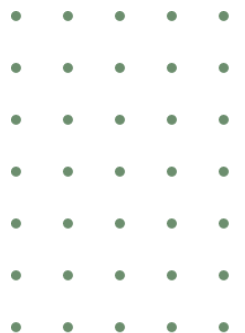


National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)



National Report 2022-23

Child Family Survey (CFS)





Human Services Research Institute

Human Services Research Institute (HSRI)

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NASDDDS

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of

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June 2024

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List of Acronyms Used in This Report

CFS	Child Family Survey
CMS	Centers for Medicare & Medicaid Services
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

Table of Contents

Executive Summary	9
Results.....	10
Presentation of the Data	11
Demographics.....	12
Child	13
Table 1. More Than One Child Living in the Home Has IDD.....	14
Table 2. Child’s Age.....	15
Table 3. Child’s Gender.....	16
Table 4. Child’s Race and Ethnicity	17
Table 5a. Child’s Conditions	18
Table 5b. Child’s Conditions (Continued).....	19
Table 5c. Child’s Conditions (Continued).....	20
Table 6a. Child’s Health Conditions.....	21
Table 6b. Child’s Health Conditions (continued)	22
Table 6c. Child’s Health Conditions (continued)	23
Table 7. Family Member’s Preferred Language	24
Table 8. Child’s Preferred Means of Communication	25
Table 9. Child’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	26
Table 10. Child’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)	27
Respondents	28
Table 11. Language Usually Spoken at Home.....	29
Table 12. Respondent’s Age.....	30
Table 13. Respondent’s Health	31
Table 14. Respondent’s Relationship to Child	32
Table 15. Respondent or Other Family Member Provides Paid Support to Child.....	33
Table 16. Number of Adults in Household.....	34
Table 17. Number of Children (Under 18 years old) in Household (including the child receiving services).....	35
Table 18. Respondent’s Highest Level of Education.....	36
Table 19. Total Taxable Household Income of Wage Earners in the Past 12 Months	37
Table 20. Residential Designation.....	38
Services and Supports Received.....	39
Table 21a. Services and Supports Received from ID/DD Agency.....	40

Table 21b. Services and Supports Received from ID/DD Agency (continued) 41

Table 22. Additional Services and Supports Received (not from the IDD Agency) 42

Main Survey Results 43

Information and Planning 44

Table 23. Do you have enough information to take part in planning services for your child? 45

Table 24. Is the information you get about services and supports easy to understand? 46

Table 25. Do you get information about services and supports in your preferred language? ... 47

Table 26. Does the case manager/service coordinator listen to your family’s choices and opinions? 48

Table 27. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)? 49

Table 28a. Do you need help planning for your child’s future in any of these areas? 50

Table 28b. Do you need help planning for your child’s future in any of these areas? (Continued) 51

Table 29. Has your family learned about alternatives to guardianship? 52

Table 30. Does your child have a service plan? 53

Table 31. Does the plan include all the services and supports your child needs? 54

Table 32. Did you or another family member help make the plan? 55

Table 33. Did your child help make the plan? 56

Table 34. Do you feel like your family had enough say or input in making the plan? 57

Table 35. Does your child have a transition plan (as part of an IEP or Section 504 plan through their high school, usually starting at age 14)? 58

Table 36. If your child has a transition plan, did you or another family member help make the plan? 59

Table 37. If your child has a transition plan, did your child help make the plan? 60

Access and Delivery of Services and Supports 61

Table 38. Does your child get all the services listed in the plan? 62

Table 39. Does your family get the supports and services it needs? 63

Table 40a. What additional services does your child need? 64

Table 40b. What additional services does your child need? (Continued) 65

Table 41. Do services and supports change when your family’s needs change? 66

Table 42. Does your child have the special equipment or accommodations they need? 67

Table 43. If you need respite services, how often are you able to get them when needed? 68

Table 44. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services? 69

Table 45. Are you able to contact your child’s support workers when you want? 70

Table 46. Are you able to contact your child’s case manager or service coordinator when you want?	71
Table 47. Do service providers for your child work together to provide support?.....	72
Table 48. Are services delivered in a way that is respectful of your family’s culture?.....	73
Table 49. Does your child use technology in their everyday life to help them do more things on their own?	74
Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home?.....	75
Table 51. How well does the internet work in your home?	76
Workforce	77
Table 52. Do support workers come and go when they are supposed to?.....	78
Table 53. Do support workers speak to you in a way you understand?	79
Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child?.....	80
Table 55. Do support workers have the right information and skills to meet your family’s needs?	81
Table 56. Do your child’s support workers change too often? Is there too much “turnover” of support workers?.....	82
Table 57. Is there always a staff person available to support your child when support is needed?.....	83
Choice, Decision Making and Control	84
Table 58. Can someone in your family choose or change the provider agency that provides your child’s services?	85
Table 59. Can someone in your family choose or change your child’s support workers?	86
Table 60. Can someone in your family directly manage support staff?	87
Table 61. Did you, your child, or someone else in your family choose your child’s case manager or service coordinator?.....	88
Involvement in the Community	89
Table 62. Does your child do things in the community?	90
Table 63. What makes it hard to do things in the community?	91
Table 64. Does your child spend time with children who do not have developmental disabilities?	92
Table 65. In your community, are there resources that your family and child can use that are not provided by the I/DD agency?	93
Table 66. Does your family take part in any family-to-family networks in your community?	94
Health, Welfare, and Safety.....	95
Table 67. Can your child see a primary care provider (doctor, registered nurse, etc.) when needed?.....	96

Table 68. Does your child’s primary care doctor understand your child’s needs related to their disability?	97
Table 69. Can your child go to the dentist when needed?	98
Table 70. Does your child’s dentist understand your child’s needs related to their disability? ..	99
Table 71. If your child takes prescription medications, do you know what they’re for?	100
Table 72. Do you 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)?	101
Table 73. Can your child get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)	102
Table 74. If your child uses mental health services, does the mental health professional understand your child’s needs related to their disability?	103
Table 75. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?	104
Table 76. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or natural disaster?	105
Table 77. Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child’s case manager/service coordinator?	106
Table 78. Do you know how to file a complaint or grievance about provider agencies or staff?	107
Table 79. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?	108
Table 80. Do you know how to report abuse or neglect related to your child?	109
Table 81. Within the past 12 months, was a report of abuse or neglect filed on behalf of your child?	110
Table 82. If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?	111
Satisfaction With Services and Supports.....	112
Table 83. Overall, are you satisfied with the services and supports your child currently receives?	113
Table 84. Do you feel that services and supports have made a positive difference in the life of your child?	114
Table 85. Have services and supports reduced your family’s out-of-pocket expenses for your child’s care?	115
Table 86. Do you feel that family supports have improved your ability to care for your child? ..	116
Table 87. Have the services or supports that your child received during the past 12 months been reduced, suspended, or terminated?	117

Table 88. 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 or your child negatively?	118
Table 89. Have the services or supports that your child received been increased in the past 12 months?	119
Table 90. Are services and supports helping your child to live a good life?	120
Overview of National Core Indicators.....	121
State Participation	121
Figure 1. NCI-IDD State Participation 2022-23	122
The Core Indicators	122
Sub-Domains and Concern Statements	123
Figure 2. Family Survey Sub-Domains and Concern Statements	123
How NCI-IDD Data Are Used	123
Caution and Limitations	124
Methodology	125
Sampling & Administration.....	126
Weighting.....	126
Significance Testing.....	127
Technical Details	127
Data Entry and Analysis.....	127
Response Rates	128
Figure 3. Child Family Survey: State Response Rates	129

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) Child Family Survey is administered to families who have a child who lives in the family home and receives at least one service in addition to case management from the state DD agency. A Child Family Survey could be completed for an individual up to 22 years if still receiving “child” services. Not all states that participate in NCI-IDD administer the Child Family Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI-IDD during the 2022-23 data collection cycle, 9 states submitted a valid sample of Child Family Survey data: Florida (FL), Indiana (IN), Missouri (MO), North Dakota (ND), Oregon (OR), South Dakota (SD), Tennessee (TN), Texas (TX), and Wisconsin (WI). This Final Report provides a summary of results based on data submitted by June 30, 2023.

Results

Presentation of the Data

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

- Each question is constructed so the respondent selects from either four possible responses (“always,” “usually,” “sometimes,” “seldom/never”) or two responses (“yes” or “no”). Respondents also have the option to indicate that they don’t know the answer to a question or that the question is not applicable.
- Demographic results are shown in table form with states listed alphabetically. Outcomes are shown first with a chart depicting the NCI-IDD Average. The charts are followed by accessible tables showing state outcomes and the NCI-IDD Average listed in descending order, grouped by level of significance.
- Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI-IDD Average range, their ‘always’ or ‘yes’ response was not statistically different from the NCI-IDD Average.
- States with 20 or fewer respondents to a question are not included in tables; however, their data **are** included in the NCI-IDD Average.
- **Note on Significance:** Statistical significance depends on both the amount by which a state differs from the average for a given item and the state’s sample size for that item. So, there may be instances where State A’s difference from the average is larger than State B’s, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.
- **Note on NCI-IDD Averages:** The NCI-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the states’ sample sizes. Prior to 2016-17, NCI-IDD averages were calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.
- **Note on language used in this report:** “You” and “Respondent” refers to the person (usually a parent or guardian) filling out the survey. “Child” 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 child’s demographics, diagnoses and personal characteristics.

Demographics

Note on responses: All data are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics. **Note on page orientation:** The pages in this section are in landscape orientation because some table headers cannot be displayed in full in portrait orientation.

Child

This section provides demographic information about the child receiving services.

Table 1. More Than One Child Living in the Home Has IDD

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

State (names abbreviated)	Yes	No	N
FL	57%	43%	152
IN	73%	27%	299
MO	70%	30%	186
ND	68%	32%	202
OR	63%	37%	603
SD	73%	27%	153
TN	69%	31%	175
TX	60%	40%	306
WI	68%	32%	675
Weighted NCI-IDD Average	66%	34%	2,751

Table 2. Child's Age

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

State (names abbreviated)	Age	N
FL	14.6	154
IN	11.3	307
MO	11.5	190
ND	10.2	209
OR	11.7	620
SD	10.3	160
TN	8.1	188
TX	12.2	316
WI	9.4	700
Weighted NCI-IDD Average	11.1	2,844

Table 3. Child's Gender

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

State (names abbreviated)	Male	Female	Other	N
FL	75%	25%	0%	154
IN	65%	35%	0%	304
MO	80%	20%	0%	190
ND	67%	33%	0%	209
OR	64%	35%	0%	621
SD	67%	33%	0%	157
TN	65%	35%	0%	189
TX	58%	42%	0%	316
WI	65%	35%	0%	700
Weighted NCI-IDD Average	64%	36%	0%	2,840

Table 4. Child's Race and Ethnicity

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

State (names abbreviated)	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer not to say
FL	1%	7%	16%	0%	63%	33%	1%	2%
IN	0%	4%	8%	0%	81%	10%	2%	0%
MO	3%	4%	12%	0%	86%	6%	2%	1%
ND	6%	3%	4%	1%	91%	6%	1%	1%
OR	5%	7%	5%	2%	78%	17%	2%	3%
SD	7%	4%	5%	1%	91%	3%	0%	1%
TN	1%	7%	10%	0%	84%	4%	1%	2%
TX	2%	3%	10%	0%	48%	48%	2%	1%
WI	4%	5%	9%	1%	80%	12%	2%	2%
Weighted NCI-IDD Average	2%	4%	9%	0%	70%	23%	2%	2%

Table 5a. Child's Conditions

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

State (names abbreviated)	Intellectual developmental disability	Mood illness/psychiatric diagnosis	Autism spectrum disorder	Cerebral palsy
FL	59%	20%	75%	20%
IN	38%	23%	65%	9%
MO	27%	32%	88%	8%
ND	59%	27%	46%	8%
OR	53%	24%	59%	10%
SD	47%	16%	37%	16%
TN	43%	13%	55%	10%
TX	56%	22%	35%	27%
WI	41%	20%	61%	8%
Weighted NCI-IDD Average	46%	22%	55%	15%

Table 5b. Child's Conditions (Continued)

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

State (names abbreviated)	Limited or no vision – legally blind	Hearing loss (severe or profound)	Brain injury	Seizure disorder or neurological problem	Chemical dependency
FL	7%	7%	10%	29%	0%
IN	3%	3%	4%	17%	0%
MO	7%	2%	3%	12%	1%
ND	7%	7%	10%	24%	0%
OR	6%	6%	6%	16%	0%
SD	8%	4%	11%	25%	0%
TN	6%	4%	9%	26%	0%
TX	21%	9%	17%	41%	1%
WI	5%	3%	5%	17%	0%
Weighted NCI-IDD Average	10%	5%	9%	25%	0%

Table 5c. Child's Conditions (Continued)

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

State (names abbreviated)	Down syndrome	Prader-Willi syndrome	Fetal alcohol spectrum disorder (FASD)	Other
FL	6%	3%	1%	29%
IN	12%	1%	1%	30%
MO	3%	0%	2%	30%
ND	14%	0%	2%	37%
OR	11%	0%	7%	32%
SD	23%	1%	2%	27%
TN	12%	1%	1%	38%
TX	11%	0%	0%	42%
WI	11%	0%	2%	27%
Weighted NCI-IDD Average	11%	0%	2%	34%

Table 6a. Child's Health Conditions

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

State (names abbreviated)	Cardiovascular disease	Diabetes	Cancer	High blood pressure	High cholesterol
FL	11%	1%	0%	1%	6%
IN	8%	2%	3%	4%	7%
MO	9%	1%	1%	3%	7%
ND	10%	2%	0%	3%	7%
OR	10%	3%	2%	2%	4%
SD	20%	3%	9%	4%	0%
TN	19%	1%	3%	3%	1%
TX	15%	3%	3%	9%	7%
WI	15%	4%	2%	2%	3%
Weighted NCI-IDD Average	13%	3%	3%	5%	6%

Table 6b. Child's Health Conditions (continued)

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

State (names abbreviated)	Dysphagia	Pressure ulcers	Oral health or dental problems	Sleep apnea	Other pulmonary diagnosis (e.g., COPD, bronchitis, emphysema)
FL	28%	4%	11%	19%	13%
IN	12%	0%	5%	26%	9%
MO	13%	4%	9%	27%	7%
ND	14%	2%	13%	24%	12%
OR	22%	1%	13%	23%	8%
SD	14%	1%	4%	22%	16%
TN	27%	4%	5%	34%	10%
TX	28%	2%	12%	37%	18%
WI	22%	1%	9%	18%	12%
Weighted NCI-IDD Average	22%	2%	10%	29%	13%

Table 6c. Child's Health Conditions (continued)

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

State (names abbreviated)	Asthma	Chronic kidney disease	Long-term health problems associated with COVID-19	Other
FL	43%	4%	0%	32%
IN	33%	0%	0%	40%
MO	39%	1%	0%	40%
ND	18%	2%	0%	43%
OR	29%	1%	2%	34%
SD	20%	1%	0%	41%
TN	11%	7%	0%	42%
TX	30%	5%	3%	30%
WI	22%	2%	1%	40%
Weighted NCI-IDD Average	29%	3%	2%	36%

Table 7. Family Member's Preferred Language

State (names abbreviated)	Englis h	Spanis h	Chines e	Tagalo g	Vietnames e	America n Sign Languag e	Othe r	N
FL	86%	7%	0%	0%	0%	2%	5%	155
IN	97%	2%	0%	0%	0%	1%	0%	307
MO	98%	1%	0%	0%	0%	0%	1%	183
ND	94%	0%	0%	0%	0%	2%	4%	208
OR	91%	3%	0%	0%	1%	1%	5%	593
SD	98%	0%	0%	0%	0%	2%	0%	160
TN	98%	1%	0%	0%	1%	1%	0%	185
TX	86%	12%	0%	0%	0%	0%	2%	312
WI	97%	1%	0%	0%	0%	0%	1%	704
Weighted NCI-IDD Average	93%	5%	0%	0%	0%	1%	2%	2,807

"Chinese" includes Mandarin, Cantonese, and Hokkien; "Tagalog" includes Filipino.

Table 8. Child's Preferred Means of Communication

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

State (names abbreviated)	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
FL	54%	25%	5%	10%	6%	154
IN	79%	12%	3%	4%	2%	306
MO	84%	11%	0%	3%	2%	183
ND	64%	15%	5%	12%	4%	208
OR	73%	14%	1%	6%	5%	571
SD	63%	21%	3%	10%	3%	156
TN	62%	24%	2%	6%	5%	186
TX	62%	21%	3%	5%	9%	312
WI	65%	22%	2%	8%	4%	706
Weighted NCI-IDD Average	68%	18%	2%	6%	5%	2,782

Table 9. Child'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 child's demographics, diagnoses and personal characteristics.

State (names abbreviated)	No support needed; no issues with managing behavior)	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
FL	20%	39%	41%	153
IN	35%	48%	17%	303
MO	34%	46%	20%	185
ND	28%	41%	31%	205
OR	19%	50%	31%	618
SD	48%	32%	20%	157
TN	42%	36%	22%	185
TX	40%	31%	29%	302
WI	33%	47%	20%	697
Weighted NCI- IDD Average	34%	42%	24%	2,805

Table 10. Child’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 child’s demographics, diagnoses and personal characteristics.

State (names abbreviated)	No support needed; no issues with personal care activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed	N
FL	4%	27%	69%	155
IN	10%	51%	39%	306
MO	13%	56%	31%	187
ND	5%	37%	58%	207
OR	4%	40%	56%	618
SD	3%	50%	47%	161
TN	4%	44%	52%	187
TX	4%	30%	66%	313
WI	6%	43%	51%	707
Weighted NCI-IDD Average	6%	41%	53%	2,841

Respondents

This section provides information about the survey respondent.

Table 11. Language Usually Spoken at Home

State (names abbreviated)	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
FL	81%	14%	0%	1%	1%	0%	5%	154
IN	94%	4%	0%	0%	0%	0%	2%	307
MO	96%	3%	0%	0%	1%	0%	1%	188
ND	97%	0%	0%	0%	0%	0%	2%	206
OR	88%	8%	1%	0%	1%	0%	3%	599
SD	99%	0%	0%	0%	0%	0%	1%	160
TN	98%	1%	0%	0%	1%	0%	1%	185
TX	79%	20%	0%	0%	0%	0%	1%	315
WI	95%	4%	0%	0%	0%	0%	2%	701
Weighted NCI-IDD Average	89%	9%	0%	0%	0%	0%	2%	2,815

"Chinese" includes Mandarin, Cantonese, and Hokkien; "Tagalog" includes Filipino.

Table 12. Respondent's Age

State (names abbreviated)	Under 34	35 – 54	55 – 74	75 or older	N
FL	5%	69%	25%	2%	155
IN	11%	77%	11%	1%	307
MO	14%	73%	12%	1%	190
ND	15%	79%	6%	0%	207
OR	10%	71%	18%	1%	621
SD	11%	81%	8%	0%	160
TN	14%	84%	2%	0%	188
TX	10%	70%	18%	1%	315
WI	17%	72%	10%	0%	705
Weighted NCI-IDD Average	12%	73%	14%	1%	2,848

Table 13. Respondent's Health

State (names abbreviated)	Excellent	Very good	Good	Fair	Poor	N
FL	14%	31%	34%	17%	3%	156
IN	17%	38%	33%	10%	1%	306
MO	9%	33%	42%	14%	2%	189
ND	14%	39%	38%	8%	0%	208
OR	10%	33%	40%	16%	2%	623
SD	19%	50%	27%	4%	0%	161
TN	19%	47%	29%	5%	1%	188
TX	12%	32%	37%	15%	3%	315
WI	12%	42%	36%	8%	1%	705
Weighted NCI-IDD Average	13%	37%	36%	12%	2%	2,851

Table 14. Respondent's Relationship to Child

State (names abbreviated)	Parent (biological, adoptive, or foster)	Sibling	Grandparent	Other	N
FL	94%	0%	5%	1%	156
IN	93%	0%	5%	3%	307
MO	97%	0%	2%	1%	190
ND	97%	0%	2%	1%	209
OR	90%	0%	8%	2%	619
SD	98%	0%	2%	0%	161
TN	100%	0%	0%	0%	188
TX	87%	0%	11%	2%	314
WI	95%	0%	4%	1%	705
Weighted NCI-IDD Average	92%	0%	6%	2%	2,849

Table 15. Respondent or Other Family Member Provides Paid Support to Child

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

State (names abbreviated)	No	Yes, I am	Yes, another family member is
FL	68%	16%	16%
IN	83%	4%	13%
MO	92%	2%	6%
ND	84%	2%	14%
OR	61%	12%	29%
SD	88%	1%	11%
TN	95%	1%	4%
TX	70%	6%	24%
WI	83%	4%	15%
Weighted NCI-IDD Average	77%	5%	18%

Table 16. Number of Adults in Household

State (names abbreviated)	One	Two	Three	Four or more	N
FL	13%	60%	21%	6%	156
IN	17%	66%	11%	5%	306
MO	24%	60%	13%	4%	186
ND	16%	70%	13%	1%	206
OR	22%	52%	20%	6%	618
SD	9%	76%	13%	2%	161
TN	6%	80%	9%	4%	187
TX	29%	51%	15%	5%	312
WI	15%	70%	11%	4%	703
Weighted NCI-IDD Average	21%	61%	14%	5%	2,835

Table 17. Number of Children (Under 18 years old) in Household (including the child receiving services)

State (names abbreviated)	One	Two	Three	Four or more	N
FL	51%	35%	11%	3%	144
IN	30%	39%	21%	10%	305
MO	33%	41%	19%	7%	189
ND	29%	41%	18%	12%	204
OR	39%	38%	14%	9%	607
SD	31%	36%	22%	11%	160
TN	32%	44%	15%	9%	187
TX	41%	33%	17%	9%	301
WI	29%	40%	19%	12%	703
Weighted NCI-IDD Average	35%	37%	18%	10%	2,800

Table 18. Respondent's Highest Level of Education

State (names abbreviated)	No high school diploma/GED	High school diploma/GED	Vocational school or certificate program	Some college	College degree or higher	N
FL	3%	12%	7%	16%	62%	156
IN	7%	11%	6%	16%	60%	308
MO	5%	11%	5%	17%	61%	186
ND	2%	12%	5%	13%	68%	208
OR	8%	18%	6%	19%	48%	599
SD	2%	9%	9%	13%	68%	160
TN	0%	4%	6%	9%	81%	188
TX	13%	17%	10%	20%	41%	307
WI	3%	10%	8%	15%	64%	704
Weighted NCI- IDD Average	7%	13%	8%	17%	55%	2,816

Table 19. Total Taxable Household Income of Wage Earners in the Past 12 Months

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

State (names abbreviated)	No earned income	Up to \$15,000	\$15,001–\$25,000	\$25,001–\$50,000	\$50,001–\$75,000	Over \$75,000	Prefer not to say	N
FL	3%	5%	9%	15%	17%	35%	17%	150
IN	6%	7%	7%	15%	16%	42%	8%	305
MO	9%	9%	6%	17%	15%	37%	8%	188
ND	1%	4%	6%	8%	20%	51%	10%	208
OR	7%	7%	10%	18%	15%	33%	11%	613
SD	3%	1%	2%	12%	17%	49%	16%	160
TN	0%	0%	1%	4%	17%	60%	18%	189
TX	9%	13%	11%	15%	13%	23%	15%	305
WI	3%	4%	6%	14%	19%	44%	10%	707
Weighted NCI-IDD Average	6%	8%	8%	15%	16%	36%	12%	2,825

Table 20. Residential Designation

State (names abbreviated)	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
FL	91%	9%	151
IN	67%	33%	293
MO	68%	32%	186
ND	79%	21%	207
OR	75%	25%	605
SD	64%	36%	157
TN	73%	27%	188
TX	77%	23%	293
WI	72%	28%	693
Weighted NCI-IDD Average	73%	27%	2,773

Services and Supports Received

This section provides information about the services and supports received by the child from the state ID/DD agency.

Table 21a. Services and Supports Received from ID/DD Agency

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

State (names abbreviated)	Financial support	In-home support	out-of-home respite care	Early intervention
FL	12%	63%	30%	5%
IN	8%	27%	25%	8%
MO	28%	29%	20%	13%
ND	22%	72%	47%	13%
OR	17%	76%	33%	9%
SD	61%	23%	52%	16%
TN	71%	20%	28%	26%
TX	15%	71%	15%	100%
WI	30%	29%	33%	22%
Weighted NCI-IDD Average	20%	48%	25%	17%

Table 21b. Services and Supports Received from ID/DD Agency (continued)

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

State (names abbreviated)	Transportation	Mental or behavioral health care or other treatments or therapies	Self-direction or fiscal intermediary services
FL	19%	79%	48%
IN	9%	83%	49%
MO	12%	74%	43%
ND	20%	83%	51%
OR	23%	74%	67%
SD	14%	78%	73%
TN	7%	87%	56%
TX	20%	74%	46%
WI	11%	75%	43%
Weighted NCI-IDD Average	15%	77%	48%

Table 22. Additional Services and Supports Received (not from the IDD Agency)

State (names abbreviated)	Social Security (SSI or SSB)	Services or supports from other agencies or organizations
FL	31%	60%
IN	29%	72%
MO	31%	80%
ND	15%	78%
OR	37%	72%
SD	13%	79%
TN	1%	61%
TX	56%	62%
WI	20%	77%
Weighted NCI-IDD Average	35%	70%

Main Survey Results

Note on Significance: Statistical significance depends on both the amount by which a state differs from the average for a given item and the state's sample size for that item. There may be instances where State A's difference from the average is larger than State B's, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.

Information and Planning

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

Note: Significance is based on “Always” or “Yes” response.

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

“Child” 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 child?

