

Family/Guardian Survey

2020-21 Final Report





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National Association of State Directors of Developmental Disabilities Services

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List of Abbreviations Used in This Report

AFS – Adult Family Survey

CIP – Core Indicators Project

CFS – Child Family Survey

CMS – Centers for Medicare & Medicaid Services

FGS – Family/Guardian Survey

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

NASDDDS – National Association of State Directors of Developmental Disabilities Services

NCI – National Core Indicators

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Executive Summary

The National Core Indicators (NCI) 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 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 Family/Guardian Survey is administered to families who have an adult (18 years or older) with a 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 administer the Family/Guardian Survey on an annual basis. Of the 46 states, the District of Columbia, and 22 sub-state entities who participated in NCI during the 2020-21 data collection cycle, eight states submitted a valid sample of Family/Guardian Survey data: Arizona (AZ), Delaware (DE), Georgia (GA), Indiana (IN), Kentucky (KY), Maryland (MD), New Jersey (NJ), and Pennsylvania (PA). This Final Report provides a summary of results based on data submitted by June 30, 2021.

Important note on Impact of COVID-19

The 2020-21 NCI Family Survey data collection cycle began July 1, 2020 and ended June 30, 2021. As COVID-19 continued to spread 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 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. The NCI Family Survey COVID-19 Supplement can be found [here](#).

Respondents

Family members and/or guardians of adults who have IDD and receive at least one service in addition to case management from the state DD service system. The respondent *does not live* with the adult receiving services.

Respondents ...**23%**

are age 75 or older



65% say they visited their family member with IDD 12 or more times in the past year

Family member with IDD ...

Where family member lives ...



11% specialized facility for people with IDD

67% group home or agency-operated apartment

14% own home or apartment

5% adult foster care or host home

3% other

71% have a guardian; among those ...

52% full guardianship

13% limited guardianship

6% level unknown

**47**

average age

58% male

**82%**

take part in community activities

62%

have friends other than family or paid staff



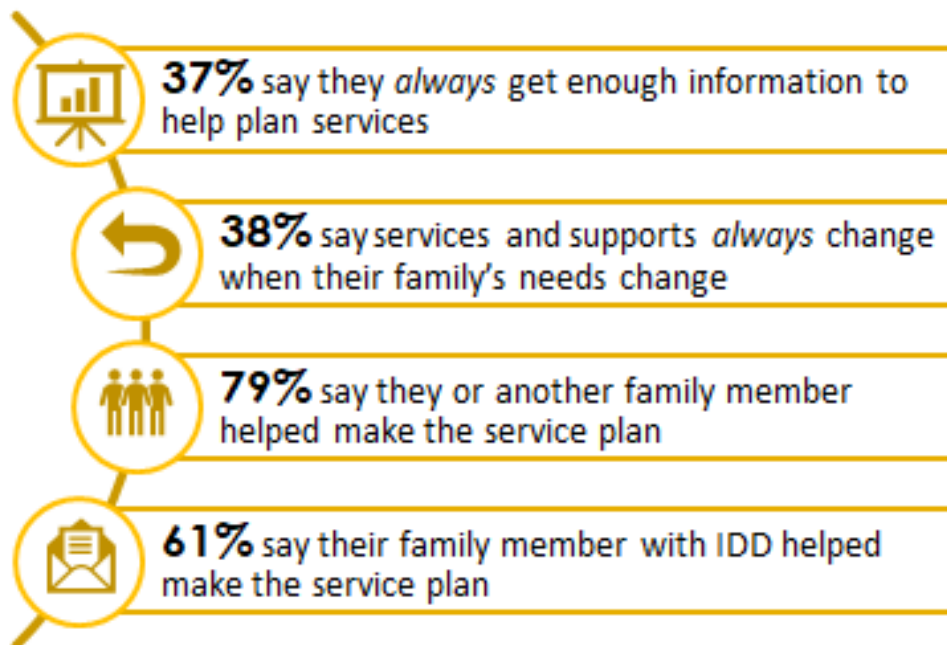
2020–21 Family/ Guardian Survey (FGS)

3,118 families participated across **8** states*

NCI-IDD averages:

- Include all participating states
- Data are weighted

*2020–21 FGS participating states were: AZ, DE, GA, IN, KY, MD, NJ, and PA



2020–21 Family/Guardian Survey

Results

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

Presentation of Data

In addition to basic demographic questions and questions on services and supports 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 Average. The charts are followed by accessible tables showing state outcomes and the NCI 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 Average range, their 'always' or 'yes' response was not statistically different from the NCI Average.

States with fewer than 20 respondents to a question **are not** included in tables; however, their data **are** included in the NCI 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 Averages: The NCI 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 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.

Family Member

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

Table 1. Family Member's Residence

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

State	Specialized facility for people with intellectual disabilities (ICF, state-run or other institutional setting)	Group home or agency-operated apartment	Independent home or apartment (not operated by an agency, may live with a roommate)	Adult foster care or host family home	Nursing home	Homeless	Other	N
AZ	11%	73%	4%	11%	0%	0%	1%	263
DE	0%	87%	7%	6%	0%	0%	0%	151
GA	8%	60%	15%	14%	1%	0%	1%	347
IN	6%	42%	48%	1%	0%	0%	3%	417
KY	9%	51%	16%	23%	0%	0%	1%	471
MD	6%	71%	17%	1%	1%	0%	4%	695
NJ	4%	80%	13%	0%	0%	0%	2%	212
PA	19%	76%	1%	2%	1%	0%	1%	515
Weighted NCI-IDD Average	11%	67%	14%	5%	1%	0%	2%	3,071

Table 2. Family Member's Residential Designation

State	Urban or Suburban	Rural	N
AZ	93%	7%	262
DE	73%	27%	146
GA	80%	20%	334
IN	88%	12%	415
KY	72%	28%	469
MD	75%	25%	695
NJ	71%	29%	207
PA	69%	31%	512
Weighted NCI-IDD Average	76%	24%	3,040

Table 3. Family Member's Age

State	Age	N
AZ	47.2	263
DE	47.1	149
GA	47.1	340
IN	44.8	413
KY	48.2	465
MD	45.9	691
NJ	39.8	215
PA	49.5	518
Weighted NCI-IDD Average	47.0	3,054

Table 4. Family Member's Gender

State	Male	Female	N
AZ	60%	40%	265
DE	58%	42%	152
GA	59%	41%	350
IN	54%	46%	421
KY	56%	44%	476
MD	62%	38%	704
NJ	67%	33%	215
PA	56%	44%	518
Weighted NCI-IDD Average	58%	42%	3,101

Table 5. Family Member's Race and Ethnicity

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	American Indian or Native Alaska	Asian	Black or African American	Hawaiian or Pacific Islander	White	Hispanic or Latino	Other	N
AZ	7%	1%	5%	0%	77%	14%	1%	262
DE	1%	1%	26%	0%	70%	3%	1%	151
GA	1%	1%	20%	0%	78%	1%	1%	335
IN	2%	1%	7%	0%	91%	2%	1%	415
KY	1%	1%	6%	0%	93%	0%	0%	471
MD	2%	3%	15%	0%	81%	2%	1%	698
NJ	1%	2%	7%	0%	88%	3%	2%	211
PA	1%	1%	5%	0%	93%	1%	0%	511
Weighted NCI-IDD Average	2%	2%	9%	0%	87%	3%	1%	3,054

Table 6a. Family Member's Disabilities (not mutually exclusive)

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Intellectual Disability	Mental Illness or psychiatric diagnosis	Autism Spectrum Disorder	Cerebral palsy	Limited or no vision	Hearing loss (severe or profound)
AZ	79%	36%	25%	21%	8%	7%
DE	79%	36%	35%	10%	8%	5%
GA	78%	37%	29%	15%	11%	4%
IN	78%	43%	28%	16%	7%	7%
KY	82%	40%	23%	14%	9%	7%
MD	78%	31%	33%	16%	10%	7%
NJ	77%	35%	41%	14%	8%	7%
PA	89%	43%	29%	16%	11%	7%
Weighted NCI-IDD Average	82%	39%	30%	16%	10%	7%

Table 6b. Family Member's Disabilities (Continued)

All data 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	Brain injury	Seizure or neurological disorder	Chemical dependency	Down syndrome	Prader-Willi syndrome	Fetal alcohol spectrum disorder (FASD)	Other
AZ	10%	33%	0%	10%	0%	4%	14%
DE	9%	23%	1%	11%	0%	3%	11%
GA	10%	31%	2%	8%	1%	2%	16%
IN	8%	23%	0%	8%	1%	3%	20%
KY	8%	23%	0%	10%	1%	3%	9%
MD	11%	25%	0%	9%	1%	1%	15%
NJ	8%	25%	1%	10%	1%	2%	15%
PA	12%	31%	0%	11%	2%	0%	10%
Weighted NCI-IDD Average	10%	28%	0%	10%	1%	2%	13%

Table 7a. Family Member's Health Conditions

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Cardiovascular disease	Diabetes	Cancer	High blood pressure	High cholesterol
AZ	9%	14%	4%	31%	31%
DE	11%	22%	4%	26%	27%
GA	8%	18%	8%	41%	34%
IN	11%	24%	4%	43%	38%
KY	13%	26%	4%	39%	35%
MD	10%	15%	7%	37%	31%
NJ	16%	11%	5%	33%	41%
PA	13%	17%	7%	26%	29%
Weighted NCI-IDD Average	11%	18%	6%	34%	32%

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

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Dysphagia	Pressure ulcers	Alzheimer's disease or other dementia	Oral health problems	Sleep apnea	Other
AZ	8%	1%	8%	21%	15%	25%
DE	19%	1%	2%	18%	22%	23%
GA	10%	1%	3%	14%	12%	18%
IN	12%	1%	5%	10%	22%	22%
KY	10%	2%	7%	11%	19%	15%
MD	11%	4%	5%	13%	15%	26%
NJ	12%	2%	6%	21%	16%	22%
PA	22%	2%	6%	16%	17%	24%
Weighted NCI-IDD Average	14%	2%	6%	14%	17%	23%

Table 8. Family Member's Preferred Means of Communication

State	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
AZ	81%	13%	2%	1%	3%	264
DE	78%	18%	1%	1%	3%	147
GA	75%	18%	2%	1%	5%	341
IN	87%	9%	1%	1%	2%	420
KY	84%	12%	1%	1%	2%	478
MD	74%	18%	3%	1%	3%	702
NJ	73%	18%	1%	0%	7%	210
PA	71%	22%	1%	1%	4%	512
Weighted NCI-IDD Average	77%	17%	2%	1%	4%	3,074

Table 9. Family Member Has Legal Court Appointed Guardian or Conservator

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

State	No, does not have a guardian or conservator	Yes, limited guardianship	Yes, full guardianship	Yes, has a guardian but not sure whether it's full or limited	N
AZ	15%	8%	74%	3%	258
DE	31%	10%	51%	7%	136
GA	30%	13%	50%	7%	314
IN	34%	9%	52%	4%	395
KY	12%	9%	76%	3%	465
MD	38%	19%	38%	5%	664
NJ	0%	7%	88%	4%	208
PA	36%	15%	41%	8%	479
Weighted NCI-IDD Average	29%	13%	52%	6%	2,919

Table 10. Guardian or Conservator Relationship to Family Member

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

State	Family	Friend	Employee of state or guardianship agency	Other	N
AZ	85%	5%	4%	6%	217
DE	93%	0%	4%	2%	91
GA	94%	2%	2%	1%	203
IN	82%	3%	9%	5%	244
KY	91%	6%	0%	3%	399
MD	89%	2%	5%	4%	375
NJ	97%	1%	0%	2%	201
PA	92%	0%	4%	3%	290
Weighted NCI-IDD Average	90%	2%	4%	4%	2,020

Table 11. Family Member's Highest level of Education

State	Did not complete high school (and not currently in school)	Currently enrolled in high school	High school certificate (not a high school diploma or GED)	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
AZ	27%	0%	27%	31%	3%	7%	5%	238
DE	38%	1%	34%	15%	3%	1%	6%	144
GA	34%	0%	43%	17%	2%	1%	2%	321
IN	30%	0%	36%	25%	1%	4%	3%	403
KY	31%	0%	33%	24%	3%	3%	6%	464
MD	26%	0%	42%	15%	4%	4%	7%	672
NJ	33%	0%	22%	24%	3%	6%	11%	201
PA	38%	0%	24%	31%	3%	1%	3%	471
Weighted NCI-IDD Average	32%	0%	32%	24%	3%	3%	5%	2,914

Table 12. Family Member's Activities in the Past Two Weeks Included *Individual Paid Job in the Community*¹

State	Yes	No	N
AZ	4%	96%	261
DE	9%	91%	145
GA	8%	92%	331
IN	18%	82%	410
KY	9%	91%	325
MD	13%	87%	676
NJ	8%	92%	202
PA	8%	92%	492
Weighted NCI-IDD Average	10%	90%	2,842

¹ An individual job is defined as work at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (for example, competitive employment).

Table 13. Family Member's Activities in the Past Two Weeks Included *Paid Small Group Job in a Community-based Setting*²

State	Yes	No	N
AZ	6%	94%	261
DE	8%	92%	142
GA	3%	97%	319
IN	7%	93%	400
KY	4%	96%	318
MD	4%	96%	658
NJ	5%	95%	201
PA	5%	95%	489
Weighted NCI-IDD Average	5%	95%	2,788

Table 14. Family Member's Activities in the Past Two Weeks Included *Paid Work in a Community Job That Primarily Hires People With Disabilities*³

State	Yes	No	N
AZ	3%	97%	260
DE	6%	94%	140
GA	2%	98%	328
IN	6%	94%	398
KY	4%	96%	327
MD	4%	96%	664
NJ	5%	95%	198
PA	3%	97%	497
Weighted NCI-IDD Average	4%	96%	2,812

² A small group job is defined as work in an integrated setting, as part of a group of not more than 8 people with disabilities (for example, enclave, work crew).

³ Paid work in a community job that primarily hires people with disabilities is defined as work in a setting where the person interacts with the non-disabled population; this is NOT in a traditional sheltered workshop and NOT enclave.

Table 15. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in the Community*⁴

State	Yes	No	N
AZ	4%	96%	252
DE	6%	94%	141
GA	15%	85%	319
IN	14%	86%	393
KY	12%	88%	319
MD	16%	84%	641
NJ	14%	86%	194
PA	14%	86%	474
Weighted NCI-IDD Average	13%	87%	2,733

Table 16. Family Member's Activities in the Past Two Weeks Included *Paid Activity in a Facility-based Setting*⁵

State	Yes	No	N
AZ	8%	92%	260
DE	7%	93%	140
GA	6%	94%	326
IN	19%	81%	403
KY	12%	88%	325
MD	5%	95%	659
NJ	11%	89%	194
PA	15%	85%	492
Weighted NCI-IDD Average	12%	88%	2,799

⁴ Unpaid work in the community includes: volunteering, skills training, and staff-supported community connections.

⁵ Paid work performed in a facility-based setting is defined as work at a location developed specifically to provide work activity exclusively for people with disabilities; may be paid sub-minimum wage. Examples include traditional sheltered workshops or work activity centers.

Table 17. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in a Facility-based Setting*⁶

State	Yes	No	N
AZ	25%	75%	253
DE	9%	91%	139
GA	27%	73%	313
IN	16%	84%	393
KY	29%	71%	323
MD	23%	77%	630
NJ	33%	67%	203
PA	23%	77%	481
Weighted NCI-IDD Average	23%	77%	2,735

Table 18. Family Member's Activities in the Past Two Weeks Included *School*

State	Yes	No	N
AZ	2%	98%	258
DE	1%	99%	139
GA	2%	98%	321
IN	2%	98%	406
KY	2%	98%	326
MD	2%	98%	661
NJ	1%	99%	202
PA	4%	96%	498
Weighted NCI-IDD Average	3%	97%	2,811

⁶ An unpaid activity in a facility-based setting includes day habilitation, senior programs, or drop-in centers.

Table 19. Family Member's Activities in the Past Two Weeks Included *Stays at Home*

State	Yes	No	N
AZ	68%	32%	249
DE	70%	30%	137
GA	57%	43%	312
IN	55%	45%	398
KY	56%	44%	323
MD	60%	40%	641
NJ	49%	51%	191
PA	55%	45%	481
Weighted NCI-IDD Average	58%	42%	2,732

Table 20. Family Member's Activities in the Past Two Weeks Included *Other Activities*

State	Yes	No	N
AZ	46%	54%	83
DE	33%	68%	40
GA	36%	64%	86
IN	22%	78%	153
KY	14%	86%	205
MD	35%	65%	205
NJ	27%	73%	56
PA	32%	68%	119
Weighted NCI-IDD Average	30%	70%	947

Table 21. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

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

State	None	Some	Extensive	N
AZ	31%	42%	26%	261
DE	33%	44%	23%	146
GA	32%	40%	28%	343
IN	32%	45%	22%	408
KY	37%	45%	18%	334
MD	42%	33%	26%	684
NJ	37%	35%	28%	205
PA	31%	38%	32%	511
Weighted NCI-IDD Average	34%	39%	27%	2,892

Table 22. Family Member's Level of Help Needed with Personal Care Activities (e.g., bathing, dressing, eating)

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

State	None	Some	Extensive	N
AZ	14%	44%	42%	260
DE	28%	38%	33%	151
GA	22%	41%	37%	347
IN	34%	39%	27%	417
KY	26%	42%	33%	337
MD	25%	34%	40%	703
NJ	14%	46%	40%	209
PA	14%	38%	48%	513
Weighted NCI-IDD Average	21%	39%	40%	2,937

Table 23. Family Member’s Need for Help with Other Daily Activities (e.g., scheduling, managing money, or shopping)

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

State	None	Some	Extensive	N
AZ	1%	15%	85%	261
DE	1%	23%	77%	151
GA	3%	17%	80%	345
IN	3%	27%	70%	414
KY	3%	19%	78%	340
MD	4%	18%	77%	705
NJ	0%	13%	86%	211
PA	2%	14%	84%	512
Weighted NCI-IDD Average	3%	17%	80%	2,939

Respondents

This section provides demographic information about the respondent.

