

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



National Report 2024-25

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 2024-25 data collection cycle, 4 states submitted a valid sample of Family/Guardian Survey data: Arizona, Maryland, New Jersey, Pennsylvania. This Final Report provides results based on data submitted by June 30, 2025.

What is the NCI-IDD Family/Guardian Survey?

The NCI-IDD Family/Guardian Survey is used to gather data on family outcomes. It is mailed to families or guardians who have an adult family member who does not live with the respondent and receives at least one service in addition to case management from the state DD agency. The survey collects demographic information on both the individual receiving services ('family member') as well as the person who fills out the survey (the 'respondent') and information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

Please note that while the term "case manager" is used throughout this report, the same role may also be referred to as "service coordinator" or "supports coordinator" depending on the state.

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

What is included in this report?

This report includes this state's Family/Guardian Survey data compared to the NCI-IDD Average.

The tables in this document, grouped by subdomain, display the state results alongside the average across states (NCI-IDD average). **Please note: the NCI-IDD averages shown throughout this report are weighted.** For more information see the [Methodology section](#).

"N" demonstrates the number of valid responses for each question. "N" can vary between questions. The N does not include missing responses, "don't know" responses or "not applicable" responses. For information on the total sample from each state, see Family/Guardian Survey Response Rates [here](#).

To find out more about the development of the Family/Guardian Survey, data analysis and state samples, check out the [National Family/Guardian Survey Report](#).

Results

This section provides state and NCI-IDD results for demographic and survey outcomes data.

Presentation of the Data

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

- States with 20 or fewer respondents to a question are not included in tables; however, their data **are** included in the NCI-IDD Average.

For 2024-25, due to the number of participating states, state averages were not tested to examine the significance of the difference from 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.

Family Member

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

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

Table 1a. Family Member's Residence

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

State	Specialized Facility for People with Intellectual Disabilities	Group Home or Agency Operated Apartment	Independent Home or Apartment	N
AZ	8%	75%	4%	227
MD	6%	76%	16%	417
NJ	0%	74%	21%	363
PA	7%	73%	16%	295
Weighted NCI-IDD Average	6%	74%	15%	1302

Table 1b. Family Member's Residence (continued)

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

State	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
AZ	6%	0%	0%	6%	227
MD	1%	0%	0%	0%	417
NJ	1%	1%	0%	2%	363
PA	1%	1%	0%	1%	295
Weighted NCI-IDD Average	2%	0%	0%	2%	1302

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

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

State	Less than One Year	One to Three Years	Four to Five Years	Over Five Years	N
AZ	13%	27%	8%	52%	228
MD	9%	30%	12%	49%	416
NJ	7%	20%	10%	63%	361
PA	8%	23%	9%	60%	291
Weighted NCI-IDD Average	9%	24%	10%	57%	1296

Table 3. Family Member’s Residential Designation

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

State	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
AZ	91%	9%	224
MD	82%	18%	412
NJ	78%	23%	360
PA	72%	28%	292
Weighted NCI-IDD Average	78%	22%	1288

Table 4. Family Member's Age

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

State	Age	N
AZ	47.3	231
MD	42.8	420
NJ	47.4	366
PA	47.6	298
Weighted NCI-IDD Average	46.6	1,315

Table 5. Family Member's Gender

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

State	Male	Female	N
AZ	55%	45%	231
MD	64%	36%	420
NJ	64%	36%	366
PA	60%	40%	298
Weighted NCI-IDD Average	61%	39%	1315

Table 6. Family Member's Race/Ethnicity

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

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer Not to Say
AZ	5%	1%	6%	0%	76%	11%	2%	2%
MD	1%	3%	16%	0%	76%	2%	2%	4%
NJ	1%	3%	4%	0%	88%	2%	1%	3%
PA	1%	1%	5%	0%	91%	2%	0%	2%
Weighted NCI-IDD Average	1%	2%	7%	0%	85%	3%	1%	2%

Table 7a. Family Member's Conditions

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

State	Intellectual Disability	Mood Illness or Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision – Legally Blind
AZ	78%	39%	29%	18%	7%
MD	81%	35%	46%	15%	6%
NJ	77%	34%	46%	15%	6%
PA	88%	41%	34%	18%	10%
Weighted NCI-IDD Average	83%	38%	38%	17%	8%

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

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

State	Hearing Loss – Severe or Profound	Brain Injury	Seizure or Neurological Disorder	Chemical Dependency
AZ	6%	12%	26%	0%
MD	6%	9%	27%	0%
NJ	6%	7%	21%	0%
PA	8%	9%	27%	0%
Weighted NCI-IDD Average	7%	9%	26%	0%

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

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

State	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other Disabilities
AZ	7%	0%	3%	12%
MD	10%	1%	2%	14%
NJ	9%	1%	0%	14%
PA	9%	1%	1%	10%
Weighted NCI-IDD Average	9%	1%	1%	12%

Table 8a. Family Member's Health Conditions

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

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
AZ	15%	28%	8%	32%	37%
MD	8%	18%	5%	29%	32%
NJ	8%	16%	7%	28%	36%
PA	8%	23%	5%	30%	39%
Weighted NCI-IDD Average	9%	21%	6%	30%	37%

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

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

State	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Dementia	Oral Health or Dental Problems	Sleep Apnea
AZ	10%	0%	7%	24%	17%
MD	6%	3%	1%	16%	17%
NJ	8%	2%	2%	16%	13%
PA	15%	2%	4%	13%	22%
Weighted NCI-IDD Average	11%	2%	4%	15%	19%

Table 8c. Family Member's Health Conditions (continued)

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

State	Asthma	Other Pulmonary Diagnosis (e.g. COPD, Bronchitis, Emphysema)	Chronic Kidney Disease	Long-Term Health Problems Associated with COVID-19 (Also Known As Long COVID)
AZ	6%	6%	6%	1%
MD	4%	8%	5%	0%
NJ	3%	7%	4%	0%
PA	6%	8%	3%	1%
Weighted NCI-IDD Average	5%	8%	4%	1%

Table 9. Family Member's Preferred Means of Communication

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

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
AZ	82%	12%	2%	1%	2%	220
MD	78%	15%	1%	1%	4%	413
NJ	79%	14%	1%	3%	3%	359
PA	80%	14%	2%	2%	2%	293
Weighted NCI-IDD Average	80%	14%	2%	2%	3%	1285

Table 10. Family Member’s Preferred Language

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

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AZ	97%	0%	0%	0%	0%	1%	1%	222
MD	97%	0%	0%	0%	0%	1%	1%	415
NJ	97%	0%	0%	0%	0%	1%	2%	360
PA	98%	0%	0%	0%	0%	1%	2%	294
Weighted NCI-IDD Average	97%	0%	0%	0%	0%	1%	2%	1291

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

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

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

State	No Guardianship or Conservatorship	Limited Guardianship or Conservatorship	Full Guardianship or Conservatorship	Has Guardianship or Conservatorship but Level is Unknown	N
AZ	13%	7%	74%	7%	228
MD	39%	16%	42%	3%	394
NJ	19%	11%	67%	3%	354
PA	36%	12%	44%	8%	268
Weighted NCI-IDD Average	30%	12%	52%	6%	1244

Table 12. Guardian or Conservator Relationship to Family Member

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

State	Family	Friend	Employee of State or Guardianship or Conservatorship Agency	Other	N
AZ	87%	3%	8%	3%	191
MD	91%	1%	4%	3%	230
NJ	98%	0%	2%	0%	284
PA	90%	0%	8%	2%	162
Weighted NCI-IDD Average	91%	1%	6%	2%	867

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

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

State	Did Not Complete High School, Not Currently in School	Currently Enrolled in High School	High School Certificate (NOT a High School Diploma/GED)	N
AZ	32%	1%	25%	220
MD	22%	0%	53%	406
NJ	29%	0%	20%	352
PA	25%	0%	28%	283
Weighted NCI-IDD Average	26%	0%	31%	1261

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

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

State	High School Diploma/GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
AZ	37%	1%	3%	1%	220
MD	15%	2%	3%	5%	406
NJ	32%	2%	5%	12%	352
PA	40%	1%	1%	4%	283
Weighted NCI-IDD Average	33%	2%	2%	5%	1261

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

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

State	No Support Needed; No Issues with Managing Behavior	Some Support Needed; Requires Only Occasional Assistance or Monitoring	Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance	N
AZ	28%	43%	29%	224
MD	34%	38%	28%	404
NJ	35%	38%	28%	349
PA	30%	44%	26%	280
Weighted NCI-IDD Average	31%	41%	27%	1257

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

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

State	No Support Needed; No Issues with Personal Care Activities	Some Support Needed; Requires Only Occasional Assistance or Monitoring	Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance	N
AZ	16%	42%	42%	230
MD	19%	39%	43%	410
NJ	18%	39%	43%	357
PA	19%	39%	42%	290
Weighted NCI-IDD Average	18%	39%	42%	1287

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

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

State	No Support Needed; No Issues with Other Daily Activities	Some Support Needed; Requires Only Occasional Assistance or Monitoring	Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance	N
AZ	1%	14%	85%	229
MD	1%	13%	85%	411
NJ	1%	20%	79%	357
PA	1%	15%	84%	293
Weighted NCI-IDD Average	1%	15%	84%	1290

Respondents

This section provides information about the survey respondent.

Table 17. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
AZ	99%	0%	0%	0%	0%	0%	1%	228
MD	99%	0%	0%	0%	0%	0%	1%	407
NJ	98%	1%	0%	0%	0%	0%	1%	342
PA	99%	1%	0%	0%	0%	0%	0%	288
Weighted NCI-IDD Average	99%	0%	0%	0%	0%	0%	1%	1265

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

Table 18. Respondent's Age

State	18 - 34	35 - 54	55 - 74	75 or Older	N
AZ	2%	18%	55%	25%	230
MD	1%	8%	70%	21%	411
NJ	1%	4%	64%	32%	360
PA	1%	8%	68%	23%	295
Weighted NCI-IDD Average	1%	9%	66%	24%	1296

Table 19. Respondent's Health

State	Excellent	Very Good	Good	Fair	Poor	N
AZ	9%	44%	35%	12%	0%	226
MD	11%	41%	33%	14%	1%	409
NJ	13%	37%	36%	12%	2%	358
PA	12%	30%	37%	19%	1%	292
Weighted NCI-IDD Average	11%	36%	36%	16%	1%	1285

Table 20. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
AZ	58%	23%	0%	1%	4%	4%	9%	230
MD	71%	22%	0%	0%	1%	1%	5%	412
NJ	70%	29%	0%	0%	0%	1%	1%	358
PA	63%	32%	0%	1%	1%	1%	1%	293
Weighted NCI-IDD Average	65%	28%	0%	1%	1%	1%	3%	1293

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

State	Did Not Visit	1 to 3 Times	4 to 6 Times	7 to 12 Times	More Than 12 Times	N
AZ	2%	10%	11%	10%	66%	231
MD	2%	5%	9%	12%	73%	414
NJ	5%	10%	10%	12%	63%	360
PA	4%	12%	8%	12%	64%	294
Weighted NCI-IDD Average	3%	10%	9%	12%	66%	1299

Table 22. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
AZ	3%	13%	5%	30%	50%	223
MD	0%	12%	2%	15%	70%	410
NJ	1%	10%	1%	14%	73%	354
PA	3%	25%	5%	14%	52%	291
Weighted NCI-IDD Average	2%	18%	4%	17%	59%	1278

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

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

State	No Earned Income	Up to \$15,000	\$15,001 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	Prefer Not to Say	N
AZ	10%	4%	5%	14%	13%	23%	31%	216
MD	7%	2%	2%	8%	7%	37%	37%	404
NJ	9%	2%	3%	9%	11%	27%	39%	353
PA	11%	4%	5%	16%	10%	19%	34%	280
Weighted NCI-IDD Average	10%	3%	4%	13%	10%	25%	35%	1253

Services and Supports Received

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

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

Table 24a. Services and Supports Received from ID/DD Agency

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

State	Financial Support	In-Home Supports	Residential Supports	Day or Employment Supports
AZ	25%	30%	96%	73%
MD	31%	43%	84%	73%
NJ	40%	37%	79%	76%
PA	26%	46%	83%	55%
Weighted NCI-IDD Average	29%	41%	84%	65%

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

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

State	Transportation	Mental or Behavioral Health Care or Other Treatments or Therapies	Self-Direction or Fiscal Intermediary Services
AZ	95%	63%	16%
MD	94%	63%	15%
NJ	91%	65%	26%
PA	93%	63%	16%
Weighted NCI-IDD Average	93%	63%	18%

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

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

State	Social security payments (SSI or SSB)	Services or Supports from other Agencies or Organizations
AZ	96%	26%
MD	95%	29%
NJ	95%	29%
PA	98%	31%
Weighted NCI-IDD Average	96%	29%

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?

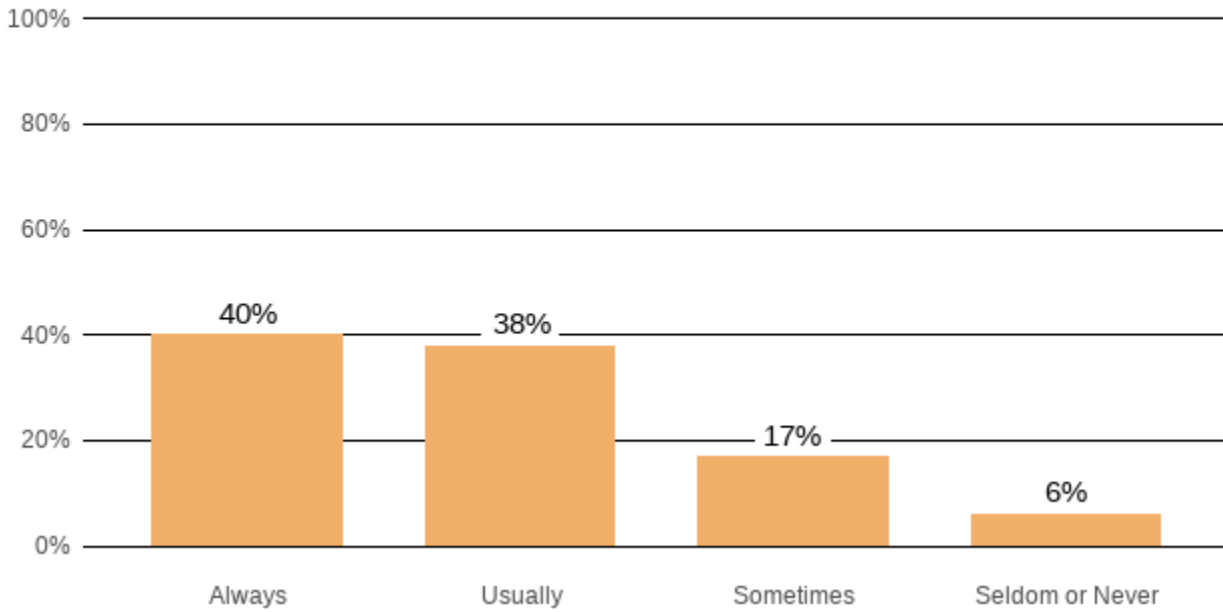


Table 26. Do you get enough information to take part in planning services for your family member?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	48%	35%	12%	5%	219
MD	33%	43%	16%	8%	401
NJ	42%	40%	12%	6%	339
PA	39%	36%	20%	5%	259
Weighted NCI-IDD Average	40%	38%	17%	6%	1218

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

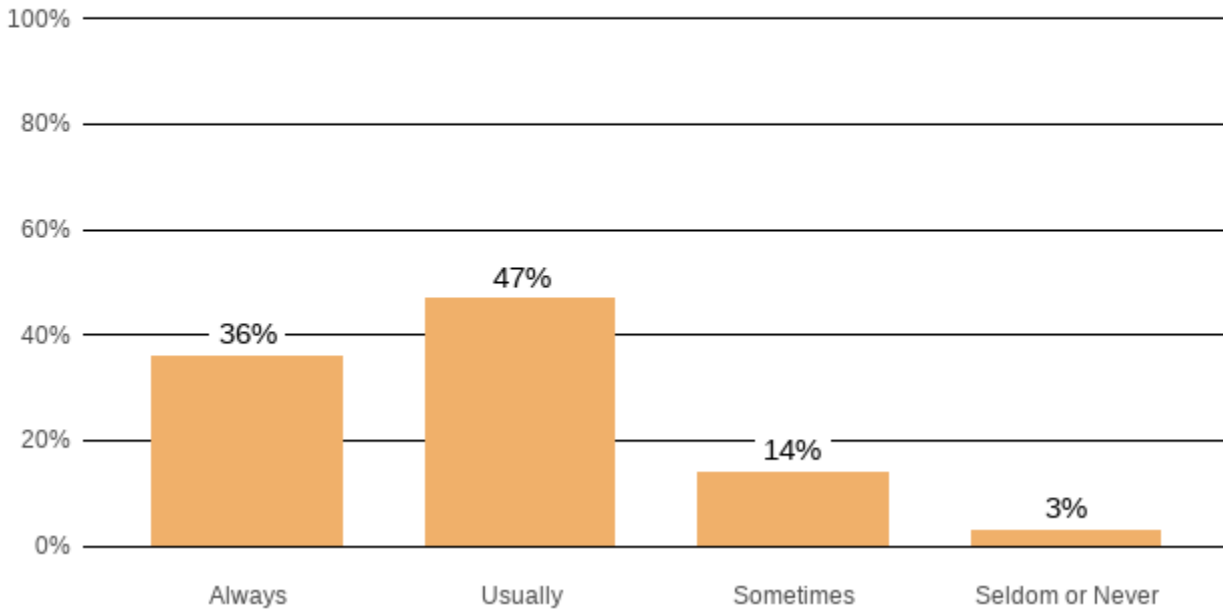


Table 27. Is the information you get about services and supports easy to understand?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	40%	46%	12%	1%	218
MD	28%	50%	15%	6%	389
NJ	37%	48%	12%	3%	343
PA	39%	45%	15%	2%	262
Weighted NCI-IDD Average	36%	47%	14%	3%	1212

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

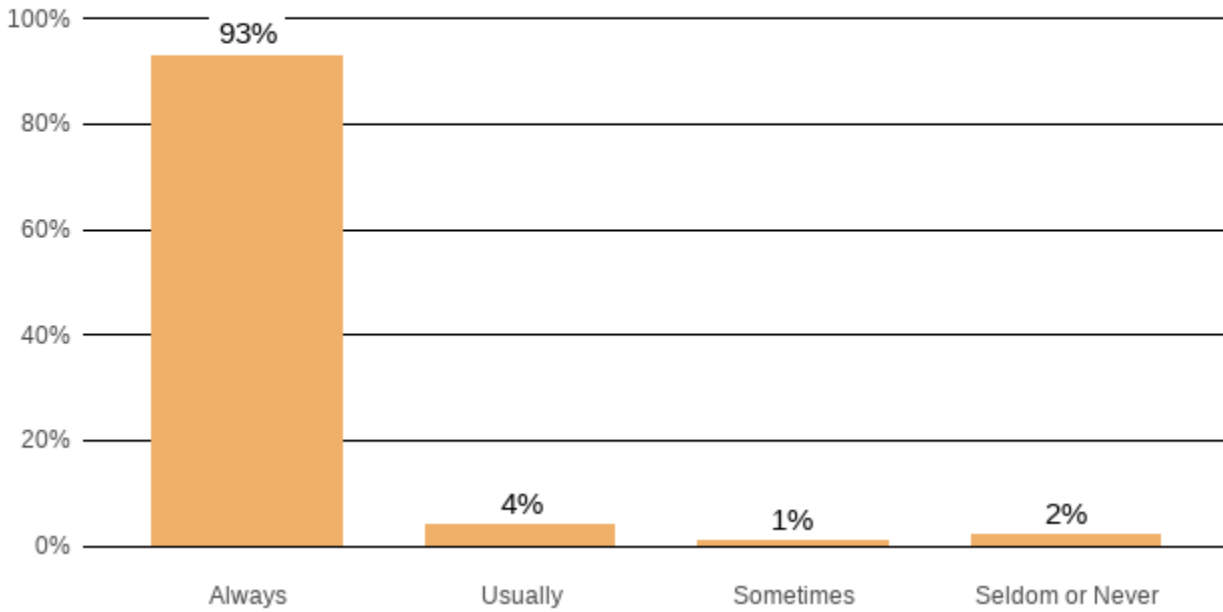


Table 28. Do you get information about services and supports in your preferred language?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	89%	7%	1%	3%	227
MD	90%	6%	1%	3%	406
NJ	93%	3%	1%	3%	355
PA	96%	2%	1%	2%	278
Weighted NCI-IDD Average	93%	4%	1%	2%	1266

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

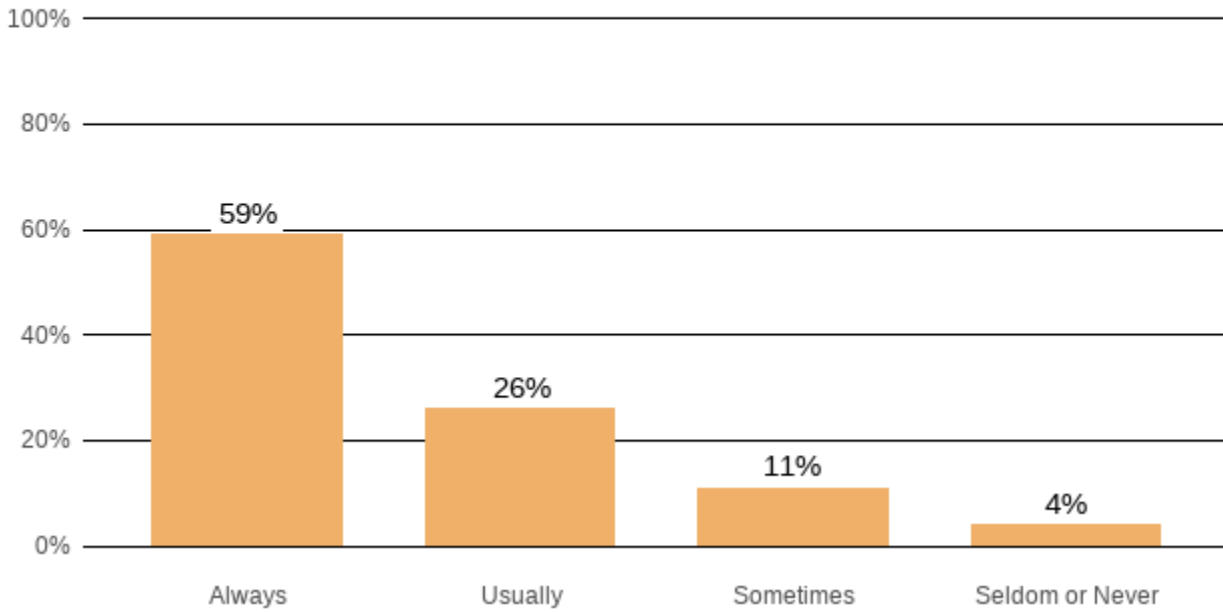


Table 29. Does the case manager or service coordinator listen to your family's choices and opinions?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	65%	22%	10%	3%	220
MD	56%	28%	10%	5%	401
NJ	71%	20%	7%	2%	338
PA	55%	28%	13%	5%	275
Weighted NCI-IDD Average	59%	26%	11%	4%	1234

