

# NCI Family/Guardian Survey Outcomes

Frank D. Lanterman Regional Center (FDLRC) Report

Fiscal Year 2013-2014



**NATIONAL CORE  
INDICATORS**

A Collaboration of  
the National Association of State Directors of  
Developmental Disabilities Services  
and Human Services Research Institute

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## Quality Assessment Project and National Core Indicators ©

This report contains regional center level results from California's statewide National Core Indicator (NCI) Family/Guardian Survey data collection from Fiscal Year 2013-2014 (FY 13/14) 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.<sup>1</sup> This report shows Family/Guardian Survey findings from Frank D. Lanterman Regional Center (FDLRC) 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 NCI program is a voluntary effort by state developmental disability agencies to gauge and track their own performance using a common and nationally validated set of performance measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the Human Services Research Institute (HSRI). NCI has developed a set of more than 100 standard performance measures (or "indicators") that states use to assess the outcomes of services provided to individuals and their families. These indicators focus on areas such as: employment, rights, service planning, community inclusion, choice, health, and safety. During the 2013-14 data collection cycle, 40 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 a mail-in survey sent to the families who have an adult family member with an intellectual/developmental disability living outside of the home who receives services from one of California's regional centers. The

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<sup>1</sup> Refer to the California Family/Guardian Survey Report FY 13/14 for detailed information about Quality Assessment Project implementation, the NCI, and California's Statewide results.

survey is used to gather data on family outcomes, and it is refined and tested to ensure that it is valid and reliable. The survey collects demographic information on the individual receiving services and the survey respondent (usually a parent), as well as information on services and supports received. It contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and family outcomes. Respondents also have the option of writing open-ended comments concerning their family's participation in the service system.

## **What topics are covered by the survey?**

The National Core Indicators are organized by topic or “domain.” Each domain consists of sub-domains, and each sub-domain is associated with a particular area of concern. The NCI Family/Guardian Survey includes items to measure the Family Outcomes domain. The table on the following page lists the NCI Family Surveys sub-domains and concerns.

**TABLE 1. NCI FAMILY SURVEY INDICATORS –SUB-DOMAINS AND CONCERN STATEMENTS**

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

## How were people selected to participate?

For each regional center, DDS selected a random sample of families who had an adult with a disability living outside of the family home and received at least one direct service or support other than service coordination.

The State Council on Developmental Disabilities mailed out a paper survey to families selected in their sample. A final sample size of 400 from each regional center guarantees a +/- 5% margin of error and a 95% confidence level when interpreting the results. Both the

confidence interval and margin of error used are widely acceptable for reviewing results, regardless of population size. Some regional centers had a lower than expected return rate and received fewer than 400 surveys; all regional centers reached a minimum threshold of a margin of error no greater than +/- 7%.

## **Limitations of Data**

The NCI Family/Guardian Survey tool is not intended to be used for monitoring individuals or providers, but rather for assessing system-wide performance. The NCI and California Averages should not be interpreted as necessarily defining “acceptable” levels of performance or satisfaction, nor does it provide benchmarks for acceptable or unacceptable levels of performance for each indicator. Instead, it describes average levels of performance or satisfaction across the State. It is up to public managers, policy-makers, and other stakeholders to decide what is an acceptable or unacceptable result (i.e., percentage of individuals achieving the indicated outcome).

## **What is contained in this report?**

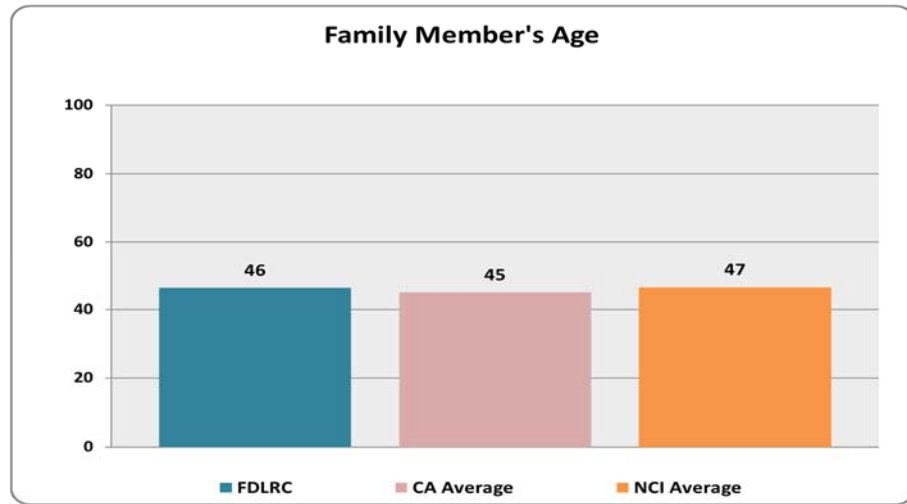
This report illustrates FY 13/14 NCI Family/Guardian Survey demographic and outcome results from FDLRC compared to the California statewide average, and NCI Average. The NCI Average is calculated by averaging all states’ estimates – it is an “average of averages”, therefore, each state contributes the same weight to the NCI Average, including California.

In FY 13/14, 12 states conducted the Family/Guardian Survey. All results are shown in chart form. Charts do not display the number of respondents to each question. Some questions may have a low response rate, particularly questions about knowledge and use of regional center money, reporting grievances, and abuse or neglect. Regional centers or states with fewer than 20 responses to a particular question were excluded from analysis for that question. The number of responses per each question are included in the state report. The state and regional center data results for this survey can be found online at <http://www.dds.ca.gov/QA>.

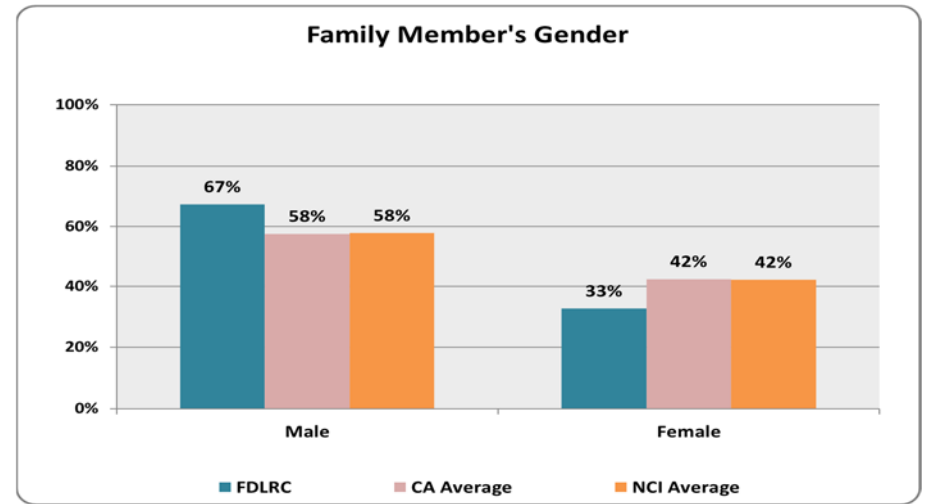
## Results: Demographics of Family Member

*ILLUSTRATES THE DEMOGRAPHIC PROFILE OF FAMILY MEMBER WITH DISABILITIES FOR WHOM THE SURVEY WAS COMPLETED*

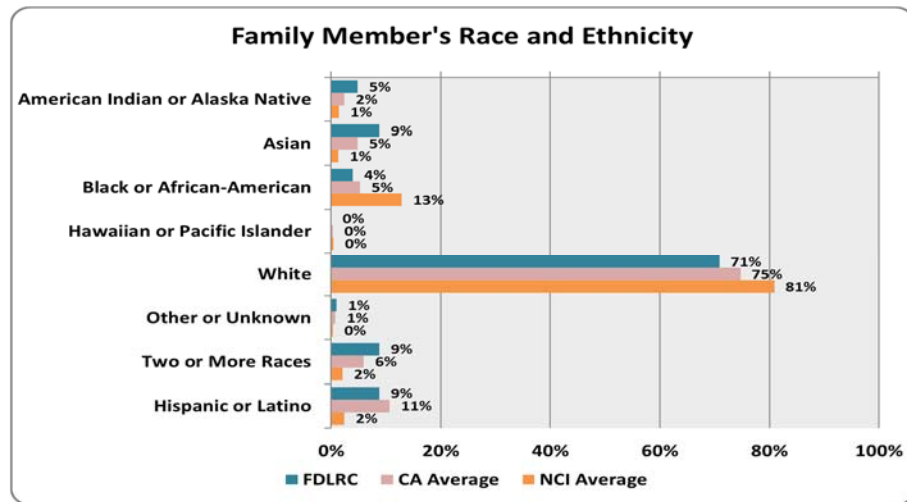
**GRAPH 1. FAMILY MEMBER'S AVERAGE AGE**



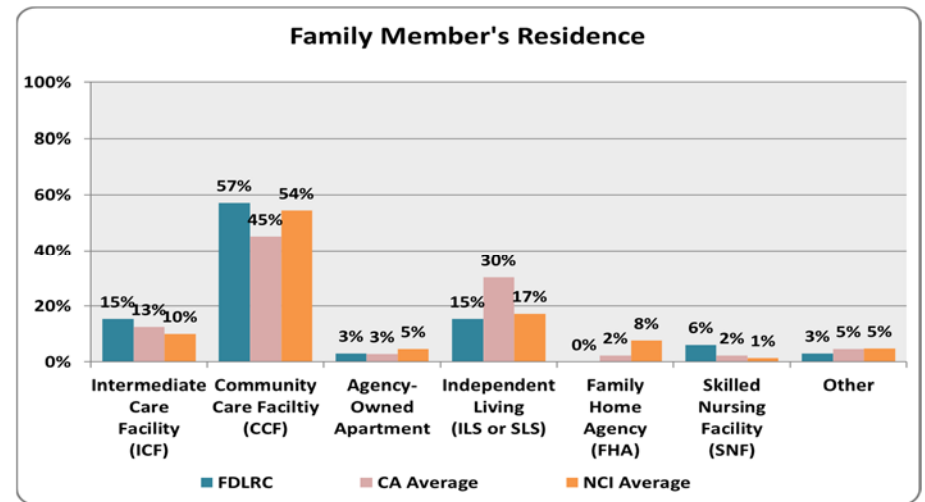
**GRAPH 2. FAMILY MEMBER'S GENDER**



**GRAPH 3 FAMILY MEMBER'S RACE AND ETHNICITY\***

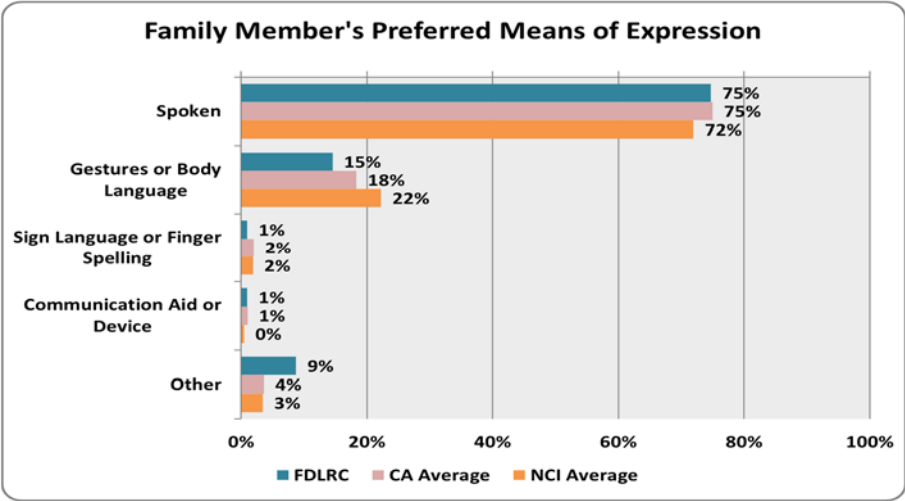


**GRAPH 4 FAMILY MEMBER'S RESIDENCE**

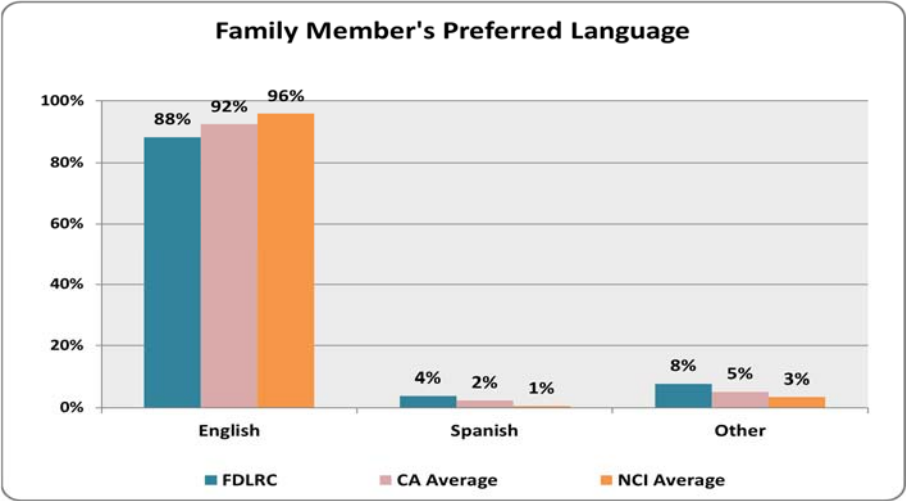


\*CATEGORIES ARE NOT MUTUALLY EXCLUSIVE, AND THEREFORE SOME RESULTS MAY ADD UP TO MORE THAN 100%. NOTE: IN THE CALIFORNIA DATA, HISPANIC IS CONSIDERED A RACE CATEGORY. NCI USES THE U.S. CENSUS MODEL, WHICH DEFINES ETHNICITY SEPARATELY AS HISPANIC VS. NON-HISPANIC.