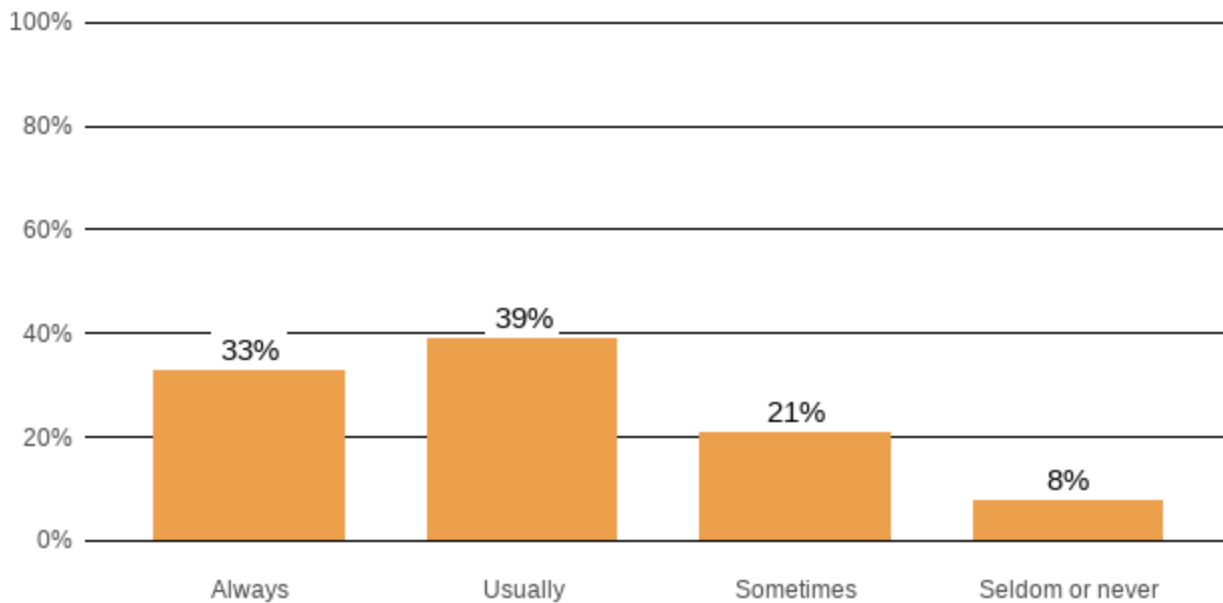


Table 23. Do you have enough information to take part in planning services for your child?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	45%	43%	11%	1%	184
IN	40%	33%	20%	7%	295
WI	34%	39%	19%	8%	689
Weighted NCI-IDD Average	33%	39%	21%	8%	2,762
ND	31%	44%	20%	4%	207
TX	31%	38%	23%	9%	298
SD	29%	54%	12%	4%	156
OR	29%	45%	21%	5%	599
MO ↓	24%	45%	23%	7%	183
FL ↓	22%	43%	21%	14%	151

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

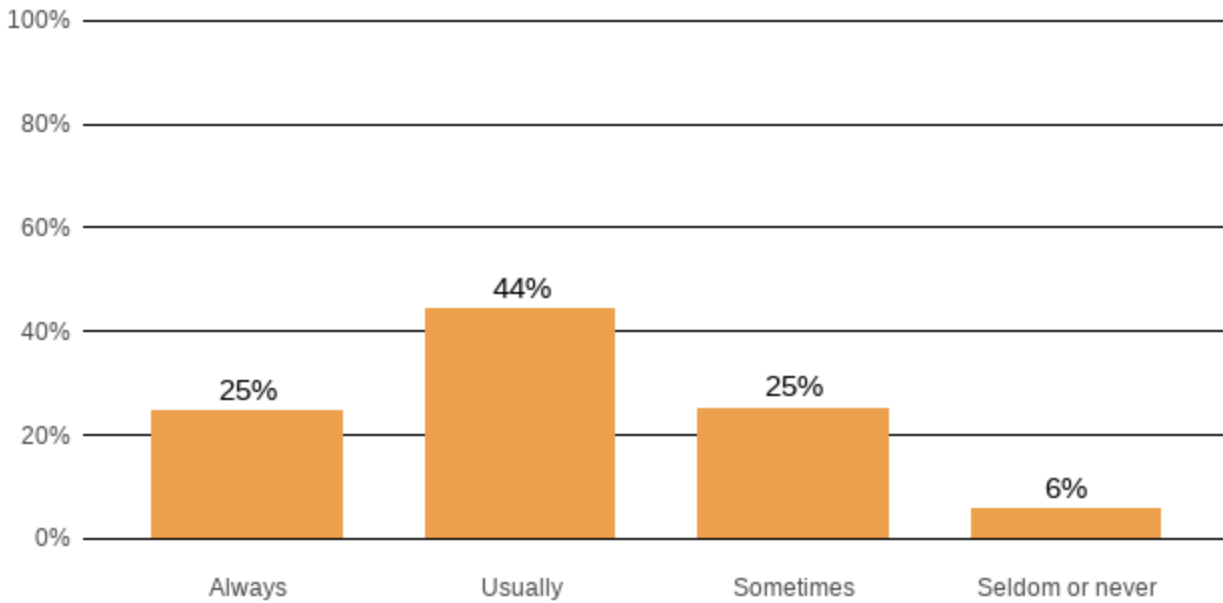


Table 24. Is the information you get about services and supports easy to understand?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
IN	28%	40%	28%	4%	299
WI	27%	46%	22%	5%	695
TN	26%	52%	20%	3%	188
Weighted NCI-IDD Average	25%	44%	25%	6%	2,791
TX	24%	41%	27%	8%	299
SD	22%	54%	21%	3%	159
ND	20%	44%	31%	4%	208
MO	20%	50%	27%	3%	183
FL	18%	45%	24%	13%	152
OR ↓	20%	51%	24%	5%	608

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

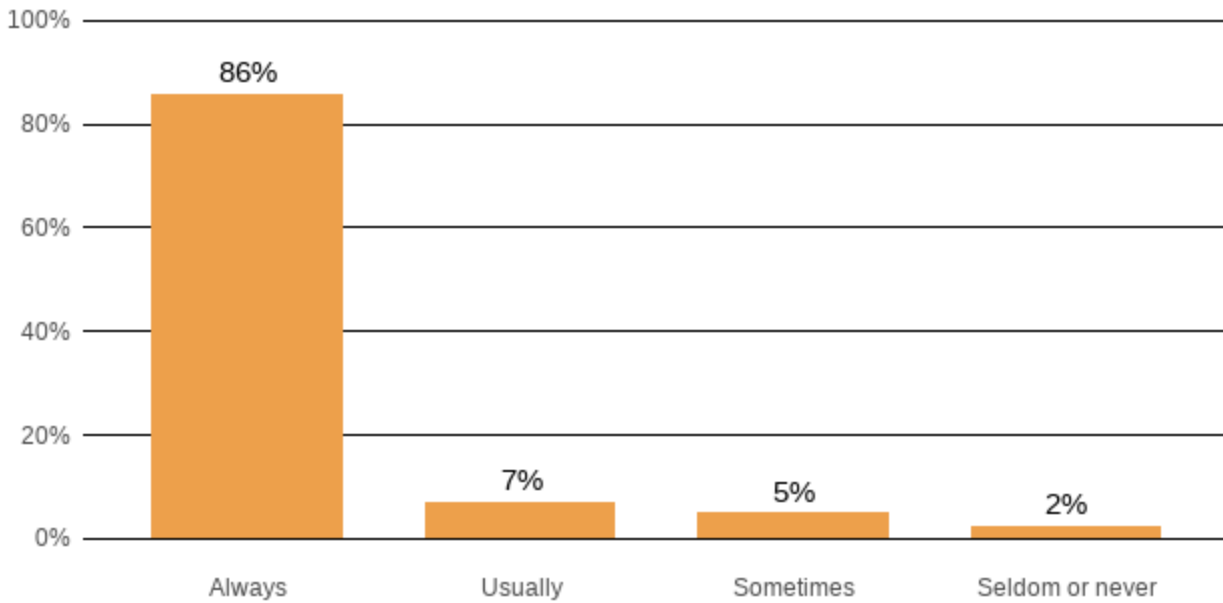


Table 25. Do you get information about services and supports in your preferred language?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	97%	3%	0%	0%	188
ND ↑	92%	6%	1%	0%	206
SD	91%	6%	1%	2%	161
MO	90%	5%	3%	2%	186
IN	90%	5%	3%	2%	300
WI	89%	7%	2%	2%	699
OR	87%	9%	3%	1%	613
Weighted NCI-IDD Average	86%	7%	5%	2%	2,813
TX ↓	80%	7%	10%	3%	309
FL ↓	75%	15%	4%	5%	151

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

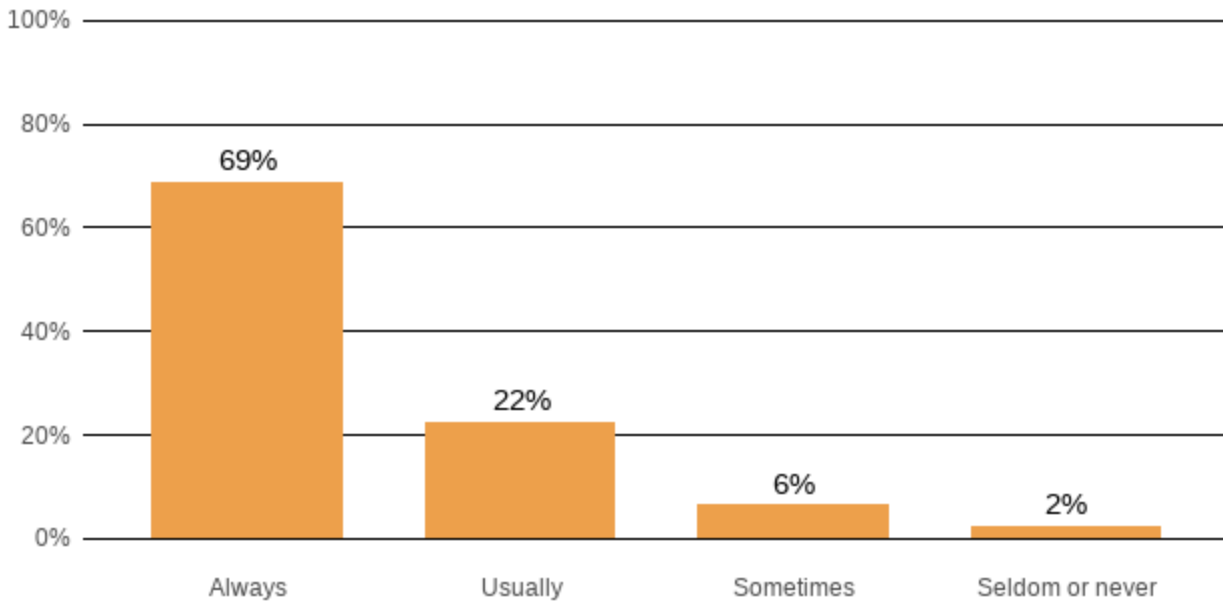


Table 26. Does the case manager/service coordinator listen to your family's choices and opinions?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	92%	8%	1%	0%	186
IN ↑	79%	15%	5%	1%	298
SD	69%	25%	5%	1%	154
Weighted NCI-IDD Average	69%	22%	6%	2%	2,729
WI	69%	18%	9%	4%	678
MO	67%	25%	8%	1%	171
TX	65%	27%	5%	3%	291
FL	63%	26%	9%	3%	151
ND	60%	31%	9%	0%	205
OR ↓	62%	31%	5%	1%	595

Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

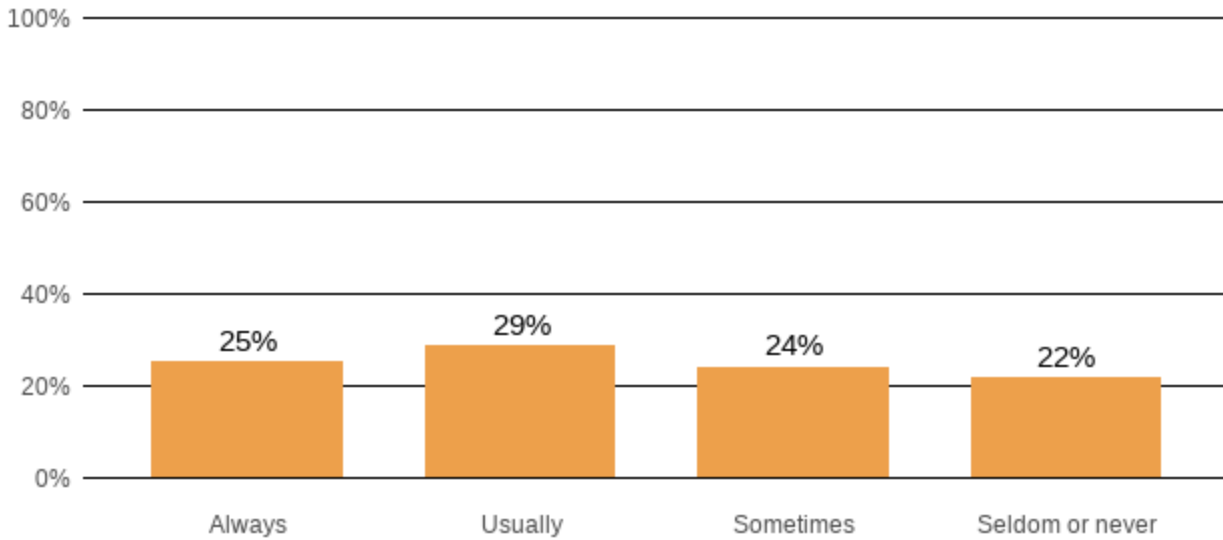


Table 27. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN	32%	29%	22%	17%	138
IN	30%	22%	23%	25%	230
SD	28%	29%	19%	24%	108
WI	27%	32%	21%	20%	551
ND	26%	35%	19%	19%	161
Weighted NCI-IDD Average	25%	29%	24%	22%	2,195
TX	23%	28%	27%	21%	247
OR	22%	35%	26%	17%	503
MO	21%	26%	25%	28%	136
FL ↓	16%	27%	25%	32%	121

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

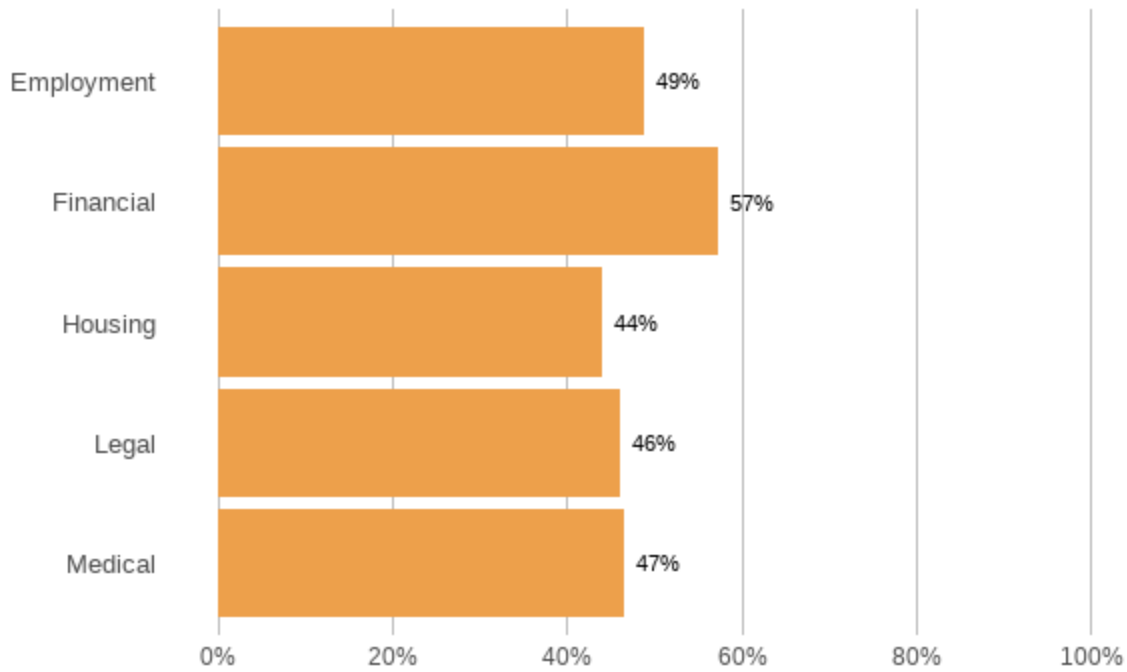


Table 28a. Do you need help planning for your child's future in any of these areas?

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

State (names abbreviated)	Employment	Financial	Housing	Legal	Medical
FL	57%	64%	57%	65%	46%
IN	57%	60%	46%	50%	43%
MO	52%	56%	45%	42%	40%
ND	59%	62%	58%	48%	52%
OR	61%	62%	49%	39%	44%
SD	47%	54%	52%	45%	36%
TN	46%	60%	35%	50%	50%
TX	36%	52%	38%	46%	53%
WI	52%	60%	46%	45%	44%
Weighted NCI-IDD Average	49%	57%	44%	46%	47%

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

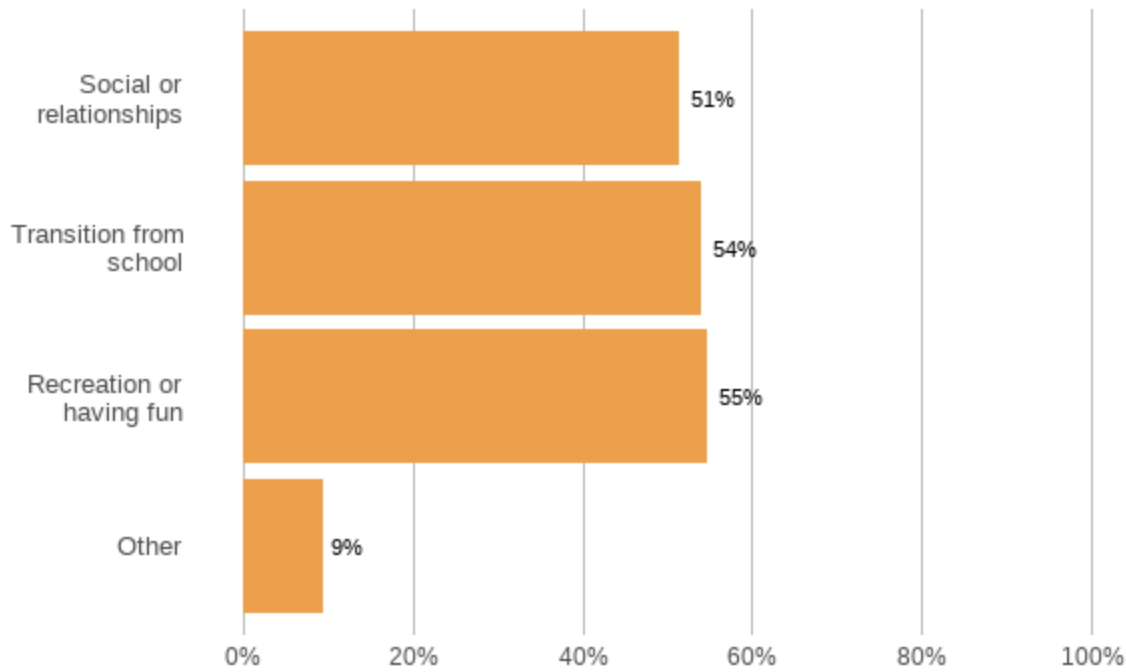


Table 28b. Do you need help planning for your child's future in any of these areas? (Continued)

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

State (names abbreviated)	Social or relationships	Transition from school	Recreation or having fun	Other
FL	59%	68%	65%	6%
IN	54%	51%	51%	12%
MO	60%	52%	54%	10%
ND	60%	68%	59%	11%
OR	57%	59%	55%	9%
SD	42%	63%	51%	7%
TN	57%	51%	53%	4%
TX	38%	52%	51%	10%
WI	60%	54%	60%	8%
Weighted NCI-IDD Average	51%	54%	55%	9%

Has your family learned about alternatives to guardianship?

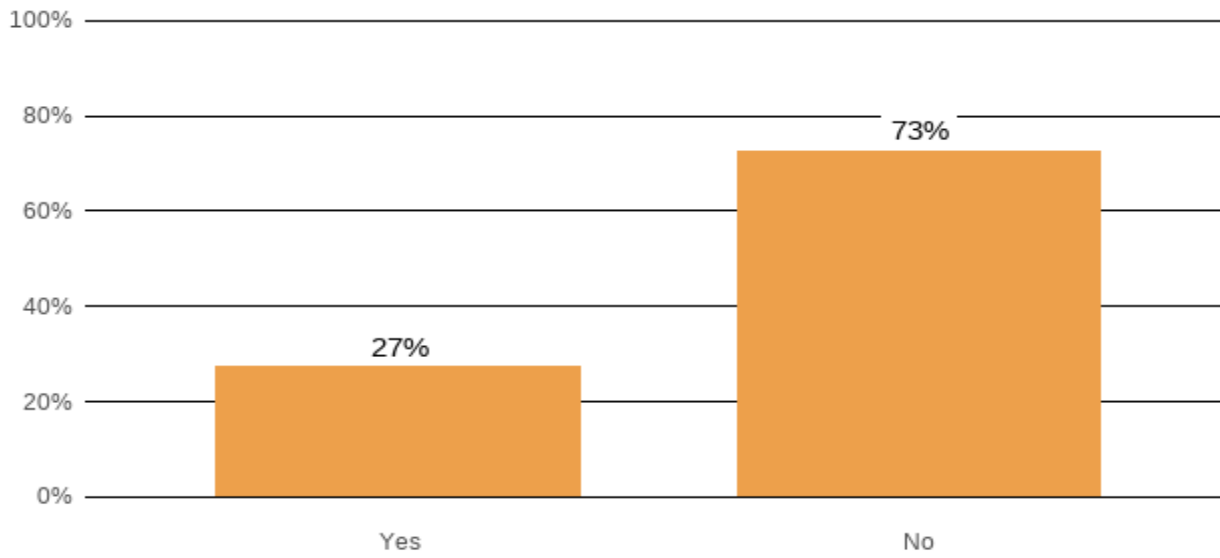


Table 29. Has your family learned about alternatives to guardianship?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TX ↑	39%	61%	261
FL	38%	62%	145
OR	28%	72%	529
Weighted NCI-IDD Average	27%	73%	2,481
SD	24%	76%	144
MO	23%	77%	166
ND	22%	78%	181
IN	21%	79%	267
WI ↓	19%	81%	620
TN ↓	17%	83%	168

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

Does your child have a service plan?

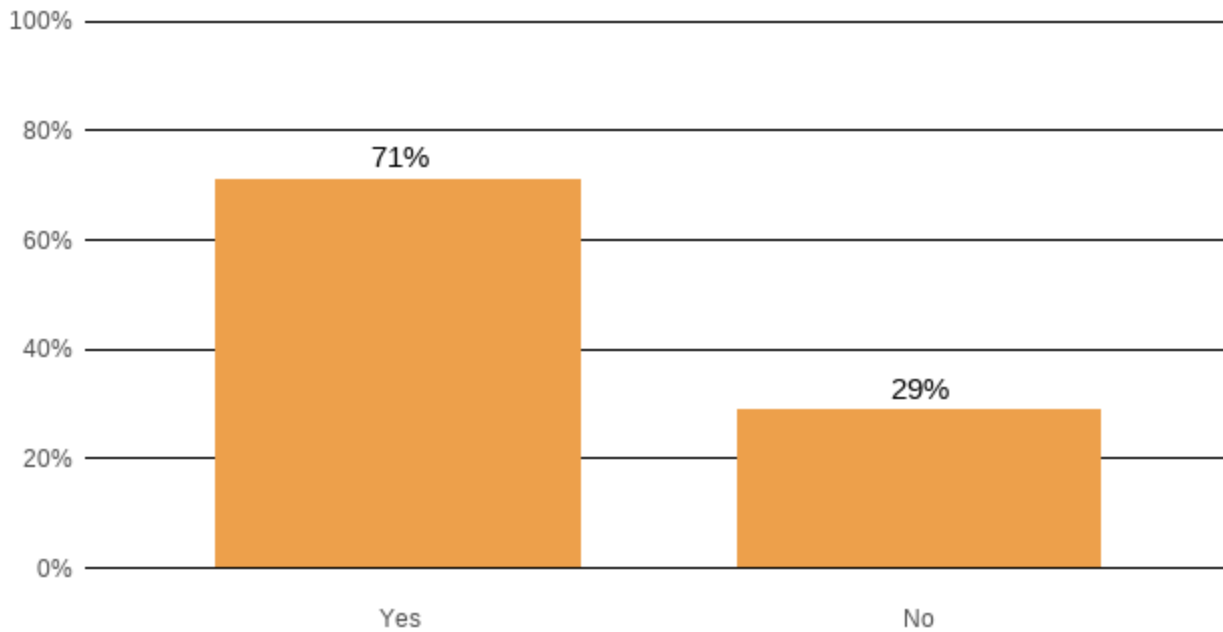


Table 30. Does your child have a service plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
OR ↑	83%	17%	529
MO ↑	80%	20%	163
FL	77%	23%	137
WI	75%	25%	596
Weighted NCI-IDD Average	71%	29%	2,366
TX	67%	33%	246
ND	65%	35%	164
SD	64%	36%	133
IN	64%	36%	241
TN ↓	61%	39%	157

Does the plan include all the services and supports your child needs?

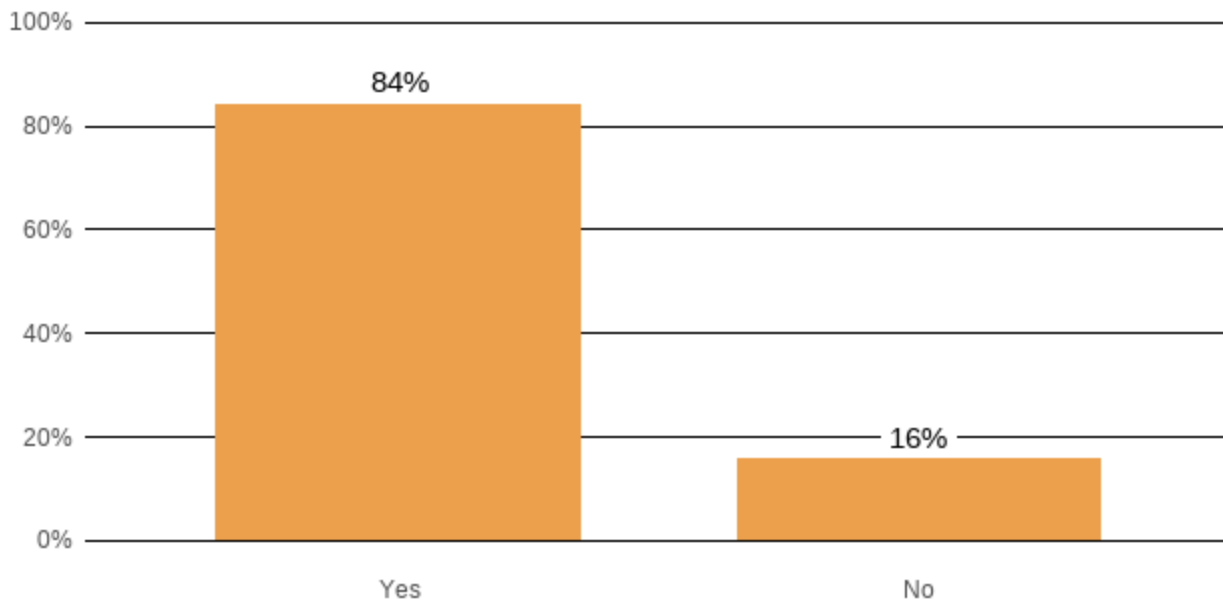


Table 31. Does the plan include all the services and supports your child needs?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TX ↑	94%	6%	140
TN	89%	11%	87
ND	85%	15%	96
SD	85%	15%	79
Weighted NCI-IDD Average	84%	16%	1,502
OR	84%	16%	379
MO	81%	19%	110
WI	80%	20%	394
FL	80%	20%	83
IN	76%	24%	134

Did you or another family member help make the plan?

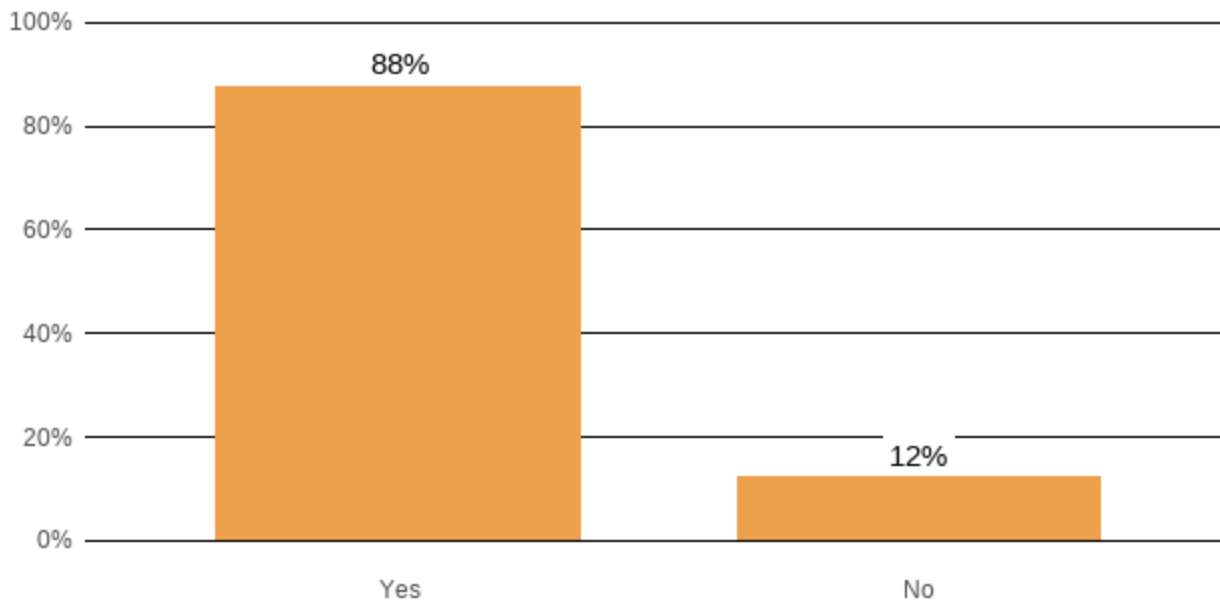


Table 32. Did you or another family member help make the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
MO ↑	97%	3%	126
OR ↑	93%	7%	427
WI ↑	92%	8%	432
TN	93%	7%	94
SD	90%	10%	83
ND	89%	11%	104
IN	88%	12%	149
Weighted NCI-IDD Average	88%	12%	1,663
FL	87%	13%	97
TX ↓	77%	23%	151

Did your child help make the plan?

