Adult Family Survey

2023-24 California Regional Center Report

Frank D. Lanterman Regional Center

Prepared by Human Services Research Institute for the
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NCI·IDD NATIONAL CORE INDICATORS PEOPLE DRIVEN DATA

DDS Department of Developmental Services

National Association of State Directors of Developmental Disabilities Services (NASDDDS)
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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, 14,131 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 14,131 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 and developmental disabilities and their families. Indicators address key areas of concern such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that result from NCI-IDD surveys are often used to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Many states also share the data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction.

The National Core Indicators (NCI-IDD) Adult Family Survey is administered to families who have an adult family member (18 years or older) 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 Adult 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, 13 states[1] submitted a valid sample of Adult Family Survey data. **Please note: the NCI-IDD averages shown throughout this report are weighted[2].**

In California, the Adult Family Survey is administered once every two years and data are collected from all 21 regional centers. The California statewide average is comprised of this 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.

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[1] Arizona (AZ), California (CA), District of Columbia (DC), Georgia (GA), Indiana (IN), Maryland (MD), Missouri (MO), Montana (MT), New Jersey (NJ), New Hampshire (NH), Oklahoma (OK), Pennsylvania (PA), and Virginia (VA)

[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.

Demographic

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 1. More Than One Person Living In the Home Has IDD

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	Yes	No	N
FDLRC	18%	82%	510
CA Average	17%	83%	13593
Weighted NCI-IDD Average	15%	85%	18027

Table 2. Family Member's Residential Designation

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	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
FDLRC	99%	1%	475
CA Average	90%	10%	13115
Weighted NCI-IDD Average	79%	21%	17493

Table 3. Family Member's Age

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	Age	N
FDLRC	32.2	528
CA Average	33.5	14,126
Weighted NCI-IDD Average	34.1	18,654

Table 4. Family Member’s Gender

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	Male	Female	Other	N
FDLRC	64%	35%	0%	500
CA Average	63%	37%	0%	13485
Weighted NCI-IDD Average	62%	38%	0%	17861

Table 5. Family Member’s Race/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
FDLRC	1%	20%	7%	0%	29%	46%	3%	3%
CA Average	2%	16%	8%	1%	42%	38%	2%	3%
Weighted NCI-IDD Average	2%	10%	12%	1%	57%	22%	2%	3%

Table 6a. 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/Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy
FDLRC	52%	24%	55%	12%
CA Average	60%	21%	46%	15%
Weighted NCI-IDD Average	65%	22%	44%	16%

Table 6b. 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	Limited or No Vision – Legally Blind	Hearing Loss – Severe or Profound	Brain Injury	Seizure or Neurological Disorder
FDLRC	7%	5%	6%	19%
CA Average	8%	5%	7%	21%
Weighted NCI-IDD Average	7%	5%	7%	24%

Table 6c. 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	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
FDLRC	1%	8%	1%	1%	9%
CA Average	1%	13%	0%	1%	14%
Weighted NCI-IDD Average	0%	14%	0%	1%	16%

Table 7a. 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
FDLRC	5%	15%	4%	27%	30%
CA Average	8%	17%	4%	25%	30%
Weighted NCI-IDD Average	9%	16%	4%	25%	29%

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	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Dementia	Oral Health Problems	Sleep Apnea
FDLRC	8%	1%	3%	10%	10%
CA Average	7%	1%	2%	12%	18%
Weighted NCI-IDD Average	9%	2%	2%	11%	19%

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	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
FDLRC	19%	4%	2%	1%	22%
CA Average	19%	5%	3%	1%	23%
Weighted NCI-IDD Average	19%	5%	3%	1%	26%

Table 8. 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 family member’s demographics, diagnoses and personal characteristics.

