Child Family Survey

2023-24 California Regional Center Report

Far Northern Regional Center

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Message from the California Department of Developmental Services

Mission: The Department of Developmental Services (DDS) is committed to providing leadership that results in quality services to the people of California and assures the opportunity for individuals with intellectual/developmental disabilities to exercise their right to make choices.

All Californians with an intellectual or developmental disability as defined by California law have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. These statutory requirements make California's service system unique and could impact comparisons between its survey results and the results of other states.

The NCI Child Family Survey report was compiled by Human Services Research Institute (HSRI) in accordance with Welfare and Institutions Code (WIC), Section 4571. It is an important effort to collect accurate, reliable, and valid individual and family satisfaction measures, as well as individual outcome data. More information about the California NCI can be found at https://www.dds.ca.gov/rc/nci/.

This is the fifth administration of the Child Family Survey, with data collected from December 2023 through June 2024. During that time, 8,277 mail-out surveys were completed by family members who live in the same residence with a child with intellectual and developmental disabilities receiving at least one service beyond case management from a regional center. The data findings in this report contribute to our understanding of how California's system is performing. California uses these reports to monitor changes in the system and to guide strategic planning and quality improvement activities. Regional centers can use the data in a similar fashion at the local level. Regional centers can use the data in a similar fashion at the local level.

This report does not compare California's data to the data of other states, but it does include the NCI average across participating NCI states. This is because California's service system is unique among states. Some of the things that make California's service system unique include:

1. California has longstanding statute that ensures services and supports are provided for eligible persons with intellectual and developmental disabilities.
2. California's laws mandate intake, evaluation and assessment within 120 days.
3. California has a broad eligibility definition for receiving services.
4. California has mandated services, including case management, with statutory limitations on caseload size.
5. California's service obligations to the families needing services are, by law, from pre-conception to death.
6. California's regional centers are, by design, autonomous in that each center has a local board of directors to best address the unique needs of each of the 21 regions.
7. Consumers or their families can call a team meeting at any time to request a change in service.

Reports like this offer DDS the opportunity to compare the results of the data across the years. System improvements will take time to identify and achieve, but this report provides valuable data and is one more tool in our continuous effort to improve services and supports to individuals with intellectual and developmental disabilities across California.

Acknowledgements

This report would not be possible if not for the 8,277 families who agreed to offer their time and discuss their lives in order to assist in improving the services of all people with intellectual and developmental disabilities in California.

List of Abbreviations Used in This Report

AFS - Adult Family Survey

ARCA - Association of Regional Center Agencies

CAC - Consumer Advisory Committee

CA-ODESA - California Online Data Entry Survey Administration

CCF - Community Care Facility

CIP - Core Indicators Project

CFS - Child Family Survey

CMS - Centers for Medicare & Medicaid Services

DDS - Department of Developmental Services

FGS - Family/Guardian Survey

FHA - Family Home Agency

HCBS – Home and Community-Based Services

HSRI - Human Services Research Institute

ICF - Intermediate Care Facility

ILS/SLS - Independent Living Services/Supported Living Services

NASDDDS - National Association of State Directors of Developmental Disabilities Services

NCI - National Core Indicators

QAC - Quality Assessment Coordinator

RC - Regional Center

SCDD - State Council of Developmental Disabilities

List of Regional Center Abbreviations

ACRC- Alta California Regional Center

CVRC- Central Valley Regional Center

ELARC- Eastern Los Angeles Regional Center

FDLRC- Frank D. Lanterman Regional Center

FNRC- Far Northern Regional Center

GGRC- Golden Gate Regional Center

HRC- Harbor Regional Center

IRC- Inland Regional Center

KRC- Kern Regional Center

NBRC- North Bay Regional Center

NLACRC- North Los Angeles County Regional Center

RCEB- Regional Center of the East Bay

RCOC- Regional Center of Orange County

RCRC- Redwood Coast Regional Center

SARC- San Andreas Regional Center

SCLARC- South Central Los Angeles Regional Center

SDRC- San Diego Regional Center

SG/PRC- San Gabriel/Pomona Regional Center

TCRC- Tri-Counties Regional Center Regional Center

VMRC- Valley Mountain Regional Center

WRC- Westside Regional Center

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Executive Summary

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 or developmental disabilities and their families. Indicators address key areas of concern such as respect and 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-IDD) Child Family Survey is administered to families who have a child[1] with an intellectual or developmental disability who lives in the family home and receives at least one service other than case management. 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 during the 2023-24 data collection cycle, five states[2] submitted a valid sample of Child Family Survey data. **Please note: the NCI-IDD averages shown throughout this report are weighted.**[3]

In California, the Child Family Survey is administered once every two years and data are collected from all 21 regional centers. The California statewide average is comprised of these data. This report provides a summary of results based on data submitted by June 30, 2024.