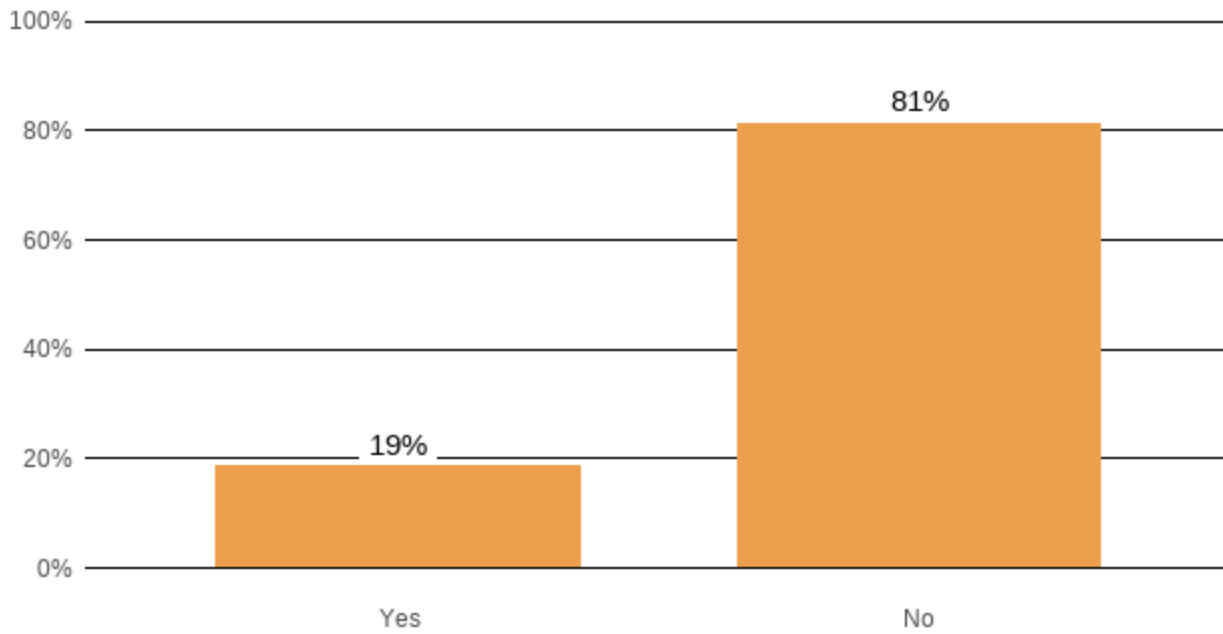


Table 33. Did your child help make the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
OR ↑	25%	75%	432
MO	29%	71%	124
SD	28%	72%	83
WI	21%	79%	436
ND	19%	81%	106
Weighted NCI-IDD Average	19%	81%	1,680
TN	15%	85%	93
FL	15%	85%	100
TX	14%	86%	158
IN	14%	86%	148

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

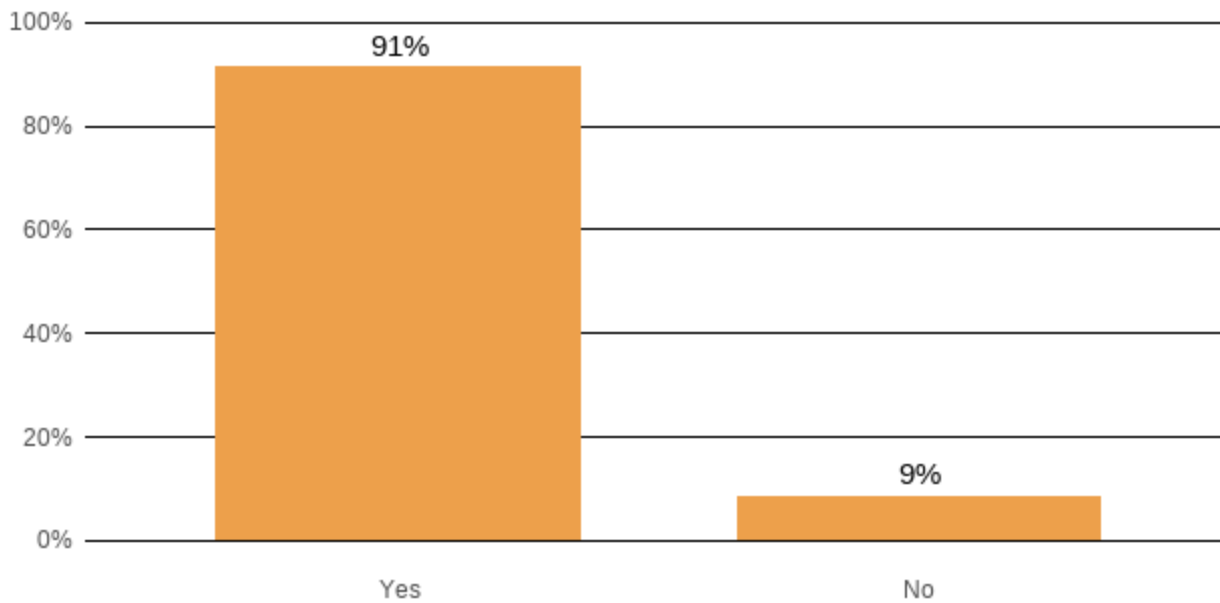


Table 34. Do you feel like your family had enough say or input in making the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
ND	95%	5%	96
IN	94%	6%	144
MO	93%	7%	122
OR	92%	8%	406
TX	92%	8%	146
Weighted NCI-IDD Average	91%	9%	1,599
SD	91%	9%	80
TN	90%	10%	94
WI	90%	10%	418
FL	83%	17%	93

Does your child have a transition plan (as part of an IEP or Section 504 plan through their high school, usually starting at age 14)?

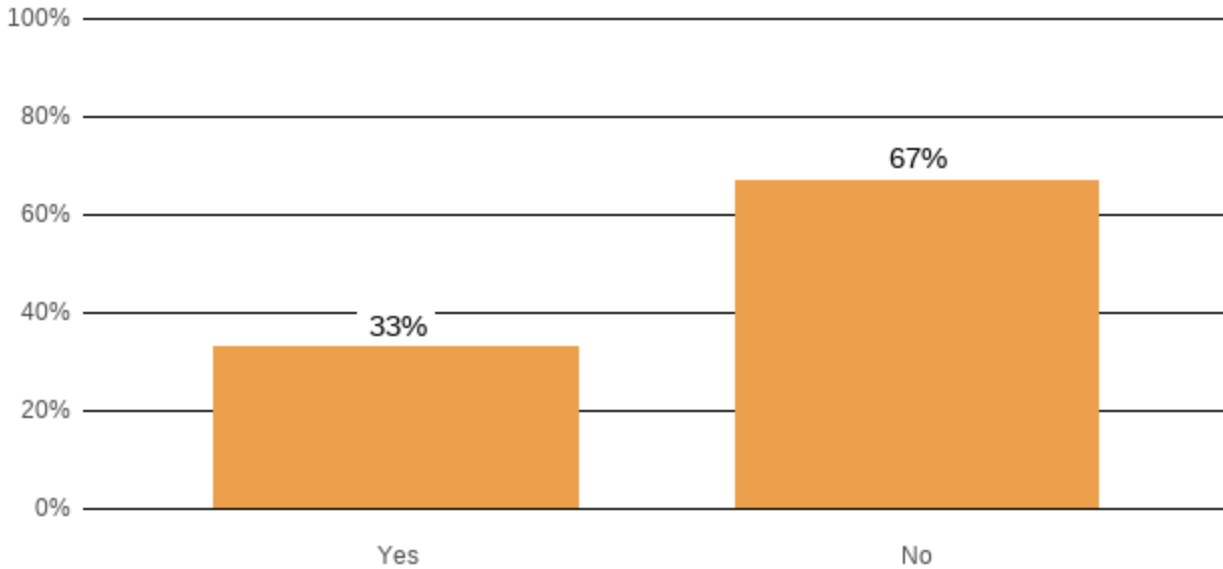


Table 35. Does your child have a transition plan (as part of an IEP or Section 504 plan through their high school, usually starting at age 14)?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
IN ↑	69%	31%	59
ND ↑	66%	34%	38
OR ↑	65%	35%	155
MO ↑	55%	45%	44
FL ↑	53%	47%	104
Weighted NCI-IDD Average	33%	67%	1,387
TX	32%	68%	265
WI ↓	20%	80%	563
SD ↓	18%	82%	146

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

If your child has a transition plan, did you or another family member help make the plan?

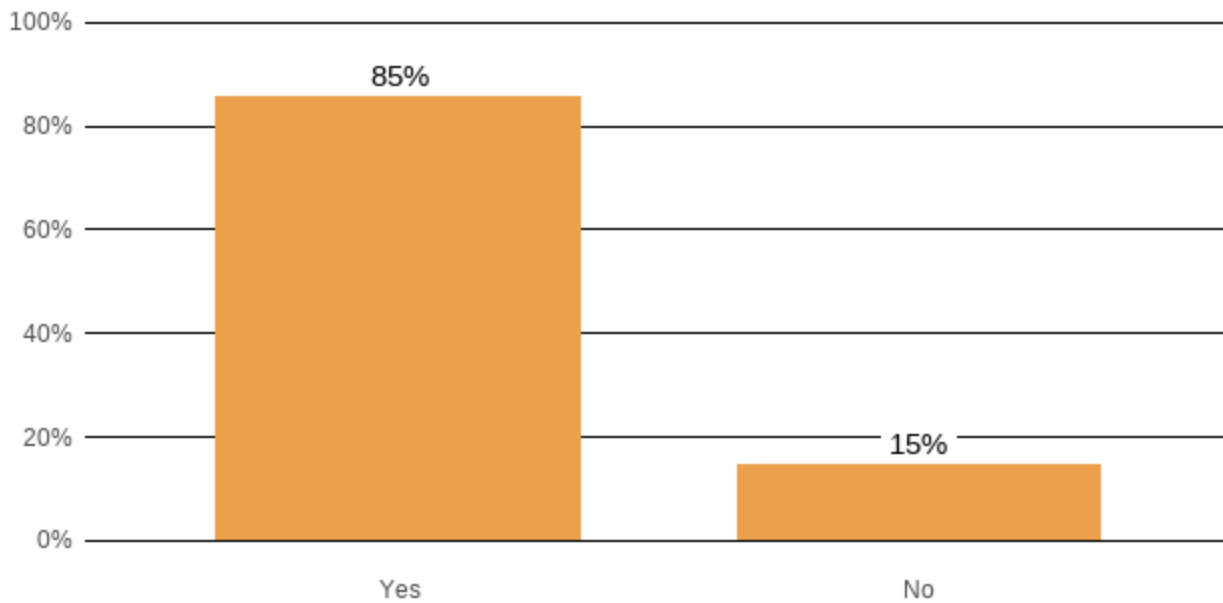


Table 36. If your child has a transition plan, did you or another family member help make the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
MO ↑	97%	3%	29
ND ↑	95%	5%	42
WI	90%	10%	112
SD	87%	13%	23
OR	86%	14%	140
Weighted NCI-IDD Average	85%	15%	550
TX	84%	16%	77
IN	81%	19%	64
FL	75%	25%	53

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

If your child has a transition plan, did your child help make the plan?

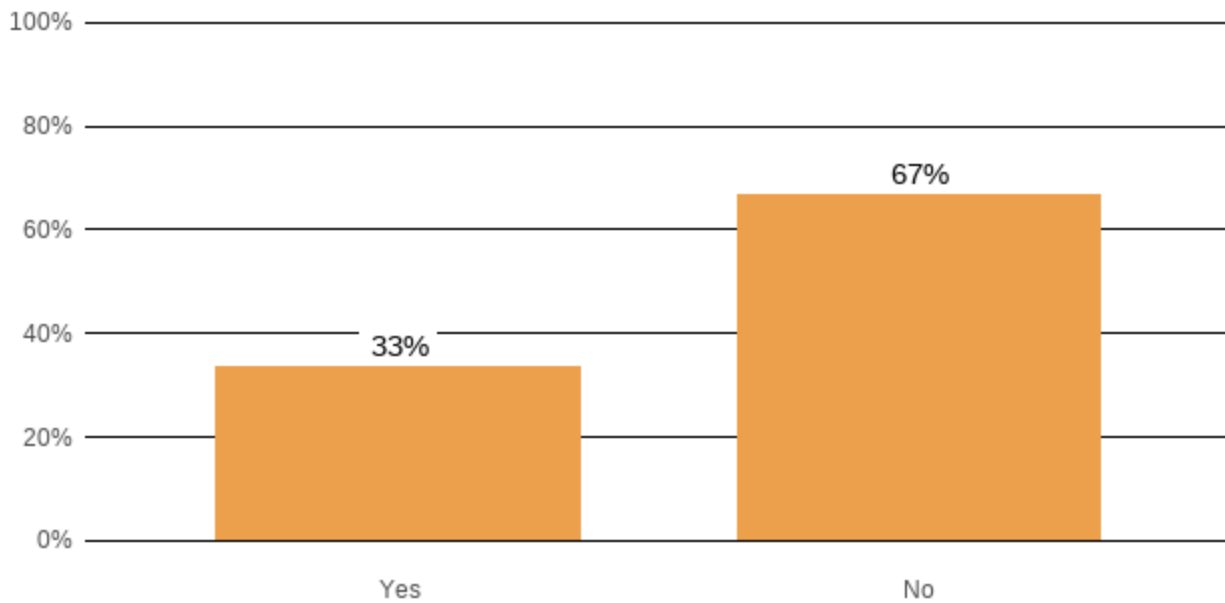


Table 37. If your child has a transition plan, did your child help make the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
WI	45%	55%	110
OR	39%	61%	133
ND	34%	66%	44
Weighted NCI-IDD Average	33%	67%	539
MO	33%	67%	30
SD	33%	67%	24
TX	30%	70%	74
IN	29%	71%	63
FL	25%	75%	51

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

Access and Delivery of Services and Supports

Families receive services and supports that are appropriate to the needs of the family and the child receiving services and supports from the state developmental disabilities system.

Note: Significance is based on “Always” or “Yes” response.

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

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

Does your child get all the services listed in the plan?

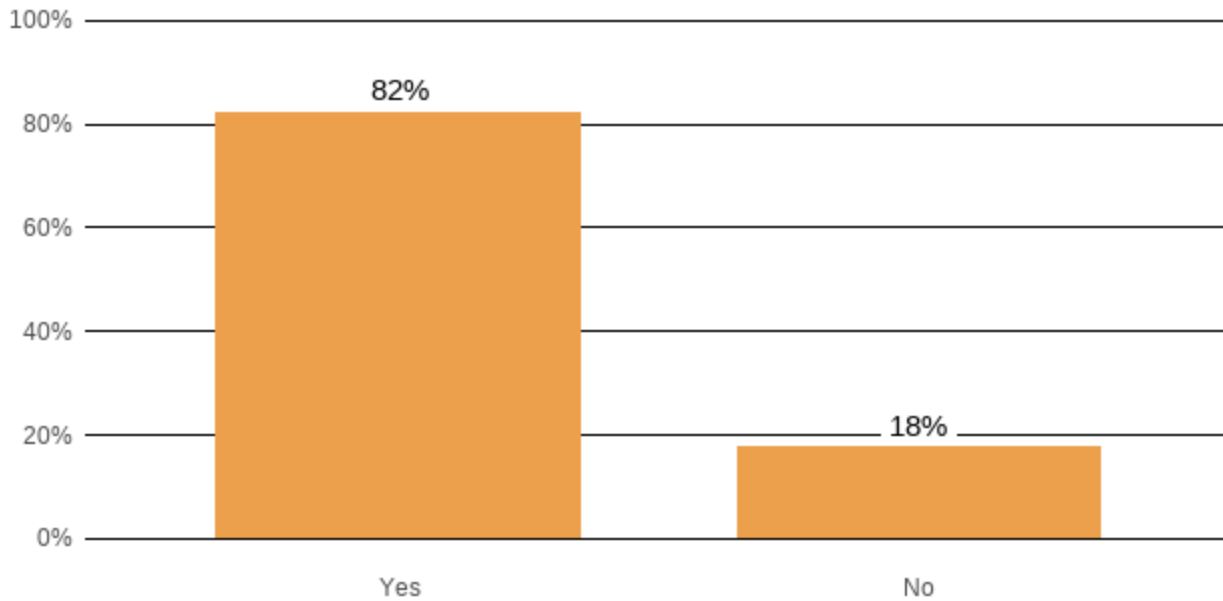


Table 38. Does your child get all the services listed in the plan?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TX	88%	12%	146
SD	88%	12%	81
MO	88%	13%	112
TN	86%	14%	84
Weighted NCI-IDD Average	82%	18%	1,536
WI	82%	18%	409
FL	81%	19%	85
ND	77%	23%	97
OR	77%	23%	387
IN	74%	26%	135

Does your family get the supports and services it needs?

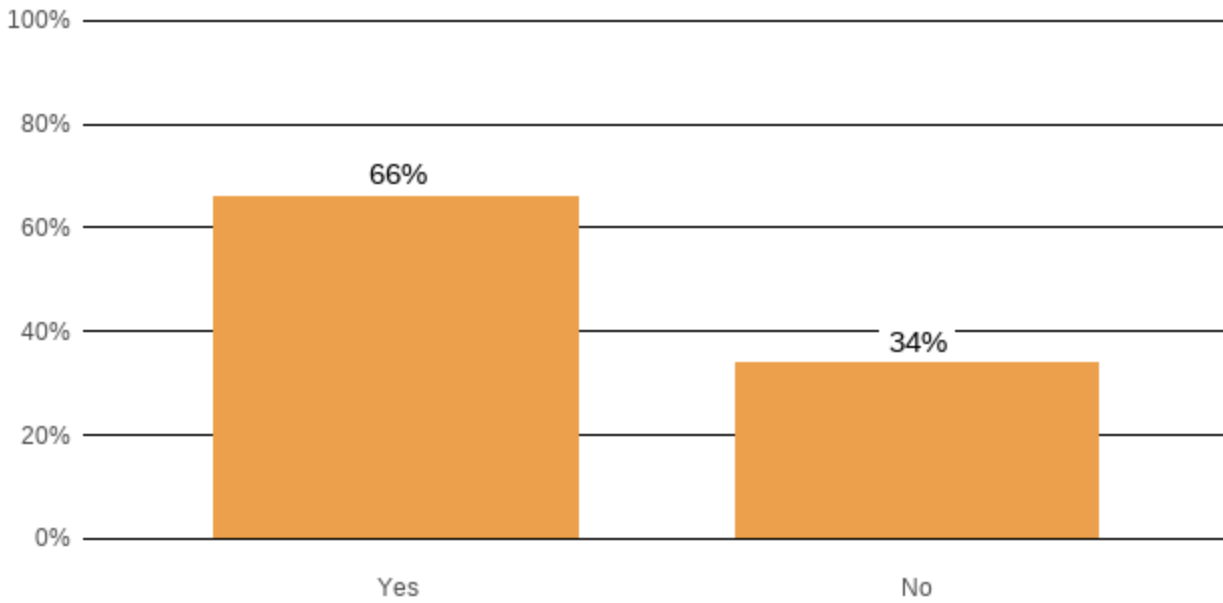


Table 39. Does your family get the supports and services it needs?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TN ↑	79%	21%	162
SD	73%	27%	151
IN	68%	32%	272
TX	67%	33%	265
Weighted NCI-IDD Average	66%	34%	2,474
WI	66%	34%	590
OR	63%	37%	556
ND	63%	37%	184
MO	60%	40%	155
FL ↓	55%	45%	139

What additional services does your child need?

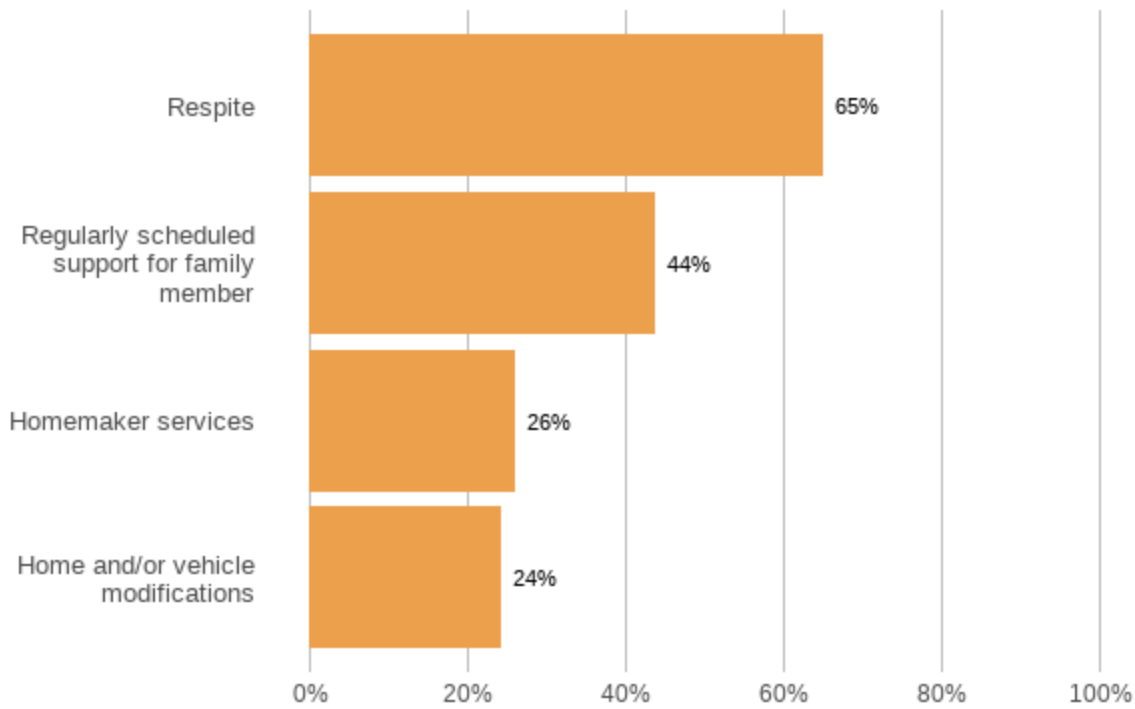


Table 40a. What additional services does your child need?

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

State (names abbreviated)	Respite	Regularly scheduled support for family member	Homemaker services	Home and/or vehicle modifications
FL	66%	47%	44%	24%
IN	71%	42%	21%	20%
MO	55%	37%	15%	13%
ND	72%	48%	15%	22%
OR	60%	47%	27%	21%
SD	56%	29%	32%	24%
TN	71%	41%	44%	26%
TX	62%	48%	25%	33%
WI	69%	41%	30%	22%
Weighted NCI-IDD Average	65%	44%	26%	24%

**What additional services does your child need?
(Continued)**

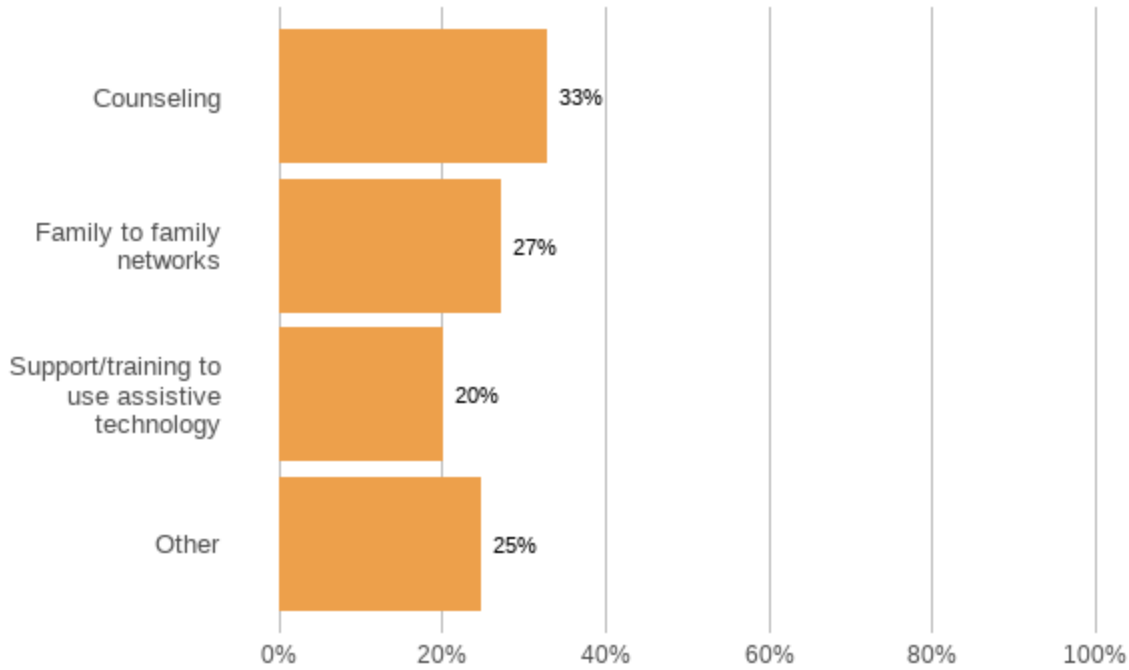


Table 40b. What additional services does your child need? (Continued)

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

State (names abbreviated)	Counseling	Family to family networks	Support/training to use assistive technology	Other
FL	32%	27%	23%	29%
IN	30%	27%	8%	23%
MO	33%	15%	13%	32%
ND	25%	31%	15%	22%
OR	36%	29%	15%	24%
SD	27%	22%	15%	34%
TN	38%	24%	15%	9%
TX	33%	22%	32%	26%
WI	34%	37%	20%	23%
Weighted NCI-IDD Average	33%	27%	20%	25%

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

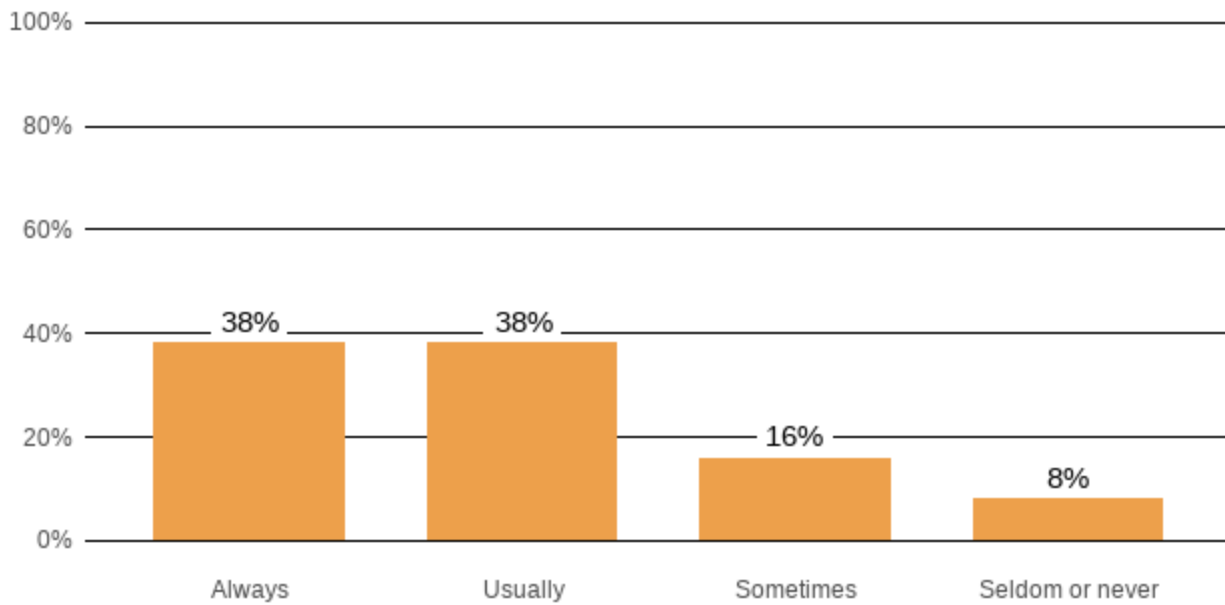


Table 41. Do services and supports change when your family's needs change?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	50%	31%	15%	3%	124
IN ↑	47%	33%	14%	5%	239
WI	41%	36%	15%	8%	537
Weighted NCI-IDD Average	38%	38%	16%	8%	2,231
SD	38%	44%	12%	5%	129
TX	36%	38%	15%	11%	250
MO	33%	44%	20%	4%	140
OR ↓	28%	47%	18%	7%	515
ND ↓	28%	42%	24%	6%	178
FL ↓	24%	41%	21%	13%	119

Does your child have the special equipment or accommodations they need?

