

# Child Family Survey

## 2023-24 California Regional Center Report

### San Gabriel/Pomona Regional Center

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## **Message from the California Department of Developmental Services**

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

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

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

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

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

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

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

## ***Acknowledgements***

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

### ***List of Abbreviations Used in This Report***

AFS - Adult Family Survey

ARCA - Association of Regional Center Agencies

CAC - Consumer Advisory Committee

CA-ODESA - California Online Data Entry Survey Administration

CCF - Community Care Facility

CIP - Core Indicators Project

CFS - Child Family Survey

CMS - Centers for Medicare & Medicaid Services

DDS - Department of Developmental Services

FGS - Family/Guardian Survey

FHA - Family Home Agency

HCBS – Home and Community-Based Services

HSRI - Human Services Research Institute

ICF - Intermediate Care Facility

ILS/SLS - Independent Living Services/Supported Living Services

NASDDDS - National Association of State Directors of Developmental Disabilities Services

NCI - National Core Indicators

QAC - Quality Assessment Coordinator

RC - Regional Center

SCDD - State Council of Developmental Disabilities

### ***List of Regional Center Abbreviations***

ACRC- Alta California Regional Center  
CVRC- Central Valley Regional Center  
ELARC- Eastern Los Angeles Regional Center  
FDLRC- Frank D. Lanterman Regional Center  
FNRC- Far Northern Regional Center  
GGRC- Golden Gate Regional Center  
HRC- Harbor Regional Center  
IRC- Inland Regional Center  
KRC- Kern Regional Center  
NBRC- North Bay Regional Center  
NLACRC- North Los Angeles County Regional Center  
RCEB- Regional Center of the East Bay  
RCOC- Regional Center of Orange County  
RCRC- Redwood Coast Regional Center  
SARC- San Andreas Regional Center  
SCLARC- South Central Los Angeles Regional Center  
SDRC- San Diego Regional Center  
SG/PRC- San Gabriel/Pomona Regional Center  
TCRC- Tri-Counties Regional Center Regional Center  
VMRC- Valley Mountain Regional Center  
WRC- Westside Regional Center

## Table of Contents

|                                                                                                                     |           |
|---------------------------------------------------------------------------------------------------------------------|-----------|
| <b>Child Family Survey</b> .....                                                                                    | <b>1</b>  |
| <b>Executive Summary</b> .....                                                                                      | <b>13</b> |
| <b>Results</b> .....                                                                                                | <b>14</b> |
| <b>Presentation of the Data</b> .....                                                                               | <b>15</b> |
| Demographic.....                                                                                                    | 16        |
| Child .....                                                                                                         | 17        |
| Table 1. More Than One Child Living in the Home Has IDD.....                                                        | 18        |
| Table 2. Child's Age .....                                                                                          | 18        |
| Table 3. Child's Gender .....                                                                                       | 18        |
| Table 4. Child's Race and Ethnicity .....                                                                           | 19        |
| Table 5a. Child's Conditions .....                                                                                  | 19        |
| Table 5b. Child's Conditions (continued).....                                                                       | 19        |
| Table 5c. Child's Conditions (continued).....                                                                       | 20        |
| Table 6a. Child's Health Conditions.....                                                                            | 20        |
| Table 6b. Child's Health Conditions (continued) .....                                                               | 20        |
| Table 6c. Child's Health Conditions (continued) .....                                                               | 21        |
| Table 7a. Child's Preferred Language.....                                                                           | 21        |
| Table 7b. Child's Preferred Language (continued) .....                                                              | 22        |
| Table 7c. Child's Preferred Language (continued) .....                                                              | 22        |
| Table 8. Child's Preferred Means of Communication .....                                                             | 23        |
| Table 9. Child's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors ....                    | 23        |
| Table 10. Child's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating) ..... | 23        |
| Respondents .....                                                                                                   | 24        |
| Table 11a. Language Usually Spoken at Home.....                                                                     | 25        |
| Table 11b. Language Usually Spoken at Home (continued) .....                                                        | 25        |
| Table 11c. Language Usually Spoken at Home (continued).....                                                         | 25        |
| Table 12. Respondent's Age.....                                                                                     | 26        |
| Table 13. Respondent's Health .....                                                                                 | 26        |
| Table 14. Respondent's Relationship to Child .....                                                                  | 26        |
| Table 15. Respondent or Other Family Member Provides Paid Support to Child.....                                     | 26        |
| Table 16. Number of Adults in Household.....                                                                        | 27        |
| Table 17. Number of Children (Under 18 years old) in Household (Including the Child Receiving Services) .....       | 27        |

|                                                                                                                                                                           |    |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Table 18. Respondent's Highest Level of Education.....                                                                                                                    | 27 |
| Table 19. Total Taxable Household Income of Wage Earners in the Past 12 Months .....                                                                                      | 28 |
| Table 20 Residential Designation.....                                                                                                                                     | 28 |
| Services and Supports Received.....                                                                                                                                       | 29 |
| Table 21a. Services and Supports Received from Regional Center .....                                                                                                      | 30 |
| Table 21b. Services and Supports Received from Regional Center (continued) .....                                                                                          | 30 |
| Table 22. Additional Services and Supports Received (not from the regional center) .....                                                                                  | 30 |
| Main Survey Results .....                                                                                                                                                 | 31 |
| Information and Planning .....                                                                                                                                            | 32 |
| Table 23. Do you have enough information to take part in planning services for your child? ....                                                                           | 33 |
| Table 24. Is the information you get about services and supports easy to understand? .....                                                                                | 33 |
| Table 25. Do you get information about services and supports in your preferred language? ...                                                                              | 33 |
| Table 26. Does the case manager/service coordinator listen to your family's choices and<br>opinions? .....                                                                | 33 |
| Table 27. Do you have enough information about other public services for which your family is<br>eligible (for example, food stamps, SSI, housing subsidies, etc.)? ..... | 34 |
| Table 28a. Do you need help planning for your child's future in any of these areas? .....                                                                                 | 34 |
| Table 28b. Do you need help planning for your child's future in any of these areas? (continued)<br>.....                                                                  | 34 |
| Table 29. Has your family learned about alternatives to guardianship/conservatorship? .....                                                                               | 34 |
| Table 30. Does your child have an individual program plan/individual family service plan<br>(IPP/IFSP)? .....                                                             | 35 |
| Table 31. Does the IPP/IFSP include all the services and supports your child needs? .....                                                                                 | 35 |
| Table 32. Did you or another family member help make the IPP/IFSP? .....                                                                                                  | 35 |
| Table 33. Did your child help make the IPP/IFSP? .....                                                                                                                    | 35 |
| Table 34. Do you feel like your family had enough say or input in making the IPP/IFSP? .....                                                                              | 36 |
| Table 35. Does your child have a transition plan (as part of an IEP or Section 504 plan through<br>their high school, usually starting at age 14)? .....                  | 36 |
| Table 36. If your child has a transition plan, did you or another family member help make the<br>plan? .....                                                              | 36 |
| Table 37. If your child has a transition plan, did your child help make the plan? .....                                                                                   | 36 |
| Access and Delivery of Services and Supports.....                                                                                                                         | 37 |
| Table 38. Does your child get all the services listed in the IPP/IFSP? .....                                                                                              | 38 |
| Table 39. Does your family get the supports and services it needs? .....                                                                                                  | 38 |
| Table 40a. If your child does not get the support and services needed, what additional services<br>does your family need? .....                                           | 38 |

|                                                                                                                                          |           |
|------------------------------------------------------------------------------------------------------------------------------------------|-----------|
| Table 40b. If your child does not get the support and services needed, what additional services does your family need? (continued) ..... | 38        |
| Table 41. Do services and supports change when your family's needs change? .....                                                         | 39        |
| Table 42. Does your child have the special equipment or accommodations they need? .....                                                  | 39        |
| Table 43. If you need respite services, how often are you able to get them when needed? .....                                            | 39        |
| Table 44. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services? .....    | 39        |
| Table 45. Are you able to contact your child's support workers when you want? .....                                                      | 40        |
| Table 46. Are you able to contact your child's case manager/ service coordinator when you want? .....                                    | 40        |
| Table 47. Do service providers for your child work together to provide support? .....                                                    | 40        |
| Table 48. Are services delivered in a way that is respectful of your family's culture? .....                                             | 40        |
| Table 49. Does your child use technology in their everyday life to help them do things on their own? .....                               | 41        |
| Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home? .....                   | 41        |
| Table 51. How well does the internet work in your home? .....                                                                            | 41        |
| <b>Workforce .....</b>                                                                                                                   | <b>42</b> |
| Table 52. Do support workers come and go when they are supposed to? .....                                                                | 43        |
| Table 53. Do support workers speak to you in a way you understand? .....                                                                 | 43        |
| Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child? .....              | 43        |
| Table 55. Do support workers have the right information and skills to meet your family's needs? .....                                    | 44        |
| Table 56. Do your child's support workers change too often? Is there too much "turnover" of support workers? .....                       | 44        |
| Table 57. Is there always a staff person available to support your child when support is needed? .....                                   | 44        |
| <b>Choice, Decision Making and Control .....</b>                                                                                         | <b>45</b> |
| Table 58. Can someone in your family choose or change the provider agency that provides your child's services? .....                     | 46        |
| Table 59. Can someone in your family choose or change your child's support workers? .....                                                | 46        |
| Table 60. Can someone in your family directly manage support staff? .....                                                                | 47        |
| Table 61. Did you, your child, or someone else in your family choose your child's case manager/service coordinator? .....                | 47        |
| <b>Community Connections .....</b>                                                                                                       | <b>48</b> |
| Table 62. Does your child do things in the community? .....                                                                              | 49        |
| Table 63. What makes it hard to do things in the community? .....                                                                        | 49        |

