2%
<b>NJ</b>	1%	4%	8%	0%	81%	5%	1%	4%
<b>PA</b>	2%	1%	5%	0%	89%	3%	1%	1%
<b>Weighted NCI-IDD Average</b>	<b>2%</b>	<b>2%</b>	<b>10%</b>	<b>0%</b>	<b>81%</b>	<b>4%</b>	<b>2%</b>	<b>2%</b>

Table 7a. Family Member's Conditions

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

State (names abbreviated)	Intellectual disability	Mood illness or psychiatric diagnosis	Autism spectrum disorder	Cerebral palsy
AZ	79%	47%	29%	18%
GA	79%	31%	29%	13%
MD	78%	39%	40%	17%
NJ	76%	36%	44%	11%
PA	88%	45%	35%	15%
<b>Weighted NCI-IDD Average</b>	<b>82%</b>	<b>41%</b>	<b>37%</b>	<b>15%</b>

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

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

State (names abbreviated)	Limited or No Vision	Hearing loss (severe or profound)	Brain injury	Seizure or neurological disorder	Chemical dependency
<b>AZ</b>	11%	3%	11%	33%	1%
<b>GA</b>	6%	7%	8%	26%	1%
<b>MD</b>	10%	7%	10%	26%	0%
<b>NJ</b>	6%	6%	6%	22%	0%
<b>PA</b>	10%	7%	10%	30%	0%
<b>Weighted NCI-IDD Average</b>	<b>9%</b>	<b>6%</b>	<b>9%</b>	<b>27%</b>	<b>0%</b>

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

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

State (names abbreviated)	Down syndrome	Prader-Willi Syndrome	Fetal alcohol spectrum disorder (FASD)	Other
AZ	8%	1%	2%	16%
GA	11%	1%	2%	11%
MD	8%	1%	2%	18%
NJ	8%	0%	2%	11%
PA	10%	2%	2%	10%
<b>Weighted NCI-IDD Average</b>	<b>9%</b>	<b>2%</b>	<b>2%</b>	<b>12%</b>

Table 8a. Family Member's Health Conditions

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

State (names abbreviated)	Cardiovascular disease	Diabetes	Cancer	High blood pressure	High cholesterol
<b>AZ</b>	10%	15%	4%	35%	38%
<b>GA</b>	7%	18%	7%	43%	31%
<b>MD</b>	7%	18%	4%	32%	31%
<b>NJ</b>	8%	17%	5%	32%	40%
<b>PA</b>	9%	18%	5%	29%	33%
<b>Weighted NCI-IDD Average</b>	<b>8%</b>	<b>18%</b>	<b>5%</b>	<b>32%</b>	<b>35%</b>



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

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

State (names abbreviated)	Dysphagia	Pressure ulcers	Alzheimer's disease or dementia	Oral health problems	Sleep apnea
<b>AZ</b>	10%	0%	8%	18%	8%
<b>GA</b>	5%	1%	3%	19%	13%
<b>MD</b>	11%	2%	2%	11%	17%
<b>NJ</b>	13%	1%	2%	17%	10%
<b>PA</b>	17%	4%	4%	17%	17%
<b>Weighted NCI-IDD Average</b>	<b>13%</b>	<b>2%</b>	<b>4%</b>	<b>16%</b>	<b>14%</b>

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

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

State (names abbreviated)	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
<b>AZ</b>	12%	7%	3%	1%	21%
<b>GA</b>	7%	3%	5%	0%	20%
<b>MD</b>	14%	4%	3%	1%	27%
<b>NJ</b>	8%	2%	3%	1%	25%
<b>PA</b>	7%	4%	5%	1%	22%
<b>Weighted NCI-IDD Average</b>	<b>9%</b>	<b>4%</b>	<b>4%</b>	<b>1%</b>	<b>23%</b>

Table 9. Family Member’s Preferred Means of Communication

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

State (names abbreviated)	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
AZ	76%	19%	1%	1%	3%	159
GA	81%	15%	1%	0%	3%	320
MD	75%	15%	3%	2%	4%	394
NJ	78%	12%	2%	2%	5%	585
PA	74%	17%	2%	1%	6%	646
<b>Weighted NCI-IDD Average</b>	<b>76%</b>	<b>16%</b>	<b>2%</b>	<b>2%</b>	<b>5%</b>	<b>2,104</b>

Table 10. Family Member's Preferred Language

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

State (names abbreviated)	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AZ	98%	1%	0%	0%	0%	0%	1%	161
GA	96%	0%	0%	0%	0%	1%	2%	321
MD	95%	0%	0%	0%	0%	3%	3%	395
NJ	97%	0%	0%	0%	0%	1%	1%	586
PA	96%	1%	0%	0%	0%	1%	2%	646
<b>Weighted NCI-IDD Average</b>	<b>96%</b>	<b>1%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>1%</b>	<b>2%</b>	<b>2,109</b>

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

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

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

State (names abbreviated)	No guardianship	Limited guardianship	Full guardianship	Has guardianship but level unknown	N
AZ	9%	6%	82%	2%	159
GA	35%	14%	47%	4%	291
MD	40%	15%	40%	5%	372
NJ	22%	9%	63%	6%	571
PA	30%	12%	53%	5%	600
<b>Weighted NCI-IDD Average</b>	<b>28%</b>	<b>11%</b>	<b>55%</b>	<b>5%</b>	<b>1,993</b>

Table 12. Guardian or Conservator Relationship to Family Member

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

State (names abbreviated)	Family	Friend	Employee of state or guardianship agency	Other	N
AZ	86%	3%	8%	4%	141
GA	96%	0%	2%	2%	169
MD	93%	0%	1%	6%	215
NJ	94%	1%	4%	1%	433
PA	92%	1%	5%	2%	395
<b>Weighted NCI-IDD Average</b>	<b>92%</b>	<b>1%</b>	<b>4%</b>	<b>3%</b>	<b>1,353</b>

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

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

State (names abbreviated)	Did not complete high school – Not currently in school	Currently enrolled in high school	High school certificate (NOT a high school diploma or GED)	N
AZ	28%	1%	32%	150
GA	29%	2%	38%	310
MD	21%	1%	51%	378
NJ	30%	0%	23%	578
PA	26%	1%	33%	611
<b>Weighted NCI-IDD Average</b>	<b>26%</b>	<b>1%</b>	<b>35%</b>	<b>2,027</b>

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

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

State (names abbreviated)	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	31%	1%	3%	3%	150
GA	25%	2%	1%	3%	310
MD	17%	3%	4%	5%	378
NJ	30%	4%	6%	7%	578
PA	36%	3%	1%	1%	611
<b>Weighted NCI-IDD Average</b>	<b>29%</b>	<b>3%</b>	<b>3%</b>	<b>4%</b>	<b>2,027</b>



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

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

State (names abbreviated)	No support needed; no issues with managing behavior	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
AZ	33%	39%	28%	160
GA	38%	34%	28%	312
MD	37%	35%	28%	381
NJ	35%	39%	26%	570
PA	28%	41%	31%	630
<b>Weighted NCI-IDD Average</b>	<b>32%</b>	<b>39%</b>	<b>29%</b>	<b>2,053</b>

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

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

State (names abbreviated)	No support needed; no issues with personal care activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
AZ	20%	42%	38%	162
GA	26%	43%	31%	318
MD	23%	34%	43%	387
NJ	21%	36%	43%	583
PA	17%	40%	43%	640
<b>Weighted NCI-IDD Average</b>	<b>20%</b>	<b>39%</b>	<b>41%</b>	<b>2,090</b>

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

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

State (names abbreviated)	No support needed; no issues with other daily activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
AZ	1%	11%	88%	161
GA	3%	24%	73%	320
MD	1%	15%	84%	389
NJ	1%	19%	79%	586
PA	1%	14%	85%	644
<b>Weighted NCI-IDD Average</b>	<b>1%</b>	<b>16%</b>	<b>83%</b>	<b>2,100</b>

## **Respondents**

This section provides information about the survey respondent.

Table 17. Language Usually Spoken at Home

State (names abbreviated)	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
<b>AZ</b>	98%	1%	1%	1%	0%	1%	0%	162
<b>GA</b>	96%	1%	1%	0%	0%	0%	2%	321
<b>MD</b>	97%	1%	0%	0%	0%	1%	1%	387
<b>NJ</b>	98%	1%	0%	0%	0%	0%	1%	565
<b>PA</b>	98%	0%	0%	0%	0%	0%	1%	639
<b>Weighted NCI-IDD Average</b>	<b>98%</b>	<b>1%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>1%</b>	<b>2,074</b>

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

Table 18. Respondent's Age

State (names abbreviated)	18 – 34	35 – 54	55 – 74	75 or older	N
<b>AZ</b>	0%	10%	69%	21%	162
<b>GA</b>	1%	10%	58%	31%	321
<b>MD</b>	1%	8%	70%	21%	388
<b>NJ</b>	1%	7%	65%	27%	586
<b>PA</b>	0%	10%	67%	23%	631
<b>Weighted NCI-IDD Average</b>	<b>1%</b>	<b>9%</b>	<b>67%</b>	<b>24%</b>	<b>2,088</b>

Table 19. Respondent's Health

State (names abbreviated)	Excellent	Very good	Good	Fair	Poor	N
<b>AZ</b>	20%	33%	37%	8%	2%	162
<b>GA</b>	12%	33%	33%	19%	3%	322
<b>MD</b>	15%	33%	37%	12%	2%	386
<b>NJ</b>	16%	37%	33%	13%	2%	587
<b>PA</b>	14%	35%	34%	13%	3%	634
<b>Weighted NCI-IDD Average</b>	<b>15%</b>	<b>35%</b>	<b>35%</b>	<b>13%</b>	<b>3%</b>	<b>2,091</b>

Table 20. Respondent’s Relationship to Family Member

State (names abbreviated)	Parent	Sibling	Spouse	Grandparent	Public guardian	Private guardian	Other	N
<b>AZ</b>	64%	21%	0%	2%	6%	3%	4%	159
<b>GA</b>	62%	23%	0%	2%	0%	0%	12%	321
<b>MD</b>	76%	17%	0%	1%	1%	0%	6%	395
<b>NJ</b>	66%	25%	0%	0%	0%	1%	8%	586
<b>PA</b>	70%	22%	0%	2%	1%	3%	3%	640
<b>Weighted NCI-IDD Average</b>	<b>69%</b>	<b>21%</b>	<b>0%</b>	<b>1%</b>	<b>1%</b>	<b>2%</b>	<b>6%</b>	<b>2,101</b>



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

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

State (names abbreviated)	Did not visit	1 to 3 times	4 to 6 times	7 to 12 times	More than 12 times	N
<b>AZ</b>	4%	10%	12%	11%	62%	162
<b>GA</b>	2%	15%	8%	16%	59%	319
<b>MD</b>	1%	4%	10%	11%	74%	392
<b>NJ</b>	5%	11%	10%	11%	62%	586
<b>PA</b>	3%	9%	12%	14%	61%	646
<b>Weighted NCI-IDD Average</b>	<b>3%</b>	<b>9%</b>	<b>11%</b>	<b>13%</b>	<b>64%</b>	<b>2,105</b>

Table 22. Respondent's Highest Level of Education

State (names abbreviated)	No high school diploma or GED	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	2%	17%	5%	28%	48%	162
GA	5%	21%	7%	20%	48%	317
MD	2%	12%	2%	18%	66%	377
NJ	1%	10%	3%	14%	71%	580
PA	3%	22%	7%	18%	50%	632
<b>Weighted NCI-IDD Average</b>	<b>3%</b>	<b>17%</b>	<b>5%</b>	<b>19%</b>	<b>57%</b>	<b>2,068</b>

Table 23. Total Taxable Household Income of Wage Earners last year

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

State (names abbreviated)	No earned income	Up to \$15,000	\$15,001–\$25,000	\$25,001–\$50,000	\$50,001–\$75,000	Over \$75,000	Prefer not to say	N
AZ	10%	5%	5%	15%	12%	19%	34%	150
GA	11%	4%	9%	12%	10%	18%	36%	302
MD	8%	2%	4%	9%	12%	35%	31%	381
NJ	9%	3%	4%	9%	10%	27%	40%	582
PA	10%	4%	5%	15%	9%	18%	38%	613
<b>Weighted NCI-IDD Average</b>	<b>10%</b>	<b>4%</b>	<b>5%</b>	<b>12%</b>	<b>10%</b>	<b>23%</b>	<b>36%</b>	<b>2,028</b>

## **Services and Supports Received**

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

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

Table 24a. Services and Supports Received IDD Agency

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

State (names abbreviated)	Financial support	In-home support	Residential supports	Day or employment supports
<b>AZ</b>	25%	28%	95%	70%
<b>GA</b>	35%	50%	79%	72%
<b>MD</b>	30%	47%	85%	72%
<b>NJ</b>	34%	34%	81%	74%
<b>PA</b>	27%	31%	96%	56%
<b>Weighted NCI-IDD Average</b>	<b>29%</b>	<b>36%</b>	<b>90%</b>	<b>65%</b>

Table 24b. Services and Supports Received from State (continued)

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

State (names abbreviated)	Transportation	Mental or behavioral health care or other treatments or therapies	Self-direction or fiscal intermediary services
AZ	96%	65%	27%
GA	94%	54%	19%
MD	91%	58%	15%
NJ	90%	59%	26%
PA	95%	68%	13%
<b>Weighted NCI-IDD Average</b>	<b>93%</b>	<b>63%</b>	<b>18%</b>

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

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

State (names abbreviated)	Social Security (SSI or SSB)	Services or supports from other agencies or organizations
AZ	99%	22%
GA	97%	25%
MD	97%	21%
NJ	95%	26%
PA	98%	29%
<b>Weighted NCI-IDD Average</b>	<b>97%</b>	<b>25%</b>

# Main Survey Results



## Information and Planning

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

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

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

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

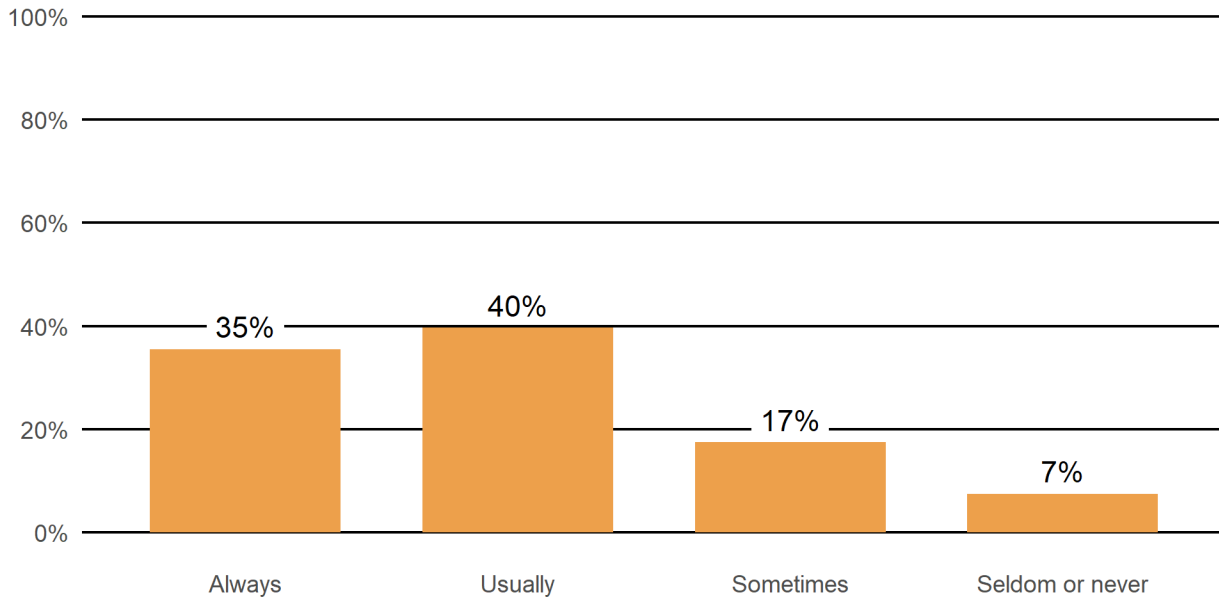


Table 26. Do you get enough information to take part in planning services for your family member?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	48%	38%	11%	3%	157
GA	27%	42%	24%	7%	278
MD	30%	37%	20%	12%	380
NJ	33%	39%	20%	9%	559
PA	37%	41%	16%	6%	601
<b>Weighted NCI-IDD Average</b>	<b>35%</b>	<b>40%</b>	<b>17%</b>	<b>7%</b>	<b>1,975</b>

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

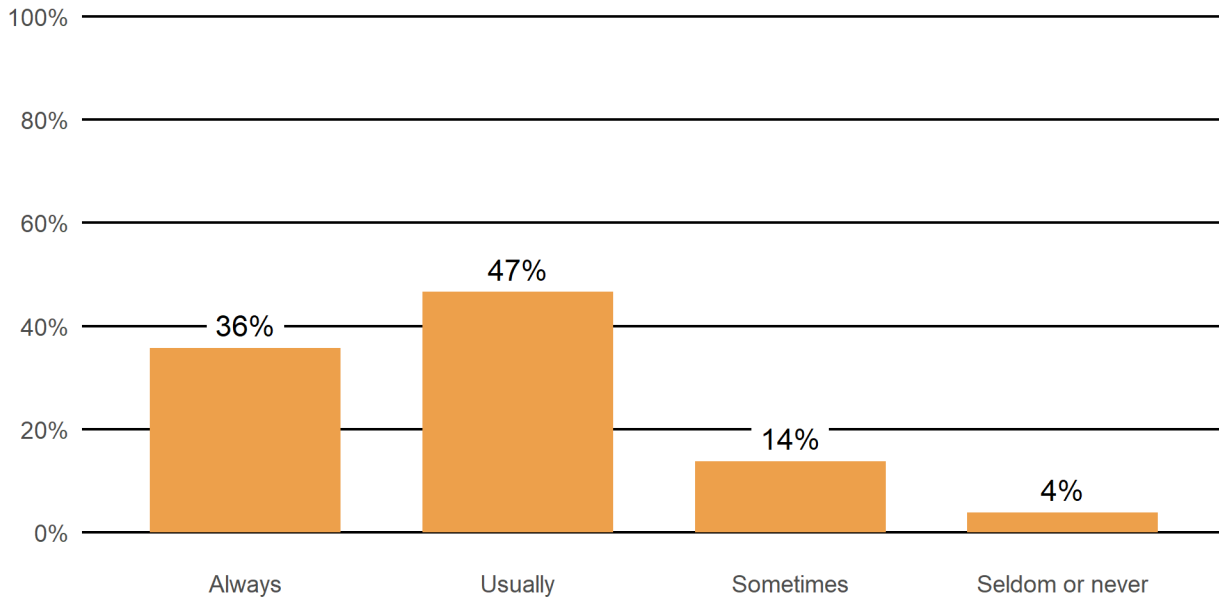


Table 27. Is the information you get about services and supports easy to understand?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	40%	52%	8%	0%	156
GA	31%	46%	20%	3%	286
MD	29%	46%	17%	8%	368
NJ	32%	48%	16%	5%	545
PA	41%	45%	12%	3%	606
<b>Weighted NCI-IDD Average</b>	<b>36%</b>	<b>47%</b>	<b>14%</b>	<b>4%</b>	<b>1,961</b>

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

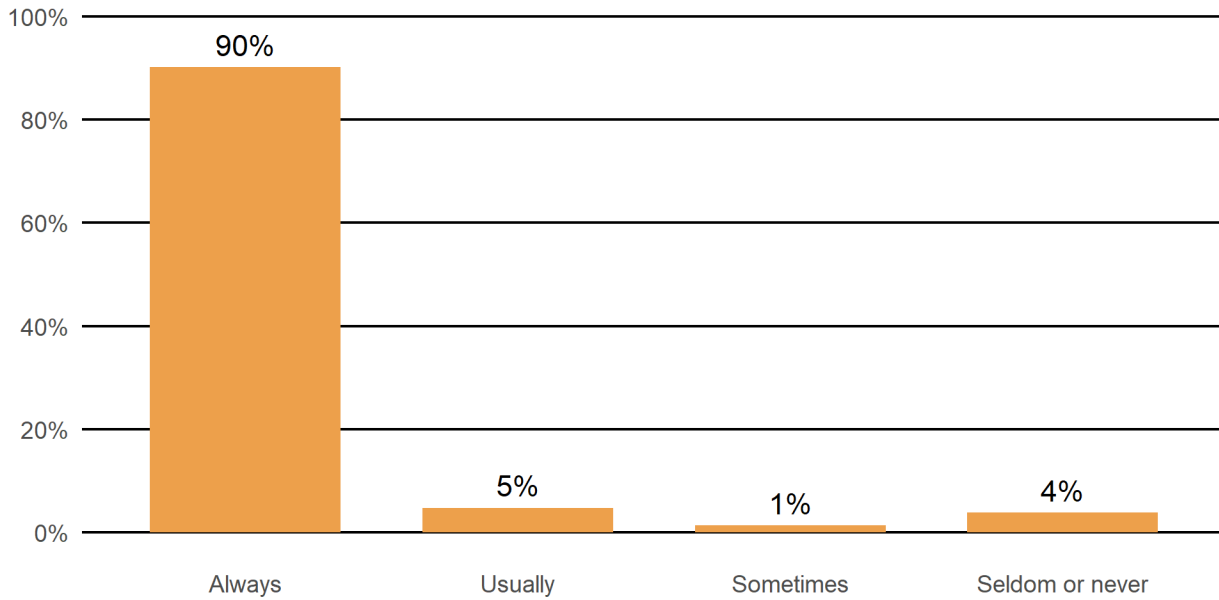


Table 28. Do you get information about services and supports in your preferred language?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	92%	4%	1%	3%	159
GA	88%	5%	3%	4%	298
MD	88%	6%	1%	5%	386
NJ	93%	2%	1%	4%	575
PA	89%	5%	2%	3%	633
<b>Weighted NCI-IDD Average</b>	<b>90%</b>	<b>5%</b>	<b>1%</b>	<b>4%</b>	<b>2,051</b>

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

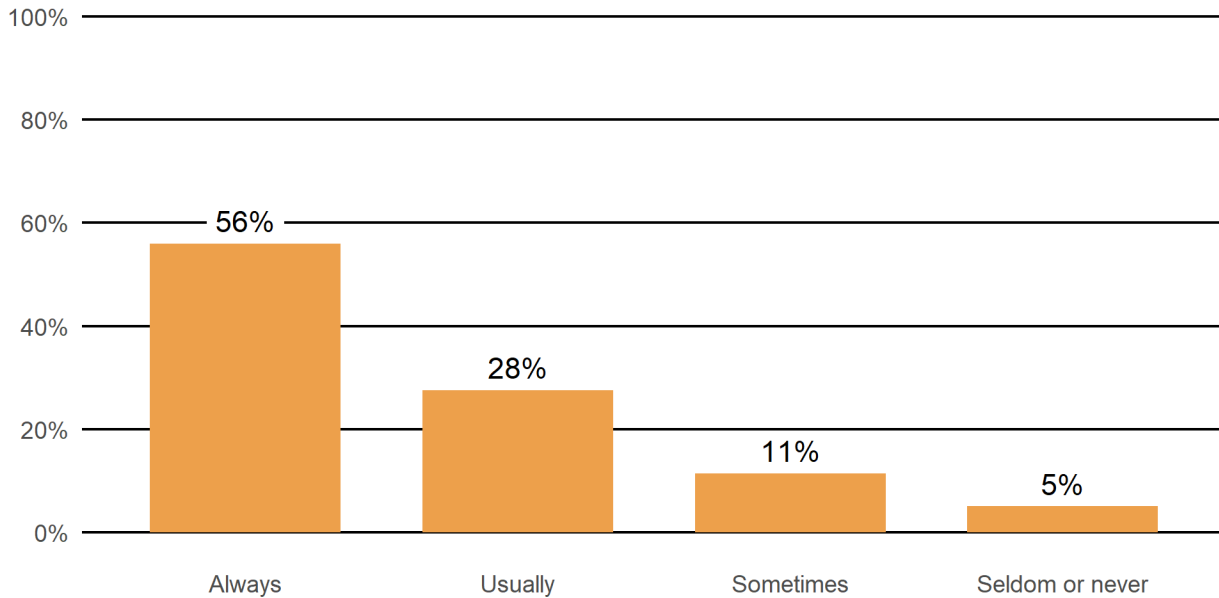


Table 29. Does the case manager or service coordinator listen to your family's choices and opinions?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	66%	22%	9%	3%	160
GA	46%	38%	11%	6%	283
MD	50%	30%	13%	7%	383
NJ	59%	25%	11%	5%	559
PA	57%	27%	12%	5%	612
<b>Weighted NCI-IDD Average</b>	<b>56%</b>	<b>28%</b>	<b>11%</b>	<b>5%</b>	<b>1,997</b>

