

NCI Adult Family Survey Outcomes

Frank D. Lanterman Regional Center (FDLRC) Report

Fiscal Year 2013-2014



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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) Adult Family 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.¹ This report shows Adult Family 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 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 Adult Family Survey?

The NCI Adult Family Survey is a mail-in survey sent to families who have an adult family member with an intellectual/developmental disability living in the home who receives services from one of California's regional centers. The 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

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

receiving services and the survey respondent (most often the individual's 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 Adult Family Survey includes items to measure the Family Outcomes domain. The table on the following page lists the NCI Family Surveys sub-domains and concern statements.

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

Sub-Domain	Concern Statement
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 & Control	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
Community Connections	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.
Family Outcomes	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 an intellectual/developmental disability living at 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 $\pm 7\%$.

Limitations of Data

The NCI Adult Family 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?

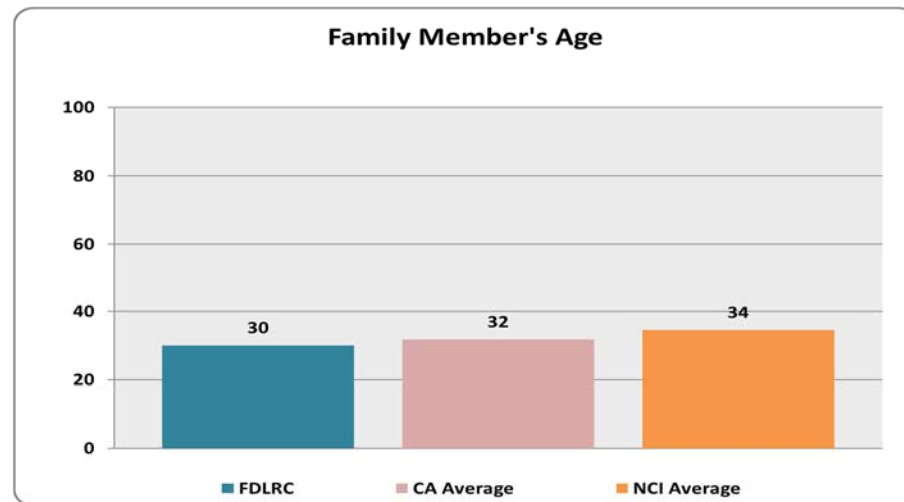
This report illustrates FY 13/14 NCI Adult Family Survey demographic and outcome results from FDLRC compared to the California statewide average, and NCI Average. The NCI Average is calculated by averaging all states’ estimates – it is an “average of averages”, therefore, each state contributes the same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

In FY 13/14, 14 states conducted the Adult Family 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 with fewer than 20 responses to a particular question were excluded from analysis for that question. The number of responses for 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/>.

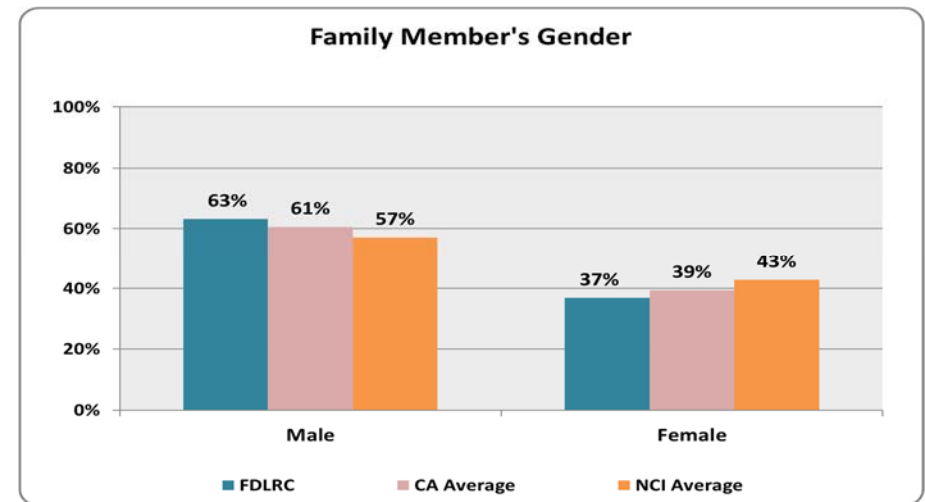
Results: Demographics of Family Member

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

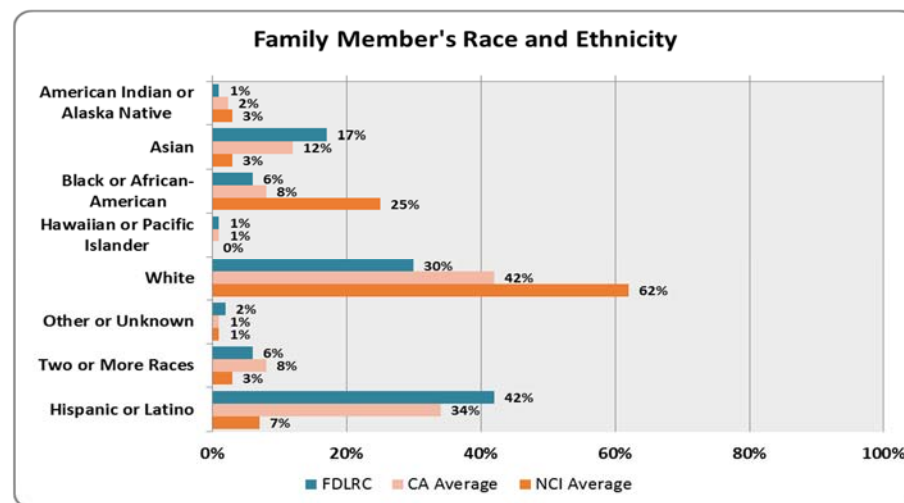
GRAPH 1. FAMILY MEMBER'S AVERAGE AGE



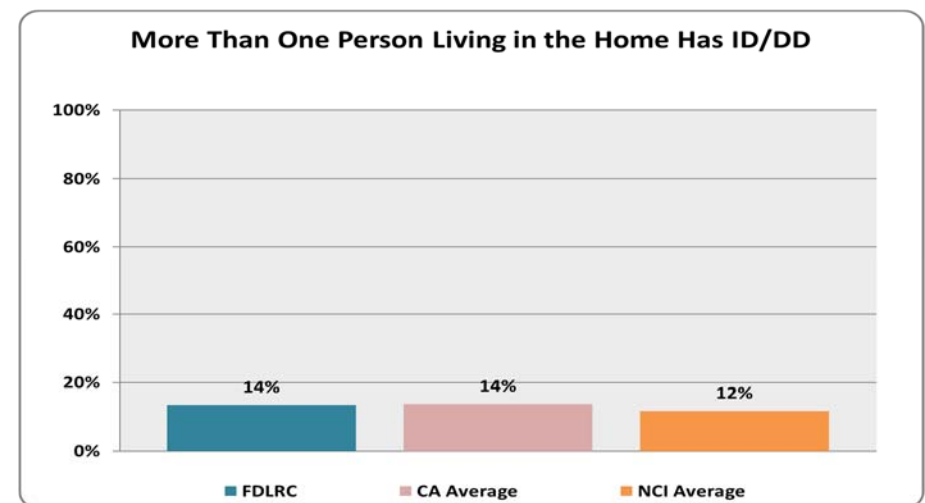
GRAPH 2. FAMILY MEMBER'S GENDER



GRAPH 3. FAMILY MEMBER'S RACE AND ETHNICITY*

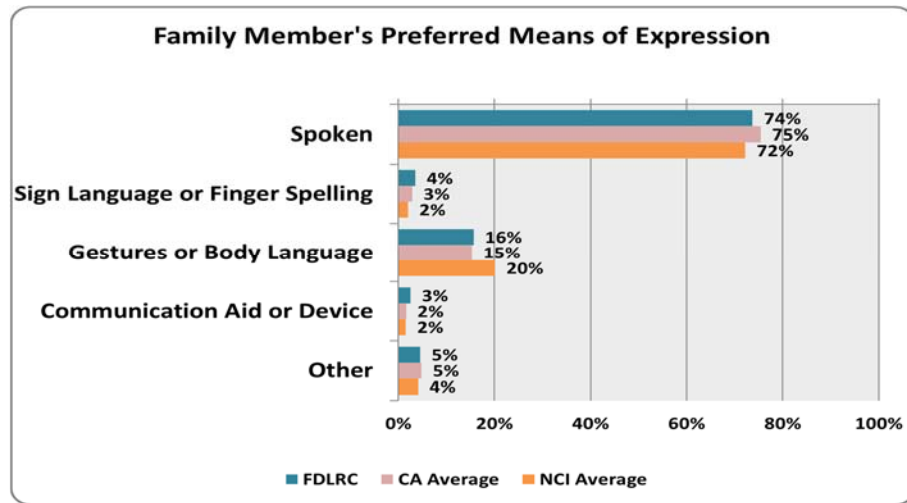


GRAPH 4. MORE THAN ONE PERSON LIVING IN THE HOME HAS ID/DD

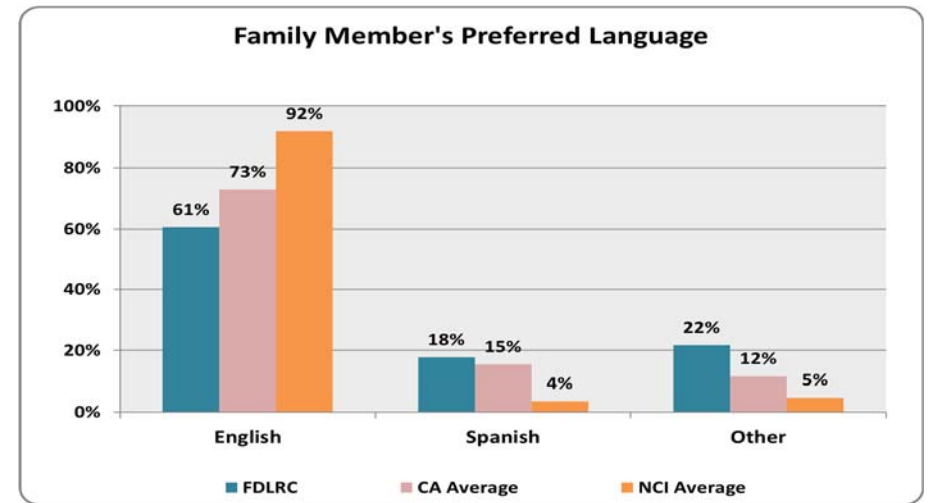


*CATEGORIES ARE NOT MUTUALLY EXCLUSIVE, AND THEREFORE SOME RESULTS MAY ADD UP TO MORE THAN 100%. NOTE: IN THE CALIFORNIA DATA, HISPANIC IS CONSIDERED A RACE CATEGORY. NCI USES THE U.S. CENSUS MODEL, WHICH DEFINES ETHNICITY SEPARATELY AS HISPANIC VS. NON-HISPANIC.

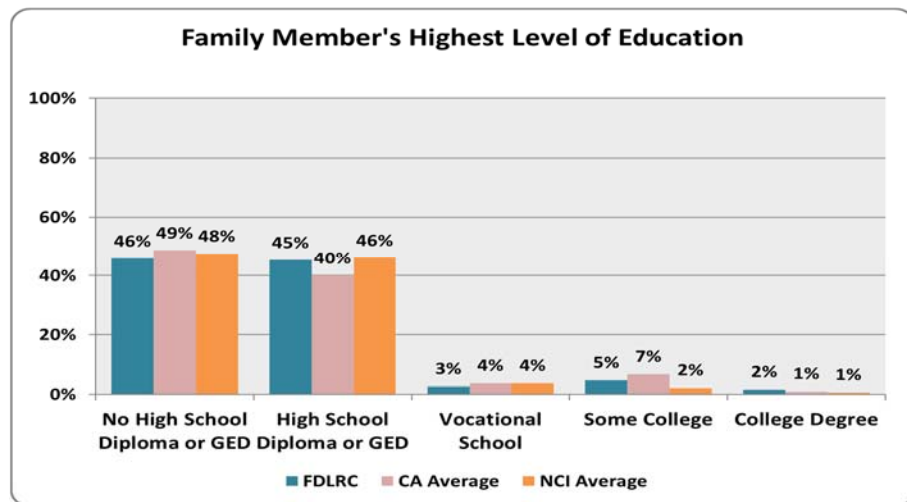
GRAPH 5. FAMILY MEMBER'S PREFERRED MEANS OF EXPRESSION



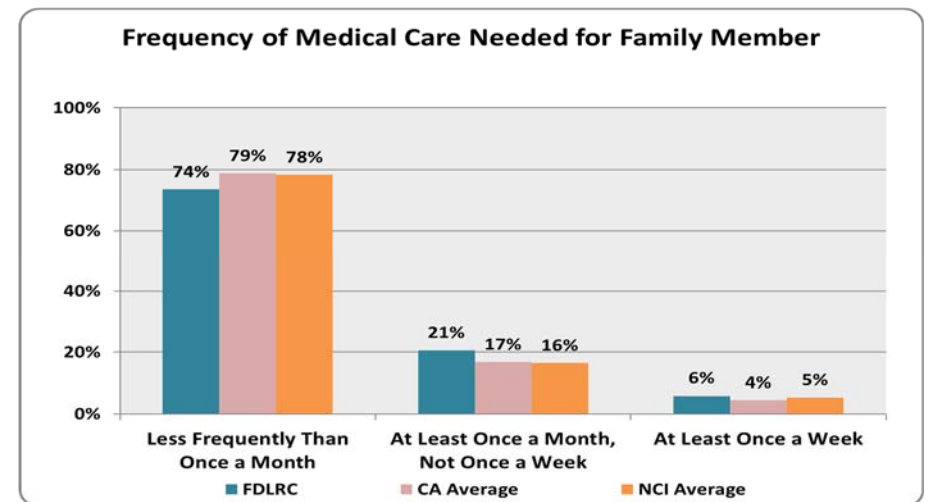
GRAPH 6. FAMILY MEMBER'S PREFERRED LANGUAGE



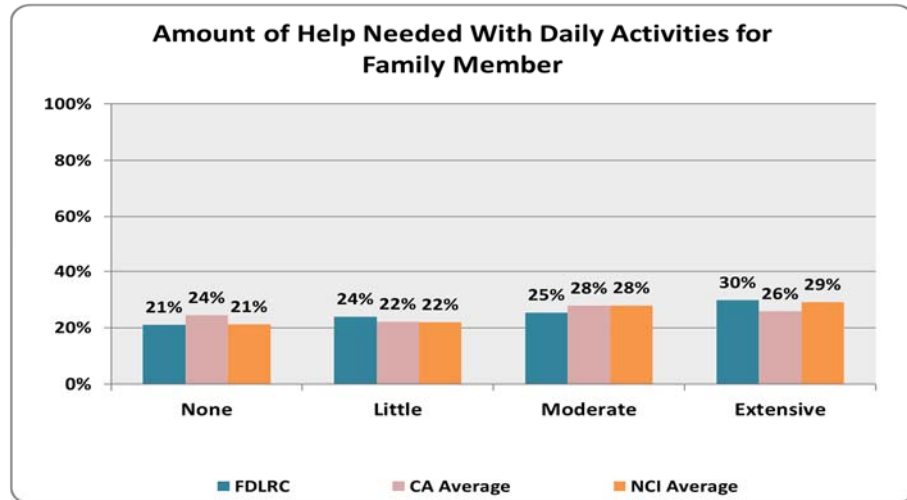
GRAPH 7. FAMILY MEMBER'S HIGHEST LEVEL OF EDUCATION



