

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



National Report 2023-24

Child Family Survey (CFS)





Human Services Research Institute

Human Services Research Institute (HSRI)

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of

Developmental Disabilities Services

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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

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Executive Summary

The National Core Indicators®-Intellectual and Developmental Disabilities (NCI-IDD) are standard measures used across states to assess the outcomes of services provided to individuals with intellectual/developmental disabilities and their families. Indicators address key areas of concern such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that result from NCI-IDD surveys are often used to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Many states also share the data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction.

The National Core Indicators (NCI) 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 2023-24 data collection cycle, 5 states submitted a valid sample of Child Family Survey data: California (CA), Louisiana (LA), Missouri (MO), Oregon (OR), and Wisconsin (WI). This Final Report provides results based on data submitted by June 30, 2024.

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.
- States with 20 or fewer respondents to a question are not included in tables; however, their data **are** included in the NCI-IDD Average.
- For 2023-24, due to the number of participating states, state averages were not tested to examine the significance of the difference from the NCI-IDD Average.
- **Note on NCI-IDD Averages:** The NCI-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the states’ sample sizes. Prior to 2016-17, NCI-IDD averages were calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.
- **Note on language used in this report:** “You” and “Respondent” refers to the person (usually a parent or guardian) filling out the survey. “Child” refers to the person receiving services whom the respondent is answering questions about in this survey.
- **State names have been abbreviated throughout the report.**
- **Note on responses:** All data are reported by the respondent based on their understanding of their child’s demographics, diagnoses and personal characteristics.
- For 2023-24, due to the number of participating states, state averages were not tested to examine the significance of the difference from the NCI-IDD Average. "
- “N” demonstrates the number of valid responses for each question. “N” can vary between questions. The N does not include missing responses, “don’t know” responses or “not applicable” responses. For information on the total sample from each state, see Figure 3.

Demographics

Note on responses: All data are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics.

Child

This section provides demographic information about the child receiving services.

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

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	Yes	No	N
CA	35%	65%	8074
LA	39%	61%	432
MO	36%	64%	169
OR	41%	59%	484
WI	29%	71%	619
Weighted NCI-IDD Average	35%	65%	9778

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	Age	N
CA	10.9	8276
LA	6.6	446
MO	11.5	174
OR	12.9	485
WI	9.3	650
Weighted NCI-IDD Average	10.6	10031

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	Male	Female	Other	N
CA	71%	28%	0%	8276
LA	62%	38%	0%	446
MO	72%	28%	0%	174
OR	64%	35%	1%	486
WI	65%	35%	0%	649
Weighted NCI-IDD Average	70%	30%	0%	10031

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

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer not to say
CA	2%	18%	8%	1%	33%	52%	2%	2%
LA	2%	3%	35%	0%	58%	6%	1%	3%
MO	4%	4%	12%	1%	84%	7%	1%	1%
OR	5%	7%	5%	2%	80%	15%	2%	2%
WI	2%	6%	9%	1%	81%	11%	1%	2%
Weighted NCI-IDD Average	2%	15%	9%	1%	42%	43%	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. Categories are not mutually exclusive, therefore N is not shown.

State	Intellectual Developmental Disability	Mood illness/ psychiatric diagnosis	Autism spectrum disorder	Cerebral palsy
CA	35%	13%	78%	7%
LA	34%	10%	50%	8%
MO	36%	30%	84%	8%
OR	56%	28%	56%	10%
WI	39%	21%	66%	6%
Weighted NCI-IDD Average	36%	15%	74%	7%

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

State	Limited or no vision – legally blind	Hearing loss – (severe or profound)	Brain injury	Seizure disorder or neurological problem	Chemical dependency
CA	5%	3%	3%	12%	0%
LA	9%	7%	7%	21%	1%
MO	6%	7%	3%	15%	0%
OR	7%	6%	6%	19%	1%
WI	3%	2%	4%	14%	0%
Weighted NCI-IDD Average	5%	4%	4%	13%	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. Categories are not mutually exclusive, therefore N is not shown.

State	Down Syndrome	Prader-Willi syndrome	Fetal alcohol spectrum disorder (FASD)	Other disabilities
CA	8%	0%	1%	18%
LA	8%	0%	0%	42%
MO	4%	1%	2%	33%
OR	12%	1%	9%	29%
WI	10%	0%	2%	27%
Weighted NCI-IDD Average	8%	0%	1%	21%

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

State	Cardiovascular disease	Diabetes	Cancer	High blood pressure	High cholesterol
CA	8%	3%	2%	3%	7%
LA	16%	1%	1%	6%	3%
MO	8%	2%	2%	2%	11%
OR	9%	5%	0%	4%	3%
WI	12%	3%	3%	3%	3%
Weighted NCI-IDD Average	9%	3%	2%	3%	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. Categories are not mutually exclusive, therefore N is not shown.

State	Dysphagia	Pressure ulcers	Oral health or dental problems	Sleep apnea	Other pulmonary diagnosis (e.g., COPD, bronchitis, emphysema)
CA	9%	1%	9%	20%	7%
LA	18%	3%	9%	18%	13%
MO	19%	2%	16%	40%	15%
OR	25%	2%	15%	24%	8%
WI	16%	1%	7%	19%	8%
Weighted NCI-IDD Average	11%	1%	9%	21%	8%

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

State	Asthma	Chronic kidney disease	Long-term health problems associated with COVID-19	Other
CA	40%	2%	1%	33%
LA	25%	3%	1%	42%
MO	31%	2%	3%	39%
OR	31%	2%	1%	35%
WI	26%	3%	1%	42%
Weighted NCI-IDD Average	36%	2%	1%	35%

Table 7. Child’s Preferred Language

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	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
CA	79%	12%	1%	0%	0%	0%	7%	8085
LA	94%	3%	0%	0%	0%	1%	2%	437
MO	97%	2%	0%	0%	0%	0%	1%	166
OR	95%	2%	0%	0%	0%	1%	2%	455
WI	97%	1%	0%	0%	0%	0%	2%	657
Weighted NCI-IDD Average	83%	10%	0%	0%	0%	0%	6%	9800

Table note: “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	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
CA	71%	17%	2%	5%	5%	8079
LA	52%	32%	4%	5%	7%	437
MO	79%	11%	1%	6%	4%	159
OR	68%	13%	1%	6%	11%	478
WI	73%	15%	2%	7%	4%	654
Weighted NCI-IDD Average	70%	17%	2%	6%	5%	9807

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	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
CA	26%	43%	30%	8011
LA	42%	35%	23%	432
MO	35%	42%	23%	171
OR	23%	43%	34%	478
WI	32%	47%	21%	653
Weighted NCI-IDD Average	28%	43%	29%	9745

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	No support needed; no issues with personal care activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed	N
CA	9%	42%	49%	8189
LA	5%	32%	63%	434
MO	12%	47%	42%	172
OR	5%	41%	54%	487
WI	6%	50%	44%	658
Weighted NCI-IDD Average	9%	42%	49%	9940

Respondents

This section provides information about the survey respondent.

Table 11. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
CA	61%	28%	2%	1%	1%	0%	6%	8114
LA	94%	4%	0%	0%	0%	0%	1%	442
MO	94%	5%	1%	0%	0%	0%	1%	167
OR	88%	8%	1%	0%	0%	0%	3%	473
WI	95%	2%	0%	0%	0%	0%	2%	649
Weighted NCI-IDD Average	69%	23%	2%	1%	1%	0%	5%	9845

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

Table 12. Respondent's Age

State	Under 35	35 – 54	55 – 74	75 or older	N
CA	9%	76%	14%	1%	8181
LA	32%	54%	13%	1%	444
MO	17%	68%	15%	1%	173
OR	5%	73%	21%	2%	491
WI	15%	73%	11%	0%	654
Weighted NCI-IDD Average	11%	74%	14%	1%	9943

Table 13. Respondent's Health

State	Excellent	Very good	Good	Fair	Poor	N
CA	13%	30%	40%	15%	2%	8184
LA	17%	32%	37%	13%	1%	445
MO	7%	29%	45%	16%	3%	173
OR	9%	30%	42%	17%	2%	486
WI	13%	39%	38%	11%	0%	656
Weighted NCI-IDD Average	13%	31%	40%	15%	2%	9944

Table 14. Respondent's Relationship to Child

State	Parent (biological, adoptive, or foster)	Sibling	Grandparent	Other	N
CA	96%	0%	3%	1%	8190
LA	91%	0%	8%	2%	443
MO	98%	0%	1%	1%	173
OR	91%	0%	8%	1%	486
WI	95%	0%	4%	1%	656
Weighted NCI-IDD Average	96%	0%	3%	1%	9948

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

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

State	No	Yes, I am	Yes, another family member is
CA	52%	32%	18%
LA	73%	17%	10%
MO	88%	6%	6%
OR	61%	8%	32%
WI	80%	4%	17%
Weighted NCI-IDD Average	58%	26%	17%

Table 16. Number of Adults in Household

State	One	Two	Three	Four or more	N
CA	16%	54%	20%	10%	8082
LA	33%	56%	9%	3%	435
MO	22%	60%	13%	5%	171
OR	16%	51%	22%	10%	484
WI	14%	71%	12%	3%	642
Weighted NCI-IDD Average	17%	56%	18%	9%	9814

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

State	One	Two	Three	Four or more	N
CA	38%	39%	16%	7%	7984
LA	40%	33%	17%	9%	430
MO	39%	37%	15%	8%	170
OR	42%	38%	12%	9%	465
WI	28%	41%	20%	12%	651
Weighted NCI-IDD Average	37%	39%	16%	8%	9700

Table 18. Respondent's Highest Level of Education

State	No high school diploma/GED	High school diploma/GED	Vocational school or certificate program	Some college	College degree or higher	N
CA	15%	18%	8%	16%	43%	8124
LA	9%	21%	9%	16%	45%	444
MO	7%	13%	6%	20%	54%	167
OR	8%	15%	5%	21%	50%	480
WI	2%	10%	8%	15%	66%	652
Weighted NCI-IDD Average	13%	18%	8%	16%	46%	9867

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	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
CA	5%	8%	10%	19%	13%	30%	14%	8049
LA	9%	11%	11%	18%	9%	24%	18%	439
MO	5%	8%	10%	19%	13%	36%	9%	173
OR	6%	5%	9%	18%	13%	37%	12%	478
WI	2%	4%	7%	13%	17%	48%	8%	654
Weighted NCI-IDD Average	5%	7%	10%	19%	13%	32%	13%	9793

Table 20. Residential Designation

State	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
CA	91%	9%	7579
LA	67%	33%	405
MO	64%	36%	167
OR	76%	24%	478
WI	68%	32%	632
Weighted NCI-IDD Average	86%	14%	9261

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	Financial support	In home support	Out-of-Home respite care	Early intervention
CA	19%	35%	31%	1%
LA	20%	36%	10%	53%
MO	22%	30%	13%	5%
OR	18%	78%	38%	1%
WI	33%	27%	35%	21%
Weighted NCI-IDD Average	20%	36%	30%	11%

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

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

State	Transportation	Mental or behavioral health care or other treatments or therapies	Self-direction or fiscal intermediary services
CA	3%	23%	19%
LA	22%	75%	31%
MO	15%	76%	42%
OR	29%	70%	69%
WI	13%	79%	46%
Weighted NCI-IDD Average	7%	35%	26%

Table 22. Additional Services and Supports Received (not from the ID/DD Agency)

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

State	Social Security (SSI/SSB)	Services or supports from other agencies or organizations
CA	30%	64%
LA	31%	48%
MO	34%	79%
OR	39%	74%
WI	20%	76%
Weighted NCI-IDD Average	30%	65%

Main Survey Results

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.

“**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 have enough information to take part in planning services for your child?

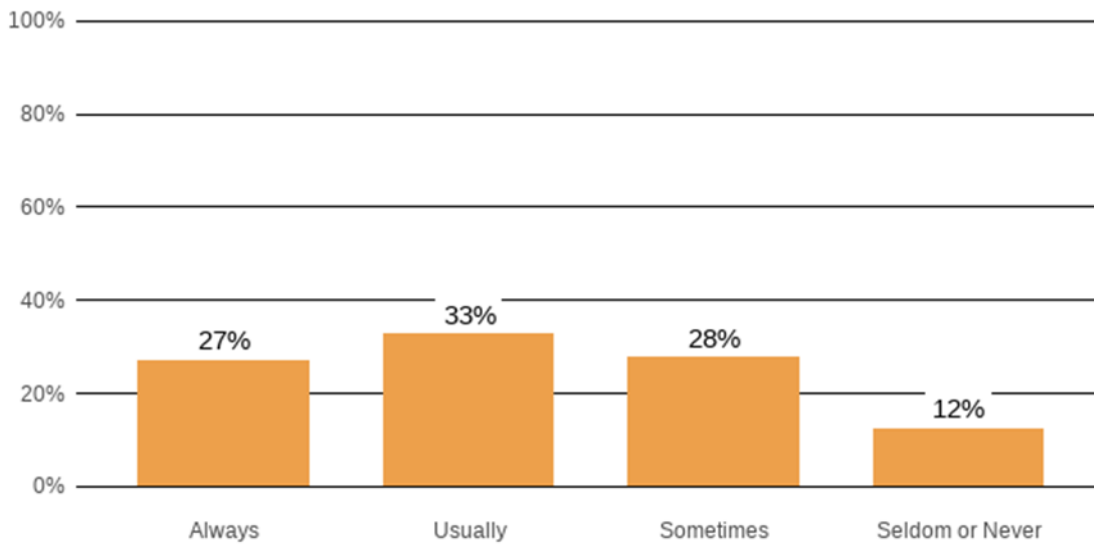


Table 23. Do you have enough information to take part in planning services for your child?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	25%	31%	30%	14%	7590
LA	35%	32%	24%	9%	390
MO	30%	44%	19%	7%	162
OR	30%	46%	19%	4%	469
WI	36%	38%	19%	7%	651
Weighted NCI-IDD Average	27%	33%	28%	12%	9262

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

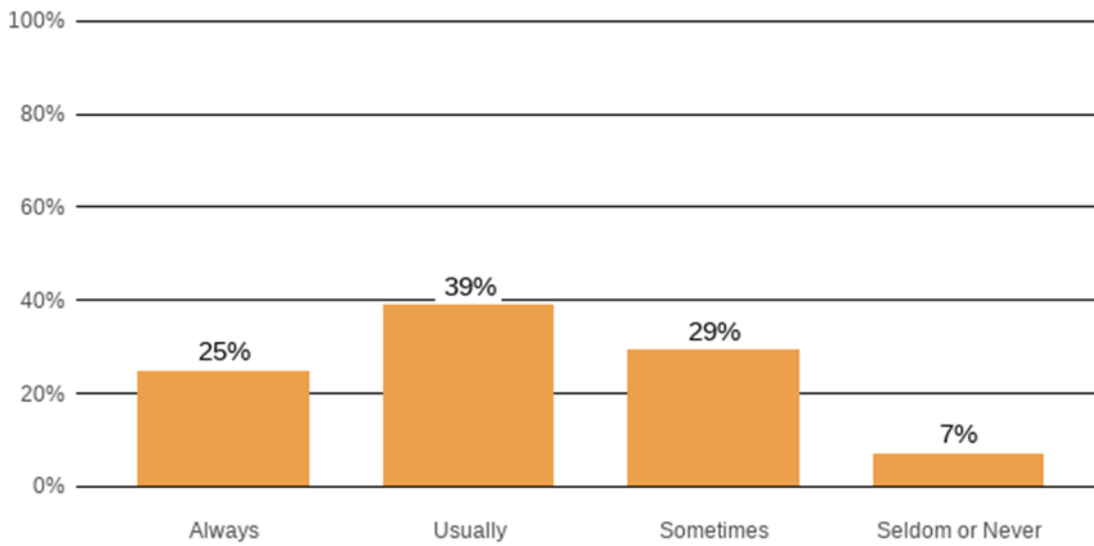


Table 24. Is the information you get about services and supports easy to understand?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	24%	38%	31%	8%	7634
LA	28%	34%	31%	7%	405
MO	21%	47%	28%	4%	165
OR	25%	50%	22%	4%	475
WI	29%	44%	22%	5%	653
Weighted NCI-IDD Average	25%	39%	29%	7%	9332

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

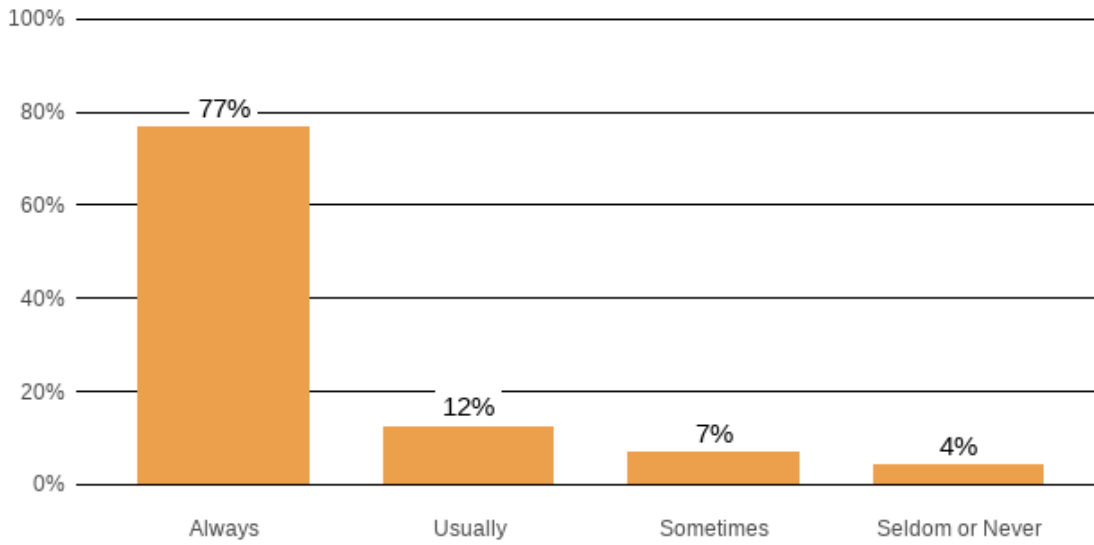


Table 25. Do you get information about services and supports in your preferred language?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	73%	14%	8%	5%	7977
LA	88%	6%	3%	3%	420
MO	90%	5%	2%	3%	169
OR	87%	9%	3%	2%	486
WI	93%	5%	1%	1%	653
Weighted NCI-IDD Average	77%	12%	7%	4%	9705

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

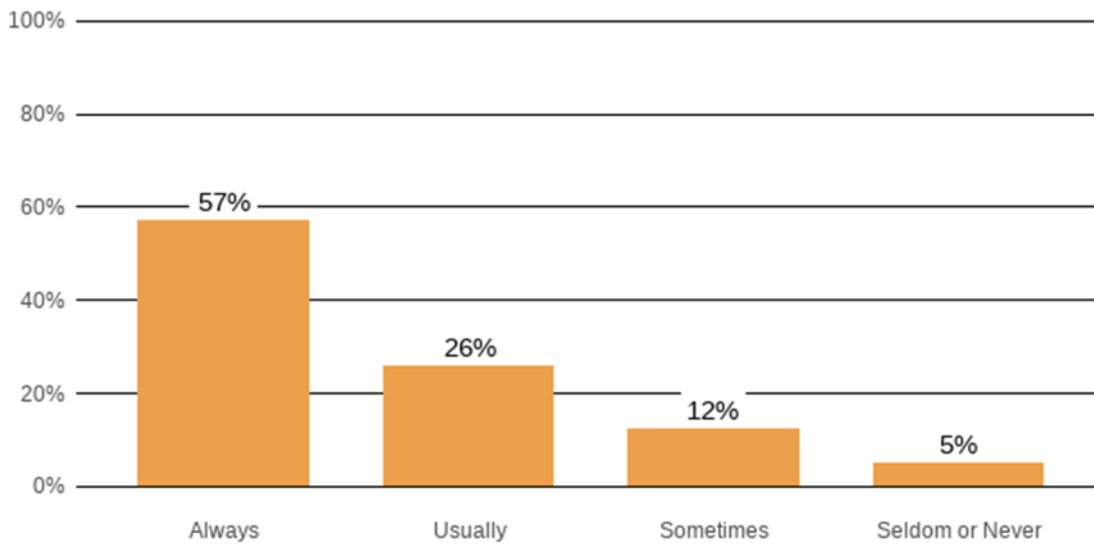


Table 26. Does the case manager/service coordinator listen to your family's choices and opinions?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	54%	27%	14%	6%	7713
LA	72%	17%	8%	3%	372
MO	62%	28%	7%	3%	161
OR	64%	27%	7%	2%	474
WI	70%	20%	7%	3%	630
Weighted NCI-IDD Average	57%	26%	12%	5%	9350

