NCI Child Family Survey Outcomes

Inland Regional Center Report

2012-2013 Data





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 first statewide National Core Indicator (NCI) Child Family Survey from fiscal year (FY) 2012-2013 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 Child Family Survey findings from Inland Regional Center compared to the California statewide average. 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 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 FY 12/13 data collection cycle, 33 states and 22 sub-state entities participated in NCI.

What is the NCI Child Family Survey?

The NCI Child Family Survey is a mail-in survey sent to families with children who live in the family home and receive services from the regional center. The NCI Child Family 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 information on the child and respondent's demographics, services and supports received, and contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services,



¹ Refer to the California Adult Consumer Survey Report FY 11/12 for detailed information about Quality Assessment Project implementation, the NCI, and California's Statewide results.

choice and control, community connections, satisfaction, and 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 Child Family Survey includes items to measure the "Family Outcomes" domain. The table on the following page lists the NCI Family Surveys sub-domains and concerns.

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 & 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.

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



How were people selected to participate?

For each regional center, DDS selected a random sample of families who had a child with a developmental disability living at home and received at least one direct service or support other than service coordination.²

The State Council on Developmental Disabilities mailed out a paper survey to families selected in their sample. A final sample size of 400 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 Child Family Survey tool is not intended to be used for monitoring individuals or providers, but rather for assessing system-wide performance. The NCI Statewide Average 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 12/13 NCI Child Family Survey demographic and outcome results from Inland Regional Center compared to the CA Average (the average of all regional center averages). All results are shown in chart form along with descriptive text to the right of each outcome chart. 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 less than 20 responses to a particular question were excluded from analysis for that question. The number of responses per each question



² Some states include child up to age 22 who are receiving services as a child.
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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/DDSHomePage.cfm.

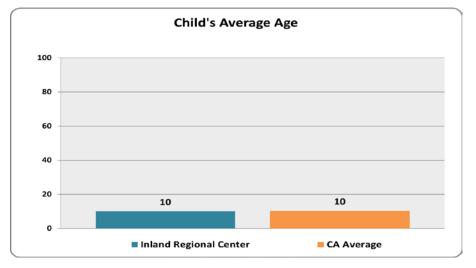


Results: Demographics of Child

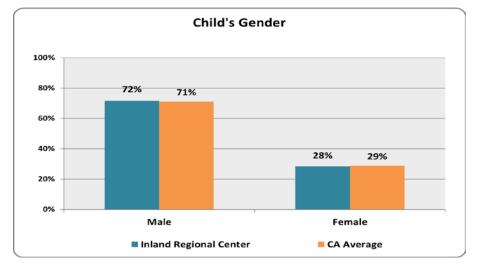
ILLUSTRATES THE DEMOGRAPHIC PROFILE OF THE CHILD FOR WHOM THE SURVEY WAS COMPLETED



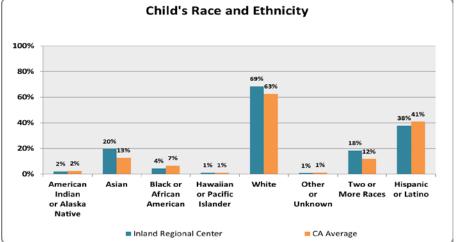
GRAPH 1. CHILD'S AVERAGE AGE



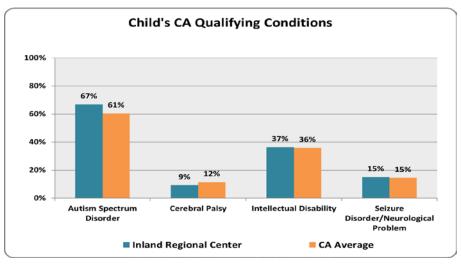
GRAPH 2. CHILD'S GENDER



GRAPH 3. CHILD'S RACE AND ETHINICITY



GRAPH 4. CHILD'S CA QUALIFYING CONDITIONS*

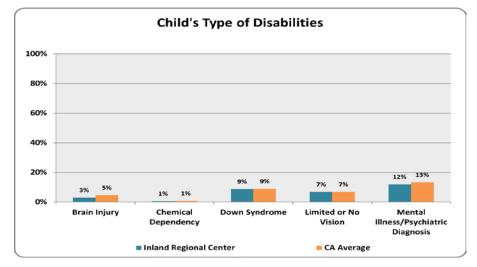


*CA Qualifying Conditions (graph 4) are not mutually exclusive; therefore, some results may add up to more than 100%.



GRAPH 5. CHILD'S TYPE OF DISABILITIES*

GRAPH 7. CHILD'S PRIMARY MEANS OF EXPRESSION



Child's Type of Disabilities 100% 80% 60% 40% 18% 20% 12% 2% 3% 4% 1% 1% 1% 1% 2% 0% Prader-Willi Severe or Profound Other Disability No Other Disability Don't Know Syndrome Hearing Loss Inland Regional Center CA Average

GRAPH 6. CHILD'S TYPE OF DISABILITIES, CONTINUED*

Child's Primary Means of Expression 100% 80% 65% 65% 60% 40% 24% 23% 20% 5% 4% 3% 3% 0% Spoken Gestures/Body Sign Language/Finger Communication Language Spelling Aid/Device Inland Regional Center CA Average

Child's Primary Language 100% 75% 73% 80% 60% 40% 22% 20% 20% 5% 4% 0% English Spanish Other Inland Regional Center CA Average

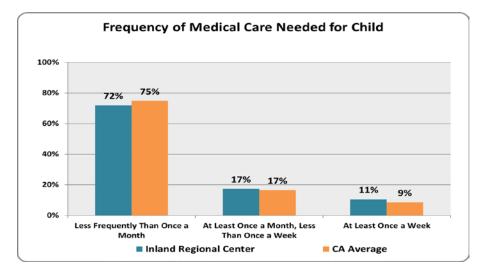
*Type of Disabilities (graphs 5 and 6) are not mutually exclusive, and therefore some results may add up to more than 100%.