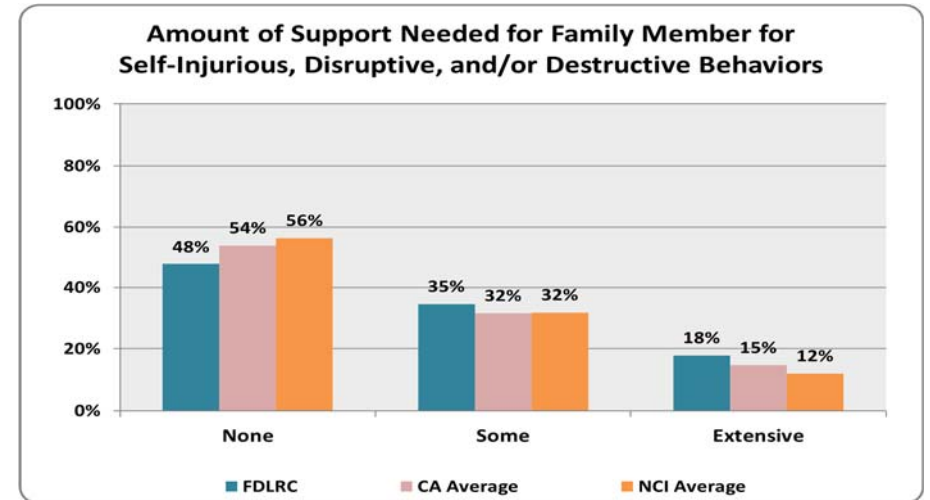
GRAPH 8. FREQUENCY OF MEDICAL CARE NEEDED FOR FAMILY MEMBER



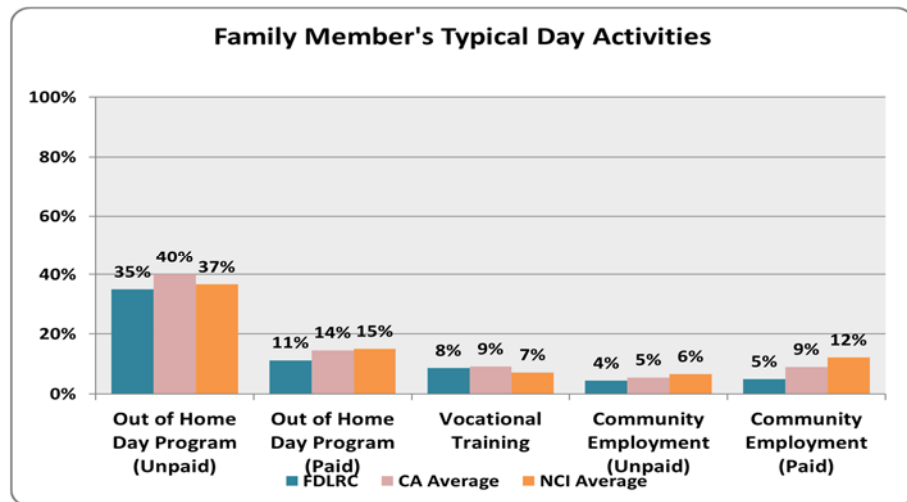
GRAPH 9. AMOUNT OF HELP NEEDED WITH DAILY ACTIVITIES FOR FAMILY MEMBER



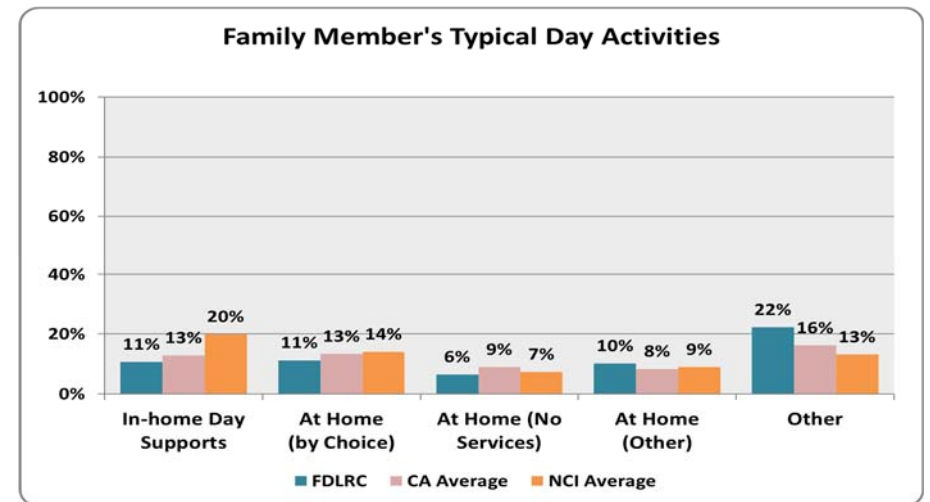
GRAPH 10. AMOUNT OF SUPPORT NEEDED FOR FAMILY MEMBER FOR SELF-INJURIOUS, DISRUPTIVE, AND/OR DESTRUCTIVE BEHAVIORS



GRAPH 11. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES



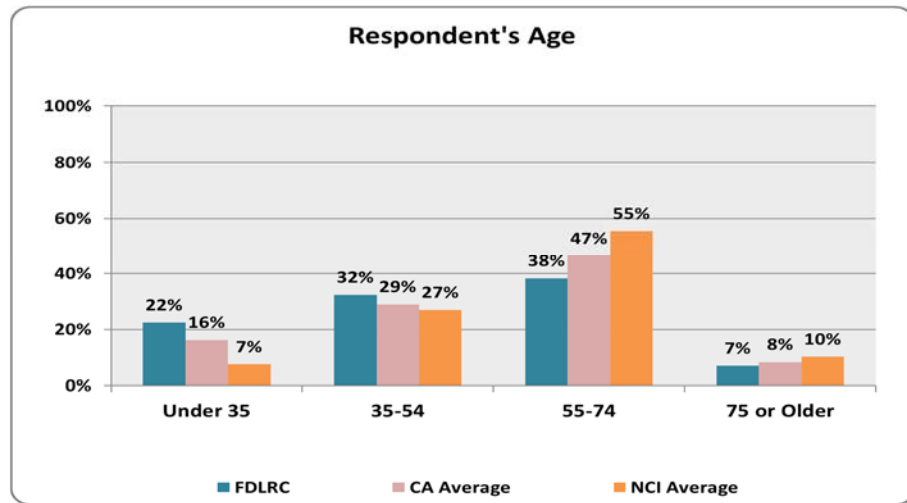
GRAPH 12. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES, CONTINUED



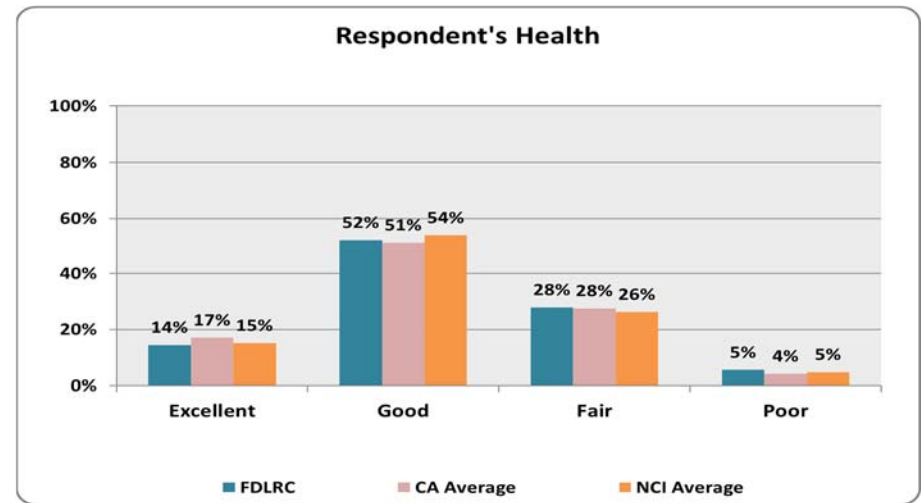
Results: Demographics of Respondent

ILLUSTRATES THE DEMOGRAPHIC PROFILE OF THE SURVEY RESPONDENTS

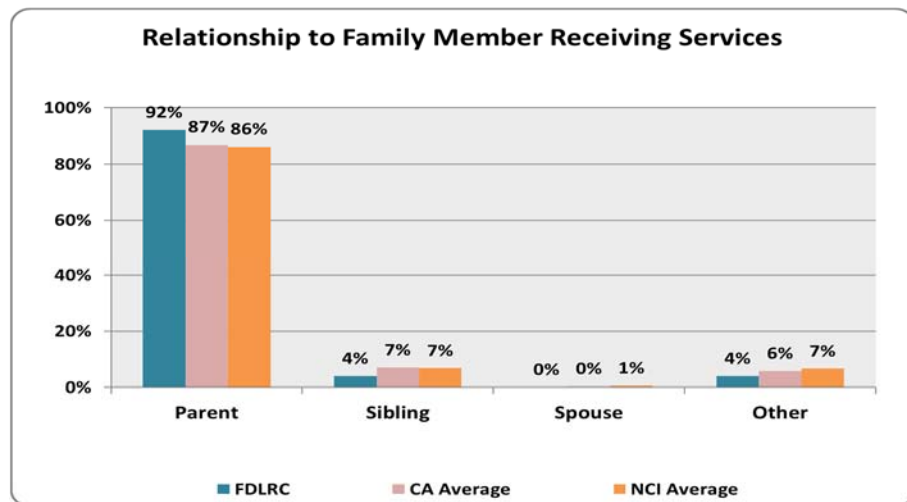
GRAPH 13. RESPONDENT'S AGE



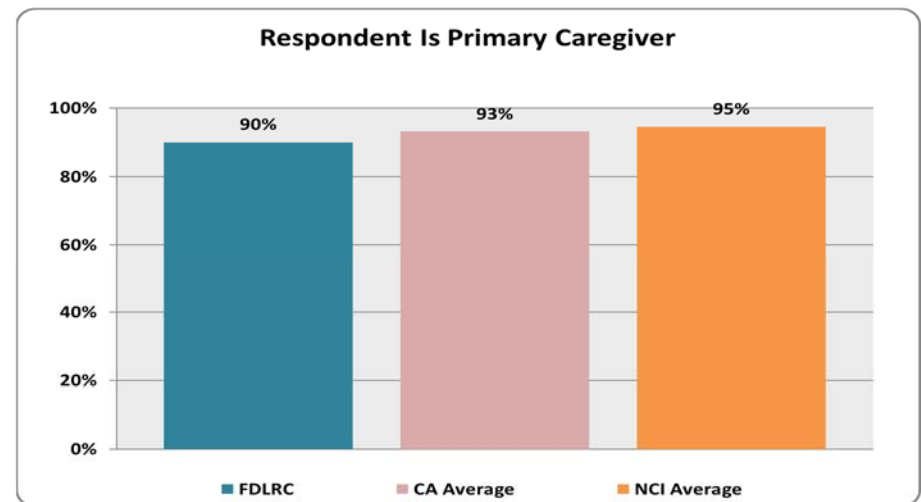
GRAPH 14. RESPONDENT'S HEALTH



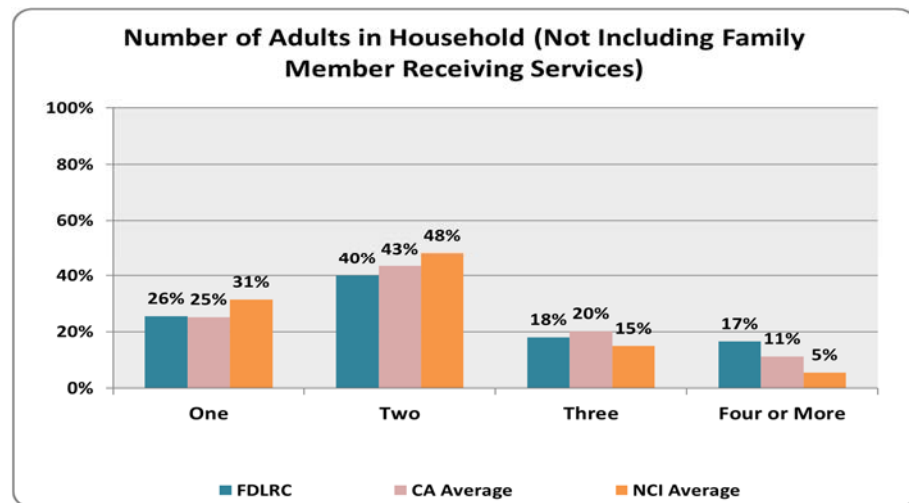
GRAPH 15. RELATIONSHIP TO FAMILY MEMBER RECEIVING SERVICES



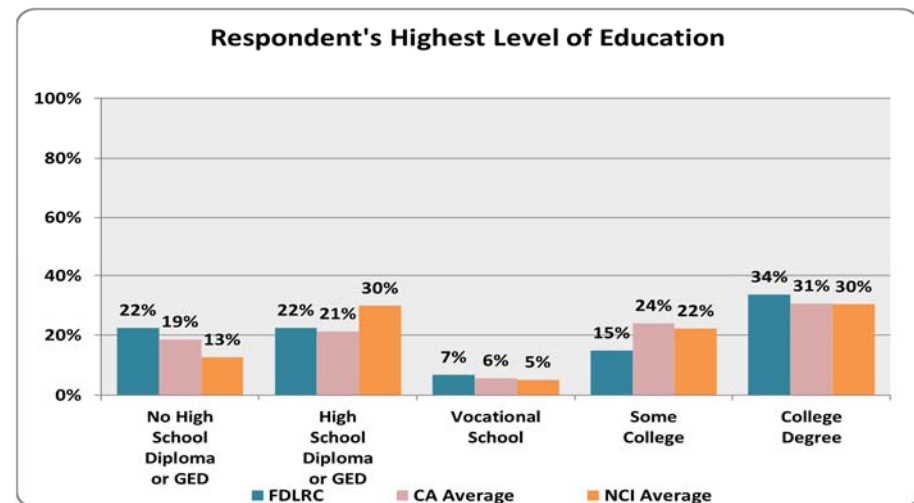
GRAPH 16. RESPONDENT IS PRIMARY CAREGIVER



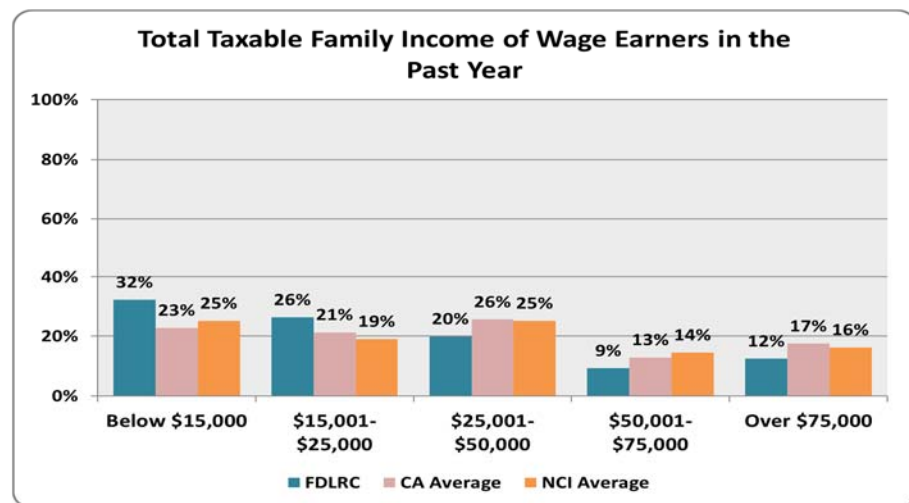
GRAPH 17. NUMBER OF ADULTS IN HOUSEHOLD (NOT INCLUDING FAMILY MEMBER RECEIVING SERVICES)



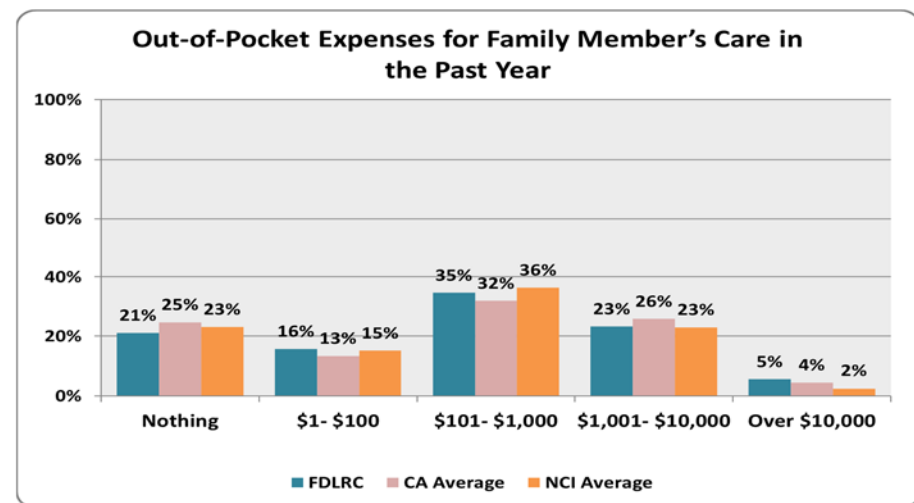
GRAPH 18. RESPONDENT'S HIGHEST LEVEL OF EDUCATION



GRAPH 19. TOTAL TAXABLE FAMILY INCOME OF WAGE EARNERS IN THE PAST YEAR



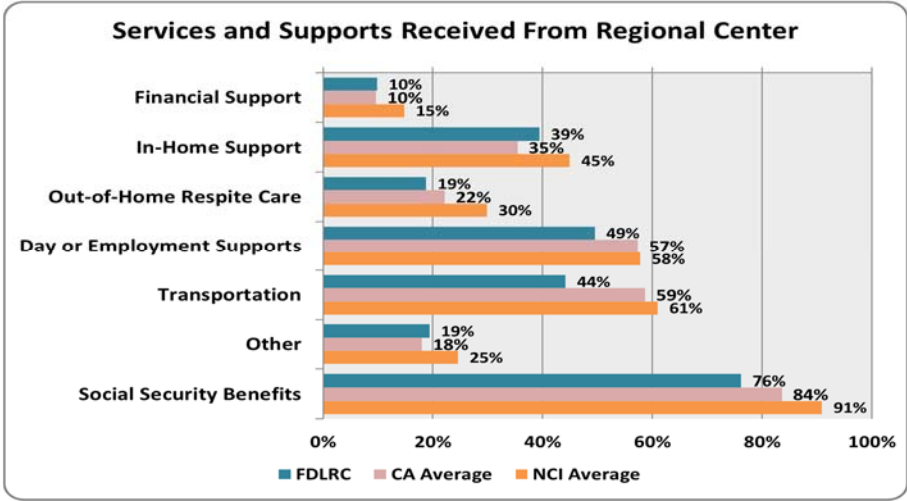
GRAPH 20. OUT-OF-POCKET EXPENSES FOR FAMILY MEMBER'S CARE IN THE PAST YEAR



Services and Supports Received

ILLUSTRATES THE SERVICES AND SUPPORTS RECEIVED BY FAMILIES AND FAMILY MEMBERS

GRAPH 21. SERVICES AND SUPPORTS RECEIVED²

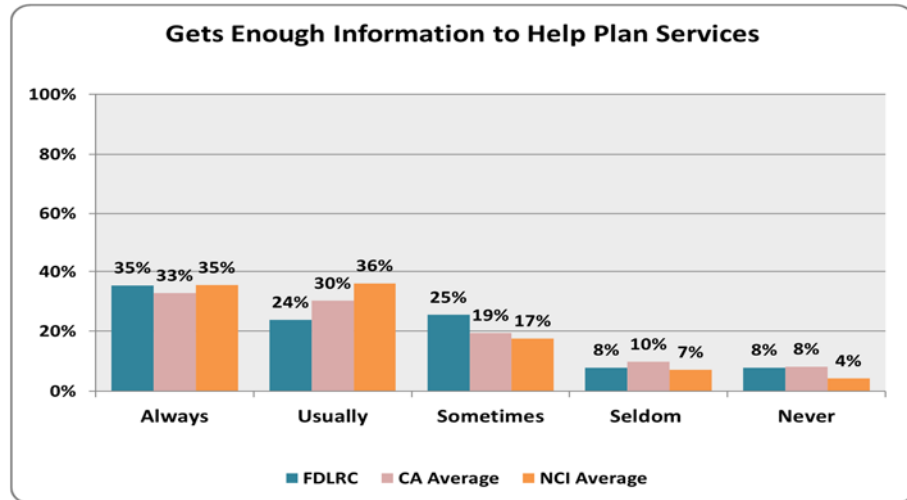


² All services and supports are received from the Regional Center **except** social security benefits.