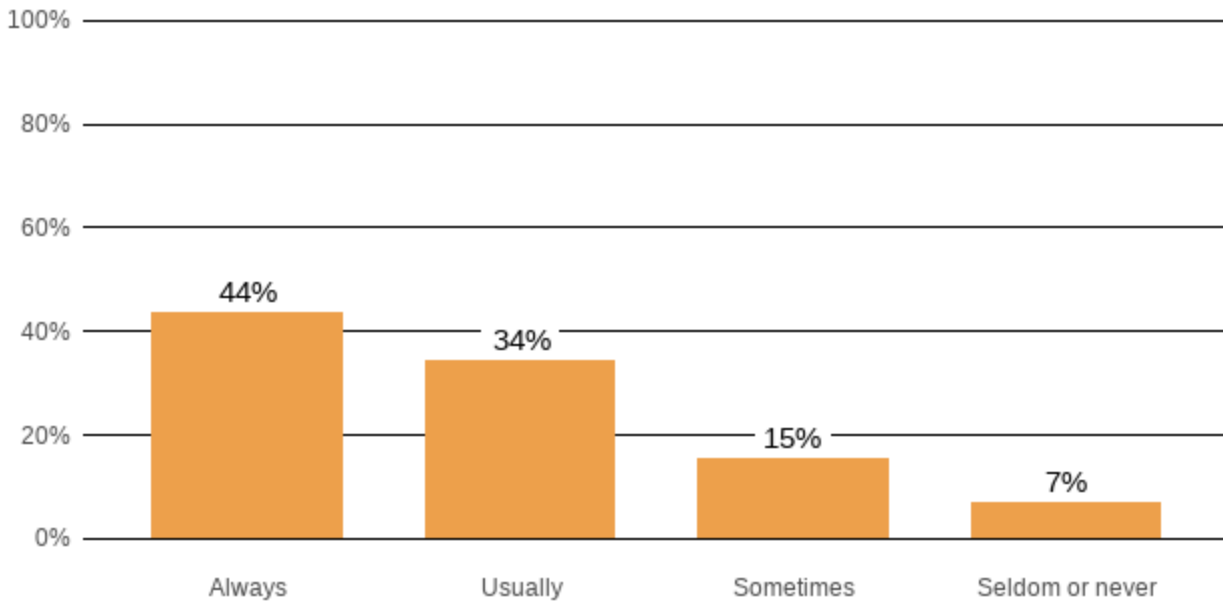


Table 42. Does your child have the special equipment or accommodations they need?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TX	50%	32%	14%	4%	213
IN	47%	30%	12%	11%	140
TN	46%	36%	15%	3%	112
FL	44%	35%	14%	7%	84
SD	44%	40%	11%	5%	105
Weighted NCI-IDD Average	44%	34%	15%	7%	1,653
MO	43%	32%	15%	10%	84
ND	39%	37%	15%	10%	122
WI ↓	36%	37%	19%	8%	420
OR ↓	33%	40%	20%	7%	373

If you need respite services, how often are you able to get them when needed?

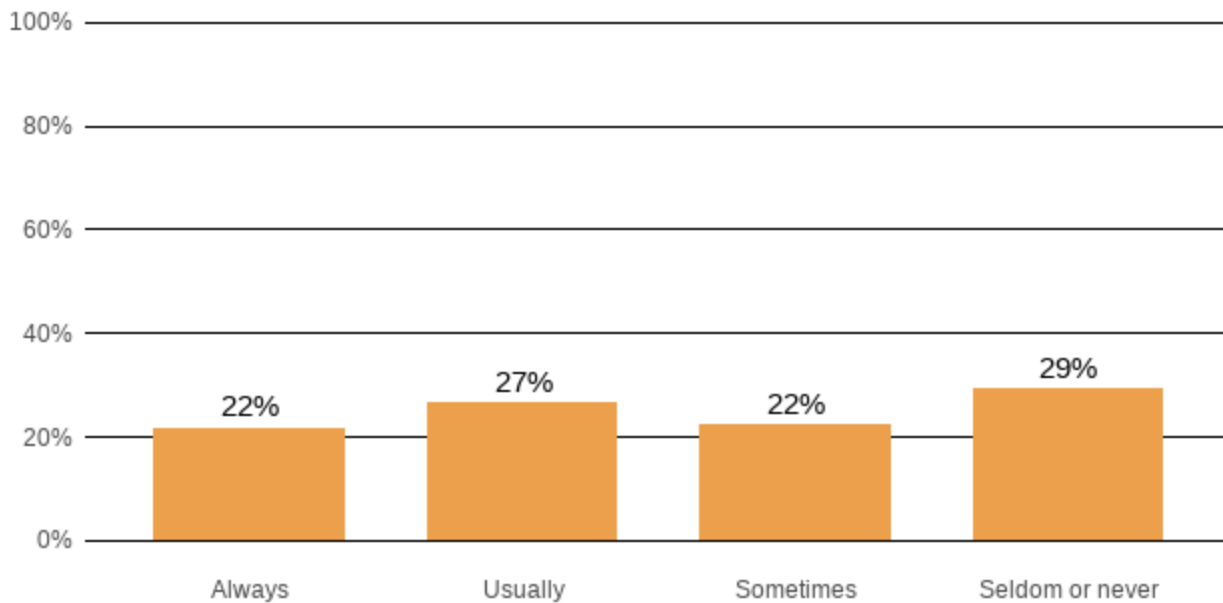


Table 43. If you need respite services, how often are you able to get them when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TX	29%	26%	21%	24%	231
Weighted NCI-IDD Average	22%	27%	22%	29%	2,076
ND	20%	32%	30%	19%	182
SD	20%	36%	25%	20%	138
IN	19%	20%	22%	39%	185
FL	19%	32%	25%	24%	134
OR	19%	29%	22%	30%	498
WI	18%	31%	25%	26%	478
TN	14%	37%	26%	23%	111
MO ↓	12%	19%	17%	52%	119

If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

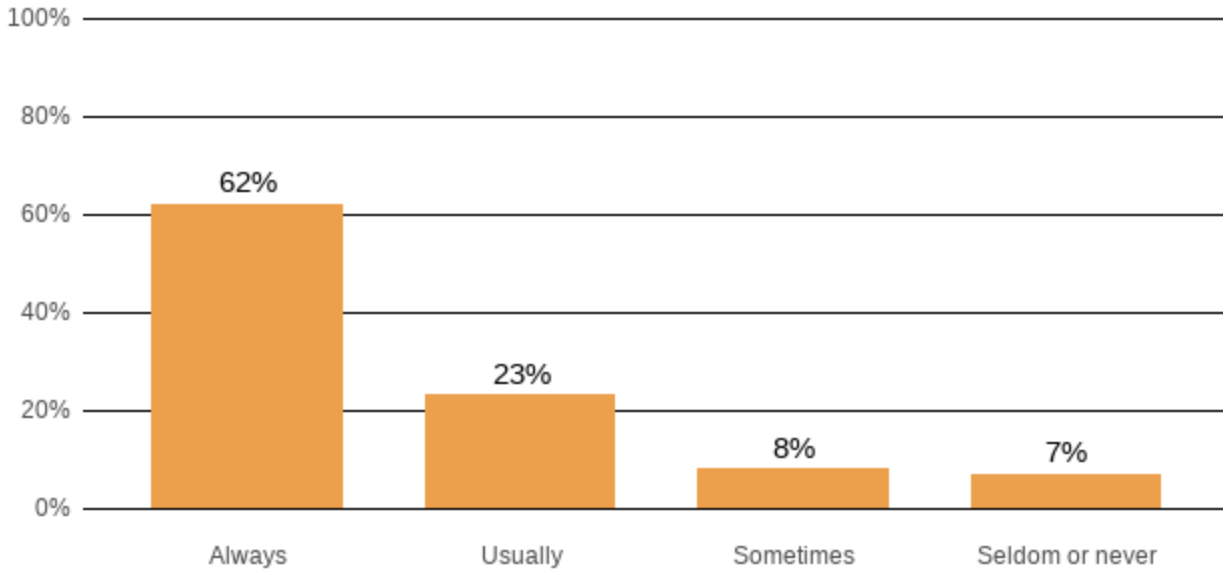


Table 44. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TX	68%	22%	4%	6%	164
SD	67%	21%	7%	6%	105
Weighted NCI-IDD Average	62%	23%	8%	7%	1,446
WI	62%	24%	8%	7%	370
IN	61%	17%	13%	10%	103
TN	59%	26%	9%	6%	81
MO	57%	22%	15%	6%	54
OR	55%	31%	7%	7%	308
FL	52%	26%	16%	6%	100
ND ↓	50%	32%	12%	6%	161

Are you able to contact your child's support workers when you want?

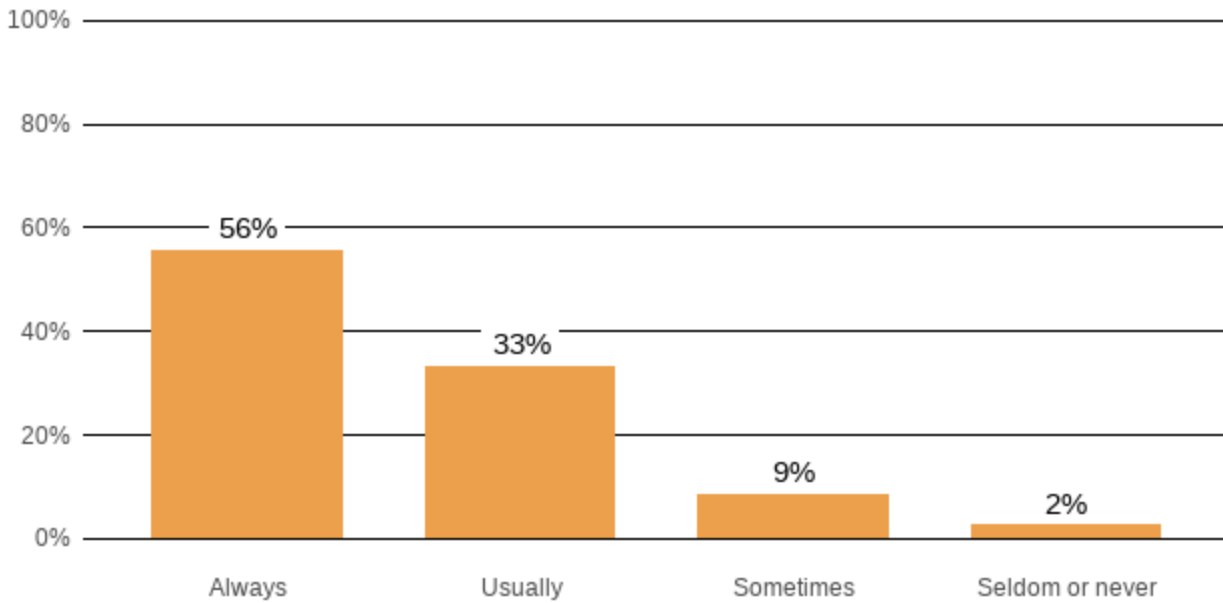


Table 45. Are you able to contact your child's support workers when you want?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	69%	27%	3%	1%	143
IN ↑	66%	27%	5%	2%	268
SD	58%	37%	4%	1%	136
OR	56%	34%	7%	2%	581
Weighted NCI-IDD Average	56%	33%	9%	2%	2,458
FL	55%	37%	5%	3%	130
WI	54%	35%	9%	3%	591
ND	53%	36%	11%	1%	198
TX	52%	33%	12%	2%	256
MO ↓	43%	44%	9%	5%	155

Are you able to contact your child's case manager or service coordinator when you want?

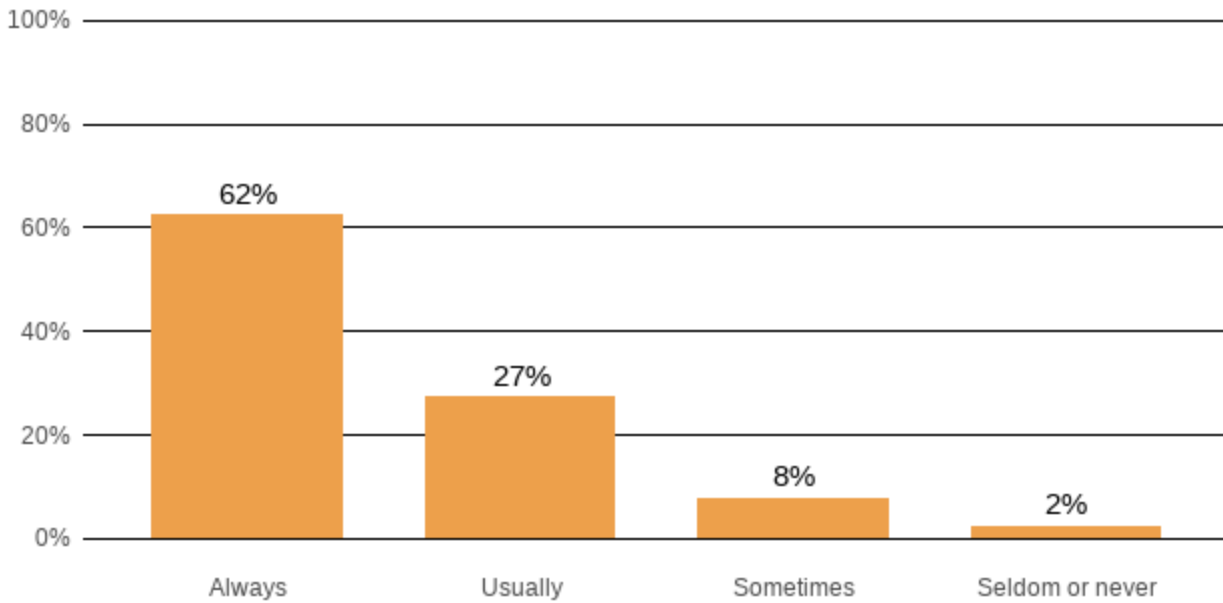


Table 46. Are you able to contact your child's case manager or service coordinator when you want?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	82%	16%	2%	0%	182
IN ↑	78%	17%	4%	1%	303
SD	66%	26%	5%	2%	152
Weighted NCI-IDD Average	62%	27%	8%	2%	2,712
WI	61%	27%	9%	3%	662
TX	58%	29%	10%	3%	288
FL	58%	32%	7%	4%	149
ND	57%	32%	9%	2%	196
OR ↓	54%	35%	8%	3%	611
MO ↓	50%	41%	8%	1%	169

Do service providers for your child work together to provide support?

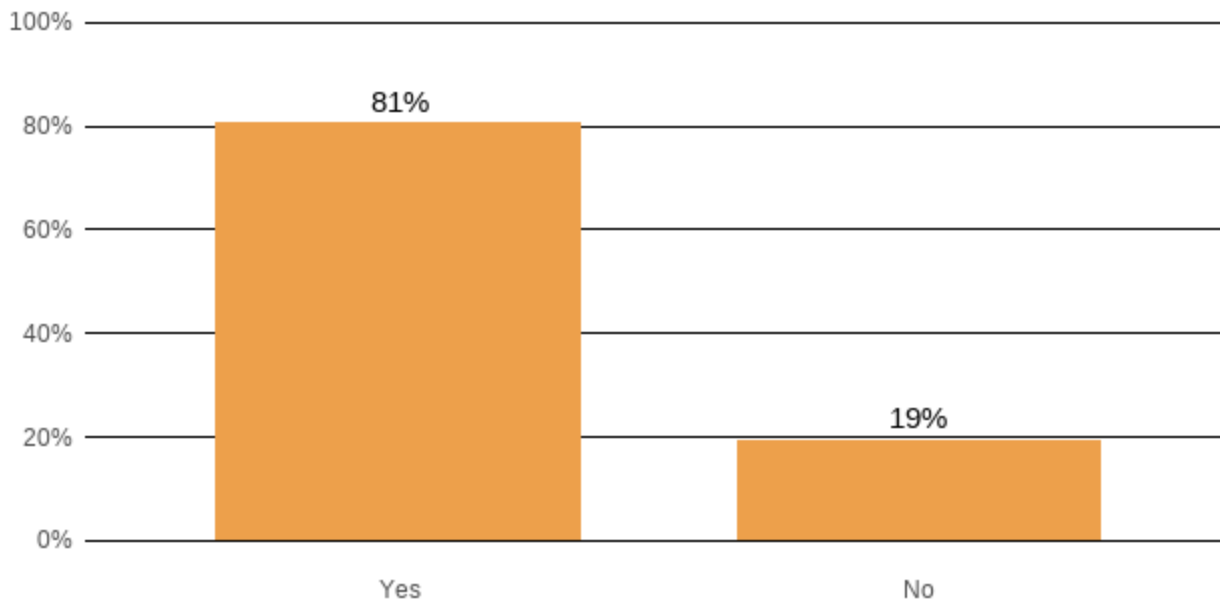


Table 47. Do service providers for your child work together to provide support?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TN ↑	91%	9%	70
IN	87%	13%	159
WI	82%	18%	303
MO	81%	19%	68
Weighted NCI-IDD Average	81%	19%	1,332
SD	79%	21%	68
ND	79%	21%	110
OR	79%	21%	313
TX	77%	23%	164
FL	68%	32%	77

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

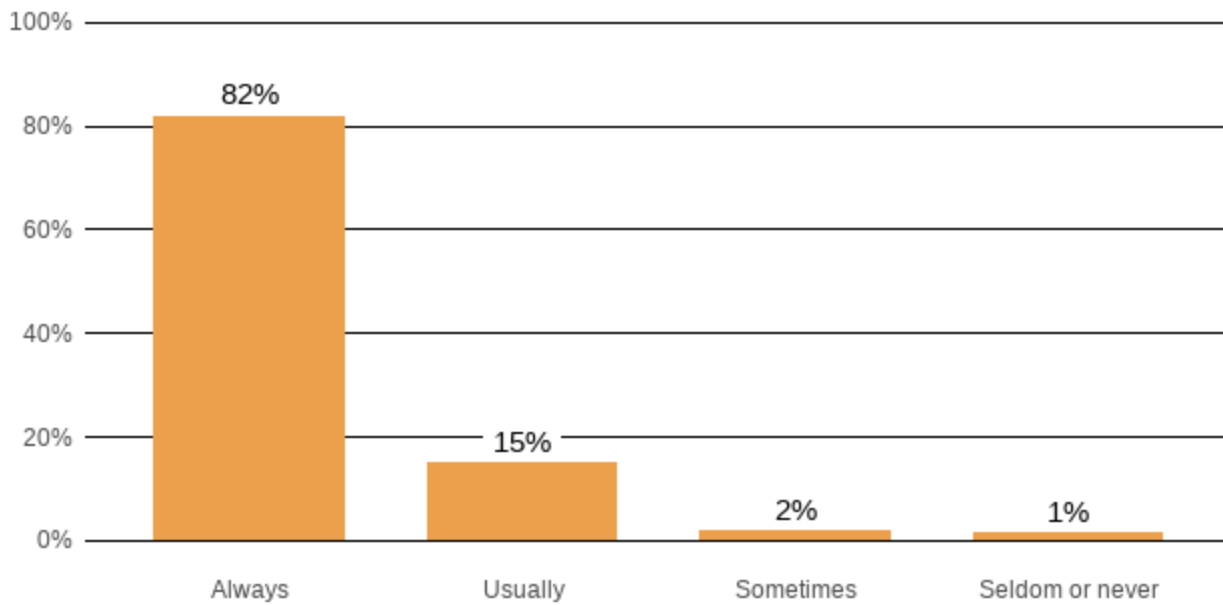


Table 48. Are services delivered in a way that is respectful of your family's culture?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	91%	8%	1%	1%	162
IN	85%	12%	1%	2%	280
MO	84%	15%	1%	1%	171
WI	83%	15%	2%	1%	631
Weighted NCI-IDD Average	82%	15%	2%	1%	2,597
SD	82%	17%	1%	0%	146
ND	82%	17%	2%	0%	200
TX	81%	16%	3%	1%	277
OR	80%	16%	2%	1%	591
FL ↓	67%	27%	2%	4%	139

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

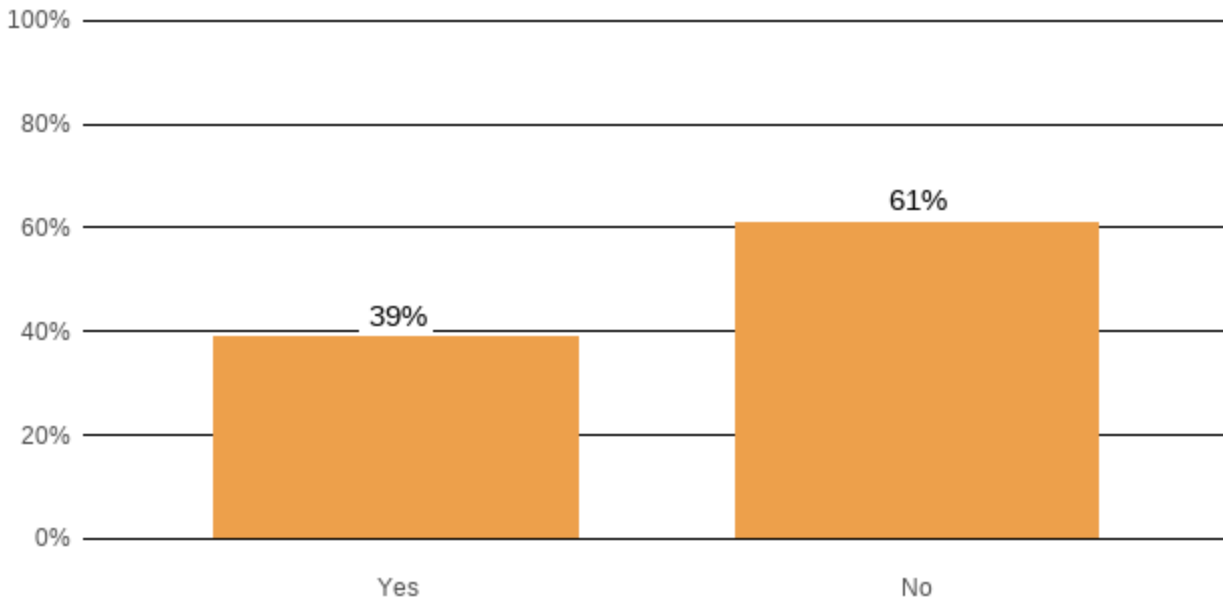


Table 49. Does your child use technology in their everyday life to help them do more things on their own?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
WI ↑	48%	52%	644
OR ↑	46%	54%	595
FL	48%	52%	150
SD	47%	53%	156
ND	43%	57%	195
Weighted NCI-IDD Average	39%	61%	2,674
TN	35%	65%	177
TX	35%	65%	288
IN	34%	66%	294
MO ↓	27%	73%	175

Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home?

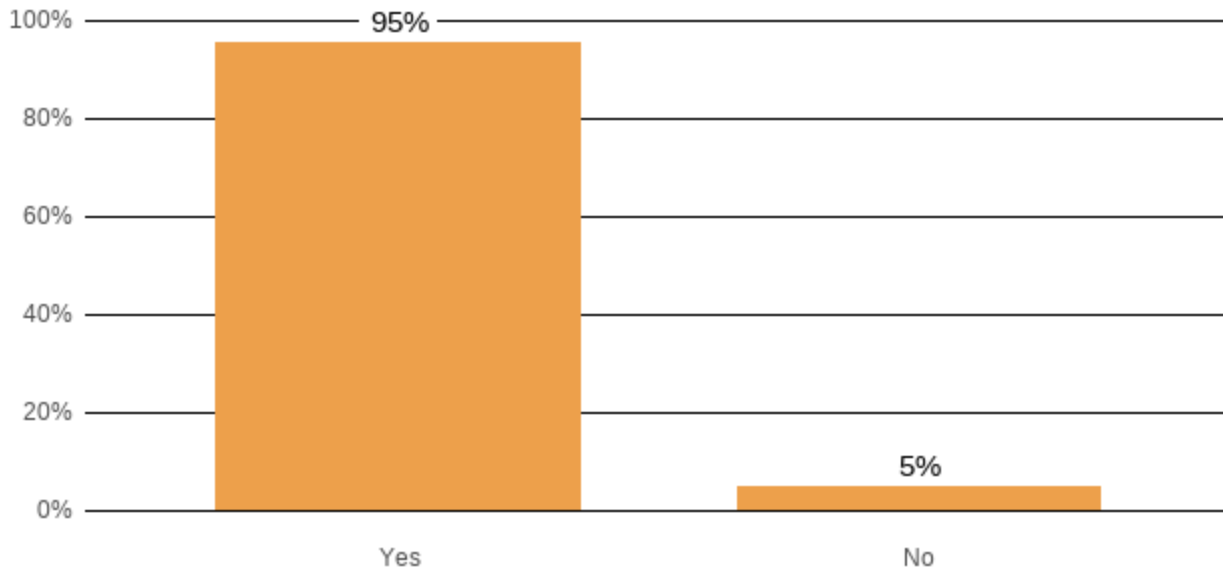


Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
MO ↑	98%	2%	182
IN ↑	98%	2%	303
TN	98%	2%	179
FL	95%	5%	153
Weighted NCI-IDD Average	95%	5%	2,768
ND	95%	5%	204
WI	94%	6%	661
TX	94%	6%	304
OR	94%	6%	622
SD	94%	6%	160

How well does the internet work in your home?

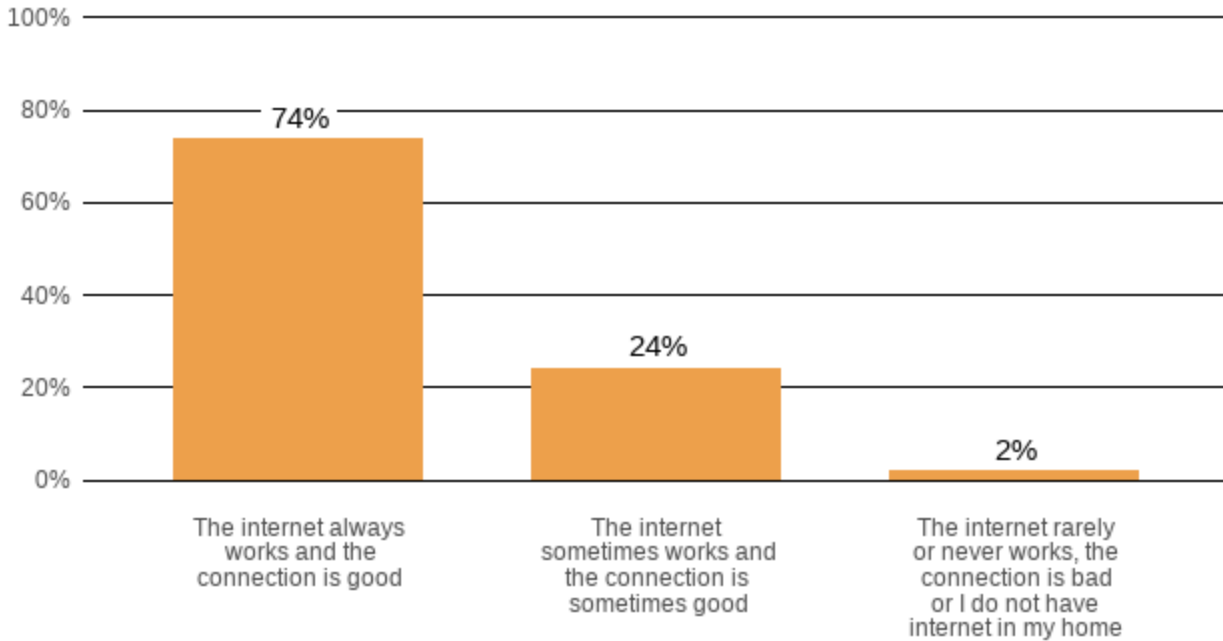


Table 51. How well does the internet work in your home?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	The internet always works and the connection is good	The internet sometimes works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
TN ↑	89%	10%	1%	180
ND ↑	87%	13%	0%	204
SD ↑	86%	12%	2%	161
FL	81%	18%	1%	155
IN	79%	20%	1%	303
WI	75%	23%	1%	664
Weighted NCI-IDD Average	74%	24%	2%	2,767
MO	73%	26%	1%	182
OR	72%	25%	2%	616
TX	67%	29%	4%	302

Workforce

There is stable and sufficient workforce to meet demand. Children 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 the children.

Note: Significance is based on “Always” or “Yes” response.

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

“Child” 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?

