

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



National Report 2024-25

Oregon

Child Family Survey (CFS)





Human Services Research Institute

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List of Acronyms Used in This Report

CFS Child Family Survey

CMS Centers for Medicare & Medicaid Services

HSRI Human Services Research Institute

IDD Intellectual and developmental disabilities

NASDDDS National Association of State Directors of Developmental Disabilities Services

NCI National Core Indicators

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Executive Summary

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

The National Core Indicators (NCI) 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 2024-25 data collection cycle, 10 states submitted a valid sample of Child Family Survey data: Arizona, Indiana, Louisiana, Minnesota, Missouri, Oregon, South Dakota, Tennessee, Texas, Wisconsin. This Final Report provides a summary of results based on data submitted by June 30, 2025.

What is the NCI-IDD Child Family Survey?

The NCI-IDD Child Family Survey is used to gather data on family outcomes. It is mailed to families who have a child who lives with the respondent and receives at least one service in addition to case management from the state DD agency. Some states survey respondents who have a “child” up to 22 years old who receive child services. The survey collects demographic information on both the individual receiving services (‘child’) as well as the person who fills out the survey (the ‘respondent’) and information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable. Please note that while the term “case manager” is used throughout this report, the same role may also be referred to as “service coordinator” or “supports coordinator” depending on the state. Important note on responses: All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses, and personal characteristics.

What is included in this report?

This report includes this state’s Child Family Survey data compared to the NCI-IDD Average. State outcomes that are significantly higher or lower than the NCI-IDD Average are indicated with an arrow:

- Outcomes where the state is significantly above the NCI-IDD average are denoted with an up arrow ↑;
- Outcomes where the state is significantly below the NCI-IDD average are denoted with a down arrow ↓.

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

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.

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

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

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

Results

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

Presentation of the Data

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

- Demographic and outcome results are shown in table form showing state outcomes and the NCI-IDD Average.
- 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.
- 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.
- 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 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.
- **Oregon been abbreviated throughout the report to OR.**
- **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.

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
OR	60%	40%	749
Weighted NCI-IDD Average	63%	37%	3957

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
OR	11.7	761
Weighted NCI-IDD Average	10.4	4,088

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
OR	66%	33%	1%	757
Weighted NCI-IDD Average	66%	34%	0%	4078

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
OR	6%	9%	5%	1%	77%	15%	2%	3%
Weighted NCI-IDD Average	3%	5%	14%	1%	60%	28%	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 Disability	Mood Illness/Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy
OR	53%	30%	63%	8%
Weighted NCI-IDD Average	44%	20%	60%	11%

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 or Neurological Disorder	Chemical Dependency
OR	5%	4%	5%	13%	1%
Weighted NCI-IDD Average	7%	5%	6%	20%	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
OR	10%	0%	8%	35%
Weighted NCI-IDD Average	9%	0%	2%	31%

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
OR	9%	4%	1%	3%	3%
Weighted NCI-IDD Average	10%	4%	2%	4%	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)
OR	24%	1%	13%	33%	6%
Weighted NCI-IDD Average	19%	1%	11%	27%	10%

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
OR	27%	3%	2%	34%
Weighted NCI-IDD Average	34%	3%	1%	33%

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
OR	90%	3%	0%	0%	0%	1%	6%	763
Weighted NCI-IDD Average	91%	6%	0%	0%	0%	1%	2%	4057

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
OR	72%	13%	2%	6%	8%	759
Weighted NCI-IDD Average	67%	19%	3%	7%	4%	4011

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
OR	20%	48%	31%	752
Weighted NCI-IDD Average	35%	42%	23%	4006

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; Frequent or Severe Enough to Require Regular Assistance	N
OR	7%	40%	53%	764
Weighted NCI-IDD Average	8%	40%	53%	4054

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
OR	87%	6%	1%	0%	1%	0%	6%	761
Weighted NCI-IDD Average	84%	13%	0%	0%	0%	0%	2%	4019

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

Table 12. Respondent’s Age

State	Under 34	35 – 54	55 – 74	75 or Older	N
OR	7%	70%	21%	1%	769
Weighted NCI-IDD Average	14%	71%	14%	1%	4081

Table 13. Respondent’s Health

State	Excellent	Very good	Good	Fair	Poor	N
OR	10%	30%	42%	16%	3%	767
Weighted NCI-IDD Average	12%	33%	38%	15%	1%	4084

Table 14. Respondent's Relationship to Child

State	Parent (Biological, Adoptive, or Foster)	Sibling	Grandparent	Other	N
OR	91%	0%	8%	1%	769
Weighted NCI-IDD Average	92%	0%	6%	1%	4089

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
OR	66%	7%	29%
Weighted NCI-IDD Average	68%	19%	16%

Table 16. Number of Adults in Household

State	One	Two	Three	Four or More	N
OR	19%	54%	20%	8%	764
Weighted NCI-IDD Average	21%	58%	15%	6%	4031