Regional Center	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
FDLRC	83%	7%	2%	2%	6%	515
CA Average	83%	10%	2%	2%	4%	13592
Weighted NCI-IDD Average	81%	11%	2%	2%	4%	18082

Table 9a. Family Member’s Preferred Language

Please note: The standard NCI-IDD Adult Family 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 Adult Family Survey report, the CA data under “Other” capture the data on the additional CA language categories. Therefore, the data for CA in the “Other” category in this report will not match the standard NCI-IDD Adult Family Survey 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
FDLRC	59%	19%	1%	1%	0%	524
CA Average	76%	14%	1%	1%	1%	13767
Weighted NCI-IDD Average	86%	8%	1%	0%	1%	18273

Table 9b. Family Member’s Preferred Language (continued)

Please note: The standard NCI-IDD Adult Family 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 Adult Family Survey report, the CA data under “Other” capture the data on the additional CA language categories. Therefore, the data for CA in the “Other” category in this report will not match the standard NCI-IDD Adult Family Survey 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
FDLRC	0%	0%	3%	0%	0%	0%	524
CA Average	0%	0%	0%	0%	0%	0%	13767
Weighted NCI-IDD Average	1%	n/a	n/a	n/a	n/a	n/a	18273

Table 9c. Family Member’s Preferred Language (continued)

Please note: The standard NCI-IDD Adult Family 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 Adult Family Survey report, the CA data under “Other” capture the data on the additional CA language categories. Therefore, the data for CA in the “Other” category in this report will not match the standard NCI-IDD Adult Family Survey 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
FDLRC	0%	0%	2%	0%	1%	15%	524
CA Average	0%	0%	0%	0%	0%	5%	13767
Weighted NCI-IDD Average	n/a	n/a	n/a	n/a	n/a	3%	18273

Table 10. 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
FDLRC	37%	30%	27%	6%	494
CA Average	41%	29%	25%	5%	13006
Weighted NCI-IDD Average	35%	19%	42%	4%	17332

Table 11. 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 family member’s demographics, diagnoses and personal characteristics.

Regional Center	Family	Friend	Regional Center Employee or Guardianship or Conservatorship Agency	Other	N
FDLRC	97%	1%	0%	2%	288
CA Average	97%	1%	0%	2%	6972
Weighted NCI-IDD Average	96%	1%	0%	3%	9876

Table 12a. 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 family member’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
FDLRC	18%	3%	28%	485
CA Average	16%	2%	37%	13095
Weighted NCI-IDD Average	14%	2%	37%	17525

Table 12b. 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 family member’s demographics, diagnoses and personal characteristics.

Regional Center	High School Diploma/GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
FDLRC	26%	5%	11%	8%	485
CA Average	24%	4%	9%	7%	13095
Weighted NCI-IDD Average	31%	4%	7%	6%	17525

Table 13. 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
FDLRC	38%	34%	27%	493
CA Average	47%	31%	22%	13324
Weighted NCI-IDD Average	51%	30%	18%	17749

Table 14. 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
FDLRC	27%	35%	37%	510
CA Average	27%	36%	37%	13704
Weighted NCI-IDD Average	25%	38%	37%	18212

Table 15. 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
FDLRC	7%	26%	67%	510
CA Average	6%	26%	68%	13756
Weighted NCI-IDD Average	5%	22%	73%	18248

Respondents

This section provides information about the survey respondent

Table 16a. 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; the NCI-IDD Average for "Other" captures the additional languages in the standard tool. 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
FDLRC	45%	31%	1%	2%	0%	515
CA Average	69%	21%	2%	1%	1%	13771
Weighted NCI-IDD Average	83%	11%	1%	1%	1%	18260

Table 16b. Language Usually Spoken at Home (continued)

Please note: The standard NCI-IDD Adult Family 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; the NCI-IDD Average for "Other" captures the additional languages in the standard tool. 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
FDLRC	0%	0%	4%	0%	0%	0%	515
CA Average	0%	0%	0%	0%	0%	0%	13771
Weighted NCI-IDD Average	0%	n/a	n/a	n/a	n/a	n/a	18260

Table 16c. Language Usually Spoken at Home (continued)

Please note: The standard NCI-IDD Adult Family 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; the NCI-IDD Average for "Other" captures the additional languages in the standard tool. 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
FDLRC	1%	0%	5%	0%	1%	10%	515
CA Average	0%	0%	1%	0%	0%	4%	13771
Weighted NCI-IDD Average	n/a	n/a	n/a	n/a	n/a	3%	18260

Table 17. Respondent's Age

Regional Center	18 - 34	35 – 54	55 – 74	75 or older	N
FDLRC	9%	23%	58%	10%	515
CA Average	6%	21%	61%	11%	13860
Weighted NCI-IDD Average	5%	19%	64%	12%	18384

