

Family/Guardian Survey

2012-13 Final Report



**NATIONAL CORE
INDICATORS**

A Collaboration of
the National Association of State Directors of
Developmental Disabilities Services
and the Human Services Research Institute



Human Services
Research Institute

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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 34 states and 22 sub-state entities who participated in NCI during the 2012-2013 data collection cycle, ten (10) states submitted a valid sample of Family/Guardian Survey data to be included in this report. This Final Report provides a summary of results based on data submitted by June 30, 2013.

The following are NCI national averages for a selection of survey items. Complete breakouts by state for each item in the Family/Guardian Survey can be found in the Results section of this report.

Demographics

- The average age of the adult receiving services was 45 years old, and males accounted for a higher percentage of respondents than females (58% versus 42%).
- Group homes were by far the most common residence type (56%), followed by independent living (13%) and specialized institutional facilities (13%).
- The most frequently indicated disability types were intellectual disability (80%), seizure disorder/neurological problem (25%), and mental illness or psychiatric diagnosis (20%); disability type categories are not mutually exclusive in the NCI surveys, and respondents can choose as many as apply.
- In terms of level of education achieved, 68% of the individuals receiving services had less than a high school diploma or GED while 28% had graduated high school or earned a GED.

- In terms of daily activities, 10% are involved in paid community employment. A little over one-quarter (28%) require a complete level of help for daily activities.

Services and Supports

- Among the services and supports specified in the survey, residential supports were the most utilized (93%), followed by transportation (91%) and social security benefits (90%).

Information and Planning

- Engagement in service planning among survey respondents (usually the parent or guardian of the adult receiving services) and the individuals themselves: 83% of respondents report that they helped develop their family member's service plan, and 65% report that their family member helped develop his or her own plan. Around half of all respondents report that they always receive enough information to help plan these services (48%) and that this information is always easy to understand (54%).
- The vast majority of respondents indicate that the service plan includes all the services and supports their family member wants (87%) and needs (85%).

Access and Delivery of Services and Supports

- More than three-fifths of all respondents report that they can always contact support workers (64%) and case managers/service coordinators (61%) when needed.
- Just over three-quarters of all respondents report that services are always delivered in a manner that is respectful to the family's culture (76%).
- Nearly three-quarters of respondents indicate that their family member's residential setting is always a healthy and safe environment (72%), and 72% say the same of their family member's day/employment setting.

Choice and Control

- Just over half of all respondents report that the residential service agency always involves the adult receiving services in important decisions (51%).
- Twenty-nine percent (29%) of respondents report that their family member always chooses his or her provider agencies; 17% report that their family member always chooses

the individual support workers; and 15% report that their family member chose his or her own case manager/service coordinator.

Community Connections

- The vast majority of respondents report that their family member participates in community activities (93%).
- Approximately three-quarters of respondents report that their family member has enough support to work or volunteer in the community (74%).

Satisfaction With Services and Supports

- A total of 91% of respondents are always or usually satisfied with the services and supports their family member receives.

Family Outcomes

- Nearly all respondents report that services and supports have made a positive difference in their family's life (97%). Most also indicate that services and supports have reduced the family's out-of-pocket expenses for their family member's care (88%).
- Of the 21% of respondents who report that services or supports were reduced, suspended or terminated in the past year, 67% felt that this change had a negative impact on their family member.

I. Results

This section briefly describes the structure of the survey instrument and presents the results of the most recent data collection cycle.

Survey Development

The Family/Guardian Survey was developed and first utilized in 1999-2000 in response to various states' interest in determining whether families were involved in the lives of their family member with a developmental disability (who did not live at home with them), whether these families had the support they needed to be involved, and whether they were satisfied with the service system that was intended to meet their family member's needs.

Many questions were drawn from survey instruments already in use in the field; others were developed specifically for NCI. NCI staff routinely refine the instrument based on feedback from families and state staff.

Most participating states use the basic survey tool developed by the project. However, some states opt to incorporate additional survey questions to look more deeply at specific issues. The addition of supplementary questions is typically done after a state participates in NCI for at least a year and establishes baseline results.

Organization of the Family/Guardian Survey

The Family/Guardian Survey is composed of the three sections described below. Additionally, at the end of the survey, respondents may write open-ended comments concerning their family's participation in the service system.

Demographics

The survey instrument begins with a series of questions relating to characteristics of the family member with a developmental disability (e.g., age, race, type of disability) followed by a series of demographic questions pertaining to the survey respondent (e.g., age, health status, relationship to the individual with the developmental disability).

Services and Supports Received

A brief section of the survey asks the respondent to identify the services and supports that they and/or their family member with a developmental disability receive.

Questions Regarding Services and Supports

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 five possible responses ("always," "usually," "sometimes," "seldom," or "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.

Presentation of Data

Direct feedback from families is an important means for states to gauge service and support satisfaction and to pinpoint areas for quality improvement. All demographic and individual outcome results from the Family/Guardian Survey are presented in this report. Outcome results are presented in six subsections that correspond with the sections of the Family/Guardian Survey. The beginning of each subsection provides an overall synopsis of findings across states.

For each question, outcome results are first shown in a graph with the NCI Average and then in a table that shows a breakout of each state's percentage.

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. 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 receive an 'n/a' designation for a survey item if fewer than 20 people responded.

The NCI Average is the average of all individual state percentages.

Note on Significance: in some cases, a state (let's call it state A) with a lower (or higher) proportion than another state (let's call it state B) may be significantly above (or below) the NCI Average even though the other state that is further away from the NCI Average is not. This may occur because statistical significance depends on both the difference between the average and the state's proportion and the sample size of the state. So, for example, when state A has a larger valid sample for the indicator than state B, state A may be significantly different from the average when state B is not, even though state B's difference from that average is larger than state A's. The

larger the sample size of a state, the smaller the difference needs to be to be statistically significant.

Demographics

Note:

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

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

Family Member

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

- The majority of family members live in a group home (56%), while equal percentages live independently and in specialized institutional facilities (13% each). Others were reported to live in: adult foster care (7%), an agency-owned apartment (5%), a nursing home (2%), or some other type of residence (4%).
- The average age of family members was 45 years old, and males accounted for a higher percentage than females (58% versus 42%).
- Most family members were identified as White (81%) or Black/African American (12%). Among the remainder: 1% were identified as American Indian or Alaska Native; 1% were identified as Asian; 2% were identified as being of two or more races; 3% were identified as Hispanic.
- The most frequently indicated disability types that family members were reported as having were:
 - 80% intellectual disability
 - 25% seizure disorder or neurological problem
 - 20% mental illness or psychiatric diagnosis
 - 17% autism spectrum disorder
 - 15% cerebral palsy
 - 15% another disability not listed
 - 11% brain injury
 - 9% Down syndrome
 - 9% limited or no vision
- 70% of family members were reported to communicate verbally, 23% communicate with gestures or body language, 2% use sign language or finger spelling, 1% use a communication aid or device, and 4% use some other form of communication.
- 97% of family members were reported as having English as their primary language.
- The highest level of education for family members was:
 - 68% less than high school diploma or GED
 - 28% high school diploma or GED
 - 2% completed vocational school
 - 1% some college experience
- The most typical day activities of family members were:
 - 40% unpaid, out-of-home program
 - 22% paid, out-of-home program

- 19% other, unlisted activities
 - 10% paid community employment
 - 9% in-home day supports
 - 8% vocational training
- 62% of family members received medical care less frequently than once a month.
- 22% of family members needed extensive behavioral support.
- 28% of family members needed a complete level of help for daily activities.

Table 1. Family Member's Residence

State	Specialized Facility for Individuals with ID	Group Home	Agency-Owned Apartment	Independent Home or Apartment	Adult Foster Care/ Host Family Home	Nursing Home	Other	N
AZ	6%	71%	2%	2%	15%	1%	2%	277
FL	8%	63%	2%	23%	2%	1%	2%	398
GA	9%	52%	4%	13%	17%	1%	4%	370
KY	12%	52%	8%	8%	12%	2%	7%	302
MD	5%	62%	7%	18%	1%	0%	6%	234
NC	43%	42%	1%	1%	8%	1%	5%	171
OH	10%	48%	7%	26%	2%	4%	3%	399
PA	17%	55%	3%	12%	3%	5%	5%	372
SC	22%	61%	5%	4%	1%	0%	6%	230
UT	2%	57%	11%	21%	6%	0%	3%	357
NCI Average	13%	56%	5%	13%	7%	2%	4%	3,110

Table 2. Family Member's Age

State	Age	N
AZ	45	266
FL	43	403
GA	45	362
KY	46	309
MD	42	240
NC	48	166
OH	44	399
PA	49	380
SC	49	209
UT	42	368
NCI Average	45	3,102

Table 3. Family Member's Gender

State	Male	Female	N
AZ	58%	42%	277
FL	57%	43%	403
GA	60%	40%	365
KY	58%	42%	306
MD	61%	39%	241
NC	56%	44%	171
OH	57%	43%	398
PA	59%	41%	377
SC	59%	41%	228
UT	59%	41%	376
NCI Average	58%	42%	3,142

Table 4. Family Member's Race

State	American Indian/ Alaska Native	Asian	Black/ African-American	Hawaiian/ Pacific Islander	White	Other/ Unknown	Two or More Races	Hispanic/ Latino
AZ	5%	0%	3%	0%	76%	1%	4%	15%
FL	1%	1%	14%	0%	77%	1%	2%	5%
GA	0%	0%	23%	1%	74%	0%	1%	1%
KY	1%	0%	5%	0%	92%	0%	1%	0%
MD	1%	3%	20%	0%	74%	0%	1%	1%
NC	1%	1%	18%	0%	80%	0%	2%	0%
OH	0%	0%	10%	0%	88%	1%	1%	1%
PA	1%	1%	2%	0%	95%	0%	1%	0%
SC	0%	0%	26%	1%	66%	6%	0%	1%
UT	3%	2%	1%	1%	91%	1%	3%	2%
NCI Average	1%	1%	12%	0%	81%	1%	2%	3%

Table 5. Family Member's Type of Disability

State	AZ	FL	GA	KY	MD	NC	OH	PA	SC	UT	NCI Average
Intellectual Disability	82%	80%	85%	85%	62%	89%	71%	89%	78%	78%	80%
Mental Illness/ Psychiatric Diagnosis	20%	22%	19%	22%	23%	21%	26%	3%	19%	22%	20%
Autism Spectrum Disorder	15%	21%	20%	18%	25%	22%	14%	1%	14%	23%	17%
Cerebral Palsy	20%	15%	14%	19%	18%	14%	16%	3%	12%	18%	15%
Brain Injury	8%	12%	8%	12%	14%	13%	12%	0%	11%	15%	11%
Seizure/Neurological Disorder	29%	25%	29%	34%	27%	35%	17%	2%	22%	30%	25%
Chemical Dependency	1%	1%	1%	0%	1%	0%	1%	0%	1%	0%	1%
Limited or No Vision	8%	10%	11%	8%	9%	13%	7%	0%	10%	10%	9%
Severe or Profound Hearing Loss	4%	4%	4%	6%	3%	6%	4%	0%	8%	5%	4%
Alzheimer's Disease/ Other Dementia	2%	3%	1%	2%	1%	3%	2%	0%	1%	1%	2%
Down Syndrome	12%	14%	12%	10%	12%	5%	8%	2%	11%	7%	9%
Prader-Willi Syndrome	0%	2%	2%	1%	1%	0%	1%	0%	0%	2%	1%
Other Disability	17%	17%	16%	14%	18%	13%	15%	0%	13%	26%	15%
Don't Know	2%	2%	3%	2%	3%	5%	3%	2%	9%	2%	3%

Table 6. Family Member's Primary Means of Expression

State	Spoken	Gestures/Body Language	Sign Language/ Finger Spelling	Communication Aid/Device	Other	N
AZ	63%	27%	4%	3%	5%	279
FL	71%	24%	1%	1%	3%	386
GA	62%	28%	2%	0%	7%	373
KY	71%	25%	0%	1%	3%	306
MD	74%	21%	1%	1%	3%	234
NC	58%	35%	0%	1%	6%	173
OH	80%	14%	3%	1%	2%	396
PA	69%	25%	1%	1%	3%	367
SC	80%	15%	2%	1%	2%	234
UT	76%	19%	2%	1%	2%	357
NCI Average	70%	23%	2%	1%	4%	3,105

Table 7. Family Member's Primary Language

State	English	Spanish	Other	N
AZ	92%	4%	4%	272
FL	96%	2%	2%	400
GA	97%	1%	2%	368
KY	99%	0%	1%	295
MD	97%	0%	2%	234
NC	97%	0%	3%	168
OH	98%	0%	2%	398
PA	98%	0%	2%	366
SC	100%	0%	0%	232
UT	97%	1%	2%	374
NCI Average	97%	1%	2%	3,107

Table 8. Family Member's Highest Level of Education

State	Does Not Have High School Diploma/GED	High School Diploma/GED	Vocational School	Some College	College Degree	N
AZ	68%	27%	4%	1%	0%	261
FL	68%	29%	3%	0%	0%	369
GA	68%	32%	0%	0%	0%	334
KY ¹	84%	16%	0%	0%	0%	229
MD	62%	30%	3%	3%	2%	226
NC	75%	19%	7%	0%	0%	150
OH	47%	51%	1%	1%	0%	399
PA	67%	32%	1%	0%	0%	342
SC	81%	16%	2%	0%	0%	213
UT	64%	33%	1%	2%	1%	356
NCI Average	68%	28%	2%	1%	0%	2,879

¹ KY added an additional response category 'high school certificate' to this question. Those who were indicated as having a high school certificate were excluded from these analyses to align with the national data analysis.

Table 9. Family Member’s Typical Day Activity

State	Out-of-Home Program (Unpaid)	Out-of-Home Program (Paid)	Vocational Training	Community Employment (Unpaid)	Community Employment (Paid)	In-Home Day Supports	At Home by Choice	At Home, No Services	At Home, Other	Other
AZ	57%	11%	9%	3%	8%	9%	3%	2%	1%	14%
FL	44%	11%	8%	4%	6%	18%	6%	5%	5%	25%
GA	52%	14%	5%	3%	6%	13%	3%	2%	4%	21%
KY	60%	13%	6%	4%	10%	7%	3%	1%	3%	14%
MD	39%	24%	11%	5%	17%	9%	3%	2%	1%	13%
NC	24%	35%	13%	7%	8%	11%	1%	1%	3%	31%
OH	20%	53%	3%	2%	19%	3%	7%	1%	4%	5%
PA	36%	15%	4%	2%	8%	5%	4%	1%	2%	22%
SC	27%	26%	13%	4%	5%	4%	2%	2%	2%	30%
UT	39%	20%	8%	6%	17%	12%	5%	1%	3%	13%
NCI Average	40%	22%	8%	4%	10%	9%	4%	2%	3%	19%

Table 10. Frequency of Medical Care Needed for Family Member

State	Less Frequently Than Once/Month	At Least Once/Month, but Not Once/Week	At Least Once/Week, or More Frequently	N
AZ	71%	21%	8%	272
FL	63%	25%	12%	398
GA	65%	24%	11%	358
KY	65%	27%	9%	302
MD	60%	29%	11%	221
NC	53%	22%	25%	165
OH	58%	30%	12%	399
PA	59%	25%	16%	340
SC	62%	28%	11%	225
UT	67%	24%	9%	361
NCI Average	62%	25%	12%	3,041

Table 11. Amount of Behavioral Support Needed for Family Member

State	No Support Needed	Some Support Needed	Extensive Support Needed	N
AZ	43%	36%	21%	279
FL	29%	41%	30%	393
GA	35%	41%	24%	364
KY	30%	48%	22%	301
MD	42%	37%	21%	235
NC	26%	49%	25%	169
OH	61%	30%	9%	399
PA	39%	41%	20%	366
SC	45%	40%	15%	229
UT	30%	41%	29%	373
NCI Average	38%	40%	22%	3,108

Table 12. Amount of Help Needed for Family Member's Daily Activities

State	None	Little	Moderate	Complete	N
AZ	14%	22%	34%	30%	278
FL	15%	19%	38%	28%	397
GA	15%	19%	32%	34%	380
KY	13%	24%	33%	31%	310
MD	24%	22%	25%	29%	238
NC	9%	19%	34%	38%	172
OH	36%	20%	24%	21%	399
PA	21%	18%	30%	31%	368
SC	29%	23%	30%	17%	233
UT	22%	24%	31%	23%	373
NCI Average	20%	21%	31%	28%	3,148

Respondents

This section provides demographic information about the respondent.

