Family/Guardian 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 (IDD) 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 Adult 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 Adult Family Survey, with data collected from December 2023 through June 2024. During that time, 5,274 mail-out surveys were completed by family members who live in the same residence with an adult 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.

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 5,274 families who agreed to offer their time and discuss their lives in order to assist in improving the services of all people with intellectual/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 employment, 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) Family/Guardian Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who lives outside of the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Family/Guardian 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, eleven states[1] submitted a valid sample of Family/Guardian Survey data. **Please note: the NCI-IDD averages shown throughout this report are weighted.** [2]

In California, the Family/Guardian 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. These statutory requirements make California's service system unique and could impact comparisons between its survey results and the results of other states.

[1] Arizona (AZ), California (CA), Delaware (DE), Georgia (GA), Indiana (IN), Maryland (MD), Minnesota (MN), New Hampshire (NH)", New Jersey (NJ), North Dakota (ND), and Pennsylvania (PA)

[2] 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. "Family Member" 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.

Demographics

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

Family Member

This section provides demographic information about the family member receiving services.

Table 1a. Family Member's Residence

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	Specialized Facility for People with Intellectual Disabilities	Group Home or Agency Operated Apartment	Independent Home or Apartment	N
FNRC	13%	33%	39%	206
CA Average	18%	41%	32%	5109
Weighted NCI-IDD Average	12%	59%	21%	8419

Table 1b. Family Member's Residence (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.

Regional Center	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
FNRC	1%	1%	0%	12%	206
CA Average	2%	1%	0%	5%	5109
Weighted NCI-IDD Average	4%	1%	0%	4%	8419

Table 2. Family Member's Time Living in Current Residence

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	Less than One Year	One to Three Years	Four to Five Years	Over Five Years	N
FNRC	11%	23%	14%	51%	201
CA Average	6%	18%	12%	65%	5113
Weighted NCI-IDD Average	9%	21%	11%	59%	8397

Table 3. Family Member's Residential Designation

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	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
FNRC	82%	18%	201
CA Average	95%	5%	5036
Weighted NCI-IDD Average	85%	15%	8302

Table 4. Family Member'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	47.2	212
CA Average	47.8	5,272
Weighted NCI-IDD Average	47.4	8,581

Table 5. Family Member'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	59%	41%	0%	212
CA Average	60%	40%	0%	5274
Weighted NCI-IDD Average	59%	41%	0%	8587

Table 6. Family Member's Race and Ethnicity

Please note: All data in this section are reported by the respondent based on their understanding of their family member'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	5%	3%	3%	0%	85%	6%	2%	3%
CA Average	3%	8%	6%	0%	74%	12%	2%	2%
Weighted NCI-IDD Average	2%	4%	7%	0%	81%	6%	1%	2%

Table 7a. Family Member's Conditions

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

Regional Center	Intellectual Disability	Mood Illness or Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision – Legally Blind
FNRC	71%	36%	26%	16%	8%
CA Average	73%	28%	34%	16%	7%
Weighted NCI-IDD Average	78%	36%	33%	16%	8%

Table 7b. Family Member's Conditions (continued)

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

Regional Center	Hearing Loss – Severe or Profound	Brain Injury	Seizure or Neurological Disorder	Chemical Dependency
FNRC	6%	8%	20%	1%
CA Average	6%	7%	24%	1%
Weighted NCI-IDD Average	6%	8%	25%	0%

Table 7c. Family Member's Conditions (continued)

Please note: All data in this section are reported by the respondent based on their understanding of their family member'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
FNRC	5%	2%	3%	14%
CA Average	8%	1%	1%	11%
Weighted NCI-IDD Average	10%	1%	1%	12%

Table 8a. Family Member's Health Conditions

Please note: All data in this section are reported by the respondent based on their understanding of their family member'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	11%	19%	6%	34%	26%
CA Average	8%	20%	6%	31%	29%
Weighted NCI-IDD Average	9%	19%	6%	31%	31%

Table 8b. Family Member's Health Conditions (continued)

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

Regional Center	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Dementia	Oral Health Problems	Sleep Apnea
FNRC	6%	2%	5%	24%	18%
CA Average	9%	2%	3%	17%	14%
Weighted NCI-IDD Average	11%	2%	4%	16%	16%

Table 8c. Family Member's Health Conditions (continued)