|                                                                                                                                                                                                                                           |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Table 64. Does your child spend time with children who do not have developmental disabilities? .....                                                                                                                                      | 49 |
| Table 65. In your community, are there resources that your family and child can use that are not provided by the regional center (for example, recreational programs, community housing, library programs, religious groups, etc.)? ..... | 50 |
| Table 66. Does your family take part in any family-to-family networks in your community? .....                                                                                                                                            | 50 |
| Health, Welfare, and Safety.....                                                                                                                                                                                                          | 51 |
| Table 67. Can your child see a primary care provider (doctor, registered nurse, etc.) when needed? .....                                                                                                                                  | 52 |
| Table 68. Does your child's primary care doctor understand your child's needs related to their intellectual/developmental disability? .....                                                                                               | 52 |
| Table 69. Can your child go to the dentist when needed? .....                                                                                                                                                                             | 52 |
| Table 70. Does your child's dentist understand your child's needs related to their intellectual/developmental disability? .....                                                                                                           | 52 |
| Table 71. If your child takes prescription medications, do you know what they're for? .....                                                                                                                                               | 53 |
| Table 72. Do you or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)? .....                                        | 53 |
| Table 73. Can your child get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling) .....                                                                                                       | 53 |
| Table 74. If your child uses mental health services, does the mental health professional understand your child's needs related to their intellectual/developmental disability? .....                                                      | 53 |
| Table 75. If you asked for crisis or emergency services during the past 12 months, were services provided when needed? .....                                                                                                              | 54 |
| Table 76. Do you feel prepared to handle the needs of your child in an emergency, such as a medical emergency or natural disaster? .....                                                                                                  | 54 |
| Table 77. Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child's case manager/service coordinator? .....                                                              | 54 |
| Table 78. Do you know how to file a complaint or grievance about provider agencies or staff? .....                                                                                                                                        | 54 |
| Table 79. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled? .....                                                                                                   | 55 |
| Table 80. Do you know how to report abuse or neglect related to your child? .....                                                                                                                                                         | 55 |
| Table 81. Within the past 12 months, was a report of abuse or neglect filed on behalf of your child? .....                                                                                                                                | 56 |
| Table 82. If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner? .....                                                                                                          | 56 |
| Satisfaction With Services and Supports .....                                                                                                                                                                                             | 57 |

|                                                                                                                                                                                                         |    |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Table 83. Overall, are you satisfied with the services and supports your child currently receives? .....                                                                                                | 58 |
| Table 84. Do you feel that services and supports have made a positive difference in the life of your child? .....                                                                                       | 58 |
| Table 85. Have services and supports reduced your family's out-of-pocket expenses for your child's care? .....                                                                                          | 58 |
| Table 86. Do you feel that family supports have improved your ability to care for your child? ..                                                                                                        | 58 |
| Table 87. Have the services or supports that your child received during the past 12 months been reduced, suspended, or terminated? .....                                                                | 59 |
| Table 88. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family or your child negatively? ..... | 59 |
| Table 89. Have the services or supports that your child received been increased in the past 12 months? .....                                                                                            | 59 |
| Table 90. Are services and supports helping your child to live a good life? .....                                                                                                                       | 59 |
| California Specific Questions.....                                                                                                                                                                      | 60 |
| Table 91a. Services Paid for Out-Of-Pocket in The Past Year .....                                                                                                                                       | 61 |
| Table 91b. Services Paid for Out-Of-Pocket in The Past Year (continued).....                                                                                                                            | 61 |
| Table 91c. Services Paid for Out-Of-Pocket in The Past Year (continued).....                                                                                                                            | 61 |
| Table 92. Total Out-of-Pocket Expenses Related to Child's Care in the Past Year .....                                                                                                                   | 61 |
| Table 93. Do you know what to do if you disagree with your regional center about services and/or eligibility? (For example, how to request a Fair Hearing) .....                                        | 62 |
| Table 94. Does your regional center keep you informed, in your preferred language, about programs or services it offers?.....                                                                           | 62 |
| Table 95. Did you get a copy of your child's IPP/IFSP in your preferred language? .....                                                                                                                 | 62 |
| Table 96. Do the support workers for your child speak to you in your preferred language? .....                                                                                                          | 62 |
| Table 97. Does your child's case manager/service coordinator speak your preferred language? .....                                                                                                       | 63 |
| Table 98. If your support workers and/or case manager/service coordinator do not speak to you in your preferred language, is a translator provided when needed? .....                                   | 63 |
| Table 99. Does your child's case manager/service coordinator support you in a way that is respectful to your culture? .....                                                                             | 63 |
| Table 100. Do support workers for your family members provide services in a way that is respectful of your culture? .....                                                                               | 63 |
| Table 101. How often does your child spend time with children who are not siblings and do not have an intellectual/developmental disability? .....                                                      | 64 |
| 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? .....                                 | 64 |
| Table 103a. What else do you need to make effective plans for emergencies? .....                                                                                                                        | 65 |

|                                                                                              |           |
|----------------------------------------------------------------------------------------------|-----------|
| Table 103b. What else do you need to make effective plans for emergencies? (continued) ..... | 65        |
| Table 103c. What else do you need to make effective plans for emergencies? (continued) ..... | 65        |
| <b>NCI History and Activities .....</b>                                                      | <b>66</b> |
| Overview of National Core Indicators—Intellectual and Developmental Disabilities .....       | 67        |
| State Participation .....                                                                    | 67        |
| The Core Indicators.....                                                                     | 67        |
| Sub-Domains and Concern Statements .....                                                     | 68        |
| Figure 1. Family Survey Sub-Domains and Concern Statements.....                              | 68        |
| How NCI-IDD Data Are Used .....                                                              | 69        |
| Caution and Limitations .....                                                                | 69        |
| <b>Methodology.....</b>                                                                      | <b>69</b> |
| Sampling & Administration.....                                                               | 70        |
| Weighting.....                                                                               | 70        |
| Data Entry and Analysis.....                                                                 | 70        |
| Response Rates .....                                                                         | 71        |
| Figure 2. Child Family Surveys Regional Center Response Rates .....                          | 72        |

## Executive Summary

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

The National Core Indicators (NCI-IDD) Child Family Survey is administered to families who have a child<sup>1</sup> with an intellectual or developmental disability who lives in the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Child Family Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI during the 2023-24 data collection cycle, five states<sup>2</sup> submitted a valid sample of Child Family Survey data. **Please note: the NCI-IDD averages shown throughout this report are weighted.**<sup>3</sup>

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

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

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<sup>1</sup> Some states include people up to 21 years old receiving child services

<sup>2</sup> California (CA), Louisiana (LA), Missouri (MO), Oregon (OR), and Wisconsin (WI)

<sup>3</sup> For more information see "Weighting" in the Methodology section

## Results

This section provides regional center, California, and NCI-IDD results for demographic and survey outcomes data.

## Presentation of the Data

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

Each question is constructed so the respondent selects from either four possible responses (“always,” “usually,” “sometimes,” “seldom/never”) or two responses (“yes” or “no”). Respondents also have the option to indicate that they don’t know the answer to a question or that the question is not applicable.

Demographic results are shown in table form with regional centers listed alphabetically. Outcomes are shown first with a chart depicting the CA average. The charts are followed by accessible tables showing regional center outcomes listed alphabetically.

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

**Note on NCI Averages:** The NCI-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the states’ sample sizes. See more about weighting in the Methodology section.

**Note on language used in this report:** “You” and “Respondent” refers to the person (usually a parent or conservator) filling out the survey. “Child” refers to the person receiving services whom the respondent is answering questions about in this survey.

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

“N” demonstrates the number of valid responses for each question. “N” can vary between questions. The N does not include missing responses, “don’t know” responses or “not applicable” responses. For information on the total sample from each regional center see Figure 2.

