

# 2021-22 Family/Guardian Survey (FGS)

## Regional Center Report

North Los Angeles County Regional Center (NLACRC)



## Contents

<b>Quality Assessment Project and National Core Indicators®</b> .....	<b>9</b>
<b>What is NCI®-IDD?</b> .....	<b>9</b>
<b>Important note on Impact of COVID-19</b> .....	<b>10</b>
<b>What is included in this report?</b> .....	<b>10</b>
<b>Demographics</b> .....	<b>11</b>
Demographics of Family Member Receiving Services.....	12
Table 1a. Family Member’s Residence.....	13
Table 1b. Family Member’s Residence (continued).....	13
Table 2. Family Member’s Time Living in Current Residence .....	14
Table 3. Family Member’s Residential Designation .....	14
Table 4. Family Member’s Age.....	14
Table 5. Family Member’s Gender .....	15
Table 6. Family Member’s Race and Ethnicity.....	15
Table 6b. Family Member’s Race and Ethnicity (continued) .....	16
Table 7a. Family Member’s Disabilities (not mutually exclusive) .....	16
Table 7b. Family Member’s Disabilities (continued).....	17
Table 8a. Family Member’s Health Conditions.....	17
Table 8b. Family Member’s Health Conditions (continued).....	18
Table 8c. Family Member’s Health Conditions (continued) .....	18
Table 9. Family Member’s Preferred Means of Communication .....	19
Table 10a. Family Member’s Preferred Language .....	19
Table 10b. Family Member’s Preferred Language (continued).....	20

Table 10c. Family Member’s Preferred Language (continued) .....	20
Table 11. Family Member Has Legal Court Appointed Guardian or Conservator .....	21
Table 12. Guardian or Conservator Relationship to Family Member .....	21
Table 13a. Family Member’s Highest level of Education .....	22
Table 13b. Family Member’s Highest level of Education .....	22
Table 14. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors .....	23
Table 15. Family Member’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating) .....	23
Table 16. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping).....	24
Demographics of Respondents.....	25
Table 17a. Language Usually Spoken at Home.....	26
Table 17b. Language Usually Spoken at Home (continued).....	26
Table 17c. Language Usually Spoken at Home (continued) .....	27
Table 18. Respondent’s Age.....	27
Table 19. Respondent’s Health.....	28
Table 20. Respondent’s Relationship to Family Member.....	28
Table 21. Respondent’s Frequency of Visits With Family Member in the Past 12 months .....	28
Table 22. Respondent’s Highest Level of Education.....	29
Table 23. Total Taxable Household Income of Wage Earners in the Past Year .....	29
Services and Supports Received .....	30
Table 24a. Services and Supports Received From Regional Center.....	31
Table 24b. Services and Supports Received From Regional Center (continued).....	31
Table 25. Additional Services and Supports Received ( <i>Not from the Regional Centers</i> ) .....	32
<b>Family/Guardian Survey Results.....</b>	<b>33</b>

Information and Planning.....	34
Table 26. Do you get enough information to take part in planning services for your family member? .....	35
Table 27. Is the information you get about services and supports easy to understand? .....	36
Table 28. Do you get information about services and supports in your preferred language? .....	37
Table 29. Do staff or the residential agency keep you informed about how your family member is doing?.....	38
Table 30. Does the case manager/service coordinator listen to your family’s choices and opinions? .....	39
Table 31. Has your family learned about alternatives to conservatorship?.....	40
Table 32a. Do you need help planning for your family member’s future with respect to any of the following? .....	41
Table 32b. Do you need help planning for your family member’s future with respect to any of the following? (continued) .....	42
Table 33. Does your family member have an individual program plan (IPP)?.....	43
Table 34. Does the IPP include all the services and supports your family member needs?.....	44
Table 35. Did you or someone else in your family (besides your family member with a disability) help make the IPP? ...	45
Table 36. Did your family member help make the IPP? .....	46
Table 37. Do you feel like your family had enough say or input in making the plan?.....	47
Table 38. Did your family member leave school services and begin adult services during the past 12 months?.....	48
Table 39. If your family member left school services during the past year, did they have a transition plan? .....	49
Table 40. If family member had a transition plan, did the transition plan include getting or continuing work in a community job? .....	50
Access and Delivery of Services and Supports .....	51
Table 41. Does your family member get all the services listed in the IPP?.....	52
Table 42. Does your family get the supports and services it needs? .....	53
Table 43a. What additional services does your family need?.....	54
Table 43b. What additional services does your family need? (continued).....	55
Table 44b. Do services and supports change when your family’s needs change? .....	56

Table 45. Does your family member have enough supports to work or volunteer in the community? .....	57
Table 46. Does your family member have the special equipment or accommodations they need? .....	58
Table 47. Are you or your family member able to contact their support workers when you want? .....	59
Table 48. Are you or your family member able to contact their case manager/service coordinator when you want? .....	60
Table 49. Do service providers for your family member work together to provide support? .....	61
Table 50. Are services delivered in a way that is respectful of your family's culture? .....	62
Table 51. Does your family member use technology in their everyday life to help them do things on their own? .....	63
Table 52. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home? .....	64
Table 53. How well does the internet work in your home? .....	65
Workforce (New in 2021-22) .....	66
Table 54. Do support workers come and go when they are supposed to? .....	67
Table 55. Do support workers speak to you in a way you understand? .....	68
Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them? .....	69
Table 57. Do support workers have the right information and skills to meet your family's needs? .....	70
Table 58. Do your family member's support workers change too often? Is there too much "turnover" of support workers? .....	71
Table 59. Is there always a staff person available to support your family member when support is needed? .....	72
Choice, Decision Making and Control .....	73
Table 60. Does the agency providing residential services to your family member involve them in important decisions? .....	74
Table 61. Can your family choose or change the provider agency that provides your family member's services? .....	75
Table 62. Can your family choose or change your family member's support workers? .....	76
Table 63. Can someone in your family directly manage support staff? .....	77
Table 64. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator? .....	78

Community Connections .....	79
Table 65. Does your family member do things in the community?.....	80
Table 66. For your family member, what makes it hard to do things in activities in the community? .....	81
Table 67. Does your family member have friends other than paid support workers or family? .....	82
Table 68. In your community, are there resources that your family can use that are not provided by the regional center (for example, recreational programs, community housing, library programs, religious groups, etc.)? .....	83
Table 69. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)? .....	84
Health, Welfare, and Safety (New in 2021-22) .....	85
Table 70. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed? .....	86
Table 71. Does your family member's primary care doctor understand your family member's needs related to their disability? .....	87
Table 72. Can your family member go to the dentist when needed? .....	88
Table 73. Does your family member's dentist understand your family member's needs related to their disability? .....	89
Table 74. If your family member takes prescription medications, do you know what they're for? .....	90
Table 75. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)? .....	91
Table 76. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)? .....	92
Table 77. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability? .....	93
Table 78. If you asked for crisis or emergency services during the past 12 months, were services provided when needed? .....	94
Table 79. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster? .....	95
Table 80. Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member's case manager/service coordinator? .....	96

Table 81. Do you know how to file a complaint or grievance about provider agencies or staff?.....	97
Table 82. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled? .....	98
Table 83. Do you know how to report abuse or neglect related to your family member? .....	99
Table 84. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member? .....	100
Table 85. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner? .....	101
Family Satisfaction.....	102
Table 86. Overall, are you satisfied with the services and supports your family member currently receives? .....	103
Table 87. Do you feel that services and supports have made a positive difference in the life of your family member? ...	104
Table 88. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated? .....	105
Table 89. If services or supports received by the family were reduced, suspended, or terminated during the past year, did the change in services affect your family member negatively? .....	106
Table 90. Have the services or supports that your family member received been increased in the past year? .....	107
Table 91. Are services and supports helping your family member to live a good life? .....	108
COVID-19 Supplement .....	109
Table 92. Were your family member's services and supports changed, canceled, or reduced during COVID time? .....	110
Table 93. If yes, are those changes still in effect (still part of your family member's life)? .....	111
Table 94. If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting? .....	112
Table 95. If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions? .....	113
Table 96. If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy? .....	114

Table 97. In preparation for the future, have you made or updated an emergency plan with your family member's case manager/service coordinator or with other staff?.....	115
California Specific Questions.....	116
Table 98. Total Out-of-pocket Expenses Related to Family Member's Care in the Past Year.....	117
Table 99a. Services Paid for Out-Of-Pocket in The Past Year.....	118
Table 99b. Services Paid for Out-of-pocket in the Past Year.....	119
Table 100. Does your regional center keep you informed, in your preferred language, about programs or services it offers? (For example, updates about new programs or services they offer) .....	120
Table 101. Did you get a copy of your family member's IPP in your preferred language?.....	121
Table 102. Do the support workers speak to you in your preferred language?.....	122
Table 103. Does your family member's case manager/service coordinator speak to you in your preferred language?..	123
Table 104. If your support workers and/or case manager/service coordinator do not speak to you in your preferred language is a translator provided when needed? .....	124
Table 105. Does your family member's case manager/service coordinator support you in a way that is respectful to your culture?.....	125
Table 106. Do support workers for your family members provide services in a way that is respectful of your culture?	126
Table 107. Do you believe your plans for how to handle your family members needs during a natural disaster (such as a wildfire or earthquake) will be effective? .....	127
Table 108. What else do you need to make an effective plan? .....	128
Table 108b. What else do you need to make an effective plan? (continued).....	129
Table 108c. What else do you need to make an effective plan? (continued) .....	130
Table 109. Do you know what to do if you disagree with your regional center about services and/or eligibility? (For example, how to request a Fair Hearing) .....	131



## Quality Assessment Project and National Core Indicators®

This report contains regional center level results from California’s statewide National Core Indicators Family/Guardian Survey data collection from fiscal year 2021-22 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>. Regional centers can use this report to help guide strategic planning and monitor systemic changes.

### What is NCI®–IDD?

The National Core Indicators® – Intellectual and Developmental Disabilities (NCI®-IDD) is a voluntary effort by state developmental disability agencies to track their performance using a standardized set of consumer and family/guardian surveys with nationally validated measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

In 2021-22, a total of 48 states, the District of Columbia and 22 sub-state entities participated in NCI-IDD.

### What is the NCI-IDD Family/Guardian Survey?

The NCI-IDD Family/Guardian Survey is used to gather data on family outcomes. It is mailed to families or guardians who have an adult family member who does not live with the respondent and receives at least one service in addition to case management from the Regional Center<sup>2</sup>. The survey collects demographic information on both the individual receiving services (‘family member’) as well as the person who fills out the survey (the ‘respondent’) and information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

---

<sup>1</sup> Refer to the California Statewide Family/Guardian Survey Report FY 21/22 for information about Quality Assessment Project implementation, NCI and California’s statewide results.

<sup>2</sup> NCI Averages include states that provide services through a central IDD Agency

Please note that while the term “case manager” is used throughout this report, the same role may also be referred to as “service coordinator” or “supports coordinator” depending on the state.

**Important note on responses:** All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses, and personal characteristics.

*Note: All Californians with an intellectual or developmental disability as defined by California law have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. As a result of these requirements, all eligible individuals are enrolled in California’s service system, and California establishes no waiting list for services. This impacts comparability between California NCI-IDD survey results and the NCI-IDD survey results of other states.*

## Important note on Impact of COVID-19

The 2021-22 NCI-IDD Family/Guardian Survey (FGS) data collection cycle began July 1, 2021 and ended June 30, 2022. California began data collection Dec 2021. As COVID-19 variants continued to impact communities across the United States, states were impacted in various ways throughout the year. Because the surveys do not collect information on the date of survey completion, these data cannot fully assess what impact the pandemic had on data collected at different times throughout the year. While these data will serve as an important baseline, and meaningful way for states to understand the overall impact of services on families of individuals being served, these data should be read with caution. To help better understand the overall impact of COVID-19 on families, NCI-IDD added a state optional COVID-19 Supplement to all NCI-IDD Surveys. The COVID-19 Supplement is intended to support the understanding of the experience of people with intellectual/developmental disabilities and their families at the beginning of the COVID-19 pandemic, and their interactions with services during that time. Last year’s Family/Guardian Survey COVID-19 Supplement can be found [here](#).

## What is included in this report?

This report includes this regional center’s Family/Guardian Survey data compared to the CA Statewide, and NCI-IDD Average.

The charts in this document, grouped by subdomain, display the state results alongside the average across states (NCI- IDD average). The charts are followed by accessible tables containing the same information.

If there are fewer than 20 respondents to a question, the data are shown as “n/a”, however, data are included in the statewide average.

This report also contains questions that California specifically requested be added. These questions are noted as “CA specific question” and for which there is no NCI-IDD comparison data. For those questions, the NCI-IDD Average is reported as “n/a”.

## *Demographics*

## *Demographics of Family Member Receiving Services*

*This section provides demographic information about the respondent.*

**Important note on responses:** All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

**Table 1a. Family Member's Residence**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses, and personal characteristics. Specialized Facility for People with ID includes ICFs, state-run or other institutional settings.

RC v CA v NCI	Specialized Facility for People with Intellectual Disabilities	Group Home or Agency-Operated Apartment	Independent Home or Apartment	N
NLACRC	16%	44%	36%	276
CA	17%	40%	38%	4,592
NCI	14%	52%	27%	7,916

**Table 1b. Family Member's Residence (continued)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses, and personal characteristics. Specialized Facility for People with ID includes ICFs, state-run or other institutional settings.

RC v CA v NCI	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
NLACRC	3%	1%	0%	0%	276
CA	2%	1%	0%	1%	4,592
NCI	4%	1%	0%	1%	7,916

**Table 2. Family Member's Time Living in Current Residence**

<b>RC v CA v NCI</b>	<b>Less than one year</b>	<b>One to three years</b>	<b>Four to five years</b>	<b>Over five years</b>	<b>N</b>
NLACRC	7%	16%	13%	64%	276
CA	8%	21%	12%	60%	4,546
NCI	7%	21%	11%	61%	7,820

**Table 3. Family Member's Residential Designation**

<b>RC v CA v NCI</b>	<b>Urban or Suburban (in or near a city or large town)</b>	<b>Rural (Outside of a City or Town)</b>	<b>N</b>
NLACRC	99%	1%	270
CA	94%	6%	4,473
NCI	87%	13%	7,755

**Table 4. Family Member's Age**

<b>RC v CA v NCI</b>	<b>Average Age</b>	<b>N</b>
NLACRC	43.9	274
CA	43.6	4,492
NCI	44.8	7,813

**Table 5. Family Member's Gender**

<b>RC v CA v NCI</b>	<b>Male</b>	<b>Female</b>	<b>Other</b>	<b>N</b>
NLACRC	60%	39%	0%	279
CA	61%	39%	0%	4,559
NCI	60%	40%	0%	7,911

**Table 6. Family Member's Race and Ethnicity**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

<b>RC v CA v NCI</b>	<b>American Indian or Alaska Native</b>	<b>Asian</b>	<b>Black or African American</b>	<b>Pacific Islander</b>	<b>N</b>
NLACRC	1%	9%	6%	0%	278
CA	2%	9%	6%	0%	4,511
NCI	2%	5%	6%	0%	7810

**Table 6b. Family Member's Race and Ethnicity (continued)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

RC v CA v NCI	White	Hispanic or Latino	Other	Prefer Not to Say	N
NLACRC	70%	14%	2%	4%	278
CA	73%	13%	2%	2%	4,511
NCI	80%	8%	2%	2%	7810

**Table 7a. Family Member's Disabilities (not mutually exclusive)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive; therefore, N is not shown.

RC v CA v NCI	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
NLACRC	65%	33%	38%	17%	10%	6%
CA	68%	28%	36%	17%	8%	5%
NCI	74%	33%	34%	16%	8%	6%



**Table 7b. Family Member's Disabilities (continued)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive; therefore, N is not shown.

RC v CA v NCI	Brain Injury	Seizure Disorder or Neurological Disorder	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
NLACRC	8%	25%	0%	9%	1%	1%	11%
CA	9%	25%	0%	8%	1%	1%	10%
NCI	9%	26%	1%	9%	1%	2%	11%

**Table 8a. Family Member's Health Conditions**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive; therefore, N is not shown.

RC v CA v NCI	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
NLACRC	9%	16%	4%	24%	33%
CA	8%	17%	5%	28%	26%
NCI	8%	18%	5%	28%	27%

**Table 8b. Family Member's Health Conditions (continued)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive; therefore, N is not shown.

RC v CA v NCI	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Oral Health or Dental Problems	Sleep Apnea
NLACRC	9%	3%	1%	7%	8%
CA	8%	2%	2%	14%	15%
NCI	12%	2%	4%	13%	17%

**Table 8c. Family Member's Health Conditions (continued)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive; therefore, N is not shown.

\*Added condition in 2021-22

RC v CA v NCI	Asthma*	Other Pulmonary Diagnosis (e.g., COPD, bronchitis, emphysema)*	Chronic Kidney Disease*	Long-term Health Problems Associated with COVID-19 (also known as Long COVID)*	Other
NLACRC	14%	3%	3%	1%	26%
CA	11%	4%	3%	1%	25%
NCI	10%	4%	4%	1%	24%

**Table 9. Family Member's Preferred Means of Communication**

RC v CA v NCI	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
NLACRC	83%	9%	2%	1%	5%	277
CA	80%	13%	2%	1%	4%	4,467
NCI	80%	13%	2%	1%	4%	7,738

**Table 10a. Family Member's Preferred Language**

The standard NCI-IDD Family/Guardian Survey responses are limited to: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and other. California adds additional language responses to their survey tool; the NCI-IDD Average for "Other" captures the additional languages in the standard tool.

RC v CA v NCI	English	Spanish	Chinese (Including Mandarin, Cantonese, and Hokkien)	Tagalog	Vietnamese	American Sign Language (ASL)	N
NLACRC	91%	4%	0%	0%	0%	1%	279
CA	93%	2%	1%	0%	0%	1%	4,497
NCI	95%	1%	0%	0%	0%	1%	7,796

**Table 10b. Family Member's Preferred Language (continued)**

The standard NCI-IDD Family/Guardian Survey responses are limited to: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and other. California adds additional language responses to their survey tool; the NCI-IDD Average for "Other" captures the additional languages in the standard tool.

RC v CA v NCI	Arabic	Armenian	Farsi	Hindi	Hmong	N
NLACRC	0%	0%	0%	0%	0%	279
CA	0%	0%	0%	0%	0%	4,497
NCI	n/a	n/a	n/a	n/a	n/a	7,796

**Table 10c. Family Member's Preferred Language (continued)**

The standard NCI-IDD Family/Guardian Survey responses are limited to: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and other. California adds additional language responses to their survey tool; the NCI-IDD Average for "Other" captures the additional languages in the standard tool.

RC v CA v NCI	Japanese	Khmer	Korean	Laotian	Russian	Other	N
NLACRC	0%	0%	0%	0%	0%	4%	279
CA	0%	0%	0%	0%	0%	3%	4,497
NCI	n/a	n/a	n/a	n/a	n/a	2%	7,796

**Table 11. Family Member Has Legal Court Appointed Guardian or Conservator**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

RC v CA v NCI	No Guardianship/ Conservatorship	Limited	Full	Has No Guardianship/ Conservatorship but Level Is Unknown	N
NLACRC	38%	32%	25%	5%	254
CA	42%	28%	24%	6%	4,159
NCI	29%	21%	44%	6%	7,312

**Table 12. Guardian or Conservator Relationship to Family Member**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses, and personal characteristics.

RC v CA v NCI	Family	Friend	Regional Center Employee or Guardianship Agency	Other	N
NLACRC	97%	0%		3% 0%	150
CA	92%	1%		5% 2%	2,255
NCI	88%	2%		6% 3%	4,676

**Table 13a. Family Member's Highest level of Education**

<b>RC v CA v NCI</b>	<b>Did Not Complete High School (and Not Currently Enrolled)</b>	<b>Currently Enrolled in High School</b>	<b>High School Certification</b>	<b>High School Diploma/GED</b>	<b>N</b>
NLACRC	28%	1%	34%	20%	266
CA	30%	1%	31%	22%	4,273
NCI	29%	1%	32%	27%	7,415

**Table 13b. Family Member's Highest level of Education**

<b>RC v CA v NCI</b>	<b>Vocational School or Certificate Program</b>	<b>Some College</b>	<b>College Degree or Higher</b>	<b>N</b>
NLACRC	4%	9%	5%	266
CA	3%	8%	5%	4,273
NCI	2%	5%	4%	7,415

**Table 14. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

RC v CA v NCI	No Support Needed	Some Support Needed	Extensive Support Needed	N
NLACRC	36%	35%	29%	269
CA	40%	35%	25%	4,348
NCI	36%	38%	26%	7,564

**Table 15. Family Member's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

RC v CA v NCI	No Support Needed	Some Support Needed	Extensive Support Needed	N
NLACRC	29%	38%	33%	273
CA	32%	36%	33%	4,435
NCI	26%	38%	36%	7,708

**Table 16. Family Member's Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

RC v CA v NCI	No Support Needed	Some Support Needed	Extensive Support Needed	N
NLACRC	4%	30%	66%	280
CA	5%	30%	65%	4,486
NCI	3%	25%	72%	7,765



## *Demographics of Respondents*

*This section provides demographic information about the respondent.*

**Table 17a. Language Usually Spoken at Home**

The standard NCI-IDD Family/Guardian Survey responses are limited to: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and other. California adds additional language responses to their survey tool; the NCI-IDD Average for “Other” captures the additional languages in the standard tool.

<b>RC v CA v NCI</b>	<b>English</b>	<b>Spanish</b>	<b>Chinese (Including Mandarin, Cantonese, and Hokkien)</b>	<b>Tagalog</b>	<b>Vietnamese</b>	<b>American Sign Language (ASL)</b>	<b>N</b>
NLACRC	87%	8%	1%	0%	0%	0%	280
CA	92%	4%	1%	0%	0%	0%	4,513
NCI	95%	2%	0%	1%	0%	0%	7,803

**Table 17b. Language Usually Spoken at Home (continued)**

The standard NCI-IDD Family/Guardian Survey responses are limited to: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and other. California adds additional language responses to their survey tool; the NCI-IDD Average for “Other” captures the additional languages in the standard tool.

<b>RC v CA v NCI</b>	<b>Arabic</b>	<b>Armenian</b>	<b>Farsi</b>	<b>Hindi</b>	<b>Hmong</b>	<b>N</b>
NLACRC	0%	0%	0%	0%	0%	280
CA	0%	0%	0%	0%	0%	4,513
NCI	n/a	n/a	n/a	n/a	n/a	7,803

**Table 17c. Language Usually Spoken at Home (continued)**

The standard NCI-IDD Family/Guardian Survey responses are limited to: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and other. California adds additional language responses to their survey tool; the NCI-IDD Average for “Other” captures the additional languages in the standard tool.

<b>RC v CA v NCI</b>	<b>Japanese</b>	<b>Khmer</b>	<b>Korean</b>	<b>Laotian</b>	<b>Russian</b>	<b>Other</b>	<b>N</b>
NLACRC	0%	0%	0%	0%	0%	3%	280
CA	0%	0%	0%	0%	0%	2%	4,513
NCI	n/a	n/a	n/a	n/a	n/a	2%	7,803

**Table 18. Respondent's Age**

<b>RC v CA v NCI</b>	<b>Under 35</b>	<b>35-54</b>	<b>55-74</b>	<b>75 and Older</b>	<b>N</b>
NLACRC	3%	6%	51%	40%	280
CA	2%	8%	55%	35%	4,505
NCI	1%	11%	60%	28%	7,797

**Table 19. Respondent's Health**

<b>RC v CA v NCI</b>	<b>Excellent</b>	<b>Very Good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>N</b>
NLACRC	12%	33%	32%	17%	6%	276
CA	15%	34%	32%	16%	3%	4463
NCI	15%	36%	33%	14%	3%	7,744

**Table 20. Respondent's Relationship to Family Member**

<b>RC v CA v NCI</b>	<b>Parent</b>	<b>Sibling</b>	<b>Spouse</b>	<b>Grandparent</b>	<b>Public Guardian</b>	<b>Private Guardian</b>	<b>Other</b>	<b>N</b>
NLACRC	90%	5%	0%	1%	0%	1%	3%	278
CA	88%	7%	0%	0%	0%	0%	4%	4,456
NCI	73%	16%	0%	1%	2%	1%	7%	7,745

**Table 21. Respondent's Frequency of Visits With Family Member in the Past 12 months**

<b>RC v CA v NCI</b>	<b>Did Not Visit</b>	<b>1 to 3 Times</b>	<b>4 to 6 Times</b>	<b>7 to 12 Times</b>	<b>More Than 12 Times</b>	<b>N</b>
NLACRC	5%	8%	11%	10%	66%	275
CA	7%	11%	9%	10%	63%	4,455
NCI	6%	11%	11%	12%	61%	7,736

**Table 22. Respondent's Highest Level of Education**

<b>RC v CA v NCI</b>	<b>No High School Diploma or GED</b>	<b>High School Diploma or GED</b>	<b>Vocational School or Certificate Program</b>	<b>Some College</b>	<b>College Degree or Higher</b>	<b>N</b>
NLACRC	7%	15%	5%	20%	53%	273
CA	5%	12%	4%	23%	55%	4,417
NCI	4%	17%	6%	22%	51%	7,669

**Table 23. Total Taxable Household Income of Wage Earners in the Past Year**

Please note: Does not include state/federal benefits such as SSI, SSDI etc.

<b>RC v CA v NCI</b>	<b>No Earned Income</b>	<b>Up to \$15,000</b>	<b>\$15,001- \$25,000</b>	<b>\$25,001- \$50,000</b>	<b>\$50,001- \$75,000</b>	<b>Over \$75,000</b>	<b>Prefer Not to Say</b>	<b>N</b>
NLACRC	11%	3%	4%	14%	11%	24%	34%	265
CA	13%	5%	6%	11%	11%	23%	32%	4,290
NCI	5%	6%	12%	12%	22%	11%	32%	7,386

## *Services and Supports Received*

*This section provides information about the services and supports received by the family from the regional center <sup>3</sup>(RC).*

---

<sup>3</sup> Some NCI states provide services through a statewide ID/DD agency

**Table 24a. Services and Supports Received From Regional Center<sup>4</sup>**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive; therefore, N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

<b>RC v CA v NCI</b>	<b>Financial Support</b>	<b>In-Home Support</b>	<b>Residential Supports</b>
NLACRC	55%	47%	66%
CA	51%	47%	64%
NCI	40%	45%	59%

**Table 24b. Services and Supports Received From Regional Center (continued)<sup>5</sup>**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive; therefore, N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

<b>RC v CA v NCI</b>	<b>Day or Employment Supports</b>	<b>Transportation</b>	<b>Mental/behavioral health care or other treatments or therapies</b>
NLACRC	60%	51%	52%
CA	60%	60%	45%
NCI	76%	52%	19%

<sup>4</sup> Some NCI states provide services through a statewide ID/DD agency

<sup>5</sup> Some NCI states provide services through a statewide ID/DD agency

**Table 25. Additional Services and Supports Received (*Not from the Regional Centers*<sup>6</sup>)**

All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics; categories are not mutually exclusive; therefore, N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

<b>RC v CA v NCI</b>	<b>Social Security Payments (SSI/SSB)</b>	<b>Services or Supports from Other Agencies or Organizations</b>
NLACRC	88%	18%
CA	90%	24%
NCI	93%	27%

---

<sup>6</sup> Some NCI states provide services through a statewide ID/DD agency



## *Family/Guardian Survey Results*

## *Information and Planning*

*Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state developmental disabilities system.*

Do you get enough information to take part in planning services for your family member?

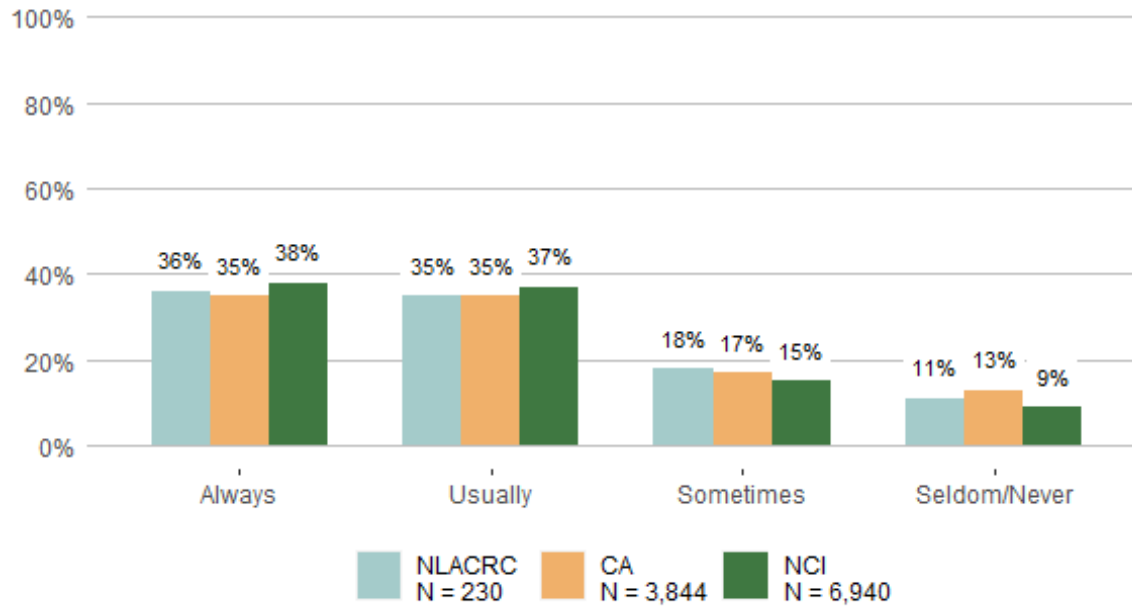


Table 26. Do you get enough information to take part in planning services for your family member?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	36%	35%	18%	11%	230
CA	35%	35%	17%	13%	3,844
NCI	38%	37%	15%	9%	6,940

Is the information you get about services and supports easy to understand?

