



Child Family Survey (CFS) State Report

2023-24 Oregon Report



Table of Contents

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

Table 21a. Services and Supports Received from ID/DD Agency.....	23
Table 21b. Services and Supports Received from ID/DD Agency (continued)	23
Table 22. Additional Services and Supports Received (not from the ID/DD Agency)	23
Main Survey Results	24
Information and Planning	25
Table 23. Do you have enough information to take part in planning services for your child?	26
Table 24. Is the information you get about services and supports easy to understand?	26
Table 25. Do you get information about services and supports in your preferred language? ...	26
Table 26. Does the case manager/service coordinator listen to your family's choices and opinions?	26
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.)?	27
Table 28a. Do you need help planning for your child's future in any of these areas?	27
Table 28b. Do you need help planning for your child's future in any of these areas? (continued)	27
Table 29. Has your family learned about alternatives to guardianship/conservatorship?	28
Table 30. Does your child have a service plan?	28
Table 31. Does the plan include all the services and supports your child needs?.....	28
Table 32. Did you or another family member help make the plan?	28
Table 33. Did your child help make the plan?	29
Table 34. Do you feel like your family had enough say or input in making the plan?	29
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)?.....	29
Table 36. If your child has a transition plan, did you or another family member help make the plan?	29
Table 37. If your child has a transition plan, did your child help make the plan?	29
Access and Delivery of Services and Supports.....	30
Table 38. Does your child get all the services listed in the plan?	31
Table 39. Does your family get the supports and services it needs?	31
Table 40a. If your child does not get the support and services needed, what additional services does your child need?	31
Table 40b. If your child does not get the support and services needed, what additional services does your child need? (continued)	32
Table 41. Do services and supports change when your family's needs change?	32
Table 42. Does your child have the special equipment or accommodations they need?	32
Table 43. If you need respite services, how often are you able to get them when needed?.....	33

Table 44. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?	33
Table 45. Are you able to contact your child’s support workers when you want?	33
Table 46. Are you able to contact your child’s case manager or service coordinator when you want?	33
Table 47. Do service providers for your child work together to provide support?	34
Table 48. Are services delivered in a way that is respectful of your family’s culture?	34
Table 49. Does your child use technology in their everyday life to help them do things on their own?	34
Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home?	34
Table 51. How well does the internet work in your home?	34
Workforce	35
Table 52. Do support workers come and go when they are supposed to?	36
Table 53. Do support workers speak to you in a way you understand?	36
Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child?	36
Table 55. Do support workers have the right information and skills to meet your family’s needs?	36
Table 56. Do your child’s support workers change too often? Is there too much “turnover” of support workers?	37
Table 57. Is there always a staff person available to support your child when support is needed?	37
Choice, Decision Making and Control	38
Table 58. Can someone in your family choose or change the provider agency that provides your child’s services?	39
Table 59. Can someone in your family choose or change your child’s support workers?	39
Table 60. Can someone in your family directly manage support staff?	39
Table 61. Did you, your child, or someone else in your family choose your child’s case manager/service coordinator?	39
Community Connections	40
Table 62. Does your child do things in the community?	41
Table 63. What makes it hard to do things in the community?	41
Table 64. Does your child spend time with children who do not have developmental disabilities?	41
Table 65. In your community, are there resources that your family and child can use that are not provided by the ID/DD agency?	41
Table 66. Does your family take part in any family-to-family networks in your community?	41

Health, Welfare, and Safety..... 42

Table 67. Can your child see a primary care provider (doctor, registered nurse, etc.) when needed? 43

Table 68. Does your child's primary care doctor understand your child's needs related to their disability? 43

Table 69. Can your child go to the dentist when needed? 43

Table 70. Does your child's dentist understand your child's needs related to their disability? .. 43

Table 71. If your child takes prescription medications, do you know what they're for? 44

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)? 44

Table 73. Can your child get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling) 44

Table 74. If your child uses mental health services, does the mental health professional understand your child's needs related to their disability? 44

Table 75. If you asked for crisis or emergency services during the past 12 months, were services provided when needed? 45

Table 76. Do you feel prepared to handle the needs of your child in an emergency such as a medical emergency or natural disaster? 45

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? 45

Table 78. Do you know how to file a complaint or grievance about provider agencies or staff? 45

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? 46

Table 80. Do you know how to report abuse or neglect related to your child? 46

Table 81. Within the past 12 months, was a report of abuse or neglect filed on behalf of your child? 46

Table 82. If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner? 46

Family Satisfaction 47

Table 83. Overall, are you satisfied with the services and supports your child currently receives? 48

Table 84. Do you feel that services and supports have made a positive difference in the life of your child? 48

Table 85. Have services and supports reduced your family's out-of-pocket expenses for your child's care? 48

Table 86. Do you feel that family supports have improved your ability to care for your child?.. 48

Table 87. Have the services or supports that your child received during the past 12 months been reduced, suspended, or terminated?	49
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?	49
Table 89. Have the services or supports that your child received been increased in the past 12 months?	49
Table 90. Are services and supports helping your child to live a good life?	49

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 a summary of results based on data submitted by June 30, 2024.