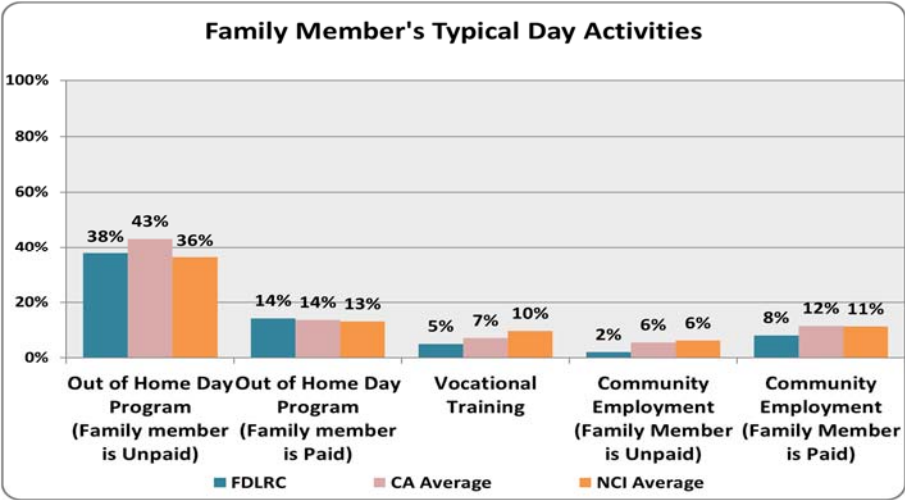
GRAPH 5. FAMILY MEMBER'S PREFERRED MEANS OF EXPRESSION



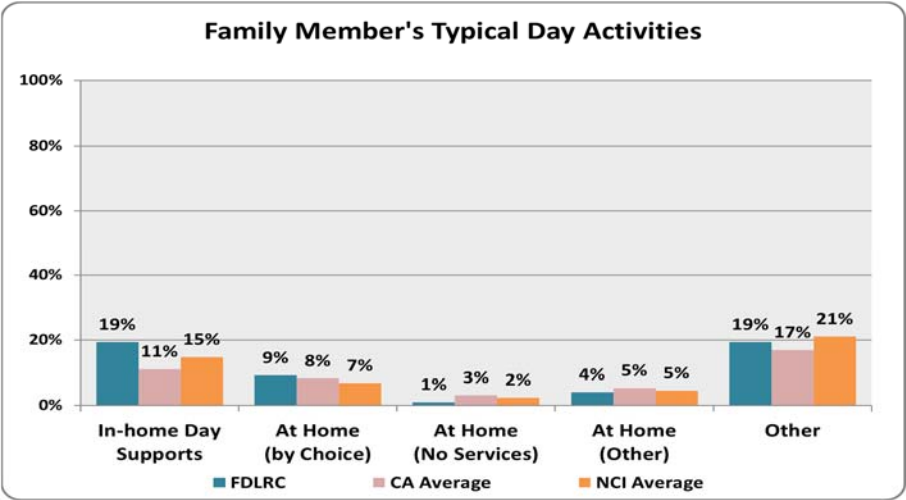
GRAPH 6. FAMILY MEMBER'S PREFERRED LANGUAGE



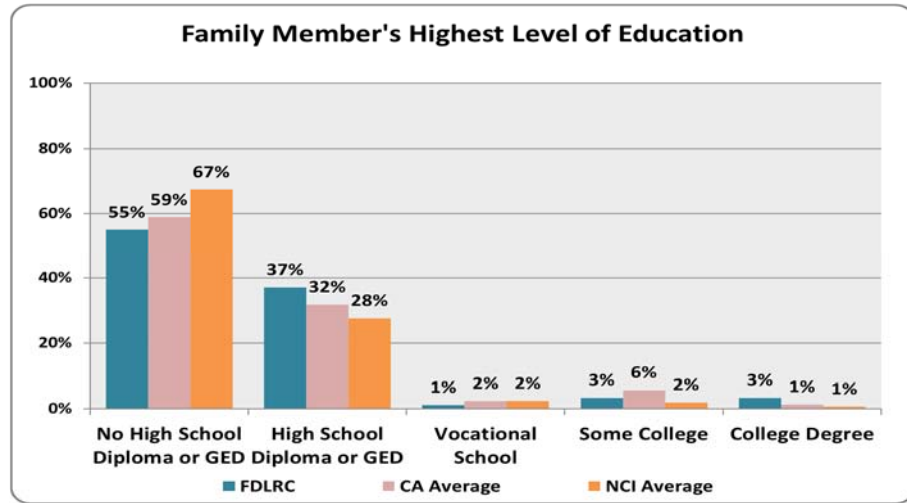
GRAPH 7. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES



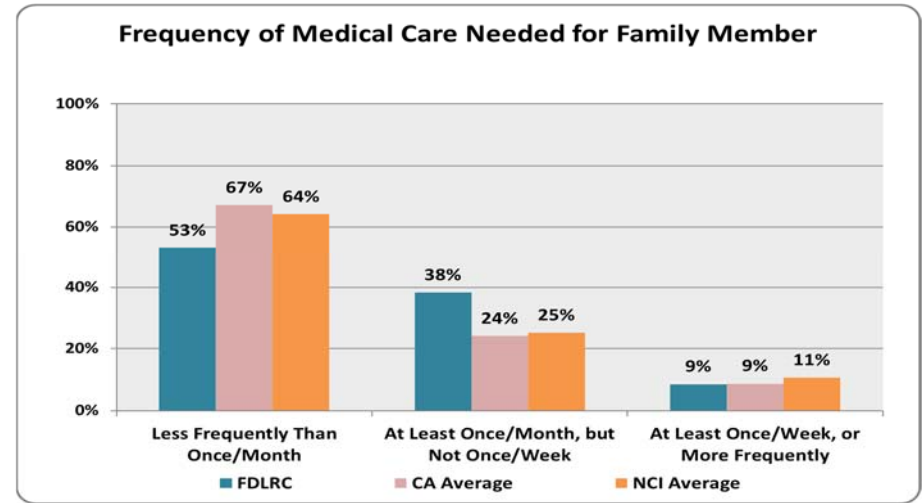
GRAPH 8. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES, CONTINUED



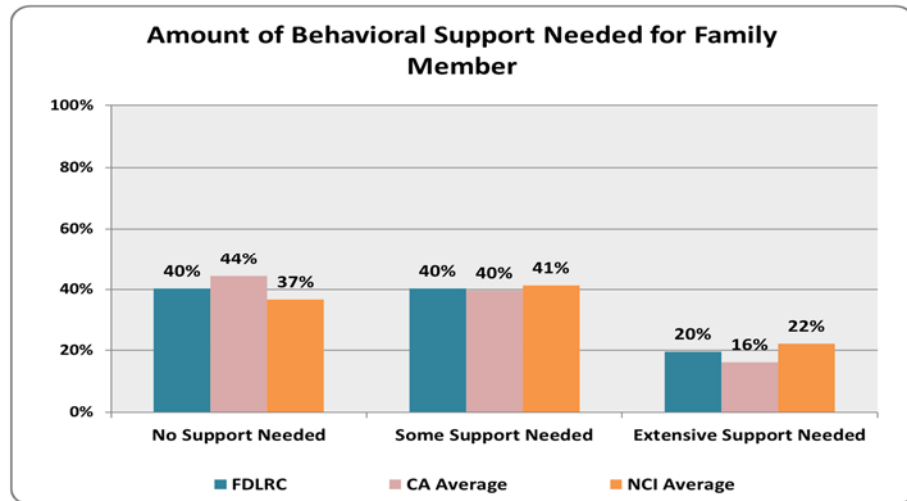
**GRAPH 9. FAMILY MEMBER'S HIGHEST LEVEL OF EDUCATION**



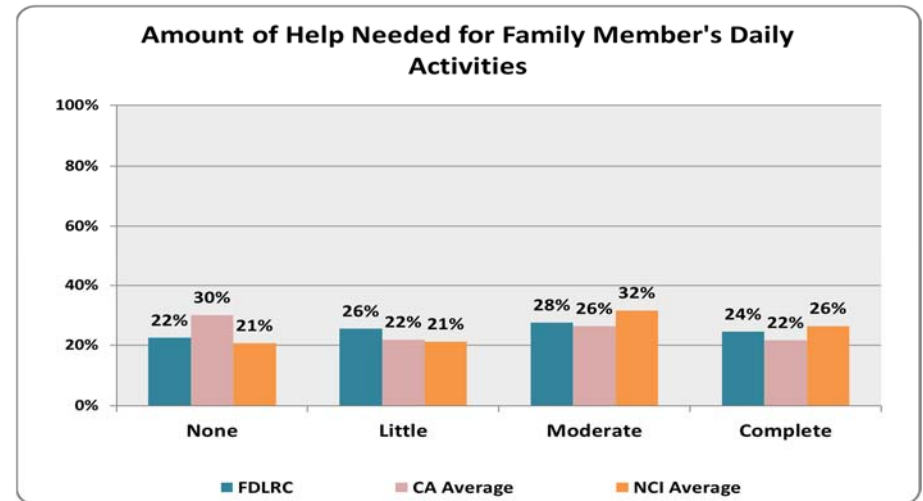
**GRAPH 10. FREQUENCY OF MEDICAL CARE NEEDED FOR FAMILY MEMBER**