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

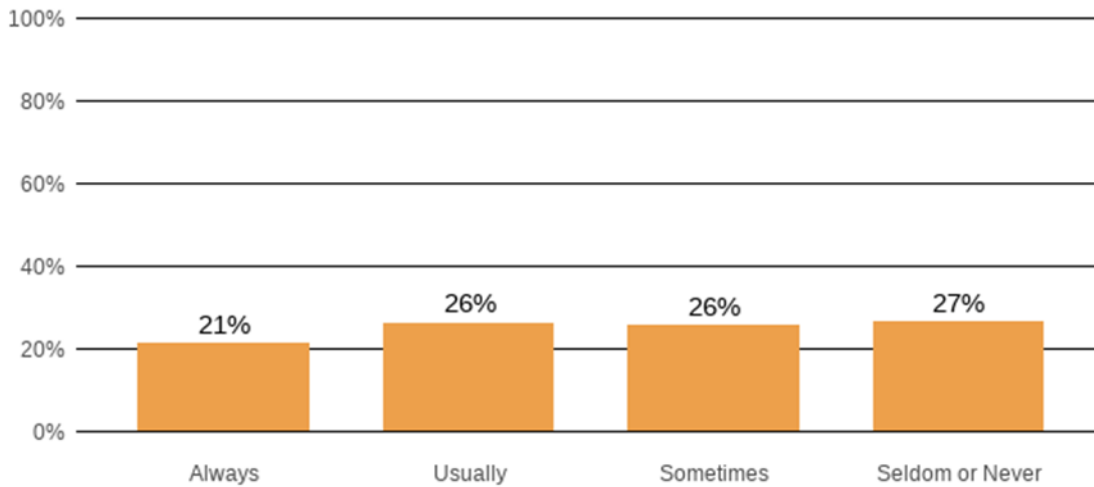


Table 27. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	20%	25%	27%	29%	6331
LA	26%	29%	17%	27%	355
MO	21%	29%	28%	21%	137
OR	23%	36%	24%	18%	400
WI	28%	33%	22%	17%	539
Weighted NCI-IDD Average	21%	26%	26%	27%	7762

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

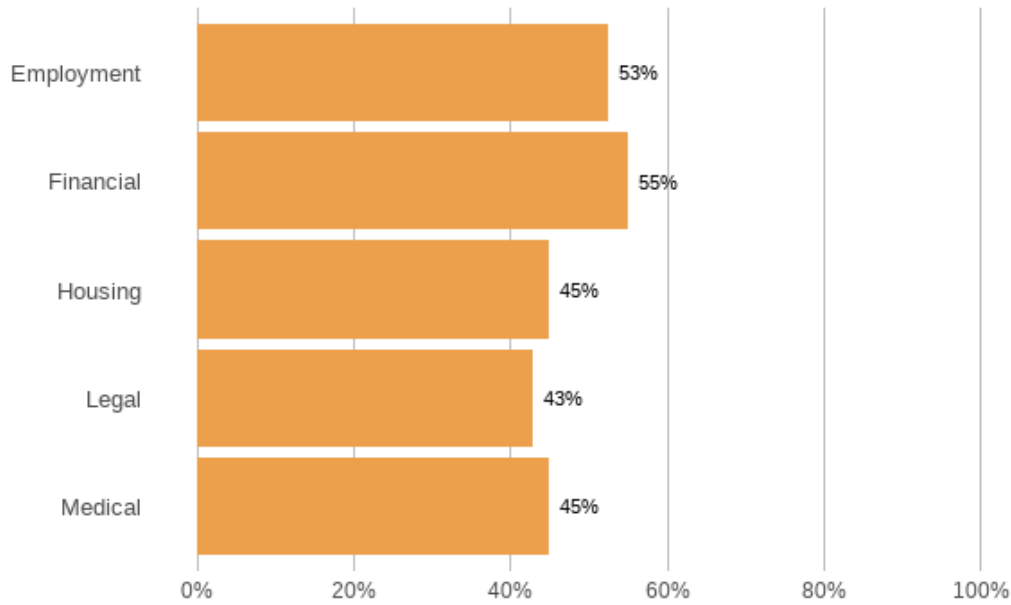


Table 28a. Do you need help planning for your child’s future in any of these areas?

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

State	Employment	Financial	Housing	Legal	Medical
CA	53%	54%	45%	43%	45%
LA	31%	51%	31%	35%	42%
MO	58%	60%	46%	46%	46%
OR	61%	62%	50%	44%	45%
WI	56%	61%	48%	50%	48%
Weighted NCI-IDD Average	53%	55%	45%	43%	45%

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

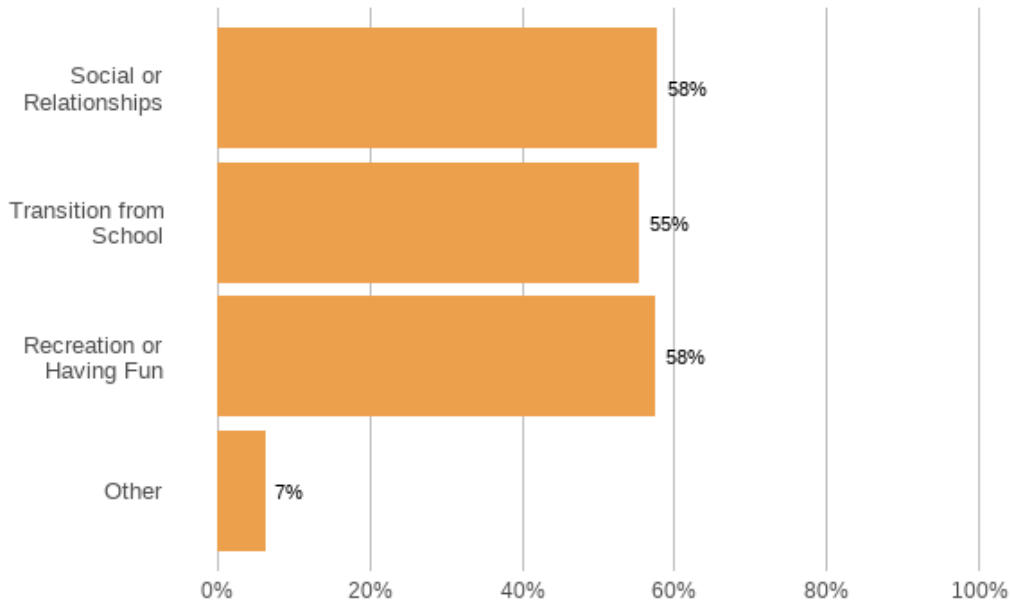


Table 28b. Do you need help planning for your child's future in any of these areas? (Continued)

Categories are not mutually exclusive, therefore N is not shown

State	Social or Relationships	Transition from School	Recreation or Having Fun	Other
CA	59%	56%	59%	6%
LA	42%	44%	43%	10%
MO	61%	58%	50%	11%
OR	55%	55%	50%	7%
WI	60%	59%	61%	7%
Weighted NCI-IDD Average	58%	55%	58%	7%

Has your family learned about alternatives to guardianship?

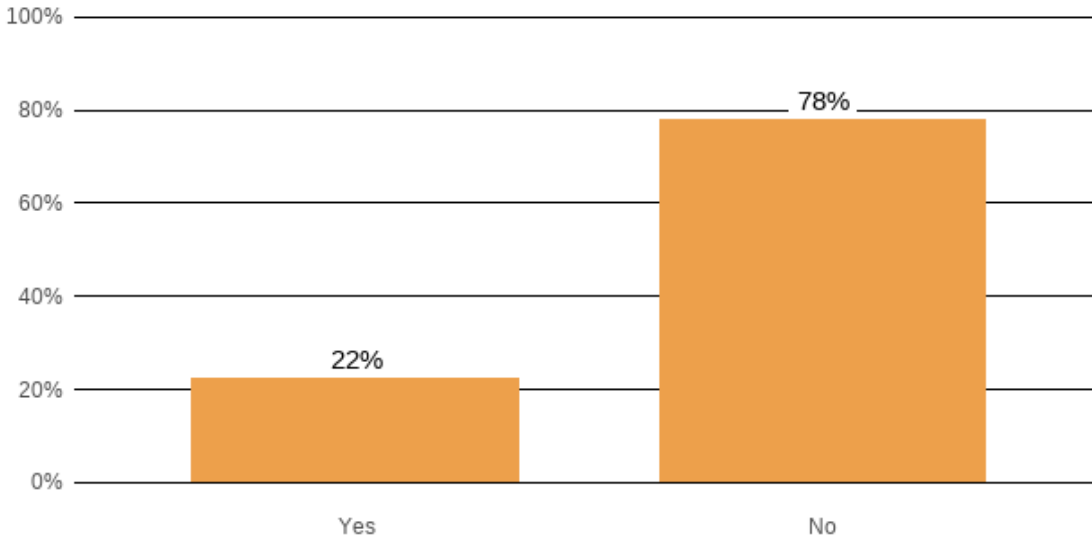


Table 29. Has your family learned about alternatives to guardianship?

State	Yes	No	N
CA	21%	79%	6568
LA	24%	76%	347
MO	23%	77%	158
OR	34%	66%	414
WI	22%	78%	591
Weighted NCI-IDD Average	22%	78%	8078

Table Note: 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?

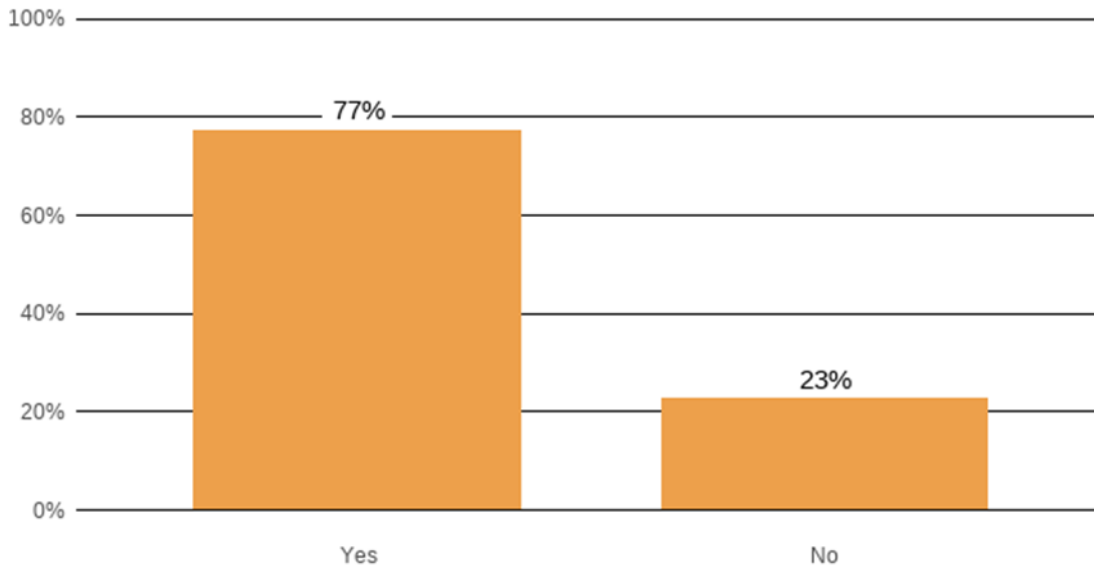


Table 30. Does your child have a service plan?

State	Yes	No	N
CA	78%	22%	7001
LA	62%	38%	350
MO	78%	22%	159
OR	85%	15%	413
WI	80%	20%	575
Weighted NCI-IDD Average	77%	23%	8498

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

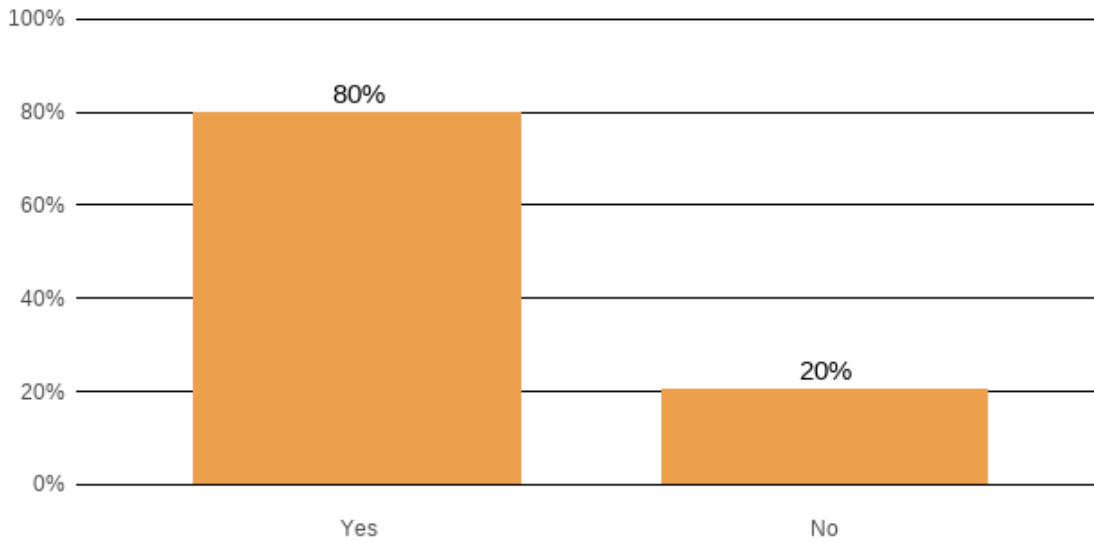


Table 31. Does the plan include all the services and supports your child needs?

State	Yes	No	N
CA	79%	21%	4220
LA	91%	9%	184
MO	81%	19%	108
OR	79%	21%	300
WI	82%	18%	416
Weighted NCI-IDD Average	80%	20%	5228

Did you or another family member help make the plan?

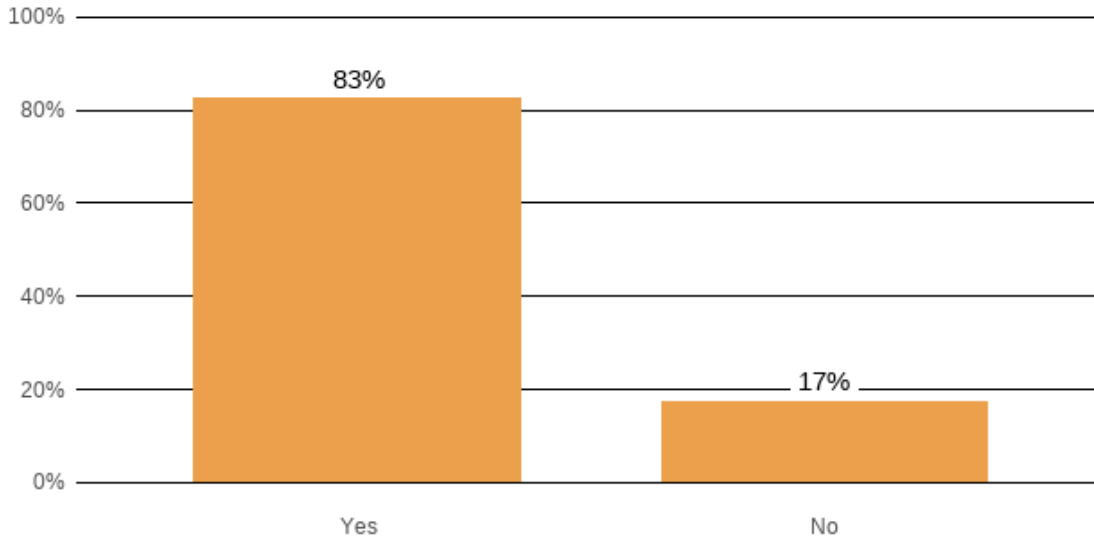


Table 32. Did you or another family member help make the plan?

State	Yes	No	N
CA	80%	20%	4696
LA	81%	19%	201
MO	95%	5%	121
OR	92%	8%	338
WI	93%	7%	452
Weighted NCI-IDD Average	83%	17%	5808

Did your child help make the plan?

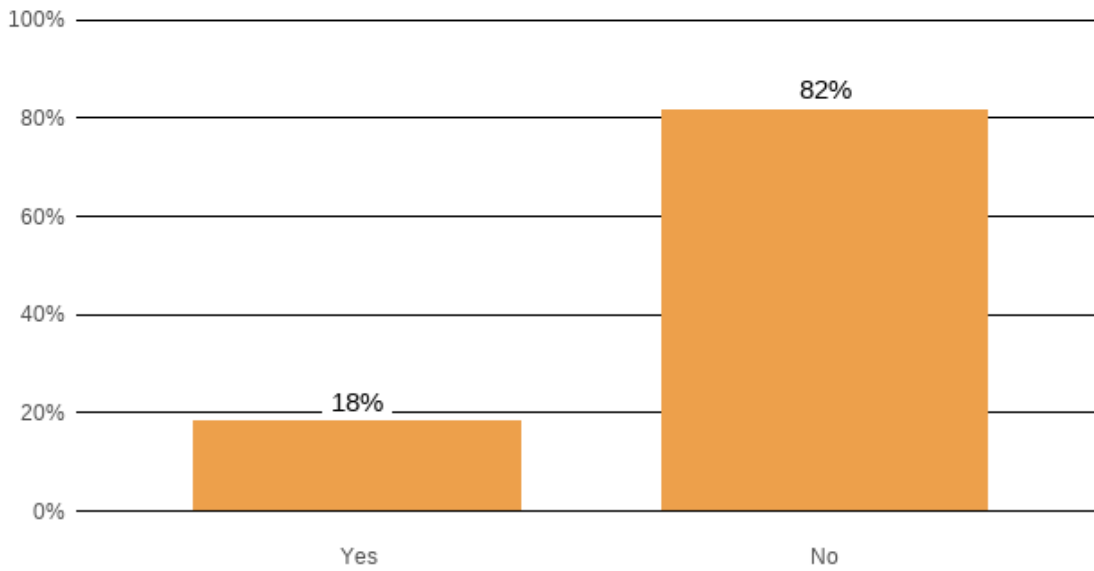


Table 33. Did your child help make the plan?

State	Yes	No	N
CA	17%	83%	4716
LA	9%	91%	210
MO	28%	72%	119
OR	28%	72%	343
WI	22%	78%	450
Weighted NCI-IDD Average	18%	82%	5838

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

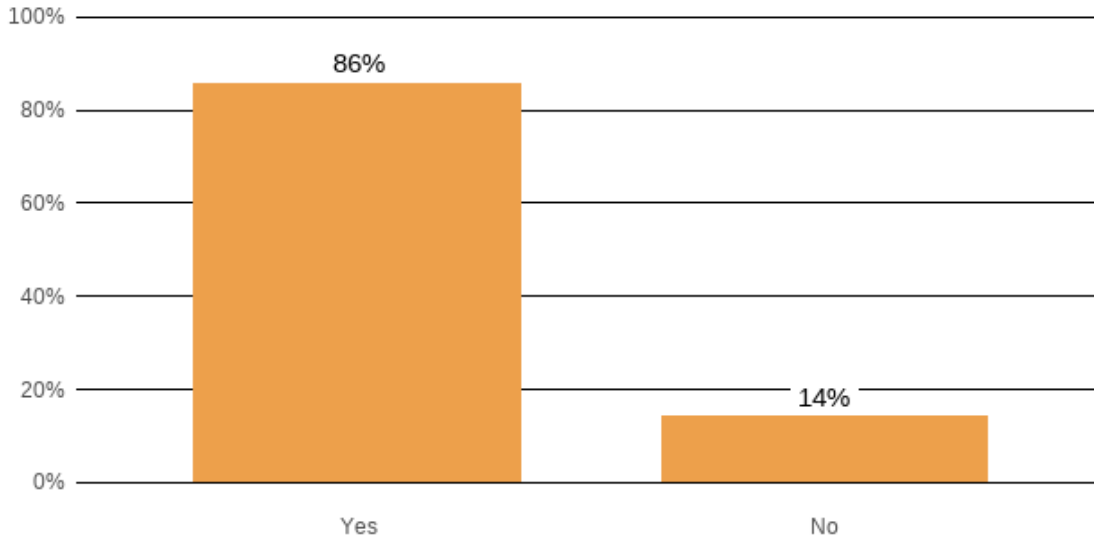


Table 34. Do you feel like your family had enough say or input in making the plan?

State	Yes	No	N
CA	84%	16%	4367
LA	90%	10%	191
MO	95%	5%	111
OR	91%	9%	322
WI	91%	9%	434
Weighted NCI-IDD Average	86%	14%	5425

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)?

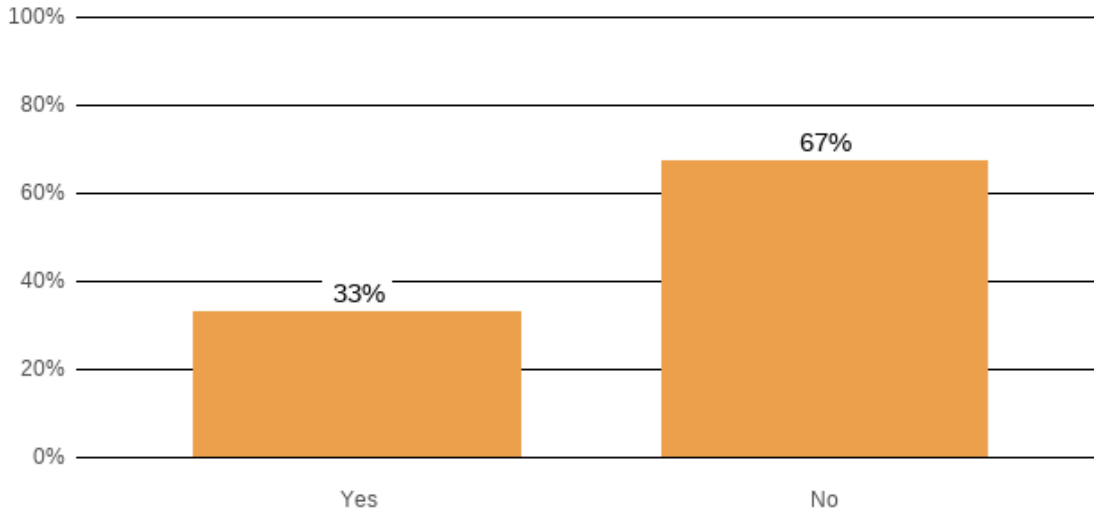


Table 35. Does your child have a transition plan (as part of an IEP or Section 504 plan through their high school, usually starting at age 14)?