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.

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.

- 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.
- **Oregon has 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.
- 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.

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	41%	59%	484
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
OR	12.9	485
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
OR	64%	35%	1%	486
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
OR	5%	7%	5%	2%	80%	15%	2%	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 Disability	Mood Illness/Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy
OR	56%	28%	56%	10%
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 or Neurological Disorder	Chemical Dependency
OR	7%	6%	6%	19%	1%
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
OR	12%	1%	9%	29%
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
OR	9%	5%	0%	4%	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)
OR	25%	2%	15%	24%	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
OR	31%	2%	1%	35%
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
OR	95%	2%	0%	0%	0%	1%	2%	455
Weighted NCI-IDD Average	83%	10%	0%	0%	0%	0%	6%	9800

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	68%	13%	1%	6%	11%	478
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
OR	23%	43%	34%	478
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; Frequent or Severe Enough to Require Regular Assistance	N
OR	5%	41%	54%	487
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
OR	88%	8%	1%	0%	0%	0%	3%	473
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 34	35 – 54	55 – 74	75 or Older	N
OR	5%	73%	21%	2%	491
Weighted NCI-IDD Average	11%	74%	14%	1%	9943

Table 13. Respondent’s Health

State	Excellent	Very good	Good	Fair	Poor	N
OR	9%	30%	42%	17%	2%	486
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
OR	91%	0%	8%	1%	486
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
OR	61%	8%	32%
Weighted NCI-IDD Average	58%	26%	17%

Table 16. Number of Adults in Household

State	One	Two	Three	Four or More	N
OR	16%	51%	22%	10%	484
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
OR	42%	38%	12%	9%	465
Weighted NCI-IDD Average	37%	39%	16%	8%	9700

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	8%	15%	5%	21%	50%	480
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 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	Prefer Not to Say	N
OR	6%	5%	9%	18%	13%	37%	12%	478
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
OR	76%	24%	478
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.

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	18%	78%	38%	1%
Weighted NCI-IDD Average	20%	36%	30%	11%

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	29%	70%	69%
Weighted NCI-IDD Average	7%	35%	26%

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 (SSI/SSB)	Services or Supports From Other Agencies or Organizations
OR	39%	74%
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.

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	30%	46%	19%	4%	469
Weighted NCI-IDD Average	27%	33%	28%	12%	9262

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	25%	50%	22%	4%	475
Weighted NCI-IDD Average	25%	39%	29%	7%	9332

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	87%	9%	3%	2%	486
Weighted NCI-IDD Average	77%	12%	7%	4%	9705

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	64%	27%	7%	2%	474
Weighted NCI-IDD Average	57%	26%	12%	5%	9350

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	23%	36%	24%	18%	400
Weighted NCI-IDD Average	21%	26%	26%	27%	7762

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	61%	62%	50%	44%	45%
Weighted NCI-IDD Average	53%	55%	45%	43%	45%

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	55%	55%	50%	7%
Weighted NCI-IDD Average	58%	55%	58%	7%

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

State	Yes	No	N
OR	34%	66%	414
Weighted NCI-IDD Average	22%	78%	8078

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	85%	15%	413
Weighted NCI-IDD Average	77%	23%	8498

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

State	Yes	No	N
OR	79%	21%	300
Weighted NCI-IDD Average	80%	20%	5228

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

State	Yes	No	N
OR	92%	8%	338
Weighted NCI-IDD Average	83%	17%	5808

Table 33. Did your child help make the plan?

State	Yes	No	N
OR	28%	72%	343
Weighted NCI-IDD Average	18%	82%	5838

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

State	Yes	No	N
OR	91%	9%	322
Weighted NCI-IDD Average	86%	14%	5425

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	25%	75%	406
Weighted NCI-IDD Average	33%	67%	7978

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%	92
Weighted NCI-IDD Average	81%	19%	2325

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

State	Yes	No	N
OR	51%	49%	90
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.