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

Regional Center	Asthma	Other Pulmonary Diagnosis (e.g., COPD, Bronchitis, Emphysema)	Chronic Kidney Disease	Long-Term Health Problems Associated with COVID-19 (Also Known As Long COVID)	Other
FNRC	15%	5%	2%	1%	21%
CA Average	11%	5%	3%	1%	23%
Weighted NCI-IDD Average	11%	4%	4%	1%	23%

Table 9. Family Member'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	90%	5%	1%	0%	4%	210
CA Average	82%	11%	2%	1%	4%	5173
Weighted NCI-IDD Average	82%	12%	1%	1%	4%	8450

Table 10a. Family Member'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	98%	0%	0%	0%	0%	210
CA Average	94%	1%	0%	0%	0%	5192
Weighted NCI-IDD Average	96%	1%	0%	0%	0%	8489

Table 10b. Family Member'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	0%	0%	0%	0%	0%	0%	210
CA Average	1%	0%	0%	0%	0%	0%	5192
Weighted NCI-IDD Average	1%	n/a	n/a	n/a	n/a	n/a	8489

Table 10c. Family Member'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%	210
CA Average	0%	0%	0%	0%	0%	2%	5192
Weighted NCI-IDD Average	n/a	n/a	n/a	n/a	n/a	2%	8489

Table 11. Family Member Has Legal Court Appointed Guardian or Conservator

Please note: 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	No Guardianship or Conservatorship	Limited Guardianship or Conservatorship	Full Guardianship or Conservatorship	Has Guardianship or Conservatorship but Level is Unknown	N
FNRC	47%	30%	19%	4%	201
CA Average	40%	30%	24%	6%	4857
Weighted NCI-IDD Average	29%	19%	46%	5%	8065

Table 12. Guardian or Conservator Relationship to Family Member

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	Family	Friend	Regional Center Employee or Guardianship or Conservatorship Agency	Other	N
FNRC	89%	1%	7%	3%	100
CA Average	90%	2%	6%	3%	2706
Weighted NCI-IDD Average	87%	2%	8%	3%	5185

Table 13a. Family Member's Highest Level of Education

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	Did Not Complete High School, Not Currently in School	Currently Enrolled in High School	High School Certificate (NOT a High School Diploma/GED)	N
FNRC	27%	0%	25%	201
CA Average	33%	1%	30%	4937
Weighted NCI-IDD Average	30%	0%	32%	8127

Table 13b. Family Member's Highest Level of Education (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.

Regional Center	High School Diploma/GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
FNRC	29%	2%	10%	6%	201
CA Average	21%	3%	7%	6%	4937
Weighted NCI-IDD Average	27%	2%	4%	4%	8127

Table 14. Family Member'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 family member'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	44%	39%	17%	206
CA Average	41%	35%	24%	5068
Weighted NCI-IDD Average	37%	38%	25%	8327

Table 15. Family Member'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 family member'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	32%	40%	28%	209
CA Average	29%	36%	35%	5154
Weighted NCI-IDD Average	24%	39%	37%	8457

Table 16. Family Member's Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)

Please note: 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	No Support Needed; No Issues with Other Daily Activities	Some Support Needed; Requires Only Occasional Assistance or Monitoring	Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance	N
FNRC	5%	40%	55%	208
CA Average	5%	28%	67%	5163
Weighted NCI-IDD Average	3%	21%	76%	8475

Respondents

This section provides information about the survey respondent.

Table 17a. 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. 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	99%	0%	0%	0%	0%	209
CA Average	94%	2%	1%	0%	0%	5177
Weighted NCI-IDD Average	97%	1%	0%	0%	0%	8447

Table 17b. 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. 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	0%	0%	0%	0%	0%	0%	209
CA Average	0%	0%	0%	0%	0%	0%	5177
Weighted NCI-IDD Average	0%	n/a	n/a	n/a	n/a	n/a	8447

Table 17c. 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. 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%	0%	209
CA Average	0%	0%	0%	0%	0%	2%	5177
Weighted NCI-IDD Average	n/a	n/a	n/a	n/a	n/a	1%	8447

Table 18. Respondent's Age

Regional Center	18 - 34	35 - 54	55 - 74	75 or Older	N
FNRC	1%	10%	62%	28%	208
CA Average	1%	8%	55%	35%	5179
Weighted NCI-IDD Average	1%	9%	61%	28%	8473