- 2% of respondents were under age 35; 20% were aged 35-54; 59% were 55-74; and 19% were 75 or older.
- 56% of respondents are the parent of the individual receiving services; 25% are a sibling; and 18% have some other relationship.
- 58% of respondents reported that they had full guardianship/conservatorship of the family member; 11% had limited guardianship/conservatorship.
- Respondents reported seeing the family member:
 - 4% less than once a year
 - 8% 1-3 times a year
 - 12% 4-6 times a year
 - 13% 7-12 times a year
 - 63% more than 12 times a year
- The respondent's highest level of education was:
 - 7% less than a high school diploma or GED
 - 25% high school diploma or GED
 - 4% had gone to vocational school
 - 24% some college
 - 39% had a college degree
- Total taxable family income for the past year was:
 - 19% below \$15,000
 - 19% between \$15,001-\$25,000
 - 27% between \$25,001-\$50,000
 - 17% between \$50,001-\$75,000
 - 16% over \$75,000
- Out-of-pocket expenses for the family member in the past year was:
 - 55% spent \$0
 - 11% spent \$1-\$100
 - 21% spent \$101-\$1,000
 - 13% spent \$1,001-\$10,000
 - 1% spent over \$10,000

Table 13. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
AZ	3%	23%	58%	16%	261
FL	2%	20%	59%	19%	402
GA	2%	21%	58%	19%	381
KY	1%	24%	59%	16%	309
MD	0%	14%	62%	24%	240
NC	1%	19%	65%	15%	170
OH	3%	27%	56%	14%	392
PA	3%	13%	64%	20%	375
SC	1%	15%	58%	26%	225
UT	4%	24%	54%	18%	370
NCI Average	2%	20%	59%	19%	3,125

Table 14. Relationship to Family Member Receiving Services

State	Parent	Sibling	Spouse	Other	N
AZ	51%	20%	0%	29%	276
FL	63%	19%	0%	18%	403
GA	54%	26%	0%	19%	375
KY	49%	35%	0%	16%	312
MD	79%	14%	0%	7%	242
NC	49%	31%	0%	20%	166
OH	49%	26%	0%	25%	399
PA	54%	38%	0%	8%	375
SC	50%	29%	0%	21%	231
UT	64%	15%	1%	20%	377
NCI Average	56%	25%	0%	18%	3,156

Table 25. Respondent Is Legal Guardian or Conservator

State	Yes, Full Guardianship/Conservatorship	Yes, Limited Guardianship/Conservatorship	No	N
AZ	73%	4%	23%	275
FL	64%	13%	23%	396
GA	59%	7%	34%	369
KY	92%	5%	3%	311
MD	32%	10%	58%	224
NC	83%	11%	6%	169
OH	57%	13%	30%	399
PA	44%	10%	47%	354
SC	41%	11%	48%	217
UT	40%	21%	39%	369
NCI Average	58%	11%	31%	3,083

Table 16. Number of Times Respondent Sees Family Member in a Year

State	Less Than Once	1-3 Times	4-6 Times	7-12 Times	More Than 12 Times	N
AZ	3%	8%	16%	14%	58%	271
FL	5%	7%	11%	13%	65%	402
GA	6%	13%	11%	11%	59%	379
KY	4%	6%	10%	17%	64%	312
MD	3%	7%	8%	13%	69%	240
NC	5%	11%	17%	10%	57%	168
OH	1%	4%	9%	9%	78%	399
PA	5%	14%	13%	13%	55%	375
SC	2%	10%	12%	13%	63%	229
UT	3%	5%	10%	18%	64%	372
NCI Average	4%	8%	12%	13%	63%	3,147

Table 17. Respondent's Highest Education Level

State	Does Not Have High School Diploma/GED	High School Diploma/GED	Vocational School	Some College	College Degree	N
AZ	4%	21%	4%	36%	35%	262
FL	6%	23%	6%	28%	36%	397
GA	9%	25%	5%	26%	34%	377
KY	9%	30%	2%	24%	34%	308
MD	8%	17%	5%	19%	51%	238
NC	8%	19%	4%	23%	46%	166
OH	5%	33%	3%	24%	36%	399
PA	8%	35%	6%	18%	32%	370
SC	12%	27%	3%	21%	38%	226
UT	4%	17%	5%	25%	49%	371
NCI Average	7%	25%	4%	24%	39%	3,114

Table 18. Total Taxable Family Income of Wage Earners in the Past Year

State	Below \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	N
AZ	21%	20%	31%	15%	13%	198
FL	22%	18%	32%	14%	13%	307
GA	21%	24%	26%	13%	16%	275
KY	21%	20%	26%	16%	17%	257
MD	12%	14%	24%	24%	25%	188
NC	19%	16%	23%	25%	16%	134
OH	16%	26%	27%	14%	17%	399
PA	21%	22%	21%	19%	17%	275
SC	26%	17%	33%	14%	10%	181
UT	14%	16%	31%	18%	20%	285
NCI Average	19%	19%	27%	17%	16%	2,499

Table 19. Out-of-Pocket Expenses for Family in the Past Year

State	Nothing	\$1- \$100	\$101- \$1,000	\$1,001- \$10,000	Over \$10,000	N
AZ	47%	10%	24%	18%	0%	232
FL	48%	12%	22%	16%	1%	383
GA	53%	11%	22%	13%	1%	358
KY	49%	12%	28%	10%	1%	276
MD	41%	9%	25%	22%	3%	226
NC	61%	9%	18%	11%	1%	156
OH	77%	5%	13%	5%	0%	399
PA	62%	10%	19%	9%	0%	341
SC	62%	10%	17%	11%	0%	205
UT	49%	17%	23%	10%	0%	358
NCI Average	55%	11%	21%	13%	1%	2,934

Services and Supports Received

This section provides information about the services and supports received by the family member from the state ID/DD agency (social security benefits being the exception).

The vast majority of respondents indicate that their family member receives residential supports (93%), transportation services (91%), and social security benefits (90%).

Table 20. Services and Supports Received From ID/DD Agency

State	Residential Supports	Day/Employment Supports	Transportation	Other Services and Supports	Social Security Benefits
AZ	97%	82%	93%	63%	92%
FL	92%	66%	88%	58%	91%
GA	91%	71%	90%	42%	90%
KY	97%	83%	96%	71%	95%
MD	89%	82%	88%	60%	87%
NC	95%	60%	89%	73%	90%
OH	89%	85%	92%	50%	91%
PA	89%	68%	91%	59%	90%
SC	95%	83%	93%	57%	89%
UT	92%	81%	93%	59%	89%
NCI Average	93%	76%	91%	59%	90%

Family/Guardian Survey Results

Note:

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

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

Information and Planning

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

Nearly half of all respondents across the states report that they always get enough information to help plan services for their family member (48%) and more than half report that this information is always easy to understand (54%). A slight majority report that they are always kept informed about how their family member is doing (55%).

Almost two-thirds of respondents report that their family member helped develop their own service plan (65%) while 83% report that they or another family member helped create their family member's service plan. The vast majority indicate that the service plan includes all the services and supports their family member wants (87%) and needs (85%).

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

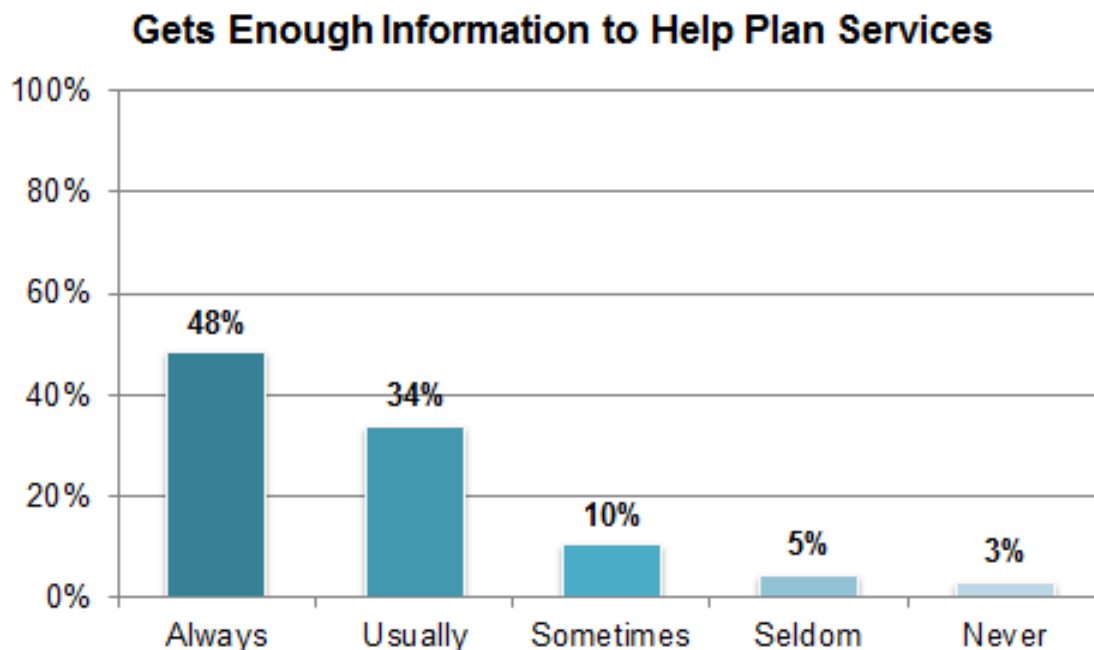


Table Q1. Do you get enough information to help you participate in planning services for your family member?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NC	62%	28%	7%	2%	1%	167
OH	56%	25%	11%	4%	4%	389
AZ	56%	36%	5%	3%	0%	268
Within Average Range						
MD	54%	28%	10%	5%	3%	227
PA	48%	36%	10%	2%	4%	335
FL	47%	34%	12%	5%	3%	389
KY	43%	41%	9%	5%	2%	306
SC	42%	35%	14%	5%	4%	218
Significantly Below Average						
GA	38%	35%	15%	6%	6%	352
UT	37%	39%	12%	8%	4%	361
NCI Average	48%	34%	10%	5%	3%	3,012

Information About Services and Supports Is Easy to Understand

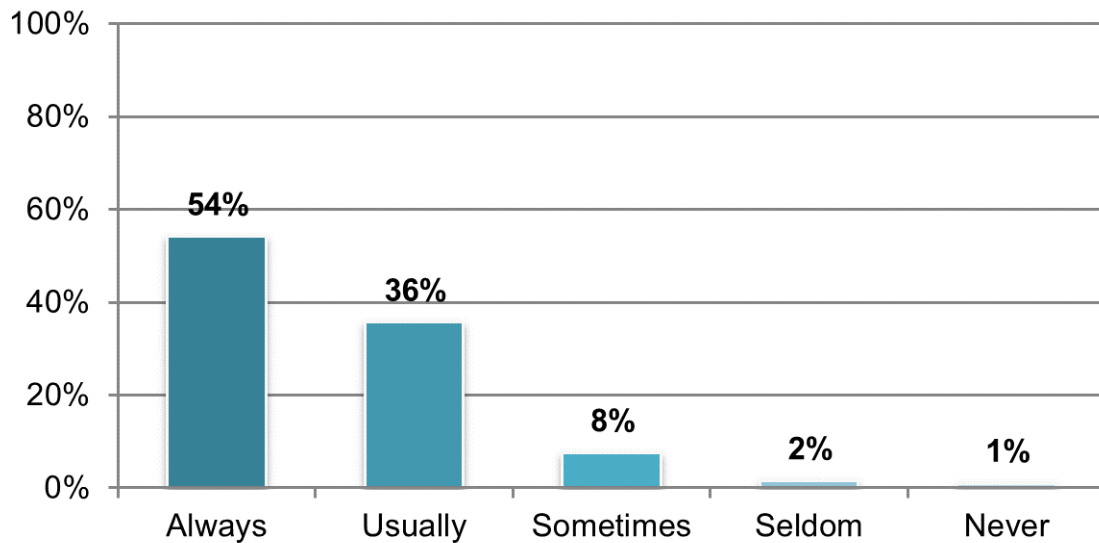


Table Q2. Is the information you receive easy to understand?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	66%	24%	7%	1%	1%	384
Within Average Range						
MD	60%	32%	5%	1%	2%	225
AZ	60%	34%	6%	1%	0%	271
NC	59%	32%	8%	1%	1%	168
SC	55%	35%	8%	1%	0%	213
PA	52%	42%	5%	1%	0%	329
UT	51%	37%	7%	3%	2%	345
KY	49%	39%	9%	3%	1%	303
Significantly Below Average						
FL	47%	39%	11%	2%	2%	379
GA	43%	43%	11%	2%	2%	338
NCI Average	54%	36%	8%	2%	1%	2,955

Kept Informed About How Family Member Is Doing

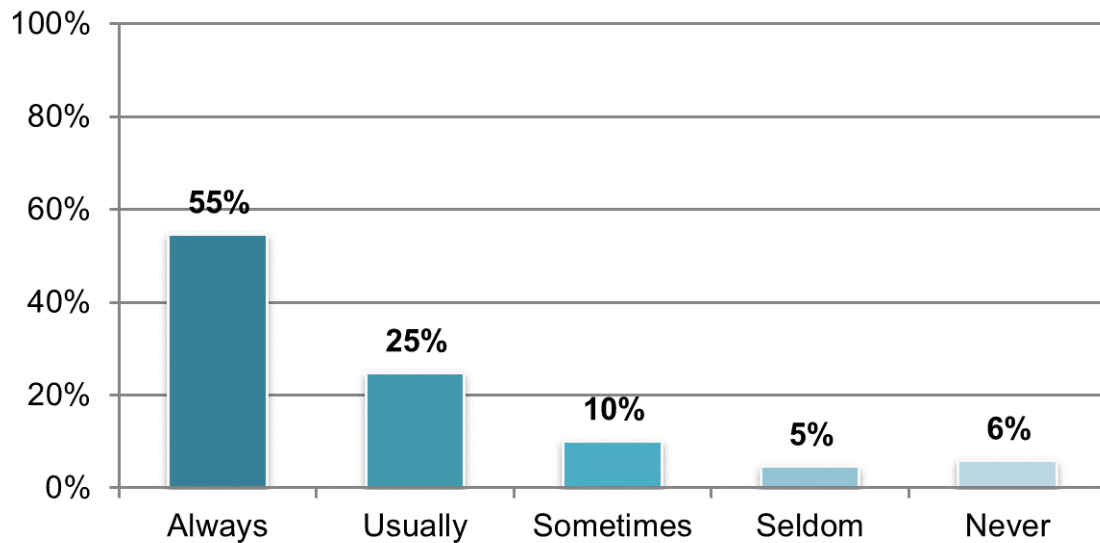


Table Q3. Are you kept informed about how your family member is doing?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	71%	18%	6%	3%	2%	393
NC	70%	21%	4%	5%	0%	172
AZ	65%	28%	6%	0%	1%	272
Within Average Range						
FL	58%	28%	8%	3%	2%	393
KY	54%	29%	13%	3%	1%	306
MD	53%	20%	15%	8%	5%	237
GA	50%	28%	14%	5%	4%	376
SC	48%	30%	13%	8%	1%	222
Significantly Below Average						
UT	42%	32%	16%	7%	3%	358
PA	36%	14%	5%	5%	40%	132
NCI Average	55%	25%	10%	5%	6%	2,861

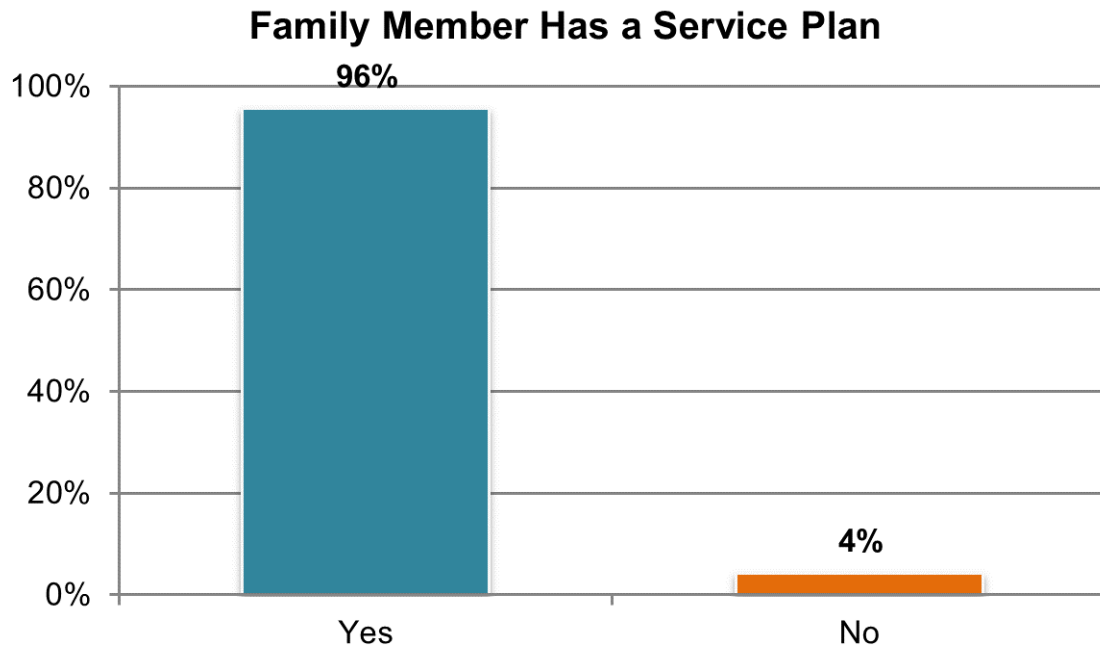


Table Q4. Does your family member have a service plan?

State	Yes	No	N
Significantly Above Average			
MD	99%	1%	208
AZ	98%	2%	260
Within Average Range			
FL	97%	3%	375
KY	97%	3%	283
UT	97%	3%	306
GA	96%	4%	288
PA	95%	5%	278
OH	93%	7%	348
SC	92%	8%	171
NC	92%	8%	144
NCI Average	96%	4%	2,661

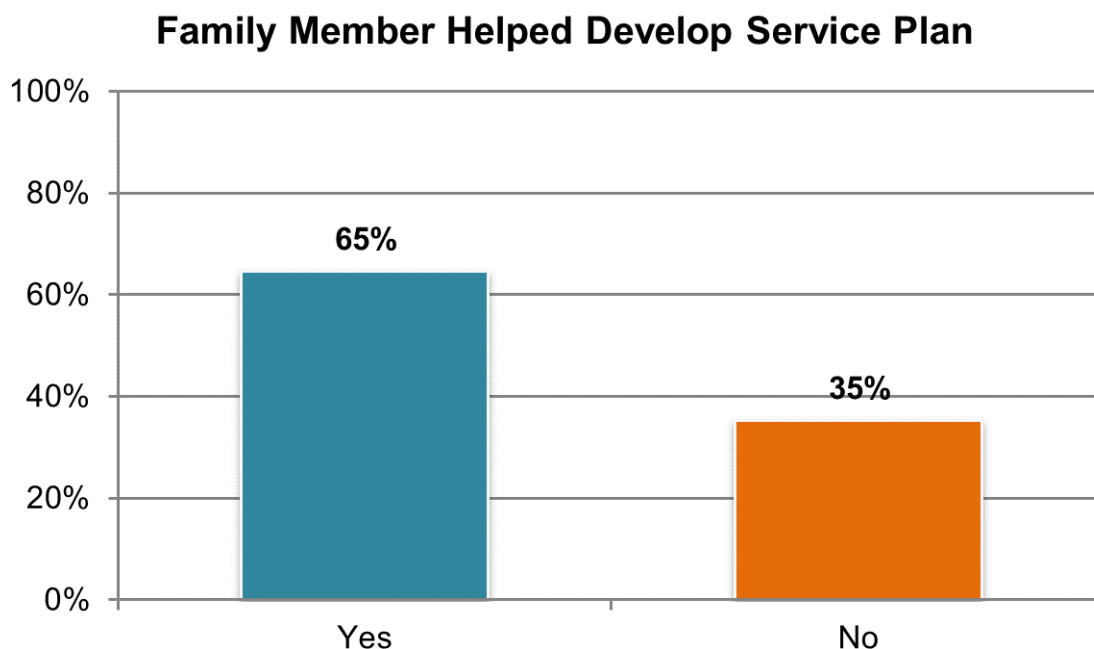


Table Q5. Did your family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
OH	78%	22%	307
Within Average Range			
SC	72%	28%	130
UT	71%	29%	252
MD	70%	30%	174
FL	67%	33%	305
GA	64%	36%	244
AZ	62%	38%	222
Significantly Below Average			
KY	57%	43%	240
PA	56%	44%	227
NC	51%	49%	117
NCI Average	65%	35%	2,218

Respondent or Another Family Member Helped Develop Service Plan

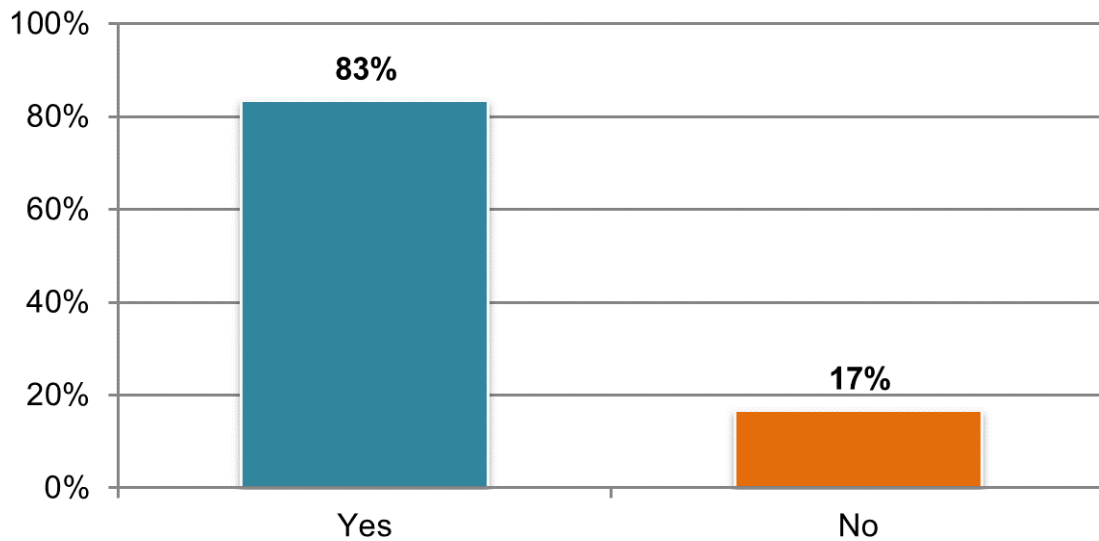


Table Q6. Did you or another family member help develop the plan?