Note: *All Californians with an intellectual or developmental disability as defined by California law have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. As a result of these requirements, all eligible individuals are enrolled in California's service system, and California establishes no waiting list for services. This impacts comparability between California NCI survey results and the NCI survey results of other states.*

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[1] Some states include people up to 21 years old receiving child services

[2] California (CA), Louisiana (LA), Missouri (MO), Oregon (OR), and Wisconsin (WI)

[3] For more information see "Weighting" in the Methodology section

Results

This section provides regional center, California, 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 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 regional centers listed alphabetically. Outcomes are shown first with a chart depicting the CA average. The charts are followed by accessible tables showing regional center outcomes listed alphabetically.

Regional centers with fewer than 20 respondents to a question ***are not*** included in outcome tables; however, their data ***are*** included in the CA average.

Note on NCI 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. 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 conservator) filling out the survey. “Child” refers to the person receiving services whom the respondent is answering questions about in this survey.

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

“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 regional center see Figure 2.

Demographic

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.

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.

Regional Center	Yes	No	N
FNRC	66%	34%	175
CA Average	65%	35%	8074
Weighted NCI-IDD Average	65%	35%	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.

Regional Center	Age	N
FNRC	10.4	183
CA Average	10.9	8,276
Weighted NCI-IDD Average	10.6	10,031

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.

Regional Center	Male	Female	Other	N
FNRC	68%	31%	1%	183
CA Average	71%	28%	0%	8276
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.

Regional Center	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer Not to Say
FNRC	9%	3%	3%	2%	69%	33%	1%	2%
CA Average	2%	18%	8%	1%	33%	52%	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.

Regional Center	Intellectual Disability	Mood Illness/ Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy
FNRC	29%	17%	79%	6%
CA Average	35%	13%	78%	7%
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.

Regional Center	Limited or No Vision – Legally Blind	Hearing Loss – Severe or Profound	Brain Injury	Seizure Disorder and/or Neurological Problem	Chemical Dependency
FNRC	3%	2%	2%	11%	1%
CA Average	5%	3%	3%	12%	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.

Regional Center	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other Disabilities
FNRC	7%	1%	2%	21%
CA Average	8%	0%	1%	18%
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.

Regional Center	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
FNRC	16%	4%	4%	7%	13%
CA Average	8%	3%	2%	3%	7%
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.

Regional Center	Dysphagia	Pressure Ulcers	Oral Health or Dental Problems	Sleep Apnea	Other Pulmonary Diagnosis (e.g., COPD, Bronchitis, Emphysema)
FNRC	13%	2%	11%	25%	4%
CA Average	9%	1%	9%	20%	7%
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.

Regional Center	Asthma	Chronic Kidney Disease	Long-term Health Problems Associated with COVID-19	Other
FNRC	44%	4%	4%	27%
CA Average	40%	2%	1%	33%
Weighted NCI-IDD Average	36%	2%	1%	35%

Table 7a. Child’s Preferred Language

Please note: The standard NCI-IDD Survey tool includes: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and Other. California adds additional language categories to their survey tool. In the standard NCI-IDD report, the CA data under “Other” capture the data on the additional CA language categories. Therefore, the data for CA and the Weighted NCI-IDD Average for the “Other” category in this report will not match the standard NCI-IDD report. All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

Regional Center	English	Spanish	Chinese	Tagalog	Vietnamese	N
FNRC	90%	9%	0%	0%	0%	181
CA Average	79%	12%	1%	0%	0%	8085
Weighted NCI-IDD Average	83%	10%	0%	0%	0%	9800

Table 7b. Child's Preferred Language (continued)

Please note: The standard NCI-IDD Survey tool includes: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and Other. California adds additional language categories to their survey tool. In the standard NCI-IDD report, the CA data under "Other" capture the data on the additional CA language categories. Therefore, the data for CA and the Weighted NCI-IDD Average for the "Other" category in this report will not match the standard NCI-IDD report. All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