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

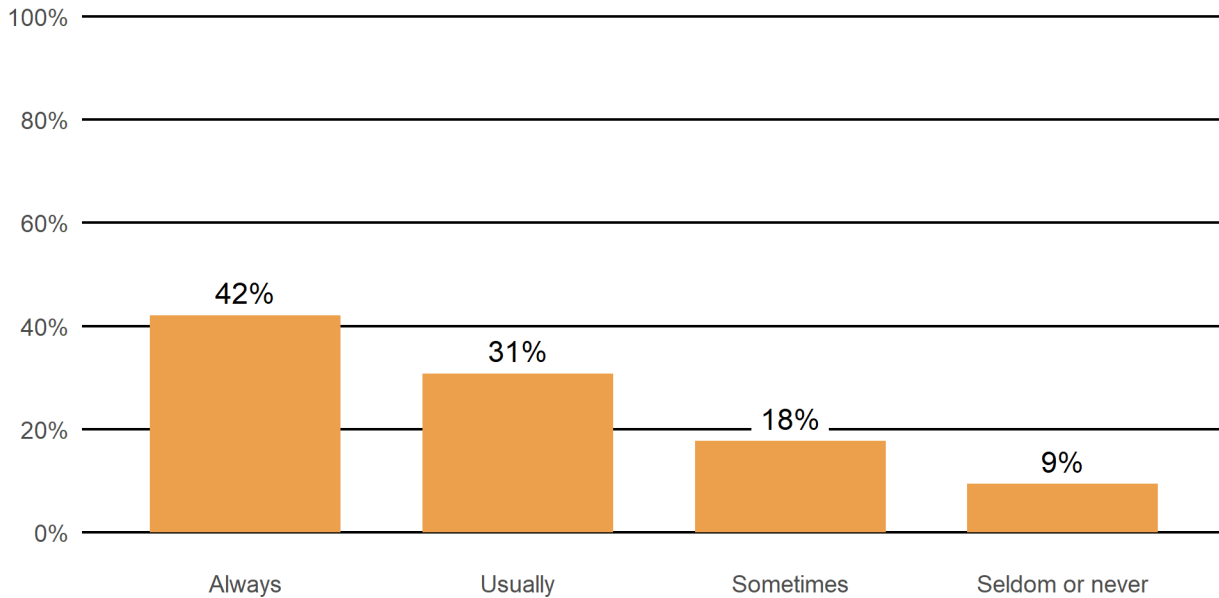


Table 30. Do staff or the residential agency keep you informed about how your family member is doing?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	48%	34%	13%	4%	159
GA	41%	32%	19%	8%	295
MD	34%	28%	23%	15%	383
NJ	40%	28%	19%	13%	522
PA	45%	32%	15%	7%	641
<b>Weighted NCI-IDD Average</b>	<b>42%</b>	<b>31%</b>	<b>18%</b>	<b>9%</b>	<b>2,000</b>

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

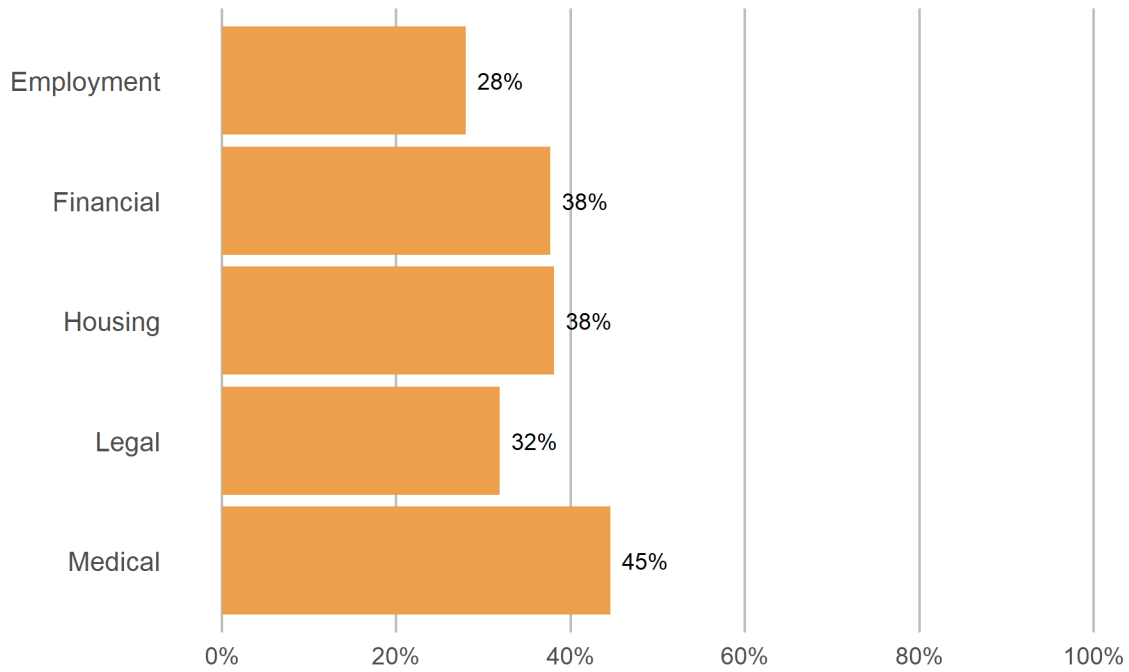


Table 31a. Do you need help planning for your family member's future in any of these areas?

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

State (names abbreviated)	Employment	Financial	Housing	Legal	Medical
<b>AZ</b>	16%	31%	36%	29%	40%
<b>GA</b>	24%	46%	49%	36%	51%
<b>MD</b>	35%	37%	38%	32%	41%
<b>NJ</b>	28%	39%	39%	31%	47%
<b>PA</b>	27%	37%	35%	32%	45%
<b>Weighted NCI-IDD Average</b>	<b>28%</b>	<b>38%</b>	<b>38%</b>	<b>32%</b>	<b>45%</b>

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

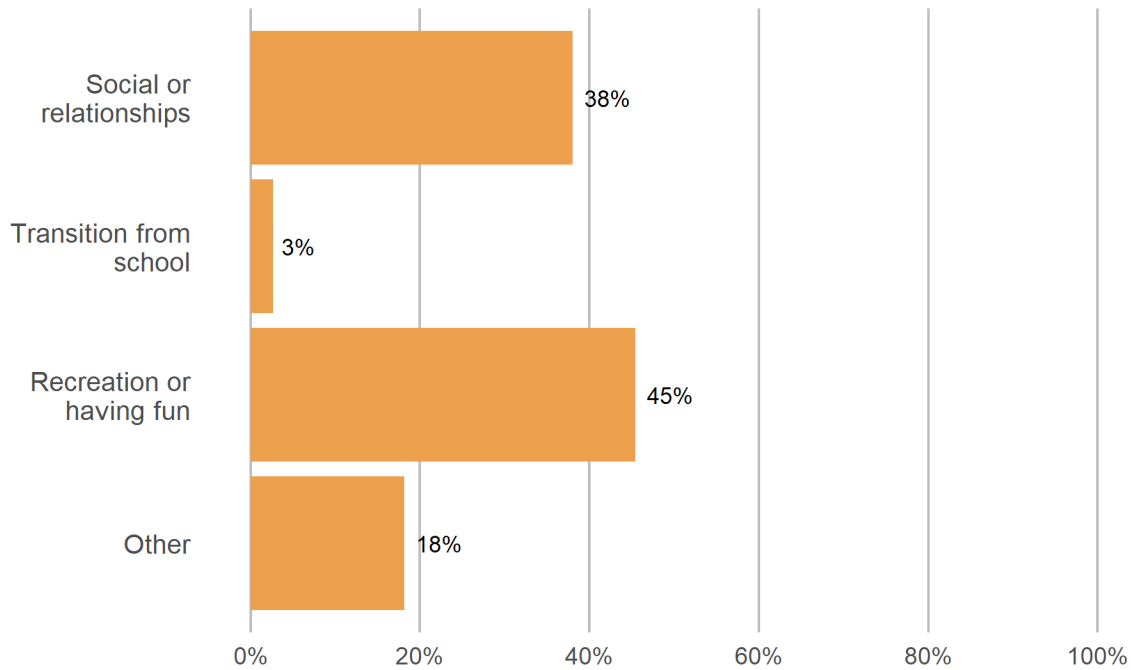


Table 31b. Do you need help planning for your family member's future in any of these areas? (Continued)

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

State (names abbreviated)	Social or relationships	Transition from school	Recreation or having fun	Other
AZ	25%	4%	32%	32%
GA	39%	2%	41%	15%
MD	36%	2%	43%	19%
NJ	42%	3%	48%	20%
PA	40%	2%	51%	13%
<b>Weighted NCI-IDD Average</b>	<b>38%</b>	<b>3%</b>	<b>45%</b>	<b>18%</b>



## Has your family learned about alternatives to guardianship?

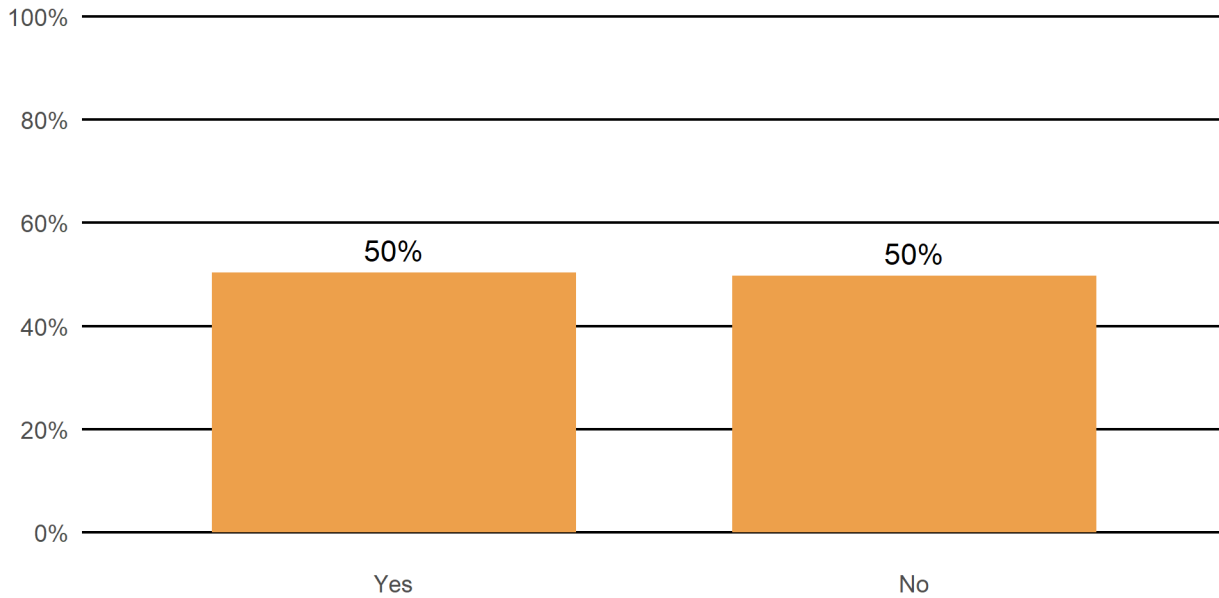


Table 32. Has your family learned about alternatives to guardianship?

State (names abbreviated)	Yes	No	N
AZ	57%	43%	138
GA	40%	60%	244
MD	53%	47%	342
NJ	50%	50%	478
PA	49%	51%	499
<b>Weighted NCI-IDD Average</b>	<b>50%</b>	<b>50%</b>	<b>1,701</b>

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

## Does your family member have a service plan?

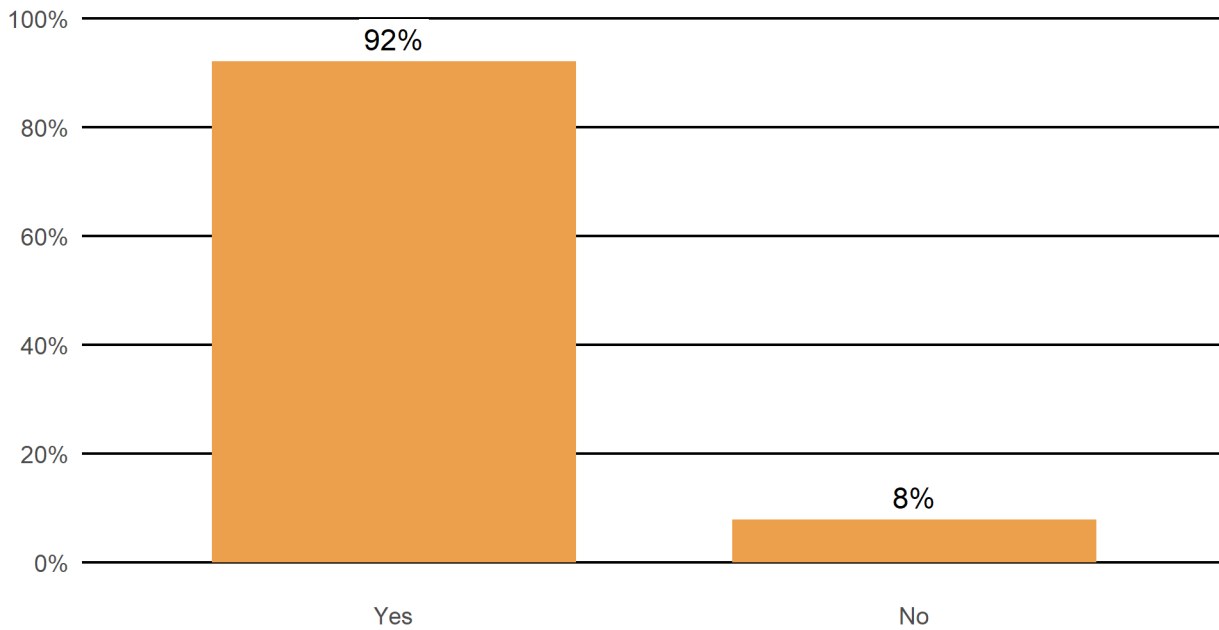


Table 33. Does your family member have a service plan?

State (names abbreviated)	Yes	No	N
<b>AZ</b>	75%	25%	123
<b>GA</b>	86%	14%	238
<b>MD</b>	91%	9%	336
<b>NJ</b>	91%	9%	467
<b>PA</b>	98%	2%	601
<b>Weighted NCI-IDD Average</b>	<b>92%</b>	<b>8%</b>	<b>1,765</b>

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

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

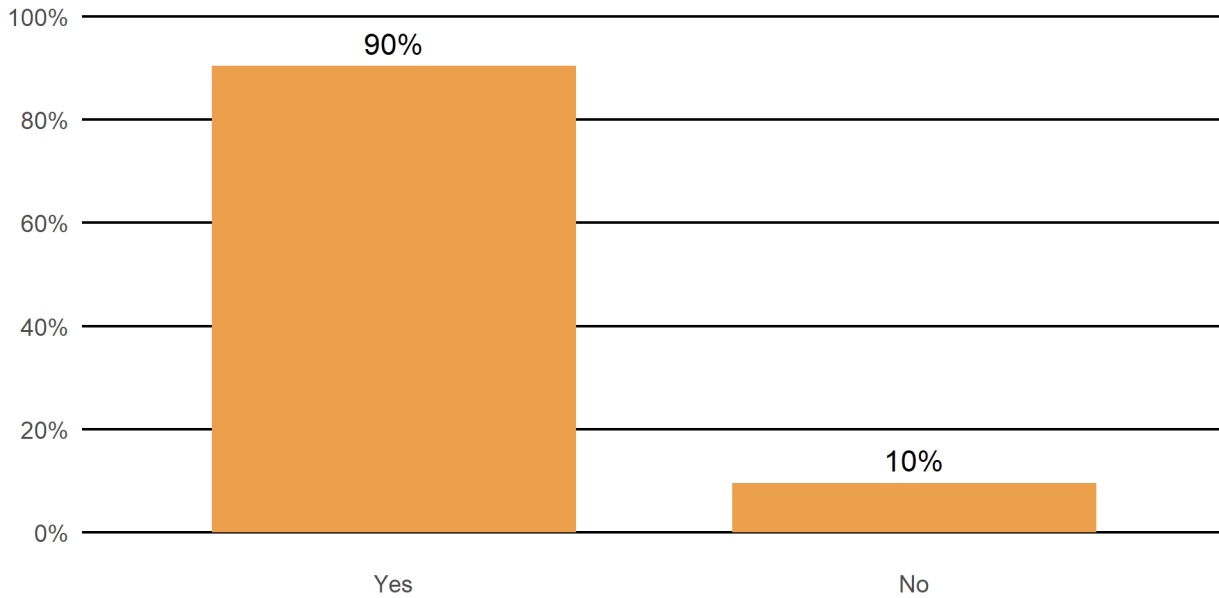


Table 34. Does the plan include all the services and supports your family member needs?

State (names abbreviated)	Yes	No	N
AZ	94%	6%	88
GA	87%	13%	180
MD	85%	15%	267
NJ	86%	14%	392
PA	94%	6%	536
<b>Weighted NCI-IDD Average</b>	<b>90%</b>	<b>10%</b>	<b>1,463</b>

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

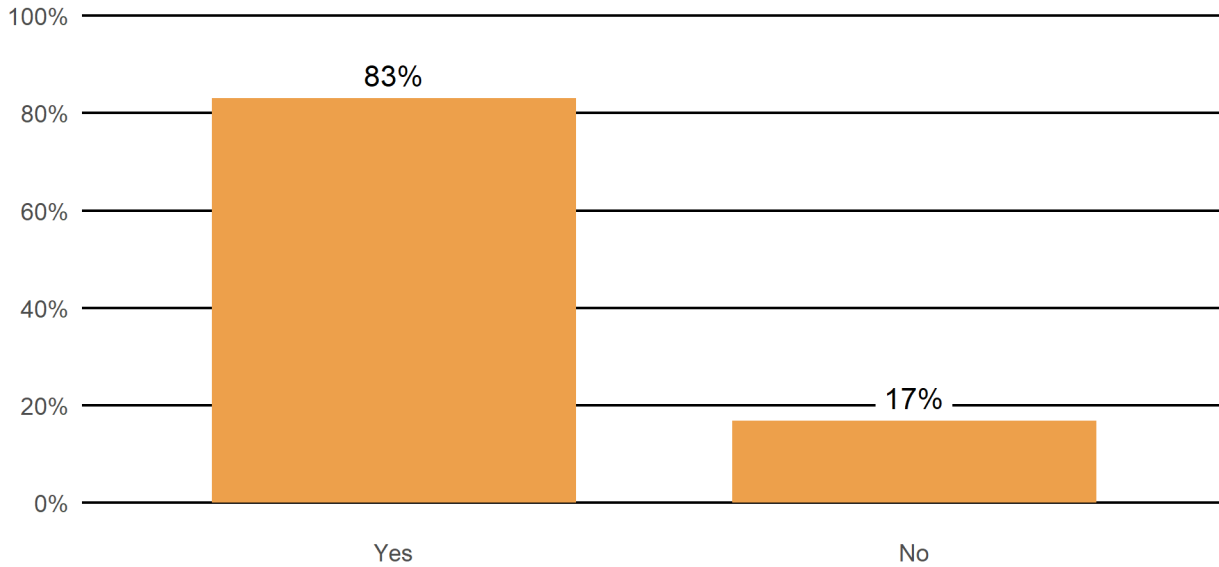


Table 35. Did you or someone else in your family (besides your family member with a disability) help make the plan?

State (names abbreviated)	Yes	No	N
AZ	90%	10%	84
GA	81%	19%	191
MD	88%	12%	294
NJ	86%	14%	412
PA	79%	21%	567
<b>Weighted NCI-IDD Average</b>	<b>83%</b>	<b>17%</b>	<b>1,548</b>

## Did your family member help make the plan?

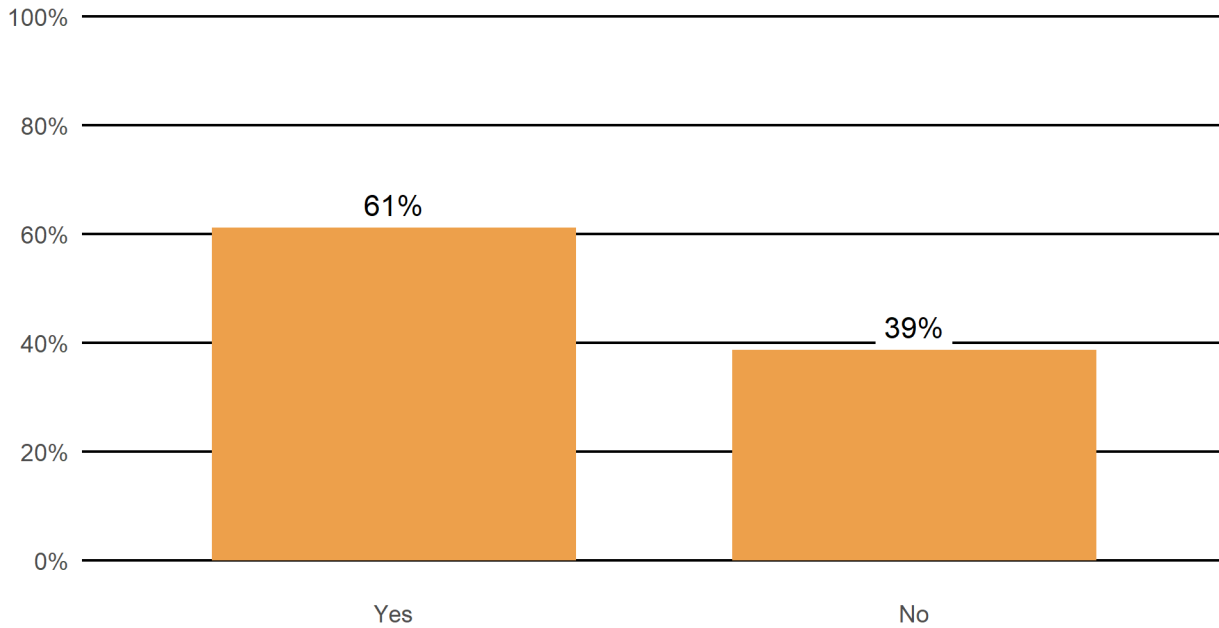


Table 36. Did your family member help make the plan?

State (names abbreviated)	Yes	No	N
AZ	54%	46%	82
GA	70%	30%	186
MD	74%	26%	289
NJ	58%	42%	399
PA	57%	43%	527
<b>Weighted NCI-IDD Average</b>	<b>61%</b>	<b>39%</b>	<b>1,483</b>

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

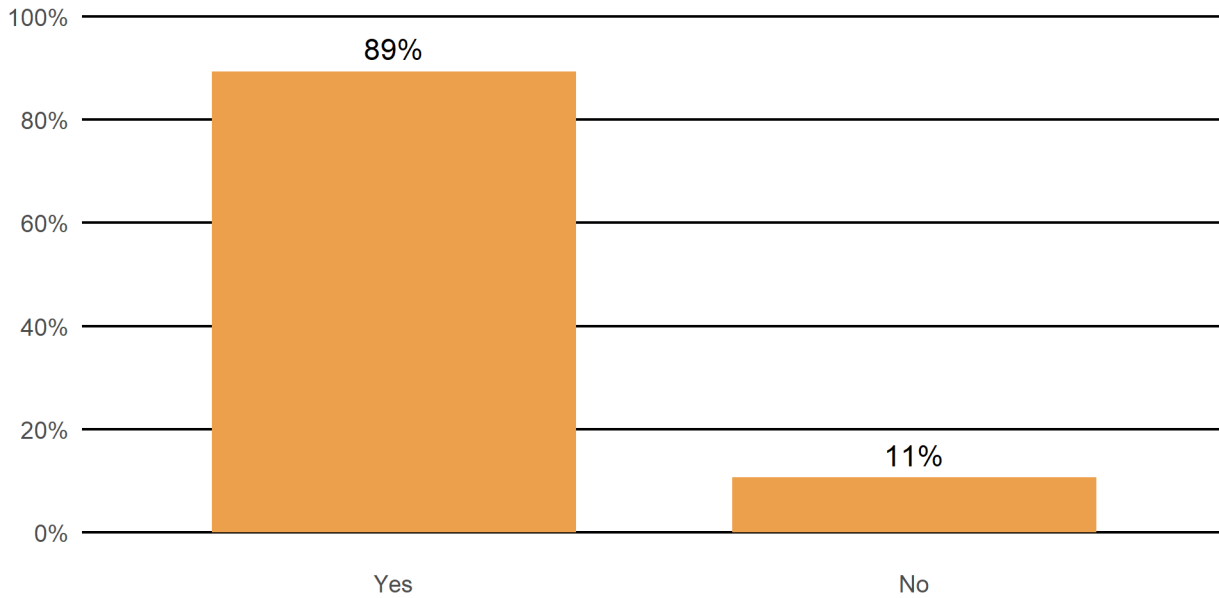


Table 37. Do you feel like your family had enough say or input in making the plan?