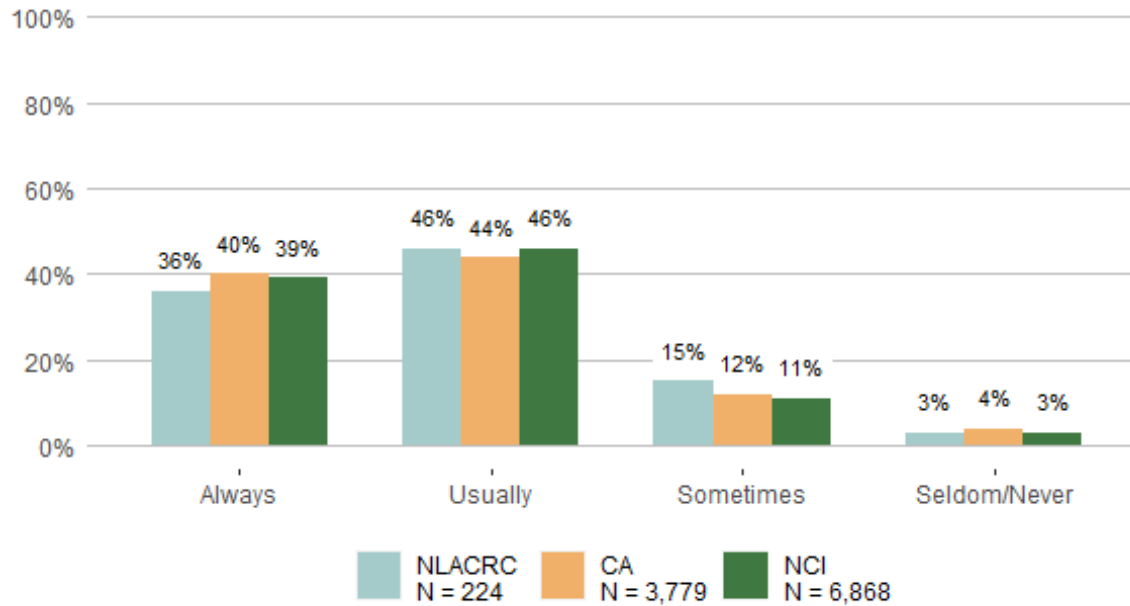
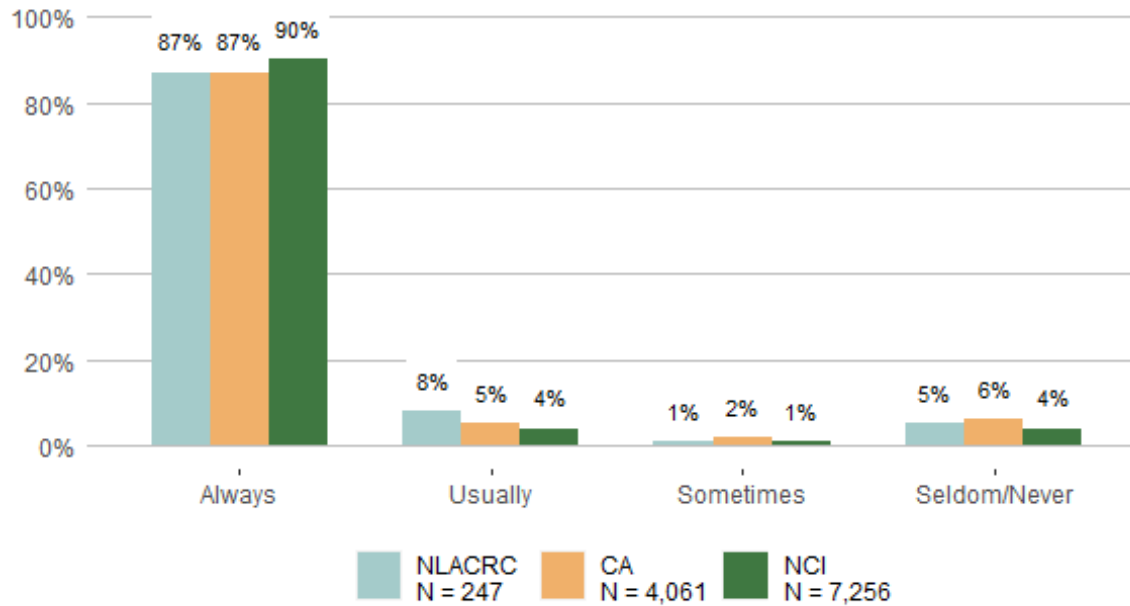


Table 27. Is the information you get about services and supports easy to understand?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	36%	46%	15%	3%	224
CA	40%	44%	12%	4%	3,779
NCI	39%	46%	11%	3%	6,868

Do you get information about services and supports  
in your preferred language?

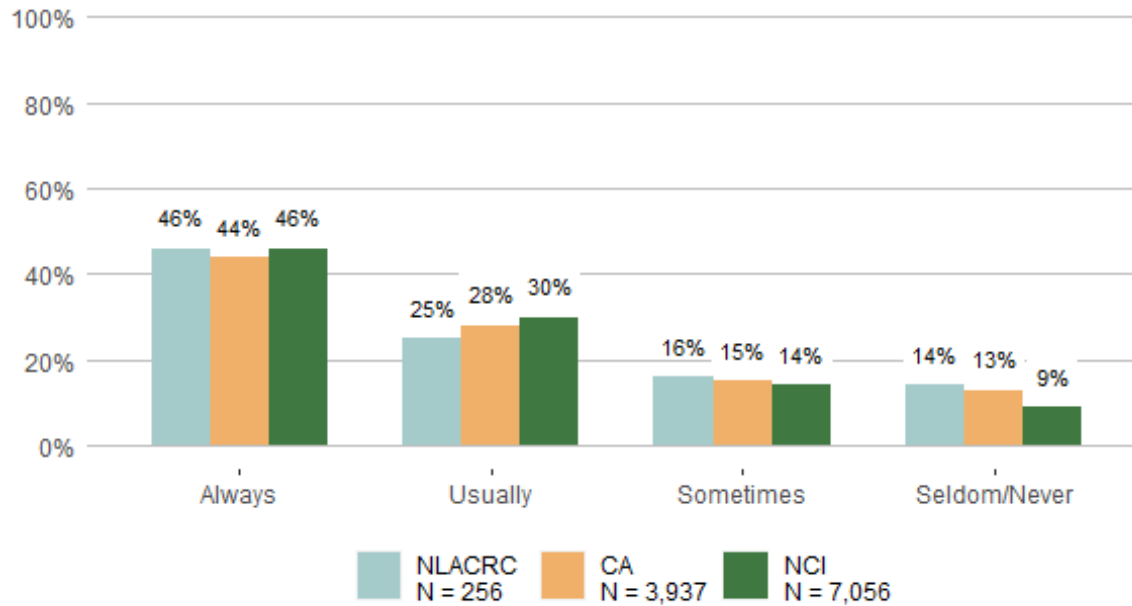


**Table 28. Do you get information about services and supports in your preferred language?**

New question in 2021-22

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	87%	8%	1%	5%	247
CA	87%	5%	2%	6%	4,061
NCI	90%	4%	1%	4%	7,256

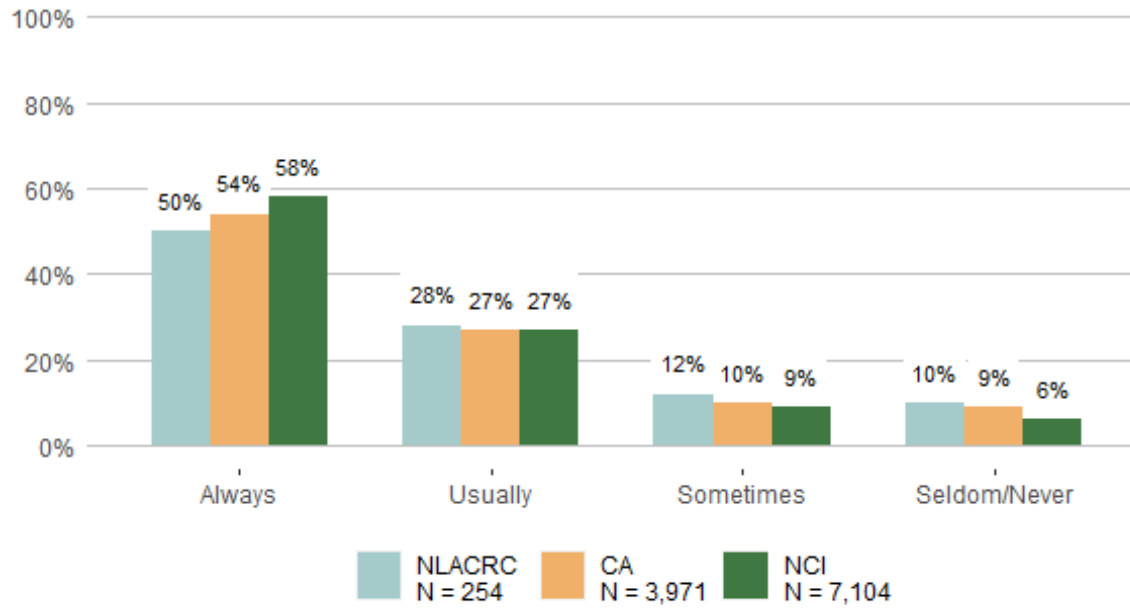
Do staff or the residential agency keep you informed about how your family member is doing?



**Table 29. Do staff or the residential agency keep you informed about how your family member is doing?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	46%	25%	16%	14%	256
CA	44%	28%	15%	13%	3,937
NCI	46%	30%	14%	9%	7,056

Does the case manager/service coordinator listen  
to your family's choices and opinions?

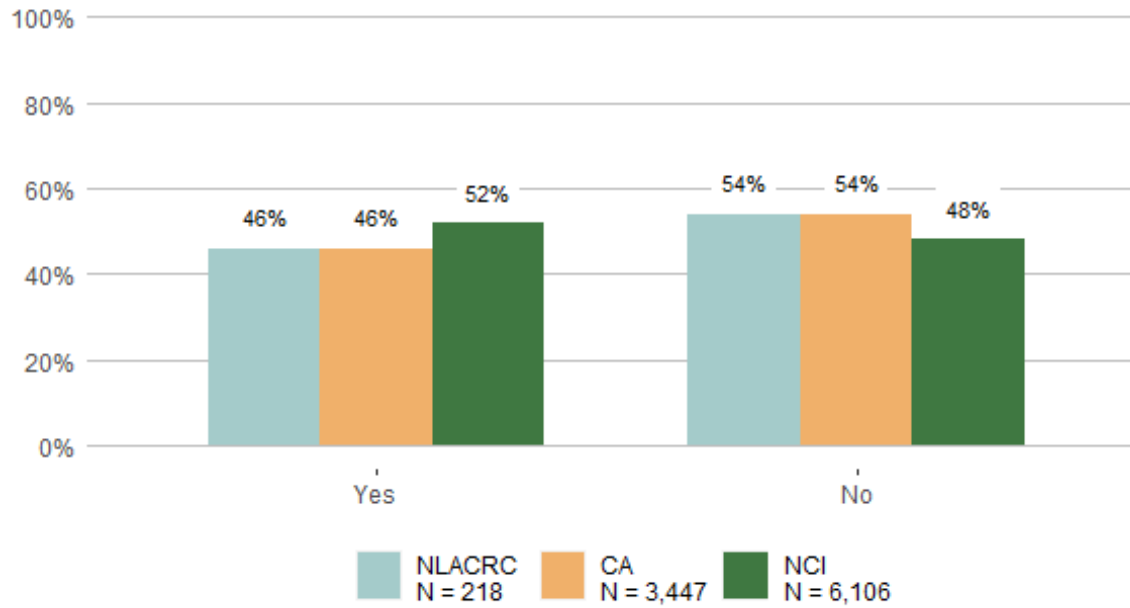


**Table 30. Does the case manager/service coordinator listen to your family's choices and opinions?**

Question changed in 2021-22

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	50%	28%	12%	10%	254
CA	54%	27%	10%	9%	3,971
NCI	58%	27%	9%	6%	7,104

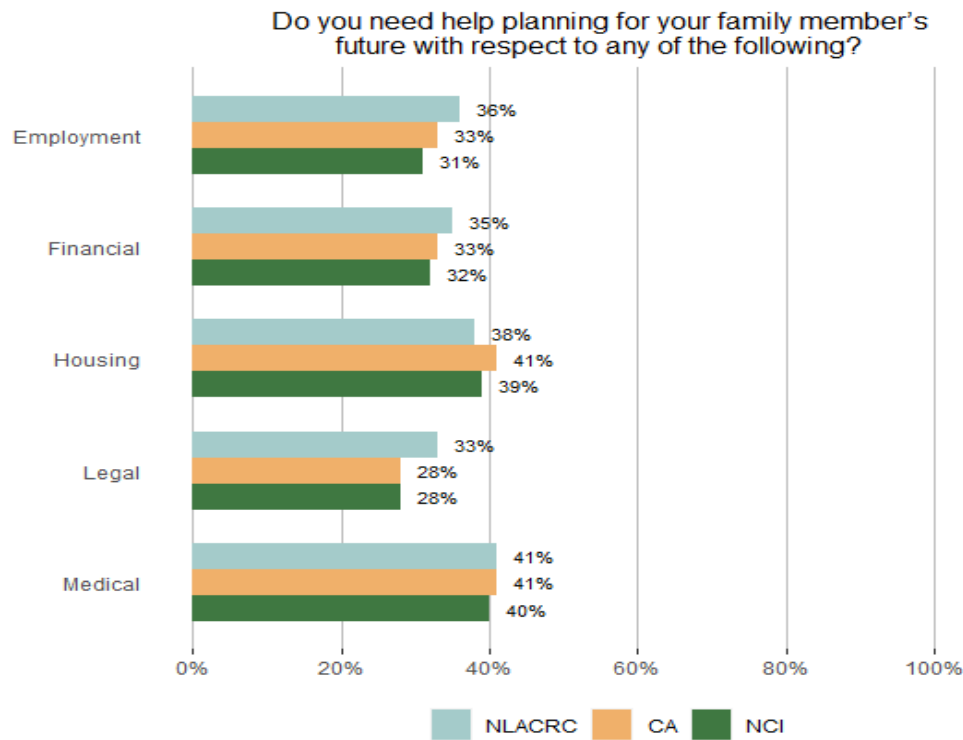
### Has your family learned about alternatives to conservatorship?



**Table 31. Has your family learned about alternatives to conservatorship?**

RC v CA v NCI	Yes	No	N
NLACRC	46%	54%	218
CA	46%	54%	3,447
NCI	52%	48%	6,106

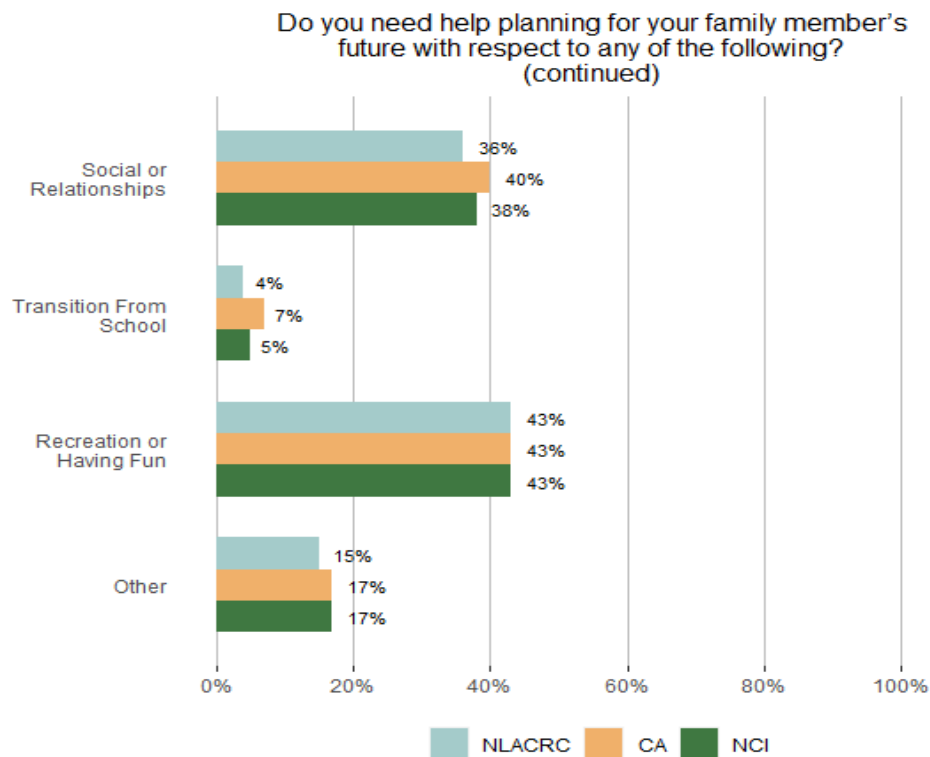




**Table 32a. Do you need help planning for your family member's future with respect to any of the following?**

Categories are not mutually exclusive, therefore N is not shown

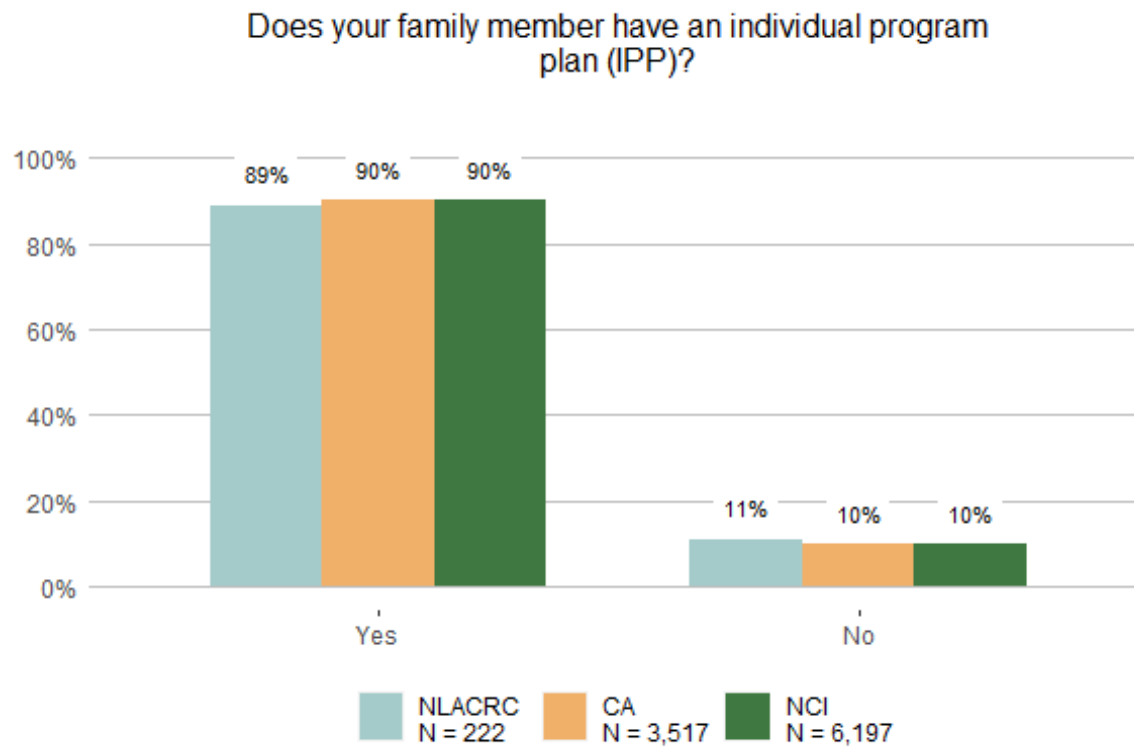
RC v CA v NCI	Employment	Financial	Housing	Legal	Medical
NLACRC	36%	35%	38%	33%	41%
CA	33%	33%	41%	28%	41%
NCI	31%	32%	39%	28%	40%



**Table 32b. Do you need help planning for your family member's future with respect to any of the following? (continued)**

Categories are not mutually exclusive, therefore N is not shown

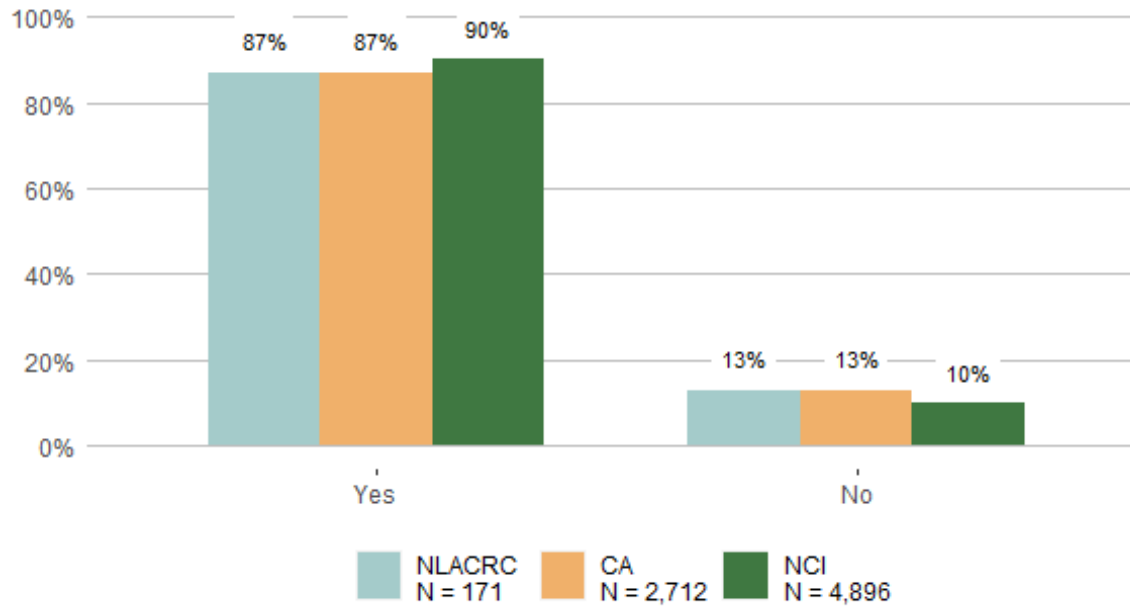
RC v CA v NCI	Social or Relationships	Transition From School	Recreation or Having Fun	Other
NLACRC	36%	4%	43%	15%
CA	40%	7%	43%	17%
NCI	38%	5%	43%	17%



**Table 33. Does your family member have an individual program plan (IPP)?**

RC v CA v NCI	Yes	No	N
NLACRC	89%	11%	222
CA	90%	10%	3,517
NCI	90%	10%	6,197

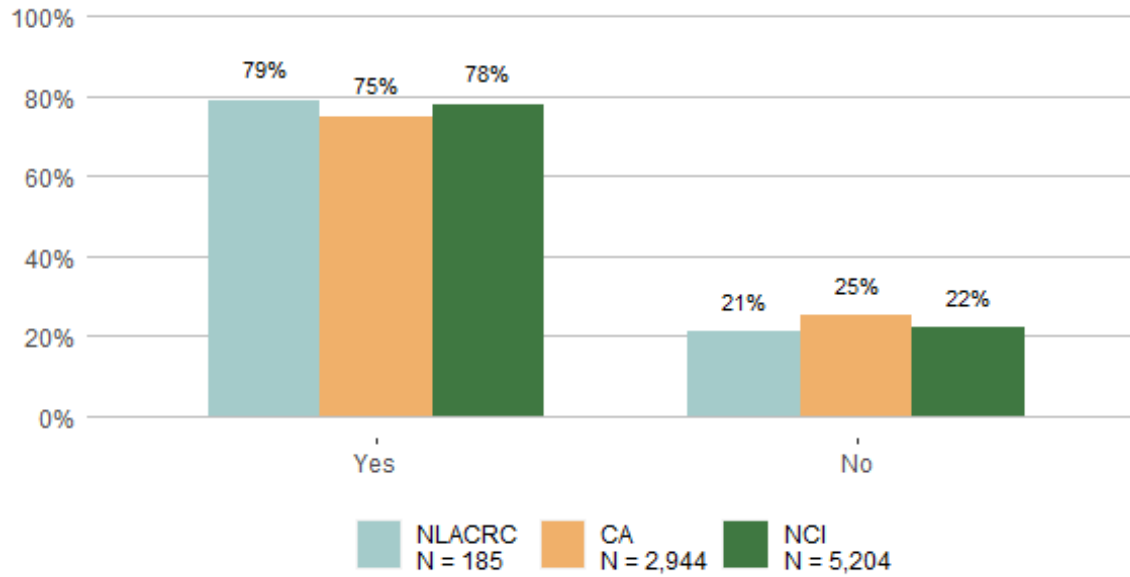
Does the IPP include all the services and supports  
your family member needs?



**Table 34. Does the IPP include all the services and supports your family member needs?**

RC v CA v NCI	Yes	No	N
NLACRC	87%	13%	171
CA	87%	13%	2,712
NCI	90%	10%	4,896

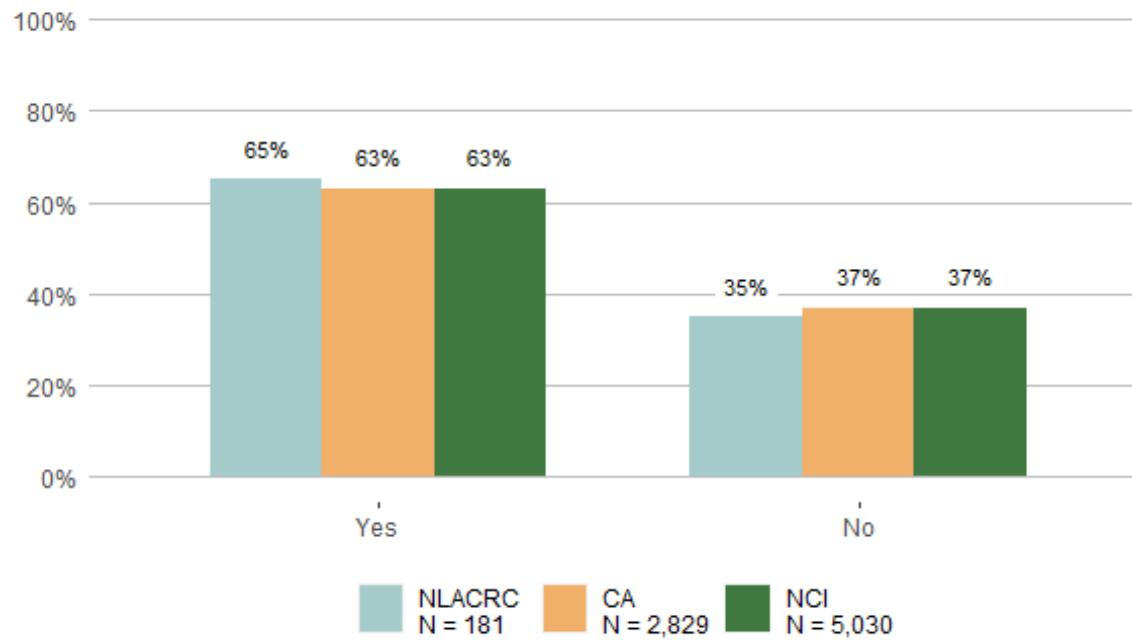
Did you or someone else in your family (besides your family member with a disability) help make the IPP?



**Table 35. Did you or someone else in your family (besides your family member with a disability) help make the IPP?**

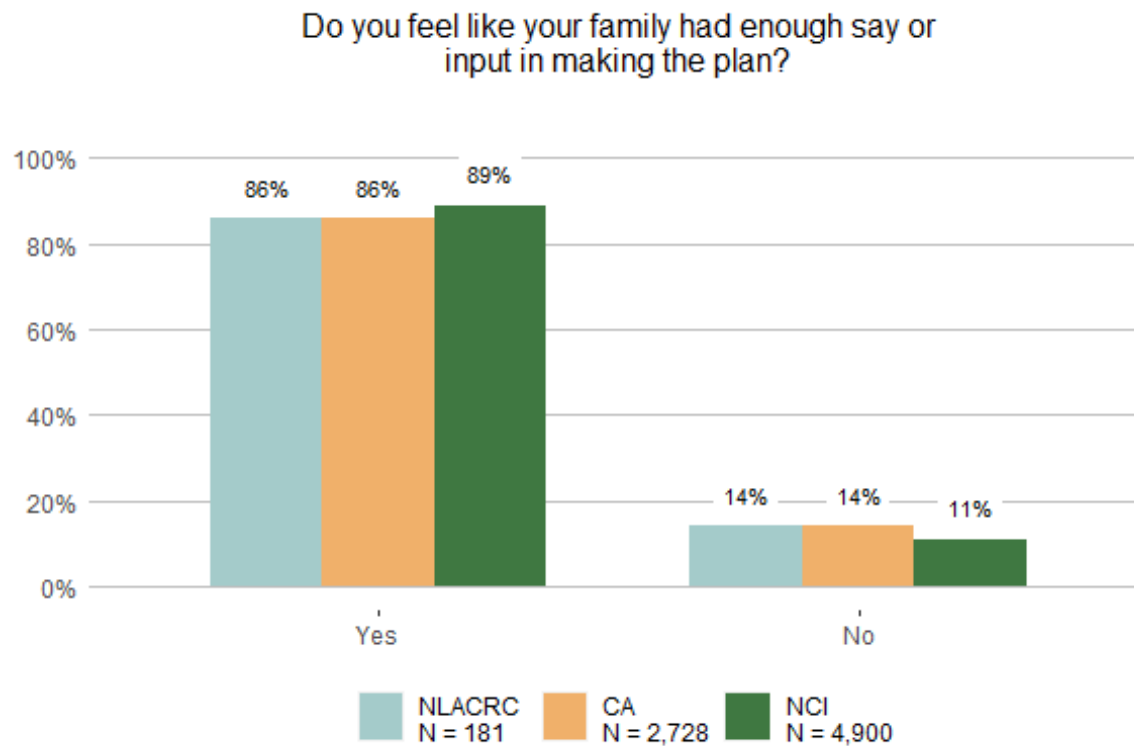
RC v CA v NCI	Yes	No	N
NLACRC	79%	21%	185
CA	75%	25%	2,944
NCI	78%	22%	5,204

### Did your family member help make the IPP?



**Table 36. Did your family member help make the IPP?**

RC v CA v NCI	Yes	No	N
NLACRC	65%	35%	181
CA	63%	37%	2,829
NCI	63%	37%	5,030

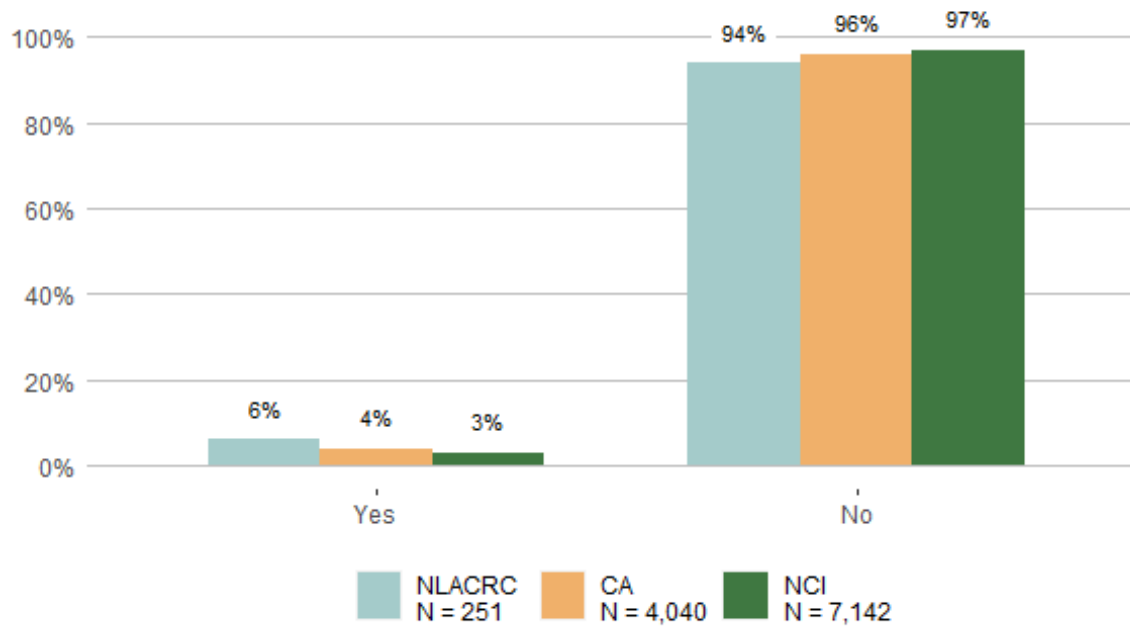


**Table 37. Do you feel like your family had enough say or input in making the plan?**

New question in 2021-22

RC v CA v NCI	Yes	No	N
NLACRC	86%	14%	181
CA	86%	14%	2,728
NCI	89%	11%	4,900

Did your family member leave school services and begin adult services during the past 12 months?