State	Yes	No	N
CA	36%	64%	6472
LA	24%	76%	361
MO	15%	85%	150
OR	25%	75%	406
WI	20%	80%	589
Weighted NCI-IDD Average	33%	67%	7978

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

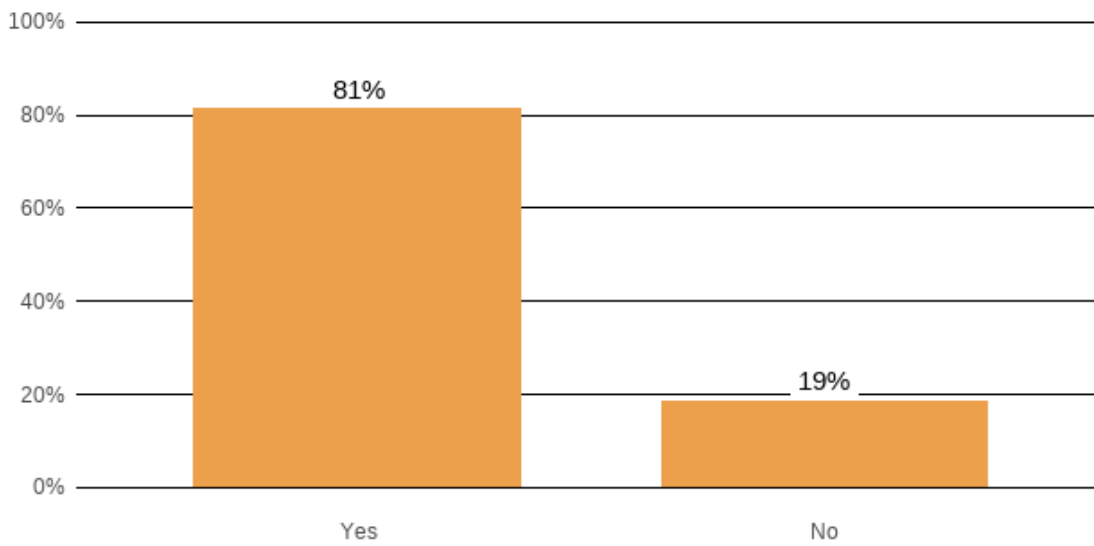


Table 36. If your child has a transition plan, did you or another family member help make the plan?

State	Yes	No	N
CA	80%	20%	2019
LA	84%	16%	82
MO	90%	10%	21
OR	90%	10%	92
WI	86%	14%	111
Weighted NCI-IDD Average	81%	19%	2325

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

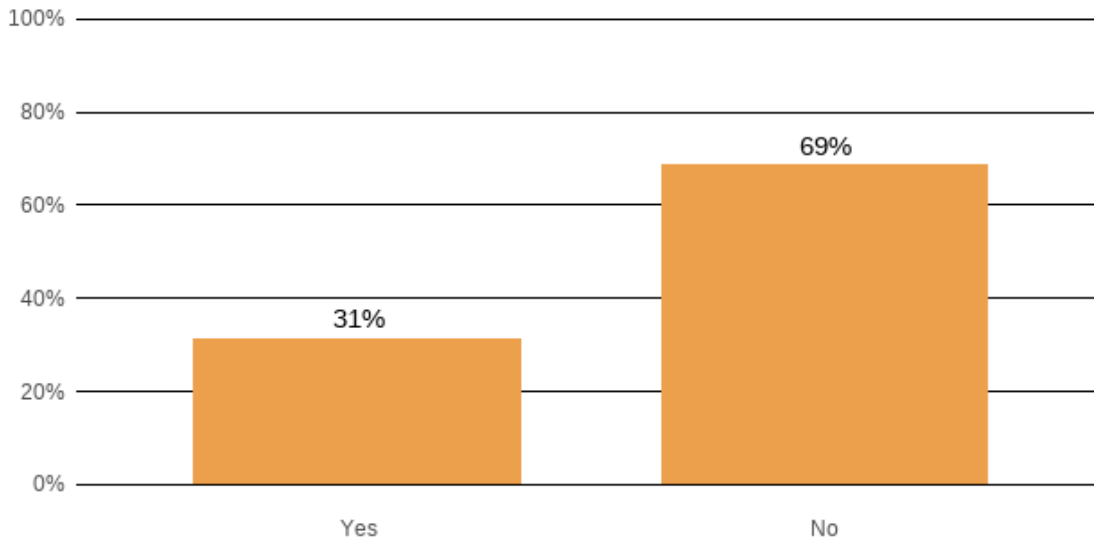


Table 37. If your child has a transition plan, did your child help make the plan?

State	Yes	No	N
CA	30%	70%	1946
LA	22%	78%	79
MO	67%	33%	21
OR	51%	49%	90
WI	33%	67%	107
Weighted NCI-IDD Average	31%	69%	2243

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.

“**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?

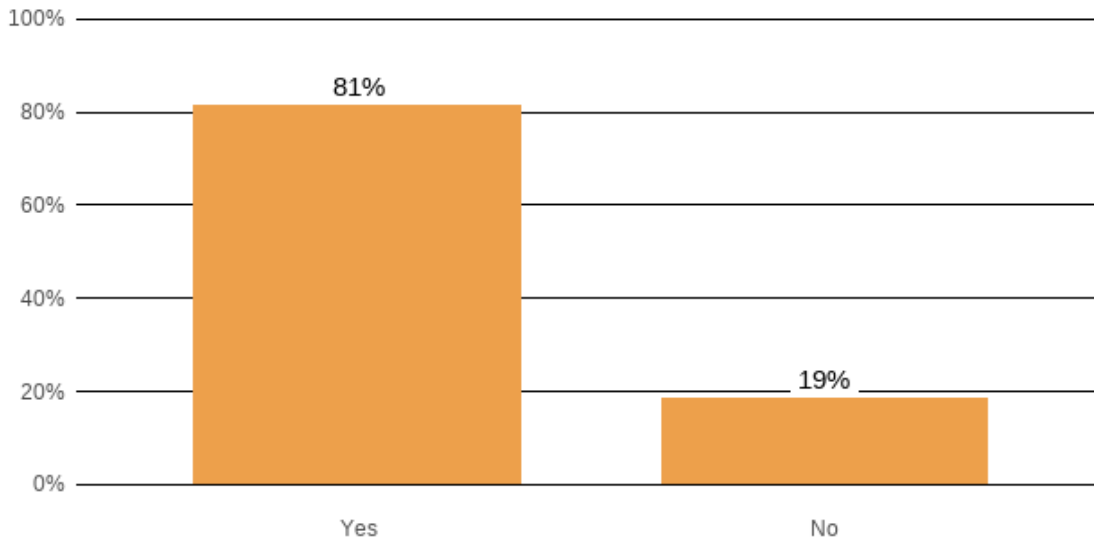


Table 38. Does your child get all the services listed in the plan?

State	Yes	No	N
CA	81%	19%	4227
LA	84%	16%	189
MO	81%	19%	113
OR	81%	19%	308
WI	82%	18%	422
Weighted NCI-IDD Average	81%	19%	5259

Does your family get the supports and services it needs?

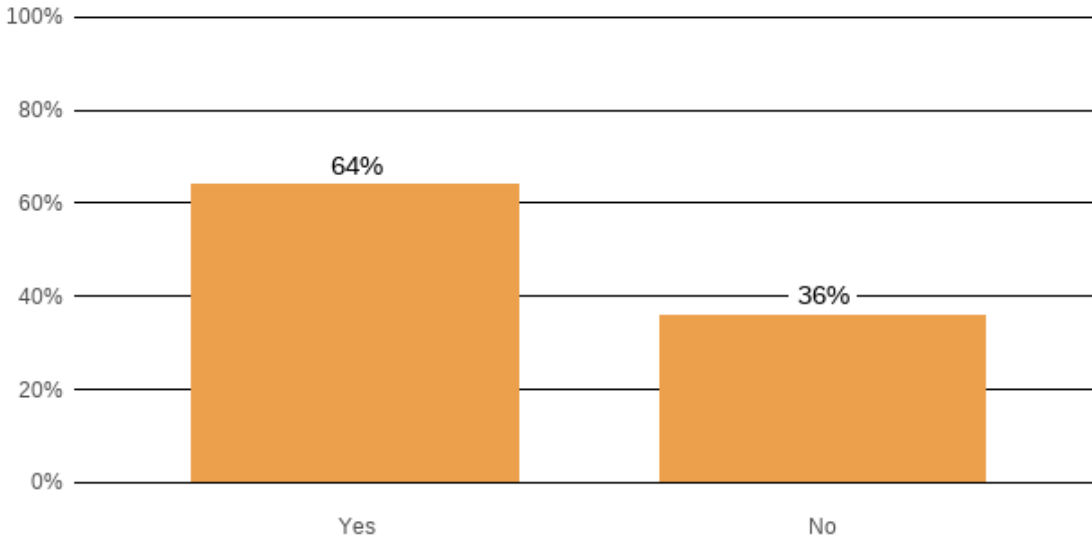


Table 39. Does your family get the supports and services it needs?

State	Yes	No	N
CA	62%	38%	6471
LA	71%	29%	345
MO	65%	35%	144
OR	66%	34%	441
WI	70%	30%	587
Weighted NCI-IDD Average	64%	36%	7988

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

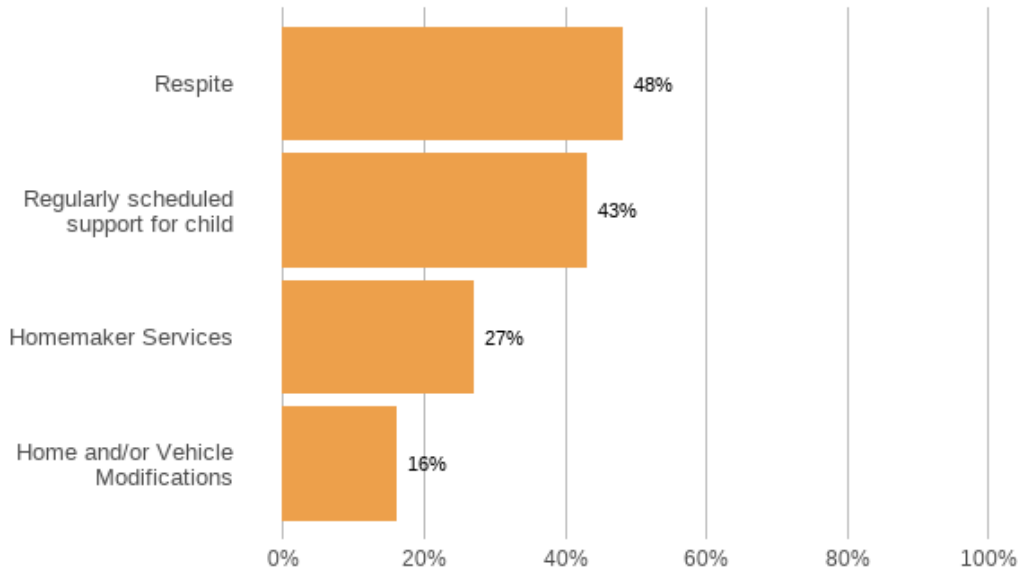


Table 40a. If your child does not get the support and services needed, what additional services does your child need?

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

State	Respite	Regularly scheduled support for child	Homemaker Services	Home and/or Vehicle Modifications
CA	45%	44%	27%	14%
LA	46%	36%	27%	29%
MO	71%	54%	29%	25%
OR	57%	49%	32%	22%
WI	66%	34%	27%	18%
Weighted NCI-IDD Average	48%	43%	27%	16%

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

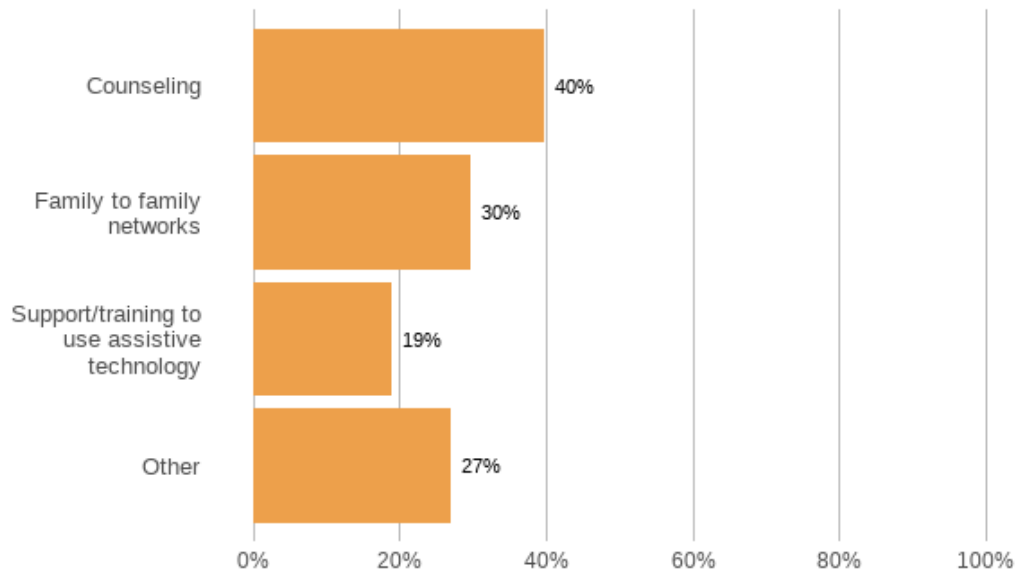


Table 40b. If your child does not get the support and services needed, what additional services does your child need? (Continued)

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

State	Counseling	Family to family networks	Support/training to using assistive technology	Other
CA	42%	30%	20%	27%
LA	19%	18%	17%	33%
MO	48%	35%	23%	25%
OR	29%	31%	20%	29%
WI	30%	30%	11%	26%
Weighted NCI-IDD Average	40%	30%	19%	27%

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

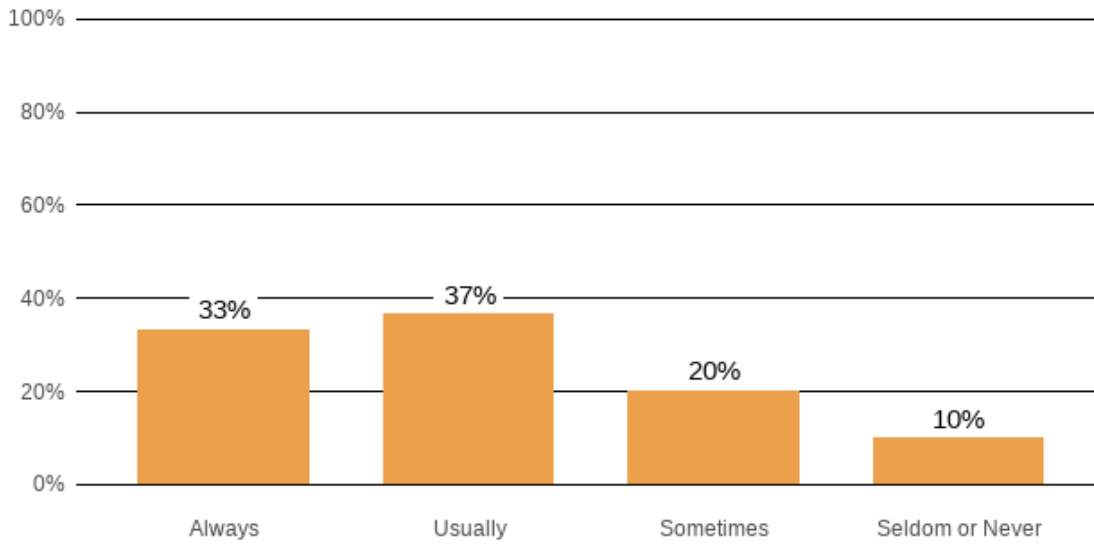


Table 41. Do services and supports change when your family's needs change?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	31%	37%	21%	11%	5929
LA	51%	31%	11%	7%	282
MO	32%	38%	22%	8%	136
OR	30%	40%	21%	9%	437
WI	43%	36%	15%	6%	534
Weighted NCI-IDD Average	33%	37%	20%	10%	7318

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

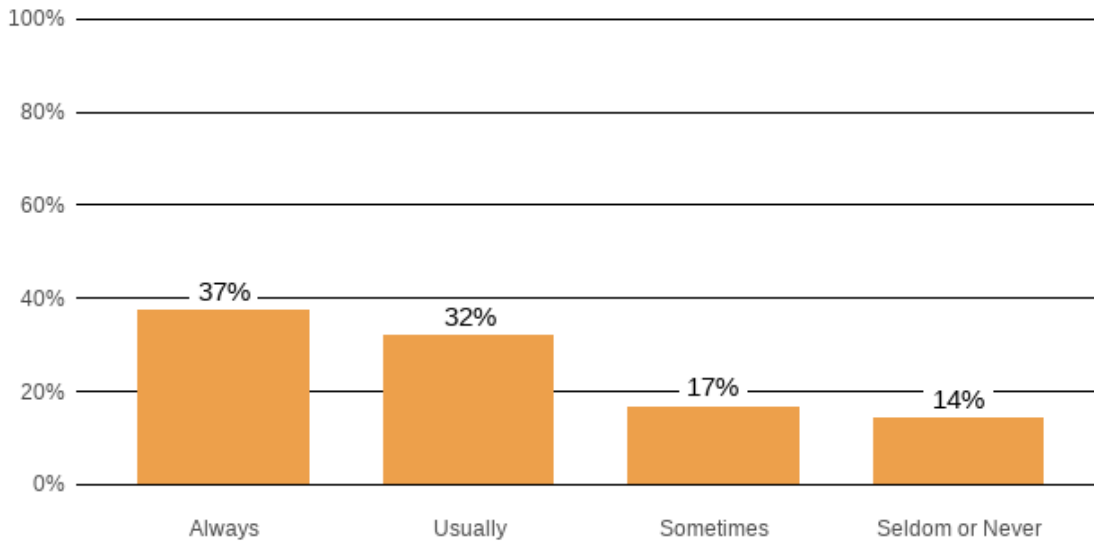


Table 42. Does your child have the special equipment or accommodations they need?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	37%	30%	17%	16%	3106
LA	44%	29%	13%	13%	217
MO	31%	37%	18%	14%	87
OR	33%	42%	18%	7%	298
WI	39%	37%	18%	7%	394
Weighted NCI-IDD Average	37%	32%	17%	14%	4102

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

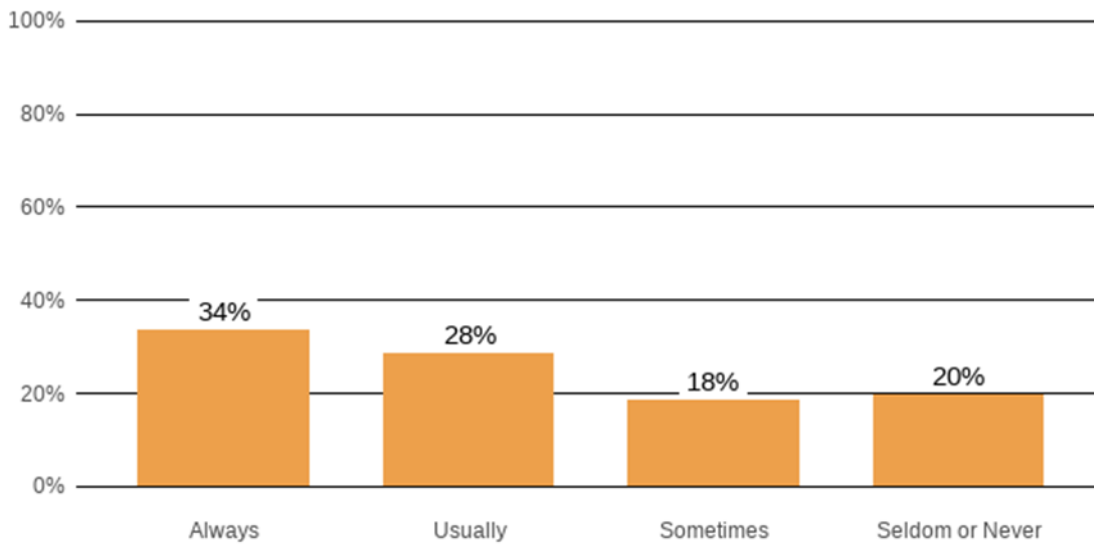


Table 43. If you need respite services, how often are you able to get them when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	37%	29%	17%	17%	5940
LA	21%	19%	14%	46%	176
MO	15%	24%	15%	47%	102
OR	21%	31%	23%	24%	384
WI	22%	29%	26%	23%	468
Weighted NCI-IDD Average	34%	28%	18%	20%	7070