**GRAPH 11. AMOUNT OF BEHAVIORAL SUPPORT NEEDED FOR FAMILY MEMBER**



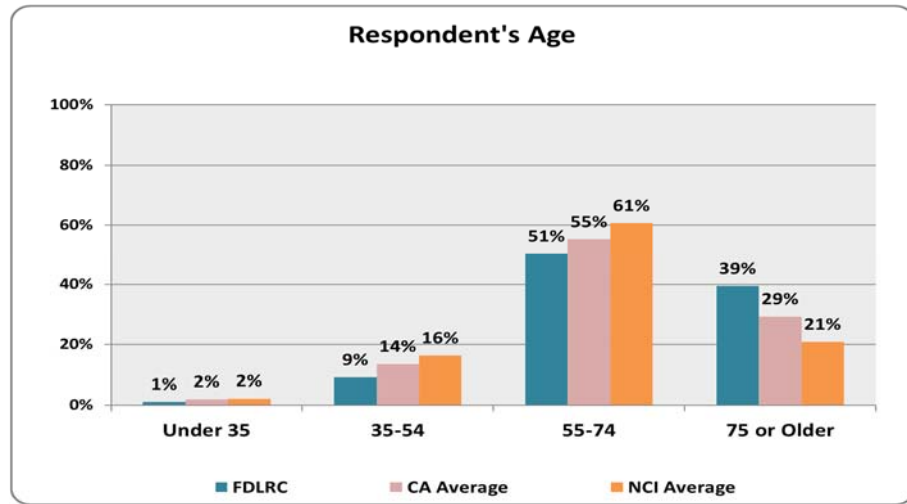
**GRAPH 12. AMOUNT OF HELP NEEDED FOR FAMILY MEMBER'S DAILY ACTIVITIES**



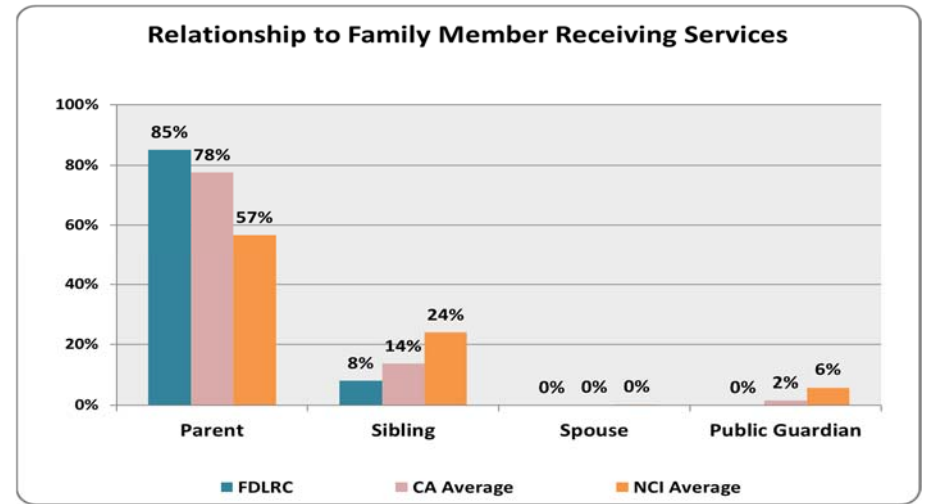
## Results: Demographics of Respondent

*ILLUSTRATES THE DEMOGRAPHIC PROFILE OF THE SURVEY RESPONDENTS*

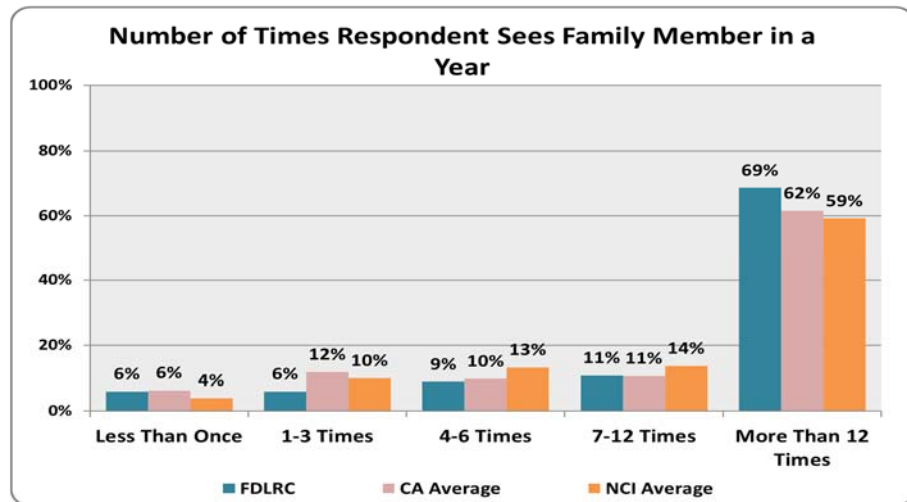
**GRAPH 13. RESPONDENT'S AGE**



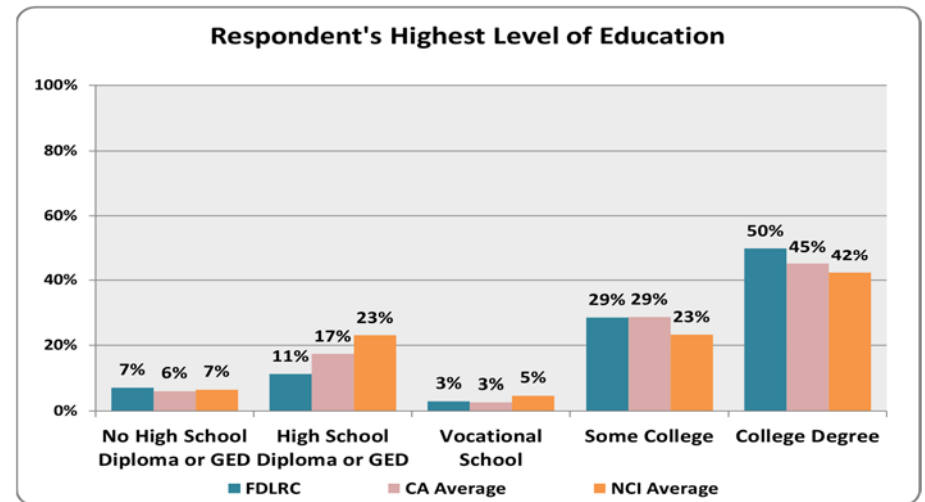
**GRAPH 14. RELATIONSHIP TO FAMILY MEMBER**



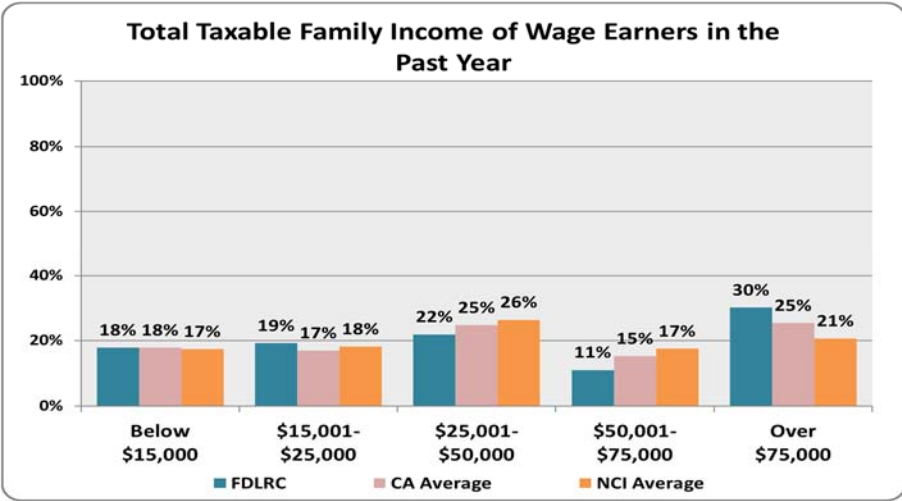
**GRAPH 15. NUMBER OF TIMES RESPONDENT SEES FAMILY MEMBER IN A YEAR**



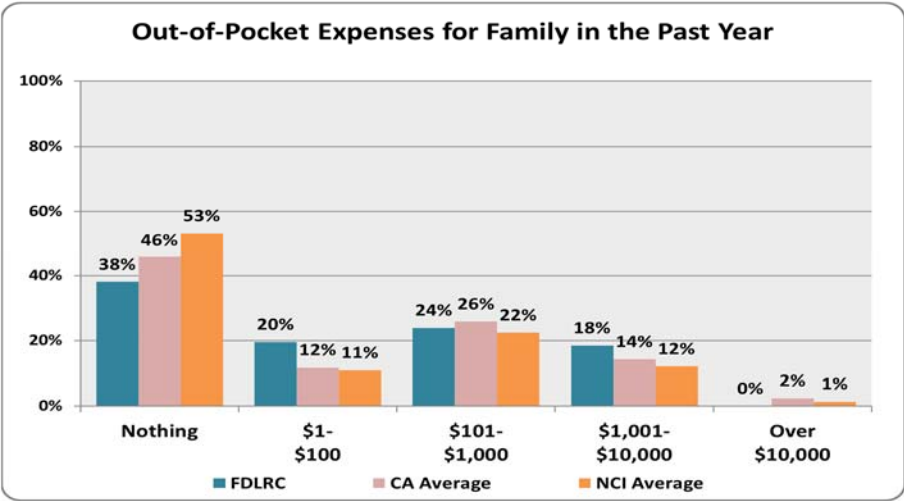
**GRAPH 16. RESPONDENT'S HIGHEST LEVEL OF EDUCATION**



GRAPH 17. TOTAL TAXABLE FAMILY INCOME OF WAGE EARNERS IN THE HOUSEHOLD IN THE PAST YEAR



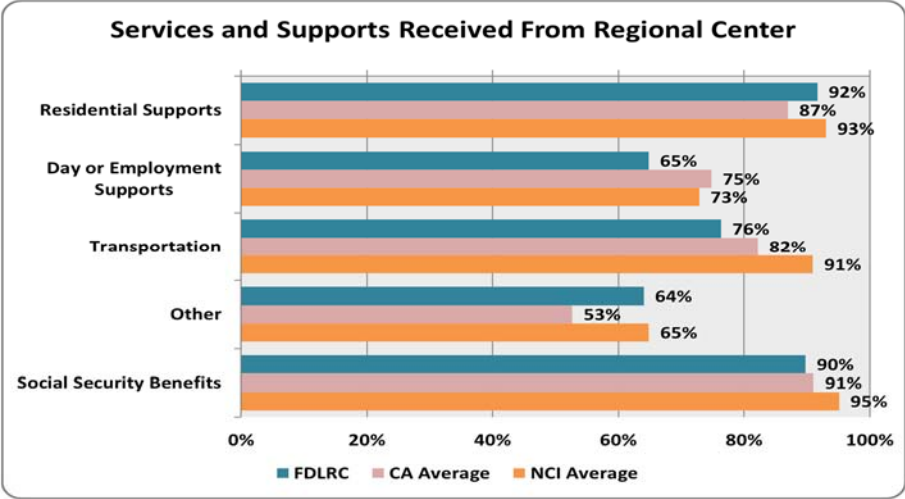
GRAPH 18. OUT-OF-POCKET EXPENSES FOR FAMILY IN THE PAST YEAR



## Services and Supports Received

*ILLUSTRATES THE SERVICES AND SUPPORTS RECEIVED BY FAMILY MEMBERS WITH A DISABILITY*

**GRAPH 19. SERVICES AND SUPPORTS RECEIVED FROM REGIONAL CENTER<sup>2</sup>**

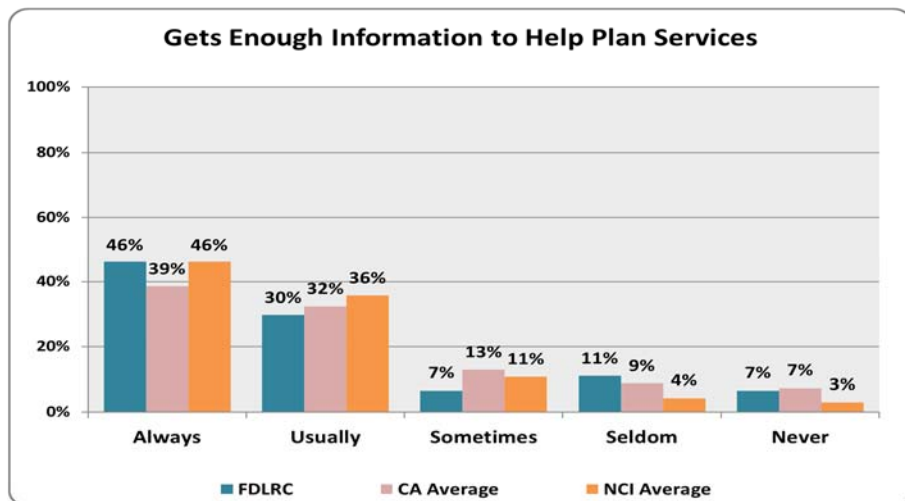


<sup>2</sup> All services and supports are received from the regional center **except** social security benefits.

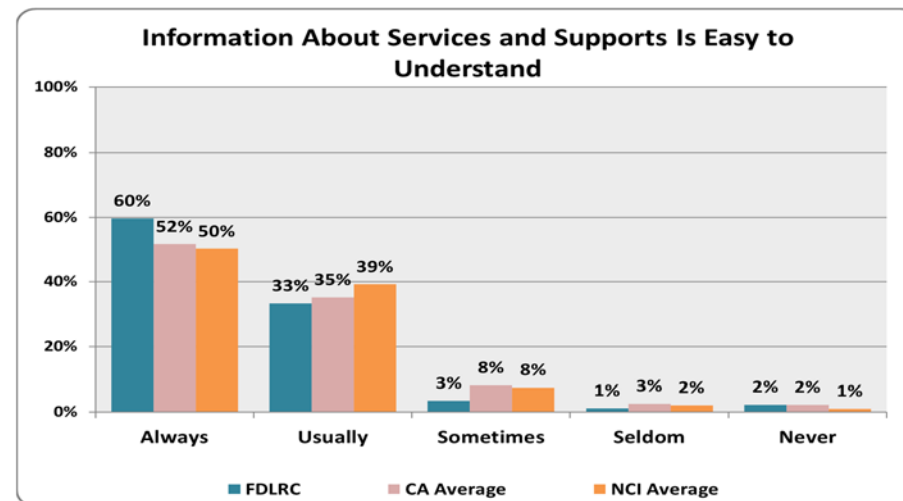
## Information and Planning

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

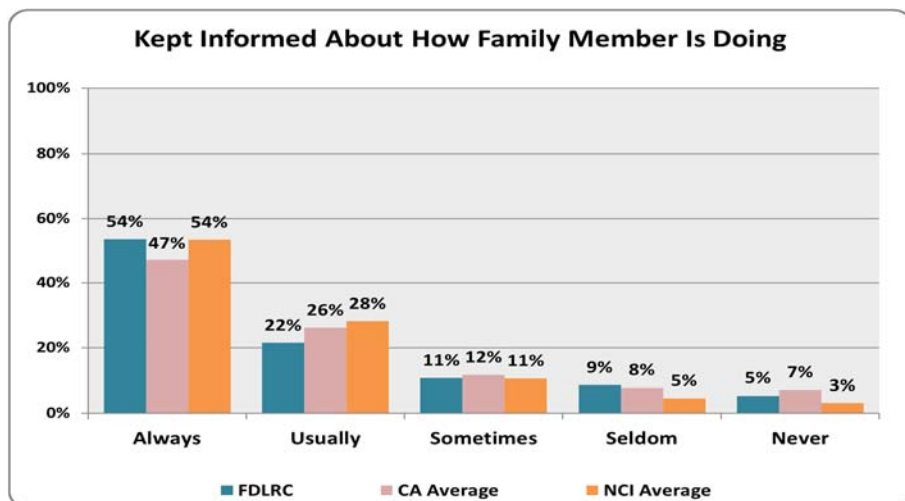
**GRAPH 20. DO YOU GET ENOUGH INFORMATION TO HELP YOU PARTICIPATE IN PLANNING SERVICES FOR YOUR FAMILY MEMBER?**