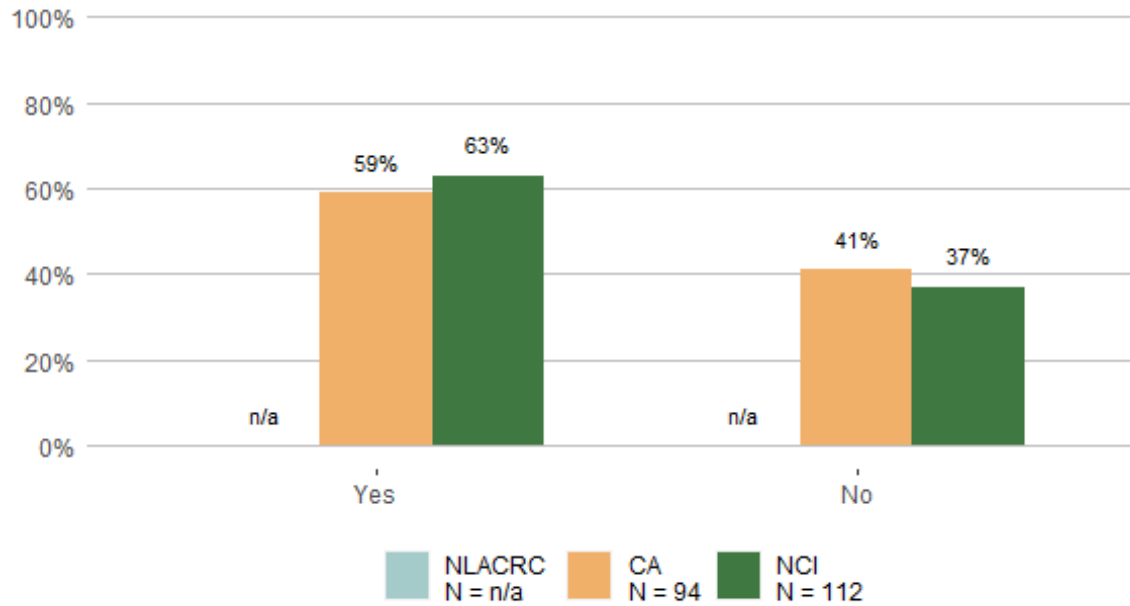


**Table 38. Did your family member leave school services and begin adult services during the past 12 months?**

RC v CA v NCI	Yes	No	N
NLACRC	6%	94%	251
CA	4%	96%	4,040
NCI	3%	97%	7,142



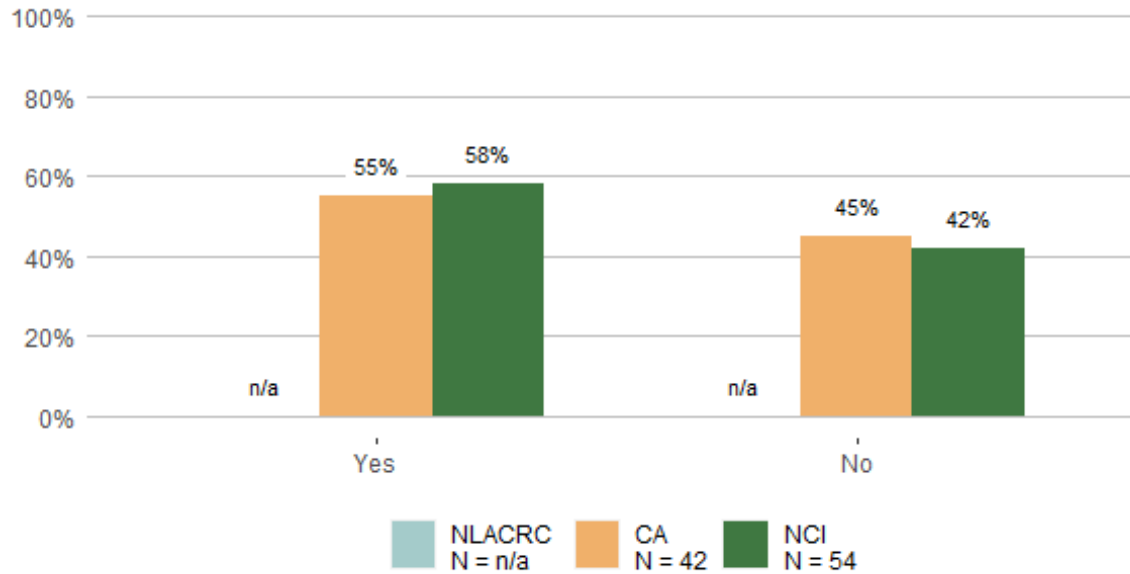
If your family member left school services during the past year, did they have a transition plan?



**Table 39. If your family member left school services during the past year, did they have a transition plan?**

RC v CA v NCI	Yes	No	N
NLACRC	n/a	n/a	n/a
CA	59%	41%	94
NCI	63%	37%	112

If family member had a transition plan, did the transition plan include getting or continuing work in a community job?

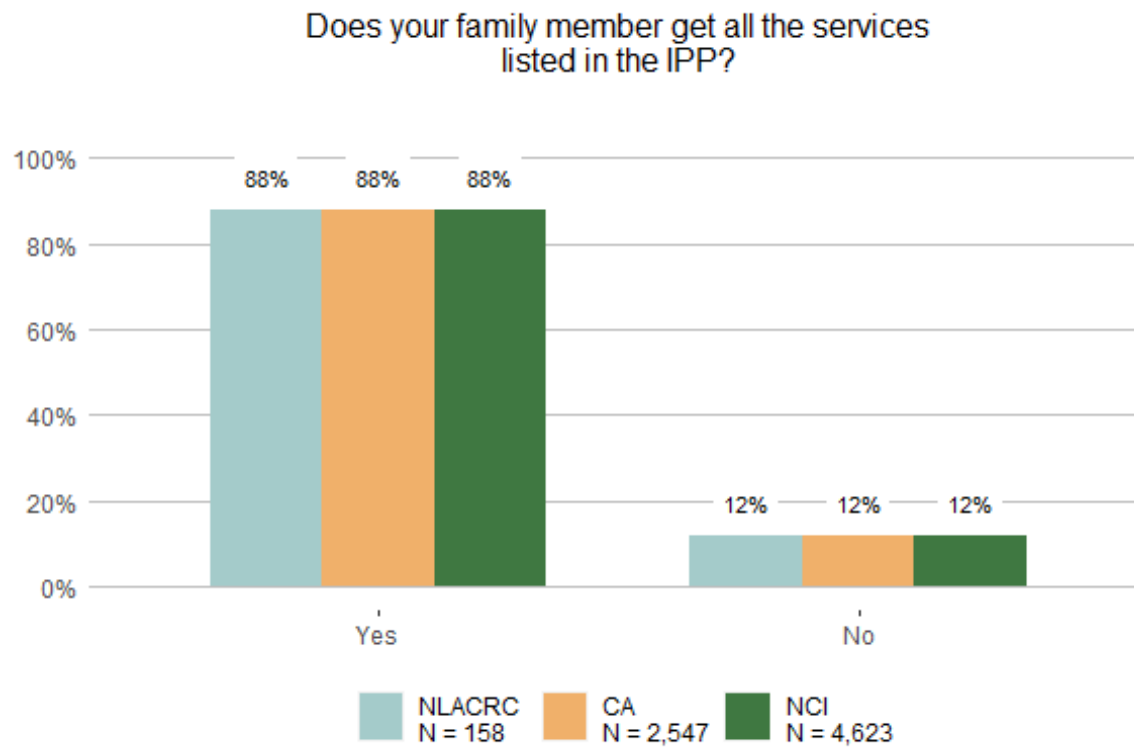


**Table 40. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?**

RC v CA v NCI	Yes	No	N
NLACRC	n/a	n/a	n/a
CA	55%	45%	42
NCI	58%	42%	54

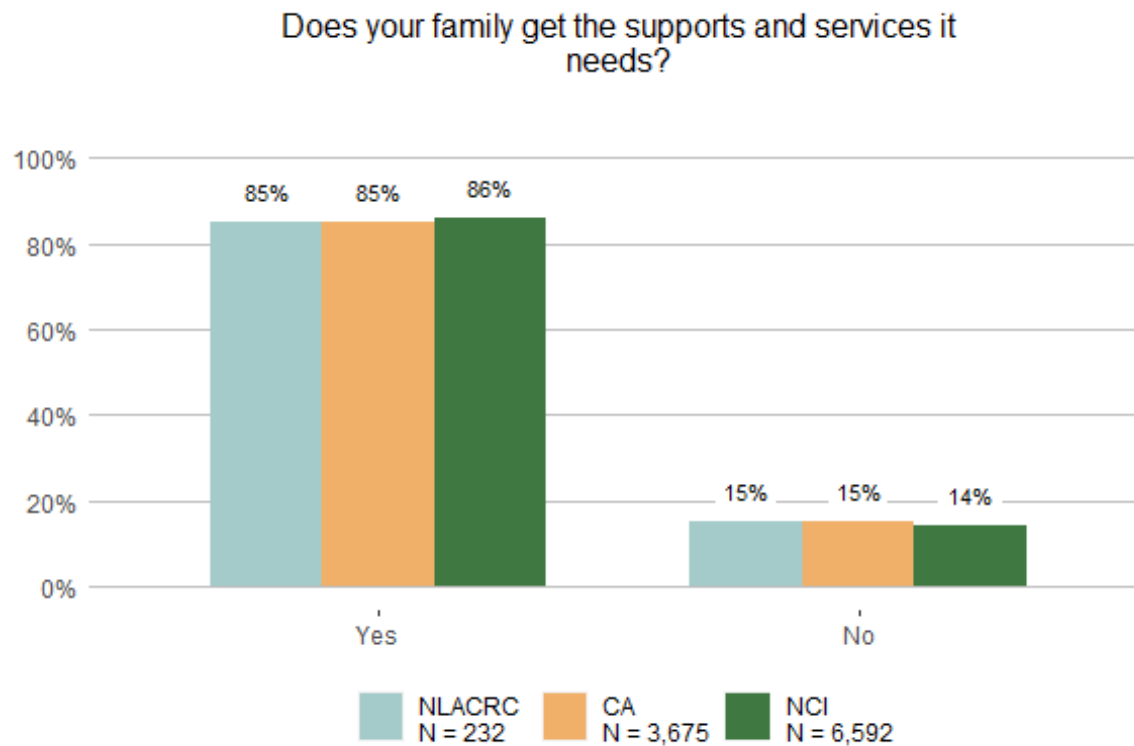
## *Access and Delivery of Services and Supports*

*Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state developmental disabilities system.*



**Table 41. Does your family member get all the services listed in the IPP?**

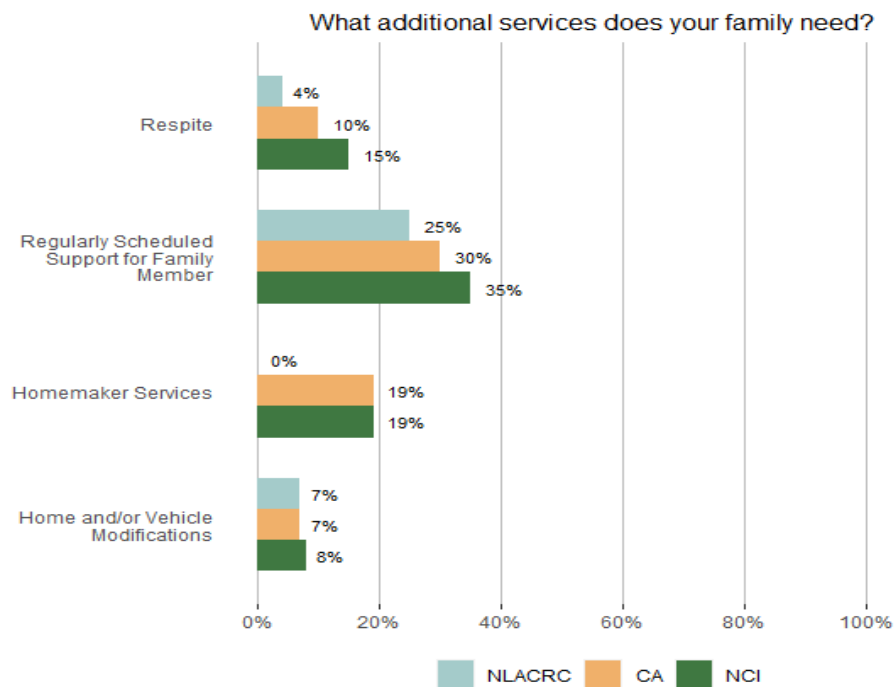
RC v CA v NCI	Yes	No	N
NLACRC	88%	12%	158
CA	88%	12%	2,547
NCI	88%	12%	4,623



**Table 42. Does your family get the supports and services it needs?**

Responses to this question might have been impacted by the COVID-19 pandemic.

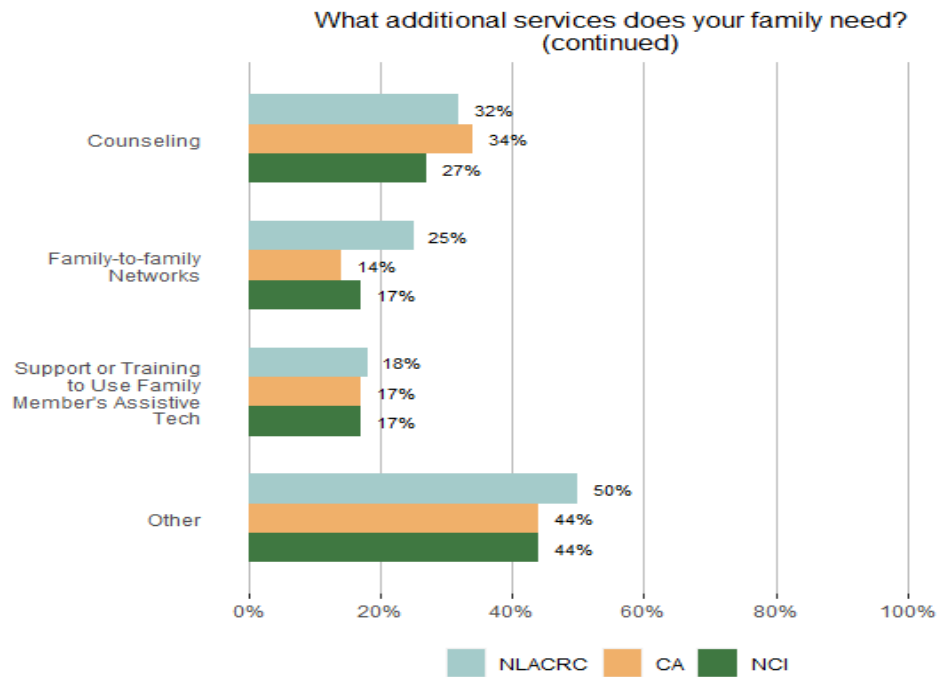
RC v CA v NCI	Yes	No	N
NLACRC	85%	15%	232
CA	85%	15%	3,675
NCI	86%	14%	6,592



**Table 43a. What additional services does your family need?**

Categories are not mutually exclusive; therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

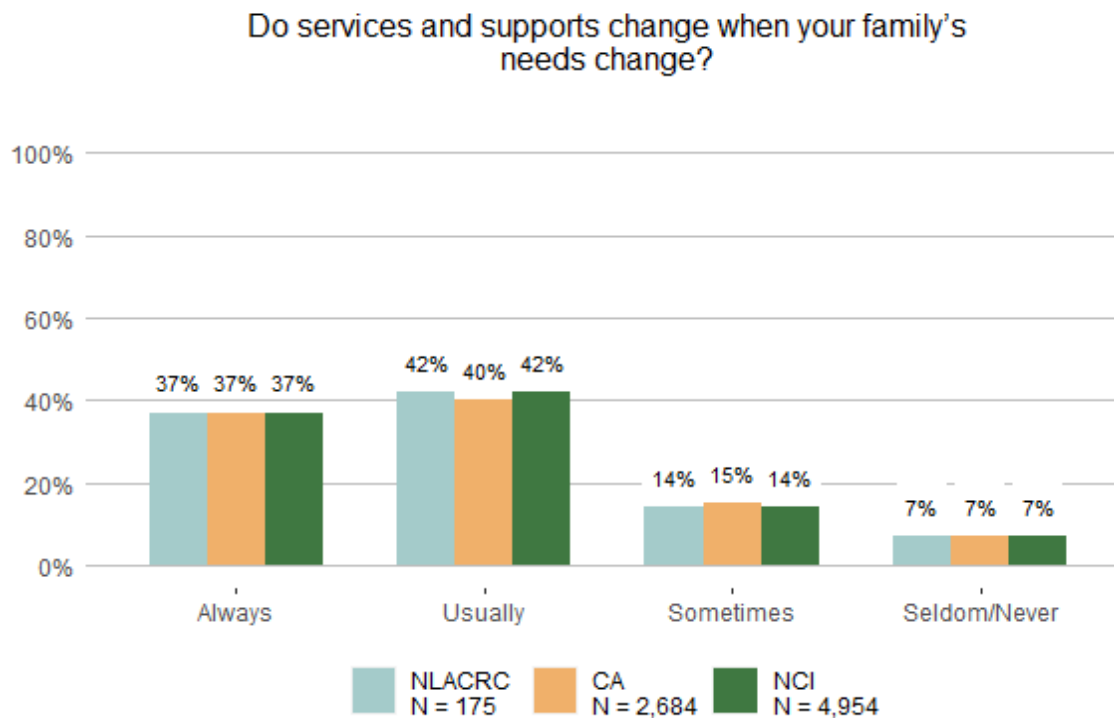
RC v CA v NCI	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home and/or Vehicle Modifications
NLACRC	4%	25%	0%	7%
CA	10%	30%	19%	7%
NCI	15%	35%	19%	8%



**Table 43b. What additional services does your family need? (continued)**

Categories are not mutually exclusive; therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Counseling	Family-to-family Networks	Support or Training to Use Family Member's Assistive Tech	Other
NLACRC	32%	25%	18%	50%
CA	34%	14%	17%	44%
NCI	27%	17%	17%	44%



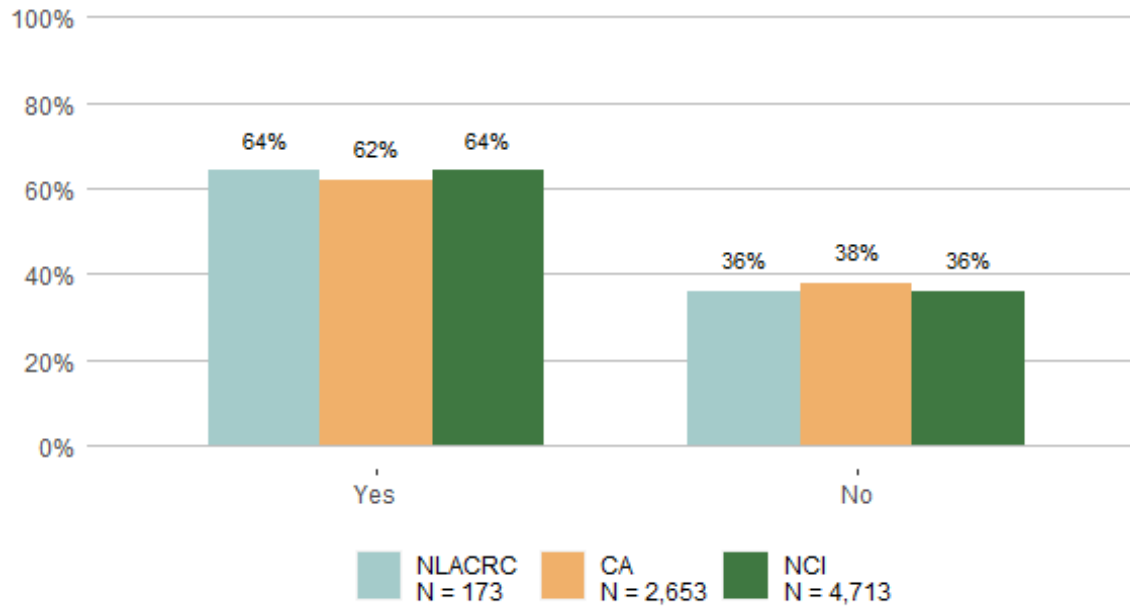
**Table 44b. Do services and supports change when your family's needs change?**

Categories are not mutually exclusive; therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	37%	42%	14%	7%	175
CA	37%	40%	15%	7%	2,684
NCI	37%	42%	14%	7%	4,954



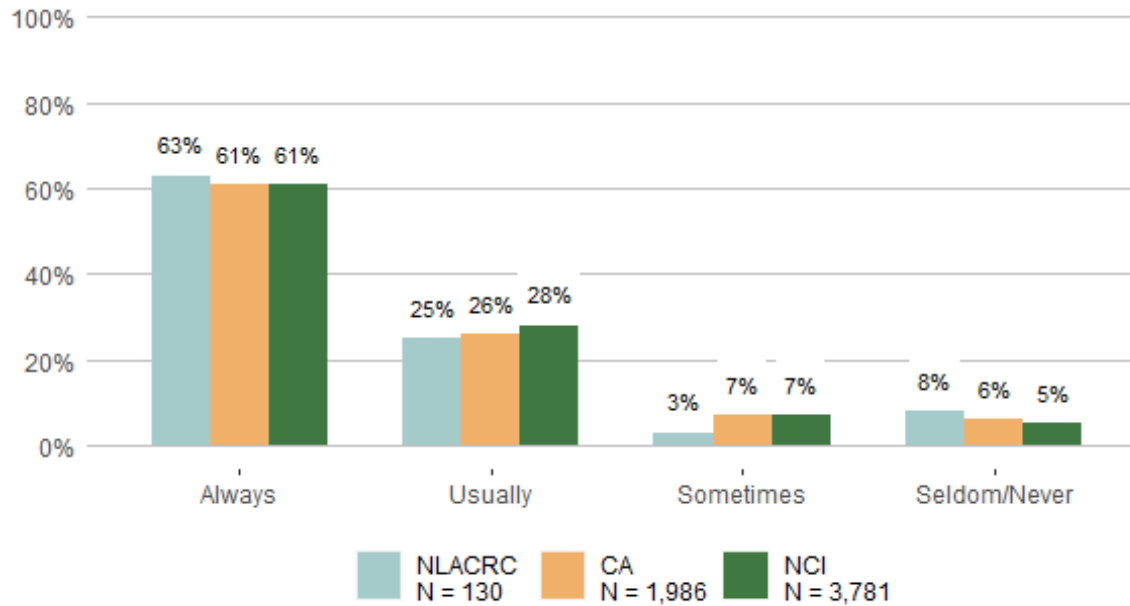
Does your family member have enough supports to work or volunteer in the community?



**Table 45. Does your family member have enough supports to work or volunteer in the community?**

RC v CA v NCI	Yes	No	N
NLACRC	64%	36%	173
CA	62%	38%	2,653
NCI	64%	36%	4,713

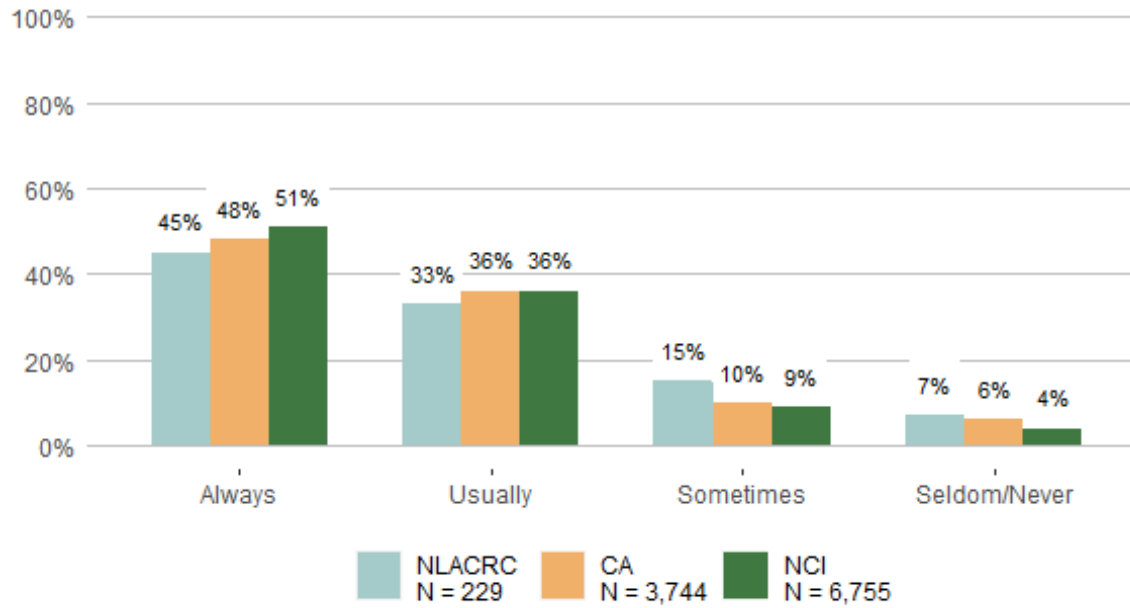
Does your family member have the special equipment or accommodations they need?



**Table 46. Does your family member have the special equipment or accommodations they need?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	63%	25%	3%	8%	130
CA	61%	26%	7%	6%	1,986
NCI	61%	28%	7%	5%	3,781

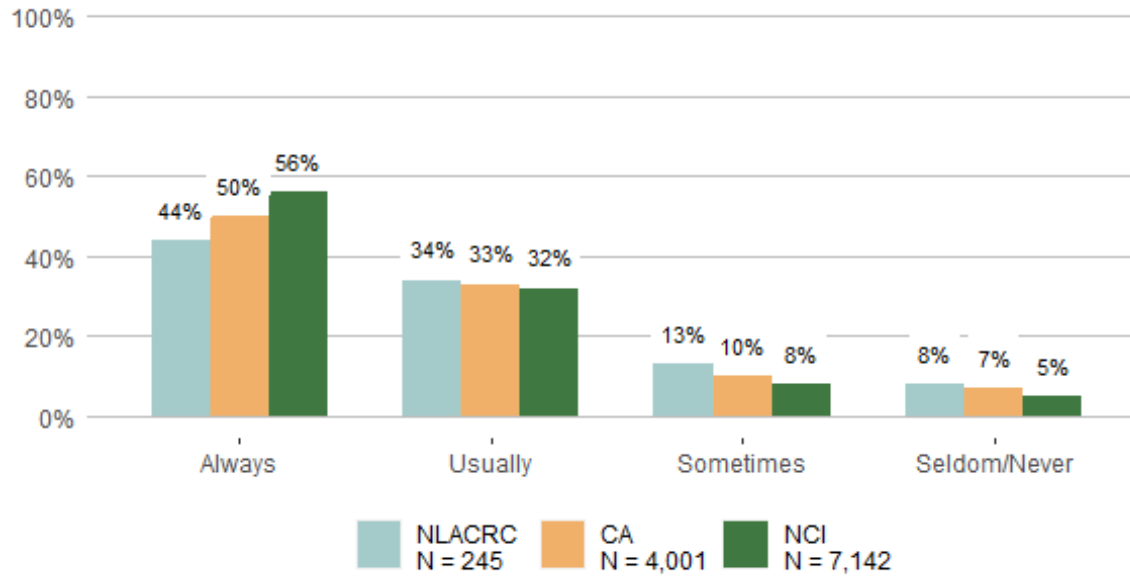
Are you or your family member able to contact their support workers when you want?



**Table 47. Are you or your family member able to contact their support workers when you want?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	45%	33%	15%	7%	229
CA	48%	36%	10%	6%	3,744
NCI	51%	36%	9%	4%	6,755

Are you or your family member able to contact  
their case manager/service coordinator when you  
want?



**Table 48. Are you or your family member able to contact their case manager/service coordinator when you want?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	44%	34%	13%	8%	245
CA	50%	33%	10%	7%	4,001
NCI	56%	32%	8%	5%	7,142

Do service providers for your family member work together to provide support?