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

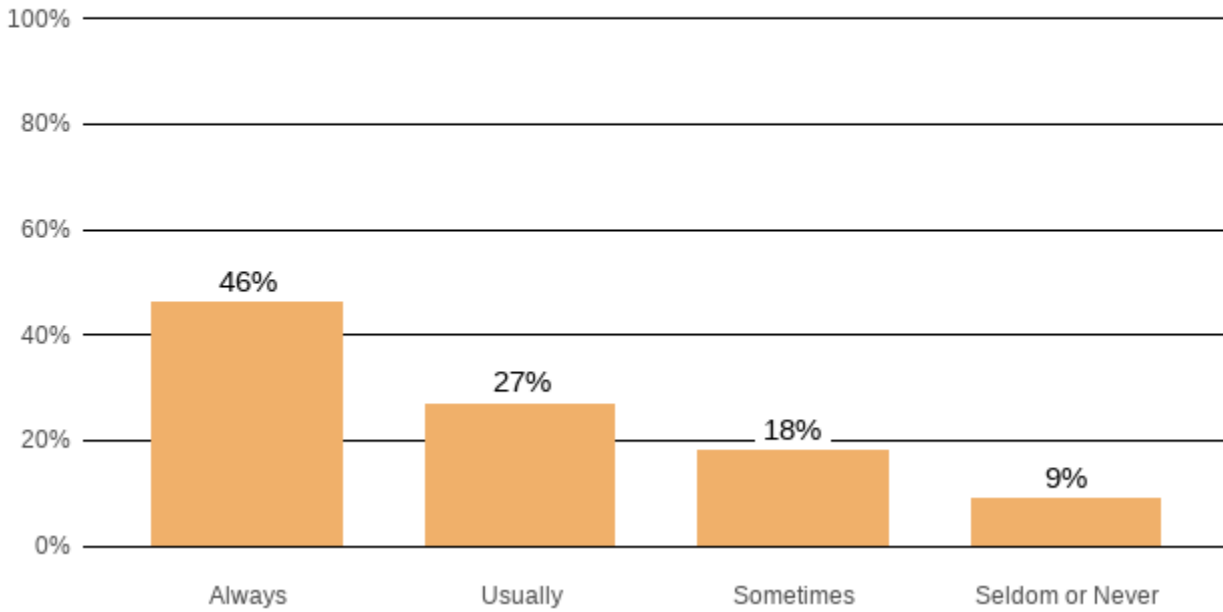


Table 30. Do staff or the residential agency keep you informed about how your family member is doing?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	52%	22%	17%	10%	227
MD	36%	35%	19%	10%	402
NJ	44%	32%	15%	8%	320
PA	49%	24%	18%	10%	282
Weighted NCI-IDD Average	46%	27%	18%	9%	1231

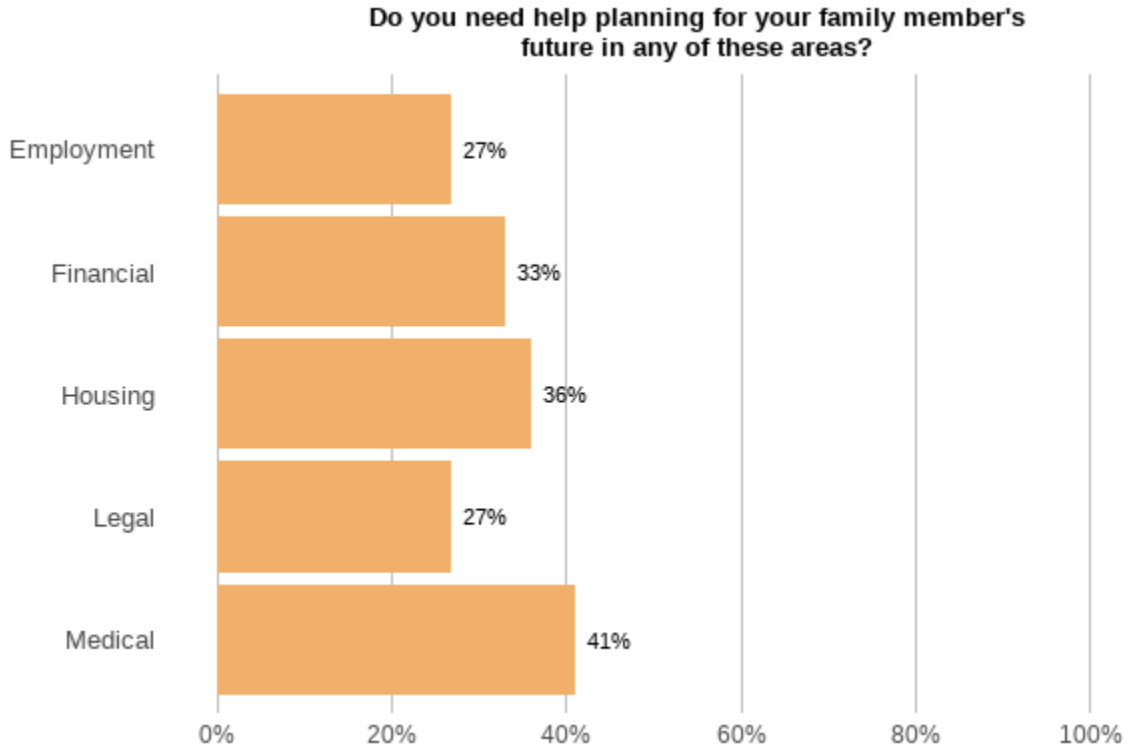


Table 31a. Do you need help planning for your family member’s future in any of these areas?

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

State	Employment	Financial	Housing	Legal	Medical
AZ	24%	37%	36%	26%	40%
MD	31%	39%	43%	32%	49%
NJ	24%	35%	41%	26%	45%
PA	26%	27%	30%	25%	35%
Weighted NCI-IDD Average	27%	33%	36%	27%	41%

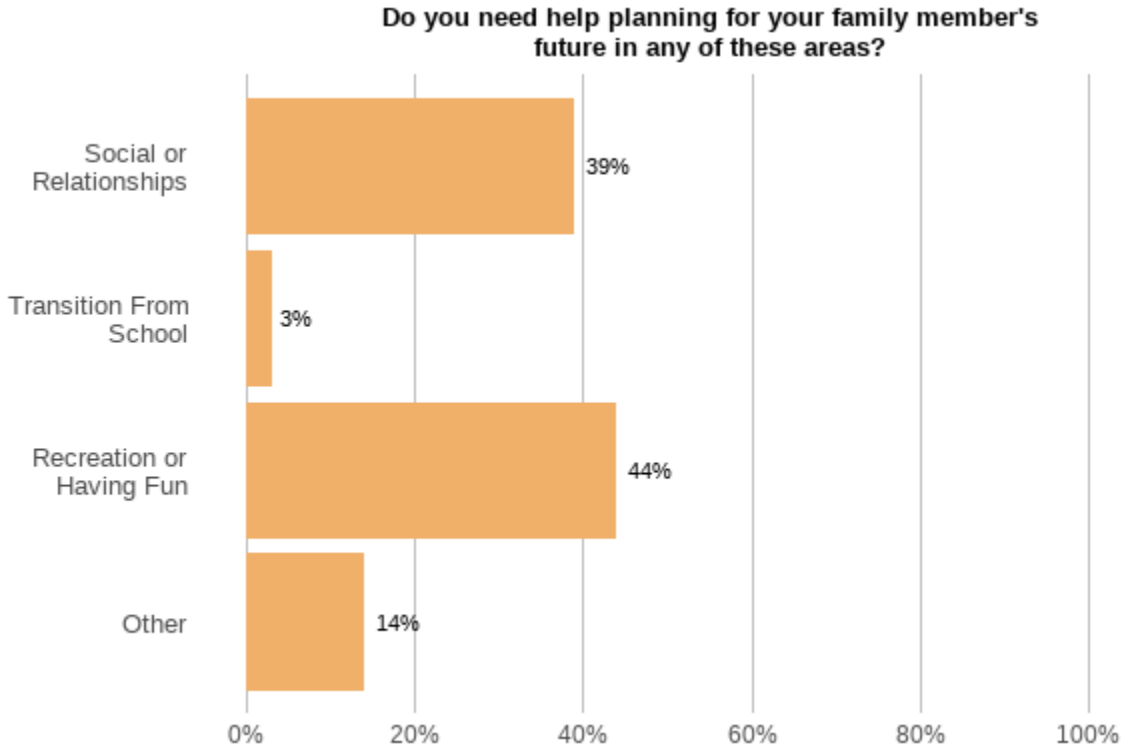


Table 31b. Do you need help planning for your family member's future in any of these areas? (continued)

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

State	Social or Relationships	Transition From School	Recreation or Having Fun	Other
AZ	26%	3%	39%	14%
MD	41%	3%	44%	15%
NJ	40%	1%	43%	11%
PA	41%	5%	45%	16%
Weighted NCI-IDD Average	39%	3%	44%	14%

Has your family learned about alternatives to guardianship or conservatorship?

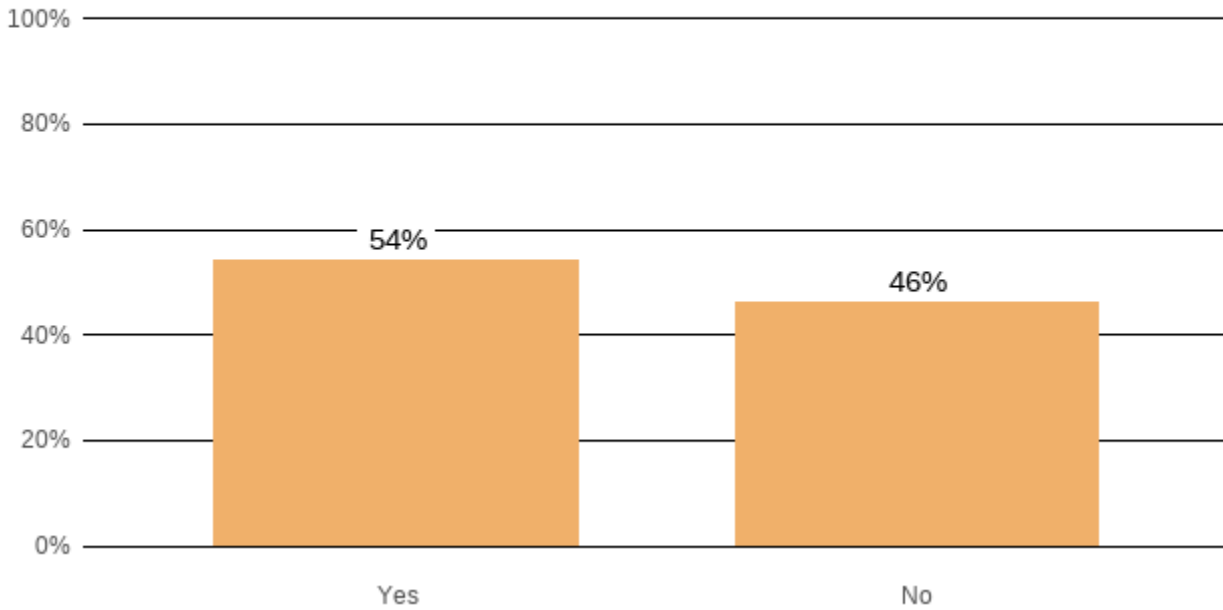


Table 32. Has your family learned about alternatives to guardianship/conservatorship?

State	Yes	No	N
AZ	50%	50%	194
MD	58%	42%	349
NJ	51%	49%	305
PA	55%	45%	213
Weighted NCI-IDD Average	54%	46%	1061

Table note: Alternatives to guardianship or conservatorship 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?

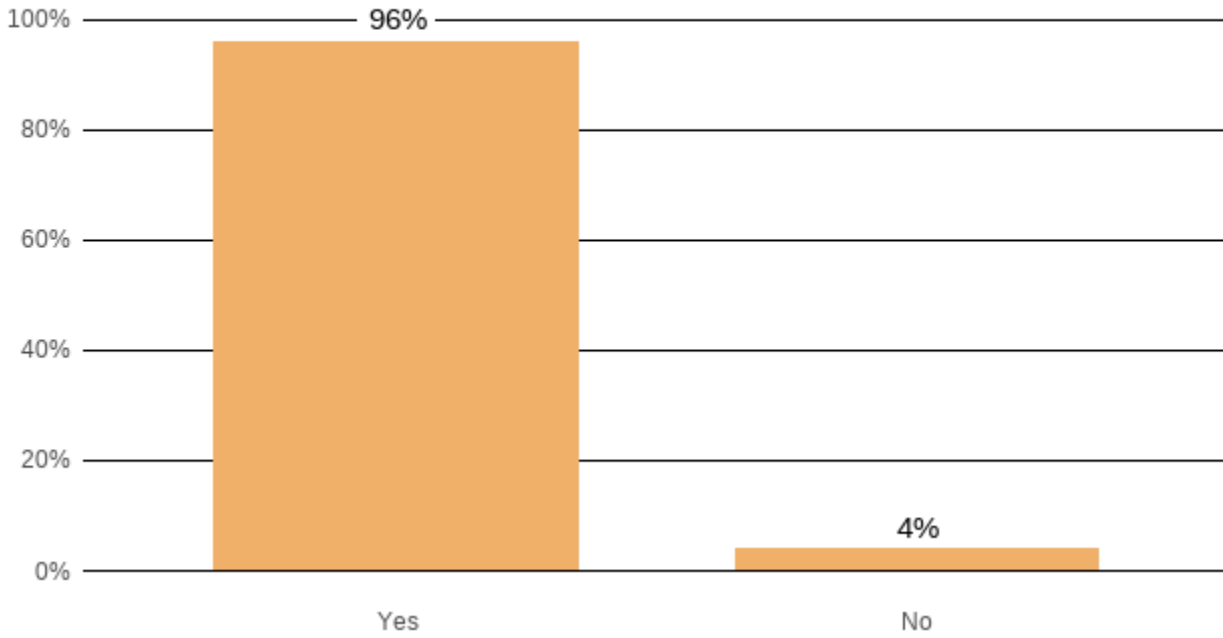


Table 33. Does your family member have a service plan?

State	Yes	No	N
AZ	88%	12%	173
MD	96%	4%	360
NJ	91%	9%	305
PA	98%	2%	266
Weighted NCI-IDD Average	96%	4%	1104

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

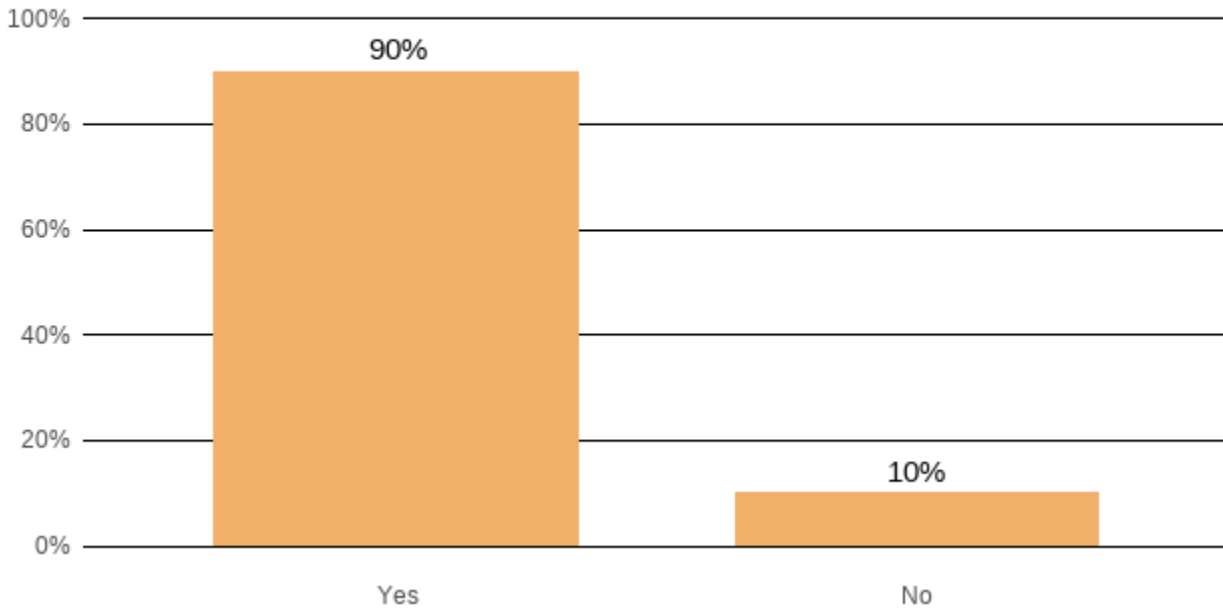


Table 34. Does the service plan include all the services and supports your family member needs?

State	Yes	No	N
AZ	89%	11%	137
MD	86%	14%	317
NJ	91%	9%	265
PA	92%	8%	237
Weighted NCI-IDD Average	90%	10%	956

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



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

State	Yes	No	N
AZ	88%	12%	143
MD	93%	7%	333
NJ	88%	12%	267
PA	78%	22%	244
Weighted NCI-IDD Average	84%	16%	987

National Core Indicators-Intellectual and Developmental Disabilities
Did your family member help make the service plan?

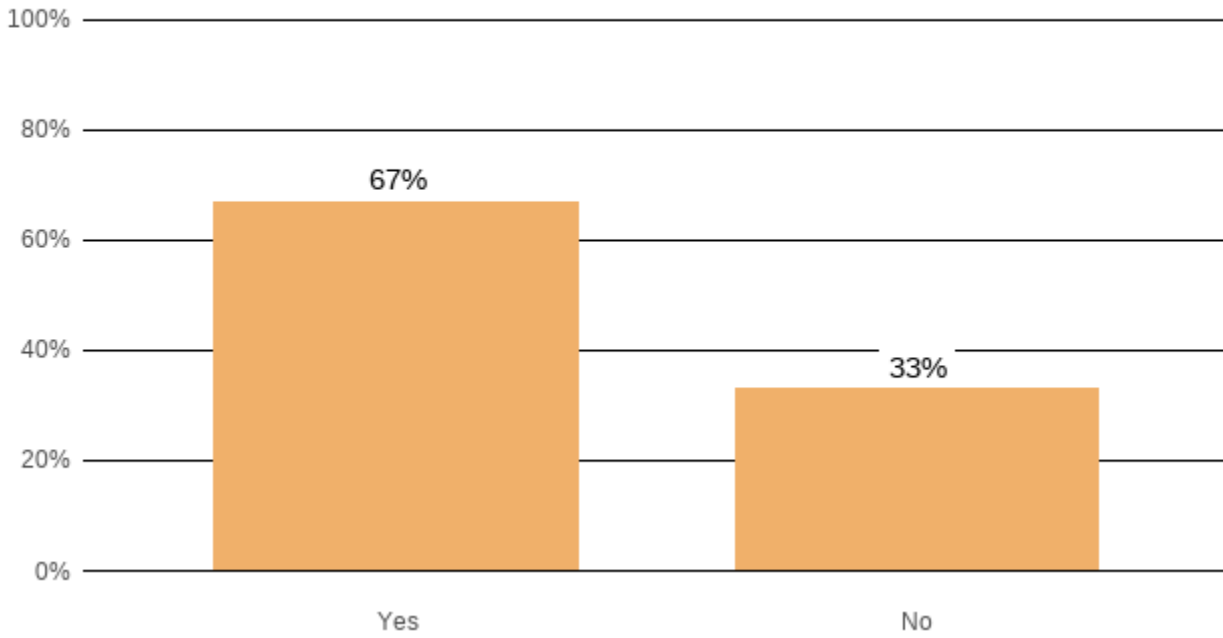


Table 36. Did your family member help make the service plan?

State	Yes	No	N
AZ	59%	41%	142
MD	78%	22%	327
NJ	57%	43%	265
PA	67%	33%	233
Weighted NCI-IDD Average	67%	33%	967

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

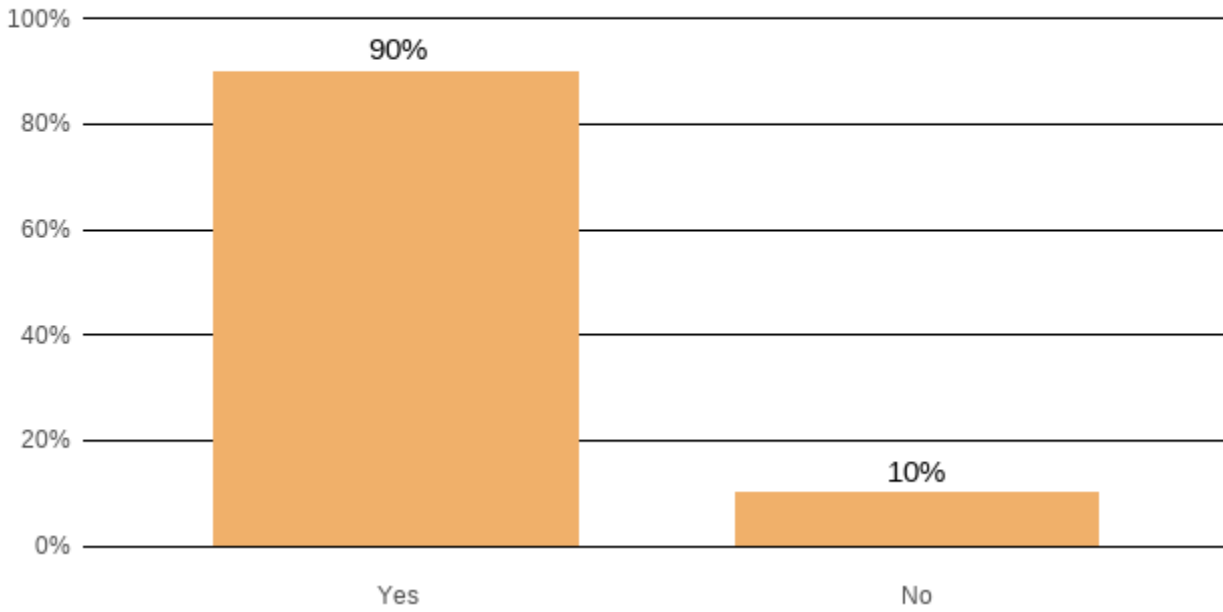


Table 37. Do you feel like your family had enough say or input in making the service plan?

State	Yes	No	N
AZ	92%	8%	140
MD	92%	8%	321
NJ	96%	4%	268
PA	88%	12%	235
Weighted NCI-IDD Average	90%	10%	964

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

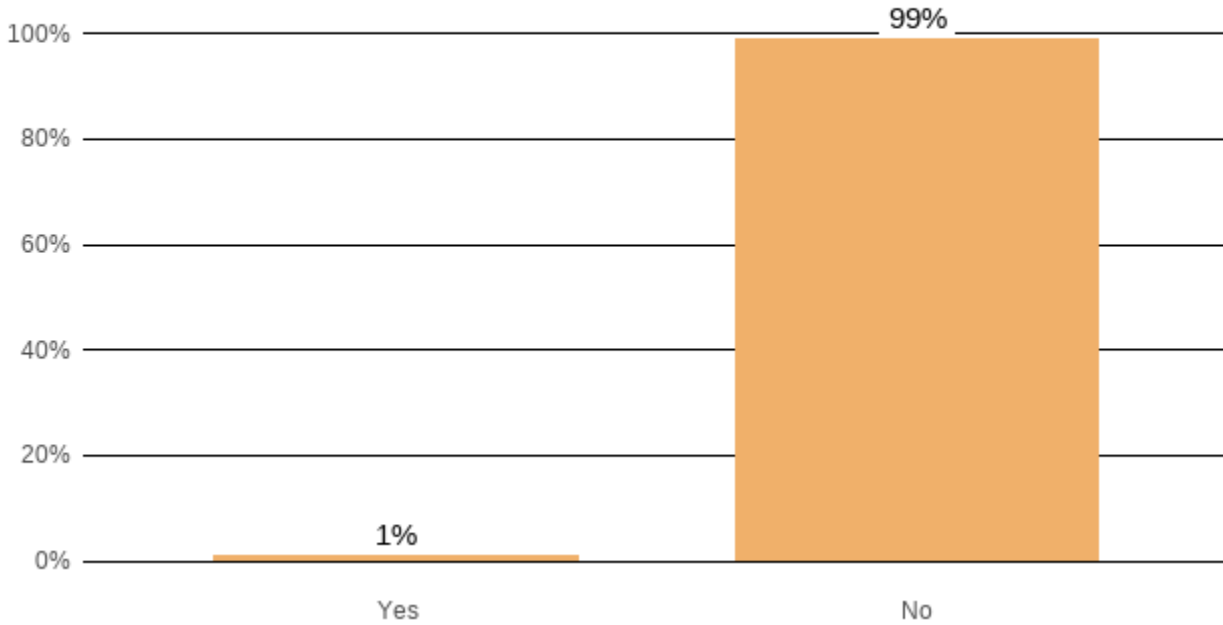


Table 38. Did your family member leave school services and begin adult services during the past 12 months?