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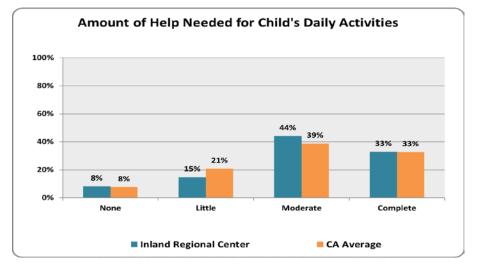


GRAPH 8. CHILD'S PRIMARY LANGUAGE

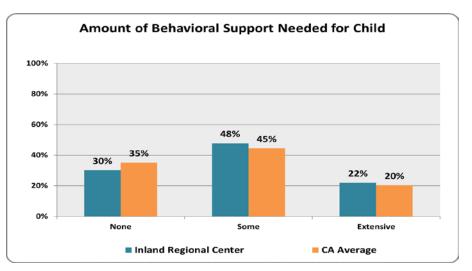
GRAPH 9. FREQUENCY OF MEDICAL CARE NEEDED FOR CHILD



GRAPH 11. AMOUNT OF HELP NEEDED FOR CHILD'S DAILY ACTIVITIES



GRAPH 10. AMOUNT OF BEHAVIORAL SUPPORT NEEDED FOR CHILD



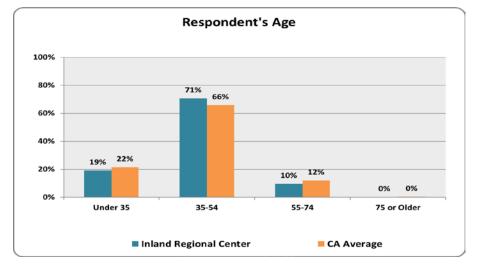


Results: Demographics of Respondent

ILLUSTRATES THE DEMOGRAPHIC PROFILE OF THE SURVEY RESPONDENTS

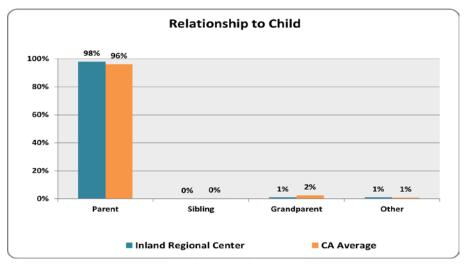


GRAPH 12. RESPONDENT'S AGE

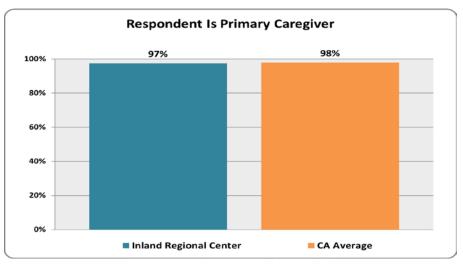


Respondent's Health 100% 80% 55% 55% 60% 40% 21% 22% 21% 21% 20% 4% 3% 0% Excellent Good Fair Poor Inland Regional Center CA Average

GRAPH 14. RELATIONSHIP TO CHILD



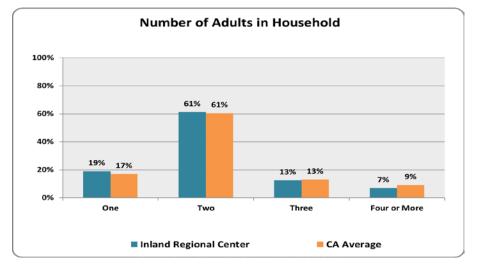
GRAPH 15. RESPONDENT IS PRIMARY CAREGIVER



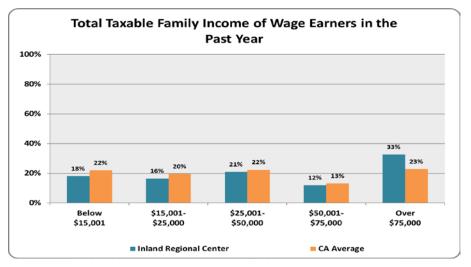


GRAPH 13. RESPONDENT'S HEALTH

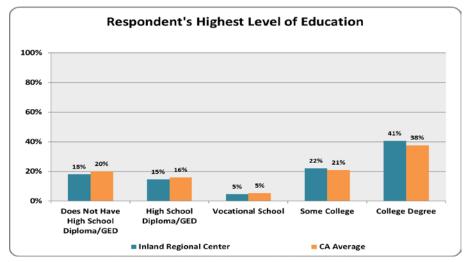
GRAPH 16. NUMBER OF ADULTS IN HOUSEHOLD



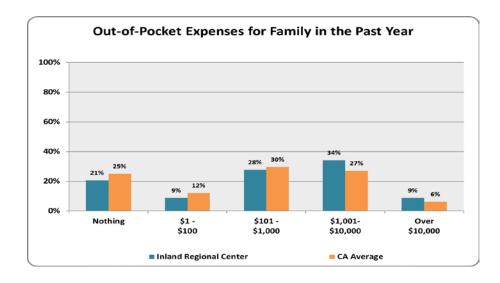
GRAPH 18. TOTAL TAXABLE FAMILY INCOME OF WAGE EARNERS IN THE PAST YEAR



GRAPH 17. RESPONDENT'S HIGHEST LEVEL OF EDUCATION



GRAPH 19. OUT-OF-POCKET EXPENSES FOR FAMILY IN THE PAST YEAR

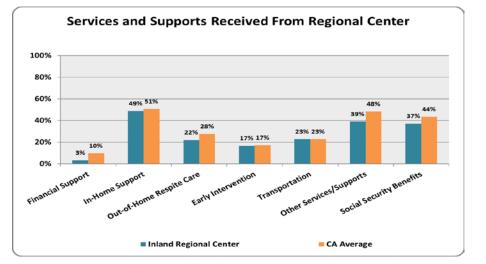




Services and Supports Received

ILLUSTRATES THE SERVICES AND SUPPORTS RECEIVED BY CHILDREN AND FAMILIES





GRAPH 20. SERVICES AND SUPPORTS RECEIVED FROM THE REGIONAL CENTER³

³ All services and supports are received from the Regional Center except social security benefits. **18** NCI Child Family Survey Regional Center Outcomes 2012-2013