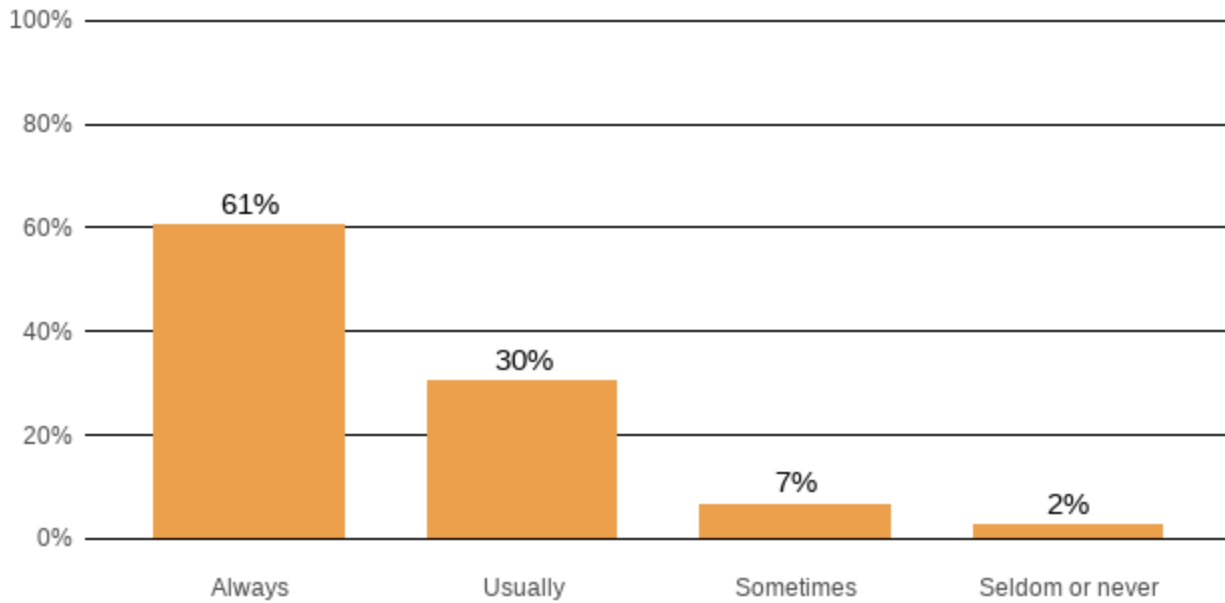


Table 52. Do support workers come and go when they are supposed to?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	79%	18%	3%	0%	120
WI ↑	68%	24%	5%	3%	518
SD	64%	30%	5%	0%	115
IN	63%	28%	6%	2%	241
Weighted NCI-IDD Average	61%	30%	7%	2%	2,240
MO	58%	36%	6%	1%	138
TX	56%	34%	7%	3%	243
FL	54%	32%	11%	3%	123
ND	51%	39%	9%	1%	191
OR ↓	54%	35%	9%	2%	551

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

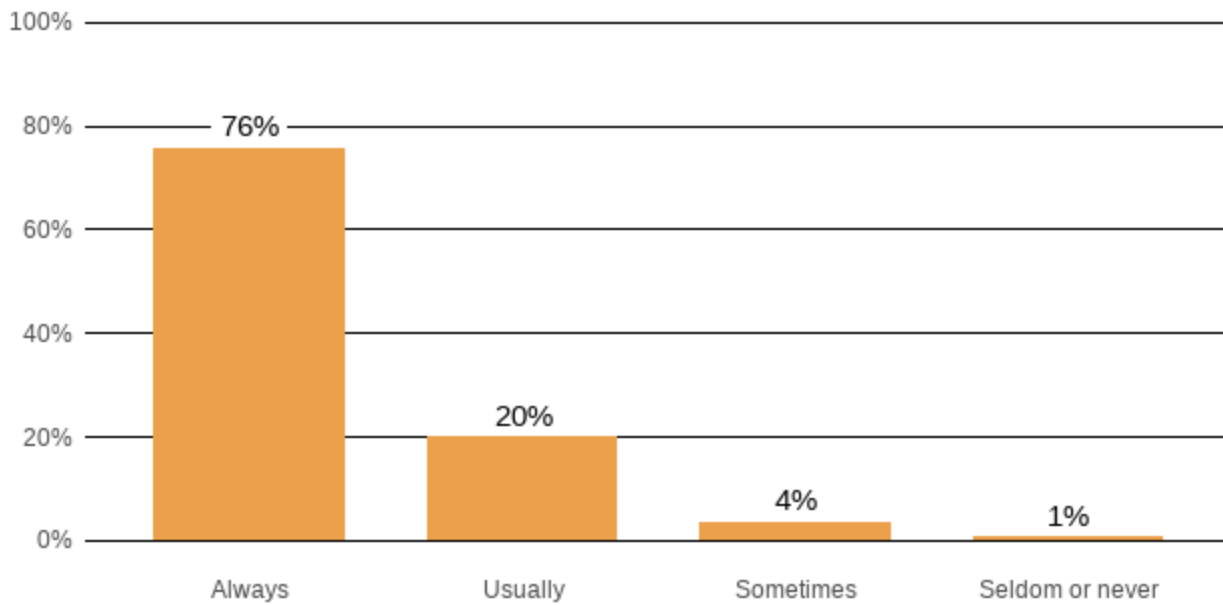


Table 53. Do support workers speak to you in a way you understand?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	88%	11%	2%	0%	128
IN	81%	18%	1%	1%	262
SD	77%	22%	2%	0%	129
Weighted NCI-IDD Average	76%	20%	4%	1%	2,390
WI	75%	20%	3%	1%	551
ND	75%	20%	4%	1%	199
OR	75%	22%	3%	0%	577
TX	74%	19%	6%	1%	268
MO	71%	26%	3%	0%	150
FL	68%	25%	5%	2%	126

If your child does not communicate verbally, are there support workers who can communicate with your child?

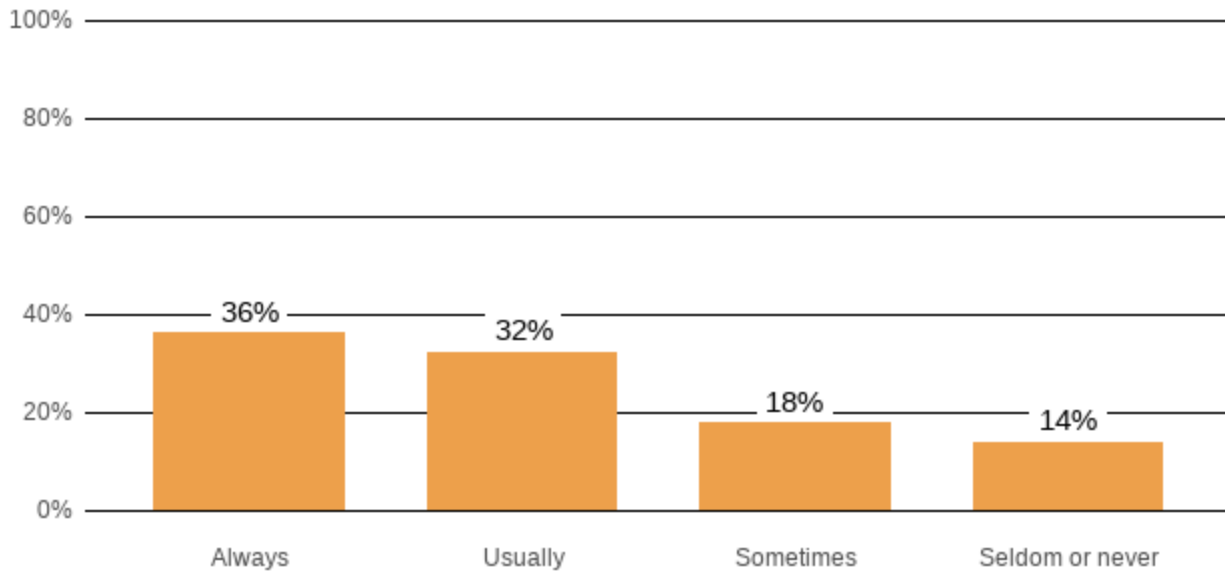


Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
IN ↑	51%	33%	11%	4%	115
TN	48%	28%	23%	1%	69
ND	42%	37%	18%	3%	115
MO	38%	29%	24%	9%	58
TX	36%	28%	18%	18%	160
Weighted NCI-IDD Average	36%	32%	18%	14%	1,270
OR	36%	37%	16%	11%	292
SD	30%	38%	27%	5%	79
FL	26%	35%	20%	19%	84
WI ↓	26%	37%	19%	17%	298

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

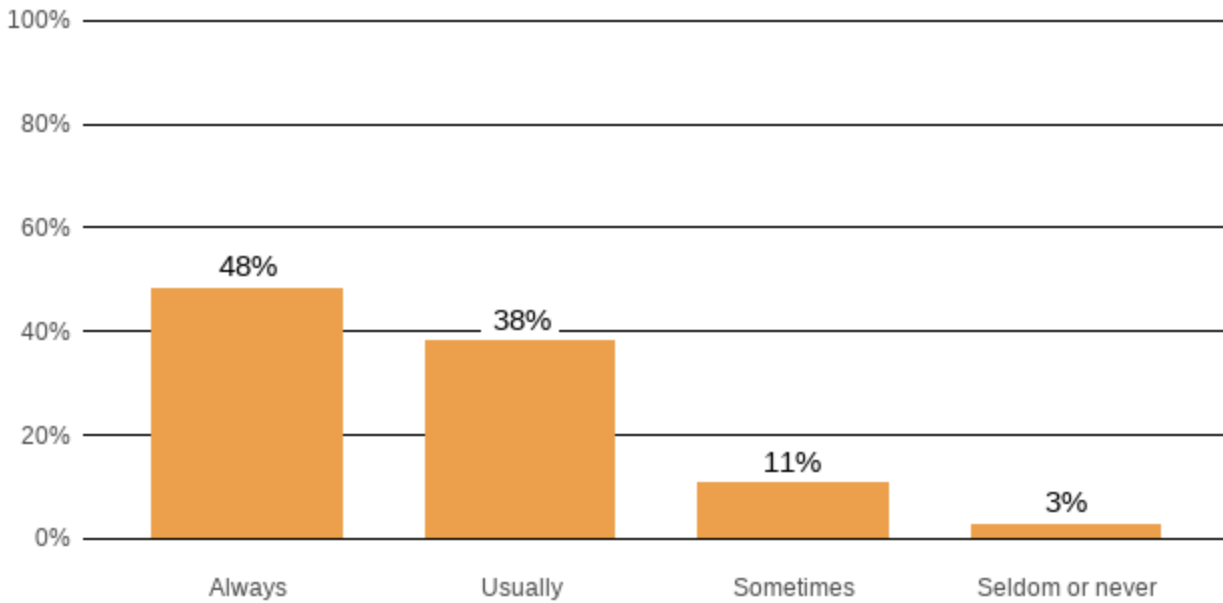


Table 55. Do support workers have the right information and skills to meet your family's needs?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	63%	34%	3%	0%	128
IN ↑	58%	33%	8%	1%	248
TX	50%	36%	13%	2%	262
Weighted NCI-IDD Average	48%	38%	11%	3%	2,308
SD	46%	44%	10%	0%	125
WI	44%	39%	11%	5%	534
MO	42%	48%	8%	2%	136
ND	42%	47%	10%	2%	192
FL	38%	46%	11%	5%	123
OR ↓	41%	42%	12%	5%	560

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

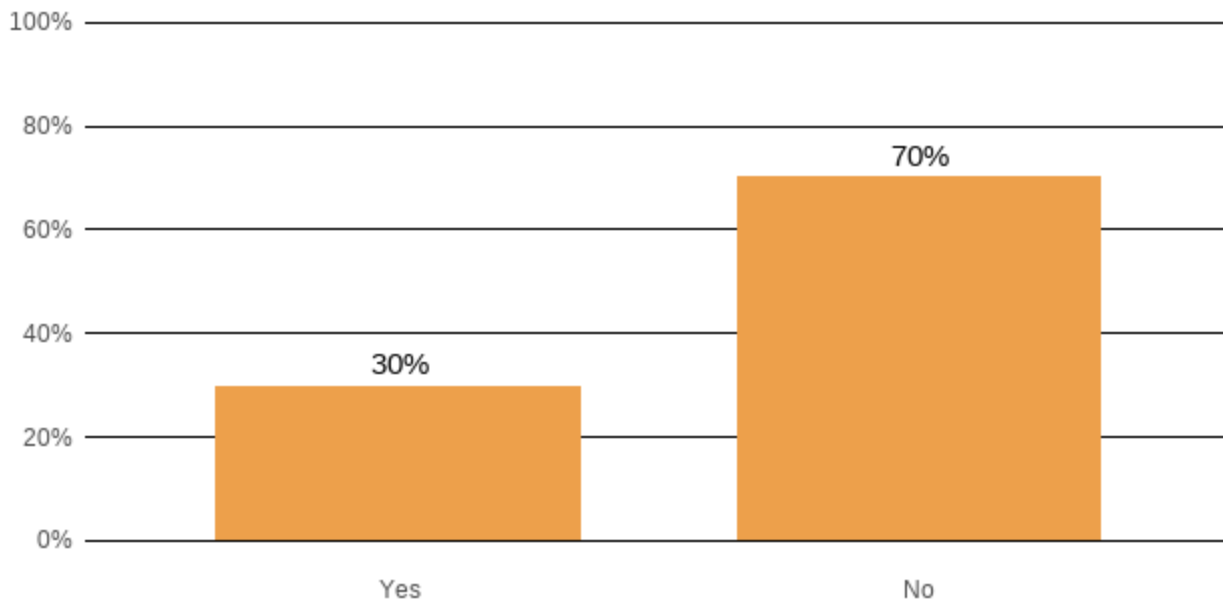


Table 56. Do your child’s support workers change too often? Is there too much “turnover” of support workers?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
ND ↑	44%	56%	180
MO ↑	42%	58%	130
OR	30%	70%	522
FL	30%	70%	120
TX	30%	70%	237
Weighted NCI-IDD Average	30%	70%	2,135
IN	29%	71%	232
WI	27%	73%	485
SD	21%	79%	114
TN ↓	19%	81%	115

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

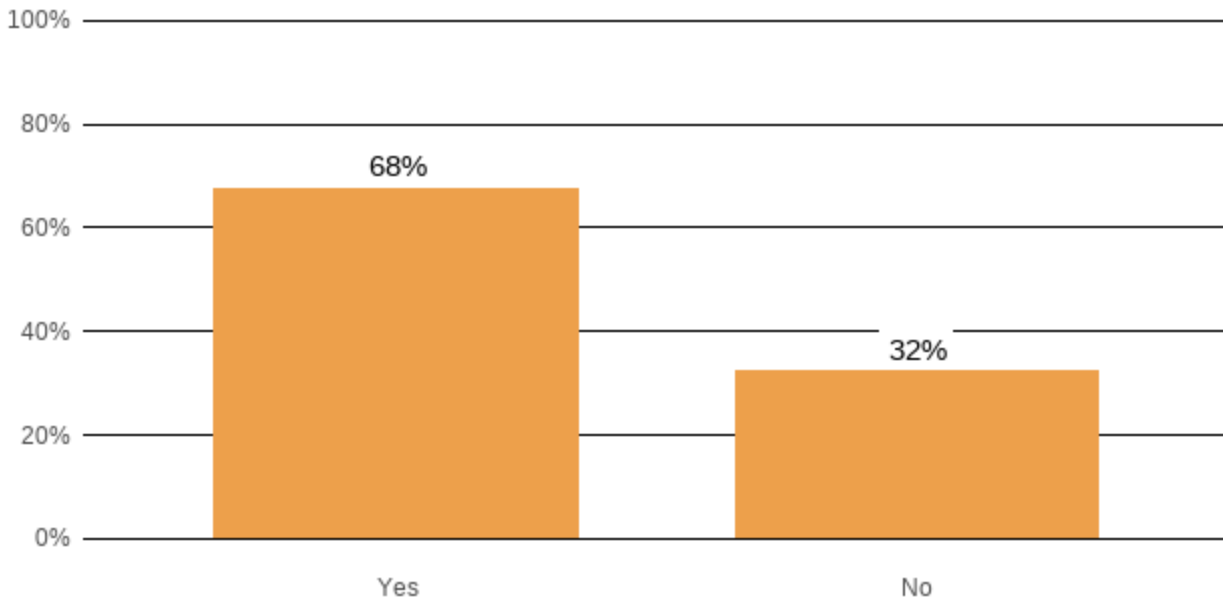


Table 57. Is there always a staff person available to support your child when support is needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TN ↑	85%	15%	115
SD	75%	25%	116
TX	74%	26%	236
Weighted NCI-IDD Average	68%	32%	2,093
WI	66%	34%	473
MO	66%	34%	114
IN	65%	35%	229
FL	61%	39%	119
OR ↓	59%	41%	501
ND ↓	46%	54%	190

Choice, Decision Making and Control

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

Note: Significance is based on “Always” or “Yes” response.

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

“Child” 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 child's services?

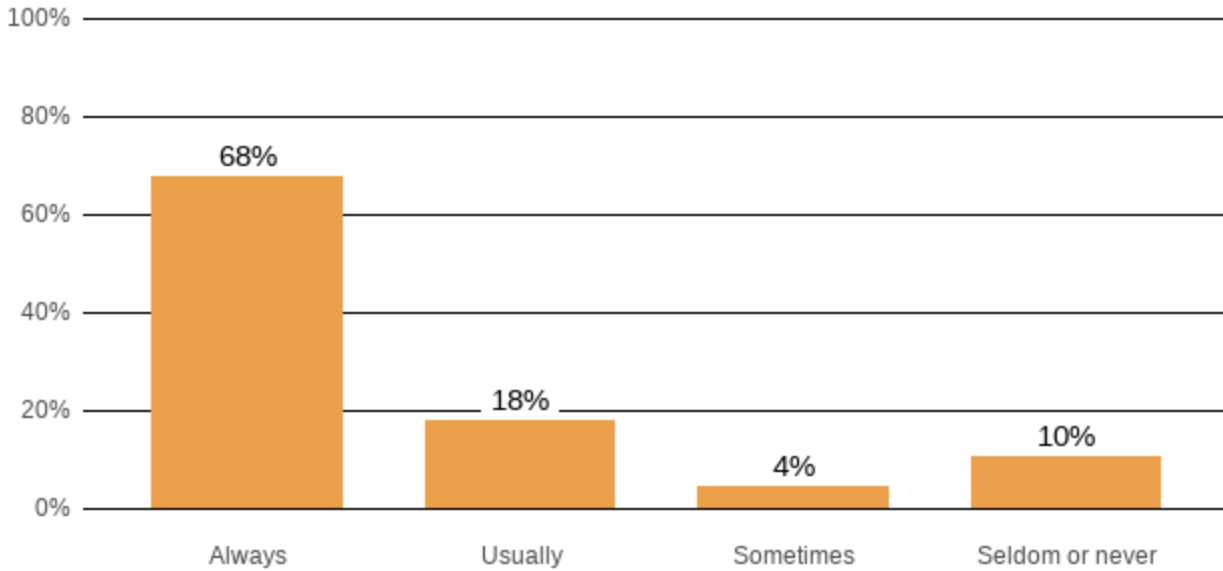


Table 58. Can someone in your family choose or change the provider agency that provides your child's services?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
IN ↑	82%	9%	4%	5%	254
TN	69%	23%	4%	4%	104
TX	69%	14%	2%	14%	243
Weighted NCI-IDD Average	68%	18%	4%	10%	1,812
ND	64%	24%	5%	8%	144
OR	63%	26%	4%	6%	460
SD	63%	23%	8%	6%	90
FL	58%	27%	4%	11%	113
MO	56%	30%	4%	10%	101
WI ↓	52%	25%	10%	14%	303

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

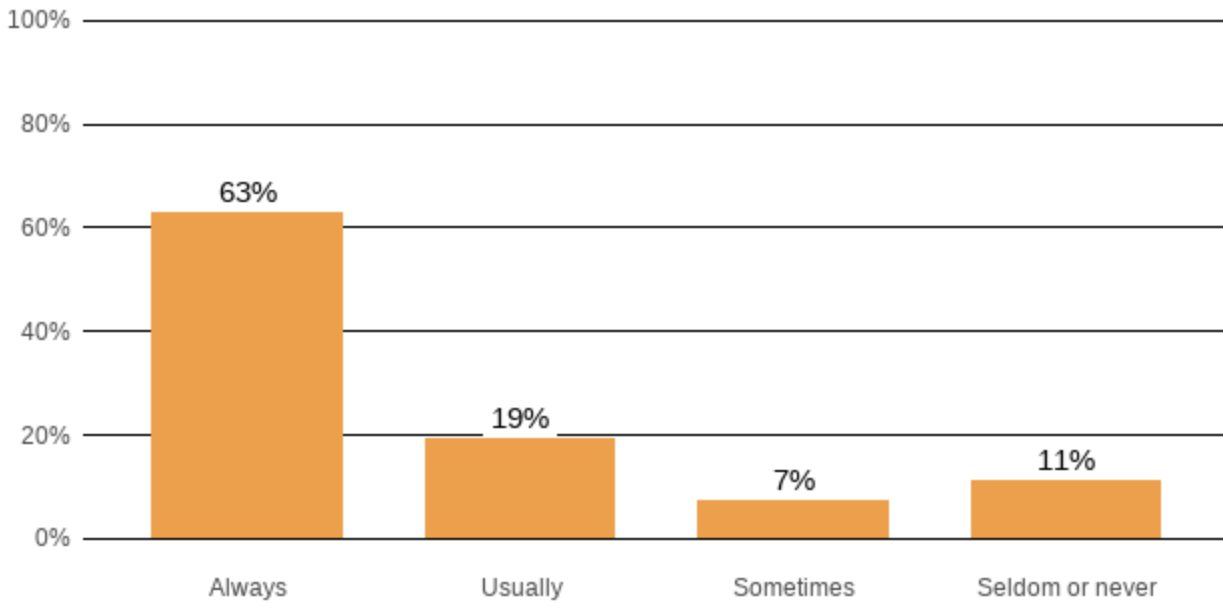


Table 59. Can someone in your family choose or change your child's support workers?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
IN ↑	73%	14%	4%	8%	236
OR	65%	22%	6%	7%	509
TN	65%	18%	11%	6%	79
SD	64%	16%	9%	11%	92
Weighted NCI-IDD Average	63%	19%	7%	11%	1,838
TX	62%	16%	7%	15%	218
FL	58%	25%	6%	11%	119
ND	58%	21%	13%	9%	168
MO	55%	25%	12%	9%	93
WI ↓	52%	27%	10%	11%	324

Can someone in your family directly manage support staff?

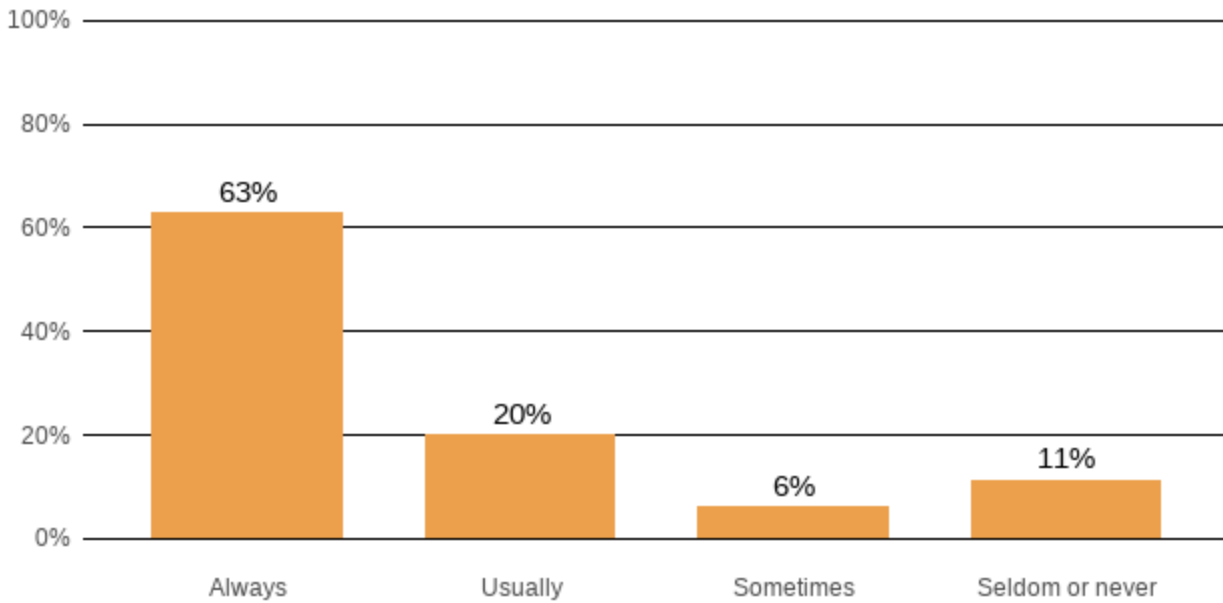


Table 60. Can someone in your family directly manage support staff?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
OR ↑	68%	21%	5%	6%	520
TN	70%	20%	6%	4%	79
IN	65%	19%	7%	9%	204
SD	64%	22%	7%	7%	89
TX	64%	15%	6%	15%	228
Weighted NCI-IDD Average	63%	20%	6%	11%	1,800
MO	62%	14%	7%	16%	85
FL	58%	25%	7%	10%	117
ND	55%	23%	8%	14%	161
WI ↓	55%	29%	6%	9%	317

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

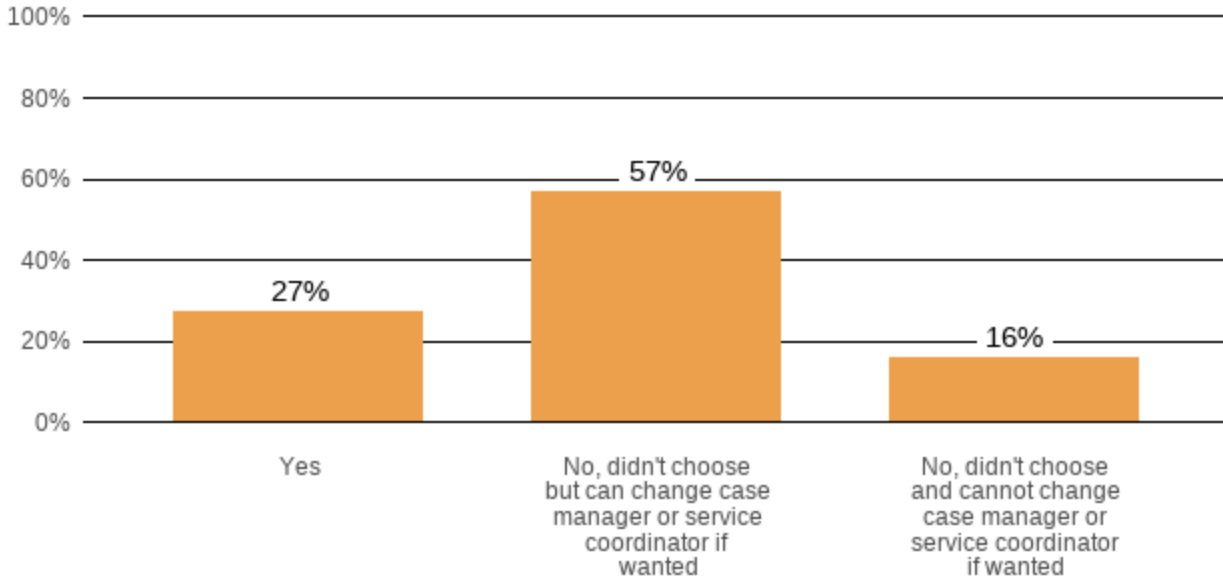


Table 61. Did you, your child, or someone else in your family choose your child's case manager or service coordinator?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No, didn't choose but can change case manager or service coordinator if wanted	No, didn't choose and cannot change case manager or service coordinator if wanted	N
FL ↑	68%	29%	3%	135
IN ↑	49%	47%	4%	288
ND ↑	48%	37%	15%	151
OR ↑	34%	54%	12%	500
Weighted NCI-IDD Average	27%	57%	16%	2,195
TX ↓	20%	62%	17%	241
SD ↓	16%	65%	19%	133
MO ↓	15%	66%	20%	123
WI ↓	9%	62%	29%	497
TN ↓	7%	80%	13%	127

Involvement in the Community

Children receiving services and supports from the state Developmental disabilities system are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.

Note: Significance is based on “Always” or “Yes” response.

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

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

Does your child do things in the community?