Table 18. Respondent's Health

Regional Center	Excellent	Very good	Good	Fair	Poor	N
FDLRC	11%	25%	38%	22%	4%	518
CA Average	11%	31%	39%	17%	2%	13884
Weighted NCI-IDD Average	12%	32%	39%	15%	2%	18409

Table 19. Respondent's Relationship to Family Member

Regional Center	Parent (Biological, Adoptive, or Foster)	Sibling	Spouse	Grandparent	Other	N
FDLRC	91%	5%	0%	2%	2%	522
CA Average	88%	6%	0%	2%	4%	13962
Weighted NCI-IDD Average	88%	6%	0%	2%	3%	18498

Table 20. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services

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

Regional Center	No	Yes, Respondent Does	Yes, Another Family Member Does
FDLRC	45%	39%	19%
CA Average	46%	42%	16%
Weighted NCI-IDD Average	51%	37%	16%

Data combined from "select all that apply" questions and therefore might sum over 100%.

Table 21. Number of Adults in Household (Not Including Family Member Receiving Supports)

Regional Center	One	Two	Three	Four or More	N
FDLRC	8%	26%	40%	26%	516
CA Average	7%	25%	42%	26%	13850
Weighted NCI-IDD Average	7%	27%	44%	22%	18353

Table 22. Number of Children (Under 18 Years Old) in Household

Regional Center	One	Two	Three	Four or Nore	None	N
FDLRC	10%	3%	0%	0%	87%	518
CA Average	10%	4%	1%	1%	84%	13918
Weighted NCI-IDD Average	8%	3%	1%	1%	88%	18444

Table 23. 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
FDLRC	24%	19%	5%	14%	37%	514
CA Average	15%	18%	6%	21%	39%	13653
Weighted NCI-IDD Average	10%	20%	6%	20%	44%	18130

Table 24. Total Taxable Household Income of Wage Earners in the Past 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–$25,000	$25,001–$50,000	$50,001–$75,000	Over $75,000	Prefer Not to Say	N
FDLRC	9%	9%	15%	16%	13%	19%	18%	497
CA Average	8%	6%	9%	18%	13%	23%	22%	13508
Weighted NCI-IDD Average	9%	6%	8%	16%	13%	25%	23%	17958

Services and Supports Received

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

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[3] Some NCI States provide services through a statewide ID/IDD agency.

Table 25a. Services and Supports Received from Regional Center[4]

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	Financial Support	In Home Support	Out-of-Home Respite Care	Day or Employment Supports
FDLRC	15%	47%	24%	36%
CA Average	20%	38%	25%	50%
Weighted NCI-IDD Average	18%	39%	24%	50%

Table 25b. Services and Supports Received from Regional Center[5] (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	Transportation	Mental/Behavioral Health Care or Other Treatments or Therapies	Self-direction/Fiscal Intermediary Services
FDLRC	23%	15%	18%
CA Average	39%	13%	23%
Weighted NCI-IDD Average	47%	24%	34%

Table 26. Additional Services and Supports Received (not from the regional centers)[6]

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	Social Security SSI/SSB	Services or Supports from Other Agencies or Organizations
FDLRC	74%	25%
CA Average	81%	24%
Weighted NCI-IDD Average	88%	28%

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

[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

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	26%	28%	30%	15%	446
CA Average	29%	33%	25%	13%	12447
Weighted NCI-IDD Average	33%	36%	21%	9%	16742

Table 28. Is the information you get about services and supports easy to understand?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	31%	37%	25%	7%	458
CA Average	31%	41%	23%	6%	12517
Weighted NCI-IDD Average	29%	44%	21%	5%	16807

Table 29. Do you get information about services and supports in your preferred language?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	67%	16%	12%	5%	486
CA Average	75%	13%	7%	5%	13317
Weighted NCI-IDD Average	82%	10%	4%	4%	17701

Table 30. Does the case manager/service coordinator listen to your family’s choices and opinions?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	50%	26%	16%	7%	476
CA Average	55%	28%	12%	5%	12898
Weighted NCI-IDD Average	63%	25%	9%	3%	17230

Table 31. 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
FDLRC	17%	30%	26%	27%	408
CA Average	22%	29%	24%	24%	11272
Weighted NCI-IDD Average	25%	30%	23%	22%	15055

Table 32a. Do you need help planning for your family member's future in any of the following areas?