Table 19. Respondent's Health

Regional Center	Excellent	Very Good	Good	Fair	Poor	N
FNRC	10%	35%	40%	13%	1%	209
CA Average	15%	35%	33%	15%	3%	5220
Weighted NCI-IDD Average	15%	36%	34%	14%	2%	8507

Table 20. Respondent's Relationship to Family Member

Regional Center	Parent (Biological, Adoptive, or Foster)	Sibling	Spouse	Grandparent	Public Guardian or Conservator	Private Guardian or Conservator	Other	N
FNRC	61%	16%	0%	2%	2%	0%	18%	209
CA Average	68%	19%	0%	1%	0%	1%	10%	5193
Weighted NCI-IDD Average	64%	23%	0%	1%	2%	3%	7%	8481

Table 21. Respondent's Frequency of Visits with Family Member in the Past 12 Months

Regional Center	Did Not visit	1 to 3 Times	4 to 6 Times	7 to 12 Times	More Than 12 Times	N
FNRC	6%	12%	13%	11%	58%	206
CA Average	7%	11%	10%	11%	61%	5209
Weighted NCI-IDD Average	4%	11%	11%	11%	63%	8508

Table 22. 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	4%	13%	6%	30%	47%	204
CA Average	4%	11%	4%	23%	58%	5160
Weighted NCI-IDD Average	3%	16%	6%	20%	55%	8395

Table 23. Total Taxable Household Income of Wage Earners in the Last Year

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 to $25,000	$25,001 to $50,000	$50,001 to $75,000	Over $75,000	Prefer Not to Say	N
FNRC	14%	7%	5%	13%	13%	20%	29%	196
CA Average	10%	4%	4%	12%	12%	26%	32%	5006
Weighted NCI-IDD Average	9%	4%	5%	12%	12%	24%	34%	8155

Services and Supports Received

This section provides information about the services and supports received by the family from the regional center[3].

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

Table 24a. Services and Supports Received from Regional Center[4]

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses, and personal characteristics; categories are not mutually exclusive; therefore N is not shown.

Regional Center	Financial Support	In Home Support	Residential Supports	Day or Employment Supports
FNRC	44%	47%	58%	58%
CA Average	38%	47%	67%	64%
Weighted NCI-IDD Average	34%	42%	79%	63%

Table 24b. Services and Supports Received from Regional Center[5] (continued)

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses, and personal characteristics; 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	64%	38%	28%
CA Average	65%	37%	21%
Weighted NCI-IDD Average	82%	52%	20%

Table 25. Additional Services and Supports Received (not from the regional center)[6]

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses, and personal characteristics; 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	90%	21%
CA Average	90%	27%
Weighted NCI-IDD Average	94%	28%

[4] Some NCI states provide services through a statewide ID/DD agency
[5] Some NCI states provide services through a statewide ID/DD agency
[6] 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 family member receiving services and supports from the regional center.

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

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

Table 26. Do you get enough information to take part in planning services for your family member?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	33%	31%	19%	18%	187
CA Average	35%	35%	17%	12%	4636
Weighted NCI-IDD Average	39%	36%	17%	8%	7769

Table 27. Is the information you get about services and supports easy to understand?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	42%	45%	9%	5%	170
CA Average	41%	43%	11%	4%	4499
Weighted NCI-IDD Average	39%	45%	12%	3%	7636

Table 28. Do you get information about services and supports in your preferred language?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	87%	4%	2%	7%	193
CA Average	87%	6%	2%	5%	4846
Weighted NCI-IDD Average	90%	5%	1%	3%	8086

Table 29. Does the case manager or service coordinator listen to your family's choices and opinions?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	59%	24%	9%	9%	173
CA Average	54%	28%	10%	8%	4581
Weighted NCI-IDD Average	58%	28%	9%	5%	7751

Table 30. Do staff or the residential agency keep you informed about how your family member is doing?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	50%	23%	13%	15%	171
CA Average	47%	26%	14%	12%	4701
Weighted NCI-IDD Average	46%	30%	15%	9%	7871

Table 31a. Do you need help planning for your family member'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	27%	35%	41%	29%	42%
CA Average	28%	35%	41%	25%	45%
Weighted NCI-IDD Average	28%	34%	40%	28%	44%

Table 31b. Do you need help planning for your family member'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	32%	5%	37%	17%
CA Average	38%	6%	41%	14%
Weighted NCI-IDD Average	36%	4%	42%	16%

Table 32. Has your family learned about alternatives to guardianship/conservatorship?

