

NCI Family/Guardian Survey Regional Center Outcomes

Frank D. Lanterman 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 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 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.² 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

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

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?

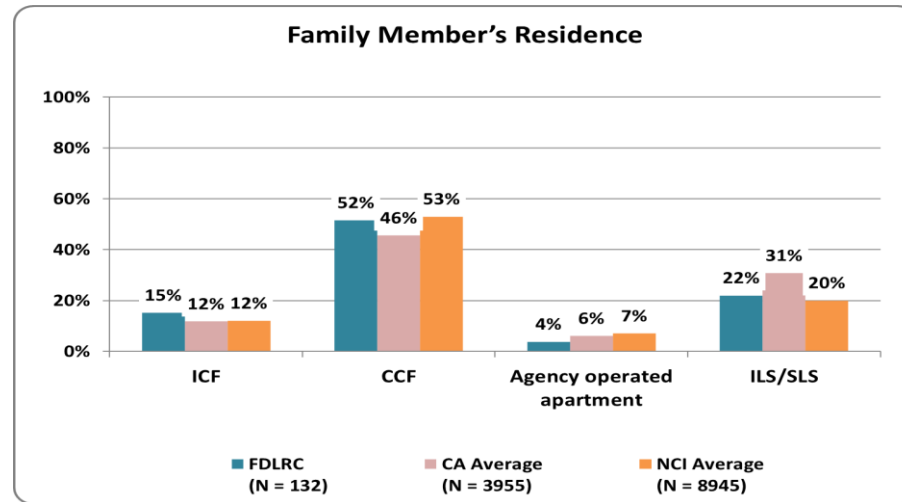
This report illustrates 2016-17 NCI Family/Guardian Survey demographic and outcome results from Frank D. Lanterman Regional Center compared to the CA statewide average and the weighted NCI average.

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/>.

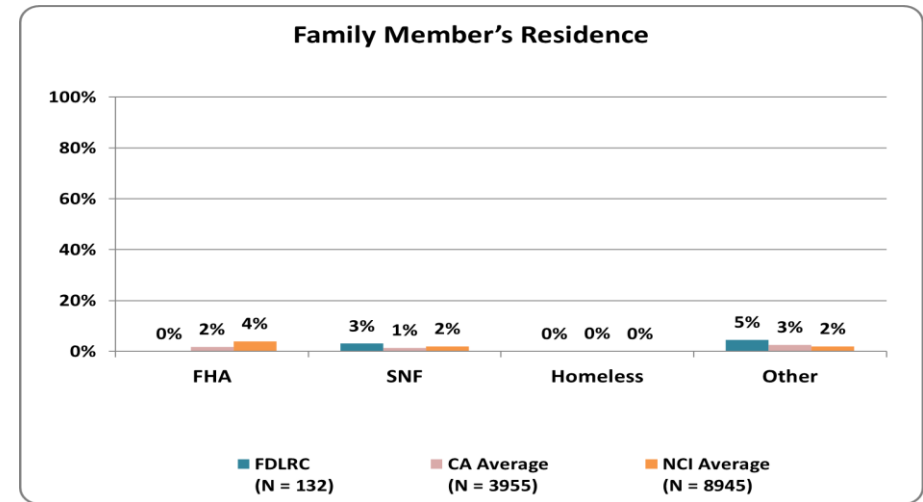
Demographics of the Family Member

THIS SECTION PROVIDES DEMOGRAPHIC PROFILES OF THE FAMILY MEMBER ABOUT WHOM THE SURVEY WAS COMPLETED.

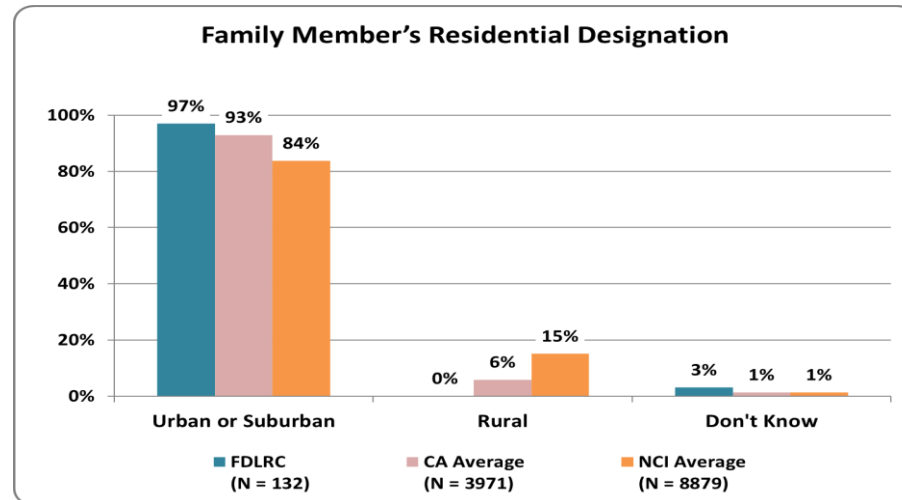
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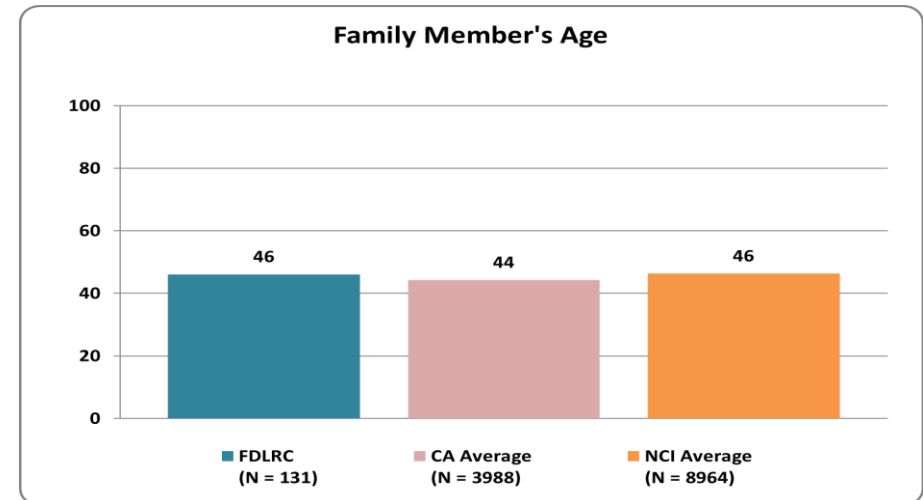
GRAPH 2. **



GRAPH 3.



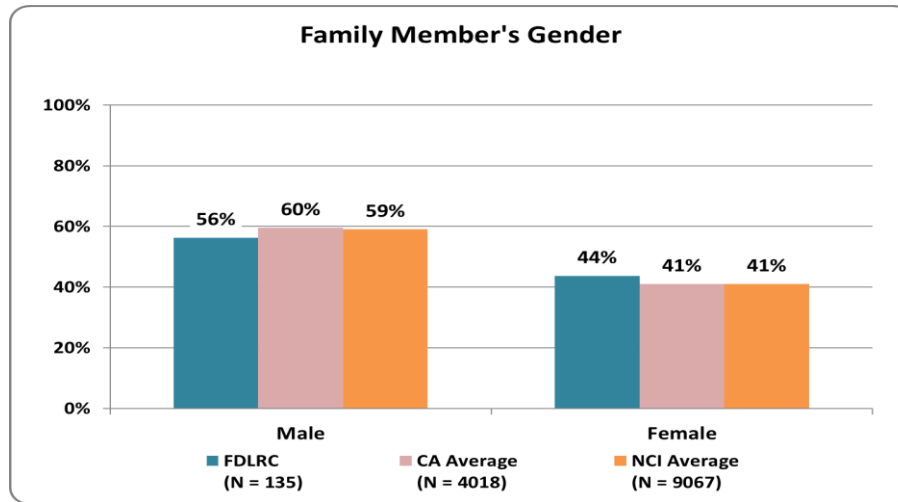
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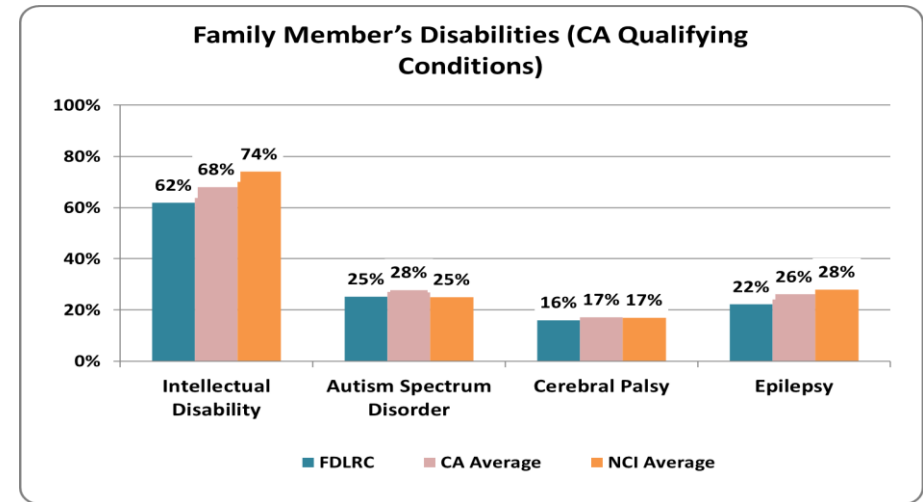
*Note, abbreviated residential categories are as follows: Institutional Care Facility (ICF); Community Care Facility (CCF); own home or apartment ILS/SLS. CCF corresponds to NCI group home settings.

** 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.

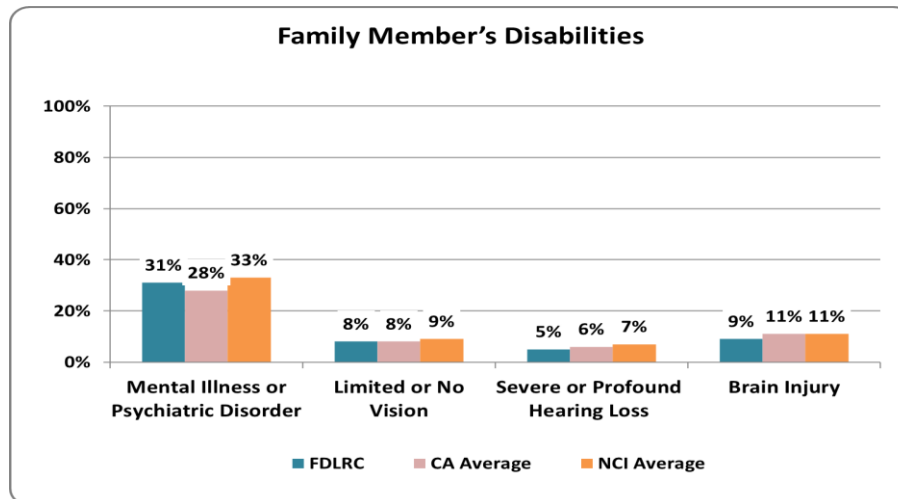
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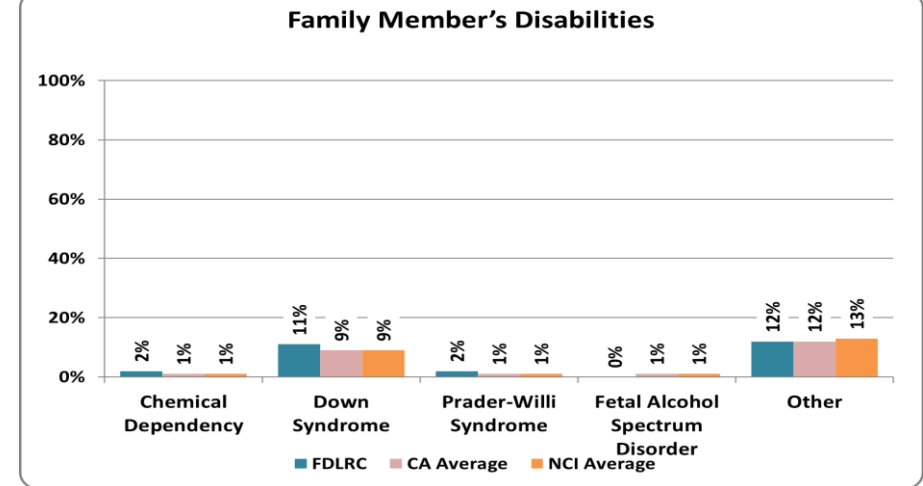
GRAPH 6. * ±



GRAPH 7. *



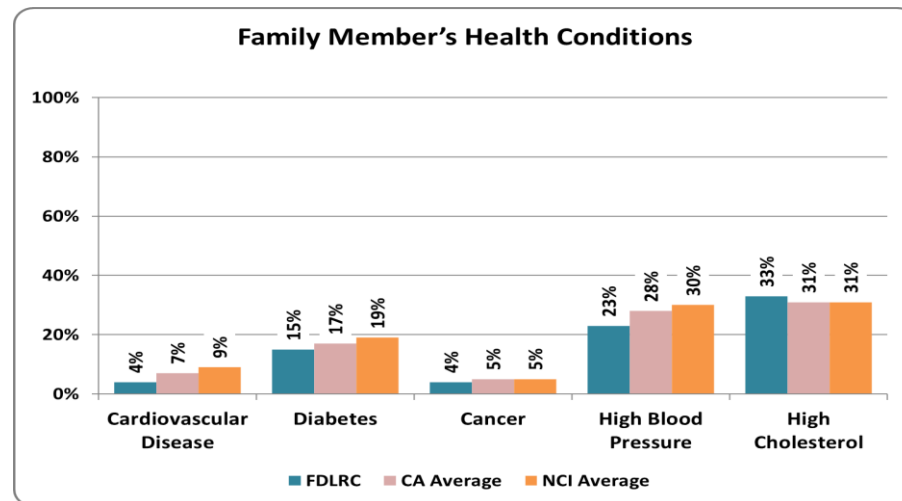
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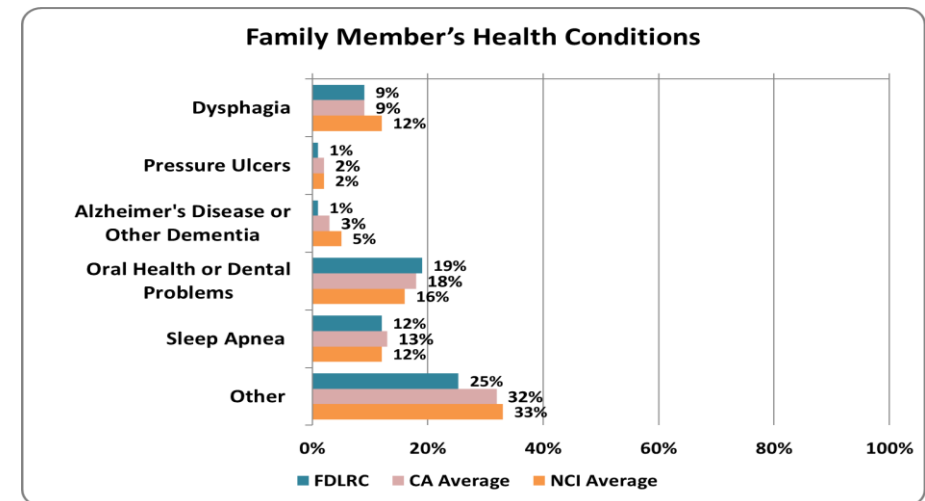
* Categories are not mutually exclusive, therefore N is not shown.

± Epilepsy corresponds to NCI category 'seizure disorder/neurological condition'.