State	Yes	No	N
AZ	2%	98%	223
MD	1%	99%	406
NJ	0%	100%	343
PA	1%	99%	288
Weighted NCI-IDD Average	1%	99%	1260

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

Due to the low N overall, the measure is not reported

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

Due to the low N overall, the measure is 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?

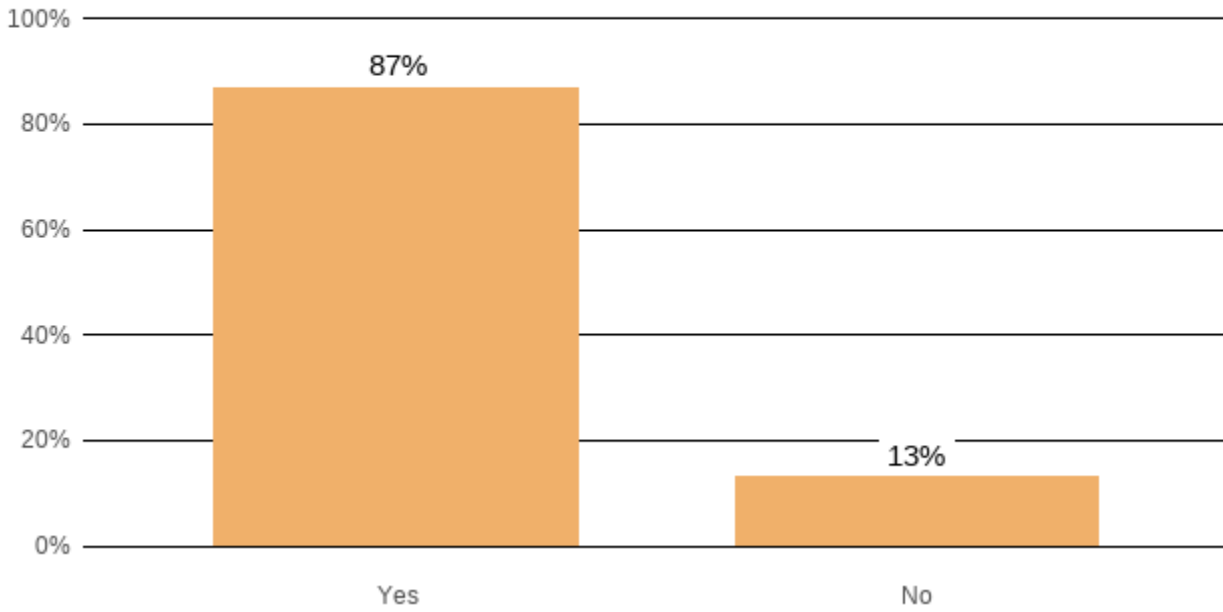


Table 41. Does your family member get all the services listed in the plan?

State	Yes	No	N
AZ	95%	5%	133
MD	82%	18%	297
NJ	89%	11%	253
PA	87%	13%	223
Weighted NCI-IDD Average	87%	13%	906

Does your family get the supports and services it needs?

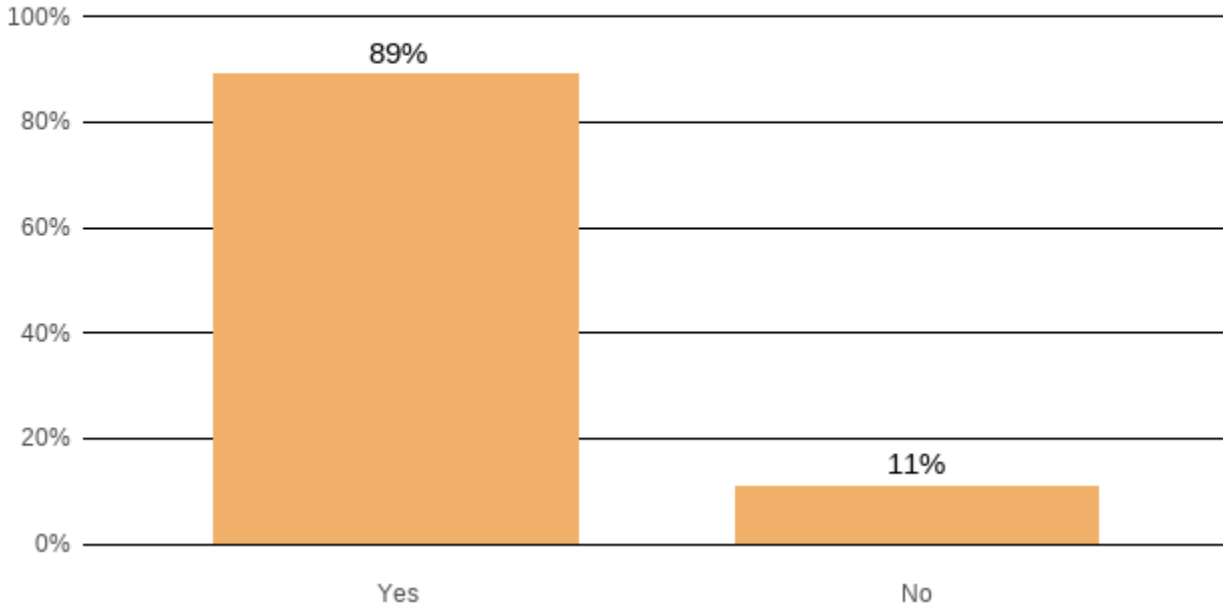


Table 42. Does your family get the supports and services it needs?

State	Yes	No	N
AZ	86%	14%	210
MD	86%	14%	362
NJ	87%	13%	310
PA	92%	8%	261
Weighted NCI-IDD Average	89%	11%	1143

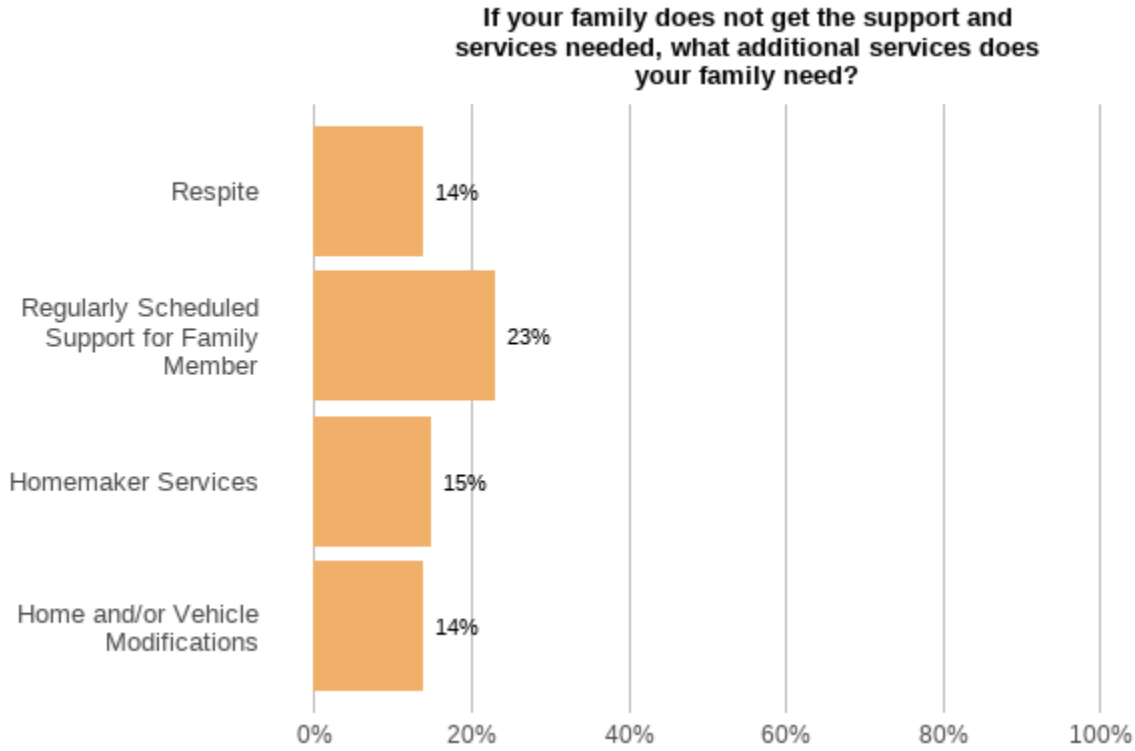


Table 43a. If your family does not get the support and services needed, what additional services does your family need?

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

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home and/or Vehicle Modifications
AZ	16%	12%	16%	20%
MD	19%	27%	13%	13%
NJ	13%	15%	18%	10%
PA	10%	30%	15%	15%
Weighted NCI-IDD Average	14%	23%	15%	14%

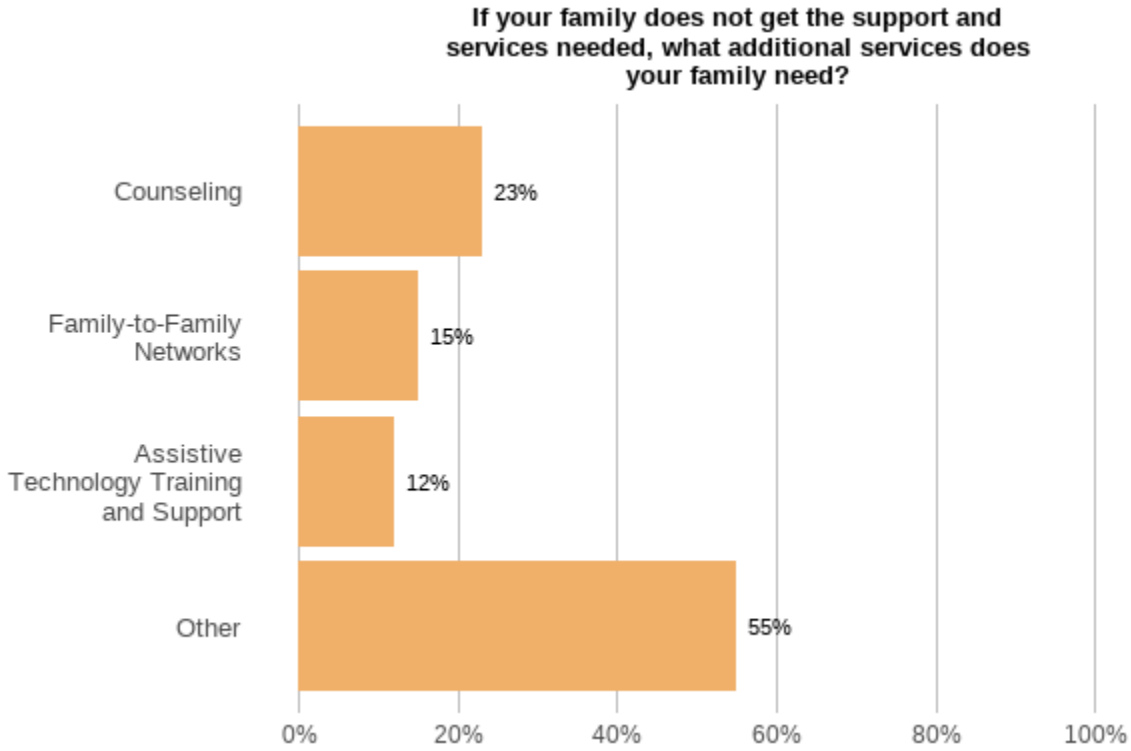


Table 43b. If your family does not get the support and services needed, what additional services does your family need? (continued)

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

State	Counseling	Family-to-Family Networks	Assistive Technology Training and Support	Other
AZ	20%	12%	8%	52%
MD	19%	10%	15%	56%
NJ	36%	23%	15%	46%
PA	20%	15%	10%	60%
Weighted NCI-IDD Average	23%	15%	12%	55%

National Core Indicators-Intellectual and Developmental Disabilities
Do services and supports change when your family's needs change?

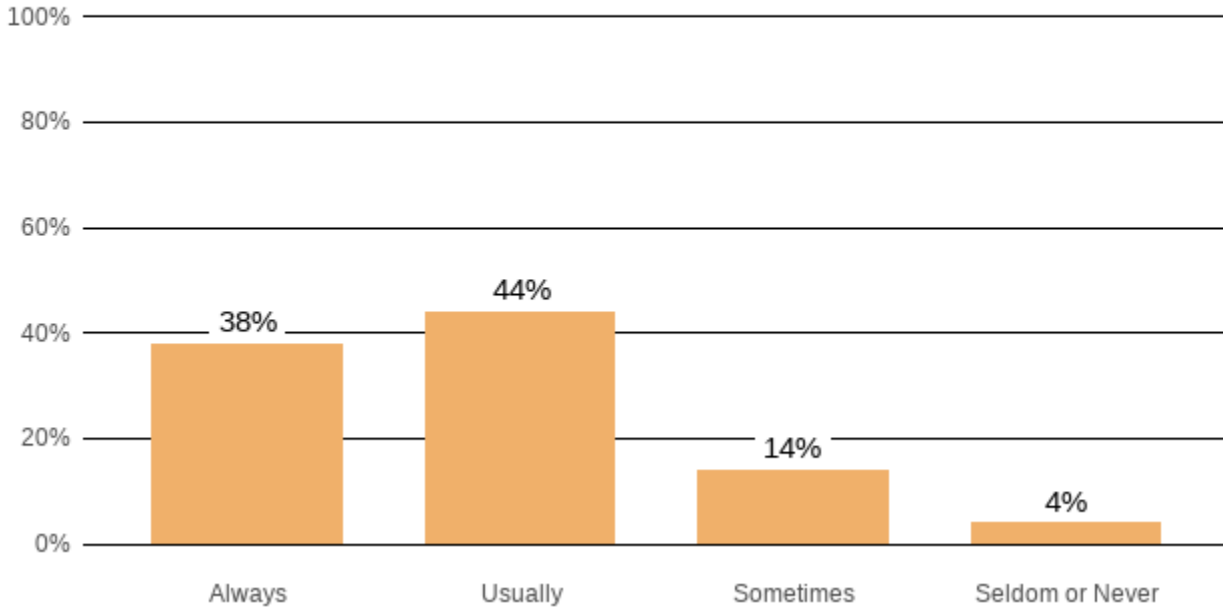


Table 44. Do services and supports change when your family's needs change?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	43%	40%	14%	4%	171
MD	30%	47%	16%	7%	280
NJ	39%	44%	12%	5%	253
PA	41%	43%	13%	4%	197
Weighted NCI-IDD Average	38%	44%	14%	4%	901

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)

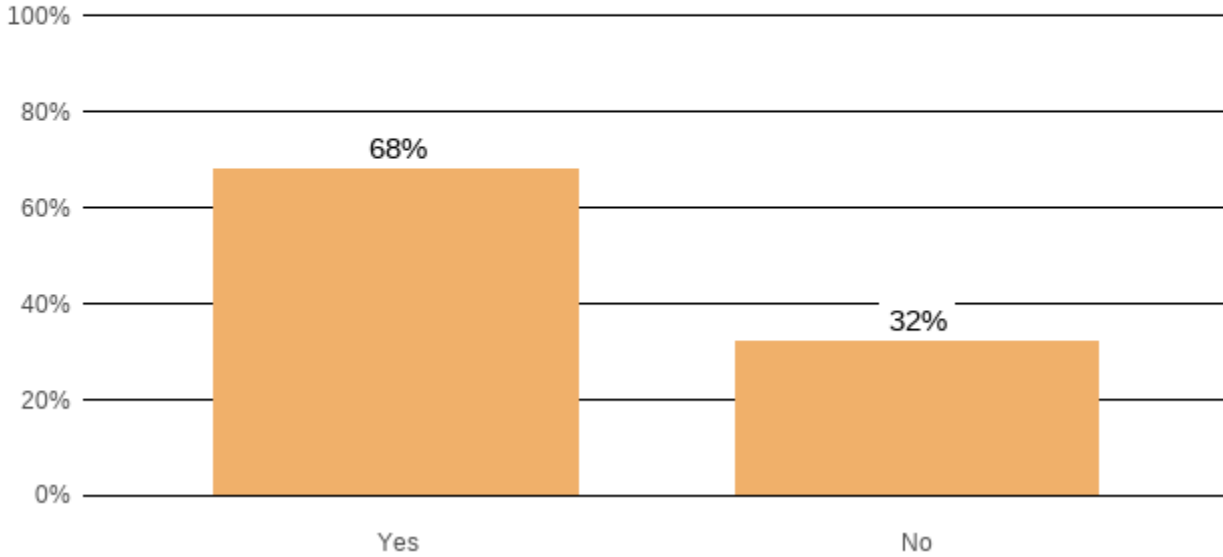


Table 45. Does your family member have enough supports to work or volunteer in the community? (These types of supports might include support workers, community resources, transportation)

State	Yes	No	N
AZ	51%	49%	137
MD	68%	32%	279
NJ	57%	43%	202
PA	76%	24%	177
Weighted NCI-IDD Average	68%	32%	795

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

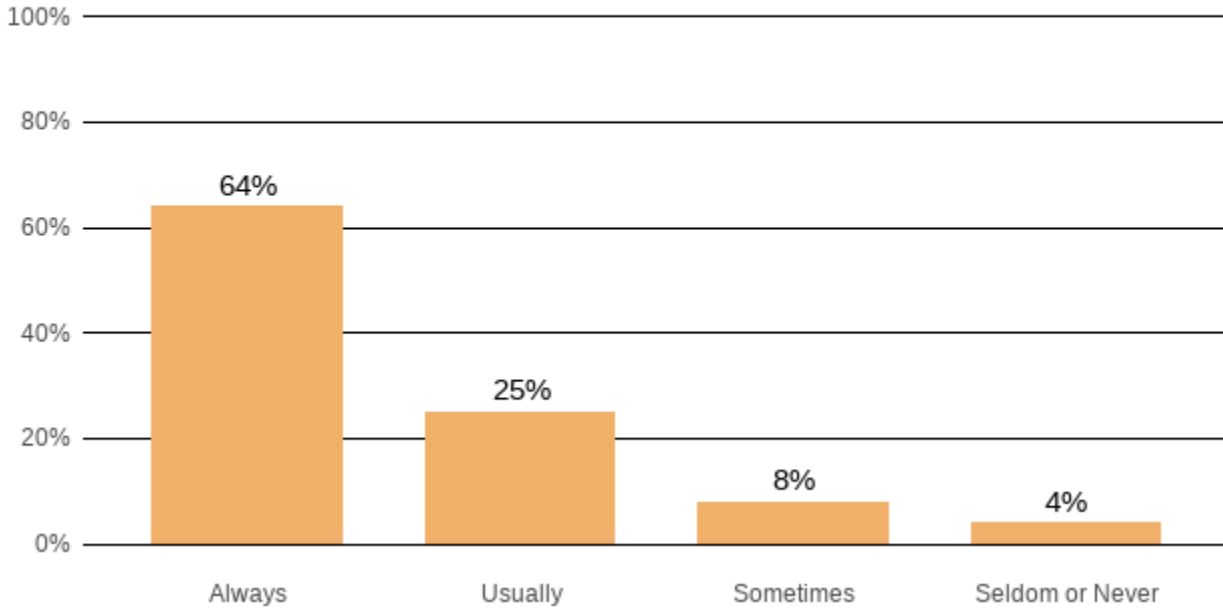


Table 46. Does your family member have the special equipment or accommodations that they need?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	69%	21%	6%	3%	126
MD	54%	33%	9%	4%	210
NJ	61%	27%	9%	3%	184
PA	67%	22%	7%	4%	155
Weighted NCI-IDD Average	64%	25%	8%	4%	675

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

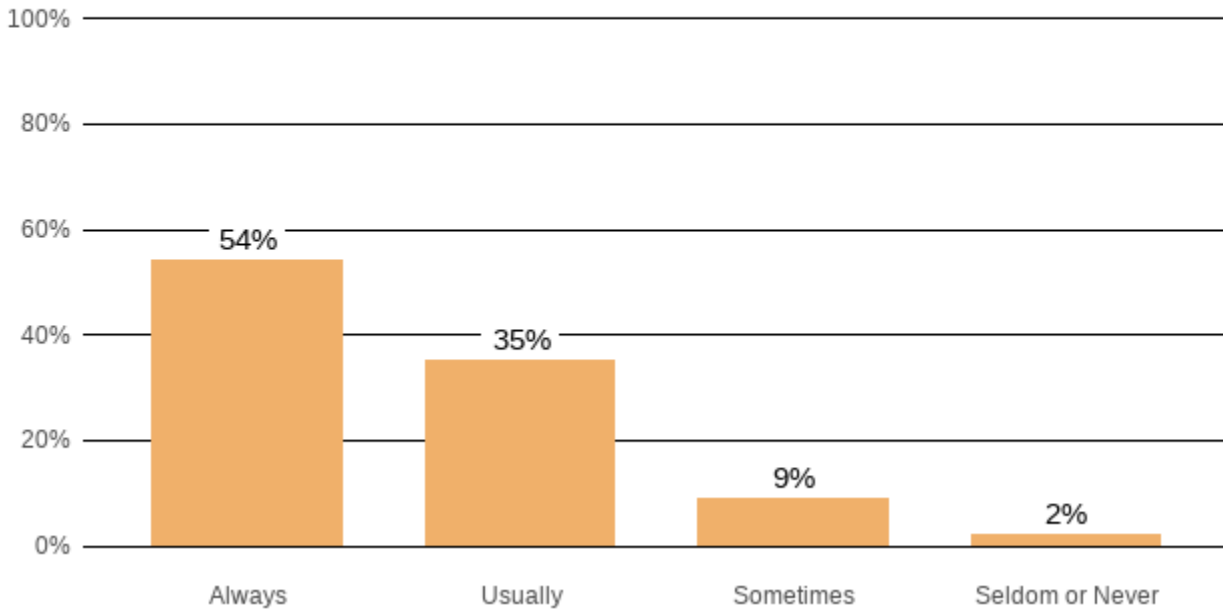


Table 47. Are you or your family member able to contact support workers when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	49%	40%	8%	4%	211
MD	43%	41%	14%	2%	386
NJ	54%	35%	9%	3%	327
PA	60%	31%	8%	1%	274
Weighted NCI-IDD Average	54%	35%	9%	2%	1198