## Demographic

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

## Child

This section provides demographic information about the child receiving services.

**Table 1. More Than One Child Living in the Home Has IDD**

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics.*

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 63% | 37% | 280  |
| <b>CA Average</b>               | 65% | 35% | 8074 |
| <b>Weighted NCI-IDD Average</b> | 65% | 35% | 9778 |

**Table 2. Child's Age**

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics.*

| Regional Center                 | Age  | N      |
|---------------------------------|------|--------|
| <b>SGPRC</b>                    | 11.0 | 284    |
| <b>CA Average</b>               | 10.9 | 8,276  |
| <b>Weighted NCI-IDD Average</b> | 10.6 | 10,031 |

**Table 3. Child's Gender**

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics.*

| Regional Center                 | Male | Female | Other | N     |
|---------------------------------|------|--------|-------|-------|
| <b>SGPRC</b>                    | 73%  | 27%    | 0%    | 284   |
| <b>CA Average</b>               | 71%  | 28%    | 0%    | 8276  |
| <b>Weighted NCI-IDD Average</b> | 70%  | 30%    | 0%    | 10031 |

**Table 4. Child's Race and Ethnicity**

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

| Regional Center                 | American Indian or Alaska Native | Asian | Black or African American | Pacific Islander | White | Hispanic or Latino | Other | Prefer Not to Say |
|---------------------------------|----------------------------------|-------|---------------------------|------------------|-------|--------------------|-------|-------------------|
| <b>SGPRC</b>                    | 2%                               | 33%   | 4%                        | 2%               | 17%   | 58%                | 1%    | 3%                |
| <b>CA Average</b>               | 2%                               | 18%   | 8%                        | 1%               | 33%   | 52%                | 2%    | 2%                |
| <b>Weighted NCI-IDD Average</b> | 2%                               | 15%   | 9%                        | 1%               | 42%   | 43%                | 2%    | 2%                |

**Table 5a. Child's Conditions**

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

| Regional Center                 | Intellectual Disability | Mood Illness/ Psychiatric Diagnosis | Autism Spectrum Disorder | Cerebral Palsy |
|---------------------------------|-------------------------|-------------------------------------|--------------------------|----------------|
| <b>SGPRC</b>                    | 43%                     | 10%                                 | 79%                      | 6%             |
| <b>CA Average</b>               | 35%                     | 13%                                 | 78%                      | 7%             |
| <b>Weighted NCI-IDD Average</b> | 36%                     | 15%                                 | 74%                      | 7%             |

**Table 5b. Child's Conditions (continued)**

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

| Regional Center                 | Limited or No Vision – Legally Blind | Hearing Loss – Severe or Profound | Brain Injury | Seizure Disorder and/or Neurological Problem | Chemical Dependency |
|---------------------------------|--------------------------------------|-----------------------------------|--------------|----------------------------------------------|---------------------|
| <b>SGPRC</b>                    | 4%                                   | 2%                                | 4%           | 10%                                          | 0%                  |
| <b>CA Average</b>               | 5%                                   | 3%                                | 3%           | 12%                                          | 0%                  |
| <b>Weighted NCI-IDD Average</b> | 5%                                   | 4%                                | 4%           | 13%                                          | 0%                  |

**Table 5c. Child's Conditions (continued)**

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

| Regional Center                 | Down Syndrome | Prader-Willi Syndrome | Fetal Alcohol Spectrum Disorder (FASD) | Other Disabilities |
|---------------------------------|---------------|-----------------------|----------------------------------------|--------------------|
| <b>SGPRC</b>                    | 6%            | 0%                    | 1%                                     | 16%                |
| <b>CA Average</b>               | 8%            | 0%                    | 1%                                     | 18%                |
| <b>Weighted NCI-IDD Average</b> | 8%            | 0%                    | 1%                                     | 21%                |

**Table 6a. Child's Health Conditions**

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

| Regional Center                 | Cardiovascular Disease | Diabetes | Cancer | High Blood Pressure | High Cholesterol |
|---------------------------------|------------------------|----------|--------|---------------------|------------------|
| <b>SGPRC</b>                    | 8%                     | 5%       | 2%     | 4%                  | 6%               |
| <b>CA Average</b>               | 8%                     | 3%       | 2%     | 3%                  | 7%               |
| <b>Weighted NCI-IDD Average</b> | 9%                     | 3%       | 2%     | 3%                  | 6%               |

**Table 6b. Child's Health Conditions (continued)**

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

| Regional Center                 | Dysphagia | Pressure Ulcers | Oral Health or Dental Problems | Sleep Apnea | Other Pulmonary Diagnosis (e.g., COPD, Bronchitis, Emphysema) |
|---------------------------------|-----------|-----------------|--------------------------------|-------------|---------------------------------------------------------------|
| <b>SGPRC</b>                    | 6%        | 1%              | 7%                             | 21%         | 5%                                                            |
| <b>CA Average</b>               | 9%        | 1%              | 9%                             | 20%         | 7%                                                            |
| <b>Weighted NCI-IDD Average</b> | 11%       | 1%              | 9%                             | 21%         | 8%                                                            |

**Table 6c. Child's Health Conditions (continued)**

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

| Regional Center                 | Asthma | Chronic Kidney Disease | Long-term Health Problems Associated with COVID-19 | Other |
|---------------------------------|--------|------------------------|----------------------------------------------------|-------|
| <b>SGPRC</b>                    | 40%    | 3%                     | 2%                                                 | 32%   |
| <b>CA Average</b>               | 40%    | 2%                     | 1%                                                 | 33%   |
| <b>Weighted NCI-IDD Average</b> | 36%    | 2%                     | 1%                                                 | 35%   |

**Table 7a. Child's Preferred Language**

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

| Regional Center                 | English | Spanish | Chinese | Tagalog | Vietnamese | N    |
|---------------------------------|---------|---------|---------|---------|------------|------|
| <b>SGPRC</b>                    | 81%     | 7%      | 4%      | 0%      | 0%         | 284  |
| <b>CA Average</b>               | 79%     | 12%     | 1%      | 0%      | 0%         | 8085 |
| <b>Weighted NCI-IDD Average</b> | 83%     | 10%     | 0%      | 0%      | 0%         | 9800 |

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

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

| Regional Center                 | American Sign Language | Arabic | Armenian | Farsi | Hindi | Hmong | N    |
|---------------------------------|------------------------|--------|----------|-------|-------|-------|------|
| <b>SGPRC</b>                    | 0%                     | 0%     | 0%       | 0%    | 0%    | 0%    | 284  |
| <b>CA Average</b>               | 0%                     | 0%     | 0%       | 0%    | 0%    | 0%    | 8085 |
| <b>Weighted NCI-IDD Average</b> | 0%                     | n/a    | n/a      | n/a   | n/a   | n/a   | 9800 |

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

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

| Regional Center                 | Japanese | Khmer | Korean | Laotian | Russian | Other | N    |
|---------------------------------|----------|-------|--------|---------|---------|-------|------|
| <b>SGPRC</b>                    | 0%       | 0%    | 1%     | 0%      | 0%      | 6%    | 284  |
| <b>CA Average</b>               | 0%       | 0%    | 0%     | 0%      | 0%      | 6%    | 8085 |
| <b>Weighted NCI-IDD Average</b> | n/a      | n/a   | n/a    | n/a     | n/a     | 5%    | 9800 |

**Table 8. Child's Preferred Means of Communication**

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics.*

| Regional Center                 | Spoken | Gestures or Body Language | Sign Language or Finger Spelling | Communication Aid or Device | Other | N    |
|---------------------------------|--------|---------------------------|----------------------------------|-----------------------------|-------|------|
| <b>SGPRC</b>                    | 69%    | 19%                       | 4%                               | 5%                          | 3%    | 280  |
| <b>CA Average</b>               | 71%    | 17%                       | 2%                               | 5%                          | 5%    | 8079 |
| <b>Weighted NCI-IDD Average</b> | 70%    | 17%                       | 2%                               | 6%                          | 5%    | 9807 |

**Table 9. Child's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors**

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics.*

| Regional Center                 | No Support Needed; No Issues with Managing Behavior | Some Support Needed; Requires Only Occasional Assistance or Monitoring | Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance | N    |
|---------------------------------|-----------------------------------------------------|------------------------------------------------------------------------|-----------------------------------------------------------------------------------|------|
| <b>SGPRC</b>                    | 28%                                                 | 42%                                                                    | 30%                                                                               | 276  |
| <b>CA Average</b>               | 26%                                                 | 43%                                                                    | 30%                                                                               | 8011 |
| <b>Weighted NCI-IDD Average</b> | 28%                                                 | 43%                                                                    | 29%                                                                               | 9745 |

**Table 10. Child's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)**

*Please note: All data in this section are reported by the respondent based on their understanding of their child's demographics, diagnoses and personal characteristics.*

| Regional Center                 | No Support Needed; No Issues with Personal Care Activities | Some Support Needed; Requires Only Occasional Assistance or Monitoring | Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance | N    |
|---------------------------------|------------------------------------------------------------|------------------------------------------------------------------------|-----------------------------------------------------------------------------------|------|
| <b>SGPRC</b>                    | 9%                                                         | 44%                                                                    | 47%                                                                               | 282  |
| <b>CA Average</b>               | 9%                                                         | 42%                                                                    | 49%                                                                               | 8189 |
| <b>Weighted NCI-IDD Average</b> | 9%                                                         | 42%                                                                    | 49%                                                                               | 9940 |

## Respondents

This section provides information about the survey respondent.