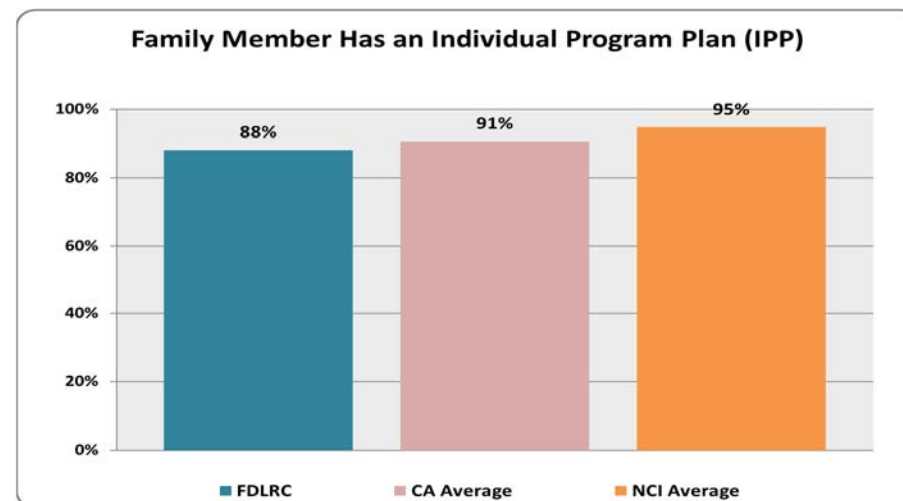
**GRAPH 21. IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND?**



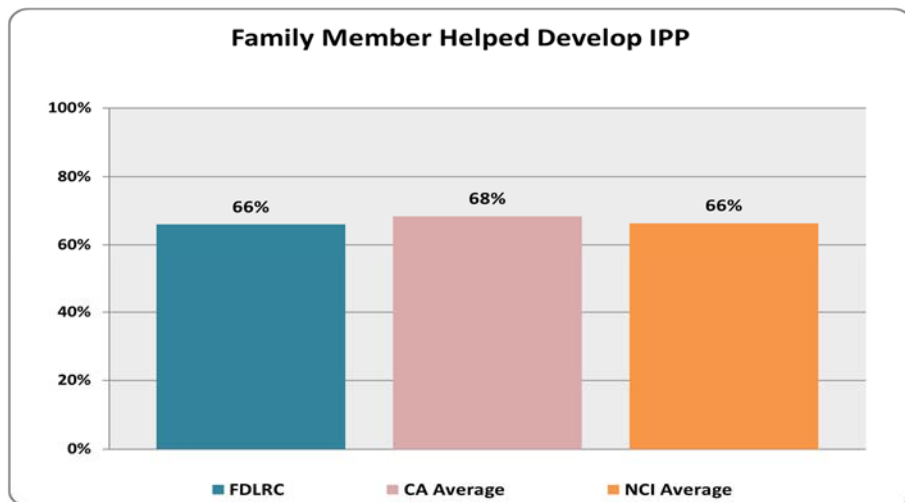
**GRAPH 22. ARE YOU KEPT INFORMED ABOUT HOW YOUR FAMILY MEMBER IS DOING?**



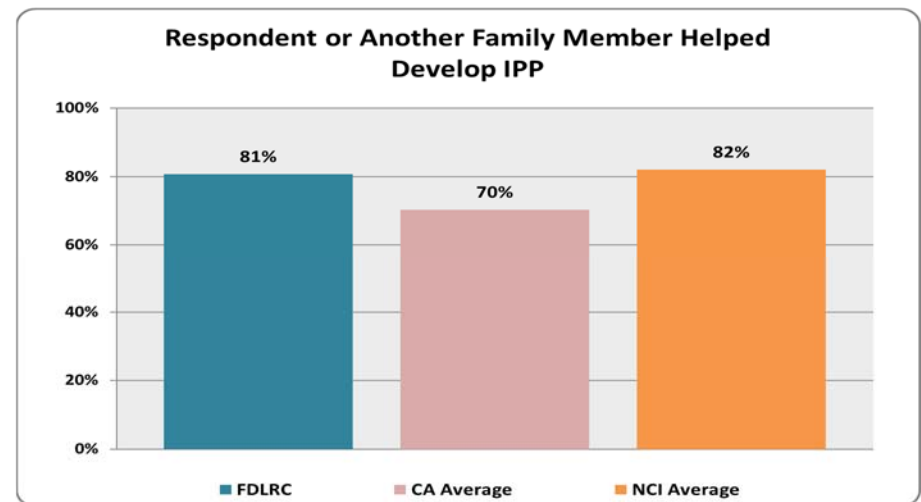
**GRAPH 23. DOES YOUR FAMILY MEMBER HAVE AN INDIVIDUAL PROGRAM PLAN (IPP)?**



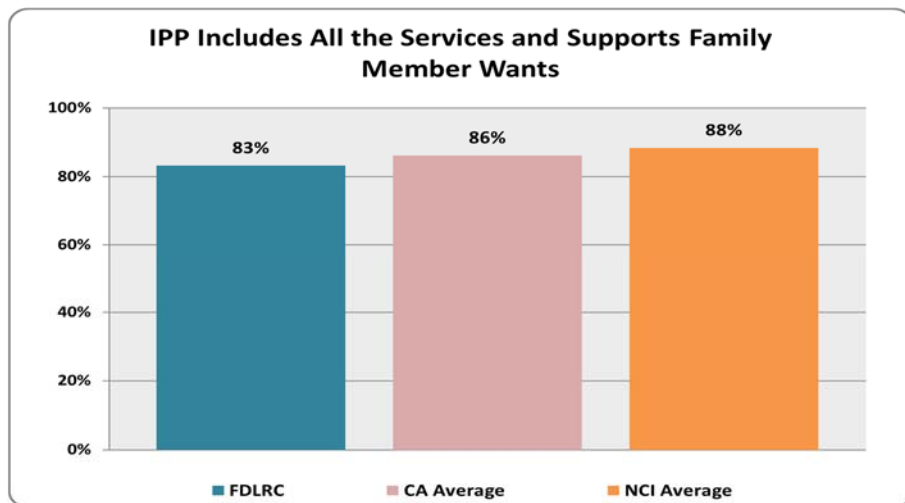
**GRAPH 24. DID YOUR FAMILY MEMBER HELP DEVELOP THE IPP?**



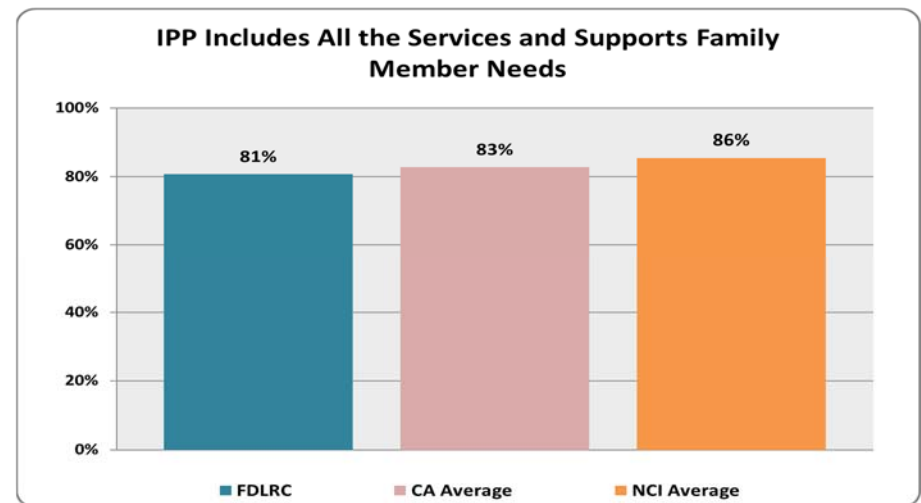
**GRAPH 25. DID YOU OR ANOTHER FAMILY MEMBER HELP DEVELOP THE IPP?**



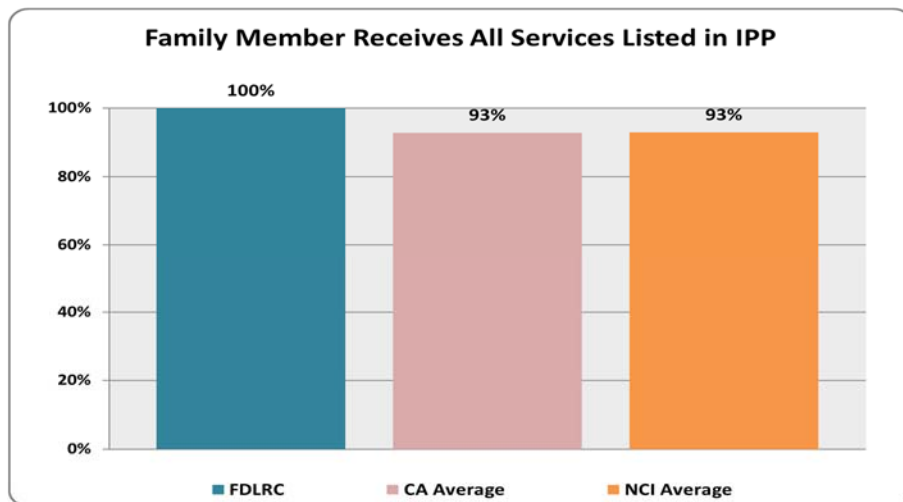
**GRAPH 26. DOES THE IPP INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER WANTS?**



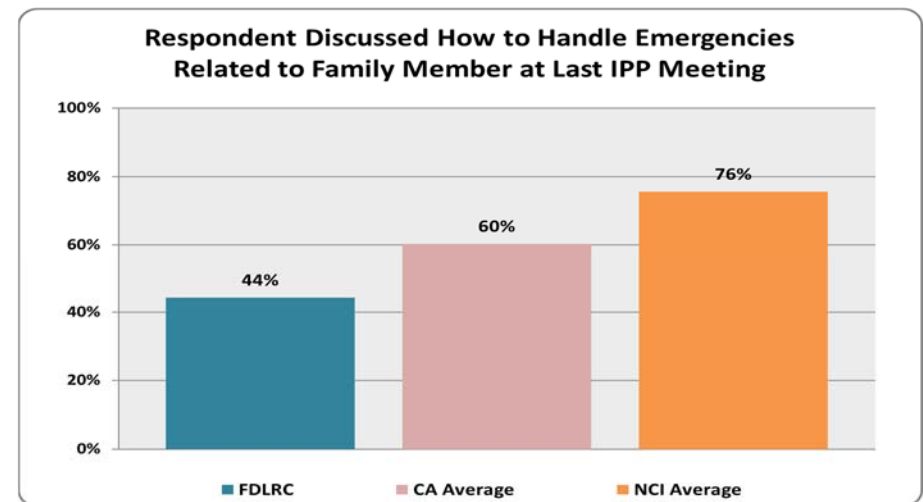
**GRAPH 27. DOES THE IPP INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER NEEDS?**