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

State	One	Two	Three	Four or More	N
OR	43%	35%	14%	9%	751
Weighted NCI-IDD Average	35%	37%	17%	11%	4010

Table 18. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
OR	9%	16%	6%	19%	51%	758
Weighted NCI-IDD Average	10%	17%	8%	16%	49%	4050

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 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	Prefer Not to Say	N
OR	7%	5%	8%	15%	14%	39%	12%	754
Weighted NCI-IDD Average	7%	8%	10%	16%	14%	31%	15%	4028

Table 20. Residential Designation

State	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
OR	72%	28%	733
Weighted NCI-IDD Average	74%	26%	3835

Services and Supports Received

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

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

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

State	Financial Support	In Home Support	Out-of-Home Respite Care	Early Intervention
OR	15%	82%	33%	5%
Weighted NCI-IDD Average	18%	39%	24%	15%

Table 21b. Services and Supports Received from ID/DD Agency (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	Transportation	Mental or Behavioral Health Care or Other Treatments or Therapies	Self-Direction or Fiscal Intermediary Services
OR	28%	75%	65%
Weighted NCI-IDD Average	18%	75%	38%

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

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	Social Security Payments (SSI or SSB)	Services or Supports from Other Agencies or Organizations
OR	31%	72%
Weighted NCI-IDD Average	38%	66%

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.

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	36%	43%	16%	4%	741
Weighted NCI-IDD Average	39%	35%	20%	6%	3865

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	27%	48%	22%	4%	754
Weighted NCI-IDD Average	29%	42%	25%	4%	3919

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↑	90%	6%	3%	1%	761
Weighted NCI-IDD Average	86%	8%	4%	3%	4000

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↓	65%	27%	7%	2%	752
Weighted NCI-IDD Average	70%	21%	7%	2%	3783

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
OR	25%	32%	26%	17%	623
Weighted NCI-IDD Average	28%	30%	24%	18%	3211

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
OR	59%	62%	51%	45%	47%
Weighted NCI-IDD Average	50%	54%	44%	44%	47%

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
OR	53%	56%	53%	9%
Weighted NCI-IDD Average	50%	53%	52%	9%

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

State	Yes	No	N
OR	29%	71%	626
Weighted NCI-IDD Average	28%	72%	3494

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

Table 30. Does your child have a service plan?

State	Yes	No	N
OR ↑	86%	14%	661
Weighted NCI-IDD Average	69%	31%	3344

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

State	Yes	No	N
OR	87%	13%	501
Weighted NCI-IDD Average	88%	12%	2048

Table 32. Did you or someone else in your family (besides your child with a disability) help make the plan?

State	Yes	No	N
OR ↑	94%	6%	549
Weighted NCI-IDD Average	87%	13%	2186

Table 33. Did your child help make the plan?

State	Yes	No	N
OR	24%	76%	548
Weighted NCI-IDD Average	21%	79%	2213

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

State	Yes	No	N
OR	93%	7%	525
Weighted NCI-IDD Average	91%	9%	2077

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
OR	27%	73%	638
Weighted NCI-IDD Average	29%	71%	3376

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

State	Yes	No	N
OR	90%	10%	98
Weighted NCI-IDD Average	82%	18%	646

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

State	Yes	No	N
OR ↑	55%	45%	98
Weighted NCI-IDD Average	38%	62%	643

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.

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

State	Yes	No	N
OR	81%	19%	490
Weighted NCI-IDD Average	83%	17%	2000

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

State	Yes	No	N
OR	67%	33%	686
Weighted NCI-IDD Average	72%	28%	3415

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
OR	69%	48%	23%	21%
Weighted NCI-IDD Average	61%	42%	30%	23%

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 Use Assistive Technology	Other
OR	33%	25%	16%	18%
Weighted NCI-IDD Average	30%	26%	18%	24%

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↓	33%	44%	19%	5%	655
Weighted NCI-IDD Average	44%	36%	15%	5%	3089

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↓	35%	37%	19%	9%	445
Weighted NCI-IDD Average	45%	30%	16%	9%	2295

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
OR ↓	21%	29%	21%	29%	597
Weighted NCI-IDD Average	29%	26%	20%	26%	2499

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	60%	22%	6%	11%	374
Weighted NCI-IDD Average	62%	21%	8%	8%	1640

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	56%	35%	8%	2%	724
Weighted NCI-IDD Average	57%	33%	8%	2%	3453

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
OR ↓	53%	35%	10%	3%	747
Weighted NCI-IDD Average	63%	26%	8%	3%	3668

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

State	Yes	No	N
OR	81%	19%	397
Weighted NCI-IDD Average	79%	21%	1934

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	81%	17%	2%	0%	739
Weighted NCI-IDD Average	81%	16%	2%	1%	3643

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

State	Yes	No	N
OR	46%	54%	732
Weighted NCI-IDD Average	44%	56%	3836

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
OR	94%	6%	752
Weighted NCI-IDD Average	94%	6%	3957