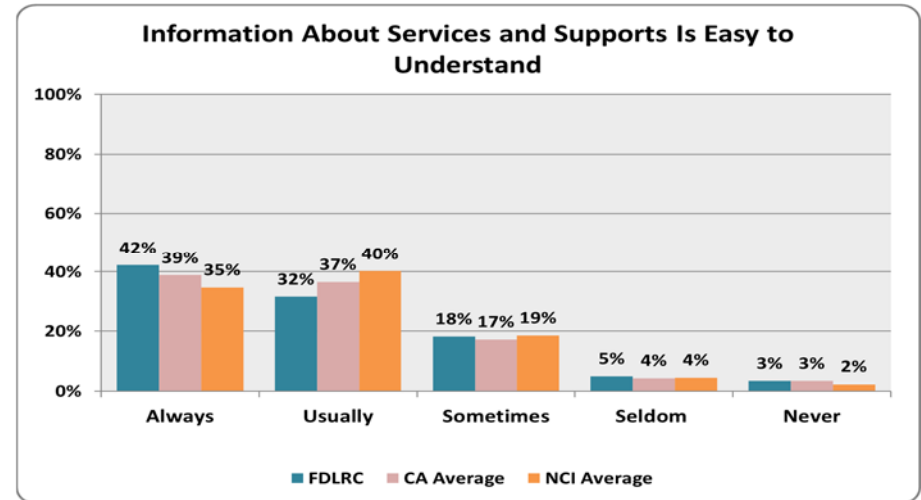
Information and Planning

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

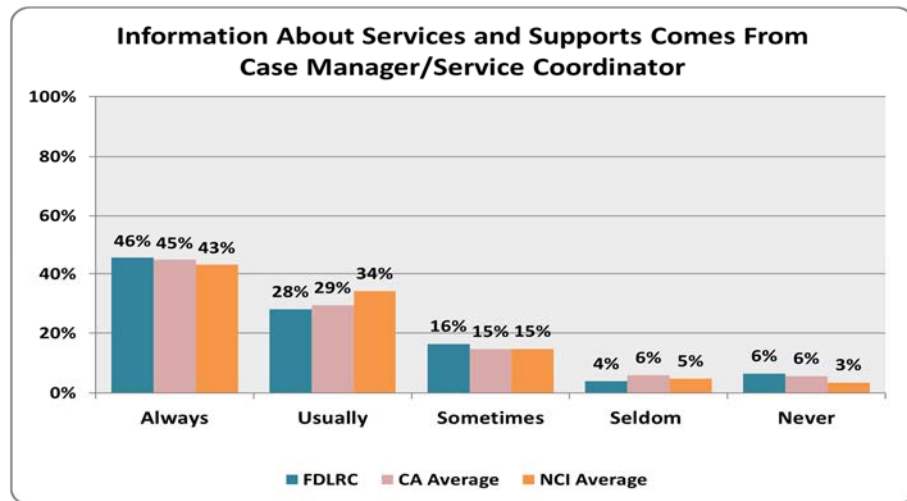
GRAPH 22. DO YOU GET ENOUGH INFORMATION TO HELP YOU PARTICIPATE IN PLANNING SERVICES FOR YOUR FAMILY?



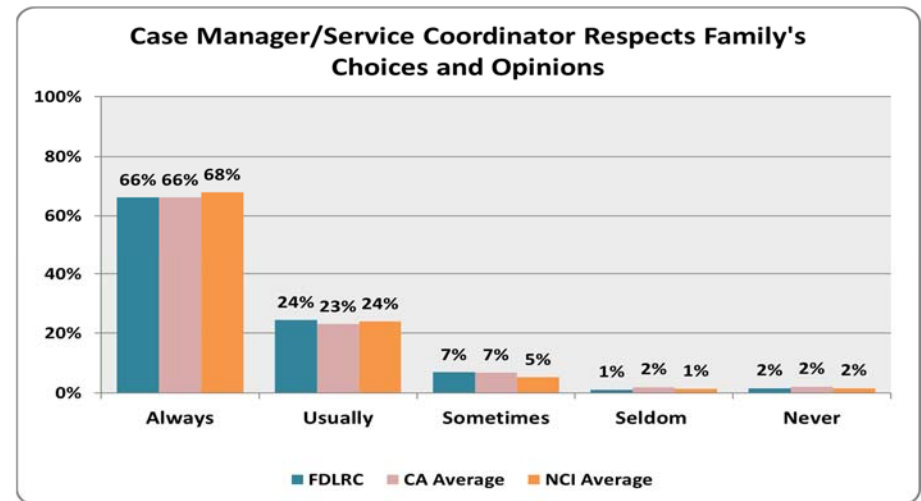
GRAPH 23. IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND?



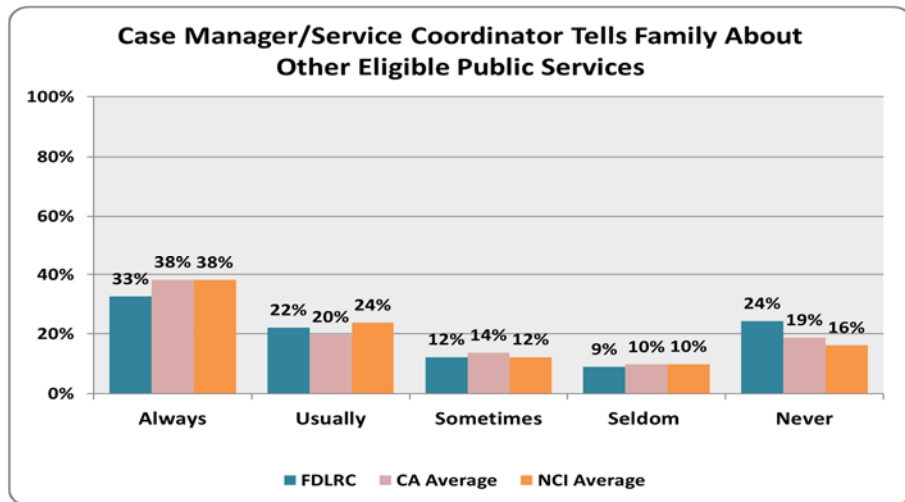
GRAPH 24. DOES THE INFORMATION YOU RECEIVE COME FROM YOUR CASE MANAGER/SERVICE COORDINATOR?



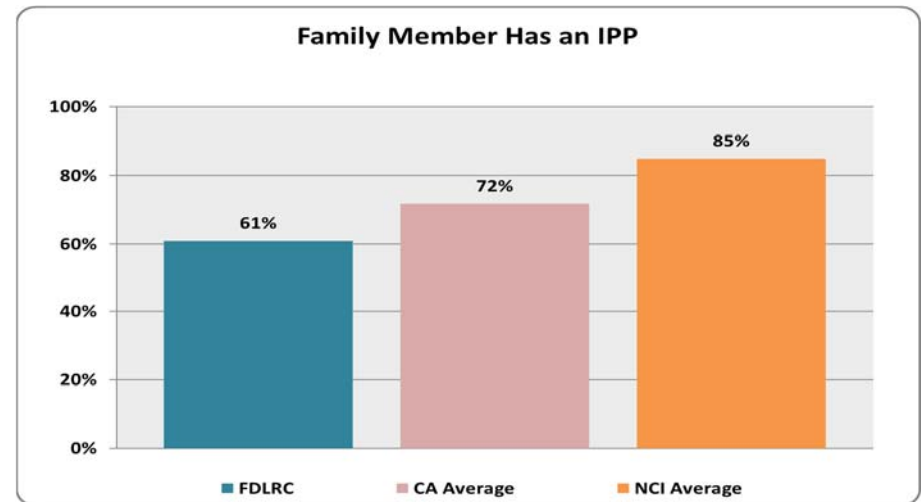
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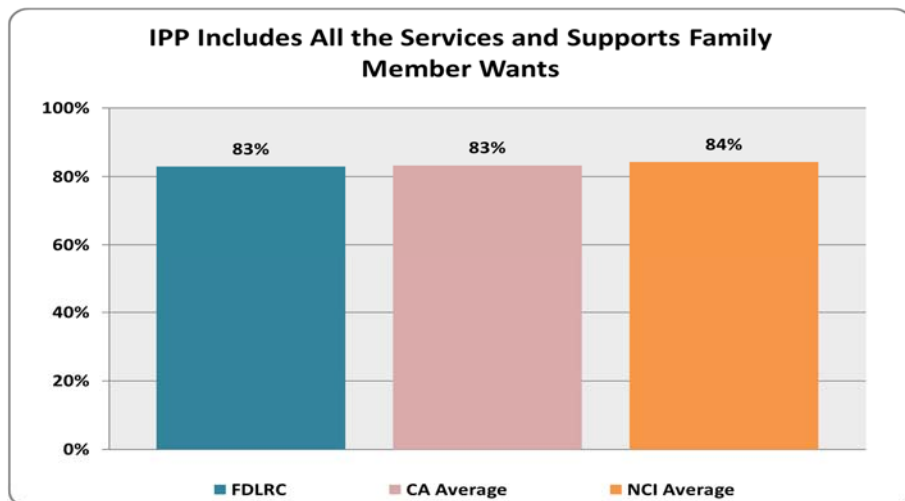
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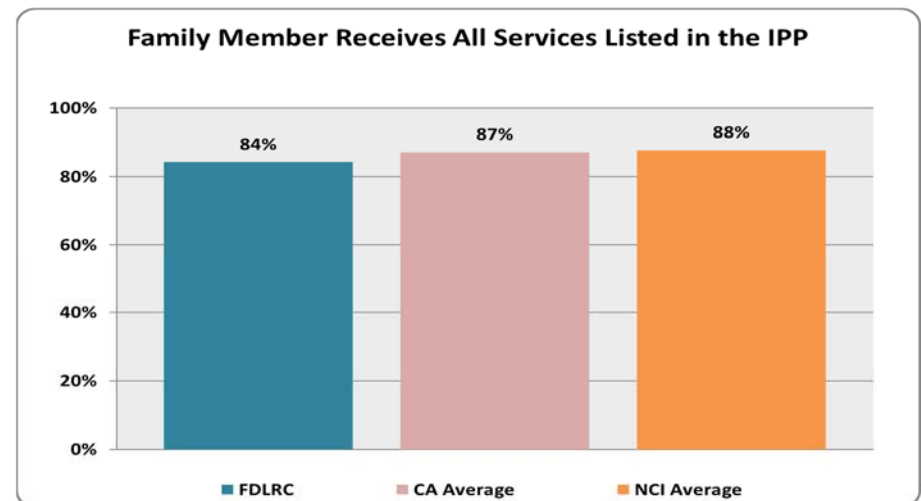
GRAPH 27. DOES YOUR FAMILY MEMBER HAVE AN INDIVIDUAL PROGRAM PLAN (IPP)?



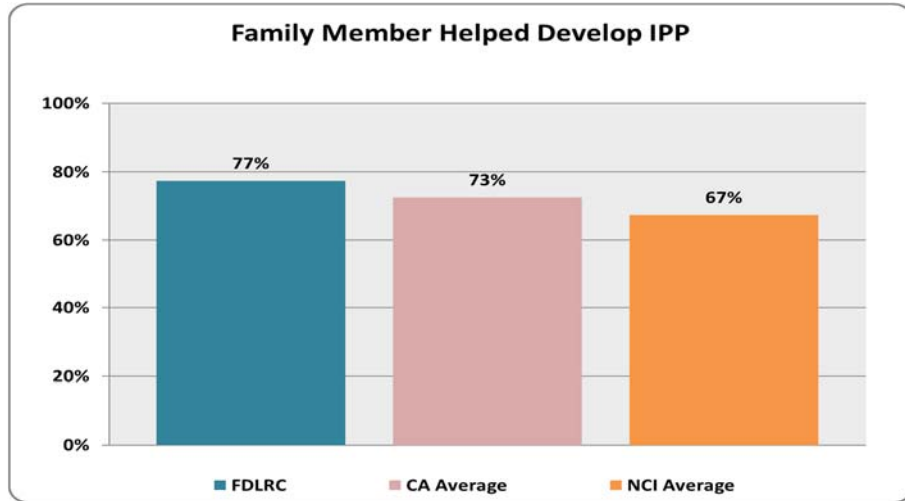
GRAPH 28. DOES THE IPP INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER WANTS?



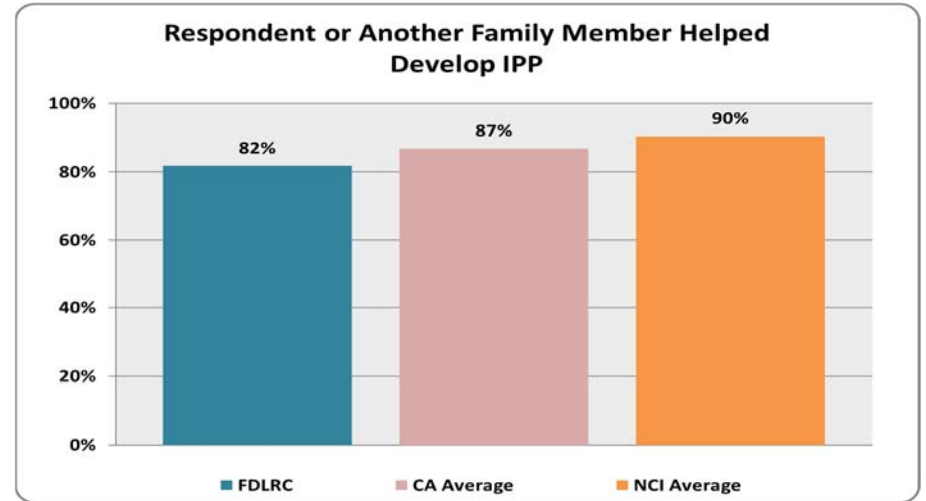
GRAPH 29. DOES YOUR FAMILY MEMBER RECEIVE ALL THE SERVICES LISTED IN THE IPP?



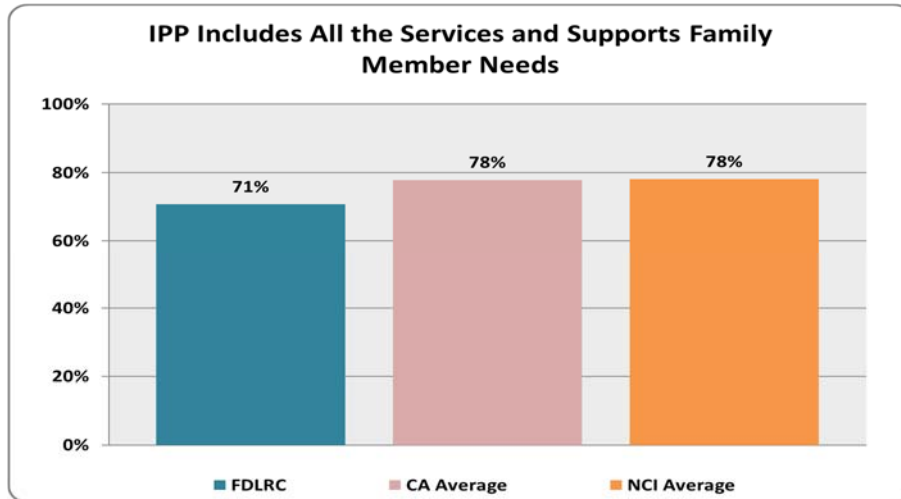
GRAPH 30. DID YOUR FAMILY MEMBER HELP DEVELOP THE IPP?



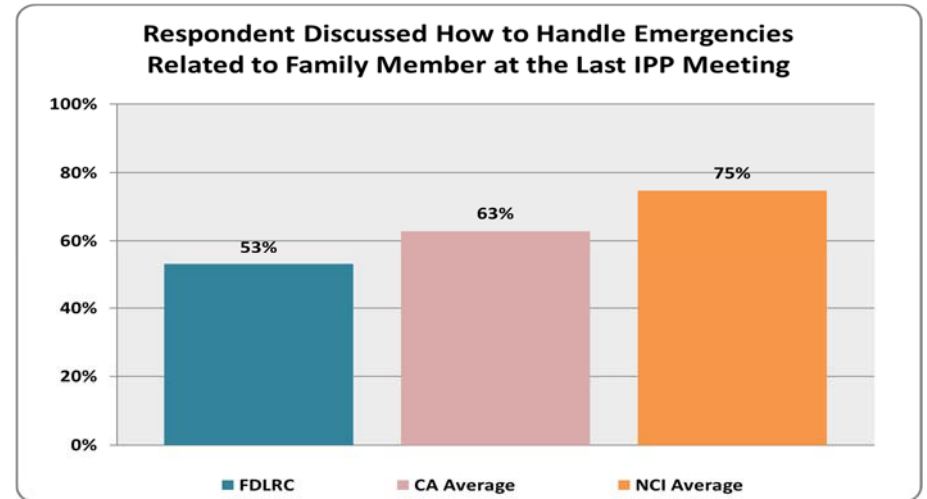
GRAPH 31. DID YOU OR ANOTHER FAMILY MEMBER HELP DEVELOP THE IPP?