State (names abbreviated)	Yes	No	N
<b>AZ</b>	99%	1%	82
<b>GA</b>	85%	15%	182
<b>MD</b>	88%	12%	282
<b>NJ</b>	89%	11%	396
<b>PA</b>	89%	11%	524
<b>Weighted NCI-IDD Average</b>	<b>89%</b>	<b>11%</b>	<b>1,466</b>

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

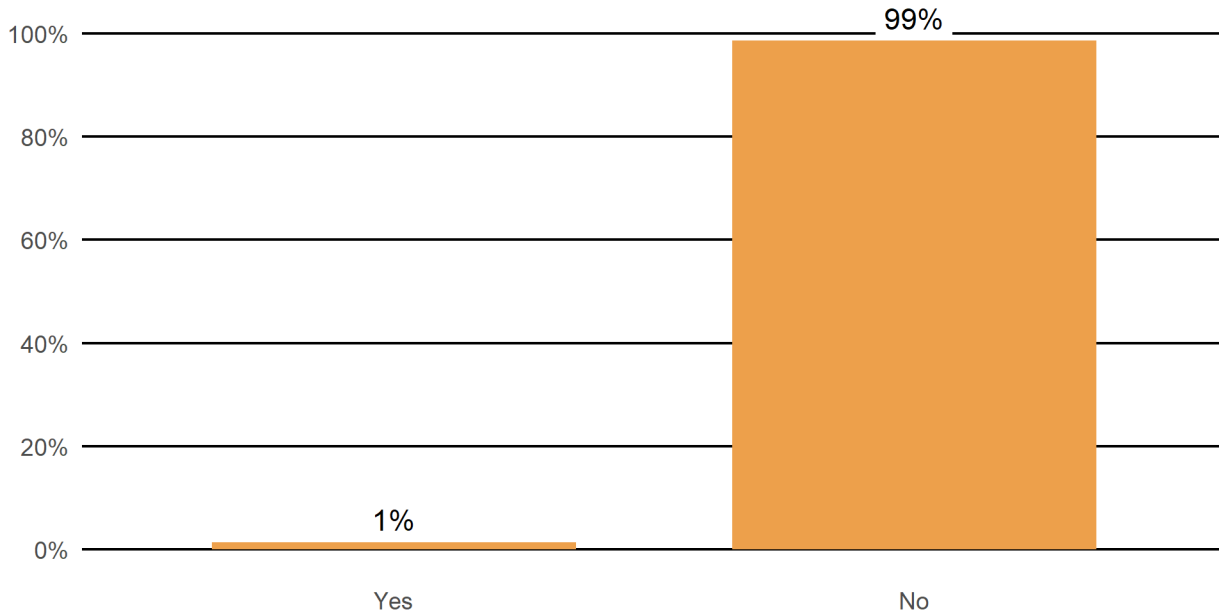


Table 38. Did your family member leave school services and begin adult services during the past 12 months?

State (names abbreviated)	Yes	No	N
AZ	0%	100%	157
GA	0%	100%	291
MD	3%	97%	389
NJ	1%	99%	558
PA	1%	99%	624
<b>Weighted NCI-IDD Average</b>	<b>1%</b>	<b>99%</b>	<b>2,019</b>

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

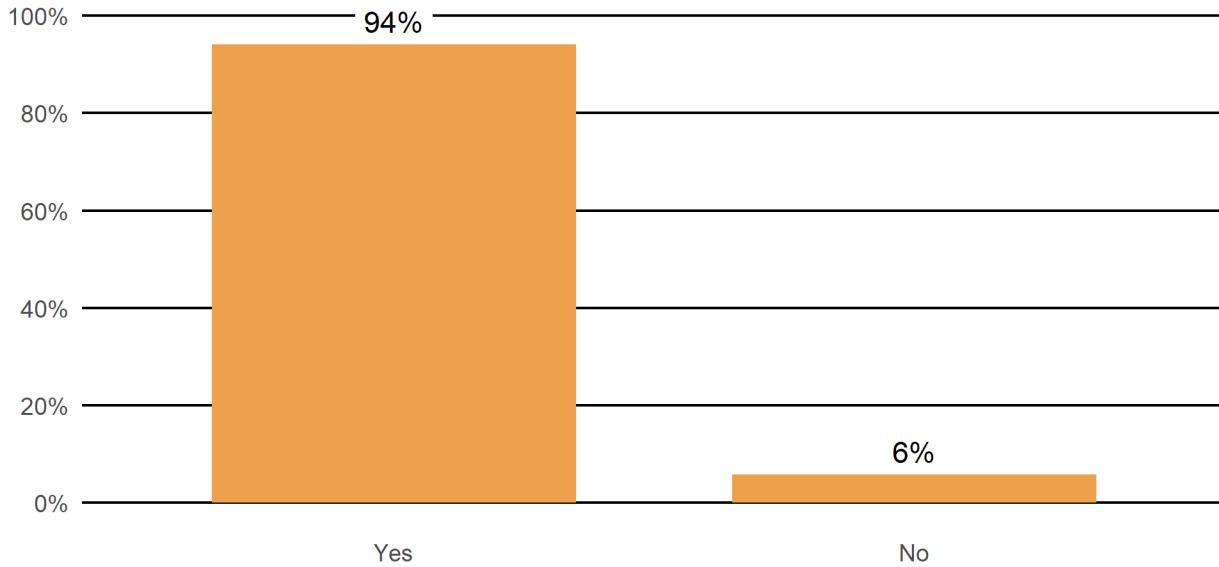


Table 39. If your family member left school services during the past 12 months, did your family member have a transition plan?

State (names abbreviated)	Yes	No	N
<b>Weighted NCI-IDD Average</b>	<b>94%</b>	<b>6%</b>	<b>24</b>

The following states had a low count of responses (N<20) and were not shown: AZ, GA, MD, NJ, PA



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

Observed N overall was less than 20. Table and chart not reported.

## 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.*

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

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

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

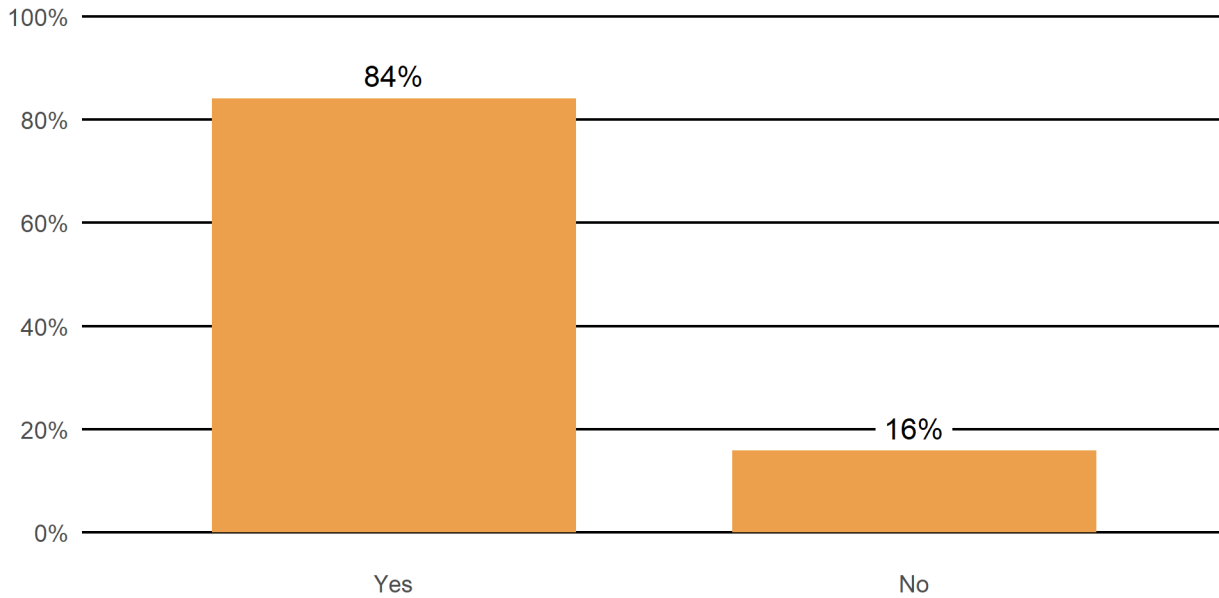


Table 41. Does your family member get all the services listed in the plan?

State (names abbreviated)	Yes	No	N
AZ	89%	11%	83
GA	83%	18%	160
MD	73%	27%	251
NJ	80%	20%	384
PA	90%	10%	489
<b>Weighted NCI-IDD Average</b>	<b>84%</b>	<b>16%</b>	<b>1,367</b>

## Does your family get the supports and services it needs?

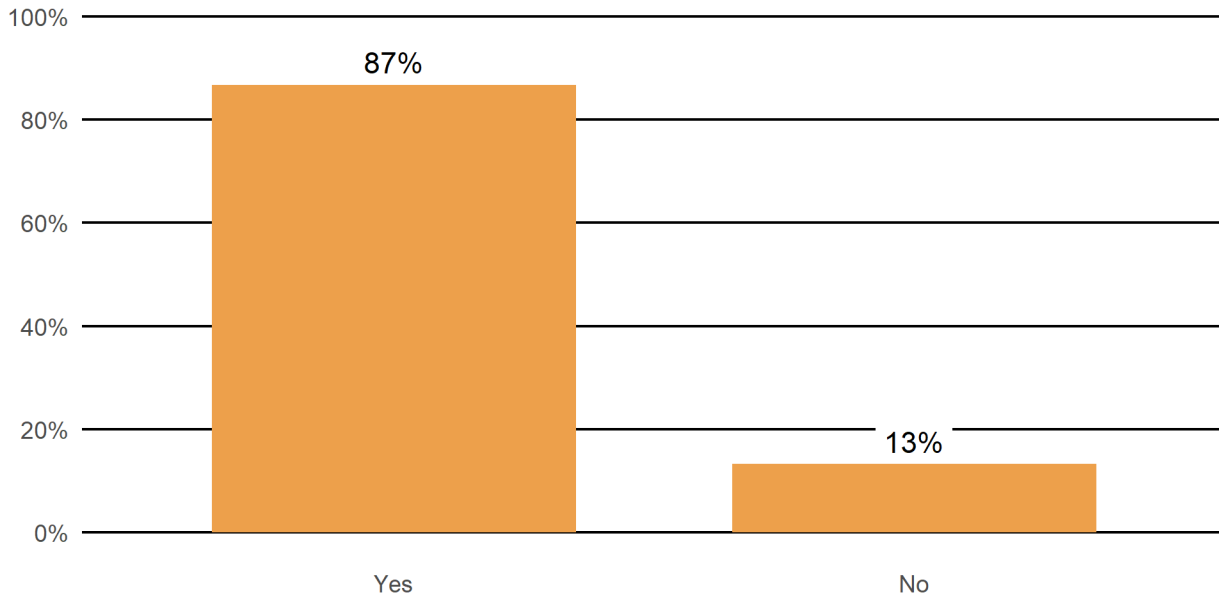


Table 42. Does your family get the supports and services it needs?

State (names abbreviated)	Yes	No	N
<b>AZ</b>	93%	7%	150
<b>GA</b>	86%	14%	265
<b>MD</b>	80%	20%	350
<b>NJ</b>	83%	17%	507
<b>PA</b>	90%	10%	589
<b>Weighted NCI-IDD Average</b>	<b>87%</b>	<b>13%</b>	<b>1,861</b>

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

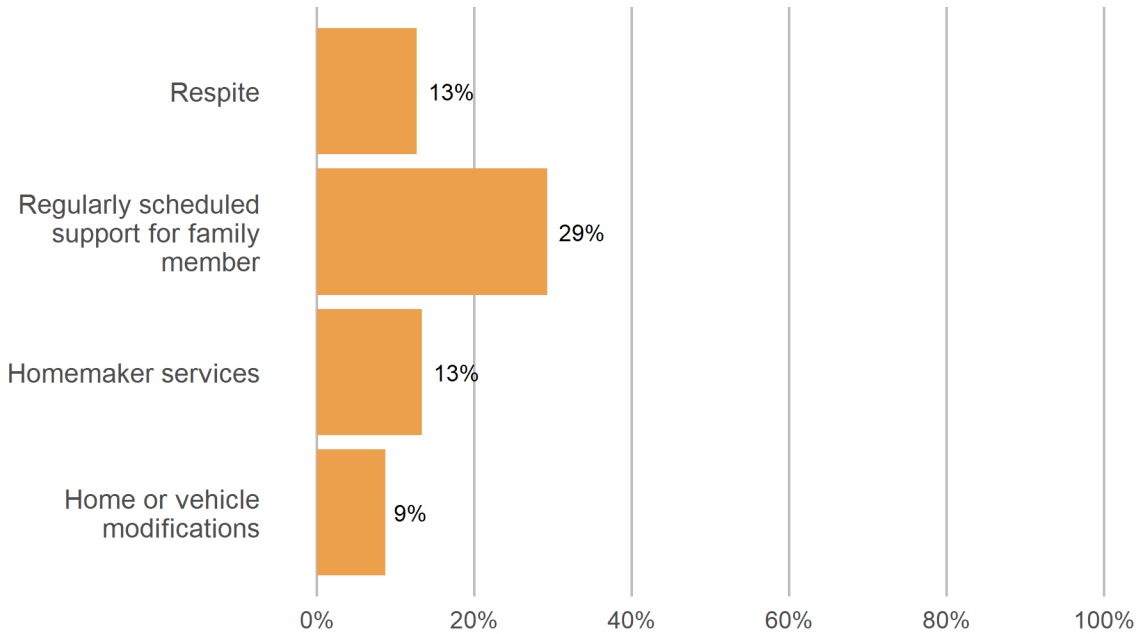


Table 43a. If your family does not get the support and services needed, what additional services does your family need?

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

State (names abbreviated)	Respite	Regularly scheduled support for family member	Homemaker services	Home or vehicle modifications
GA	13%	41%	13%	3%
MD	12%	38%	15%	8%
NJ	15%	32%	27%	10%
PA	12%	20%	2%	10%
<b>Weighted NCI-IDD Average</b>	<b>13%</b>	<b>29%</b>	<b>13%</b>	<b>9%</b>

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

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

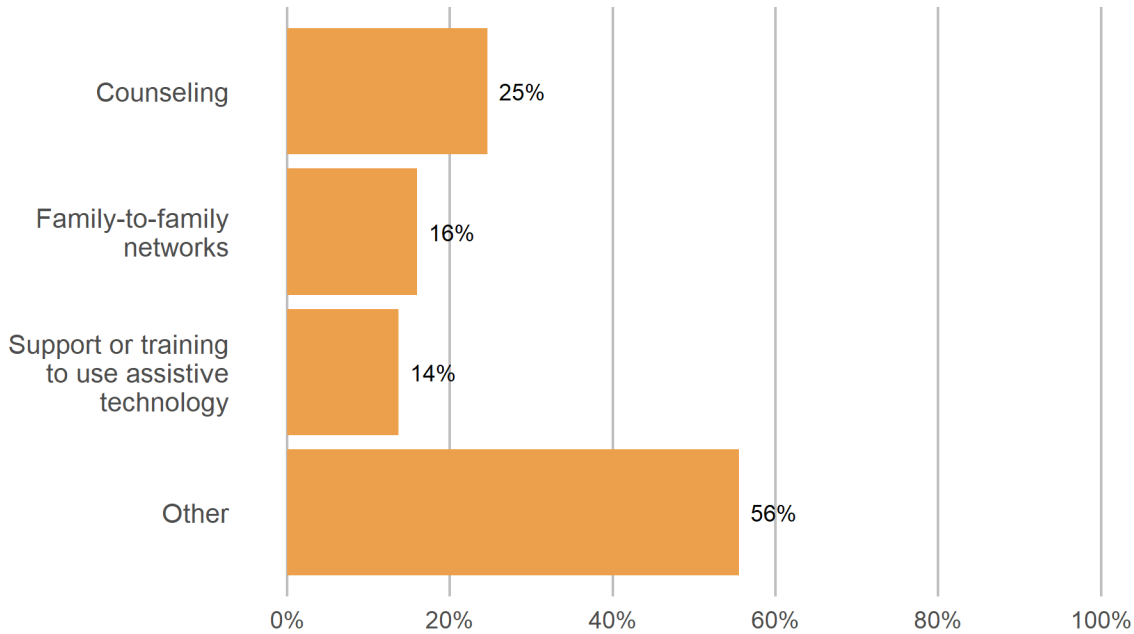


Table 43b. If your family does not get the support and services needed, what additional services does your family need? (Continued)

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

State (names abbreviated)	Counseling	Family-to-family networks	Support or training to use assistive technology	Other
<b>GA</b>	28%	19%	13%	44%
<b>MD</b>	23%	18%	15%	65%
<b>NJ</b>	30%	24%	13%	53%
<b>PA</b>	20%	8%	12%	55%
<b>Weighted NCI-IDD Average</b>	<b>25%</b>	<b>16%</b>	<b>14%</b>	<b>56%</b>

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

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

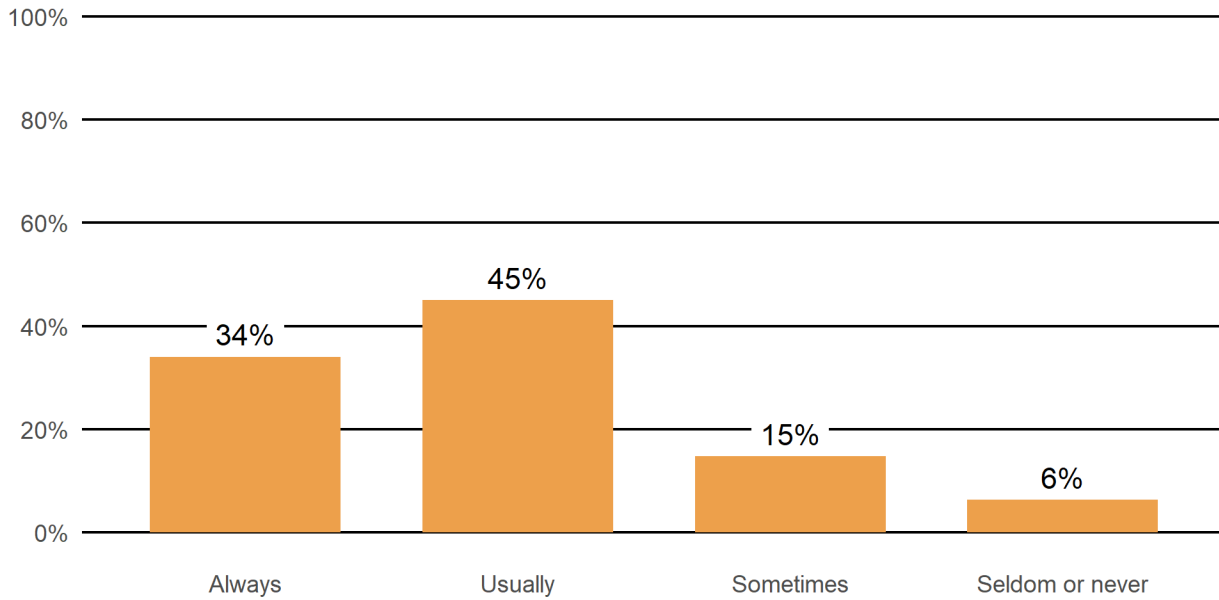


Table 44. Do services and supports change when your family's needs change?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>AZ</b>	32%	56%	10%	3%	117
<b>GA</b>	28%	41%	22%	8%	187
<b>MD</b>	29%	41%	20%	10%	274
<b>NJ</b>	34%	41%	17%	8%	392
<b>PA</b>	38%	47%	11%	4%	433
<b>Weighted NCI-IDD Average</b>	<b>34%</b>	<b>45%</b>	<b>15%</b>	<b>6%</b>	<b>1,403</b>

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

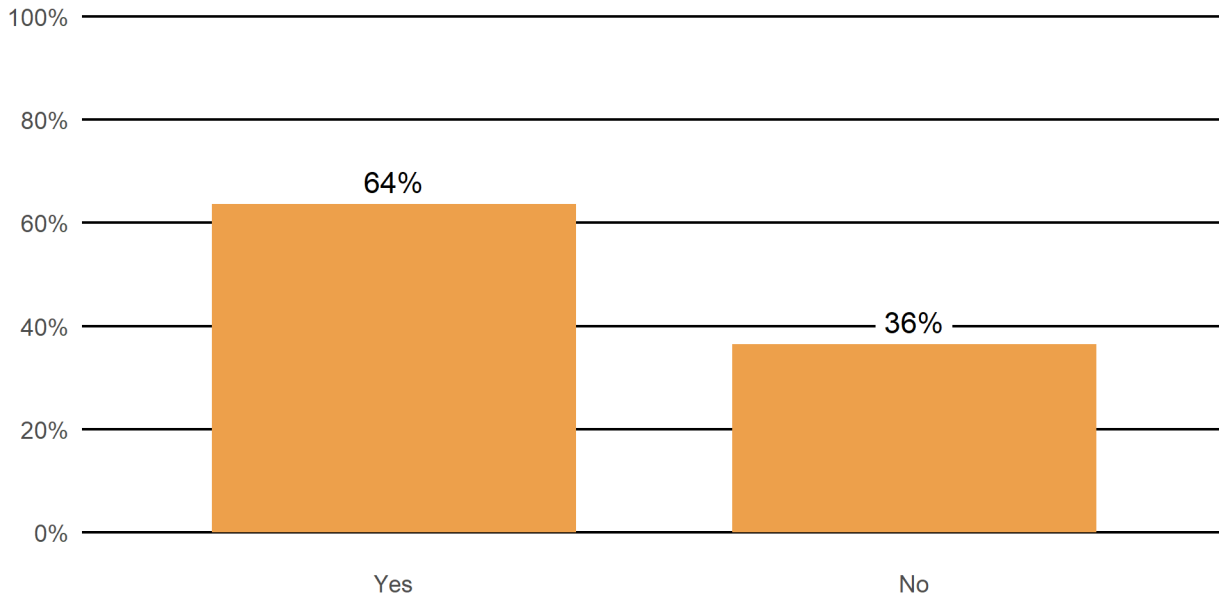


Table 45. Does your family member have enough supports to work or volunteer in the community? (These types of supports might include support workers, community resources, transportation)

State (names abbreviated)	Yes	No	N
AZ	57%	43%	79
GA	59%	41%	191
MD	62%	38%	267
NJ	58%	42%	318
PA	69%	31%	380
<b>Weighted NCI-IDD Average</b>	<b>64%</b>	<b>36%</b>	<b>1,235</b>



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

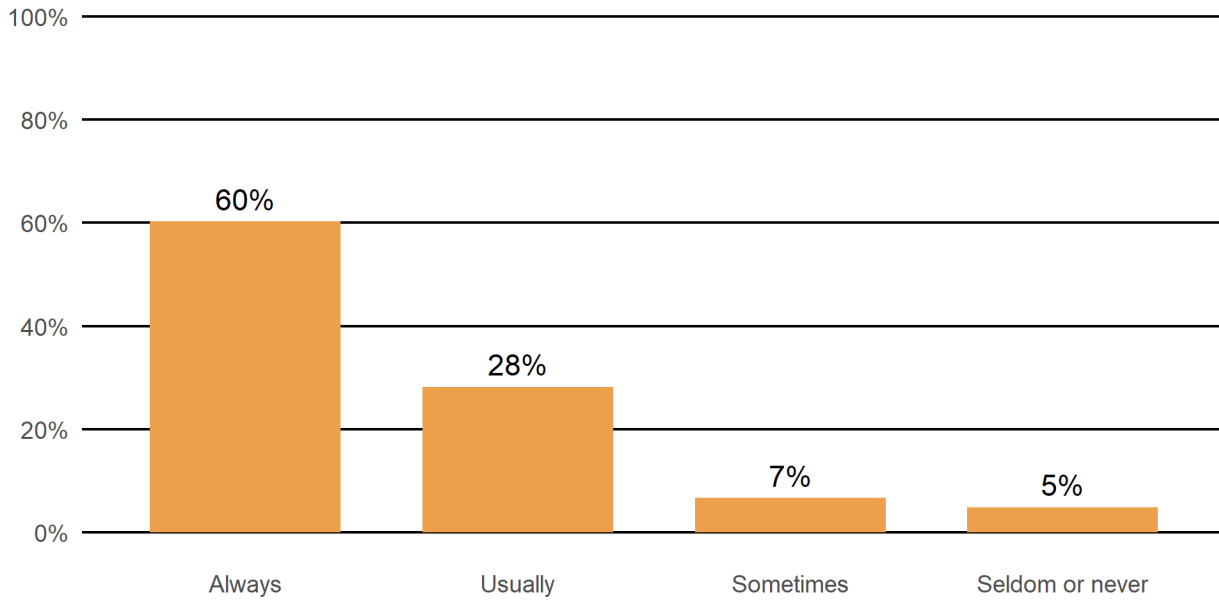


Table 46. Does your family member have the special equipment or accommodations that they need?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	60%	37%	3%	0%	106
GA	49%	37%	10%	4%	156
MD	47%	34%	9%	10%	208
NJ	58%	26%	10%	6%	277
PA	69%	22%	5%	4%	365
<b>Weighted NCI-IDD Average</b>	<b>60%</b>	<b>28%</b>	<b>7%</b>	<b>5%</b>	<b>1,112</b>

