NCI Adult Family Survey Regional Center Outcomes

Regional Center of the East Bay Report

Fiscal Year 2016-17
# Table of Contents

Quality Assessment Project and National Core Indicators™ ................................................................. 1
What is NCI? ............................................................................................................................................... 1
What is the NCI Adult Family Survey? ...................................................................................................... 1
How were people selected to participate? ................................................................................................. 3
Data Analysis ............................................................................................................................................ 4
Weighting .................................................................................................................................................. 4
Limitations of Data ................................................................................................................................... 4
What is Contained in This Report? ........................................................................................................... 5

Demographics of the Family Member ........................................................................................................ 6

<table>
<thead>
<tr>
<th>Graph</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>GRAPH 1.</td>
<td>More than one person living in the home has IDD</td>
<td>7</td>
</tr>
<tr>
<td>GRAPH 2.</td>
<td>Family member's age</td>
<td>7</td>
</tr>
<tr>
<td>GRAPH 3.</td>
<td>Family member's gender</td>
<td>7</td>
</tr>
<tr>
<td>GRAPH 4.</td>
<td>Family member's disabilities (CA qualifying conditions)</td>
<td>7</td>
</tr>
<tr>
<td>GRAPH 5.</td>
<td>Family member's types of disabilities (continued)</td>
<td>8</td>
</tr>
<tr>
<td>GRAPH 6.</td>
<td>Family member's types of disabilities (continued)</td>
<td>8</td>
</tr>
<tr>
<td>GRAPH 7.</td>
<td>Family member's health conditions</td>
<td>8</td>
</tr>
<tr>
<td>GRAPH 8.</td>
<td>Family member's health conditions (continued)</td>
<td>8</td>
</tr>
<tr>
<td>GRAPH 9.</td>
<td>Family member's race and ethnicity</td>
<td>9</td>
</tr>
<tr>
<td>GRAPH 10.</td>
<td>Family member's preferred means of communication</td>
<td>9</td>
</tr>
<tr>
<td>GRAPH 11.</td>
<td>Family member's preferred language</td>
<td>9</td>
</tr>
<tr>
<td>GRAPH 12.</td>
<td>Family member's preferred language (continued)</td>
<td>9</td>
</tr>
<tr>
<td>GRAPH 13.</td>
<td>Family member's preferred language (continued)</td>
<td>10</td>
</tr>
<tr>
<td>GRAPH 14.</td>
<td>Family member has legal court appointed guardian or conservator</td>
<td>10</td>
</tr>
<tr>
<td>GRAPH 15.</td>
<td>Guardian or conservator relationship to family member</td>
<td>10</td>
</tr>
<tr>
<td>GRAPH 16.</td>
<td>Family member's highest level of education</td>
<td>10</td>
</tr>
</tbody>
</table>
Access and Delivery

GRAPH 44. DOES THE CASE MANAGER/SERVICE COORDINATOR RESPECT YOUR FAMILY’S CHOICES AND OPINIONS? ................................................................. 21

GRAPH 45. DO YOU GET ENOUGH INFORMATION ABOUT OTHER PUBLIC SERVICES FOR WHICH YOUR FAMILY IS ELIGIBLE? .................................................. 21

GRAPH 46. DO YOU NEED HELP PLANNING FOR YOUR FAMILY MEMBER’S FUTURE WITH RESPECT TO ANY OF THE FOLLOWING? .................................................. 22

GRAPH 47. DO YOU NEED HELP PLANNING FOR YOUR FAMILY MEMBER’S FUTURE WITH RESPECT TO ANY OF THE FOLLOWING? (CONTINUED) .................................. 22

GRAPH 48. IF YOU ASKED FOR CRISIS OR EMERGENCY SERVICES DURING THE PAST YEAR, WERE SERVICES PROVIDED WHEN NEEDED? .................................... 22

GRAPH 49. DOES YOUR FAMILY MEMBER HAVE AN INDIVIDUAL PROGRAM PLAN (IPP)? ................................................................................................................. 22