**Table 11a. Language Usually Spoken at Home**

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

| Regional Center                 | English | Spanish | Chinese | Tagalog | Vietnamese | N    |
|---------------------------------|---------|---------|---------|---------|------------|------|
| <b>SGPRC</b>                    | 59%     | 24%     | 11%     | 1%      | 1%         | 283  |
| <b>CA Average</b>               | 61%     | 28%     | 2%      | 1%      | 1%         | 8114 |
| <b>Weighted NCI-IDD Average</b> | 69%     | 23%     | 2%      | 1%      | 1%         | 9845 |

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

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

| Regional Center                 | American Sign Language | Arabic | Armenian | Farsi | Hindi | Hmong | N    |
|---------------------------------|------------------------|--------|----------|-------|-------|-------|------|
| <b>SGPRC</b>                    | 0%                     | 0%     | 0%       | 0%    | 0%    | 0%    | 283  |
| <b>CA Average</b>               | 0%                     | 0%     | 0%       | 0%    | 0%    | 0%    | 8114 |
| <b>Weighted NCI-IDD Average</b> | 0%                     | n/a    | n/a      | n/a   | n/a   | n/a   | 9845 |

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

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

| Regional Center                 | Japanese | Khmer | Korean | Laotian | Russian | Other | N    |
|---------------------------------|----------|-------|--------|---------|---------|-------|------|
| <b>SGPRC</b>                    | 0%       | 0%    | 1%     | 0%      | 0%      | 2%    | 283  |
| <b>CA Average</b>               | 0%       | 0%    | 1%     | 0%      | 0%      | 5%    | 8114 |
| <b>Weighted NCI-IDD Average</b> | n/a      | n/a   | n/a    | n/a     | n/a     | 4%    | 9845 |

Table 12. Respondent's Age

| Regional Center                 | Under 35 | 35 – 54 | 55 – 74 | 75 or Older | N    |
|---------------------------------|----------|---------|---------|-------------|------|
| <b>SGPRC</b>                    | 9%       | 76%     | 15%     | 0%          | 282  |
| <b>CA Average</b>               | 9%       | 76%     | 14%     | 1%          | 8181 |
| <b>Weighted NCI-IDD Average</b> | 11%      | 74%     | 14%     | 1%          | 9943 |

Table 13. Respondent's Health

| Regional Center                 | Excellent | Very Good | Good | Fair | Poor | N    |
|---------------------------------|-----------|-----------|------|------|------|------|
| <b>SGPRC</b>                    | 8%        | 30%       | 38%  | 22%  | 2%   | 283  |
| <b>CA Average</b>               | 13%       | 30%       | 40%  | 15%  | 2%   | 8184 |
| <b>Weighted NCI-IDD Average</b> | 13%       | 31%       | 40%  | 15%  | 2%   | 9944 |

Table 14. Respondent's Relationship to Child

| Regional Center                 | Parent (Biological, Adoptive, or Foster) | Sibling | Grandparent | Other | N    |
|---------------------------------|------------------------------------------|---------|-------------|-------|------|
| <b>SGPRC</b>                    | 98%                                      | 0%      | 1%          | 1%    | 284  |
| <b>CA Average</b>               | 96%                                      | 0%      | 3%          | 1%    | 8190 |
| <b>Weighted NCI-IDD Average</b> | 96%                                      | 0%      | 3%          | 1%    | 9948 |

Table 15. Respondent or Other Family Member Provides Paid Support to Child

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

| Regional Center                 | No  | Yes, I Am | Yes, Another Family Member Is |
|---------------------------------|-----|-----------|-------------------------------|
| <b>SGPRC</b>                    | 50% | 33%       | 19%                           |
| <b>CA Average</b>               | 52% | 32%       | 18%                           |
| <b>Weighted NCI-IDD Average</b> | 58% | 26%       | 17%                           |

Table 16. Number of Adults in Household

| Regional Center                 | One | Two | Three | Four or More | N    |
|---------------------------------|-----|-----|-------|--------------|------|
| <b>SGPRC</b>                    | 12% | 54% | 20%   | 15%          | 281  |
| <b>CA Average</b>               | 16% | 54% | 20%   | 10%          | 8082 |
| <b>Weighted NCI-IDD Average</b> | 17% | 56% | 18%   | 9%           | 9814 |

Table 17. Number of Children (Under 18 years old) in Household (Including the Child Receiving Services)

| Regional Center                 | One | Two | Three | Four or More | N    |
|---------------------------------|-----|-----|-------|--------------|------|
| <b>SGPRC</b>                    | 38% | 44% | 11%   | 7%           | 274  |
| <b>CA Average</b>               | 38% | 39% | 16%   | 7%           | 7984 |
| <b>Weighted NCI-IDD Average</b> | 37% | 39% | 16%   | 8%           | 9700 |

Table 18. Respondent's Highest Level of Education

| Regional Center                 | No High School Diploma or GED | High School Diploma or GED | Vocational School or Certificate Program | Some College | College Degree or Higher | N    |
|---------------------------------|-------------------------------|----------------------------|------------------------------------------|--------------|--------------------------|------|
| <b>SGPRC</b>                    | 17%                           | 15%                        | 8%                                       | 16%          | 44%                      | 283  |
| <b>CA Average</b>               | 15%                           | 18%                        | 8%                                       | 16%          | 43%                      | 8124 |
| <b>Weighted NCI-IDD Average</b> | 13%                           | 18%                        | 8%                                       | 16%          | 46%                      | 9867 |

**Table 19. Total Taxable Household Income of Wage Earners in the Past 12 Months**

*Please note: Respondents did not respond if they were a public conservator/administrator, or if they represent a financial institution or conservatorship agency. Does not include state/federal benefits such as SSI, SSDI etc.*

| Regional Center                      | No<br>Earned<br>Income | Up to<br>\$15,000 | \$15,001–<br>\$25,000 | \$25,001–<br>\$50,000 | \$50,001–<br>\$75,000 | Over<br>\$75,000 | Prefer<br>Not to<br>Say | N    |
|--------------------------------------|------------------------|-------------------|-----------------------|-----------------------|-----------------------|------------------|-------------------------|------|
| <b>SGPRC</b>                         | 4%                     | 9%                | 12%                   | 19%                   | 14%                   | 29%              | 14%                     | 278  |
| <b>CA Average</b>                    | 5%                     | 8%                | 10%                   | 19%                   | 13%                   | 30%              | 14%                     | 8049 |
| <b>Weighted NCI-<br/>IDD Average</b> | 5%                     | 7%                | 10%                   | 19%                   | 13%                   | 32%              | 13%                     | 9793 |

**Table 20 Residential Designation**

| Regional Center                      | Urban or<br>Suburban (In<br>or Near a<br>City or<br>Large Town) | Rural<br>(Outside of a<br>City or<br>Town) | N    |
|--------------------------------------|-----------------------------------------------------------------|--------------------------------------------|------|
| <b>SGPRC</b>                         | 96%                                                             | 4%                                         | 264  |
| <b>CA Average</b>                    | 91%                                                             | 9%                                         | 7579 |
| <b>Weighted NCI-<br/>IDD Average</b> | 86%                                                             | 14%                                        | 9261 |

## Services and Supports Received

This section provides information about the services and supports received by the child from the regional center<sup>4</sup>.