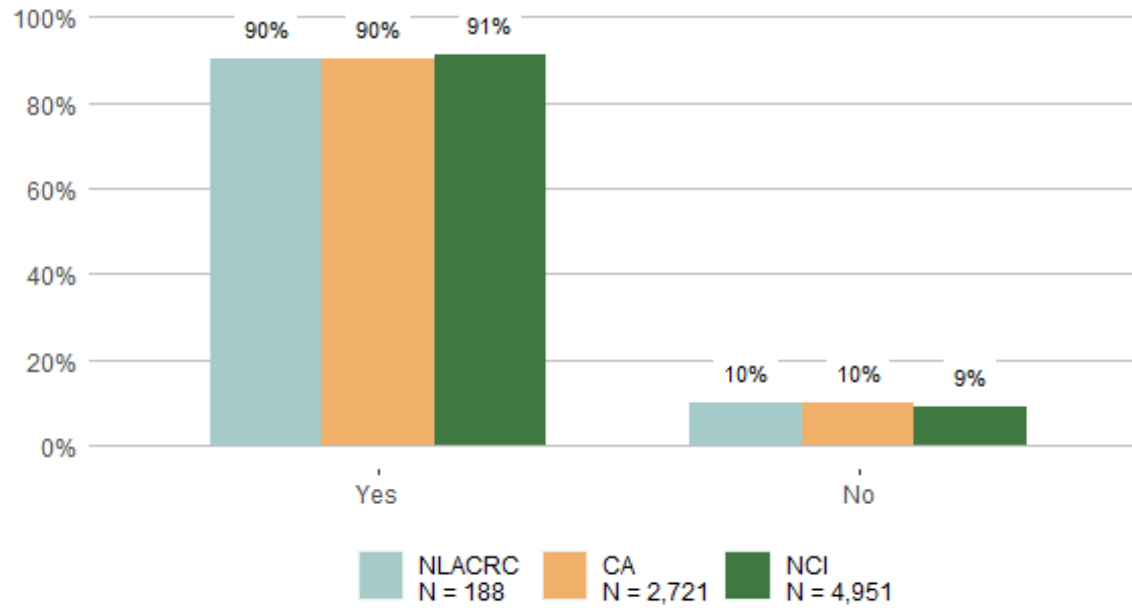
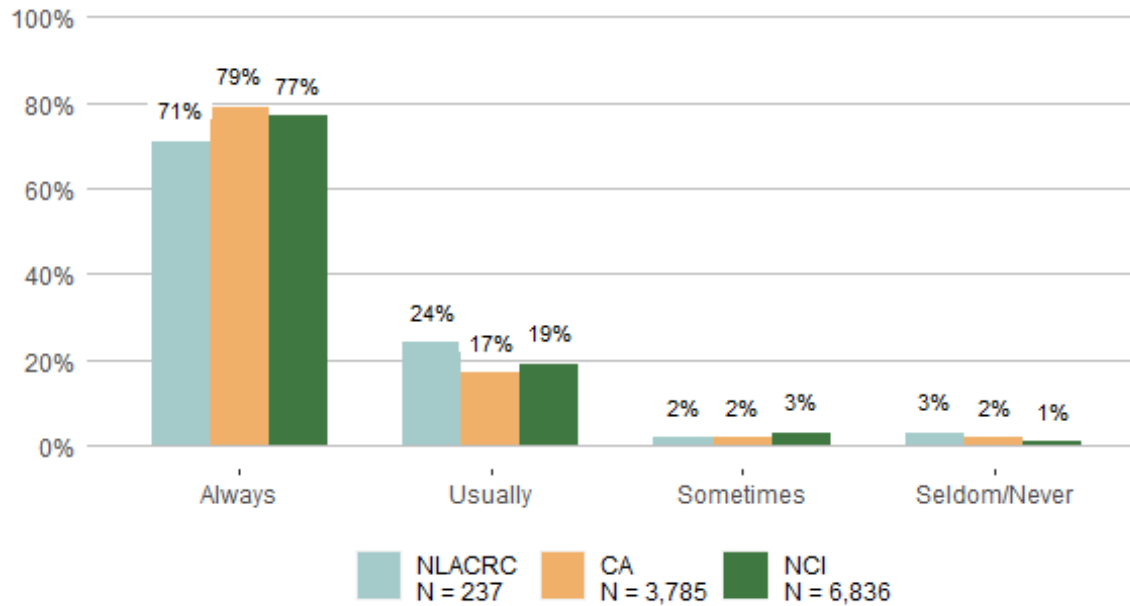


Table 49. Do service providers for your family member work together to provide support?

RC v CA v NCI	Yes	No	N
NLACRC	90%	10%	188
CA	90%	10%	2,721
NCI	91%	9%	4,951

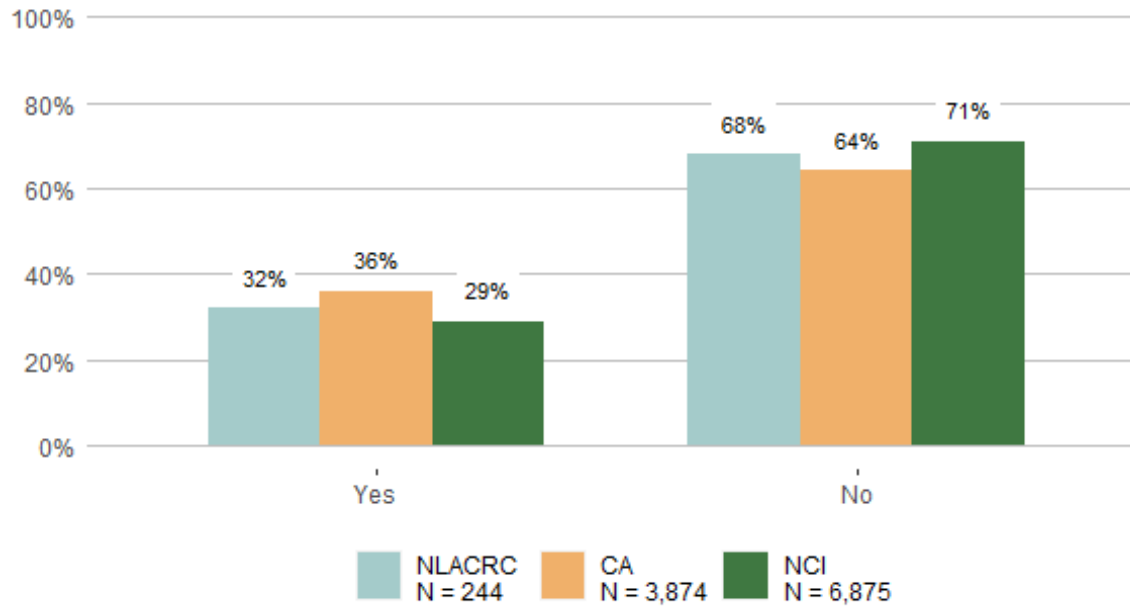
Are services delivered in a way that is respectful  
of your family's culture?



**Table 50. Are services delivered in a way that is respectful of your family's culture?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	71%	24%	2%	3%	237
CA	79%	17%	2%	2%	3,785
NCI	77%	19%	3%	1%	6,836

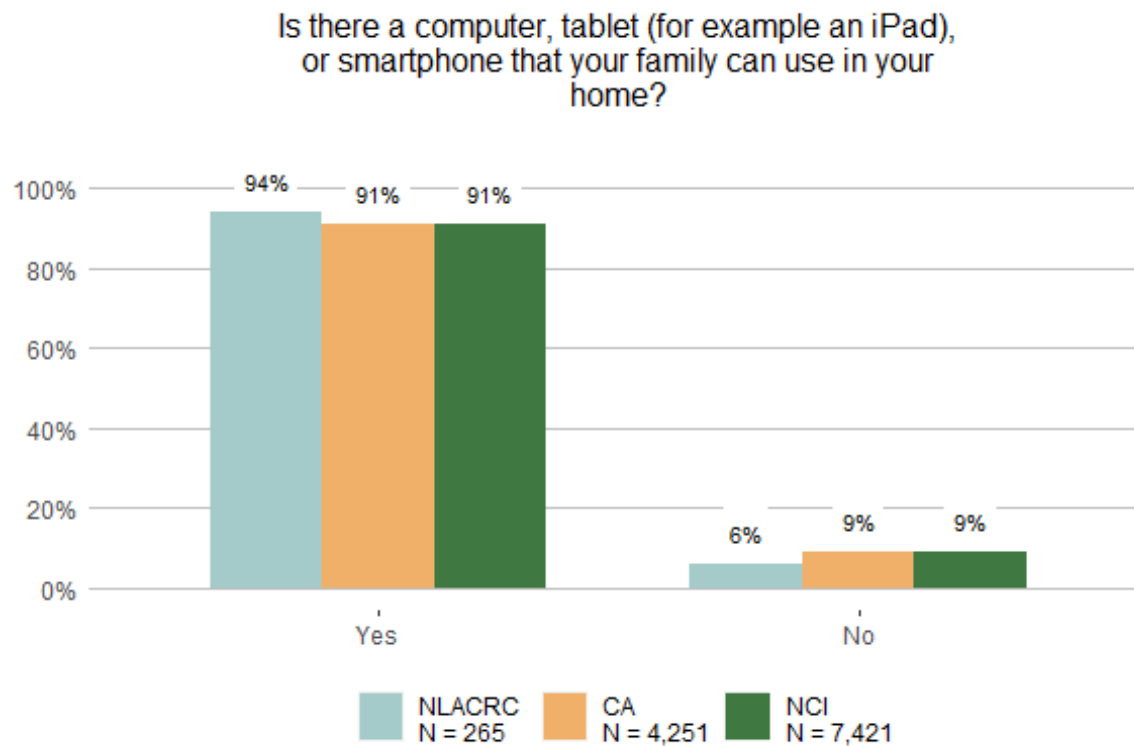
Does your family member use technology in their everyday life to help them do things on their own?



**Table 51. Does your family member use technology in their everyday life to help them do things on their own?**

New question in 2021-22

RC v CA v NCI	Yes	No	N
NLACRC	32%	68%	244
CA	36%	64%	3,874
NCI	29%	71%	6,875



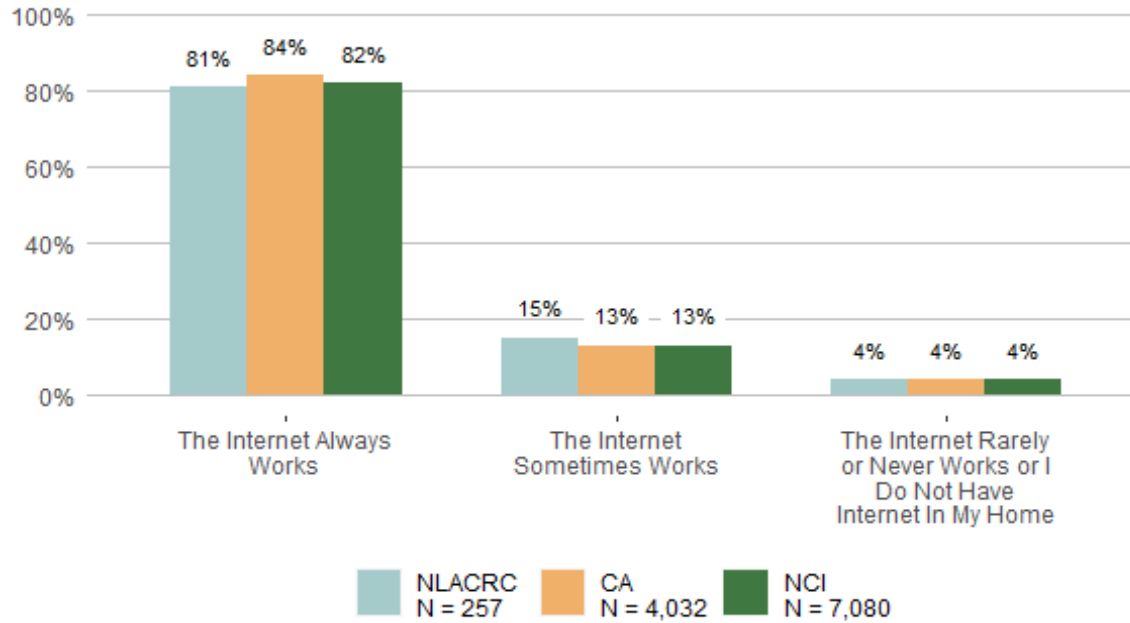
**Table 52. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?**

New question in 2021-22

RC v CA v NCI	Yes	No	N
NLACRC	94%	6%	265
CA	91%	9%	4,251
NCI	91%	9%	7,421



### How well does the internet work in your home?



**Table 53. How well does the internet work in your home?**

New question in 2021-22

RC v CA v NCI	The Internet Always Works	The Internet Sometimes Works	The Internet Rarely or Never Works or I Do Not Have Internet In My Home	N
NLACRC	81%	15%	4%	257
CA	84%	13%	4%	4,032
NCI	82%	13%	4%	7,080

## *Workforce (New in 2021-22)*

*There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.*

Do support workers come and go when they are supposed to?

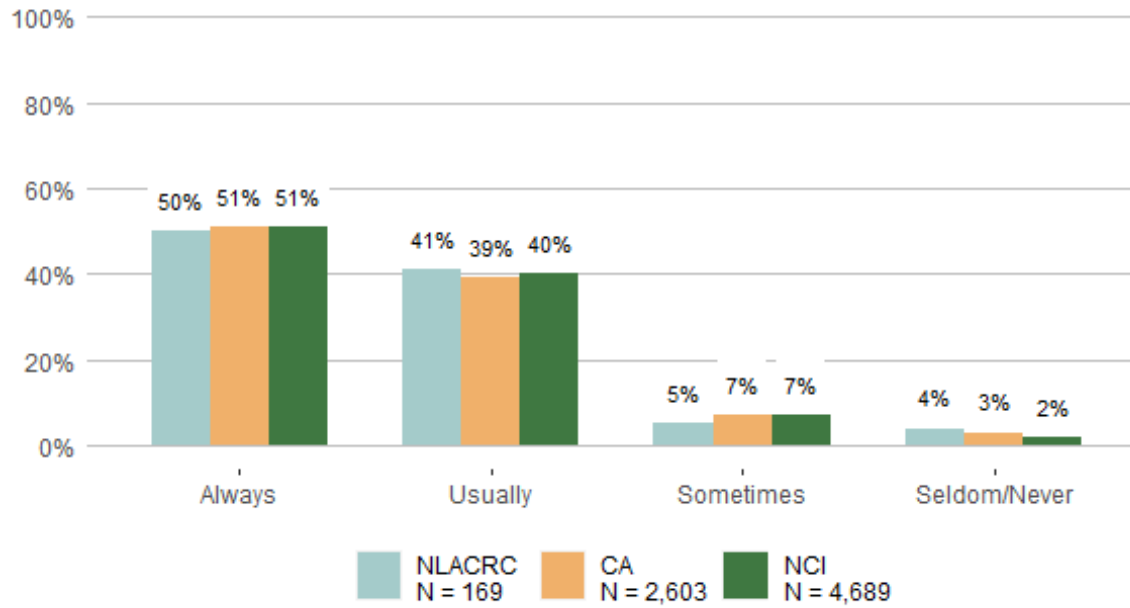


Table 54. Do support workers come and go when they are supposed to?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	50%	41%	5%	4%	169
CA	51%	39%	7%	3%	2,603
NCI	51%	40%	7%	2%	4,689

Do support workers speak to you in a way you understand?

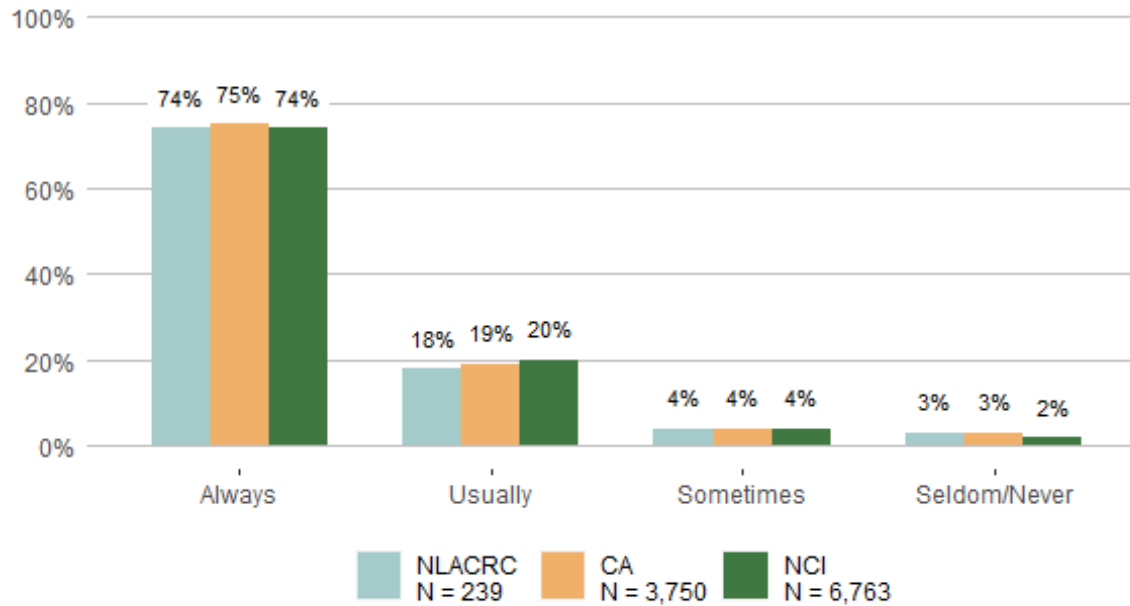
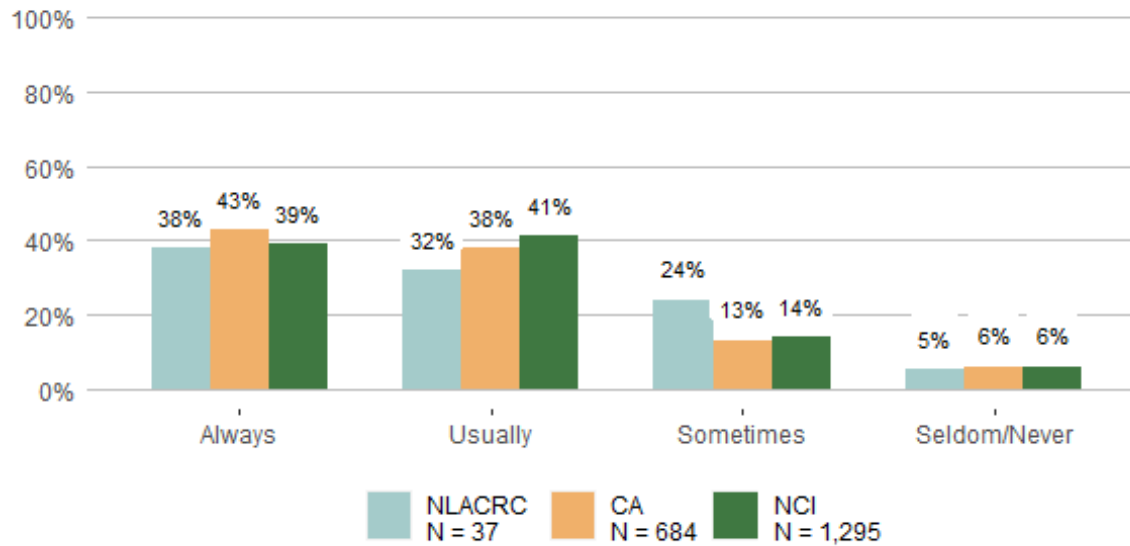


Table 55. Do support workers speak to you in a way you understand?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	74%	18%	4%	3%	239
CA	75%	19%	4%	3%	3,750
NCI	74%	20%	4%	2%	6,763

If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?



**Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	38%	32%	24%	5%	37
CA	43%	38%	13%	6%	684
NCI	39%	41%	14%	6%	1,295

Do support workers have the right information and skills to meet your family's needs?

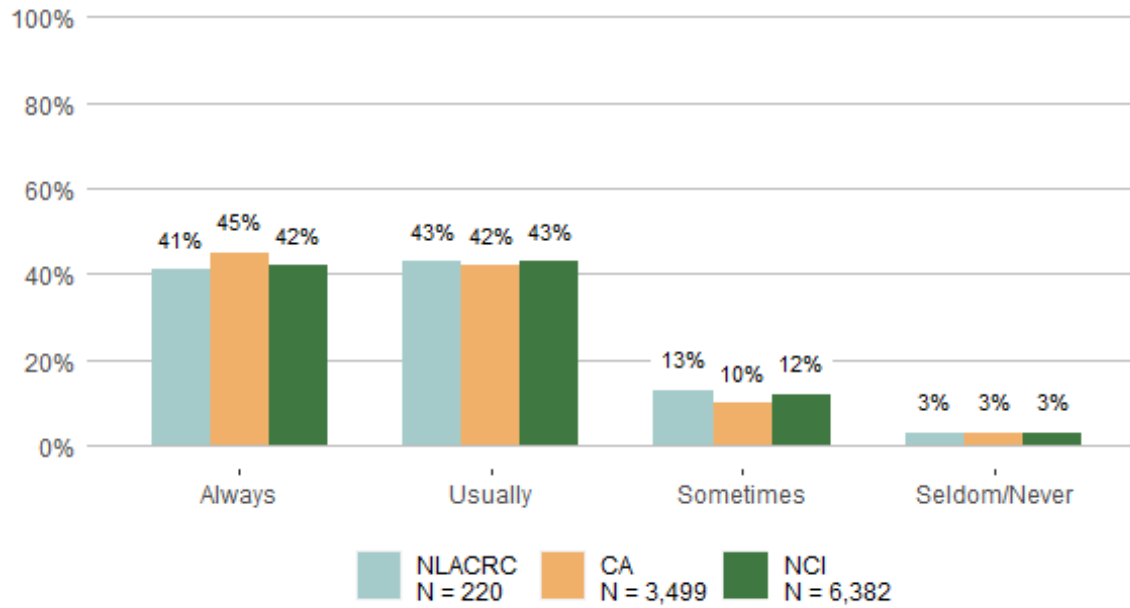
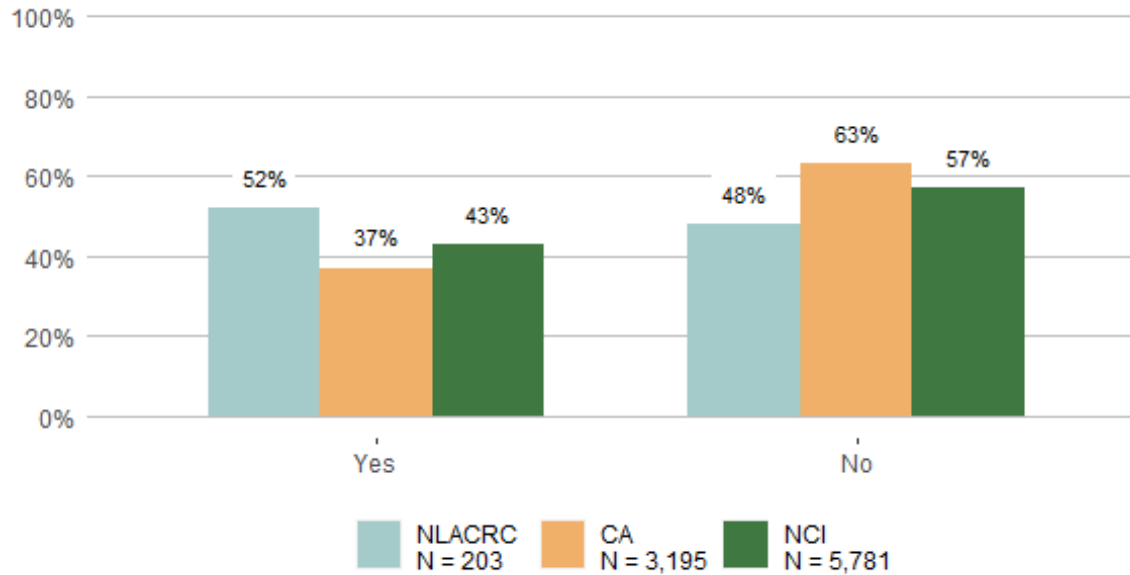


Table 57. Do support workers have the right information and skills to meet your family's needs?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	41%	43%	13%	3%	220
CA	45%	42%	10%	3%	3,499
NCI	42%	43%	12%	3%	6,382

Do your family member's support workers change too often? Is there too much "turnover" of support workers?

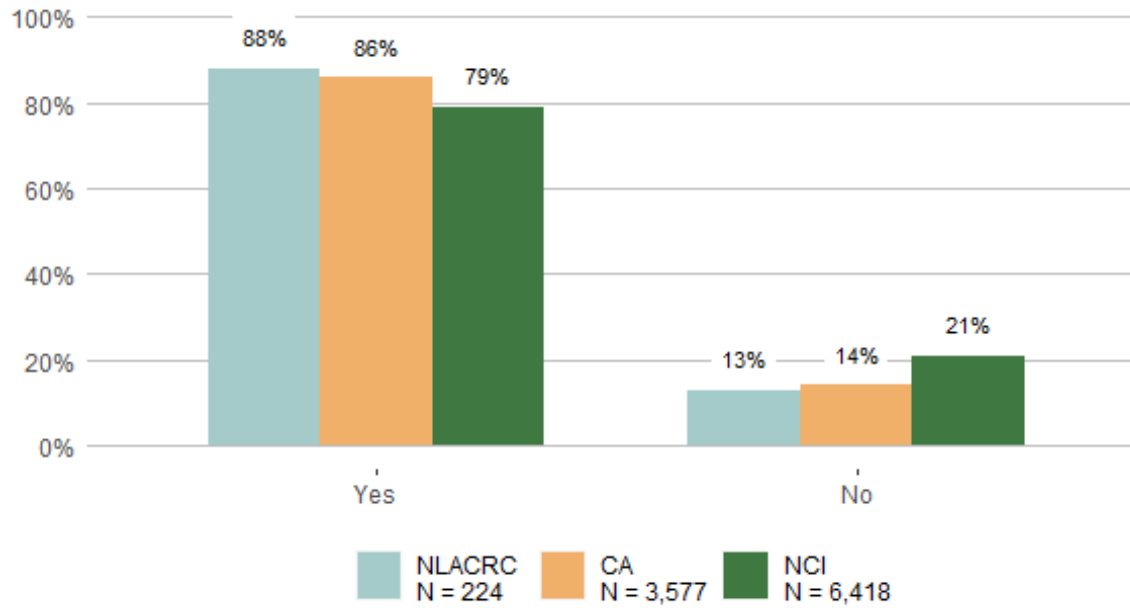


**Table 58. Do your family member's support workers change too often? Is there too much "turnover" of support workers?**

New question in 2021-22

RC v CA v NCI	Yes	No	N
NLACRC	52%	48%	203
CA	37%	63%	3,195
NCI	43%	57%	5,781

Is there always a staff person available to support your family member when support is needed?



**Table 59. Is there always a staff person available to support your family member when support is needed?**

New question in 2021-22

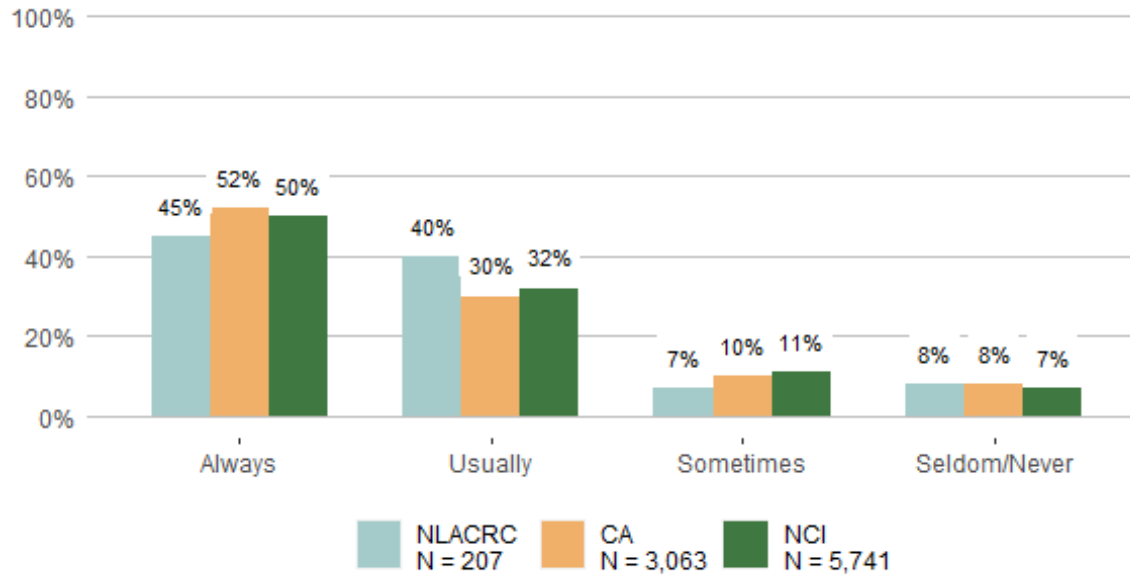
RC v CA v NCI	Yes	No	N
NLACRC	88%	13%	224
CA	86%	14%	3,577
NCI	79%	21%	6,418



## *Choice, Decision Making and Control*

*Families and family members with intellectual/developmental disabilities determine the services and supports they receive and the individuals or agencies who provide them.*

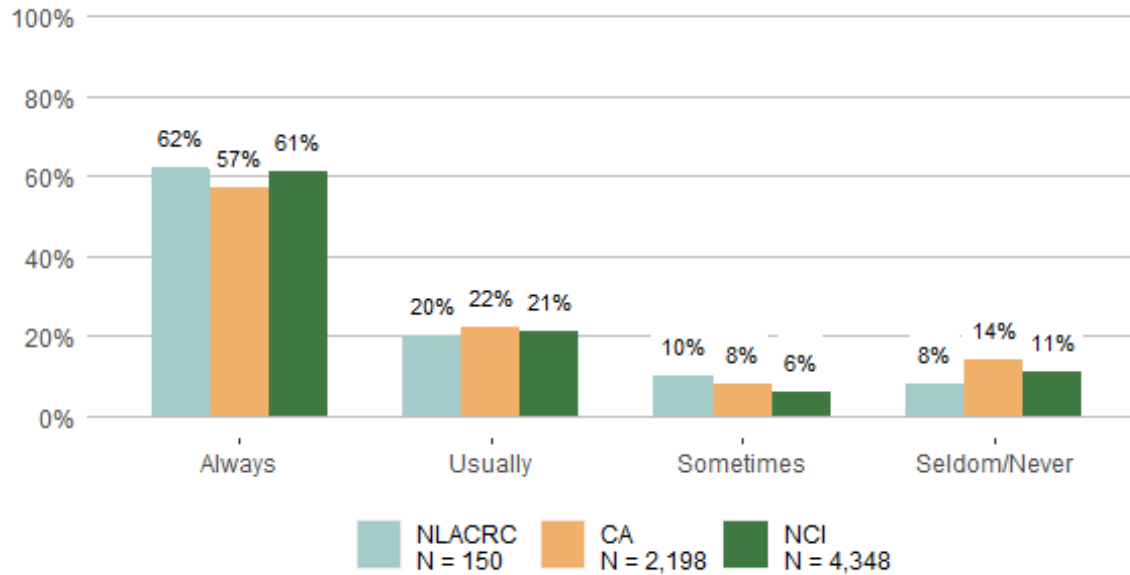
Does the agency providing residential services to your family member involve them in important decisions?



**Table 60. Does the agency providing residential services to your family member involve them in important decisions?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	45%	40%	7%	8%	207
CA	52%	30%	10%	8%	3,063
NCI	50%	32%	11%	7%	5,741

Can your family choose or change the provider agency that provides your family member's services?



**Table 61. Can your family choose or change the provider agency that provides your family member's services?**

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	62%	20%	10%	8%	150
CA	57%	22%	8%	14%	2,198
NCI	61%	21%	6%	11%	4,348

Can your family choose or change your family member's support workers?