Table 24. Language Spoken at Home

State	English	Spanish	Other	N
AZ	98%	0%	2%	264
DE	99%	1%	0%	151
GA	99%	0%	1%	343
IN	99%	0%	0%	408
KY	100%	0%	0%	338
MD	98%	1%	1%	699
NJ	100%	0%	0%	209
PA	99%	0%	1%	507
Weighted NCI-IDD Average	99%	0%	1%	2,919

Table 25. Respondent's Age

State	Under 35	35-54	55-74	75 and older	N
AZ	2%	15%	63%	20%	263
DE	1%	10%	66%	23%	148
GA	1%	11%	64%	24%	340
IN	2%	14%	62%	22%	415
KY	2%	17%	67%	13%	338
MD	2%	7%	66%	26%	705
NJ	1%	10%	70%	20%	207
PA	0%	6%	67%	26%	507
Weighted NCI-IDD Average	1%	10%	66%	23%	2,923

Table 26. Respondent's Health

State	Excellent	Very good	Fairly good	Poor	N
AZ	18%	47%	32%	3%	263
DE	10%	41%	39%	9%	150
GA	12%	43%	37%	7%	340
IN	13%	43%	37%	6%	414
KY	15%	44%	37%	4%	338
MD	17%	44%	33%	6%	705
NJ	19%	50%	29%	2%	209
PA	17%	45%	32%	5%	505
Weighted NCI-IDD Average	16%	45%	34%	5%	2,924

Table 27. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public guardian	Private guardian	Other	N
AZ	58%	22%	1%	2%	6%	3%	9%	264
DE	59%	29%	0%	3%	0%	1%	7%	150
GA	59%	26%	0%	1%	0%	1%	12%	343
IN	61%	23%	0%	1%	1%	4%	10%	416
KY	44%	34%	0%	1%	1%	5%	15%	340
MD	65%	28%	0%	0%	1%	1%	4%	704
NJ	59%	29%	0%	0%	0%	3%	8%	211
PA	62%	35%	0%	1%	0%	0%	1%	508
Weighted NCI-IDD Average	61%	30%	0%	1%	1%	2%	6%	2,936

Table 28. Respondent's Frequency of Visits with Family Member Last Year

State	Did not visit	1 to 3 times	4 to 6 times	7 to 12 times	More than 12 times	N
AZ	3%	10%	13%	13%	62%	262
DE	3%	10%	12%	14%	61%	145
GA	4%	11%	13%	15%	57%	342
IN	2%	5%	7%	9%	77%	417
KY	2%	11%	7%	12%	68%	339
MD	3%	7%	9%	11%	71%	703
NJ	1%	9%	8%	11%	70%	211
PA	4%	11%	10%	17%	58%	508
Weighted NCI-IDD Average	3%	9%	9%	14%	65%	2,927

Table 29. 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	2%	13%	6%	36%	43%	261
DE	5%	21%	4%	23%	46%	149
GA	6%	19%	4%	22%	49%	342
IN	3%	25%	6%	18%	48%	411
KY	5%	21%	5%	20%	49%	334
MD	3%	13%	4%	15%	65%	704
NJ	2%	11%	1%	19%	67%	203
PA	4%	24%	7%	21%	45%	507
Weighted NCI-IDD Average	3%	20%	5%	21%	51%	2,911

Table 30. Total Taxable Household Income of Wage Earners in the Past Year

State	No earned income	Up to \$15,000	\$15,001- \$25,000	\$25,001- \$50,000	\$50,001- \$75,000	Over \$75,000	Prefer not to say	N
AZ	8%	5%	7%	15%	17%	17%	31%	237
DE	11%	7%	7%	14%	15%	15%	32%	137
GA	14%	5%	9%	12%	16%	14%	30%	305
IN	8%	3%	6%	16%	15%	19%	34%	380
KY	7%	4%	8%	15%	11%	21%	34%	317
MD	11%	2%	7%	11%	10%	31%	29%	645
NJ	9%	2%	2%	8%	12%	27%	40%	204
PA	15%	3%	7%	15%	12%	18%	30%	474
Weighted NCI-IDD Average	12%	3%	7%	13%	13%	21%	31%	2,699

Services and Supports Received

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

Table 31. Services and Supports Received from ID/DD Agency

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Financial support	In-home support	Residential supports	Day or employment supports	Transportation	Other	Self direction or fiscal intermediary services
AZ	25%	32%	90%	58%	92%	55%	25%
DE	43%	36%	93%	57%	90%	45%	18%
GA	29%	50%	92%	63%	90%	44%	27%
IN	28%	72%	82%	47%	81%	63%	47%
KY	22%	51%	90%	68%	90%	60%	45%
MD	34%	54%	87%	60%	86%	53%	17%
NJ	30%	36%	92%	73%	92%	56%	28%
PA	27%	45%	96%	53%	94%	66%	17%
Weighted NCI-IDD Average	29%	50%	91%	57%	90%	59%	25%

Table 32. Additional Services and Supports Received

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive, therefore N is not shown.

State	Social Security (SSI/SSB)	Services or supports from other agencies or organizations
AZ	95%	22%
DE	90%	27%
GA	97%	19%
IN	94%	28%
KY	98%	24%
MD	94%	30%
NJ	98%	27%
PA	98%	27%
Weighted NCI-IDD Average	96%	26%

Family/Guardian 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.

Information and Planning

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

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.

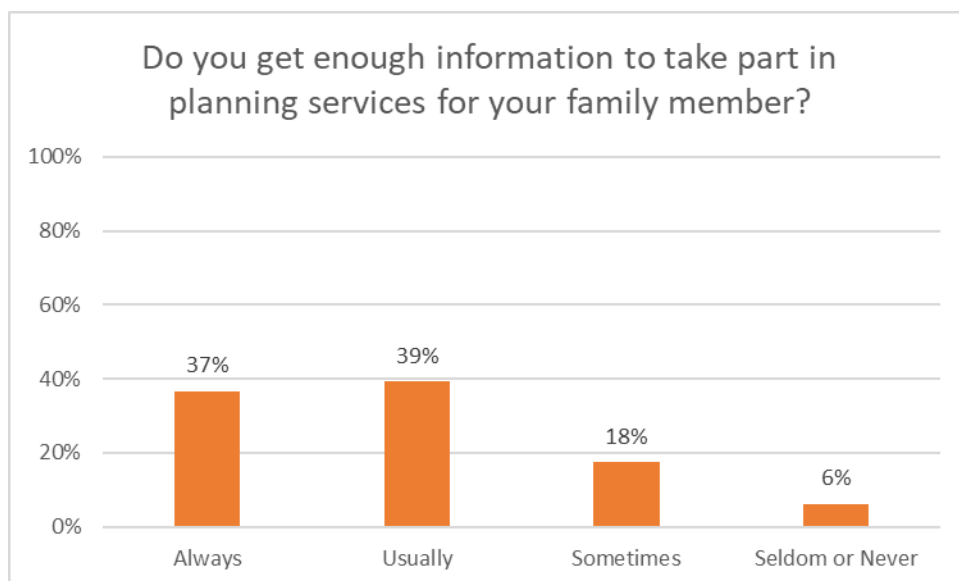


Table Q1. Do you get enough information to take part in planning services for your family member?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	46%	39%	12%	3%	314

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	42%	41%	13%	4%	252
PA	41%	37%	17%	4%	468
IN	40%	38%	14%	8%	387
NJ	38%	40%	16%	6%	210
Weighted NCI-IDD Average	37%	39%	18%	6%	2,740
GA	30%	40%	22%	8%	312

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	26%	41%	23%	9%	653
DE	25%	49%	18%	8%	144

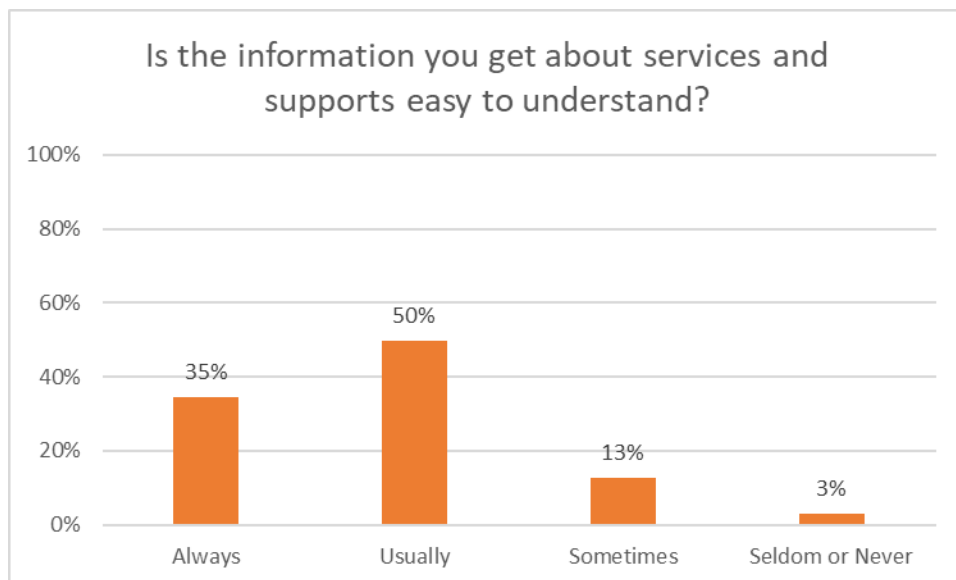


Table Q2. Is the information you get about services and supports easy to understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	41%	46%	10%	2%	485

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	38%	47%	14%	1%	254
KY	36%	51%	10%	3%	319
Weighted NCI-IDD Average	35%	50%	13%	3%	2,752
GA	33%	50%	15%	2%	311
IN	33%	50%	14%	4%	384
NJ	29%	53%	12%	6%	207
DE	28%	58%	11%	3%	144

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	26%	54%	16%	4%	648

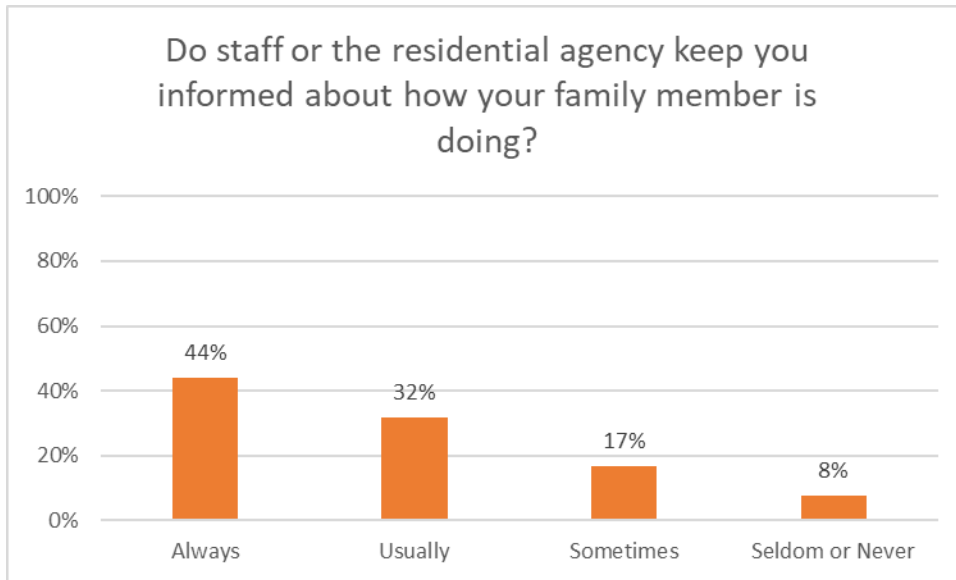


Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	53%	30%	12%	4%	316
PA	51%	30%	13%	6%	513

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	48%	34%	13%	5%	258
GA	46%	29%	16%	9%	336
Weighted NCI-IDD Average	44%	32%	17%	8%	2,821
DE	41%	30%	22%	8%	143
NJ	40%	34%	19%	7%	205

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	37%	34%	19%	10%	386
MD	32%	34%	23%	11%	664

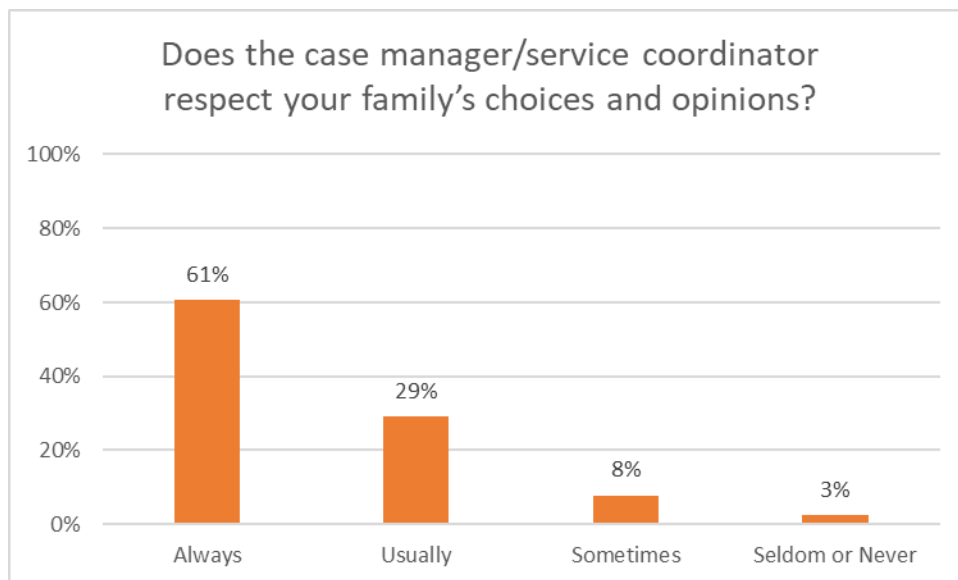


Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	80%	17%	2%	1%	329
IN	68%	24%	6%	2%	398

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	64%	30%	5%	2%	253
NJ	63%	30%	4%	3%	208
Weighted NCI-IDD Average	61%	29%	8%	3%	2,727
PA	59%	30%	9%	1%	483
GA	56%	32%	8%	4%	317
DE	52%	34%	12%	2%	142

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	53%	31%	11%	5%	597

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

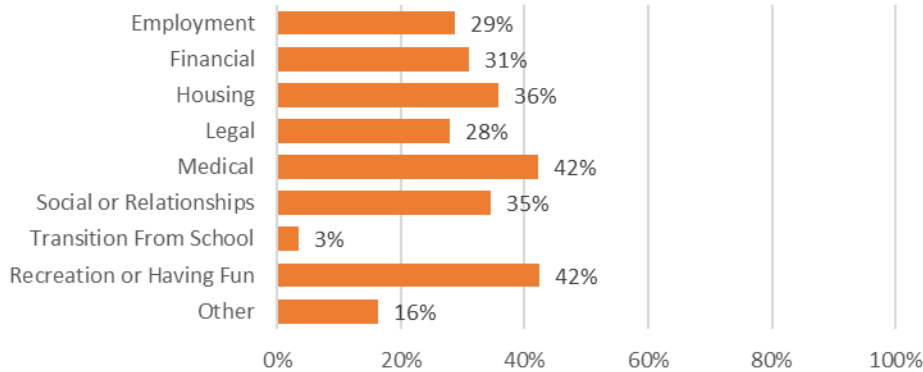


Table Q5. Do you need help planning for your family member's future with respect to any of the following?

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	30%	25%	38%	24%	39%	31%	2%	43%	14%
DE	31%	25%	29%	20%	40%	32%	5%	44%	18%
GA	24%	35%	45%	30%	43%	35%	4%	30%	19%
IN	28%	36%	35%	28%	40%	36%	4%	44%	16%
KY	19%	20%	29%	28%	29%	23%	4%	30%	9%
MD	38%	35%	39%	32%	44%	38%	2%	45%	16%
NJ	31%	34%	45%	30%	41%	37%	7%	43%	14%
PA	23%	27%	30%	25%	46%	34%	3%	45%	19%
Weighted NCI-IDD Average	29%	31%	36%	28%	42%	35%	3%	42%	16%

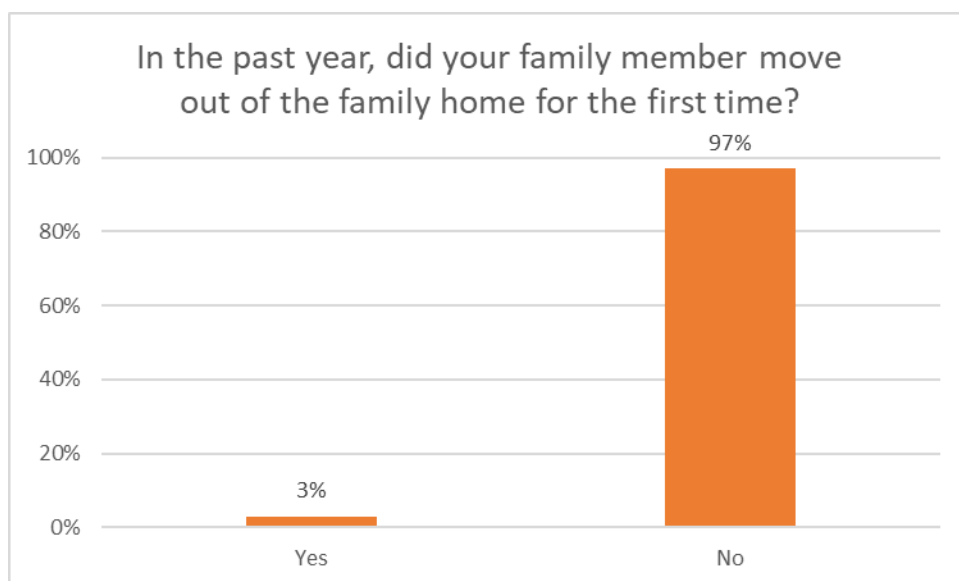


Table Q6. In the past year, did your family member move out of the family home for the first time?

Within Average Range

State	Yes	No	N
NJ	6%	94%	206
DE	5%	95%	141
MD	5%	95%	692
GA	4%	96%	332
AZ	4%	96%	257
Weighted NCI-IDD Average	3%	97%	2,872
IN	3%	97%	410
KY	2%	98%	331

Significantly Below Average

State	Yes	No	N
PA	1%	99%	503

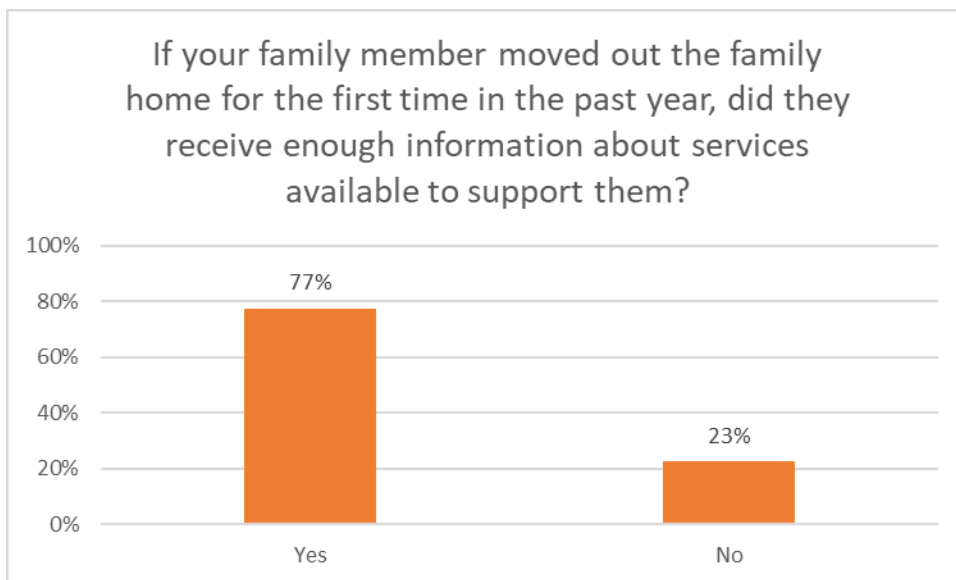


Table Q7. If your family member moved out of the family home for the first time in the past year, did your family member receive enough information about services available to support them? ⁷

Within Average Range

State	Yes	No	N
State	Yes	No	N
MD	91%	9%	32
Weighted NCI-IDD Average	77%	23%	90

⁷ The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: AZ, DE, GA, IN, KY, NJ, PA.