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

Regional Center	Employment	Financial	Housing	Legal
FDLRC	43%	40%	57%	33%
CA Average	38%	38%	48%	34%
Weighted NCI-IDD Average	34%	38%	51%	35%

Table 32b. Do you need help planning for your family member's future in any of the following areas? (continued)

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

Regional Center	Medical	Social or Relationships	Transition from School	Recreation or Having Fun	Other
FDLRC	37%	42%	18%	44%	7%
CA Average	34%	38%	14%	42%	10%
Weighted NCI-IDD Average	32%	37%	11%	41%	11%

Table 33. Has your family learned about alternatives to guardianship/conservatorship?

Regional Center	Yes	No	N
FDLRC	51%	49%	402
CA Average	49%	51%	11154
Weighted NCI-IDD Average	51%	49%	14984

*Alternatives to guardianship/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 34. Does your family member have an individual program plan (IPP)?

Regional Center	Yes	No	N
FDLRC	74%	26%	422
CA Average	80%	20%	11819
Weighted NCI-IDD Average	83%	17%	15776

Table 35. Does the IPP include all the services and supports your family member needs?

Regional Center	Yes	No	N
FDLRC	84%	16%	257
CA Average	82%	18%	7805
Weighted NCI-IDD Average	85%	15%	10865

Table 36. 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
FDLRC	76%	24%	289
CA Average	79%	21%	8745
Weighted NCI-IDD Average	83%	17%	12060

Table 37. Did your family member help make the IPP?

Regional Center	Yes	No	N
FDLRC	56%	44%	289
CA Average	63%	37%	8707
Weighted NCI-IDD Average	65%	35%	11996

Table 38. Do you feel like your family had enough say or input in making the IPP?

Regional Center	Yes	No	N
FDLRC	74%	26%	262
CA Average	81%	19%	8136
Weighted NCI-IDD Average	89%	11%	11308

Table 39. Did your family member leave school services and begin adult services during the past 12 months?

Regional Center	Yes	No	N
FDLRC	25%	75%	449
CA Average	17%	83%	12500
Weighted NCI-IDD Average	11%	89%	16820

Table 40. If your family member left school services during the past 12 months, did they have a transition plan?

Regional Center	Yes	No	N
FDLRC	64%	36%	76
CA Average	68%	32%	1569
Weighted NCI-IDD Average	71%	29%	1724

Table 41. If your family member had a transition plan, did the plan include getting or continuing work in a community job?

Regional Center	Yes	No	N
FDLRC	46%	54%	41
CA Average	49%	51%	925
Weighted NCI-IDD Average	48%	52%	1037

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

Regional Center	Yes	No	N
FDLRC	80%	20%	256
CA Average	82%	18%	7860
Weighted NCI-IDD Average	83%	17%	10970

Table 43. Does your family get the supports and services it needs?

Regional Center	Yes	No	N
FDLRC	72%	28%	397
CA Average	72%	28%	10923
Weighted NCI-IDD Average	73%	27%	14789

Table 44a. 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
FDLRC	31%	40%	21%	9%
CA Average	43%	34%	19%	10%
Weighted NCI-IDD Average	52%	34%	18%	12%

Table 44b. 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	Assistive Technology Training and Support	Other
FDLRC	43%	21%	19%	33%
CA Average	29%	19%	18%	33%
Weighted NCI-IDD Average	23%	17%	14%	33%

Table 45. Do services and supports change when your family’s needs change?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	35%	33%	21%	10%	361
CA Average	34%	37%	19%	10%	9185
Weighted NCI-IDD Average	39%	38%	16%	7%	12442

Table 46. Does your family member have enough supports to work or volunteer in the community?

Regional Center	Yes	No	N
FDLRC	39%	61%	326
CA Average	50%	50%	8959
Weighted NCI-IDD Average	55%	45%	12095

Table 47. Does your family member have the special equipment or accommodations they need?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	48%	24%	14%	15%	160
CA Average	48%	29%	12%	12%	4810
Weighted NCI-IDD Average	49%	29%	11%	10%	6704

Table 48. If you need respite services, how often are you able to get them when needed?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	40%	26%	14%	21%	294
CA Average	36%	28%	15%	20%	8121
Weighted NCI-IDD Average	32%	28%	15%	25%	10692

Table 49. 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
FDLRC	59%	27%	6%	8%	215
CA Average	62%	23%	8%	7%	5693
Weighted NCI-IDD Average	61%	23%	8%	8%	7042

Table 50. Are you or your family member able to contact their support workers when you want?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	39%	28%	21%	12%	409
CA Average	40%	35%	17%	8%	11092
Weighted NCI-IDD Average	47%	35%	12%	5%	15009

Table 51. Are you or your family member able to contact their case manager/service coordinator when you want?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	43%	27%	22%	9%	479
CA Average	46%	33%	15%	6%	12871
Weighted NCI-IDD Average	55%	31%	10%	4%	17199

Table 52. Do service providers for your family member work together to provide support?