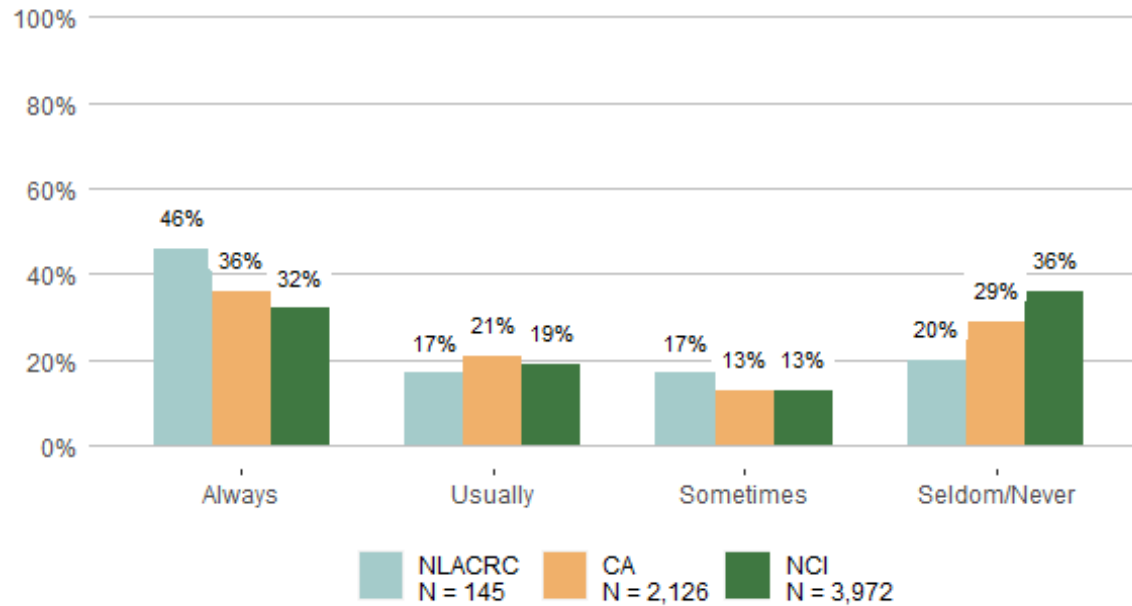
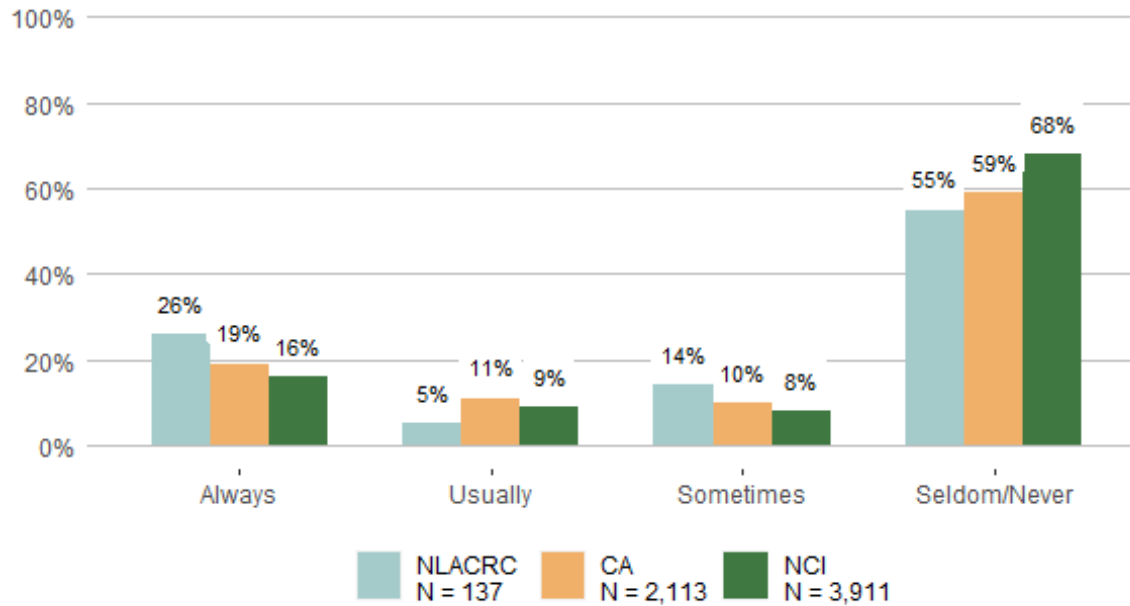


Table 62. Can your family choose or change your family member's support workers?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	46%	17%	17%	20%	145
CA	36%	21%	13%	29%	2,126
NCI	32%	19%	13%	36%	3,972

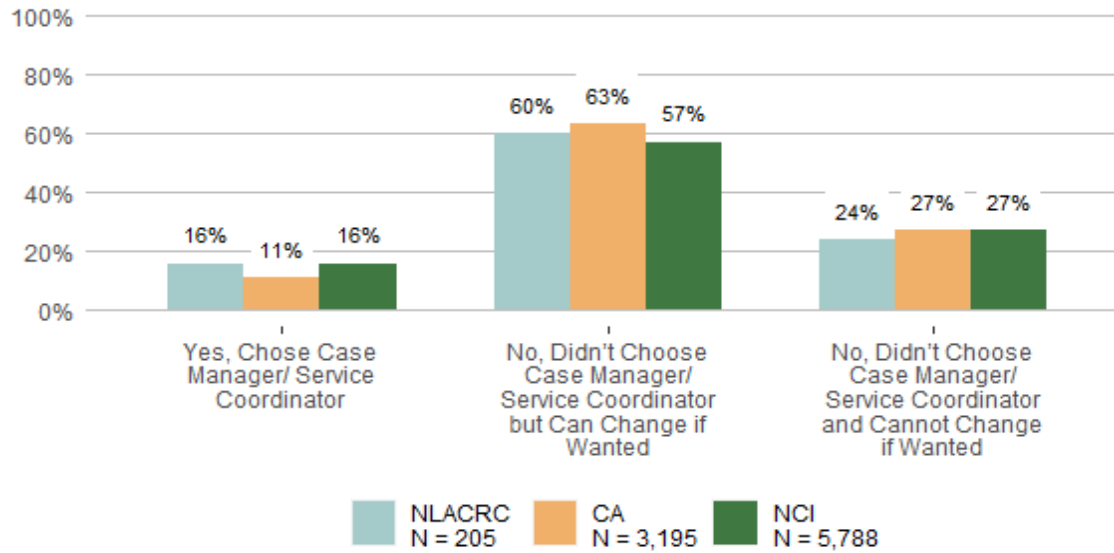
Can someone in your family directly manage support staff?



**Table 63. Can someone in your family directly manage support staff?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	26%	5%	14%	55%	137
CA	19%	11%	10%	59%	2,113
NCI	16%	9%	8%	68%	3,911

Did you, your family member, or someone else  
in your family choose your family member's case  
manager/service coordinator?



**Table 64. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?**

RC v CA v NCI	Yes, Chose Case Manager/ Service Coordinator	No, Didn't Choose Case Manager/ Service Coordinator but Can Change if Wanted	No, Didn't Choose Case Manager/ Service Coordinator and Cannot Change if Wanted	N
NLACRC	16%	60%	24%	205
CA	11%	63%	27%	3,195
NCI	16%	57%	27%	5,788

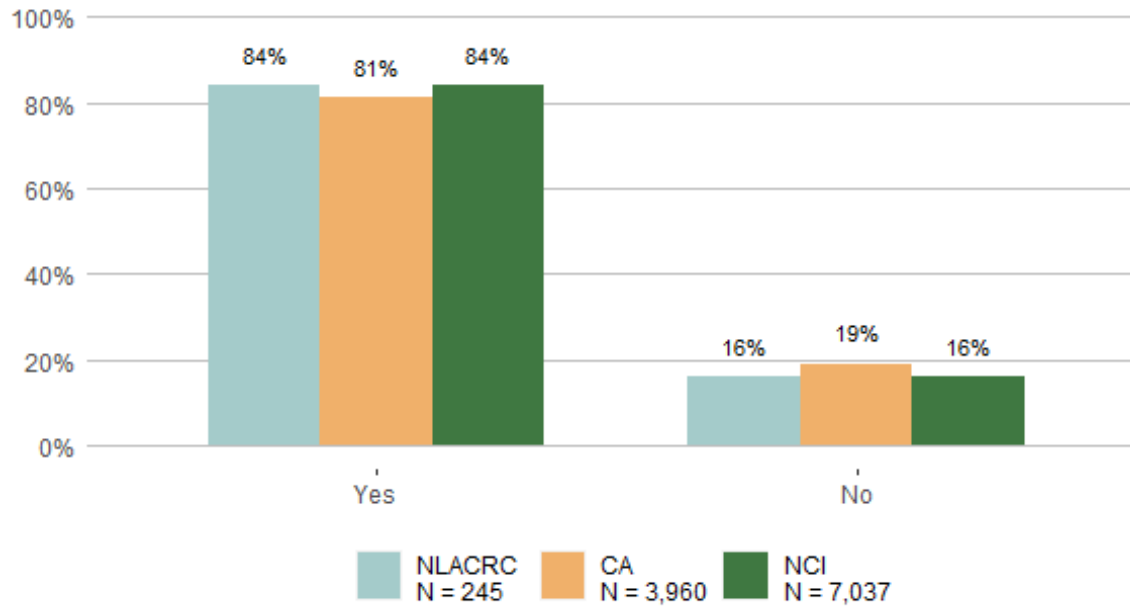
## Community Connections

*Family members receiving services and supports from the Regional Center (RC)<sup>7</sup> are meaningfully engaged as members of their communities and have strong relationships. Families and family members can use supports in their community.*

---

<sup>7</sup> Some NCI states provide services through a statewide ID/DD agency\*

Does your family member do things in the community?

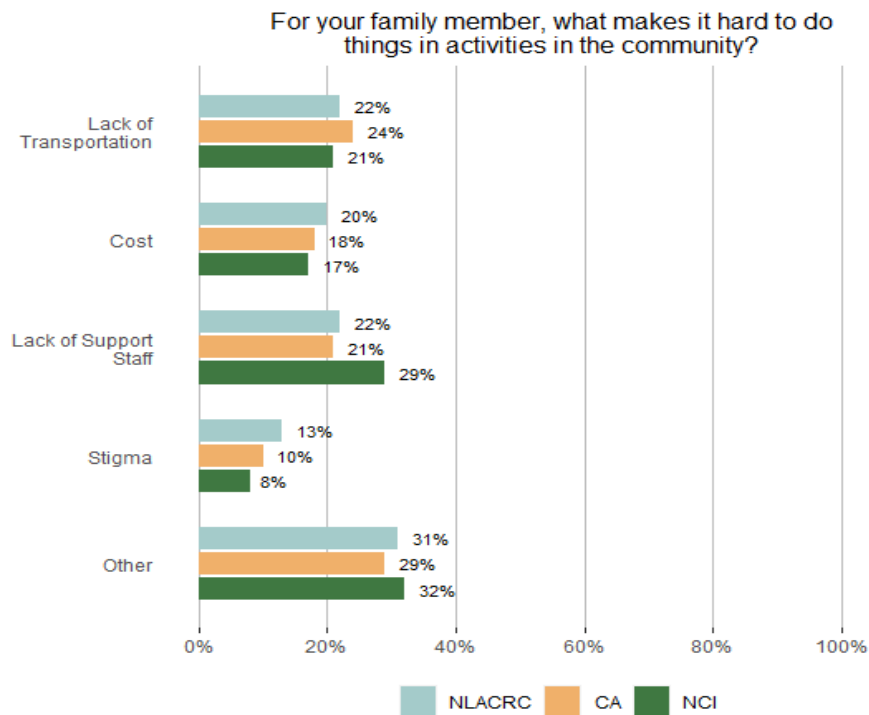


**Table 65. Does your family member do things in the community?**

Question changed in 2021-22

RC v CA v NCI	Yes	No	N
NLACRC	84%	16%	245
CA	81%	19%	3,960
NCI	84%	16%	7,037



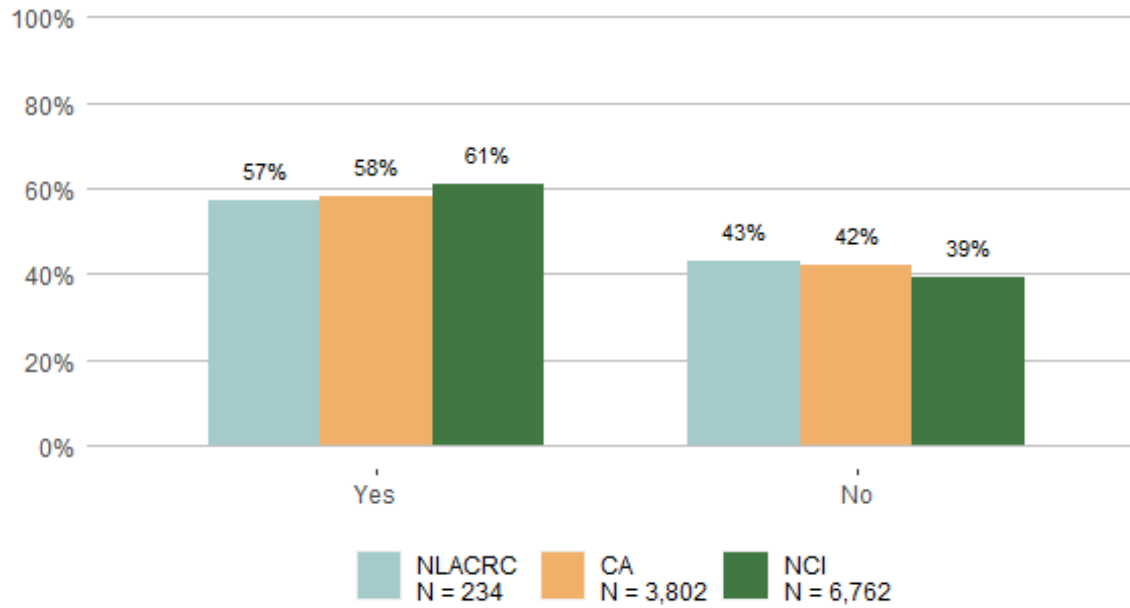


**Table 66. For your family member, what makes it hard to do things in activities in the community?**

Categories are not mutually exclusive; therefore, N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
NLACRC	22%	20%	22%	13%	31%
CA	24%	18%	21%	10%	29%
NCI	21%	17%	29%	8%	32%

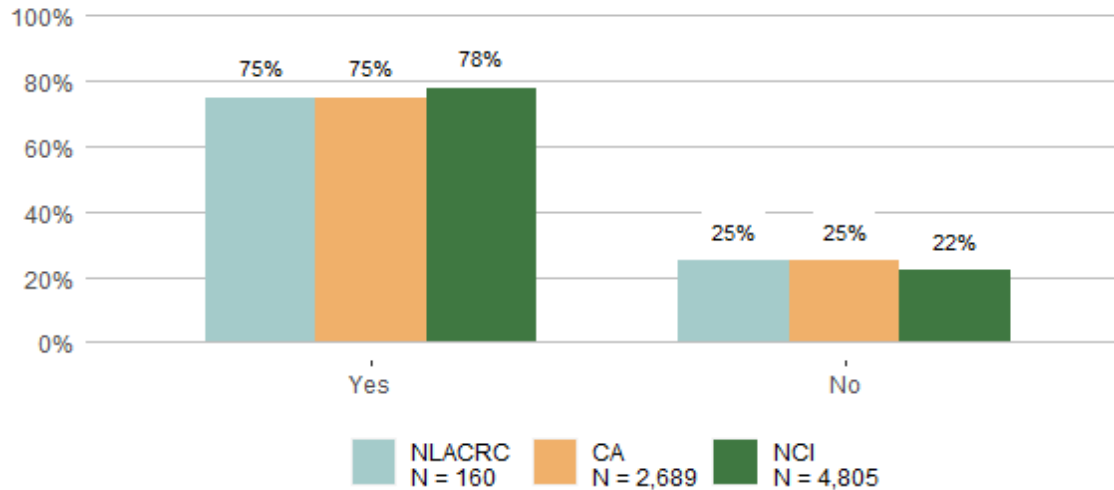
Does your family member have friends other than paid support workers or family?



**Table 67. Does your family member have friends other than paid support workers or family?**

RC v CA v NCI	Yes	No	N
NLACRC	57%	43%	234
CA	58%	42%	3,802
NCI	61%	39%	6,762

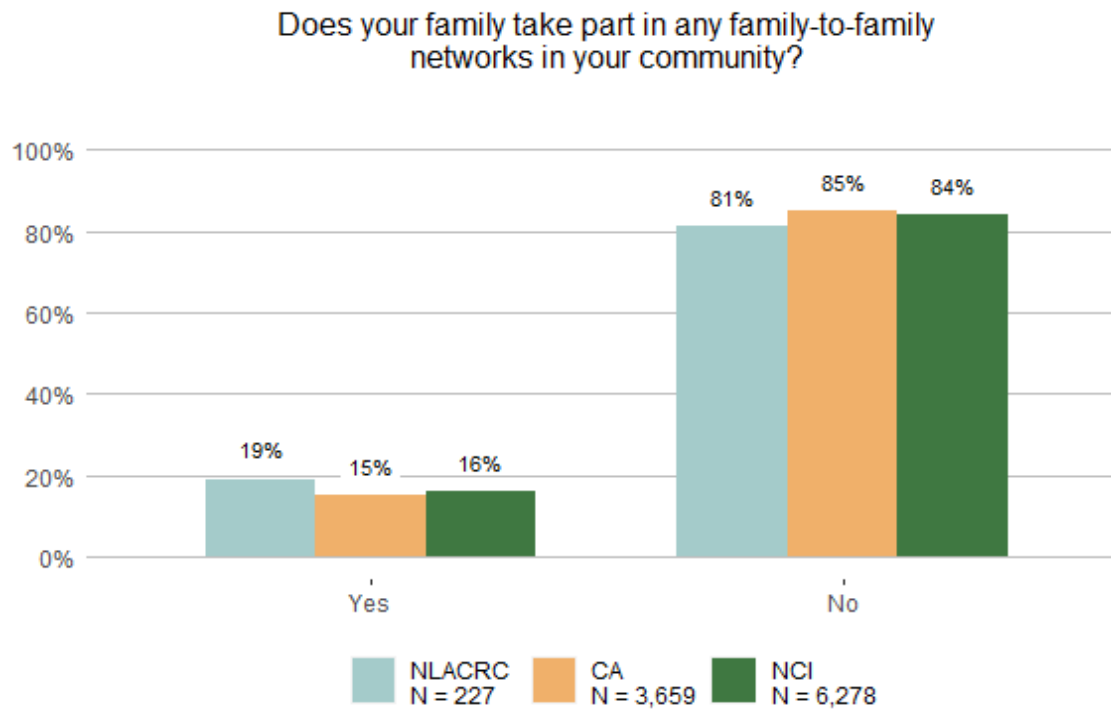
In your community, are there resources that your family can use that are not provided by the regional center (for example, recreational programs, community housing, library programs, religious groups, etc.)?



**Table 68. In your community, are there resources that your family can use that are not provided by the regional center (for example, recreational programs, community housing, library programs, religious groups, etc.)?**

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Yes	No	N
NLACRC	75%	25%	160
CA	75%	25%	2,689
NCI	78%	22%	4,805



**Table 69. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?**

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Yes	No	N
NLACRC	19%	81%	227
CA	15%	85%	3,659
NCI	16%	84%	6,278

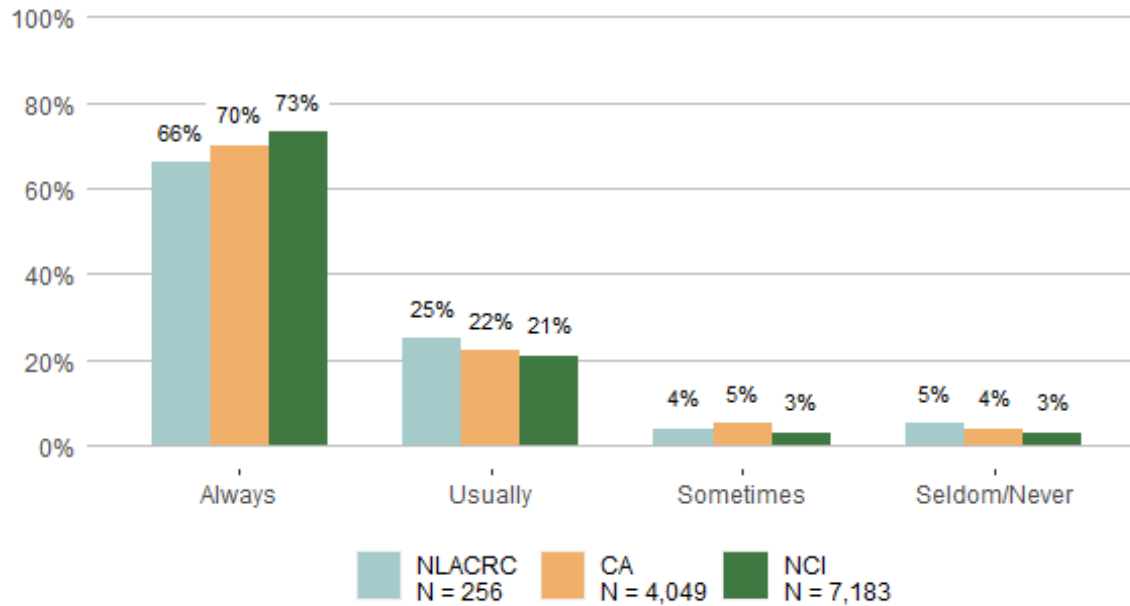
## *Health, Welfare, and Safety (New in 2021-22)*

*Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the Regional Center<sup>8</sup>(RC).*

---

<sup>8</sup> Some NCI states provide services through a statewide ID/DD agency

Can your family member see a primary care provider  
(doctor, registered nurse, etc.) when needed?

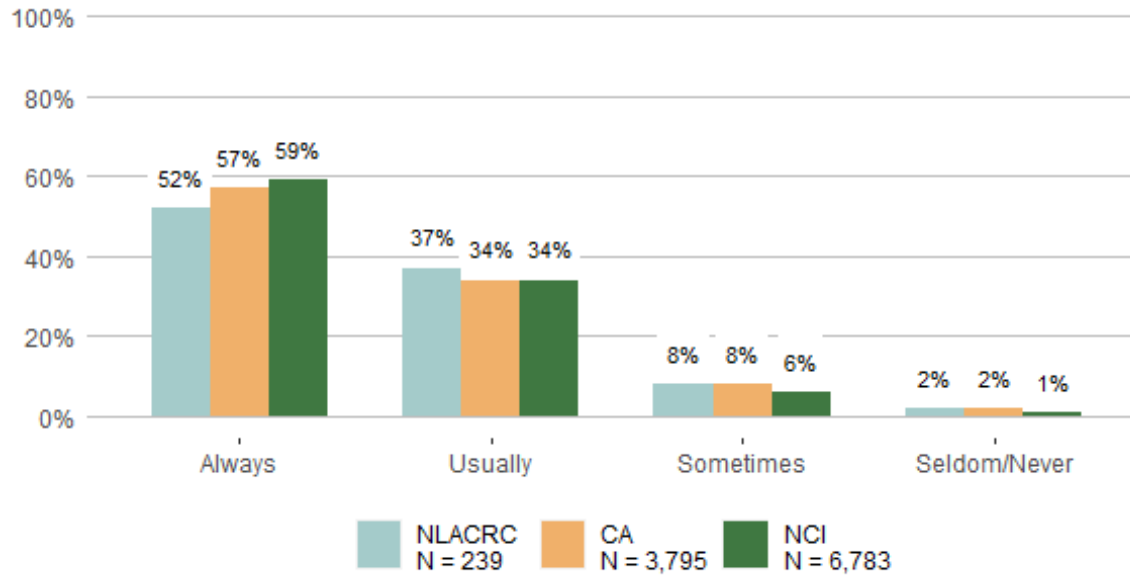


**Table 70. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?**

New question in 2021-22. Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	66%	25%	4%	5%	256
CA	70%	22%	5%	4%	4,049
NCI	73%	21%	3%	3%	7,183

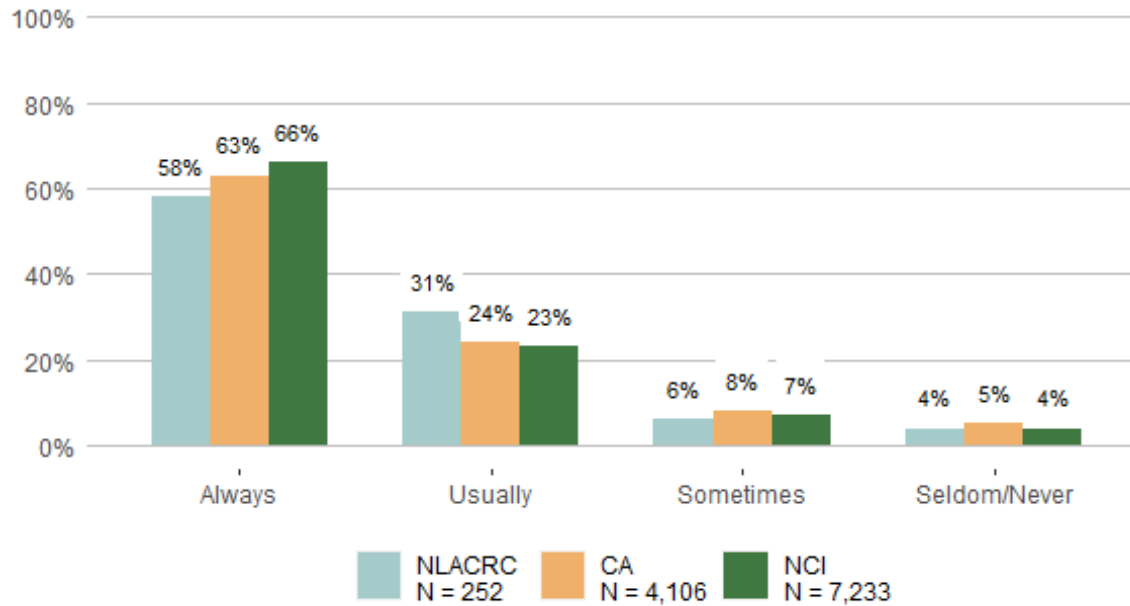
Does your family member's primary care doctor understand your family member's needs related to their disability?



**Table 71. Does your family member's primary care doctor understand your family member's needs related to their disability?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	52%	37%	8%	2%	239
CA	57%	34%	8%	2%	3,795
NCI	59%	34%	6%	1%	6,783

Can your family member go to the dentist when needed?



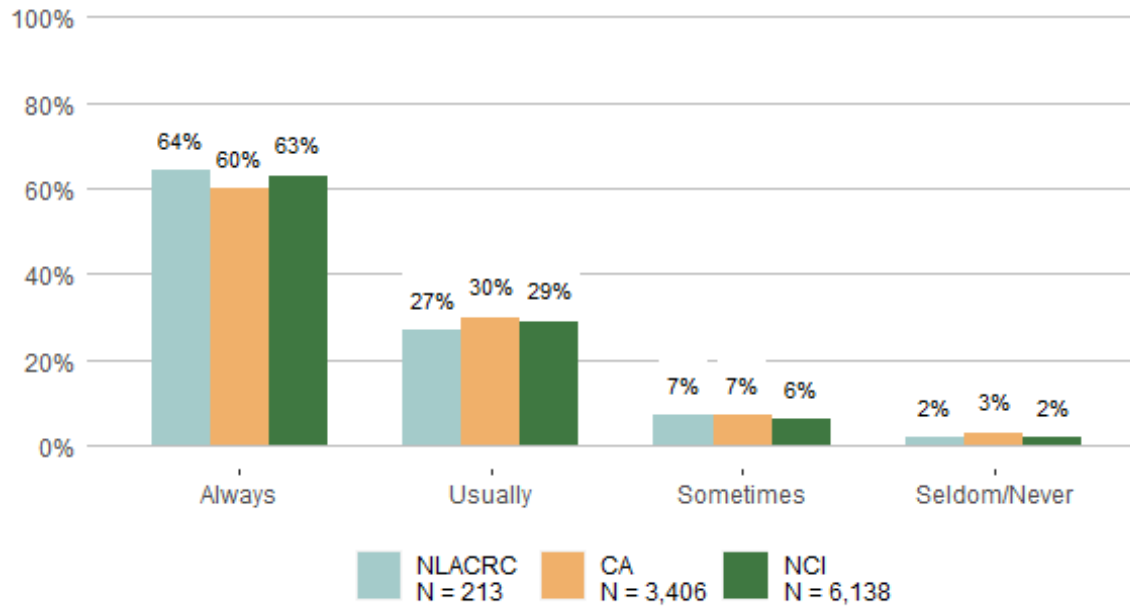
**Table 72. Can your family member go to the dentist when needed?**

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	58%	31%	6%	4%	252
CA	63%	24%	8%	5%	4,106
NCI	66%	23%	7%	4%	7,233



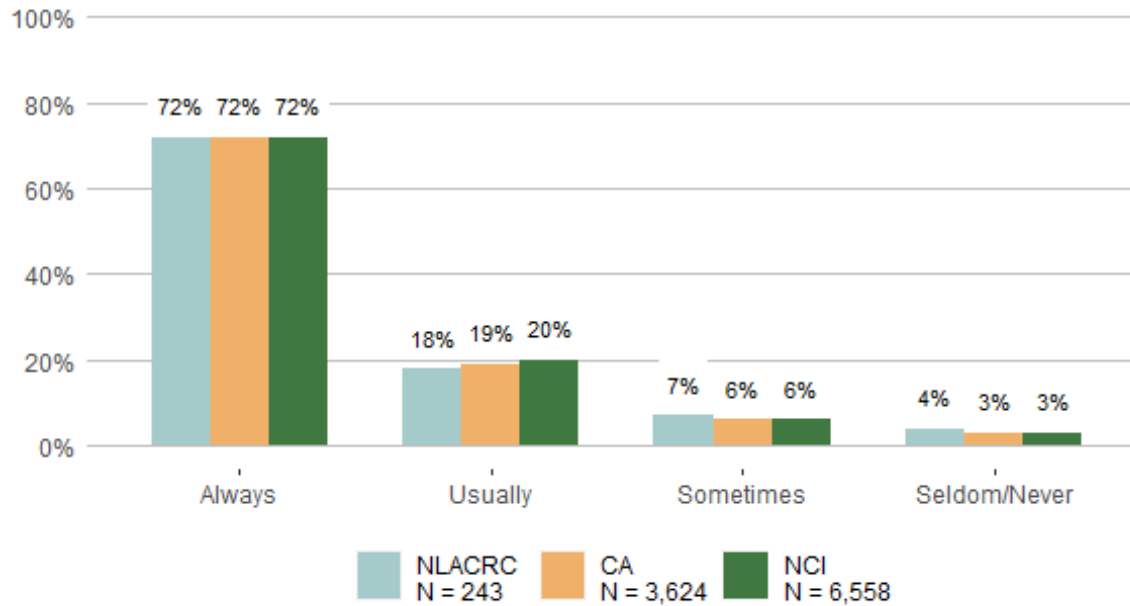
Does your family member's dentist understand your family member's needs related to their disability?



**Table 73. Does your family member's dentist understand your family member's needs related to their disability?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	64%	27%	7%	2%	213
CA	60%	30%	7%	3%	3,406
NCI	63%	29%	6%	2%	6,138

If your family member takes prescription medications, do you know what they're for?