GRAPH 50. IF FAMILY MEMBER HAS AN IPP, DOES THE IPP INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER NEEDS? ........................................... 23

GRAPH 51. IF FAMILY MEMBER HAS AN IPP, DOES YOUR FAMILY MEMBER GET ALL OF THE SERVICES LISTED IN THE IPP? ....................................................................... 23

GRAPH 52. IF FAMILY MEMBER HAS AN IPP, DID YOU OR ANOTHER FAMILY MEMBER (BESIDE YOUR FAMILY MEMBER WITH A DISABILITY) HELP MAKE THE IPP? ....................... 23

GRAPH 53. IF FAMILY MEMBER HAS AN IPP, DID YOU OR ANOTHER FAMILY MEMBER HELP MAKE THE IPP? ..................................................................................... 23

GRAPH 54. DID YOU DISCUSS HOW TO HANDLE EMERGENCIES (SUCH AS A MEDICAL EMERGENCY OR A NATURAL DISASTER) AT YOUR FAMILY MEMBER’S LAST IPP MEETING? ................................................................................................................................. 24

GRAPH 55. DOES YOUR FAMILY MEMBER HAVE ENOUGH SUPPORTS (FOR EXAMPLE, SUPPORT WORKERS, COMMUNITY RESOURCES) TO WORK OR VOLUNTEER IN THE COMMUNITY? ......................................................................................... 24

GRAPH 56. DO YOU FEEL PREPARED TO HANDLE THE NEEDS OF YOUR FAMILY MEMBER IN AN EMERGENCY SUCH AS A MEDICAL EMERGENCY OR A NATURAL DISASTER? .. 24

Access and Delivery ............................................................................................................................................................................................ 25

GRAPH 57. ARE YOU OR YOUR FAMILY MEMBER ABLE TO CONTACT HIS/HER SUPPORT WORKERS WHEN YOU WANT TO? ................................................................. 25

GRAPH 58. ARE YOU OR YOUR FAMILY MEMBER ABLE TO CONTACT YOUR FAMILY MEMBER’S CASE MANAGER/SERVICE COORDINATOR WHEN YOU WANT TO? ............................. 26

GRAPH 59. DO SUPPORT WORKERS COME AND LEAVE WHEN THEY ARE SUPPOSED TO? ................................................................................................................. 26

GRAPH 60. DO SERVICES AND SUPPORTS CHANGE WHEN YOUR FAMILY MEMBER’S NEEDS CHANGE? ................................................................................................. 26

GRAPH 61. DO SUPPORT WORKERS SPEAK TO YOU IN A WAY THAT YOU UNDERSTAND? ..................................................................................................................... 27

GRAPH 62. ARE SERVICES DELIVERED IN A WAY THAT IS RESPECTFUL OF YOUR FAMILY’S CULTURE? ....................................................................................... 27

GRAPH 63. IF YOUR FAMILY MEMBER DOES NOT COMMUNICATE VERBALLY (FOR EXAMPLE, USES GESTURES OR SIGN LANGUAGE), ARE THERE SUPPORT WORKERS WHO CAN COMMUNICATE WITH HIM/HER? ...................................................................................... 27

GRAPH 64. DO SUPPORT WORKERS HAVE THE RIGHT INFORMATION AND SKILLS TO MEET YOUR FAMILY’S NEEDS? .............................................................................. 27

GRAPH 65. DOES YOUR FAMILY MEMBER HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT S/HE NEEDS (FOR EXAMPLE, WHEELCHAIR, RAMP, COMMUNICATION BOARD)? ............................................................................................. 27

GRAPH 66. CAN YOUR FAMILY MEMBER SEE HEALTH PROFESSIONALS WHEN NEEDED (FOR EXAMPLE, DOCTOR, DENTIST, PSYCHOLOGIST)? ........................................... 28

GRAPH 67. DOES YOUR FAMILY MEMBER’S PRIMARY CARE DOCTOR UNDERSTAND HIS/HER NEEDS RELATED TO HIS/HER DISABILITY? .......................................................... 28