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

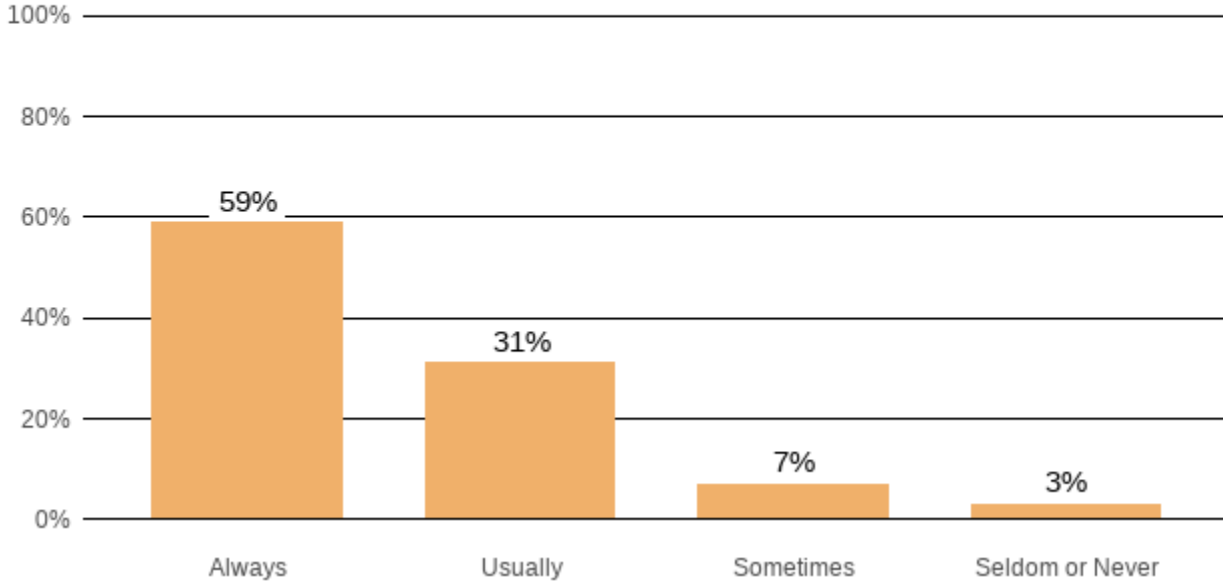


Table 48. Are you or your family member able to contact the case manager or service coordinator when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	56%	34%	6%	4%	219
MD	53%	33%	11%	2%	386
NJ	67%	28%	3%	2%	336
PA	59%	31%	7%	3%	271
Weighted NCI-IDD Average	59%	31%	7%	3%	1212

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

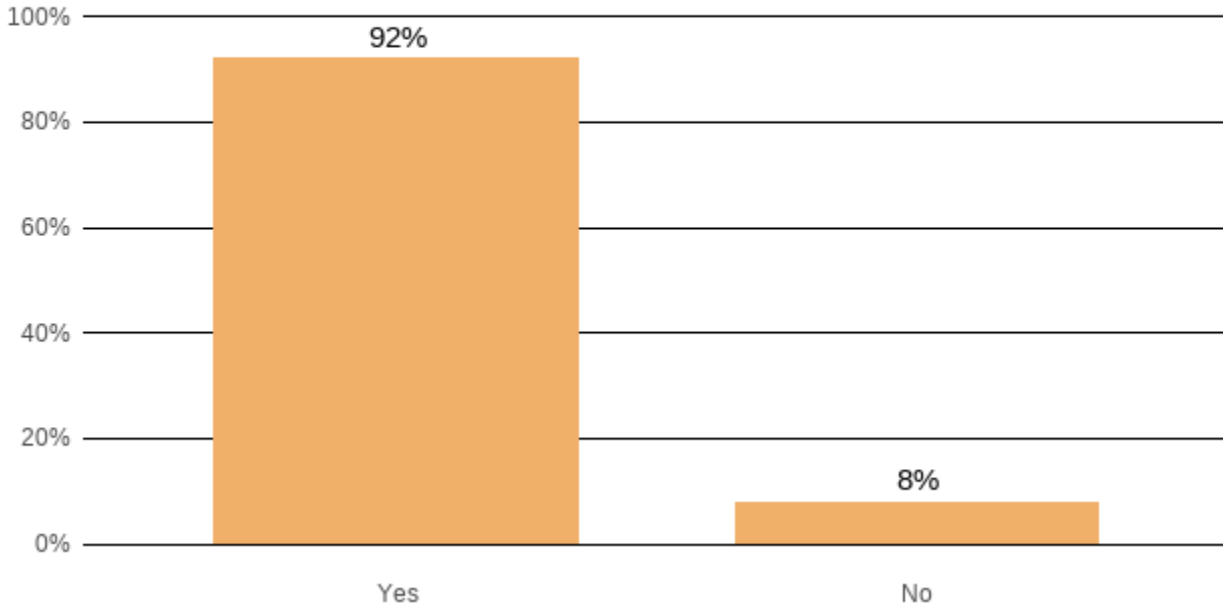


Table 49. Do service providers for your family member work together to provide support?

State	Yes	No	N
AZ	94%	6%	165
MD	91%	9%	289
NJ	93%	7%	250
PA	92%	8%	193
Weighted NCI-IDD Average	92%	8%	897

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

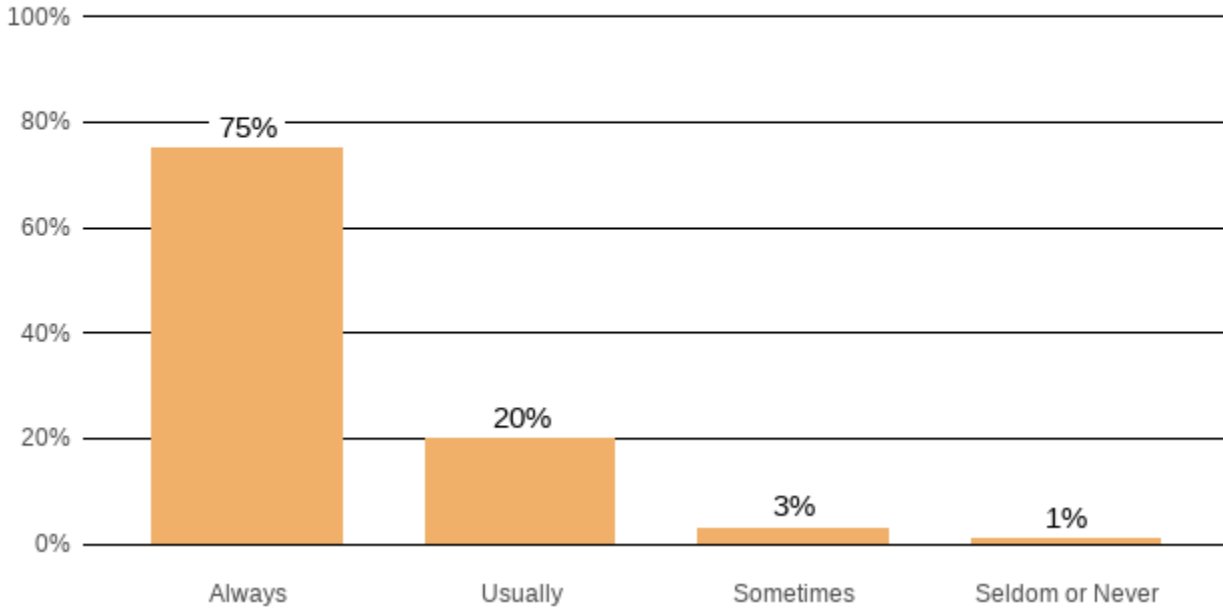


Table 50. Are services delivered in a way that is respectful of your family's culture?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	68%	27%	2%	2%	212
MD	67%	26%	5%	1%	383
NJ	83%	15%	2%	1%	329
PA	78%	17%	4%	1%	274
Weighted NCI-IDD Average	75%	20%	3%	1%	1198

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

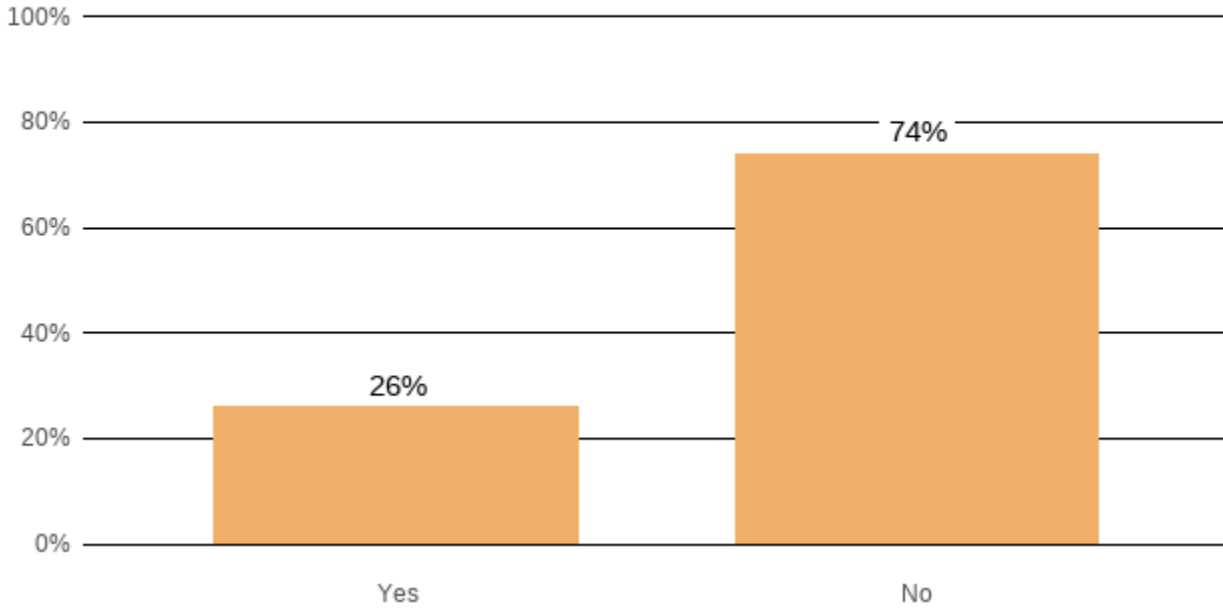


Table 51. Does your family member use technology in their everyday life to help them do things on their own?

State	Yes	No	N
AZ	22%	78%	212
MD	31%	69%	383
NJ	33%	67%	323
PA	24%	76%	262
Weighted NCI-IDD Average	26%	74%	1180

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

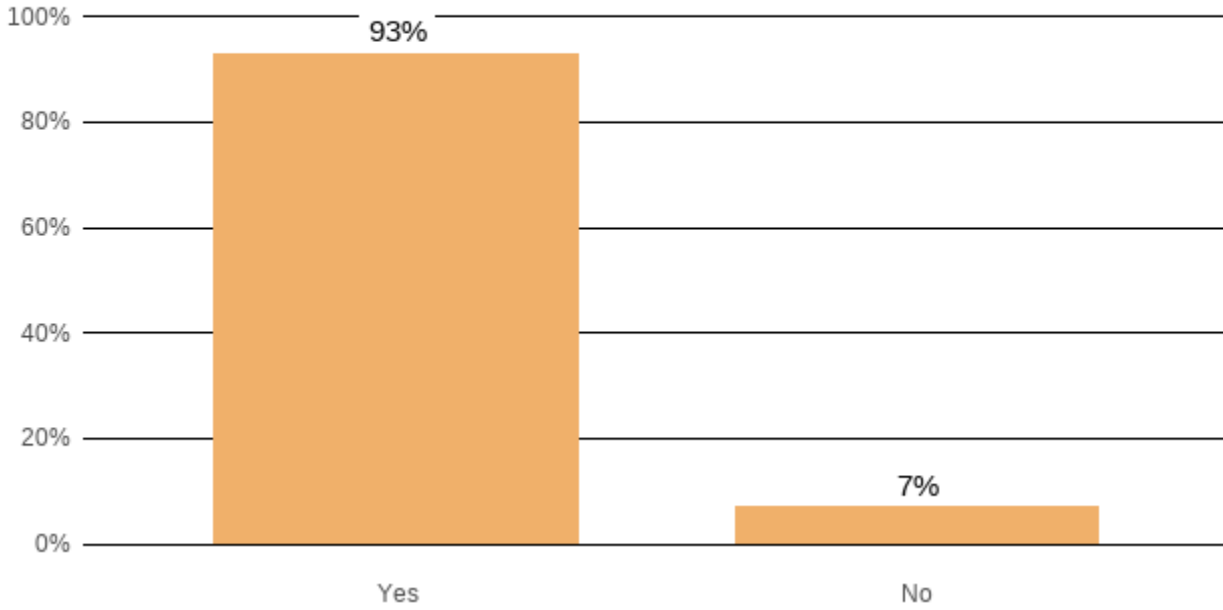


Table 52. Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?

State	Yes	No	N
AZ	93%	7%	221
MD	94%	6%	396
NJ	94%	6%	333
PA	92%	8%	274
Weighted NCI-IDD Average	93%	7%	1224

How well does the internet work in your home?

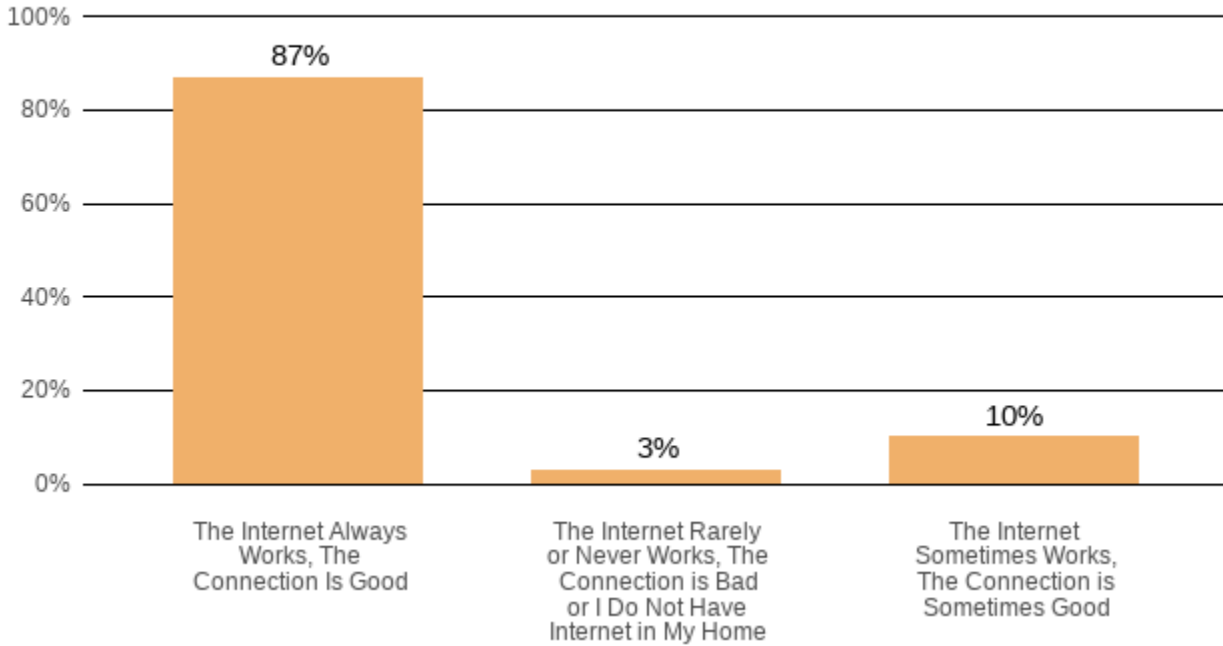


Table 53. How well does the internet work in your home?

State	The Internet Always Works, The Connection Is Good	The Internet Rarely or Never Works, The Connection is Bad or I Do Not Have Internet in My Home	The Internet Sometimes Works, The Connection is Sometimes Good	N
AZ	83%	4%	13%	215
MD	89%	2%	9%	388
NJ	93%	0%	7%	328
PA	85%	4%	11%	265
Weighted NCI-IDD Average	87%	3%	10%	1196

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?

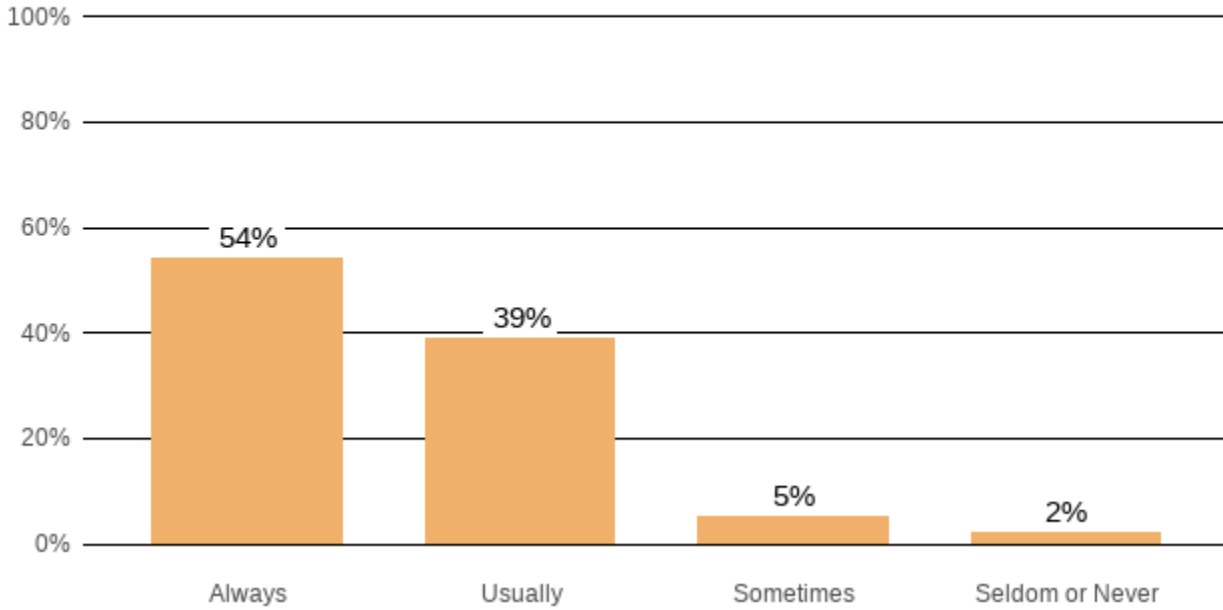


Table 54. Do support workers come and go when they are supposed to?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	51%	42%	4%	3%	174
MD	49%	43%	5%	2%	269
NJ	57%	37%	5%	1%	233
PA	57%	37%	5%	2%	194
Weighted NCI-IDD Average	54%	39%	5%	2%	870

National Core Indicators-Intellectual and Developmental Disabilities
Do support workers speak to you in a way you understand?

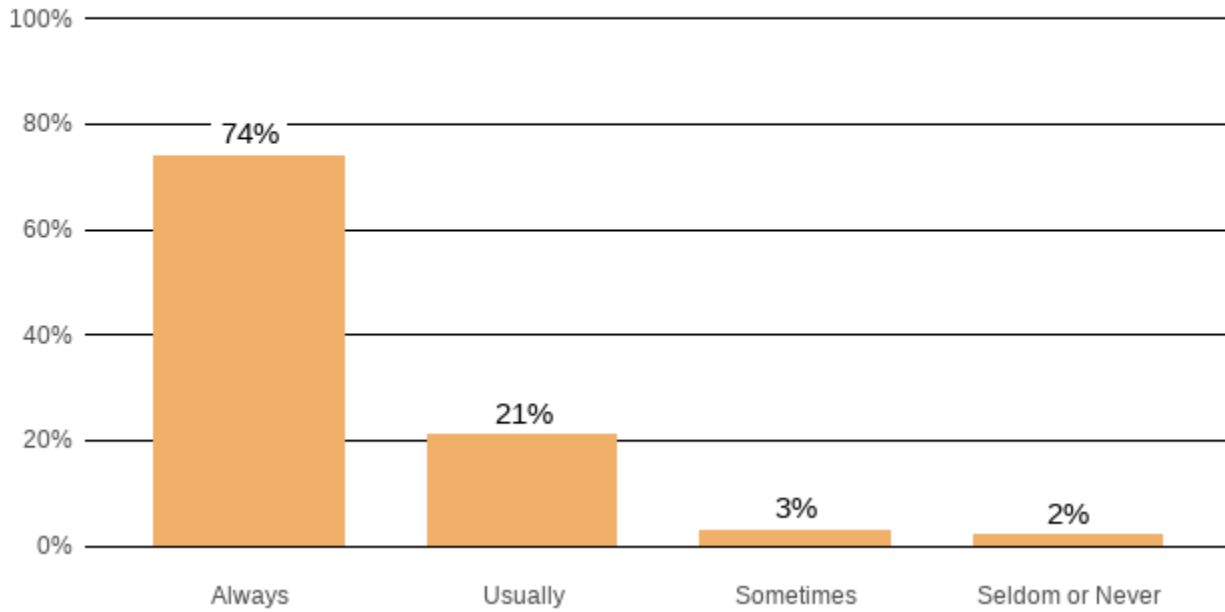


Table 55. Do support workers speak to you in a way you understand?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	72%	20%	5%	2%	212
MD	62%	33%	4%	2%	386
NJ	76%	18%	4%	2%	320
PA	79%	18%	1%	1%	274
Weighted NCI-IDD Average	74%	21%	3%	2%	1192

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

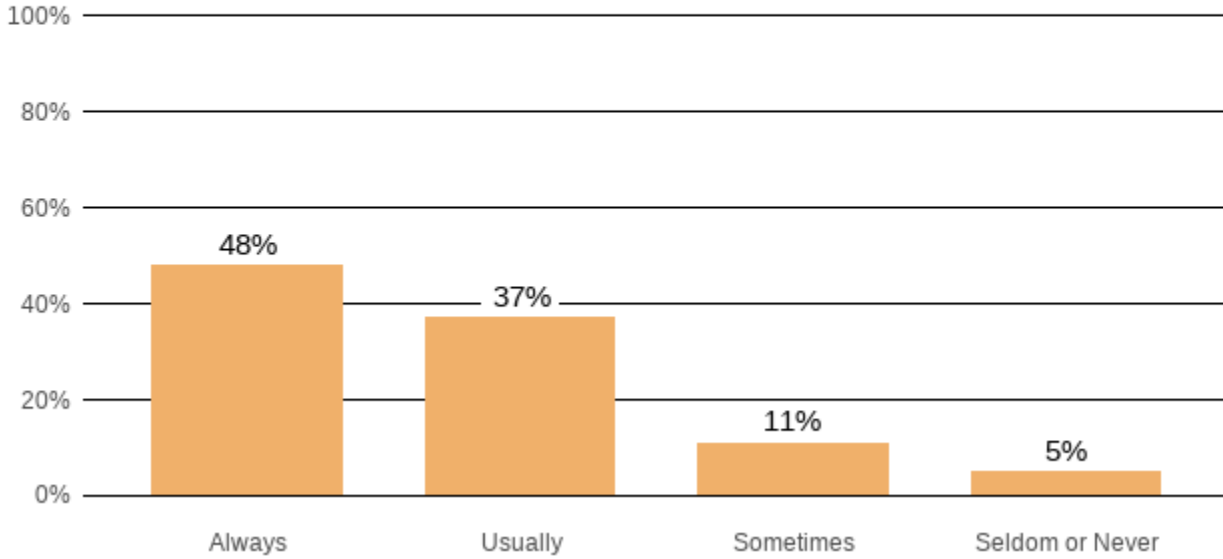


Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	42%	40%	12%	6%	102
MD	38%	44%	14%	5%	176
NJ	40%	41%	13%	6%	121
PA	57%	31%	8%	4%	118
Weighted NCI-IDD Average	48%	37%	11%	5%	517