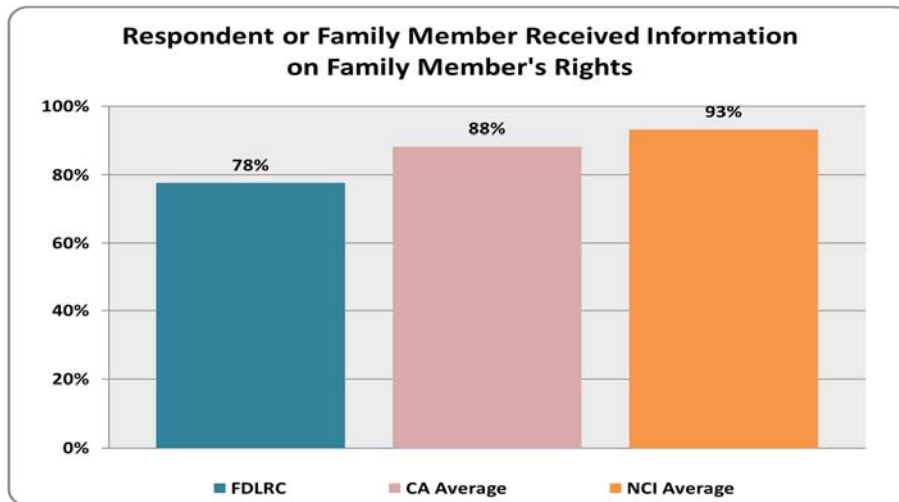
GRAPH 32. DOES THE IPP INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER NEEDS?



GRAPH 33. DID YOU DISCUSS HOW TO HANDLE EMERGENCIES RELATED TO YOUR FAMILY MEMBER AT THE LAST IPP MEETING?



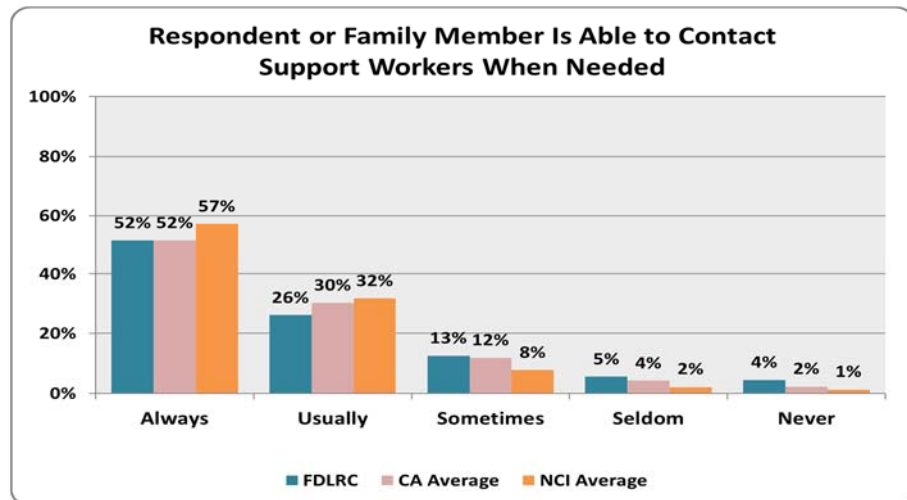
GRAPH 34. HAVE YOU OR YOUR FAMILY MEMBER RECEIVED INFORMATION ABOUT HIS/HER RIGHTS?



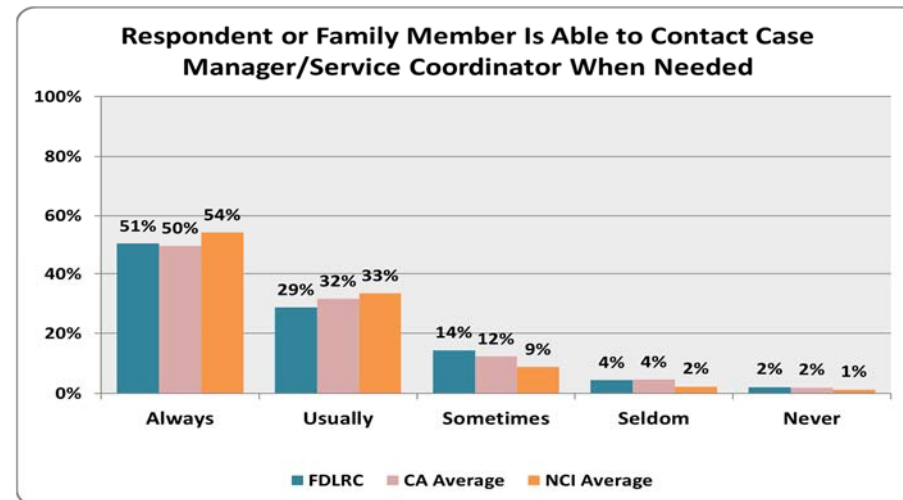
Access and Delivery

PEOPLE MAKE CHOICES ABOUT THEIR LIVES AND ARE ACTIVELY ENGAGED IN PLANNING THEIR SERVICES AND SUPPORTS

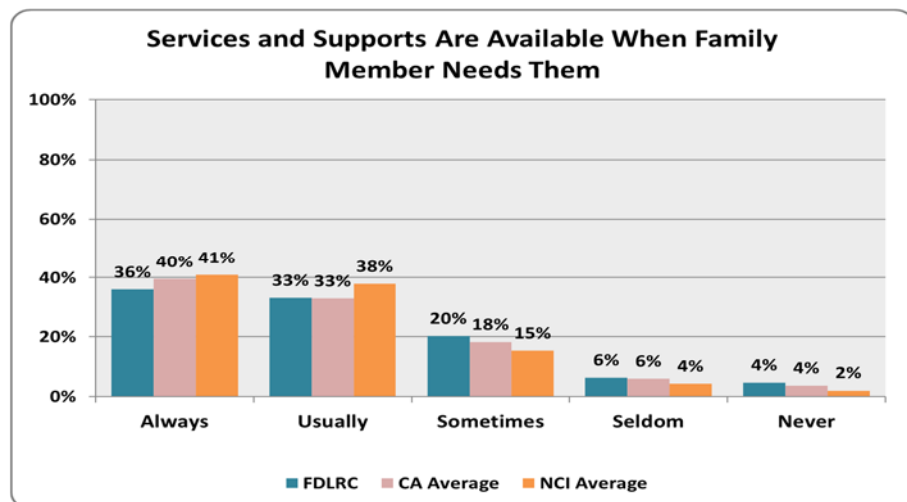
GRAPH 35. ARE YOU OR YOUR FAMILY MEMBER ABLE TO CONTACT HIS/HER SUPPORT WORKERS WHEN YOU NEED TO?



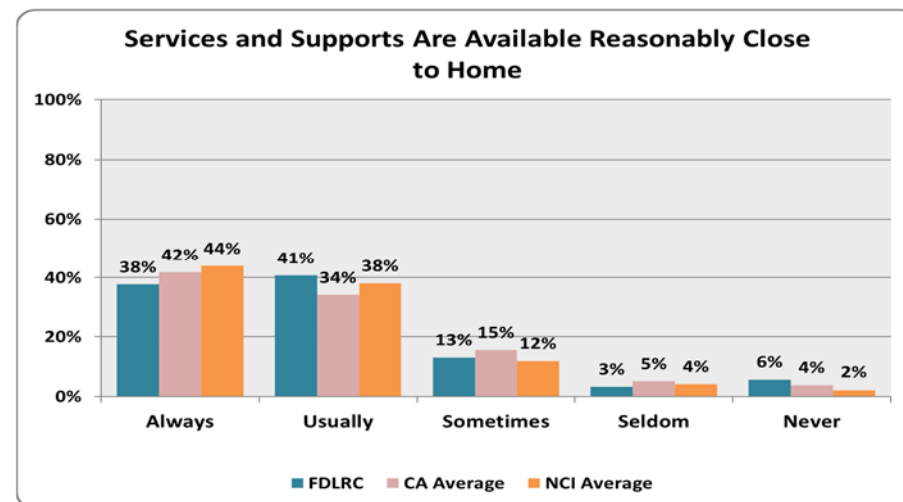
GRAPH 36. ARE YOU OR YOUR FAMILY MEMBER ABLE TO CONTACT HIS/HER CASE MANAGER/SERVICE COORDINATOR WHEN YOU NEED TO?



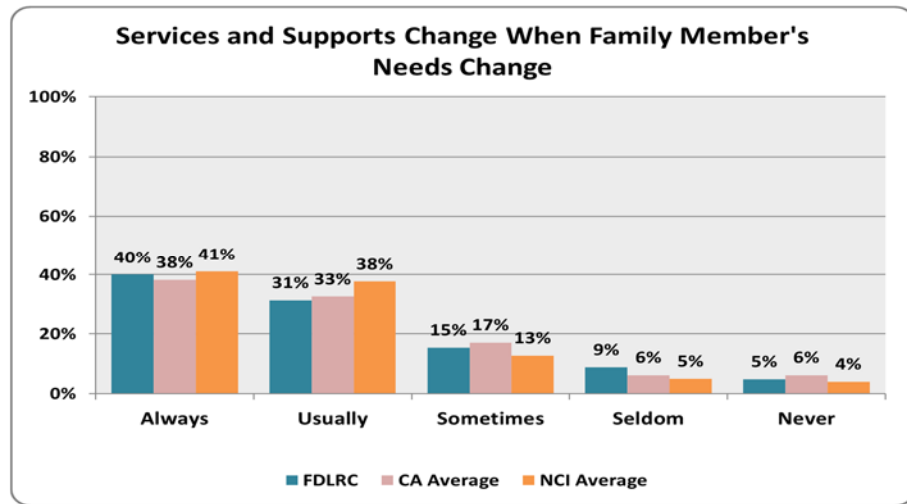
GRAPH 37. ARE SERVICES AND SUPPORTS AVAILABLE WHEN YOUR FAMILY MEMBER NEEDS THEM?



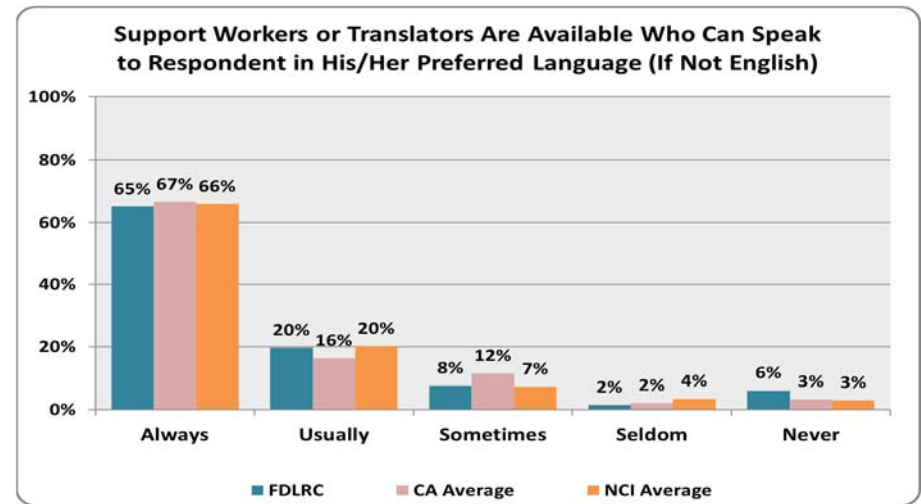
GRAPH 38. ARE SERVICES AND SUPPORTS AVAILABLE WITHIN A REASONABLE DISTANCE FROM YOUR HOME?



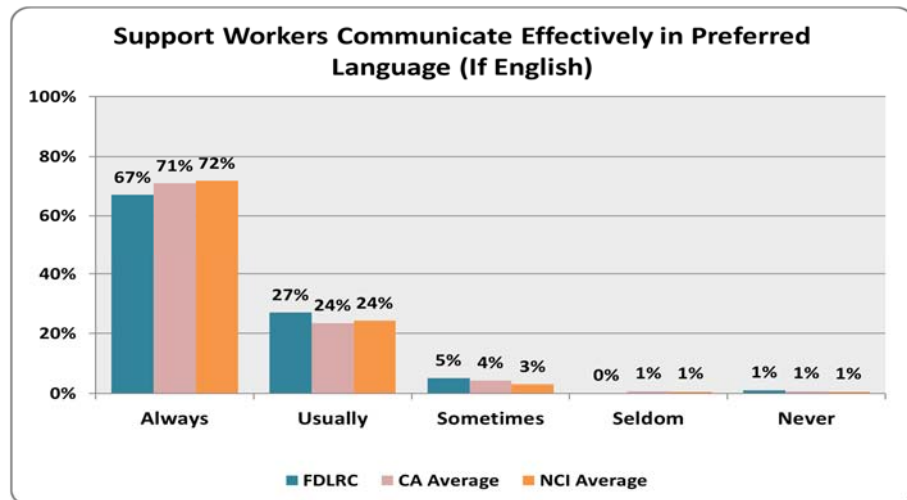
GRAPH 39. DO THE SERVICES AND SUPPORTS CHANGE WHEN YOUR FAMILY MEMBER'S NEEDS CHANGE?



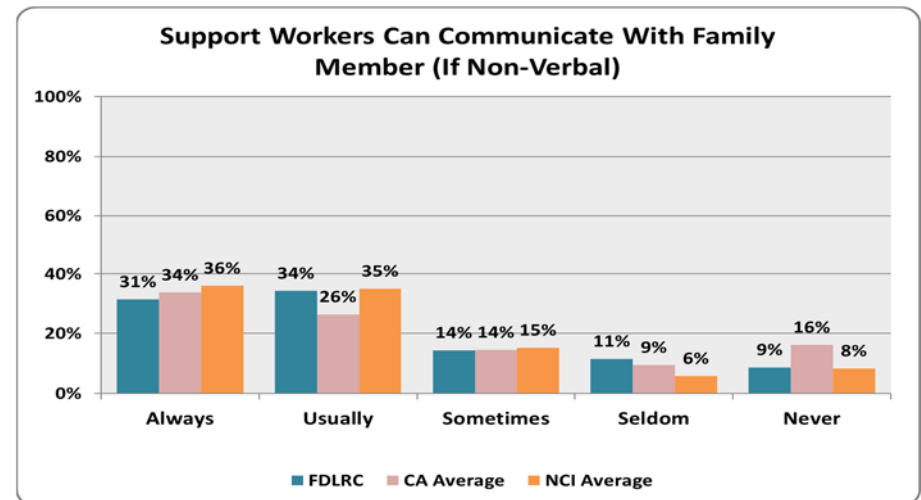
GRAPH 40. IF ENGLISH IS NOT YOUR PREFERRED LANGUAGE, ARE THERE SUPPORT WORKERS OR TRANSLATORS WHO CAN SPEAK TO YOU IN YOUR LANGUAGE?



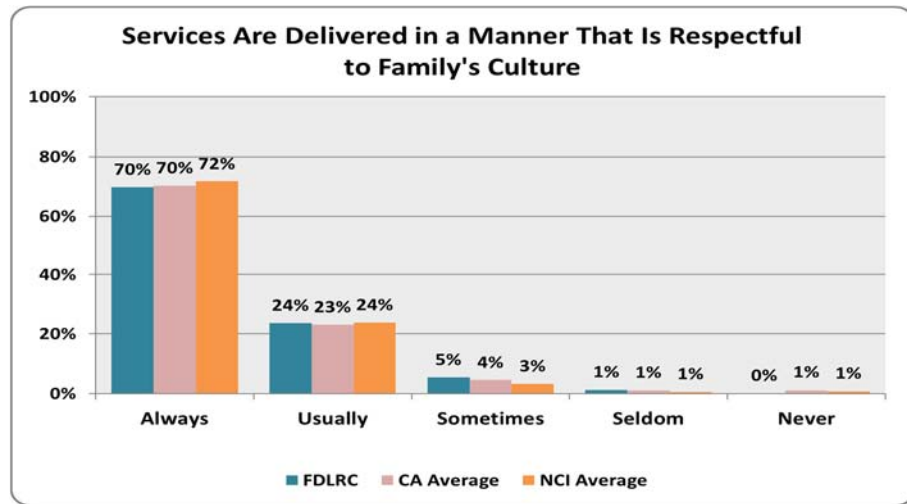
GRAPH 41. IF ENGLISH IS YOUR PREFERRED LANGUAGE, DO SUPPORT WORKERS SPEAK TO YOU EFFECTIVELY?



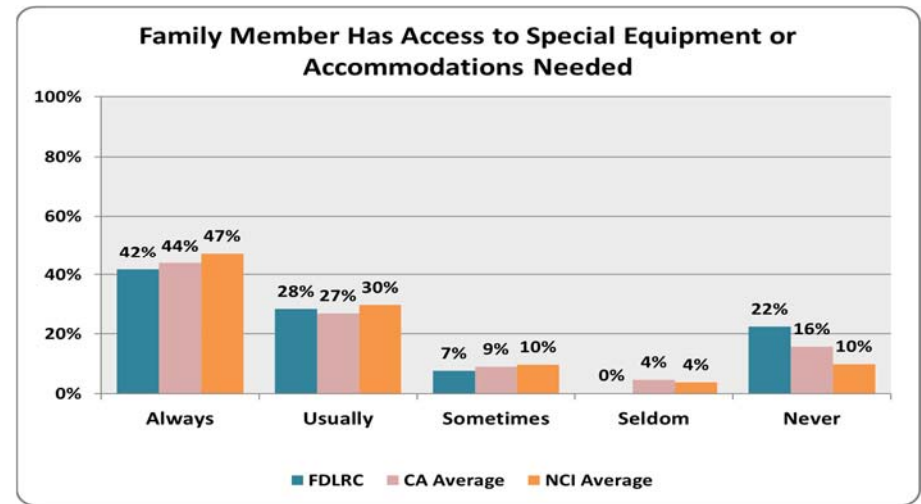
GRAPH 42. IF YOUR FAMILY MEMBER DOES NOT COMMUNICATE VERBALLY (FOR EXAMPLE, USES GESTURES OR SIGN LANGUAGE), ARE THERE SUPPORT WORKERS WHO CAN COMMUNICATE WITH HIM/HER?