GRAPH 68. DO YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR FAMILY MEMBER? ......................................................................................................................... 28

GRAPH 69. DOES YOUR FAMILY MEMBER’S DENTIST UNDERSTAND HIS/HER NEEDS RELATED TO HIS/HER DISABILITY? ............................................................................. 29

GRAPH 70. IF YOUR FAMILY MEMBER TAKES MEDICATIONS, DO YOU KNOW WHAT THEY’RE FOR? ............................................................................................................. 29

GRAPH 71. IF YOUR FAMILY MEMBER TAKES MEDICATIONS, DO YOU, YOUR FAMILY MEMBER OR SOMEONE ELSE IN YOUR FAMILY KNOW WHAT IS NEEDED TO SAFELY TAKE THE MEDICATIONS (WHEN IT SHOULD BE TAKEN, HOW MUCH TO TAKE, POTENTIAL SIDE EFFECTS)? .......................................................................................................................... 29

Adult Family Survey Regional Center Results: FY16/17 | iv
Choice, Decision Making and Control ................................................................. 32

Graph 78. Can your family choose or change the agency that provides your family member’s services?................................................................. 33
Graph 79. Can your family choose or change your family member’s support workers?................................................................. 33
Graph 80. Does your family directly manage support workers (for example, hiring and deciding schedule)?................................................................. 33
Graph 81. Do service providers for your family member work together to provide support?................................................................. 33
Graph 82. Did you, your family member, or someone else in your family choose or can change case manager/service coordinator if wanted?............. 34

Involvement in the Community ........................................................................... 35

Graph 83. Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)?.... 36
Graph 84. For your family member, what are the obstacles or barriers to participation in activities in the community?................................................................. 36
Graph 85. Does your family member have friends or relationships with people other than paid support workers or family?................................................................. 36
Graph 86. In your community, are there resources that your family can use that are not provided by the regional center?................................................................. 36
Graph 87. Does your family take part in any family-to-family networks in your community?................................................................. 37

Satisfaction ........................................................................................................ 38

Graph 88. Overall, are you satisfied with the services and supports your family member currently receives?................................................................. 39
Graph 89. Do you know the process for filing a complaint or grievance about provider agencies or staff?................................................................. 39
Graph 90. If a complaint or grievance related to your family member was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?................................................................. 39
Graph 91. Do you know how to report abuse or neglect related to your family member?................................................................. 39
Graph 92. Within the past year, was a report of abuse or neglect filed on behalf of your family member?................................................................. 40
Graph 93. Do you feel that services and supports have made a positive difference in the life of your family member?................................................................. 40
Graph 94. Do you feel that services and supports have reduced your family’s out-of-pocket expenses for your family member’s care?................................................................. 40
Graph 95. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?............. 40
Graph 96. Have the services or supports that your family member received been increased in the past year?................................................................. 41
Graph 97. Are services and supports helping your family member to live a good life?................................................................. 41
CA Specific Questions

GRAPH 98. DID YOU GET A COPY OF YOUR IPP IN YOUR PREFERRED LANGUAGE?

GRAPH 99. ARE THERE SUPPORT WORKERS AVAILABLE WHO CAN SPEAK TO YOU IN YOUR PREFERRED LANGUAGE?

GRAPH 100. HAVE SERVICES AND SUPPORTS HELPED KEEP YOUR FAMILY MEMBER HOME?

GRAPH 101. HAS YOUR FAMILY MEMBER MOVED FROM A DEVELOPMENTAL CENTER (DC) TO THE COMMUNITY IN THE PAST FIVE YEARS?
Quality Assessment Project and National Core Indicators™

This report contains regional center level results from California’s statewide National Core Indicators (NCI) Adult Family Survey data collection from fiscal year 2016-17 (FY 16/17) in accordance with Welfare and Institutions Code (WIC), Section 4571. WIC, Section 4571 directs the Department of Developmental Services (DDS) to collect accurate, reliable, and valid consumer and family satisfaction measures as well as individual outcome data. In California, data from this project will be used to review and benchmark statewide and regional center developmental disability service system performance. ¹ This report shows Adult Family Survey findings from Regional Center of the East Bay compared to the California statewide and NCI averages. Regional centers can use this report to help guide strategic planning and monitor systemic changes.