State	Yes	No	N
Significantly Above Average			
AZ	90%	10%	238
OH	89%	11%	320
UT	88%	12%	280
Within Average Range			
KY	87%	13%	259
NC	86%	14%	127
GA	85%	15%	264
FL	82%	18%	343
MD	81%	19%	187
SC	77%	23%	143
Significantly Below Average			
PA	69%	31%	270
NCI Average	83%	17%	2,431

Service Plan Includes All the Services and Supports Family Member Wants

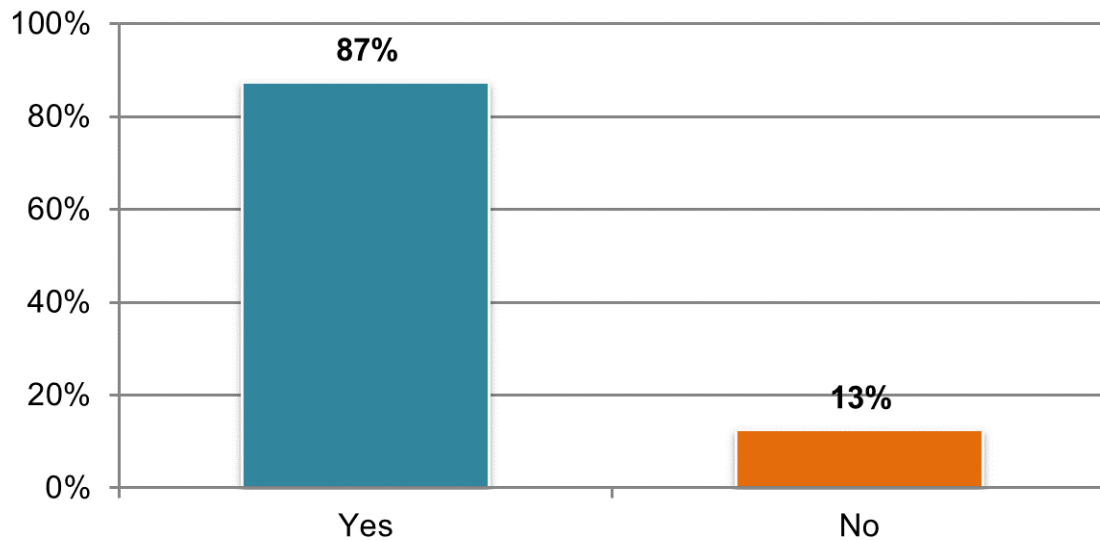


Table Q7. Does the plan include all the services and supports your family member wants?

State	Yes	No	N
Significantly Above Average			
OH	95%	5%	311
PA	93%	7%	224
Within Average Range			
AZ	92%	8%	229
SC	89%	11%	133
UT	88%	12%	241
KY	88%	13%	240
NC	86%	14%	123
GA	85%	15%	228
MD	81%	19%	166
Significantly Below Average			
FL	78%	22%	304
NCI Average	87%	13%	2,199

Service Plan Includes All the Services and Supports Family Member Needs

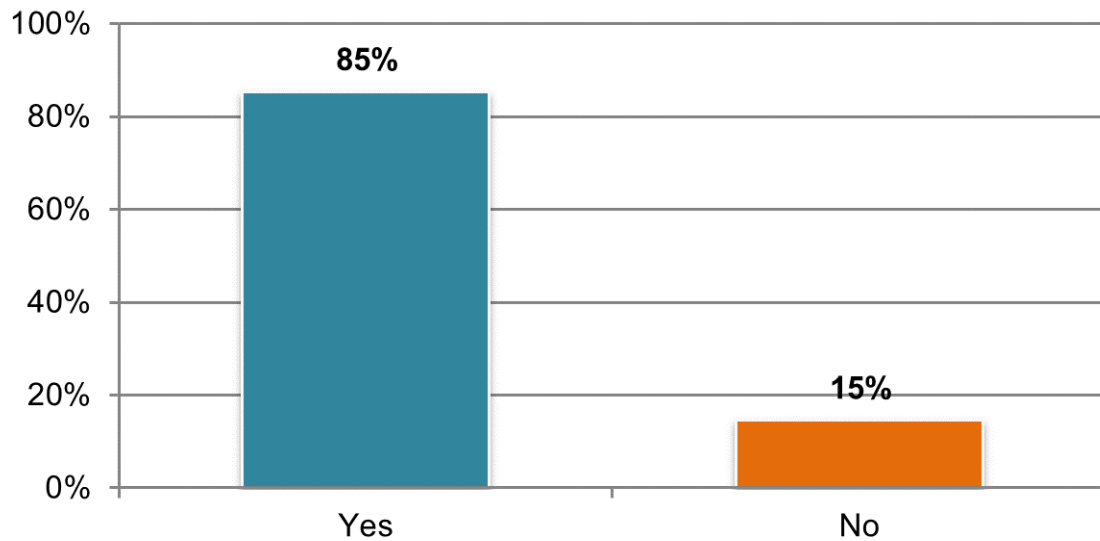


Table Q8. Does the plan include all the services and supports your family member needs?

State	Yes	No	N
Significantly Above Average			
OH	96%	4%	315
PA	90%	10%	250
AZ	90%	10%	237
Within Average Range			
UT	89%	11%	264
NC	88%	12%	125
KY	87%	13%	241
SC	85%	15%	144
GA	80%	20%	234
Significantly Below Average			
MD	75%	25%	182
FL	73%	27%	325
NCI Average	85%	15%	2,317

Family Member Receives All Services Listed in Service Plan

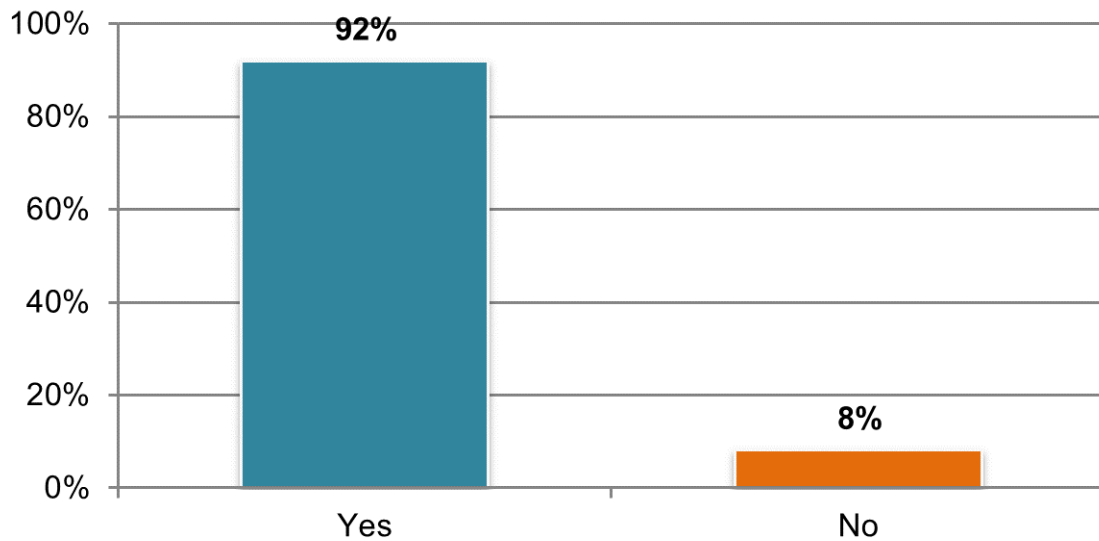


Table Q9. Does your family member receive all of the services listed in the plan?

State	Yes	No	N
Significantly Above Average			
NC	97%	3%	120
OH	96%	4%	316
Within Average Range			
AZ	95%	5%	221
PA	94%	6%	228
UT	93%	7%	242
SC	93%	7%	125
FL	92%	8%	312
KY	90%	10%	232
GA	87%	13%	216
Significantly Below Average			
MD	82%	18%	170
NCI Average	92%	8%	2,182

Respondent Discussed How to Handle Emergencies Related to Family Member at Last Service Planning Meeting

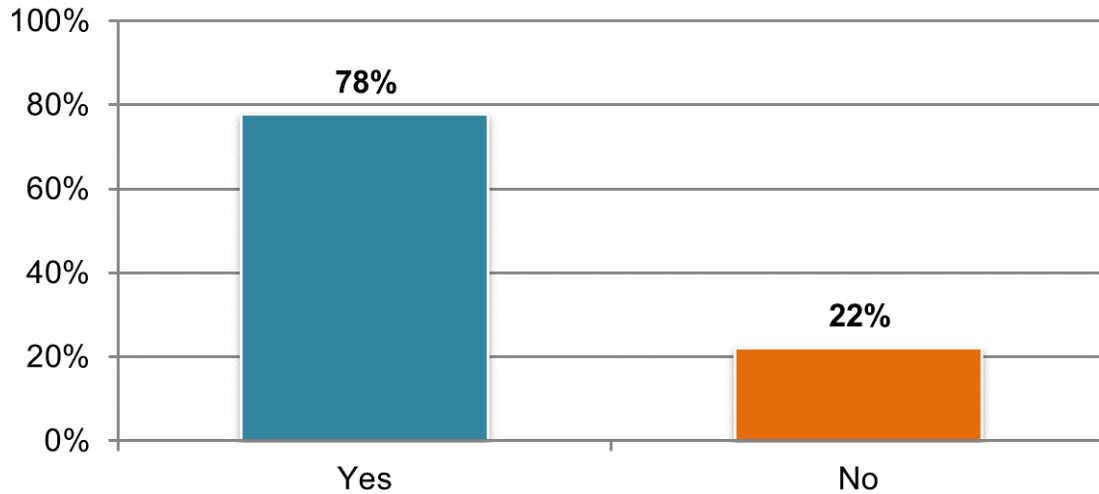


Table Q10. Did you discuss how to handle emergencies related to your family member at the last service planning meeting?

State	Yes	No	N
Significantly Above Average			
OH	90%	10%	291
NC	88%	12%	126
KY	88%	13%	256
Within Average Range			
FL	80%	20%	334
AZ	78%	22%	232
GA	77%	23%	235
UT	72%	28%	267
SC	71%	29%	140
Significantly Below Average			
PA	69%	31%	240
MD	65%	35%	178
NCI Average	78%	22%	2,299

Respondent or Family Member Has Received Information About Family Member's Rights

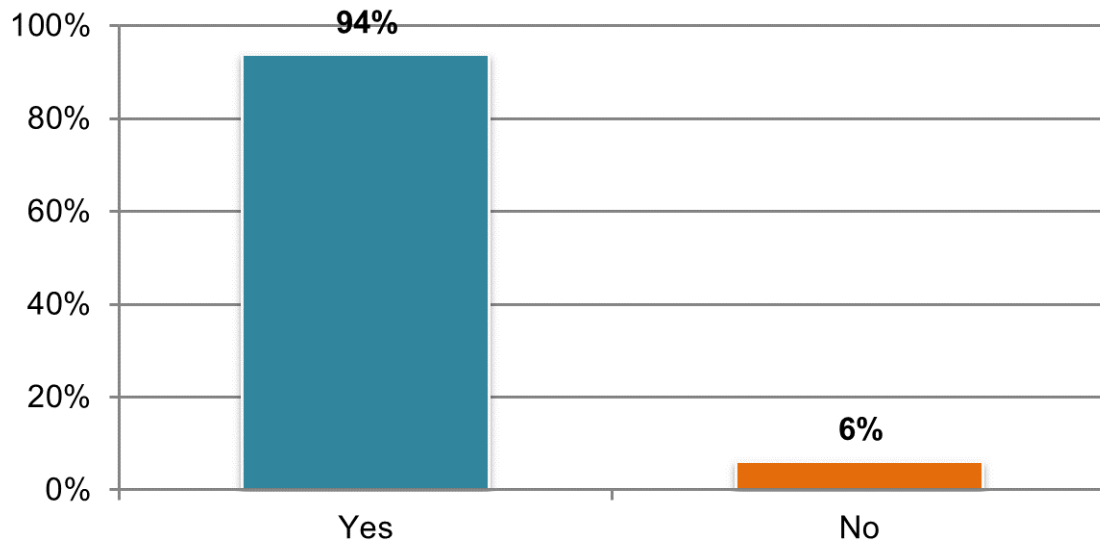


Table Q11. Have you or your family member received information about his/her rights?

State	Yes	No	N
Significantly Above Average			
AZ	98%	2%	260
NC	98%	2%	162
OH	97%	3%	384
KY	97%	3%	290
FL	97%	3%	375
Within Average Range			
UT	94%	6%	321
PA	92%	8%	284
GA	90%	10%	306
SC	90%	10%	195
Significantly Below Average			
MD	86%	14%	204
NCI Average	94%	6%	2,781

Access and Delivery of Services and Supports

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

More than three-fifths of respondents report that they are always able to contact support workers and the case manager/service coordinator when needed (64% and 61%, respectively). Over half indicate that services and supports always change when their family member's needs change (56%). While 55% of respondents report that support workers always communicate effectively with their family member who is nonverbal, 73% indicate that support workers communicate effectively with their family member whose primary language is English. The same percentage of respondents report that their family member's residential setting is always a healthy and safe environment and the day or employment setting is always a healthy and safe environment (both 72%).

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

***Please note Question 18 is omitted from this year's report as all states had too low a response rate to report.**

Respondent Is Able to Contact Support Workers When Needed

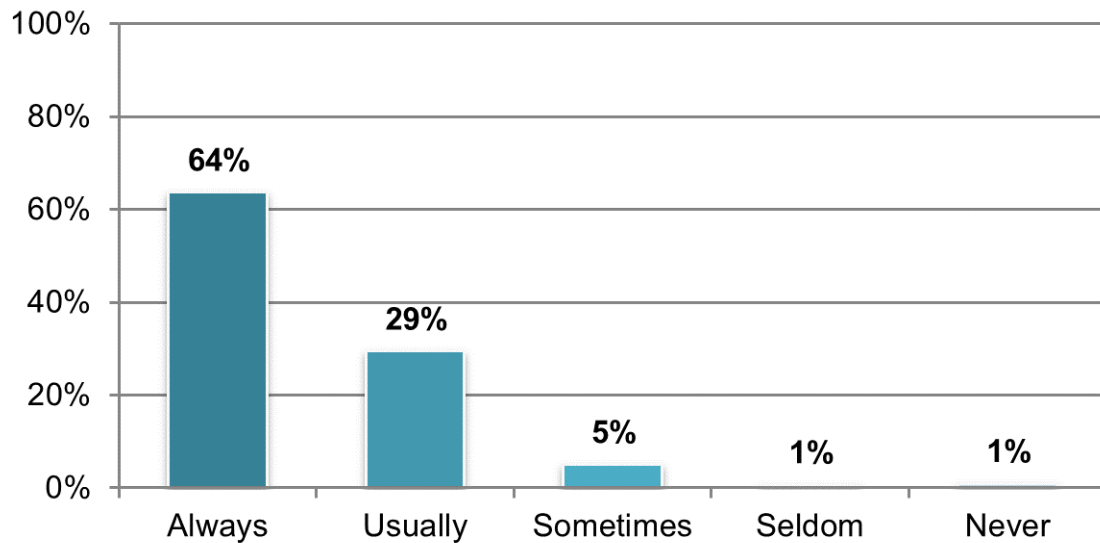


Table Q12. Are you able to contact your family member's support workers when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	78%	16%	4%	1%	1%	392
NC	73%	23%	4%	0%	0%	169
Within Average Range						
AZ	67%	28%	4%	0%	1%	278
FL	66%	27%	6%	0%	1%	391
PA	65%	30%	3%	1%	1%	354
MD	63%	28%	6%	2%	2%	195
KY	60%	34%	4%	1%	1%	297
SC	56%	36%	7%	0%	0%	230
Significantly Below Average						
GA	57%	34%	6%	2%	2%	375
UT	53%	39%	6%	1%	2%	358
NCI Average	64%	29%	5%	1%	1%	3,039

Respondent Is Able to Contact Case Manager/Service Coordinator When Needed

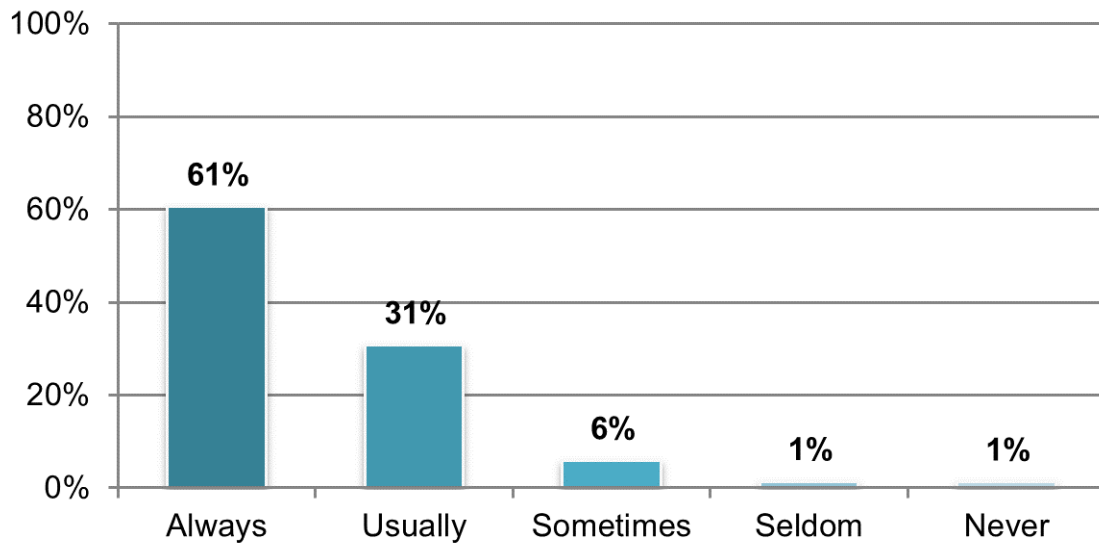


Table Q13. Are you able to contact your family member's case manager/service coordinator when you need to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	72%	20%	6%	1%	1%	376
FL	68%	25%	5%	1%	1%	389
Within Average Range						
NC	67%	28%	3%	0%	1%	165
MD	62%	26%	7%	2%	2%	208
AZ	60%	34%	4%	1%	1%	270
KY	57%	35%	7%	0%	1%	300
PA	56%	36%	6%	1%	1%	342
SC	56%	34%	7%	2%	1%	224
UT	55%	36%	4%	3%	2%	351
Significantly Below Average						
GA	53%	33%	9%	3%	2%	366
NCI Average	61%	31%	6%	1%	1%	2,991