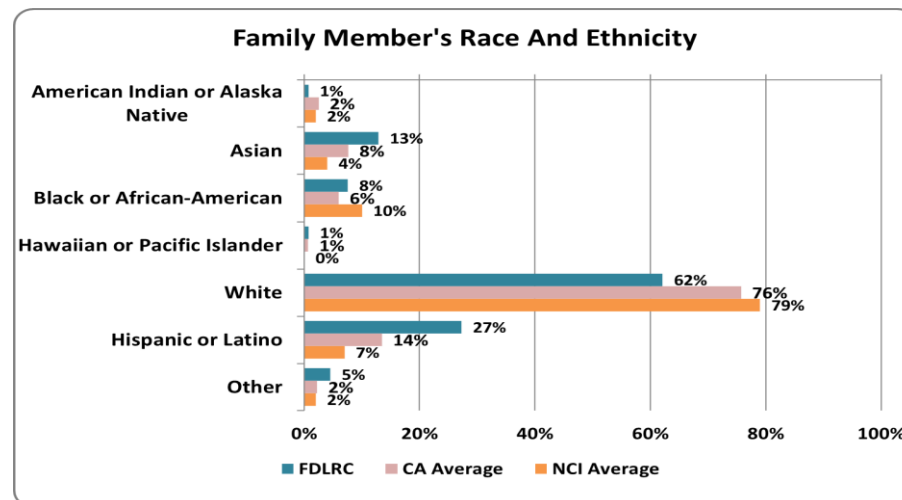
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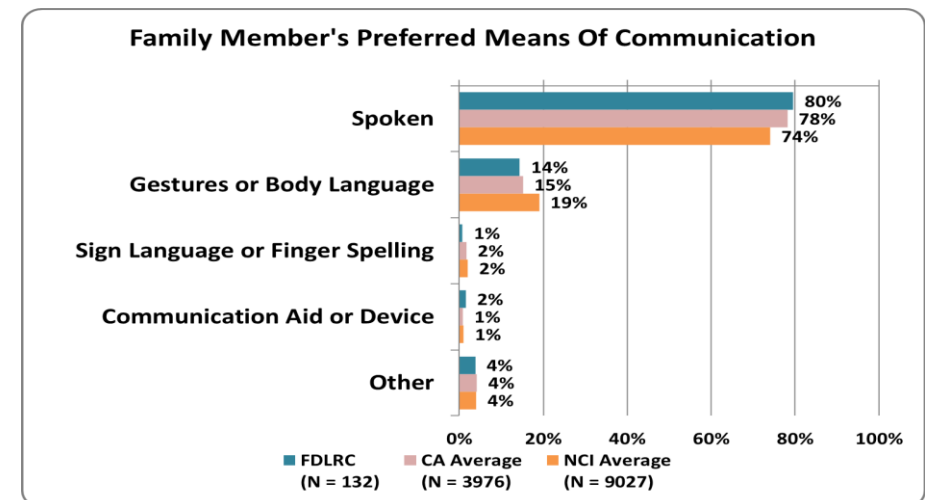
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GRAPH 11. * ±



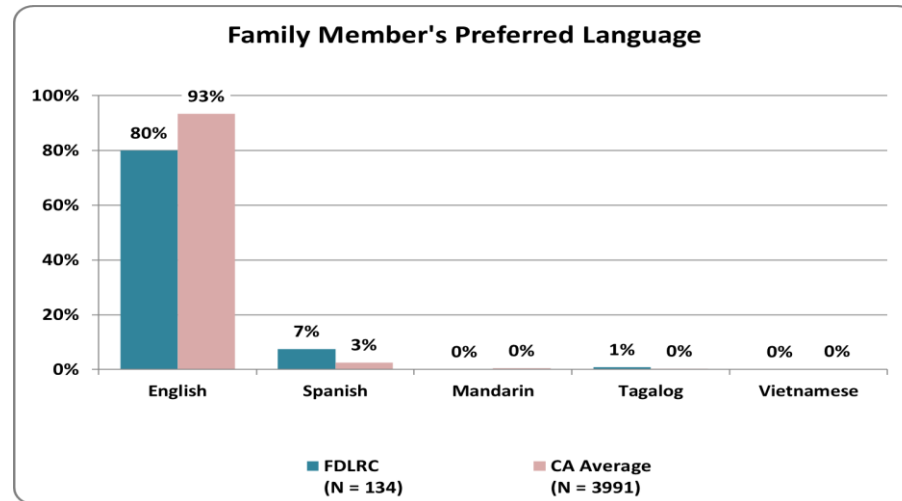
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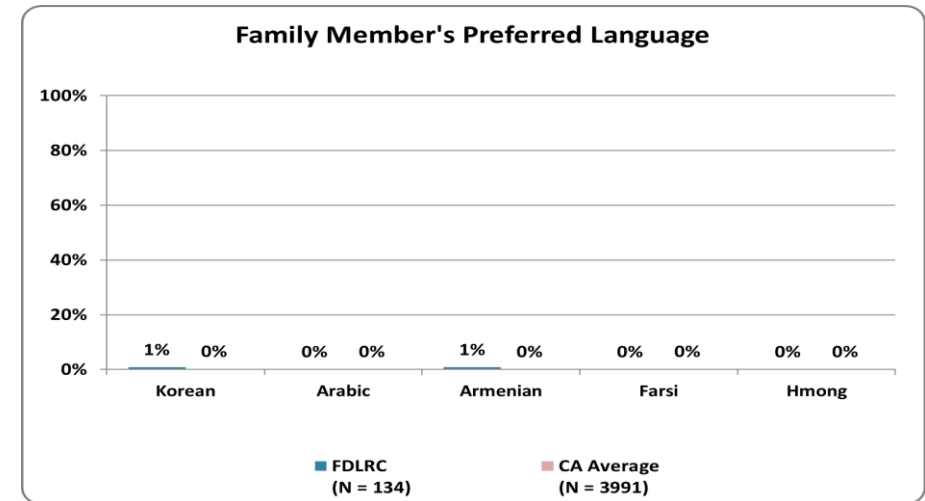
* Categories are not mutually exclusive, therefore N is not shown.

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

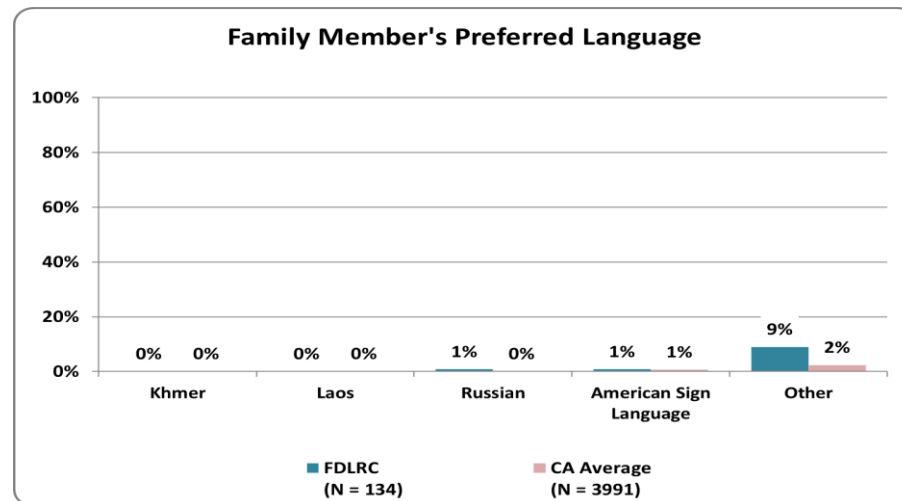
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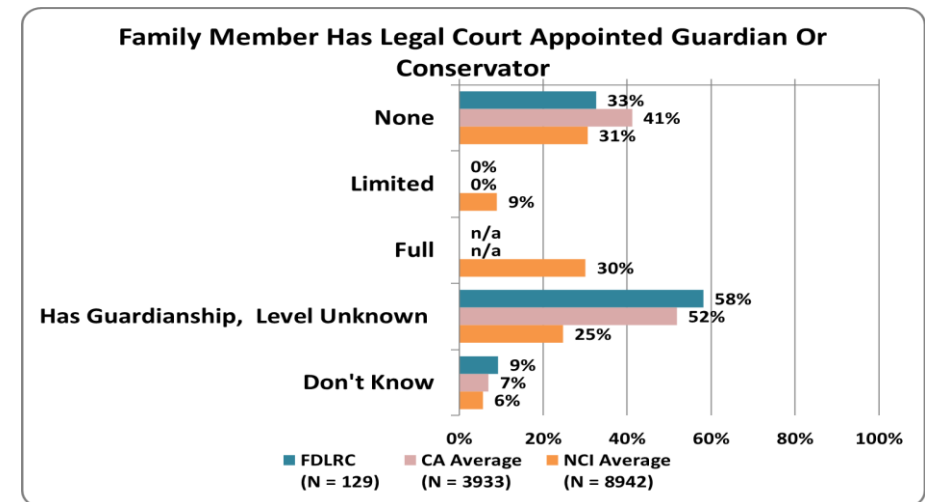
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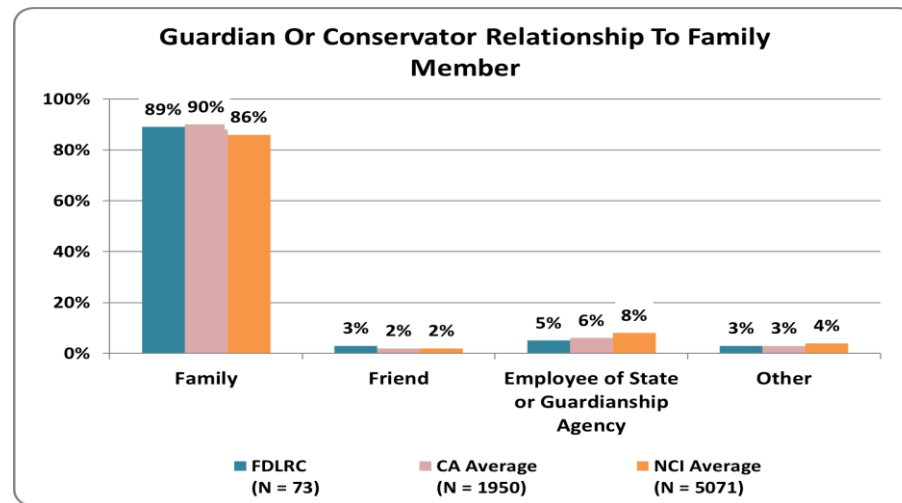
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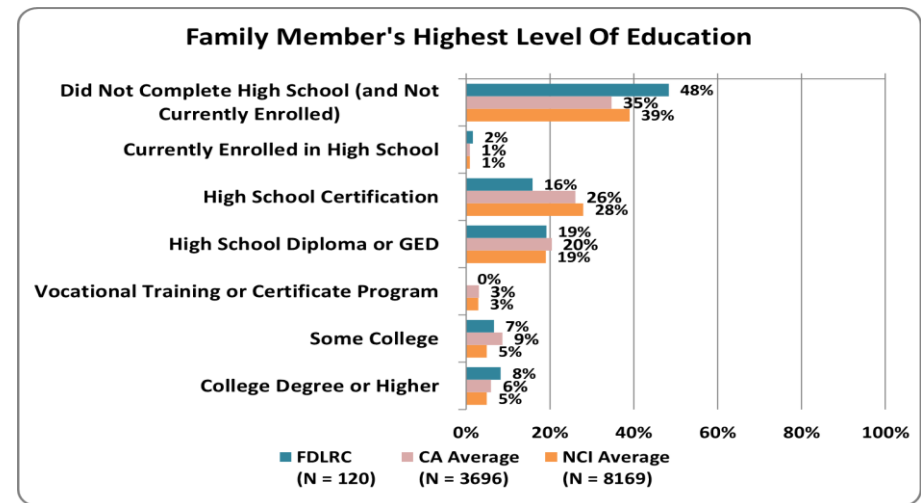
∞ California-specific question

√ Full guardianship is not applicable in California.

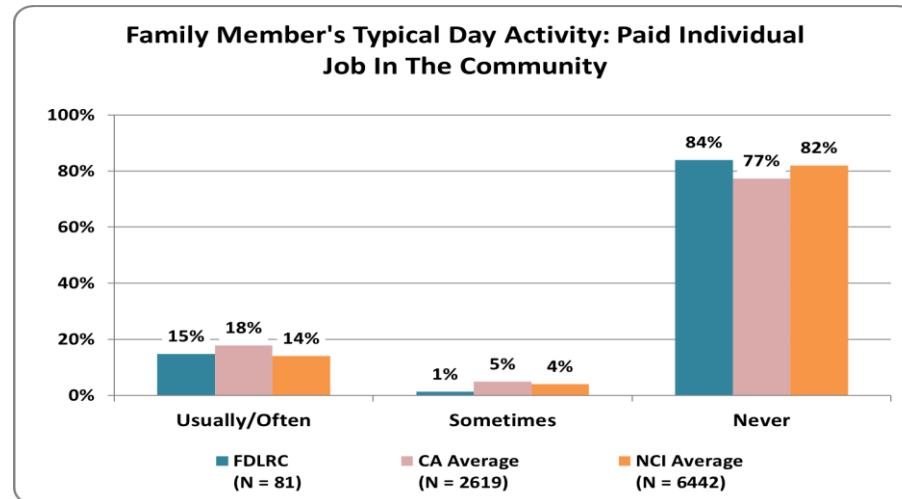
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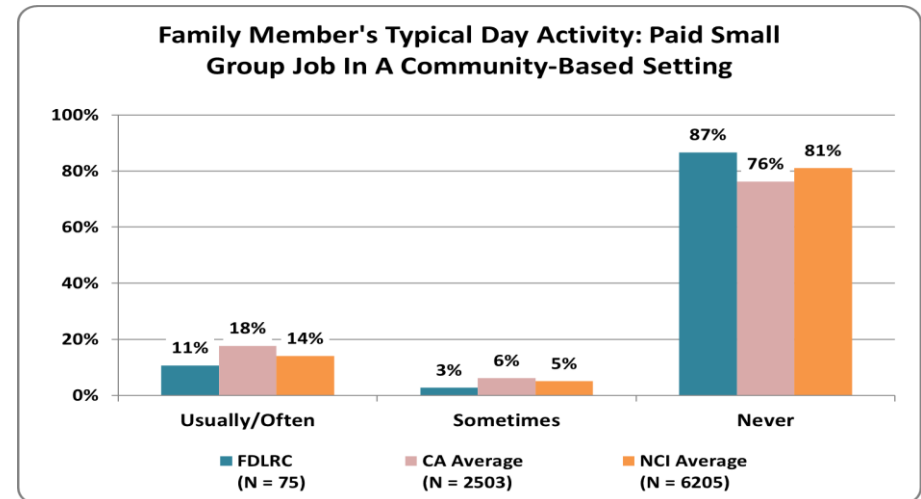
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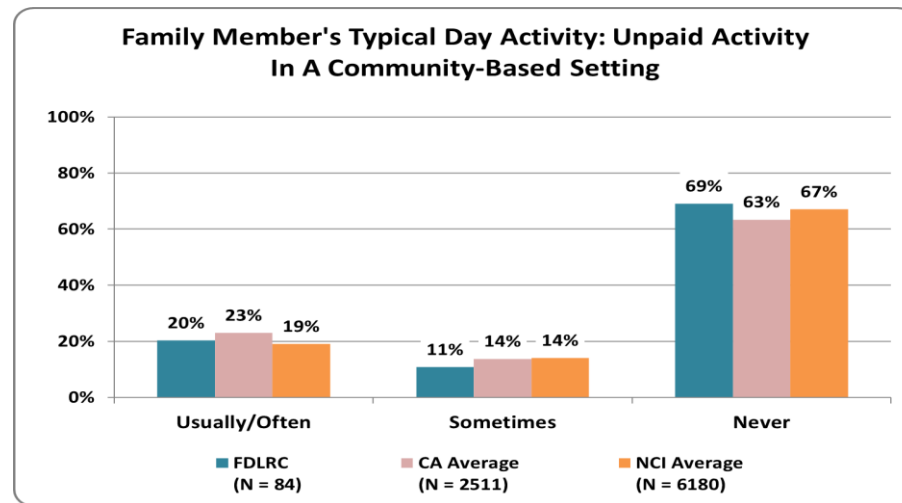
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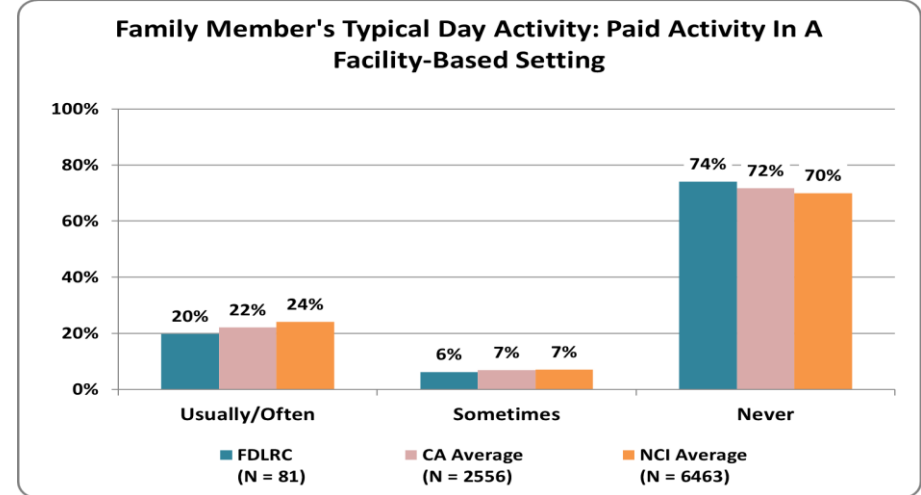
*"Paid individual job in the community" is defined as: a person working at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (e.g., competitive employment).

**"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).

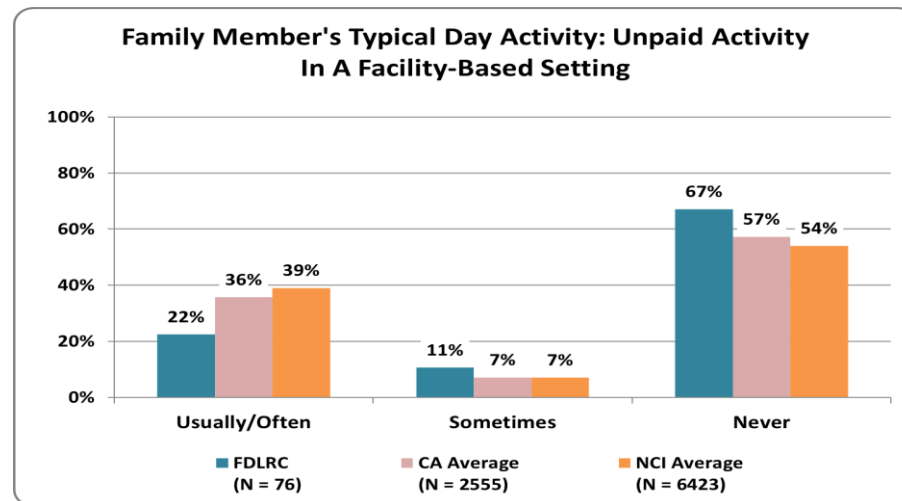
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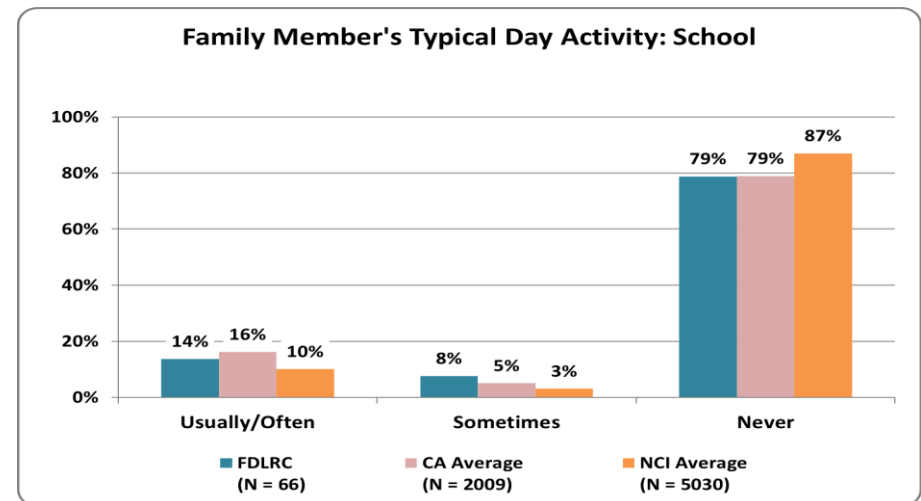
GRAPH 22. **



GRAPH 23. ***



GRAPH 24.