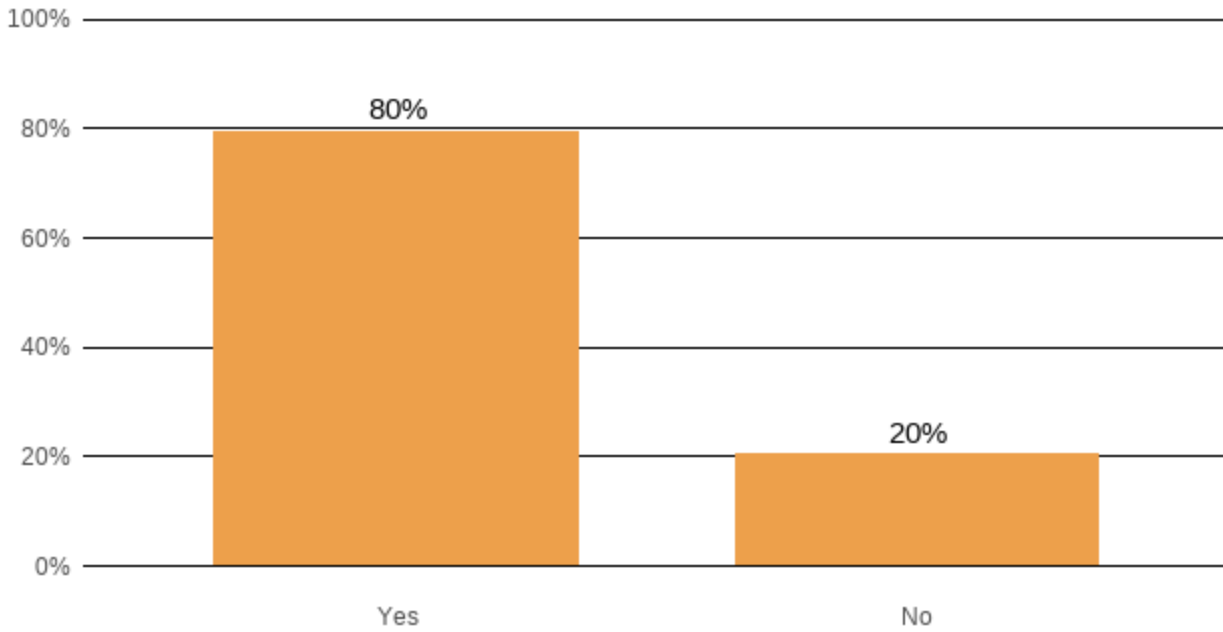


Table 62. Does your child do things in the community?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
SD ↑	89%	11%	159
ND ↑	89%	11%	195
TN ↑	88%	12%	177
IN	84%	16%	302
MO	83%	17%	187
WI	83%	17%	642
OR	81%	19%	613
Weighted NCI-IDD Average	80%	20%	2,720
FL	76%	24%	148
TX ↓	71%	29%	297

What makes it hard to do things in the community?

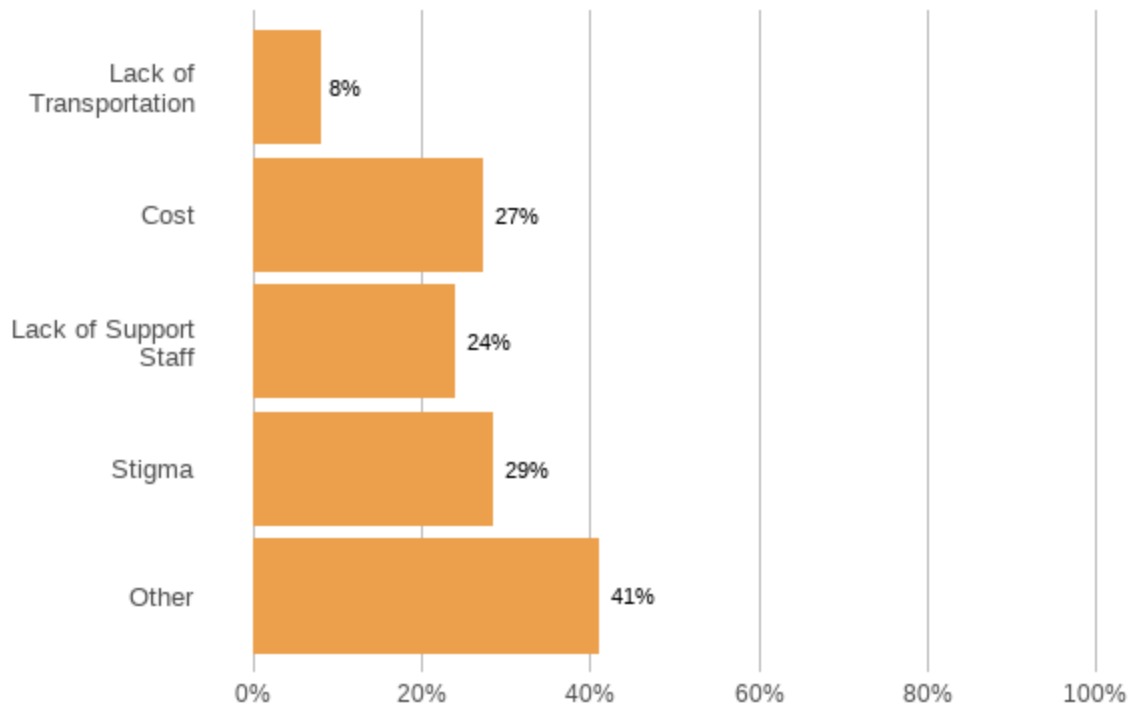


Table 63. What makes it hard to do things in the community?

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

State (names abbreviated)	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
FL	13%	30%	32%	26%	48%
IN	7%	21%	20%	27%	39%
MO	9%	31%	19%	34%	47%
ND	11%	26%	35%	30%	42%
OR	9%	32%	27%	33%	42%
SD	9%	19%	15%	20%	41%
TN	2%	19%	18%	31%	45%
TX	7%	28%	22%	21%	41%
WI	8%	30%	28%	37%	39%
Weighted NCI-IDD Average	8%	27%	24%	29%	41%

Does your child spend time with children who do not have developmental disabilities?

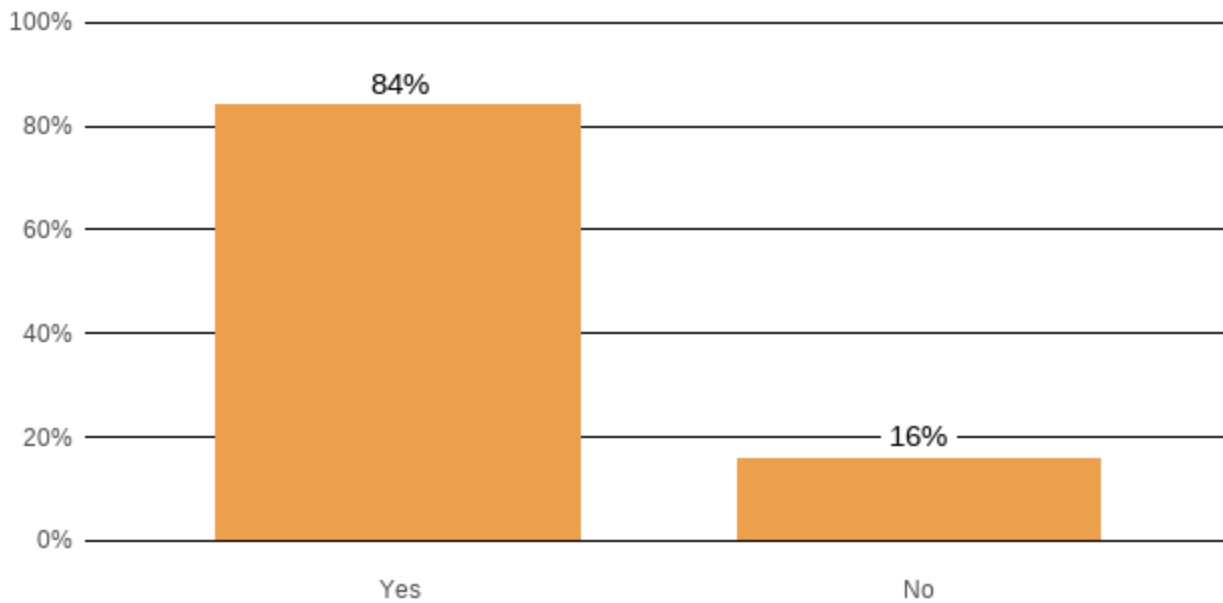


Table 64. Does your child spend time with children who do not have developmental disabilities?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
SD ↑	94%	6%	159
TN ↑	90%	10%	180
MO	89%	11%	183
IN	88%	12%	302
ND	88%	12%	201
OR	86%	14%	618
Weighted NCI-IDD Average	84%	16%	2,741
WI	83%	17%	647
TX	80%	20%	300
FL ↓	75%	25%	151

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

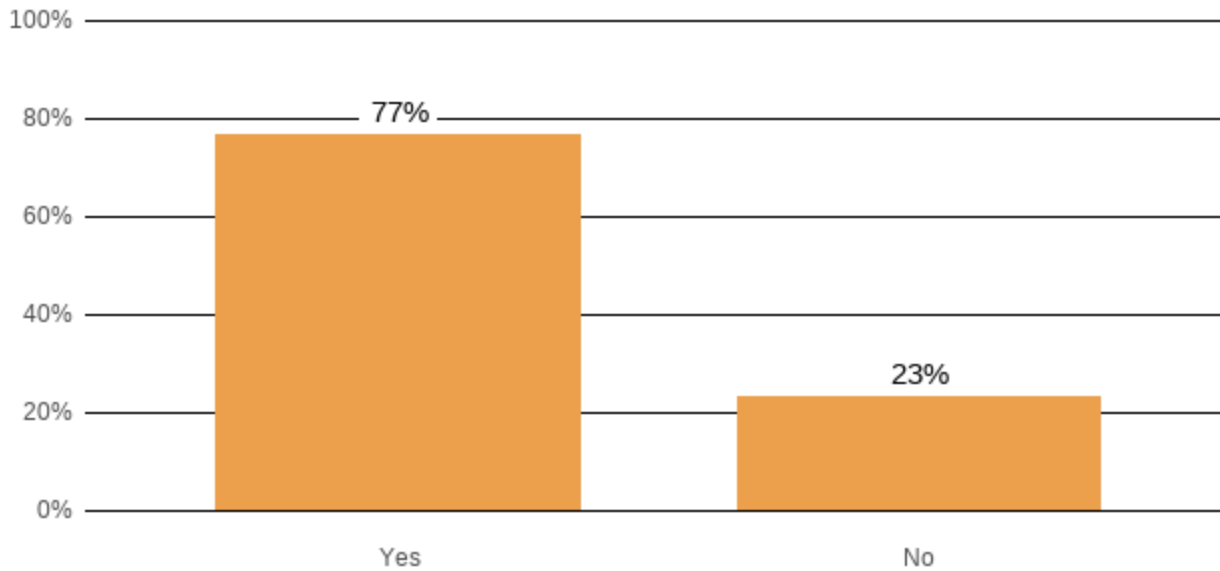


Table 65. In your community, are there resources that your family and child can use that are not provided by the I/DD agency?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TN ↑	86%	14%	143
SD	84%	16%	110
IN	80%	20%	220
WI	79%	21%	496
MO	79%	21%	133
ND	78%	22%	156
Weighted NCI-IDD Average	77%	23%	1,989
OR	76%	24%	428
FL	74%	26%	102
TX	71%	29%	201

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

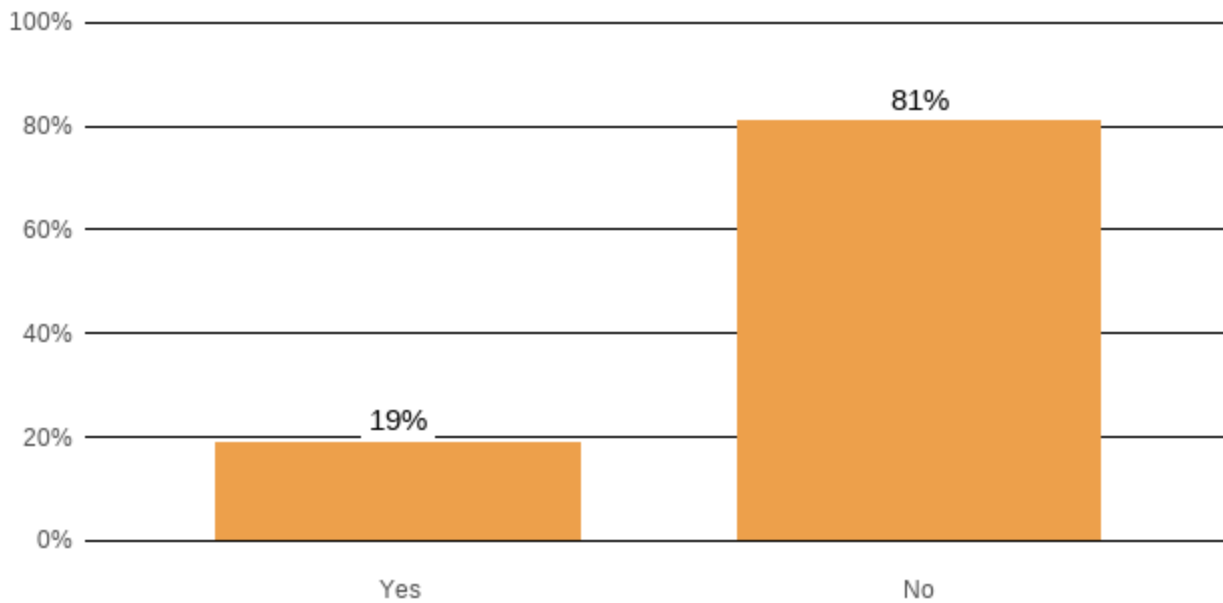


Table 66. Does your family take part in any family-to-family networks in your community?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TX	24%	76%	260
TN	24%	76%	154
ND	23%	77%	170
OR	20%	80%	542
Weighted NCI-IDD Average	19%	81%	2,355
FL	19%	81%	138
WI	17%	83%	551
SD	14%	86%	132
IN	14%	86%	258
MO	13%	87%	150

Health, Welfare, and Safety

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

Note: Significance is based on “Always” or “Yes” response.

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

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

Can your child see a primary care provider (doctor, registered nurse, etc.) when needed?

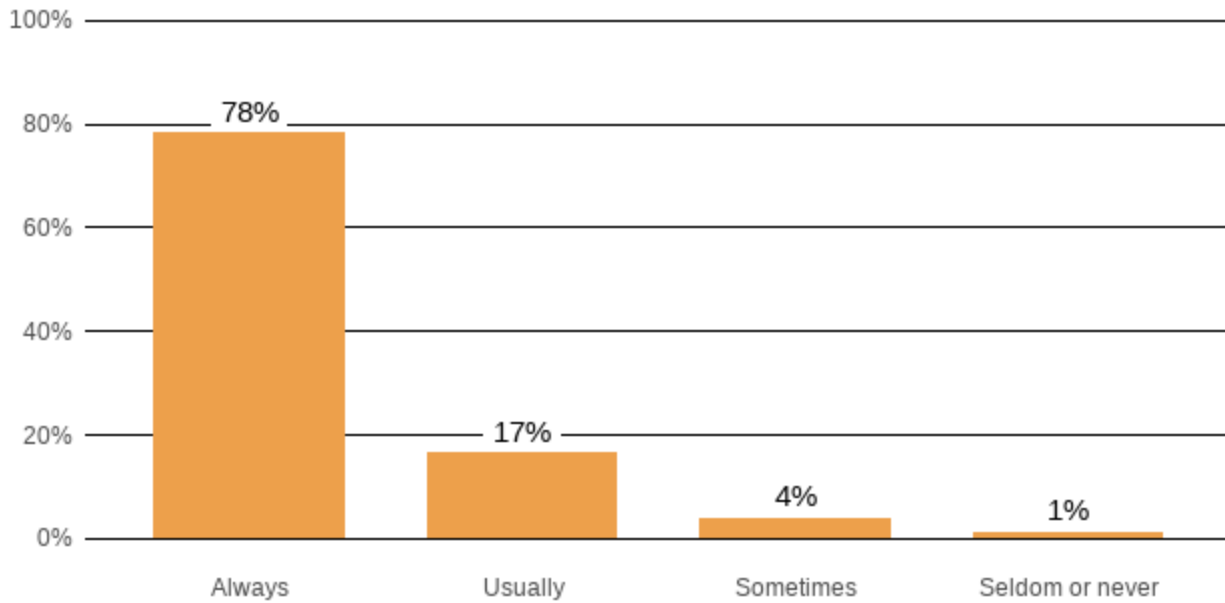


Table 67. Can your child see a primary care provider (doctor, registered nurse, etc.) when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	87%	11%	1%	2%	179
IN ↑	86%	11%	3%	0%	301
MO	84%	13%	2%	0%	186
FL	82%	16%	2%	0%	154
Weighted NCI-IDD Average	78%	17%	4%	1%	2,733
TX	78%	14%	6%	2%	285
SD	77%	22%	1%	0%	161
ND	76%	20%	2%	1%	202
WI ↓	73%	23%	3%	1%	651
OR ↓	69%	25%	4%	2%	614

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

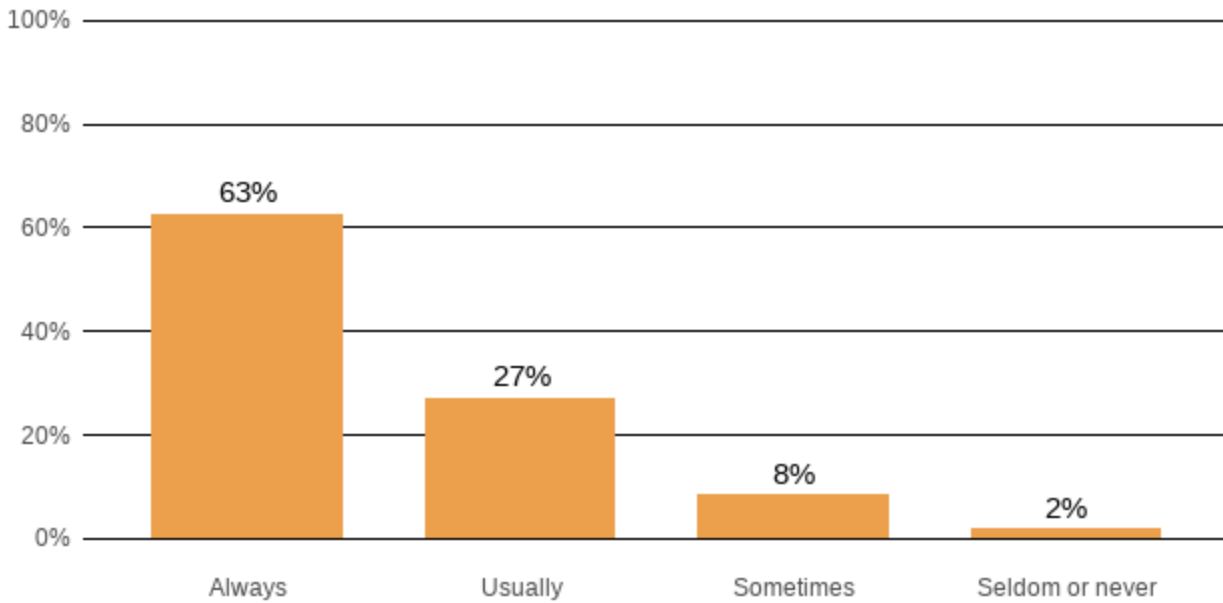


Table 68. Does your child's primary care doctor understand your child's needs related to their disability?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TX ↑	74%	19%	5%	1%	294
IN	67%	22%	9%	2%	302
FL	67%	27%	5%	1%	152
Weighted NCI-IDD Average	63%	27%	8%	2%	2,729
ND	62%	29%	8%	1%	203
TN	58%	33%	8%	1%	180
MO	55%	35%	10%	0%	181
SD	55%	34%	9%	2%	161
WI ↓	53%	33%	11%	3%	651
OR ↓	46%	38%	13%	2%	605

Can your child go to the dentist when needed?

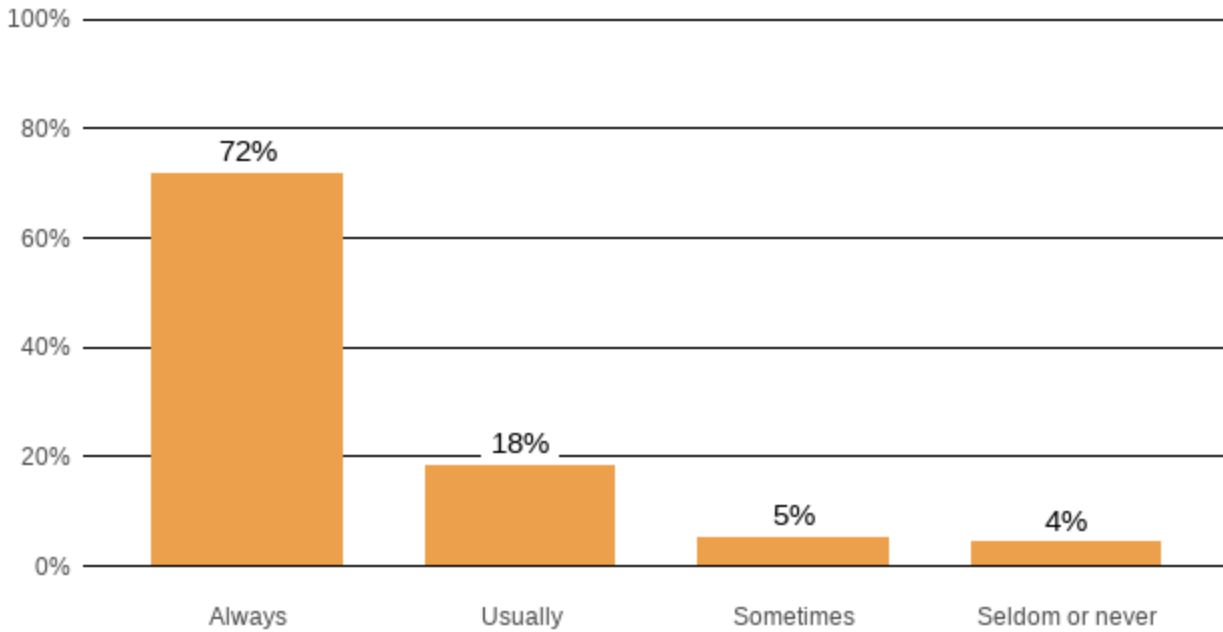


Table 69. Can your child go to the dentist when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
IN ↑	83%	12%	4%	2%	302
SD	79%	14%	4%	3%	159
TN	79%	15%	2%	3%	176
TX	75%	18%	3%	3%	296
MO	74%	14%	8%	4%	183
Weighted NCI-IDD Average	72%	18%	5%	4%	2,721
ND	68%	23%	5%	4%	202
FL	63%	19%	8%	9%	153
WI ↓	64%	23%	6%	7%	638
OR ↓	57%	25%	10%	8%	612

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

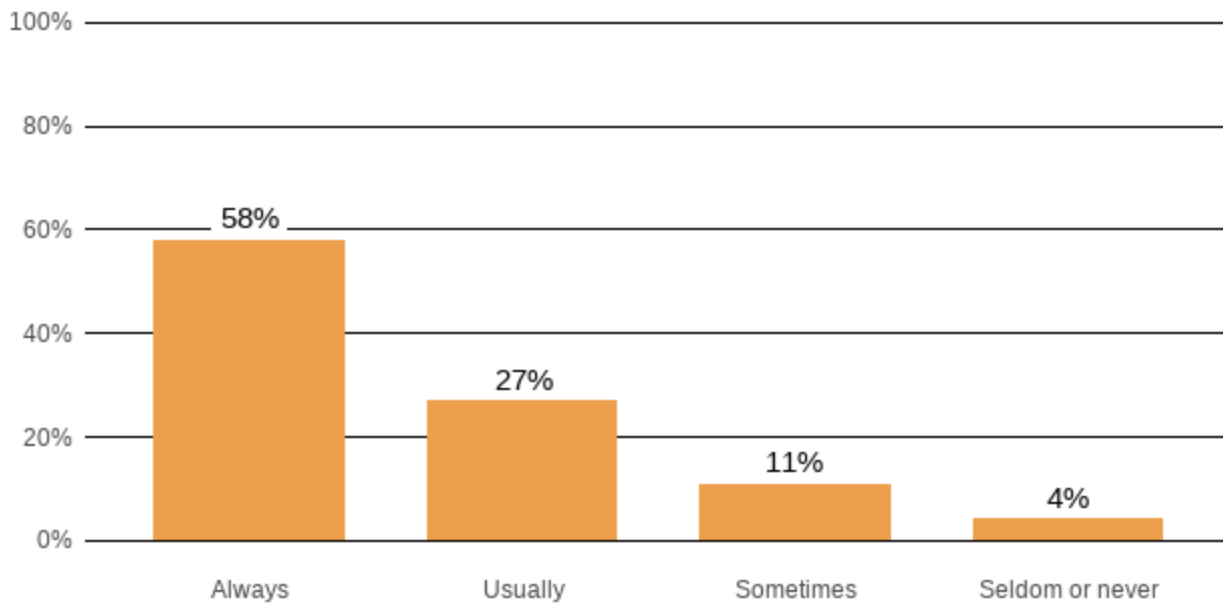


Table 70. Does your child's dentist understand your child's needs related to their disability?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
IN ↑	69%	21%	9%	1%	287
TX	63%	23%	11%	3%	291
FL	62%	26%	9%	4%	140
ND	61%	29%	9%	2%	185
TN	58%	34%	7%	2%	167
Weighted NCI-IDD Average	58%	27%	11%	4%	2,540
SD	49%	32%	16%	3%	155
WI ↓	51%	30%	11%	8%	595
MO ↓	45%	36%	14%	4%	166
OR ↓	44%	37%	14%	6%	554

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

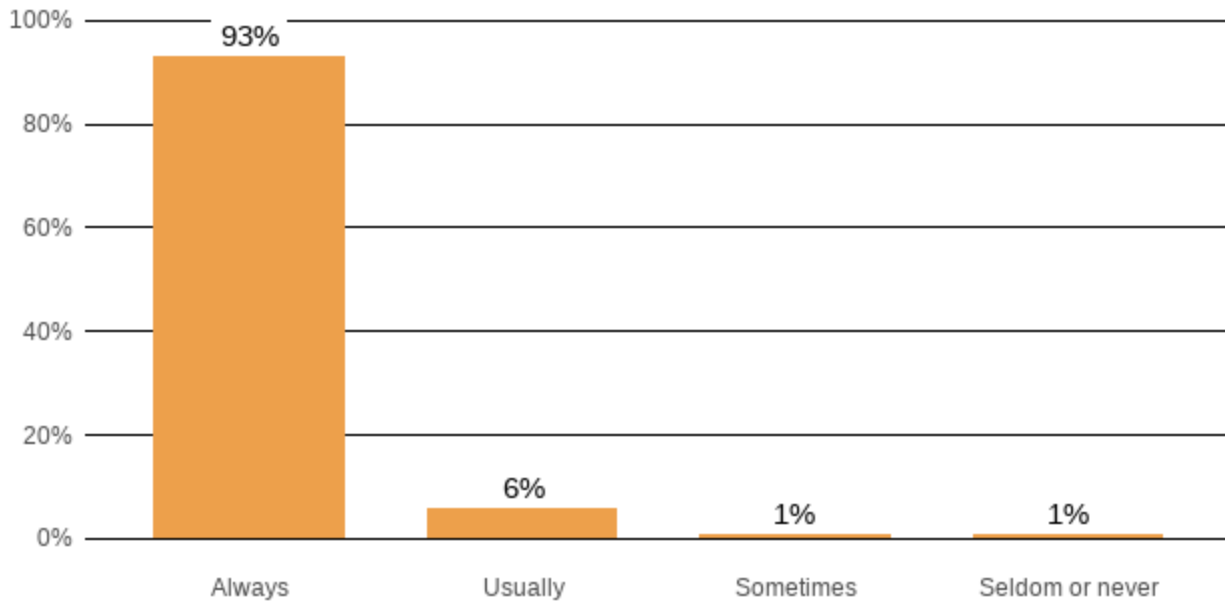


Table 71. If your child takes prescription medications, do you know what they're for?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	97%	3%	0%	0%	130
SD	97%	2%	1%	1%	118
ND	94%	3%	0%	3%	155
FL	94%	6%	0%	0%	132
TX	93%	6%	1%	0%	284
OR	93%	4%	2%	1%	443
IN	93%	6%	0%	1%	240
Weighted NCI-IDD Average	93%	6%	1%	1%	2,103
MO	93%	4%	3%	0%	140
WI	91%	7%	0%	1%	461

Do you 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)?