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

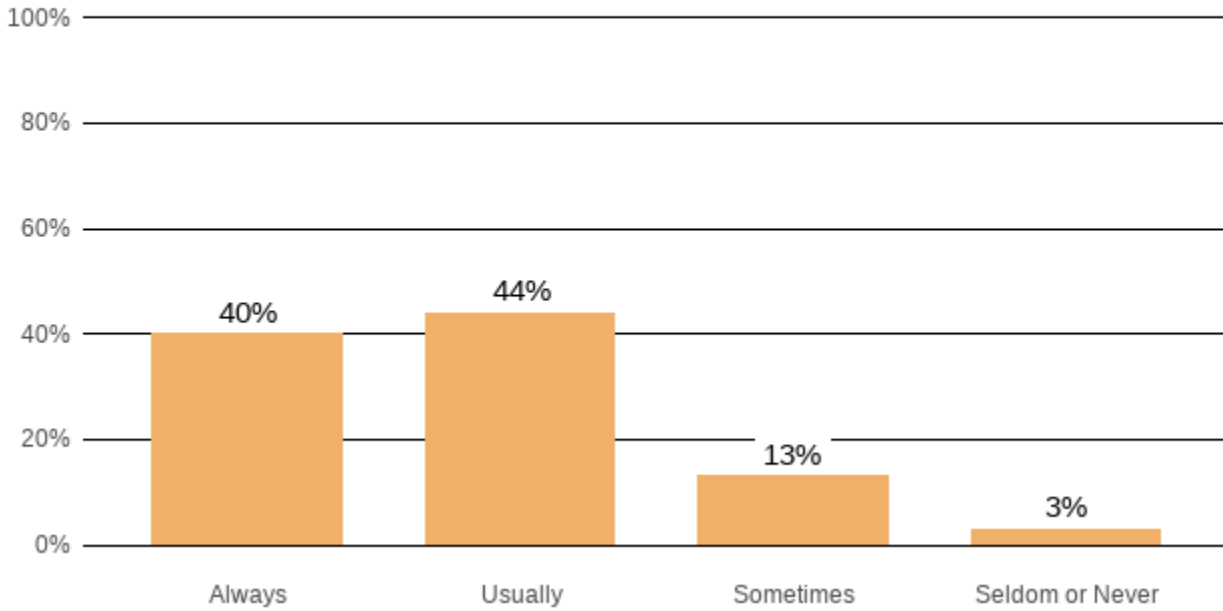


Table 57. Do support workers have the right information and skills to meet your family's needs?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	43%	39%	15%	3%	209
MD	28%	53%	17%	2%	367
NJ	40%	44%	14%	3%	311
PA	46%	41%	10%	3%	261
Weighted NCI-IDD Average	40%	44%	13%	3%	1148

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

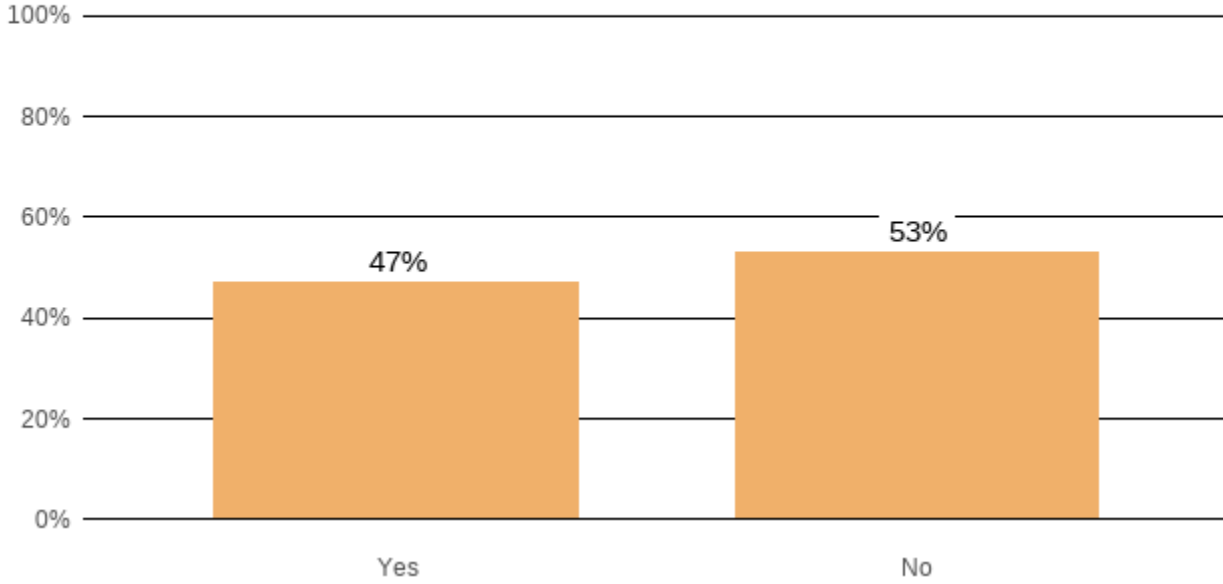


Table 58. Do your family member’s support workers change too often? Is there too much “turnover” of support workers?

State	Yes	No	N
AZ	53%	47%	190
MD	44%	56%	342
NJ	44%	56%	291
PA	48%	52%	239
Weighted NCI-IDD Average	47%	53%	1062

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

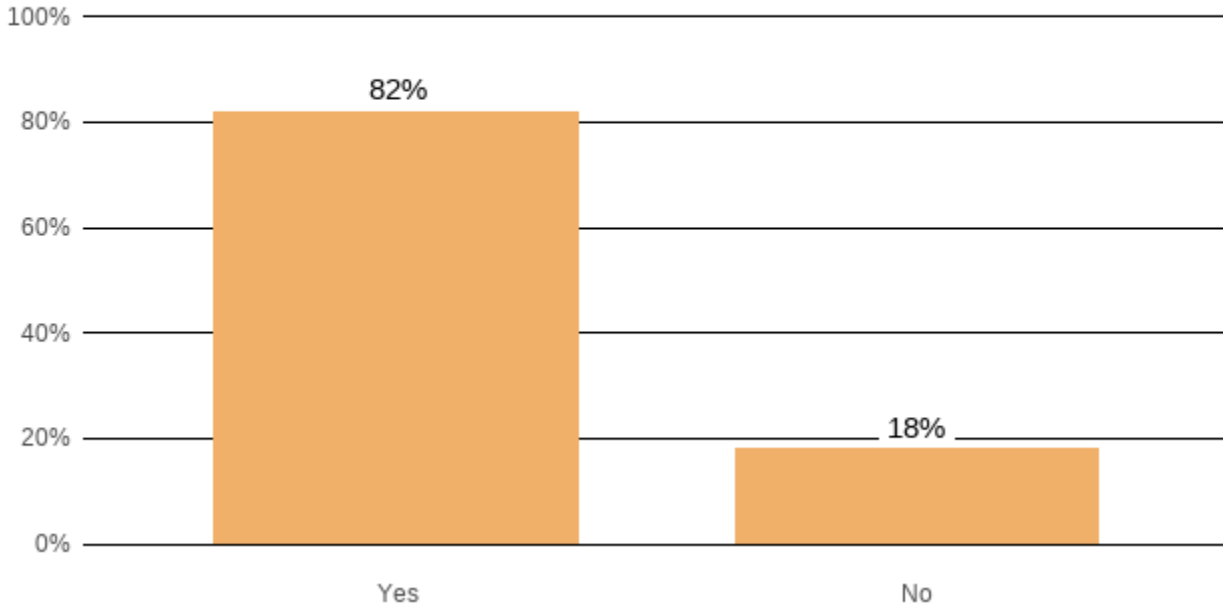


Table 59. Is there always a staff person available to support your family member when support is needed?

State	Yes	No	N
AZ	36%	64%	201
MD	88%	12%	364
NJ	88%	12%	307
PA	91%	9%	260
Weighted NCI-IDD Average	82%	18%	1132

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?

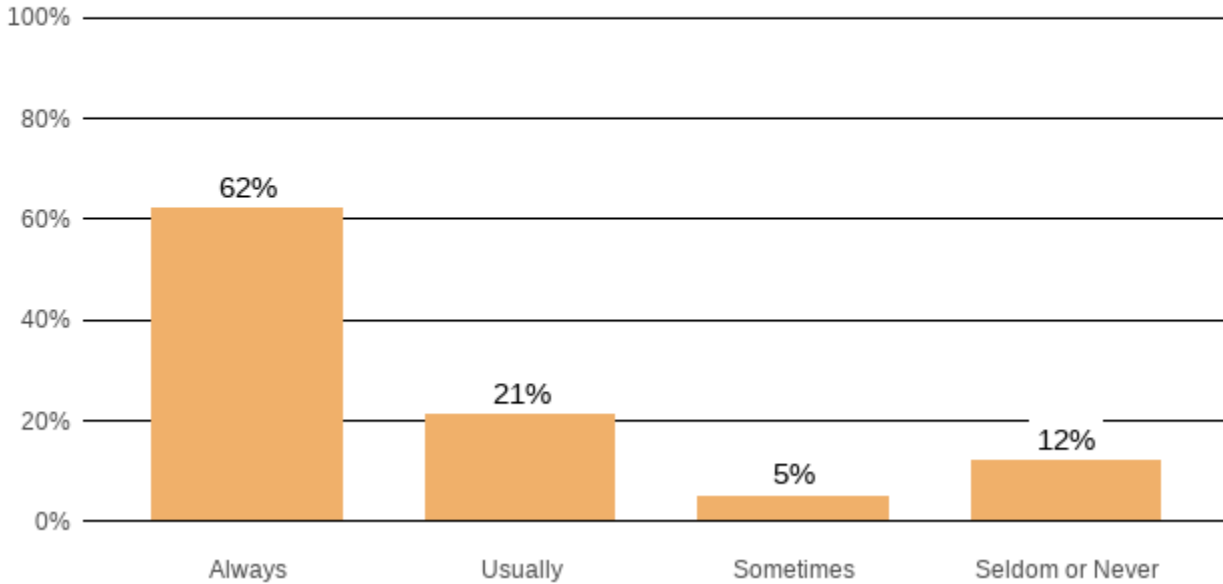


Table 60. Can someone in your family choose or change the provider agency that provides your family member's services?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	60%	19%	9%	13%	159
MD	63%	23%	5%	9%	260
NJ	57%	21%	7%	16%	223
PA	65%	21%	3%	11%	164
Weighted NCI-IDD Average	62%	21%	5%	12%	806

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

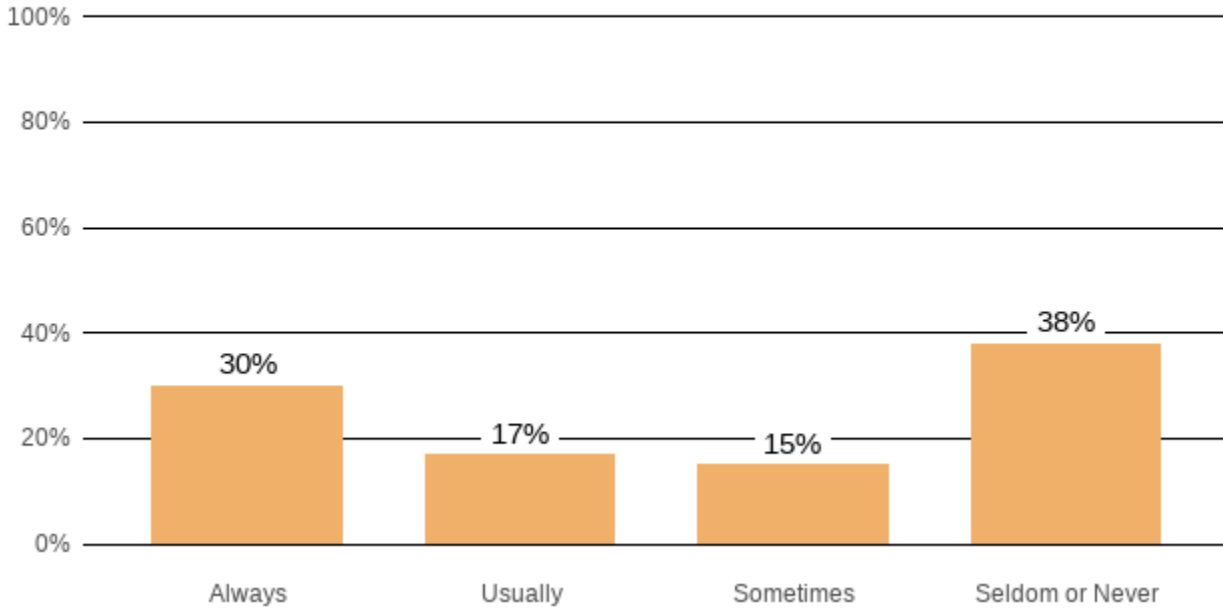


Table 61. Can someone in your family choose or change your family member's support workers?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	39%	15%	15%	31%	131
MD	23%	18%	17%	43%	244
NJ	28%	16%	9%	48%	206
PA	32%	17%	18%	33%	153
Weighted NCI-IDD Average	30%	17%	15%	38%	734

Can someone in your family directly manage support staff?

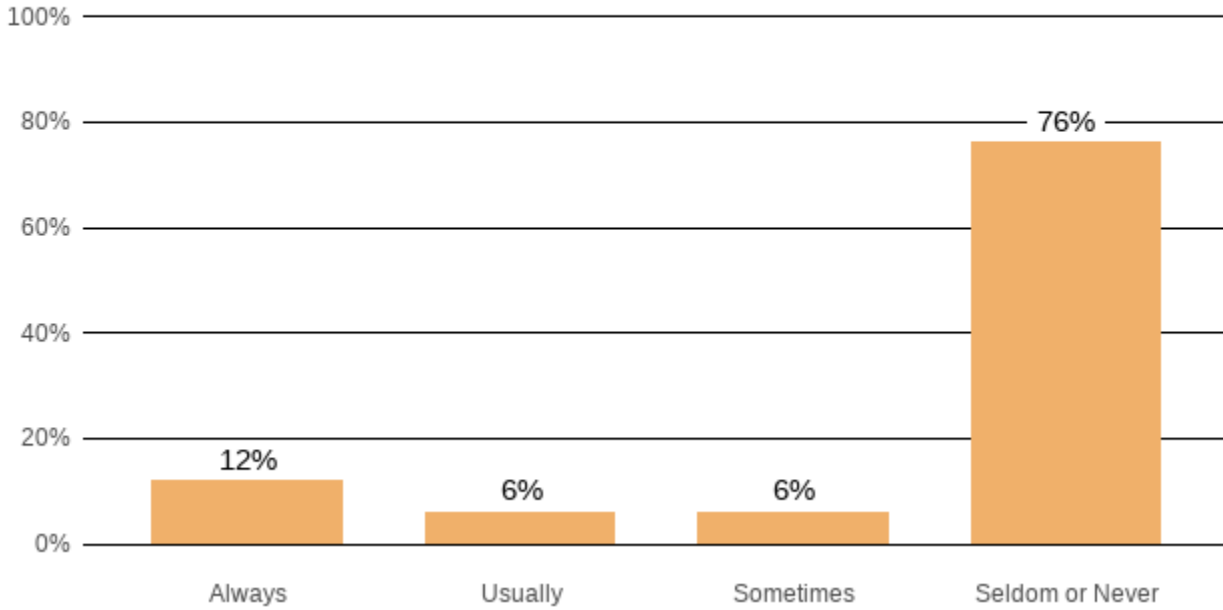


Table 62. Can someone in your family directly manage support staff?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	15%	2%	7%	77%	132
MD	12%	7%	6%	74%	254
NJ	17%	6%	5%	72%	222
PA	10%	6%	6%	79%	163
Weighted NCI-IDD Average	12%	6%	6%	76%	771

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

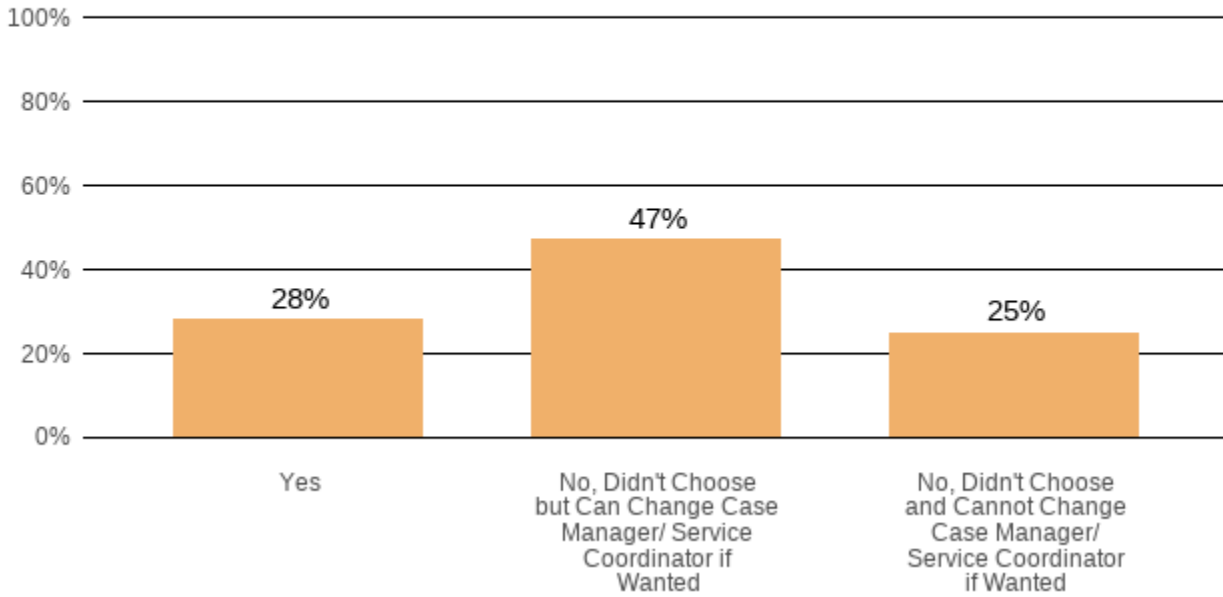


Table 63. Did you, your family member, or someone else in your family choose your family member's case manager or service coordinator?

State	Yes	No, Didn't Choose but Can Change Case Manager/ Service Coordinator if Wanted	No, Didn't Choose and Cannot Change Case Manager/ Service Coordinator if Wanted	N
AZ	13%	61%	26%	187
MD	28%	54%	19%	323
NJ	53%	28%	18%	302
PA	23%	47%	30%	213
Weighted NCI-IDD Average	28%	47%	25%	1025

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?

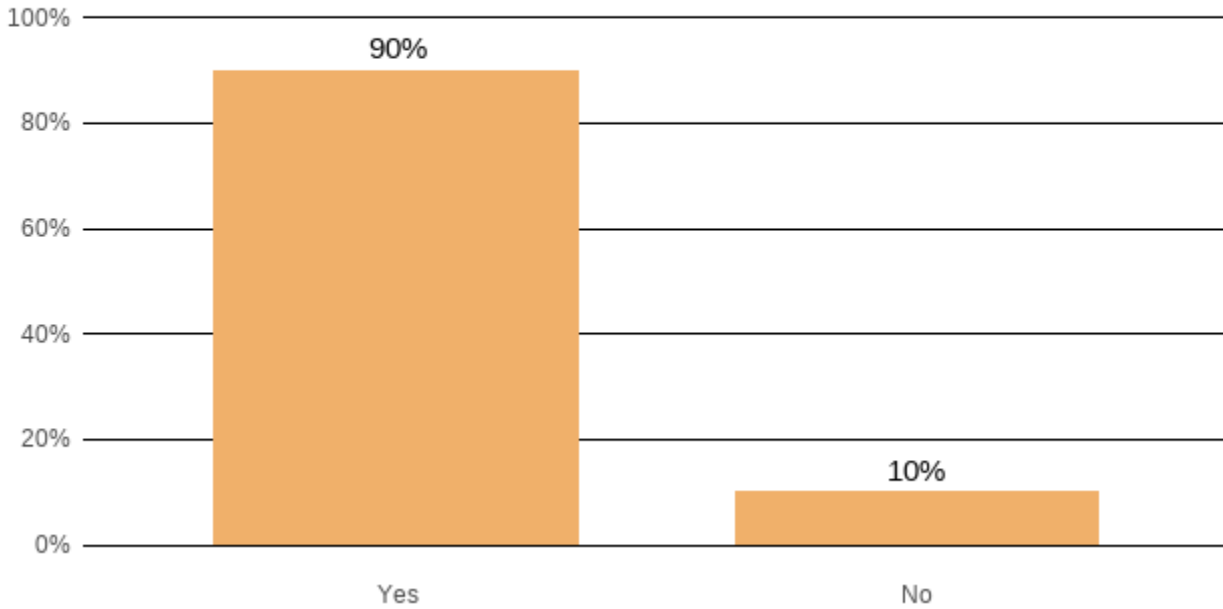


Table 64. Does your family member do things in the community?

State	Yes	No	N
AZ	88%	12%	218
MD	92%	8%	385
NJ	84%	16%	319
PA	91%	9%	264
Weighted NCI-IDD Average	90%	10%	1186

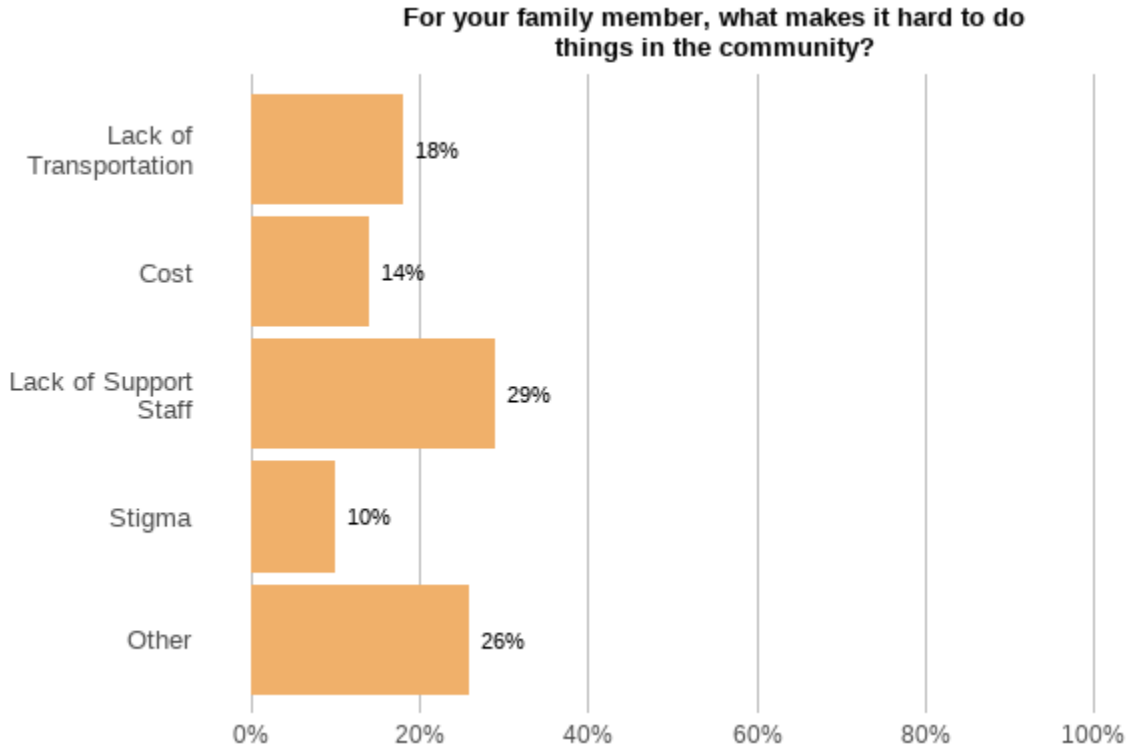


Table 65. For your family member, what makes it hard to do things in the community?