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<sup>4</sup> Some NCI-IDD states provide services through a statewide ID/DD agency

Table 21a. Services and Supports Received from Regional Center<sup>5</sup>

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

| Regional Center                 | Financial Support | In Home Support | Out-of-Home Respite Care | Early Intervention |
|---------------------------------|-------------------|-----------------|--------------------------|--------------------|
| <b>SGPRC</b>                    | 20%               | 38%             | 31%                      | 1%                 |
| <b>CA Average</b>               | 19%               | 35%             | 31%                      | 1%                 |
| <b>Weighted NCI-IDD Average</b> | 20%               | 36%             | 30%                      | 11%                |

Table 21b. Services and Supports Received from Regional Center<sup>6</sup> (continued)

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

| Regional Center                 | Transportation | Mental or Behavioral Health Care or Other Treatments or Therapies | Self-Direction or Fiscal Intermediary Services |
|---------------------------------|----------------|-------------------------------------------------------------------|------------------------------------------------|
| <b>SGPRC</b>                    | 2%             | 25%                                                               | 17%                                            |
| <b>CA Average</b>               | 3%             | 23%                                                               | 19%                                            |
| <b>Weighted NCI-IDD Average</b> | 7%             | 35%                                                               | 26%                                            |

Table 22. Additional Services and Supports Received (not from the regional center) <sup>7</sup>

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

| Regional Center                 | Social Security (SSI/SSB) | Services or Supports from Other Agencies or Organizations |
|---------------------------------|---------------------------|-----------------------------------------------------------|
| <b>SGPRC</b>                    | 27%                       | 65%                                                       |
| <b>CA Average</b>               | 30%                       | 64%                                                       |
| <b>Weighted NCI-IDD Average</b> | 30%                       | 65%                                                       |

<sup>5</sup> Some NCI-IDD states provide services through a statewide ID/DD agency

<sup>6</sup> Some NCI-IDD states provide services through a statewide ID/DD agency

<sup>7</sup> Some NCI-IDD states provide services through a statewide ID/DD agency

## **Main Survey Results**

## Information and Planning

Families have the information and support needed to take part in planning supports and services for their child receiving services and supports from the regional center.

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

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

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 23%    | 36%     | 30%       | 10%             | 261  |
| <b>CA Average</b>               | 25%    | 31%     | 30%       | 14%             | 7590 |
| <b>Weighted NCI-IDD Average</b> | 27%    | 33%     | 28%       | 12%             | 9262 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 21%    | 41%     | 33%       | 5%              | 264  |
| <b>CA Average</b>               | 24%    | 38%     | 31%       | 8%              | 7634 |
| <b>Weighted NCI-IDD Average</b> | 25%    | 39%     | 29%       | 7%              | 9332 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 71%    | 15%     | 12%       | 3%              | 268  |
| <b>CA Average</b>               | 73%    | 14%     | 8%        | 5%              | 7977 |
| <b>Weighted NCI-IDD Average</b> | 77%    | 12%     | 7%        | 4%              | 9705 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 53%    | 29%     | 12%       | 5%              | 265  |
| <b>CA Average</b>               | 54%    | 27%     | 14%       | 6%              | 7713 |
| <b>Weighted NCI-IDD Average</b> | 57%    | 26%     | 12%       | 5%              | 9350 |

Table 27. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

| Regional Center          | Always | Usually | Sometimes | Seldom or Never | N    |
|--------------------------|--------|---------|-----------|-----------------|------|
| SGPRC                    | 21%    | 24%     | 30%       | 26%             | 222  |
| CA Average               | 20%    | 25%     | 27%       | 29%             | 6331 |
| Weighted NCI-IDD Average | 21%    | 26%     | 26%       | 27%             | 7762 |

Table 28a. Do you need help planning for your child's future in any of these areas?

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

| Regional Center          | Employment | Financial | Housing | Legal | Medical |
|--------------------------|------------|-----------|---------|-------|---------|
| SGPRC                    | 61%        | 58%       | 47%     | 49%   | 54%     |
| CA Average               | 53%        | 54%       | 45%     | 43%   | 45%     |
| Weighted NCI-IDD Average | 53%        | 55%       | 45%     | 43%   | 45%     |

Table 28b. Do you need help planning for your child's future in any of these areas? (continued)

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

| Regional Center          | Social or Relationships | Transition from School | Recreation or Having Fun | Other |
|--------------------------|-------------------------|------------------------|--------------------------|-------|
| SGPRC                    | 65%                     | 63%                    | 60%                      | 4%    |
| CA Average               | 59%                     | 56%                    | 59%                      | 6%    |
| Weighted NCI-IDD Average | 58%                     | 55%                    | 58%                      | 7%    |

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

| Regional Center          | Yes | No  | N    |
|--------------------------|-----|-----|------|
| SGPRC                    | 21% | 79% | 231  |
| CA Average               | 21% | 79% | 6568 |
| Weighted NCI-IDD Average | 22% | 78% | 8078 |

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

Table 30. Does your child have an individual program plan/individual family service plan (IPP/IFSP)?

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 78% | 22% | 238  |
| <b>CA Average</b>               | 78% | 22% | 7001 |
| <b>Weighted NCI-IDD Average</b> | 77% | 23% | 8498 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 80% | 20% | 153  |
| <b>CA Average</b>               | 79% | 21% | 4220 |
| <b>Weighted NCI-IDD Average</b> | 80% | 20% | 5228 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 81% | 19% | 161  |
| <b>CA Average</b>               | 80% | 20% | 4696 |
| <b>Weighted NCI-IDD Average</b> | 83% | 17% | 5808 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 16% | 84% | 160  |
| <b>CA Average</b>               | 17% | 83% | 4716 |
| <b>Weighted NCI-IDD Average</b> | 18% | 82% | 5838 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 89% | 11% | 150  |
| <b>CA Average</b>               | 84% | 16% | 4367 |
| <b>Weighted NCI-IDD Average</b> | 86% | 14% | 5425 |

Table 35. Does your child have a transition plan (as part of an IEP or Section 504 plan through their high school, usually starting at age 14)?

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 38% | 62% | 221  |
| <b>CA Average</b>               | 36% | 64% | 6472 |
| <b>Weighted NCI-IDD Average</b> | 33% | 67% | 7978 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 85% | 15% | 78   |
| <b>CA Average</b>               | 80% | 20% | 2019 |
| <b>Weighted NCI-IDD Average</b> | 81% | 19% | 2325 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 26% | 74% | 76   |
| <b>CA Average</b>               | 30% | 70% | 1946 |
| <b>Weighted NCI-IDD Average</b> | 31% | 69% | 2243 |

## Access and Delivery of Services and Supports

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

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

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

Table 38. Does your child get all the services listed in the IPP/IFSP?

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 81% | 19% | 156  |
| <b>CA Average</b>               | 81% | 19% | 4227 |
| <b>Weighted NCI-IDD Average</b> | 81% | 19% | 5259 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 65% | 35% | 226  |
| <b>CA Average</b>               | 62% | 38% | 6471 |
| <b>Weighted NCI-IDD Average</b> | 64% | 36% | 7988 |

Table 40a. If your child does not get the support and services needed, what additional services does your family need?

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

| Regional Center                 | Respite | Regularly Scheduled Support for Child | Homemaker Services | Home and/or Vehicle Modifications |
|---------------------------------|---------|---------------------------------------|--------------------|-----------------------------------|
| <b>SGPRC</b>                    | 43%     | 47%                                   | 31%                | 14%                               |
| <b>CA Average</b>               | 45%     | 44%                                   | 27%                | 14%                               |
| <b>Weighted NCI-IDD Average</b> | 48%     | 43%                                   | 27%                | 16%                               |

Table 40b. If your child does not get the support and services needed, what additional services does your family need? (continued)

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

| Regional Center                 | Counseling | Family to Family Networks | Support/Training to Use Assistive Technology | Other |
|---------------------------------|------------|---------------------------|----------------------------------------------|-------|
| <b>SGPRC</b>                    | 32%        | 31%                       | 21%                                          | 19%   |
| <b>CA Average</b>               | 42%        | 30%                       | 20%                                          | 27%   |
| <b>Weighted NCI-IDD Average</b> | 40%        | 30%                       | 19%                                          | 27%   |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 30%    | 40%     | 21%       | 10%             | 209  |
| <b>CA Average</b>               | 31%    | 37%     | 21%       | 11%             | 5929 |
| <b>Weighted NCI-IDD Average</b> | 33%    | 37%     | 20%       | 10%             | 7318 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 28%    | 32%     | 17%       | 23%             | 107  |
| <b>CA Average</b>               | 37%    | 30%     | 17%       | 16%             | 3106 |
| <b>Weighted NCI-IDD Average</b> | 37%    | 32%     | 17%       | 14%             | 4102 |

Table 43. If you need respite services, how often are you able to get them when needed?