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

State	The Internet Always Works, The Connection Is Good	The Internet Sometimes Works, 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
OR	76%	22%	2%	757
Weighted NCI-IDD Average	76%	22%	2%	3955

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↓	58%	34%	6%	3%	709
Weighted NCI-IDD Average	66%	27%	5%	2%	3202

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	76%	20%	3%	1%	729
Weighted NCI-IDD Average	75%	20%	4%	1%	3386

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
OR	41%	36%	15%	7%	388
Weighted NCI-IDD Average	45%	28%	18%	10%	2047

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
OR ↓	46%	38%	13%	3%	715
Weighted NCI-IDD Average	51%	35%	11%	2%	3261

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

State	Yes	No	N
OR	27%	73%	677
Weighted NCI-IDD Average	28%	72%	2988

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

State	Yes	No	N
OR ↓	62%	38%	644
Weighted NCI-IDD Average	76%	24%	2892

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.

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
OR ↑	70%	21%	4%	5%	598
Weighted NCI-IDD Average	62%	22%	7%	9%	2595

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↑	70%	19%	5%	5%	659
Weighted NCI-IDD Average	62%	20%	8%	10%	2494

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↑	69%	20%	6%	4%	645
Weighted NCI-IDD Average	60%	23%	5%	11%	2399

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

State	Yes	No, Didn't Choose but Can Change Case Manager/Service Coordinator if Wanted	No, Didn't Choose and Cannot Change Case Manager/Service Coordinator if Wanted	N
OR ↑	42%	46%	12%	619
Weighted NCI-IDD Average	23%	61%	16%	2997

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.

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.

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

State	Yes	No	N
OR ↑	85%	15%	747
Weighted NCI-IDD Average	80%	20%	3899

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
OR	11%	36%	24%	30%	42%
Weighted NCI-IDD Average	10%	29%	19%	28%	32%

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

State	Yes	No	N
OR	86%	14%	756
Weighted NCI-IDD Average	86%	14%	3915

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

State	Yes	No	N
OR	79%	21%	583
Weighted NCI-IDD Average	75%	25%	2908

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

State	Yes	No	N
OR	21%	79%	666
Weighted NCI-IDD Average	19%	81%	3305

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↓	74%	20%	4%	2%	744
Weighted NCI-IDD Average	79%	16%	3%	2%	3861

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
OR ↓	56%	31%	11%	2%	750
Weighted NCI-IDD Average	64%	26%	9%	1%	3899

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↓	66%	20%	9%	6%	752
Weighted NCI-IDD Average	75%	16%	5%	4%	3885

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↓	51%	29%	16%	5%	701
Weighted NCI-IDD Average	61%	25%	10%	4%	3632

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	90%	7%	2%	2%	574
Weighted NCI-IDD Average	91%	5%	2%	2%	2893

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
OR	91%	7%	1%	1%	572
Weighted NCI-IDD Average	91%	6%	2%	1%	2869

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
OR ↓	42%	25%	16%	16%	660
Weighted NCI-IDD Average	50%	24%	11%	14%	3073

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
OR	52%	29%	14%	5%	503
Weighted NCI-IDD Average	58%	29%	10%	3%	2269

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

State	Yes	No	N
OR	68%	32%	190
Weighted NCI-IDD Average	67%	33%	1073

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
OR	85%	15%	682
Weighted NCI-IDD Average	88%	12%	3594

Table 77. 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?

State	Yes	No	N
OR ↑	54%	46%	699
Weighted NCI-IDD Average	43%	57%	3602

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
OR	52%	48%	751
Weighted NCI-IDD Average	49%	51%	3924

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
OR	45%	55%	66
Weighted NCI-IDD Average	46%	54%	384

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

State	Yes	No or Don't Know	N
OR ↑	81%	19%	750
Weighted NCI-IDD Average	76%	24%	3930

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

State	Yes	No	N
OR	4%	96%	727
Weighted NCI-IDD Average	3%	97%	3792

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

State	Yes	No	N
OR	71%	29%	24
Weighted NCI-IDD Average	83%	17%	91

Family Satisfaction

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR ↓	38%	45%	15%	3%	751
Weighted NCI-IDD Average	47%	36%	14%	3%	3876

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

State	Yes	No	N
OR	97%	3%	727
Weighted NCI-IDD Average	96%	4%	3708

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

State	Yes	No	N
OR	78%	22%	699
Weighted NCI-IDD Average	80%	20%	3593

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

State	Yes	No	N
OR	93%	7%	721
Weighted NCI-IDD Average	92%	8%	3666

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
OR	16%	84%	711
Weighted NCI-IDD Average	18%	82%	3651

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
OR	77%	23%	94
Weighted NCI-IDD Average	73%	27%	568

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

State	Yes	No	N
OR	28%	72%	667
Weighted NCI-IDD Average	26%	74%	3532

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

State	Yes	No	N
OR	97%	3%	685
Weighted NCI-IDD Average	97%	3%	3598