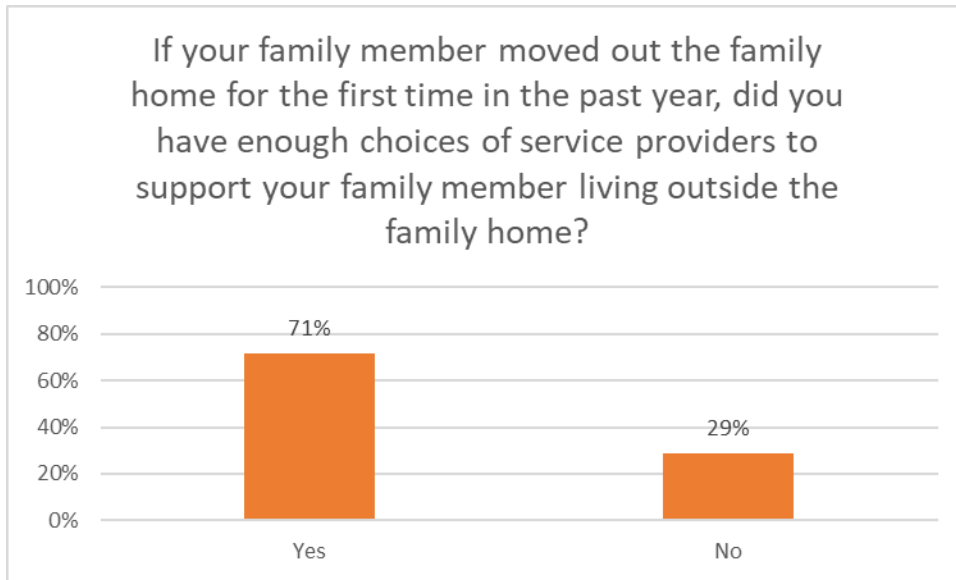


Table Q8. If your family member moved out of the family home for the first time in the past year, did you have enough choices of service providers to support your family? ⁸

Within Average Range

State	Yes	No	N
MD	73%	27%	30
Weighted NCI-IDD Average	71%	29%	88

⁸ The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: AZ, DE, GA, IN, KY, NJ, PA.

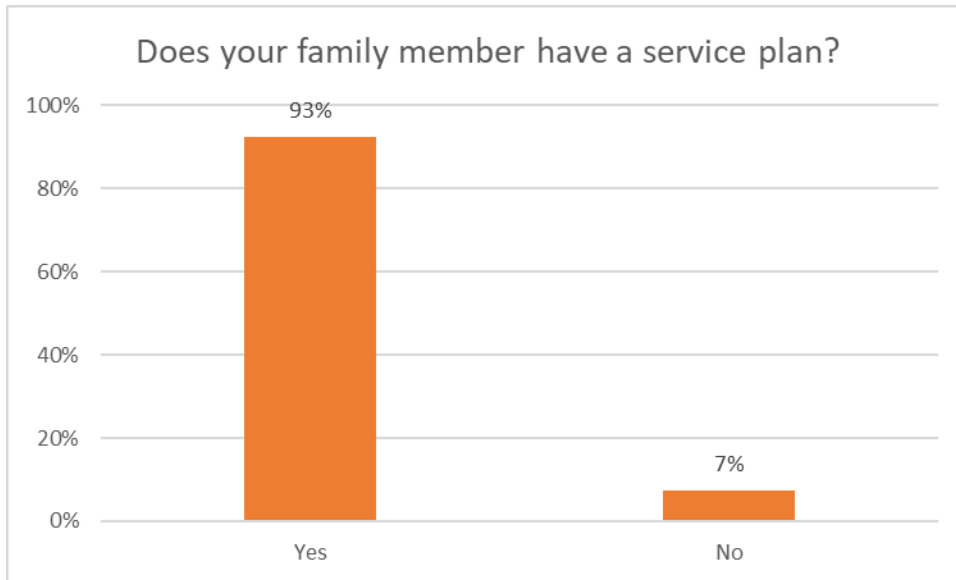


Table Q9. Does your family member have a service plan?

Significantly Above Average

State	Yes	No	N
PA	97%	3%	478

Within Average Range

State	Yes	No	N
KY	95%	5%	310
Weighted NCI-IDD Average	93%	7%	2,426
IN	92%	8%	320
NJ	90%	10%	183
MD	90%	10%	557
GA	90%	10%	240
AZ	87%	13%	227

Significantly Below Average

State	Yes	No	N
DE	77%	23%	111

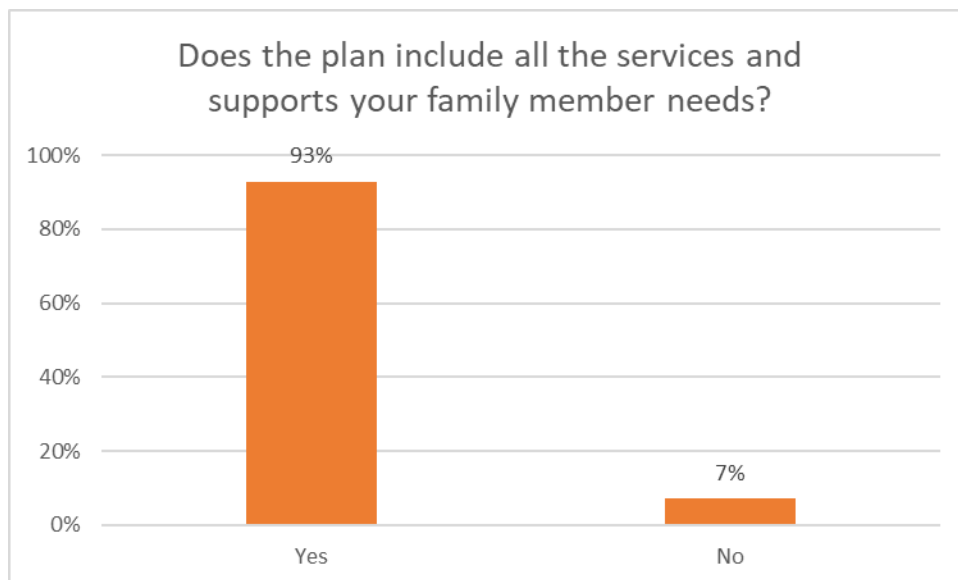


Table Q10. Does the plan include all the services and supports your family member needs?

Significantly Above Average

State	Yes	No	N
KY	97%	3%	271
PA	96%	4%	431

Within Average Range

State	Yes	No	N
AZ	95%	5%	189
DE	93%	7%	75
Weighted NCI-IDD Average	93%	7%	2,018
IN	90%	10%	264
NJ	89%	11%	151
GA	88%	12%	198

Significantly Below Average

State	Yes	No	N
MD	89%	11%	439

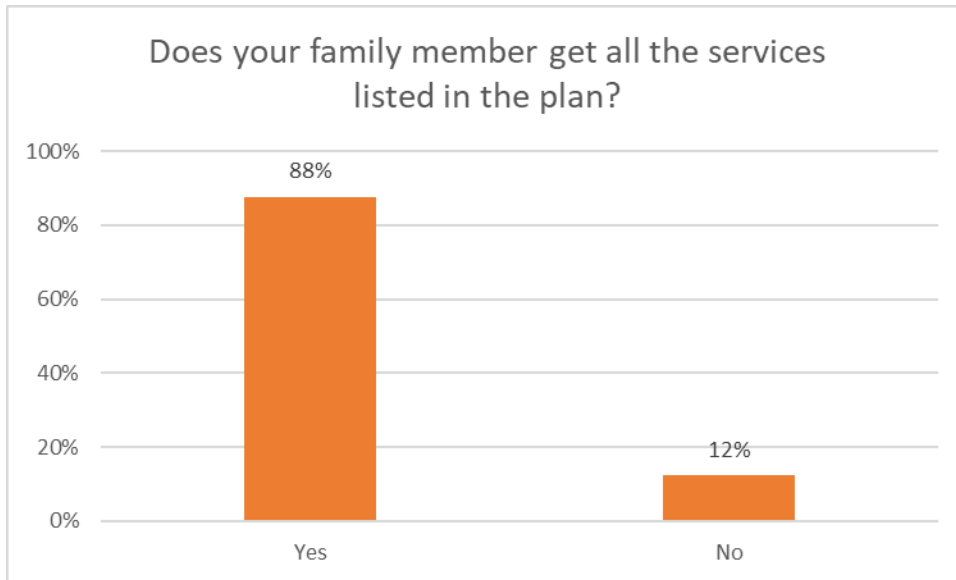


Table Q11. Does your family member get all of the services listed in the plan?

Significantly Above Average

State	Yes	No	N
KY	95%	5%	259
AZ	94%	6%	184

Within Average Range

State	Yes	No	N
PA	91%	9%	398
Weighted NCI-IDD Average	88%	12%	1,879
GA	85%	15%	170
IN	84%	16%	251
NJ	82%	18%	147
DE	79%	21%	61

Significantly Below Average

State	Yes	No	N
MD	81%	19%	409

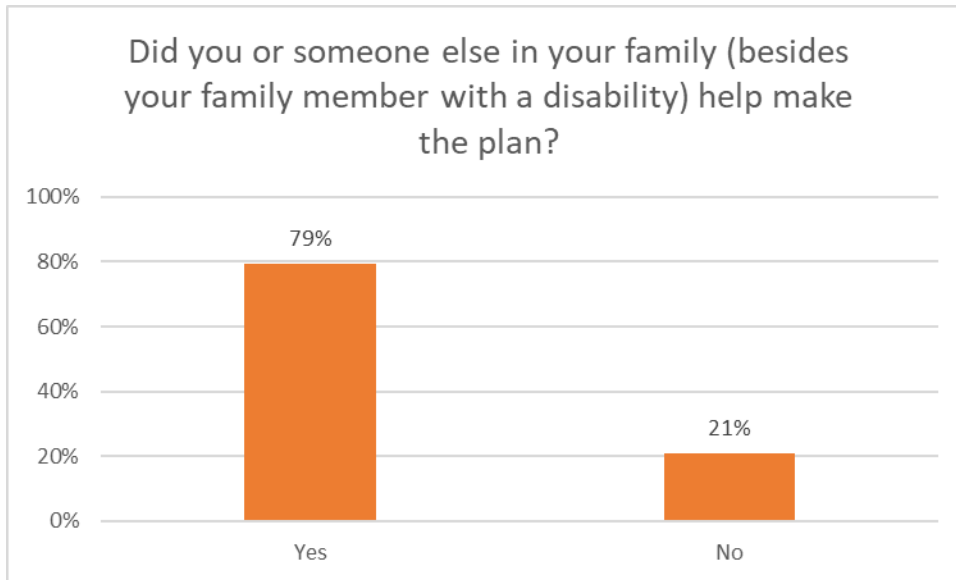


Table Q12. Did you or someone else in your family (besides your family member with a disability) help make the plan?

Significantly Above Average

State	Yes	No	N
KY	87%	13%	280

Within Average Range

State	Yes	No	N
DE	86%	14%	81
NJ	86%	14%	160
GA	86%	14%	201
AZ	85%	15%	190
MD	83%	17%	479
IN	81%	19%	277
Weighted NCI-IDD Average	79%	21%	2,106

Significantly Below Average

State	Yes	No	N
PA	71%	29%	438

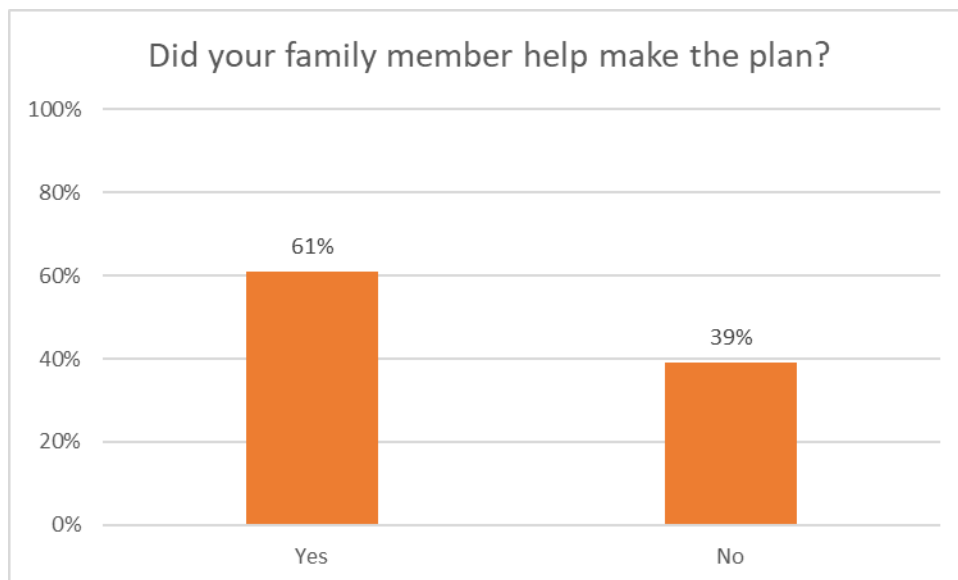


Table Q13. Did your family member help make the plan?

Significantly Above Average

State	Yes	No	N
IN	76%	24%	275
MD	67%	33%	466

Within Average Range

State	Yes	No	N
KY	67%	33%	276
GA	65%	35%	202
DE	62%	38%	81
Weighted NCI-IDD Average	61%	39%	2,065
AZ	56%	44%	185
NJ	52%	48%	159

Significantly Below Average

State	Yes	No	N
PA	53%	47%	421

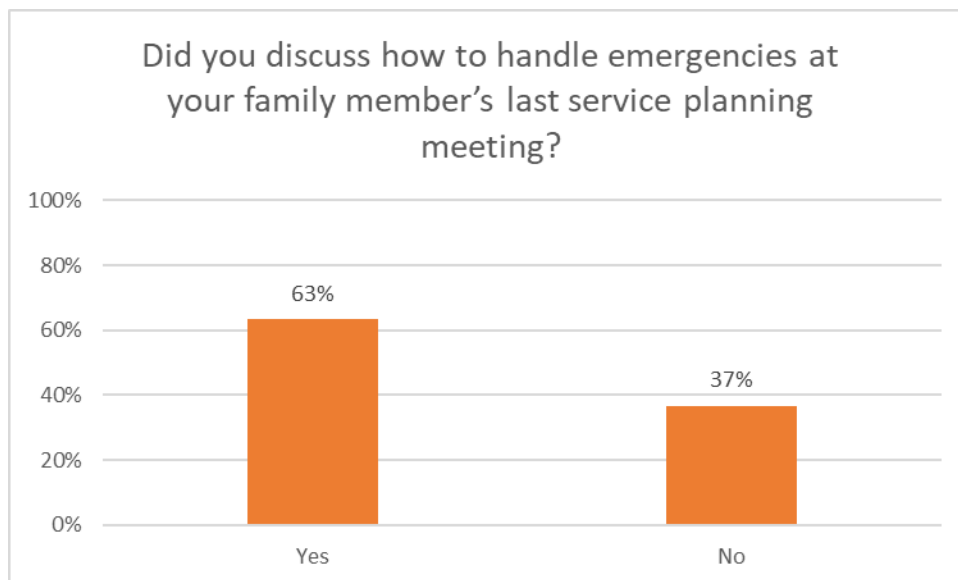


Table Q14. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?

Significantly Above Average

State	Yes	No	N
KY	75%	25%	263

Within Average Range

State	Yes	No	N
NJ	65%	35%	149
PA	64%	36%	376
GA	64%	36%	181
IN	63%	37%	248
Weighted NCI-IDD Average	63%	37%	1,881
AZ	63%	37%	176
MD	58%	42%	419
DE	48%	52%	69

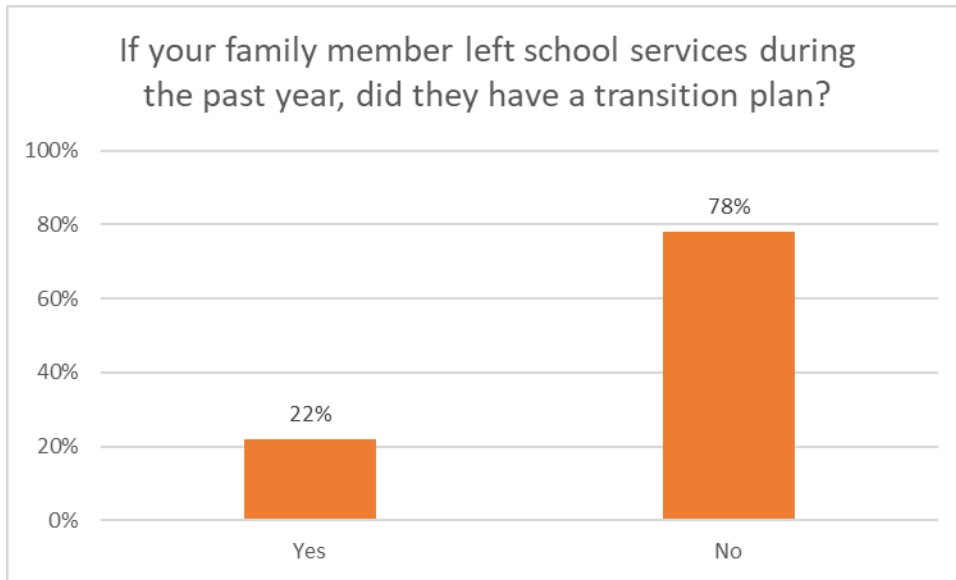


Table Q15. If your family member left school services during the past year, did they have a transition plan?⁹

Within Average Range

State	Yes	No	N
MD	22%	78%	27
Weighted NCI-IDD Average	22%	78%	93

⁹ The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: AZ, DE, GA, IN, KY, NJ, PA.

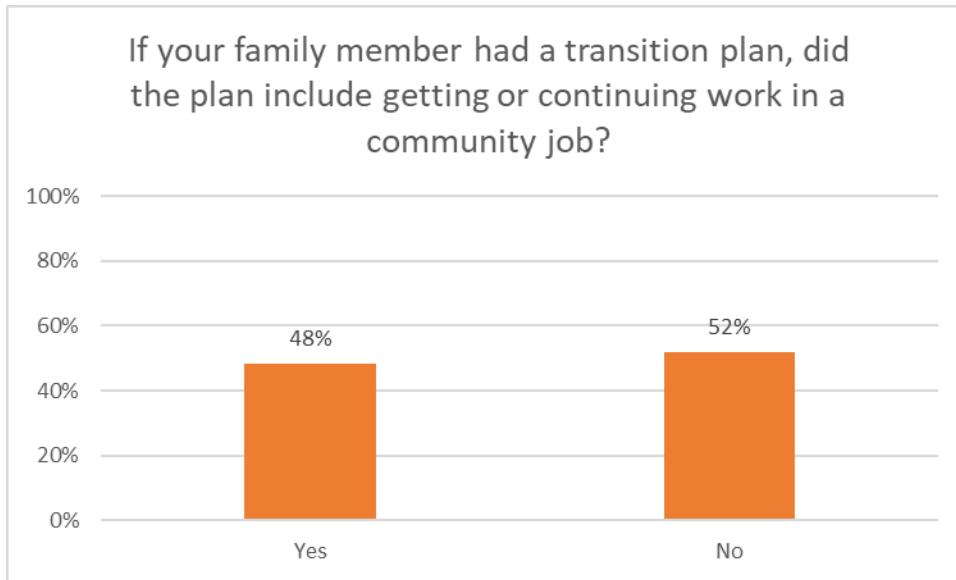


Table Q16. If transition out of school services during past year and had a transition plan, did the transition plan include getting or continuing work in a community job? ¹⁰

Within Average Range

State	Yes	No	N
Weighted NCI-IDD Average	48%	52%	31

¹⁰ No states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average.