What is NCI?

The National Core Indicators (NCI) program is a voluntary effort by state developmental disability agencies to track their performance using a standardized set of consumer and family/guardian surveys with nationally validated measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

NCI has developed more than 100 standard performance measures (or ‘indicators’) that states use to assess the outcomes of services for individuals and families, including outcomes in the areas of employment, rights, service planning, community inclusion, choice, health, and safety. In 2016-17 a total of 46 states, the District of Columbia and 22 sub-state entities participated in NCI.

What is the NCI Adult Family Survey?

The NCI Adult Family Survey is used to gather data on family outcomes. It is mailed to families who have an adult family member who lives in the family home and receives at least one service other than case management from the state developmental disabilities agency.

¹ Refer to the California Adult Family Survey Report FY 16/17 for information about Quality Assessment Project implementation, NCI and California’s statewide results.
The survey collects demographic information on both the individual receiving services and the person who fills out the survey (the ‘respondent’) as well as information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

In 2016-17, a total of 11,419 Adult Family Surveys were completed across 16 states. The survey contained six groupings of questions ("sub-domains") that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes (see Table A1 below). Respondents also had the option of writing open-ended comments concerning their family's participation in the service system.

Table A1. NCI Family Survey – sub-domains and concern statements

<table>
<thead>
<tr>
<th>Sub-Domain</th>
<th>Concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and Planning</td>
<td>Families/family members with disabilities have the information and support necessary to plan for their services and supports.</td>
</tr>
<tr>
<td>Access &amp; Support Delivery</td>
<td>Families/family members with disabilities get the services and supports they need.</td>
</tr>
<tr>
<td>Choice, Decision Making &amp; Control</td>
<td>Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.</td>
</tr>
<tr>
<td>Involvement in the Community</td>
<td>Family members with disabilities use integrated community services and participate in everyday community activities.</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>Families/family members with disabilities receive adequate and satisfactory supports.</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Individual and family supports make a positive difference in the lives of families.</td>
</tr>
</tbody>
</table>

2 States that conducted the Adult Family Survey in 2016-17 were: CA, DC, DE, FL, GA, KY, LA, MD, MN, MO, MS, NC, NJ, OK, PA, and UT.
How were people selected to participate?

In California, all eligible families were mailed a survey for the Adult Family Survey FY16/17. The State Council on Developmental Disabilities (SCDD) mailed out the paper survey to 22,348 eligible families. A total of 4,917 usable surveys across the 21 regional centers were returned.

All participating states were asked to administer the survey to a random sample of at least 1,000 families, all of whom have an adult family member with a developmental disability who lives in the family home and receives at least one direct service or support other than service coordination.

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 both. In previous years, states only had the option to mail paper surveys. A total of seven states (not including California) had at least a portion of surveys completed via direct entry mode.3

All states mailed out a paper survey to families selected in their sample. A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. Both the confidence level and margin of error used are widely accepted standards for reviewing results, regardless of population size. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we included in our national reports those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.

3 States that used the direct entry or mail and direct entry options were: DE, KY, LA, MO, MS, NC, and NJ. For more information on response rates and mode, please see the Methodology section within the national edition of the 2016-17 Adult Family Survey Report.
Data Analysis

Surveys received from the state were considered valid, based on the following two criteria:

1. The respondent indicated the individual with an intellectual or developmental disability receiving services lived in the family home.
2. At least a portion of survey questions were answered aside from demographic information.

Questions left blank or marked ‘not applicable’ are not included in analysis. For most questions, ‘don’t know’ responses were excluded from analysis. Two questions in the Satisfaction section combine ‘no’ and ‘don’t know’ responses, those questions are asterisked. Data are not shown for items if the regional center had fewer than 20 respondents.