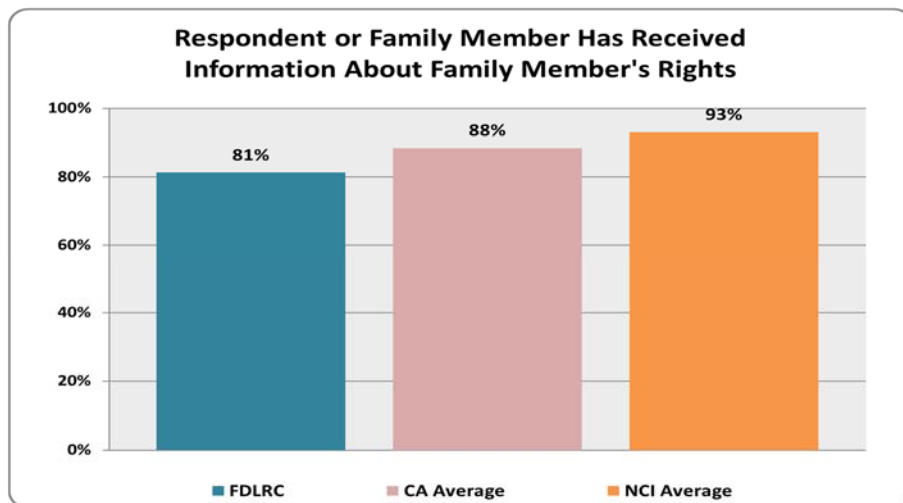
**GRAPH 28. DOES YOUR FAMILY MEMBER RECEIVE ALL OF THE SERVICES LISTED IN THE IPP?**



**GRAPH 29. DID YOU DISCUSS HOW TO HANDLE EMERGENCIES RELATED TO YOUR FAMILY MEMBER AT THE LAST IPP MEETING?**



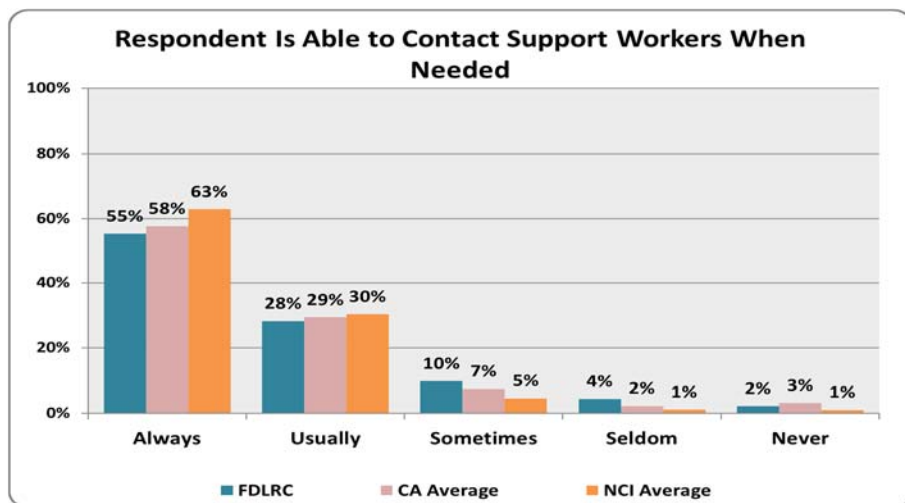
**GRAPH 30. HAVE YOU OR YOUR FAMILY MEMBER RECEIVED INFORMATION ABOUT HIS/HER RIGHTS?**



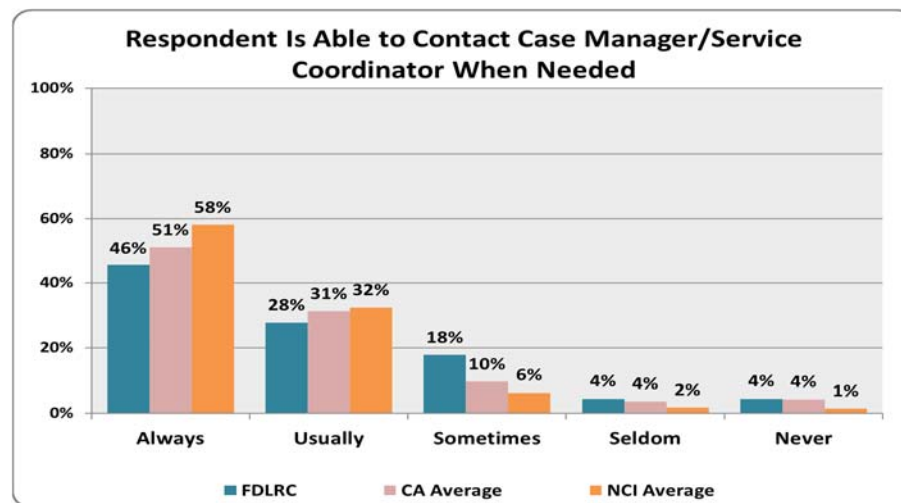
## Access and Delivery

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

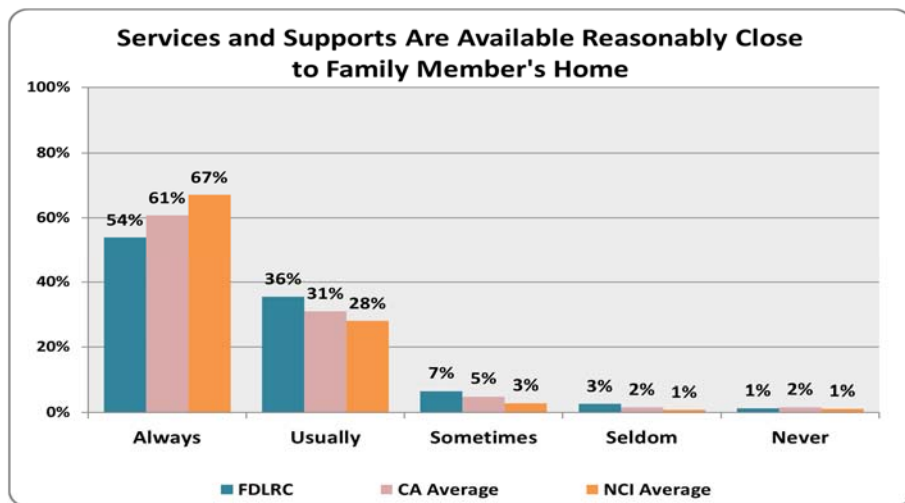
**GRAPH 31. ARE YOU ABLE TO CONTACT YOUR FAMILY MEMBER'S SUPPORT WORKERS WHEN YOU NEED TO?**



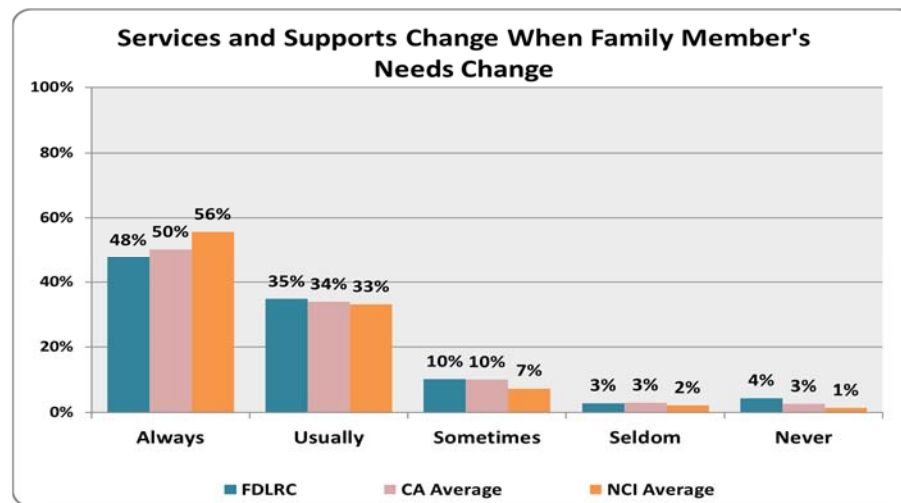
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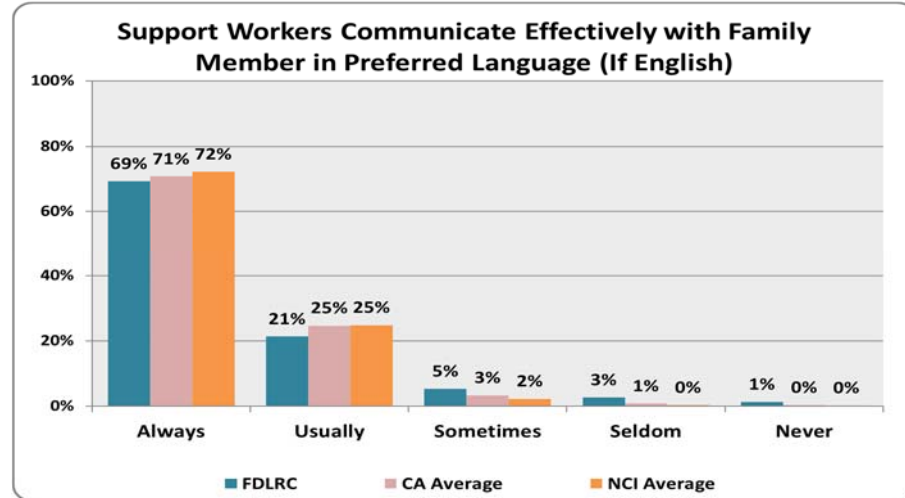
**GRAPH 33. ARE SERVICES AND SUPPORTS AVAILABLE WITHIN A REASONABLE DISTANCE FROM YOUR FAMILY MEMBER'S HOME?**



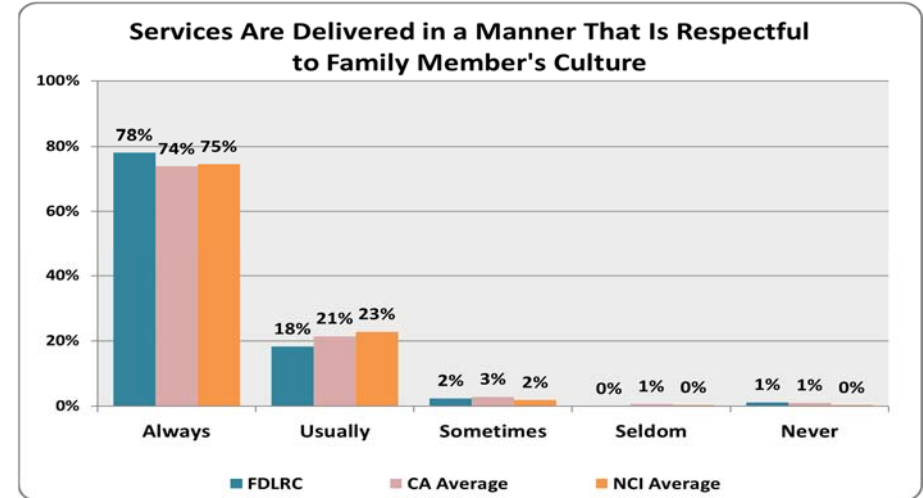
**GRAPH 34. DO THE SERVICES AND SUPPORTS CHANGE WHEN YOUR FAMILY MEMBER'S NEEDS CHANGE?**



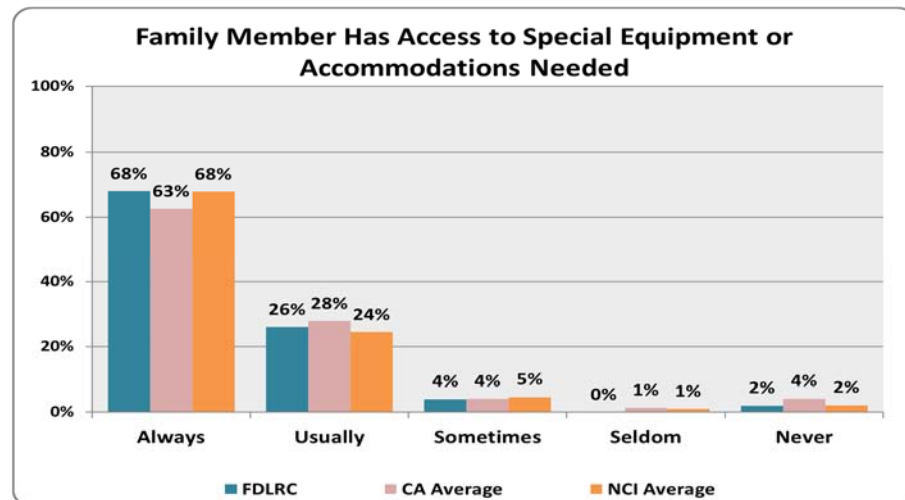
**GRAPH 35. IF ENGLISH IS YOUR FAMILY MEMBER'S PREFERRED LANGUAGE, DO THE SUPPORT WORKERS SPEAK TO HIM/HER EFFECTIVELY?**