Services and Supports Are Available Reasonably Close to Family Member's Home

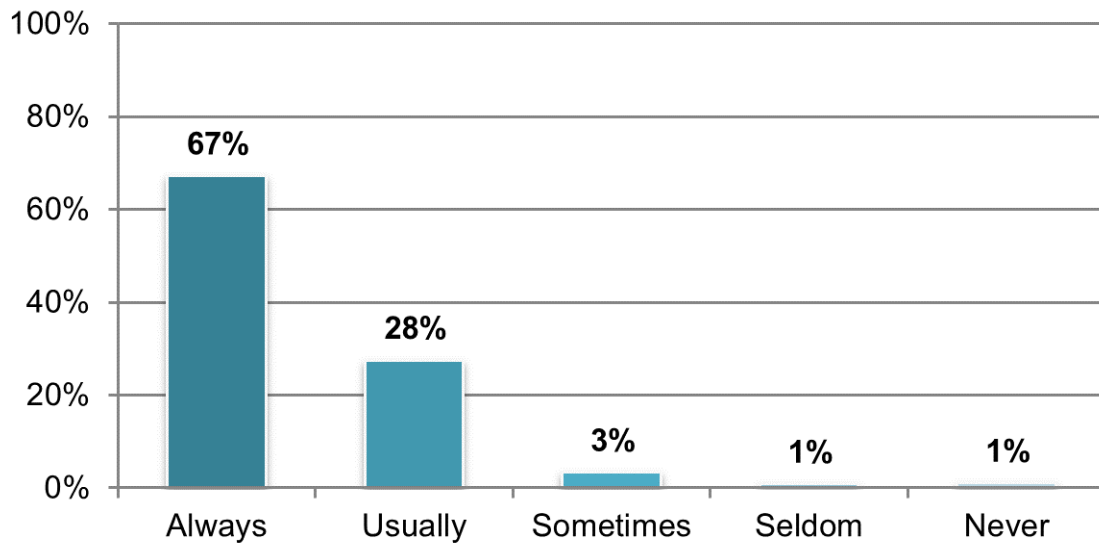


Table Q14. Are services and supports available within a reasonable distance from your family member's home?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	82%	14%	2%	1%	1%	384
Within Average Range						
PA	69%	28%	1%	0%	2%	328
UT	67%	27%	3%	1%	1%	335
FL	67%	27%	4%	1%	1%	369
SC	66%	29%	4%	0%	1%	216
AZ	66%	29%	5%	0%	0%	267
MD	65%	31%	2%	1%	0%	208
KY	65%	31%	3%	1%	1%	288
GA	64%	27%	5%	2%	2%	337
NC	62%	32%	4%	2%	1%	163
NCI Average	67%	28%	3%	1%	1%	2,895

Services and Supports Change When Family Member's Needs Change

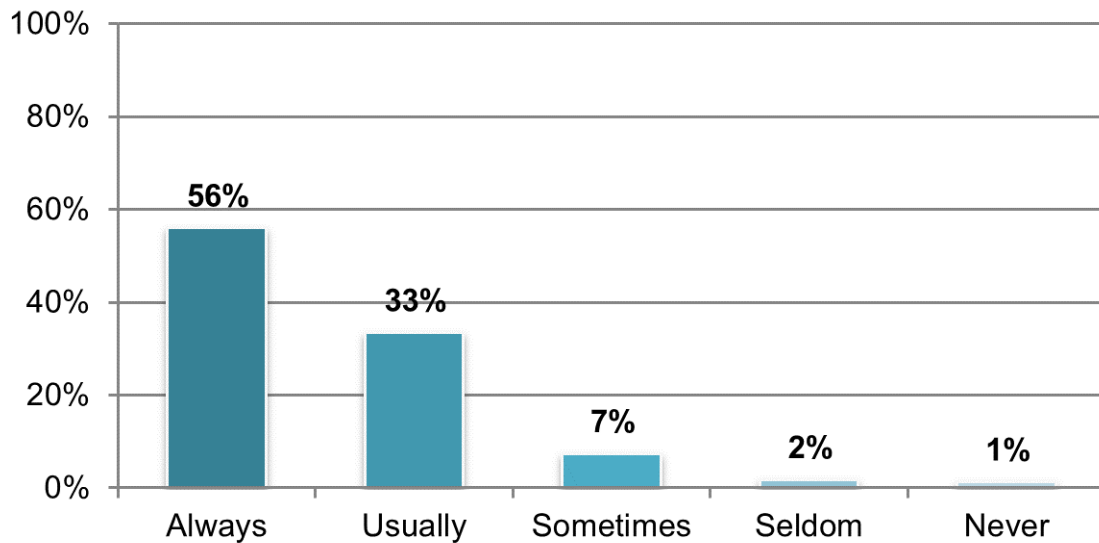


Table Q15. Do the services and supports change when your family member's needs change?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	72%	21%	4%	1%	1%	358
Within Average Range						
AZ	59%	35%	4%	1%	0%	254
NC	58%	33%	6%	2%	1%	159
SC	58%	30%	10%	2%	1%	187
KY	54%	31%	11%	3%	1%	274
MD	54%	31%	9%	3%	3%	197
UT	52%	44%	3%	1%	0%	311
PA	51%	38%	9%	0%	2%	303
GA	51%	35%	9%	3%	2%	296
FL	50%	36%	10%	3%	2%	345
NCI Average	56%	33%	7%	2%	1%	2,684

Support Workers Can Communicate with Family Member (If Non-Verbal)

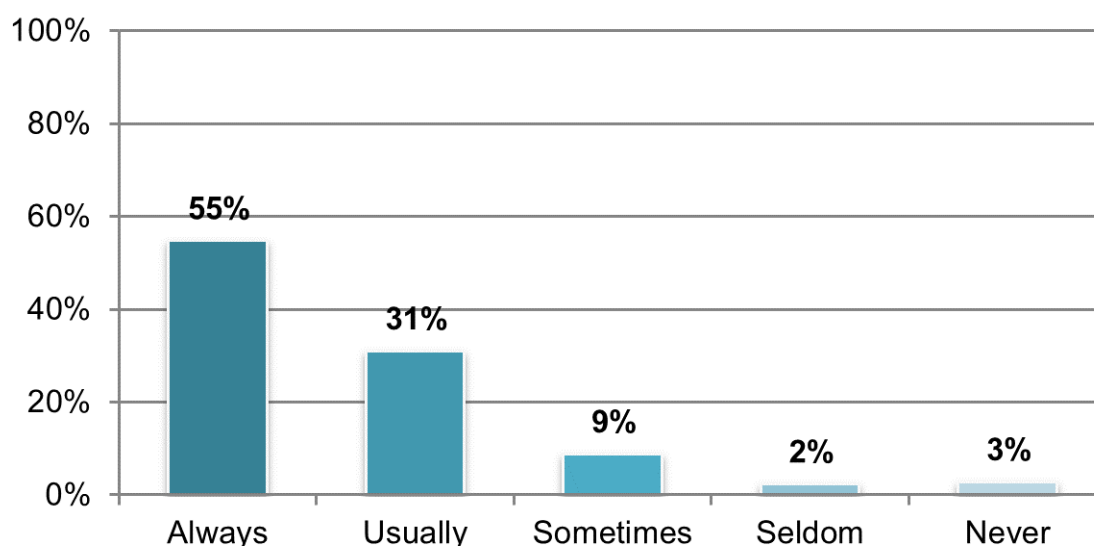


Table Q16. If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
NC	74%	18%	5%	0%	3%	66
Within Average Range						
PA	59%	28%	9%	2%	2%	111
FL	57%	23%	12%	4%	5%	113
MD	56%	32%	10%	0%	2%	62
AZ	56%	32%	7%	2%	3%	97
SC	55%	33%	8%	5%	0%	40
UT	52%	35%	10%	3%	0%	91
GA	50%	34%	6%	5%	5%	128
OH	49%	35%	11%	0%	6%	72
Significantly Below Average						
KY	40%	40%	12%	4%	4%	84
NCI Average	55%	31%	9%	2%	3%	864

Support Workers Communicate Effectively with Family Member in Primary Language (If English)

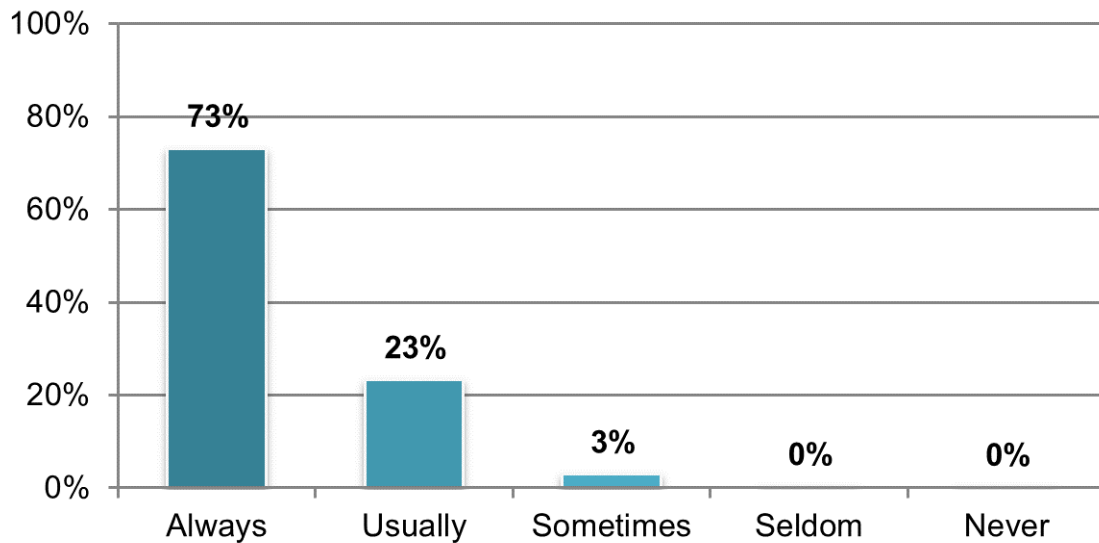


Table Q17. If English is your family member's primary language, do the support workers speak to him/her effectively?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
NC	80%	19%	1%	0%	0%	160
PA	78%	20%	2%	1%	0%	328
UT	75%	23%	1%	0%	0%	342
SC	74%	22%	3%	0%	0%	211
AZ	74%	23%	3%	0%	0%	242
FL	72%	25%	2%	1%	0%	356
GA	72%	24%	3%	0%	0%	324
KY	71%	26%	3%	0%	0%	297
MD	68%	26%	5%	0%	0%	216
OH	67%	25%	7%	0%	1%	345
NCI Average	73%	23%	3%	0%	0%	2,821

Services Are Delivered in a Manner That Is Respectful to Family Member's Culture

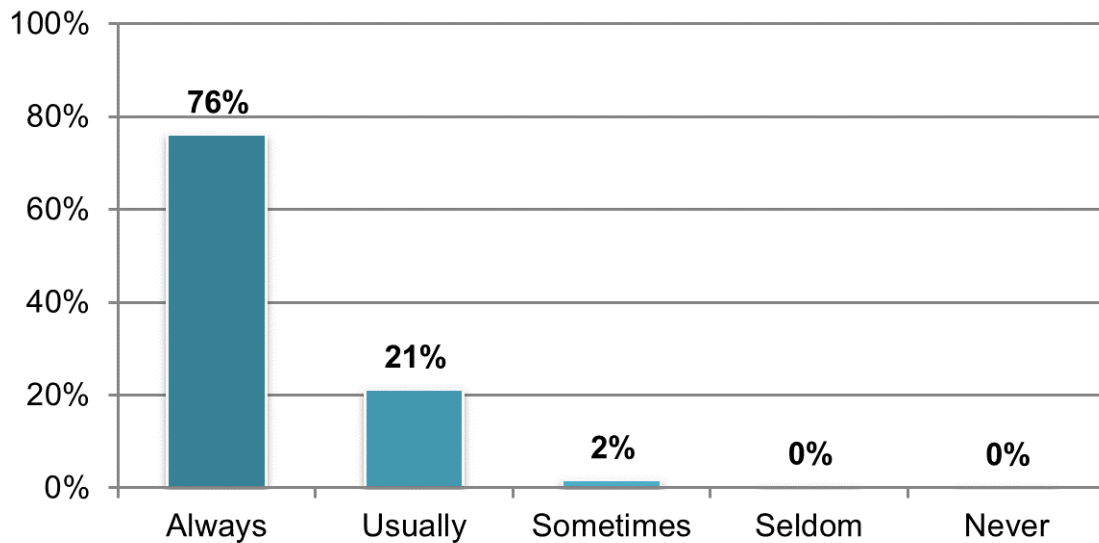


Table Q19 Are services delivered in a way that is respectful to your family member's culture?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	90%	8%	2%	1%	0%	386
Within Average Range						
NC	80%	20%	1%	0%	0%	157
PA	78%	19%	2%	0%	1%	313
FL	75%	22%	1%	1%	0%	347
UT	75%	23%	2%	0%	0%	328
AZ	75%	23%	2%	0%	0%	245
GA	73%	24%	2%	0%	1%	323
KY	73%	25%	2%	0%	0%	281
MD	72%	24%	3%	2%	0%	195
SC	72%	25%	2%	1%	0%	202
NCI Average	76%	21%	2%	0%	0%	2,777

Family Member Has Access to Special Equipment or Accommodations Needed

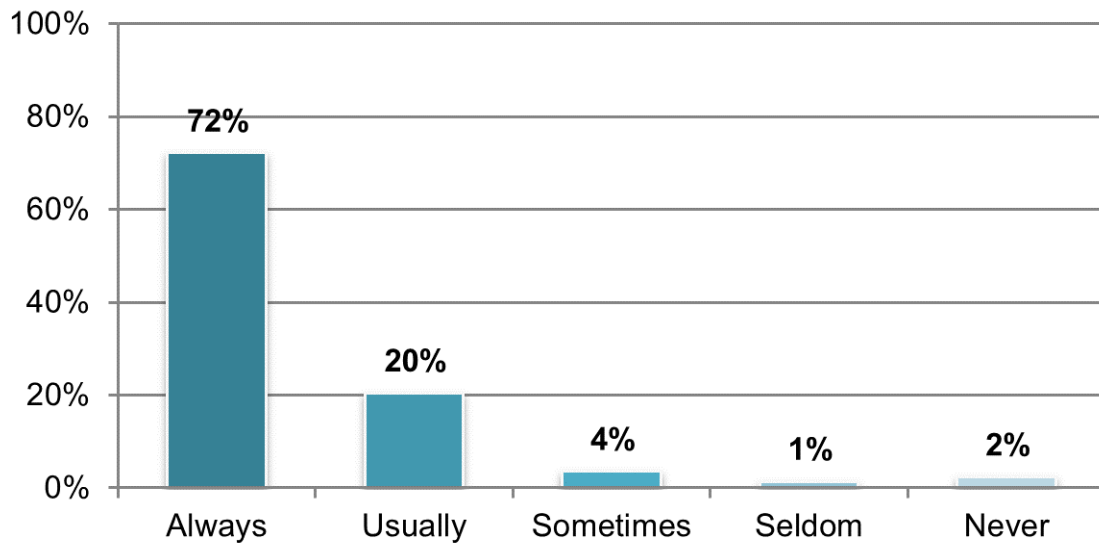


Table Q20. Family Member Has Access to Special Equipment or Accommodations Needed

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	88%	8%	3%	1%	1%	195
Within Average Range						
NC	79%	16%	2%	2%	1%	126
PA	76%	18%	4%	0%	1%	219
SC	72%	19%	5%	3%	2%	130
MD	71%	21%	2%	2%	4%	104
FL	69%	22%	4%	2%	2%	203
AZ	69%	25%	3%	1%	2%	169
UT	68%	24%	5%	1%	2%	207
KY	65%	26%	7%	1%	2%	193
GA	65%	26%	2%	2%	7%	192
NCI Average	72%	20%	4%	1%	2%	1,738

Support Workers Have the Right Training to Meet Family Member's Needs

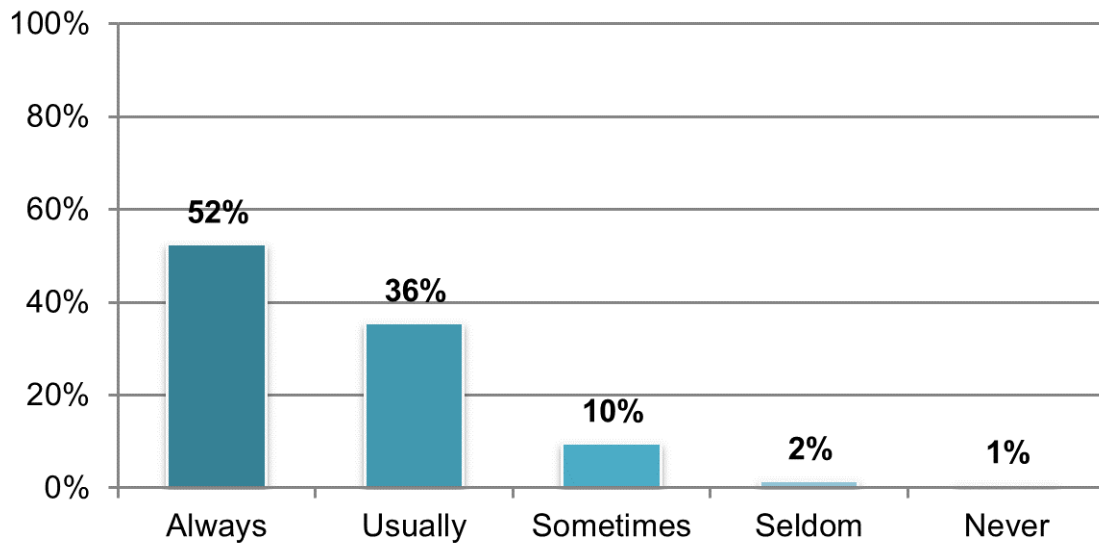


Table Q21. Do the support workers have the right training to meet your family member's needs?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	60%	30%	9%	1%	0%	357
OH	59%	33%	6%	1%	1%	368
Within Average Range						
NC	59%	33%	7%	1%	0%	159
PA	55%	35%	9%	1%	1%	321
SC	53%	34%	11%	3%	0%	194
GA	52%	34%	10%	3%	1%	322
AZ	51%	39%	9%	0%	0%	251
KY	48%	39%	9%	3%	1%	284
MD	46%	33%	17%	1%	2%	209
Significantly Below Average						
UT	43%	46%	10%	0%	1%	326
NCI Average	52%	36%	10%	2%	1%	2,791