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

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
AZ	22%	17%	32%	11%	23%
MD	22%	16%	29%	9%	33%
NJ	18%	13%	30%	10%	25%
PA	16%	13%	28%	10%	24%
Weighted NCI-IDD Average	18%	14%	29%	10%	26%

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

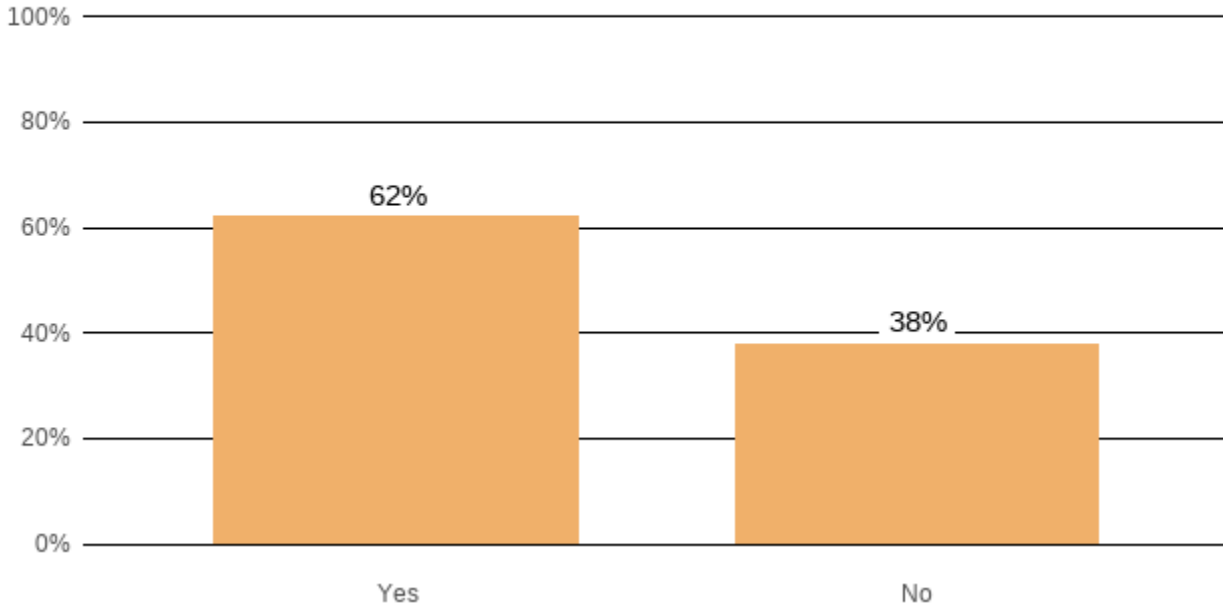


Table 66. Does your family member have friends other than paid support workers or family?

State	Yes	No	N
AZ	58%	42%	205
MD	60%	40%	379
NJ	58%	42%	310
PA	67%	33%	259
Weighted NCI-IDD Average	62%	38%	1153

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

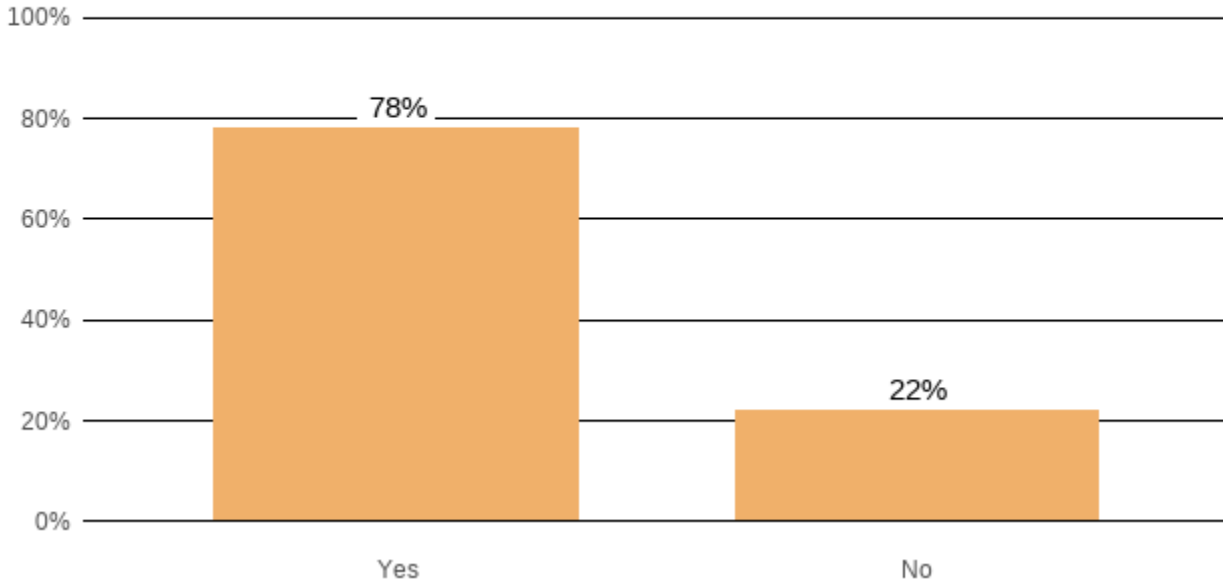


Table 67. In your community, are there resources or support that your family member can use that are not provided by the I/DD agency?

State	Yes	No	N
AZ	74%	26%	156
MD	83%	17%	288
NJ	66%	34%	232
PA	80%	20%	179
Weighted NCI-IDD Average	78%	22%	855

National Core Indicators-Intellectual and Developmental Disabilities
Does your family take part in any family-to-family networks in your community?

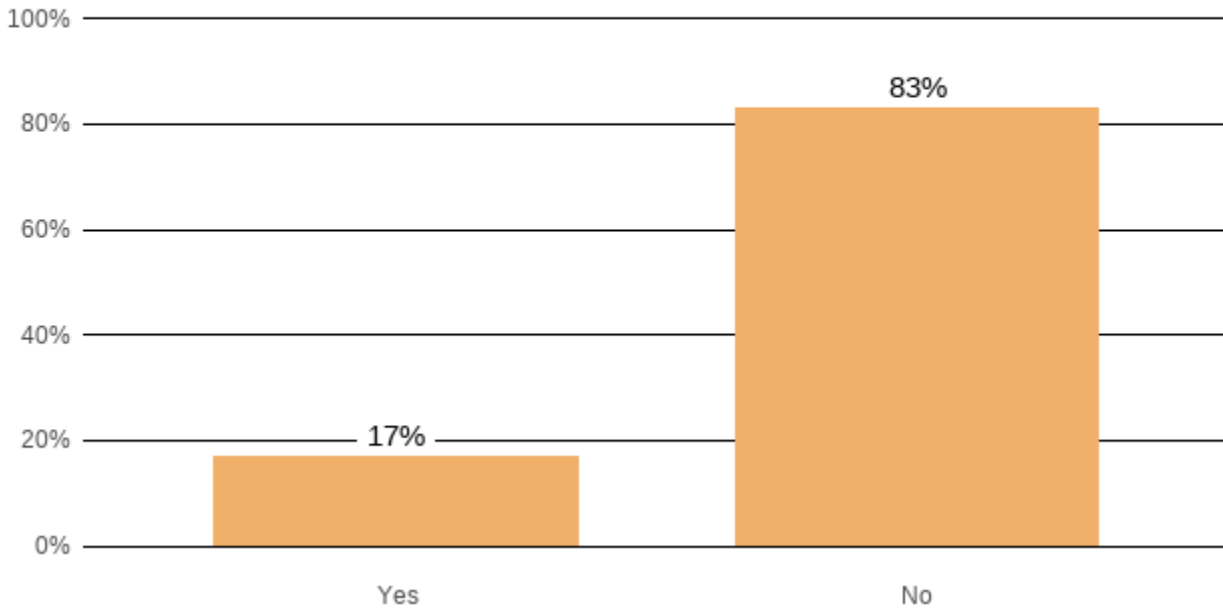


Table 68. Does your family take part in any family-to-family networks in your community?

State	Yes	No	N
AZ	10%	90%	194
MD	19%	81%	349
NJ	19%	81%	294
PA	17%	83%	224
Weighted NCI-IDD Average	17%	83%	1061

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 (doctor, registered nurse, etc.) when needed?

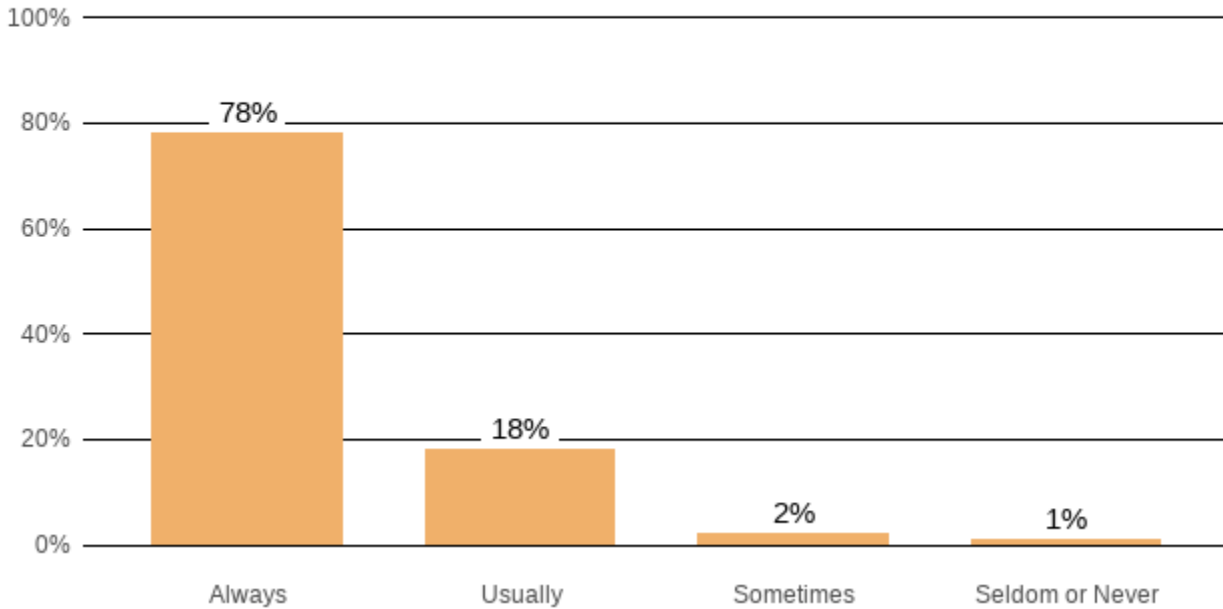


Table 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	73%	21%	4%	2%	216
MD	79%	19%	2%	1%	389
NJ	81%	17%	2%	1%	320
PA	79%	18%	1%	1%	271
Weighted NCI-IDD Average	78%	18%	2%	1%	1196

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

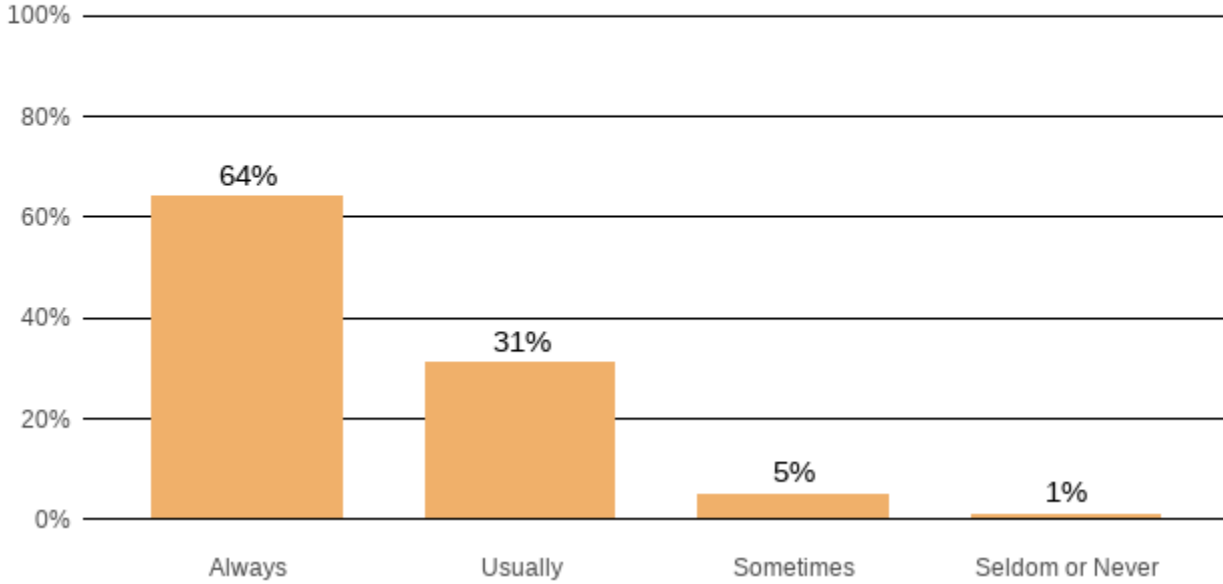


Table 70. Does your family member’s primary care provider (doctor, registered nurse, etc.) understand your family member’s needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	55%	36%	8%	1%	206
MD	59%	33%	7%	1%	368
NJ	64%	30%	4%	1%	312
PA	69%	28%	3%	0%	259
Weighted NCI-IDD Average	64%	31%	5%	1%	1145

Can your family member go to the dentist when needed?

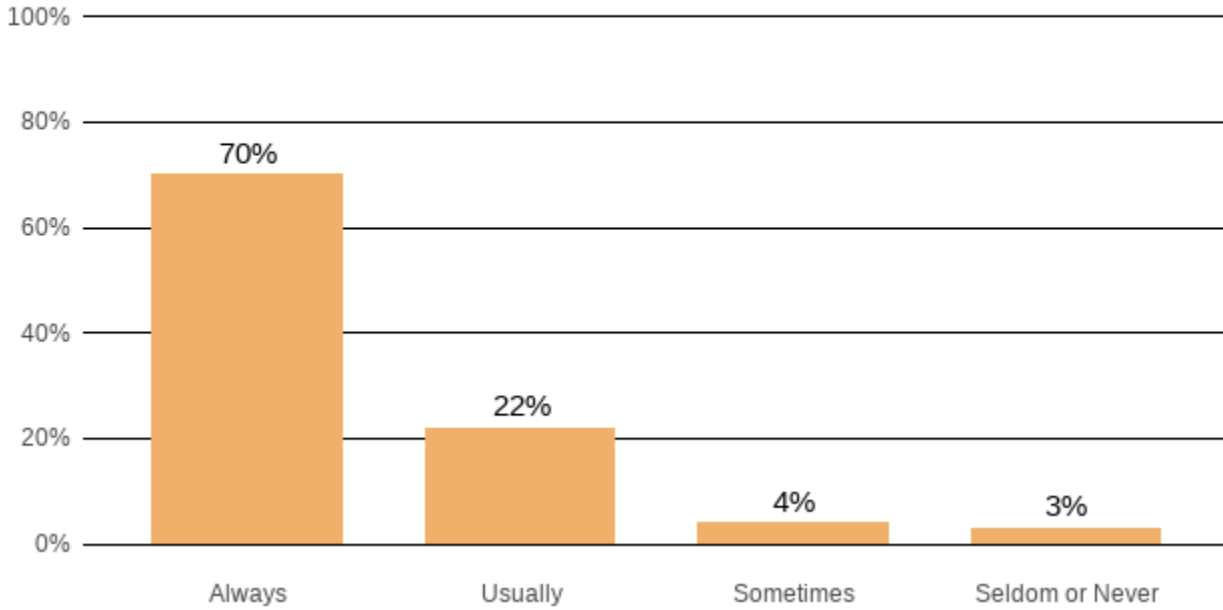


Table 71. Can your family member go to the dentist when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	59%	30%	5%	6%	217
MD	69%	23%	4%	3%	386
NJ	72%	20%	6%	2%	327
PA	73%	21%	4%	2%	273
Weighted NCI-IDD Average	70%	22%	4%	3%	1203

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

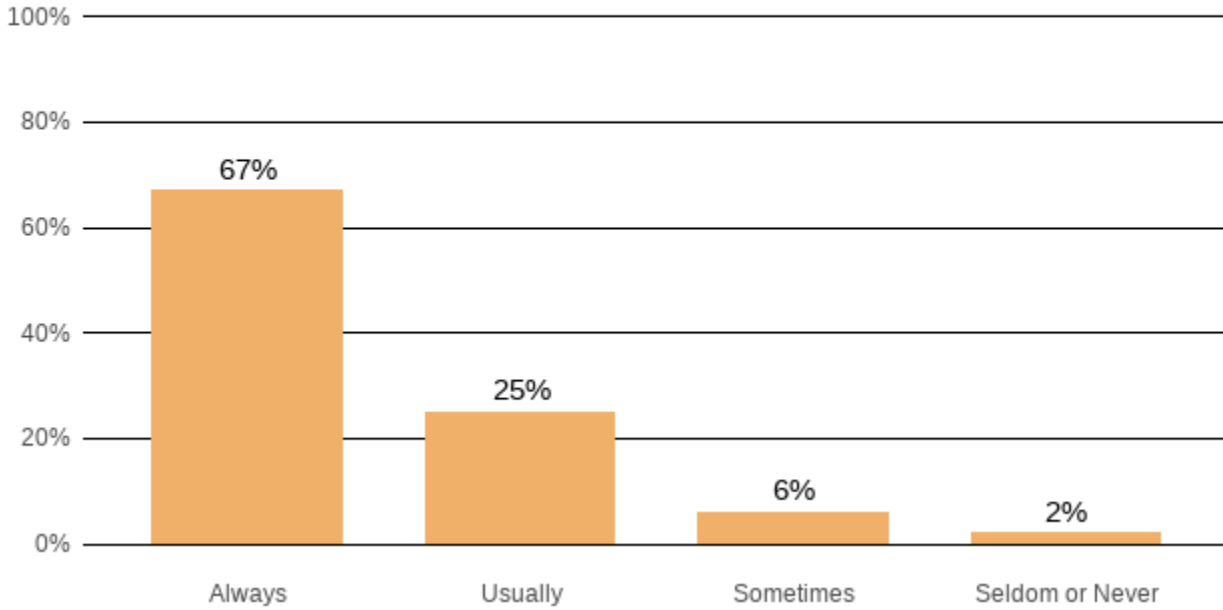


Table 72. Does your family member’s dentist understand your family member’s needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	58%	35%	5%	2%	187
MD	64%	24%	7%	4%	341
NJ	69%	24%	5%	2%	294
PA	70%	23%	7%	0%	233
Weighted NCI-IDD Average	67%	25%	6%	2%	1055

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

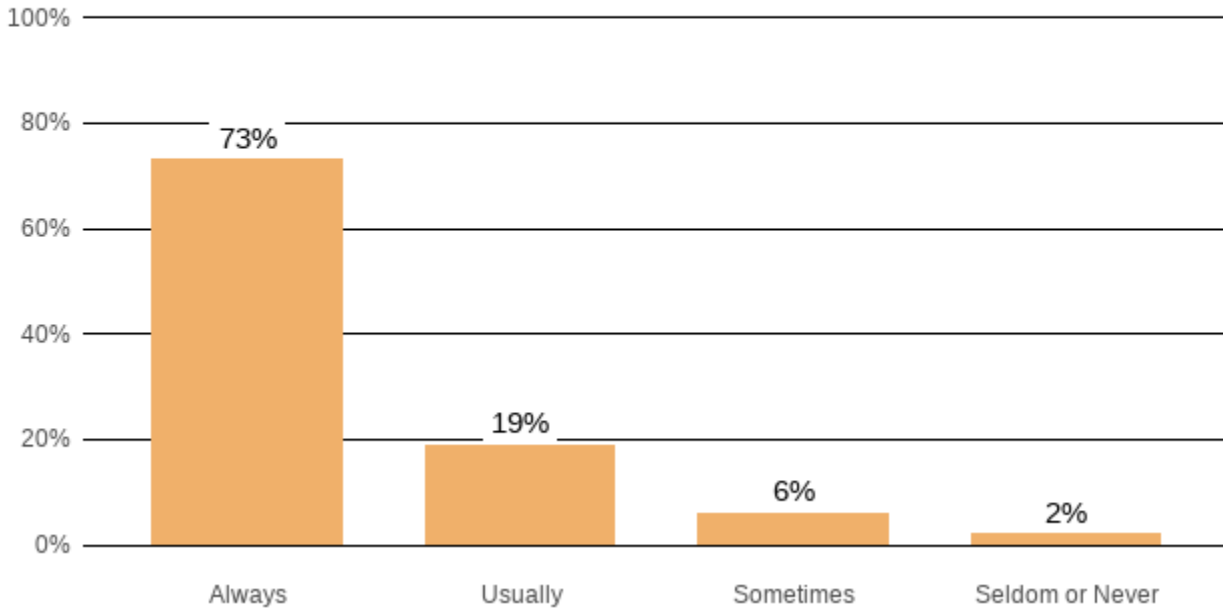


Table 73. If your family member takes prescription medications, do you know what they're for?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	78%	17%	4%	1%	207
MD	73%	20%	5%	2%	353
NJ	78%	16%	4%	2%	298
PA	69%	21%	7%	3%	251
Weighted NCI-IDD Average	73%	19%	6%	2%	1109

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)?

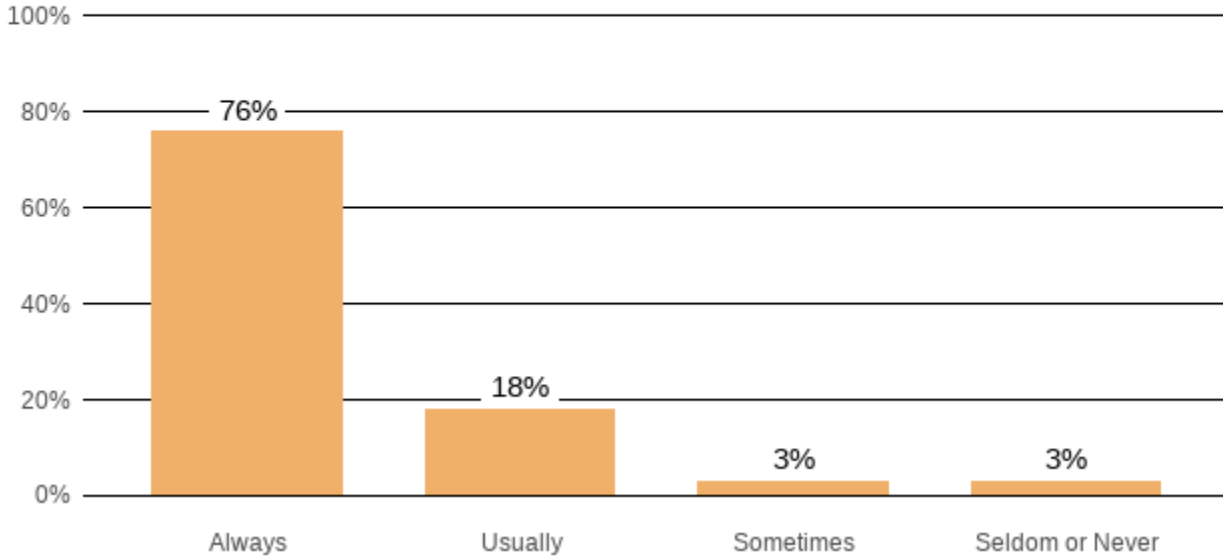


Table 74. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	76%	17%	4%	3%	201
MD	75%	18%	5%	2%	349
NJ	78%	17%	2%	2%	288
PA	76%	18%	3%	4%	242
Weighted NCI-IDD Average	76%	18%	3%	3%	1080

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

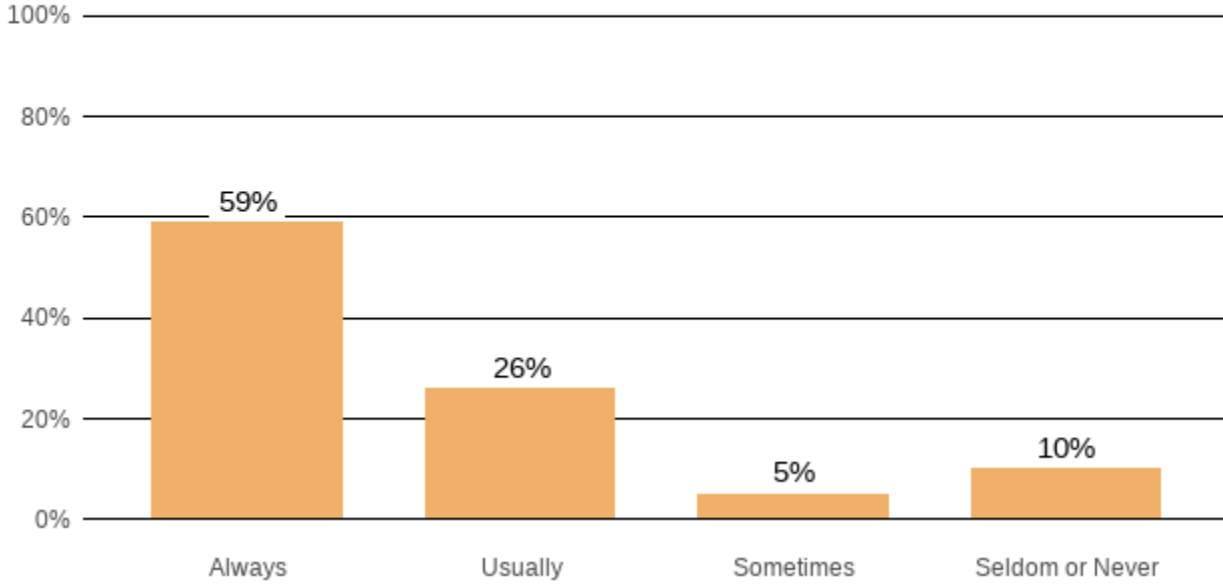


Table 75. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling.)