Regional Center	Yes	No	N
FDLRC	65%	35%	256
CA Average	74%	26%	6609
Weighted NCI-IDD Average	81%	19%	8992

Table 53. Are services delivered in a way that is respectful of your family's culture?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	67%	25%	4%	3%	435
CA Average	73%	21%	3%	3%	11393
Weighted NCI-IDD Average	78%	18%	2%	2%	15443

Table 54. Does your family member use technology in their everyday life to help them do things on their own?

Regional Center	Yes	No	N
FDLRC	39%	61%	478
CA Average	34%	66%	13042
Weighted NCI-IDD Average	32%	68%	17341

Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?

Regional Center	Yes	No	N
FDLRC	90%	10%	512
CA Average	91%	9%	13725
Weighted NCI-IDD Average	91%	9%	18136

Table 56. 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
FDLRC	69%	28%	3%	490
CA Average	77%	21%	3%	13516
Weighted NCI-IDD Average	79%	19%	3%	17869

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	50%	33%	11%	6%	386
CA Average	52%	35%	9%	4%	9511
Weighted NCI-IDD Average	58%	32%	8%	3%	13056

Table 58. Do support workers speak to you in a way you understand?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	67%	22%	6%	4%	418
CA Average	70%	23%	5%	2%	10709
Weighted NCI-IDD Average	74%	21%	4%	1%	14474

Table 59. 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
FDLRC	43%	27%	17%	13%	205
CA Average	42%	30%	15%	13%	5211
Weighted NCI-IDD Average	45%	32%	13%	10%	6942

Table 60. Do support workers have the right information and skills to meet your family's needs?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	42%	36%	16%	7%	398
CA Average	42%	40%	14%	4%	10155
Weighted NCI-IDD Average	48%	37%	12%	3%	13801

Table 61. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

Regional Center	Yes	No	N
FDLRC	37%	63%	375
CA Average	37%	63%	9329
Weighted NCI-IDD Average	35%	65%	12750

Table 62. Is there always a staff person available to support your family member when support is needed?

Regional Center	Yes	No	N
FDLRC	71%	29%	369
CA Average	74%	26%	9219
Weighted NCI-IDD Average	75%	25%	12645

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	41%	31%	14%	14%	271
CA Average	51%	28%	9%	12%	7158
Weighted NCI-IDD Average	62%	24%	7%	8%	10234

Table 64. Can someone in your family choose or change your family member's support workers?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	42%	25%	13%	20%	284
CA Average	49%	27%	11%	14%	7012
Weighted NCI-IDD Average	57%	24%	9%	10%	9896

Table 65. Can someone in your family directly manage support staff?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	42%	26%	16%	17%	277
CA Average	52%	25%	9%	14%	6711
Weighted NCI-IDD Average	59%	21%	7%	13%	9417

Table 66. 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
FDLRC	12%	65%	23%	393
CA Average	14%	64%	22%	9970
Weighted NCI-IDD Average	26%	59%	16%	13687

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.

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

Table 67. Does your family member do things in the community?

Regional Center	Yes	No	N
FDLRC	76%	24%	497
CA Average	79%	21%	13555
Weighted NCI-IDD Average	83%	17%	17917

Table 68. 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
FDLRC	22%	26%	18%	17%	20%
CA Average	20%	20%	19%	13%	23%
Weighted NCI-IDD Average	20%	19%	19%	12%	24%

Table 69. Does your family member have friends other than paid support workers or family?

Regional Center	Yes	No	N
FDLRC	45%	55%	493
CA Average	55%	45%	13138
Weighted NCI-IDD Average	59%	41%	17419

Table 70. In your community, are there resources that your family can use that are not provided by the regional center[7] (for example, recreational programs, community housing, library programs, religious groups, etc.)?