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

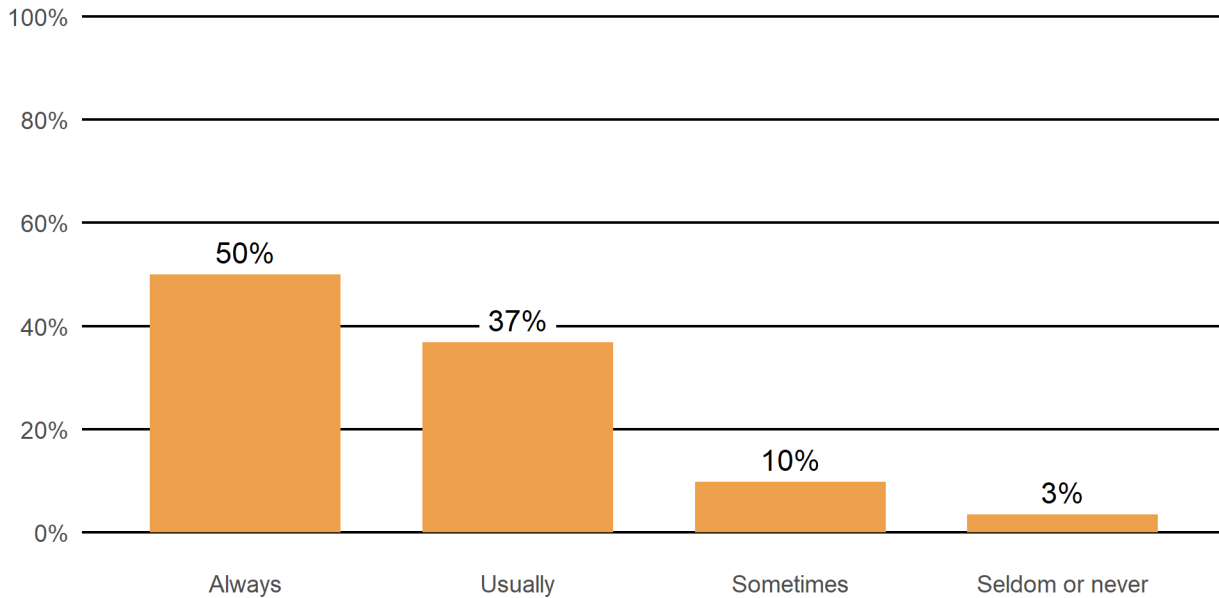


Table 47. Are you or your family member able to contact support workers when you want?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	51%	37%	10%	2%	148
GA	43%	44%	11%	3%	285
MD	42%	38%	16%	5%	361
NJ	51%	34%	9%	6%	525
PA	55%	36%	7%	2%	604
<b>Weighted NCI-IDD Average</b>	<b>50%</b>	<b>37%</b>	<b>10%</b>	<b>3%</b>	<b>1,923</b>

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

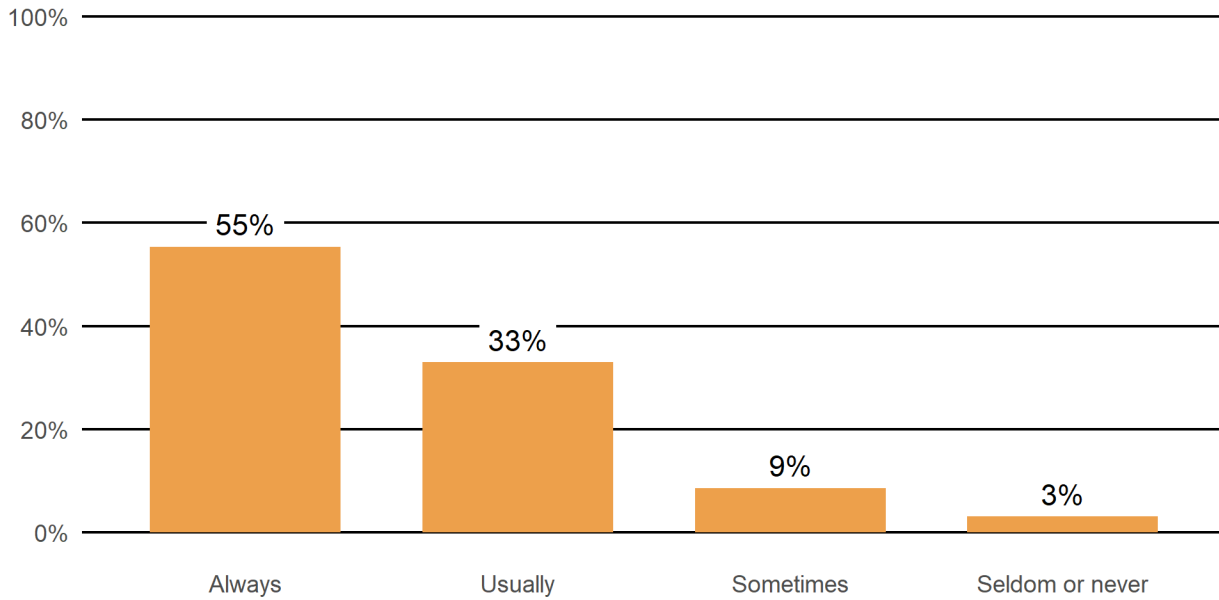


Table 48. Are you or your family member able to contact the case manager or service coordinator when you want?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	56%	35%	6%	2%	154
GA	50%	35%	13%	2%	288
MD	49%	36%	10%	5%	367
NJ	62%	28%	6%	4%	555
PA	56%	33%	9%	2%	608
<b>Weighted NCI-IDD Average</b>	<b>55%</b>	<b>33%</b>	<b>9%</b>	<b>3%</b>	<b>1,972</b>

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

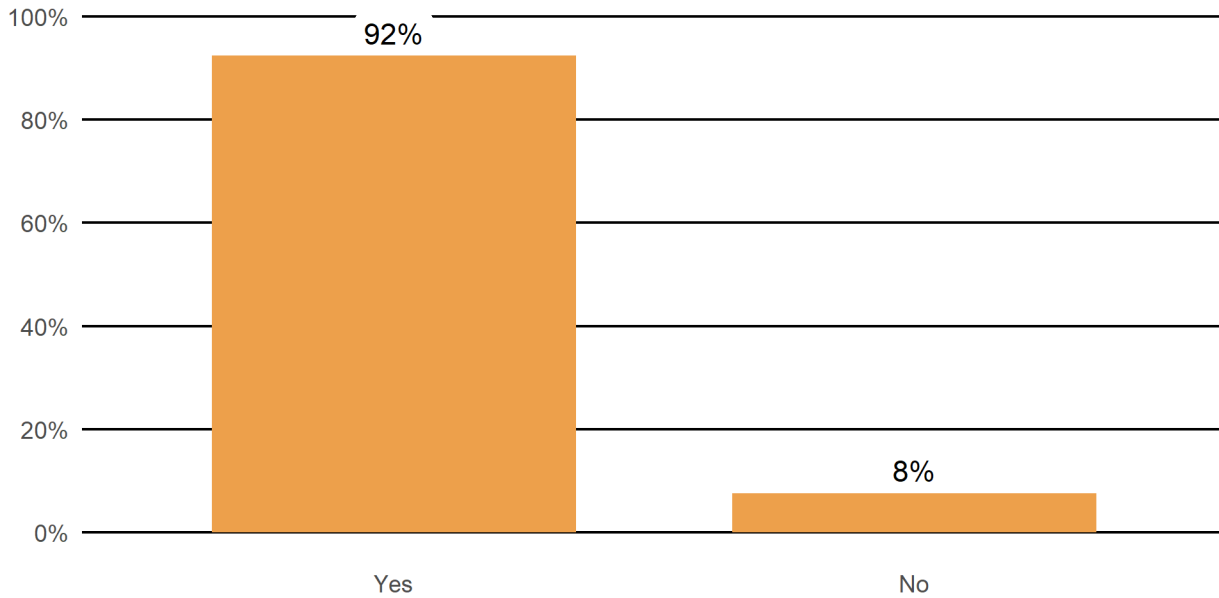


Table 49. Do service providers for your family member work together to provide support?

State (names abbreviated)	Yes	No	N
AZ	95%	5%	129
GA	91%	9%	199
MD	87%	13%	272
NJ	87%	13%	374
PA	97%	3%	443
<b>Weighted NCI-IDD Average</b>	<b>92%</b>	<b>8%</b>	<b>1,417</b>

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

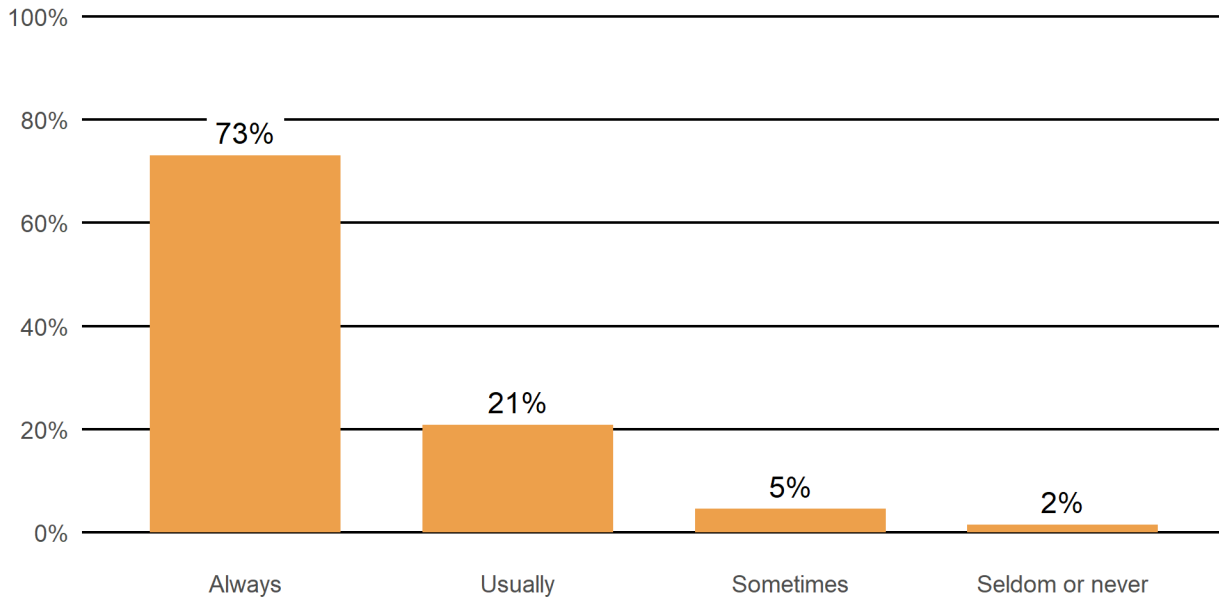


Table 50. Are services delivered in a way that is respectful of your family's culture?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	71%	23%	4%	2%	153
GA	66%	28%	5%	1%	280
MD	68%	25%	4%	3%	368
NJ	77%	18%	4%	1%	528
PA	76%	18%	5%	1%	611
<b>Weighted NCI-IDD Average</b>	<b>73%</b>	<b>21%</b>	<b>5%</b>	<b>2%</b>	<b>1,940</b>

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

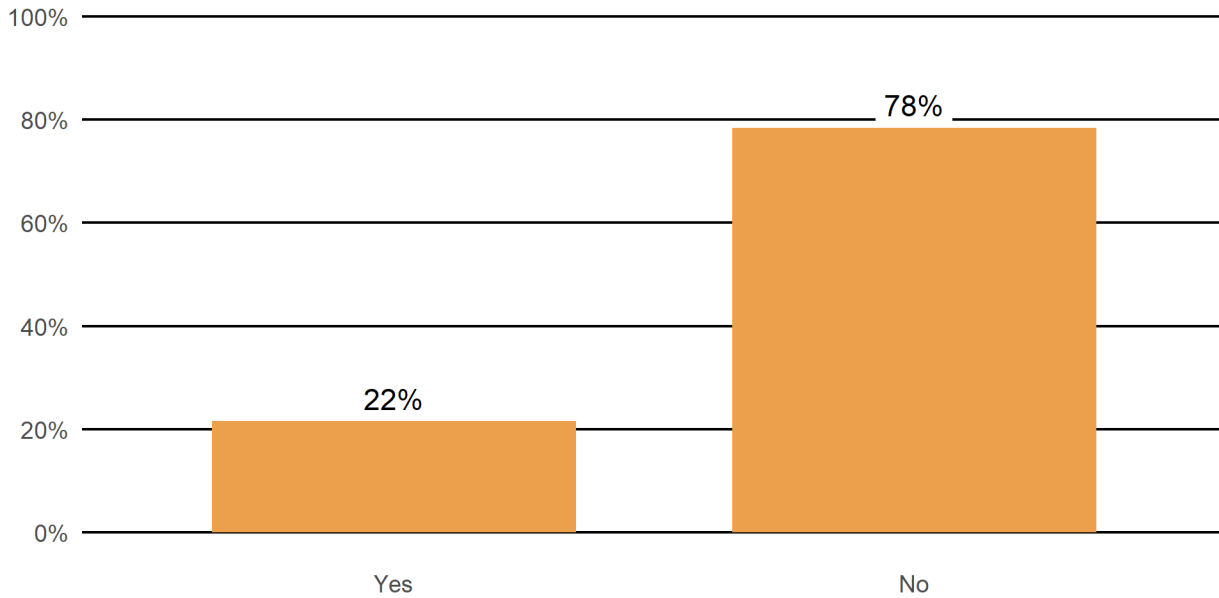


Table 51. Does your family member use technology in their everyday life to help them do things on their own?

State (names abbreviated)	Yes	No	N
AZ	22%	78%	151
GA	22%	78%	282
MD	25%	75%	365
NJ	30%	70%	526
PA	16%	84%	592
<b>Weighted NCI-IDD Average</b>	<b>22%</b>	<b>78%</b>	<b>1,916</b>

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

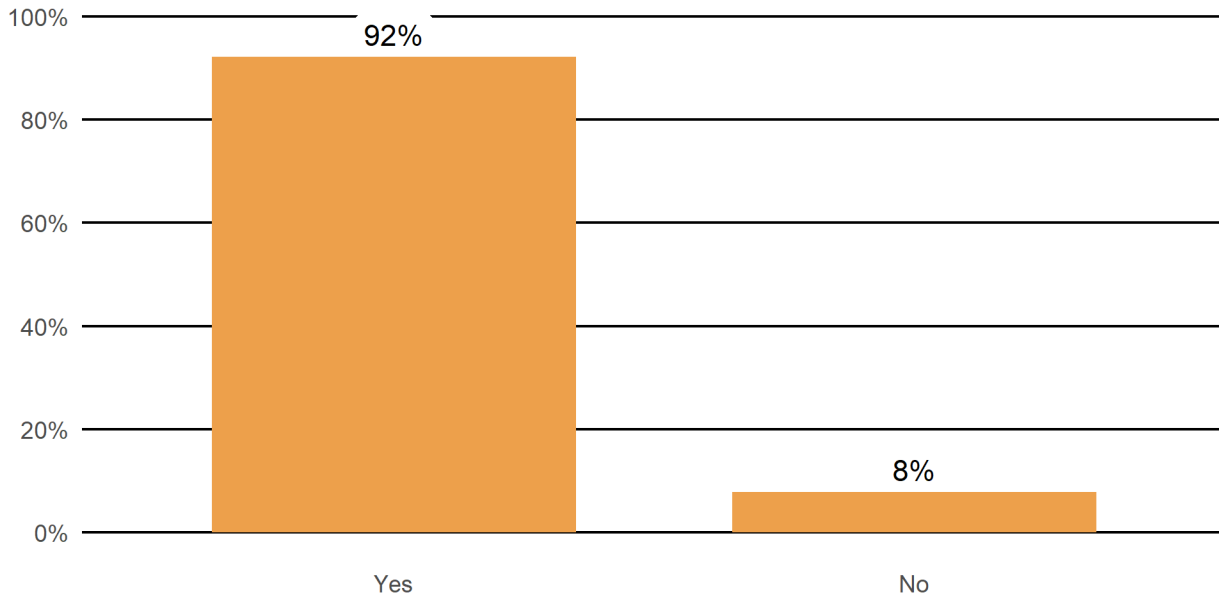


Table 52. Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?

State (names abbreviated)	Yes	No	N
AZ	92%	8%	162
GA	92%	8%	303
MD	92%	8%	388
NJ	94%	6%	557
PA	91%	9%	630
<b>Weighted NCI-IDD Average</b>	<b>92%</b>	<b>8%</b>	<b>2,040</b>

## How well does the internet work in your home?

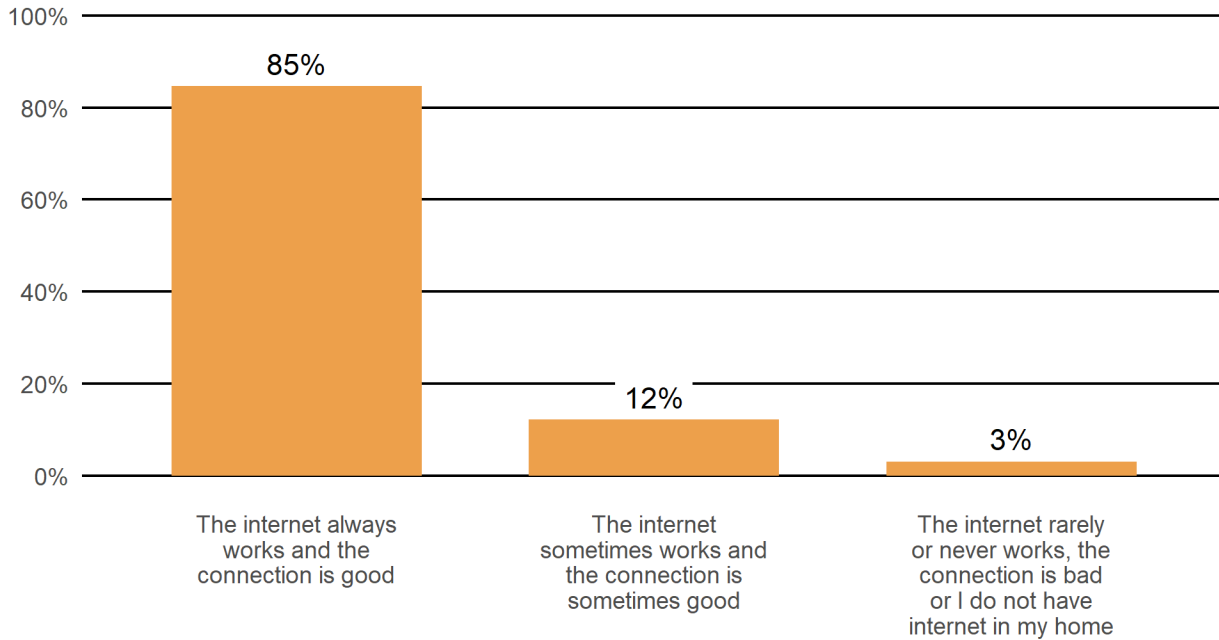


Table 53. How well does the internet work in your home?

State (names abbreviated)	The internet always works and the connection is good	The internet sometimes works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
AZ	83%	14%	3%	151
GA	81%	13%	5%	290
MD	85%	12%	3%	380
NJ	91%	8%	1%	548
PA	83%	14%	4%	600
<b>Weighted NCI-IDD Average</b>	<b>85%</b>	<b>12%</b>	<b>3%</b>	<b>1,969</b>



## Workforce

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

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

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

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

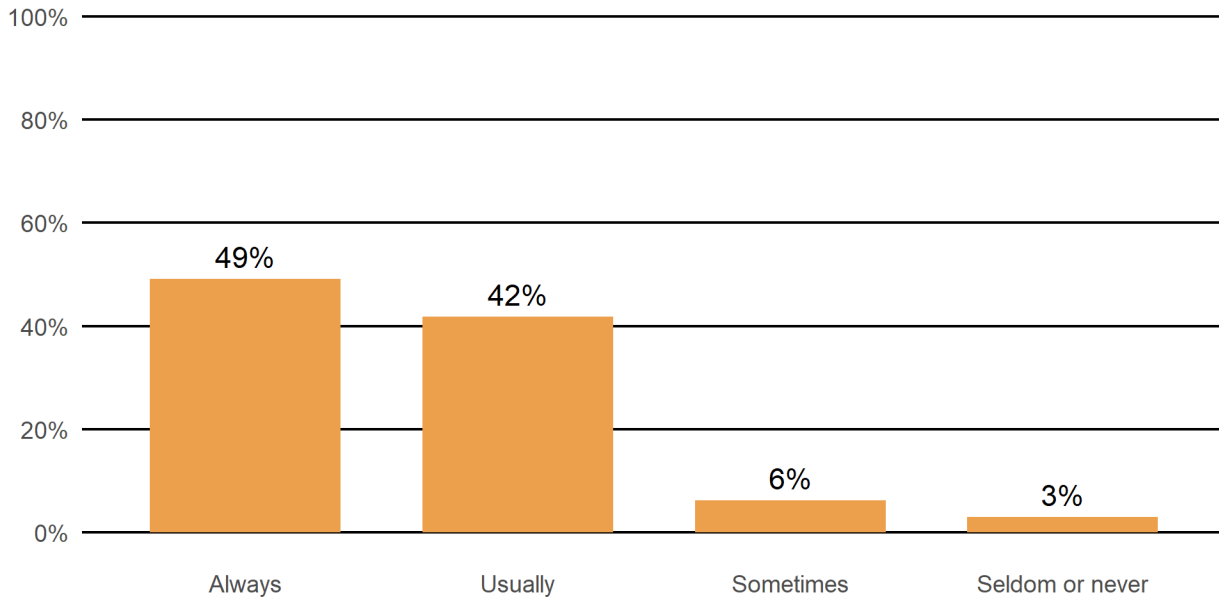


Table 54. Do support workers come and go when they are supposed to?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	49%	45%	6%	1%	107
GA	41%	50%	7%	3%	184
MD	41%	45%	9%	4%	258
NJ	52%	36%	9%	3%	380
PA	54%	40%	3%	3%	364
<b>Weighted NCI-IDD Average</b>	<b>49%</b>	<b>42%</b>	<b>6%</b>	<b>3%</b>	<b>1,293</b>

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

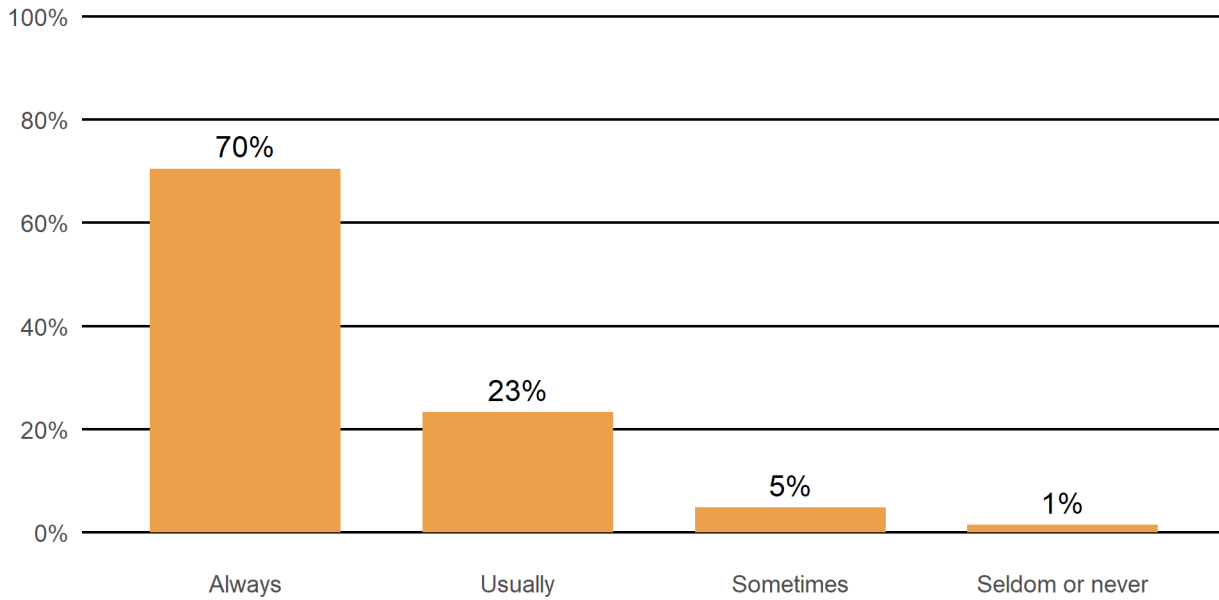


Table 55. Do support workers speak to you in a way you understand?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	67%	26%	7%	1%	148
GA	68%	25%	5%	2%	282
MD	58%	31%	8%	3%	360
NJ	73%	20%	5%	2%	515
PA	76%	20%	3%	1%	611
<b>Weighted NCI-IDD Average</b>	<b>70%</b>	<b>23%</b>	<b>5%</b>	<b>1%</b>	<b>1,916</b>