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 39%    | 34%     | 17%       | 11%             | 202  |
| <b>CA Average</b>               | 37%    | 29%     | 17%       | 17%             | 5940 |
| <b>Weighted NCI-IDD Average</b> | 34%    | 28%     | 18%       | 20%             | 7070 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 62%    | 19%     | 12%       | 6%              | 170  |
| <b>CA Average</b>               | 61%    | 21%     | 9%        | 8%              | 4677 |
| <b>Weighted NCI-IDD Average</b> | 61%    | 22%     | 9%        | 8%              | 5396 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 45%    | 37%     | 13%       | 5%              | 241  |
| <b>CA Average</b>               | 41%    | 34%     | 19%       | 6%              | 7020 |
| <b>Weighted NCI-IDD Average</b> | 44%    | 34%     | 17%       | 5%              | 8536 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 42%    | 40%     | 16%       | 3%              | 264  |
| <b>CA Average</b>               | 43%    | 33%     | 18%       | 6%              | 7654 |
| <b>Weighted NCI-IDD Average</b> | 47%    | 32%     | 15%       | 5%              | 9272 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 62% | 38% | 120  |
| <b>CA Average</b>               | 62% | 38% | 3260 |
| <b>Weighted NCI-IDD Average</b> | 65% | 35% | 4047 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 71%    | 22%     | 6%        | 1%              | 240  |
| <b>CA Average</b>               | 71%    | 23%     | 4%        | 2%              | 7021 |
| <b>Weighted NCI-IDD Average</b> | 74%    | 21%     | 3%        | 2%              | 8622 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 36% | 64% | 257  |
| <b>CA Average</b>               | 36% | 64% | 7545 |
| <b>Weighted NCI-IDD Average</b> | 37% | 63% | 9211 |

Table 50. Is there a computer, tablet (for example an iPad), or smartphone that your child can use in your home?

| Regional Center                 | Yes | No | N    |
|---------------------------------|-----|----|------|
| <b>SGPRC</b>                    | 97% | 3% | 272  |
| <b>CA Average</b>               | 95% | 5% | 7944 |
| <b>Weighted NCI-IDD Average</b> | 95% | 5% | 9643 |

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

| Regional Center                 | The Internet Always Works, The Connection Is Good | The Internet Sometimes Works, The Connection is Sometimes Good | The Internet Rarely or Never Works, The Connection is Bad or I Do Not Have Internet in My Home | N    |
|---------------------------------|---------------------------------------------------|----------------------------------------------------------------|------------------------------------------------------------------------------------------------|------|
| <b>SGPRC</b>                    | 75%                                               | 23%                                                            | 2%                                                                                             | 272  |
| <b>CA Average</b>               | 70%                                               | 27%                                                            | 3%                                                                                             | 7969 |
| <b>Weighted NCI-IDD Average</b> | 72%                                               | 26%                                                            | 2%                                                                                             | 9670 |

## Workforce

There is stable and sufficient workforce to meet demand. Children are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support the children.

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

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

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 46%    | 41%     | 9%        | 5%              | 217  |
| <b>CA Average</b>               | 53%    | 33%     | 9%        | 5%              | 5848 |
| <b>Weighted NCI-IDD Average</b> | 56%    | 31%     | 9%        | 4%              | 7265 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 64%    | 28%     | 6%        | 3%              | 231  |
| <b>CA Average</b>               | 65%    | 27%     | 7%        | 2%              | 6671 |
| <b>Weighted NCI-IDD Average</b> | 67%    | 25%     | 6%        | 2%              | 8150 |

Table 54. If your child does not communicate verbally, are there support workers who can communicate with your child?

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 29%    | 29%     | 22%       | 21%             | 125  |
| <b>CA Average</b>               | 36%    | 29%     | 20%       | 16%             | 3684 |
| <b>Weighted NCI-IDD Average</b> | 37%    | 29%     | 19%       | 15%             | 4509 |

Table 55. Do support workers have the right information and skills to meet your family's needs?

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 34%    | 44%     | 16%       | 6%              | 216  |
| <b>CA Average</b>               | 41%    | 38%     | 16%       | 5%              | 6132 |
| <b>Weighted NCI-IDD Average</b> | 43%    | 37%     | 15%       | 5%              | 7572 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 43% | 57% | 194  |
| <b>CA Average</b>               | 38% | 62% | 5449 |
| <b>Weighted NCI-IDD Average</b> | 36% | 64% | 6786 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 74% | 26% | 183  |
| <b>CA Average</b>               | 70% | 30% | 5283 |
| <b>Weighted NCI-IDD Average</b> | 70% | 30% | 6549 |

## Choice, Decision Making and Control

Families and children with disabilities determine the services and supports they receive and the individuals or agencies who provide them.

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

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

Table 58. Can someone in your family choose or change the provider agency that provides your child's services?

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 45%    | 31%     | 10%       | 14%             | 177  |
| <b>CA Average</b>               | 48%    | 27%     | 10%       | 14%             | 4401 |
| <b>Weighted NCI-IDD Average</b> | 51%    | 26%     | 9%        | 14%             | 5448 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 40%    | 30%     | 10%       | 20%             | 161  |
| <b>CA Average</b>               | 46%    | 26%     | 11%       | 17%             | 4234 |
| <b>Weighted NCI-IDD Average</b> | 50%    | 25%     | 10%       | 15%             | 5297 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 41%    | 28%     | 10%       | 21%             | 140  |
| <b>CA Average</b>               | 48%    | 25%     | 9%        | 17%             | 4120 |
| <b>Weighted NCI-IDD Average</b> | 52%    | 24%     | 9%        | 15%             | 5167 |

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

| Regional Center                 | Yes | No, Didn't Choose But Can Change Case Manager or Service Coordinator if Wanted | No, Didn't Choose and Cannot Change Case Manager or Service Coordinator if Wanted | N    |
|---------------------------------|-----|--------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|------|
| <b>SGPRC</b>                    | 10% | 68%                                                                            | 22%                                                                               | 202  |
| <b>CA Average</b>               | 11% | 66%                                                                            | 23%                                                                               | 5853 |
| <b>Weighted NCI-IDD Average</b> | 14% | 64%                                                                            | 22%                                                                               | 7141 |

## Community Connections

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

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

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

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 66% | 34% | 267  |
| <b>CA Average</b>               | 72% | 28% | 7900 |
| <b>Weighted NCI-IDD Average</b> | 75% | 25% | 9564 |

Table 63. What makes it hard to do things in the community?

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

| Regional Center                 | Lack of Transportation | Cost | Lack of Support Staff | Stigma | Other |
|---------------------------------|------------------------|------|-----------------------|--------|-------|
| <b>SGPRC</b>                    | 10%                    | 31%  | 26%                   | 31%    | 25%   |
| <b>CA Average</b>               | 11%                    | 31%  | 24%                   | 29%    | 27%   |
| <b>Weighted NCI-IDD Average</b> | 10%                    | 31%  | 24%                   | 30%    | 29%   |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 78% | 22% | 264  |
| <b>CA Average</b>               | 82% | 18% | 7924 |
| <b>Weighted NCI-IDD Average</b> | 83% | 17% | 9605 |

Table 65. In your community, are there resources that your family and child can use that are not provided by the regional center<sup>8</sup> (for example, recreational programs, community housing, library programs, religious groups, etc.)?

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 69% | 31% | 190  |
| <b>CA Average</b>               | 72% | 28% | 5818 |
| <b>Weighted NCI-IDD Average</b> | 74% | 26% | 7060 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 19% | 81% | 233  |
| <b>CA Average</b>               | 21% | 79% | 7014 |
| <b>Weighted NCI-IDD Average</b> | 21% | 79% | 8461 |

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<sup>8</sup> Some NCI states provide services through a statewide ID/DD agency

## Health, Welfare, and Safety

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

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

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

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 71%    | 21%     | 4%        | 4%              | 269  |
| <b>CA Average</b>               | 72%    | 18%     | 6%        | 5%              | 7781 |
| <b>Weighted NCI-IDD Average</b> | 73%    | 18%     | 5%        | 4%              | 9451 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 49%    | 29%     | 19%       | 3%              | 261  |
| <b>CA Average</b>               | 55%    | 29%     | 12%       | 4%              | 7743 |
| <b>Weighted NCI-IDD Average</b> | 57%    | 29%     | 12%       | 3%              | 9420 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 67%    | 19%     | 9%        | 6%              | 268  |
| <b>CA Average</b>               | 69%    | 18%     | 7%        | 6%              | 7960 |
| <b>Weighted NCI-IDD Average</b> | 69%    | 19%     | 7%        | 5%              | 9617 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 55%    | 23%     | 17%       | 6%              | 253  |
| <b>CA Average</b>               | 55%    | 26%     | 14%       | 5%              | 7510 |
| <b>Weighted NCI-IDD Average</b> | 56%    | 27%     | 13%       | 5%              | 9038 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 82%    | 8%      | 5%        | 5%              | 151  |
| <b>CA Average</b>               | 86%    | 8%      | 3%        | 4%              | 4640 |
| <b>Weighted NCI-IDD Average</b> | 87%    | 7%      | 3%        | 3%              | 5858 |

Table 72. Do you or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 84%    | 12%     | 1%        | 3%              | 149  |
| <b>CA Average</b>               | 88%    | 9%      | 2%        | 1%              | 4577 |
| <b>Weighted NCI-IDD Average</b> | 89%    | 9%      | 2%        | 1%              | 5792 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 36%    | 30%     | 11%       | 23%             | 211  |
| <b>CA Average</b>               | 39%    | 25%     | 15%       | 21%             | 6168 |
| <b>Weighted NCI-IDD Average</b> | 40%    | 25%     | 15%       | 20%             | 7401 |

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 47%    | 35%     | 12%       | 6%              | 173  |
| <b>CA Average</b>               | 50%    | 31%     | 13%       | 6%              | 4990 |
| <b>Weighted NCI-IDD Average</b> | 50%    | 31%     | 13%       | 6%              | 5926 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 55% | 45% | 60   |
| <b>CA Average</b>               | 53% | 47% | 2187 |
| <b>Weighted NCI-IDD Average</b> | 56% | 44% | 2597 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 75% | 25% | 236  |
| <b>CA Average</b>               | 80% | 20% | 7098 |
| <b>Weighted NCI-IDD Average</b> | 82% | 18% | 8632 |

Table 77. Have you discussed how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your child's case manager/service coordinator?