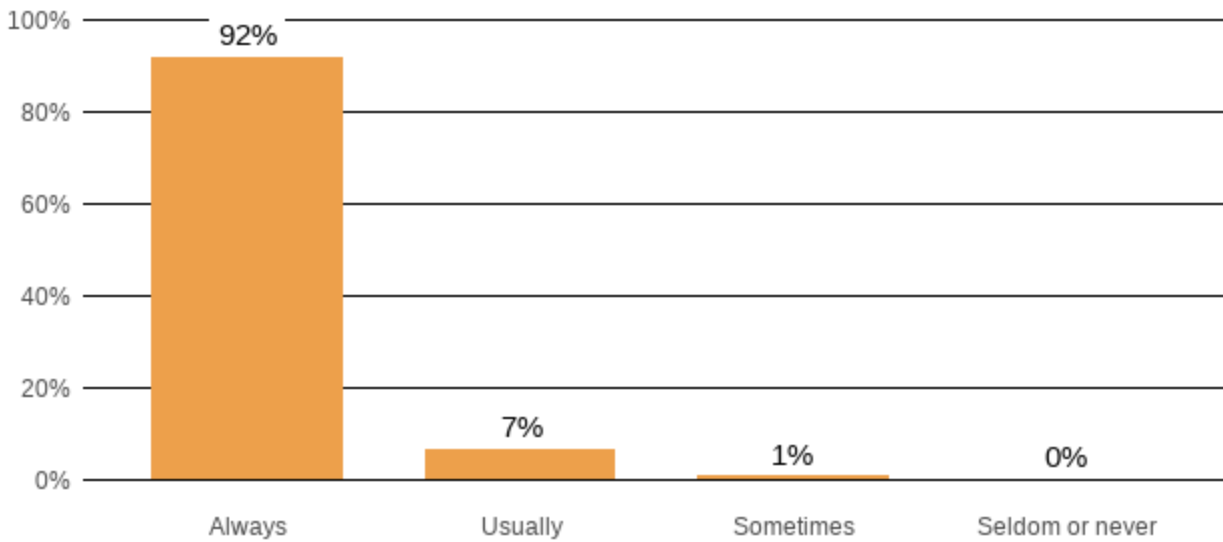


Table 72. Do you or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
FL	95%	4%	1%	0%	131
TN	95%	5%	0%	0%	130
MO	94%	4%	1%	0%	141
ND	93%	6%	0%	1%	154
IN	93%	6%	1%	0%	240
SD	93%	8%	0%	0%	120
WI	92%	6%	1%	1%	459
Weighted NCI-IDD Average	92%	7%	1%	0%	2,095
OR	92%	6%	1%	0%	441
TX	90%	9%	1%	0%	279

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

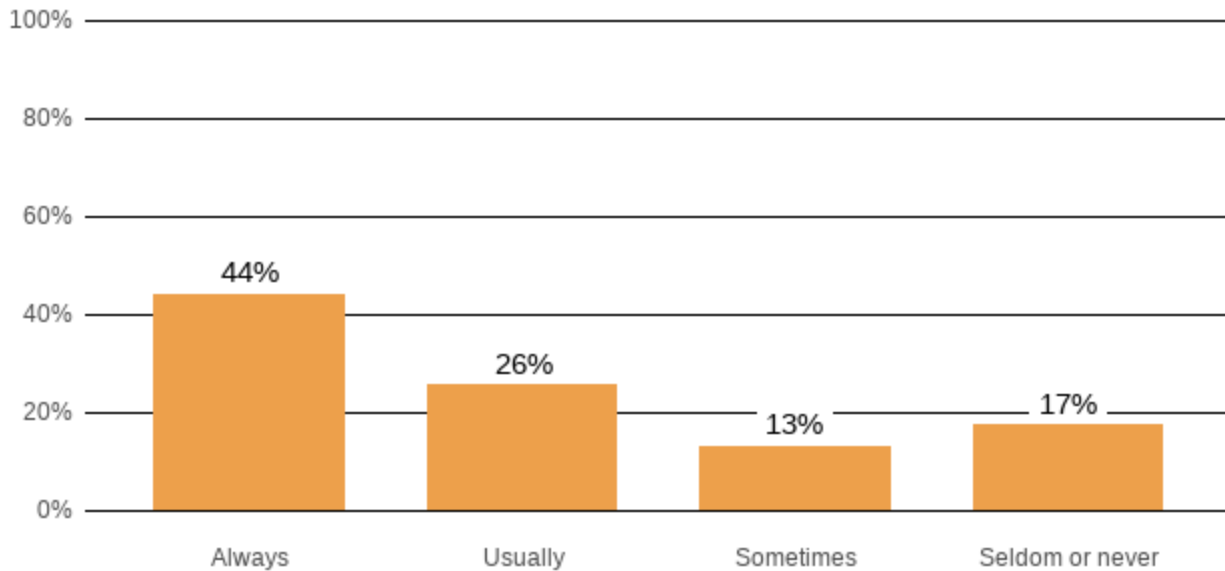


Table 73. Can your child get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN ↑	61%	21%	10%	8%	133
SD	57%	24%	6%	13%	100
IN	52%	26%	12%	10%	230
TX	50%	23%	8%	19%	213
Weighted NCI-IDD Average	44%	26%	13%	17%	2,029
ND	42%	36%	14%	8%	156
MO	41%	22%	14%	23%	145
FL	36%	27%	18%	19%	120
WI ↓	34%	27%	19%	20%	468
OR ↓	33%	30%	16%	20%	464

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

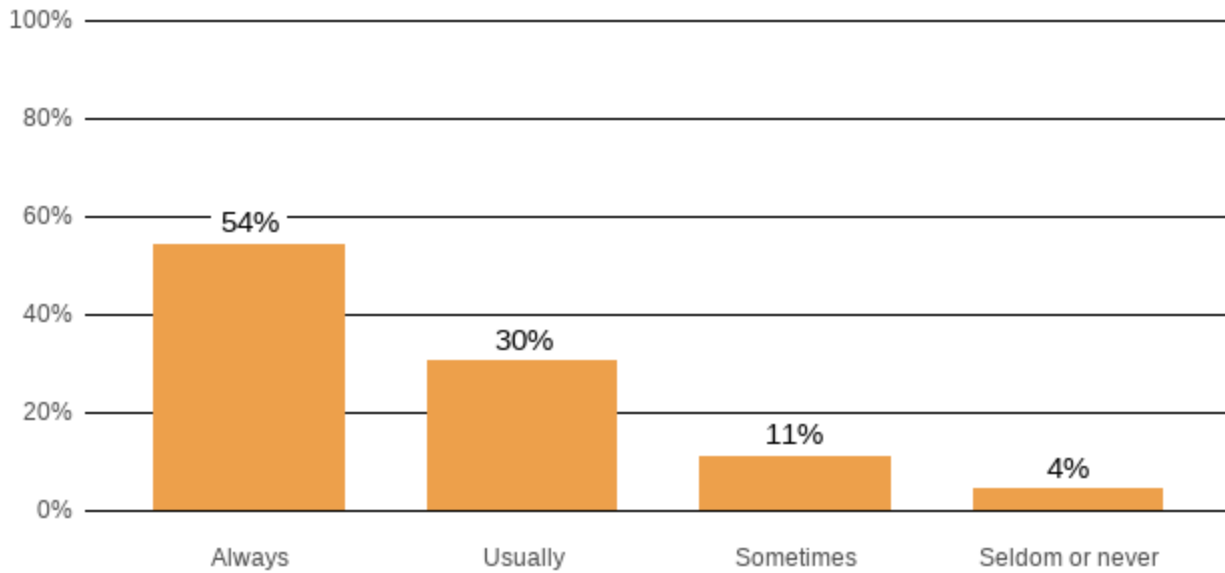


Table 74. If your child uses mental health services, does the mental health professional understand your child's needs related to their disability?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TX	61%	26%	10%	4%	156
IN	59%	28%	10%	3%	201
MO	57%	34%	8%	2%	106
TN	56%	30%	10%	4%	93
Weighted NCI-IDD Average	54%	30%	11%	4%	1,530
SD	52%	36%	6%	6%	64
ND	50%	31%	13%	6%	112
FL	47%	38%	11%	3%	99
WI ↓	46%	34%	14%	6%	343
OR ↓	44%	35%	14%	7%	356

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

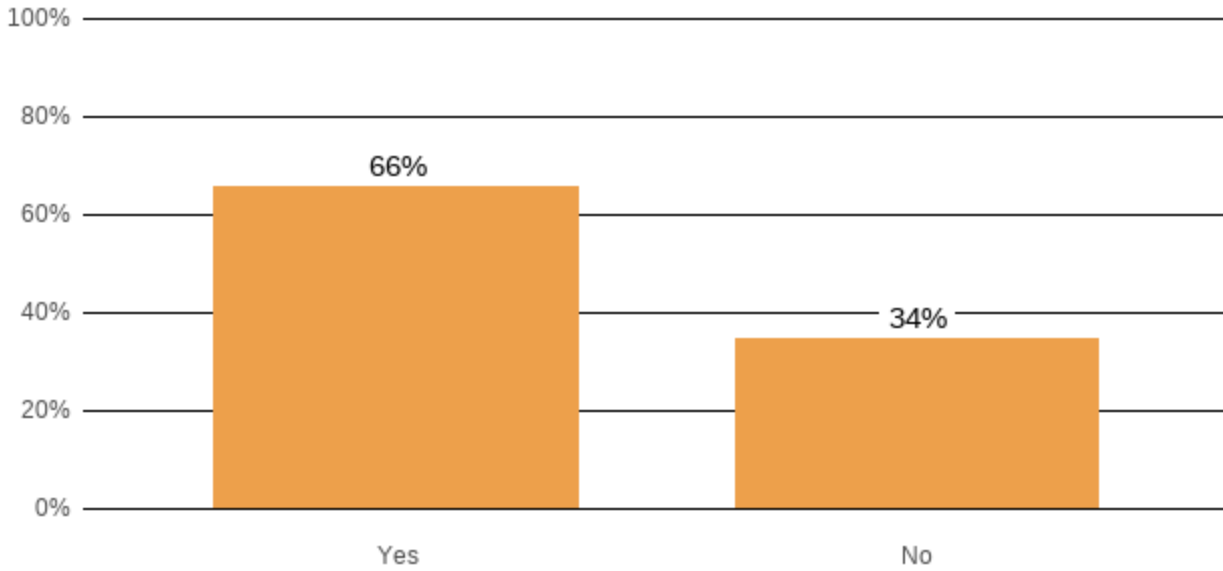


Table 75. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TN	79%	21%	33
ND	77%	23%	39
TX	71%	29%	101
Weighted NCI-IDD Average	66%	34%	638
SD	65%	35%	34
OR	64%	36%	140
IN	63%	38%	64
WI	61%	39%	135
FL	59%	41%	39
MO	53%	47%	53

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

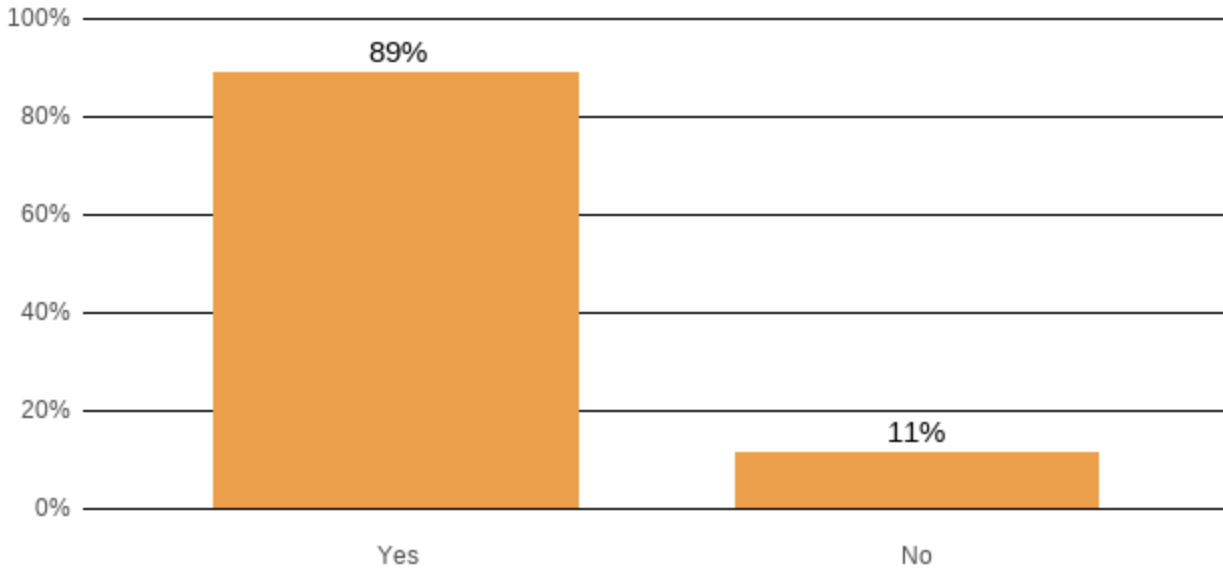


Table 76. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or natural disaster?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
SD ↑	94%	6%	153
IN	93%	7%	282
TX	91%	9%	260
TN	91%	9%	161
Weighted NCI-IDD Average	89%	11%	2,478
FL	89%	11%	143
MO	88%	12%	165
ND	87%	13%	189
WI	85%	15%	576
OR ↓	83%	17%	549

Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child's case manager/service coordinator?

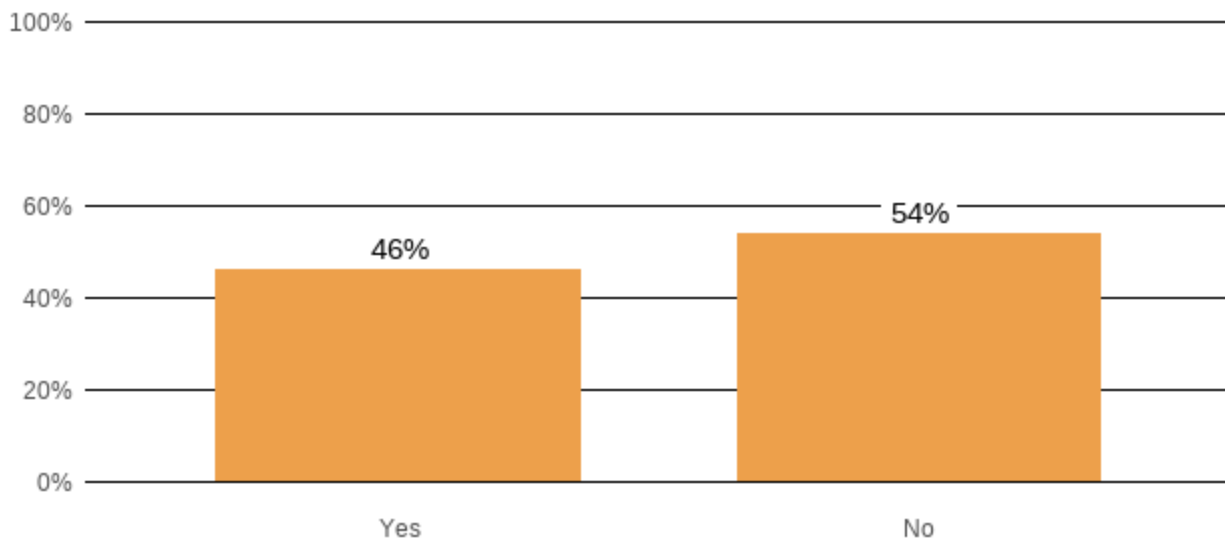


Table 77. Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child’s case manager/service coordinator?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
FL ↑	75%	25%	147
ND ↑	60%	40%	189
TX ↑	56%	44%	269
SD	51%	49%	148
Weighted NCI-IDD Average	46%	54%	2,551
OR	46%	54%	571
MO	46%	54%	169
IN	45%	55%	283
TN ↓	34%	66%	168
WI ↓	30%	70%	607

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

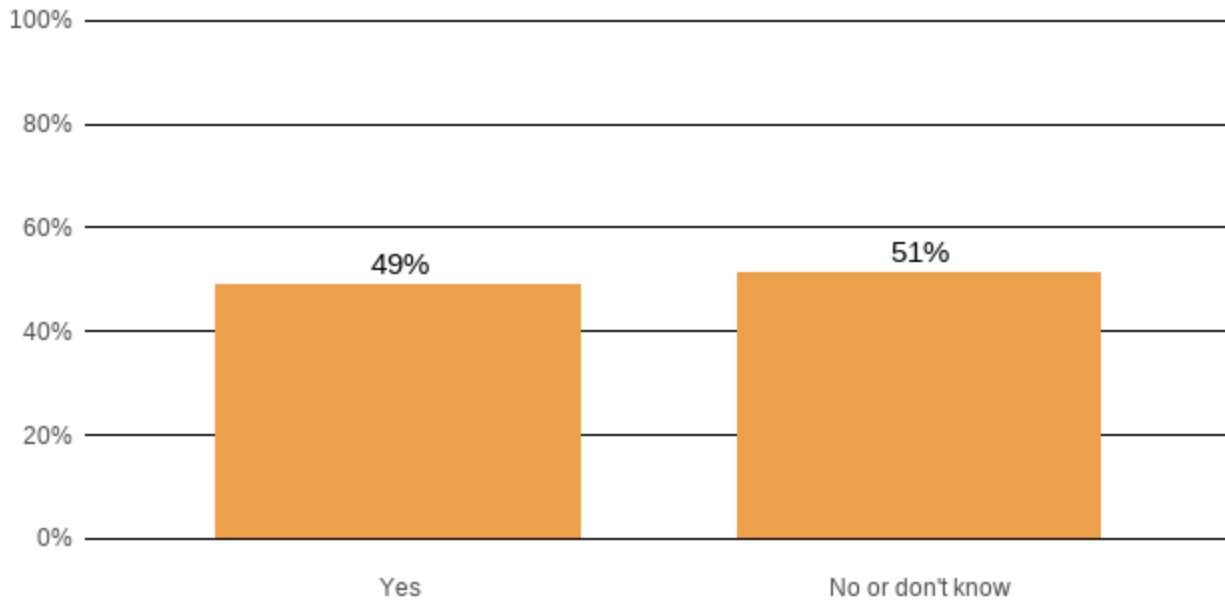


Table 78. Do you know how to file a complaint or grievance about provider agencies or staff?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No or don't know	N
SD ↑	60%	40%	161
FL	55%	45%	154
WI	53%	47%	649
TX	51%	49%	298
Weighted NCI-IDD Average	49%	51%	2,743
OR	49%	51%	618
ND	47%	53%	197
TN	47%	53%	176
IN	44%	56%	302
MO ↓	36%	64%	188

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

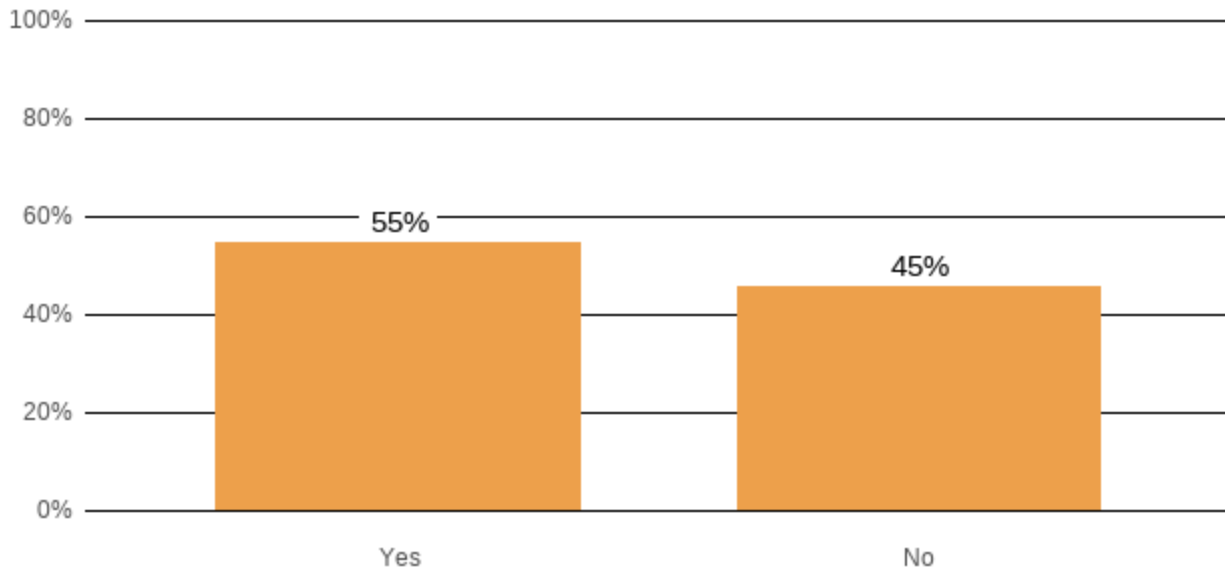


Table 79. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TX	56%	44%	41
Weighted NCI-IDD Average	55%	45%	187
OR	54%	46%	57
WI	44%	56%	34

The following states had a low count of responses (N<20) and were not shown: IN, ND, MO, FL, SD, TN

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

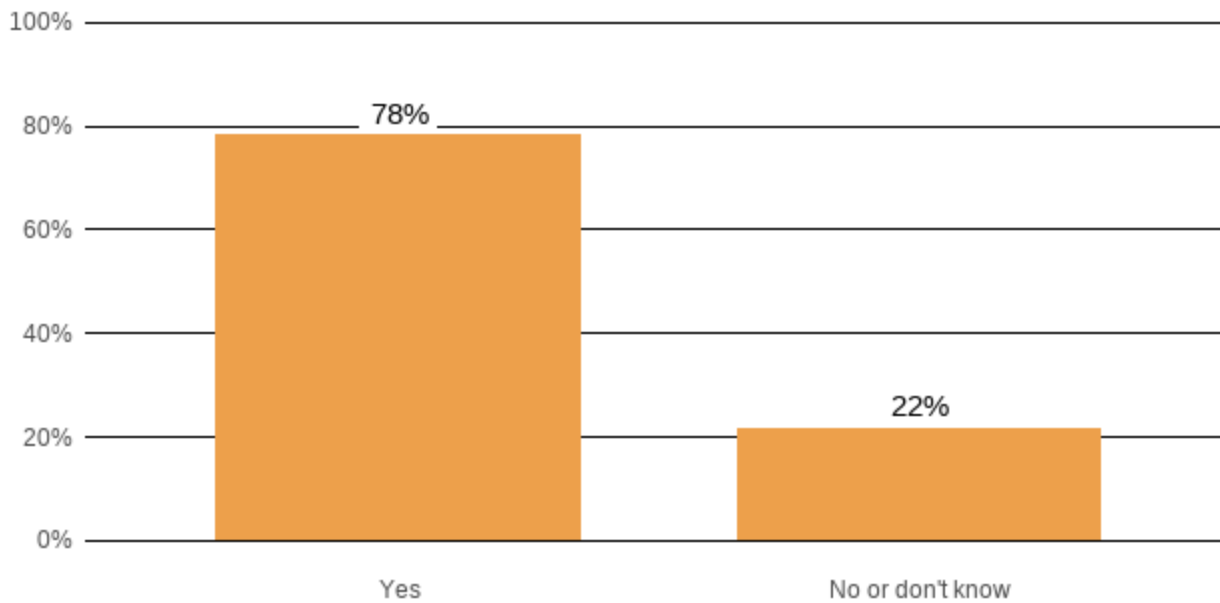


Table 80. Do you know how to report abuse or neglect related to your child?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No or don't know	N
SD	83%	17%	160
MO	82%	18%	186
OR	81%	19%	621
TX	81%	19%	296
FL	79%	21%	154
Weighted NCI-IDD Average	78%	22%	2,750
TN	76%	24%	178
WI	76%	24%	651
IN	75%	25%	303
ND	74%	26%	201

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

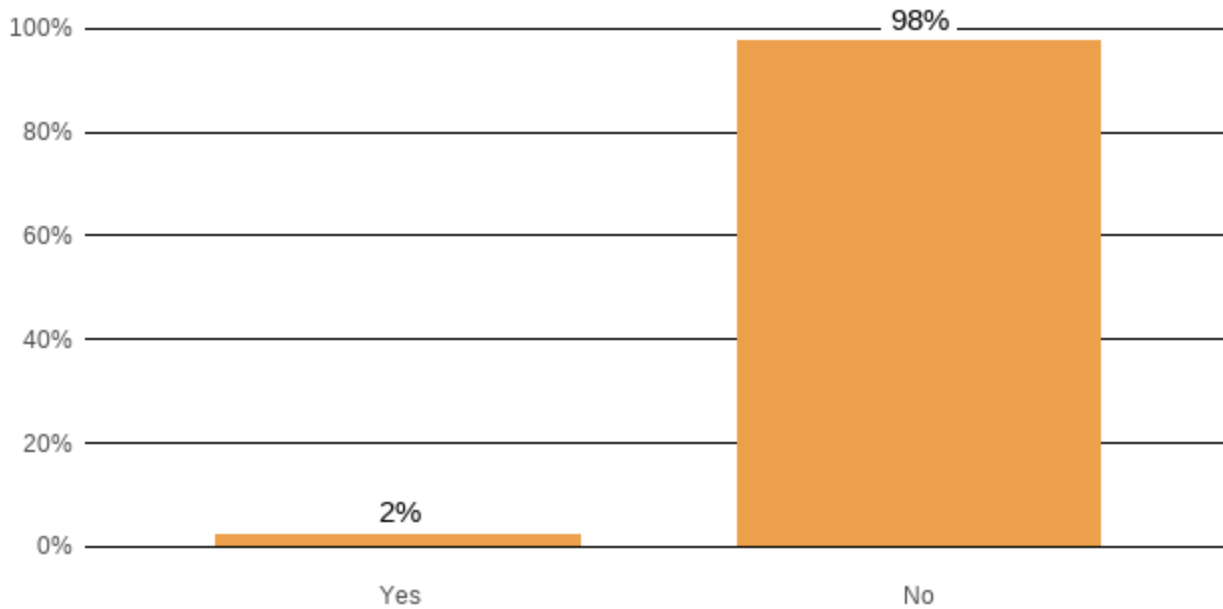


Table 81. Within the past 12 months, was a report of abuse or neglect filed on behalf of your child?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
OR	4%	96%	603
SD	3%	97%	155
TX	3%	97%	294
Weighted NCI-IDD Average	2%	98%	2,674
MO	2%	98%	184
ND	2%	98%	188
FL	2%	98%	152
IN	2%	98%	293
WI	2%	98%	632
TN	1%	99%	173

If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?

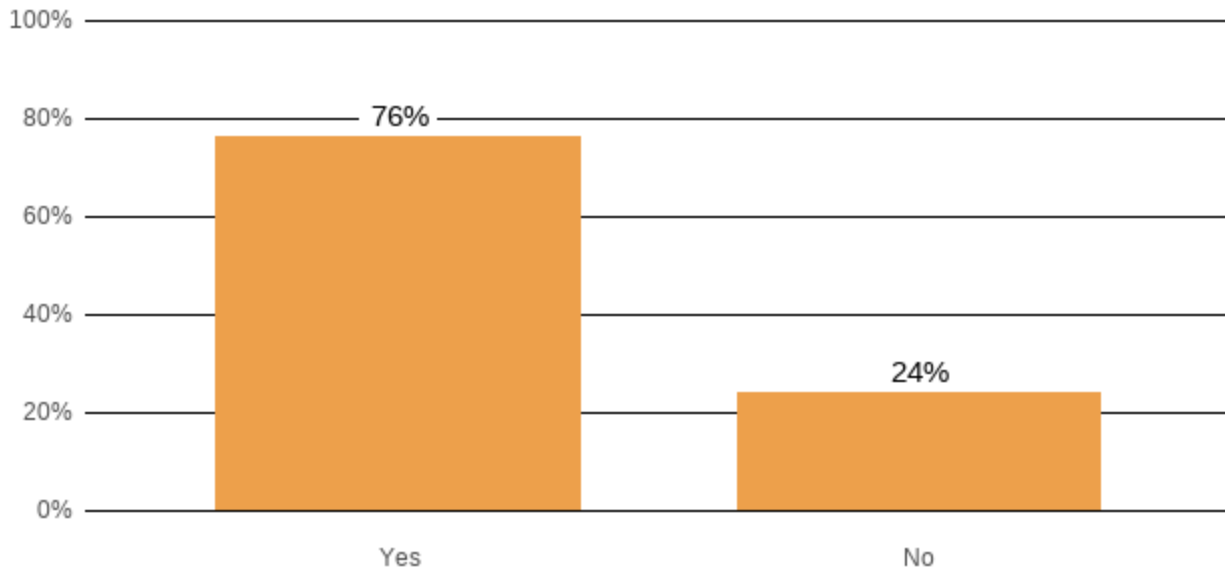


Table 82. If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
Weighted NCI-IDD Average	76%	24%	51

The following states had a low count of responses (N<20) and were not shown: FL, IN, ND, TN, WI, TX, OR, MO, SD

Satisfaction With Services and Supports

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

Note: Significance is based on “Always” or “Yes” response.