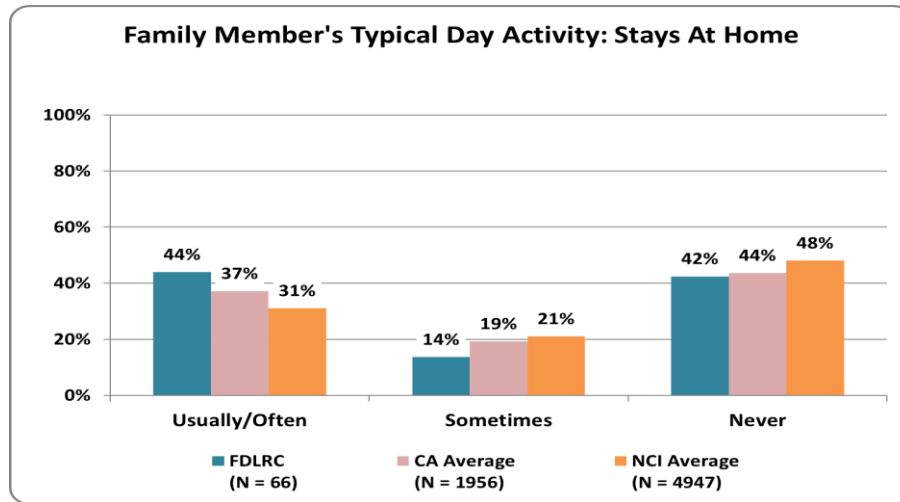


* "Unpaid Activity in a Community-based Setting" may include: volunteering, skills training, and staff-supported community connections.

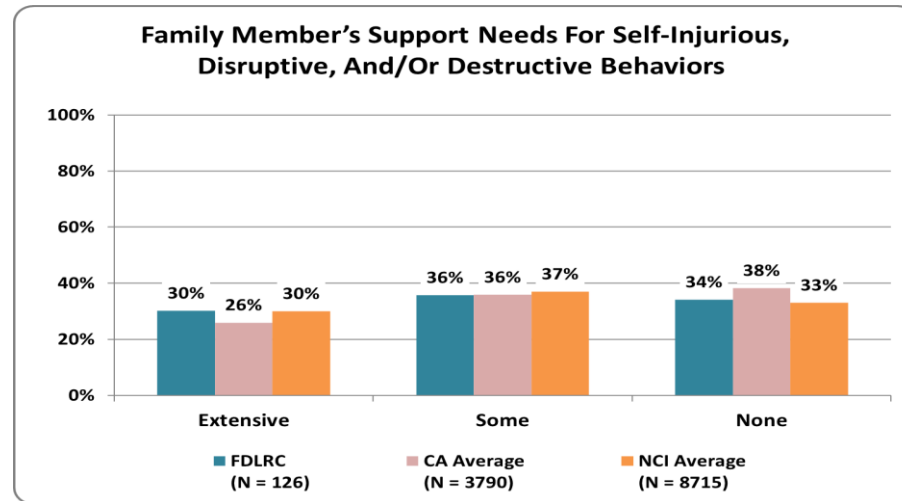
** "Paid activity in a facility-based setting" may include activities in a workshop, activity center, or business that primarily hires people with disabilities

*** "Unpaid activity in a facility-based setting" may include day habilitation, senior programs or drop-in centers.

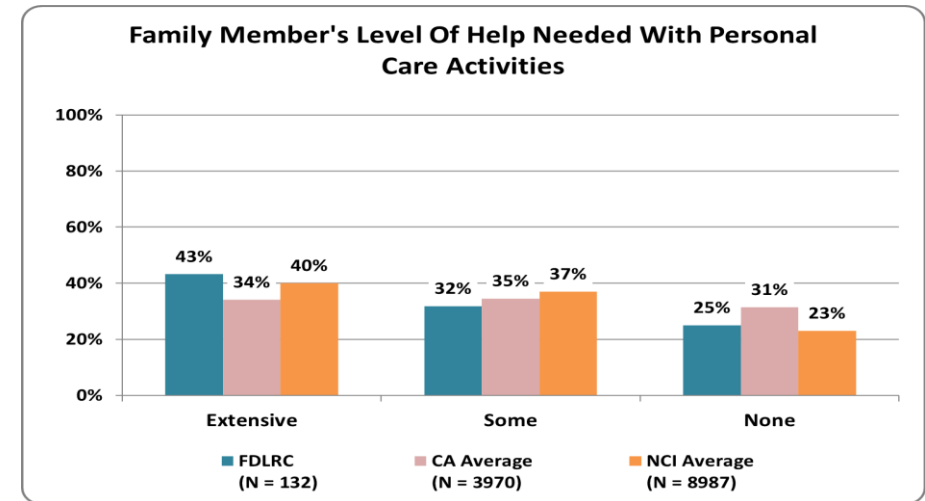
GRAPH 25.



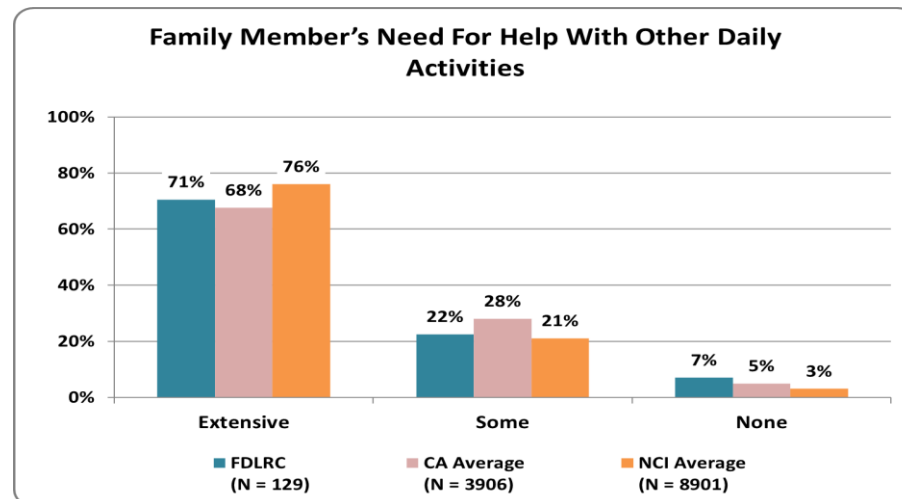
GRAPH 26.



GRAPH 27.



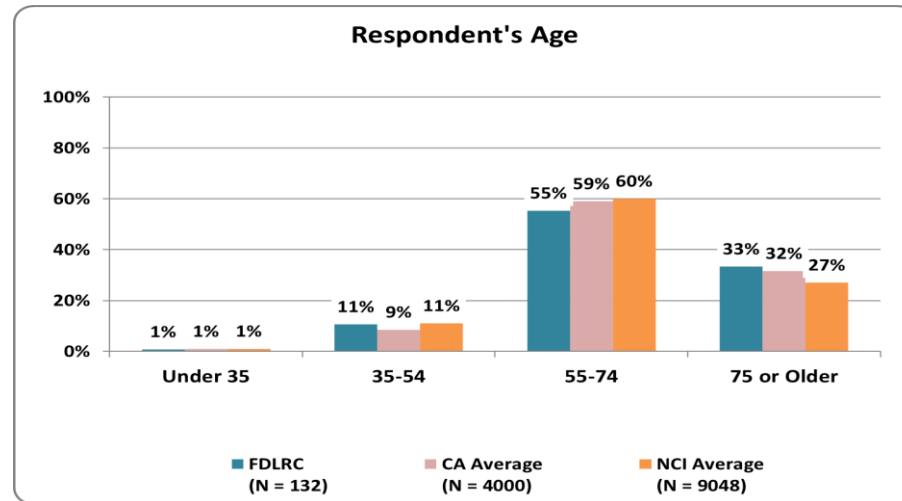
GRAPH 28.



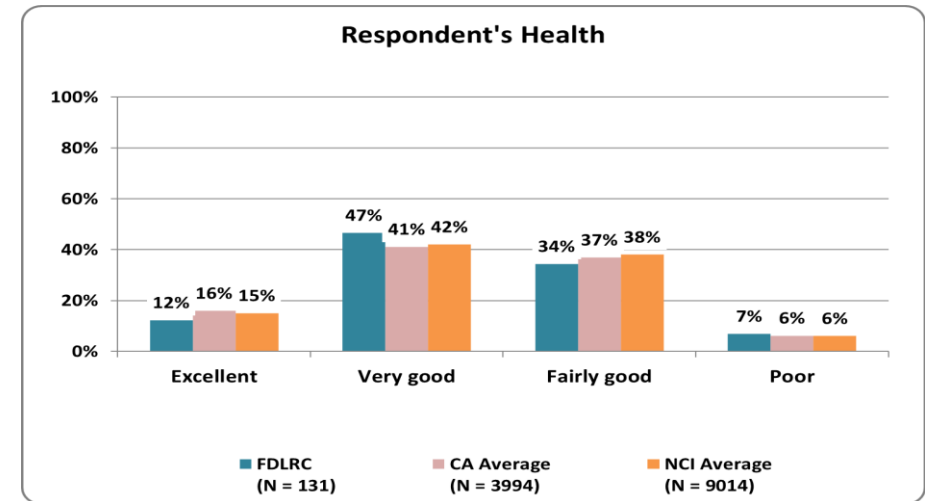
Demographics of Respondent

THIS SECTION PROVIDES DEMOGRAPHIC INFORMATION ABOUT THE RESPONDENT.

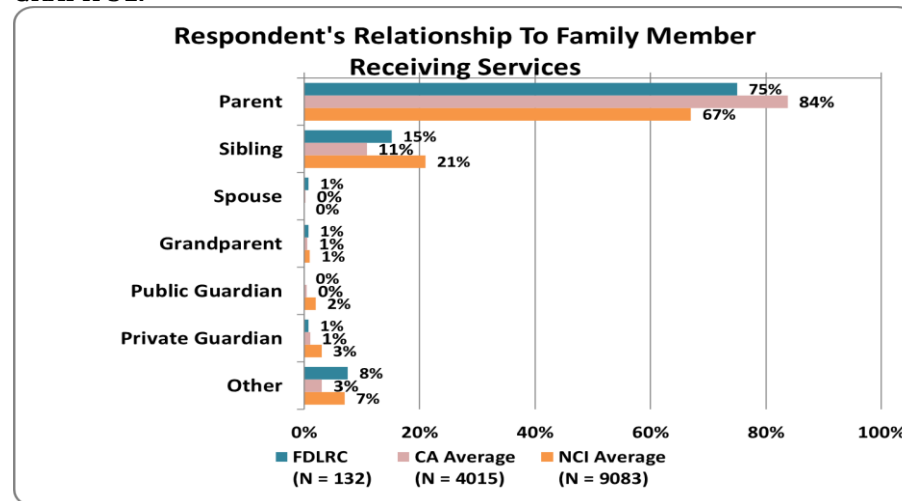
GRAPH 29.



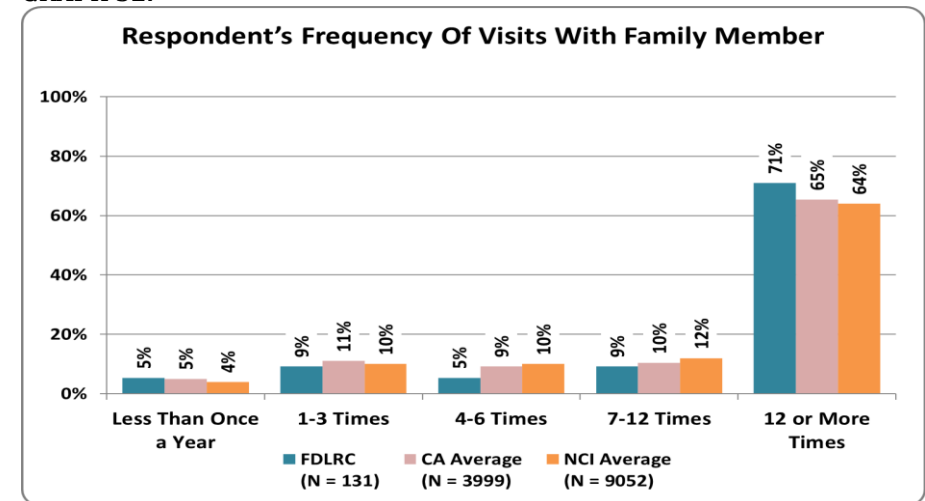
GRAPH 30.



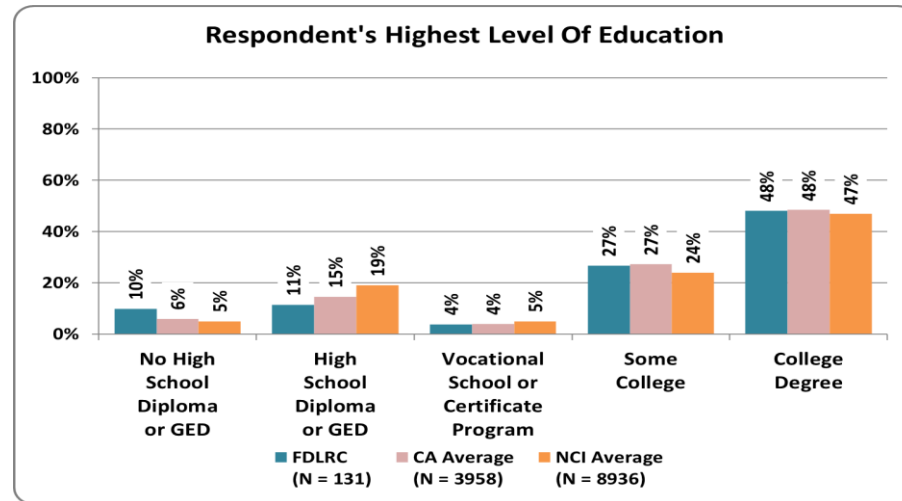
GRAPH 31.



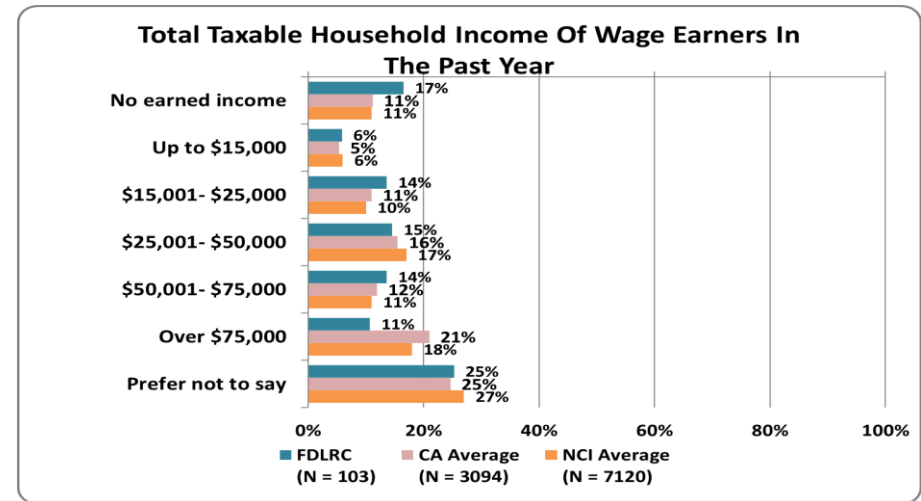
GRAPH 32.



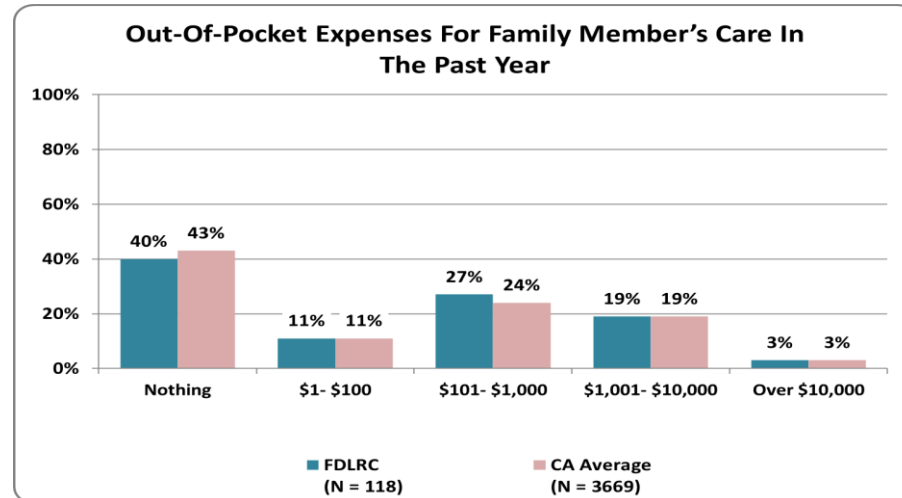
GRAPH 33.



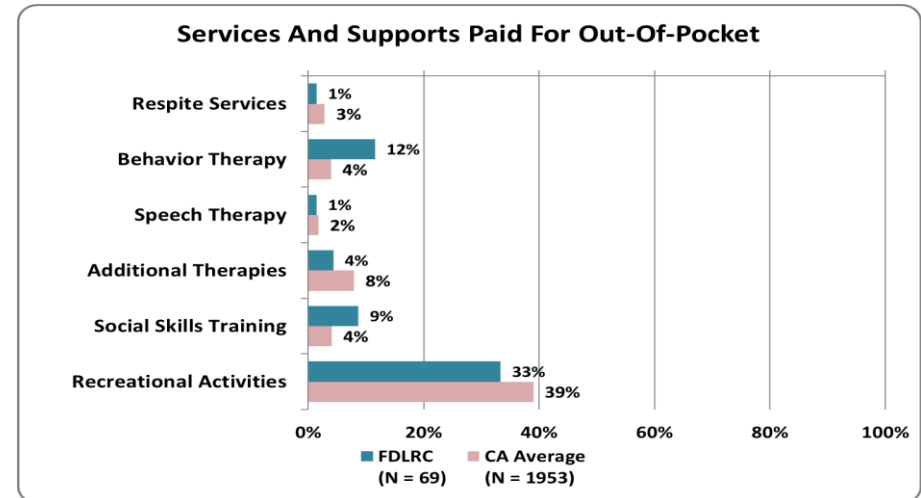
GRAPH 34.