Regional Center	American Sign Language	Arabic	Armenian	Farsi	Hindi	Hmong	N
FNRC	1%	0%	0%	0%	0%	0%	181
CA Average	0%	0%	0%	0%	0%	0%	8085
Weighted NCI-IDD Average	0%	n/a	n/a	n/a	n/a	n/a	9800

Table 7c. Child's Preferred Language (continued)

Please note: The standard NCI-IDD Survey tool includes: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and Other. California adds additional language categories to their survey tool. In the standard NCI-IDD report, the CA data under "Other" capture the data on the additional CA language categories. Therefore, the data for CA and the Weighted NCI-IDD Average for the "Other" category in this report will not match the standard NCI-IDD report. All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

Regional Center	Japanese	Khmer	Korean	Laotian	Russian	Other	N
FNRC	0%	0%	0%	0%	0%	1%	181
CA Average	0%	0%	0%	0%	0%	6%	8085
Weighted NCI-IDD Average	n/a	n/a	n/a	n/a	n/a	5%	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.

Regional Center	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
FNRC	76%	16%	3%	3%	2%	177
CA Average	71%	17%	2%	5%	5%	8079
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.

Regional Center	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
FNRC	27%	42%	30%	179
CA Average	26%	43%	30%	8011
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.

Regional Center	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
FNRC	9%	46%	45%	181
CA Average	9%	42%	49%	8189
Weighted NCI-IDD Average	9%	42%	49%	9940

Respondents

This section provides information about the survey respondent.

Table 11a. Language Usually Spoken at Home

Please note: The standard NCI-IDD Survey tool includes: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and Other. California adds additional language categories to their survey tool. In the standard NCI-IDD report, the CA data under "Other" capture the data on the additional CA language categories. Therefore, the data for CA and the Weighted NCI-IDD Average for the "Other" category in this report will not match the standard NCI-IDD report.

Regional Center	English	Spanish	Chinese	Tagalog	Vietnamese	N
FNRC	86%	14%	0%	0%	0%	176
CA Average	61%	28%	2%	1%	1%	8114
Weighted NCI-IDD Average	69%	23%	2%	1%	1%	9845

Table 11b. Language Usually Spoken at Home (continued)

Please note: The standard NCI-IDD Survey tool includes: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and Other. California adds additional language categories to their survey tool. In the standard NCI-IDD report, the CA data under "Other" capture the data on the additional CA language categories. Therefore, the data for CA and the Weighted NCI-IDD Average for the "Other" category in this report will not match the standard NCI-IDD report.

Regional Center	American Sign Language	Arabic	Armenian	Farsi	Hindi	Hmong	N
FNRC	0%	0%	0%	0%	0%	0%	176
CA Average	0%	0%	0%	0%	0%	0%	8114
Weighted NCI-IDD Average	0%	n/a	n/a	n/a	n/a	n/a	9845

Table 11c. Language Usually Spoken at Home (continued)

Please note: The standard NCI-IDD Survey tool includes: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and Other. California adds additional language categories to their survey tool. In the standard NCI-IDD report, the CA data under "Other" capture the data on the additional CA language categories. Therefore, the data for CA and the Weighted NCI-IDD Average for the "Other" category in this report will not match the standard NCI-IDD report.

Regional Center	Japanese	Khmer	Korean	Laotian	Russian	Other	N
FNRC	0%	0%	0%	0%	0%	0%	176
CA Average	0%	0%	1%	0%	0%	5%	8114
Weighted NCI-IDD Average	n/a	n/a	n/a	n/a	n/a	4%	9845

Table 12. Respondent's Age

Regional Center	Under 35	35 – 54	55 – 74	75 or Older	N
FNRC	13%	70%	16%	1%	178
CA Average	9%	76%	14%	1%	8181
Weighted NCI-IDD Average	11%	74%	14%	1%	9943

Table 13. Respondent's Health

Regional Center	Excellent	Very Good	Good	Fair	Poor	N
FNRC	11%	36%	39%	12%	2%	179
CA Average	13%	30%	40%	15%	2%	8184
Weighted NCI-IDD Average	13%	31%	40%	15%	2%	9944

Table 14. Respondent's Relationship to Child

Regional Center	Parent (Biological, Adoptive, or Foster)	Sibling	Grandparent	Other	N
FNRC	93%	0%	6%	1%	179
CA Average	96%	0%	3%	1%	8190
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.