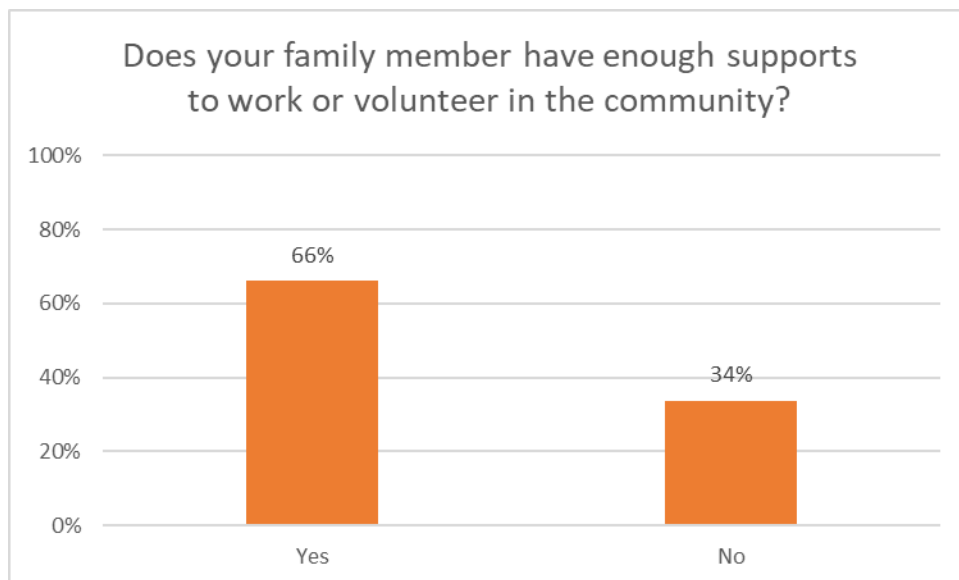


Table Q17. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

Significantly Above Average

State	Yes	No	N
KY	75%	25%	205

Within Average Range

State	Yes	No	N
PA	71%	29%	284
AZ	70%	30%	159
Weighted NCI-IDD Average	66%	34%	1,777
IN	64%	36%	282
DE	63%	38%	88
MD	62%	38%	429
GA	62%	38%	204
NJ	54%	46%	126

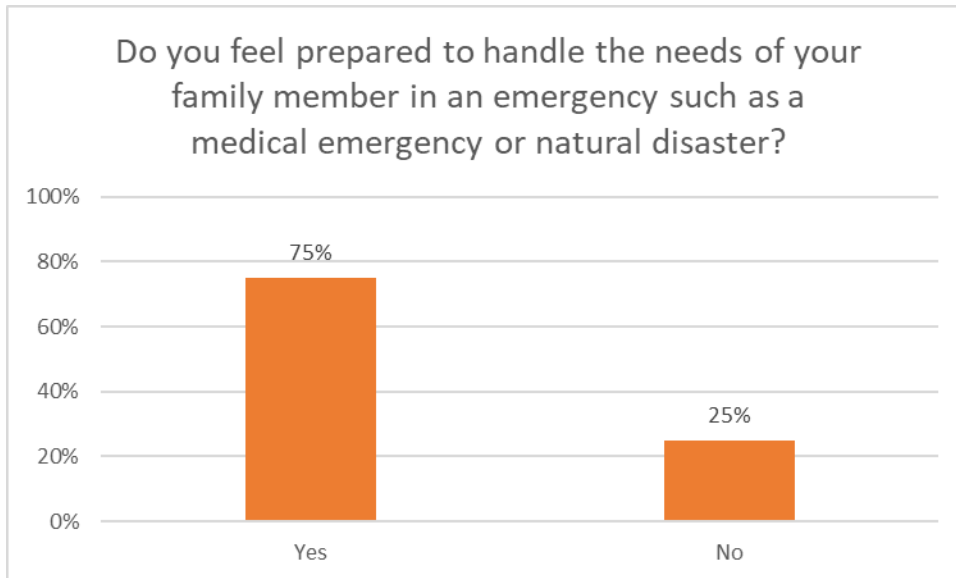


Table Q18. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

Significantly Above Average

State	Yes	No	N
KY	89%	11%	303

Within Average Range

State	Yes	No	N
IN	79%	21%	351
AZ	78%	22%	232
NJ	75%	25%	175
Weighted NCI-IDD Average	75%	25%	2,480
PA	74%	26%	420
MD	72%	28%	589
GA	70%	30%	290
DE	68%	33%	120

Access and Delivery of Services and Supports

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

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.

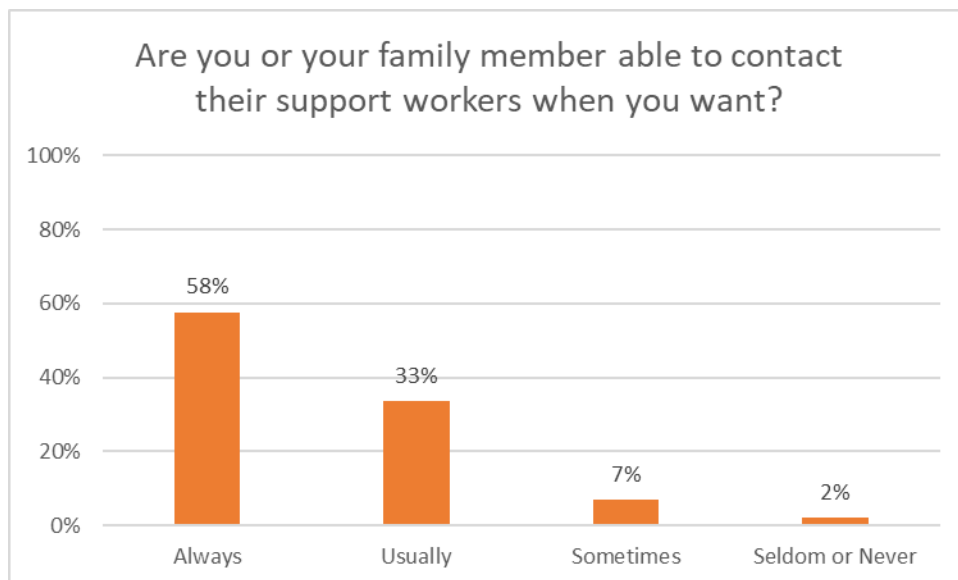


Table Q19. Are you or your family member able to contact their support workers when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	69%	27%	4%	1%	332
PA	64%	29%	5%	1%	492

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	59%	30%	10%	1%	197
GA	58%	33%	7%	2%	329
Weighted NCI-IDD Average	58%	33%	7%	2%	2,810
DE	57%	33%	7%	3%	139
IN	54%	36%	8%	3%	393
AZ	53%	40%	6%	2%	258

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	48%	39%	9%	3%	670

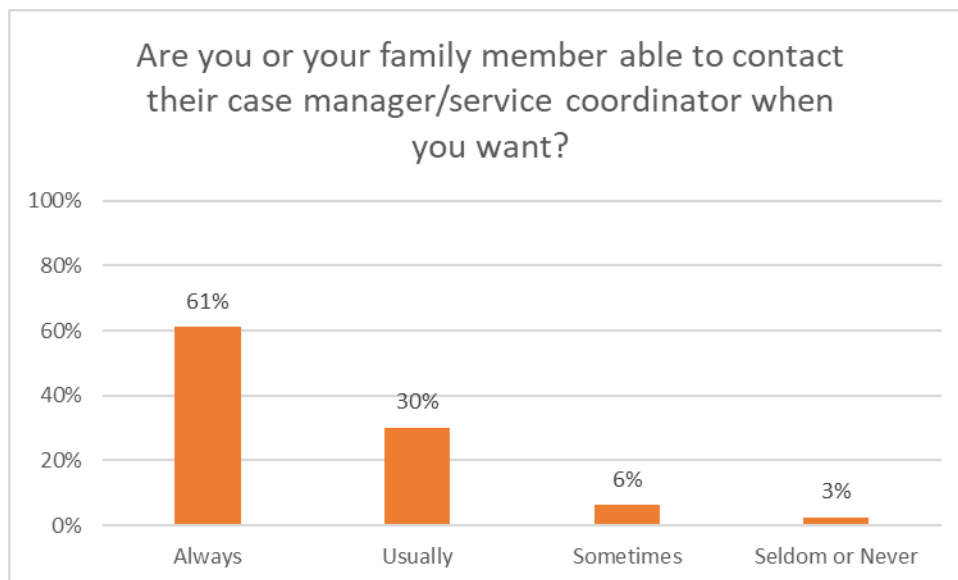


Table Q20. Are you or your family member able to contact their case manager/service coordinator when you want to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	78%	20%	1%	1%	330
IN	70%	24%	6%	1%	395

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	66%	28%	5%	2%	496
NJ	65%	27%	5%	2%	201
Weighted NCI-IDD Average	61%	30%	6%	3%	2,770
AZ	55%	35%	7%	3%	253
DE	53%	37%	8%	2%	143

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
GA	50%	36%	9%	4%	327
MD	48%	38%	9%	5%	625

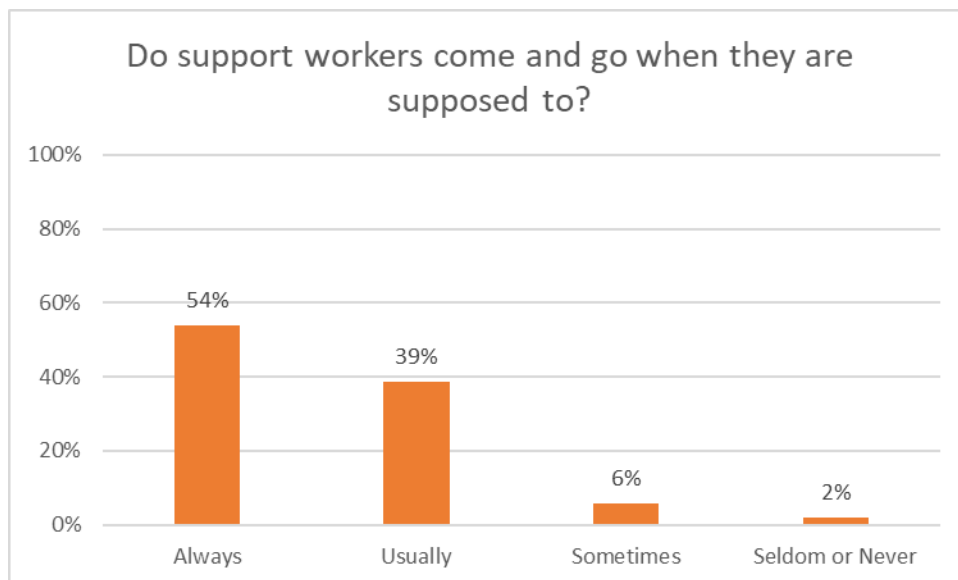


Table Q21. Do support workers come and go when they are supposed to?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	66%	32%	2%	0%	251
PA	65%	32%	3%	1%	271

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	60%	35%	5%	1%	162
DE	55%	37%	4%	4%	78
Weighted NCI-IDD Average	54%	39%	6%	2%	1,824
GA	47%	45%	6%	3%	193
NJ	45%	44%	7%	4%	133

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	46%	41%	11%	3%	312
MD	43%	47%	8%	3%	424

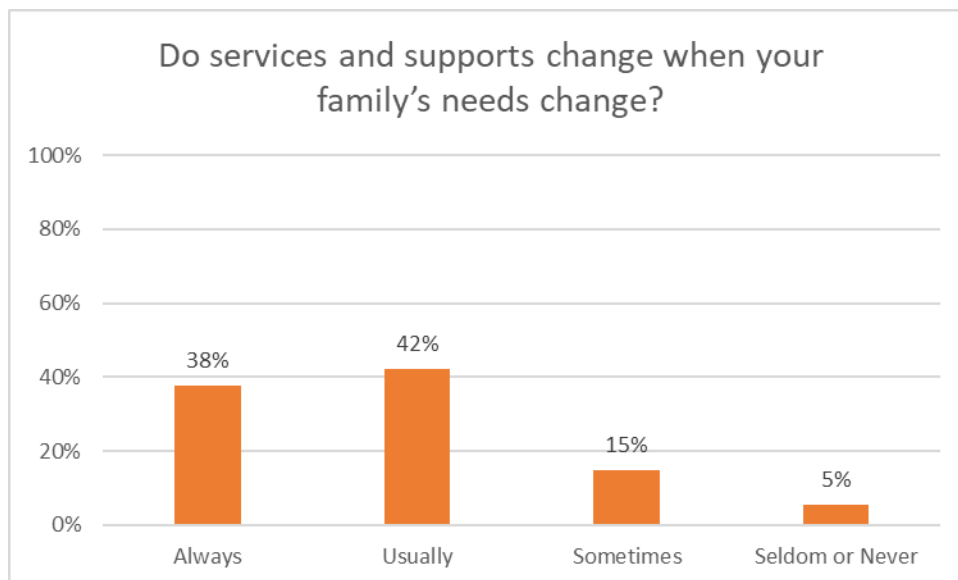


Table Q22. Do services and supports change when your family's needs change?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	51%	41%	5%	3%	256

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	42%	38%	16%	3%	333
AZ	42%	45%	9%	4%	183
Weighted NCI-IDD Average	38%	42%	15%	5%	1,892
GA	33%	44%	17%	6%	212
IN	33%	43%	18%	6%	306
DE	33%	51%	5%	11%	76
NJ	32%	39%	19%	10%	125

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	30%	46%	15%	8%	401

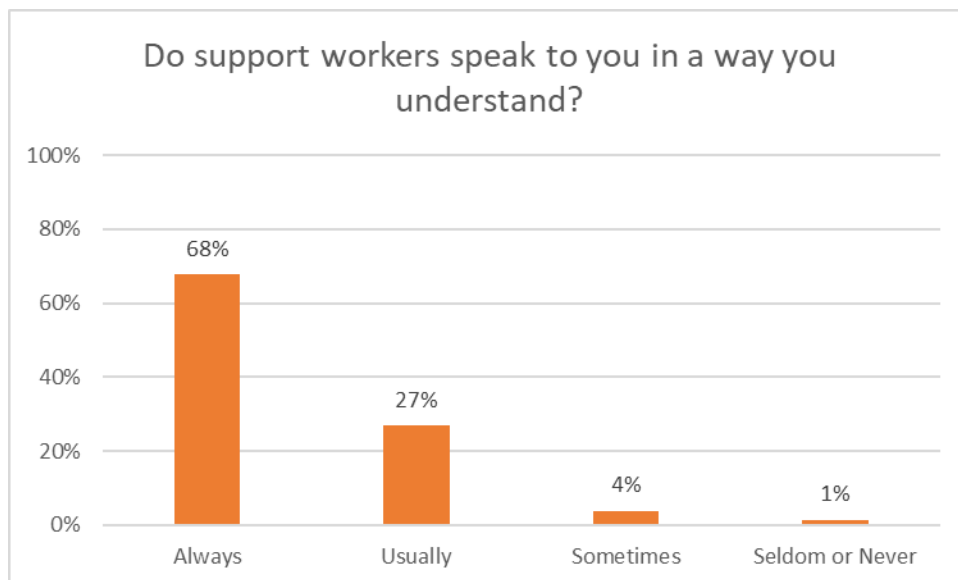


Table Q23. Do support workers speak to you in a way you understand?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	80%	17%	2%	0%	328
PA	73%	23%	2%	1%	485

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DE	68%	25%	4%	2%	135
NJ	68%	26%	4%	2%	185
Weighted NCI-IDD Average	68%	27%	4%	1%	2,715
IN	66%	29%	4%	2%	387
GA	65%	28%	5%	2%	317
AZ	64%	31%	4%	1%	247

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	58%	33%	6%	2%	631

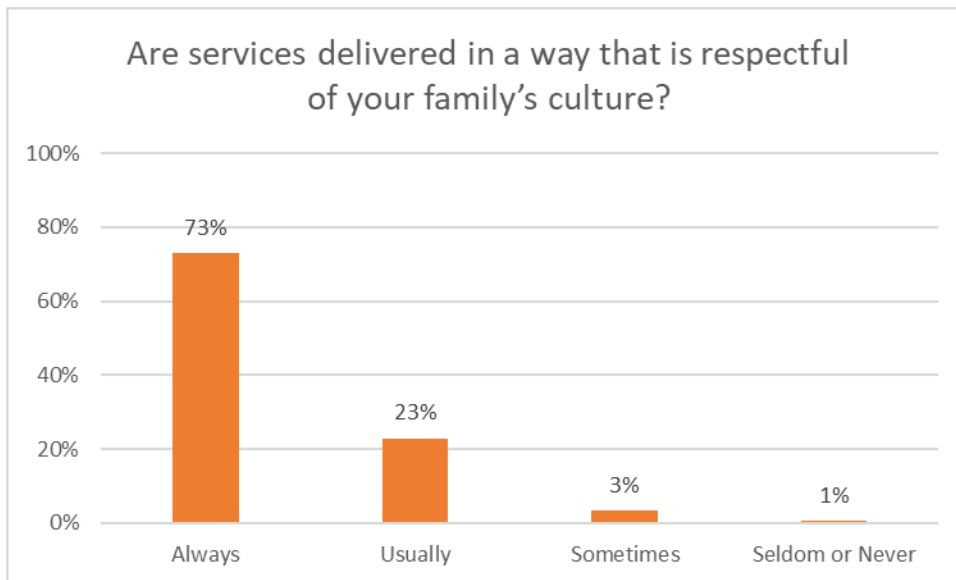


Table Q24. Are services delivered in a way that is respectful of your family's culture?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	80%	17%	3%	0%	325

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	78%	19%	3%	0%	486
NJ	74%	23%	3%	0%	185
Weighted NCI-IDD Average	73%	23%	3%	1%	2,708
IN	71%	26%	3%	0%	380
AZ	70%	27%	2%	1%	242
DE	70%	26%	4%	1%	135
GA	68%	29%	2%	1%	314

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	67%	26%	5%	2%	641

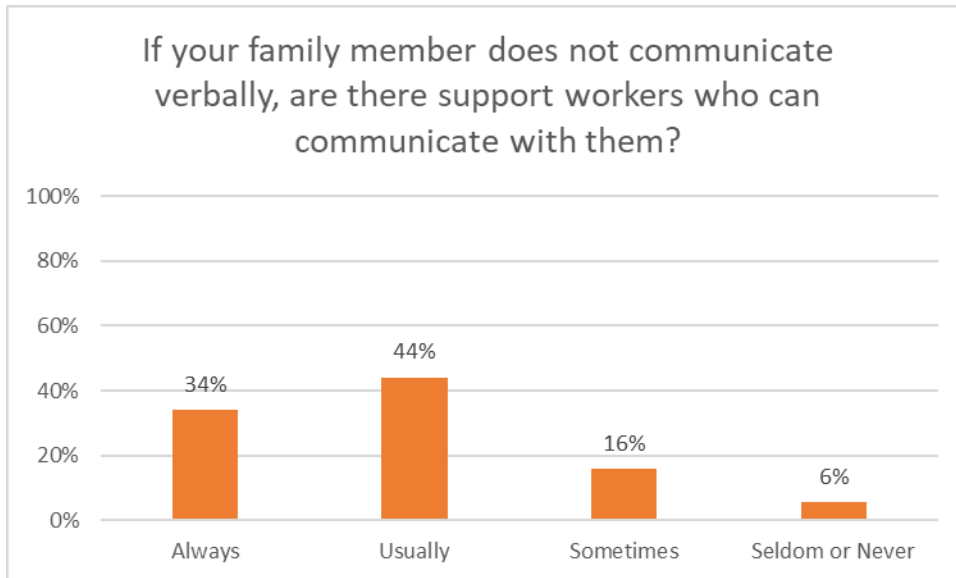


Table Q25. If your family member does not communicate verbally (for example, uses gestures or sign language, or a communication aid), are there support workers who can communicate with him/her?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	48%	43%	6%	4%	54
DE	39%	42%	10%	10%	31
PA	38%	46%	13%	4%	136
GA	37%	41%	17%	5%	78
Weighted NCI-IDD Average	34%	44%	16%	6%	617
AZ	31%	49%	16%	4%	45
MD	29%	42%	20%	8%	165
IN	29%	51%	16%	4%	55
NJ	25%	34%	28%	13%	53