GRAPH 35. ∞



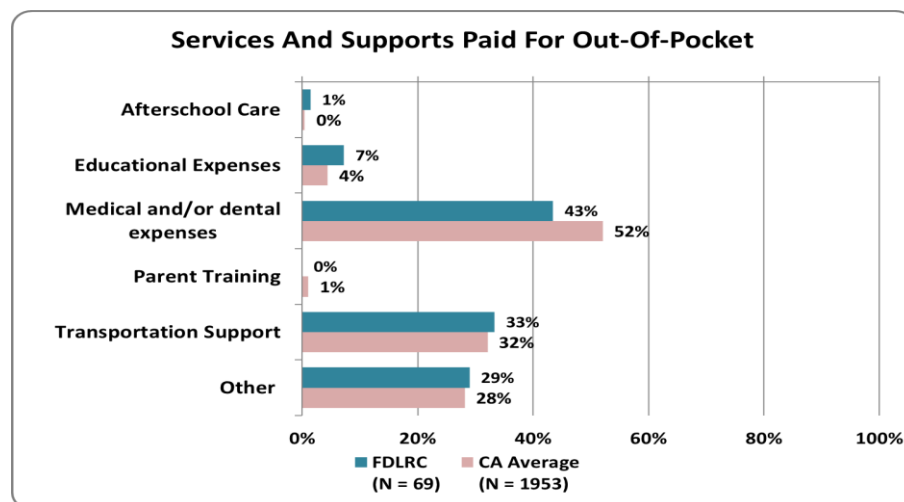
GRAPH 36. ∞ *



∞ California-specific question

*Categories are not mutually exclusive

GRAPH 37. ∞ *



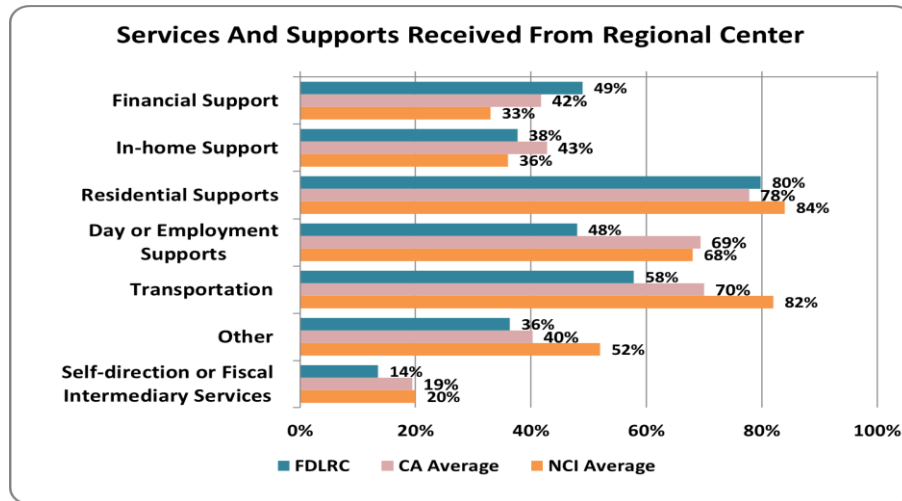
∞ California-specific question

*Categories are not mutually exclusive

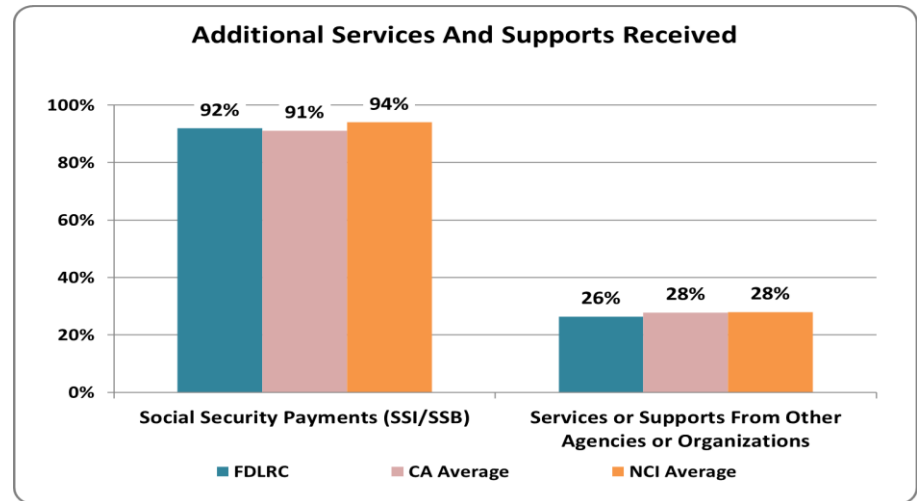
Services and Supports Received

THIS SECTION PROVIDES INFORMATION ABOUT THE SERVICES AND SUPPORTS RECEIVED.

GRAPH 38. * **



GRAPH 39. *



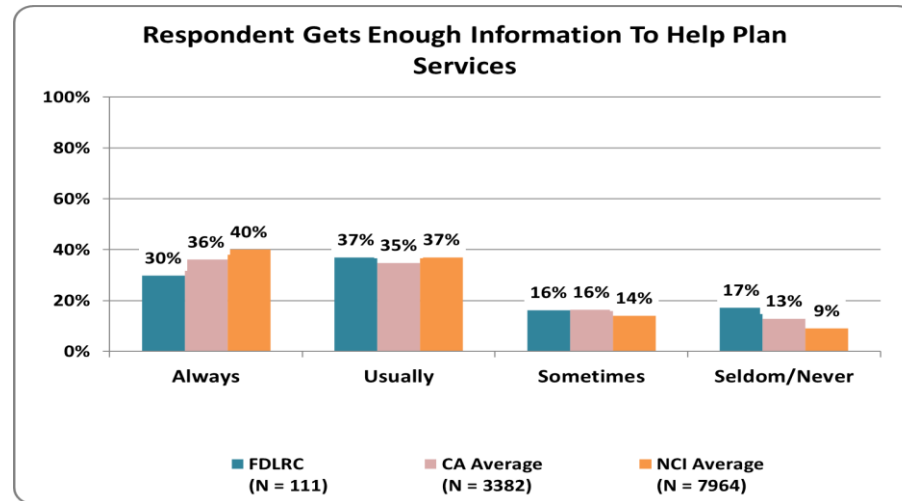
*Categories are not mutually exclusive, therefore N is not shown

**Note, NCI average refers to DD agency support

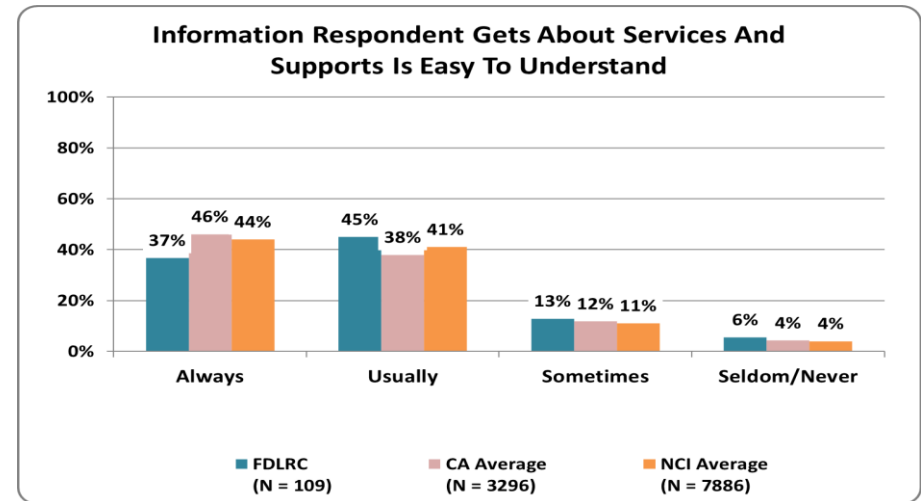
Information and Planning

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES HAVE THE INFORMATION AND SUPPORT NECESSARY TO PLAN FOR THEIR SERVICES AND SUPPORTS.

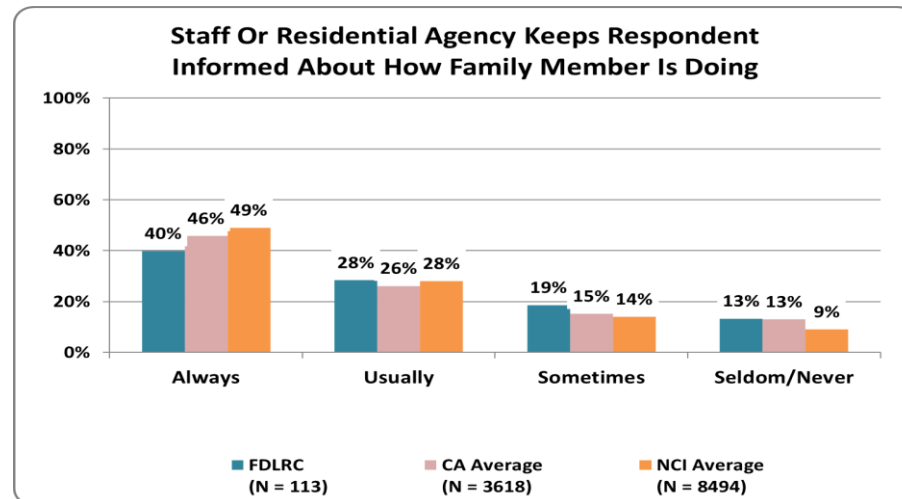
GRAPH 40.



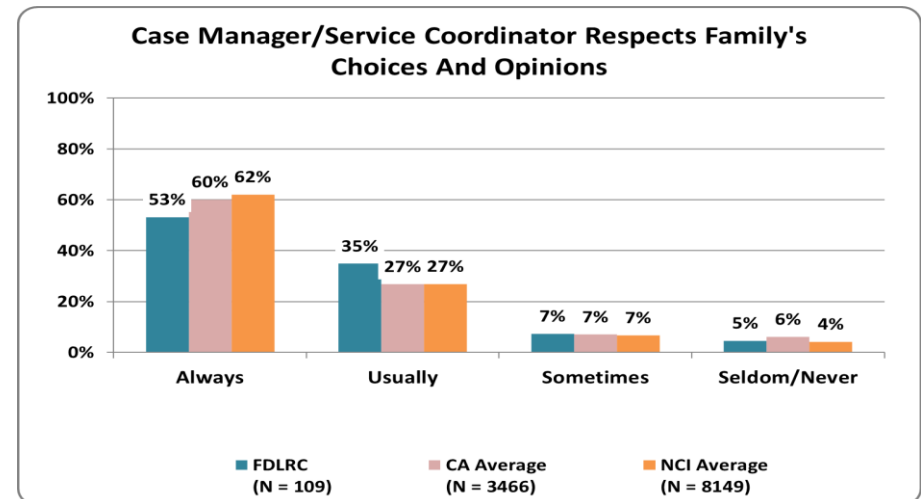
GRAPH 41.



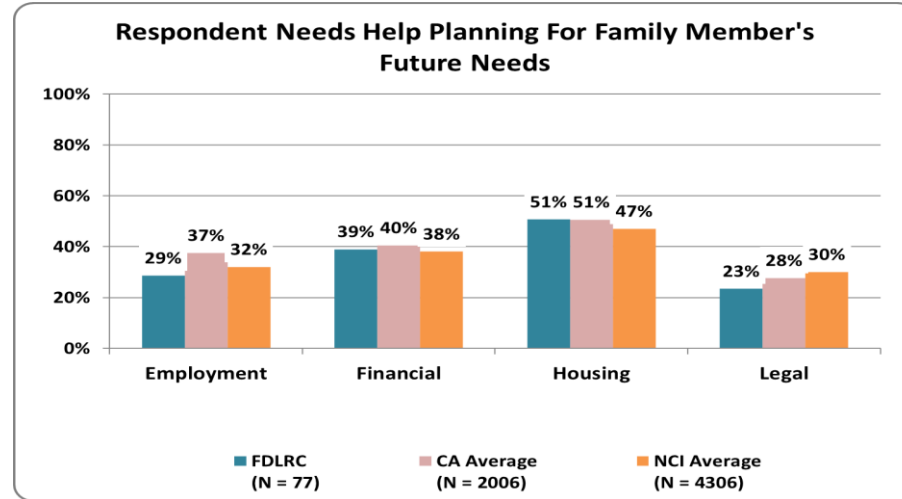
GRAPH 42.



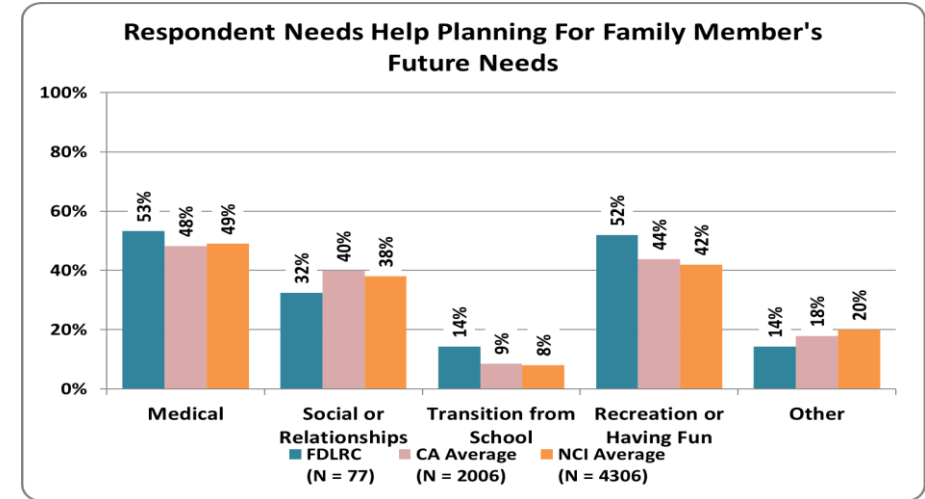
GRAPH 43.



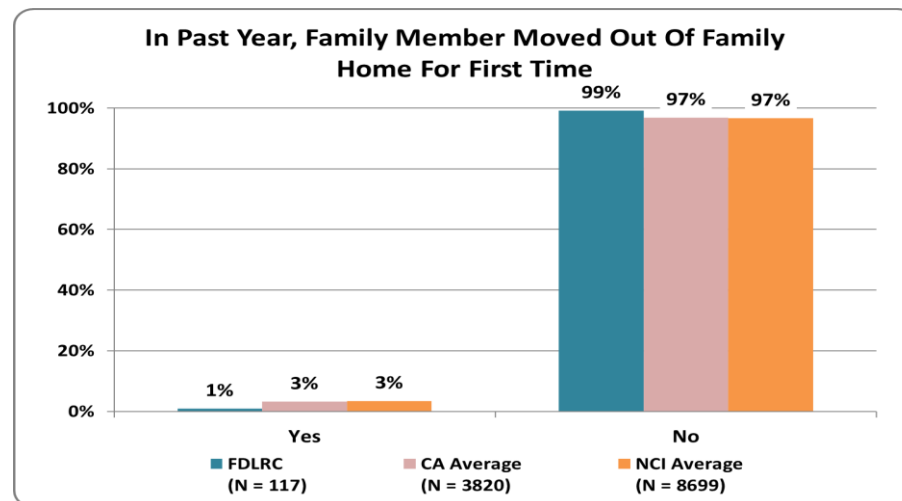
GRAPH 44. *



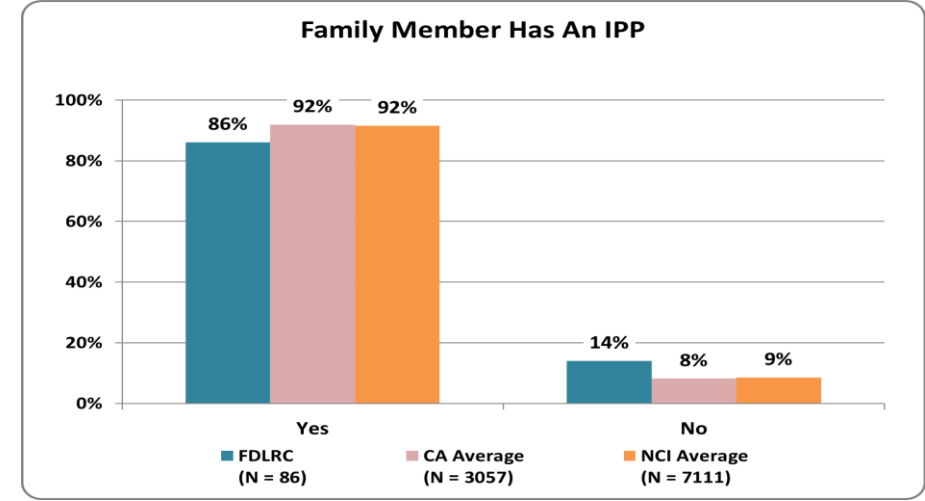
GRAPH 45. *



GRAPH 46.

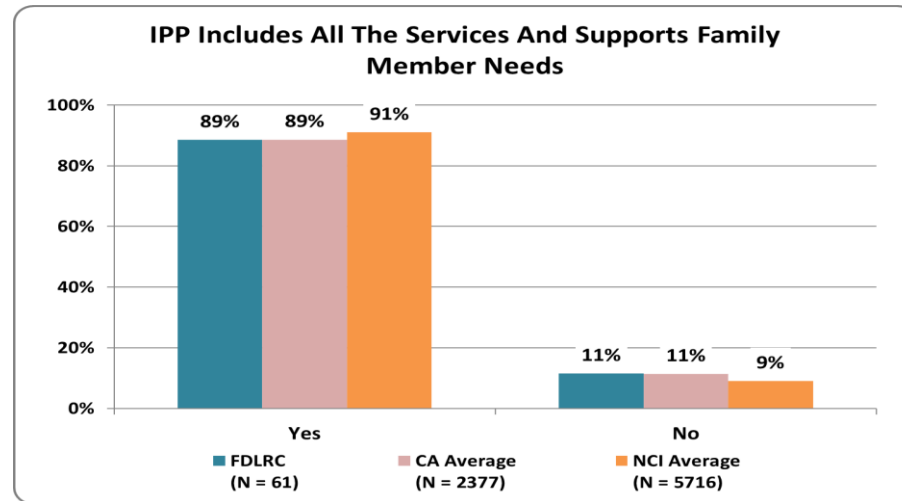


GRAPH 47.