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

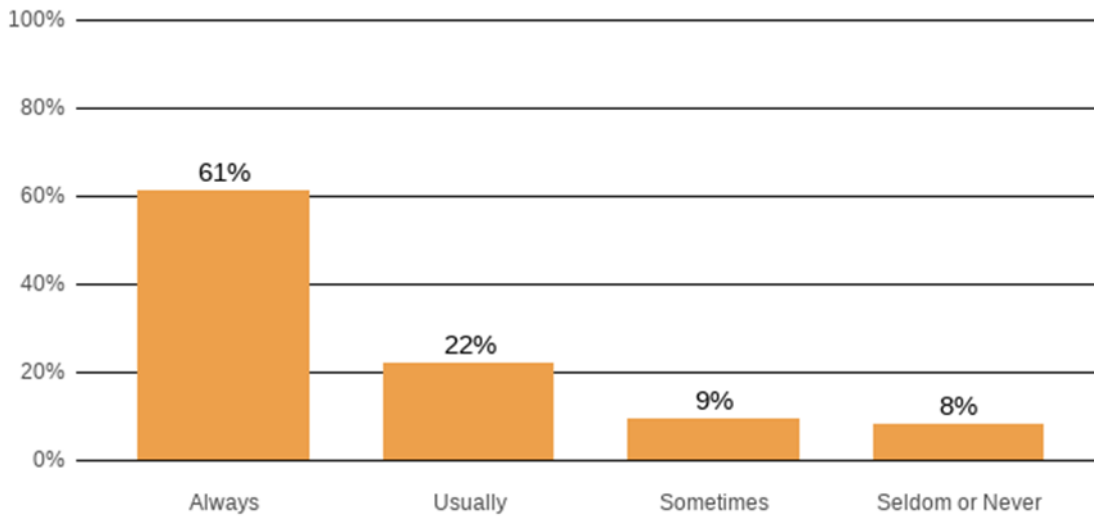


Table 44. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	61%	21%	9%	8%	4677
LA	53%	19%	15%	14%	59
MO	56%	21%	8%	15%	48
OR	54%	27%	12%	7%	261
WI	64%	23%	8%	4%	351
Weighted NCI-IDD Average	61%	22%	9%	8%	5396

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

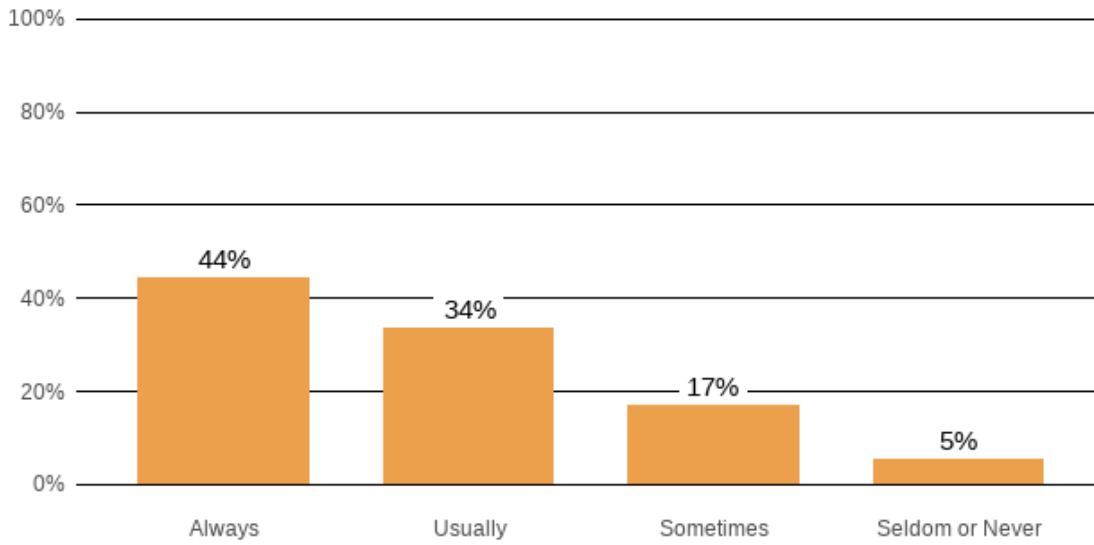


Table 45. Are you able to contact your child’s support workers when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	41%	34%	19%	6%	7020
LA	64%	28%	7%	2%	337
MO	49%	39%	10%	2%	150
OR	53%	36%	10%	2%	456
WI	58%	33%	8%	1%	573
Weighted NCI-IDD Average	44%	34%	17%	5%	8536

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

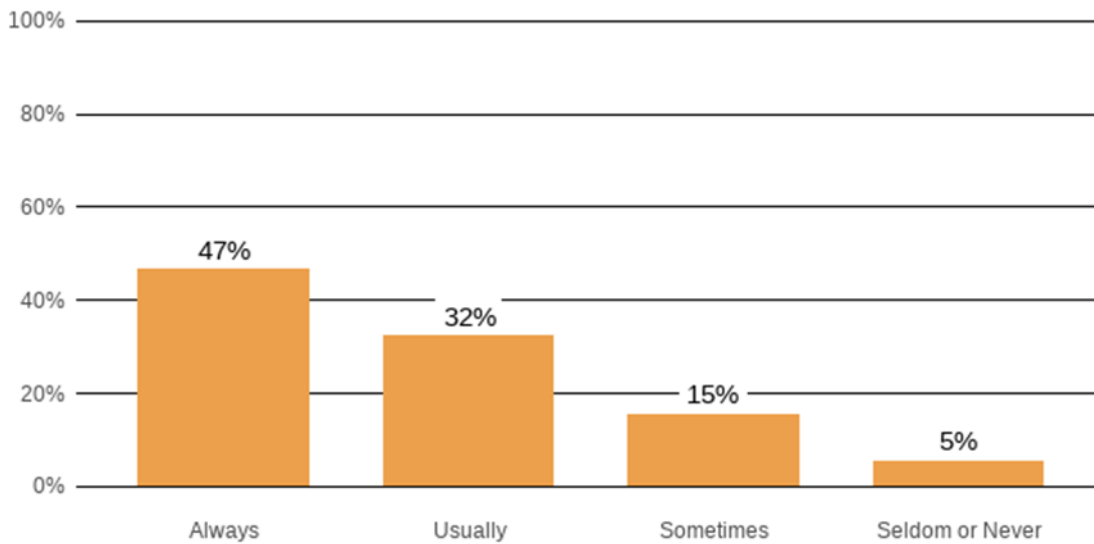


Table 46. Are you able to contact your child’s case manager or service coordinator when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	43%	33%	18%	6%	7654
LA	64%	27%	7%	2%	350
MO	51%	39%	7%	3%	161
OR	50%	38%	10%	2%	475
WI	62%	27%	8%	3%	632
Weighted NCI-IDD Average	47%	32%	15%	5%	9272

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

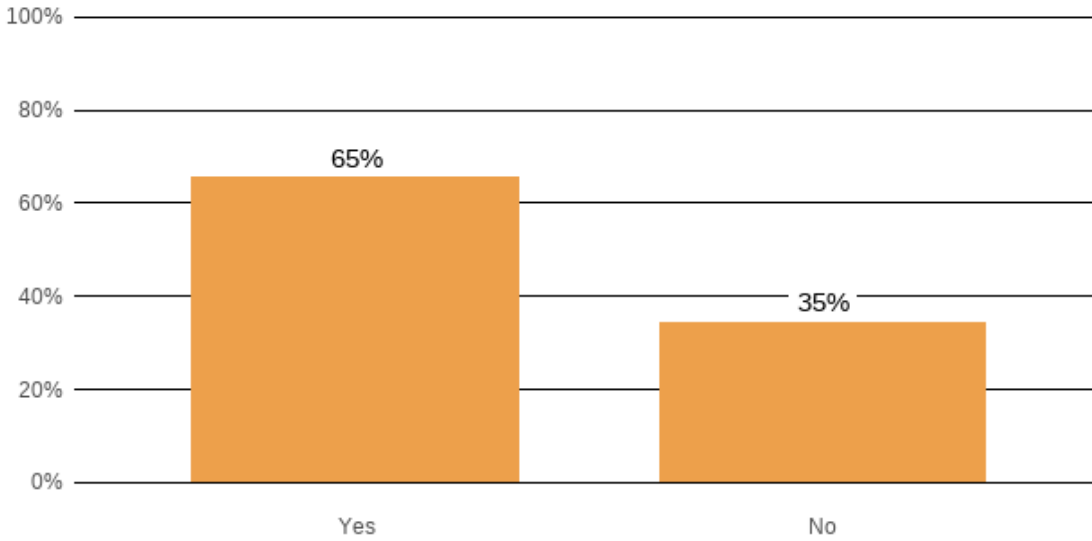


Table 47. Do service providers for your child work together to provide support?

State	Yes	No	N
CA	62%	38%	3260
LA	77%	23%	184
MO	72%	28%	68
OR	79%	21%	250
WI	78%	22%	285
Weighted NCI-IDD Average	65%	35%	4047

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

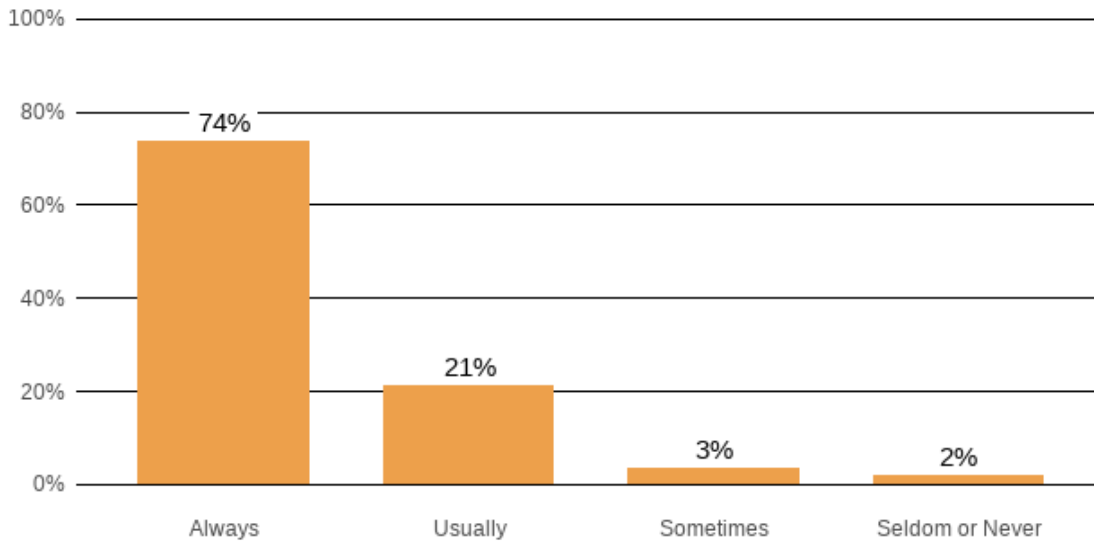


Table 48. Are services delivered in a way that is respectful of your family's culture?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	71%	23%	4%	2%	7021
LA	85%	13%	1%	1%	365
MO	80%	18%	1%	1%	163
OR	77%	20%	2%	1%	469
WI	83%	14%	2%	1%	604
Weighted NCI-IDD Average	74%	21%	3%	2%	8622

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

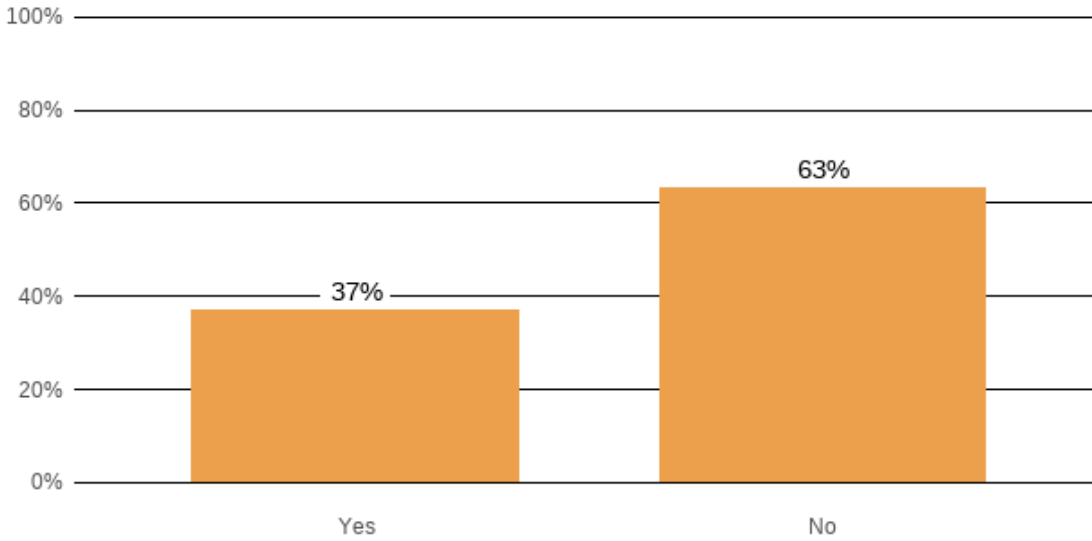


Table 49. Does your child use technology in their everyday life to help them do things on their own?

State	Yes	No	N
CA	36%	64%	7545
LA	28%	72%	418
MO	36%	64%	171
OR	51%	49%	461
WI	44%	56%	616
Weighted NCI-IDD Average	37%	63%	9211

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

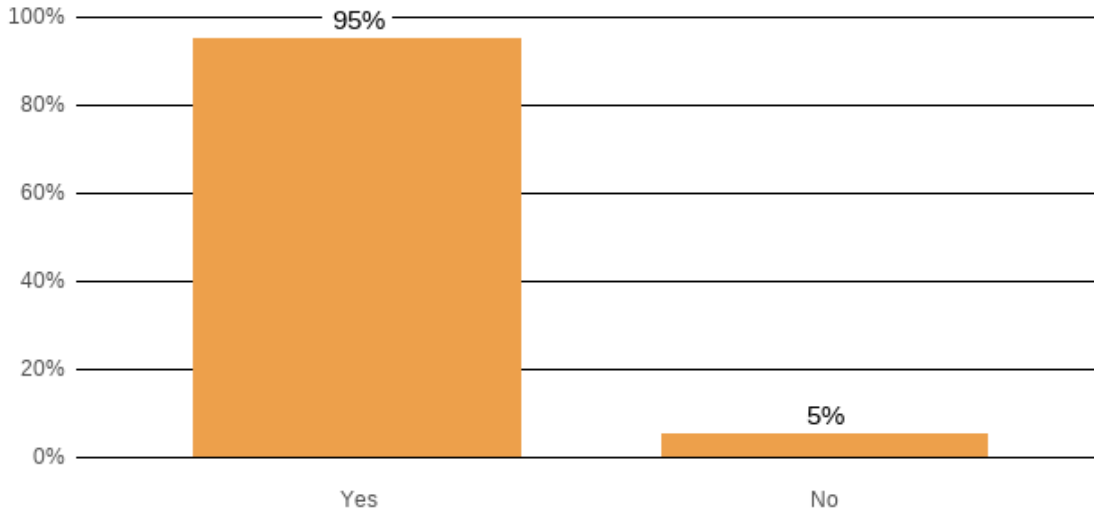


Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home?

State	Yes	No	N
CA	95%	5%	7944
LA	93%	7%	427
MO	99%	1%	172
OR	95%	5%	475
WI	96%	4%	625
Weighted NCI-IDD Average	95%	5%	9643

How well does internet work in your home?

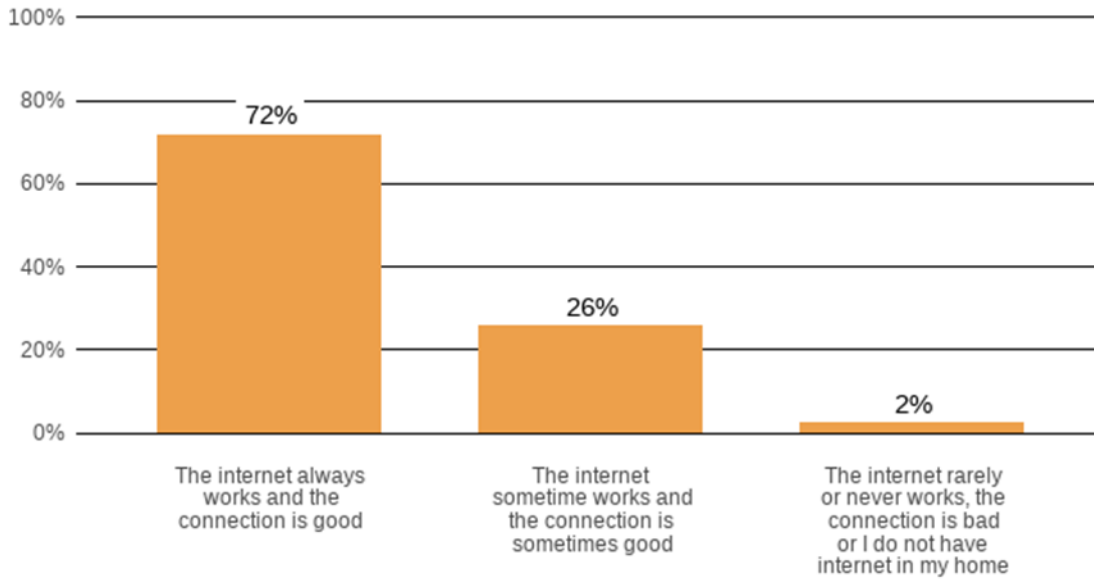


Table 51. How well does the internet work in your home?

State	The internet always works and the connection is good	The internet sometime 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
CA	70%	27%	3%	7969
LA	71%	27%	2%	427
MO	83%	15%	2%	174
OR	74%	24%	2%	474
WI	79%	20%	1%	626
Weighted NCI-IDD Average	72%	26%	2%	9670

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.

“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?