Information and Planning

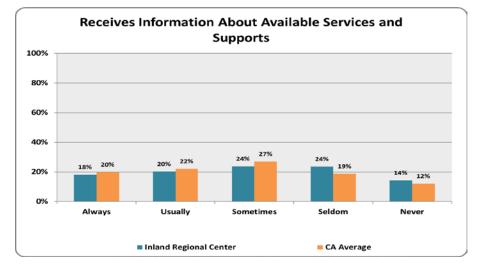
FAMILIES AND CHILDREN WITH DISABILITIES HAVE THE INFORMATION AND SUPPORT NECESSARY TO PLAN FOR THEIR SERVICES AND SUPPORTS



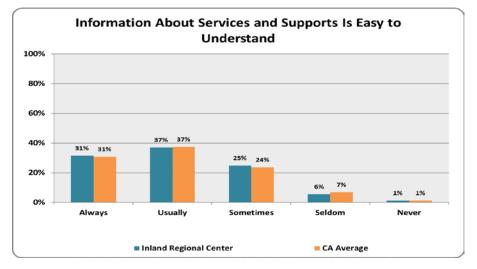


GRAPH 21. DO YOU RECEIVE INFORMATION ABOUT THE SERVICES AND

SUPPORTS THAT ARE AVAILABLE TO YOUR CHILD AND FAMILY?



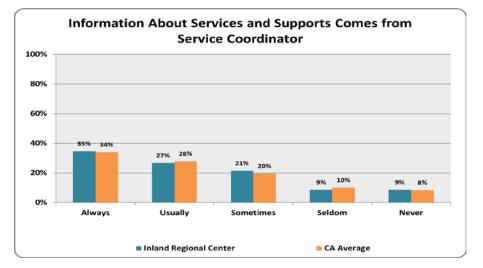
GRAPH 22. IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND?





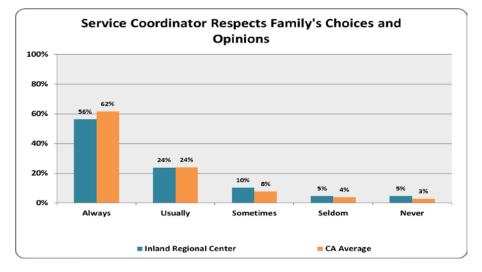
GRAPH 23. DOES THE INFORMATION YOU RECEIVE COME FROM YOUR SERVICE

COORDINATOR?



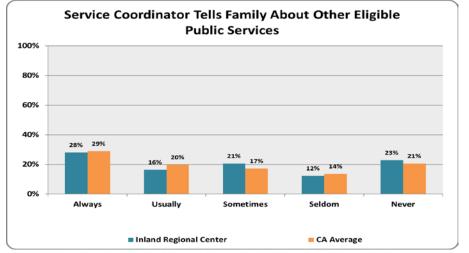
GRAPH 24. DOES THE SERVICE COORDINATOR RESPECT YOUR FAMILY'S

CHOICES AND OPINIONS?

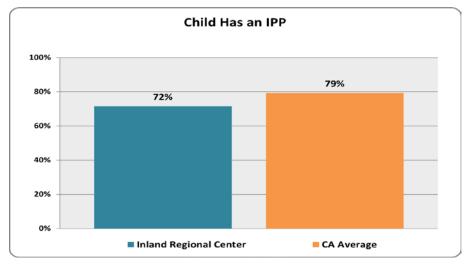




GRAPH 25. DOES THE SERVICE COORDINATOR TELL YOU ABOUT OTHER PUBLIC SERVICES THAT YOU ARE ELIGIBLE FOR (E.G., FOOD STAMPS, SUPPLEMENTAL SECURITY INCOME [SSI], HOUSING SUBSIDIES, ETC.)?

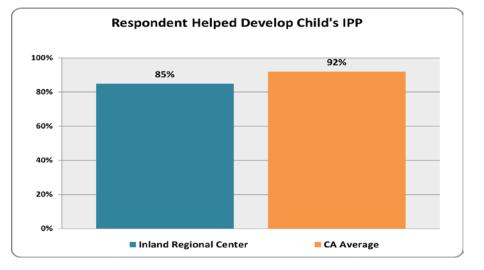


GRAPH 26. DOES YOUR CHILD HAVE AN INDIVIDUAL PROGRAM PLAN (IPP)?



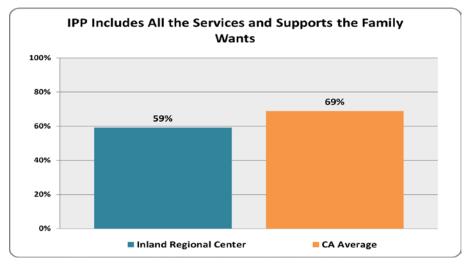


GRAPH 27. DID YOU HELP DEVELOP THE PLAN?



GRAPH 28. DOES THE PLAN INCLUDE ALL THE SERVICES AND SUPPORTS YOUR

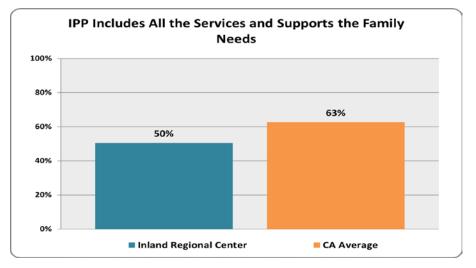
FAMILY WANTS?