Regional Center	Yes	No	N
FNRC	56%	44%	144
CA Average	51%	49%	3914
Weighted NCI-IDD Average	54%	46%	6560

*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 support** like health-care proxies, advance directives, powers of attorney, notarized statements, representation agreements, etc."*

Table 33. Does your family member have an individual program plan (IPP)?

Regional Center	Yes	No	N
FNRC	94%	6%	156
CA Average	90%	10%	4165
Weighted NCI-IDD Average	92%	8%	6930

Table 34. Does the IPP include all the services and supports your family member needs?

Regional Center	Yes	No	N
FNRC	93%	7%	127
CA Average	89%	11%	3268
Weighted NCI-IDD Average	90%	10%	5633

Table 35. Did you or someone else in your family (besides your family member with an intellectual/developmental disability) help make the IPP?

Regional Center	Yes	No	N
FNRC	67%	33%	141
CA Average	76%	24%	3506
Weighted NCI-IDD Average	82%	18%	5948

Table 36. Did your family member help make the IPP?

Regional Center	Yes	No	N
FNRC	73%	27%	127
CA Average	65%	35%	3409
Weighted NCI-IDD Average	66%	34%	5804

Table 37. Do you feel like your family had enough say or input in making the IPP?

Regional Center	Yes	No	N
FNRC	85%	15%	126
CA Average	86%	14%	3301
Weighted NCI-IDD Average	89%	11%	5651

Table 38. Did your family member leave school services and begin adult services during the past 12 months?

Regional Center	Yes	No	N
FNRC	3%	97%	194
CA Average	3%	97%	4753
Weighted NCI-IDD Average	2%	98%	7915

Table 39. If your family member left school services during the past 12 months, did your family member have a transition plan?

Regional Center	Yes	No	N
FNRC	n/a	n/a	n/a
CA Average	43%	57%	101
Weighted NCI-IDD Average	60%	40%	135

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 40. If your family member had a transition plan, did the transition plan include getting or continuing work in a community job?

Regional Center	Yes	No	N
FNRC	n/a	n/a	n/a
CA Average	41%	59%	37
Weighted NCI-IDD Average	59%	41%	60

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.

Access and Delivery of Services and Supports

Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the regional center.

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

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

Table 41. Does your family member get all the services listed in the IPP?

Regional Center	Yes	No	N
FNRC	92%	8%	124
CA Average	89%	11%	3129
Weighted NCI-IDD Average	88%	12%	5360

Table 42. Does your family get the supports and services it needs?

Regional Center	Yes	No	N
FNRC	84%	16%	175
CA Average	86%	14%	4326
Weighted NCI-IDD Average	88%	12%	7254

Table 43a. If your family 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 Family Member	Homemaker Services	Home and/or Vehicle Modifications
FNRC	0%	15%	12%	0%
CA Average	9%	33%	20%	6%
Weighted NCI-IDD Average	10%	30%	19%	8%

Table 43b. If your family 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 or Training to Use Assistive Technology	Other
FNRC	31%	15%	4%	50%
CA Average	35%	13%	13%	46%
Weighted NCI-IDD Average	26%	14%	16%	46%

Table 44. Do services and supports change when your family's needs change?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	43%	42%	12%	4%	138
CA Average	39%	42%	13%	6%	3258
Weighted NCI-IDD Average	39%	41%	14%	6%	5563

Table 45. Does your family member have enough supports to work or volunteer in the community? (These types of supports might include support workers, community resources, transportation)

Regional Center	Yes	No	N
FNRC	73%	27%	127
CA Average	62%	38%	2928
Weighted NCI-IDD Average	66%	34%	4937

Table 46. Does your family member have the special equipment or accommodations that they need?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	69%	26%	2%	3%	90
CA Average	61%	28%	6%	5%	2447
Weighted NCI-IDD Average	63%	28%	6%	3%	4261

Table 47. Are you or your family member able to contact support workers when you want?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	47%	37%	7%	8%	180
CA Average	48%	38%	9%	6%	4451
Weighted NCI-IDD Average	50%	37%	9%	4%	7511

Table 48. Are you or your family member able to contact the case manager/service coordinator when you want?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	48%	35%	10%	6%	187
CA Average	49%	33%	10%	7%	4734
Weighted NCI-IDD Average	55%	32%	8%	4%	7879

Table 49. Do service providers for your family member work together to provide support?

