NCI Family/Guardian Survey Regional Center Outcomes

Eastern Los Angeles Regional Center Report

Fiscal Year 2016-17
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Quality Assessment Project and National Core Indicators™

This report contains regional center level results from California’s statewide National Core Indicators Family/Guardian 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 Family/Guardian Survey findings from Eastern Los Angeles Regional Center 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 measure and 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 Family/Guardian Survey?

The NCI Family/Guardian Survey is used to gather data on family outcomes. It is mailed to families and guardians who have an adult family member who does not live in the family home and receives at least one service other than case management from the state

¹ Refer to the California Family/Guardian Survey Report FY 16/17 for information about Quality Assessment Project implementation, NCI and California’s statewide results.
developmental disabilities agency. 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 9,194 Family/Guardian Surveys were completed across 12 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). 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 Family/Guardian Survey in 2016-17 were: AZ, CA, FL, GA, KY, LA, MD, NC, NJ, PA, SD and VA.
How were people selected to participate?

In California, all eligible families were mailed a survey for the Family/Guardian Survey FY16/17. The State Council on Developmental Disabilities (SCDD) mailed out the paper survey to 19,799 eligible families. A total of 4,062 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 an intellectual or developmental disability who lives somewhere other than 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 five 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: KY, LA, NC, NJ, and SD. For more information on response rates and mode, please see the Methodology section within the national edition of the 2016-17 Family/Guardian 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 somewhere other than 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 Family/Guardian Survey is a tool for assessing system-wide performance. It is not intended to be used to monitor individuals or providers. The NCI 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 and regional center; 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 Family/Guardian Survey demographic and outcome results from Eastern Los Angeles Regional Center 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.
*Note, abbreviated residential categories are as follows: Institutional Care Facility (ICF); Community Care Facility (CCF); own home or apartment ILS/SLS. CCF corresponds to NCI group home settings.

** Note, abbreviated residential categories are as follows: Family Home Agency (FHA); Skilled Nursing Facility (SNF). FHA corresponds to NCI foster care or host home category. SNF corresponds to NCI nursing homes category.
GRAPH 5.

Family Member's Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>ELARC (N = 172)</th>
<th>CA Average (N = 4018)</th>
<th>NCI Average (N = 9097)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>69%</td>
<td>60%</td>
<td>59%</td>
</tr>
<tr>
<td>Female</td>
<td>31%</td>
<td>41%</td>
<td>41%</td>
</tr>
</tbody>
</table>

GRAPH 6. * ±

Family Member’s Disabilities (CA Qualifying Conditions)

<table>
<thead>
<tr>
<th>Condition</th>
<th>ELARC</th>
<th>CA Average</th>
<th>NCI Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual Disability</td>
<td>67%</td>
<td>68%</td>
<td>74%</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>33%</td>
<td>28%</td>
<td>25%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>20%</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>29%</td>
<td>26%</td>
<td>28%</td>
</tr>
</tbody>
</table>

GRAPH 7. *

Family Member's Disabilities

<table>
<thead>
<tr>
<th>Disability</th>
<th>ELARC</th>
<th>CA Average</th>
<th>NCI Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Illness or Psychiatric Disorder</td>
<td>32%</td>
<td>28%</td>
<td>33%</td>
</tr>
<tr>
<td>Limited or No Vision</td>
<td>11%</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Severe or Profound Hearing Loss</td>
<td>5%</td>
<td>6%</td>
<td>7%</td>
</tr>
<tr>
<td>Brain Injury</td>
<td>9%</td>
<td>11%</td>
<td>11%</td>
</tr>
</tbody>
</table>

GRAPH 8. *

Family Member’s Disabilities

<table>
<thead>
<tr>
<th>Disability</th>
<th>ELARC</th>
<th>CA Average</th>
<th>NCI Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemical Dependency</td>
<td>2%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Prader-Willi Syndrome</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Fetal Alcohol Spectrum Disorder</td>
<td>9%</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Other</td>
<td>12%</td>
<td>13%</td>
<td>13%</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.

± NCI race and ethnicity categories are based on the Census model; CA records Hispanic/Latino as a race group.
GRAPH 13. Infinity

Family Member’s Preferred Language

<table>
<thead>
<tr>
<th>Language</th>
<th>ELARC (N = 170)</th>
<th>CA Average (N = 3991)</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>80%</td>
<td>0%</td>
</tr>
<tr>
<td>Spanish</td>
<td>11%</td>
<td>93%</td>
</tr>
<tr>
<td>Mandarin</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>Tagalog</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>0%</td>
<td>1%</td>
</tr>
</tbody>
</table>

GRAPH 14. Infinity

Family Member’s Preferred Language

<table>
<thead>
<tr>
<th>Language</th>
<th>ELARC (N = 170)</th>
<th>CA Average (N = 3991)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Korean</td>
<td>1%</td>
<td>0%</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>

GRAPH 15. Infinity

Family Member’s Preferred Language

<table>
<thead>
<tr>
<th>Language</th>
<th>ELARC (N = 170)</th>
<th>CA Average (N = 3991)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Khmer</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Laos</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Russian</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>American Sign Language</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
<td>5%</td>
</tr>
</tbody>
</table>

GRAPH 16. Infinity

Family Member Has Legal Court Appointed Guardian Or Conservator

<table>
<thead>
<tr>
<th>Type</th>
<th>ELARC (N = 168)</th>
<th>CA Average (N = 3933)</th>
<th>NCI Average (N = 8942)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>39%</td>
<td>0%</td>
<td>41%</td>
</tr>
<tr>
<td>Limited</td>
<td>0%</td>
<td>0%</td>
<td>9%</td>
</tr>
<tr>
<td>Full</td>
<td>30%</td>
<td>53%</td>
<td>52%</td>
</tr>
<tr>
<td>Has Guardianship, Level Unknown</td>
<td>0%</td>
<td>0%</td>
<td></td>
</tr>
<tr>
<td>Don't Know</td>
<td>8%</td>
<td>25%</td>
<td>6%</td>
</tr>
</tbody>
</table>

∞ California-specific question

* 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.
GRAPH 29.