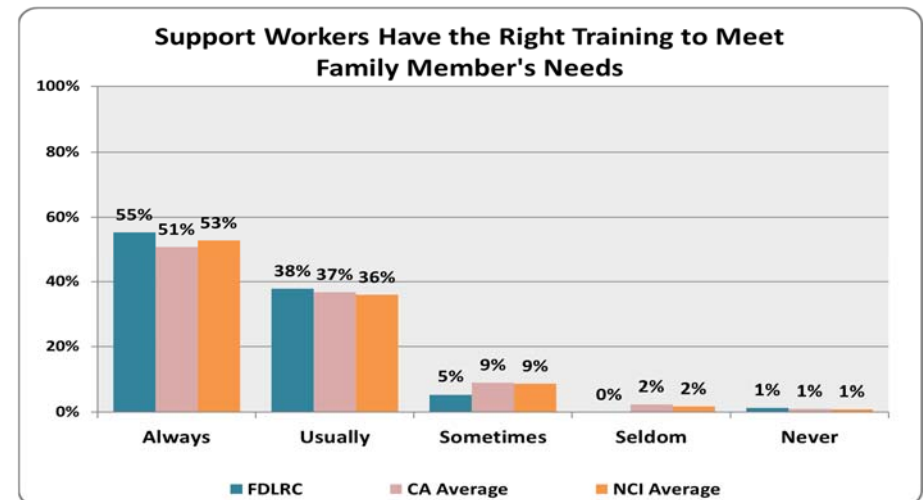
**GRAPH 36. ARE SERVICES DELIVERED IN A WAY THAT IS RESPECTFUL TO YOUR FAMILY MEMBER'S CULTURE?**



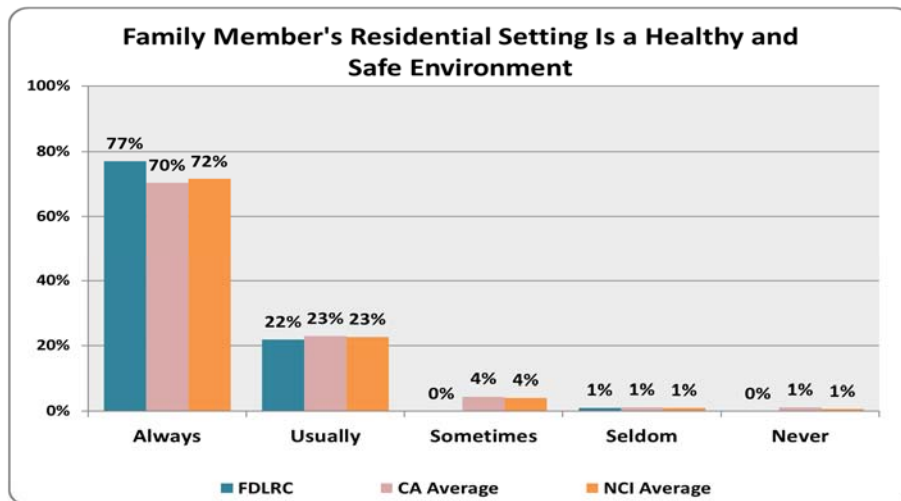
**GRAPH 37. DOES YOUR FAMILY MEMBER HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT HE/SHE NEEDS (FOR EXAMPLE, WHEELCHAIRS, RAMPS, COMMUNICATION BOARDS)?**



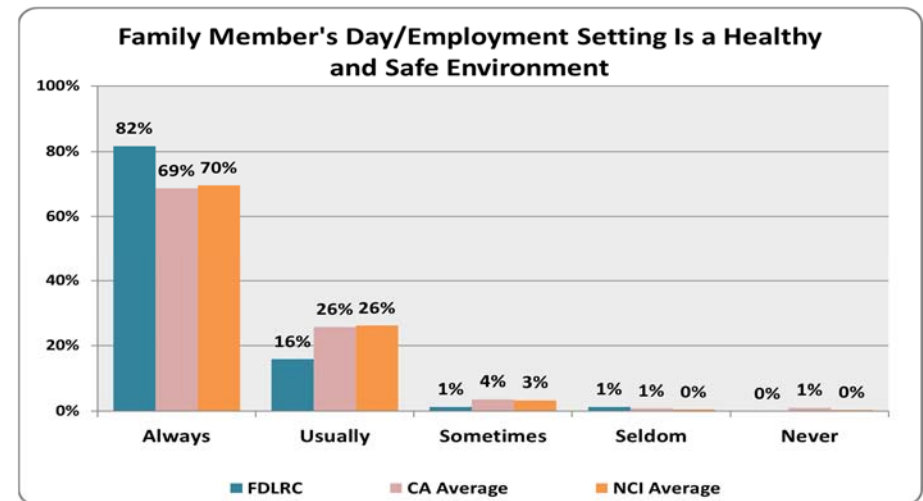
**GRAPH 38. DO SUPPORT WORKERS HAVE THE RIGHT TRAINING TO MEET YOUR FAMILY MEMBER'S NEEDS?**



**GRAPH 39. DO YOU FEEL THAT YOUR FAMILY MEMBER'S RESIDENTIAL SETTING IS A HEALTHY AND SAFE ENVIRONMENT?**



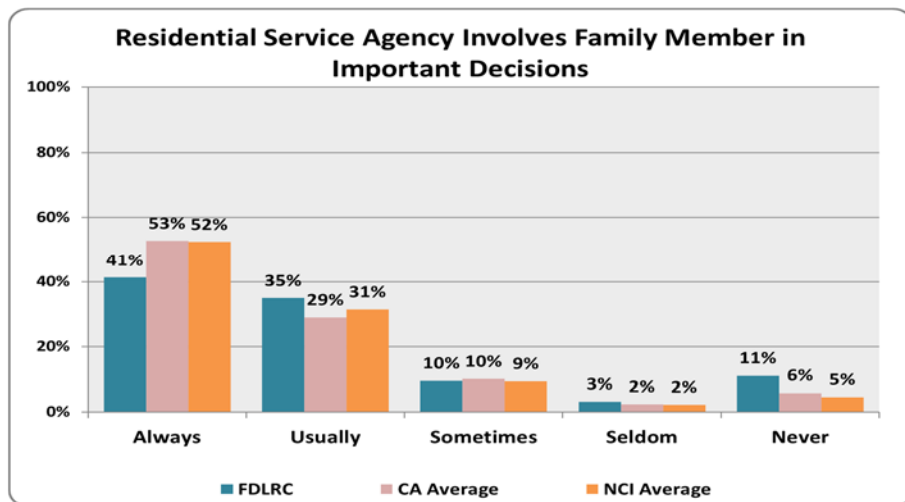
**GRAPH 40. DO YOU FEEL THAT YOUR FAMILY MEMBER'S DAY/EMPLOYMENT SETTING IS A HEALTHY AND SAFE ENVIRONMENT?**



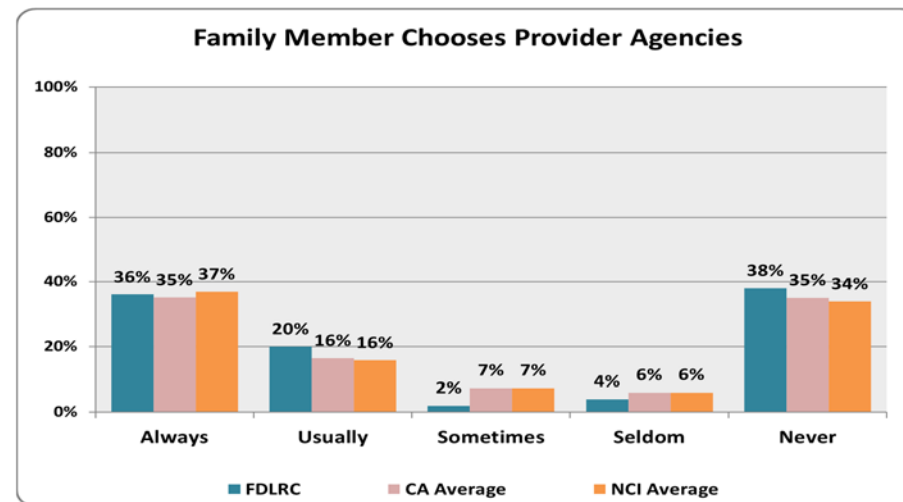
## Choice and Control

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

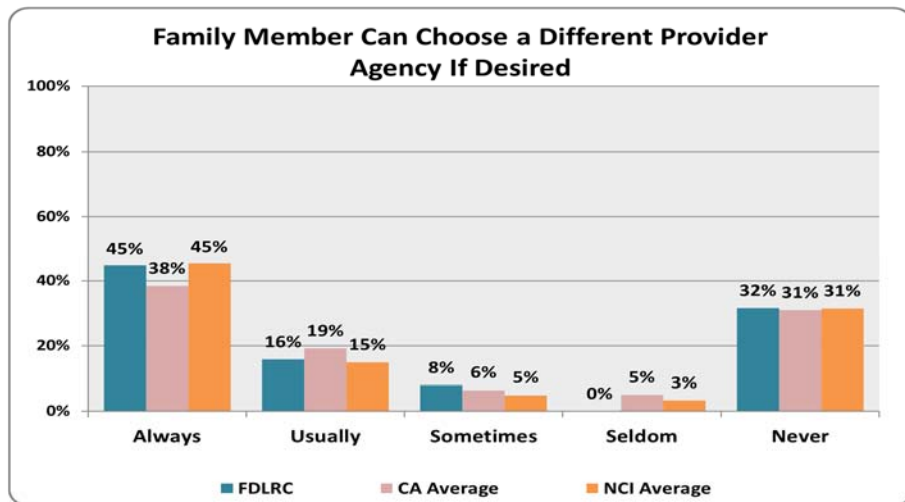
**GRAPH 41. DOES THE AGENCY PROVIDING RESIDENTIAL SERVICES TO YOUR FAMILY MEMBER INVOLVE HIM/HER IN IMPORTANT DECISIONS?**



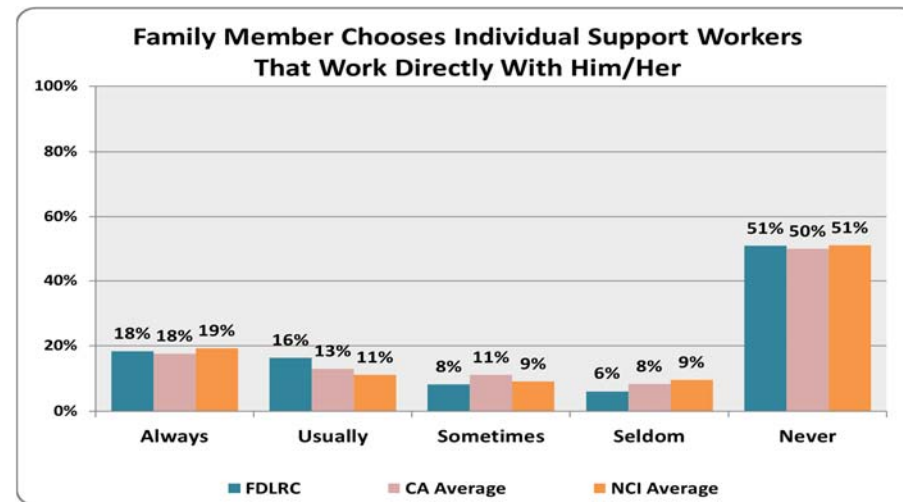
**GRAPH 42. DOES YOUR FAMILY MEMBER CHOOSE THE PROVIDER AGENCIES THAT WORK WITH HIM OR HER?**



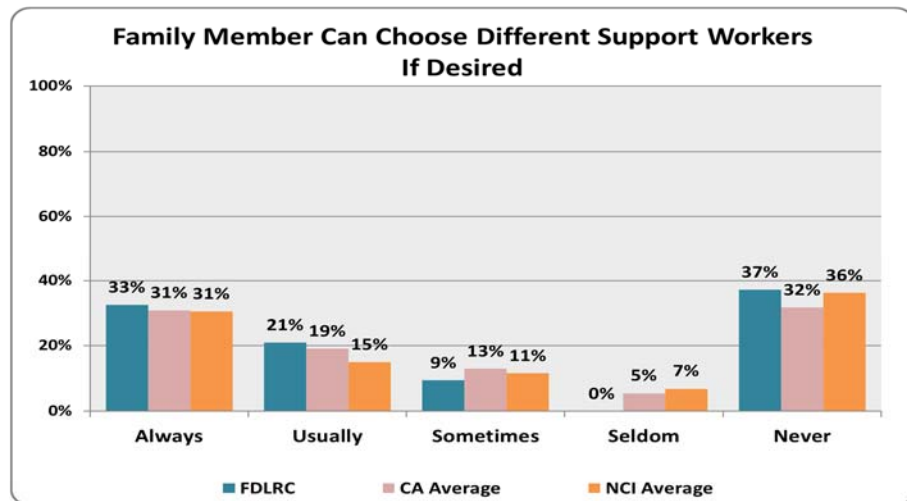
**GRAPH 43. CAN YOUR FAMILY MEMBER CHOOSE A DIFFERENT PROVIDER AGENCY IF S/HE WANTS TO?**