Regional Center	Yes	No	N
FNRC	93%	8%	120
CA Average	92%	8%	3225
Weighted NCI-IDD Average	93%	7%	5546

Table 50. Are services delivered in a way that is respectful of your family's culture?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	77%	18%	4%	2%	169
CA Average	77%	19%	2%	2%	4423
Weighted NCI-IDD Average	75%	21%	3%	1%	7523

Table 51. Does your family member use technology in their everyday life to help them do things on their own?

Regional Center	Yes	No	N
FNRC	41%	59%	181
CA Average	31%	69%	4679
Weighted NCI-IDD Average	28%	72%	7724

Table 52. Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?

Regional Center	Yes	No	N
FNRC	92%	8%	198
CA Average	92%	8%	5006
Weighted NCI-IDD Average	91%	9%	8183

Table 53. How well does 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	84%	14%	2%	189
CA Average	86%	11%	3%	4863
Weighted NCI-IDD Average	86%	11%	3%	7907

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.

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

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

Table 54. Do support workers come and go when they are supposed to?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	57%	32%	10%	1%	127
CA Average	51%	40%	6%	2%	3160
Weighted NCI-IDD Average	52%	41%	6%	2%	5363

Table 55. Do support workers speak to you in a way you understand?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	75%	19%	4%	2%	175
CA Average	72%	23%	4%	2%	4361
Weighted NCI-IDD Average	72%	23%	4%	1%	7400

Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	56%	34%	7%	2%	41
CA Average	49%	36%	11%	4%	1737
Weighted NCI-IDD Average	44%	40%	12%	5%	3041

Table 57. 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	45%	40%	13%	3%	152
CA Average	41%	45%	11%	3%	4124
Weighted NCI-IDD Average	40%	45%	13%	3%	7050

Table 58. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

Regional Center	Yes	No	N
FNRC	39%	61%	137
CA Average	32%	68%	3701
Weighted NCI-IDD Average	42%	58%	6372

Table 59. Is there always a staff person available to support your family member when support is needed?

Regional Center	Yes	No	N
FNRC	88%	12%	150
CA Average	88%	12%	4184
Weighted NCI-IDD Average	88%	12%	7079

Choice, Decision Making and Control

Families and family members 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.

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

Table 60. Can someone in your family choose or change the provider agency that provides your family member's services?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	57%	23%	6%	14%	100
CA Average	54%	24%	7%	15%	2648
Weighted NCI-IDD Average	61%	22%	6%	12%	4855

Table 61. Can someone in your family choose or change your family member's support workers?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	40%	15%	15%	31%	101
CA Average	35%	21%	13%	31%	2573
Weighted NCI-IDD Average	32%	19%	13%	37%	4519

Table 62. Can someone in your family directly manage support staff?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	21%	13%	7%	60%	104
CA Average	18%	11%	9%	62%	2611
Weighted NCI-IDD Average	15%	9%	7%	70%	4538

Table 63. Did you, your family member, or someone else in your family choose your family member'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%	66%	27%	149
CA Average	11%	60%	29%	3897
Weighted NCI-IDD Average	20%	55%	25%	6569

Community Connections

Family members 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.

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

"Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.

Table 64. Does your family member do things in the community?

Regional Center	Yes	No	N
FNRC	88%	12%	190
CA Average	83%	17%	4824
Weighted NCI-IDD Average	87%	13%	7943

Table 65. For your family member, 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	22%	30%	15%	7%	27%
CA Average	22%	19%	19%	10%	25%
Weighted NCI-IDD Average	20%	17%	27%	9%	25%

Table 66. Does your family member have friends other than paid support workers or family?

Regional Center	Yes	No	N
FNRC	73%	27%	181
CA Average	60%	40%	4600
Weighted NCI-IDD Average	63%	37%	7578

Table 67. In your community, are there resources or support that your family member can use that are not provided by the regional center[7]?