Regional Center	No	Yes, I Am	Yes, Another Family Member Is
FNRC	56%	29%	16%
CA Average	52%	32%	18%
Weighted NCI-IDD Average	58%	26%	17%

Table 16. Number of Adults in Household

Regional Center	One	Two	Three	Four or More	N
FNRC	22%	59%	14%	5%	179
CA Average	16%	54%	20%	10%	8082
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)

Regional Center	One	Two	Three	Four or More	N
FNRC	38%	36%	19%	8%	176
CA Average	38%	39%	16%	7%	7984
Weighted NCI-IDD Average	37%	39%	16%	8%	9700

Table 18. Respondent's Highest Level of Education

Regional Center	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
FNRC	7%	16%	9%	25%	42%	179
CA Average	15%	18%	8%	16%	43%	8124
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 conservator/administrator, or if they represent a financial institution or conservatorship agency. Does not include state/federal benefits such as SSI, SSDI etc.

Regional Center	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
FNRC	9%	6%	10%	21%	18%	25%	10%	179
CA Average	5%	8%	10%	19%	13%	30%	14%	8049
Weighted NCI-IDD Average	5%	7%	10%	19%	13%	32%	13%	9793

Table 20 Residential Designation

Regional Center	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
FNRC	53%	47%	174
CA Average	91%	9%	7579
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 regional center[4].

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[4] Some NCI-IDD states provide services through a statewide ID/DD agency

Table 21a. Services and Supports Received from Regional Center[5]

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

Regional Center	Financial Support	In Home Support	Out-of-Home Respite Care	Early Intervention
FNRC	13%	29%	39%	0%
CA Average	19%	35%	31%	1%
Weighted NCI-IDD Average	20%	36%	30%	11%

Table 21b. Services and Supports Received from Regional Center[6] (continued)

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

Regional Center	Transportation	Mental or Behavioral Health Care or Other Treatments or Therapies	Self-Direction or Fiscal Intermediary Services
FNRC	3%	23%	22%
CA Average	3%	23%	19%
Weighted NCI-IDD Average	7%	35%	26%

Table 22. Additional Services and Supports Received (not from the regional center) [7]

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

Regional Center	Social Security (SSI/SSB)	Services or Supports from Other Agencies or Organizations
FNRC	30%	64%
CA Average	30%	64%
Weighted NCI-IDD Average	30%	65%

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[5] Some NCI-IDD states provide services through a statewide ID/DD agency

[6] Some NCI-IDD states provide services through a statewide ID/DD agency

[7] Some NCI-IDD states provide services through a statewide ID/DD agency

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 regional center.

“You” and **“Respondent”** refers to the person (usually a parent or conservator) 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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	23%	33%	27%	18%	172
CA Average	25%	31%	30%	14%	7590
Weighted NCI-IDD Average	27%	33%	28%	12%	9262

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	22%	45%	28%	5%	169
CA Average	24%	38%	31%	8%	7634
Weighted NCI-IDD Average	25%	39%	29%	7%	9332

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	84%	8%	3%	5%	178
CA Average	73%	14%	8%	5%	7977
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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	46%	30%	14%	10%	173
CA Average	54%	27%	14%	6%	7713
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.)?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	22%	22%	24%	32%	139
CA Average	20%	25%	27%	29%	6331
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.

Regional Center	Employment	Financial	Housing	Legal	Medical
FNRC	60%	50%	46%	39%	33%
CA Average	53%	54%	45%	43%	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.

Regional Center	Social or Relationships	Transition from School	Recreation or Having Fun	Other
FNRC	61%	51%	52%	5%
CA Average	59%	56%	59%	6%
Weighted NCI-IDD Average	58%	55%	58%	7%

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

Regional Center	Yes	No	N
FNRC	18%	82%	146
CA Average	21%	79%	6568
Weighted NCI-IDD Average	22%	78%	8078

*"Alternatives to 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 an intellectual/developmental 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 an individual program plan/individual family service plan (IPP/IFSP)?

Regional Center	Yes	No	N
FNRC	78%	22%	152
CA Average	78%	22%	7001
Weighted NCI-IDD Average	77%	23%	8498

Table 31. Does the IPP/IFSP include all the services and supports your child needs?

Regional Center	Yes	No	N
FNRC	71%	29%	97
CA Average	79%	21%	4220
Weighted NCI-IDD Average	80%	20%	5228

Table 32. Did you or another family member help make the IPP/IFSP?