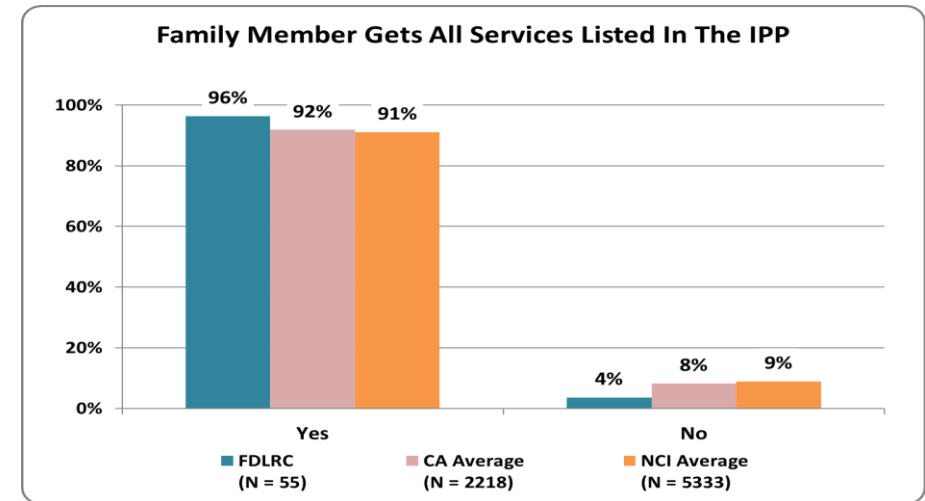


*Categories are not mutually exclusive

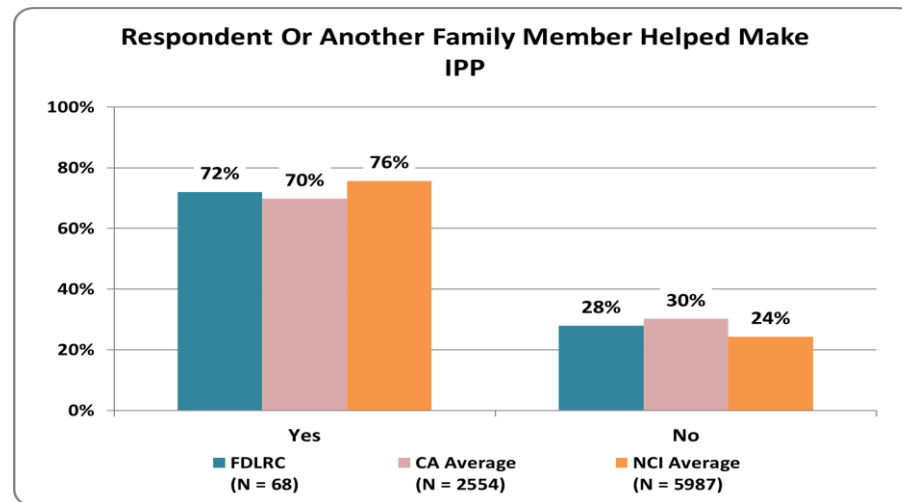
GRAPH 48.



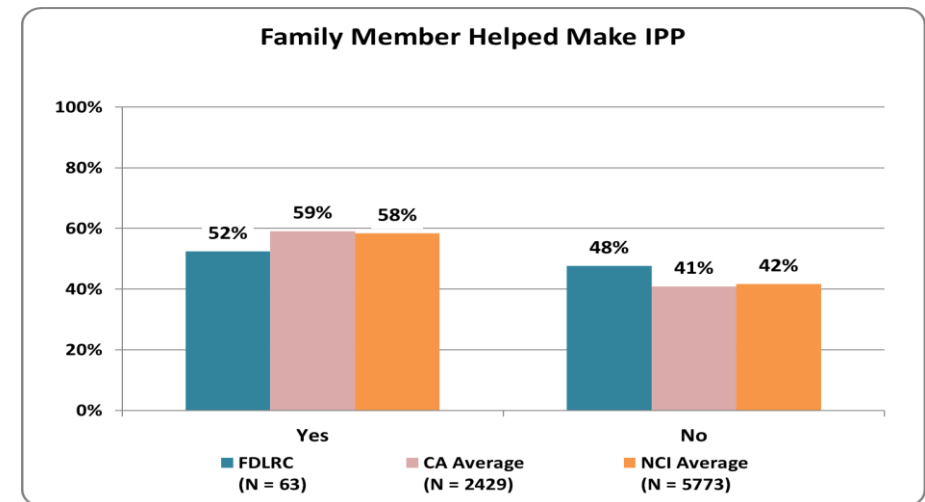
GRAPH 49.



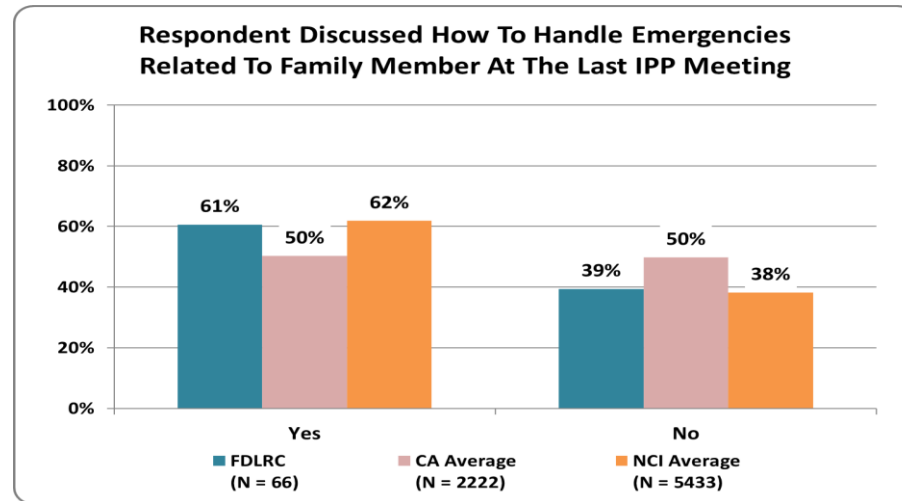
GRAPH 50.



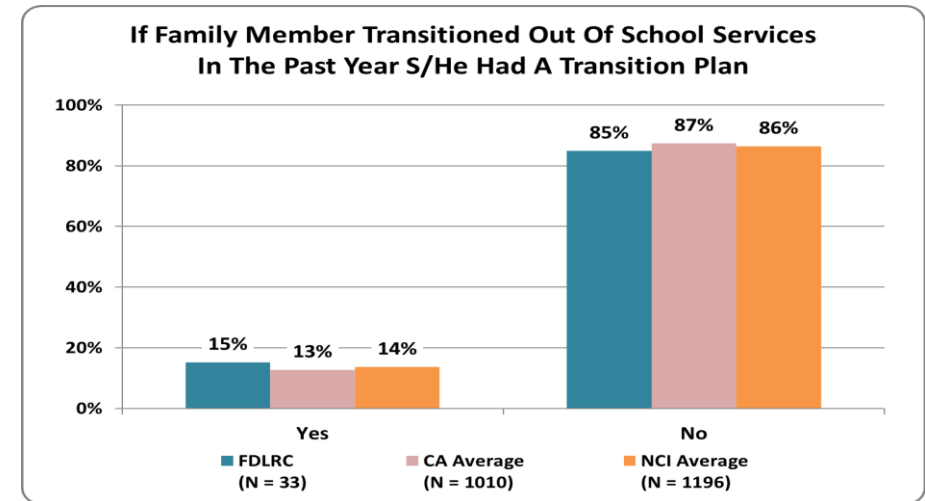
GRAPH 51.



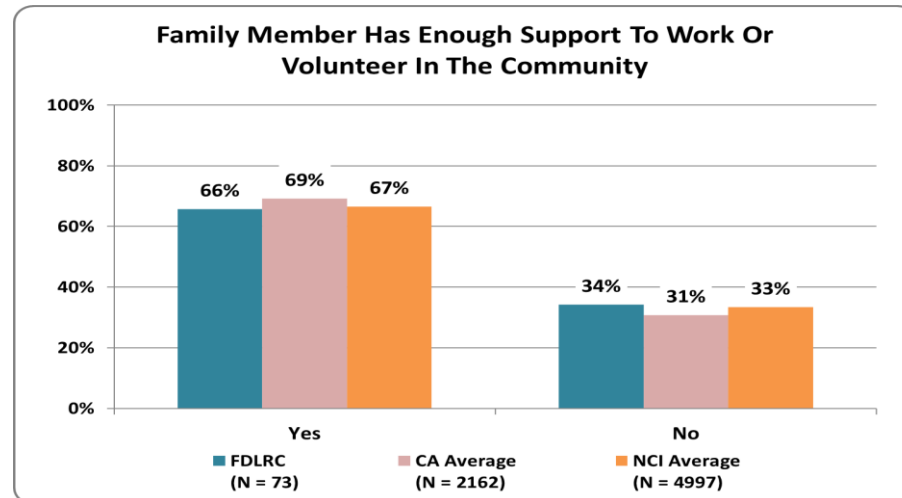
GRAPH 52.



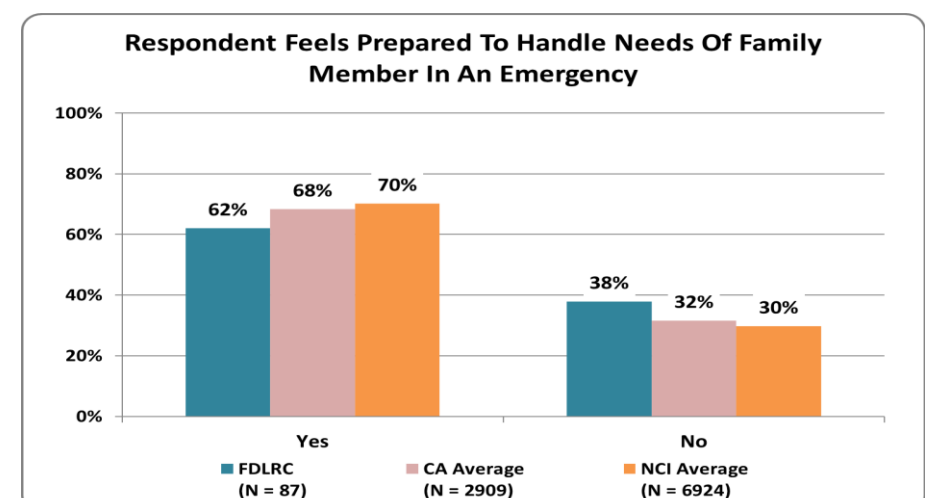
GRAPH 53.



GRAPH 54.



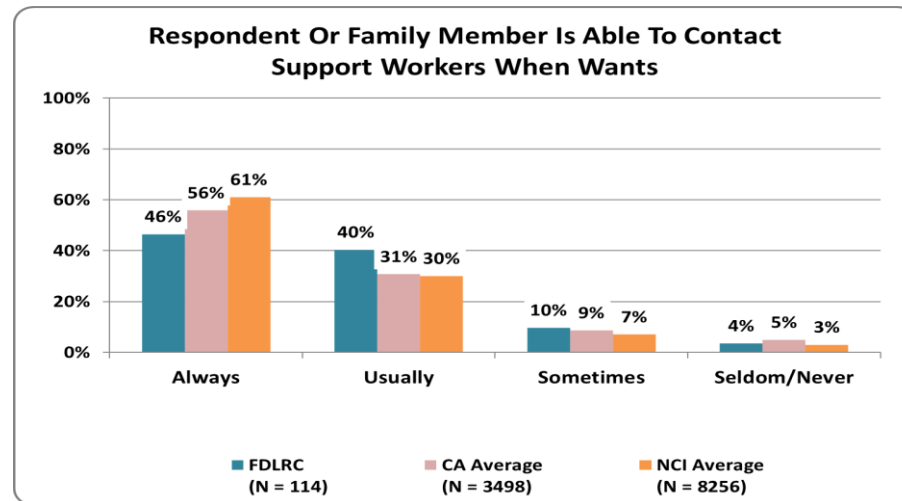
GRAPH 55.



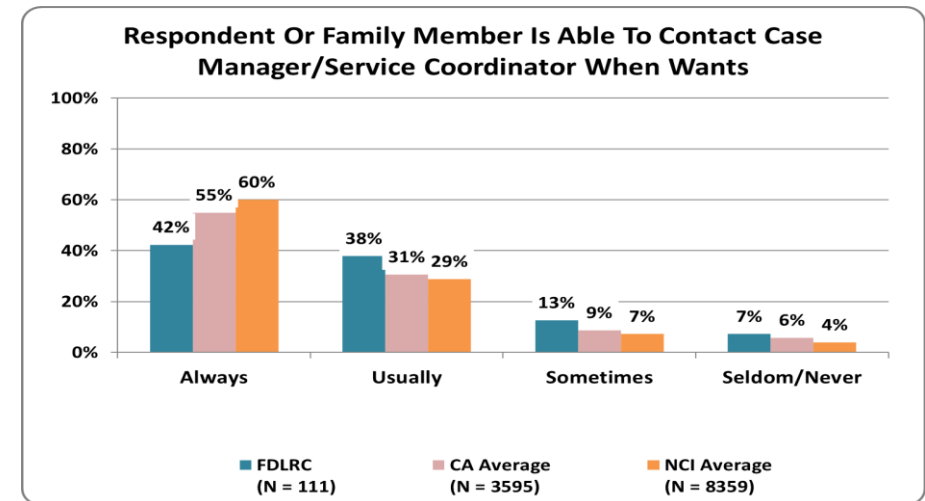
Access and Delivery

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES GET THE SERVICES AND SUPPORTS THEY NEED.

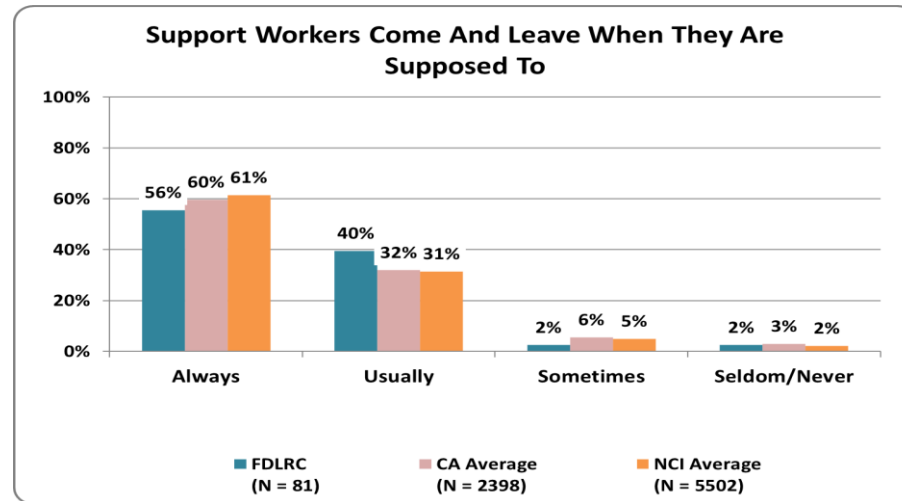
GRAPH 56.



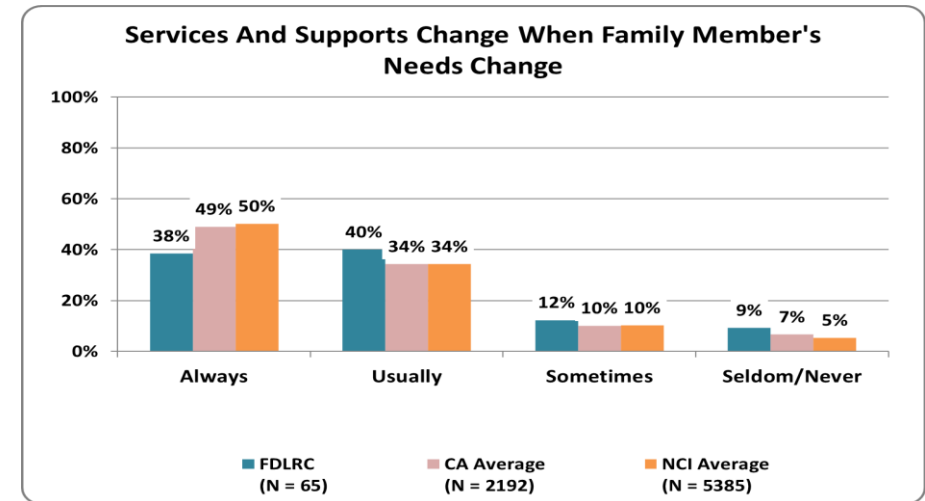
GRAPH 57.



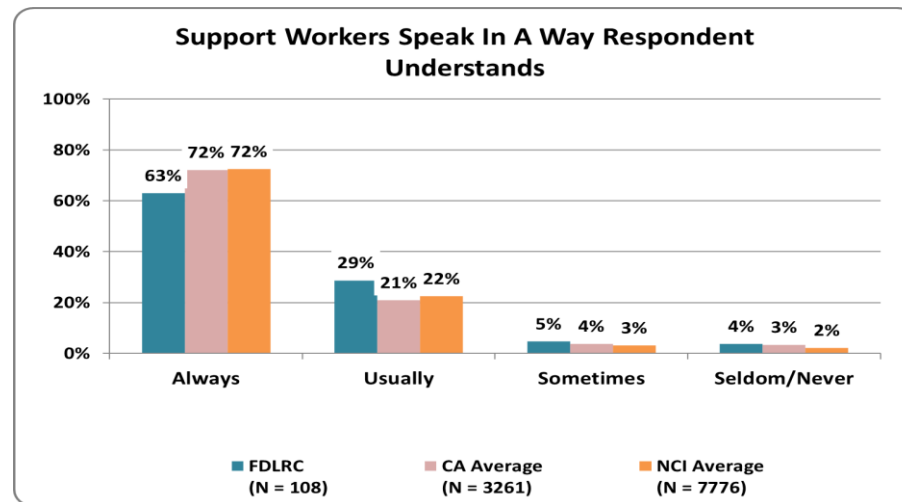
GRAPH 58.