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

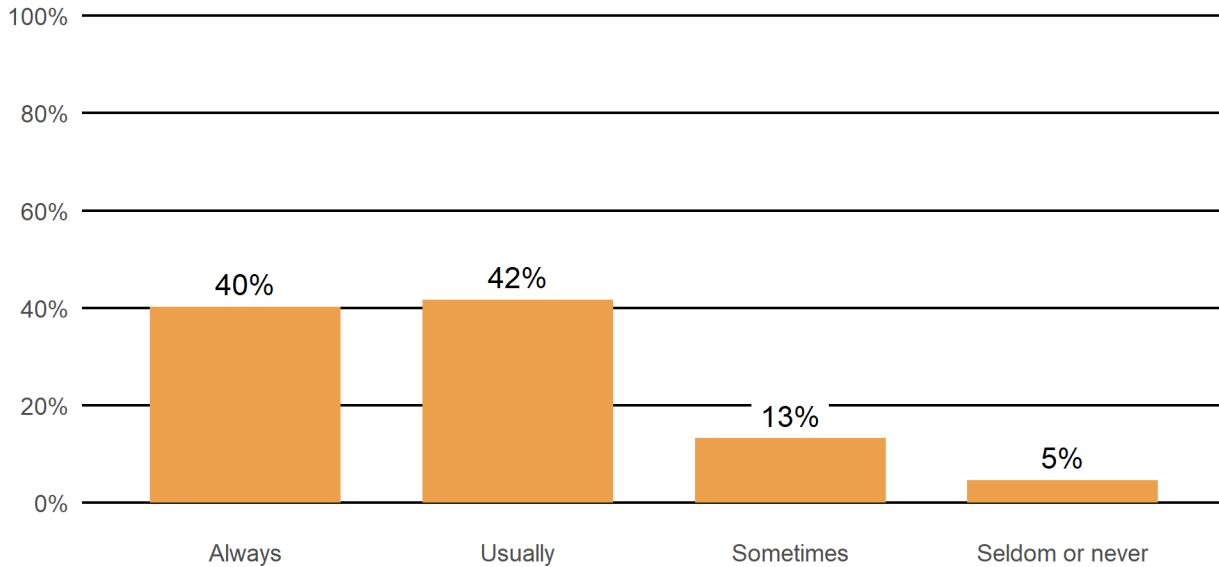


Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	42%	43%	11%	4%	79
GA	37%	49%	13%	2%	101
MD	31%	40%	19%	10%	154
NJ	39%	37%	20%	4%	215
PA	45%	43%	8%	3%	258
<b>Weighted NCI-IDD Average</b>	<b>40%</b>	<b>42%</b>	<b>13%</b>	<b>5%</b>	<b>807</b>

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

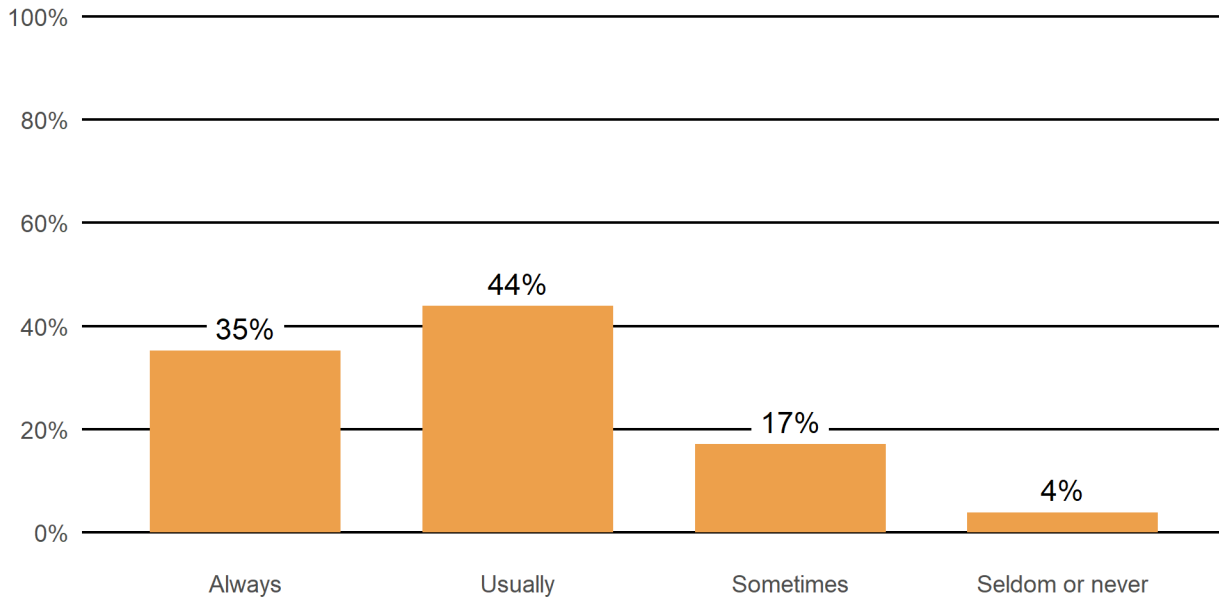


Table 57. Do support workers have the right information and skills to meet your family's needs?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	33%	49%	14%	4%	144
GA	34%	45%	17%	4%	273
MD	29%	39%	25%	7%	356
NJ	36%	39%	20%	5%	488
PA	39%	46%	13%	2%	581
<b>Weighted NCI-IDD Average</b>	<b>35%</b>	<b>44%</b>	<b>17%</b>	<b>4%</b>	<b>1,842</b>

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

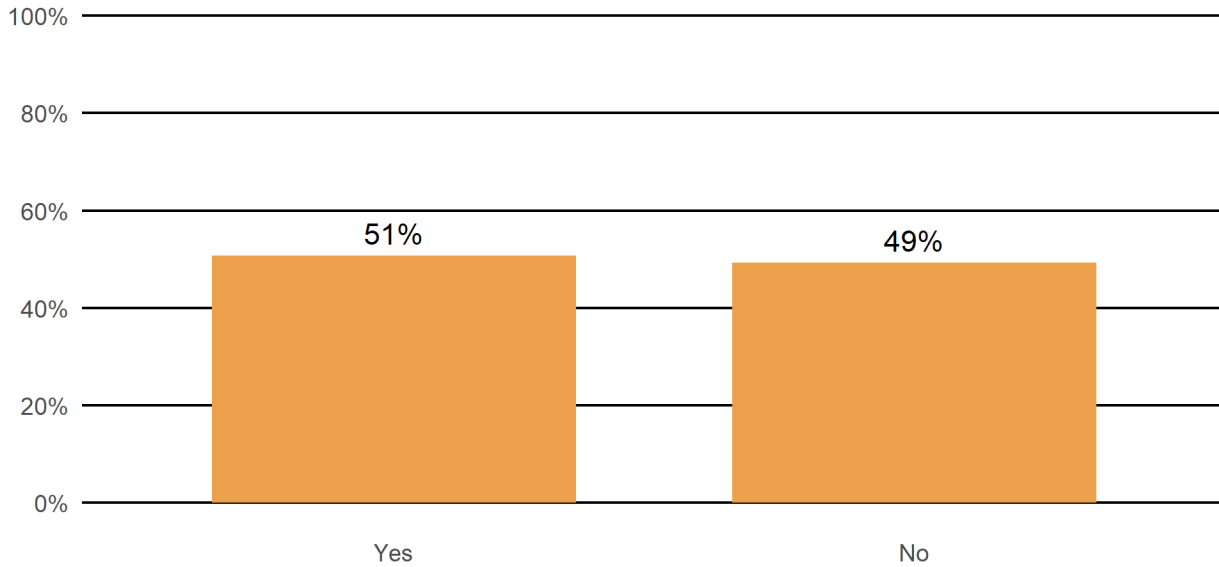


Table 58. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

State (names abbreviated)	Yes	No	N
AZ	47%	53%	131
GA	43%	57%	242
MD	55%	45%	331
NJ	49%	51%	455
PA	52%	48%	506
<b>Weighted NCI-IDD Average</b>	<b>51%</b>	<b>49%</b>	<b>1,665</b>

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

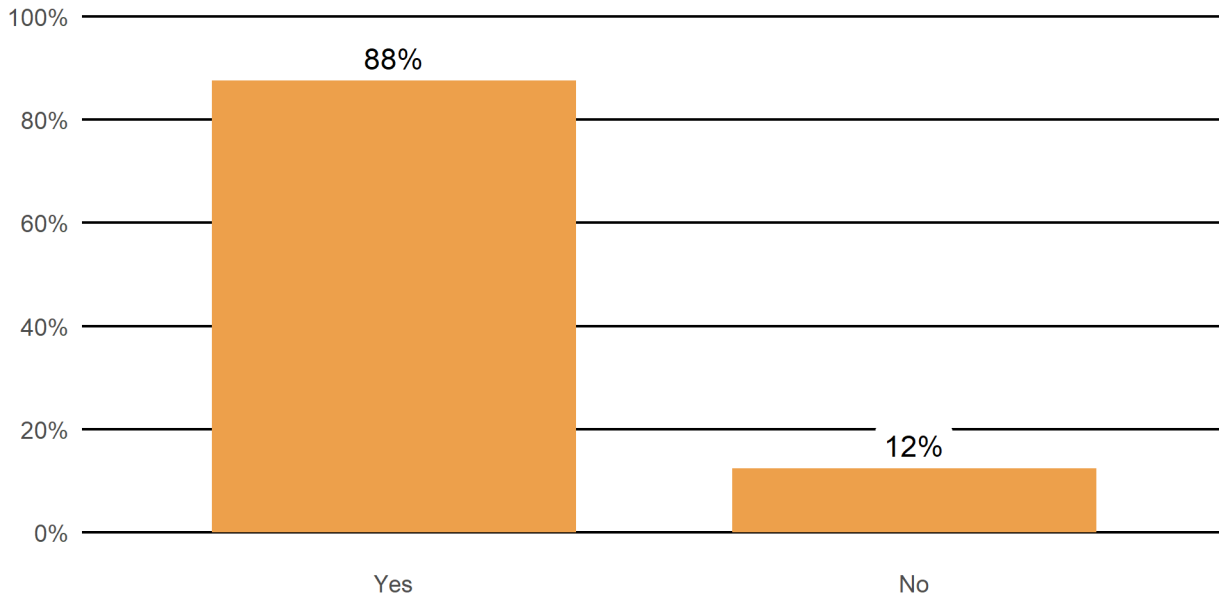


Table 59. Is there always a staff person available to support your family member when support is needed?

State (names abbreviated)	Yes	No	N
AZ	90%	10%	142
GA	89%	11%	251
MD	81%	19%	351
NJ	84%	16%	482
PA	91%	9%	594
<b>Weighted NCI-IDD Average</b>	<b>88%</b>	<b>12%</b>	<b>1,820</b>

## **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.*

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

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



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

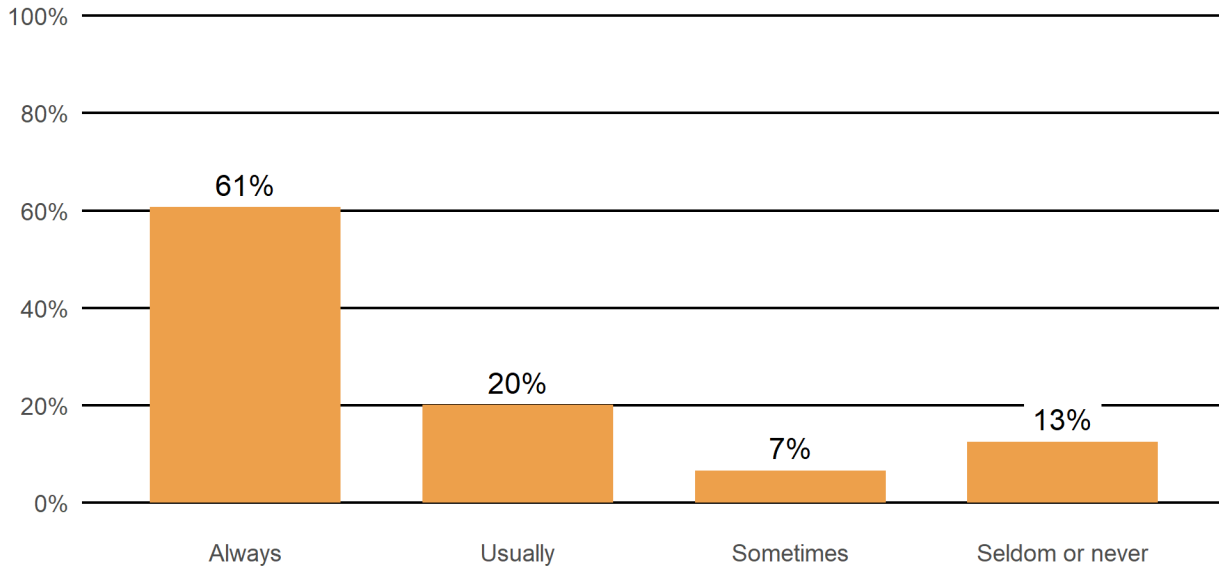


Table 60. Can someone in your family choose or change the provider agency that provides your family member's services?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>AZ</b>	67%	18%	8%	8%	120
<b>GA</b>	65%	18%	5%	12%	187
<b>MD</b>	61%	21%	8%	9%	259
<b>NJ</b>	57%	20%	5%	18%	339
<b>PA</b>	59%	21%	6%	14%	370
<b>Weighted NCI-IDD Average</b>	<b>61%</b>	<b>20%</b>	<b>7%</b>	<b>13%</b>	<b>1,275</b>

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

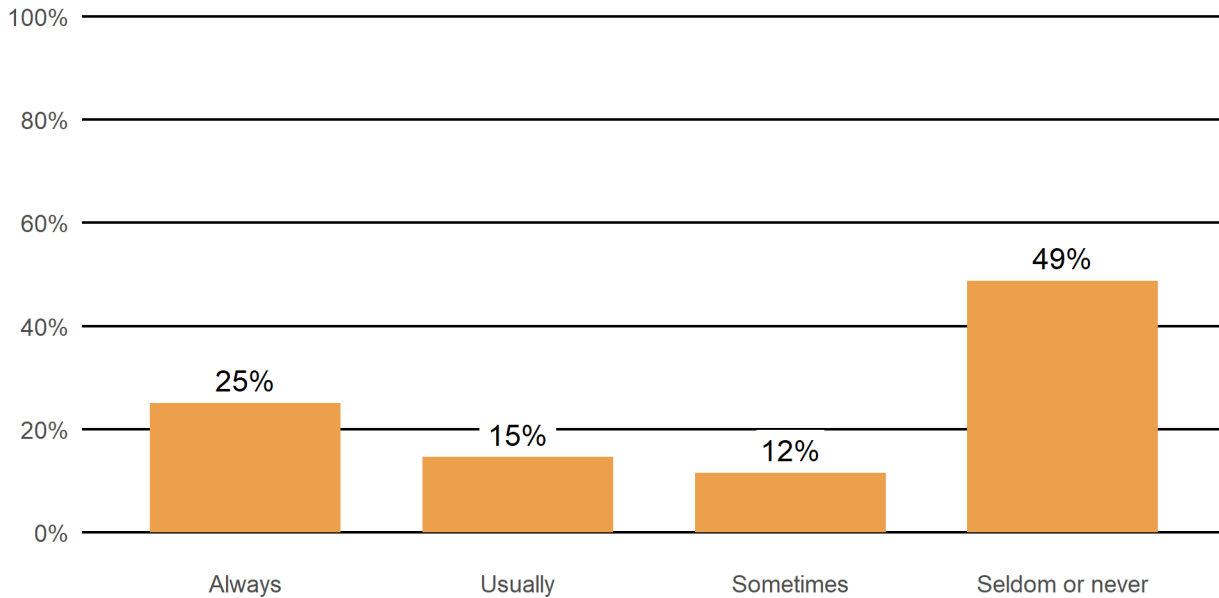


Table 61. Can someone in your family choose or change your family member's support workers?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	32%	18%	14%	36%	91
GA	32%	18%	11%	39%	163
MD	24%	13%	14%	49%	251
NJ	27%	16%	8%	49%	316
PA	21%	13%	11%	54%	342
<b>Weighted NCI-IDD Average</b>	<b>25%</b>	<b>15%</b>	<b>12%</b>	<b>49%</b>	<b>1,163</b>

## Can someone in your family directly manage support staff?

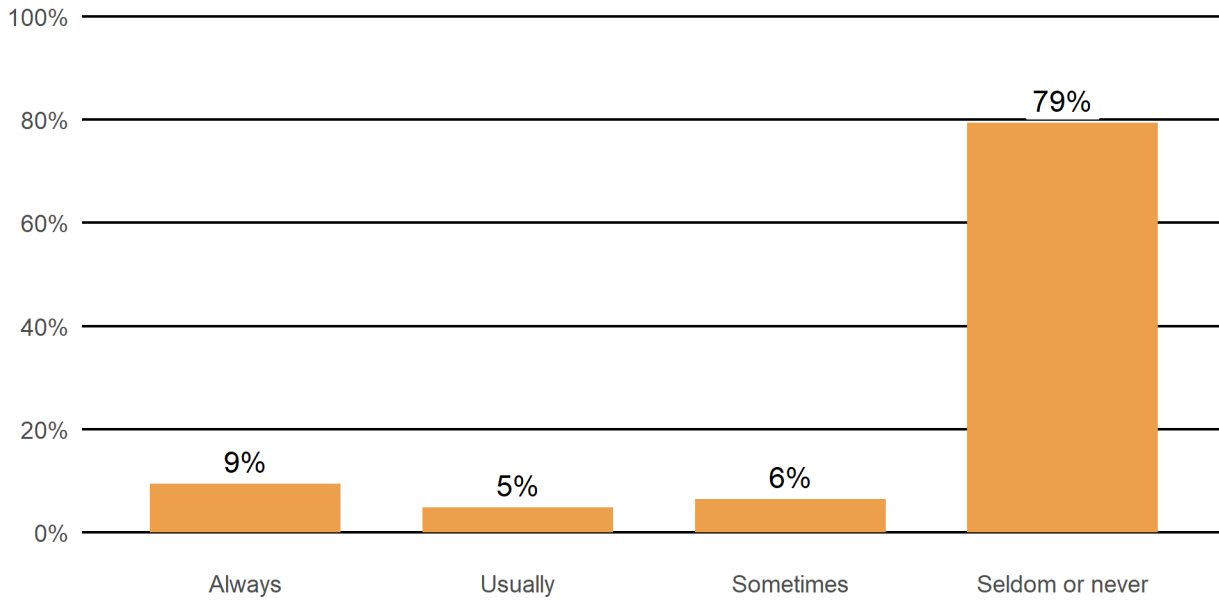


Table 62. Can someone in your family directly manage support staff?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	15%	8%	9%	68%	88
GA	12%	8%	9%	71%	168
MD	11%	3%	6%	79%	248
NJ	16%	7%	5%	72%	316
PA	4%	3%	6%	87%	400
<b>Weighted NCI-IDD Average</b>	<b>9%</b>	<b>5%</b>	<b>6%</b>	<b>79%</b>	<b>1,220</b>

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

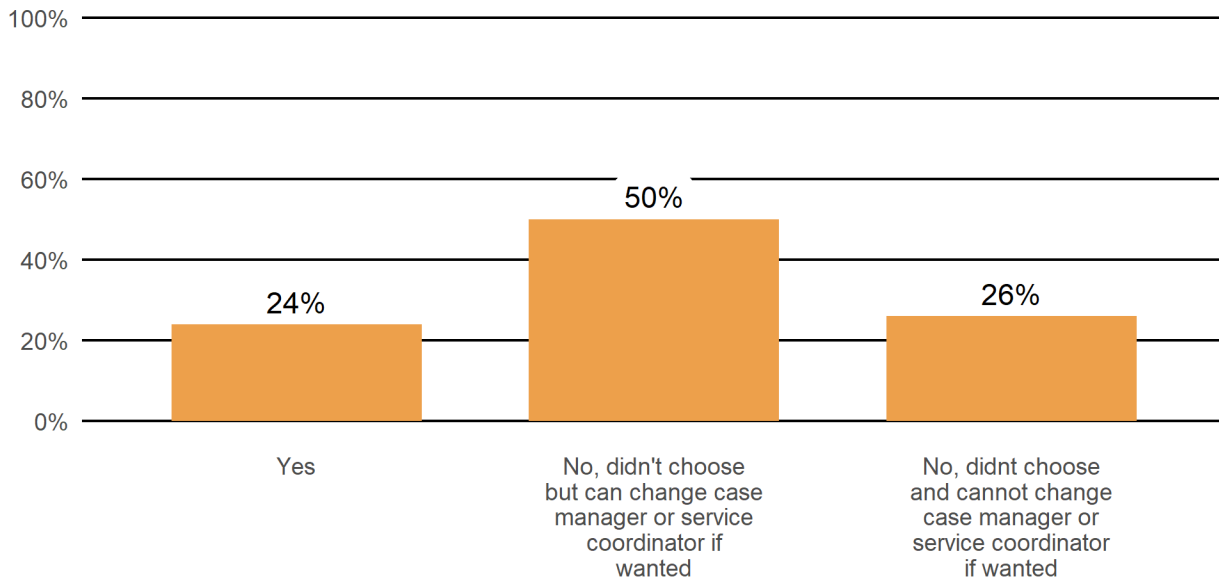


Table 63. Did you, your family member, or someone else in your family choose your family member's case manager or service coordinator?

State (names abbreviated)	Yes	No, didn't choose but can change case manager or service coordinator if wanted	No, didnt choose and cannot change case manager or service coordinator if wanted	N
AZ	15%	64%	20%	138
GA	14%	59%	27%	250
MD	24%	49%	27%	318
NJ	47%	30%	23%	483
PA	17%	54%	29%	491
<b>Weighted NCI-IDD Average</b>	<b>24%</b>	<b>50%</b>	<b>26%</b>	<b>1,680</b>

## 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.*

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

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

## Does your family member do things in the community?

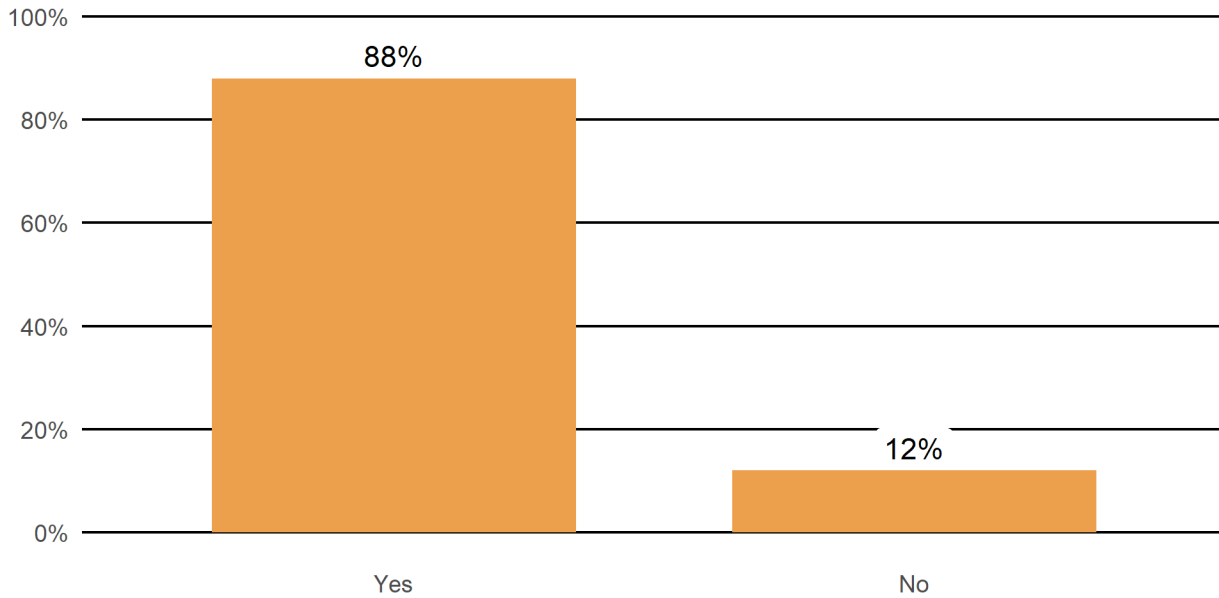


Table 64. Does your family member do things in the community?