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 33% | 67% | 243  |
| <b>CA Average</b>               | 32% | 68% | 7311 |
| <b>Weighted NCI-IDD Average</b> | 35% | 65% | 8875 |

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

| Regional Center                 | Yes | No or Don't Know | N    |
|---------------------------------|-----|------------------|------|
| <b>SGPRC</b>                    | 33% | 67%              | 276  |
| <b>CA Average</b>               | 32% | 68%              | 8060 |
| <b>Weighted NCI-IDD Average</b> | 36% | 64%              | 9738 |

Table 79. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 39% | 61% | 36   |
| <b>CA Average</b>               | 33% | 67% | 994  |
| <b>Weighted NCI-IDD Average</b> | 35% | 65% | 1105 |

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

| Regional Center                 | Yes | No or Don't Know | N    |
|---------------------------------|-----|------------------|------|
| <b>SGPRC</b>                    | 60% | 40%              | 277  |
| <b>CA Average</b>               | 61% | 39%              | 8016 |
| <b>Weighted NCI-IDD Average</b> | 65% | 35%              | 9701 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 1%  | 99% | 265  |
| <b>CA Average</b>               | 2%  | 98% | 7592 |
| <b>Weighted NCI-IDD Average</b> | 3%  | 97% | 9239 |

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

| Regional Center                 | Yes | No  | N   |
|---------------------------------|-----|-----|-----|
| <b>SGPRC</b>                    | n/a | n/a | n/a |
| <b>CA Average</b>               | 72% | 28% | 123 |
| <b>Weighted NCI-IDD Average</b> | 72% | 28% | 155 |

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

## Satisfaction With Services and Supports

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

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

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

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

| Regional Center                 | Always | Usually | Sometimes | Seldom or Never | N    |
|---------------------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>                    | 30%    | 40%     | 24%       | 6%              | 274  |
| <b>CA Average</b>               | 32%    | 37%     | 24%       | 7%              | 7830 |
| <b>Weighted NCI-IDD Average</b> | 33%    | 38%     | 22%       | 7%              | 9494 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 94% | 6%  | 244  |
| <b>CA Average</b>               | 90% | 10% | 7238 |
| <b>Weighted NCI-IDD Average</b> | 91% | 9%  | 8812 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 72% | 28% | 244  |
| <b>CA Average</b>               | 68% | 32% | 7033 |
| <b>Weighted NCI-IDD Average</b> | 70% | 30% | 8578 |

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

| Regional Center                 | Yes | No  | N    |
|---------------------------------|-----|-----|------|
| <b>SGPRC</b>                    | 86% | 14% | 240  |
| <b>CA Average</b>               | 83% | 17% | 7142 |
| <b>Weighted NCI-IDD Average</b> | 85% | 15% | 8706 |

Table 87. Have the services or supports that your child received during the past 12 months been reduced, suspended, or terminated?

| Regional Center          | Yes | No  | N    |
|--------------------------|-----|-----|------|
| SGPRC                    | 17% | 83% | 236  |
| CA Average               | 18% | 82% | 7032 |
| Weighted NCI-IDD Average | 18% | 82% | 8624 |

Table 88. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family or your child negatively?

| Regional Center          | Yes | No  | N    |
|--------------------------|-----|-----|------|
| SGPRC                    | 75% | 25% | 36   |
| CA Average               | 72% | 28% | 1063 |
| Weighted NCI-IDD Average | 73% | 27% | 1313 |

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

| Regional Center          | Yes | No  | N    |
|--------------------------|-----|-----|------|
| SGPRC                    | 22% | 78% | 243  |
| CA Average               | 23% | 77% | 7165 |
| Weighted NCI-IDD Average | 23% | 77% | 8705 |

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

| Regional Center          | Yes | No | N    |
|--------------------------|-----|----|------|
| SGPRC                    | 94% | 6% | 235  |
| CA Average               | 91% | 9% | 6898 |
| Weighted NCI-IDD Average | 92% | 8% | 8422 |

### California Specific Questions

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

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

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

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

| Regional Center   | Childcare/<br>Afterschool<br>Care | Behavior<br>Therapy | Educational<br>Expenses | Medical<br>and/or<br>Dental<br>Expenses |
|-------------------|-----------------------------------|---------------------|-------------------------|-----------------------------------------|
| <b>SGPRC</b>      | 17%                               | 11%                 | 21%                     | 36%                                     |
| <b>CA Average</b> | 18%                               | 10%                 | 19%                     | 32%                                     |

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

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

| Regional Center   | Other<br>Therapies | Parent<br>Training | Recreational<br>Activities<br>and<br>Programs | Respite<br>Services |
|-------------------|--------------------|--------------------|-----------------------------------------------|---------------------|
| <b>SGPRC</b>      | 18%                | 3%                 | 31%                                           | 6%                  |
| <b>CA Average</b> | 17%                | 5%                 | 35%                                           | 5%                  |

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

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

| Regional Center   | Social Skills<br>Training | Speech<br>Therapy | Transportati<br>on Support | Other | None |
|-------------------|---------------------------|-------------------|----------------------------|-------|------|
| <b>SGPRC</b>      | 5%                        | 17%               | 16%                        | 6%    | 35%  |
| <b>CA Average</b> | 6%                        | 11%               | 15%                        | 4%    | 37%  |

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

| Regional Center   | None | \$1 – \$1,999 | \$2,000 –<br>\$5,999 | \$6,000 –<br>\$11,999 | \$12,000 or<br>Over | N    |
|-------------------|------|---------------|----------------------|-----------------------|---------------------|------|
| <b>SGPRC</b>      | 30%  | 36%           | 21%                  | 9%                    | 4%                  | 270  |
| <b>CA Average</b> | 34%  | 34%           | 20%                  | 7%                    | 5%                  | 7634 |

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

| Regional Center   | Yes | No  | N    |
|-------------------|-----|-----|------|
| <b>SGPRC</b>      | 52% | 48% | 223  |
| <b>CA Average</b> | 46% | 54% | 6652 |

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

| Regional Center   | Yes | No  | N    |
|-------------------|-----|-----|------|
| <b>SGPRC</b>      | 81% | 19% | 249  |
| <b>CA Average</b> | 76% | 24% | 7309 |

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

| Regional Center   | Yes | No | N    |
|-------------------|-----|----|------|
| <b>SGPRC</b>      | 97% | 3% | 171  |
| <b>CA Average</b> | 94% | 6% | 4980 |

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

| Regional Center   | Yes, They Speak My Preferred Language | Yes, But Only Through a Translator When One Is Available | No | N    |
|-------------------|---------------------------------------|----------------------------------------------------------|----|------|
| <b>SGPRC</b>      | 93%                                   | 4%                                                       | 3% | 243  |
| <b>CA Average</b> | 95%                                   | 3%                                                       | 2% | 7010 |

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

| Regional Center   | Yes, They Speak My Preferred Language | Yes, But Only Through a Translator When One Is Available | No | N    |
|-------------------|---------------------------------------|----------------------------------------------------------|----|------|
| <b>SGPRC</b>      | 95%                                   | 4%                                                       | 2% | 262  |
| <b>CA Average</b> | 96%                                   | 3%                                                       | 2% | 7660 |

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

| Regional Center   | Always | Usually | Sometimes | Seldom or Never | N   |
|-------------------|--------|---------|-----------|-----------------|-----|
| <b>SGPRC</b>      | n/a    | n/a     | n/a       | n/a             | n/a |
| <b>CA Average</b> | 20%    | 24%     | 23%       | 34%             | 122 |

