NCI Adult Family Survey Regional Center Outcomes

Frank D. Lanterman Regional Center Report

Fiscal Year 2016-17
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Involvement in the Community

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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 (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. This report shows Adult Family Survey findings from Frank D. Lanterman 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 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>

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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%.

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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 Frank D. Lanterman 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.*
* 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.
*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
GRAPH 13.  

Family Member's Preferred Language

GRAPH 14. *

Family Member Has Legal Court Appointed Guardian Or Conservator

GRAPH 15.

Guardian Or Conservator Relationship To Family Member

GRAPH 16.

Family Member's Highest Level Of Education

∞ 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 32.

Number Of Adults In Household (Not Including Family Member Receiving Services)

GRAPH 33.

Number Of Children In Household

GRAPH 34.

Respondent's Highest Level Of Education

GRAPH 35.

Total Taxable Household Income Of Wage Earners In The Past Year
**GRAPH 36. * 

Family Member’s Residential Designation

- **Urban or Suburban**: 92%, 81%, 72%
- **Rural**: 1%, 13%, 24%
- **Don’t Know**: 7%, 6%, 5%

FDLRC (N = 236)
CA Average (N = 4686)
NCI Average (N = 11041)

**GRAPH 37. 00

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

- **Nothing**: 37%, 30%
- **$1-$100**: 11%, 10%
- **$101-$1,000**: 24%, 30%
- **$1,001-$10,000**: 24%, 49%
- **Over $10,000**: 4%, 4%

FDLRC (N = 225)
CA Average (N = 4459)

**GRAPH 38. 00

Services And Supports Paid For Out-Of-Pocket

- **Respite Services**: 8%, 14%
- **Behavior Therapy**: 1%, 4%
- **Speech Therapy**: 3%, 2%
- **Additional Therapies**: 7%, 9%
- **Social Skills Training**: 9%, 5%
- **Recreational Activities**: 34%, 38%

FDLRC (N = 143)
CA Average (N = 3060)

**GRAPH 39. 00

Services And Supports Paid For Out-Of-Pocket

- **Afterschool Care**: 6%, 6%
- **Educational Expenses**: 17%, 11%
- **Medical and/or dental expenses**: 59%, 55%
- **Parent Training**: 2%, 2%
- **Transportation Support**: 38%, 40%
- **Other**: 14%, 13%

FDLRC (N = 143)
CA Average (N = 3060)

*‘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
GRAPH 50.

**IPP Includes All The Services And Supports Family Member Needs**

- Yes: 73% (FDLRC N = 99), 84% (CA Average N = 2589), 86% (NCI Average N = 6383)
- No: 27% (FDLRC N = 99), 16% (CA Average N = 2589), 14% (NCI Average N = 6383)

GRAPH 51.

**Family Member Gets All Services Listed In The IPP**

- Yes: 79% (FDLRC N = 95), 88% (CA Average N = 2555), 87% (NCI Average N = 6364)
- No: 21% (FDLRC N = 95), 12% (CA Average N = 2555), 13% (NCI Average N = 6364)

GRAPH 52.

**Respondent Or Another Family Member Helped Make IPP**

- Yes: 75% (FDLRC N = 106), 79% (CA Average N = 2778), 84% (NCI Average N = 6846)
- No: 25% (FDLRC N = 106), 21% (CA Average N = 2778), 16% (NCI Average N = 6846)

GRAPH 53.

**Family Member Helped Make IPP**

- Yes: 56% (FDLRC N = 109), 66% (CA Average N = 2748), 64% (NCI Average N = 6772)
- No: 44% (FDLRC N = 109), 34% (CA Average N = 2748), 36% (NCI Average N = 6772)
Access and Delivery

Families and family members with disabilities get the services and supports they need.
GRAPH 66.

Family Member Has Access To Equipment Or Accommodations Needed

GRAPH 67.

Family Member Can See Health Professionals When Needed

GRAPH 68.

Family Member's Primary Care Doctor Understands His/Her Needs Related To His/Her Disability

GRAPH 69.

Respondent Has Access To Dental Services For Family Member
* Categories are not mutually exclusive, therefore N is not shown.
If Family Does Not Get All Services and Supports Needed, What Additional Services And Supports Needed

* 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 83.

Respondent, Family Member With A Disability Or Another Family Member Chose Or Can Change Case Manager/Service Coordinator

- Chose Case Manager/Service Coordinator: 15% FDLRC (N = 158), 14% CA Average (N = 3120), 26% NCI Average (N = 8241)
- Did Not Choose Case Manager/Service Coordinator but Can Change If Wanted: 66% FDLRC (N = 158), 68% CA Average (N = 3120), 59% NCI Average (N = 8241)
- Did Not Choose Case Manager/Service Coordinator and Cannot Change If Wanted: 19% FDLRC (N = 158), 17% CA Average (N = 3120), 15% NCI Average (N = 8241)
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
Family Takes Part In Family-to-family Networks

Yes
- FDLRC (N = 193)
- CA Average (N = 3922)
- NCI Average (N = 8350)

No
- 82%
- 81%
- 80%

Graph 88.
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 100.
Respondent Got A Copy Of The IPP In His/Her Preferred Language

<table>
<thead>
<tr>
<th></th>
<th>FDLRC (N = 114)</th>
<th>CA Average (N = 2825)</th>
</tr>
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<tbody>
<tr>
<td>Yes</td>
<td>90%</td>
<td>95%</td>
</tr>
<tr>
<td>No</td>
<td>10%</td>
<td>5%</td>
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</table>

GRAPH 101.
There Are Support Workers Available Who Can Speak To Respondent In His/Her Preferred Language

<table>
<thead>
<tr>
<th></th>
<th>FDLRC (N = 195)</th>
<th>CA Average (N = 3771)</th>
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<tbody>
<tr>
<td>Always</td>
<td>79%</td>
<td>85%</td>
</tr>
<tr>
<td>Usually</td>
<td>14%</td>
<td>10%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Seldom/Neve</td>
<td>2%</td>
<td>1%</td>
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GRAPH 102.
Services And Supports Made A Difference In Helping Keep Family Member Home

<table>
<thead>
<tr>
<th></th>
<th>FDLRC (N = 197)</th>
<th>CA Average (N = 3856)</th>
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<tr>
<td>Yes</td>
<td>80%</td>
<td>83%</td>
</tr>
<tr>
<td>No</td>
<td>20%</td>
<td>17%</td>
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GRAPH 103.
Family Member Moved From A Developmental Center In Past Five Years

<table>
<thead>
<tr>
<th></th>
<th>FDLRC (N = 220)</th>
<th>CA Average (N = 4232)</th>
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<tbody>
<tr>
<td>Yes</td>
<td>99%</td>
<td>98%</td>
</tr>
<tr>
<td>No</td>
<td>1%</td>
<td>2%</td>
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GRAPH 104.

Length Of Time Family Member Lived In The Community

<table>
<thead>
<tr>
<th>Time</th>
<th>FDLRC (N = 41)</th>
<th>CA Average (N = 875)</th>
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<tbody>
<tr>
<td>Less Than One Year</td>
<td>2%</td>
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<td>5%</td>
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<tr>
<td>More Than Five Years</td>
<td>88%</td>
<td>83%</td>
</tr>
</tbody>
</table>

GRAPH 105.

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

<table>
<thead>
<tr>
<th>Services Decided</th>
<th>FDLRC (N = 28)</th>
<th>CA Average (N = 491)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>50%</td>
<td>70%</td>
</tr>
<tr>
<td>No</td>
<td>50%</td>
<td>30%</td>
</tr>
</tbody>
</table>