Family Member's Residential Setting Is Healthy and Safe

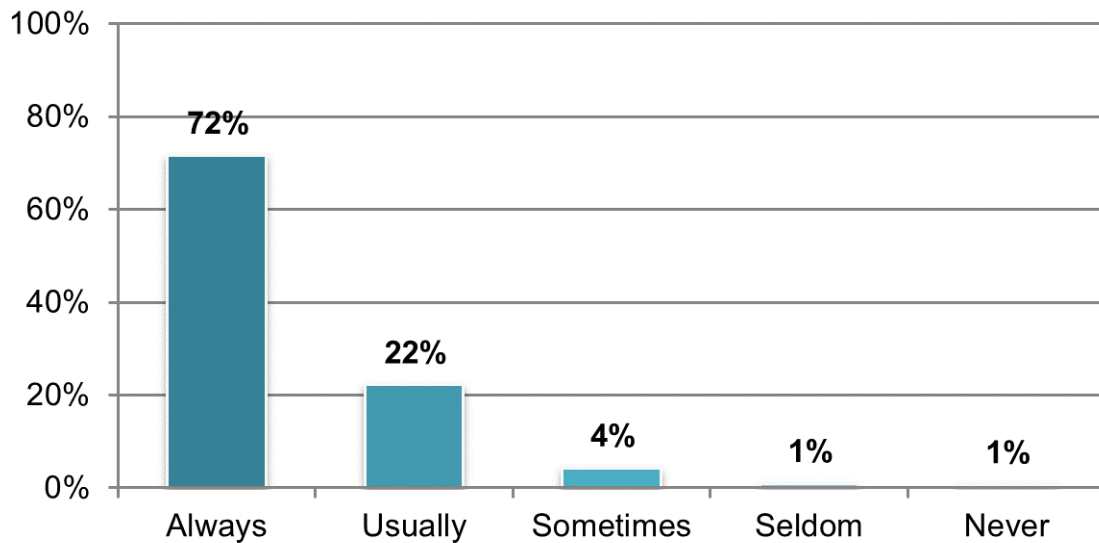


Table Q22. Do you feel that your family member's residential setting is a healthy and safe environment?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	79%	13%	6%	1%	1%	394
Within Average Range						
NC	76%	22%	2%	0%	0%	171
AZ	75%	22%	3%	0%	0%	274
PA	74%	22%	2%	1%	1%	356
FL	73%	23%	3%	0%	1%	383
GA	72%	20%	6%	1%	1%	364
SC	71%	23%	5%	2%	0%	221
MD	67%	25%	5%	2%	2%	224
KY	66%	25%	5%	3%	0%	306
Significantly Below Average						
UT	65%	27%	7%	1%	1%	363
NCI Average	72%	22%	4%	1%	1%	3,056

Family Member's Day/Employment Setting Is Healthy and Safe

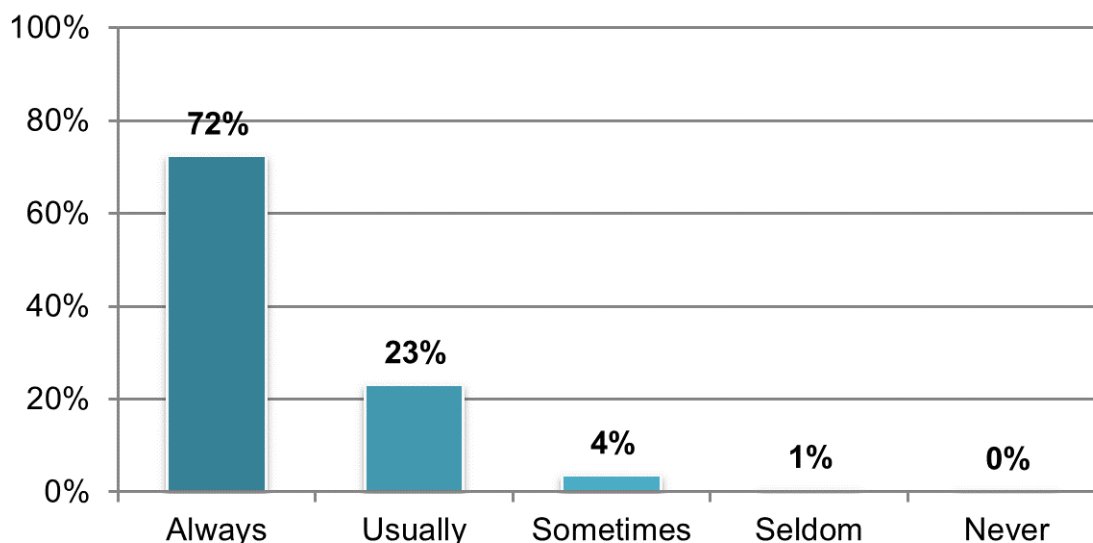


Table Q23. Do you feel that your family member's day/employment setting is a healthy and safe environment?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	84%	14%	2%	0%	0%	362
Within Average Range						
NC	80%	15%	4%	1%	1%	133
PA	76%	22%	2%	0%	0%	286
AZ	76%	21%	2%	0%	0%	244
SC	70%	24%	6%	1%	0%	193
KY	69%	26%	3%	1%	0%	270
GA	68%	25%	6%	0%	0%	294
MD	68%	29%	3%	0%	1%	192
FL	67%	29%	2%	1%	0%	301
UT	66%	27%	6%	0%	0%	319
NCI Average	72%	23%	4%	1%	0%	2,594

Happy with Transition from School Services to State-Funded Services (In Past Year)

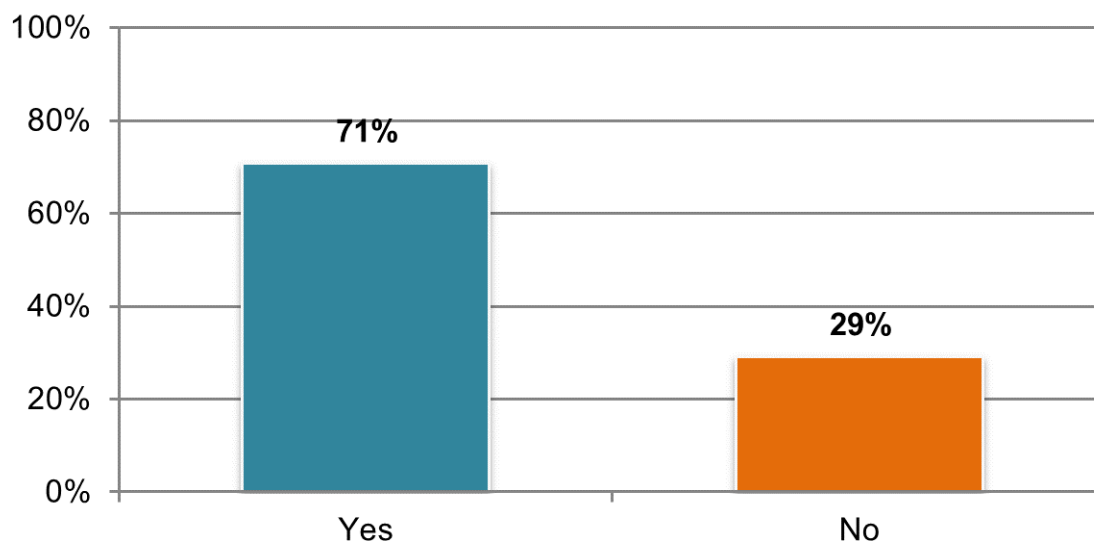


Table Q24. If your family member transitioned from school services to state-funded services in the past year, were you happy with the transition process?²

State	Yes	No	N
Within Average Range			
FL	71%	29%	24
AZ	n/a	n/a	n/a
GA	n/a	n/a	n/a
KY	n/a	n/a	n/a
MD	n/a	n/a	n/a
NC	n/a	n/a	n/a
OH	n/a	n/a	n/a
PA	n/a	n/a	n/a
SC	n/a	n/a	n/a
UT	n/a	n/a	n/a
NCI Average	71%	29%	24

² An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Choice and Control

Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.

Just over half of all respondents report that the residential service agency always involves their family member in important decisions (51%). Twenty-nine percent (29%) of respondents report that their family member always chooses his or her provider agencies; 17% report that their family member always chooses the individual support workers; and 15% report that their family member chose his or her own case manager/service coordinator.

Fifteen percent (15%) of family members were reported to have control or input over the hiring and management of their support workers. While 13% of respondents indicate that their family member knows how much money is spent by the ID/DD agency on his or her behalf, 31% report that their family member has a say in how this money is spent. Of those whose family member provides input into how ID/DD money is spent, 87% report that their family member has all the information needed to make this decision.

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Residential Service Agency Involves Family Member in Important Decisions

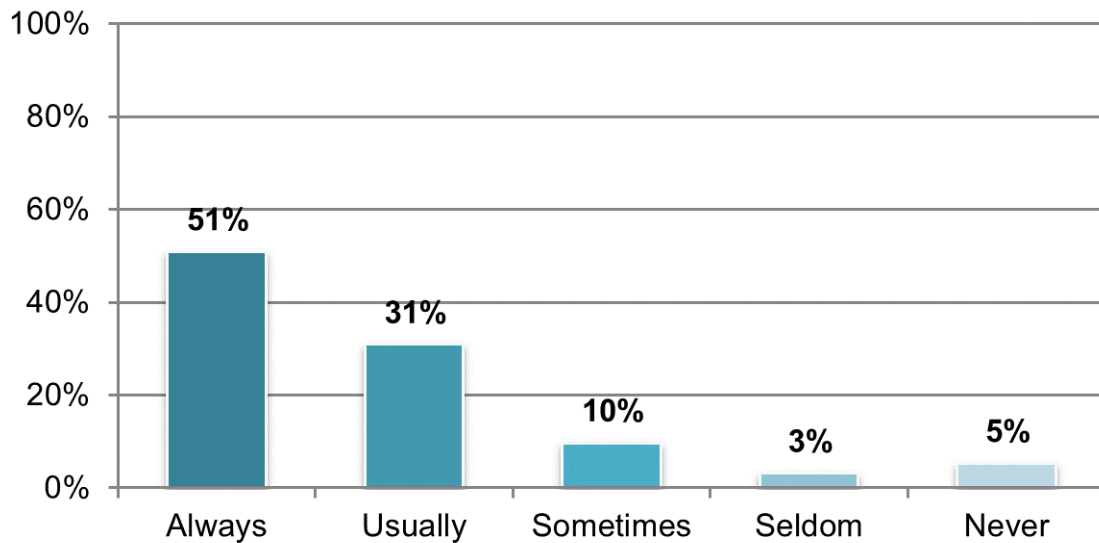


Table Q25. Does the agency providing residential services to your family member involve him/her in important decisions?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
NC	59%	28%	9%	4%	1%	141
AZ	56%	28%	8%	4%	4%	207
MD	53%	24%	11%	4%	8%	161
OH	52%	21%	10%	4%	13%	316
SC	51%	38%	9%	1%	2%	184
FL	51%	31%	9%	2%	7%	296
PA	50%	33%	8%	4%	5%	251
GA	47%	34%	9%	2%	7%	245
UT	45%	39%	11%	2%	3%	279
KY	45%	32%	16%	5%	2%	224
NCI Average	51%	31%	10%	3%	5%	2,304

Family Member Chooses Provider Agencies

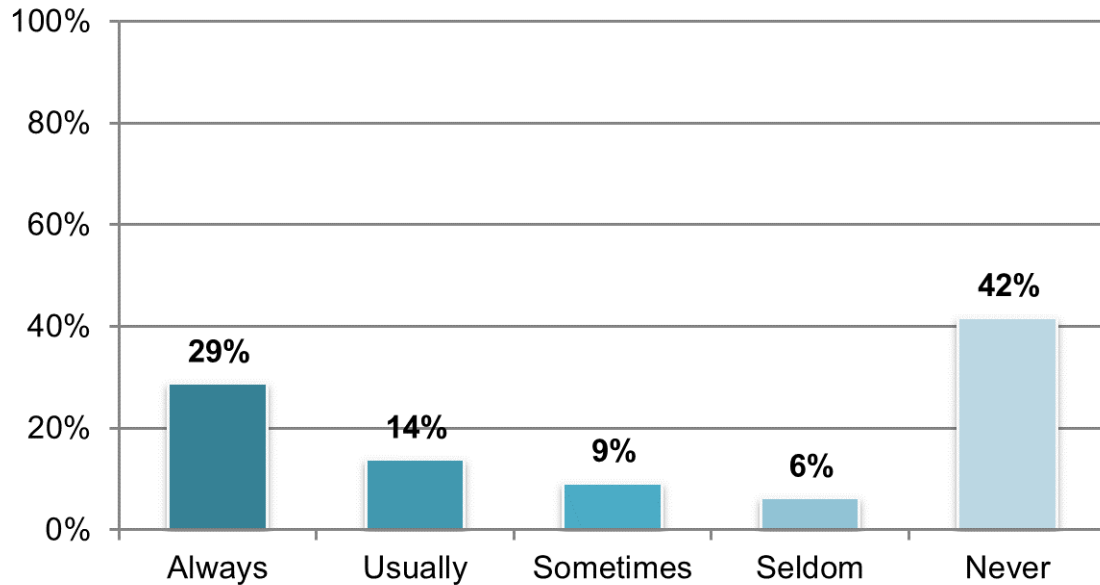


Table Q26. Does your family member choose the provider agencies that work with him or her?

State	Always	Usually	Sometimes	Seldom	Never	N
Within Average Range						
FL	36%	17%	12%	4%	31%	281
OH	34%	11%	4%	2%	49%	334
AZ	33%	10%	9%	5%	43%	171
UT	30%	20%	14%	7%	29%	218
SC	27%	17%	12%	7%	37%	123
NC	27%	10%	10%	9%	45%	105
MD	26%	13%	13%	9%	39%	149
GA	26%	14%	4%	4%	52%	222
KY	25%	13%	7%	10%	45%	195
PA	25%	12%	8%	7%	48%	174
NCI Average	29%	14%	9%	6%	42%	1,972

Family Member Can Choose a Different Provider Agency If Desired

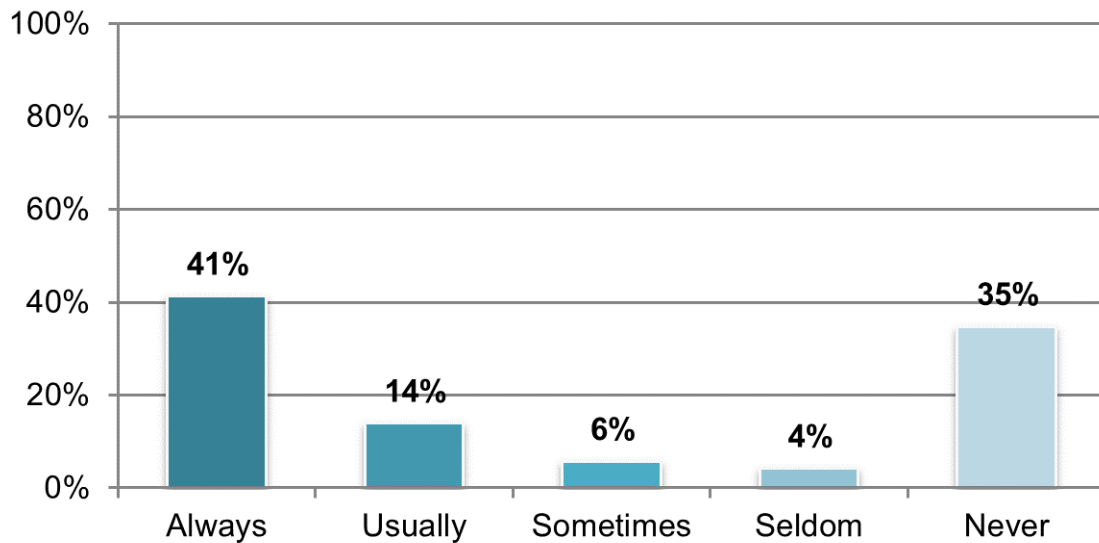


Table Q27. Can your family member choose a different provider agency if s/he wants to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	55%	8%	2%	1%	33%	308
FL	51%	16%	10%	3%	20%	239
Within Average Range						
AZ	46%	13%	4%	2%	35%	149
SC	43%	15%	4%	7%	31%	107
KY	42%	12%	6%	6%	35%	171
UT	41%	16%	12%	6%	25%	191
GA	38%	13%	2%	3%	43%	175
PA	36%	14%	5%	5%	40%	132
MD	33%	16%	8%	4%	39%	118
NC	29%	16%	4%	3%	48%	90
NCI Average	41%	14%	6%	4%	35%	1,680

Family Member Chooses Individual Support Workers That Work Directly With Him/Her

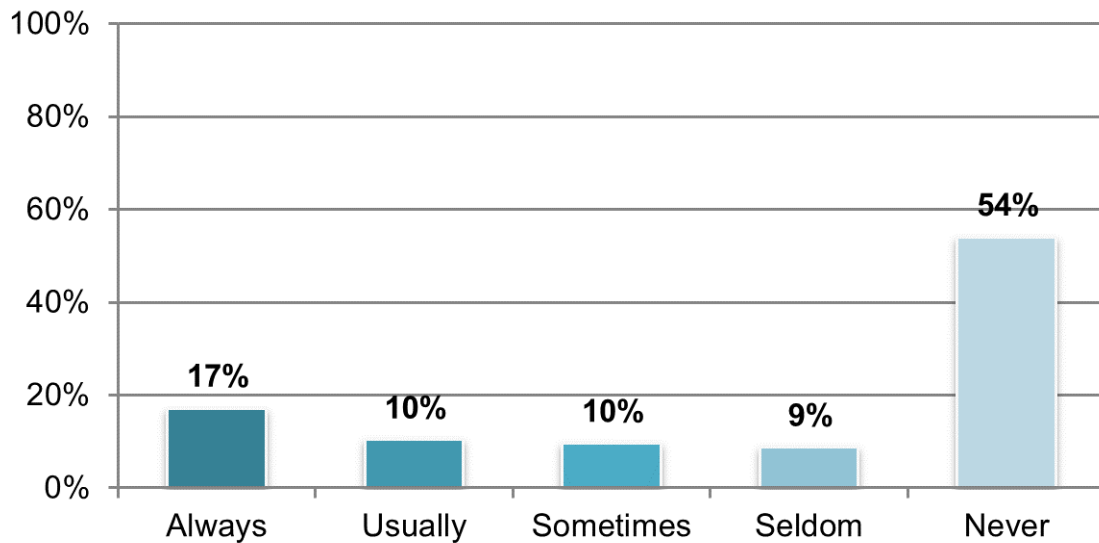


Table Q28. Does your family member choose the individual support workers who work directly with him/her?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	33%	16%	11%	8%	32%	279
Within Average Range						
SC	22%	10%	6%	9%	54%	125
UT	20%	18%	17%	10%	35%	222
AZ	20%	9%	6%	8%	56%	173
KY	16%	7%	13%	11%	52%	204
GA	14%	10%	7%	5%	64%	221
NC	13%	11%	9%	12%	54%	97
OH	13%	6%	5%	4%	71%	340
PA	12%	7%	9%	9%	62%	194
Significantly Below Average						
MD	9%	9%	12%	10%	60%	170
NCI Average	17%	10%	10%	9%	54%	2,025