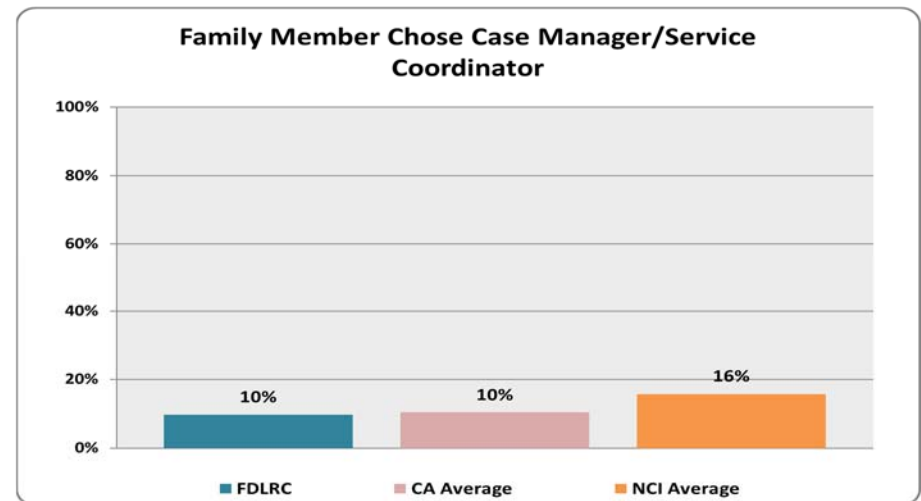
**GRAPH 44. DOES YOUR FAMILY MEMBER CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH HIM/HER?**



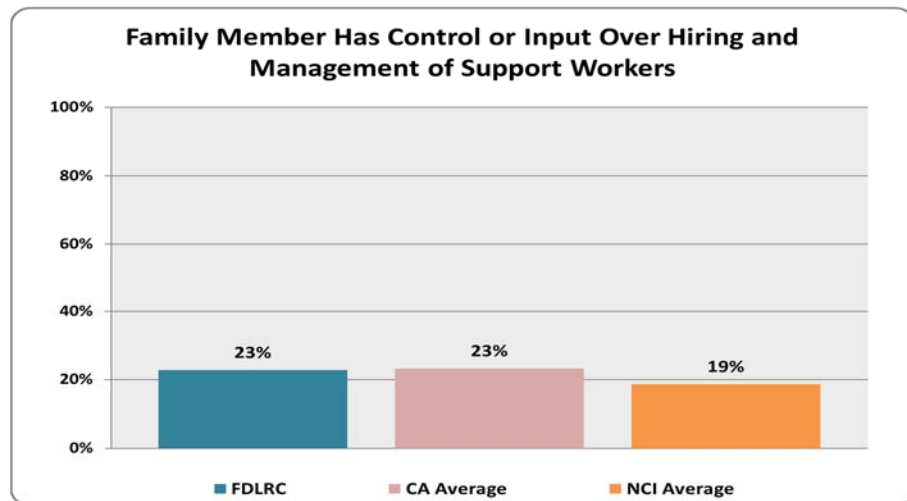
**GRAPH 45. CAN YOUR FAMILY MEMBER CHOOSE DIFFERENT SUPPORT WORKERS IF S/HE WANTS TO?**



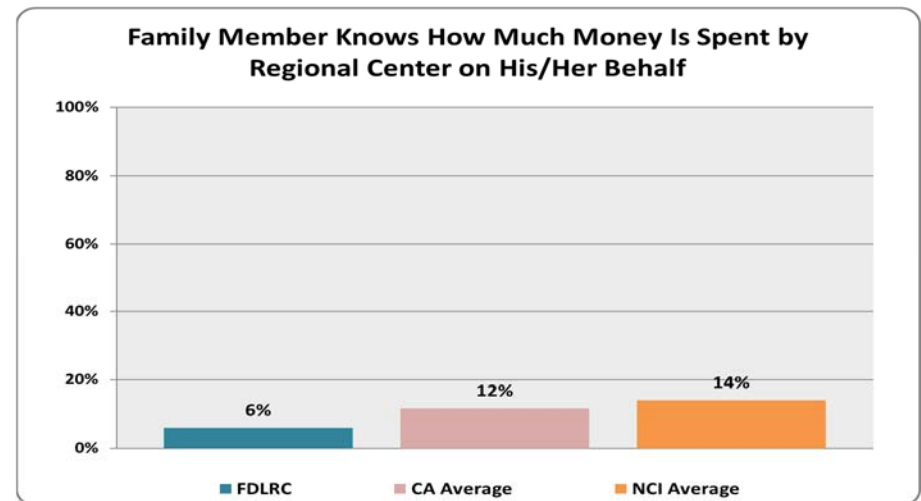
**GRAPH 46. DID YOUR FAMILY MEMBER CHOOSE HIS/HER CASE MANAGER/SERVICE COORDINATOR?**



**GRAPH 47. DOES YOUR FAMILY MEMBER HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF HIS/HER SUPPORT WORKERS?**

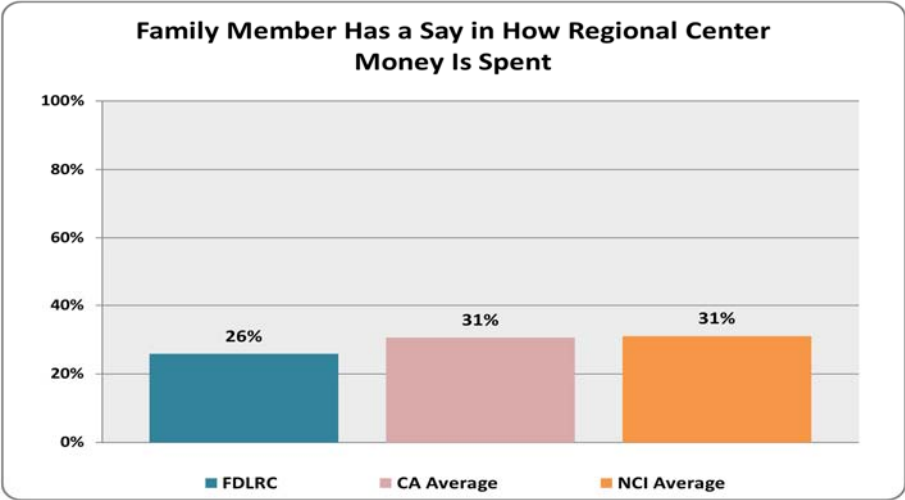


**GRAPH 48. DOES YOUR FAMILY MEMBER KNOW HOW MUCH MONEY IS SPENT BY THE REGIONAL CENTER ON HIS/HER BEHALF?\***



\*'DON'T KNOW' RESPONSES WERE INCLUDED IN 'NO' RESPONSES FOR THIS QUESTION.

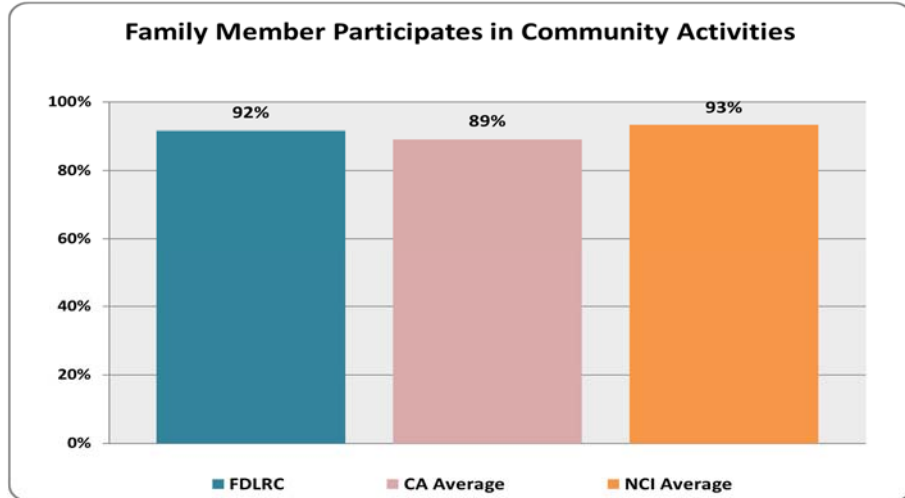
**GRAPH 49. DOES YOUR FAMILY MEMBER HAVE A SAY IN HOW REGIONAL CENTER MONEY IS SPENT ON HIS/HER BEHALF?**



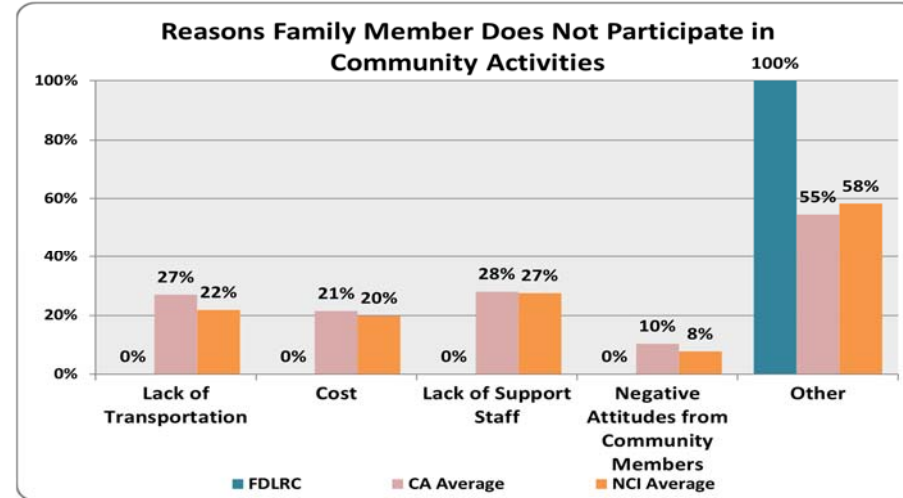
## Community Connections

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

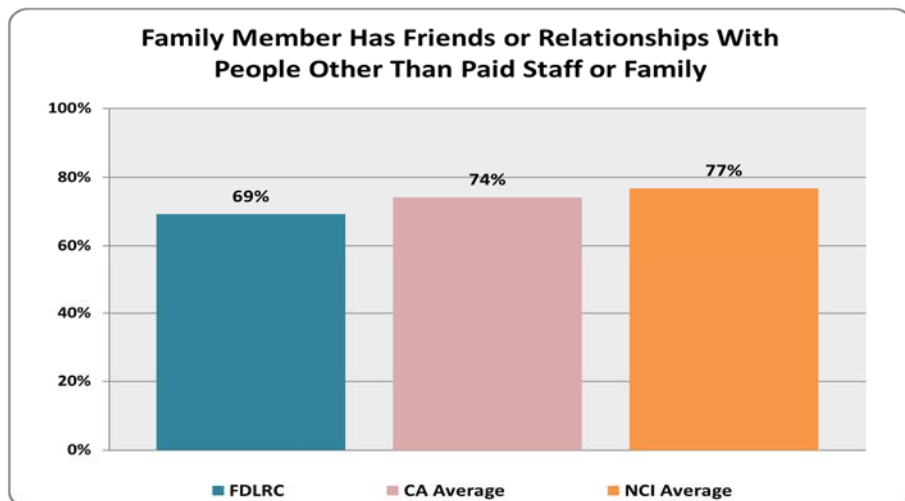
**GRAPH 50. DOES YOUR FAMILY MEMBER PARTICIPATE IN COMMUNITY ACTIVITIES (SUCH AS GOING OUT TO A RESTAURANT, MOVIE, OR SPORTING EVENT)?**



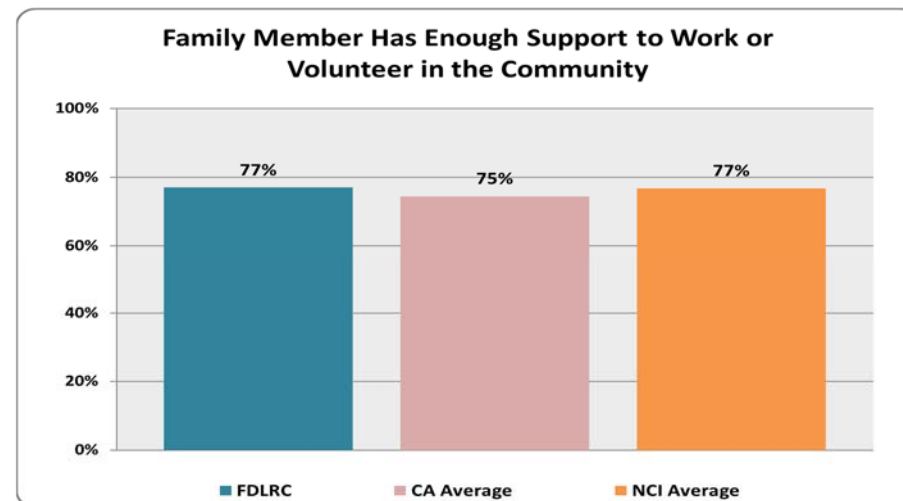
**GRAPH 51. IF YOUR FAMILY MEMBER DOESN'T PARTICIPATE IN COMMUNITY ACTIVITIES, WHY NOT?**