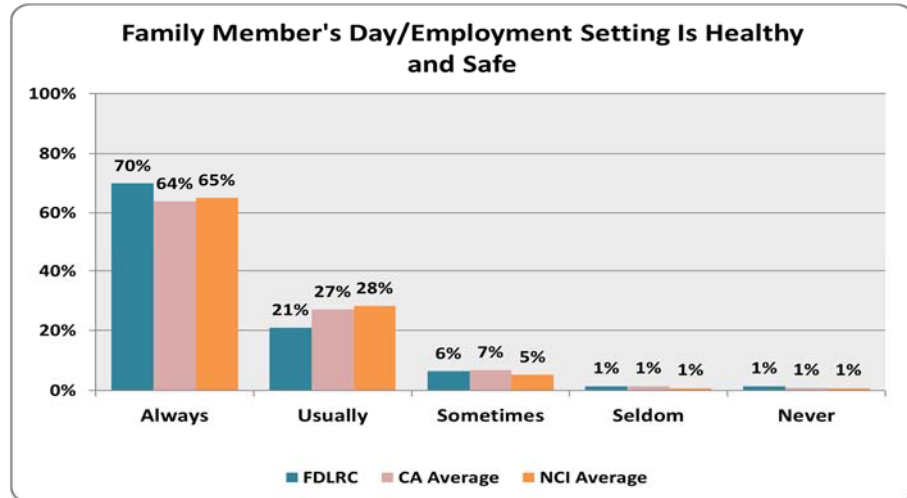
GRAPH 43. ARE SERVICES DELIVERED IN A WAY THAT IS RESPECTFUL TO YOUR FAMILY'S CULTURE?



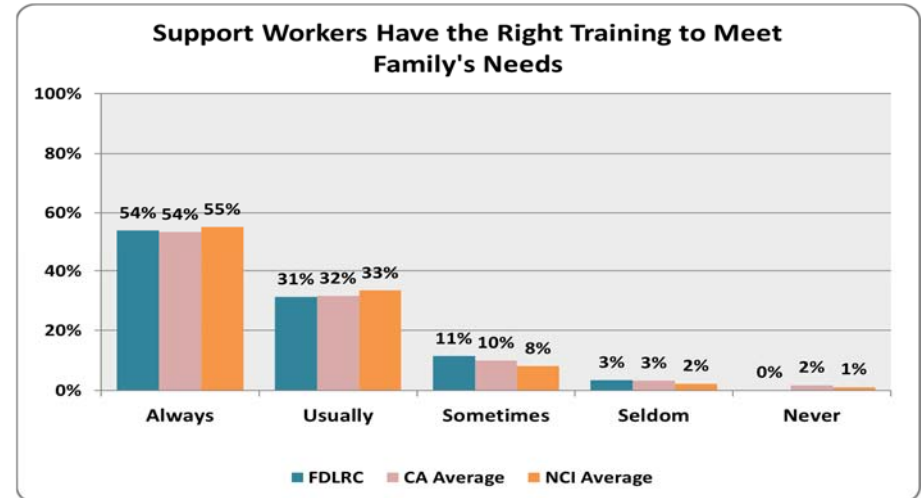
GRAPH 44. DOES YOUR FAMILY MEMBER HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT S/HE NEEDS (FOR EXAMPLE, WHEELCHAIR, RAMP, COMMUNICATION BOARD)?



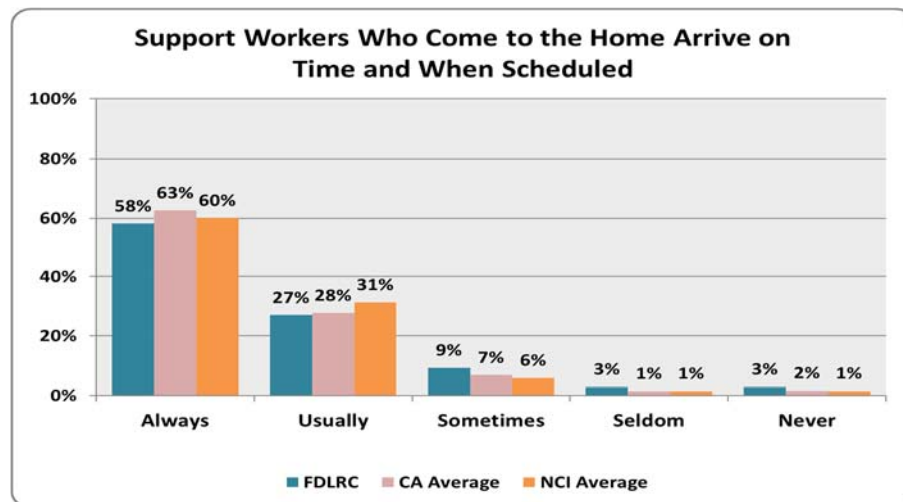
GRAPH 45. DO YOU FEEL THAT YOUR FAMILY MEMBER'S DAY/EMPLOYMENT SETTING IS A HEALTHY AND SAFE ENVIRONMENT?



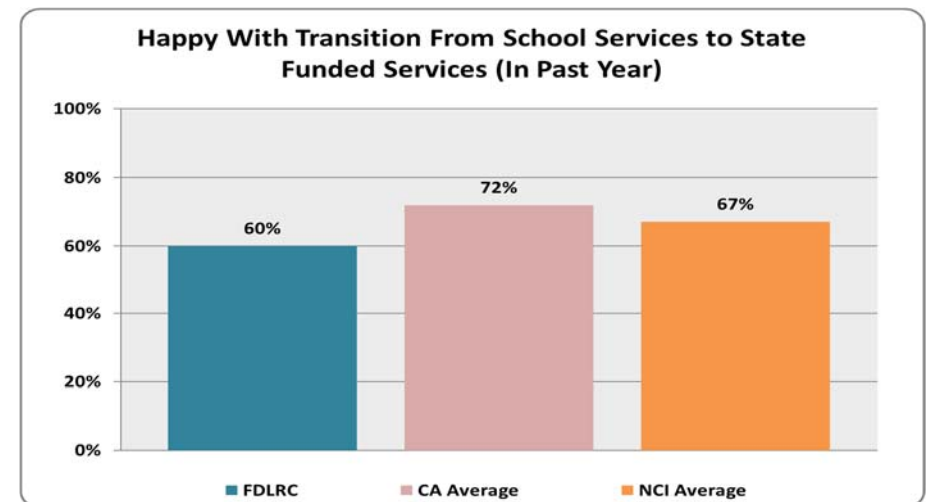
GRAPH 46. DO SUPPORT WORKERS HAVE THE RIGHT TRAINING TO MEET YOUR FAMILY'S NEEDS?



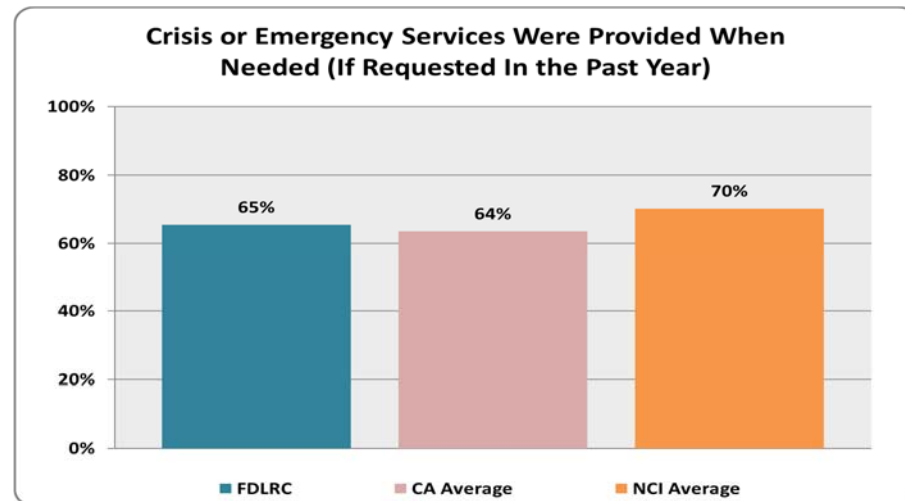
GRAPH 47. DO THE SUPPORT WORKERS WHO COME TO YOUR HOME ARRIVE ON TIME AND WHEN SCHEDULED?



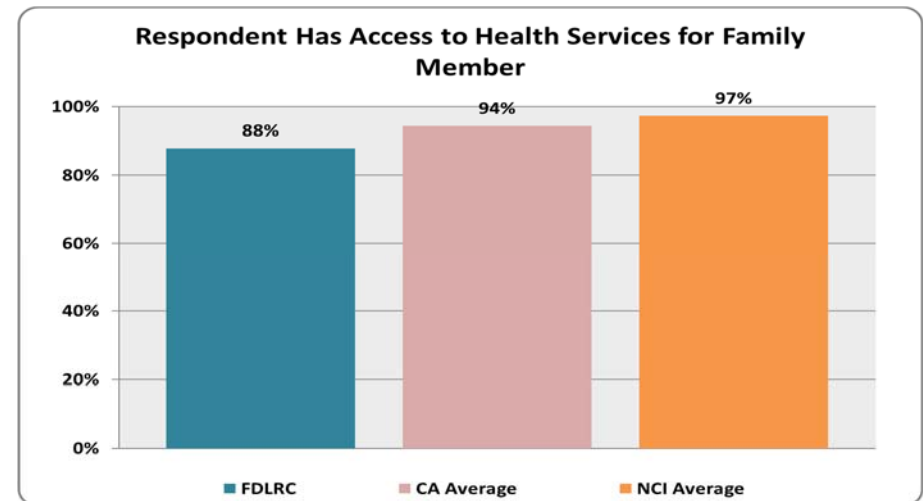
GRAPH 48. IF YOUR FAMILY MEMBER TRANSITIONED FROM SCHOOL SERVICES TO STATE FUNDED SERVICES IN THE PAST YEAR, WERE YOU HAPPY WITH THE TRANSITION PROCESS?



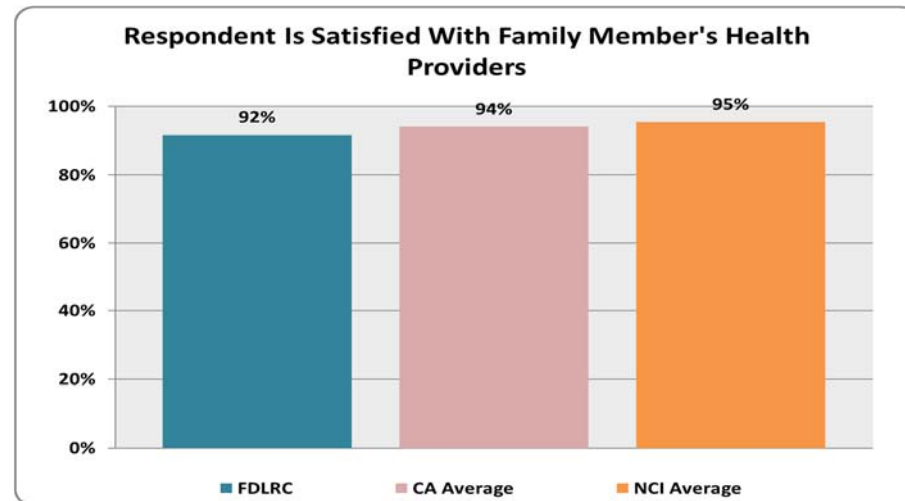
GRAPH 49. IF YOU ASKED FOR CRISIS OR EMERGENCY SERVICES IN THE PAST YEAR, WERE SERVICES PROVIDED WHEN NEEDED?



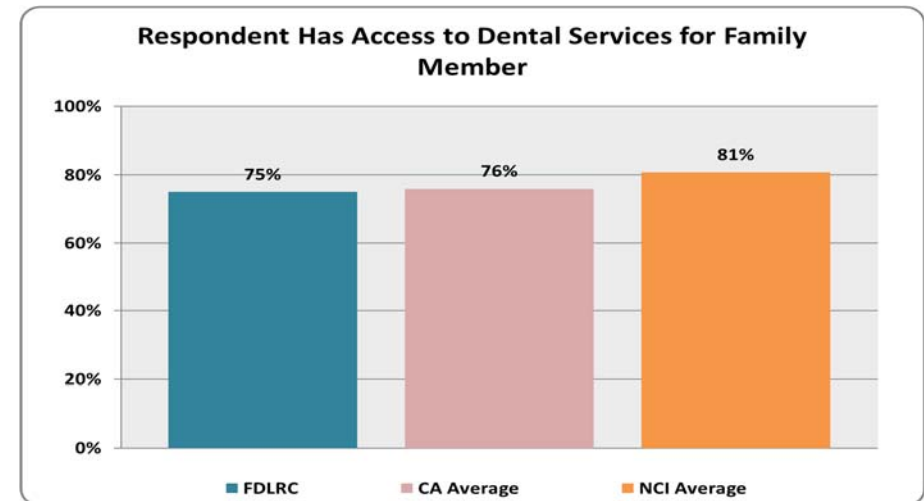
GRAPH 50. DO YOU HAVE ACCESS TO HEALTH SERVICES FOR YOUR FAMILY MEMBER?



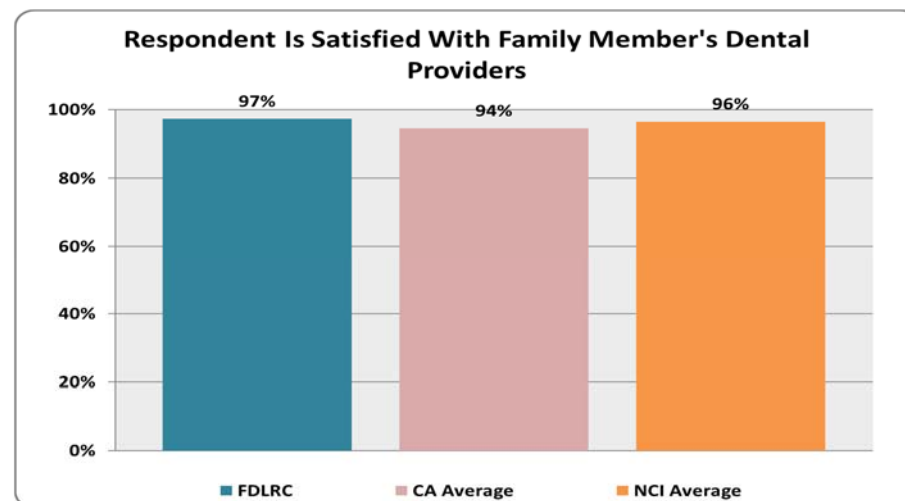
GRAPH 51. IF YOU HAVE ACCESS TO HEALTH SERVICES FOR YOUR FAMILY MEMBER, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



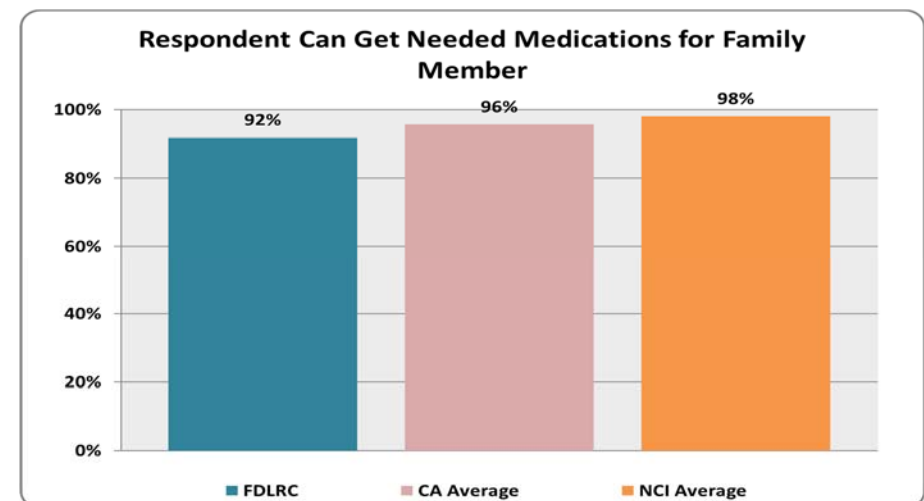
GRAPH 52. DO YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR FAMILY MEMBER?



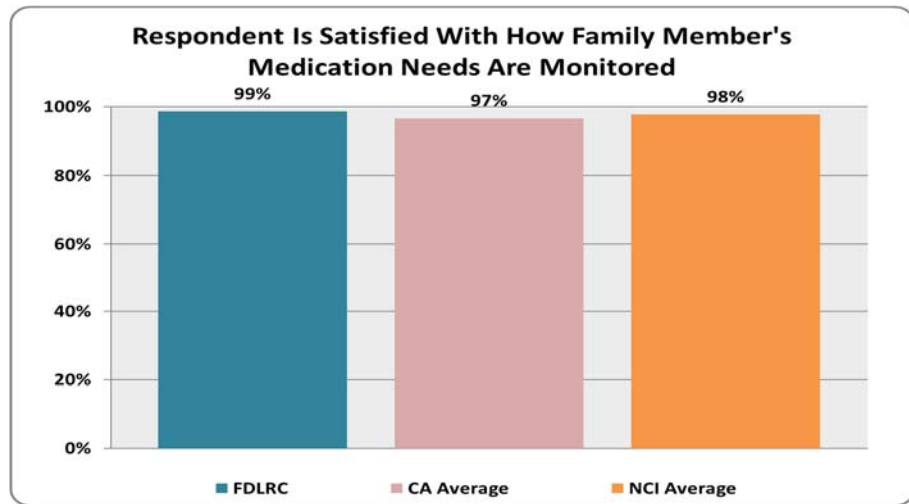
GRAPH 53. IF YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR FAMILY MEMBER, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



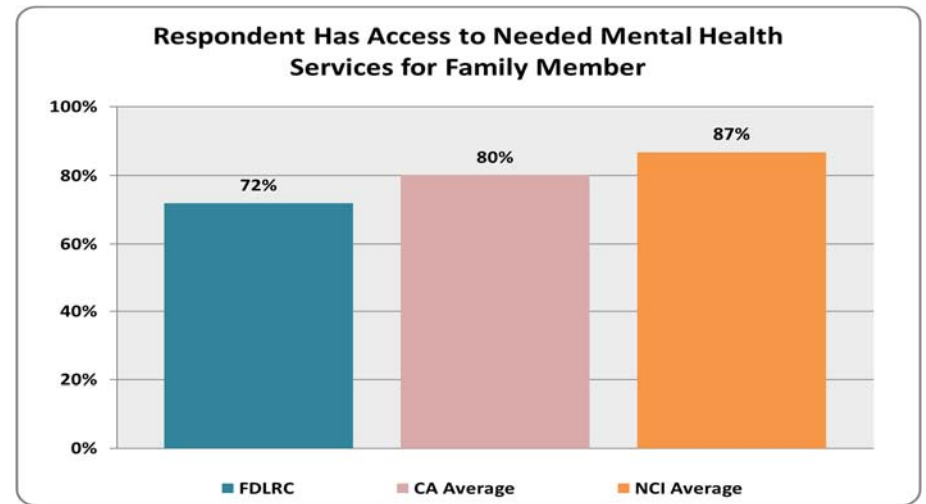
GRAPH 54. ARE YOU ABLE TO GET MEDICATIONS NEEDED FOR YOUR FAMILY MEMBER?