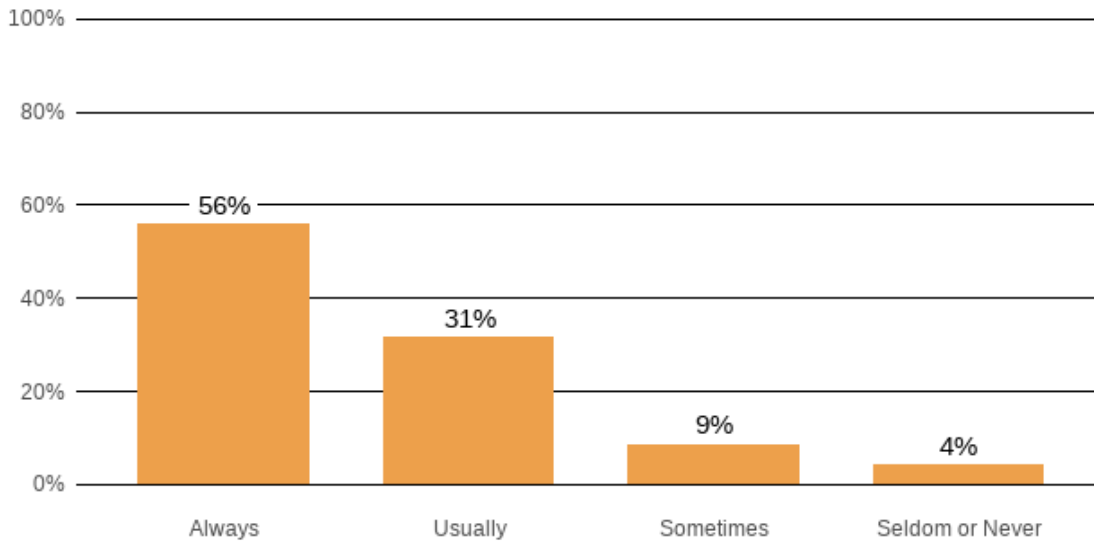


Table 52. Do support workers come and go when they are supposed to?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	53%	33%	9%	5%	5848
LA	64%	27%	5%	4%	320
MO	58%	33%	7%	2%	132
OR	56%	33%	7%	3%	448
WI	68%	23%	8%	1%	517
Weighted NCI-IDD Average	56%	31%	9%	4%	7265

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

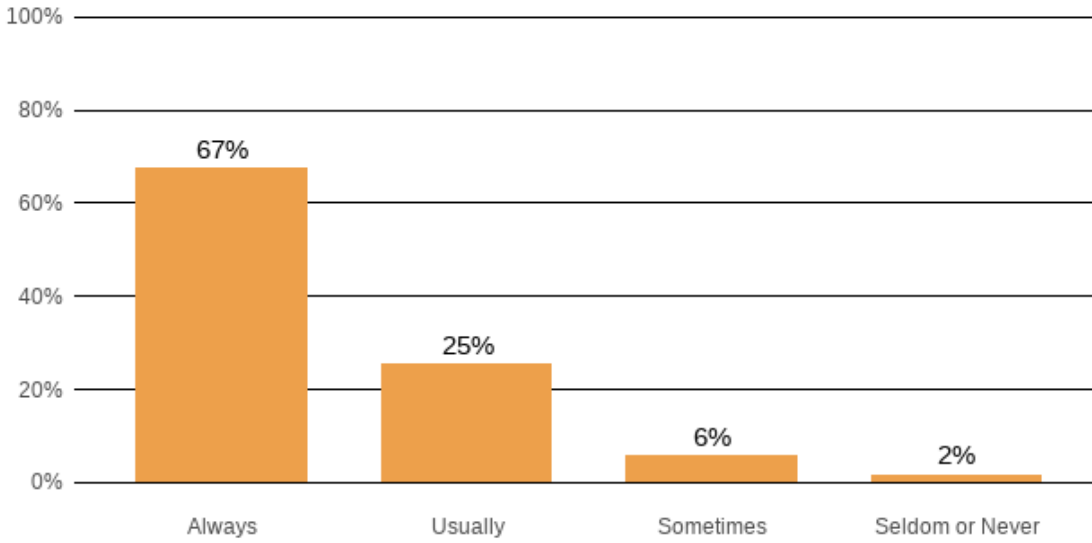


Table 53. Do support workers speak to you in a way you understand?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	65%	27%	7%	2%	6671
LA	78%	19%	3%	0%	336
MO	77%	20%	2%	1%	148
OR	76%	20%	3%	1%	459
WI	76%	21%	1%	1%	536
Weighted NCI-IDD Average	67%	25%	6%	2%	8150

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

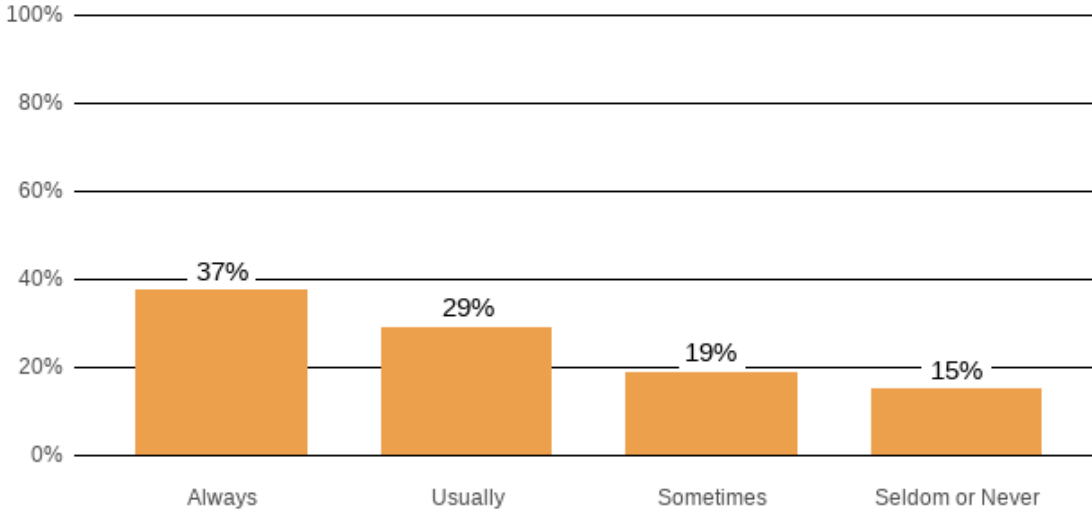


Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	36%	29%	20%	16%	3684
LA	57%	23%	12%	9%	244
MO	33%	38%	16%	13%	61
OR	39%	37%	15%	9%	238
WI	39%	32%	18%	12%	282
Weighted NCI-IDD Average	37%	29%	19%	15%	4509

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

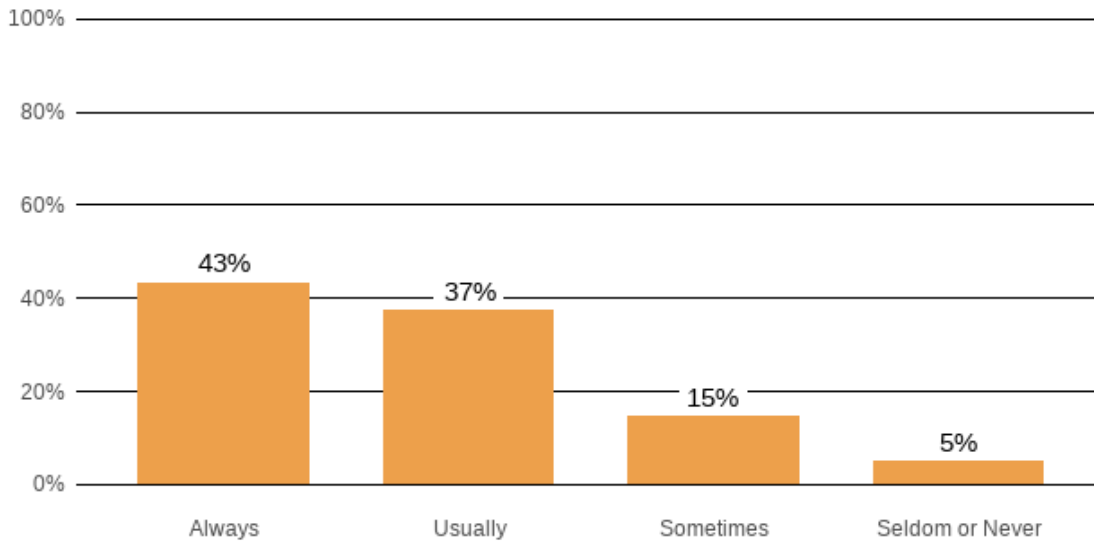


Table 55. Do support workers have the right information and skills to meet your family's needs?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	41%	38%	16%	5%	6132
LA	59%	29%	9%	3%	331
MO	41%	46%	12%	1%	142
OR	46%	38%	12%	4%	448
WI	49%	34%	12%	5%	519
Weighted NCI-IDD Average	43%	37%	15%	5%	7572

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

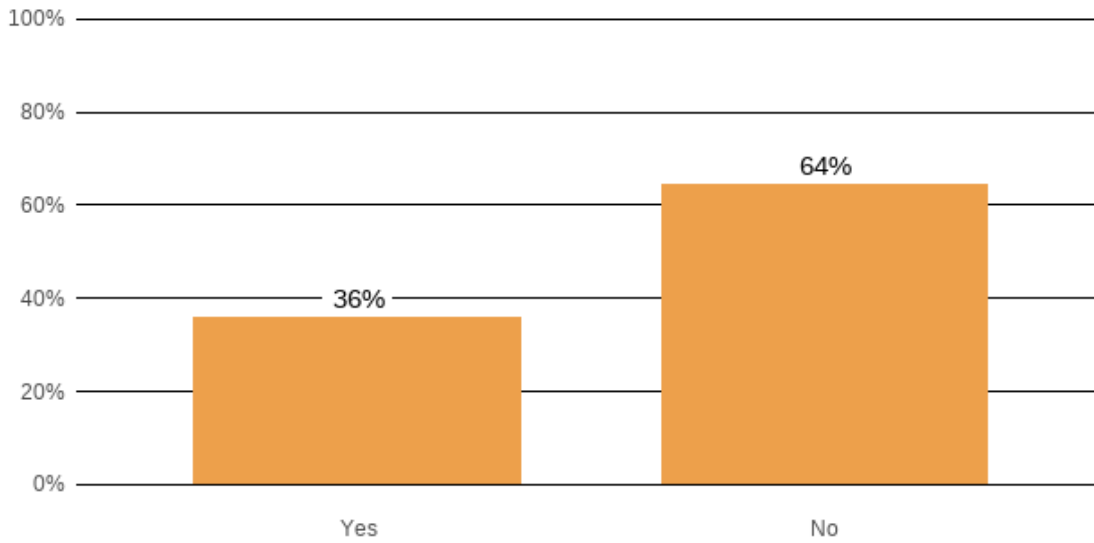


Table 56. Do your child's support workers change too often? Is there too much "turnover" of support workers?

State	Yes	No	N
CA	38%	62%	5449
LA	23%	77%	299
MO	35%	65%	129
OR	35%	65%	432
WI	24%	76%	477
Weighted NCI-IDD Average	36%	64%	6786

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

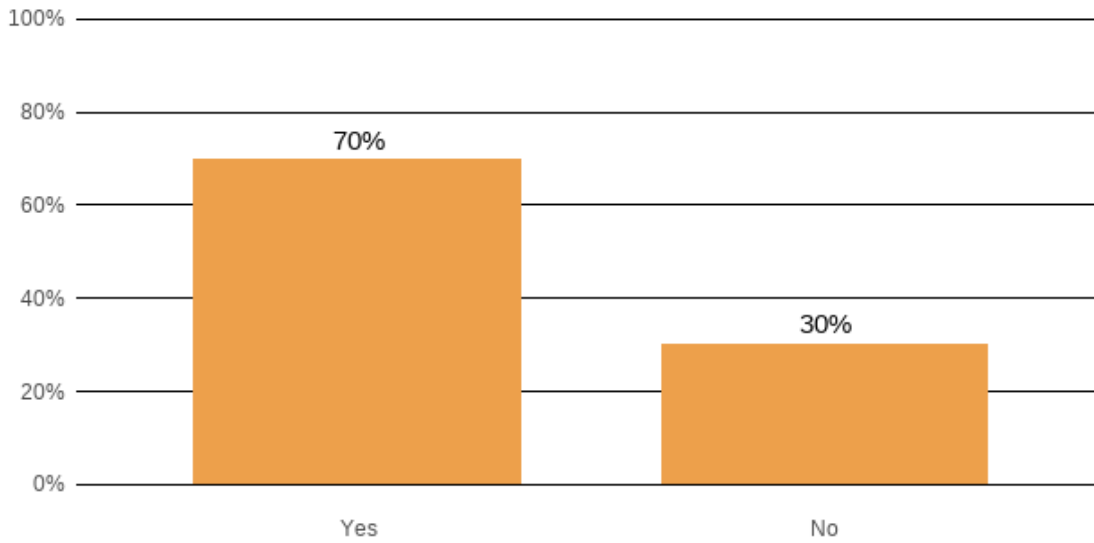


Table 57. Is there always a staff person available to support your child when support is needed?

State	Yes	No	N
CA	70%	30%	5283
LA	78%	22%	275
MO	71%	29%	125
OR	54%	46%	399
WI	70%	30%	467
Weighted NCI-IDD Average	70%	30%	6549

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.

“**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?

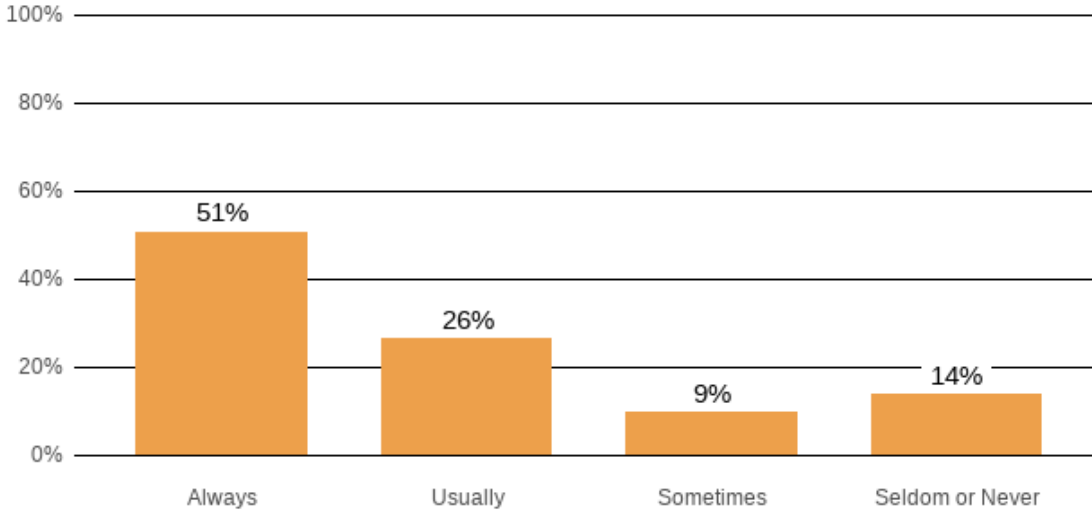


Table 58. Can someone in your family choose or change the provider agency that provides your child's services?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	48%	27%	10%	14%	4401
LA	71%	13%	5%	11%	289
MO	49%	28%	7%	16%	94
OR	65%	25%	5%	5%	371
WI	51%	26%	9%	15%	293
Weighted NCI-IDD Average	51%	26%	9%	14%	5448

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

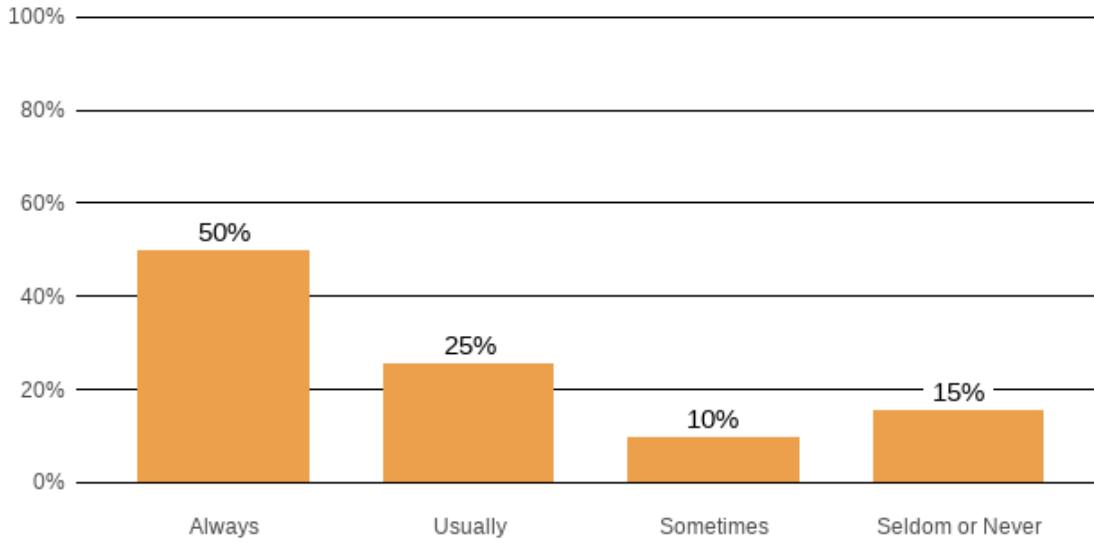


Table 59. Can someone in your family choose or change your child's support workers?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	46%	26%	11%	17%	4234
LA	65%	16%	4%	15%	257
MO	55%	24%	8%	14%	88
OR	66%	22%	7%	5%	407
WI	52%	26%	8%	13%	311
Weighted NCI-IDD Average	50%	25%	10%	15%	5297

Can someone in your family directly manage support staff?

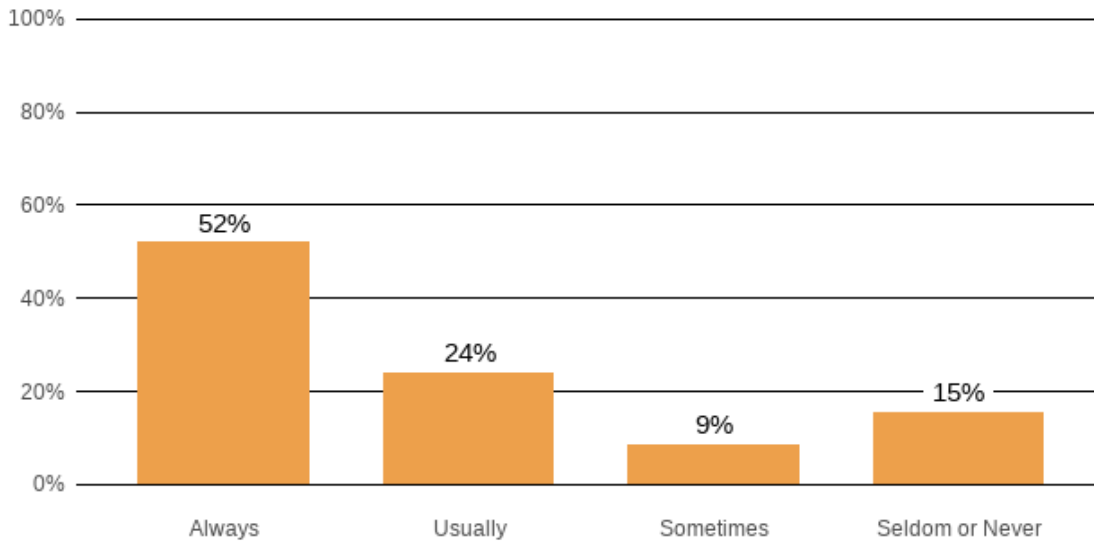


Table 60. Can someone in your family directly manage support staff?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	48%	25%	9%	17%	4120
LA	70%	13%	3%	15%	224
MO	57%	24%	2%	16%	86
OR	72%	19%	5%	4%	410
WI	54%	23%	10%	13%	327
Weighted NCI-IDD Average	52%	24%	9%	15%	5167

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

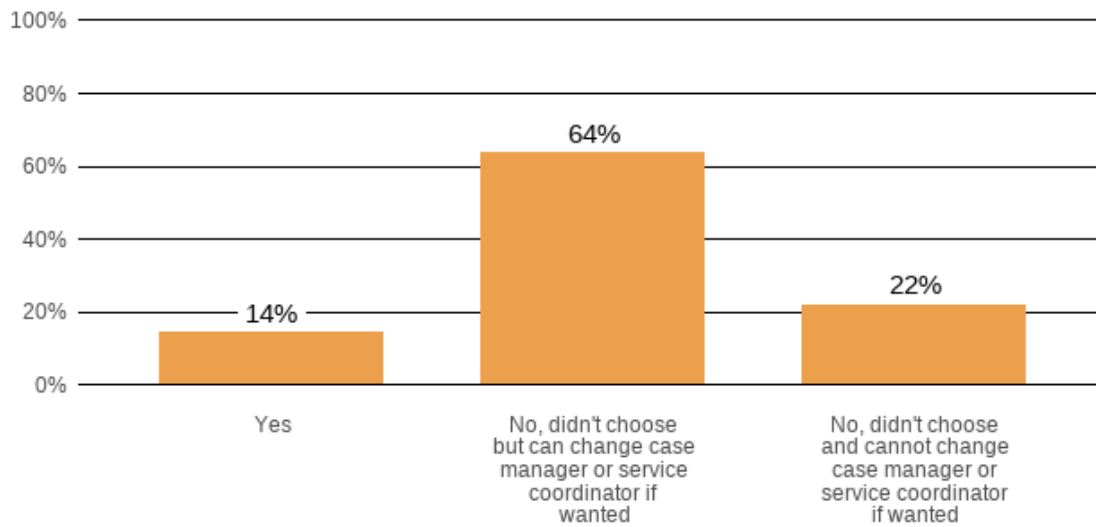


Table 61. Did you, your child, or someone else in your family choose your child's case manager or service coordinator?

State	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
CA	11%	66%	23%	5853
LA	53%	38%	9%	293
MO	13%	60%	28%	126
OR	32%	55%	12%	390
WI	9%	63%	27%	479
Weighted NCI-IDD Average	14%	64%	22%	7141

Community Connections

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.

“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?

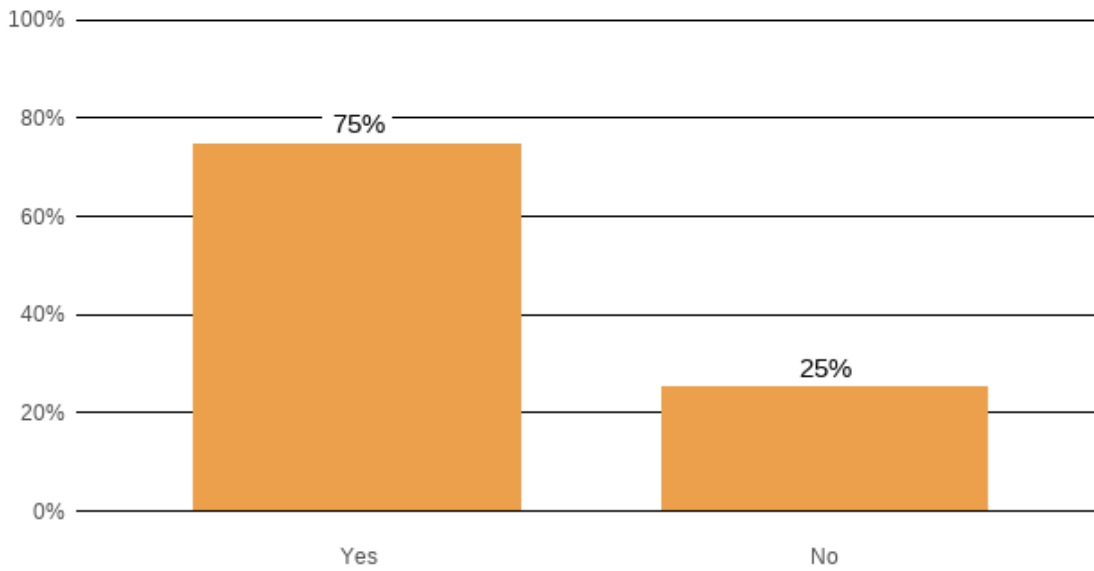


Table 62. Does your child do things in the community?