Regional Center	Yes	No	N
FDLRC	65%	35%	353
CA Average	72%	28%	9280
Weighted NCI-IDD Average	74%	26%	12548

Table 71. Does your family take part in any family-to-family networks in your community?

Regional Center	Yes	No	N
FDLRC	23%	77%	440
CA Average	17%	83%	11844
Weighted NCI-IDD Average	18%	82%	15563

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

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	63%	19%	7%	11%	478
CA Average	69%	19%	6%	6%	13267
Weighted NCI-IDD Average	74%	18%	4%	4%	17615

Table 73. Does your family member's primary care doctor understand your family member's needs related to their intellectual/developmental disability?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	54%	31%	11%	4%	479
CA Average	55%	31%	11%	3%	12987
Weighted NCI-IDD Average	59%	30%	9%	2%	17304

Table 74. Can your family member go to the dentist when needed?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	61%	18%	12%	9%	497
CA Average	64%	19%	9%	8%	13509
Weighted NCI-IDD Average	67%	18%	7%	8%	17852

Table 75. 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
FDLRC	55%	25%	13%	7%	469
CA Average	58%	27%	10%	5%	12164
Weighted NCI-IDD Average	62%	26%	8%	4%	16129

Table 76. If your family member takes prescription medications, do you know what they're for?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	83%	9%	4%	4%	399
CA Average	87%	8%	2%	2%	10957
Weighted NCI-IDD Average	89%	7%	2%	2%	14760

Table 77. 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
FDLRC	84%	11%	3%	2%	393
CA Average	88%	10%	2%	1%	10806
Weighted NCI-IDD Average	90%	8%	1%	1%	14623

Table 78. 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
FDLRC	33%	19%	13%	34%	383
CA Average	40%	21%	11%	28%	9937
Weighted NCI-IDD Average	46%	21%	9%	24%	13080

Table 79. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their intellectual/developmental disability?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	54%	29%	11%	6%	299
CA Average	52%	29%	12%	7%	7399
Weighted NCI-IDD Average	55%	29%	10%	6%	9624

Table 80. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

Regional Center	Yes	No	N
FDLRC	48%	52%	164
CA Average	55%	45%	3592
Weighted NCI-IDD Average	57%	43%	4376

Table 81. Do you feel prepared to handle the needs of your family member in an emergency, such as a medical emergency or natural disaster?

Regional Center	Yes	No	N
FDLRC	84%	16%	450
CA Average	90%	10%	12445
Weighted NCI-IDD Average	92%	8%	16533

Table 82. 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
FDLRC	44%	56%	450
CA Average	50%	50%	12349
Weighted NCI-IDD Average	54%	46%	16420

Table 83. Do you know how to file a complaint or grievance about provider agencies or staff?

Regional Center	Yes	No or Don't Know	N
FDLRC	35%	65%	508
CA Average	44%	56%	13718
Weighted NCI-IDD Average	50%	50%	18077

Table 84. 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 or Don't Know	N
FDLRC	26%	74%	116
CA Average	29%	71%	2089
Weighted NCI-IDD Average	35%	65%	2508

Table 85. Do you know how to report abuse or neglect related to your family member?

Regional Center	Yes	No or Don't Know	N
FDLRC	69%	31%	442
CA Average	78%	22%	12096
Weighted NCI-IDD Average	82%	18%	16134

Table 86. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

Regional Center	Yes	No	N
FDLRC	1%	99%	478
CA Average	1%	99%	13184
Weighted NCI-IDD Average	2%	98%	17445

Table 87. If a report of abuse or neglect was filed on behalf of your 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
FDLRC	n/a	n/a	n/a
CA Average	70%	30%	115
Weighted NCI-IDD Average	70%	30%	160

FDLRC 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 88. Overall, are you satisfied with the services and supports your family member currently receives?

Regional Center	Always	Usually	Sometimes	Seldom or Never	N
FDLRC	37%	38%	18%	7%	495
CA Average	39%	40%	16%	5%	13436
Weighted NCI-IDD Average	41%	40%	14%	4%	17756

Table 89. Do you feel that services and supports have made a positive difference in the life of your family member?