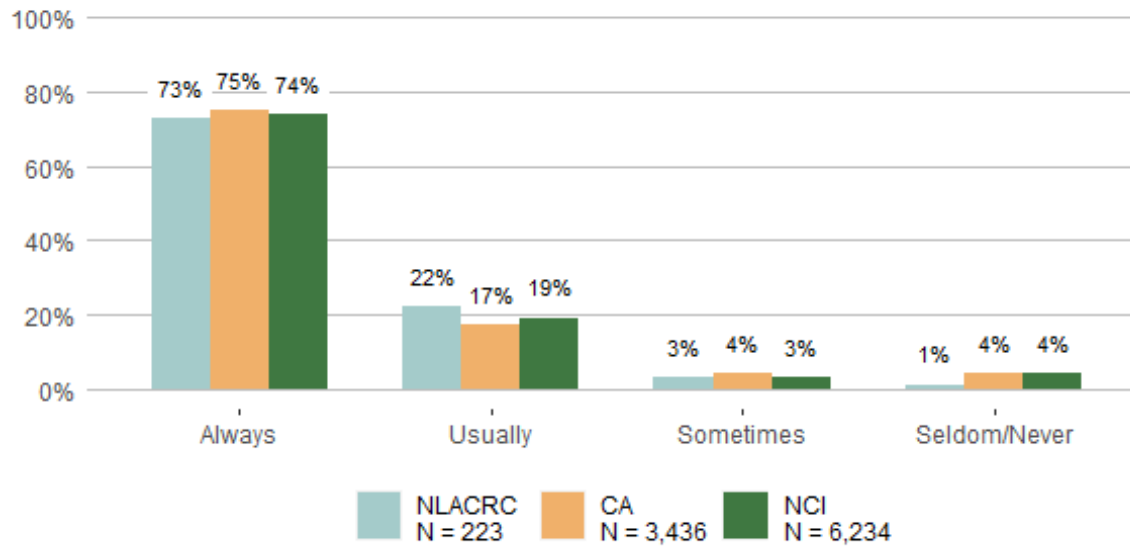


**Table 74. If your family member takes prescription medications, do you know what they're for?**

Question changed in 2021-22

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	72%	18%	7%	4%	243
CA	72%	19%	6%	3%	3,624
NCI	72%	20%	6%	3%	6,558

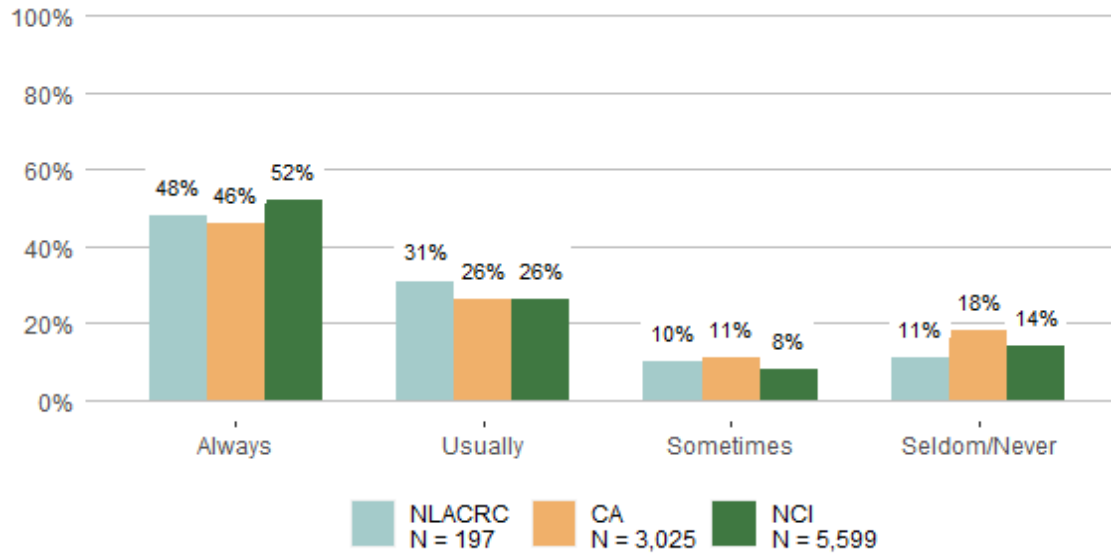
Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?



**Table 75. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	73%	22%	3%	1%	223
CA	75%	17%	4%	4%	3,436
NCI	74%	19%	3%	4%	6,234

Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?

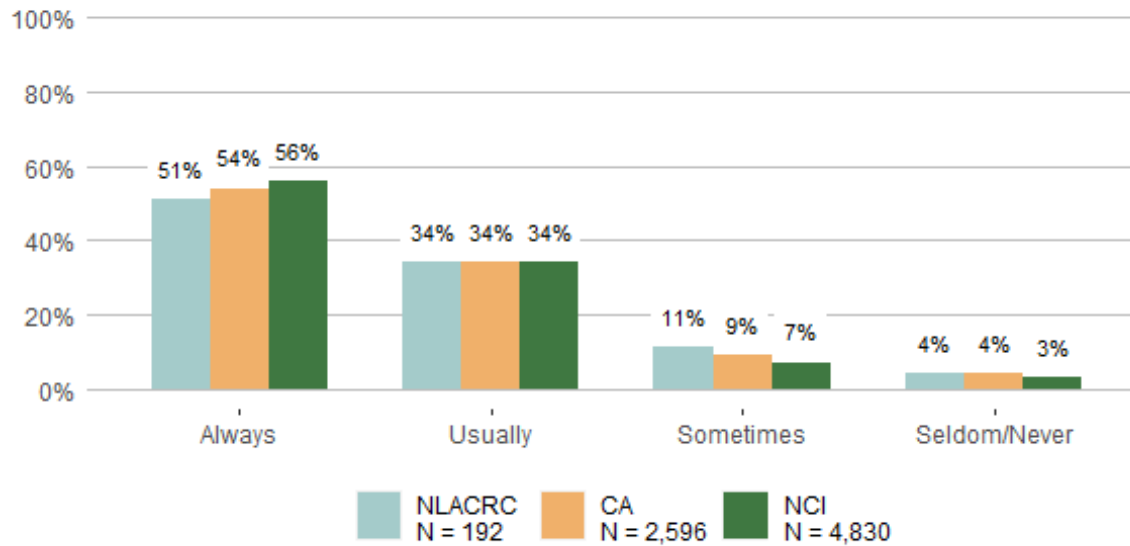


**Table 76. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?**

New question in 2021-22

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	48%	31%	10%	11%	197
CA	46%	26%	11%	18%	3,025
NCI	52%	26%	8%	14%	5,599

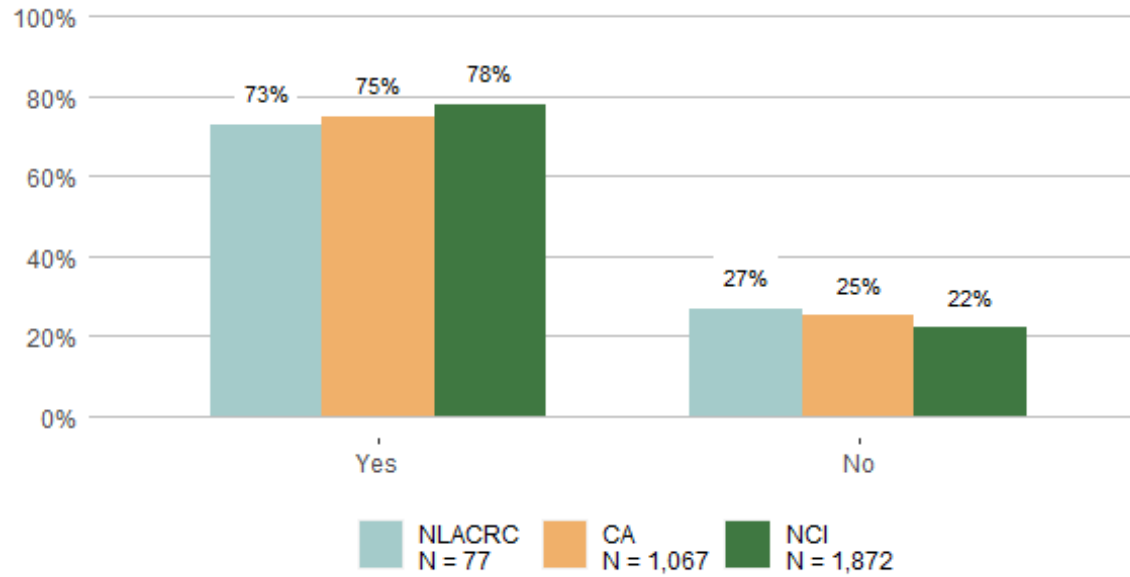
If your family member uses mental health services,  
does the mental health professional understand  
your family member's needs related to their  
disability?



**Table 77. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?**

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	51%	34%	11%	4%	192
CA	54%	34%	9%	4%	2,596
NCI	56%	34%	7%	3%	4,830

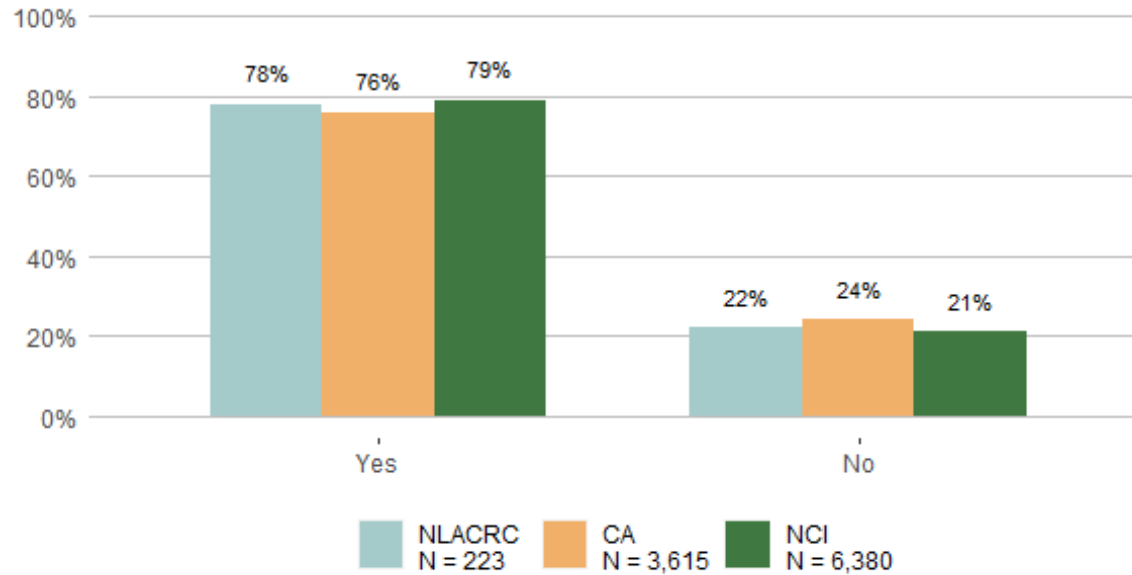
If you asked for crisis or emergency services during the past 12 months, were services provided when needed?



**Table 78. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?**

RC v CA v NCI	Yes	No	N
NLACRC	73%	27%	77
CA	75%	25%	1,067
NCI	78%	22%	1,872

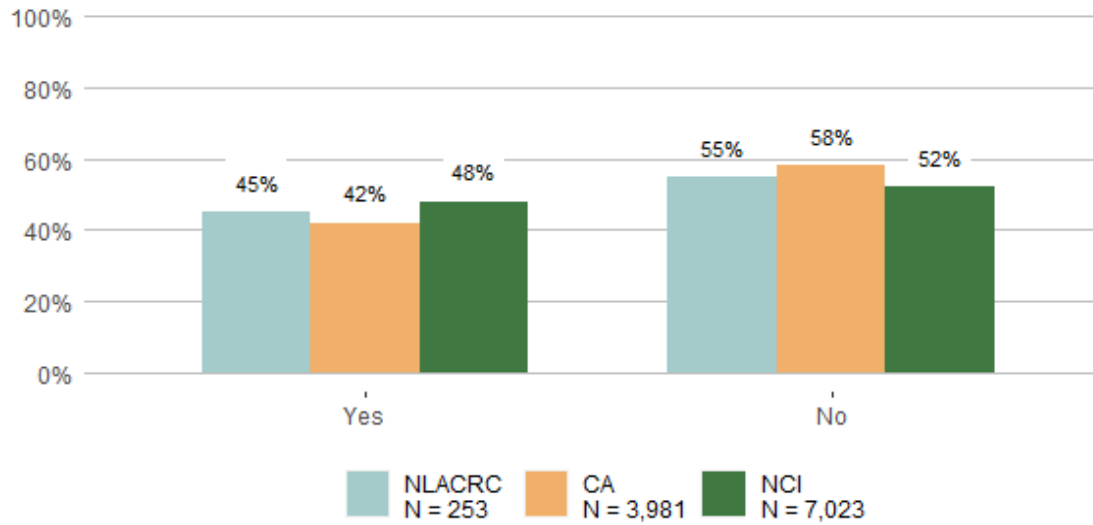
Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?



**Table 79. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?**

RC v CA v NCI	Yes	No	N
NLACRC	78%	22%	223
CA	76%	24%	3,615
NCI	79%	21%	6,380

Have you talked about how to handle emergencies  
(such as a medical emergency, pandemic, or natural  
disaster) with your family member's case manager/  
service coordinator?



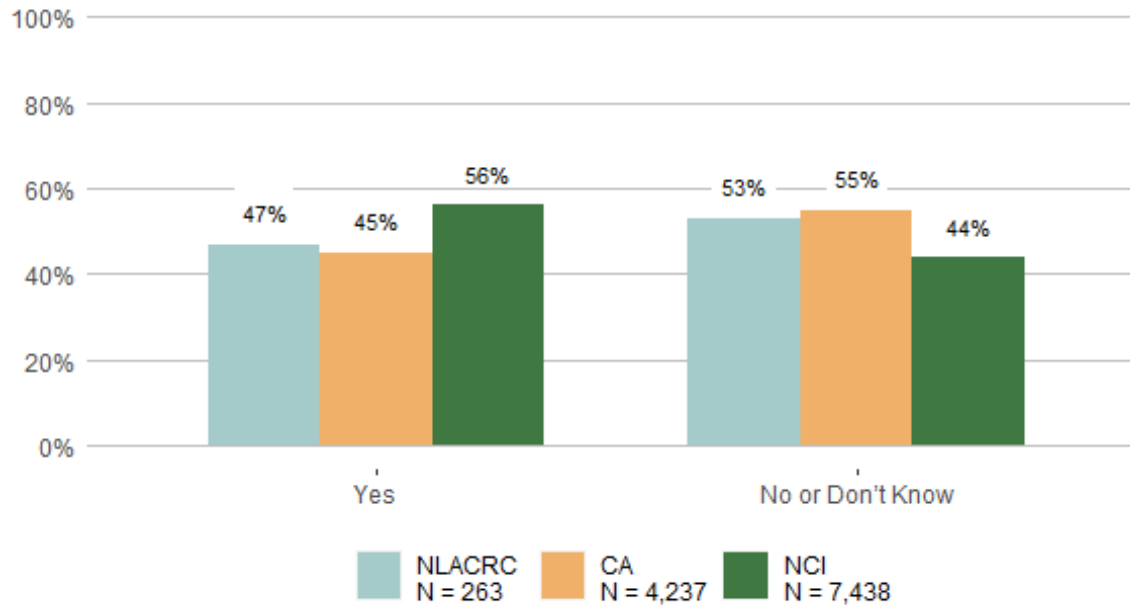
**Table 80. Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member's case manager/service coordinator?**

New question in 2021-22.

RC v CA v NCI	Yes	No	N
NLACRC	45%	55%	253
CA	42%	58%	3,981
NCI	48%	52%	7,023



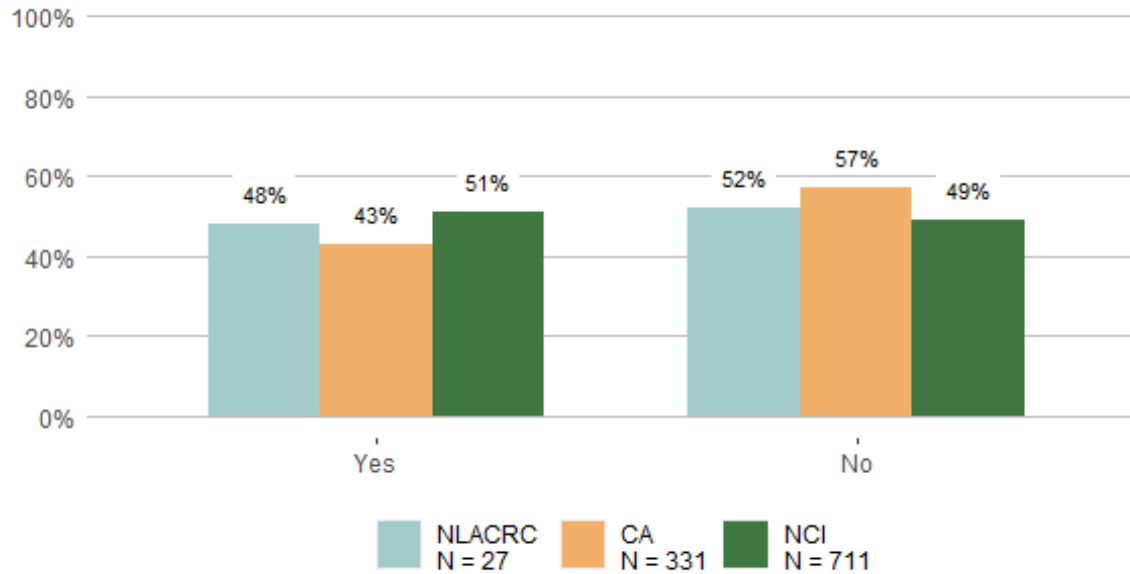
Do you know how to file a complaint or grievance about provider agencies or staff?



**Table 81. Do you know how to file a complaint or grievance about provider agencies or staff?**

RC v CA v NCI	Yes	No or Don't Know	N
NLACRC	47%	53%	263
CA	45%	55%	4,237
NCI	56%	44%	7,438

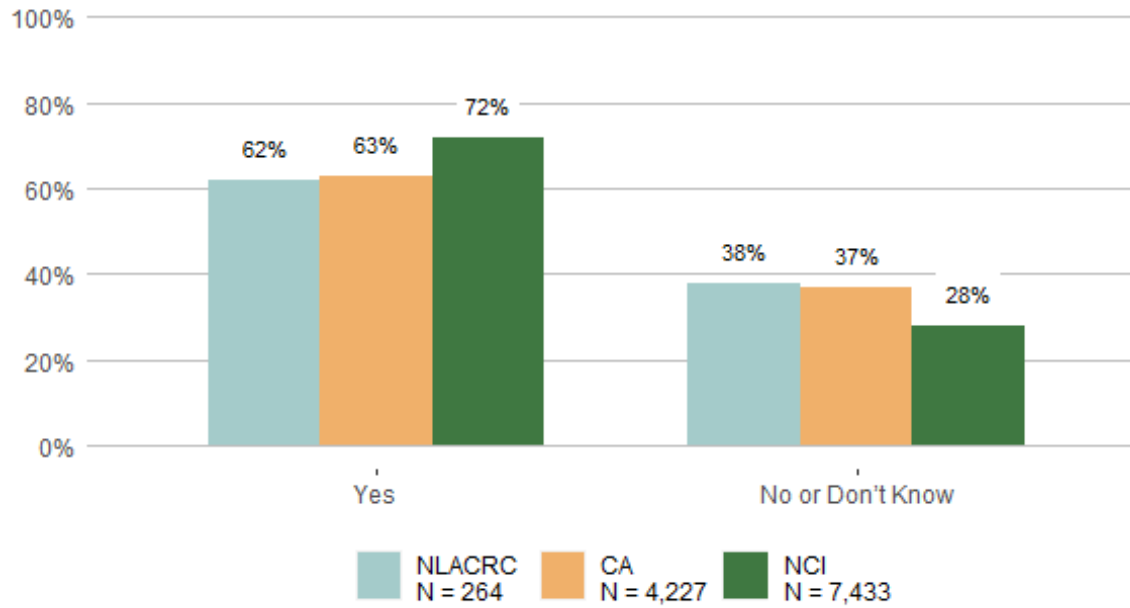
If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?



**Table 82. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?**

RC v CA v NCI	Yes	No	N
NLACRC	48%	52%	27
CA	43%	57%	331
NCI	51%	49%	711

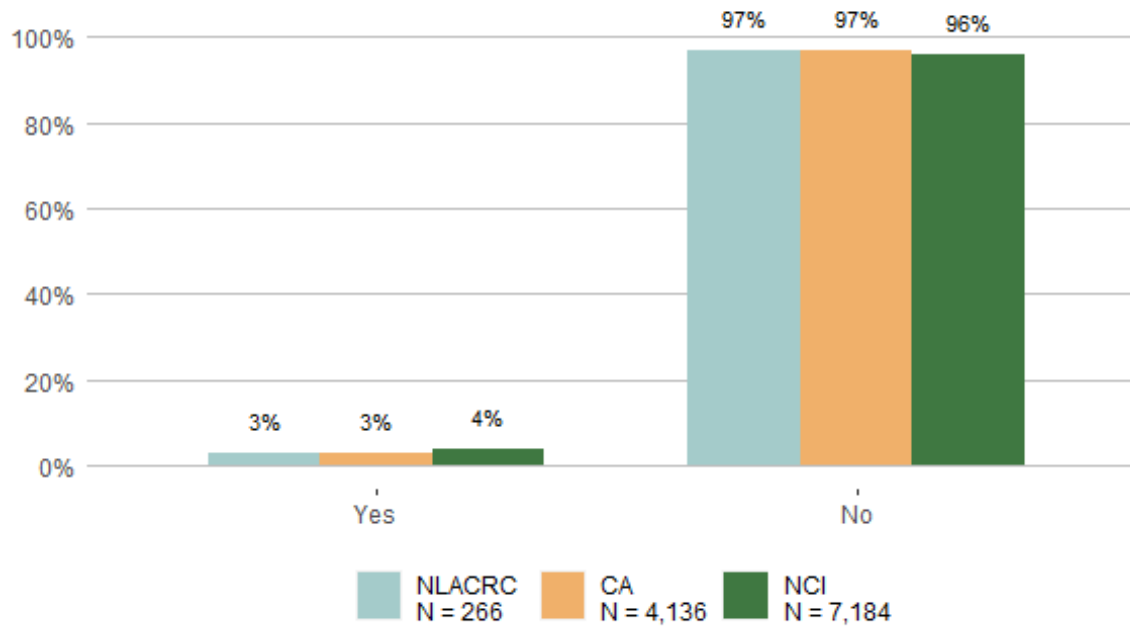
Do you know how to report abuse or neglect related to your family member?



**Table 83. Do you know how to report abuse or neglect related to your family member?**

RC v CA v NCI	Yes	No or Don't Know	N
NLACRC	62%	38%	264
CA	63%	37%	4,227
NCI	72%	28%	7,433

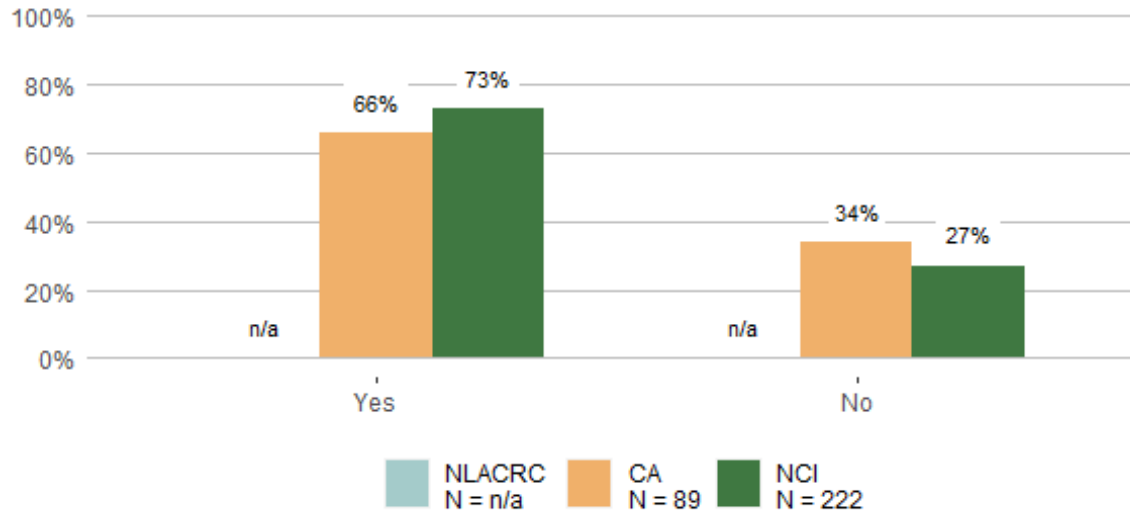
Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?



**Table 84. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?**

RC v CA v NCI	Yes	No	N
NLACRC	3%	97%	266
CA	3%	97%	4,136
NCI	4%	96%	7,184

If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?



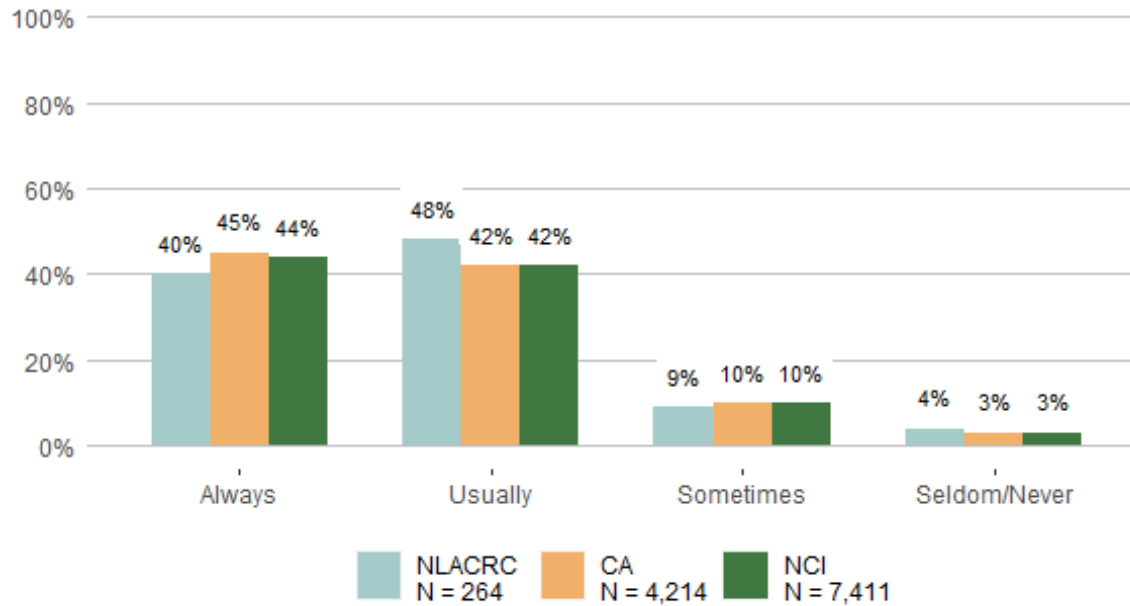
**Table 85. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?**

RC v CA v NCI	Yes	No	N
NLACRC	n/a	n/a	n/a
CA	66%	34%	89
NCI	73%	27%	222

## *Family Satisfaction*

*Services and supports lead to better lives for people with intellectual/developmental disabilities and their families.*

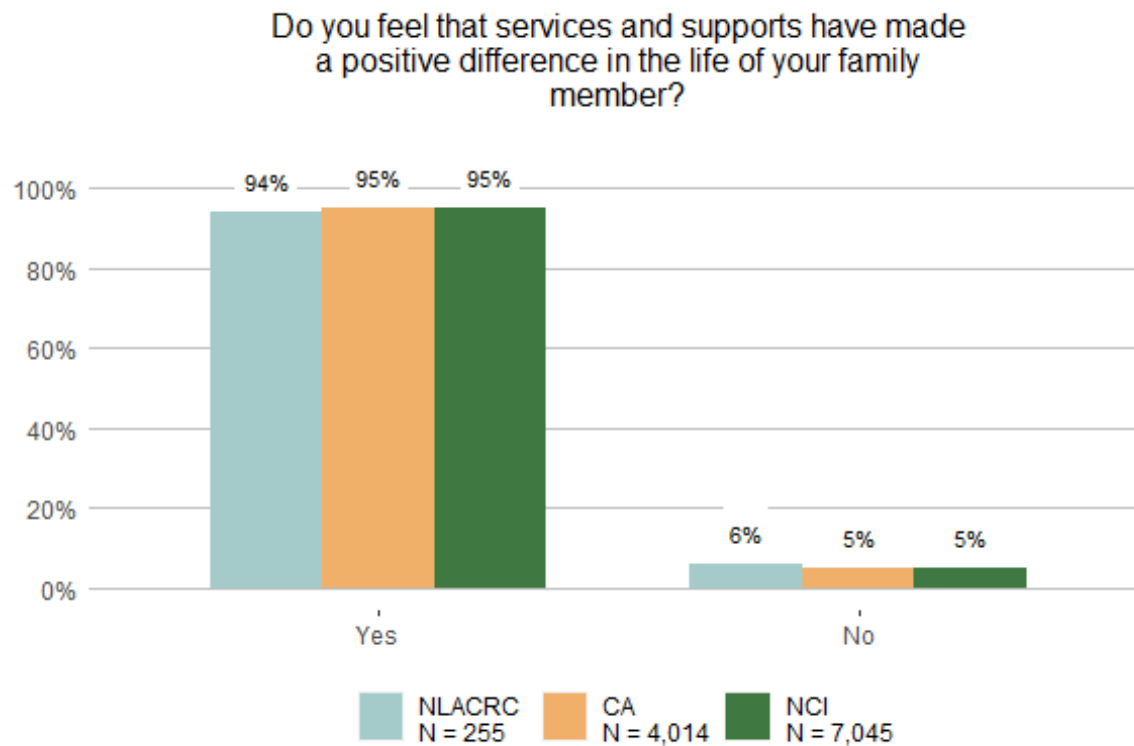
Overall, are you satisfied with the services and supports your family member currently receives?