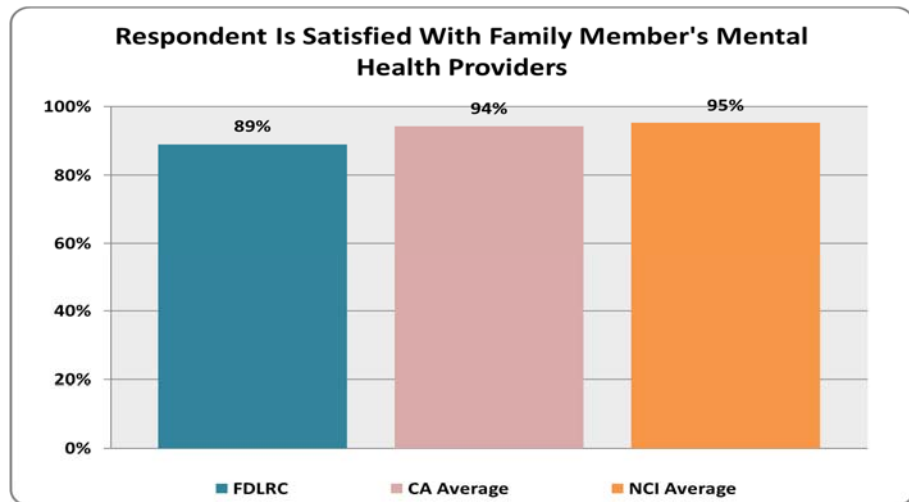
GRAPH 55. IF YOU ARE ABLE TO GET MEDICATIONS NEEDED FOR YOUR FAMILY MEMBER, ARE YOU SATISFIED WITH HOW YOUR FAMILY MEMBER'S MEDICATION NEEDS ARE MONITORED?



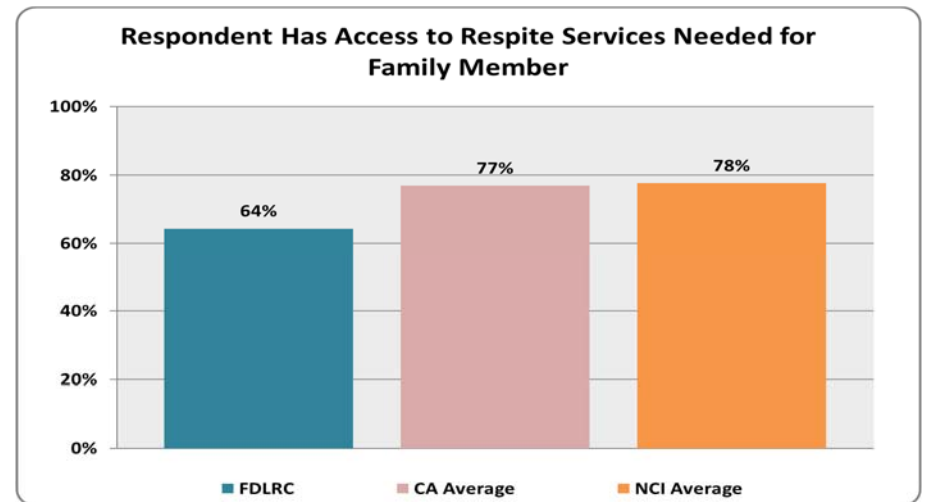
GRAPH 56. IF NEEDED, DO YOU HAVE ACCESS TO MENTAL HEALTH SERVICES FOR YOUR FAMILY MEMBER?



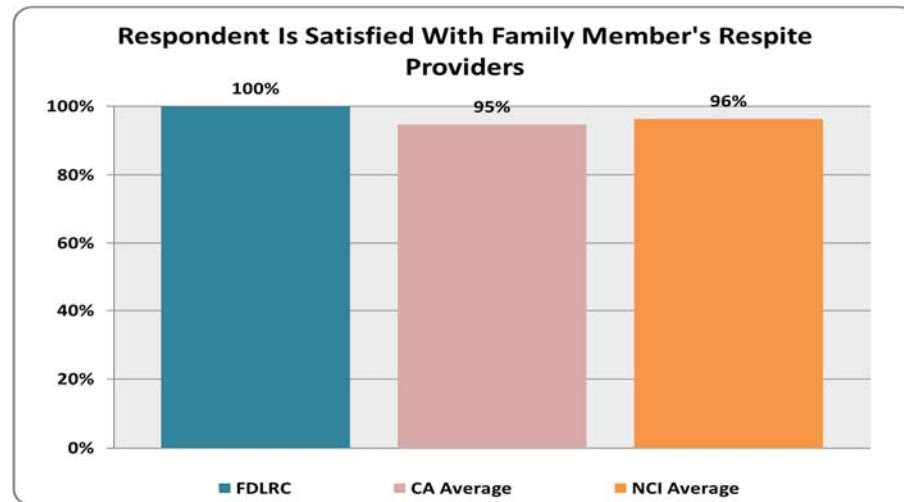
GRAPH 57. IF YOU HAVE ACCESS TO MENTAL HEALTH SERVICES NEEDED FOR YOUR FAMILY MEMBER, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



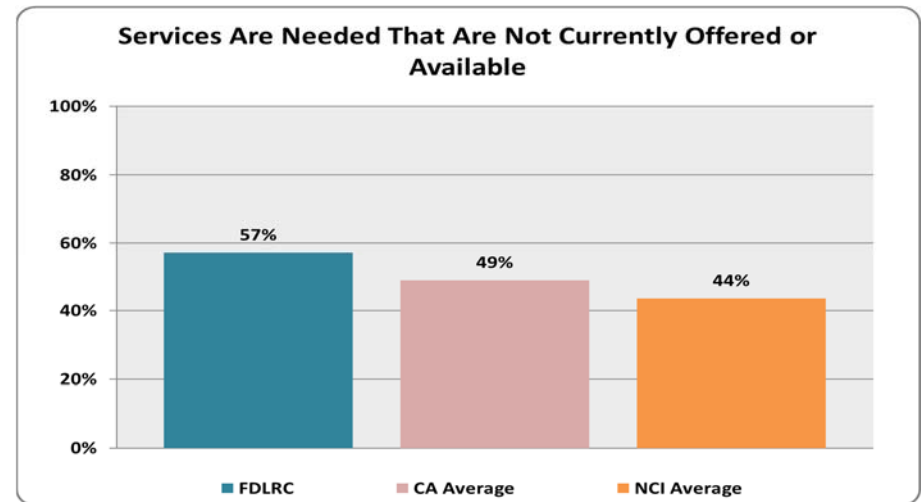
GRAPH 58. IF YOU NEED RESPITE SERVICES, DO YOU HAVE ACCESS TO THEM?



GRAPH 59. IF YOU HAVE ACCESS TO RESPITE SERVICES NEEDED, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



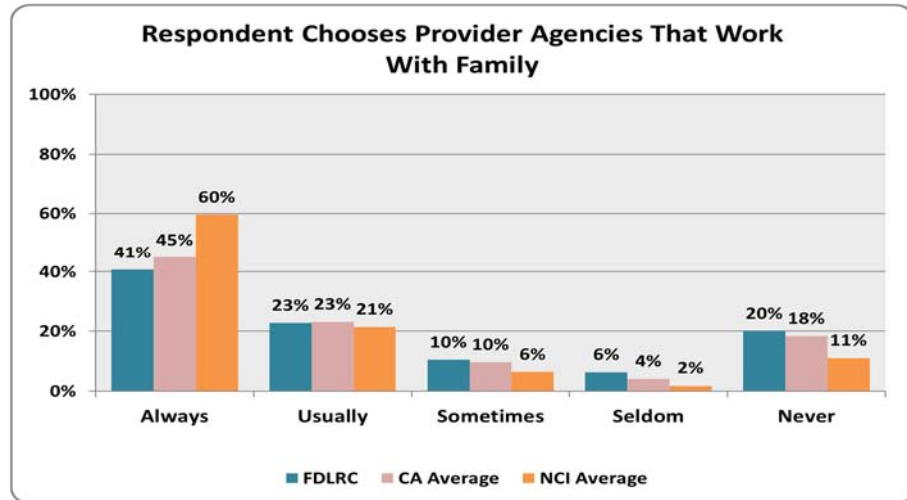
GRAPH 60. ARE THERE SERVICES YOUR FAMILY MEMBER NEEDS THAT ARE NOT CURRENTLY OFFERED OR AVAILABLE?



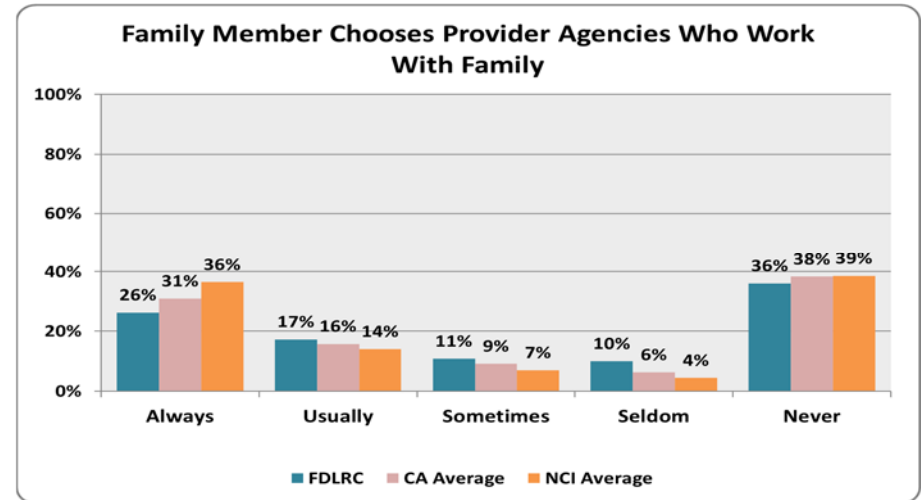
Choice and Control

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

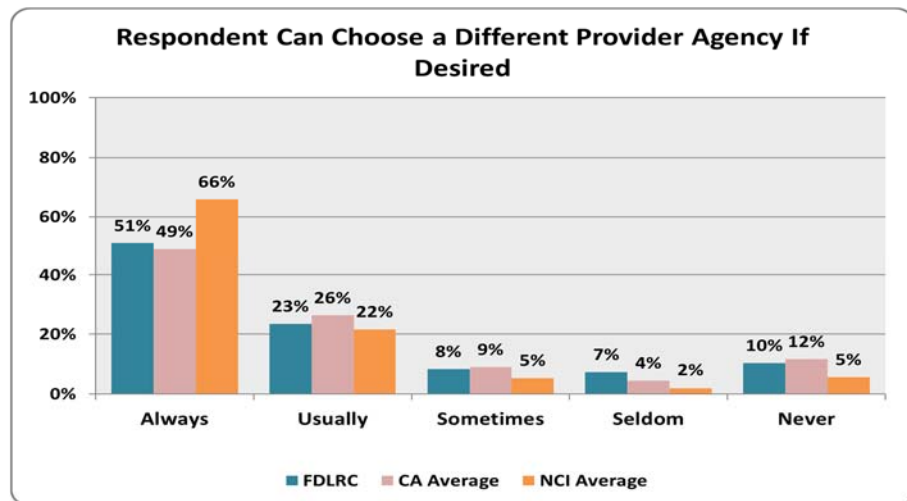
GRAPH 61. DO YOU CHOOSE THE PROVIDER AGENCIES WHO WORK WITH YOUR FAMILY?



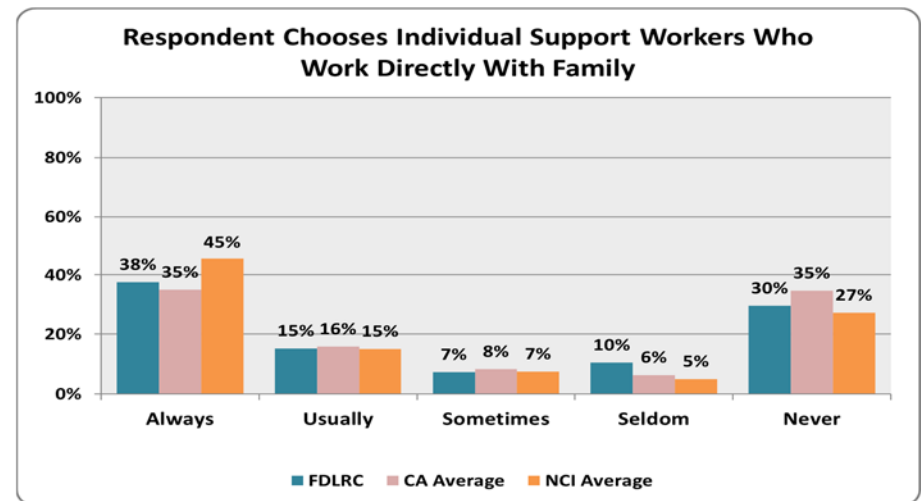
GRAPH 62. DOES YOUR FAMILY MEMBER CHOOSE THE PROVIDER AGENCIES WHO WORK WITH YOUR FAMILY?



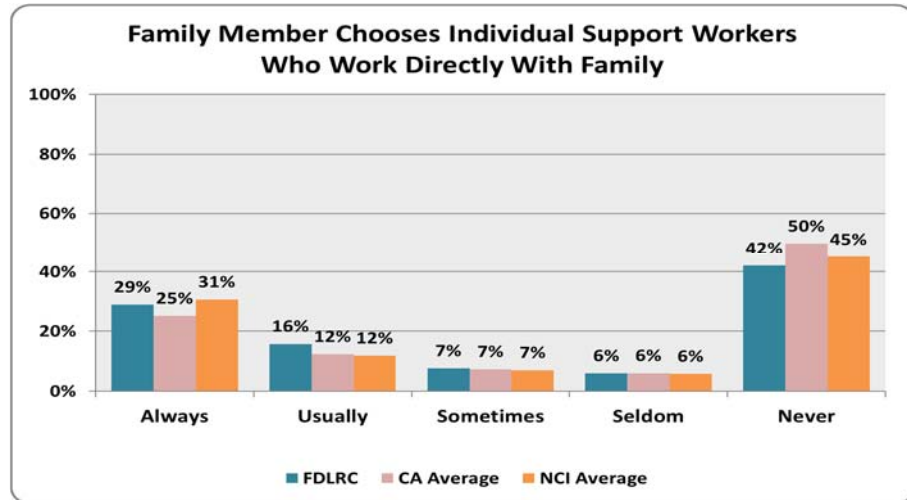
GRAPH 63. CAN YOU CHOOSE A DIFFERENT PROVIDER AGENCY IF YOU WANT TO?



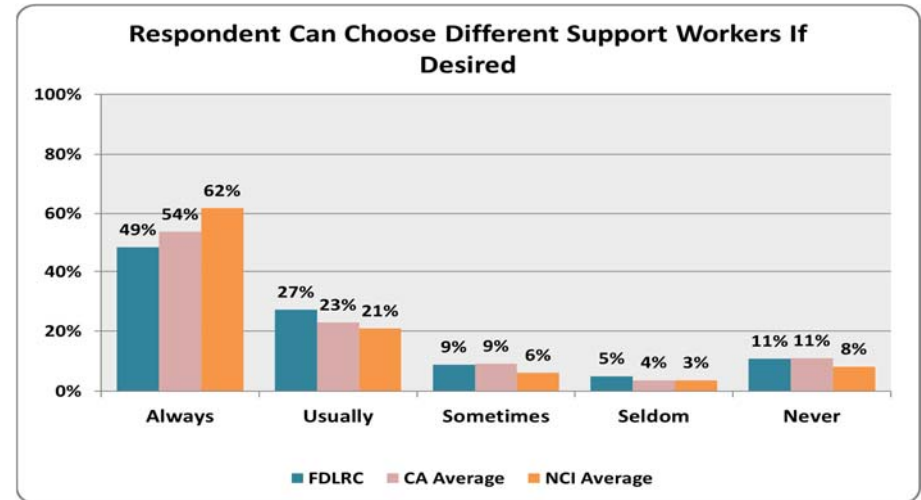
GRAPH 64. DO YOU CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH YOUR FAMILY?