Family Member Can Choose Different Support Workers If Desired

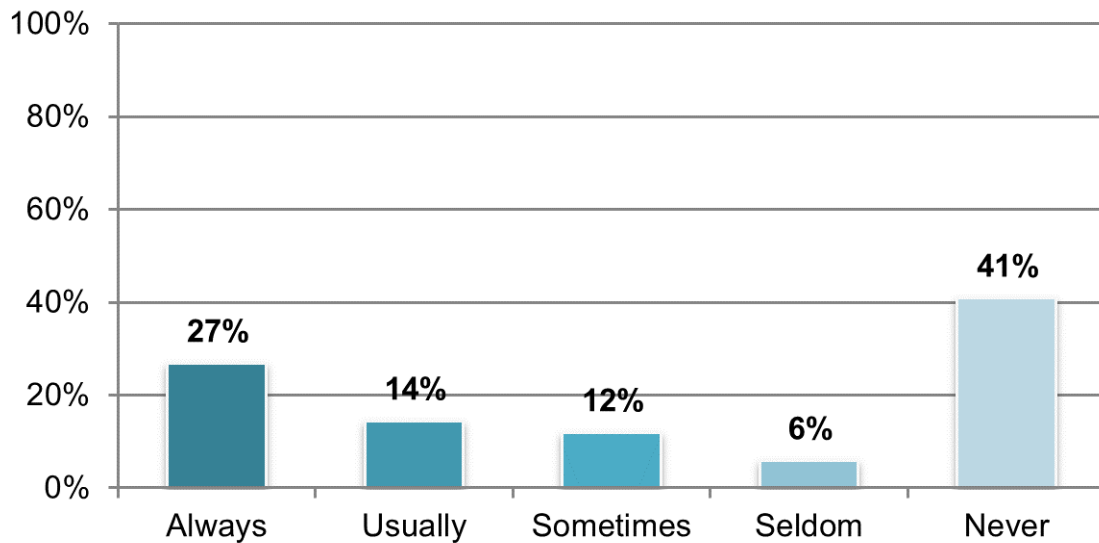


Table Q29. Can your family member choose different support workers if s/he wants to?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
FL	42%	19%	11%	5%	24%	250
OH	41%	14%	10%	2%	32%	314
Within Average Range						
AZ	32%	13%	8%	4%	43%	152
UT	27%	19%	21%	8%	25%	187
SC	26%	13%	13%	8%	40%	95
KY	23%	14%	10%	6%	47%	168
PA	22%	9%	14%	7%	48%	148
GA	21%	14%	9%	6%	51%	184
NC	19%	15%	13%	6%	47%	85
Significantly Below Average						
MD	17%	13%	12%	6%	52%	126
NCI Average	27%	14%	12%	6%	41%	1,709

Family Member Chose Case Manager/Service Coordinator

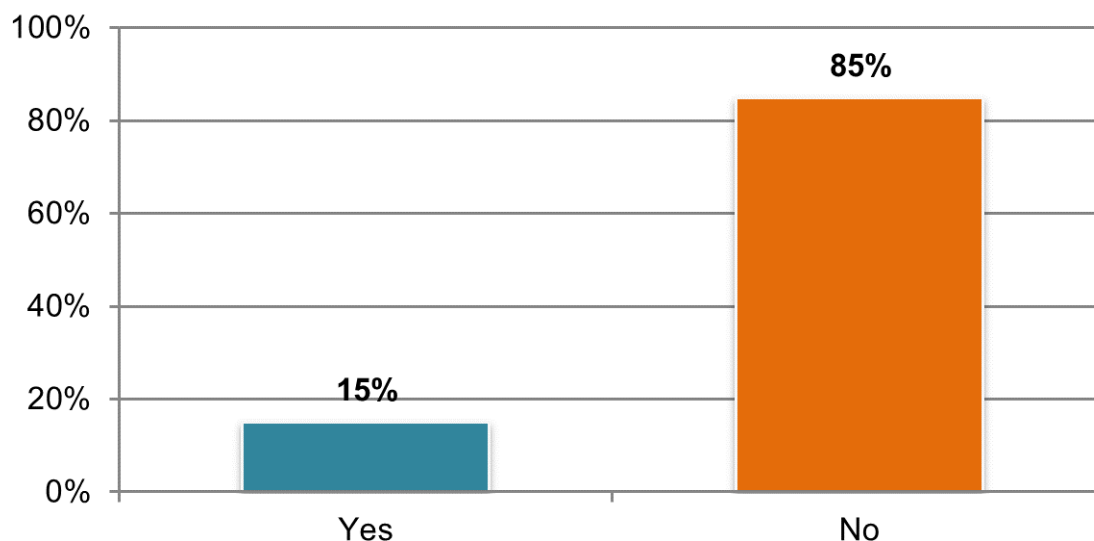


Table Q30. Did your family member choose his/her case manager/service coordinator?

State	Yes	No	N
Significantly Above Average			
FL	43%	57%	310
UT	34%	66%	242
Within Average Range			
KY	14%	86%	258
AZ	13%	87%	222
SC	11%	89%	161
Significantly Below Average			
PA	9%	91%	230
GA	9%	91%	262
MD	6%	94%	190
OH	6%	94%	345
NC	6%	94%	123
NCI Average	15%	85%	2,343

Family Member Has Control or Input Over Hiring and Management of Support Workers

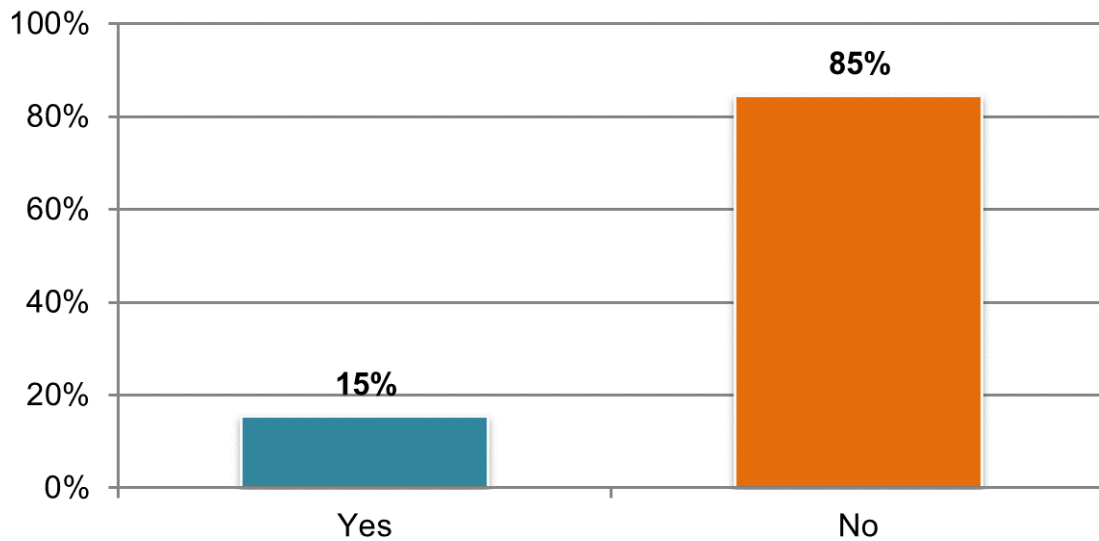


Table Q31. Does your family member have control and/or input over the hiring and management of his/her support workers?

State	Yes	No	N
Significantly Above Average			
FL	40%	60%	296
UT	26%	74%	229
Within Average Range			
OH	17%	83%	343
KY	14%	86%	245
AZ	12%	88%	200
MD	11%	89%	181
GA	11%	89%	245
PA	11%	89%	229
Significantly Below Average			
SC	7%	93%	144
NC	6%	94%	124
NCI Average	15%	85%	2,236

Family Member Knows How Much Money Is Spent by ID/DD Agency on His/Her Behalf

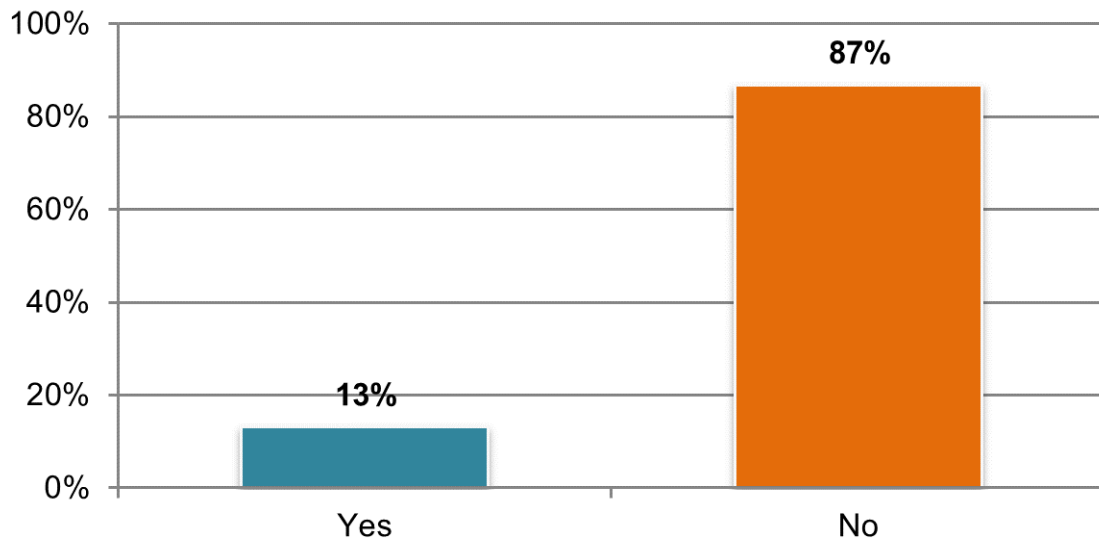


Table Q32. Does your family member know how much money is spent by the ID/DD agency on his/her behalf?³

State	Yes	No	N
Significantly Above Average			
FL	28%	72%	334
Within Average Range			
SC	19%	81%	212
AZ	16%	84%	236
OH	14%	86%	387
KY	14%	86%	264
GA	10%	90%	307
PA	10%	90%	298
Significantly Below Average			
UT	8%	92%	320
NC	6%	94%	142
MD	6%	94%	211
NCI Average	13%	87%	2,711

³ Don't know' responses are included with 'no' responses.

Family Member Has a Say in How ID/DD Agency Money Is Spent

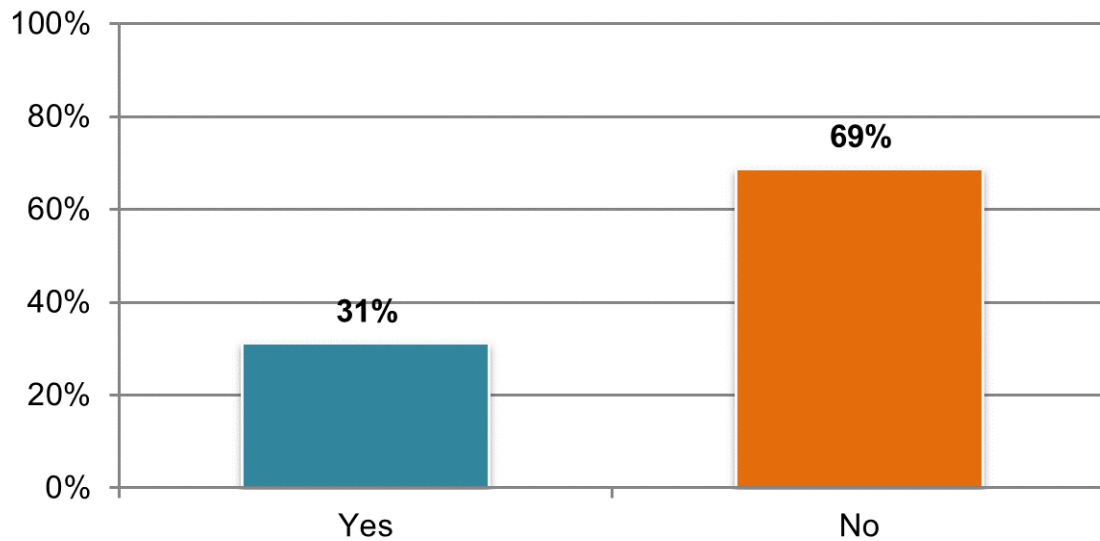


Table Q33. Does your family member have a say in how this money is spent?

State	Yes	No	N
Significantly Above Average			
UT	42%	58%	224
Within Average Range			
SC	41%	59%	139
FL	37%	63%	292
AZ	36%	64%	211
PA	33%	67%	210
KY	30%	70%	235
OH	28%	72%	350
NC	27%	73%	116
Significantly Below Average			
MD	22%	78%	171
GA	16%	84%	245
NCI Average	31%	69%	2,193

Family Member Has All Information Needed to Decide How to Spend ID/DD Agency Money

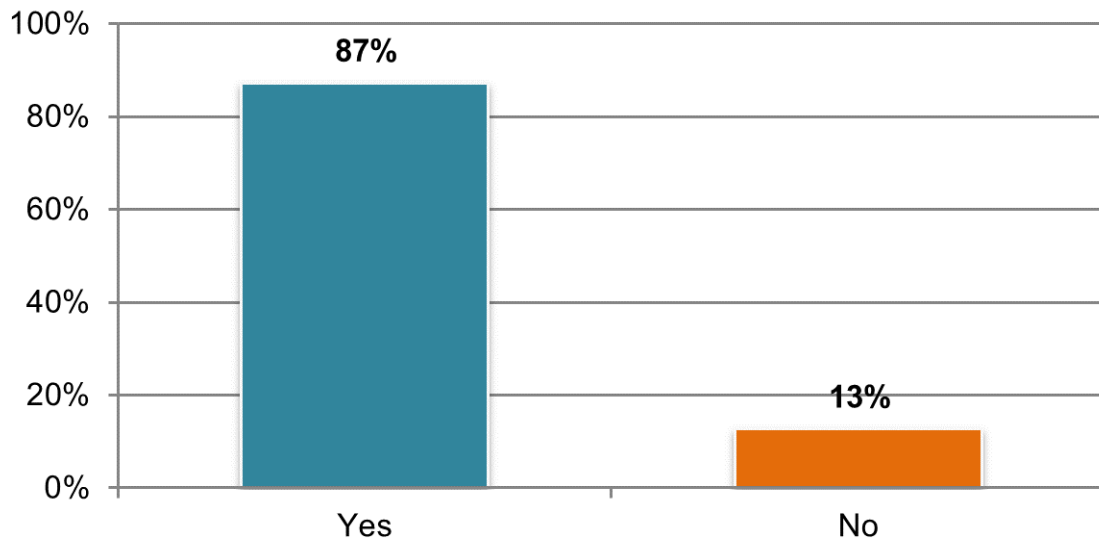


Table 33a. If your family member has a say in how agency money is spent, does s/he have all the information s/he needs to make decisions about how to spend this money?

State	Yes	No	N
Significantly Above Average			
FL	96%	4%	92
OH	95%	5%	94
Within Average Range			
MD	90%	10%	29
AZ	87%	13%	63
GA	87%	13%	31
KY	87%	13%	53
UT	87%	13%	68
SC	83%	17%	42
NC	81%	19%	26
PA	81%	19%	57
NCI Average	87%	13%	555

Community Connections

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

Across states, the vast majority of respondents indicate that their family member participates in community activities (93%); of those who report that their family member does not, 20% cite a lack of transportation as the main reason, 32% cite a lack of support staff, and 58% cite other reasons not listed. About three-quarters of respondents report that their family member has enough support to work or volunteer in the community (74%).

Note: An ‘n/a’ designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Family Member Participates in Community Activities

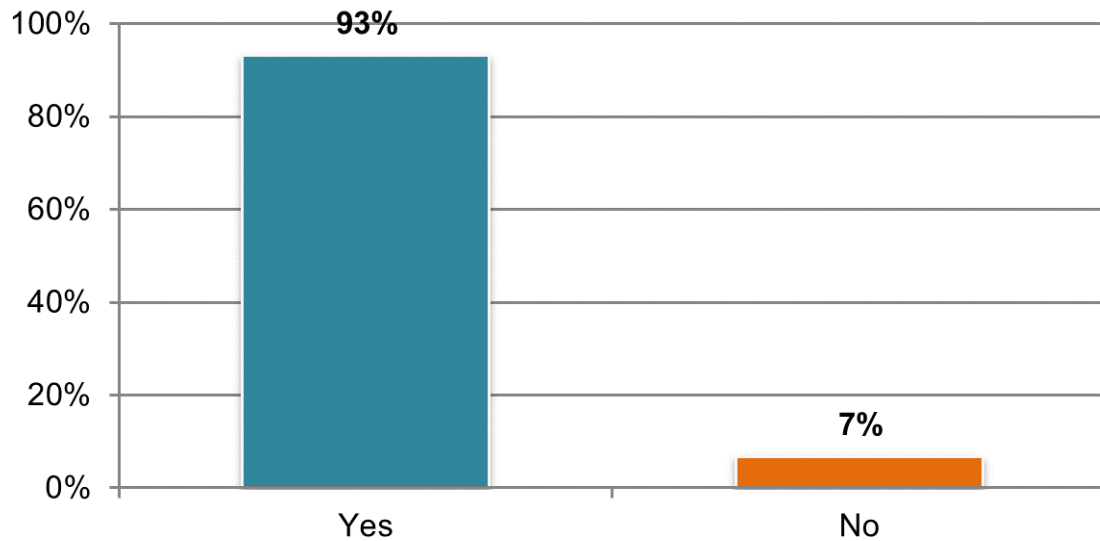


Table Q34. Does your family member participate in community activities (such as going out to a restaurant, movie, or sporting event)?