State	Yes	No	N
CA	72%	28%	7900
LA	74%	26%	409
MO	84%	16%	168
OR	86%	14%	471
WI	87%	13%	616
Weighted NCI-IDD Average	75%	25%	9564

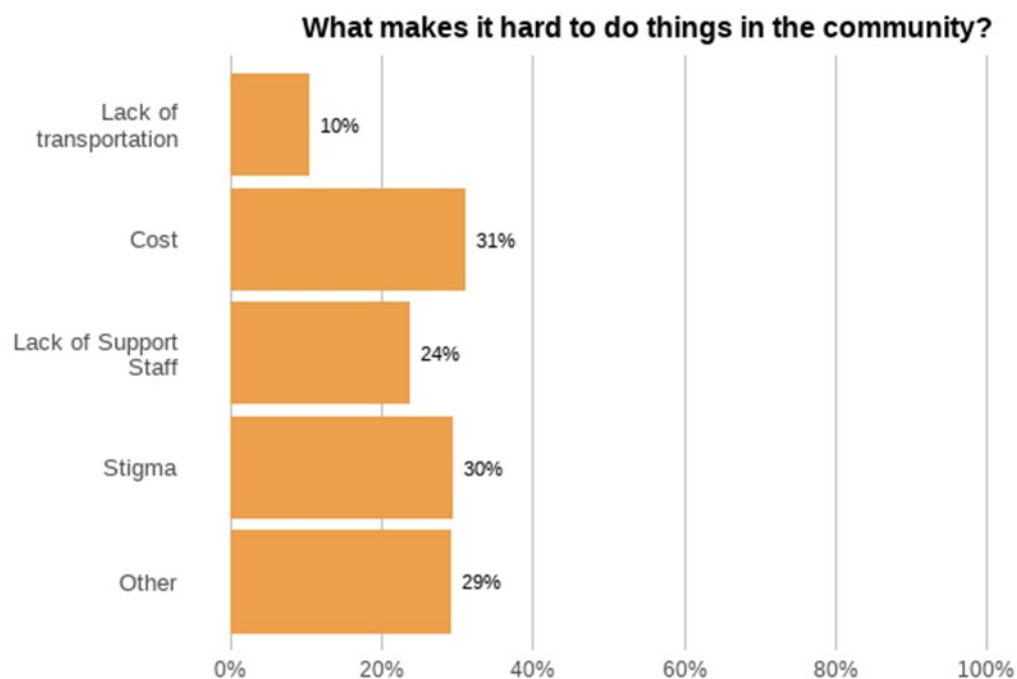


Table 63. What makes it hard to do things in the community?

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

State	Lack of transportation	Cost	Lack of Support Staff	Stigma	Other
CA	11%	31%	24%	29%	27%
LA	9%	23%	16%	18%	31%
MO	10%	33%	22%	33%	41%
OR	11%	37%	30%	33%	40%
WI	5%	30%	26%	37%	36%
Weighted NCI-IDD Average	10%	31%	24%	30%	29%

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

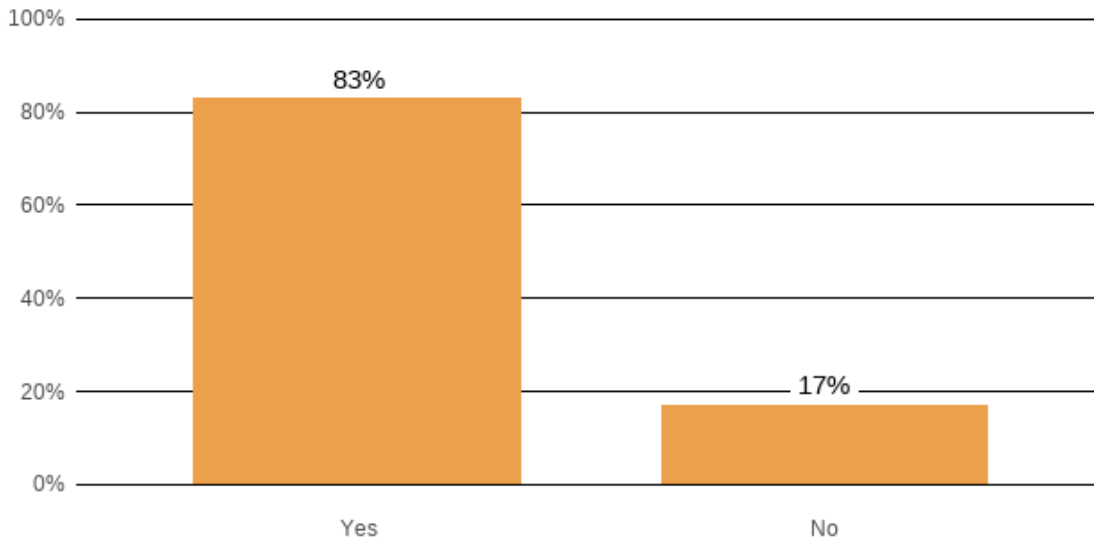


Table 64. Does your child spend time with children who do not have developmental disabilities?

State	Yes	No	N
CA	82%	18%	7924
LA	85%	15%	417
MO	88%	12%	172
OR	83%	17%	476
WI	89%	11%	616
Weighted NCI-IDD Average	83%	17%	9605

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

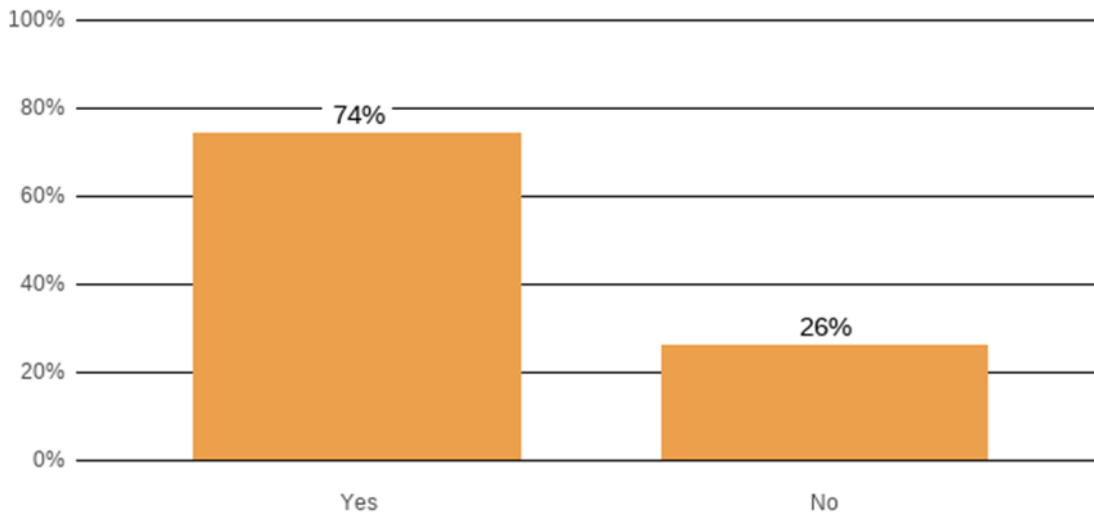


Table 65. In your community, are there resources that your family and child can use that are not provided by the ID/DD agency?

State	Yes	No	N
CA	72%	28%	5818
LA	73%	28%	280
MO	84%	16%	122
OR	77%	23%	363
WI	84%	16%	477
Weighted NCI-IDD Average	74%	26%	7060

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

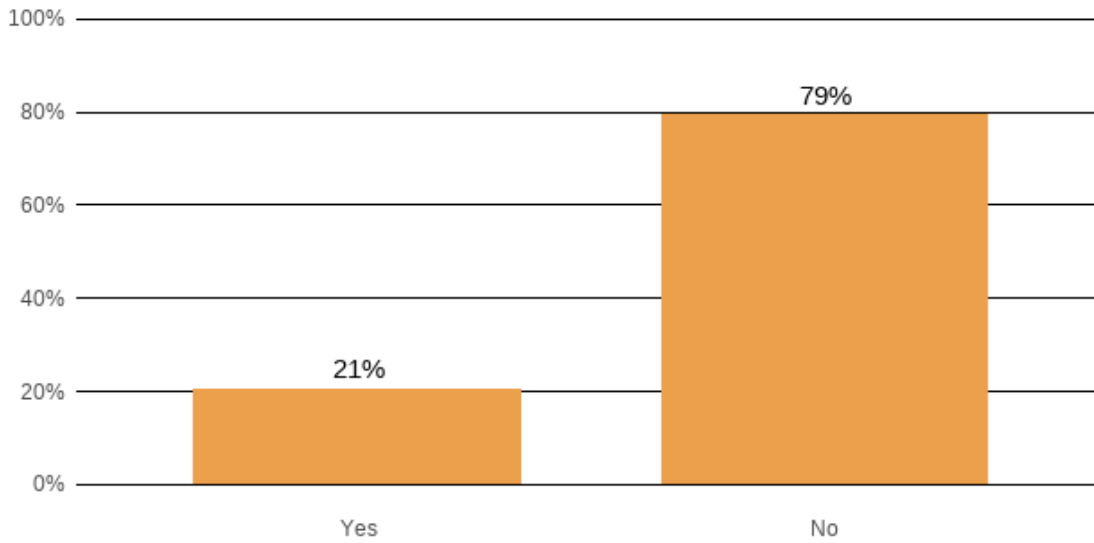


Table 66. Does your family take part in any family-to-family networks in your community?

State	Yes	No	N
CA	21%	79%	7014
LA	23%	77%	334
MO	16%	84%	142
OR	22%	78%	427
WI	17%	83%	544
Weighted NCI-IDD Average	21%	79%	8461

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.

“**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?**

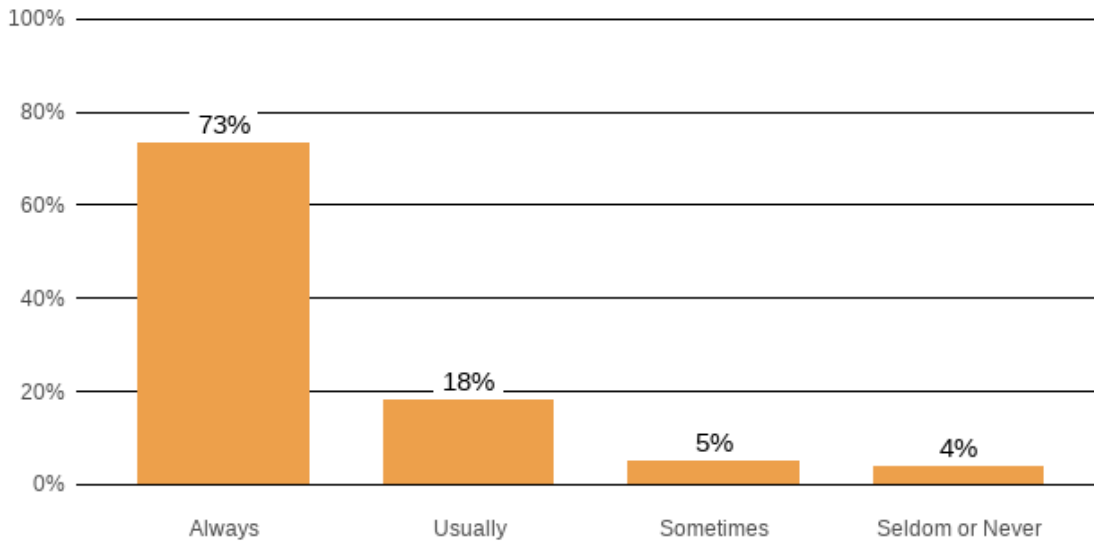


Table 67. Can your child see a primary care provider (doctor, registered nurse, etc.) when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	72%	18%	6%	5%	7781
LA	89%	8%	1%	1%	416
MO	83%	14%	2%	1%	169
OR	69%	25%	5%	1%	469
WI	74%	21%	4%	1%	616
Weighted NCI-IDD Average	73%	18%	5%	4%	9451

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

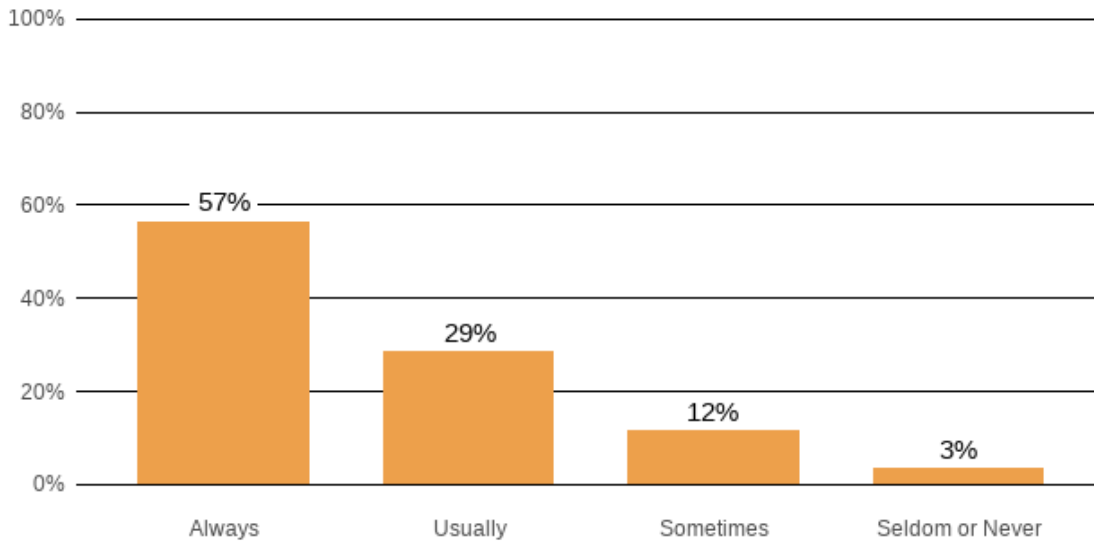


Table 68. Does your child’s primary care doctor understand your child’s needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	55%	29%	12%	4%	7743
LA	77%	19%	4%	0%	420
MO	67%	25%	5%	2%	169
OR	51%	34%	12%	4%	470
WI	54%	33%	10%	2%	618
Weighted NCI-IDD Average	57%	29%	12%	3%	9420

Can your child go to the dentist when needed?

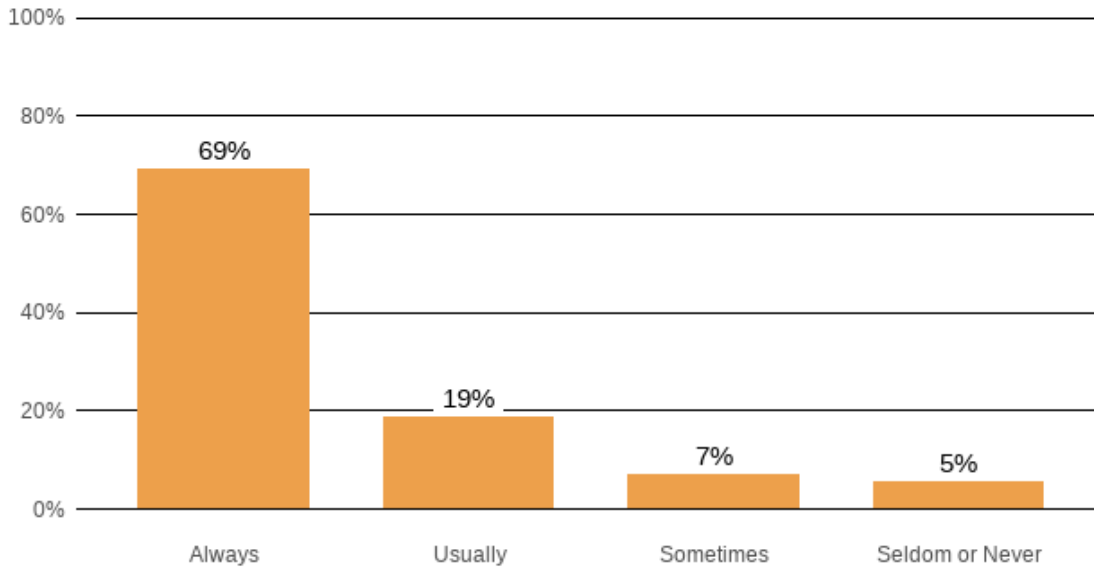


Table 69. Can your child go to the dentist when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	69%	18%	7%	6%	7960
LA	78%	16%	3%	4%	406
MO	68%	25%	5%	3%	170
OR	61%	23%	11%	6%	470
WI	67%	22%	6%	5%	611
Weighted NCI-IDD Average	69%	19%	7%	5%	9617

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

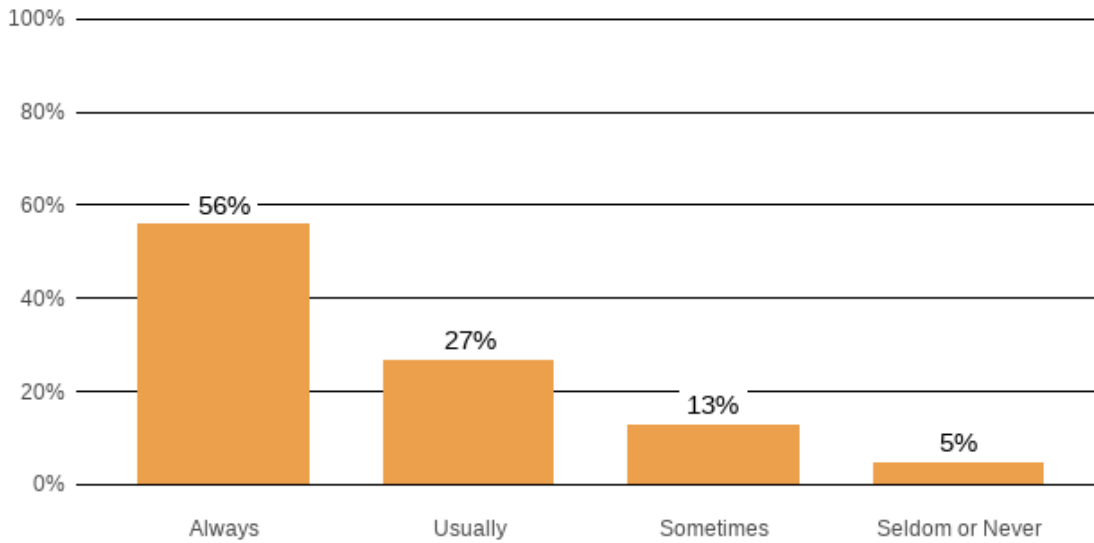


Table 70. Does your child’s dentist understand your child’s needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	55%	26%	14%	5%	7510
LA	72%	21%	4%	3%	347
MO	61%	24%	10%	5%	160
OR	48%	29%	15%	8%	452
WI	53%	32%	10%	6%	569
Weighted NCI-IDD Average	56%	27%	13%	5%	9038

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

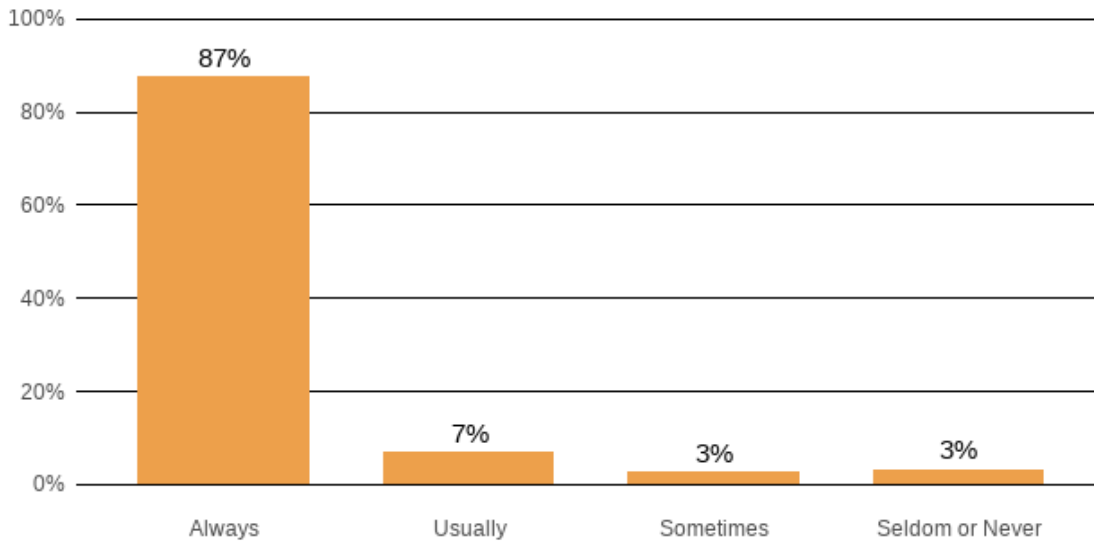


Table 71. If your child takes prescription medications, do you know what they're for?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	86%	8%	3%	4%	4640
LA	98%	1%	1%	0%	287
MO	91%	5%	2%	2%	133
OR	89%	7%	2%	1%	372
WI	92%	5%	2%	2%	426
Weighted NCI-IDD Average	87%	7%	3%	3%	5858

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)?