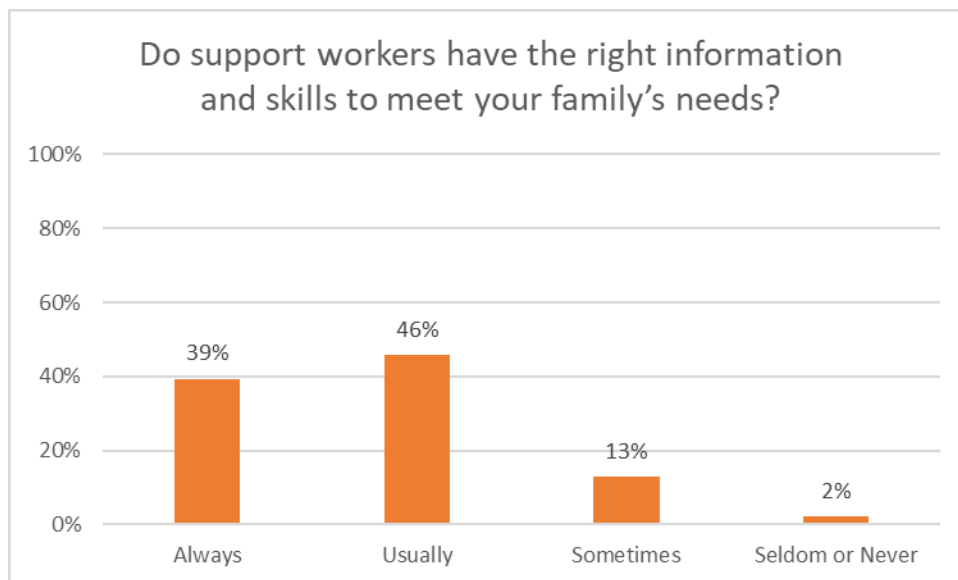


Table Q26. Do support workers have the right information and skills to meet your family's needs?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	55%	38%	5%	2%	311
PA	46%	43%	10%	2%	461

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	40%	47%	10%	2%	231
Weighted NCI-IDD Average	39%	46%	13%	2%	2,566
IN	37%	45%	16%	2%	367
GA	36%	51%	11%	2%	297
DE	34%	51%	11%	4%	122

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	30%	45%	21%	4%	182
MD	29%	51%	16%	3%	595

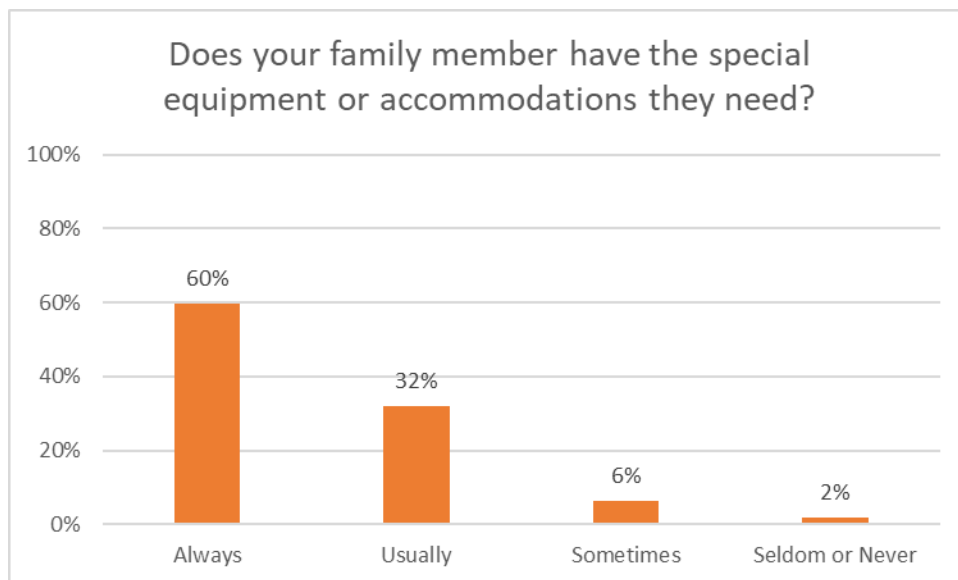


Table Q27. Does your family member have the special equipment or accommodations that s/he needs?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	72%	23%	4%	1%	172
PA	67%	27%	5%	1%	304

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	66%	26%	5%	3%	152
Weighted NCI-IDD Average	60%	32%	6%	2%	1,549
IN	54%	36%	9%	1%	218
GA	50%	40%	8%	2%	167
NJ	48%	37%	11%	5%	101
DE	47%	41%	9%	3%	70

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	52%	39%	7%	2%	365

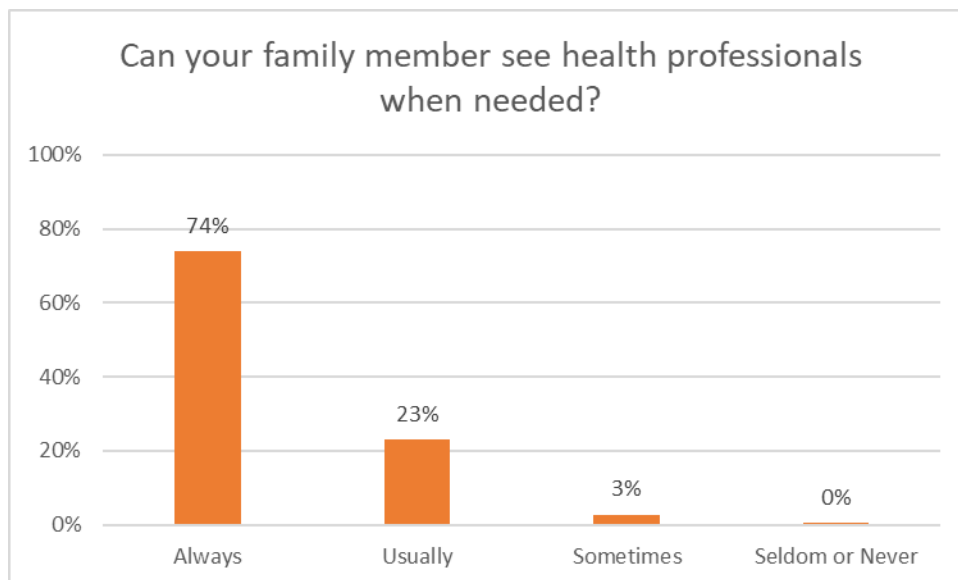


Table Q28. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	81%	16%	2%	0%	499
KY	80%	18%	1%	1%	336

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
Weighted NCI-IDD Average	74%	23%	3%	0%	2,838
IN	73%	23%	3%	0%	403
DE	72%	23%	4%	1%	141
GA	70%	27%	3%	0%	332
AZ	69%	28%	3%	0%	263

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	67%	29%	3%	1%	672
NJ	64%	32%	4%	1%	192

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

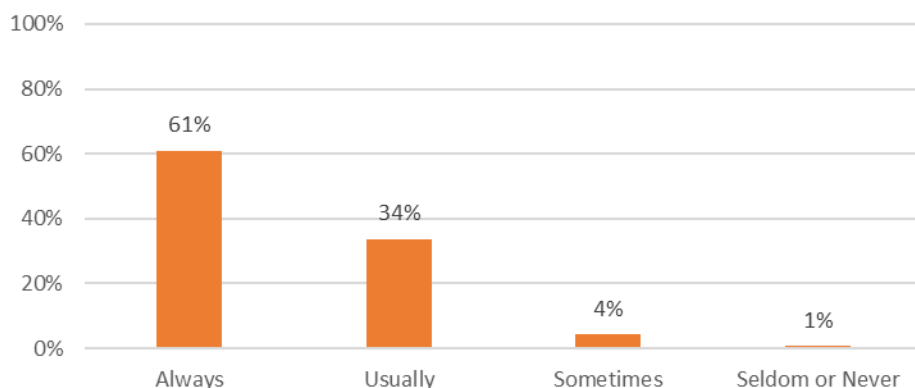


Table Q29. Does your family member's primary care doctor understand your family member's needs related to their disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	69%	27%	4%	0%	311

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
DE	69%	27%	4%	0%	125
IN	63%	30%	6%	1%	360
PA	63%	33%	3%	1%	426
Weighted NCI-IDD Average	61%	34%	4%	1%	2,536
AZ	60%	34%	4%	1%	242
NJ	59%	31%	9%	1%	175
GA	57%	37%	5%	1%	296

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	55%	39%	4%	1%	601

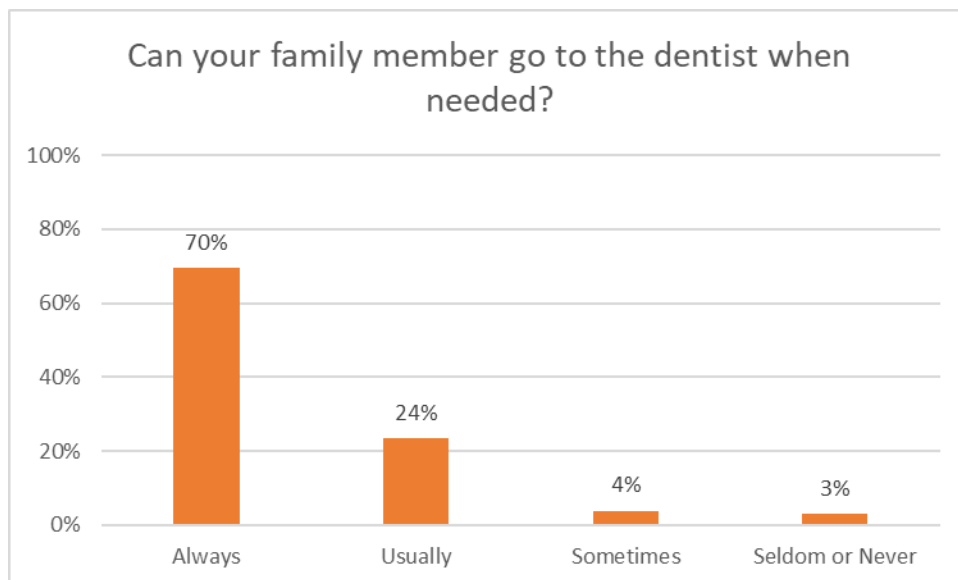


Table Q30. Does your family member go to the dentist when needed?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	77%	19%	3%	2%	322
PA	77%	19%	3%	2%	496

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
IN	73%	21%	3%	3%	395
Weighted NCI-IDD Average	70%	24%	4%	3%	2,776
AZ	65%	22%	6%	7%	254
DE	60%	30%	6%	4%	134

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	65%	28%	5%	3%	655
NJ	59%	34%	6%	1%	192
GA	57%	32%	5%	7%	328

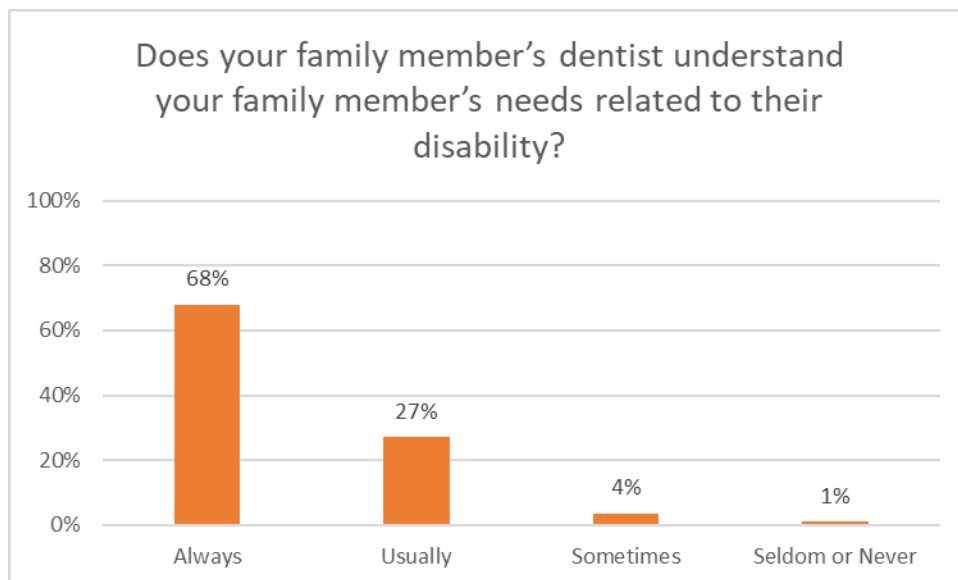


Table Q31. Can your family member's dentist understand your family member's needs related to their disability?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	78%	20%	1%	2%	299

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
PA	71%	27%	2%	0%	423
AZ	69%	25%	5%	1%	222
Weighted NCI-IDD Average	68%	27%	4%	1%	2,362
NJ	67%	26%	7%	0%	168
MD	65%	29%	3%	2%	555
IN	64%	28%	7%	1%	327
DE	64%	30%	5%	2%	108
GA	60%	33%	4%	3%	260

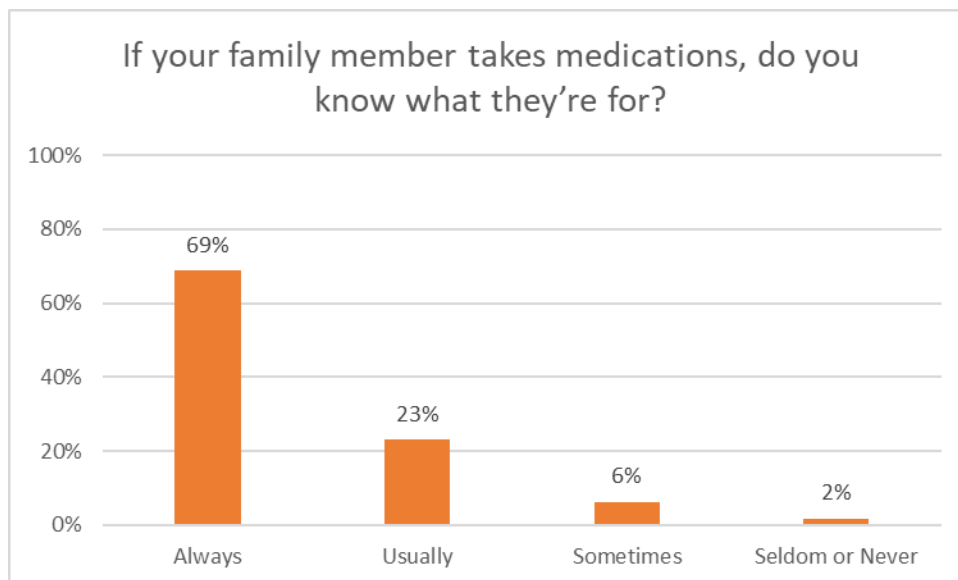


Table Q32. If your family member takes medications, do you know what they're for?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	77%	19%	3%	1%	186

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	73%	19%	5%	3%	310
AZ	72%	23%	5%	0%	241
PA	70%	20%	7%	2%	472
Weighted NCI-IDD Average	69%	23%	6%	2%	2,647
IN	68%	22%	7%	2%	369
DE	65%	30%	5%	0%	130
MD	65%	27%	6%	2%	626
GA	63%	30%	6%	1%	313

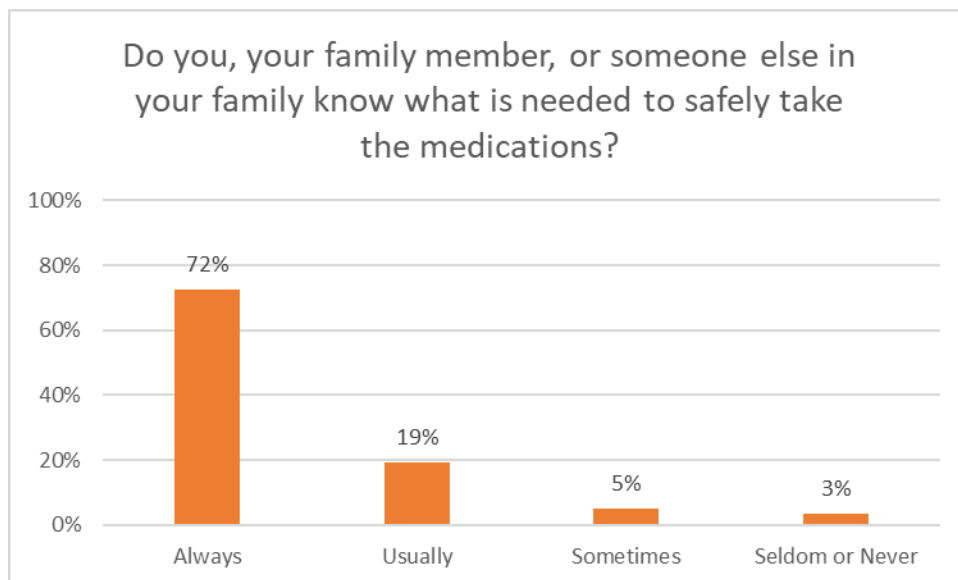


Table Q33. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	79%	18%	1%	1%	294

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	75%	15%	7%	3%	175
GA	74%	19%	4%	3%	298
PA	73%	17%	6%	4%	435
IN	73%	21%	3%	3%	347
AZ	73%	20%	2%	6%	233
Weighted NCI-IDD Average	72%	19%	5%	3%	2,503
MD	69%	22%	6%	3%	601
DE	64%	29%	3%	3%	120

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

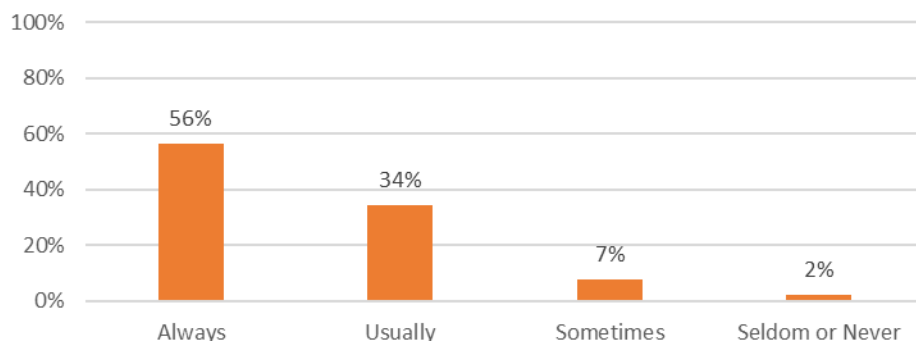


Table Q34. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	63%	27%	6%	3%	205
PA	60%	32%	8%	1%	304
IN	59%	34%	5%	2%	266
Weighted NCI-IDD Average	56%	34%	7%	2%	1,632
NJ	55%	36%	6%	3%	111
MD	54%	34%	11%	1%	350
GA	50%	42%	5%	3%	171
DE	47%	43%	5%	5%	81
AZ	47%	42%	10%	2%	144

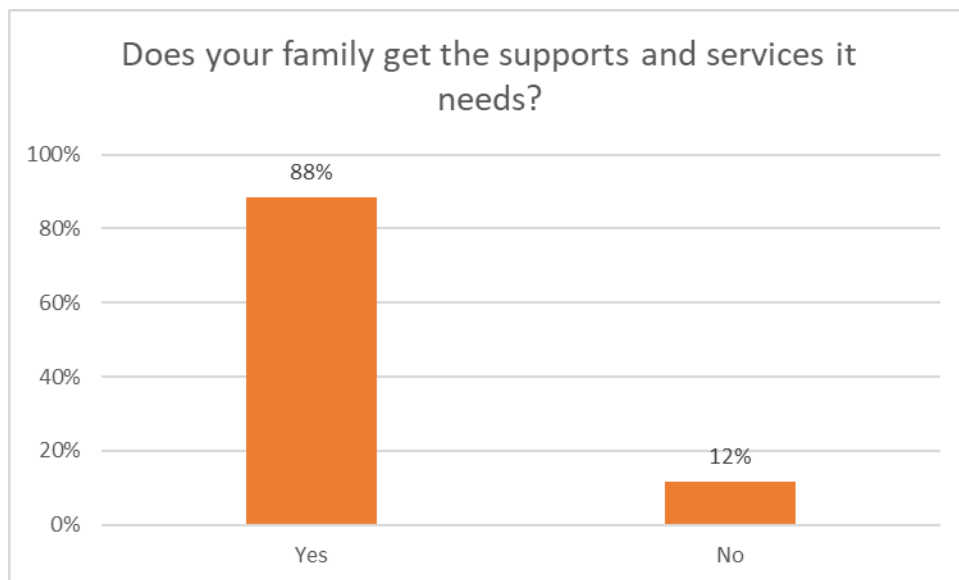


Table Q35. Does your family get the supports and services it needs?