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

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

| Regional Center   | Always | Usually | Sometimes | Seldom or Never | N    |
|-------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>      | 81%    | 15%     | 3%        | 1%              | 259  |
| <b>CA Average</b> | 82%    | 15%     | 2%        | 1%              | 7402 |

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

| Regional Center   | Always | Usually | Sometimes | Seldom or Never | N    |
|-------------------|--------|---------|-----------|-----------------|------|
| <b>SGPRC</b>      | 80%    | 17%     | 3%        | 0%              | 230  |
| <b>CA Average</b> | 82%    | 15%     | 2%        | 1%              | 6649 |

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

| Regional Center   | Often | Sometimes | Seldom | Never | N    |
|-------------------|-------|-----------|--------|-------|------|
| <b>SGPRC</b>      | 32%   | 26%       | 34%    | 8%    | 262  |
| <b>CA Average</b> | 34%   | 30%       | 26%    | 10%   | 7705 |

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

| Regional Center   | Yes | No  | N    |
|-------------------|-----|-----|------|
| <b>SGPRC</b>      | 73% | 27% | 155  |
| <b>CA Average</b> | 81% | 19% | 4621 |

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

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

| Regional Center   | Location of Evacuation Sites/ Shelters | Evacuation Routes | Public Safety Power Shut Off Information (PSPS) | Locations of Community Resource Centers | More Information on What I Need for Life Sustaining Equipment I Use |
|-------------------|----------------------------------------|-------------------|-------------------------------------------------|-----------------------------------------|---------------------------------------------------------------------|
| <b>SGPRC</b>      | 63%                                    | 46%               | 35%                                             | 49%                                     | 25%                                                                 |
| <b>CA Average</b> | 53%                                    | 39%               | 31%                                             | 41%                                     | 21%                                                                 |

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

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

| Regional Center   | Key People to Contact | How to Reach My Regional Center in an Emergency | How to Reach My Support Workers in an Emergency | How to Get Additional Emergency Supplies | How to Prepare an Emergency Supply Kit |
|-------------------|-----------------------|-------------------------------------------------|-------------------------------------------------|------------------------------------------|----------------------------------------|
| <b>SGPRC</b>      | 37%                   | 41%                                             | 29%                                             | 51%                                      | 41%                                    |
| <b>CA Average</b> | 33%                   | 37%                                             | 25%                                             | 45%                                      | 38%                                    |

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

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

| Regional Center   | How to Sign Up For Emergency Alerts | Important Personal Documents to Have Ready | Other | No Other Information Is Needed |
|-------------------|-------------------------------------|--------------------------------------------|-------|--------------------------------|
| <b>SGPRC</b>      | 33%                                 | 34%                                        | 2%    | 20%                            |
| <b>CA Average</b> | 29%                                 | 29%                                        | 3%    | 26%                            |

## NCI History and Activities

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

## Overview of National Core Indicators—Intellectual and Developmental Disabilities

In December 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI), launched the Core Indicators Project (CIP). The aim of the project was to support state developmental disabilities authorities in the development and implementation of performance and outcome indicators—and related data collection strategies—so that they could measure service delivery system performance. This effort, now called National Core Indicators-Intellectual and Developmental Disabilities (NCI-IDD), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI-IDD facilitates pooled knowledge, expertise, and resources among the states.

In 1997, 15 states convened to discuss the scope and content of a potential performance measurement framework. Directors and staff from these 15 states worked to identify the major domains and sub-domains of performance, indicators, measures, and data sources. The original 61 indicators, developed through a consensus process, were intended to provide a system-level “snapshot” of how well each state was performing. The states were guided by a set of criteria that was designed to select indicators that were:

1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of disability or residential setting

During this initial phase, data collection protocols were developed and field-tested, including a face-to-face Adult In-Person Survey (for individuals age 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states volunteered to pilot test the indicators. Eight additional states served on the Steering Committee.

Since the initial field test, NCI-IDD has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families. In addition, NCI-IDD continues to develop and refine the indicators and expand state participation. For more information about NCI-IDD states, technical reports, and other resources please visit the NCI-IDD website at <https://idd.nationalcoreindicators.org/>.

### State Participation

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

### The Core Indicators

The Core Indicators are the standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern, including employment, respect/rights, service planning, community inclusion, choice, and health and safety. An example of a Core Indicator would be, “The proportion of people who have a paid job in the community.” To see the entire list of Core Indicators, please visit the Indicators page on the NCI-IDD

website at [https://idd.nationalcoreindicators.org/wp-content/uploads/2022/09/NCI\\_IDD\\_Indicators\\_FINAL\\_21-22.pdf](https://idd.nationalcoreindicators.org/wp-content/uploads/2022/09/NCI_IDD_Indicators_FINAL_21-22.pdf).

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

The current set of performance indicators includes approximately 100 individual, family, system, and health and safety outcomes—outcomes that are important to understanding the overall health of public developmental disabilities agencies. Indicators are organized across four broad domains: Individual Outcomes; System Performance, Health, Wellness and Rights, and Family Experience. Each domain is broken down into sub-domains, as shown in the following table. Four data sources are used to assess outcomes: the In-Person Survey, three Family Surveys, and a State of the Workforce Survey (e.g., staff turnover).

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

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

### Sub-Domains and Concern Statements

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

Figure 1. Family Survey Sub-Domains and Concern Statements

| Sub-Domain                           | Concern Statement                                                                                                                                                                                                           |
|--------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Information and Planning</b>      | 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.                                           |
| <b>Access &amp; Support Delivery</b> | 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.                                                      |
| <b>Workforce</b>                     | 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. |
| <b>Choice &amp; Decision-making</b>  | Families and their family members receiving services and supports from the state DD system are involved in making choices about supports, services, and providers.                                                          |
| <b>Community Connections</b>         | Family members receiving services and supports from the state DD system are meaningfully engaged as members of their communities and have strong relationships.<br>Families can use supports in their community.            |
| <b>Health, Welfare, And Safety</b>   | Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state DD system.                                                                           |
| <b>Satisfaction</b>                  | 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](#).<sup>9</sup>

## 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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<sup>9</sup> Located on the National Core Indicators website: <https://www.nationalcoreindicators.org>

## Sampling & Administration

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

1. Had a child<sup>10</sup> with an intellectual or developmental disability living in the home; and
2. The child with an intellectual or developmental disability living in the home received at least one direct service or support in addition to service coordination.

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

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or a combination of both modes. Prior to that, states only had the option to mail paper surveys. A total of 5 states (CA, LA, MO, OR, WI) had at least a portion of surveys completed via direct entry for the 2023-24 data collection cycle.

## Weighting

Statistically, the term “average” refers to a calculated central or middle value of a set of numbers. In NCI-IDD reports, we use the “NCI-IDD average” to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). The approach has since been enhanced to consider the relative numbers of people receiving services through participating states’ systems. The NCI-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the sample sizes.

Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI-IDD average—that is, the state’s contribution to the NCI-IDD average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.

## Data Entry and Analysis

Each state or regional center entered its survey responses into the Online Data Entry Survey Application (ODESA). All raw data files were reviewed for completeness, invalid responses were eliminated, and quality checks were performed. The data files were then cleaned and merged to create the national dataset.

Data were considered invalid, and therefore excluded, based on the following two criteria:

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

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<sup>10</sup> Some states include people up to age 21 who were receiving child services

<sup>11</sup> See “Response Rates” for information on total surveys mailed and received by regional centers as well as each regional center’s margin of error.

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

## Response Rates

During 2023-24, 5 states, including California administered the Child Family Survey and submitted a valid sample size for comparison—a sample that would yield a 95% confidence level with +/- 7% (7.49% or less) margin of error; their data are included in this report. The following table shows the number of individuals receiving services who were eligible to be drawn into the sample (“total population”), the number of surveys each regional center sent, complete surveys, response rates, margins of error, and survey submission modes.

Please note: The family surveys are mail surveys or completed online by respondents who choose to take part in the survey. As such, the final sample is a sample of convenience and cannot be considered representative of the entire service.

Figure 2. Child Family Surveys Regional Center Response Rates<sup>12 13</sup>

| Regional Center | Total Population | Surveys Sent | Usable Surveys | Response Rate | Margin of Error | Paper Submission | Direct Entry Submission |
|-----------------|------------------|--------------|----------------|---------------|-----------------|------------------|-------------------------|
| <b>SGPRC</b>    | 3,060            | 3,060        | 284            | 9%            | 5.3%            | 67%              | 33%                     |
| <b>CA</b>       | 98,003           | 98,003       | 8,277          | 8%            | 1.0%            | 73%              | 27%                     |
| <b>NCI</b>      | 132,220          | 109,959      | 10,050         | 9%            | 0.9%            | 68%              | 32%                     |

<sup>12</sup> 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>

<sup>13</sup> 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).