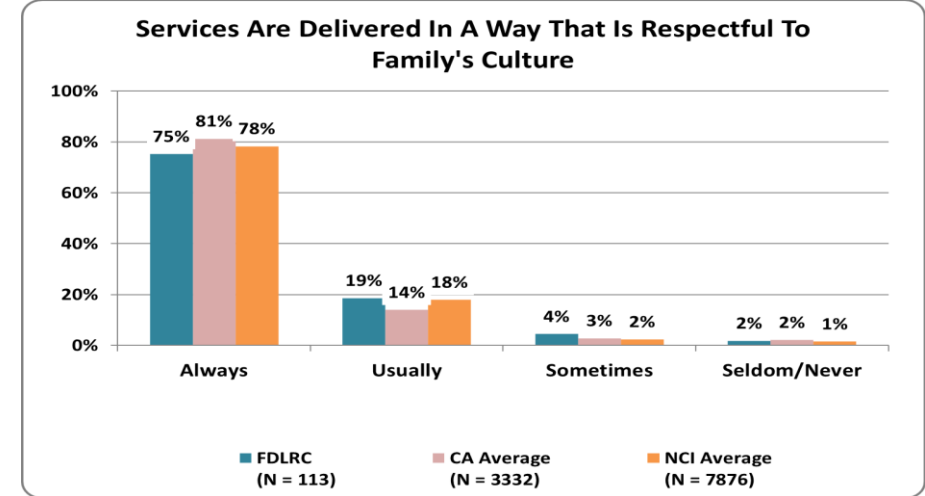
GRAPH 59.



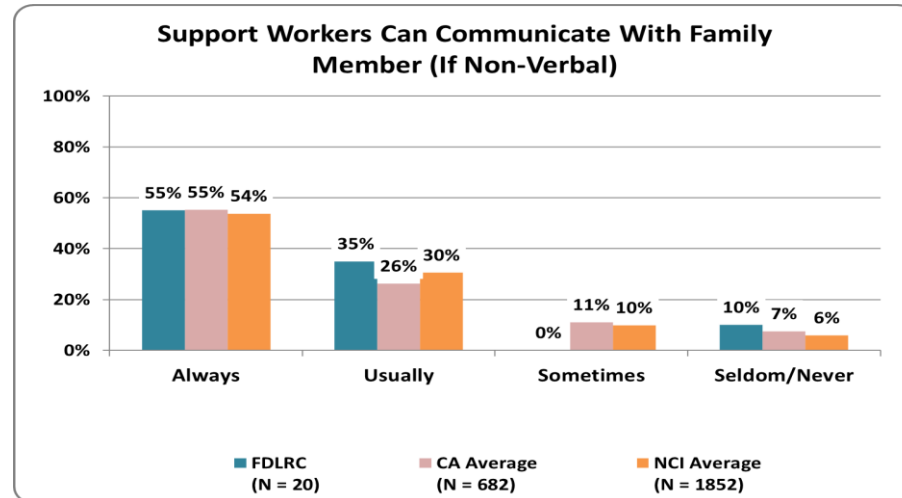
GRAPH 60.



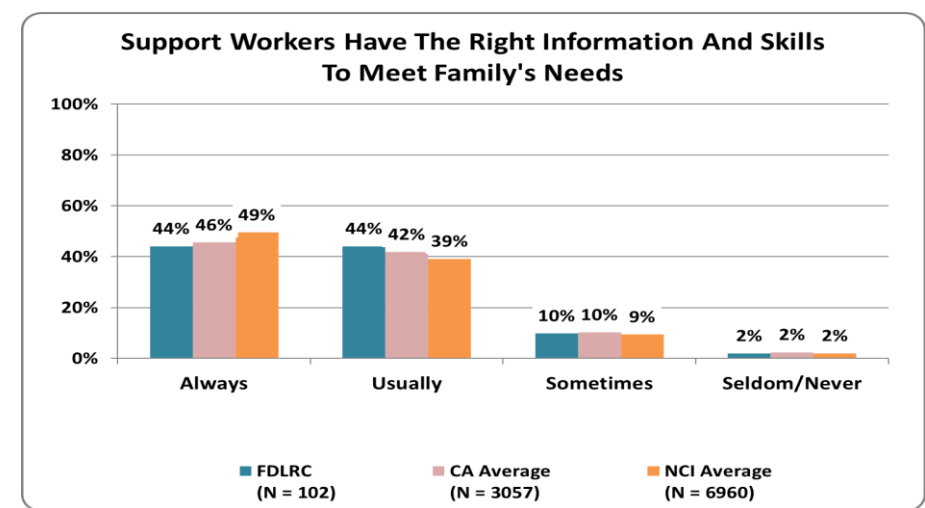
GRAPH 61.



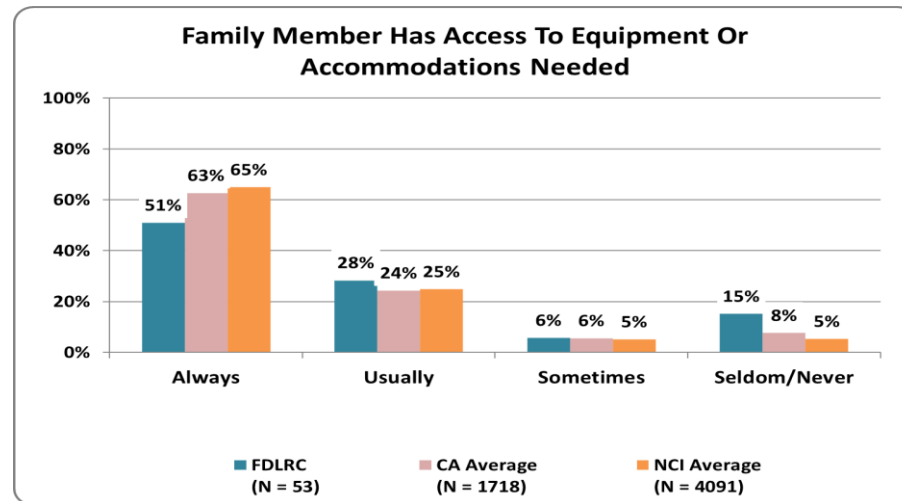
GRAPH 62.



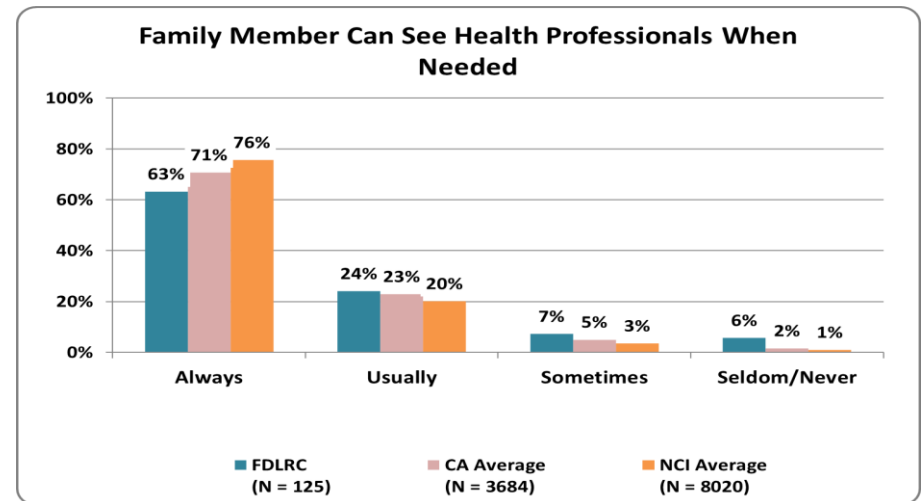
GRAPH 63.



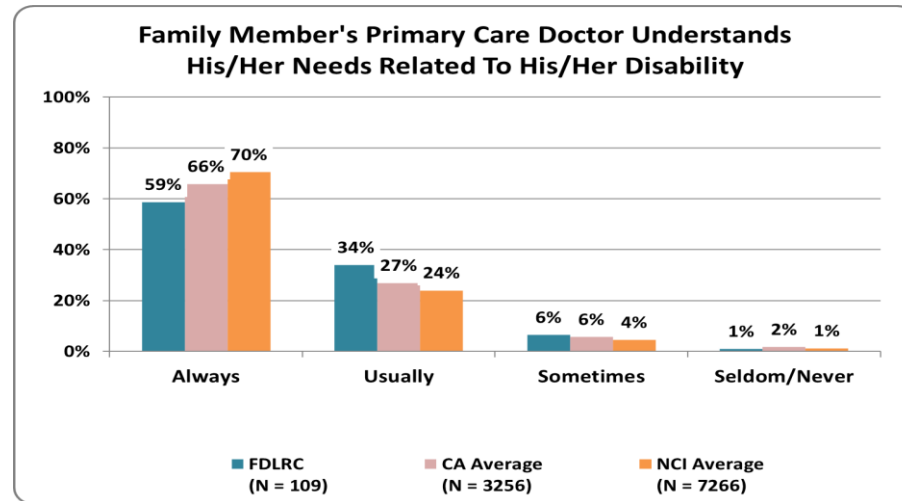
GRAPH 64.



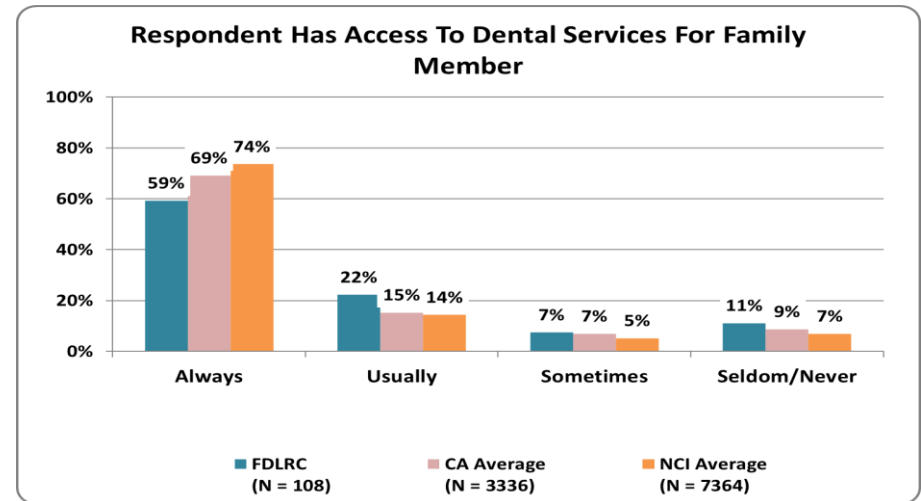
GRAPH 65.



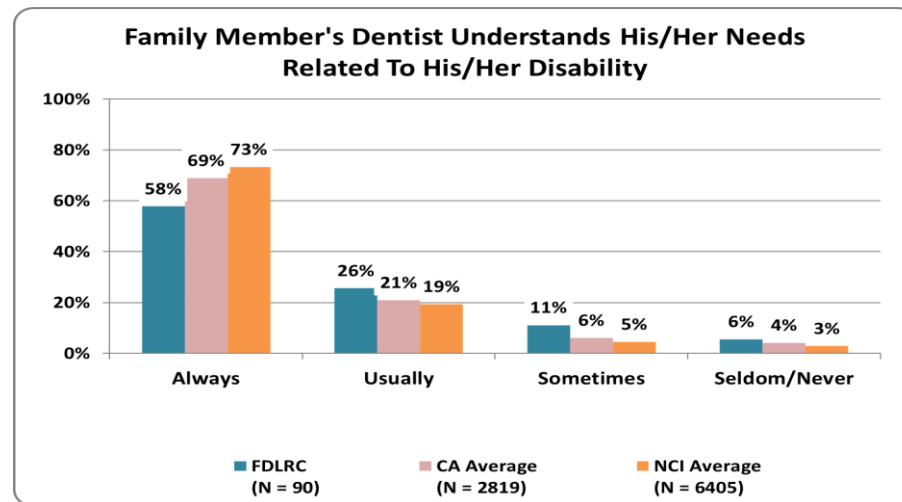
GRAPH 66.



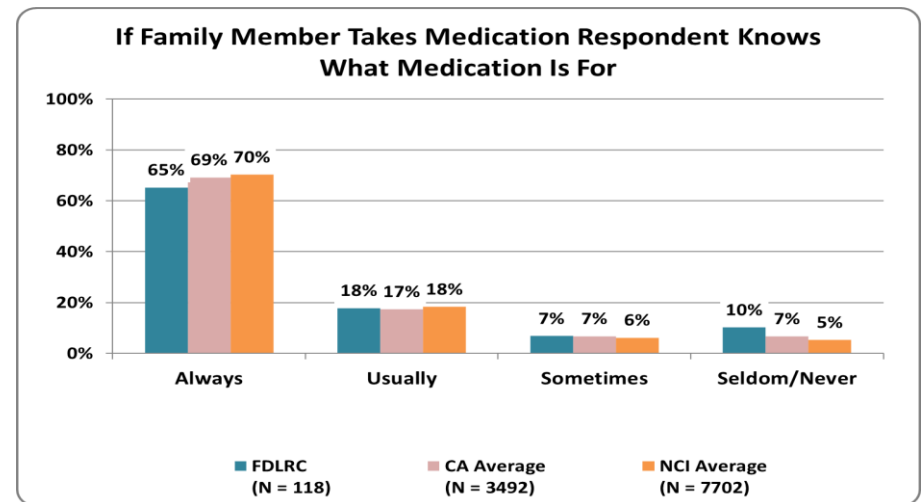
GRAPH 67.



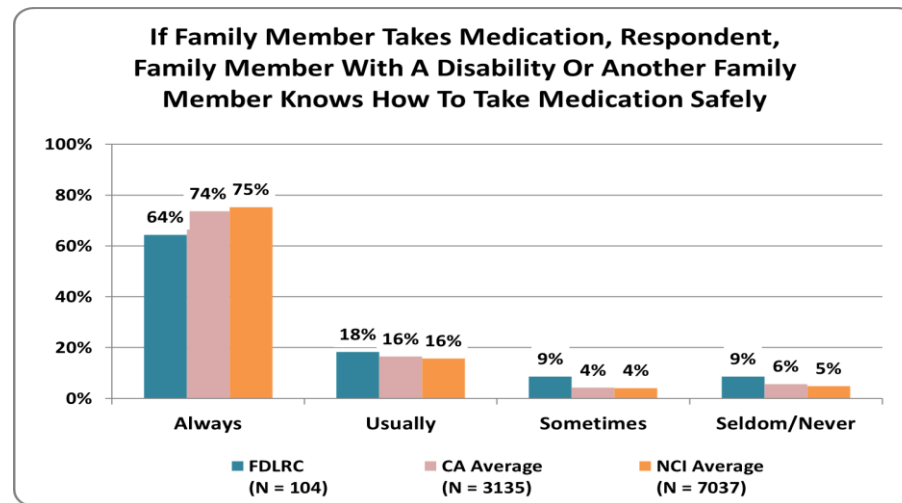
GRAPH 68.



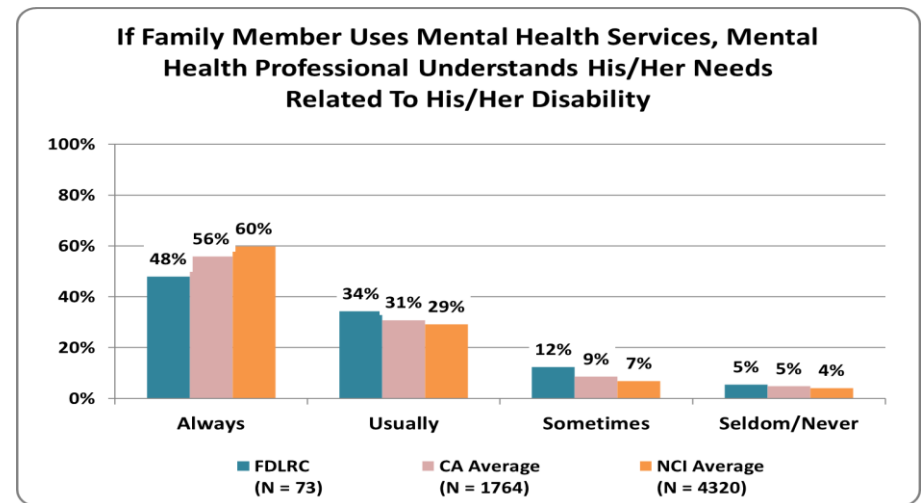
GRAPH 69.



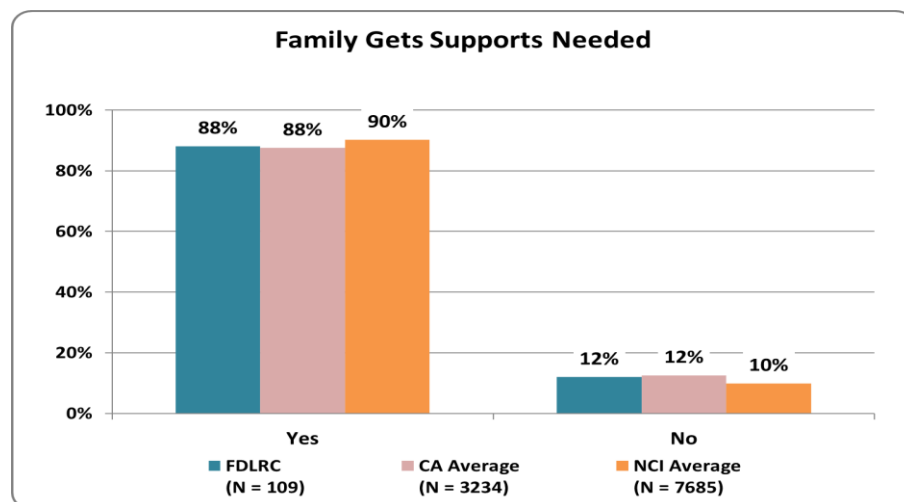
GRAPH 70.



GRAPH 71.



GRAPH 72.