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

“Child” 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 child currently receives?

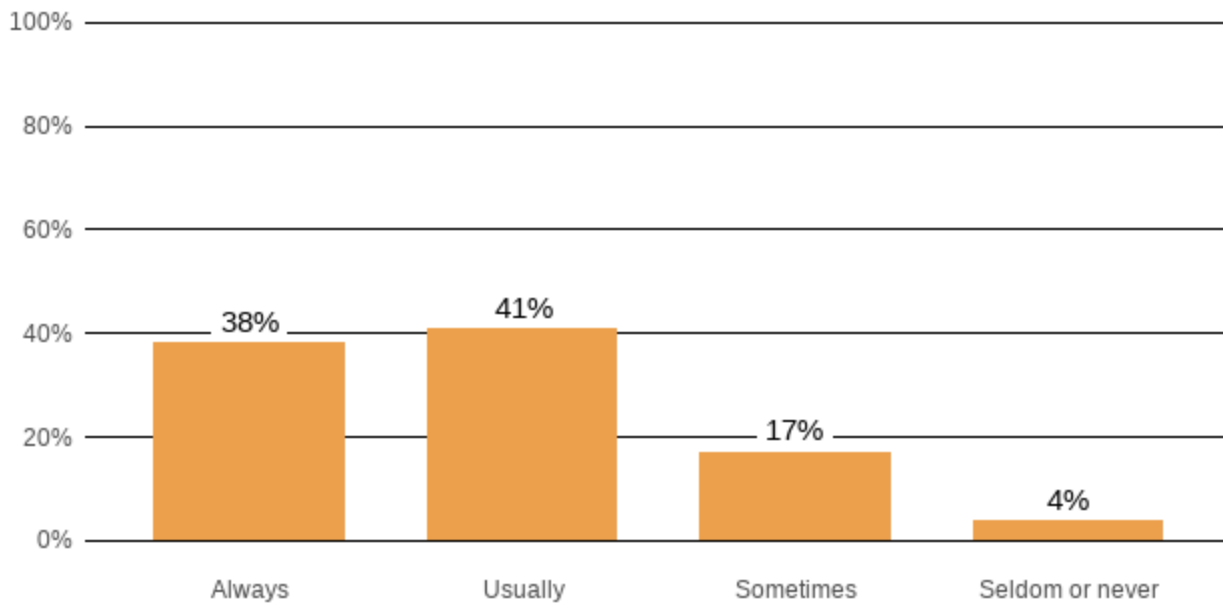


Table 83. Overall, are you satisfied with the services and supports your child currently receives?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
TN	46%	45%	9%	0%	177
TX	44%	38%	16%	2%	292
IN	42%	38%	17%	3%	298
Weighted NCI-IDD Average	38%	41%	17%	4%	2,734
WI	36%	41%	17%	6%	651
SD	33%	53%	13%	2%	159
MO	30%	45%	21%	4%	184
OR ↓	29%	50%	17%	4%	621
FL ↓	26%	42%	22%	10%	152
ND ↓	26%	51%	20%	5%	200

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

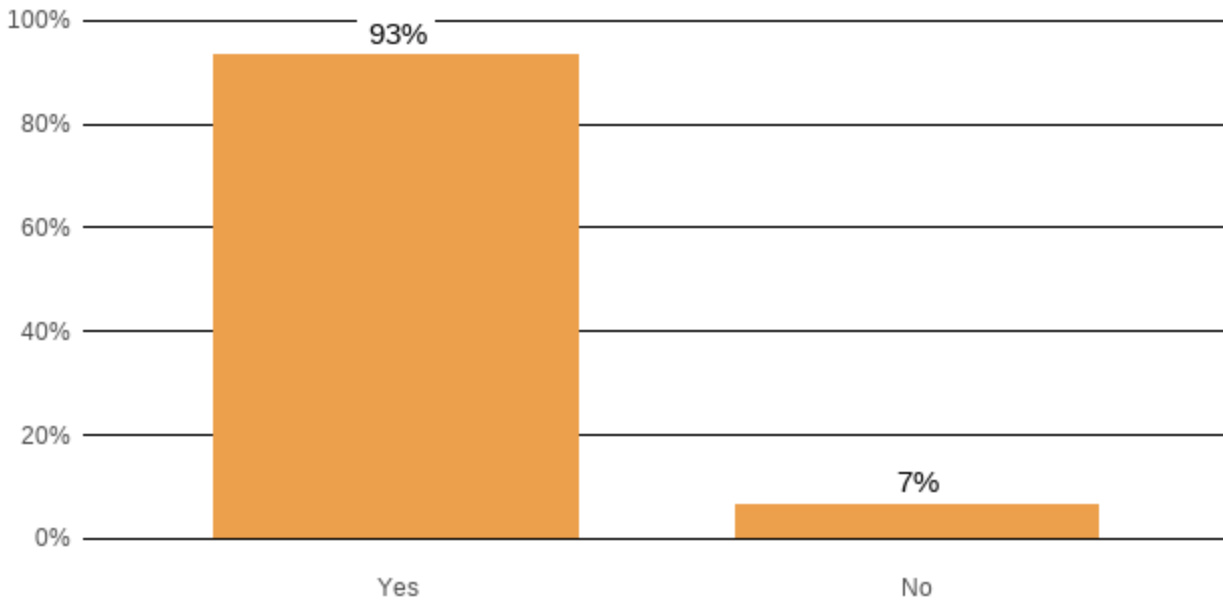


Table 84. Do you feel that services and supports have made a positive difference in the life of your child?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TN ↑	100%	0%	178
SD ↑	98%	2%	155
ND ↑	97%	3%	192
OR ↑	96%	4%	581
IN	94%	6%	286
Weighted NCI-IDD Average	93%	7%	2,595
WI	93%	7%	613
TX	92%	8%	277
FL	91%	9%	143
MO	89%	11%	170

Have services and supports reduced your family's out-of-pocket expenses for your child's care?

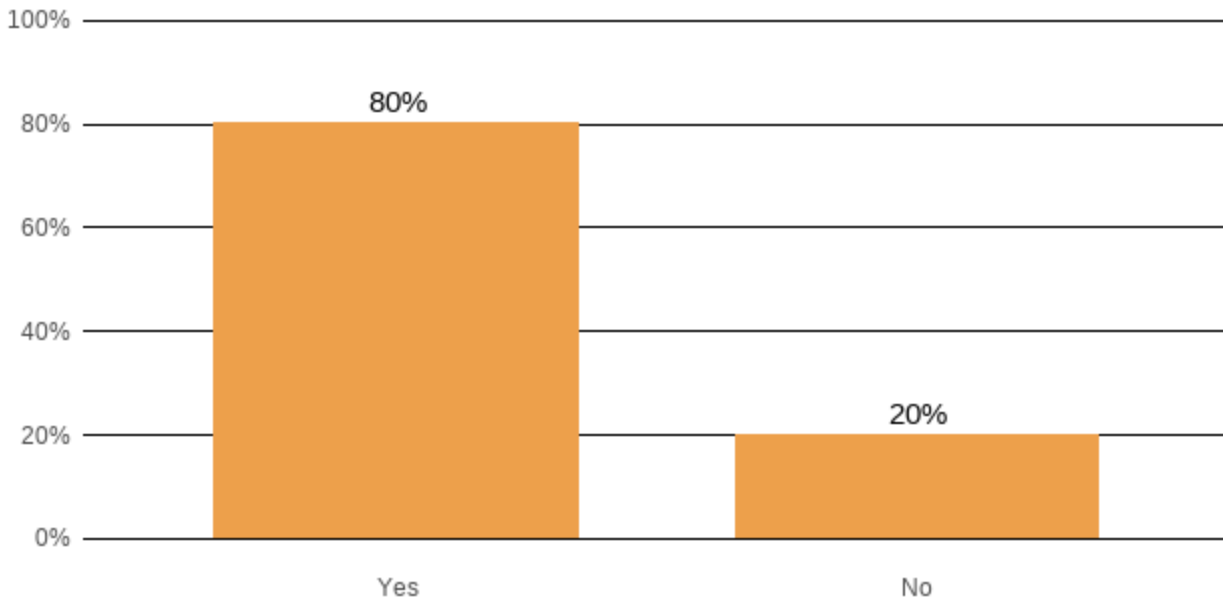


Table 85. Have services and supports reduced your family's out-of-pocket expenses for your child's care?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TN ↑	97%	3%	177
SD ↑	89%	11%	154
WI ↑	86%	14%	625
TX	84%	16%	266
Weighted NCI-IDD Average	80%	20%	2,582
FL	79%	21%	143
OR	78%	22%	578
ND	75%	25%	194
IN ↓	72%	28%	278
MO ↓	64%	36%	167

Do you feel that family supports have improved your ability to care for your child?

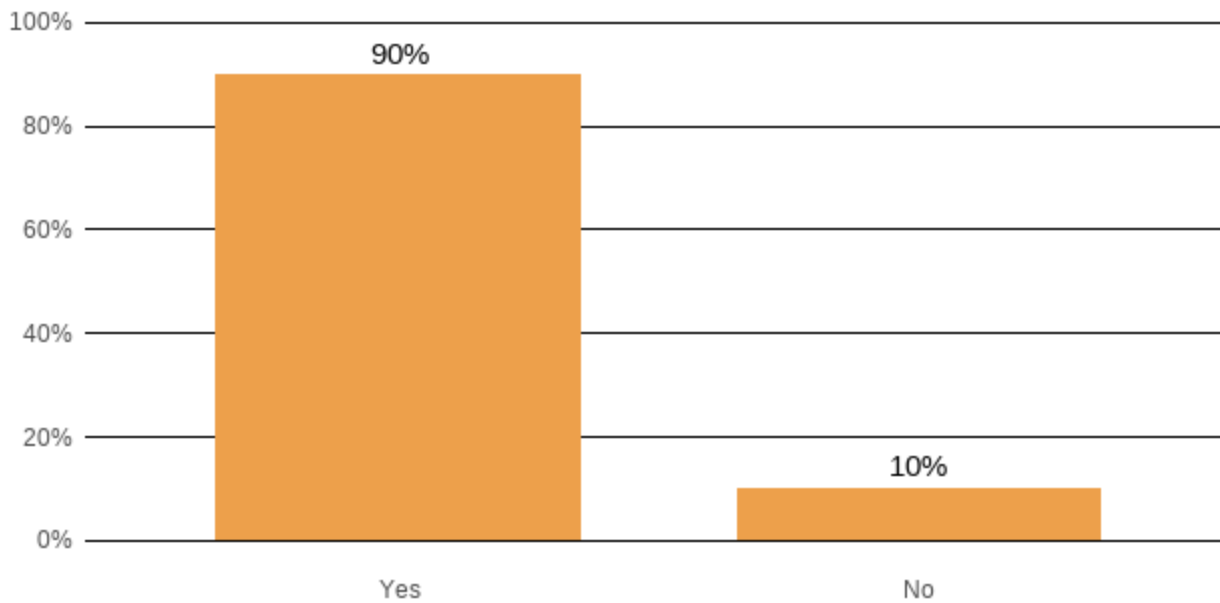


Table 86. Do you feel that family supports have improved your ability to care for your child?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TN ↑	98%	2%	172
OR	92%	8%	581
ND	92%	8%	190
TX	92%	8%	272
SD	91%	9%	157
WI	90%	10%	612
Weighted NCI-IDD Average	90%	10%	2,574
IN	89%	11%	283
FL	87%	13%	137
MO ↓	81%	19%	170

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

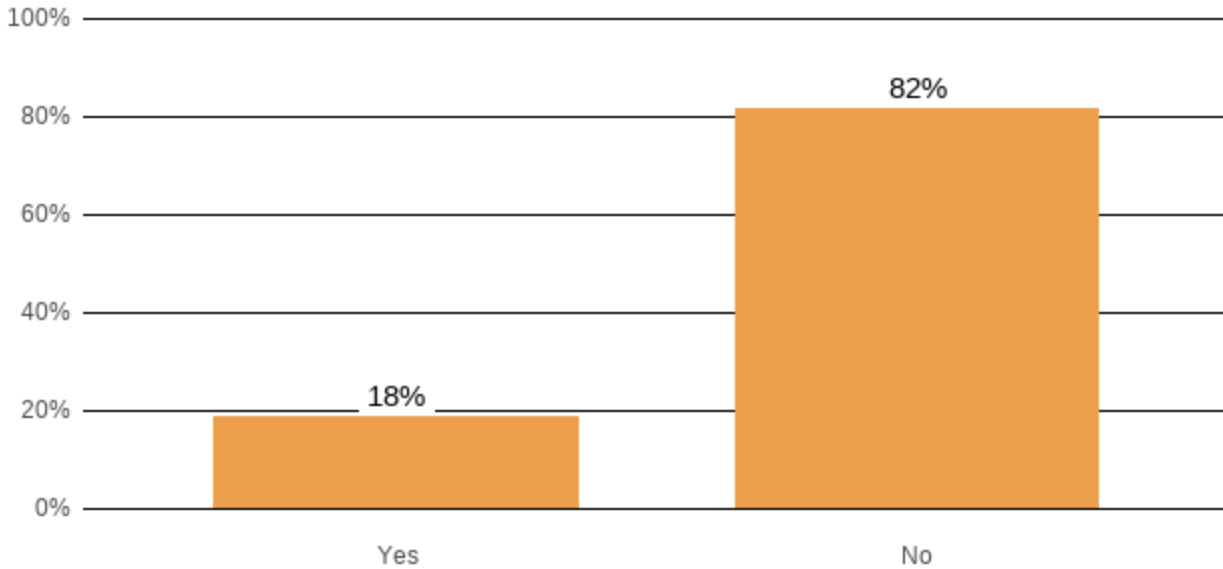


Table 87. Have the services or supports that your child received during the past 12 months been reduced, suspended, or terminated?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
FL	28%	72%	140
TX	23%	77%	282
MO	21%	79%	184
IN	19%	81%	295
Weighted NCI-IDD Average	18%	82%	2,619
ND	18%	82%	197
SD	13%	87%	150
OR ↓	14%	86%	584
WI ↓	13%	87%	614
TN ↓	10%	90%	173

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 or your child negatively?

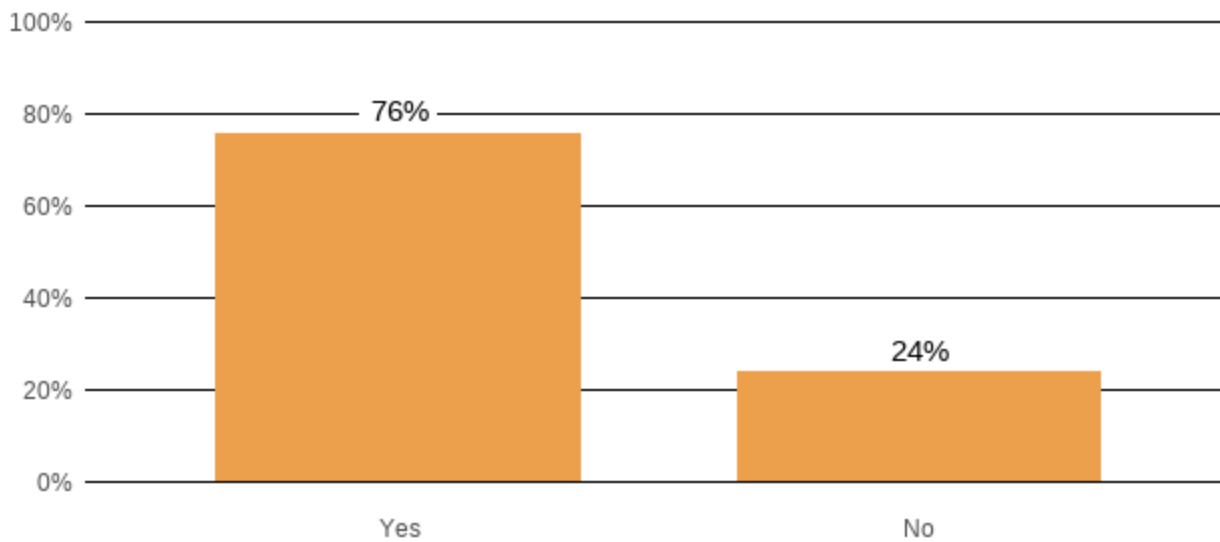


Table 88. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family or your child negatively?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
OR ↑	88%	12%	67
FL	88%	12%	33
ND	84%	16%	32
TX	78%	22%	54
Weighted NCI-IDD Average	76%	24%	359
MO	75%	25%	28
IN	71%	29%	48
WI	71%	29%	65

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

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

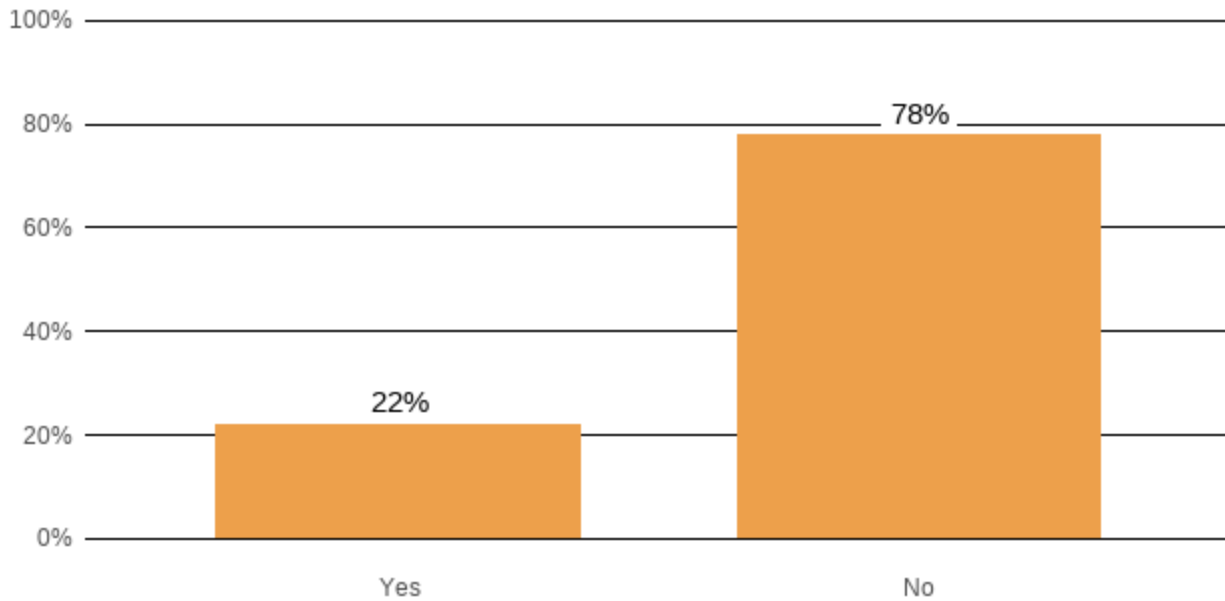


Table 89. Have the services or supports that your child received been increased in the past 12 months?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
WI ↑	28%	72%	587
TN	27%	73%	171
OR	23%	77%	555
TX	23%	77%	262
Weighted NCI-IDD Average	22%	78%	2,503
MO	20%	80%	173
FL	17%	83%	146
ND	17%	83%	193
IN ↓	14%	86%	267
SD ↓	13%	87%	149

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

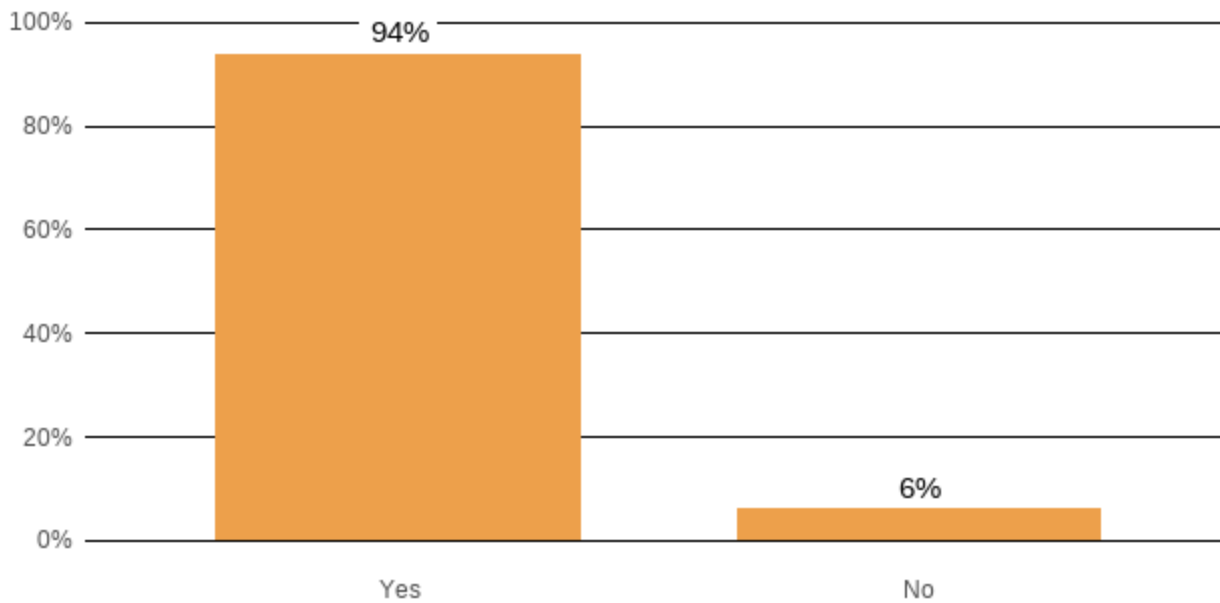


Table 90. Are services and supports helping your child to live a good life?

Key: Up arrow (↑) represents Significantly Above Average; down arrow (↓) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
TN ↑	99%	1%	175
ND	96%	4%	191
SD	95%	5%	154
OR	95%	5%	557
IN	95%	5%	272
WI	94%	6%	594
Weighted NCI-IDD Average	94%	6%	2,523
TX	94%	6%	278
FL	93%	7%	137
MO	88%	12%	165

Overview of National Core Indicators

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

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

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

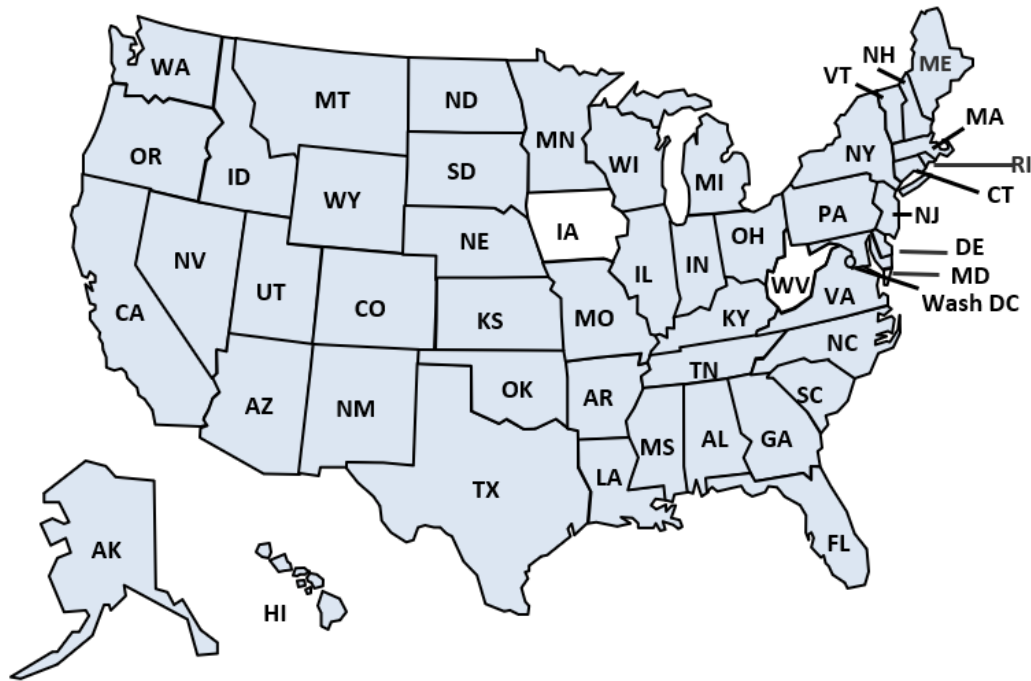
During this initial phase, data collection protocols were developed and field-tested, including a face-to-face In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states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

State Participation

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

Figure 1. NCI-IDD State Participation 2022-23



The Core Indicators

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

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

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

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

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

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

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

¹ Located on the National Core Indicators website: <https://idd.nationalcoreindicators.org/> →How it Works →How to Use the Data

Methodology

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

Sampling & Administration

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

1. Had a child under age 18 living in the home; and
2. The child living in the home received at least one direct service or support in addition to service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys.

A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we also included those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.²

Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI-IDD reports, we use “NCI-IDD average” to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI-IDD average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). The approach has since been enhanced to consider the relative numbers of people receiving services through participating states’ systems. The NCI-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the sample sizes.

Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI-IDD average—that is, the state’s contribution to the NCI-IDD average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.

² See “Response Rates” for information on total surveys mailed and received by states as well as each state’s margin of error.

Significance Testing

For each of the items in the report, each state's percentage was compared to the weighted NCI-IDD average (described above), and the differences between the two were tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state's result depends in part on the size of the state's sample—the larger the sample, the more likely it is that even a small difference will be found *statistically* significant. A statistically significant difference for a state with a large sample size, in and by itself, does not necessarily mean there is a *practically* significant difference. The inclusion of effect sizes allows us to present “meaningfully significant” results, which take the magnitude or size of the differences into account.

The state percentages in this report are categorized into one of three classes:

1. **Significantly above the NCI-IDD average**, where the difference between the state's percentage and the weighted NCI-IDD average: a) was in favor of the state, b) was statistically significant (i.e., $p < .01$), **and** c) met the effect size criterion (i.e., Cohen's $d > 0.2$, see below for details);
2. **Within the NCI-IDD average range**, where the difference between the state's percentage and the weighted NCI-IDD average was: a) not statistically significant (i.e., $p \geq .01$), **or** b) did not meet the effect size criterion (i.e., Cohen's $d \leq 0.2$); or
3. **Significantly below the NCI-IDD average**, where the difference between the state's percentage and the weighted NCI-IDD average: a) was in favor of the NCI-IDD average, b) was statistically significant (i.e., $p < .01$), **and** c) met the effect size criterion (i.e., Cohen's $d > 0.2$).

For all outcome data, tables are formatted so that all states are listed in descending order of percentage and are categorized as statistically significantly above the NCI-IDD Average, within the range of the NCI-IDD Average, and significantly below the NCI-IDD Average.

Technical Details

The comparisons were done through one sample t-tests using the weighted NCI-IDD average as the benchmark. A conservative cut-off point (alpha) of $p < .01$ was used to detect statistically significant differences. Effect sizes are calculated using the formula: Cohen's $d = 2t/\sqrt{df}$. A cutoff point of Cohen's $d = 0.2$ was chosen for the effect size to be considered “meaningfully significant,” following the standard interpretation offered by Cohen (1988) that Cohen's d of 0.8 = large, 0.5 = moderate, and 0.2 = at least a small effect.

Data Entry and Analysis

Each state entered its survey responses into the Online Data Entry Survey Application (ODESA). All raw data files were reviewed for completeness, invalid responses were

eliminated, and quality checks were performed. The data files were then cleaned and merged to create the national dataset.

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

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

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the NCI-IDD average³; 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 2022-23, 9 states administered the Child Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The following table shows the number of individuals receiving services who were eligible to be drawn into the sample ("total population"), the number of surveys each state sent, complete surveys, response rates, margins of error, and survey submission modes.

³ The NCI-IDD Average is a weighted average. Please see the section "Weighting" for more details.

Figure 3. Child Family Survey: State Response Rates ⁴

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
FL	1659	1500	156	10%	7.2%	78%	22%
IN	9870	1500	309	21%	5.1%	71%	29%
MO	3729	1500	190	13%	6.5%	78%	22%
ND	906	935	209	22%	6.2%	71%	29%
OR	4903	4903	628	13%	3.6%	86%	14%
SD	725	725	161	22%	7.1%	100%	0%
TN	1218	1284	189	15%	6.5%	34%	66%
TX	16418	11968	316	3%	2.6%	95%	5%
WI	13162	13162	711	5%	3.4%	0%	100%
Total	52590	37477	3760	8%	1.5%	68%	32%

⁴ Please note: The family surveys are mail surveys or completed online by respondents who choose to take part in the survey. As such, the final sample is a sample of convenience and cannot be considered representative of the entire service population in the state.