Regional Center	Yes	No	N
FNRC	86%	14%	110
CA Average	80%	20%	4696
Weighted NCI-IDD Average	83%	17%	5808

Table 33. Did your child help make the IPP/IFSP?

Regional Center	Yes	No	N
FNRC	17%	83%	111
CA Average	17%	83%	4716
Weighted NCI-IDD Average	18%	82%	5838

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

Regional Center	Yes	No	N
FNRC	87%	13%	99
CA Average	84%	16%	4367
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)?

Regional Center	Yes	No	N
FNRC	19%	81%	147
CA Average	36%	64%	6472
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?

Regional Center	Yes	No	N
FNRC	83%	17%	24
CA Average	80%	20%	2019
Weighted NCI-IDD Average	81%	19%	2325

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

Regional Center	Yes	No	N
FNRC	45%	55%	22
CA Average	30%	70%	1946
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 regional center.

“You” and **“Respondent”** refers to the person (usually a parent or conservator) 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 IPP/IFSP?

Regional Center	Yes	No	N
FNRC	81%	19%	96
CA Average	81%	19%	4227
Weighted NCI-IDD Average	81%	19%	5259

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

Regional Center	Yes	No	N
FNRC	57%	43%	148
CA Average	62%	38%	6471
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 family need?

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

Regional Center	Respite	Regularly Scheduled Support for Child	Homemaker Services	Home and/or Vehicle Modifications
FNRC	47%	34%	23%	15%
CA Average	45%	44%	27%	14%
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 family need? (continued)

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

Regional Center	Counseling	Family to Family Networks	Support/Training to Use Assistive Technology	Other
FNRC	26%	31%	15%	45%
CA Average	42%	30%	20%	27%
Weighted NCI-IDD Average	40%	30%	19%	27%

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	25%	37%	28%	9%	131
CA Average	31%	37%	21%	11%	5929
Weighted NCI-IDD Average	33%	37%	20%	10%	7318

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	29%	37%	18%	15%	78
CA Average	37%	30%	17%	16%	3106
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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	28%	24%	23%	24%	137
CA Average	37%	29%	17%	17%	5940
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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	60%	20%	10%	10%	101
CA Average	61%	21%	9%	8%	4677
Weighted NCI-IDD Average	61%	22%	9%	8%	5396

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	35%	36%	19%	9%	159
CA Average	41%	34%	19%	6%	7020
Weighted NCI-IDD Average	44%	34%	17%	5%	8536

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	34%	34%	21%	11%	172
CA Average	43%	33%	18%	6%	7654
Weighted NCI-IDD Average	47%	32%	15%	5%	9272

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

Regional Center	Yes	No	N
FNRC	56%	44%	57
CA Average	62%	38%	3260
Weighted NCI-IDD Average	65%	35%	4047

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	76%	16%	4%	3%	164
CA Average	71%	23%	4%	2%	7021
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?

Regional Center	Yes	No	N
FNRC	40%	60%	168
CA Average	36%	64%	7545
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?

Regional Center	Yes	No	N
FNRC	93%	7%	176
CA Average	95%	5%	7944
Weighted NCI-IDD Average	95%	5%	9643

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

Regional Center	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
FNRC	69%	29%	2%	177
CA Average	70%	27%	3%	7969
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 conservator) 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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	60%	24%	12%	4%	135
CA Average	53%	33%	9%	5%	5848
Weighted NCI-IDD Average	56%	31%	9%	4%	7265

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	68%	24%	4%	4%	148
CA Average	65%	27%	7%	2%	6671
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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	31%	25%	21%	23%	71
CA Average	36%	29%	20%	16%	3684
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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	39%	32%	21%	8%	136
CA Average	41%	38%	16%	5%	6132
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?

Regional Center	Yes	No	N
FNRC	48%	52%	124
CA Average	38%	62%	5449
Weighted NCI-IDD Average	36%	64%	6786

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

Regional Center	Yes	No	N
FNRC	61%	39%	121
CA Average	70%	30%	5283
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 conservator) 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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	53%	17%	9%	21%	76
CA Average	48%	27%	10%	14%	4401
Weighted NCI-IDD Average	51%	26%	9%	14%	5448

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	50%	21%	8%	21%	76
CA Average	46%	26%	11%	17%	4234
Weighted NCI-IDD Average	50%	25%	10%	15%	5297

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	52%	27%	7%	13%	82
CA Average	48%	25%	9%	17%	4120
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?