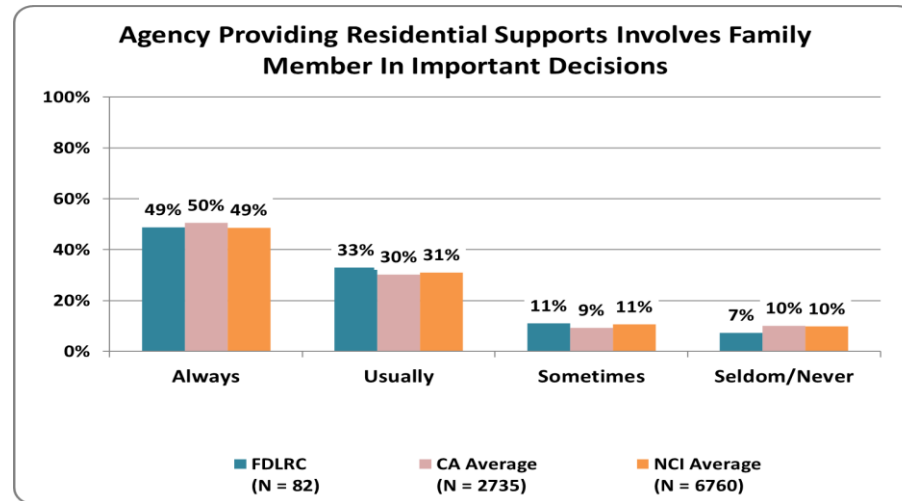


* Categories are not mutually exclusive, therefore N is not shown.

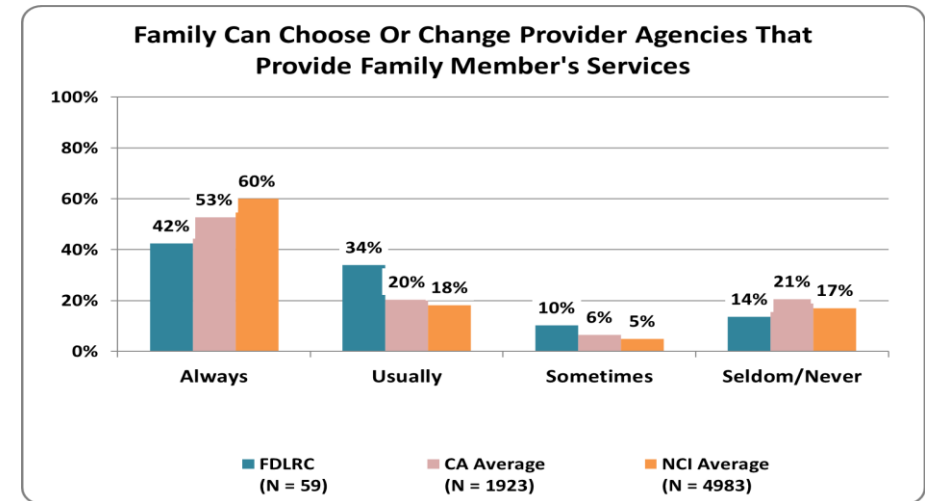
Choice, Decision Making and Control

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

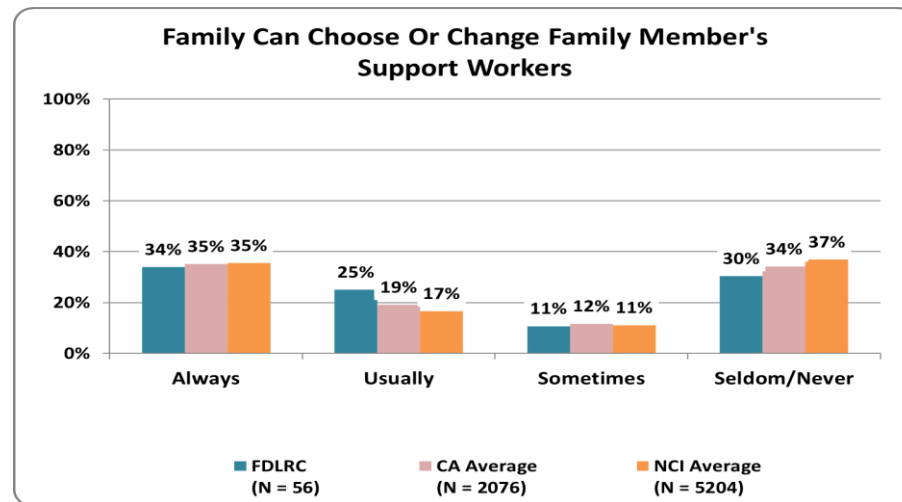
GRAPH 73.



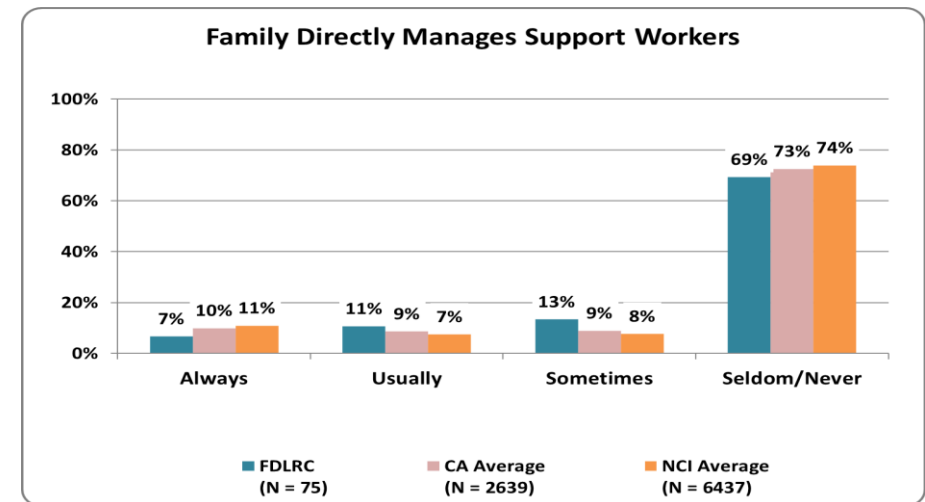
GRAPH 74.



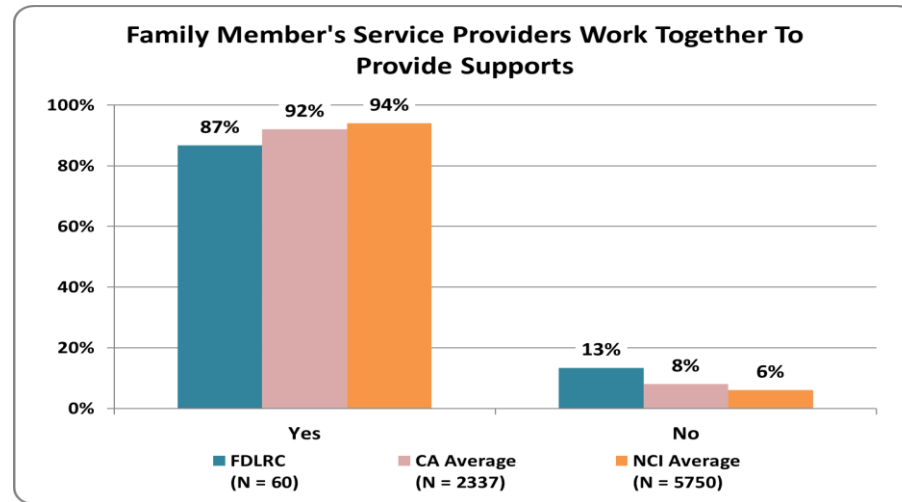
GRAPH 75.



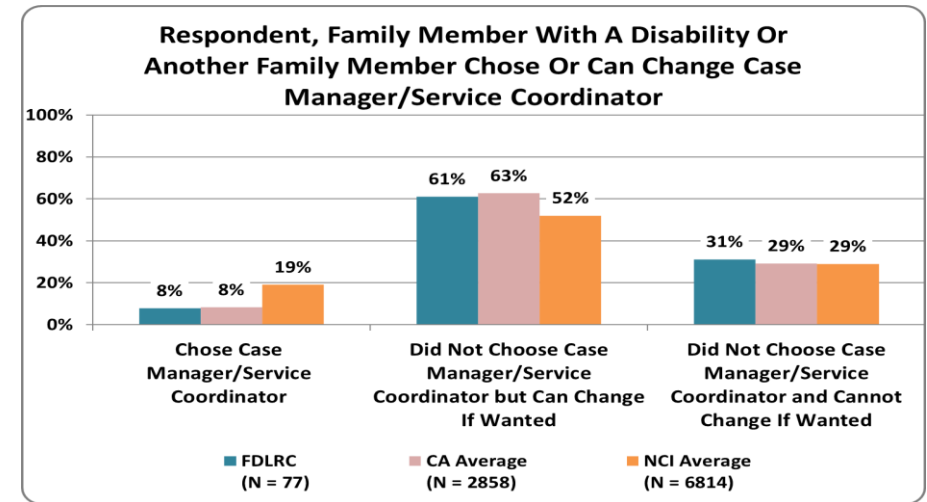
GRAPH 76.



GRAPH 77.



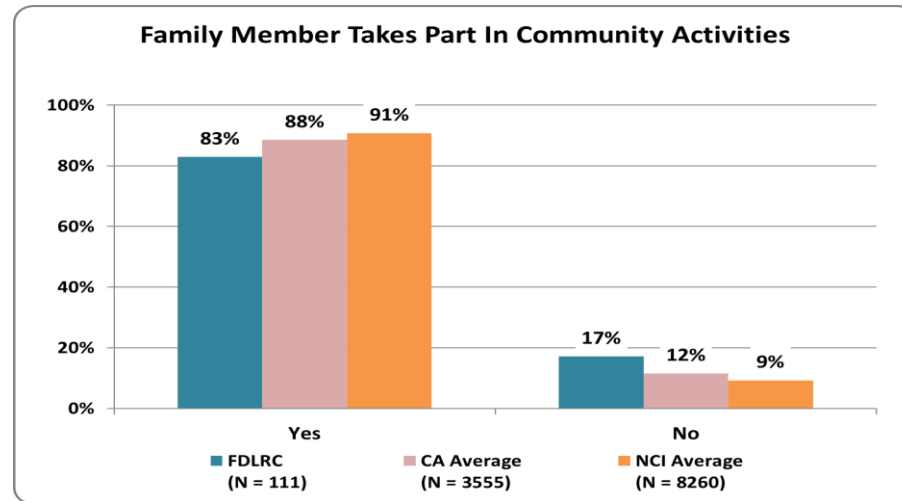
GRAPH 78.



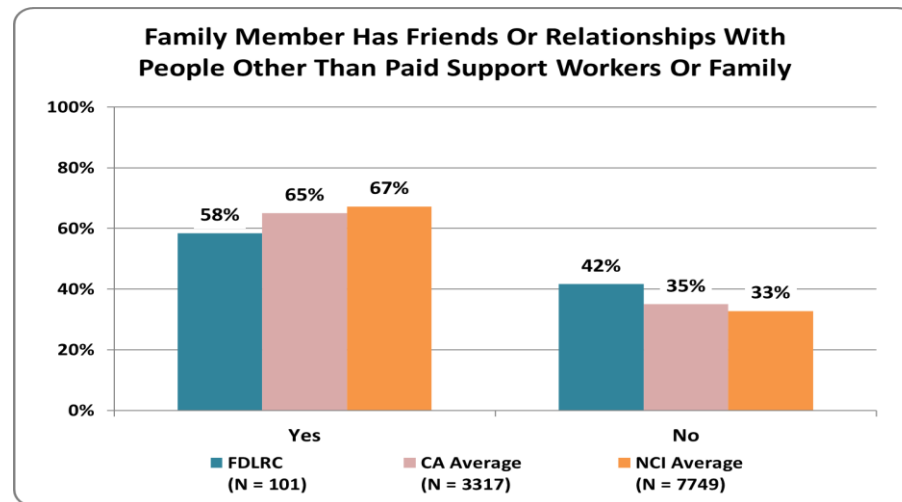
Involvement in the Community

FAMILY MEMBERS WITH DISABILITIES USE INTEGRATED COMMUNITY SERVICES AND PARTICIPATE IN EVERYDAY COMMUNITY ACTIVITIES.

GRAPH 79.



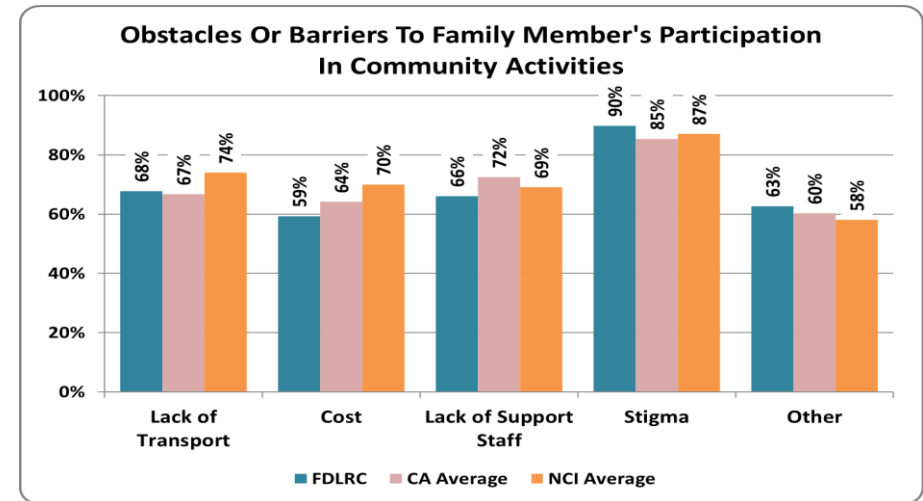
GRAPH 81.



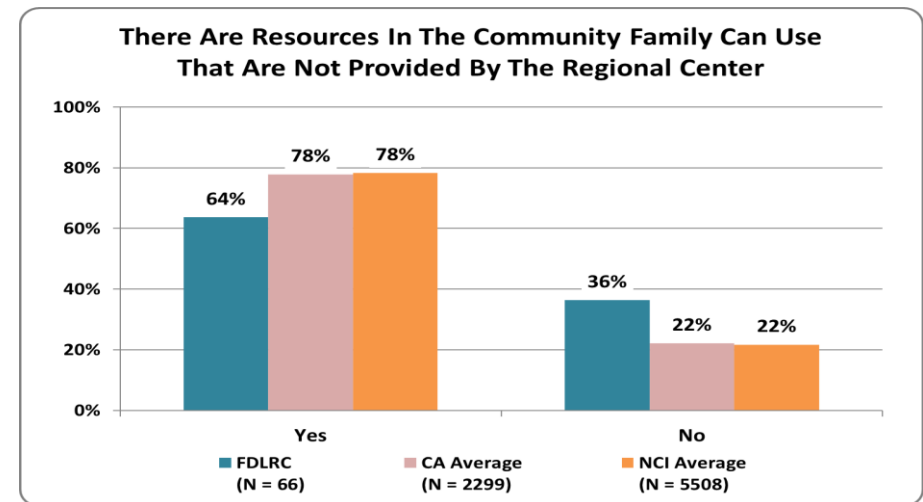
*Categories are not mutually exclusive, therefore N is not shown.

** Note, NCI average refers to DD agency support

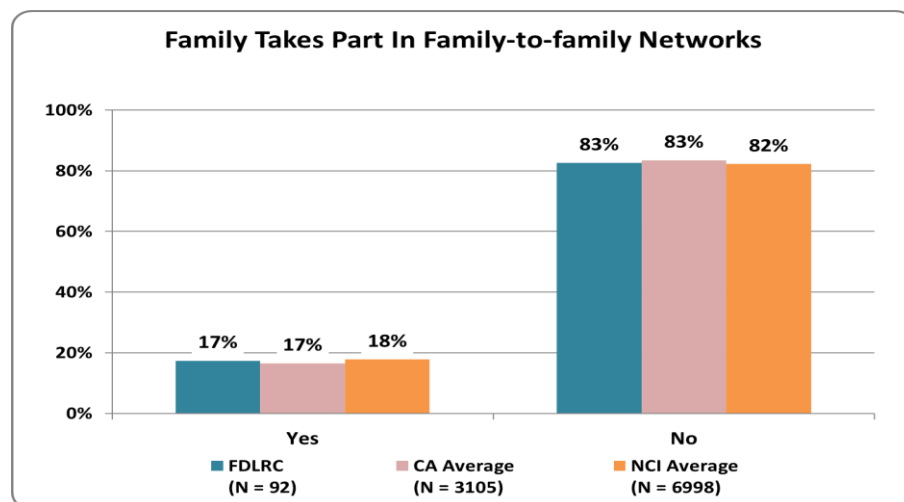
GRAPH 80. *



GRAPH 82. **



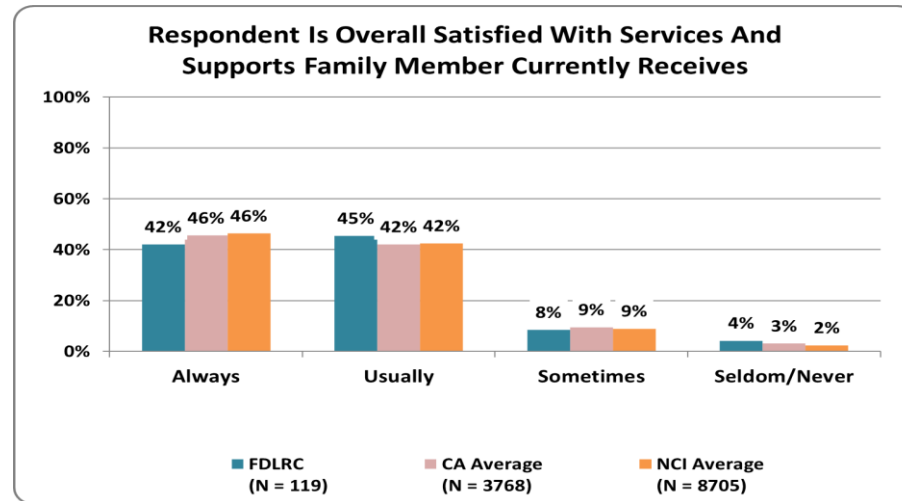
GRAPH 83.