Significantly Above Average

State	Yes	No	N
KY	95%	5%	297
PA	93%	7%	447

Within Average Range

State	Yes	No	N
AZ	91%	9%	239
Weighted NCI-IDD Average	88%	12%	2,521
DE	88%	12%	128
MD	86%	14%	588
GA	84%	16%	284
IN	83%	17%	359
NJ	80%	20%	179

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

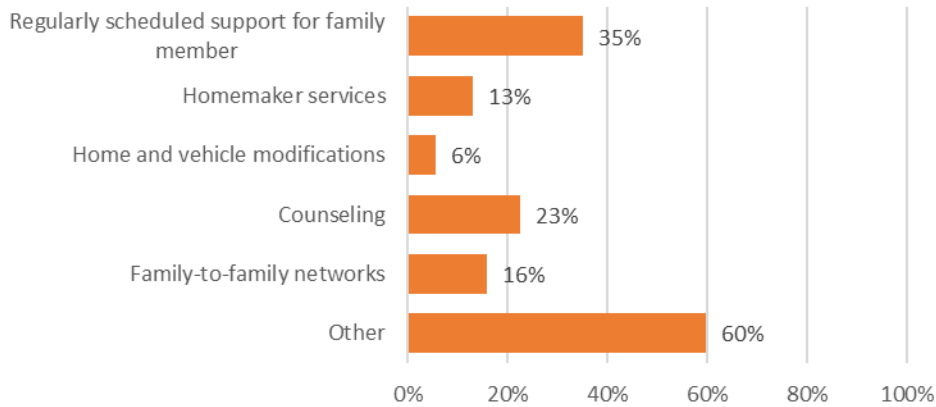


Table Q36. If your family does not get the support and services needed, what additional services does your family need?

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

State	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications	Counseling	Family-to-family Networks	Other
AZ	14%	5%	5%	33%	14%	81%
DE	42%	0%	8%	58%	17%	67%
GA	24%	2%	5%	24%	7%	57%
IN	33%	28%	10%	18%	21%	54%
KY	40%	27%	0%	7%	7%	53%
MD	39%	16%	6%	27%	16%	60%
NJ	40%	17%	0%	31%	20%	77%
PA	43%	0%	4%	11%	14%	50%
Weighted NCI-IDD Average	35%	13%	6%	23%	16%	60%

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.

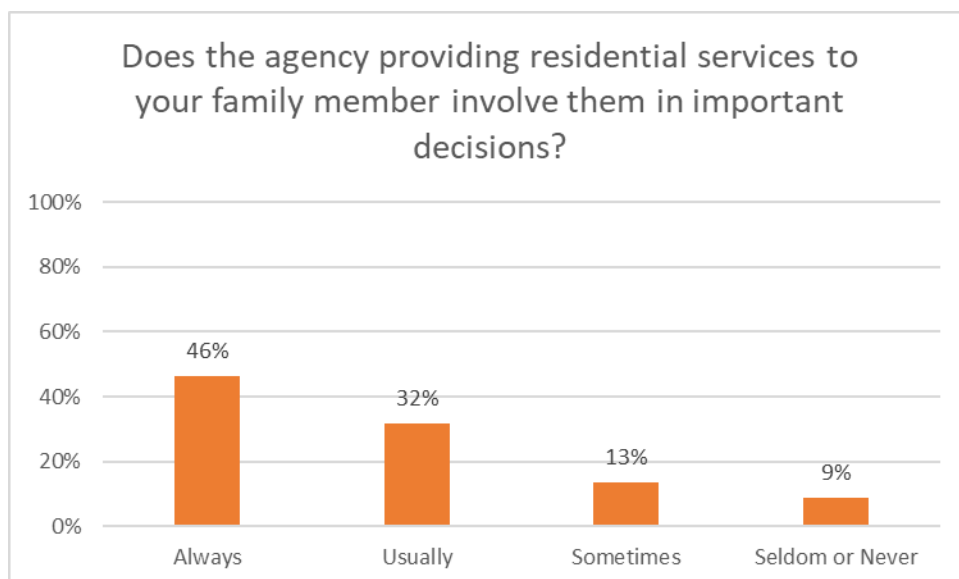


Table Q37. Does the agency providing residential services to your family member involve them in important decisions?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	55%	30%	7%	7%	284

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	50%	30%	9%	11%	226
PA	49%	30%	14%	7%	424
Weighted NCI-IDD Average	46%	32%	13%	9%	2,352
IN	46%	33%	14%	8%	345
MD	43%	33%	13%	11%	540
GA	42%	33%	16%	8%	259
DE	41%	36%	12%	12%	118

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	31%	29%	23%	16%	156

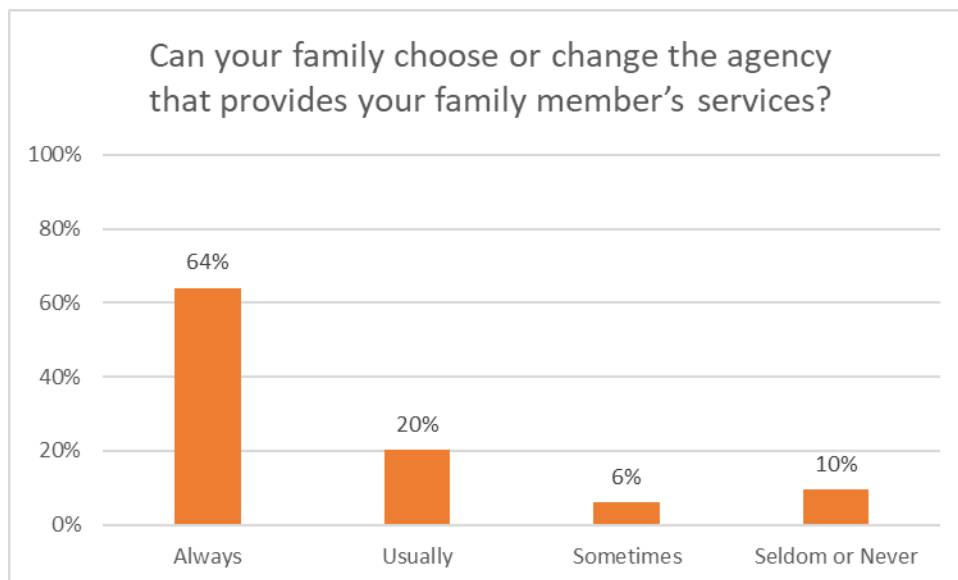


Table Q38. Can your family choose or change the agency that provides your family member's services?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	81%	13%	3%	3%	269
IN	74%	16%	5%	5%	333

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
GA	65%	19%	6%	11%	232
Weighted NCI-IDD Average	64%	20%	6%	10%	1,880
PA	61%	21%	7%	11%	272
MD	61%	21%	7%	11%	403
AZ	58%	27%	3%	12%	178
DE	57%	28%	5%	11%	76

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
NJ	47%	26%	14%	13%	117

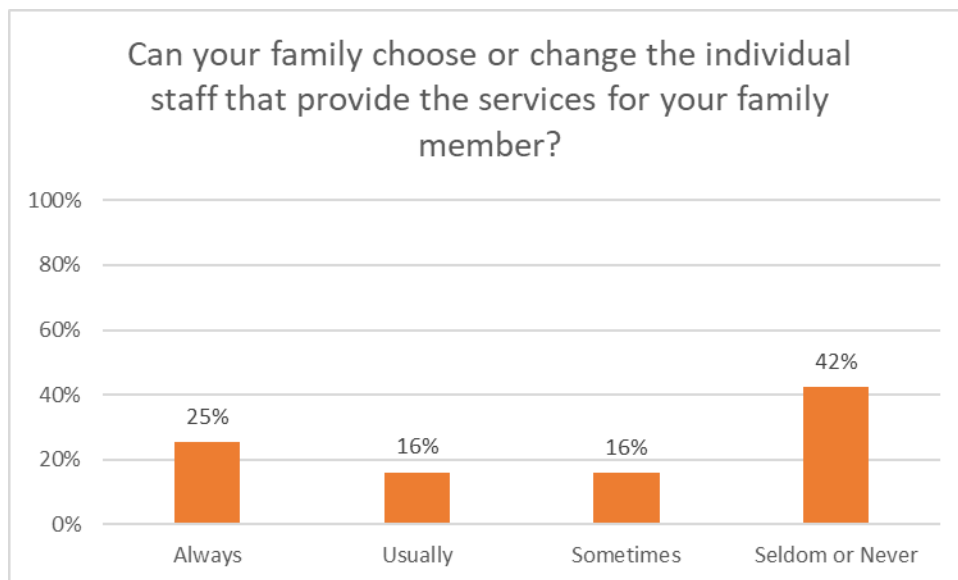


Table Q39. Can your family choose or change the individual staff that provide the services for your family member?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
KY	53%	18%	10%	19%	242
IN	39%	20%	23%	18%	331

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	30%	16%	13%	41%	160
GA	27%	20%	12%	41%	216
Weighted NCI-IDD Average	25%	16%	16%	42%	1,850
DE	18%	11%	9%	62%	65

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
MD	17%	17%	15%	50%	431
PA	17%	13%	17%	53%	283
NJ	16%	11%	12%	61%	122

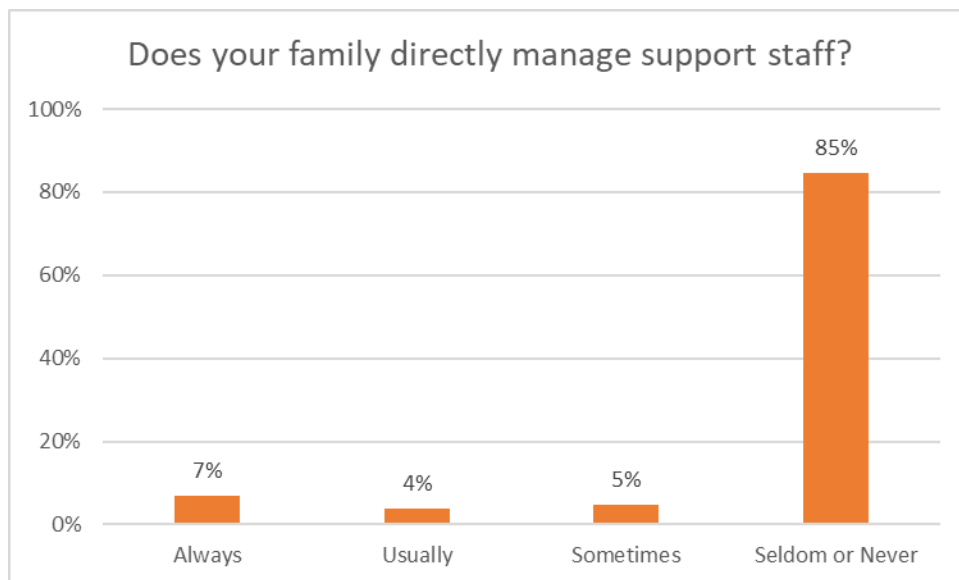


Table Q40. Does your family directly manage support staff?

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
KY	18%	7%	8%	67%	234
IN	13%	8%	7%	72%	315
NJ	10%	3%	3%	84%	145
GA	9%	5%	5%	81%	239
Weighted NCI-IDD Average	7%	4%	5%	85%	2,053
AZ	6%	5%	4%	85%	166
MD	6%	3%	5%	86%	509
DE	0%	4%	0%	96%	90

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	3%	1%	3%	93%	355

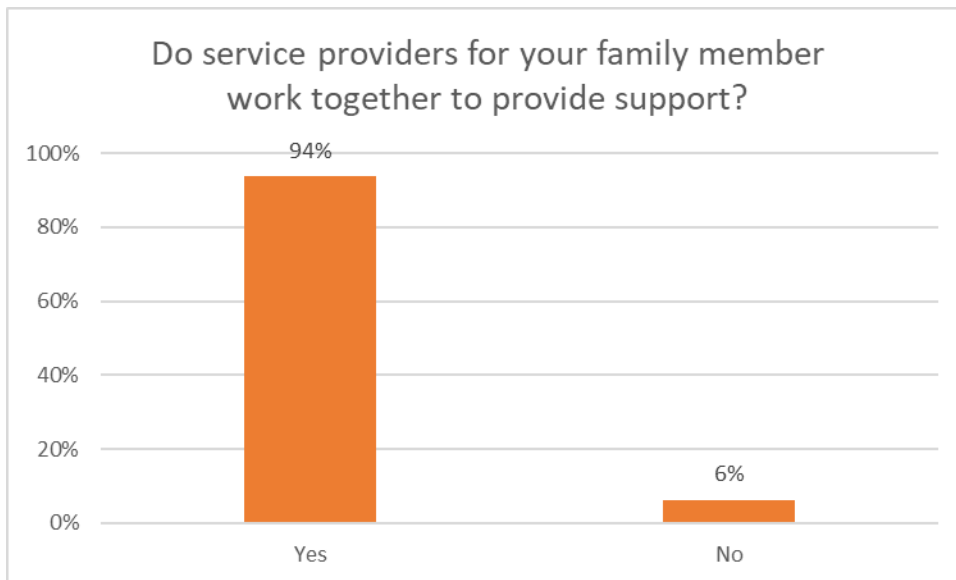


Table Q41. Do service providers for your family member work together to provide support?

Significantly Above Average

State	Yes	No	N
GA	97%	3%	225

Within Average Range

State	Yes	No	N
AZ	97%	3%	192
KY	96%	4%	264
PA	95%	5%	303
Weighted NCI-IDD Average	94%	6%	1,957
DE	93%	7%	111
IN	93%	7%	271
NJ	90%	10%	136

Significantly Below Average

State	Yes	No	N
MD	90%	10%	455

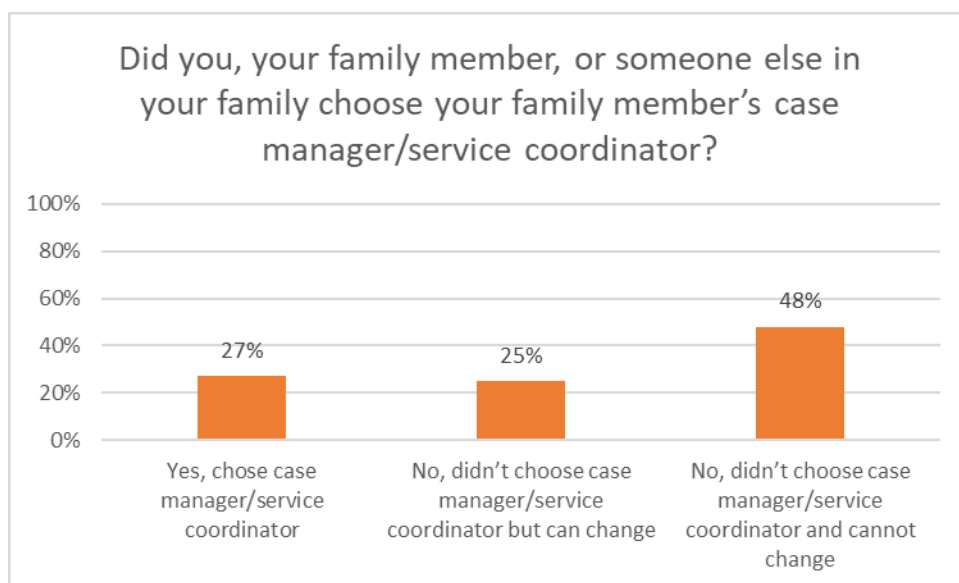


Table Q42. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

Significantly Above Average

State	Yes, chose case manager/service coordinator	No, didn't choose case manager/service coordinator but can change	No, didn't choose case manager/service coordinator and cannot change	N
IN	52%	12%	35%	357
KY	52%	8%	40%	299
NJ	46%	17%	37%	172

Within Average Range

State	Yes, chose case manager/service coordinator	No, didn't choose case manager/service coordinator but can change	No, didn't choose case manager/service coordinator and cannot change	N
Weighted NCI-IDD Average	27%	25%	48%	2,327
MD	25%	25%	49%	518

Significantly Below Average

State	Yes, chose case manager/service coordinator	No, didn't choose case manager/service coordinator but can change	No, didn't choose case manager/service coordinator and cannot change	N
PA	15%	36%	49%	382
GA	15%	30%	56%	268
AZ	10%	18%	72%	228
DE	8%	53%	39%	103

Involvement in the Community

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

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.

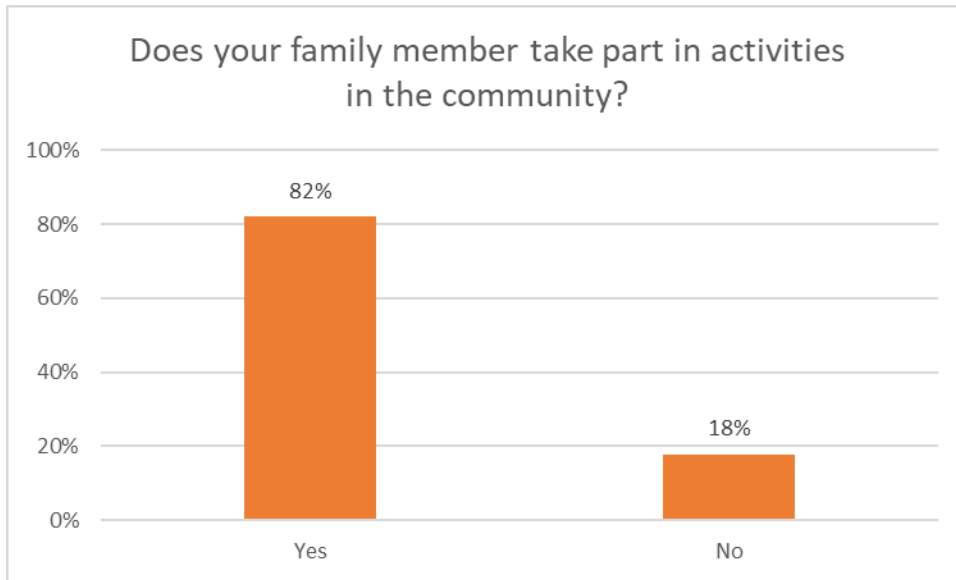


Table Q43. Does your family member take part in activities in the community?