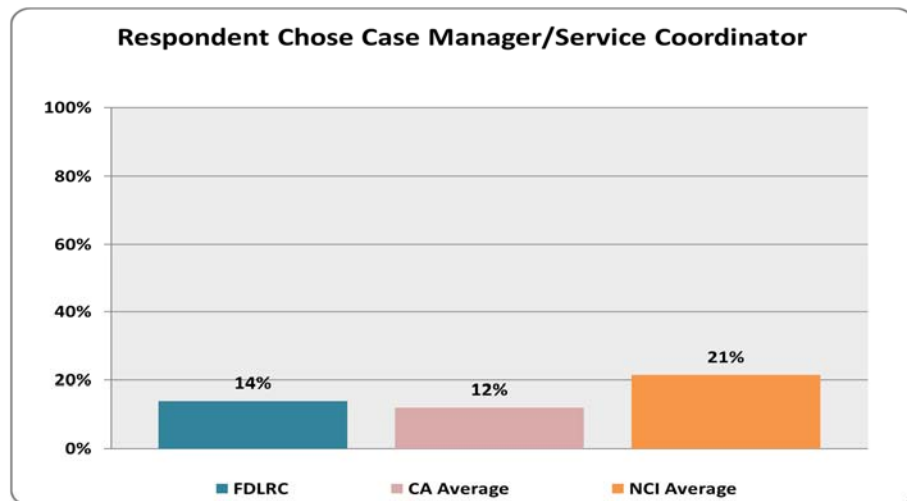
GRAPH 65. DOES YOUR FAMILY MEMBER CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH YOUR FAMILY?



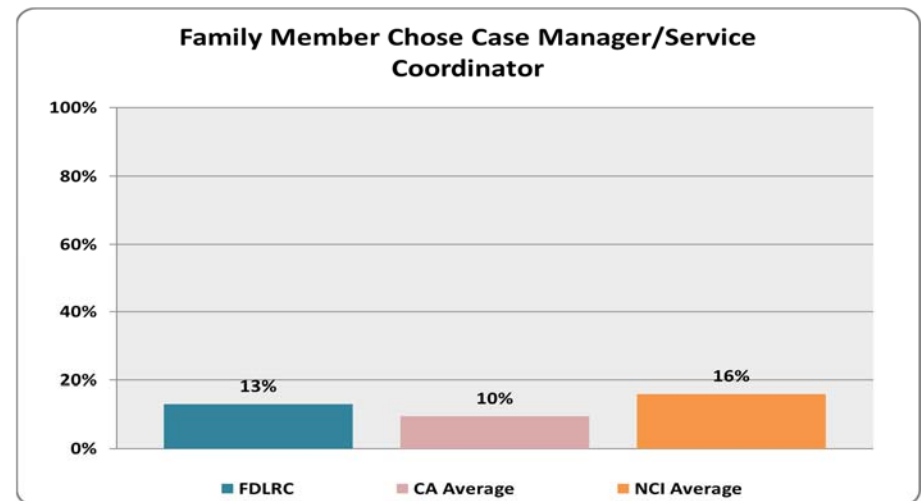
GRAPH 66. CAN YOU CHOOSE DIFFERENT SUPPORT WORKERS IF YOU WANT TO?



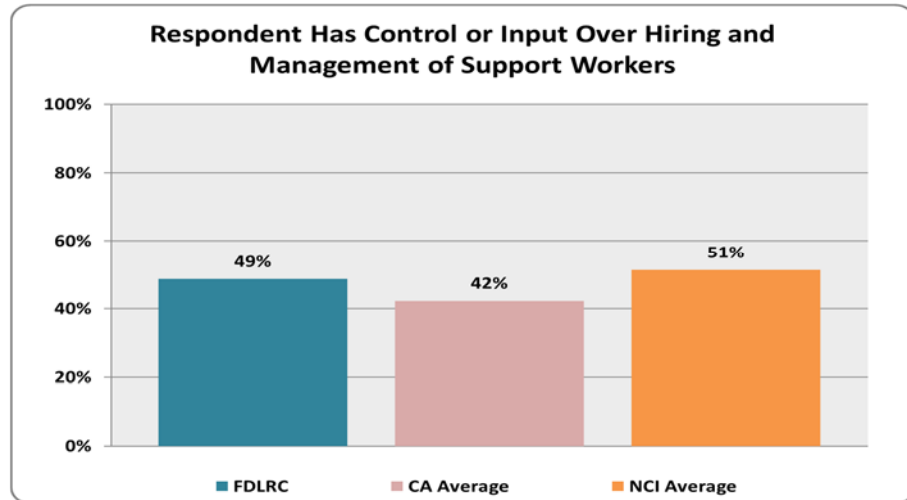
GRAPH 67. DID YOU CHOOSE YOUR FAMILY MEMBER'S CASE MANAGER/SERVICE COORDINATOR?



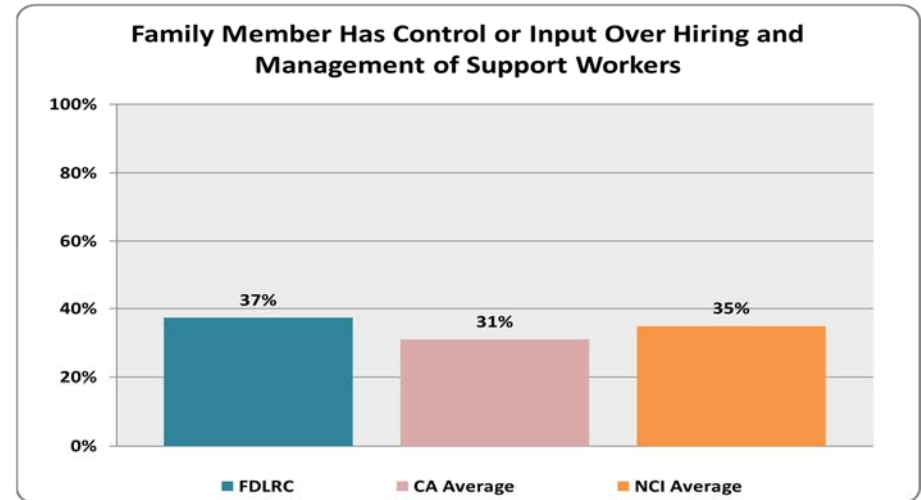
GRAPH 68. DID YOUR FAMILY MEMBER CHOOSE HIS/HER CASE MANAGER/SERVICE COORDINATOR?



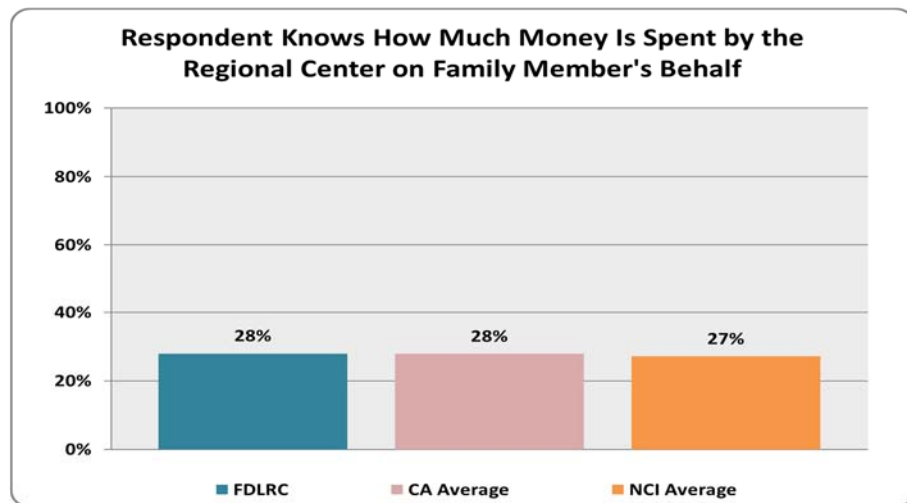
GRAPH 69. DO YOU HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF YOUR FAMILY MEMBER'S SUPPORT WORKERS?



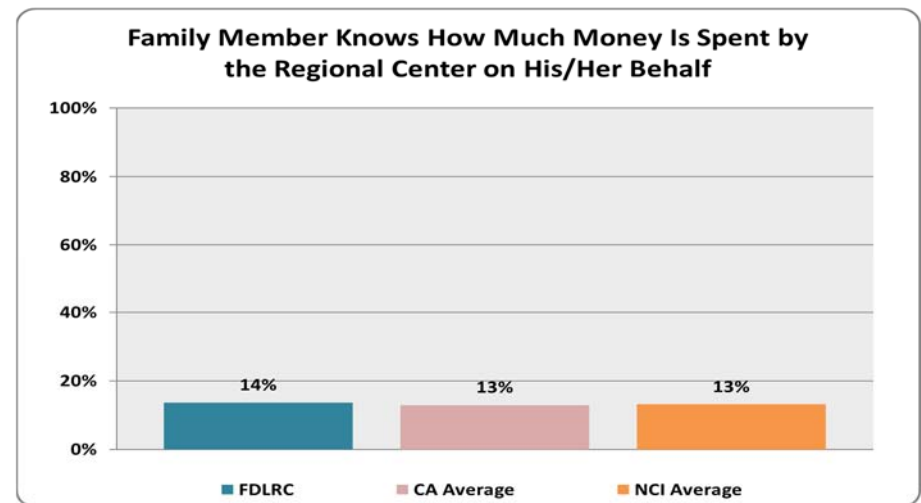
GRAPH 70. DOES YOUR FAMILY MEMBER HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF HIS/HER SUPPORT WORKERS?



GRAPH 71. DO YOU KNOW HOW MUCH MONEY IS SPENT BY THE REGIONAL CENTER ON BEHALF OF YOUR FAMILY MEMBER WITH A DEVELOPMENTAL DISABILITY?*

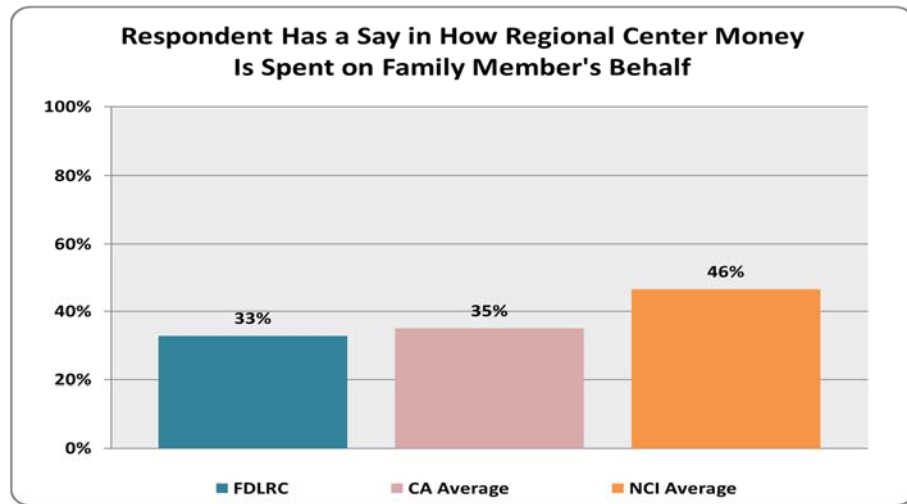


GRAPH 72. DOES YOUR FAMILY MEMBER KNOW HOW MUCH MONEY IS SPENT BY THE REGIONAL CENTER ON HIS/HER BEHALF?*

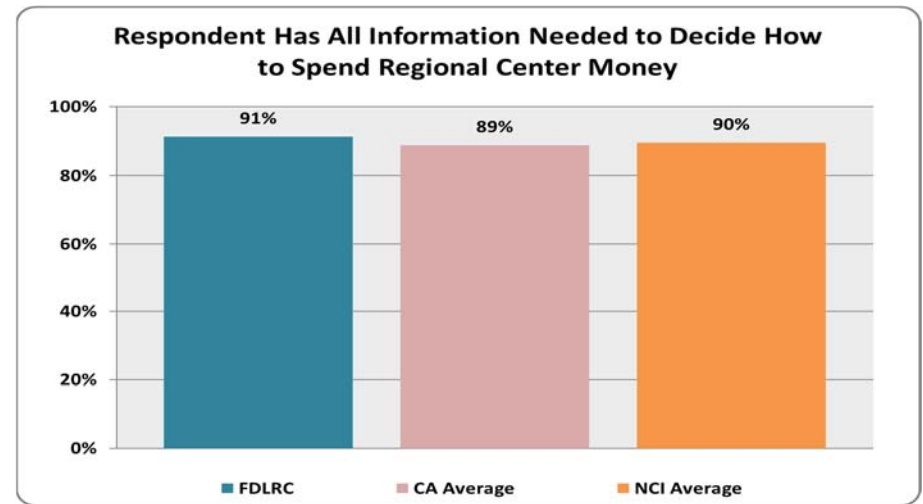


*'Don't Know' responses were included in 'No' responses for this question.

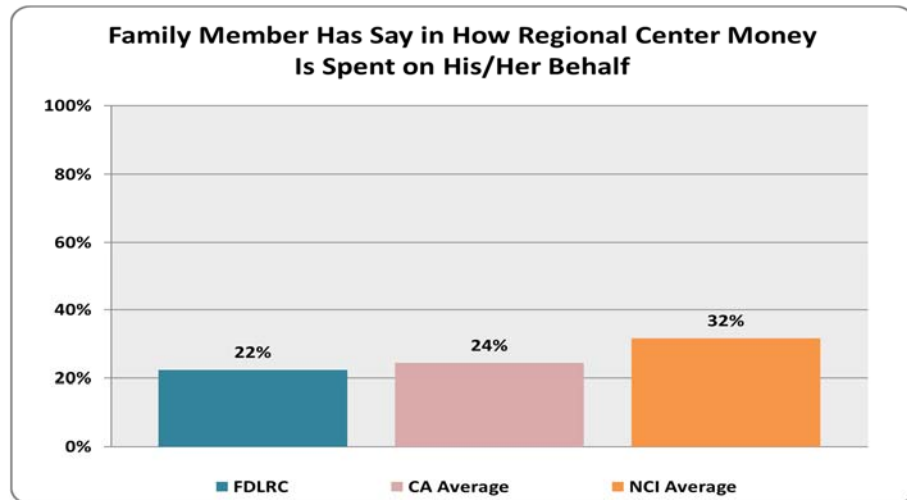
GRAPH 73. DO YOU HAVE A SAY IN HOW REGIONAL CENTER MONEY IS SPENT ON YOUR FAMILY MEMBER'S BEHALF?



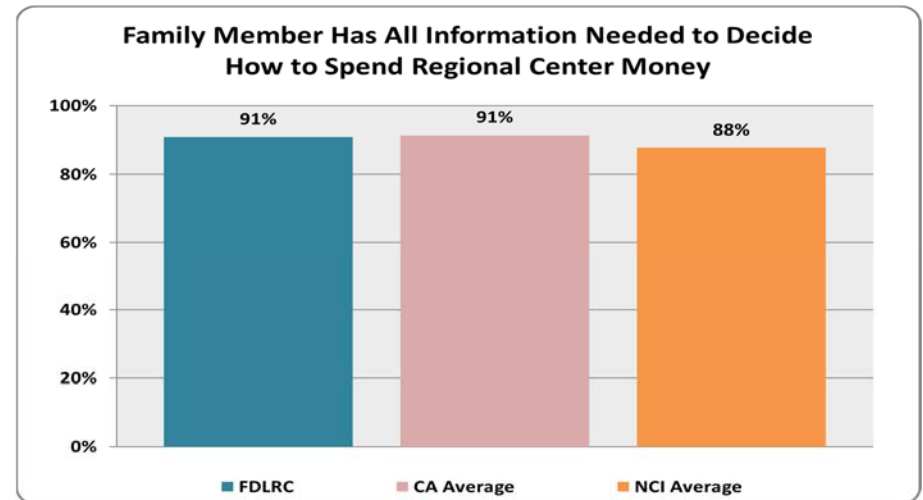
GRAPH 74. IF YOU HAVE A SAY IN HOW REGIONAL CENTER MONEY IS SPENT, DO YOU HAVE ALL THE INFORMATION YOU NEED TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?



GRAPH 75. DOES YOUR FAMILY MEMBER HAVE A SAY IN HOW REGIONAL CENTER MONEY IS SPENT ON HIS/HER BEHALF?



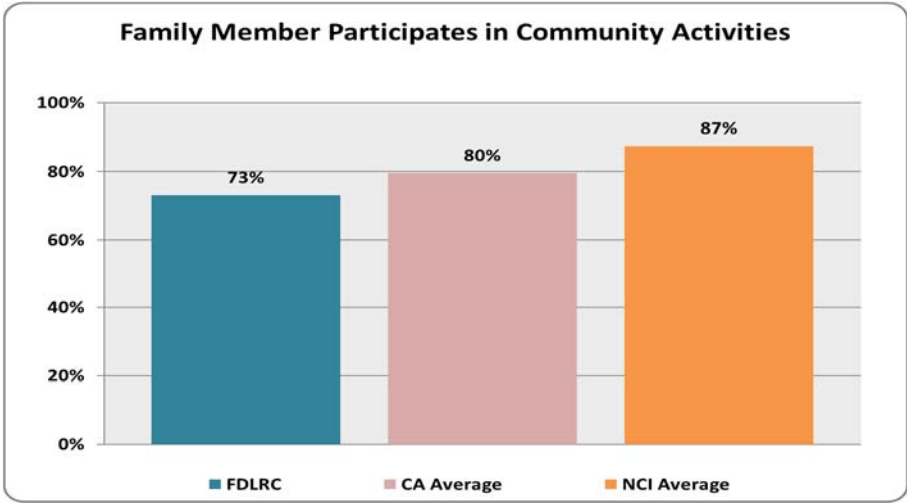
GRAPH 76. IF YOUR FAMILY MEMBER HAS A SAY IN HOW REGIONAL CENTER MONEY IS SPENT, DOES YOUR FAMILY MEMBER HAVE ALL THE INFORMATION S/HE NEEDS TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?