State (names abbreviated)	Yes	No	N
AZ	86%	14%	158
GA	89%	11%	281
MD	89%	11%	366
NJ	82%	18%	534
PA	90%	10%	615
<b>Weighted NCI-IDD Average</b>	<b>88%</b>	<b>12%</b>	<b>1,954</b>

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

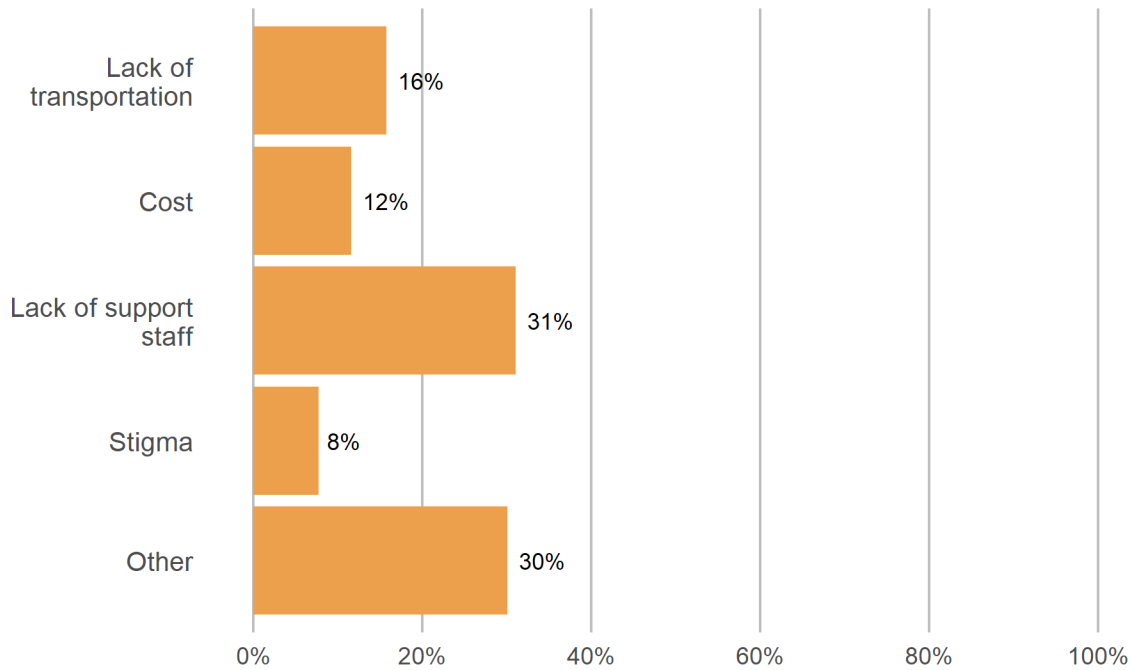


Table 65. For your family member, what makes it hard to do things in the community?

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

State (names abbreviated)	Lack of transportation	Cost	Lack of support staff	Stigma	Other
<b>AZ</b>	14%	18%	26%	4%	29%
<b>GA</b>	17%	15%	29%	7%	26%
<b>MD</b>	22%	14%	35%	8%	31%
<b>NJ</b>	24%	15%	33%	9%	27%
<b>PA</b>	9%	6%	30%	8%	32%
<b>Weighted NCI-IDD Average</b>	<b>16%</b>	<b>12%</b>	<b>31%</b>	<b>8%</b>	<b>30%</b>

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

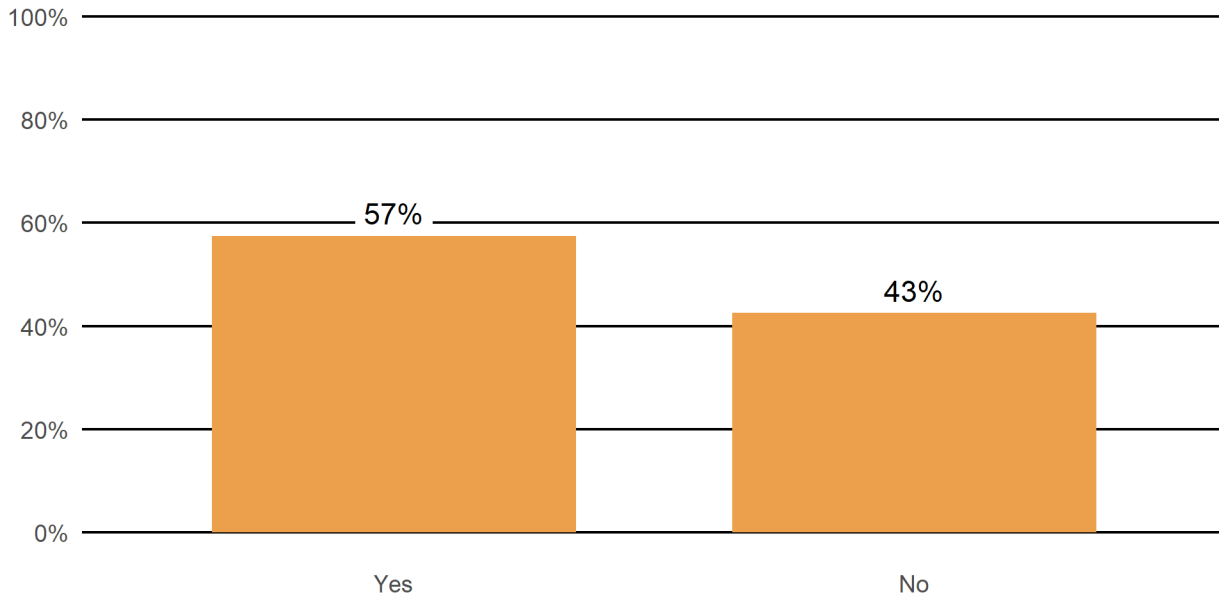


Table 66. Does your family member have friends other than paid support workers or family?

State (names abbreviated)	Yes	No	N
AZ	50%	50%	155
GA	72%	28%	280
MD	61%	39%	373
NJ	54%	46%	516
PA	57%	43%	580
<b>Weighted NCI-IDD Average</b>	<b>57%</b>	<b>43%</b>	<b>1,904</b>



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

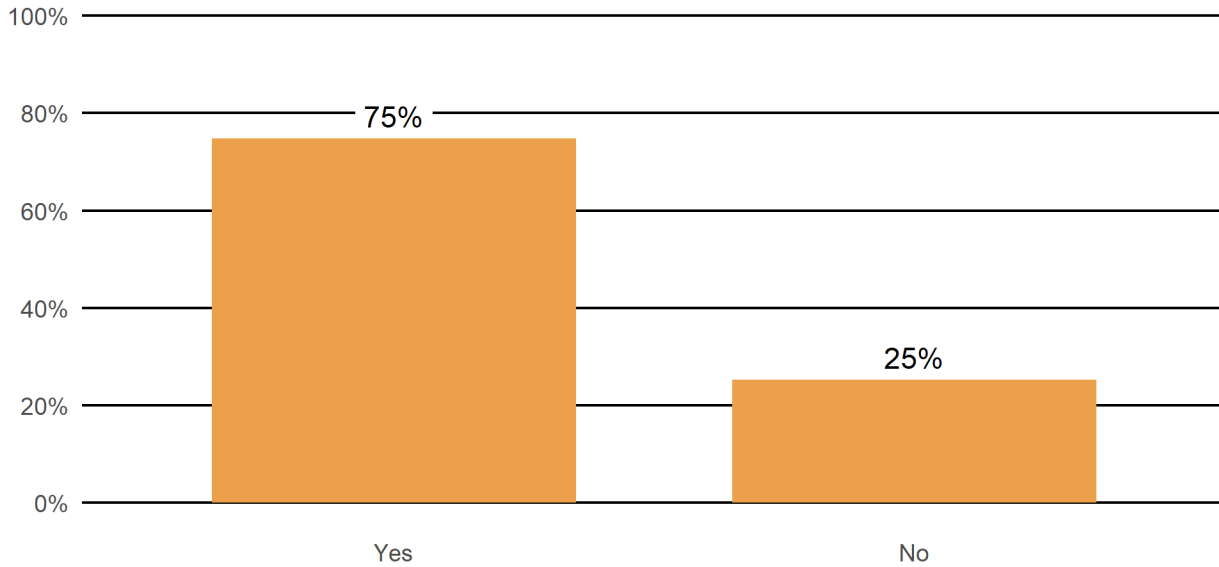


Table 67. In your community, are there resources or support that your family member can use that are not provided by the I/DD agency?

State (names abbreviated)	Yes	No	N
AZ	70%	30%	119
GA	72%	28%	191
MD	78%	22%	293
NJ	68%	32%	340
PA	78%	22%	358
<b>Weighted NCI-IDD Average</b>	<b>75%</b>	<b>25%</b>	<b>1,301</b>

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

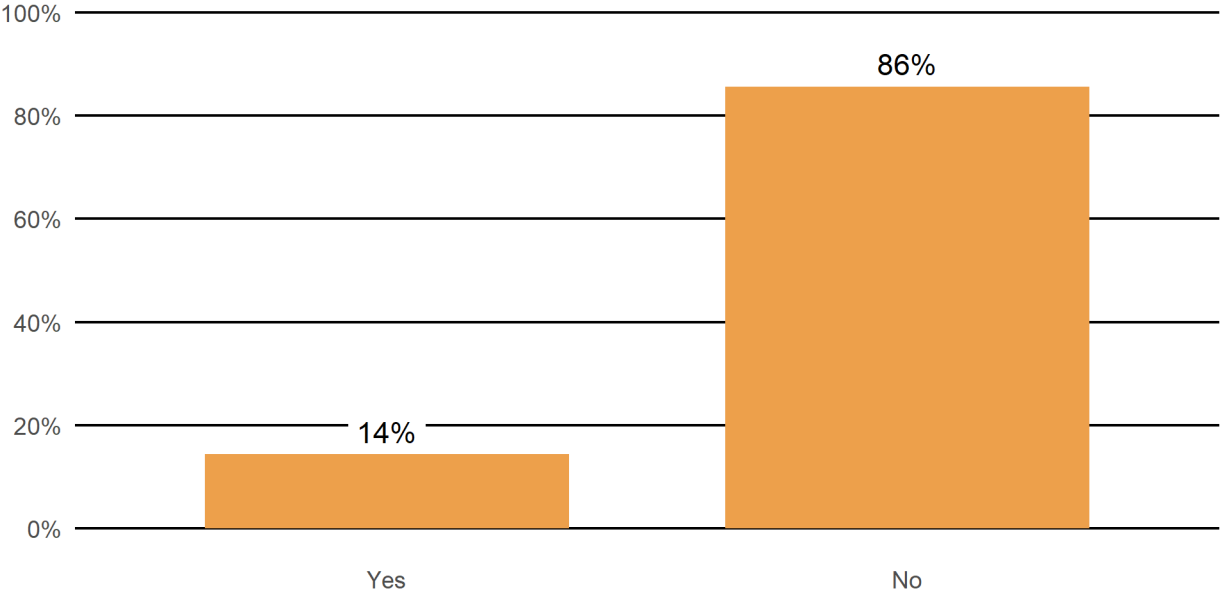


Table 68. Does your family take part in any family-to-family networks in your community?

State (names abbreviated)	Yes	No	N
AZ	8%	92%	133
GA	21%	79%	257
MD	17%	83%	334
NJ	15%	85%	471
PA	13%	87%	534
<b>Weighted NCI-IDD Average</b>	<b>14%</b>	<b>86%</b>	<b>1,729</b>

## Health, Welfare and Safety

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

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

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

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

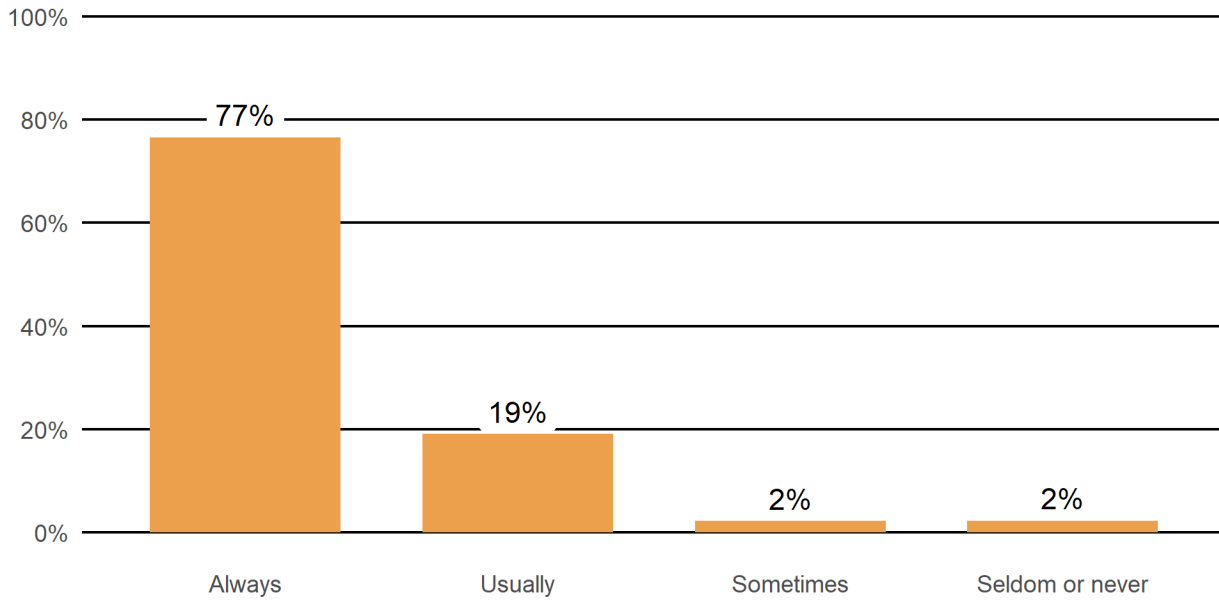


Table 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	75%	22%	2%	1%	162
GA	71%	24%	2%	3%	293
MD	78%	19%	2%	1%	372
NJ	72%	22%	3%	3%	535
PA	79%	16%	2%	3%	619
<b>Weighted NCI-IDD Average</b>	<b>77%</b>	<b>19%</b>	<b>2%</b>	<b>2%</b>	<b>1,981</b>

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

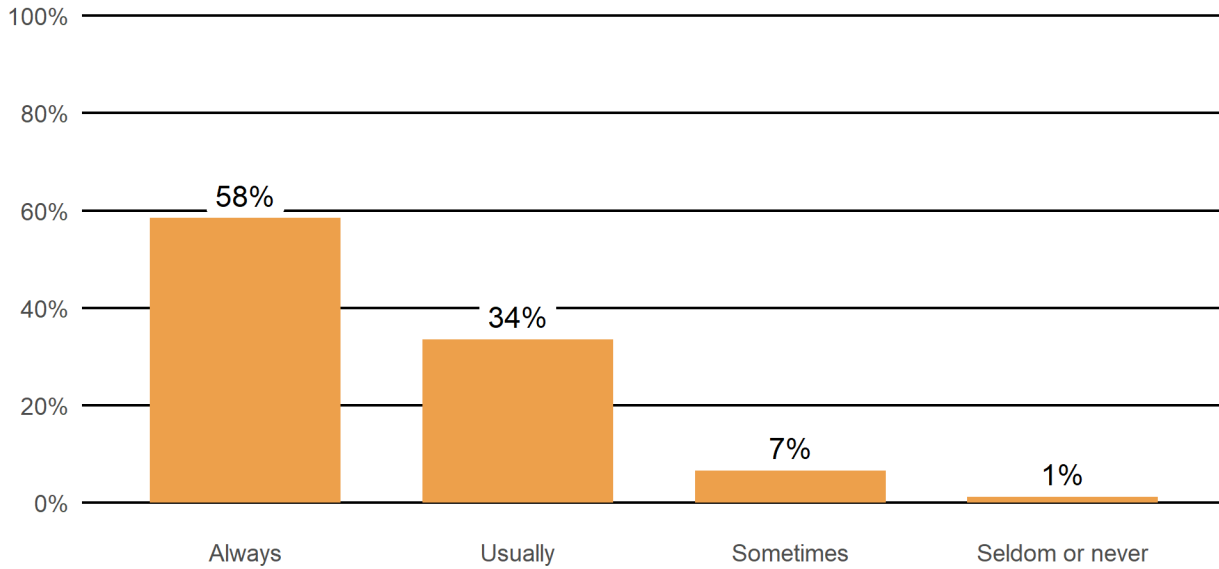


Table 70. Does your family member’s primary care provider (doctor, registered nurse, etc.) understand your family member’s needs related to their disability?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>AZ</b>	56%	35%	6%	3%	156
<b>GA</b>	52%	40%	7%	0%	283
<b>MD</b>	61%	27%	9%	3%	351
<b>NJ</b>	62%	33%	5%	0%	510
<b>PA</b>	58%	35%	6%	1%	581
<b>Weighted NCI-IDD Average</b>	<b>58%</b>	<b>34%</b>	<b>7%</b>	<b>1%</b>	<b>1,881</b>

## Can your family member go to the dentist when needed?

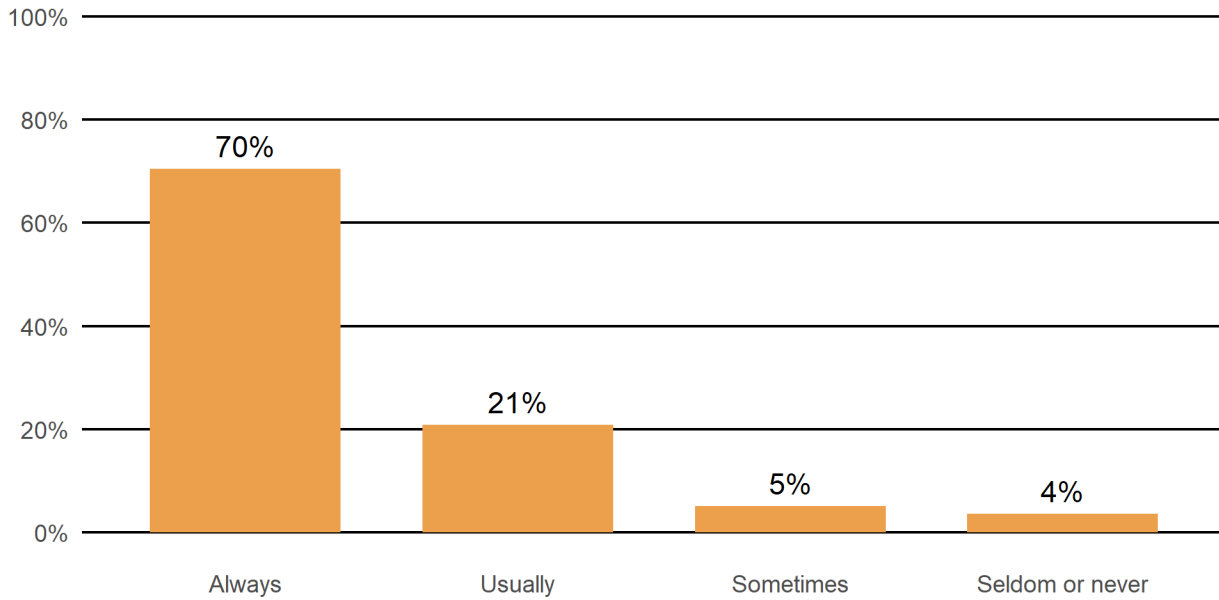


Table 71. Can your family member go to the dentist when needed?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	63%	23%	6%	8%	162
GA	58%	26%	9%	8%	292
MD	72%	18%	5%	4%	365
NJ	66%	25%	6%	3%	533
PA	76%	19%	4%	1%	622
<b>Weighted NCI-IDD Average</b>	<b>70%</b>	<b>21%</b>	<b>5%</b>	<b>4%</b>	<b>1,974</b>

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

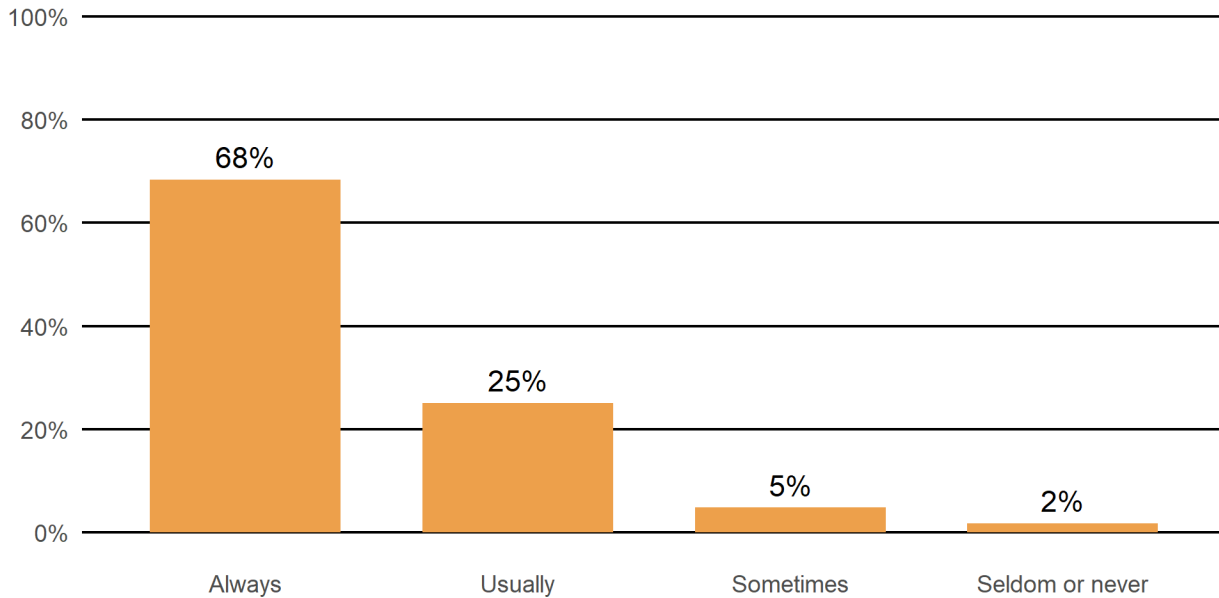


Table 72. Does your family member's dentist understand your family member's needs related to their disability?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>AZ</b>	56%	33%	8%	3%	146
<b>GA</b>	64%	29%	6%	2%	245
<b>MD</b>	70%	20%	7%	3%	308
<b>NJ</b>	68%	24%	6%	2%	459
<b>PA</b>	72%	25%	3%	1%	557
<b>Weighted NCI-IDD Average</b>	<b>68%</b>	<b>25%</b>	<b>5%</b>	<b>2%</b>	<b>1,715</b>

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

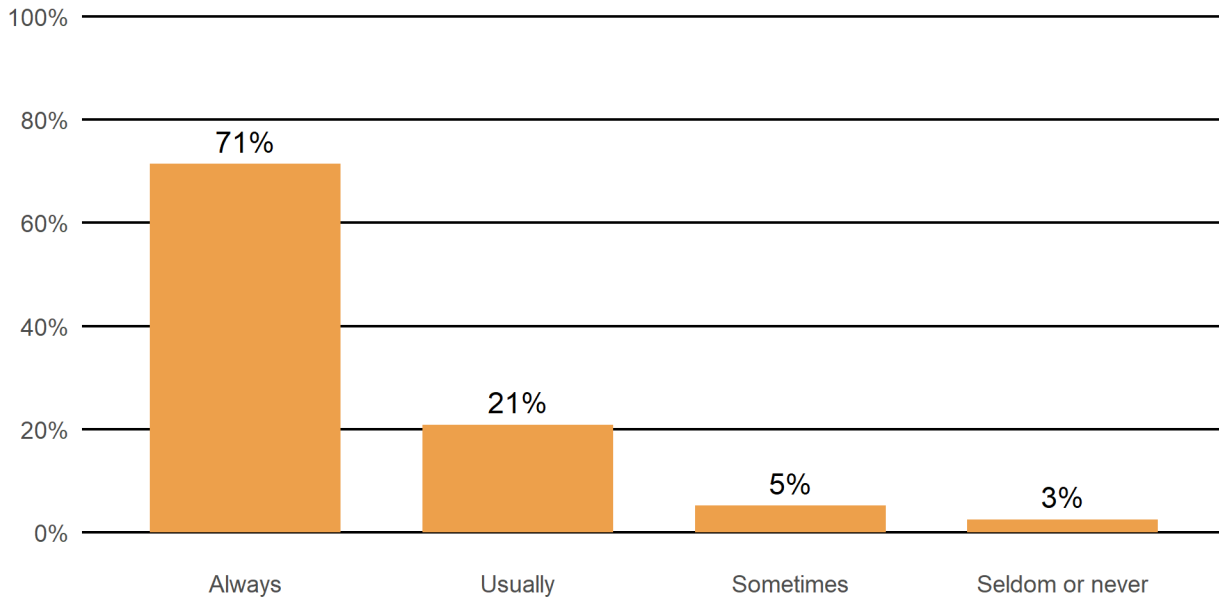


Table 73. If your family member takes prescription medications, do you know what they're for?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	70%	19%	6%	5%	149
GA	69%	22%	8%	1%	277
MD	73%	18%	6%	3%	358
NJ	76%	19%	4%	1%	495
PA	70%	23%	4%	2%	601
<b>Weighted NCI-IDD Average</b>	<b>71%</b>	<b>21%</b>	<b>5%</b>	<b>3%</b>	<b>1,880</b>