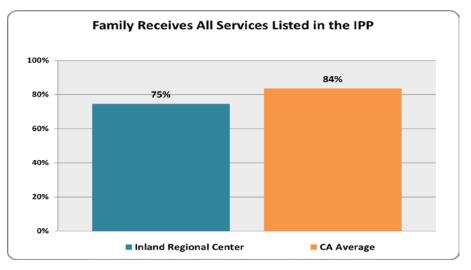


GRAPH 29. DOES THE PLAN INCLUDE ALL THE SERVICES AND SUPPORTS YOUR

FAMILY NEEDS?



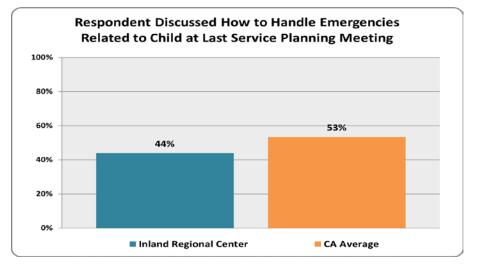
GRAPH 30. DOES YOUR FAMILY RECEIVE ALL THE SERVICES LISTED IN THE PLAN?



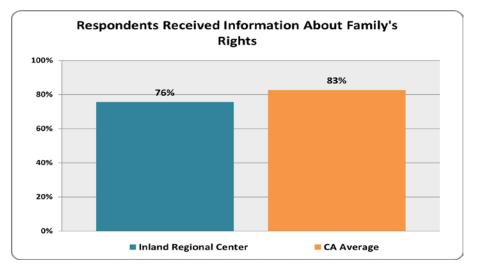


GRAPH 31. DID YOU DISCUSS HOW TO HANDLE EMERGENCIES RELATED TO

YOUR CHILD AT THE LAST SERVICE PLANNING MEETING?



GRAPH 32. HAVE YOU RECEIVED INFORMATION ABOUT YOUR FAMILY'S RIGHTS?





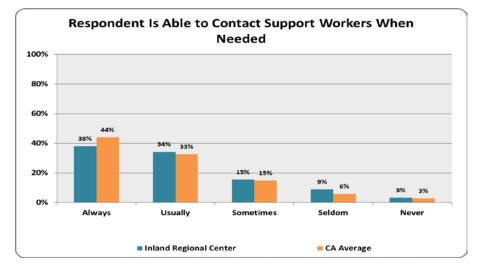
Access and Delivery

FAMILIES AND CHILDREN WITH DISABILITIES GET THE SERVICES AND SUPPORTS THEY NEED



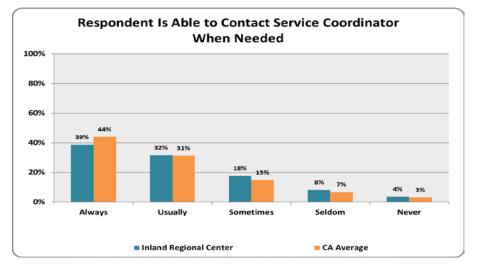
GRAPH 33. ARE YOU ABLE TO CONTACT YOUR SUPPORT WORKERS WHEN YOU

NEED TO?

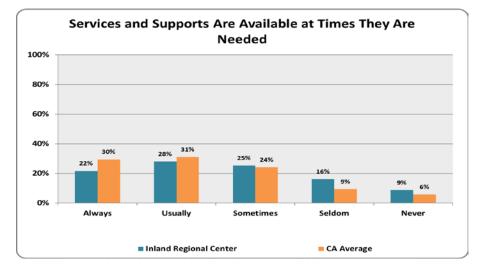


GRAPH 34. ARE YOU ABLE TO CONTACT YOUR SERVICE COORDINATOR WHEN

YOU NEED TO?

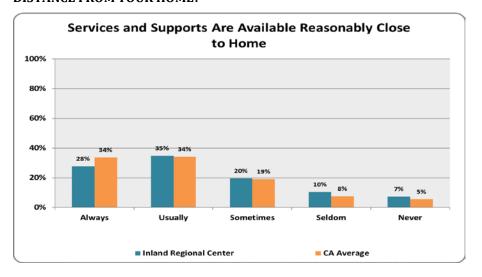






GRAPH 35. ARE SERVICES AND SUPPORTS AVAILABLE WHEN YOU NEED THEM?

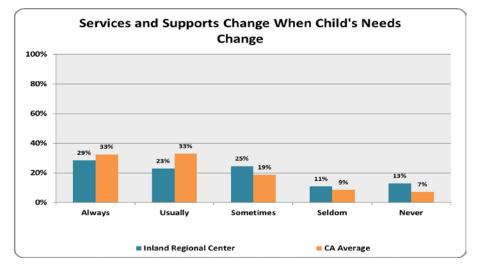
GRAPH 36. ARE SERVICES AND SUPPORTS AVAILABLE WITHIN A REASONABLE DISTANCE FROM YOUR HOME?



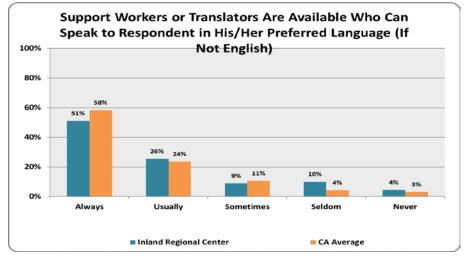


GRAPH 37. DO THE SERVICES AND SUPPORTS CHANGE WHEN YOUR CHILD'S

NEEDS CHANGE?



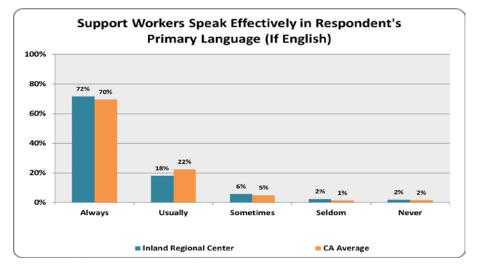
GRAPH 38. IF ENGLISH IS NOT YOUR PRIMARY LANGUAGE, ARE THERE SUPPORT WORKERS OR TRANSLATORS WHO CAN SPEAK WITH YOU IN YOUR PREFERRED LANGUAGE?