Within Average Range

State	Yes	No	N
PA	87%	13%	484
KY	84%	16%	325
IN	84%	16%	391
Weighted NCI-IDD Average	82%	18%	2,730
MD	81%	19%	646
NJ	78%	22%	180
GA	78%	22%	324
DE	74%	26%	132

Significantly Below Average

State	Yes	No	N
AZ	71%	29%	248

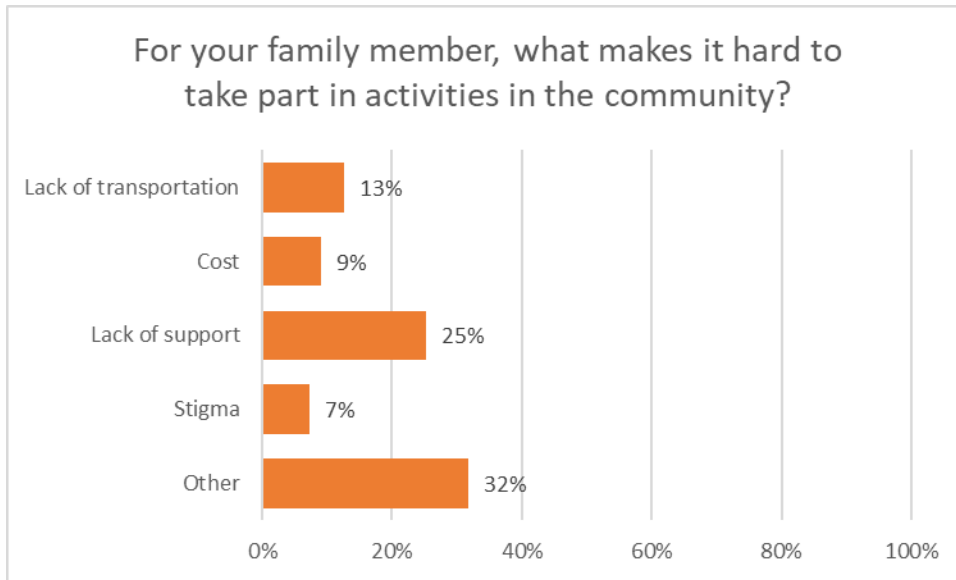


Table Q44. For your family member, what makes it hard to take part in activities in the community?

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

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	9%	7%	20%	6%	44%
DE	10%	10%	19%	7%	39%
GA	12%	11%	18%	5%	35%
IN	21%	17%	37%	8%	28%
KY	15%	6%	18%	8%	26%
MD	19%	11%	30%	8%	26%
NJ	22%	12%	37%	7%	33%
PA	5%	5%	21%	8%	33%
Weighted NCI-IDD Average	13%	9%	25%	7%	32%

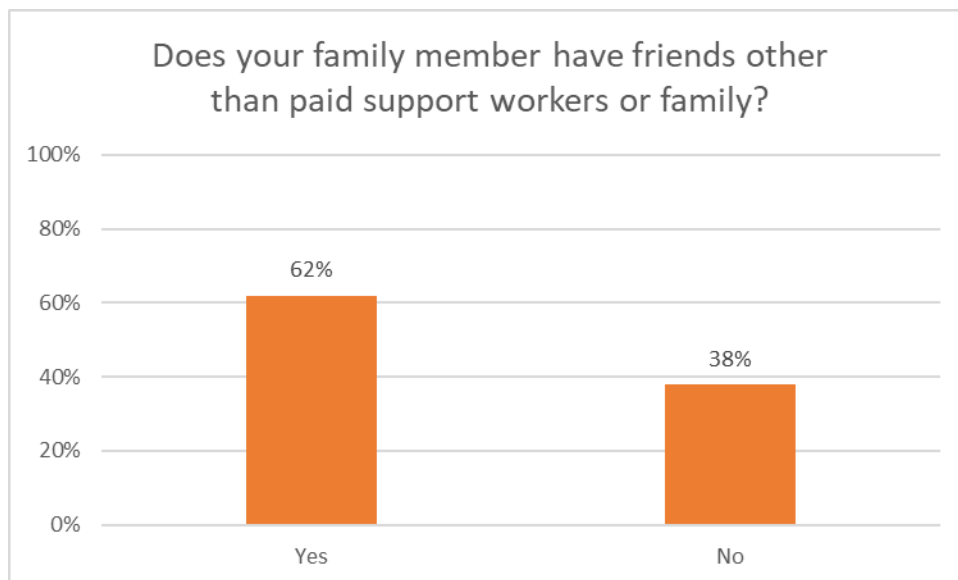


Table Q45. Does your family member have friends other than paid support workers or family?

Significantly Above Average

State	Yes	No	N
KY	73%	27%	314
IN	68%	32%	384

Within Average Range

State	Yes	No	N
GA	67%	33%	305
Weighted NCI-IDD Average	62%	38%	2,620
PA	60%	40%	443
MD	60%	40%	636
NJ	59%	41%	175
DE	57%	43%	123
AZ	54%	46%	240

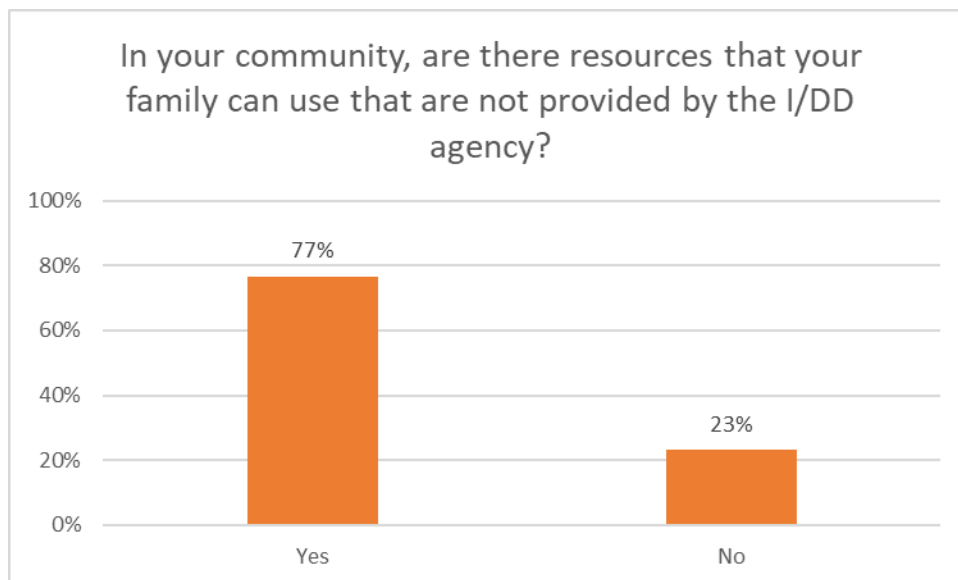


Table Q46. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

Significantly Above Average

State	Yes	No	N
IN	87%	13%	260

Within Average Range

State	Yes	No	N
KY	82%	18%	225
DE	80%	20%	91
MD	79%	21%	473
Weighted NCI-IDD Average	77%	23%	1,861
GA	74%	26%	210
NJ	73%	27%	128
PA	73%	27%	289

Significantly Below Average

State	Yes	No	N
AZ	67%	33%	185

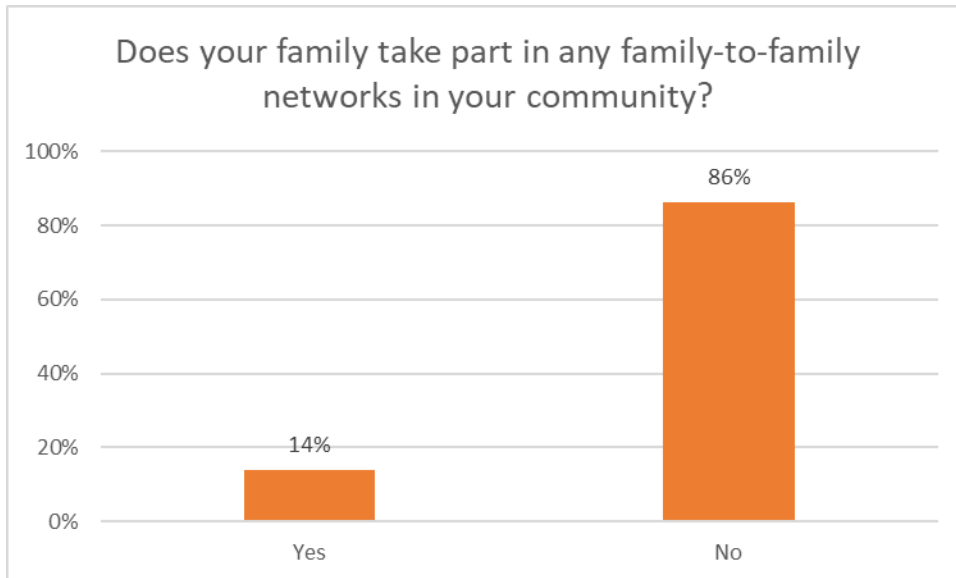


Table Q47. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?

Significantly Above Average

State	Yes	No	N
KY	21%	79%	267

Within Average Range

State	Yes	No	N
NJ	18%	82%	166
GA	17%	83%	276
DE	17%	83%	113
IN	14%	86%	325
Weighted NCI-IDD Average	14%	86%	2,380
MD	13%	87%	596
PA	12%	88%	421

Significantly Below Average

State	Yes	No	N
AZ	8%	92%	216

Satisfaction With Services and Supports

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

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.

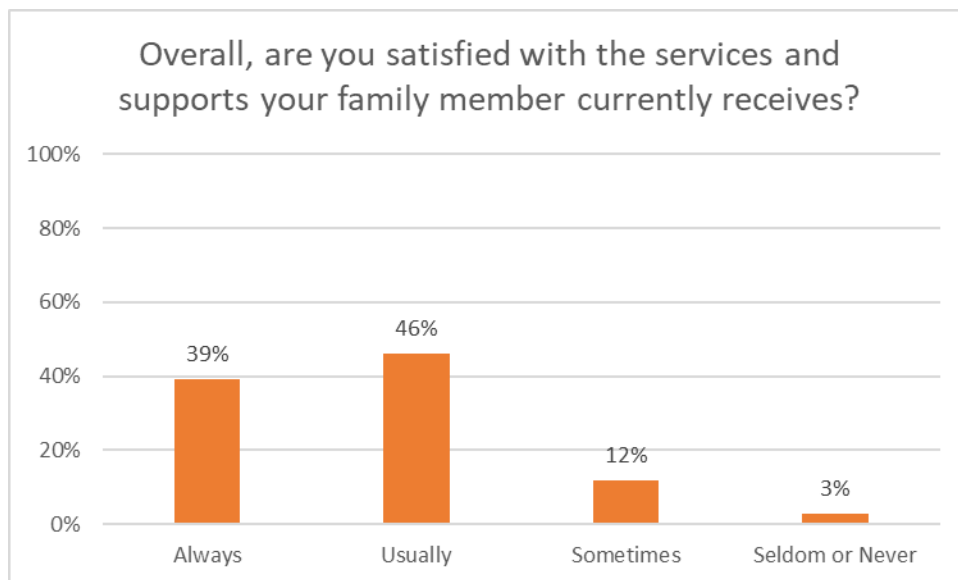


Table Q48. Overall, are you satisfied with the services and supports your family member currently receives?

Significantly Above Average

State	Always	Usually	Sometimes	Seldom or Never	N
PA	48%	41%	9%	2%	513
KY	46%	44%	7%	2%	334

Within Average Range

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	42%	46%	10%	2%	254
GA	39%	47%	12%	3%	339
Weighted NCI-IDD Average	39%	46%	12%	3%	2,865
DE	37%	45%	14%	4%	142

Significantly Below Average

State	Always	Usually	Sometimes	Seldom or Never	N
IN	31%	50%	15%	4%	401
NJ	29%	48%	19%	4%	194
MD	29%	52%	14%	5%	688

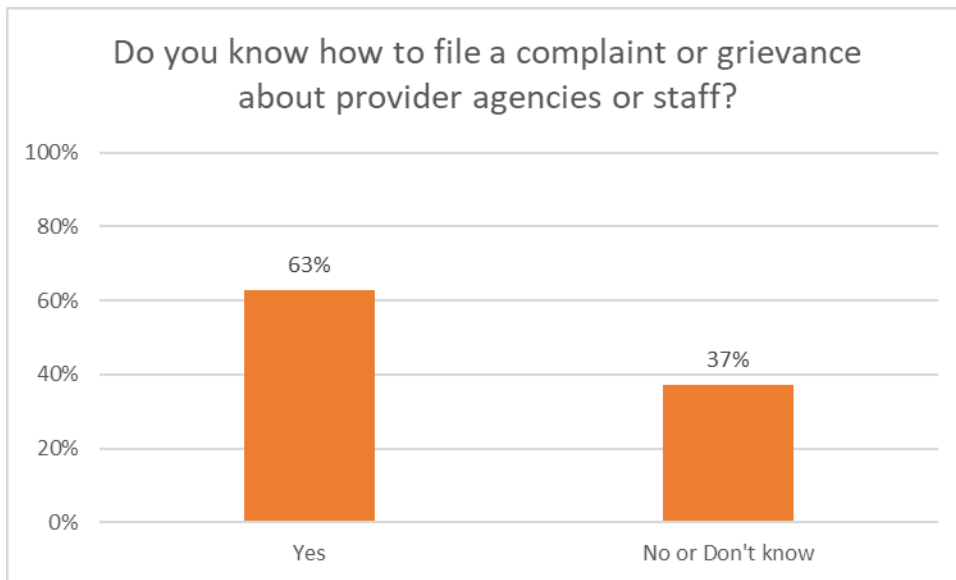


Table Q49. Do you know how to file a complaint or grievance about provider agencies or staff?¹¹

Significantly Above Average

State	Yes	No or Don't Know	N
KY	76%	24%	338
AZ	73%	27%	262

Within Average Range

State	Yes	No or Don't Know	N
PA	64%	36%	512
Weighted NCI-IDD Average	63%	37%	2,893
IN	62%	38%	402
GA	61%	39%	345
DE	58%	42%	143
NJ	58%	42%	194

Significantly Below Average

State	Yes	No or Don't Know	N
MD	57%	43%	697

¹¹ 'Don't Know' responses were included in 'No' responses for this question.



Table Q50. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?

Within Average Range

State	Yes	No	N
PA	73%	27%	70
KY	69%	31%	35
IN	65%	35%	71
AZ	64%	36%	39
Weighted NCI-IDD Average	62%	38%	417
GA	54%	46%	37
DE	52%	48%	29
MD	49%	51%	91
NJ	49%	51%	45

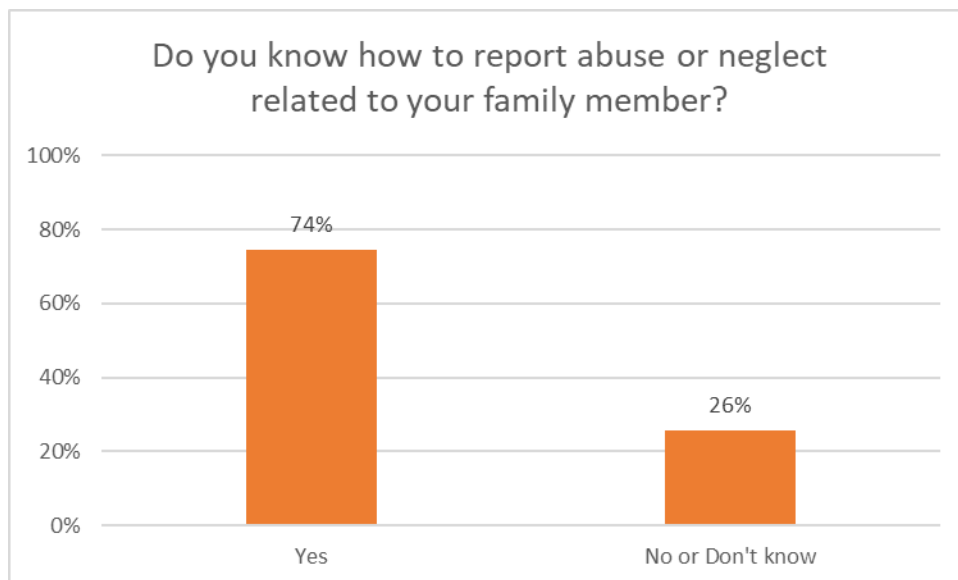


Table Q51. Do you know how to report abuse or neglect related to your family member? ¹²

Significantly Above Average

State	Yes	No or Don't Know	N
KY	84%	16%	339
AZ	82%	18%	263

Within Average Range

State	Yes	No or Don't Know	N
DE	77%	23%	144
GA	77%	23%	343
IN	76%	24%	400
Weighted NCI-IDD Average	74%	26%	2,892
PA	74%	26%	511
NJ	71%	29%	195

Significantly Below Average

State	Yes	No or Don't Know	N
MD	69%	31%	697

¹² 'Don't Know' responses were included in 'No' responses for this question.

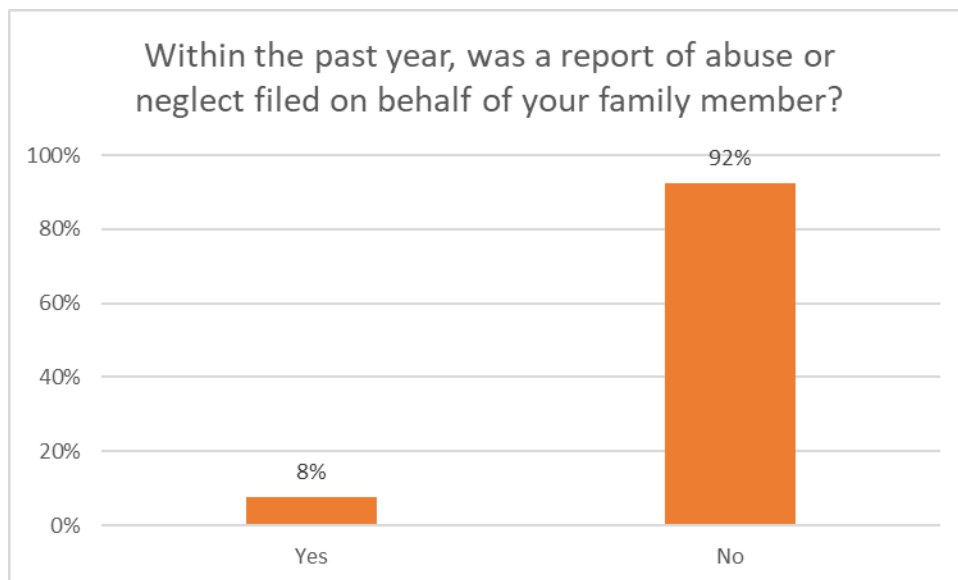


Table Q52. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

Significantly Above Average

State	Yes	No	N
NJ	16%	84%	190

Within Average Range

State	Yes	No	N
DE	9%	91%	130
AZ	9%	91%	250
PA	9%	91%	488
IN	8%	92%	385
Weighted NCI-IDD Average	8%	92%	2,766
GA	5%	95%	331
KY	5%	95%	326

Significantly Below Average

State	Yes	No	N
MD	4%	96%	666

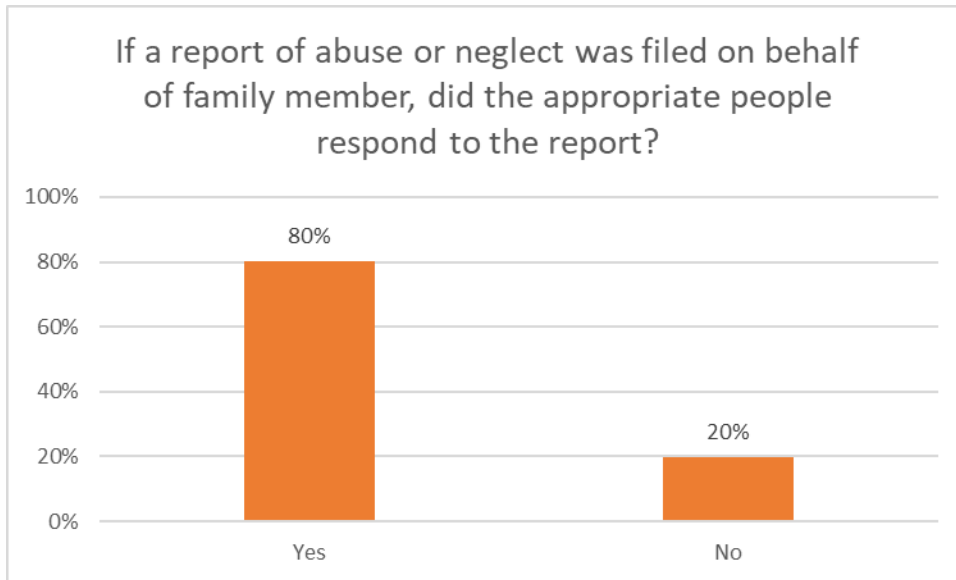


Table Q53. If a report of abuse or neglect was filed on behalf of your family member in the past year, did the appropriate people respond to the report? ¹³

Within Average Range

State	Yes	No	N
PA	91%	9%	35
Weighted NCI-IDD Average	80%	20%	163
IN	78%	22%	27
MD	73%	27%	22
NJ	57%	43%	21

¹³ The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: AZ, DE, GA, KY.