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

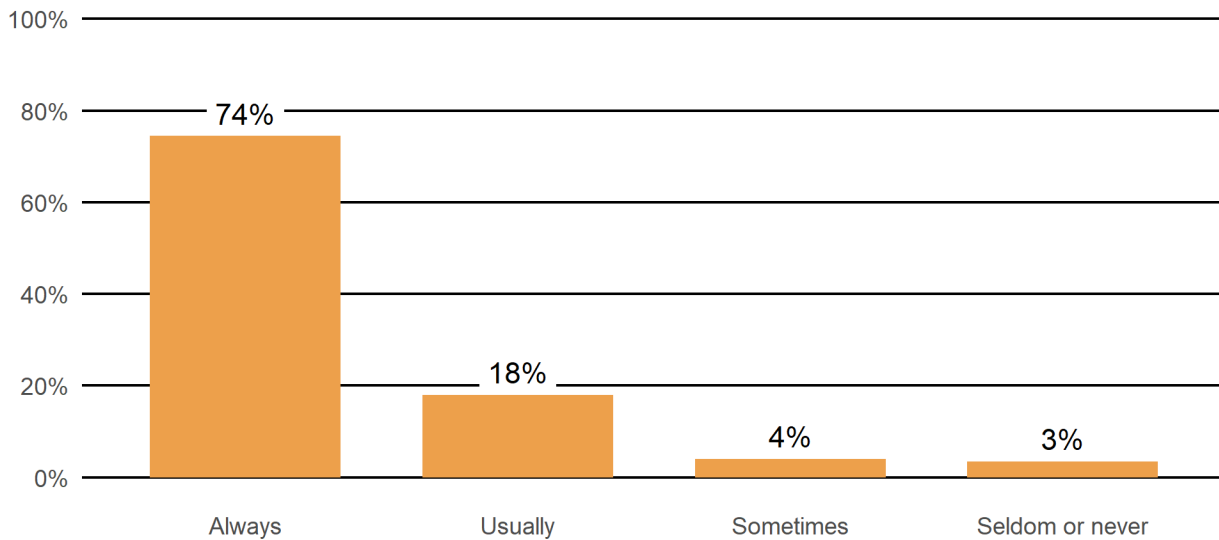


Table 74. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	76%	15%	8%	2%	143
GA	78%	18%	3%	1%	268
MD	74%	18%	4%	4%	349
NJ	75%	16%	4%	5%	489
PA	74%	20%	3%	3%	578
<b>Weighted NCI-IDD Average</b>	<b>74%</b>	<b>18%</b>	<b>4%</b>	<b>3%</b>	<b>1,827</b>

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

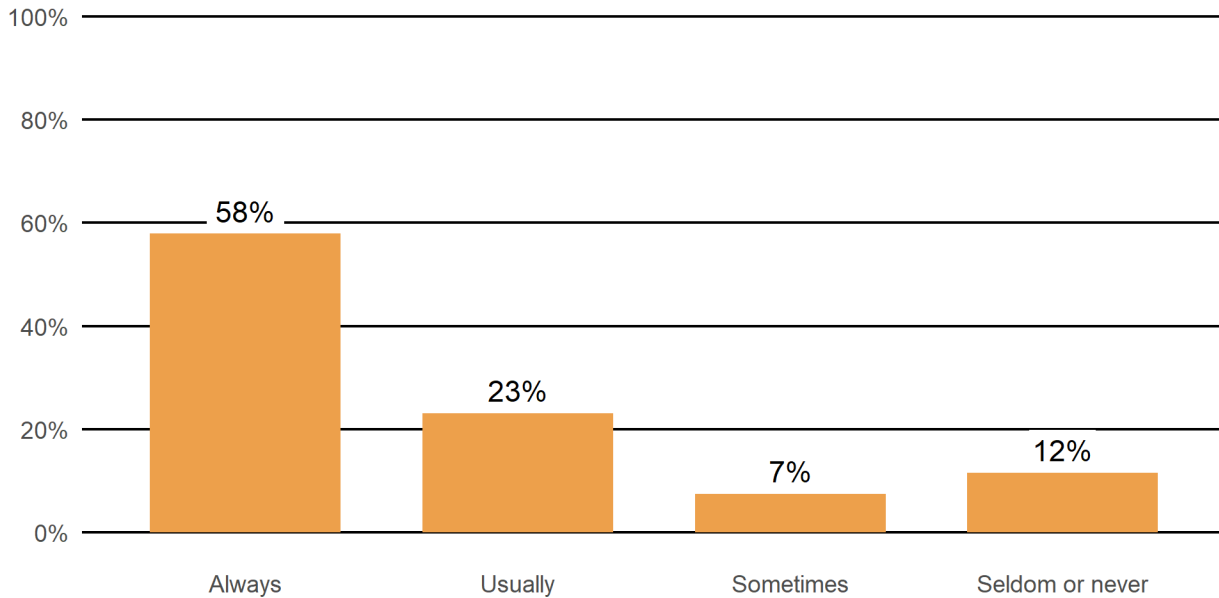


Table 75. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling.)

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	54%	21%	10%	16%	125
GA	52%	25%	9%	14%	225
MD	56%	19%	10%	15%	304
NJ	52%	25%	8%	15%	435
PA	64%	24%	5%	7%	501
<b>Weighted NCI-IDD Average</b>	<b>58%</b>	<b>23%</b>	<b>7%</b>	<b>12%</b>	<b>1,590</b>

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

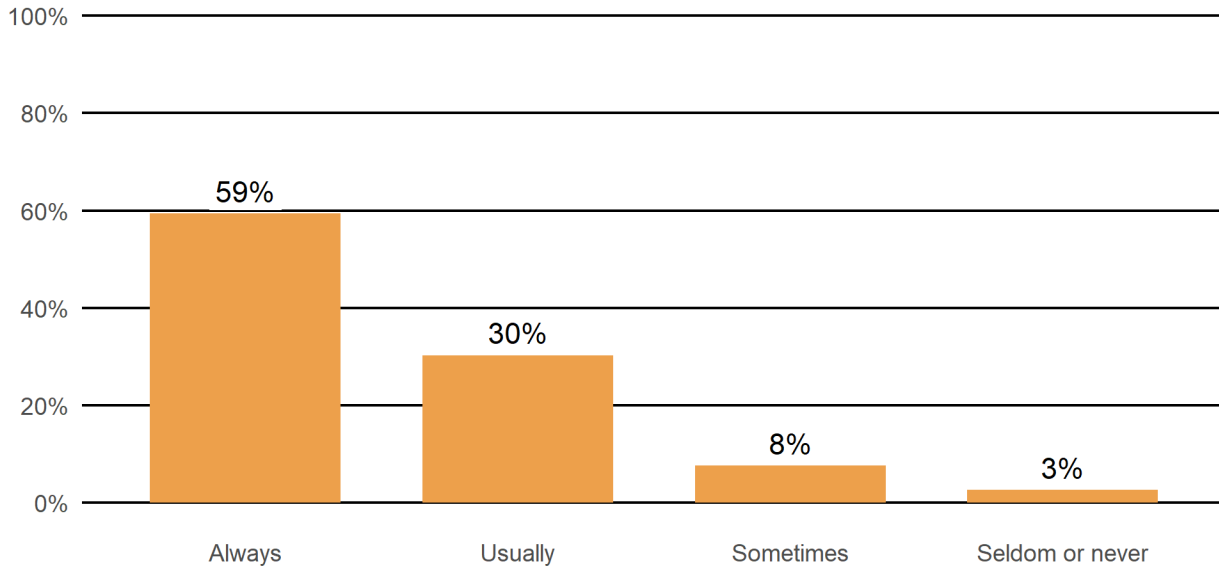


Table 76. Does your family member’s mental or behavioral health professional understand your family member’s needs related to their disability?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>AZ</b>	54%	36%	8%	3%	114
<b>GA</b>	58%	33%	8%	1%	192
<b>MD</b>	61%	26%	10%	2%	249
<b>NJ</b>	60%	27%	9%	4%	369
<b>PA</b>	60%	31%	6%	3%	462
<b>Weighted NCI-IDD Average</b>	<b>59%</b>	<b>30%</b>	<b>8%</b>	<b>3%</b>	<b>1,386</b>

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

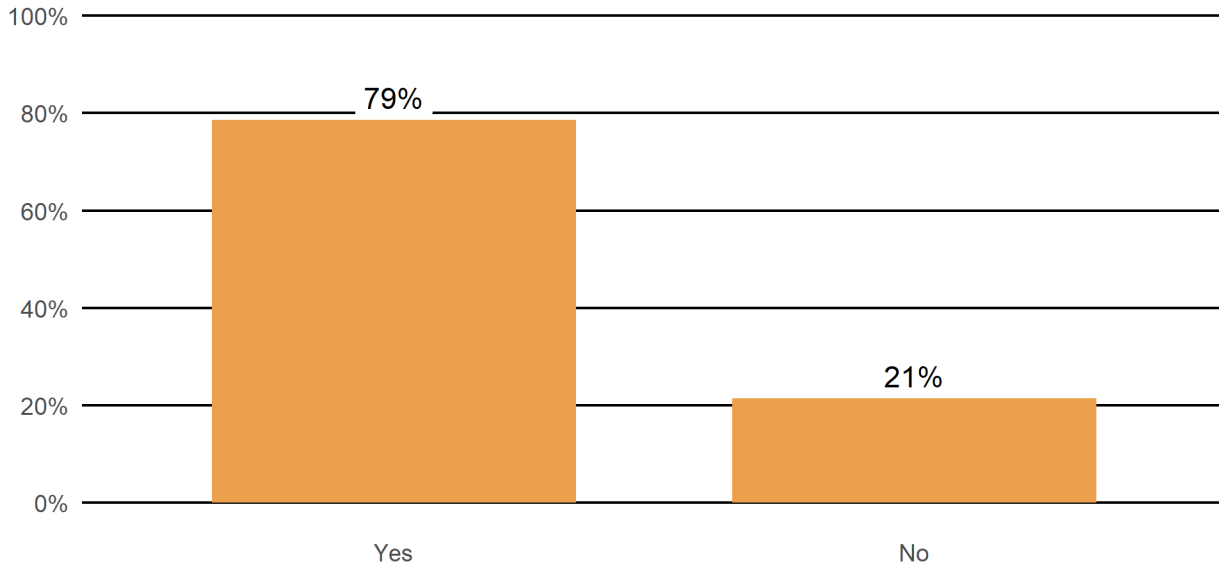


Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

State (names abbreviated)	Yes	No	N
AZ	90%	10%	51
GA	75%	25%	77
MD	66%	34%	104
NJ	71%	29%	130
PA	85%	15%	151
Weighted NCI-IDD Average	79%	21%	513

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

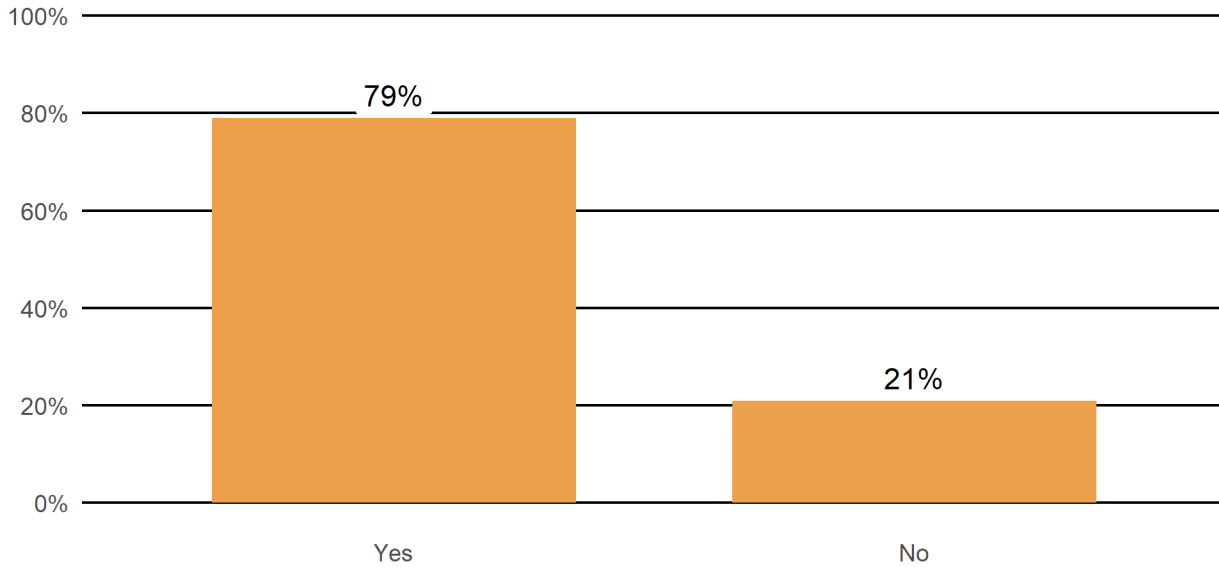


Table 78. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency, pandemic or natural disaster?

State (names abbreviated)	Yes	No	N
AZ	88%	12%	137
GA	78%	22%	258
MD	78%	22%	343
NJ	77%	23%	462
PA	78%	22%	520
<b>Weighted NCI-IDD Average</b>	<b>79%</b>	<b>21%</b>	<b>1,720</b>

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

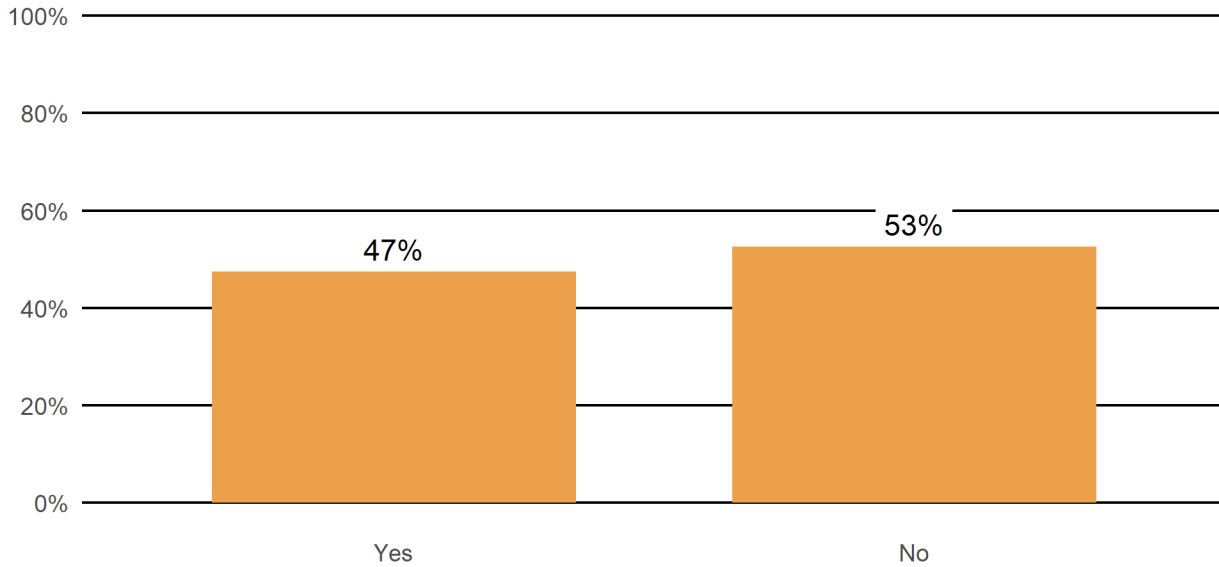


Table 79. Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member’s case manager or service coordinator?

State (names abbreviated)	Yes	No	N
AZ	54%	46%	153
GA	48%	52%	292
MD	47%	53%	365
NJ	47%	53%	530
PA	46%	54%	587
<b>Weighted NCI-IDD Average</b>	<b>47%</b>	<b>53%</b>	<b>1,927</b>

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

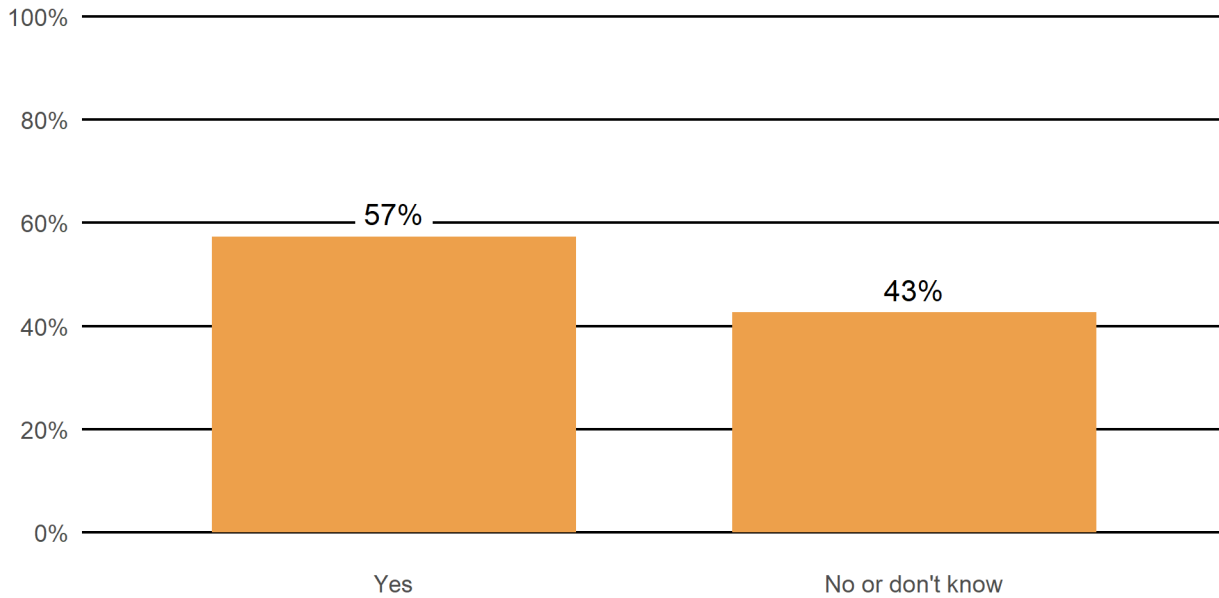


Table 80. Do you know how to file a complaint or grievance about provider agencies or staff?

State (names abbreviated)	Yes	No or don't know	N
AZ	64%	36%	159
GA	49%	51%	309
MD	46%	54%	388
NJ	50%	50%	542
PA	66%	34%	628
<b>Weighted NCI-IDD Average</b>	<b>57%</b>	<b>43%</b>	<b>2,026</b>

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

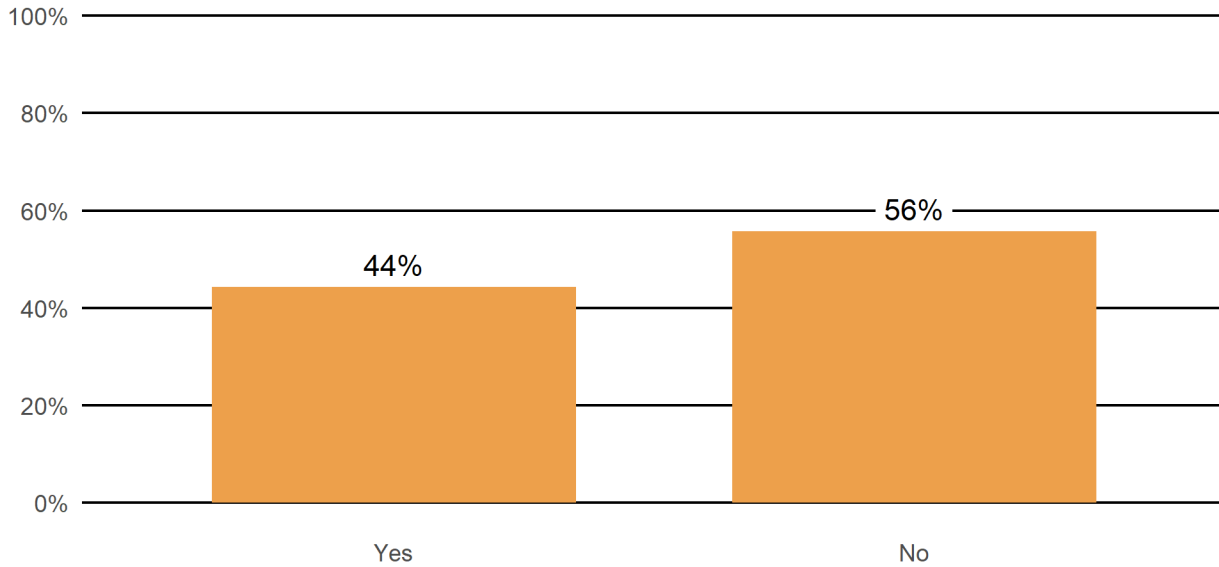


Table 81. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

State (names abbreviated)	Yes	No	N
AZ	44%	56%	25
GA	57%	43%	46
MD	27%	73%	77
NJ	40%	60%	80
PA	55%	45%	91
<b>Weighted NCI-IDD Average</b>	<b>44%</b>	<b>56%</b>	<b>319</b>



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

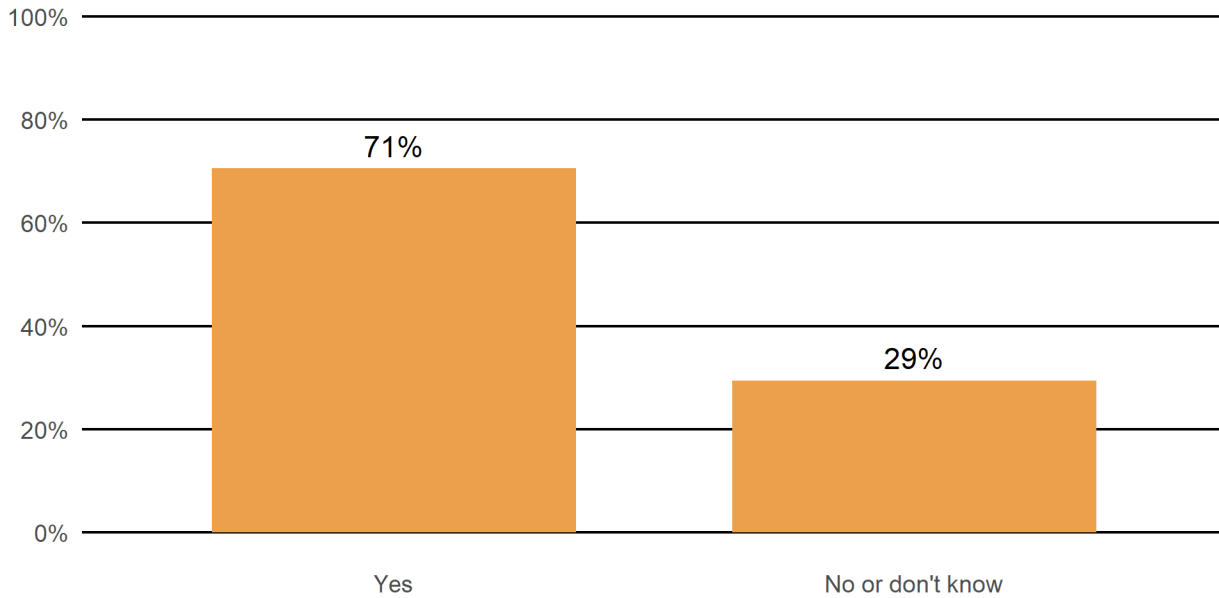


Table 82. Do you know how to report abuse or neglect related to your family member?