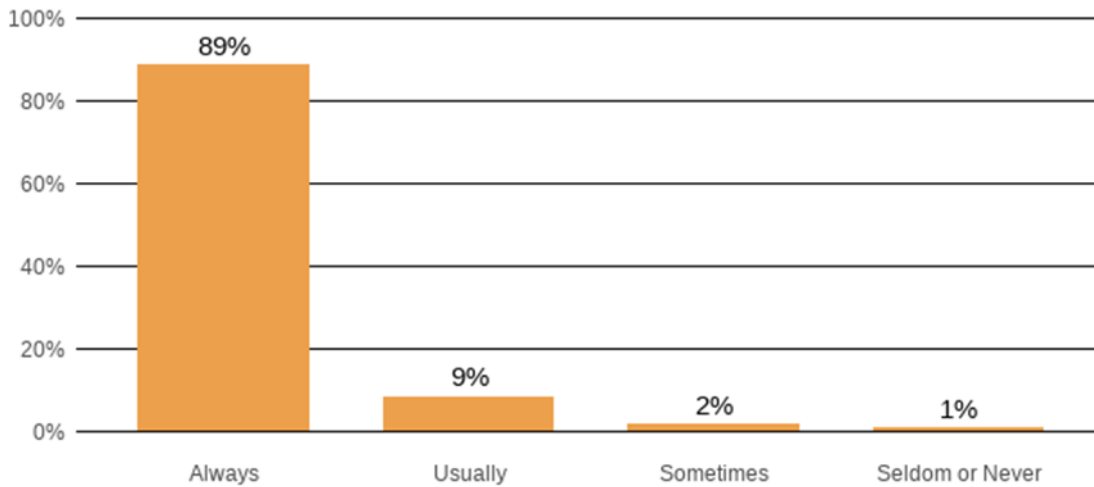


Table 72. Do you or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	88%	9%	2%	1%	4577
LA	93%	6%	1%	0%	287
MO	92%	6%	1%	2%	132
OR	92%	8%	1%	0%	372
WI	91%	8%	1%	0%	424
Weighted NCI-IDD Average	89%	9%	2%	1%	5792

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

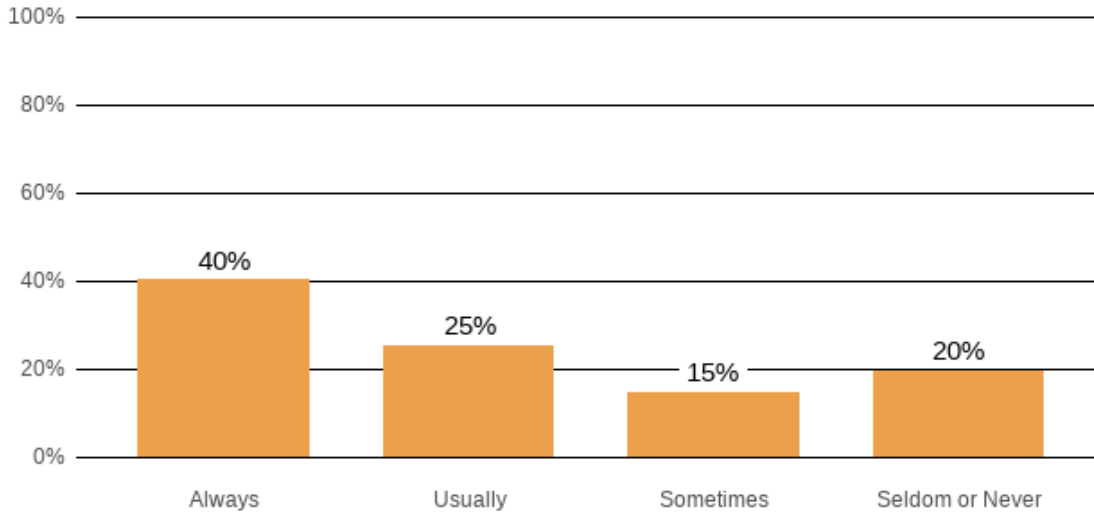


Table 73. Can your child get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)

State	Always	Usually	Sometimes	Seldom or Never	N
CA	39%	25%	15%	21%	6168
LA	57%	17%	10%	16%	269
MO	46%	20%	17%	17%	138
OR	38%	29%	16%	17%	373
WI	43%	28%	14%	15%	453
Weighted NCI-IDD Average	40%	25%	15%	20%	7401

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

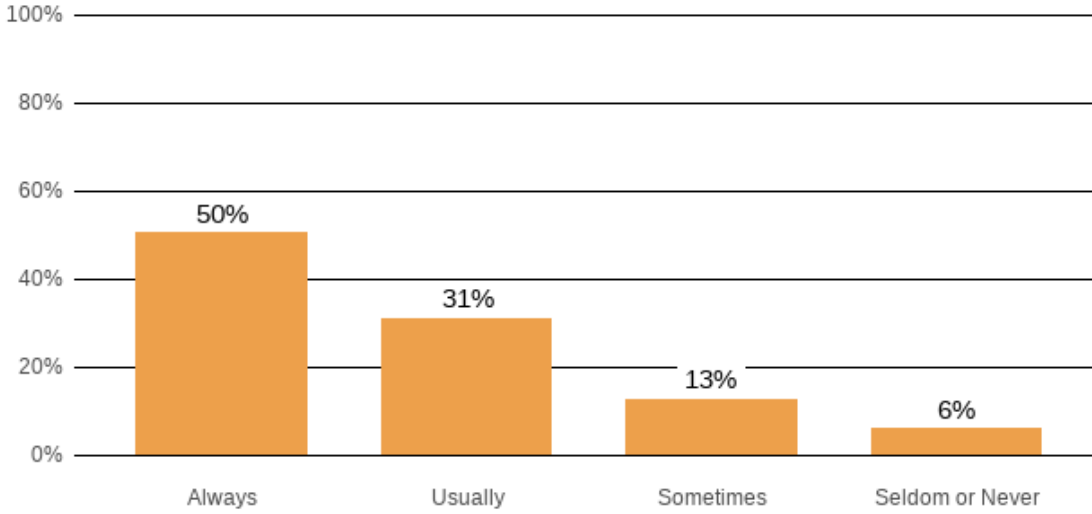


Table 74. If your child uses mental health services, does the mental health professional understand your child's needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	50%	31%	13%	6%	4990
LA	66%	23%	9%	2%	197
MO	57%	27%	11%	5%	100
OR	48%	30%	15%	7%	283
WI	50%	34%	11%	5%	356
Weighted NCI-IDD Average	50%	31%	13%	6%	5926

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

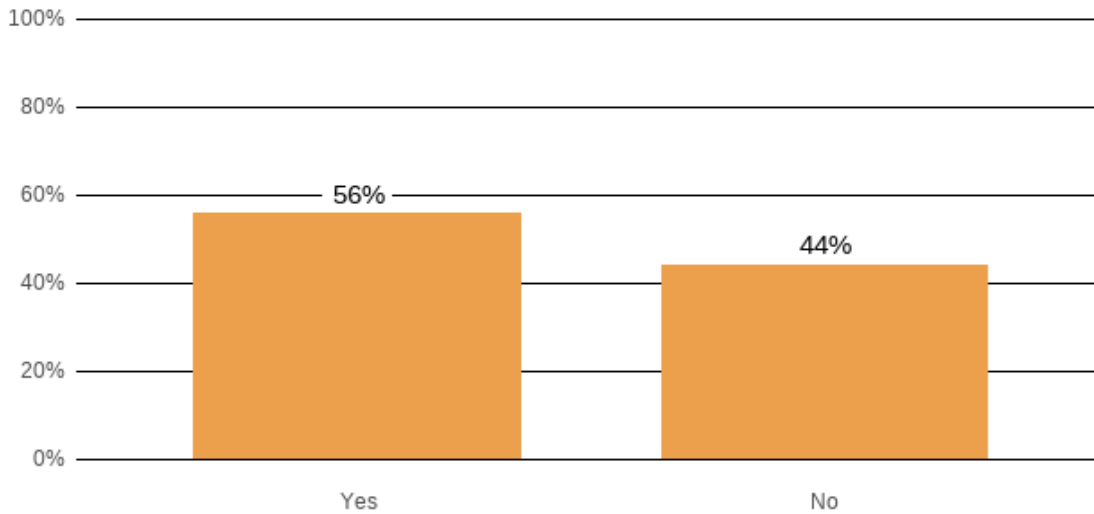


Table 75. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

State	Yes	No	N
CA	53%	47%	2187
LA	76%	24%	119
MO	60%	40%	40
OR	57%	43%	120
WI	66%	34%	131
Weighted NCI-IDD Average	56%	44%	2597

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

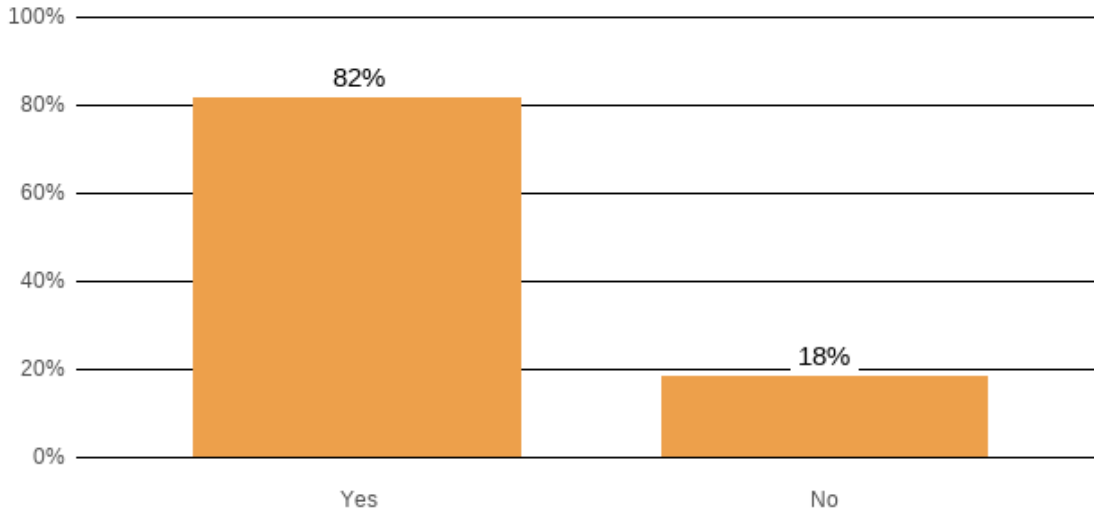


Table 76. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or natural disaster?

State	Yes	No	N
CA	80%	20%	7098
LA	92%	8%	391
MO	87%	13%	157
OR	79%	21%	422
WI	88%	12%	564
Weighted NCI-IDD Average	82%	18%	8632

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

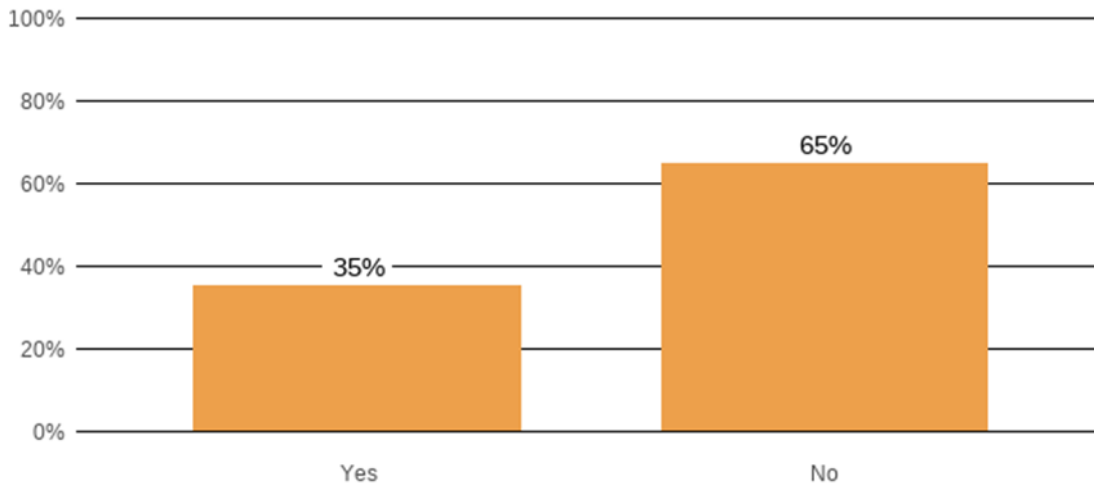


Table 77. Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child's case manager/service coordinator?

State	Yes	No	N
CA	32%	68%	7311
LA	64%	36%	389
MO	51%	49%	161
OR	50%	50%	431
WI	31%	69%	583
Weighted NCI-IDD Average	35%	65%	8875

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

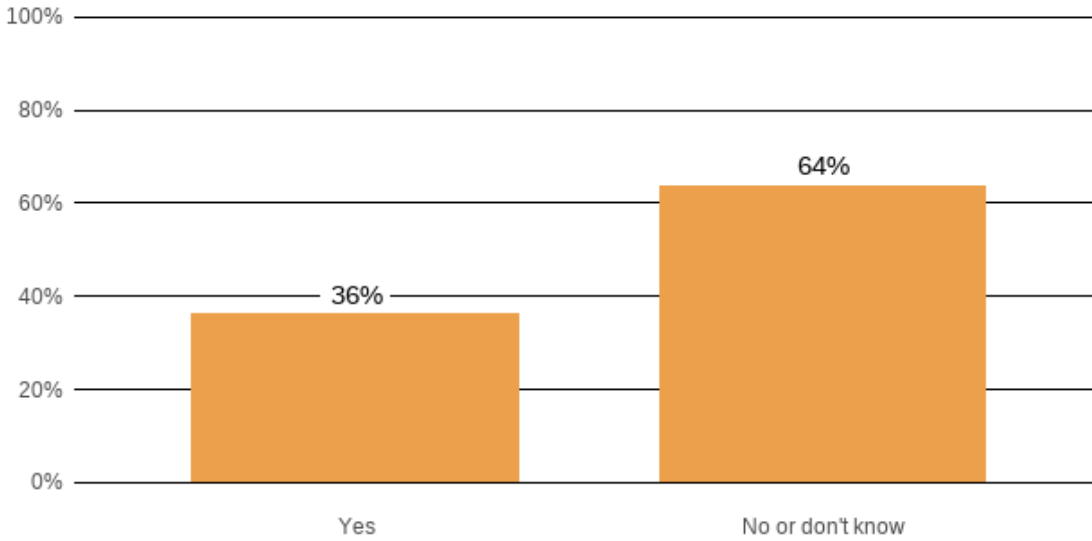


Table 78. Do you know how to file a complaint or grievance about provider agencies or staff?

State	Yes	No or don't know	N
CA	32%	68%	8060
LA	44%	56%	416
MO	41%	59%	172
OR	51%	49%	476
WI	57%	43%	614
Weighted NCI-IDD Average	36%	64%	9738

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

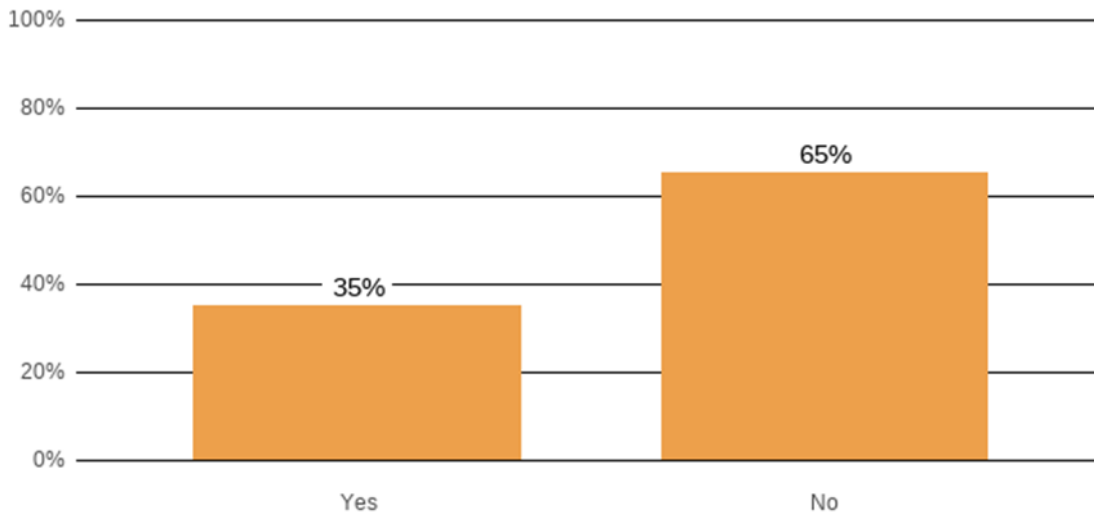


Table 79. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

State	Yes	No	N
CA	33%	67%	994
LA	55%	45%	31
OR	53%	47%	36
WI	44%	56%	32
Weighted NCI-IDD Average	35%	65%	1105

Table note: The following states had an N of less than 20 and were not shown: MO

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

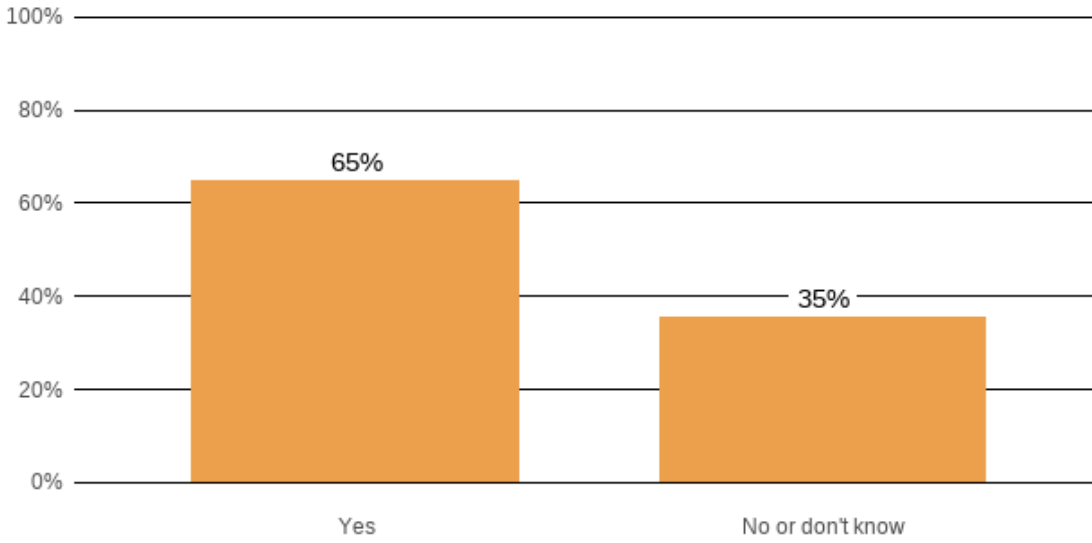


Table 80. Do you know how to report abuse or neglect related to your child?

State	Yes	No or don't know	N
CA	61%	39%	8016
LA	74%	26%	420
MO	76%	24%	170
OR	84%	16%	479
WI	78%	22%	616
Weighted NCI-IDD Average	65%	35%	9701

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

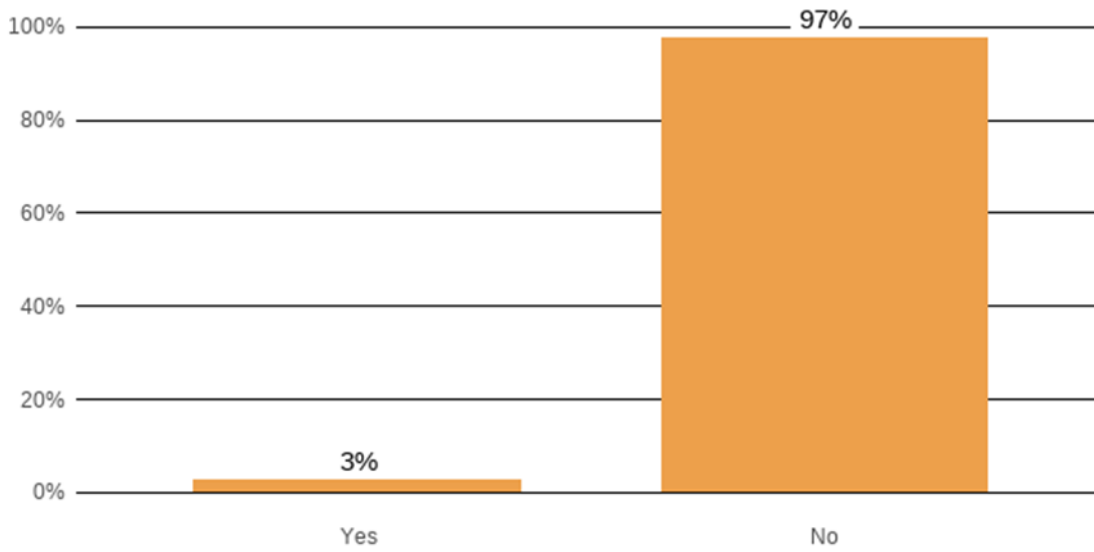


Table 81. Within the past 12 months, was a report of abuse or neglect filed on behalf of your child?