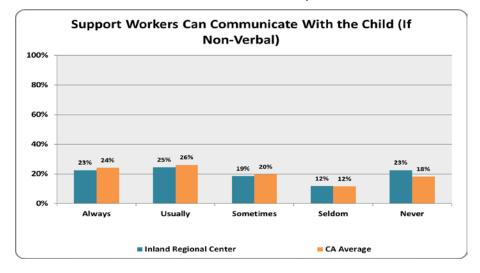


GRAPH 39. IF ENGLISH IS YOUR FIRST LANGUAGE, DO THE SUPPORT

WORKERS SPEAK TO YOU EFFECTIVELY?



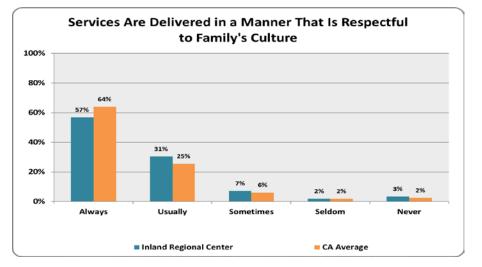
GRAPH 40. IF YOUR CHILD DOES NOT COMMUNICATE VERBALLY (FOR EXAMPLE, USES GESTURES OR SIGN LANGUAGE), ARE THERE SUPPORT WORKERS WHO CAN COMMUNICATE WITH HIM/HER?



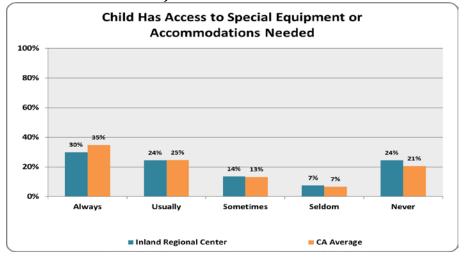


GRAPH 41. ARE SERVICES DELIVERED IN A WAY THAT IS RESPECTFUL TO

YOUR FAMILY'S CULTURE?



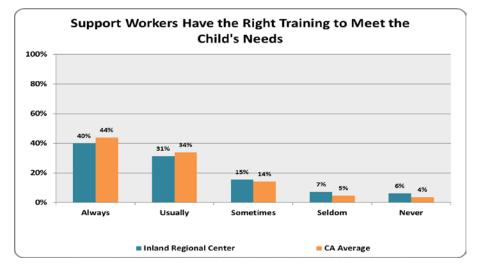
GRAPH 42. DOES YOUR CHILD HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT S/HE NEEDS (E.G., WHEELCHAIR, RAMP, COMMUNICATION BOARD)?





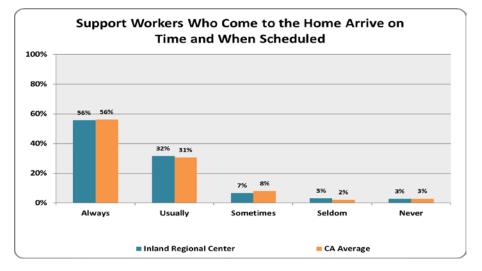
GRAPH 43. DO THE SUPPORT WORKERS HAVE THE RIGHT TRAINING TO MEET

YOUR CHILD'S NEEDS?



GRAPH 44. DO THE SUPPORT WORKERS WHO COME TO YOUR HOME ARRIVE

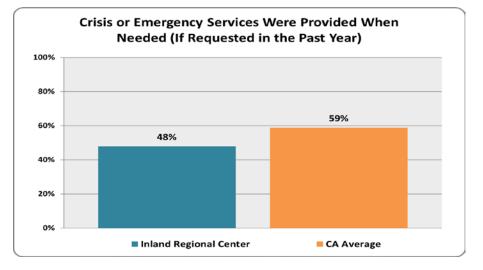
ON TIME AND WHEN SCHEDULED?



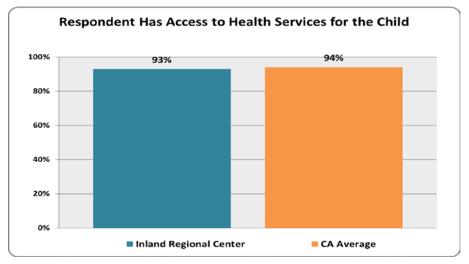


GRAPH 45. IF YOU ASKED FOR CRISIS/EMERGENCY SERVICES DURING THE

PAST YEAR, WERE SERVICES PROVIDED WHEN NEEDED?



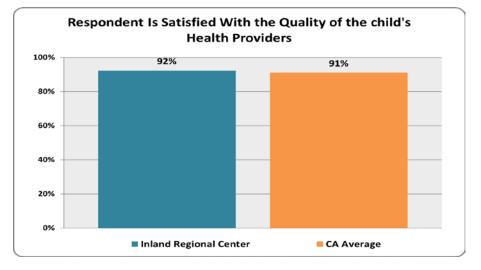
GRAPH 46. DO YOU HAVE ACCESS TO HEALTH SERVICES FOR YOUR CHILD?



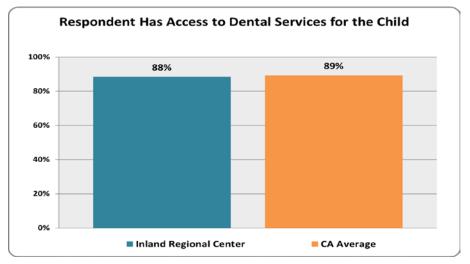


GRAPH 47. IF YOU HAVE ACCESS TO HEALTH SERVICES FOR YOUR CHILD, ARE

YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



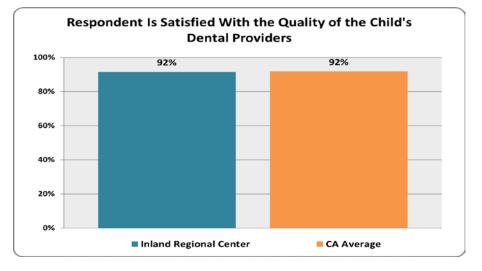
GRAPH 48. DO YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR CHILD?