Regional Center	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
FNRC	7%	58%	36%	135
CA Average	11%	66%	23%	5853
Weighted NCI-IDD Average	14%	64%	22%	7141

Community Connections

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

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“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?

Regional Center	Yes	No	N
FNRC	78%	22%	169
CA Average	72%	28%	7900
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.

Regional Center	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
FNRC	9%	25%	23%	37%	37%
CA Average	11%	31%	24%	29%	27%
Weighted NCI-IDD Average	10%	31%	24%	30%	29%

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

Regional Center	Yes	No	N
FNRC	89%	11%	171
CA Average	82%	18%	7924
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 regional center[8] (for example, recreational programs, community housing, library programs, religious groups, etc.)?

Regional Center	Yes	No	N
FNRC	74%	26%	128
CA Average	72%	28%	5818
Weighted NCI-IDD Average	74%	26%	7060

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

Regional Center	Yes	No	N
FNRC	17%	83%	151
CA Average	21%	79%	7014
Weighted NCI-IDD Average	21%	79%	8461

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[8] Some NCI states provide services through a statewide ID/DD agency

Health, Welfare, and Safety

Families are supported to ensure the health, welfare, and safety of their child receiving services and supports from the regional center.

“You” and **“Respondent”** refers to the person (usually a parent or conservator) 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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	72%	18%	6%	3%	173
CA Average	72%	18%	6%	5%	7781
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 intellectual/developmental disability?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	51%	31%	14%	4%	169
CA Average	55%	29%	12%	4%	7743
Weighted NCI-IDD Average	57%	29%	12%	3%	9420

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	65%	24%	5%	6%	174
CA Average	69%	18%	7%	6%	7960
Weighted NCI-IDD Average	69%	19%	7%	5%	9617

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	46%	31%	15%	7%	163
CA Average	55%	26%	14%	5%	7510
Weighted NCI-IDD Average	56%	27%	13%	5%	9038

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	92%	7%	0%	1%	91
CA Average	86%	8%	3%	4%	4640
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)?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	90%	9%	0%	1%	89
CA Average	88%	9%	2%	1%	4577
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)

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	31%	28%	16%	25%	127
CA Average	39%	25%	15%	21%	6168
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 intellectual/developmental disability?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	47%	35%	11%	7%	88
CA Average	50%	31%	13%	6%	4990
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?

Regional Center	Yes	No	N
FNRC	50%	50%	30
CA Average	53%	47%	2187
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?

Regional Center	Yes	No	N
FNRC	83%	17%	162
CA Average	80%	20%	7098
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/service coordinator?

Regional Center	Yes	No	N
FNRC	32%	68%	162
CA Average	32%	68%	7311
Weighted NCI-IDD Average	35%	65%	8875

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

Regional Center	Yes	No or Don't Know	N
FNRC	39%	61%	178
CA Average	32%	68%	8060
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?

Regional Center	Yes	No	N
FNRC	n/a	n/a	n/a
CA Average	33%	67%	994
Weighted NCI-IDD Average	35%	65%	1105

FNRC had an N of less than 20 and was not shown. They are still included in the overall CA Average and Weighted NCI average.

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

Regional Center	Yes	No or Don't Know	N
FNRC	70%	30%	176
CA Average	61%	39%	8016
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?

Regional Center	Yes	No	N
FNRC	2%	98%	173
CA Average	2%	98%	7592
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?

Regional Center	Yes	No	N
FNRC	n/a	n/a	n/a
CA Average	72%	28%	123
Weighted NCI-IDD Average	72%	28%	155

FNRC had an N of less than 20 and was not shown. They are still included in the overall CA Average and Weighted NCI average.

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 conservator) 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?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	26%	38%	25%	12%	171
CA Average	32%	37%	24%	7%	7830
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?

Regional Center	Yes	No	N
FNRC	88%	12%	157
CA Average	90%	10%	7238
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?

Regional Center	Yes	No	N
FNRC	65%	35%	164
CA Average	68%	32%	7033
Weighted NCI-IDD Average	70%	30%	8578

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

Regional Center	Yes	No	N
FNRC	77%	23%	164
CA Average	83%	17%	7142
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?

Regional Center	Yes	No	N
FNRC	15%	85%	161
CA Average	18%	82%	7032
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?