State	Yes	No	N
Within Average Range			
NC	96%	4%	167
UT	95%	5%	355
OH	94%	6%	392
FL	94%	6%	371
SC	94%	6%	213
AZ	93%	7%	273
GA	93%	7%	326
PA	92%	8%	345
KY	92%	8%	296
MD	89%	11%	221
NCI Average	93%	7%	2,959

Reasons Family Member Does Not Participate in Community Activities

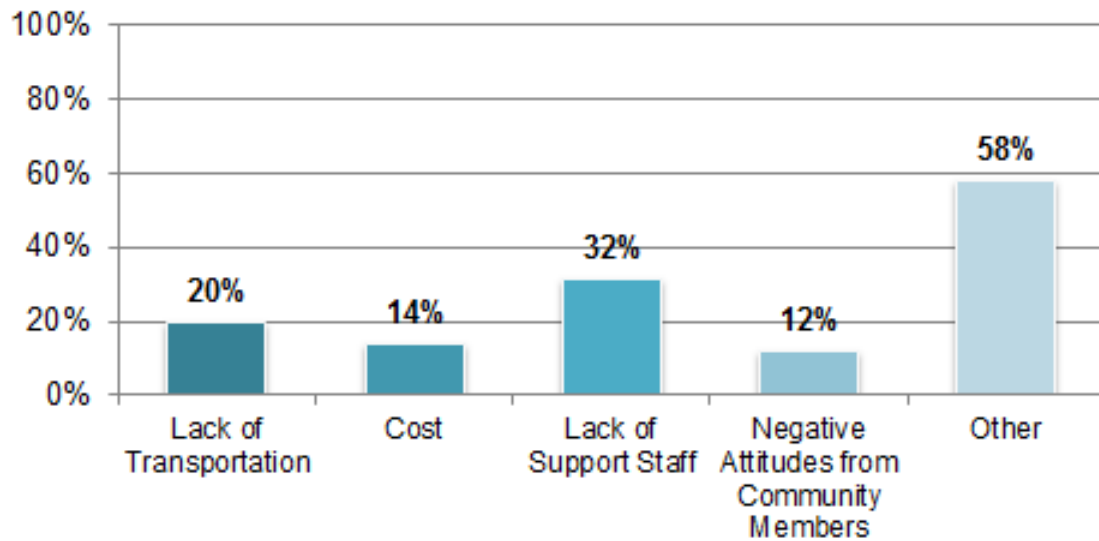


Table 34a. If your family member doesn't participate in community activities, why not?⁴

State	Lack of Transportation	Cost	Lack of Support Staff	Negative Attitudes from Community Members	Other
Within Average Range					
GA	27%	23%	23%	23%	41%
KY	38%	10%	62%	0%	43%
MD	24%	28%	40%	28%	64%
OH	0%	5%	9%	5%	86%
PA	10%	5%	24%	5%	57%
AZ	n/a	n/a	n/a	n/a	n/a
FL	n/a	n/a	n/a	n/a	n/a
NC	n/a	n/a	n/a	n/a	n/a
SC	n/a	n/a	n/a	n/a	n/a
UT	n/a	n/a	n/a	n/a	n/a
NCI Average	20%	14%	32%	12%	58%

⁴ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Family Member Has Friends or Relationships With People Other Than Paid Staff or Family

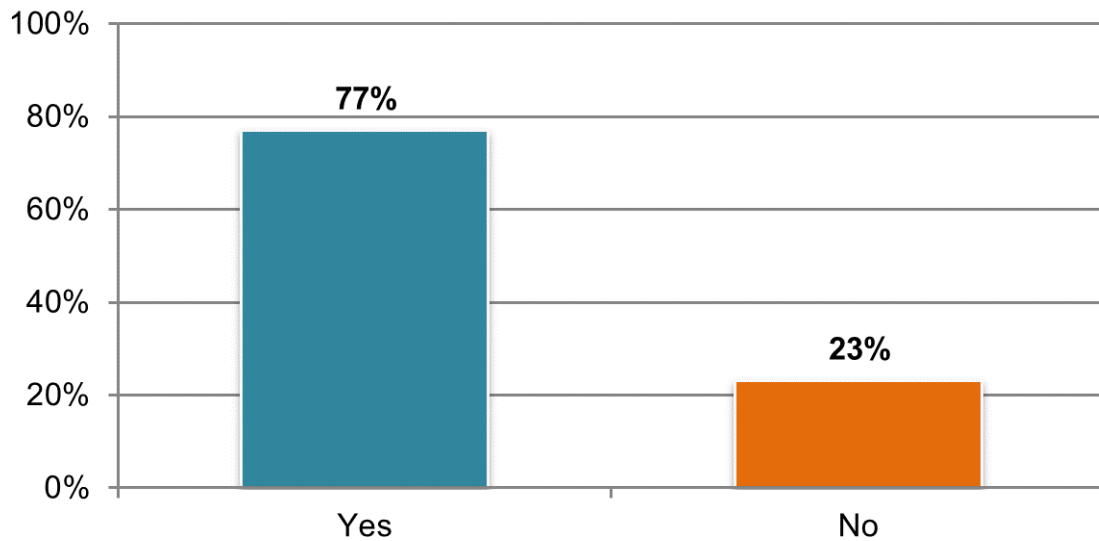


Table Q35. Does your family member have friends or relationships with persons other than paid staff or family?

State	Yes	No	N
Significantly Above Average			
KY	83%	17%	266
Within Average Range			
PA	82%	18%	309
OH	80%	20%	372
SC	80%	20%	206
FL	77%	23%	345
GA	75%	25%	305
MD	74%	26%	205
NC	73%	27%	147
UT	73%	27%	326
AZ	73%	27%	255
NCI Average	77%	23%	2,736

Family Member Has Enough Support to Work or Volunteer in the Community

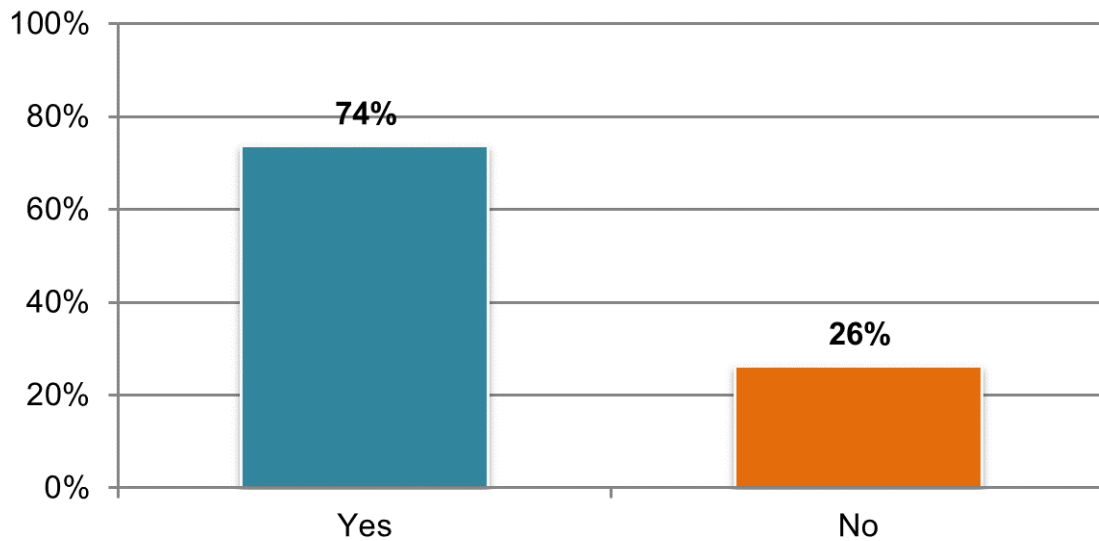


Table Q36. Does your family member have enough support (support workers, community resources, etc.) to work or volunteer in the community?

State	Yes	No	N
Within Average Range			
AZ	80%	20%	198
PA	80%	20%	237
UT	80%	20%	259
SC	77%	23%	136
NC	74%	26%	111
KY	73%	27%	204
GA	72%	28%	227
MD	69%	31%	157
FL	66%	34%	243
Significantly Below Average			
OH	66%	34%	337
NCI Average	74%	26%	2,109

Satisfaction With Services and Supports

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

Close to half of all respondents across the states report that they are always satisfied with the services and supports their family member receives (48%). Two-thirds indicate that they know the process for filing a complaint or grievance against their family member's provider agency or staff (66%) and 79% indicate that they know how to report abuse or neglect.

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

Respondent Is Overall Satisfied With Services and Supports Family Member Receives

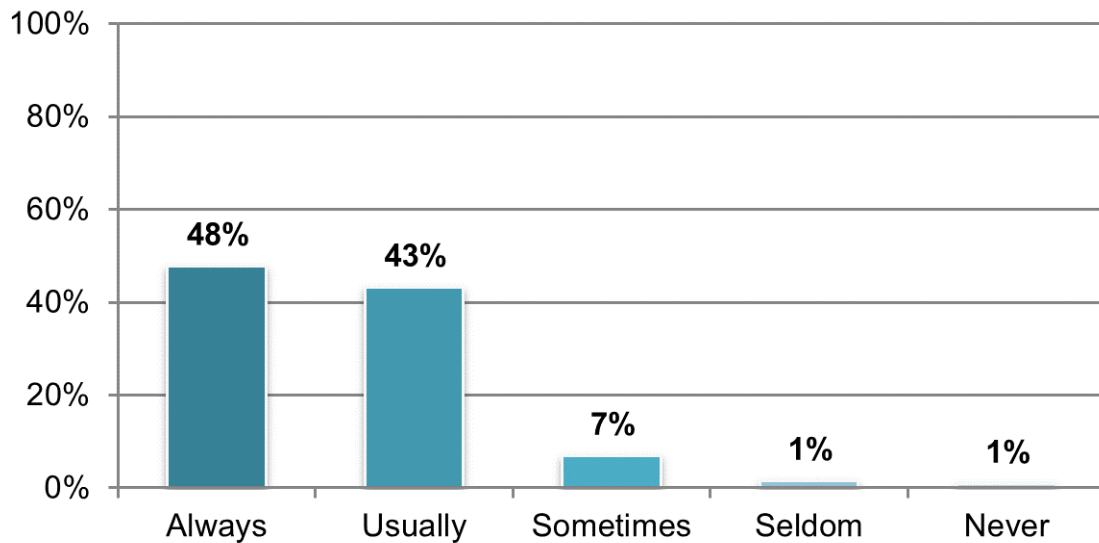


Table Q37. Overall, are you satisfied with the services and supports your family member currently receives?

State	Always	Usually	Sometimes	Seldom	Never	N
Significantly Above Average						
OH	62%	28%	6%	2%	2%	394
NC	60%	36%	4%	0%	0%	171
Within Average Range						
AZ	50%	46%	3%	1%	0%	276
SC	47%	43%	8%	1%	0%	226
PA	46%	47%	6%	1%	0%	352
FL	45%	43%	9%	1%	1%	373
GA	45%	42%	9%	3%	1%	343
MD	42%	45%	9%	2%	2%	222
Significantly Below Average						
UT	40%	50%	7%	1%	1%	354
KY	39%	51%	8%	2%	0%	302
NCI Average	48%	43%	7%	1%	1%	3,013

Respondent Knows How to File a Complaint or Grievance Against Provider Agencies or Staff

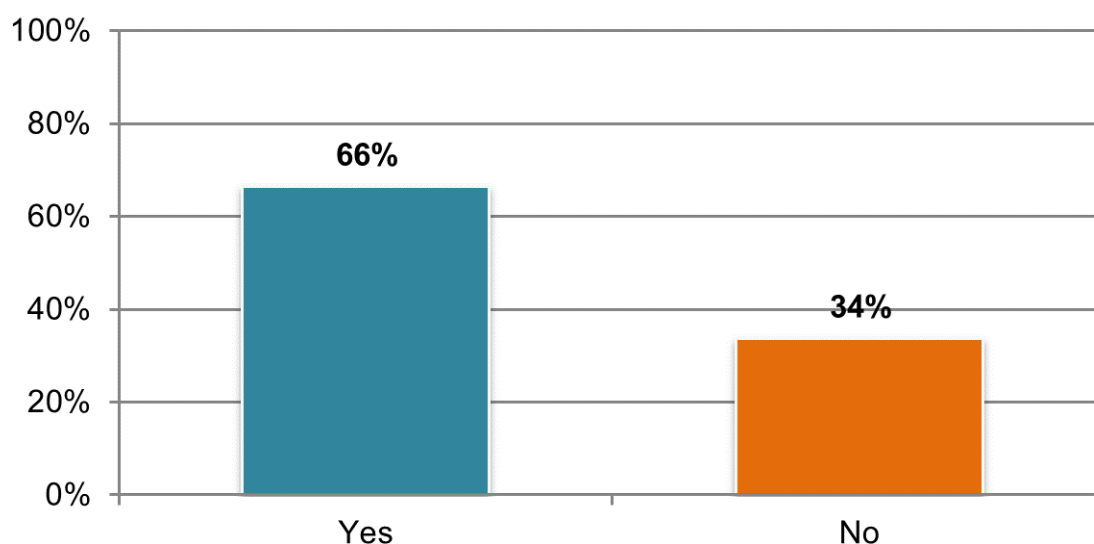


Table Q38. Do you know the process for filing a complaint or grievance against provider agencies or staff?⁵

State	Yes	No	N
Significantly Above Average			
NC	80%	20%	166
FL	77%	23%	373
OH	75%	25%	397
KY	74%	26%	301
Within Average Range			
AZ	71%	29%	275
UT	64%	36%	358
PA	63%	37%	342
Significantly Below Average			
GA	58%	42%	347
SC	55%	45%	226
MD	48%	52%	227
NCI Average	66%	34%	3,012

⁵ 'Don't know' responses are included with 'no' responses.

Respondent Is Satisfied With How Complaints or Grievances Against Provider Agencies or Staff Are Handled and Resolved

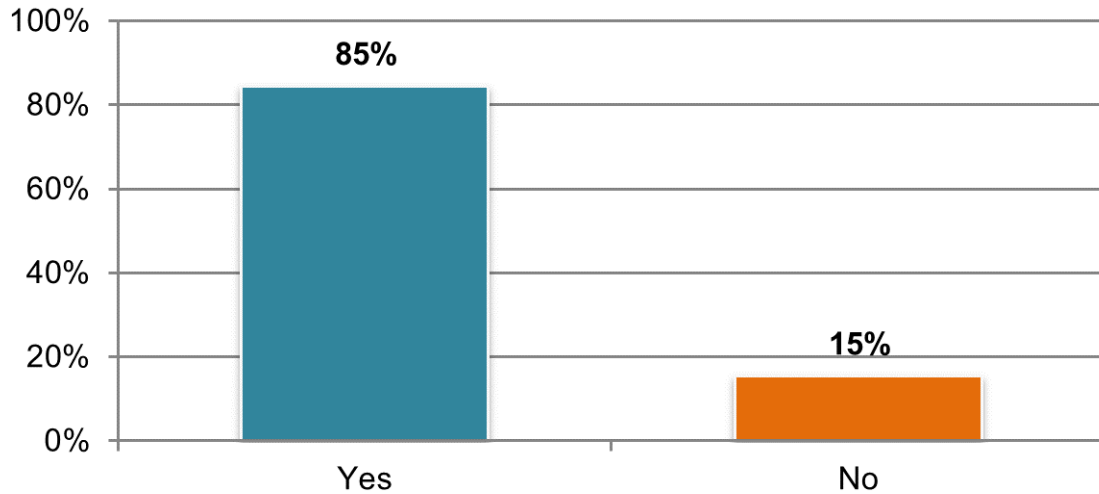


Table Q39. Are you satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved?

State	Yes	No	N
Within Average Range			
PA	91%	9%	180
AZ	90%	10%	156
UT	90%	10%	213
OH	89%	11%	217
SC	84%	16%	131
FL	83%	17%	224
GA	83%	17%	170
NC	82%	18%	113
KY	81%	19%	200
Significantly Below Average			
MD	72%	28%	115
NCI Average	85%	15%	1,719

Respondent Knows How to Report Abuse or Neglect

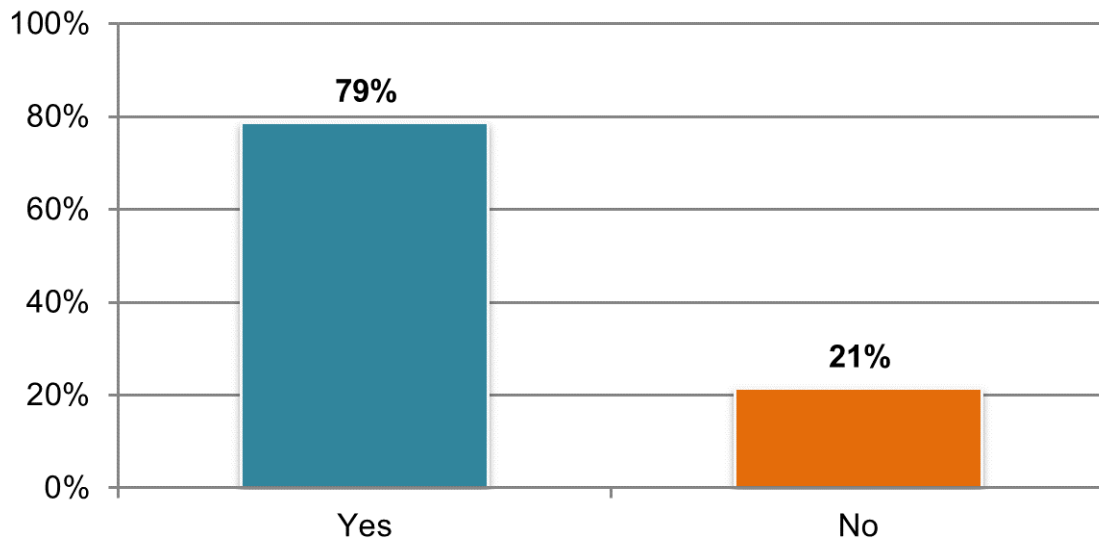


Table Q40. Do you know how to report abuse or neglect?⁶

State	Yes	No	N
Significantly Above Average			
FL	87%	13%	366
OH	87%	13%	397
KY	85%	15%	297
Within Average Range			
AZ	84%	16%	271
NC	83%	17%	169
SC	76%	24%	224
UT	76%	24%	358
PA	75%	25%	340
Significantly Below Average			
GA	72%	28%	344
MD	60%	40%	223
NCI Average	79%	21%	2,989

⁶ 'Don't know' responses are included with 'no' responses.

Respondent Reported Abuse or Neglect in the Past Year

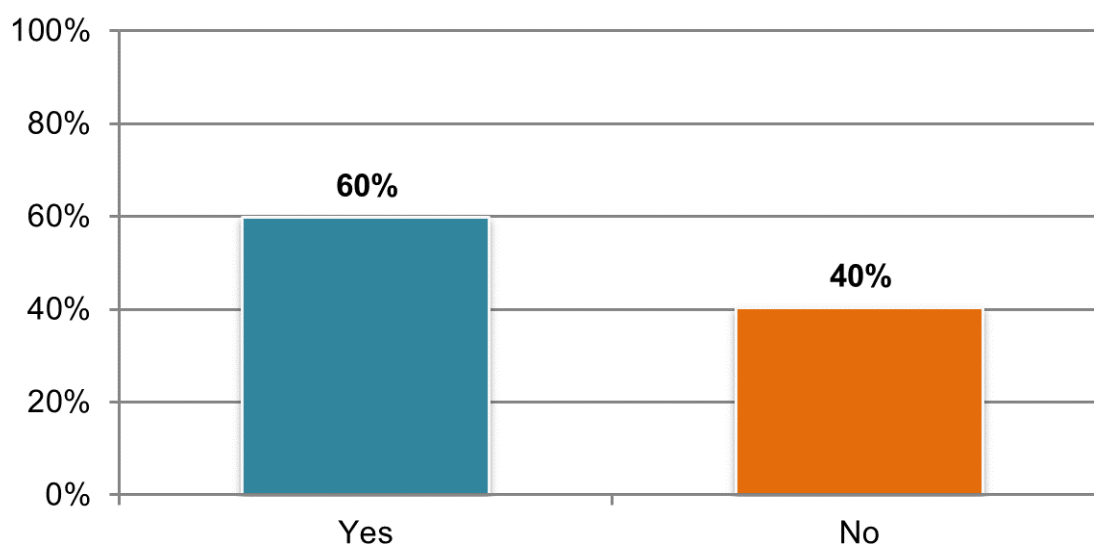


Table Q41. Within the past year, if abuse or neglect occurred, did you report it?