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	56%	26%	7%	12%	178
MD	55%	28%	8%	8%	323
NJ	50%	28%	9%	13%	286
PA	66%	24%	2%	9%	217
Weighted NCI-IDD Average	59%	26%	5%	10%	1004

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

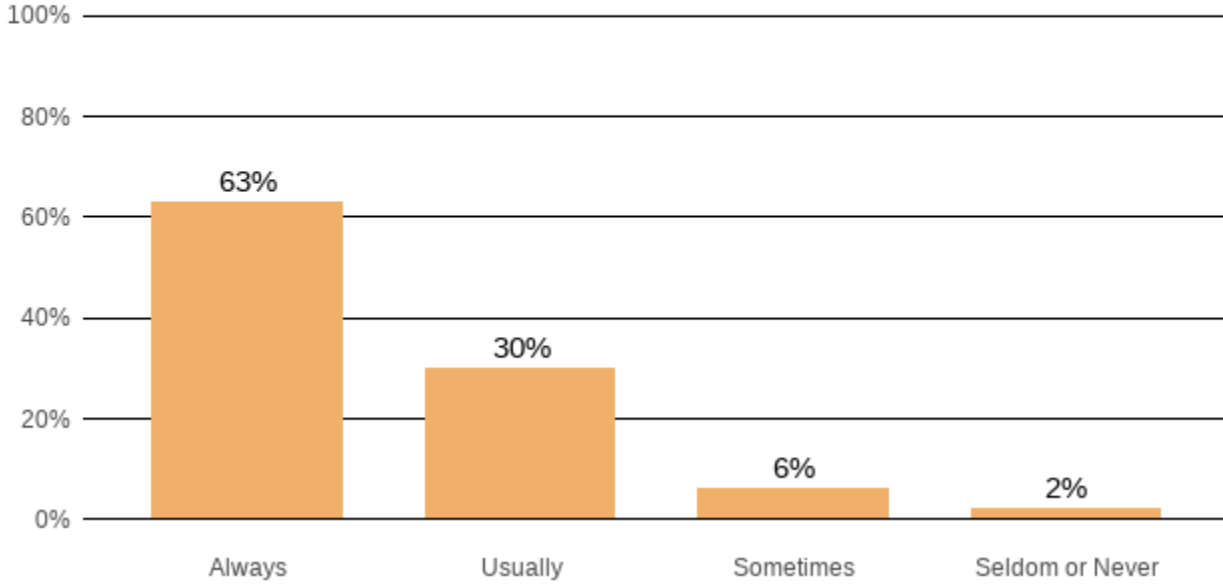


Table 76. Does your family member’s mental or behavioral health professional understand your family member’s needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	54%	36%	7%	3%	152
MD	54%	37%	8%	1%	272
NJ	54%	35%	7%	4%	237
PA	72%	23%	5%	1%	199
Weighted NCI-IDD Average	63%	30%	6%	2%	860

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

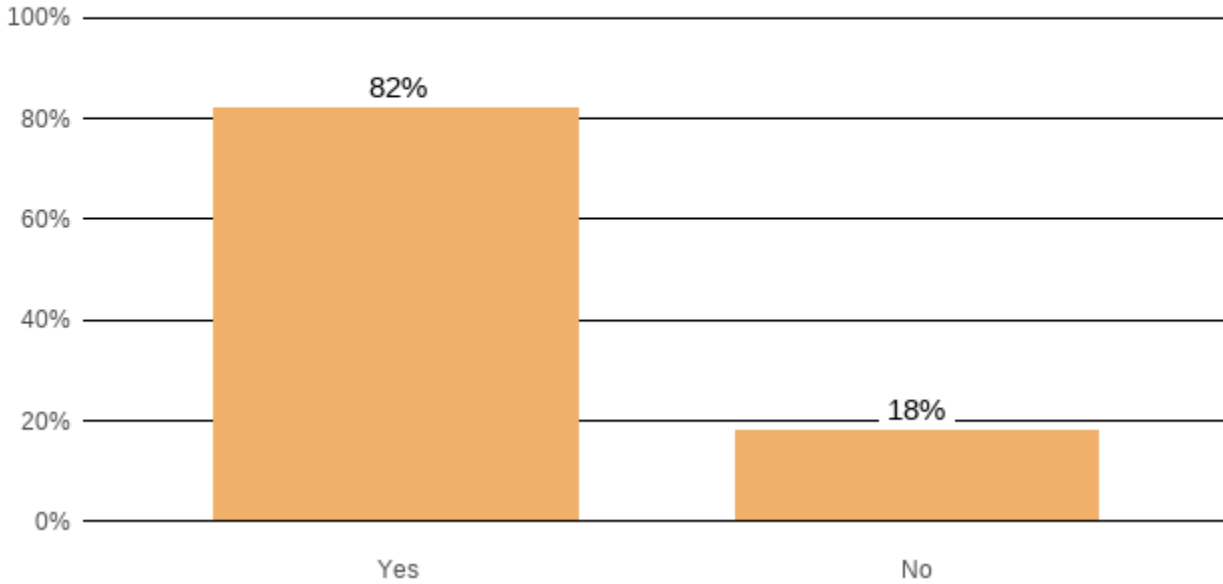


Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

State	Yes	No	N
AZ	81%	19%	68
MD	78%	22%	110
NJ	80%	20%	79
PA	85%	15%	72
Weighted NCI-IDD Average	82%	18%	329

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

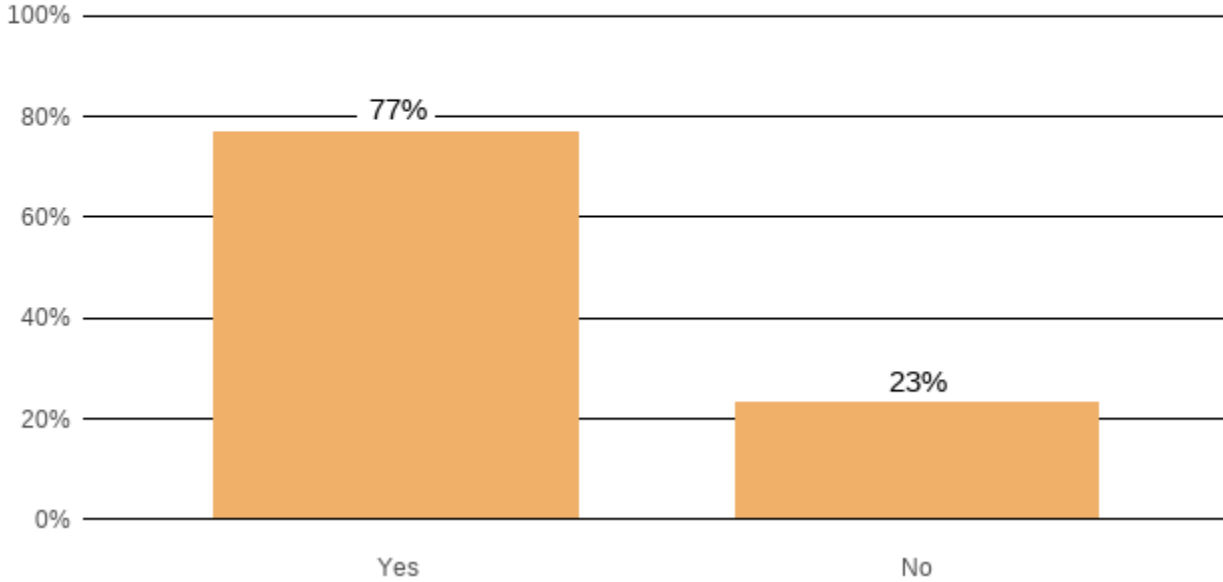


Table 78. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency, pandemic or natural disaster?

State	Yes	No	N
AZ	82%	18%	202
MD	73%	27%	328
NJ	78%	22%	288
PA	76%	24%	233
Weighted NCI-IDD Average	77%	23%	1051

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?

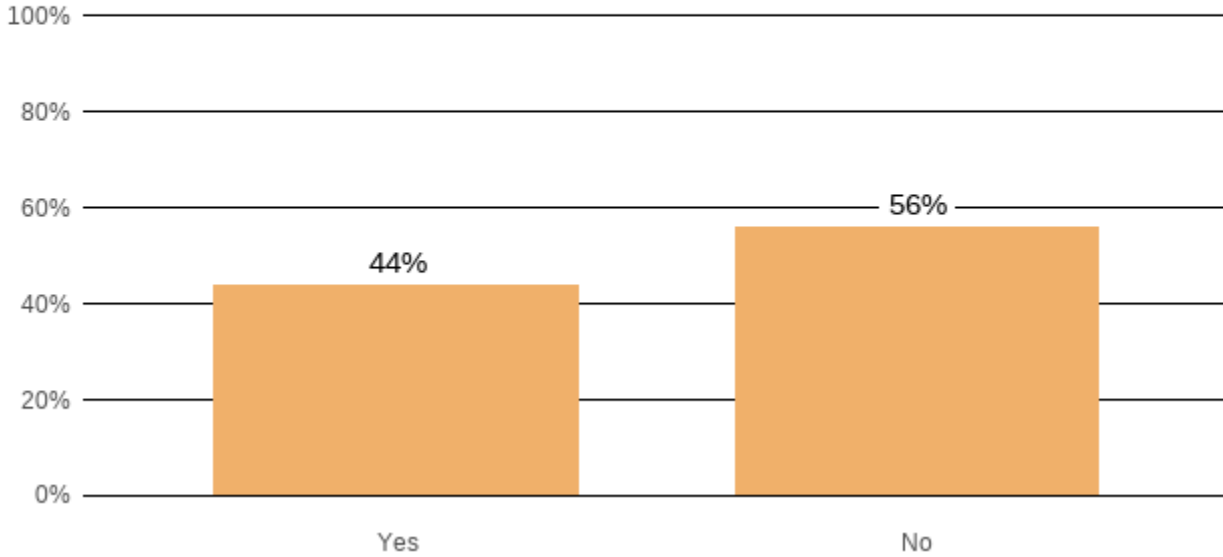


Table 79. Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member’s case manager or service coordinator?

State	Yes	No	N
AZ	44%	56%	211
MD	36%	64%	376
NJ	46%	54%	316
PA	47%	53%	260
Weighted NCI-IDD Average	44%	56%	1163

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

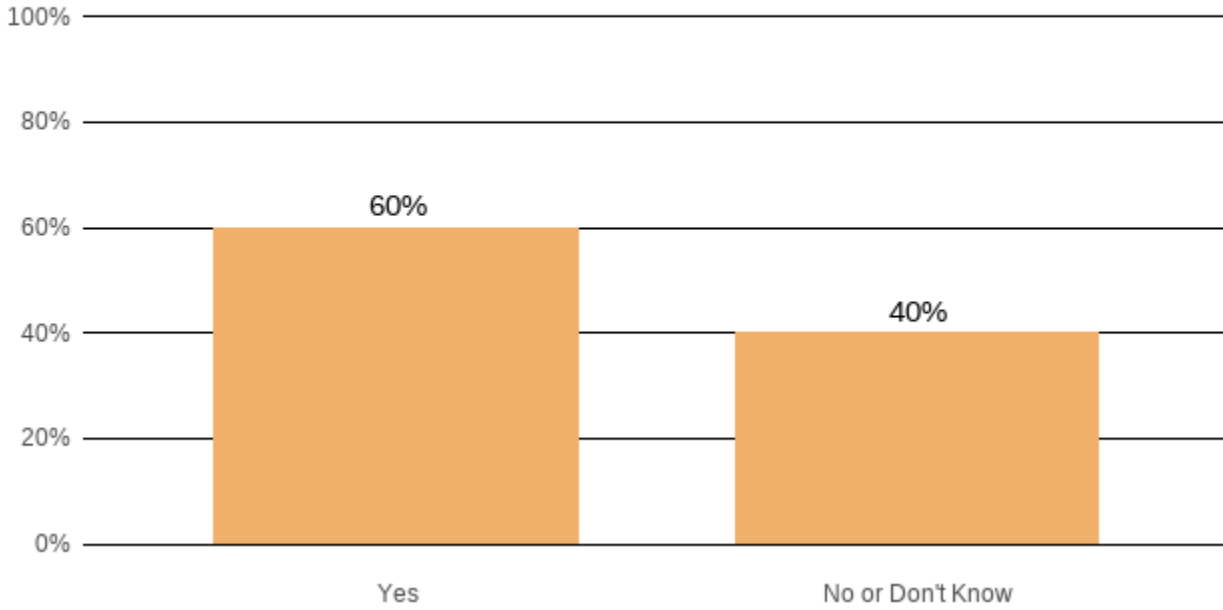


Table 80. Do you know how to file a complaint or grievance about provider agencies or staff?

State	Yes	No or Don't Know	N
AZ	59%	41%	218
MD	51%	49%	395
NJ	59%	41%	324
PA	66%	34%	276
Weighted NCI-IDD Average	60%	40%	1213

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

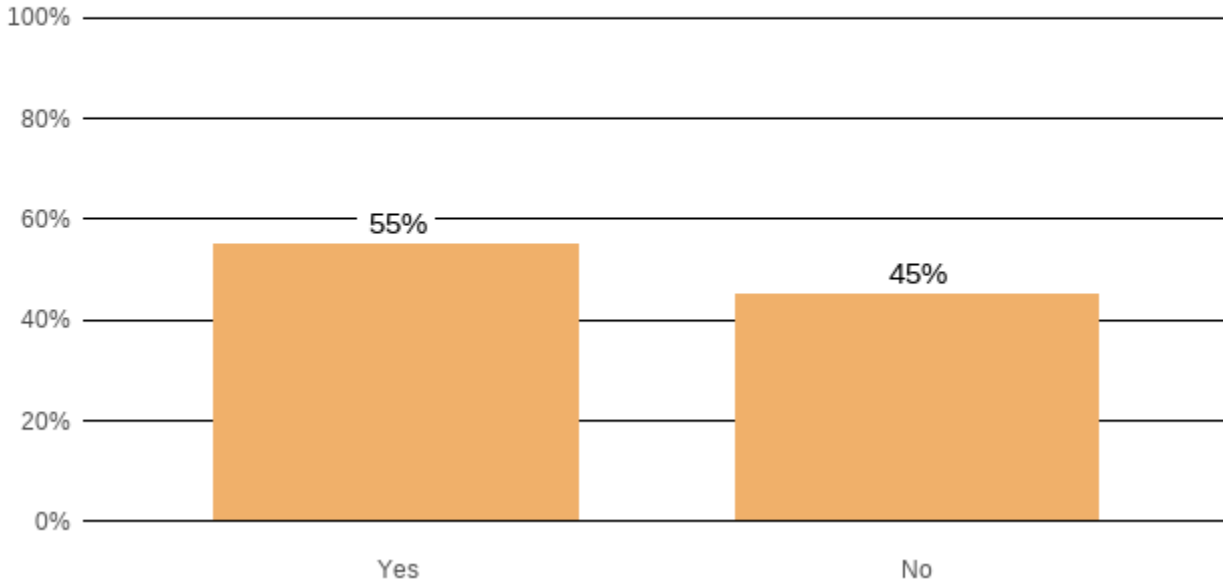


Table 81. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

State	Yes	No	N
AZ	48%	52%	42
MD	46%	54%	52
NJ	49%	51%	53
PA	65%	35%	34
Weighted NCI-IDD Average	55%	45%	181

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

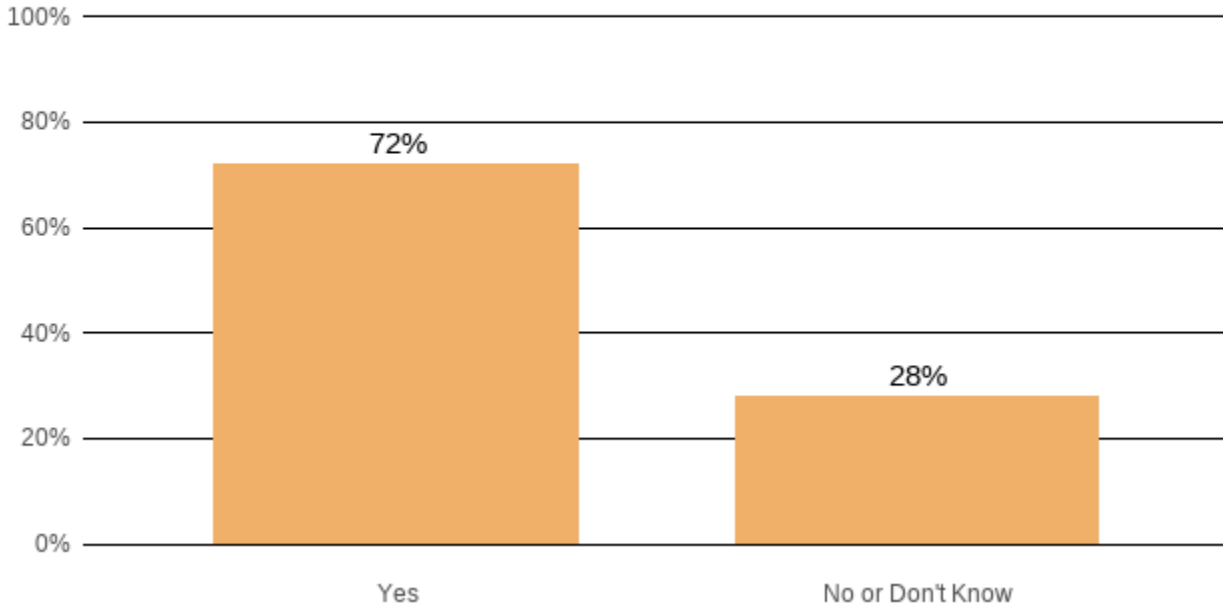


Table 82. Do you know how to report abuse or neglect related to your family member?

State	Yes	No or Don't Know	N
AZ	73%	27%	221
MD	63%	37%	391
NJ	69%	31%	331
PA	76%	24%	270
Weighted NCI-IDD Average	72%	28%	1213

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

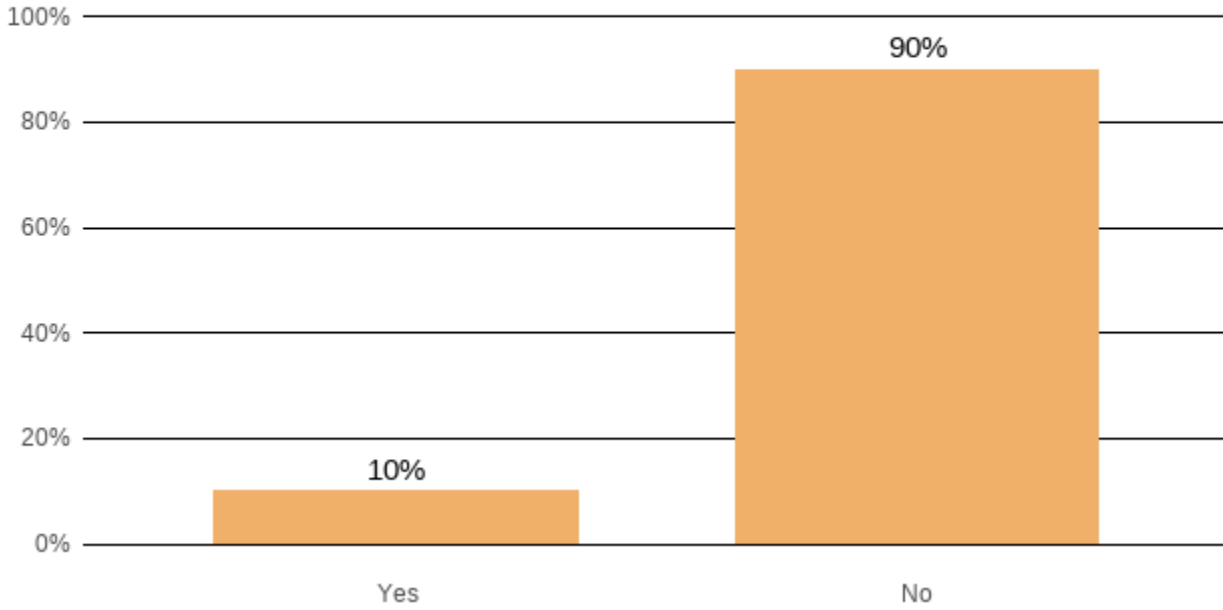


Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

State	Yes	No	N
AZ	12%	88%	213
MD	8%	92%	370
NJ	10%	90%	313
PA	11%	89%	257
Weighted NCI-IDD Average	10%	90%	1153

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

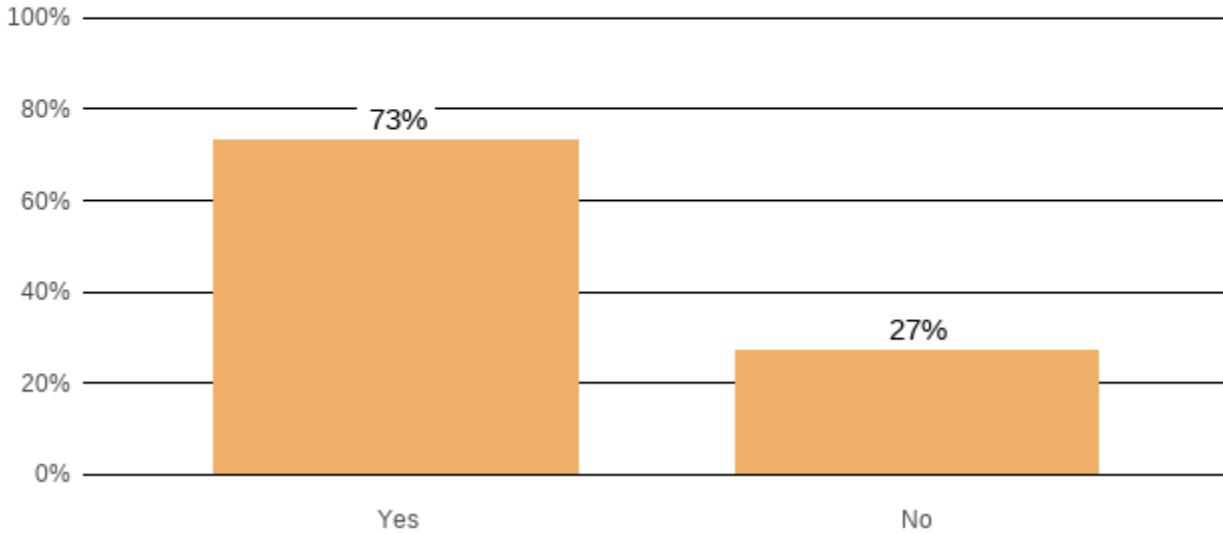


Table 84. If a report of abuse or neglect in the past 12 months was filed on behalf of a family member, or if someone other than you or another family member reported abuse or neglect in the 12 months, were you notified of the report in a timely manner?