Regional Center	Yes	No	N
FNRC	73%	27%	22
CA Average	72%	28%	1063
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?

Regional Center	Yes	No	N
FNRC	19%	81%	160
CA Average	23%	77%	7165
Weighted NCI-IDD Average	23%	77%	8705

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

Regional Center	Yes	No	N
FNRC	88%	12%	149
CA Average	91%	9%	6898
Weighted NCI-IDD Average	92%	8%	8422

California Specific Questions

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

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

Table 91a. Services Paid for Out-Of-Pocket in The Past Year

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

Regional Center	Childcare/ Afterschool Care	Behavior Therapy	Educational Expenses	Medical and/or Dental Expenses
FNRC	15%	10%	24%	35%
CA Average	18%	10%	19%	32%

Table 91b. Services Paid for Out-Of-Pocket in The Past Year (continued)

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

Regional Center	Other Therapies	Parent Training	Recreational Activities and Programs	Respite Services
FNRC	17%	9%	51%	8%
CA Average	17%	5%	35%	5%

Table 91c. Services Paid for Out-Of-Pocket in The Past Year (continued)

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

Regional Center	Social Skills Training	Speech Therapy	Transportation Support	Other	None
FNRC	3%	8%	19%	8%	26%
CA Average	6%	11%	15%	4%	37%

Table 92. Total Out-of-Pocket Expenses Related to Child’s Care in the Past Year

Regional Center	None	$1 – $1,999	$2,000 – $5,999	$6,000 – $11,999	$12,000 or Over	N
FNRC	26%	45%	23%	5%	1%	173
CA Average	34%	34%	20%	7%	5%	7634

Table 93. Do you know what to do if you disagree with your regional center about services and/or eligibility? (For example, how to request a Fair Hearing)

Regional Center	Yes	No	N
FNRC	47%	53%	159
CA Average	46%	54%	6652

Table 94. Does your regional center keep you informed, in your preferred language, about programs or services it offers?

Regional Center	Yes	No	N
FNRC	67%	33%	164
CA Average	76%	24%	7309

Table 95. Did you get a copy of your child's IPP/IFSP in your preferred language?

Regional Center	Yes	No	N
FNRC	94%	6%	112
CA Average	94%	6%	4980

Table 96. Do the support workers for your child speak to you in your preferred language?

Regional Center	Yes, They Speak My Preferred Language	Yes, But Only Through a Translator When One Is Available	No	N
FNRC	98%	1%	1%	161
CA Average	95%	3%	2%	7010

Table 97. Does your child's case manager/service coordinator speak your preferred language?

Regional Center	Yes, They Speak My Preferred Language	Yes, But Only Through a Translator When One Is Available	No	N
FNRC	99%	1%	0%	169
CA Average	96%	3%	2%	7660

Table 98. If your support workers and/or case manager/service coordinator do not speak to you in your preferred language, is a translator provided when needed?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	n/a	n/a	n/a	n/a	n/a
CA Average	20%	24%	23%	34%	122

FNRC had an N of less than 20 and was not shown. They are still included in the overall CA Average.

Table 99. Does your child's case manager/service coordinator support you in a way that is respectful to your culture?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	87%	11%	3%	0%	156
CA Average	82%	15%	2%	1%	7402

Table 100. Do support workers for your family members provide services in a way that is respectful of your culture?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	84%	10%	6%	1%	143
CA Average	82%	15%	2%	1%	6649

Table 101. How often does your child spend time with children who are not siblings and do not have an intellectual/developmental disability?

Regional Center	Often	Sometimes	Seldom	Never	N
FNRC	41%	24%	31%	3%	172
CA Average	34%	30%	26%	10%	7705

Table 102. Do you believe your plans for how to handle your family member's needs during a natural disaster (such as a wildfire or earthquake) will be effective?

Regional Center	Yes	No	N
FNRC	92%	8%	117
CA Average	81%	19%	4621

Table 103a. What else do you need to make effective plans for emergencies?