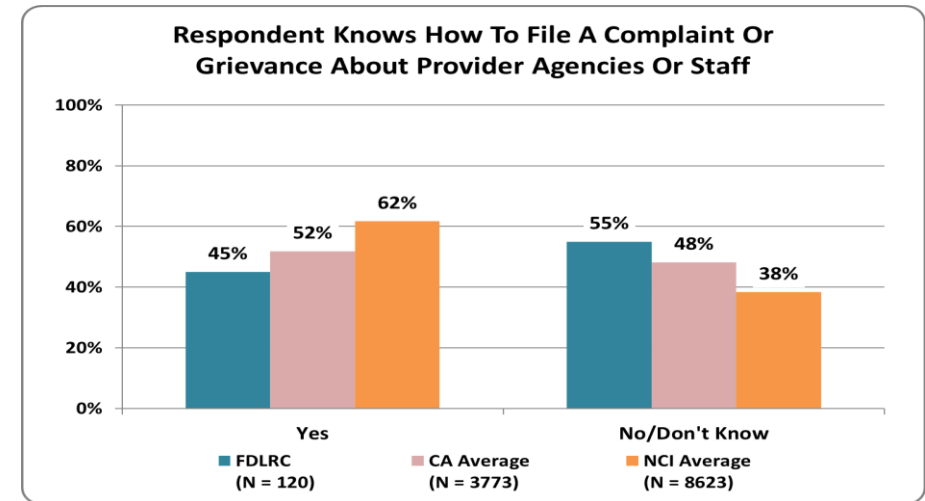
Satisfaction

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES RECEIVE ADEQUATE AND SATISFACTORY SUPPORTS.

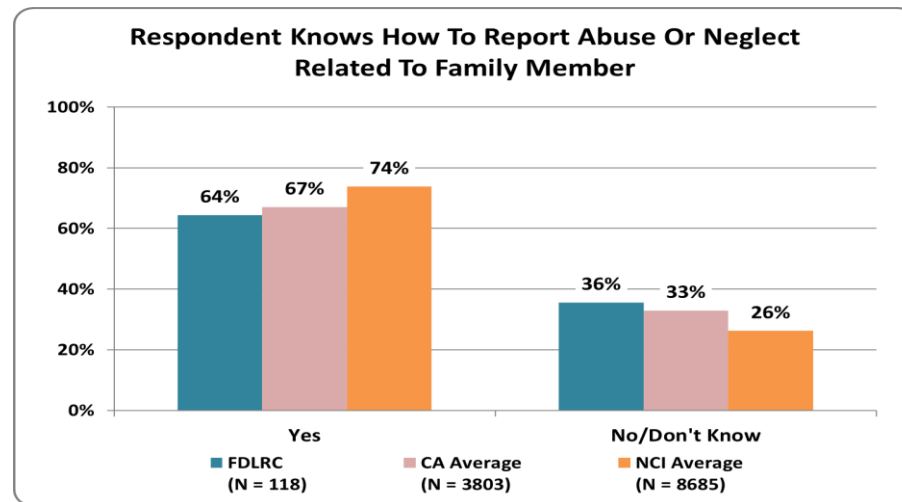
GRAPH 84.



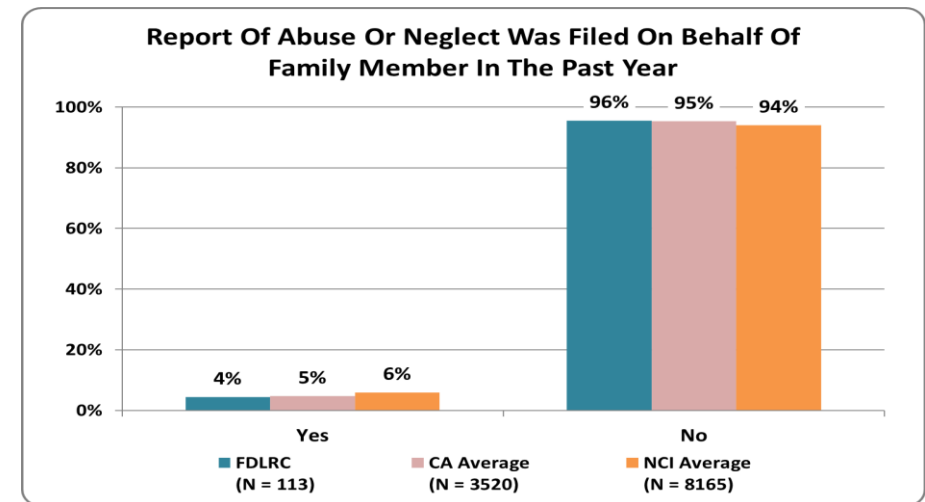
GRAPH 85.*



GRAPH 86.*

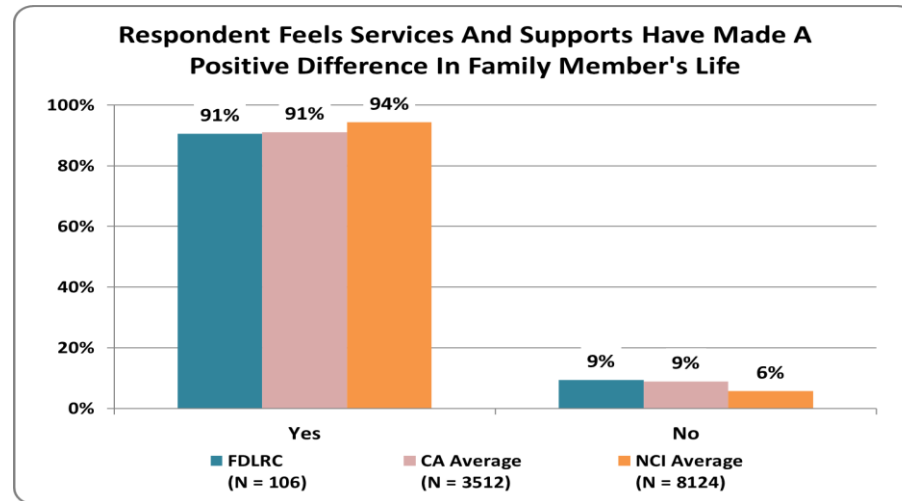


GRAPH 87.

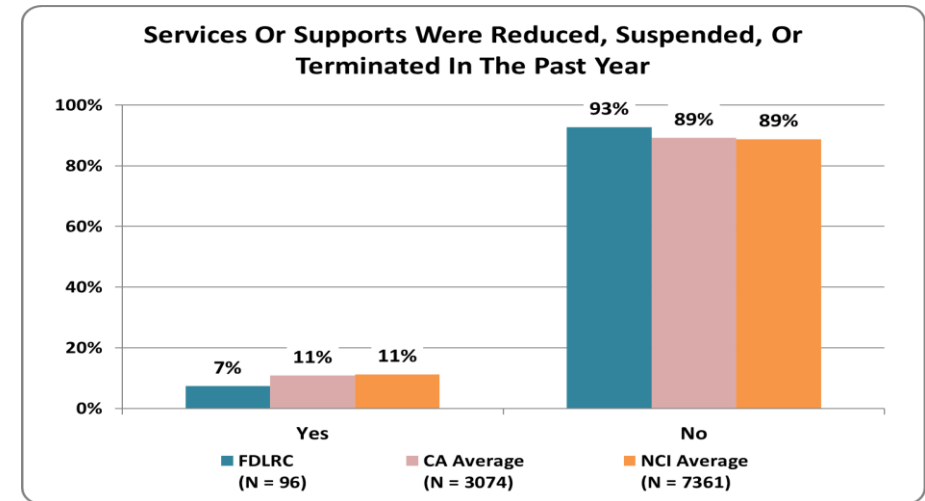


*For this question, 'No' and 'Don't Know' responses were combined.

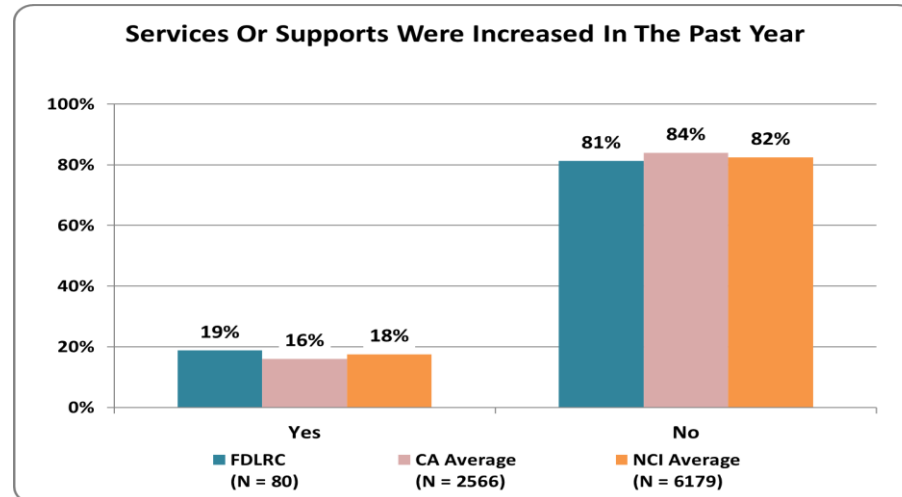
GRAPH 88.



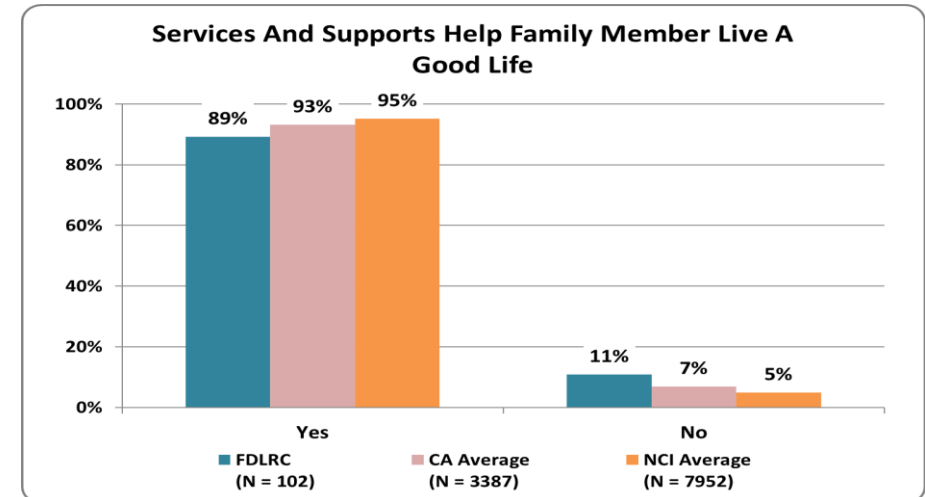
GRAPH 89.



GRAPH 90.

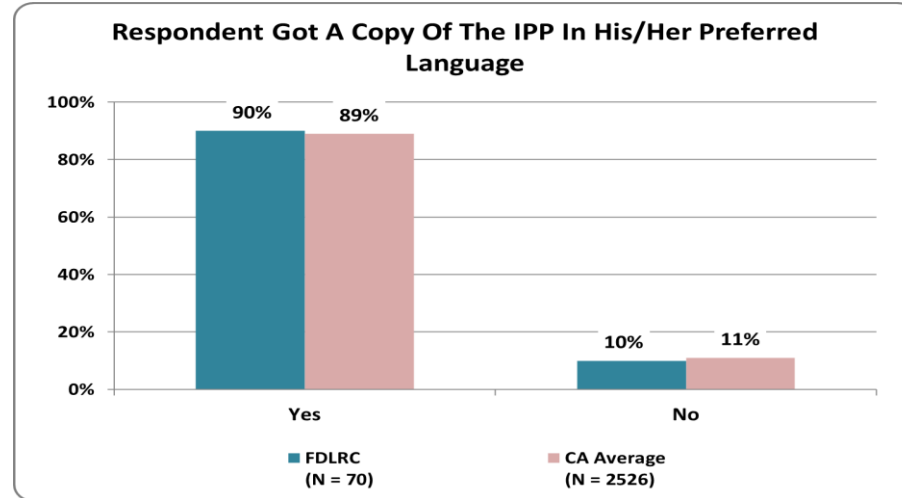


GRAPH 91.

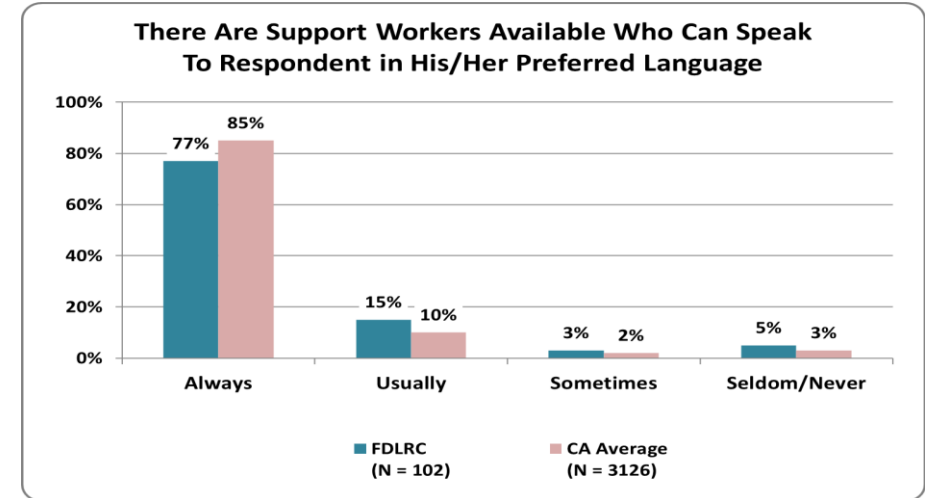


CA Specific Questions: Cultural Competency

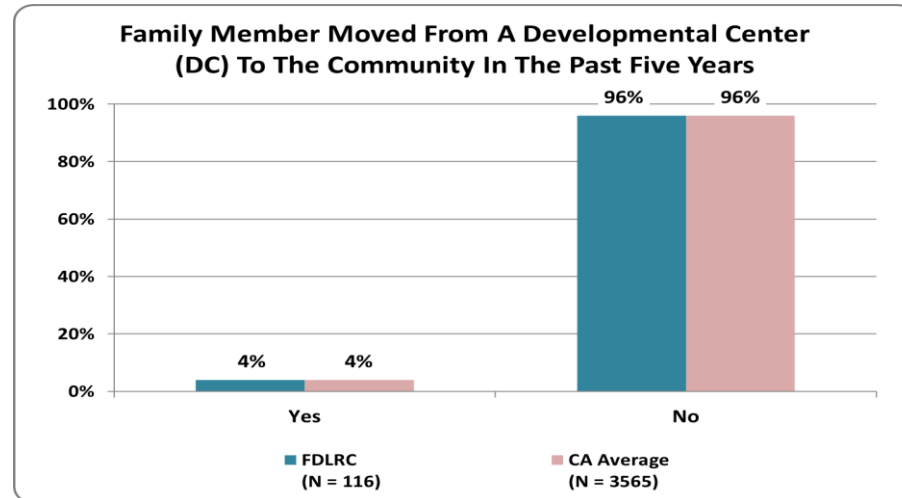
GRAPH 92.



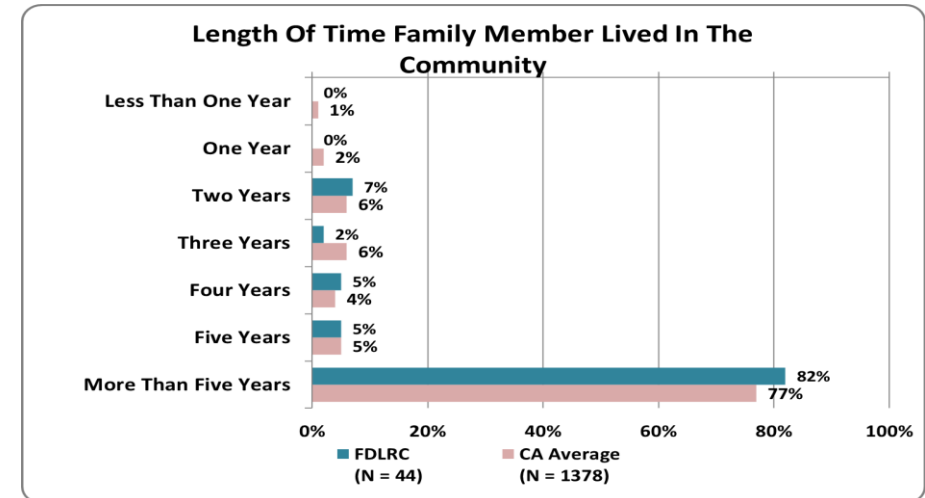
GRAPH 93.



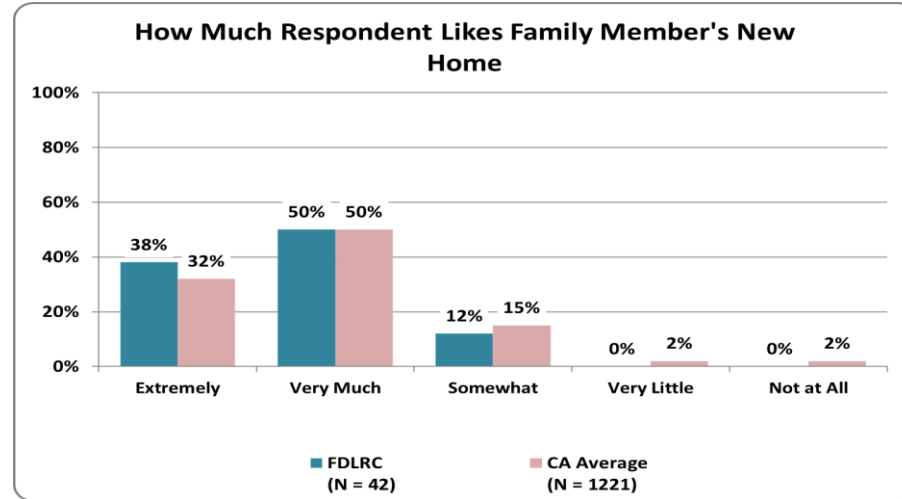
GRAPH 94.



GRAPH 95.



GRAPH 96.



GRAPH 97.