Regional Center	Yes	No	N
FNRC	84%	16%	131
CA Average	75%	25%	3299
Weighted NCI-IDD Average	79%	21%	5511

Table 68. Does your family take part in any family-to-family networks in your community?

Regional Center	Yes	No	N
FNRC	10%	90%	168
CA Average	15%	85%	4342
Weighted NCI-IDD Average	15%	85%	7009

[7] 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 family member receiving services and supports from the regional center.

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

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

Table 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	65%	25%	8%	3%	192
CA Average	71%	22%	4%	3%	4843
Weighted NCI-IDD Average	75%	20%	3%	3%	7999

Table 70. Does your family member's primary care provider (doctor, registered nurse, etc.) understand your family member's needs related to their intellectual/developmental disability?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	53%	32%	15%	0%	177
CA Average	56%	34%	8%	2%	4526
Weighted NCI-IDD Average	60%	33%	6%	1%	7564

Table 71. Can your family member go to the dentist when needed?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	53%	23%	10%	13%	193
CA Average	64%	23%	8%	6%	4855
Weighted NCI-IDD Average	68%	22%	6%	4%	8016

Table 72. Does your family member's dentist understand your family member's needs related to their intellectual/developmental disability?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	56%	33%	7%	4%	142
CA Average	63%	29%	6%	3%	4015
Weighted NCI-IDD Average	65%	28%	5%	2%	6799

Table 73. If your family member takes prescription medications, do you know what they're for?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	69%	24%	5%	2%	170
CA Average	71%	21%	6%	2%	4328
Weighted NCI-IDD Average	70%	22%	6%	2%	7335

Table 74. Do you, your family member, 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	74%	18%	5%	3%	162
CA Average	75%	18%	4%	3%	4107
Weighted NCI-IDD Average	74%	20%	3%	3%	7003

Table 75. Can your family member 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	40%	32%	9%	19%	159
CA Average	48%	25%	9%	18%	3676
Weighted NCI-IDD Average	55%	25%	8%	13%	6310

Table 76. Does your family member's mental or behavioral health professional understand your family member's needs related to their intellectual/developmental disability?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	54%	35%	6%	5%	117
CA Average	56%	32%	8%	4%	3085
Weighted NCI-IDD Average	58%	31%	7%	3%	5363

Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

Regional Center	Yes	No	N
FNRC	79%	21%	42
CA Average	80%	20%	1321
Weighted NCI-IDD Average	79%	21%	2161

Table 78. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency, pandemic or natural disaster?

Regional Center	Yes	No	N
FNRC	82%	18%	181
CA Average	78%	22%	4304
Weighted NCI-IDD Average	81%	19%	7078

Table 79. Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member's case manager/service coordinator?

Regional Center	Yes	No	N
FNRC	48%	52%	196
CA Average	44%	56%	4732
Weighted NCI-IDD Average	48%	52%	7788

Table 80. 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	50%	50%	206
CA Average	48%	52%	5113
Weighted NCI-IDD Average	56%	44%	8333

Table 81. 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	56%	44%	433
Weighted NCI-IDD Average	57%	43%	883

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 82. Do you know how to report abuse or neglect related to your family member?

Regional Center	Yes	No or Don't Know	N
FNRC	74%	26%	201
CA Average	63%	37%	5104
Weighted NCI-IDD Average	69%	31%	8325

Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

Regional Center	Yes	No	N
FNRC	3%	97%	186
CA Average	3%	97%	4770
Weighted NCI-IDD Average	6%	94%	7842

Table 84. If a report of abuse or neglect was filed on behalf of a family member, or if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

Regional Center	Yes	No	N
FNRC	n/a	n/a	n/a
CA Average	66%	34%	88
Weighted NCI-IDD Average	77%	23%	309

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.

Family Satisfaction

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

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

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

Table 85. Overall, are you satisfied with the services and supports your family member currently receives?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	42%	40%	13%	5%	198
CA Average	46%	41%	9%	3%	4996
Weighted NCI-IDD Average	44%	43%	11%	3%	8223

Table 86. Do you feel that services and supports have made a positive difference in the life of your family member?