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

Regional Center	Location of Evacuation Sites/ Shelters	Evacuation Routes	Public Safety Power Shut Off Information (PSPS)	Locations of Community Resource Centers	More Information on What I Need for Life Sustaining Equipment I Use
FNRC	34%	28%	21%	27%	7%
CA Average	53%	39%	31%	41%	21%

Table 103b. What else do you need to make effective plans for emergencies? (continued)

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

Regional Center	Key People to Contact	How to Reach My Regional Center in an Emergency	How to Reach My Support Workers in an Emergency	How to Get Additional Emergency Supplies	How to Prepare an Emergency Supply Kit
FNRC	26%	28%	17%	37%	27%
CA Average	33%	37%	25%	45%	38%

Table 103c. What else do you need to make effective plans for emergencies? (continued)

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

Regional Center	How to Sign Up For Emergency Alerts	Important Personal Documents to Have Ready	Other	No Other Information Is Needed
FNRC	22%	22%	3%	39%
CA Average	29%	29%	3%	26%

NCI History and Activities

This section briefly describes the history of the National Core Indicators and NCI surveys.

Overview of National Core Indicators—Intellectual and Developmental Disabilities

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 Adult 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://idd.nationalcoreindicators.org/.

State Participation

During the 2023-24 data collection cycle, 48 states, the District of Columbia and 22 sub-state entities participated in NCI-IDD. State participation is entirely voluntary, and participating states are highlighted on the map below. Not all states participate in all surveys each year.

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://idd.nationalcoreindicators.org/wp-content/uploads/2022/09/NCI_IDD_Indicators_FINAL_21-22.pdf.

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 individual, 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 four broad domains: Individual Outcomes; System Performance, Health, Wellness and Rights, and Family Experience. 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 (e.g., staff turnover).

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI-IDD program is a dynamic effort that allows for measures to be added, dropped, or changed to reflect current and future priorities of participating states.

The data collection tools used to gather indicator data are regularly refined and tested to ensure they remain valid, reliable, and applicable to current issues within the field. Details on the design and testing of this tool are provided in the next section of this report.

Sub-Domains and Concern Statements

The following table lists the sub-domains under the “Family Outcomes” domain.

Figure 1. Family Survey Sub-Domains and Concern Statements

Sub-Domain	Concern 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 DD system.
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 DD 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.
Choice & Decision-making	Families and their family members receiving services and supports from the state DD system are involved in making choices about supports, services, and providers.
Community Connections	Family members receiving services and supports from the state DD 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 DD system.
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. [9]

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. 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 regional centers; this denotes that the majority of states and regional centers are performing similarly. Instances in which several regional center results are especially high (considerably above the average level) indicate the levels of performance or satisfaction achieved in those regional centers 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 and regional centers 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 staff to aggregate and analyze the data.

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[9] Located on the National Core Indicators website: https://www.nationalcoreindicators.org

Sampling & Administration

States were asked to administer the Child Family Survey families who:

1. Had a child[10] with an intellectual or developmental disability living in the home; and

2. The child with an intellectual or developmental disability living in the home received at least one direct service or support in addition to service coordination.

California has chosen to enhance data collection by focusing on obtaining a sample from each RC that has proportionate representation from five ethno-racial groups (i.e., African American/Black, Asian, Hispanic, White and Other). [11]

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 total of 5 states (CA, LA, MO, OR, WI) had at least a portion of surveys completed via direct entry for the 2023-24 data collection cycle.

Weighting

Statistically, the term "average" refers to a calculated central or middle value of a set of numbers. In NCI-IDD reports, we use the "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 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.

Data Entry and Analysis

Each state or regional center 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.

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[10] Some states include people up to age 21 who were receiving child services

[11] See "Response Rates" for information on total surveys mailed and received by regional centers as well as each regional center's margin of error.

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

Response Rates

During 2023-24, 5 states, including California 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 regional center 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.

Figure 2. Child Family Surveys Regional Center Response Rates[12] [13]

Regional Center	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
FNRC	2,044	2,044	183	9%	6.6%	78%	22%
CA	98,003	98,003	8,277	8%	1.0%	73%	27%
NCI	132,220	109,959	10,050	9%	0.9%	68%	32%

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[12] State or regional center response rates are calculated as following: the number of complete surveys divided by total surveys sent in that state or regional center (type "RR1" as defined by the American Association for Public Opinion Research). For more details on the definition, please see the AAPOR report: https://aapor.org/wp-content/uploads/2022/11/Standard-Definitions20169theditionfinal.pdf

[13] The NCI Average includes California; consistent with past years, the overall response rate and margin of error were calculated as the average of state averages, and the overall paper submission and direct entry submission rates were calculated as averages weighted by state total service population sizes (column 2 of this table).