Weighting

In previous years, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). This year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states’ systems. Beginning this year, the NCI averages contained in this report are “weighted” means. 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 average—that is, the state’s contribution to the NCI 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.

Please note: the California Averages included in this report are unweighted averages across the state.

Limitations of Data

The NCI Adult Family Survey is a tool for assessing system-wide performance. It is not intended to be used to monitor individuals or providers. The NCI Statewide Average should not be interpreted as defining or providing a benchmark for “acceptable” levels of
performance or satisfaction. Instead, it describes average levels of performance or satisfaction across the State; it is up to public managers, policy-makers, and other stakeholders to use the data to determine programmatic and policy-related priorities.

What is Contained in This Report?

This report illustrates 2016-17 NCI Adult Family Survey demographic and outcome results from Regional Center of the East Bay compared to the CA statewide average and the weighted NCI average.

The number of responses per each question by regional center, state, and across NCI states are included in each chart. All results are shown in chart form. In charts, “N” refers to the total number of respondents. All state and national data results for this survey can be found online at: http://www.dds.ca.gov/QA/.
Demographics of the Family Member

This section provides demographic profiles of the family member about whom the survey was completed.
GRAPH 1.

More Than One Person In Home Has IDD

<table>
<thead>
<tr>
<th></th>
<th>RCEB (N = 186)</th>
<th>CA Average (N = 4737)</th>
<th>NCI Average (N = 11046)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>17%</td>
<td>16%</td>
<td>14%</td>
</tr>
<tr>
<td>No</td>
<td>83%</td>
<td>84%</td>
<td>86%</td>
</tr>
</tbody>
</table>

GRAPH 2.

Family Member's Age

<table>
<thead>
<tr>
<th></th>
<th>RCEB (N = 188)</th>
<th>CA Average (N = 4830)</th>
<th>NCI Average (N = 11245)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>33</td>
<td>35</td>
<td>34</td>
</tr>
</tbody>
</table>

GRAPH 3.

Family Member’s Gender

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>RCEB</td>
<td>64%</td>
<td>36%</td>
</tr>
<tr>
<td>CA Average</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>NCI Average</td>
<td>58%</td>
<td>41%</td>
</tr>
</tbody>
</table>

GRAPH 4. * ±

Family Member’s Disabilities (CA Qualifying Conditions)

<table>
<thead>
<tr>
<th></th>
<th>Intellectual Disability</th>
<th>Autism Spectrum Disorder</th>
<th>Cerebral Palsy</th>
<th>Epilepsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>RCEB</td>
<td>66%</td>
<td>35%</td>
<td>18%</td>
<td>20%</td>
</tr>
<tr>
<td>CA Average</td>
<td>61%</td>
<td>33%</td>
<td>18%</td>
<td>20%</td>
</tr>
<tr>
<td>NCI Average</td>
<td>65%</td>
<td>31%</td>
<td>20%</td>
<td>24%</td>
</tr>
</tbody>
</table>

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

* ± Epilepsy corresponds to NCI category ‘seizure disorder/neurological condition’.
* Categories are not mutually exclusive, therefore N is not shown.
**GRAPH 9. *±**

**Family Member’s Race And Ethnicity**

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>RCEB</th>
<th>CA Average</th>
<th>NCI Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian or Alaska Native</td>
<td>1%</td>
<td>2%</td>
<td>27%</td>
</tr>
<tr>
<td>Asian</td>
<td>8%</td>
<td>14%</td>
<td>57%</td>
</tr>
<tr>
<td>Black or African-American</td>
<td>1%</td>
<td>2%</td>
<td>15%</td>
</tr>
<tr>
<td>Hawaiian or Pacific Islander</td>
<td>1%</td>
<td>2%</td>
<td>14%</td>
</tr>
<tr>
<td>White</td>
<td>1%</td>
<td>1%</td>
<td>4%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>20%</td>
<td>37%</td>
<td>61%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
<td>2%</td>
<td>15%</td>
</tr>
</tbody>
</table>