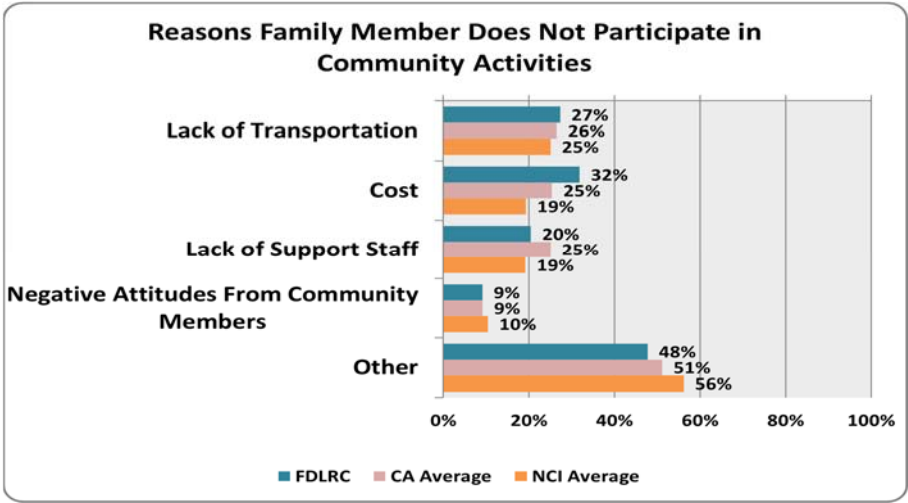
Community Connections

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

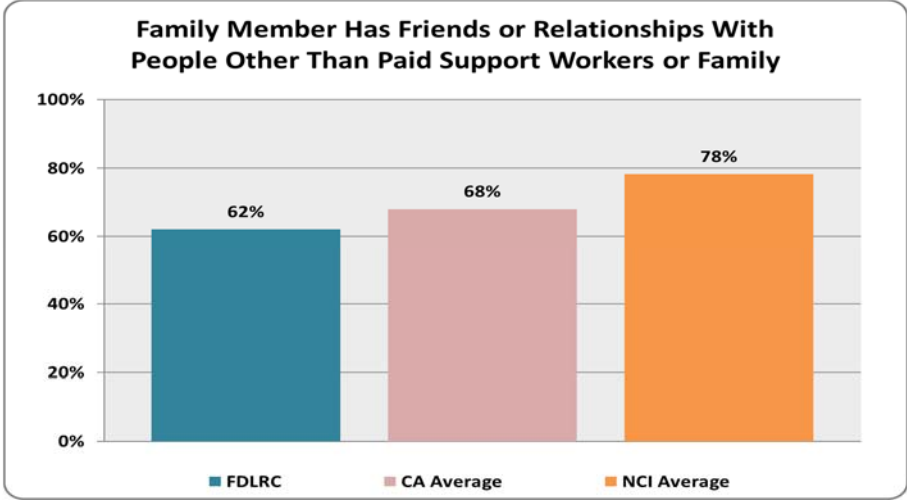
GRAPH 77. DOES YOUR FAMILY MEMBER PARTICIPATE IN COMMUNITY ACTIVITIES (SUCH AS GOING OUT TO A RESTAURANT, MOVIE, OR SPORTING EVENT)?



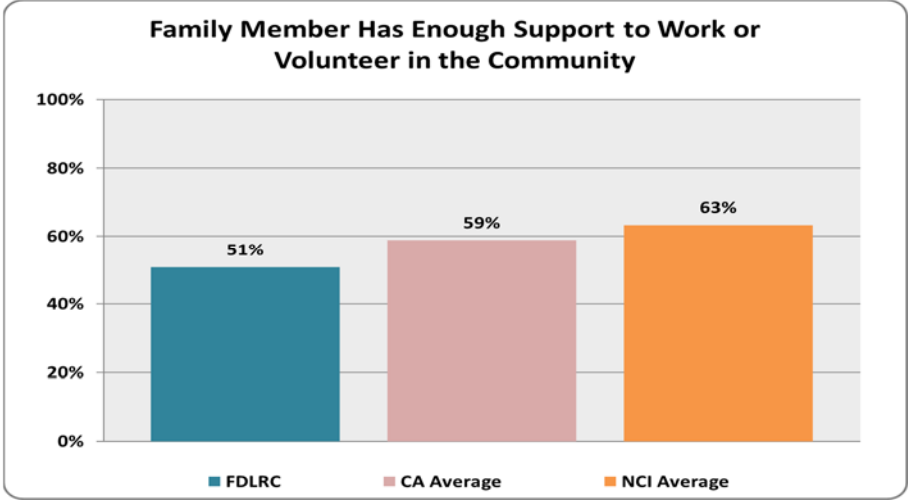
GRAPH 78. IF YOUR FAMILY MEMBER DOESN'T PARTICIPATE IN COMMUNITY ACTIVITIES, WHY NOT?



GRAPH 79. DOES YOUR FAMILY MEMBER HAVE FRIENDS OR RELATIONSHIPS WITH PERSONS OTHER THAN PAID SUPPORT WORKERS OR FAMILY?



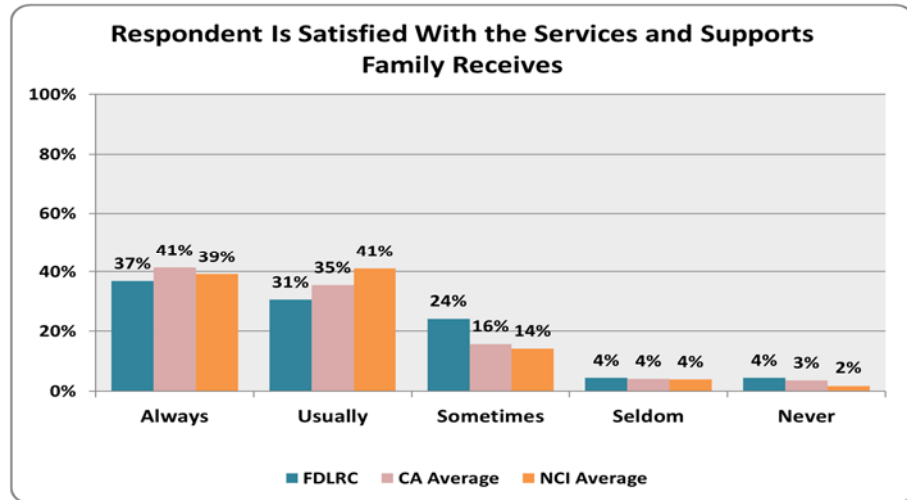
GRAPH 80. DOES YOUR FAMILY MEMBER HAVE ENOUGH SUPPORTS (E.G., SUPPORT WORKERS, COMMUNITY RESOURCES) TO WORK OR VOLUNTEER IN THE COMMUNITY?



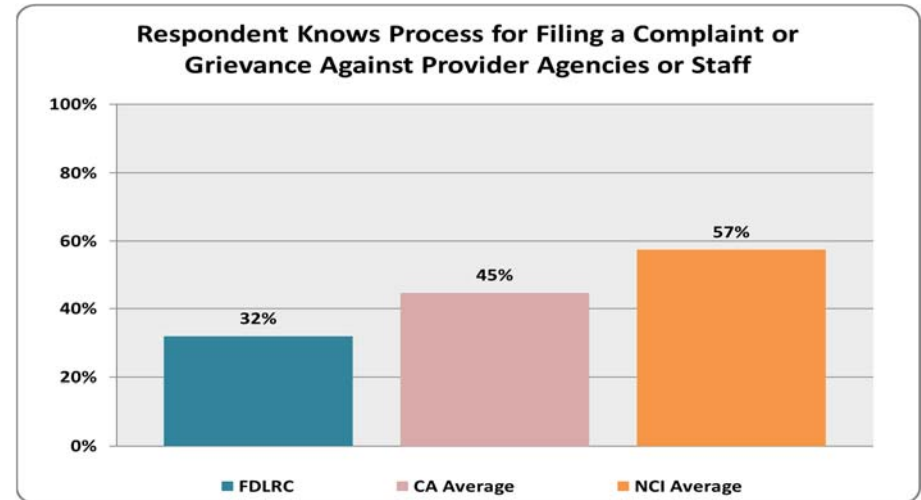
Satisfaction

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES RECEIVE ADEQUATE AND SATISFACTORY SUPPORTS

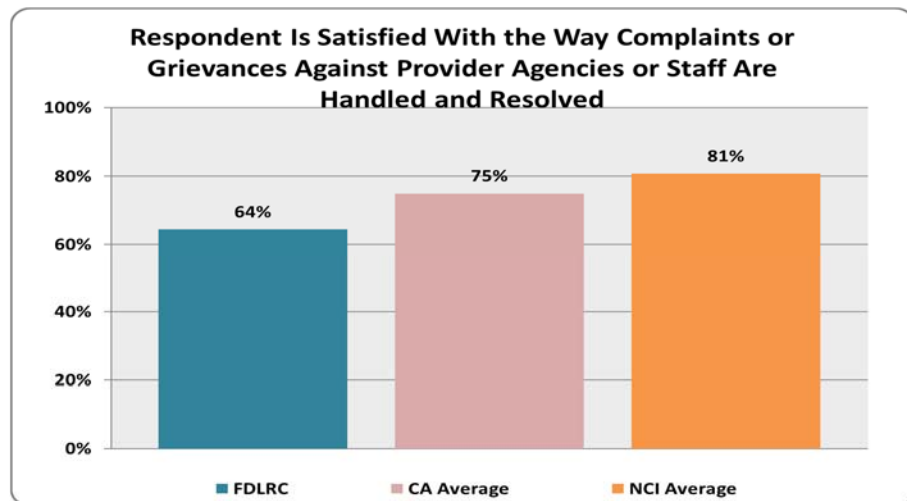
GRAPH 81. OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS YOUR FAMILY CURRENTLY RECEIVES?



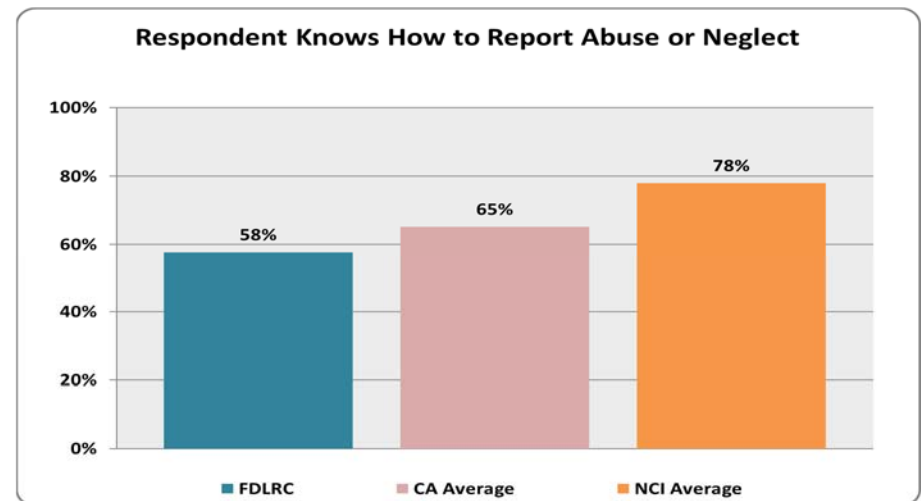
GRAPH 82. DO YOU KNOW THE PROCESS FOR FILING A COMPLAINT OR GRIEVANCE AGAINST PROVIDER AGENCIES OR STAFF?*



GRAPH 83. ARE YOU SATISFIED WITH THE WAY COMPLAINTS OR GRIEVANCES AGAINST PROVIDER AGENCIES OR STAFF ARE HANDLED AND RESOLVED?

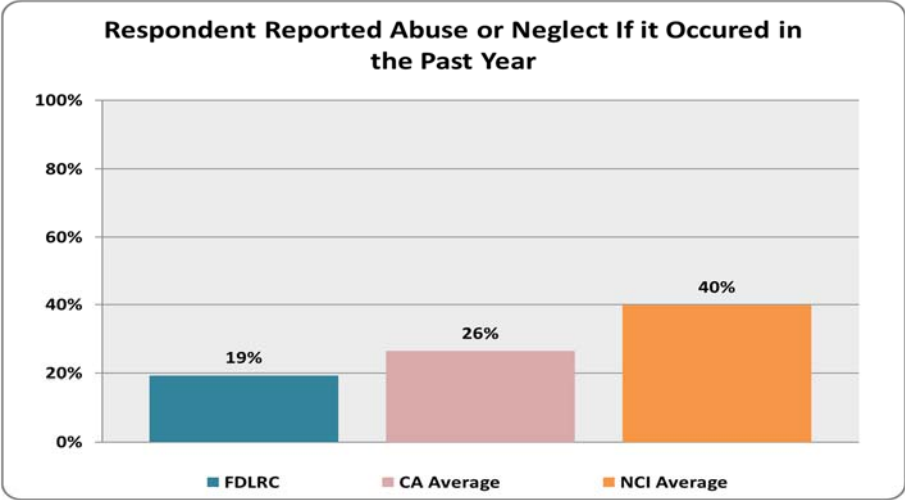


GRAPH 84. DO YOU KNOW HOW TO REPORT ABUSE OR NEGLECT?*



*'Don't Know' responses were included in 'No' responses for this question.

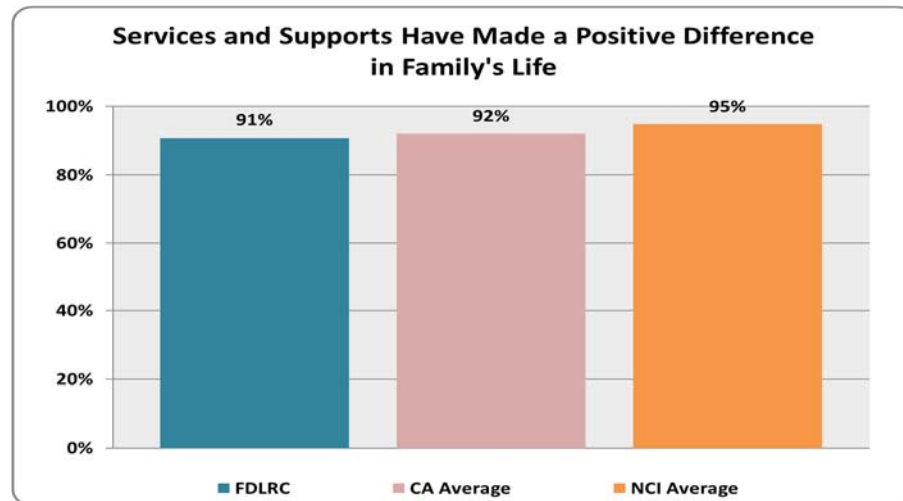
GRAPH 85. WITHIN THE PAST YEAR, IF ABUSE OR NEGLECT OCCURRED, DID YOU REPORT IT?



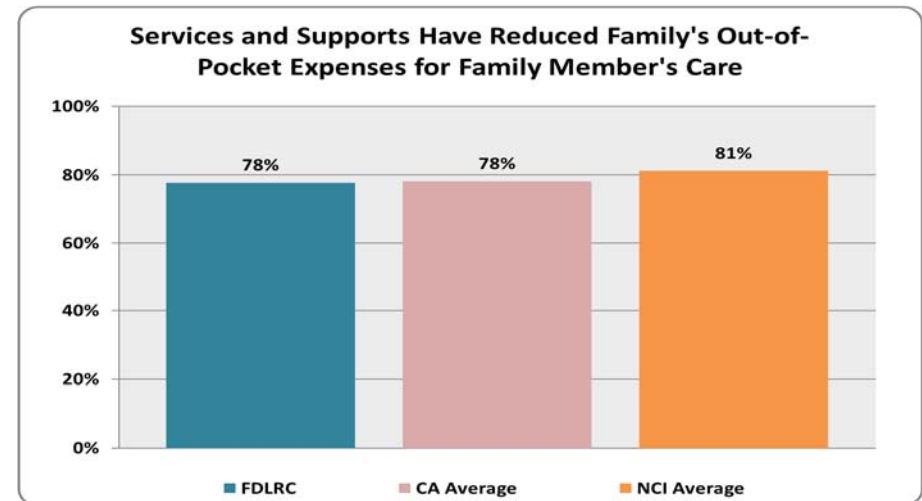
Family Outcomes

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

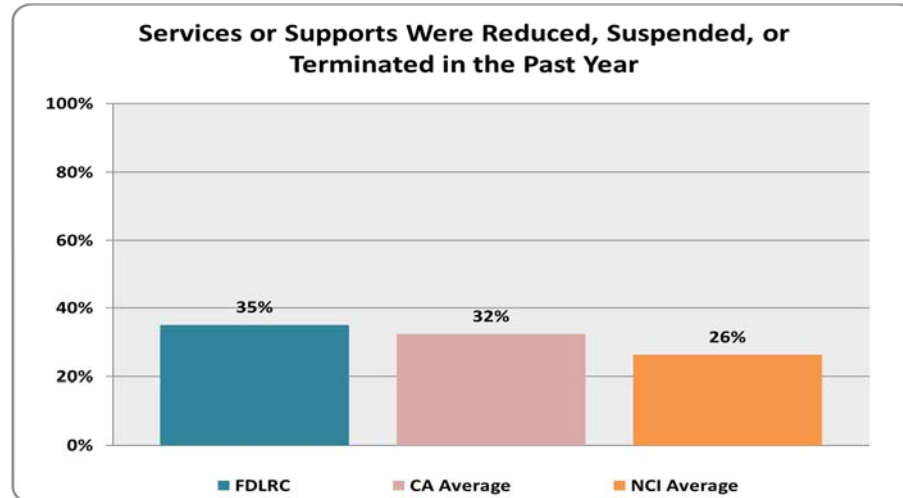
GRAPH 86. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE MADE A POSITIVE DIFFERENCE IN THE LIFE OF YOUR FAMILY?



GRAPH 87. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE REDUCED YOUR FAMILY'S OUT-OF-POCKET EXPENSES FOR YOUR FAMILY MEMBER'S CARE?



GRAPH 88. HAVE THE SERVICES OR SUPPORTS THAT YOU OR YOUR FAMILY MEMBER RECEIVED BEEN REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR?



GRAPH 89. IF SERVICES OR SUPPORTS RECEIVED BY THE FAMILY WERE REDUCED, SUSPENDED OR TERMINATED DURING THE PAST YEAR, DID THIS CHANGE AFFECT YOUR FAMILY OR YOUR FAMILY MEMBER NEGATIVELY?