Family Member’s Need For Help With Other Daily Activities

- Extensive: 74% ELARC (N = 168), 68% CA Average (N = 3906), 76% NCI Average (N = 8901)
- Some: 23% ELARC, 28% CA Average, 21% NCI Average
- None: 4% ELARC, 5% CA Average, 3% NCI Average
Demographics of Respondent

This section provides demographic information about the respondent.
GRAPH 34. Respondent's Highest Level Of Education

GRAPH 35. Total Taxable Household Income Of Wage Earners In The Past Year

GRAPH 36. Out-Of-Pocket Expenses For Family Member’s Care In The Past Year

GRAPH 37. Services And Supports Paid For Out-Of-Pocket

∞ California-specific question
*Categories are not mutually exclusive
GRAPH 38. ∞ *

<table>
<thead>
<tr>
<th>Services And Supports Paid For Out-Of-Pocket</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afterschool Care</td>
</tr>
<tr>
<td>Educational Expenses</td>
</tr>
<tr>
<td>Medical and/or dental expenses</td>
</tr>
<tr>
<td>Parent Training</td>
</tr>
<tr>
<td>Transportation Support</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>0%</td>
</tr>
<tr>
<td>0%</td>
</tr>
<tr>
<td>4%</td>
</tr>
<tr>
<td>10%</td>
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∞ California-specific question
*Categories are not mutually exclusive
Services and Supports Received

*This section provides information about the services and supports received.*
*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.
Graph 41.

Respondent Gets Enough Information To Help Plan Services

Graph 42.

Information Respondent Gets About Services And Supports Is Easy To Understand

Graph 43.

Staff Or Residential Agency Keeps Respondent Informed About How Family Member Is Doing

Graph 44.

Case Manager/Service Coordinator Respects Family’s Choices And Opinions
*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.
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 74.

Agency Providing Residential Supports Involves Family Member In Important Decisions

- Always: ELARC (N = 113), CA Average (N = 2735), NCI Average (N = 6760)
- Usually: 43%, 33%, 30%
- Sometimes: 50%, 30%, 51%
- Seldom/Never: 49%, 31%, 11%

GRAPH 75.

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

- Always: ELARC (N = 90), CA Average (N = 1923), NCI Average (N = 4983)
- Usually: 44%, 18%, 60%
- Sometimes: 53%, 20%, 18%
- Seldom/Never: 60%, 7%, 5%

GRAPH 76.

Family Can Choose Or Change Family Member's Support Workers

- Always: ELARC (N = 97), CA Average (N = 2076), NCI Average (N = 5204)
- Usually: 35%, 15%, 29%
- Sometimes: 35%, 12%, 12%
- Seldom/Never: 35%, 43%, 37%

GRAPH 77.

Family Directly Manages Support Workers

- Always: ELARC (N = 117), CA Average (N = 2639), NCI Average (N = 6437)
- Usually: 13%, 7%, 9%
- Sometimes: 10%, 9%, 9%
- Seldom/Never: 11%, 8%, 8%
Involvement in the Community

*Family members with disabilities use integrated community services and participate in everyday community activities.*
GRAPH 80.

Family Member Takes Part In Community Activities

GRAPH 81. *

Obstacles Or Barriers To Family Member’s Participation In Community Activities

GRAPH 82.

Family Member Has Friends Or Relationships With People Other Than Paid Support Workers Or Family

GRAPH 83. **

There Are Resources In The Community Family Can Use That Are Not Provided By The Regional Center

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

** Note, NCI average refers to DD agency support
Family Takes Part In Family-to-family Networks

- Yes
  - ELARC (N = 121): 15%
  - CA Average (N = 3105): 17%
  - NCI Average (N = 6998): 18%
- No
  - ELARC (N = 121): 85%
  - CA Average (N = 3105): 83%
  - NCI Average (N = 6998): 82%
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: Cultural Competency
**GRAPH 98.**

How Much Respondent Likes Family Member's New Home

- **Extremely:** ELARC (N = 46) - 26%, CA Average (N = 1221) - 32%
- **Very Much:** ELARC (N = 46) - 52%, CA Average (N = 1221) - 50%
- **Somewhat:** ELARC (N = 46) - 17%, CA Average (N = 1221) - 15%
- **Very Little:** ELARC (N = 46) - 4%, CA Average (N = 1221) - 2%
- **Not at All:** ELARC (N = 46) - 0%, CA Average (N = 1221) - 2%

**GRAPH 99.**

There Are Services That Were Decided Upon In The IDT Meeting That Are Being Delivered To Your Family Member In The Community

- **Yes:** ELARC (N = 35) - 89%, CA Average (N = 779) - 89%
- **No:** ELARC (N = 35) - 11%, CA Average (N = 779) - 11%