State	Yes	No	N
AZ	n/a	n/a	n/a
MD	n/a	n/a	n/a
NJ	57%	43%	23
PA	81%	19%	21
Weighted NCI-IDD Average	73%	27%	82

Table note: The following states had an N of less than 20 so their data is reported as n/a: MD. They are included in the Weighted NCI-IDD Average.

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?

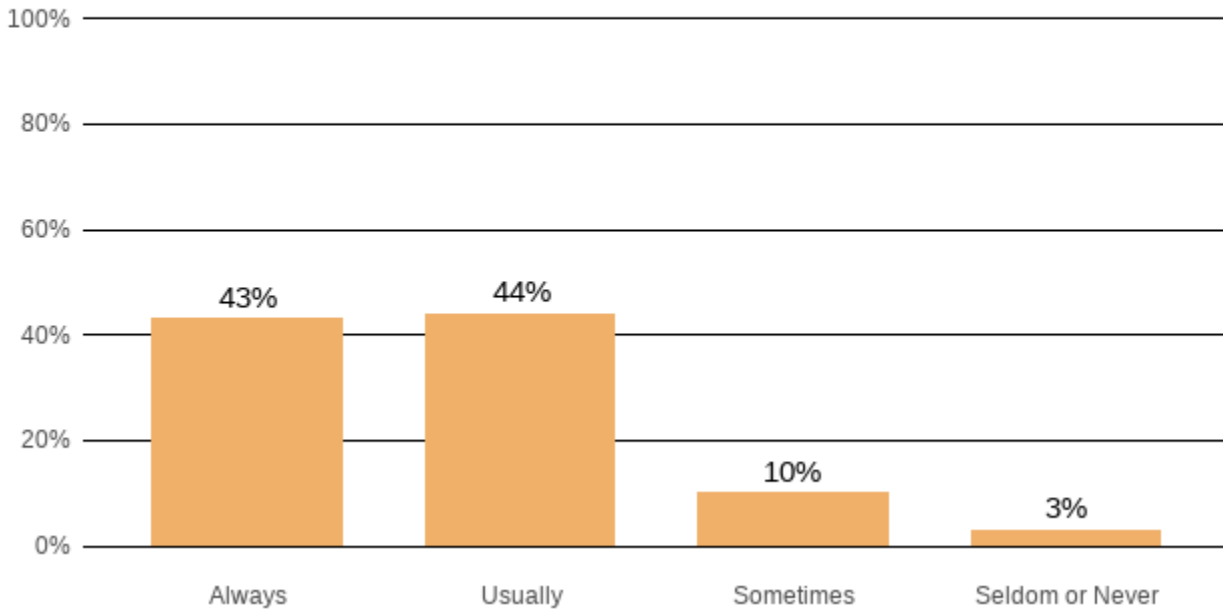


Table 85. Overall, are you satisfied with the services and supports your family member currently receives?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	42%	45%	11%	2%	222
MD	33%	53%	12%	2%	388
NJ	44%	42%	12%	2%	330
PA	48%	40%	8%	4%	273
Weighted NCI-IDD Average	43%	44%	10%	3%	1213

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

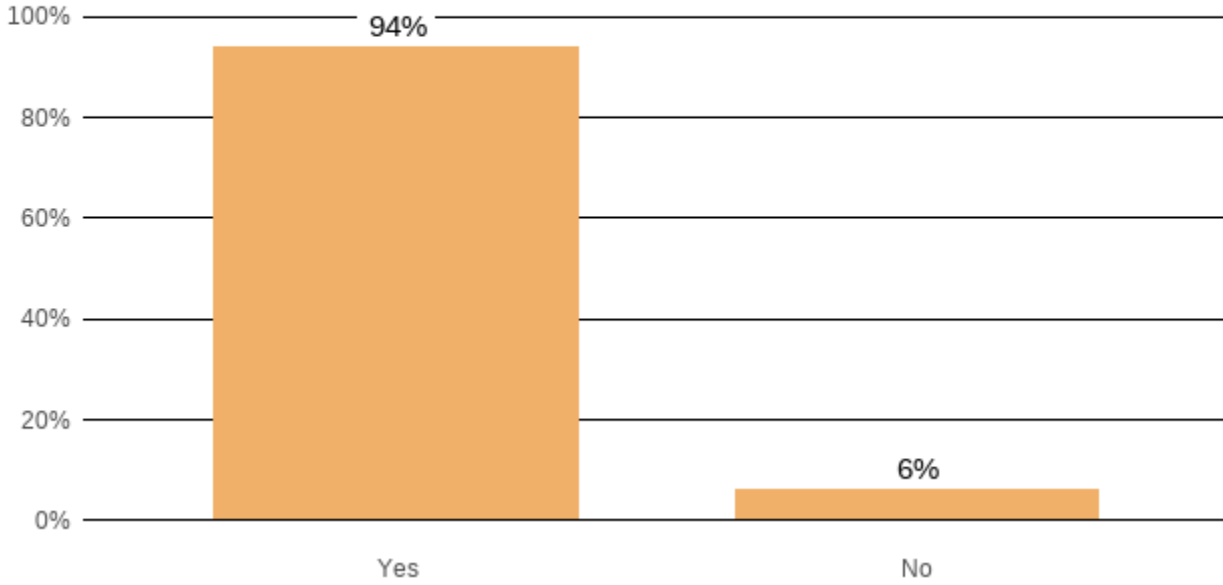


Table 86. Do you feel that services and supports have made a positive difference in the life of your family member?

State	Yes	No	N
AZ	93%	7%	210
MD	95%	5%	374
NJ	96%	4%	322
PA	94%	6%	265
Weighted NCI-IDD Average	94%	6%	1171

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

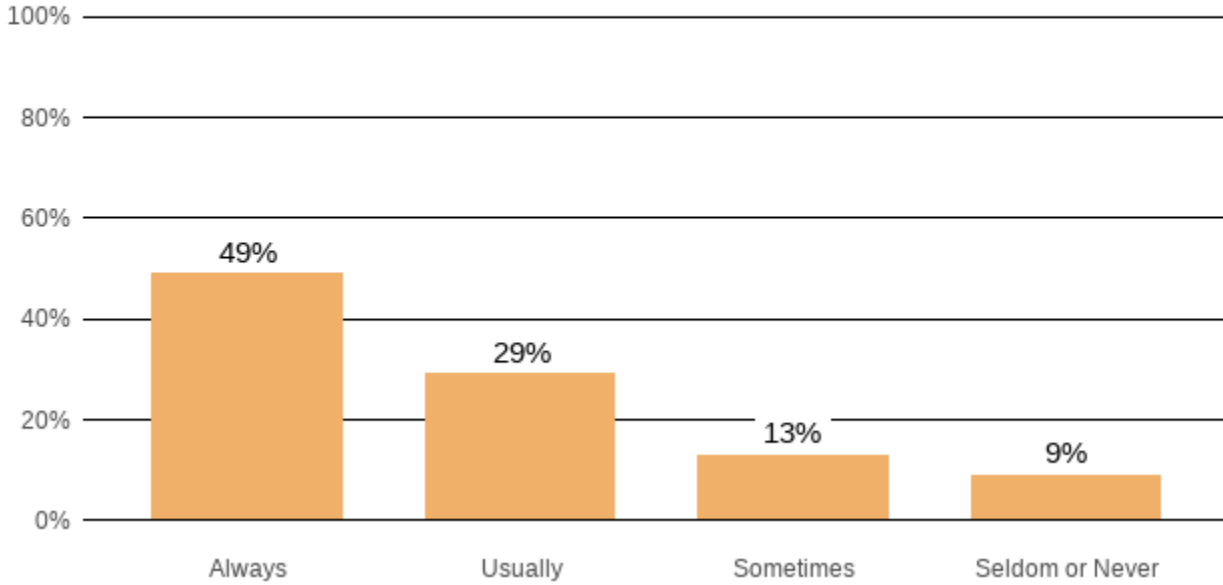


Table 87. Does the agency providing residential services to your family member involve them in important decisions?

State	Always	Usually	Sometimes	Seldom or Never	N
AZ	46%	29%	13%	12%	190
MD	48%	34%	10%	8%	325
NJ	46%	28%	15%	11%	273
PA	52%	28%	13%	7%	224
Weighted NCI-IDD Average	49%	29%	13%	9%	1012

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

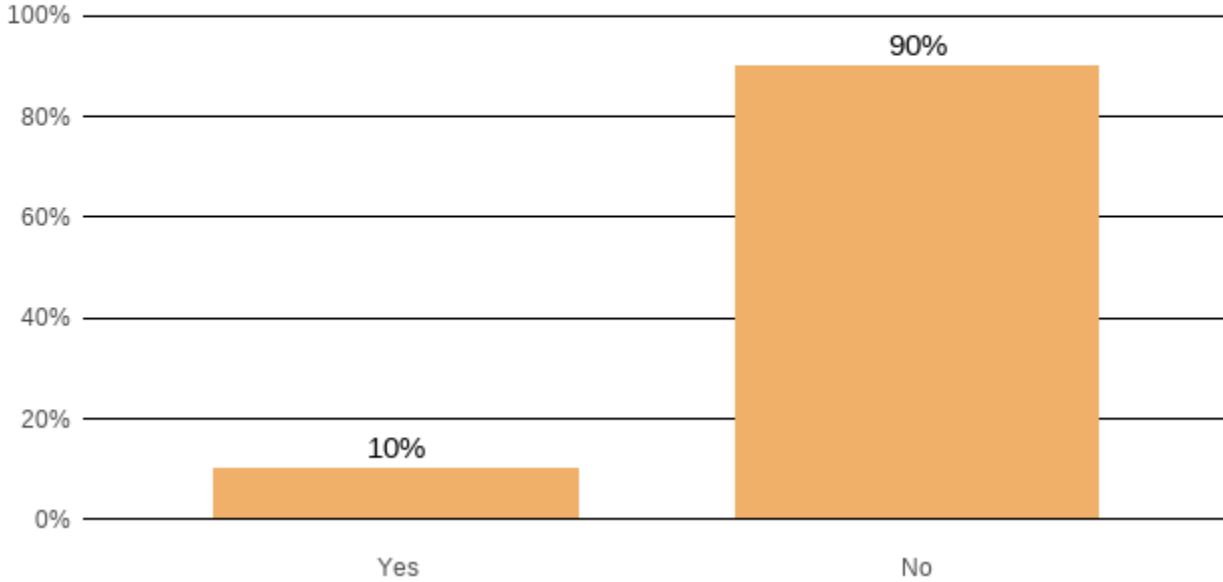


Table 88. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

State	Yes	No	N
AZ	10%	90%	212
MD	14%	86%	353
NJ	8%	92%	308
PA	9%	91%	245
Weighted NCI-IDD Average	10%	90%	1118

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?

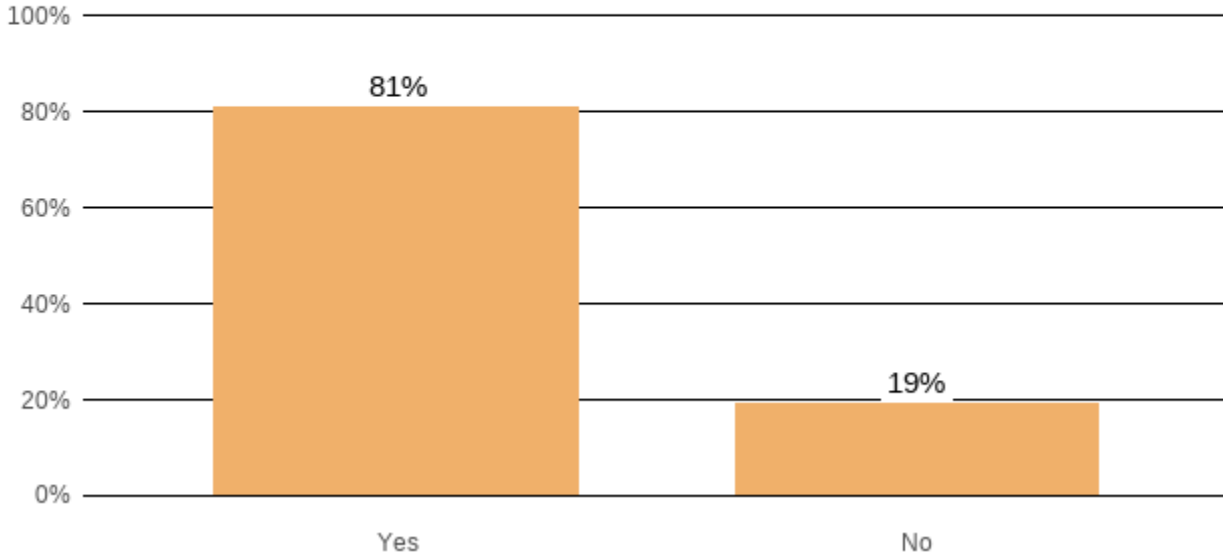


Table 89. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?

State	Yes	No	N
AZ	n/a	n/a	n/a
MD	92%	8%	38
NJ	n/a	n/a	n/a
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	81%	19%	91

Table note: The following states had an N of less than 20 so their data is reported as n/a: AZ, NJ, PA. They are included in the Weighted NCI-IDD Average.

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

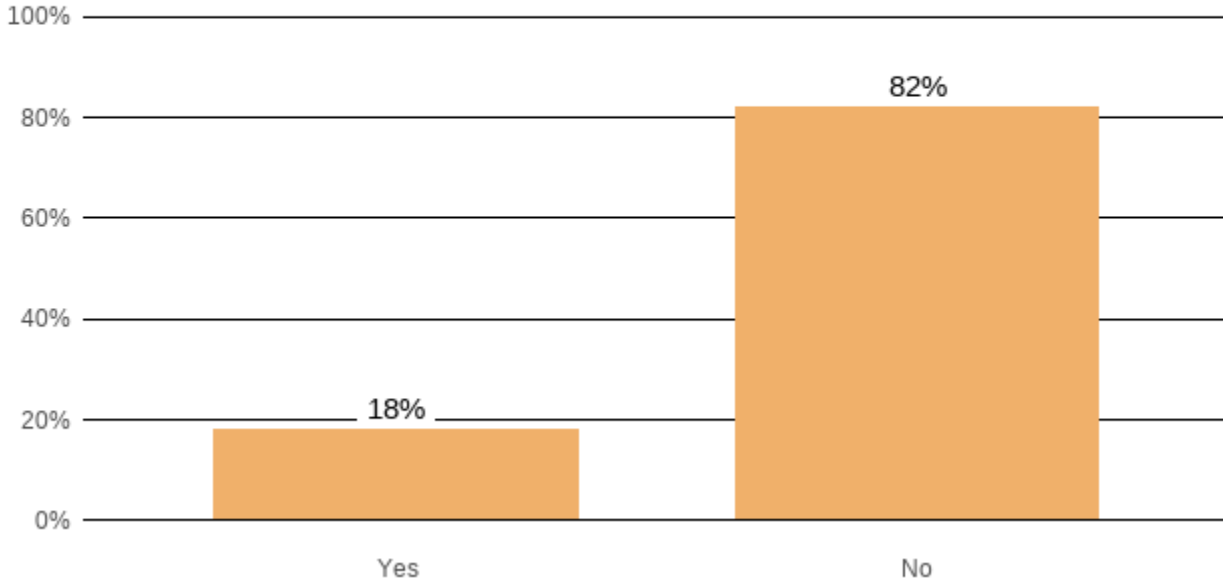


Table 90. Have the services or supports that your family member received been increased in the past 12 months?

State	Yes	No	N
AZ	12%	88%	191
MD	20%	80%	326
NJ	21%	79%	274
PA	18%	82%	218
Weighted NCI-IDD Average	18%	82%	1009

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

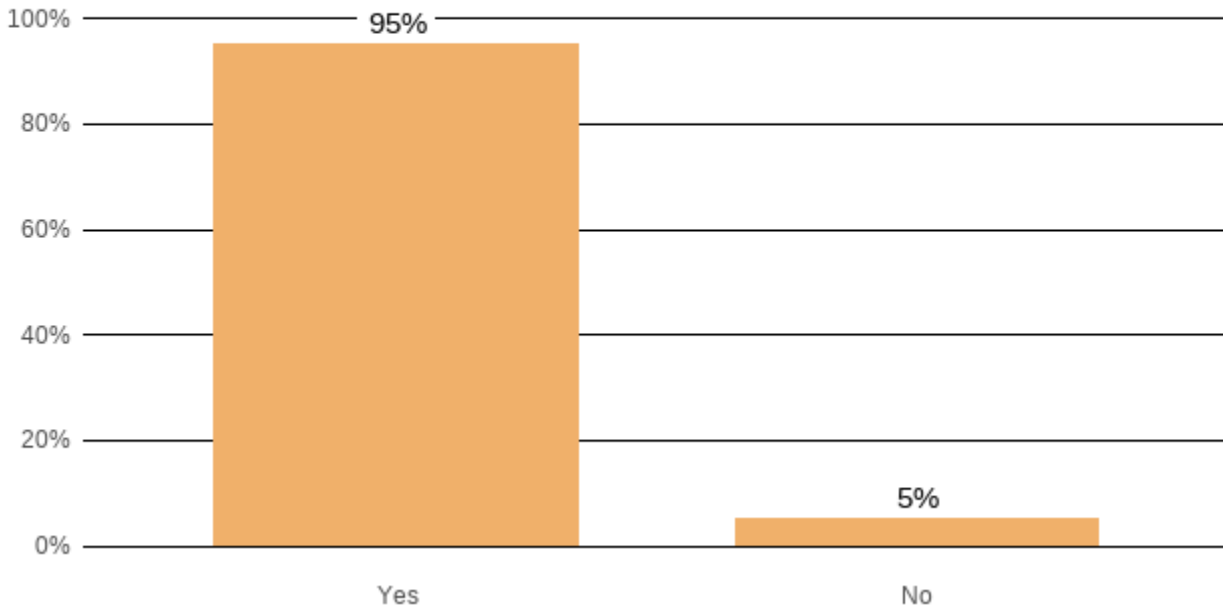


Table 91. Are services and supports helping your family member to live a good life?

State	Yes	No	N
AZ	96%	4%	201
MD	96%	4%	368
NJ	96%	4%	314
PA	95%	5%	254
Weighted NCI-IDD Average	95%	5%	1137

NCI History and Activities

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

Overview of National Core Indicators—Intellectual and Developmental Disabilities

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:

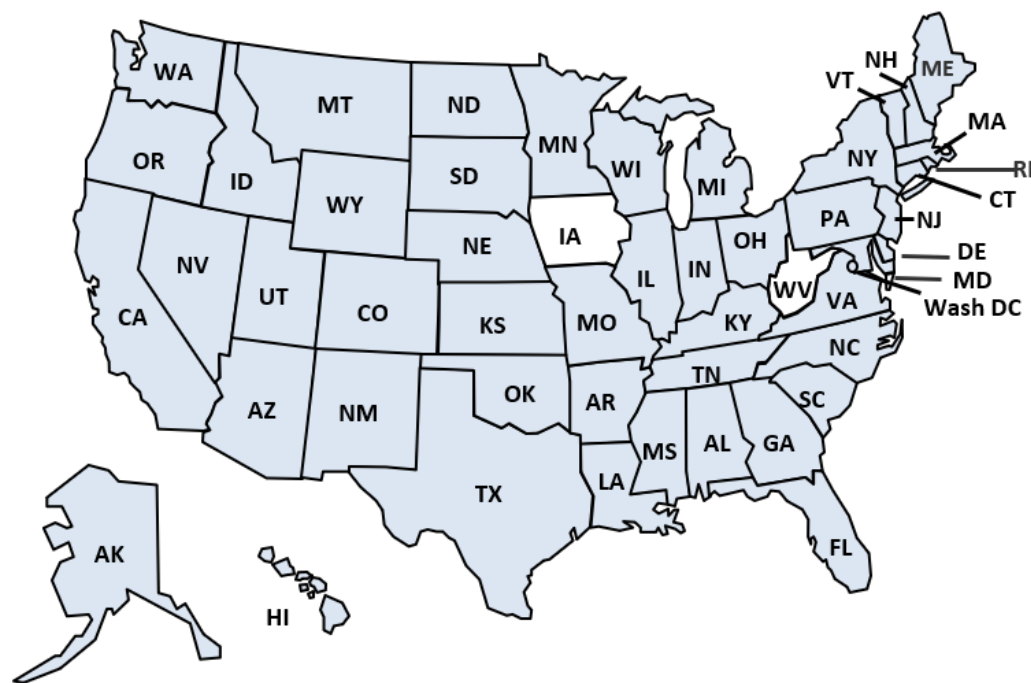
1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of intellectual/developmental disability or residential setting

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

During the 2024-25 data collection cycle, 48 states, the District of Columbia and 22 sub-state entities participated in NCI-IDD. 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 2024-25

The Core Indicators

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

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

The current set of performance indicators includes approximately 100 individual, 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; System Performance, Health, Wellness and Rights, and Family Experience. 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 Staff Stability 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-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 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	Value Statement
Information and Planning	Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state Developmental disabilities system.
Choice and Decision Making	Families and their family members receiving services and supports from the state Developmental disabilities system are involved in making choices about supports, services, and providers.
Access & Support Delivery	Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state Developmental disabilities system.
Workforce	There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.
Community Connections	Family members receiving services and supports from the state Developmental disabilities system are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.
Health, Welfare, and Safety	Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state Developmental disabilities system.
Family Satisfaction	Services and supports lead to better lives for people with disabilities and their families.

How NCI-IDD Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic

National Core Indicators-Intellectual and Developmental Disabilities planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI-IDD as a data source for supplemental performance measures in their home and community-based services (HCBS) waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

For more information on how to use these data for quality improvement, please see this handbook: [Using National Core Indicators for Quality Improvement Initiatives](#).¹

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.

Moreover, the Weighted 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 Weighted 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 staff to aggregate and analyze the data.

¹ Located on the National Core Indicators website: <https://www.nationalcoreindicators.org>

Sampling & Administration

States were asked to administer the Family/Guardian Survey by selecting a random sample of 2,000 families who:

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

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys. A total of 4 states (AZ, MD, NJ, PA) had at least a portion of surveys completed via direct entry for the 2024-25 data collection cycle.

A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%. Please see “Response Rates” for information on total surveys mailed and received by states as well as each state’s margin of error.

Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI-IDD reports, we use the “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 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 or regional center 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.

Response Rates

During 2024-25, 4 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 regional center sent, complete surveys, response rates, margins of error, and survey submission modes.

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

Figure 3. Family/Guardian Surveys Regional Center Response Rates

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
AZ	5135	1400	231	17%	5.9%	68%	32%
MD	7458	11944	420	4%	4.4%	29%	71%
NJ	6411	6411	366	6%	4.7%	1%	99%
PA	17118	2000	298	15%	5.2%	42%	58%
Total	36122	21755	1315	6%	2.5%	31%	69%