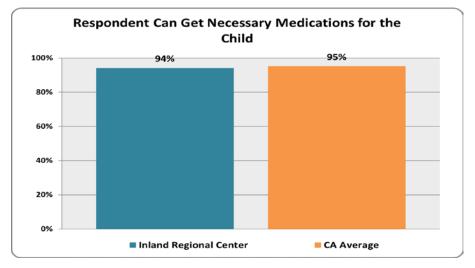


GRAPH 49. IF YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR CHILD, ARE

YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



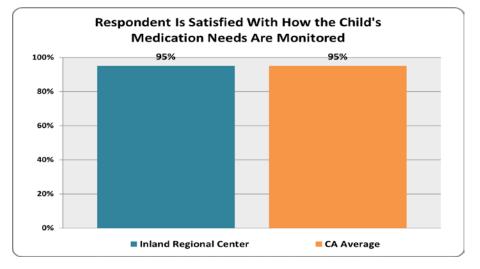
GRAPH 50. ARE YOU ABLE TO GET MEDICATIONS NEEDED FOR YOUR CHILD?





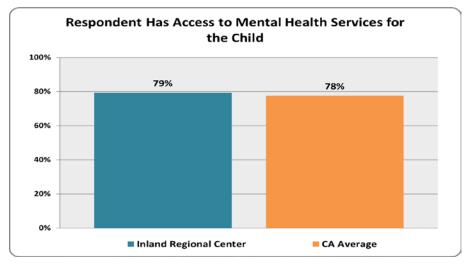
GRAPH 51. IF YOU CAN GET NEEDED MEDICATIONS FOR YOUR CHILD, ARE YOU

SATISFIED WITH HOW YOUR CHILD'S MEDICATION NEEDS ARE MONITORED?



GRAPH 52. IF NEEDED, DO YOU HAVE ACCESS TO MENTAL HEALTH SERVICES

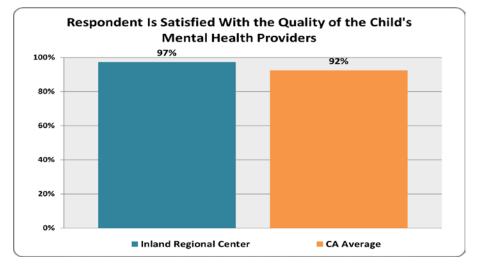
FOR YOUR CHILD?



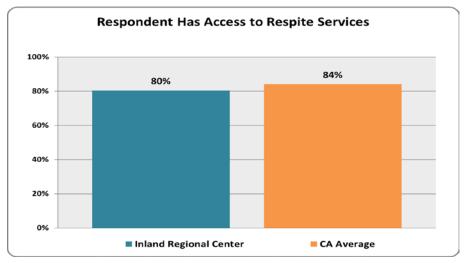


GRAPH 53. IF YOU HAVE ACCESS TO MENTAL HEALTH SERVICES FOR YOUR

CHILD, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



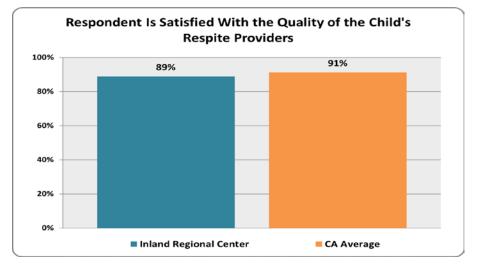
GRAPH 54. IF YOU NEED RESPITE SERVICES, DO YOU HAVE ACCESS TO THEM?



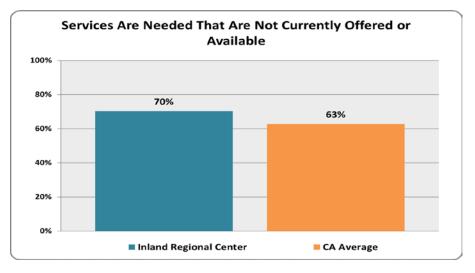


GRAPH 55. IF YOU HAVE ACCESS TO NEEDED RESPITE SERVICES, ARE YOU

SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



GRAPH 56. ARE THERE SERVICES THAT YOUR FAMILY NEEDS THAT ARE NOT CURRENTLY OFFERED OR AVAILABLE?





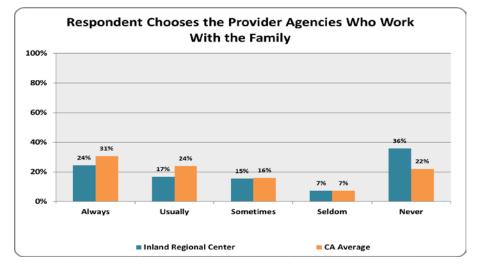
Choice and Control

FAMILIES DETERMINE THE SERVICES AND SUPPORTS THEY AND THEIR CHILDREN RECEIVE AND THE INDIVIDUALS OR AGENCIES WHO PROVIDE THEM



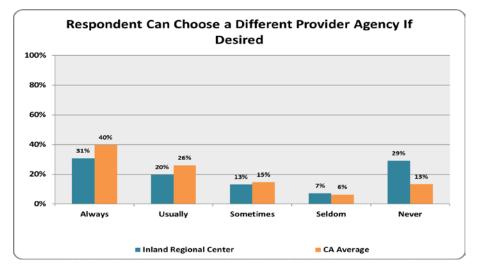
GRAPH 57. DO YOU CHOOSE THE PROVIDER AGENCIES WHO WORK WITH

YOUR FAMILY?



GRAPH 58. CAN YOU CHOOSE A DIFFERENT PROVIDER AGENCY IF YOU WANT

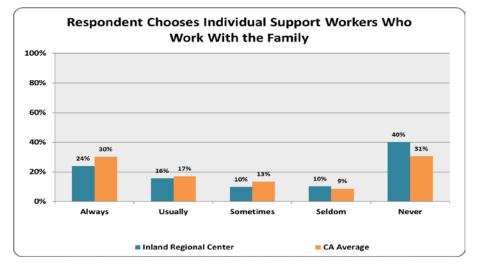
TO?