**Table 86. Overall, are you satisfied with the services and supports your family member currently receives?**

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	40%	48%	9%	4%	264
CA	45%	42%	10%	3%	4,214
NCI	44%	42%	10%	3%	7,411



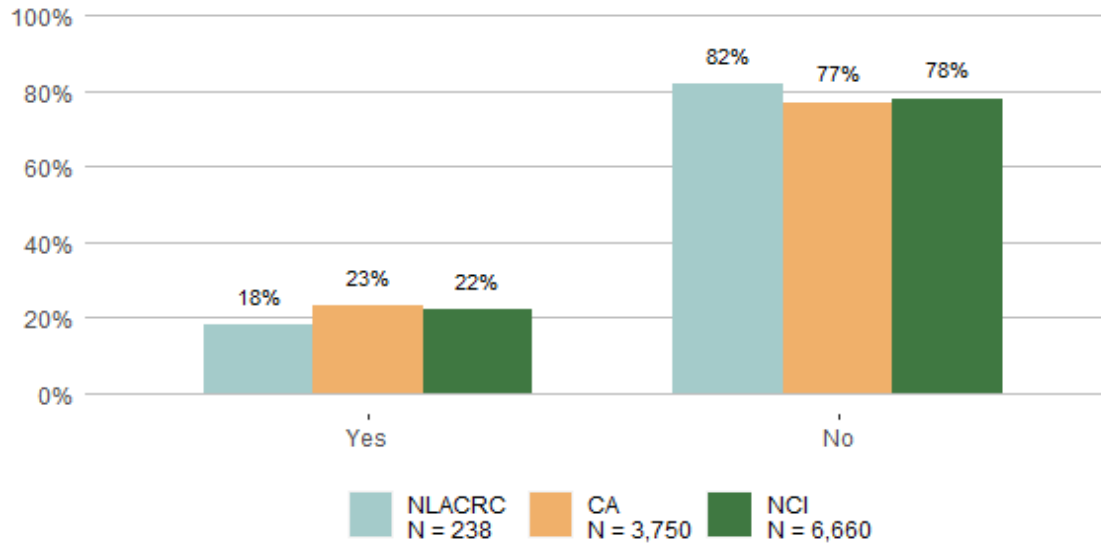
**Table 87. Do you feel that services and supports have made a positive difference in the life of your family member?**

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Yes	No	N
NLACRC	94%	6%	255
CA	95%	5%	4,014
NCI	95%	5%	7,045



Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

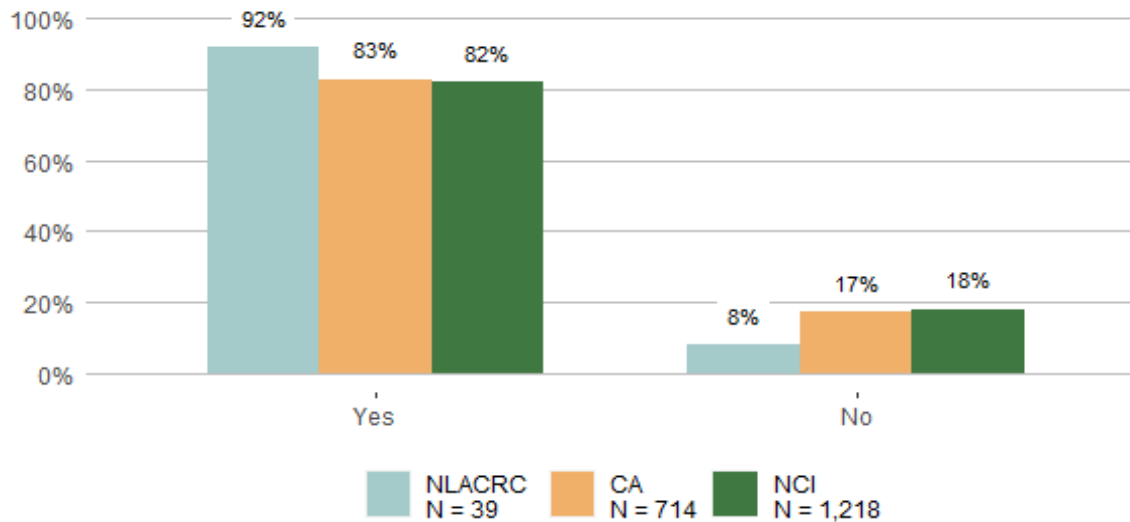


**Table 88. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?**

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Yes	No	N
NLACRC	18%	82%	238
CA	23%	77%	3,750
NCI	22%	78%	6,660

If services or supports received by the family were reduced, suspended, or terminated during the past year, did the change in services affect your family member negatively?

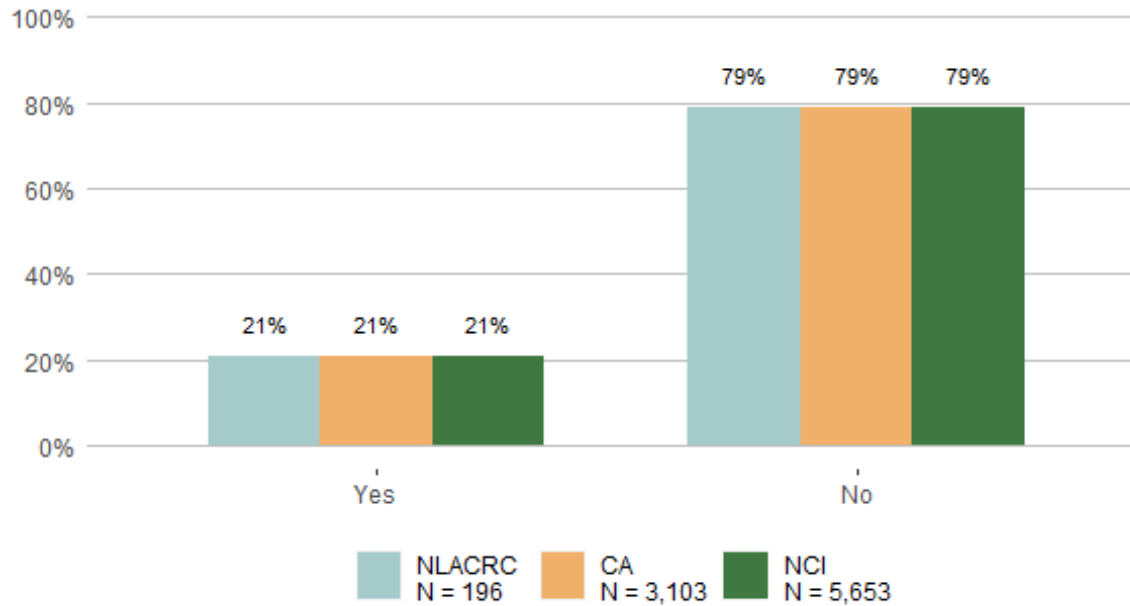


**Table 89. If services or supports received by the family were reduced, suspended, or terminated during the past year, did the change in services affect your family member negatively?**

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Yes	No	N
NLACRC	92%	8%	39
CA	83%	17%	714
NCI	82%	18%	1,218

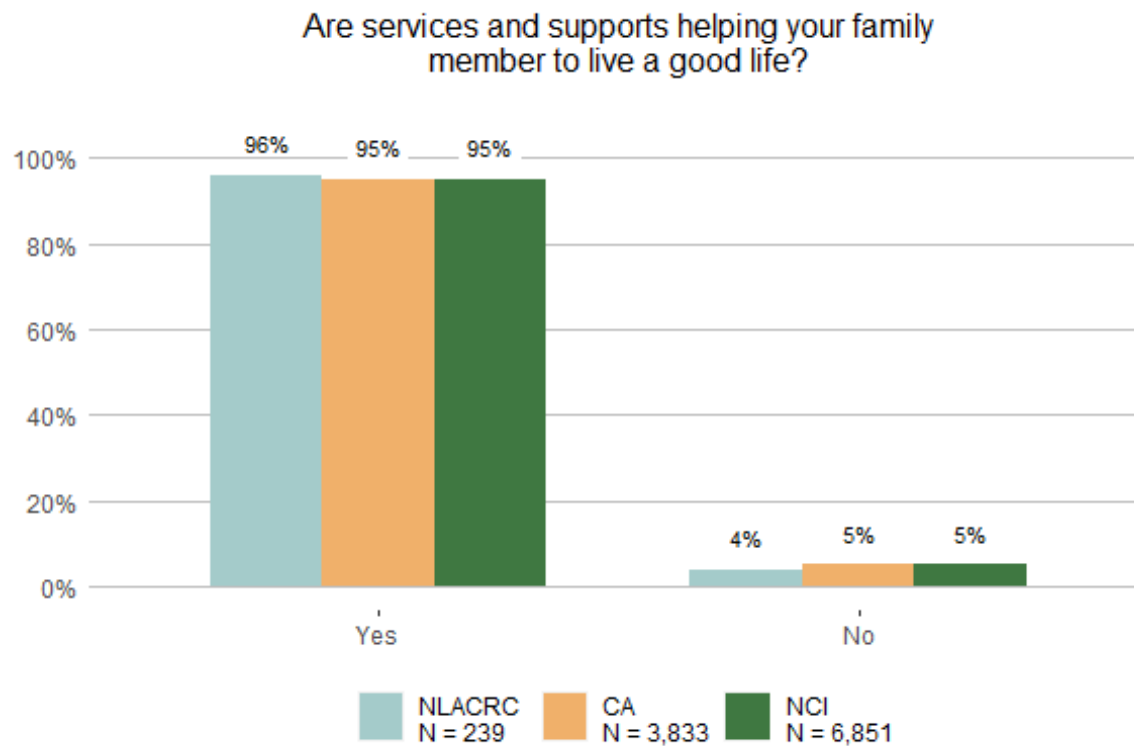
Have the services or supports that your family member received been increased in the past year?



**Table 90. Have the services or supports that your family member received been increased in the past year?**

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Yes	No	N
NLACRC	21%	79%	196
CA	21%	79%	3,103
NCI	21%	79%	5,653



**Table 91. Are services and supports helping your family member to live a good life?**

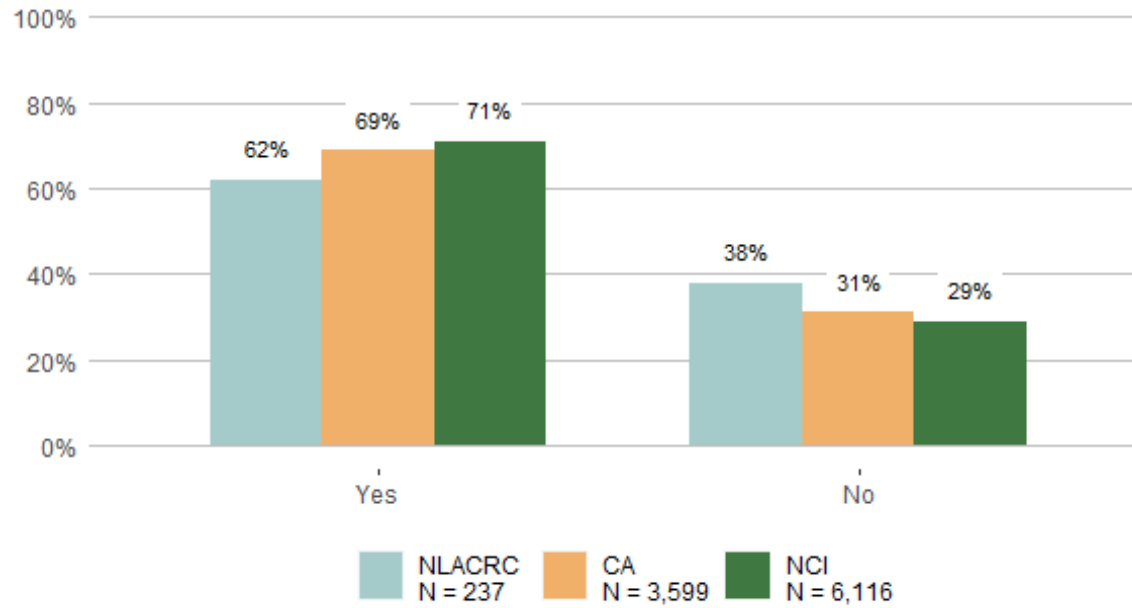
Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Yes	No	N
NLACRC	96%	4%	239
CA	95%	5%	3,833
NCI	95%	5%	6,851

## *COVID-19 Supplement*

*The COVID-19 Supplement is intended to support an ongoing understanding of the continuing effects of the pandemic on people's lives and services. Note: the COVID-19 Supplement was state optional, one state chose not to administer the Supplement.*

Were your family member's services and supports changed, canceled, or reduced during COVID time?



**Table 92. Were your family member's services and supports changed, canceled, or reduced during COVID time?**

RC v CA v NCI	Yes	No	N
NLACRC	62%	38%	237
CA	69%	31%	3,599
NCI	71%	29%	6,116

If yes, are those changes still in effect (still part of your family member's life)?

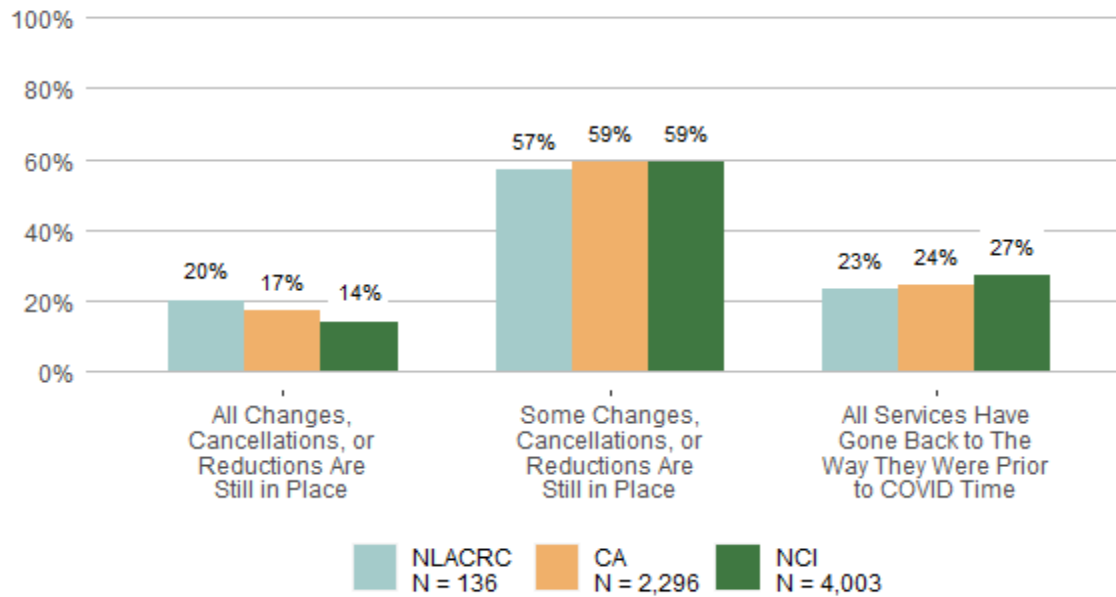
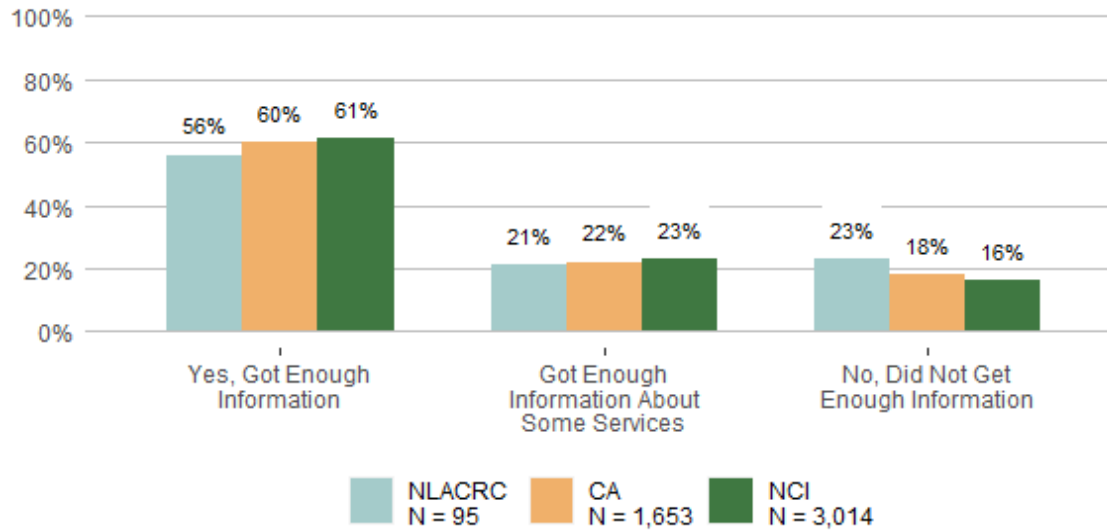


Table 93. If yes, are those changes still in effect (still part of your family member's life)?

RC v CA v NCI	All Changes, Cancellations, or Reductions Are Still in Place	Some Changes, Cancellations, or Reductions Are Still in Place	All Services Have Gone Back to The Way They Were Prior to COVID Time	N
NLACRC	20%	57%	23%	136
CA	17%	59%	24%	2,296
NCI	14%	59%	27%	4,003

If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?

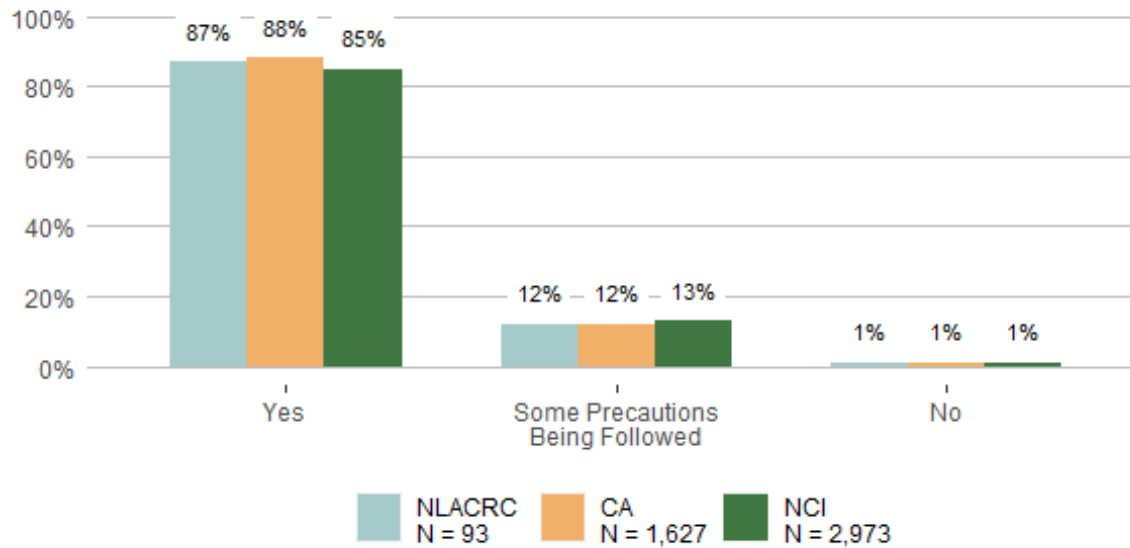


**Table 94. If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?**

RC v CA v NCI	Yes, Got Enough Information	Got Enough Information About Some Services	No, Did Not Get Enough Information	N
NLACRC	56%	21%	23%	95
CA	60%	22%	18%	1,653
NCI	61%	23%	16%	3,014



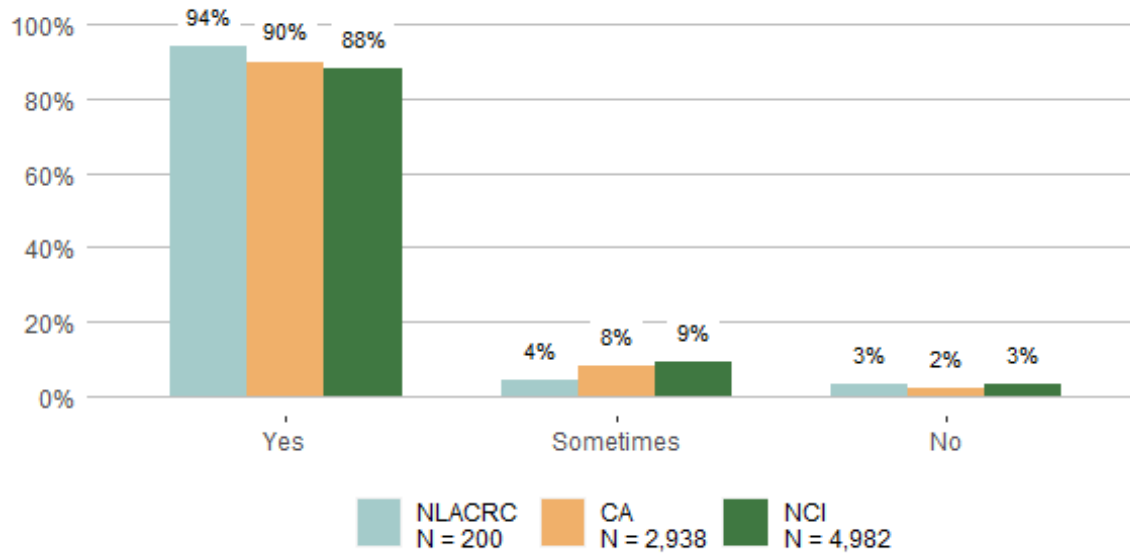
If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?



**Table 95. If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?**

RC v CA v NCI	Yes	Some Precautions Being Followed	No	N
NLACRC	87%	12%	1%	93
CA	88%	12%	1%	1,627
NCI	85%	13%	1%	2,973

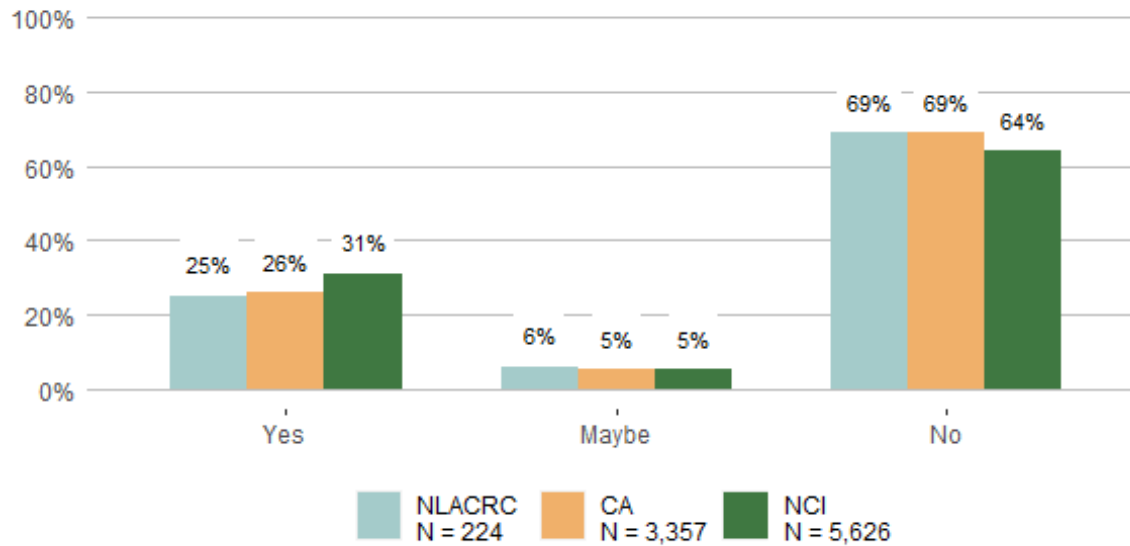
If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?



**Table 96. If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?**

RC v CA v NCI	Yes	Sometimes	No	N
NLACRC	94%	4%	3%	200
CA	90%	8%	2%	2,938
NCI	88%	9%	3%	4,982

In preparation for the future, have you made or updated an emergency plan with your family member's case manager/service coordinator or with other staff?

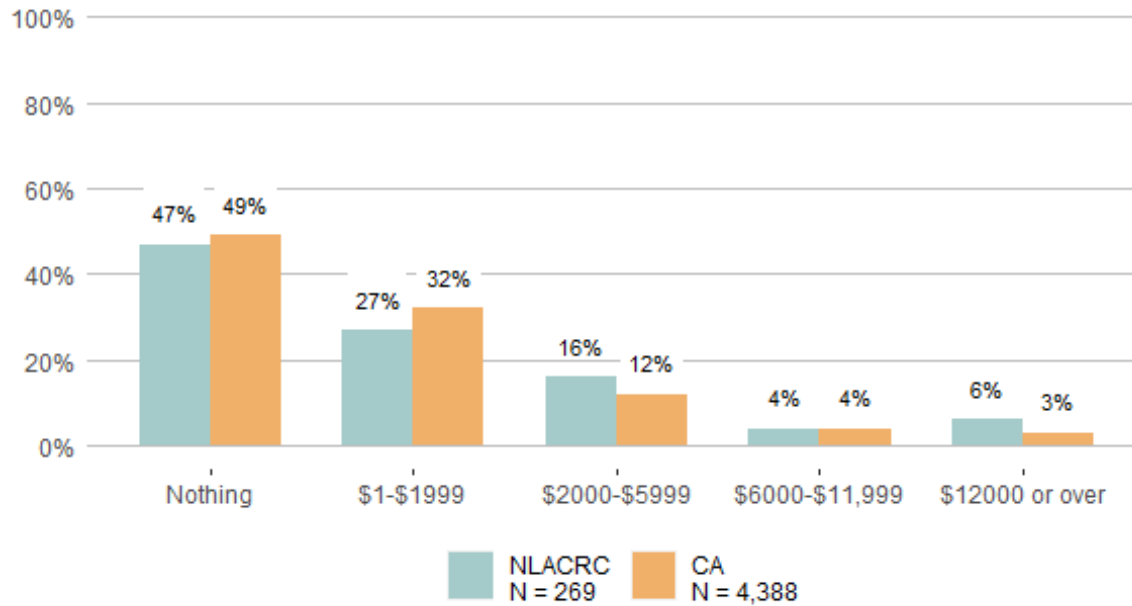


**Table 97. In preparation for the future, have you made or updated an emergency plan with your family member's case manager/service coordinator or with other staff?**

RC v CA v NCI	Yes	Maybe	No	N
NLACRC	25%	6%	69%	224
CA	26%	5%	69%	3,357
NCI	31%	5%	64%	5,626

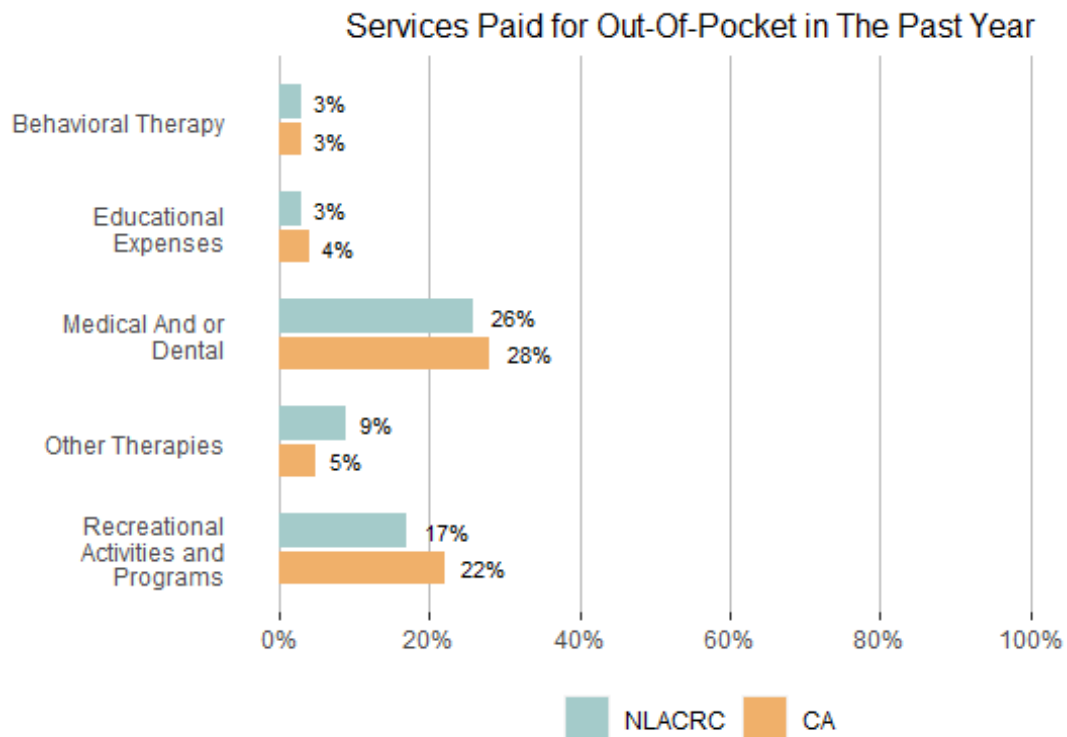
## *California Specific Questions*

Total Out-of-pocket Expenses Related to Family  
Member's Care in the Past Year



**Table 98. Total Out-of-pocket Expenses Related to Family Member's Care in the Past Year**

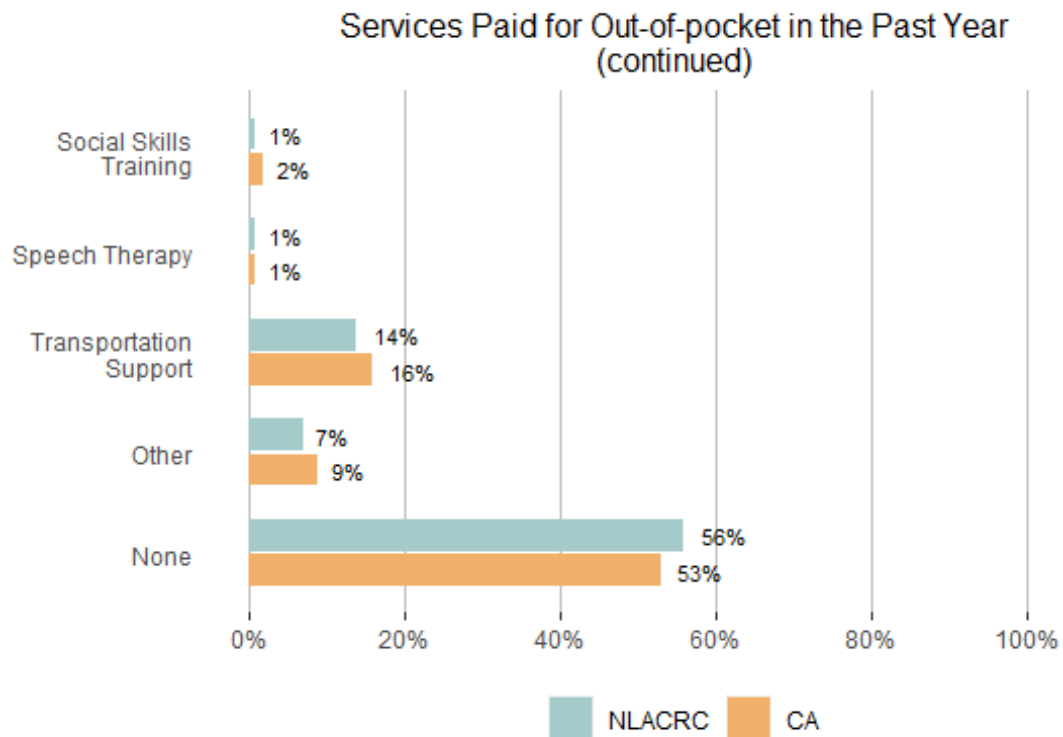
RC v CA	Nothing	\$1-\$1999	\$2000-\$5999	\$6000-\$11,999	\$12000 or over	N
NLACRC	47%	27%	16%	4%	6%	269
CA	49%	32%	12%	4%	3%	4,388



**Table 99a. Services Paid for Out-Of-Pocket in The Past Year**

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

RC v CA	Behavioral Therapy	Educational Expenses	Medical And or Dental	Other Therapies	Recreational Activities and Programs
NLACRC	3%	3%	26%	9%	17%
CA	3%	4%	28%	5%	22%