Regional Center	Yes	No	N
FDLRC	90%	10%	468
CA Average	92%	8%	12541
Weighted NCI-IDD Average	93%	7%	16655

Table 90. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

Regional Center	Yes	No	N
FDLRC	67%	33%	418
CA Average	67%	33%	11723
Weighted NCI-IDD Average	69%	31%	15649

Table 91. 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
FDLRC	13%	87%	455
CA Average	12%	88%	12350
Weighted NCI-IDD Average	12%	88%	16464

Table 92. 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
FDLRC	81%	19%	48
CA Average	77%	23%	1292
Weighted NCI-IDD Average	78%	22%	1756

Table 93. Have the services or supports that your family member received been increased in the past 12 months?

Regional Center	Yes	No	N
FDLRC	23%	77%	463
CA Average	22%	78%	12149
Weighted NCI-IDD Average	22%	78%	16050

Table 94. Are services and supports helping your family member to live a good life?

Regional Center	Yes	No	N
FDLRC	91%	9%	443
CA Average	92%	8%	12025
Weighted NCI-IDD Average	93%	7%	16043

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 95a. Services Paid for Out-Of-Pocket in the Past Year

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

Regional Center	Afterschool Care	Behavior Therapy	Educational Expenses	Medical and/or Dental Expenses
FDLRC	4%	6%	11%	33%
CA Average	3%	5%	8%	40%

Table 95b. 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
FDLRC	7%	2%	24%	7%
CA Average	9%	2%	30%	7%

Table 95c. 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
FDLRC	3%	4%	21%	6%	43%
CA Average	3%	3%	20%	6%	38%

Table 96. Total Out-of-pocket Expenses Related to Family Member’s Care in the Past Year

Regional Center	Nothing	$1 - $1,999	$2,000 - $5,999	$6,000 - $11,999	$12,000 Or Over	N
FDLRC	42%	29%	17%	5%	6%	486
CA Average	35%	38%	17%	5%	4%	12911

Table 97. 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
FDLRC	54%	46%	408
CA Average	61%	39%	11155

Table 98. Does your regional center keep you informed, in your preferred language, about programs or services it offers?

Regional Center	Yes	No	N
FDLRC	74%	26%	471
CA Average	75%	25%	12236

Table 99. Did you get a copy of your family member’s individual program plan (IPP) in your preferred language?

Regional Center	Yes	No	N
FDLRC	89%	11%	300
CA Average	95%	5%	8917

Table 100. 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
FDLRC	95%	2%	3%	460
CA Average	96%	2%	2%	11963

Table 101. Does your family member's case manager/service coordinator 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
FDLRC	94%	3%	3%	494
CA Average	96%	2%	2%	13014

Table 102. 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
FDLRC	n/a	n/a	n/a	n/a	n/a
CA Average	16%	16%	28%	41%	202

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

Table 103. 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
FDLRC	77%	17%	4%	2%	471
CA Average	83%	15%	2%	1%	12337

Table 104. 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
FDLRC	76%	19%	3%	2%	436
CA Average	82%	15%	2%	1%	11137

Table 105. 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
FDLRC	81%	19%	298
CA Average	89%	11%	8867

Table 106a. 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
FDLRC	55%	37%	31%	47%	18%
CA Average	46%	32%	26%	35%	13%

Table 106b. 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
FDLRC	33%	40%	26%	42%	35%
CA Average	27%	34%	21%	37%	29%

Table 106c. 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
FDLRC	30%	32%	3%	24%
CA Average	23%	26%	3%	34%

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 In-Person Survey[8] (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

In recent years, 48 states, the District of Columbia and 22 sub-state entities participated in NCI-IDD. State participation is entirely voluntary. 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

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[8] Formerly named 'Adult Consumer Survey'

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 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.

Sub-Domains and Concern Statements

The following table lists the sub-domains under the "Family Experience" 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 Adult Family Survey who:

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

2. The adult individual 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). [10]

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, DC, IN, MD, MO, MT, 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:

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] 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, 13 states, including California administered the Adult 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. Adult Family Surveys Regional Center Response Rates[11] [12]

Regional Center	Total Population	Surveys Sent	Usable Surveys	Response Rate	Margin of Error	Paper Submission	Direct Entry Submission
FDLRC	2,891	2,891	528	18%	3.9%	84%	16%
CA Average	98,223	98,223	14,131	14%	0.8%	83%	17%
NCI	204,619	121,084	18,724	15%	0.7%	80%	20%

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[11] 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

[12] 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).