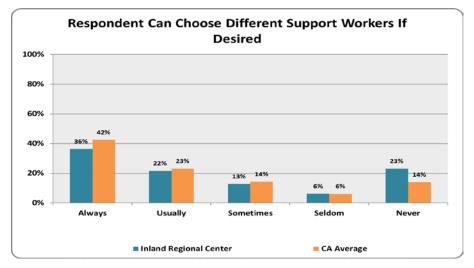
GRAPH 59. DO YOU CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK

DIRECTLY WITH YOUR FAMILY?



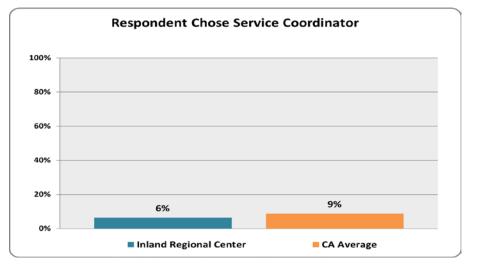
GRAPH 60. CAN YOU CHOOSE DIFFERENT SUPPORT WORKERS IF YOU WANT

TO?

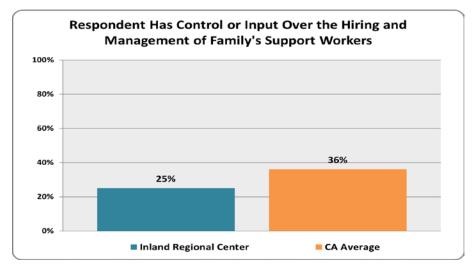




GRAPH 61. DID YOU CHOOSE YOUR SERVICE COORDINATOR?



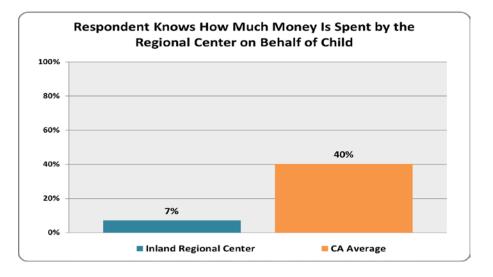
GRAPH 62. DO YOU HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF YOUR FAMILY'S SUPPORT WORKERS?





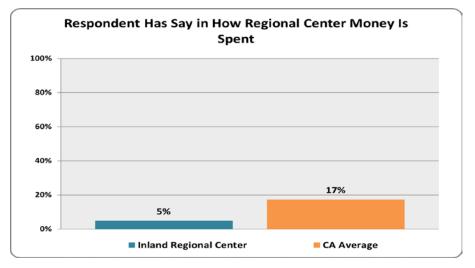
GRAPH 63. DO YOU KNOW HOW MUCH MONEY IS SPENT BY THE REGIONAL

CENTER ON BEHALF OF YOUR CHILD?*



GRAPH 64. DO YOU HAVE A SAY IN HOW REGIONAL CENTER MONEY IS SPENT

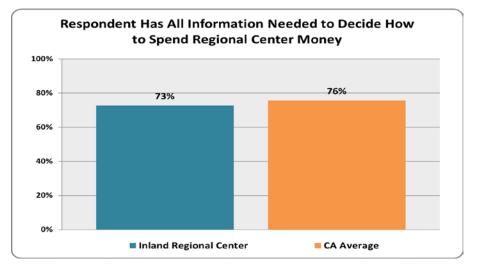
ON BEHALF OF YOUR CHILD?



*'Don't know' responses are included with 'no' responses.



GRAPH 65. 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?





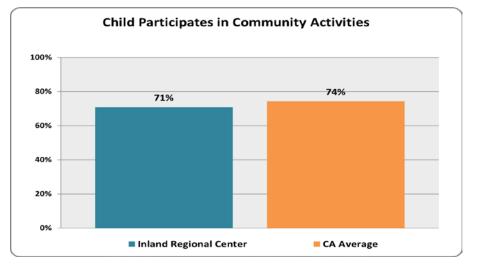
Community Connections

CHILDREN WITH DISABILITIES USE INTEGRATED COMMUNITY SERVICES AND PARTICIPATE IN EVERYDAY COMMUNITY ACTIVITIES



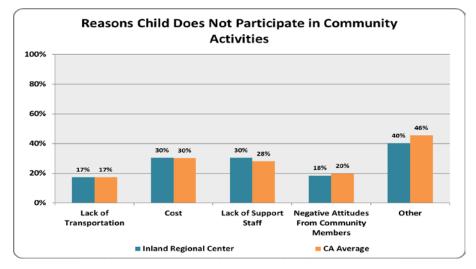
GRAPH 66. DOES YOUR CHILD PARTICIPATE IN COMMUNITY ACTIVITIES (SUCH

AS GOING OUT TO A RESTAURANT, MOVIE, OR SPORTING EVENT)?



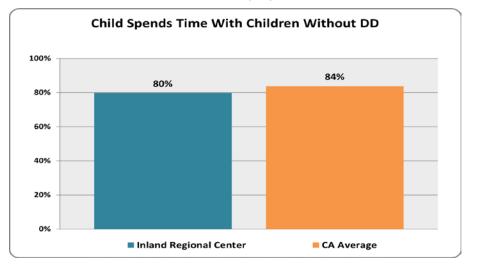
GRAPH 67. IF YOUR CHILD DOESN'T PARTICIPATE IN COMMUNITY ACTIVITIES,

WHY NOT?





GRAPH 68. DOES YOUR CHILD SPEND TIME WITH CHILDREN WHO DO NOT HAVE DEVELOPMENTAL DISABILITIES (DD)?