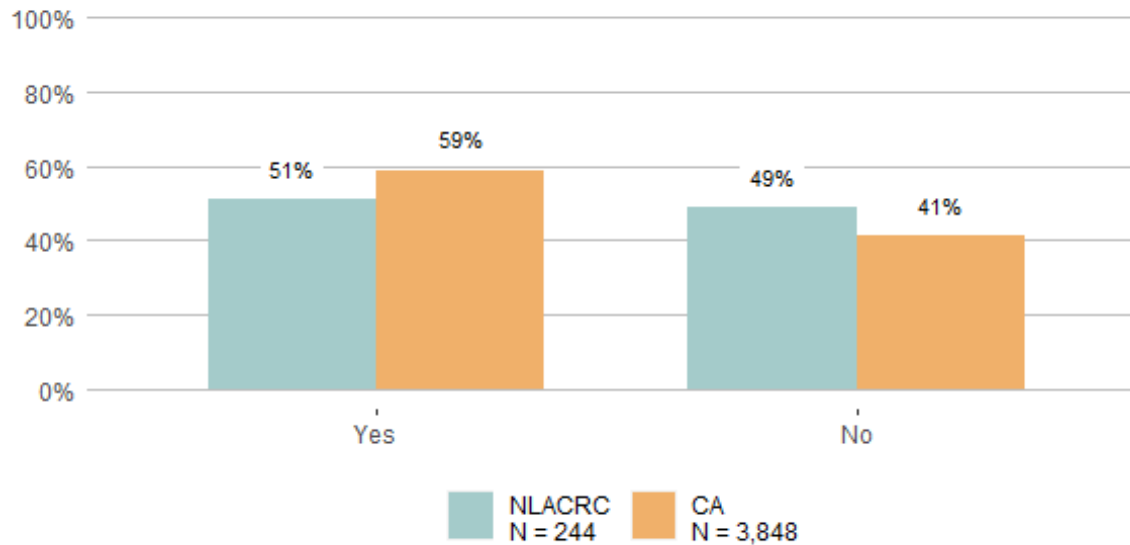


**Table 99b. Services Paid for Out-of-pocket in the Past Year**

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

RC v CA	Social Skills Training	Speech Therapy	Transportation Support	Other	None
NLACRC	1%	1%	14%	7%	56%
CA	2%	1%	16%	9%	53%

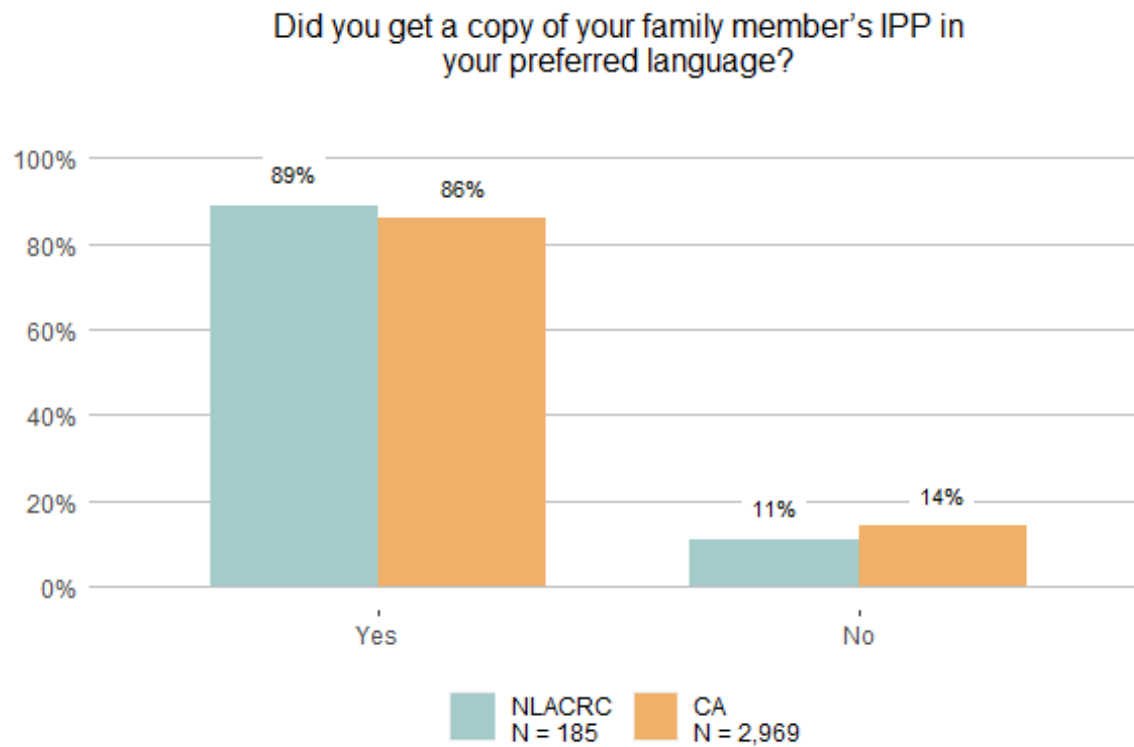
Does your regional center keep you informed, in your preferred language, about programs or services it offers? (For example, updates about new programs or services they offer)



**Table 100. Does your regional center keep you informed, in your preferred language, about programs or services it offers? (For example, updates about new programs or services they offer)**

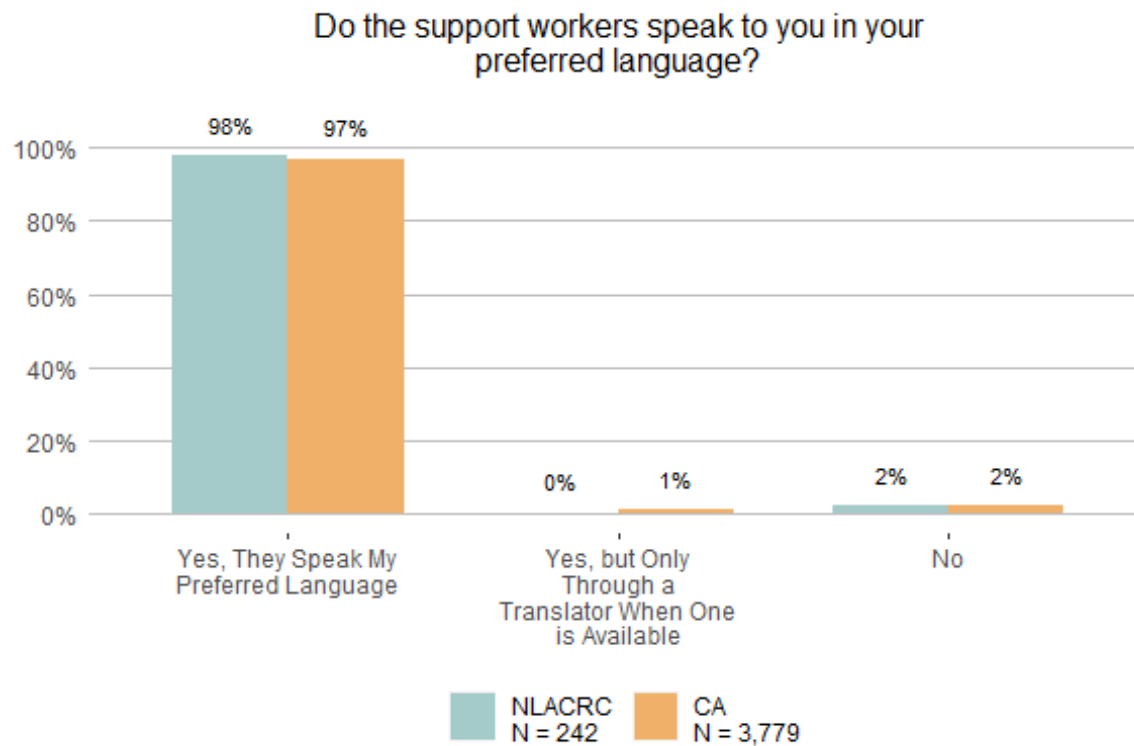
RC v CA	Yes	No	N
NLACRC	51%	49%	244
CA	59%	41%	3,848





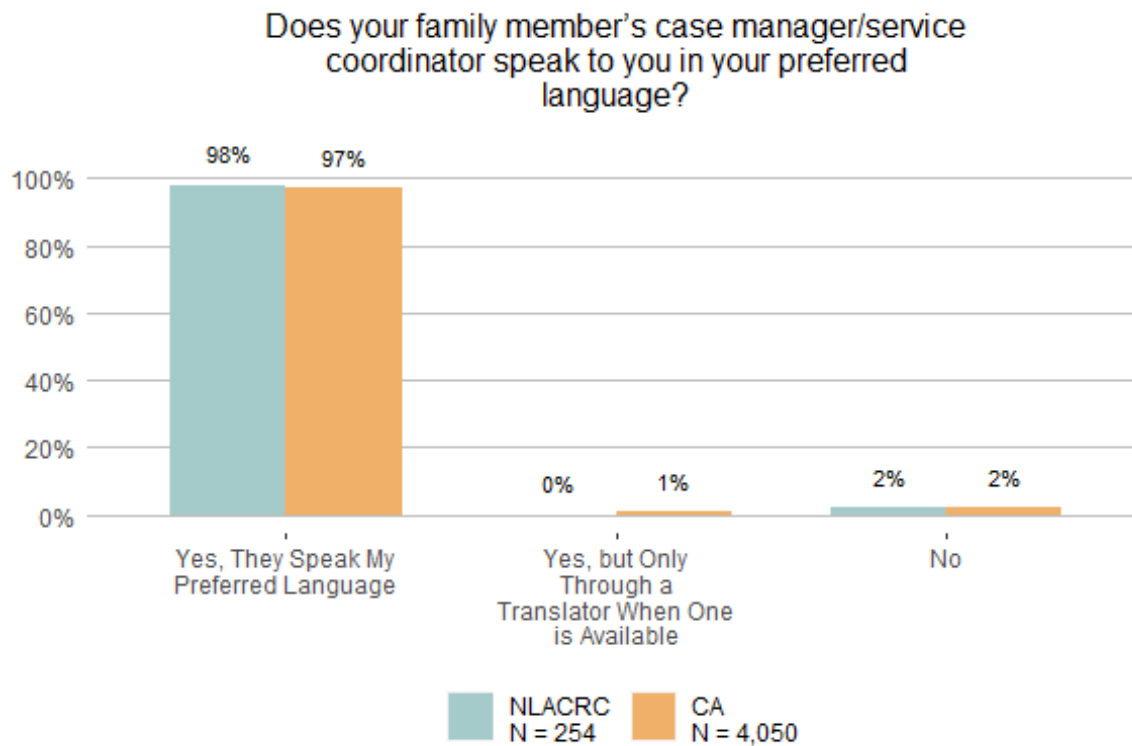
**Table 101. Did you get a copy of your family member's IPP in your preferred language?**

RC v CA	Yes	No	N
NLACRC	89%	11%	185
CA	86%	14%	2,969



**Table 102. Do the support workers speak to you in your preferred language?**

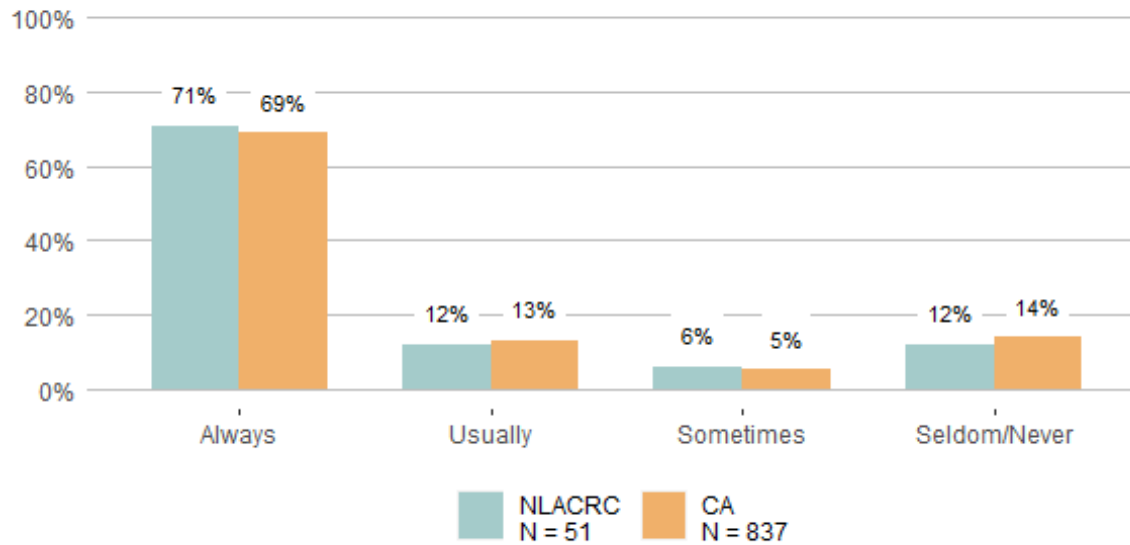
RC v CA	Yes, They Speak My Preferred Language	Yes, but Only Through a Translator When One is Available	No	N
NLACRC	98%	0%	2%	242
CA	97%	1%	2%	3,779



**Table 103. Does your family member's case manager/service coordinator speak to you in your preferred language?**

RC v CA	Yes, They Speak My Preferred Language	Yes, but Only Through a Translator When One is Available	No	N
NLACRC	98%	0%	2%	254
CA	97%	1%	2%	4,050

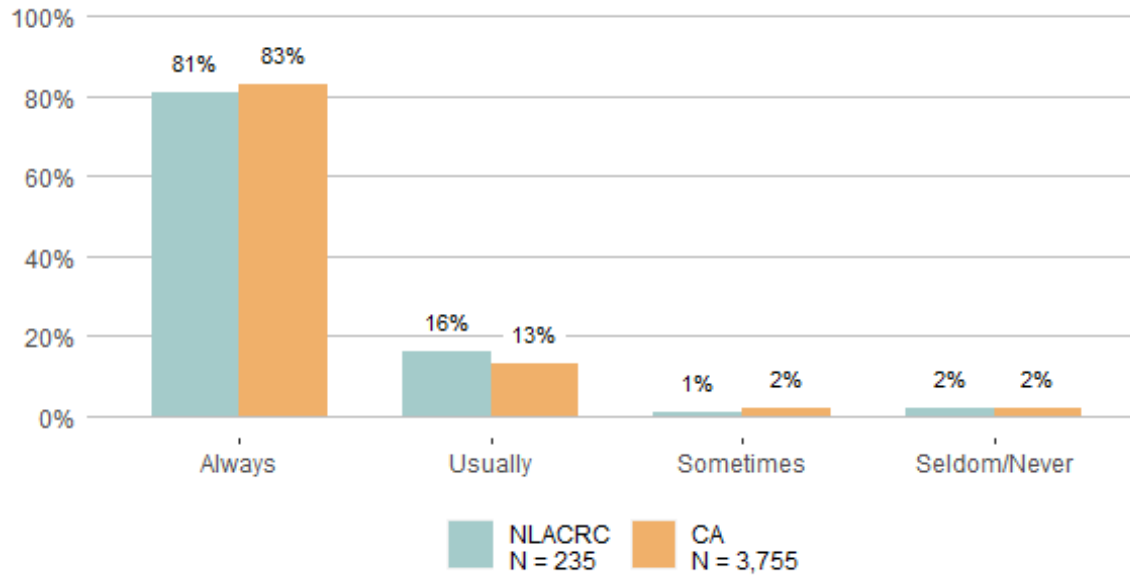
If your support workers and/or case manager/  
service coordinator do not speak to you in your  
preferred language is a translator provided when  
needed?



**Table 104. If your support workers and/or case manager/service coordinator do not speak to you in your preferred language is a translator provided when needed?**

RC v CA	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	71%	12%	6%	12%	51
CA	69%	13%	5%	14%	837

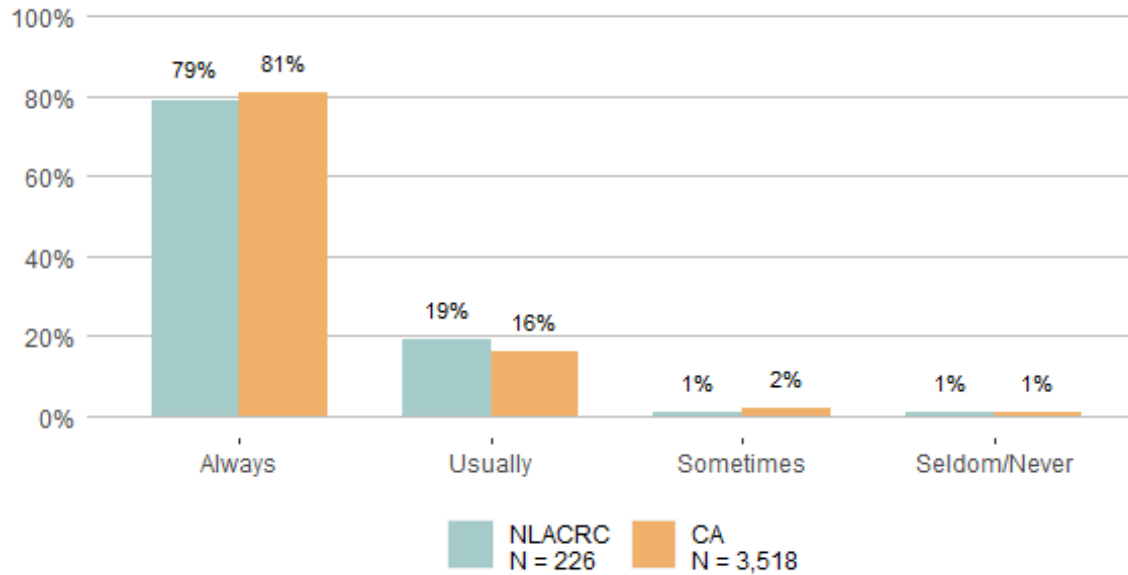
Does your family member's case manager/service coordinator support you in a way that is respectful to your culture?



**Table 105. Does your family member's case manager/service coordinator support you in a way that is respectful to your culture?**

RC v CA	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	81%	16%	1%	2%	235
CA	83%	13%	2%	2%	3,755

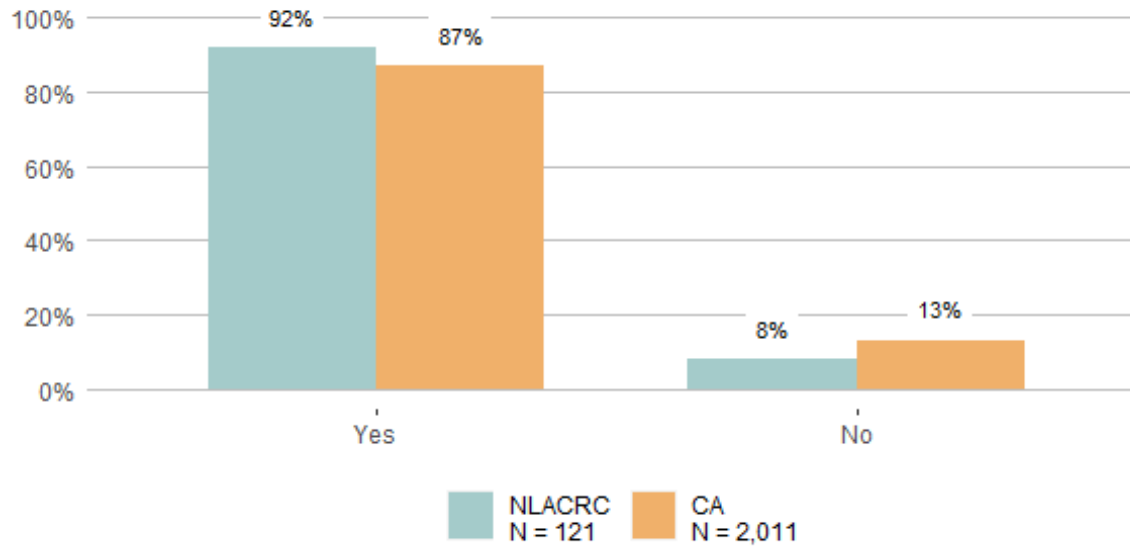
Do support workers for your family members provide services in a way that is respectful of your culture?



**Table 106. Do support workers for your family members provide services in a way that is respectful of your culture?**

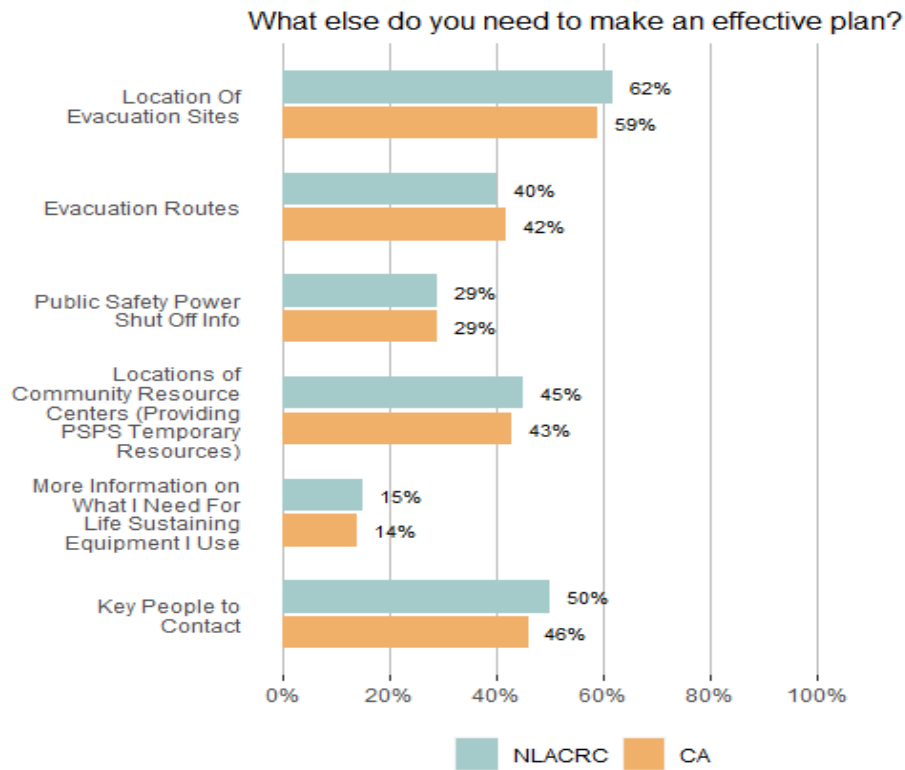
RC v CA	Always	Usually	Sometimes	Seldom/Never	N
NLACRC	79%	19%	1%	1%	226
CA	81%	16%	2%	1%	3,518

Do you believe your plans for how to handle your family members needs during a natural disaster (such as a wildfire or earthquake) will be effective?



**Table 107. Do you believe your plans for how to handle your family members needs during a natural disaster (such as a wildfire or earthquake) will be effective?**

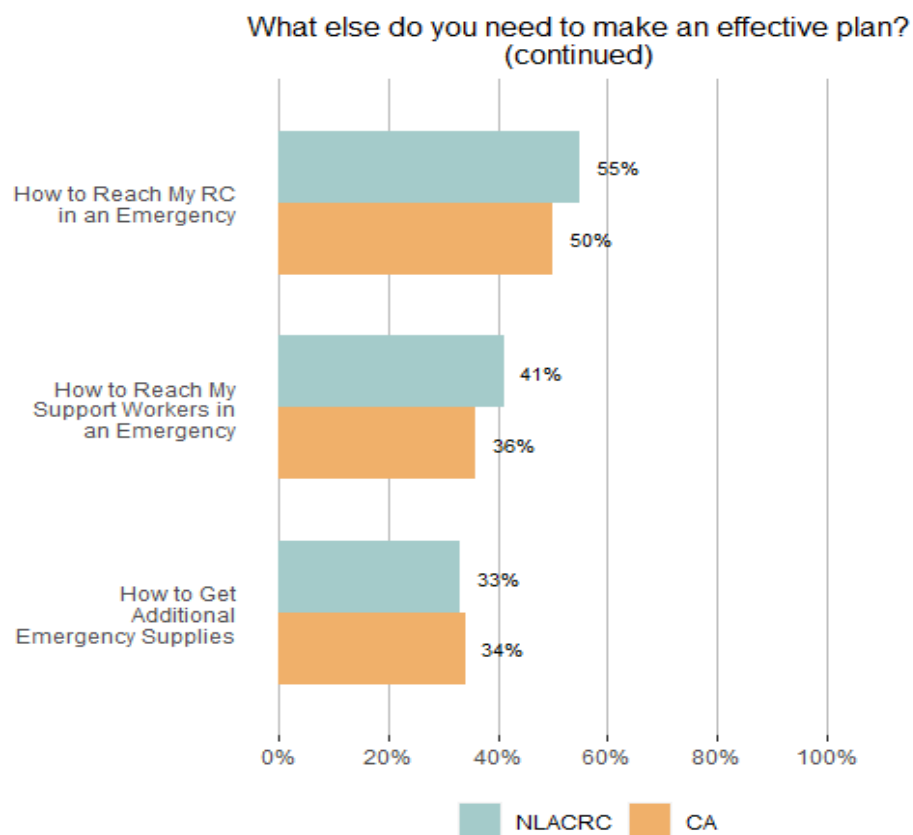
RC v CA	Yes	No	N
NLACRC	92%	8%	121
CA	87%	13%	2,011



**Table 108. What else do you need to make an effective plan?**

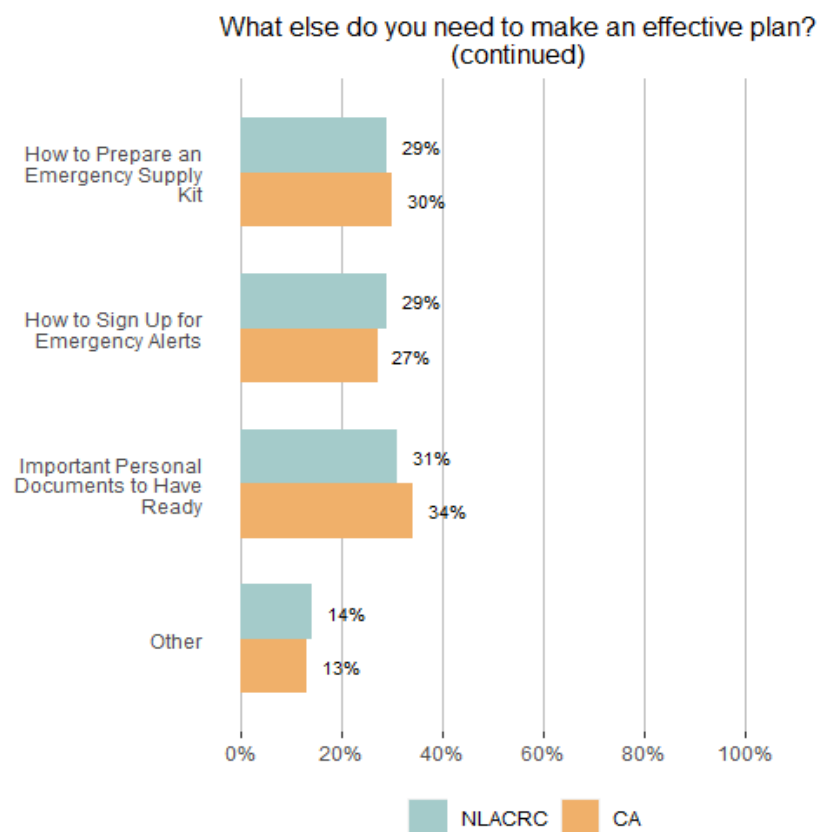
RC v CA	Location Of Evacuation Sites	Evacuation Routes	Public Safety Power Shut Off Info	Locations of Community Resource Centers (Providing PSPS Temporary Resources)	More Information on What I Need For Life Sustaining Equipment I Use	Key People to Contact
NLACRC	62%	40%	29%	45%	15%	50%
CA	59%	42%	29%	43%	14%	46%





**Table 108b. What else do you need to make an effective plan? (continued)**

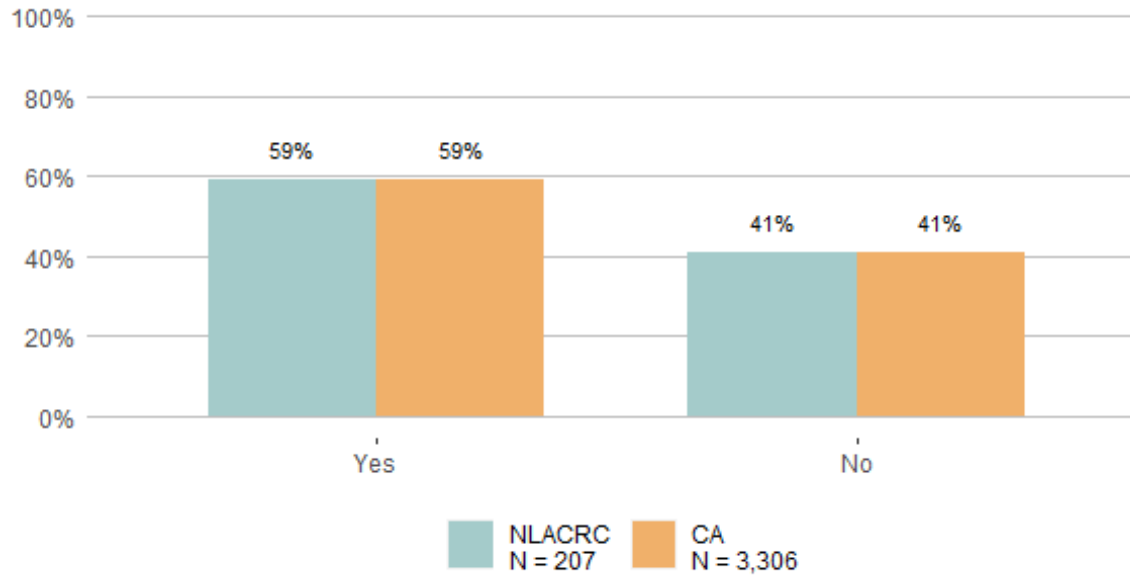
RC v CA	How to Reach My RC in an Emergency	How to Reach My Support Workers in an Emergency	How to Get Additional Emergency Supplies
NLACRC	55%	41%	33%
CA	50%	36%	34%



**Table 108c. What else do you need to make an effective plan? (continued)**

RC v CA	How to Prepare an Emergency Supply Kit	How to Sign Up for Emergency Alerts	Important Personal Documents to Have Ready	Other
NLACRC	29%	29%	31%	14%
CA	30%	27%	34%	13%

Do you know what to do if you disagree with your regional center about services and/or eligibility?  
(For example, how to request a Fair Hearing)



**Table 109. Do you know what to do if you disagree with your regional center about services and/or eligibility? (For example, how to request a Fair Hearing)**

RC v CA	Yes	No	N
NLACRC	59%	41%	207
CA	59%	41%	3,306