State (names abbreviated)	Yes	No or don't know	N
AZ	72%	28%	161
GA	60%	40%	311
MD	64%	36%	389
NJ	66%	34%	548
PA	77%	23%	629
<b>Weighted NCI-IDD Average</b>	<b>71%</b>	<b>29%</b>	<b>2,038</b>

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

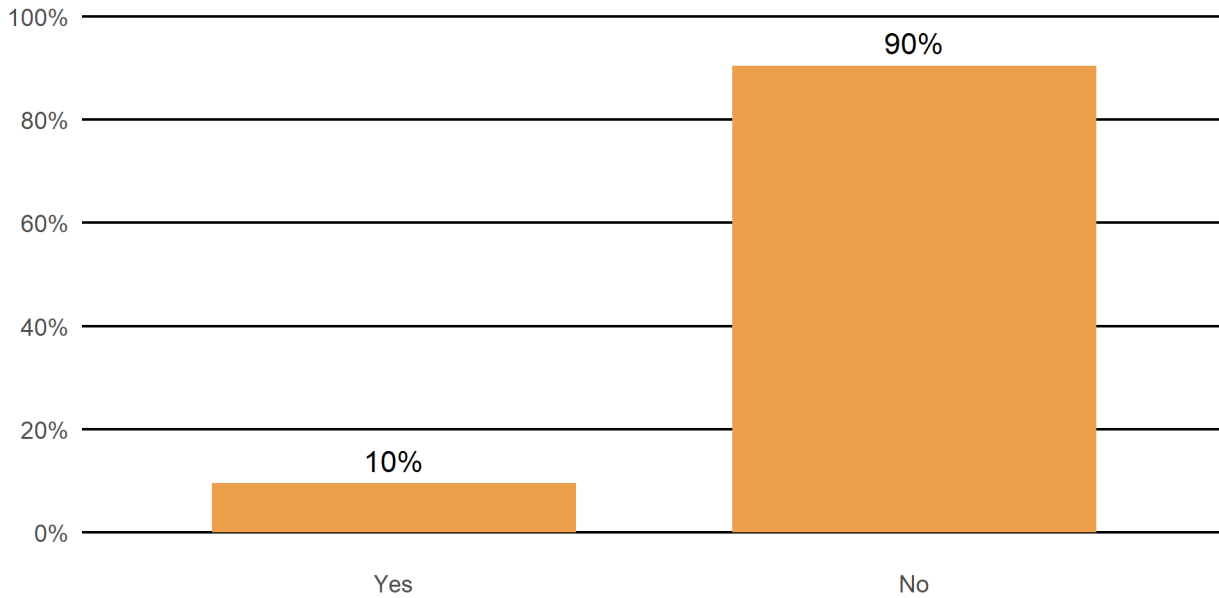


Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

State (names abbreviated)	Yes	No	N
AZ	12%	88%	155
GA	5%	95%	297
MD	9%	91%	369
NJ	9%	91%	514
PA	10%	90%	606
<b>Weighted NCI-IDD Average</b>	<b>10%</b>	<b>90%</b>	<b>1,941</b>

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

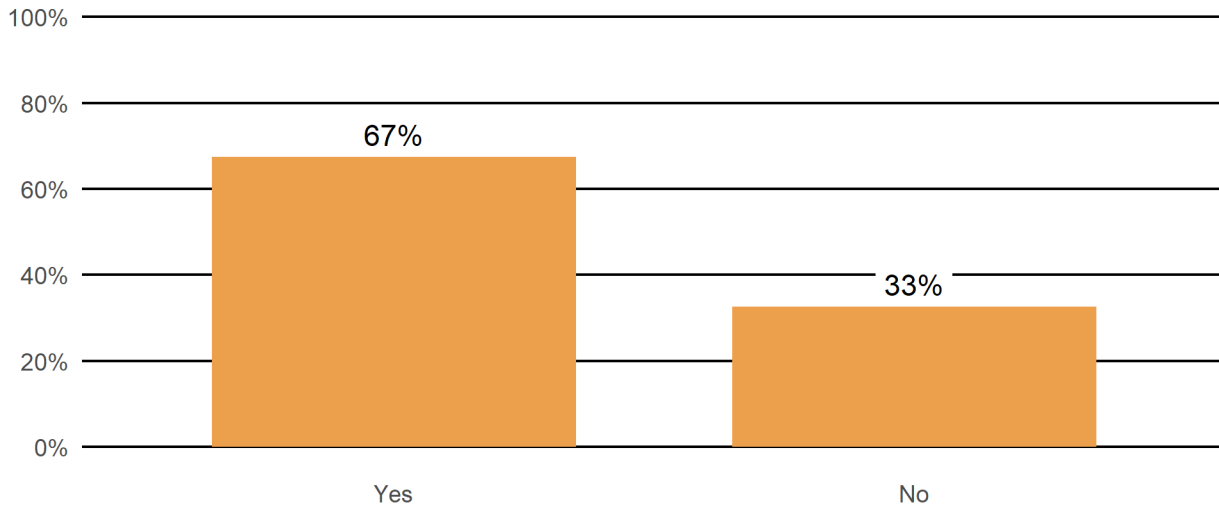


Table 84. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

State (names abbreviated)	Yes	No	N
MD	56%	44%	27
NJ	58%	42%	31
PA	69%	31%	52
<b>Weighted NCI-IDD Average</b>	<b>67%</b>	<b>33%</b>	<b>138</b>

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

## Family Satisfaction

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

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

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

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

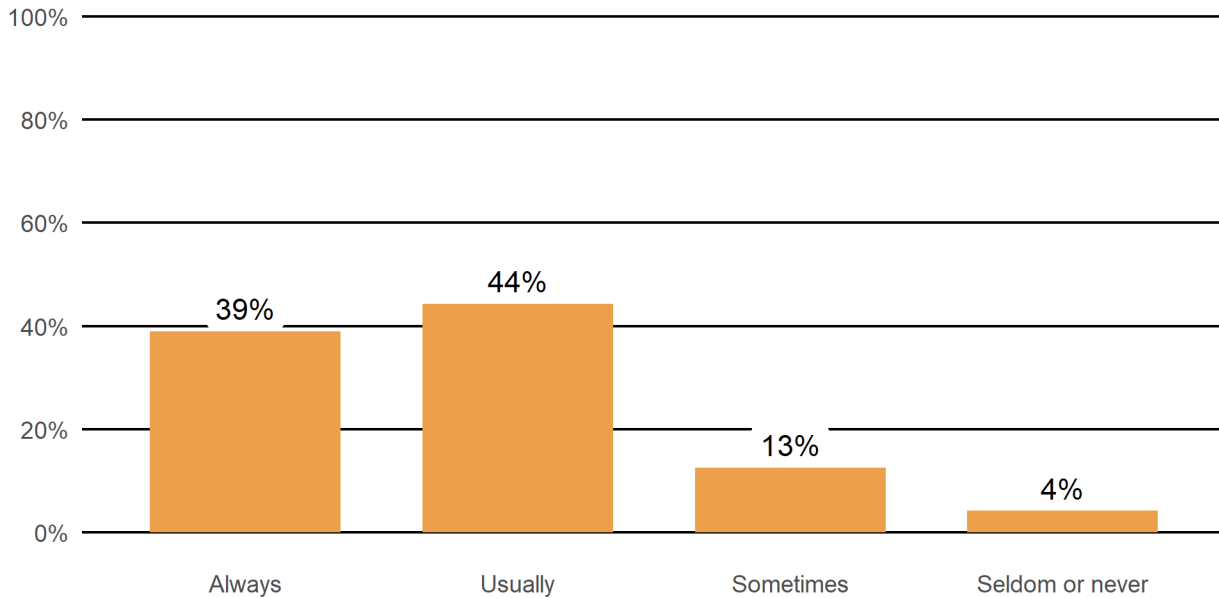


Table 85. Overall, are you satisfied with the services and supports your family member currently receives?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	42%	47%	8%	3%	163
GA	35%	46%	16%	2%	306
MD	31%	43%	18%	7%	382
NJ	36%	44%	15%	5%	541
PA	43%	44%	9%	3%	637
<b>Weighted NCI-IDD Average</b>	<b>39%</b>	<b>44%</b>	<b>13%</b>	<b>4%</b>	<b>2,029</b>

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

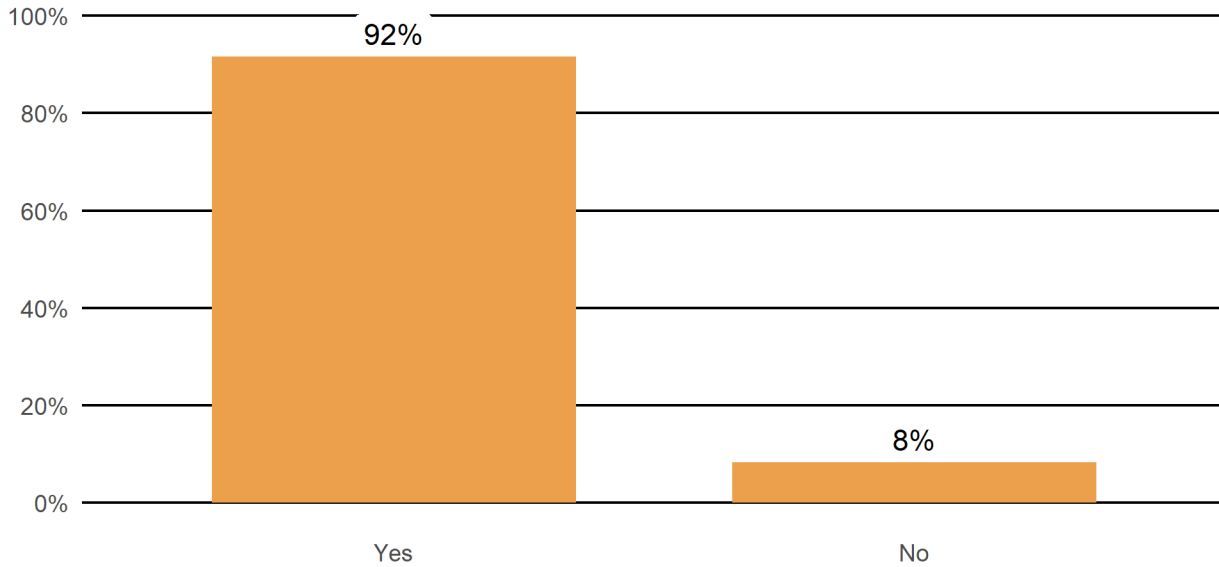


Table 86. Do you feel that services and supports have made a positive difference in the life of your family member?

State (names abbreviated)	Yes	No	N
AZ	93%	7%	155
GA	95%	5%	288
MD	87%	13%	356
NJ	92%	8%	510
PA	93%	7%	597
<b>Weighted NCI-IDD Average</b>	<b>92%</b>	<b>8%</b>	<b>1,906</b>

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

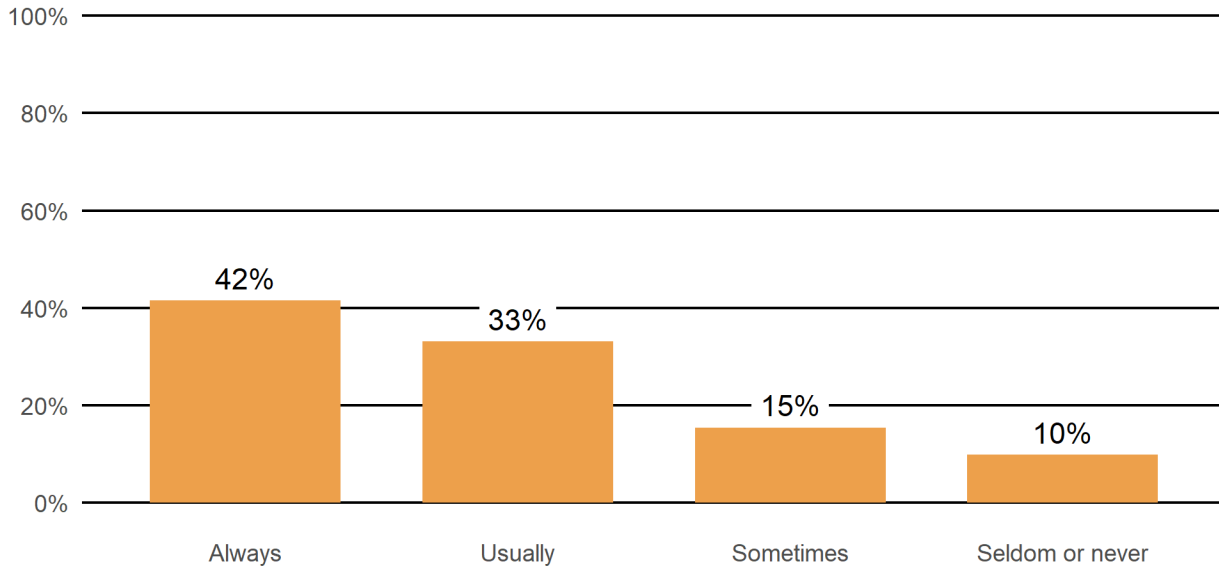


Table 87. Does the agency providing residential services to your family member involve them in important decisions?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
AZ	42%	35%	17%	6%	143
GA	38%	37%	16%	9%	235
MD	42%	31%	16%	10%	307
NJ	42%	28%	17%	13%	416
PA	42%	35%	14%	10%	543
<b>Weighted NCI-IDD Average</b>	<b>42%</b>	<b>33%</b>	<b>15%</b>	<b>10%</b>	<b>1,644</b>

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

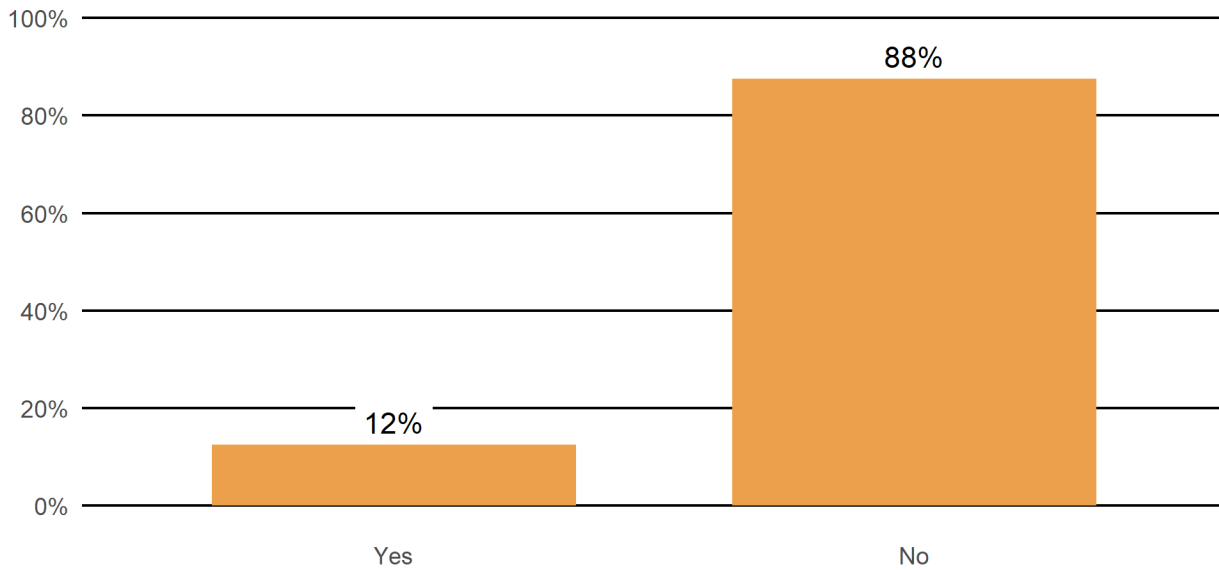


Table 88. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

State (names abbreviated)	Yes	No	N
AZ	10%	90%	158
GA	15%	85%	263
MD	16%	84%	348
NJ	14%	86%	499
PA	11%	89%	567
<b>Weighted NCI-IDD Average</b>	<b>12%</b>	<b>88%</b>	<b>1,835</b>



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

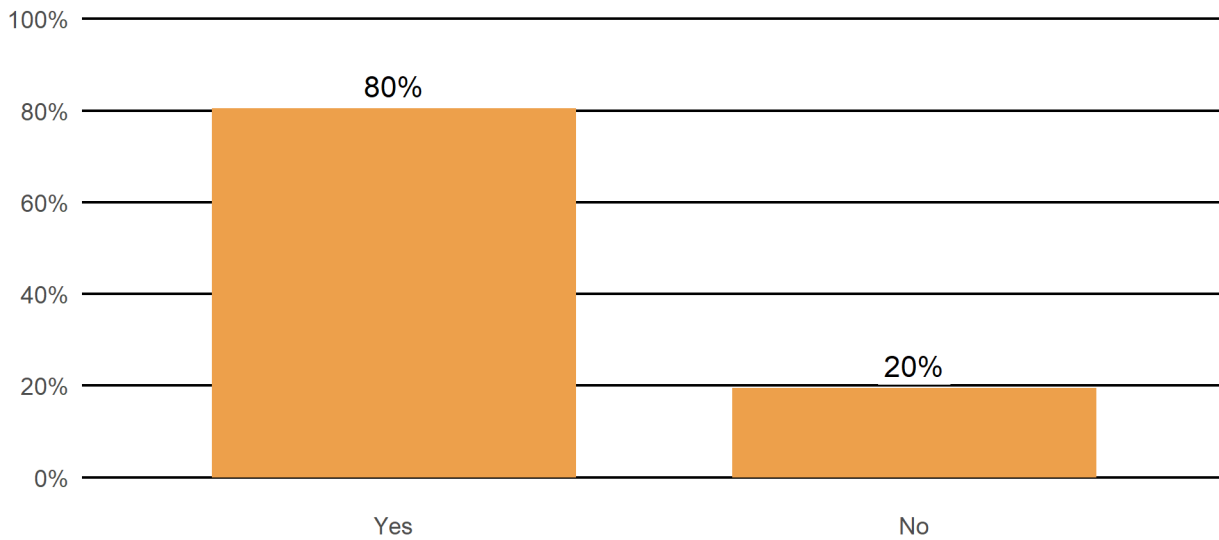


Table 89. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?

State (names abbreviated)	Yes	No	N
GA	76%	24%	34
MD	77%	23%	53
NJ	88%	12%	66
PA	84%	16%	50
Weighted NCI-IDD Average	80%	20%	218

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

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

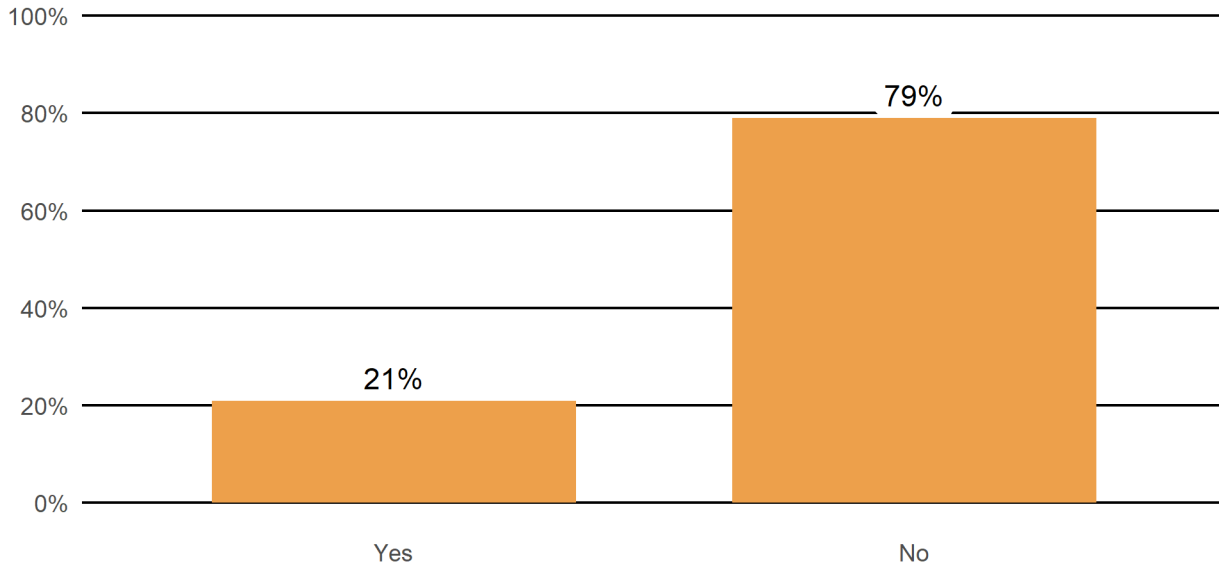


Table 90. Have the services or supports that your family member received been increased in the past 12 months?

State (names abbreviated)	Yes	No	N
AZ	21%	79%	142
GA	21%	79%	229
MD	27%	73%	312
NJ	23%	77%	451
PA	17%	83%	492
<b>Weighted NCI-IDD Average</b>	<b>21%</b>	<b>79%</b>	<b>1,626</b>

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

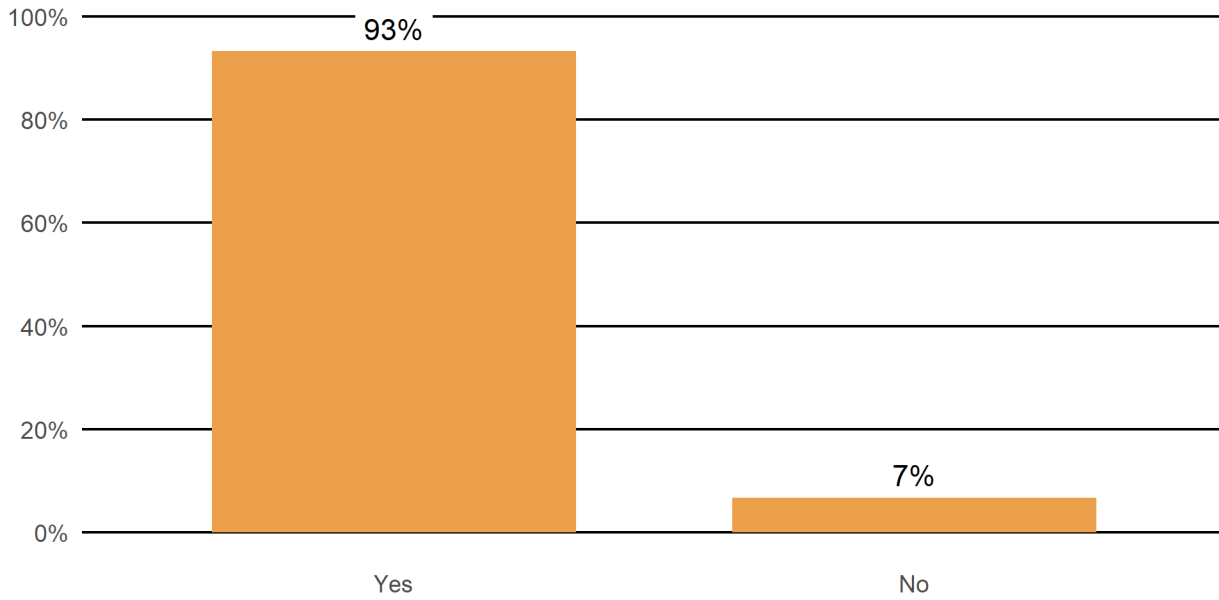


Table 91. Are services and supports helping your family member to live a good life?

State (names abbreviated)	Yes	No	N
AZ	94%	6%	154
GA	95%	5%	278
MD	89%	11%	344
NJ	92%	8%	492
PA	95%	5%	591
<b>Weighted NCI-IDD Average</b>	<b>93%</b>	<b>7%</b>	<b>1,859</b>

## **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

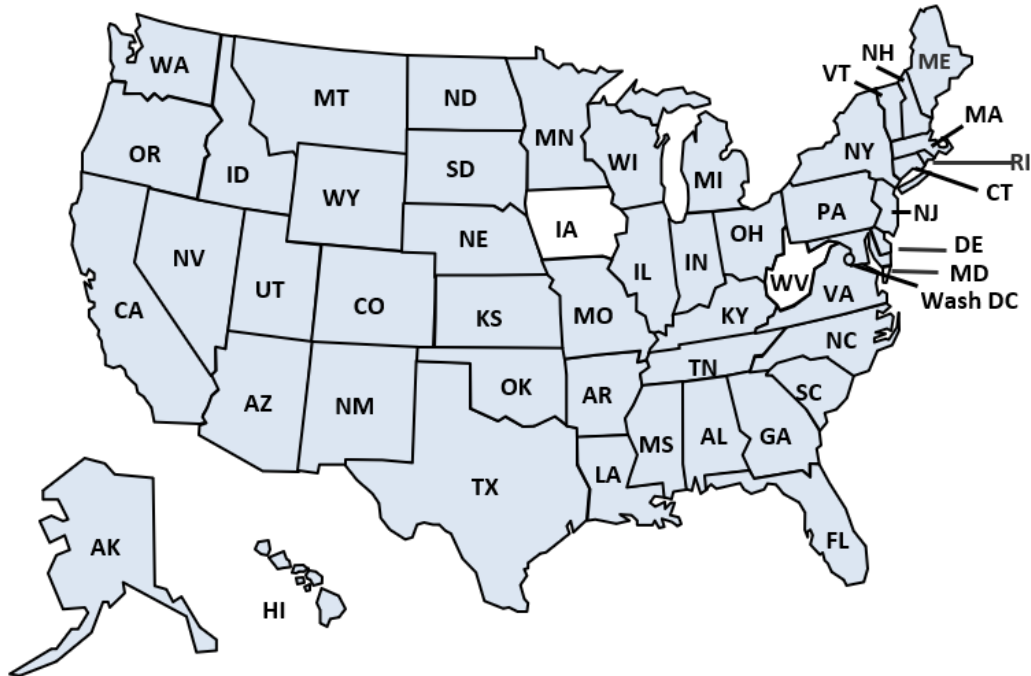
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven 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 2022-23**



## 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
<b>Information and Planning</b>	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.
<b>Choice and Decision Making</b>	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.
<b>Access &amp; Support Delivery</b>	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.
<b>Workforce</b>	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.
<b>Community Connections</b>	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.
<b>Health, Welfare, and Safety</b>	Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state Developmental disabilities system.
<b>Family Satisfaction</b>	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 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.

## 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.

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

### **Response Rates**

During 2022-23, five 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	4798	1400	164	12%	7.0%	95%	5%
GA	3527	1200	322	27%	5.0%	100%	0%
MD	8421	7454	411	6%	4.4%	33%	67%
NJ	7834	-	598	-	3.7%	1%	99%
PA	16980	2000	650	33%	3.5%	100%	0%
<b>Total</b>	41560	-	2145	-	1.9%	59%	41%

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