Satisfaction

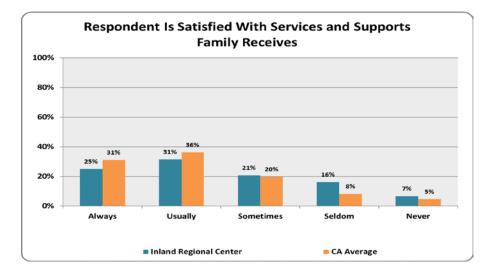
FAMILIES AND CHILDREN WITH DISABILITIES RECEIVE ADEQUATE AND SATISFACTORY SUPPORTS

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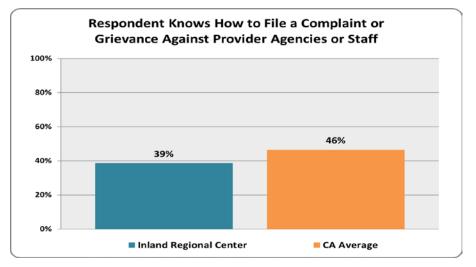
GRAPH 69. OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS

YOUR FAMILY CURRENTLY RECEIVES?



GRAPH 70. DO YOU KNOW THE PROCESS FOR FILING A COMPLAINT OR

GRIEVANCE AGAINST PROVIDER AGENCIES OR STAFF?*

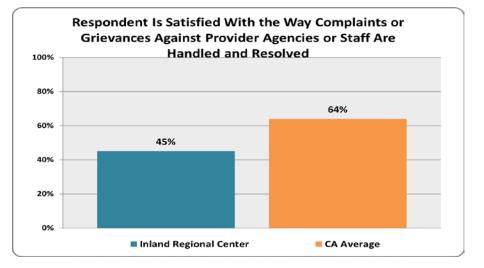


*'Don't know' responses are included with 'no' responses.

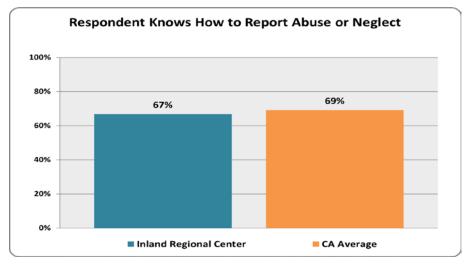


GRAPH 71. ARE YOU SATISFIED WITH THE WAY COMPLAINTS OR GRIEVANCES

AGAINST PROVIDER AGENCIES OR STAFF ARE HANDLED AND RESOLVED?



GRAPH 72. DO YOU KNOW HOW TO REPORT ABUSE OR NEGLECT?*

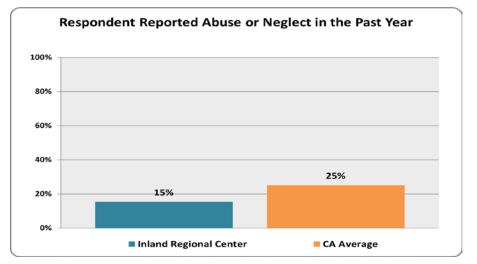


*'Don't know' responses are included with 'no' responses.



GRAPH 73. WITHIN THE PAST YEAR, IF ABUSE OR NEGLECT OCCURRED, DID

YOU REPORT IT?





Family Outcomes

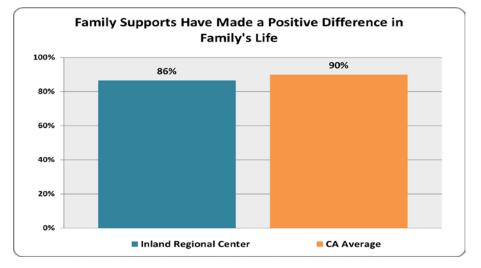
INDIVIDUAL AND FAMILY SUPPORTS MAKE A POSITIVE DIFFERENCE IN THE LIVES OF FAMILIES

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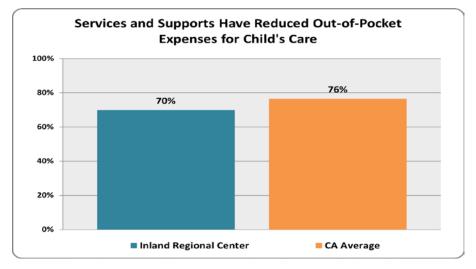
GRAPH 74. DO YOU FEEL THAT FAMILY SUPPORTS HAVE MADE A POSITIVE

DIFFERENCE IN THE LIFE OF YOUR FAMILY?



GRAPH 75. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE REDUCED

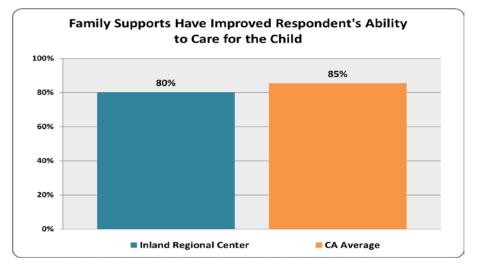
YOUR FAMILY'S OUT-OF-POCKET EXPENSES FOR YOUR CHILD'S CARE?





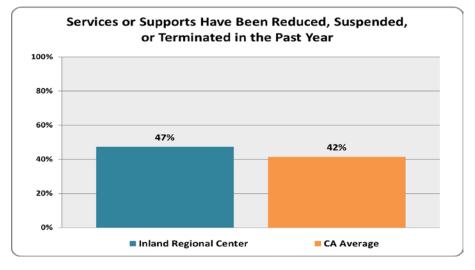
GRAPH 76. DO YOU FEEL THAT FAMILY SUPPORTS HAVE IMPROVED YOUR

ABILITY TO CARE FOR YOUR CHILD?



GRAPH 77. HAVE THE SERVICES OR SUPPORTS THAT YOUR CHILD/FAMILY

RECEIVES BEEN REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR?





GRAPH 78. IF SERVICES OR SUPPORTS RECEIVED BY FAMILY WERE REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR, DID THIS CHANGE AFFECT YOUR FAMILY NEGATIVELY?