**GRAPH 10.**

**Family Member’s Preferred Means Of Communication**

<table>
<thead>
<tr>
<th>Communication Type</th>
<th>RCEB (N = 183)</th>
<th>CA Average (N = 4728)</th>
<th>NCI Average (N = 11053)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spoken</td>
<td>81%</td>
<td>77%</td>
<td>83%</td>
</tr>
<tr>
<td>Gestures or Body Language</td>
<td>9%</td>
<td>12%</td>
<td>14%</td>
</tr>
<tr>
<td>Sign Language or Finger Spelling</td>
<td>4%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Communication Aid or Device</td>
<td>2%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
<td>1%</td>
<td>4%</td>
</tr>
</tbody>
</table>

**GRAPH 11. ∞**

**Family Member’s Preferred Language**

<table>
<thead>
<tr>
<th>Language</th>
<th>RCEB (N = 188)</th>
<th>CA Average (N = 4849)</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>72%</td>
<td>73%</td>
</tr>
<tr>
<td>Spanish</td>
<td>12%</td>
<td>16%</td>
</tr>
<tr>
<td>Mandarin</td>
<td>7%</td>
<td>1%</td>
</tr>
<tr>
<td>Tagalog</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>1%</td>
<td>1%</td>
</tr>
</tbody>
</table>

**GRAPH 12. ∞**

**Family Member’s Preferred Language**

<table>
<thead>
<tr>
<th>Language</th>
<th>RCEB (N = 188)</th>
<th>CA Average (N = 4849)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Korean</td>
<td>0%</td>
<td>1%</td>
</tr>
<tr>
<td>Arabic</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Armenian</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Farsi</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Hmong</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

*Categories are not mutually exclusive, therefore N is not shown.
± NCI race and ethnicity categories are based on the Census model; CA records Hispanic/Latino as a race group.
∞ California-specific question
∞ California-specific question

*‘Don’t Know’ responses included in denominator

ˇ Full guardianship is not applicable in California.
“Paid individual job in the community” is defined as: a person working at an individual job in a local business alongside peers who do not have disabilities.

Job is part of the typical labor market (e.g., competitive employment).

“Paid small group job in a community-based setting” is defined as: an activity is done in an integrated setting, as part of a group of not more than 8 people with disabilities (e.g., enclave, work crew).

“Unpaid Activity in a Community-based Setting” may include: volunteering, skills training, and staff-supported community connections.

“Paid activity in a facility-based setting” may include activities in a workshop, activity center, or business that primarily hires people with disabilities.
"Unpaid activity in a facility-based setting" may include day habilitation, senior programs or drop-in centers.
Demographics of Respondent

This section provides demographic information about the respondent.
GRAPH 36. *

Family Member’s Residential Designation

- Urban or Suburban: 91% (RCEB), 81% (CA Average), 72% (NCI Average)
- Rural: 4% (RCEB), 13% (CA Average), 24% (NCI Average)
- Don’t Know: 4% (RCEB), 6% (CA Average), 5% (NCI Average)

GRAPH 37. ∞

Out-Of-Pocket Expenses For Family Member’s Care In The Past Year

- Nothing: 18% (RCEB), 10% (CA Average)
- $1-$100: 30% (RCEB), 10% (CA Average)
- $101-$1,000: 35% (RCEB), 30% (CA Average)
- $1,001-$10,000: 11% (RCEB), 20% (CA Average)
- Over $10,000: 4% (RCEB), 6% (CA Average)

GRAPH 38. ∞

Services And Supports Paid For Out-Of-Pocket

- Respite Services: 9% (RCEB), 14% (CA Average)
- Behavior Therapy: 5% (RCEB), 4% (CA Average)
- Speech Therapy: 4% (RCEB), 2% (CA Average)
- Additional Therapies: 11% (RCEB), 9% (CA Average)
- Social Skills Training: 3% (RCEB), 5% (CA Average)
- Recreational Activities: 37% (RCEB), 38% (CA Average)