State	Yes	No	N
CA	2%	98%	7592
LA	2%	98%	408
MO	5%	95%	167
OR	3%	97%	462
WI	2%	98%	610
Weighted NCI-IDD Average	3%	97%	9239

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

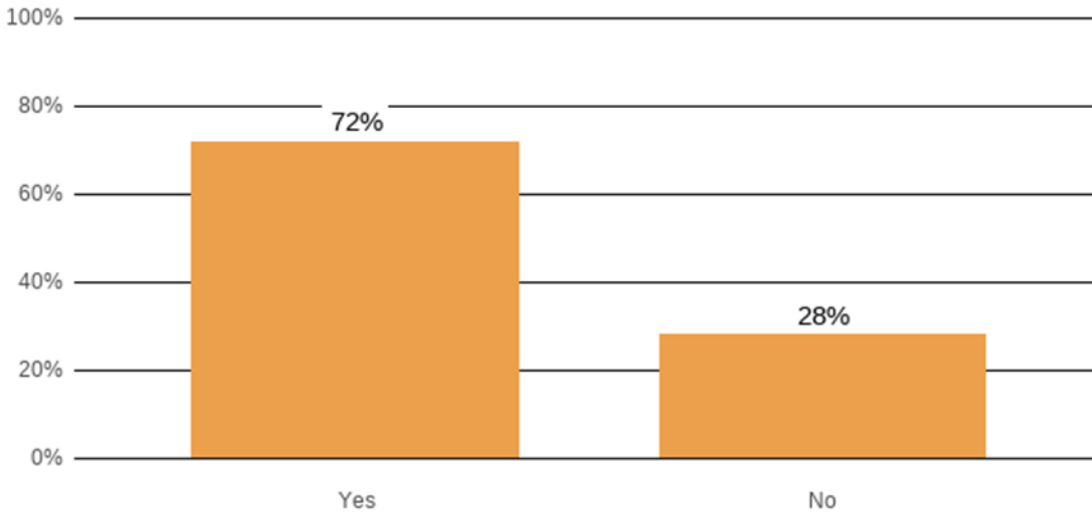


Table 82. If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?

State	Yes	No	N
CA	72%	28%	123
Weighted NCI-IDD Average	72%	28%	155

Table note: The following states had an N of less than 20 and were not shown: LA, MO, OR, WI

Satisfaction With Services and Supports

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

“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?

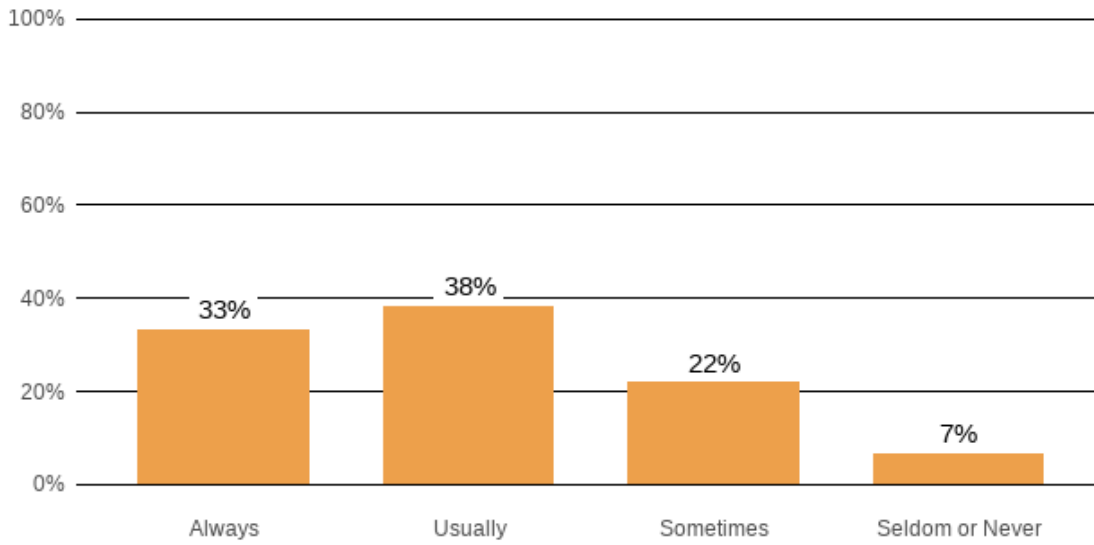


Table 83. Overall, are you satisfied with the services and supports your child currently receives?

State	Always	Usually	Sometimes	Seldom or Never	N
CA	32%	37%	24%	7%	7830
LA	51%	31%	15%	3%	402
MO	29%	48%	15%	8%	168
OR	32%	46%	19%	3%	476
WI	39%	43%	14%	4%	618
Weighted NCI-IDD Average	33%	38%	22%	7%	9494

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

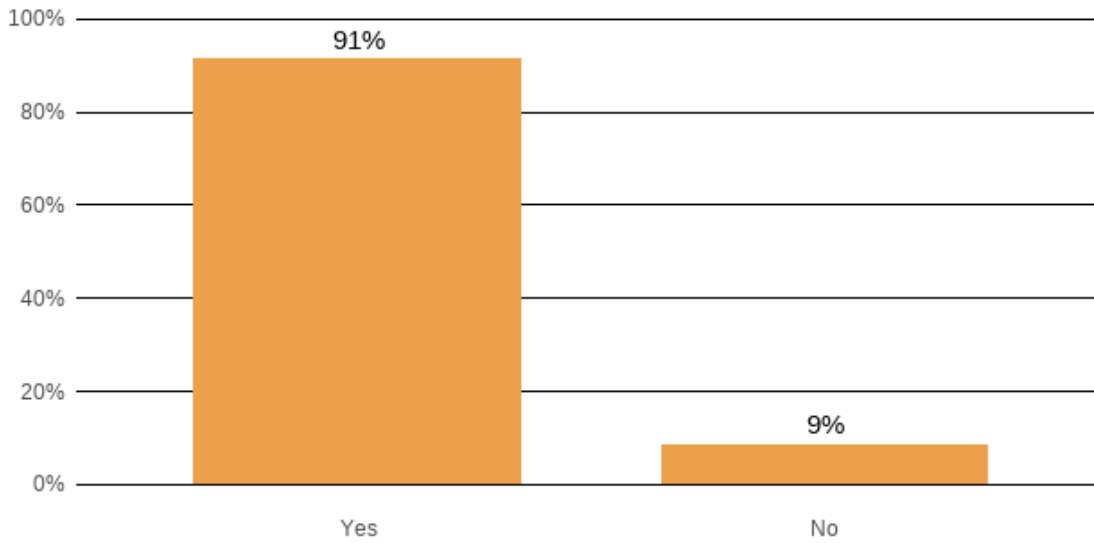


Table 84. Do you feel that services and supports have made a positive difference in the life of your child?

State	Yes	No	N
CA	90%	10%	7238
LA	94%	6%	375
MO	94%	6%	159
OR	97%	3%	459
WI	95%	5%	581
Weighted NCI-IDD Average	91%	9%	8812

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

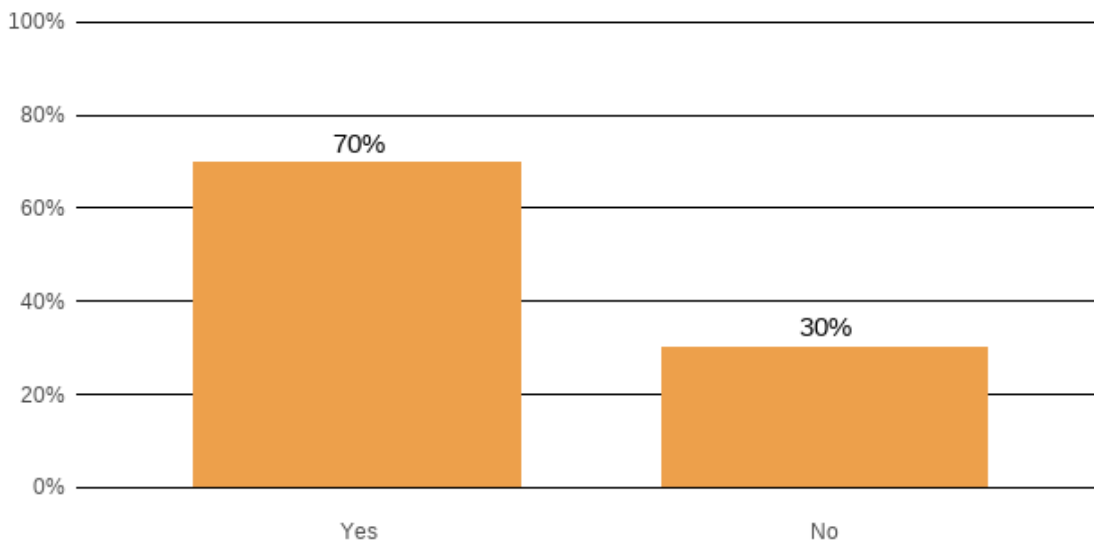


Table 85. Have services and supports reduced your family’s out-of-pocket expenses for your child’s care?

State	Yes	No	N
CA	68%	32%	7033
LA	66%	34%	358
MO	66%	34%	150
OR	77%	23%	445
WI	86%	14%	592
Weighted NCI-IDD Average	70%	30%	8578

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

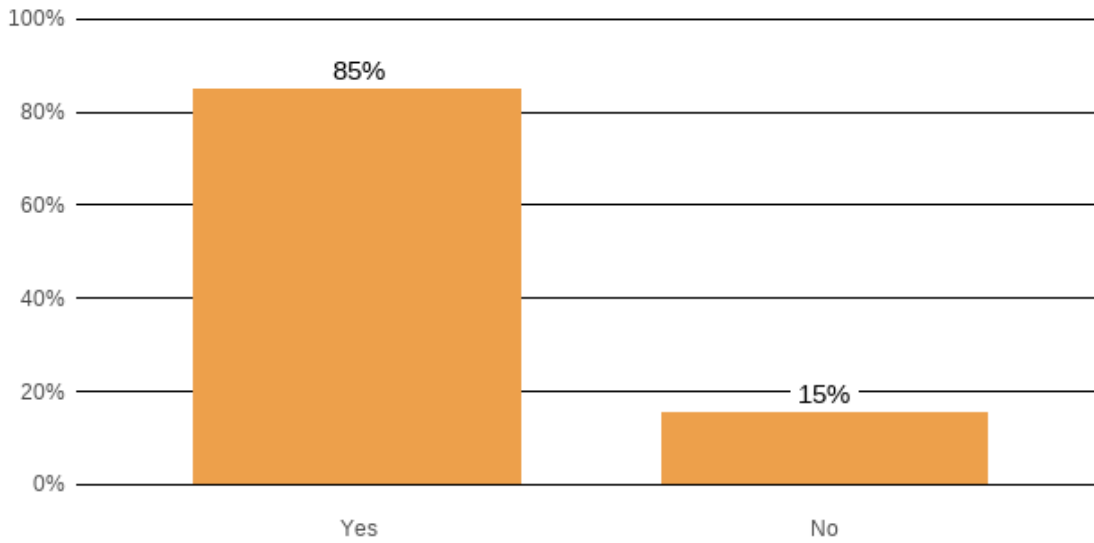


Table 86. Do you feel that family supports have improved your ability to care for your child?

State	Yes	No	N
CA	83%	17%	7142
LA	90%	10%	366
MO	85%	15%	158
OR	92%	8%	453
WI	90%	10%	587
Weighted NCI-IDD Average	85%	15%	8706

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

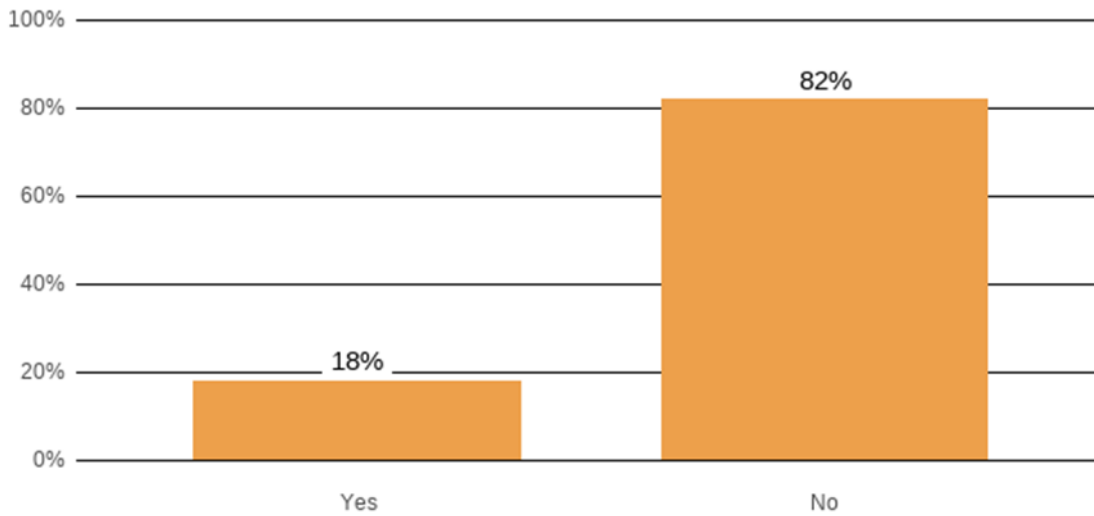


Table 87. Have the services or supports that your child received during the past 12 months been reduced, suspended, or terminated?

State	Yes	No	N
CA	18%	82%	7032
LA	25%	75%	374
MO	15%	85%	158
OR	16%	84%	464
WI	17%	83%	596
Weighted NCI-IDD Average	18%	82%	8624

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?

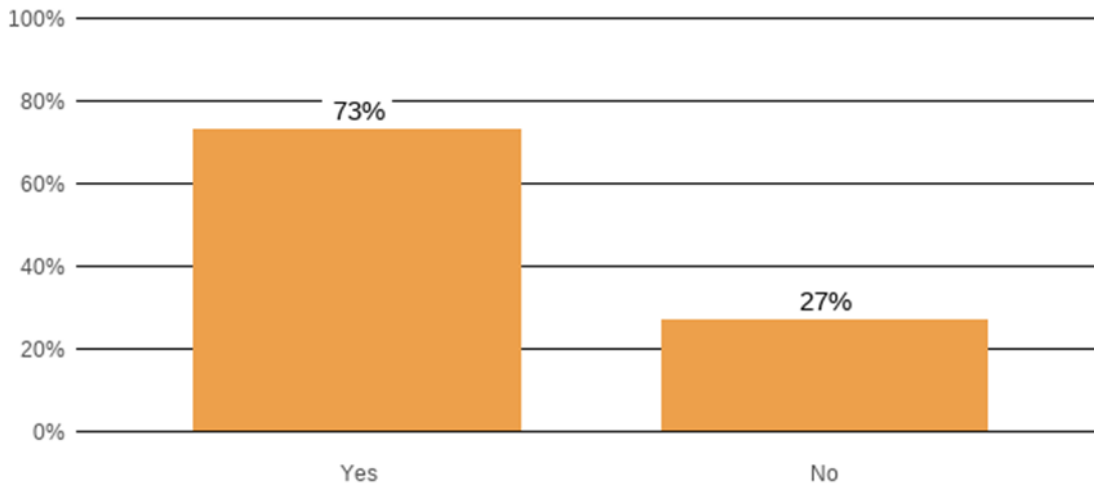


Table 88. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family or your child negatively?

State	Yes	No	N
CA	72%	28%	1063
LA	65%	35%	75
OR	91%	9%	64
WI	76%	24%	93
Weighted NCI-IDD Average	73%	27%	1313

Table note: The following states had an N of less than 20 and were not shown: MO

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

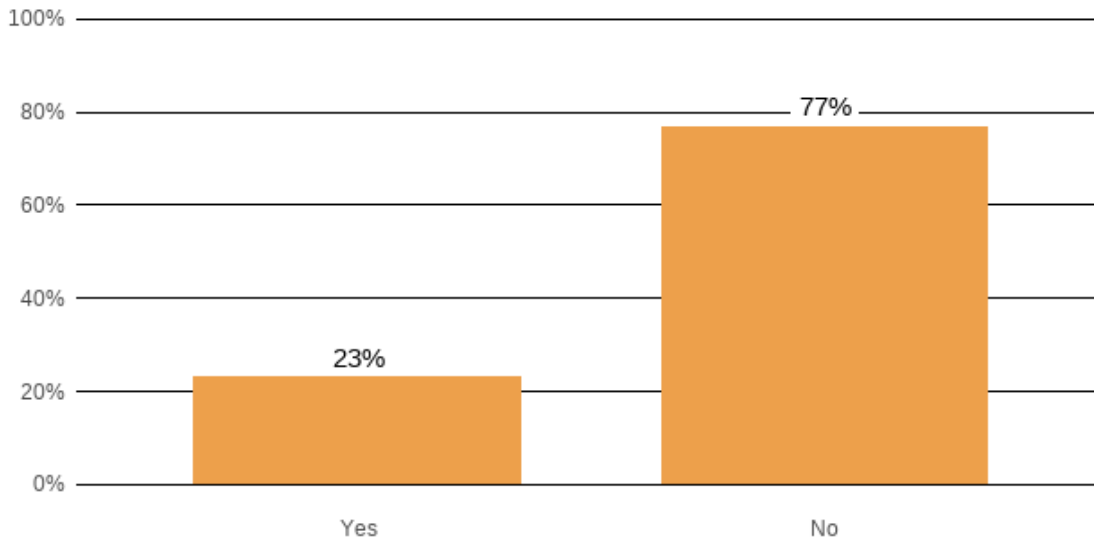


Table 89. Have the services or supports that your child received been increased in the past 12 months?

State	Yes	No	N
CA	23%	77%	7165
LA	21%	79%	371
MO	17%	83%	160
OR	27%	73%	441
WI	27%	73%	568
Weighted NCI-IDD Average	23%	77%	8705

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

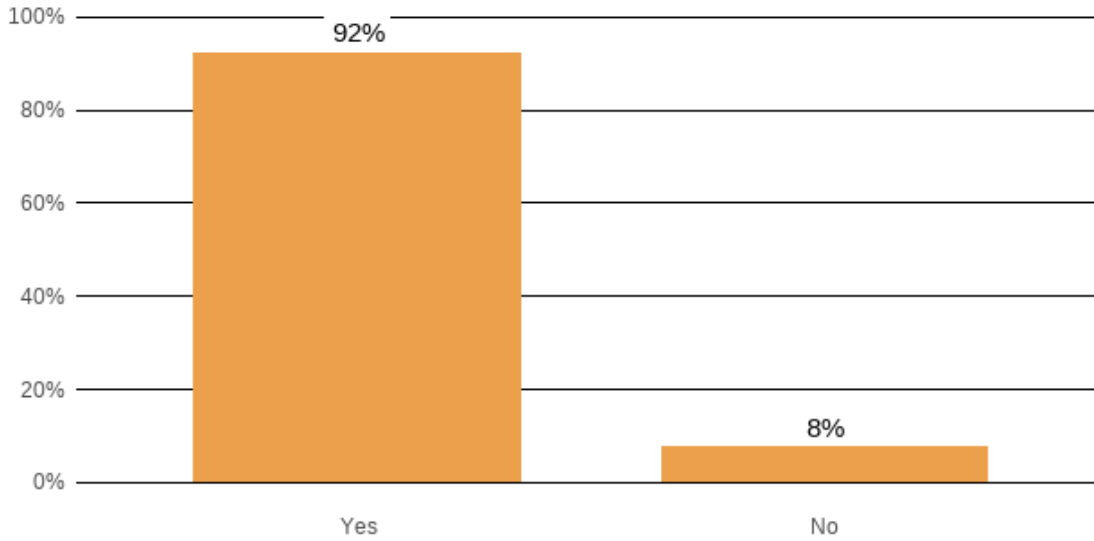


Table 90. Are services and supports helping your child to live a good life?

State	Yes	No	N
CA	91%	9%	6898
LA	93%	7%	362
MO	94%	6%	153
OR	96%	4%	439
WI	96%	4%	570
Weighted NCI-IDD Average	92%	8%	8422

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/>.

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 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.

Family Survey Sub-Domains and Concern Statements

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

How NCI-IDD Data Are Used

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

Caution and Limitations

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

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

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

Methodology

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

Sampling & Administration

States were asked to administer the 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%.¹

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.

¹ See “Response Rates” for information on total surveys mailed and received by states as well as each state’s margin of error.

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.

Response Rates

During 2023-24, 5 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.

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.

Child Family Survey: State Response Rates

State	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
CA	103926	84000	8277	10%	1.0%	73%	27%
LA	7550	7466	446	6%	4.3%	61%	39%
MO	3751	1500	174	12%	6.8%	77%	23%
OR	3993	3993	491	12%	4.1%	84%	16%
WI	13000	13000	662	5%	3.5%	0%	100%
Total	132220	109959	10050	9%	0.9%	68%	32%