Regional Center	Yes	No	N
FNRC	93%	7%	189
CA Average	95%	5%	4766
Weighted NCI-IDD Average	95%	5%	7827

Table 87. Does the agency providing residential services to your family member involve them in important decisions?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FNRC	59%	24%	10%	7%	147
CA Average	51%	30%	10%	8%	3713
Weighted NCI-IDD Average	48%	32%	12%	8%	6437

Table 88. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

Regional Center	Yes	No	N
FNRC	15%	85%	167
CA Average	11%	89%	4314
Weighted NCI-IDD Average	10%	90%	7298

Table 89. 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 member negatively?

Regional Center	Yes	No	N
FNRC	90%	10%	20
CA Average	81%	19%	389
Weighted NCI-IDD Average	84%	16%	667

Table 90. Have the services or supports that your family member received been increased in the past 12 months?

Regional Center	Yes	No	N
FNRC	24%	76%	147
CA Average	21%	79%	3597
Weighted NCI-IDD Average	21%	79%	6228

Table 91. Are services and supports helping your family member to live a good life?

Regional Center	Yes	No	N
FNRC	95%	5%	172
CA Average	95%	5%	4628
Weighted NCI-IDD Average	95%	5%	7617

California Specific Questions

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

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

Table 92a. Services Paid for Out-Of-Pocket in the Past Year

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

Regional Center	Behavior Therapy	Educational Expenses	Medical and/or Dental Expenses	Other Therapies	Recreational Activities and Programs
FNRC	3%	4%	24%	3%	24%
CA Average	5%	3%	30%	6%	24%

Table 92b. 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	1%	1%	14%	7%	57%
CA Average	2%	1%	13%	7%	53%

Table 93. Total Out-of-Pocket Expenses Related to Family Member'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	58%	30%	8%	3%	1%	192
CA Average	50%	32%	12%	4%	3%	4923

Table 94. 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	67%	33%	170
CA Average	62%	38%	4173

Table 95. Does your regional center keep you informed, in your preferred language, about programs or services it offers? (For example, updates about new programs or services they offer)

Regional Center	Yes	No	N
FNRC	71%	29%	174
CA Average	64%	36%	4482

Table 96. Did you get a copy of your family member's IPP in your preferred language?

Regional Center	Yes	No	N
FNRC	92%	8%	131
CA Average	88%	12%	3484

Table 97. Do the support workers 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	99%	0%	1%	177
CA Average	97%	1%	2%	4616

Table 98. Does your family member'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%	0%	1%	185
CA Average	98%	1%	2%	4663

Table 99. 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	18%	12%	18%	52%	50

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

Table 100. Does your family member'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	93%	6%	0%	1%	164
CA Average	85%	12%	2%	2%	4408

Table 101. 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	91%	8%	1%	0%	153
CA Average	84%	13%	2%	1%	4288

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	94%	6%	125
CA Average	91%	9%	2535

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 (Providing PSPS Temporary Resources)	More Information on What I Need for Life Sustaining Equipment I Use
FNRC	29%	24%	13%	17%	4%
CA Average	34%	23%	15%	23%	7%

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	23%	29%	22%	21%	16%
CA Average	26%	30%	21%	20%	17%

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	17%	14%	3%	55%
CA Average	15%	19%	5%	47%

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 intellectual/developmental 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.

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.

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 Experiencee. Each domain is broken down into sub-domains, as shown in the following table. Four data sources are used to assess outcomes: the Adult In-Person Survey, three Family Surveys, a Staff Stability Survey (e.g., staff turnover), and system data from state administrative records (e.g., mortality rates).

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. [8]

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.

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

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.

Sampling & Administration

States were asked to administer the Child Family Survey by selecting a random sample of 2,000 families who:

1. Had an adult individual (aged 18 or over) with an intellectual or developmental disability living outside of the home; and

2. The adult individual with an intellectual or developmental disability living outside of the home received at least one direct service or support other than 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). [9]

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 9 states (AZ, CA, DE, IN, MD, MN, ND, NJ, PA) 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:

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

1. The respondent indicated the individual with an intellectual or developmental disability receiving services lived outside of the family home.

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

Response Rates

During 2023-24, 11 states, including California administered the Family/Guardian 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. Family/Guardian Surveys Regional Center Response Rates[10] [11]

Regional Center	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
FNRC	1635	1635	212	13%	6.2%	89%	11%
CA	37204	37204	5274	14%	1.2%	81%	19%
NCI	103,302	104,705	8,614	8%	1.0%	76%	24%

[10] 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

[11] 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).