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

State	Yes	No	N
OR	81%	19%	308
Weighted NCI-IDD Average	81%	19%	5259

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

State	Yes	No	N
OR	66%	34%	441
Weighted NCI-IDD Average	64%	36%	7988

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	57%	49%	32%	22%
Weighted NCI-IDD Average	48%	43%	27%	16%

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	29%	31%	20%	29%
Weighted NCI-IDD Average	40%	30%	19%	27%

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	30%	40%	21%	9%	437
Weighted NCI-IDD Average	33%	37%	20%	10%	7318

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	33%	42%	18%	7%	298
Weighted NCI-IDD Average	37%	32%	17%	14%	4102

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%	31%	23%	24%	384
Weighted NCI-IDD Average	34%	28%	18%	20%	7070

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
OR	54%	27%	12%	7%	261
Weighted NCI-IDD Average	61%	22%	9%	8%	5396

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	53%	36%	10%	2%	456
Weighted NCI-IDD Average	44%	34%	17%	5%	8536

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	50%	38%	10%	2%	475
Weighted NCI-IDD Average	47%	32%	15%	5%	9272

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

State	Yes	No	N
OR	79%	21%	250
Weighted NCI-IDD Average	65%	35%	4047

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	77%	20%	2%	1%	469
Weighted NCI-IDD Average	74%	21%	3%	2%	8622

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

State	Yes	No	N
OR	51%	49%	461
Weighted NCI-IDD Average	37%	63%	9211

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	95%	5%	475
Weighted NCI-IDD Average	95%	5%	9643

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	74%	24%	2%	474
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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	56%	33%	7%	3%	448
Weighted NCI-IDD Average	56%	31%	9%	4%	7265

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%	459
Weighted NCI-IDD Average	67%	25%	6%	2%	8150

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	39%	37%	15%	9%	238
Weighted NCI-IDD Average	37%	29%	19%	15%	4509

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%	12%	4%	448
Weighted NCI-IDD Average	43%	37%	15%	5%	7572

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

State	Yes	No	N
OR	35%	65%	432
Weighted NCI-IDD Average	36%	64%	6786

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

State	Yes	No	N
OR	54%	46%	399
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.

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	65%	25%	5%	5%	371
Weighted NCI-IDD Average	51%	26%	9%	14%	5448

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	66%	22%	7%	5%	407
Weighted NCI-IDD Average	50%	25%	10%	15%	5297

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	72%	19%	5%	4%	410
Weighted NCI-IDD Average	52%	24%	9%	15%	5167

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	32%	55%	12%	390
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.

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

State	Yes	No	N
OR	86%	14%	471
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
OR	11%	37%	30%	33%	40%
Weighted NCI-IDD Average	10%	31%	24%	30%	29%

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

State	Yes	No	N
OR	83%	17%	476
Weighted NCI-IDD Average	83%	17%	9605

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
OR	77%	23%	363
Weighted NCI-IDD Average	74%	26%	7060

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

State	Yes	No	N
OR	22%	78%	427
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.

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	69%	25%	5%	1%	469
Weighted NCI-IDD Average	73%	18%	5%	4%	9451

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	51%	34%	12%	4%	470
Weighted NCI-IDD Average	57%	29%	12%	3%	9420

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	61%	23%	11%	6%	470
Weighted NCI-IDD Average	69%	19%	7%	5%	9617

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	48%	29%	15%	8%	452
Weighted NCI-IDD Average	56%	27%	13%	5%	9038

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	89%	7%	2%	1%	372
Weighted NCI-IDD Average	87%	7%	3%	3%	5858

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	92%	8%	1%	0%	372
Weighted NCI-IDD Average	89%	9%	2%	1%	5792

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	38%	29%	16%	17%	373
Weighted NCI-IDD Average	40%	25%	15%	20%	7401

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	48%	30%	15%	7%	283
Weighted NCI-IDD Average	50%	31%	13%	6%	5926

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	57%	43%	120
Weighted NCI-IDD Average	56%	44%	2597

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	79%	21%	422
Weighted NCI-IDD Average	82%	18%	8632

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	50%	50%	431
Weighted NCI-IDD Average	35%	65%	8875

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	51%	49%	476
Weighted NCI-IDD Average	36%	64%	9738

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	53%	47%	36
Weighted NCI-IDD Average	35%	65%	1105

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

State	Yes	No or Don't Know	N
OR	84%	16%	479
Weighted NCI-IDD Average	65%	35%	9701

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	3%	97%	462
Weighted NCI-IDD Average	3%	97%	9239

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
OR	n/a	n/a	n/a
Weighted NCI-IDD Average	72%	28%	155

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

Family Satisfaction

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
OR	32%	46%	19%	3%	476
Weighted NCI-IDD Average	33%	38%	22%	7%	9494

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%	459
Weighted NCI-IDD Average	91%	9%	8812

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

State	Yes	No	N
OR	77%	23%	445
Weighted NCI-IDD Average	70%	30%	8578

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

State	Yes	No	N
OR	92%	8%	453
Weighted NCI-IDD Average	85%	15%	8706

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%	464
Weighted NCI-IDD Average	18%	82%	8624

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	91%	9%	64
Weighted NCI-IDD Average	73%	27%	1313

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

State	Yes	No	N
OR	27%	73%	441
Weighted NCI-IDD Average	23%	77%	8705

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

State	Yes	No	N
OR	96%	4%	439
Weighted NCI-IDD Average	92%	8%	8422