GRAPH 39. ∞

Services And Supports Paid For Out-Of-Pocket

- Afterschool Care: 7% (RCEB), 6% (CA Average)
- Educational Expenses: 10% (RCEB), 11% (CA Average)
- Medical and/or dental expenses: 63% (RCEB), 59% (CA Average)
- Parent Training: 2% (RCEB), 2% (CA Average)
- Transportation Support: 37% (RCEB), 40% (CA Average)
- Other: 15% (RCEB), 13% (CA Average)

* ‘Don’t Know’ responses included in denominator
∞ California-specific question; categories are not mutually exclusive
Services and Supports Received

*This section provides information about the services and supports received by the family from the Regional Center.*
*Categories are not mutually exclusive, therefore N is not shown

** Note, NCI average refers to DD agency support
Information and Planning

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES HAVE THE INFORMATION AND SUPPORT NECESSARY TO PLAN FOR THEIR SERVICES AND SUPPORTS.
*Categories are not mutually exclusive
Access and Delivery

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES GET THE SERVICES AND SUPPORTS THEY NEED.
* Categories are not mutually exclusive, therefore N is not shown.
GRAPH 77. *

* Categories are not mutually exclusive, therefore N is not shown.
Choice, Decision Making and Control

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES DETERMINE THE SERVICES AND SUPPORTS THEY RECEIVE AND THE INDIVIDUALS OR AGENCIES WHO PROVIDE THEM.
GRAPH 78.

Family Can Choose Or Change Provider Agencies That Provide Family Member Services

GRAPH 79.

Family Can Choose Or Change Family Member's Support Workers

GRAPH 80.

Family Directly Manages Support Workers

GRAPH 81.

Family Member's Service Providers Work Together To Provide Supports
Respondent, Family Member With A Disability Or Another Family Member Chose Or Can Change Case Manager/Service Coordinator

- Chose Case Manager/Service Coordinator: RCEB (N = 129), CA Average (N = 3120), NCI Average (N = 8241)
- Did Not Choose Case Manager/Service Coordinator but Can Change If Wanted: 68% RCEB, 68% CA Average, 59% NCI Average
- Did Not Choose Case Manager/Service Coordinator and Cannot Change If Wanted: 22% RCEB, 17% CA Average, 15% NCI Average
Involvement in the Community

*FAMILY MEMBERS WITH DISABILITIES USE INTEGRATED COMMUNITY SERVICES AND PARTICIPATE IN EVERYDAY COMMUNITY ACTIVITIES.*
*Categories are not mutually exclusive, therefore N is not shown.

**Note, NCI average refers to DD agency support
Graph 87.

Family Takes Part In Family-to-family Networks

- Yes
  - RCEB (N = 159): 21%
  - CA Average (N = 3922): 19%
  - NCI Average (N = 8350): 20%

- No
  - RCEB (N = 159): 79%
  - CA Average (N = 3922): 81%
  - NCI Average (N = 8350): 80%
Satisfaction

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES RECEIVE ADEQUATE AND SATISFACTORY SUPPORTS.
*For this question, ‘No’ and ‘Don’t Know’ responses were combined.
CA Specific Questions
**GRAPH 98.**

**Respondent Got A Copy Of The IPP In His/Her Preferred Language**

- Yes: 95% (RCEB N = 131) vs. 95% (CA Average N = 2825)
- No: 5% vs. 5%

**GRAPH 99.**

**There Are Support Workers Available Who Can Speak To Respondent in His/Her Preferred Language**

- Always: 85% (RCEB N = 129) vs. 85% (CA Average N = 3771)
- Usually: 9% vs. 10%
- Sometimes: 2% vs. 3%
- Seldom/Never: 3% vs. 1%

**GRAPH 100.**

**Services And Supports Made A Difference In Helping Keep Family Member Home**

- Yes: 83% (RCEB N = 150) vs. 83%
- No: 17% vs. 17%

**GRAPH 101.**

**Family Member Moved From A Developmental Center In Past Five Years**

- Yes: 99% (RCEB N = 150) vs. 98%
- No: 1% vs. 2%