**GRAPH 52. DOES YOUR FAMILY MEMBER HAVE FRIENDS OR RELATIONSHIPS WITH PERSONS OTHER THAN PAID STAFF OR FAMILY?**



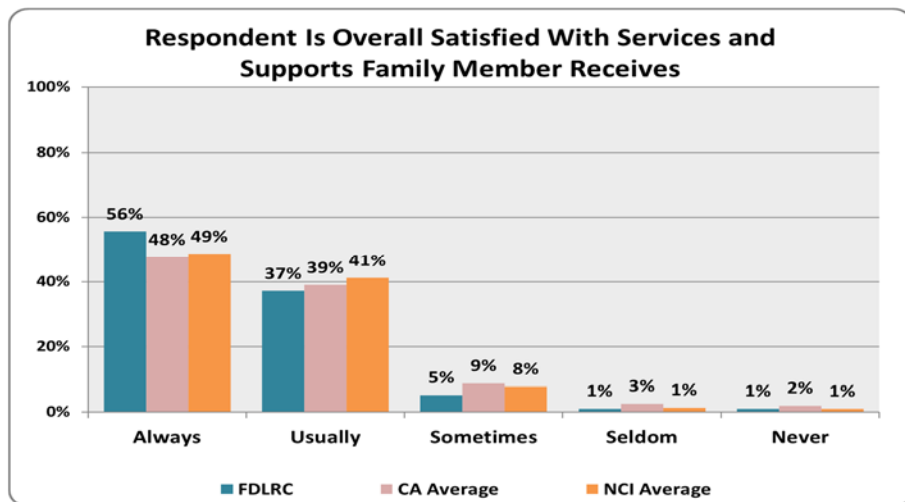
**GRAPH 53. DOES YOUR FAMILY MEMBER HAVE ENOUGH SUPPORT (FOR EXAMPLE, SUPPORT WORKERS, COMMUNITY RESOURCES) TO WORK OR VOLUNTEER IN THE COMMUNITY?**



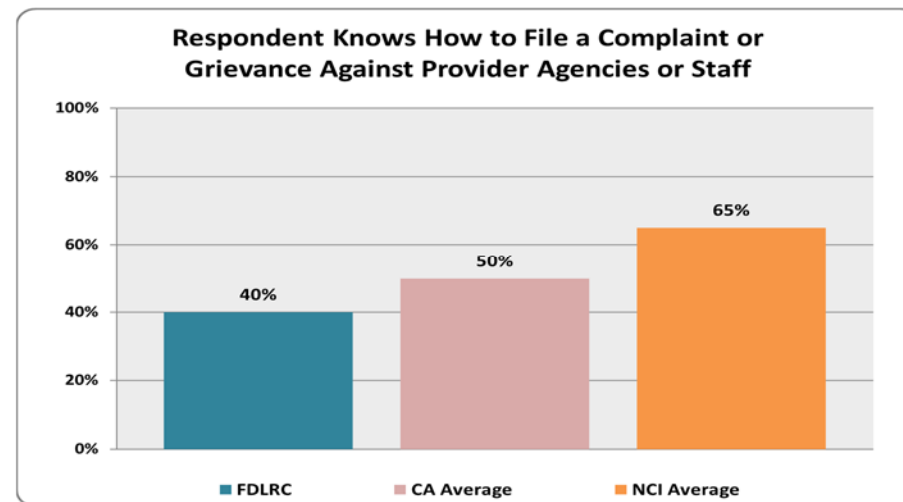
## Satisfaction

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

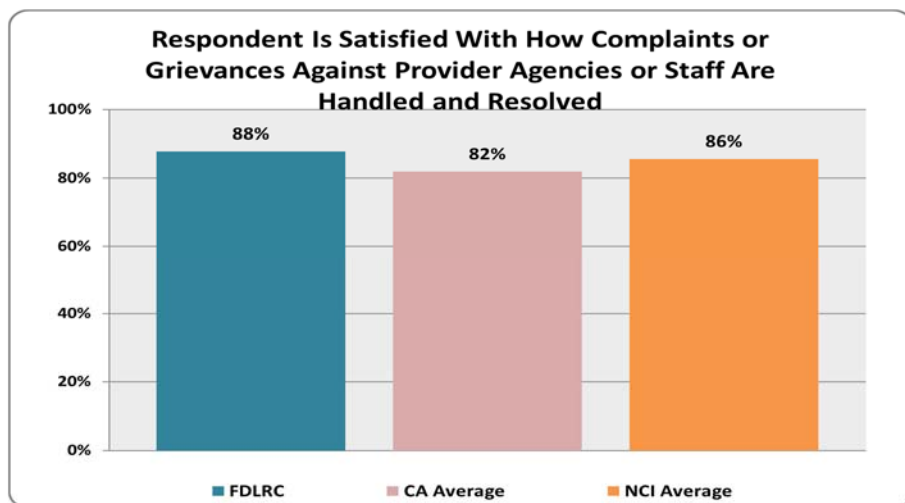
**GRAPH 54. OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER CURRENTLY RECEIVES?**



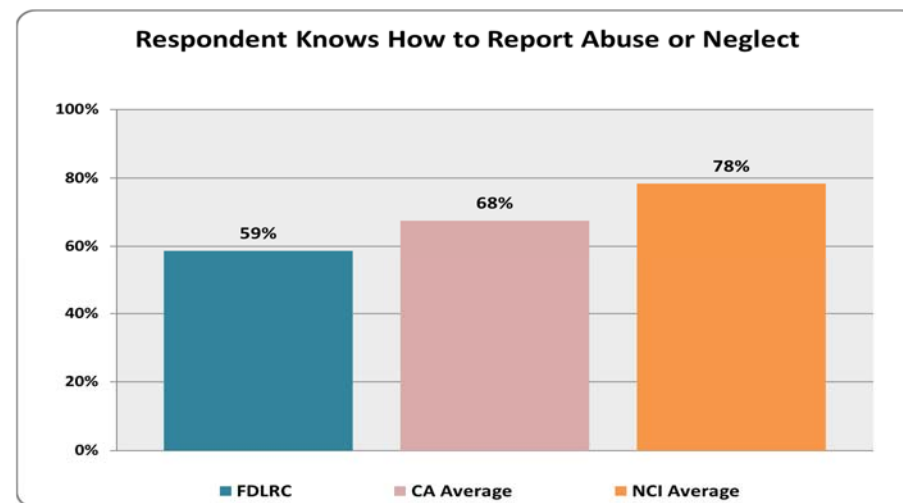
**GRAPH 55. DO YOU KNOW THE PROCESS FOR FILING A COMPLAINT OR GRIEVANCE AGAINST PROVIDER AGENCIES OR STAFF?\***



**GRAPH 56. ARE YOU SATISFIED WITH THE WAY COMPLAINTS OR GRIEVANCES AGAINST PROVIDER AGENCIES OR STAFF ARE HANDLED AND RESOLVED?**

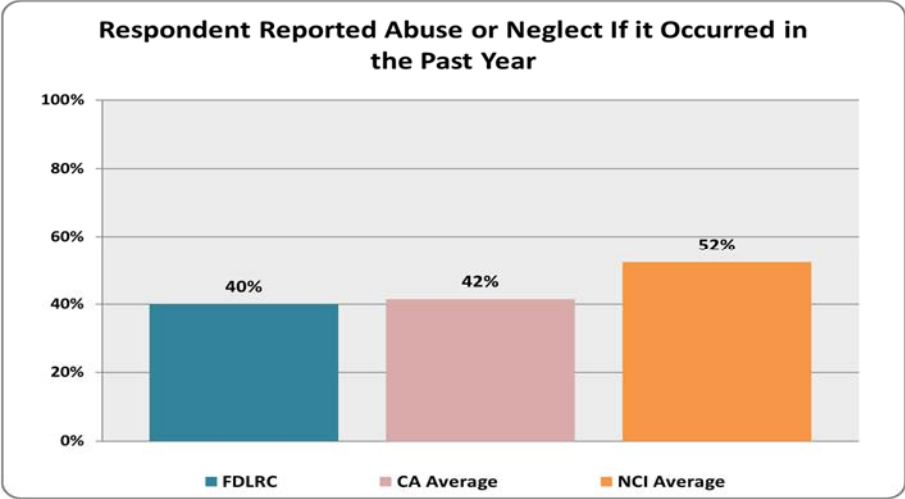


**GRAPH 57. DO YOU KNOW HOW TO REPORT ABUSE OR NEGLECT?\***



**\*'DON'T KNOW' RESPONSES WERE INCLUDED IN 'NO' RESPONSES FOR THIS QUESTION.**

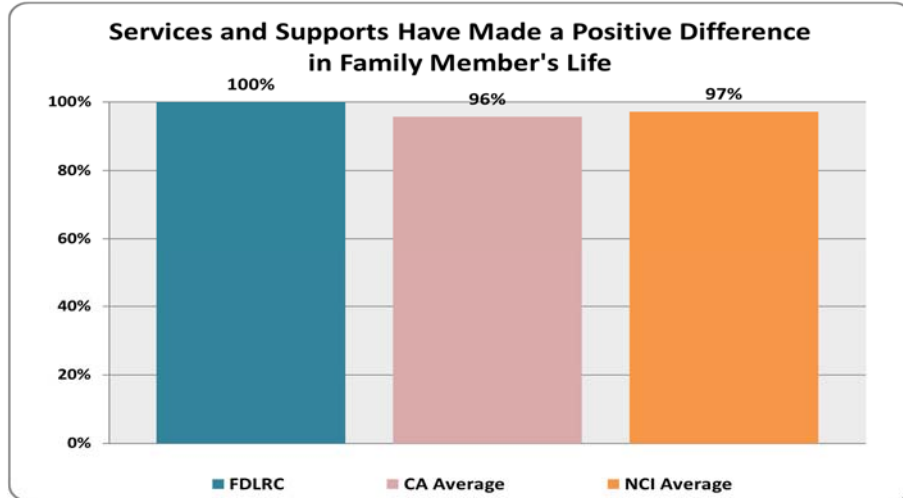
**GRAPH 58. WITHIN THE PAST YEAR, IF ABUSE OR NEGLECT OCCURRED, DID YOU REPORT IT?**



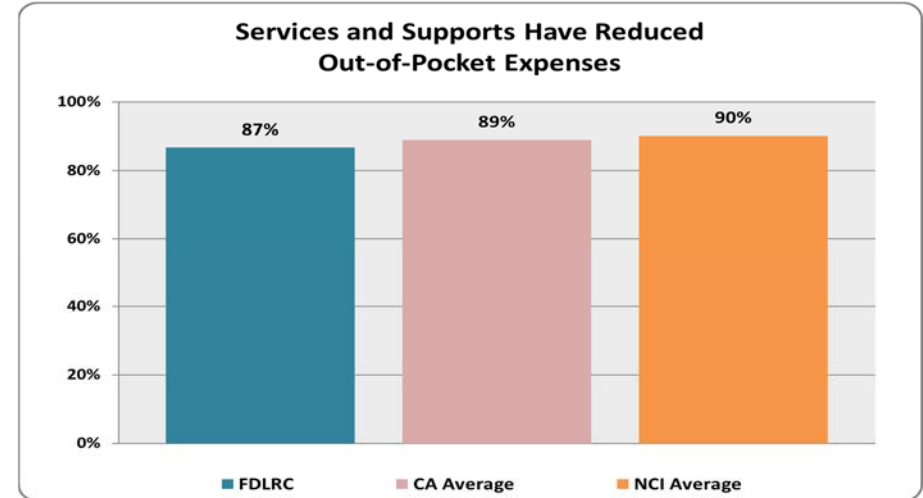
## Family Outcomes

*INDIVIDUAL AND FAMILY SUPPORTS MAKE A POSITIVE DIFFERENCE IN THE LIVES OF FAMILIES*

**GRAPH 59. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE MADE A POSITIVE DIFFERENCE IN THE LIFE OF YOUR FAMILY MEMBER?**



**GRAPH 60. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE REDUCED YOUR FAMILY'S OUT-OF-POCKET EXPENSES FOR YOUR FAMILY MEMBER'S CARE?**



**GRAPH 61. HAVE THE SERVICES OR SUPPORTS THAT YOUR FAMILY MEMBER RECEIVED BEEN REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR?**