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?

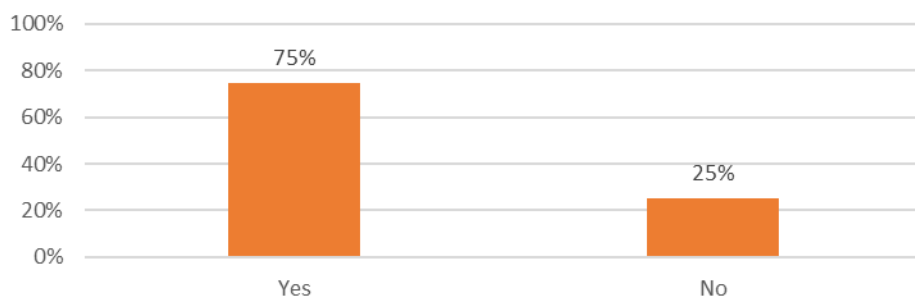


Table Q54. If someone outside of your family reported abuse or neglect on behalf of your family member in the past year, were you notified of the report in a timely manner? ¹⁴

Within Average Range

State	Yes	No	N
PA	88%	12%	33
Weighted NCI-IDD Average	75%	25%	133
IN	68%	32%	22

¹⁴ The following states are not included in the table due to low N (20 or fewer respondents), but their responses are included in the NCI Average: AZ, DE, GA, MD, NJ, KY.

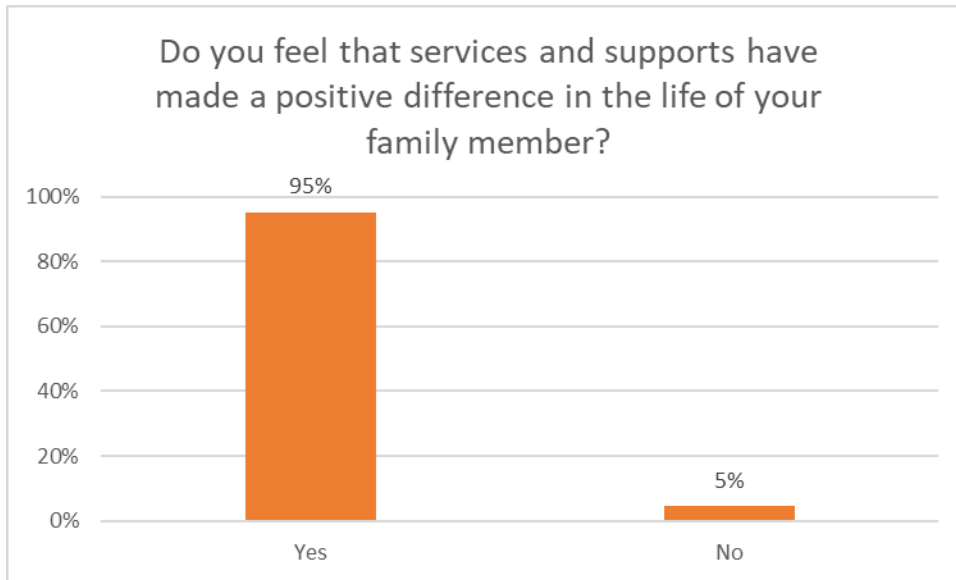


Table Q55. Do you feel that services and supports have made a positive difference in the life of your family member?

Significantly Above Average

State	Yes	No	N
PA	97%	3%	480

Within Average Range

State	Yes	No	N
AZ	97%	3%	247
KY	97%	3%	318
GA	96%	4%	320
Weighted NCI-IDD Average	95%	5%	2,667
IN	93%	7%	375
DE	93%	7%	133
NJ	93%	7%	181

Significantly Below Average

State	Yes	No	N
MD	92%	8%	613

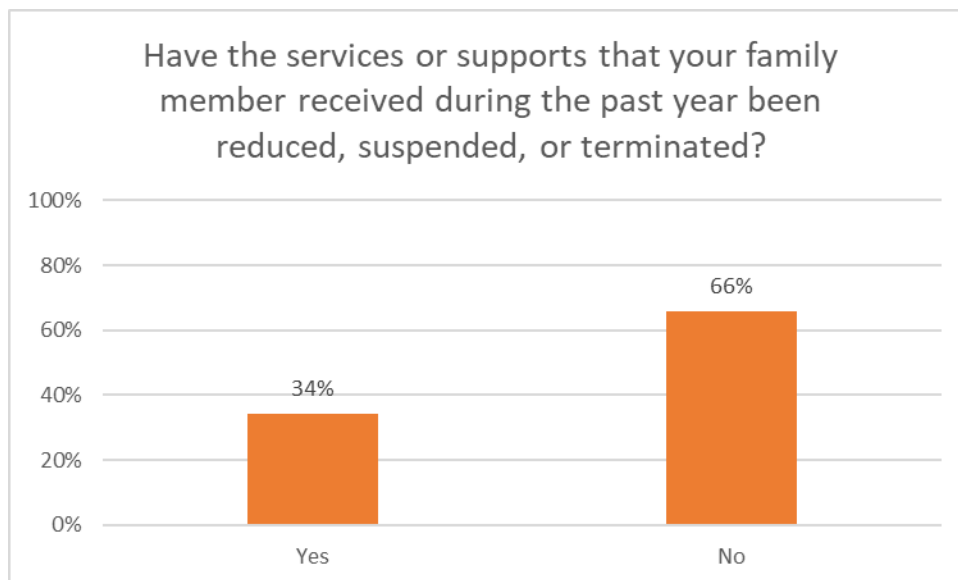


Table Q56. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

Significantly Above Average

State	Yes	No	N
NJ	44%	56%	179

Within Average Range

State	Yes	No	N
MD	36%	64%	596
AZ	35%	65%	249
PA	34%	66%	443
Weighted NCI-IDD Average	34%	66%	2,542
KY	33%	67%	314
IN	33%	67%	352
DE	30%	70%	120

Significantly Below Average

State	Yes	No	N
GA	26%	74%	289

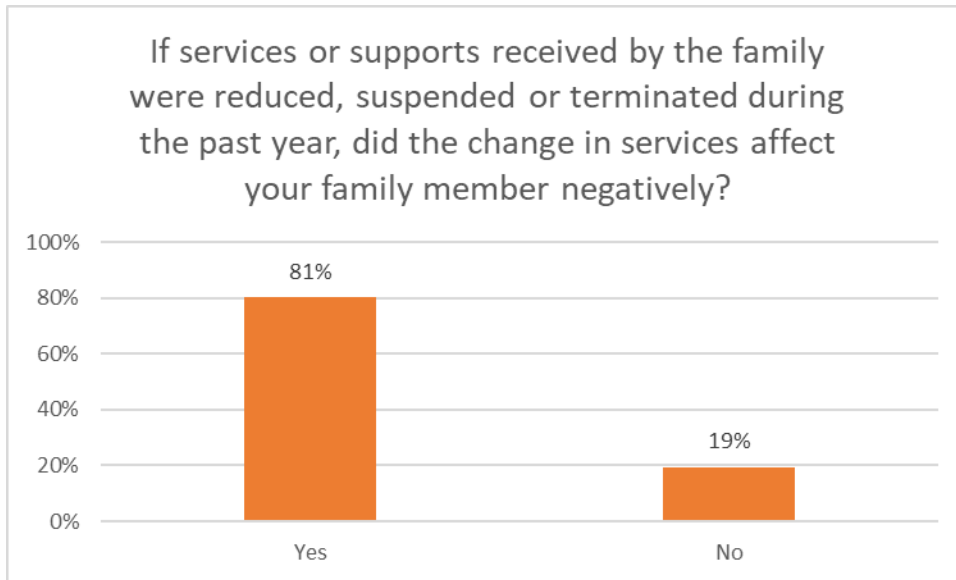


Table Q57. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?

Within Average Range

State	Yes	No	N
NJ	88%	12%	73
IN	86%	14%	101
DE	83%	17%	30
AZ	82%	18%	77
PA	81%	19%	129
Weighted NCI-IDD Average	81%	19%	741
MD	79%	21%	180
KY	72%	28%	87
GA	69%	31%	64

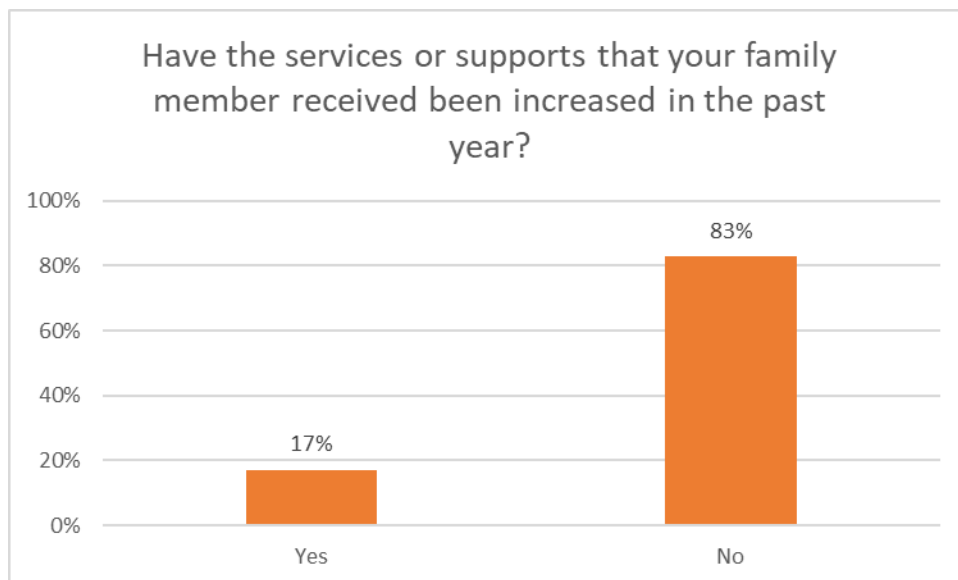


Table Q58. Have the services or supports that your family member received been increased in the past year?

Significantly Above Average

State	Yes	No	N
NJ	27%	73%	166

Within Average Range

State	Yes	No	N
DE	22%	78%	99
PA	18%	82%	381
Weighted NCI-IDD Average	17%	83%	2,263
IN	17%	83%	320
KY	17%	83%	278
GA	16%	84%	249
MD	15%	85%	543

Significantly Below Average

State	Yes	No	N
AZ	11%	89%	227

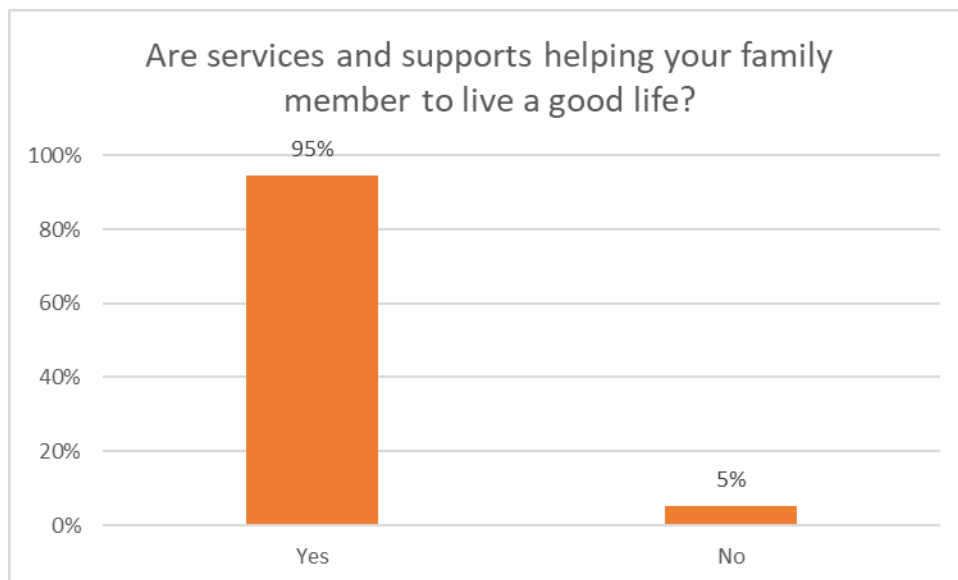


Table Q59. Are services and supports helping your family member to live a good life?

Significantly Above Average

State	Yes	No	N
PA	97%	3%	473

Within Average Range

State	Yes	No	N
KY	97%	3%	321
AZ	96%	4%	240
GA	96%	4%	316
Weighted NCI-IDD Average	95%	5%	2,632
MD	92%	8%	617
IN	92%	8%	360
DE	91%	9%	133
NJ	91%	9%	172

NCI History and Activities

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

Overview of National Core Indicators

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

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

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

During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult 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.

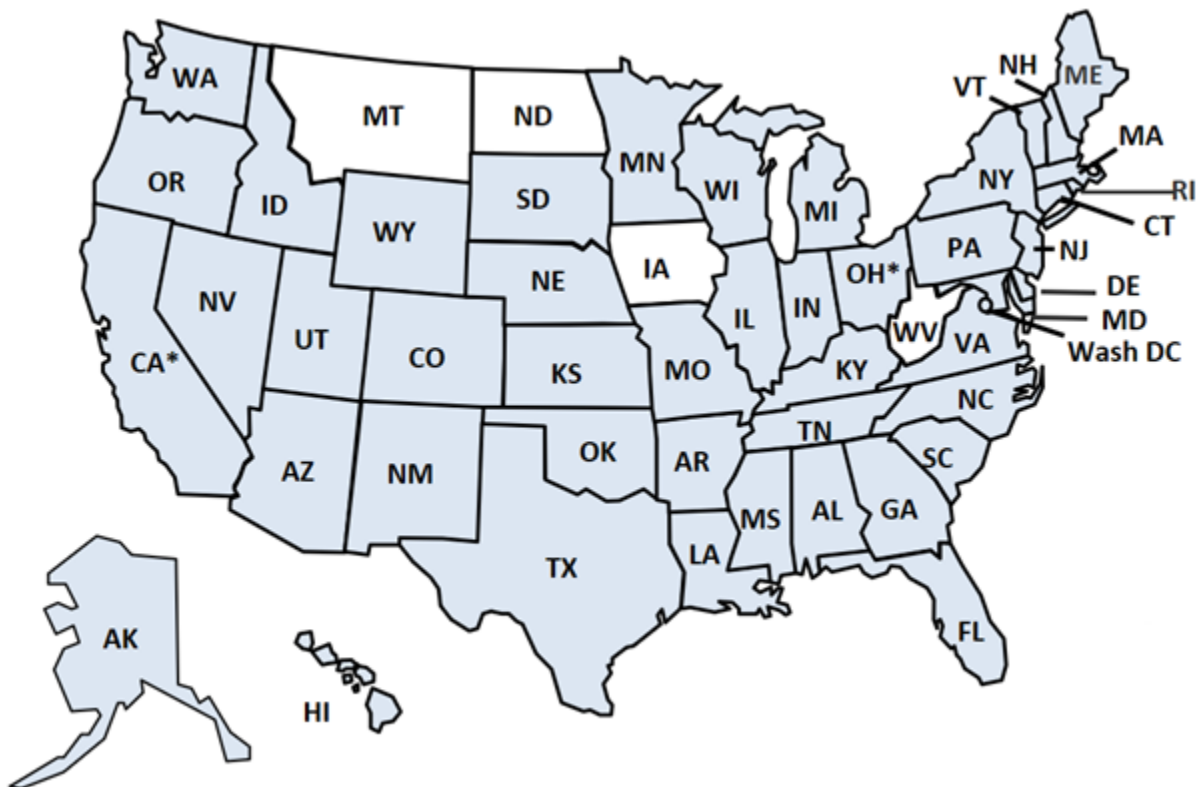
Since the initial field test, NCI has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI continues to develop and refine the indicators and expand state participation. For more information about NCI states,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

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

State Participation

During the 2020-21 data collection cycle, 46 states, the District of Columbia and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and participating states are highlighted on the map below. Not all states participate in all surveys each year.

Figure 1. NCI State Participation 2020-21



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 complete list of Core Indicators, please visit the Indicators page on the NCI website at <https://www.nationalcoreindicators.org/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 five broad domains: Individual Outcomes; Health, Welfare, and Rights; Staff Stability and Competency; Family Outcomes; 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, a Provider Survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates).

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI 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 Concern Statements

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

Figure 2. Family Survey Sub-Domains and Concern Statements

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

How NCI Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI as a data source for supplemental performance measures in their home and community-based services (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](#).¹⁵

¹⁵ Located on the National Core Indicators website: <https://www.nationalcoreindicators.org> → Resources → Technical Reports

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 Average suggests that changes or further investigation are necessary.

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

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

Methodology

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

Sampling & Administration

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

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

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 three states had at least a portion of surveys completed via direct entry for the 2019-20 data collection cycle.¹⁶

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%.¹⁷

Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI reports, we use “NCI average” to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI 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 averages contained in this report are “weighted”

¹⁶ States that used the direct entry or mail and direct entry options were: CA, MD, NC.

¹⁷ See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

means; their calculations reflect the relative population sizes of participating states, as well as 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 average—that is, the state’s contribution to the NCI 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 average**, where the difference between the state’s percentage and the weighted NCI 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 average range**, where the difference between the state’s percentage and the weighted NCI 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 average**, where the difference between the state’s percentage and the weighted NCI average: a) was in favor of the NCI 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 Average, within the range of the NCI Average, and significantly below the NCI 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 $d = 2t / \sqrt{df}$. A cutoff point of Cohen's $d = 0.2$ was chosen for the effect size to be considered “meaningfully significant,” following the standard interpretation offered by Cohen (1988) that Cohen's d of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

Data Entry and Analysis

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

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

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

Statistical significance testing was conducted on each state's “always” or “yes” response compared to the NCI average¹⁸; significance is shown at the .01 level and cited in tables. Demographics data and data on services received were not tested for statistically significant differences.

Response Rates

During 2020-21, eight 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.

¹⁸ The NCI Average is a weighted average. Please see the section “Weighting” for more details.

Figure 3. Family/Guardian Survey: State Response Rates¹⁹

State	Total Population	Surveys Sent	Complete Surveys	Response Rate ²⁰	Margin of Error	Paper Submission	Direct Entry Submission
AZ	4,621	1,400	265	18.9%	5.85%	100%	0%
DE	1,625	400	152	38.0%	7.57%	53%	47%
GA	4,432	1,700	350	20.6%	5.03%	100%	0%
IN	7,686	1,500	423	28.2%	4.63%	0%	100%
KY	4,796	1,404	481	34.3%	4.24%	100%	0%
MD	11,813	11,813	714	6.0%	3.56%	87%	13%
NJ	3,221	3,221	215	6.7%	6.46%	0%	100%
PA	18,723	2,100	518	24.7%	4.25%	100%	0%
Total	56,917	23,538	3,118	22.2%	5.20%	74%	26%

¹⁹ Please note: The family surveys are mail out 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.

²⁰ State response rates are calculated as following: the number of complete surveys divided by total surveys sent in that state (type “RR1” as defined by the American Association for Public Opinion Research). For more details on the definition, please see the AAPOR report: https://www.aapor.org/AAPOR_Main/media/publications/Standard-Definitions20169theditionfinal.pdf