State	Yes	No	N
Within Average Range			
SC	74%	26%	61
NC	69%	31%	32
PA	62%	38%	50
MD	61%	39%	51
KY	60%	40%	68
GA	59%	41%	74
FL	59%	41%	73
AZ	54%	46%	56
UT	52%	48%	79
OH	48%	52%	71
NCI Average	60%	40%	615

Appropriate People Were Responsive to Abuse/Neglect Report (Past Year)

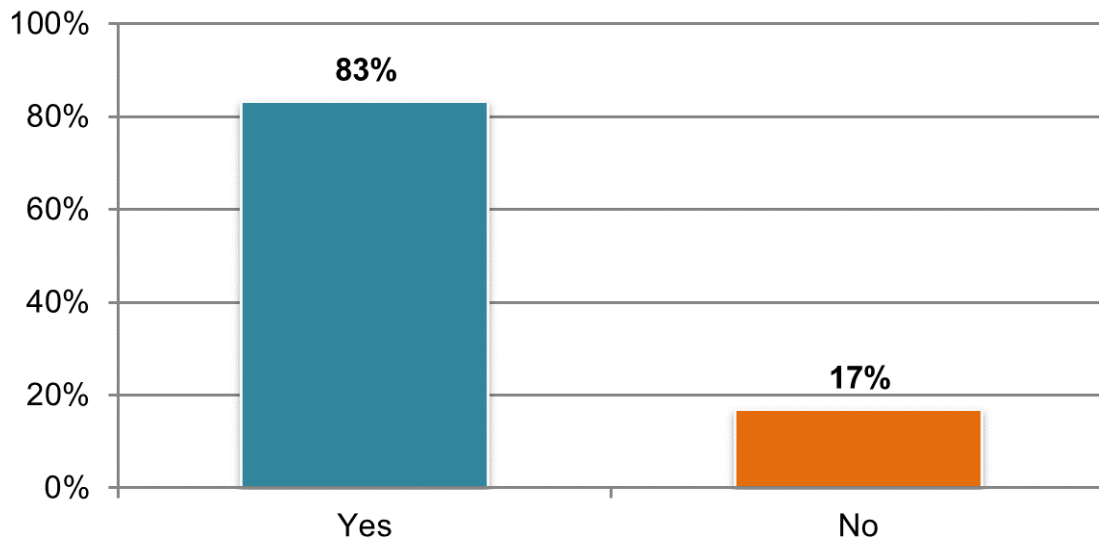


Table 41a. If you reported abuse or neglect in the past year, were the appropriate people responsive to your report?⁷

State	Yes	No	N
Within Average Range			
SC	93%	7%	29
UT	92%	8%	26
PA	90%	10%	29
MD	86%	14%	21
GA	85%	15%	26
AZ	83%	17%	23
OH	77%	23%	30
FL	74%	26%	31
KY	70%	30%	33
NC	n/a	n/a	n/a
NCI Average	83%	17%	248

⁷ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

Family Outcomes

Individual and family supports make a positive difference in the lives of families.

Nearly all respondents say that services and supports have made a positive difference in their family member's life (97%). Most report that services and supports have reduced out-of-pocket expenses for their family member's care (88%). Just over one-fifth of respondents indicate that services and supports have been reduced, suspended, or terminated in the past year (21%); of those, 67% felt that this change had a negative impact on their family member.

Note: An 'n/a' designation within the following tables indicates that there were too few cases to report (fewer than 20 responses).

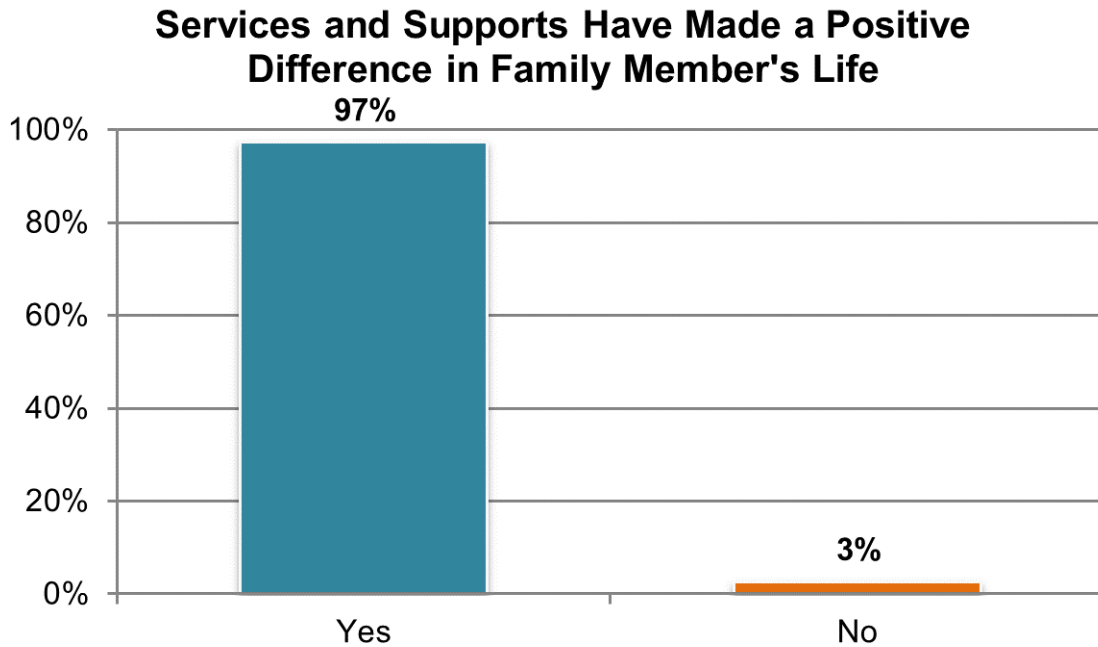


Table Q42. Do you feel that services and supports have made a positive difference in the life of your family member?

State	Yes	No	N
Significantly Above Average			
NC	99%	1%	170
Within Average Range			
PA	99%	1%	337
UT	98%	2%	349
AZ	98%	2%	264
KY	98%	2%	249
OH	97%	3%	389
FL	97%	3%	360
GA	96%	4%	299
MD	96%	4%	217
SC	95%	5%	209
NCI Average	97%	3%	2,843

Services and Supports Have Reduced Out-of-Pocket Expenses

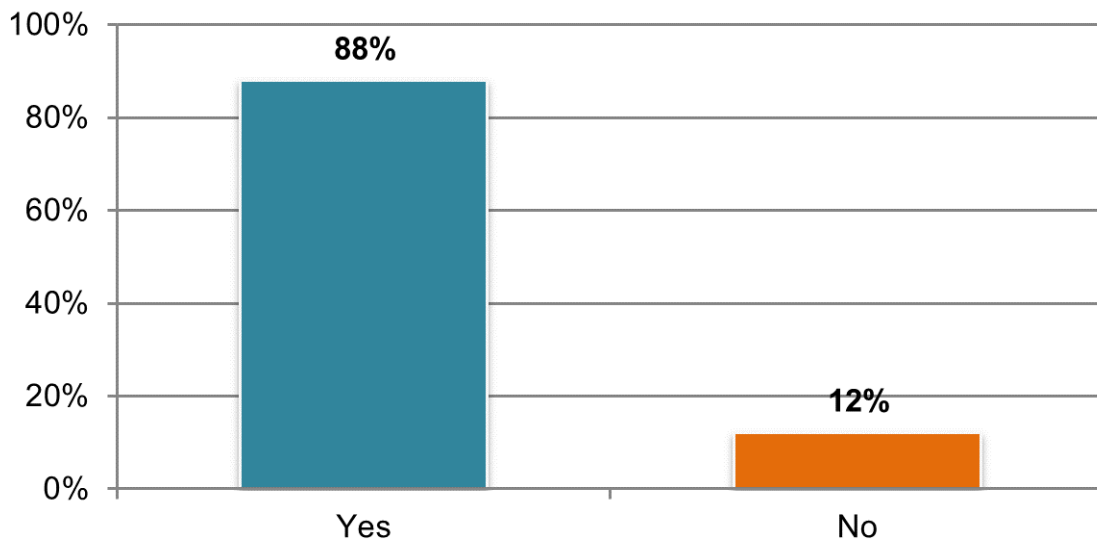


Table Q43. Do you feel that services and supports have reduced your family's out-of-pocket expenses for your family member's care?

State	Yes	No	N
Significantly Above Average			
PA	93%	7%	254
Within Average Range			
MD	90%	10%	195
UT	90%	10%	280
SC	89%	11%	179
NC	89%	11%	123
FL	87%	13%	308
OH	87%	13%	343
KY	86%	14%	223
AZ	85%	15%	220
GA	84%	16%	242
NCI Average	88%	12%	2,367

Services or Supports Have Been Reduced, Suspended, or Terminated in the Past Year

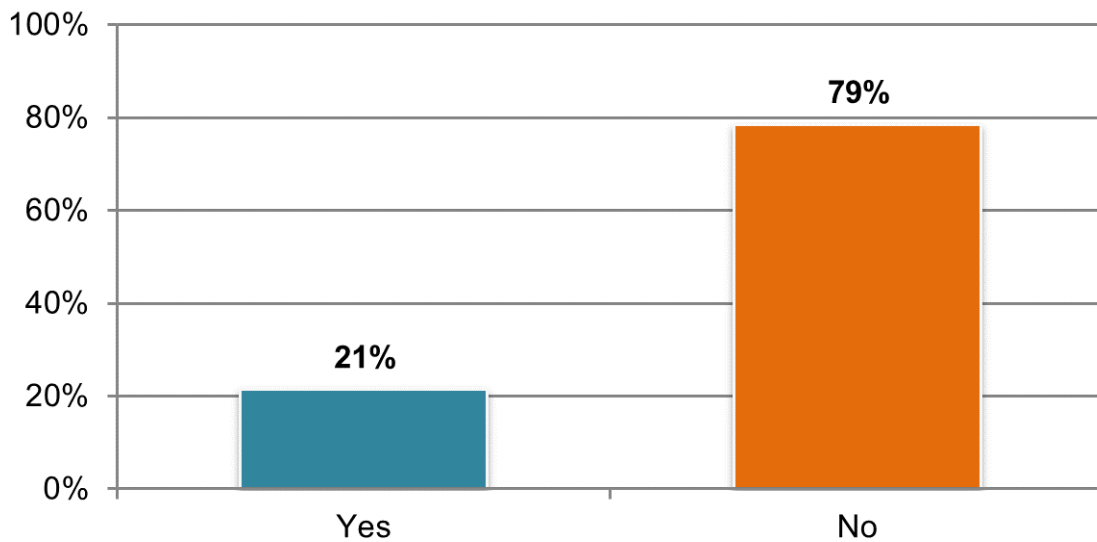


Table Q44. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?⁸

State	Yes	No	N
Significantly Above Average			
FL	59%	41%	314
Within Average Range			
NC	26%	74%	130
SC	19%	81%	161
AZ	19%	81%	227
PA	18%	82%	250
GA	17%	83%	226
OH	17%	83%	345
MD	14%	86%	173
Significantly Below Average			
UT	14%	86%	248
KY	11%	89%	224
NCI Average	21%	79%	2,298

⁸ The 'yes' response is the less desired response; a higher average means more people reported services or supports were reduced, suspended or terminated in the past year.

Service Reduction, Suspension, or Termination Affected the Family Member Negatively

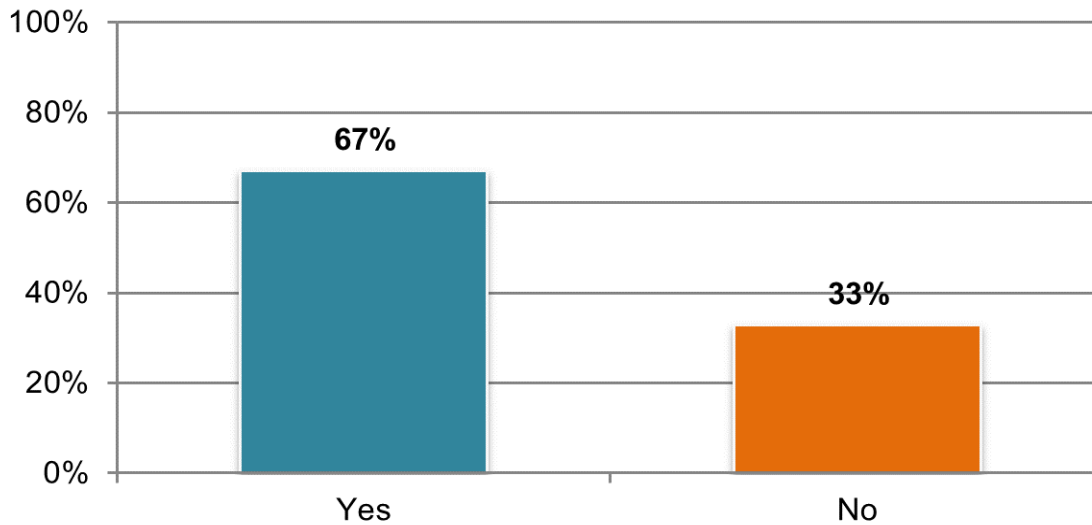


Table 44a. If services or supports received by your family member were reduced, suspended, or terminated during the past year, did the reduction, suspension, or termination of these services or supports affect your family member negatively?⁹¹⁰

State	Yes	No	N
Significantly Above Average			
FL	84%	16%	140
Within Average Range			
UT	80%	20%	25
AZ	76%	24%	37
SC	70%	30%	23
NC	67%	33%	30
GA	66%	34%	29
OH	51%	49%	53
Significantly Below Average			
PA	45%	55%	40
KY	n/a	n/a	n/a
MD	n/a	n/a	n/a
NCI Average	67%	33%	377

⁹ The 'yes' response is the less desired response; a higher average means more people reported reduction, suspension, or termination of services had a negative impact on the family.

¹⁰ An 'n/a' designation indicates that there were too few cases to report (fewer than 20 responses).

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

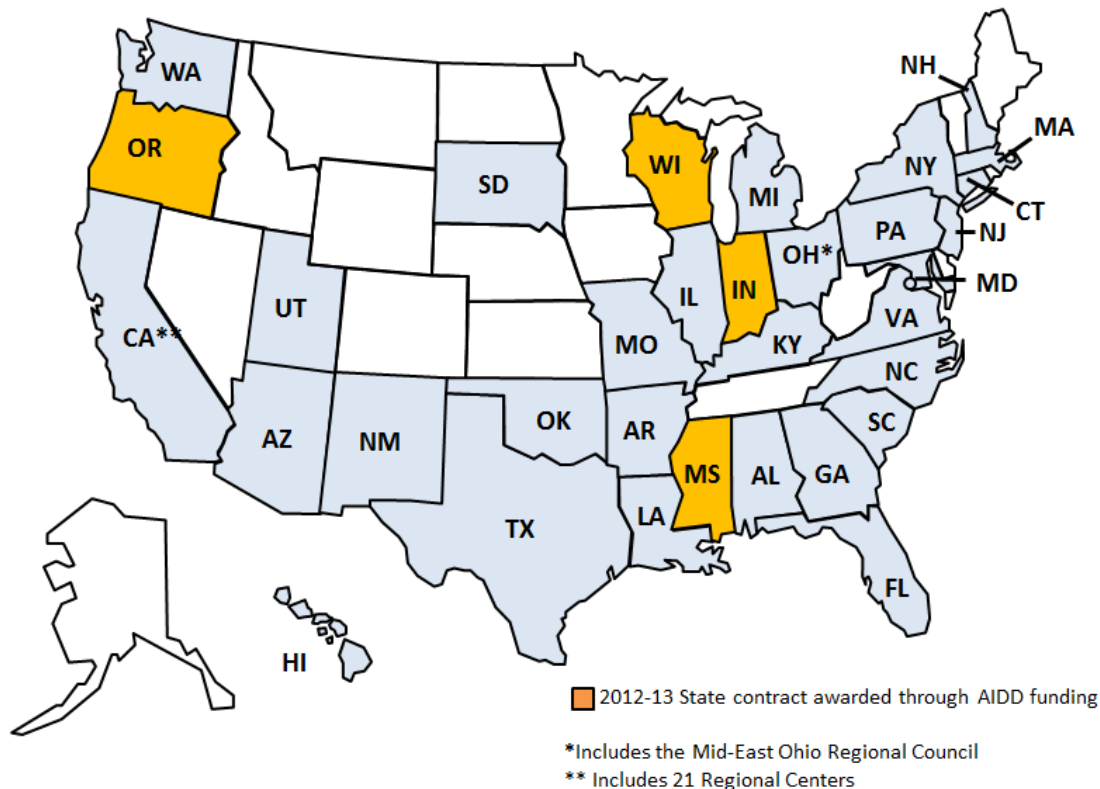
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult Consumer Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states 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 <http://www.nationalcoreindicators.org>.

State Participation

During the 2012-2013 data collection cycle, 34 states and 22 sub-state entities participated in NCI. State participation is entirely voluntary, and the participating states are shown in the chart below.

Chart 1. NCI State Participation 2012-13



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 <http://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 include 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 (please see Table 1 on the following page). Four data sources are used to assess outcomes: the Adult Consumer 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.

Family Survey Sub-Domains and Concern Statements

Sub-Domain	Concern
Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.
Choice & Control	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
Community Connections	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.
Family 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).

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 in which several states’ results are especially high (considerably above the average level) indicate the levels of performance or satisfaction achieved in those states might define a level of performance that may serve as a guidepost for other states.

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

III. 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 living outside the home; and
2. Received at least one direct service or support other than service coordination.

All states mailed out a paper survey to families selected in their sample¹¹. 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 no greater than +/- 7%.¹²

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 a developmental disability lived in the family home.

¹¹ Ohio conducted surveys via phone, their data should be reviewed with caution.

¹² See “Response Rates” section for information on total surveys mailed and received by states as well as each state’s margin of error.

2. Demographic information was entered into the file but no survey questions were answered.

Statistical significance testing was conducted on each state’s “yes” or “always” response compared to the NCI average¹³; 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 2012-2013, 10 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% and less) margin of error; their data are included in this report. The table below shows the number of surveys each state mailed, usable surveys returned, response rates, the number of individuals receiving services who were eligible to be drawn into the sample, and each state’s margin of error.

Family/Guardian Survey: State Response Rates¹⁴

State	Number Eligible to Be Drawn Into the Sample	Surveys Mailed	Usable Surveys Returned	Response Rate	Margin of Error
AZ	3,625	1,000	281	28%	5.6%
FL	6,853	1,700	409	24%	4.7%
GA	2,936	1,600	388	24%	4.6%
MD	10,227	1,756	242	14%	6.2%
NC	9,240	800	174	22%	7.4%
SC	4,847	1,000	234	23%	6.3%
UT	1,700	980	380	39%	4.4%

¹³ The NCI Average is the sum of all state averages divided by the total number of states.

¹⁴ KY, OH, and PA did not provide sampling information